# Citizen Brief

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

9 March 2018

McMaster University | **McMaster** HEALTH FORUM

**EVIDENCE >> INSIGHT >> ACTION**

## The McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence 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. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

## About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on supporting survivors and families to 'move on' from cancer treatment to primary- and community-care supports in Canada. Building on the findings of the Canadian Partnership Against Cancer's 'Experiences of Cancer Patients in Transition' study, this brief includes information on this topic, including what is known about:

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

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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# Key Messages

## What's the problem?

Four main factors add to the challenge of supporting survivors and families to 'move on' from cancer treatment, which include:

- the strain that cancer is placing on health systems is increasing;
- more supports are needed for survivors and families to move on from cancer treatment into primary- and community-care settings;
- the best ways to support survivors to move on remain poorly understood; and
- system-level factors can make it complicated to ensure survivors and their families are supported.

## What do we know about elements of a possible approach for addressing the problem?

- **Element 1:** Support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be moving on after cancer treatment
  - This element could include: 1) engaging survivors and their families in conversations about moving on from cancer treatment; 2) equipping health professionals to identify and address the full range of survivor and family needs; and 3) creating the systems and processes to support 1 and 2.
- **Element 2:** Make sure money flows appropriately to the organizations and professionals that need to support survivors and families in moving on
  - This element could include a number of changes to how: 1) primary- and community-care organizations involved in providing support services are funded; 2) professionals providing these services are paid; 3) the needed programs, services and drugs are purchased; and 4) incentives (and potential disincentives) for accessing programs, services and drugs are used.
- **Element 3:** Help survivors and families learn how to manage the moving-on process after cancer treatment
  - This element could include: 1) ensuring information and education supports are provided to survivors and families; 2) supporting the development of self-management skills; 3) engaging survivors and their families as advisors in program and service planning; and 4) engaging survivors in system monitoring and feedback.

## What implementation considerations need to be kept in mind?

- Barriers to implementing these elements might include: 1) financial constraints faced by provinces and territories; 2) limited awareness of the need for improvements to support survivors and families to move on from cancer treatment; and 3) little political will to address the issue before other healthcare priorities.
- Factors that may be contributing to opening a 'window of opportunity' for implementing these elements include: 1) growing attention to expanding the home- and community-care sector to help individuals move on from primary cancer treatment; 2) findings from the Canadian Partnership Against Cancer's Experiences of Cancer Patients in Transition study that can help to identify and create awareness around the needs and challenges faced by cancer survivors; and 3) some provincial cancer care organizations and programs have developed the types of expertise needed to support survivors to move on.

# Questions for the citizen panel

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

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**Box 1: What do we know about 'moving on' from cancer treatment?**

In 2016, the Canadian Partnership Against Cancer (hereafter referred to as the Partnership) initiated a study across the 10 provinces to understand the experiences of cancer survivors as they transition from the end of their cancer treatment (for example, surgery, chemotherapy, radiotherapy, etc.) to follow-up care (for example, primary and community care).(3)

The more than 13,000 Canadian cancer survivors who participated in the survey had completed treatment within the last one to three years for one of five types of non-metastatic cancer: 1) breast cancer; 2) colorectal cancer; 3) hematological cancer; 4) melanoma; and 5) prostate cancer. The study included adolescents and young adults aged 18-29 with any form of non-metastatic cancer and metastatic testicular cancer, as this group has a unique set of challenges. The study looked at survivors' needs (for example, symptom burden, emotional needs, informational and practical needs), the extent to which their needs were met (for example the types of support they accessed), and the enablers and barriers that affected whether and how their needs were (or were not) met.(3)

Preliminary findings from the study show that:
- one to three years after treatment, adult participants continue to experience physical (87%), emotional (78%) and practical challenges (44%);
- one to three years after treatment, the majority of adolescents and young adult participants continue to have physical (90%), emotional (89%) and practical challenges (78%);
- survivors experience a wide range of physical, emotional and practical concerns such as fatigue, changes in sexual activity or function, anxiety about cancer returning, depression, sadness and challenges returning to work or school;
- 22% to 67% of adult cancer survivors had difficulty getting help for their health concerns; and
- 28% to 57% of adult survivors did not seek help for at least one concern, with the most often cited reason being that they were told it was normal and did not think anything could be done about it (physical concern - 33%; emotional concern - 22%).(3)

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## Box 2: Questions for citizens

### Questions related to the problem

- Are the challenges and experiences you or a family member faced after cancer treatment similar to those shared by thousands of other Canadians (see Box 1)?
- Where are the biggest gaps in supports available to survivors and their families after treatment? For example, are there gaps in:
  - particular sectors (such as primary care, community care or speciality care);
  - the types of programs or services available (such as peer support); or
  - the extent to which physical, emotional or practical challenges are addressed?
- What challenges have you, your family and/or friends encountered when seeking post-treatment support in primary- and community-care settings?
- What are the health-system factors that create the greatest challenges in getting the needed supports after cancer treatment (for example, lack of communication between cancer specialists and those working in primary care, or challenges with accessing programs, services and drugs that might or not be publicly funded)?

