

PANEL SUMMARY

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

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18 OCTOBER 2014

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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 summary

On October 18, 2014, the McMaster Health Forum convened a citizen panel in Charlottetown (Prince Edward Island) 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.

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Summary of the panel

Panel participants discussed the shortfalls in the delivery of complex cancer surgeries in Canada and the causes of these shortfalls. In particular they focused on six challenges facing those living in the province of Prince Edward Island (P.E.I.), which gave them the opportunity to begin to articulate the values underlying their positions on this topic: 1) the long-term outlook for those in P.E.I. requiring complex cancer surgeries is poor; 2) making decisions in the midst of a cancer diagnosis is difficult; 3) out-of-province care processes are complex and not optimally coordinated; 4) patients rely heavily on support from informal and family caregivers; 5) inequities exist in access to formal system-level support; and 6) existing regulatory and financial arrangements in the Maritime provinces are not set up to optimize the delivery of complex cancer surgeries.

Participants reflected on three options (among many) for improving the delivery of complex cancer surgeries in Canada: 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); and regionalize complex cancer surgeries into designated surgical centres of excellence (option 3). Participants generally agreed that option 3 was already the status quo, and that efforts should focus on improvements to the current model. Three values-related themes emerged during the discussion about option 3, which include: 1) collaboration among all involved health-system stakeholders, as well as among local patient recovery supports; 2) fairness; and 3) excellent patient and family experience. Participants considered three additional features of option 3 that might improve the delivery of complex cancer surgeries for patients and families in P.E.I.: introducing telemedicine initiatives to reduce the burden associated with travelling for care; implementing post-care recovery centres in P.E.I., and increasing the role of ‘patient navigators.’

When turning to potential barriers and facilitators to moving forward, participants mostly emphasized the challenges associated with Canada’s federalist structure, nurturing a quality-improvement culture, and the lack of funding available to achieve desired changes in the system. Participants emphasized that efforts should be focused on improving existing processes of care within and outside of P.E.I., rather than making major structural changes to the existing system.



"[Most residents of P.E.I. are] blind to the way the system works [on the island]."

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 six challenges facing those living in the province of Prince Edward Island (P.E.I.), which gave them the opportunity to begin to articulate the values underlying their positions on this topic:

- the long-term outlook for those in P.E.I. requiring complex cancer surgeries is poor;
- making decisions in the midst of a cancer diagnosis is difficult;
- out-of-province care processes are complex and not optimally coordinated;
- patients rely heavily on support from informal and family caregivers;
- inequities exist in access to formal system-level support; and

- existing regulatory and financial arrangements in the Maritime provinces are not set up to optimize the delivery of complex cancer surgeries.

We review each of these challenges in turn below.

Long-term outlook for those in P.E.I. requiring complex cancer surgeries is poor

The first set of challenges raised by participants was related to the fact that people who are diagnosed with any of the five types of cancer discussed in the brief (i.e., esophagus cancer, hepato-biliary cancer, lung cancer, ovarian cancer and pancreatic cancer), or any other cancer that is in a later stage, have a poor long-term prognosis. Participants suggested that there are at least three factors that may contribute to, or exacerbate, this challenge in the province: 1) a lack of specialists; 2) a lack of proactive cancer screening; and 3) a lack of regulation for certain practices that may be linked to higher cancer risk in the province.

Several participants noted that there was a perceived lack of specialists in the province, particularly those equipped to identify and diagnose high-risk cancers at their earliest stages of development (which could help to improve the long-term outlook for patients who are diagnosed). Furthermore, several participants suggested

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.

that there might be a lack of awareness about, and knowledge of, cancer among family physicians (which some call general practitioners, or GPs) in the province. This situation reduces the chances that patients, who have early stages of cancer, will be identified by family physicians before it advances.

Some participants noted that, while public health measures in P.E.I. are generally considered adequate, more effort could be placed on proactive cancer-screening campaigns, whether integrated into family practice or as a broader public health initiative. Participants who highlighted this point suggested that these types of initiatives could be used to both raise awareness among the population to identify the early signs of cancer, and to work to identify those who have cancer in an earlier stage of progression.

