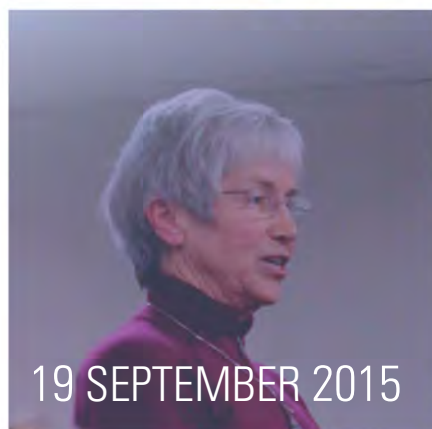


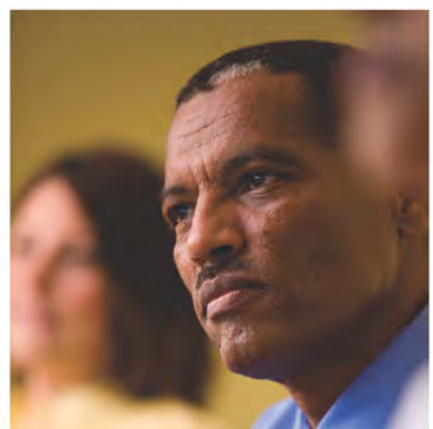
## IMPROVING PAIN AND SYMPTOM MANAGEMENT IN CANCER CARE IN ONTARIO

action

best available evidence



19 SEPTEMBER 2015



EVIDENCE >> INSIGHT >> ACTION

## The McMaster Health Forum

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

## About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

## About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on how to improve cancer pain and symptom management in Ontario. This brief includes information on this topic, including what is known about:

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

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

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# Key Messages

## **What's the problem?**

There are many challenges facing individuals living with cancer, including experiencing pain and other distressing symptoms (e.g. fatigue, difficulty breathing, depression and nausea), all of which can have a negative effect on an individual's physical, emotional, social or spiritual well-being. As advances in cancer care continue to improve the chances of surviving with cancer, more people in Ontario and Canada will live with the disease and require pain and symptom management support. In Ontario, improving pain and symptom management is a challenge, given the widespread implementation of pain and symptom management guidelines has encountered difficulties such as the low use of guidelines among healthcare professionals, and health system arrangements that are not optimally suited to promote the use of guidelines in practice.

## **What do we know about three options for addressing the problem?**

- **Option 1: Getting the best information about pain and symptom management to everyone who needs it**
  - Educating individuals living with cancer about best practices can lead to several positive outcomes (e.g. reduced pain, knowledge about pain, better communication with healthcare professionals)
  - Educating healthcare providers can improve their knowledge and attitudes about cancer pain management
  - The benefits to monitoring, setting targets for, and publicly reporting the use of best practice guidelines are not yet known
- **Option 2: Providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management**
  - It is unclear whether there are benefits to targeted payments, but there are likely to be unintended negative consequences if targeted payments to healthcare providers and healthcare organizations are linked to performance
- **Option 3: Organizing care differently to make it easier to provide pain and symptom management**
  - There are likely benefits to electronically linking patient records across providers and settings, but there may be a lack of agreement between healthcare professionals about patient needs during care transitions (particularly to palliative care)
  - Introducing team care and supporting home care can improve patient outcomes

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

While there are a number of potential barriers for implementing each option in Ontario, there are also many facilitators. These include preliminary efforts among regional cancer centres to improve the use of pain and symptom management guidelines, prioritizing evidence-based cancer care among cancer care organizations, and a willingness among key health system stakeholders to change how care is organized in order to improve services and patient outcomes.



It is estimated that there are 400,000 Ontarians living with cancer today. In 2015, 76,000 new cases are expected to be diagnosed.

## **The context:** Why is improving pain and symptom management in cancer care a high priority?

>> Growth in the number of people diagnosed and living with cancer in Ontario (and across Canada) has made it more important than ever to ensure comprehensive, evidence-based and patient-centred pain and symptom management supports exist across the entire continuum of care.

### **The number of people diagnosed with cancer continues to increase**

The number of new cancer cases has continued to rise in Ontario over the last two decades.<sup>(6,7)</sup> The most recent estimates suggest that there will be 76,000 new cancer cases and approximately 28,500 deaths from cancer in the province in 2015 (up from 65,338 and 26,076 in 2009, respectively).<sup>(7-9)</sup> These trends are shared across Canada, where it is estimated that there will be 196,900 new cancer cases and approximately 78,000 deaths from cancer in 2015, also increases from previous years. Unfortunately, increases in the number of new cases are also

expected to continue. For example, by 2031, the number of new cancer cases is projected to rise to nearly 300,000 in Canada.(8)

The increasing number of new cancer cases is due in part to the aging Canadian population .(8) However, while the vast majority (89%) of those who develop cancer are over the age of 50,(7,10) cancer is the leading cause of death for Canadians aged 35 to 64, killing more younger Canadians than heart disease, injuries, stroke and diabetes combined.(8)

Overall, these trends suggest that the importance of focusing on cancer care in the province of Ontario and in Canada will not diminish anytime soon. With two out of every five people expected to develop cancer, and one out of every four people expected to die of cancer, it is an issue that most Ontarians and Canadians may have to face – either as a patient or as a family member or friend of a patient.

