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McMaster Health Forum

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

About citizen panels

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

About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by a series of citizen panels about improving the delivery of complex cancer surgeries in Canada. This brief includes information on this topic, including what is known about:

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

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

Table of contents

Key messages	1
The context: Complex cancer surgeries are a high priority issue.....	2
The problem: Improving the delivery of these surgeries is challenging.....	4
Cancer represents a significant burden on individuals, the health system and society.....	5
Patients in need of complex cancer surgeries and their families face a difficult journey.....	5
The health system is not currently designed to provide optimal care for such patients.....	11
Options to address the problem	19
Option 1 – Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided	21
Option 2 – Implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided	22
Option 3 – Regionalize complex cancer surgeries into designated surgical centres of excellence	24
Summarizing what we know about the three options	26
Implementation considerations	28
Questions for the citizen panels	30
Acknowledgments.....	31
References.....	32

Key messages

What's the problem?

Improving the delivery of complex cancer surgeries is challenging because:

- cancer represents a significant burden on individuals, the health system and society;
- patients in need of complex cancer surgeries and their families face a difficult journey; and
- the health system is not currently designed to provide optimal care for such patients.

What do we know about three options to address the problem?

- **Option 1** - Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided
 - A range of interventions were found to be beneficial, whether or not they were driven locally, such as: audit and feedback, clinical decision support systems, continuing medical education, and enhanced recovery programs.
- **Option 2** - Implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided
 - A range of provincially-driven quality-improvement strategies may be effective, including: practice guidelines; interventions targeting problem-solving and communication skills of cancer caregivers; and publicly reporting about quality indicators and other performance measures.
 - The research evidence regarding the effectiveness of pay-for-performance as a quality-improvement strategy is not convincing. In addition, pay-for-performance and public reporting may have unintended consequences to consider.
- **Option 3** - Regionalize complex cancer surgeries into designated surgical centres of excellence
 - There is some evidence that regional collaboration is a promising tool for quality improvement in surgery.
 - There is a positive association between hospital or surgeon volume and post-operative outcomes for various types of cancer.

What implementation considerations need to be kept in mind?

- Barriers to implementing these options might include healthcare providers and managers not buying into quality-improvement initiatives without tangible supports, incentives or directives, or policymakers not being able to make the long-term commitments needed to encourage the necessary infrastructure investments.
- Facilitators to implementing these options might include healthcare providers and managers being increasingly used to province-wide quality-improvement initiatives, as well as recent efforts in some provinces to regionalize some surgical procedures and other types of care.



While prevention and screening may be the most promising way to reduce the burden of cancer, in many patients cancer is detected at a later stage and may require complex surgery.

The context:

Complex cancer surgeries are a high priority issue

>> The high risk of complications, wide variations in post-surgical and long-term survival, and significant resources that these surgeries require suggest the need to find ways to improve patients' and families' experiences with this type of care and the way this care is organized.

Cancer is the leading cause of mortality in Canada. The number of new cases of cancer is expected to increase due, in large part, to population growth and aging. It is estimated that 20 Canadians are diagnosed with cancer every hour, and eight of them will die from it.(6) While prevention and screening may be the most promising way to reduce the burden of cancer, in many patients cancer is detected at a later stage and may require complex surgery.(5)

Glossary (part 1)

Surgery

Refers to a procedure (or operation) to remove or repair tissue, an organ or a part of the body. In cancer, surgeries are used to remove tumours or cancerous cells, or to provide relief from problems such as pain, bleeding or infection.

Complex surgery

Refers to cancer surgeries that are associated with a high risk of complications during and after the surgeries; wide variations in post-surgical and long-term survival depending on where and by whom the surgeries are performed; and the need for significant healthcare resources before, during and after the surgeries.

Volume

Refers to the number of surgical procedures performed on unique patients by a hospital or surgeon in a year.

There are more than 200 types of cancer. Certain types of cancer may necessitate surgeries that are particularly complex, for example:

- **esophagus cancer** (a cancer that forms in tissues lining the muscular tube through which food passes from the throat to the stomach);
- **hepato-biliary cancer** (a cancer that forms in tissues of the liver, bile ducts, and/or gallbladder);
- **lung cancer** (a cancer that forms in tissues of the lungs);
- **ovarian cancer** (a cancer that forms in tissues of the ovaries and fallopian tubes); and
- **pancreatic cancer** (a cancer that forms in tissues of the pancreas).

These cancer surgeries are considered to be complex because they are associated with: 1) a high risk of complications during and after the surgeries; 2) wide variations in post-surgical and long-term survival depending on where and by whom the surgeries are performed; and 3) the need for significant healthcare resources before, during and after the surgeries (e.g., multiple diagnostic examinations, long hospitalizations, extended follow-up care, rehabilitation care, supportive care, and home care).(5) These features suggest the need to find ways to improve patients' and families' experiences with this type of care and the way this care is organized.(2)

This brief was prepared to support the discussions of three citizen panels about improving the delivery of complex cancer surgeries in Canada. The input from the citizen panels will be widely shared in order to inform the efforts of policymakers, managers and professional leaders who make decisions about our health systems.

In the following sections of the brief, we explore why it is challenging to improve the delivery of complex cancer surgeries. We then explore three options (among many) that could be used to improve the delivery of these cancer surgeries. We conclude with a discussion about the potential barriers and facilitators for moving forward.



Surgical interventions for these cancers are among the most demanding of all surgical procedures, and serious complications often occur.

The problem:

Improving the delivery of these surgeries is challenging

>> Improving the delivery of complex cancer surgeries is challenging because many factors affecting patients, caregivers, healthcare providers and the health system must be considered.

In this section, we highlight three sets of factors that contribute to the problem and that require careful consideration:

1. cancer represents a significant burden on individuals, the health system and society;
2. patients in need of complex cancer surgeries and their families face a difficult journey; and
3. the health system is not currently designed to provide optimal care for such patients.

Glossary (part 2)

Cancer

Refers to “more than 200 diseases in which abnormal cells grow without control. Cancer cells can invade and destroy healthy tissues. Most cancers can also spread to other parts of the body through the blood or lymphatic system.” (1) The main types of cancer are carcinoma (i.e., cancer starting in the skin or organ lining), sarcoma (i.e., cancer that develops from bones or muscles), leukemia (cancer of the body’s blood-forming tissues) and lymphoma (cancer of the lymphatic system).(1)

Mortality rate

Refers to the percentage of people who die from a particular cause.

Survival rate

Refers to the percentage of people who are alive for a given period of time (in this case, after a cancer diagnosis).

These factors are described in more detail below.

