

# Evidence Brief

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

27 March 2018



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**Evidence Brief:**  
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Primary- and Community-care Supports in Canada**

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## McMaster Health Forum

### 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.

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### Conflict of interest

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## KEY MESSAGES

### What's the problem?

- Four main factors underpin existing challenges in optimizing survivor and family transitions from cancer treatment to primary- and community-care supports in Canada:
  - the burden that cancer is placing on health systems in Canada is increasing;
  - additional supports are required to meet the needs of cancer survivors who are transitioning into primary- and community-care settings;
  - the best ways to optimally support survivor and family transitions remain poorly understood; and
  - system-level factors can make it complicated to ensure survivors and their families are supported.

### What do we know (from systematic reviews) about three viable elements to address 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 transitions; 2) equipping health professionals and teams to identify and address the full range of survivor and family needs; and 3) creating the systems and processes to support 1 and 2.
  - Reviews about this element showed that the use of information technology had positive effects on improving coordination and communication supports. There is uncertainty regarding benefits of: 1) models of care that aim to improve the coordination of cancer treatment between primary-care and oncology-care providers; 2) survivorship-care plans; and 3) patient-navigation programs.
- Element 2 – Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community
  - This element could include a number of changes to how: 1) primary- and community-care organizations involved in providing support services are funded; 2) providers of these services are remunerated; 3) the needed programs, services and drugs are purchased; and 4) incentives (and potential disincentives) for accessing programs, services and drugs are used.
  - Overall there is a lack of evidence focused specifically on funding approaches to support transitions out of cancer treatment. Mixed results were found with respect to the effectiveness of approaches specific to cancer care.
- Element 3 – Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship
  - 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.
  - No clear evidence was found for approaches to ensure information and education supports.
  - Group-based self-management programs and self-management education interventions were found to improve physical and psychological functioning in patients with cancer.

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

- While many barriers to implementing these elements may exist at the level of patients/individuals, providers, organizations and systems, perhaps the biggest barriers lie in the existing financial constraints faced by provincial and territorial health systems, limited awareness of the need for improvements in survivor and family transitions, and the little political momentum behind addressing the issue compared to other health-system priorities.
- Windows of opportunity for implementing these elements might include: 1) a growing focus on expanding the home- and community-care sector to help individuals live well beyond the diagnosis; 2) findings from the Canadian Partnership Against Cancer's Experiences of Cancer Patients in Transition study that will identify and create awareness around the needs and challenges faced by cancer survivors post-treatment; and 3) cancer-care organizations and programs across select provinces have developed some of the types of expertise required to support the implementation of these elements.





## REPORT

It is estimated that one in every two Canadians will develop some form of cancer over their lifetimes.(2) While the number of Canadians diagnosed with cancer is increasing, advancements in treatment have improved the likelihood of survival.(3) Although there is variability depending on a number of factors (e.g., cancer type, age and sex), the five-year age-standardized net survival for people diagnosed with cancer is now 60%.(2) As such, the majority of people with a cancer diagnosis are surviving for several years after their diagnosis. As this trend continues, the number of individuals completing their treatment and transitioning out of the cancer system will also increase, creating a need for the primary- and community-care sectors to enhance capacity to support their survivorship.(4)

Despite this need, the reality is that in many jurisdictions across Canada, the provision of cancer programs, services and drugs is still handled by a parallel cancer sub-system that has little overlap or integration with primary care and community care.(5)

In considering this aspect of how caring for patients with cancer is handled, it is important to recognize that many cancer sub-systems across the country share some or all of the following characteristics:

- planning, oversight and accountability falling to arm's-length crown agencies or separate branches within ministries of health;
- unique funding arrangements that are specific to the organizations within cancer sub-systems, alongside specific programs designed to pay for the unique programs and services needed by patients with cancer; and
- treatment that is often centralized in specialist hospitals that serve entire regions within jurisdictions.(5)

Given these characteristics, many cancer sub-systems in the country currently skew the balance of their efforts towards disease treatment, despite an increasing awareness that (and growing need to support) cancer survivorship is an important part of the cancer journey. With this imbalance, many individuals finish treatment, transition out of the cancer sub-system and back into the broader health system without accessing the full range of supports they need.(1) Ironically, a mismatch between what individuals need after treatment and what primary- and community-care programs and services

### Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three elements for addressing the problem, and key implementation considerations. It was developed as a way to build on the findings of the Canadian Partnership Against Cancer's transitions study, which served as a jumping off point for the brief.(1) Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved five steps:

- 1) convening a Steering Committee comprised of representatives from the Canadian Partnership Against Cancer, Canadian Cancer Society, Institut de la Statistique du Québec, Cancer Care Ontario, and McMaster University (including the McMaster Health Forum);
- 2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three viable elements for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
- 3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, elements and implementation considerations;
- 4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
- 5) finalizing the evidence brief based on the input of several merit reviewers.

The three elements for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or in a sequenced way, and each element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants' views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

currently provide to them has emerged despite a growing awareness of the important role these sectors play at different points during a patient's cancer journey (e.g., prevention, screening, diagnosis, treatment support, end-of-life care, recovery or survivorship).(3; 4)

Adding another dimension to the issue is the fact that cancer survivorship is poorly understood, and an often neglected phase of the cancer journey when compared to other parts of the cancer-care continuum.(6) Cancer survivors require ongoing additional supports and medical care for years following treatment.(6) As they transition, challenges include a range of physical, psychosocial and functional issues.(6-8) It is also important to recognize that there are a number of long-term impacts that can result from cancer treatment, which vary based on a number of factors (e.g., cancer type, treatment type, age, and sex). For example, childhood and young adult cancer survivors have a unique set of survivorship needs compared to adult-onset survivors (e.g., infertility, entry/re-entry into education or workforce).(9-12)

In 2016, the Canadian Partnership Against Cancer (hereafter referred to as the Partnership) initiated a study across the 10 provinces to understand the challenges associated with survivor transitions.(1) The overarching aims of the study were to identify common challenges and use the insights gained as a jumping-off point for a national discussion about how jurisdictions could share experiences and develop innovative solutions. The Partnership worked in collaboration with cancer agencies and programs across Canada to conduct a survey focused on understanding the experiences of cancer survivors as they transition from the end of their cancer treatment (e.g., surgery, chemotherapy, radiotherapy, etc.) to follow-up care (e.g., primary and community care).(1)

A total of 13,319 cancer survivors participated in the survey, with representation from all 10 provinces.(1) The majority of study participants 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 sample included adolescents and young adults aged 18-29 with any form of non-metastatic cancer and metastatic testicular cancer (n=329), as this group has a unique set of challenges. The needs of survivors were examined (e.g., physical/symptom burden and emotional/psychosocial, informational and practical challenges), as well as the influencers of their needs, the extent to which their needs were met, the types of support accessed to meet their needs, and the enablers and barriers that affected whether and how their needs were (or were not) met.(1)

## **Box 2: Equity considerations**

A problem may disproportionately affect some groups in society. The benefits, harms and costs of elements to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use "PROGRESS," which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in "precarious work" arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Canadians, but (where possible) it also gives particular attention to two groups:

- people living in rural and remote areas; and
- linguistic minorities or particular ethnocultural groups.

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11-12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

Preliminary findings from the study indicate that:

- adult participants continued to experience physical (87%), emotional (78%) and practical challenges (44%) one to three years after treatment;
- the majority of adolescents and young adult participants continued to have physical (90%), emotional (89%) and practical challenges (78%) one to three years after treatment;
- survivors experienced 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;
- 28% to 57% of adult survivors did not seek help for their concern(s), 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%);
- for both emotional and practical concerns, almost 20% of adult participants reported that they did not seek help because they did not want to ask, and 18% were unaware that services were available to address their practical concerns;
- some adult survivors who tried to get help reported waiting too long for some concerns (e.g., 11% waited more than a year) or did not get help at all (42%); and
- almost all adult participants (98%) reported having a primary-care provider, but a third of these reported that their primary-care provider was not actually involved in their care.(1)

The Partnership's analysis of the study is ongoing and leading practices to improve the transition experience for cancer survivors have not yet been identified.(1) However, preliminary findings from the study concluded that much needs to be done across Canada to better support survivors when cancer treatment ends.

This evidence brief, and the stakeholder dialogue it was designed to inform, has been developed within the context of the findings of the transitions study. The focus of the brief is to mobilize the best-available data and research evidence in order to clarify the most important problems underpinning survivor transitions, to frame three elements of a potentially comprehensive approach for addressing these problems, and to identify implementation considerations. The aim is to provide evidence-informed insights that will serve as a jumping-off point for dialogue participants who will bring their own views and experiences to bear on the issue as well. Ultimately, this could spark important insights that will underpin future efforts to optimize survivor and family transitions out of cancer treatment in Canada.

## Key definitions

We recognize that there are a range of terms used to refer to patients with cancer and survivors (e.g., person with cancer, people who have been through cancer, cancer thriver, etc.). Specifically, a number of the 17 key informants we interviewed in preparing this brief suggested that important distinctions need to be made between being a cancer survivor and survivorship. For the purposes of this brief, we apply the definitions provided by the National Cancer Institutes, which is consistent with the research literature in the field. The term cancer survivor is used to refer to a person from the point of cancer diagnosis until the end of life.(13) Survivorship refers to a distinct phase within the cancer journey and is specific to the health and life of a person post cancer treatment.(6; 13) 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.(13)

**Table 1: Definitions of key terms**

<b>Term</b>	<b>Working definition</b>
Cancer patient	Someone who was been diagnosed with cancer and is in the treatment process.(14)
Cancer survivor	The term survivor is used to refer to a person from the point of cancer diagnosis until the end of life.(13)
Cancer treatment	There are at least five groups of cancer treatments including surgery, transfusion or transplant therapies (e.g., bone marrow or stem cell), radiation therapy and chemotherapy (which includes drug therapy), as well as a number of therapies that fall under complementary and alternative medicine. Those living with cancer are given individualized treatment plans based on cancer type, stage and personal factors (e.g., individual preferences and circumstances).(1; 15)
Support services	Cancer support services (e.g., peer support, information services and online communities) offer assistance and information for individuals affected by cancer.(16)
Survivorship	Survivorship in cancer “focuses on the health and life of a person with cancer post treatment until the end of life”.(13) 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, detection and management of comorbid conditions (e.g., cardiac conditions and mental health).(4)

**THE PROBLEM**

Increases in cancer prevalence coupled with improvements in cancer treatment efficacy and the growing aging population mean that the primary-care and community-care sectors will play an important role in cancer survivorship.(4; 17; 18) However, as the previous section highlighted, survivors (and their families) across the country are not currently receiving the supports they need as they transition from the cancer sub-systems in which they receive treatment into these sectors.

The factors underpinning the problem can be broken down into the following four themes (Figure 1):

- 1) the burden that cancer is placing on health systems in Canada is increasing;
- 2) additional supports are required to meet the needs of cancer survivors who are transitioning to primary- and community-care settings;
- 3) the best ways to optimally support survivor and family transitions remain poorly understood; and
- 4) system-level factors can make it complicated to ensure survivors and their families are supported.

**Figure 1. Factors contributing to the challenge related to survivor and family transitions from cancer treatment to primary- and community-care supports**

**Box 3: Mobilizing research evidence about the problem**

The available research evidence about the problem was sought from a range of published and ‘grey’ research literature sources, while findings from the Canadian Partnership Against Cancer’s Experiences of Cancer Patients in Transition Study were used as a key source of information to help frame various aspects of the problem, and provided data to support a number of points made about the problem.(1) Published literature that provided a comparative dimension to an understanding of the problem was sought using three health services research ‘hedges’ in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Grey literature was sought by reviewing the websites of a number of domestic and international organizations, such as the Canadian Cancer Society, Canadian Partnership Against Cancer, Statistics Canada, and Organisation for Economic Cooperation and Development.

Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada), and that took equity considerations into account.



## **The burden that cancer is placing on health systems in Canada is increasing**

The burden that cancer is placing on health systems in Canada is increasing and is likely to continue to grow due to at least four inter-related reasons: 1) increases in the number of individuals diagnosed with cancer; 2) increases in the aging population; 3) the improved likelihood of cancer survival; and 4) the financial impact of cancer. First, the number of new cancer cases has continued to rise across Canada, with an estimated 206,200 new cancer cases and approximately 80,800 deaths from cancer in 2017, which were higher than previous years.(2) As mentioned in the introduction, it is estimated that one in every two Canadians will develop some form of cancer over their lifetimes, and the number of cancer cases is projected to be 79% higher in 2028 to 2032 than it was in 2003 to 2007.(2)

Second, the burden of cancer is increasing, which is due in part to the growing number of Canadians aged 65 or over.(19) The majority (90%) of those who develop cancer in Canada are over the age of 50.(2) There has been a demographic shift in the population, and for the first time in census history there are more persons aged 65 years and older in Canada than children under 15.(17; 18) In addition, it is estimated that the number of Canadians aged 65 and older is expected to more than double, from 4.2 million in 2003 to 2007 to 9.4 million in 2028 to 2032.(2; 20; 21) These factors suggest that the number of people living with or surviving cancer will continue to grow as the incidence of cancer increases with the aging population.(6)

Third, despite increases in the number of people diagnosed with cancer and increases in the aging population, there is a much higher chance of surviving after a diagnosis today than even a decade ago.(22) The average five-year net survival rate for people diagnosed with any type of cancer in Canada is 60% (although this varies across types of cancer), and while the total number of cancer deaths per year continues to increase, the rates at which people are dying from cancer are declining.(2) Reports also show that 810,045 Canadians who had been diagnosed with cancer in the preceding decade were still alive in 2009, and that by 2031 nearly 2.2 million Canadians will be living with a cancer diagnosis.(19; 22) With advances in prevention, diagnosis, detection and treatment, more than one million people in Canada are living as cancer survivors, and the total number of cancer survivors is expected to continue to increase in the future.(2; 6)

Fourth, the burden of cancer has a significant financial impact on health systems. The combination of increases in the number of individuals diagnosed with cancer and the aging population, along with the improved likelihood of cancer survival, mean that health systems are expected to face increasing demand for cancer services.(2) The economic burden of cancer in Canada has more than doubled from \$2.9 billion in 2005 to \$7.5 billion in 2012.(23) Hospital care expenditures made up the largest portion of costs, which is attributable to increased costs of hospital-based care (e.g., chemotherapy and radiation therapy expenditures), followed by physician care, drug expenditures and other expenditures.(23) The cost of cancer is likely significantly higher today, given the increases in the number of individuals diagnosed with cancer, inflation, underestimates in actual hospital care expenditures, and the increasing costs of cancer treatments.(23; 24)

## **Additional supports are required to meet the needs of cancer survivors who are transitioning into primary- and community-care settings**

As a result of advances in cancer treatment, the majority of those diagnosed with cancer will survive, however, this creates a new set of unique needs for which they need support. For instance, survivors will be at risk of developing late and long-term effects of treatment.(6) These effects include physical, psychological, social and financial, which have an impact on both the individual and their families.(3) While some of these effects will occur during the treatment process, many will develop over time and even years after primary treatment.(6) Common long-term effects include fatigue, pain, infertility, learning and memory issues, anxiety and depression.(6; 25) Late-term effects include musculoskeletal conditions (e.g., osteoporosis), organ dysfunction (e.g., heart disease) and the development of a second cancer.(3; 6) Research on the late and long-term effects of treatment indicate that approximately 25% to 30% of patients with cancer will develop some form of psychological disorder during the cancer continuum, including the survivorship phase.(3)

In addition, transitions in care following treatment to survivorship also require new adjustments in how survivors and their families interact with the health system. Specifically, as survivors transition from cancer care to primary- and community-care settings, follow-up care requires primary-care providers to manage the late and long-term effects of treatment (e.g., comorbid conditions and psychological disorders) as well as monitor for signs of recurrence.(4) However, the primary- and community-care sector and the cancer sub-system often function in relative isolation from one another. As such, survivors and their families are likely unaware of the scope and nature of survivorship supports that they ought to be receiving. Past and present cancer care initiatives in Canadian health systems have narrowly focused on improving the cancer sub-system, while overlooking the full range of settings within which individuals may receive care outside of cancer treatment centres (e.g., primary- and community-care settings). In follow-up care, survivors require additional supports for symptom management, psychosocial needs and lifestyle behaviour change.(26; 27) These transitions can be made even more difficult if survivors are suffering from symptoms that negatively affect their daily lives at any point in the cancer journey.(28)

### **The best ways to optimally support survivor and family transitions remain poorly understood**

Despite widespread acknowledgment of their importance, optimal pathways in terms of provider roles and responsibilities in survivorship care remain poorly understood.(29) Transitions from treatment in a regional cancer centre to survivorship in the community require clarity about: 1) which part of the system (e.g., the primary- and community-care sectors or the cancer care sub-system), and who in that system (e.g., physicians or nurses), will address the physical, emotional and social late 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; and 3) how the communication, coordination and integration between these sectors will work.(3; 4; 30-35)

Additionally, the transition from treatment to survivorship is a shift from siloed care between medical specialties in the cancer sub-system back to the broader health system.(36) As a result, the transition to survivorship is often accompanied by challenges in information flow (e.g., between cancer specialists and primary-care providers), and the potentially competing interests between healthcare providers.(36) This is further complicated by the fact that the primary- and community-care system is focused on providing continuous, comprehensive primary care through the lens of the whole person (e.g., addressing all comorbidities, emotional and social issues, and ethnocultural issues),(36) while the cancer care sub-system is typically focused on providing secondary and tertiary care through the lens of one disease. For survivors and their families, this lack of clarity may be one factor which contributes to a sense of not knowing what to expect once their cancer treatments have been completed.(27; 28) This can lead to feelings of abandonment or loss of appropriate care supports as they transition.(36; 37)

To better understand the unique challenges faced by survivors and their families during these transitions, as well as the optimal ways to overcome these challenges, a number of survivorship initiatives have been pursued across Canada. To date, the majority of survivorship initiatives are focused on specific jurisdictions or supported by targeted research investments.(6) Examples of these initiatives include:

- the ELLICSR Health, Wellness, and Cancer Survivorship Centre located at the Toronto General Hospital, which is funded by the Canadian Foundation for Healthcare Innovation, the Ontario Research Fund and the Princess Margaret Cancer Foundation, and focused on collaboration between researchers, healthcare providers and cancer survivors to better understand survivorship;(40)
- Caring for Cancer Survivors in Family Medicine, which is based at McGill University Health Centre and focuses on providing educational workshops for primary-care providers in Montreal;(38; 39)
- efforts by the Saskatchewan Cancer Agency to provide a range of informational and support services to patients throughout their cancer journey,(40) by CancerCare Manitoba to provide supports to survivors after treatment through the Moving Forward After Cancer Treatment Program,(41) and by Cancer Care Nova Scotia and the Eastern Health Cancer Care Program in Newfoundland and Labrador to implement the Cancer Transitions: Moving Beyond Treatment Program, a program which focuses on supporting



survivors after treatment through a number of initiatives including supports for exercise, emotional and physical well-being, nutrition, and navigating the health system as a survivor;(42; 43)

- efforts by Cancer Care Ontario's Program in Evidence-Based Care to describe the core models of survivorship follow-up care, and understand the clinical outcomes and survivor quality-of-life outcomes associated with the models;(31; 44)
- the Cancer and Work website ([www.cancerandwork.ca](http://www.cancerandwork.ca)), which is an initiative led by faculty at McGill University and the BC Cancer Agency in partnership with the de Souza Institute (and with funding support from the Canadian Partnership Against Cancer and Health Canada), with the aim of providing information and resources about returning to work for cancer survivors, healthcare providers and employers;(45)
- the Cancer Outcomes Research Program, which is based at Dalhousie University's Department of Surgery and focuses on researching the cancer-care continuum with a special interest on issues related to cancer treatment and cancer survivorship, as well as the interface between specialist and primary care (Stream 2: Cancer health services research);(46) and
- the Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT) which is funded by the Canadian Institutes of Health Research, focused on understanding continuity and coordination of care in seven provinces, patient perspectives along the cancer continuum and best practices,(47) and which has resulted in a number of important outputs such as:
  - a 2015 casebook, which collected and presented data on 24 initiatives in Canada focused on improving coordination cancer care along the continuum,(48; 49) and
  - a 2016 consultative workshop focused on developing recommendations for improving integration of care between cancer specialties and primary care, which built on the insights provided by 74 participants representing nine provinces (primary-care providers, cancer specialists, policymakers, managers, researchers, and patients).(50)

In addition to these initiatives, there has been an explicit acknowledgment of cancer survivorship as a policy focus by a number of cancer-care organizations at the provincial level, including the BC Cancer Agency, Saskatchewan Health Quality Council, CancerCare Manitoba and Cancer Care Ontario, with both the Canadian Cancer Research Alliance, and the Partnership establishing the same priority at the pan-Canadian level.(41; 51-56) Furthermore, a number of community-support organizations focused on cancer survivorship have been established across the country, including the Canadian Cancer Society, Gilda's Club, Wellspring, and Young Adult Cancer Canada.(16; 45; 57-59)

Despite this clear progress in cancer survivorship initiatives across Canada, efforts remain fragmented.(6) Survivorship initiatives are most often not coordinated and research is primarily led by individual researchers with limited collaboration across the range of stakeholders (e.g., interdisciplinary researchers, decision-makers, cancer survivors, and families/caregivers).(6) The CCRA's Pan-Canadian Framework for Cancer Survivorship Research focuses on four key directions to coordinate survivorship research in Canada through: 1) engaging cancer survivors and their family/caregivers; 2) aligning research funding with population needs; 3) knowledge translation to support collaborative research that includes healthcare providers and decision-makers; and 4) creating and maintaining research capacity and infrastructure (e.g., longitudinal database).(6) As these domains are increasingly addressed through targeted research initiatives over the medium and long term, some of the challenges outlined above may be addressed. However, given the magnitude of the challenges outlined in this section, it is clear that more immediate efforts to address the full range of challenges identified are needed.

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

A number of system-level challenges further complicate efforts to optimize survivor and family transitions from cancer treatment to primary- and community-care supports. We describe several notable challenges related to health-system governance, financial and delivery arrangements.



*Governance arrangements*

There are two main challenges related to governance arrangements and optimizing survivor and family transitions. In a number of jurisdictions across Canada, the majority of cancer care is planned for and overseen in relative isolation from other sectors, with little coordination or collaboration with other sectors (e.g., primary care). In many cases, this has led to a misalignment between patient needs and the programs and services they can access across the cancer continuum. However, it is increasingly becoming the norm to explicitly acknowledge the role of primary-care providers in cancer follow-up guidelines in a number of jurisdictions (e.g., Ontario) for specific types of cancer (e.g., colorectal cancer).(60)

The second governance challenge relates to the lack of formal feedback mechanisms in primary- and community-care settings. While there are often mechanisms for patients with cancer to provide feedback and express their specific needs during treatment in specialty-care settings, similar efforts to engage survivors in their care and in continuous quality improvement are absent in the settings that are integral to their survivorship experience. In addition, while the majority of community-based charities or not-for-profit organizations that provide support to cancer survivors collect feedback from individuals accessing their programs, this information is rarely fed back into publicly-funded provincial health systems to inform decision-making.

