



THE SCHOOL OF PUBLIC POLICY

MASTER OF PUBLIC POLICY CAPSTONE PROJECT

Systematic Review of Models of Follow-up Care for Childhood Cancer Survivors: The Role of Policies and Guidelines in Guiding Future Care

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Rachelle Drummond

Table of Contents

ACKNOWLEDGEMENTS	3
ABSTRACT	5
INTRODUCTION	5
METHODS	7
SEARCH STRATEGY.....	7
INCLUSION/EXCLUSION CRITERIA	7
STUDY SELECTION.....	7
DATA EXTRACTION.....	8
QUALITY ASSESSMENT.....	8
ETHICS	8
RESULTS	8
<i>Figure 1.0 PRISMA Flow Chart</i>	9
DESCRIPTIVE CHARACTERISTICS OF EXCLUDED STUDIES	9
DESCRIPTIVE CHARACTERISTICS OF INCLUDED STUDIES.....	9
<i>Table 1.0 Table of Included Studies</i>	10
STUDY FINDINGS	10
CURRENT POLICIES AND GUIDELINES.....	12
<i>Table 2.0 Current follow-up care policies, guidelines, and resources by province</i>	13
DISCUSSION	18
LIMITATIONS OF RESEARCH	23
AREAS FOR FURTHER RESEARCH	23
POLICY RECOMMENDATIONS	23
RECOMMENDATION 1:	24
RECOMMENDATION 2:	24
RECOMMENDATION 3:	25
CONCLUSION	26
APPENDIX A.	27
SYSTEMATIC REVIEW KEY WORDS.....	27
SYSTEMATIC REVIEW SEARCH STRINGS.....	28
APPENDIX B.	28
GREY LITERATURE SEARCH TERMS.....	28
EXAMPLE GREY LITERATURE SEARCH STRING.....	28
REFERENCES	30

ABSTRACT

Background/Objectives: Within Alberta, there exist multiple models of follow-up care for survivors of childhood cancer which has the potential to lead to disparate outcomes. There is a need to review the outcomes of these models so that survivors in Alberta can receive consistent and reliable care. This review aimed to achieve the following objectives: (1) review the existing research that compared outcomes across different models of follow-up care, (2) review the policies and guidelines for follow-up care in Canada, (3) create policy recommendations to guide the long-term care of survivors of childhood cancer. **Methods:** This systematic review utilized the Cochrane Handbook's Population, Intervention, Comparison(s), Outcome (PICO) systematic review tool and the Cochrane risk-of-bias tool to identify and evaluate eligible studies. The following databases were searched: MEDLINE (Ovid), EMBASE, PsycINFO, Cochrane Library, PubMed, CINAHL, and Web of Science. A Canada-wide scan for follow-up care guidelines and policies was conducted as a separate search that looked through grey literature from provincial healthcare websites. **Results:** 2051 articles were identified from the search. One article met our inclusion and exclusion criteria. The limited findings of this review indicated that a cancer-center follow-up care model ensured that a high percentage of survivors of childhood cancer were appropriately screened for diagnosis-specific late effects, that patients experienced fewer long-term effects, and received more Children's Oncology Group (COG)-recommended tests than those who utilized a community-based follow-up care model. The Canada-wide scan for care guidelines and policies revealed substantial gaps and inconsistencies across the country, with limited follow-up care policies and guidelines available. **Conclusions:** The results of this review demonstrate that there is a significant need for 1) further research that compares models of follow-up care to guide the province of Alberta in establishing follow-up care guidelines and policies specific to survivors of childhood cancer, and 2) the creation of a national standard for follow-up care for survivors of childhood cancer.

INTRODUCTION

Advances in modern medicine over the last century have resulted in significant increases in the number of survivors of childhood cancer within Alberta (AB), and within Canada. It is estimated that in North America alone, there are more than 500,000 survivors of pediatric cancer, with research showing that 80% of all children diagnosed with cancer will live into adulthood (Reynolds., 2019). Yet, children who survive childhood cancer and enter survivorship are not free from their diagnosis, but rather, are at risk for long-term late effects for the rest of their lives. According to the National Cancer Institute (NCI), late effects are defined as "a health problem that occurs months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems and second cancers" (n.d). The presence, severity, and type of late effects vary based on the survivor, their diagnosis, and the duration and type of treatment that they received (Stein et al., 2008). Late effects range from physical effects, effects on behavior and social skills, fertility, and growth rates, as well as the development of secondary cancers (Heirs et al., 2013). Effective models of care that are guided by consistent policies and guidelines can work to minimize long-term effects through prevention and early detection. Yet, models of care for the long-term follow-up of survivors of childhood cancer are not consistent across the country. With such substantive increases in the population of survivors of childhood cancer in Canada, it is imperative now more than ever that inconsistencies in follow-up care are addressed,

and the best models of care are identified through a systematic review to ensure that advances in follow-up care follow advances in survivorship.

In Canada, the federal government's role in healthcare includes "setting and administering national principles for the system under the *Canada Health Act*," health protection and regulation, and providing financial support through cash and tax transfers to the provinces and territories (Canada, 2019). The provinces and territories on the other hand, are responsible for the administration and delivery of most of Canada's health care services (Canada, 2019). Such divisions in the system and the federal government's "hands-off" approach in healthcare delivery has resulted in substantive inconsistencies in the follow-up care models that are available for survivors of childhood cancer and the policies that guide such care. Furthermore, this substantial variability itself creates an additional barrier in establishing consistent and reliable care in Canada. Uniform health policies across Canada that ensure consistent models of care, training, and knowledge of follow-up care for healthcare workers, and accessibility to care can aim to address various gaps in follow-up care. Through such, Canadian survivors can not only have access to higher quality of care, but also improved quality of life (QOL) in their survivorship.

While some follow-up care guidelines and policies exist in Canada, these documents and practices vary by province. Ultimately, there continues to be a lack of consensus and consistency regarding the optimal model of follow-up care and the resources required to adequately treat survivors (Heirs et al., 2013). While it is likely that all cancer diagnoses and age ranges could benefit from the creation of standardized and age-based follow-up care guidelines, the pediatric cancer community could see substantial benefits. Due to toxic treatments administered during an exceptionally vulnerable time of development, children, adolescents, and young adults, are at a significant risk for late effects and psychosocial and behavioural disruptions (Zebrack 2011). While an estimated 80% of children treated for cancer will survive 5 or years from diagnosis, it is estimated that more than 80% of these survivors will experience a serious/disabling or life-threatening chronic condition by the age of 45 (Robsin & Hudson., 2013). Because of such, this population could further benefit from specialized follow-up care programs to minimize these risks. The current national cost of survivorship care in Canada is estimated at \$12.5 billion (Garaszczuk et al., 2022). As the population of survivors continues to grow on a national scale, the costs of survivorship care will continue to rise and could pose a significant financial risk to the healthcare system and become unsustainable. Follow-up models of care that are supported by evidence, meet the needs of survivors, and prevent long-term risks could minimize these risks.