### Questions related to the elements of a possible approach to address the problem

- Are there points in the cancer journey where more effort should be made to ensure survivors and families transition smoothly from treatment into primary- and community-care settings?
  - What specific types of efforts should be focused on (for example, training professionals to do better, making sure money flows in ways that help organizations and professionals do better, or giving survivors and families a greater voice in making things better)?
- What kinds of changes should be made to the types of programs, services and drugs that governments have decided to pay for?
- What knowledge and skills should survivors and their families be equipped with, and when?

### Question related to implementation considerations

- What are the biggest barriers to improving how survivors and their families move on from cancer treatment to survivorship?
- What changes are you seeing that can help to open a 'window of opportunity' for doing better?

## Box 3: Glossary*

**Cancer patient**
Someone who was been diagnosed with cancer and is in the treatment process.(1)

**Cancer survivor**
The term survivor is used to refer to a person from the point of cancer diagnosis until the end of life.(5)

**Cancer treatment**
There are at least five groups of cancer treatments, namely: 1) surgery, 2) transfusion or transplant therapies (for example, bone marrow or stem cell); 3) radiation therapy; 4) chemotherapy (which includes drug therapy); and 5) a number of therapies that fall under the head of 'complementary and alternative therapies.' Those living with cancer are given individualized treatment plans based on cancer type, stage and personal factors (for example, individual preferences and circumstances).(3; 7)

**Support services**
Cancer support services (for example, peer support, information services and online communities) offer assistance and information for individuals affected by cancer.(8)

**Survivorship**
Survivorship in cancer "focuses on the health and life of a person with cancer post treatment until the end of life."(5) Survivorship includes the range of physical, psychosocial and economic impacts associated with cancer, and is inclusive of family, friends and caregivers who are considered part of the survivorship experience.

**Follow-up care**
Cancer follow-up care consists of monitoring for signs of recurrence, management of adverse effects of treatment, and detection and management of comorbid conditions (for example, cardiac conditions and mental health).(10)

*We recognize that there are many terms used to refer to patients with cancer and survivors (for example, person with cancer, people who have been through cancer, cancer thriver, etc.). For the purposes of this brief, we use the definitions provided by the National Cancer Institutes, which is consistent with much of the research literature in the field.

As the number of Canadian cancer survivors increases, health systems need to adapt to support their needs

# **The context:** Why is supporting survivors and families to 'move on' from cancer treatment a high priority?

It is estimated that one in every two Canadians will develop some form of cancer over their lifetime.(2) While the number of Canadians diagnosed with cancer is increasing, advances in treatment have improved the chances of surviving for years after a diagnosis of cancer.(11) With these increased chances, the number of Canadians completing cancer treatment and transitioning out of the specialized part of the health system that treats cancer will also rise.(10) In doing so, they will be returning to the primary-care supports (such as their family physicians) and community-care sectors (such as visiting nurses or personal support workers) that can take care of the full range of their health concerns.(10)

Despite the good news about the number of Canadians with cancer who survive, survivorship is poorly understood and an often neglected phase of the cancer journey when compared to other parts of it (such as treatment).(12) Complicating matters, cancer survivors can face a number of unique challenges, which include:

- the need for ongoing additional supports and medical care for years following treatment;(12)
- having to deal with a range of physical, psychosocial and functional issues that are associated with survivorship;(12-14) and
- coping with the long-term impacts that can result from cancer treatment, which vary based on a number of factors (for example, cancer type, treatment type, age and sex).(15-18)

As noted above, in many regions across Canada, cancer programs, services and drugs are handled by a specialized part of the health system that treats cancer, which is sometimes called the 'cancer system' (see Box 4).(9) The broader health system has many different sectors (such as primary care, and home and community care) within which a much wider range of programs and services are delivered. Unfortunately, the cancer system and the broader health system aren't always coordinated.(9)

Currently, the efforts of provincial cancer systems are largely focused on cancer treatment, despite a growing awareness that cancer survivorship is an important part of the cancer journey and brings with it the many unique challenges outlined above. This focus on cancer treatment means that many people transition out of the cancer system and back into the broader health system without having access to all the supports they need.(3)

