



Technical Brief
Number 39

Disparities and Barriers to Pediatric Cancer Survivorship Care



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Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No. 75Q80120D00009

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AHRQ Publication No. 21-EHC014
March 2021

Key Messages

Purpose of Review

This Agency for Healthcare Research and Quality (AHRQ) Technical Brief was commissioned by the National Cancer Institute (NCI) to support the development of a research agenda associated with the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act. This Technical Brief provides an overview of the existing evidence and forthcoming research relevant to disparities and barriers for pediatric cancer survivorship care, outlines open questions, and offers concrete guidance for future research in a user-friendly format.

Key Messages

- In total, 110 studies were identified that addressed disparities, barriers to survivorship care, proposed strategies, evaluated interventions, and ongoing studies in childhood cancer survivors.
- Twenty-six studies assessed disparities in survivorship care. The most commonly examined sources of disparities impacting survivorship care were biological sex and insurance.
- Forty-seven studies assessed barriers to survivorship care at various levels and their impact on key outcome domains. The most frequently studied barriers were at the level of the patient and provider, and predominantly impacted outcomes in the care domain.
- Sixteen organizations have proposed strategies to address survivorship care, most frequently endorsing the presence of disparities and barriers to care, with variation in the level of detail of specific recommendations. We identified only 8 ongoing and 27 published studies evaluating interventions to alleviate disparities and reduce barriers to care.
- While research has addressed disparities and barriers to survivorship care for childhood cancer survivors, evidence-based interventions to address these disparities and barriers to care are sparse. Interventions at the patient level were most frequently evaluated and include raising awareness of the need for life-long survivorship care.
- Additional research and corresponding funding opportunities are needed to successfully study large and diverse survivorship cohorts representative of disparate subgroups, to examine less frequently studied disparities and barriers, and to evaluate suggested strategies to alleviate barriers that can lead to disparities.

This report is based on research conducted by the Southern California Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 75Q80120D00009). The National Cancer Institute (NCI) of the National Institutes of Health (NIH) funded the report. The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ or NCI/NIH. Therefore, no statement in this report should be construed as an official position of AHRQ, NCI/NIH, or the U.S. Department of Health and Human Services.

None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

The information in this report is intended to help healthcare decision makers—patients and clinicians, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of healthcare services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

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AHRQ appreciates appropriate acknowledgment and citation of its work. Suggested language for acknowledgment: This work was based on an evidence report, Disparities and Barriers to Pediatric Cancer Survivorship Care, by the Evidence-based Practice Center Program at the Agency for Healthcare Research and Quality (AHRQ).

Suggested citation: Mobley EM, Moke DJ, Milam J, Ochoa CY, Stal J, Osazuwa N, Bolshakova M, Kemp J, Dinalo JE, Motala A, Baluyot D, Hempel S. Disparities and Barriers to Pediatric Cancer Survivorship Care. Technical Brief No. 39. (Prepared by the Southern California Evidence-based Practice Center under Contract No. 75Q80120D00009.) Rockville, MD: Agency for Healthcare Research and Quality; March 2021.

DOI: <https://doi.org/10.23970/AHRQEPCTB39>. Posted final reports are located on the Effective Health Care Program [search page](#).

Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new healthcare technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments. This report from the EPC Program at AHRQ is one of several efforts underway across the U.S. Department of Health and Human Services to implement provisions of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2018 (Public Law No: 115-180). The National Cancer Institute of the National Institutes of Health funded this report from the EPC Program at AHRQ.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy, or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Acknowledgments

The authors gratefully acknowledge the following individuals for their contributions to this project: We thank Mary Butler, Paul Jacobsen, Emily Tonorezos, Shobha Srinivasan, Danielle Dae, Amy Kennedy, Lionel Bañez, and Meghan Wagner for their helpful comments, and David Freyer and Kimberly Miller for help identifying Key Informants.

Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the Technical Brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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Disparities and Barriers to Pediatric Cancer Survivorship Care

Structured Abstract

Objectives. Survival rates for pediatric cancer have dramatically increased since the 1970s, and the population of childhood cancer survivors (CCS) exceeds 500,000 in the United States. Cancer during childhood and related treatments lead to long-term health problems, many of which are poorly understood. These problems can be amplified by suboptimal survivorship care. This report provides an overview of the existing evidence and forthcoming research relevant to disparities and barriers for pediatric cancer survivorship care, outlines pending questions, and offers guidance for future research.

Data sources. This Technical Brief reviews published peer-reviewed literature, grey literature, and Key Informant interviews to answer five Guiding Questions regarding disparities in the care of pediatric survivors, barriers to cancer survivorship care, proposed strategies, evaluated interventions, and future directions.

Review methods. We searched research databases, research registries, and published reviews for ongoing and published studies in CCS to October 2020. We used the authors' definition of CCS; where not specified, CCS included those diagnosed with any cancer prior to age 21. The grey literature search included relevant professional and nonprofit organizational websites and guideline clearinghouses. Key Informants provided content expertise regarding published and ongoing research, and recommended approaches to fill identified gaps.

Results. In total, 110 studies met inclusion criteria. We identified 26 studies that assessed disparities in survivorship care for CCS. Key Informants discussed subgroups of CCS by race or ethnicity, sex, socioeconomic status, and insurance coverage that may experience disparities in survivorship care, and these were supported in the published literature. Key Informants indicated that major barriers to care are providers (e.g., insufficient knowledge), the health system (e.g., availability of services), and payers (e.g., network adequacy); we identified 47 studies that assessed a large range of barriers to survivorship care. Sixteen organizations have outlined strategies to address pediatric survivorship care. Our searches identified only 27 published studies that evaluated interventions to alleviate disparities and reduce barriers to care. These predominantly assessed approaches that targeted patients. We found only eight ongoing studies that evaluated strategies to address disparities and barriers.

Conclusions. While research has addressed disparities and barriers to survivorship care for childhood cancer survivors, evidence-based interventions to address these disparities and barriers to care are sparse. Additional research is also needed to examine less frequently studied disparities and barriers and to evaluate ameliorative strategies in order to improve the survivorship care for CCS.

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Introduction

Background and Objectives

It is estimated that there are more than 500,000 survivors of childhood cancer—that is, survivors who were diagnosed under the age of 21, whether currently children, adolescents, or adults—in the United States. The 5-year survival rate for childhood cancer has increased dramatically from the 1970s, when it was about 62 percent, to 86 percent in the 2010s.¹ This increase in survival is attributed to improved treatment, which may include surgery, chemotherapy, radiation, immunotherapy, hematopoietic stem-cell transplantation, or a combination of these treatments using a risk-stratified approach and improvements in supportive care. After completion of treatment, childhood cancer survivors (CCS) face many challenges regarding long-term health outcomes as a result of their cancer diagnosis and treatment. Despite gains in survival, CCS are at risk for adverse physical, psychosocial, functional, and behavioral outcomes. These *late effects* range in severity and complexity, and commonly result in multimorbidity, including cardiovascular disease and heart failure, decreased pulmonary function, infertility, hormonal changes, kidney failure, osteopenia and osteoporosis, neurocognitive deficits, and secondary malignancies.² Moreover, CCS exhibit disparities and effects in social, economic, and health-related quality of life outcomes in comparison to healthy peers, including poor academic or professional performance, lower income, and greater burden of mental health disorders.^{3,4} Indeed, these nonclinical factors have been demonstrated to impact disparities as much as biological factors.⁵ Survivorship care is a clinical approach to address the health and well-being of cancer survivors, ideally using risk-based methods (e.g., according to exposure to potentially harmful therapies) of surveillance, screening, management, and prevention of late effects, along with coordination of care with primary care and other healthcare providers.⁶ Many CCS do not receive recommended survivorship care, particularly after transitioning into adulthood.⁶ Barriers to survivorship care can encompass barriers at the level of patient and caregiver, healthcare provider, health system or payer, and many other levels.^{6,7} As a result of these barriers, disparities exist for a range of outcomes among CCS, and this complexity poses unique challenges for research, clinical care, education, and advocacy.

While disparities are increasingly recognized in the pediatric survivorship field, practitioners often are at a loss for how to mitigate disparities. The lack of rigorous assessment of strategies to reduce barriers and the fragmented nature of existing research hinder the establishment of appropriate policies at multiple levels. Effective and efficient access to care for CCS is critical to minimize and alleviate disparities among this population who are burdened by the adverse sequelae of their prior malignancy and treatment.

Purpose and Scope

This Agency for Healthcare Research and Quality Technical Brief was commissioned by the National Cancer Institute as a result of the passage of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act.⁸ The STAR Act is resulting in enhanced support for pediatric, adolescent, and young adult cancer research, including ongoing efforts to address pediatric cancer survivorship disparities. The goals of a Technical Brief are to provide an early objective description of the current science, a potential framework for assessing the intervention, and identification of future research needs. A Technical Brief does not grade evidence or synthesize data on outcomes, and does not attempt to determine whether an intervention is safe

or effective.⁹ This Technical Brief provides an overview of the existing evidence and forthcoming research relevant to disparities and barriers for pediatric cancer survivorship care, outlines open questions, and offers concrete guidance for future research in a user-friendly format. Furthermore, this Technical Brief also discusses disparities in biomedical, psychosocial, health services/economics, and survivorship related outcomes among CCS as a presumed result of barriers to care.

Guiding Questions

The Technical Brief addresses five Guiding Questions:

Guiding Question 1. What are the disparities in survivorship care for pediatric cancer survivors?

Guiding Question 2. What are the barriers to survivorship care for pediatric cancer survivors who experience disparities?

Guiding Question 3. What are proposed strategies for addressing those barriers?

Guiding Question 4. What published and unpublished studies have assessed these strategies?

Guiding Question 5. What are future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?

Methods

This Technical Brief provides a user-friendly synopsis of the existing evidence regarding disparities and barriers to survivorship care for pediatric cancer survivors, outlines unanswered questions, and suggests topic areas for future research.

Technical Brief Approach

The methods for this Technical Brief follows the Content and Procedures Guide for Evidence-based Practice Center Program. The topic of this report was developed by the National Cancer Institute (NCI) in consultation with the Agency for Healthcare Research and Quality (AHRQ). Key Informants provided input on the Guiding Questions to be addressed and future research directions. The protocol was posted on AHRQ's Effective Health Care website (<https://effectivehealthcare.ahrq.gov/products/pediatric-cancer-survivorship/protocol>) on June 24, 2020 and a notice referencing the protocol was posted on the Federal Register (<https://www.federalregister.gov/documents/2020/07/15/2020-15190/supplemental-evidence-and-data-request-on-disparities-and-barriers-for-pediatric-cancer-survivorship>) on July 15, 2020. We solicited submission of supplemental evidence and data from the public from June 24 to August 14, 2020. The Technical Brief is organized by five Guiding Questions that address observed disparities and barriers to survivorship care, as well as the strategies and their effects to address barriers and disparities.

Data Collection

Key Informants

In consultation with AHRQ and NCI, our team identified areas of expertise that were targeted for Key Informant solicitation, which included: patient, family, or caregiver perspective (N = 2); clinical implications, patient care, and disparities research (N = 4); health services research and access to care for populations that experience disparities (N = 2); and administrative and payer perspective (N = 1). Individual representatives for the key stakeholder groups were determined with the help of content experts and approached for their willingness to serve as a Key Informant. Key Informants were asked to provide feedback regarding topics related to pediatric cancer survivor disparities and barriers to survivorship care, in particular those that have been insufficiently covered in formal research studies. They also helped identify notable subgroups that may experience a disparity, explain barriers that could cause a disparity, and, ultimately, how disparities and barriers could impact key outcomes of interest. Additionally, Key Informant input was used to identify grey literature resources, ongoing research, and recommend approaches to help fill identified gaps.

Key Informants addressed the following Guiding Questions and subquestions:

- What are the disparities in survivorship care for pediatric cancer survivors?
 - What types of disparities impact survivorship care for pediatric survivors?
 - What disparities do you think are most significant in impacting pediatric cancer survivorship care?

- Which domains of disparities should be distinguished?
- What are the barriers to survivorship care for pediatric cancer survivors who experience disparities?
 - What are the most influential barriers to pediatric cancer survivorship care?
 - How do those barriers change as childhood cancer survivors (CCS) transition from pediatric to adult survivorship care?
 - How do barriers to survivorship care vary by subgroups of pediatric cancer survivors?
 - How do barriers affecting specific subgroups change over time, specifically as they transition from pediatric to adult care?
- What are proposed strategies for addressing those barriers?
 - What strategies to address barriers to survivorship care that lead to disparities are most promising?
 - Do those strategies need to be implemented using different approaches for subgroups of survivors?
 - Which professional bodies have proposed strategies?
- What published and unpublished studies have assessed these strategies?
 - How effective are the strategies that you are familiar with?
 - What confounding factors pose a challenge to interpreting research and evaluation studies?
- What are future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?
 - What are the most important gaps in our current knowledge of disparities and barriers to survivorship care, and how would you recommend filling those gaps?
 - How can future research be designed to minimize the confounding factors influencing barriers, and ultimately, disparities?
 - Are you aware of any important ongoing studies addressing disparities or barriers in pediatric survivorship care?

Prior to the Key Informant interviews preliminary feedback was gathered using a Web-based survey regarding the abovementioned Guiding Questions. Data received before the Key Informant calls were included as prompts on the meeting slides to promote discussion. Representatives from AHRQ and NCI attended all three Key Informant interviews meetings, which were held over the course of three weeks. The online survey also enabled Key Informants to provide additional feedback to the EPC after the calls. Key Informant interviews were recorded and the content was discussed in the investigative team. We reviewed themes in the responses and organized resulting themes by Guiding Questions.

Grey Literature Search

Key to identifying strategies that have been proposed to reduce or mitigate disparities and barriers to pediatric cancer survivorship care is a thorough grey literature search and the grey literature search strategy is detailed in Appendix A. Briefly, we searched the websites of relevant organizations and reviewed clinical practice guideline clearing houses using specified key search terms. We searched clinicaltrials.gov, NIH RePORTER, and Open Science Framework for ongoing research studies. Systematic reviews were identified using PubMed and PROSPERO, an international database of systematic reviews, and reviews were reference-mined to identify further studies.

Published Literature Search

We designed targeted search strategies for the individual Guiding Question, also detailed in Appendix A. Search strategies were designed, executed, and documented by the Evidence-based Practice Center librarian. We searched PubMed®, CINAHL®, and PsycINFO® databases for published research. We identified studies in CCS that addressed either disparities or barriers directly (either in the title, abstract, or key word). In addition to using synonyms for the term disparity, we also searched for specific disparities using the National Institutes of Health definition of populations that experience health disparities: racial/ethnic minorities (including those who are Blacks/African Americans, Hispanics/Latinos, American Indians/Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders); socioeconomic status; underserved or rural populations; sexual and gender minorities; and educational attainment.^{10, 11} We also used a sample of publications in CCS that did not highlight disparities in the title or abstract of the publication but that used an important study design (e.g., long-term follow-up or longitudinal studies). We screened the full text of the publications to identify subgroup results that suggest disparities or barriers to survivorship care.

Appendix A details the methods and search strategies.

Inclusion and Exclusion Criteria

The eligibility criteria are shown in Table 1 below, organized in a PICOTSS (population, independent variables/intervention, comparator, outcomes, timing, setting, and study design/other limiters) framework.

Table 1. Criteria for inclusion/exclusion of studies in the Technical Brief

PICOTSS	Inclusion	Exclusion
Population	<u>All Guiding Questions:</u> Childhood cancer survivors (CCS) of all ages. We accepted the authors' definition of CCS. Mixed samples were eligible where studies include at least 50% CCS or report a subgroup analysis. In studies not self-identifying as CCS research, we applied the following criteria: diagnosed before age 21, received primary acute treatment for any cancer, currently in remission, and currently receiving or eligible to receive survivorship care services, care plans, and/or models of follow-up care.	<u>All Guiding Questions:</u> Studies that predominantly included other populations than CCS, that included patients diagnosed predominantly after the age of 20, that had other conditions than cancer, or that were currently undergoing treatment for cancer.

PICOTSS	Inclusion	Exclusion
Independent variables and interventions	<p><u>Guiding Question 1:</u> Survivorship care. We included studies addressing healthcare approaches aimed at the health and well-being of cancer survivors.</p> <p><u>Guiding Question 2:</u> Barriers and facilitators of survivorship care for CCS.</p> <p><u>Guiding Question 3, 4, 5:</u> Strategies to address barriers to survivorship care and to reduce care disparities. We included care initiatives, structured care programs, care plan, care models, and healthcare interventions aiming to address barriers or disparities. Strategies may have targeted CCS (e.g., providing patient information), primary caregivers (e.g., parents), healthcare providers (e.g., initiating training), or healthcare systems (e.g., implementing health information technologies such as telemedicine).</p>	<p><u>All Guiding Questions:</u> Studies without reference to survivorship care and studies not addressing care disparities, barriers to care, or strategies outside of healthcare.</p>
Comparators	<p><u>Guiding Question 1, 2:</u> We accepted the authors' choice of a participant characteristic comparator. Studies could compare subgroups to the general population of CCS or compare multiple participant subgroups defined by participant characteristics (e.g., race/ethnicity, socioeconomic status, gender, rural residence, educational attainment or patient or their parents, other populations that experience health disparities).</p> <p><u>Guiding Question 3:</u> Strategies did not need to document alternative care models in detail as long as the difference of the proposed survivorship care strategy to usual care was described.</p> <p><u>Guiding Question 4, 5:</u> Studies comparing participant subgroups as defined in Guiding Question 1 and 2 and studies comparing to other care strategies (no intervention, waitlist, usual care, other active strategies aiming to address barriers or disparities).</p>	<p><u>All Guiding Questions:</u> Studies not addressing patient characteristics or intervention characteristics.</p>
Outcomes	<p><u>Guiding Question 1, 2:</u> Disparities and barriers (causes of disparity) in any patient outcomes related to utilization of survivorship care services, care plans, or models of care; intermediate health outcomes and adverse events; mortality; late effects and morbidity (including psychosocial); quality of life, well-being, and satisfaction with care; and cost and resource utilization.</p> <p><u>Guiding Question 3:</u> Strategies were documented regardless of any information on outcome effects, but strategies had to aim to prevent, reduce, or mitigate disparities and barriers to survivorship care.</p> <p><u>Guiding Question 4:</u> Changes (reduction) in disparities between comparison groups for outcomes listed in Guiding Question 1 and 2.</p> <p><u>Guiding Question 5:</u> Ongoing and upcoming studies had to indicate that the study will report on outcomes eligible for Guiding Question 1, 2, or 4.</p>	<p><u>All Guiding Questions:</u> Studies that did not address disparities or barriers to survivorship care for pediatric survivors.</p>
Timing	<p><u>All Guiding Questions:</u> No timing restriction applied. Studies may have addressed CCS who recently or long in the past experienced pediatric cancer now in remission.</p>	<p><u>All Guiding Questions:</u> No exclusions applied.</p>
Setting(s)	<p><u>All Guiding Questions:</u> All care settings applicable to US settings were eligible, including primary, secondary, and tertiary care; inpatient and outpatient care; pediatric and adult care context.</p>	<p><u>All Guiding Questions:</u> Studies in resource-limited settings such as developing countries were reviewed for comparability with US settings.</p>

PICOTSS	Inclusion	Exclusion
Study design and other limiters	<p><u>All Guiding Questions:</u> English-language publications.</p> <p><u>Guiding Question 1, 2, 4, 5:</u> Primary studies reporting empirical data (including both quantitative and qualitative data).</p> <p><u>Guiding Question 1, 2:</u> Studies may have either report on distinct subgroups (e.g., dividing the sample by geographic characteristic and reporting data separately for rural and for urban participants) or studies may report associations with participant characteristics (e.g., reporting correlations with a factor of interest such as gender differences).</p> <p><u>Guiding Question 3:</u> Strategies had to have been suggested by an authoritative source such as a clinical practice guideline or relevant professional organization.</p> <p><u>Guiding Question 4:</u> Studies with concurrent (e.g., randomized controlled trial) or historic comparator (e.g., organizational pre-post studies). Studies with results published in clinicaltrials.gov were included regardless of whether a journal publication was available.</p> <p><u>Guiding Question 5:</u> Ongoing and upcoming studies with a published protocol or registered in a research registry.</p>	<p><u>All Guiding Questions:</u> Evaluations reported only in abbreviated format (e.g., in a conference abstract) with the exception of trial records.</p> <p>Studies exclusively reported in non-English publications.</p> <p>Systematic reviews were retained for reference mining but are not eligible for inclusion.</p>

P = population; I = independent variables and interventions; C = comparators; O = outcomes; T = timing; S = setting(s); S = study design and other limiters; CCS = childhood cancer survivors

Screening and Abstraction

Literature screening and data abstraction were conducted in an online database designed for systematic reviews (DistillerSR). Literature reviewers screened all citations at the title and abstract level and citations determined to be potentially relevant to the Technical Brief were obtained as full text. Excluded citations were assessed for relevance using a machine learning algorithm in the database software that modeled the inclusion screening decisions of the human reviewers. We applied a conservative cut-off identifying all citations that the algorithm was more likely to include than to exclude. The algorithm confirmed the exclusion for the majority of citations. All citations not confirmed by the machine learning algorithm were screened by a second, independent human reviewer to avoid reviewer errors and bias.

Full text studies were screened by two independent reviewers against the explicit eligibility criteria; any disagreements were resolved by group discussion and consensus. The literature searches were updated during the peer review process for this report.

Data were abstracted by one reviewer and checked by an experienced content expert to confirm accuracy of data collected for all included studies. Data were collected regarding:

- Publication type and country of publication
- Study participant characteristics, including cancer type and proportion of CCS
- Guiding Question addressed
- Disparity category and description
- Barrier category and description
- Outcome(s) assessed and type of analysis
- Proposed or evaluated strategy and description
- Study design and expected date of completion for ongoing studies
- Survivorship care domain (e.g., survivorship care service, care plan, model of care)

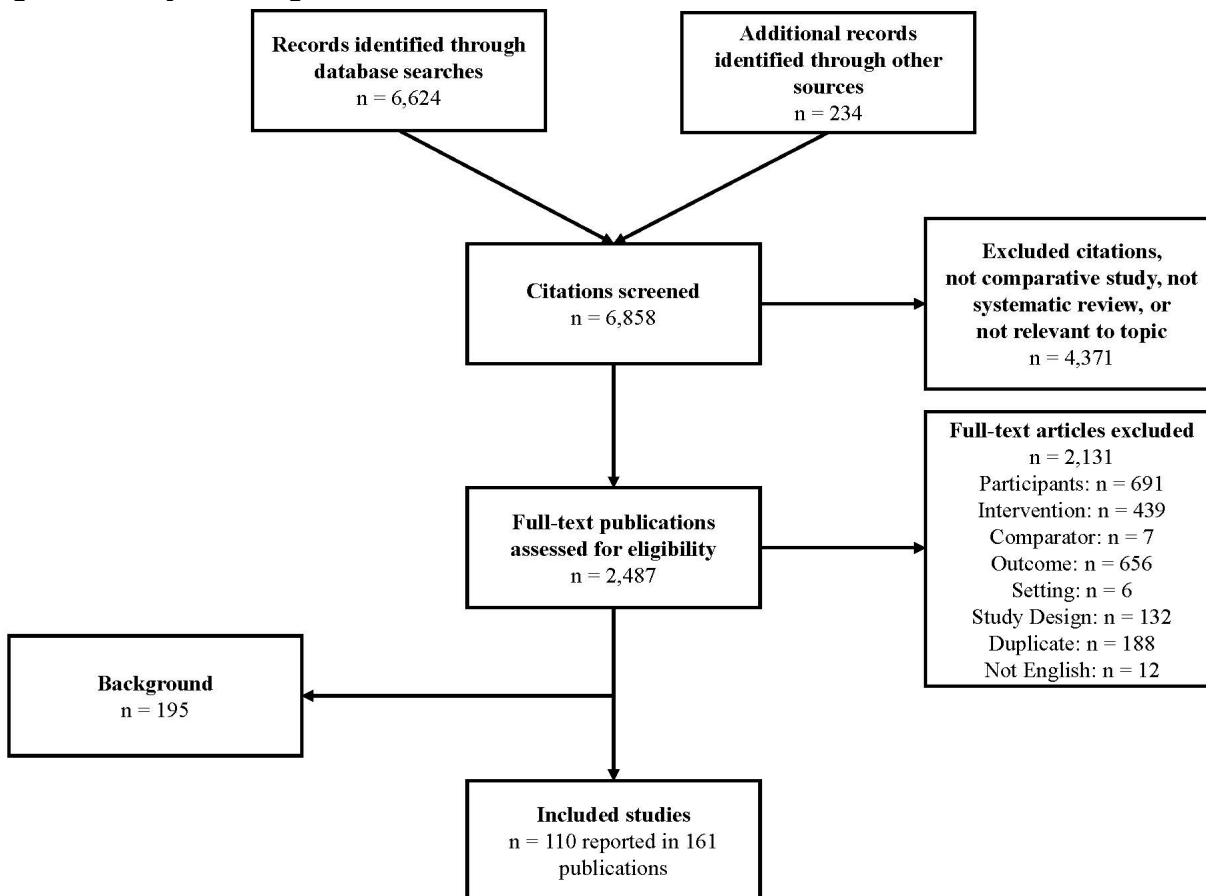
The outcomes of interest were categorized representing the following domains:

- Survivorship care domain (utilization of survivorship care services, care plans, or models of care)
- Biomedical domain (intermediate health outcomes and adverse events; clinical or physical late effects and morbidity; mortality)
- Psychosocial (psychological or health-related quality of life; education or employment; substance use)
- Health services/economics (primary care, specialty care, or other care utilization; quality and satisfaction with care; financial hardship, costs, resource utilization)

Findings

The brief was directed by five Guiding Questions, which documented and outlined our findings of Key Informant input, grey literature resources, and published and unpublished research. Figure 1 displays the number of studies included and excluded at each stage of the evidence review process for all Guiding Questions.

