
SUPPORTING THE ROLE OF PRIMARY CARE IN CANCER FOLLOW-UP

**Prepared for the Canadian Association of Provincial Cancer
Agencies**

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Preface

Guided by its goal to reduce the burden of cancer on Canadians, the Canadian Association of Cancer Prevention Agencies (CAPCA) has undertaken work to identify and describe communication and education initiatives to support the role of primary care in cancer follow-up. This initiative consisted of a three-way data collection process including: a literature review, key informant interviews with leaders in the field, and an environmental scan of Canadian cancer related agencies, organizations, foundations and educational institutions

Two domains to improve follow-up care for cancer patients were prioritized and served as a foundation for this work:

- **Communication practices and processes** designed to improve communication between oncology providers and primary care providers when medical responsibility for follow-up care is transitioning or complete.
- **Formal and continuing educational initiatives** aimed at supporting primary care providers in the provision of high quality survivorship care to cancer patients.

This report, *Supporting the Role of Primary Care in Care in Cancer Follow-up*, consists of three sections:

- Section 1: Presents the findings of the literature review
- Section 2: Reports on the findings of the key informant interviews
- Section 3: Summarizes the results of the environmental scan

SECTION ONE:

LITERATURE REVIEW

1.0 Context

With the growing rate of cancer survivors, there comes a growing need for research related to best practices in cancer follow-up and survivorship care. One particular area of concern surrounds the most efficacious practices and policies for the transition between treatment and cancer follow-up, particularly in relation to care at the interface between primary care and specialist care during the survivorship period. The objectives of this literature review are twofold: 1) to discuss communication practices and processes between primary care providers (PCPs), most of whom are family physicians, and specialists at the time of complete or partial transfer of medical responsibility for follow-up care to primary care providers after potentially curative treatment; and 2) to describe the content and availability of formal and continuing education activities and programs designed to support primary care physicians and other health care providers in the provision of survivorship care to cancer patients.

Specifically, the first portion of the literature review will describe the current state of communication practices between primary care providers and specialists; challenges in shared care and communication, including concerns raised by general practitioners and other primary care providers, oncologists, and patients, respectively; and proposed methods of addressing the issues with current practices in shared care, including a discussion of survivorship care plans, development of practice guidelines, models of care, a system for financial reimbursement, and areas for future research (refer to Appendix A for an annotated bibliography of communication references). Further, the second portion of this document will address the quality of shared care and will address the second paper objective. That is, it will include a discussion on the current state of oncology education for primary care providers; issues that exist with the current education system; educational interventions in formal education contexts; and finally, a brief discussion on continuing education programs and resources available to the public (refer to Appendix B for an annotated bibliography of education references).

2.0 Methods

An article database search was completed in June, 2010 using: British Medical Journal, CINAHL, Evidence Based Medicine Reviews, MEDLINE, Health Source: Nursing/Academic Edition, PubMed, Science Direct, and Web of Science databases. Search terms and phrases included: cancer, communication, education, health care (providers), primary care (providers), oncology (providers), survivorship care, care plan, follow-up care, and shared care. Truncations were used to search alternate term endings. Further, specific searches were conducted for literature published by researchers known to be working in the field interest (e.g., Linda Jacobs, Eva Grunfeld, Craig Earle, Patricia Ganz, Claire Snyder, and Julia Rowland). In addition to conducting a database search, pertinent research articles and documents were identified by key informants and were included in the review. Finally, manual searches were conducted using the reference lists of retrieved articles and in journals known to contain articles addressing cancer survivorship (i.e., Journal of Cancer Survivorship and Journal of the National Cancer Institute: Monographs).

3.0 Results - Communication

3.1 The Current State of Communication

There is a great deal of discussion about best practices in care provision during the transition to survivorship. Currently, literature indicates that responsibility for survivorship care is distributed differentially. For instance, some have reported that in all stages, with the exception of active treatment, cancer patients saw their family physician (FP) more frequently than any other physician (Del Giudice et al., 2006), whereas data from OncoLife users indicated that about one third routinely receive follow-up care from both their oncologist and a PCP, with the majority of the remaining patients seeing only an oncologist (Hewitt, Bamundo, Day, & Harvey, 2007). Another study reported that 86% of specialists stated that they 'cooperated with other specialists' in the management of breast cancer follow-up. This data was confirmed by GPs, who reported that their patients were typically followed by two or more specialists in 85% of cases (Paradiso, Nitti, Frezza, & Scorpiglione, 1995). Secondary analysis of data from The National Survey of NHS Patients: Cancer showed that, following discharge, almost half of survivors received care from their GP and almost half from a community, district or specialist nurse. Patients with different cancers had different discharge arrangements in terms of who they were told to see and who they did see (Allgar & Neal, 2005). Others have shown that rural survivors tend to receive care from their FP as opposed to an oncologist comparatively more frequently than their urban counterparts (Miedema, Tatemichi, & MacDonald, 2004). In an analysis of retrospective data, authors have shown that patient visits to their PCP significantly increase over a five year period of follow-up, accompanied by a significant decrease in visits to oncology specialists (Snyder et al., 2008a). Also, comparative analysis of data from 1997 and 2001 showed an increase over time in the number of survivors seeing both a PCP and an oncologist, and a decrease in the number seeing neither (Snyder et al., 2008b).

It seems that there is a relationship between the type of follow-up care survivors receive and the physician(s) from whom they receive care. One study found that each of the preventive care services investigated was more frequently received by survivors who visited both a PCP and oncology specialist, followed by survivors who saw a PCP only (Snyder et al., 2008b). However, a literature review found that cancer surveillance was more likely to occur when an oncologist was involved in survivorship care, and further, that the type of follow-up care provided differed between provider types. That is, patients who were followed only by primary care physicians were more likely to receive preventive interventions directed at non-cancer conditions, whereas those followed by oncologists were more likely to receive interventions directed at cancer surveillance (Grunfeld & Earle, 2010).

While the focus of follow-up procedures may differ between GPs and oncologists, research indicates that outcomes related to cancer recurrence appear to be similar. A study by Grunfeld and colleagues (2006) demonstrated that regardless of the follow-up care arrangements, serious clinical events (SCEs) are both extremely rare and equal in frequency. In another study of postsurgical colon cancer patients randomly assigned to either 'GP-led' or 'surgeon-led' follow-up, no significant differences were found between groups for quality of life, depression and anxiety, or patient satisfaction (Wattchow et al., 2006).

Although evidence shows differences in follow-up care, common sense dictates, and research supports, that communication is essential. A meta-analysis for collaboration between primary care physicians and specialists found that interactive communication is associated with

improved patient outcomes (Foy et al., 2010). While this study only found evidence relating to collaborations with psychiatrists and endocrinologists, the consistency of the effects across different criteria suggests the potential of interactive communication to improve the effect of collaboration across other specialties and conditions. Therefore, regardless of the duties carried out by each cancer provider, what is clear from collective research in current practices is that both GPs and oncologists have a role in cancer care follow-up and consequently, there is a need for comprehensive communication among physicians and between physicians and survivors in order to ensure that the best possible quality of care is provided. Unfortunately, despite the necessity of clear communication, oncology specialists, GPs and other primary care providers, and survivors all report a number of issues that exist with communication and follow-up care practices.

3.2 Issues that exist with current communication practices

According to a systematic review of qualitative studies exploring patients' and healthcare professionals' views and preferences with regard to cancer follow-up, significant communication problems exist, in both directions, between primary and secondary care (Lewis et al., 2009). As stated by Preston and colleagues (1999), health professionals must recognize the interdependency of their roles within the health care system if patients are to avoid the fragmented care and system failures that cause patients to feel 'in limbo', or a state of unsupported transition. However, the functioning of the care team and their communication may be affected by a number of factors. For example, one study found that the functioning of multi-disciplinary care teams was influenced by: organizational culture and management support; financial incentives, referral policies or hospital and/or practice characteristics; level of competition for cancer services in the local market; and availability of reimbursement of physician time (Fennell et al., 2010). Various other factors have been reported by both care providers and patients as affecting communication and service delivery.

a.) The Perspectives of GPs and other Primary Care Providers

Several studies have investigated the attitudes of GPs towards providing follow-up care for cancer survivors. A self-administered survey found that 50-55% of PCPs were willing to assume exclusive care for breast, prostate, and CR cancer within 2 years after completion of active treatment and 42% were willing for lymphoma. PCPs not currently providing exclusive follow-up care were more likely to favour specialist care and less likely to agree that PCPs have the skills necessary to provide routine follow-up for patients with cancer (Del Giudice et al., 2009). Similarly, another study found that 52.0% were comfortable or very comfortable in having responsibility for the surveillance of cancer recurrence, and 43.0% were confident or very confident that they were following standard guidelines of surveillance for cancer recurrence, with similar percentages for breast and colorectal cancer (Nissen, et al., 2007). Papagrigradias and Koreli (2001) found that 43% of physicians thought that following up with colorectal cancer (CRC) patients after the first post-operative year was a natural part of the care GPs provide, whereas 39% said it was not really their job. Finally, a literature review conducted by Grunfeld and colleagues (2009) reported that the results of two randomized controlled trials indicated that PCPs were willing to assume follow-up care with proper guidelines and a clear transition of care. An earlier study found that 68.6% of GPs' 'most preferred' follow-up routine was by the patient's GP with referral back to hospital clinics if problems developed (Grunfeld et al, 1995). On the other hand, a study by Wood (1993) found that very few family physicians wanted to

take full responsibility for follow-up care. Two studies also found that a majority of GPs wanted to be involved at an earlier stage in cancer follow-up care and that PCPs believe that they are better placed than oncologists to provide psychosocial support to their patients (Del Giudice et al., 2009; Grunfeld et al., 2009).

In order to participate in follow-up care, many studies indicated that PCPs expressed needs that were either unmet or needed to be met. These included: provision of guidelines (Papagrigroriadis & Koreli, 2001); fast re-referral of their patients (Papagrigroriadis & Koreli, 2001; Grunfeld et al., 1995); further training and access to resources (Grunfeld et al., 1995; Kantsiper et al., 2009; Nissen et al., 2007; Papagrigroriadis & Koreli, 2001); tools to stay connected with the oncologist (e.g., survivorship care plan or other written communication) (Kantsiper et al., 2009; Nissen et al., 2007; Braun et al., 2003); a system for communication with the oncologist (Paradiso et al., 1995; Kantsiper et al., 2009; Nissen et al., 2007); assurance that patients are satisfied with PCP versus specialist follow-up (Del Giudice et al., 2009); a defined role in the delivery of care (Wood, 1993); and adequate compensation for participation (Grunfeld et al., 1995). Furthermore, Wood (1993) found that FPs experience both extrinsic and intrinsic barriers to communication. These included: not being aware of the correct specialist to contact for information; follow-up care by several physicians resulting in poor continuity of care, conflicting information being given to patients, and a lack of trust between patient and specialist; preferring personal communication; delays in referrals to specialists and in reports and results of tests; lack of information about discharge and follow-up plans; inability to access information about guidelines for follow up in remission of each cancer site; intimidation by specialists and a lack of self-confidence and credibility in cancer care; fear of being blamed for mismanagement, missing a recurrence, or losing specialist support; and inadequate knowledge.

In summary, while PCPs generally express interest in participating in follow-up care for survivors, the current process of transfer of care from the oncologist to the PCP is reportedly unsatisfactory, and several barriers exist that prevent successful transition. As such, PCPs believe that a formal transfer of care and a close working relationship between care providers is needed.

b.) The Perspectives of Oncology Specialists

Several studies have investigated the attitudes and practices of oncology specialists in relation to follow-up responsibilities and discharge to primary care. In one study, the majority of specialists reported that they routinely discharge patients at some point to their primary care physicians for follow-up, but only a small percentage did so immediately after completing primary treatment. Further, only about a quarter of respondents believed primary care physicians should have primary responsibility for follow-up care; this may be related to the fact that about half of specialists believed they were more efficient providers of follow-up care than PCPs. However, 66% were in favour of coordinating follow-up care between PCPs and specialists and over half believed that PCPs have the skills to provide follow-up and were typically better at providing psychosocial support (Earle et al, 2003). Another study similarly reported support for shared follow-up care (Watson, Sugden, & Rose, 2010). It is important to note that confidence in primary care was a consideration in discharge for almost half of respondents in one study (Watson et al., 2010). It has also been reported that specialists believed the greatest benefit of discharge to primary care was 'reduced clinic workload' (Donnelly et al., 2007).

As with PCPs, oncologists report a number of barriers to shared care or transfer of follow-up care. First, while it has been documented that most oncologists use guidelines to determine discharge from follow-up, most used local rather than national guidelines (Watson et al., 2010; Donnelly et al., 2007), which likely contributes to variability in practice and confusion surrounding protocols for other parties involved in care. Also, similar to results found with PCPs, many specialists are concerned that GPs do not have the necessary skills or training to conduct follow-up (Grunfeld et al., 1995; Donnelly et al., 2007; Kantsiper et al., 2009). Oncologists have also expressed concern that transfer may lead to the loss of patient outcome data (Donnelly et al., 2007) and are concerned that survivors' needs may not continue to be met (Kantsiper et al., 2009). In addition, Wood (1996) reported that although oncologists desired to have better communication with PCPs, they perceived a number of barriers. Extrinsic barriers included: variability in FPs interest and commitment to ongoing cancer care and surveillance; difficulty becoming acquainted with all FPs in the area; inadequate time; inability to contact FPs; and seldom receiving information from FPs about tests, hospital admissions, incidental illness, or surgery. Intrinsic barriers included: making little effort to include family physicians on the management team; operating within the exclusive domain of the cancer centre, and using the primary care nurse as a key contact and resource for patients during treatment and follow up; time and work pressures; and fulfilling personal needs of seeing patients in remission.

Oncology specialists agree that communication with PCPs could be improved (Kantsiper et al., 2009). Several suggestions for improved communication and care provision have been made, many of which echo the suggestions of PCPs. These include: identifying a core group of FPs to act as key resources (Wood, 1996); making an effort to communicate and collaborate (Wood, 1996); developing follow-up guidelines and protocols (Wood, 1996; Paradiso et al., 1995; Donnelly et al., 2007); offering informal seminars or discussion groups for FPs (Wood, 1996); maintaining a two-way flow of information (Wood, 1996); having a shared plan of follow-up care (Wood, 1996; Kantsiper et al., 2009; Watson et al., 2010); having an open house at the cancer centre (Wood, 1996); increased GP education and training (Donnelly et al., 2007); and including oncology nurses in primary care (Donnelly et al., 2007).

c.) The Perspectives of Survivors

Patients report having a variety of discharge arrangements following cancer treatment along with varying levels of satisfaction. For instance, Grunfeld (2009) found that follow-up other than with the specialist, including primary care-based follow-up and nurse-led follow-up, are not only acceptable for breast cancer patients, but also produce good quality-of-life outcomes. Another study of patients who underwent GP follow-up found that most patients felt that their GP was given enough information about their treatment, although this differed by type of cancer (Allgar & Neal, 2005). A study in New Brunswick showed that patients would readily accept follow-up care from their FP, particularly in rural areas (Miedema et al., 2004). Also, breast cancer survivors have reported general satisfaction with primary care delivery of survivorship care, particularly in relation to psychological care, health promotion, and holism; however, PCP-oncologist communication was rated poorly (Mao et al., 2009). Conversely, others reported being very satisfied with the clinical aspects of their care, but dissatisfied with their physician's lack of attention to their psychological needs (Hewitt et al., 2007), or have indicated that neither their oncology specialists nor their PCPs had adequately addressed psychosocial needs (Kantsiper et al., 2009). Further, Grunfeld and colleagues (2006) noted that while family physician follow-up was interpreted as acceptable to the majority of patients, some patients would be unwilling to have follow-up care transferred to their FP. Indeed, this is supported by

other research, where survivors reported a special regard for the expertise of oncology specialists and, even when they had established PCPs, most did not believe they should have a central role in their cancer-related needs (Kantsiper et al., 2009).

Much like their follow-up providers, survivors also identified a number of issues with the follow-up procedures. These include: loss of medical and emotional support after completion of acute treatment (Miedema et al., 2004); low confidence about being referred, or receiving appropriate treatment, when relations with personal GP were poor or absent (Preston et al., 1999); inconsistent care across settings resulting in reduced confidence in care providers, increased anxiety, and feelings of not being valued as individuals (Preston et al., 1999); and delay or absence of expected services (Preston et al., 1999).

In order to provide comprehensive and continuous care, several suggestions have been made, that again, resemble those of care providers. Cancer specialists should make an attempt to involve FPs in follow-up care in order to ensure continuity of care after acute treatment and thus meet patient needs (Miedema et al., 2004). Breast cancer survivors reported that the following actions were needed: teaching PCPs about issues relevant to BCS; improving communication between oncologists and PCPs; teaching themselves about how to communicate with their PCPs and oncologists so that the care could be cohesive; and developing a primary care clinic specifically for BCSs (Mao et al., 2009). Survivors also felt that a written document or ongoing communication between their specialty providers and PCP would be an asset to coordinating their care, although they argued it must not take the place of active participation of oncology specialists in their health care (Kantsiper et al., 2009). Finally, it is noteworthy that one study found that telling patients to contact their GP post-discharge influenced their choice to visit their GP. The authors suggest that it would thus make sense to recommend this to all patients on discharge if it is necessary, as failing to do so may reinforce beliefs that GPs lack sufficient expertise to assess and manage cancer problems (Allgar & Neal, 2005).

d.) Lack of Role Clarity

It is apparent from the preceding discussion that oncologists, PCPs, and patients express confusion about the roles of each participant in the follow-up care process. In an examination of patients', oncologists', and PCPs' perspectives on roles in survivorship care, Cheung and colleagues (2009) found the concordance rates for several survivorship care domains were poor, with PCPs and oncologists expressing an overlap in their duty expectations. Patients and their PCPs had highly incongruent opinions for primary cancer follow-up, with PCPs indicating they should contribute a much greater role than patients believed. These incongruencies in role definition indicate uncertainty on the parts of patients and providers about who is and should be responsible for follow-up care, which may result in overuse or underuse of appropriate medical services. In addition, Grunfeld and Earle (2010) suggest that differences in provision of preventive care between PCPs and specialists may result in failure to deliver important services when a primary care physician is not actually involved in follow-up. Indeed, they report that primary care providers express concerns about the lack of role clarity and thus have low confidence in managing survivors. In conclusion, if transfer of at least some responsibility for follow-up is to be passed to primary care and shared care is going to be effective, there is a dire need for delineation of roles and responsibilities for PCPs and specialists and coordination among all providers.

3.3 Proposed Solutions to Communication Challenges in Follow-up Care

Several recommendations have been made to address the many challenges and issues that exist with physician communication and follow-up care with cancer survivors, including: the implementation of survivorship care plans; evaluation of various models of care; creation of guidelines; conducting research; changes to policy and practice in compensation; and changes to formal and continuing education. Each of these is described in more detail in the following section.

a.) The Use of Survivorship Care Plans

One of the key suggestions for addressing issues related to poor shared care communication and suboptimal follow-up care is the survivorship care plan (e.g., Ganz, 2009; Ganz & Hahn, 2008; Horning, 2008; Ristovski-Slijepcevic, 2008). Survivorship care plans (SCPs) have been identified as an important means of promoting coordination of care and aiding the transition from cancer patient to cancer survivor (Faul et al., 2010; Lewis et al., 2009). Ideally, SCPs should be: tailored to each cancer survivor; modified according to developing concerns and needs; shared with the patient, the primary care provider and members of the patient's support network; and modifiable upon completion of active therapy (Gilbert et al., 2008).

i.) Contents of care plans

Several review documents provide summaries of care plan contents (e.g., Ganz & Hahn, 2008; Horning, 2008; Ganz et al., 2008). Collectively, authors have suggested that care plans should include the following components: protocol for surveillance of recurrence (ideally organized around a set of widely known clinical practice guidelines) (Earle, 2006; Gilbert et al., 2008); identify health priorities, including psychosocial concerns and lifestyle practices (Earle, 2006, Gilbert et al., 2008; Ristovski-Slijepcevic, 2008); address employment, insurance and economic issues (Earle, 2006); identify which providers will be responsible for which roles (Earle, 2006; Gilbert et al., 2008); specify information outlining recommended tests and their frequency to monitor for recurrence, second malignancies, ongoing toxicities, and late effects (Faul et al., 2010); patient's cancer and treatment history (Gilbert et al., 2008; Miller, 2008; Ristovski-Slijepcevic, 2008); and contact information for each specialist (Miller, 2008). The SCP should be patient-centered and tailored to each patient's situation and preferences (Earle, 2006; Gilbert et al., 2008) and copies should be provided to all care providers as well as the patient (Miller, 2008).

ii.) Acceptability of SCPs to Stakeholders

Generally, it has been found that the SCPs are acceptable to all stakeholders involved in follow-up care. With survivors, some data show that cancer survivors feel that they did not receive the information recommended for inclusion in the SCP (Baravelli et al., 2009), and prior to delivery of the care plans they reported confusion about care terminology (Miller, 2008). After viewing care plans, survivors reported that information provided clarified several issues regarding their cancer histories and treatments (Miller, 2008), and other studies have reported that participants are especially satisfied with the inclusion of elements such as lifestyle changes, psychosocial and practical issues. (Baravelli et al., 2009; Hewitt et al., 2007). Similarly, PCPs reported that the information that should be included in the SCP is currently absent, fragmented or hard to find (Baravelli et al., 2009), and that receiving this information in the form of a SCP would be

valuable as a way to strengthen collaborative communication (Baravelli et al., 2009; Miller, 2008) and simplify coordinated care (Hewitt et al., 2007). Also, in one study, both PCPs and oncologists agreed that patients would benefit by having the follow-up plan provided to them by their health care provider (Hewitt et al., 2007). Nurses also acknowledged that there is no formalized approach to the post-treatment transition period and believed they could develop and deliver survivorship care plans from the clinical record and their knowledge of the patient, though believed that staffing, the recognition of a nursing role in care planning, and reimbursement were barriers to their involvement (Hewitt et al., 2007). Generally all stakeholders agreed that the document would have to be modifiable throughout the course of treatment and follow-up in order for it to be useful (Hewitt et al., 2007). Although oncology providers believed the plan would have benefits, in one study they also indicated that they would not be inclined to provide it unless it could replace other documents sent to both insurers and other care providers, and would take no longer than 20 minutes to complete (Hewitt et al., 2007).

iii.) *Barriers to SCP implementation*

Several barriers to SCP implementation have been reported. Some stakeholders did not believe a care plan would be easy to produce (Watson, et al., 2010). Other reported barriers included: time and resource constraints (Watson, et al., 2010; Baravelli); need for a standardised format (Watson et al., 2010; Earle, 2006) and lack of role definition for various care providers (Watson et al., 2010; Earle, 2006). At this point, it is also unknown whether the creation of care plans saves money or costs money, and thus is unclear to payers whether it is in their interest to fund this activity. Consequently, widespread implementation of survivorship care plans will require a culture change in which it becomes a required part of good cancer practice. Patients and referring physicians, such as the PCP, can help effect this change by demanding a care plan (Grunfeld & Earle, 2010; Hewitt et al., 2007) and encouraging the adoption of electronic medical records, which will facilitate the creation of the summary and care plan (Hewitt et al., 2007).

iv.) *Examples of SCP templates*

Several organizations have created templates for survivorship care plans. The ASCO Cancer Survivorship Expert Panel has created templates of a treatment summary and a survivorship care plan for colon cancer (Faul et al., 2010) and breast cancer patients as well as an associated 1-page survivorship care plan that outlines the recommended follow-up care and surveillance for both of these groups of patients. ASCO has also released a generic template that can be used for any cancer site, with plans for other disease-specific sites such as lung and prostate cancer (Ganz et al., 2008; Jacobs, et al, 2009). The ASCO templates are available on the ASCO Web site at <http://www.asco.org>.

The LIVESTRONG Care Plan (formerly OncoLink) (<http://www.livestrongcareplan.org>) allows the generation of several versions of a care plan for the differing needs of patients and providers and can be completed by survivors, families, or providers (Jacobs et al., 2009; Hill-Kayser et al., 2009). The National Comprehensive Cancer Network and the American Cancer Society also have resources and materials focused on survivorship issues, guidelines, and survivorship care plans (Ganz et al, 2008). Journey Forward is a program designed for providers and patients who have recently completed active cancer treatment. Journey Forward kits are available online at <http://www.JourneyForward.org>, and they are tailored to oncologists, patients, and primary care physicians. The Cancer Survivor's Prescription for Living is a template developed by and for nurses in oncological practices (available at <http://tiny.cc/SFA8e>). It requires handwritten input of

treatment and disease information and is not currently available in an electronic version. A number of institutions are developing and implementing their own internal treatment summary and/or consensus-driven survivor care plan templates, including the Abramson Cancer Center at the University of Pennsylvania, Fred Hutchinson Cancer Research Center, Memorial Sloan-Kettering Cancer Center (<http://tiny.cc/rqgxq>), the University of Colorado Cancer Center, and the Dana Farber Cancer Institute (Jacobs et al, 2009).

b.) Models of Care

Identifying a model of care for use may be one way to address the issue of lack of role definition of care providers during the transfer to survivorship care. The literature describes several models of care that have relevance for survivorship care. First, Fennell and colleagues (2010) describe collaborative care through development of multidisciplinary (MDC) teams, which include primary care providers, specialists, and patient involvement, with the primary care provider acting in a care coordinator role. Quality of life considerations may also be addressed through the inclusion of psychologists, social workers, nurses, nutritionists, and/or spiritual advisors. Second, the shared-care model involves care coordinated between two or more health care providers in different specialties or locations and may include the development of an SCP. A care manager may also serve as a coordinating intermediary between the oncologist and primary care physician. This model may be easier than others to implement because it utilizes existing resources (Gilbert et al., 2008). Third, a “consult” model has survivors participate in a one time comprehensive consultative service either by a physician and/or a mid-level practitioner (Shapiro et al., 2009); this may also occur in addition to ongoing care with the treatment team (McCabe & Jacobs, 2008). Fourth, is an ongoing care model in which patients are transferred to a physician and/or nurse practitioner with expertise in survivorship care at a predetermined time post-treatment (Shapiro et al., 2009). McCabe and Jacobs (2008) also describe several clinic-based models of care including the nurse practitioner-led clinic where care is transferred to a nurse practitioner after the completion of therapy. Nurses may also be involved in the development of care plans at a post-treatment follow-up visit, and subsequently enable a smooth transfer of care to other providers.