# Box 4: Key features of provincial health systems in Canada

### Key features of the health system

- The responsibility for health systems falls primarily to provincial and territorial governments, albeit within broad rules set by the federal government for care that is delivered in hospitals or by physicians.(4)
- Medically necessary care provided in hospitals or by a physician is fully paid for as part of each publicly funded provincial/territorial health system.(4)
- Other healthcare professionals (for example, nurses, physiotherapists and occupational therapists) are sometimes not paid for by provincial/territorial health systems, unless the care is being provided in a hospital. Government funding for these professionals when they're working outside of a hospital varies by province and territory.
- Other aspects of healthcare (for example, prescription drug coverage) and community services (for example, home care) may be partly government funded, with the remaining portion of the costs paid through private insurance plans and/or by patients paying out of their own pocket.(6)
- Healthcare is often organized by region within provinces and territories. Planning and funding of healthcare is the responsibility of the regions.(4)

### Features most relevant to cancer care

- Cancer programs, services and drugs are handled by a cancer-care system that often operates quite separately from primary care and community care.(9)
- Many cancer-care systems across the country share some or all of the following characteristics:
  o planning, oversight and accountability fall to arm's-length crown agencies or separate branches within ministries of health;
  o funding arrangements are often specific to the organizations within cancer-care systems and to the programs and services needed by patients with cancer; and
  o treatment is often centralized in a specialist hospital or centre that serves an entire region of a province or territory.(9)

### Features most relevant to primary care

- Team-based care is becoming more common in primary care, with the family physician typically the 'most responsible' provider in the team.

### Features most relevant to home and community care

- The extent of government funding for home and community care varies by province/territory. The coordination of services is often conducted at the regional level, either by or in collaboration with the regional authorities responsible for planning and funding healthcare.(6)

It is estimated that one in every two Canadians will develop some form of cancer over their lifetime.(2)

# **The problem:** Why is supporting survivors and families to 'move on' from cancer treatment challenging?

We identified four factors that contribute to the challenge of supporting survivors and families to move on from cancer treatment in Canada. These are outlined in Figure 1 and described below.

**Figure 1. Factors contributing to the challenge of supporting survivors and families to 'move on' from cancer treatment in Canada**

The strain that cancer is placing on health systems is increasing

The best ways to support survivors to move on remain poorly understood

More supports are needed for survivors and families to move on from cancer treatment into primary- and community-care settings

System-level factors can make it complicated to ensure survivors and their families are supported
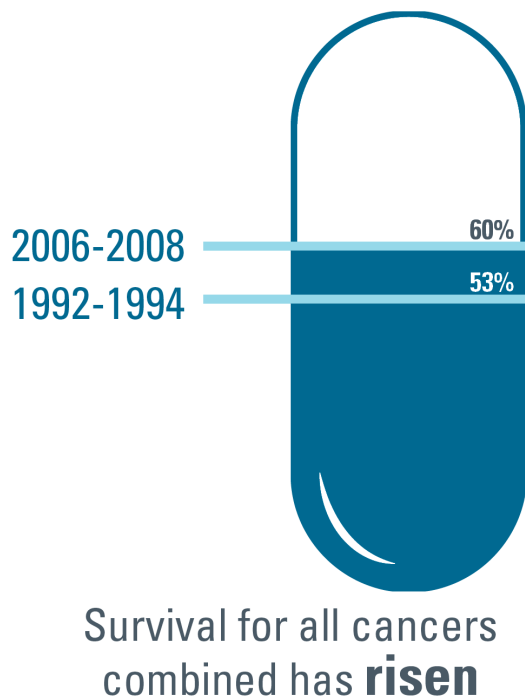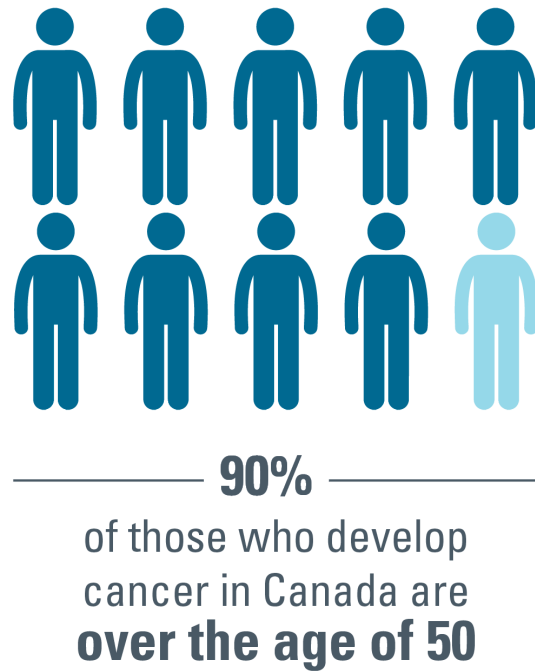
# The strain that cancer is placing on health systems is increasing

