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**EVIDENCE >> INSIGHT >> ACTION**

## 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 summary

On September 19, 2015, the McMaster Health Forum convened a citizen panel on how to improve pain and symptom management in cancer care in Ontario. The purpose of the panel was to guide the efforts of policymakers, managers and professional leaders who make decisions about our health system. This summary highlights the views and experiences of panel participants about:

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

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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## Summary of the panel

Participants discussed the main challenges related to improving pain and symptom management in cancer care in Ontario, and the following seven problems were viewed as the most pressing: 1) healthcare providers don't have the time to support the full range of pain and symptom management needs of individuals living with cancer; 2) there are major inconsistencies in the pain and symptom management supports patients receive across providers and settings, particularly during transitions from regional cancer centres to primary-care and community-care settings; 3) healthcare providers and individuals living with cancer are not communicating effectively about pain and symptom management; 4) individuals living with cancer often lack vital information and knowledge that would enable them to play an active role in managing their pain and symptoms; 5) accessing the full range of pain and symptom management support is not always easy; 6) there is a lack of accountability measures in the system that assign responsibility for ensuring individuals living with cancer receive comprehensive pain and symptom management support ; and 7) too much emphasis is placed on pain management, while supportive care for other distressful symptoms can often be overlooked.

Panel participants considered three possible options for improving cancer pain and symptom management: 1) getting the best information about pain and symptom management to everyone who needs it; 2) providing targeted payments to health providers 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. All participants supported options 1 and 3, while many participants strongly opposed to option 2, particularly when discussions focused on the possibility of payments targeted at individual healthcare providers. Several values-based themes emerged during the discussion, although the theme of collaboration was most consistently discussed. Participants felt this values-based theme was especially important with respect to improving how information moves among patients and healthcare providers, and among providers working in teams (option 1). Strengthening collaboration among the full range of providers and across all settings where pain and symptom management care is (or could be) delivered was also frequently discussed (option 3).

When considering barriers to implementing the options considered, participants viewed limited resources, engrained physician behaviour and fragmentation between cancer care and other supportive services (e.g., mental health services) as the most challenging. Despite these barriers, participants were optimistic about the potential for change given improvements in information technology, and the perceived commitment of decision-makers in the cancer-care system in Ontario to make things better.



“The doctor can refer you to a therapist, but it is expensive and you have to pay for it”

**Discussing the problem:** What are the most important challenges to improving pain and symptom management in cancer care in Ontario?

Panel participants began by considering how the pre-circulated citizen brief described the full range of problems (and their causes) related to pain and symptom management in cancer care in Ontario. They focused on seven problems that they, individually and collectively, considered to be the most pressing. These included:

- healthcare providers don't have the time to support the full range of pain and symptom management needs of individuals living with cancer;
- there are major inconsistencies in the pain and symptom management supports patients receive across providers and settings, particularly during transitions from regional cancer centres to primary-care and community-care settings;
- healthcare providers and individuals living with cancer are not communicating effectively about pain and symptom management;
- individuals living with cancer often lack vital information and knowledge that would enable them to play an active role in managing their pain and symptoms;
- accessing the full range of pain and symptom management support is not always easy;
- there is a lack of accountability measures in the system that assign responsibility for ensuring individuals living with cancer receive comprehensive pain and symptom management support; and
- too much emphasis is placed on pain management, while supportive care for other distressful symptoms can often be overlooked.

We review each of these challenges in turn below.

### **Box 1: Key features of the citizen panel**

The citizen panel about improving pain and symptom management in cancer care in Ontario had the following 11 features:

1. it addressed a high-priority issue in Ontario;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three options for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

## Healthcare providers don't have the time to support the full range of pain and symptom management needs of individuals living with cancer

Most participants felt that the time available to healthcare providers – and particularly physicians – was a major challenge that hindered their ability to provide comprehensive, evidence-based pain and symptom management support. Specifically, several participants shared the experiences they had while receiving treatment for cancer (or while supporting a loved one who was receiving treatment). They noted that their oncologist did not seem to have enough time to consider their individual needs by familiarizing themselves with the feedback provided during symptom screening upon arrival at their regional cancer centre. They also felt that their oncologist did not have enough time to then use this feedback to determine the most appropriate care options based on pain and symptom management guidelines. Participants attributed this to a number of different factors.

