# THE FAMILY NURSE PRACTITIONER ROLE TO INCORPORATE LONG-TERM FOLLOW-UP GUIDELINES FOR ADULT CHILDHOOD CANCER SURVIVORS INTO PRACTICE

by

## Suzanne Liu

BSc, The University of British Columbia, 2004 BScN, British Columbia Institute of Technology, 2008

# PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING: FAMILY NURSE PRACTITIONER

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### Abstract

The purpose of this project was to answer the question: how can nurse practitioners best incorporate the Children's Oncology Group guidelines into long-term follow-up care for adults who are childhood cancer survivors in a primary care practice? A comprehensive review of the literature was conducted to help answer the research question. The findings of this review demonstrated that adherence to and awareness of the Children's Oncology Group guidelines by primary providers was low, and that a multi-component approach would be the most effective to improve incorporation of the Children's Oncology Group guidelines into clinical practice. The research also showed that a multi-disciplinary, consultant led or shared model of care would be most successful with respect to the long-term follow-up of Childhood Cancer Survivors. Patient, provider and system related barriers to the use of the Children's Oncology Group guidelines were examined and discussed. The project concluded with specific recommendations for nurse practitioners to apply to their practice to improve the long-term follow-up for childhood cancer survivors.

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#### Introduction

A diagnosis of cancer in a child can be devastating for both the patient and the family. Cancer not only puts the child's life in jeopardy, but it is also associated with intense treatments and potentially life changing side effects. Some of these side effects are acute, such as hair loss, while others may not develop until the child reaches adulthood. Because of both short and long-term side effects, once a child has been diagnosed with cancer, their diagnosis and the treatment they have received has the potential to impact all of their future health care decisions. This highlights the importance of ensuring coordinated care and appropriate follow-up for this specialized population.

Medical advancements in cancer treatment have resulted in an overall five-year survivorship rate of 80% for pediatric malignancies (Edgar, Borthwick, Duffin, Marciniak-Stepak, & Wallace, 2012; Scottish Intercollegiate Guidelines Network [SIGN], 2013). Seventy five percent of children diagnosed with cancer now live for at least 10 years after diagnosis (Bhatia & Meadows, 2006). These current outcomes are a substantial improvement when compared with the 1960s, when only 25% of children survived more than five years after receiving a diagnosis of cancer (Edgar et al., 2012).

Due to these improved outcomes, there has been an increase in the number of adults who are childhood cancer survivors (CCS) (Edgar et al., 2012; Suh et al., 2014). These patients comprise a specialized population for whom additional screening and surveillance by their health care provider is recommended, and this screening is dependent upon their individual cancer histories (Children's Oncology Group [COG], 2013; Edgar et al., 2012; Suh et al., 2014). The additional screening that is recommended is essential to facilitate early detection of the potential long-term sequelae of cancer treatment, for which CCS are at increased risk (COG, 2013; Friedman, Fryer & Levitt, 2006; Suh et al., 2013).

Despite the existence of evidence-based guidelines released by the COG, many adults who have survived pediatric cancer do not receive the recommended screening (Essig, Skinner, von der Weid, Kuehni, & Michel, 2012; Suh et al., 2014). Attendance of this patient population in long-term follow-up (LTFU) remains low as does the familiarity of primary care providers (PCPs) with the COG guidelines themselves (COG, 2013; Nathan et al., 2013; Oeffinger et al., 2009; SIGN, 2013; Suh et al., 2014). Because CCS are a group at high risk for susceptibility to many different side effects of their cancer treatments, nurse practitioners (NPs) and other providers caring for this population must devise a way to coordinate the recommended screening practices into their care.

Given the focus of this paper is family nurse practitioner practice, when using the term NP, it is with the intent that other PCPs may also be appropriate providers in a similar context of primary care. The COG (2013) does identify NPs as appropriate providers for directing the LTFU care of CCS. When using the term PCP, it is to allude to studies that included PCPs as a group of participants, which sometimes included NPs. However there is no literature that pertains solely to the care delivered to CCS by NPs. Therefore, in this paper when discussing data from studies pertaining to PCPs, it is with the understanding that NPs are also considered primary care providers (CRNBC, 2013b).

The complexity involved in combining the individual pediatric diagnoses of CCS with the types of treatment received in order to devise a plan for surveillance could be overwhelming to any NP who has not specialized in oncology. The COG sought to reduce that complexity and was the first organization in North America to release comprehensive guidelines that outlined the necessary screening for CCS (Edgar et al., 2012). These recommendations are both evidence-based, as well as updated every five years (COG, 2013; Edgar et al., 2012). These guidelines represent a valid tool that NPs may use in the clinical setting to facilitate the formation of a surveillance plan for CCS.

In Canada, PCPs are the professionals who provide most of the care to CCS once their pediatric oncology treatments have been completed (Granek et al., 2012). These practitioners are also best suited to assess patients who are CCS once they have become adults and have transitioned into non-specialized health care, which can also be understood as a transition back to primary care (Blaauwbroek, Tuinier, Jong, Kamps, & Postma, 2008; Singer et al., 2013). Childhood cancer survivors often present with a range of needs and complex health issues that require a variety of approaches for which pediatric oncologists may be too specialized (Blaauwbroek et al., 2008), thus a primary care setting is more suitable.

In the context of primary care, NPs are able to develop a long-term relationship with CCS, as they provide ongoing care in a familiar setting for any health concerns, and where CCS can eliminate the stigma of being a cancer patient (Blaauwbroek et al., 2008; Casillas et al., 2010). Since it will be PCPs who address the various health issues of these patients, it is appropriate that they also continue to monitor them and order the appropriate screening in follow-up to their cancer diagnosis and treatment (Singer et al., 2013). Sufficient knowledge on the part of PCPs regarding the recommended COG guidelines is therefore crucial in order to offer evidence-based surveillance practices to any of their patients who are CCS (Suh et al., 2013).

It was during my practice as a registered nurse that I became interested in the LTFU for CCS. I have worked in pediatric oncology for six years, and have cared for hundreds of children who have been treated for cancer. There is so much support, care and follow-up that is expertly coordinated through our pediatric oncology team, that it stimulated my thinking in regards to what happened to these patients once their treatments have been completed. I also wondered what it would be like for these patients to enter the primary care setting with a complex history at such a young age. I questioned how the long-term effects of their chemotherapy and radiation would impact their future care and how and with whom the responsibility of their future care should reside. All of these questions generated the impetus to begin exploring the literature upon which this project has been based.

In January 2015, funding was approved for a new plan that suggests stratifying CCS into one of four different tiers of care which is dependent on both the expertise of the provider and the risk and/or existing side effects experienced by the CCS (BC Cancer Agency, n.d.). Since NPs fit into both tier one (primary care, 25 or more low risk patients per year and low risk recall) and possibly tier two (primary care with specialized knowledge, 35 or more new moderate risk patients per year and moderate risk recall) of this provincial program, it is important that they are familiar with the COG guidelines, as these contain the recommendations for this patient population (BC Cancer Agency, n.d.). Although CCS in BC will now be organized into these various tiers, there are many patients living in rural areas that will fit into tier one or tier two, and therefore an examination of the literature to determine which model of care is most appropriate is still warranted. Additionally, although this program will benefit both patients and providers, gaps related to knowledge and use of

the guidelines still exist in primary care and these must be addressed (Nathan et al., 2013; Suh et al., 2014).

The purpose of this paper is to conduct a literature review by exploring and analyzing the question: How can NPs best incorporate the COG guidelines into LTFU care for adults who are CCS in a primary care practice? Considerations and implications for the lack of follow-up and surveillance for CCS will also be explored.

To introduce the paper, background information about the significance of LTFU for CCS will be discussed, as will various barriers that exist regarding LTFU for CCS. The existing gaps in current knowledge pertaining to my question will be addressed. This will be followed by a discussion in Chapter 3 of the methods used for the integrative literature search, including a table summarizing the search process. Next, the search findings will be outlined and synthesized in Chapter 4, followed by a discussion of their significance in Chapter 5. Recommendations that target the reduction or elimination of potential barriers to using the COG guidelines in the clinical setting will be offered in Chapter 6. These recommendations include strategies that NPs can employ to increase the use of screening practices in their clinical setting. Finally, concluding statements that summarize the research findings will be made.

#### Background

CCS comprise a small proportion of the clientele cared for by PCPs, yet each year this number increases by three percent (BC Cancer Agency, 2014). In 2014 there were approximately 3,400 survivors in British Columbia (BC), and as more of these patients are surviving, they become at risk for future complications potentially involving almost every organ as a direct result of the intensive cancer treatments they received as children (Casillas et al., 2010). If providers are not aware of the recommended screening that can identify these complications, the health of CCS will be at risk, resulting in increased morbidity for this patient population.

The first section of this Chapter describes the various treatments for childhood cancers in order to provide a basis for understanding the way in which these treatments can have late effects with the potential to affect several body systems. Late effects can be defined as "any physical, psychological, or social consequence of the disease or treatment that can appear months or even years after treatment" (Bradwell, 2009, p. 21).

# History of Childhood Cancer Survivors and Establishment of Guidelines

In 1948, Sidney Farber was the first to suggest a treatment regime for childhood cancer (Shad, 2015). Since then, long-term survival has been increasing, with the most rapid improvements first noted in the 1970s with the discovery that multiple chemotherapy agents used in combination produced greater success than treatment with a single chemotherapy drug (Dixon-Woods et al., 2005; Meadows, 2001). After the discovery of multi-agent therapy, the number of survivors increased gradually and exponentially up to the 75-80% of children that now survive 5 years or more after being treated for cancer (Bhatia & Meadows, 2006). By the mid-1970s, concern over the late effects of these treatments began to arise, and individual institutions started to conduct research to specifically study these late effects (Meadows, 2001). Shortly afterwards, it was noted that more subjects were necessary to confirm the connection between late effects and cancer treatments and a consortium comprised of several institutions was formed, which included many of the members of the future COG (Meadows, 2001). In 2003, the COG (2013) released their initial version of LTFU guidelines for CCS. Based on the literature search conducted for this project, the COG guidelines that were released in 2003 represent the first published guidelines for this patient population, as no other similar documents were retrieved with an earlier publishing date.

## **Treatments of Childhood Cancers**

There are a variety of different treatments employed in pediatric cancers; some of them may be used either alone or in combination with other treatments depending on the type of malignancy (COG, n.d.). Treatment in BC's pediatric cancer centre, the BC Children's Hospital, utilizes protocols outlined by the COG (BC Children's Hospital, 2013). Surgery is a common therapy that can be used to either treat or diagnose certain cancers (COG, n.d.). In some cases the treatment will include only surgery, while in others, radiation may be used first to shrink the tumour so it can then be surgically removed (COG, n.d.).

Chemotherapy is another form of therapy used in the treatment of childhood cancers (COG, n.d.). This involves the administration of drugs either intravenously, subcutaneously, intrathecally, intraperitoneally, intracavitarily, intramuscularly or orally to treat pediatric malignancies (COG, n.d.). As opposed to surgery or radiation which target cancer cells in one area, chemotherapy works through the entire body to eliminate and prevent the growth of new cancer cells (COG, n.d.; Dixon-Woods, Young, & Heney, 2005). There are many

different chemotherapy medicines that are used in combination to target different phases in cancer cell reproduction (COG, n.d.). Extensive research has formed the basis of the recommendations regarding the combination of chemotherapy drugs that is most effective in treating certain diagnoses, and these treatment plans are known as protocols (COG, n.d.). Chemotherapy is given in cycles, the intensity and length of which is determined by the diagnosis, and each cycle is followed by a period of recovery (COG, n.d.).

Radiation therapy involves the use of high energy radiation to eliminate cancer cells (COG, n.d.; Dixon-Woods et al., 2005). The most common type used is termed external beam radiation, where the radiation is specifically targeted to a particular part of the body (COG, n.d.). Before this therapy is administered, measurements are made to ensure adequate placement and dosage of the radiation beams (COG, n.d.). Whether a child receives radiation or not is a complex decision based on each child's diagnosis, and whether a particular cancer is treatable by radiation therapy is determined by a radiation oncologists in consultation with the multi-disciplinary team (COG, n.d.).

If a child's cancer is resistant to chemotherapy or if the prognosis is poor, a stem cell transplant is another treatment that can be considered (COG, n.d.). This treatment allows for extremely high levels of chemotherapy, termed myeloablative, because it eradicates the child's bone marrow (COG, n.d.). A stem cell transplant is then infused intravenously after this chemotherapy to restore the patient's bone marrow so they may have a functioning immune system after completion of the cancer treatment (COG, n.d.). The stem cells are collected from a donor either peripherally, or from the donor's bone marrow, and this is termed an allogeneic transplant (COG, n.d.). If the child's cancer diagnosis does not involve the bone marrow, the patient's own stem cells may be collected and then re-infused to restore

their bone marrow and this type of transplant is known as an autologous transplant (COG, n.d.).

## Late Effects of Cancer and its Treatment

Receiving a diagnosis of cancer as a child and subsequently undergoing treatment can leave that child at risk for developing side effects later in life. McClellan et al. (2013) sent surveys to 710 survivors found in the tumour registries (databases containing detailed information about cancer patients and their treatments) from two hospitals in the United States and found that the intensity (type, duration and/or dosage) of treatment had a positive correlation with the number of late effects. Similarly, Eiser et al. (2006) surveyed 198 survivors and stratified them according to three levels: level one patients had undergone surgery alone or low risk chemotherapy, level two patients had been treated with chemotherapy and low dose cranial irradiation, and level three patients had received radiation therapy (except low dose cranial irradiation) and/or megatherapy such as high dose chemotherapy and/or bone marrow transplant (BMT). These findings indicated that level three patients reported more late effects than level two patients, and therefore these results also demonstrated a positive correlation between treatment intensity and late effects (Eiser et al., 2006).

The incidence of late effects in cancer survivors is greatly increased compared to the incidence of the same conditions in the general population. Oeffinger et al. (2006) received questionnaires from 14,372 cancer survivors and compared these to questionnaires received from 3,846 siblings of the survivors. Survivors were almost three times more likely to experience ovarian failure, more than ten times more likely to have congestive heart failure, they were about fifty times at greater risk of having a major joint replaced, and they were

seven times more likely to experience a second neoplasm (Oeffinger et al., 2006). Again, these results illustrate the ways in which the effects of chemotherapy, radiation and a diagnosis of cancer can continue to impact a patient's quality of life long after the treatment itself has concluded. Evidence-based screening practices and effective care provision by PCPs are essential for early detection and treatment of such late effects (Haddy, Mosher, & Reaman, 2009).

# **COG Guidelines**

The COG guidelines consist of risk-based recommended screening practices for CCS that are correlated with an individual's exposure to cancer treatments (COG, 2013). They are based both on research evidence and on a consensus of surveillance practices determined by expert experience (COG, 2013). The document also emphasizes that in no way are the recommendations intended to replace or override any findings that are identified by a PCP during the history and physical (H&P) assessment of a survivor (COG, 2013). Therefore, the guidelines released by the COG are meant to be used in conjunction with the assessment of CCS by PCPs. Specifically, 51% of the recommendations are derived from the H&P exam alone, 20% consist of the H&P in addition to a diagnostic study (for example bloodwork or imaging), 26% are comprised of recurrent laboratory or other diagnostic testing performed at appropriate intervals, and 3% of the surveillance guidelines recommend no screening (COG, 2013). BC Children's Hospital is a member of the COG, and although it does not provide LTFU to survivors, their treatments are based on COG protocols (BC Children's Hospital, 2013).

Goals of the COG guidelines. The COG identifies four separate goals related to their recommendations. First, the CCS follow-up guidelines are designed to encourage healthy

lifestyles for CCS through a process of health promotion (COG, 2013). This goal is mirrored in one of the competencies described for NPs in BC, which emphasizes health promotion when caring for patients (College of Registered Nurses of British Columbia [CRNBC], 2013a). The second goal of the COG suggests that PCPs should utilize the guidelines to provide ongoing monitoring of the health of CCS (COG, 2013a). Again, this forms part of the competencies of NPs as delineated by the CRNBC (2013a), and the COG emphasizes the importance of such monitoring in the context of a history of pediatric malignancy.

The next objective of the COG recommendations is to facilitate the early detection of any late effects that a survivor may experience. Similar to the first two goals, the NP competencies of health assessment and diagnosis, and health promotion and prevention of illness and injury are in accordance with this third intention of the COG guidelines (CRNBC, 2013a). Finally, with their suggested screening practices, the COG (2013) hopes to assist PCPs to implement early interventions for identified late effects. This final goal is also congruent with the fourth NP competency regarding health promotion and prevention of illness and injury (CRNBC, 2013a).

Intended users of the guidelines. The COG asserts that their guidelines are intended for use as follow-up for the care of CCS with the exception of follow-up of the survivor's primary disease (COG, 2013). Practitioners deemed appropriate by the COG to conduct follow-up screening of CCS are Physicians, NPs and Physician Assistants (COG, 2013). The CRNBC (2013b) delineates those assessments and diagnostic testing procedures that are within the scope of practice for NPs in BC, and the majority of the assessments, lab testing and imaging listed in the COG guidelines (2013) are clearly within this scope. Magnetic Resonance Imaging (MRI) is a diagnostic procedure that is not within current NP scope (CRNBC, 2013b). This type of imaging is recommended for patients who are experiencing neurological late effects from either chemotherapy, radiation or BMT (COG, 2013). Breast MRI is recommended as an adjunct to mammography for women who have received chest radiation as childhood cancer treatment (COG, 2013). Considering the aforementioned circumstances, a NP caring for a patient requiring these tests will need to consult with a specialist to order this screening procedure, as it is not within the scope of other PCPs, such as family physicians, either (CRNBC, 2013b). All of the other screening recommended by the COG (2013) is within the scope of practice for a NP in BC (CRNBC, 2013b).

**Creation of the guidelines.** The evidence upon which the COG guidelines were based drew upon the past 20 years of medical literature, which was compiled by the COG by performing a complete search using the *Medline* database (COG, 2013). References were also retrieved from bibliographies of selected articles to broaden the search, and some of these included articles that were published more than 20 years prior to the search (COG, 2013). The process for the selection of these older articles is not described in the COG document. A seven member task force appointed by the COG reviewed the research, and based on this research and a previous guideline written by the National Comprehensive Cancer Network, a draft practice guideline was developed for LTFU for CCS in 2002 (COG, 2013). The draft was then subjected to review by experts in various fields such as nursing, oncology, behavioural science and patient advocacy, and the draft was subsequently modified based upon their recommendations (COG, 2013). The second version of the guidelines was then reviewed by 62 multi-disciplinary experts, followed by a final review and scoring of the evidence by this panel of experts (COG, 2013). The initial version of the guidelines was released in March 2003 to COG members for final review and then it was released to the public in September, 2003 (COG, 2013). The scoring system employed by the COG is described below; there is no mention of any evaluation such as the Appraisal of Guidelines for Research and Evaluation instrument (AGREE tool, commonly used to evaluate guidelines) that was used to assess the guidelines (AGREE, 2015; COG, 2013).

**Guideline grading.** Each recommendation by the COG regarding LTFU of CCS is graded according to the level of supporting evidence available at the time. The grading criteria in the COG guidelines represent varying levels of consensus by an expert panel on the strength of support found in the literature for each particular screening recommendation (COG, 2013). High level evidence is defined as category 1; it consists of supporting literature that includes either high quality case control or cohort studies (COG, 2013). Categories 2A and 2B comprise evidence from case reports, case series, non-analytic studies and clinical experience (COG, 2013). Any recommendation that involves a significant discrepancy in opinions (classified as category 3) would either be deleted or revised by the panel of experts so that the lowest level of evidence represented in the actual COG guidelines would be category 2B (COG, 2013). Such disagreements typically involve suggested screening recommendations; however, the COG (2013) did not explain specifically what these encompassed.