The strain that cancer is placing on health systems in Canada is increasing, and is likely to continue to grow due to at least four related reasons:
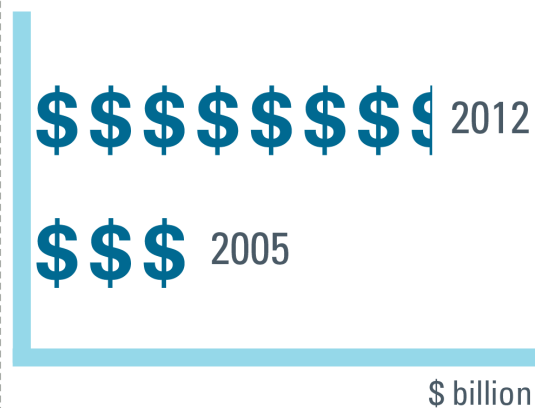
- the number of individuals diagnosed with cancer is expected to increase;
- the population is aging (and older adults make up a large proportion of those diagnosed and living with cancer);
- the number of people surviving after being diagnosed with cancer continues to grow; and
- it is becoming more expensive to provide treatment and follow-up care to individuals who are diagnosed with cancer.

These reasons are shown in Figure 2 below.

**Figure 2. The main factors contributing to the strain that cancer is placing on health systems in Canada**



1 in every 2 Canadians

will develop some form of cancer over their lifetime

**90%**

of those who develop cancer in Canada are **over the age of 50**

2006-2008    60%
1992-1994    53%

Survival for all cancers combined has **risen**

\$ \$ \$ \$ \$ \$ \$ \$ 2012

\$ \$ \$ 2005

$ billion

The cost of cancer in Canada has increased to **$7.5 billion**

\* Based on the five-year age-standardized net survival for people diagnosed with cancer

Source: mcmasterforum.org/find-evidence/products

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# More supports are needed for survivors and families to 'move on' from cancer treatment into primary- and community-care settings

Due to advances in cancer treatment, the majority of those diagnosed with cancer will survive, however, these advances can also create new needs for support. Specifically, cancer survivors may develop a number of late (that occurs months or even years after cancer treatment) and long-term effects (ongoing challenges that continue to affect survivors) of treatment, which span across symptom burden, emotional needs, informational and practical needs.(12)

Common late-term physical effects include:
- musculoskeletal conditions (for example, osteoporosis);
- organ dysfunction (for example, heart disease); and
- development of a second cancer.(11; 12)

Common long-term effects include:
- pain;
- fatigue;
- infertility;
- anxiety;
- depression; and
- learning and memory issues.(12; 19)

# The best ways to support survivors to 'move on' remain poorly understood

In general, health professionals' roles and responsibilities in survivorship care remain poorly understood.(20) This is likely related to the fact that transitions from cancer treatment in a regional cancer centre to survivorship in the community can be complex, and require clarity about:

1) which part of the system (for example, the primary- and community-care sectors or the cancer-care system), and who in that system (for example, physicians or nurses) will address the late and long-term effects of treatment that might limit the quality of life of survivors;

2) which part of the system, and who in that system, will provide secondary cancer prevention, surveillance for recurrence, and health promotion to maximize the health outcomes of survivors;

3) which part of the system, and who in that system, will provide the ongoing holistic care of survivors (including other chronic diseases, like diabetes or heart disease, and any acute illnesses, such as the flu or back strain); and

4) how the communication, coordination and integration between these sectors will work.(10; 11; 21-26)

# System-level factors can make it complicated to ensure survivors and their families are supported

A number of challenges in the health system further complicate efforts to improve cancer-care transitions. In Table 1, we describe the challenges as they relate to health-system governance, financial and delivery arrangements.

**Table 1.** Main system-level challenges related to supporting survivors

| Health-system arrangements | Main challenges |
|---|---|
| **Governance arrangements (who can make what types of decisions)** | • The majority of cancer care is planned for and overseen in relative isolation from other sectors, with little coordination or collaboration with other sectors. |
| **Financial arrangements (how money flows from taxpayers to government to organizations and professionals)** | • Funding for cancer-care programs and services tends to be separate from the funding provided in primary- and community-care settings:<br>  ○ many programs and services that support cancer-care transitions are funded by other government ministries;<br>  ○ funding is often tied to specific services in a single setting rather than for the whole bundle of services that a cancer survivor may need from multiple settings and providers; and<br>  ○ few places in Canada have specific ways to pay providers for care to support cancer-care transitions (either for cancer-care providers to support moving on or primary- and community-care providers to accept the move). |
| **Delivery arrangements (how care is organized)** | • The main challenges associated with delivery arrangements stem from the fact that cancer survivors have an array of complex needs, which can go unaddressed because:<br>  ○ there is a lack of integration between cancer systems and primary- and community-care sectors across Canada;<br>  ○ there is poor coordination across providers (for example, oncologists and family physicians), with too few efforts to find ways to work together; and<br>  ○ many cancer centres routinely assess and monitor a wide range of patient needs (for example, symptom burden, emotional and psychosocial needs, as well as informational and other practical considerations), yet these assessments are rare in primary- and community-care settings.(27; 28) |