First, several participants suggested that each healthcare provider had too many patients to see each day, which limited the amount of time available for each consultation. One participant noted that their wait times at the cancer centre often exceeded two hours, and could be as long as five hours on particularly busy days. As such, there was a belief among several participants that it was next to impossible for their provider to read the results of their Edmonton Symptom Assessment Scale-revised (ESAS-r) form as a starting point for discussions on how to proceed with the most appropriate care. One participant stated that they “did ESAS every time and it never seemed to have an impact [on the nature of care that they received].” The same participant also shared one instance in which they “put ‘worst ever’ [...] just to see, and nothing happened.” This created a negative perception about the usefulness of spending time to fill out the screening tool prior to meeting with their doctor.

A second factor that participants felt contributed to the time constraints faced by their healthcare providers related to the fact that providers had too much to cover with each patient, given wide array of symptoms that individuals living with cancer may experience. Such breadth of support was perceived by several participants as falling outside of their providers' traditional scope of practice. In particular, a number of participants felt that many current healthcare providers (again, focusing primarily on physicians) were not trained to take on many of the psychosocial elements of pain and symptom management, such as counselling for anxiety and depression. As such, some participants believed that this type of support would be considered 'additional care' that constituted going above and beyond what was expected. Given the volume of patients and resulting time constraints already discussed, it wasn't likely that most providers would have the time to provide patients with this 'extra' support. As part of this discussion, some participants also noted the challenge of changing old habits. Specifically, asking an individual healthcare provider to expand the type of support they are accustomed to providing while also expecting them to change their consultation routine to include information from patient screening (i.e. ESAS) and consulting practice guidelines, was perceived as difficult. Some participants suggested that this challenge would not be overcome in the currently active generation of healthcare providers, and that working with younger generations who were open to doing things differently was important. A third factor participants felt contributed to the time constraints faced by individual healthcare providers related to apparent lack of help from other providers. Specifically, many participants believed that there didn't appear to be enough support from other

## **Box 2: Profile of panel participants**

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- **How many participants?**  
7 (although this number was lower than usual given a number of last-minute cancellations)
- **Where were they from?**  
Region covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network
- **How old were they?**  
25-44 (2), 45-60 (2), older than 60 (3)
- **Were they men, or women?**  
Men (4) and women (3)
- **What was the income level of participants?**  
One participant earned less than \$20,000, three between \$20,000 and \$40,000, one between \$40,000 and \$60,000, one more than \$80,000, and one preferred not to disclose their income
- **How were they recruited?**  
Selected based on explicit criteria from the AskingCanadians™ panel

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providers who are often better positioned to ensure that patients' pain and symptom management needs are identified prior to a consultation, and then addressed using practice guidelines within a consultation. One participant shared their own positive experience with nurses and volunteers, who were responsible for assessing the pre-consultation ESAS screening results, and then communicating them with the physician prior to the consultation. In this arrangement, the participant felt that their doctor always had the information they needed, and could focus on spending the time required in the appointment to address the patient's needs. Many participants echoed that this type of coordinated team care was ideal, but that it is the exception, not the rule.

Finally, a number of participants believed there was both a lack of financial resources available to cancer care organizations, and chronic staffing shortages in the health system, which contributed significantly to the time constraints they felt their healthcare providers faced.

There are major inconsistencies in the pain and symptom management supports patients receive across providers and settings, particularly during transitions from regional cancer centres to primary-care and community-care settings

A second major problem that was discussed by participants was related to the inconsistencies in the care they experienced. Most participants suggested that these were most acute and challenging in instances when they were transitioning from team support in a regional cancer centre to an individual primary care practitioner. In this scenario, many participants (although not all) described feeling as though they went from a supportive environment where the majority of their unique needs were met, to one where providers' interest and capacity to provide the same level of service was lacking. One participant experienced a primary care provider who was not at all understanding of the unique needs of a family member who had recently completed chemotherapy, despite receiving all of the necessary patient information. Another participant echoed these sentiments, and also noted that it was clear that the provider to whom he was transferred didn't have the skills or expertise to address his needs. Another participant acknowledged that while transitioning from specialist cancer care to generalist care was quite challenging from the patient perspective, they felt that this was likely a challenge from the provider perspective as well. In particular, the participant suggested that it was unreasonable to expect a primary care provider to be able to offer the same standard of cancer care as an expert oncologist supported by a team at a regional cancer centre.