#### Barriers to Use of the Guidelines.

The COG (2013) identifies the length of its document as being one potential barrier to its use in the clinical setting. Taking into account that most NPs have only a very small portion of their patients who are CCS, it would be very time consuming for them to be required to review a 200 page document in order to determine the proper screening and testing to recommend (COG, 2013; The Foundation for Medical Practice Education, 2014). As one potential solution, the COG has developed an internet tool entitled "Passport for Care" (PFC) to help determine the necessary surveillance practices for CCS (COG, 2013). However, this web resource is only available free of charge to those institutions that are already COG members, and most of these current member organizations are located in the United States only (Poplack et al., 2014). Additionally, in order to utilize the PFC, a patient summary is required, which is not completed much of the time by the patient's pediatric oncologist (Nathan et al., 2013; Poplack et al., 2014).

Another barrier that may affect the uptake of the COG guidelines concerns the costeffectiveness of their recommendations. Upon review of the literature, it is evident that there is insufficient data that specifically evaluates the cost-effectiveness of the recommended COG screening practices (Wong et al., 2014). One study that did evaluate the costeffectiveness of the COG recommendation regarding echocardiography found that a decrease in the recommended screening frequency resulted in a decrease in cost without a corresponding decrease in health benefits (Wong et al., 2014). However, this result represents only one single study evaluating one specific screening practice and many more studies are needed to determine whether or not the COG recommendations are actually costeffective. The lack of certainty concerning the cost-effectiveness of the COG recommendations may be another reason for the reluctance of providers to use the guidelines (Wong et al., 2014).

#### **COG and SIGN Guidelines**

In addition to the COG guidelines, the SIGN guidelines (2013) used in the United Kingdom are also well known and established recommendations for patients with a history of a pediatric malignancy (Skinner & Oeffinger, 2013). The following section compares and contrasts these two guidelines.

Similarities. There are several similarities between the two documents. The target population for each of these guidelines is the same: Survivors of childhood cancer (COG, 2013; SIGN, 2013). This is an important similarity as it identifies that the recommended surveillance practices are to be directed to a specific subset of patients. Collectively, the guidelines published by the COG and the SIGN represent some of the few published clinical guidelines directing the care of CCS (COG, 2013; SIGN, 2013). They both provide evidence-based and expert-recommended surveillance practices for CCS, which have great potential for use in a wide variety of healthcare facilities (COG, 2013; SIGN, 2013).

Differences. There are also several differences that arise when comparing the COG and the SIGN guidelines. The COG guidelines (2013) are used internationally and are recommended to all of North America, while the SIGN guidelines, in contrast, are national in nature since they are employed solely in the United Kingdom (SIGN, 2013). The SIGN guidelines were developed after the COG recommendations were released in order to offer guidelines that were specific for use in the United Kingdom (SIGN, 2013). While the COG does not specify an applicable age range for its target population, it does state that CCS should be at least two years post treatment before the guidelines are applied to their situation. In contrast, the SIGN found that the literature defines CCS as being anywhere from less than 15 to less than 24 years of age at diagnosis, and as being two to five years post diagnosis (SIGN, 2013). Therefore, this is the definition they adopted (SIGN, 2013).

The literature search procedure utilized in the development of each of the guidelines also differed between the COG and the SIGN. The literature search and method of review employed in the creation of the COG guidelines have been previously described in this paper. In contrast to the COG literature search, the SIGN searched the literature in five databases as well as performing an Internet search (SIGN, 2013). Once the guidelines were completed, they were reviewed several times by expert independent reviewers in an attempt to minimize bias (SIGN, 2013). Although the COG, as of 2013, had reviewed relevant studies over the preceding 20 years, the SIGN utilized research findings only from the preceding nine years, potentially limiting applicable research data.

Some of the recommendations provided in the COG guidelines were not present in the SIGN guidelines. For example, the SIGN failed to provide recommendations for renal and liver function as well as hearing and vision testing (Skinner & Oeffinger, 2013). It is unclear whether the SIGN had determined that the evidence was not strong enough to justify recommendations pertaining to liver function, vision and hearing. The SIGN (2013) does identify a need for more research on the effects of cancer treatments in children on renal outcomes, so that may be one potential reason for the exclusion of recommendations regarding this body system. Within the COG guidelines, screening for cataracts, renal and liver function contains level one evidence, which is the strongest evidence cited within these guidelines (COG, 2013). This last fact indicates that the screening practices suggested by the COG are more comprehensive in comparison to the SIGN guidelines. There are also differences in the amount of detail provided by the COG compared to the SIGN for the same recommendations (Landier et al., 2006). For example, regarding cardiac screening, the SIGN recommends that high risk patients who have received cumulative anthracycline doses greater than 250mg/m<sup>2</sup> and/or any radiation to the chest should receive echocardiograms every 2-3 years (SIGN, 2013). For patients at low risk, or those who have received less than 250mg/m<sup>2</sup> of anthracycline, the frequency of echocardiograms may be reduced to every five years (SIGN, 2013). In contrast, the COG bases the frequency of echocardiograms not only on the dosage of anthracycline and whether or not the survivor received chest radiation, but also on the age of the patient at initial cancer diagnosis (COG, 2013).

In addition to recommendations regarding echocardiograms, the SIGN (2013) suggests that providers counsel patients regarding a healthy lifestyle such as decreasing smoking and increasing exercise and healthy eating. In contrast, the counselling recommendations by the COG are much more detailed. The COG guidelines describes the types of exercise, such as aerobic exercise, that are appropriate for CCS with cardiac effects, as well as indicating that certain high intensity activities such as wrestling and heavy weight lifting should be avoided indefinitely (COG, 2013). The increased detail and specificity contained within the COG guidelines would provide NPs with much more guidance when they are developing their LTFU plan for CCS and providing advice and education to patients.

**Future guidelines.** A need to create worldwide standards for the LTFU of CCS was acknowledged by the Childhood Cancer Guideline Harmonizing Group (which includes representatives from both the COG and the SIGN) in 2010 (Skinner & Oeffinger, 2013). There have been efforts put forward to devise such new guidelines, and include the collaboration of the COG, SIGN, PanCareSurFup from Europe and several other groups from Europe, Japan, Australia, New Zealand and North America (Skinner & Oeffinger, 2013). The hope is to develop consistent standards for global application, and by coordinating with experts across the world, LTFU care for CCS can then be optimized (Skinner & Oeffinger, 2013). This initiative is still a work in progress and the creation of these global guidelines is still in the development stages (Skinner & Oeffinger, 2013). The only guidelines currently offered by the Childhood Cancer Guidelines Harmonizing Group at this time pertain to breast cancer and cardiomyopathy (International Guideline Harmonizing Group, 2015).

# **Evaluation of the SIGN and COG Guidelines**

Using the AGREE tool, I evaluated both the SIGN and the COG guidelines for LTFU of CCS. The AGREE tool is an instrument that "evaluates the process of practice guideline development and the quality of reporting" (AGREE, 2015). The COG guidelines scored 100% in the editorial independence, clarity and presentation and scope and purpose domains (The Agree Collaboration, 2001). They scored 89% in applicability, 81% in rigour of development and 92% in stakeholder involvement (The Agree Collaboration, 2001). In contrast, the SIGN (2013) guidelines scored 78% on scope and purpose, 67% on stakeholder involvement, 81% on rigour of development, 67% on clarity and presentation, 63% on applicability, and 50% on the editorial independence domains (The Agree Collaboration, 2001). The full AGREE evaluations for these guidelines are found in Appendix I and II.

**Recommendations.** Given the above comparison, my suggestion based on the analysis of these two widely used screening guidelines would be to utilize the COG guidelines in the surveillance of CCS. Until the development of global standardized guidelines, the COG guidelines are currently the most regularly updated and detailed

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guidelines, and therefore these are the ones that should be used by NPs when identifying the appropriate screening for CCS. Additionally, the COG guidelines are particularly appropriate for clinical use because they are updated every five years and can be easily accessed by NPs online (Singer et al., 2013). Patients can also access the guidelines; however, it is recommended that they do so with their NP as the guidelines are targeted to NPs (as well as to other primary providers) and may be too complex for the patients to interpret independently (COG, 2013). Finally, using the AGREE tool to assess both guidelines demonstrated that the COG (2013) guidelines scored higher in four out of five domains when compare to the SIGN (2013) guidelines. This is another indication that the COG (2013) guidelines are the ones that should be used by NPs in the clinical setting.

### How to Use the Guidelines

Before using the guidelines, the NP must obtain some detailed information from his or her patient. This information is most often found on the patient's treatment summary, which includes the cancer history of the patient and the treatment received (COG, 2013; Nathan et al., 2013; Singer et al., 2013). These documents provide the date of cancer diagnosis, the patient's date of birth and sex, names of all chemotherapy medications received, their doses and routes of administration, all fields of radiation and doses, whether the patient underwent a BMT (since this particular treatment comes with specific risks such as graft versus host disease and osteonecrosis), and the names of all relevant surgical procedures (COG, 2013). Once this information has been obtained from the patient's treatment summary sheet, their previous records, or from the patient him/herself, the guidelines can be utilized to direct their care (COG, 2013). The guidelines are not intended to be used until at least two years following the completion of cancer treatment, since before that time the patient will still be receiving follow-up care from their pediatric oncologist (COG, 2013; Landier et al., 2004). The criterion for LTFU for CCS in all clinics in Canada is that the survivor is two years post treatment (Ped-Onc Resource Center, 2015).

# The Importance of Screening Survivors of Childhood Cancers

The Canadian Cancer Society, the American Society of Clinical Oncology and the National Cancer Institute all stress the importance of regular follow-up care for CCS (American Society of Clinical Oncology [ASCO], 2013; Canadian Cancer Society, 2015; National Cancer Institute [NCI], 2015). The NCI emphasizes the importance of regular follow-up and screening for this population in order to decrease early mortality and to ensure the early recognition and management of late effects. Similarly, both the Canadian Cancer Society and ASCO identify early detection of secondary malignancies as well as screening and surveillance of late effects as important reasons for continued follow-up in this specialized population. All three of these groups indicate that each patient should be stratified into a risk group according to their cancer histories, and that the frequency of screening should be based on the risk category to which they belong (ASCO, 2013; Canadian Cancer Society, 2015; NCI, 2015). Primary care providers are directed to the COG guidelines to determine their patient's risk category and the associated recommended screening practices (ASCO, 2013; Canadian Cancer Society, 2015; NCI, 2015).

Historically, there is low attendance of CCS in follow-up care and clinics (Blaauwbroek et al., 2008). Unfortunately, most adults in BC who are CCS are not followed by PCPs who are familiar with their health risks (MacDonald, Fryer, McBride, Rogers, & Pritchard, 2010). Additionally, although there is one small survivorship clinic in Vancouver, it is under-funded and has limited resources (K. Goddard, personal communication, August 18, 2015). Therefore, the follow-up strategies for these patients is especially salient in this province.

#### **Guideline Implementation**

Implementing evidence-based guidelines into practice is not simple and it has historically been a very slow process (Morris & Clarkson, 2009; Damschroder et al., 2009). Evidence and up to date information that has been incorporated into practice guidelines does not guarantee adherence by practitioners, and in fact, there tends to be much resistance in the medical field to practice changes, despite evidence-based recommendations (Morris & Clarkson, 2009; Damschroder et al., 2009). That is, even the existence of the highest quality evidence supporting a practice will not translate directly into its uptake into practice.

# The Principles of Implementation Science

The study of how best to implement study findings into practice is known as implementation science (Damschroder et al., 2009), and incorporating the principles of this discipline will facilitate the use of the COG guidelines by NPs in the clinical setting. Implementation science comprises a specific approach whereby major barriers to implementing interventions are addressed and by testing new methods to identify, understand and overcome these barriers (Sturke et al., 2014).

The Promoting Action on Research Implementation of Health Services (PARIHS) framework is a widely accepted concept in the field of implementation science, and it emphasizes three key concepts: evidence, context and facilitation (Stetler, Damschroder, Helfrich, & Hagedorn, 2011). Research, clinical experience, patient experience and evaluation of the local context all comprise the evidence component of implementation science (Rycroft-Malone et al., 2004; Stetler et al., 2011). The context component includes the receptive context (physical, social, cultural, structural, system and professional networks), culture, leadership and evaluation (Rycroft-Malone et al., 2004; Stetler et al., 2011). Finally, the concept of facilitation involves the implementer's individual role and skill, as well as specific strategies and maintenance for implementation of the intervention (Rycroft-Malone et al., 2004; Stetler et al., 2011). These principles will be evident in the strategies suggested in the Recommendations Chapter. Articles that can potentially address the application of the principles of implementation science to the COG guidelines will be discussed in the Findings and Discussion Chapters.

# Patient, Provider, and System Related Barriers

Patient related barriers. One significant barrier to LTFU of CCS is in regards to where follow-up care should be provided. Maeda, Horibe, Kato, Kojima, and Tsurusawa (2010) found that most survivors would prefer to have their follow-up care at the same facility in which they were treated for their malignancy. Often, these are pediatric centres so it may not possible or appropriate for the same healthcare team to coordinate the LTFU care of CCS once such a patient has become an adult (Blaauwbroek et al., 2008; Maeda et al., 2010; Michel et al., 2009). The reason postulated for the desire of CCS to be treated at the same centre as they were for their primary disease is the close set of relationships that tend to build between pediatric cancer patients and their health care team during a traumatic time for the patient (Maeda et al., 2010).

When seeking care for their follow-up treatment, it is natural that many CCS would prefer to be seen by the team of professionals who has cared for them in the past and whom they trust (Maeda et al., 2010). However, continued evaluation in a pediatric centre may not promote normal psychological development, as these patients are no longer children (Maeda et al., 2010; Michel et al., 2009). Additionally, there is only one pediatric care centre for cancer patients in BC, and many patients do not reside in close proximity to where they received treatment for their primary disease (BC Children's Hospital, 2013). An alternative follow-up care model should therefore be considered and these will be discussed further in the next section.

A second reason for the inadequate access of LTFU care by CCS may be related to the emotional trauma incurred during the time of their initial diagnosis and treatment (Aslett et al., 2007; Casillas et al., 2010; Parkes, Jenkinson, Griffiths, Kinch, & Mann, 2008). Not wanting to relive these painful memories, CCS may avoid follow-up care so they are not reminded of this difficult time in their lives (Casillas et al., 2010; Parkes et al., 2008). These patients often want to simply move on with their lives and past the stigma of being labelled as a cancer patient (Aslett et al., 2007; Blaauwbroek et al., 2008; Parkes et al., 2008). This is an important factor to consider when considering LTFU for CCS as the desire to move beyond their diagnosis has the potential to affect both the setting and the provider that would be most appropriate for LTFU care. Follow-up care by a NP may be a viable solution to transition CCS back into primary care, and this will be further explored in the Discussion and Recommendations Chapters.

A final reason patients who have survived childhood cancer may not access LTFU may be because they are unaware of the importance of doing so (Aslett et al., 2007; Blaauwbroek et al., 2008; Nathan et al., 2013). Up to 70% of CCS receive little to no information regarding the late effects of their malignancy and treatments and that lifetime screening may be necessary (Blaauwbroek et al., 2008). Many studies reporting the view of CCS show a concurrent lack of, and a desire for education about the late effects associated with having a history of a pediatric malignancy (Edgar et al., 2012; Essig et al., 2012; McClellan et al., 2013; Suh et al., 2014). Singer et al. (2013) acknowledge that if CCS are not aware of the importance of lifetime surveillance, then it should not be surprising if there is low attendance for LTFU initiatives. Therefore, lack of knowledge and the importance of the consistency of LTFU for CCS are integral to the successful implementation of the COG guidelines into clinical practice.

**Provider related barriers.** Similar to a lack of knowledge on the part of the patient, PCPs have also been found to have inadequate knowledge to provide the recommended screening for CCS (Nathan et al., 2013; Singer et al., 2013; Suh et al., 2014). Less than 10% of surveyed North American PCPs reported to Nathan et al. (2013) that they were very familiar with the recommendations put forward by the COG. Suh et al. (2014) and Nathan et al. (2013) also found that the North American physicians they surveyed were not familiar with the recommendations of the COG. Research shows that patients desire providers who are familiar with their disease and their treatment and who can recommend evidence-based screening practices that have been tailored to their situation (Singer et al., 2013). Although not all of these research results specifically assess the knowledge of NPs, previous data describing the lack of adequate LTFU care for CCS across North America allows the extrapolation regarding a lack of familiarity with the COG guidelines to these providers, as they share a similar scope of practice with physicians when caring for CCS.

Most CCS who do seek care attend follow-up in a primary care setting rather than a specialized LTFU clinic (Casillas et al., 2010). As previously mentioned, BC offers limited follow-up in LTFU clinics, therefore follow-up in primary care would be a viable option (K. Goddard, personal communication, August 18, 2015). Studies have shown that primary care

clinics do not care for large numbers of CCS and it may not be feasible for the providers within these clinics to care for such specialized patients (Friedman et al., 2006; The Foundation for Medical Practice Education, 2014). Therefore, at the provider level, there are two main factors that affect the ability to create a detailed plan for CCS: a lack of knowledge and a lack of experience with patients who are CCS. It is these two deficiencies that affect the implementation of the COG guidelines into practice at the level of the NP.

System related barriers. In addition to patient and provider barriers, system barriers also contribute to inadequate follow-up of CCS (Aslett et al., 2007). Difficulty in retrieving previous medical records and a lack of coordination between providers are pervasive issues that are representative of these types of challenges (Aslett et al., 2007; Singer et al., 2013). If a PCP is unable to obtain accurate records of the survivor's original diagnosis and treatment, it can be very difficult to create an appropriate screening schedule (COG, 2013).

When providing LTFU care for CCS patients, the funding model can also have a serious impact on patient care. This is especially salient when organizing the complex screening and survivorship plans that are essential to ongoing follow-up of CCS. A survivorship plan is a document that describes the recommended screening procedures and their suggested frequency based on the individual patient's cancer and treatment history (Singer et al., 2013). In a fee-for-service practice for example, where the emphasis is on the number of patients seen (Newcomer, Gould, Page, Donelan, & Perkins, 2014), these specialized patients might not receive the detailed assessments and recommendations that are necessary for optimal care. At the system level, it is a lack of coordinated care and having an appropriate funding model conducive to the time-consuming nature of caring for CCS that affect the implementation of the COG guidelines into clinical practice (Frayne, 2012).

## **Models of LTFU Care**

Many different models for the follow-up care of CCS have been suggested, one of these being survivorship clinics focusing specifically on the needs of this particular patient population (Friedman et al., 2006). In this model, care is directed by an oncologist and coordinated by a NP (Friedman et al., 2006). The structure of such follow-up centres provides a multi-disciplinary environment in which providers collaborate with each other and offer well-rounded and comprehensive care for CCS (Friedman et al., 2006). Another model of care that has been suggested is the establishment of transitional care centres for CCS (Aslett et al., 2007; Bhatia & Meadows, 2006). Similar to survivorship clinics, these facilities consist of the same or many of the same care givers who treated the patient for their original malignancy; however, they do not receive care there for life (Bhatia & Meadows, 2006). Transitional care centres are specialized facilities that help ease the process for CCS in moving on from their pediatric oncology team to a primary care setting (Aslett et al., 2007).

