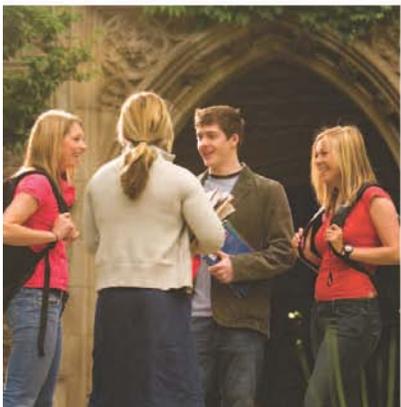




ENHANCING PATIENT TRANSITIONS  
FROM TREATMENT IN A  
REGIONAL CANCER CENTRE TO  
SURVIVORSHIP IN THE HAMILTON  
NIAGARA HALDIMAND BRANT  
COMMUNITY



**Dialogue Summary:  
Enhancing Patient Transitions from Treatment in a Regional Cancer Centre to  
Survivorship in the Hamilton Niagara Haldimand Brant Community**

5 April 2011

#### 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 the regional/provincial level 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.

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## SUMMARY OF THE DIALOGUE

Dialogue participants tended to come at this problem in one of two ways. One large group generally agreed with how the problem was framed in the evidence brief, namely that the cancer care sub-system lacks a sustained approach to supporting cancer patients in the transition from receiving treatment in a regional cancer centre to survivorship in the community. A second, smaller group framed the problem in a different way, namely that patients are not all living well after treatment, either because of gaps in the system (particularly in terms of psychosocial care and self-management supports) or because of the lack of a comprehensive, organized approach to supporting patients to live well after treatment.

Dialogue participants generally agreed that the regional cancer centre should play a leadership role in building a more comprehensive strategy for supporting patients to live well after treatment, and ensuring the optimal use of existing resources. They also agreed that Cancer Care Ontario's Program in Evidence-Based Care, with its partners and with other divisions at Cancer Care Ontario, should accelerate its development of a range of disease site-sensitive and setting-appropriate cancer survivorship support plans that encompass a more holistic (physical *and* psychosocial) orientation.

Dialogue participants identified a number of factors that would facilitate implementation: 1) emergence of a compelling argument for change; 2) rapid growth in the use of electronic health records in the primary healthcare subsector; 3) Cancer Care Ontario's nascent capacity to generate lists of cancer patients; and 4) possibility of funding and an evaluation framework coming from at least two sources. Dialogue participants also noted a number of processes that would facilitate implementation, most of which were participatory processes, and specifically an approach that engages patients and their families, primary care groups/teams, community resources, and regional cancer centre staff.

If the regional cancer centre has the will to take on this challenge now, some of the decision points that emerged during the deliberations (including the final deliberation about next steps) included:

- establish the goal – is it better support for patients to live well after treatment, enhanced transitions from care in a regional cancer centre to care in the community, or both?;
- clarify the messages for different target audiences – is it patient experiences with not being fully supported to live well after treatment, the 'burning platform' of increased demand and constrained supply, research evidence about the comparable safety and effectiveness of care in the community, or some combination?
- decide on the appropriate sequencing of tasks – is it the development of the cancer survivorship support plans first, the identification and coordination of community resources first, the greater engagement of primary care providers in supporting survivorship first, or all of these simultaneously?
- choose a good process for executing these tasks - is it engaging patients and their families in some or all of these tasks, engaging community resources in some or all of these tasks, engaging primary care providers in some or all of these tasks, or engaging some of these groups in some of these tasks at some times?
- seek funding for demonstration projects and their evaluation – is it funding from the Canadian Institutes of Health Research, Cancer Care Ontario, the regional cancer centre, or some combination of the three?
- decide on whether to take on bigger issues, such as removing disincentives to the efficient delivery of care by oncologists and primary care providers.