As Grunfeld (2009) notes, alternative models of follow-up are likely to be equivalent to specialist follow-up which suggests that perhaps the adoption of a ‘best practice’ model should not be the goal. Rather, it may be that models should be adopted on an individual basis to best meet the specific needs of the patient. Lewis and colleagues (2009) suggest that regardless of the model of survivorship care applied, each should include: a system of rapid referral for investigations; include training and specialist support for GPs, nurses, and other healthcare professionals; collaboration of the whole cancer team and primary care from the outset; clear protocol/guidelines agreed upon by all parties in advance; and allow for alternative (other than GP) primary care-based follow-up if the patient wishes.

c.) Development of Follow-up Practice Guidelines

Although many have expressed the need for the development of guidelines for follow-up care, few examples exist to date, and further, there is still a need for evidence of their effectiveness in clinical settings. Grunfeld and colleagues (2005) provide updated clinical practice guidelines for breast cancer. Also, other organizations are currently working towards the development of guidelines. For instance, the LIVESTRONG survivorship center of excellence network includes in its mandate the development of best practices regarding survivorship care for dissemination

to the general community (Shapiro et al., 2009). The BC Family Physician Oncology Network is also collaborating with the provincial Guidelines and Protocols Advisory Committee to develop practical, user-friendly cancer care guidelines for family physicians (BC Cancer Agency, 2010). Although evidence for effectiveness of guidelines is still limited, published guidelines provide clinicians with basic communication strategies to prepare them for difficult interactions and therefore seem intuitively useful. Considering the limited evidence base, Eggly and colleagues (2009) suggest that another potential method of developing practice guidelines is the application of transdisciplinary theories and approaches by researchers, clinicians, patient advocates, and patients. These include the convergence model of communication, the Common Group Identity Model, and the Cognitive-Social Health Information Processing model, all of which are drawn from the fields of social psychology and communications.

d.) System for Financial Reimbursement for Activities Related to Survivorship Care

At present, health care providers working in some systems are not reimbursed for consultation visits that address survivorship care and the time invested to create SCPs. To ensure that the practice is implemented and sustained, strategies for reimbursement are needed. One study suggests that if GPs/FPs are to assume greater responsibility for cancer care, they need to be supported by remunerating their activities appropriately (Del Giudice et al., 2006). Likewise for insurers to reimburse oncologists, the initial care summary and updates could be used to preauthorize elements of care and to provide proof of service for reimbursement purposes (Hewitt et al., 2007).

e.) Calls for Further Research

To date, research in the area of best practices in survivorship care is lacking. As such, there are many areas that necessitate further research. First and foremost, the IOM report called for implementation and evaluation of SCPs, which have yet to be widely adopted or investigated despite potential benefits (Faul et al., 2010). Other areas for future research include: observational studies to determine survivor's knowledge and desire for this information (Earle, 2006); evaluating levels of satisfaction with transition to follow-up care and how this relates to reception of care plans (Earle, 2006; Taplin et al., 2010); assessing variation in follow-up practices and models of care, including acceptability to stakeholders (Earle, 2006; Grunfeld, 2009); evaluating ways to optimize communication between care providers, including development and use of information technology such as electronic medical records (Wood, 1996); assessment of different survivorship care plan formats (Earle, 2006; Taplin et al., 2010; Levitt & Lupea, 2009); determining optimal levels of involvement of different physicians in the creation and execution of survivorship plans (Earle, 2006); and exploring new ways to improve the engagement of primary care providers in follow-up care (Levitt & Lupea, 2009).

f.) Education changes related to cancer patient and survivor care

Ultimately, to achieve truly patient-centered communication, physicians need to develop skills to assess individual patient communication needs and preferences, and to tailor their communication accordingly. Also, it is clear from the assessment of barriers in effective survivorship care provision that all stakeholders involved in the care process believe that PCPs could enhance their role in survivorship care through oncology specific education and training. The next section of this paper will provide a further description of the content and availability of

formal and continuing education activities and programs designed to support PCPs and other health care providers in the provision of survivorship care for cancer patients.

4.0 Results - Education

4.1 Current Issues in Education

Evaluations of formal education content and student knowledge indicate that significant gaps exist in the area of oncology. In a study that evaluated oncology education among undergraduate studies (UGS) in medicine, nursing, and pharmacy, as well as post-graduate studies (PGR) in family medicine and internal medicine across Canada, the researchers found that few UGS and PGR devoted more than one week during their entire program towards cancer education. Further, cancer-related courses and rotations constituted less than 10% of the curriculum in the majority of programs. Clinical electives in cancer and cancer-related subspecialties were largely available to trainees enrolled in programs such as medical schools and IM residencies, but less so in nursing, pharmacy schools, and FM residencies. However, even in programs where cancer electives were available, only a minority of trainees actually participated in these optional clinical activities. This may suggest the necessity of promoting oncology as a meaningful and rewarding field (Cheung, Fishman, & Verma, 2009).

In addition, another study found that even after attempts to improve university oncology curricula via increasing the number of specialized oncology staff, compulsory instruction hours focusing on cancer-related issues, range of electives on basic and clinical oncology courses, elective medical rotations, and the distribution of a comprehensive oncology book to the 4th year students, few students believed that the quality of education was high. However, there was an increase in the number of students who believed the quality of education was satisfactory. Results indicated that the total amount of instruction hours dedicated to oncology-related topics and the time of clinical practice with cancer patients were still considered limited. Further, students emphasized the need for development of pre-clinical experience in cancer care and creating better awareness of the psychosocial aspects, ethical issues, and behavioral prejudices during patient care. It appears that excessive emphasis is put on clinical topics, whereas the importance of interpersonal skills and cancer prevention receive comparatively little attention (Karamouzis et al., 2006).

In keeping with the preceding discussion on the gaps in formal oncology education curriculum, it is not surprising that a study that surveyed oncologists and teachers (and previously students) in the undergraduate cancer curriculum in Australian Medical schools found that, although teachers identified cancer screening and prevention as important in undergrad training, there were deficiencies in student knowledge which may have indicated differences in faculty knowledge. There were indications of a lack of familiarity with epidemiological data even by specialists treating the disease on a regular basis (Tattersall et al., 1993).

4.2 Formal Education and Curriculum Interventions

Interventions aimed at addressing issues in oncology education have shown some success. One intervention conducted by Elliot and colleagues (2001; 2002) included educational activities directed at physicians, nurses, and pharmacists practicing in rural communities that had been randomly assigned to the experimental condition. The eight components of the educational intervention included: clinical opinion leaders; annual mini-fellowships for the clinical opinion

leaders; bimonthly cancer conferences in each experimental community; quarterly project newsletters; a rapid-cycle quality improvement system based on feedback of practice data; clinical practice guidelines; a telecommunication system linking experimental communities with the regional cancer center; and annual rural advisory committee meetings held in each experimental community. Results of intervention indicated that knowledge scores on discipline-specific cancer-management tests for physicians, nurses, and pharmacists increased significantly from pre-test to post-test. Providers exposed to the educational intervention also outperformed the healthcare providers in both control groups at post-test. Neither the clinical opinion leader nor the outreach oncology consultations in the rural community had a measurable effect on knowledge (Elliot et al., 2001). On the other hand, the intervention was only effective in significantly improving 5 of the 37 behavioural end points; however, physicians had a better than expected baseline performance which limited the possibility of detecting an intervention effect (Elliot et al., 2002).

Another study provided a workshop for oncology fellows that combined lectures, interviews with simulated patients, role playing and exercises encouraging reflection and introspection. Results indicated increased self-efficacy, knowledge of specific communication strategies, and a change in attitudes toward communication. An additional change that occurred related to the ability to reflect on their own reaction to patients' emotions and the ability to respond with an empathic statement rather than offering a practical "remedy". Immediately after the workshop, the fellows reported that they were significantly more likely to engage in 9 of the 15 breaking-bad-news tasks and were more likely to implement 3 of the 15 tasks 6 weeks after the workshop (Lenzi et al., 2005).

Uijtdehaage and colleagues (2009a) conducted an assessment of the need for change in curriculum at three universities based on senior medical student knowledge about cancer. On average, students answered about half of the questions correctly, whereas oncology fellows performed only slightly better. An average negative score indicated that students may have misconceptions, and not just lack of knowledge, about some of the consequences of cancer treatment. Students were exposed to cancer survivors frequently in medical school but only half of the students received direct instruction or practiced critical components of survivorship care and, perhaps consequently, reported low confidence in all cancer survivorship-related patient care activities such as giving bad news, tailoring pain medication, and working with a specialty team (Uijtdehaage et al., 2009a).

Following this survey, the three participating institutions implemented a four-year comprehensive survivorship curriculum which focused on common cancers with increasing survival rates. Results of student evaluations and a cohort study with a historical control group showed that educational outcomes gradually improved as the cancer survivorship modules were introduced into the curriculum. Compared to the historical controls, the intervention groups at two of the universities improved their scores on average by 43%. Students at all institutions reported being more comfortable in several care activities and having encountered more cancer survivors compared to the control group. Many of the curriculum materials can be downloaded from a dedicated website or requested free of charge (Uijtdehaage et al., 2009b).

4.3 Examples of Continuing Education Programs

As more already practicing PCPs are participating in survivorship care, there is an increasing need for professional training in order to prepare them for this role. Curricula have been

developed to train physicians to communicate effectively in a variety of interaction contexts. Further, accreditation agencies for many health professional training programs currently require documentation of trainees' level of competence in interpersonal communication (Eggly et al., 2009). Other continuing education programs include the Preceptor Program, offered through the Family Physician Oncology Network, which provides the opportunity for physicians to strengthen their oncology skills and subsequently enhance cancer care in their communities through providing support for oncology care. The program is offered in a flexible, modular format that can be taken in eight consecutive weeks or over a six-month period. This first session also includes the opportunity to attend clinical rounds and tumour site conferences. Participants are encouraged to tailor their learning specific to their community's needs. (BC Cancer Agency, 2010). Also, Cancer Care Ontario (2009) has created a self-directed learning manual for general practitioners in oncology. The program includes clinical scenarios, recommended reading lists, and resources available on-line to assist a general practitioner/family medicine physician in efficiently gaining knowledge to use in clinical practice. The manual is organized on a disease site-specific basis and will be updated on an annual basis to ensure relevancy of resources.

In addition, other continuing education programs have been implemented and have available evaluation data. In one colorectal cancer program, training began with a day-long workshop which included instruction and community team development of strategies for conducting a community needs assessment and completing a community plan. At a second workshop, each team presented their draft plan and received expert feedback. From pre-test to post-test, there were significant increases in correct responses about community-based public health, sponsorship of the National Plan, and CRC survivorship and treatment (following the first workshop), as well as increases for knowledge of PRECEDE-PROCEED as a community health planning model and that memory loss is not a necessary part of CRC survivorship (following the second workshop). Teams developed plans to better address CRC care, with most including efforts to enhance treatment-related care, psychosocial care, and primary health care. The data suggest that this study helped increase the linkage of local survivorship initiatives in rural areas to national efforts in cancer survivorship (Lengerich et al., 2007). Also, Sisler and McCormack-Speak (2009) describe the uniting Primary Care and Oncology (UPCON) Network, a program of CancerCare Manitoba (CCMB), designed to enhance partnerships between family physicians and the cancer system. The main focus of the program involved the development of lead FPs who participated in orientation events, 8 hours of cancer clinic exposure, periodic meetings, and monthly small group education sessions about cancer and access to the cancer care system. They could subsequently act as cancer care resources for others in practice. Participant reports generally indicated that UPCON effectively improved the working relationship with CCMB and having lead physicians in their clinics was useful. Most cancer patients who had been referred to new FPs through UPCON were satisfied with coordination of care due in part to receiving consistent information from the FP and the cancer clinic, and FP awareness of tests and treatments done at CCMB.

A final training program included four annual three-day courses based on concepts of cancer survivor quality of life, performance improvement, and principles of adult education. For this survivorship course, several follow up approaches were implemented in order to provide additional resources and keep participants engaged following the course. Approaches included provision of course materials, resources, faculty and participant contact information, and a quarterly newsletter. Initial process evaluation data showed that the majority of the participants viewed the training as meeting their goals and objectives. Participants' views of their institutions prior to attending the course revealed the need for improvement in survivorship care, as well as

an increase in comfort of staff providing care for this population; following the course, few anticipated a lack of administrative support in carrying out developed goals (Grant et al., 2007).

5.0 Conclusion

Ultimately, it is clear from this review of the literature that a number of challenges currently exist with the communication practices between specialists and primary care providers at the transition from treatment to follow-up care, as well as within the period of follow-up care. Urgent changes are needed in practice and policy if survivors are to receive adequate and effective care during this vulnerable period of life.

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SECTION TWO:

INTERVIEWS WITH KEY INFORMANTS

1.0 Purpose

This section presents the findings of the key informant interviews which collected information about from key leaders in the field. The interviews garnered perspectives on: the current approach to cancer follow-up and survivorship care; the preferred model of cancer follow-up and survivorship care; and how to bridge the gap between the current and preferred approaches. Specifically, interview participants were asked questions related to:

- “*What Is*” - the current state of affairs relative to communication and education programs and activities
- “*What Ought to Be*” - the envisioned, optimal model of care
- “*How Will We Get There*” - the requirements to move from present to optimal approaches
- “*How Will It Be Better*” - the anticipated value and impact of making this shift

2.0 Method

Twenty key informants participated in the interviews. Of these, 10 responded to questions on Communication, 7 responded to questions on Education, and 3 responded to questions on both domains. Interviewees were drawn from across the country and represented cancer agencies and networks, universities, research and clinical practice. Interviews took place by telephone and participants were provided a copy of the interview questions in advance. (Please see Appendix C for a listing of the interview questions.)

3.0 Report on the Findings

The results of the key informant interviews follow. Findings for Communications come first, followed by results relative to Education. Each section is organized by the interview questions that were asked of key informants. Core themes include: status quo, gaps, envisioned status, best practices, influencing factors, addressing needs, resource requirements, partners and roles, and impacts.

Part A: Communications

A.1 Status Quo

Question 1: *In a few sentences, please describe the current status of communication practices and processes between oncology and primary care providers when medical responsibility for follow-up care is transitioning or complete.*

Currently, there is no standard approach to communication practices and processes at the time of complete or partial transfer of medical responsibility for follow-up cancer care. Both very formal and informal methods exist. Communication practices are highly variable with respect to process, method and timelines.

Process:

- *Relationships* - One interviewee indicated that communication functions are somewhat dependent on existing relationships. He noted that relationships between “old” specialists and family physicians are entrenched; but younger providers have not had the necessary time to build relationships in the community, and are less likely to have effective follow-up communication in place.

Methods:

- *Transcription* - Within the hospital setting, transcription services are typically centralized, whereby oncology dictation is transcribed and sent by fax to the primary care physician. (dictated letter)
- *Letter* - Besides communication through a formally-dictated letter above, some communication occurs quite informally via a hand-written note from the oncology provider to the family practitioner. In some cases, letter templates have been developed in collaboration with family physicians; these tend to be more structured and standardized in their content, style and format.
- *Direct communication* - When this occurs, it is typically “physician-to-physician” communication over the telephone.
- *Guidelines* - Primary care letters may include informal guidelines for follow-up care; but in some cases the approach is more formal, whereby oncology providers provide specific guidelines that outline what to do, what to expect, and what to look for. However, since no “Canada-made” guidelines exist, they vary widely across provinces and regions.
- *Electronic record* - One interviewee referenced that they are in the process of implementing fully electronic health records (Alberta), but many other provinces are not as far along.
- *Patients* - Besides communication practices between primary and specialist care, some data surfaced related to communication with patients. One interviewee spoke about a patient orientation session where patients receive information on the role of family doctors in the cancer journey; they are also planning to build up the patient aspect of the cancer agency’s website to include follow-up guidelines for patients. Another interview participant commented on their plan to disseminate a follow-up template letter to both the family doctor and the patient.

Timeline:

- For those oncology providers who have a formal process in place, communication on follow-up care to primary care typically occurs in a timely manner.
- Some interview participants mentioned that reporting to family practice is often the responsibility of tumor groups, and significant variability exists as to when (i.e., timeframe) correspondence is communicated. One interviewee shared that follow-up communication typically comes about 2 months after specialist treatment is complete.

- One interview participant indicated that while most cancer centres transfer care the moment active treatment is over, some centres remains available for consultation with primary care providers on an ongoing basis as needs arise.

A.2 Gaps and Needs

Question 2: *What are the greatest gaps or needs related to communication practices and processes in cancer follow-up?*

Interview respondents identified a number of current gaps or needs. These included: limitations related to guidelines, need for electronic medical records/transmission, need for patient-directed information, and the need to work with other health professionals. Additional gaps related to timeliness as well as a lack of attention to healthy lifestyles and preventive care. A description of each of these topics is provided in Table 1 along with interviewee comments to exemplify the point being made.

Table A.2 Gaps and Needs

Factor	Description/ Comment (quote)
Guidelines or standards	<p>Respondents believed that deficiencies in guidelines relate to:</p> <ul style="list-style-type: none"> • <i>Content</i> - There is a lack of clearly articulated standards of care with respect to types and frequency of tests, follow-up visits, and imagining. • <i>Communication</i> - Guidelines, while available, are not always communicated from oncology to primary care; and even when they are, little feedback on the guidelines is provided back from primary to oncology care. <i>“The biggest gap is that we don’t get feedback once we send out our information [to primary physicans]; there is no tracking, no follow-up to say this will get done or this got done.”</i> • <i>Context</i> - Guidelines need to be embedded in a broader context that precisely describes the transition of care process; a clear outline of what patients need to be provided when transfer of care occurs. <i>“There is certainly a need for guidelines, but they are part of a larger picture where there needs to be a process of transition of care that takes into account the patients needs as well as the community doctor’s and nurse practitioner’s needs.”</i> • <i>Discrepancy</i> - One respondent commented on the variability of guidelines in terms of their origin and content and how different professions vary with respect to follow-up care (e.g. oncology & surgery), which can <i>“leave the poor family doctor caught in the middle.”</i>
Electronic format	<p>Respondents acknowledged needs related to electronic information transfer:</p> <ul style="list-style-type: none"> • Respondents recognize the capacity of electronic records to improve follow-up care, and believe this should be a priority action in the short term: <i>“Learning as I have about the capacity that is possible, and how little it seems we actually do electronically, it seem that would be the area that has the greatest promise and the greatest urgency in terms of doing things better.”</i> • While some jurisdictions have made headway with electronic medical records, progress is limited to the cancer system only and does not typically allow access by primary care providers. For example, in Alberta, <i>“cancer care and family practices are still on different platforms.”</i> • Similarly, gaps exist with respect to linkage across regions, where for example, waiting is required for receipt of hard copies of imaging results vs. what could happen must faster if electronic transmission was an option. • Finally, one interviewee commented on the communication gap that occurs when

Factor	Description/ Comment (quote)
	patients change doctors; and the need to ensure that information follows patients, which is facilitated by use of electronic records and information systems.
Informing patients	<ul style="list-style-type: none"> Insufficient communication with patients impacts follow-up care. Respondents suggested that patients need to be assured that transfer of care is “safe,” and that they will be well managed in primary care; while assuring them that they are welcomed back to the cancer center should the need arise. <i>“I think communication needs to be not only to the primary care physician, but also to the patient saying that it is safe for you to be seen by your family doctor.”</i> On a related note, one interviewee commented on the high percentage of people who do not have a family doctor and the obvious gap that leaves in follow-up care.
Professional relationship/ resources	<ul style="list-style-type: none"> Interviewees acknowledge the need to engage other health professionals. One respondent referenced mental health: <i>“If someone is getting depressed, mental health resources need to be pulled in.”</i> Another respondent commented on the need for the effective management of palliative issues once patients re-enter primary care. The need for better or different working relationships between oncology and primary care physicians also surfaced. One respondent noted that primary care providers <i>“see the whole cancer world as very foreign, very esoteric...,”</i> and the cancer centres <i>“tend to think of themselves as an expert system unto themselves and often neglect the fact that their patients come from primary care.”</i> As such, <i>“we need to be more thoughtful and deliberate about how it is we could better orient one another.”</i>
Timeliness	<ul style="list-style-type: none"> The need for timely communication was identified by some participants. This was linked back to the electronic medical record and the time it takes (often, 3-4 weeks) to transfer hard copy patient notes from oncology to primary care providers. <i>“Another gap is in the timeliness of the information getting to the family physicians.... A lot of family doctors only use computers... so the problem is we are not linked.”</i>
Prevention	<ul style="list-style-type: none"> Focus on cancer testing and management, in the view of one participant, has limited cancer follow-up care that should include healthy lifestyle messaging and preventive care. This participant commented that <i>“patients get knocked out of primary care because the oncologist is doing the follow-up,”</i> and hence, they do not receive usual preventive care. She notes that good evidence exists that exercise and reduced alcohol use decreases recurrence of breast and bowel cancer, and that <i>“some of this non-medical lifestyle stuff that could be done by a nutritionist or nurse gets lost.”</i>
Other	<ul style="list-style-type: none"> One respondent commented on significant gaps in communication in follow-up care with respect to Aboriginal populations. This is due in part to the delivery of federally-funded health services within a provincial context. A lack of cohesion with visiting health providers coming in and out of Aboriginal communities widens the communication gap.

A.3 Envisioned Status

Question 3: *How would communication practices and processes look or operate if an optimal model of care existed between primary health care and the cancer care system?*

Interview participants repeated some of the themes that surfaced in the previous question in response to this question, and added some new ideas / view points. An optimal model of care rests on two core requirements - clear roles and clear information.

Requirement 1: *Roles and responsibilities are clearly defined and delineated in an optimal model of care.*

- Actions and roles for both primary care providers and patients need to be specified and documented in a way that clearly describes, “*who is supposed to do what, and for how long*”
- Methods to ensure clear articulation of roles and responsibilities for follow-up could take various forms at the health provider, patient and system levels.

Health provider level:

- Survivorship care plans
 - A few interviewees spoke about the role of survivorship plans and their value in having everything all in one place - the diagnosis, stages, side effects, proposed treatment and therapy to be delivered. The plan could also suggest “*where the GP could play a role.*”
- Guidelines
 - As noted above, guidelines that clearly identify the common points and practices to guide transfer of care from cancer centers to primary care. In an optimal system, guidelines serve as a road map that set direction in an “*ad hoc system*,” they facilitate effective preparation of the patient for transition into the community and subsequent medical visits to his/her family doctor.
 - One interviewee suggested the need for pan-Canadian guidelines as a way to help alleviate some of the problems related to follow up care, especially with respect to the type and frequency of follow-up investigations: “*Having some pan-Canadian guidelines that state that, on the basis of evidence, these are the things that one should do... that would help... rather than over-investigating and over following-up.*”
- Shared care protocols
 - Besides setting forth roles and responsibilities, shared care contracts or protocols can serve as a basis for trust building, where each provider/disciplines understands the roles of other providers, leading to respect and acceptance of the professional judgment of others.
 - Shared care needs to reinforced and continued between the family and oncology physician during follow-up care. In the words of one interviewee: “*This is where the shared care model comes in.... The family doctor may be managing other chronic diseases or health problems. Once the patient is transferred back [to shared care] the shared part is that the specialist service remains available to answer questions and is willing, if necessary to get involved again.*”
 - Other respondents envision shared care more broadly within an optimal model of care; they see it as being “primary care based,” with contributions from providers in health promotion and disease prevention, mental health, nutrition, and other disciplines.

Patient level:

- Patient held care plans
 - In an optimal model of care, patients would have their own care plans that include all their records on a care chip or memory card that is updated at every visit and travels with the patient.
 - Providing patients some type of “discharge protocol” (a template that can be easily filled in) that outlines next appointments, required tests, etc is another option. This

- should be followed by a scheduled telephone call a few weeks later to ensure things are done or underway.
- Patient education sessions
 - Besides providing patients with written or electronic care plans, one participant suggested “*an educational piece,*” which could include a 45 minute discussion with an advanced practice nurse or a “*wellness person*” to ensure the patient is informed and prepared to take the next steps in his or her follow-up care.
 - Another suggestion was a “*discharge discussion,*” where the patient (and family members) participates in a meeting with the care team to review what the plan ahead and the respective roles for all involved.
 - Patient portals
 - Patients login into a secured website could view a video from an oncologist who would walk them through the steps of the cancer treatment and provide information on what is to be expected.

Systems level:

- Nurse navigation - One respondent reported that nurse navigators should not be based within the cancer system, but should undertake the coordinating function at the primary care level: “[Patients] *need their navigation and they need the involvement of primary care,*” to assure them that all pertinent test have been taken, preventive measures are in place, and where to go next and what to do is well understood.
- Follow-up care is a work activity or function that requires its own support, process, and time to complete. In the view of one participant, who compares cancer follow up to the discharge function in hospitals, follow-up has been neglected to date: “*I think there should be a system within cancer hospitals or centers that would be supporting this work around discharge, because it is work... and up until now, we have not paid a lot of attention to.*”

Requirement 2: *Follow-up information needs to be consistent and effectively transmitted in an optimal model of care.* This is facilitated by:

- Electronic records
 - The key here is that all physicians and allied health providers have access to a single, linked electronic patient record. Interviewees acknowledged while this would be a complex task to achieve in and of itself, additional effort would be required to ensure that a supportive system is in place to keep electronic records working, updated and accessible to all.
 - The key is consistency where, for example, all dictated notes could be viewed by all primary providers involved in the care, regardless of region or location.
- Electronic transmission
 - Electronic-based systems needs to be seamless between the oncology center/providers and family physicians in the community: “*I think the only way you can get seamless in this day and age, is to [go] electronic.*”
 - Transfer of information for primary care should be ongoing and regular so that the family doctor is aware of the care that is being provided along the way and knows what and when to expect the patient to return to primary care. “*They should be kept advised all through the process so it not a surprise with the patient shows up in the office two years later and says I have been discharged.*”

- One interviewee commented on the value-added of using electronic platforms. They allow the primary care provider to signal back to oncologists and the cancer clinics that *“the message was accepted and done.”* This closes the loop on each cycle of care.
- Electronic capacity
 - One participant commented that within an optimal model of care, the capacity for information technology would expand to meet the needs and desires of health practitioners in the field: *“If only my IT partners were a little bit more in line with some of the visions [we] have... There is so much that clinicians are now beginning to understand that they could do, but the IT capacity just isn’t there.”*

A.4 Best Practices

Question 4: *Can you provide any specific examples of current or planned communication practices and processes that are “exemplar” or considered to be best practice in cancer follow-up today?*

Interview respondents identified some examples of what they considered to be best practices in cancer follow-up. They are grouped by processes, people, plans and systems below.