Cancer represents a significant burden on individuals, the health system and society

Cancer is the leading cause of premature death in Canada, and is the fourth leading cause of hospital admissions. It is estimated that a total of 187,600 Canadians were diagnosed with cancer in 2013, including 25,000 with lung cancer, 4,700 with pancreatic cancer, 2,600 with ovarian cancer, 2,100 with hepato-biliary cancer, and 2,000 with esophagus cancer.(8)

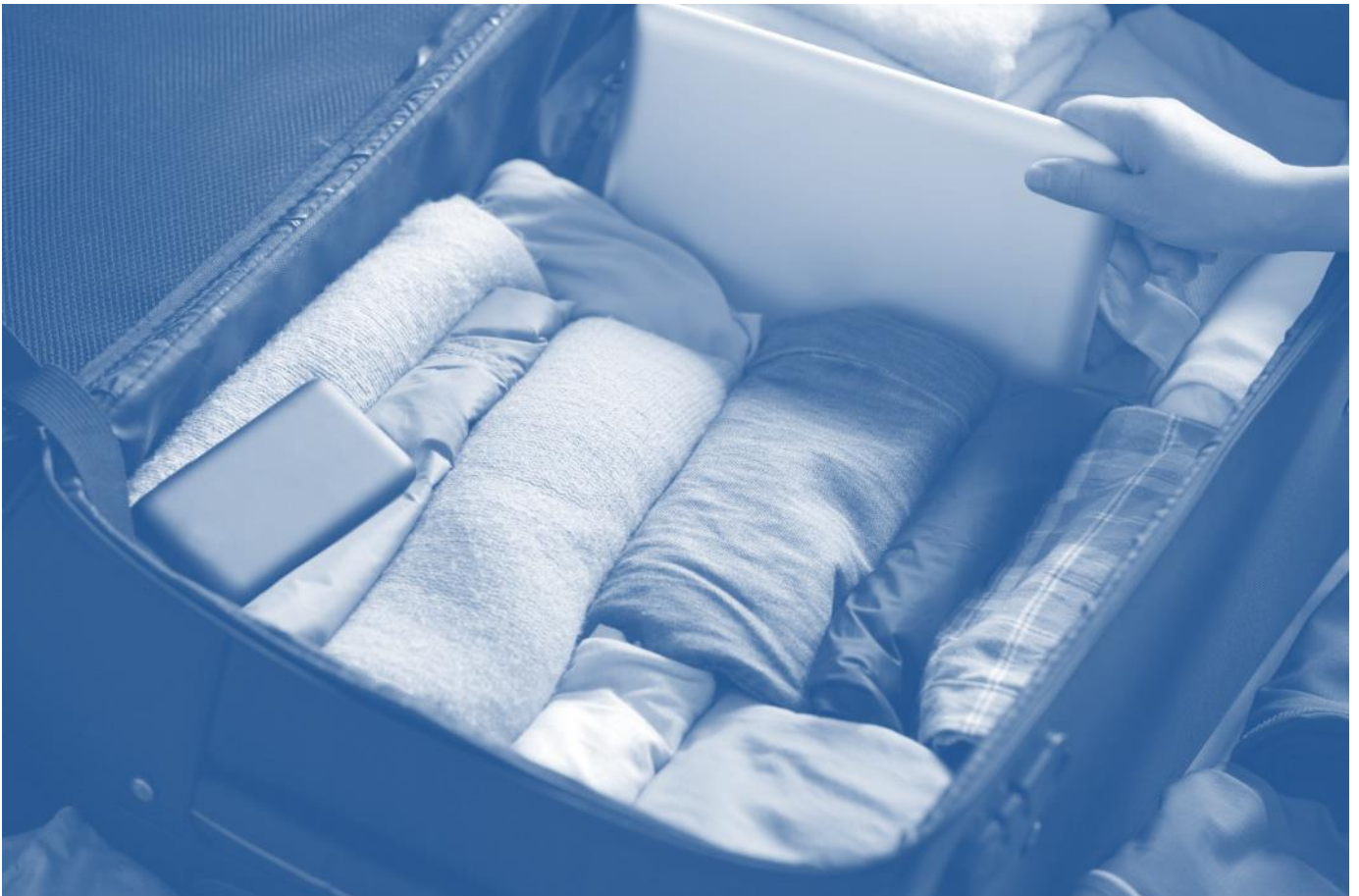
With population growth and aging, the number of new cases of cancer in Canada is expected to increase. Since surgery is the primary treatment option for certain high-risk cancers, the costs associated with cancer surgeries are expected to rise over time. An Ontario study examined the post-diagnosis cost of treating patients who had one of 21 types of cancer and who survived beyond one year. The study revealed that the highest average cost per patient treated was for esophagus cancer (\$50,620). The average cost per individual treated for the four other types of cancers examined in this brief were also amongst the highest: \$41,846 for pancreatic cancer; \$32,717 for liver cancer; \$29,878 for lung cancer; and \$29,640 for ovarian cancer. These costs included expenditures associated with inpatient hospital admissions, physician services, chemotherapy, radiotherapy, outpatient drugs, same-day surgery, diagnostic tests, long-term care, continuing care, and home care.(9)

Patients in need of complex cancer surgeries and their families face a difficult journey

Patients diagnosed with these cancers face a difficult journey from the moment they first experience cancer symptoms. For individuals diagnosed at an early stage with any of the five types of cancer examined in this brief, major surgery has the greatest chance to provide a cure, although cure rates are

generally low. Early on, patients and families will have to make complex and potentially life-changing decisions (e.g., undergoing surgery or not, undergoing surgery at a local low-volume hospital or travelling to a high-volume hospital with the hope of better outcomes). However, information to guide such decisions is often not readily available (e.g., the number of surgical procedures performed by surgeons/hospitals and post-operative surgical mortality data).

The long-term outlook for those diagnosed with any of these five types of cancer is generally quite intimidating, since a significant number of patients will die despite curative-intent surgery. Surgeries for these cancers are among the most demanding undertaken by surgeons. Other healthcare providers face significant challenges in caring for these patients too, as serious complications often occur during and after the surgeries.(10)



We describe below the journey of a cancer patient after being diagnosed with esophagus cancer, and how this journey varies based on her province of residence (Ontario in Box 1, Alberta in Box 2, or P.E.I. in Box 3).