We have selected three elements of an approach to address the problem for which we are seeking public input.
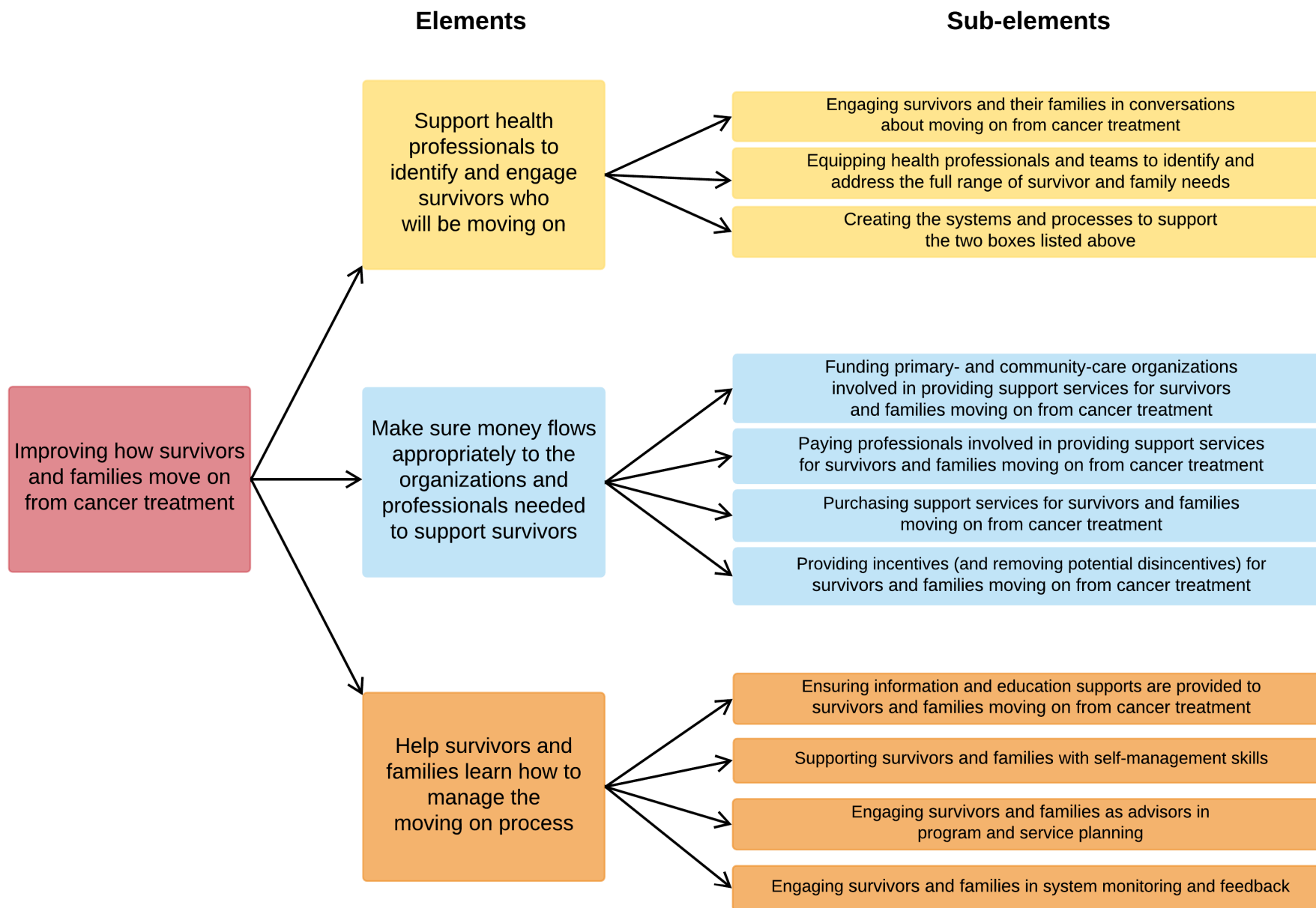
# Elements of an approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to improving cancer-care transitions in Canada

Many approaches could be selected as a starting point for discussion. We have selected the following three elements of an approach for which we are seeking public input (see figure 3 for additional detail about the potential sub-elements that fall within each element):

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

**Figure 3. Areas of focus for improving how survivors and families 'move on' from cancer treatment**

These elements should not be considered separately. Instead, each should be considered as contributing to a possible approach to addressing the problem. New elements could also emerge during the discussions. Box 5 below summarizes how the authors identified, selected and synthesized the best-available research evidence for each element.