# SUMMARIES OF THE FOUR DELIBERATIONS

## DELIBERATION ABOUT THE PROBLEM

Dialogue participants generally agreed that the cancer care sub-system lacks a sustained approach to supporting cancer patients in the transition from receiving treatment in a regional cancer centre (in this case, in the Hamilton Niagara Haldimand Brant region) to survivorship in the community. They also agreed with a number of key features of the problem, including that:

- the burden of cancer is growing in Canada because of aging, population growth and improved survival from many types of cancers;
- a variety of gaps exist in the health system arrangements within which cancer care is provided, which limits the supports for cancer survivorship; and
- existing implementation efforts have been focused on earlier stages in the cancer care continuum.

One participant noted, in regard to the first point, that the fact that we’re having a deliberation about supporting survivorship is in some ways a reflection of the cancer subsector’s success in improving survival rates.

Dialogue participants gave particular attention to the growing numbers of patients entering treatment and the large numbers of well patients receiving follow-up care at the regional cancer centre many years after their treatments had been successfully completed. Resource constraints, a new funding formula and political pressures mean that the regional cancer centre must focus on the former group, however, there are many reasons why the latter group continues to be seen in the regional cancer centre. Some of these reasons are medically indicated (e.g., extended hormonal treatment of patients who had breast cancer) and hence easily justified. Another category of reasons likely reflect the implicit or explicit preferences of patients, such as wanting to stay with the person who ‘saved’ them (and with whom they’ve developed a bond, based on trust, that’s hard to break), wanting to have immediate access to care if something goes wrong, and possibly not wanting to go back to the primary care physician who (they perceive) did not diagnose their cancer rapidly enough, or mis-diagnosed it initially, or who ‘doesn’t know anything about cancer.’ A third category of reasons likely reflect the implicit or explicit preferences of oncologists and nurses, such as wanting to keep the patients to whom they’ve grown attached, wanting to bring back patients in three or six months rather than spend the significant amount of time needed to support a

### **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 the Hamilton Niagara Haldimand Brant community;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three options (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 options 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 options 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.

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.

transition to care in the community, and wanting to keep a mix of well and sick patients in their clinics (either to reduce the emotional toll of the work or, given that oncologists are paid the same whether they provide care to well or sick patients, to balance the physical toll of the work within a largely fixed salary drawn from an alternative funding plan that penalizes a drop in the volume of visits and does not reward ‘discharging’ patients from care at a regional cancer centre). As one participant said: “Seeing well patients is cheaper and easier... and good for the mental health of physicians....” Plus “patients may be angry with their family physician.” A fourth category of reasons had to do with the current absence of a mechanism for easily tracking patients as they transition from a regional cancer centre to the community, either so that they can be identified quickly if there is a change in guidelines about follow-up care, or so that they can participate in research studies.

Dialogue participants also gave attention to how primary and community care programs intersect only minimally with cancer care programs (and the related absence of communication tools between these subsectors), and how little attention is being given to identifying “packages” of cancer monitoring and support that could be delivered in primary and community care. They gave less attention to why there may be little demand coming from primary care providers for the ‘repatriation’ of their patients (and even some resistance to this), although some reasons were mentioned, including primary care providers having often been ‘cut out of the loop’ of patient care early on (i.e., a longitudinal relationship among the patient, primary care provider and oncologist wasn’t maintained from day 1), receiving notes that don’t explain their role in on-going care, not receiving the guidance and tools to support their role, being concerned about the workload implications, and not being remunerated in a way that compensates them for the additional time and resources required (and possibly even being penalized if they are remunerated within a capitation model that adjusts for the age and sex of their patients, but not their diagnoses or the complexity of the care they require).

One dialogue participant noted that there is research evidence indicating that both patients and primary care providers are more open to transitions to the community than some of these comments would suggest. This participant argued that there needed to be more proactive communication with patients and their families about the benefits of care in the community, including the comparable safety and effectiveness of primary care providers in providing follow-up care.

