

IMPROVING THE DELIVERY  
OF COMPLEX CANCER  
SURGERIES IN CANADA  
(HAMILTON PANEL)



20 SEPTEMBER 2014

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 20, 2014, the McMaster Health Forum convened a citizen panel in Hamilton (Ontario) on how to improve the delivery of complex cancer surgeries in Canada. The purpose of the panel was to guide the efforts of policymakers, managers and professional leaders who make decisions about our health systems. 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.

# Table of Contents

<b>Summary of the panel</b> .....	1
<b>Discussing the problem:</b> What are the most important challenges to improving the delivery of complex cancer surgeries? .....	2
Making decisions in the midst of a cancer diagnosis is difficult.....	3
Inequities exist in access to complex cancer surgeries.....	5
The patient journey is marked by communication breakdowns with (and between) healthcare providers.....	7
Current financial arrangements limit our capacity to improve the delivery of complex cancer surgeries .....	8
Regulations for surgeons and hospitals are lacking .....	8
<b>Discussing the options:</b> How can we address the problem? .....	9
<b>Option 1</b> – Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided.....	10
<b>Option 2</b> – Implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided .....	13
<b>Option 3</b> – Regionalize complex cancer surgeries into designated surgical centres of excellence .....	16
<b>Option 4</b> – Introduce flexible care pathways that combine care in a regional centre of excellence with care provided close to home whenever possible .....	18
<b>Discussing the implementation considerations:</b> What are the potential barriers and facilitators to implementing these options? .....	20
<b>Discussing how to move forward</b> .....	21
Acknowledgments.....	22

# Summary of the panel

Panel participants discussed shortfalls in the delivery of complex cancer surgeries in Canada and the causes of these shortfalls. In particular they focused on five challenges, which gave them the opportunity to begin to articulate the values underlying their positions on this topic: 1) making decisions in the midst of a cancer diagnosis is difficult; 2) inequities exist in access to complex cancer surgeries; 3) the cancer patient journey is marked by communication breakdowns with (and between) healthcare providers; 4) current financial arrangements limit our capacity to improve delivery of complex cancer surgeries; and 5) regulations for surgeons and hospitals are lacking.

Participants reflected on four options (among many) for improving the delivery of complex cancer surgeries in Canada. The first three options were originally proposed in the pre-circulated citizen brief and the fourth option emerged during the discussion: encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided (option 1); implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided (option 2); regionalize complex cancer surgeries into designated surgical centres of excellence (option 3); and introduce flexible care pathways that combine care in a regional centre of excellence with care provided close to home whenever possible (option 4). Overall, option 3 generally resonated most strongly with participants. Eight values-related themes emerged during the discussion, which highlighted the potential benefits of option 3 as well as areas in need of particular attention: 1) the need to continuously improve both surgical and post-operative care; 2) implementing policies based on data and evidence; 3) excellent health outcomes; 4) cost-effectiveness; 5) expertise; 6) innovation; 7) collaboration; and 8) fairness towards the patients and families who must travel to obtain surgical care. Several participants suggested option 4 as a way to introduce more flexible care pathways.

When turning to potential barriers and facilitators to moving forward, participants mostly emphasized the challenges associated with the lack of human and financial resources, and with developing commonly agreed provincial standards and regional infrastructures. However, participants acknowledged current efforts in the province to regionalize certain complex cancer surgeries and to establish province-wide standards.



"I'd rather travel long distances to get something that is good than stay local and get inferior care."

## **Discussing the problem:** What are the most important challenges to improving the delivery of complex cancer surgeries?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying problem – shortfalls in the delivery of complex cancer surgeries in Canada – and its causes. In particular, they focused on five challenges, which gave them the opportunity to begin to articulate the values underlying their positions on this topic:

- making decisions in the midst of a cancer diagnosis is difficult;
- inequities exist in access to complex cancer surgeries;
- the patient journey is marked by communication breakdowns with (and between) healthcare providers;
- current financial arrangements limit our capacity to improve delivery of complex cancer surgeries; and
- regulations for surgeons and hospitals are lacking.

We review each of these challenges in turn below.



## Making decisions in the midst of a cancer diagnosis is difficult

Participants initially focused on the challenges of making an informed decision in the midst of a cancer diagnosis. They identified four sets of related challenges that may affect decisions faced by patients requiring complex cancer surgeries and their families: 1) a cancer diagnosis triggers very emotional reactions; 2) treatment decisions must be made quickly; 3) patients and families face uncertainty about which course of action to take; and 4) there is a lack of support to make informed decisions.