*Financial arrangements*

Funding for cancer-care programs and services tends to be approached separately from those provided in primary- and community-care settings, which creates a situation in which the approaches for funding programs and services in specialty-care settings are not coordinated with the approaches used to fund supports for survivors and their families after treatment and outside of these settings. To further highlight issues related to financial arrangements for optimizing survivor and family transitions, we provide below a high-level summary of the array of financial arrangements that are used for both publicly and privately financed cancer-care supports, to give a sense of the nature of the systems. These include:

- many programs and services provided in communities that support survivors and families transitioning from cancer treatment operate outside of the health system and are funded by other government ministries (or through private sources, including charities);
- many jurisdictions in Canada fund cancer-care organizations for delivering specific services to patients in a single setting, rather than funding an entire bundle of services that may be delivered across a number of settings (e.g., from hospital to primary care) and by a number of different providers (e.g., physicians, nurses, social workers, nutritionists, etc.); and
- despite the unique nature of supporting survivors transitioning from cancer treatment to survivorship in primary- and community-care settings, few jurisdictions in Canada have specific remuneration mechanisms in place that:
  - support the greater involvement of professionals working in these settings in the provision of follow-up care (unlike many chronic diseases such as diabetes, for which targeted payments are often provided to support disease-specific care such as self-management support and symptom management),
  - support specialists to encourage survivor and family transitions to primary- and community-care settings after treatment is completed (e.g., by paying them less for follow-up visits than for visits during active treatment), and then to work with providers in primary- and community-care settings once the transition has taken place, or
  - can ensure the proper supports are in place for comprehensive follow-up care (e.g., digital consultations through robust telehealth systems).

### *Delivery arrangements*

The main challenges associated with delivery arrangements stem from the fact that cancer survivors have an array of complex needs, such as a requirement for supports in follow-up care to address their physical, emotional and practical needs, as well as supports for managing multiple comorbidities that may arise as they age. These needs have been overlooked in a number of health systems, including in Canada.(61; 62) This may be related to four distinct aspects of health systems across Canada.

First, cancer sub-systems and primary- and community-care sectors have traditionally been poorly integrated across Canada, which can contribute to insufficient transition planning to guide survivors and families through their next steps as they move out of cancer-treatment centres. As highlighted by the preliminary results of the Partnership's transition study, despite being available, many survivors are not aware of or do not receive a formal written plan for their follow-up care either during or after treatment.(1) Specifically, just over one-third of adolescents and young adults reported receiving one, and 40% of adults older than 30 reported receiving one either during or after treatment.

Second, coordination is typically poor across providers, with too few efforts to integrate team-based care in primary- and community-care settings. For instance, just over 40% of adult cancer survivors surveyed in the transition study rely solely on their cancer specialists and their oncology team in the years following treatment. While more than half suggested that the coordination between healthcare providers during this stage was either good or very good, approximately 17% felt it was only fair, poor or very poor. With respect to team-based care, while some jurisdictions are increasingly moving towards interdisciplinary teams and the realignment of primary-care systems to provide individuals with comprehensive care that addresses many interrelated needs, most have little access to, or interactions with, healthcare teams that can help to address their wide range of needs as they transition from cancer treatment to survivorship in primary- and community-care settings. This is particularly important given broad agreement that the engagement of interdisciplinary teams across the continuum of care is needed to support survivors throughout their journey.(28)

Third, healthcare providers in primary care often have little, if any, specialty training in how to support cancer survivors or their families with the most appropriate, effective and person-centred follow-up care.(29)

Fourth and finally, although many cancer centres routinely assess and monitor a wide range of patient needs (e.g., those related to symptom burden, emotional and psychosocial needs as well as informational and other practical considerations), these assessments are rare in primary- and community-care settings.(36; 63) As a result, once survivors transition into these settings, there are few (if any) opportunities for a comprehensive assessment to establish the full range of needs they have, and then develop a tailored care plan that can adequately address these needs.

As highlighted in the previous section, work being pursued through the CanIMPACT project may serve as a logical jumping-off point for determining how best to address the full range of challenges outlined above, given its focus on determining the optimal survivorship models through coordination of care between cancer specialists and primary healthcare providers,(9; 34; 47; 49; 50; 61) as well as its focus on integrated cancer-care teams, and more generally how best to integrate and align cancer specialty services with primary care along the entire continuum of cancer care (61; 64)

### **Additional equity-related observations about the problem**

As noted in box 2, an important element of the problem that requires further discussion is how the problem may disproportionately affect certain groups or communities. With respect to optimizing survivor and family transitions from cancer treatment to primary- and community-care supports in Canada, many groups warrant attention. Based on feedback from the 17 key informants we interviewed in preparing this brief, we focus on those living in rural or remote areas, and linguistic minorities or particular ethnocultural

groups (which could include recently arrived immigrants and refugees, minority populations, Indigenous peoples, and certain religious groups). We recognize that there are unique issues related to certain age groups as they transition and that cancer survivorship is very different for young adults than it is for the older adult population.(2; 6) Where available, we also present the evidence as it relates to particular challenges that these age groups face.

People living in rural or remote areas often experience difficulties accessing healthcare services, which affects a large number of people given that:

- approximately one in five (19%) Canadians live in rural areas (defined by Statistics Canada as those with a population less than 1,000 and with less than 400 persons per square kilometre);(65) and
- there are 292 remote communities in Canada with a total population of approximately 194,281 (remote communities do not have year-round access to roads or they rely on a third party for transportation such as ferry or airplane).(66; 67)

Given that health professionals, programs and services are not distributed equitably across geographic areas in Canada, individuals living in rural and remote areas often face barriers to accessing needed healthcare services. These barriers include isolation from medical and psychosocial supports, and significant travel required for primary- and community-care supports.(6; 68) For young adult cancer survivors, living in rural areas has been associated with delayed diagnosis and lack of community supports when compared to living in urban settings, although those living in rural settings are more satisfied with their care, which could mean they are more appreciative of it when they can access the services they need.(68) On the other hand, there are specific challenges facing older adults living in these settings as well, which is particularly important given they account for a significant proportion of the rural and remote population, particularly in Atlantic Canada where they make up half of rural and remote populations.(69) Older adults also make up the majority of cancer patients, with the median age of cancer diagnosis now between 65 and 69 years of age.(2) It should also be noted that 60% of survivors participating in the transitions study were 65 years of age or older.(1)

Individuals from different ethnocultural communities may differ from the general population in their understanding of the cancer-care journey, and in their values and preferences for survivorship care. For example, groups may differ in whether they ascribe to a more biomedical, biopsychosocial or specific ethnocultural (e.g., traditional eastern) model,(70) and in whether they give significant weight to spiritual, social or environmental factors, or to Indigenous ways of knowing. Such understandings, values and preferences can include whether and from whom they seek support for follow-up care and their adherence to what is recommended.(71) Language differences may further complicate the situation. Many health professionals have not received training in cultural competencies and how to adapt their approaches to survivor and family transitions from cancer treatment to primary- and community-care supports.

### **Citizens' views about key challenges related to survivor and family transitions from cancer treatment to primary- and community-care supports in Canada**

Two citizen panels were convened in Hamilton (Ontario) on 2 March 2018, and Quebec City (Quebec) on 9 March 2018. The Hamilton panel consisted of English-speaking panellists from across the country. The Quebec City panel was conducted in French and panellists were all from the province of Quebec. A total of 22 ethnoculturally and socio-economically diverse panellists were provided with either an English or French abridged version of the evidence brief, which was written in plain language.(72) Panellists were cancer survivors for one of five types of non-metastatic cancer (breast cancer, colorectal cancer, hematological cancer, melanoma, and prostate cancer) and had experiences with a variety of programs and services along the cancer-care continuum.

During the deliberation about the problem, panellists reviewed the preliminary findings from the transitions study and were asked if their experiences were similar to those reported in the study. We also asked panellists to identify the biggest gaps in supports available to survivors and their families' post-treatment. Panellists

agreed with the points raised in the citizen brief about what is driving the problem. However, in deliberating about the problem based on their views and experiences, they focused on seven areas that seem particularly challenging in terms of transitions from cancer treatment to primary- and community-care supports: 1) limited coordination and integration between primary 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 are not always identified and addressed; 4) limited involvement of survivors and their families in care to determine the types of supports needed after primary cancer treatment; 5) access to supports from primary and community care is not the same 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. We describe the specific challenges raised in relation to these six areas in Table 2 below.

**Table 2. Summary of citizens’ views about challenges**

Challenge	Description
<p>Limited coordination and integration between primary cancer treatment and primary- and community-care supports</p>	<ul style="list-style-type: none"> <li>• Most panellists agreed that there are significant challenges in communication between the range of health professionals, particularly between specialists (e.g., oncologists and radiologists) and between specialists and family physicians during the transition period.</li> <li>• Many described how the lack of communication between health professionals affects the ability of survivors and their families to ensure coordinated follow-up care in terms of knowing what types of supports are needed and what is available.</li> <li>• 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.”</li> <li>• As result of the limited coordination and integration, many panellists mentioned that there is too much reliance on survivors and their families to find their own way in the system by: 1) coordinating care between health professionals and settings; and 2) becoming experts in navigating the system in a way that allows them to integrate the different components of their care.</li> </ul>
<p>Limitations in information and communication technology infrastructure create challenges for those who receive and provide care</p>	<ul style="list-style-type: none"> <li>• The majority of panellists cited limitations in information and communication technology infrastructure as one of the main challenges to supporting coordination between health professionals and sectors.</li> <li>• Many panellists expressed frustration with the long-standing difficulties with implementing electronic medical records and electronic health records which impede optimal transition.</li> <li>• A number of panellists had professional experience in other fields (e.g., police and armed forces) and described successful electronic information-sharing systems. They expressed frustration as to why such robust infrastructures can exist in some social policy domains to share sensitive data, but not be adopted in healthcare, which has similar types of privacy and security concerns.</li> </ul>
<p>A siloed approach means that the range of concerns are not always identified and addressed</p>	<ul style="list-style-type: none"> <li>• The majority of panellists discussed experiences with the late and long-term effects of cancer treatment, primarily psychological (e.g., anxiety and depression) and physical (e.g., dealing with scars and intimacy issues), and that the siloed approach limited their ability to get appropriate supports.</li> <li>• Many panellists discussed that the siloed approach in cancer care limits learning from other systems and cited this as a lost opportunity for efficiencies.</li> <li>• Panellists also noted that many of the survivorship programs are working in isolation from each other, and that there is a need for a core program that can be modelled and tailored based on individual needs.</li> </ul>

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<p>There is limited involvement of survivors and their families in care to determine the types of supports needed after primary cancer treatment</p>	<ul style="list-style-type: none"> <li>• Panellists highlighted that the transition is different for everyone and as a result the package of supports needs to be customized based on the individual, but this is challenging or impossible without meaningful engagement of survivors and their families to identify these needs.</li> <li>• Some panellists discussed the lack of follow-up after primary cancer treatment and that they were not aware of their options in terms of programs and services post-treatment.</li> <li>• One panellist summarized the challenge as, “they are either confused or they don’t know where to go. When you get cancer, you have lost control.”</li> </ul>
<p>Access to supports from primary and community care is not the same for everyone</p>	<ul style="list-style-type: none"> <li>• Many of the panellists discussed variations in the available supports based on where they lived, and some panellists living in rural and remote areas discussed challenges in accessing necessary supports.</li> <li>• As one panellist summarized, “the services are not arranged around needs or efficiency, they are arranged around borders.”</li> </ul>
<p>The transitions phase of the cancer journey is hard to define</p>	<ul style="list-style-type: none"> <li>• Some panellists noted that to understand the transition period, there needs to be a clear understanding of the entire cancer journey, including the diagnosis and treatment periods.</li> <li>• Panellists highlighted that the circumstances and interactions with health professionals during diagnosis will set the tone for subsequent care and the transition period.</li> <li>• Other examples provided by panellists included a cancer patient having a bad experience with their family physician (e.g., significant delays in prescribing needed tests) which affected trust, which in turn had a serious impact on their relationship with their family physician as they transitioned back to primary care.</li> </ul>
<p>Lack of clarity and comfort with terms used to refer to survivorship</p>	<ul style="list-style-type: none"> <li>• Many panellists expressed discomfort with the terms used to refer to the survivorship phase of the cancer-care continuum and felt the term survivor defined them by their cancer diagnosis, which was a constant reminder of the trauma of the experience.</li> </ul>

### **THREE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM**

Many approaches could be selected as a starting point for deliberations about optimizing survivor and family transitions from cancer treatment to primary- and community-care supports in Canada. To promote discussion about the pros and cons of potentially viable approaches, we have selected three elements of a larger, more comprehensive approach to optimizing survivor and family transitions. The three elements were developed and refined through consultation with the Steering Committee and 17 key informants who we interviewed during the development of this evidence brief. The elements are:

- 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) 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 opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship.

The elements could be pursued separately or simultaneously, or components could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and potential of or need for sequencing, and their feasibility.

To inform the two citizen panels convened in March 2018, we included the same three elements of a potentially comprehensive approach to address the problem in the citizen brief as are included in this evidence brief. These elements were used as a starting point for their deliberations. During the deliberations, we identified values and preferences, which we summarize below in relation to each element.

In addition to citizens' values and preferences for each element, the focus in this section is on what is known about these elements based on findings from systematic reviews. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool)(9) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years. In the next section, the focus turns to the barriers to adopting and implementing these elements, and to possible implementation strategies to address the barriers.

#### **Box 4: Mobilizing research evidence about elements for addressing the problem**

The available research evidence about elements of a potentially comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence ([www.healthsystemsevidence.org](http://www.healthsystemsevidence.org)), which is a continuously updated database containing more than 6,200 systematic reviews and more than 2,500 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of each of the elements and sub-elements.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were 'empty' reviews), while others concluded that there was substantial uncertainty about the element based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

**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 is set within the context of individuals who are deemed eligible to transition out of treatment, but would include the full range of efforts – including during treatment – that could help to facilitate a smoother transition out of treatment when the time comes (e.g., earlier screening for potential emotional and physical challenges that could persist post-treatment). The approach would include efforts that could improve the process of moving across providers and settings for survivors and families by focusing on three sub-elements representing key dimensions that are required to facilitate successful transitions:

- 1) engaging survivors and their families in conversations about transition from treatments, and into survivorship care that includes primary- and community-care supports, and supporting the active engagement of these survivors and their families in identifying all of their potential needs (including those that exist during treatment but that could persist post-treatment) and in decision-making about whether and how to proceed;
- 2) equipping health professionals and teams to identify and address the full range of survivor and family needs, which could be supported through:
  - developing and supporting the use of best-practice guidelines,
  - adjusting curricula used in professional training programs to ensure non-specialist providers who plan to practise in primary-care settings have a baseline knowledge of supporting survivors with cancer transitioning from treatment,
  - training existing non-specialist providers practising in primary-care settings on core aspects of supporting survivors with cancer transitioning from treatment,
  - providing information and educational opportunities for providers who want to increase knowledge and skills related to supporting survivors and families transitioning from cancer treatment to primary- and community-care, and
  - developing and implementing evidence-based assessment tools for primary-care providers to gauge the full range of physical, emotional and practical needs survivors have after transitioning out of treatment; and
- 3) creating the systems and processes to support 1 and 2, by:
  - supporting ‘shared-care’ models in which program and service planning and delivery involve multiple providers from both speciality-care settings as well as from primary- and community-care settings,
  - defining provider roles to clarify who is responsible for what during survivor and family transitions (e.g., establishing family physicians as the coordinators of patient follow-up care after treatment),
  - defining optimal survivor care pathways,
  - establishing community partnerships to support better planning and integration between primary-care providers and community care,
  - improving communication supports that facilitate better coordination of patient information across providers and settings (e.g., information communication technology systems that ensure the transfer of patient information to the appropriate settings and providers, and patient-held medical records), and
  - making better use of information tools to help navigate the system (e.g., survivorship-care plans and nurse navigators).

*Key findings from the citizen panels*

There were three main values-related themes that 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; and
- efficiency of the transition process, with a particular focus on the flow of information

The 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 (e.g., 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.

In relation to the third values-related theme of 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 this needs to be central to achieve efficient coordination and integration between primary cancer treatment and primary- and community-care supports.

*Engaging survivors and their families in conversations about transition from treatment into survivorship care*

For the first sub-element, engaging survivors and their families in conversations about transition from treatment into survivorship care, we identified three systematic reviews focused on decision-making processes between healthcare providers and patients in cancer care.

One recent medium-quality review found that the building of critical skills in manoeuvring the initial medical encounter, gaining patient trust, engaging with the patient's extended family, addressing patients appropriately according to their cultural preference, and engaging in culturally sensitive communication was key to physician-patient relationships.<sup>(73)</sup> The importance of acquiring sound factual knowledge and an understanding of various cultural aspects was highlighted in terms of healthcare-provider knowledge.<sup>(73)</sup> Factual understanding of the healthcare provider's and patient's respective cultures, health belief systems, decision-making processes, and standards of etiquette was critical to successful patient-provider communication.<sup>(73)</sup>

Two medium-quality reviews, one recent and one older, found limited but suggestive evidence for positive effects of patient involvement in decision-making.<sup>(74; 75)</sup> The first review found an association between perceived patient involvement in decision-making and quality-of-life outcomes in cancer.<sup>(74)</sup> The second review focused on shared decision-making models for cancer treatment among racial and ethnic minority patients, and found effective provider communication was associated with improved psychological outcomes, quality of life, and physiological functioning, as well as significantly increased adherence to treatment recommendations.<sup>(75)</sup> Despite these benefits, the review found that patients with cancer continued to have high rates of unmet communication needs from their providers, and these unmet needs were amplified among racial/ethnic minority patients.<sup>(75)</sup> Challenges to communication included different communication styles, different medical belief models, language barriers, lack of provider skills in cross-cultural communication, lack of patients' control, lack of providers' knowledge of Indigenous culture and history, distrust of providers and the healthcare system, lack of a personal relationship between the provider and



patient, and an alienating healthcare environment.(75)

*Equipping health professionals and teams to identify and address the full range of patient and family needs*

For the second sub-element, equipping health professionals and teams to identify and address the full range of patient and family needs, we found four systematic reviews focused on training non-specialist providers practising in primary-care settings on core aspects of supporting cancer patients, and one review focused on assessment tools for primary-care providers to gauge the full range of patients' needs.

Of these reviews, three focused specifically on training non-specialist providers practising in primary- and community-care settings on core aspects of supporting transitions. One recent medium-quality review evaluated the impact of multidimensional rehabilitation programs on outcomes of physical and emotional health, as well as health-related quality of life in adult cancer survivors.(76) The review found that unidimensional rehabilitation programs benefit from their focus and demonstrate greater success when compared to multidimensional programs.(76) Including patients with a range of cancer diagnoses in a rehabilitation program demonstrated similar success as cancer site-specific programs, and face-to-face program delivery was most effective.(76) Another recent medium-quality review found that broad-reach intervention delivery modalities for healthy lifestyle programs provide a means to meet the needs of a growing and disparate group of cancer survivors, and may improve health behaviours and in turn treatment-related side effects, quality of life, and health outcomes.(77) One recent medium-quality review identified patient barriers to engaging family physicians in follow-up cancer care, which included lack of solid relationship, poor communication and coordination, issues with diagnosis/treatment, and poor access to facilities.(78) Finally, one older high-quality review that did not focus specifically on transitions, found that healthcare providers involved in cancer care who received communication skills training were significantly more likely to use open-ended questions in post-intervention interviews than the control group, and they were also more likely to show empathy towards patients.(79)

One recent medium-quality review focused on assessment tools for primary-care providers to gauge the full needs of patients. The review assessed how patients are involved as partners in developing patient-reported outcome measures (PROMs) for use with cancer patients, and found that patient samples were often homogenous and did not accurately represent the diversity in age, ethnicity and sex that would be seen in the broader population of a certain disease.(80)

*Creating the systems and processes to support 1 and 2*

For the final sub-element, creating the systems and processes to support 1 and 2, we identified four systematic reviews focused on 'shared-care' models, four systematic reviews on improving communication supports, and seven systematic reviews related to making better use of information tools to help navigate the system.

No clear message emerged from the evidence found on 'shared-care' models to support sub-elements 1 and 2. One recent high-quality review evaluated models of care aimed at improving the coordination of cancer treatment between primary-care and oncology-care providers, and the analysis did not support any one model, largely due to the heterogeneity of outcomes and overall low quality of the studies.(33) Similarly, another recent high-quality review found substantial variation in survivorship-care models and that these models were highly individualized based on the institution and/or care setting.(30) The evidence on survivorship-care models was limited, particularly regarding potential advantages of different models, effects on survivors' health outcomes, structural or process barriers to offering survivorship care, evaluation of existing survivorship programs, and costs and benefits of survivorship care.(30) In addition, one older high-quality review on continuity of care for cancer patients in case management, shared care, and interdisciplinary team models found no significant difference in patient health-related outcomes between patients assigned to the three models compared to those assigned to usual care.(81) Lastly, one older medium-quality review on methods of follow-up care for survivors of childhood cancer found that clinical-care models (e.g., checking

for symptoms and developments) were highly valued among survivors, and supportive care was seen as more important by survivors who had greater clinical needs.(82)

Four reviews found generally positive effects for information technology in facilitating coordination. One older high-quality review found that health information technology (e.g., decision support, telemedicine) had a positive effect on process outcomes (e.g., compliance with standards of care and use of healthcare resources) and facilitated shared decision-making between patients and providers.(83) Patients reported satisfaction with technological support (e.g., telephone follow-up services) in one recent medium-quality review on the impact of technology in follow-up cancer care,(84) and family-caregiver outcomes improved following technological interventions (e.g., telehealth interventions focused on education, consultation, psychosocial/cognitive behavioural therapy, social support, data collection and monitoring systems, and clinical-care delivery) in one recent medium-quality review.(85) One recent low-quality review found that patients widely reported value in having patient-held records to track health, remember events, and share information, however, negative impacts included that some patients viewed patient-held records as the allocation of unwanted responsibility.(86)

Seven systematic reviews focused on making better use of information tools to help navigate the system. Of these reviews, mixed results were found for the five reviews focused on decision-aid and patient-navigator programs:

- one older medium-quality review found that while the effect of a decision-aid and patient-navigator intervention on communication with health providers was found to be positive, and the use of decision aids successfully facilitated shared decision-making and patients' perception of treatment adherence, the use of patient navigators was ineffective; (87)
- one recent high-quality review found that patient-navigation programs increased the likelihood of a patient attending health screening (e.g., cancer screening), and were effective in promoting attendance to care events (e.g., cardiac rehabilitation) and adherence to follow-up treatment (for marginalized minority populations);(88)
- one older medium-quality review found some economic (e.g., reducing readmissions and hospital days), psychosocial and quality-of-life benefits for navigator programs supporting chronically ill older adults through healthcare transitions;(89)
- one recent medium-quality review found that breast care nurse-led programs in the follow-up stage of breast cancer contributed positively to quality of life among patients;(90) and
- one recent high-quality review found no significant difference in quality of life in patients undergoing cancer treatments who had entered navigation programs in comparison to patients who had not.(91)

With regards to the role of survivorship-care plans in making better use of information tools to help navigate the system, no clear message was derived from one recent medium-quality review. No significant differences in health-related quality of life were found for survivorship-care plans.(92) There was some evidence that they may reduce distress, while other evidence suggested that distress may be higher due to increased worry about one's health and negative memories that may be triggered by reading the care plan.(92)

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about the systematic reviews contained in Table 3 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 1.