> ## Box 5: Identification, selection and synthesis of research evidence presented in this brief
>
> - Whenever possible, we describe what is known about each element based on systematic reviews.
> - A systematic review is a summary of all the research studies looking at a specific topic.
> - A systematic review uses very rigorous methods to identify, select and appraise the quality of all the studies, and to summarize the key findings from these studies.
> - A systematic review gives a much more complete and reliable picture of the key research findings, as opposed to looking at just a few individual studies.
> - We identified systematic reviews in Health Systems Evidence (www.healthsystemsevidence.org). Health Systems Evidence is the world's most comprehensive database of research evidence on health systems.
> - A systematic review was included if it was relevant to one of the elements covered in the brief.
> - We then summarized the key findings from all the relevant systematic reviews.

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

**Overview**

This element focuses on enabling health professionals to identify and engage survivors and families who will be moving on after cancer treatment to primary and community care through early identification and engagement, which could include:

- engaging survivors and their families in decision-making about moving on 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).

**Evidence to consider**

We found several systematic reviews that provide evidence about these sub-elements. Overall, the evidence suggests there are a number of benefits associated with engaging patients, equipping professionals through training, and with the use of information technology to improve care processes. Given the literature we identified was so extensive, we present a summary of the evidence in Table 2, rather than describe each study in text.

**Questions to consider**

*Overarching questions to consider*
- Are there points in the cancer journey where more effort should be made by health professionals to ensure survivors and families move on smoothly from treatment into primary- and community-care settings?

*Additional questions to consider*
- What types of supports should be introduced to help health professionals improve cancer treatment follow-up for survivors and families?
- What is the best way for health professionals to engage survivors and families to be in conversations about moving on from cancer treatment?
    o Are there specific ways to have conversations about their needs?
    o Are there specific ways to have conversations about whether and how to address their needs?
- What should be done to ensure that health professionals are better equipped to address the full range of survivor and family needs?
    o Adjust how they are trained?
    o Support their use of best-practice guidelines?
    o Provide them with tools to identify survivor needs?
    o Improve the information and education provided to them?
- What are the other systems and/or processes that are required to support health professionals with this element?
    o Change how programs and services are planned so that providers across sectors can work together to provide 'shared care' (for example, oncologists and family physicians working together)?
    o Clarify health professional roles and define care pathways?
    o Establish community partnerships?
    o Improve communication and the transfer of patient information between health professionals?
    o Improve the use of available information (including patient information)?

## **Table 2.** Summary of the evidence about element 1

| Area of focus | Key findings |
|---|---|
| **Engaging individuals and their families** | • Gaining patient trust, engaging with the patient's extended family, addressing patients appropriately according to their cultural preference, and culturally sensitive communication was found to be key to establishing physician-patient relationships.(29)<br>• Challenges to communication identified included differences in communication styles, medical belief models, cultural communication (including language barriers), perceived lack of patients' control, and distrust of providers and the health system.(30) |
| **Equipping professionals** | • Face-to-face, rehabilitation program delivery was found to be most effective.(31)<br>• Providing health professionals involved in cancer care with communication-skills training was found to increase empathy shown towards patients.(32) |
| **Supporting processes 1 and 2** | • The evidence provided no clear messages about 'shared-care' models (for example, coordination of care between an oncologist and family physician), most likely because there were large differences in the models studied, and limited research on each of the models. (21; 24; 33)<br>• Information technology was found to facilitate coordination through:<br>    ○ shared decision-making between patients and providers;(34)<br>    ○ technological support (for example, telephone follow-up cancer care);(35) and<br>    ○ patient-held records helped to track health, remember events, and share information, however, negative impacts included that some patients viewed them as an unwanted responsibility.(36)<br>• Mixed results were found for decision-aid and patient-navigator programs, in particular:<br>    ○ decision aids helped shared decision-making and patients' perception of treatment adherence, however the use of patient navigators was not helpful; (37)<br>    ○ patient-navigation programs increased getting health screening, care events (for example, cardiac rehabilitation) and sticking to follow-up treatment;(38)<br>    ○ there were some benefits (for example, financial and quality of life) for navigator programs supporting chronically ill older adults through healthcare transitions;(39)<br>    ○ nurse-led programs in the follow-up stage of breast cancer contributed positively to patients' quality of life;(40) and<br>    ○ no difference was found in quality of life in patients undergoing cancer treatments who had navigation programs compared to patients who did not.(41)<br>• Mixed results were found for survivorship care plans.(42) |

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

**Overview**

The focus of this element is to ensure that approaches to funding organizations and paying health providers facilitate survivors and families to move on from cancer treatment. Sub-elements could include making adjustments to the approaches currently used for:

1) funding primary- and community-care organizations;
2) paying providers involved in delivering support services for survivors and families to move on from cancer treatment;
3) purchasing programs and services for survivors and families to move on from cancer treatment (for example, making changes to public insurance plans); and
4) 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).

