

Dialogue Summary

Optimizing Patient and Family Transitions from
Cancer Treatment to Primary- and Community-
care Supports in Canada

27 March 2018



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Primary- and Community-care Supports in Canada**

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McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Dialogue

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SUMMARY OF THE DIALOGUE

Dialogue participants generally agreed that the four features of the problem as outlined in the evidence brief are a helpful framing, however, they collectively suggested that five issues related to the problem warranted more attention, including that: 1) many of the difficulties survivors face when trying to get help for symptoms they experience after treatment are not specific to cancer, but common across the health system; 2) the range of supports that survivors may need after cancer treatment are often not proactively identified at important junctures in a patient's cancer journey by health professionals in their care team; 3) the expectations placed on primary-care teams to provide survivorship care may be unrealistic given that not all will have the ability (e.g., because lack of time and/or training) to provide the full range of supports needed; 4) limited information about available services and how to access them for survivors, family members and health professionals makes it challenging for them to make informed decisions; and 5) the lack of long-term health-system planning needs to be addressed given anticipated increases in the prevalence of cancer and in cancer survival.

Dialogue participants expressed support for three main strategies to improve the survivorship experience as identified in the evidence brief: 1) provide training and information tools to help health professionals to better support survivors and families transitioning after cancer treatment; 2) align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community; and 3) provide survivors and families with reliable information and tools that can enable them to better manage their transition from treatment to survivorship. Participants particularly emphasized the importance of having appropriate psychosocial and other supports available across the cancer journey.

Overall, in discussing how to move forward with these elements, participants agreed there is a need to balance a focus on short-term achievable goals with addressing harder-to-change elements that require long-term political commitments. The short-term achievable goals and next steps discussed included: 1) identifying and learning from successful survivorship models implemented across the country, including those outside of cancer care, and supporting the adoption of successful elements in health systems across Canada; 2) increasing awareness, availability and integration of existing community, cancer-system, and virtual resources to enable survivors, families and health professionals to better manage the transition from treatment to survivorship; and 3) supporting health professionals in identifying survivors having difficulty in transition (e.g., through risk-stratified discharge planning and follow-up care pathways).

The harder-to-change elements identified by participants included addressing broader structural issues that exist in provincial and territorial health systems more generally (e.g., enhancing timely access to primary care as well as to comprehensive and affordable home and community care), developing national standards of care for cancer which include long-term survivorship care, and changing funding models to incorporate care associated with transitions, including supports that are typically delivered in the community (e.g., psychosocial services and physiotherapy). Pursuing significant changes to funding and remuneration models was recognized as the most challenging element to address as change will require sustained political will and leadership. Participants also emphasized that models of survivorship care need to reflect the values and culture of the communities in which they are delivered.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Participants were keen to discuss the ways to optimize patient and family transitions from cancer treatment to primary- and community-care supports in Canada. In deliberating about the problem, participants generally agreed that the four features of the problem as outlined in the evidence brief were a helpful framing:

- 1) the burden that cancer is placing on health systems in Canada is increasing;
- 2) additional supports are required to meet the needs of cancer survivors who are transitioning into primary- and community-care settings;
- 3) the best ways to optimally support survivor and family transitions remain poorly understood; and
- 4) system-level factors can make it complicated to ensure survivors and their families are supported.

In addition, participants collectively agreed that there were five issues related to the problem that warranted more attention:

- 1) many of the difficulties survivors face when trying to get help for symptoms they experience after treatment are not specific to cancer, but common across the health system;
- 2) the range of supports that survivors may need after cancer treatment are often not proactively identified at important junctures in a patient's cancer journey by health professionals in their care team;
- 3) the expectations placed on primary-care teams to provide survivorship care may be unrealistic given that not all will have the ability (e.g., because of lack of time and/or training) to provide the full range of supports needed;
- 4) limited information about available services and how to access them for survivors, family members and health professionals makes it challenging for them to make informed decisions; and
- 5) the lack of long-term health-system planning needs to be addressed given anticipated increases in the prevalence of cancer and in cancer survival.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

- 1) it addressed an issue currently being faced in Canada;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three elements of a potentially comprehensive approach (among many) for addressing the policy issue;
- 4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements for addressing the problem, and key implementation considerations;
- 5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible elements for addressing it;
- 6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
- 7) it ensured fair representation among policymakers, stakeholders and researchers;
- 8) it engaged a facilitator to assist with the deliberations;
- 9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
- 10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

Many of the difficulties survivors face when trying to get help for symptoms they experience after treatment are not specific to cancer, but common across the health system

In considering the many difficulties faced by survivors, a number of participants noted that while important in the context of cancer treatment and survivorship, a number of challenges are encountered across the health system, and not only in the cancer system. Specifically, participants identified six broader health-system challenges that contribute to survivors having difficulties during the transition from cancer treatment to primary- and community-care supports: 1) limited coordination and support for system navigation; 2) limited use of technology and information sharing; 3) funding not being conducive to patient-centred approaches to care; 4) lack of awareness of and learning from existing models of care that have been found to be successful; 5) marginalized groups often require additional and more complex supports; and 6) supports for caregivers are often neglected.