### **Living with cancer is associated with many challenges**

Dealing with a cancer diagnosis and progressing through the journey that follows can pose significant challenges and disruptions to daily life. For example, people living with cancer may undergo a range of treatments and receive care from multiple healthcare providers located across a number of different settings. Undergoing treatment may cause immediate changes to an individual's and/or their family's financial situation (e.g. if treatment and care require a patient or their caregivers to take time away from their job), which creates the potential for another source of unanticipated stress. Following treatment, transitioning to either survivorship or palliative care also require new adjustments. These challenges can be made even more difficult if patients are in pain or suffering from symptoms that negatively affect their daily lives.

Many people living with cancer report significant amounts of distressing symptoms including pain, fatigue, difficult breathing, depression and nausea.(11-13) In addition they may also experience distress associated with emotional, practical, informational, social and spiritual needs.(14) While levels of distress from the full range of symptoms varies, some studies have suggested 35-45% of cancer patients are dealing with one or more types of distress.(2) Pain and symptoms that cause distress may result in poor quality of life, psychological issues and increased healthcare costs.(15-18)

### **Improvements in the chances of surviving with or beyond cancer will increase the number of people in need of pain and symptom management support in Ontario**

People diagnosed with cancer today have better chances of surviving for the next five years than they did a decade ago.(7) In Ontario, better screening, early detection and treatment have improved outcomes for those with cancer, and increased the number of those living with the disease. It is estimated that in 2015, more than 400,000 Ontarians are living with and beyond



the diagnosis and treatment for cancer.(6) At the national level, it has been reported that 810,045 Canadians who had been diagnosed with cancer in the preceding decade were still alive in 2009.(7) By 2031 it is estimated that nearly 2.2 million Canadians will be living beyond a cancer diagnosis.(8) Average five-year survival for people diagnosed with any type of cancer in Canada is 63% (although this varies across type 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.(7) Table 1 presents the quick facts about the cancer burden in Ontario and across Canada.

As the number of people diagnosed with cancer in Ontario and across the country grows, improvements in care mean that these people will also live longer with the disease. As such, the number of patients who are in need of pain and symptom management is also likely to increase, making improving pain and symptom management in cancer care a priority.(7) The focus should be placed on pain and symptom management support that is based on evidence-based clinical practice guidelines to ensure the best care possible.

**Table 1. Cancer burden in Ontario and Canada**

<b>Indicators</b>	<b>What we know</b>
<b>New cancer cases estimated in 2015</b>	76,000 in Ontario 196,900 across Canada
<b>New cancer cases expected by 2031</b>	300,000 across Canada
<b>Number of people estimated to be living with cancer</b>	400,000 Ontarians living with or have survived cancer in 2015 810,045 Canadians who had been diagnosed with cancer in the decade leading up to 2009 (most recent estimates)
<b>Number of people estimated to be living with cancer by 2031</b>	2.2 million across Canada
<b>Chances of surviving</b>	63% of those diagnosed with cancer in Canada will survive for at least five years
<b>Number of cancer deaths estimated in 2015</b>	28,500 in Ontario 78, 000 across Canada
<b>Probability of developing cancer during lifetime</b>	45% for males in Canada 42 % for females in Canada
<b>Probability of dying from cancer during lifetime</b>	29% for males in Canada 24% for females in Canada

Sources: Canadian Cancer Society (7), Cancer Care Ontario (6,9), Canadian Partnership Against Cancer (8)



## **Glossary**

### **Pain**

An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (1)

### **Cancer pain**

A complex, changing symptom which is a subjective experience that can differ across individuals. The pain can be disease- or treatment-related, occur at any point in the cancer journey (from diagnosis to treatment to survivorship or palliative care), and be considered acute, persistent and/or chronic

### **Symptom**

A change in body or mind which indicates that a disease is present, or something that indicates the presence of bodily disorder (3)

### **Distress**

A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (2)

### **Palliative care**

Care provided by a range of different types of providers focused on relieving pain and other symptoms to try and ensure the best quality of life for patients with serious illness and their families. It provides an extra layer of support for patients and their families (5)

## **Efforts have been made to improve pain and symptom management in cancer care**

It is important to identify distressful pain and symptoms in people with cancer as early as possible, since late detection can interfere with patients' ability to follow recommended treatments, reduce satisfaction with care, and result in poor quality of life.(14) Once distressful pain and symptoms are identified, care based on symptom management practice guidelines, should be provided.(2)

For nearly a decade in Ontario, there have been efforts to ensure screening for pain and other distressing symptoms, and that supportive pain and symptom management care is based on the best available evidence. In 2006, Cancer Care Ontario launched the Provincial Palliative Care Integration Project to improve evidence-based pain and symptom management, and this project was expanded in 2008 to become the Ontario Cancer Symptom Management Collaborative (OCSMC).(19,20) The initiative now promotes the use of a widely accepted screening tool called the Edmonton Symptom Assessment System-revised (ESAS-r) to screen individuals for pain and symptoms, and recommends care based on a clear set of guidelines.

Increasing numbers of those involved in cancer care across the country have also recognized that dealing with the full range of physical, emotional, social, informational, spiritual and practical challenges throughout the cancer journey is an important aspect of quality care.(2) This has resulted in the

establishment by the Canadian Partnership Against Cancer – a federally funded group of Canadian cancer experts, charitable organizations, governments, cancer agencies, national health organizations, individuals with cancer and survivors – of the ‘Screening for Distress’ approach, which focuses on distress alongside other more widely considered vital signs such as temperature, pulse, blood pressure, respiratory rate and pain.(2) Accreditation organizations, such as Accreditation Canada, have also incorporated the Screening for Distress approach into their established standards to try to ensure cancer care organizations across the country adopt it in practice.(2) Box 1 provides additional detail about Screening for Distress.