Adult oncologist-directed follow-up care is another suggestion made by Bhatia and Meadows (2006) for providing appropriate surveillance of CCS. In this model, an adult oncologist coordinates ongoing monitoring and screening for CCS (Bhatia & Meadows, 2006). Follow-up care directed solely by a PCP is another strategy for providing LTFU for CCS (Singer et al., 2013). In this model, the PCP does not have contact with any specialists and instead provides all LTFU for CCS independently (Singer et al., 2013). Finally, a shared care model consists of collaboration between a survivor's pediatric oncologist and their PCP (Blaauwbroek et al., 2008; Nathan et al., 2013). The care is mainly provided by the PCP; however, the survivor's pediatric oncologist would provide guidance as needed. These models of care will be addressed in greater detail in the Discussion Chapter. Long-term follow-up of CCS patients is crucial to the ongoing care of this patient population and the COG guidelines would be a useful tool for NPs to utilize in primary care when caring for these patients. Despite this, there are many barriers at various levels of patient care as described above that prevent optimal care for CCS in practice. Targeting these barriers as well as establishing a feasible model of care is necessary for providing optimal care for CCS in primary practice. By addressing barriers to the incorporation of the COG guidelines into NP clinical practice, and within the context of a feasible care model, the principles of implementation science can improve the LTFU care of CCS in primary care. Specific strategies for NPs that have the potential to improve care for CCS will be described in detail in the Discussion and Recommendations Chapters.

The following Chapter will describe the literature search process that was employed to answer the question: how can NPs best incorporate the COG guidelines into LTFU care for adults who are CCS? The purpose of the literature search was to identify solutions targeting the barriers outlined above in this section utilizing the principles of implementation science. The information retrieved was then synthesized and analyzed and is presented in the Findings and Discussion Chapters.

#### Methods

The search strategy employed when conducting a literature search for an integrative review paper can greatly impact the number and quality of articles that are retrieved. It is therefore integral to conduct focused and thorough searches so that the most relevant articles will be included (Dicenso, Guyatt, & Ciliska, 2005). Varying the keywords and including Boolean phrasing such as "and" and "or" can have a positive impact when exploring the research on a particular topic (Dicenso et al., 2005). Search terms used for this literature review were: "follow up", "long term follow up", "primary care", "models of care", "childhood cancer survivors", and "pediatric cancer survivors." The inclusion criteria that I applied to my search consisted of the following:

:articles that reference the COG guidelines when providing LTFU;

:seminal articles (those first to present an idea); and

articles that explored and/or compared models of care involved in LTFU.

:articles that focused on pediatric care;

:articles written in a language other than English; and

:those that studied a specific side effect of cancer or its treatment.

Studies that were greater than ten years old were also excluded (Grove, Burns, & Gray, 2013) to ensure that the research reflected the most recent cancer treatments and their corresponding late effects. Additionally, the COG guidelines were first released in 2003, therefore research evaluating their recommendations and how to apply them to practice would not have existed prior to 2004 (COG, 2013). A second literature search was conducted to identify implementation science articles in order to address ways in which NPs can best incorporate the COG guidelines into their care. Since there is no available data specifically

related to NPs and the COG guidelines, more general search terms were employed. Search terms that were used were comprised of: "guideline implementation" and "primary care." The inclusion criterion for this search was:

articles that focused on the implementation of guidelines in general in primary care. Exclusion criteria consisted of:

:articles written in a language other than English; and

articles that focused on guideline implementation in acute care rather than primary care.

For this second search, articles were not limited to 10 years, as research regarding the general implementation of guidelines is not dependent on the advancements of treatments. The following section describes the process that I used when searching the databases.

The search was initiated by first exploring the *Cochrane* reviews since they contain studies that have been reviewed and selected based on their high quality and strength (Dicenso et al., 2005). The keywords "childhood cancer survivors" AND "primary care" were used, resulting in 44 articles. Nine of the articles retrieved were eliminated as they studied smoking cessation, and another five because they focused on exercise interventions. Five were excluded because they investigated the coping skills of parents or siblings of children experiencing cancer instead of focusing on the assessment and surveillance of adults who have survived a pediatric malignancy. This resulted in a total of 25 research articles.

A second search was conducted through the *Cochrane* library, this time using the search terms "pediatric cancer survivors" and eight articles were retrieved, two being eliminated because they focused on smoking cessation. Another article was excluded because it examined post-traumatic stress syndrome (PTSD) in mothers of children who had been

diagnosed with cancer. The remaining five articles were saved to a search folder. A third search was conducted using the terms "long term follow up" AND "childhood cancer survivors" which resulted in eight articles. One concerned interventions relating to adolescents and was eliminated, and another three were excluded because they focused on acute cardiotoxicity, and nutritional and nephrotoxicity interventions. Two were also eliminated because they were published before 2004, and two were saved. Finally, the keywords "follow up" AND "childhood cancer survivors" were searched. This resulted in 22 articles; one was eliminated because it concerned emotional coping strategies, and seven because they studied smoking cessation. Another article was eliminated because it concerned fertility treatments, and another five because they focused on pediatric care. One article was excluded because it concerned nutritional interventions, and one because it investigated exercise strategies. Six articles were saved, resulting in a total of 38 relevant articles found using the *Cochrane* database that focused on CCS care.

The *Cochrane* library was also utilized in my second search. The keywords "guideline implementation" AND "primary care" were used and this resulted in 47 articles. Thirteen studies were eliminated as they addressed specific treatment outcomes instead of guidelines, and three more were excluded since they concerned strategy implementation in emergency care. A further three studies were eliminated as they focused on pediatric care settings, and two articles were excluded as they evaluated imaging practices. The remaining 26 articles were saved.

Medline was the second database searched to retrieve articles on the research question. This database was chosen because of the large number of journals included within it (Dicenso et al., 2005). The keywords "pediatric cancer survivors" were used, and the search resulted in 144 articles. This search was narrowed and was then combined with AND "primary health care or primary care nursing or physician primary care or continuity of patient care." This resulted in nine studies. One of the studies was eliminated because it was published in 2003 and the remaining eight studies were saved.

The next search was also conducted through the *Medline* database. This time, the search phrase "childhood cancer survivors" was entered and this resulted in 141 studies. To further refine the search, the first search was combined with AND "primary health care or primary care nursing or physician primary care or continuity of patient care". This search yielded 11 articles, one of which was eliminated since it focused on smoking. A further four studies were eliminated because they were more than ten years old and the focus was to be on recent research regarding the primary care of these patients. One final result was excluded because it studied the care of pediatric cancer patients. Therefore, this second search resulted in five articles which were added to the eight previously saved in the *Medline* folder.

The final search within the *Medline* database was initiated by searching "long term follow up" AND "childhood cancer survivors." This search yielded 10 results and the articles were further narrowed to only include those published in 2004 or later. Nine articles were found; one focused on salivary gland tumours and was eliminated, and another was directed to care of pediatric patients and therefore it was also excluded. The remaining seven articles were saved. *Medline* was then searched using the keywords "follow up" AND "childhood cancer survivors," and the results were limited to articles published in 2004 or later. There were 15 results and two were eliminated because they concerned the treatment of genitourinary cancers, and another was excluded because it focused on pediatric care. Another discussed thyroid cancer therapies and so it was excluded, and finally one was excluded because it concerned patients with diabetes. The remaining 10 articles were relevant and saved. The total number of studies found in the *Medline* database concerning CCS care was 30 articles.

*Medline* was then used to search for research pertaining to guideline implementation. The search terms "guideline implementation" AND "primary care" were utilized, and this returned 108 articles. Limits were then set to only include human studies and research pertaining to adults and to exclude articles written in a language other than English. Once these limitations were applied, 49 studies were found. Fourteen of the articles retrieved were not included as they examined specific screening practices (none related to CCS or cancer) or a particular treatment. Three articles were eliminated as the context was acute care, and two more were excluded as they evaluated the familiarity of specific guidelines other than the COG recommendations. The remaining 30 articles were saved.

The final database searched was *CINAHL*. This database was included because of the large number of publications it contains regarding nursing and health care specifically (Dicenso et al., 2005). A keyword search using the terms "childhood cancer survivors" was conducted and this yielded 86 results. The search was further narrowed by combining it with AND "primary health care or primary care nursing or physicians primary care or continuity of care." Six relevant articles were retrieved from this search and all were saved to a *CINAHL* folder.

The next search conducted was also through *CINAHL*. "Pediatric cancer survivors" was the phrase used, and this search resulted in 75 articles. This was then combined with AND "primary health care or primary care nursing or physicians primary care or continuity of care" and ten articles were retrieved. Three were excluded because they studied PTSD in
mothers who had children diagnosed with cancer. Two further studies were eliminated because they focused on developing exercise programs for cancer survivors. The remaining five articles were then saved to the folder, totaling in 11 studies that had been retrieved using the *CINAHL* database.

A final search in the *CINAHL* database for CCS care was conducted using the terms "long term follow up" AND "childhood cancer survivors." There were three relevant articles retrieved, one was eliminated because it focused on therapies for genitourinary cancer and another because it was published before 2004, and one article was saved. Finally, the keywords "follow up" AND "childhood cancer survivors" were used to conduct a search with a limit including only articles published in 2004 or later. There were four results; one was eliminated because it concerned genitourinary cancer treatments and another because it focused on diabetes. The remaining two articles were saved, for a total of 14 in the *CINAHL* searches. Using the search terms "models of care" AND "childhood cancer survivors" was also attempted within the *CINAHL* and *Medline* databases and neither resulted in any articles.

The *CINAHL* database was also used to search for research pertaining to guideline implementation. "Guideline implementation" AND "primary care" were the keywords used, and this resulted in 26 articles. Seven of the studies retrieved evaluated specific interventions and treatments not relating to guidelines, and five of the articles also failed to address guidelines of any type. The remaining 14 studies concerned guideline implementation and were saved.

Many of the searches resulted in overlap, and this shows that an exhaustive and complete search was accomplished by using the various keywords in several databases. This comprehensive search of three research databases resulted in a total of 82 relevant articles pertaining to care of CCS. After briefly reviewing the articles, 18 overlapped between the three search libraries, one study was eliminated as it was based on a single case study examining the treatment of Wilms tumour, ten articles were excluded as they examined acute effects of cancer treatments, and four were not used as they were one-page news articles. This second refinement process left 49 studies remaining for review. As the literature was more thoroughly assessed, articles not addressing either late effects or screening for adults who have survived a pediatric malignancy were removed. After revision was completed, 11 relevant articles remained that satisfied the inclusion and exclusion criteria for the first search (Blaauwbroek et al., 2008; Essig et al., 2012; Friedman et al., 2006; Heirs et al., 2013; Landier, Wallace & Hudson, 2006; Michel et al., 2009; Nathan et al., 2013; Oeffinger et al., 2009; Singer et al., 2013; Suh et al., 2014; Wong et al., 2014).

After the second search addressing guideline implementation, 70 articles were saved for further evaluation. Ten of these articles overlapped, resulting in 60 studies left for review. Eleven of these were eliminated as they explored whether or not guidelines were being employed in practice rather than focusing on strategies for their implementation. A further 16 studies were excluded as they investigated the effectiveness of specific guidelines rather than implementation strategies. After the studies were read in detail, those that did not describe implementation strategies and/or those that did not apply to primary care were eliminated. After a more thorough review, three studies were found to be most relevant to exploring guideline implementation in primary care. Therefore, the literature review resulted in 14 articles that would be most pertinent when attempting to answer my research question. Two tables have been presented following this Chapter that summarize the literature search process. The following Chapters will review the most relevant articles found in the searches described, and summarize their findings.

Table 1

Search	Database	Search terms	Results	Articles Eliminated	Total
1	Cochrane	Childhood cancer survivors AND primary care	44 articles	<ul><li>9-smoking cessation</li><li>5-exercise intervention</li><li>5-coping skills of parents or siblings of CCS</li></ul>	25 articles
2	Cochrane	Pediatric cancer survivors	8 articles	2-smoking cessation 1-PTSD of mothers of children diagnosed with cancer	5 articles
3	Cochrane	Long term follow up AND childhood cancer survivors	8 articles	1-interventions for adolescents 3-acute cardiotoxicity, nephrotoxicity and nutritional interventions 2-published before 2004	2 articles
4	Cochrane	Follow up AND childhood cancer survivors	22 articles	<ul> <li>1-emotional coping</li> <li>7-smoking cessation</li> <li>1-fertility treatments</li> <li>5-pediatric care</li> <li>1-nutritional intervention</li> <li>1-exercise intervention</li> </ul>	6 articles
5	Cochrane	Guideline implementation AND primary care	47 articles	<ul> <li>13-addressed specific</li> <li>treatments, not guidelines</li> <li>3-strategy implementation</li> <li>in emergency care</li> <li>3-pediatric care</li> <li>2-appropriate imaging</li> </ul>	26 articles
6	Medline	Pediatric cancer survivors AND primary health care or primary care nursing or physician primary care or continuity of patient care	9 articles	1-published in 2003	8 articles
7	Medline	Childhood cancer survivors AND primary health care or primary care	11 articles	1-smoking cessation 4-greater than ten years old 1-pediatric care	5 articles

Search	Database	Search terms	Results	Articles Eliminated	Total
		nursing or physician primary care or continuity of patient care			
8	Medline	Long term follow up AND childhood cancer survivors	10 articles	1-more than 10 years old 1-salivary gland tumours 1-pediatric care	7 articles
9	Medline	Follow up AND childhood cancer survivors	15 articles	2-treatment of GU cancers 1-pediatric care 1-treatment of thyroid cancer 1-diabetes	10 articles
10	Medline	Guideline implementation AND primary care	49 articles	<ul> <li>14-specific screening</li> <li>practices not related to CCS</li> <li>or cancer</li> <li>3-acute care</li> <li>2-evaluated specific</li> <li>guidelines other than COG</li> </ul>	30 articles
11	Cinahl	Childhood cancer survivors AND primary health care or primary care nursing or physician primary care or continuity of patient care	6 articles	None eliminated	6 articles
12	Cinahl	Pediatric cancer survivors AND primary health care or primary care nursing or physician primary care or continuity of patient care	10 articles	3-PTSD of mother of children with cancer 2-exercise program development	5 articles
13	Cinahl	Long term follow up AND childhood cancer survivors	3 articles	1-GU cancer treatment 1-more than 10 years old	1 article
14	Cinahl	Follow up AND childhood cancer survivors	4 articles	1-GU cancer treatment 1-diabetes care	2 articles
15	Cinahl	Guideline implementation AND primary care	26 articles	7-interventions and treatments not related to guidelines 5-did not reference any guideline	14 articles

# Table 2

Searches	Total studies retrieved	Number of overlapped studies	Articles further eliminated	Final total
Related to CCS and primary care	82	18	<ul> <li>1-single case of</li> <li>Wilms' tumour</li> <li>10-acute effects of</li> <li>cancer treatment</li> <li>4-one page news</li> <li>articles</li> <li>38-did not fulfill</li> <li>inclusion criteria</li> <li>after detailed</li> <li>review</li> </ul>	11
Related to guideline implementation	70	10	21-investigated whether or not guidelines were used; not strategies 16-explored specific guideline effectiveness, not strategies 20-did not fulfill inclusion criteria after detailed review	3

## Findings

The search strategy described in the Methods Chapter resulted in a total of 14 articles to assist in answering the research question: how can NPs best incorporate the COG guidelines into LTFU care for adults who are CCS? The following Chapter analyzes and compares the data presented in these articles and describes application of their findings to LTFU for CCS.

## **Analysis of Research Studies**

Literature reviews. Two of the articles retrieved from the search were informative papers that were largely derived from a review of the literature. The papers authored by Landier et al. (2006), and Friedman et al. (2006) were literature reviews. Both of these articles performed reviews of the literature regarding their prospective topics and these studies will be described in detail below.

Landier et al. (2006) explored the development, benefits and the limitations of both the COG and the SIGN guidelines and the ways in which LTFU for CCS should be approached. These authors cited 63 references in their study; however, they did not explain the process they utilized to retrieve these articles. Landier et al. (2006) substantiated the knowledge deficit on the part of both the patient and the provider with respect to LTFU of CCS. A study conducted in 2004 by Oeffinger, Hudson, and Marina (as cited in Landier et al., 2006) consisted of a convenience sample of 236 physicians, and in this study a 36 item questionnaire was utilized to assess the knowledge and comfort level of physicians with CCS. The results showed that PCPs demonstrated about 50% less knowledge and comfort level regarding LTFU for CCS compared to adult and pediatric oncologists (Landier et al., 2006). In Hudson et al.'s 2002 study (as cited in Landier et al., 2006) 272 adult CCS were surveyed and of these patients 52% were not aware that their previous cancer histories and treatments placed them at increased risk for a secondary malignancy, and 42% were unaware that their previous cancer treatments increased their risk of heart disease

Landier et al. (2006) offer a side by side comparison of the SIGN guidelines and the COG guidelines regarding thyroid screening after neck radiation and cardiovascular screening after chest radiation and/or anthracycline chemotherapy. These authors conclude that both the SIGN and the COG guidelines are appropriate tools to utilize when initiating LTFU for CCS (Landier et al., 2006). As a strategy to implement LTFU guidelines, these researchers emphasized the importance of educating both providers and survivors regarding late effects (Landier et al., 2006). Specifically, Landier et al. (2006) suggest educating CCS regarding indications for follow-up as well as providing education programs for PCPs that address the individualized care and surveillance required for CCS. Additionally, these authors advocate stratifying patients according to level of risk when providing LTFU to CCS (Landier et al., 2006).

In addition to conducting research, the authors from the Landier et al. (2006) study all work in a clinical pediatric oncology setting, and as evidenced in the literature search results, many of them regularly publish studies on LTFU of CCS. Their clinical backgrounds add relevance to their findings, although more data will still be needed to solidify their research.

Weaknesses of the Landier et al. (2006) research include the fact that this study is derived from a compilation of other studies and as Howick et al. (2011) explains, the resulting evidence from such studies is not as strong. Additionally, a description of the search methods employed to find the included studies was omitted (Landier et al., 2006). Nurse practitioners were not identified as PCPs who were included in the study, which may limit the applicability of these findings. Finally, this article was financially sponsored by the COG, which may have resulted in a bias in their findings (Landier et al., 2006). Nevertheless, the suggestions presented in the Landier et al. (2006) study offer some focused solutions regarding how PCPs can improve LTFU for CCS, therefore this research is helpful in answering my research question. Targeting strategies toward increasing the knowledge base of both patients and providers, as well as stratifying CCS into levels of risk, are suggestions that can be extracted from this research to improve the incorporation of the COG guidelines into NP practice.

Friedman et al. (2006) reviewed the barriers to LTFU and they compared various models of care for CCS by reviewing 72 studies on which they based their evaluations. These authors also failed to describe the process by which they selected the research studies they included (Friedman et al., 2006). Friedman et al. (2006) cited a 2002 study conducted by Kadan-Lottick et al. that demonstrated that only 35% of CCS were aware that their previous treatments could result in serious effects later in life. In order to address this lack of knowledge, Friedman et al. (2006) suggest that the education of survivors, along with the incorporation of an effective model of care, are critical when providing LTFU for CCS. Similar to the previous study, the demonstrated lack of knowledge on the part of CCS and the suggestion for education targeting this population offers insight into how the COG guidelines may be incorporated into NP practice. As there is a lack of specificity regarding the type of education that may be most effective, further inquiry as to specific solutions to improve LTFU will be required in order to apply them to practice.

Friedman et al. (2006) also compared various models of care for the delivery of LTFU for CCS, and they divided these into cancer-centre based models and community-

based models. Cancer-centre based models are defined as oncology clinics and LTFU clinics whereas community models are based out of primary clinics (Friedman et al., 2006). Cancercentre based models offer expert guided follow-up; however, they may prevent the patient from moving past their cancer histories (Friedman et al., 2006). Community-based models tend to involve PCPs who have much less experience and knowledge regarding cancer; however, this model promotes independence for CCS as they will be able to attend their LTFU in a generalized care setting (Friedman et al., 2006). Friedman et al. (2006) concluded that a combined approach offers the most benefits. That is, the ideal model would involve follow-up in a cancer-based centre for a defined time period followed by transfer to the community-based centre with ongoing guidance from the cancer centre as needed. The suggestion of a specific model presented in this study offers one solution regarding the setting that may be most effective when applying the COG guidelines to the LTFU of CCS.