First, throughout the deliberations, participants consistently identified challenges related to limited coordination and support for system navigation, which was viewed by many participants as being critical for guiding survivors to the services they need. One main challenge cited was the siloed approach to care, which limits coordination across health professionals and services, making it a challenge to establish and communicate a clear care pathway for survivors transitioning after cancer treatment. Moreover, participants discussed the emotional, physical and practical challenges associated with survivorship, which create a range of diverse needs for each individual survivor. Given this complexity, some noted that primary-care teams are often not aware of the range of supports available (e.g., psychosocial oncology and community supports), which is a gap that greater supports for system navigation could fill. Participants also noted that in order to better support transitions, there needs to be an improved understanding of the cancer journey so that there is better integration across the continuum of care.

Second, participants discussed that another key factor limiting coordination is inconsistent information sharing between professionals and between health professionals and survivors. Participants expressed that there were significant limitations in use of technology and information sharing (e.g., electronic health records), and that this results in a disconnect during transitions from cancer treatment to primary and community care. Challenges cited were the inability of sectors to talk to one another (e.g., acute care, oncology and primary care), and that privacy concerns, not always warranted, create a barrier to implementing information-communication technologies to their full extent.

Third, participants noted that the ways in which physicians are remunerated is not always conducive to the provision of patient-centred care. Specifically, some participants suggested that the way physicians are paid places emphasis on disease-focused treatment, instead of on a more comprehensive approach that focuses on the broader range of needs that a survivor might have. Participants also discussed how physician reimbursement systems are not currently set up to adequately address transitions in care. One example given was that oncologists are not paid for providing transition supports, and in some cases are incentivized for activities that do not support optimal transitions in care. Specifically, one participant highlighted that having survivors return for routine follow-up visits with the oncologist is far easier and is remunerated, while arranging a transition to primary care takes a lot of unpaid work and results in loss of future income for the oncologist.

Fourth, throughout the deliberations about the problem, participants noted the lack of learning from existing models of care which could be used to continually enhance approaches to care across provincial and territorial health systems. Participants identified examples of models of care that they viewed as being important sources of learning for provincial and territorial health systems, including the navigator model for complex chronic diseases in Australia, risk-stratified follow-up pathways for cancer in England's National Health Service, and models that have successfully supported seamless transitions (e.g., through bundled care, shared-care models and moving away from physician-centric models to include nurse-led care).

Fifth, participants highlighted that marginalized groups often require additional and more complex supports from the health system, yet often do not have access to what they need. It was noted that while models of care provide primary care to marginalized populations (e.g., Community Health Centres in Ontario), there are still system-level challenges in connecting primary-care teams with home- and community-care services. More broadly, participants discussed the added layer of challenges to address the social determinants of health in addressing health equity (e.g., food security and precarious housing), which would require collaboration and coordination between health and social systems within each province and/or with the federal government. It was noted that because of limited collaboration and coordination, many cancer survivors from marginalized groups end up back in the hospital because of lack of appropriate community supports.

Lastly, participants recognized the challenges that caregivers face, and that they are often neglected across the care continuum. Participants noted that recommendations also need to be cognizant of caregiver burden.

The range of supports that survivors may need after cancer treatment are often not proactively identified at important junctures in a patient’s cancer journey by health professionals in their care team

Participants highlighted that the broad range of supports that are needed by many during and after cancer treatment (e.g., supports for psychosocial care and a wide range of practical and informational needs) are often not proactively identified through a patient’s cancer journey, and particularly at important stages when it may matter most. After treatment, survivors are no longer connected into care pathways for cancer and are often unable to access appropriate supports when needed. This disconnect results in unmet needs with many survivors not knowing that they may need supports after cancer treatment.