Participants initially focused on the emotional nature of the cancer diagnosis. They illustrated the situation as a ‘bomb’ being dropped in their life. This bomb could literally “disorient and blind” patients and families. One participant said: “When you are hit between the eyes with the diagnosis from your GP, your world is turned upside down. During the same time, all of the information is thrown at you.”

Participants then emphasized the rapid pace at which several life-changing decisions must be made. One participant indicated that he had to make “rushed decisions that could mean life and death.” A second participant said that he had less than 48 hours to make a decision. “I didn’t have the time to see the family physician. I didn’t have a conversation with my

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

The citizen panel about improving the delivery of complex cancer surgeries in Canada had the following 11 features:

1. it addressed a high-priority issue in Canada;
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.

oncologist.” A third participant noted that the biggest challenge is being able to slow down the whole process, in order to have the time to think and ask the right questions.

Several participants mentioned being uncertain about which course of action to take after receiving their cancer diagnosis (e.g., balancing the benefits and risks associated with the different treatment options, while considering the implications of their decision on their life and family). Many participants pointed out that their decisions were often made in the absence of complete information. A few participants emphasized the need to encourage the public to make advance care plans that could help them face such difficult situations. They suggested that advance care planning could be beneficial in decreasing anxiety and decisional conflict. As one participant said: “Sometimes you’re not sure about whether the decision being made is correct. You second guess yourself, but you feel as though you have to make the decision because waiting isn’t an option.” This same participant indicated that advance care planning was also essential to make one’s wishes clearly known to family members, caregivers and substitute decision-makers. “[When] you have to make decisions for others, it’s a challenge to have the confidence in [such] decisions.” However, one participant doubted that advance care plans could solve this. “Patients’ ears turn off [when receiving a cancer diagnosis] and decisions often change. So planning is difficult because people never know what they’re going to do when they’re actually diagnosed. Humanity is a factor that must be considered.”

Still referring to the decisional conflict they experienced, several participants pointed out the lack of support to make informed decisions about treatment options. Many pointed out that they were generally unaware of what questions to ask or the types of information to request. They said that patients are usually “on their own” and have to “be their own coach.” They sometimes relied on ‘insiders’ (e.g., friends or relatives who are health professionals) to informally help them navigate the system, and to provide them with information that they could use to guide decisions.

Participants then discussed the different types of questions they believed were important to ask in order to make informed treatment decisions.

- What is the prognosis?
- What is the full scope of treatment options available?
- What are the recovery and survival rates for each treatment option?
- Where to get the ‘best’ care or ‘better care’, and what are the implications (e.g., travel and costs)?
- Am I healthy enough to go through surgery?

- Who will be doing the surgery (e.g., expertise and how many surgeries a surgeon has done)?
- What are my best treatment options locally if surgery requires travelling far away from home?
- What type of post-operative care is required and who will be responsible for this (e.g., what is the family expected to do and for how long)?
- Is post-operative care (as well as home and community support) available close to where I live?

These questions illustrate that participants want clear information about their condition, the full scope of treatment options, and the availability of high-quality surgical and post-operative care. Regarding surgery more specifically, many participants indicated that it is crucial to know the surgeon's and hospital's volume of cancer surgeries since it would likely affect their decision about whether or not to undergo surgery, or where to get surgical care. As one participant indicated, it is important to know who is "top-notch" and who is doing this job "five days a week." A second participant went further and indicated that having information about surgical volumes and outcomes was critical. "You're basically deciding whether you're going to live or die. This must be known before making a decision." However, some participants admitted that such information is probably difficult for any layperson to access and interpret.

Thus, several participants called for mechanisms to help patients obtain timely and trustworthy information, but also for mechanisms to help them interpret this information. They indicated that a personal coach, patient navigator or case manager would be extremely helpful as a source of information and trusted decision-support mechanism right at the beginning of the cancer journey.