Processes:

- One respondent provided an best practice example from another therapeutic area - a group of lung surgeons in Toronto East General Hospital established a “just in time” clinic whereby the surgeons give out their email address to the family doctors who can email them at any time. *“They never go home without checking their email and responding.”* They also provide phone numbers where family physicians can leave messages. The goal is to bring in any patients with suspected lung cancer early on in order to improve lung cancer outcomes in the longer term.

People:

- Improved communication between primary care physicians and medical oncology has been attributed to the role of General Practice Oncologists (GPOs) in New Brunswick. Education sessions are hosted by GPOs who seem to be able to connect with other general practice physicians as they (the GPOs) understand what family doctors working in the community need to know. In this way, GPOs serve as an “intermediary” to facilitate communication between the two.
- Patient navigators also surfaced as a best practice. Navigators understand the system, and how and where things get done. They ensure that the transitions oncology want to happen, happen. As well, the patient navigator stays in close communication with the patient and feeds information back to health providers.

Plans:

- Survivorship care planning is the focus of a pilot project in Manitoba where the process for transition to follow-up care is being carefully documented. The focus is on rectal cancer patients and includes CT scans; patient cancer and treatment summary documents generated from the electronic patient record and shared with the patient, family physician, and surgeon; a resource/written piece entitled, “Moving Forward After Rectal Cancer” which explains what comes next for the patient; and clear delineation of responsibility for required medical tests, generated by the cancer clinic. The aim of the survivorship care

plan is to ensure that complete information is provided to everybody involved, as well as transparency and clarity around how follow-up care is organized and delivered.

- One respondent commented on an initiative headed by the American Society of Clinical Oncology which has developed a template for a core or basic survivorship care plan for transition of care in the US. Others commented that similar initiatives may be underway in Australia and the United Kingdom.

Systems:

- Primary care teams in Ontario were identified as a best practice in cancer follow-up by one interviewee who provided a summary of how they work:
 - The Regional Primary Care and Cancer Network in Ontario hired an oncology nurse who served as a primary care lead or coordinator. She is the first point of contact for patients, maintains communication throughout treatment, and connects patients with other resources as required (e.g., mental health). She also supports the oncology team by providing information and contacts related to the primary care system. The salary of the primary care lead is covered by the province.
 - Similarly, Cancer Care Ontario has funded one primary care lead for the province whose job is to coordinate fourteen primary care doctors. Her role is to “*connect primary care to the cancer centre.*” One of the fourteen participating doctors has convened a primary care committee with a one-year mandate. It consists of eight primary care leaders who meet monthly to discuss issues related to cancer and primary care. They conduct web conferences, address local issues with the hospital/community, and provide talks/presentations about bowel, breast cancer and cervical screening on a regular basis.

A.5 Facilitating Factors

Question 5: *What factors or conditions encourage or facilitate reaching the optimal vision/model with respect to communication practices and processes between oncology and primary care providers?*

- **Technology and the link to electronic methods** surfaced as a key feature in facilitating optimal follow-up care.

“I think the infrastructure technology is an enabler.”

“I think that part of the concept... is to make it impossible for a provider to practice badly... If you are using electronic medical records it will ask you or remind you to do A, B, or C....”

- Optimal follow-up care requires putting the **appropriate human resources** in place and encouraging health providers from different disciplines to work well together.

“We need to utilize those who are caring for patient already in family practice more effectively... Perhaps we need less nurses in the actual acute care clinic and more nurse navigators managing the patient’s health.”

“We need a culture that is trusting, where all professional groups are valued, where multi-disciplinary care is valued, where transitions between primary care and the cancer system are respected and understood.”

- Optimal follow-up care requires new and significant **financial resources**.
“... resources are [a] key ingredient to make it happen. In resources, I am thinking of financial, the financial resources for the development of technology itself.”
- Optimal follow up is further facilitated by **patient involvement**.
“Patients need to take as much ownership as they are willing to do.”
“I think a lot of oncology patients have learned to be very good advocates, some out of necessity maybe. I think a lot of them are very proactive in trying to keep that flow of information going, and trying to keep treatment and physicians on track.”
- **Individual will and organizational consensus and motivation** encourages best practices in cancer follow-up.
“I think that the will of individuals to change is an enabler.”
“We need a clear road map about what is expected and when, and some group agreement around how long we are going to follow our patients before they are sent back to primary care for follow up ... agreement around that and I think motivation on the part of the agency to make it happen is key.”
- **Education and shared learning** between specialist and primary care further facilitates communication between them.
“Another thing I think would be important is ongoing educational initiatives between oncologists and primary care physicians, updating them on what is happening in the oncology field by way of treatment and as things are changing, what to expect... I think this is probably more on the education side of things but I think keeping them updated on these issues will enhance communication too.”

A.6 Challenging Factors

Question 6: *What factors or conditions challenge reaching the optimal vision/model with respect to communication practices and processes between oncology and primary care providers?*

Interview participants highlighted a number of challenges to communication in cancer follow-up. Some are recurrent themes (also identified in the questions above) and some are new.

Recurrent themes/challenges:

- Lack of a **standardized, electronic patient medical record** that is accessible across health providers, locations or regions, and the health system; and absence of any infrastructure to support this. Privacy issues also surfaced as a challenge associated with electronic approaches.
- Lack of **standard practices or guidelines** that clearly define the processes and actions required in transition or follow-up care. Associated challenges include: a lack of effective methods to disseminate guidelines and to ensure their application or use; inconsistency

among the different guidelines that are available; and similarity, no national or pan-Canadian guidelines to guide cancer follow-up.

- A lack of **financial resources** to support improvement of communication practices and processes in follow-up care.
- The fact that follow-up and **discharge “is work.”** Discharge planning takes more time and effort (e.g. to develop a survivorship care plan) than to “see someone every six months.”

New themes/challenges:

- Optimal follow-up care is challenged by the **long-standing relationships and attachment** that is established between oncology providers and patients and associated reluctance to move them into primary care.

“There is a lot of pleasure and reward in seeing people you have helped. That’s understandable... A lot of follow-up is pleasant.... I guess what I am saying is there is an attachment that can form, for patients as well [as physicians], and so why would you want to interrupt that.”

- A **lack of trust** between oncology and primary care providers serves as another challenge to achieving effective communication in cancer follow-up.

“There is a lack of knowledge and trust between primary care physicians and the cancer community. They generally don’t know each other.... I think the lack of trust that the work will be done well by the unknown family doc out there is an obstacle as well.”

- Optimal follow-up is challenged by the **supply and continuity of family physicians.**

“This is a challenge because patients need to be followed and if there is a shortage of family physicians that becomes difficult because the volumes in cancer centers are becoming unmanageable.”

“The other big issue is that if the family care physician changes or the patient doesn’t have some kind of continuity in primary care, follow-up is going to be a bit of a problem.”

- **Time**, also a challenge.

“Another thing is time constraints.... Time constraints are huge because a lot of times you are so busy just trying to treat the patients who are on active chemo in an environment where we are short on oncologists and our patient base is not diminishing... you are just trying to keep your head above water, and room for those extra things to make the [communication] process flow more smoothly isn’t always there.”

A.7 Addressing Needs

Question 7: *What types of strategies (activities, methods, tools or processes) should be pursued or developed to improve communication between oncology and primary care providers when medical responsibility for follow-up care is transitioning or complete?*

With respect to strategies, interview participants highlight some recurrent themes: standardized practice, electronic medical records and supportive infrastructure, care maps, use of patient navigators, and timeliness of communication regardless of method. Additional strategies to improve communication between oncology and primary care providers include:

Face-to-face communications - One participant spoke about the need for “*supported dialogue*,” which can happen quite informally, such as “shoulder-to-shoulder” conversation in the physicians lounge; or it can be much more structured such as scheduled meetings where oncology and primary care providers come together on a regular basis to ask questions and discuss issues that are relevant to each. Round tables, a group discussion organized around a theme of interest, are another way to bring cancer and primary care professionals together to discuss issues and resolve problems related to follow-up care. Ensuring an oncology presence at family physician events with primary care networks is another strategy to consider. Face-to-face communications allows for 2-way conversations and help to ensure that any new communication processes and products that are put in place meet the needs of the parties involved.

Telephone communications - This could take the form of allocating specific telephone time, whereby for example, a regional cancer center could schedule one hour every Thursday morning to take calls from family physicians or other primary health care providers. This has a positive secondary effect related to timeliness by ensuring that someone is available to respond to concerns or questions when it is needed most. Another suggestion is having a physician or oncology nurse who understands the cancer system on call at all times to respond to questions from primary care providers and to provide decision support for any clinical issues they may have.

Transition evaluation - Based on the information provided by one interviewee, Accreditation Canada is now requiring cancer care centers to evaluate transitions in care from the perspective of the patient, after medical care is complete. This provides a feedback mechanism to assess the degree to which information was received and followed.

Shared care - One respondent highlighted the role of shared care models as being an effective method to improve communication as it leads to joint decision making: “*I think really what you do is get people from primary care and oncology to sit down and roll up their sleeves and admit this is a shared population... We have to create ways and means of looking at that together and make an effort towards an agreed upon solution, rather than my solution, your solution, and we have to try and make them meet in the middle.*”

Continuing medical education - CME activities and ongoing professional development that bring oncology and primary care providers together represents another strategy to improve communication. In the view of one participant, this should extend to other professions that are involved in the treatment of cancer patients such as social workers. (Note: The next section of this report deals with education matters in depth.)

Other strategies suggested by interview participants to improve communication between oncology and primary care providers included, setting aside dedicated time to answer and respond to **email communications**; as well as **synoptic reporting**, to facilitate reporting on key elements as a way to standardize practice. Finally, one respondent suggested **co-location**, whereby oncologists and primary care physicians would work in the same space, but acknowledged the difficult logistics related to this, especially among primary care physicians who are well established in their own communities.

A.8 Resource Requirements

Question 8: *What types of resources need to be in place to optimize communication practices and processes in follow-up care?*

Interview participants articulated a clear need for financial and personnel resources if communication practices between oncology and primary care are to be improved.

Financial:

- Principally, financial resources need to be directed toward the development of electronic communication tools, especially electronic medical records, and the infrastructure and personnel to support such. Funding to support electronic platforms for patients, such as a patient portal, was also highlighted.
- Additional financial support should be directed toward workshops, symposiums or learning sessions that focus on development of effective and practical communication strategies.
- Financial compensation for oncology physicians who undertake telephone consultations was identified as another area for financial investment. *“I would recommend that the provincial plans look at how they can build in a billable fee for telephone consultations.”*
- Similarly, financial coverage for physicians who participate in committee work or learning sessions was viewed as important if physicians are to remain involved. *“So many of the committees they just expect doctors to go for nothing. I think they have to get paid if they are expected to come.”*
- One respondent also highlighted the benefit of using existing “open sources” such as Skype to enable better communications and avoid incurring major budgetary expenses.
- Another interviewee commented that improving communication is not so much about getting new monies, but about re-directing monies. She provided the example of doing *“fourth and fifth line treatments that are not only bad for patients but bad for us fiscally,”* and moving these funds *“back into primary care providers and better supportive care... Resources could be taken out of those less than useful places in cancer treatment and put into a more useful spot.”*

Personnel:

- Some interview participants acknowledged the need for a dedicated position for primary care within the cancer system. One interviewee provided an example of a primary care physician who had an academic appointment and spent one day per week at the cancer center. *“This supports the dialogue and gives a presence and a constant awareness of primary care within cancer care.”*
- Another respondent suggested that a dedicated person skilled in communication methods and processes needs to be an integral part of the cancer center. *“Every cancer clinic of any size at least probably needs someone whose job it is to help support and supervise these [communication] processes... on a day-to-day basis. We need a designated champion who could be a skilled clerk or a nurse who is given responsibility for that.”*
- Patients serve as another resource for improved communications. One participant suggested that *“looking at the patient experience and understanding the patient journey from the family’s experience,”* provides information to inform how communication between oncology and primary care can be improved. Patient data could be gathered through patient surveys or focus groups.

- Finally, “*the right kind of people*” need to be at the table to encourage interest and buy-in for communications technology and processes at the administration level. Physicians are busy with patient care and may not have the interest or skill to make a case for improvement. People who are highly-skilled in information technology, and who ideally have some experience in health care, “*would be the sort of human resources we need to cultivate.*”

A.9 Partners and Roles

Question 9: *Who are the key stakeholders or partners that need to be involved in efforts to improve communication practices and processes in cancer follow-up?*

Table A.9 summarizes information drawn from interview participants about who should be involved in efforts to advance communication and what their likely contributions could be.

Table A.9 Partners and Roles

Stakeholder	Role
Oncology leadership (oncologists)	<ul style="list-style-type: none"> - Content for guidelines - Description of transition of care processes - Generate confidence that patients will be well cared for in primary care
Primary care leadership (family physicians)	<ul style="list-style-type: none"> - Content for guidelines - Description of transition of care processes - Provide feedback on content of guidelines - Provide options to receive (disseminate) communication materials
Other health providers	<ul style="list-style-type: none"> - Engage those who are potentially affected by changes/improvements in communication - This could include community and home care nursing, advanced practice nurses, navigators, social workers and other allied health professionals; as well as community organizations such as the Red Cross and community care access centers - They represent the “end-users” and as such should provide feedback on communication tools & processes - Should suggest ways on how best to receive information (be communicated with) - Serve as a source of information about shared care approaches and support building consensus on roles of all professionals involved in follow-up care
Cancer Agencies	<ul style="list-style-type: none"> - Define and support methods to disseminate guidelines - Serve as “champion” for effective communication - Support evaluation of follow-up care
Professional Colleges	<ul style="list-style-type: none"> - Canadian College of Family Physicians and provincial counterparts to lead credibility to communication practices and processes being proposed & implemented
Professional Associations	<ul style="list-style-type: none"> - Develop and implement supportive policies - Provide and support continuous professional learning related to improved communications
Other cancer organizations	<ul style="list-style-type: none"> - Such as CAPCA, Canadian Partnership Against Cancer to share their broader understanding and expertise about communication

	strategies and tools that might be useful (not specific to oncology)
Government - Ministries of Health, Regional/District Health Authorities	<ul style="list-style-type: none"> - Budget / funding support - Provide helpful information about other models that may link to or support optimal communication (e.g., chronic disease management model)
Patients	<ul style="list-style-type: none"> - Be receptive to messages that they will receive quality follow-up care and will be able to reenter the cancer system if necessary - Provide feedback on patient portals and other communication tools and processes - Advocate for good follow-up care - Share responsibility for follow-up care
Information technology experts/companies	<ul style="list-style-type: none"> - Set the vision for electronic communication platforms - Provide technical knowledge and development - Problem solve / trouble shoot along the way
Other	<ul style="list-style-type: none"> - Cancer centre tumor groups to define their own role is supporting communications in follow-up care - Academics to facilitate research and identification of best practices - Hospital administration to motivate and sustain communication efforts

A. 10 Impacts

Question 10: *What are the anticipated impacts or outcomes of implementing improved communication practices between oncology and primary care providers in cancer follow-up?*

Interview participants identified impacts at the patient, health provider and health system levels, described below.

Patient outcomes include:

- Improved patient care
 - *“Less falling through the cracks,”*
 - Greater percentage of patients receiving recommended tests
 - Increased clarity about how patients are doing and what they need in the future
 - More seamless care
 - More timely access to care
- Increased patient satisfaction
 - Greater clarity about how patient follow-up care is planned and organized
 - Patients feel supported, safe and informed
 - Reduced anxiety and worry about their own care path and next steps
 - Increased understanding, sense of responsibility, and *“taking charge of making sure things get done on schedule”*
 - Enhance patient confidence that their care is on the right path and they are in good hands

Health provider outcomes:

- Providers working from evidence-based practice

- Better working relationships among health providers from all disciplines as each is clearer about the others' roles: *"Everyone would be happy"*
- Clinical decision support for family physicians and increased understanding and clarity about *"who they can turn to with questions and what resources are out there"*
- Improved confidence among family doctors that they have what they need to deliver good follow-up care, as informed by guidelines and protocols to guide them
- Family physicians feel more supported by oncology and more willing and able to manage cancer patients over the longer term: *"Primary care would actually embrace looking after patients on a longer term basis knowing that they have the back up of the cancer system"*
- Improved provider satisfaction among primary care providers and a sense that they are working in partnership with oncology: *"This feels like a collaborative partnership"*

Health system outcomes:

- Less repetition of testing because tests would be easily readily accessible to providers in different locations (via EMR) and would not need to be re-ordered
- This could yield costs savings to the health system
- Increased health system capacity given that fewer follow-ups in the cancer system would leave more room for new or difficult cases: *"Basically there will be more capacity in the cancer system to see new patients and patients with metastasis disease who probably require the special skills of oncologists indefinitely."*
- Increased health system efficiency as administrators and practitioners spend less time trying to acquire information: *"There are a lot of efficiencies to be gained when the communications are well established and the information moves quickly."*
- Lessons learned and models developed from improved communications in cancer follow-up could be replicated to other clinical/therapeutic areas within the health system

A. 11 Final Thoughts

Question 11: *Do you have any final thoughts or comments that you would like to share related to the topics discussed here.*

To close the interviews on communication practices and procedures between oncology and primary care in cancer follow-up, a few participants offered some final words:

"To me, communication is a foundational element in patient care and I think it's one of the areas where our system has really fallen down..."

"I think in most cases patients depend on their clinician for direction and guidance and expertise and support. A smooth pathway to do that is based on information flowing."

"I think this is a big issue and I think the more we can do the better it can be. I think it's one thing that there hasn't really been shared responsibility about, but I think it is time and the cancer system has got to get out of their ivory towers and realize that if they don't do the change leveraging with primary care systems, nothing is going to change."

"Thank you. You basically have gotten everything I have been thinking about for the past ten years."

Part B: Education

This section reports on the interview findings related to formal and continuing education designed to support primary care providers in the provision of survivorship care to cancer patients. In comparison to Section A above, which reported on Communication practices and processes, the findings relative to Education are less substantive, but very informative. It is worthwhile noting that some overlap exists between the Education and Communication domains, so some of what is reported on this section may have also been touched upon in the Communications section above.

B.1 Status Quo

Question 1: *In a few sentences, please describe the current status of formal and continuing education activities and programs designed to support primary care providers in the provision of high quality survivorship care to cancer patients.*

Interview participants were in agreement with regard to the current status of formal and continuing education activities and programs for primary care providers who are providing survivorship care to their patients. Their comments are grouped by theme and provided below.

- There are some formal and informal continuing education activities and programs offered across the country. These include formal training courses annual conferences and seminars for CME credits. However, there are not a lot of opportunities for education and the types of educational activities and programs are not consistent across the country. As one interviewee stated: *“As part of formal education, there are sessions offered here and there on this topic but it is not well organized.”*

Types of educational opportunities

- With regard to educational opportunities, one respondent commented that *“a lot of what goes on is discipline specific, annual meetings or self-directed professional learning education through a variety of venues that are well established.”* These opportunities include the following:
 - Conferences
Sessions on survivorship are offered at cancer related conferences, integrated into primary care conferences or part of a specific conference for General Practice Oncologists. For example, Cancer Care Manitoba co-hosts an annual conference which enables health professionals to come together and participate in educational opportunities and network around cancer care.
 - CME seminars and web casts

Continuing medical education opportunities are offered in many provinces however, the opportunities are *“ad hoc and one offs.”* The opportunities are offered through web casts and seminars on a variety of topics. For example, the BC Cancer Agency holds web casts once a month to provide an opportunity for primary care providers to participate in interactive oncology presentations on the internet. These sessions are attended by primary care providers from across the country.

- Formal training opportunities

A few of the provinces offer formal training opportunities in oncology for family care providers. Topics range from diagnosis, treatment, and follow-up care. In most instances, these training opportunities are for family physicians that provide services within the cancer centers (to other family physicians). The opportunities are offered in module format through small group and large group education and clinical partnerships.

In terms of formal training within medical programs, McGill University, Department of Oncology is currently developing an oncology course for undergraduate and postgraduate training (as well as for primary care physicians interested in providing cancer care to patients). However this is quite unique, as many of the interviewees commented that presently any undergraduate and residency training in oncology is limited and generally focuses on diagnosis and screening.

B.2 Gaps and Needs

Question 2: *What are the greatest gaps or needs related to education activities and programs in survivorship care?*

Interviewees shared their views on current gaps.

- Establishing the **timeframe for survivorship care** has implications for content and focus of education programming. For example, some cancers such as breast or colorectal cancer can have extended follow-up care that can last for years.

“So when does the cancer treatment begin and end, and when does survivorship care start and who is responsible for what. I think that needs to be sorted out.”

- This is complicated by the potential **number and mix of health providers** that are involved in survivorship care which raises questions about who should be targeted for education activities.

“I think colorectal is a good example around gaps in survivorship care... you have your surgery, plus or minus your chemotherapy, and then you are cancer free and on your way, and post follow-up care for that group can involved a number of providers... Patients may be referred back to the surgeon for ongoing follow-up. It is not as cut and dried anymore so survivorship care should still include people who are getting some kind of cancer therapy but who is the best person to provide that?”

- Current education efforts do not adequately focus on the all the **various aspects of survivorship care**, including how to support patients in the consequences they face as a result of cancer treatment.

“There are consequences of having cancer on the psyche, on relationships, on work.... Sexuality, body image, pain... You can't help with those things very well without some guidance and discussion around them. It is an area that really hasn't been developed very well.”

- A gap exists with respect to having **effective mechanisms or “mediums”** in place to provide education about survivorship care. One participant linked this to survivorship care plans.

“... the most beneficial medium that has been developed is the survivorship care plan which is a document that is educational as well as a compilation of information for the family physician, for the patient and for the oncologist.”

- The **complexity of cancer** and how to integrate all the aspects of cancer into formal and continuing education curricula is increasingly challenging, especially given that new knowledge (e.g. treatments & medications) is being generated at increasing speeds.

“Curricula is always hotly contested. There are too many things to teach and not enough time.”

- There is a **need for champions** at the community level to promote and advance follow-up education in primary care.

“There generally has been strong advocates in family medicine for a cancer curriculum but there often hasn’t been a local champion saying we need to be teaching folks about this.”

- There is a lack of **models or modules** to draw upon to support or advance education programs or activities in cancer follow-up for primary care providers.

“There often aren’t finely developed models for this type of education that can be adapted... so I think a gap is there .. there aren’t any easily available, well developed kinds of sessions that a certain department or university group could borrow in both areas, for CME as well as for the more formal training.”

- A lack of understanding of the **overlap** between how follow-up care is being communicated and how it is being taught represents a gap or need.

“The need is to understand where education and communication overlap because education doesn’t just happen in formal settings. [Education] happens through supportive dialogue and conversations and the opportunities to consult.... They should really go hand in hand and one support the other. If we had a solid communication foundation our education would be much easier.”

B.3 Envisioned Status

Question 3: *How would education activities and programs look or operate if an optimal model of care existed between primary health care and the cancer care system?*

As reflected in the question above, interview participants acknowledged the connection between education and communication; that effectively communicated information is a pathway to education, and hence, they work together.

Core features of education within an optimal model of care that surfaced from the interviews can be grouped by recipients, approach, and methods.

Table 3B: Education in optimal care

Feature	Description / Comment
Recipients	<ul style="list-style-type: none"> - Given the mix of health professionals involved in follow-up care, education activities and programs need to include wide-ranging health disciplines - Education should be available to independent family physicians working in the community, as well as more coordinated primary care teams (e.g. family health teams) - Education on survivorship needs a well defined presence in medical education
Approach	<ul style="list-style-type: none"> - Education needs to be interactive and practical - Education approaches need to be flexible and easy to update to keep current as new knowledge is developed - Education should be grounded in an interdisciplinary approach to engage all health providers involved in follow-up care: <i>“So the kind of education that would take place would be a provider education program which is interdisciplinary and multi-disciplinary with specialists, family physicians, and other who might see the patient.”</i> - Education approaches should align with unique needs of people along the life course including children and young adults: <i>“One of the hot topics now is post-treatment care for adolescents and young adults. We actually might be looking at different educational programs and services for the different groups.”</i> - Education should consider innovative models such as nurse-led survivorship initiatives
Methods	<ul style="list-style-type: none"> - A variety of education methods and a sustained effort is key: <i>“There needs to be effort applied through multiple channels over time.”</i> - Electronic platforms should be used whenever possible: <i>“The optimal education framework has to be built on an electronic platform, because there has to be access to information for learning.”</i> - Cased-based learning is best for family doctors, delivered in small groups, in a time-relevant way: <i>“It needs to be something that provides information at the time it is required, and linked to a specific patient.”</i> - Education needs to be evidence based, with guidelines as the lead mechanism - Continuing medical education including conferences and workshops that are relevant and timely. CME materials should be appropriate to the group and well designed: <i>“Creating attractive, well-designed education packages that are scalable to the group size would be helpful.”</i> - On the informal side, methods include small group sessions, one-on-one learning and hospital rounds - Educational tools or materials should have a consistent method but can be provided in a variety of ways including: electronic medical record, disease pathway management tools, educational newsletters and journals, or desktop materials. - Education materials for primary care physicians need to be clear, concise and easily accessible: <i>“They want two pages, no more, they want a few bullets to summarize it all, they want to be able to get it just in time, and they want it to be available electronically.... They also want it on the same website they go to for their other information.”</i>
Other	<ul style="list-style-type: none"> - Education activities and programs to support primary providers in survivorship and follow-up care should be evaluated on a regular basis: <i>“There is the issue of</i>

	<i>measuring and monitoring to make sure you are spending your time in a constructive way and getting the outcomes you want which I think is quite challenging around education.”</i>
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B.4 Best Practices

Question 4: *Can you provide any specific examples of current or planned education activities and programs that are “exemplar” or considered to be best practice in survivorship care today?*

Interview respondents identified some examples of what they considered to be best practices in survivorship care.