**Table 3: Summary of key findings from systematic reviews relevant to Element 1 – Improve cancer treatment follow-up through the introduction of supports early in the cancer journey and across the key dimensions of survivor and family transitions**

Category of finding	Summary of key findings
Benefits	<p><b>Engaging survivors in conversation about transition from treatments and into survivorship care</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review found that cultural awareness (e.g., factual understanding of the family physician’s and patient’s respective cultures, health belief systems, decision-making processes, and standards of etiquette) was an essential aspect of delivering culturally competent patient-provider communication in the management of cancer.(73)               <ul style="list-style-type: none"> <li>○ The same review identified the following models for effective cross-cultural communication: Kleinman’s questions; the LEARN Model; the BELIEF Model; and the Four Habits Model of Highly Effective Clinicians.(73)</li> </ul> </li> <li>• One recent medium-quality review found limited but suggestive evidence for a positive association between perceived patient involvement in decision-making and quality-of-life outcomes in cancer.(74)</li> <li>• One older medium-quality review on shared decision-making models for cancer treatment among racial and ethnic minority patients found effective provider communication was associated with improved psychological outcomes, quality of life, and physiological functioning, as well as significantly increased adherence to treatment recommendations.(75)</li> </ul> <p><b>Equipping health professionals and teams to identify and address the full range of survivor and family needs</b></p> <ul style="list-style-type: none"> <li>• Training existing non-specialist providers practising in primary-care settings on core aspects of supporting cancer survivors transitioning from treatment               <ul style="list-style-type: none"> <li>○ One older high-quality review found that healthcare providers involved in cancer care who received communication-skills training were significantly more likely to use open-ended questions in post-intervention interviews than the control group, and they were also more likely to show empathy towards patients.(79)</li> <li>○ One recent medium-quality review found that broad-reach intervention delivery modalities for healthy-lifestyle programs provide a means to meet the needs of a growing and disparate group of cancer survivors, and may improve health behaviours and in turn treatment-related side effects, quality of life and health outcomes.(77)</li> <li>○ One recent medium-quality review found that unidimensional rehabilitation programs benefit from their focus and demonstrate greater success when compared to multidimensional (a focus on improving functioning in both physical and psychosocial domains) rehabilitation programs in adult cancer survivors.(76)</li> </ul> </li> </ul> <p><b>Creating the systems and processes to support 1 and 2</b></p> <ul style="list-style-type: none"> <li>• Improving communication supports that facilitate better coordination of patient information across providers and settings               <ul style="list-style-type: none"> <li>○ One older high-quality review found that health information technology had a positive effect on process outcomes (e.g., compliance with standards of care and use of healthcare resources) and shared decision-making in the patient-clinician context.(83)</li> <li>○ One recent medium-quality review found an improvement in family-caregiver outcomes following technological interventions (e.g., telehealth interventions focused on education, consultation, psychosocial/cognitive behavioural therapy, social support, data collection and monitoring systems, and clinical-care delivery).(85)</li> </ul> </li> <li>• Making better use of information tools to help navigate the system               <ul style="list-style-type: none"> <li>○ One older medium-quality review found that while the effect of a decision aid and patient-navigator intervention on communication with health providers was found to be positive, and the use of decision aids successfully facilitated shared decision-making and patients’ perception of treatment adherence, the use of patient navigators was ineffective. (87)</li> <li>○ One recent high-quality review found that patient-navigation programs increased the likelihood of a patient attending health screening (e.g., cancer screening), and were effective</li> </ul> </li> </ul>

	<p>in promoting attendance to care events (e.g., cardiac rehabilitation) and adherence to follow-up treatment (for marginalized minority populations).(88)</p> <ul style="list-style-type: none"> <li>○ One older medium-quality review found some economic, psychosocial and quality-of-life benefits for navigator programs supporting chronically ill older adults through healthcare transitions.(89)</li> <li>○ One recent medium-quality review found that breast care nurse-led interventions in the follow-up stage of breast cancer contributed positively to quality of life among patients (e.g., symptoms such as constipation, nausea and pain).(90)</li> </ul>
<p>Potential harms</p>	<p><b>Engaging survivors in conversation about transition from treatments and into survivorship care</b></p> <ul style="list-style-type: none"> <li>● One older medium-quality review on shared decision-making models found that cancer patients continued to have high rates of unmet communication needs from their providers, and these unmet needs were amplified among racial/ethnic minority patients.(75)</li> </ul> <p><b>Equipping health professionals and teams to identify and address the full range of survivor and family needs</b></p> <ul style="list-style-type: none"> <li>● One recent medium-quality review identified patient barriers to engaging family physicians in follow-up cancer care, which included lack of solid relationship, poor communication and coordination, issues with diagnosis/treatment, and poor access to facilities.(78)</li> <li>● One recent medium-quality review assessed how patients are involved as partners in developing patient-reported outcome measures for use with cancer patients, and found that patient samples were often homogenous and did not accurately represent the diversity in age, ethnicity and sex that would be seen in the broader population of a certain disease.(80)</li> </ul> <p><b>Creating the systems and processes to support 1 and 2</b></p> <ul style="list-style-type: none"> <li>● One recent low-quality review identified some negative impacts of patient-held records as some patients saw the use of patient-held records as the allocation of unwanted responsibility.(86)</li> </ul>
<p>Costs and/or cost-effectiveness in relation to the status quo</p>	<p><b>Equipping health professionals and teams to identify and address the full range of survivor and family needs</b></p> <ul style="list-style-type: none"> <li>● One recent medium-quality review evaluating the efficacy of physical activity, dietary, and weight-control interventions for cancer survivors found that broad-reach intervention modalities were cost-effective and a more easily accessible means of delivering the repeated contacts necessary to sustain behavioural change.(77)</li> </ul> <p><b>Creating the systems and processes to support 1 and 2</b></p> <ul style="list-style-type: none"> <li>● One recent medium-quality review on the impact of technology in follow-up cancer care found that telephone follow-up services were more costly, however, these costs were anticipated to decrease after staff training and were overall less costly for patients.(84)</li> <li>● One older medium-quality review found positive economic outcomes for navigator programs supporting chronically ill older adults through healthcare transitions by reducing readmissions and hospital days.(89)</li> </ul>
<p>Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)</p>	<ul style="list-style-type: none"> <li>● Uncertainty because no systematic reviews were identified             <ul style="list-style-type: none"> <li>○ Not applicable</li> </ul> </li> <li>● Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review             <ul style="list-style-type: none"> <li>○ Not applicable (no ‘empty’ reviews were identified)</li> </ul> </li> <li>● No clear message from studies included in a systematic review             <ul style="list-style-type: none"> <li>○ <b>Creating the systems and processes to support 1 and 2</b> <ul style="list-style-type: none"> <li>▪ No clear message was derived from one recent high-quality review that evaluated models of care that aim to improve the coordination of cancer treatment between primary-care and oncology-care providers, finding that the analysis did not support any one model, largely due to the heterogeneity of outcomes and overall low quality of the studies.(33)</li> <li>▪ No clear message was derived from one recent high-quality review on survivorship-care models, the findings were limited regarding the potential advantages of different models, effects on survivors’ health outcomes, structural or process barriers to offering survivorship care, evaluation of existing survivorship programs, and costs and benefits</li> </ul> </li> </ul> </li> </ul>

	<p>of survivorship care.(30)</p> <ul style="list-style-type: none"> <li>▪ No clear message was derived from one older high-quality review on continuity of care for cancer patients in case-management, shared-care, and interdisciplinary-team models, finding no significant difference in patient health-related outcomes between patients assigned to interventions and those assigned to usual care.(81)</li> <li>▪ No clear message was derived from one recent medium-quality review on the use of survivorship-care plans for cancer survivors that found no major differences in health-related quality of life, however, there was some evidence that they may reduce distress in cancer survivors, while other evidence has suggested that distress may be higher due to increased worry about one’s health and negative memories that may be triggered by reading the care plan.(92)</li> <li>▪ No clear message was derived from one recent high-quality review that found no significant difference in quality of life in patients undergoing cancer treatments who had entered navigation programs in comparison to patients who had not.(91)</li> </ul>
<p>Key elements of the policy element if it was tried elsewhere</p>	<ul style="list-style-type: none"> <li>• No systematic reviews were identified.</li> </ul>
<p>Stakeholders’ views and experience</p>	<p><b>Engaging survivors in conversation about transition from treatments and into survivorship care</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review on the experiences and support services for Indigenous cancer survivors following the completion of cancer treatment found that: 1) family was paramount as a source of emotional support; 2) fear was a common emotion underpinning the Indigenous cancer survivor experience; 3) stigma from the community was reported by some as an experience; and 4) spirituality was of significant importance to many people through the recovery journey.(93)</li> </ul> <p><b>Equipping health professionals and teams to identify and address the full range of survivor and family needs</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review on the role of family physicians in the provision of follow-up cancer care found that patients recognized the benefits of family physicians’ involvement in follow-up care, citing factors such as greater trust, convenience and continuity of care, and family physicians found that their involvement varied depending on the needs of their population.(78)</li> </ul> <p><b>Creating the systems and processes to support 1 and 2</b></p> <ul style="list-style-type: none"> <li>• One recent high-quality review found that the type of survivorship care preferred by patients may also vary depending on the context (e.g., survivors’ preference for continuity of care and the value they place on relationships with specialists who treat their cancer).(30)</li> <li>• One recent medium-quality review on the impact of technology in follow-up cancer care found that patients reported satisfaction with technological support (e.g., telephone follow-up services).(84)</li> <li>• One older medium-quality review on methods of follow-up care for survivors of childhood cancer found that clinical care was highly valued among survivors, and supportive care was seen as more important by survivors who had greater clinical needs.(82)</li> <li>• One recent low-quality review found that patients widely reported value in having patient-held records to track health, remember events, and share information, and it was also viewed as a valuable tool across healthcare providers.(86)</li> </ul>

**Element 2 – Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community**

This element would ensure that approaches to funding organizations and remunerating providers facilitate patient and family transitions. Sub-elements could include decisions to adjust existing approaches for:

- 1) funding primary- and community-care organizations involved in providing support services for survivors and families transitioning out of cancer treatment, by introducing, changing or scaling-up the use of:
  - a) fee-for-service (organizations receive a fixed fee for each service performed in their facilities),
  - b) capitation (organizations receive a fixed fee to cover all necessary care for a given period of time),
  - c) global budgets (organizations receive a fixed budget to cover all necessary care for a given period of time),
  - d) case-mix funding (organizations receive pre-determined payments for particular types of diagnoses or services that are meant to cover the costs associated with an entire episode of care, regardless of the programs, services and drugs provided), and
  - e) targeted payments and/or penalties (organizations receive additional payments for taking a measurable action or achieving a pre-determined performance target, or penalties for failure to do so);
- 2) remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment, by introducing, changing or scaling up the use of:
  - a) fee-for-service (providers receive a fixed fee for each healthcare service performed),
  - b) capitation (providers receive a fixed fee for each patient under their care),
  - c) salary (providers receive a fixed income on a regular basis, which may vary depending on the hours worked),
  - d) episode-based payment (providers receive a pre-determined amount for particular types of diagnoses for an entire episode of care, regardless of the services performed),
  - e) fundholding (providers receive a fixed budget to cover all necessary care provided in their practice, often including prescription drugs, and to purchase the necessary secondary care for survivors registered to their practice for a given period of time), and
  - f) targeted payments and/or penalties (providers receive additional payments/penalties for taking a measurable action or achieving a pre-determined performance target);
- 3) purchasing support services for survivors and families transitioning out of cancer treatment through:
  - a) making changes to the scope and nature of public-insurance plans,
  - b) establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services,
  - c) placing or removing restrictions in coverage/reimbursement rates for organizations, providers, and products and services,
  - d) placing caps on coverage/reimbursement for organizations, providers, products and services,
  - e) establishing prior approval requirements for organizations, providers, and products and services, and
  - f) adjusting the lists of substitutable products and services (e.g., establishing which products and services are not currently covered or may be substituted for similar covered products and services); and
- 4) removing potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports, through:
  - a) adjustments to the level and features of premiums (e.g., the amount paid out-of-pocket by individuals for certain programs and services that support their transition out of cancer treatment),
  - b) the removal of cost-sharing, and
  - c) by using targeted payments that promote specific behaviours.

*Key findings from the citizen panels*

Four values-related themes emerged in the discussion about element 2:

- 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, (this was particularly salient in the Quebec context where the remuneration of physicians has been a highly debated topic in the media);
- decision-making based on data and evidence in terms of the scope and nature of public-insurance plans; and
- centralization versus decentralization of funding arrangements (with divergent views where some thought it could support greater accountability and efficiency, while others felt it would lead to a loss of specificity of locally available services).

In emphasizing equity to ensure that all survivors have access to services regardless of their ability to pay, panellists in both panels emphasized that there is significant variability with and between provinces in terms of the resources available (e.g., range of health professionals, programs and services and what is covered under public insurance plans). Panellists highlighted the need for consistency to ensure that all of those in need of supports had access regardless of ability to pay. Access to personal-support workers was cited as a core example, 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. In addition, panellists emphasized the decisions in terms of programs and services for survivors that are covered by public-insurance plans should be based on data and evidence. 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.

It should be noted that panellists in both panels found element 2 the most challenging in the deliberations, both in terms of the complexity of health systems and in terms of understanding the evidence.

*Funding primary- and community-care organizations involved in providing support services for survivors and families transitioning out of cancer treatment*

For the first sub-element, funding primary- and community-care organizations involved in providing support services for survivors and families transitioning out of cancer treatment, we identified seven systematic reviews focused on case-mix funding (1d) and targeted payments and penalties (1e).

Of these reviews, none focused specifically on supporting transitions out of cancer treatment. However, we identified four systematic reviews relevant to modifying case-mix funding generally,(94-97) of which three focused on activity-based funding (i.e., shaping payments, incentives using diagnosis-related groups and bundled payments) and the other on capturing patient needs in case-mix funding models.(94; 96; 97) One recent high-quality review found that activity-based funding was associated with an increase in admission to post-acute care after hospitalization, an increase in severity of illness (though this may be due to changes in diagnostic coding), and no change in mortality rates or volume of care compared to usual payment models.(97) One older high-quality review suggested that bundled payments were also associated with a decrease in utilization of services and costs of services included in the bundle, and may create financial incentives for providers to decrease the number and cost of services included in the bundle.(96) In addition, a recent high-quality review identified the following recommendations for implementing activity-based funding:

- ensuring appropriate supports are in place from the outset of implementation;

- providing education resources;
- fostering enhanced collaboration, communication and interaction between units and committees; and
- sharing personnel for data collection, protocols and tools.(94)

With regards to targeted payments and/or penalties for primary- or community-care organizations,(1e) we found mixed results with respect to the effectiveness of approaches, with much of it based on perceived outcomes from organizational leaders. One recent high-quality review found that perceived benefits of pay-for-performance models include: 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.(94) The same review indicated unintended consequences may include opportunistic behaviour, cherry-picking survivors with less complex conditions and who are less expensive to treat, and inaccurate reporting and evaluation of the quality outcomes.(94) One older medium-quality review and one recent overview of systematic reviews focused on the implementation of pay-for-performance programs and recommended:

- using process and intermediary outcome indicators as target measures;
- engaging stakeholders and communicating information directly on both quality improvement and achievement;
- targeting individuals and teams within primary- and community-care organizations;
- ensuring new funds are made available for program implementation; and
- fostering awareness about the elements of the pay-for-performance program.(98)

*Remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment*

For the second sub-element, remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment, we found three overviews of systematic reviews and six systematic reviews that focused on fee for service (2a) and targeted payments and penalties.(2f) Of these, only one focused specifically on remunerating providers in the cancer-care sub-system, however findings remain relevant as they speak to the broad range of providers involved in providing support services for survivors and their families.

Two older reviews, one high-quality and one medium-quality, found that fee-for-service models in primary care were associated with an increase in primary-care visits and physician contact, a higher number of referrals to specialists, as well as an increase in diagnostic and curative services.(99; 100) The reviews also found that fee-for-service payments were associated with a greater degree of continuity of care, higher compliance with the recommended number of visits, and fewer repeat prescriptions compared to a capitation model.(99; 100)

We found one older high-quality review relevant to fundholding, which found that instituting drug budgets for physicians may limit drug expenditure by limiting the volume of prescription drugs, increasing the use of generic drugs, or both.(101)

Mixed results were found from three overviews of systematic reviews and two older high-quality reviews for the use of targeted payments and penalties for providers generally,(2f) and from one older low-quality review specific to cancer care.(76; 102-106) Generally, overviews concluded that there are few rigorous studies of results-based financing, but that financial incentives for health professionals appear to be effective in the short run for simple, distinct and well-defined behavioural goals, but that there is relatively little evidence supporting long-term changes.(102) However, one overview suggests that financial incentives may be effective for delivering specific services, 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,(105) and another older low-quality review specific to cancer care identified risks associated with the use of financial incentives.(104) Identified risks include limiting access to certain types of care, lack of continuity of care, and conflict of interest between the physician and the patient.(104) Finally, one overview of reviews indicated that pay-for-performance programs:



- were generally more effective for chronic care than acute care;
- did not have a negative effect on access; and
- had no clear association between incentive size and the effectiveness of pay-for-performance programs.(94)

*Change the approaches used for purchasing support services for survivors and families transitioning out of cancer treatment*

For the third sub-element, change the approach used for purchasing support services for survivors and families transitioning out of cancer treatment, we found six systematic reviews that addressed the sub-bullets: establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services; establishing prior approval requirements for organizations; and adjusting the lists of substitutable products and services. Again, none of the reviews included focus specifically on purchasing support services for survivors and families transitioning out of cancer treatment, however, the findings remain relevant given the specific policy levers evaluated in them could be used in the context of supporting cancer-care transitions through changes to how programs, services and drugs are paid for.

Four older low-quality systematic reviews addressed aspects of establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services, three of which focused on the outcomes of restricting providers, products and services, and found:

- most managed-care organizations have had limited success using formularies, therapeutic interchange, and prior approval to influence prescribing and dispensing decisions;
- closed formularies have been found to be effective in reducing the utilization of prescription drugs, but not their costs;
- evidence from the U.S. does not support the assumption that restriction of specific drugs results in savings in drug costs, because restricting formularies leads to dynamic changes in the health system;
- the most common concern regarding preferred drug lists was that restrictions would lead to increased healthcare service utilization, such as hospital and clinician visits; and
- clinical evidence about drug benefits and the quality of that evidence were the main criteria used in the priority-setting process for including or excluding drugs from reimbursement lists.(107-110)

We identified one older medium-quality review of policies involving prior authorization for pharmaceutical prescriptions on drug use, healthcare utilization, healthcare expenditures, and health outcomes. The review found prior authorization resulted in decreases in overall drug expenditure, but no significant changes in the utilization of other medical services in the short term, and there was a lack of evidence in relation to either the medium or long term.(111)

Finally, with respect to adjusting the lists of substitutable products and services, we identified one recent high-quality review, which found that reference pricing may reduce insurers' cumulative drug expenditures, increase the use of reference drugs and reduce the use of cost-share drugs. The same review found that index pricing may increase the use of generic drugs, reduce the use of brand-name drugs, and reduce the price of generic drugs, but has little or no effect on the price of brand name drugs.(112)

*Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports*

For the final sub-element, remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports, the majority of the evidence found focused on targeting payments that promote specific behaviours. The key messages emerging from one overview and four reviews (three of which were recent and high-quality and one which was recent and medium-quality) which evaluated the use of targeted payments for patients and families were that these incentives can be effective at changing behaviours, but that the evidence supporting these effects is inconsistent (e.g., for improving adherence to medicines), indicates that effects are not sustained in the long

term (e.g., for promoting healthy behaviours such as changes in eating, alcohol consumption and physical activity), or requires substantial cash incentives to sustain behaviour changes (e.g., for smoking cessation).(113-117)

A summary of the key findings from the synthesized research evidence is provided in Table 4. For those who want to know more about the overviews and systematic reviews contained in Table 4 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 2.