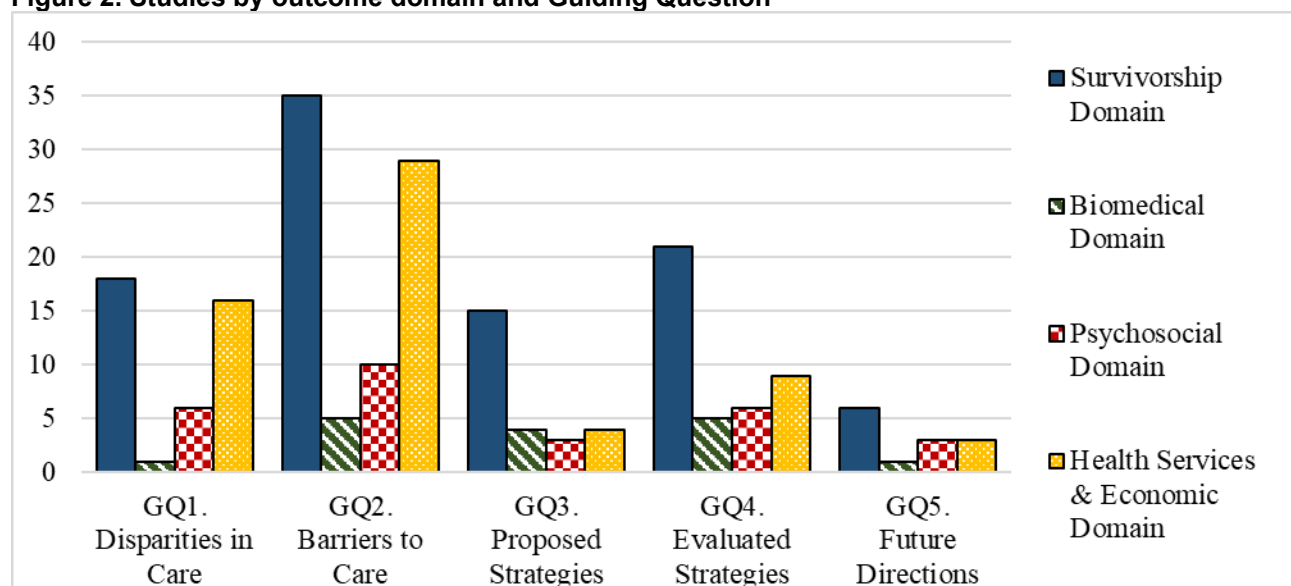
Figure 1. Study flow diagram



Appendix B lists excluded studies and reasons for exclusion. A large number of publications were retained as background. While not meeting inclusion criteria, the publications were cited in the introduction and discussion and/or were retained for reference-mining to identify additional studies where appropriate. A total of 110 studies reported in 161 publications were included to frame the findings of this Technical Brief.¹²⁻¹⁷² Appendix C details the discussion with the Key Informants. Appendix D provides evidence tables for each Guiding Question.

Figure 2 depicts the number of studies included by outcome domain and Guiding Question. A large number of studies addressed barriers to care (N = 47), followed by disparities in care (N = 26) and evaluated strategies (N = 27). Discussed less frequently were proposed strategies (N = 16) and future research directions (N = 8). Because an individual study could have addressed multiple outcomes of interest, the total indicated in the figure does not sum to the total number of included studies.

Figure 2. Studies by outcome domain and Guiding Question



Note: N = 110 studies; each individual study could have addressed multiple outcome domains and Guiding Questions (GQs).

Notably, most studies examined multiple outcome domains and more than one Guiding Question. The most frequently studied were survivorship care (N = 95) and health services and economic (N = 62) outcome domains; less frequently examined were psychosocial (N = 28) and biomedical (N = 16) outcome domains. Among the studies that examined survivorship, health services and economic, and psychosocial outcome domains, barriers to care (Guiding Question 2) were most frequently studied, followed by disparities in care (Guiding Question 1).

The following describes the results for the five Guiding Questions.

Guiding Question 1. What Are the Disparities in Survivorship Care for Pediatric Cancer Survivors?

Key Informants provided insight and detail regarding disparities experienced by childhood cancer survivors (CCS) concerning their survivorship care. Appendix C details the discussion with the Key Informants. The primary themes of disparities or challenges faced by CCS included a complex and multifactorial interplay of social determinants of health, such as socioeconomic hardship (e.g., income, medical bills, debt), lower educational attainment, detrimental employment factors (e.g., employment status, benefits, paid time off, sick leave), and inadequate insurance coverage (e.g., under/uninsured, type of insurance, churns/transitions in insurance coverage), and underserved minorities or groups (e.g., urban, rural, nonmetropolitan).

We identified 26 studies reporting on disparities in survivorship care and classified them by disparity category. In addition to the disparities identified by the Key Informants, disparities by biological sex, insurance, and race or ethnicity were commonly studied. The literature is documented in Table 2.

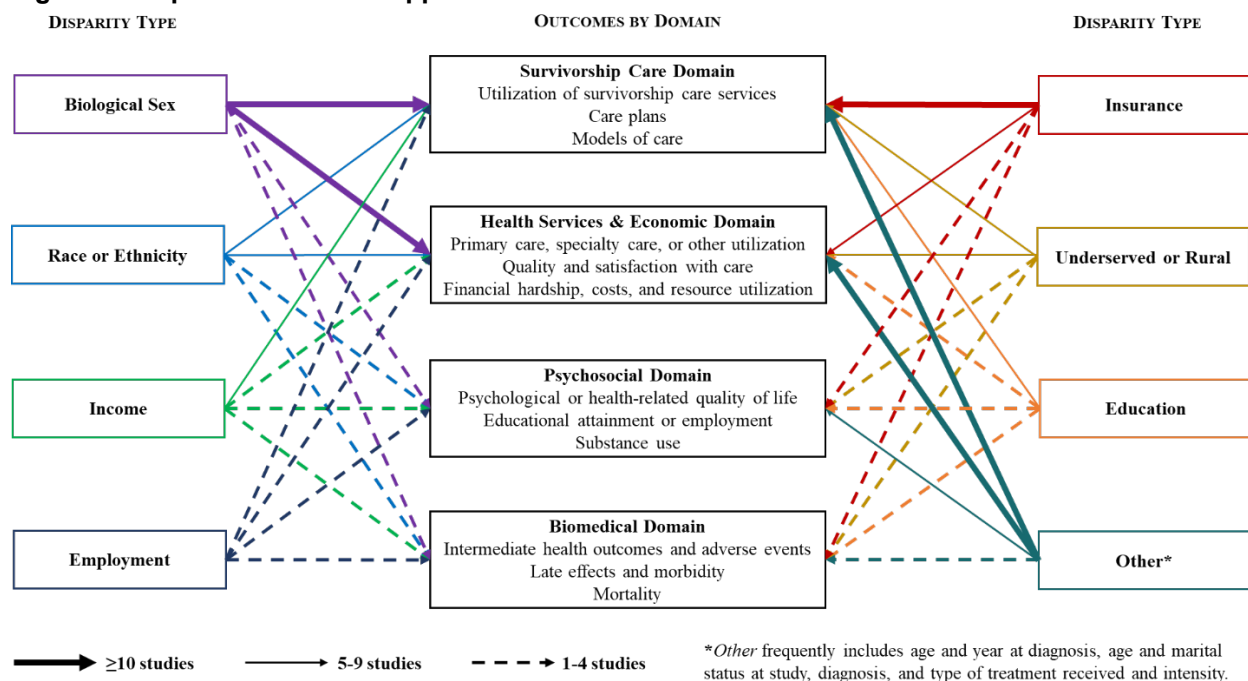
Table 2. Research on disparities in childhood cancer survivor care

Disparity Category	Number of Studies Identified Studies
Biological Sex	N = 15 Barakat, 2012 ¹⁸ ; Berg, 2016 ²⁰ ; Crom, 2007 ⁴⁷ ; de Fine Licht, 2017 ⁵⁰ ; Gardner, 2014 ⁶⁸ ; Holmes, 1986 ⁷⁶ ; McBride, 2011 ¹¹¹ ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Nathan, 2016 ¹²³ ; Oeffinger, 2004 ¹²⁷ ; Ojha, 2014 ¹³⁰ ; Streefkerk, 2019 ¹⁵⁷ ; vanLaar, 2013 ¹⁶⁴ ; Zheng, 2016 ¹⁷²
Insurance	N = 13 Barakat, 2012 ¹⁸ ; Berg, 2016 ²⁰ ; Berkman, 2019 ²¹ ; Crom, 2007 ⁴⁷ ; Daly, 2019 ⁴⁸ ; Gardner, 2014 ⁶⁸ ; May, 2017 ¹¹⁰ ; Milam, 2015 ¹¹⁷ ; Oeffinger, 2004 ¹²⁷ ; Ojha, 2014 ¹³⁰ ; Szalda, 2016 ¹⁶⁰ ; Welch, 2017 ¹⁶⁹ ; Zheng, 2016 ¹⁷²
Race or Ethnicity	N = 11 Barakat, 2012 ¹⁸ ; Berkman, 2019 ²¹ ; Casillas, 2011 ³² ; Crom, 2007 ⁴⁷ ; Daly, 2019 ⁴⁸ ; Gardner, 2014 ⁶⁸ ; May, 2017 ¹¹⁰ ; Milam, 2015 ¹¹⁷ ; Oeffinger, 2004 ¹²⁷ ; Ojha, 2014 ¹³⁰ ; Zheng, 2016 ¹⁷²
Underserved or Rural	N = 9 Barakat, 2012 ¹⁸ ; Crom, 2007 ⁴⁷ ; Daly, 2019 ⁴⁸ ; McBride, 2011 ¹¹¹ ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Nathan, 2016 ¹²³ ; Oeffinger, 2004 ¹²⁷ ; Sutradhar, 2015 ¹⁵⁸
Income	N = 8 Crom, 2007 ⁴⁷ ; Johnson, 2004 ⁸⁵ ; McBride, 2011 ¹¹¹ ; Mendoza, 2018 ¹¹³ ; Milam, 2015 ¹¹⁷ ; Nathan, 2016 ¹²³ ; Oeffinger, 2004 ¹²⁷ ; Zheng, 2016 ¹⁷²
Education	N = 5 Crom, 2007 ⁴⁷ ; Johnson, 2004 ⁸⁵ ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Oeffinger, 2004 ¹²⁷
Employment	N = 3 Crom, 2007 ⁴⁷ ; Michel, 2011 ¹¹⁶ ; Oeffinger, 2004 ¹²⁷
Other	N = 14 Crom, 2007 ⁴⁷ ; de Fine Licht, 2017 ⁵⁰ ; Gardner, 2014 ⁶⁸ ; Kazak, 1999 ⁹¹ ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Nathan, 2016 ¹²³ ; Oeffinger, 2004 ¹²⁷ ; Reppucci, 2017 ¹³⁶ ; Streefkerk, 2019 ¹⁵⁷ ; Sutradhar, 2015 ¹⁵⁸ ; vanLaar, 2013 ¹⁶⁴ ; Welch, 2017 ¹⁶⁹ ; Zheng, 2016 ¹⁷²

Overall, the most commonly studied groups that experience disparities were based on biological sex (N = 15), insurance (N = 13), and race or ethnicity (N = 11). The least studied disparities were those based on education (N = 5) and employment (N = 3). The other category of disparities predominantly captured age and year at diagnosis, age and marital status at study, diagnosis, and type of cancer treatment received and intensity, among other variables.

Figure 3 depicts assessed disparity categories and evaluated outcome domains in the included studies. Within types of disparities, the evidence showed that the more frequently studied disparities tied to the survivorship care outcome domain (survivorship care services, care plans, or models of care) were among biological sex and insurance (bolded arrows signifying ≥ 10 studies). The next most commonly examined type of disparities in the survivorship care outcome domain outcome was among racial or ethnic minorities, income, underserved or rural, and education disparities (the solid lines represent 5-9 studies). It is important to note that variables indicating examination of disparities in the literature could have been either independent or dependent variables, based on the individual study. Additionally, variables commonly categorized as social determinants of health (e.g., income, education, employment) were parsed out individually rather than considering these holistically to better understand disparities in care.

Figure 3. Disparities in care mapped to outcome domains



The second most assessed domain was the health services and economic domain. Study outcomes in the health services and economic domain included utilization of primary, specialty, or other care; quality and satisfaction with care; or financial hardship, costs, and resource utilization. Biological sex was most frequently documented in the literature among outcomes in the health services and economic domains (e.g., ≥ 10 studies). Outcomes in the biomedical and psychosocial domains were less frequently addressed (displayed by the dashed arrows in Figure 3 indicating 1 to 4 studies). Only six studies assessed either biomedical or psychosocial outcomes caused by one of the eight disparity types. Potential disparities examined by gender minorities (assessed by how someone identifies or expresses themselves) were not examined in any included studies; however, biological sex was the most frequently examined as a group that experiences disparities.

Guiding Question 2. What Are the Barriers to Survivorship Care for Pediatric Cancer Survivors Who Experience Disparities?

Key Informants also discussed barriers to survivorship care faced by CCS. Key Informants conveyed that barriers experienced by the patient and, by extension, their caregiver or family and local environment included a lack of knowledge or knowledge gaps in the need for life-long survivorship care; the inability to prioritize survivorship care in the midst of other life needs, a lack of adequate financial or employment resources (e.g., money for copayments or coinsurance, time off work, childcare); patient autonomy; the presence of cultural, language, and literacy difficulties; and mistrust in providers and the medical community, in general.

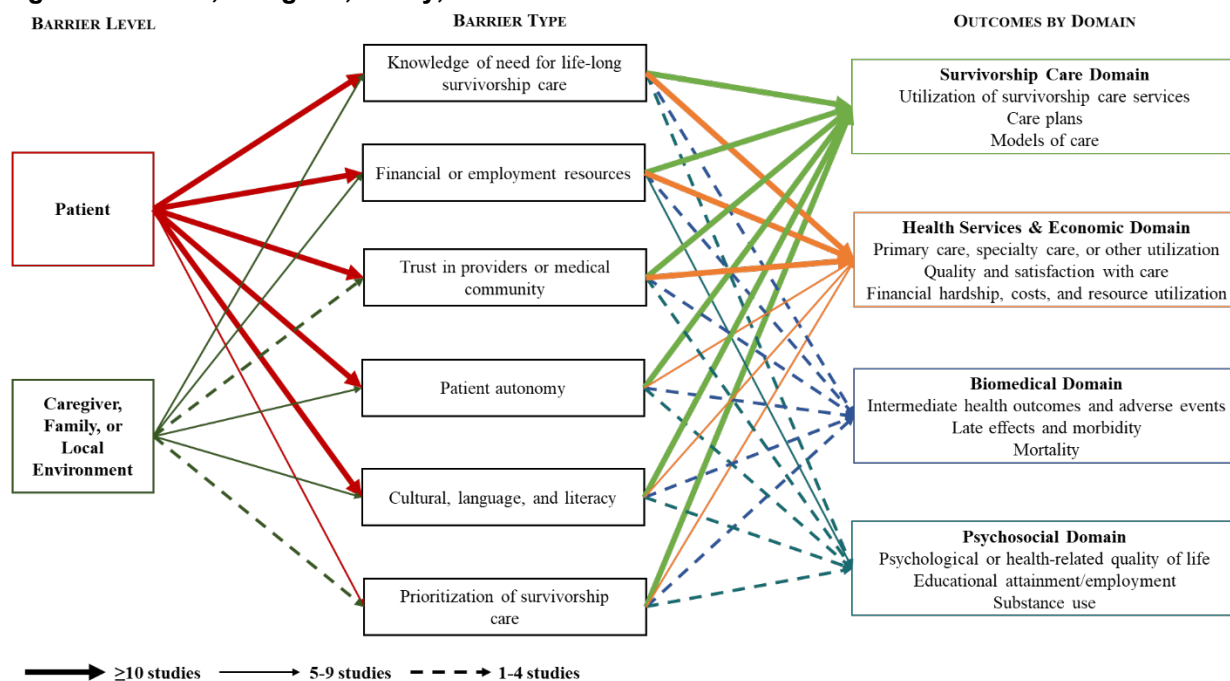
The primary themes of barriers impacting survivorship care can be organized by levels of care delivery (patient; caregiver, family, or local environment; provider; health system; and payer). Our literature searches identified 47 studies that assessed barriers to care in CCS. Table 3 stratified the identified studies by barrier level.

Table 3. Research on barriers to pediatric cancer survivorship care

Barrier Level	Number of Studies Identified Studies
Patient	N = 36 Ahn, 2017 ¹² ; Aziz, 2006 ¹⁷ ; Berg, 2016 ²⁰ ; Berkman, 2019 ²¹ ; Casillas, 2010 ³¹ ; Casillas, 2011 ³² ; Cherven, 2014 ³⁸ ; Crom, 2007 ⁴⁷ ; Eshelman-Kent, 2011 ⁶³ ; Frederick, 2017 ⁶⁶ ; Frobisher, 2008 ⁶⁷ ; Gardner, 2014 ⁶⁸ ; Granek, 2012 ⁷² ; Holmes, 1986 ⁷⁶ ; Howard, 2018 ⁷⁷ ; Iwai, 2017 ⁸² ; Jereb, 2000 ⁸⁴ ; Keats, 2019 ⁹² ; Kirchhoff, 2014 ⁹⁴ ; Knighting, 2020 ⁹⁷ ; Kuhlthau, 2016 ⁹⁹ ; Maeda, 2010 ¹⁰⁶ ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Mouw, 2017 ¹²⁰ ; Novakovic, 1997 ¹²⁶ ; Oeffinger, 2004 ¹²⁷ ; Quillen, 2017 ¹³³ ; Rosenberg-Yunger, 2013 ¹³⁹ ; Sadak, 2012 ¹⁴⁰ ; Sadak, 2017 ¹⁴² ; Sadak, 2020 ¹⁴¹ ; Szalda, 2016 ¹⁶⁰ ; vanLaar, 2013 ¹⁶⁴ ; Vetsch, 2017 ¹⁶⁵ ; Warner, 2014 ¹⁶⁸
Caregiver, Family, or Local Environment	N = 10 Ahn, 2017 ¹² ; Casillas, 2010 ³¹ ; Cherven, 2014 ³⁸ ; DiNofia, 2017 ⁵⁷ ; Jereb, 2000 ⁸⁴ ; Keats, 2019 ⁹² ; Michel, 2011 ¹¹⁶ ; Milam, 2015 ¹¹⁷ ; Oeffinger, 2004 ¹²⁷ ; Vetsch, 2017 ¹⁶⁵
Provider	N = 17 Aziz, 2006 ¹⁷ ; Casillas, 2011 ³² ; de Moor, 2007 ⁵¹ ; Eshelman-Kent, 2011 ⁶³ ; Henderson, 2010 ⁷⁴ ; Iyer, 2017 ⁸³ ; Jereb, 2000 ⁸⁴ ; Keats, 2019 ⁹² ; Li, 1976 ¹⁰⁴ ; Michel, 2011 ¹¹⁶ ; Mouw, 2017 ¹²⁰ ; Oeffinger, 2004 ¹²⁷ ; Sadak, 2017 ¹⁴² ; Sima, 2014 ¹⁵⁰ ; Vetsch, 2017 ¹⁶⁵ ; Warner, 2014 ¹⁶⁸ ; Wadhwa, 2019 ^{#5365}
Health System	N = 11 Aziz, 2006 ¹⁷ ; de Moor, 2007 ⁵¹ ; Eshelman-Kent, 2011 ⁶³ ; Howard, 2018 ⁷⁷ ; Mendoza, 2018 ¹¹³ ; Mouw, 2017 ¹²⁰ ; Oeffinger, 2004 ¹²⁷ ; Sadak, 2019 ¹⁴³ ; Sherman, 2004 ¹⁴⁷ ; Vetsch, 2017 ¹⁶⁵ ; Warner, 2014 ¹⁶⁸
Payer	N = 4 Hays, 1992 ⁷³ ; Mouw, 2017 ¹²⁰ ; Oeffinger, 2004 ¹²⁷ ; Sadak, 2012 ¹⁴⁰

The most frequently cited barrier was at the level of the patient (N = 36). Displayed in Figure 4 are the most commonly studied types of barriers to CCS' survivorship care, such as knowledge of the need for life-long survivorship care (N = 20) and financial or employment resources (N = 19), followed by trust in providers or the medical community (N = 18). Barriers identified at the patient level were commonly studied among all barrier types identified (e.g., ≥ 10 studies) with the exception of prioritization of survivorship care (N = 9); less frequently studied were barriers at the level of the caregiver, family, or local environment. All barrier types were commonly studied impacting the survivorship care domain outcome (e.g., ≥ 10 studies), which includes survivorship care services, care plans, or models of care. The types of barriers to care that impacted outcomes in the health services and economic domain (including utilization of primary, specialty, or other care; quality and satisfaction with care; or financial hardship, costs, and resource utilization) most frequently included knowledge of the need for life-long survivorship care (N = 13), financial or employment resources (N = 15), and trust in providers or medical community (N = 11). The biomedical and psychosocial outcome domains were less frequently reported as being impacted by patient or caregiver, family, or local environment barriers to care.

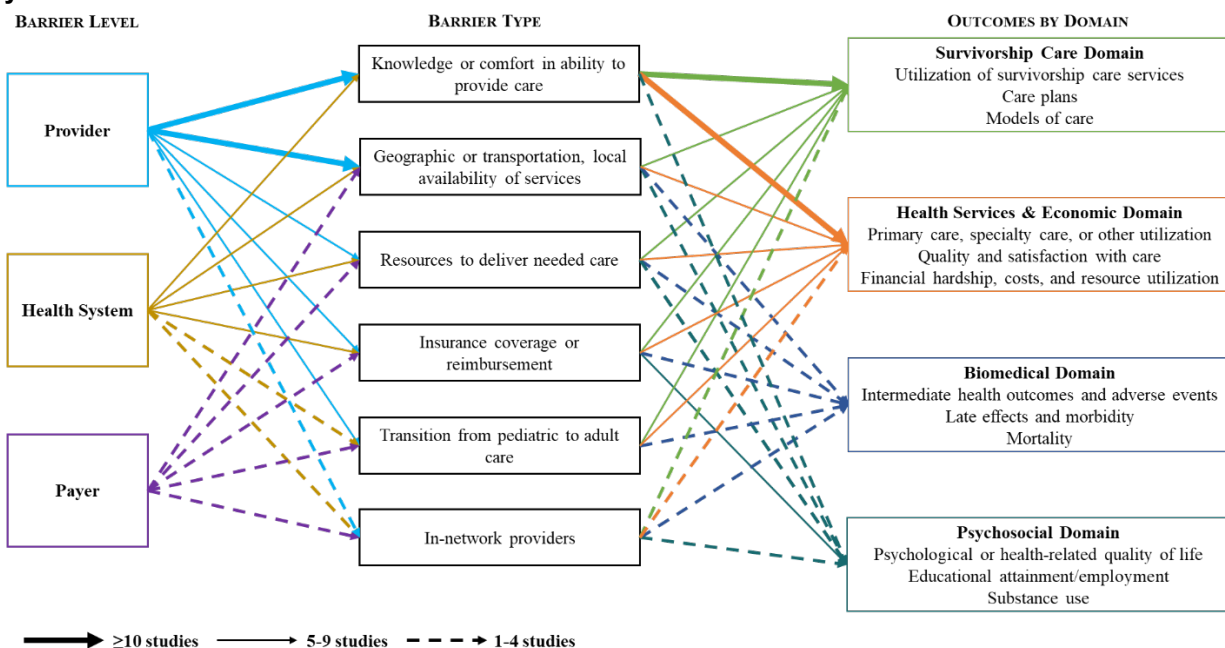
Figure 4. Patient, caregiver, family, and local environment barriers and assessed outcomes



At the provider, health system, and payer levels, barriers identified by our Key Informants included lack of adequate resources to deliver needed care; potential geographic obstacles and related lack of availability of specialized services; a difficulty or lack transitioning a CCS from pediatric to adult care; the lack of insurance coverage or reimbursement for complex services provided; and a lack of knowledge or comfort regarding follow-up care guidelines and/or recommended care; and lack of adequate in-network providers and specialists required to address long term health outcomes. Key Informants specifically discussed that payers may not be aware of follow-up care guidelines and/or recommended care for CCS, and this could lead to the barriers to accessing survivorship care.