A few participants also agreed that the government of P.E.I. does not do enough to regulate certain practices that may be linked to higher cancer risk in the province. In particular, the use of pesticides in agriculture was mentioned several times as an example of one of the perceived driving forces behind P.E.I.'s relatively high incidence of cancer. The impact of agricultural practices on water quality in the province was mentioned by participants as a key area in which the government has traditionally fallen short on regulatory action, and which needs more attention going forward.

Making decisions in the midst of a cancer diagnosis is difficult

Participants discussed the challenge of making an informed decision in the midst of a cancer diagnosis. They highlighted the emotional difficulties for patients and their informal/family caregivers in being diagnosed with cancer and having to make life-changing decisions regarding treatment options. Such decisions are made more challenging for patients and families in P.E.I. since complex cancer surgeries are provided outside of the province (e.g., Nova Scotia and New Brunswick). Thus, making a decision whether to undergo surgery was greatly influenced by the capacity of patients and families to face the significant emotional, financial and practical challenges associated with having to travel outside of the province to undergo lengthy and complex surgical procedures.

Out-of-province care processes are complex and not optimally coordinated

Participants discussed the challenges that emerge after a patient is diagnosed with cancer that requires complex surgery. In particular, participants focused on two major issues: 1) having to travel out-of-province to undergo complex cancer surgery can complicate the process of care, and may lead to care that is poorly coordinated; and 2) patients and families

face challenges in getting information related to how the system works, their likely care pathway, and the supports available to them.

Participants indicated that having to travel out-of-province may lead to care that is poorly coordinated. They discussed at length the complexity of referral processes, which may contribute to communication gaps between both healthcare providers and patients, as well as between healthcare providers and their colleagues in other provinces (e.g., between a physician in Charlottetown and a physician in Halifax, Nova Scotia or Moncton, New Brunswick). Participants also indicated that undergoing complex cancer surgery outside of the province might complicate post-operative care even further. For instance, they expressed concern that having to travel might raise additional health risks. Specifically, panel participants noted that the stress of having to travel long distances before and after surgery, sometimes in an ambulance, may result in a more challenging path to recovery, and could also increase the risk of post-operative complications.

In one particularly salient illustration of poor care coordination, a participant described their own experience of driving more than five hours each way to Moncton for a consultation with a specialist that lasted only 10 minutes and resulted in a follow-up consultation being scheduled weeks later without any further detail about where this additional consultation was situated within their broader plan of care. The participant described this as a frustrating encounter that also helped to highlight the communication gaps, as well as the uncertainty surrounding the care of cancer patients from P.E.I. travelling to receive care in other provinces.

Participants also emphasized that patients and families face challenges in getting information related to how the system works, their likely care pathway, and the supports available to them. One participant suggested early in the discussion that one of the core challenges in P.E.I. was navigating the system on the island, as well as understanding the ways in which care on the island extends to care provided elsewhere (e.g., Halifax and Moncton) when capacity doesn't exist in P.E.I. Another pointed out that most residents of P.E.I. were "blind to the way the system works [on the island]." While patients are given general information about where and when their next appointment will take place after initial cancer diagnosis, they aren't routinely provided with additional information about how their care can be practically supported in another province through services that exist there, such as discounted hotel rooms for cancer patients and their families. They are also provided with little information about the details of their care pathway after travelling to another province (e.g., how long their consultation will take, whether they will be required to stay overnight or be asked to come back at a later date), which makes planning around their medical needs challenging.

A few participants suspected that, given the requirement that they travel for care outside of P.E.I., they are subject to wait times that are longer than would be the case if they had specialists and capacity to deal with complex cancer surgeries within the province. In addition, the lack of information about how their care pathway will unfold makes their life more difficult since they don't know who to follow up with when nothing happens. Some participants also suspected that over-burdened specialists in other provinces might prefer to treat patients from their own province over those travelling from P.E.I.