**Table 4: Summary of key findings from systematic reviews relevant to Element 2 – Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community**

Category of finding	Summary of key findings
Benefits	<p><b>Funding primary- and community-care organizations involved in providing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>• Case-mix funding                             <ul style="list-style-type: none"> <li>○ A recent low-quality review about capturing patient needs in case-mix funding indicated that the addition of functional information to case-mix systems enhances predictive ability and improves homogeneity across case-mix groups for costs and length of stay.(95)</li> <li>○ The same review indicated that case-mix systems that incorporate functioning information can better predict resources needed and outcomes for frail older adults and those with functional impairments.</li> <li>○ One high-quality systematic review on bundled payments found that they may create financial incentives for providers to decrease the number and cost of services included in the bundle, and that the transition from a cost-based or fee-for-service reimbursement to a bundled payment was generally associated with a decline in spending of 10% or less. Bundled payments were also associated with a decrease in utilization of services (between 5% and 15%) and costs of services included in the bundle.(96)</li> </ul> </li> <li>• Targeted payments and penalties                             <ul style="list-style-type: none"> <li>○ A recent high-quality systematic review that assessed leaders’ experiences and perceptions implementing activity-based funding and pay-for-performance hospital funding models found that:                                     <ul style="list-style-type: none"> <li>▪ perceived benefits for activity-based funding included improved productivity and efficiency, ability to reallocate funds, support for greater emphasis on evaluation, accountability and discharge planning, improved data accuracy, and improved collaboration and communication, and improved quality and enhanced organizational transparency were associated with pay-for-performance models;</li> <li>▪ unintended consequences included opportunistic behaviour, ‘cherry-picking’ patients with less complex conditions and who are less expensive to treat (possibly leading to the exclusion of more vulnerable patients), and inaccurate reporting and evaluation of quality outcomes; and</li> <li>▪ barriers to implementation included lack of resources (e.g., constrained human resources given additional workload for providers), data collection (e.g., difficulty gathering accurate data and lack of experienced staff), and commitment factors (e.g., leaders’ skepticism or suspicion about the funding model).(94)</li> </ul> </li> </ul> </li> </ul> <p><b>Remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>• Fee for service                             <ul style="list-style-type: none"> <li>○ Two older reviews, one high-quality and one medium-quality, found that under fee-for-service primary care, physicians provide more primary-care visits/contacts, referrals to specialists and diagnostic and curative services.                                     <ul style="list-style-type: none"> <li>▪ The same reviews found that fee-for-service payments were associated with a greater degree of continuity of care, higher compliance with recommended number of visits,</li> </ul> </li> </ul> </li> </ul>

	<p>and fewer hospital referrals and repeat prescriptions compared to a capitation model.(99; 100)</p> <ul style="list-style-type: none"> <li>• Fundholding             <ul style="list-style-type: none"> <li>○ One older high-quality review found that instituting drug budgets for physicians may limit drug expenditure by limiting the volume of prescription drugs, increasing the use of generic drugs, or both.(101)</li> </ul> </li> <li>• Targeted payments and penalties             <ul style="list-style-type: none"> <li>○ There are mixed results for financial incentives to improve health professional behaviours and patient outcomes:                 <ul style="list-style-type: none"> <li>▪ a recent overview of systematic reviews found that payments for service, providing 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, were effective;(105)</li> <li>▪ the same overview noted that payments for working a specified time period, improving consultation or visit rates and promoting compliance with guidelines are ineffective;(105)</li> <li>▪ a high-quality review that was published more recently than the overview found mixed effects for the use of pay-for-performance schemes for healthcare providers to improve quality of patient care and patient-relevant outcomes, and concluded that current evidence targeting individual providers is insufficient to support its adoption;(118) and</li> <li>▪ an older high-quality review similarly found modest and variable effects of financial incentives on improving the quality of healthcare provided by family physicians.(105)</li> </ul> </li> <li>○ A recent overview of systematic reviews indicated that:                 <ul style="list-style-type: none"> <li>▪ pay-for-performance programs were generally more effective for chronic care than acute care;</li> <li>▪ pay-for-performance programs did not have a negative effect on access;</li> <li>▪ there is no clear association between incentive size and the effectiveness of pay-for-performance programs; and</li> <li>▪ the majority of the evidence suggests that England’s ‘quality and outcomes framework’ (a pay-for-performance scheme that rewards family physicians for the quality of care they provide, but that also involved many other simultaneous changes, such as electronic health records) is associated with some improved quality-of-care processes and intermediate patient outcomes (e.g., blood pressure and cholesterol levels).(119)</li> </ul> </li> <li>○ A recent overview of systematic reviews found that there are few rigorous studies of results-based financing, but that financial incentives for health professionals appear to be effective in the short run for simple, distinct and well-defined behavioural goals (but that there is less evidence supporting long-term changes).(120)</li> </ul> </li> </ul> <p><b>Change the approaches used for purchasing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>• Establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ One older low-quality review on managed-care organizations found that closed formularies were found to be effective in reducing utilization of prescription drugs, but not their costs.(110)</li> </ul> </li> <li>• Placing or removing restrictions in coverage/reimbursement rates for organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ One recent high-quality review found that reference pricing may reduce insurers’ cumulative drug expenditures, decrease the insurer’s drug expenditures, increase the use of reference drugs and reduce the use of cost-share drugs.</li> <li>○ The same review found that index pricing may increase the use of generic drugs, reduce the use of brand-name drugs, reduce the price of generic drugs, and may have little or no effect on the price of brand drugs.(112)</li> </ul> </li> <li>• Establishing prior approval requirements for organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ An older medium-quality review of policies involving prior authorization for pharmaceutical prescriptions found decreases in overall drug expenditure, no significant</li> </ul> </li> </ul>
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	<p>changes in the utilization of other medical services, and a lack of evidence in relation to medium- and long-term policy effects.(111)</p> <p><b>Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community care supports</b></p> <ul style="list-style-type: none"> <li>• Targeting payments that promote specific behaviours             <ul style="list-style-type: none"> <li>○ A recent overview of systematic reviews concluded that there is some evidence to support the use of financial incentives for improving adherence to medicines by patients, but that the evidence is inconsistent.(121)</li> <li>○ Two recent high-quality reviews (122; 123) and one recent medium-quality review (124) assessed financial incentives for encouraging healthy behaviours (e.g., achieving sustained changes in smoking, eating, alcohol consumption and physical activity) and found that they:                 <ul style="list-style-type: none"> <li>▪ were generally more effective than providing no financial incentive for health behaviour change, and on average have greater effects when cash-only incentives are used as compared to other formats;(122)</li> <li>▪ increased attainment and maintenance (up to 18 months from baseline) of target levels of behaviour change;(123)</li> <li>▪ sustained change in overall behaviour up to two to three months after the removal of incentive, but this change was not maintained thereafter;(123)</li> <li>▪ had a decreased effect over time, with increased post-intervention follow-up and increased incentive value;(122-124) and</li> <li>▪ were more accepted if they are found to be effective, safe, recipient-focused, intrusion-minimizing and viewed as benefiting both recipients and wider society, but may also be perceived as paternalistic, which can undermine an individual’s autonomy.(124)</li> </ul> </li> <li>○ A recent high-quality review that assessed financial incentives for supporting long-term smoking cessation found that:                 <ul style="list-style-type: none"> <li>▪ incentives may boost cessation rates while in place, but that sustained success rates are seen only where resources were concentrated into substantial cash payments for abstinence; and</li> <li>▪ incentives for pregnant smokers may improve cessation rates, both at end-of-pregnancy and at post-partum assessment stages.(113)</li> </ul> </li> </ul> </li> </ul>
<p>Potential harms</p>	<p><b>Remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>• Targeted payments or penalties             <ul style="list-style-type: none"> <li>○ Possible risks associated with results-based financing include: motivating unintended behaviours; ignoring important tasks that are not rewarded with incentives; improving or cheating on reporting rather than improving performance; widening the resource gap between rich and poor; and dependency on financial incentives.(120)</li> <li>○ A low-quality, older review identified several risks associated with the use of financial incentives, including limited access to certain types of care, lack of continuity of care, and conflict of interest between the physician and the patient.(104)</li> </ul> </li> </ul> <p><b>Change the approaches used for purchasing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>• Establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ Restricting formularies may lead to dynamic changes in other parts of the system and, as a result, there may be unexpected costs seen in other health services or technologies such as increased hospitalization and physician visits.(101; 125)</li> </ul> </li> <li>• Placing caps on coverage/reimbursement for organizations, providers, products and services             <ul style="list-style-type: none"> <li>○ One recent high-quality review found that introducing caps on coverage/reimbursement may decrease the overall use of medicines and may decrease both patients’ and insurers expenditures.(112)</li> </ul> </li> </ul> <p><b>Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community care supports</b></p> <ul style="list-style-type: none"> <li>• Remove cost-sharing</li> </ul>

	<ul style="list-style-type: none"> <li>○ Results from the RAND Health Insurance Experiment discussing the impact of cost-sharing found that higher cost-sharing was associated with reduced use of healthcare services, but that patients were just as likely to reduce the use of necessary as unnecessary services.(126)</li> </ul>
<p>Costs and/or cost-effectiveness in relation to the status quo</p>	<p><b>Remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>● Targeted payments or penalties             <ul style="list-style-type: none"> <li>○ An older non-systematic review found one study that reported on the cost-effectiveness of a pay-for-performance program, and found that the estimated cost per quality-adjusted life years saved ranged from \$13,000 to \$30,000.(127)</li> </ul> </li> </ul> <p><b>Change the approaches used for purchasing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>● Establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ An older low-quality review found that restricting specific drugs does not result in savings in overall drug costs, and indicated that the impact of restricted formularies on administrative costs and therapeutic appropriateness of substituted drugs is unclear.(101)</li> </ul> </li> </ul>
<p>Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)</p>	<ul style="list-style-type: none"> <li>● Uncertainty because no systematic reviews were identified             <ul style="list-style-type: none"> <li>○ Not applicable</li> </ul> </li> <li>● Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review             <ul style="list-style-type: none"> <li>○ Not applicable (no ‘empty’ reviews were identified)</li> </ul> </li> <li>● No clear message from studies included in a systematic review             <ul style="list-style-type: none"> <li>○ <b>Remunerating providers involved in providing support services for survivors and families transitioning out of cancer treatment</b> <ul style="list-style-type: none"> <li>▪ No clear message was derived in the reviews about the effects of financial incentives (e.g., financial bonuses) and the use of performance feedback on quality of care measures for cancer-screening guidelines.(128; 129)</li> <li>▪ No clear message was derived from one recent high-quality review about the effect of changes in the method or level of payment on the quality of care or referral rates provided by family physicians.(112)</li> </ul> </li> <li>○ <b>Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports</b> <ul style="list-style-type: none"> <li>▪ No clear message was derived from one recent high-quality review about whether financial incentives to increase adherence to short-term treatments improve adherence or patient outcomes, though they may improve adherence in the long-term.(112)</li> <li>▪ The same review was unable to determine the effects of reference pricing, index pricing and maximum pricing on healthcare utilization or health outcomes.(112)</li> </ul> </li> </ul> </li> </ul>
<p>Key elements of the policy element if it was tried elsewhere</p>	<p><b>Funding primary- and community-care organizations involved in providing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>● Case-mix funding             <ul style="list-style-type: none"> <li>○ A recent high-quality review identified several recommendations from leaders for implementing activity-based funding, which included ensuring appropriate supports are in place from the outset of implementation, providing educational resources, fostering enhanced collaboration, communication and interaction between units and committees, and shared personnel for data collection, protocols and tools.(130)</li> </ul> </li> <li>● Targeted payments or penalties             <ul style="list-style-type: none"> <li>○ A high-quality systematic review of activity-based funding found that prerequisites for success include: organizational commitment to and support for the chosen funding model; required infrastructure to support the individuals and activities required to accurately measure quality in pay-for-performance models; information-technology and decision-support systems for producing, tracking and aggregating data; committed leaders who are supportive of the funding model; and involving physician leaders to support accurate data collection and to act as ‘champions’.(131)</li> <li>○ An older medium-quality review noted that future pay-for-performance programs should define targets based on baseline room for improvement, use process and intermediary</li> </ul> </li> </ul>

	<p>outcome indicators as target measures, engage stakeholders and communicate information directly, focus on both quality improvement and achievement, and target individuals and teams.(132)</p> <ul style="list-style-type: none"> <li>○ A recent overview of systematic reviews indicated that:             <ul style="list-style-type: none"> <li>▪ key features of effective pay-for-performance programs included lower baseline levels, involvement of stakeholders in target selection, and the utilization of process indicators instead of outcome measures;</li> <li>▪ implementation of pay-for-performance yielded stronger effects where new funds were available and where there was sufficient awareness about the elements of the programs; and</li> <li>▪ incentives targeted at the individual or team level achieve more positive results than those targeted at the hospital level.(119)</li> </ul> </li> </ul> <p><b>Change the approaches used for purchasing support services for survivors and families transitioning out of cancer treatment</b></p> <ul style="list-style-type: none"> <li>● Establishing and iteratively revising lists of covered/reimbursed organizations, providers, and products and services             <ul style="list-style-type: none"> <li>○ One older low-quality review found that clinical evidence related to the benefits of drugs and the quality of that evidence were the main criteria used in priority setting concerning medicines.(128)</li> </ul> </li> </ul> <p><b>Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports</b></p> <ul style="list-style-type: none"> <li>● Targeted payments that promote specific behaviours             <ul style="list-style-type: none"> <li>○ Cash incentives for promoting healthy behaviours in citizens on average have greater effects as compared to other formats,(122) and sustained success rates are seen when resources are concentrated into substantial cash payments.(130)</li> </ul> </li> </ul>
Stakeholders' views and experience	<p><b>Remove potential disincentives for survivors and families that can influence whether and how they access needed primary- and community-care supports</b></p> <ul style="list-style-type: none"> <li>● Targeted payments that promote specific behaviours             <ul style="list-style-type: none"> <li>○ A recent, medium-quality review found that financial incentives targeting citizens were more accepted if they are found to be effective, safe, recipient-focused and intrusion-minimizing, but may also be perceived as paternalistic, which can undermine an individual's autonomy.(124)</li> </ul> </li> </ul>

**Element 3 – Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship**

This element would include a number of efforts to support survivors and families by providing more information and helping them develop knowledge and skills to optimize the transition from cancer treatment to primary and community care. Sub-elements could include:

- 1) ensuring information and education supports, as well as opportunities for learning, that can be accessed in specialty care (e.g., cancer centres) are also available in primary- and community-care settings, through efforts such as:
  - developing tailored informational and educational resources that meet patient needs, and that are unique to individuals following cancer treatment (with a particular focus on addressing all of the important emotional, physical and practical concerns Canadian cancer survivors have), and
  - providing education about their health system and about best practices in addressing their own needs, as well as about community resources and supports outside of the health system (that can help survivors and families successfully transition from cancer treatment by addressing a wide range of related needs such as exercise and nutrition, and peer support programs);
- 2) supporting survivors with the self-management skills necessary to help them address some of their concerns on their own;
- 3) engaging survivors and their families as advisors in program and service planning; and
- 4) engaging survivors in system monitoring and feedback to promote patient-centred continuous quality improvement.

*Key findings from the citizen panels*

Two main 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; and
- collaboration among survivors, health professionals and organizations within the health system to provide reliable information and education supports for transitions.

Preferences about how to access reliable information focused on having a central access point (e.g., 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 (e.g., survivors); and
- peer-to-peer support services.

The second values-related theme related to enhancing collaboration among survivors, health professionals and organizations within the health system, to provide 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 (e.g., cancer care system or primary and community care) it was felt that the professional should be situated within the family physician’s office.

*Key findings from systematic reviews*

We identified eight systematic reviews that related to the first sub-element – ensuring information and education supports, as well as opportunities for learning that can be accessed in specialty-care settings as well as in primary- and community-care settings – and the second sub-element (supporting survivors with self-management skills).

No clear message emerged from the evidence identified that related to the first sub-element. Specifically, no conclusive findings were reported in two systematic reviews (one older high-quality and one recent high-quality) on educational interventions on prescribed and over-the-counter medication, and on psycho-education interventions for managing symptom clusters in cancer, respectively.(133) However, another recent medium-quality review did report benefits from psycho-educational counselling of patients and supporters of women with breast cancer, including improvements in psychological well-being, anxiety, and relationship and individual functioning.(134)

We found five systematic reviews relevant to the second sub-element (supporting survivors with self-management skills). Two were recent medium-quality reviews, and they reported that group-based self-management programs and self-management education interventions were beneficial to patients with cancer, resulting in improvements in physical and psychological functioning as well as symptoms of fatigue, pain, depression, anxiety, emotional distress and quality of life, respectively.(135; 136) One recent medium-quality systematic review was unable to report conclusive findings on the use of electronic symptom reporting, however the review suggested that it may support 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.(137) Finally, two recent medium-quality reviews focused on identifying core components of self-management interventions.(136; 138) While neither review was able to determine the most effective core components of self-management interventions, one of the systematic reviews detailed the views of patients on the important qualities of self-management and self-management support outcomes, which included:

- personally relevant knowledge that is applicable and sensitive to their personal situation;
- independence over health and well-being;
- receiving help from informal support groups of those with shared experience;
- close relationships with health professionals and services;
- to remain as “normal” as possible throughout treatment;
- the skills and attributes necessary to assist in managing their own health; and
- high levels of physical and mental health.(138)

A summary of the key findings from the synthesized research evidence is provided in Table 5. For those who want to know more about the systematic reviews contained in Table 5 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 3.

**Table 5: Summary of key findings from systematic reviews relevant to Element 3 – Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship**

Category of finding	Summary of key findings
Benefits	<p><b>Ensuring information and education supports, as well as opportunities for learning that can be accessed in specialty (e.g., cancer centres) as well as in primary- and community-care settings</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review reported positive results including improvements in psychological well-being, anxiety, and relationship and individual functioning from psycho-education interventions (e.g., interpersonal counselling, self-managed exercise encouragement, psycho-education, phone counselling, educational counselling, and information and skill building) for patients and supporters of women with breast cancer.(134)</li> </ul> <p><b>Supporting survivors with self-management skills</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review reported that internet-based education or self-help programs did not improve quality of life or physical well-being, but were not found to result in any harm.(139)</li> <li>• One recent medium-quality review found that group-based self-management programs</li> </ul>



	<p>improved physical function, however a sub-group analysis revealed no significant differences between intervention groups for either quality of life or physical activity level.(136)</p> <ul style="list-style-type: none"> <li>• One recent medium-quality review found that self-management education interventions to support patients with cancer improved symptoms of fatigue, pain, depression, anxiety, emotional distress, and quality of life.(135)</li> </ul>
Potential harms	None identified.
Costs and/or cost-effectiveness in relation to the status quo	None identified.
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the element were pursued)	<ul style="list-style-type: none"> <li>• Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> <li>○ <b>Engaging survivors and their families in program and service planning</b></li> <li>○ <b>Engaging survivors in system monitoring and feedback to promote patient-centred continuous quality improvement</b></li> </ul> </li> <li>• Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> <li>○ None identified</li> </ul> </li> <li>• No clear message from studies included in a systematic review <ul style="list-style-type: none"> <li>○ <b>Ensuring information and education supports, as well as opportunities for learning that can be accessed in specialty (e.g., cancer centres) as well as in primary- and community-care settings</b> <ul style="list-style-type: none"> <li>▪ While one older high-quality review reported positive findings for the knowledge and skill-acquisition about prescribed and over-the-counter medication from educational interventions, due to methodological limitations in the included studies the review was unable to determine whether differences were of clinical importance.(140)</li> <li>▪ One recent high-quality systematic review reported encouraging, but inconclusive findings for the use of psycho-education interventions on managing symptom clusters in patients with cancer.(133)</li> </ul> </li> <li>○ <b>Supporting survivors with self-management skills</b> <ul style="list-style-type: none"> <li>▪ One older high-quality review found that the literature on electronic symptom reporting is generally of low quality, reducing the ability to make conclusive statements, however the review reported that electronic symptom reporting may support 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.(137)</li> <li>▪ One recent medium-quality review was unable to determine core components of self-management interventions to support patients with cancer.(135)</li> </ul> </li> </ul> </li> </ul>
Key sub-elements of the policy element if it was tried elsewhere	<ul style="list-style-type: none"> <li>• No systematic reviews were identified.</li> </ul>
Stakeholders' views and experience	<p><b>Supporting survivors with self-management skills</b></p> <ul style="list-style-type: none"> <li>• One recent medium-quality review examined the views of patients on the important qualities of self-management and self-management support outcomes among colorectal cancer, diabetes and stroke patients. For colorectal cancer specifically, patients expressed the need to: gain personally relevant knowledge that is applicable and sensitive to their personal situation; have independence over health and well-being; receive help from informal support groups of those with shared experience; maintain close relationships with health professionals and services; remain as "normal" as possible; develop the skills and attributes necessary to assist in managing their own health; and maintain high levels of physical and mental health. <ul style="list-style-type: none"> <li>○ The review was unable to determine which of these outcomes of supported self-management was ranked as being most important to patients.(138)</li> </ul> </li> </ul>

### **Additional equity-related observations about the three elements**

Several equity-related observations can be made in relation to the three elements for those living in rural or remote areas, and linguistic minorities or particular ethnocultural groups (which could include recently arrived immigrants and refugees, minority populations, Indigenous peoples, and certain religious groups). A review found significant differences in the involvement of family physicians in the provision of follow-up cancer care between urban and rural and remote areas.(78) The level of involvement varied depending on the needs of the population, with family physicians in rural and remote areas viewing themselves as advocates for their patients and playing a greater role in their follow-up care.(78)

With respect to individuals who are from a linguistic minority or particular ethnocultural group, one important consideration to emerge – which is particularly salient to elements 1 and 3 – is that culturally competent communication should be emphasized in efforts to support survivors and families as they transition after treatment. Some of the identified reviews addressed this aspect of care. For example, two reviews showed that, among cancer patients, effective provider communication was associated with improved psychological outcomes, quality of life, and physiological functioning, as well as significantly increased adherence to treatment recommendations.(73; 75) Despite these benefits, it was found that cancer patients have high rates of unmet communication needs from their providers, and these unmet needs were amplified among linguistic minorities and ethnocultural groups.(75) In particular, low-acculturated minority women reported less participation in and satisfaction with cancer treatment decision-making, which sometimes led to non-adherence to care.(75) Another review found that current cancer-recovery programs may not meet the needs of Indigenous cancer survivors (e.g., inclusion of family in the cancer journey, stigma and the role of spirituality).(93) In addition, culturally competent communication extends beyond the individual provider to the healthcare system as a whole. Culturally competent healthcare systems are agents for the provision of appropriate patient care for diverse population groups.(73)

**IMPLEMENTATION CONSIDERATIONS**

A number of barriers might hinder implementation of the three elements for optimizing patient and family transitions, which need to be factored into any decision about whether and how to pursue any given element (Table 6). While potential barriers exist at the levels of patients and individuals, providers, organizations and systems, perhaps the biggest barriers lie in the existing financial constraints faced by provincial and territorial health systems, the lack of awareness of the need for improvements in patient and family transitions, and the fact that there is little political momentum behind addressing the issue compared to other health-system priorities (e.g., the opioid crisis and long-term care reform). Without targeted efforts to try and downplay these barriers (or overcome them with specific implementation strategies), they will likely make it challenging to pursue any or all of the three elements above. However, as Table 7 shows, there are also a number of potential windows of opportunity, which could help to provide traction for pushing these elements forward.

**Table 6: Potential barriers to implementing the elements**

<b>Levels</b>	<b>Element 1 – Improve cancer treatment follow-up through the introduction of supports early in the cancer journey and across the key dimensions of patient and family transitions</b>	<b>Element 2 – Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community</b>	<b>Element 3 – Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship</b>
<b>Patient/ Individual</b>	<ul style="list-style-type: none"> <li>• 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</li> </ul>	<ul style="list-style-type: none"> <li>• Survivors and their families may be concerned that changes to purchasing support services may limit their access to existing programs</li> </ul>	<ul style="list-style-type: none"> <li>• Survivors and their families may not be aware of existing or new supports available to them as they transition</li> <li>• 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</li> </ul>
<b>Care provider</b>	<ul style="list-style-type: none"> <li>• Some healthcare providers may not have the knowledge and skills needed to support the full range of survivor and family needs when transitioning, and may see few cancer survivors in their practice to help them apply and refine their skills for supporting survivors with cancer as necessary</li> <li>• Healthcare providers may face challenges in coordinating with many sectors (e.g., specialty, primary and community care) to support additional efforts to help their survivors acquire needed supports</li> <li>• Primary-care providers may resist the implementation of shared-care models given</li> </ul>	<ul style="list-style-type: none"> <li>• Some healthcare providers may resist changes to how they are remunerated for fear of reducing income</li> <li>• Healthcare providers may be incentivized to deliver select services and supports and unintentionally neglect others</li> <li>• Some healthcare providers such as nurses and psychologists may not be eligible to receive financial incentives for supporting cancer survivorship</li> </ul>	<ul style="list-style-type: none"> <li>• Healthcare providers may not have the knowledge and skills needed to support self-management and provide links to community-based services</li> <li>• Healthcare providers may not have the time needed to support survivors and family members in the development of self-management skills</li> </ul>

	<p>their resource requirements and additional coordinating responsibilities</p> <ul style="list-style-type: none"> <li>• The increased demands placed on healthcare providers in terms of supporting informed decision-making and system navigation (including program eligibility and coverage) may not be feasible given existing time and resource constraints</li> </ul>		
<b>Organization</b>	<ul style="list-style-type: none"> <li>• Some organizations may not have the infrastructure needed to support communication and coordination of survivors transitioning to primary care</li> <li>• Some organizations may face challenges in coordinating with the many primary- and community-care supports that are needed to help survivors transition</li> <li>• Rural and remote communities may have few primary- and community-care organizations that can support transitions out of specialty treatment centres</li> </ul>	<ul style="list-style-type: none"> <li>• Some organizations may resist changes to their funding mechanisms for fear of reducing their available budgets</li> </ul>	<ul style="list-style-type: none"> <li>• Some organizations may not have the resources (financial or time) to develop and deliver information and education supports for survivors and family members</li> </ul>
<b>System</b>	<ul style="list-style-type: none"> <li>• Policymakers will face additional costs associated with new training for healthcare providers and investments in information communication technology supports</li> </ul>	<ul style="list-style-type: none"> <li>• Policymakers may face political challenges in proposing changes to the funding and remuneration of healthcare providers and primary- and community-care organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Policymakers may be unwilling to dedicate additional funds to finance/support the development of materials</li> <li>• Achieving significant collaboration in planning for programs and services and in system monitoring and feedback may be challenging</li> </ul>

**Table 7: Potential windows of opportunity for implementing the elements**

<b>Type</b>	<b>Element 1</b> – Improve cancer treatment follow-up through the introduction of supports early in the cancer journey and across the key dimensions of survivor and family transitions	<b>Element 2</b> – Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community	<b>Element 3</b> – Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship
<b>General</b>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Findings from Canadian Partnership Against Cancer’s Experiences of Cancer Patients in Transition study will identify and create awareness around the needs and challenges faced by cancer survivors post-treatment.(1)</li> <li>• Cancer care organizations and programs across select provinces have developed some of the types of expertise required to support the implementation of these elements (e.g., BC Cancer Agency, Saskatchewan Health Quality Council, CancerCare Manitoba, Cancer Care Ontario, Canadian Cancer Research Alliance, CanIMPACT, ELLICSR, and Canadian Partnership Against Cancer).(6; 9; 41; 47; 49-56; 141)</li> </ul>		
<b>Element-specific</b>	Closing the gaps in the continuum of care (including transitions to primary and community care) is a key theme in the 2017-2022 advancement of the national cancer strategy.(142)	Tightening of health-system budgets across provinces and territories, and policymakers’ search for efficiencies may support the alignment of funding and remuneration arrangements.	Increased focus on patient-centred care (e.g., through shared decision-making and self-management) may mean that survivors are eager to be involved in the planning, evaluation and monitoring of programs and services.