Despite these positive efforts in Ontario and in Canada more generally, several problems exist which make it challenging to ensure that people with cancer receive timely and appropriate pain and symptom management support based on evidence-based best-practice guidelines.

### **Box 1 >> The ‘Screening for Distress’ model for pain and symptom management in cancer care**

Screening for Distress is a widely accepted cancer pain and symptom management model that involves five steps, all of which are required to ensure people living with cancer receive patient-centred, comprehensive and evidence-based support for managing their pain and symptoms throughout the cancer journey:

- 1) screen for symptoms and distress (with the most widely accepted approach for achieving this known as the Edmonton Symptom Assessment System described below);
- 2) open a dialogue with the patient and initiate a therapeutic relationship;
- 3) assess risk factors, intensively assess problem(s)
- 4) ascertain patient perception of problem and negotiate a relevant plan of care; and
- 5) select appropriate interventions based on best evidence (i.e. symptom management guidelines).(2)

The Edmonton Symptom Assessment System (ESAS), is a validated assessment tool to screen for the intensity of nine common symptoms experienced by cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. In Canada, ESAS (and now the revised version known as ESAS-r) is the most frequently used self-reported screening system. (4)

The Canadian Problem Checklist (CPC) is a complementary list that screens for emotional and physical problems and is also commonly accepted across the country.



Symptom management guidelines are not routinely used to support people living with cancer who are experiencing distressful pain and symptoms

## **The problem:** Why is improving pain and symptom management challenging?

>> Widespread implementation of pain and symptom management guidelines in cancer care in Ontario has encountered several challenges, while existing health system governance, financial and delivery arrangements are not optimally suited to promote guideline use in practice.

Despite the efforts outlined above, some evidence suggests that many individuals living with cancer who have distressful pain and symptoms do not receive appropriate care.<sup>(19)</sup> There are several possible reasons for this, which include: 1) healthcare providers do not consistently use pain and symptom management guidelines in practice settings; 2) the health system has not been designed to promote the use of pain and symptom management guidelines in practice; and 3) little is known about the pain and symptom management support actually provided to patients, which makes it difficult to establish the full extent of the problem.

## **Healthcare providers do not consistently use pain and symptom management guidelines in practice settings**

Despite widespread endorsement of the Screening for Distress approach in Ontario – which includes both the identification of patients’ pain and symptom management needs as well as evidence-based guidance about how to address these needs– there is variation in how this approach is used in practice. With respect to identifying patient needs, there is wide variation in the use of ESAS-r for pain and symptom screening across regional cancer centres, with many not meeting the provincial target of 70%.<sup>(19)</sup> Furthermore, the actual use of the results from this screening among health professionals is inconsistent, with one study finding that only about half of physicians regularly use the information.<sup>(21)</sup> Another study from 2013 found that only 41% of patients consistently discussed their pain and symptom management needs, identified through screening, with their oncology team.<sup>(19)</sup>

In terms of responding to patients’ needs by providing care based on pain and symptom management guidelines, the situation does not appear to be any better. A study of one region in Ontario in 2009 showed that only 56% of healthcare providers used symptom management guidelines in their practice.<sup>(20)</sup> Results from a 2015 study similarly found that health professionals across regional cancer centres in the province report low levels of guideline use in daily practice.<sup>(22)</sup>

In Ontario some of the underlying reasons for these variations in practice include:

- a lack of agreement among professionals about the need for the screening tool;
- a lack of knowledge about the guidelines and about available supports for dealing with patients who are distressed;
- a lack of time and resources to act on the results of screening and incorporate pain and symptom management guidelines into practice; and
- resistance to change among some health professionals.<sup>(23)</sup>

Other barriers to healthcare providers’ use of the pain and symptom management guidelines relate to their perceptions that they already provide expert pain and symptom management care based on experience, and that their practices are consistent with the guidelines.<sup>(24)</sup>

Healthcare providers have also identified limitations of the guidelines and offer a number of recommendations to improve their implementation in practice, including: making the guidelines easier to access in clinics; embedding guideline recommendations into electronic documentation systems, and in routine policies and care delivery processes; and providing simpler and modified versions adapted to address varied team and patient contexts.<sup>(24)</sup>

In addition, existing efforts to support healthcare providers' use of the pain and symptom management guidelines may not be sufficient.(22) The majority of approaches used to date have focused on passive provider education (e.g. simple dissemination of the guidelines through email or via printed materials), with few strategies actively engaging healthcare providers in more comprehensive attempts to identify and overcome barriers to using the guidelines in practice. The passive educational approaches have been found to be oversimplified, failing to directly address the complex changes required to ensure the use of guidelines at the level of the individual patients and providers, care teams and in cancer care organizations.(22,24) While improving knowledge of the guidelines through education is important, there is a need to actively engage patients and their informal/family caregivers, healthcare providers and those working in cancer care organizations to adopt more person-centred approaches to care that integrate routine use of pain and symptoms management guidelines in practice.

Findings from other provinces echo these challenges. For example, in Nova Scotia and Quebec some health professionals view the addition of the Screening for Distress model as a burden in terms of workload and time commitment.(25) In these provinces providers also reported a lack of training and knowledge about the approach, including how to best integrate symptom management guidelines into practice.(25) This suggests there is a need for improvements across the country.