Patients rely heavily on support from informal and family caregivers

One of the major issues raised by nearly all participants was the important role of informal caregivers - including family, friends or community volunteers - in caring for patients from P.E.I. who undergo complex cancer surgeries. Given the need to travel long distances for specialist care, and the lack of supports on the island for both pre- and post-operative care, several participants noted that it was the informal caregivers who played the most significant support role. These caregivers are often needed to assist in arranging travel to cities in

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?**
11
- **Where were they from?**
P.E.I. (10) and rural Nova Scotia (1)
- **How old were they?**
All participants were at least 45 years of age – 45-64 (70%) and 65 and older (30%)
- **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 (64%) and women (36%)
- **What was the educational level of participants?**
20% completed high school, 30% completed technical school, 20% completed community college, and 30% completed a bachelor's degree/post-graduate training or professional degree
- **What was the work status of participants?**
10% self-employed, 10% working part-time, 20% working full-time, 50% retired, and 10% disabled
- **What was the income level of participants?**
10% earned less than \$20,000, 30% between \$20,000 and \$40,000, 20% between \$40,000 and \$60,000, 20% between \$60,000 and \$80,000, 10% earned more than \$80,000, and 10% 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

the provinces where the surgery will be conducted (and often travel with the person as a support). They are also key sources of information for the patient, who may or may not be able to seek out important information about their pre- and post-operative care pathway while preparing for or recovering from a complex surgical procedure. Participants noted that there are no formalized mechanisms for this type of essential support in P.E.I., and that this should be viewed as a major gap in cancer care. Participants generally agreed that it is particularly troublesome for those who don't have friends or relatives available to help them navigate the system and to support them throughout the cancer journey, as well as for those who have family or friends who cannot afford to take extended periods away from work to support the patient's care.

Inequities exist in access to formal system-level support

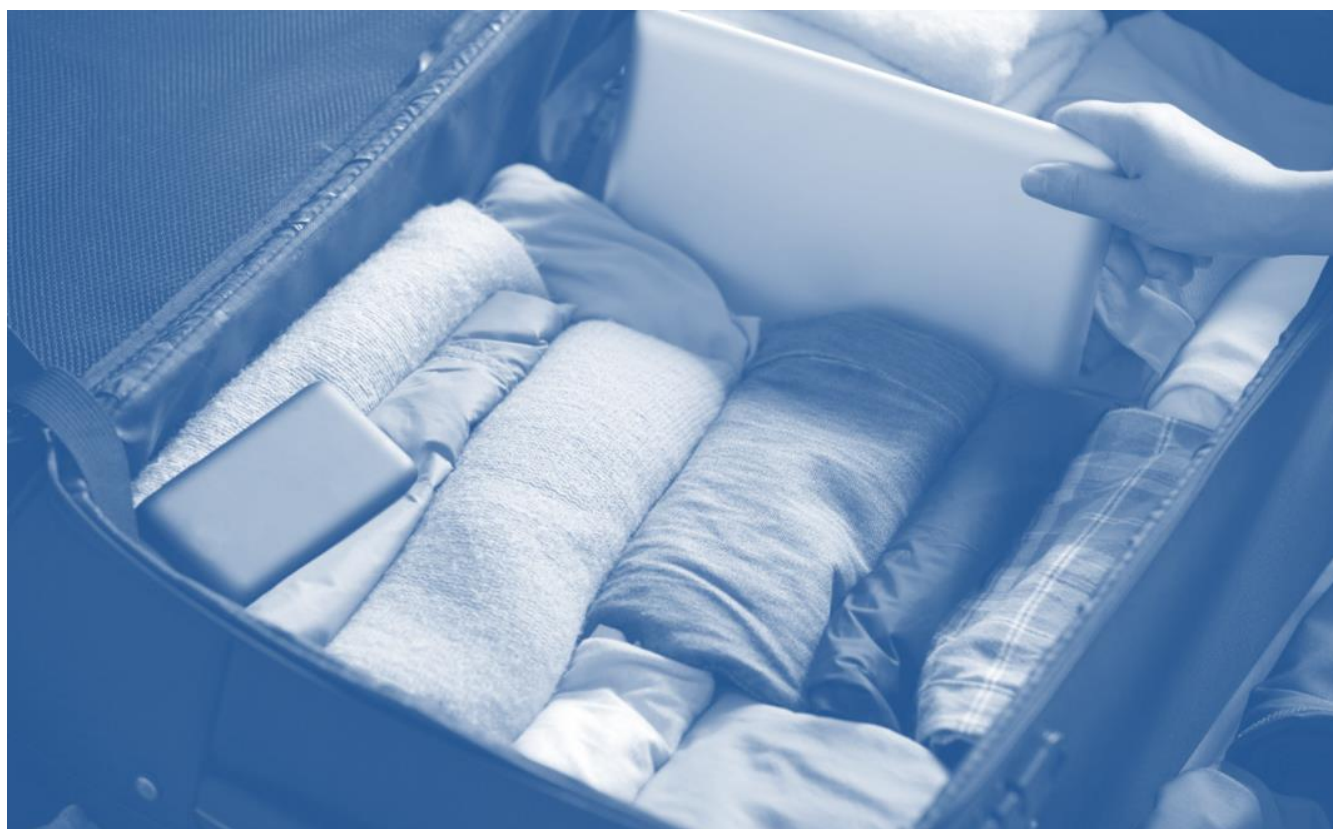
A related issue identified by participants is inequities in access to formal system-level support (e.g., transportation to and from hospital, post-operative homecare, and even benefits to caregivers). These inequities may be fuelled, in part, by disparities in supplementary health insurance coverage. In particular, families with coverage through their employers have increased access to the necessary support services, and may also have additional coverage that allows one or more informal caregivers to take time away from work to support someone who requires complex cancer surgery. Participants noted that many people do not have this kind of coverage, which creates significant financial challenges.