Box 1: The journey of an Ontario patient diagnosed with esophagus cancer

(based on the work of Finley et al. 2014)

- Helen is a 67-year-old retiree from Niagara Falls. She lives with her partner who is still in the workforce. She was recently diagnosed with early stage esophagus cancer and decided to undergo major surgery, as well as pre-operative chemotherapy and radiation therapy.
- Helen's cancer treatment will be provided in two different locations:
 - Juravinski Cancer Centre (JCC) for chemotherapy and radiation therapy (71 kilometres or 45 minutes from home); and
 - St. Joseph's Healthcare Hamilton (SJHH) for surgery (74 kilometres or 50 minutes from home).
- If there are no complications, her treatment will require at least 66 visits:
 - consultations with medical oncologist, radio oncologist and surgeon for multidisciplinary plan (one visit to JCC);
 - radiology or ancillary service visits (e.g., PET scan, CT scan, endoscopy, echography, central catheter to ensure intravenous access that can be used for a prolonged period of time) (five visits to SJHH);
 - simulation for radiation therapy (one visit to JCC);
 - daily radiation treatments (25 visits to JCC);
 - chemotherapy (four visits to JCC);
 - radiation oncology (six visits to JCC);
 - medical oncology (including post-operative consultations with the assumption of no need for additional treatments) and dietitian (eight visits to JCC);
 - pre-operative surgeon visits (two visits to SJHH);
 - pre-admission assessment unit visit (one visit to SJHH);
 - surgery with two-week hospitalization (12 visits by informal/family caregiver to SJHH); and
 - post-operative surgeon visit (one visit to SJHH).
- She will also require at least six months of weekly home care services coordinated by her Community Care Access Centre.

Box 2: The journey of an Alberta patient diagnosed with esophagus cancer

(based on the work of Finley et al. 2014)

- Helen is a 67-year-old retiree from Fort McMurray. She lives with her partner who is still in the workforce. She was recently diagnosed with early stage esophagus cancer and decided to undergo major surgery, as well as pre-operative chemotherapy and radiation therapy.
- Helen's cancer treatment will be provided in Edmonton, which is 380 kilometres away from Fort McMurray. This means either a five-hour drive or a \$350 return flight (if she books in advance and is flexible about the day of the week and time of day when she flies).
- If there are no complications, her treatment will require at least 56 visits:
 - consultations with medical oncologist, radio oncologist and surgeon for multidisciplinary plan (one visit);
 - radiology or ancillary service visits (e.g., PET scan, CT scan, endoscopy, echography, central catheter to ensure intravenous access that can be used for a prolonged period of time) (five visits);
 - simulation for radiation therapy (one visit);
 - daily radiation treatments (25 visits);
 - chemotherapy (four visits);
 - radiation oncology (six visits);
 - medical oncology (including post-operative consultations with the assumption of no need for additional treatments) and dietitian (eight visits);
 - pre-operative surgeon visits (two visits);
 - pre-admission assessment unit visit (one visit);
 - surgery with two week hospitalization (two visits by informal/family caregiver); and
 - post-operative surgeon visit (one visit).
- She will also require at least six months of weekly home care services.

Box 3: The journey of a P.E.I. patient diagnosed with esophagus cancer

(based on the work of Finley et al. 2014)

- Helen is a 67-year-old retiree from Cornwall. She lives with her partner who is still in the workforce. She was recently diagnosed with early stage esophagus cancer and decided to undergo major surgery, as well as pre-operative chemotherapy and radiation therapy.
- Helen's cancer treatment will be provided in Halifax, which is 300 kilometres away from Cornwall. This means a three-to-four hour drive.
- If there are no complications, her treatment will require at least 56 visits:
 - consultations with medical oncologist, radio oncologist and surgeon for multidisciplinary plan (one visit);
 - radiology or ancillary service visits (e.g., PET scan, CT scan, endoscopy, echography, central catheter to ensure intravenous access that can be used for a prolonged period of time) (five visits);
 - simulation for radiation therapy (one visit);
 - daily radiation treatments (25 visits);
 - chemotherapy (four visits);
 - radiation oncology (six visits);
 - medical oncology (including post-operative consultations with the assumption of no need for additional treatments) and dietitian (eight visits);
 - pre-operative surgeon visits (two visits);
 - pre-admission assessment unit visit (one visit);
 - surgery with two week hospitalization (two visits by informal/family caregiver); and
 - post-operative surgeon visit (one visit).
- She will also require at least six months of weekly home care services.

Table 1 provides an overview of these five types of cancer as reported in the literature. It should be noted that these statistics may vary depending on the types of surgical procedures, the stage of cancer, and various patient-related factors such as age, the presence of other diseases or conditions, and the hospital environments where the surgeries are performed (e.g., volume, surgeon specialty and patient's access to post-operative care).

Table 1. Overview of five complex cancer surgeries

	Esophagus cancer	Hepato-biliary cancer	Lung cancer	Ovarian cancer	Pancreatic cancer
New cases in Canada (2013 estimates) (8)	2,000	2,100	25,500	2,600	4,700
Median length of hospital stay in Canada (days) (2004-2012)	14	8	6	4	11
In-hospital mortality rates in Canada (%) (2004-2012)	6 (varying from 4 - 6)*	5 (varying from 1- 6)*	2 (varying from 1 - 7)*	1 (varying from 1 - 4)*	4 (varying from 1 - 4)*
Overall 1-5 year post-surgery survival rates (%)	17 - 64	34 – 47	5 - 44	24 - 51	11 – 44
Examples of complications after all such surgeries	<ul style="list-style-type: none"> • Reactions to anaesthesia • Excess bleeding (anemia) • Nausea/vomiting • Infections (wound, urinary tract) • Pneumonia • Cardiac events (heart attack, atrial fibrillation) 		<ul style="list-style-type: none"> • Renal failure • Pulmonary embolism • Injury to blood vessels • Paraplegia/hemiplegia/cerebral infarction • Organ damage • Haemorrhage • Urinary retention 		
Examples of complications unique to particular surgeries	<ul style="list-style-type: none"> • Leaks where stomach (or intestine) is connected to esophagus • Problems swallowing • Post-procedural respiratory disorders 	<ul style="list-style-type: none"> • Blood clots in the legs • Bile leaking from the liver • Jaundice • Liver failure 	<ul style="list-style-type: none"> • Respiratory Failure (pulmonary collapse) • Post-procedural pneumothorax • Post-procedural disorders of circulatory system • Fluid overload • Chest infections 	<ul style="list-style-type: none"> • Accidental damage to surrounding organs • Blood clots in the legs or pelvis • Post-operative intestinal obstruction 	<ul style="list-style-type: none"> • Leaks where bowel and the liver and pancreas are connected • Delayed stomach emptying • Fluid build-up in the abdomen • Problems with food absorption

* mortality rates vary for specific resection types for each organ cancer. For example, there are three main types of pancreatic resections each associated with a different mortality rate: 1) Whipple procedure (5.8%); 2) minimally invasive pancreatectomy (0.91%); and 3) open distal pancreatectomy (2.88%).