One dialogue participant framed the problem in a different way: the problem is that patients are not living well after treatment because of gaps in the system, particularly in terms of health promotion (i.e., non-medical) programs and services, which include psychosocial care and self-management supports. In other words, the problem isn’t just the lack of an approach to supporting transitions, but to supporting survivorship in general (and, as one individual put it, “supporting survivorship holistically and not just medically”). Several dialogue participants echoed this view, and noted a number of possible explanations for these gaps:

- lack of awareness (e.g., patients and their families and physicians may be unaware of resources available in the community or online and how these resources could help them);
- financial barriers to access (e.g., patients may lack extended health benefits through a private insurance plan and cannot afford to purchase what they need);
- lack of programs and services in the community or insufficient supply for the existing demand;
- a performance measurement system focused on measuring access to care (e.g., wait times), but not the quality of care being received (particularly in the domain of survivorship care); and
- media attention driven to stories about treatment access and not to stories about access to psychosocial and other supports for survivorship.

One dialogue participant noted that the current economic climate is such that the focus should be on identifying the contributions of these possible explanations and, initially at least, prioritizing efforts to address awareness about what is already available. In response to this comment, a dialogue participant noted that

additional data about the magnitude of the problem and the relative contribution of (at least some of these) potential causes of the problem should be available within three months.

A second dialogue participant argued that the problem wasn't a substitution issue (i.e., replacing cancer centre-based specialists with community-based primary care providers), but an issue of supplementation and enhancement (i.e., bringing in new types of nursing roles and new types of psychosocial programs).

A third dialogue participant argued that the problem wasn't just one of gaps, but rather the lack of a comprehensive, organized approach to supporting patients to live well after treatment, which means periodically assessing and prioritizing needs, periodically assessing and prioritizing what's already being done to meet these needs, filling gaps, coordinating the initiatives, streamlining and facilitating access to them, measuring performance, and making continuous improvements based on feedback from patients and providers. This participant went further to say that the real problem is a lack of accountability for a comprehensive, organized approach to supporting patients to live well after treatment.

### **DELIBERATION ABOUT POLICY AND PROGRAM OPTIONS**

Dialogue participants liked aspects of the first and third of the options, but they also introduced supplementary or complementary elements of each of these options, and they raised issues in relation to the second option that have broader implications for which options are embraced.

#### **Option 1 - Researchers develop cancer survivorship support plans**

In reacting to option 1, most dialogue participants agreed that Cancer Care Ontario's Program in Evidence-Based Care should accelerate its use of a systematic and transparent approach to develop a range of disease site-sensitive and setting-appropriate cancer survivorship support plans that can be implemented and monitored by any actor in the healthcare system, as well as develop plans to support their local adaptation and implementation. As one dialogue participant noted: "Supporting survivorship should follow a template or checklist in order to make sure that all patients, families and providers know what to do and what to expect will be done." One dialogue participant noted that these cancer survivorship support plans should ideally align with the way that other conditions are being approached and managed. Several dialogue participants emphasized the need for flexibility in how the support plans are implemented and used.

However, a number of dialogue participants argued that the development of support plans should be:

- undertaken through a participatory process that builds the relationships that will support the use of these survivorship support plans; and
- supplemented with the identification of the full range of 'non-medical' survivorship-related needs (possibly using a to-be-developed needs-assessment tool for use at the patient level and focusing initially on high-needs patients), the assessment of the research evidence about the benefits, harms and costs of programs and services to meet these needs, the identification or creation of these programs and services, and the building of the capacity of primary care groups/teams (among others) to use these resources.

Regarding the first point – the importance of a participatory process in developing support plans – several dialogue participants noted that those involved in developing support plans could learn from:

- individuals with experience in citizen engagement, which in this case would mean patient and family engagement (both those who focus on citizen engagement on a regular basis and those, like staff at the regional cancer centre in Ottawa, who established a representative sample of several hundred patients to inform their programming);

- individuals with experience in integrating psychosocial care and medical care, which could mean those in the mental health and addictions field; and
- individuals with experience in developing the antenatal record, which has proven to be a powerful tool in enhancing obstetrical care and facilitating longitudinal relationships between obstetricians and primary care providers (both family physicians and midwives).

One dialogue participant noted that even if the antenatal record analogy proved unhelpful, it would be important to spend significant time working through how to turn whatever is done into a useful set of tools and resources that can be applied easily across a range of settings.