Common models of follow-up care in Canada include: (1) the cancer center model (specialized care); (2) the community model (primary-care provider (PCP); and (3) the combination model (a mixed approach utilizing both PCPs and cancer-center care) (Reynolds et., al 2019). Despite the longstanding use of these existing models, there continues to be a lack of research comparing outcomes between existing models. Additionally, little data exists regarding innovations in follow-up care including virtual health visits. A systematic review conducted in 2013 by Heirs et al., examined published and unpublished research to find comparisons amongst the different models of follow-up care for childhood cancer survivors. Unfortunately, their research identified no comparative studies in accordance with their inclusion criteria, yet these authors concluded that there was a need for more research to examine difference in outcomes between models.

The purpose of this review, therefore, was to examine the literature that compares follow-up care models for survivors of childhood cancer and existing policies and guidelines that guide follow-up care in Canada. This review set out to reach the following objectives: (1) Review the existing research that compared outcomes across different models of follow-up care, (2) review the policies and guidelines for follow-up care in Canada, (3) create policy recommendations to guide the long-term care of survivors of childhood cancer. With ongoing changes and innovation seen in healthcare delivery throughout the COVID-19 pandemic, the Canadian healthcare system has been provided with a unique window for potential policy change to better serve the needs of current and future generations of survivors.

METHODS

This study utilized a systematic review approach that aimed to review published literature that compared models of follow-up care for survivors of childhood cancer.

Search Strategy

Through the assistance of a medical librarian, a comprehensive search strategy was developed consistent with the Cochrane Handbook's Participants, Interventions, Comparisons, and Outcomes (PICO) systematic review tool. Outcomes that were searched for included health outcomes, quality of life, psychosocial outcomes for survivors of pediatric cancer, and the methods of care that resulted in such outcomes. A detailed list of search terms utilized in the systematic review and grey literature scan can be found in Appendix A.

The following electronic databases were scanned for relevant publications: MEDLINE (Ovid), EMBASE, PsycINFO, Cochrane Library, PubMed, CINAHL, and Web of Science.

Inclusion/Exclusion Criteria

Inclusion criteria were that studies had to describe: 1) Survivors of cancer who were diagnosed < 21 years; 2) survivors were a minimum of 2 years post-treatment and/or 5 years post-diagnosis at the time of the study; 3) studies had to compare models of care on health, quality of life, or psychosocial outcomes; 4) published in English. No maximum age for a survivor of childhood cancer was identified if they met the above criteria. All qualitative research and grey literature including but not limited to, opinion papers, letters, editorials, reviews, and case studies were excluded from the search. However, to achieve our second objective, we conducted searches specific to identifying existing policies and guidelines for follow-up care by examining: 1) Published research identified using policy and guideline-specific search terms (See appendix A); and 2) web searches on google were conducted to find information on existing policies and guidelines in Canada (See appendix B). Healthcare websites that listed guidelines and policies for follow-up care or other follow-up care resources were included.

Study selection

Database searches were uploaded into the Covidence systematic review tool. Duplicates were removed. Each independent reviewer (RD, FS) screened the uploaded papers in accordance with the forementioned inclusion criteria. Those papers that met inclusion criteria based on title and abstract review were subject to a full paper review. Conflicts were resolved through a combination of re-screening and discussion.

Data extraction

Included studies were subjected to data extraction using pre-defined data abstraction forms. Study elements to be included in data abstraction: study design (e.g., randomized control trial, qualitative, quantitative, etc.), sample size, country of study, outcomes assessed, models compared, title, author(s), year of publication, journal, search question, participant demographics (e.g., age, brief medical history; reason for inclusion in study).

Quality Assessment

The Cochrane risk-of-bias tool was used in accordance with the Cochrane Handbook for Systematic Reviews ([link](#)). The utilized domains included selection/subject bias, attrition bias, instrumentation and missing data, and reporting outcomes. In accordance with the Cochrane Handbook, each category was given a label of “low risk of bias,” “high risk of bias,” or “unclear.”

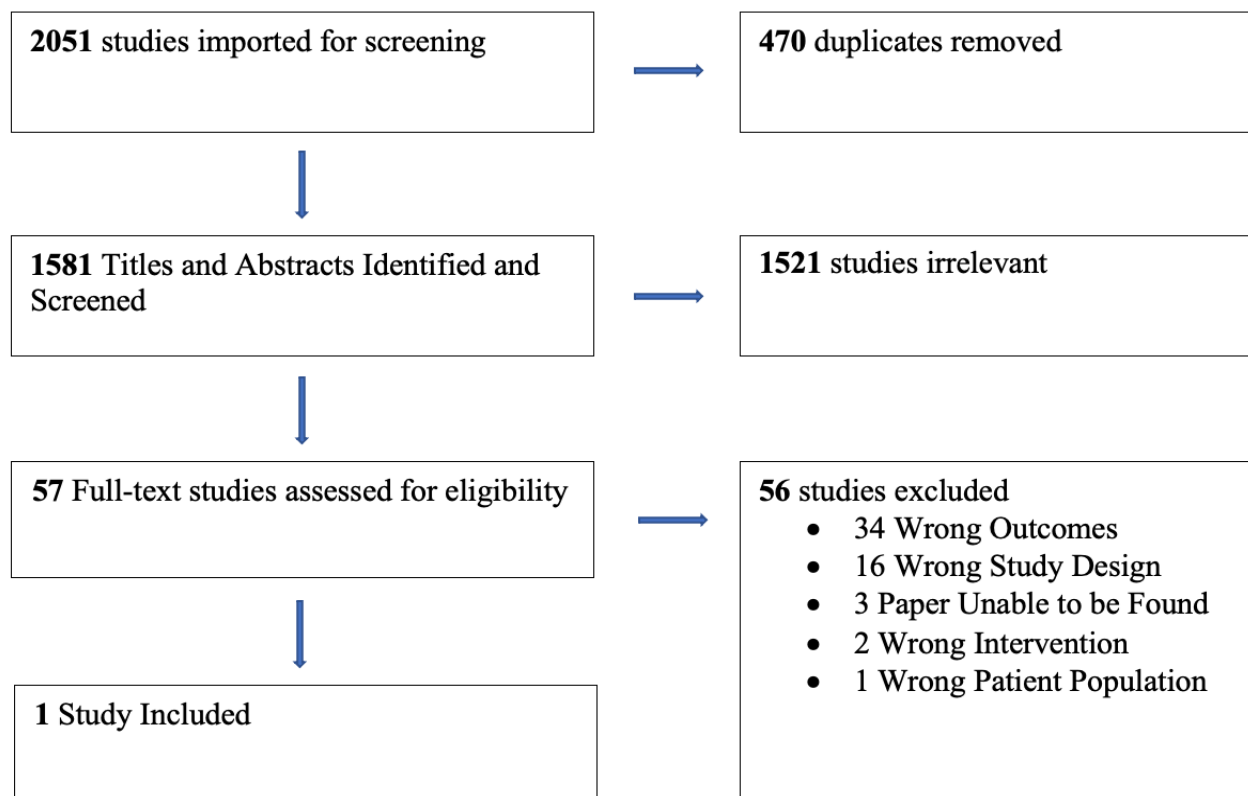
Ethics

Ethics approval was not required for this research. All utilized information was gathered through publicly available published research.

