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Disparities and Barriers to Pediatric Cancer Survivorship Care

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

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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, 88 studies were identified addressing identified disparities, barriers to survivorship care, proposed strategies, evaluated interventions, and ongoing studies in childhood cancer survivors.
- Of these, 26 assessed disparities in survivorship care (e.g., based on race or ethnicity, biological sex, or insurance coverage) in a range of domains and 33 studies assessed barriers to survivorship care at various levels (e.g., patient level, provider level).
- Fifteen organizations have proposed strategies to address barriers to survivorship care. We identified only seven ongoing and 23 published studies evaluating interventions to alleviate disparities and reduce barriers to care.
- Evidence of disparities and barriers to survivorship care exist for childhood cancer survivors but evidence-based interventions to address disparities and barriers to care are sparse. Additional research is needed to examine less frequently studied disparities and barriers, and to evaluate suggested strategies to alleviate barriers that lead to disparities in order to improve the survivorship care for pediatric cancer survivors.

This report is based on research conducted by the [to be inserted in the final report] Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. [to be inserted in the final 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. Therefore, no statement in this report should be construed as an official position of AHRQ or of 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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Suggested citation: [to be inserted in the final report].

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 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.

Gopal Khanna, M.B.A.
Director
Agency for Healthcare Research and Quality

Arlene Bierman, M.D., M.S.
Director
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Stephanie Chang, M.D., M.P.H.
Director
Evidence-based Practice Center Program
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Lionel L. Bañez, M.D.
Task Order Officer
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

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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.

The list of Key Informants who provided input to this report follows:

[to be inserted in the final report]

Peer Reviewers

Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report does not necessarily represent the views of individual reviewers.

Peer Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential non-financial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential non-financial conflicts of interest identified.

The list of Peer Reviewers follows:

[to be inserted in the final report]

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) is projected to exceed 500,000 by 2020. 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 summarizes published peer-reviewed literature, grey literature, and key informant interviews to answer five guiding questions regarding disparities in the care of survivors, barriers to pediatric 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. We used the authors' definition of CCS; where not specified, CCS included those diagnosed with any cancer prior to age 21. The grey literature strategy included a search of relevant professional and non-profit organizational websites and clinical practice guideline clearing houses. Key informants provided content expertise regarding published and ongoing research, and recommended approaches to fill identified gaps.

Results. At the time of the draft report we identified 26 studies that assessed disparities in survivorship care for CCS; 33 assessed barriers to survivorship care. 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 findings were supported in the published literature. Key informants indicated that providers, the health system, and payers are major sources of barriers to care; however, these barriers were reported in a small minority of studies. Fifteen organizations have outlined strategies to address disparities and barriers to pediatric survivorship care. Our searches identified only 23 published studies that evaluated interventions to alleviate disparities and reduce barriers to care. These predominantly assessed approaches that targeted patients. We found only seven ongoing studies that evaluated strategies to address disparities and barriers.

Conclusions. We found evidence of disparities and barriers to survivorship care for CCS, however significant gaps in the research field remain, particularly regarding evaluations of interventions. Additional research is needed to examine less frequently studied disparities and barriers and to evaluate ameliorative strategies in order to improve the survivorship care for pediatric cancer survivors.

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Introduction

Background and Objectives

It is estimated that there will be more than 500,000 survivors of childhood cancer who were diagnosed under the age of 20 – whether currently a child, adolescent, or adult – in the United States in 2020. 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, or a combination of these treatments.

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 and many challenges are still poorly understood or unknown. Despite gains in survival, CCS are at risk for adverse physical, psychosocial, and behavioral outcomes. These *late effects* range in severity and complexity, and commonly include cardiovascular disease and heart failure, decreased pulmonary function, infertility, hormonal changes, kidney failure, liver disease, 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 mental health disorders.^{3,4}

Survivorship care is a clinical approach to address the health and wellbeing of cancer survivors, ideally using risk-based methods of surveillance, screening, management, and prevention of late effects, along with coordination of care with primary care and other healthcare providers.⁵ Many CCS do not receive recommended survivorship care, particularly after transitioning into adulthood.⁵ Barriers to survivorship care can encompass barriers at the level of patient and caregiver, health care provider, the health system or payer level, and many others.^{5,6} As a result of these barriers, disparities exist for a range of outcomes among CCS, and this complexity poses unique challenges for research.

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 (AHRQ) technical brief was commissioned by the National Cancer Institute (NCI), as a result of the passage of the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act.⁷ This has resulted in enhanced support for pediatric, adolescent, and young adult cancer research, including ongoing efforts to address pediatric cancer survivorship disparities. 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.

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 follow the Methods Guide for Evidence-based Practice Center Program. The topic of this report was developed by the National Cancer Institute (NCI) in consultation with 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 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 strategy (N = 1). 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 that could impact key outcomes of interest. Additionally, key informant input was used to identify additional grey literature resources, provide information about 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 CCS transition from pediatric to adult survivorship care?

- How do barriers to survivorship care vary by subgroups of pediatric cancer survivors?
- How do barriers effecting 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 slides to promote discussion during the calls. Representatives from AHRQ and NCI attended all three key informant interviews, 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 question.

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. The grey literature search strategy is detailed in Appendix B. Briefly, we searched the websites of relevant professional organizations and reviewed clinical practice guideline clearing houses using specified key search terms.

Published Literature Search

We designed targeted search strategies for the individual guiding question, also detailed in Appendix B. Search strategies were designed, executed, and documented by the EPC 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 NIH 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.^{8,9} 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.

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. 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	<p><u>All GQs:</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 eligible to receive survivorship care services, care plans, and/or models of follow-up care.</p>	<p><u>All GQs:</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.</p>
Independent variables and interventions	<p><u>GQ1:</u> Survivorship care. We included studies addressing healthcare approaches aimed at the health and wellbeing of cancer survivors.</p> <p><u>GQ2:</u> Barriers and facilitators of survivorship care for CCS.</p> <p><u>GQ3, GQ4, GQ5:</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 GQs:</u> Studies without reference to survivorship care and studies not addressing care disparities, barriers to care, or strategies outside of healthcare.</p>

PICOTSS	Inclusion	Exclusion
Comparators	<p><u>GQ1, GQ2:</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>GQ3:</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>GQ4, GQ5:</u> Studies comparing participant subgroups as defined in GQ1 and GQ2 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 GQs:</u> Studies not addressing patient characteristics or intervention characteristics.</p>
Outcomes	<p><u>GQ1, GQ2:</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, wellbeing, and satisfaction with care; and cost and resource utilization.</p> <p><u>GQ3:</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>GQ4:</u> Changes (reduction) in disparities between comparison groups for outcomes listed in GQ1 and GQ2.</p> <p><u>GQ5:</u> Ongoing and upcoming studies had to indicate that the study will report on outcomes eligible for GQ1, GQ2, or GQ4.</p>	<p><u>All GQs:</u> Studies that did not address disparities or barriers to survivorship care for pediatric survivors.</p>
Timing	<p><u>All GQs:</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 GQs:</u> No exclusions applied.</p>
Setting(s)	<p><u>All GQs:</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 GQs:</u> Studies in resource-limited settings such as developing countries were reviewed for comparability with US settings.</p>
Study design and other limiters	<p><u>All GQs:</u> English-language publications.</p> <p><u>GQ1, GQ2, GQ4, GQ5:</u> Primary studies reporting empirical data (including both quantitative and qualitative data).</p> <p><u>GQ1, GQ2:</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>GQ3:</u> Strategies had to have been suggested by an authoritative source such as a clinical practice guideline or relevant professional organization.</p>	<p><u>All GQs:</u> Evaluations reported only in abbreviated format (e.g., in a conference abstract) with the exception of trial records. Studies exclusively reported in non-English publications. Systematic reviews were retained for reference mining but are not eligible for inclusion.</p>

PICOTSS	Inclusion	Exclusion
	<p><u>GQ4:</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>GQ5:</u> Ongoing and upcoming studies with a published protocol or registered in a research registry.</p>	

CCS, Childhood Cancer Survivor; GQ, guiding question

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 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 will be updated during the peer review process for this report, before finalizing the Technical Brief.