## Inequities exist in access to complex cancer surgeries

Participants were concerned about inequities in access to complex cancer surgeries across Ontario, but also across the country. While many participants acknowledged that they were lucky to live near the region's centre of excellence for cancer (i.e., the Juravinski Cancer Centre in Hamilton), they also agreed that many people living in rural and remote areas could face very difficult decisions: whether to choose a treatment option offered at a hospital close to home (and potentially undergoing surgery in a local, low-volume hospital), or travelling far away from home to receive the surgery at a high-volume hospital with a concentration of expertise (with the hope of better outcomes).

Many participants indicated that they would do everything possible to access a high-volume centre, even if it required travelling to another region. As one participant said: "I'd rather



travel long distances to get something that is good than stay local and get inferior care.” Yet, one participant clearly indicated that, whatever the cancer diagnosis and treatment options available, she would always choose local treatment options and “hope for the best”, because she “couldn’t put that burden [of travelling to get surgical care]” on her family. Thus, personal and familial circumstances are important factors that will influence decisions regarding treatment options and where to obtain care.

This discussion revealed that it was essential to participants that every patient should be able to choose to undergo complex cancer surgery in a high-volume surgical centre of excellence. However, as several participants indicated, choice is often more feasible for some patients than others. For example, those living in rural and remote areas, those living in certain provinces and territories (e.g., Prince Edward Island or Nunavut), or those from socioeconomically disadvantaged groups are likely to experience additional stress and prohibitive out-of-pocket expenses associated with travelling to a regional surgical centre of excellence. Participants worried that such barriers can be enough to dissuade patients from accessing optimal surgical care, and that the barriers restricting access to complex cancer surgeries need to be addressed. Participants remarked that such disparities are too often taken as a given in a large country like Canada, and that we need to collectively figure out how to change the system to remove such barriers.



## The patient journey is marked by communication breakdowns with (and between) healthcare providers

Several participants indicated that there were communication breakdowns with (and between) healthcare providers during their cancer journey. For instance, a few participants experienced difficult interactions with their family physicians and specialists about their initial symptoms, which may have delayed their cancer diagnosis. Other participants provided examples of communication lapses between the regional cancer centre and their local Community Care Access Centre, which affected the coordination of post-operative care. These participants indicated that too many people fall through the cracks due to communication breakdowns. As one participant said: “When patients leave the hospital, there is a risk of getting into a void.” The result is that people do not receive the care they need unless they are able to advocate and push for it (or have someone to do it on their behalf). Participants indicated that it was essential to bridge such communication gaps to ensure the optimal delivery of complex cancer surgery and post-operative care.

### 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?**

14

- **Where were they from?**

Region covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network

- **How old were they?**

All participants were at least 25 years of age – 25-44 (21%), 45-64 (36%), and 65 and older (43%)

- **What perspective did they bring?**

All participants had experience with cancer, complex cancer surgeries or other major surgeries, as patients or informal/family caregivers

- **Were they men, or women?**

Men (50%) and women (50%)

- **What was the educational level of participants?**

14% completed high school, 14% completed community college, 14% completed technical school, 50% completed a bachelor's degree/post-graduate training or professional degree, and 7% completed post-graduate training

- **What was the work status of participants?**

21% were disabled, 7% working part-time, 29% working full-time, 36% retired, and 7% students

- **What was the income level of participants?**

21% earned less than \$20,000, 29% between \$20,000 and \$40,000, 21% between \$40,000 and \$60,000, 14% more than \$80,000, and 15% preferred not to answer

- **How were they recruited?**

Selected based on explicit criteria from the AskingCanadians™ panel and from advertisements via cancer organizations and societies

## Current financial arrangements limit our capacity to improve the delivery of complex cancer surgeries

Participants talked to a lesser extent about current financial arrangements and how they may limit our capacity to improve the delivery of complex cancer surgeries. Participants were generally concerned about the rising costs associated with cancer care and the overall financial sustainability of the health system. They perceived that current budget constraints have trickled down and affect doctors' ability to do their jobs, which negatively affects patient care. Some participants also expressed concern that the predominant funding model for hospitals (i.e., global budgets) may not create incentives for hospitals to improve the delivery of complex cancer surgeries, or to increase surgical volumes for certain complex cancer surgeries.

## Regulations for surgeons and hospitals are lacking

Participants also talked, although to a lesser extent, about the lack of regulation for surgeons and hospitals. A few participants emphasized that the lack of regulation does not create the necessary incentives for hospitals to respond to the needs of their communities (specifically those in smaller towns). However, some participants indicated that it isn't necessary that all hospitals (including smaller hospitals) are 'all things to all people', and therefore that complex cancer surgeries should not necessarily be available in every hospital setting.