RESULTS

Overall, the review yielded 2051 studies, 1581 once duplicates were removed. Of the 1581 screened articles, 1521 met our inclusion criteria. Following full text review, only one article met all the search criteria (see Figure 1).

Figure 1.0 PRISMA Flow Chart



Descriptive Characteristics of Excluded Studies

Despite the presence of many articles within the literature search that spoke to models of follow-up-care, the majority of these articles revealed the wrong outcomes (n=34) or utilized the wrong study design (n=16) (see *Figure 1*). Many studies utilized cohort studies or surveys, and looked specifically at clinic attendance, adherence, and patient/provider care preferences. Cohort studies, surveys and other qualitative studies were not included in this current study as this study aimed to systematically compare models of care, rather than specific situations or gather opinions. Other studies provided reviews of current models of follow-up care, that while useful, did not provide the desired comparative approach to models of follow-up care. Studies that spoke to preferences for follow-up care amongst healthcare workers, patients, and or caregivers are useful when considering the development of new guidelines but were not included in this study as they did not compare existing models. A small number (n=3) of the uploaded papers were unable to be located which may be due in part to their removal from a database, grey literature, or other circumstances. These articles were automatically excluded. The remaining excluded studies were excluded in relation to study design (n=2) and the wrong patient population (n=1) (see inclusion criteria for specifics on included study designs and patient populations).

Descriptive Characteristics of Included Studies

Table 1.0 identifies the descriptive characteristics of the included study. The included study aimed to compare cancer-center based follow-up care and community-based care available for adult survivors of childhood cancer in Alberta Canada (Reynolds et al., 2019). Survivors (n=156) (community-based care n=86; cancer-center based care n=70) were compared through chart

review and questionnaires to measure adherence to Children’s Oncology Group (COG) guideline-recommended follow-up care, quality of life (QOL), and physical symptoms in community-based care versus cancer-center based care (Reynolds et al., 2019). All participants were adult survivors of childhood cancer (ASCCs) who were either: (1) discharged from the Alberta Children’s Hospital (ACH) Long-Term Survivor Clinic to the community model between 1998 and 2013, or (2) patients currently followed from the cancer center model at the Stollery Children’s Hospital (SCH) with birth years between 1973-1993 (Reynolds et al., 2019).

Table 1.0 Table of Included Studies

Title of Publication	“A comparison of two models of follow-up care for adult survivors of childhood cancer.”
Authors	Reynolds et al.
Year of Publication	2019
Relevant Population	All ASCCs discharged from the ACH Long-Term Survivor Clinic to the community model (no longer active patients) between 1998 and 2013, and patients currently followed from the cancer center model at SCH with birth years 1973-1993.
Sample Size	N=186
Study design	Qualitative- Questionnaires
Intervention	Comparison between two follow-up-care models, cancer-center-based versus community based.
Outcomes	The research demonstrated the superiority for adherence to exposure-based medical late effect screening guidelines, cancer-specific follow-up behaviours, and the reporting of fewer physical complaints in ASCCs.
Language of Publication	English
Country of Publication	Canada

Study Findings

The included study demonstrated significant differences in the quality of follow-up-care offered between the cancer-center based model and the community model, with a cancer-center model being strongly supported as the superior model of care amongst the two models. COG follow-up guidelines were utilized in both models; however, ASCCs received an average of 29.2% of COG-recommended follow-up tests in the community model. This varied significantly with those in the cancer center model, who received an average of 85.4% of all COG guideline-recommended follow-up tests for their specific diagnosis (Reynolds et al., 2019). When looking specifically at consistency and timing of care, community-model patients were found to have gone longer without follow-up care than those in the cancer-center based model, with 37.2% of community-model patients reporting that their most recent cancer-related follow-up appointment was 5 or more years ago, and cancer-center patients comparing at 5.7% (Reynolds et al., 2019). While such rates can relate to other factors such as geographical region and availability of resources (i.e., physicians, appointment spaces, etc.), it is important to note such differences as a significant gap in care. This study revealed significant differences in follow-up care found

between these two models, indicating a substantial risk of long-term effects, co-morbidities, secondary cancers, and reduced likelihood of identifying physical problems in a timely manner for adequate treatment. In both models however, participants reported having received education about their diagnosis, the follow-up care that is recommended following their treatment, and the potential late effects that they might encounter (Reynolds et al., 2019).

Quality Assessment of Included Studies

Table 2.0 Quality Assessment: Cochrane Risk-of-Bias Tool

Bias	Author's Judgement	Support for Judgement
<i>Bias arising from the study design</i>	Low-risk bias	Reynolds et al., utilized a qualitative approach that included both questionnaires to gather patient opinions, as well as chart review to gather background information. These combined methods allowed for a diverse comparative approach that was both evidence and opinion based.
<i>Bias due to missing data</i>	Low-risk bias	The authors noted that 96% (149/156 participants) of consenting participants completed questionnaires and 97% (152/156 participants) had adherence data. 95% of community model PCPs complied with requests for chart review and returned COG test compliance lists. Some PCPs did not return data, while some ASCCs lacked a PCP. Because of such, there are some gaps within the data, but not a significant amount. In a secondary analysis, 92% of ASCCs in the community model completed questionnaires, and 100% of ASCCs in the cancer center model completed the questionnaires. With such information, limited data was missing within this study.
<i>Bias in reporting outcomes</i>	Low-risk bias	Reynolds et al., note a potential limitation of the study that included the potential bias of clinicians who documented evidence of completed follow-up tests rather than independent chart reviewers. In these instances, however, the work of these clinicians was cross-checked with their team members. There were no reported conflicts of interest associated with the authors and this study.
<i>Bias in defining recruitment criteria</i>	Low-risk bias	The authors ensured the birth year range (1973-1993) of patients currently followed

		in a cancer center model matched those of participants who were discharged from the ACH Long-Term Survivor Clinic (LTSC) to a community model. The criteria for ASCCs discharged from the ACH LTSC included years from the program's inception (1998) and 2013. It is not noted why this criterion did not surpass 2013.
<i>Bias in recruitment methods</i>	Moderate-risk bias	Reynolds et al., used a variety of recruitment methods that included TV, newspaper, radio, websites from cancer community organizations, health-service newsletters, personal contact from the physicians of record, last charted phone number/contact address, and additional media. These methods allowed for a diverse recruitment approach that would have allowed for different demographics of survivors (socioeconomic status, age, etc.) to be included. The authors note that a limitation of the study was that it was difficult to recruit community-model ASCCs as most of their pediatric-hospital contact information was outdated.
<i>Bias in randomization</i>	Moderate-risk bias	The authors noted a limitation associated with a lack of randomization amongst the models of follow-up care by noting that it is difficult to randomize models of follow-up care and few studies document consequences of institutional choices in follow-up models.