The identified research literature discussed below mirrored the Key Informants' discussion regarding provider, health system, and payer level barriers to care (N = 23; see Figure 5).

Figure 5. Provider, health system, and payer barriers to survivorship care connection to outcomes by domain



Overall, the second most frequently cited barrier to survivorship care for CCS were at the provider (N = 17) and health system (N = 11) levels and the most commonly studied barrier types were knowledge or comfort in ability to provide care and geographic, transportation, or local availability of services (N = 12, respectively). The barrier types that were frequently cited as impacting the survivorship care outcome domain (encompassing survivorship care services, care plans, or models of care) and the health services and economic outcome domain predominantly studied were those barriers due to knowledge or comfort in the ability to provide needed care (≥ 10 studies).

Guiding Question 3. What Are Proposed Strategies for Addressing Those Barriers?

Proposed strategies to address disparities in and barriers to survivorship care were also discussed with Key Informants. The primary themes identified by Key Informants included improving dissemination and education of long-term follow-up guidelines to primary care providers and payers; combining forces with fellow advocacy groups that focus on chronic lifelong conditions that span from pediatrics to adulthood (e.g., diabetes) to increase awareness and resources for CCS; designing a risk-stratification tool for long-term follow-up surveillance (including prioritization and preference of follow-up provider); and instituting health policy changes that support providers via adequate education and reimbursement.

Through discussion with the Key Informants and grey literature searches, we identified a total of sixteen proposed strategies endorsed by different organizations and entities with an interest in CCS (see Table 4). All organizations acknowledged disparities regarding pediatric cancer survivorship care but the level of detail and specific recommendations regarding how to alleviate barriers experienced by CCS varied. In 1996, the International Society of Paediatric Oncology suggested that initiatives not only focus on clinical care, but also on educating the public, informing policy change, and educating CCS about future concerns (such as financial or

social issues as a result of their cancer diagnosis and treatment).¹⁰⁹ And, in 2003, the National Cancer Policy Board of what is now the National Academies of Sciences, Engineering, and Medicine proposed a comprehensive policy agenda to improve healthcare delivery, invested in education and training, and expanded research to improve the long-term outlook for CCS.⁸⁰ However many of the aims of these proposed strategies still remain as gaps today.

Table 4. Guiding Question 3: Proposed strategies

Author, Year Study Name/Trial ID	Country	Cancer Origin	Proportion of CCS	Strategy Type Strategy Title Strategy Description
Masera, 1996 ¹⁰⁹ International Society of Paediatric Oncology	Multiple countries	Multiple cancer origin	100%	Clinical Practice Guideline SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Care of Long-Term Survivors Establish a specialty clinic oriented to the preventive medical and psychosocial care of long-term survivors which includes public education and advocacy.
National Cancer Policy Board, 2003 ⁸⁰ National Academies of Sciences, Engineering, and Medicine	USA	Multiple cancer origin	100%	Policy Statement Childhood Cancer Survivorship: Improving Care and Quality of Life Comprehensive policy agenda that links improved healthcare delivery, investments in education and training, and expanded research to improve the long-term outlook for survivors of childhood cancer.
Goldsby, 2004 ⁷¹ International Society of Paediatric Oncology	Multiple countries	Multiple cancer origin	100%	Meeting Summaries and Recommendations International Society of Paediatric Oncology 2003 meeting summary of the Symposium on Long-Term Follow-up Guidelines Four models of survivorship care were endorsed with strengths and limitations.
Skinner, 2005 ¹⁵¹ United Kingdom Children's Cancer Study Group: Late Effects Subcommittee	UK	Multiple cancer origin	100%	Clinical Practice Guideline Therapy Based Long Term Follow Up: Practice Statement: United Kingdom Children's Cancer Study Group (Late Effects Group) Exposure-based clinical practice guidelines for pediatric cancer survivors.
Skinner, 2006 ¹⁵² UK Children's Cancer Study Group (UKCCSG) Late Effects Group (LEG)	UK	Multiple cancer origin	100%	Clinical Practice Guideline Long-Term Follow-Up of People Who Have Survived Cancer During Childhood Ideal survivorship strategy will be one that captures the largest number of long-term survivors by ensuring that appropriate clinical and psychosocial care, health education, and health promotion advice are all delivered in an appropriate manner at an appropriate location, while taking advantage of important research opportunities that will benefit future generations of survivors.
Children's Oncology Group Nursing Discipline, 2007 ⁴¹	USA	Multiple cancer origin	50% or more	Meeting Summaries and Recommendations Establishing and Enhancing Services for Childhood Cancer Survivors: Long-term follow-up program resource guide Healthcare organizations and providers should deliver care and alleviate barriers to survivorship care for pediatric survivors.
American Academy of Pediatrics, 2009 ¹⁴	USA	Multiple cancer origin	100%	Clinical Practice Guideline Long-Term Follow-Up Care for Pediatric Cancer Survivors Follow up care for pediatric cancer survivors concerning detecting serious late effects and promoting healthy lifestyles.

Author, Year Study Name/Trial ID	Country	Cancer Origin	Proportion of CCS	Strategy Type Strategy Title Strategy Description
Late Effects Taskforce of the Dutch Childhood Oncology Group, 2010 ¹⁰³	Netherlands	Multiple cancer origin	100%	Clinical Practice Guideline Guidelines for Follow-Up after Childhood Cancer More Than 5 Years After Diagnosis Exposure-based clinical practice guidelines for pediatric cancer survivors.
Scottish Intercollegiate Guidelines Network, 2013 ¹⁴⁶	UK	Multiple cancer origin	100%	Clinical Practice Guideline Long term follow up of survivors of childhood cancer Exposure- and risk- based clinical practice guidelines for pediatric cancer survivors.
American Academy of Pediatrics, 2014 ^{15, 16}	USA	Multiple cancer origin	100%	Policy Statement Standards for Pediatric Cancer Centers Strategies for helping survivors transition to primary care with emphasis on pediatric cancer centers.
Eshrich, 2017 ⁶¹ Working Group on Adolescents, Young Adults, and Transition (Arbeitsgemeinschaft Adoleszenten, junge Erwachsene, Transition)	Germany	Multiple cancer origin	Less than 50%	Meeting Summaries and Recommendations Building a National Framework for Adolescent and Young Adult Hematology and Oncology and Transition from Pediatric to Adult Care: Report of the Inaugural Meeting of the Working Group of the German Society for Pediatric Oncology and Hematology Establish a solid infrastructure for transition nationwide so that transition in care can start during adolescence.
Children's Oncology Group, 2018 ⁴²	USA	Multiple cancer origin	50% or more	Clinical Practice Guideline Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers Exposure-based clinical practice guidelines for pediatric cancer survivors.
Cancer Leadership Council, 2019 ^{25, 26}	USA	Multiple cancer origin	Less than 50%	Policy Statement Improve the Delivery of Survivorship Care Encouraged Congress to explore how to define and finance distinct episodes of survivorship care and encouraged the Centers for Medicare and Medicaid Innovation to carefully consider what to base payment for survivorship care on.
Denlinger, 2020 ⁵³ National Comprehensive Cancer Network	USA	Multiple cancer origin	Less than 50%	Clinical Practice Guideline National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology: Survivorship Clinical practice guidelines for cancer survivors, including focus on screening for cardiovascular, psychosocial, and chronic pain late effects and receipt of immunizations to prevent infections for pediatric survivors.
International Guideline Harmonization Group, 2020 ⁸¹	Multiple countries	Multiple cancer origin	50% or more	Clinical Practice Guideline Long-Term Follow-Up Guidelines Surveillance recommendations regarding what surveillance modalities should be used, at what frequency surveillance should be performed, and what interventions are available if abnormalities are found.
Children's Cancer Cause, 2020 ^{37, 39, 40}	USA	Multiple cancer origin	100%	Policy Statement Childhood Cancer Survivorship Proposal Endorsed testing of a comprehensive new model of care and survivorship care plan initiative (Child and Survivorship Transition Model), which uses local service delivery and state payment for those covered by Medicaid, coupled with the Children's Oncology Group record – Summary of Cancer Treatment (Comprehensive) and a survivorship care plan; endorsed improving access to survivorship care via

Author, Year Study Name/Trial ID	Country	Cancer Origin	Proportion of CCS	Strategy Type Strategy Title Strategy Description
				digital technology, improved data collection, and addressing barriers to clinical trial participation for survivors.

CCS = childhood cancer survivors

At the International Society of Paediatric Oncology annual meeting in 2004, a spectrum of models of care with four types were endorsed ranging from least intensive or involved (survivor is given the responsibility to seek their own follow-up care) to most intensive or involved (new genre of family physicians/internists with knowledge of pediatric cancer late effects and local physicians working in close cooperation with the specialty follow-up clinic).⁷¹ The Children’s Oncology Group (COG), the United Kingdom Children’s Cancer Study Group: Late Effects Subcommittee, the Late Effects of Childhood Cancer task force of the Dutch Childhood Oncology Group, and the Scottish Intercollegiate Guidelines Network all endorse exposure-based clinical practice guidelines targeting CCS for the surveillance, prevention, management, and treatment of late effects.^{42, 103, 146, 151} Furthermore, the International Guideline Harmonization Group (IGHG) is working to bring together international experts to develop consistent, effective, and efficient recommendations for CCS.⁸¹ The American Academy of Pediatrics and National Comprehensive Cancer Network (NCCN) have endorsed specific strategies to minimize the burden of disparities and alleviate barriers to care for CCS.^{14, 53} The NCCN Clinical Practice Guidelines in Oncology: Survivorship frequently reference assessing barriers to care with the patient; however, the only reference regarding how to address barriers to care was pertaining to barriers to physical activity.⁵³

More recently, organizations such as the American Academy of Pediatrics, the Working Group on Adolescents, Young Adults, and Transition (Arbeitsgemeinschaft Adoleszenten, junge Erwachsene, Transition) in Germany, and the COG Nursing Discipline have endorsed specific strategies to deliver care to CCS, including the use of a survivorship care plan and transition clinics to assist CCS’ and their families with transitioning from pediatric to adult care settings.^{15, 41, 61} In 2019, the Cancer Leadership Council, representing a variety of cancer-related organizations, suggested that Congress explore how to define and finance distinct episodes of survivorship care and encouraged the Centers for Medicare and Medicaid Innovation to carefully consider what to base payment for survivorship care on.²⁶ More recently, the Children’s Cancer Cause endorsed the creation of a new demonstration project called the Child and Survivorship Transition Model, which would allow testing of a new model of care and survivorship care plan initiative with local service delivery and state payment for those covered by Medicaid.³⁹ As endorsed, the model would address barriers to survivorship care including staffing capacity, electronic medical records, interoperability of medical records, and legal constraints regarding confidentiality.³⁹ Furthermore, the Children’s Cancer Cause endorsed improving access to survivorship care via digital technology (e.g., telehealth, integration of existing survivorship platforms), improved data collection (e.g., focus on insurance, survivorship care planning, and longitudinal studies), and addressing barriers to clinical trial participation for survivors (e.g., required coverage for routine costs for those insured by Medicaid, alleviating the burden of incidental costs such as food, housing, and transportation).³⁹

Guiding Question 4. What Published and Unpublished Studies Have Assessed These Strategies?

Key Informants were also asked about studies that have evaluated strategies to decrease or alleviate disparities and barriers to survivorship care. It was evident from the discussion that content experts thought there is only very limited information in the research literature (published or unpublished) that have assessed strategies to overcome barriers to pediatric cancer survivorship care. The Key Informants also mentioned that older research does not necessarily reflect the contemporary US or CCS populations and thus has limited applicability or relevance now. Key Informants proposed reasoning for why strategies have not been assessed, including lack of data, the heterogeneous nature of CCS, and difficulties obtaining funding and support to study these strategies.

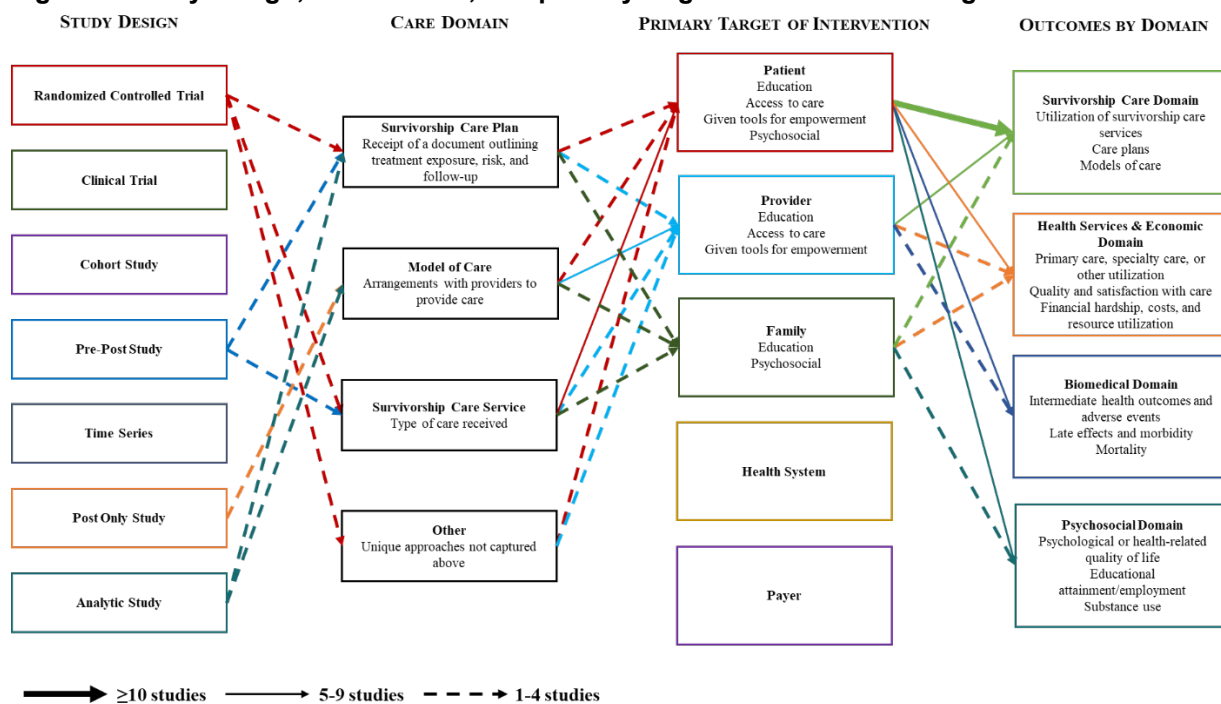
Our searches identified 27 studies reporting on an evaluation of a strategy to alleviate disparities and barriers to pediatric cancer survivorship care (see Table 5). The strategies were categorized by survivorship care domain, which included establishing survivorship care plans (N = 11; e.g., receipt of a document outlining treatment exposure, risk, and follow-up care needs), implementing models of care (N = 11; e.g., arrangements with providers to provide care), specific survivorship care services (N = 9; type of care received), and other, unique approaches (N = 6).

Table 5. Research on evaluated strategies to overcome disparities and barriers to pediatric cancer survivorship care

Survivorship Care Domain	Number of Studies Identified Studies
Survivorship care plan	N = 11 Bashore, 2016 ¹⁹ ; Blaauwbroek, 2012 ²³ ; Casillas, 2019 ³⁴ ; Hudson, 2020 ⁷⁸ ; Iyer, 2017 ⁸³ ; Kadan-Lottick, 2018 ⁸⁸ ; Kunin-Batson, 2016 ¹⁰⁰ ; Landier, 2015 ¹⁰² ; Oeffinger, 2011 ¹²⁹ ; Santacroce, 2010 ⁸⁶ ; Williamson, 2014 ¹⁷⁰
Model of care	N = 11 Bashore, 2016 ¹⁹ ; Blaauwbroek, 2008 ²⁴ ; Costello, 2017 ⁴⁵ ; Ducassou, 2017 ⁵⁸ ; Eilertsen, 2004 ⁵⁹ ; Ford, 2013 ⁶⁴ ; Hudson, 2020 ⁷⁸ ; Iyer, 2017 ⁸³ ; Kadan-Lottick, 2018 ⁸⁸ ; Reynolds, 2019 ¹³⁷ ; Williamson, 2014 ¹⁷⁰
Survivorship care service	N = 9 Casillas, 2017 ³⁰ ; Casillas, 2019 ³⁴ ; Casillas, 2020 ³⁵ ; Costello, 2017 ⁴⁵ ; Devine, 2020 ⁵⁵ ; Oeffinger, 2019 ¹²⁸ ; Raj, 2018 ¹³⁴ ; Santacroce, 2010 ⁸⁶ ; Schwartz, 2019 ¹⁴⁴
Other	N = 6 Casillas, 2019 ³⁴ ; Crom, 2007 ⁴⁷ ; de Moor, 2011 ⁵² ; Iyer, 2017 ⁸³ ; Rose; Felker, 2019 ¹³⁸ ; Schwartz, 2018 ¹⁴⁵

All identified studies are documented in detail in Appendix D and displayed visually in Figure 6. Almost all of the evaluated strategies (N = 24) have been published in the last ten years. With the exception of the studies targeting providers (N = 3), all of the evaluated strategies have been examined using cohorts of patients diagnosed with a variety of pediatric malignancies (N = 25). Analytic studies (N = 8) and randomized controlled trials (N = 7) made up the majority of identified study designs. Most studies evaluated interventions involving survivorship care plans or models of care (N = 11, respectively), followed by survivorship care service (N = 9) and other (N = 6). Studies almost always targeted the patient (≥ 10 studies) rather than providers or organizations. Figure 6 depicts the available literature.

Figure 6. Study design, care domain, and primary target of evaluated strategies



The majority of evaluated strategies assessed survivorship care as a primary or secondary outcome of interest (N = 21). Other outcome domains less frequently cited included: health services and economics (N = 9), psychosocial (N = 6), and biomedical (N = 5) domains.

Among the randomized controlled trials (N = 7) and clinical trials (nonrandomized, quasi-experimental studies; N = 3), models of care (N = 6) and survivorship care services (N = 4) were frequently examined either on their own or in combination. The primary targets of the interventions among the randomized controlled trials and clinical trials were patients in all studies; however, two studies had primary targets of both patients and providers and one study targeted patients and family members. Of the ten randomized controlled trials and clinical trials, six used education interventions and/or intervened by giving tools for empowerment. Less frequently studied were interventions providing access to care (N = 2) or psychosocial support (N = 1).

Among the cohort (N = 3), pre-post (N = 4), time series (N = 1), post-only (N = 1), and analytic (N = 8) studies, models of care were most frequently evaluated (N = 8), followed by survivorship care plans and survivorship care services (N = 5, respectively). The primary targets of these studies were almost always patients (N = 14); less frequently targets of the intervention were providers (N = 5) and family members (N = 3). Three of the five provider focused studies examined interventions only involved the providers themselves (e.g., no patients). Of these 17 studies, most evaluated educational interventions (N = 9; all but two of these involved the patient), followed by access to care interventions (N = 6), giving tools for empowerment (N = 3), and psychosocial support (N = 2).

Technology

A total of 10 studies evaluated strategies that used technological-based interventions, all of which involved the patient, two involving both the patient and family and one involving the patient and provider. An evaluation of a Web-based informational intervention reported no

improvement in cancer-related knowledge or anxiety surrounding health beliefs.¹⁰⁰ In another study, CCS reported satisfaction, benefits, and ease of use regarding self-management of their health and use of survivorship care plan as a result of a text messaging pilot.¹⁴⁴ In another text messaging intervention, CCS reported improved survivorship care knowledge, healthcare self-efficacy, and increased positive attitudes towards survivorship care.³⁴ An intervention using a photonovela among Hispanic/Latino CCS, reported improvement in confidence related to survivorship care, effects on cancer stigma among family members, and improved knowledge of survivorship care among family members.³⁵ One study found that text messaging was an acceptable way to communicate with CCS regarding both reminders about upcoming survivorship care needs and tailored suggestions for resources available in the community.³⁰ Survivors felt that communicating via text message could help alleviate barriers to care, enhance self-management, and assist CCS in reaching their health goals. Similar sentiments from patients were found in a study using telemedicine to facilitate transition of survivorship care from pediatric oncologists to adult primary care providers.⁴⁵ This service improved patient knowledge of survivorship care needs and overall satisfaction; the only negative comments addressed difficulties with the equipment.

The remaining two studies evaluated a Web-based platform. In one study, SurvivorLink provided a personal health record that was securely stored and electronically shared with the patients' providers.¹⁷⁰ The strongest predictor of registering and using the platform was having attended a survivorship clinic. Providing both an electronic and paper-based survivorship care plan that could be shared electronically with providers showed that most survivors and providers found the website user-friendly and the care plan availability helpful.²³ The majority of survivors reported that their knowledge of late effects had improved and they had become more aware of how survivorship care can be beneficial. One study reported positive effects for a Web-based psychosocial intervention called "A Survivor's Journey" for pediatric brain tumor survivors and caregivers.¹³⁴ One study found that encouragement by CCS' oncologist or regular doctor to quit smoking resulted in an increase in the number of cessation attempts.⁵²

Education

In a recent study, a self-management and peer mentoring intervention found a positive relationship regarding transition readiness and grit.⁵⁵ An evaluation of an educational intervention targeting CCS who attend a survivorship clinic reported female survivors reported higher knowledge than male survivors.⁴⁷ In a sample of female CCSS participants, motivational interviewing showed improved use of screening mammography.¹²⁸ Additionally, survivorship care plans mailed to high-risk survivors appeared to be feasible and effective to deliver information regarding late effects and surveillance needs and resulted in improved compliance with guideline-concordant survivorship care.¹²⁹ Similarly, a distance-delivered intervention of two personalized telephone counseling sessions increased cardiomyopathy screening among at-risk survivors, therefore improving compliance with guideline-concordant survivorship care.⁷⁸

Two evaluated strategies used educational approaches in an effort to improve outcomes in the survivorship care domain. One assessed the usefulness of a workbook to assist CCS in transition readiness and reported that the most helpful sections of the workbook were information regarding medical history, provider information, and insurance.¹⁹ A risk-based education intervention among CCS already engaged in a survivorship clinic found an increase in awareness of personal health risk in CCS after three sessions.¹⁰²

Three studies evaluated the effect of an intervention addressing healthcare providers. One followed up on survivorship care plans that had been mailed to CCS's primary care providers that the most significant barrier to providing survivorship care was the provider's lack of knowledge and level of comfort.⁸³ After completing an educational intervention, pediatric cardiologists' reported increased knowledge of CCS' needs for surveillance, risk due to treatment received, potential cardiac dysfunction as time since treatment increases, cardioprotective methods, use of a Web-based risk-assessment tool to estimate risk in CCS experiencing heart failure before the age of 40, and that African American CCS are at particular increased risk of late effects impacting their cardiovascular health.¹³⁸ Lastly, residents' knowledge, skills, and comfort discussing topics related to survivorship care improved after receiving CCS-focused curriculum.¹⁴⁵

Shared Care, Collaboration, and Location-Based Strategies

Four studies used shared care models of survivorship care. One examined the effect of shared care between an oncologist and primary care provider and found that those who used the shared care model experienced an improvement in CCS adherence to survivorship care.⁵⁸ However, empowering CCS with the distribution of a survivorship care plan and implementation by primary care providers, in comparison to a traditional approach to survivorship care using a survivorship clinic model, resulted in lower adherence to guideline-recommended care and identification of late effects.⁸⁸ A phone-based coping skills training that also discussed plans for surveillance among CCS (primary target) and their parents' (secondary target) found that outcomes improved including post-traumatic growth; however, among those that were in the comparison group, outcomes remained the same or decreased.⁸⁶ Lastly, survivors and local primary care providers participated in a shared care model over three years.²⁴ Advantages of locally-delivered primary care using this shared care model were less travel required for the patient, shorter waiting times for appointments, better patient familiarity with the clinical setting, and less stigmatization.²⁴

Three studies evaluated collaboration- or location-based strategies to improve survivorship care. One reported that collaboration among CCS, family members, and health professionals in the family's home community is beneficial and valuable for survivorship care adherence.⁵⁹ A second reported a higher compliance rate with COG-recommended guidelines in cancer-center based facilities compared to primary care or community-based facilities.¹³⁷ However, the third study found no significant differences in CCS knowledge regarding their cancer diagnosis or potential risk for future health problems (including psychosocial or emotional struggles) among those who attended specialized survivorship clinics when compared to those seen in a nonspecialized clinic.⁶⁴

Guiding Question 5. What Are Future Directions for Research in Addressing Barriers to Survivorship Care for Pediatric Cancer Survivors?