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## APPENDICES

The following tables provide detailed information about the systematic reviews identified for each element. Each row in a table corresponds to a particular systematic review and the reviews are organized by element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the element are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A Measurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review’s issue applicability in terms of the proportion of studies focused on transitions. Similarly, for each economic evaluation and costing study, the last three columns note whether the country focus is Canada, if it deals explicitly with one of the prioritized groups and if it focuses on transitions.

All of the information provided in the appendix tables was taken into account by the evidence brief’s authors in compiling Tables 2-4 in the main text of the brief.

**Appendix 1: Systematic reviews relevant to Element 1 - Improve cancer treatment follow-up through the introduction of supports early in the cancer journey and across the key dimensions of patient and family transitions**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
<p>Engaging patients and their families in conversations about transition from treatments and into survivorship care that includes primary- and community-care supports, and supporting the active engagement of these patients and their families in identifying all of their potential needs (including those that exist during treatment but that could persist post-treatment) and in decision-making about whether and how to proceed</p>	<p>An overview of cancer survivorship-care models (30)</p>	<p>This review included nine studies describing various cancer survivorship-care models.</p> <p>Overall, the results found that there is substantial variation in survivorship-care models, with the optimal nature, timing, intensity, format, and outcomes of models being uncertain and requiring further research. These models were found to be highly individualized to the institution or setting where they are provided. In addition, it is anticipated that future shortages in the oncology workforce may require the expanded use of nurse practitioners, physician assistants, and shared-care models to deliver survivorship care to a growing number of survivors. Concerns associated with survivorship-care models include payment considerations, adequacy of training, and the potential for lack of coordination and fragmented care.</p> <p>Of all the survivorship interventions described, only three models involving survivorship-care plans explicitly incorporated transition of care into the intervention.</p> <p>Examining the context of survivorship care, it was found that patient characteristics may affect needs for survivorship care. For example, age, race, number of comorbidities, income, and stage of disease may predict unmet survivor need.</p> <p>The type of care preferred by patients may also vary depending on the context. A survey of adult cancer survivors in the United Kingdom suggested that cancer survivors prefer consultant-led (i.e., oncologist or other specialist) care to nurse-led, telephone-based, or family physician-led care. A study of breast cancer survivors in the United States similarly found that visits with oncologists significantly decreased the odds of worrying among survivors compared with visits to primary-care providers. This may reflect survivors' preference</p>	<p>2013</p>	<p>7/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>	<p>2/9</p>



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>for continuity of care and the value they place on relationships with specialists who treat their cancer.</p> <p>Evidence from survivorship-care models was limited, particularly regarding potential advantages of different models, effects on survivors' health outcomes, structural or process barriers to offering survivorship care, evaluation of existing survivorship programs, and costs and benefits of survivorship care. Among the included studies that did provide comparative information on survivors' health outcomes, no significant differences were observed.</p> <p>The authors of the review cite the heterogeneity in program setting, components, timing, healthcare providers involved, and even the very definition of "cancer survivor" as a limitation of the study. The review was also based on a technical brief, which the authors recognize did not capture the entirety of every aspect of survivorship-care models.</p>					
	<p>An overview of strategies, personal characteristics, and attitudes associated with culturally competent patient-provider communication in cancer management (73)</p>	<p>This review included 35 studies examining the strategies, personal characteristics, and attitudes associated with culturally competent patient-provider communication in the management of cancer.</p> <p>In this review, various strategies and personal characteristics and attitudes for culturally competent communication were identified and grouped into various themes: healthcare-provider skills, awareness and knowledge, culturally competent healthcare, healthcare providers' personal characteristics and attitudes, and models of effective cross-cultural communication.</p> <p>The theme of healthcare-provider skills primarily encompasses the skills required for culturally competent communication. The literature underscored that healthcare providers should avoid stereotyping and generalizations when managing patient care. The building of critical skills in manoeuvring of the initial medical encounter, building physician-patient rapport, gaining patient trust, engaging with the patient's extended family, addressing patients</p>	<p>2015</p>	<p>5/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>2/35</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>appropriately according to their cultural preference, and engaging in culturally sensitive communication, was also found to be crucial. The importance of assessment skills was also underscored in the literature, particularly with regards to patient assessment beyond the biomedical aspect.</p> <p>Cultural awareness has also proven to be an essential aspect of delivering culturally competent patient-provider communication. Self-awareness with regard to the provider's own culture, cultural beliefs, health belief systems, spirituality and cultural assumptions, personal biases, and stereotypes is critical to effective delivery of care. The importance of developing interpersonal awareness with regards to the inherent patient-provider power differences, and communication regarding potential differences in cultures, is also underscored in the literature.</p> <p>The importance of acquiring sound factual knowledge and an understanding of various cultural aspects is highlighted in the theme of healthcare-provider knowledge. Factual understanding of the family physician's and patient's respective cultures, health belief systems, decision-making processes, and standards of etiquette critically underlies successful patient-provider communication.</p> <p>It must be noted that culturally competent communication extends beyond the individual provider to the healthcare system as a whole. Culturally competent healthcare systems are agents for the provision of appropriate patient care for diverse population groups that extend beyond addressing individual patient needs, to policy and community level. Specific organisational strategies for culturally competent communication are well represented in the literature, the most common of which are the use of patient navigators and professional translators to facilitate communication.</p> <p>The personal characteristics and attitudes of healthcare providers also contribute to successful patient-provider communication, with the most prominent being the</p>					

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>demonstration of respect for cultural diversity and patients' cultural values.</p> <p>Models of effective cross-cultural communication have also been cited in some of the documents included in this review. Kleinman's questions, the LEARN Model, the BELIEF Model, and the Four Habits Model of Highly Effective Clinicians emerged as key findings relating to this theme.</p> <p>The findings of the review provide some insight into various methods of delivering culturally competent patient-provider communication to adult patients diagnosed with cancer. However, the results should be treated with caution as they are largely drawn from low-level evidence, highlighting a lack of high-level research in this study area.</p>					
	<p>Shared decision-making in cancer treatment (74)</p>	<p>This review included 17 studies examining the role of shared decision-making in cancer treatment.</p> <p>The review found weak but suggestive evidence for a positive association between perceived patient involvement in decision-making, a central dimension of shared decision-making, and quality-of-life outcomes in cancer. The review did not find evidence for an inverse association between shared decision-making and quality of life.</p> <p>Overall, there was very little evidence presented showing a negative association between shared decision-making and quality of life, and there was suggestive evidence demonstrating a positive association between the two constructs. The authors contend that the implementation of shared decision-making approaches may be beyond the scope of this assessment, but stated that the lack of evidence of impaired quality of life may be sufficient to justify shared decision-making methods, particularly considering patient preferences for shared decision-making. In this day and age, it has been found that patients are increasingly viewing and conducting themselves as consumers of health services, and thus overwhelmingly prefer some involvement in treatment decision-making. As a result, the implementation of shared</p>	<p>2014</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>3/17</p>	<p>Not reported in detail</p>	<p>17/17</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>decision-making may ultimately be necessitated by patient demand rather than clinical utility. Moreover, shared decision-making has been convincingly shown to increase patient clinical knowledge, reduce decisional conflict, and improve satisfaction.</p> <p>The poor methodological quality and heterogeneity of the extant literature presents as a primary constraint of the review's conclusions. In addition, the literature commonly treated various sub-scales of quality-of-life instruments as separate outcomes, increasing the probability of spurious findings.</p>					
	<p>Efficacy of interventions to improve patient participation in the treatment process for culturally and linguistically diverse people with cancer (87)</p>	<p>This review included seven studies investigating interventions to improve patient participation in the treatment process for culturally and linguistically diverse people with cancer.</p> <p>Overall, it was found that the impact of patient interventions was varied. While the effect of a decision aid and patient-navigator intervention on communication with health providers was found to be positive, and the use of decision aids successfully facilitated shared decision-making and patients' perception of treatment adherence, the use of patient navigators was ineffective. A computer support system was found to improve general patient participation, but little clarification was provided with regards to what this involved.</p> <p>Two studies reported outcomes on communication with health providers, both with positive results. In the pilot decision-support intervention using patient navigators with Latina patients with breast cancer, 67% self-reported improvements with communication with their clinician as a result of the intervention. In the video intervention with Navajo patients with breast cancer, 93% of participants self-reported at six months post-intervention that they believed that the culturally tailored video enhanced their communication with providers and encouraged them to seek additional information about their condition.</p>	<p>2011</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/7</p>	<p>7/7</p>	<p>7/7</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>Two studies reported outcomes on decision-making. Six months after the video intervention, 93% of patients self-reported that they believed that video helped them with treatment decision-making, encouraging them to make deliberate treatment choices. In contrast, in the decision-support intervention with Latina women, only 33% reported that the intervention facilitated greater involvement with the treatment decision-making process.</p> <p>Two studies reported mixed effects of interventions on adherence to treatment. In the randomized control trial of patient navigation for low-income, predominately Hispanic women with breast cancer, there were no significant difference between the intervention and control groups in terms of adjuvant treatment adherence and attendance at follow-up appointments. However, six months after the mixed-method evaluation using a single sample of a video intervention, 92% reported that they thought that the knowledge from the video helped them adhere to their treatment regimens.</p> <p>Three articles reported positive effects on health-care participation with the comprehensive health enhancement support system intervention. Study authors found that African-American women’s health-care participation increased to a larger extent than that of Caucasian women with greater use of didactic and narrative information within the comprehensive health enhancement support system intervention. Similarly, in the two other studies, there were greater improvements in health-care participation following the comprehensive health enhancement support system intervention among minority women than Caucasian women at two and four months post-intervention. In a separate randomized control trial of a culturally tailored intervention for Hawaiian patients with cancer and their families, there were no significant differences between groups in “self-efficacy”, which was defined as getting information on one’s own, communication, and requesting help.</p>					

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

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>One key limitation of this review was the difficulty in defining cultural and linguistic diversity. As well, the search criteria were confined to studies in English, potentially limiting the review's findings.</p>					
	<p>Shared decision-making models for cancer treatment among racial and ethnic minority patients (75)</p>	<p>This review included 23 studies assessing shared decision-making models for cancer treatment among racial and ethnic minority patients.</p> <p>Three major findings were uncovered from the review, based on its five major themes of treatment decision-making factors, patient factors, family factors, community factors, and provider factors. Thematic data overlapped categories, indicating that individuals' preferences for medical decision-making cannot be practically examined outside the context of family and community. The findings were grouped into the categories of social support, communication and cultural congruence.</p> <p>It was found that social support was generally provided by the spouse and family members, but could also include friends, community members, and members or leaders of a religious community. Although several studies noted that social support had the potential of reducing individual autonomy and contributing to non-receipt of treatment, strong social support more commonly resulted in decision-making for more aggressive treatment. These findings are supported across other diseases and have been expanded by studies indicating that providers are more likely to recommend more aggressive treatment when they perceive strong social support. In fact, the presence of strong social support was associated robustly with improved cancer survival, suggesting that social support may be an appropriate area for intervention in a patient-centred approach to cancer care.</p> <p>Among patients with cancer, effective provider communication was associated with improved psychological outcomes, quality of life, and physiological functioning, as well as significantly increased adherence to treatment recommendations. Despite these benefits, authors found that</p>	<p>2011</p>	<p>4/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>2/23</p>	<p>23/23</p>	<p>23/23</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>patients with cancer continued to have high rates of unmet communication needs from their providers, and these unmet needs were amplified among racial/ethnic minority patients. These findings are supported by the few studies conducted on provider communication with indigenous patients worldwide, which identify significant challenges and a high prevalence of miscommunication. Challenges to communication include different communication styles, different medical belief models, language barriers, lack of provider skills in cross-cultural communication, lack of patients' control, lack of providers' knowledge of Indigenous culture and history, distrust of providers and the healthcare system, lack of a personal relationship between the provider and patient, and an alienating healthcare environment. Cultural values and norms among racial/ethnic minority populations may have a significant impact on patient-provider communication, which warrants further investigation.</p> <p>The review found that cultural congruence was primarily explored in terms of language among quantitative studies. Across studies, low-aculturated minority women reported less participation in and satisfaction with cancer treatment decision-making, which sometimes led to non-adherence to care. The qualitative studies were more likely to explore nuances of cultural competence and to offer examples of how providers might bridge cultural divides. Given that a culturally congruent approach to care has been associated with improved communication, less use of costly services, and better health outcomes, the case for understanding and strengthening cultural congruence among providers is strong. This is especially so among socially vulnerable minority patients, for whom family and community relationships are an important source of identity and support.</p> <p>Limits of this review include publication bias, which the authors attempted to mitigate by using comprehensive search terms. It must also be noted that while the authors included studies with a broad range of racial and ethnic minority patients, this cannot represent the experiences or perspectives of a single group.</p>					

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

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	Efficacy of interventions aiming to improve continuity of cancer care on patient, healthcare-provider, and process outcomes (81)	<p>This review included 51 studies aiming to classify, describe and evaluate the effectiveness of interventions aiming to improve continuity of cancer care on patient, healthcare-provider, and process outcomes.</p> <p>Three intervention models were analyzed in the present review: case management, shared care, and interdisciplinary teams. Six additional intervention strategies were used in addition to these models: patient-held record, telephone follow-up, communication and case discussion between distant healthcare professionals, change in medical record system, care protocols, directives and guidelines, and coordination of assessments and treatment. No significant difference in patient health-related outcomes was found between patients assigned to interventions and those assigned to usual care. A limited number of studies reported psychological health, satisfaction of providers, or process-of-care measures.</p> <p>The main limitations of this review were the various differences between the included studies, especially in their study designs, interventions, participants, patients' phase of care, measured outcomes, healthcare settings, and length of follow-up.</p>	2009	9/11 (AMSTAR rating from McMaster Health Forum)	4/51	Not reported in detail	51/51
	Assessing the experiences and support services for Indigenous cancer survivors following the completion of cancer treatment (93)	<p>This review analyzed 17 studies in order to assess the experiences and support services for Indigenous cancer survivors following the completion of cancer treatment.</p> <p>Cancer care for members of Indigenous communities must take into consideration cultural needs and social factors, in order to ensure equitable access to care. This review aimed to understand the current state of cancer support for Indigenous cancer survivors, by reviewing experiences from either the survivor's, family's or clinician's perspective. Secondary to this analysis, this review aimed to understand the barriers or enablers to care that may be faced by Indigenous cancer survivors.</p>	2014	5/10 (AMSTAR rating from McMaster Health Forum)	0/17	17/17	17/17



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>A number of important factors were reported when exploring the experience of Indigenous cancer survivors. The importance of family was paramount, as these connections serve as a source of emotional support. Fear was a common emotion underpinning the Indigenous cancer survivor experience, as there is sometimes a belief among family that this diagnosis arose as a result of sin and that consequences would continue. Stigma from the community was reported by some as an experience, but many survivors also reported feeling the support of their communities through their recovery. Spirituality was of significant importance to many people through the recovery journey. Quality of life was lower among Indigenous survivors, who reported feelings of isolation, distress and financial burden.</p> <p>In light of these experiences, interventions must focus on re-integrating survivors back into families and communities, in order to enhance quality of life and create a network of support. Spirituality may be considered as a key component of the recovery journey of many Indigenous survivors, and thus should be considered as part of the survivorship program.</p> <p>As it stands, current cancer-recovery programs may not cater to the needs of Indigenous survivors. Services should listen to the needs of these survivors and should develop programs that assist in re-integration. Patient-navigator programs may be a potential avenue for additional support and access to care, as they have proven successful among Indigenous populations in the past. Tailoring survivor-care programs to the needs of this community will enhance quality of life and contribute to recovery.</p>					
Equipping health professionals and teams to identify and address the full range of patient and family needs	Efficacy of communication-skills training in improving the communication skills of healthcare professionals involved in cancer care, patient	<p>This review included 15 studies assessing whether communication-skills training is effective in improving the communication skills of healthcare professionals involved in cancer care, and in improving patient health status and satisfaction.</p> <p>In the review, 11 studies compared communication-skills training with no communication-skills-training intervention,</p>	2012	11/11 (AMSTAR rating from McMaster Health Forum)	1/15	Not reported in detail	0/15

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	health status, and satisfaction (79)	<p>three studies compared the effect of a follow-up communication-skills-training intervention after initial communication-skills training, and one study compared two types of communication-skills training. The types of communication-skills-training courses evaluated in these trials were diverse. Study participants included oncologists (six studies), residents (one study), other physicians (one study), nurses (six studies) and a mixed team of healthcare professionals (one study).</p> <p>It was found that healthcare professionals in the communication-skills-training group were significantly more likely to use open questions in post-intervention interviews than the control group, and were more likely to show empathy towards patients. Physicians and nurses did not perform statistically significantly differently for any healthcare-professional outcomes. There were no statistically significant differences in the other healthcare professional communication skills except for the sub-group of participant interviews with simulated patients, where the intervention group was significantly less likely to present 'facts only' compared with the control group. There were no significant differences between the groups with regard to outcomes assessing healthcare professional 'burnout', patient satisfaction or patient perception of the healthcare professional communication skills.</p> <p>The diversity of studies, particularly in the scales used to measure healthcare professional communication skills, was cited as a key limitation to this review.</p>					
	Efficacy of telephone, print and web-based interventions for physical activity, diet, and weight control among cancer survivors (77)	<p>This review included 27 studies evaluating the efficacy of physical activity, dietary, and weight-control interventions for cancer survivors in which telephone, short-message service, print, and web are the primary methods of delivery.</p> <p>Of the 27 studies in the review, 16 targeted physical activity, two targeted diet, and nine targeted multiple behaviours. Most studies targeted a single survivor group, namely breast cancer. Nineteen of 27 studies found evidence for initiation of</p>	2013	7/9 (AMSTAR rating from McMaster Health Forum)	3/27	0/27	27/27

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>behaviour change, with only eight reporting on maintenance and one on cost-effectiveness.</p> <p>Most studies targeted physical activity only, although a notable proportion targeted both physical activity and diet, with five also targeting weight control. Based on a lenient definition to categorize studies as successful (i.e., at least one significant end-of-intervention effect for one behavioral or weight outcome), nearly three-quarters were efficacious. However, when examining studies targeting multiple behaviors, few achieved improvements across all targets.</p> <p>With almost three-quarters of studies using the telephone as the primary means of intervention delivery, the majority of support is for telephone-delivered interventions among cancer survivors. An evident lack of studies using other modalities, particularly newer technologies, was noted. This is in contrast to evidence from the general adult population in which there has been a dramatic increase in trials of interventions using newer communication methods. In particular, there is growing evidence demonstrating short-term, modest effectiveness of SMS-delivered interventions for behaviour change. However, SMS-delivered services offer an as yet unexplored means for both primary delivery of lifestyle interventions for cancer survivors, as well as a potentially cost-effective adjunct to address long-term maintenance following telephone-delivered interventions.</p> <p>Overall, evidence from this review supporting the maintenance of behaviour change and weight loss is somewhat limited, with only one-third of studies evaluating outcomes after the end of intervention. However, similar to adults without cancer, it is likely that cancer survivors will face challenges to maintaining regular physical activity, a healthy diet, and weight. Broad-reach intervention modalities appear ideal as they have the potential to offer a cost-effective and more easily accessible means of delivering the repeated contacts necessary to sustain behavioural change.</p>					

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>Overall, broad-reach intervention delivery modalities for healthy-lifestyle programs provide a means to meet the needs of a growing and disparate group of cancer survivors, and have strong potential to improve health behaviours and in turn treatment-related side effects, quality of life, and health outcomes.</p> <p>The authors note that this review is limited by the inclusion of studies which were underpowered, some of which were pilot studies. The heterogeneity of outcomes reported across physical activity and diet limited their ability to draw conclusions about the magnitude of intervention effects.</p>					
	Exploring the role of family physicians in the provision of follow-up cancer care (78)	<p>This review examined 48 studies to explore the role family physicians in the provision of follow-up cancer care.</p> <p>There are many benefits to including primary-care providers (family physicians) in cancer treatment, including for reasons of cost-effectiveness, management of side effects and symptoms, and continuity of care. However, the existing role of family physicians in cancer care must be explored, from the perspective of both patients and primary-care providers.</p> <p>From the perspective of the patient, thoughts on the family physician role were largely influenced by the existing relationship between patients and providers. Patients were more likely to report the expectation of primary healthcare not related to cancer from their family physician. Patients broadly recognized the benefits of family physician involvement in follow-up care, citing factors such as greater trust, convenience and continuity of care. However, patients also broadly cited the barriers to engaging family physicians for follow-up care. This engagement was reported to be influenced by a lack of solid relationship, poor communication and coordination, issues with diagnosis/treatment, and poor access to facilities. Building on these barriers, patients still reported a desire to engage their family physician in care. Patients suggested that family physicians be involved in the management, coordination and</p>	2015	7/9 (AMSTAR rating from McMaster Health Forum)	8/58	5/58 (interviews with rural family physicians)	58/58