Current Policies and Guidelines

Currently, no national health policies and guidelines exist that speak to the specific follow-up care models that must be available or offered in all provinces and territories. There are however some provincial guidelines and policies that vary per region. Despite the utilized search string including key words related to policies and guidelines, no relevant publications were identified within the searched data bases that spoke directly to policy or guidelines that guide models of care and met this study's search criteria. While there are provincial guidelines that guide follow-up care throughout Canada, these guidelines are not consistent throughout the country and are not always enforced and or understood. Further, the majority of documents that contain information on policies and guidelines specific to cancer follow-up care are found on government and healthcare websites, and do not exist as publications within research databases. Therefore, information on policies and guidelines were identified through grey-literature web searches.

The following section outlines the current cancer guidelines and policies throughout the five regions in Canada, and a brief analysis on their role in follow-up care for childhood cancer survivors.

Table 2.0 Current follow-up care policies, guidelines, and resources by province

	General Cancer Follow-up Guidelines and Policies (YES/NO)	Pediatric/Young Adult-specific Follow-up Guidelines and Policies (Online) (YES/NO)	Other follow-up care programs and resources
PRARIE PROVINCES			
Alberta (AB)	<p>YES</p> <p>Published by: Alberta Health Services (AHS) and the Guideline Resource Unit (GURU)</p> <p>Coverage: Follow-up guidelines only available online for breast cancer</p>	NO	<ul style="list-style-type: none"> • AHS has a “After Treatment” page on their website with resources for the end of treatment that include books and videos, an after-treatment worksheet, and guides on returning to work and school after a cancer diagnosis. • Website page dedicated to resources for healthcare professionals related to cancer care that includes the cancer guidelines, counselling services (for patients and health providers), surveillance and reporting, and supportive care. • Alberta Cancer Foundation Patient Navigator Program & Provincial Adolescent and Young Adult (AYA) Patient Navigator Program
Saskatchewan (SK)	<p>YES</p> <p>Published by: The Saskatchewan Cancer Agency (SCA) and the</p>	NO	<ul style="list-style-type: none"> • SCA delivers outpatient cancer treatment and follow-up care through 2 main cancer centres in the province, and 16 community-based oncology centers.

	<p>Saskatchewan Health Authority (SHA).</p> <p>Coverage: 12 different cancer diagnoses</p>		
Manitoba (MB)	<p>YES</p> <p>Published by: Cancer Care Manitoba (CCMB)</p> <p>Coverage: 17 different diagnoses *some noted as “coming soon.”</p>	<p>YES- limited</p> <ul style="list-style-type: none"> • “Moving forward after cancer and blood disorder treatment as an adolescent or young adult” booklet. 	<ul style="list-style-type: none"> • Follow-up care plan packages available for patients and survivors which include 1) a personalized follow-up care plan and treatment summary, 2) a “moving forward after (cancer diagnosis)” booklet, and 3) a follow-up care plan. • CancerCare Manitoba’s AfterCare Program (CAP): a program for survivors of childhood or adolescent cancer. At a patient’s first follow-up appointment with CAP, they will receive a summary of their treatment and a teaching package. This program focused on assessment, screening, education about diagnosis and late effects, and prevention strategies.
ATLANTIC PROVINCES			
Newfoundland and Labrador	<p>YES</p> <p>Published by: Eastern Health</p> <p>Coverage: only the lung cancer guidelines contain follow-up care guidelines</p>	NO	N/A

<p>Prince Edward Island (PEI)</p>	<p>In Development</p> <p>Published by: The Government of PEI</p> <p>Coverage: the 2016-2019 <i>PEI Cancer Strategy</i> lists “patient support and follow-up care” as a priority.</p>	<p>NO</p>	<ul style="list-style-type: none"> • The Cancer Patient Navigation Program assists those prior to, during, and after diagnosis with navigating cancer. • PEI Cancer Treatment Center (PEICTC)
<p>Nova Scotia (NS)</p>	<p>YES</p> <p>Published by: The Nova Scotia Health Authority (NSHA)</p> <p>Coverage: “Living beyond cancer” follow-up guides for survivors of breast, colon, rectal, thyroid, and prostate cancer, as well as general survivorship guidelines.</p>	<p>NO</p>	<ul style="list-style-type: none"> • NS Cancer Care Program that provides a variety of services throughout the province that include but are not limited to the prevention, screening, and treatment of cancer, psychological oncology resources, survivorship care guidelines for patients, as well as guidelines and standards for healthcare workers. • Two adult cancer care clinics, and several community cancers centers across the province that offer follow-up care. • The NSHA website lists resources for patients to deal with their cancer such as “emotional and practical support” that speaks to cancer-related brain fog, pain, fatigue, anxiety and fear, and sadness and depression. • The NSHA website lists resources for caregivers and family members such as comfort rooms and support groups.

<p>New Brunswick (NB)</p>	<p>MAYBE: no official guideline documents were located online but the “<i>Cancer Patient Navigation System</i>” states that it aids and supports patients and their families “especially in the pre-diagnostic and post-treatment transition to cancer survivorship.”</p> <p>Published by: The New Brunswick Cancer Network (NBCN)</p> <p>Coverage: unclear</p>	<p>NO</p>	<ul style="list-style-type: none"> • The <i>Cancer Patient Navigation System</i> • Two cancer centers in NB • The Pediatric Cancer Navigator (By The Horizon Health Network)- a nurse with education and experience in children and adolescent cancer that assists by helping families access resources, financial support for treatment, travel, and transition of care.
CENTRAL CANADA			
<p>Ontario (ON)</p>	<p>YES</p> <p>Published by: Pediatric Oncology Group of Ontario (POGO) and Cancer Care Ontario</p> <p>Coverage: general guiding principles for follow-up care</p>	<p>NO- *see programs</p>	<ul style="list-style-type: none"> • POGO Aftercare Program provides systematic follow-up for childhood cancer survivors through resources such as school and work transition programs, monitoring, and health education.
<p>Quebec (QC)</p>	<p>NO</p>	<p>NO</p>	<ul style="list-style-type: none"> • The Quebec Cancer Foundation has a page on their website (fqc.qc.ca)

			that is called “After cancer” and has 3 sections that include resuming an active life after cancer, medical follow-up (what it means and why it is important) and returning to work after surviving cancer.
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WEST COAST