All Key Informant discussions concluded with dialogue surrounding future directions for research to address barriers and disparities to survivorship care among CCS. The primary themes for future directions for research included:

- Developing patient and family-endorsed measures of social determinants of health that are amenable to intervention

- Use of technology and advanced analytic methods to predict and automate risk stratification (low-, intermediate-, or high-risk) for CCS during and after their treatment in order to facilitate transitions and long-term access to care and support
- Identifying where effective patient and provider relationships can be emphasized, including identification of care teams and formalized planning for transitions of care
- Creating a data commons for data sharing and promoting interoperability; and,
- Increasing awareness among funders that pediatric cancer survivorship research is essential, needs financial support, and would benefit from the removal of barriers to submitting grant applications (e.g., exclusion of CCS in funding opportunity announcement and requests for applications).

Our literature searches identified eight ongoing studies assessing strategies that targeted reducing disparities and barriers to survivorship care for CCS (Table 6). Studies addressing Guiding Question 5 addressed survivorship care service (N = 4; e.g., type of care received), survivorship care plan (N = 4; e.g., receipt of a document outlining treatment exposure, risk, and follow-up care needs), models of care (N = 2; e.g., arrangements with providers to provide care), and other (N = 1).

Table 6. Ongoing studies to assess strategies targeting reducing disparities and barriers

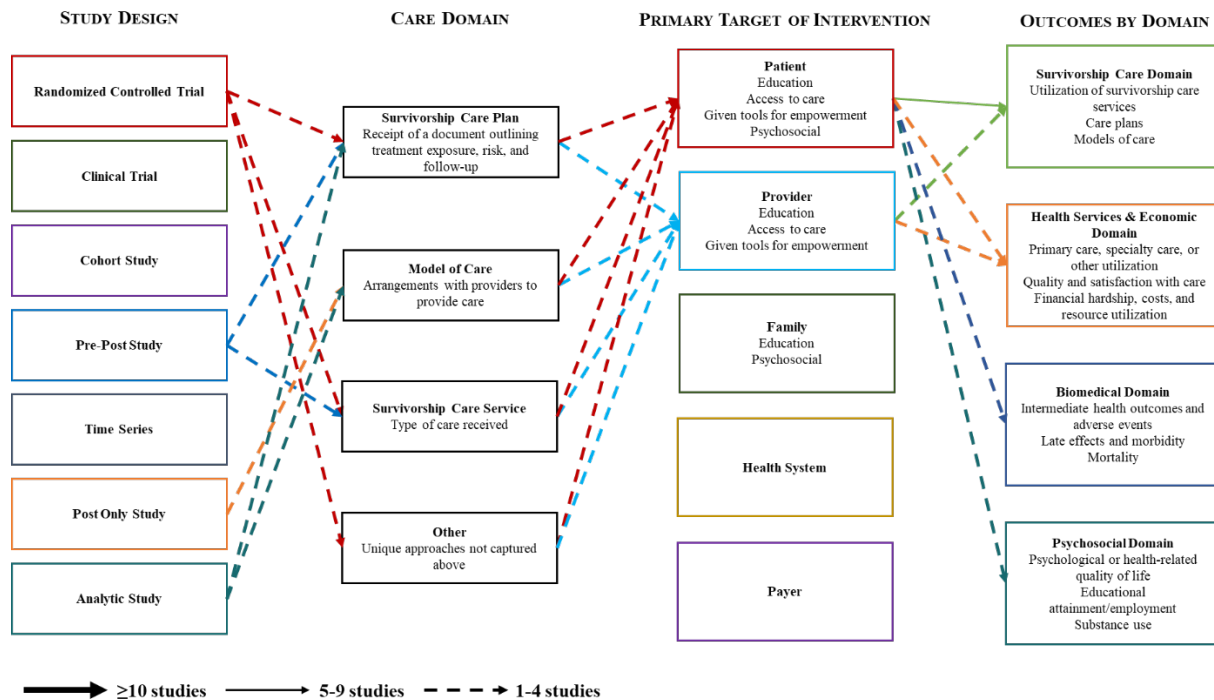
Survivorship Care Domain	Number of Studies Identified Studies
Survivorship care service	N = 4 Chow, 2020 ⁴³ ; Devine, 2019 ⁵⁶ ; Escoffery, 2019 ⁶² ; Marchak, 2020 ¹⁰⁷
Survivorship care plan	N = 4 Devine, 2019 ⁵⁶ ; Escoffery, 2019 ⁶² ; Hill-Kayser, 2020 ⁷⁵ ; Marchak, 2020 ¹⁰⁷
Model of care	N = 2 Denzler, 2020 ⁵⁴ ; McClellan, 2015 ¹¹²
Other	N = 1 Daniel, 2015 ⁴⁹

Half of the ongoing studies are randomized controlled trials (N = 4) and the remaining are pre-post (N = 1), post-only (N = 1), and cross-sectional analytic studies (N = 2). Survivorship care services and care plans (N = 4, respectively) are the most frequently addressed domain of care, with the primary target most often being the patient (N = 5) or patient and provider together (N = 2).

Similar to Guiding Question 4, half of the ongoing studies evaluate patient education approaches (N = 4). The remaining studies evaluate the patient being given tools for empowerment (N = 2), access to care (N = 2), and the provider being given tools for empowerment (N = 1). Providers were only cited as one of the primary targets of an intervention when coupled with a patient intervention (N = 2), and no ongoing studies were identified that focus their interventions on family members, health systems, or payers.

Figure 7 depicts the identified studies.

Figure 7. Study design, care domain, and primary target of ongoing studies assessing strategies mapped to outcomes by domain



Currently, four studies are underway and planned to be completed between 2021 and 2023.^{43, 54, 62, 107} Two evaluate a patient-targeted education intervention, one with and one without a survivorship care plan, both of which focus on survivorship care service as an outcome.^{43, 107} Notably, only one study was designed to directly address disparities in survivorship care, and uses a sample of patients predicted to be at high-risk based on their treatment exposure.⁴³ One study investigates which long-term follow-up care model (or parts of the model) are the best fit for Swiss CCS, while evaluating transition readiness, facilitators to transition readiness, and adherence to survivorship care.⁵⁴ This study also compares the transition models across the three participating centers.⁵⁴ One study uses a Web-based, patient-controlled personalized health record (SurvivorLink) to evaluate survivorship care services.⁶² Two studies indicated completion by the end of 2020, both evaluate an online survivorship care plan.^{56, 75} One of these studies examines the feasibility and acceptability of an online survivorship care plan for adult CCS.⁷⁵ The other study empowers patients through an online self-management skills and peer mentoring intervention to remove barriers to survivorship care.⁵⁶

Two of the seven ongoing studies have yet to report their findings and have passed their expected completion date.^{49, 112} One of these studies examines a model of care by providing transition support from oncology to adult primary care by a nurse navigator in combination with follow-up care with a primary care provider who is knowledgeable about late effects for CCS.¹¹² The other is focused on skin examination using a dual-approach of providing education to the patient and provider and tools for empowerment to the provider.⁴⁹ More detail is documented in Appendix D, Table D4.

Summary and Implications

This review of the literature, in conjunction with feedback from Key Informants and grey literature, documents disparities, barriers, and strategies to overcome potential barriers to care among childhood cancer survivors (CCS).

What Are the Disparities in Survivorship Care for Pediatric Cancer Survivors?

A total of 26 studies investigated disparities in survivorship care for pediatric cancer survivors. Disparities by biologic sex and insurance were most frequently addressed. Disparities by educational attainment and employment status were less frequently documented in the literature. The survivorship care and health services and economic domains were more commonly studied in relation to disparities for CCS; however, biomedical and psychosocial outcome domains were less frequently studied with disparities. The literature documents that pediatric cancer survivors are experiencing disparities in survivorship care. These survivors are likely at higher risk of poor long-term health outcomes, psychosocial distress, lower social and work productivity, and early mortality compared to other survivors.

What Are the Barriers to Survivorship Care for Pediatric Cancer Survivors Who Experience Disparities?

A total of 47 studies were identified that have assessed specific barriers to receipt of survivorship care, and many studies overlapped in describing disparities and barriers. Barriers can be organized at the level of the patient; caregiver, family member, or community; at the level of the provider; at the level of the health system; and at the level of the payer. Barriers at the level of the patient have been most frequently assessed thus far. For example, CCS may not recall (or have never been told about) their need for life-long survivorship care – and in fact, this was one of the most frequently examined barriers to survivorship care identified through our reviews. Furthermore, lack of adequate financial or employment resources was studied equally as much, and trust in providers or the medical community was closely behind and are commonly studied with the survivorship care and health services and economic outcome domains.

Barriers to care at the provider and health system levels are also associated with CCS' ability to improve outcomes related to survivorship care, biomedical, psychosocial, and health services and economic domains. Most commonly studied are barriers at the level of the provider, including resources needed to deliver care; geographic, transportation, or local availability of services; and knowledge or comfort in ability to provide needed care were noted – all of which significantly act as barriers to survivorship care.

What Are Proposed Strategies for Addressing Those Barriers?

Along with the results from the published studies that have identified barriers and disparities, the need for strategies aimed at addressing these barriers are frequently acknowledged. We found a total of 16 organizations that acknowledged disparities regarding pediatric cancer survivorship care. However, specific recommendations regarding how to alleviate barriers experienced by CCS are limited. Although additional data and research are clearly needed, initial strategies based on the current literature include: increasing access to care, improving health insurance enrollment and coverage, enhancing continuity of care, knowledge of the need for survivorship care, knowledge of long-term follow-up guidelines, and implementation of risk-stratified care.

What Published and Unpublished Studies Have Assessed These Strategies?

We only found 27 published studies evaluating the effectiveness of strategies to reduce barriers and disparities to pediatric survivorship care. Studies have predominantly focused on addressing barriers at the patient level, most frequently evaluating education-based interventions, followed by access to care and empowerment interventions. Only a few assessed overcoming barriers at the provider level. A minority of evaluated interventions involved a family member, coupled with patient- and provider-based studies, using education or psychosocial interventions. Only one was designed to specifically address disparities in survivorship care. We did not find any studies assessing strategies addressing barriers at the healthcare system or payer levels. Until we have a better understanding of what will be effective in overcoming barriers to survivorship care at all levels that impact CCS outcomes, disparities may persist.

What Are Future Directions for Research in Addressing Barriers to Survivorship Care for Pediatric Cancer Survivors?

Eight ongoing studies were identified that included directions for future research in addressing barriers to survivorship care for pediatric cancer survivors. Despite the number of studies reporting disparities and barriers, few studies evaluate approaches to overcoming barriers and lessening disparities. Only one identified ongoing study was explicitly designed to address disparities in survivorship care. Identifying and eliminating barriers to care for patients and families is an important first step; however, studies are still needed to determine potential differential impacts once barriers are removed. This includes documenting efforts that address institutional policies and practices that may reinforce inequities. Currently, it is possible for researchers to utilize existing cohorts to compare survivorship care across health systems, examine the use of alternative methods of care delivery and reimbursement models (e.g., virtual or telehealth services), etc.. With the passage of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, it is now possible to envision more innovative approaches such as those recommended by Key Informants, including the creation and shared utilization of a large data commons (possibly via the Childhood Cancer Data Initiative), use of advanced analytic techniques (e.g., identify patients and notify providers of surveillance needs automatically through the electronic medical record), and targeting intervention not only at the patient or provider level, but also at the health services and payer level (e.g., examining technology and telemedicine interventions, and improving coverage and reimbursement to incentivize equitable survivorship care; see Appendix C, Table C5).

Next Steps

Based on the research findings and their implications, we have outlined suggestions to resolve disparities and barriers impacting childhood cancer survivorship care in a PICOS (population, independent variables/interventions, comparators, outcomes, and study design) framework.

Population

The majority of published pediatric cancer survivorship research comes from the Childhood Cancer Survivor Study (CCSS), a large cohort of survivors of pediatric cancer. The scope of survivorship care represented by the CCSS includes identification of late health effects from cancer and treatment, fertility outcomes, psychosocial assessments, and the recognition and screening for subsequent malignant neoplasms. While the CCSS is a robust survivorship cohort and has been instrumental in identifying the needs of pediatric cancer survivors, its generalizability to the overall population of childhood cancer survivors (CCS), including underrepresented groups, and those treated with more modern therapies is limited. More specifically, the proportion of racial or ethnic minorities in the CCSS is reflective of the general demographic composition of the U.S. from the 1970s-1990s, and both have diversified greatly over the past twenty years.¹⁷³ Notably, all disparities examined by the CCSS were also assessed among other studies, typically using smaller cohorts.

Survivorship care is impacted by various social determinants of health (e.g., racial or ethnic minority status, income, rural and underserved populations, insurance status or type, sexual or gender minorities, and education level), and interplays between barriers at the patient, family, provider, health system, and payer levels. While many of the social determinants of health can directly impact access to and successful receipt of care, our understanding of why racial and/or ethnic minorities face disparities is unclear and likely highly complex. As a result, diverse samples of survivors, including with adequate representation of racial and ethnic minorities, are needed to gain more insight into barriers experienced by populations that experience health disparities and considerable thought and support should be aimed at funding creative ways to overcome these barriers, given the fragmented nature of the US healthcare system.

Another issue among published research is that it is largely clinic or hospital-based and/or comprised of convenience samples. These data largely represent CCS who are already or partially engaged in the healthcare system. Identification of cohorts via a cancer registry represent one strategy for recruiting samples that are more representative (e.g., population-based), with greater numbers of participants who are under-represented in the current literature (e.g., ethnic/racial minorities, rural populations, those not in follow-up care). Other strategies for representative cohort recruitment include the use of social media or networks of nonprofit organizations that provide support for CCS. Our Key Informants also stressed that survival from primary cancer treatment is also closely associated with many of the same issues pertaining to social determinants of health (although during cancer treatment, there is more support for patients and families). Thus, the study of survivors of pediatric cancer has already selected a biased sample for patients with more favorable social determinants. It is not until we address disparities at the primary cancer treatment level, does the picture of how to alleviate disparities and barriers to survivorship care become complete.

Parent, families, caregivers, and local community members are vital to the outcomes of the cancer experience for survivors and are known to provide support for CCS follow-up care.

However, little is known about their roles longer term. Thus, the impact of community-, family-, and peer-support on longer term outcomes merits further examination to identify potential facilitators of care (versus solely a focus on barriers/inhibitors) and interventions are needed to foster these protective relationships.

Independent Variables/Interventions and Comparators

Many studies have examined disparities in survivorship care for pediatric cancer survivors, most frequently including biologic sex, insurance, and race or ethnicity. Less frequently studied are disparities by education or employment; furthermore, disparities by sexual identity or among gender minorities have not yet been studied in the pediatric cancer survivorship literature. This underscores the importance of designing studies that examine disparities in survivorship care with a careful attention paid to interventions and comparisons for these populations. Most current studies that address barriers do so at the patient level. But, as this report outlines, multiple other levels exist, in which barriers inherently affect certain subgroups of survivors more-so than others. Next steps need to include interventions that address barriers at the provider, healthcare system, and payer levels, in addition to interventions targeting the caregivers, family members, and local environment. Our Key Informants highlighted some potential interventions that could be evaluated as next steps to overcome barriers and improve survivorship care delivery and usage, including the application of technology (e.g., social media, telehealth) and innovative methods to identify and classify patients for risk-stratification, in order to better direct patients to the level of care required based on their cancer, treatment and comorbidities. Because of practical or logistic barriers, the use of telemedicine or virtual visits with a survivorship care provider during a time that is convenient for the patient (e.g., outside of typical work hours) is worth examining. Key Informants also discussed CCS-focused nonprofit organizations potentially partnering with other chronic disease-focused nonprofits to raise their voice regarding similar disparities and barriers to care.

Key to all CCS interventions focused on survivorship care is that they are tailored to the local culture and community of the survivor and they should address barriers on multiple levels (e.g., not everything needs to use a patient education approach). Comprehensive, innovative approaches using interventions to impact the provider, health system, and payer are needed, ideally first with pilot projects to implement experimental models in order to eventually establish a feasible standard of care. For example, an intervention could be designed to empower primary care providers with adequate tools to respond to the needs of CCS. Using individual states as policy laboratories, an intervention in a group of states via partnership with state-based professional organizations to encourage continuing education regarding pediatric cancer survivorship care could be evaluated with the goal of improving the receipt of guideline-concordant care. Notably, insurance and reimbursement constraints serve as barriers at many levels including the patient, provider, health system, and payer, and viable interventions are needed to alleviate these barriers. For example, at the payer level, again using states as policy laboratories, federal subsidies could be used to incentivize payers and health systems to provide guideline-concordant survivorship care targeting disparate CCS subgroups to engage these populations in the health system. These proposed interventions would require different ideal comparator groups dependent on the level of intervention, such as 1) those receiving or delivering usual care for interventions at the patient or provider level, 2) contrasting healthcare delivery systems for interventions at the healthcare delivery level, and 3) insurance providers that may provide varying levels of coverage and reimbursement for interventions at the payer level.

Finally, it is not proven that enhanced survivorship care mitigates or prevents the incidence or severity of late effects, and as a result, alternative models merit examination (e.g., improving the precision of risk-based modeling using big data to understand the impact of survivorship care provided through primary care providers or utilizing telemedicine). Given the complex landscape of the US healthcare system and the heterogeneous nature of CCS, it is difficult to decipher the best approach for comparator groups across all studies. “One size does not fit all” - for example, it is difficult to compare the CCSS cohort to a local, clinic-based cohort of patients given the limitations discussed above. Likewise, it is also difficult to compare outcomes from a public health system providing a high level of indigent care to a private, for-profit clinic-based sample.

Outcome

In addition to traditional health and utilization measures, assessment of how to best alleviate or decrease some of the more practical or logistical aspects of barriers to care (e.g., parking fees, transportation, childcare, time off work, out-of-pocket costs for what insurance does not cover) warrant further investigation. Biomedical and psychosocial outcome domains are less frequently examined in reference to disparities and barriers to survivorship care. This may be because biomedical and psychosocial outcomes are more distal and mediated or moderated by access to care; however, further investigation may be warranted to better understand the relationship between access to survivorship care and biomedical and psychosocial outcomes.

More recently, there has been discussion in the pediatric cancer survivorship community regarding striking the right balance of surveillance for late effects, to avoid over-surveillance and under-surveillance. In particular, debate surrounding real impact that it has on CCS’ survival and quality of life is key. However, more information is needed about what critical outcomes are for CCS and their families and how to measure them in a reliable and valid way that captures variation in disparate subgroups of CCS.

Finally, there is a need to invest in, and test interventions that address health promoting facilitators of desired outcomes (e.g., peer support, occupational therapy). By focusing solely on barriers or strategies to mitigate negative outcomes (e.g., disparities) we may miss additional opportunities to promote positive outcomes and ultimately achieve health equity.¹⁷⁴

Study Design

Ideally, randomized controlled trials would allow strong evidence statements about the effectiveness of proposed interventions. To incorporate diverse cohorts with varying levels of access to care and social and cultural representation, other approaches may be suitable to advance our knowledge. For example, cluster randomized studies that intervene at the provider level or natural experiments focused on health system or payer interventions could provide much-needed insight. Furthermore, there is a need for collaboration (e.g., multi-site studies) to reach sufficient sample sizes. In addition, longitudinal studies that examine disparities and barriers over time are needed to enhance our understanding of how they impact long-term outcomes for CCS. Finally, an economics-based approach using cost-effectiveness or cost-benefit analyses conducted with representative, actual cost data from various levels will provide important information. Examining a variety of perspectives will help to truly understand the costs and benefits, including the patient, family, provider, health system, and payer perspectives.

Conclusion

Pediatric cancer survivors face a variety of barriers to care, and these barriers often lead to disparities in care. This report highlights the strengths and limitations of the literature surrounding disparities and barriers to pediatric cancer survivorship care. Disparities by biologic sex and insurance were most frequently addressed; while barriers at the level of the patient and provider were most commonly examined. We identified few studies specifically designed to ameliorate disparities among pediatric cancer survivorship care. Given the growing number of CCS, the lifelong impact of cancer, and the growing population, careful attention should be paid to how studies are designed to examine the effectiveness of intervention on reducing barriers and eliminating disparities among CCS. Pediatric cancer is a rare diagnosis, and effectively and efficiently studying an understudied sub-group needs support to encourage and sustain research in disparities and barriers to pediatric cancer survivorship care.

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Abbreviations and Acronyms

AHRQ	Agency for Healthcare Research and Quality
AMC	Academic Medical Centers
ASCO	American Society for Clinical Oncology
CCDI	Childhood Cancer Data Initiative
CCS	Childhood cancer survivor(s)
CCSS	Childhood Cancer Survivor Study
COE	Center of Excellence
COG	Children’s Oncology Group
EPC	Evidence-based Practice Center
GIN	Guidelines International Network
GQ	Guiding Question
IGHG	International Guideline Harmonization Group
LEG	Late Effects Group
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NIH	National Institutes of Health
PAE	Patient Activation and Education
PCP	Primary Care Providers
PICOTSS	Population, independent variables/intervention, comparator, outcomes, timing, setting, and study design/other limiters
SES	Socioeconomic status
SEADS	Supplemental Evidence And Data for Systematic review
STAR Act	Childhood Cancer Survivorship, Treatment, Access, and Research Act
UKCCSG	UK Children’s Cancer Study Group

Appendix A. Methods

This appendix summarizes the methods used for this technical brief. While the draft report is undergoing peer review, we will undertake an updated search so that the final report is current and includes the most up-to-date information.

Search Strategy and Sources

For this brief, we searched a variety of sources and applied several measures to reduce potential reviewer errors and bias. This section describes the search strategies for published and unpublished studies. The search strategies for the individual databases were developed, executed, and documented by an experienced EPC librarian and were peer-reviewed by an experienced methodologist. Furthermore, we sought input from Key Informant content experts and a Supplemental Evidence And Data for Systematic review (SEADS) portal was available, in addition to a Notice released by the Federal Register for this review to ensure that all relevant evidence has been considered.