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>reporting aspects of care, as well as providing emotional and social support.</p> <p>From the perspective of the family physician, significant differences in involvement were noted between urban, rural and remote family physicians – level of involvement varied depending on the needs of a family physician’s population. Family physicians generally viewed themselves as advocates, a role which was more likely for rural and remote family physicians. The types of care reported by family physicians as being of focus included general medical care, comorbid management, psychosocial care and management of pain and other side effects. Family physicians pointed to a number of factors that could facilitate their involvement in follow-up cancer care, including enhanced communication between primary and tertiary care providers and the use of electronic records. Barriers to care provision were identified as miscommunication, loss of contact with patients, uncertainty of role, and lack of training and information. Family physicians suggested that their role could be improved by addressing these barriers and enhancing the provision of emotional support and symptom relief. Further, a study of Canadian family physicians indicated that specialist follow-up was crucial in order to keep patients in the system.</p> <p>Taken together, this evidence indicates that some of the responsibility for follow-up cancer care should be redirected from the tertiary sector to the primary sector. In order for this transfer to be successful, guidelines must be provided and roles must be outlined.</p>					
	<p>Summarizing the role of patients in the development of patient-reported outcome measures for use with patients with cancer (80)</p>	<p>This review examined 20 articles in order to assess how patients are involved as partners in developing patient-reported outcome measures for use with patients with cancer.</p> <p>The use of patient-reported outcomes is a valuable tool in assessing issues that are most relevant to patients themselves. Patient-reported outcome measures help clinicians assess health factors, and also allow researchers and decision-makers to assess initiatives. Engaging patients early on in the</p>	<p>2014</p>	<p>5/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/20</p>	<p>0/20</p>	<p>20/20</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>formation of these tools is crucial to ensure that important outcome measures are incorporated. This review aimed to assess the engagement of patients at the item-generation stage in patient-reported outcome measures development, and to summarize this engagement.</p> <p>This review examined models of patient engagement, and found that the details of engagement in tool construction were often sparse. The most common methods of engagement identified by this review of the literature were open-ended qualitative interviews and focus groups. This method of engagement abides by the recommendations disseminated by the Food and Drug Administration (FDA) and European Organisation for the Research and Treatment of Cancer (EORTC) on how to appropriately collect patient guidance and input. Despite the fact that the EORTC recommends the input of five to 10 patients, these numbers varied widely among the studies under review. Further, patient samples were often homogenous and did not accurately represent the diversity in age, ethnicity and sex that would be seen in the broader population of a certain disease. The diversion of methodology in collecting patient input from the recommendations given by the FDA and EORTC indicates that greater consistency needs to be applied in engaging patients.</p> <p>The results of this review support the notion that a framework for patient-reported outcome measures tool development would assist in the creation of meaningful, high-quality and patient-oriented healthcare. Further research is required to inform this framework.</p>					
	Examining the impact of multidimensional rehabilitation programs on physical and psychosocial health outcomes in adult cancer survivors (76)	Increases in the number of people surviving cancer has necessitated the development of ongoing treatment programs. Survivors of cancer may experience adverse physical and psychosocial effects, and access to support becomes difficult after the completion of treatment. Multidimensional rehabilitation programs include physical and psychosocial interventions aimed at enhancing the knowledge, coping behaviour, self-efficacy, and quality of life among persons	2012	11/11 (AMSTAR rating from McMaster Health Forum)	1/11	0/11	11/11

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>who have survived cancer. The current review examined the effect of multidimensional rehabilitation programs on a range of physical and psychosocial outcomes.</p> <p>The selected studies examined models of care that were categorized as having either a multidimensional or unidimensional focus.</p> <p>Interventions with a multidimensional focus aimed to improve functioning across both physical and psychosocial domains. The evidence of efficacy among these programs was limited in the current review. Three studies demonstrated physical and psychosocial benefits of programs. The first study combined cognitive behavioural therapy with exercise therapy to enhance the quality of life among nasopharyngeal cancer patients. This intervention indicated positive outcomes among physical, cognitive, emotional, fatigue, and quality-of-life measures. Similarly, the second study combined a stress-management program with physical activity to improve energy levels, quality of life, fitness and distress among breast cancer survivors. Improvement was seen on outcomes of fatigue, energy levels and emotional distress. The third study implemented a social cognitive model, including group discussions, supervised exercise, home-based exercise, and counselling sessions with an exercise specialist. Improvements were seen across measures of physical fitness and psychosocial measures among breast cancer survivors. However, bias among all three of these studies was assessed as moderate or high. None of the remaining multidimensional programs indicated success among physical and psychosocial measures.</p> <p>Four of five unidimensional programs indicated significant outcomes for the stated aim of the given program. It should be noted, however, that the majority of the studies indicating significance had the goal of improving physical outcomes. Improvements in physical outcomes across these studies included an increase in physical activity and lifestyle behaviours such as diet quality. Only one unidimensional study aimed to improve psychosocial outcomes; this study</p>					

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>indicated that participants who had received information on “cancer, diet and exercise” demonstrated improved mental health, fewer interpersonal conflicts, improved self-efficacy, and reduced distress. However, similar to other unidimensional studies in this review, this study had a high risk of bias.</p> <p>Given the diversity of the studies included in this review, it was not possible to assess the effectiveness of multidimensional rehabilitation programs in improving physical and psychosocial outcomes. The majority of participants had received a diagnosis of either prostate or breast cancer. There was an under-representation of older participants, people with lower education or people of lower socio-economic status, limiting the generalizability of findings. However, the results suggest that multidimensional rehabilitation programs had a positive impact on physical outcomes among adult cancer survivors. Unidimensional programs yielded greater success among targeted outcomes, and programs that targeted cancer site-specific diagnoses did not demonstrate advantages over programs for people with mixed diagnoses. The evidence suggests that patients may benefit from choosing a program that matches their specific needs.</p>					
Creating the systems and processes to support 1 and 2	Examining models of care that aim to improve the coordination of cancer treatment between primary -care and oncology-care providers (33)	<p>This review examined 22 studies in order to evaluate models of care that aim to improve the coordination of cancer treatment, specifically for adults with breast and/or colorectal cancer, between primary-care and oncology-care providers.</p> <p>For people diagnosed with cancer, primary care is often the first and most frequent point of contact with the health system. However, in order to enhance continuity and quality of care, the coordination of treatment between primary- and oncology-care providers is essential. The eligibility of articles for this review did not depend on any specific set of outcomes; however, patient outcomes such as survival, quality of life, and side effects of treatment were prioritized. This review included five systematic reviews, six randomized control trials, and 11 non-randomized studies.</p>	2015	11/11 (AMSTAR rating from McMaster Health Forum)	5/22	0/22	22/22



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>The systematic reviews chosen for analysis did not support any one model, largely due to the heterogeneity of outcomes and overall low quality of the studies. The most notable result from this literature was the finding that primary care and nurse-led care are equivalent models in the post-surgical period for patients with colorectal cancer, and following treatment in patients with breast cancer. All studies indicated that better quality research must be pursued in this area.</p> <p>Of the six RCTs chosen for review, many demonstrated risk of bias. These studies did not indicate any significant changes in the measured outcomes resulting from a specific model of care.</p> <p>Of the 11 non-randomized studies included in this review, eight were of serious risk of bias and three were at moderate risk of bias. While these studies examined a range of care models, interventions and outcomes, all results were inconclusive.</p> <p>The lack of findings presented in this review indicated two conceptual issues with the existing research. First, the studies included in this review did not provide sufficient systematic rationale for the model or intervention being examined. Second, the evaluation of the model at hand was often a secondary objective of the study, which led to inconsistent monitoring and analysis. Methodological concerns such as small sample sizes, bias and lack of clarity were prevalent across studies.</p> <p>Taken together, the inconsistencies and lack of definitiveness demonstrated by these studies indicates that little progress has been made in this field of research. In order to develop policies that strengthen continuity of cancer care across primary and oncological providers, high-quality research must be conducted.</p>					
	Evaluating methods of follow-up care for	This paper reviewed 4,010 articles to identify studies that evaluated methods of follow-up care for survivors of	2010	6/10 (AMSTAR)	1/8	0/8	8/8

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	<p>survivors of childhood cancer (82)</p>	<p>childhood cancer. This search yielded no comparative studies, indicating a need for this focus on future research efforts. However, this paper retained eight papers from this search in order to reflect current evidence.</p> <p>While the review of these eight studies did not lead to any overall conclusions as to clinical benefits or perceived patient needs, this review did yield a number of important outcomes. A number of different clinical models were examined in these studies.</p> <p>A number of these clinical models explored provision of care that extended past hospital-based clinics. For instance, one study found that targeting high-risk patients to encourage attendance in follow-up clinics led to increased knowledge among patients, and helped to identify areas of further intervention. A shared-care model in the Netherlands, combining hospital clinics with primary care, was found to be feasible and acceptable to patients and primary-care providers. A multidisciplinary clinic was found to enhance clinical efficiency, while providing greater satisfaction to families.</p> <p>A number of the studies in this review focused on hospital-based clinics. A long-term follow-up hospital-based clinic that focused on transferring care from parents to young adults contributed to patient satisfaction, while pointing to patients who preferred seeing a family physician rather than being seen in a hospital-based clinic. A study on the perspectives of survivors and families who had attended a survivorship clinic illustrated that there were a number of perceived health benefits of follow-up care. These included late-effects care, personal relationship with the nurse, and health maintenance. One hospital-based clinic offered support to young adults from a pediatric oncologist, endocrinologist and late-effects special nurse. Clinical care, such as checking for symptoms and developments, was generally rated as more important in this scenario, although supportive care was rated highly among patients with more symptoms and poorer mental health. Finally, a study examining predictors of patient satisfaction in a traditional pediatric late-effects clinic and a</p>		<p>rating from McMaster Health Forum)</p>			

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>multidisciplinary adult clinic found that survivors were satisfied with care regardless of group. Patients who understood the clinical nature of these follow-ups were more satisfied than those who expected psychological support.</p> <p>Taken together, the outcomes of these eight studies were based largely on patient- or parent-reported data. Clinical care was highly valued among survivors, and supportive care was seen as more important by survivors who had greater clinical needs. Ultimately, however, this systematic review did not identify any studies that presented comparative data that evaluated methods of follow-up care for survivors of childhood cancer. The results of this review suggest that further research is crucial in exploring models of care that best support survivors of childhood cancer.</p>					
	<p>Assessing the impact of health information technology that supports patient-centred care on a number of health outcomes (83)</p>	<p>This paper reviewed 327 studies to assess the impact of health information technology that supports patient-centred care on a number of outcomes. Health information-technology applications included tools such as decision support, telemedicine, and tools for patient self-management. Components of patient-centred care included the coordination and integration of care and clinician-patient relationships. These outcomes included healthcare processes, clinical outcomes, intermediate outcomes such as satisfaction and knowledge, decision-making and communication, and access to information. Further, this review aimed to explore barriers and facilitators in health information technology use, and gaps in evidence that may inform future research.</p> <p>First, this study reviewed articles addressing the impact of information-technology applications that address patient-centred care on a range of outcomes. This review found that health information-technology applications had a positive effect on process outcomes such as compliance with standards of care and use of healthcare resources. Clinical outcomes were also improved by health information-technology applications that enhanced patient-centred care, with telehealth applications and care-management tools being most frequently cited as positive tools. The studies under</p>	<p>2010</p>	<p>9/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>15/327</p>	<p>Not reported in detail</p>	<p>Not reported in detail</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>review did not consistently measure intermediate outcomes, such as satisfaction and knowledge. While it is difficult to summarize the impact of information technology on intermediate outcomes, the impact was found to be positive. This review found that studies reported that health information technology had a positive outcome on the responsiveness to individual patient needs and preferences. Telehealth was most frequently cited as the application that supported this outcome. Finally, health information technology was found to have a positive impact on improving shared decision-making in the patient-clinician context. Decision-making applications were most often cited as having positive effects on this outcome.</p> <p>Following the study of health information technology on various outcomes, this review examined the barriers and facilitators that affect the use and implementation of health information-technology applications. Barriers to utilizations included poor usability and issues with access due to factors such as age, socio-economic status and education. Logically, poor computer literacy skills negatively affected health information technology use. Physicians cited concerns of added work and issues with implementation, and all users expressed concern over confidentiality. High satisfaction, usefulness and efficiency are factors that enable use of health information technology.</p> <p>The knowledge and evidence deficits that inhibit the implementation of health information technology were examined in this review. While most evidence focused on outcomes, greater attention must be devoted to the effects of health information technology on responsiveness to needs of unique individuals, and the cost and sustainability of these interventions. Further, there is a lack of evidence examining how health information technology may promote patient-centred care based on racial background, education, socio-economic status and age.</p> <p>This review concluded that all stakeholders must have information about the usefulness and applicability of health</p>					

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	Examining the use of technology in cancer care follow-up (84)	<p>information-technology applications. While health information technology that supports patient-centred care was found to have a positive impact across a number of outcomes, more studies are needed to diversify and develop these findings.</p> <p>This review examined 17 studies exploring the use of technology in cancer care follow-up. This review posited that current models of cancer follow-up care, which are generally in-person visits focused on monitoring disease and effects of treatment, are likely to become unsustainable. While this care is valued by patients, the number of cancer diagnoses is growing and certain groups of patients, such as those who live in rural areas, may be unable to access cancer centre care. Taken together, these factors merit study into modern models of cancer follow-up care.</p> <p>The impact of technology in follow-up care was evaluated across a number of factors, including patient acceptability/satisfaction, clinical safety, health-related quality of life, and health economic outcomes. Patients reported satisfaction with technological support, such as telephone calls, across studies. In some cases, this type of intervention was preferred. No significant differences were found in the study that examined clinical safety across technological intervention and control groups. Studies on health quality of life suggest that quality of life may improve in patients who are given technological support in the follow-up period. Some studies indicated that monitoring symptoms via a telephone system yielded the reporting of more severe symptoms when compared to a nurse-assisted program. Taken together, the studies examining health quality of life indicated that there were no significant differences in psychological distress or quality of life between groups. Lastly, studies of health economic outcomes indicated that telephone follow-up services were costlier, however, these costs were anticipated to decrease after staff training, and were overall less costly for patients.</p>	2014	6/10	2/16	Not reported in detail; however, purpose of study is to examine form of care that may benefit rural patients	16/16

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>This review indicates the potential for the use of technology in cancer care follow-up. However, further research is required to deduce the cost-effectiveness of this model of care.</p>					
	<p>Synthesizing patient views on patient-held records to examine the effectiveness, benefits and drawbacks of these records (86)</p>	<p>This review examined 10 papers in order to synthesize patient views on patient-held records and to examine the effectiveness, benefits and drawbacks of this form of record. Patient-held records are used across healthcare systems and are designed to facilitate communication between patients and health professionals. Three major themes emerged from this work pertaining to patient-held records: practical benefits, psychological benefits and drawbacks.</p> <p>The practical benefits of the patient-held records examined the usefulness of this type of record to the patient. Patients widely reported value in having personal records, to track health, remember events and share information. The sharing of information using patient-held records was seen as valuable across patients and healthcare providers.</p> <p>Psychological benefits arising from the use of patient-held records included empowerment through the ability to ask questions and challenge assumptions, to be actively involved in care, and the sense of having more control as a patient.</p> <p>While practical and psychological benefits arise from the use of patient-held records, negative impacts were also seen across some studies in this review. Some patients saw the use of patient-held records as the allocation of unwanted responsibility. The ineffectiveness of this type of record was touched upon, with the lack of awareness across staff being a barrier to use.</p> <p>Given the potential benefits of patient-held records use, this review concluded that in order to yield these benefits the use of patient-held records must be embedded across health systems. Further, more robust qualitative studies examining patient experience are required to gain insight into patient perspectives.</p>	2013	3/9 (AMSTAR rating from McMaster Health Forum)	0/10	1/10 (advanced cancer needing palliative care)	5/10

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	Exploring telehealth interventions that focused on family-caregiver outcomes (85)	<p>This review examined 65 studies in order to explore telehealth interventions that focused on family-caregiver outcomes.</p> <p>Family caregivers are informal persons who take care of loved ones, a role that has been found to adversely affect physical and psychological health, among other factors. Technology such as telehealth has been used to support coping and healing, but few studies have examined the effect of telehealth interventions on family caregivers. The current review examined studies in which there were six main categories of telehealth interventions: education, consultation, psychosocial/cognitive behavioural therapy, social support, data collection and monitoring systems, and clinical-care delivery.</p> <p>The majority of the studies under review indicated an improvement in caregiver outcomes following technological interventions. These outcomes included improved psychological health, satisfaction with telehealth, social support, coping, communication, cost saving, physical health, and productivity. While a minority (5%) of studies indicated that caregivers using telehealth interventions did not experience significant improvement in comparison to face-to-face care, the effects of both types of care were similar.</p> <p>This review examined studies that found a positive effect of technological interventions on caregiver outcomes.</p>	2014	4/9 (AMSTAR rating from McMaster Health Forum)	8/65	33/65 (dealt with adults and older patients)	3/65
	Examining the evidence for use of survivorship care plans for cancer survivors (92)	<p>This paper reviewed 10 studies to examine the evidence for the use of survivorship-care plans for cancer survivors.</p> <p>Survivorship-care plans were recommended by the Institute of Medicine in 2006 to address the many issues that cancer survivors face, including the late effects of treatments, long-term emotional effects, and tumor recurrence. The current review examined the effect of survivorship-care plans on outcomes of health-related quality of life, distress, survivor satisfaction with care plan, understanding of information in the survivorship-care plan, satisfaction with care, uptake of recommended screening, and feasibility.</p>	2013	5/10 (AMSTAR rating from McMaster Health Forum)	2/10	0/10	10/10

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>No major differences were found in health-related quality of life – however, one study found that the use of a survivorship-care plan in a follow-up care package resulted in fewer unmet needs among patients. There was some evidence that survivorship-care plans may reduce distress in cancer survivors; however, other evidence has suggested that distress may be higher due to increased worry about one’s health and negative memories that may be triggered by reading the survivorship care plan. Survivor satisfaction with care plans was very high across studies, accompanied by positive feelings towards the survivorship care plans. Studies demonstrate good understanding of survivorship care-plan content among survivors. Evidence suggests that patient satisfaction with medical care does not vary greatly based on the use of survivorship-care plans. The use of survivorship-care plans may promote the uptake of recommended screening. While survivorship-care plans are feasible, they are resource intensive, taking hours to develop and coming at a cost to health resources.</p> <p>The unclear benefits of survivorship-care plans drawn from this review may be due to other factors that prevented the detection of these benefits. Patient feedback about survivorship-care plans was extremely positive, with survivors reporting value to the information provided. The fact that some studies point to the potential distress that may arise due to survivorship-care plans points to the fact that some patients may be better suited to this content than others.</p> <p>Going forward, there is a need for more long-term data examining the impacts of survivorship-care plans, in order to examine the potential benefits of use among survivors.</p>					
	Collecting and examining evidence on the effectiveness of patient-navigation programs in adults	<p>This review examined four studies to collect evidence on the effectiveness of patient-navigation programs in adults undergoing cancer treatments.</p> <p>In light of recent advancements in medical treatment, patients often receive care from a number of areas and specialists</p>	2013	8/10 (AMSTAR rating from McMaster)			4/4



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	undergoing cancer treatments (91)	<p>within the medical system. In light of this, there is a growing need to coordinate care for patients in order to improve quality of life and care. Patient-navigation programs have been introduced in healthcare settings, with nurses being considered potential navigators. However, this review posited that the effectiveness of these programs must be examined. This review focused on the impact of patient-navigation programs on measures of quality of life, patient satisfaction, and early treatment outcomes.</p> <p>The studies in the current review indicated no significant difference in quality of life among patients who had entered navigation programs in comparison to patients who had not. However, patient satisfaction was significantly increased among those who had entered a nurse-led navigation program. No significant differences were found in patient distress levels.</p> <p>Given the improvements in patient satisfaction after involvement in a navigation program, this review suggests that these programs be implemented in acute settings. Further research should be conducted to assess effectiveness of these programs.</p>		Health Forum)			
	Assessing the effectiveness of patient navigation on healthcare-utilization outcomes (88)	<p>This review examined 25 studies to assess the effectiveness of patient navigation on healthcare-utilization outcomes.</p> <p>Patient-navigation programs can decrease barriers to care and improve survival among patients, however, evidence remains mixed on the effectiveness of patient navigation. This review sought to evaluate the effectiveness of patient navigation on measures of health-utilization outcomes such as health screening rates, attendance to care events, adherence to cancer care follow-up treatment, and completion of an appointment for a diagnostic resolution.</p> <p>Patient navigation was found to significantly increase the likelihood of a patient attending health screening. The majority of the studies in this review examined cancer screening, indicating that patient navigation was effective for</p>	2015	9/11 (AMSTAR rating from McMaster Health Forum)	1/25	25/25	24/25

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>screenings such as Pap tests, mammograms, colonoscopies and endoscopies.</p> <p>Patient navigation was also effective in promoting attendance to care events, such as cardiac rehabilitation after a cardiac event. Participants were almost three times more likely to attend these events if they were part of a patient-navigation intervention.</p> <p>The impact of patient navigation on outcomes of adherence to follow-up treatment and completion of an appointment for a diagnostic resolution indicated promising potential for this intervention.</p> <p>The majority of participants in these studies were ethnic minorities – patient navigation was initiated as an intervention for marginalized minority populations and continues to be an effective mechanism for reducing barriers to care. The majority of participants in these studies were women; future research should consider the effects of patient navigation for men.</p>					
	<p>Assessing the role of navigators in supporting chronically ill older adults through healthcare transitions (89)</p>	<p>This review examined 15 articles in order to assess the role of navigators in supporting chronically ill older adults through healthcare transitions. Transitions are exceptionally difficult for older persons, and any medical episodes often result in many interactions with the health system due to the multiple morbidities that these patients often have.</p> <p>Outcome measures of navigator programs fell into three general categories: economic benefits, psychosocial benefits, and quality of life benefits. Of the nine navigator programs identified by this review, five reported positive economic outcomes. This may have been due to reduced readmissions and hospital days in intervention groups. Two studies reported higher patient satisfaction after involvement with the intervention. Finally, five of the included studies reported increased patient quality of life and functionality. The emphasis on the post-acute care period for older patients may</p>	<p>2011</p>	<p>5/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>2/9</p>	<p>15/15</p>	<p>0/15</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>have eased the transition back into daily living, hence contributing to an improved overall quality of life.</p> <p>The results of this review indicate that special care must be provided to older adults in the healthcare system in order to preserve their desires while health declines. This review indicated mixed results in terms of navigation program effectiveness; while greater patient satisfaction and quality of life was reported, some studies revealed no effects and one study reported higher use of emergency health services by these patients. However, the promising positive results indicate that navigator roles may help divert older patients from higher levels of care, and in doing so improve patient lives. Future research must further explore the role of the navigator, considering economic and systems impacts.</p>					
	<p>Exploring how nurse-led follow-up breast cancer interventions have been evaluated, with a specific focus on patient outcomes and cost-effectiveness (90)</p>	<p>This review examined 13 articles in order to explore how nurse-led follow-up interventions in breast cancer have been evaluated, with a specific focus on patient outcomes and cost-effectiveness.</p> <p>Breast care nurses are key figures in the care pathway for women with breast cancer. Breast care nurses provide supportive care that improves quality of life for patients with cancer, including supporting the physical, psychological and social needs of patients. As survival rates increase, nurse-led breast cancer follow-up has become an increasingly common route of care as opposed to traditional hospital outpatient clinics. This review explored how nurse-led interventions have been evaluated, focusing on patient outcomes such as quality of life, psychosocial support and cost-effectiveness.</p> <p>The studies included in this review indicated that nurse-led interventions in the follow-up stage of breast cancer contributed positively to quality of life among patients. Significant improvements in symptoms such as constipation, nausea and pain were also seen among patients involved in this intervention. Patients involved in nurse-led care experienced similar levels of anxiety to patients not involved</p>	<p>2013</p>	<p>6/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/13</p>	<p>0/13</p>	<p>13/13</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>in this form of intervention, but nurse-led programs led to higher levels of satisfaction than hospital clinics.</p> <p>In terms of outcomes of psychosocial support, no significant differences were found along measures of mood disturbance, cancer-related worry, or symptom distress when nurse-led groups were compared to control groups. However, patients enrolled in nurse-led follow-up studies reported more perceived benefits, and experienced less worry about their disease-related problems.</p> <p>Patients enrolled in nurse-led interventions reported fewer financial problems, and telephone follow-up visits yielded lower cost. However, telephone-led interventions should be paired with educational group programs in order to benefit patient quality of life while balancing cost-effectiveness.</p> <p>This review found promising results for the effectiveness of nurse-led follow-up breast cancer care. These interventions contributed to continuity of care and psychosocial support, however, future research should focus on survival, recurrence, patient well-being and cost-effectiveness, as no concrete conclusions on these outcomes could be drawn from this review.</p>					