British Columbia (BC)	YES Published by: BC Cancer and the BC Guidelines and Protocol Advisory Committee (GPAC). Coverage: follow-up guidelines only for colorectal cancer, and breast cancer.	NO	<ul style="list-style-type: none"> The BC Cancer website (bccancer.bc.ca) offers resources for follow-up care such as a frequently asked questions section, links to the two follow-up care guides, common experiences after treatment, and information on staying healthy in survivorship.
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THE NORTHERN TERRITORIES

The Yukon (YT)	NO	NO	<ul style="list-style-type: none"> The Yukon hospital website (yukonhospitals.ca) has a small paragraph in relation to follow-up care that states that “patients should expect to undergo “regular assessment” following their cancer treatment and that follow-up care will depend on one’s diagnosis.
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Northwest Territories (NT)	In development	NO	<ul style="list-style-type: none"> The Northwest Territories Health and Social Services Authority (NTHSSA) <i>Cancer Navigation Program</i> is comprised of (per patient)
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			<p>a registered nurse and a registered social worker who aim to “help support cancer patients as they navigate the healthcare system during their cancer journey.” This program provides resources for navigating tests, appointments, and treatments, as well as how to access other cancer related resources such as emotional, psychological, and spiritual support.</p> <ul style="list-style-type: none"> • The <i>Northwest Territories Cancer Strategy 2021-2025</i> notes that it is their goal to develop survivorship care planning tools by approximately 2025.
Nunavut (NU)	NO	NO	<ul style="list-style-type: none"> • As of July 2022, cancer patients can receive some follow-up care in Iqaluit at the Qikiqtani general hospital

DISCUSSION

This systematic review aimed to review published literature that compared models of follow-up care for survivors of childhood cancer to help identify the best models of care. Additionally, this study aimed to review published policies and guidelines across Canada that guide follow-up care and propose policy recommendations to address existing gaps in care. Despite extensive search efforts, only one comparative study was identified that met the pre-determined search criteria. Given the limited results of this review, it was difficult to draw sound conclusions regarding the most effective models of follow-up care for survivors of childhood cancer. The one identified paper compared two models of follow-up care utilized in Alberta Canada but did not speak to other models used throughout Canada or other jurisdictions that have seen success. The limited results of this review highlight significant gaps in our research surrounding the best models of care and demonstrate the priority for future research in this area

In comparing the number of relevant results to those Hiers et al., (2013) study, there has been a continuous and lamentable lack of progress in the development of the knowledge base in the past 9 years. Such findings question if traditional research pathways such as randomized control trials (RCTs) and cohort studies are adequate for analyzing these types of outcomes for patient care in

this kind of setting and for driving improvement in follow-up care in general. While RCTs provide a rigorous way of determining a cause-effect relationship between a treatment and outcomes (Nichol et al., 2010), this method is not without challenges. Some common challenges associated with RCTs according to Thiryvenkatachari (2015) include the high costs associated with the RCT, recruitment issues, a high degree of manpower and time that is required, high dropout rates, and issues around generalization and the sacrifice of external validity for internal validity. A significant barrier to the launch and completion of clinical outcome research using RCTs and cohort studies is the long follow-up periods required for meaningful clinical outcome research. This problem is compounded in childhood cancer care where patient populations are relatively small and require increased complexity and multi-centre participation to ensure statistical power and meaningful results.

One way to increase the amount of research, analysis, and outcome data available in this area may be to re-focus academic activity on Quality Improvement (QI) methodology. Compared to RCTs and traditional research, QI methodology has several advantages. QI uses continuous and iterative processes to test smaller interventions or packages of interventions over time, often producing greater quantities of useful or actionable knowledge outputs at dramatically lower cost than research studies focused on evaluating individual interventions over a single defined period of time. According to Varkey et al., (2007), a systematic measurement of quality in this manner can demonstrate verifiably whether improvement efforts 1) lead to change in the primary end point in the desired direction, 2) contribute to unintended results in different parts of the system, 3) require additional efforts to bring a process back into acceptable ranges. Crucially, this allows for performance to be evaluated repeatedly over time, thereby eliminating many of the difficulties described above with long follow-up periods. Furthermore, testing interventions in active systems (rather than rigid trial environments) improves external validity and allows for other areas of improvement to be more readily identified. Traditionally, changes in healthcare have relied on RCTs, where researchers are checking for defects and recommending changes without recognizing how such changes can affect overall systems, sometimes resulting in unintended consequences and harm (Varkey et al., 2007). Broader adoption of QI methods in the setting of follow-up care for survivors of childhood cancer has the potential to contribute to more meaningful improvement efforts by healthcare providers through continuous feedback over time as to whether changes in follow-up care are working. Process and outcome measures can be selected to evaluate efficacy for meeting the needs of patients and caregivers on individual levels, but also for the system as a whole.

While consistent and system-wide models of follow-up care across the country would address some aspects of inconsistencies of care, there remain some critical barriers that warrant further discussion. Three levels of barriers of care include (1) system level, (2) healthcare provider level, and (3) patient level barriers. System level barriers relate to the capacity of a hospital and clinic themselves, as well as the geographical level that supports them. It must be considered that not all hospitals or clinics have the capacity for permanent follow-up care clinics to support pediatric cancer survivors. Many Canadians living in rural and remote areas are placed in a position where they must choose between attending a local community clinic for follow-up care for themselves or their child or travelling long distances to attend a specialized cancer-center. A 2014 study conducted on cancer survivors in rural northern British Columbia found that survivors were travelling 5.7 hours on average to receive follow-up care from a regional center (Howard et al.).

Further, Nathan et al., (2016) found that travel distance significantly impacted follow-up care attendance and adherence with survivors living >50km away from a cancer center less likely to attend follow-up care than those living 10km away. Not only does long travel distances for care increase costs associated with cancer treatments, but it also further increases the likelihood that a patient may not attend follow-up care or be treated in a timely manner to prevent long-term effects (Howard et al., 2014). Further system level barriers include the availability of care. In a cross-Canada survey of clinical programs for the care of survivors of childhood cancer, it was found that while there are 17 pediatric cancer programs throughout Canada, only 6 of them provide care for survivors of childhood cancer into adulthood (Ristovski-Slijepcevic et al., 2009). By pediatric cancer programs limiting their treatment programs to those 18 years and under, continuity of care is broken, and a young adult is now forced to look for care elsewhere, by a physician who may not know their full medical history up until this point. A 2016 report by the North America Childhood Cancer Survivor Study (CCSS) found that while 88% of survivors in the study reported receiving some form of follow-up care, only 17.8% reported receiving care that was survivor-focused and included advice about their future risks in their survivorship, or discussions around further screening and testing (Nathan et al., 2016).