Grey Literature

To search for grey literature, we screened the websites of relevant professional organizations listed below. The following terms were used to search grey literature websites: childhood OR pediatric cancer survivor AND (disparit* OR barrier*), alone or in combination. The grey literature sources included:

- Centers for Disease Control and Prevention
- National Academies of Science, Engineering, and Medicine
- National Cancer Institute
- Children’s Oncology Group
- American Cancer Society
- American Cancer Society Cancer Action Network
- American Academy of Pediatrics
- American Society of Pediatric Hematology and Oncology
- American Society of Clinical Oncology
- National Comprehensive Cancer Network
- Leukemia and Lymphoma Society
- St. Baldrick’s Foundation
- American Society for Transplantation and Cellular Therapy
- Center for International Blood and Marrow Transplantation Research
- International Guideline Harmonization Group for Late Effects of Childhood Cancer
- Alex’s Lemonade Stand Foundation
- CureSearch

ECRI Guidelines Trust

Date: 10/8/2020

Terms:

childhood OR pediatric cancer survivor

Guidelines International Network (GIN)

Date: 10/8/2020

Terms:

childhood OR pediatric cancer survivor

NIH RePORTER

Date: 10/8/2020

Text search

Limit to: publications from 1995-2020

Terms:

"childhood cancer survivor" and disparities

"childhood cancer survivor" and barriers

"childhood cancer survivor" and care and barriers

"childhood cancer survivor" and care and disparities

"adolescent cancer survivor"

"pediatric cancer survivor"

National Cancer Institute Research-Tested Intervention Programs

Date: 10/8/2020

Terms:

Childhood cancer survivor

ClinicalTrials.gov

Date: 10/8/2020

Terms:

AREA[ConditionSearch] Cancer

AND

(neonate OR neonatal OR newborn OR newborns OR infant OR baby OR babies OR nursery OR nurseries OR toddler OR toddlers OR preschool OR pre school OR child OR children OR childhood OR kid OR kids OR juvenile OR juveniles OR minor OR minors OR youth OR youths OR youngster OR youngsters OR girl OR girls OR boy OR boys OR elementary school OR elementary schools OR grade school OR grade schools OR preadolescent OR preadolescents OR preadolescence OR pre adolescent OR pre adolescents OR pre adolescence OR preteen OR preteens OR preteenager OR preteenagers OR pre teen OR pre teens OR pre teenager OR pre teenagers OR middle school OR middle schools OR middle schooling OR adolescent OR adolescents OR adolescence OR teen OR teens OR teenager OR teenagers OR high school OR high schools OR high schooling OR pediatric OR pediatrics OR PICU OR NICU OR young adult OR young adults)

AND

(social determinants of health OR socioeconomic OR access to healthcare OR Barriers to healthcare OR ((Black OR African American OR Alaskan Native OR native American OR white OR Asian OR Native Hawaiian OR Pacific Islander OR Hispanic OR Hispanics OR Latino OR Latina OR LatinX OR Latinos OR Latinas OR Blacks OR African Americans OR Alaskan Natives OR native Americans OR whites OR Asians OR Native Hawaiians OR Pacific Islanders OR health OR medic OR medicine OR medical OR insurance OR insurances OR education OR educations) AND (inequity OR inequities OR disparity OR disparities OR inequality OR

inequalities)) OR ((social OR sociological OR sociology) AND (factor OR factors OR trait OR traits OR attribute OR attributes OR characteristic OR characteristics OR phenomenon OR phenomena)))

AND

(Survivor OR survivors OR survivorship OR surveillance OR aftercare OR post-treatment OR post treatment OR post-treatments OR post treatment OR follow up care OR follow-up care OR Long term follow up OR long-term follow-up)

PROSPERO and Open Science Framework

Date: 10/8/2020

Terms:

“Cancer” OR “Oncolog*” OR “tumor” OR “tumors”

AND

“child” OR “Childhood” OR “kid“ OR “kids“ OR “juvenile“ OR “juveniles“ OR “minor“ OR “minors“ OR “youth“ OR “youths“ OR “girl“ OR “girls“ OR “boy“ OR “boys“ OR “preadolescent“ OR “preteen*“ OR “pre teen*” OR “adolescent“ OR “teen” or “teenager” OR “pediatric*“ OR “young adult” OR “young adults”

AND

“survivor” OR “survivorship” or “survivors” OR “aftercare” OR “post treatment” OR “follow up”

AND

“barriers” OR “barrier” OR “disparity” OR “disparities” OR “inequality” OR “unequal”

Published Literature

We searched the research databases PubMed, CINAHL, and PsycINFO using the specified terminology below for each Guiding Question. PubMed indexes biomedical literature, CINAHL includes nursing literature, and PsycINFO is a resource for behavioral and social science research. We also searched the trial registry, clinicaltrials.gov, and NIH RePORTER for ongoing studies. Increasingly, authors provide results in trial records, and particularly for new interventions, trial registries are an important source of research information. PROSPERO, an international database of systematic reviews, was searched using the strategy listed below. We reference-mined these published systematic reviews to ensure that all relevant studies were identified (e.g., rather than summarizing the reviews, we used them as sources to identify available research studies). Open Science Framework was queried for registered protocols of relevance using the terms listed below. We also searched ClinicalTrials.gov and NIH RePORTER for ongoing research using search terms specified below.

PubMed

Guiding Question 1 Strategy

Date: 10/8/2020

Terms:

(“Neoplasms”[Mesh] OR “Medical Oncology”[Mesh] OR “Oncology Service, Hospital”[Mesh] OR “Oncology Nursing”[Mesh] OR “Cancer Care Facilities”[Mesh] OR “National Cancer Institute (U.S.)”[Mesh] OR “American Cancer Society”[Mesh] OR “antineoplastic*” OR “anti-

neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

("child"[MeSH] OR "adolescent"[MeSH] OR "Minors"[Mesh] OR "Pediatrics"[Mesh] OR "Pediatricians"[Mesh] OR "Hospitals, Pediatric"[Mesh] OR "Intensive Care Units, Pediatric"[Mesh] OR "Intensive Care, Neonatal"[Mesh] OR "neonat*" OR "newborn" OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR "toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids" OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR "youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

("Social Determinants of Health"[MeSH] OR "Health Status Disparities"[MeSH] OR "Sociology, Medical"[MeSH] OR "Healthcare Disparities"[MeSH] OR "Sociological Factors"[MeSH] OR "social determinants of health" OR "socioeconomic" OR "access to healthcare" OR "Barriers to healthcare" OR ("Black" OR "African American" OR "Alaskan Native" OR "native American" OR "white" OR "Asian" OR "Native Hawaiian" OR "Pacific Islander" OR "Hispanic" OR "Hispanics" OR "Latino" OR "Latina" OR "LatinX" OR "Latinos" OR "Latinas" OR "Blacks" OR "African Americans" OR "Alaskan Natives" OR "native Americans" OR "whites" OR "Asians" OR "Native Hawaiians" OR "Pacific Islanders" OR "health*" OR "medic*" OR "insurance" OR "insurances" OR "education*") AND ("inequit*" OR "disparit*" OR "inequal*")) OR ("social*" OR "sociolog*" OR "sociology*") AND ("factor" OR "factors" OR "trait" OR "traits" OR "attribute" OR "attributes" OR "characteristic" OR "characteristics" OR "phenomen*"))

AND

("Survivors"[Mesh] OR "Survivorship"[Mesh] OR "Population Surveillance"[Mesh] OR "Aftercare"[Mesh] OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long term follow up" OR "long-term follow-up")

Guiding Question 2 Strategy

Date: 10/8/2020

Terms:

("Neoplasms"[Mesh] OR "Medical Oncology"[Mesh] OR "Oncology Service, Hospital"[Mesh] OR "Oncology Nursing"[Mesh] OR "Cancer Care Facilities"[Mesh] OR "National Cancer Institute (U.S.)"[Mesh] OR "American Cancer Society"[Mesh] OR "antineoplastic*" OR "anti-neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

("child"[MeSH] OR "adolescent"[MeSH] OR "Minors"[Mesh] OR "Pediatrics"[Mesh] OR "Pediatricians"[Mesh] OR "Hospitals, Pediatric"[Mesh] OR "Intensive Care Units,

Pediatric"[Mesh] OR "Intensive Care, Neonatal"[Mesh] OR "neonat*" OR "newborn" OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR "toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids" OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR "youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

("Survivors"[Mesh] OR "Survivorship"[Mesh] OR "Population Surveillance"[Mesh] OR "Aftercare"[Mesh] OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long term follow up" OR "long-term follow-up")

AND

("Health Services Accessibility"[Mesh] OR "Standard of Care"[Mesh] OR "Case Managers"[Mesh] OR "access to healthcare" OR "access to health care" OR "healthcare access" OR "health care access" OR "health service access" OR "health services access" OR "access to health service" OR "access to health services" OR "Barriers to healthcare" OR "standard of care" OR "standards of care" OR "care standard" OR "care standards" OR "case manager" OR "case managers" OR "facilitator" OR "facilitators")

Guiding Question 3-5 Strategy

Date: 10/8/2020

Terms:

("Neoplasms"[Mesh] OR "Medical Oncology"[Mesh] OR "Oncology Service, Hospital"[Mesh] OR "Oncology Nursing"[Mesh] OR "Cancer Care Facilities"[Mesh] OR "National Cancer Institute (U.S.)"[Mesh] OR "American Cancer Society"[Mesh] OR "antineoplastic*" OR "anti-neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

("child"[MeSH] OR "adolescent"[MeSH] OR "Minors"[Mesh] OR "Pediatrics"[Mesh] OR "Pediatricians"[Mesh] OR "Hospitals, Pediatric"[Mesh] OR "Intensive Care Units, Pediatric"[Mesh] OR "Intensive Care, Neonatal"[Mesh] OR "neonat*" OR "newborn" OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR "toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids" OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR "youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

("Survivors"[Mesh] OR "Survivorship"[Mesh] OR "Population Surveillance"[Mesh] OR "Aftercare"[Mesh] OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment")

OR “follow up care” OR “follow-up care” OR “Long term follow up” OR “long-term follow-up”)

AND

("Follow-Up Studies"[Mesh] OR "Longitudinal Studies"[Mesh] OR “follow-up study” OR “follow-up studies” OR “follow up study” OR “follow up studies” OR “followup study” OR “followup studies” OR “longitudinal study” OR “longitudinal studies”)

Guiding Question 4 Strategy Experimental Studies

Date: 10/8/2020

Terms:

childhood cancer survivor*

Filters: Clinical Trial, Randomized Controlled Trial, English

CINAHL

Guiding Question 1 Strategy

Date: 10/8/2020

Terms:

(MH "Neoplasms+" OR MH "Oncology+" OR MH "Oncology Care Units" OR MH "Oncologic Nursing+" OR MH "Oncologic Care+" OR MH “Cancer Care Facilities” OR MH "National Cancer Institute (U.S.)" OR MH "American Cancer Society" OR “antineoplastic*” OR “anti-neoplastic*” OR “anti neoplastic*” OR “oncolog*” OR “neoplasm” OR “neoplasms” OR “tumor” OR “tumors” OR “cancer” OR “cancers” OR “malignan*” OR “carcinoma” OR “carcinomas”)

AND

(MH "Child+" OR MH "Minors (Legal)" OR MH "Adolescence+" OR MH "Pediatrics+" OR MH "Hospitals, Pediatric" OR MH "Intensive Care Units, Pediatric+" OR MH "Pediatric Units+" OR MH "Pediatricians" OR MH "Pediatric Nursing+" OR MH "Neonatal Intensive Care Nursing" OR MH "Intensive Care Units, Neonatal" OR MH "Intensive Care, Neonatal+" OR “neonat*” OR “newborn” OR “newborns” OR “infan*” OR “baby” OR “babies” OR “nursery” OR “nurseries” OR “toddler” OR “toddlers” OR “preschool*” OR “pre school*” OR “child*” OR “kid” OR “kids” OR “juvenile” OR “juveniles” OR “minor” OR “minors” OR “youth” OR “youths” OR “youngster” OR “youngsters” OR “girl” OR “girls” OR “boy” OR “boys” OR “elementary school*” OR “grade school*” OR “preadolescen*” OR “pre adolescen*” OR “preteen*” OR “pre teen*” OR “middle school*” OR “adolescen*” OR “teen*” OR “high school*” OR “pediatric*” OR “PICU” OR “NICU” OR “young adult” OR “young adults”)

AND

(MH "Social Determinants of Health" OR MH "Health Status Disparities" OR MH "Healthcare Disparities" OR “social determinants of health” OR “socioeconomic” OR “access to healthcare” OR “Barriers to healthcare” OR (“Black” OR “African American” OR “Alaskan Native” OR “native American” OR “white” OR “Asian” OR “Native Hawaiian” OR “Pacific Islander” OR “Hispanic” OR “Hispanics” OR “Latino” OR “Latina” OR “LatinX” OR “Latinos” OR “Latinas” OR “Blacks” OR “African Americans” OR “Alaskan Natives” OR “native Americans” OR “whites” OR “Asians” OR “Native Hawaiians” OR “Pacific Islanders” OR “health*” OR “medic*” OR “insurance” OR “insurances” OR “education*”) AND (“inequit*” OR “disparit*” OR “inequal*”)) OR (“social*” OR “sociolog*” OR “sociology*”) AND (“factor” OR “factors”

OR "trait" OR "traits" OR "attribute" OR "attributes" OR "characteristic" OR "characteristics"
OR "phenomen*"))

AND

(MH "Survivors" OR MH "Survivorship" OR MH "Population Surveillance" OR MH "After
care" OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR
"post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment" OR "follow up
care" OR "follow-up care" OR "Long term follow up" OR "long-term follow-up")

Guiding Question 2 Strategy

Date: 10/8/2020

Terms:

(MH "Neoplasms+" OR MH "Oncology+" OR MH "Oncology Care Units" OR MH "Oncologic
Nursing+" OR MH "Oncologic Care+" OR MH "Cancer Care Facilities" OR MH "National
Cancer Institute (U.S.)" OR MH "American Cancer Society" OR "antineoplastic*" OR "anti-
neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR
"tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR
"carcinomas")

AND

(MH "Child+" OR MH "Minors (Legal)" OR MH "Adolescence+" OR MH "Pediatrics+" OR
MH "Hospitals, Pediatric" OR MH "Intensive Care Units, Pediatric+" OR MH "Pediatric
Units+" OR MH "Pediatricians" OR MH "Pediatric Nursing+" OR MH "Neonatal Intensive
Care Nursing" OR MH "Intensive Care Units, Neonatal" OR MH "Intensive Care, Neonatal+"
OR "neonat*" OR "newborn" OR "newborns" OR "infan*" OR "baby" OR "babies" OR
"nursery" OR "nurseries" OR "toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR
"child*" OR "kid" OR "kids" OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR
"youth" OR "youths" OR "youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR
"boys" OR "elementary school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*"
OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescenc*" OR "teen*" OR "high
school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

(MH "Survivors" OR MH "Survivorship" OR MH "Population Surveillance" OR MH "After
care" OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR
"post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment" OR "follow up
care" OR "follow-up care" OR "Long term follow up" OR "long-term follow-up")

AND

(MH "Health Services Accessibility+" OR "access to healthcare" OR "access to health care" OR
"healthcare access" OR "health care access" OR "health service access" OR "health services
access" OR "access to health service" OR "access to health services" OR "Barriers to
healthcare" OR "standard of care" OR "standards of care" OR "care standard" OR "care
standards")

Guiding Question 4 Strategy

Date: 10/8/2020

Terms:

(MH "Neoplasms+" OR MH "Oncology+" OR MH "Oncology Care Units" OR MH "Oncologic
Nursing+" OR MH "Oncologic Care+" OR MH "Cancer Care Facilities" OR MH "National

Cancer Institute (U.S.)" OR MH "American Cancer Society" OR "antineoplastic*" OR "anti-neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

(MH "Child+" OR MH "Minors (Legal)" OR MH "Adolescence+" OR MH "Pediatrics+" OR MH "Hospitals, Pediatric" OR MH "Intensive Care Units, Pediatric+" OR MH "Pediatric Units+" OR MH "Pediatricians" OR MH "Pediatric Nursing+" OR MH "Neonatal Intensive Care Nursing" OR MH "Intensive Care Units, Neonatal" OR MH "Intensive Care, Neonatal+" OR "neonat*" OR "newborn" OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR "toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids" OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR "youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

(MH "Social Determinants of Health" OR MH "Health Status Disparities" OR MH "Healthcare Disparities" OR "social determinants of health" OR "socioeconomic" OR "access to healthcare" OR "Barriers to healthcare" OR ("Black" OR "African American" OR "Alaskan Native" OR "native American" OR "white" OR "Asian" OR "Native Hawaiian" OR "Pacific Islander" OR "Hispanic" OR "Hispanics" OR "Latino" OR "Latina" OR "LatinX" OR "Latinos" OR "Latinas" OR "Blacks" OR "African Americans" OR "Alaskan Natives" OR "native Americans" OR "whites" OR "Asians" OR "Native Hawaiians" OR "Pacific Islanders" OR "health*" OR "medic*" OR "insurance" OR "insurances" OR "education*") AND ("inequit*" OR "disparit*" OR "inequal*")) OR ("social*" OR "sociolog*" OR "sociology*") AND ("factor" OR "factors" OR "trait" OR "traits" OR "attribute" OR "attributes" OR "characteristic" OR "characteristics" OR "phenomen*"))

AND

(MH "Survivors" OR MH "Survivorship" OR MH "Population Surveillance" OR MH "After care" OR "Survivor" OR "survivors" OR "survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR "post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long term follow up" OR "long-term follow-up")

AND

(MH "Experimental Studies+")

PsyInfo

Guiding Question 1 Strategy

Date: 10/8/2020

Terms:

(MAINSUBJECT.EXACT.EXPLODE("Neoplasms") OR MAINSUBJECT.EXACT.EXPLODE("Oncology") OR "antineoplastic*" OR "anti-neoplastic*" OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR "tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

(MAINSUBJECT.EXACT("Adolescent Development") OR
MAINSUBJECT.EXACT.EXPLODE("Pediatrics") OR
MAINSUBJECT.EXACT.EXPLODE("Pediatricians") OR
MAINSUBJECT.EXACT.EXPLODE("Neonatal Intensive Care") OR "neonat*" OR "newborn"
OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR
"toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids"
OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR
"youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary
school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre
teen*" OR "middle school*" OR "adolescenc*" OR "teen*" OR "high school*" OR "pediatric*"
OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

(MAINSUBJECT.EXACT("Social Discrimination") OR
MAINSUBJECT.EXACT.EXPLODE("Health Disparities") OR "social determinants of health"
OR "socioeconomic" OR "access to healthcare" OR "Barriers to healthcare" OR (("Black" OR
"African American" OR "Alaskan Native" OR "native American" OR "white" OR "Asian" OR
"Native Hawaiian" OR "Pacific Islander" OR "Hispanic" OR "Hispanics" OR "Latino" OR
"Latina" OR "LatinX" OR "Latinos" OR "Latinas" OR "Blacks" OR "African Americans" OR
"Alaskan Natives" OR "native Americans" OR "whites" OR "Asians" OR "Native Hawaiians"
OR "Pacific Islanders" OR "health*" OR "medic*" OR "insurance" OR "insurances" OR
"education*") AND ("inequit*" OR "disparit*" OR "inequal*")) OR (("social*" OR "sociolog*"
OR "sociology*") AND ("factor" OR "factors" OR "trait" OR "traits" OR "attribute" OR
"attributes" OR "characteristic" OR "characteristics" OR "phenomen*")))

AND

(MAINSUBJECT.EXACT.EXPLODE("Survivors") OR
MAINSUBJECT.EXACT.EXPLODE("Aftercare") OR "Survivor" OR "survivors" OR
"survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR
"post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long
term follow up" OR "long-term follow-up")

Guiding Question 2 Strategy

Date: 10/8/2020

Terms:

(MAINSUBJECT.EXACT.EXPLODE("Neoplasms") OR
MAINSUBJECT.EXACT.EXPLODE("Oncology") OR "antineoplastic*" OR "anti-neoplastic*"
OR "anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR
"tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

(MAINSUBJECT.EXACT("Adolescent Development") OR
MAINSUBJECT.EXACT.EXPLODE("Pediatrics") OR
MAINSUBJECT.EXACT.EXPLODE("Pediatricians") OR
MAINSUBJECT.EXACT.EXPLODE("Neonatal Intensive Care") OR "neonat*" OR "newborn"
OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR
"toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids"
OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR
"youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary

school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR "PICU" OR "NICU" OR "young adult" OR "young adults")

AND

(MAINSUBJECT.EXACT.EXPLODE("Survivors") OR
MAINSUBJECT.EXACT.EXPLODE("Aftercare") OR "Survivor" OR "survivors" OR
"survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR
"post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long
term follow up" OR "long-term follow-up")

AND

(MAINSUBJECT.EXACT.EXPLODE("Health Care Access") OR "access to healthcare" OR
"access to health care" OR "healthcare access" OR "health care access" OR "health service
access" OR "health services access" OR "access to health service" OR "access to health
services" OR "Barriers to healthcare" OR "standard of care" OR "standards of care" OR "care
standard" OR "care standards")

Guiding Question 4 Strategy

Date: 10/8/2020

Terms:

Methodology Filters used: Clinical Trial, Clinical Case Study, Empirical Study, Experimental
Replication, Followup Study, Longitudinal Study, Prospective Study, Retrospective Study,
Nonclinical Case Study, Qualitative Study, Quantitative Study, Treatment Outcome

(MAINSUBJECT.EXACT.EXPLODE("Neoplasms") OR

MAINSUBJECT.EXACT.EXPLODE("Oncology") OR "antineoplastic*" OR "anti-neoplastic*" OR
"anti neoplastic*" OR "oncolog*" OR "neoplasm" OR "neoplasms" OR "tumor" OR
"tumors" OR "cancer" OR "cancers" OR "malignan*" OR "carcinoma" OR "carcinomas")

AND

(MAINSUBJECT.EXACT("Adolescent Development") OR

MAINSUBJECT.EXACT.EXPLODE("Pediatrics") OR

MAINSUBJECT.EXACT.EXPLODE("Pediatricians") OR

MAINSUBJECT.EXACT.EXPLODE("Neonatal Intensive Care") OR "neonat*" OR "newborn"
OR "newborns" OR "infan*" OR "baby" OR "babies" OR "nursery" OR "nurseries" OR
"toddler" OR "toddlers" OR "preschool*" OR "pre school*" OR "child*" OR "kid" OR "kids"
OR "juvenile" OR "juveniles" OR "minor" OR "minors" OR "youth" OR "youths" OR
"youngster" OR "youngsters" OR "girl" OR "girls" OR "boy" OR "boys" OR "elementary
school*" OR "grade school*" OR "preadolescen*" OR "pre adolescen*" OR "preteen*" OR "pre
teen*" OR "middle school*" OR "adolescen*" OR "teen*" OR "high school*" OR "pediatric*" OR
"PICU" OR "NICU" OR "young adult" OR "young adults")

AND

(MAINSUBJECT.EXACT.EXPLODE("Survivors") OR

MAINSUBJECT.EXACT.EXPLODE("Aftercare") OR "Survivor" OR "survivors" OR
"survivorship" OR "surveillance" OR "aftercare" OR "post-treatment" OR "post treatment" OR
"post-treatments" OR "post treatment" OR "follow up care" OR "follow-up care" OR "Long
term follow up" OR "long-term follow-up")

AND

(MAINSUBJECT.EXACT("Social Discrimination") OR
MAINSUBJECT.EXACT.EXPLODE("Health Disparities") OR "social determinants of health"
OR "socioeconomic" OR "access to healthcare" OR "Barriers to healthcare" OR (("Black" OR
"African American" OR "Alaskan Native" OR "native American" OR "white" OR "Asian" OR
"Native Hawaiian" OR "Pacific Islander" OR "Hispanic" OR "Hispanics" OR "Latino" OR
"Latina" OR "LatinX" OR "Latinos" OR "Latinas" OR "Blacks" OR "African Americans" OR
"Alaskan Natives" OR "native Americans" OR "whites" OR "Asians" OR "Native Hawaiians"
OR "Pacific Islanders" OR "health*" OR "medic*" OR "insurance" OR "insurances" OR
"education*") AND ("inequit*" OR "disparit*" OR "inequal*")) OR (("social*" OR "sociolog*"
OR "sociology*") AND ("factor" OR "factors" OR "trait" OR "traits" OR "attribute" OR
"attributes" OR "characteristic" OR "characteristics" OR "phenomen*"))))

Results: 6,857

Appendix B. Excluded Studies

1. 2008 SNRS abstracts -- M. Southern Online Journal of Nursing Research. 2008;8(4):9-. PMID: 105496452. Language: English. Entry Date: 20090807. Revision Date: 20150711. Publication Type: Journal Article. *Outcome*
2. 2008 SNRS abstracts -- W - Z. Southern Online Journal of Nursing Research. 2008;8(4):14-. PMID: 105496459. Language: English. Entry Date: 20090807. Revision Date: 20150711. Publication Type: Journal Article. *Study design*
3. 2008 SNRS abstracts -- L. Southern Online Journal of Nursing Research. 2008;8(4):8-. PMID: 105496451. Language: English. Entry Date: 20090807. Revision Date: 20150711. Publication Type: Journal Article. *Study design*
4. 2008 SNRS abstracts -- S. Southern Online Journal of Nursing Research. 2008;8(4):12-. PMID: 105496455. Language: English. Entry Date: 20090807. Revision Date: 20150711. Publication Type: Journal Article. *Study design*
5. Advancing Survivorship Care Through the National Cancer Survivorship Resource Center. CA Cancer J Clin. 2013;63(3):147-50. *Participants*
6. Dying after cure: A case of suicide in an adolescent treated for cancer. Wolters Kluwer India Pvt Ltd; 2015. p. 667-. *Outcome*
7. Handbook of oncology social work: Psychosocial care for people with cancer: Oxford University Press, New York, NY; 2015. *Study design*
8. RESEARCH BRIEFS. P&T: A Peer-Reviewed Journal for Managed Care & Formulary Management. 2018;43(11):696-700. PMID: 133446789. Language: English. Entry Date: 20181211. Revision Date: 20190715. Publication Type: Article. *Outcome*
9. The global burden of childhood and adolescent cancer in 2017: an analysis of the Global Burden of Disease Study 2017. Lancet Oncology. 2019;20(9):1211-25. doi: 10.1016/S1470-2045(19)30339-0. PMID: 138390099. Corporate Author: GBD 2017 Childhood Cancer Collaborators. Language: English. Entry Date: 20200617. Revision Date: 20200701. Publication Type: journal article. *Outcome*
10. Survivors of childhood brain tumours have lasting cognitive and socioeconomic burdens. British Journal of Hospital Medicine (17508460). 2019;80(8):428-. PMID: 138027431. Language: English. Entry Date: 20190816. Revision Date: 20190817. Publication Type: Article. *Outcome*
11. Clinical News. British Journal of Hospital Medicine (17508460). 2019;80(4):188-91. doi: 10.12968/hmed.2019.80.4.188. PMID: 135776404. Language: English. Entry Date: 20190410. Revision Date: 20191120. Publication Type: Article. *Outcome*
12. Joint Letter to HHS Secretary Azar on Barriers to Coverage During COVID. 2020. <https://www.fightcancer.org/sites/default/files/Letter%20to%20HHS%20Sec%20Azar%20on%20Covid%20Fixes%20for%20Cancer%20Patients%20FINAL.pdf>. Accessed on August 10 2020. *Participants*