Similar to the Landier et al. (2006) study, the authors in the Friedman et al. (2006) article all work clinically with pediatric oncology patients as well as regularly publish studies in this field of practice, and their active role in this area adds influence to their findings. That said, there are also some weaknesses in this study. Since this research utilizes data retrieved from existing studies, it represents a lower level of research and other findings are necessary to strengthen their data (Howick et al., 2011). Again, there was a lack of explicitly stated inclusion and exclusion criteria with respect to choosing the included articles, and this may be indicative of selection bias. Additionally, both these articles are almost ten years old and more recent studies in this field have stronger validity with respect to my research question. Finally, this research paper was funded by the COG, which also may have resulted in a bias regarding the findings and conclusions (Friedman et al., 2006). Despite these limitations, this

study provides some suggestions regarding the education of CCS and appropriate care models that assist in answering my research question.

Systematic reviews. Systematic reviews represented two of the studies retrieved from my literature search. In contrast to the literature reviews described previously, the search methods and inclusion and exclusion criteria were explicitly stated in these reviews (Heirs et al., 2013; Singer et al., 2013). Heirs et al. (2013) conducted a systematic review by searching the literature in 11 different databases. The stated goal of their paper was to evaluate research comparing LTFU models of care for CCS. After applying their inclusion and exclusion criteria, followed by an assessment by two independent reviewers, eight papers were retained in the review. This represents one of the strengths of this study as independent review can help to reduce bias (Howick et al., 2011). The participants in these studies were convenience samples and the data was retrieved mainly via questionnaires (Heirs et al., 2013). Systematic reviews are also considered a stronger level of evidence and therefore this adds significance to the results of this study (Howick et al., 2011).

The findings of this study demonstrated that most patients and providers preferred a multi-disciplinary model of care, although no studies comparing LTFU models were found (Heirs et al., 2013). A lack of relevant research also resulted in the inclusion of uncontrolled studies (Heirs et al., 2013). The authors also acknowledged that the outcomes of clinic success were based on provider or patient perception, which may or may not be an accurate evaluation of true clinic success (Heirs et al., 2013). For example, specific measurements of patient outcomes, such as appropriate screening recommendations, were not evaluated. Again, NPs were not explicitly identified as being included in the studies, which may limit the application of the findings. Finally, much of the data contained in the retrieved articles

consisted of observational findings, which have a large potential for bias. This systematic review provided some useful information regarding my question as it gave insight into the model of care for LTFU desired by patients and providers. This finding offers a context within which NPs may best be able to incorporate the COG guidelines into practice. However, due to the many limitations of this study, additional research is needed to support its findings.

The second systematic review was conducted by Singer et al. (2013) and the goal of these researchers was to compare two models of LTFU care for CCS. Four databases were accessed and there were no language restrictions (Singer et al., 2013). The literature search resulted in 26 articles being found, consisting mainly of descriptive data (Singer et al., 2013). Two independent reviewers evaluated the relevance of the article abstracts in an attempt to decrease selection bias (Singer et al., 2013). The findings demonstrated that a shared care model had more advantages compared to a general practitioner (GP)-led model of LTFU care for CCS (Singer et al., 2013). This model combines the advantages of access to an expert in pediatric oncology with the provision of care in an environment that promotes independence for CCS (Singer et al., 2013).

There are several weaknesses inherent in the Singer et al. (2013) study. Most of the articles retrieved involved studies conducted in the United States, which may limit the generalizability of their results due to the differences in health care structure between Canada and the United States (Singer et al., 2013). Specifically, in the United States health care is not universal as it is in Canada, and Canada spends only 10.4% of its gross domestic product on health care versus 16% in America (National Bureau of Economic Research, 2015). These differences may affect the delivery of health care services and ultimately may limit the

generalization of research conducted in the United States to Canada. Also, as only two models of LTFU care were compared, more studies are necessary to evaluate other models and to provide strong evidence to suggest one over the others (Singer et al., 2013). Finally, NPs were not explicitly stated as being included within the GP-led model of care (Singer et al., 2013). Nevertheless, due to the lack of research comparing LTFU models, this article provides good information regarding the two models of care evaluated, and which model may be best suited to when implementing the COG guidelines into NP practice.

In contrast to the studies previously described, Wong et al. (2014) used a retrospective cohort study structure. This article was unique in that the researchers applied a mathematical simulation to evaluate the cost-effectiveness of current screening recommendations (Wong et al., 2014). The simulation was based on data collected from the Childhood Cancer Survivor Study (CCSS), which consisted of a database of 4,635 children who had been exposed to anthracyclines between 1970 and 1986 (Wong et al., 2014). The mathematical model used risk estimates based on the survey information retrieved from the CCSS, and simulated lifetime costs and total risks of heart failure were then calculated for different screening intervals (Wong et al., 2014).

The findings from this study revealed that decreasing screening practices (compared with those suggested by the COG) could be recommended, which could reduce the financial cost by 50% without significantly compromising the health benefits (Wong et al., 2014). For example, Wong et al. (2014) found that, for those CCS for whom the COG recommends annual echocardiograms, this surveillance could be safely decreased to every 2-4 years. Patients who are risk-stratified to receive echocardiograms every 2 years by the COG may decrease this surveillance to every 5 years, and those for whom the COG recommends

echocardiograms every 5 years may decrease the frequency to every 10 years (Wong et al., 2014). The mathematical equation used showed that decreasing the frequency of echocardiograms as described above maintained approximately 80% of the health benefits as those achieved with the COG recommendations, but at half the cost (Wong et al., 2014).

The Wong et al. (2014) study is an important one as it is one of the very few studies in existence evaluating the cost-effectiveness of the COG recommendations contained within their LTFU guidelines. The strength of its evidence is illustrated by the fact that an entire cohort of children who were exposed to anthracyclines was included, not only a narrow subset of subjects (Wong et al., 2014). Nevertheless, there are a few limitations associated with this research. First, the cumulative incidence of heart failure was extrapolated from the CCSS data, so it may not necessarily reflect what would be found in reality (Wong et al., 2014). Second, although the health benefits did not decrease overall as a result of decreasing the screening frequency, there may be subsets of populations for whom there would be a sharper decrease in health benefits and this was not examined.

Another limitation of the Wong et al. (2014) study pertains to the process of determining cost-effectiveness. The estimations of cost-effectiveness were based on a simulation, and again, this may limit the application of the study's findings (Wong et al., 2014). Additionally, it is very difficult to incorporate variables such as medication adherence, as well as the sensitivity and specificity of echocardiogram screening, into a simulation, therefore the findings from this study may not reflect what would be observed in practice (Wong et al., 2014). Finally, since there is a lack of research regarding the heart failure risks of CCS after 20 years, it is difficult to determine the value and necessity of lifelong screening practices (Wong et al., 2014). Despite its many limitations, the results from this study are highly valuable as they represent one of the first articles evaluating the COG guidelines, and whether their recommendations are cost-effective (Wong et al., 2014). The findings from this study offer some insight into research gaps that NPs may be able to address in order to improve the cost-effectiveness of the COG guidelines. This study however, does not include suggestions as to the ways in which NPs can better incorporate the COG guidelines into their practice. Therefore, although these findings would be useful in terms of suggesting future research topics, they do not provide much evidence that would assist in answering my research question. That said, it is important for NPs to take into consideration a cost-benefit analysis when recommending screening, and to be aware of any additional studies on this topic that may be published in the future.

**Descriptive studies.** The remaining six articles that were found are classified as descriptive study designs and they all utilized either questionnaires or surveys to obtain quantitative data. Three of the studies found in the literature search addressed models of care for LTFU of CCS and three evaluated the use of LTFU guidelines.

Michel et al. (2009) used questionnaires to gather data from 112 participants regarding preference for care delivery. They used one questionnaire prior to receiving follow-up, and then the participants received a second questionnaire after their follow-up care to complete at home. Four models of follow-up were described (postal/telephone follow-up, GP-led follow up, nurse-led follow-up and consultant-led follow-up), and then patients rated which model they felt was best suited to them (Michel et al., 2009). The findings from the Michel et al. (2009) study showed that 85.7% of patients desired a discussion of late effects during their health visits, and 51.7% of CCS rated consultant-led care higher than follow-up administered by phone, GP or nurse. There were many strengths present in these studies. Firstly, Michel et al. (2009) had a high response rate (79%), and since many of the selected patients participated, this decreased the likelihood of participation bias. Also, four different types of follow-up were evaluated by Michel et al. (2009), which offers evidence of a comparison when utilizing the literature findings to recommend a certain form of follow-up.

Although there were several strengths in this study, there were some limitations. The data collected from this study was self-reported and a bias can exist where the answers given by the respondents may reflect what they think the researchers desire, instead of how they actually feel or what is truly seen in practice (Howick et al., 2011). Michel et al. (2009) acknowledged an important bias in their research, as only patients receiving consultant-led LTFU were surveyed. This is definitely a factor that could have affected their findings as these patients may not have experienced the other care models to be able to offer a fair comparison between them. For example, patients may indicate that they would not desire a shared-model; however, this may simply reflect the fact that they may not know what that particular model would consist of or could offer to their care, rather than actually reflecting an informed preference. Additionally, NPs were not specifically included in this study, thereby potentially limiting the applicability to these providers.

This study may offer a solution as to which context may be effective when implementing the COG guidelines; however, since only patients who received consultant-led LTFU were included, and NPs were excluded, the true application of these findings is unknown. Blaauwbroek et al. (2008) analyzed answers from 103 questionnaires that were completed by physicians to obtain information about 101 randomly selected CCS. Selected patients were recalled to a LTFU clinic where family physicians subsequently conducted an assessment. Patients completed a seven-item questionnaire while family physicians completed a three-item questionnaire, and then a Likert scale was used to interpret the satisfaction of each group with a shared care model (Blaauwbroek et al., 2008). These questionnaires showed that 88% of patients and 82% of physicians who responded were satisfied with a shared care model (Blauuwbroek et al., 2008).

There were several strengths in this study. Blaauwbroek et al. (2008) had a high response rate in which 92% of participating patients and 90% of participating physicians completed the questionnaires. This high participation rate minimizes the chances of a response bias, which occurs when the answers differ between those who return the survey versus those who do not return it (Howick et al., 2011). Additionally, Blaauwbroek et al. (2008) randomly selected their patients by computer, which would decrease the likelihood of selection bias, and increase the validity of their results.

Despite its strengths, there were also some limitations to the Blaauwbroek et al. (2008) study. First, as the data is self-reported, there is a potential difference between what is reported and what actually occurs in clinical practice (Howick et al., 2011). Additionally, the CCS in the Blaauwbroek et al. (2008) study had not experienced other care models to compare a shared care model to, similar to the concerns raised in the Michel et al. (2009) study. This second point limits the ability of this research to answer my question; although the findings from Blauuwbroek et al. (2008) did indicate high satisfaction with a shared care model, only patients who were being cared for in a shared care model were surveyed. It is therefore difficult to ascertain whether this is the most appropriate context for the implementation of the COG guidelines. Also, satisfaction with a shared care model does not necessarily imply improved LTFU care and/or adherence to guidelines.

Essig et al. (2012) collected data from 179 European institutions regarding information pertaining to both guideline usage and LTFU programs in place. The list of institutions was compiled by contacting those who were participating in the PanCare late effects network, a multi-disciplinary network in which most European countries are represented (Essig et al., 2012). Although these institutions were largely acute care, as they were centres in which CCS had been treated, the questionnaires examined several aspects of follow-up: whether or not LTFU was offered to CCS, whether or not guidelines were employed, and which models were used (Essig et al., 2012). All of the aforementioned facets of care could provide information pertaining to my research question. These researchers found that a follow-up model that included a multi-disciplinary team was most desired by the aforementioned institutions; however, only 38% of responders had LTFU programs in place for adult survivors (Essig et al., 2012). The results of this study also indicated that, although 88% of institutions reported using guidelines, 25% offered little to no education to CCS on late effects or screening (Essig et al., 2012).

There are two main strengths in the Essig et al. (2012) study. The research conducted by Essig et al. (2012) retrieved data from a wide geographical range as it spanned across Europe, which would strengthen the applicability of their results. They also analyzed data by region, thereby decreasing the likelihood of findings from one region being inappropriately applied to other countries (Essig et al., 2012). There were also some limitations to the research conducted by Essig et al. (2012). First, as in the other studies previously discussed in this paper, the data is self-reported, which carries an inherent potential bias (Howick et al., 2011). Second, some small countries who were not participating in PanCare were not included in the Essig et al. (2012) study and this could have affected findings regarding models of follow-up, guideline use and the education of CCS on screening and late effects. Finally, this research was conducted in Europe, and due to the differences in health care systems, the results may not be generalizable to other continents.

This study is useful in answering my research question as it offers a desired and feasible structure (multi-disciplinary model) within which NPs may implement the COG guidelines. The research conducted by Essig et al. (2012) reinforces the findings of both Landier et al. (2006) and Friedman et al. (2006) as it also identified the need for the education of survivors regarding screening practices. This represents a solution which can be utilized to incorporate the COG guidelines into LTFU care.

Although the previous three studies described have some limitations regarding comparing different models of LTFU care, their results provide some insight into my research question. First, this research highlights the lack of studies that compare multiple models of LTFU care for CCS. This indicates a gap in the research regarding these type of studies, therefore further exploration into comparing LTFU care delivery is necessary. This may be conducted by NPs and could give further insight into how they may better care for CCS. Secondly, despite the limitations, both Essig et al. (2012) and Blaauwbroek et al. (2008) demonstrated high satisfaction with either a shared care or multi-disciplinary team model for LTFU for CCS. This gives some evidence-based insight into the structure of care for which a NP could advocate when attempting to improve LTFU care delivery in their practice, thereby providing insight which is useful to answer my research question. The results from Michel et al. (2009) indicating a preference for consultant-led care also supports the findings of the other two studies, as it suggests the value of a delivery system that incorporates the expertise of at least one other provider into the LTFU of CCS.

Evaluation of the use of LTFU guidelines was addressed by the final three studies that were retrieved in the literature search. A quantitative descriptive study design was used by Suh et al. (2014) to assess COG guideline use, and they distributed surveys to 2,000 physicians (1,100 responded) across the United States. These surveys evaluated both the familiarity of physicians with the COG guidelines and the physicians' knowledge of specific recommendations contained within those guidelines (Suh et al., 2014). Additionally, physicians were questioned on suggestions they had for the improvement of LTFU of CCS (Suh et al., 2014). The findings from Suh et al. (2014) showed that only 9.4% and 14.9% of physicians were able to correctly identify the COG guidelines for mammography and echocardiography respectively. They also revealed that easier access to LTFU guidelines and treatment summaries were suggested by physicians as ways to improve care for CCS.

There are several strengths of the Suh et al. (2014) study. First, a large number of surveys were completed and returned in the Suh et al. (2014) studies, and the response rate was over 50%. Acceptable response rates for surveys in research have been defined as anywhere between 50-60% (Nulty, 2008). The high numbers of physicians surveyed decreases the likelihood of bias and increases the validity of the results. Additionally, it was one of the few studies that tested the knowledge within the guidelines, which may give a better indication as to the prevalence of COG guideline usage.

Despite the strengths, there are a few limitations with this study. Again, the data within this study is self-reported, which may not reflect the reality of practice (Howick et al., 2011). Second, NPs were not included in the surveys. There are approximately 177,325 NPs in the United States who practice in primary care, so this is a significant proportion of PCPs who were excluded from this study (American Association of Nurse Practitioners, 2015). In the literature search, there were no studies that exclusively evaluated the LTFU care given by NPs to CCS, and at this time the only recourse is to extrapolate data pertaining to physicians to NPs, where possible and appropriate. Despite some differences in scope of practice, both these providers have been identified in the literature as appropriate care givers for CCS, therefore until NP-specific research is conducted, the findings from physicians need to be applied to NPs as well.

Overall, the Suh et al. (2014) study is pertinent to my question as it not only investigated those stages of care where a lack of follow-up is occurring, but it also examined possible solutions from the physicians themselves as to how to improve LTFU for CCS. These figures demonstrate a need for an improvement in the familiarity of PCPs with the COG guidelines. Strategies targeted to increasing the awareness and use of the guidelines by PCPs that are based on these findings will allow NPs to incorporate the COG guidelines into their practice, making these results applicable in addressing part of my research question. These strategies will be further discussed in the Recommendations Chapter.

Nathan et al. (2013) also employed quantitative descriptive methods and mailed surveys to 2,520 (1,124 responded) physicians in the United States and Canada to assess familiarity with the COG guidelines. Findings demonstrated that only 2% of physicians were aware of the recommended thyroid, breast and cardiac screening (Nathan et al., 2013). These surveys also assessed the frequency of receiving treatment summaries, as well as which model of care was most desired by physicians (Nathan et al., 2013). Nathan et al. (2013) reported that treatment summaries were only received by 48% of physicians, and 85% of physicians desired providing LTFU care in consultation with a cancer-centre based physician.

The study conducted by Nathan et al. (2013) had many strengths. The response rate in this research was relatively high (45%), thereby decreasing the likelihood of responder bias. Additionally, this study evaluated responses from physicians in both Canada (37% of responders were Canadian) and the United States, thereby broadening the applicability of the results (Nathan et al., 2013). Finally, these authors analyzed the demographics between the responders and the non-responders and found no significant differences, which further decreases the likelihood of bias and increases the validity of their findings (Nathan et al., 2013).

Limitations of the Nathan et al. (2013) study include the potential bias in selfreported data, as well as the exclusion of NPs in the surveys. As previously mentioned, there is no information regarding NPs and the COG guidelines in the literature, so findings that pertain to physicians are extrapolated to these PCPs. Again, the findings from this study provide useful information to answer my research question, as they identify a need for an increase in the distribution of treatment summaries, an increase in education on the part of providers, and a desire for LTFU that involves collaboration. Therefore, this data provides insight as to how NPs can better incorporate the COG guidelines into their care of CCS. Specific suggestions regarding ways to address these results will be described in the Recommendations Chapter. Finally, Oeffinger et al. (2009) employed quantitative descriptive methods by sending surveys to 625 females (551 responded) who had received chest radiation in order to evaluate their mammography screening practices. This study also analyzed demographic data to determine the factors most likely to affect the screening practices of these patients (Oeffinger et al., 2009). The findings in this study showed that 63.5% of women aged 25-39 years who had a history of chest radiation had not received mammography screening in the past two years, despite the COG recommendations. Mammography rates were 30-50% higher in women who received screening recommendations from their physician, and the frequency of screening increased with increased age (Oeffinger et al., 2009).

There are two main strengths that can be identified through the analysis of this study. Oeffinger et al. (2009) performed statistical analyses on their data to account for variables (including age, race, living area, last Papanicolaou smear, cancer knowledge and perception, and usual source of care), which would increase their validity. Also, since the Oeffinger et al. (2009) study was the first large scale study to evaluate breast screening practices in detail, its findings address a gap in the research and offers insight into improvements for screening.

As with all studies that utilize surveys, one of the limitations of this article is the possible bias inherent in self-reported data (Howick et al., 2011). Additionally, the rates of mammography screening in this study may have been over estimated, since this cohort of women was also involved in a longitudinal study where they received newsletters outlining current cancer screening guidelines (Oeffinger et al., 2009).

Considering these limitations and the study results, this research reveals some information regarding the prevalence of breast mammography for CCS, as suggested by the COG. Given that the compliance with the COG guidelines regarding mammography is suboptimal, strategies can be targeted at increasing awareness of these recommendations to improve screening. Also, it was shown that physician recommendation could have a significant impact on patient screening practices pertaining to mammography for CCS. That said, since this study only addressed one of the many recommendations of the COG regarding screening CCS, and it does not offer specific strategies, it has limited application to my research question.