While the inconsistencies around transitioning from regional cancer centres to primary and community care were discussed at length, participants also discussed four other themes that were viewed as directly related to the concept of inconsistent care. First, several participants suggested that differences across individual providers caused inconsistent care. For example, one participant who received care in a team setting noted that the care and support they received differed dramatically across different members of their team, and especially when they compared their regular physician with others. The participant felt that a new provider didn't know enough about their unique situation and needs, and didn't appear to be in a position to quickly get up to speed. Another participant felt strongly that each individual provider's personality had a large role to play, and this type of inconsistency was unavoidable.

Second, the absence of preferred providers (or challenges accessing preferred providers) was discussed as a factor that caused inconsistencies in care. In particular, several participants found it challenging when their preferred care provider wasn't available to them, either as a result of being busy with other patients, or because they were taking time off. While it wasn't clear what expectations participants felt were realistic in terms of ensuring their preferred providers were available, many experienced inconsistencies in the care they received when they were seen by a replacement provider.

Third, some participants viewed staff turnover at the regional cancer centre that they attended as a factor that caused inconsistencies in care. In particular, one participant experienced a significant disruption in their cancer care journey when their regular physician decided to move to a different city. The participant who initially raised the point acknowledged that the issue of turnover was a human one (particularly when issues in one's personal life affected career choices), but that there should be systems in place to ensure consistency in the care received – regardless of staff turnover.

The fourth and final factor discussed by participants as causing inconsistencies in care was the varying nature of information supports, which appeared to underpin many of the challenges already discussed. In particular, some participants noted:

- inconsistencies in the information provided to patients about their care journey by healthcare providers, especially when being supported by multiple healthcare providers (e.g. conflicting and confusing information about prognosis, treatment, etc.);
- inconsistencies in the patient information used across providers and settings, given there are no systems in place in Ontario to ensure that patient information is transferred from one provider/setting to the next, and no systems in place to ensure it is consulted when it is transferred; and
- inconsistencies in the information available to both patients and healthcare providers over time, as rapid transformations in both technology and care standards continually shifted the informational landscape.

## Healthcare providers and individuals living with cancer are not communicating effectively about pain and symptom management

Another problem discussed by participants related to communication challenges between healthcare providers and individuals living with cancer. Participants highlighted three aspects of this problem: 1) patients aren't communicating effectively with healthcare providers; 2) healthcare providers aren't communicating effectively with patients, or among themselves; and 3) systems aren't in place to ensure effective communication. Ultimately, many participants felt these communication breakdowns compromised their care, resulting in the provision of inadequate and inconsistent (as discussed earlier), pain and symptom management support.

Several participants felt that patients aren't doing a good job in communicating their needs to their healthcare providers. A few participants suggested that one possible reason for this is a lack of patient knowledge. While participants acknowledged that there could be many reasons for this, one important factor was that patients simply didn't know the right questions to ask to obtain the information they need. Some participants suggested that even when patients were clear on the questions they wanted to ask, they were too afraid or intimidated to ask their healthcare provider. As a result of this challenge, participants suggested that patients were not made aware of some of the most important aspects of their care, which led to them become less proactive and less engaged in decisions. While some participants felt that some of this could be attributed to a lack of patient communication supports (e.g., a mediator or case manager who could help each individual communicate more effectively with their cancer care providers), one participant felt strongly that it was the patient's responsibility to take the initiative to communicate their needs, and seek out knowledge when they wanted it.

Participants also suggested that, in many cases, providers were not doing a good job in communicating – both with their patients and among themselves. Throughout the panel discussion, a number of participants flagged that the information that they provided about their pain and symptom management needs (and specifically that which was provided during the ESAS screening process) was not consulted. Furthermore, many participants felt that healthcare providers were not actively listening to better understand each individual's full range of fears and expectations, or prompting patients with the right questions to elicit this information. As a result, there was a general consensus among participants that many healthcare providers were not doing a good job of understanding individual needs, or

appropriately briefing patients on what they can expect from their care journey, or about how different members of their care team will contribute to their care. One participant remarked: “It is essential that when you first meet the oncologist, you meet everyone on the team and understand what they are there to do for you.” Another participant expressed concern that most healthcare providers were not communicating about the options for care that were supplementary to those provided in the regional cancer centre (e.g., psychosocial therapy and other social support), and provided even less support for navigating services provided outside of the cancer-care system. Most participants felt that healthcare providers, while not entirely responsible for this aspect of pain and symptom management, should take responsibility for at least some of it. Additionally, as discussed earlier in this summary, there were many instances in which participants felt that their health-related personal information was not passed on from one provider to another (particularly during care transitions), which signalled to many that communication challenges among individual providers exist in the system as well. Finally, system-level communication problems were mentioned at several points throughout the panel discussion. In particular, participants perceived that the administrative systems in place to ensure files containing patient information were managed and shared properly across providers and settings were inadequate.