13. Aarsen FK, Paquier PF, Reddingius RE, et al. Functional outcome after low-grade astrocytoma treatment in childhood. *Cancer*. 2006 Jan 15;106(2):396-402. doi: 10.1002/cncr.21612. PMID: 16353203. *Intervention*
14. Aarts MJ, Kamphuis CBm, Louwman MJ, et al. Educational inequalities in cancer survival: a role for comorbidities and health behaviours? *Journal of Epidemiology & Community Health*. 2013;67(4):365-73. doi: 10.1136/jech-2012-201404. PMID: 86009049. Language: English. Entry Date: 20130314. Revision Date: 20130930. Publication Type: Article. *Outcome*
15. Abrahamsen AF, Loge JH, Hannisdal E, et al. Socio-medical situation for long-term survivors of Hodgkin's disease: a survey of 459 patients treated at one institution. *Eur J Cancer*. 1998 Nov;34(12):1865-70. doi: 10.1016/s0959-8049(98)00269-x. PMID: 10023307. *Participants*
16. Abrahão R, Li QW, Malogolowkin MH, et al. Chronic medical conditions and late effects following non-Hodgkin lymphoma in HIV-uninfected and HIV-infected adolescents and young adults: a population-based study. *Br J Haematol*. 2020 Feb 20. doi: 10.1111/bjh.16539. PMID: 32080836. *Participants*
17. Abrahão R, Ribeiro RC, Medeiros BC, et al. Disparities in early death and survival in children, adolescents, and young adults with acute promyelocytic leukemia in California. *Cancer*. 2015 Nov 15 2017-09-25;121(22):3990-7. doi: <http://dx.doi.org/10.1002/cncr.29631>. PMID: 1769711031; 2015-50576-009. *Outcome*
18. Absolom K, Eiser C, Michel G, et al. Follow-up care for cancer survivors: views of the younger adult. *Br J Cancer*. 2009 Aug 18;101(4):561-7. doi: 10.1038/sj.bjc.6605213. PMID: 19638979. *Participants*
19. Absolom K, Greenfield D, Ross R, et al. Predictors of clinic satisfaction among adult survivors of childhood cancer. *Eur J Cancer*. 2006 Jul;42(10):1421-7. doi: 10.1016/j.ejca.2006.01.053. PMID: 16759851. *Intervention*
20. Ach E, Gerhardt CA, Barrera M, et al. Family factors associated with academic achievement deficits in pediatric brain tumor survivors. *Psychooncology*. 2013 Aug;22(8):1731-7. doi: 10.1002/pon.3202. PMID: 23059621. *Intervention*
21. Adam S, Doege D, Koch-Gallenkamp L, et al. Age-specific health-related quality of life in disease-free long-term prostate cancer survivors versus male population controls-results from a population-based study. *Supportive Care in Cancer*. 2020;28(6):2875-85. doi: 10.1007/s00520-019-05120-5. PMID: 142867423. Language: English. Entry Date: 20200701. Revision Date: 20200701. Publication Type: journal article. Journal Subset: Biomedical. *Participants*
22. Adams HS. Young adult survivors face unique challenges. *Oncology (Williston Park)*. 2009 Oct;23(11 Suppl Nurse Ed):33-4. PMID: 19856606. *Participants*
23. Adel Fahmideh M, Lavebratt C, Schüz J, et al. CCDC26, CDKN2BAS, RTEL1 and TERT Polymorphisms in pediatric brain tumor susceptibility. *Carcinogenesis*. 2015 Aug;36(8):876-82. doi: 10.1093/carcin/bgv074. PMID: 26014354. *Outcome*

24. Adelman AS, Groves FD, O'Rourke K, et al. Residential mobility and risk of childhood acute lymphoblastic leukaemia: an ecological study. *Br J Cancer*. 2007 Jul 2;97(1):140-4. doi: 10.1038/sj.bjc.6603793. PMID: 17533404. *Study design*
25. Affret A, His M, Severi G, et al. Influence of a cancer diagnosis on changes in fruit and vegetable consumption according to cancer site, stage at diagnosis and socioeconomic factors: Results from the large E3N-EPIC study. *Int J Cancer*. 2018 Oct 1;143(7):1678-87. doi: 10.1002/ijc.31572. PMID: 29717489. *Participants*
26. Afshar N, English DR, Thursfield V, et al. Differences in cancer survival by sex: a population-based study using cancer registry data. *Cancer Causes Control*. 2018 Nov;29(11):1059-69. doi: 10.1007/s10552-018-1079-z. PMID: 30194549. *Participants*
27. Agaku IT, Adisa AO. Nativity status and oral cancer survival in the United States: Implications for dental clinical practice. *Quintessence International*. 2014;45(4):355-9. doi: 10.3290/j.qi.a31344. PMID: 103957056. Language: English. Entry Date: 20140605. Revision Date: 20150710. Publication Type: Journal Article. *Outcome*
28. Agarwal A, Katz AJ, Chen RC. The Impact of the Affordable Care Act on Disparities in Private and Medicaid Insurance Coverage Among Patients Under 65 With Newly Diagnosed Cancer. *Int J Radiat Oncol Biol Phys*. 2019 Sep 1;105(1):25-30. doi: 10.1016/j.ijrobp.2019.05.033. PMID: 31150741. *Participants*
29. Agarwal S, Ying J, Boucher KM, et al. The association between socioeconomic factors and breast cancer-specific survival varies by race. *PLoS One*. 2017;12(12):e0187018. doi: 10.1371/journal.pone.0187018. PMID: 29211739. *Participants*
30. Agnese A, Lamparelli T, Bacigalupo A, et al. Supportive care with art therapy, for patients in isolation during stem cell transplant. *Palliat Support Care*. 2012 Jun;10(2):91-8. doi: 10.1017/s147895151100071x. PMID: 22436493. *Participants*
31. Agnew F, Higgins A, Casey M, et al. The experience of fatherhood following childhood cancer survival. *J Health Psychol*. 2020 Mar;25(3):340-9. doi: 10.1177/1359105317717598. PMID: 28810483. *Study design*
32. Aharon D, Calderon M, Solari V, et al. Barriers to Follow-Up for Abnormal Papanicolaou Smears among Female Sex Workers in Lima, Peru. *PLoS One*. 2017;12(1):e0169327. doi: 10.1371/journal.pone.0169327. PMID: 28060937. *Participants*
33. Ahomäki R, Gunn ME, Madanat-Harjuoja LM, et al. Late psychiatric morbidity in survivors of cancer at a young age: a nationwide registry-based study. *Int J Cancer*. 2015 Jul 1;137(1):183-92. doi: 10.1002/ijc.29371. PMID: 25450095. *Participants*

34. Ahomäki R, Harila-Saari A, Matomäki J, et al. Non-graduation after comprehensive school, and early retirement but not unemployment are prominent in childhood cancer survivors-a Finnish registry-based study. *Journal of Cancer Survivorship*. 2017;11(2):284-94. doi: 10.1007/s11764-016-0574-z. PMID: 121919971. Language: English. Entry Date: 20170919. Revision Date: 20181026. Publication Type: journal article. *Outcome*
35. Ahomäki R, Kero A, Koivisto M, et al. Purchases of antidepressants after cancer at a young age in Finland. *Int J Cancer*. 2019 Mar 15;144(6):1227-33. doi: 10.1002/ijc.31942. PMID: 30357818. *Participants*
36. Ailawadhi S, Advani P, Yang D, et al. Impact of access to NCI- and NCCN-designated cancer centers on outcomes for multiple myeloma patients: A SEER registry analysis. *Cancer (0008543X)*. 2016;122(4):618-25. doi: 10.1002/cncr.29771. PMID: 112733341. Language: English. Entry Date: 20160605. Revision Date: 20190513. Publication Type: journal article. Journal Subset: Biomedical. *Outcome*
37. Ailawadhi S, Frank RD, Sharma M, et al. Trends in multiple myeloma presentation, management, cost of care, and outcomes in the Medicare population: A comprehensive look at racial disparities. *Cancer (0008543X)*. 2018;124(8):1710-21. doi: 10.1002/cncr.31237. PMID: 128972856. Language: English. Entry Date: 20190913. Revision Date: 20190915. Publication Type: journal article. *Outcome*
38. Al Hasani F, Knoepfli M, Gemperli A, et al. Factors affecting screening for hepatocellular carcinoma. *Ann Hepatol*. 2014 Mar-Apr;13(2):204-10. PMID: 24552862. *Participants*
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Appendix C. Key Informant Interviews

Findings from the Key Informant interviews are detailed in the tables below, by Guiding Question. Discussions by individual Key Informants are separated by the “---” line.

Table C1. Key Informant interviews for Guiding Question 1: What are the disparities in survivorship care for pediatric cancer survivors?

Question	What Types of Disparities Impact Survivorship Care for Pediatric Survivors?	What Disparities Do You Think Are Most Significant in Impacting Pediatric Cancer Survivorship Care?	Which Domains of Disparities Should Be Distinguished?
Preliminary Feedback (included as prompt on slide)	<ol style="list-style-type: none"> 1. Socioeconomic status (SES) 2. Employment 3. Insurance: under/uninsured, type of insurance, inconsistency/transitions in insurance 4. Access to care, rehabilitation services, green space for physical activity/health food options 5. Caregiver, family, and community dynamics 6. Relationship to the health system, including providers 7. Transitions in care from pediatric to adult settings 	<ol style="list-style-type: none"> 1. Access to care (including recommended prevention, surveillance, and treatment), sub-specialty providers, rehabilitation services 2. Transitions in care, including changes in insurance, primary care providers (PCP), and other health care teams that may disproportionately impact vulnerable, low SES, racial/ethnic minority groups 	<ol style="list-style-type: none"> 1. Medical 2. SES 3. Cultural

<p>KI Feedback</p>	<p>All of these issues are intertwined and dramatically impact survivors; parent insurance lapses at age 26 and visits/scans could get postponed and can be very expensive if paid out of pocket; mental health issues and social isolation are big problems, life may never go back to “normal” and it never does.</p> <p>---</p> <p>Even when barriers are reduced (e.g., free care, room & board, transportation), there are still other issues that can prevent survivorship care (e.g., other children to care for, job requirements); this becomes even more complicated as they transition to adult care, there is much less outreach to help them get care; we need a better understanding of what is going on in their personal lives that prevent care.</p> <p>We are successful in keeping kids insured. However, community-based public health insurance (state-based), can be lacking in support. St. Jude may foster co-dependency, because their experience at St. Jude cannot be replicated easily in other places/communities.</p> <p>---</p> <p>We need a better understanding of the different aspects of low SES, it is not just education and income – there are other issues to consider such as paid time off/sick leave; health literacy, health finance, and insurance literacy.</p> <p>---</p> <p>Health-related social needs/determinants (e.g., food insecurity, housing).</p> <p>---</p> <p>Geography, which relates to SES and insurance barriers.</p> <p>---</p> <p>Expertise more in disparities in upfront treatment/therapy; enormous dearth of data in survivors in children; more disadvantaged or vulnerable populations never actually become survivors, so overall goals need to also look at upstream barriers to cancer treatment.</p> <p>Very large dearth of data in regard to survivorship care disparities in each of the domains: certainly, are CCS publications – health related QOL by race/ethnicity; thinking of insurance, underinsurance, and loss of insurance; SES is particularly important, very few data on SES and disparities in pediatric survivorship care.</p> <p>In pediatric oncology, we have failed to include family reported measures at baseline– don’t have access to SES of family at diagnosis to be able to track outcomes. SES data that are available are cross-sectional at time of CCSS cohort enrollment</p>	<p>Knowledge of providers (or home community); access and coverage in the health care plan; feel that pediatric guidelines are lacking data and dissemination for what is available; opportunities to partner w/ NCCN/ASCO may be helpful</p> <p>---</p> <p>Mentioned the COG guidelines but acknowledged that end-users do not necessarily have high utilization; however, evidence supporting the beneficial impact of screening is limited.</p> <p>---</p> <p>We need to reach/educate adult primary care providers; but has had challenges dissemination/publishing in adult/primary care journals.</p> <p>---</p> <p>Sometimes the patient has to work on “bridging the gap” with their PCPs.</p> <p>---</p> <p>SES is likely to be one of the more important exposures driving disparities in survivorship care – research is sorely needed</p> <p>SES (by multiple measures) is a main driver of these access disparities</p> <p>How SES interfaces with access to care – think of this at the patient/family level– are they available and understandable by the family– language/literacy; risk/benefit analyses to get to these appointments/access care with all the resources needed to get to an appointment (childcare, time off work, food insecurity, etc.)</p> <p>Age related barriers (parent bringing a 5-year-old, versus 20-year-old)</p> <p>Regional availability: Are they even there? Does insurance cover it?</p>	<p>No further discussion.</p>
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Question	What Types of Disparities Impact Survivorship Care for Pediatric Survivors?	What Disparities Do You Think Are Most Significant in Impacting Pediatric Cancer Survivorship Care?	Which Domains of Disparities Should Be Distinguished?
	<p>and not necessarily at time of diagnosis, which would be important to know.</p> <p>There is data on number of subspecialty providers based on distance and correlated to adherence to survivorship guidelines. Not robust data on caregiver, family and community dynamics; transitions, large drop off cliff when get to adult providers, lots of data out there.</p> <p>---</p> <p>Health care system; pediatric cancer survivors have had majority of care in academic medical centers (AMC), and very little (versus young/older adults) in community setting/private practice. Thus, the system itself is an ameliorating factor. Place of initial treatment makes a difference because survivorship care is more likely at major centers. Place of treatment is a source of disparity. Where do they get survivorship care? Do the pediatric providers do this? What happens as the survivor ages (is adulthood at 18 or 21)? Where do they go for care at older ages? Issues related to access to care across the cancer care continuum matters (e.g., insurance). SES challenges in the family also matter (can the family prioritize survivorship care?), employment status, insurance coverage, etc.</p>		

Table C2. Key Informant interviews for Guiding Question 2: What are the barriers to survivorship care for pediatric cancer survivors who experience disparities?

Question	What Are the Most Influential Barriers to Pediatric Cancer Survivorship Care? How Do Those Barriers Change as CCS Transition From Pediatric to Adult Survivorship Care?	How Do Barriers to Survivorship Care Vary by Subgroups of Pediatric Cancer Survivors? How Do Barriers Affecting Specific Subgroups Change Over Time, Specifically as They Transition From Pediatric to Adult Care?
<p>Survey Monkey feedback (included as prompt on slide)</p>	<ol style="list-style-type: none"> 1. Lack of awareness of community providers and survivors. 2. Lack of reimbursement for survivorship care, particularly care that addresses psychosocial needs. 3. Loss of psychosocial support more routinely provided in pediatric centers, particularly with care coordination of medically complex patients. 4. Access to care (insurance, geographic, employment-based insurance) changes during this transition, responsibility shifts from parent/family to self, shifts in care teams from pediatric to adult medicine providers. 	<ol style="list-style-type: none"> 1. Particularly vulnerable subgroups include those with (or at high risk for) multimorbidity; may have more difficulty replicating quality of comprehensive multidisciplinary care provided at a pediatric center. 2. Relationship/familiarity and trust with pediatric providers may not exist with adult providers. 3. Access to adult medicine providers may shift due to employment and SES status of the individual.

Question	What Are the Most Influential Barriers to Pediatric Cancer Survivorship Care? How Do Those Barriers Change as CCS Transition From Pediatric to Adult Survivorship Care?	How Do Barriers to Survivorship Care Vary by Subgroups of Pediatric Cancer Survivors? How Do Barriers Affecting Specific Subgroups Change Over Time, Specifically as They Transition From Pediatric to Adult Care?
KI Feedback	<p>Low prevalence in the general population. One experience with 1 patient, will not inform the clinician about the next cancer survivor. Another complicating issue is the age range of the survivor. As a young adult, it is difficult to self-advocate in a complicated system, with intermittent care. Some young adults don't care or prioritize this.</p> <p>---</p> <p>In pediatric settings, there are usually easier access to specialists and integrative care is easier. Otherwise, PCPs have to negotiate access. Care for medical conditions is easier than care for mental health issues.</p> <p>---</p> <p>Most influential barriers – complex and multifactorial – reimbursement and vulnerable patients (less likely to adhere to care/guidelines) – if no reimbursement and a provider is pressed for time- could drive disparities.</p> <p>---</p> <p>Health system itself probably the biggest barrier; during treatment, pediatric patients are well-taken care of and “overprotected” by our system and this goes away when therapy is completed.</p> <p>Transition to adulthood with PC where they can be followed long term is key; PCPs need to be on the forefront of this, but they face huge challenges (e.g., system-limiting factors and resources).</p> <p>Anything beyond surveillance is difficult, especially for more complex cases – the system may limit where these patients are seen for follow-up care; but, is this what is best for the patient? This care may be highly fragmented.</p> <p>Vulnerable groups in 2 buckets – 1) those that have barriers from SES or educational level (biggest barrier are SES related) and 2) patients really complex needs and need multidisciplinary care (biggest barrier is our health care system).</p>	<p>Those in rural areas. It is a big deal for them to enter a city. Insurance may not matter as much because a provider may not be in their area.</p> <p>---</p> <p>Broader issue than access to adult medicine providers that could shift due to employment and SES – subgroups w/ certain types of jobs that don't offer insurance or paid sick leave may be particularly disadvantaged; health insurance coverage and sick leave through an employer will make a difference.</p> <p>---</p> <p>People with neurocognitive issues. Those with significant disability may have more support than those with “mild” disabilities (who are more “on their own”)</p> <p>---</p> <p>Underlying, these vulnerable populations could already have disadvantages- these are magnified when the transition happens. Lower SES population (more likely to be racial/ethnic minorities), underemployed, underinsured, lack of resources, cost shifting from day to day fires (food, electricity, etc.). Survivors will age out of public insurance programs.</p> <p>Trust – different depending on the setting – new cancer versus surveillance later.</p> <p>Language – if family is not English speaking or uncomfortable health literacy, then can be an enormous barrier – you may not understand the guidelines.</p> <p>Things that may enhance survivorship care – not familiar with data, but anecdotally – family or patient resilience – warrants examination.</p>

Table C3. Key Informant interview for Guiding Question 3: What are proposed strategies for addressing those barriers?

Question	What Strategies To Address Barriers to Survivorship Care That Lead to Disparities Are Most Promising?	Do Those Strategies Need To Be Implemented Using Different Approaches for Subgroups of Survivors?	Which Professional Bodies Have Proposed Strategies?
<p>Preliminary Feedback (included as prompt on slide)</p>	<ol style="list-style-type: none"> 1. Development and dissemination of health surveillance recommendations have helped link survivors to resources and address unmet needs 2. Policy changes aimed at reducing barriers to accessing preventive services and eliminating pre-existing clauses to care has been important 3. Policy changes are also needed to properly reimburse clinicians for comprehensive care coordination 4. For cancer survivorship care in general, incorporating primary care and multidisciplinary care teams will be important moving forward 	<ol style="list-style-type: none"> 1. More medically or psychosocially complex survivors benefit the most from care coordination by dedicated staff. <ol style="list-style-type: none"> A. Risk-stratification of care is essential; depending on cancer type, age at diagnosis, etc. 	<ol style="list-style-type: none"> 1. Children’s Oncology Group 2. American Society of Clinical Oncology

<p>KI Feedback</p>	<p>Eliminating preexisting conditions clauses helped reduced barriers, yes, but there are many others – in states that did not expand Medicaid, challenges are likely significant – would suggest expanding</p> <p>---</p> <p>Think about what CCS have in common with other children w/ illnesses to leverage broader platform; if there are issues that are common among other groups, if you could expand the base, could raise the prominence of the issue</p> <p>---</p> <p>Policy level - Under or un-insurance Policies that have improved insurance at at-risk populations (for example, the Patient Protection and Affordable Care Act) – potentially have an impact to access the care recommended Not familiar with policy changes around reimbursement Having a comprehensive document that summarizes their cancer care and recommended guidelines, can increase adherence among PCPs These are available, but rarely ever studied It is expensive to take care of late effects – can be many years/decades – an intervention that helps insurance companies see that it is cost effective and provide the guidelines for insurance companies to follow</p> <p>---</p> <p>It has to go past what you have in “A”. It is important to have follow-up guidelines for providers. It is easy to follow guidelines at major health centers. However, the majority of survivors will not be seen at specialty centers. PCPs will not easily use these guidelines (e.g., does the PCP have the resources to carry them out? If they discover an issue, does the PCP and/or patient have the resources to follow through?). A risk-adapted follow-up plan can be undermined by the system (e.g., care is essential, but resources/reimbursement are inadequate; capitated payment for PC is a disincentive for adequate/expensive survivorship care). Without the following policy changes, there won’t be enough resources:</p> <ol style="list-style-type: none"> 1. Insurance coverage of survivorship care 	<p>Maybe “strategies to address barriers” for children w/ chronic conditions could help raise prominence for pediatric providers</p> <p>---</p> <p>Not robust data on what disparities exist to begin with – hard to talk about implementing strategies There needs to be more robust examination of disparities and at a certain time continuum – this needs to be defined first Comprehensive survivorship care – survivorship clinic versus adhering to survivorship guidelines and how that changes over time and how it varies over age group (child versus young adult) For example, you demonstrate that CCS from low income homes or material hardship are less likely to adhere – the reason why – (time off work versus childcare) – then that could be tackled.</p> <p>---</p> <p>Risk-stratification is essential; guidelines are written by exposure, disease site, and age; but, how do you take this information and best use/implement this in a health system? We need to create risk buckets (e.g., low, intermediate, high), and then develop models of care based on those buckets. To treat all survivors as one is not realistic. Consider adding access to care, comorbidities, SES, social determinants of health, etc. to the risk stratification criteria using technology; potentially in existing cohorts (there was a recent NCI supplement focused on this). The CCSS is a limited cohort for this type of work, because other institutions do not have the same resources. Once developed, this algorithm can provide a better risk assessment that can facilitate the creation of more accurate</p>	<p>COG – has made a significant effort to make sure each CCS has a treatment summary and guidelines for surveillance/management. Regarding strategies for more nuanced barriers (language, income, insurance) – not familiar with that from COG or ASCO.</p>
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Question	What Strategies To Address Barriers to Survivorship Care That Lead to Disparities Are Most Promising?	Do Those Strategies Need To Be Implemented Using Different Approaches for Subgroups of Survivors?	Which Professional Bodies Have Proposed Strategies?
	<p>2. Reimbursement for risk-stratified survivorship care</p> <p>3. Provide opportunities for the uninsured/underinsured via surveillance (e.g., adequate reimbursement and resources at safety net clinics).</p> <p>The answer cannot be survivorship clinics at all pediatric hospitals. At AMCs, oncologists can see adult survivors of pediatric cancers, but most institutions do not have the funds to do this. Even in the best of circumstances, the survivor needs to still walk in the door, and have insurance that covers their survivorship care.</p>	<p>guidelines which can then reduce disparities between survivors. We should do a better job of measuring financial toxicity; if done more systematically, the algorithm may do a better job of identifying risk. We can't define a perfect system that is not attainable.</p>	

Table C4. Key Informant interviews for Guiding Question 4: What published and unpublished studies have assessed these strategies?