### **The health system has not been designed to promote the use of pain and symptom management guidelines in practice**

Several features of the health system in Ontario contribute to the poor use of pain and symptom management guidelines in cancer care. These can be understood in terms of the delivery arrangements, the financial arrangements, and the governance arrangements that exist.

#### ***Delivery arrangements***

At least four aspects of existing delivery arrangements in Ontario make it challenging to ensure pain and symptom management support is based on best practice guidelines. First, emerging results from a provincial study suggest that there are significant disparities across cancer centres in Ontario in terms of the leadership, knowledge, capacity, financial and human resources required to improve symptom management.(22) As indicated in the previous section, there is also wide variation in the use of screening results across Ontario, with many centres not meeting provincial screening targets of 70%.(19) This variation means that patients at settings with fewer resources that are under-performing in terms of screening

may not have equal access to pain and symptom management support based on best practice guidelines.

Second, existing quality-improvement initiatives like Ontario's Cancer System Quality Index have focused on reporting symptom screening rates publicly,(19) but they haven't focused on the quality of care that is actually provided to patients. In particular, no systems are in place to monitor and report on the extent to which screening results are used in combination with pain and symptom management guidelines to support patients living with cancer.

Third, there are no systems in place to ensure patients receive comprehensive, evidence-based pain and symptom management support across the entire continuum of care. In particular, most of the focus on the Screening for Distress model has been on integrating it into regional cancer centres, with much less attention on the provided to patients when they transition to other settings such as primary care.

Fourth and finally, it has been acknowledged that much broader engagement of inter-professional healthcare teams is needed to improve evidence-based pain and symptom management.(22) These teams often include professionals from a range of different healthcare disciplines (including but not limited to doctors and nurses), working together towards common goals to meet the full range of diverse needs of individuals living with cancer.

### ***Financial arrangements***

Current financial arrangements in the health system in Ontario do not include routine targeted payments that would enable health professionals and organizations to focus on overcoming barriers to using pain and symptom management guidelines in practice. Specifically, regular payments to providers and funding provided to organizations do not explicitly provide additional resources to enable more time and effort on ensuring the use of guidelines in practice for each episode of care or consultation. Time and resource constraints are frequently cited as a barrier to ensuring the most comprehensive care based on the practice guidelines. While project-based funds have been made available since 2008 through the OSCMC and Cancer Care Ontario to support regional cancer centres in developing twice yearly plans to translate pain and symptom management guidelines into practice across their respective regions, these were not focused on supporting a more comprehensive package of care for each patient consultation.(22)



### **Governance arrangements**

While provincial initiatives exist to promote evidence-based pain and symptom management (e.g. OCSMC), there are no accountability measures to ensure individual healthcare professionals and organizations actually use pain and symptom management guidelines in practice. While the Screening for Distress approach is endorsed by Accreditation Canada as a standard of care,(2) it is adopted and implemented on a voluntary basis, leaving wide variation in care across cancer centres in the province (and across the rest of the country more generally).

### **Little is known about the pain and symptom management support actually provided to patients, which makes it difficult to establish the full extent of the problem**

Most evaluations of pain and symptom management conducted in Ontario have placed emphasis on the extent to which screening has been incorporated into care.(23,26,27) Furthermore, and as already highlighted above, existing quality improvement initiatives in Ontario emphasize measuring and reporting pain and symptom screening rates. Few efforts have focused on determining the extent to which patients in need receive care based on pain and symptom management guidelines.(22,24) This has created a major gap in understanding how different providers and organizations are using symptom management guidelines, which also makes it difficult to determine what efforts are needed to promote evidence-based standards of care across all practice settings. A lack of integrated electronic documentation systems and ability to update and modify existing electronic systems in a timely manner is a major barrier to addressing this issue.(22,23)







Addressing the problem will require strategies that target patients and their informal/family caregivers, providers and organizations

## **Options:** How can we address the problem of inadequate use of pain and symptom management guidelines in cancer care?

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for improving pain and symptom management in Ontario

Many options could be selected as a starting point for discussion. We have selected three options (among many) for which we are seeking public input. They were developed with input from a range of key informants as a response to the problems highlighted above, and include:

- 1) getting the best information about pain and symptom management to everyone who needs it;
- 2) providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management; and
- 3) organizing care differently to make it easier to provide pain and symptom management.

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions. In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review.

- High-quality reviews: conclusions drawn from these reviews can be applied with a high degree of confidence.
- Medium-quality reviews: conclusions drawn from these reviews can be applied with a medium degree of confidence.
- Low-quality reviews: conclusions drawn from these reviews can be applied with a low degree of confidence.

## **Option 1** – Getting the best information about pain and symptom management to everyone who needs it

The first option aims to improve the use of pain and symptom management guidelines in routine care through what are often called ‘knowledge translation’ strategies (i.e., strategies to move knowledge or evidence into practice). These efforts can be targeted at three levels:

- 1) at patients and/or their informal/family caregivers, by informing and educating them about what care should be provided based on guidelines;
- 2) at the range of healthcare providers who are collectively responsible for providing supportive care to patients experiencing distressful pain and symptoms, by informing and educating them about the content of the guidelines, and then ensuring they consult and use them when appropriate; and
- 3) at the organizations that deliver cancer care, by changing the way routine processes facilitate use of the guidelines.