### Individuals living with cancer often lack vital information and knowledge that would enable them to play an active role in managing their pain and symptoms

All participants agreed that patient knowledge was essential, and that all individuals living with cancer needed information about the full range of support that they would require throughout their care. However, there were at least four issues that participants felt stood in the way of ensuring patients had the right information when they needed it. First, participants felt that most of the information available to them was too generic to be useful. For example, the pamphlets that were handed to them after being diagnosed with cancer were not tailored to their unique situations, and therefore provided little information that could be acted upon. Most of the resources encountered by panel participants did not include information about where and how to access the types of supportive care that fell outside of the cancer system in their own city or region (e.g., psychosocial supports such as mental health services). Additionally, most resources didn't include any information that

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could assist them in some of the more practical aspects of accessing these services (e.g., whether and how they could access financial support for services not covered by OHIP).

A second issue highlighted by participants was a concern that there wasn't a centralized information hub for them to go to in order to access a wide range of information about the system when they needed it. While some participants noted that government or organization websites provide information about being a cancer patient in Ontario, many felt that these sources were difficult to navigate to find the most relevant information to them at various points in their cancer care journey. One participant highlighted that many of the resources they encountered advised them to ask their provider for additional information, despite the reality that healthcare providers don't always have all of the information either, and aren't always easy to access.

A third important issue about information was raised during discussions related to participants' awareness of what constitutes best practice. Specifically, many patients noted that they were unaware of the fact that evidence-based guidelines that focused on pain and symptom management in cancer care existed. Additionally, participants didn't know that healthcare providers were expected to provide support based on these guidelines, or that in some cases they weren't doing so. As a result of this discussion, many participants suggested that as part of existing packages of care, it was important to educate individuals living with cancer and their informal/family caregivers about the guidelines so that they had this information (or could get it when they wanted it).

The fourth important challenge related to information that was raised by participants overlapped with the challenges related to communication discussed earlier in the day (and covered earlier in this summary). In particular, a few participants repeatedly raised the point that most patients don't do a good enough job advocating for the information that they need, which explains why the information currently available seems inadequate at times. One participant emphasized that individuals with cancer, or their informal/family caregivers, need to 'step up' to play a more active role, as it was their responsibility to ensure they had the information that was most relevant to them. One participant extended this notion beyond information seeking to the appropriateness of the pain and symptom management support received by individuals, suggesting that in many cases it was the patient's responsibility to ensure they were "getting the professional help [they] actually need, and a lot of that has to do with being proactive." Not all participants agreed with this notion, and one strong dissenting viewpoint emerged. Specifically, one participant believed that patients should be supported by healthcare providers and by the system to get

appropriate information and appropriate pain and symptom management support, given they may not have the ability or confidence to proactively ensure this on their own.

In light of these issues, many participants emphasized that the real need was ensuring individuals living with cancer had the right information at the right time. This was positioned by participants as being something that could be facilitated within a team-based care model where, for example, a surgeon could be relied upon to provide the most useful information prior to surgery, a dietitian could be relied upon when nutrition was an important consideration, and a nurse practitioner could be ‘on call’ to answer questions as they emerged throughout the care pathway.

## Accessing the full range of pain and symptom management support is not always easy

Many participants felt that there were challenges related to accessing the most appropriate pain and symptom management support, with three specific types of barriers mentioned: 1) those related to location; 2) those related to finances; and 3) those related to personal/cultural factors. When considering the impact that location had on access, most participants acknowledged that where you live has a major influence on the supports available to you. In particular, participants noted that some cancer centres have teams that can help to address the full range of distressful pain and symptoms, but often patients are required to go outside of the cancer system to receive care – particularly the kind that addresses the many psychosocial and mental health issues that arise from diagnosis to treatment to post-treatment. In these instances, not only is it difficult to know where to go, but in rural or remote areas, it may mean you’re required to travel long distances from your home (or your regional cancer centre) to access care. Furthermore, many participants noted that the regional cancer centre itself may be a significant distance from home, which creates additional challenges with respect to accessing even the most core aspects of care. One participant noted that they had “seen people who run out of pain medication, and can’t get access to a doctor on a long weekend.” Another participant noted that disparities could exist across provinces as well. Specifically, they shared a personal example in which a family member needed a very expensive drug that wasn’t available in Ontario, but was covered in other provinces. Participants couldn’t understand why, if a drug was approved by the federal government, it wasn’t available to all Canadians.