Glossary (part 3)

Informal/family caregiver

Refers to an individual who is providing unpaid and ongoing care or social support to a family member, neighbour or friend who is in need due to physical, cognitive or mental health conditions.(3)

Quality improvement

Refers to “a systematic approach to making changes that lead to better patient outcomes (health), stronger system performance (care) and enhanced professional development. It draws on the combined and continuous efforts of all stakeholders — healthcare professionals, patients and their families, researchers, planners and educators — to make better and sustained improvements.”(4)

Regionalization

Refers to the deliberate re-organization of cancer surgeries, so that services and structures are integrated at the regional level, and with the intent of improving the quality of care. The term ‘regionalization’ is often used interchangeably with centralization, consolidation or designation of cancer care (e.g., a designated cancer centre).(5)

As we can see from Table 1, there are wide variations in terms of the 30-day mortality rates and five-year survival rates after surgery for each type of cancer. While the long-term outlook for these patients is generally poor, it is important to stress that mortality rates have been declining and survival rates have been improving for these cancers over the years. These improvements are possibly due to a combination of factors including a better selection of patients who could benefit from surgery, improved surgical techniques, and improved care provided before, during and after surgery.(5)

The health system is not currently designed to provide optimal care for such patients

Improving the delivery of complex cancer surgeries in Canada is also challenging because of how the health system is currently designed. These challenges lie in how care is delivered, how it is paid for, and how it is regulated across the country.

Challenges related to how care is delivered

In terms of how care is delivered now, we can identify three key challenges. First, there are disparities in access to complex cancer surgeries across Canada. A report by the Canadian Institute for Health Information (CIHI) examined complex cancer surgeries in Canada for pancreatic and esophagus cancer.(10) The report revealed that, while most Canadians could receive surgery in their own region, those residing in rural areas were more likely than urban residents to have to travel outside of their region to receive surgical care (74% of rural residents versus 49% of urban residents in the case of pancreatic surgery, and 76% of rural residents versus 43% of urban residents in the case of esophagus surgery). In addition, cancer patients from Prince Edward Island, the Yukon, the Northwest Territories and Nunavut have to travel outside of their province/territory because such complex surgeries are not performed in local hospitals.(10)

The disparities in access to complex cancer surgeries may be partially explained by the fact that we live in a very large country, and large parts of the country have a very low population density. Such disparities in access can have important consequences. For example, being referred outside of a region to obtain surgical care can potentially delay treatment (e.g., different administrative rules in referral sites) and, if there are such delays, it can increase the likelihood of patients presenting with advanced cancer. In addition, some cancer patients may choose to stay at home and receive care locally if they know that the surgery will require them to travel away from home, which mean that they may not have access to the same treatment options with the same potential for curing their cancer. Alternatively, some patients may prefer to travel in the hope that the surgical care they will receive could lead to better outcomes. Nevertheless, having to travel outside a region to obtain surgical care can increase the financial and emotional burden of patients and their informal/family caregivers (e.g., increased costs for travel and accommodation, increased isolation, having to travel to a ‘big city’ out of province because you can’t access those services in your own community, and cultural and linguistic barriers). Lastly, such travel can also complicate the care patients receive following a surgery since the specialists who performed the surgery will not be located in the patient’s home region.(11)

A second challenge relates to the availability of expertise to conduct these complex cancer surgeries. In some provinces, these complex surgeries are being delivered in any hospital setting, without any restriction. There have been efforts to regionalize (or centralize) some of these complex cancer surgeries into high-volume centres (i.e., centres providing surgical care to many patients) in a few provinces. In some cases, this was done based on research evidence showing that higher volume, higher skilled and more experienced hospital environments, in general, experience fewer complications and fewer deaths associated with these surgeries either during or following the surgeries. However, the degree of regionalization varies across provinces and types of surgeries. For example, the report by CIHI revealed that 24% of hospitals in Ontario (eight of 34 hospitals) that performed pancreatic surgery were high-volume hospitals, but only 8% of hospitals in Quebec (three of 37 hospitals) that performed the same surgery were high-volume ones (see Table 2).(10) While some patients may undergo complex surgeries in high-volume hospitals where there is a concentration of expertise, other patients undergo the same surgeries in low-volume hospitals where health professionals and hospitals have less experience (see Table 3). Thus, some patients are not receiving the most optimal surgical care and may face higher risk of complications and mortality depending on where the surgery is performed and by which surgeon.

Table 2. Number of hospitals performing pancreatic surgery and esophagus surgery (for cancer and non-cancer indications) in 2009-2010 (10)

Province/territory	Pancreatic surgery		Esophagus surgery	
	Number of hospitals performing the surgery	Number of hospitals performing high volumes of the surgery	Number of hospitals performing the surgery	Number of hospitals performing high volumes of the surgery
British Columbia	13	2	17	4
Alberta	11	2	10	3
Saskatchewan	5	0	5	1
Manitoba	3	1	4	1
Ontario	34	8	39	8
Quebec	37	3	35	4
New Brunswick	6	0	4	0
Nova Scotia	2	1	3	1
Prince Edward Island	1	0	0	0
Newfoundland and Labrador	2	1	2	0
Yukon	0	0	0	0
Northwest Territories	0	0	0	0
Nunavut	0	0	0	0
Canada	114	18	119	22

Table 3. Number and percentage of cancer patients undergoing pancreatic surgery and esophagus surgery at high-volume hospitals from 2006 to 2010 (10)

Province/territory	Pancreatic cancer surgery		Esophagus cancer surgery	
	Number of patients	Number who received care in a high-volume hospital (%)	Number of patients	Number who received care in a high-volume hospital (%)
British Columbia	322	251 (78%)	378	337 (89%)
Alberta	238	210 (88%)	205	155 (76%)
Saskatchewan	51	*	107	15 (14%)
Manitoba	63	48 (76%)	95	80 (84%)
Ontario	870	688 (79%)	1,112	700 (63%)
Quebec	432	277 (64%)	338	43 (13%)
New Brunswick	31	*	59	*
Nova Scotia	76	67 (88%)	107	77 (72%)
Prince Edward Island	11	11 (100%)	9	*
Newfoundland and Labrador	32	19 (59%)	36	14 (39%)
Yukon	*	*	*	*
Northwest Territories	*	*	*	*
Nunavut	0	0	*	*
Canada	2,130	1,582 (74%)	2,449	1,432 (58%)

* Figures suppressed due to small numbers

A third challenge about how care is currently being delivered is that there is a lack of support for informal and family caregivers. Given the particularly difficult cancer journey (as illustrated by the examples in Boxes 1-3), patients undergoing these surgeries will need care and support from informal and family caregivers, such as:(12)

- providing emotional support;
- accompanying patients to medical appointments;
- reporting or managing side effects;
- giving medicines;
- keeping track of medicines, test results and papers;
- providing physical care (e.g., feeding, dressing and bathing);
- coordinating care;
- keeping family and friends informed; and
- making legal and financial arrangements.