Although the range of emotional, physical and practical supports needed by survivors were mentioned, some participants particularly emphasized the importance of having appropriate psychosocial supports available throughout the cancer journey. Access to psychosocial oncology was discussed as being critical given that the specialty focuses on provision of supports that aim to enhance quality of life for cancer populations.

The expectations placed on primary-care teams to provide survivorship care may be unrealistic given that not all will have the ability (e.g., because of time, lack of training and/or because of their scope of practice) to provide the full range of supports needed

Participants raised concerns that the expectations of primary-care teams to provide survivorship care are too high, and that family physicians are often viewed as the solution to many health-system problems. For example, one participant indicated that “we are falling into a common misconception that we can train family physicians to be superheroes in all areas.” Building on this, participants focused on three main challenges related to expectations of primary-care teams: 1) limited training in cancer survivorship care and infrequent exposure to survivors; 2) a potential lack of trust between the survivor and primary-care team regarding cancer care; and 3) a failure to acknowledge that primary and community care is increasingly moving beyond solo family physicians to interprofessional teams with members from primary and community care.

First, there were differing perspectives on the expectations of primary-care teams in delivering survivorship care. Some participants highlighted that family physicians have limited education in and clinical exposure to cancer care given that it forms a small part of their practice, with many only seeing a few patients with cancer each year, and these patients often have different types of cancer. Participants also emphasized that relationships between family physicians and their primary-care teams, and cancer-care teams, are not sustained, despite linkages being needed to ensure coordinated post-treatment care for cancer survivors. Conversely, one participant voiced that there does indeed need to be a change in the culture of expectations for family physicians. The intention is for family physicians to be a ‘jack of all trades,’ and a commitment to continuous learning is part of their role. The same participant noted that while family physicians may have limited clinical exposure to cancer survivors, in general, survivorship needs are not complicated to address.

Second, participants discussed the importance of building trusting relationships between survivors and family physicians and primary-care teams, which can be strained following cancer treatment depending on what unfolded during the individual's cancer diagnosis. For example, some participants noted that sometimes trust in a family physician has been compromised if the survivor felt that a diagnosis was missed or delayed because of the family physician. This, combined with the feeling from many survivors that their oncologist saved their lives, makes it crucial to build trust in the family physician to ensure successful transition back to primary and community care.

Third, participants voiced challenges with focusing solely on family physicians and ignoring the larger group of health professionals increasingly engaged in providing care and supports in primary- and community-care settings. It was felt that the health system defaults to family physicians for providing primary care and that the focus needs to shift to team- and community-based approaches, especially for ensuring that the full range of practical and emotional challenges of survivorship are addressed. Furthermore, participants expressed that the primary-care team is often not linked to resources and services in the community, which makes the provision of coordinated care more challenging. Another related challenge is the lack of recognition of the variety of types of care and supports provided to survivors (e.g., virtual supports, home care, travel and transportation), and that the individuals involved in providing these services are important members of the care team, but often not recognized as such within the health system.

Limited information about available services and how to access them for survivors, family members and health professionals makes it challenging for them to make informed decisions

Participants acknowledged the lack of proactive information sharing and education for both survivors and health professionals, which means that making informed decisions about cancer survivorship is a challenge. For example, several participants highlighted that while there is a strong demand for information from survivors, they often do not know where to go to get that information and related resources, especially for the wide range of psychosocial and other supports that they may need over time. Web-based resources were cited as the first stop for information, but many noted their concerns with the credibility of sources on the internet, and as a result, survivors often don't know what to trust and end up with information that is either conflicting or inappropriate for a survivor's unique context.

Participants also identified that there are a range of information sharing and education supports available to survivors in transition, but they are often missed or overlooked. Charitable and non-profit organizations (e.g., Canadian Cancer Society, Gilda's Club and Wellspring) provide many such supports, but some participants highlighted that, in their experience, survivors are often not aware of these resources. One barrier to increasing awareness of these resources that participants discussed was the perceived competition from these organizations with hospital charitable foundations. Some participants shared examples of their experiences with some hospital foundations limiting or restricting other organizations from making pamphlets available in their waiting rooms.

The lack of long-term health-system planning needs to be addressed given anticipated increases in the prevalence of cancer and in cancer survival

Participants identified the lack of long-term health-system planning as another important part of the challenge. For example, one participant stated that "we're not very good planners for the future." Participants agreed that due to political constraints (e.g., election cycles that make long-term planning and commitments difficult to achieve) health-system planning is often incremental and focused on shorter-term goals. In particular, concerns were raised by participants regarding the expected significant increases in the prevalence of cancer and survivorship, and that the challenges with long-term health-system planning will mean that progress will be slow to address increasingly pressing issues. It was also expressed that cancer systems are very focused on treatment and do not always consider what happens next in terms of creating appropriate

resources for cancer survivorship, with one participant stating that “we don’t prepare people for when treatment is done.”