A few participants also raised concerns about the lack of regulation of surgeons specifically. These participants were alarmed by the minimal regulation about which procedures surgeons can deliver within their specialty area, or how frequently they need to deliver these procedures, to ensure their surgical skills remain up to date. They worried that decisions to perform surgeries might be made that are not optimal for patients. One participant, while acknowledging that there is a need for stricter regulations for surgeons, also called for greater regulation of those providing post-operative care. This participant emphasized that, given the complexity of these surgeries and the high risk of complications, it was essential to ensure that those providing post-operative care at home or in the community have the required skills and competencies.



“Full access and fairness, it’s a utopia. Until we reach population density allowing that, [it will not be possible].”

## **Discussing the options:**

### How can we address the problem?

After discussing the challenges that reflect or contribute to shortfalls in the delivery of complex cancer surgeries in Canada, participants discussed four options for making improvements:

- 1) encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided;
- 2) implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided;
- 3) regionalize complex cancer surgeries into designated surgical centres of excellence; and
- 4) introduce flexible care pathways that combine care in a regional centre of excellence with care provided close to home whenever possible.

The first three options were originally proposed in the pre-circulated citizen brief. The fourth option emerged during the discussion and was seen by several participants as offering more flexible care pathways. Several values-related themes emerged during the discussion about these options with some consistency, including: continuously improving both surgical and post-operative care; implementing policies based on data and evidence; excellent health outcomes; and cost-effectiveness. We review the values-related themes for each option in more detail below.

## **Option 1** – Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided

The discussion about the first option focused on encouraging healthcare providers (e.g., surgeons, nurses and others) and managers to adopt quality-improvement initiatives in local hospitals in order to improve the delivery of complex cancer surgeries. Examples of such local quality-improvement initiatives may include: promoting audit and feedback; promoting the use of clinical decision support systems; promoting continuing medical education; and implementing enhanced recovery programs.

Seven values-related themes emerged during the discussion, which highlighted potential benefits of option 1. These values-related themes include:

- continuously improving (option 1 may support local continuous-improvement efforts for both surgical and post-operative care);
- cost-effectiveness (option 1 aims for the best possible local health system with the limited resources available);
- collaboration (option 1 relies on the collaboration of all local health-system stakeholders);
- accountability (option 1 may provide greater checks and balances at the local level);
- care based on data and evidence (option 1 may improve the local use of data and evidence in clinical decision-making);
- access to local support (option 1 may increase information, decision and navigation support); and
- excellent patient and family experience (option 1 may seek to address the local needs of patients and families).

Discussions highlighted some key features of option 1 that participants judged favourably. For instance, several participants indicated that it was necessary to support locally driven quality-improvement initiatives that could continuously improve the quality of surgical care delivered by local hospitals, as well as post-operative care delivered at home and in community settings. One participant said that local quality-improvement initiatives are essential to achieve the best possible health system with the limited resources available. Participants generally appreciated the ‘locally driven’ nature of this option because it could nurture collaboration, and through collaboration, local stakeholders’ buy-in, which was perceived as essential to bring about change.



Some participants also indicated that implementing audit and feedback was an interesting strategy to add more checks and balances to the hospital system. They suggested that it could alleviate (to some extent) the lack of regulation of both surgeons and hospitals.

Some participants also expressed the view that implementing clinical decision support systems could improve the local use of data and evidence in making decisions. They suggested that such systems needed to be complemented by personal coaches, case managers and patient navigators. These local supports could ensure that patients and families have access to timely and trustworthy information about treatment options, are able to interpret such information, can navigate the system, access needed support systems, and receive care that is fully coordinated.

A few participants also indicated that another benefit of option 1 was that it was seeking to strengthen local health systems and lead to excellent patient and family experience. Strong local health systems could potentially be more attuned to the values, needs and preferences of patients and families than regional centres, and also enable or facilitate family support systems to fully play their roles.

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

- Participants generally agreed that the limitations of option 1 outweighed its benefits.
- When discussing the limitations of option 1, six values-related themes emerged, which include:
  - choice (may not allow patients to choose treatment options from a list of the full range of options);
  - cost-effectiveness (may not make the best use of the limited financial resources and expertise available);
  - policies based on data and evidence (may lead to policies that are not aligned with what is known about the relationship between surgical volumes and outcomes);
  - excellent health outcomes (may improve the local delivery of care, but not patient outcomes);
  - stewardship (may lack the clear direction and incentives needed to implement quality-improvement initiatives); and
  - collaboration (may increase fragmentation within the system).