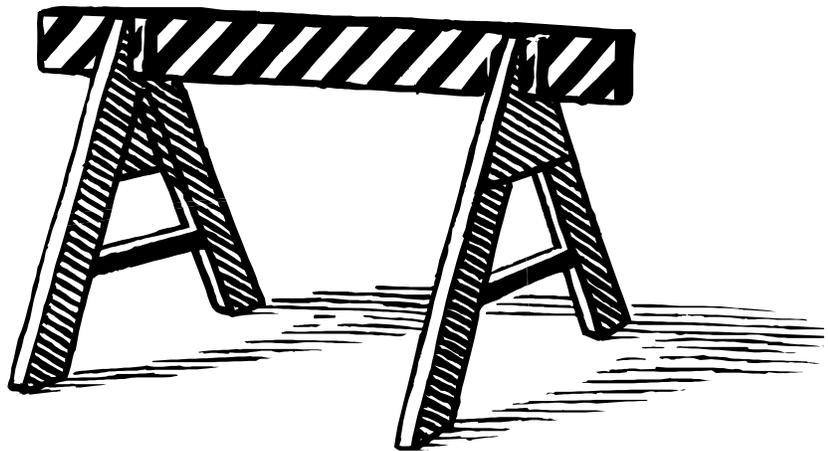
With respect to financial barriers, many participants noted that there were several important aspects of pain and symptom management support that were not accessible to everyone because they were expensive, and not covered by OHIP. Specifically, many participants noted that dealing with mental health issues throughout the cancer journey wasn't an option for everyone. One participant summed up the group's sentiment by acknowledging that "the doctor can refer you to a therapist [to deal with your depression and anxiety] but it is expensive and you have to pay for it."

Participants also noted that there may be instances in which cultural bias, and particularly personal appearance, affects access to services. For example, one participant noted that discriminatory practices may be applied where people with certain appearances may be assumed to be drug addicts, and as such may not be given the same access to prescription medications that can alleviate certain pain and symptoms.

There is a lack of accountability measures in the system that assign responsibility for ensuring individuals living with cancer receive comprehensive pain and symptom management support

Participants also discussed the notion of accountability, and most felt that it wasn't clear where accountability lies in the cancer-care system for ensuring patients receive evidence-based pain and symptom management support. Patients felt that one particularly important aspect of this issue was that most individuals with cancer don't know the guidelines exist, and relied on trust in healthcare

providers to ensure care was based on the guidelines. Furthermore, many participants noted that it wasn't clear why some providers wouldn't adhere to these guidelines, since they felt this was what they were paid to do. Overall, many participants felt that patients should be able to trust their healthcare provider, and it wasn't clear who should be responsible for holding them to account for doing this.



## Too much emphasis is placed on pain management, while supportive care for other distressful symptoms can often be overlooked

A final problem that emerged during discussions was related to a perceived over-emphasis in the health system on cancer pain. Many participants noted that while they felt pain was generally handled relatively well and it was often front and centre in discussions with their care providers, there was far less focus on the many other, and sometimes more distressful, symptoms that came along with cancer diagnosis, treatment, and recovery (e.g., anxiety, depression or financial concerns). Some participants questioned whether this imbalance was the result of provider training and the relative level of comfort they had in dealing with pain compared to the many other psychosocial issues that individuals living with cancer experience. Others asserted that it could be the lack of integration between what is currently provided in regional cancer centres and the many other services (e.g., therapy) that could be required. Overall, many participants noted again that an individual care provider could not be expected to have the time or skills to take care of everything.



“It is one thing to provide a stack of pamphlets [and another] to have someone tailoring the information and guiding you through it.”

## **Discussing the options:**

### How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three options (among potentially many) for improving pain and symptom management in cancer care in Ontario:

- 1) getting the best information about pain and symptom management to everyone who needs it;
- 2) providing targeted payments to health providers 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.

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

The discussion about the first option focused on improving the use of pain and symptom management guidelines in routine care through strategies to move evidence into practice (i.e., knowledge translation strategies). This option could include strategies targeted at:

- patients and/or their informal/family caregivers by informing and educating them about what care should be provided based on guidelines;
- 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
- organizations that deliver cancer care, by changing the way routine processes facilitate the use of guidelines.