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)

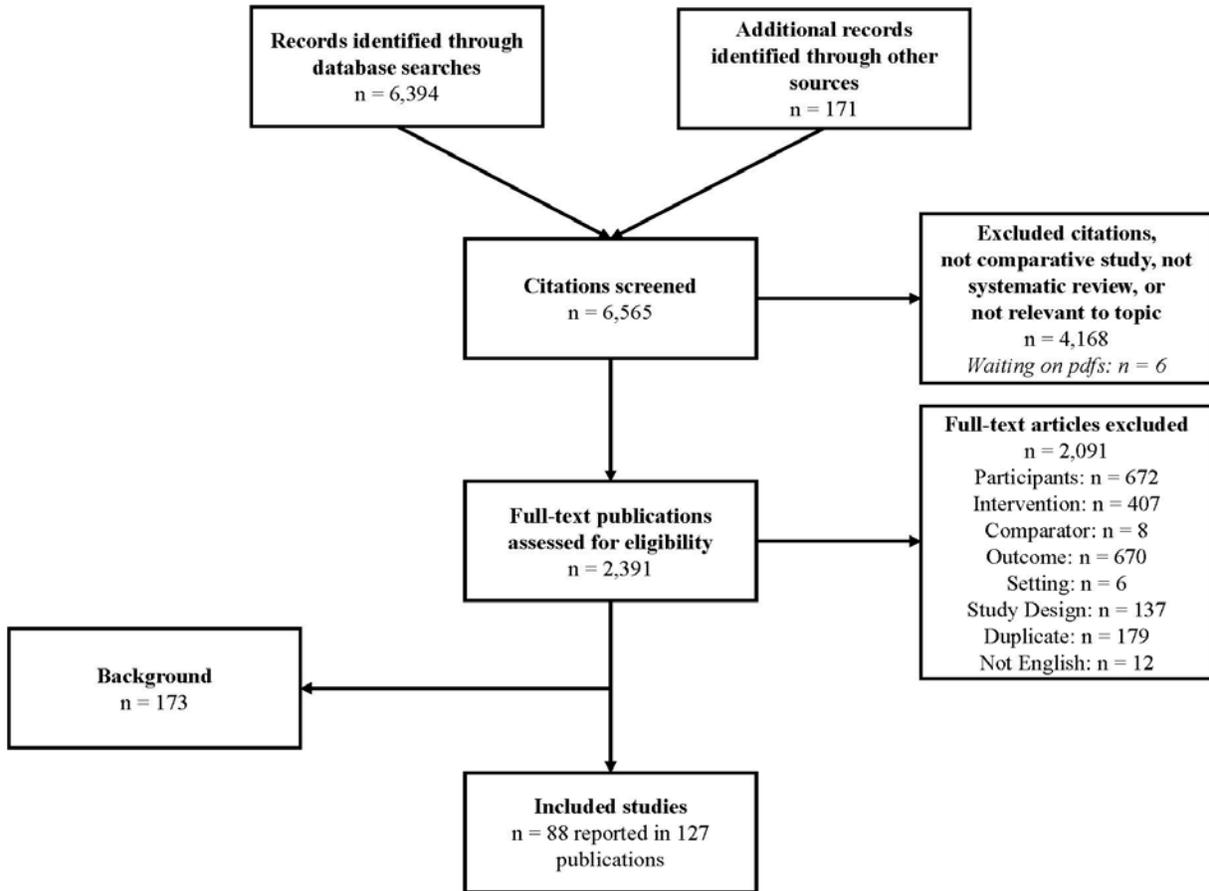
The outcomes of interest were categorized representing the following domains:

- 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; educational attainment/employment; substance use)
- Health services/economics (primary care, specialty care, or other care utilization; quality of life, 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.

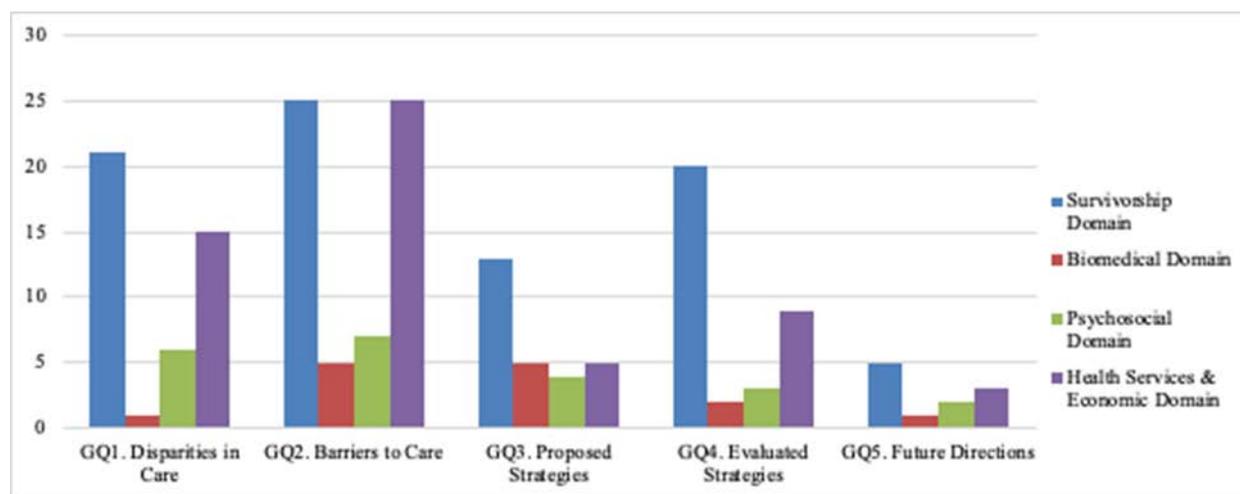
Figure 1. Study flow diagram



Appendix B lists excluded studies and reasons for exclusion. A large number of publications was 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 88 citations from 127 publications were included to frame the findings of this technical brief.¹⁰⁻¹³⁶ 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 = 33), followed by disparities in care (N = 26) and evaluated strategies (N = 23). Discussed less frequently were proposed strategies (N = 15) and future research directions (N = 7). 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 = 88 studies; each individual study could have addressed multiple outcome domains and guiding questions

Notably, most studies examined multiple outcome domains and more than one guiding question. The most frequently studied were survivorship care (N = 84) and health services and economic (N = 58) outcome domains; less frequently examined were psychosocial (N = 22) and biomedical (N = 14) 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 faced by CCS concerning their survivorship care. Appendix C details the discussion with the key informants. The primary themes of disparities faced by CCS included issues related to racial/ethnic and sexual/gender minorities, underserved minorities or groups (urban vs. rural/non-metropolitan), and those burdened by a complex and multifactorial interplay of social determinants of health, such as socioeconomic hardship (income, medical bills, debt), lower educational attainment, detrimental employment factors (status, benefits – paid time off, sick leave), and inadequate insurance coverage (under/uninsured, type of insurance, churns/transitions in insurance coverage).

We identified 27 studies reporting on disparities in survivorship care. The literature is documented in the table below.

Table 2. Research on Disparities in CCS Care

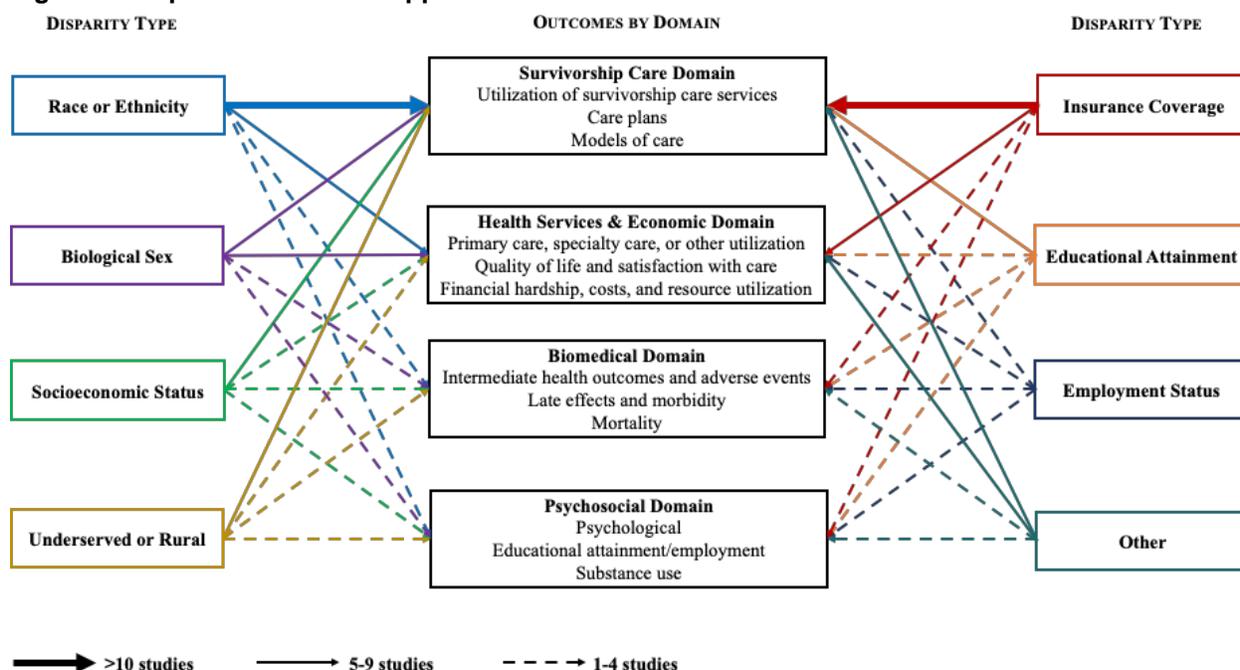
Disparity Category	Number of studies Identified studies
Race or Ethnicity	N = 12 Barakat, 2012 ¹⁷ ; Berkman, 2019 ²⁰ ; Casillas, 2010 ²⁷ ; Casillas, 2011 ²⁸ ; Crom, 2007 ³⁸ ; Daly, 2019 ³⁹ ; Landier, 2015 ⁸⁴ ; May, 2017 ⁹² ; Milam, 2015 ⁹⁸ ; Oeffinger, 2004 ¹⁰⁶ ; Ojha, 2014 ¹⁰⁸ ; Zheng, 2016 ¹³⁶
Biological Sex	N = 12