**Appendix 2: Systematic reviews relevant to Element 2 – Align funding and remuneration arrangements to better support patients with cancer as they transition from treatment to survivorship in the community**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
Funding primary- and community-care organizations involved in providing support services for patients and families transitioning out of cancer treatment	Leaders' experiences and perceptions implementing activity-based funding and pay for-performance hospital funding models (94)	<p>All of the included studies focused on leaders' experiences with implementing organizational incentives, but none clearly described 'how' funding models were implemented.</p> <p>Five themes were identified based on leaders' experiences: 1) prerequisites for success; 2) perceived benefits; 3) barriers/challenges; 4) unintended consequences; and 5) leader recommendations.</p> <p>Prerequisites for success include: full organizational commitment to and support for the chosen funding model; required infrastructure to support the individuals and activities required to accurately measure quality in pay-for-performance models; information-technology and decision-support systems for producing, tracking and aggregating high-quality, timely, accessible, clinically relevant data; committed leaders who are supportive of the funding model and recognize the benefits that can be achieved; and involving physician leaders to support accurate data collection and to act as 'champions'.</p> <p>Perceived benefits for activity-based funding included improved productivity and efficiency, ability to reallocate funds, supporting greater emphasis on evaluation, accountability and discharge planning, improved data accuracy, and improved collaboration and communication. Improved quality and enhanced organizational transparency were associated with pay-for-performance models.</p> <p>Barriers/challenges to implementation included lack of resources (e.g., constrained human resources given additional workload for providers), data collection (e.g., difficulty gathering accurate data and lack of experienced staff for data collection), and commitment factors (e.g., leaders' skepticism or suspicion about the funding model).</p> <p>Unintended consequences included opportunistic behaviour, 'cherry-picking' patients with less complex conditions and who are less expensive to treat (possibly leading to the exclusion of more vulnerable patients), and inaccurate reporting and evaluation of quality outcomes.</p> <p>Leader recommendations included the need to have support for the funding model change from different leaders within the organization (including</p>	2013	8/9 (AMSTAR rating from McMaster Health Forum)	0/14	1/14	0/14

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>administrators, health professionals and staff) from the beginning of the transition to ensure full engagement during the entire implementation process. Recommendations to support quality improvement at the program/unit level included providing educational resources for hospitals and training programs, increasing collaboration and cooperation with other units and project groups/committees, increasing interprofessional communication and interaction, and sharing data collection personnel, protocols and tools.</p>					
	<p>Effectiveness of pay-for performance on clinical efficacy, access and equity, coordination and continuity, patient-centredness and cost-effectiveness (98)</p>	<p>Congruent with previous evidence on the pay-for-performance scheme in primary- or acute-care settings, the review suggested that clinical effectiveness results from 47 studies suggested a general improvement of 5% in clinical effectiveness. While positive effects were reported in diabetes, asthma and smoking cessation, the scheme most frequently failed to affect acute care. Effects on non-incentivized quality measures varied greatly. One study also suggested a potential positive spillover effect as well.</p> <p>Twenty-eight studies supported the notion that the pay-for performance scheme did not have negative effects on patients belonging to certain age groups, ethnic groups, comorbid statuses or socio-economic statuses. Before-and-after studies without control groups have provided some support for positive effects with coordination of care, although a time-series study suggested no effect and a potential negative spillover effect as well. In terms of patient-centredness, two studies found no effect (potentially due to a ceiling effect), while one found positive effects. Cost-effectiveness of pay-for-performance schemes was confirmed by four studies, although health gain findings were varied.</p> <p>Findings suggested that purely positive financial rewards generate more positive effects than competition-based incentives with winners and losers. Fixed threshold and continuous scale rewards for target achievements or improvements have both been found to have positive effects in some studies, and no or mixed effects in others. In general, positive effects are clearly larger in initially low performers with significant room for improvement, relative to already high performers. Programs aimed at the individual provider and/or team level(s) generally reported positive results; programs aimed at hospitals generally reported smaller positive effects. While a combination of incentives at different target units was rarely used, two studies reported positive results.</p> <p>As per the findings of this review, future pay-for-performance programs should define targets based on baseline room for improvement, use process and intermediary outcome indicators as target measures, engage stakeholders and</p>	2009	7/10 (AMSTAR rating from McMaster Health Forum)	2/128	0/128	0/128

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		communicate information directly, focus on both quality improvement and achievement, and target individuals and teams.					
	Examine the impact of activity-based funding of hospitals on mortality, severity of illness and volume of care (97)	<p>This review focused on assessing the effect of activity-based funding (ABF) on mortality rates, discharge rates following hospitalization, severity of illness and volume of care.</p> <p>The review found consistent and robust differences between ABF and no-ABF in discharge to post-acute care, showing a 24% increase with ABF. Results also suggest a possible increase in readmission with ABF, and an apparent increase in severity of illness (perhaps reflecting differences in diagnostic coding). Although the review found no consistent, systematic differences in mortality rates and volume of care, results varied widely across studies, some suggesting benefits from ABF, and others suggesting deleterious consequences.</p> <p>The review concludes by stating that the available evidence does not demonstrate a consistent impact of ABF on mortality in either acute or post-acute care. The most notable finding was a large increase in admissions to post-acute care after a hospital stay; however, these results were limited to the U.S.</p>	2012	10/11 (AMSTAR rating from McMaster Health Forum)	0/65	0/65	0/65
	Examine the effect of bundled payment on healthcare spending and quality (96)	<p>The review included 58 studies that examined 20 different bundled-payment interventions. Bundled payment was defined as a method in which payments to healthcare providers are based on the predetermined expected costs of a grouping of related healthcare services. Bundled-payment interventions may aggregate costs over time within a single provider, aggregate costs across providers, and/or involve warranties where costs of complications are rolled into a single payment. Bundled payments may create financial incentive for providers to decrease the number and cost of services included in the bundle.</p> <p>The review found that the transition from a cost-based or fee-for-service reimbursement to bundled payment was generally associated with a decline in spending of 10% or less. Additionally, bundled payment was associated with a decrease in utilization of services included in the bundle, demonstrated through reductions in length of stay or use of specific services. Most of these reductions were between 5% and 15%. There were inconsistent and mixed findings on the effect of bundled payment on quality measures.</p> <p>Only a few studies included analyses of differential effects by key contextual factors. There was low-quality evidence that for-profit providers generally experienced larger declines in utilization under bundled payment than their non-profit counterparts. Additionally, providers with greater financial pressure had</p>	2011	10/11 (AMSTAR rating from McMaster Health Forum)	2/58	3/58	0/58

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		greater reductions in utilization. None of the studies included analyses of differential effects by key design factors.					
	Examine the value of adding functioning information into case-mix systems with respect to the prediction of resource use as measured by costs and length of stay (95)	<p>This review focused on examining the value of adding functioning information into case-mix systems with respect to the prediction of resource use as measured by costs and length of patient stay.</p> <p>Four studies addressed the value of adding functioning information into case-mix systems with costs as the outcome parameter. Three of these studies focused on the Diagnosis Related Groups case-mix systems in hospital settings. An undisclosed number of these suggest that older patients have higher dependence on activities of daily living (ADL), and that this is significantly associated with higher costs of hospitalization even after adjusting for Diagnosis Related Groups costs and other patient characteristics.</p> <p>Five studies investigated the effects of adding functioning information to case-mix systems with respect to patient length of stay. These studies suggest that adding functional information into Diagnosis Related Groups case-mix systems in acute hospital settings increases the explained variance in length of stay in elderly patients from 8% to 28%.</p> <p>Overall, the review provides evidence that functioning information is an important factor for determining patients' healthcare needs and resource use. Adding functioning information into case-mix systems strengthens the predictive power of these systems as well as the variance explained with regard to costs and length of stay.</p>	2014	3/9 (AMSTAR rating from McMaster Health Forum)	0/10	7/10	0/10
	Efficacy of financial arrangements for health systems in low-income countries (112)	<p>The review examined 15 systematic reviews for evidence on the effects of financial arrangements for health systems in low-income countries. This review examined a range of effects, including the different effects of ways of collecting funds, types of insurance schemes, ways of paying for services, and types of financial incentives for both recipients of care and health workers.</p> <p>The effects of changes in user fees on the utilization and equity of health-care systems was explored in two reviews – these effects are uncertain. The review also found that it was unclear whether aid delivered under the Paris Principles improves health outcomes.</p> <p>One systematic review examined the effects of different types of insurance schemes on health systems. This review found that community-based health insurance may increase the use of services. However, this evidence is uncertain,</p>	2016	10/11	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)



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		<p>and the effects of this utilization on health are unclear. Further, it is unclear whether social health insurance affects the use of services.</p> <p>One review examined the effects of the different ways of paying for health services. This review found that the effect of increasing the salaries of public healthcare workers has uncertain effects on the quantity and quality of their work.</p> <p>Six systematic reviews examined the effects of different types of financial incentives on the recipients of care. These reviews found that incentives may improve patient adherence to treatment, although the effects of this on health are uncertain. One-time incentives likely increase the likelihood for patient return or initiation of treatment. These incentives may improve patient return for tuberculosis test results. Conditional cash transfers and vouchers likely increase patient use of services, although this increased use has mixed effects on health. These reviews found that combining ceiling and co-insurance models of funding increases use of health services and decreases use of medicines. Finally, these reviews found that limiting the amount insurers pay for different drugs has mixed effects on the expenditures of patients and insurers, and has further mixed effects on the use of brand and generic drugs.</p> <p>Five systematic reviews examined the effects of different types of financial incentives on health workers. In terms of worker performance and quality of care, the effects of financial incentives are uncertain. Further research is needed to clarify the effects of incentives on bringing workers to remote areas.</p> <p>Further research is required to evaluate all outcomes of financial arrangements in low-income health service settings. There are gaps in research due to uncertainty and inconclusiveness.</p>					
Remunerating providers involved in providing support services for patients and families transitioning out of cancer	Incentives for improving human resource outcomes in healthcare (103)	Thirty-three reviews summarizing the effectiveness of incentives for improving human resources in healthcare (e.g., job satisfaction, turnover rates, recruitment, retention) were identified, of which 13 reviews meeting quality criteria were included. Mixed evidence was found for the use of financial incentives: while there may be a positive influence on job satisfaction and healthcare-provider recruitment, there was a lack of evidence supporting such an influence on retention. Higher wages were found to influence job satisfaction and aid recruitment and initial retention, although the effectiveness on retention was found to decline after five years. Financial compensation was also found to not necessarily be the most effective strategy to retain nurses versus other factors	2012	No rating tool available for this type of document	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)

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		<p>such as a positive work environment. While there is a relative lack of evidence to show that financial incentives are important for medical student and physician retention for rural and remote communities, findings suggest that financial compensation, scholarship schemes, benefits and loan repayments may be linked to healthcare-provider recruitment in these areas.</p> <p>The review found that direct compensation through salaries, indirect payment through benefit packages, and financial incentives in general were often the first incentives considered, and higher salaries and indirect compensation remained popular, although their effectiveness for key outcomes remained unclear. Mixed results were reported for the effectiveness of non-financial incentives, and incentives emphasizing work-life balance (e.g., child care). Strategies such as those providing opportunities for collaboration, were both found to improve job satisfaction and staff retention. While child-care supports, social hours, family supports and workload adjustments were found to be effective, they were not always clearly defined in included reviews. Based on the findings of the review, the authors suggested a strategy combining financial and non-financial incentives (e.g., high-quality working environments, opportunities for professional growth) might be more effective on human resource outcome improvements than financial incentives alone.</p>					
	Examining the impact of financial incentives on health professional behaviour and patient outcomes (105)	Overall, researchers concluded that payment for service, payment for providing care for a patient or specific population, payment for providing a pre-specified level of care or providing change in activity or quality of care, were effective. Mixed results were obtained for mixed or other system interventions, and payment for working for a specified time period was generally ineffective. Financial incentives were found to be effective in improving processes of care, referrals and admissions, and prescribing costs. They showed mixed effects for consultation or visit rates, and they were found to be generally ineffective in promoting compliance with guidelines. However, these results should be treated with caution due to the low to moderate quality of evidence of the studies included in each review.	2010	No rating tool available for this type of document	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)
	Effectiveness of pay-for performance schemes targeting individual healthcare providers for	Uncontrolled studies included in this review indicated that the pay-for-performance scheme improved quality of care, although higher quality studies did not report similar findings. Interrupted time series studies suggested mixed effects of the scheme, with two not detecting any process of care or clinical outcome improvements, one reporting initially statistically significant improvements in guideline adherence which became minimal over time, and two others reporting statistically significant blood pressure control improvements and hemoglobin A1C control declines.	2012	9/10 (AMSTAR rating from McMaster Health Forum)	1/30	0/30	0/30

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	improving quality of patient care and patient-relevant outcomes (118)	Specific to preventive care, two randomized controlled trials ranked highly by the authors found significant but small effects on vaccination rates, while two other studies found no effect on mammography, and Pap spears and mammography combined. Other studies found mixed results between significant effects on one outcome and no effect on another. Specific to long-term care and chronic conditions, one highly-ranked randomized controlled trial found no differences between treatment and control arms in assessing proportion of patients smoke-free. Additionally, an interrupted time series study reported no findings suggestive of a faster rate of increase in quality scores for incentivized indicators (asthma, diabetes, hypertension, coronary disease) compared to before pay-for-performance implementation, and no improvements in non-incentivized indicators. While pay-for-performance schemes may be useful in identifying elements of care valued within a given healthcare organization, current evidence targeting individual family physicians is insufficient to support its adoption, and its efficacy on quality of care and patient relevant-outcomes remains uncertain.					
	Interventions for supporting nurse retention in rural and remote areas (106)	<p>Five relevant reviews were identified. With regards to financial incentives, one review synthesizing 43 empirical studies targeting nurses and physicians identified five types of programs addressing return of service: service requiring scholarships; educational loans with service requirements; service-option educational loans; loan repayment programs; and direct financial incentives. While the review identified substantial evidence on incentives for return of service as a health policy intervention to attract human health resources to underserved areas, there was limited evidence on rural area retention. Financial-incentive programs were found to place substantial numbers of health workers in underserved areas, and participants were more likely to work in underserved areas for longer durations relative to non-participants, although they were less likely to remain at their site of original placement.</p> <p>A second systematic review addressing effectiveness of different retention strategies found 14 relevant papers (one on nurse retention, 11 on health professionals with an emphasis on physicians, and one on psychiatrists). While financial incentives were the most commonly reported strategy, the review offered limited support for their efficacy, with results indicating they were more effective in improving recruitment and short-term retention than fostering long-term underserved-area service retention. Some evidence suggested strategies involving some form of obligation (e.g., visa conditions restricting area of practice or loan repayment) might be effective in longer retention durations. Other evidence indicated non-financial incentives (e.g., providing quality working</p>	2012	No rating tool available for this type of document	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)	n/a (includes reviews, not single studies)

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		<p>and housing conditions) might have a greater impact on retention-related decisions.</p> <p>Overall, while financial incentives were the only strategies that had been evaluated properly, evidence supporting their effectiveness on long-term nurse retention was still found to be very limited, with some evidence suggesting they lacked effectiveness. Evidence on “direct and indirect financial incentives (direct payments, service requiring scholarships, educational loans with service requirements, loan repayment programs)” was classified as being of moderate strength and indirect. In comparison, effectiveness of education and continuous professional-development interventions (e.g., recruitment from and training in rural areas, targeted admission of students from rural backgrounds) was rated as being based on moderate-strength, indirect evidence. Regulatory interventions (e.g., increased opportunities for recruitment to civil service) were rated as having low-strength and indirect evidence, and personal and professional support interventions (e.g., general rural infrastructure improvement, supportive supervision, and measures to reduce healthcare workers’ feelings of isolation) were rated as having a combination of moderate-strength, indirect evidence and strong direct evidence.</p>					
	Determining the effect of policies for financial incentives for drug prescribers on drug use, healthcare utilization, health outcomes, and costs (101)	<p>The proportion of total healthcare expenditures spent on drugs continues to grow. Financial incentives influence prescribers’ behaviour through budgetary arrangements, financial rewards for target outcomes, and reduced pharmaceutical reimbursement rate.</p> <p>Eighteen evaluations of pharmaceutical policies from six high-income countries were analyzed. Pharmaceutical budgets may lead to a modest reduction (2.8%) in drug use. The impact of policies involving financial incentives on drug costs and healthcare utilization are uncertain due to low-quality evidence.</p>	2011	10/10 (AMSTAR rating from McMaster Health Forum)	0/18	0/18	0/18
	Evaluating the impact of different methods of payment on the clinical behaviour of	<p>This review examined four studies to explore the effects of different payment models on the clinical behaviours of family physicians.</p> <p>The primary models of payment assessed in this review are salary (payment is made based on hours worked), capitation (payment is made for each patient), fee-for-service (payment is made based on service provided), and mixed models of payment. Salary and capitation models of pay are prospective, in that family physicians are aware of their pay prior to providing a service. Fee-for-service is a</p>	1997	8/11 (AMSTAR rating from www.rxforchange.ca)	Not reported in detail	0/4	0/4

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	family physicians (99)	<p>retrospective model of pay in which family physicians receive pay based on the services they provide to a patient. Literature has indicated that different payment models uniquely influence a range of factors when it comes to care provision, based on the incentives offered by that model of payment. For instance, salaried payment may encourage the containment of costs, but it may not necessarily improve quality of care. Capitation models may result in larger patient lists in order to increase income. While this may have the effect of shortening consultations, it may also increase quality of care as physicians aim to attract patients to their practice. Further, the literature indicates that fee-for-service payment methods may result in over-treatment of patients and requires a great deal of administrative work.</p> <p>The review aimed to examine the effect of varying models of payment on a range of factors including family physician satisfaction, the cost, quantity, and type of care provided, equity of care, and overall quality of care as measured by patient health and satisfaction. There were few studies fulfilling the search criteria, indicating that there may be barriers to conducting these experiments, such as political interests or unforeseen changes in payment systems.</p> <p>None of the selected studies examined the effect of payment systems on job satisfaction among family physicians.</p> <p>There were a number of relevant findings among the studies exploring the effect of payment model on the cost and quantity of care services. Specifically, this review examined whether cost and quantity of care was lowest in systems using salaried and capitation payments systems, and highest in fee-for-service systems. The evidence suggests that the quantity of care provided by family physicians is higher under a fee-for-service system; a higher number of patient visits among this group may indicate that physicians in a capitation system may limit services in order to minimize costs. One study indicated that patients in a capitation model receive fewer visits from their family physician, however, the validity of this study was questioned. Changing models of payment from capitation to mixed capitation/fee-for-service increases the number of services provided by family physicians. Further, one study indicated that this change in model resulted in a decrease in prescription renewals and referral to specialists; these were surprising findings, as these patterns did not increase income. Thus, it is possible that family physicians do not respond to financial incentives, or that these incentives were not sufficiently significant. Finally, it was found that systems implanting a salaried payment method resulted in a lower number of primary-care visits when compared to fee-for-service models.</p>					

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		<p>This review examined whether family physicians change the pattern and type of care they provide based on the incentive of the financial model they are working within. It was hypothesized that fee-for-service family physicians would provide a high number of low-cost services, while capitation family physicians would deliver more cost-saving care such as health promotion. However, none of the selected studies provided conclusive evidence on this topic.</p> <p>None of the included studies examined issues of equity in relation to health access for population sub-groups.</p> <p>None of the included studies examined the impact of a particular payment model on the health of patients. While there was evidence suggesting that patient satisfaction did not differ between models of payment, it is essential to examine health status before forming conclusions.</p> <p>In sum, this review provides evidence that payment systems do influence the behaviours of family physicians. The selected studies suggest that fee-for-service models increase the quantity of primary-care services when compared to capitation and salary models. However, further studies are necessary to form conclusions. Future research should focus on longer follow-up, the standardization and consistency of interventions and results, and the inclusion of a broader range of outcome variables.</p>					
	Evaluating the impact of payment method on the behaviour of family physicians (100)	<p>The review examined six studies in order to evaluate the impact of payment method on behaviour of family physicians.</p> <p>Capitation, salary and fee-for-service models of payment are the main modes of paying family physicians. Each of these models provides a different incentive. Capitation models deliver a payment for each patient, salaried physicians receive a lump sum payment for hours worked, and fee-for-service models provide pay for each unit of care delivered. Fee-for-service models include target payments, a model under which physicians are paid if they reach a certain target. Each model of payment has advantages: capitation contains personal and financial costs and attracts patients; salaries contain personal costs; fee-for-service induces demand and increases quantity of care; and target payments contain costs. The review compared models of payment to examine influence on physician behaviour.</p> <p>In comparing capitation payment versus fee-for-service payment models, one study found that patients in a fee-for-service group paid more visits to primary</p>	1997	7/11 (AMSTAR rating from McMaster Health Forum)	1/6	0/6	0/6

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		<p>care and specialist services. This suggests that capitation physicians may limit the number of services provided in order to contain costs. Number of hospitalizations was also lower in the capitation group, however, healthcare expenditure was higher among capitation payment groups. Another study found that after the introduction of fees into a capitation payment system, the number of consultations and diagnostic services rose, while the number of prescriptions and referrals fell. Finally, the Canadian study found that contrary to incentives, hospitalization rates did not change after physicians switched from fee-for-service to a capitation payment system.</p> <p>In comparing salary payment versus fee-for-service payment, one study demonstrated that salaried payment models are associated with fewer well-child visits and reduced continuity of care. Despite this, there were no major differences in patient satisfaction, although patients reported salaried physicians as being easier to access. Physicians working in a salaried model are more likely to have interests in private practice, which may explain the higher number of enrolled patients found in salaried practices.</p> <p>One study compared mixed capitation systems and fee-for-service systems, and found that there were no significant differences in hospital use between groups.</p> <p>In comparing target payments and fee-for-service payments, two studies indicated that target payments may have a positive impact on immunization rates. However, this was not found to be statistically significant.</p> <p>The results of this review indicate that payment models do impact physician behaviours. However, there is a need for more high-quality evidence in order to draw conclusions. Longer follow-up and greater consistency in methods will strengthen future studies and better inform future policies.</p>					
	Evaluating the effects of financial incentives on medical practice (104)	<p>The review examined evidence from 89 studies to assess the effects of financial incentives on the costs, processes and outcomes of medical care.</p> <p>Financial incentives may be used in the context of medical care provision to reduce the utilization of resources, transform practice, and improve quality of care or achieve a health target. The review aimed to identify all financial incentives that had been proposed, described or used in the field in order to assess outcomes. A number of financial models were noted in the included studies. These models included payment by salary, fee-for-service and capitation – both physician based (in which the physician is given a set sum of money to</p>	1999	5/11 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/89	1/89