Existing regulatory and financial arrangements in the Maritime provinces are not set up to optimize the delivery of complex cancer surgeries

The issue of regulation and the ways in which healthcare providers and hospitals are paid also emerged as a challenge among participants. With respect to regulation, many participants noted that there were no explicit mechanisms in place to ensure accountability among healthcare providers or hospitals in P.E.I., or to ensure that the patients referred out of province receive the highest quality care possible in a timely way. On a related point, participants questioned whether healthcare providers or hospitals in P.E.I. are subject to ongoing performance measurement, and they indicated that quality indicators and related performance measures (including patient outcomes) could be used more effectively to ensure stronger linkages between providers in the province and the care that their patients receive outside of the province. The lack of these same types of accountability mechanisms

for healthcare providers and hospitals in other provinces was also highlighted as a challenge. With respect to funding, participants discussed the challenges with the current use of global budgets for hospitals performing complex cancer surgeries. Participants believed that this was a particularly challenging arrangement because it did not provide incentives for quality improvement. Furthermore, participants suggested that global hospital budgets may create disincentives for providers in other provinces to take on patients requiring complex cancer surgeries from P.E.I., as they tend to be more expensive to treat.

At several points during participants' discussion about the regulatory, accountability and financial arrangements that are challenging in both P.E.I. and in other Maritime provinces, many argued that one of the main issues underpinning these challenges was the complex political context. In particular, the dynamics of Canada's federalist structure of government and interprovincial politics were thought to complicate the situation, blurring lines of accountability and making it challenging to pursue changes to the status quo in a consolidated and coordinated way. Several participants noted that a regional strategy (i.e., a Maritimes strategy) for complex cancer surgery was needed to ensure that better regulation and accountabilities are in place and reflect on-the-ground realities. However, participants recognized that this was likely an extremely difficult avenue to pursue given the dynamics created by federalism.





"[All the] information must be given here, before we leave the island."

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

The three options were originally proposed in the pre-circulated citizen brief as potentially viable solutions to improve the delivery of complex cancer surgeries in Canada. However, participants highlighted the need to adapt them to reflect the particular circumstances of P.E.I. Participants noted that local and provincial quality-improvement initiatives in P.E.I. (options 1 and 2) would most likely need to focus on pre- and post-operative care, and on care coordination, since all complex cancer surgeries are delivered in other Maritime provinces. Participants also emphasized that the regionalization of complex cancer surgeries (option 3) reflects the current situation in P.E.I. Therefore, they indicated that the focus

should be on how to improve referral processes and coordination of the full spectrum of care for patients who require complex cancer surgeries that are delivered in surgical centres of excellence in other provinces. We review the views of participants about each option, along with the values-related themes that emerged, 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.

Given the particular circumstances of P.E.I., participants highlighted the need to distinguish between quality-improvement initiatives that address care provided in local hospitals, and the complex surgical procedures offered to residents of P.E.I. in New Brunswick and Nova Scotia. In particular, participants noted that quality-improvement initiatives focused on care provided in P.E.I. would most likely need to focus on pre- and post-operative care, and on care coordination.

Three values-related themes emerged during the discussion, which highlighted potential benefits of option 1:

- excellent patient and family experience (option 1 may ensure that care pathways are more attuned to the needs of patients and families who must travel outside the province to undergo surgery);
- continuously improving (option 1 may support continuous-improvement efforts for the pre- and post-operative care offered locally, the surgical care provided outside the province, and the care coordination undertaken across jurisdictions); and
- collaboration (option 1 relies on the collaboration of all local health-system stakeholders).