In 2012, it was estimated that 8.1 million Canadians provided care to a family member or friend with a long-term health condition (most commonly cancer) or aging-related needs.(13) However, support for informal and family caregivers is often lacking and inconsistently available across the country. This includes:

- practical, social and emotional support;
- informational support (e.g., advice, guidance, suggestions or useful information to help them navigate a complex health system);
- respite care services and counselling; and
- financial support (e.g., governmental assistance programs to offset the loss of income, and the out-of-pocket expenses associated with travel and accommodation to obtain medical care, medication and homecare services).

This lack of support can have a negative impact on the physical and mental health of informal and family caregivers, on their personal and professional lives, and on the quality of care that they provide. As reported by a forum of Canada's leading cancer, mental health and caregiver groups: "Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming 'collateral casualties' of the illness, compromises their health, reduces the efficacy of the help they can provide to their relatives, and increases costs to the health and social service systems."(14)

Challenges related to how care is paid for

Improving the delivery of complex cancer surgeries can also be challenging because of how care is paid for. For example, how hospitals are funded can influence the delivery, the quality and volume of care provided.⁽¹⁵⁾ Currently, the predominant funding model for Canadian hospitals is a global budget, which is a fixed (or global) amount of funding that is distributed to each hospital and that is used to pay for all hospital-based services for a fixed period of time (usually one year). In many provinces, the global budget of a hospital is based on historical spending, politics and inflation instead of the type of care and the volume of care provided. There are some advantages to funding hospitals with a global budget as it provides predictability that can facilitate planning for hospitals, and can help governments control healthcare spending. However, it has been shown that global budgets provide little incentive for hospitals to focus on innovation, increasing surgery volumes, improving access, coordinating care across facilities and sectors, or improving quality of care.⁽¹⁵⁾ Another downside is that hospitals in some provinces may be reluctant to treat specific patients who require complex cancer surgeries, since these patients may consume a significant portion of their global budgets, which leaves fewer funds for other needed services. That being said, some provinces are experimenting with alternative ways to fund hospitals that may influence what types of care hospitals choose to deliver and improve the quality of care delivered.

Challenges related to how care is regulated

We can identify at least three key challenges related to how care is regulated. First, colleges of physicians and surgeons regulate who can call themselves a ‘surgeon.’ However, in general, there is minimal regulation as to 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.

Second, most Canadian hospitals are regulated in terms of what institutions can call themselves a ‘hospital,’ but not which procedures they deliver or how frequently they need to deliver them to ensure that quality remains high. In addition, most hospitals are regulated by legislation that establishes an appeal process for doctors who feel aggrieved by decisions made by hospital boards (e.g., allocations of operating room time and types of procedures delivered in a hospital). Such appeal processes can make it difficult to bring about change in where different types of surgical procedures can be delivered.

Third, there is a lack of coordinated efforts among all stakeholders to improve complex cancer surgeries across the country. For instance, there is no regulated set of quality indicators at the pan-Canadian level regarding these surgeries.⁽¹⁰⁾

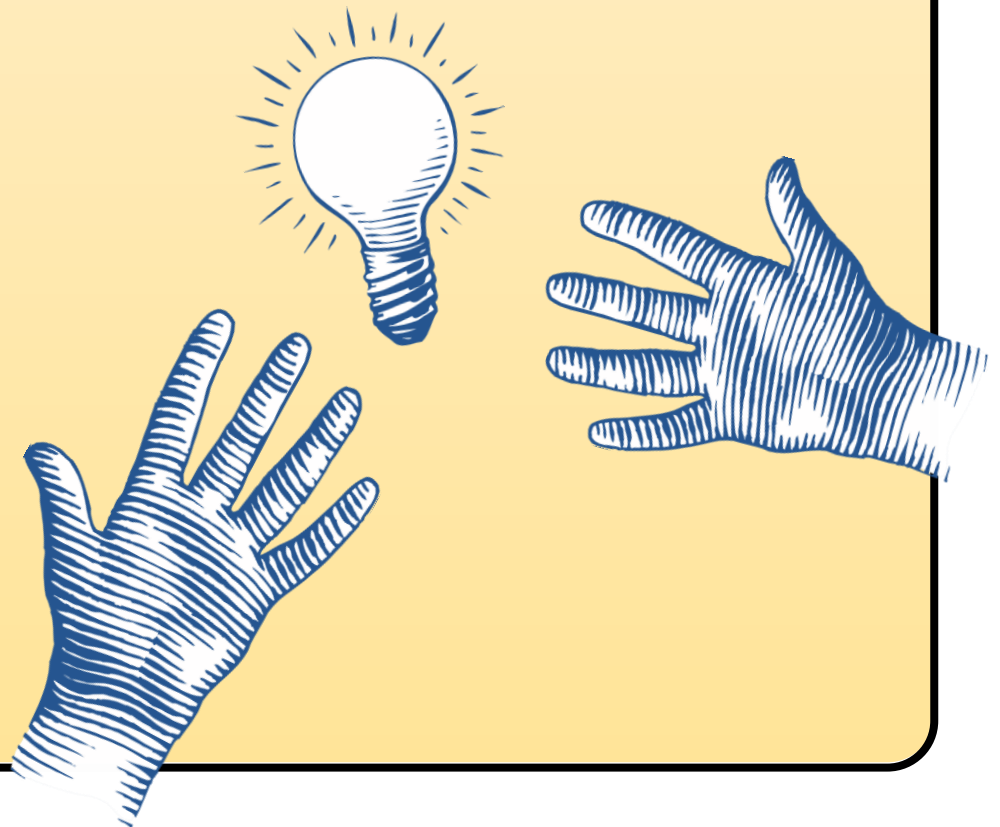
We provide below, for illustrative purposes, a brief description of how the cancer system is organized in Ontario (Box 4), Alberta (Box 5) and P.E.I. and Nova Scotia (Box 6).