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		<p>provide care) and patient-based (in which the sum is adjusted to the number and type of patients in office).</p> <p>The review found a number of effects resulting from capitated payment for each registered patient. These included a reduction in prescription costs and in the total number of drugs per prescription. Shifting from fee-for-service to this model of payment reduced the number of referrals made by healthcare providers to private clinics and for elective surgeries.</p> <p>Studies examining fee-for-service payment models indicated an increase in service provision in light of increased incentives. For instance, one study observed an increase in the number of night visits made by family physicians when the fee of this service increased. In another study, fee-for-service seemed to encourage gynecologists to perform elective services, while capitation discouraged these procedures. Capping the maximum annual revenue of physicians resulted in a redistribution of patients among providers. This study suggested that physicians are able to influence the demand of their patients.</p> <p>Studies examining salaried physician behaviours observed that these physicians referred patients less and were less active.</p> <p>Studies examining managed care, the model of care used in the American health system, indicated a reduction in patient costs. Hospital admission rates and general length of stay were reduced; however, managed care plans can vary widely and results varied accordingly. Recommendations made to patients by physicians may change based on if the patients are insured or uninsured. Financial incentives were found to further influence physician behaviours; for instance, incentives of a bonus for higher prescribing increased total prescription volume from 12% to 23% per physician. This review also examined the effects of managed care on process of care. Studies suggested that within this model, physicians reduce costs and provide higher quality care. Studies also find that financial incentives tend to enhance physician compliance to guidelines, although contesting findings have been found across studies on this topic. Studies indicate that patients in a managed care model may experience better general health.</p> <p>A number of confounds and limitations must be considered when examining these outcomes. Effects of incentives differ based on the type of health professional, institution or patient. For instance, physicians respond differently based on factors such as a patient's disease, age, sex, the nature of the practice and institution, and the volume of activity. Physicians who have experienced</p>					



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		<p>financial penalty in the past comply more readily with incentives. The results of the studies in this review did not maintain consistency in how financial incentives were assessed, and many did not meet the criteria proposed by the Cochrane group.</p> <p>The results of this review shed light on the effects of payment models on medical care. Financial incentives can be efficacious in reducing the use of resources and encouraging physician compliance with guidelines.</p>					
Change the approaches used for purchasing support services for patients and families transitioning out of cancer treatment	Examining whether various methods used by managed-care organizations influence prescribing and dispensing of drugs (107)	Most managed-care organizations have had limited success using formularies, therapeutic interchange, and prior approval to influence prescribing and dispensing decisions. Closed formularies were effective in reducing utilization, but not cost, of prescription drugs. Prior approval programs reduce use and costs of drugs, but only in a small number of drug classes. Voluntary therapeutic interchange programs have been shown to be successful in staff-model health maintenance organizations, but not in independent-practice models. Currently, managed care organizations exert little control over prescribing and dispensing decisions. Managed-care organizations might better control pharmaceutical costs through other methods such as tiered co-payments.	2001	3/11 (AMSTAR rating from www.rxforchange.ca)	Not reported in detail	0/56	0/56
	Assessing the impact of restricted Medicaid formularies, and whether other formulary drugs were substituted for restricted drugs, and their costs, therapeutic appropriateness, and current practices (108)	Eleven articles from 1972 to 1985 were analyzed for impact of restricted Medicaid formularies on usage of unrestricted substitute drugs, administrative costs, drug costs and quality of care. The evidence does not support the assumption that restriction of specific drugs results in savings in drug costs. The impact of restricted formularies on administrative costs and therapeutic appropriateness of substituted drugs is unclear. In Michigan, 23.7% of patients received alternate drugs and 30.7% of patients still received prescriptions for the restricted drugs. In Louisiana, there was a 34% increase in the number of hospitalized patients and the state saved \$4.1 million in its drug program, but spent \$15.1 million in non-prescription services. Overall, restricting formularies leads to dynamic changes in the Medicaid program and should be carefully considered before implementing.	1987	2/10 (AMSTAR rating from McMaster Health Forum)	0/11	0/11	0/11
	Analyzing the implementation of Medicaid preferred drug lists (PDLs) in several states,	The most common and well-studied concern regarding preferred drug lists was identified to be medical restrictions increasing healthcare service utilization, such as hospital and physician visits. While State Medicaid departments have assured beneficiaries that drug coverage is provided for the best medications in every class accounting for both safety and efficacy, beneficiaries have emphasized concerns about whether their medications will continue to be covered.	Not reported	0/10 (AMSTAR rating from McMaster)	Not reported in detail	Not reported in detail	Not reported in detail

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	and its impact on quality of care and cost relative to other segments of healthcare (110)			Health Forum)			
	Evaluating the impact of pharmaceutical prior authorization policies on drug use, healthcare utilization, healthcare expenditures, and health outcomes (125)	<p>This review examined 15 studies in order to examine the impact of pharmaceutical prior authorization policies on factors including drug use, healthcare utilization, healthcare expenditures and health outcomes.</p> <p>Prior authorization policies are put in place to control drug spending, one of the fastest growing expenditures in healthcare worldwide. By requiring prior approval to reimburse a given drug, these policies limit the use of certain medications and thus limit expenditure. Prior authorization policies reduce costs by substituting less expensive therapies when possible. These policies require two objectives: to reduce negative health incomes by improving prescription quality, and to contain costs within the system.</p> <p>This review examined the effect of prior authorization policies on pharmaceutical use/expenditure, health services use/expenditure, and health outcomes.</p> <p>The majority of the reviews indicated that individual patient drug use/expenditure significantly decreased after the implementation of a prior authorization policy. System-wide pharmaceutical expenditure also dropped after policy implementation; variation exists depending on the specific medication class affected. These studies largely focused on expenditure, and less on outcomes of appropriate prescription use.</p> <p>Seven of the 15 studies examined the impact of prior authorization policies on other healthcare services. In most cases, the implementation of these policies was not associated with significant changes in healthcare use; significant changes would indicate health outcomes. One study, however, indicated that prior authorization restrictions on the drug cimetidine resulted in increased physician and hospital costs.</p> <p>Only one study examined the effects of prior authorization policies on health outcomes and health-related quality of life. This study found that prior authorization policies applied to branded-NSAIDs did not affect quality of life among patients.</p>	2006	5/10 (AMSTAR rating from McMaster Health Forum)	1/15	0/15	0/15

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>Many of these studies present serious limitations in design, affecting the ultimate validity of results. As well, the generalizability of results is limited due to the difference in policy implementation styles based on the institution. As well, interventions must distinguish between cost-savings measures that result from the use of generic drugs as compared to lower drug utilization.</p> <p>Despite limitations, this review draws upon the results to present three main implications. First, improvements in cost and outcomes will result when prior authorization policies are implemented for drugs with previous inappropriate use and higher prices. Second, the cost-effectiveness of prior authorization policies increases when patient outcomes are more homogenous, and when the delay of treatments will not negatively affect health outcomes. Third, reducing administrative burden will increase the cost-effectiveness of these policies. Fourth, policy implementation should be based on evidence and recommendations. Finally, prior authorization policies are one option for cost-saving; other policy options should be explored in a given context to assure that cost-effectiveness is optimized.</p>					
<p>Removing potential disincentives for patients and families that can influence whether and how they access needed primary- and community-care supports</p>	<p>Effectiveness of financial incentives and contingency management programs on long-term smoking cessation rates (113)</p>	<p>Incentives included lottery tickets, prize draws, cash payments, item vouchers, grocery vouchers, and money deposits. The odds for sustaining smoking cessation at longest follow-up was 1.42 relative to the control group, and only three studies demonstrated significantly higher quit rates in the incentive group compared to the control.</p> <p>In eight of nine trials with data on pregnant smokers, an adjusted odds ratio at longest follow-up (up to 24 weeks post-partum) of 3.60 was reported based on moderate quality studies, favouring incentives. Three trials indicated a clear benefit for contingent rewards; the largest included trial provided intervention quitters up to 400 British sterling pounds of vouchers, and found rates of 15.4% versus 4% for the two groups at longest follow-up. Four trials showed that successful quit attempt rewards compared to fixed payments for antenatal appointment attendance resulted in higher quit rates.</p> <p>The results of the review indicated that incentives may boost cessation rates while in place, with sustained success rates seen only where resources were concentrated into substantial cash payments for abstinence. Incentives for pregnant smokers may improve cessation rates, both at end-of-pregnancy and post-partum assessment stages.</p>	<p>2014</p>	<p>10/11</p>	<p>0/21</p>	<p>0/21</p>	<p>0/21</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	Effectiveness of financial incentives for encouraging healthy behaviours (115)	<p>Five themes were identified: fair exchange, design and delivery, effectiveness and cost-effectiveness, recipients, and impact on individuals and wider society. Fair exchange is when financial incentives that promote health involve a beneficial exchange between the recipient and incentive provider. There is lack of consensus on whether health-promoting financial incentives are beneficial or fair for the parties involved. There is evidence that the design and delivery of health-promoting financial incentives contribute to perceptions of whether they are acceptable or not. If health-promoting financial incentives are found to be effective, safe, recipient-focused, and intrusion minimizing, they tend to be more accepted.</p> <p>Concerns raised in reference to appropriate providers of health-promoting financial incentives include that many socio-economically disadvantaged individuals are unwilling to accept federally funded health-promoting financial incentives, and that there is potentially negative impact of health-promoting financial incentives on physician-patient relationships. Moreover, there is strong consensus that if health-promoting financial incentives are effective and cost-effective, they are more likely to be acceptable. A common criticism of health-promoting financial incentives is that they offer only short-term motivation. There is no consensus on the reason for this. There is some evidence to suggest there are concerns with cash incentives as they may be used to fund behaviours they were designed to prevent. In terms of the impact of health-promoting financial incentives on individuals and wider society, there is evidence to suggest that health-promoting financial incentives can encourage individuals to take responsibility for themselves, however there is also evidence that health-promoting financial incentives may be perceived as paternalistic and undermine an individual's autonomy.</p> <p>Financial incentive programs that benefit recipients and wider society are likely to be considered more acceptable.</p>	2014	6/10 (AMSTAR rating from McMaster's Health Forum Impact Lab)	0/81	0/81	0/81
	Effectiveness of financial incentives to achieve sustained changes in smoking, eating, alcohol consumption	<p>Overall, the findings of this review suggested that financial incentives were found to increase attainment of target levels of behaviour change, sustained up to 18 months from baseline. Sustained change in overall behaviour with financial incentives was noted up to two to three months after incentive removal, but was not maintained thereafter. Behavioural effects were observed to weaken over time.</p> <p>Financial incentives were found to be effective with smoking cessation rates (effects seen for 12-18 months, sustained for two to three months after incentive removal) and healthier eating targets (for six to 12 months, not sustained after</p>	2012	8/11 (AMSTAR rating from Program in Policy Decision-Making)	0/34	0/34	0/34

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	and physical activity (116)	<p>incentive removal), but not for physical activity (at six, 12-18 months and three months after incentive removal). High deprivation increased the effect of financial incentives, but only six to 12 months from baseline. Other variables did not independently have a significant modifying effect at any follow-up time-point.</p> <p>This study indicates personal financial incentives may have an effect on individual health-related behaviours, but may not have a sustained effect on disease burden reduction.</p>					
	Effects of interventions on healthcare consumers promoting evidence-based prescribing for and medicine use by consumers (117)	<p>The review found that no single strategy improved medicine use outcomes across all tested diseases. The overview sought to assess support for behaviour change, promotion of communication and informed decision-making, risk minimization, skills acquisition and education/information provision. Effective interventions included medicines self-monitoring and self-management, simplified dosing, and interventions directly involving the pharmacist in medicine management. The overview noted that specific research is needed to assess outcomes in those with multiple co-existent conditions. The presence of comorbidity led to the view that interventions must focus on the patient context and healthcare system.</p>	2012	No rating tool available for this type of document	Not applicable	Not applicable	Not applicable

**Appendix 3: Systematic reviews relevant to Element 3 – Provide patients and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
Ensuring information and education supports, as well as opportunities for learning that can be accessed in specialty care (e.g., cancer centres) as well as in primary- and community-care settings	Effects of multimedia patient-education interventions about prescribed and over-the-counter medications (140)	<p>This review included 24 studies assessing the effects of multimedia patient-education interventions about prescribed and over-the-counter medications in people of all ages, including children and carers.</p> <p>With regards to knowledge, it was found that multimedia education was more effective than usual care (non-standardized education provided as part of usual clinical care) or no education. Moderate-quality evidence demonstrated that multimedia education was not more effective at improving knowledge than control multimedia interventions (i.e., multimedia programs that do not provide information about the medication). Moderate-quality evidence showed that multimedia education was more effective when added to a co-intervention (written information or brief standardized instructions provided by a health professional) compared with the co-intervention alone.</p> <p>In terms of skill acquisition, the review presented moderate-quality evidence demonstrating that multimedia education was more effective than usual care or no education and written education of improved inhaler technique. In addition, very low-quality evidence showed that multimedia education was equally effective as education by a health professional.</p> <p>Finally, moderate-quality evidence demonstrated that there was no difference between multimedia education and usual care or no education in terms of compliance with medications.</p> <p>Unfortunately, there was significant heterogeneity in the comparators used and the outcomes measured across the included studies, which limited the ability to pool data. Many of the studies did not report sufficient information in their methods to allow judgment of their risk of bias. From the information that was reported, three of the studies had a high risk of selection bias and one was at high risk of bias due to lack of blinding of the outcome assessors. None of the included studies reported the minimum clinically important difference for the outcomes that were measured. The authors thus reported results from the studies, but were unable to interpret whether differences were of clinical importance.</p>	2012	10/10 (AMSTAR rating from McMaster Health Forum)	1/24	0/24	Not reported in detail

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	Effectiveness of psycho-educational interventions on the management of symptom clusters in patients with cancer (133)	<p>This review included four studies evaluating the effectiveness of psycho-educational interventions on managing symptom clusters in patients with cancer.</p> <p>The review found that symptom clusters seemed to improve with the provision of psycho-educational interventions. A meta-analysis showed significant improvement in functional performance. The evidence that psycho-educational interventions could alleviate cancer symptom clusters is encouraging but inconclusive in this review. The review also suggests a promising role of psycho-educational interventions in managing cancer symptom clusters.</p> <p>Of the four included studies, three showed statistically significant improvement in symptom clusters for the intervention groups. One study had a significant reduction in symptom severity for four of five symptom clusters, except the affective symptom clusters (nervousness, anxiety and stress). Significantly improved symptom clusters in these three studies included breathlessness, fatigue, and anxiety; pain, fatigue, and sleep disturbance; and gastrointestinal cluster (nausea, vomiting, stomach pain, loss of appetite, and diarrhea); cognitive cluster (diminished concentration, memory problems, and fatigue); functional cluster (muscle aches and joint aches); and mucositis cluster (mouth pain, throat pain, and difficulty swallowing). All three studies adopted progressive muscle relaxation as one of the intervention components, with one adding patient education. Furthermore, interventions of the three studies were all provided by nurses, in an individual format and during the active treatment period; one study continued the intervention after the completion of treatment. Duration of the interventions lasted for two to 12 weeks.</p> <p>Symptom clusters in the studies were found to be improved, however, the results did not reach statistical significance. These symptom clusters included gastrointestinal cluster (nausea, vomiting, lack of appetite, shortness of breath, dry mouth and numbness), cognitive/psychological cluster (distress, sadness, pain and remembering), and fatigue cluster (fatigue, disturbed sleep and drowsiness). This study combined meditation with social support as its intervention, which was delivered by a clinical psychologist and in a group format. The intervention was conducted after the completion of cancer treatment and lasted for six weeks.</p>	2014	8/10 (AMSTAR rating from McMaster Health Forum)	0/4	Not reported in detail	4/4

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

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		<p>With regard to functional performance, the pooled results of two studies revealed a statistically significant improvement in symptom interference with daily living for the intervention group. Functional ability was also found to be enhanced over time in the intervention group. None of the included studies measured the outcome of quality of life; thus, the effect of psycho-educational interventions on quality of life in patients with cancer is unknown in the situation of studying symptom clusters.</p> <p>Unfortunately, the small sample size of included studies in this review prevented any definitive conclusions from being made.</p>					
	Evaluation of psycho-educational interventions for supporters of women with early-stage breast cancer (134)	<p>This review included six studies aiming to identify and evaluate psycho-educational interventions for supporters of women with early-stage breast cancer.</p> <p>Families and spouses experience distress equal to that of women diagnosed with breast cancer. Intervention studies addressing the psycho-educational needs of spouses used a variety of delivery modes, including telephone and video counselling. While psycho-educational counselling in these studies appears generally clinically effective (if not always statistically significant) whether delivered in person, group, or by phone, the variety of interventions, differential reporting of outcomes, and the prominence of pre-experimental and pilot studies included in the review made it difficult for authors translate the findings into a consistent message for clinical practice. Additionally, the included studies are predominantly racially homogeneous in study sample (Caucasian), and thus do not contribute to reversing the paucity of evidence pertaining to the psychological care of racially diverse populations affected by cancer.</p> <p>All of the interventions included in the review demonstrated some efficacy. However, limitations in design, sample and reporting of outcomes were identified.</p>	2013	6/9 (AMSTAR rating from McMaster Health Forum)	1/6	0/6	6/6
Supporting patients with self-management skills	Evaluation of electronic symptom reporting between patient and provider for improved	<p>This review included 32 studies exploring electronic symptom reporting between patients and providers to improve healthcare service quality.</p> <p>Findings of the review were divided into four categories based on effects: in terms of consultation support, monitoring with clinical support, self-management, and therapy.</p>	2011	8/10 (AMSTAR rating from McMaster Health Forum)	0/32	0/32	3/32



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
	healthcare service delivery (137)	<p>Effects in consultation support were categorized by the Institute of Medicine’s quality domains. In the consultation support category, all studies provided patient-centered care, ensuring that patient-reported symptoms guided the clinical decisions. Except for the study where nurses coached patients, symptom reporting was generally conducted while the patient was present at the clinic, and a summary of the reported symptoms was made available to the physician. These summaries were found effective in identifying and prompting discussion of troublesome symptoms, which made it possible to focus the conversation on issues relevant to the patient’s problems. The electronic symptom reporting systems also showed positive outcomes for patient symptom distress, symptom management, and health-related quality of life.</p> <p>In terms of effects in monitoring with clinical support, only two monitoring studies reported benefits for patients, while nearly no benefits for the health system and none for the health professionals were reported. The two studies identifying health benefits for the patient focused on asthma outcomes. Both studies included a strong self-management element. In one of the studies, some side effects for the healthcare system and patient need to be resolved. No healthcare costs or healthcare system benefits were identified in any of the monitoring studies: there was no improvement in total number of home care services or informal social support, number of consultations, occurrence of emergency room visits, hospital or specialist team use, number of hospital admissions, or mean costs per patient.</p> <p>In terms of self-management, all self-management interventions were found equally effective to or better than the control option, with one exception. Substantial benefits for patients, and partly also for health professionals and healthcare systems, have been documented in this area. For health professionals, a decrease in resource utilization was reported. At the healthcare system level, healthcare cost benefits were analyzed and reported for internet treatment of panic disorder, which was nearly four times cheaper than group treatment.</p> <p>With regards to therapy, patients receiving email therapy for complicated grief improved significantly relative to participants in the waiting list condition, and were quite satisfied with the treatment. Only 20% missed face-to-face contact with a therapist, and 85% had positive attitudes toward being treated via the internet instead of face-to-face.</p>					

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

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		The authors note that some of the articles included in the review had sources of bias, which may have had an impact on its findings. As well, the presence of unclear statistical analyzes may have hindered the credibility of its results.					
	Self-management and self-management support as an approach for long-term condition management (138)	<p>This review included 41 studies exploring self-management and self-management support as an approach for long-term condition management.</p> <p>The majority of evidence included in the review related to diabetes. Few studies directly focused on stakeholders' views concerning desired self-management outcomes; the majority of evidence was derived from studies focusing upon the experience of self-management. The views of healthcare commissioners were absent from the literature. Authors identified that self-management outcomes embrace a range of indicators, from knowledge, skills, and bio-psychosocial markers of health through to positive social networks.</p> <p>One of the key limitations of the review lies in the fact that no included study explicitly focused on the outcomes of self-management. Further research is therefore required to build on these early findings from the existing literature to identify which outcomes of self-management are important from the perspectives of differing stakeholders.</p>	2014	6/10 (AMSTAR rating from McMaster Health Forum)	2/41	Not reported in detail	No reported in detail
	Impact of telehealth interventions to support self-management on disease control and healthcare utilization (139)	<p>This review included 53 systematic reviews examining the impact of telehealth interventions to support self-management on disease control and healthcare utilization.</p> <p>Of the 53 systematic reviews, six related to diabetes, nine related to heart failure, eight related to asthma, eight related to COPD, and three related to cancer. Findings varied between and within disease areas. The highest-weighted reviews showed that blood glucose telemonitoring with feedback and some educational and lifestyle interventions improved glycemic control in Type 2, but not Type 1, diabetes, and that telemonitoring and telephone interventions reduced mortality and hospital admissions in heart failure, but these findings were not consistent in all reviews. Results for the other conditions were mixed, although no reviews showed evidence of harm. Analysis of the mediating role of self-management, and of components of successful interventions, was limited and inconclusive. More intensive and multifaceted interventions were associated with greater improvements in diabetes, heart failure and asthma.</p>	2016	5/9 (AMSTAR rating from McMaster Health Forum)	6/53	Not reported in detail	Not reported in detail

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on transitions in cancer care
		As this meta-review considered only six long-term conditions, the authors conceded that different conclusions may have been reached had a different set of conditions been selected. In addition, not all the included systematic reviews explicitly focused on self-management.					
	Efficacy of group-based self-management programs to improve physical and psychological outcomes in patients with cancer (136)	<p>This review included six studies examining the efficacy of group-based self-management programs for patients with cancer.</p> <p>Group-based self-management programs were found to improve physical function. No significant results were found between groups for quality-of-life and physical-activity-level outcomes. Group-based self-management programs for individuals with cancer resulted in improvements in physical outcomes.</p> <p>Unfortunately, considerable heterogeneity was found between the included studies and the quality of evidence was very low for all main outcomes. Another limitation of this review is the small number of included studies, all of which had a high risk of bias and a very low quality of evidence. Blinding of participants and assessors was also poorly executed in the included studies.</p>	2014	7/11 (AMSTAR rating from McMaster Health Forum)	0/6	Not reported in detail	11/11
	Efficacy of self-management education interventions to support patients with cancer (135)	<p>This review included 42 studies examining the effectiveness and essential components of self-management education interventions to support patients with cancer.</p> <p>Narrative qualitative synthesis suggested that self-management education interventions improve symptoms of fatigue, pain, depression, anxiety, emotional distress and quality of life. Results for specific combinations of core elements were inconclusive. Very few studies used the same combinations of core elements, and among those that did, results were conflicting. Thus, conclusions as to the components or elements of self-management education interventions associated with the strength of the effects could not be assessed by this review.</p> <p>Variations in outcome measures, study design, and execution of interventions precluded a meta-analysis of effects and presented as one of the key limitations of the review. In addition, scarce details were provided in many studies regarding the various interventions carried out. The inclusion of only English studies is another limitation of this review.</p>	2015	7/10 (AMSTAR rating from McMaster Health Forum)	0/42	Not reported in detail	42/42



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