Guideline implementation studies. Three of the studies retrieved from my literature search addressed the implementation of guidelines in primary care. Literature pertaining to guidelines implementation was searched to address the second part of my question, which is how NPs can incorporate the COG LTFU guidelines into primary care practice. Bernhardsson et al. (2014) conducted a non-randomized controlled trial that evaluated the effectiveness of guideline implementation by sending questionnaires to physical therapists (PTs) in primary care. The sample consisted of 168 PTs in the intervention group, whose responses were compared to the 88 PTs in the control group at baseline and six months later (Bernhardsson et al., 2014). The guidelines that were examined consisted of recommendations for PT treatment for low back pain, neck pain, and subacromial pain (Benhardsson et al., 2014).

The implementation intervention was multi-component and involved the provision of these PT treatment guidelines for low back, neck and subacromial pain in both a printed and electronic format, participation in a three hour seminar and group discussions, provision of a website with links, and finally conducting telephone and email reminders regarding the use of the guidelines (Bernhardsson et al., 2014). The seminars involved both a learning component and an hour-long discussion group, and they were held on nine separate occasions in a three-month period, and anywhere from nine to 28 PTs attended each session (Benhardsson et al., 2014). In total, of the 277 PTs assigned to the intervention group, 188 attended the education seminars (Benhardsson et al., 2014).

The findings from the Benhardsson et al. (2014) study showed some modest improvement with the intervention. The results demonstrated that 59% of PTs in the intervention group (compared with 44% in the control group) reported being aware of the guidelines; 40% indicated in the experimental group (compared to 16% in the control group) they knew where to find the guidelines; 26% of the intervention group (compared to 7% of the control group) reported easier access to the guidelines; and 63% of PTs in the intervention group showed greater frequency of guideline use compared with 48% of PTs in the control group (Benhardsson et al., 2014). The findings from this study can give some insight into my question, as to which strategies may improve access to the COG guidelines by NPs; however, the findings only show a modest improvement.

The Bernhardsson et al. (2014) paper also contained several limitations. Firstly, a bias may be inherent as the data is self-reported, and this may not necessarily represent what is seen in practice (Bernhardsson et al., 2014). That is, some PTs may have responded based on what they think the researchers may have wanted to find instead of giving a true response.

The authors also acknowledge that patient outcomes were not evaluated, and only outcomes from the perspective of provider were measured (Bernhardsson et al., 2014). Additionally, the data for this study were collected at baseline and six months later. If these interventions were continued long-term, this might have affected the findings by showing either a greater or a decreased improvement in guideline awareness and use. Finally, because this research did not involve randomization, it is difficult to discern whether the results may be directly attributed to the intervention (Bernhardsson et al., 2014).

Despite its limitations, and although this study only showed a modest improvement based on the intervention, it may give some insight as to possible solutions to improve the awareness of adherence to the COG guidelines for NP practice. That said, this study evaluates PTs, not NPs or other PCPs, making it is difficult to say whether or not the findings can be generalized to NPs caring for CCS. Comparatively the types of patients seen by PTs in this study address health issues that are much more common in contrast to CCS seen by PCPs regarding LTFU. Therefore, the applications of these findings are limited, since they apply to a different population, regarding different concerns that are being addressed by different providers. However, incorporating strategies that impart guideline information in a multi-component delivery system such as offering interactive discussion sessions, websites that are easily navigated, and reminder systems are all solutions that adhere to the principles of implementation science and could be applied to LTFU for CCS.

In contrast to the Bernhardsson et al. (2014) article, the study by Lesho, Myers, Ott, Winslow and Brown (2005) did evaluate patient outcomes after the implementation of clinical guidelines. This research consisted of a before and after study that examined 68,000 patients retrieved from electronic records (Lesho et al., 2005). These researchers evaluated the effects of implementing asthma, diabetic and smoking cessation guidelines on patient outcomes in primary care (Lesho et al., 2005). The implementation of the clinical guidelines was established by lectures and "tool kits" which contained algorithms and patient education materials to facilitate guideline adherence (Lesho et al., 2005). The results demonstrated that, after the asthma guideline was put into place via the implementation strategies, there was a 52% decrease in nebulizer treatments, a 65% reduction in exacerbation-related emergency visits, and a 28% increase in patient education (Lesho et al., 2005). Similarly, after the diabetes clinical guideline was implemented, there was a 15% increase in patient education, a 3% reduction in hemoglobin A1C levels, and a 23% decrease in blood pressure measurements (Lesho et al., 2005). Finally, the smoking cessation guidelines resulted in a 38% improvement in screening for tobacco use, and a 7% increase in patient education (Lesho et al., 2005).

Lesho et al. (2005) minimized a bias in measuring outcomes by using a computerized database to evaluate the effects of guideline implementation, by patient administration and management personnel who were unaware that the study was being conducted. That said, the data obtained from their research may have been different depending on the amount of time passed since the implementation of the guidelines (which was never explicitly stated) (Lesho et al., 2005). Additionally, there was no control group in this study since adherence to these guidelines was mandatory across the whole healthcare organization that participated (Lesho et al., 2005).

Finally, although these conditions are much more common than late effects from previous cancer treatments would be, they are conditions for which patient outcomes are much more easily measured. For example, it would be very difficult to determine if regular mammography as recommended by the COG for women who have received chest radiation resulted in earlier detection and less morbidity of breast cancers. So although these conditions are not as complex as LTFU for CCS, they offer easily measured patient outcomes and they incorporate the principles of implementation science. Therefore, since Lesho et al. (2005) offer measureable findings that apply the principles of implementation science, and since there is no measureable outcome data on the COG (2013) LTFU recommendations, their results can then be applied to more complex issues such as implementing the COG guidelines into the care of CCS.

Despite these limitations, the findings from this research provide some strong evidence regarding the important effect that adherence to clinical guidelines can evoke (Lesho et al., 2005). By incorporating simple strategies such as algorithms and patient education materials, this study showed that a substantial improvement in patient outcomes can be achieved. These results can be applied to incorporating the COG guidelines into NP practice, and therefore they are relevant in helping to answer my research question. These strategies will be further discussed in the Discussion and Recommendations Chapters.

The findings reported by Prior, Guerin and Grimmer-Somers (2008) represent the final study found from the literature search that pertains to guideline implementation in primary care. Thirty-three systematic reviews comprised of a total of 714 individual studies were analyzed in this systematic review (Prior et al., 2008). Five databases were searched, and the studies found were critically appraised using an evidence-based tool known as AMSTAR, an 11 item instrument used to evaluate the methodology of systematic reviews (Prior et al., 2008). This tool has been demonstrated by the research to be a reliable and effective tool in the evaluation of systematic reviews (Shea et al., 2009).

Prior et al. (2008) evaluated various methods of delivery for education, all with varying results. The findings of the literature reviewed showed that educational strategies aimed at staff, such as continuing medical education (CME), were found to have conflicting data regarding their success (Prior et al., 2008). Some studies found up to an 80% improvement in physician knowledge after a CME intervention, while others found improvements to be minimal or inconclusive (Prior et al., 2008). The components of the CME were not well described, but factors that may improve success were increased physician knowledge, increased intensity and increased duration of the CME, although this varied largely across studies (Prior et al., 2008). Traditional education sessions such as lectures, conferences and websites were found to be ineffective across all of the research (Prior et al., 2008).

In contrast to CMEs, interactive educational sessions such as workshops and practical sessions were determined by 10 of the 11 systematic reviews to be successful, and effectiveness ranged from 1-39% (Prior et al., 2008). Strategies involving audit and feedback also ranged in success from a 17% decline to a 63% improvement in guideline compliance, and costs with this strategy decreased by up to 37% (Prior et al., 2008). Evidence clearly demonstrated that a multi-faceted approach was more effective than a single strategy (up to 60% increase in compliance to guidelines); however, there was no relationship shown between the number of interventions and their effectiveness (Prior et al., 2008). Solutions involving mass media and distribution had inconclusive results, and the complexity of guidelines was inversely related to their compliance (Prior et al., 2008). Since the COG (2013) LTFU guidelines are complex and lengthy, according to Prior et al. (2008) this would decrease adherence to the guidelines. Electronic reminders regarding guideline use demonstrated significant success, improving adherence up to 71.8% while decreasing costs up to 30% (Prior et al., 2008).

Despite the informative results revealed by their data, there were some limitations in the Prior et al. (2008) study. Although the reviews retrieved by this research were evaluated by two independent reviewers, publication bias was not assessed by the authors (Prior et al., 2008). Also, the authors noted that the methodology was flawed in some of the articles they retrieved, which may have affected their results. Finally, the researchers acknowledged that they assumed the study results were accurately described in the systematic reviews they included, since their findings would be impacted if this was not the case (Prior et al., 2008).

Regardless of these limitations, the research conducted by Prior et al. (2008) offers some solid evidence regarding which strategies may prove to be effective when implementing guidelines into clinical practice. Specifically, those strategies identified as largely successful across the research may be applied to incorporating the COG guidelines into NP practice, in order to improve LTFU for CCS. These specific strategies will be further addressed in the Discussion and Recommendations Chapters.

#### **Summary of Findings**

In summary, the research has indicated a clear lack of LTFU care for CCS (Essig et al., 2012; Friedman, et al. 2006). Guidelines such as those devised by the COG and the SIGN have attempted to standardize screening practices for this patient population; however, adherence remains low as does awareness of the guidelines themselves with patient, provider and system barriers confounding efforts to successfully implement the guidelines (COG, 2013; Nathan et al., 2013; Oeffinger et al., 2009; SIGN, 2013; Suh et al., 2014). The data retrieved indicates some discrepancy as to which care model is best for LTFU for CCS. Studies showed that either a multi-disciplinary approach (Essig et al., 2012), consultant-led (Michel et al., 2009) or a shared model of care (Blaauwbroek et al., 2008) is most appropriate when providing LTFU to CCS. Therefore, these models will be further examined and compared in the Discussion Chapter.

The articles found that address the implementation of guidelines emphasized the importance of a multi-component strategy (Bernhardsson et al., 2014; Prior, et al., 2008). Additionally, patient outcomes were found to correlate positively with the implementation of guidelines, thereby highlighting their importance (Lesho et al., 2005). The following Chapter will discuss the research previously analyzed, combined with supplementary research in order to further explore LTFU for CCS.

## Discussion

The research described in the Findings Chapter has provided the basis for various insights into my research question. This Chapter will further discuss those research findings by first addressing the lack of patient and provider knowledge regarding LTFU. Different models of care will then be compared. Finally, the role of NPs in coordinating the care of CCS will be addressed and the utility of the findings to answering my research question will be discussed.

### Lack of Provider and Patient Knowledge

The lack of knowledge on the part of patients and/or providers was identified within the evidence as an important aspect of LTFU for CCS that currently requires improvement. Nathan et al. (2013), Landier et al. (2006) and Suh et al. (2014) all suggested that education strategies targeted to PCPs would help improve LTFU for CCS. Similarly, Landier et al. (2006), Friedman et al. (2006) and Essig et al. (2012) emphasized the importance of providing accurate information to survivors regarding late effects and screening practices. The fact that several studies have issued similar recommendations strengthens these findings. The evidence collected by these authors helps to focus the answer to my research question, in that the education of both patients and providers was shown to be integral when improving LTFU for CCS. When combined with the evidence presented by Lesho et al. (2005) and Prior et al. (2008), further insight is provided as to which specific education strategies tend to be most effective for guideline implementation. These specific suggestions for education strategies to improve the incorporation of the COG guidelines into NP practice will be outlined in the Recommendations Chapter.

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In addition to the provision of education, the context in which LTFU care was provided has been identified in the research as essential to its success. Consultant-led, shared care and multi-disciplinary teams were some of the care models found to be most desired and/or effective; these will be further compared below.

## **Models of Care**

In BC, LTFU for CCS is inconsistent as some survivors address their health concerns via primary care, while others discuss their health issues with their oncologist, whether or not they are related to their primary cancer diagnosis (BC Cancer Agency, 2013). Still other CCS utilize the Emergency Department for their concerns (BC Cancer Agency, 2013). These inconsistencies demonstrate the necessity for well-coordinated follow-up care structured within one LTFU model. As a new tiered strategy has been developed for CCS in BC (BC Cancer Agency, n.d.), the context of delivery of this new program (i.e., the model of care) must be taken into consideration, and the various options for these models of care are discussed in this section.

As mentioned previously, survivorship clinics represent one model of LTFU care for CCS. These facilities could be located at the same centre at which the patient received their cancer treatments, thereby providing continuity and maintaining the relationships previously built between the patient and their pediatric oncology team (Friedman et al., 2006). A multi-disciplinary approach has been suggested by many researchers as an ideal model for LTFU care of CCS, and a survivorship clinic is one way to provide this type of environment (Edgar et al., 2012; Friedman et al., 2006; Haddy et al., 2009).

Although survivorship clinics have several advantages in providing ongoing patient care for CCS, there are some potential drawbacks. These facilities may not be located in an

area that is convenient for CCS to access (Bhatia & Meadows, 2006). Most of these centres would likely be located in urban areas, therefore there would be limited or no access for those living in rural settings. Clinics that follow adult survivors in BC are not comprehensive and follow a very small proportion of CCS, and are only located in Vancouver (K. Goddard, personal communication, August 18, 2015). Therefore, many survivors in BC would have a difficult time attending LTFU in these facilities, and they offer limited resources. Many patients desire continued care by the oncology team with whom they have built partnerships; however, most of this patient population access primary care centres for their health concerns (Casillas et al., 2010; Singer et al., 2013). These patients also would like to move past their identification as a cancer patient, and they may be disinclined to return to the same centre where they had received their cancer treatment (Friedman et al., 2006). Additionally, specialized survivorships clinics are more costly and less sustainable for CCS patients in the long-term compared with primary care (Blaauwbrock et al., 2008; Singer et al., 2013).

A transitional model of care is another framework for the LTFU of CCS that has been mentioned in the research. An example of one of these facilities is located at St. Jude's Hospital in Tennessee (Aslett et al., 2007). Here, once patients have been discharged from pediatric oncology, they then spend one to two years in a specialized transition program called "living well after cancer" (Aslett et al., 2007, p. 1787). In this care model, pediatric and adult specialties are combined to provide care for CCS, and to ease their transition into the non-oncology primary care setting (Aslett et al., 2007).

Long-term follow-up directed by pediatric oncologists may seem to be the most appropriate care model for CCS; however, this is neither the most cost-effective nor the most feasible approach (Blaauwbroek et al., 2008). Although patients desire the continuity of care provided by a familiar care giver, such as their pediatric oncologist, it would not be costeffective to utilize these specialists to assess adult patients for generalized care (Blaauwbroek et al., 2008; Maeda et al., 2010). Pediatric oncologists have specialized knowledge in one area, so they are not necessarily appropriate providers in a primary care context, as they may not have as much experience in treating more common health concerns such as contraception (Blaauwbroek et al., 2008). Additionally, if CCS remained in a pediatric environment, this may delay their psychological growth and could affect their transition into adulthood (Bradwell, 2009; Michel et al., 2009). Transitional care could offer this continuity of care without the risk of compromising the developmental progress of the patient.

Advantages and disadvantages of the transitional care model are similar to those of LTFU clinics. Continuity of care by a familiar health care team and easy access to oncologists, social workers, psychologists and GPs may ease the difficult transition of CCS into primary care (Bhatia & Meadows, 2006; Haddy et al., 2009). Moving directly from receiving care from a well-known and coordinated oncology team to that provided by a general PCP may be too difficult for some patients, and a transitional facility may be one potential solution. That said, since pediatric oncology centres are much less numerous than primary care centres, distance to transitional care facilities may prove difficult for some CCS (Aslett et al., 2007). This model has been successful in some centres in the United States and it could be a viable strategy for care in some locations (Aslett et al., 2007; Bhatia & Meadows, 2006).

Adult-oncologist directed care is another strategy for providing LTFU for CCS. In this case, CCS would receive care in an age-appropriate setting from a specialist who is familiar with cancer diagnoses and cancer treatments (Bhatia & Meadows, 2006). However, a provider who is trained in adult cancers and therapies may have limited familiarity with the late effects of those cancer treatments that a patient had received as a child (Bhatia & Meadows, 2006). They also may not have adequate knowledge regarding the multi-agent chemotherapy regimes that many children receive when being treated for cancer (Bhatia & Meadows, 2006). Finally, an adult oncologist would not be the appropriate provider for general, non-late-effects related health concerns for which CCS may require care (Blaauwbroek et al., 2008; Michel et al., 2009). This would then require the survivor to see two different types of health providers for different concerns, resulting in the potential for less coordinated or more fragmented care.

Offering LTFU within a shared care model is another strategy for providing care to CCS. Follow-up care provided using this framework is less costly when compared to survivorship clinics and the problem of travelling to these specialized clinics is solved by offering care in the primary care setting (Blaauwbroek et al., 2008; Singer et al., 2013). The pediatric oncologists would provide information and advice regarding late effects of cancer treatments and proper surveillance procedures to the PCPs (Blaauwbroek et al., 2008; Nathan et al., 2013). Care in this model should also involve providers with enthusiasm and knowledge regarding LTFU of CCS, and these professionals may be medical oncologists, pediatric oncologists, family physicians, radiation oncologists and internal medicine specialists (K. Goddard, personal communication, August 18, 2015). It is essential that both pediatric oncologists and radiation oncologists are involved in the LTFU care of CCS since the knowledge of late effects can inform practice and give insight on how to reduce the risk of late effects in the future (K. Goddard, personal communication, August 18, 2015). The advantages of this care model include shorter waits, and normalizing health care for CCS by removing the stigma of being a cancer patient, since they would receive care in a primary care clinic or office (Blaauwbroek et al., 2008; Casillas et al., 2010; Parkes et al., 2008; Singer et al., 2013). This framework also fosters effective collaboration between pediatric oncologists, radiation oncologists and PCPs, thus resulting in well-coordinated care for CCS; studies have shown that both of these types of providers are in favour of this model (Bhatia & Meadows, 2006; Singer et al., 2013).

The degree of involvement of the pediatric oncologist and other specialists may also vary depending on the level of risk into which the survivor has been stratified, further individualizing care (Singer et al., 2013). Access to a care giver who knows the history of the patient, as well as access to their expertise in the environment of a primary care facility, is an effective combination that has great potential to provide CCS with appropriate LTFU care (Bhatia & Meadows, 2006). The oncology specialists would be able to provide ongoing guidance using evidence-based guidelines to ensure that the patient is receiving appropriate screening (Friedman et al., 2006).

Despite the benefits of a shared care model, there are a few disadvantages. One challenge of the shared care model would be that the survivor may feel unfamiliar with the NP compared to their previous oncology team, and building a therapeutic relationship with a new care provider might be challenging (Bhatia & Meadows, 2006; Singer et al., 2013). In contrast to care provided in a LTFU care centre, caring for CCS in a primary care setting would decrease the ease of access to providers in other disciplines, thereby making quick referrals or consultations more time-consuming (Singer et al., 2013).
It should also be noted that, although pediatric oncologists and other specialists practicing in the context of this model would be providing guidance regarding surveillance practices of CCS, NPs should still be familiar with the recommended guidelines (Singer et al., 2013). This familiarity is essential as they will be the providers responsible for follow-up of these patients and it was identified as being important to CCS that providers be knowledgeable regarding potential late effects (Singer et al., 2013). Nevertheless, this model represents one potential solution that targets many of the previously identified barriers to LTFU care. These barriers include but are not limited to the emotional and travelling challenges faced by the survivor, as well as the logistic and financial concerns identified in the barriers faced by the NPs and the healthcare system itself. Telehealth and/or access to instant consultation with specialists could assist in facilitating the success of a shared care model, and could also instantly connect patients with specialists as needed.