Box 4: Cancer system in Ontario

- In 1997, the provincial government formally launched Cancer Care Ontario, a government agency with the mandate to support continuous improvement in cancer services, and to ensure that cancer services are well planned and coordinated across the province.(2)
- There have been active efforts to regionalize complex cancer surgeries in Ontario:
 - Efforts to regionalize surgeries for pancreatic cancer started in 1999; and
 - Cancer Care Ontario developed guidelines about minimum volume standards for surgical sites and for surgeons: thoracic (esophagus and lung) cancer guidelines (2003), liver cancer guidelines (2003), and guidelines for ovarian cancer (in development since 2010).
- The cancer system is organized into Regional Cancer Programs corresponding to the province's 14 Local Health Integration Networks. Regional Cancer Programs are networks of healthcare providers (including regional cancer centres) and stakeholders (including patient groups involved in providing cancer prevention, screening, and diagnostic and treatment services in each region).(2)
- Cancer Care Ontario has established a quality framework that includes eight dimensions of quality (i.e., safe, effective, accessible, timely, responsive, patient-centred, efficient and equitable). Each of these dimensions is integrated in the development of initiatives to improve the cancer system in Ontario.(2)
- The Ontario Cancer Plan 2011-2015 states that “as treatments for cancers become more complex and specialized, we become more directly involved to ensure patients have access to appropriate care. These treatments require centralized planning and delivery.”(7)

Box 5: Cancer system in Alberta

- From 1994-2008, the health system in Alberta was organized into health regions. However, the province established a single provincial authority in 2008, called Alberta Health Services.
- CancerControl Alberta is the agency in charge of organizing cancer care in the province. CancerControl Alberta is a department within Alberta Health Services.
- There has been a passive form of regionalization for some surgical procedures over the years. The transition took place in large part because surgeons preferred to provide care in a team setting rather than on their own.
- The Cancer Strategic Clinical Network (SCN) brings together stakeholders from across the province to lead and support evidence-informed improvements and bring innovation to health care. The SCN has a number of initiatives underway to improve the health of Albertans and the care they receive, including:
 - supporting the early diagnosis and management of lung cancer; and
 - establishing province-wide central access for referral and triage for cancer.



Box 6: Cancer system in P.E.I. and Nova Scotia

- Prince Edward Island
 - The health system in Prince Edward Island is operated by Health PEI.
 - The Prince Edward Island Cancer Treatment Centre, located in Queen Elizabeth Hospital, is the major cancer care centre on the island. The treatment centre has one satellite location, located in Prince County Hospital.
 - Complex cancer surgeries are largely done in neighbouring provinces (most often Nova Scotia).
- Nova Scotia
 - The health system in Nova Scotia is currently organized into nine district health authorities and the IWK Health Centre. Each district health authority is responsible for the planning and delivery of healthcare services, both to local residents and to the residents of neighbouring Maritime provinces. In April 2015, the health system will be reorganized into two health authorities: one for the province and one for the IWK.
 - The provincial government's Department of Health and Wellness funds the nine authorities and sets the overall direction for the health system.
 - The major cancer centres in the province are the Nova Scotia Cancer Centre in Halifax and the Cape Breton Cancer Center in Sydney.
 - Each cancer centre operates satellite clinics at other hospitals so patients can receive consultations regarding their cancer closer to home.



We have selected three options (among many) for which we are seeking public input.

Options to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for improving the delivery of complex cancer surgeries in Canada.

Improving the delivery of care can be achieved in various ways. For example, we can implement quality-improvement initiatives focusing on measuring and improving the process of care (e.g., what individual surgeons or nurses do). In addition, we can improve the structure of the health system (e.g., how care is organized, how it is paid for, and how it is regulated).(2)

Many options could be selected as a starting point for discussion. We have selected three (among many) for which we are seeking public input:

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; and
3. regionalize complex cancer surgeries into designated surgical centres of excellence.

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions.

In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all the studies addressing a clearly formulated question. The authors use systematic and explicit methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

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

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



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 first option aims to encourage 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 high-risk and resource-intensive cancer surgeries. This option assumes that healthcare providers and hospital managers will adopt quality-improvement initiatives without the need for supports, incentives or directives to change behaviour, and without the need for regulatory changes about where (and by whom) these cancer surgeries can be provided. In sum, this option proposes a locally driven approach to improve the delivery of cancer surgeries.

There are a large number of quality-improvement strategies that can be driven locally by healthcare providers and hospital managers, for example:

- promoting audit and feedback (i.e., collecting information from healthcare providers or from hospitals and then providing feedback to them in order to help them improve their practices);
- promoting the use of clinical decision support systems (i.e., a formal manual or a computerized system that prompts, reminds and cautions healthcare providers to do, or not do, certain things under specific clinical circumstances);
- promoting continuing medical education (i.e., educational activities that help those in the medical field maintain their competencies and learn about new and developing areas of their field); and
- implementing enhanced recovery programs (i.e., a care pathway designed to speed up recovery for patients who have had major surgeries).

We found evidence from high-quality systematic reviews about the four types of interventions, whether or not they were driven locally. More specifically:

- audit and feedback generally leads to small but potentially important improvements in professional practice, is more effective when baseline performance is low, and when the feedback comes from a supervisor or colleague, is provided more than once, is delivered in both verbal and written formats, and includes both explicit targets and an action plan.(16)
- clinical decision support systems are effective for improving the process of care in various settings, but there is a lack of evidence that they can improve clinical, economic, workload and efficiency outcomes.(17)
- continuing medical education can improve professional practice and healthcare outcomes for the patients, but the effect is most likely to be small and similar to other types of

interventions like audit and feedback, and educational meetings alone are not likely to be effective for changing complex behaviours.(18)

- enhanced recovery programs are effective in reducing length of hospital stay and overall complication rates across surgical specialties.(19)

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

The second option aims to implement province-wide* quality-improvement initiatives to improve the delivery of complex cancer surgeries. Like the first option, this option is not intended to change where and by whom these cancer surgeries are being provided. However, in contrast to the first option, this option proposes a top-down approach to quality improvement and assumes that healthcare providers and hospital managers can achieve significant improvements, but that they need appropriate support, incentives and directives to do this.

These province-wide quality-improvement initiatives could take different forms, for example:

- developing provincial guidelines and standards for these cancer surgeries (e.g., regarding the specialization of surgeons providing care to cancer patients, minimum hospital volumes, and the use of multidisciplinary teams to coordinate care for them);
- implementing pay-for-performance for hospitals (i.e., a funding system for hospitals where they are rewarded for achieving improvements on specific quality indicators and for specific diseases);
- developing or expanding supports for patients and families (e.g., practical, social, emotional, informational and financial supports); and
- establishing requirements for reporting to the public about quality indicators and other performance measures (e.g., each hospital or surgeon being asked to report publicly the number of surgical procedures performed and their post-operative surgical mortality data).