The strategies outlined above will often require additional elements to ensure progress with the use of guidelines is tracked, that expectations for healthcare providers and organizations are set, and that the extent of progress is shared publicly. In this brief, we have focused on the following three additional sub-elements in particular:

- 4) developing monitoring and evaluation strategies to measure and document the use of best practice guidelines by healthcare providers and/or organizations;
- 5) establishing province-wide targets for the use of best-practice guidelines by healthcare providers and/or organizations; and

- 6) publicly reporting progress towards meeting established province-wide targets for the use of best-practice guidelines, to promote accountability and quality improvement.

Below, we outline the evidence identified related to specific knowledge translation strategies available to improve the use of guidelines by targeting patients, providers and organizations, as well as the evidence related to these additional sub-elements.

At the level of patients and their informal/family caregivers, many reviews were identified that focused on mix of strategies (e.g. audio, booklets, brochures and face-to-face interviews) for educating individuals living with cancer about pain and/or symptoms – including, with many finding benefits.(28-34) The specific benefits of education included:

- reduced pain, which was found in one high-quality, (31) three medium-quality (29,33,35) and one low-quality review (36);
- improved knowledge about pain and treatments, found in three medium-quality (29,33,34) and one low-quality review, (36) with similar results when provided by nurses reported in one medium- and one-low quality review (28,37);
- increased satisfaction with care when provided by pharmacists, according to a medium-quality review (32);
- improved communication with providers, found in one medium-quality review (34)

In addition to education, one older low-quality review found that working with individuals to identify stressors and develop strategies to improve their situation improves symptom management, reduces distressful symptoms and leads to the development of coping strategies.(38) Finally, one older but high-quality review showed that involving patients in the development of patient information materials could improve their knowledge (although the results weren't specific to cancer).(39)

Fewer directly-relevant reviews were found that focused on strategies for providers. However, two older low-quality reviews found that educating providers using a number of approaches (e.g. lectures, workshops, booklets, teleconferences and role modelling) could improve their knowledge and attitudes towards cancer pain management, while encouraging their participation in these activities.(36,37) A costing study was also identified that found cancer management to be more cost-effective when providers followed guidelines.(40) Despite a lack of evidence about strategies specifically for cancer care, a large body of high-quality evidence on the best ways to promote the use of guidelines among healthcare providers exists. Table 2 summarizes details about these strategies and the benefits of using them to improve care.

No reviews were identified that focused on strategies targeted at the organizations that provide cancer care in order to improve the use of clinical practice guidelines.

**Table 2: Overview of strategies targeted at providers that can improve practice**

Type of strategy	Strategy details	What the evidence says
<b>Printed education materials(41)</b>	<ul style="list-style-type: none"> <li>• Involves the distribution of published or printed materials (including audio-visual materials and electronic publications) that provide care recommendations</li> <li>• Can be delivered in a number of ways (e.g. personally delivered or through mass mailings)</li> </ul>	<ul style="list-style-type: none"> <li>• Results in a 2% improvement in extent to which care aligns with specific practice recommendations, and a 13% improvement in the quality of practice</li> <li>• There is also evidence of improvements in patient outcomes</li> </ul>
<b>Educational meetings (42)</b>	<ul style="list-style-type: none"> <li>• Involves healthcare providers' participation in conferences, lectures, workshops or traineeships to improve knowledge, attitudes and skills related to care</li> <li>• Can be delivered in a number of ways</li> </ul>	<ul style="list-style-type: none"> <li>• Results in a 6% improvement in the quality of practice</li> </ul>
<b>Educational outreach (43)</b>	<p>Involves the use of a trained person who meets with providers in their own practice setting to give information and training related to care</p> <ul style="list-style-type: none"> <li>• Can be tailored to specific providers or settings</li> </ul>	<ul style="list-style-type: none"> <li>• Results in 4.8% improvement in prescribing, and 6% improvement in other outcomes measuring the quality of practice</li> </ul>
<b>Local opinion leaders(44)</b>	<ul style="list-style-type: none"> <li>• Involves the use of providers who are nominated by their colleagues as influential to communicate with and persuade other care providers to improve some specific aspect of care, such as adherence to practice guidelines</li> <li>• Success depends on existence of social networks within professional communities</li> </ul>	<ul style="list-style-type: none"> <li>• Results in 12% improvement in quality of practice</li> </ul>
<b>Audit and feedback(45)</b>	<ul style="list-style-type: none"> <li>• Involves observing (i.e. monitoring) and providing a summary of clinical performance to professionals (which may include recommendations for change), with the intention of educating, persuading and enabling changes in practice</li> </ul>	<ul style="list-style-type: none"> <li>• Results in 4.3% improvement in quality of practice, but 16% improvement if baseline performance is low</li> </ul>
<b>Reminders (46)</b>	<ul style="list-style-type: none"> <li>• Involves the provision of information that is either specific to the patient, or to the type of visit to prompt providers to recall information and remind them to provide care in a certain way</li> <li>• Can take a number of different forms, including verbal and paper reminders, as well as electronic and computerized reminders</li> </ul>	<ul style="list-style-type: none"> <li>• Results in 4.2% improvement in quality of practice</li> </ul>
<b>Tailored interventions(47)</b>	<ul style="list-style-type: none"> <li>• Involves identifying specific barriers to practice change (including the use of guidelines), and planning an approach to overcome the barriers</li> <li>• Can take many forms, depending on the barriers identified and strategies developed</li> </ul>	<ul style="list-style-type: none"> <li>• Can increase the odds of achieving practice improvements, although specific levels of improvement depend on the details of each strategy</li> </ul>
<b>Multifaceted interventions (48)</b>	<ul style="list-style-type: none"> <li>• Involves combining two or more strategies</li> <li>• Can take many forms, depending on the different strategies combined</li> </ul>	<ul style="list-style-type: none"> <li>• Dependent on the form of the combined strategy</li> </ul>