Mentorship - One interviewee shared her experience providing a nationally-recognized mentorship program where a palliative care specialist mentored GPs and nurses over a 2.5 day intensive formal training program. The program provided opportunities to learn about each others roles, how the health system is organized; as well as structured materials, tools and an interactive website for access to online resources. The mentors provided support to their trainees over a six-month period. It was evaluated and received high approval. *“It may be a model we want to consider.”*

Webinars - Refer to web conferencing that is used to conduct live meetings, trainings and presentations via camera and the Internet represents another best practice identified by one participant. Webinars are growing in popularity as they allow direct visual contact and are highly interactive. *“The webinars I find are really good... It is more like you are right there and you feel like you can participate.”*

Decision support - Also mentioned was the development of a *“decision support framework”* to guide physicians in their judgments related to follow up care. This would rest upon a well constructed survivorship care plan, both on paper and an EMR version. Similarly, another interview respondent commented on the promise of the Chronic Care Model (CCM), which has been used extensively with chronic conditions in Canada, the US, and around the world; and *“is readily transferable to the cancer arena.”* The CCM has clearly defined methods and processes to support decision making among primary care workers along the continuum of care, including follow-up.

GPOs - Also highlighted with respect to best practices in Communication in the previous section, GPOs have a role to play in education about follow-up and survivorship care. GPOs are family physicians with special training in oncology so they are able to relate to the information/training needs of family physicians and the delivery mechanisms that would work best for them.

Web Library - One interview participant offered an idea that has not been developed yet, but believes that development of an on line library would be an effective way to support follow-up education. He proposes a web library that would house all published cancer guidelines for access by all primary providers. It would be interactive so that guidelines could be updated as required. *“Lay versions”* of the guidelines would also be posted on the site for easy access by patients. Given that evidence exists, *“that the publishing of lay guidelines promotes adherence*

to those guidelines by family doctors,” this interviewee believes that the lay or patient component should be an integral part of the web library tool.

B.5 Facilitating Factors

Question 5: *What factors or conditions encourage or facilitate reaching the optimal vision/model with respect to education activities and programs in survivorship care?*

- **Integrate education activities with existing training opportunities** surfaced as a key feature related to improved education in survivorship care. It is difficult for primary physicians to allocate time to learn about cancer only as there are so many areas they need to acquire understanding and knowledge. Combining cancer training with education on other diseases or health conditions saves primary care providers time and increases their likelihood of exposure to needs related to cancer/survivorship care.

“To take an entire day or two days for primary care physicians for just cancer is a big step. We are trying to integrate cancer into appropriate venues. We are trying to get where education is already happening.”

- Direct education activities and programs to **established groupings** of primary care providers, where messaging about survivorship care can be delivered to a number of providers at a time, versus an individual approach. Established primary care teams or networks often have an infrastructure that can support the educational effort and encourage participation.

“The other thing I think is an enabler is to work with primary care networks instead of the buckshot approach. Within Alberta.... we have primary care networks and they have an infrastructure ... and part of its responsibility is to disseminate information to physicians.”

- **Craft a definition of survivorship care** that both oncology and primary care providers can embrace and relate to.

“There needs to be a definition of survivorship care that speaks to both the cancer care system and the primary care system. It needs to be one they can both buy into and is relevant to both.”

- Ensure primary care participants receive **professional credits** for attending education activities and programs on survivorship care.
- Attending education programs means that primary care physicians are out of their offices and do not receive income for that day. Therefore, efforts should be made to provide **financial compensation** for participation in education activities and programs.
- Links need to be established between cancer centers and **universities**. Cancer agencies need to provide leadership and work in concert with academic leaders to advance continuing education programming and products related to survivorship care.

“Again there needs to be leadership from the cancer agency... There are a lot of people involved in [education] but I think the key thing is the leadership of the cancer center, and good links with the universities, so that the kind of [education] products created are attractive and high quality.

- Similarly, cancer agencies need to collaborate with medical school leadership to ensure that cancer survivorship is **embedded in medical education curricula**. One participant shared his viewpoint in the form of a question:

“How are we lobbying with our undergraduate curricula in medicine at least and with our post-graduate family medicine training to make sure that undergrad students and post-graduate family medicine residents are exposed to what they need to be in providing survivorship [care]?”

- Finally, **asking patients what they need** surfaced as a facilitating factor for education activities and programs. This can serve as a driving factor for survivorship education. Patients want and expect to understand what options are available to and suitable for them after cancer treatment, and primary care providers should feel motivated and be prepared to provide the answers.

B.6 Challenging Factors

Question 6: *What factors or conditions challenge reaching the optimal vision/model with respect to education activities and programs in survivorship care?*

- Primary care providers only have access to a **limited supply of money** to support their professional development activities.
- A **lack of coordination and infrastructure** at the primary care level challenges education initiatives. This makes it difficult to work directly with primary care practices to support training about survivorship care.

“You need a structure in place that is going to help you link the education message to providers.

- **Competing demands** in continuing education surfaced as a challenge. Primary care physicians can choose what areas of practice they want to focus on to meet their continuing education requirements. Cancer and survivorship is only one of many options available to them.

“Although doctors have to do so many hours per year of continuing education, what they choose to do is their choice, so the challenge is trying to make a case for the fact that this is important work and this is learning that should be prioritized over other things.... going to a session on starting insulin with a new diabetic might be seen as a more important topic. So there are competing demands.”

- **Geography and regional needs** challenge partaking in educational opportunities for some primary care providers. Providers in the northern part of Canada for example, often practice in rural and remote communities which requires “*flying out to the south*” to attend

professional development events. They also have different educational needs as they may be the only health provider in the area and responsible for wide-ranging health needs of the population.

“I think there are also issues around the geographic delivery of primary care services.... How they deal with survivorship issues is an issue. We need to think about what are the skill sets of different providers of primary care services and what might be the regional needs.”

- **Education is not prioritized** within cancer centers where the emphasis is placed on treatment. In the view of one participant, this is linked to the broader economic environment.

“[Education] is not seen as the core business of the cancer center. I think many cancer centers don’t have the obvious educational leaders, people with defined expertise or responsibility for that. That’s one of the obstacles.... I think in times of restraint particularly, cancer treatment is going to trump any other kind of activity that we do.”

B.7 Addressing Needs

Question 7: *What types of strategies (activities, methods, tools or processes) should be pursued or developed to enhance education aimed at supporting primary care providers in providing high quality survivorship care?*

With respect to strategies, interview participants highlight some recurrent themes that surfaced in their response to earlier questions. These included:

- **Mentorship**, where family doctors spend a couple of half days per week with a breast cancer specialist to learn and garner expertise to support cancer care for his/her own patients. While this program in a *“really young concept,”* this interviewee believes it will “demonstrate success” and is a good education model to consider going forward.
- **Web-based approaches** to education are preferred as they ensure easy access by all who are interested in advancing their knowledge about survivorship care.

Additional strategies to improve education that supports primary care providers in the provision of survivorship care include:

- Design and offer **graduate level, interdisciplinary courses** that focus on survivorship for various health professionals working in primary care. Not only would this increase knowledge and understanding of survivorship, but would assist in career development as well as bring more attention and focus to survivorship practice.
- Similarly, courses should be **competency based** to ensure adequate knowledge and skills are being acquired. This aligns with what has been done in palliative care education.

“We need to develop competency-based programs that are designed to give providers skill sets... we’ve got them for palliative care, so what about competency for survivorship care?”

- Develop a comprehensive **education / knowledge exchange strategy** that clearly articulates education objectives, audiences and activities.

“I think we need a proper KTE strategy... including education, a whole framework of activities with articulated goals and expectations of what we hope to accomplish.”

- Develop a **learning module in survivorship care** and make this available to CMEs on the local level with a focus on delivering practical information to smaller learning groups.
- Through leadership provided by cancer agencies, work with universities to identify how cancer survivorship training can be integrated into **post graduate curricula** for family medicine trainees.
- Through leadership provided by cancer agencies, collaborate with organizations such as the AFMC (undergraduate) and the College of Family Physicians (postgraduate), and put forward a case to **include survivorship into medical education**.

A.8 Resource Requirements

Question 8: *What types of resources need to be in place to optimize education activities and programs in survivorship care?*

Interview participants articulated a clear need for financial and personnel resources if education programs and activities are to be improved.

Financial:

- An outstanding requirement is funding for specialized training and education. As noted by one interviewee, provincial governments have steered away from funding specialty-based education programs and are more inclined to provide support for “*generic workers who can work across specialties.*” This limits the number of dollars available for training targeted at specialty fields such as survivorship care.
- Additionally, funding is required for organizing and delivering educational events or activities such as CMEs.
- Funding for health providers in information technology represents another cost item, since providers really need to have some basic understating of IT to work effectively within an EMR environment.

Personnel:

- Quality education that is ongoing and sustainable requires support from experts in education, especially adult education. This includes not only developing or designing the programs, but also delivering them where appropriate; since, in the view of one interview participant that, “*doctors don’t always make the best teachers.*”
- Another respondent suggested that volunteers with suitable expertise should be used whenever possible as they typically are provided an honorarium only which reduces the overall costs of education. He added however, “*for something that is really systematic though, you probably need to have some educational leader...*” which would require professional compensation.

Other:

- One participant identified time as a resource in tight supply for primary care providers. As such, any education programs or activities should be flexible with respect to scheduling. She calls for structured learning that, “is not structured as to on this day, at this time.”
- Another interviewee linked the communication and education domains. Tools such as survivorship care plans need to be supported by education sessions to optimize their value. “So, its both communication efforts and education efforts as well.”

B.9 Partners and Roles

Question 9: *Who are the key stakeholders or partners that need to be involved in efforts to improve formal and continuing education activities and programs in survivorship care?*

Table B.9 summarizes information drawn from interview participants about who should be involved in efforts to advance education and what their likely contributions could be.

Table A.9 Partners and Roles

Stakeholder	Role
Cancer Agencies	<ul style="list-style-type: none"> - Lead the way in implementing education technologies and alternative forms of learning - Develop policies to follow the patient and provide survivorship support through setting standards, developing guidelines, and facilitating quality education - House / have people in place who can effectively liaise with primary care community
Universities	<ul style="list-style-type: none"> - Including “experts in evidence” (researchers) to support the design and delivery of education initiatives and materials - Coordination role - understand and plan education initiatives across various stakeholders
Professional Colleges	<ul style="list-style-type: none"> - College of Family Physicians to provide opportunities for learning - Monitor continuing education requirements for health providers - At the local/provincial level, lead development of new education sessions and preparation of education materials
Professional Associations	<ul style="list-style-type: none"> - Canadian Association of Nursing in Oncology to facilitate interdisciplinary education in survivorship care and to support research in this area
Oncologists	<ul style="list-style-type: none"> - To serve as “designated education leaders,” especially those with graduate training in education - Canadian Association of Advanced Nurse Practitioners, because they cut across all sectors, to identify and suggest individuals from various disciplines who could be involved in education programs and activities, and materials development
Government - Ministries of Health	<ul style="list-style-type: none"> - Budget / funding support - Reflect and promote “society’s values” relative to cancer issues
NGOs	<ul style="list-style-type: none"> - CAPCA to provide overall leadership on key issues in cancer care and survivorship - Canadian Cancer Society and local foundations to support communications around education activities and motivate interest

Other	- Cancer centre administration to encourage and sustain education initiatives in survivorship care
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A. 10 Impacts

Question 10: *What are the anticipated impacts or outcomes of implementing education activities and programs aimed at supporting primary care providers in survivorship care?*

In considering impacts, one interviewee reflected on the link between the Communication and Education domains: *“I think the [education] outcomes are very similar to what they would be with an ideal communications system in place.”* Impacts at the patient, health provider and system levels are described below.

Patient outcomes include:

- Improved patient care
 - Greater opportunity for patients to receive care in their own communities
 - Similarly, more timely access to care
 - Reduced cancer recurrences through follow-up care that includes preventive risk reduction (e.g. diet, exercise)
- Improved patient satisfaction
 - Improved overall patient journey
 - Increase confidence about *“what is happening”*
 - Increased patient confidence that they are receiving quality care

Health provider outcomes:

- Increased access to survivorship information and materials
- *“Primary physicians would be better equipped”* to deal with survivorship issues
- Similarly, increased compliance with recommended care / best practice
- Through interdisciplinary approaches to education, increased understanding of *“each other’s role and knowledge about what each one has to offer to cancer patients,”*
- Improved provider satisfaction as education would *“make it easier, better, and less anxiety-provoking for the family doctor”*

Health system outcomes:

- More appropriate use of health care resources as patients are directed to the follow-up care they need from the right person at the right time (e.g. psychological support after chemotherapy)
- Increased movement toward a patient-focused cancer care system
- Ultimately, less cancer morbidity and mortality and reduced burden on the health care system

B. 11 Final Thoughts

Question 11: *Do you have any final thoughts or comments that you would like to share related to the topics discussed here.*

To close the interviews on education activities and programs in survivorship care, a few participants offered some final words:

The question is almost one of adaptation, to think about this education support piece and what we create for one, the other can use. The work we do to help patients is work we can easily adapt and create educational products and sessions for primary care physicians to help them with this stuff... The drive to make sure patients are equipped with information is pretty strong, and I think family docs will benefit from it too. That would be my parting shot.

*I am tired of talking about it and not seeing much done about it. I haven't seen a lot of progress. We have a lot of evidence about what works and what doesn't work....
I think we just need to apply it."*

SECTION THREE:

ENVIRONMENTAL SCAN

1.0 Purpose

This section gathers information on activities and initiatives that are occurring across Canada to support the role of primary care in cancer follow-up. This information, along with data generated from the literature review and key informant interviews, will help to inform CAPCA and other cancer organizations in their work to support best practices in communication and education when medical responsibility for cancer follow-up is transitioning or complete.

2.0 Method

The primary source of data for the environmental scan was the Internet. The scan was carried out between June and July 2010. In total 67 sites were reviewed and included the following:

- Canadian Provincial Cancer Agencies (n=10)
- Canadian Provincial Cancer Societies, foundations, networks and organizations (n=24)
- Provincial Medical Associations (n=12)
- National Medical Related Associations (n=3)
- University Medical Programs (n=18)

The data were entered into an excel grid which was organized according to the following: contact information, communication tools, professional education programs, web page references and relevant notes. Sites specifically related to breast and colorectal cancer were noted and highlighted. Key words used in the search included: professional healthcare providers, cancer care, primary care physicians, oncology, family medicine, continuing education, information for health care professionals, cancer management, and survivorship programs. The data were further analyzed and summarized and entered into tables which are provided below. The reader should note a few limitations to the data collection. They are as follows:

- Only Canadian sites were reviewed
- The majority of the Medical Association sites had a “members only” section which the study team was not able to access

For a listing of the sites reviewed please see Appendix D.

3.0 Findings

The tables below are organized according to: 1) communication practices and processes and 2) formal and continuing educational initiatives. Within each table the data are further divided by the organization or group supporting the initiative, initiative name, a brief summary of the initiative and where applicable, the pertinent web link.

Only initiatives that are currently underway are included in the tables that follow. It is important to note that earlier efforts aimed at researching and generating learnings in the field of cancer survivorship and follow-up have preceded this work. Specifically, the Canadian Partnership Against Cancer (CPAC) undertook an environmental scan which suggested that the success of future efforts in cancer survivorship rests on the need for a cultural shift in the recognition of cancer survivorship; the need for closer ties between researchers, practitioners and the community outside the cancer care system; as well as the need for an integrated approach with

policy, specific actions and timelines (*Environmental Scan of Cancer Survivorship in Canada: Conceptualization, Practice and Research*, April 2008). Moreover, CPAC's Health Human Resource Advisory Group has developed an extensive database which provides an inventory of innovative, leading and promising models of service delivery in cancer control and care. Each model links to a summary description that includes details regarding: the nature of the innovation, evaluation (where applicable), and the model's feasibility for implementation. Additional efforts have centered on the cancer journey. CPAC is working with the cancer community to enhance programs and services that provide support along the cancer journey - from the discovery of symptoms or signs through diagnosis and treatment and on to survival or end-of-life care (www.cancerview.ca/portal/server.pt/community/supporting_the_cancer_journey/457).

Table 1: Communication Practices and Processes

Source	Initiative	Focus	Web Link
Guidelines			
BC Cancer Agency	Family Practice Oncology Network Cancer Care Guidelines and BC Cancer Agency Cancer Management Guidelines	The BC Cancer Agency has published 2 types of guidelines: cancer care and cancer management guidelines. The cancer care guidelines provide easy to follow, guidelines for family physicians. The first guideline – The Palliative Approach to Care-is published and work is underway on subsequent guidelines for pain and symptom management and grief and bereavement. Efforts will begin this fall to develop guidelines for colorectal, breast and prostate cancer. The Cancer Management Guidelines are a statement of consensus of BC Cancer Agency professionals regarding their views of currently accepted approaches to cancer treatment. Up to 20 guidelines are complete which include breast and gastrointestinal cancers.	http://www.bccancer.bc.ca/HPI/FPON/CN/GuidelinesandProtocols.htm and http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/default.htm
Alberta Health Services	Cancer Guidelines	Alberta Health Services has published 2 types of cancer guidelines: treatment and follow-up. The recommendations contained in the Cancer Guidelines are a consensus of the relevant Provincial Tumor Team synthesis of currently accepted approaches to management (treatment and follow-up), derived from a review of relevant scientific literature. Nine treatment guidelines are complete which include breast and gastrointestinal guidelines. Follow-up guidelines include guidelines for early stage colorectal cancer surveillance . However, numerous follow-up guidelines are currently under development.	http://www.albertahealthservices.com/cancerguidelines.aspx
Saskatchewan Cancer Agency	Cancer Guidelines	Saskatchewan Cancer Agency has published 2 types of guidelines: clinical practice and follow-up. Prostate Cancer Guidelines are the only guidelines published for clinical practice guidelines. There are 10 cancer follow-up guidelines 1 of which is for breast cancer and another for colorectal cancer.	http://www.saskcancer.ca/Default.aspx?DN=b1586bc3-431f-4998-a55c-ec2c34c090ba
Cancer Care Manitoba	Cancer Care Manitoba Cancer	Cancer Care Manitoba disease site groups are in the process of developing a number of guidelines for the follow-up care of	http://www.cancercare.mb.ca/home/health_care_profession

Source	Initiative	Focus	Web Link
	Management Guidelines	cancer patients by community physicians. To date, breast and thyroid cancer guidelines are complete	als/information_for_health_care_professionals/ccmb_cancer_management_guidelines/
Cancer Care Nova Scotia	Cancer Management Guidelines	Cancer Care Nova Scotia has published fourteen different cancer management guidelines which include guidelines for breast and gastrointestinal cancer. All guidelines have follow-up guidelines embedded within the guideline document.	http://www.cancercare.ns.ca/en/home/healthprofessionals/resourcestools/cancermanagementguidelines/allapprovedguidelines/default.aspx
Cancer Care Ontario	Program in Evidence-Based Care (PEBC)	Program in Evidence-Based Care's (PEBC) is an internationally recognized guideline development program that works to improve the quality of cancer care by helping clinicians and policy makers to apply the best scientific evidence in practice and policy decisions. A number of treatment guidelines have been developed and have been organized by practice, cancer drugs, radiation, surgical oncology, symptom management, and multi-disciplinary cancer conferences.	http://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=10144
Alberta Medical Association	Towards Optimized Practice (TOP)	TOP offers Alberta physicians a unique way of incorporating innovative processes and practices into their practices with the goal of engaging physicians and their teams in using measurement and evidence for continuous quality improvement. Guidelines for cancer include: Breast Cancer , Cervical Cancer, Prostate Cancer, and Colorectal Cancer . These guidelines are focused primarily on screening.	http://www.topalbertadoctors.org/informed_practice/clinical_practice_guidelines.html
Canadian Partnership Against Cancer	Pan Canadian Guideline on Psychosocial and Supportive Care Services and Clinical Practices for Adult Cancer Survivors	This guideline document is intended to inform Canadian health authorities, key administrative and policy decision-makers, advocacy groups, as well as health and supportive care practitioners on the optimum survivorship services and clinical practices for adult cancer survivors who are clinically disease-free in the post-treatment survivorship period. Health and supportive care professionals can use this guideline to help inform survivorship services and best practices to optimize the health and well-being of adult cancer survivors. This guideline is also intended for use by survivors and their caregivers to assist	Draft form

Source	Initiative	Focus	Web Link
		them make informed decisions on survivorship services.	
Networks and Liaisons			
BC Cancer Agency	Family Practice Oncology Network	The Family Practice Oncology Network exists to provide more comprehensive support for family physicians caring for cancer patients including the development of useful resources and tools. To date these include: preceptor program, CME opportunities, newsletter, and cancer care guidelines	http://www.bccancer.bc.ca/HPI/FPON/default.htm
Alberta Health Services	Provincial Family Physician Initiative	The Provincial Family Physician Initiative aims to support a strategic and collaborative relationship between the Alberta Cancer Board and family physicians across Alberta. The Provincial Family Physician Initiative focuses on: access to cancer specialists and information, communication between care providers; education to support the care of cancer patients closer to home and across the cancer care spectrum. Specific strategies are being developed to address each of these priorities.	http://www.cancerboard.ab.ca/Professionals/For+Family+Physicians/
Alberta Health Services	Community Cancer Support Network	There are 2 Cancer Support Networks: 1) psychosocial and palliative oncology network and 2) nutrition and rehabilitation oncology network. The goal of the networks is to improve access to quality supportive care services for people living with cancer and their caregivers. This is done by providing support to those who provide direct patient care through: educational initiatives, information sharing, virtual networking and partnering	http://www.cancerboard.ab.ca/Professionals/CommunityCancerSupportNetworks
Cancer Care Manitoba	Uniting Primary Care and Oncology Network (UPCON)	UPCON is dedicated to promoting and supporting the shared care of the cancer patient. The UPCON works with 13 Lead Physicians who act as liaisons between Cancer Care Manitoba and the other family physicians and primary health care providers in the partner clinics. Each Lead Physician dedicates time to learning about Cancer Care Manitoba's systems and shares this information with family physicians. From their clinic sites, trained physicians and primary health care providers have immediate access to information in the patients' Cancer Care Manitoba electronic	http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/upcon/

Source	Initiative	Focus	Web Link
		health record to support clinical decision making and to provide support to patients and their families undergoing a cancer experience.	
Cancer Care Manitoba	Community Cancer Programs Network	Community Cancer Programs Network staff work together with Cancer Care Manitoba, their local RHA and other interested stakeholders to assist their communities to define cancer needs and to develop solutions for the regions they serve.	http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/community_cancer_programs_network/
Cancer Care Ontario	Primary Care and Cancer Network	To implement the Cancer Primary Care Strategy across the province, regional primary care leads in each Local Health Integration Network (LHIN) act as local contacts for primary care providers and regional cancer programs in Ontario. Together with the provincial primary care lead, they form a Provincial Primary Care and Cancer Network (PPCCN).	http://www.cancercare.on.ca/pcs/primcare/
Shared Care			
Alberta Health Services	Comprehensive Breast Care Program	The Comprehensive Breast Care Program (CBCP) is a collaborative program of Alberta Health Services and Covenant Health. The goal of the CBCP is to offer a seamless, integrated, patient-centered approach to diagnosing and treating breast abnormalities. The CBCP is intended for diagnostic and treatment services, not routine screening. The CBCP ensures the family physician remains the primary care provider. Physicians are directly supported by a nurse navigator and a breast expert (physician with special training) who are backed by a multi-disciplinary team including radiologists, pathologists, surgeons, radiation and medical oncologists, psychologists and social workers.	http://www.cancerboard.ab.ca/Professionals/CBCP/
Cancer Care Ontario	Multidisciplinary Cancer Conferences	Multidisciplinary Cancer Conferences (MCCs) are regularly scheduled meetings where healthcare providers discuss the diagnosis and treatment of individual cancer patients. Participants represent medical oncology, radiation oncology, surgical oncology, pathology, diagnostic radiology and nursing. Other healthcare providers involved in a patient's care -- such as	http://www.cancercare.on.ca/pcs/treatment/multiconfers/

Source	Initiative	Focus	Web Link
		dietitians, rehabilitation specialists and pharmacists -- may also attend. There are documents online to assist with these meetings e.g. how to start a meeting, patient case, and recording tools.	
Newsletters			
BC Cancer Agency	The Family Practice Oncology Network Newsletter	The goal of the Family Practice Oncology Newsletter is to keep family practitioners informed on new initiatives and developments and to promote awareness of Network resources and relevant activities at the BC Cancer Agency. The newsletter is distributed every spring and fall.	http://www.bccancer.bc.ca/HPI/FPON/Newsletters.htm
Cancer Care Manitoba	Cancer Talk Newsletter	The Cancer Talk Newsletter is Cancer Care Manitoba's information resource for family physicians and primary health Care providers. The newsletter provides information for family physicians that care for patients during the workup and diagnosis of a suspected cancer, support them during treatment, and provide follow-up care when treatment is completed.	http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/cancertalk_newsletter_/
Ask an Expert			
Alberta Health Services	Alberta Cancer Line	The Alberta Cancer Line is a toll-free phone number for health professionals to get their questions about cancer answered.	http://www.albertahealthservices.ca/2294.asp
Alberta Health Services	The Telehealth Pain and Symptom Control/Palliative Radiotherapy Clinic	The Telehealth Pain and Symptom Control/Palliative Radiotherapy Clinic helps patients with the pain and symptoms associated with cancer. The program provides real-time support to physicians caring for cancer patients in rural and remote communities. High-definition televisions link the remote care centre to a multi-disciplinary team at the Cross Cancer Institute in Edmonton. The multi-disciplinary team can then assess the patient without the patient leaving his or her home community. The patient may still require travel to Edmonton during their care, but many parts of the care can be provided to the patient through Telehealth.	http://www.cancerboard.ab.ca/Professionals/For+Family+Physicians/TelehealthPainClinic.htm

Source	Initiative	Focus	Web Link
Cancer Care Manitoba	Ask an Expert	Ask an Expert is an on-line form that physicians can use to ask a question about cancer prevention, early detection, diagnosis, treatment, follow-up or palliation.	https://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/ask_an_expert/index.cfm?