We found a recent and high-quality review revealing that practice guidelines (i.e., documents with the aim of guiding decisions and criteria regarding diagnosis, management and treatment in specific areas of healthcare) were effective in improving the quality of care. This review also found that the dissemination of practice guidelines can be effective in reducing regional variations in the use of surgery.(20)

* For small provinces, province-wide should be taken to mean across the small province or across both the small province and a neighbouring larger province to which referrals are frequently made.

We found one overview of systematic reviews examining pay-for-performance. The authors concluded that a pay-for-performance system could be an effective quality-improvement strategy, but the research evidence is not yet convincing. In addition, there is some evidence that pay-for-performance may have unintended consequences, such as encouraging hospitals and healthcare providers not to accept sicker patients because doing so could negatively affect their overall performance score.(21)

We found a recent and medium-quality review examining psychological and social interventions to improve the quality of life of caregivers for cancer patients. The review revealed that interventions to improve problem-solving and communication skills may ease the burden associated with patient care and improve the caregiver's overall quality of life. However, the review found little evidence about other types of interventions to improve the caregiving experience, or the differences in caregiver experiences with different types of cancer.(22)

We found three reviews, two medium-quality and one high-quality, revealing the following benefits of making public information about the performance of hospitals and healthcare providers:

- quality measures are likely to improve over time;(23)
- development of other quality-improvement strategies is stimulated;(24) and
- there is a small but increasing impact on decisions made by patients.(25)

Three systematic reviews (one of medium-quality and two of high-quality) found inconsistent or limited evidence about the effectiveness of public reporting in improving the following:

- patient, professional and organizational behaviours;(23;26)
- safety;(24)
- patient-centred care;(24;25)
- access to care;(23;27) and
- mortality rates.(23)

An older and low-quality review exploring the evidence about making performance data publicly available revealed that, while hospitals may be responsive to publicly reported information, consumers and healthcare providers rarely search out this type of information and may not understand or trust it.(25)

Lastly, a recent and medium-quality review found that both pay-for-performance and public reporting may widen racial disparities in healthcare (through 'cherry-picking patients' who may help healthcare providers and hospitals score well, or avoiding those who may cause them to score poorly, or who may be racial minorities, in order to make their statistics look better).(27)

These findings suggest that we should be mindful about the potential implications of such quality-improvement initiatives and the possible risk of widening disparities for patients with complex healthcare needs.

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

The third option aims to regionalize 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.

We found only two relevant systematic reviews examining specifically the regionalization of cancer surgeries. The first one is a recent and high-quality systematic review examining the centralization of services for gynecological cancer. The review found that centralization can prolong the lives of women with gynecological cancer, and in particular ovarian cancer.(28)

The second is an older and medium-quality review examining the effectiveness of regional collaborations as a quality-improvement strategy in surgery.(29) The review found that regional collaborations can improve processes of care and clinical outcomes (e.g., reducing mortality rates, lower duration of postoperative intubations, and fewer surgical-site infections). The review revealed that motivations for initiating these regional collaborations were often in response to external demands for performance data. The review also identified success factors for regional collaborations, such as:

- the establishment of trust among health professionals and health institutions;
- the availability of accurate, complete, relevant data;
- clinical leadership;
- institutional commitment; and
- system supports for quality management (e.g., infrastructure and processes).

There is also a large body of research evidence showing a positive association between hospital or surgeon volume and post-operative outcomes for various types of cancer.(30) This research evidence has prompted various researchers and policymakers to push for the regionalization of

complex cancer surgeries into ‘centres of excellence.’⁽⁵⁾ They argued that regionalization could achieve the following benefits:⁽⁵⁾

- improvements in short-term and long-term survival;
- lower mortality rates in hospital and at 30 and 90 days after discharge from hospital;
- better access to specialist surgeons;
- better access to diagnostic techniques;
- availability of multidisciplinary staff for perioperative and post-operative care;
- efficient sharing of standards;
- better links between primary care and community organizations;
- collecting reliable performance data; and
- greater support for research and innovation (e.g., may be easier to conduct clinical trials).

However, it is important to note that the regionalization of complex cancer surgeries into high-volume hospitals may not be an automatic win. For example, a study examining the regionalization of pancreatic cancer surgeries revealed that regionalization was associated with a lower mortality rate during and after surgery in Ontario, but not in Quebec.⁽³¹⁾

In addition, the idea of regionalizing complex cancer surgeries is not without criticism. Regionalization can have unintended consequences for patients, caregivers, healthcare providers and the health system more broadly. For example, regionalization means that complex cancer surgeries will be moved to high-volume hospitals in urban centres. Thus, rural and remote patients will increasingly face access barriers (e.g., increased travel time and associated inconvenience). This could also increase their likelihood of patients presenting with advanced cancer due to the delays of transferring their cases from a local hospital to a high-volume hospital. It could create challenges in terms of continuity of care when they go back home after their surgery. Regionalization could also result in smaller and local hospitals losing expertise to high-volume hospitals (or make it more difficult for them to recruit and retain surgeons and physicians). It may also threaten their financial stability by transferring some surgical procedures to high-volume hospitals.

Summarizing what we know about the three options

In the following table we summarize what we know about each of the three options.

<p>Option 1— Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided</p>
<p>What is known about option 1</p> <ul style="list-style-type: none"> • Audit and feedback (i.e., collecting data about performance and feeding it back to healthcare providers) <ul style="list-style-type: none"> - Generally leads to small but potentially important improvements in professional practice - Effectiveness depends on the initial level of performance and how the feedback is provided • Clinical decision support systems (i.e., computer software that helps doctors make better decisions): <ul style="list-style-type: none"> - Effective at improving the process of care in various settings - Lack of evidence that they can improve clinical, economic, workload and efficiency outcomes • Continuing medical education <ul style="list-style-type: none"> - Effective at improving professional practice and patient outcomes - Effect is most likely to be small and similar to other types of interventions like audit and feedback - Educational meetings alone are not likely to be effective for changing complex behaviours • Enhanced recovery programs <ul style="list-style-type: none"> - Effective in reducing length of hospital stay and overall complication rates across surgical specialties
<p>Option 2— Implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided</p>
<p>What is known about option 2</p> <ul style="list-style-type: none"> • Potentially effective provincially-driven quality-improvement strategies: <ul style="list-style-type: none"> - practice guidelines (may reduce regional variation in the use of surgery);(20) - interventions targeting problem-solving and communication skills of cancer caregivers;(22) and - publicly reporting about quality indicators and other performance measures.(23-25) • The research evidence regarding the effectiveness of pay-for-performance as a quality-improvement strategy is not convincing.(21) • Pay-for-performance and public reporting may widen racial disparities in healthcare (through ‘cherry-picking patients’ who may help physicians and hospitals score well, or avoiding those who may cause them to score poorly).(27) • While hospitals may be responsive to publicly reported information, patients and healthcare providers rarely search out this type of information and do not understand or trust it.(25)