\*Table adapted from Grimshaw et al. 2012 (49), and variations presented in Lavis et al. 2015(50) and Wilson et al. 2015(51)

With respect to the additional three sub-elements (monitoring guideline use, setting targets and public reporting), no reviews were identified that were directly relevant to cancer care. Two reviews were found that addressed monitoring guideline use in general. One was medium-quality and found that guidelines are frequently out-of-date, time-consuming to update, and that ongoing monitoring can help keep recommendations up-to-date.(52) A low-quality review focused on letting physicians assess their own use of guidelines, but didn't draw any conclusions.(53) No reviews were found that focused on setting targets for guideline use.

The evidence focused on public reporting (the last sub-element) was mixed, with no consistent messages about the benefits or harms of this approach.(54-57) However, one low-quality review suggested reporting should target providers and managers who had the power to change practice,(56) and another showed that clear objectives, targets, transparent and comprehensive content, easy-to-use formats and wide distribution were all essential.(58)

## **Option 2** – Providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management

While it isn't always the case that providing more money to healthcare providers and healthcare organizations guarantees improvements in practice such as the greater use of guidelines, targeted payments to overcome specific challenges may be appropriate in some situations. In particular, they can be used to overcome challenges that are identified as barriers to the use of guidelines in practice. They can also be used to signal for providers and organizations the priorities in terms of quality improvement. As such, in this brief we considered two types of targeted payments:

- 1) additional payments made to providers of care (i.e. on top of the payments already received) that ensure the time spent consulting symptom management guidelines, and providing care based on the guidelines, is appropriately compensated, while making available financial support for those who are involved in “knowledge translation” activities to promote the use of guidelines; and
- 2) additional payments to cancer care organizations that ensure resources are allocated to support care based on pain and symptom management guidelines (e.g. by earmarking funds to support evidence-based pain and symptom management within routine packages of care), complemented by bonus payments for organizations that are able to meet targets set in option 1.

Many reviews were identified that focused on targeted payments to providers and to organizations, with most of them more narrowly focused on payment for performance, and none of them focused specifically on cancer care.

Overall, there were mixed findings about the benefits of paying for performance.(44,59-71) However, the evidence identified consistently suggested that these strategies may have negative unintended consequences, both at the level of healthcare providers and organizations. At the level of providers, the unintended consequences could include ignoring other tasks, false reporting, reduced access for high-risk patients, corruption, widening the resource gap between rich and poor, dependency, demoralization and dilution of motivation.(59,61) At the level of organizations, the unintended consequences identified were increased inequalities in access to care and in health status, and ignoring services that aren't targeted by the payments.(60,66,68,71-73)

## **Option 3 – Organizing care differently to make it easier to provide pain and symptom management**

In addition to supporting the use guidelines through knowledge translation strategies and targeted payments (options 1 and 2), system-level challenges also need to be addressed. In particular, organizing cancer care delivery in Ontario to help with the use of guidelines should be considered. This could include one or more of the following sub-elements:

- 1) establishing referral and transition routines that signal to healthcare providers that they need to provide a full list of each patient's existing pain and symptom management needs during transition from one provider or setting to another;
- 2) improving the extent to which patient records (and particularly information about their pain and symptom management needs) are electronically linked across providers and settings;
- 3) improving the extent to which healthcare providers involved in pain and symptom management engage in team-based, patient-centred and collaborative care; and
- 4) improving home pain and symptom management services, including remote-monitoring, web-based and telehealth services, self-management support and support for informal/family caregivers.

With respect to establishing referral and transition routines for sharing patient needs, there is very limited evidence available. One high-quality review flagged that transitions to palliative care can be challenging due to a lack of agreement between physicians and nurses about patient needs, combined with poor awareness among patients of their own needs.(74) Both a high- and

medium-quality review found little evidence to support other approaches for improving transitions in care such as care planning, and case management.(75,76)

Several reviews were identified related to electronically linking patient records across providers and settings. Overall, the evidence suggests that there are benefits to adopting electronic systems to capture and transfer patient information. These benefits include:

- improvements in the use of guidelines, according to a medium-quality review (although not cancer-specific) (77);
- increases in the extent to which care is ‘patient-centred’, found in one high-quality review (78);
- improvements in decision-making and test-ordering among providers, according to a high-quality review (79);
- improvements in communication between primary care providers and specialists, according to a medium-quality review (80); and
- improvements in chemotherapy prescribing, according to another medium-quality review.(81)

Despite these largely positive findings, one medium-quality review stated that the evidence about computerized decision supports was unclear.(82)

Only one medium-quality review was identified that assessed cancer care teams (sub-element 3).(83) The authors found that cancer teams that involve a range of professionals improve planning of therapy as well as pain control.