One dialogue participant raised the question as to whether the traditional approach to the Program's work (i.e., a literature search first and consultation second) will work best in this situation, or whether the approach should start with engaging cancer survivors and their families (and possibly the individuals who offer resources in the community,) and use their views and experiences to drive the search for evidence and the development of the cancer survivorship support plan. Another dialogue participant raised the issue of how to sustain the regular updating of these plans once they are developed, while another argued for cycles of rapid testing of and improvements to the plans.

Regarding the second point – the importance of cancer survivorship support plans addressing ‘non-medical’ as well as medical issues – several dialogue participants pointed out that these survivorship support plans would be helpful for oncologists, nurses and other staff at a regional cancer centre as much as for primary care providers in the community. As was pointed out during the deliberation about the problem, in some dialogue participants' view, the problem is the lack of an approach to supporting survivorship in general and not just in supporting transitions. A few dialogue participants argued that survivorship support plans should be for all ‘stakeholders,’ not just for the physicians and nurses involved in their medical care.

A number of dialogue participants noted that developing cancer survivorship support plans would be necessary but not sufficient to support patients living well after treatment and to enhance transitions, which raises the issue of what other options or option elements are needed to complement option 1.

## **Option 2 - Ministry accredits and incentivizes teams/centres to support cancer survivorship**

From option 2, many dialogue participants liked the idea of the Ontario Ministry of Health and Long-Term Care:

- being open to sector-specific or local efforts to address or ‘work around’ specific barriers such as oncologists being paid for all types of follow-up care (which can lead them to want to continue seeing well patients who could be supported in the community), and some primary care groups/teams being paid using a capitation model (which can lead them to want only “healthy” patients on their rosters);
- supporting local innovations, such as investing in survivorship support centres or nurse-led high-volume clinics, if there was a desire to move in these directions; and
- supporting broad-based efforts to improve quality in primary care, such as those led by the Quality Improvement and Innovation Partnership (now amalgamated into Health Quality Ontario), which opens up the possibility of cancer care being incorporated into these efforts.

A number of dialogue participants were not supportive of the Ministry steering the process, however, which included it taking on a role of accrediting and incentivizing primary care teams and community care centres to become engaged in supporting cancer survivorship in the community. One reason for this reticence about the ministry's role was that some of the changes discussed in the context of this option could require changes to fee schedules, which would then mean a complex negotiation process with the Ontario Medical Association. That said, dialogue participants did note that steps taken by the ministry, such as convening a group to examine ‘enhanced’ capitation models that adjust for patients requiring more complex care (not just age- and

sex-adjusted historical Ontario Health Insurance Plan billings), would make their lives easier in supporting transitions to the community. A second reason for concerns about the ministry steering the process in this way is that it would create a second tier of primary care and hence another degree of fragmentation in the system. One dialogue participant noted that even if this might be a viable solution in a large urban centre like Toronto, it would be very unlikely to be embraced in smaller urban or mixed urban/rural regions like the Hamilton Niagara Haldimand Brant region where primary care providers are more likely to embrace a broad spectrum of types of care.

One dialogue participant noted that work is underway at Cancer Care Ontario, with the involvement of both provincial clinical leads and provincial business leads, to examine a number of payment issues, including the possibility of moving towards a single approach to payment across all types of medical providers of specialized cancer care (e.g., medical oncology, radiation oncology, surgical oncology, gynecologic oncology, etc.). These discussions would be a logical forum for discussions about the challenges associated with paying oncologists for all types of follow-up care (which can lead them to want to continue seeing well patients who could be supported in the community), and not paying them for personalizing survivorship support plans and supporting transitions to care in the community.

Deliberations about this option elicited remarkably mixed views about financial incentives. Some participants:

- saw financial incentives as “a solution looking for a problem;”
- considered that no healthcare provider should be paid extra for doing their job well (while recognizing that it may be appropriate to pay someone extra for taking on new work while resources are being put in place to make this new work part of a routine);
- recognized some benefits with financial incentives but also many concerns; and/or
- accepted that financial incentives are one of the few ‘levers’ available that, if properly employed, can lead to widespread changes in clinical practice.