These discussions were found to be underpinned by participants' desire to ensure that care was patient- and family-centred, which would be achieved if the care pathways associated with travelling outside of the province for care were made less burdensome on patients and their families.

The discussions were also fuelled by the desire to continuously improve local (here taken to mean provincial) health systems. For instance, clinical decision support systems could be introduced into practices as a way to encourage better care for patients who are diagnosed with cancer and who require complex surgeries in another provinces (e.g., by creating opportunities for better communication between patients and providers and between providers in different provinces). As one participant said: “[All the] information must be given here, before we leave the island.”

In addition, a few participants appreciated that option 1 was nurturing more collaborative efforts from all local health-system stakeholders to improve the quality of care (e.g., through audit and feedback or continuing medical education), rather than trying to impose things on providers.

Despite the potential benefits of option 1, participants focused their discussion much more on the potential drawbacks of encouraging the local adoption of quality-improvement initiatives. When discussing the limitations of option 1, two values-related themes emerged:

- stewardship (option 1 may lack clear direction and incentives to implement these local quality-improvement initiatives); and
- sustainability (P.E.I. may lack the resources to implement option 1 and sustain locally-driven quality-improvement initiatives).

First, participants suggested that option 1 was lacking clear stewardship. Leaving the decision to engage in such quality-improvement initiatives up to healthcare providers and hospitals may not be ideal, especially since these initiatives aim to change their behaviours. Several participants also questioned whether there is a culture of quality improvement in place among the province’s healthcare providers and hospitals. In particular, some participants noted that there may not be the “desire to raise the quality bar” among them. Thus, participants emphasized the need for a local ‘champion’ who can push for change in P.E.I. Some participants noted that

Box 3: Key messages about option 1

- Most participants agreed that the challenges inherent and drawbacks associated with option 1 made it the least promising among the three considered.
- When discussing the limitations of option 1, two values-related themes emerged:
 - stewardship (may lack clear direction and incentives to implement these local quality-improvement initiatives); and
 - sustainability (may lack the resources to implement and sustain locally driven quality-improvement initiatives).

without a community leader to take reform ideas to the next stage, any decision would be viewed with skepticism, given the decision would be perceived as having been made without any inputs from the public.

Another potential limitation of option 1 is the lack of resources in P.E.I. to implement and sustain locally driven quality-improvement initiatives. Some participants expressed concerns that enhancing the care provided for patients from P.E.I. who require complex cancer surgery, whether by introducing quality standards for providers during pre-operative consultations, or introducing enhanced recovery programs, would require additional funding. It wasn't clear to participants where these additional funds would come from.

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 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, but that they need appropriate support, incentives and directives to do this. Examples of province-wide quality improvement initiatives may include: developing provincial guidelines and standards for these cancer surgeries; implementing pay-for-performance 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.

The discussion about option 2 focused again on the P.E.I. dynamic in light of the fact that many complex care surgeries are not provided in the province, let alone in multiple centres in the province. As such, the discussion gave some consideration to the ways in which care provided on the island (e.g., pre- and post-operative care) would be captured within this option.

Three values-related themes emerged during the discussion, which highlighted potential benefits of option 2:

- excellent patient and family experience (option 2 may ensure that care pathways are more attuned to the needs of patients and families who must travel outside the province to undergo surgery);

- continuously improving (option 2 may continuously improve the quality of the pre- and post-operative care offered locally, the surgical care provided outside the province, and the care coordination across jurisdictions); and
- stewardship (option 2 may provide the necessary direction and incentives to implement these local quality-improvement initiatives).