DELIBERATION ABOUT ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH

In deliberating about how to optimize survivor and family transitions from cancer treatment to primary- and community-care supports in Canada, most dialogue participants expressed support for components from each of the three elements of the potentially comprehensive approach that was presented in the evidence brief. These elements are: 1) support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be transitioning after cancer treatment; 2) align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community; and 3) provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship.

Element 1 - Support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be transitioning after cancer treatment

For element 1, participants emphasized two approaches that could be pursued to support, train and provide organizational and system supports that enable health professionals to identify and engage survivors and families who will be transitioning after cancer treatment: 1) using risk stratification to determine survivors’ needs; and 2) ensuring that the full range of supports are available across the cancer journey.

Using risk stratification to determine survivors’ needs

Participants generally agreed with the importance of the sub-elements presented in the evidence brief (engaging survivors and their families in conversations about transition, equipping health professionals and teams to address needs, and creating systems to support the two). Participants thought that implementing risk-stratified care pathways early in the cancer journey (e.g., at the start of or during treatment) would help to continually identify survivors’ needs, improve care during transition to primary and community care, and adjust care plans as their needs evolve. During the deliberations, it became clear that participants were using ‘risk stratification’ to mean two different things: 1) stratification by risk of cancer recurrence, which can help determine which survivors should continue to be followed within the cancer system and those that can be followed in primary- and community-care settings; and 2) deliberate identification of survivors who are having difficulty with psychosocial, long-term, or late effects of cancer and its treatment. Once the level of need has been established, participants indicated that health professionals could then create appropriate transition plans and adjust them over time as needs evolve. Participants generally agreed that establishing clear discharge planning procedures in this way would help to ensure that survivors are connected to the services they need, and to proactively identify needs and supports to meet the needs when they arise.

Ensuring that the full range of supports are available across the cancer journey

Participants focused on using existing medical settings to connect to additional supports, community services, and private health professionals to ensure that the full range of supports are available across the cancer journey. An important example raised by some participants was psychosocial care. These participants indicated that in many cancer centres, psychosocial services are only available for patients undergoing active treatment. As a result, primary-care teams caring for cancer survivors with psychosocial needs may not know where to turn to access appropriate services. Moreover, it was emphasized that working with partners in the community-care sector to better understand survivorship outcomes through the use of data (e.g., Community

Health Centres' use of electronic medical records in Ontario) will be important for connecting survivors with the supports they need across their journey and not just at one point in time.

A number of models were discussed that could be applied more broadly to cancer transitions, including: 1) a community-based hospice hub model that provides interdisciplinary (and non-medical) palliative care; 2) navigation models that reach out to individuals at key points in the cancer journey (e.g., nurse navigator teams or using a clerical staff member to conduct follow-up and to connect cancer survivors with services); and 3) person-centred care facilitated through the use of patient-reported outcome measures such as in the survivorship care and peer navigation model in Saskatchewan, and CancerCare Manitoba's Moving Forward after Cancer Treatment program. One participant discussed the experience of using patient-reported outcome measures for transitions in their jurisdiction. The tool is used for system-level programming and to identify needs in survivorship, which supports self-management by helping to educate the individual. The participant also discussed the advantages of adding a screening-for-distress scale in the tool to allow for greater responsiveness by health professionals during transitions. Overall, it was suggested that models like these offer important opportunities to identify successful elements from existing models of care, and to incorporate them into cancer systems across the country.

Element 2 - Align funding and remuneration arrangements to better support survivors with cancer as they transition from treatment to survivorship in the community

Participants agreed that this element was important to address, but also the most difficult one to change. Participants recognized that elements 1 and 2 were intertwined, and deliberations focused on: 1) changing funding for cancer centres and oncology specialists; 2) changing remuneration for family physicians; and 3) making changes to the scope and nature of employer-insurance plans.