The final potential model for follow-up care consists of care directed solely by a PCP (Singer et al., 2013). Long-term follow-up structured in this way is more cost-effective and sustainable when compared to specialized follow-up centres (Singer et al., 2013). Primary care providers are usually in close proximity to CCS and therefore difficulties with travelling longer distances to care facilities are greatly decreased (Singer et al., 2013).

A NP has excellent training to facilitate health promotion, as this aspect of care is reflected within the competencies of NPs in BC (CRNBC, 2013a). Nurse practitioners are therefore well-suited to encourage CCS to attend the recommended screening practices for their care. Disadvantages include the lack of knowledge that NPs may have regarding the late effects of pediatric malignancies and their treatments, as well as a lack of information that is required to devise a survivorship plan if they are not in contact with the survivor's pediatric oncologist or they do not have a comprehensive treatment summary (Singer et al., 2013). Finally, similar to the shared care model, care directed solely by a PCP does not necessarily facilitate access to other disciplines and specialists as necessary (Singer et al., 2013). This final point is more pronounced in this model compared to the shared care model because collaboration with specialists is not specifically indicated (as will be further described below) (Singer et al., 2014). In contrast, in the shared care model, regular contact with a pediatric oncologist comprises part of the very definition of this framework (Singer et al., 2013). Therefore, considering the above comparison, a shared care model is the most appropriate framework for LTFU for CCS as it is cost-effective, and it combines the expertise offered by access to a pediatric oncologist with the aspects of normalizing health in a primary care setting offered by a NP.

#### **Role of Nurse Practitioners in LTFU for CCS**

Establishing a shared care model for the LTFU of CCS needs to be accomplished in accordance with the competencies for NPs in BC (CRNBC, 2013a). Nurse practitioners are required to "use consultation and collaboration as appropriate to confirm a diagnosis, identify a health need, or establish/confirm treatment recommendations" (CRNBC, 2013a, p. 13). Since collaboration and consultation are identified as core competencies for NPs, and the most feasible care models involve consulting or collaborating, this establishes NPs as optimal care givers with regards to LTFU for CCS. As previously described, the shared care model is the framework revealed by researchers to be most appropriate and desirable for LTFU of CCS. Consultation, collaboration and referrals are present in every competency outlined by the CRNBC (2013a) for NPs in BC. Nurse practitioners are autonomous providers who work in collaborative models (CRNBC, 2013b) and therefore the

collaborative nature of the shared care model would be easily incorporated into the NP scope of practice (CRNBC, 2013b).

### Recommendations

In order to improve LTFU for CCS, strategies must be aimed at the various challenges and gaps that currently exist. These strategies can be categorized as being directed towards the patient, the provider, or the health care system, in accordance with the aforementioned difficulties in coordinating LTFU for these patients. Many of the suggestions that follow can be implemented or initiated by NPs and these care providers are therefore integral to the establishment and maintenance of LTFU for CCS. The recommendations provided in this Chapter address my research question, regarding the ways in which NPs can best incorporate the COG guidelines into their clinical practice in a primary care setting.

## **Strategies Targeting Patients**

In exploring the improvement of LTFU for CCS, solutions directed towards survivors themselves comprise the first subset of strategies that will be discussed. Providing CCS with both treatment summaries and survivorship plans, along with educational resources such as websites and phone applications, are the topics that will be suggested in this section.

Many CCS were very young at the time of their initial diagnosis, and may be unable to provide accurate information regarding their cancer and treatment when attending future appointments (Nathan et al., 2013). This point illustrates the necessity of providing treatment summaries to patients and families once patients are discharged from pediatric oncology (Nathan et al., 2013). Many researchers, as well as the COG (2013) itself, stress the importance of providing the patient with treatment summaries once their oncology care has been completed (Aslett et al., 2007; Maeda et al., 2010; Nathan et al., 2013; Singer et al., 2013; Suh et al., 2014). Widespread use of this type of communication tool would facilitate the transition of CCS into adult care by NPs; however, they are not being consistently completed (Nathan et al., 2013).

As previously discussed, treatment summaries are not being completed and shared consistently. Primary care providers report receiving such treatment summaries only 52% of the time, further validating the need for more consistency on the part of pediatric cancer centres in providing such documents (Nathan, 2013). Each survivor should receive a treatment summary in the form of a hard copy of the necessary information to determine the recommended screening and that can be accessed for years after the completion of therapy (Maeda et al., 2010). If a treatment summary has not been provided, NPs should be aware that they can contact the COG to assist with retrieving some of the information that would otherwise have been contained within such a summary (The Foundation for Medical Practice Education, 2014). Additionally, patients may advocate for themselves and request a summary from their pediatric oncologist after completion of their cancer treatments.

Patients who have survived childhood cancers can be given information regarding the late effects of their diagnosis and treatments, and the importance of regular follow-up can be discussed with them (Maeda et al., 2010). A treatment summary can be given to patients in both a written and an electronic format. CCS could even download their treatment summaries to their cellular telephones so they are able to easily access them any time they are required.

Advocating for patients regarding access to health care, therapeutic interventions and the healthcare system forms part of the competencies for NPs in BC (CRNBC, 2013a). If a NP is caring for CCS in their practice, it is their responsibility to assist by advocating for these patients and to either create or retrieve both treatment summaries and survivorship plans for these patients. This could be completed at the time of acceptance of a survivor into the practice of the NP in a primary care setting. As demonstrated in the literature, providing care for CCS would be most effective in a shared care context (Singer et al., 2013). A shared care framework would facilitate retrieving treatment summaries since this model emphasizes collaboration and close contact between the NP and the patient's pediatric oncologist.

In addition to treatment summaries, a survivorship plan should also be provided to the survivor by their pediatric oncologist (Aslett et al., 2007; Singer et al., 2013). Again, the pediatric oncologist is the most appropriate provider to compose these plans, since they are most familiar with various cancer diagnoses and therapies (Nathan et al., 2013).

Although new evidence emerges regularly regarding the frequency and type of screening that CCS should be undergoing, a survivorship plan would provide both the patient and the NP with an expert-recommended guideline for continued cancer surveillance (Singer et al., 2013; Suh et al., 2014). That said, a NP who is the primary care giver for the LTFU of a survivor would be responsible for regularly updating the survivorship plan. This way, the patient is receiving the most up to date screening recommendations and the NP will be suggesting surveillance that is supported by the latest evidence. Suh et al. (2014) determined that providing this information to CCS relieved their anxiety regarding their history and subsequent surveillance, thereby addressing another barrier to the seeking of follow-up care.

The COG can also assist the NP in devising a survivorship plan if one was not provided by the patient's pediatric oncologist (The Foundation for Medical Practice Education, 2014). A list of COG clinics for LTFU can be found at the http://www.childrensoncologygroup.org/index/php/locations website; providers can consult with and refer to these centres for assistance in providing both treatment summaries as well as creating survivorship plans for CCS (The Foundation for Medical Practice Education, 2014).

In addition to giving the patient both treatment summaries and survivorship plans, coordinated transitional care would be facilitated if the pediatric oncologist sends these documents directly to the PCP who provides ongoing care for CCS (Suh et al., 2014). This would also initiate a direct line of communication between the two providers, thereby establishing more coordinated follow-up. If these documents are not provided, NPs should contact the patient's pediatric oncologist to request them (Suh et al., 2014).

Patients desire more information regarding potential long-term sequelae, and efforts should be made to ensure that accurate and timely information is given both verbally and in writing to the patient (Casillas et al., 2010; Maeda et al., 2010; Suh et al., 2014). Some of the information regarding late effects can be included in the individual survivorship plan, but it would be useful for the patients to have easier access to more detailed information should they desire or require it. This information could include what specific late effects they may experience given their individual histories, and how often screening would be recommended for these late effects. Providing CCS with easily accessible resources will assist them in taking ownership in their own health care, and in more effectively collaborating with their NP when making health care decisions.

Directing CCS to websites or telephone applications targeting their specialized needs should be incorporated into both discharge planning from a pediatric oncology facility, and upon seeking care in a primary care centre (Aslett et al., 2007; Singer et al., 2013; Suh et al., 2014). As there is limited follow-up care for CCS in BC (K. Goddard, personal communication, August 18, 2015), websites such as the BC Cancer Agency (BCCA) should have pertinent information for CCS and providers that can easily be accessed. This is also essential because, in BC, most PCPs who care for CCS are not fully familiar with the potential late effects they may experience (MacDonald et al., 2010). Currently, the BCCA has sections for both patients and providers; however, they do not offer detailed information regarding late effects that CCS may experience or the recommended screening practices (BCCA, 2015). It would be useful if this website contained the COG guidelines and/or screening recommendations for both providers and patients, as well a summary of potential late effects.

These websites and applications could also serve as teaching tools for PCPs to use during visits with the CCS in their practice (Aslett et al., 2007). In addition to their guidelines, the COG website (www.childrensoncologygroup.org) has many resources for patients who have a history of cancer. Various "health links" with specific information concerning late effects of each body system is available on this site for patient use. Bradwell (2009) emphasizes the importance of relaying age appropriate information to patients, and as CCS become adults, they may desire more detailed knowledge regarding their histories and the late effects of the treatments they received as children. The links located on the COG website contain detailed and accurate information that would be appropriate for older patients who desire more information regarding their care. For example, the health link addressing cardiovascular risk factors indicates what lifestyle factors and treatment factors (types of radiation and chemotherapy) can increase or decrease the risk of cardiovascular effects. The recommended screening to evaluate cardiovascular effects is also available on this website, although it is very general and not specific to previous cancer treatments. A free telephone application developed by the Akron Children's Hospital, called CancerLateFX, provides CCS with easily accessible resources, tools, tips and individualized goals and prevention strategies (Akron Children's Hospital, 2014). CancerLateFX can also provide reminders to the patient about appointments, store talking points to help patients remember what questions to ask their provider during the next visit, and it can even store all of their medical information if they need to relay this to a NP who does not regularly provide their care (Akron Children's Hospital, 2014). This application is available for both iPhone and Android cellular telephones; it can also be accessed online at http://www.cancerlateeffects.org/ if the patient does not have a cellular telephone.

## **Strategies Targeting Providers**

When addressing LTFU for CCS, it is also important to offer solutions directed towards providers. In this section, educational strategies, risk stratification, the length of the guidelines, documentation, research opportunities and changes to institutional policies will be discussed. These topics will be explored within the context of NP practice and the ways in which these providers can specifically improve LTFU for CCS will be discussed.

Similar to CCS, PCPs also require more information and support regarding LTFU for patients who have suffered a pediatric malignancy (Suh et al., 2014). Ongoing education for pediatricians and pediatric oncologists, as well as for family physicians, physician assistants and NPs, is essential for providing coordinated LTFU care for CCS (Friedman et al., 2006). Educational sessions for those providers who care for this patient population would offer up to date information pertaining to the necessary ongoing screening and potential late effects that CCS may experience (Suh et al., 2014).

As demonstrated by Prior et al. (2008), passive education strategies such as lectures and seminars are generally not highly effective when attempting to increase guideline adherence. Therefore, interactive workshops offered on a regular basis (Prior et al., 2008), such as every three months, could be helpful in order to improve the use of the COG guidelines. These workshops could be available to NPs and physicians caring for CCS, and they could involve working through case studies and navigating the COG guidelines to determine the appropriate screening recommendations for case study patients. This would increase the familiarity of NPs with the guidelines, and give them practice in utilizing them to determine the appropriate surveillance for their patients who are CCS. Complex and pertinent cases could be presented by NPs to offer tangible examples about effectively addressing such cases in the primary care setting. Time for these education sessions could be allocated within the NP's educational hours to facilitate regular learning and practice for this complex patient population. Increased awareness and skill pertaining to the ongoing surveillance of CCS will promote increased diligence on the part of NPs in recommending the appropriate screening practices for these patients.

Some researchers have suggested that PCPs stratify their CCS into three different levels of risk, and then base the type of follow-up on the category in which the patient is placed (AAP, 2009; Bradwell, 2009; Granek et al., 2012; Landier et al., 2006). Low risk patients (or level one) would include those who received only surgery or low risk chemotherapy, and follow-up by a PCP by telephone every one to two years would be appropriate (Bradwell, 2009). Level two or intermediate risk patients are CCS who received higher risk chemotherapy, and follow-up could consist of appropriate screening at a frequency as directed by a PCP (Bradwell, 2009). Finally, high risk or level three patients are those who underwent a BMT or radiation, and it is recommended they receive life-long follow-up by a PCP (Bradwell, 2009). Once CCS have been assigned a level of risk, the frequency and type of screening should be determined by the PCPs using the COG guidelines (COG, 2013). This stratification is similar to the new tier system in BC regarding LTFU of CCS (BC Cancer Agency, n.d.), and categorizing patients according to risk can be done in accordance with this initiative.

Risk stratification for CCS may not always be applicable. If a NP has only a few CCS in his/her practice, risk stratification may not be useful in that particular clinical setting. However, if a NP has greater than five CCS in his/her practice, I would recommend the aforementioned strategy pertaining to patient stratification. This solution would assist in providing the most efficient and appropriate care to CCS according to their individual histories. Therefore, in a clinic with greater than five CCS, this would result in more streamlined and time efficient LTFU while still providing the recommended frequency of screening.

As previously described, the lengthy nature of the COG guidelines has been cited by the COG (2013) itself as a barrier to its implementation into practice. The findings from Prior et al. (2008) also demonstrated that increasing guideline complexity results in decreased compliance. I have devised several algorithms (see Appendix III) that are organized by category of chemotherapy treatment and that summarize the recommendations of the COG. These algorithms can be used by NPs to formulate a survivorship plan for their patients who are CCS. With each of these algorithms, there are some risk factors that would increase the likelihood of late effects occurring; however, these have not been included in this paper since they do not change the frequency of screening (COG, 2013). Nurse practitioners caring for CCS can use their documentation system to improve the follow-up provided to these patients. For example, electronic reminders can be set for the care providers of CCS so that screening recommendations are both regularly updated and suggested in a timely manner as dictated by the guidelines. That is, when a NP opens the electronic chart of a survivor, the NP will be alerted to any screening that should be recommended at the next visit. Setting electronic reminders was demonstrated by Prior et al. (2008) as significantly increasing guideline compliance, and it can be relatively easily applied to improving the practice of NPs with respect to the COG guidelines. Depending on their associated level of risk and screening frequencies, these patients should be assessed every 1-2 years at minimum to specifically review their screening practices, and to answer any questions that the patients may have regarding their follow-up. This will allow for maximum time to discuss their LTFU plan and will result in improved overall care for these patients.

As illustrated by the lack of level I and level II evidence represented in the COG guidelines, there is a great need for more research exploring appropriate screening practices for CCS (COG, 2013; Howick et al., 2011). Stronger evidence supporting surveillance recommendations will facilitate their incorporation into the practice of NPs. Increased research on the uptake of guidelines will also be able to identify barriers according to CCS, as well as evaluate the effectiveness of the COG recommended practices (Bhatia & Meadows, 2006). As barriers are specifically identified, solutions can be tailored to address them, and effective screening can be recommended as determined by the evidence. Research specifically studying the uptake of the COG guidelines by NPs would be extremely useful in identifying strategies to improve LTFU for CCS within the context of NP practice. Similarly,

a study evaluating COG guideline implementation in primary care would offer solutions regarding how to improve the incorporation of the COG guidelines into NP practice.

Nurse practitioners in BC are required to undergo regular chart audits (CRNBC, 2015). Data obtained during these audits could contribute substantially to the research regarding use of the COG guidelines. Audit and feedback is an effective method to improve adherence to guidelines (Ivers et al., 2012; Prior et al., 2008). It is defined as a process whereby the professional practice of an individual is evaluated and compared to a predetermined practice standard (Ivers et al., 2012). The results of this comparison is then communicated back to the individual in order to improve their practice (Ivers et al., 2012). This strategy would encourage NPs to stay up to date in their practice by learning to use and follow the COG guidelines effectively.

The process of audit and feedback could also more specifically identify where, when and how the COG guidelines are not being recommended to CCS by their NPs. This information could be further used to devise strategies to improve the adherence of NPs to surveillance recommendations. For example, chart audit information could be utilized to determine if the COG guidelines are being used by NPs in the clinical setting, and if so, how, when, and which recommendations are being incorporated regularly into practice. Chart audits could also be studied to determine outcome measures, for example in determining the likelihood of CCS for developing breast cancer in patients who undergo the recommended screening versus those patients who do not. This type of study would be a long-term study, and would require much coordination and a large sample size. That said, it would offer valuable information regarding how and if the COG guidelines have a direct impact on the development of late effects in CCS. Studies evaluating the cost-effectiveness of the COG guidelines are also lacking. An economic analysis of the COG recommendations should also be undertaken to ensure that the guidelines reflect screening practices that are both evidence-based and financially sound (Skinner & Oeffinger, 2013; Wong et al., 2014). Once there is a larger body of data regarding the COG recommendations, an evidence-based, appropriate balance between overscreening and under-screening can be reached (Landier et al., 2006). Collecting data and collaborating with other members of the health care team to identify opportunities for research and to conduct studies are part of the competencies for NPs identified by the CRNBC (2013a). Nurse practitioners could seek out opportunities to study these topics by collaborating with other clinics and other professionals who care for CCS. Results of this research would give insight on how to structure LTFU and incorporate the COG guidelines into care and would ultimately result in improved patient outcomes.

Finally, NPs can initiate changes in policy for their practice setting. The CRNBC (2013a) identifies NPs as leaders who are involved in the implementation of standards and who influence policy. Nurse practitioners should advocate for clear, precise practice standards to use when caring for CCS, which would incorporate the COG guidelines into the care of these patients, as well as into the regularly scheduled visits to discuss appropriate screening practices. Requests can be written by NPs to the COG asking to broaden their criteria for access to their PFC tool (COG, 2013). This would allow NPs to access a valuable resource that would further assist them in devising and updating survivorship plans for CCS.

Within their clinical setting, NPs can create tools to assist them with LTFU care for CCS. A policy or template could be devised by NPs to include essential topics for discussion during these visits such as past cancer history and treatment received, screening done in the

last 1-2 years, future screening recommendations, and any late effects noticed by the patient. This will ensure that these specialized patients are being seen regularly and will decrease the likelihood of them being lost to follow-up.

#### **Strategies Targeting System Barriers**

With the variety of LTFU models, it can be difficult to determine which one is likely to be the most appropriate when caring for CCS. Taking all of the research findings into account, it seems that the shared care model may be the most viable for LTFU for CCS (Bhatia & Meadows, 2006; Singer et al., 2013). This framework is the most cost-effective, which is essential in health-care systems that are financially strained (Singer et al., 2013). This model would also be most appropriate in BC, as there are currently limited care provided in survivorship centres, and therefore the shared care framework would be much more feasible to adopt (K. Goddard, personal communication, August 18, 2015). Additionally, this model seems to blend the benefits of access to specialized knowledge demonstrated in the survivorship clinics with the convenience of being located in a primary care centre (Blaauwbroek et al., 2008; Singer et al., 2013). Stratifying CCS into the various tiers as BC's new program identifies (BC Cancer Agency, n.d.) can be done by NPs caring for these patients, and depending on which tier they belong to, their care may remain with that provider within a shared care model, or they may be referred for specialized follow-up.