	Barakat, 2012 ¹⁷ ; Crom, 2007 ³⁸ ; de Fine Licht, 2017 ⁴¹ ; Holmes, 1986 ⁶⁰ ; McBride, 2011 ⁹³ ; McClellan, 2015 ⁹⁴ ; Michel, 2011 ⁹⁷ ; Milam, 2015 ⁹⁸ ; Nathan, 2016 ¹⁰² ; Oeffinger, 2004 ¹⁰⁶ ; Ojha, 2014 ¹⁰⁸ ; van Laar, 2013 ¹³⁰
Insurance Coverage	N = 12 Barakat, 2012 ¹⁷ ; Berkman, 2019 ²⁰ ; Crom, 2007 ³⁸ ; Daly, 2019 ³⁹ ; Li, 1976 ⁸⁶ ; May, 2017 ⁹² ; Milam, 2015 ⁹⁸ ; Oeffinger, 2004 ¹⁰⁶ ; Ojha, 2014 ¹⁰⁸ ; Szalda, 2016 ¹²⁶ ; Welch, 2017 ¹³² ; Zheng, 2016 ¹³⁶
Socioeconomic Status	N = 7 Crom, 2007 ³⁸ ; Johnson, 2004 ⁶⁷ ; McBride, 2011 ⁹³ ; Mendoza, 2018 ⁹⁵ ; ;Milam, 2015 ⁹⁸ ; Nathan, 2016 ¹⁰² ; Oeffinger, 2004 ¹⁰⁶
Underserved or Rural	N = 8 Barakat, 2012 ¹⁷ ; Crom, 2007 ³⁸ ; Daly, 2019 ³⁹ ; McBride, 2011 ⁹³ ; Michel, 2011 ⁹⁷ ; Nathan, 2016 ¹⁰² ; Oeffinger, 2004 ¹⁰⁶ ; Sutradhar, 2015 ¹²⁴
Educational Attainment	N = 6 Johnson, 2004 ⁶⁷ ; Landier, 2015 ⁸⁴ ; Li, 1976 ⁸⁶ ; Michel, 2011 ⁹⁷ ; Milam, 2015 ⁹⁸ ; Oeffinger, 2004 ¹⁰⁶
Employment Status	N = 2 Crom, 2007 ³⁸ ; Oeffinger, 2004 ¹⁰⁶
Other	N = 11 Crom, 2007 ³⁸ ; de Fine Licht, 2017 ⁴¹ ; Kazak, 1999 ⁷³ ; Landier, 2015 ⁸⁴ ; Michel, 2011 ⁹⁷ ; Milam, 2015 ⁹⁸ ; Oeffinger, 2004 ¹⁰⁶ ; Reppucci, 2017 ¹¹³ ; Sutradhar, 2015 ¹²⁴ ; vanLaar, 2013 ¹³⁰ ; Welch, 2017 ¹³²

Overall, the most commonly cited disparities were among racial or ethnic minorities, biological sex, and insurance coverage (N = 12, respectively). The least cited disparities were by educational attainment (N = 6) and employment status (N = 2). The other category of disparities predominantly captured current age at study and marital status, among other variables.

Figure 3 depicts the relationship between assessed disparities and 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 were among racial or ethnic minorities and insurance coverage (bolded arrows signifying ≥ 10 studies). The next most commonly examined type of disparities in the survivorship care outcome domain outcome was among biological sex, socioeconomic status, underserved or rural, educational attainment, or other types of disparities (the solid lines represent 5-9 studies).

Figure 3. Disparities in Care Mapped to Outcome Domains



The second most documented evidence of a disparity was among outcomes in the health services and economic domain. Race or ethnicity, biological sex, insurance coverage, and other types of disparities were most frequently documented in the literature. Outcomes in the biomedical and psychosocial domains were less frequently cited (displayed by the dashed arrows in Figure 3 indicating 1 to 4 studies). Only five studies provided evidence of a significant disparity in either biomedical or psychosocial outcomes caused by one of the eight disparity types. Disparities examined by gender minorities, assessed by how someone identifies or expresses themselves, were not examined in any included studies; however, biological sex was 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 community 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); a patient’s dependence or independence in decision-making; the presence of cultural, language, and literacy difficulties; and a mistrust in providers and the medical community, in general.

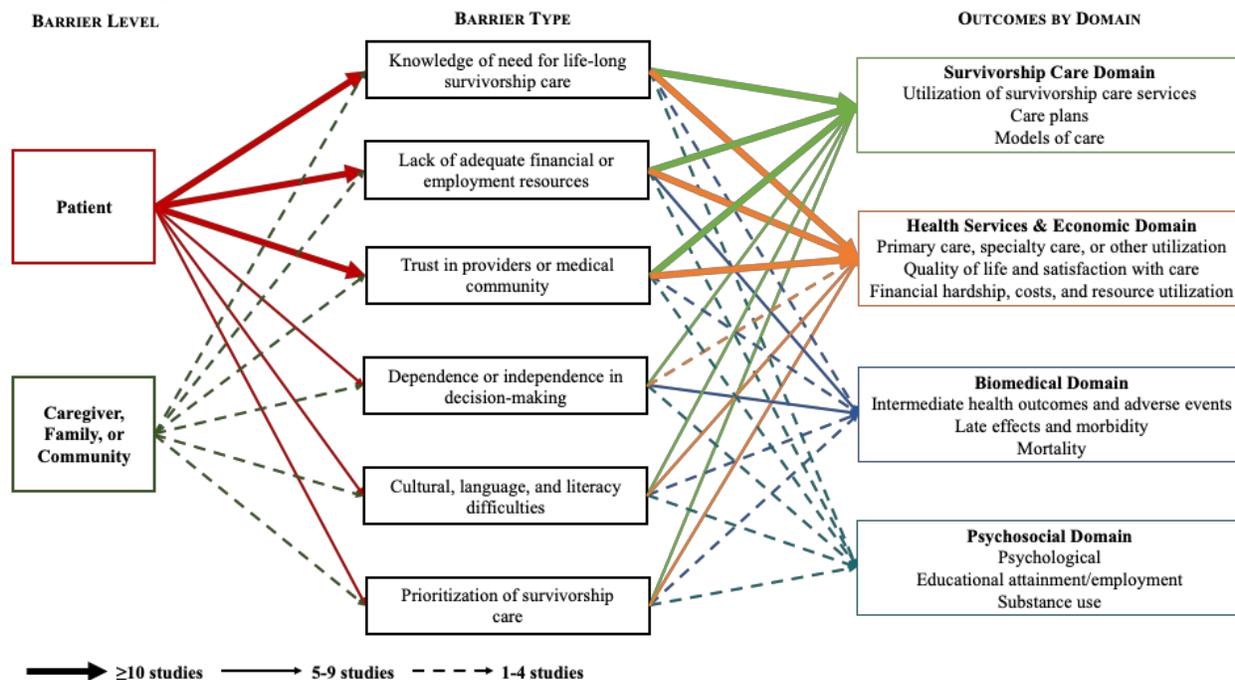
The primary themes of barriers impacting survivorship care that ultimately lead to disparities can be organized by levels of care delivery (patient; caregiver, family, or community; provider; health system; and payer). Our literature searches identified 33 studies that assessed barriers to care in CCS. 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 = 27 Ahn, 2017 ¹⁰ ; Berg, 2016 ¹⁹ ; Berkman, 2019 ²⁰ ; Casillas, 2010 ²⁷ ; Casillas, 2011 ²⁸ ; Crom, 2007 ³⁸ ; Eshelman-Kent, 2011 ⁵² ; Gardner, 2014 ⁵⁵ ; Holmes, 1986 ⁶⁰ ; Iwai, 2017 ⁶⁴ ; Jereb, 2000 ⁶⁶ ; Keats, 2019 ⁷⁴ ; Knighting, 2020 ⁷⁹ Kuhlthau, 2016 ⁸¹ ; Li, 1976 ⁸⁶ ; Maeda, 2010 ⁸⁸ ; McClellan, 2015 ⁹⁴ ; Michel, 2011 ⁹⁷ ; Milam, 2015 ⁹⁸ ; Novakovic, 1997 ¹⁰⁵ ; Oeffinger, 2004 ¹⁰⁶ ; Quillen, 2017 ¹¹¹ ; Rosenberg-Yunger, 2013 ¹¹⁶ ; Sadak, 2012 ¹¹⁷ ; Szalda, 2016 ¹²⁶ ; vanLaar, 2013 ¹³⁰ ; Warner, 2014 ¹³¹
Caregiver, Family, or Community	N = 6 Ahn, 2017 ¹⁰ ; Casillas, 2010 ²⁷ ; Jereb, 2000 ⁶⁶ ; Keats, 2019 ⁷⁴ ; Milam, 2015 ⁹⁸ Oeffinger, 2004 ¹⁰⁶
Provider	N = 10 Casillas, 2011 ²⁸ ; de Moor, 2007 ⁴² ; Eshelman-Kent, 2011 ⁵² ; Iyer, 2017 ⁶⁵ ; Jereb, 2000 ⁶⁶ ; Keats, 2019 ⁷⁴ ; Li, 1976 ⁸⁶ ; McClellan, 2015 ⁹⁴ ; Oeffinger, 2004 ¹⁰⁶ ; Warner, 2014 ¹³¹
Health System	N = 7 de Moor, 2007 ⁴² ; Eshelman-Kent, 2011 ⁵² ; Mendoza, 2018 ⁹⁵ ; Oeffinger, 2004 ¹⁰⁶ Sadak, 2019 ¹¹⁸ ; Sherman, 2004 ¹²¹ ; Warner, 2014 ¹³¹
Payer	N = 3 Hays, 1992 ⁵⁸ ; Oeffinger, 2004 ¹⁰⁶ ; Sadak, 2012 ¹¹⁷