Table 2: Formal and Continuing Educational Initiatives

Source	Initiative	Focus	Web Link
Training			
BC Cancer Agency	The Family Practice Oncology Network Preceptorship Program	The Preceptorship Program is a two-month course in module format that can be taken as an entire program or in individual modules. The program is offered in each of the five BC Cancer Agency regional cancer centres. It is designed to serve the needs of physicians who have patients who are at risk to develop cancer, are being treated for cancer, are recovering from cancer or have persistent cancer.	http://www.bccancer.bc.ca/HPI/FPON/Precep/default.htm
Cancer Care Manitoba	Learning opportunities for Uniting Primary Care and Oncology Network (UPCON) physicians.	Many learning opportunities exist at Cancer Care Manitoba for UPCON Lead Physicians and their clinic colleagues: small group education, large group education and clinical partnerships.	http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/upcon/
Alberta Health Services	Oncology Nursing Distance Education Course	The course is designed to meet the needs of nurses who provide cancer care for patients with cancer and their families.	http://www.cancerboard.ab.ca/Professionals/EducationAndTraining/ONDEC
McGill University	Dept of Oncology - Community Cancer Care	The Department of Oncology-Community Cancer Care, plans to expand knowledge of cancer treatment to general practitioners both in the form of increased undergraduate and post-graduate training, as well as to organize specific training sessions of several months long for general practitioners / family medicine practitioners who are interested in providing cancer care to	http://www.medicine.mcgill.ca/oncology/programs/programs_communityoncology.asp

Source	Initiative	Focus	Web Link
		patients both outside of hospital and, in some cases, as part of in-hospital care teams.	
Webcasts/Seminars			
BC Cancer Agency	CME Webcasts	Webcasts are held once a month and provide an opportunity for primary care providers to participate in topical, interactive oncology presentations on the Internet.	http://www.bccancer.bc.ca/HPI/FPON/CME/default.htm
BC Cancer Agency	Seminars	These seminars are brief, practical seminars on key cancer care subjects for interested family physicians located in communities throughout BC.	http://www.bccancer.bc.ca/HPI/FPON/CME/default.htm
Conferences			
BC Cancer Agency	Annual Conference	Each year the BC Cancer Agency hosts a Family Practice CME day/BC Cancer Agency Annual Conference.	http://www.bccancer.bc.ca/HPI/ACC2010/default.htm
Cancer Care Manitoba	Cancer Day for Primary Care	Cancer Care Manitoba hosts an annual full day symposium every January, for family physicians, nurse practitioners and primary health care providers to learn more about caring for patients with cancer.	http://www.cancercare.mb.ca/home/health_care_professionals/education_and_training/cancer_day_for_doctors/
Cancer Care Manitoba	Community Cancer Programs Annual Educational Conference	An annual conference offered by the Community Cancer Programs Network (CCPN) and Cancer Care Manitoba (CCMB) which enables health care professionals, to come together and participate in educational and networking opportunities designed to meet the diverse needs of this professional group	http://www.cancercare.mb.ca/home/health_care_professionals/education_and_training/ccpn_annual_conference/
Other			
Cancer Care Manitoba	Scholarships in Community Cancer Care	The Community Cancer Programs Network (CCPN) and Uniting Primary Care and Oncology (UPCON) offer Community Cancer Care Scholarships are designed for all health professionals affiliated with Community Cancer Programs (CCPs) and to family physicians, pediatricians and nurse practitioners in primary care practice who would like to enhance their knowledge and skills in cancer care and blood disorders in order to better serve the needs of their community.	http://www.cancercare.mb.ca/home/health_care_professionals/education_and_training/ccmf_scholarships_of_primary_care_oncology/

4.0 Summary

Below is a summary of key findings from the Environmental Scan:

- Several of the Provincial Cancer Agencies have developed guidelines for cancer treatment and follow-up care, and most of these include guidelines for breast and gastrointestinal or colorectal cancers. It appears that many guidelines are currently under development.
- Networks directed at connecting primary care providers with the cancer system are in place in several of the Provincial Cancer Agencies. These networks are dedicated to promoting communication between the cancer agency and primary care providers. Several of the networks have well established communication systems such as implementation of educational initiatives, information sharing through newsletters, ask the expert opportunities and virtual networking.
- There are some formal and informal educational activities and programs offered across the country. These primarily include formal training courses and annual conferences and seminars/webcasts for CME credits. However, the types of educational opportunities are not consistent across the country.
- Most of the activities and initiatives underway in Cancer Societies, Cancer Foundations and other cancer related organizations focus on supporting the cancer patients and their families and fundraising. As a result their activities are not listed in the tables above.

While it is clear that there is some degree of activity within agencies, organizations and educational institutions to support the role of primary care physicians in cancer follow-up, there does not appear to be a standard practice across the county or within types of organizations (e.g. cancer agencies, cancer societies, medical schools). While each province may wish to enhance communication practices and processes and educational opportunities in a manner that is unique to their particular context, there would certainly be merit in working towards a coordinated approach to improving communication between primary care providers and oncologists when medical responsibility for follow-up care is transitioning or complete.

Appendix A: Annotated Bibliography of Communication References

Allgar, V. L., & Neal, R. D. (2005). General practitioners' management of cancer in England: Secondary analysis of data from the national survey of NHS patients- cancer. *European Journal of Cancer Care*, 14, 409-416.

The aim of this paper was to explore the role of the GP in the management of patients with cancer. A clear understanding of these issues is vital in order to ensure that GPs are appropriately trained and resourced to deliver high-quality clinical care. Secondary analysis was undertaken of data from The National Survey of NHS Patients: Cancer. Data were available for 65 337 patients which represented a response rate of 74% (prior to exclusion of 145 male patients with breast cancer due to low numbers) Following discharge, almost half received care from their GP (46%), almost half from a community, district or specialist nurse (49%), and 0.5% from a private nurse. Patients with different cancers had different discharge arrangements in terms of who they were told to see and who they did see. Most patients felt that their GP was given enough information about their treatment or condition although there was a significant difference between cancers. This makes sense given the different treatment options and survival rates between the cancers, but does highlight that cancer diagnosis and management in primary care is not the same across all cancers. Interestingly, the effect of being told to contact the GP post-discharge seemed to be a strong influence over actually seeing the GP. Thus it seems logical to recommend to all patients on discharge to see their GP if they need to. Not doing so may reinforce beliefs in some quarters that GPs lack sufficient expertise to assess and manage cancer problems. There is clearly considerable scope for GPs to have greater involvement in cancer care, especially if they are to have a 'continuous, comprehensive, and coordinated' role.

Baravelli, C., Krishnasamy, M., Pezaro, C., Schofield, P., Lotfi-Jam, K., Rogers, M., et al. (2009). The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. *Journal of Cancer Survivorship*, 3, 99-108.

The aim of this study was to establish the acceptability of survivorship care plans (SCPs) within a local population to inform the development of a SCP for routine care. Attitudes of CRC survivors, general practitioners (primary care providers [PCPs]) and hospital-based HCPs working with cancer survivors regarding the adequacy of current information and follow-up care and their views regarding the development and communication of a SCP were assessed over two studies. Study 1 was designed to explore views of CRC survivors and PCPs regarding follow-up experiences and to review the components of the SCP. Study 2 was a questionnaire exploring the views of healthcare professionals around follow-up and SCP components. For Study 1, a convenience sample of CRC survivors was identified through a comprehensive cancer centre in Melbourne, Australia. A sample SCP for a fictitious patient who had completed surgery and chemotherapy for stage III colon cancer was developed based on the IOM template. PCPs of eligible CRC survivors were contacted and asked to participate in a brief structured telephone interview regarding SCPs for CRC survivors. For Study 2, the sample comprised medical practitioners and nurses attending the 2008 Colorectal Cancer Conference in Melbourne. Results indicated that all participants endorsed the core elements of the SCP, including information about diagnosis, diagnostic tests, a summary of treatments received, surveillance plan, and information regarding potential late and long-term effects. However, some of the most positive statements by survivors about the SCP involved the 'novel' components.

These included lifestyle changes, psychosocial and practical issues. While nurses also strongly supported the inclusion of these components, hospital-based doctors were less supportive. There was no clear consensus amongst hospital-based HCPs regarding who should write and deliver the SCP. Data show that cancer survivors feel that they do not currently receive the information recommended for inclusion in the SCP, but feel that receiving this information would be helpful, reassuring and would likely reduce uncertainty. PCPs reported the information recommended for inclusion is currently absent, fragmented or hard to find, and that receipt of this information in the form of a SCP would be very relevant and helpful to their role in caring for CRC survivors. This study also identified barriers to introducing SCPs in routine practice, including the time and resources required to complete plans. Data also reflect lack of consensus around the development, content and delivery of the SCP.

Braun, T. C., Hagen, N., Smith, C., & Summers, N. (2003). Oncologists and family physicians: Using a standardized letter to improve communication. *Canadian Family Physician, 49*, 882-886.

The objective of this program was to improve the quality of dictated consultation letters from oncologists to community family physicians through use of a standardized letter. A project team, consisting of an oncologist, a community family physician, a palliative care physician, and a palliative home-care nurse, was established to develop the standardized letter template. The template was subsequently reviewed by 10 community family physicians who were respected as local opinion leaders. Evaluation was done with a before-after survey. To collect baseline data, 138 surveys were mailed to family physicians. Seventy-six were returned (55% response rate). After implementation, 56 surveys were mailed to family physicians and 27 were returned (48% response rate). Baseline data revealed that most (85%) family physicians were generally satisfied or very satisfied overall with the letters they received. Given the relatively high satisfaction rate before implementation, evaluation analyses focused on the difference in the percentage of family physicians who were very satisfied with non-standardized letters and, after implementation, very satisfied with the standardized consultation letters. The percentage of family physicians who were overall "very satisfied" with clinic notes increased from 10% at baseline to 56% after the implementation of the template. However, 75% had already reported being at least "satisfied" at baseline if not "very satisfied".

Cheung, W., Neville, B., Cameron, D., Cook, E., & Earle, C. (2009). Comparisons of patient and physician expectations for cancer survivorship care. *Journal of Clinical Oncology, 27*(15), 2489-2495.

This study conducted self-administered surveys to compare cancer survivors' expectations of care from their PCPs and oncologists with the roles that these physicians perceive for themselves and to identify potential patient and physician characteristics for areas in which there is disagreement. A better understanding of patient and physician perceptions of their roles in the survivorship process can help inform future survivorship care planning. Two separate questionnaires were distributed to cancer survivors who were asked to identify their PCP and the oncologist most responsible for their ongoing cancer care. The physician version of the survey was then sent to these providers. The overall response rate for patients was 54% (532 of 992) and for physicians was 62% (378 of 607). With the exception of treatment of general medical problems, where agreement in expectation was high, the concordance rates for the remaining survivorship care domains were poor, including primary cancer surveillance (3%), cancer screening (44%), and preventive health care (51%). Both PCPs and oncologists expected to be prominently involved in these areas, resulting in overlaps in expectations.

Between patients and their PCPs, expectations were most incongruent for primary cancer follow-up (agreement rate, 35%), with PCPs indicating they should contribute a much greater part to this aspect of care. Expectations between patients and their PCPs were generally more concordant than between patients and their oncologists. In the domains of primary care follow-up and cancer screening, the requirement for substantial coordination of care among several specialties for certain items, may lead to uncertainty on the part of both patients and providers about who is responsible. Conversely, there may also at times be overuse of medical services caused by poor communication as patients visit different physicians for the same issue.

Del Giudice, L., Bondy, S. J., Chen, Z., & Maaten, S. Physician care of cancer patients. (pp. 162-174). In: ICES Atlas.

The Ontario Cancer Registry and the Ministry of Health and Long-term Care Ontario Health Insurance Plan database were used to describe health care contact rates and proportion of visits by physician specialty for each of the four most common cancers (lung, colorectal, breast, and prostate) before, during and after diagnosis and treatment as well as end of life. Results indicated that during each of these periods, compared to pre-diagnosis, cancer patients had increased contact rates with their primary care providers. Except during active treatment, cancer patients saw their GP/FPs more frequently than any other physician. GP/FPs have key roles in each phase of the cancer treatment cycle and in the coordination of care, and therefore must be aware of best practices in each phase and have access to diagnostic technology and specialist oncology services. As they assume increasing responsibility for cancer care, they need to be supported through inherent challenges by: remunerating their activities appropriately; providing funding to develop programs in knowledge translation of cancer care through medical school curriculum changes and continuing medical education; and providing consistent, updated diagnostic and treatment decision aids and guidelines.

Del Giudice, M. E., Grunfeld, E., Harvey, B. J., Piliotis, E., & Verma, S. (2009). Primary care physicians' views of routine follow-up care of cancer survivors. *Journal of Clinical Oncology*, 27(20), 3338-3345.

The primary study objective was to determine Canadian PCP willingness as well as time from completion of active treatment PCPs would prefer to assume exclusive follow-up care of cancer survivors. Secondary objectives explored PCP current practices and their needs and concerns in assuming this care. A self-administered survey was mailed to a stratified random sample of PCPs. The response rate was 51.7%. Approximately 50-55% of PCPs were willing to accept exclusive care of patients with breast, prostate, and CR cancer within 2 years after completion of active treatment (only 42% were willing for lymphoma). The most useful modalities to help PCPs provide exclusive follow-up care to cancer survivors were (from most to least useful): a patient-specific letter from the specialist; printed guidelines; expedited routes of re-referral; and expedited access to investigations for suspected recurrence. Respondents felt that PCPs are better placed to provide psychosocial support to their patients than oncologists (79.8%) and that they should be involved at an earlier stage in cancer follow-up care (63.7%). PCPs were concerned that patients expect to receive follow-up for cancer by their cancer specialists (71.7%) and that patients will not be adequately reassured if they receive exclusive follow-up from their PCP. PCPs not currently providing exclusive follow-up care were more likely to agree with statements that favored specialist care and less likely to agree that PCPs have the skills necessary to provide routine follow-up for patients with cancer.

Donnelly, P., Hiller, L., Bathers, S., Bowden, S., & Coleman, R. (2007). Questioning specialists' attitudes to breast cancer follow-up in primary care. *Annals of Oncology*, 18(9), 1467.

This study surveyed breast cancer specialists regarding how long breast cancer patients should be followed up after initial treatment, what tests should be done and who should be conducting the follow-up. A 20-point questionnaire was sent to 562 specialists. When asked which lead clinician took charge of follow-up, 60% of respondents indicated the surgeon, while for 31% the role varied according to disease stage or circumstance. Asked if there was a protocol for managing follow-up of women with early breast cancer, 84% confirmed that there was, but only 9% conformed to NICE guidelines. The remainder had a locally developed protocol. Forty-five respondents (18%) stated that they offered patients a choice in follow-up protocol of whom only 9% routinely gave patients a written plan. Respondents perceived the greatest benefit of discharge to primary care was 'reduced clinic workload'. The most frequently reported disadvantages were 'lack of GP experience or training in oncology' and 'loss of patient outcome data'. Specialists felt the following changes in primary care infrastructure would make them more likely to adopt earlier discharge: 'increased GP education and training', 'development of shared protocols', and 'recruitment of Primary Care Trust-based oncology nurses'. Asked if GPs were aware that their patients were being discussed at multidisciplinary meetings, 84% responded positively although only 2% of these encouraged GPs to attend the meetings or participate through tele- or videoconferencing. With regard to the options available for arranging monitoring after secondary discharge, the preferred options were patient-driven telephone calls to hospital breast care nurses (43%) and patients seen annually by GPs, plus additional as required access (43%). Less favoured options were patients seen annually by community nurses and additional as required access (13%) or patients telephoned annually by community nurses and as required (6%). Twenty-eight per cent of respondents considered all of the above would be appropriate and should be determined by patient choice. Asked who was best placed to determine the balance between frequency of surveillance tests to determine recurrence and the patient's anxiety generated by the uncertainty of outcome, the responses were as follows—all in partnership 56%, hospital specialist 28%, patient 7% and GP 2%.

Earle, C. C., Grunfeld, E., Coyle, D., Cripps, M. C., & Stern, H. S. (2003). Cancer physicians' attitudes toward colorectal cancer follow-up. *Annals of Oncology*, 14, 400-405.

This study undertook a national survey of all Canadian physicians (surgeons, radiation oncologists and medical oncologists) who could be identified as specializing in colorectal cancer (CRC), in order to assess empirically the current standards of follow-up care and the attitudes and beliefs behind these practices, and to estimate the impact of different patterns of practice on costs. A standardized questionnaire was developed based on a survey instrument used previously to measure follow-up practices for breast cancer, modified for CRC. The overall adjusted response rate was 58% (160/275). Only two respondents (1.3%) agreed with a practice of no routine follow-up, advising patients to return to clinic if they developed symptoms. 103 (64%) stated that they routinely discharge patients at some point to their primary care physicians for follow-up. Only 12 (7.5%) did so immediately after completing primary therapy. Only 43 (27%) agreed with routine follow-up being performed entirely by primary care physicians who would refer patients back to their surgeon or oncologist on an as needed basis. 106 respondents (66%) agreed that alternating follow-up between primary care physicians and specialists was appropriate. About half of the respondents felt that specialists were more efficient at providing follow-up care than primary care physicians, because they were less likely to order unnecessary tests such as bone scans. 138 (86%) thought that patients expect follow-up by a specialist. However, 89 (56%) allowed that primary care physicians have the skills to

provide follow-up, 147 (92%) would refer patients back if a recurrence developed, and 87 (55%) acknowledged that primary care physicians were generally better at psychosocial support than specialists. Whether follow-up is best accomplished in the primary or tertiary care setting is not known, but it is likely that both specialist and generalist physicians have different contributions to make to high quality care for cancer survivors.

Earle, C. (2006). Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *Journal of Clinical Oncology*, 24(32), 5112-6.

This article discusses components of survivorship care plans, including: treatment summary, ongoing care plan, guidelines for surveillance, long-term and late effects of treatment, non-cancer health care and health maintenance, and identification of providers; and considerations in the use of care plans. Survivorship care plans need to be patient-centred and tailored to the patient's clinical situation and preferences. It must lay out the protocol for surveillance of recurrence, ideally organized around a set of widely known clinical practice guidelines, though few of these currently exist (with the exceptions of breast and CRC) due to a lack of evidence and lack of expert consensus. Guidelines can decrease variation in care, particularly overuse of investigations. It is also suggested that plans address psychosocial concerns and even employment, insurance and economic issues. Because the quality of routine care for cancer survivors is related to their level of engagement with the health care system, it is important for the plan to identify which providers will be responsible for which issues/roles. Barriers to the creation of care plans include current lack of consensus on standardized content, assignment of responsibility for plan creation and a culture shift ensuring that providers view survivorship care planning as a standard and expected component of quality cancer care. Future research in this area should include: observational studies to determine survivor's knowledge and desire for this information; evaluating levels of satisfaction with transition to follow-up care and how this relates to reception of care plans; assessing variation in follow-up practices; evaluating ways to optimize communication between care providers, including developing and use of information technology; assessing ability of different survivorship care plan formats; testing acceptability of survivors and providers who use different models of care; and determining the current and optimal levels of involvement of different specialists and primary care physicians in the creation and execution of survivorship plans.

Eggle, S., Albrecht, T., Kelly, K., Prigerson, H., Sheldon, L., & Studts, J. (2009). The role of the clinician in cancer clinical communication. *Journal of Health Communication*, (Suppl1), 66-75.

This report describes highlights of three areas of cancer clinician communication: (1) key areas of current research, (2) emerging areas of active investigation, and (3) theories and approaches for future research. Ultimately, to achieve truly patient-centered communication, clinicians need to develop skills both to assess individual patient communication needs and preferences and to tailor their communication accordingly. Curricula to train clinicians at every level of expertise in how to communicate effectively in a variety of interaction contexts have developed to keep pace with evolving evidence. Accreditation agencies for many health professional training programs (e.g., Accreditation Council on Graduate Medical Education) currently require documentation of trainees' level of competence in interpersonal communication. Despite somewhat limited evidence of their effectiveness in clinical settings, published guidelines provide clinicians with basic communication strategies to prepare them for these complex, high-stakes interactions. Clinician-clinician communication in the context of survivorship is challenging and critical to patient and family outcomes, yet under-studied. A key challenge in moving research on clinician

communication forward is the integration of transdisciplinary theories and approaches by researchers, clinicians, patient advocates, and patients. The fields of social psychology and communication studies provide useful theories that only occasionally have been applied to shape research questions in this context, including: the convergence model of communication, the Common Group Identity Model, and the Cognitive-Social Health Information Processing (C-SHIP) model.

Faul, L., Shibata, D., Townsend, I., & Jacobsen, P. (2010). Improving survivorship care for patients with colorectal cancer. *Cancer Control*, 17(1), 35-43.

In this paper, we highlight important problems that have been identified in the quality of care currently provided to cancer survivors. In addition, we describe recommended changes in clinical practice designed to improve the quality of care following completion of initial treatment. Finally, we identify research that is needed to advance these proposed changes in clinical practice. The Institute of Medicine (IOM) report titled *From Cancer Patient to Cancer Survivor: Lost in Transition* highlighted gaps between the needs of survivors following completion of initial treatment and current oncology practice and also endorsed the proactive anticipation of patients' needs, rather than impromptu or improvised response/reaction to emergent events. Given the complex and ongoing nature of cancer care, anticipation of needs and coordination of care for patients and survivors appear to be reasonable approaches. The IOM report identified the provision of treatment summaries and survivorship care plans to cancer patients and their health care providers upon completion of active treatment as an important means of promoting coordination of care and aiding the transition from cancer patient to cancer survivor. The ASCO Cancer Survivorship Expert Panel has created templates of a treatment summary and a survivorship care plan for colon cancer (an example template is included in this article). The survivorship care plan should include specific information outlining recommended tests and their frequency to monitor for recurrence, second malignancies, ongoing toxicities, and late effects, along with designation of the responsible physician(s). The IOM report advocated for the concurrent implementation and investigation of treatment summaries and survivorship care plans. Treatment summaries and survivorship care plans have yet to be widely adopted despite these foreseeable benefits. Even when adopted, their impact has not been subjected to rigorous empirical investigation. Several types of research are necessary to expand the evidence base, including studies using qualitative, observational, and interventional study designs.

Fennell, M., Das, I., Clauser, S., Petrelli, N., & Salner, A. (2010). The organization of multidisciplinary care teams: Modeling internal and external influences on cancer care quality. *Journal of the National Cancer Institute Monographs*, 40, 72-80.

This article presents a targeted review of the literature on what is known about various types of multidisciplinary (MDC) team structures and their impact on the quality of cancer care; the use of MDC teams for health-care delivery in other diseases; external environmental factors; and the influence of structural characteristics at the level of the practice or hospital setting have on the ability of MDC teams to improve care quality. MDC teams allow for collaborative consultation which permits consideration of the cancer patient's psychosocial needs. The team concept is integral to effective functioning of MDC care and patient involvement with the MDC team is essential to ensure patient-centred care as well as understanding of diagnosis and treatment options. Philosophically and practically, primary care seems essential to facilitate the continuity of medical management and to coordinate all of the care the patient receives over time. Furthermore, to integrate QOL considerations and support services during and subsequent to treatment, psychologists, social workers, nurses, nutritionists, and spiritual advisors may be

necessary. Additional team members may be physically present to meet or available for consult. MDC team functioning can be influenced by a number of factors, including: organizational culture and management support; financial incentives, referral policies or hospital and/or practice characteristics; level of competition for cancer services in the local market; and availability of reimbursement of physician time. While the available literature has scant quantitative evidence on the relationship between team performance and clinical effectiveness, the authors utilize available information to propose a conceptual model to predict the influence of team context, structure, and process on team performance and patient outcomes. Both structure and process are considered primary determinants of health-care organizational performance. The model assumes that if high-quality structures and processes are put in place, good performances will result.

Foy, R., Hempel, S., Rubenstein, L., Suttorp, M., Seelig, M., Shanman, R., et al. (2010). Meta-analysis: Effect of interactive communication between collaborating primary care physicians and specialists. *Annals of Internal Medicine*, 152(4), 247-258.

* The majority of studies in this meta-analysis address mental health issues. None of them address cancer specifically.

This study used meta-analysis to assess effectiveness of collaboration between primary care physicians and specialists and meta-regression to understand the relative contributions of specific collaboration features. Evaluations that described collaborative arrangements in which fewer than 75% of the collaborating professionals on either side were in a group of interest (primary care physicians, endocrinologists, psychiatrists, or oncologists) were excluded as were studies where the specialist predominantly collaborated with primary care nurses rather than other physicians. Twenty-three studies provided usable patient outcome data for meta-analysis. The interventions included face-to-face meetings (9 studies), paper letters or notes (8 studies), telephone discussions (7 studies), videoconferencing (3 studies), and electronic records or letters (2 studies). Fourteen studies examined combined methods of communication. On the basis of our conceptual framework for collaboration between primary care physicians and specialists, we found that interactive communication is associated with improved patient outcomes. We found evidence only relating to collaborations with psychiatrists and endocrinologists. However, the consistency of the statistical and clinical significance of the effects across different primary care–specialty collaborations, health care conditions, and study designs suggests the potential of interactive communication to improve the effect of collaboration across other specialties and conditions.

Ganz, P. (2009). Survivorship: Adult cancer survivors. *Primary Care*, 36(4), 721-41.

* This article provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography.

Ganz, P. A., Casillas, J., & Hahn, E. E. (2008). Ensuring quality of care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing*, 24(3), 208-217.

* This article provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography. This information is therefore not summarized again here. Survivor care plan templates are discussed as in the Jacobs et al article.