Examples of the concerns that were raised about financial incentives included that: 1) they focus on specific, narrowly defined behaviours and not on broad-based efforts to improve the quality of care; 2) they divert attention from other more pressing issues (e.g., a bonus tied to reaching targets within a fiscal year channelled attention almost exclusively to the targeted domain as the end of the fiscal year approached); and 3) they often have unanticipated consequences (e.g., a ‘negation fee’ caused primary care providers to ‘disenrol’ patients if they needed cancer care because having any of their care at the regional cancer centre provided by a general practitioner (GP) oncologist meant that, until the issue was addressed recently, the referring primary care group/team lost revenue).

Some measure of agreement came with the idea of removing disincentives for oncologists, primary care providers and others working in the most efficient way to support patients to live well after treatment. This could include removing disincentives for oncologists to provide input on specific follow-up issues being encountered by primary care providers involved in providing survivorship care (whereas the current system pays oncologists only for complete consultations).

Deliberations about this option also elicited very mixed views about approaches to quality improvement. Some participants:

- embraced the holistic approach to quality improvement used by Health Quality Ontario in the primary healthcare subsector, which involves the use of virtual learning communities and learning collaboratives, among many other approaches;
- preferred the more subsector-specific approach used by Cancer Care Ontario, which until now has focused primarily on using an audit and feedback approach to increase cancer screening (and not other approaches or a focus on supporting survivorship); and/or
- argued that quality improvement needs to be driven internally within a practice (albeit with the supports and resources provided by Health Quality Ontario, Cancer Care Ontario, or both).

One dialogue participant argued that regardless of where the ‘centre of gravity’ for quality improvement was situated, it was important to pay attention to the issues that the quality-improvement literature emphasized, such as clarifying leadership roles within teams, the presence of an external facilitator or coach, and the use of data to monitor changes.

Several dialogue participants also noted that this option highlighted for them the importance of alignments between how patients are being supported after cancer treatment with how patients with other chronic conditions are being supported. For example, one participant noted that financial incentives are being used for many other chronic conditions, which raises concerns that ‘cancer will be left behind.’ Another participant noted that quality-improvement initiatives in primary healthcare (such as those led by Health Quality Ontario) are focusing on many other chronic conditions, but not cancer. A third participant noted that hospitals are very focused on emergency-room visits and re-admission rates and hence on chronic conditions that might affect these indicators, of which cancer might be one. One dialogue participant expressed the dissenting view that cancer care does not fit the Chronic Care Model prototype because “it is not an episodic condition and self-management doesn’t work.”

### **Option 3 - Regional cancer centre purchases cancer survivorship supports**

From option 3, many participants liked the idea of the regional cancer centre:

- continuing to focus on new patients and beginning to proactively keep patients connected to their primary care provider and community supports (or in what one dialogue participant called a ‘longitudinal relationship’ with the people who will be with them over the long haul); and
- extending the reach of its existing survivorship support programs to include:
  - other types of cancer;
  - capacity to provide or link to educational, coaching, technical and referral supports and electronic tools for providers (in the form of a facilitator);
  - capacity to support self-management by patients and their families;
  - mandate to address barriers in existing local operating procedures; and
  - role for patients and their families in the design of new supports and in providing continuous feedback about them.

Some participants questioned whether a survivorship support centre should really be based in the regional cancer centre or if it would be better to base it in the community. One participant noted that the advanced practice nurse-led clinic based at Women’s College Hospital (but supported by Princess Margaret Hospital) is arguably somewhere in between these two extremes – it is out of the regional cancer centre, but in a hospital, not in the community. The concern over where the initiative was located was in part related to the belief that any steps that are taken should reduce fragmentation in the system and not increase it. One dialogue participant noted that the palliative care model in use in the region, while having achieved some successes, has increased fragmentation and suffered from a lack of ownership and accountability.

A number of dialogue participants were intrigued by the notion of having one or more facilitators in the region with the capacity to link patients to educational, coaching and a range of psychosocial supports, and to link primary care groups/teams to technical and referral supports, and to facilitate access to investigations, whether or not the individual was based in a formal centre. Some participants used the term ‘community-based facilitator,’ others ‘navigator,’ and still others ‘survivorship resource broker.’ Dialogue participants noted that many types of backgrounds might be relevant, including cancer care, community resources and quality improvement.