The shared care model also seems to address many of the identified barriers for CCS in seeking LTFU care, which should increase the uptake of surveillance practices (Aslett et al., 2007; Blaauwbroek et al., 2008; Singer et al., 2013). Despite its disadvantages, a shared care model directed by a knowledgeable PCP and guided by providers with expertise in oncology including a pediatric oncologist and a radiology oncologist would be the most

appropriate when providing LTFU care to CCS (Blaauwbroek et al., 2008; K. Goddard, personal communication, August 18, 2015; Singer et al., 2013). As previously outlined, since collaboration and consultation is cited by the CRNBC (2013a) as part of the NP competencies, NPs are providers who are highly qualified to participate in a shared care model for LTFU of CCS. Nurse practitioners would serve as the main providers in overseeing the screening practices and any late effects reported by a survivor, and would collaborate and consult with oncology specialist as necessary. For example, in BC, a survivor could be seeking care from an NP in their primary care setting for questions regarding cardiovascular screening. The NP may be unsure of recommended frequency of this screening as it is dependent on many factors, such as age and cumulative dosage of anthracycline (COG, 2013). The NP could then consult with a pediatric oncologist to determine how frequently this patient should be receiving echocardiograms, and then would subsequently relay this information to the patient, either during their visit or by telephone afterwards.

As opposed to a fee-for-service funding model, a blended funding model that bases funding on patient complexity for example, is one option that could decrease the incentive to see more patients in a shorter time frame (Frayne, 2012). This model would allow for longer visits for complex patients, and therefore the practice would have an incentive to allow more time for patients such as CCS. Although the costs and mechanism of this type of funding model are more complex, ultimately the costs to the system would be reduced as it encourages well-coordinated referrals and decreases hospital visits (Frayne, 2012). Nurse practitioners working in this funding model would then be in an ideal position to offer LTFU for CCS.

#### **Summary of Recommendations**

In summary, in order to improve LTFU for CCS, an approach that targets many of the identified barriers is warranted. First, strategies addressing patient barriers such as ensuring that treatment summaries and surveillance plans are given is essential (Casillas et al., 2010; Maeda et al., 2010; Singer et al., 2013; Suh et al., 2014). If these are not given, it is the responsibility of the NP to retrieve them by either contacting the patient's pediatric oncologist or the COG or both (Suh et al., 2014; The Foundation for Medical Practice Examination, 2014). Patients can also advocate for themselves by requesting treatment summaries and survivorship plans prior to discharge by their pediatric oncologist. Websites such as the COG website and telephone applications such as CancerLateFX should be provided to patients during their visits with their NP so that they may access information and tools as necessary to assist them with their LTFU care.

Secondly, provider-related challenges should be addressed. This would include providing relevant information through workshops to NPs who are caring for CCS, ensuring that they stratify these patients according to level of risk (if there are five or greater CCS in their practice), and encouraging the conduction of research and policy making (Bradwell, 2009; Poplack et al., 2014; Singer et al., 2013; Suh et al., 2014). A process of audit and feedback will serve to facilitate optimal and coordinated follow-up for CCS (COG, 2013; Howick et al., 2011; Ivers et al., 2012; Prior et al., 2008; Singer et al., 2013).

Additionally, strategies aimed at facilitating guideline implementation should be incorporated into the clinical setting in order to improve the uptake of the COG

recommendations (Lesho et al., 2005; Prior et al., 2008). Finally, system barriers should be targeted by establishing a shared model of care framework, which is both financially sound as well as the model most desired by patients and providers (Aslett et al., 2007; Blaauwbroek et al., 2008; Singer et al., 2013). From my analysis of the literature, combined with my experience in pediatric oncology, I consider the above strategies to be essential to put into practice when caring for CCS in primary care. If the above solutions are implemented, I am confident that the COG guidelines can be better incorporated into NP practice, and LTFU for this population will be greatly improved.

### Conclusion

In conclusion, my experience as a RN, along with preliminary research regarding LTFU of CCS, led me to the research question: how can NPs best incorporate the COG guidelines into LTFU care for adults who are CCS in a primary care practice? After a comparison between the SIGN and COG guidelines for LTFU of CCS using the AGREE tool, it was determined that NPs should employ the COG guidelines in their practice. The literature was then searched within three databases (*The Cochrane Library, CINAHL* and *Medline*) to assist in finding articles to answer my research question. After a thorough search of these databases using various combinations of search terms, and then subsequently applying inclusion and exclusion criteria, I retrieved 14 relevant articles pertaining to my research question.

The research findings showed a clear lack of LTFU care for CCS (Essig et al., 2012; Friedman, et al. 2006). Additionally, although both the COG and the SIGN guidelines for LTFU have attempted to offer recommended screening practices for CCS, compliance by PCPs with respect to these recommendations remains low (COG, 2013; Nathan et al., 2013; Oeffinger et al., 2009; SIGN, 2013; Suh et al., 2014). The studies that addressed the implementation of guidelines suggested a multi-component strategy in the clinical setting (Bernhardsson et al., 2014; Prior, et al., 2008). Electronic reminders were also shown in the literature to be effective when attempting to implement guidelines into practice (Prior et al., 2008). After analysis of the various models of delivery for LTFU care, it was determined that the most appropriate framework in BC would be the shared care model (Singer et al., 2013).

Specific recommendations included those targeting patients, providers and the healthcare system as a whole. Treatment summaries and survivorship plans were identified in the literature as essential tools for providers when caring for CCS (Casillas et al., 2010;

Maeda et al., 2010; Singer et al., 2013; Suh et al., 2014). Therefore, these documents should be provided by NPs, in collaboration with a pediatric oncologist as needed, when providing LTFU for CCS. Nurse practitioners could also offer educational tools such as the COG website and the CancerLateFX telephone application to their patients as additional resources. Interactive workshops could be offered to NPs every three months; such as workshops could include case studies to re-inforce the most effective ways to incorporate the COG guidelines into their plan of care for the CCS in their practice. Nurse practitioners could also be encouraged to initiate research into under-studied topics pertaining to LTFU of CCS, such as implementation of the COG guidelines, cost-effectiveness of the COG guidelines, and adherence of the COG recommendations by NPs via chart audits.

Finally, as there is limited LTFU in BC, all of the aforementioned recommendations are best offered within a shared care model. This would allow CCS to continue to receive regular care from their NPs with the added expertise that would result from collaboration with oncology specialists. By following the above evidence-based recommendations, NPs would be able to better incorporate the COG guidelines into their practice. This will ultimately result in standardized LTFU for CCS, and improve the lack of follow-up currently evident in this patient population.

#### References

- AGREE. (2015). Advancing the science of practice guidelines: Welcome to the AGREE Enterprise website. Retrieved from http://www.agreetrust.org/
- Akron Children's Hospital. (2014). New mobile app helps childhood cancer survivors stay healthy. Retrieved from https://www.akronchildrens.org/cms/sharing\_blog /6d9169f93b5b63d2/
- American Academy of Pediatrics. (2009). Long-term follow-up care for pediatric cancer survivors. *Pediatrics*, 123(3), 906-916. doi:10.1542/peds.2008-3688
- American Association of Nurse Practitioners. (2015). NP fact sheet. Retrieved from http://www.aanp.org/all-about-nps/np-fact-sheet
- American Society of Clinical Oncology. (2013). *The importance of follow-up care*. Retrieved from http://www.cancer.net/survivorship/follow-care-after-cancertreatment /importance-follow-care
- Aslett, H., Levitt, G., Richardson, A., & Gibson, F. (2007). A review of long term follow up for survivors of childhood cancer. *European Journal of Cancer*, 43(12), 1781-1790. doi:10.1016/j.ejca.2007.04.009
- BC Cancer Agency. (2015). Survivorship & primary care. Retrieved from http://www .bccancer.bc.ca/survivorship-site/Pages/Survivorship---Primary-Care.aspx
- BC Cancer Agency. (2014). Funding announced to help adult survivors of childhood cancer. Retrieved from http://www.bccancer.bc.ca/NR/rdonlyres/A9FC8E71-A9F2-4BC5-B6EA-7873C7BE3717/73045/20141029\_NR\_PediatricSurvivorshipgrants\_FINALf .pdf

BC Cancer Agency. (2013). Nurse practitioner. Retrieved from http://www.bccancer.bc.ca /RES/ResearchPrograms/SBR/NursePractitioner.htm

- BC Cancer Agency. (n.d.). The new adult childhood cancer survivors program. Retrieved from http://www.bccancer.bc.ca/survivorship-site/Documents /ThenewACCSprogram.pdf
- BC Children's Hospital. (2013). Oncology, hematology & BMT. Retrieved from http://www .bcchildrens.ca/Services/Onc-HemBMT/default.htm
- Bernhardsson, S., Larsson, M. E. H., Eggertsen, R., Johansson, K., Nilsen, P., Nordeman,
   L., ... Oberg, B. (2014). Evaluation of a tailored, multi-component intervention for
   implementation of evidence-based clinical practice guidelines in primary care
   physical therapy: A non-randomized controlled trial. *BMC Health Services Research*,
   14(105). doi:10.1186/1472-6963-14-105
- Bhatia, S., & Meadows, A. T. (2006). Long-term follow-up of childhood cancer survivors: Future directions for clinical care and research. *Pediatric Blood Cancer*, 46(2), 143-148. doi:10.1002/pbc.20613
- Blaauwbroek, R., Tuinier, W., Jong, B. M., Kamps, W. A., & Postma, A. (2008). Shared care by paediatric oncologists and family doctors for long-term follow-up of adult childhood cancer survivors: A pilot study. *The Lancet Oncology*, 9(3), 232-238. doi:10.1016/S1470-2045(08)70034-2
- Bradwell, M. (2009). Survivors of childhood cancer. *Paediatric Nursing*, 21(4), 21-24. Retrieved from http://dx.doi.org/10.7748/paed2009.05.21.4.21.c7069

- Canadian Cancer Society. (2015). Late effects of childhood cancer. Retrieved from http://www.cancer.ca/en/cancer-information/cancer-type/childhood-cancerinformation/supportive-care/late-effects-of-childhood-cancer/?region=on
- Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., & Zeltzer, L. K.
   (2010). Transitioning childhood cancer survivors to adult-centered healthcare: Insights from parents, adolescent, and young adult survivors. *Psycho-Oncology*, 19(9), 982-990. doi:10.1002/pon.1650
- Children's Oncology Group. (2014). *Member institution: Institutional performance monitoring program.* Retrieved from http://www.childrensoncologygroup.org /downloads/MI\_PerformanceMonitoringProgram.pdf
- Children's Oncology Group. (2013). Long-term follow-up guidelines for survivors childhood, adolescent and young adult cancers. Retrieved from http://www .survivorshipguidelines.org/pdf/LTFUGuidelines\_40.pdf
- Children's Oncology Group. (n.d.). *Treatment options*. Retrieved from http://www .childrensoncologygroup.org/index.php/treatmentoptions
- College of Registered Nurses of British Columbia. (2015). Nurse practitioners. Retrieved from https://www.crnbc.ca/QA/NP/Pages/Default.aspx
- College of Registered Nurses of British Columbia. (2013a). *Applying the competencies required for nurse practitioners in British Columbia*. Retrieved from https://www .crnbc.ca/Registration/Lists/RegistrationResources/440PLAR.pdf
- College of Registered Nurses of British Columbia. (2013b). Scope of practice for nurse practitioners: Standards, limits and conditions. Retrieved from https://www.crnbc.ca /Standards/Lists/StandardResources/688ScopeforNPs.pdf

- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. A., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(50), 1-15. doi:10.1186/1748-5908-4-50
- Dicenso, A., Guyatt, G., & Ciliska, D. (2005). Evidence-based nursing: A guide to clinical practice. St. Louis, MO: Elsevier Mosby.
- Dixon-Woods, M., Young, B., & Heney, D. (2005). Rethinking experiences of childhood cancer: A multidisciplinary approach to chronic childhood illness. Retrieved from https://books.google.ca/books?isbn=0335212557
- Edgar, A. B., Borthwick, S., Duffin, K., Marciniak-Stepak, P., & Wallace, W. H. B. (2012). Survivors of childhood cancers lost to follow-up can be re-engaged into active longterm follow-up by a postal health questionnaire intervention. *European Journal of Cancer, 48*(7), 1066-1073. doi:10.1016/j.ejca.2011.06.009.
- Eiser, C., Absolom, K., Greenfield, D., Glaser, A., Horne, B., Waite, H., ... Davies, H.
  (2006). Follow-up after childhood cancer: Evaluation of a three level model. *European Journal of Cancer*, 42(18), 3186-3190. doi:10.1016/j.ejca.2006.08.001
- Essig, S., Skinner, R., von der Weid, N. X., Kuehni, C. E., & Michel, G. (2012). Follow-up programs for childhood cancer survivors in Europe: A questionnaire survey. *PLOS One*, 7(12), 0-8. doi:10.1371/journal.pone.0053201
- Frayne, A. (2012). Population based funding: A better primary care option? British Columbia Medical Journal, 54(5), 250-251. Retrieved from http://www.bcmj.org/premise /population-based-funding-better-primary-care-option

Friedman, D. L., Fryer, D. R., & Levitt, G. A. (2006). Models of care for survivors of childhood cancers. *Pediatric Blood Cancer*, 46(2), 159-168. doi:10.1002/pbc.20611.

- Geenen, M. M., Cardous-Ubbink, M. C., Kremer, L. C. M., van den Bos, C., van der Pal, H. J. H., Heinen, R. C., ... van Leeuwen, F. E. (2007). Medical assessment of adverse health outcomes in long-term survivors of childhood cancer. *Journal of the American Medical Association, 297*(24), 2705-2715. doi:10.1001/jama.297.24.2705
- Granek, L., Nathan, P. C., Rosenburg-Yunger, Z. R. S., D'Agostino, N., Amin, L., Barr., R.
  D., ... Klassen, A. F. (2012). Psychological factors impacting transition from pediatric to adult care by childhood cancer survivors. *Journal of Cancer Survivorship*, 6(3), 260-269. doi:10.1007/s11764-012-0223-0
- Grove, S. K., Burns, N., & Gray, J. R. (2013). The practice of nursing research: Appraisal, synthesis and generation of evidence. St. Louis, MO: Elsevier Saunders.
- Haddy, T. B., Mosher, R. B., & Reaman, G. H. (2009). Late effects in long term survivors after treatment for childhood acute leukemia. *Clinical Pediatrics*, 48(6), 601-608. doi:10.1177/0009922809332680
- Heirs, M., Suekarran, S., Slack, R., Light, K., Gibson, F., Glaser, A., ... Phillips, R.
  (2013). A systematic review of models of care for the follow-up of childhood cancer survivors. *Pediatric Blood Cancer*, 60(3), 351-356. doi:10.1002/pbc.24253
- Howick, J., Chalmers, I., Glasziou, P., Greenhalgh, T., Heneghan, C., Liberati, A., ...
   Thornton, H. (2011). *The 2011 Oxford CEBM evidence levels of evidence* (*introductory document*). Retrieved from http://www.cebm.net/wp-content/uploads
   /2014/06/CEBM-Levels-of-Evidence-Introduction-2.1.pdf

International Guideline Harmonizing Group. (2015). Long-term follow-up guidelines. Retrieved from http://www.ighg.org/guidelines/

- Ivers, M., Jamtvedt, G., Flottorp, S., Young, J. M., Odgaard-Jensen, J., French, S. D., ... Oxman, A. D. (2012). Audit and feedback: Effects on professional practice and health care outcomes. *The Cochrane Database of Systematic Reviews*, (6). Retrieved from http://apps.who.int/rhl/reviews/CD000259.pdf
- Landier, W., Bhatia, S., Eshelman, D. A., Forte, K. J., Sweeny, T., Hester, A. L., ... Hudson, M. M. (2004). Development of risk based guidelines for pediatric cancer survivors:
  The Children's Oncology Group long-term follow-up guidelines from the Children's Oncology Group late effects committee and nursing discipline. *Journal of Clinical Oncology, 22*(24), 4979-4990. doi:10.1200/JCO.2004.11.032
- Landier, W., Wallace, W. H. B., & Hudson, M. M. (2006). Long-term follow-up of pediatric cancer survivors: Education, surveillance and screening. *Pediatric Blood Cancer*, 46(2), 149-158. doi:10.1002/pbc.20612
- Lesho, E. P., Myers, C. P., Ott., M., Winslow, C., & Brown, J. E. (2005). Do clinical practice guidelines improve processes or outcomes in primary care? *Military Medicine*, 170(3), 243-246. Retrieved from http://proxy.library.unbc.ca:5265/ehost/pdfviewer /pdfviewer?sid=c2c17b7c-3814-4451-9676-6b7d8afd65c8%40sessionmgr4004&vid =1&hid=4204
- MacDonald, L., Fryer, C., McBride, M.L., Rogers, P.C., & Pritchard, S. (2010). The need for long-term follow-up of childhood cancer survivors in British Columbia. *British Columbia Medical Journal, 52*(10), 504-509. Retrieved from http://www.bcmj.org /articles/need-long-term-follow-childhood-cancer-survivors-british-columbia

- Maeda, N., Horibe, K., Kato, K., Kojima, S., & Tsurusawa, M. (2010). Survey of childhood cancer survivors who stopped follow-up physician visits. *Pediatrics International*, 52(5), 806-812. doi:10.1111/j.1442-200X.2010.03158.x
- McClellan, W., Klemp, J., Krebill, H., Ryan, R., Nelson, E. L., Panicker, J., ... Stegenga, K. (2013). Understanding the functional late effects and informational needs of adult survivors of childhood cancer. *Oncology Nursing Forum*, 40(3), 254-262. doi: 10.1188/13.ONF
- Meadows, A. T. (2001). *Pediatric cancer survivors: Past history and future challenges*. Retrieved from http://www.iom.edu/~/media/Files/Activity%20Files/Disease/NCPF /BackgroundPaperPediatricCancerSurvivorsPastHistoryandFutureChallanges.pdf
- Michel, G., Greenfield, D. M., Absolom, K., Ross, R. J., Davies, H., & Eiser, C. (2009).
  Follow -up care after childhood cancer: Survivors' expectations and preferences for care. *European Journal of Cancer*, 45(9), 1616-1623. doi:10.1016/j.ejca.2009.02.026
- Morris, Z. S., & Clarkson, P. J. (2009). Does social marketing provide a framework for changing healthcare practice? *Health Policy*, 91(2), 135-141. doi:10.1016/j.healthpol .2008.11.09
- Nathan, P. C., Daugherty, C. K., Wroblewski, K. E., Kigin, M. L., Stewart, T. V., Hlubocky,
  F. J., ... Henderson, T. O. (2013). Family physician preferences and knowledge gaps
  regarding the care of adolescent and young adult survivors of childhood cancer.
  Journal of Cancer Survivorship, 7(3), 275-282. doi:10.1007/s11764-013-0271-0
- National Bureau of Economic Research. (2015). Comparing the U.S. and Canadian health care systems. Retrieved from http://www.nber.org/bah/fall07/w13429.html

National Cancer Institute. (2015). General information about late effects of treatment for childhood cancer. Retrieved from http://www.cancer.gov/cancertopics/pdq/treatment /lateeffects/HealthProfessional/page1

- Newcomer, L. N., Gould, B., Page, R. D., Donelan, S. A., & Perkins, M. (2014). Changing physician incentives for affordable, quality cancer care: Results of an episode payment model. *Journal of Oncology Practice*, 10(5), 322-326. doi:10.1200/JOP .2014.001488
- Nulty, D. D. (2008). The adequacy of response rates to online and paper surveys: What can be done? *Assessment & Evaluation in Higher Education*, 33(3), 301-314. Retrieved from https://www.uaf.edu/files/uafgov/fsadmin-nulty5-19-10.pdf
- Oeffinger, K. C., Mertens, A. C., Sklar, C. A., Kawashima, T., Hudson, M. M., Meadows, A. T., ... Robinson, L. L. (2006). Chronic health conditions in adult survivors of childhood cancer. *The New England Journal of Medicine*, 355(15), 1572-1582.
   doi:10.1056/NEJMsa060185
- Oeffinger, K. C., Ford, J. S., Moskowitz, C. S., Diller, L. R., Hudson, M. M., Chou, J. F., ... Robison, L. L. (2009). Breast cancer surveillance practices among women previously treated with chest radiation for childhood cancer. *Journal of American Medical Association, 301*(4), 404-414. doi:10.1001/jama.2008.1039
- Parkes, S. E., Jenkinson, H. C., Griffiths, A., Kinch, D., & Mann, J. R. (2008). Is postal follow-up of childhood cancer survivors worthwhile? *Pediatric Blood Cancer*, 50(1), 80-84. doi:10.1002/pbc.21196
- Ped-Onc Resource Center. Survivors: Follow-up clinics. Retrieved from http://www.ped-onc .org/treatment/surclinics.html

Poplack, D. G., Fordis, M., Landier, W., Bhatia, S., Hudson, M. M., & Horowitz, M. E. (2014). Childhood cancer survivor care: Development of the passport for care. *Nature Reviews Clinical Oncology*, 11(12), 740-750. doi:10.1038/nrclinonc.2014.175

- Prior, M., Guerin, M., & Grimmer-Somers, K. (2008). The effectiveness of clinical guideline implementation strategies: A synthesis of systematic review findings. *Journal of Evaluation in Clinical Practice*, 14(5), 888-897. doi:10.1111/j.13652753.2008
   .01014.x
- Rycroft-Malone, J., Harvey, G., Seers, K., Kitson, A., McCormack, B., & Titchen, A. (2004). An exploration of the factors that influence the implementation of evidence into practice. *Journal of Clinical Nursing*, *13*(8), 913-924. doi:10.1111/j.1365-2702 .2004.01007.x
- Scottish Intercollegiate Guidelines Network. (2013). Long term follow up of survivors of childhood cancer: A national clinical guideline. Retrieved from http://www.sign.ac .uk/pdf/sign132.pdf
- Shad, A. (2015). Late effects of childhood cancer and treatment. Retrieved from http:// /emedicine.medscape.com/article/990815-overview
- Shea, B. J., Hamel, C., Wells, G. A., Bouter, L. M., Kristjansson, E., Grimshaw, J., ... Boers, M. (2009). AMSTAR is a reliable and valid measurement tool to assess the methodological quality of systematic reviews. *Journal of Clinical Epidemiology*, 62(10), 1013-1020. doi:10.1016/j.jclinepi.2008.10.009
- Singer, S., Gianinazzi, M. E., Hohn, A., Keuhni, C. E., & Michel, G. (2013). Review: General practitioner involvement in follow-up of childhood cancer survivors: A

systematic review. Pediatric Blood Cancer, 60(10), 1565-1573. doi:10.1002/pbc .24586.