While participants saw several benefits to option 1, they generally agreed that its limitations outweighed its benefits. When discussing the limitations of option 1, six values-related themes emerged, which include:

- choice (option 1 may not allow patients to choose treatment options from a list of the full range of options);
- cost-effectiveness (option 1 may not make the best use of the limited financial resources and expertise available);
- policies based on data and evidence (option 1 may lead to policies that are not aligned with what is known about the relationship between surgical volumes and outcomes);
- excellent health outcomes (option 1 may improve the local delivery of care, but not patient outcomes);
- stewardship (option 1 may lack the clear direction and incentives needed to implement quality-improvement initiatives); and
- collaboration (option 1 may increase fragmentation within the system).

Participants debated whether option 1 allowed greater patient choice. One participant expressed the view that improving the delivery of complex cancer surgeries where they are now being provided (including in low-volume hospitals) would allow greater patient choice. This participant indicated that, ideally, patients should be able to choose among all possible treatment options, and that all these options should be offered locally (including complex cancer surgeries). Many participants disagreed with this opinion. They argued that investing efforts to improve the delivery of complex cancer surgeries in low-volume hospitals may broaden the treatment options available locally, but at the expense of patients having to choose among sub-optimal treatment options. One participant went further and indicated that focusing on improving the delivery of complex cancer surgeries in low-volume hospitals could actually remove the possibility of patients choosing the optimal treatment option: undergoing complex cancer surgery in a regional surgical centre of excellence where there is a concentration of expertise and the potential for the best possible health outcomes.

Several participants indicated that improving the delivery of complex cancer surgeries in low-volume hospitals was not the best use of scarce public dollars (i.e., it wasn't cost-effective), especially given what is known from existing data and evidence about the relationship between surgical volumes and outcomes.

Some participants even questioned the feasibility of option 1 to achieve excellent health outcomes. One participant indicated that trying to provide full access to these complex cancer surgeries in all hospitals was impossible. "Full access and fairness, it's a utopia. Until we reach population density allowing that, [it will not be possible]." In the same vein, other

participants emphasized the lack of available expertise for these complex cancer surgeries. As one participant pointed out: “There is a lack of expertise to go around.” Thus, implementing option 1 does not solve the problem of not having enough surgeons and healthcare providers available to achieve excellent health outcomes in all hospitals.

Several participants also emphasized that this option lacked a focus on stewardship. They questioned the potential effectiveness of locally driven quality-improvement initiatives with no clear instigator, no clear champion to drive the change, and no clear incentives to mobilize stakeholders. Thus, they perceived ‘encouraging’ the local adoption of quality-improvement initiatives as a ‘weak’ approach to improving the delivery of complex cancer surgeries. As one participant illustrated: “It’s like telling a child, *‘please be good’*.”

Lastly, a few participants worried that the focus on the local level may generate even more fragmentation in the health system, and reduce the potential for effective collaboration and coordination across the system for patients requiring complex cancer surgeries.

## **Option 2** – Implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided

The discussion about the second option focused on implementing province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided. Like the first option, option 2 is not intended to change where and by whom these cancer surgeries are being provided. However, in contrast to the first option, it proposes a top-down approach to quality improvement and assumes that healthcare providers and hospital managers can achieve significant improvements, albeit with appropriate support, incentives and directives to do so. Examples of province-wide quality improvement initiatives may include: developing provincial guidelines and standards for these cancer surgeries; implementing a pay-for-performance scheme for hospitals; developing or expanding supports for patients and families; and establishing requirements for reporting to the public about quality indicators and other performance measures.

Six values-related themes emerged during the discussion, which highlighted potential benefits of option 2. These values-related themes include:

- continuously improving (option 2 may support province-wide continuous-improvement efforts for both surgical and post-operative care);

- cost-effectiveness (option 2 aims for the best possible local health system with the limited resources available);
- stewardship (option 2 identifies the provincial government as playing an active role in the planning of complex cancer surgeries);
- fairness (option 2 aims to standardize the quality of care across the province, and aims to improve access to optimal surgical care for all);
- accountability (option 2 may increase public accountability by requiring public reporting of surgeons' and hospitals' performance, and establishing clear provincial benchmarks); and
- care based on data and evidence (option 2 may facilitate the dissemination and uptake of best practices across the province).