The most frequently cited barrier was at the level of the patient (N = 27), followed by healthcare providers (N = 10). Displayed in Figure 4 are the most significant of these barriers to CCS' survivorship care, such as knowledge of the need for life-long survivorship care (N = 14), lack of adequate financial or employment resources (N = 14), and trust in providers or the medical community (N = 12). These were also the most frequently cited barriers to impact the survivorship care domain outcome. The barriers to care that impacted the health services and economic domain most frequently included knowledge of the need for life-long survivorship care, lack of adequate financial or employment resources, and trust in providers or medical community. The biomedical and psychosocial outcome domains were less frequently reported as being impacted by patient or caregiver, family, or community barriers to care.

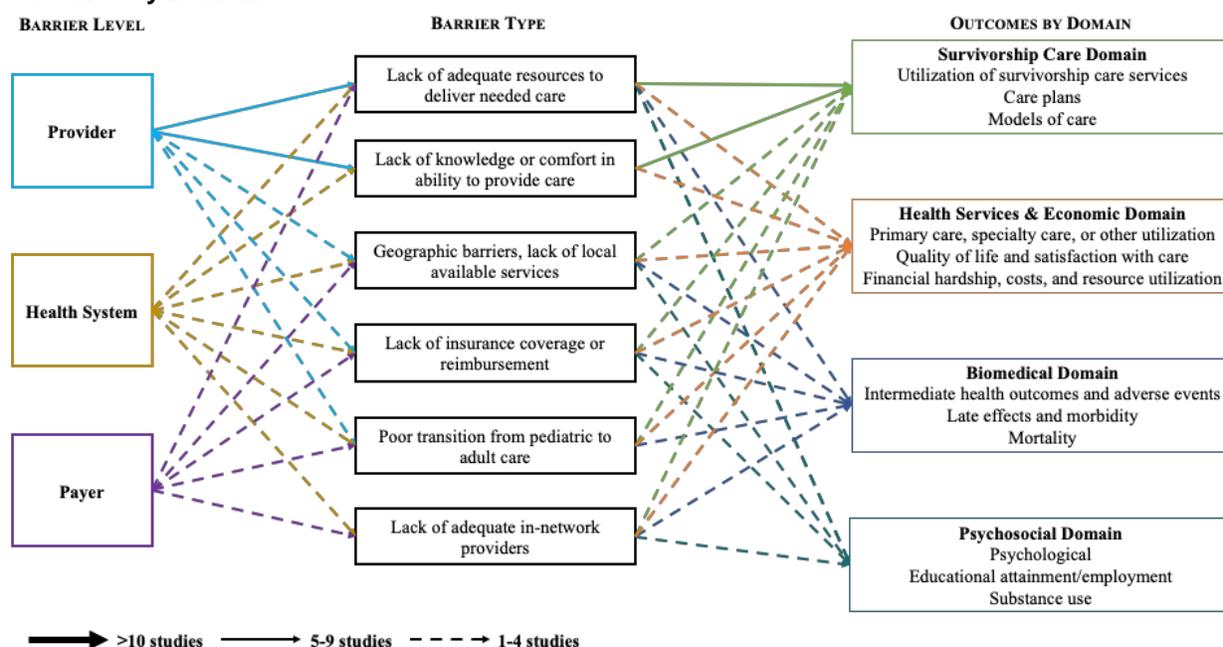
Figure 4. Patient, Caregiver, Family, and Community Barriers to Survivorship Care Connection to Outcomes by Domain



Furthermore, 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 mirrored the key informants' discussion regarding provider, health system, and payer level barriers to care (N = 15; see Figure 5 below).

Figure 5. Provider, Health System, and Payer Barriers to Survivorship Care Connection to Outcomes by Domain



The most frequently cited barrier to survivorship care for CCS were at the provider (N = 10) and health system (N = 7) levels. The barrier types that were frequently cited as impacting the survivorship care outcome domain included lack of adequate resources to deliver needed care and lack of knowledge or comfort in the ability to provide needed care.

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

Proposed strategies to address barriers to survivorship care were also discussed with key informants. The primary themes identified regarding proposed strategies 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 the grey literature searches, we identified a total of fifteen proposed strategies endorsed by different types of 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).⁹¹ 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 health care delivery, invested in education and training, and expanded research to improve the long-term outlook for CCS.⁶² However many of the aims of these proposed strategies still remain as gaps today.

Table 4. Guiding Question 3: Proposed Strategies

ID	Country	Multiple cancer origin	CCS proportion	Guideline Title Description
Masera, 1996 ⁹¹ International Society of Paediatric Oncology	Multiple countries	Multiple cancer origin	NR	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 ⁶²	USA	Multiple cancer origin	100%	Childhood Cancer Survivorship: Improving Care and Quality of Life Comprehensive policy agenda that links improved health care delivery, investments in education and training, and expanded research to improve the long-term outlook for survivors of childhood cancer
Skinner, 2005 ¹²² United Kingdom Children's Cancer Study Group: Late Effects Subcommittee	UK	Multiple cancer origin	NR	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
Children's Oncology Group Nursing Discipline, 2007 ³³	USA	Multiple cancer origin	100%	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 ¹²	USA	Multiple cancer origin	100%	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
Late Effects Taskforce of the Dutch Childhood Oncology Group, 2010 ⁸⁵	Multiple countries	Multiple cancer origin	NR	Guidelines for follow-up after childhood cancer more than 5 years after diagnosis Exposure-based clinical practice guidelines for pediatric cancer survivors
Majhail, 2012 ⁸⁹ American Society of Transplantation and Cellular Therapy	USA	Multiple cancer origin	NR	Recommended Screening and Preventive Practices for Long-Term Survivors after Hematopoietic Cell Transplantation Transplant recipients should be provided a survivorship care plan that includes a treatment summary and follow-up care plan
American Academy of Pediatrics, 2014 ¹³	USA	Multiple cancer origin	NR	Policy Statement: Standards for Pediatric Cancer Centers Strategies for helping survivors transition to primary care with emphasis on pediatric cancer centers
Esherich, 2017 ⁵⁰ Working Group on Adolescents, Young Adults, and Transition (Arbeitsgemeinschaft Adoleszenten, junge	Germany	Multiple cancer origin	NR	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

Erwachsene, Transition)				
Children's Oncology Group, 2018 ³⁴	USA	Multiple cancer origin	NR	Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers Exposure-based clinical practice guidelines for pediatric cancer survivors
American Society of Clinical Oncology, 2020 ¹⁶	USA	Multiple cancer origin	NR	ASCO in Action Brief: ASCO's Survivorship Initiatives Encourage transitions in care for patients ages 15 to 39 to an adult-focused care team
American Society of Pediatric Hematology and Oncology, 2020 ¹²⁷ Alliance for Childhood Cancer	USA	Multiple cancer origin	NR	ASPHO Joins the Alliance for Childhood Cancer's FY21 NIH, NCI, and STAR Act Appropriations Requests to House March 2020 Enhanced funding and support of issues impacting pediatric cancer survivors, including the Childhood Cancer STAR Act and the Childhood Cancer Data Initiative
Denlinger, 2020 ⁴⁴ National Comprehensive Cancer Network	USA	Multiple cancer origin	NR	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 ⁶³	USA	Multiple cancer origin	100%	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
Klipstein, 2020 ⁷⁷ American Academy of Pediatrics	USA	Multiple cancer origin	100%	Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations Clinical practice guidelines concerning strategies to preserve fertility in male and female survivors of childhood cancer

The Children's Oncology Group (COG), the United Kingdom Children's Cancer Study Group: Late Effects Subcommittee, and the Late Effects of Childhood Cancer task force of the Dutch Childhood Oncology Group all endorse exposure-based clinical practice guidelines targeting CCS for the surveillance, prevention, management, and treatment of late effects.^{34, 85, 122} Furthermore, the International Guideline Harmonization Group (IGHG) is working to bring together international experts to develop consistent, effective, and efficient recommendations for CCS.⁶³ The American Academy of Pediatrics (AAP), American Society for Clinical Oncology (ASCO), and National Comprehensive Cancer Network (NCCN) have endorsed specific strategies to minimize the burden of disparities and alleviate barriers to care for CCS.^{12, 16, 44, 77}

More recently, organizations such as AAP, ASCO, the Working Group on Adolescents, Young Adults, and Transition (Arbeitsgemeinschaft Adoleszenten, junge Erwachsene, Transition) in Germany, the American Society for Transplantation and Cellular Therapy 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.^{13, 16, 33, 50} In 2020, the Alliance for Childhood Cancer, which included the American Society of Pediatric Hematology and Oncology (ASPHO), among other organizations, raised awareness of the need to enhanced funding and support of issues impacting CCS. Specifically, the Alliance advocated for the passage of the Childhood Cancer STAR Act and the support of the Childhood Cancer Data Initiative.¹²⁷

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

Key informants were also asked about published studies that have assessed 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 23 studies reporting 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 specific survivorship care services (N = 8), establishing survivorship care plans (N = 9), implementing models of care (N = 7), and other, unique approaches (N = 5).