- Skinner, R., & Oeffinger, K. C. (2013). Developing international consensus for late effects screening and guidance. *Current Opinion in Supportive and Palliative Care*, 7(3), 303-308. Retrieved from http://journals.lww.com/co-supportiveandpalliativecare /Fulltext/2013/09000/Developing\_international\_consensus\_for\_late.12.aspx#
- Stetler, C. B., Damschroder, L. J., Helfrich, C. D., & Hagedorn, H. J. (2011). A guide for applying a revised version of the PARIHS framework for implementation. *Implementation Science*, 6(99), 1-10. doi:10.1186/1748-5908-6-99
- Sturke, R., Harmston, C., Simonds, R. J., Mofenson, L. M., Siberry, G. K., Watts, H.D., ... Nagel, J. D. (2014). A multi-disciplinary approach to implementation science: The NIH-PEPFAR PMTCT Implementation Science Alliance. *Journal of Acquired Immune Deficiency Syndromes*, 67(2), S163-S167. doi:10.1097/QAI .00000000000323
- Suh, E., Daugherty, C. K., Wroblewski, K., Lee, H., Kigin, M. L., Rasinski, K.A., ... Henderson, T. O. (2014). General Internists' preferences and knowledge about the care of adult survivors of childhood cancer. *Annals of Internal Medicine*, 160(1), 11-17. doi:10.7326/M13-1941
- The Agree Collaboration. (2001). Appraisal of guidelines for research & evaluation instrument. Retrieved from http://apps.who.int/rhl/agreeinstrumentfinal.pdf
- The Foundation for Medical Practice Education. (2014). Childhood cancer: Long-term follow-up. *Practice Based Learning Programs, 22*(5), 1-19.

Wong, F. L., Bhatia, S., Landier, W., Francisco, L., Leisenring, W., Hudson, M. M., ... Armenien, S. H. (2014). Cost effectiveness of the Children's Oncology Group screening guidelines for childhood cancer survivors at risk for treatment-related heart failure. *Annals of Internal Medicine*, 160(10), 672-683. Retrieved from http://annals .org/article.aspx?articleid=1872846

# Appendix I

# Agree II Tool for Guideline Evaluation-COG guidelines

Each domain score is calculated by using the following:

# (obtained score-minimum possible score)

# (maximum possible score – minimum possible score)

Торіс	Score (Strongly Agree 4 3 2 1 Strongly
Course and Doorses	Disagiee)
Scope and Purpose	
1.The overall objective(s) of the guideline is(are) specifically described.	4
"Implementation of these guidelines are intended to increase quality of life and decrease complication-related healthcare costs for pediatric cancer survivors by providing standardized and enhanced follow-up care throughout the lifespan that a) promotes healthy lifestyles b) provides for ongoing monitoring of health status c) facilitates early identification of late effects and d) provides timely interventions for late effects" (COG, 2013, p. xxiii).	
2. The clinical question (s) covered by the guideline is(are) specifically described.	4
The COG guidelines answer the question as to how often and which type of screening and assessments are recommended for survivors of childhood cancers.	
3. The patients to whom the guideline is meant to apply to are specifically described.	4

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Scope and Purpose	
"The COG LTFU guidelines are appropriate for asymptomatic survivors of childhood, adolescent or young adult cancers who present for routine, exposure-related medical follow- up"(COG, 2013, p. xxiii). "These guidelines are intended for use beginning two or more years following the completion of cancer therapy, and provide a framework for ongoing late effects monitoring in childhood cancer survivors; however these guidelines are not intended to provide guidance for follow-up of the pediatric cancer survivor's primary disease" (COG, 2013, p. xxiii).	Domain score = 100%
Topic	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Topic Stakeholder Involvement	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Topic         Stakeholder Involvement         4. The guideline development group includes individuals from all the relevant professional groups.	Score (Strongly Agree 4 3 2 1 Strongly Disagree) 4

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Stakeholder Involvement	2 104 gr 00)
5. The patient's views and preferences have been sought.	3
Patient advocates were part of the review process. Patient Advocacy Committee provided feedback. Providers are encouraged to consider patient preferences when implementing the guidelines (COG, 2013).	
6. The target users of the guidelines are clearly defined.	4
The guidelines are intended to be used by clinicians such as physicians, NPs, physician assistants and nurses in the fields of pediatrics, oncology, internal medicine, gynecology and family practice as well as in subspecialties (COG, 2013).	
7. The guideline has been piloted among target users.	4
The initial version of the COG guidelines was released in 2003 for a six month trial period. After this it was revised based on feedback. It continues to be revised and updated regularly (COG, 2013).	Domain score = 92%
Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
<b>Rigour of Development</b>	
8. Systematic methods were used to search for evidence.	4
The evidence upon which the COG guidelines are based has been drawn upon the past 20 years of medical literature, which was compiled by	

Topic	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
performing a complete search using the <i>Medline</i> database. A seven member task force appointed by the COG reviewed the research, and based on this and a previous guideline written by the National Comprehensive Cancer Network, a draft practice guideline was developed (COG, 2013).	
<b>Rigour of Development</b>	
9. The criteria for selecting the evidence is clearly described.	
Keywords included "childhood cancer therapy", "complications" and "late effects," and these were combined with each therapeutic exposure. Inclusion and exclusion criteria are not explicitly stated (COG, 2013).	2
10. The methods used for formulating the recommendations are clearly described.	4
The draft formed as described above was then subjected to recommendations by experts in various fields including nursing, oncology, behavioural science and patient advocacy, and the draft was subsequently modified. The second version of the guidelines was then reviewed by 62 multi-disciplinary experts followed by a final review and scoring by a panel of experts (COG, 2013).	
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.	4
Both potential benefits and harms of implementing the COG guidelines are described. Benefits include earlier identification and intervention of late	

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
effects resulting in improved health. Risks include potential anxiety for patients with increased awareness of late effects, as well as with false- positive results. Cost is identified as a possible deterrent to patients in seeking LTFU (COG, 2013).	Disagice)
<b>Rigour of Development</b>	
12. There is an explicit link between the recommendations and the evidence.	4
Categories of consensus determined by the opinion of a panel of experts regarding whether there is adequate evidence for the recommendation. This is based on the existing evidence, and grading ranges from 1-2B (COG, 2013).	
13. The guideline has been externally reviewed by experts prior to its publication.	2
Guidelines were reviewed by Committees associated with or appointed by the COG (COG, 2013).	
14. A procedure for updating the guideline is provided.	4
The Task Forces continue to monitor and update the guidelines and they report to the COG LTFU Core Committee during each guideline update cycle. As new information becomes available, updates are planned, as well as at least every five years (COG, 2013).	Domain score = 81%
Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
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Clarity and Presentation	
15. The recommendations are specific and unambiguous.	4
Guideline consists of 200 pages of tables with categories such as therapeutic agent or treatment received, potential late effects, risk factors, periodic evaluations and health counseling (COG, 2013).	
16. The different options for management of the conditions are clearly presented.	4
For each therapeutic agent, specific history, assessments, screening and counseling are described, as well as any considerations for further testing (COG, 2013).	
17. Key recommendations are easily identifiable.	4
Assessment and screening suggestions are clearly labelled with headings, along with associated references (COG, 2013).	
18. The guideline is supported with tools for application.	4
Complementary patient education tools known as "Health-Links" are available. Materials that accompany the guidelines include templates for summary forms, detailed instructions for use, a radiation reference guide, and a tool to determine guideline applicability to individual	
patients. The guidelines also reference using the web tool "Passport for Care" which is available to users who are COG members (COG, 2013).	Domain score = 100%

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Applicability	
19. The potential organizational barriers in applying the recommendations have been discussed.	4
The authors acknowledge the lack of current evidence establishing efficacy of screening, which may deter providers from using the guideline. Additionally, the lengthy nature of the document is also discussed as a possible barrier to clinical use (COG, 2013).	
20. The potential cost implications of applying the recommendations has been considered.	4
The authors also acknowledge that a lack of insurance on the part of patients may prove to be a barrier to their attendance of LTFU care. Other costs include time constraints on the part of providers in order to utilize the guideline (COG, 2013).	
21. The guideline presents key review criteria for monitoring/audit purposes.	3
The multi-disciplinary task forces continue to monitor the literature and informs the LTFU core committee of any updates during each review cycle (every 5 years) (COG, 2013).	
	Domain score = 89%
Topic	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Editorial Independence	
22. The guideline is editorially independent from the funding body.	4
The COG guidelines were funded by the National Cancer Institute (COG, 2013).	

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
23. Conflicts of interest of guideline development has been recorded.	4
Conflicts of interest are declared (COG, 2013).	Domain score = 100%

Adapted from "Appraisal of guidelines for research & evaluation instrument," by The

AGREE Collaboration (2001). Retrieved from http://apps.who.int/rhl/agreeinstrumentfinal

.pdf

## Appendix II

# Agree II Tool for Guideline Evaluation-SIGN guidelines

Topic	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Scope and Purpose	
1.The overall objective(s) of the guideline is(are) specifically described.	4
"This guideline provides recommendations based on current evidence for best practice in identification, assessment and management of late effects in survivors of childhood cancer" (SIGN, 2013, p. 2).	
2. The clinical question (s) covered by the guideline is(are) specifically described.	4
The SIGN guidelines answer the question as to how often and which type of screening and assessments are recommended for survivors of childhood cancers.	
3. The patients to whom the guideline is meant to apply to are specifically described.	2
"[This guideline] is applicable to everyone who has been treated for cancer as a child or teenager, who may be at risk for developing late effects that are largely, but not exclusively, related to the treatment they received for their cancer. Survivors of childhood cancer are defined by age at cancer diagnosis and treatment. Across studies this varies from age less than 15 to age less than 24 years. Survival is commonly defined in studies as from two or five or more years post treatment" (SIGN, 2013, p. 2)no specific age is stated.	Domain score = 78%

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Stakeholder Involvement	
4. The guideline development group includes individuals from all the relevant professional groups.	4
The SIGN Development group for the LTFU guidelines was made up of cardiologists, pediatric hematologists, pediatric oncologists, a pediatric endocrinologist, a general practitioner, a pediatrician and a cancer survivor. (SIGN, 2013).	
5. The patient's views and preferences have been sought.	3
Literature was searched regarding patient issues, and one survivor was part of the SIGN development group for the LTFU guidelines (SIGN, 2013).	
6. The target users of the guidelines are clearly defined.	4
"This guideline is aimed at primary care staff who provide health care for cancer survivors, as well as secondary care and long-term follow-up (late effects) clinic staff who assess patients and manage the long-term care of this group. This guideline will be of relevance to general practitioners and other primary care practitioners, specialist nurses, oncologists, haematologists, endocrinologists, reproductive medicine specialists, cardiologists and radiation oncologists. It will also be relevant to counsellors, psychologists, dietitians, physiotherapists and dentists as well as to patients and their families" (SIGN, 2013, p. 2).	

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Stakeholder Involvement	
7. The guideline has been piloted among target users.	1
There is no mention of piloting the guidelines among intended users. The guideline draft was reviewed by experts, however there is no mention of a trial (SIGN, 2013).	Domain score = 67%
<b>Rigour of Development</b>	
8. Systematic methods were used to search for evidence.	4
"The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Evidence and Information Scientist. Databases searched include Medline, Embase, Cinahl, PsycINFO and the Cochrane Library. The year range covered was 2002-2011. Internet searches were carried out on various websites including the US National Guidelines Clearinghouse. The main searches were supplemented by material identified by individual members of the development group" (SIGN, 2013, p. 44).	
9. The criteria for selecting the evidence is clearly described.	1
Databases searched were provided, however no keywords, or inclusion or exclusion criteria were given (SIGN, 2013). 10. The methods used for formulating the recommendations are clearly described.	3

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Rigour of Development	
Recommendations within the SIGN guideline are based on the best clinical evidence. Guideline development and literature review expertise, support and facilitation were provided by the SIGN Executive. The guideline was also reviewed in draft form by independent expert referees, who were asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline (SIGN, 2013).	
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.	4
"This guideline provides recommendations based on current evidence for best practice in identification, assessment and management of late effects in survivors of childhood cancer. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan (SIGN, 2013, p. 2).	
12. There is an explicit link between the recommendations and the evidence.	4
Recommendations are graded using the Grading of Recommendations,	

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Assessment and Evaluation scale (A-D) (SIGN, 2013).	
<b>Rigour of Development</b>	
13. The guideline has been externally reviewed by experts prior to its publication.	4
Guidelines were reviewed by Independent expert referees (SIGN, 2013).	
14. A procedure for updating the guideline is provided.	4
This guideline was published in 2013 and will be considered for review in three years. Any updates to the guideline in the interim period will be noted on the SIGN website www.sign.ac.uk (SIGN, 2013).	Domain score = 81%
Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Clarity and Presentation	
15. The recommendations are specific and unambiguous.	3
Recommendations are given after a description of normal function followed by common chemotherapy/radiation effects. Recommendations are organized by body system, however recommendations pertaining to specific chemotherapy drugs are only provided for methotrexate and for the cardiac effects of anthracyclines. (SIGN, 2013).	
16 The different options for	
management of the conditions are clearly presented.	4

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
For each body system, specific history, assessments, screening and possible treatments are described (SIGN, 2013).	
Clarity and Presentation	
17. Key recommendations are easily identifiable.	4
Assessment and screening suggestions are bolded and accompanied by level of evidence (SIGN, 2013).	
18. The guideline is supported with tools for application.	1
No tools for application of the guidelines are either referenced or provided (SIGN 2013)	Domain score = $67\%$
Topic	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Applicability	
19. The potential organizational barriers in applying the recommendations have been discussed.	4
"Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan" (SIGN, 2013, p. 2).	
The authors also acknowledge the lack of current evidence establishing efficacy of screening (SIGN, 2013).	

Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Applicability	9.7
20. The potential cost implications of applying the recommendations has been considered.	1
Cost implications for guideline implementation are not addressed (SIGN, 2013).	
21. The guideline presents key review criteria for monitoring/audit purposes.	4
The guidelines describe some key points to consider in the future auditing the guidelines (SIGN, 2013).	Domain score = 63%
Торіс	Score (Strongly Agree 4 3 2 1 Strongly Disagree)
Editorial Independence	
22. The guideline is editorially independent from the funding body.	2
There is no mention of who the funding body for the SIGN guidelines is (SIGN, 2013).	
23. Conflicts of interest of guideline development has been recorded.	4
Conflicts of interest are declared by the SIGN executive committee yearly (SIGN, 2013).	Domain score = 50%

Adapted from "Appraisal of guidelines for research & evaluation instrument," by The

AGREE Collaboration (2001). Retrieved from http://apps.who.int/rhl/agreeinstrumentfinal

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### Appendix III

#### Alkylating or heavy metals

Proceed to other appropriate algorithm

#### Childhood history of cancer

Yearly assessment of: educational progress, social withdrawal, anxiety, depression, PTSD, risky behaviors, psychosocial pain issues, sleep disturbance, health care and insurance access. Treatment with alkylating or heavy metal chemotherapy: Busulfan, carmustine, chlorambucil, cyclophosphamide, ifosfamide, lomustine, mechlorethamine, melphalan, procarbazine, thiotepa, carboplatin, cisplatin, dacarbazine, or temozolomide

Yearly assessment of pubertal onset, sexual functions and tanner stages and semen analysis as needed (spermatogenesis may take up to 10 years to return)

Baseline testosterone at age 14 (males) and estradiol at age 13 (females) and as clinically indicated for delayed puberty

Assess yearly for 10 years post treatment for bruising, bleeding and fatigue, and examine skin for pallor and neterhiae as these may indicate a serondary malienancy.

Received busulfan, carmustine or lomustine Receiv

Received carboplatin or cisplatin Received ifosfamide or cyclophosphamide

Assess yearly for hearing loss, vertigo or tinnitus. Yearly neuro and otoscopic exam. Yearly BP and urinalysis. Audiology at baseline and at entry to LTFU. If hearing loss, assess yearly or as recommended by audiologist. If audiology exam inconclusive, refer to audiology and if deficit consider referral to speech and language therapy.

BUN, Cr., Na, K. Cl. CO2, Ca Mg, PD4 upon entry into LTFU and prn. Supplement with electrolytes if persistent wasting and refer to nephron if HTN, proteinuria or renal insufficiency. Assess yearly until 2-3 years post therapy, yearly if s/s persist for paresthesia, numbress tingling and dysesthesia. If s/s refer to physical therapy and consider treatment for peripheral neuropathy. [Fe gaba or amitriptyline]

Yearly blood pressure and urinalysis

BLIN, Cr. Na, K. El, CO2, Ca Mg, PO4 upon entry into LTFU and prn. Supplement with electrolytes (f persistent wasting and refer to nephrology (f HTN, proteinuria or renal insufficiency. Assess yearly for hematuria, urgency, frequency incontinence, nocturia, dysuria, or abnormal stream. If these are positive consider bladder o kidney US. Refer to nephron if negative culture hematuria abnormal US and/or abnormal Ca/Ci



UN, Cr. Na, K. Cl. CO2, Ca Mg, PO4 upon entry into LTFU and prn. Refer t nephralogy if HTN, proteinuria or renal insufficiency.







Adapted from "Long-term follow-up guidelines for survivors childhood, adolescent and young adult cancers" by the COG (2013). Retrieved from http://www.survivorshipguidelines .org/pdf/LTFUGuidelines\_40.pdf