Payment models are another system level barrier. The current structure of the Canadian healthcare system largely disincentivizes and undervalues comprehensive and long-term care. In caring for a patient, physicians are asked to “deliver care that maximizes patient benefit” (McPherson et al., 2016). A care that a physician provides however can be largely influenced through incentive-based models of payment. One study showed that providers who were reimbursed through a fee-for-service model tended to take on patients with less complicated conditions than cancer patients and survivors since the fee levels were seen as insufficient for treating these complex patients (McPherson et al., 2016). Provider retainment is a delicate balance in conversations surrounding payment models and patient attainment. Providers who may feel that they are inadequately compensated due to models such as fee-for-service, or who may feel that they are overworked due to the complexity/number of their patients, may avoid treating complex patients such as survivors of cancer. Thus, in an already overwhelmed healthcare system due to complexities such as the COVID-19 pandemic, it is important that policy makers continue to prioritize the implementation of payment models that facilitate adequate long-term care for complex patients.

Healthcare provider level barriers relate to the training, education, and resources available to healthcare providers who are directly and indirectly involved in the care of pediatric cancer patients and survivors. Howard et al., (2017), notes the large inconsistencies in and lack of education for medical students and older generation physicians surrounding the treatment of pediatric cancer survivors and the awareness of the long-term effects of their treatments. According to Reynolds et al., (2019), no Canadian educational system provides PCPs with education surrounding treatment and care plans for medically complex populations such as survivors of childhood cancer. Such gaps in the healthcare provider level can result in inconsistencies in care or lack of adequate care from the time of diagnosis and into survivorship. A study by Bober et al., (2009) found that out of a survey of 227 primary care physicians (PCPs), only 24% of met criteria for routinely providing multidimensional survivorship care, despite PCPs providing a large majority of care for survivors of cancer.

The last level of barriers concern those directly related to patients. Barriers directly related to patients includes but is not limited to: a lack of understanding surrounding one's diagnosis and its associated long-term risks, as well as the importance of follow-up care in preventing such risks. The Institute of Medicine and the National Research Council (2006) state that many cancer patients have difficulty retaining information regarding their diagnosis and follow-up care due to the stressful nature of their diagnosis, however, they further state that despite knowing this, "patients do not routinely receive a summary of their treatments or possible late effects." This concept identifies a prominent and concerning gap in knowledge sharing where it is recognized that patients and survivors of cancer may have difficulties in understanding their diagnosis and the information provided to them, yet there is no further attempt to improve this knowledge translation. A 2017 study conducted in British Columbia looked at barriers to long-term follow-up care for adult survivors of childhood cancer (Howard et al.). This study found that 73% of their participants (22 out of 30) knew the importance of knowing their long-term health risks but lacked sufficient details and information on their risks (Howard et al., 2017). Those that did receive information on their potential risks, felt that this information was communicated "much too late," often at the age of 18, and at a point in their life where they felt they could have prevented many long-term effects if they had known sooner (Howard et al., 2017).

Many adult survivors of childhood cancer face increased risks to adherence due to the presence of major life changes at this stage in life. Patients who may have been under the full care of their parents throughout their cancer treatment, may now be moving away from home or the community that they grew up in, attending post-secondary, or finding work. White et al., (2017) notes that adult survivors of childhood cancer can experience "unmet needs that impact life transitions and can lead to increased psychosocial distress and decreased compliance with follow-up screening". The author further notes that common predictors of unmet needs can include but not be limited to "geographic isolation from health services, lack of social support, and poor health status" (White et al., 2017). Several studies note that adherence to follow-up care decreases with age and time from diagnosis. Possible reasoning for such findings could include misunderstanding the importance of lifelong follow-up care, life changes as summarized above, a lack of inadequate care available, or emotional and physical fatigue attached to continuous appointments. Psychosocial and emotional barriers may affect a patient's willingness to adhere to follow-up care. Sustained fear of reoccurrence and anxiety around testing, also commonly referred to as "scanxiety," may cause a patient to fear doctor visits and testing to avoid the possibility of hearing bad news (White et al., 2017). In contrast to transitioning from pediatric to adult care or seeing a PCP for care, having consistent follow-up care that allows patients to remain with their original oncology team can allow patients to build up trust with their provider, which may reduce anxiety, or allow them to communicate more openly with them.

There is limited availability and a lack of consistency in follow-up care for cancer survivors across the country. Guidelines for follow-up care specific to young adults and survivors of childhood cancer were only found online within the Manitoba (MB) healthcare system. Of the provinces who had follow-up care for specific types of cancer such as Alberta, Newfoundland, Nova Scotia, and British Columbia, no provinces had pediatric-specific guidelines and policies for follow-up care. Further, while some provinces have a wider range of cancer diagnoses covered with their guidelines, available guidelines contained limited information and were only approximately 1-2 pages long, such as those in Saskatchewan, or were listed as a "goal" or

“coming soon,” such as in the case of the Northwest Territories, Prince Edward Island, and Manitoba respectively.

Some Canadian provinces such as Alberta, Saskatchewan, Ontario, Nova Scotia, and Manitoba are leading the way in follow-up care policies, guidelines, and practices. Alberta currently does not have any follow-up guidelines and policies that are specific to survivors of childhood cancer. In Alberta, there are two tertiary centers that provide acute pediatric cancer treatment and follow-up care for survivors of childhood cancer (Reynolds et al., 2019). These include the Long-Term Survivor Clinic at the Alberta Children’s Hospital (ACH) in Calgary, and the Northern Alberta Childhood Cancer Survivor Program at the Stollery Children’s Hospital (SCH) (Reynolds et al., 2019). The ACH aims to serve the southern half of Alberta, with the SCH serving the northern half of Alberta (Reynolds et al., 2019). While the ACH provides medical support and surveillance from 2 years off of therapy until the age of 20 or 10 years off treatment (whichever comes last), the SCH provides surveillance and support with no age limit (Reynolds et al., 2019). Alberta could further benefit by creating pediatric or young adult-specific follow-up guidelines, expanding the range of their current guidelines to include additional cancer types and modifying the ACH Survivor Clinic to have no age range in the services they offer to survivors.

Much like Alberta, the Saskatchewan Cancer Agency has established a strong framework of policies and guidelines for follow-up care, with separate guidelines for 12 different cancer diagnoses that include discharge letters and other relevant follow-up care documents. Saskatchewan could further strengthen these documents by creating pediatric and young-adult specific follow-up guidelines, as well as expanding the amount of information in the already published documents, as all are between 1-2 pages.

Ontario’s Pediatric Oncology Group of Ontario (POGO) has worked diligently to establish follow-up care clinics for childhood cancer survivors through the POGO Aftercare Clinic program, with 7 clinics located across Ontario, 2 of which are in adult survivor hospital sites. Ontario could further improve their follow-up care by following through on the recommendations for follow-up care that we brought forward in their 2020 report titled *Follow-up Models of Care for Cancer Survival: Recommendations for the Delivery of Follow-up Care for Cancer Survivors in Ontario* (Cancer Care Ontario, n.d.).

The Nova Scotia Health Authority (NSHA) currently does not have pediatric-specific guidelines, but they do have 6 published documents that speak to follow-up care for cancer patients in general. These documents are extensive, patient focused, and address many different facets of survivorships. The NSHA could further improve their guidelines by using their current model of cancer guidelines to develop policies and guidelines specifically for childhood cancer survivors or young adult survivors.