Participants emphasized that it was necessary to support province-wide quality-improvement initiatives that could improve the delivery of complex cancer surgeries, as well as post-operative care. They perceived option 2 as a promising strategy to continuously improve the quality of surgical and post-operative care, but also to support the development of the best possible local health system with the available resources.

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

- Six values-related themes emerged during the discussion, which highlighted the potential benefits of option 2. These values-related themes include:
  - continuously improving (may support province-wide continuous-improvement efforts for both surgical and post-operative care);
  - cost-effectiveness (aims for the best possible local health system with the limited resources available);
  - stewardship (identifies the provincial government as playing an active role in the planning of complex cancer surgeries);
  - fairness (aims to standardize the quality of care across the province, and aims to improve access to optimal surgical care for all);
  - accountability (may increase public accountability by requiring public reporting of surgeons' and hospitals' performance, and establishing clear provincial benchmarks); and
  - care based on data and evidence (may facilitate the dissemination and uptake of best practices across the province).
- However, by not making structural changes, participants generally agreed that the impact of option 2 would most likely be limited in improving health outcomes.

## *Improving the Delivery of Complex Cancer Surgeries in Canada [Hamilton Panel]*

Participants generally appreciated that option 2, in contrast to the previous option, embodied greater stewardship, with the provincial government playing an active role in the planning of complex cancer surgeries.

They also emphasized that option 2 could lead to greater standardization of the quality of surgical and post-operative care across the province (and hence to greater fairness among Ontarians). Establishing and monitoring quality indicators across the province, and also requiring surgeons and hospitals to publicly report them, could increase the system's public accountability. Ultimately, public reporting could help patients and families make more informed decisions, and potentially lead to better outcomes for all patients across the province. However, a few participants acknowledged that the available research evidence on public reporting reveals that the public rarely search out this type of information. Participants were also unsure whether surgeons and hospitals would be forthcoming with this information. A few participants were particularly concerned about the unintended consequences of public reporting and pay-for-performance, with the potential risk of 'cherry-picking' patients who may help physicians and hospitals score well, or avoiding those who may cause them to score poorly. A few participants noted that establishing and monitoring quality indicators across the province was necessary, but that it could potentially worsen access to complex cancer surgeries by decreasing the number of hospitals that can meet standards to provide surgical and post-operative care.

Participants also highlighted that option 2 could support care based on the best available data and evidence. They indicated that province-wide quality-improvement initiatives could facilitate the dissemination and uptake of 'best practices' in the delivery of complex cancer surgeries and post-operative care across the province.

While participants saw several benefits to option 2, participants generally agreed that, by not making structural changes (i.e., maintaining the delivery of complex cancer surgeries where they are now being provided), its impact would most likely be limited in improving health outcomes.

## **Option 3** – Regionalize complex cancer surgeries into designated surgical centres of excellence

The discussion about the third option focused on regionalizing complex cancer surgeries into designated surgical centres of excellence. This option includes efforts to change the structure of the health system and to set province-wide standards to support the regionalization of complex cancer surgeries. This option assumes that changes to who performs the surgeries and where they are performed will be needed to improve the delivery of care. This option proposes a top-down, province-wide approach to design and implement changes to who does what and where across the province. As with option 2, this option can include developing or expanding supports for patients and families.

Overall, option 3 resonated most strongly with participants. Eight values-related themes emerged during the discussion, which highlighted potential benefits of option 3. These values-related themes include:

- continuously improving (option 3 may yield continuous improvements in the quality of both surgical and post-operative care);
- policies based on data and evidence (option 3 may lead to policies that are aligned with what is known about the relationship between surgical volumes and outcomes);
- excellent health outcomes (option 3 is more likely to improve patient outcomes);
- cost-effectiveness (option 3 aims for the best possible surgical care with the available resources);
- expertise (option 3 aims to create a concentration of highly skilled surgeons and healthcare providers to deliver these very complex and risky procedures);
- innovation (option 3 offers an environment more likely to facilitate or trigger innovation);
- collaboration (option 3 should strengthen coordination between regional centres of excellence and local units coordinating home and community care services); and
- fairness (option 3 should increase support for patients and families who must travel to obtain surgical care).