**Evidence to consider**

Similar to element 1, a lot of literature was identified, and overall, the results were varied across approaches (such as funding organizations, paying healthcare providers, purchasing services and removing disincentives). Given the extent of the evidence, we present a summary in Table 3.

## Questions to consider

*Overarching question to consider*

- What kinds of changes should be made to the types of programs, services and drugs that governments have decided to pay for in supporting survivors and families?

*Additional questions to consider*

- If changes were to be made to how primary- and community-care organizations are funded by government to support survivors and families in transition, what goals should be kept in mind (for example, accepting responsibility to be an intermediary with the cancer-care system when needed)?

- If changes were to be made to how providers are paid for the services they provide survivors and families in transition, what goals should be kept in mind?

- What types of programs and services for survivors and families moving on from treatment should the government pay for? What should be paid for privately?

- Are there currently primary- and community-care supports that are not covered by government, making them difficult to access for most survivors and their families moving on from treatment to survivorship?

**Table 3.** Summary of the evidence about element 2

| Area of focus | Key findings |
|---|---|
| **Funding organizations** | • None of the research evidence focused specifically on supporting survivors and families to move on from cancer treatment, however:<br>  ○ activity-based funding (for example, payments based on diagnosis) was found to increase: 1) post-acute care admissions after hospitalization; and 2) severity of illness (though this may be due to changes in diagnostic coding);(43)<br>  ○ bundled payments (for example, grouping payment for services across settings and providers) were found to decrease utilization and costs of services included in the bundle, but may create financial incentives for providers to decrease the number and cost of services included in the bundle;(44)<br>  ○ mixed results were found for targeted payments and/or penalties, which included:<br>    ▪ perceived benefits of pay-for-performance models (for example, paying providers for meeting certain targets): improved productivity and efficiency; ability to reallocate funds; support for greater emphasis on evaluation; accountability and discharge planning; improved data accuracy; improved collaboration and communication; and improved quality and enhanced organizational transparency; and (45)<br>    ▪ unintended consequences may include opportunistic behaviour, cherry-picking patients with less complex conditions and who are less expensive to treat, and inaccurate reporting and evaluation of the quality outcomes.(45) |
| **Paying providers** | • Fee-for-service models (for example, a payment for each service given by the provider), compared to capitation (for example, a set amount for each patient enrolled in the practice), in primary care were associated with increases in: physician contact; referrals to specialists; diagnostic and curative services; continuity of care; and following the recommended number of visits.(46; 47)<br>• Implementing drug budgets for physicians may decrease prescription drug spending by limiting the volume of drugs, increasing the use of generic drugs, or both.(48)<br>• Mixed results were found for the use of targeted payments and penalties for providers:<br>  ○ financial incentives for providers were effective in the short run for simple, distinct, and well-defined goals for changing what they are expected to do differently, but there was little evidence to support long-term changes;(49)<br>  ○ financial incentives may be effective for delivering specific services or care to specific populations, providing a pre-specified level of care, changing |

| | |
|---|---|
| | activity, as well as improving quality, processes of care, referrals, admissions and prescribing costs;(50)<br><br>○ identified risks in cancer care included limiting access to certain types of care, lack of continuity of care, and conflict of interest between the physician and the patient;(51) and<br><br>○ pay-for-performance programs were more effective for chronic care than acute care, did not have a negative effect on access, and there was no link between the size of the incentive and effectiveness of the program.(45) |
| **Purchasing support services** | • Policies involving prior authorization for prescriptions decreased overall drug spending.(52)<br><br>• Reference pricing (for example, certain drugs are interchangeable based on their health benefits) may reduce insurers' drug spending, increase the use of reference drugs and reduce the use of cost-share drugs.(53) |
| **Removing potential disincentives** | • Incentives can be effective at changing behaviours, but the evidence supporting these effects is either inconsistent (for example, for improving adherence to drugs), indicates that effects are not sustained in the long-term (for example, for promoting healthy behaviours such as changes in eating, alcohol consumption, and physical activity), or require substantial cash incentives to sustain behaviour changes (for example, smoking cessation).(54-58) |

# Element 3 – Help survivors and families learn how to manage the 'moving-on' process after cancer treatment

**Overview**

The focus of this element is on efforts to support survivors and families by providing more information and helping them develop knowledge and skills which can improve the transition from cancer treatment to primary and community care. Sub-elements could include:

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

**Evidence to consider**

While there was only limited evidence identified that addressed this element, some systematic reviews were found that were related to the first and second sub-elements. For the first sub-element (ensuring information and education supports are available), no clear messages were identified, however, one systematic review found benefits from psycho-educational counselling of patients and supporters of women with breast cancer, which included improvements in:

- anxiety;
- psychological well-being; and
- relationship and individual functioning.(59)

For the second sub-element (supporting patients with self-management skills):

- group-based self-management programs and self-management education were found to be beneficial to patients with cancer and improved physical and psychological functioning (for example, symptoms of fatigue, pain, depression, anxiety, emotional distress and quality of life);(60; 61) and

- electronic symptom reporting may help providers in the diagnostic process, save time and money, and improve the quality of care and effectiveness of patient-physician encounters by increasing patients' preparedness.(62)

## Questions to consider

*Overarching question to consider*
- What knowledge and skills should survivors and their families be equipped with in order to support them moving on from treatment to survivorship? What would be the ideal timing for equipping them with the needed knowledge and skills?