Cancer Care Manitoba (CCMB) also does not have pediatric-specific guidelines but they do have a follow-up care plan package that contains a “moving forward after cancer and blood disorder treatment as an adolescent or young adult” booklet. This booklet contains information on isolation and wellbeing, fertility, finances, education and work, substance use, LGBT2SQ+, physical activity and nutrition. Further, the CancerCare Manitoba’s AfterCare Program (CAP) is a program for survivors of childhood or adolescent cancer. This program focused on assessment,

screening, education about diagnosis and late effects, and prevention strategies. CCMB could further improve their follow-up care work by publishing the guidelines that are listed as “coming soon” and integrating their young adult and adolescent guidelines into each cancer-specific guideline.

LIMITATIONS OF RESEARCH

There were some limitations of the current review. First, by not limiting our search to a specific geographic location, we acknowledge that there may be complications in drawing conclusions from, or directly applying a model of care, and establishing policies that are based on a healthcare system that is different from the model of care delivery in Canada. In the end, however, the only study included in the review was from Canada, so this was not a concern. Limitations also include the notion that qualitative and case-study research were excluded from the overall search. These types of studies can be useful for capturing patient and healthcare provider perspectives regarding different models of care, but this review aimed to provide an overview of the system in general without focusing on specific instances or the opinions of physicians and patients. Finally, the exclusion of grey literature may have missed publications of policies or guidelines not available through a google search and rather only be available internally, making it appear as if the jurisdiction does not have any follow-up care guidelines and policies.

AREAS FOR FURTHER RESEARCH

This review has identified several areas for further research. The first notable area includes an in-depth analysis of the existing policies and guidelines surrounding cancer follow-up care in Canada for pediatric cancers. While it is important to identify gaps in pediatric-specific follow-up care, it is also important to ensure that there is consistency in all aspects of follow-up care throughout the country. The second area of further research is directly related to the objective of this systematic review, in that models of care for cancer follow-up care should be compared both within Canada, and on a global scale to allow for healthcare innovation and harmonization. Follow-up care and the policies and guidelines that guide such care is a complex and multifaceted issue, what some would call a “wicked problem” in policy terms. Because of such, when developing new policies and adjusting current policies, it will be important to research all aspects that affect cancer follow-up care such as funding and payment models for physicians, delivery models, as well as stakeholder opinions including patients, survivors, caregivers, and medical staff. The COVID-19 pandemic has created a unique policy window for change and improvements in healthcare. Thus, further research could be conducted regarding challenges faced by survivors of childhood cancer during the pandemic as well as potential solutions. The effectiveness of alternative follow-up care methods, such as telemedicine, that were heavily utilized during the pandemic can be assessed, with further research to determine if they are an effective model to integrate after pandemic protocols have ended.

POLICY RECOMMENDATIONS

This section provides 3 recommendations for the federal and provincial governments to improve follow-up care for childhood cancer survivors in Canada. The need for improvement is strongly supported by a growing population of survivors in Canada and a lack of currently existing

research that compares models of follow-up care as displayed in this review, and Reynolds et al., (2019). The proposed recommendations will seek to create evidence-based follow-up care guidelines in Alberta that meet the needs of survivors of childhood cancer, are guided by evidence, and exemplify the best model of care. In making these recommendations, several factors will be prioritized: (1) the long-term wellbeing of survivors, (2) evidence-informed recommendations that are supported by the most current research, (3) opinions from survivors, caregivers, and healthcare workers involved in the care of survivors and patients of pediatric cancer, (4) cost-effectiveness to minimize further economic burden on the healthcare system, and the need for high-intensity and high-cost interventions in acute care. These recommendations would allow for inconsistencies in care as discussed previously to be addressed through policies and guidelines that all jurisdictions are accountable for upholding, while also providing consistency in care that is easier for patients and caregivers to understand.

Recommendation 1:

The Alberta provincial government should further develop their follow-up care guidelines to include follow-up care guidelines specific to care for survivors of childhood cancer.

As previously noted, the current follow-up care guidelines in Alberta established by the AHS Guideline Resource Unit (GURU) are limited in the diagnoses that they cover, and currently do not include policies and guidelines specific to follow-up care for survivors of childhood cancer. Establishing these guidelines will be a critical aspect of ensuring that survivors receive the care that they need, while minimizing late-effects, and unnecessary financial burdens of care on the health care system. In establishing these guidelines, it will be critical that the provincial government utilizes existing research on patient and provider preferences for follow-up care to ensure that follow-up policies meet the specific needs of Albertans. Further to this, the provincial government should seek funding from the federal government, as well as other Canadian cancer organizations such as the Canadian Cancer Society and Canadian Institute of Health Research (CIHR) to conduct current research that compares existing models of care to gain further evidence to inform new policies.

It is recommended that all new guidelines and policies for follow-up care are available for healthcare workers, patients, and caregivers to increase transparency, understanding, and autonomy in care. Guidelines should speak to various diagnoses as critical differences exist amongst the long-term follow-up care and expected risks. Further research should be conducted to determine what contents should be included in guidelines and policies for survivors and what tools and resources are necessary. The Alberta government may benefit from consulting with the province of Manitoba, who currently has some guidelines and policies for the follow-up care of survivors of childhood cancer. Following the COVID-19 pandemic and the conjoined complexity of COVID-19 with survivorship care, the Alberta healthcare system is in a unique position where there is a policy window for improvements in care and policies in the province.

Recommendation 2:

The federal and provincial governments should work together in a conjoined research effort to compare existing and new models of follow-up care that are utilized in Canada with models of care in other countries that have been found to be successful

As demonstrated in this review as well as through the work of Reynolds et al., (2019), limited research exists that compares models of follow-up care for childhood cancer survivors, and research in this area has remained relatively stagnant over time. To develop succinct and objective follow-up care models that will work in the country, it is important that both the federal and provincial governments are in conversation together. The provinces and territories will be able to speak to the current state of the models of care that are offered within their specific jurisdiction, as well as what will work and not work within their jurisdiction in developing a new model. Further, while the federal government could contribute to the conversation by providing a Canada-wide lens and the financial perspective, the provinces and territories will be able to speak to the specific resources that are required to implement the decided plan.

In order to accomplish this recommendation, the following objectives must be met. Follow-up care and the long-term outcomes of survivors of childhood cancer must be established as a priority for research to ensure that models of follow-up care not only meet the needs of survivors, but that are evidence-based and consistent. The federal government may assist with the increased funding and facilitating this research through the assistance of organizations such as the Canadian Institute of Health Research (CIHR). Further, Provincial governments can facilitate increased research by improving IT infrastructure to facilitate analysis and knowledge exchange. In order to drive comparative analysis, knowledge dissemination and comparison amongst models, the federal government can establish a leadership forum, conference, or ongoing taskforce in partnership with provincial governments to compare models across different provinces. This comparative analysis will allow for a nation-wide consensus on the standards of follow-up care and allow for consistency in the delivery of care.