During discussions about option 1, four values-related themes emerged that participants felt were important for guiding efforts to get information about pain and symptom management guidelines to both individuals living with cancer (and their informal/family caregivers) as well as providers:

- self-reliance (by enabling individuals to understand and use information about pain and symptom management guidelines);
- patient-centredness (in considering the ways in which the information is provided to individuals);
- collaboration (among healthcare providers); and
- adaptability (in the approaches used to inform and educate healthcare providers).

Participants unanimously supported option 1, although much of the focus of discussions around this option centred on how best to support individuals living with cancer and their informal/family caregivers to engage with information about pain and symptom management guidelines, and about their care more generally. Participants felt that information provision was essential because it gave individuals living with cancer the opportunity to be more self-reliant and proactive throughout all stages of their care (the first values-related theme to emerge). However, participants suggested that when pursuing strategies to achieve this, particular attention had to be paid to the nature of the approaches adopted, and care had to be taken to ensure they were clearly informed by patient needs.

Specifically, participants noted that there was a risk when providing information to people living with cancer that they will not be able to understand it, that there will be information overload, or that they will be too distressed to absorb the information (particularly when provided immediately after diagnosis).

Participants continually emphasized the need to take a patient-centred approach to information provision (the second values-related theme to emerge). Such patient-centredness would ensure that the timing was appropriate with respect to each individual's state of mind (e.g., not providing information when an individual was still processing a diagnosis or prognosis), that the method of delivery was responsive to each individual's unique requirements (e.g., that different formats were available, and someone was available to work through the information and answer questions when needed), and that there was a clear centralized 'hub' that individuals could rely on to access the right information at the right time. The concept of a 'hub' for information – whether it be a virtual online entity or a physical space like a library – was discussed at length, with most participants feeling it was an essential step towards supporting the use of the best available information about pain and symptom management by individuals living with cancer and their informal/family caregivers. Such a hub could include information in a variety of formats so patients could choose how to engage with it (e.g., videos or written materials), it could be responsive to diverse cultural needs (e.g., if a community has a high

### **Box 3: Key messages about option 1**

- All participants supported this option, with many emphasizing the importance of ensuring that individuals living with cancer and their informal/family caregivers have access to information from best practice guidelines, as well as information about care more generally.
- Four values-related themes emerged during discussions about option 1:
  - self-reliance (by enabling individuals to understand and use information about pain and symptom management guidelines);
  - patient-centredness (in considering the ways in which the information is provided to individuals);
  - collaboration (among healthcare providers and patients); and
  - adaptability (in the approaches used to inform and educate healthcare providers).



proportion of people who don't speak English, materials could be available in different languages), and it could be dynamic and kept up to date.

While discussing the importance of patient-centredness, participants suggested that enhanced collaboration and communication between individuals living with cancer and their healthcare providers, as well as among a broader range of healthcare providers, was particularly important (the third values-related theme to emerge). Specifically, many participants viewed healthcare providers as 'information facilitators' who could effectively navigate the information as well as each individual's personal circumstance in order to intervene with their patients when appropriate. However, participants noted that this would be difficult for an individual healthcare provider, and some suggested other options, including the use of volunteers or a 'cancer midwife' who could act as guides, and help them to engage with information more effectively. Most participants envisioned these providers working in close collaboration with cancer-care physicians and nurses in team-based settings.

The fourth and final values-based theme to emerge in the discussions about option 1 was about the need for adaptability – particularly as it related to the ways in which healthcare providers are supported to access information about evidence-based pain and symptom management guidelines. Many participants thought it was important to use technology to support providers' access to information, especially as younger tech-savvy generations become healthcare providers in Ontario's cancer-care system. Participants felt that it was highly unlikely that providers today would read through a 20-page guideline document placed on their desk, and that bullet point messages in electronic formats that can be accessed using mobile devices would be more appropriate.

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

The discussion about option 2 focused on facilitating the greater use of pain and symptom management guidelines by providing targeted payments to healthcare providers and to the organizations in which cancer care is provided. This would involve:

- additional payments made to providers of care (i.e., on top of the payments already received) that ensured the time spent consulting pain and symptom management

guidelines and providing care based on these 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

- 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) as well as bonus payments if specific targets are met.

Most participants strongly opposed option 2, particularly when discussions focused on the possibility of payments targeted at individual healthcare providers to ensure care was based on pain and symptom management guidelines. These sentiments were expressed through two values-based themes that emerged during discussions:

- responsibility (for providing patients with the highest standards of care); and
- fairness (with respect to how healthcare providers are paid).