*Additional questions to consider*
- How can survivors and families best be supported to gain the knowledge and skills they need?
- What types of information and education supports are best suited to survivors and families transitioning from cancer treatment to survivorship (for example, tailored resources, educational opportunities in speciality care, primary care and community care)?
- What types of self-management skills do survivors and families need (for example, the ability to manage their anxiety)?
- What are the most appropriate ways to engage survivors and their families as advisors in how programs and services are delivered?
- What are the most appropriate ways to engage survivors and their families in monitoring how well the health system is performing with respect to meeting the unique needs of those experiencing a transition from cancer treatment to survivorship?

# Implementation considerations

It is important to consider what barriers we may face if we implement the proposed elements of a possible approach to address the problem. These barriers may affect different groups (for example, cancer survivors, family, health professionals), different healthcare organizations or the health system. While some barriers could be overcome relatively easily, others could be so substantial that they force a re-evaluation of whether we should pursue that element. Some potential barriers to implementing the elements could include:

- existing financial constraints faced by provincial and territorial health systems;
- limited awareness of the need for improvements in survivor and family transitions, and
- little political will to address the issue compared to other competing healthcare priorities (for example, the opioid crisis and long-term care reform).

These and other barriers are summarized in Table 4.

## **Table 4:** Potential barriers to implementing the elements

| Element | Description of potential barriers |
|---|---|
| **Element 1 –** Support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be moving on after cancer treatment | • Survivors and their families may be concerned that they do not have the ability to play a meaningful role in decision-making about their care transitions.<br>• Some health professionals may see few cancer survivors in their practice and lack the experience needed to support survivor/family needs.<br>• Healthcare providers may face challenges in coordinating with many sectors necessary to help their survivors acquire needed supports.<br>• Some organizations may not have the infrastructure needed to support communication and coordination of survivors transitioning to primary and community care.<br>• Policymakers will face additional costs associated with new training for healthcare providers and investments in information communication technology supports. |
| **Element 2 -** Make sure money flows appropriately to the organizations and professionals that need to support survivors and families in moving on | • Survivors and their families may be concerned that changes to purchasing support services may limit their access to existing programs.<br>• Some healthcare providers may resist changes to how they are paid for fear of reducing income.<br>• Healthcare providers may be incentivized to deliver select services and supports, and unintentionally neglect others.<br>• Some healthcare providers such as nurses and psychologists may not be eligible to receive financial incentives for supporting cancer survivorship.<br>• Some organizations may resist changes to their funding mechanisms for fear of reducing their available budgets.<br>• Policymakers may face political challenges in proposing changes to the funding and remuneration of healthcare providers and primary- and community-care organizations. |
| **Element 3 –** Help survivors and families learn how to manage the moving-on process after cancer treatment | • Survivors and their families may not be aware of existing or new supports available to them as they transition.<br>• Survivors and their families may be concerned that they do not have the necessary knowledge or skills to manage their own care or to participate in program and service planning.<br>• Health professionals may not have the time needed to support survivors and family, or the knowledge and skills needed to support self-management and provide links to community-based services.<br>• Some organizations may not have the resources (financial or time) to develop and deliver information and education supports for survivors and family members.<br>• Policymakers may be unwilling to dedicate additional funds to finance/support the development of materials. |

The implementation of each of the three elements could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be opened by, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an element.

**Examples of potential windows of opportunity that may exist for this issue**

- **Focus on expanding the home- and community-care sectors:** Federal, provincial and territorial governments are focusing on expanding the home- and community-care sector to help individuals manage their care from home, which could include a focus on improving transitions from specialist services (such as cancer centres) to programs and services offered in primary- and community-care settings.

- **Findings from the Partnership's Transitions Study:** Findings from the Partnership's Experiences of Cancer Patients in Transition study will identify and create awareness around the needs and challenges faced by cancer survivors post-treatment.(3)

- **Existing expertise:** Cancer-care organizations and programs nationally and across select provinces have developed some of the types of expertise required to support the implementation of these elements (for example, BC Cancer Agency, Saskatchewan Health Quality Council, CancerCare Manitoba, Cancer Care Ontario, Canadian Cancer Research Alliance, CanIMPACT, ELLICSR, and Canadian Partnership Against Cancer).(12; 15; 63-74)

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