Participants generally agreed that, by making structural changes to the system, option 3 may yield more significant improvements in the delivery of both surgical and post-operative care, but also lead to more optimal patient outcomes. In addition, option 3 was perceived as the one most closely aligned with what is known about the relationship between surgical volumes and outcomes.

A few participants indicated that, ideally, they would like to see excellent care that is easily accessible to everyone. However, participants generally agreed that the regionalization of complex cancer surgeries into centres of excellence was most likely a better use of scarce resources. This option appeared more cost-effective given current evidence about the relationship between surgical volumes and outcomes, but also the most practical since these regional centres of excellences are most likely going to be located in high-density areas with a lot of demand for these services.

Participants also emphasized the importance of expertise and innovation. By referring patients to regional surgical centres of excellence, patients would be treated where there is a concentration of highly skilled surgeons and healthcare providers to deliver these very complex and risky procedures. In addition, participants expressed the view that regional surgical centres of excellence created environments that were more

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

- Overall, option 3 generally resonated the most with participants.
- Eight values-related themes emerged during the discussion, which highlighted potential benefits of option 3. These values-related themes include:
  - continuously improving (may yield continuous improvements in the quality of both surgical and post-operative care);
  - policies based on data and evidence (may lead to policies that are aligned with what is known about the relationship between surgical volumes and outcomes);
  - excellent health outcomes (more likely to improve patient outcomes);
  - cost-effectiveness (aims for the best possible surgical care with the available resources);
  - expertise (aims to create a concentration of highly skilled surgeons and healthcare providers to deliver these very complex and risky procedures);
  - innovation (offers an environment more likely to facilitate or trigger innovation);
  - collaboration (should strengthen collaboration between regional centres of excellence and local units coordinating home and community care services); and
  - fairness (should increase support for patients and families who must travel to obtain surgical care).



likely to facilitate or trigger innovation, in contrast with local and low-volume hospitals. Thus, option 3 appeared to be the most favoured option to deliver optimal care and, as many participants indicated, it reflected the current direction being taken in Ontario.

Participants emphasized that while regionalization was most likely the way forward, they noted two sets of issues that should be addressed. First, they highlighted that it was crucial to strengthen collaboration between regional centres of excellence and local units coordinating home and community care services (i.e., Community Care Access Centres). Better coordination was necessary to ensure that local healthcare providers receive all the relevant information to provide optimal post-operative care when the patients go back home.

The second set of issues to address was the inevitable burden for some patients and families who would have to travel to regional centres of excellence. Participants called for greater fairness towards these patients. They insisted on the need for greater support for ensuring that family members can accompany their loved ones undergoing complex cancer surgeries (e.g., through not-for-profit hotels or affordable housing arrangements). There should also be guarantees that patients and their families have access, in their local communities, to high-quality post-operative care. This would help to alleviate the practical, emotional and financial burden associated with travelling for surgical care.

## **Option 4 – Introduce flexible care pathways that combine care in a regional centre of excellence with care provided close to home whenever possible**

When considering the full array of options, participants generally agreed that options 1 and 2, without option 3, have the potential to constrain excellence. In addition, while participants generally leaned towards option 3, several participants suggested a fourth option: introducing flexible care pathways, whereby every patient could receive optimal surgical care in a regional centre of excellence, but with the remaining care (e.g., chemotherapy, radiotherapy and ancillary cancer care) provided close to home whenever possible.