Table 5. Research on Evaluated Strategies to Overcome Disparities and Barriers to Pediatric Cancer Survivorship Care

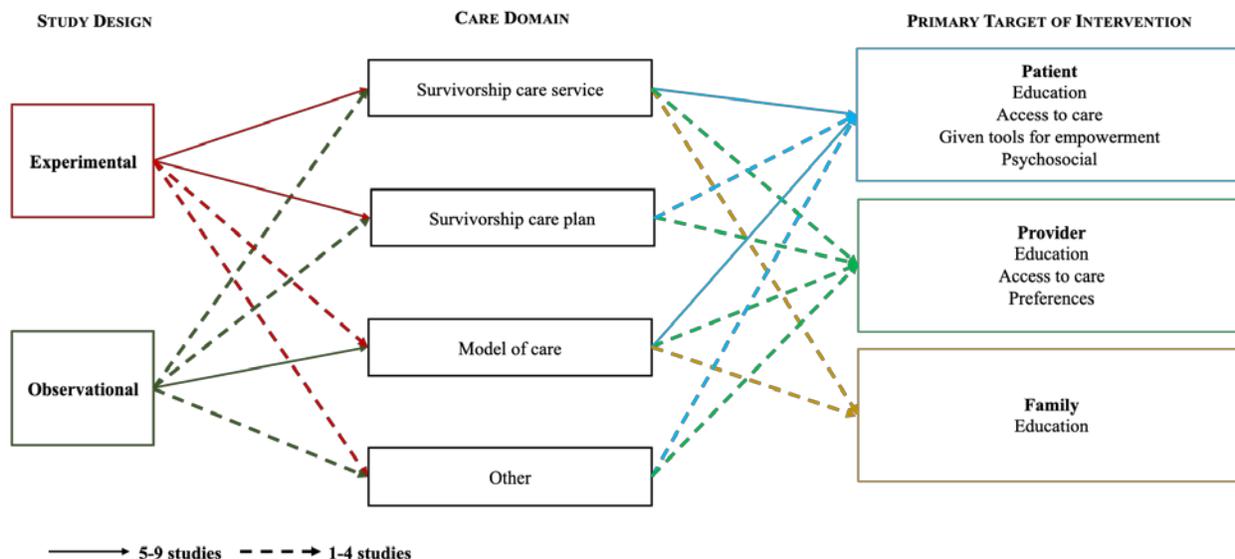
Survivorship Care Domain	Number of studies Identified studies
Survivorship care service	N = 8 Casillas, 2019 ³⁰ ; Casillas, 2020 ³¹ ; Casillas, 2017 ²⁶ ; Costello, 2017 ³⁶ ; Devine, 2020 ⁴⁵ ; Oeffinger, 2019 ¹⁰⁷ ; Santacroce, 2010 ⁶⁸ ; Schwartz, 2019 ¹¹⁹
Survivorship care plan	N = 9 Bashore, 2016 ¹⁸ ; Blaauwbroek, 2012 ²² ; Casillas, 2019 ³⁰ ; Iyer, 2017 ⁶⁵ ; Kadan-Lottick, 2018 ⁷⁰ ; Kunin-Batson, 2016 ⁸² ; Landier, 2015 ⁸⁴ ; Santacroce, 2010 ⁶⁸ ; Williamson, 2014 ¹³³
Model of care	N = 7 Bashore, 2016 ¹⁸ ; Costello, 2017 ³⁶ ; Ducassou, 2017 ⁴⁷ ; Eilertsen, 2004 ⁴⁸ ; Iyer, 2017 ⁶⁵ ; Reynolds, 2019 ¹¹⁴ ; Williamson, 2014 ¹³³
Other	N = 5 Crom, 2007 ³⁸ ; de Moor, 2011 ⁴³ ; Ford, 2013 ⁵³ ; Rose-Felker, 2019 ¹¹⁵ ; Schwartz, 2018 ¹²⁰

All identified studies are documented in detail in Appendix D. Observational studies made up the majority of identified studies (N = 13), more than half of which evaluated model of care interventions, and three of those models of care interventions were combined with a survivorship care plan. Less frequently evaluated in the observational studies were specific survivorship care services (N = 2). The most frequent target in the observational studies were patients (N = 8), followed by providers (N = 3), patients and providers (N = 1), and patients and family (N = 1). Educational interventions were most often utilized for the patient-focused studies (N = 6). Patient-targeted interventions increasing access to care (N = 3) and giving the patient the tools for empowerment (N = 2) were less often evaluated. Less frequently targeted were providers (N = 2), of which, both provided an educational intervention and one study provided access to care.

Among the experimental studies (N = 10), most used a randomized controlled trial design (N = 7) examining the intervention impact on survivorship care services (N = 6). Four of the experimental studies evaluated survivorship care plans and one a model of care. Most of the experimental studies evaluated patient-focused educational interventions (N = 7). The remaining experimental studies used patient-focused psychosocial interventions (N = 1), patient and family

educational interventions (N = 1), patient access to care (N = 1), and patient and provider access to care (N = 1). Figure 6 depicts the available literature.

Figure 6. Study Design, Care Domain, and Primary Target of Evaluated Strategies



Almost all of the evaluated strategies (N = 21) have been published in the last ten years. With the exception of the studies targeting providers (N = 2), all of the evaluated strategies have been examined using cohorts of patients diagnosed with a variety of pediatric malignancies (N = 21). The majority of evaluated strategies assessed survivorship care as a primary or secondary outcome of interest (N = 20). Other outcome domains less frequently cited included: health services and economics (N = 10) and biomedical and psychosocial domains (N = 3, respectively).

Among the experimental studies, four studies evaluated strategies that used technological-based interventions, all of which involved the patient and one involving both the patient and family. An evaluation of a web-based informational intervention reported no improvement in cancer-related knowledge or anxiety surrounding health beliefs.⁸² Utilization of the website was low among the CCS randomized to the web-based intervention; however, among those who did visit the website, the most visited page was regarding treatment summaries and links to external sites for health-related resources. 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.¹¹⁹ In another text messaging intervention, CCS reported improved survivorship care knowledge, health care self-efficacy, and increased positive attitudes towards survivorship care.³⁰ Finally, in an intervention using a photonovela among Hispanic/Latino CCS, Cassillas et al. saw an improvement in confidence related to survivorship care, small-to-medium effect on cancer stigma among family members, and improved knowledge of survivorship care among family members.³¹

In a recent study, a self-management and peer mentoring intervention was conducted among CCS and their fellow survivor mentors.⁴⁵ A significant positive relationship was found regarding transition readiness using multiple measures, a positive association with grit, and negatively associated with barriers to survivorship care in this study. An evaluation of an educational intervention targeting CCS who attend a survivorship clinic, one year follow-up of female

survivors reported higher knowledge than male survivors.³⁸ In a sample of female CCSS participants, motivational interviewing focused on improving the use of screening mammography.¹⁰⁷ After one year of follow-up, participants reported an increase in screening mammography, particularly among those ages 25 to 39 (compared to those 40-49).¹⁰⁷

Three experimental studies focused on 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.⁴⁷ 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.⁷⁰ Finally, 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.⁶⁸

Within the observational studies, four studies evaluated technology-based interventions involving the patient and one involving both the patient and provider. 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.²⁶ Notably, 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.³⁶ 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.¹³³ 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.²² 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. Additionally, one study encouraged CCS to quit smoking using electronic and print materials and found that encouragement by CCS' oncologist or regular doctor resulted in an increase in the number of cessation attempts.⁴³

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.¹⁸ Following completion of the workbook, transition readiness improved and more CCS were ready to make the transition in to adult care. 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.⁸⁴

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.⁴⁸ A second reported a higher compliance rate with COG-recommended guidelines in cancer-center

based facilities compared to primary care or community-based facilities.¹¹⁴ 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 non-specialized clinic.⁵³

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.⁶⁵ 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 forty, and that African American CCS are at particular increased risk of late effects impacting their cardiovascular health.¹¹⁵ Lastly, residents' knowledge, skills, and attitudes towards cancer survivorship were examined before and after receiving CCS-focused curriculum.¹²⁰ Residents' knowledge, skills, and comfort discussing topics related to survivorship care improved.¹²⁰

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 seven ongoing studies assessing strategies that targeted reducing disparities and barriers to survivorship care for CCS (see Table 6). Studies addressing Guiding Question 5 addressed survivorship care service (N = 4), survivorship care plan (N = 4), models of care (N = 1), and other (N = 1).