Prospective preparation of the treatment summary and care plan is preferred to retrospective reconstruction of past treatments. Several publicly available resources and guidelines that can be used to create or supplement survivorship care plans in clinical practice exist. ASCO recently created sample templates for a combined treatment plan/treatment summary for breast and colon cancer patients; there is also an associated 1-page survivorship care plan that outlines the recommended follow-up care and surveillance for these patients. ASCO has also released a generic template that can be used for any cancer site, with plans for other disease-specific sites such as lung and prostate cancer. These short templates can be quickly completed before or during a patient visit by the treating physician or other staff, and they cover all of the core elements of the survivorship care plan. A more comprehensive approach to the survivorship care plan may include information on the patient's co-morbid conditions from primary care as well as specialist care such as cardiology, endocrinology, or pulmonology. ASCO is also currently promoting integration of the treatment plan and summaries into oncology electronic health records by hosting a vendor challenge for electronic health record systems. The National Comprehensive Cancer Network and the American Cancer Society also have resources and materials focused on survivorship issues, guidelines, and survivorship care plans; additionally, the COG provides exceptional guidelines for survivors of childhood cancers. Other e-resources such as the Oncolink survivorship care plan tool, Oncolife, and A Prescription for Living (a care planning tool developed for use in nursing), are providing web-based survivorship tools specifically for patients to use with their health care team.

Ganz, P., & Hahn, E. (2008). Implementing a survivorship care plan for patients with breast cancer. *Journal of Clinical Oncology*, 26(5), 759-767.

* This article provides a review of information on survivorship care plans that is very similar to and drawn from other articles in this annotated bibliography. It focuses on the rationale for a breast cancer survivorship treatment summary and care plan; describes its contents; and discusses potential strategies for delivery of the care plan, including timing and who should prepare and deliver it, as well as how frequently the care plan might need to be updated. Finally, it describes resources that are available to assist in care planning and a vision of how survivorship care plans can enhance the quality of breast cancer care as well as help meet the looming challenge of a gap in the oncology work force.

Gilbert, S., Miller, D., Hollenbeck, B., Montie, J., & Wei, J. (2008). Cancer survivorship: Challenges and changing paradigms. *The Journal of Urology*, 179(2), 431-8.

The purpose of this review is to outline the range of issues faced by cancer survivors, describe a conceptual framework for cancer survivorship, and review several proposed survivorship programs and potential challenges associated with improving the quality of survivorship care. Establishing a Survivorship Care Plan has been suggested as one way to prevent the disconnect between successful initial cancer therapy and sub-optimal long-term follow-up care. The Survivorship Care Plan is a tailored document created by those primarily responsible for cancer treatment for the purpose of providing detailed information regarding a patient's cancer and treatment history and to define surveillance schedules, identify health priorities related to both cancer therapy and general health, and indicate how (by whom and in what setting) follow-up care is provided. It is tailored to each cancer survivor, can be modified according to developing concerns and needs, is shared with the patient, the primary care provider and members of the patient's support network, and is modifiable upon completion of active therapy. A second goal of the Survivorship Care Plan is to optimize the continuity and coordination of care. The shared-care model, as implied, involves care shared and coordinated between two or

more health care providers in different specialties or locations. This approach has been shown to improve outcomes and facilitate effective management in chronic diseases, such as diabetes and chronic renal disease. Although additional assessment is necessary, the shared care model may be beneficial in improving the quality of cancer survivorship care. Involving more than one physician in the care of cancer survivors appears to increase the likelihood of quality care. Because the shared care model utilizes existing resources, it may be more easily implemented than other survivorship models. In addition, application of a Survivorship Care Plan may increase physician communication and coordination of care, and direct re-referral to the cancer specialist when late-term effects and concerns arise. The use of a care manager to serve as a coordinating intermediary between the oncologist and primary care physician has also been proposed as a potential refinement. Advances in technology may also improve the effectiveness and efficiency of the shared-care model.

Grunfeld, E., & Earle, C. C. (2010). The interface between primary and oncology specialty care: Treatment through survivorship. *Journal of the National Cancer Institute Monographs*, 40, 25-30.

This article, explores the unique challenges of care and health service delivery in terms of the interface between primary care and specialist care during the survivorship period. Studies have found that patients who were followed only by primary care physicians were more likely to receive preventive interventions directed at non-cancer conditions, whereas those followed by oncologists were more likely to receive interventions directed at cancer surveillance. Studies also show that recommended cancer surveillance is more likely to occur when an oncologist is involved in survivorship care. Underuse of cancer surveillance by primary care physicians may reflect an assumption that an oncologist has remained involved and is leading this aspect of care. The fact that primary care physicians are more likely to provide preventive care suggests that oncologists may not see this as part of their area of responsibility. If a primary care physician is not actually involved, or the patient has looked to their specialist to provide all care, these important services may not be delivered, much to the detriment of the patient. Primary care providers express concerns about the lack of role clarity and confidence managing the care of survivors. However, studies show they are keen to take on responsibility for cancer survivorship care and several randomized controlled trials have shown that both clinical and quality-of-life outcomes are unaffected when the primary care physician is primarily responsible for routine follow-up care. Survivorship care plans, as envisioned by IOM, are designed to address potential deficiencies in communication by explicitly laying out for patients and all involved providers a plan for surveillance and other care in the future. At this point, however, it is not clear exactly who should be responsible for developing these plans. The essential thing is that it is clear to the patient and all involved health-care providers who will be primarily responsible for what aspect of follow-up care, including both cancer and non-cancer care. At this point, it is also unknown whether this saves money or costs money, and so it is unclear to payers whether it is in their interests to fund this activity. Consequently, widespread implementation of survivorship care plans will require a culture change in which it becomes a required part of good cancer practice. Patients and referring physicians, such as the primary care physician, can help effect this change by demanding a care plan.

Grunfeld, E. (2009). Optimizing follow-up after breast cancer treatment. *Current Opinion in Obstetrics and Gynecology*, 21(1), 92-6.

This review focuses on studies published in 2007 or 2008 that help elucidate the optimum approach to survivorship care. Guideline statements support transfer to the PCP for follow-up on the basis of evidence from randomized controlled trials. Further, one survey and two RCTs indicate that PCPs were willing to assume follow-up care with proper guidelines and a clear transition of care. This is consistent with the guideline recommendations that any transfer of care should be accompanied by a clear allocation of care to a single physician with the PCP, patient, and specialist all aware. It is in this situation, too, that survivorship care plans can be an important tool to facilitate communication among patients and healthcare providers. Alternative models to cancer specialist follow-up such as primary care-based follow-up, nurse-led follow-up, or less frequent follow-up are all acceptable to patients with good patient satisfaction and quality-of-life outcomes. Primary care-based follow-up results in similar clinical outcomes as specialist-based follow-up. Alternative models of follow-up are likely to be equivalent to specialist follow-up which suggests that there is likely to be more than one right answer. As such, we be thinking in terms of personalized follow-up care, individualized to meet specific patients' needs within the context of informed decision making: informed about the evidence base of actual benefits and risks of the different approaches. Instead of trying to find a one-size-fits-all approach we should be evaluating a tailored approach in which the patient decides on the basis of a clear presentation of the available options and the evidence supporting them.

Grunfeld, E., Levine, M., Julian, J., Coyle, D., Szechtman, B., Mirsky, D., et al. (2006). Randomized trial of long-term follow-up for early-stage breast cancer: A comparison of family physician versus specialist care. *Journal of Clinical Oncology*, 24(6), 848-55.

We hypothesized that routine follow-up by the patient's family physician is a safe and acceptable alternative to specialist follow-up of breast cancer patients. We conducted a multi-center, randomized, controlled trial of routine follow-up care after patients completed adjuvant therapy for early-stage breast cancer. Six of the nine regional cancer centers in Ontario, Canada, participated in the study. Patients were enrolled onto the study through tertiary-care cancer centers in Ontario where they had received their adjuvant treatment and were now receiving routine follow-up care. This study showed both that serious clinical events (SCEs) are extremely rare (35 during 3,240 patient-years) and that they occur with equal frequency, regardless of the follow-up arrangements. Prompt diagnosis of recurrence is a principal concern of both patients and physicians during follow-up. These events were selected because they are potentially preventable if identified early, and may not be recognized by a physician who is not specifically trained and experienced in oncology. The quality of life of the two study groups was compared using standardized validated questionnaires. No difference was detected between groups for any of these measures. One of our objectives was to determine the acceptability of family physician follow-up to breast cancer patients. In this study, 55% of the patients (968 of 1,760) approached agreed to participate. This is similar to the 58% acceptance rate in another trial involving breast cancer survivors. This leads to the conclusion that while family physician follow-up is acceptable to the majority of patients, some patients will be unwilling to have follow-up care transferred to their family physician.

Grunfeld, E., Mant, D., Vessey, M., & Fitzpatrick, R. (1995). Specialist and general practice views on routine follow-up of breast cancer patients in general practice. *Family Practice*, 12(1), 60-5.

The objective of this study was to learn the views of carers (GPs and specialists) on breast cancer follow-up in general, and, more specifically, on a system of follow-up which is general practice-centred rather than hospital-centred. A questionnaire was posted to a variety of cancer

specialists. Three months after the start of a randomised trial comparing community versus hospital routine follow-up of breast cancer patients, we began a personal interview survey was conducted with all GPs who had patients eligible for the trial. 180 GPs completed interview surveys for a response rate of 81.8%. The majority of specialists (78.9%) agreed with the statement that hospital follow-up is important because it provides psychosocial support to the patient. Of GPs only 17.5% agreed and 37.3% were uncertain about this statement. However, 73.3% of GPs agreed, as compared with 46.1% of specialists, that hospital breast clinics are a problem because patients rarely see the same doctor. There was good agreement between GPs and specialists (65.1% and 75.2% respectively) with the statement that hospital breast clinics are overcrowded. While most GPs (68.9%) considered that they had the skills necessary to do the follow-up, only 37.6% of specialists agreed with this. Similarly, far more GPs (81.7%) than specialists (24.6%) thought that GPs are better placed than hospital breast clinics to provide psychosocial support to their patients. When asked about the specific skills required for examining irradiated breasts to detect local recurrence, more specialists (47.3%) than GPs (37.8%) agreed that GPs have the necessary skills. GPs and specialists were asked to select which system of follow-up they 'most preferred'. More than two-thirds (69.7%) of specialists 'most preferred' the system of routine follow-up as it is presently practised in hospital clinics; similarly, 68.6% of GPs 'most preferred' routine follow-up by the patient's GP with referral back to hospital clinics if problems develop. Over half of GPs (55.9%) agreed that they should be involved at an earlier stage in the after care of their patients with breast cancer, but 57.5% considered that they require further training. However, only a quarter (25.9%) agreed that they are currently adequately compensated to take on this new role. Over 70% agreed that communication between the hospital and GP works well and that average waiting time for referral back to hospital is satisfactory with respect to patients with breast cancer.

Grunfeld, E., Dhesy-Thind, S., & Levine, M. (2005). Clinical practice guidelines for the care and treatment of breast cancer: Follow-up after treatment for breast cancer (summary of the 2005 update). *Canadian Medical Association Journal CMAJ*, 172(10), 1319-1320.

* A reference for clinical practice guidelines for the follow-up treatment of breast cancer.

Hewitt, M., Bamundo, A., Day, R., & Harvey, C. (2007). Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. *Journal of Clinical Oncology*, 25(16), 2270-2273.

This study gathered the perspectives of cancer survivors, nurses, primary care physicians, and oncologists related to survivorship care planning. Focus groups were conducted with cancer survivors, nurses, and primary care physicians and oncologists participated in in-depth, one-on-one, structured interviews. Survivors in all three focus groups expressed a great desire for a written follow-up plan. Survivors reported being very satisfied with the clinical aspects of their care, however, many expressed dissatisfaction with their physician's lack of attention to their psychological needs. Participants generally liked the format and the content of the draft template especially aspects that addressed psychosocial needs, but participants in all groups stressed that plans should be individualized. Nurses viewed the draft survivorship care plan enthusiastically and acknowledged that there is no formalized approach to the post-treatment transition period, though there are often informal activities. They believed they could develop and deliver survivorship care plans from the clinical record and their knowledge of the patient, though there were three main barriers to their involvement in care planning: staffing, the recognition of a nursing role in care planning, and reimbursement. Primary care physicians and oncology providers generally agreed that cancer patients would benefit greatly if a summary of

their diagnosis, primary treatment, and follow-up plan were provided to them and their healthcare providers. Primary care physicians would benefit because they could assess their patients with a history of cancer without having to wade through multiple letters from oncology providers. Oncology providers were disinclined to provide this summary because they would receive no time-saving or monetary benefit as a result of doing so, and would benefit only if the document created could replace that which is sent to insurers and the other physicians who are treating the patient. It was typically suggested that the template must take no longer than 20 minutes. Oncology providers reported rarely discharging their cancer patients to primary care physicians for follow-up after active treatment.

First, primary care physicians who view the summary as very helpful to their practices could ask for such a summary. Second, patient advocate groups could inform patients that follow-up care plans are a recommended component of quality cancer care and encourage patients to ask for them. Third, medical schools that educate oncology providers and the institutions where they train could encourage this practice. Fourth, insurers could reimburse oncology providers for the time spent creating the summary. The initial summary and updates could be used by insurers to preauthorize elements of care and to provide proof of service for reimbursement purposes. Lastly, steps could be taken by professional associations, institutions providing care, and consumer advocacy groups to encourage the adoption of electronic medical records, which will facilitate the creation of the summary and care plan. Virtually all participants felt that, for the document to be of value, it could not be a static snapshot of the patient's diagnosis, acute treatment, and the initial plan for follow-up treatment. Steps could also be taken to encourage electronic medical record software designers to develop software packages that allow for the creation of the care plan document with minimal effort.

Hill-Kayser, C., Vachani, C., Hampshire, M., Jacobs, L., & Metz, J. (2009). An internet tool for creation of cancer survivorship care plans for survivors and health care providers: Design, implementation, use and user satisfaction. *Journal of Medical Internet Research*, 11(3), e39.

In May 2007, we launched the world's first Internet-based tool for creation of survivorship care plans, OncoLife. OncoLink is a general cancer information website maintained by physicians and nurses. The OncoLife format includes a publicly accessible, five-screen series of 17 queries regarding demographics, cancer diagnosis, and cancer treatments received, and provides users with lists from which to select surgeries, sites of radiotherapy, and chemotherapy/biologic agents by both generic and trademark names. Completion of the OncoLife survey results in generation of individualized, detailed, comprehensive survivorship care plans providing surveillance recommendations for tumor recurrence, in addition to guidelines for overall health care in the setting of increased risk for certain morbidities secondary to cancer treatment. Prior to submission of the OncoLife survey, users are able to review and change answers; however, because the tool is anonymous, entries are not maintained or saved for reuse or review at a later date. A study of OncoLife users indicated that only approximately one third reported routinely receiving follow-up care from both a PCP and an oncologist. Of the remaining two-thirds, the majority reported seeing only an oncologist. These findings emphasize the need for comprehensive communication among physicians and between physicians and survivors. The vast majority reported never having received survivorship information, and this suggests a broad communication deficit. The data demonstrate that survivors, as well as their family members, friends, and health care providers, appear to be willing to use this type of tool.

Horning, S. (2008). Follow-up of adult cancer survivors: New paradigms for survivorship care planning. *Hematology/oncology Clinics of North America*, 22, 201-210.

* This article provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography. Topics include: description of the treatment summary, survivorship care plans, implementation of care plans, example plan templates, discussion of the use of care plan consultation as a forum for teachable moments (re: addressing healthy lifestyle behaviours), and adults survivorship care.

Jacobs, L. A., Palmer, S. C., Schwartz, L. A., DeMichele, A., Mao, J. J., Carver, J., et al. (2009). Adult cancer survivorship: Evolution, research, and planning care. *CA A Cancer Journal for Clinicians*, 59, 391-410.

* This article provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography. This information is therefore not summarized again here. However, several survivor care plan templates are discussed and information and links are included below.

ASCO offers survivor care plan templates specifically for survivors of breast and colorectal cancers and a general template that can be used for any cancer diagnosis. These templates can be completed online and saved which allow the user to integrate ASCO recommendations into the document to guide the care of the individual cancer survivor. The ASCO templates are available on the ASCO Web site at <http://www.asco.org>. Journey Forward is a program designed for providers and patients who have recently completed active cancer treatment. Journey Forward kits are available online at <http://www.JourneyForward.org>, and they are tailored to oncologists, patients, and primary care physicians. Journey Forward focuses on survivors of breast and colon cancers and has plans to expand to other cancer diagnoses. The Cancer Survivor's Prescription for Living is a template developed by and for nurses in oncological practices. This comprehensive template (available at <http://tiny.cc/SFA8e>) outlines cancer treatment history, significant problems related to or presenting as late effects of treatment, and other health issues. However, it requires handwritten input of treatment and disease information and is not currently available in an electronic version that allows easy input and modification or saving of information entered. A number of institutions are developing and implementing their own internal treatment summary and/or consensus-driven survivor care plan templates, including the Abramson Cancer Center at the University of Pennsylvania, Fred Hutchinson Cancer Research Center, Memorial Sloan-Kettering Cancer Center (<http://tiny.cc/rqgxq>), the University of Colorado Cancer Center, and the Dana Farber Cancer Institute. These documents can be obtained by contacting individuals connected to the cancer survivor programs at each given institute (personal communications). The first Internet-based tool was the LIVESTRONG Care Plan (formerly OncoLink) (<http://www.livestrongcareplan.org>). This care plan will allow the generation of several versions of a care plan that will more appropriately meet the differing needs of patients and providers. The LIVESTRONG Care Plan can be completed by survivors, families, or providers and a variety of user-specific questions are included and modified with each new version based on survivor and clinician feedback. It is not intended to replace provider recommendations, and users are advised on the Web site to discuss the information with their medical team.

Kantsiper, M., McDonald, E., Geller, G., Shockney, L., Snyder, C., & Wolff, A. (2009). Transitioning to breast cancer survivorship: Perspectives of patients, cancer specialists, and primary care providers. *Journal of General Internal Medicine*, 24 Suppl 2, S459-66.

We present the results of a qualitative study exploring the experiences of female breast cancer survivors, PCPs, and oncology specialists and what these stakeholder groups believe is the best approach to survivorship care. Focus groups were conducted with twenty-one female breast cancer survivors, 16 specialists, and 15 PCPs. Survivors frequently noted that they relied on their oncology providers for support, and some associated the emotional connection with their providers with more effective treatment. Survivors held a special regard for the expertise of oncology specialists. Even when participants had established PCPs, most patients did not regard them as having a central role in their cancer-related needs. Some participants indicated that neither their oncology specialists nor their PCPs had adequately addressed psychosocial needs related to physical and psychological side effects. Survivors felt that a written document or ongoing communication between their specialty providers and PCP would be an asset to coordinating their care; however, they did not view it as supplanting the active participation of oncology specialists in their health care. Specialists stated that they struggle with discharging survivors because of the bonds that develop with patients and their deep concern for survivors' needs. Many providers stated that they have expertise in identifying recurrences or side effects that PCPs lack. Specialists acknowledged the role of PCPs in addressing other health concerns but viewed cancer care as a special domain. While they seek to maintain connections with their survivor patients, they expressed that communication with PCPs could be improved. When asked about written survivorship care plans, specialists agreed that some form of communication or tool to be shared between providers would be valuable. The strongest theme expressed by PCPs was their ambivalence about assuming responsibility for survivors' cancer-related needs. Some PCPs reported that they would be comfortable taking on more responsibility for cancer survivors if ongoing training or tools such as a written survivorship care plan and a way to stay connected to the oncologist were available. Many providers were concerned about missing a recurrence of cancer in their patients. PCPs did not have ready access to information about the latest clinical trials, treatment options, and related opportunities for survivors. PCPs were frustrated with the limited or delayed communication with cancer specialists. PCPs felt comfortable addressing patient concerns with new or ongoing physical symptoms outside of survivorship cancer care. This study highlights the value attributed to the relationship between patients and oncology specialists by all stakeholder groups, and the difficulties in defining a role for both oncology specialists and PCPs.

Levitt, C., A., & Lupea, D. (2009). Provincial primary care and cancer engagement strategy. *Canadian Family Physician, 55*(11), e55-e59.

The Ontario Cancer Plan 2008–20112 proposed a primary care engagement strategy as a key new initiative to reduce the burden of cancer. Based on an extensive international jurisdictional review, a literature review, key informant interviews, in-depth discussions with the steering committee, and focus group discussions with primary care providers, a conceptual framework was developed to help primary care providers and the cancer system better understand what could be done to improve integration both at the provincial and regional levels. The conceptual framework consists of 3 key domains of interest surrounded by 2 broad-based initiatives. The 3 domains include: vertical integration, which is the process of actively seeking out and engaging with decision makers, committees, and organizations responsible for the cancer system thus bringing the voice of primary care to the cancer system; Clinical integration which is a process of developing solutions to key challenges facing the primary care community in the province via a gap analysis and needs assessment; and Functional integration, a process of helping at the practice level, which involves discovering what works and what does not work on a day-to-day basis. Navigation tools, decision aids for providers and patients, and helpful, quick responses to

questions raised are some of the provincial support systems envisaged. Surrounding the 3 key domains are 2 broad encompassing initiatives.

The first is a culture of knowledge transfer and exchange that involves systematic outreach to providers with innovative education and decision tools, a wide-reaching communication plan, and research initiatives that will help better explain the challenges to success or help explore new ways of improving engagement. The second is a culture of accountability and measurement and monitoring through the development of tools to assist in measuring and monitoring the effectiveness of this primary care and cancer engagement strategy.

Lewis, R., Neal, R., Hendry, M., France, B., Williams, N., Russell, D., et al. (2009). Patients' and healthcare professionals' views of cancer follow-up: Systematic review. *The British Journal of General Practice*, 59(564), e248-59.

A systematic review of qualitative studies was undertaken to explore patients' and healthcare professionals' views and preferences with regard to cancer follow-up. The search included qualitative studies that used interviews, focus groups, or open-ended questions to elicit patients' or healthcare professionals' views or preferences regarding cancer follow-up. Surveys using only closed questions were excluded. There were significant communication problems, in both directions, between primary and secondary care, which hindered GPs' ability to provide support. Analysis of results led authors to several proposed solutions to the issues that exist: 1) multidisciplinary teams should include representation from primary care; 2) there needs to be a formal handover and exchange of information between primary and secondary care. This should include complete discharge information and exchange of contact details; 3) as an adjunct to routine hospital follow-up, a member of the primary care team should make contact with the patient immediately after hospital discharge to discuss the type of support that primary care could offer; 4) if alternative models of follow-up (for example, primary care, nurse, or patient-initiated follow-up) are to be developed and tested in further research, then these models should: include a system of rapid referral for investigations (to be explained to patients); include training/education for GPs, nurses, and other healthcare professionals; include support from specialist team at hospital; be established with the collaboration of the whole cancer team and primary care from the outset; clear protocol/guidelines should be agreed by all parties in advance; and enable individual GPs (for primary care follow-up) to be able to opt out; alternative primary care-based follow-up should be provided if the patient wishes this.

Mao, J. J., Bowman, M. A., Stricker, C. T., DeMichele, A., Jacobs, L. A., Chan, D., et al. (2009). Delivery of survivorship care by primary care physicians: The perspective of breast cancer patients. *Journal of Clinical Oncology*, 27(6), 933-938.

We conducted this study among a cohort of breast cancer survivors (BCSs) to describe the perceived survivorship care delivered by PCPs, identify the factors that are associated with higher rankings in survivor-perceived survivorship care, and identify survivor recommendations for breast cancer follow-up care. We conducted a cross-sectional survey of 300 BCSs seen in an outpatient breast oncology clinic at a large university hospital. Overall, BCSs rated primary care delivery of survivorship care as 65 out of a maximum of 100. The lowest rated item was interspecialty communication; only 28% of the survivors felt that their PCPs and oncologists communicate well. Most items related to specific cancer survivorship care (symptom diagnosis and management, follow-up, and surveillance for late effects of cancer therapies) had lower endorsements (41%, 50%, and 59%, respectively), whereas survivors highly endorsed the care provided by their PCP on items related to psychological well-being, health promotion, and holism (73%, 73%, and 78%, respectively). Survivors who perceived the care provided by their

PCPs and oncologists as cohesive had higher scores on the PCDSOS than those who did not feel that their care was cohesive. Among participants, 79% considered teaching PCPs about issues relevant to BCS as important or very important. Seventy-six percent of BCSs considered improving communication between oncologists and PCPs as important, 72% felt it was important to teach themselves about how to communicate with their PCPs and oncologists so that the care could be cohesive, and 68% thought it was important or very important to develop a primary care clinic specifically for BCSs.

McCabe, M., & Jacobs, L. (2008). Survivorship care: Models and programs. *Seminars in Oncology Nursing*, 24(3), 202-7.

* In addition to the information included below, this article also provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography.

As more and more cancer centers, hospitals, and practices are developing survivorship clinics, a number of unique models are evolving. In the first model, some institutions offer a consultative service where the survivor is referred to the survivorship staff for a one-time visit while ongoing care continues to be provided by the original treatment team. Here a multidisciplinary team develops a treatment summary and follow-up care plan for the survivor, reviewing surveillance for late effect as well as health promotion recommendations. The second type of clinic is a multidisciplinary clinic that follows the pediatric survivorship model. Here the survivor is seen by the survivorship team on an ongoing basis. Because this model is complex and resource intense, it is most often established to provide care for the adult survivors of pediatric cancer. The third model of care is the nurse practitioner-led clinic where the nurse may be embedded with the treatment team and manage the survivor as an extension of the care continuum. The handoff to the nurse practitioner occurs at a predetermined time after the completion of therapy once the immediate effects of treatment have resolved. A fourth and final model of care for cancer survivors requires that the oncology nurse initiate the development of an end-of-treatment summary and care plan for each patient when the patient completes treatment using a standardized treatment summary form. The end-of-treatment summary form can be developed by and for an individual oncology practice or for institutional use. It can also be one of several templates that are currently available. This model will allow the primary oncology practices to continue to follow these patients in a more organized fashion with a specific care plan or transition patients to other providers more smoothly. Ideally, nurse practitioners and staff nurses in oncology practices could assume responsibility for a post-treatment follow-up visit and take that opportunity to review the care plan, provide symptom management, and refer for supportive care in consultation with the oncologist.