Funding arrangements for cancer centres and specialists

In addressing remuneration for oncology health professionals, participants emphasized that current remuneration arrangements need to be changed to remove incentives that contribute to keeping survivors within cancer systems after treatment (e.g., as one participant noted, it is currently easier to schedule a six-month follow-up with survivors rather than taking the steps needed to transition them to primary care). One participant described that survivors often feel more comfortable staying within specialist care, and that making arrangements for transition (e.g., writing a letter describing the care a patient received and recommendations for future surveillance) requires unpaid time from oncology teams that are already overburdened. Transition of care generally also results in loss of income for future visits for the specialist doing that unpaid work. Moreover, while cancer centres may wish that survivors be transitioned to primary care, oncologists are generally not paid by the cancer centres and as such, the centres cannot dictate their practices and do not have funding to support other health professionals (e.g., nurse practitioners) to do the complex work of supporting transitions in care. While specific recommendations for how to change remuneration arrangements were not identified, there was consensus among participants that whatever changes are made need to be implemented in a way that makes it easier for oncologists to support transitions to primary and community care (e.g., by providing a billing code for preparing a transition plan, or funding to cancer centres to hire someone to assist).

Remuneration arrangements for family physicians

Participants also discussed remuneration for family physicians. Current billing structures do not compensate family physicians to provide comprehensive and complex transition supports. Recommendations to address the issue focused on adding cancer to the list of conditions for which premiums are paid for complex care management. Many participants viewed this as an 'easy win' as it would not require a new fee code, but rather a modification to the list of included conditions.

Changes to the scope and nature of employer-insurance plans

Lastly, participants recognized the role of employers in providing funding arrangements to better support survivors. Specifically, lost productivity at work was identified as a common concern for employers and, as a result, participants identified changes to the scope and nature of insurance plans as an opportunity for employers to address part of the challenge of ensuring cancer survivors receive the types of care and support after treatment that they need to fully re-engage in the workplace.

Element 3 - Provide survivors and families with opportunities to gain the knowledge and skills that can enable them to better manage their transition from treatment to survivorship

Participants focused on two approaches as being essential for this element: 1) creating routine and robust ways to engage survivors and their families in program and policy development; and 2) promoting the use of existing resources.

First, participants discussed that in order to provide the necessary skills for survivors to manage their transition, survivors need to be engaged in care and also in program and policy development. Participants discussed that such engagement has to be continuous and not just one-off consultations. Diversity in terms of culture, age and experiences with the cancer system was also highlighted as an important consideration in efforts to engage survivors in program and policy development, to ensure that changes made are reflective of the diverse needs of those who will be affected by them.

Second, participants agreed that there is a need to collectively do a better job of promoting existing resources, and this change was seen as an example of 'low-hanging fruit' that is straight forward to achieve. In considering the challenge of the lack of awareness of supports offered by charities such as the Canadian Cancer Society, one participant emphasized the importance of collaboration among charities, cancer centres and hospital foundations to provide pamphlets with reliable information in waiting rooms, as for many, these pamphlets are the only information they will receive on cancer supports available to them. There were also recommendations to enhancing information and education supports for survivors and their families through reliable sources of virtual care (e.g., Canadian Cancer Society, Canadian Virtual Hospice, and Cancer Chat Canada) in order to provide increased access to these types of resources for hard-to-reach populations (e.g., those living in rural and remote areas). Another example of an important resource identified by participants is the large peer-support network that exists for cancer (e.g., volunteer drivers are providing significant supports to survivors). Many saw this network as having significant potential to be harnessed for enhancing transitions, by connecting survivors with peers who have previously transitioned from cancer treatment to primary and community care (e.g., to help identify resources in their community and/or share experiences about what worked well and how they addressed challenges). Moreover, participants felt that there is room for the medical community to better acknowledge the value that these services and networks add to the system.

Considering the full array of elements

In considering the full array of elements, there was general agreement that a focus on achieving both short-term (i.e., those that could yield quick wins) and long-term goals (i.e., those that likely require political buy-in) is needed. Participants noted that there were components within the elements that were feasible to act on within a four-year election cycle. In element 1, this included using existing models that could be applied more broadly to cancer transitions (e.g., navigation models, psychosocial oncology, and person-centred care through the use of patient-reported outcome measures). For element 2, participants indicated that changing billing structures to allow family physicians to bill for complex patient visits would be feasible in the short-term and could be a change that helps to spark momentum towards making additional changes to financial arrangements to enhance transitions from treatment to primary and community care. Lastly, for element 3, participants discussed a range of existing resources that could be better promoted (e.g., collaboration to

provide pamphlets with reliable information). When considering longer-term goals, participants acknowledged the instrumental role of the Canadian Partnership Against Cancer's 2016 transitions study, and using findings from it to spark action towards changes in health systems. While some of the goals will take many years to achieve, participants felt that as a community they could apply pressure to achieve long-term goals.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Discussion about the barriers to optimizing survivor and family transitions generally focused on four themes: 1) financial sustainability; 2) competition between charitable foundations; 3) awareness of programs versus availability of resources to meet increased demand; and 4) lack of recognition of the importance of volunteer resources in the medical community.