Question	How Effective Are Strategies That You Are Familiar With?	What Confounding Factors Pose a Challenge to Interpreting Research and Evaluation Studies?
<p>Survey Monkey feedback (included as prompt on slide)</p>	<p>1. Limited, high-level evidence of effectiveness of the strategies used by COG (e.g., does adherence to guideline recommended health surveillance reduce mortality/improve quality of life; most definitely, there is evidence that adherence facilitates early detection)</p>	<p>1. Relative rarity of pediatric cancer</p> <p>2. Heterogeneous cancer subtypes and treatment (that keeps evolving)</p> <p>3. Very delayed onset of health events in relation to treatment</p> <p>4. Need for collaboration to have meaningful numbers in cohorts to address confounders of outcomes</p>
<p>KI Feedback</p>	<p>There has been a lot of research, but not as much on current/conventional risk factors (racial/ethnic minorities, low SES); our US (and cancer) population is more heterogeneous now than US (and cancer) population 20-30 years ago.</p> <p>---</p> <p>We suffer from an absence of detailed information; prospective data is rare; CCS treated outside of large pediatric centers is unknown, we know much less about those who are not enrolled in survivorship cohorts (or not in care), particularly rural survivors; this is exacerbated by the relative rarity of the disease.</p> <p>---</p> <p>Some in the adult oncology literature that has talked about risk stratification, but not been in practice; UK guidelines are the furthest along (then Australia); but no systematic reviews on whether risk stratification works or doesn't work, but there is evidence that adherence facilitates early detection.</p>	<p>These 4 are the 4 biggest. One of the greatest challenges. Almost impossible to comprehensively study this.</p> <p>---</p> <p>Additional issue – simply lack data (or lack of access to this data) to appropriately do these analyses. We don't have data on SES/health literacy/culture/financial literacy/language at time of treatment.</p> <p>---</p> <p>Who is going to fund a study that will look these issues? (due to low power, and length of time needed). Anything outside of the CCSS is commonly deemed as redundant, but other cohorts (looking at different issues) should be funded. This would be expensive, but there may be benefits if the different cohorts have some overlap.</p>

Table C5. Key Informant interviews for Guiding Question 5: What are future directions for research in addressing barriers to survivorship care for pediatric cancer survivors?

Question	What Are the Most Important Gaps in Our Current Knowledge of Disparities and Barriers to Survivorship Care, and How Would You Recommend Filling Those?	How Can Future Research Be Designed To Minimize the Confounding Factors Influencing Barriers, and Ultimately, Disparities?	Are You Aware of Any Important Ongoing Studies Addressing Disparities or Barriers in Pediatric Survivorship Care?
Preliminary Feedback (included as prompt on slide)	<ol style="list-style-type: none"> 1. How to address information needs of community clinicians (at point of care) to expedite quality survivorship care 2. How to educate/empower survivors to self-advocate for care 3. How to address the need for development of easily accessible resources (app or in EMR) 	<ol style="list-style-type: none"> 1. Data sharing and collaboration across institutions and nations is important to assure diversity of population and characterize needs of clinically heterogeneous survivors 	<ol style="list-style-type: none"> 1. Medical 2. SES 3. Cultural

<p>KI Feedback</p>	<p>Some CCS don't even realize that you can apply for disability; connecting people to resources to help survivors advocate for their care/other needs is important.</p> <p>---</p> <p>Identifying the "healthcare neighborhood" will be important for survivors and what are the POC-related to those neighborhoods; are there teams in these neighborhoods; need to understand who is involved in transitions in care.</p> <p>---</p> <p>How to define SES – we don't know what the right social determinants are. Kira's bias is to utilize measurements that are amenable to INTERVENTION. So, we can take the next step. For example, use zip code to link to poverty level – not a highly impactful measure because can't change. However, primary language would be a possible one – providing materials/education in a patient's primary language.</p> <p>Another is Health literacy – providing materials in a way patients and families can understand.</p> <p>Income perspective – parent reported income is important – because state and federal programs may be available</p> <p>Concrete materials screen – food insecurity measuring (2-point question screener)</p> <p>Having a 1-page social determinants of health screener – available and validated in adults, could be utilized for pediatric patients – could be a starting point.</p> <p>---</p> <p>Answer has to be in technology. We have to focus on technological answers that can facilitate the survivor, oncologist and PCP. Community clinicians are extremely busy and don't have the ability to do the survivorship care plan. Educating and empowering survivors is great, but if there isn't someone on the provider end with</p>	<p>Setting is important and variable; some orgs, like St. Jude, is integrative whereas other are more treatment focused and less dedicated to survivorship; one size does not fit all settings – those with limited treatments, have limited risks (brain survivors have higher needs and related services); our healthcare systems need to be flexible to the variable needs of CCS.</p> <p>---</p> <p>Lack of a data commons that we can all submit to – this is a big barrier to advancing the science. Getting access to data is a year-long process – can delay moving care delivery forward. Less access to robust research or consortiums among providers that are at smaller/less-connected centers</p> <p>Not aware of multi center interventions</p> <p>Studies are single institution.</p>	<p>Most studies are just describing the disparities, not addressing them.</p> <p>---</p> <p>US healthcare is different, but how do survivorship outcomes differ with other countries.</p> <p>---</p> <p>UK has established levels of care that determine the provider type survivor will see; other groups are increasingly using risk-stratification for care, but most have access to PSP; Study looking at Passport through Pancare (giving survivorship care plan). Most other countries are struggling with transitioning from oncology to primary/community care, similar to the US; but access to care is more difficult in the US.</p> <p>---</p> <p>Perhaps telehealth can provide better care, utilizing experts remotely, possibly using pandemic to help push this forward?</p> <p>---</p> <p>Provider survey on pandemic services is being implemented. Could there be Centers of Excellence that provide services to anyone remotely? This can improve care more broadly that can be universally disseminated.</p> <p>---</p> <p>Agree that this is a great idea, especially to help w/ barriers related to transportation for those living in a rural area; thinking about how we can take advantage of some of the positive outcomes of the pandemic</p> <p>---</p> <p>Many of the telehealth rules are still evolving, know that there is a desire to maintain telehealth especially for those w/ chronic conditions to maintain access, but there's also awareness that these types of visits could be abused or fraudulent; questions about reimbursement for telehealth (figuring out whether these visits really are commensurate is needed); this wide-spread adoption has been great, but need to figure out the best practices and incentives for telehealth use; Center of</p>
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Question	What Are the Most Important Gaps in Our Current Knowledge of Disparities and Barriers to Survivorship Care, and How Would You Recommend Filling Those?	How Can Future Research Be Designed To Minimize the Confounding Factors Influencing Barriers, and Ultimately, Disparities?	Are You Aware of Any Important Ongoing Studies Addressing Disparities or Barriers in Pediatric Survivorship Care?
	<p>adequate resources, then it can be incredibly frustrating.</p> <p>App or EMR – can this help and provide a solution; technology, using risk stratification to create an automated survivorship care plan using low, intermediate, and high-risk buckets and recommending and facilitating the appropriate model of care is best; this could all be followed using apps and dashboards. For example, low risk patients may be seen using telehealth (direct to patient to remove barriers to care); high risk seen by specialist + PCP; COVID is increasing telehealth direct to patient and this can be an essential strategy going forward.</p>		<p>Excellence (COE) type model can provide access to the needed expertise but issue of referral to that program is a problem, from the health plan side, COEs are used to only allow care at one of these types of centers, which could create a barrier – it's a balance of suggesting the use of COE but using when necessary – need clear guidelines of when survivorship care should only be done at COE</p> <p>---</p> <p>Grant recently proposed was not funded; reviewers thought it was not a problem. We do have a pilot with rural providers for survivorship care using telehealth; this is an IMPORTANT area and an RFA on this would be ideal. Some RFAs exclude pediatric survivors. The CCSS is amazing, but there is too much emphasis on this resource (versus other work focused on disparities/barriers). We do have barriers/disparities that funders/reviewers do not appreciate. Survivorship is NOT the same as pediatric cancer treatment.</p>

Appendix D. Evidence Tables

Table D1. Guiding Question 1: Disparities in care

Author, Year Related Publications Study Name/Trial ID	Country	Proportion of CCS Cancer Origin	Disparities Analyzed
Barakat, 2012 ¹⁸ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Underserved or rural populations, Sex (biological), Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
Berg, 2016 ²⁰ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
Berkman, 2019 ²¹ N/A	USA	Proportion of CCS: 100% Brain/CNS	Racial/ethnic minorities, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
Casillas, 2011 ³² LIVESTRONG Survivorship Center of Excellence Network	USA	Proportion of CCS: 50% or more Multiple cancer origin	Racial/ethnic minorities
Crom, 2007 ⁴⁷ Klosky, 2008 ⁹⁶ ; Hudson, 2002 ⁷⁹ After Completion of Therapy (ACT) Clinic	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Income, Underserved or rural populations, Sex (biological), Employment, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Age, marital status
Daly, 2019 ⁴⁸ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Underserved or rural populations, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
de Fine Licht, 2017 ⁵⁰ Adult Life after Childhood Cancer in Scandinavia (ALiCCS)	Multiple countries	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Other: age at hospitalization, age at cancer diagnosis, type of cancer diagnosis, country (Denmark, Finland, Iceland, or Sweden)
Gardner, 2014 ⁶⁸ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Sex (biological), Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Age at diagnosis, age at study, time since treatment completion
Holmes, 1986 ⁷⁶ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Sex (biological)
Johnson, 2004 ⁸⁵ N/A	UK	Proportion of CCS: 100% Multiple cancer origin	Income, Education

Author, Year Related Publications Study Name/Trial ID	Country	Proportion of CCS Cancer Origin	Disparities Analyzed
Kazak, 1999 ⁹¹ Alderfer, 2009 ¹³ ; Kazak, 2004 ⁹⁰ Surviving Cancer Competently Intervention Program (SCCIP)	USA	Proportion of CCS: 100% Multiple cancer origin	Other: Poor family functioning as measured by Family Assessment Device scale
May, 2017 ¹¹⁰ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
McBride, 2011 ¹¹¹ Childhood, Adolescent, and Young Adult Cancer Survivors (CAYACS) Research Program	Canada	Proportion of CCS: 100% Multiple cancer origin	Income, Underserved or rural populations, Sex (biological)
Mendoza, 2018 ¹¹³ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Income
Michel, 2011 ¹¹⁶ Michel, 2016 ¹¹⁴ ; Lupatsch, 2016 ¹⁰⁵ ; Gianinazzi, 2014 ⁷⁰ ; University of Bern, 2007 ²² ; Vetsch, 2016 ¹⁶⁶ ; Michel, 2017 ¹¹⁵ Swiss Childhood Cancer Survivor Study	Switzerland	Proportion of CCS: 100% Multiple cancer origin	Underserved or rural populations, Sex (biological), Education, Employment, Other: Treatment reported late effects, age at study, parental education; cultural background (migration background and language region), diagnosis, treatment, type of treating hospital, relapse, parent-reported late effects, parent's age at study, child's age at study, time since diagnosis
Milam, 2015 ¹¹⁷ Miller, 2018 ¹¹⁸ ; Miller, 2017 ¹¹⁹ ; Cousineau, 2019 ⁴⁶ ; Slaughter, 2020 ¹⁵³ ; Tobin, 2020 ¹⁶¹ ; Sleight, 2019 ¹⁵⁵ ; Slaughter, 2020 ¹⁵⁴ Project Forward 1	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Income, Underserved or rural populations, Sex (biological), Education, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Prior survivorship care, higher treatment intensity, younger age at survey; parents' age, cancer treatment hospital site, treatment intensity; receipt of survivorship care in prior two years, treatment intensity, current age; Mobility

Author, Year Related Publications Study Name/Trial ID	Country	Proportion of CCS Cancer Origin	Disparities Analyzed
Nathan, 2016 ¹²³ Marr, 2017 ¹⁰⁸ Pediatric Oncology Group of Ontario Networked Information System	Canada	Proportion of CCS: 100% Multiple cancer origin	Income, Underserved or rural populations, Sex (biological), Other: Age at diagnosis, year of diagnosis, treatment intensity, radiation, prior recurrence
Oeffinger, 2004 ¹²⁷ Kirchhoff, 2013 ⁹³ ; Casillas, 2015 ³³ ; Nathan, 2008 ¹²² ; Caplin, 2017 ²⁸ ; Casillas, 2011 ²⁹ ; Castellino, 2005 ³⁶ ; Geller, 2019 ⁶⁹ ; Kaste, 2009 ⁸⁹ ; Kirchhoff, 2018 ⁹⁵ ; Nipp, 2017 ¹²⁵ ; Recklitis, 2010 ¹³⁵ ; Yeazel, 2004 ¹⁷¹ ; Ford, 2020 ⁶⁵ ; Park, 2017 ¹³¹ ; Smith, 2010 ¹⁵⁶ ; Park, 2012 ¹³² ; Krull, 2011 ⁹⁸ ; Nathan, 2010 ¹²⁴ ; Kadan-Lottick, 2002 ⁸⁷ ; Kurt, 2012 ¹⁰¹ Childhood Cancer Survivor Study	Multiple countries	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Income, Underserved or rural populations, Sex (biological), Education, Employment, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Current age; severe, disabling, or life-threatening chronic condition; presence of neurocognitive problems and antidepressant use; cancer diagnosis; marital status, receipt of a survivorship care plan, survivorship care in prior two years, written treatment summary, and those in chronic pain
Ojha, 2014 ¹³⁰ Behavioral Risk Factor Surveillance System	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Sex (biological), Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
Reppucci, 2017 ¹³⁶ SuRFF Program at the Cohen Children's Medical Center of New York	USA	Proportion of CCS: 100% Multiple cancer origin	Other: Current age
Streefkerk, 2019 ¹⁵⁷ DCOG-LATER	Netherlands	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Other: Age at diagnosis, decade of diagnosis, diagnosis, treatment modality, stem cell transplant, comorbid conditions

Author, Year Related Publications Study Name/Trial ID	Country	Proportion of CCS Cancer Origin	Disparities Analyzed
Sutradhar, 2015 ¹⁵⁸ Pediatric Oncology Group of Ontario Networked Information System (POGONIS)	Canada	Proportion of CCS: 100% Multiple cancer origin	Underserved or rural populations, Other: Diagnosis, age at diagnosis, treatment with radiation, treatment intensity (ITR, Cyclophosphamide-equivalent dose, Doxorubicin-equivalent dose), continuity of care, annual physical examination
Szalda, 2016 ¹⁶⁰ Szalda, 2017 ¹⁵⁹ Cancer Survivorship Program at Children's Hospital of Philadelphia	USA	Proportion of CCS: 100% Multiple cancer origin	Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
van Laar, 2013 ¹⁶⁴ N/A	UK	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Other: Age
Welch, 2017 ¹⁶⁹ Consortium for New England Childhood Cancer Survivors	USA	Proportion of CCS: 100% Leukemia	Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Age (adult at follow-up); enrolled on a clinical trial; type of leukemia
Zheng, 2016 ¹⁷² N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Income, Sex (biological), Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Diagnosis, treatment, enrolled on a clinical trial, relapsed disease, travel time to hospital

Table D2. Guiding Question 2: Barriers to care

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Ahn, 2017 ¹² Korean Childhood Cancer Survivors	Korea Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient Category: Patient/Provider knowledge, Health literacy, Other: Age Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Cultural, language, and literacy factors
Aziz, 2006 ¹⁷ N/A	USA Survey	Proportion of CCS: NR Multiple cancer origin	Level: Patient, Provider, Health system Category: Access to care, Patient/Provider knowledge, Insurance coverage Patient or caregiver/family/community barrier type: Prioritization of survivorship care Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Insurance coverage/reimbursement; Other: Lack of institutional value, capacity for care, difficulty in communication with community physicians, and survivor-driven barriers
Berg, 2016 ²⁰ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Insurance coverage, Health literacy Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Trust in providers/medical community
Berkman, 2019 ²¹ N/A	USA Analytic study	Proportion of CCS: 100% Brain/CNS	Level: Patient Category: Access to care, Insurance coverage Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare)
Casillas, 2010 ³¹ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient Category: Patient/Provider knowledge, Cultural, Health literacy, Other: cancer experience as traumatic for family, don't want to think about late effects, stigma of cancer Patient or caregiver/family/community barrier type: Cultural, language, and literacy factors

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Casillas, 2011 ³² LIVESTRONG Survivorship Center of Excellence Network	USA Survey	Proportion of CCS: 50% or more Multiple cancer origin	Level: Patient, Provider Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Trust in providers/medical community; Other: health care self-efficacy Provider, health system, or payer barrier type: Geographic or transportation factors, local availability of services
Cherven, 2014 ³⁸ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient Category: Patient/Provider knowledge, Health literacy, Other: Parents' education level Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care
Crom, 2007 ⁴⁷ Klosky, 2008 ⁹⁶ ; Hudson, 2002 ⁷⁹ After Completion of Therapy (ACT) Clinic	USA Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Insurance coverage, Other: Employment Status Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Other: Acuity of survivorship visit; social work consult also scheduled
de Moor, 2007 ⁵¹ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Provider, Health system Category: Access to care, Other: Health system characteristics Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Other: Staffing and time constraints to offer smoking cessation services

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
DiNofia, 2017 ⁵⁷ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment Category: Cultural, Other: parent perspective Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Trust in providers/medical community; Other: flexible scheduling, include parents, availability and access to a variety of providers (e.g., mental health), access to primary care physician, access to vocational training, survivor feeling ready to transition, parent feeling ready to transition, gradual introduction of transition
Eshelman-Kent, 2011 ⁶³ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient, Provider, Health system Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Insurance coverage/reimbursement; Knowledge or comfort in ability to provide survivorship care; Other: Conflict between COG recommendations for risk-based care and adult provider recommendations; perceived lack of interest in caring for survivors from adult health care providers
Frederick, 2017 ⁶⁶ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Patient autonomy; Trust in providers/medical community; Other: Education preferences, family role in transition, survivor expectation of providers, and knowledge deficits

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Frobisher, 2008 ⁶⁷ British Childhood Cancer Survivorship Study	UK Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Other: Employment, Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare)
Gardner, 2014 ⁶⁸ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Insurance coverage Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Other: Use of prescription medication, have a primary care provider, see primary care provider less than once per year, count of the number of barriers to psychosocial support services, personal preference of provider type and social norm (mental health professional, pastor, support group)
Granek, 2012 ⁷² N/A	Canada Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Other: Identification with being a cancer survivor (cancer identity, cancer a thing of the past); emotional components (fear and anxiety, gratitude/having perspective)
Hays, 1992 ⁷³ N/A	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Payer Category: Insurance coverage Provider, health system, or payer barrier type: Insurance coverage/reimbursement

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Henderson, 2010 ⁷⁴ N/A	USA Survey	Proportion of CCS: NR Multiple cancer origin	Level: Provider Category: Patient/Provider knowledge Provider, health system, or payer barrier type: Geographic or transportation factors, local availability of services; Knowledge or comfort in ability to provide survivorship care; Other: Familiarity with available guidelines, years of practice, number of patients seen per week, prior training in the care of childhood cancer survivors, practice location, available long-term follow-up clinic, routine referral of survivors to other physicians, and indicators of whether they were very comfortable (e.g., Likert score of 5 or higher) with survivors 21 years, older than 21 years but less than 30 years, and 30 years
Holmes, 1986 ⁷⁶ N/A	USA Survey, Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Insurance coverage, Other: Life insurance Patient or caregiver/family/community barrier type: Other: Ability to get needed coverage
Howard, 2018 ⁷⁷ N/A	Canada Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient, Health system Category: Access to care Patient or caregiver/family/community barrier type: Trust in providers/medical community Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Transition from pediatric to adult care; Knowledge or comfort in ability to provide survivorship care
Iwai, 2017 ⁸² N/A	Japan Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Other: Financial concerns, employment issues Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Iyer, 2017 ⁸³ N/A	USA Survey, Interview	Proportion of CCS: 50% or more Multiple cancer origin	Level: Provider Category: Access to care, Patient/Provider knowledge Provider, health system, or payer barrier type: Transition from pediatric to adult care; Knowledge or comfort in ability to provide survivorship care; Other: Unsure of which provider is responsible for which late effects/comorbid conditions
Jereb, 2000 ⁸⁴ N/A	Slovenia Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient, Provider Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Other: Reluctance to give up on their patients
Keats, 2019 ⁹² N/A	Canada Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient, Provider Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Patient autonomy; Trust in providers/medical community; Other: Perceived lack of sharing of medical information among providers Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Knowledge or comfort in ability to provide survivorship care
Kirchhoff, 2014 ⁹⁴ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Insurance coverage, Health literacy Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community; Other: Current primary health-care experiences (provider recently moved, provider retired/relocated); cancer-related communication with primary care providers (limited to no communication with primary care providers); Knowledge and impressions about survivorship care (care plans need to include longitudinal detailed plans about where to go for specific types of health care needs and where they can go that accepts their insurance and tells them how much the care will cost)

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Knighting, 2020 ⁹⁷ N/A	UK Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community
Kuhlthau, 2016 ⁹⁹ National Health Interview Survey	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Other: Delayed medical care; forgone medical care
Li, 1976 ¹⁰⁴ N/A	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Provider Category: Access to care, Insurance coverage Provider, health system, or payer barrier type: Transition from pediatric to adult care, Knowledge or comfort in ability to provide survivorship care
Maeda, 2010 ¹⁰⁶ N/A	Japan Survey	Proportion of CCS: 50% or more Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Health literacy Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Cultural, language, and literacy factors
Mendoza, 2018 ¹¹³ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Health system Category: Access to care, Insurance coverage Provider, health system, or payer barrier type: Insurance coverage/reimbursement

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Michel, 2011 ¹¹⁶ Michel, 2016 ¹¹⁴ ; Lupatsch, 2016 ¹⁰⁵ ; Gianinazzi, 2014 ⁷⁰ ; University of Bern, 2007 ²² ; Vetsch, 2016 ¹⁶⁶ ; Michel, 2017 ¹¹⁵ Swiss Childhood Cancer Survivor Study	Switzerland Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient, Provider Category: Access to care, Patient/Provider knowledge, Cultural, Health literacy Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Other: Distressed versus non-distressed survivors; Illness Perception Questionnaire (IPQ) Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Transition from pediatric to adult care; Insurance coverage/reimbursement; Knowledge or comfort in ability to provide survivorship care
Milam, 2015 ¹¹⁷ Miller, 2018 ¹¹⁸ ; Miller, 2017 ¹¹⁹ ; Cousineau, 2019 ⁴⁶ ; Slaughter, 2020 ¹⁵³ ; Tobin, 2020 ¹⁶¹ ; Sleight, 2019 ¹⁵⁵ ; Slaughter, 2020 ¹⁵⁴ Project Forward 1	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient Category: Access to care, Patient/Provider knowledge, Cultural, Insurance coverage Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors; Other: Higher health care self-efficacy (being uninsured was financial driver); parents' mental health/psychosocial status

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Mouw, 2017 ¹²⁰ N/A	USA Interview	Proportion of CCS: NR Multiple cancer origin	<p>Level: Patient, Provider, Health system, Payer</p> <p>Category: Access to care, Patient/Provider knowledge, Cultural, Insurance coverage, Health literacy</p> <p>Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors</p> <p>Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Transition from pediatric to adult care; Insurance coverage/reimbursement; Knowledge or comfort in ability to provide survivorship care; In-network providers; Other: Provider-driven patient education; adequate funding to support survivorship clinic activities</p>
Novakovic, 1997 ¹²⁶ N/A	USA Survey	Proportion of CCS: 50% or more Bone cancer	<p>Level: Patient</p> <p>Category: Access to care, Insurance coverage</p> <p>Patient or caregiver/family/community barrier type: Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare)</p>

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Oeffinger, 2004 ¹²⁷ Kirchhoff, 2013 ⁹³ ; Casillas, 2015 ³³ ; Nathan, 2008 ¹²² ; Caplin, 2017 ²⁸ ; Casillas, 2011 ²⁹ ; Castellino, 2005 ³⁶ ; Geller, 2019 ⁶⁹ ; Kaste, 2009 ⁸⁹ ; Kirchhoff, 2018 ⁹⁵ ; Nipp, 2017 ¹²⁵ ; Recklitis, 2010 ¹³⁵ ; Yeazel, 2004 ¹⁷¹ ; Ford, 2020 ⁶⁵ ; Park, 2017 ¹³¹ ; Smith, 2010 ¹⁵⁶ ; Park, 2012 ¹³² ; Krull, 2011 ⁹⁸ ; Nathan, 2010 ¹²⁴ ; Kadan-Lottick, 2002 ⁸⁷ ; Kurt, 2012 ¹⁰¹ CCSS	Multiple countries Survey, Interview, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient, Provider, Health system, Payer Category: Access to care, Patient/Provider knowledge, Cultural, Insurance coverage, Health literacy, Other: Late effects; financial hardship (medical, psychosocial, and behavioral) Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community; Other: Prepared list of concerns for routine care visit, asked about screening during visit, heard about ABCDE rule for melanoma Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Insurance coverage/reimbursement; In-network providers
Quillen, 2017 ¹³³ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community
Rosenberg-Yunger, 2013 ¹³⁹ N/A	Canada Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Health literacy Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of need for life-long survivorship care; Trust in providers/medical community
Sadak, 2012 ¹⁴⁰ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient, Payer Category: Access to care, Patient/Provider knowledge, Insurance coverage, Health literacy Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Patient autonomy Provider, health system, or payer barrier type: Transition from pediatric to adult care; Insurance coverage/reimbursement