Given the similarities between options 1 and 2, much of this discussion was underpinned by similar values-related themes such as excellent patient and family experience, and continuously improving. Participants generally agreed that one of the major benefits of option 2 was that implementing quality-improvement initiatives, rather than simply encouraging them, was likely to gain more traction, particularly in the event that healthcare providers and hospitals do not want to volunteer to take part in them. They felt that greater provincial stewardship (or oversight) was essential to collectively ‘raise the bar’ and get results with respect to quality improvements. However, some participants noted that complex cancer surgeries for P.E.I. residents should realistically be considered as a Maritime issue - given the surgeries themselves are provided in Moncton or Halifax - and as such, the option may need to be considered as a Maritime-wide initiative

Box 4: Key messages about option 2

- Four values-related themes emerged during the discussion about option 2:
 - excellent patient and family experience (may ensure that care pathways are more attuned to the needs of patients and families who must travel outside the province to undergo surgery);
 - continuously improving (may continuously improve the quality of pre- and post-operative care offered locally, surgical care provided outside the province, and patient coordination across jurisdictions);
 - stewardship (may provide the necessary direction and incentives to implement these local quality-improvement initiatives); and
 - fairness (may have unintended consequences that would jeopardize equitable access to care for all residents of the Maritimes).
- Participants generally agreed that option 2 was preferred to option 1, although significant challenges still existed.

rather than a province-wide initiative. This would enable the implementation of quality-improvement initiatives across the full continuum of care related to complex cancer surgeries for residents of P.E.I., including diagnostics and pre-/post-operative care provided on the island, the surgeries provided in other provinces, and the coordination of the full care pathway that requires linkages across settings.

While these benefits were seen as promising among many participants, several downsides to option 2 were also discussed, during which the following values-related theme emerged:

- fairness (option 2 may have unintended consequences that would jeopardize equitable access to care for all residents of the Maritimes).

Some participants were concerned that implementing some of the proposed quality-improvement initiatives (more specifically pay-for-performance and public reporting) may have unintended consequences, as illustrated by research evidence. These participants worried that these initiatives may create incentives for ‘cream-skimming’ only the healthiest and easiest-to-treat patients (as a way for healthcare providers and hospitals to ensure they have the best chance at performing well on specific indicators). Participants considered this to be a major issue for patients from P.E.I., particularly if they were implemented to improve quality in the provinces where most cancer patients who required complex surgery travel for care (i.e., New Brunswick or Nova Scotia). Specifically, participants believed that if healthcare providers and hospitals were evaluated along specific indicators related to quality and patient outcomes, they might be less willing to treat patients from P.E.I., who may have to travel frequently to receive care, and as such may be at higher risk for poorer outcomes, particularly during the immediate post-operative period.

Participants pointed out a number of other downsides to option 2. For instance, several participants emphasized the relatively small size of P.E.I., which could make the idea of ‘province-wide’ quality-improvement initiatives irrelevant. This challenge was linked back to the earlier suggestion that a Maritime-wide, rather than province-wide, initiative was a more fruitful approach to implementing quality-improvement initiatives.

Finally, as was the case when option 1 was discussed, participants mentioned that the lack of a ‘quality-improvement culture’ in P.E.I. meant that gaining traction for this option was challenging. Most participants felt that changing the status quo was a significant challenge that made this option, or option 1, quite difficult to achieve.

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

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. The discussion of option 3 among participants extended beyond considering whether to move towards a more regionalized approach to complex cancer surgery, given that the residents of P.E.I. are already sent to regional ‘centres of excellence’ in Nova Scotia and New Brunswick for their care. Participants generally agreed that because of P.E.I.’s small population, regionalization was likely the only realistic option to pursue. As such, most of the discussion surrounding this option focused on how to improve referral processes and coordination of the full spectrum of care for patients who require complex cancer surgeries in other provinces.

Three values-related themes emerged during the discussion about option 3:

- collaboration (option 3 relies on collaboration among all health-system stakeholders in the Maritimes, as well as among local patient recovery supports);
- fairness (option 3 may have unintended consequences that would jeopardize equitable access to care for all residents of the Maritimes); and
- excellent patient and family experience (option 3 must include interventions to reduce the burden on patients who undergo complex cancer surgeries out of province and their families).

Participants emphasized that option 3 illustrated the need for collaboration among all health-system stakeholders in the Maritimes, as well as among local patient recovery supports. In particular, some participants suggested that one helpful approach could be to establish networks of providers and patients who could support each other in managing the process of care through better information sharing and communication. This would provide patients requiring complex cancer surgeries, who need to travel to an established ‘centre of excellence’ for their care, with information about and guidance on the decisions that need to be made by them and their informal/family caregivers at all stages of the care process.

This approach was also discussed as a way to help establish better channels of communication between providers from P.E.I. and those in other provinces, to ensure continuity between the full spectrum of care provided across the provinces. Participants also considered this enhanced communication and coordination as a mechanism to ensure that care was provided in the most appropriate way.