Others asked where the funding for psychosocial supports would come from (and specifically whether it would be feasible to re-allocate enough funds from existing programs to do this), and how the accountability

for supporting survivorship would be established. One individual argued against investing in such resources, many of which already exist, but rather investing in how primary care groups/teams use these resources. This individual considered that supporting patients to live well after treatment (including enabling peer support and self-management support) was part of the role of all primary care groups/teams, and anything that located resources outside these groups/teams contributed to the further fragmentation of the system and effectively undermined these groups/teams. Another dialogue participant concurred, arguing that the focus needed to be on supporting primary care groups/teams to leverage expertise and resources at a variety of levels (including through the facilitator or centre described above).

Regardless of whether the regional cancer centre houses a survivorship support centre (with an enhanced set of survivorship programs) or employs the facilitators, many dialogue participants supported the regional cancer centre playing a leadership role in building a more comprehensive strategy for helping all patients to live well after treatment, and for ensuring the optimal use of existing resources (which could include, over time, enhancing transitions from care in the regional cancer centre to care in the community). This means both doing what it can within the cancer centre (e.g., ensuring that its managers' performance reviews include, in part, whether they are supporting transitions to the community), and working with partners in the community.

### **Considering the full array of options**

As described previously, most participants agreed that Cancer Care Ontario's Program in Evidence-Based Care should accelerate its development of a range of disease site-sensitive and setting-appropriate cancer survivorship support plans (which could be inspired by the antenatal record as well as other tools widely used in clinical practice). However, a number of dialogue participants argued that it should be: 1) undertaken through a participatory process that builds the relationships that will support the use of these plans; and 2) supplemented with the identification of the full range of 'non-medical' survivorship-related needs, the identification or creation of the resources needed to address these needs, and the building of the capacity of primary care groups/teams to use them.

Also, many dialogue participants liked the idea of the regional cancer centre playing a leadership role in building a more comprehensive strategy for supporting patients to live well after treatment, and ensuring the optimal use of existing resources, and for now: 1) continuing to focus on new patients and beginning to proactively keep patients connected to their primary care provider and community supports from the onset of care; 2) extending the reach of its existing survivorship support programs or supporting one or more community-based facilitators; and 3) supporting (and not taking any steps that undermine) primary care groups/teams that wish to start playing a greater role in helping patients live well after treatment. A few dialogue participants expressed a preference for leadership coming from the provincial level (through Cancer Care Ontario) rather than from the regional level, however, even those individuals agreed that demonstration projects would be needed at the regional level, and that much adaptation of provincial programs necessarily takes place at the regional level where accountability resides for their success.

When the question was asked about whether any options had not been mentioned that might warrant deliberation, three options were proposed:

- 1) enhanced cancer care-related training in medical school and in family medicine residency programs (as a way to ensure receptivity and readiness among future primary care providers), and among primary healthcare providers themselves;
- 2) introduction or expansion of nurse-led high-volume clinics to provide much of the care for well patients after treatment has been completed; and

- 3) as was already mentioned, addressing the challenges associated with paying oncologists for all types of follow-up care (which can lead them to want to continue seeing well patients who could be supported in the community).

No dialogue participants argued that these options should at the present time be given greater attention than the development of cancer survivorship support plans and the regional cancer centre playing a leadership role in building a more comprehensive strategy for supporting patients to live well after treatment and ensuring the optimal use of existing resources.

One dialogue participant argued that a one-size-fits-all approach will not work, but rather what is needed is accountability for recognizing and addressing complexity, which means: 1) multiple approaches for different types of patients (e.g., those wanting active versus passive roles in their care), types of diseases (e.g., breast cancer versus genito-urinary cancer), and types of settings (e.g., urban versus rural); and 2) likely an emphasis on relationships (e.g., shared care) and contractual obligations in all circumstances. This participant argued that obstetrical care provided the best analogy to what is needed for survivorship care in the community. Establishing accountability for recognizing and addressing complexity could be seen as linked to the regional cancer centre playing a leadership role, as a fourth ‘additional’ option for future consideration or as an issue to be taken up at the implementation stage. However, the suggestion wasn’t picked up by other dialogue participants.