With respect to improving home pain and symptom management services (sub-element 4), many reviews were identified. One high-quality review suggested that self-management (supported by electronic symptom reporting) is at least as beneficial for patients as regular care.(78) Many medium-quality reviews were identified that addressed this element, and found that:

- providing patients with opportunities to communicate with their care provider online improved their knowledge and self-management skills (84);
- strategies to reduce anxiety and depression could be delivered effectively using the internet (85); and
- supervised exercise, equipping patients with coping strategies, and educating them about self-care during end-of-life are beneficial.(34,86,87)

No definitive messages were found with respect to costs of improving home pain and symptom management. However, one study suggested that home visits by nurses after cancer pain treatment might decrease healthcare costs,(88) and another found that there were no additional costs associated with enabling individuals to report pain and symptoms over the phone.(89)



**Table 3. What is known from systematic reviews about three options to address the problem**

<b>Option 1 – Getting the best information about pain and symptom management to everyone who needs it</b>
<b>What is known about option 1</b>
<b>Sub-element 1</b> <ul style="list-style-type: none"><li>• Educating patients about best practices through a variety of approaches (e.g. audio, booklets, brochures, interviews) can lead to several positive outcomes<ul style="list-style-type: none"><li>○ Five reviews (one high-quality, three medium-quality and one low-quality), found that education could help reduce pain (29,31,33,35,36)</li><li>○ Four reviews (three medium-quality and one low-quality), found that education could improve patients' knowledge about their pain,(29,33,34,36) and one older high-quality review not focused on cancer care specifically found that improving knowledge could be achieved by engaging patients in the development of educational materials (39)</li><li>○ One medium-quality review found that educating patients could improve communication with providers (34)</li></ul></li></ul>
<b>Sub-element 2</b> <ul style="list-style-type: none"><li>• Two older low-quality reviews found that educating providers through a number of different approaches (e.g. lectures, workshops, booklets, teleconferences and role modelling) could improve knowledge and attitudes about cancer pain management activities,(36,37) and the body of literature about promising strategies to improve providers' use of best practices in general suggests that there are many different strategies that work (see Table 2)</li></ul>
<b>No reviews were identified for addressing sub-element 3 (strategies targeted at organizations)</b>
<b>Sub-element 4</b> <ul style="list-style-type: none"><li>• There is little evidence about how to best monitor and evaluate the use of guidelines in cancer care specifically, but one medium-quality review found that ongoing monitoring is required to keep guidelines up-to-date with new evidence,(52) and one low-quality review found that the evidence is unclear about whether allowing providers to self-monitor their own use could improve it (53)</li></ul>
<b>No reviews were identified for addressing sub-element 5 (establishing targets for guideline use)</b>
<b>Sub-element 6</b> <ul style="list-style-type: none"><li>• The evidence about public reporting is mixed, with one medium-quality review suggesting it leads to improvements,(54) and three other reviews (two medium-quality, one low-quality) reporting mixed or limited evidence (55-57)</li></ul>

## **Option 2 – Providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management**

### **What is known about option 2**

#### **Full option**

- Paying for performance may result in unintended consequences among providers and at the level of organizations
  - One overview of reviews, and one high-quality review found that paying providers for performance could lead to ignoring other tasks, false reporting, reduced access for high-risk patients, corruption, widening the resource gap between rich and poor, dependency, demoralization and dilution of motivation (59,61)
  - A number of medium- and low-quality reviews found that paying organizations for performance may lead to increased inequalities in access to care and in health status, and ignoring services that aren't targeted (60,66,68,71-73)

#### **Sub-element 1**

- The evidence is mixed about whether there are positive benefits of paying individual providers for performance, although two overviews of reviews suggested that targeted payments for specific types of services could improve care,(44,59) although only in the short term(59)

#### **Sub-element 2**

- The evidence is also mixed about whether there are positive benefits of paying organizations for performance

## **Option 3 – Organizing care differently to make it easier to provide pain and symptom management**

### **What is known about option 3**

#### **Sub-element 1**

- There may be a lack of agreement between physicians and other healthcare professionals about patient needs during transitions to palliative care, and poor awareness among patients about their own needs according to a high-quality review (74)
- One high-quality and one low-quality review found little evidence about optimal models of care to support referrals and transitions (75,76)

#### **Sub-element 2**

- There are likely benefits to electronically linking patient records across providers and settings
  - While not specific to cancer care, one medium-quality review found that the widespread use of health information technology could improve adherence to practice guidelines (77)
  - One high-quality review found that electronic systems could support patient-centred care (78) and another high-quality review found that they could help providers improve test ordering (79)
  - One medium-quality review found that technology may enhance communication between specialists and primary care providers,(80), and a second medium-quality review found that it improved chemotherapy prescribing (81)
  - Despite the generally positive findings, one medium-quality review found that the evidence was unclear about the benefits of computerized decision support (82)

**Sub-element 3**

- One medium-quality review found that cancer care teams could improve therapy planning and pain control (83)

**Sub-element 4**

- Supporting pain and symptom management from home is generally beneficial
  - A high-quality review found that self-management supported by electronic symptom reporting was at least as good as regular care (78)
  - One medium-quality review found that enabling communication between patients and providers improved knowledge and self-management skills,(84) and another found that anxiety and depression care could be provided to patients through the internet (85)
  - Medium-quality reviews also found that supported exercise, providing coping strategies, and self-care education within end-of-life care were beneficial (34,86,87)

## Implementation considerations

It is important to consider what barriers we may face if we implement the proposed options. These barriers may affect different groups (e.g., patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that option.