When considering option 3, participants also noted that this approach would require much more emphasis be placed on local support for patient recovery, and potentially, on recovery centres located in P.E.I. for patients who are discharged from ‘centres of excellence.’ One participant noted that “Halifax is sending us home anyways...”, and some participants viewed this as a result of the current model of global budget funding for hospitals performing complex cancer surgeries. Some participants noted that the current lack of local supports in place following discharge from hospital placed a significant burden on friends and family serving as unpaid caregivers providing post-operative care, and made taking care of a loved one emotionally, financially and practically challenging.

Participants noted several specific challenges with the current regionalized structure. First, as discussed earlier, within this structure participants feared an unwillingness among healthcare providers and hospitals in other provinces to take on cases from P.E.I. Second, to some participants, embracing the ‘centres of excellence’ approach meant that any existing capacity in P.E.I. would be pulled away and into other provinces to further strengthen these centres. Third, some participants highlighted that not all cancers are the same, meaning that regionalization across the full spectrum of care (pre-operative care to surgical care to post-operative care) should not be considered a ‘one-size fits all’ approach. Fourth, despite the need for better recovery support in P.E.I., participants clearly stated that funding for these types of programs is likely unavailable.

Participants considered three additional features of option 3 that might improve the delivery of complex cancer surgeries for patients and families in P.E.I.: 1) introducing telemedicine initiatives to reduce the burden associated with travelling for care; 2) implementing post-care recovery centres in P.E.I., and 3) increasing the role of ‘patient navigators.’ These features were also found to be underpinned by values related to improving patient experiences by being more patient- and family-centred, with a particular emphasis on achieving this by reducing the burden associated with travelling for care. The first additional feature included the widespread introduction of telemedicine initiatives that could be used to ensure the most appropriate care pathways are established for patients in P.E.I. For example, several participants pointed out that it isn’t always necessary for a patient to travel all the way to Halifax or Moncton for a 10-minute consultation, particularly if this process could effectively utilize advances in telemedicine or other technologies that enable remote

consultations. Participants also noted that despite the promise of this option, there could be administrative barriers to implementing new telemedicine initiatives that would be required to link providers from different provincial health systems, as well as challenges in ensuring providers would be willing to adopt this new technology in their practices – particularly if there were uncertainties about how providers bill for time spent on telemedicine consultations.

The second and third additional features considered were the development of post-operative care recovery centres in P.E.I., and the increased role for ‘patient navigators’ who can provide support for patients and their informal/family caregivers throughout the entire care pathway. These additional features were considered in light of the reality that, while complex cancer surgeries are provided outside of P.E.I., much of the pre- and post-operative care and coordination occurs while residents are in P.E.I., and current programs are inadequate to meet patient needs. Despite the promise that recovery centres and patient navigators have for filling current gaps in the province, participants still felt funding for such initiatives would be difficult to find.

Box 5: Key messages about option 3

- Three values-related themes emerged during the discussion about option 3:
 - collaboration (relies on the collaboration among all regional health-system stakeholders, as well as among local patient recovery supports);
 - fairness (may have unintended consequences that would jeopardize equitable access to care for all residents of the Maritimes); and
 - excellent patient and family experience (must include interventions to reduce the burden on patients who undergo complex cancer surgeries out of province, and their families).
- Participants generally agreed that option 3 was already the status quo, and efforts should focus on improvements to existing care pathways.
- Participants considered three additional features that should be considered for option 3:
 - introducing telemedicine initiatives to reduce the burden associated with travelling for care;
 - developing post-operative care recovery centres in P.E.I.; and
 - increasing the role for ‘patient navigators.’



Participants indicated that regional political dynamics in the Maritimes make coordinating improvements in cancer care in P.E.I. a challenge.

Discussing the implementation considerations:

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

After discussing the three options (among many) for improving the delivery of complex cancer surgeries in Canada, participants examined potential barriers and facilitators to moving forward.