## **DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS**

Dialogue participants identified a number of factors that would facilitate implementation: 1) emergence of a compelling argument for change; 2) rapid growth in the use of electronic health records in the primary healthcare subsector; 3) Cancer Care Ontario’s nascent capacity to generate lists of cancer patients; and 4) the possibility of funding and an evaluation framework coming from at least two sources. However, the first facilitator had elements to it that would also create challenges.

In terms of the first facilitator – the emergence of a compelling argument for change – most dialogue participants felt there was a ‘burning platform’ for enhancing transitions from care in a regional cancer centre to survivorship in the community. They noted as system-level imperatives for change the growing demand for cancer care, increased cost containment pressures and shortages of particular types of human resources. However, others pointed out that at the level of individual healthcare providers, particularly oncologists, but also primary care providers, the story is more complicated given that patient care would be comparable (i.e., equally safe and effective) in the community, but not necessarily better than care in a regional cancer centre, pay would not be better for either oncologists or primary care providers, and work would be harder for both oncologists and primary care providers. Accordingly some dialogue participants argued that for these two groups at least, the focus would need to be on the ‘burning platform’ at the system level. Other dialogue participants noted that the bigger motivator for patients and their families would likely be the prospect for greater supports for living well after treatment (and what would not work would be any messaging that even implied that they were being ‘dumped’ from one part of the healthcare system into another).

The rapid growth in the use of electronic health records in the primary healthcare subsector – the second facilitator – would help by making it easier to monitor patients who have had cancer and to generate the data about how well different approaches to supporting survivorship care are working (including the distribution of accountability for care in shared-care models).

The third facilitator – Cancer Care Ontario’s nascent capacity to generate lists of cancer patients – would assist by allowing primary care teams/centres to identify their patients who have had cancer and allow them to begin to play a more active role in their care.

The possibility of funding and an evaluation framework coming from at least two sources – the fourth facilitator – would help to make possible demonstration projects in a resource-constrained environment, and provide the research evidence that will be needed to inform whether particular models should be more widely used. One possibility for funding would be the Canadian Institutes of Health Research through their Partnerships for Health System Improvement program, or their knowledge-translation programs. A second possibility for funding would be Cancer Care Ontario, if it broadened its work on organizational models beyond medical care (to include community resources), and if it included demonstration projects in its work.

Dialogue participants also noted a number of processes that would facilitate implementation, most of which were participatory processes, and specifically an approach that engages patients and their families, primary care groups/teams, community resources, and regional cancer centre staff.

Engaging the first group – patients and their families – could range from engaging small numbers of them on planning committees or convening a number of citizen panels. As was pointed out during the deliberation of option 1, this could involve working with individuals with experience in citizen engagement. One dialogue participant cautioned that particular attention would need to be paid to vulnerable patients. In engaging patients and their families, the most helpful way to frame the issue might be what is needed to help you or your family member live well after treatment.

Engaging primary care providers – the second group – was recognized as being challenging given the lack of governance arrangements in that subsector. However, dialogue participants noted that conversations could begin with some primary care providers with lots of ‘front line’ experience, which might include discussing how those with an interest in supporting survivorship care in the community are facing a crowded landscape in which these providers already “have the regional diabetes lead visiting them one day and the chronic obstructive lung disease lead visiting them the next day.” Other dialogue participants suggested working with and through the primary healthcare network established by the Local Health Integration Network. In engaging primary care providers, the most helpful way to frame the issue might be what is needed to help them provide optimal care to their patients who have been treated for cancer, what is already available to them as resources, and what they perceive as lacking. The list of what’s needed could begin with a list of their patients who have been treated for cancer, a ‘discharge planning’ meeting with regional cancer centre staff, a flexible set of options for shared care between oncologists and primary care providers, easy access to investigations, a direct referral mechanism for quick assessments, an inventory of community resources, and someone to call if they ‘get stuck.’ As one dialogue participant said: “Remember that primary care providers are, like most people, trying to achieve balance in their worklife, which includes knowing that they have the ability and access to the resources needed to take good care of their patients.”