The first major barrier noted by participants was the lack of financial supports for transitions. Budgets fluctuate, and some participants noted that the long-term sustainability of programs they offer (particularly smaller programs that are not able to easily absorb budget reductions) are heavily influenced by political agendas. At the time of the dialogue, participants did not think that there was sufficient awareness about the issues related to cancer transitions, and that political agendas were more focused on other high-profile policy issues such as cannabis legalization and the opioid crisis.

Second, participants recognized that competition between charitable foundations was a barrier to optimizing transitions. As discussed in relation to element 3, charitable and non-profit organizations provide many information and education supports, but survivors are often not aware of them. Competition for donations results in restrictions to the promotion of community supports within a hospital or cancer centre, leaving many survivors without knowledge of the range of supports available to them.

The third barrier raised by participants, interconnected with the two described above, was the difficulty in balancing increased awareness of programs against the availability of resources to meet increased demand. Specifically, participants discussed that many programs offering transition supports are underfunded, and that as the prevalence of cancer survivorship increases and awareness grows, there may not be enough resources to meet the increased demands placed on these programs.

Lastly, participants indicated that volunteers are central to providing transition supports for survivors, such as system navigation and transportation, yet their important role in transitions is not recognized by the medical community. This creates a barrier to these services.

Having discussed barriers, several participants highlighted five important enablers to change that will be essential for implementing the three elements:

- 1) ensuring meaningful engagement of cancer survivors and their families using a flexible and fluid approach that is attuned to community needs and values, to ensure that care reflects the needs and culture of the communities in which care and supports are delivered;
- 2) engaging oncology champions (e.g., clinicians with expertise across the cancer journey) who can act as a key resource to provide local transition supports;
- 3) increasing the availability of virtual supports provided by charities to enhance accessibility to needed care (e.g., for psychosocial needs) that are not available in all communities;
- 4) sharing learning from successful survivorship models already in place; and
- 5) ensuring timely access to data and evidence to enable continuous monitoring and evaluation coupled with change management, to identify changes that are needed to continue to enhance the experience of survivors and their families and improve outcomes while keeping costs manageable.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

During the deliberations about next steps, participants outlined what they would bring back to their respective constituencies and how their suggestions could work to advance the proposed solutions. There was general agreement on the need to focus on achieving both the short-term (particularly on actions that could yield quick wins) and the long-term goals (i.e., those that may require political buy-in to move forward) that had been identified through the deliberations.

With respect to short-term goals, participants noted that there were components within the elements in the evidence brief that were feasible to implement within a four-year election cycle. These focused on using existing infrastructure for:

- 1) identifying and learning from successful survivorship models implemented across the country (e.g. the use of patient-reported outcome measures in the survivorship care and peer navigation model in Saskatchewan, and CancerCare Manitoba's Moving Forward after Cancer Treatment program), including those outside of cancer care, and supporting the adoption of successful elements in health systems across Canada;
- 2) increasing awareness, availability and integration of existing community, cancer system, and virtual resources to enable survivors, families and health professionals to better manage the transition from cancer treatment to survivorship; and
- 3) supporting health professionals in identifying survivors having difficulty in transition (e.g., through risk-stratified discharge planning and follow-up care pathways).

When considering the longer-term goals, participants acknowledged the instrumental role of the Canadian Partnership Against Cancer's 2016 transitions study in laying the groundwork for action, and suggested using these findings to motivate changes in health systems in areas that may be harder to change. The harder-to-change elements identified by participants focused on those that would require long-term political buy-in, and included:

- addressing broader structural issues that exist in provincial and territorial health systems more generally, including changes to funding and remuneration models, and enhancing timely access to primary care as well as to comprehensive and affordable home and community care;
- developing national standards of care for cancer survivors, which includes greater focus on risk identification and interventions to meet long-term needs; and
- changing funding models to incorporate care associated with transitions, including non-medical supports (e.g., psychosocial services and physiotherapy).

Pursuing significant changes to the broader structural issues that exist in provincial and territorial health systems was recognized as the most challenging element to address as change will require sustained political will. However, while there was recognition that these changes would take many years to achieve, participants agreed that the efforts required to build momentum are worthwhile and could be achieved collectively within the community.



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