Table 6. Ongoing Studies to Assess Strategies Targeting Reducing Disparities and Barriers

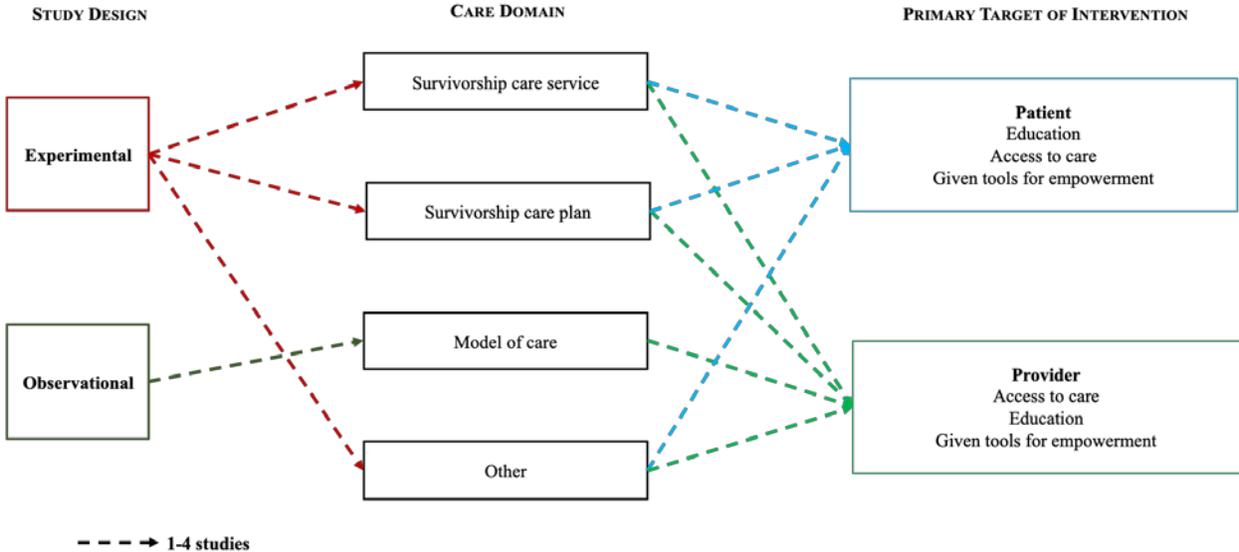
Survivorship Care Domain	Number of studies Identified studies
Survivorship care service	N = 4 Chow, 2020 ³⁵ ; Devine, 2019 ⁴⁶ ; Escoffery, 2019 ⁵¹ ; Marchak, 2020 ⁹⁰

Survivorship care plan	N = 4 Devine, 2019 ⁴⁶ ; Escoffery, 2019 ⁵¹ ; Hill-Kayser, 2020 ⁵⁹ ; Marchak, 2020 ⁹⁰
Model of care	N = 1 McClellan, 2015 ⁹⁴
Other	N = 1 Daniel, 2015 ⁴⁰

Almost all of the ongoing studies are experimental (N = 6) and one is observational. 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, ongoing studies evaluate predominantly patient education approaches (N = 4), followed by the patient being given tools for empowerment (N = 2). 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



Currently, three studies are underway and planned to be completed in 2022 and 2023.^{35, 51, 90} 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.^{35, 90} One study uses a web-based, patient-controlled personalized health record (SurvivorLink) to evaluate survivorship care services.⁵¹ Two studies will be complete by the end of 2020 and are pending publication of their results, both of which use an online survivorship care plan in their intervention.^{46, 59} One of these studies examines the feasibility and acceptability of an online survivorship care plan for adult CCS.⁵⁹ The other study empowers patients through an online self-management skills and peer mentoring intervention to remove barriers to survivorship care.⁴⁶

Two of the seven ongoing studies have yet to report their findings and have passed their expected completion date.^{40, 94} 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.⁹⁴ The other pending study is focused on skin examination using a dual-approach of providing education to the patient and provider and tools for empowerment to the provider.⁴⁰ More detail is documented in Appendix D.

Summary and Implications

This review of the literature, in conjunction with feedback from key informants and grey literature sources documents disparities, barriers, and strategies to overcome potential barriers to care among CCS. Notably, key informants provided insight into disparities and barriers experienced by CCS which were consistently documented in the literature.

What are the disparities in survivorship care for pediatric cancer survivors?

As of July 2020, a total of 27 studies investigated disparities in survivorship care for pediatric cancer survivors. Disparities by race or ethnicity and insurance were most frequently addressed. Disparities by biological sex, socioeconomic status, underserved or rural populations, 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 33 studies were identified that have assessed specific barriers that lead to disparities in 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 the primary source of evidence thus far. However, many of the types of barriers faced by patients are not by any fault of their own. 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 largest barriers to survivorship care identified through our reviews. Furthermore, lack of adequate financial or employment resources and struggles with placing trust in providers or the medical community is associated with the survivorship care outcome domains and the health services and economic outcome domain.

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 significant are barriers at the level of the provider. Lack of adequate resources needed to deliver care and lack of knowledge or comfort in their ability to provide needed care were noted – both 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 15 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 (at CCS, family, health system, primary care provider, and payer levels), knowledge of long-term follow-up guidelines [at CCS, parent, and provider (especially primary care provider) level], and implementation of risk-stratified care. Notably, while disparities are increasingly recognized in the pediatric survivorship field, practitioners may be at a loss for how to mitigate disparities or they may feel that the resources of an individual provider may not be sufficient to address the problem. This underscores the importance of working in collaboration with professional organizations and entities who have endorsed strategies to address disparities and barriers to pediatric survivorship care.

What published and unpublished studies have assessed these strategies?

We only found 23 published studies evaluating the effectiveness of strategies to reduce barriers and disparities to pediatric survivorship care. While these published studies exist, results have primarily focused on barriers at the patient level, without many assessing overcoming barriers at the provider, health care system, payer, or family/caregiver/community levels. Until we have a better understanding of what will be effective in overcoming barriers to survivorship care at all levels impact CCS outcomes, disparities may persist.

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

Seven ongoing studies were identified that included directions for future research in addressing barriers to survivorship care for pediatric cancer survivors. An imbalance was observed between the studies identifying disparities and barriers and studies aimed at overcoming these barriers and lessening disparities. 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.; but, as our key informants discussed, it is difficult to find funding to support this work. However, after the passage of the Childhood Cancer STAR Act, it is now possible to envision more innovative approaches such as those recommended by our 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 to identify patients and notify providers of surveillance needed automatically through the electronic medical record, and many other opportunities – but a missing link is funding to adequately support this work and an effective environment that is supportive of CCS research. And, now more than ever, it is possible to support this vital work after the passage of the Childhood Cancer STAR Act which provides dedicated funding to support research targeting pediatric cancer survivorship care.

Next Steps

Based on the research findings above and implications, we have outlined what should be done to resolve disparities and barriers impacting childhood cancer survivorship care in the future using a PICOS (population, intervention, comparator, outcomes, and study design) framework.

Population

The majority of published pediatric cancer survivorship research comes from the CCSS, a large cohort of survivors of pediatric cancer. While the CCSS is a robust survivorship cohort and has been instrumental in the identifying the needs of pediatric cancer survivors, its generalizability to the overall population of CCS, including underrepresented groups, and those treated with more modern therapies is limited. More specifically, the CCSS has had historically low representation of racial or ethnic minorities, and low representation of a variety of health care delivery systems for survivorship care.

Survivorship care is impacted by various social determinants of health (e.g., racial/ethnic minority status, socioeconomic status, rural and underserved populations, insurance status/type, sexual/gender minorities, and education level), and interplays between barriers at the patient, family, provider, health system, and payer levels. As a result, diverse samples of survivors 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 health care 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 health care 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 non-profit 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.

Interventions and comparators

Most current studies that address barriers do so on 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 community. 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. As endorsed by our key informants, 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 non-profit organizations potentially partnering with other chronic disease-focused non-profits 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 approach using interventions to impact the provider, health system, and payer are needed. 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. 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.

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. Given the complex nature of the US health care 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 alleviating or decreasing some of the more practical or logistic 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. Furthermore, the findings underscore that biomedical and psychosocial outcome domains were less frequently examined in reference to disparities and barriers to survivorship care; however, there is research documenting that biomedical and psychosocial disparities exist among CCS. 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.

More recently, there has been discussion in the pediatric cancer survivorship community regarding striking the 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, we need more information 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.

Study design

Ideally, randomized controlled trials would allow strong evidence statements about the effectiveness of proposed interventions. However, due to need for collaboration (e.g., multi-site studies) to reach sufficient sample sizes and 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, 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 should be performed. The analyses should be examined from a variety of perspectives to truly understanding the costs and benefits including the patient, family, provider, health system, and payer.

Conclusion

Pediatric cancer survivors face a variety of barriers to care, and these barriers often lead to disparities in 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 subgroup of an already understudied group is difficult. Support is needed to encourage and sustain research in disparities and barriers to pediatric cancer survivorship care.