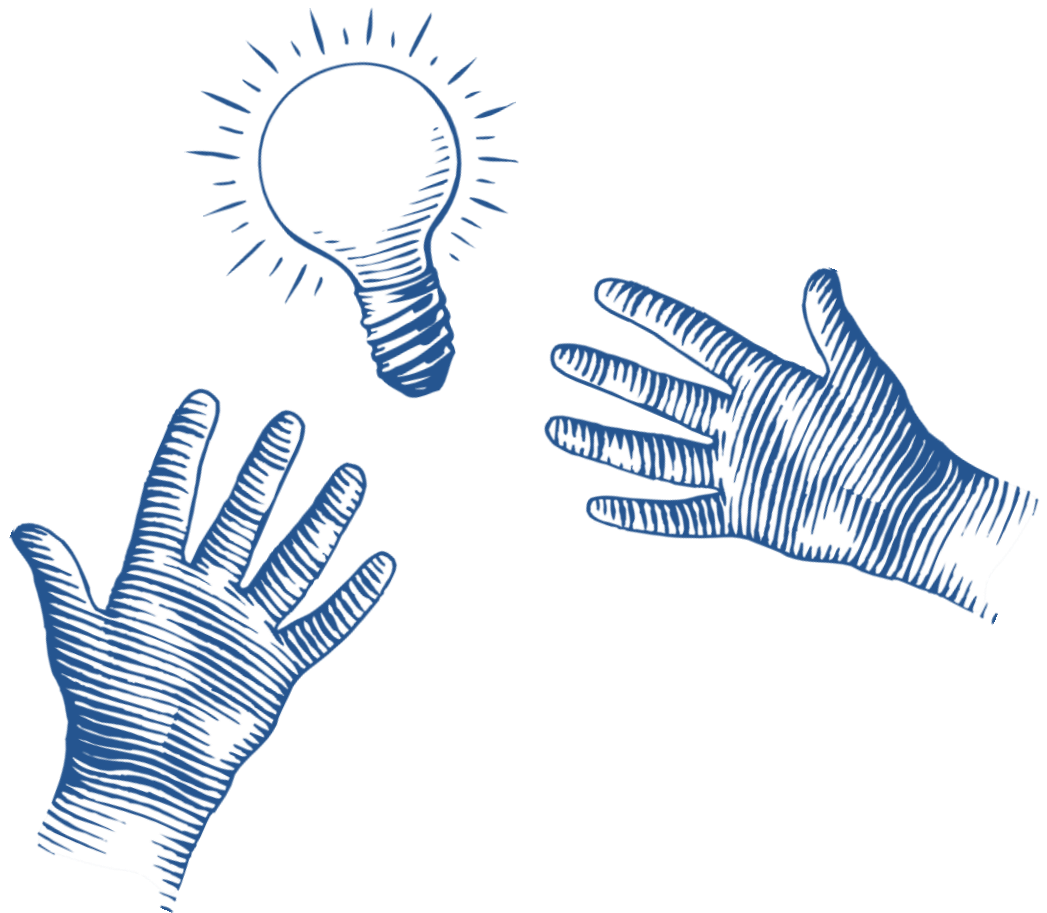
In general the discussion focused on three broad groupings of barriers: 1) the separation of powers between provinces that exists given Canada's federalist structure, which makes it difficult to coordinate health services across jurisdictions; 2) the difficulties in changing provider behaviour and organizational culture to embrace quality improvement; and 3) the lack of funding available to achieve desired changes in the system (with particular reference to improving pre- and post-operative support and recovery initiatives in P.E.I.).

When turning to potential facilitators, participants tended to focus on the positive things already happening in their system as a foundation upon which future efforts could be built. Specifically, many participants acknowledged the reality that it probably wasn't feasible to

bring complex cancer surgeries to local hospitals in P.E.I. Given this reality, participants were accepting of the current situation in which much of this care is regionalized to centres of excellence in other Maritime provinces. As such, efforts to improve the existing processes of care within and outside of P.E.I., rather than make major structural changes to the existing system, were seen as welcome.

Discussing how to move forward

As the citizen panel concluded, participants expressed a desire to move forward in three ways. First, in addressing the challenges with coordinating health services related to complex cancer surgeries regionally, participants suggested the establishment of a regional body with participation from members of each Maritime province as a means for initiating discussions about next steps. Second, engaging community opinion leaders in P.E.I. to promote a culture of change towards quality improvement was mentioned by some participants as a way to overcome the challenges associated with changing healthcare provider and hospital behaviour. Lastly, participants emphasized that it was imperative to examine the financial capacity required to implement and sustain any quality-improvement initiatives in the province.



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