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Sadak, 2017 ¹⁴² N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin, Other: focused on providers not CCS	Level: Patient, Provider Category: Patient/Provider knowledge, Insurance coverage Provider, health system, or payer barrier type: Transition from pediatric to adult care
Sadak, 2019 ¹⁴³ N/A	USA Survey	Proportion of CCS: Unclear Other: Focused on facilities, not individual CCS	Level: Health system Category: Other: Size of the transition program Provider, health system, or payer barrier type: Geographic or transportation factors, local availability of services; Transition from pediatric to adult care
Sadak, 2020 ¹⁴¹ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Knowledge of the need for life-long survivorship care; Financial or employment resources; Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community; Other: Transition practices should be flexible and individually tailored (optimal age to transition must be flexible); effective communication is critical to a successful transition; survivors desire continuity during the transition (reliable transfer of medical information to new providers is key, consistent provider(s) during the transition is helpful); comprehensive care means care that also addresses psychosocial wellbeing (educational messages on health insurance are timely and very much needed, support during life transitions is a necessary component of psychosocial support)
Sherman, 2004 ¹⁴⁷ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Health system Category: Access to care Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist)

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Sima, 2014 ¹⁵⁰ N/A	USA Survey	Proportion of CCS: NR Other: provider-focused	Level: Provider Category: Patient/Provider knowledge Provider, health system, or payer barrier type: Resources to deliver needed care or respond to needs (PCP or specialist); Geographic or transportation factors, local availability of services; Transition from pediatric to adult care; Knowledge or comfort in ability to provide survivorship care; Other: Awareness and interest in the medical problems of adult CCS
Szalda, 2016 ¹⁶⁰ Szalda, 2017 ¹⁵⁹ Cancer Survivorship Program at CHOP	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Insurance coverage Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community
Van Laar, 2013 ¹⁶⁴ N/A	UK Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Other: less waiting time

Author, Year Related Publications Study Name/Trial ID	Country Methodology	Proportion of CCS Cancer Origin	Barrier Level Barrier Category Barrier Type
Vetsch, 2017 ¹⁶⁵ Signorelli, 2019 ¹⁴⁸ ; Nandakumar, 2018 ¹²¹ ; Signorelli, 2017 ¹⁴⁹ ANZCHOG Survivorship Study	Australia and New Zealand Survey, Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/local environment, Patient, Provider, Health system Category: Access to care, Patient/Provider knowledge, Cultural, Insurance coverage, Health literacy Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Patient autonomy; Cultural, language, and literacy factors; Trust in providers/medical community; Other: Low confidence in PCPs' ability to deliver survivorship care; age, cognitive difficulties Provider, health system, or payer barrier type: Geographic or transportation factors, local availability of services, Transition from pediatric to adult care; Insurance coverage/reimbursement; Knowledge or comfort in ability to provide survivorship care; Other: Dependence on pediatric providers; inconsistent transition practices, lack of resources for research, multidisciplinary team, location of nearby providers, helpful patient education materials (facilitator)
Wadhwa, 2019 ¹⁶⁷ N/A	USA Survey	Proportion of CCS: 50% or more Other: primary care providers	Level: Provider Category: Patient/Provider knowledge Patient or caregiver/family/community barrier type: Knowledge or comfort in ability to provide survivorship care
Warner, 2014 ¹⁶⁸ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Patient, Provider, Health system Category: Access to care, Patient/Provider knowledge, Insurance coverage, Other: Quality of care Patient or caregiver/family/community barrier type: Prioritization of survivorship care; Financial or employment resources (e.g., money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community Provider, health system, or payer barrier type: Knowledge or comfort in ability to provide survivorship care

Table D3. Guiding Question 4: Evaluated strategies

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Bashore, 2016 ¹⁹ N/A Pre-Post USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan, Model of care Intervention category: Education, Given tools for empowerment Evaluation regarding the usefulness of a workbook to assist survivors to become ready to transition to adult care. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: transition in care Authors' conclusion: The majority of the participants reported the sections of the workbook on their medical history, provider information, and insurance were the most helpful. After completing the workbook intervention, survivors reported higher mean scores on readiness to transition and being ready to make the changes to transition.
Blaauwbroek, 2008 ²⁴ N/A CT UK	Proportion of CCS: 100% Multiple cancer origin	Strategy: Model of care Intervention category: Access to care, Given tools for empowerment Survivor and local primary care provider satisfaction with shared care model: year 1 - all survivors had survivorship care visit with primary care provider at long-term follow-up clinic at start of study; year 2 - follow-up one year later with primary care provider (given survivorship care plan); and year 3 - survivors returned to the survivorship clinic and saw a primary care provider, discussed risk-stratified care needs in the future Primary target: Patient, Provider	Outcomes: Health services/Economics: Quality and satisfaction with care Authors' conclusion: Most survivors and primary care providers were satisfied with this shared-care model; clear advantages of follow-up care given by local family doctors rather than by hospital staff include less patient travel, shorter waiting times, better patient familiarity with surroundings (e.g., the doctor's practice), and less stigmatization; as survivors age and possibly develop additional chronic illnesses, access to care in the context of total health needs is more useful.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Blaauwbroek, 2012 ²³ N/A Analytic study Netherlands	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan Intervention category: Given tools for empowerment Web-based survivorship care plan given to survivors and primary care providers. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care plan Authors' conclusion: Most survivors and primary care providers found the survivorship care plan user-friendly (both online and printed versions); most survivors thought their knowledge of late effects had improved and nearly all survivors had become more aware of the benefits of follow-up.
Casillas, 2017 ³⁰ N/A Analytic study USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service Intervention category: Education Develop and examine the acceptability, feasibility, and usability of a text messaging system for improving the receipt of survivorship care; text messages delivered programmed reminders to schedule and attend survivorship appointments, tailored suggestions for community resources for cancer survivors, and messages prompting participant feedback regarding appointments and resources. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Survivorship care Authors' conclusion: Text messaging system is an acceptable form of communication, the screening reminders and feedback prompts feasible for improving the receipt of survivorship care, and the tailored suggestions for community resources usable for connecting survivors to relevant services; survivors shared that this has the potential to mitigate barriers in coordinating survivorship care, encourage active self-management of survivorship care, and help survivors reach personal survivorship health behavior goals beyond late effect screening.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Casillas, 2019 ³⁴ N/A RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service, Care plan, Other: Knowledge of survivorship care, survivorship care self-efficacy, attitude towards survivor-focused care Intervention category: Education, Given tools for empowerment Evaluation of text-messaging and peer navigation interventions were compared to standard-of-care survivorship educational materials to increase survivors' (1) late effects knowledge and (2) knowledge, attitudes, and self-efficacy towards seeking survivor-focused care; no clear provider target because the educational materials provided to patients could be delivered by anyone on the care team Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Knowledge of survivorship care, survivorship care self-efficacy, attitude towards survivor-focused care Authors' conclusion: The text-messaging group had increased survivorship care knowledge compared to the control group (current standard-of-care educational materials); the peer navigation group had increased survivorship care self-efficacy compared to the control group. Both intervention groups showed increased attitudes towards seeking survivor-focused care compared to the control group.
Casillas, 2020 ³⁵ N/A Pre-Post USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service Intervention category: Education Single-arm pilot study evaluated a novel intervention (a photonovela) on its ability to educate Latino AYA survivors and their family members and engage them in survivorship care; a health advocate led each photonovela intervention session. The patient targets were CCS and their parents Primary target: Patient, Family	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Educate Latino survivors and their family and engage them in survivorship care Authors' conclusion: The photonovela intervention was effective in improving survivorship care confidence of Latino AYA survivors and their families both at the follow-up and booster assessments. Additionally, the intervention had small to medium effect on family members on higher mean scores for cancer stigma from baseline to booster assessment, but also improved knowledge for family members from baseline to booster.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Costello, 2017 ⁴⁵ N/A Analytic study USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service, Model of care Intervention category: Access to care Pediatric oncologists and adult primary care providers used telemedicine to help aid childhood cancer survivors with their transition in follow-up care to their primary care provider. Primary target: Patient, Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: telemedicine of survivorship visit with oncologist and PCP; Health services/Economics: Primary care, specialty care, or other care utilization: telemedicine of survivorship visit with oncologist and PCP Authors' conclusion: Use of telemedicine technology for transition visit increased knowledge, comfort and abilities, and patient satisfaction in survivorship care. Negative comments from CCS were primarily related to equipment difficulties.
Crom, 2007 ⁴⁷ Klosky, 2008 ⁹⁶ ; Hudson, 2002 ⁷⁹ After Completion of Therapy (ACT) Clinic RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Other: Knowledge of late effects Intervention category: Education Assess the efficacy of an educational intervention targeting survivorship clinic attendees' health knowledge about cancer treatment and risks, health perceptions, and health behavior practice at baseline and follow-up one year later. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Attenders versus non-attenders at survivorship visits; Health services/Economics: Primary care, specialty care, or other care utilization: Difficulty obtaining care; Health services/Economics: Financial hardship, costs, and resource utilization; Other: Health knowledge of late effects Authors' conclusion: Female survivors in the intervention group (standard of care plus the educational intervention) reported higher health knowledge than male survivors at one year follow-up.
de Moor, 2011 ⁵² Emmons, 2013 ⁶⁰ NCT00588107 Analytic study USA	Proportion of CCS: NR Multiple cancer origin	Strategy: Other: Access to survivorship care/primary care providers were included as covariates Intervention category: Education, Psychosocial Website and print materials intervention for smoking cessation for childhood, adolescent, and young adult cancer survivors Primary target: Patient	Outcomes: Biomedical: Late effects and morbidity, Psychosocial: Substance use Authors' conclusion: Encouragement to quit smoking by one's regular doctor or oncologist was associated with a making more quit attempts.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Devine, 2020 ⁵⁵ NCT02699996 CT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service Intervention category: Education, Given tools for empowerment Self-management (5 online educational modules) and peer mentoring (6 video conference or phone calls) intervention to promote self-management of follow-up care; the main target was the survivor and the secondary target was the peer mentor. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Feasibility; Psychosocial: Psychological; Health services/Economics: Primary care, specialty care, or other care utilization: Barriers to care, transition readiness; Health services/Economics: Quality and satisfaction with care Authors' conclusion: Significant positive relationship with transition readiness using multiple measures including knowledge, beliefs/expectations, goals/motivation; positively associated w/ grit; negatively associated w/ FOCUS instrument (measures barriers to care).
Ducassou, 2017 ⁵⁸ N/A Cohort France	Proportion of CCS: 100% Multiple cancer origin	Strategy: Model of care Intervention category: Access to care Shared care program between primary care provider and oncologist Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: shared care (oncologist and PCP); Health services/Economics: Primary care, specialty care, or other care utilization: shared care (oncologist and PCP) Authors' conclusion: Personalized and incentive-based guidance was very useful in helping survivors adhere to follow-up care.
Eilertsen, 2004 ⁵⁹ N/A Analytic study Norway	Proportion of CCS: 100% Multiple cancer origin	Strategy: Model of care Intervention category: Education Held a collaborative meeting between the child, their parents, and the professionals in the family's home community and the pediatric unit. Primary target: Patient, Family, Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Survivorship care Authors' conclusion: Health professionals regard collaboration with CCS, family, and other professionals as being valuable and important for follow-up care for CCS.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Ford, 2013 ⁶⁴ N/A Cohort USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Model of care Intervention category: Access to care Survivorship clinic attendance. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care; knowledge of the need for life-long survivorship care; Psychosocial: Psychological Authors' conclusion: No significant differences in survivors knowledge about their cancer diagnosis, perceptions of risk of future health problems, or psychological or emotional problems reported by those in long-term survivorship clinic versus those in non-specialized clinic.
Hudson, 2020 ⁷⁸ NCT01003574 (Evaluation of Cardiovascular Health Outcomes Among Survivors (ECHOS)) RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan, Model of care Intervention category: Education, Given tools for empowerment Distance-delivered intervention of two sessions of tailored telephone counseling delivered by an advanced practice provider (treatment group) to see if this would increase the proportion of at-risk survivors who completed cardiomyopathy screening; the control group received the mailed survivorship care plan only. Primary target: Patient	Outcomes: Biomedical: Late effects and morbidity Authors' conclusion: Intervention significantly increased the likelihood of cardiomyopathy screening among at-risk survivors of childhood cancer; this method of intervention provides evidence that distance-delivered survivorship services could help reach at-risk populations.
Iyer, 2017 ⁸³ N/A Analytic study USA	Proportion of CCS: 50% or more Multiple cancer origin	Strategy: Care plan, Model of care, Other: Primary care provider knowledge of survivorship care plan Intervention category: Access to care Survivorship care plans, preferences, and barriers from the perspective of primary care provider and CCS Primary target: Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care; Survivorship care plans, barriers, and preferences regarding care; Health services/Economics: Primary care, specialty care, or other care utilization Authors' conclusion: Primary care providers generally felt uncomfortable using the survivorship care plan and providing survivorship care, the biggest barrier was lack of knowledge.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Kadan-Lottick, 2018 ⁸⁸ Yale University, 2010 ¹⁶³ NCT02816866 RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan, Model of care Intervention category: Access to care, Given tools for empowerment Distribution of survivorship care plan to patient and primary care providers (both primary targets); to be implemented by either primary care provider or survivorship clinic provider. Primary target: Patient, Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Survivorship care plan taken to oncologist or PCP; Health services/Economics: Primary care, specialty care, or other care utilization: Survivorship care plan taken to oncologist or PCP Authors' conclusion: Empowering childhood cancer survivors with survivorship care plan to be implemented by their primary care provider is not sufficient to meet consensus follow-up recommendations compared to those who attend survivorship clinic; those who had a survivorship care plan and attended follow-up care with primary care reported much lower adherence to guideline-recommended surveillance tests and less identification of late complications of therapy.
Kunin-Batson, 2016 ¹⁰⁰ NCT01593618 RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan Intervention category: Education Web-based educational intervention for adolescent and young adult survivors of childhood cancer that provided their survivorship care plans electronically to improve cancer-related knowledge and psychosocial functioning. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Knowledge of cancer diagnosis, history, and treatment; Psychosocial: Psychological Authors' conclusion: The web-based intervention was not statistically better in improving cancer-related knowledge compared to the standard of care (face-to-face counseling); anxiety and health beliefs were associated with survivors' knowledge about cancer, including knowledge of steps survivors could take to mitigate risks for late effects.
Landier, 2015 ¹⁰² N/A Time series USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan Intervention category: Access to care, Education Survivorship clinic and tailored education regarding risk for late effects. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Awareness of health risks in survivorship Authors' conclusion: Risk-based education in a survivorship clinic significantly increases awareness of personal health risk through three sessions.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Oeffinger, 2011 ¹²⁹ N/A CT Multiple countries	Proportion of CCS: 100% Lymphoma	Strategy: Care plan Intervention category: Given tools for empowerment Mailed survivorship care plan to high-risk survivors who were not receiving recommended cancer or cardiac surveillance (primary target) in hopes that they would communicate with their local primary care provider (secondary target); also sought to evaluate the use of a web-based virtual information center for survivors (primary target) and clinicians (secondary target). Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care; Screening echocardiogram and/or mammogram; Biomedical: Late effects and morbidity Authors' conclusion: Mailed survivorship care plans were found to be a feasible and effective way to deliver cancer treatment summaries and screening recommendations for high-risk survivors to encourage risk-based surveillance for late effects.
Oeffinger, 2019 ¹²⁸ NCT01579552 (EMPOWER Study) RCT Multiple countries	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service Intervention category: Education Mailed informational packet and participated in a motivational interview from trained counselors to examine the impact on screening mammography by 12 months after the intervention. Primary target: Patient	Outcomes: Biomedical: Late effects and morbidity; Health services/Economics: Primary care, specialty care, or other care utilization: Mammography screening Authors' conclusion: At a one-year follow-up, women in the intervention group were significantly more likely than those in the control group to report a mammogram (intervention was more successful among women age 25 to 39 years than among those age 40 to 50 years).
Raj, 2018 ¹³⁴ N/A Analytic study USA	Proportion of CCS: 100% Brain/CNS	Strategy: Survivorship care service Intervention category: Psychosocial To evaluate the development of a web-based psychosocial intervention ("A Survivor's Journey") for pediatric brain tumor survivors and caregivers on improvement in psychosocial functioning for the survivor. Primary target: Patient, Family	Outcomes: Psychosocial: Psychological Authors' conclusion: Feedback from survivors, their parents, and care providers all favored the web-based delivery of this intervention and supported the need for accessible interventions that are customizable to the unique needs of survivors; survivors and caregivers favored interventions that can be delivered remotely (e.g., do not require additional visits).

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Reynolds, 2019 ¹³⁷ N/A Cohort Canada	Proportion of CCS: 100% Multiple cancer origin	Strategy: Model of care Intervention category: Access to care Survivorship care at specialized long-term follow-up care facilities versus at primary-care facilities. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care at oncologist (versus PCP); Health services/Economics: Primary care, specialty care, or other care utilization: survivorship care at primary care provider (versus oncologist) Authors' conclusion: Cancer-center based models reported higher rates of compliance with exposure-based medical late effect screening guidelines, cancer-specific follow-up behaviors, and the reporting of fewer physical complaints than the community-based providers.
Rose-Felker, 2019 ¹³⁸ N/A Pre-Post USA	Proportion of CCS: NR Other: not specified	Strategy: Other: Educational intervention targeting pediatric cardiologists Intervention category: Education Educational intervention using pre/post test to assess knowledge of surveillance needs for childhood cancer survivors among pediatric cardiologists Primary target: Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: pediatric cardiologists; Biomedical: Late effects and morbidity Authors' conclusion: Post-intervention, there was an improvement in pediatric cardiologist knowledge including childhood cancer survivors surveillance, treatment related risk, risk of cardiac dysfunction with time since treatment, the role of dexrazoxane in cardioprotection, that a web-based risk-assessment tool to estimate the risk of congestive heart failure in survivors by age 40 exists and can be used, and that African-Americans childhood cancer survivors are at increased risk for late cardiotoxicity.
Santacroce, 2010 ⁸⁶ HEROS PLUS AYA RCT USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service, Care plan Intervention category: Psychosocial Coping skills training intervention via telephone and discussed plans for future monitoring with survivors (main target) and parents (secondary) Primary target: Patient, Family	Outcomes: Psychosocial: Psychological; Other: Psychosocial outcomes for survivors and parents Authors' conclusion: Post-intervention, outcomes for HEROS (standard of care for long-term follow up care) AYA and parents remained the same or deteriorated; while outcomes for HEROS PLUS (standard of care plus telephone-delivered psychosocial care) AYA and parents improved in Posttraumatic Growth Inventory.

Author, Year Related Publications Study Name/Trial ID Design Country	Proportion of CCS Cancer Origin	Strategy and Intervention Approach Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure Authors' Conclusion
Schwartz, 2018 ¹⁴⁵ N/A Pre-Post USA	Proportion of CCS: NR Multiple cancer origin	Strategy: Other: Educational intervention targeting pediatric residents Intervention category: Education Examined residents' knowledge, clinical skills, and attitudes towards cancer survivorship topics before and after receiving curriculum. Primary target: Provider	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: pediatric residents' knowledge and clinical skills related to caring for childhood cancer survivors Authors' conclusion: The post-curriculum evaluation showed a significant improvement in residents' knowledge, clinical skills, and comfort in discussing topics relevant to survivorship care; residents also reported that they would recommend it to other residency programs.
Schwartz, 2019 ¹⁴⁴ AYA STEPS (AYA Self- management via Texting, Education, and Plans for Survivorship) Post-only USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Survivorship care service Intervention category: Education Creation and initial use of the AYA STEPS (Adolescent and Young Adult Self-management via Texting, Education, and Plans for Survivorship) mobile app to encourage adherence to survivorship care plans. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Survivorship care plan Authors' conclusion: Survivors reported that the app and the embedded tailored messages related to their health and survivorship care plan were easy to use and generally satisfying and beneficial; final results of the RCT (approximately 200 participants) is pending.
Williamson, 2014 ¹⁷⁰ SurvivorLink Analytic study USA	Proportion of CCS: 100% Multiple cancer origin	Strategy: Care plan, Model of care Intervention category: Given tools for empowerment Creation of a personal health record, stored a health document, and electronically shared their health record with a provider. Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Survivorship care engagement via use of SurvivorLink Authors' conclusion: Having attended survivorship clinic is the most significant predictor of registering and using SurvivorLink, a patient-controlled communication tool where survivors can electronically store and share documents with healthcare providers.

Notes: CCS childhood cancer survivor

Table D4. Guiding Question 5: Ongoing studies

Author, Year Related Publications Study Name/Trial ID Design Country Expected completion	Proportion of CCS Cancer Origin	Intervention Type Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure
Chow, 2020 ⁴³ Chow, 2020 ⁴⁴ NCT03104543 [Communicating Health Information and Improving Coordination With Primary Care (CHIIP)] RCT USA Expected completion: 03/01/2022	Proportion of CCS: 100% Multiple cancer origin	Survivorship care service Printed, mailed survivorship care plan with personalized health history (e.g., absolute and relative risk estimates of ischemic heart disease and cardiomyopathy/heart failure compared with the general population, based on each participant's prior childhood cancer treatment exposures), recommendations, and clinically meaningful results from the baseline home visit (e.g., average blood pressure, lipid profile, diabetes screening, body mass index).	Biomedical: Late effects and morbidity; Psychosocial: Psychological; Health services/Economics: Primary care, specialty care, or other care utilization
Daniel, 2015 ⁴⁹ NCT02046811 RCT USA Expected completion: 01/01/2018	Proportion of CCS: 100% Multiple cancer origin	Other: Self examination Patient activation and education (PAE) including text messaging, print and web-based tutorials; PAE plus physician activation (PAE+MD) adding physician activation/educational materials about survivors' increased skin cancer risk and conducting full-body skin exams; PAE plus physician activation, plus teledermoscopy (PAE+MD+TD) adding participant receipt of a dermatoscope intended to empower them to photograph suspect moles or lesions for review by the study dermatologist	Health services/Economics: Primary care, specialty care, or other care utilization: skin examination by survivor or provider

Author, Year Related Publications Study Name/Trial ID Design Country Expected completion	Proportion of CCS Cancer Origin	Intervention Type Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure
Denzler, 2020 ⁵⁴ NCT04284189 (After Care of Childhood Cancer Survivors Switzerland) Analytic study Switzerland Expected completion: August 2021	Proportion of CCS: 100% Multiple cancer origin	Model of care Investigate which long-term follow-up care model (or which parts of the models) have the best fit for Swiss childhood cancer survivors (primary target); evaluate transition readiness, identify facilitators factors for transition and adherence to follow-up care, and compare the transition models of the three participating centers.	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care
Devine, 2019 ⁵⁶ NCT04075734 RCT USA Expected completion: 09/30/2020	Proportion of CCS: 100% Multiple cancer origin	Survivorship care service, Care plan Managing Your Health, an online self-management skills and peer mentoring intervention, which focuses on overcoming survivor barriers to self-management of their survivorship care.	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Knowledge of survivorship care needs, self-efficacy for survivorship care planning, attitudes towards survivorship care; Psychosocial: Psychological; Health services/Economics: Primary care, specialty care, or other care utilization: Communication from survivor to PCP
Escoffery, 2019 ⁶² Emory University, 2020 ¹⁶² ; SurvivorLink, 2020 ²⁷ NCT03543852 RCT USA Expected completion: 05/01/2023	Proportion of CCS: 100% Multiple cancer origin	Survivorship care service, Care plan Patient-controlled electronic personal health record and system (SurvivorLink)	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care plan

Author, Year Related Publications Study Name/Trial ID Design Country Expected completion	Proportion of CCS Cancer Origin	Intervention Type Description of Survivorship Care Strategy	Assessed Outcome Domain and Measure
Hill-Kayser, 2020 ⁷⁵ NCT02559219 (SmartALACC) Analytic study USA Expected completion: NR; study complete as of 04/24/2020, publication of results pending	Proportion of CCS: 100% Leukemia, Lymphoma	Care plan Test the feasibility and acceptability of an online survivorship care plan generator for adult survivors of pediatric cancers.	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: feasibility of online platform for survivorship care plan
Marchak, 2020 ¹⁰⁷ NCT04257058 Pre-Post USA Expected completion: 04/01/2023	Proportion of CCS: 100% Multiple cancer origin	Survivorship care service, Care plan Examination of electronic educational materials on survivors' (main target) knowledge about late effects, perceived benefits, self-efficacy, and intentions to engage in lifelong survivorship care.	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Knowledge about late effects, perceived benefits, self-efficacy, and intentions to engage in lifelong survivorship care; Psychosocial: Psychological
McClellan, 2015 ¹¹² N/A Post-only USA Expected completion: NR	Proportion of CCS: NR Multiple cancer origin	Model of care Follow-up with a primary care physician in the adult setting who is knowledgeable about late effects of childhood cancer treatment; transition support and education was provided by a transition nurse navigator.	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care clinic