Engaging the third group – community resources – was recognized to be a challenge given the lack of coordination within that domain as well. Dialogue participants noted that much could be learned from both local organizations and from organizations that have local reach, such as The Carewell Community and Wellwood. Key questions here could include what resources are already out there, how can the reach of existing resources be extended, and how can these resources be better coordinated. One individual pointed out that lessons could be learned from cardiac care in terms of how to mobilize community resources. Another dialogue participant argued that the research evidence about the benefits, harms and costs of these programs and services would need to be assessed in order to inform decisions about which are prioritized for being given greater attention.

Engaging regional cancer centre staff – the fourth group – was perceived to be more straightforward, but equally critical. Several dialogue participants noted that oncologists and nurses presumably have an implicit

template for a cancer survivorship support plan in mind, and knowledge of a certain number of existing approaches to supporting survivorship care (e.g., GP oncologists). Plus these groups will be essential to prioritize disease sites and patients and to engage in a cultural shift that will, over time, position them as members of a team that works in partnership with primary care providers and community resources.

Several dialogue participants emphasized that, regardless of the option(s) pursued, the approach to implementation should involve careful planning, taking a few steps, testing reactions to them, making adjustments, and more planning and more steps (i.e., plan, do, study, act cycles). As one dialogue participant put it: “System change requires small steps and continuous adaptation” locally, as well as “patients and their families being active partners” (who can hold the system accountable and keep collaborations together) and the source of “continued input on the small changes that would help.”

Where divergent views may have been emerging was in how to begin. One dialogue participant argued for “watching for emerging ‘grass roots’ initiatives and finding champions,” and only later asking how these developments can be spread across the system. As another individual noted, “it won’t be easy for primary care groups to take on all cancer patients, but the process needs to begin” and clear wins achieved. Coming from a different perspective, another dialogue participant said that “we need to have a comprehensive, integrated plan from the beginning,” and not one divided into medical versus ‘non-medical’ or into regional cancer centre versus community. As another individual noted: “Think about how all of the pieces fit together.” Where there seemed to be widespread agreement was in the need for flexibility in implementation.

## **DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES**

Dialogue participants generally agreed that the regional cancer centre should play a leadership role in building a more comprehensive strategy for supporting patients to live well after treatment, and ensuring the optimal use of existing resources. They also agreed that Cancer Care Ontario’s Program in Evidence-Based Care, with its partners and with other divisions at Cancer Care Ontario, should accelerate its development of a range of disease site-sensitive and setting-appropriate cancer survivorship support plans that encompass a more holistic (physical *and* psychosocial) orientation. Moreover, the program should explore collaborations with the regional cancer centre leaders to design, implement and evaluate initiatives to facilitate the local adaptation and uptake of these plans in the community.

If the regional cancer centre has the will to take on this challenge now, some of the decision points that emerged during the deliberations (including the final deliberation about next steps) included:

- establish the goal – is it better support for patients to live well after treatment, enhanced transitions from care in a regional cancer centre to care in the community, or both?;
- clarify the messages for different target audiences – is it patient experiences with not being fully supported to live well after treatment, the ‘burning platform’ of increased demand and constrained supply, research evidence about the comparable safety and effectiveness of care in the community, or some combination of the three?
- decide on the appropriate sequencing of tasks – is it the development of the cancer survivorship support plans first, the identification and coordination of community resources first, the greater engagement of primary care providers in supporting survivorship first (and within the latter, is it the focus on continuing longitudinal relationships with primary care providers at intake and later, as supports are put in place, capacity grows and demand grows, enable transitions to care in the community), or all of these simultaneously?
- choose a good process for executing these tasks – is it engaging patients and their families in some or all of these tasks, engaging community resources in some or all of these tasks, engaging primary care

providers in some or all of these tasks, or engaging some of these groups in some of these tasks at some times?

- seek funding for demonstration projects and their evaluation – is it funding from the Canadian Institutes of Health Research, Cancer Care Ontario, the regional cancer centre, or some combination of the three? and
- decide on whether to take on bigger issues, such as removing disincentives to the efficient delivery of care by oncologists and primary care providers.