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

What is known about option 3

- Centralization can prolong the lives of women with gynecological cancer, and in particular ovarian cancer.(28)
- Regional collaboration is a promising tool for quality improvement in surgery.(29)
- There is a positive association between hospital or surgeon volume and post-operative outcomes for various types of cancer.(30)
- Regionalization could have the following benefits:(5)
 - improvements in short-term and long-term survival;
 - lower mortality rates in-hospital and at 30 and 90 days;
 - better access to specialist surgeons;
 - better access to diagnostic techniques;
 - availability of multidisciplinary staffs for perioperative and post-operative care;
 - efficient sharing of standards;
 - better links between primary care and community organizations;
 - capture of reliable performance data; and
 - support for research and innovation.
- Regionalization could have the following unintended consequences:(5)
 - increase patients' travel distance and associated inconvenience;
 - likelihood of presenting with advanced cancer;
 - problems in continuity of care after surgeries;
 - loss of local services;
 - loss of expertise in local hospitals; and
 - loss of revenues for local hospitals.



Implementation considerations

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

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

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

Option 1 – Encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided	
Barriers	Windows of opportunity
<ul style="list-style-type: none"> Healthcare providers and managers may not buy into quality-improvement initiatives without tangible supports, incentives or directives. Surgeons working alone in small- or medium-size hospitals may be reluctant to engage in such quality-improvement initiatives by themselves. Data and data management expertise may not be present at the local level. Educational/training opportunities may be lacking to support local quality-improvement initiatives. 	<ul style="list-style-type: none"> The difficult fiscal situation (i.e., large deficit and debt and limited economic growth) can be conducive to embracing new ways of doing things. The sustained focus on wait-times management and (more recently) on quality improvement can be conducive to embracing new ways of doing things.

Improving the Delivery of Complex Cancer Surgeries in Canada

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

Barriers	Windows of opportunity
<ul style="list-style-type: none"> Healthcare providers and managers may not buy into top-down quality-improvement initiatives without tangible incentives or directives, especially if they are not adapted to local needs. It may be challenging to develop and implement quality standards that would be relevant across all regions. Healthcare providers and managers may not be receptive if they have not been actively involved in developing the province-wide guidelines and standards. Healthcare providers may perceive such province-wide guidelines and standards as a threat to their professional autonomy. There is a sense of territoriality (i.e., the need to protect someone's turf) among hospitals and healthcare providers that can influence whether and how services are reformed/provided. 	<ul style="list-style-type: none"> The difficult fiscal situation (i.e., large deficit and debt and limited economic growth) can be conducive to embracing new ways of doing things. The sustained focus on wait-times management and (more recently) on quality improvement can be conducive to embracing new ways of doing things. Some healthcare providers and managers are increasingly used to province-wide quality improvement initiatives (e.g., the quality framework by Cancer Care Ontario). Various provincial and national organizations are calling for more rigorous standards in surgery residency programs (e.g., minimum procedure volumes and stricter requirements for credentials). The American College of Surgeons National Surgical Quality Improvement Program is being implemented in various sites across Canada to evaluate patient outcomes and quality indicators, make comparisons across sites, and set targets for improvement.

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

Barriers	Windows of opportunity
<ul style="list-style-type: none"> Citizens/patients may resist the loss of skills and services in their local hospitals. Hospitals and regional health authorities may resist a top-down approach to change structures. There is a sense of territoriality (i.e., the need to protect someone's turf) among hospitals and healthcare providers that can influence whether and how services are reformed/provided. Policymakers may not be able to make the type of long-term commitments needed to encourage the necessary infrastructure investments. 	<ul style="list-style-type: none"> The sustained focus on wait-times management and (more recently) on quality improvement can be conducive to embracing new ways of doing things. Some provinces have already regionalized some surgical procedures and other types of care (e.g., cancer centres providing chemotherapy and radiation therapy, centres providing cardiac surgeries).

Questions for the citizen panels

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

This brief was prepared to stimulate discussion during three citizen panels. The views, experiences and knowledge of cancer patients and informal/family caregivers can make a significant contribution to finding viable, patient-centred solutions to the problem.

More specifically, the panels will provide an opportunity to explore the questions outlined in Box 7. Although we will be looking for common ground during these discussions, the goal of the panels is not to reach consensus, but to gather a range of perspectives on this topic.

Box 7: Questions for the citizen panels

What are the most important challenges for patients and families facing complex cancer surgeries?

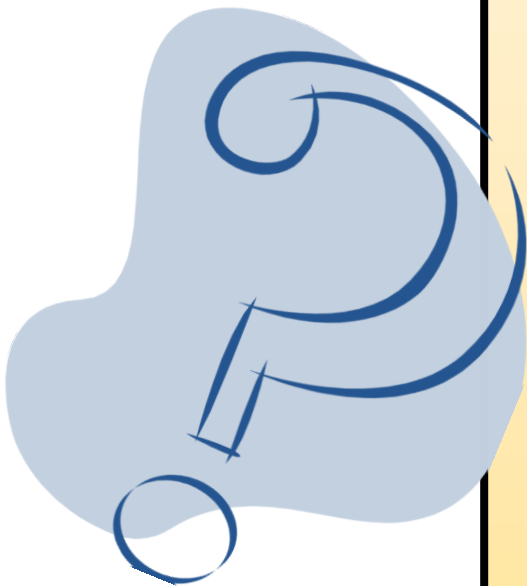
What should we value the most when improving the delivery of complex cancer surgeries (e.g., quality, access, equity)?

What are your views about the three proposed options?

>> **Option 1:** encourage the local adoption of quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided;

>> **Option 2:** implement province-wide quality-improvement initiatives to improve the delivery of complex cancer surgeries where they are now being provided; and

>> **Option 3:** regionalize complex cancer surgeries into designated surgical centres of excellence.



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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the citizen brief. One merit reviewer did have a connection to the funder, however, Forum staff had complete discretion in whether and how to act on the review.

Merit review

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

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