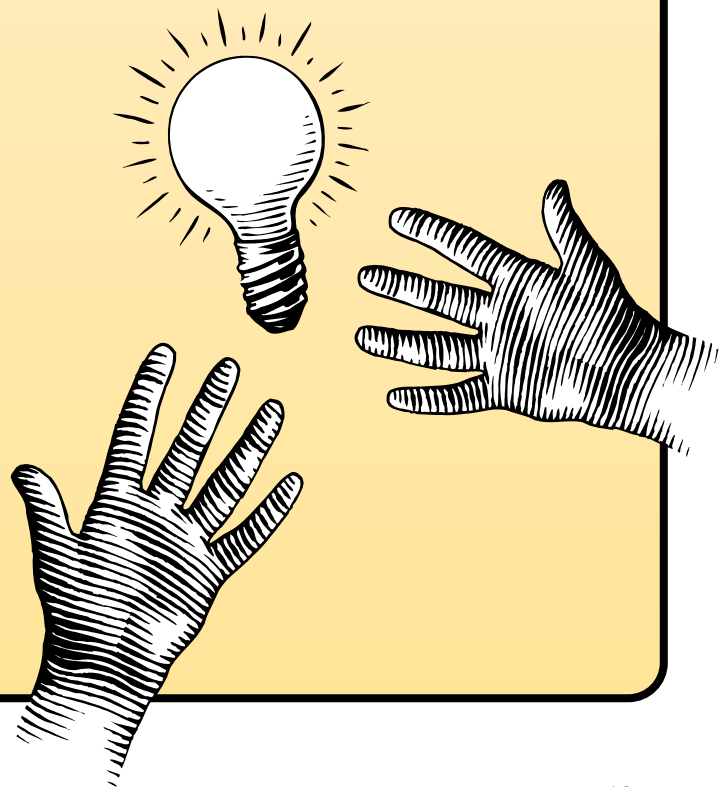
Two values-related themes emerged during the discussion about option 4:

- adaptability (option 4 may provide flexible care pathways allowing every patient to receive optimal surgical care in a regional centre of excellence, but the remaining care provided locally); and
- proximity (option 4 may allow patients to receive cancer care close to home whenever possible).

The discussion about option 4 illustrated that some participants were hesitant about full-blown regionalization of cancer care, especially given the significant burden that it would put on the shoulders of patients and families from rural and remote communities. These participants indicated that regionalization might be a good option for the surgeries, which have high-risk of complications, are resource intensive, and require highly skilled surgeons and providers. However, these participants questioned whether all aspects of cancer care needed to be regionalized (e.g., chemotherapy, radiotherapy, and ancillary cancer care). Thus, option 4 would offer more flexible care pathways with the surgery being regionalized, but other cancer care being offered locally whenever possible. This would ensure that patients and families are close to home for as long as possible during the cancer journey, which was perceived as an environment more favourable to recovery.

#### **Box 6: Key messages about option 4**

- Several participants suggested a fourth option: Introducing flexible care pathways that combine care in a regional centre of excellence with care provided close to home whenever possible.
- Two values-related themes emerged during the discussion about option 4:
  - adaptability (may provide flexible care pathways allowing every patient to receive optimal surgical care in a regional centre of excellence, but the remaining care provided locally); and
  - proximity (may allow patients to receive cancer care close to home whenever possible).





"All these numbers are people.  
They are human beings."

## **Discussing the implementation considerations:** What are the potential barriers and facilitators to implementing these options?

After discussing the options for improving the delivery of complex cancer surgeries in Canada, participants examined potential barriers and facilitators for moving forward.

When discussing potential barriers, participants generally agreed that a key barrier was the lack of resources. Participants indicated that it would be challenging to develop the critical mass of highly skilled surgeons and healthcare providers to meet the demands for complex cancer surgeries. They were also concerned about the financial resources necessary to implement these new regional infrastructures and to ensure their sustainability. In addition, a few participants believed that any efforts to establish province-wide standards and regional infrastructures could face 'push back' from certain health-system stakeholders. These participants also emphasized that it may be difficult (politically) to get all stakeholders aligned on what is considered an appropriate set of standards and regional infrastructures.

When turning to potential facilitators, participants mostly focused on the current direction taken in the province. They were encouraged by the active efforts in the province to regionalize certain complex cancer surgeries and to establish province-wide standards.

## **Discussing how to move forward**

As the citizen panel concluded its deliberations, participants expressed a desire to move forward in five ways. First, participants called for health-system leaders to act now in order to deal with the burden of cancer, which is likely to increase with the growing and aging population. Second, participants emphasized that health-system leaders should not forget what lies behind the cancer statistics: “All these numbers are people. They are human beings.” So, leaders’ efforts to improve the delivery of complex cancer surgeries must be patient- and family-centred. Third, participants would like to encourage health-system leaders to create incentives for quality improvement and innovation in the health system, rather than impose a one-size-fits-all solution. As one participant said: “Don’t try to equalize everything.” Fourth, participants called for greater efforts to improve the delivery of complex cancer surgeries in a coordinated and integrated way. As one participant indicated: “The right hand needs to know what the left hand is doing.” Lastly, they encouraged health-system leaders to work collaboratively with healthcare providers in these quality-improvement efforts.



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