Miedema, B., Tatemichi, S., & MacDonald, I. (2004). Cancer follow-up care in New Brunswick: Cancer surveillance, support issues and fear of recurrence. *Canadian Journal of Rural Medicine*, 9(2), 101-107.

In this paper, we present the findings of the focus group discussions regarding patient experiences with physicians who provide cancer follow-up care in New Brunswick. Data collection consisted of 5 focus group discussions with a total of 23 participants. The participants' experiences were remarkably homogenous, with the exception that rural participants more often received their follow-up care from their FPs than did the urban participants. Two participants did not have a physician who was in charge of their follow-up care and they felt "adrift" in the health care system. During acute treatment they had all kinds of support, medical and emotional, but

this ceased when acute treatment was completed. From this we argue that cancer specialists should make an attempt to involve FPs in follow-up care, to ensure continuity of care after acute treatment. Although the concept of “cancer follow-up care” was not readily recognized by the participants, they were clear about their needs after acute treatment had been completed. Hence, it is important on the part of the specialists to inform the patient’s FP of their patient’s progress. Patients in New Brunswick would readily accept follow-up care from their FP, particularly in rural areas. Based on this research, and supported by other studies, a formal transition of care (or shared care) between the specialists and the FP when the patient moves from acute care to follow-up may eliminate instances of patients “falling between the cracks”.

Miller, R. (2008). Implementing a surviving care plan for patients with breast cancer. *Clinical Journal of Oncology Nursing*, 12(3), 479-487.

* Includes a care plan template.

The intent of this article is to describe the development, implementation, and evaluation of a breast cancer survivorship care plan to guide others to replicate the program in other clinical areas. The first step in designing the plan was to research how leading institutions were developing and implementing survivorship care plans in their specialties because little information existed in the literature regarding implementing such a plan into practice. The survivorship care plan contains two parts. The first part details cancer diagnosis, stage, nodal status, hormonal and tumor markers, treatments received and any significant events that occurred during treatments, side effects experienced, and treatment responses. Information is documented for the survivor about personal risk and future need for continued monitoring related to the therapies provided. Contact information is included for each specialist. The second part of the plan focuses on follow-up care for the specific cancer type and personal experiences encountered during treatment. A consultation appointment with the nurse is scheduled for the survivor and family members within about two weeks of their last visit with the oncologist. Copies of the plan are provided to the patient and to the survivor’s PCP. Prior to delivery of the care plans, the patients reported that they were confused about the meaning of remission, cure, chronic illness, and follow-up care. After care plans were shared with the survivors, the survivors were asked to evaluate whether the plans were effective, clearly written, and helpful to them as they faced their transitions as survivors. All five survivors remarked favorably that the summary information clarified several issues regarding their cancer histories and the treatments they received, and they found that receiving written information was helpful. The PCPs evaluated the care plans positively and stated that the intervention was valuable and should be promoted and sustained as a standard in practice for the benefit of the survivors and the teams involved in their care. The care plans enabled the PCPs to integrate the work of the specialists and avoid duplication of services, and to interact with the survivors in a more informed manner. The care plan became a tool that strengthened collaborative communication among disciplines and placed survivorship care as a central focus for the survivors’ future care management. A way to improve communication is to have care plan forms available on patient charts at the time of diagnosis. The development of electronic medical records (EMRs) would improve the facilitation of communication and rapid retrieval of pertinent information. At present, consultation visits that address survivorship care are not reimbursed. To ensure that the practice is sustained in the clinical setting, creative strategies are needed to seek reimbursement and to build systems where nursing can coordinate the services required for long-term survivorship care.

Nissen, M., Beran, M., Lee, M., Mehta, S., Pine, D., & Swenson, K. (2007). Views of primary care providers on follow-up care of cancer patients. *Family Medicine*, 39(7), 477-482.

Views of PCPs regarding the current transfer of care are not well known. We sought to address three issues: (1) their comfort with and confidence in providing follow-up care, (2) how soon following cancer diagnosis such patients should return to primary care, and (3) problems PCPs perceive in the transfer of follow-up care from medical oncologists to PCPs. The survey focused on the care of breast and colorectal cancer survivors. A cover letter, the questionnaire, and a postage-free return envelope were mailed to all PNHS PCPs. Of the 175 PCPs in the population, 132 (75.4%) responded. On average, 52.0% were comfortable or very comfortable in having responsibility for the surveillance of cancer recurrence, and 43.0% were confident or very confident they are following standard guidelines for surveillance for cancer recurrence. These percentages did not differ significantly for breast versus colorectal cancer. More than 84% of PCPs at our institution indicated uncertainty regarding the type, frequency, or duration of surveillance tests for breast or colorectal cancer. The time when PCPs would prefer to see patients for the first time following a diagnosis of breast or colorectal cancer was distributed across response alternatives as follows: 18.0% indicated during treatment, 36.1% within 3 months after treatment, 14.7% within 6 months after treatment, 17.2% within 1 year after treatment, and 13.9% between 1 and 2 years after treatment. When asked to evaluate the current process of transfer of care from the oncologist to the PCP, 8.4% described it as poor, 48.7% fair, 34.4% good, and 8.4% excellent. In response to "What would make this process better?" suggestions focused on the need for more communication from oncologists and especially for much more specific information regarding the surveillance plan. Responses to either question that focused on issues other than communication included: there should be a more formal transfer of care so that it is clear to patients that their care is being returned to their PCP, some patients might not be comfortable returning to their PCP for follow-up, the availability of new treatments would necessitate a revisit to the oncologist, and PCPs need to be more aware of supportive services available to cancer patients.

Papagrigroriadis, S., & Koreli, A. (2001). The needs of general practitioners in the follow-up of patients with colorectal cancer. *European Journal of Surgical Oncology*, 27(6), 541-544.

The aim of this study was to investigate the views of general practitioners on follow-up of patients with colorectal cancer. A total of 164 out of 278 GPs responded to the survey for a response rate of 59%. 31% of GPs were already aware of the existence of community-based follow-up schemes, but 64% were not aware. Switching follow-up of CRC to the community was thought to be 'good' by 14%, 'interesting' by 36%, and 'wrong' by 8.9%. When this question was phrased as "the idea of following-up patients with CRC after the first post-operative year is..." 43% thought it was a natural part of the care GPs provide, and 39% said it is not really their job. When asked about their requirements in order to participate in follow-up, responses included: the provision of guidelines (76%), fast re-referral of their patients (72%), and additional resources (35%). Our results show that a substantial number of GPs would view favourably their participation in the follow-up of CRC provided that their requirements were satisfied.

Paradiso, A., Nitti, P., Frezza, P., & Scorpiglione, N. (1995). A survey in puglia: The attitudes and opinions of specialists, general physicians and patients on follow-up practice. *Annals of Oncology*, 6 Suppl 2, 53.

The present study is based on a survey of opinions and attitudes of specialists, general practitioners and patients directly involved in breast cancer follow-up. 86% of the various

specialists stated that they 'cooperated with other specialists' in the management of breast cancer follow-up. This data was confirmed by that reported in the general practitioner's questionnaire which stated that their 'patients were generally followed' by two or more specialists in 85% of cases. These multiple controls to which the majority of patients were subjected are perhaps responsible for the 'diagnostic tests reported to be performed repeatedly' as stated by 28% of patients and judged by the general practitioner as 'apparently without any reason' in 33% of cases. Specialists responded that in terms of their management role in follow-up, general physicians were either passive or completely absent in 38% of cases, which is in direct opposition to the 93% of general physicians who reported to prefer a more active role in the management of the follow-up of their patients. The limited role of the general physician at present seems to be essentially dependent on the fact that they usually do not receive any information on the goals and procedures of follow-up as dictated by the specialist (agreement by 78% of general practitioners). In summary, it appears that the potential availability of the general physician is related to the lack of confidence of the specialist to delegate routine aspects of follow-up procedures, at least regarding those general practitioners without previous preparation in this field. GPs suggestions to improve the global quality of follow-up included requesting a written document to be placed in the hands of the woman herself, thereby facilitating self-management, limiting coordination problems among specialists and resolving the flow of information from the specialist to the general physician regarding the goals and schedules of follow-up. On the contrary, specialists seem to prefer the production of guide-lines which would be potentially capable of improving assistance (agreement of 82% of responders), of reducing costs (agreement of 41% of responders) and of reflecting local realities (agreement of 71% of the responders).

Preston, C., Cheater, F., Baker, R., & Hearnshaw, H. (1999). Left in limbo: Patients' views on care across the primary/secondary interface. *Quality in Health Care*, 8(1), 16-21.

In this paper, we describe a study to identify and describe patients' views about their experiences of the healthcare system. It was the first phase of a project to develop a new instrument to measure patients' views across the interface. From lists of patients a smaller, random sample was selected which was then examined for purposeful sampling to recruit patients who might hold a range of views about their care. A sample of carers of relatives with chronic health conditions including respiratory disease, renal disease, and psychiatric conditions, unrelated to the patient participants, was also identified. Six focus groups involving 28 patients were held, and five patients and eight carers were interviewed in their own homes. Good patient/doctor relationships were associated with fewer barriers to referral. Patients were generally less confident about being referred, or receiving appropriate treatment, when they were unable to see their personal doctor or when the relationship with their GP was poor. When care was provided across different settings, communication and coordination were crucial. Lack of consistency across settings was a frequent source of problems, for example patients receiving conflicting information from their GP and the consultant. This could prevent patients making progress and could result in reduced confidence in care providers, increasing anxiety, and feelings of not being valued as individuals. Services which patients expected to be arranged were sometimes not provided or were delayed. Sometimes GPs were not informed of outcomes of their patients' treatment or care. Limbo was most often experienced as patients moved from one stage of care to another across interfaces or between professionals, or when awaiting the results of investigations or decisions about their management. At these times, they could experience feelings of discomfort and uncertainty which were exacerbated by lack of information or failures of continuity. Health professionals also need to recognise the interdependency of their roles within the health system as a whole if patients are to avoid the fragmented care that

frequently leads to limbo. The findings also suggest that services should be organised to avoid system failures that cause patients to feel in limbo.

Ristovski-Slijepcevic, S. (2008). *Environmental scan of cancer survivorship in Canada: Conceptualization, practice, and research*. Vancouver, BC: Canadian Partnership Against Cancer; BC Cancer Agency.

* In addition to the information included below, this article also provides a review of information on survivorship communication that is very similar to and drawn from other articles in this annotated bibliography.

A message was echoed by respondents that survivors need to be provided with a care plan. Respondents identified 3 key components for the plans: medical/clinical (e.g., surveillance for high-risk malignancies, screening, testing); psychosocial (e.g., education & employment issues, family issues & relationships); lifestyle (e.g., dietary & exercise practices, other self-management practices). Key priority steps identified for planning and implementing future cancer survivorship care were to: identify survivors' needs, particularly to identify those who are at risk and focus on populations that are marginalized and underserved; develop and implement appropriate model(s) for care, guidelines, and follow-up care plan(s); and increase collaboration between the health/cancer system and the community.

Shapiro, C., McCabe, M., Syrjala, K., Friedman, D., Jacobs, L., Ganz, P., et al. (2009). The LIVESTRONG survivorship center of excellence network. *Journal of Cancer Survivorship*, 3(1), 4-11.

The goals of the LIVESTRONG survivorship center of excellence network are to 1) increase the quality of life for individuals living with, through, and beyond cancer; 2) transform how survivors are treated and served; 3) contribute to the collective body of knowledge on survivorship; 4) increase the accessibility and quality of services for survivors and their seamless integration into primary cancer treatment; and 5) explore reimbursement issues and develop financial strategies to cover the cost of survivor care. An overriding goal of the Network is the development of best practices regarding survivorship care that can be disseminated beyond the confines of COE to the general community. There are three models for survivorship care being evaluated by the COE's. The first is the "consult" model where survivors are seen one time in a comprehensive visit either by a physician and/or a mid-level practitioner(s) with special expertise in survivorship care. The second model is an ongoing care model in which the care of the survivor is transferred to a physician and/or nurse practitioner with expertise in survivorship care at a predetermined time post-treatment. The third model integrates survivorship care into the continuum of cancer care provided by the primary oncology team. With this model of care, an end of treatment summary and survivorship care plan are developed at a survivorship visit after completion of treatment and then on a yearly basis by the nurse practitioner on the oncology team. The patient continues to be followed by the oncology team and is transitioned to primary care at some point when deemed appropriate. The Network is building the infrastructure to develop feasible interventions and explore the best models of survivorship care and uniquely positioned to identify the critical elements necessary for optimal survivorship follow-up care and to disseminate this information to the largest number of cancer professionals, survivors and their caregivers in diverse settings across the country.

Snyder, C., Earle, C., Herbert, R., Neville, B., Blackford, A., & Frick, K. (2008a). Preventive care for colorectal cancer survivors: A 5-year longitudinal study. *Journal of Clinical Oncology*, 26(7), 1073-1079.

This retrospective, longitudinal cohort study examined the patterns of physician visits and preventive care of colorectal cancer survivors each year for 5 years after the end of active treatment. For each year, we calculated the number of visits to different physician types and the percentage of survivors who received preventive care services. We used the Surveillance, Epidemiology, and End Results (SEER) Medicare database. A total of 1,541 survivors met the eligibility criteria. The mean number of PCP visits increased from 4.2 in year 1 to 4.7 in year 5. In contrast, the mean number of oncology specialist visits decreased from 1.3 in year 1 to 0.5 in year 5. Over time, there was a statistically significant decrease in shared care between PCPs and oncologists, and more focus on PCP care only. We found a statistically significant increase in visits to PCPs over time accompanied by a statistically significant decrease in visits to oncology specialists. Coinciding with the decrease in oncology specialist visits, there was a statistically significant decrease in the rates of mammography and cervical cancer screening (and an increase in influenza vaccination). After adjusting for a variety of factors, the physician mix remained important, with survivors who saw both a PCP and oncology specialist most likely to have influenza vaccination, mammography, and cervical cancer screening, and survivors who saw a PCP only most likely to have cholesterol screening and bone densitometry. As oncology specialists become less involved in survivors' care, the system may fail to identify the need to transfer responsibility for these preventive services to the PCP. Our results support the need for survivorship care plans, as recommended by the Institute of Medicine.

Snyder, C., Earle, C., Herbert, R., Neville, B., Blackford, A., & Frick, K. (2008b). Trends in follow-up and preventive care for colorectal cancer survivors. *Journal of General Internal Medicine*, 23(3), 254-259.

This study was undertaken to examine the physician types visited and preventive care received by colorectal cancer survivors during their first year after active treatment. This was a retrospective, cross-sectional study. The data for this study come from the SEER-Medicare database. A total of 20,068 survivors were included in this analysis. There was a statistically significant change over time in the mix of provider types seen by survivors. The odds of a survivor seeing both a PCP and oncology specialist increased over time with 31.6% of survivors diagnosed in 1997 seeing both and 36.4% of survivors diagnosed in 2001 seeing both. The odds of a survivor seeing neither a PCP nor oncology specialist decreased over time with 14.2% of survivors diagnosed in 1997 seeing neither and 11.2% of survivors diagnosed in 2001 seeing neither. Survivors who had visits to both a PCP and oncology specialist most frequently received each preventive care service, followed by survivors who saw a PCP only. The cause for the increase in visits is unclear, but as a result, in the more recently diagnosed cohorts, survivors are more likely to be followed-up by both a PCP and oncology specialist during the first year of survivorship, and fewer survivors are being followed-up by neither a PCP nor oncology specialist. However, the volume of care provided by PCPs is substantially larger and remains so across time. These results suggest that shared care for cancer survivors can promote quality. However, effective shared care requires appropriately delineating roles and responsibilities for PCPs and specialists and coordination among all providers.

Taplin, S., Clauser, S., Rodgers, A., Breslau, E., & Rayson, D. (2010). Interfaces across the cancer continuum offer opportunities to improve the process of care. *Journal of the National Cancer Institute Monographs*, 40, 104-110.

There is evidence that problems exist at the interfaces of cancer care, including between providers and patients, primary and subspecialty care providers, and their respective organizations. During the treatment through survivorship phase, some of the major problems identified have been related to patients being lost in the transition from oncology care back to primary care; a lack of definition of collaborative care; and a lack of definition and testing for characteristics of care plans. Suggestions for research needed therefore include: defining the necessary components of a care plan and testing them in practice; identifying patients' views of care plans; and identifying patient preferences for primary and oncology care provider involvement. The challenges at these interfaces, and their potential evaluation and solutions, could profoundly affect care delivery because they appear to have the following effects: role confusion; inadequate exchange of verbal or written information critical to completing the next step in care and/or the management of comorbid conditions; inappropriate or missed referrals; and inefficient diagnosis and treatment of the cancer. We suggest that efforts directed toward understanding how to objectively assess and measure care at the interfaces and subsequently resolve the ambiguities and inadequacies arising in the process of cancer care should be a high-priority research and programmatic agenda for many years to come. Several trials of care plans suggest the potential for improvement in the transition from treatment to survivorship. Some evidence among long-term survivors also indicates that clearly communicated guidelines for follow-up and survivorship care from specialists to primary care physicians results in similar cancer care and outcomes as that delivered by specialists.

Watson, E. K., Sugden, E. M., & Rose, P. W. (2010). Views of primary care physicians and oncologists on cancer follow-up initiatives in primary care: An online survey. *Journal of Cancer Survivorship*, 4, 159-166.

This study aimed to evaluate PCPs' views on the content and usefulness of the cancer care review. Its second aim was to explore the issues around the discharge of patients from secondary care follow-up and the generation of a cancer survivor care plan. These aims were addressed by undertaking an online survey of PCPs and oncologists. To supplement the survey, an audit of the current content of letters to the PCP at the time of completion of hospital follow-up was undertaken. Less than half of PCPs were satisfied with aspects of communication with secondary care including the content of inpatient (30%) and out patient discharge letters (28%), the ease of access to advice about a patient (32%) and the ease of getting patients seen between routine appointments (37%). Most oncologists followed guidelines to determine discharge from follow-up, but most of these used local (73%) rather than national (34%) guidelines. A number of factors affected the discharge decision, including the level of risk of recurrence (79%), patient choice (66%), length of time from diagnosis (65%), level of risk of side effects (58%), confidence in primary care (42%) and resources in secondary care (34%). Forty percent oncologists felt patients could be discharged sooner than was current practice and 73% felt there was scope for sharing follow-up care with primary care. There was broad agreement between oncologists and PCPs on what information was currently provided, but PCPs stated that in all areas the information was often inadequate and further felt there were several important areas of information that were not currently provided in the discharge summaries. Seventy-three percent oncologists felt a survivorship care plan would be useful, but less (58%) felt that it would be useful specifically for patients. Fifty-eight percent oncologists felt the PCP and patient should receive the same care plan. Only 40% thought a care plan would be easy to produce, and 53% stated barriers including time constraints (38%), need for a standardised format but the difficulty of doing this for different cancers (23%) and the reluctance of primary care to take responsibility for follow up (11%). The survey showed that currently the cancer care review was mostly undertaken by PCPs, with some nurse involvement. Half of the reviews were

being done opportunistically which implies the review was not the main focus of the consultation. The content of the review varied but was reported as usually including reviewing treatment, offering psychological and social support and discussing family and carer needs. Addressing the patient's agenda and patient choice of care were also important aspects.

Wattchow, D. A., Weller, D. P., Esterman, A., Pilotto, L. S., McGorm, K., Hammett, Z., et al. (2006). General practice vs surgical-based follow-up for patients with colon cancer: Randomised controlled trial. *The British Journal of Cancer*, 94(8), 1116.

In response to the identified lack of evidence examining setting of cancer follow-up, we report a randomised controlled trial comparing outcomes in GP-led and surgeon-led follow-up arms in patients treated for colorectal cancer. The objective of the study was to determine whether, among these patients, the setting of follow-up impacts on our primary outcomes: quality of life, psychological well-being and satisfaction with care. Also, recorded were the follow-up procedures undertaken in the two arms, and data on recurrences and death. The study was a multicentre, randomised controlled trial, which recruited patients from hospitals in Australia. Consenting patients were randomly allocated to either 'GP-led' or 'surgeon-led' follow-up using an Excel random number generator. The setting and environment of follow-up (primary vs secondary care) constituted our intervention. Follow-up guidance, based on current clinical practice and guidance was provided, and inserted into either the patient's GP or surgeon/hospital records. Nevertheless, in accordance with the study's pragmatic design, there was no compulsion for clinicians in either setting to adhere to the guidance. We found no significant differences between postsurgical colon cancer patients undergoing either GP-led or surgeon-led follow-up for our primary outcome measures of quality of life, depression and anxiety and patient satisfaction. There were insufficient numbers to demonstrate differences in number of recurrences and deaths, but the data do not suggest the emergence of any trend.

Wood, M., & McWilliam, C. (1996). Cancer in remission: Challenge in collaboration for family physicians and oncologists. *Canadian Family Physician*, 42, 899-910.

The purpose of our study was to explore oncologists' perspectives on the process of cancer patient follow up in the remission stage and to identify oncologists' own needs during this stage of the disease. The aim was to elaborate on oncologists' experiences and attitudes toward family doctors' involvement during remission and to generate ideas for establishing a more collaborative approach to cancer care. Interviews were conducted to elicit understanding of the oncologist participants' experience in their own words and framework.. A purposive sample of 10 oncologists was selected. Oncologists described four key roles they fill in managing cancer in remission: reassurance of remission, early detection of recurrence, monitoring toxicity of treatment, and gathering data for clinical trials. Despite an expressed desire to interact more with family physicians, oncologists' work environment was seen as obstructing both communication and collaboration. Global funding to the cancer centres of Ontario means oncologists, unlike most other specialists, have a salaried income, thus have little need to promote good relationships with a network of family physicians to facilitate fee-for-service referrals for consultation. Barriers described were either extrinsic to the cancer centre or an intrinsic part of the cancer centre's organization. Extrinsic barriers included: variability in FPS interest and commitment to ongoing cancer care and surveillance; difficulty becoming acquainted with the 300 or more family physicians in the immediate area; inadequate time, inability to contact family physicians, and unfamiliarity with each other; and seldom receiving information from family physicians about tests, hospital admissions, incidental illness, or surgery. Intrinsic barriers included: making little effort to include family physicians on the

management team; operating within the exclusive domain of the cancer centre, and using the primary care nurse as a key contact and resource to patients during treatment and follow up; time and work pressures; and fulfilling personal needs of seeing patients in remission. Proposed solutions included: identifying a core group of FPs to act as key resources; making an effort to communicate and collaborate; developing follow-up guidelines; offering informal seminars or discussion groups for FPs; maintaining a two-way flow of information; having a shared plan of follow-up care; and having an open house at the cancer centre.

Wood, M.L. (1993). Communication between cancer specialists and family doctors. *Canadian Family Physician*, 39, 49-57.

The objectives of the study were to elicit family physicians' perceptions of their role in the remission stage of cancer; to determine how well family physicians were able to fulfill these roles; to discover barriers to fulfilling these roles; and to find ways of increasing family physicians' satisfaction in this area of practice. Family physicians were recruited by telephone and participated in focus groups. Cancer care was described by many family physicians as a "team affair," but the role the family physician played on that team was not clearly perceived or understood. Very few wanted to take full responsibility for follow-up care. Most perceived a close working relationship with specialists as ideal, with room for flexibility in the amount of responsibility assumed by the family physician. Of more concern, they believed that their position was neither acknowledged nor respected by specialist physicians involved in cancer follow-up care. The greatest source of dissatisfaction for family physicians in the study was the failure on the part of cancer specialists to assign them a communication was identified as the key issue in failing to develop and define a place for family physicians. Both extrinsic and intrinsic barriers to communication were identified from the family physicians' experience in follow-up cancer care. These included: not being aware of the correct specialist to contact for information; follow-up care by several physicians resulting in poor continuity of care, conflicting information being given to patients, and a lack of trust between patient and specialist; preferring personal communication; delays in referrals to specialists and in reports and results of tests; lack of information about discharge and follow-up plans; inability to access information about guidelines for follow up in remission of each cancer site; intimidation by specialists and a lack of self-confidence and credibility in cancer care; fear of being blamed for mismanagement, missing a recurrence, or losing specialist support; and inadequate knowledge. An important barrier to the development of communication and change is the great variability in family physicians' and patients' needs and wishes in follow-up care. Establishing a contact person at the cancer centre, whether attending physician, nurse, or social worker, was described by many family physicians as the most essential step in improving communication with oncologists. Three important steps emerged from suggestions about how to overcome communication barriers and increase satisfaction in this area of care. The "communication gap" could be closed by developing a system that would enable family physicians to make personal contact with cancer specialists. The role of family physicians on the cancer care team could be defined through face-to-face dialogue between family physicians and cancer specialists. Family physicians could be involved in developing discharge plans and guidelines for follow up in each case.

Appendix B: Annotated Bibliography of Education References

BC Cancer Agency [website] (2010). *Family physician oncology network: Preceptor program*. Retrieved July 6, 2010, from: <http://www.bccancer.bc.ca/HPI/FPON/Precep/default.htm>

The Preceptor Program provides opportunity for physicians, particularly those from outside major urban centres, to strengthen their oncology skills and enhance cancer care in their communities. These physicians can then support all aspects of oncology care in their community. The BC Cancer Agency developed the Preceptor Program in 2004, with the support of the UBC's Department of Family Practice Enhanced Skills Program and with input from many family physicians. The program is offered in a flexible, modular format that can be taken in eight consecutive weeks or over a six-month period. The two-week introductory module is offered every February and September at the BC Cancer Agency in Vancouver focusing on medical and radiation oncology, surgery, cancer screening, oncological emergencies and diagnostic imaging. This first session also includes the opportunity to attend clinical rounds and tumour site conferences. The remaining modules can be completed at any of the Agency's five Cancer Centres. Participants are encouraged to tailor their learning specific to their community's needs. The Network is also collaborating with the provincial Guidelines and Protocols Advisory Committee, jointly sponsored by the Ministry of Health and the BC Medical Association, to develop practical, easy-to-follow cancer care guidelines for family physicians.