Participants had concerns with option 2, in large part because they didn't believe providers should have to be paid to do their job to a high standard. Specifically, many participants commented that it was the responsibility of all healthcare providers to ensure that patients are getting care based on the best available research evidence (the first values-related theme to emerge). As such, it didn't make sense to many participants that additional payments should be provided to providers for something that they are already responsible for. Additionally, many participants noted that there were healthcare providers within and outside the cancer-care system who were already doing their jobs well – including undertaking efforts to ensure that the care they provided to patients was in line with best practices. Since additional payments may not be

#### **Box 4: Key messages about option 2**

- Many participants strongly opposed the possibility of payments targeted at individual healthcare providers. This was underpinned by two values-based themes:
  - responsibility (for providing patients with the highest standards of care); and
  - fairness (with respect to how healthcare providers are paid).
- Most participants didn't strongly support or oppose targeted payments for cancer care organizations, and the values-based theme of accountability emerged as important if such payments were to be made.



made to these other providers, participants felt that it would be unfair to single out healthcare providers in cancer care and pay them to do their job to the same standard that others are performing at without additional funds (the second values-related theme to emerge). One participant invoked the book *Animal Farm*, stating “you cannot treat people differently and expect them to be happy,” while another provided a concrete illustration of the repercussions of such an option: “If I am a [pediatric] nurse, I am going to be pissed off because a cancer nurse gets more money. You are just giving them more money for what they should be doing in the first place.”

When it came to considering providing targeted payments to organizations to support practice that was informed by evidence-based guidelines, participants were ‘on the fence,’ with no strong positions for or against this approach. The values-based theme of accountability underpinned much of this shorter discussion. Specifically, many participants felt that as long as organizations remained accountable for how they are spending additional funds, and that these funds are used to support improved patient care, then this wasn’t a particularly bad option. Some participants questioned whether pay-for-performance and targeted payments were more appropriate within a business environment, and suggested that it may be inappropriate in the context of healthcare. However, at the organizational level, most participants acknowledged that financial considerations and sources of funding were very important. As such the sentiment was that as long as accountability could be ensured, business practices were OK.

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

The discussion about option 3 focused on changing the way cancer care is organized to make it easier to provide pain and symptom management support that aligns with best-practice guidelines. This would involve a number of different sub-elements, including:

- establishing referral and transition routines that signal to healthcare providers that they need to ensure information about each patient’s pain and symptom management needs are communicated from one provider or setting to another;
- improving the extent to which patient records (and specifically, information about their pain and symptom management needs) are electronically linked across providers and settings;
- improving the extent to which healthcare providers involved in pain and symptom management engage in team-based, patient-centred and collaborative care; and

- improving home-based pain and symptom management services, including remote-monitoring, web-based and telehealth services, self-management support, and support for informal/family caregivers.

When discussing option 3 and its various elements, participants focused on three values-related themes that were considered important in any efforts to reorganize care in the ways described:

- privacy (of patients and their personal information);
- collaboration (between providers); and
- community (to ensure strong support systems are in place for individuals with cancer and their informal/family caregivers).

Many participants considered privacy – the first values-related theme – to be of great importance when considering option 3, in particular when transferring patient information across providers and settings or in linking the information through electronic means (e.g., online administrative databases that could be accessed from a number of locations by a number of people). While many participants acknowledged the benefits and even the necessity of efficiently and effectively communicating their individual care needs to different providers working in multiple settings via patient records (electronic or otherwise), ensuring this information was secure emerged as an important priority that should be addressed.

Participants also considered privacy to be important during the actual process of receiving pain and symptom management support. Specifically, some participants felt that it was important to provide individuals living with cancer the opportunity to access support from the comfort of their own home (e.g. by providing home-care services or by supporting self-management), given many of these individuals prefer to keep the matter private. One participant played devil’s advocate and stated that

#### **Box 5: Key messages about option 3**

- Participants were generally supportive of option 3
- Three values-based themes emerged when discussing option 3 and its various elements:
  - privacy (of patients and their personal information);
  - collaboration (between providers); and
  - community (to ensure strong support systems are in place for individuals with cancer and their informal/family caregivers).



caution should be taken when considering self-management, particularly because individuals living with cancer and going through treatment have the tendency to over-react and over-medicate. There is also a risk when patients are living in what one participant referred to as ‘the fog,’ wherein they can’t focus and shouldn’t be self-managing their pain and symptoms. In this context, individuals likely require significant support from trained healthcare providers.