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Abbreviations and Acronyms

AAP	American Academy of Pediatrics
AHRQ	Agency for Healthcare Research and Quality
ASCO	American Society for Clinical Oncology
ASPHO	American Society of Pediatric Hematology and Oncology
ASTCT	American Society of Transplantation and Cellular Therapy
CCDI	Childhood Cancer Data Initiative
CCS	Childhood cancer survivor
COG	Children’s Oncology Group
GQ	Guiding Question
IGHG	International Guideline Harmonization Group
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NIH	National Institutes of Health
STAR Act	Childhood Cancer Survivorship, Treatment, Access, and Research Act

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. We also reviewed guidance published in clinical practice guideline clearing houses, including the ECRI Guideline Trust and the Guidelines International Library (GIN). 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
- Guidelines International Library (GIN)

Published Literature

We searched the research databases PubMed, CINAHL, and PsycINFO using the specified terminology below for each GQ. 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:

Results on 5 Jun 2020: 4,077 citations

(“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:

Results on 5 Jun 2020: 639 citations

("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:

Results on 5 Jun 2020: 7,677 citations

("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:

Results on 17 Aug 2020: 255 citations

Terms: childhood cancer survivor*

Filters: Clinical Trial, Randomized Controlled Trial, English

CINAHL

Guiding Question 1 Strategy:

Results on 14 Jul 2020: citations

(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 "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:

Results on 14 Jul 2020: citations

(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:

Results on 14 Jul 2020: citations

(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+")

PsycInfo

Guiding Question 1 Strategy:

Results on 14 Jul 2020: citations

(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("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:

Results on 20 Jul 2020: 56 citations

(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.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:

Results on 20 Jul 2020: citations

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*”))

NIH RePORTER

Text search

Limit to: publications from 1995-2020

Search 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

Search terms:

Childhood cancer survivor

ClinicalTrials.gov

409 results

Searched: 05June2020

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: 07/09/2020

Search 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”

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. *Study design*
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 2015-09-25;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. *Outcome*
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*
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Intervention

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Outcome

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Appendix C. Key Informant Interviews

Findings from the key informant interviews are detailed in the tables below, by GQ. Discussion by individual key informants are separated by the “---” line.

Table C1. Key Informant interviews to GQ1. 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?
<p>Preliminary Feedback (included as prompt on slide)</p>	<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. --- 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. 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. --- 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>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 --- 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. --- We need to reach/educate adult primary care providers; but has had challenges dissemination/publishing in adult/primary care journals. --- Sometimes the patient has to work on “bridging the gap” with their PCPs. --- SES is likely to be one of the more important exposures driving disparities in survivorship care – research is sorely needed SES (by multiple measures) is a main driver of these access disparities</p>	<p>No further discussion.</p>

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>Health-related social needs/determinants (e.g., food insecurity, housing). --- Geography, which relates to SES and insurance barriers. --- 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. 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. 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 and not necessarily at time of diagnosis, which would be important to know. 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. --- Health care system; pediatric cancer survivors have had majority of care in academic medical centers (AMC), and very little (vs. 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>	<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.) Age related barriers (parent bringing a 5-year-old, vs 20-year-old) Regional availability: Are they even there? Does insurance cover it?</p>	

Table C2. Key Informant interviews to GQ2. 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 effecting specific subgroups change over time, specifically as they transition from pediatric to adult care?
Survey Monkey feedback (included as prompt on slide)	<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) 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.
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 vs. 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 to GQ3. 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?	What strategies to address barriers to survivorship care that lead to disparities are most promising?
<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. 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
<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 (ACA) – 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</p>	<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 vs. adhering to survivorship guidelines and how that changes over time and how it varies over age group (child vs. 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 vs. childcare) – then that could be tackled.</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>

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?	What strategies to address barriers to survivorship care that lead to disparities are most promising?
	<p>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> <ul style="list-style-type: none"> • Insurance coverage of survivorship care • Reimbursement for risk-stratified survivorship care • Provide opportunities for the uninsured/underinsured via surveillance (e.g., adequate reimbursement and resources at safety net clinics). <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>---</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.</p> <p>Once developed, this algorithm can provide a better risk assessment that can facilitate the creation of more accurate 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 to GQ4. 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 2. Heterogeneous cancer subtypes and treatment (that keeps evolving) 3. Very delayed onset of health events in relation to treatment 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. --- 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. --- 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. --- 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. --- 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 to GQ5. 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?
<p>Preliminary Feedback (included as prompt on slide)</p>	<p>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)</p>	<p>1. Data sharing and collaboration across institutions and nations is important to assure diversity of population and characterize needs of clinically heterogeneous survivors</p>	<p>1. Medical 2. SES 3. Cultural</p>
<p>KI Feedback</p>	<p>Some CCS don't even realize that you can apply for disability; connecting people to</p>	<p>Setting is important and variable; some orgs, like St. Jude, is integrative whereas other are more treatment</p>	<p>Most studies are just describing the disparities, not addressing them. ---</p>

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>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</p>	<p>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>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</p>

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>isn't someone on the provider end with 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>and incentives for telehealth use; Center of 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 (vs. 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. GQ1: Disparities in Care

Study Main publication Multiple publications Study ID	Country	Sample Characteristics	Disparities Analyzed
Barakat, 2012 ¹⁷ 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)
Berkman, 2019 ²⁰ N/A	USA	Proportion of CCS: 100% Brain/CNS	Racial/ethnic minorities, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
Casillas, 2010 ²⁷ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities
Casillas, 2011 ²⁸ LIVESTRONG Survivorship COE Network	USA	Proportion of CCS: 50% or more Multiple cancer origin	Racial/ethnic minorities
Crom, 2007 ³⁸ Klosky, 2008 ⁷⁸ ; Hudson, 2002 ⁶¹ After Completion of Therapy (ACT) Clinic	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Socioeconomic status, Underserved or rural populations, Sex (biological), Employment, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Age, marital status
Daly, 2019 ³⁹ 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 ⁴¹ Adult Life after Childhood Cancer in Scandinavia (ALiCCS)	Multiple countries	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Other: Age at hospitalization, cancer diagnosis
Holmes, 1986 ⁶⁰	USA	Proportion of CCS: 100% Multiple cancer origin	Sex (biological)
Johnson, 2004 ⁶⁷ N/A	UK	Proportion of CCS: 100% Multiple cancer origin	Socioeconomic status, Education
Kazak, 1999 ⁷³	USA	Proportion of CCS: 100%	Other: Poor family functioning as measured by Family Assessment Device scale

Study Main publication Multiple publications Study ID	Country	Sample Characteristics	Disparities Analyzed
Alderfer, 2009 ¹¹ ; Kazak, 2004 ⁷² Surviving Cancer Competently Intervention Program (SCCIP)		Multiple cancer origin	
Landier, 2015 ⁸⁴ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Education, Other: Longer time since diagnosis, diagnosed with leukemia, and those at lower risk
Li, 1976 ⁸⁶ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Education, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
May, 2017 ⁹² 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 ⁹³ Childhood, Adolescent, and Young Adult Cancer Survivors (CAYACS) Research Program	Canada	Proportion of CCS: 100% Multiple cancer origin	Socioeconomic status, Underserved or rural populations, Sex (biological)
McClellan, 2015 ⁹⁴ N/A	USA	Proportion of CCS: NR Multiple cancer origin	Sex (biological)
Mendoza, 2018 ⁹⁵	USA	Proportion of CCS: 100% Multiple cancer origin	Socioeconomic status
Michel, 2011 ⁹⁷ Michel, 2016 ⁹⁶ ; Lupatsch, 2016 ⁸⁷ ; Gianinazzi, 2014 ⁵⁷ ; University of Bern, 2007 ²¹ Swiss Childhood Cancer Survivor Study (SCCSS)	Other (specify)	Proportion of CCS: 100% Multiple cancer origin	Underserved or rural populations, Sex (biological), Education, Other: Treatment, reported late effects, age at study, parental education
Milam, 2015 ⁹⁸ Miller, 2018 ⁹⁹ ; Miller, 2017 ¹⁰⁰ ; Cousineau, 2019 ³⁷ Project Forward 1	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Socioeconomic status, 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
Nathan, 2016 ¹⁰²	Canada	Proportion of CCS: 100%	Socioeconomic status, Underserved or rural populations, Sex (biological)