The implementation of each of the three options could also be influenced by potential barriers (those things which pose challenges or hinder implementation) and facilitators (those things that assist or act as a catalyst to implementation). Barriers and facilitators may include a recent event that was highly publicized in the media, a crisis, a change in public opinion, the publication of a new report, or an upcoming election.

A list of potential barriers and facilitators (or windows of opportunity) for implementing the three options is provided on the next page. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and facilitators from a range of sources (not just the research literature) and we have not rank ordered them in any way.



**Table 4. Summary of barriers and facilitators for moving forward**

<b>Option 1 – Getting the best information about pain and symptom management to everyone who needs it</b>	
<b>Barriers</b>	<b>Facilitators</b>
<ul style="list-style-type: none"> <li>• Patients and their informal/family caregivers may not feel empowered to change the way care is provided to them, or to advocate for care that aligns with symptom management guidelines (sub-element 1)</li> <li>• Patients and their informal/family caregivers may find it difficult to absorb additional information provided to them in the midst of a cancer diagnosis and treatment (sub-element 1)</li> <li>• Healthcare providers may feel existing symptom management guidelines are difficult to incorporate into their routine practice given a lack of time and challenges with adapting the guidelines to meet the needs of complex patients (sub-element 2)</li> <li>• Healthcare providers may feel they are already providing care that aligns with the best practices outlined by the symptom management guidelines (sub-element 2)</li> <li>• Organizations may not have the resources or capacity to ensure pain and symptom management guidelines can easily be acquired, assessed, adapted and applied by their staff in clinical practice (sub-element 3)</li> </ul>	<ul style="list-style-type: none"> <li>• Patients and their informal/family caregivers are likely to welcome the opportunity to receive more information about the best evidence-based approaches to support the management of their pain and symptoms (sub-element 1)</li> <li>• Healthcare providers are open to opportunities that will enable them to provide the best possible care to patients (sub-element 2)</li> <li>• Regional cancer centres in Ontario have already developed and implemented ‘knowledge translation’ plans to try to promote the use of symptom management guidelines in best practices (sub-element 3)</li> </ul>

**Option 2 – Providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management**

Barriers	Facilitators
<ul style="list-style-type: none"> <li>Healthcare providers may feel targeted payments and/or financial incentives send the wrong message by implying they are only willing to provide high-quality care if paid extra to do it (sub-element 1)</li> <li>Cancer care organizations may not support a targeted payment strategy that has the potential to create gaps in funding between high performers and low performers (sub-element 2)</li> <li>Healthcare budgets are already stretched in the province, making it difficult to find additional funds (overarching barrier)</li> </ul>	<ul style="list-style-type: none"> <li>Additional payments would be welcome among providers and organizations wanting to provide the best possible care to patients (overarching facilitator)</li> <li>Funds provided by the Ontario Government and Cancer Care Ontario to support the work of the OCSMC suggests there is a willingness to allocate additional resources to improve the use of pain and symptom management guidelines (overarching facilitator)</li> <li>Promoting evidence-based cancer care is a strategic goal and priority of Cancer Care Ontario (overarching facilitator)(90)</li> </ul>

**Option 3 – Organizing care differently to make it easier to provide pain and symptom management**

Barriers	Facilitators
<ul style="list-style-type: none"> <li>Cancer care in Ontario has traditionally emphasised treatment provided in hospitals and regional cancer centres, making it difficult to coordinate care transitions across many different settings and providers outside of these centres (sub-element 1)</li> <li>Ontario is lagging in the implementation of electronic medical records, making it difficult (and in some cases impossible) to efficiently link data across providers and settings in order to communicate patients' pain and symptom management needs (sub-element 2)</li> <li>Patients may be uncomfortable with an emphasis on self-management and care provided in their home, feeling that it is a signal the system is abandoning them (sub-element 4)</li> <li>The emphasis on technology-supported home care may cater to younger individuals, and may not be appropriate for older adults who are not tech-savvy (sub-element 4)</li> </ul>	<ul style="list-style-type: none"> <li>Team care is already provided in several cancer treatment centres (although this varies significantly across centres, as well as within centres and across different types of cancer) (sub-element 4)</li> <li>Enhancing the model of care delivery provides opportunity to optimize the underutilized roles and scope of practice of nurses and other members of the healthcare team. Reallocation of roles and changes to how healthcare teams deliver care may result in more efficient and effective use of existing human resources. (overarching facilitator)</li> <li>Improving cancer services and outcomes through the introduction of innovative models of care delivery is a strategic priority of Cancer Care Ontario (e.g., the Models of Care Initiative) (overarching facilitator)(90)</li> </ul>

# Questions for the citizen panel

>> We want to hear your views about the problem, the three options for addressing it, and how we can move forward.

This brief was prepared to stimulate the discussion during the citizen panel.

The views, experiences and knowledge of citizens can make a great contribution

## Box 2 >> Questions for the citizen panels

**Among the many issues facing the healthcare system today, is there a need to prioritize improving pain and symptom management for cancer patients in Ontario?**

**What do you see as the major problems with pain and symptom management for cancer patients in Ontario?**

**What are your views about the three proposed options?**

>> **Option 1:** getting the best information about pain and symptom management to everyone who needs it;

>> **Option 2:** providing targeted payments to health professionals and organizations for following guidelines about pain and symptom management;

>> **Option 3:** organizing care differently to make it easier to provide pain and symptom management.

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## Conflict of interest

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## Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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