A second important values-based theme that emerged in the discussions of option 3 was a recurring theme mentioned by participants at other points in the discussion: the need for collaboration among healthcare providers responsible for providing pain and symptom management support. Participants felt strongly that, while the team-based model of care has taken root in some cancer-care settings, there is a need for more widespread collaboration and team-based approaches that engage the full range of providers required to ensure comprehensive pain and symptom management support. Most participants felt that this should be the focus of any effort to reorganize the system, and that this type of effort could help overcome many of the challenges discussed earlier in the day. In particular, one participant used the example of a Volvo car plant, wherein many people with different types of skills and expertise work together in the same space and towards a common goal, as a way to think about the best approaches to collaborative care in Ontario.

Finally, the values-based theme of community underpinned additional observations about option 3. Some participants mentioned the importance of community in terms of belonging, by which they meant reorganizing care to focus on creating strong support networks for individuals. Some participants believed that this could facilitate linkages with both information and services as they are required. While some participants initially framed this particular theme in an abstract sense, several later noted that community could be nurtured in a physical place – a ‘hub’ – where all of their pain and symptom management needs could be addressed ‘under one roof.’ One participant suggested that this physical hub could complement (or integrate) a virtual hub to facilitate access to information.

## Considering all of the options together

Overall, when taking the three options together, most participants felt that options 1 and 3 were appropriately framed, and that option 2 could be appropriate if the focus was only on the organizations in which cancer care is provided. Additionally, at different points in the discussions, participants identified at least three more (and complementary) options that could be pursued to improve pain and symptom management in cancer care in Ontario:

- 1) the creation of a virtual information hub, which would enable individuals living with cancer to access the most relevant information, when they need it, from a single source;
- 2) the introduction of ‘information facilitators’ (which they also referred to as ‘cancer midwives’) who could help patients to navigate the system and the information they need as they progress through diagnosis to treatment and to survivorship or palliative care; and
- 3) the integration of services into a community ‘hub’ (a single place) that ensured easy linkages among all aspects of care and could help to establish strong support networks.



“Cancer care should include a place where we can go and feel like we belong, where everything is under one roof and there are linkages to other [supports we may need]”

## **Discussing implementation considerations:**

What are the potential barriers and facilitators to implementing these options?

After discussing the three options (among potentially many) for improving pain and symptom management in cancer care in Ontario, participants briefly examined potential barriers to and facilitators for moving forward. Many of these barriers had also been identified during discussions earlier in the day, including financial resources and system barriers. First, several participants suggested that the group probably expected a lot from the options, perhaps too much. One participant said that they saw the options as a “Christmas list that will lead to strong and healthy communities that are also well-informed.” Many participants agreed that we are living in a time of constrained budgets, which would make moving forward with the options difficult. Second, participants noted that there are system-level challenges that may impede progress in improving pain and symptom management in Ontario. One of these challenges is that many healthcare providers – and particularly physicians – are set in a particular way of doing things, making it difficult to ensure they change their behaviour to incorporate best practices into routine care. Participants also acknowledged that the sheer scope and complexity of managing the full range of distressful symptoms meant that it would be difficult to coordinate services

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across the system. This was particularly challenging given many of the services required by individuals who experience distressful symptoms (e.g. anxiety, depression and other psychosocial issues) fall outside the traditional scope of the cancer-care system, and are quite fragmented across various providers and settings.

Despite these challenges, participants felt that improvements in technology, healthcare professional training programs and a willingness within the system to improve should all be considered key facilitators for positive developments in cancer pain and symptom management in Ontario. Technology was viewed as a way to make information about best practices widely available, and training programs were considered as key ways to engage the next generation of healthcare providers who would be willing to rely on practice guidelines and work in team-based models of care. Finally, many participants were enthused by the fact – and saw as a facilitator – that decision-makers in the system appear to want continuous improvement and patient-centred care.

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### Authors

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Julia Abelson, PhD, Faculty, McMaster Health Forum and Professor, McMaster University  
John N. Lavis, PhD, Director, McMaster Health Forum and Professor, McMaster University

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McMaster Health Forum  
1280 Main St. West, MML-417  
Hamilton, ON Canada L8S 4L6  
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Email: [mhf@mcmaster.ca](mailto:mhf@mcmaster.ca)

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