Cancer Care Ontario [website] (2009). *General practitioner in oncology self-directed learning program*. Retrieved July 6, 2010 from: <http://www.cancercare.on.ca/cms/one.aspx?pagelid=9359>

Cancer Care Ontario commissioned this self-directed learning manual for general practitioners in oncology to assist general/family medicine physicians who currently work or plan to work in an oncology setting. The program includes clinical scenarios, recommended reading lists, and resources available on-line to assist a general practitioner/family medicine physician in efficiently gaining knowledge to use in clinical practice. The manual is organized on a disease site-specific basis. This manual will be updated on an annual basis so that the resource materials contained within it continue to be relevant to the general practitioner seeking quality information resources on cancer care.

Cheung, W., Fishman, P., & Verma, S. (2009). Oncology education in Canadian undergraduate and postgraduate training programs. *Journal of Cancer Education*, 24, 284-290.

We conducted surveys to evaluate oncology education among undergraduate studies (UGS) in medicine, nursing, and pharmacy as well as post-graduate studies (PGR) in family medicine and internal medicine across Canada. The goals of the study were to help identify deficiencies in training programs and to provide an impetus for improvements where needed, to better equip the future to address growing cancer needs. Web-based, self-administered questionnaires were distributed via e-mail to 58 UGS in medicine, nursing, and pharmacy and 26 PGR in IM and FM across Canada in October 2006. A brief letter that outlined the goals of the questionnaire and details of the study was included with each e-mail invitation. A total of 52 surveys were completed and evaluable. The response rates were 58.6% (34/58) for UGS and 69.2% (18/26) for PGR. Few UGS and PGR (14.7% and 27.8%, respectively) devoted more than 1 week during their entire program towards cancer education. Cancer-related courses and rotations

constituted less than 10% of the curriculum in the majority of undergraduate and postgraduate programs. Formal oncology courses and mandatory oncology rotations were offered in only 38.2% of UGS and 22.2% of PGR, respectively. Although clinical electives in cancer and cancer-related subspecialties were largely available to trainees enrolled in programs such as medical schools and IM residencies, only a minority of trainees actually participated in these optional clinical activities. Nursing and pharmacy schools as well as FM residencies were less inclined to provide cancer-related electives as options to their students. The fact that cancer electives were available but few trainees participated in them also highlights the potential misconceptions held by trainees and the value of promoting oncology as a meaningful and rewarding field.

Elliott, T., Elliott, B., Regal, R., Renier, C., Crouse, B., Gangeness, D., et al. (2001). Lake superior rural cancer care project: Part II: Provider knowledge. *Cancer Practice*, 9(1), 37-46.

These investigators conducted a randomized, controlled trial to evaluate a multimodal educational, practice site, and systems-level intervention that was based on previously tested methods to improve the cancer management knowledge. Six communities were assigned to control conditions with observations collected throughout the study and six communities were assigned to experimental conditions with observations collected throughout the study. Over 4 years, all eligible cancer cases in the 18 communities were recruited into the study. The intervention included educational activities directed at physicians, nurses, and pharmacists practicing in rural communities that had been randomly assigned to the experimental condition. The eight components of the educational intervention included use of the following: 1) clinical opinion leaders; 2) annual mini-fellowships for the clinical opinion leaders; 3) bimonthly cancer conferences in each experimental community; 4) quarterly project newsletters; 5) a rapid-cycle quality improvement system based on feedback of practice data; 6) clinical practice guidelines (CPGs); 7) a telecommunication system linking experimental communities with the regional cancer center; and 8) annual rural advisory committee meetings held in each experimental community. Change in cancer knowledge was assessed using a mailed survey. Knowledge scores on discipline-specific, cancer-management tests for physicians, nurses, and pharmacists increased significantly from pre-test to post-test scores. Providers exposed to the educational intervention also outperformed the healthcare providers to both control groups at post-test. Neither the clinical opinion leader nor the outreach oncology consultations in the rural community had a measurable effect on knowledge (although outreach info is provided to patients rather than directly to providers).

Elliott, T., Elliott, B., Regal, R., Renier, C., Haller, I., Crouse, B., et al. (2002). Lake superior rural cancer care project: Part III: Provider practice. *Cancer Practice*, 10(2), 75-84.

In relation to the second objective of this randomized controlled trial, the intervention (described in Elliot et al., 2001 of this document) was effective in significantly improving only the following 5 of the 37 end points: medical-surgical score for non-small cell lung cancer patients; post-treatment surveillance score for breast cancer patients who were less than 55 years of age; and clinical trial participation for patients with colon, non-small cell lung, and rectal cancers. Although the nine hypotheses were not largely supported and most end points were not affected, many end points were measured at near or greater than 70% of optimal performance in the control and experimental groups. This finding suggested a better than expected performance by physicians in the region and limited the possibility of detecting an intervention effect. A more powerful intervention may be needed.

Grant, M., Economou, D., Ferrell, B., & Bhatia, S. (2007). Preparing professional staff to care for cancer survivors. *Journal of Cancer Survivorship*, 1(1), 98-106.

The purpose of this paper is to describe a course developed to respond to the need for increased education of health care professionals in cancer survivorship and provide the foundation for survivorship programs across the US. Several specific objectives are addressed in the training program including: (1) development of the cancer survivorship curriculum, (2) recruitment of health professional teams to attend an intensive cancer survivorship course, (3) identification of evaluation methods for the course, (4) description of support activities following the course and (5) description of participating institutions and their projected post course goals. Four annual three-day courses were planned between 2006–2009. The educational framework for designing the curriculum included three concepts: Cancer Survivor Quality of Life, Changing Practice via Performance Improvement, and Principles of Adult Education. The overall course objective was to describe the current status of adult cancer survivorship in the United States and to recognize the impact of cancer survivorship on quality of life. Eligibility requirements included a team of two professional members of an institution, with at least one member being a nurse, physician, or an administrator. For this survivorship course, several follow up approaches were implemented in order to keep participants engaged following the course and provide additional resources. The extensive syllabus provided to each participant included all course content, slides, bibliographies, resources, and faculty and participant addresses. Also a quarterly Newsletter was created that provided information on additional resources, other survivorship courses, and identified specific projects that course participants were implementing. Short term anecdotal evaluation of the program indicated that the majority of the participants viewed the training as meeting their goals and objectives. Participants' views of their institutions prior to attending the course revealed the need for improvement in survivorship care, as well as an increase in comfort of staff providing care for this population. In identifying anticipated barriers, a lack of knowledge about survivorship care was identified as the most common barrier, and points to the need for educational efforts at most of the institutions. Only 10% anticipated a lack of administrative support in carrying out goals following the course.

Karamouzis, M., Ifanti, A., Iconomou, G., Vagenakis, A., & Kalofonos, H. (2006). Medical students' views of undergraduate oncology education: A comparative study. *Education for Health*, 19(1), 61.

The aim of the present report was to investigate the views of undergraduate medical students at the University of Patras about the status of Oncology in the revised curriculum, six years after the first study was conducted at the same school, and to compare the findings with the prospect to assess the impact of the changes on the curriculum. The main changes in Oncology that occurred in the undergraduate medical curriculum as a result of the publication of the first report are the following: increase in the number of specialized oncology staff; increase in the instruction hours of compulsory clinical courses focusing on cancer-related issues; increase in the range of elective basic and clinical courses oriented towards more specialized cancer topics; increase in the elective medical rotations; distribution of a comprehensive book to the 4th year students compiled by the staff of the Division of Oncology. Based on the aforementioned changes in the syllabus of the medical school, we initiated a second-step investigation to evaluate the extent to which these changes had any impact on the status of oncology education and, consequently on students' attitudes. Two-hundred-and-ten medical students participated in the comparative study in 2002, with a response rate of 94% (198/210). It was found that in 2002, 113 out of 198 (57%) students considered the quality of education satisfactory, whereas in 1996 only 53 out of 147 (36.1%) students expressed the same opinion. In both cases a

remarkable low percentage answered that the quality of education was high (3.3% in 1996 versus 5.5% in 2002). The more favourable responses of the 2002 group could be mainly attributed to the enhanced presence of specialists and the increased tutorial and practical approach to cancer research. The total amount of instruction hours dedicated to oncology-related topics and the time of clinical practice with cancer patients are still considered limited. In the comments section, the majority of students put emphasis on the development of pre-clinical experience in managing cancer patients and their families and creating better awareness of the psychosocial aspects, ethical issues, and behavioral prejudices during patient care. It appears excessive emphasis is put on clinical topics, whereas the importance of interpersonal skills and cancer prevention receives rather little attention. However, there is a significant increase in the number of students who support the idea of being taught Oncology as a separate subject in the curriculum and not merely as a part of other subjects.

Lengerich, E. J., Kluhsman, B. C., Bencivenga, M., Allen, R., Miele, M. B., & Farace, E. (2007). Development of community plans to enhance survivorship from colorectal cancer: Community-based participatory research in rural communities. *Journal of Cancer Survivorship*, 1, 205-211.

The goal of the current study was to develop and test a participatory method by which cancer organizations in rural areas could address community-based barriers to CRC survivorship. The training began with a day-long workshop which included instruction by physicians, social workers, and researchers on CRC diagnosis and care followed by team selection of strategies for conducting their community needs assessment and completing a CP. The teams then completed the assessment and CP during the 5 months after the first workshop. At a second workshop, representatives of each team presented their draft CP, to which experts in cancer survivorship and community-based research offered feedback. Thirty-two persons attended the initial workshop, with 100% completing both the pre-training and the immediate post-training assessments. Increases in correct responses between the pre-training assessment and the immediate post-training assessment were statistically significant for community-based public health, sponsorship of the National Plan, and CRC survivorship and treatment. At the second training, 16 of the initial 32 participants (50.0%) attended and completed the evaluation. Increases in correct responses between the pre-training assessment and the long-term assessment was statistically significant for knowledge of PRECEDE-PROCEED as a community health planning model and that memory loss is not a necessary part of CRC survivorship. Based upon the perceived barriers and assets, teams developed a CP to enhance CRC survivorship. All teams included efforts to increase access to and knowledge of community resources. Most teams included efforts to enhance treatment-related care (92.9%), psychosocial care (85.7%), and primary health care (71.4%). Approximately one-half of coalitions and hospitals included efforts to enhance transportation services (50.0%), CRC screening (50.0%), and financial assistance and health insurance (42.9%). area of community-based public health, sponsorship of the National Plan, and CRC survivorship and treatment. These data suggest that this study helped increase the linkage of local survivorship initiatives in rural areas to national efforts in cancer survivorship.

Lenzi, R., Baile, W., Berek, J., Back, A., Buckman, R., Cohen, L., et al. (2005). Design, conduct and evaluation of a communication course for oncology fellows. *Journal of Cancer Education*, 20(3), 143-149.

We describe the design and evaluation of a workshop for oncology fellows that combined lectures, interviews with simulated patients, role playing and exercises encouraging reflection

and introspection. An enhanced autonomy model was used which focuses on a balanced relationship in which both the patient's values and perspectives and the physician's points of view are discussed; and choices regarding patient care are made by reaching a common ground. A total of 3 exercises were conducted to promote active listening, awareness of emotional reactions to patients and reflection on loss and grieving. Fellows completed questionnaires prior, immediately after and 6 weeks after the workshop. The study shows that increased self-efficacy and knowledge of specific communication strategies could be achieved through a residential workshop integrating formal teaching with simulated patient interviews and role playing. A change in attitudes toward communication was suggested by the qualitative analysis of the fellows' comments and by the expressed intent of 65% of the fellows to become involved in teaching communication. An important change related to the fellows' addressing of patients' emotional reactions occurred involving the ability to reflect on their own reaction to patients' emotions and the ability to respond with an empathic statement rather than offering a practical "remedy". Because of logistical constraints, no information could be collected regarding effects on the fellows' actual behavior during real-life encounters with patients. Immediately after the workshop, the fellows reported that they were significantly more likely to engage in 9 of the 15 breaking-bad-news tasks; 6 weeks after the workshop, learners reported that they were significantly more likely to implement 3 of the 15 tasks. Because the knowledge of communication skills and self-efficacy remained significantly higher after the course than before the course, it is possible that the fellows implemented new communication skills cautiously and gradually.

Sisler, J., & McCormack-Speak, P. (2009). Bridging the gap between primary care and the cancer system: The UPCON network of CancerCare manitoba. *Canadian Family Physician*, 55(3), 273-278.

The uniting Primary Care and Oncology (UPCON) Network is a program of CancerCare Manitoba (CCMB), designed to enhance partnerships between FPs and the cancer system. The program resources include an academic FP (as the medical leader), a full-time manager, and an administrative assistant. Lead FPs were the primary focus of the program and were paid honoraria for participation in orientation events, 8 hours of cancer clinic exposure, periodic meetings, and monthly small group education sessions about cancer and access to the cancer care system. Lead FPs were equipped to act as informal resources about cancer care questions that arose in practice. The UPCON clinic physicians and support staff were offered training in the use of the comprehensive cancer electronic medical record (EMR) used throughout Manitoba and were granted "read-only" access to the records of all clinic patients. Telephone surveys were conducted with FPs of the UPCON Network to assess the effects of the program. 6996 agreed that UPCON was effective in improving the working relationship with CCMB; 56% of non-lead FPs viewed the presence of UPCON lead physicians in their clinics as useful; and 61% of non-lead FPs had sought advice from their lead FPs in the past year, most often regarding the name of a CCMB contact, making referrals to the agency, cancer treatment or follow-up care, or symptom management. Twenty small group education sessions of 3 hours each were held for UPCON lead FPs. Evaluations were very positive, with mean ratings of 4.7 out of 5 for clarity, relevance, and quality of discussion at the sessions. Most cancer patients who had been referred to new FPs through UPCON (7696 to 89%) expressed satisfaction with coordination of care, with the strongest drivers of satisfaction with FP care identified as receiving consistent information from the FP and the cancer clinic and FP awareness of tests and treatments done at CCMB.

Tattersall, M., Langlands, A., Smith, W., & Irwig, L. (1993). Undergraduate education about cancer. A survey of clinical oncologists and clinicians responsible for cancer teaching in Australian medical schools. *European Journal of Cancer*, 29A(11), 1639-42.

This study surveyed Australian oncologists and teachers (and previously students) in the undergraduate cancer curriculum at all Australian Medical schools. Views were sought about the type and duration of teaching desirable in undergraduate cancer education of medical students. The questionnaire measured knowledge, perception of skills, exposure to teaching, and rating of instruction in oncology. A total of 179 oncologists were sent the survey instrument resulting in an overall response rate of 70%. Although teachers identified cancer screening and prevention as important in undergrad training, deficiencies in student knowledge may indicate differences in opinion about what is correct. Some results indicate a lack of familiarity with epidemiological data even by specialists treating the actual disease on a regular basis. Results also highlight the need for teachers to agree on definitions of treatment goals, worthwhile outcomes, and the conceptions underlying treatment utility.

Uijtdehaage, S., Hauer, K., Stuber, M., Go, V., Rajagopalan, S., & Wilkerson, L. (2009). Preparedness for caring of cancer survivors: A multi-institutional study of medical students and oncology fellows. *Journal of Cancer Education*, 24(1), 28-32.

Three institutions are collaborating on a Cancer as a Chronic Disease curriculum spanning the first 3 years of medical school. A growing set of new teaching “products” are being developed and implemented by the 3 schools and all are available online. This study was conducted as a needs assessment prior to the implementation of the new curriculum. We surveyed early 4th-year medical students who had not experienced the Cancer as Chronic Disease curriculum in 2005. Senior medical students in 3 institutions demonstrated limited knowledge about cancer as a chronic disease. On average, students answered about half of the questions correctly, whereas oncology fellows performed only slightly better. An average negative score indicated that students may have misconceptions, and not just lack of knowledge, about the consequences of cancer treatment on growth, osteoporosis, learning, sexual function, and fertility. Students were exposed to cancer survivors frequently in medical school (with the exception of childhood cancer survivors). Nonetheless, about half of the students never received direct instruction or practiced critical components of survivorship care and, perhaps consequently, reported low confidence in all cancer survivorship-related patient care activities such as giving bad news, tailoring pain medication, and working with a specialty team. Since this survey, the 3 participating institutions have been implementing a comprehensive survivorship curriculum using the survey instrument to monitor its effect. Evidence was recently presented that the new curriculum improved knowledge and self-rated competency. We also found that oncology fellows showed a surprising lack of knowledge in this domain. Improvement of both undergraduate and postgraduate training in survivorship care is urgently warranted. Additional efforts are needed to ensure that knowledge and experience gained during undergraduate training transfer into subsequent phases of the educational continuum.

Uijtdehaage, S., Hauer, K., Stuber, M., Rajagopalan, S., Go, V., & Wilkerson, L. (2009). A framework for developing, implementing, and evaluating a cancer survivorship curriculum for medical students. *Journal of General Internal Medicine*, 24(Suppl 2), 491-494.

In this paper we describe a framework for the development, implementation, evaluation, and dissemination of a curriculum that is portable to other educational settings and is designed to provide medical students with a foundation of knowledge, attitudes, and skills related to cancer

survivorship. During the last 5 years 3 schools have collaboratively developed a 4-year, integrated curriculum in cancer survivorship. Development of this curriculum occurred in several phases: (1) identification of curriculum objectives; (2) development of educational interventions and integration into the existing curriculum; (3) evaluation and dissemination. The curriculum focused on common cancers with increasing survival rates: breast, colorectal, prostate, and gynecological cancers along with childhood cancers such as leukemia. Students evaluated the usefulness of each curricular module and provided suggestions for improvement. In addition, we used a cohort study with a historical control group to assess the effect of the curriculum on students' knowledge of and experience with cancer survivorship. Educational outcomes gradually improved as the cancer survivorship modules were introduced into the curriculum. Compared to the historical controls, the intervention groups at UCLA and CDU improved their scores on average by about 43%. Students at UCSF, where fewer modules were implemented, did not demonstrate such a knowledge gain. Students at all institutions, however, reported to be more comfortable in several care activities, including working in a specialty team and identifying patients with high cancer recurrence risks. Students also reported having encountered more cancer survivors compared to the control group. We also created a dedicated website where many of the materials can be downloaded or requested free of charge. Our evaluation strategy lacked objective evaluation of students' skills either by patients or trained observers. Thus, the effect of our curriculum on actual survivorship care (beyond knowledge, attitudes, and experience) was not determined.

Appendix C: Key Informant Interview Guide

“What Is”		
Category	Communication	Education
Current status	1. In a few sentences, please describe the current status of communication practices and processes between oncology and primary care providers when medical responsibility for follow-up care is transitioning or complete?	1. In a few sentences, please describe the current status of formal and continuing education activities and programs designed to support primary care providers in the provision of high quality survivorship care to cancer patients?
Gaps	2. Where are the greatest gaps or needs related to communication practices/processes in cancer follow-up?	2. Where are the greatest gaps or needs related to education activities/programs in survivorship care?
“What Ought to Be”		
Category	Communication	Education
Envisioned status	3. How would communication practices/processes look or operate if an optimal model of care existed between primary health care and the cancer care system?	3. How would education activities/programs look or operate if an optimal model of care existed between primary health care and the cancer care system?
Best Practices	4. Can you provide any specific examples of current or planned communication practices/processes that are “exemplar” or considered to be “best practice” in cancer follow-up today?	4. Can you provide any specific examples of current or planned education activities/programs that are “exemplar” or considered to be “best practice” in survivorship care today?
Influencing factors	5. What factors or conditions encourage or facilitate reaching the optimal vision/model with respect to communication practices/processes between oncology and primary care providers?	5. What factors or conditions encourage or facilitate reaching the optimal vision/model with respect to education activities/programs in survivorship care?
	6. What factors or conditions challenge reaching the optimal vision/model with respect to communication practices/processes between oncology and primary care providers?	6. What factors or conditions challenge reaching the optimal vision/model with respect to education activities/programs in survivorship care?

“How Do We Get There”		
Category	Communication	Education
Addressing needs	7. What types of strategies (activities, methods, tools or processes) should be pursued or developed to improve communication between oncology and primary care providers when medical responsibility for follow-up care is transitioning or complete?	7. What types of strategies (activities, methods, tools or processes) should be pursued or developed to enhance education aimed at supporting primary care providers in providing high quality survivorship care?
Resource requirements	8. What kinds of resources - human, material, financial - need to be in place to optimize communication practices/procedures in follow-up care?	8. What kinds of resources - human, material, financial - need to be in place to optimize education activities/programs in survivorship care?
Partners and roles	9. Who are the key stakeholders or partners that need to be involved in efforts to improve communication practices/processes in cancer follow-up?	9. Who are the key stakeholders or partners that need to be involved in efforts to improve formal and continuing education activities/programs in survivorship care?
	10. What should their role(s) be?	10. What should their role(s) be?
“How Will It Be Better”		
Category	Communication	Education
Value	11. What are the anticipated impacts or outcomes of implementing improved communication practices between oncology and primary care providers in cancer follow-up?	11. What are the anticipated impacts or outcomes of implementing education activities/programs aimed at supporting primary care providers in survivorship care?
Closing		
Category	Communication	Education
Final thoughts	12. Do you have any final thoughts or comments that you would like to share related to the topics discussed here?	12. Do you have any final thoughts or comments that you would like to share related to the topics discussed here?

Appendix D: Listing of Internet Sites Searched

Canadian Cancer Agencies

BC Cancer Agency	www.bccancer.bc.ca
Alberta Health Services	www.albertahealthservices.com
Saskatchewan Cancer Agency	www.saskcancer.ca
Cancer Care Manitoba	www.cancercare.mb.ca
Cancer Care Ontario	www.cancercare.on.ca
Quebec Health and Social Services	www.mssss.gouv.qc.ca
New Brunswick Cancer Network	www.gnb.ca/0051/cancer
Cancer Care Nova Scotia	www.cancercare.ns.ca
PEI Cancer Treatment Centre	www.cancercentre.pe.ca
Easter Health (Newfoundland and Labrador)	www.easternhealth.ca

Canadian and Provincial Cancer Societies, Foundations and Networks

Canadian Cancer Society	www.cancer.ca
BC & Yukon Cancer Society	www.cancer.ca/British%20ColumbiaYukon
Alberta Cancer Society	www.cancer.ca/Alberta-NWT
Manitoba Cancer Society	http://www.cancer.ca/manitoba.aspx?sc_lang=en
Saskatchewan Cancer Society	http://www.cancer.ca/Saskatchewan.aspx?sc_lang=en
Ontario Cancer Society	http://www.cancer.ca/Ontario.aspx?sc_lang=en
Quebec Cancer Society	http://www.cancer.ca/Quebec.aspx?sc_lang=en
Nova Scotia Cancer Society	http://www.cancer.ca/Nova%20Scotia.aspx?sc_lang=en
New Brunswick Cancer Society	http://www.cancer.ca/New%20Brunswick.aspx?sc_lang=en
Nfld & Labrador Cancer Society	http://www.cancer.ca/Newfoundland-Labrador/
PEI Cancer Society	http://www.cancer.ca/Prince%20Edward%20Island.aspx?sc_lang=en
Nunavut Cancer Society	http://www.cancer.ca/Nunavut.aspx?sc_lang=en
BC Cancer Foundation	http://www.bccancerfoundation.com/cms/page1138.cfm
Alberta Cancer Foundation	http://albertacancer.ca/Page.aspx?pid=653
Quebec Breast Cancer Foundation	http://www.rubanrose.org/en
The Newfoundland Cancer Treatment and Research Foundation	http://www.easternhealth.ca
Breast Cancer Society of Canada	http://bcsc.ca/
Canadian Breast Cancer Network	http://www.cbcn.ca/
Canadian Breast Cancer Initiative	http://www.phac-aspc.gc.ca/ccdpc-cpcmc/bc-cds/projects/
First Nations Breast Cancer Society	http://www.fnbreastcancer.bc.ca/frames.htm
Alberta Innovates Health Solutions	http://www.albertainnovates.ca/health/introduction
Canadian Partnership Against Cancer	http://www.partnershipagainstcancer.ca/index.html
Ontario Institute for Cancer Research	http://www.oicr.on.ca/
Terry Fox Foundation	http://www.terryfox.org/

Provincial Medical Association

British Columbia Medical Association	www.bcma.org
Alberta Medical Association	www.albertadoctors.org
Saskatchewan Medical Association	www.sma.sk.ca
Doctors Manitoba	www.docsmb.org
Ontario Medical Association	www.oma.org
Quebec Medical Association	www.amq.ca
New Brunswick Medical Society	www.nbms.nb.ca
Doctors Nova Scotia	http://www.doctorsns.com/

Medical Society of Prince Edward Island	http://www.mspei.org/
Newfoundland and Labrador Medical Association	www.nlma.nl.ca
Northwest Territories Medical Association	http://www.nwtma.ca
Yukon Medical Association	www.yukondoctors.ca

National Medical Related Organizations

Canadian Medical Association	http://www.cma.ca/index.php/ci_id/19812/la_id/1.htm
College of Family Physicians of Canada	http://www.cfpc.ca/English/cfpc/home/default.asp?s=1
Royal College of Physicians and Surgeons of Canada	http://rcpsc.medical.org/

University Medical Programs

The Association of Faculties of Medicine of Canada (AFMC)	http://www.afmc.ca/faculties-e.php
Memorial University of Newfoundland	http://www.med.mun.ca/medicine/home.aspx
Dalhousie University	http://www.medicine.dal.ca/
Université Laval	http://www.fmed.ulaval.ca/site_fac/
Université de Sherbrooke	http://www.usherbrooke.ca/medecine/
Université de Montréal	http://www.med.umontreal.ca/
McGill University	http://www.mcgill.ca/medicine/
University of Ottawa	http://www.intermed.med.uottawa.ca/
Queen's University	http://meds.queensu.ca/
University of Toronto	http://www.facmed.utoronto.ca/site4.aspx
McMaster University	http://fhs.mcmaster.ca/main/medschool.html
University of Western Ontario	http://www.med.uwo.ca/
Northern Ontario School of Medicine	http://www.nosm.ca/
University of Manitoba	http://www.umanitoba.ca/faculties/medicine/
University of Saskatchewan	http://www.medicine.usask.ca/
University of Alberta	http://www.med.ualberta.ca/Home/index.cfm
University of Calgary	http://medicine.ucalgary.ca/
University of British Columbia	http://www.med.ubc.ca/home.htm