Recommendation 3:

The federal, provincial, and territorial governments should work together with Canadian health and oncology organizations to review and compare existing follow-up care guidelines and policies to guide a national standard of follow-up care policies.

The second recommendation should be conducted alongside the third recommendation. In coordination with Canadian health and oncology organizations such as Cancer Care Canada and Alberta Health Services, the provincial, territorial, and federal governments should work together to create follow-up care guidelines and policies to guide a national standard of follow-up care policies. The presence of oncology and health organizations within this conversation will be critical to creating evidence-informed policy that will correctly guide care in Canada. As noted previously, many provinces and territories have large gaps in the guidelines and policies that are currently available. By bringing together a representative from each jurisdiction, areas of overlap and new information may be able to fill in existing gaps and create strong and uniform guidelines and policies that can guide care across the country. Such guidelines should be readily available for all healthcare workers, as well as patients and their families. It is recommended that two versions are available: one version for healthcare workers that speaks specifically to the care of oncology patients and survivors of childhood cancer and other forms of cancer, as well as a version for patients and providers that helps guide patients through follow-up care. These guidelines should also provide enough specificity to allow for adequate and consistent care,

while still allowing for some flexibility to adjust to various jurisdictional needs (such as a higher elderly population in Atlantic regions, etc.).

CONCLUSION

Survivors of childhood cancer continue to face substantive inconsistencies in the models of follow-up care that are available in Canada and around the globe. Such inconsistencies create gaps in care that put survivors at an increased risk of long-term effects and reoccurrence. The limited findings of this systematic review demonstrate the strong need for future areas of research that focus on comparing models of follow-up care both within the province of Alberta, and within Canada. Furthermore, there is a need to examine healthcare innovation such as virtual models of care which might contribute to improved healthcare innovation and outcomes. Increasing transparency and knowledge sharing in follow-up care can allow for an increase in patient autonomy and understanding of risk following cancer treatment, allowing patients to better navigate their lives after cancer, while understanding their risks, and knowing the next steps. Advances in modern medicine continue to provide an increasing number of childhood cancer patients with a second chance at life, but it is critical to ensure that the follow-up care that is available to survivors is consistent, meets their needs, and allows them to live a high-quality life that is not only free of cancer, but free of preventable long-term risks.

Appendix A.

Systematic Review Key Words

Concept	Synonyms
Models/Policies	Model* [Keyword]; framework* [Keyword]; pathway* [Keyword]; standard* [Keyword]; “models of care” [Keyword]; models, organizational [MeSH]; models, theoretical [MeSH]; forecasting [Keyword, MeSH]; policy [Keyword, MeSH]; “health policy” [Keyword, MeSH]; “organizational policy” [Keyword, MeSH]; “policy making” [Keyword, MeSH]
Follow-up Care	“follow-up care” [Keyword]; “follow up care” [Keyword]; follow-up studies [MeSH]; “long-term follow-up” [Keyword]; “long-term outcome*” [Keyword]; “long term outcome*” [Keyword]; aftercare [Keyword, MeSH]; “after care” [Keyword]; “after treatment” [Keyword]; after-treatment [Keyword]; “post treatment” [Keyword]; post-treatment [Keyword]; post-care [Keyword]; “post care” [Keyword]
Evaluation	Evaluat* [Keyword]; evaluation studies as topic [MeSH]; evaluation study [MeSH]; “program evaluation” [Keyword, MeSH]
Childhood Cancer Survivors	“child* cancer survivor*” [Keyword]; “pediatric cancer survivor*” [Keyword]; “paediatric cancer survivor*” [Keyword]; “childhood cancer survivor*” [Keyword]
Childhood	child* [Keyword]; child [MeSH]; childhood [Keyword]; pediatric [Keyword]; paediatric [Keyword]; pediatrics [MeSH]; adolescent* [Keyword]; adolescent [MeSH]; child, preschool [MeSH]; teen* [Keyword]; “young adult*” [Keyword]; young adult [MeSH];
Cancer Survivor	“cancer survivor*” [Keyword]; cancer survivors [MeSH];
Cancer ¹	Cancer [Keyword]; neoplasm* [Keyword]; neoplasms [MeSH]; carcinoma [Keyword,

	MeSH]; tumor* [Keyword]; tumour* [Keyword]; oncology [Keyword]; “medical oncology” [Keyword, MeSH]
Survivor	Survivor* [Keyword]; survivors [MeSH]; survivorship [Keyword];

Systematic Review Search Strings

(model* OR framework* OR pathway* OR standard* OR “models of care” OR forecasting OR policy OR “health policy” OR “organizational policy” OR “policy making”) AND (“follow-up care” OR “follow up care” OR aftercare OR “after care” OR “after treatment” OR after-treatment OR “post treatment” OR post-treatment OR post-care OR “post care” OR “long-term follow-up” OR “long-term outcome*”) AND (“child* cancer survivor*” OR “pediatric cancer survivor*” OR “paediatric cancer survivor*” OR “childhood cancer survivor*”) AND (evaluat* OR “program evaluation”)

(model* OR framework* OR pathway* OR standard* OR “models of care” OR forecasting OR policy OR “health policy” OR “organizational policy”) AND (“follow-up care” OR “follow up care” OR aftercare OR “after care” OR “after treatment” OR after-treatment OR “post treatment” OR post-treatment OR post-care OR “post care” OR “long-term follow-up” OR “long-term outcome*”) AND (child* OR childhood OR pediatric OR paediatric OR adolescent* OR teen* OR “young adult*”) AND “cancer survivor*” AND (evaluat* OR “program evaluation”)

Appendix B

Grey Literature Search Terms

Concept	Synonyms
Survivor	Survivor*; survivors; survivorship
Childhood cancer survivor	pediatric cancer survivor; paediatric cancer survivor; childhood cancer survivors
Cancer	Childhood cancer; pediatric cancer; oncology
Follow-up Care	Follow-up*; follow-up models of care; survivorship care; follow-up care program*; follow-up care resources; follow-up resources; follow-up program*
Policies/guidelines	Policy; follow-up policies; guideline*; follow-up guidelines
Models	Models of care; models of follow-up care; follow-up care models;
*Each of the above concepts would have contained one provincial identifier to make the search specific to that province.	Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia, Ontario, Prince Edward Island, Quebec, and Saskatchewan.

Example Grey Literature Search String

The following are some utilized searches on google to identify healthcare websites and documentation on follow-up care policies and guidelines in Canada:

- “Alberta Health Services Follow-up guidelines and Cancer.”
- “Ontario Cancer follow-up care guidelines.”
- “Cancer Follow-up care program* Saskatchewan.”
- “Pediatric cancer follow-up care guidelines British Columbia.”
- “Childhood cancer follow-up care policies Quebec.”

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