Study Main publication Multiple publications Study ID	Country	Sample Characteristics	Disparities Analyzed
Pediatric Oncology Group of Ontario Networked Information System (POGONIS)		Multiple cancer origin	
Oeffinger, 2004 ¹⁰⁶ Kirchhoff, 2013 ⁷⁵ ; Casillas, 2015 ²⁹ ; Nathan, 2008 ¹⁰¹ ; Caplin, 2017 ²⁴ ; Casillas, 2011 ²⁵ ; Castellino, 2005 ³² ; Geller, 2019 ⁵⁶ ; Kaste, 2009 ⁷¹ ; Kirchhoff, 2018 ⁷⁶ ; Nipp, 2017 ¹⁰⁴ ; Recklitis, 2010 ¹¹² ; Yeazel, 2004 ¹³⁴ ; Zebrack, 2012 ¹³⁵ ; Ford, 2020 ⁵⁴ ; Park, 2017 ¹⁰⁹ ; Smith, 2010 ¹²³ ; Park, 2012 ¹¹⁰ ; Krull, 2011 ⁸⁰ ; Nathan, 2010 ¹⁰³ ; Kadan-Lottick, 2002 ⁶⁹ ; Kurt, 2012 ⁸³ Childhood Cancer Survivor Study (CCSS)	Multiple countries	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Socioeconomic status, Underserved or rural populations, Sex (biological), Education, Employment, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage), Other: Lacking health insurance and older age at survey date; current age (younger, <26); severe, disabling, or life-threatening chronic condition; presence of neurocognitive problems and antidepressant use; cancer diagnosis; age at interview, marital status, receipt of a survivorship care plan, survivorship care in prior two years, written treatment summary, and those in chronic pain
Ojha, 2014 ¹⁰⁸ Behavioral Risk Factor Surveillance System (BRFSS)	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 ¹¹³ SuRFF Program at the Cohen Children's Medical Center of New York	USA	Proportion of CCS: 100% Multiple cancer origin	Other: Current age
Sutradhar, 2015 ¹²⁴ 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 (Intensity of Treatment Rating, Cyclophosphamide-equivalent dose, Doxorubicin-equivalent dose), continuity of care, annual physical examination
Szalda, 2016 ¹²⁶ Szalda, 2017 ¹²⁵ Cancer Survivorship Program at CHOP	USA	Proportion of CCS: 100% Multiple cancer origin	Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)
vanLaar, 2013 ¹³⁰ N/A	UK	Proportion of CCS: 100% Multiple cancer origin	Sex (biological), Other: Age
Welch, 2017 ¹³²	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

Study Main publication Multiple publications Study ID	Country	Sample Characteristics	Disparities Analyzed
Consortium for New England Childhood Cancer Survivors			
Zheng, 2016 ¹³⁶ N/A	USA	Proportion of CCS: 100% Multiple cancer origin	Racial/ethnic minorities, Insurance (under/uninsured, type of insurance coverage, churns/transitions in coverage)

Table D2. GQ2: Barriers to Care

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
Ahn, 2017 ¹⁰ Korean CCS	Korea Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, 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 difficulties
Berg, 2016 ¹⁹ 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: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Dependence/independence in decision-making; Trust in providers/medical community
Berkman, 2019 ²⁰ 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: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare)
Casillas, 2010 ²⁷ N/A	USA Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, 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 difficulties

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
Casillas, 2011 ²⁸ LIVESTRONG Survivorship Center of Excellence (COE) 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 barriers, lack of local availability of services
Crom, 2007 ³⁸ Klosky, 2008 ⁷⁸ ; Hudson, 2002 ⁶¹ 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: Lack of adequate financial or employment resources (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 ⁴² 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: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist); Geographic barriers, lack of local availability of services; Other: Staffing and time constraints to offer smoking cessation services
Eshelman-Kent, 2011 ⁵² 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community Provider, health system, or payer barrier type: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist); Geographic barriers, lack of local availability of services; Lack of insurance coverage/reimbursement; Lack of knowledge or comfort in ability to provide survivorship care
Gardner, 2014 ⁵⁵ N/A	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care, Patient/Provider knowledge, Insurance coverage

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
			Patient or caregiver/family/community barrier type: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare), Other: Use of prescription medication
Hays, 1992 ⁵⁸ 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: Lack of insurance coverage/reimbursement
Holmes, 1986 ⁶⁰ 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
Iwai, 2017 ⁶⁴ N/A	Other (specify) 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: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Dependence/independence in decision-making; Cultural, language, and literacy difficulties;Trust in providers/medical community
Iyer, 2017 ⁶⁵ 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: Poor transition from pediatric to adult care; Lack of knowledge or comfort in ability to provide survivorship care; Other: Unsure of which provider is responsible for which late effects/comorbid conditions
Jereb, 2000 ⁶⁶ N/A	Japan Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, 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: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist); Other: Reluctance to give up on their patients
Keats, 2019 ⁷⁴ N/A	Canada Interview	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, Patient, Provider Category: Access to care, Patient/Provider knowledge Patient or caregiver/family/community barrier type: Dependence/independence in decision-making; Trust in providers/medical

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
			community; Other: Perceived lack of sharing of medical information among providers Provider, health system, or payer barrier type: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist); Lack of knowledge or comfort in ability to provide survivorship care
Knighting, 2020 ⁷⁹ 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Dependence/independence in decision-making; Cultural, language, and literacy difficulties; Trust in providers/medical community
Kuhlthau, 2016 ⁸¹ NHIS	USA Survey	Proportion of CCS: 100% Multiple cancer origin	Level: Patient Category: Access to care Patient or caregiver/family/community barrier type: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Other: Delayed medical care, forgone medical care
Li, 1976 ⁸⁶ N/A	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Patient, Provider Category: Access to care, Insurance coverage Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care Provider, health system, or payer barrier type: Lack of knowledge or comfort in ability to provide survivorship care
Maeda, 2010 ⁸⁸ N/A	Slovenia 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Cultural, language, and literacy difficulties
McClellan, 2015 ⁹⁴ N/A	USA Survey	Proportion of CCS: NR Multiple cancer origin	Level: Patient, Provider Category: Access to care Patient or caregiver/family/community barrier type: Trust in providers/medical community

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
			Provider, health system, or payer barrier type: Poor transition from pediatric to adult care; Lack of knowledge or comfort in ability to provide survivorship care
Mendoza, 2018 ⁹⁵ 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: Lack of insurance coverage/reimbursement
Michel, 2011 ⁹⁷ Michel, 2016 ⁹⁶ ; Lupatsch, 2016 ⁸⁷ ; Gianinazzi, 2014 ⁵⁷ ; University of Bern, 2007 ²¹ Swiss Childhood Cancer Survivor Study (SCCSS)	Switzerland Survey	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: Knowledge of need for life-long survivorship care; Other: Distressed vs. nondistressed survivors
Milam, 2015 ⁹⁸ Miller, 2018 ⁹⁹ ; Miller, 2017 ¹⁰⁰ ; Cousineau, 2019 ³⁷ Project Forward 1	USA Survey, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, Patient Category: Access to care, Patient/Provider knowledge, Cultural, Insurance coverage Patient or caregiver/family/community barrier type: Knowledge of need for life-long survivorship care; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Dependence/independence in decision-making; Cultural, language, and literacy difficulties; Other: Barriers to seeking LTFU care: higher health care self-efficacy (being uninsured was financial driver)
Novakovic, 1997 ¹⁰⁵ N/A	USA Survey	Proportion of CCS: 50% or more Bone cancer	Level: Patient Category: Access to care, Insurance coverage Patient or caregiver/family/community barrier type: Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare)
Oeffinger, 2004 ¹⁰⁶ Kirchhoff, 2013 ⁷⁵ ; Casillas, 2015 ²⁹ ; Nathan, 2008 ¹⁰¹ ; Caplin, 2017 ²⁴ ; Casillas, 2011 ²⁵ ; Castellino, 2005 ³² ; Geller, 2019 ⁵⁶ ; Kaste, 2009 ⁷¹ ; Kirchhoff, 2018 ⁷⁶ ; Nipp, 2017 ¹⁰⁴ ; Recklitis,	Multiple countries Survey, Interview, Analytic study	Proportion of CCS: 100% Multiple cancer origin	Level: Caregiver/family/community, 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Dependence/independence in

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
2010 ¹¹² ; Yeazel, 2004 ¹³⁴ ; Zebrack, 2012 ¹³⁵ ; Ford, 2020 ⁵⁴ ; Park, 2017 ¹⁰⁹ ; Smith, 2010 ¹²³ ; Park, 2012 ¹¹⁰ ; Krull, 2011 ⁸⁰ ; Nathan, 2010 ¹⁰³ ; Kadan- Lottick, 2002 ⁶⁹ ; Kurt, 2012 ⁸³ Childhood Cancer Survivor Study (CCSS)			decision-making; Cultural, language, and literacy difficulties; 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: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist); Geographic barriers, lack of local availability of services; Lack of insurance coverage/reimbursement; Lack of adequate in-network providers
Quillen, 2017 ¹¹¹ 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community
Rosenberg-Yunger, 2013 ¹¹⁶ 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 ¹¹⁷ 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; Dependence/independence in decision-making Provider, health system, or payer barrier type: Poor transition from pediatric to adult care; Lack of insurance coverage/reimbursement
Sadak, 2019 ¹¹⁸ N/A	USA Survey	Proportion of CCS: Unclear Other (specify) : Focused on facility, not individual CCS	Level: Health system Category: Other: Size of the transition program Provider, health system, or payer barrier type: Geographic barriers, lack of local availability of services; Poor transition from pediatric to adult care
Sherman, 2004 ¹²¹	USA	Proportion of CCS: 100%	Level: Health system

ID and related publications Study ID	Country Methodology	Proportion of CCS Cancer origin	Barrier level Barrier category Barrier detail
N/A	Survey	Multiple cancer origin	Category: Access to care Provider, health system, or payer barrier type: Lack of adequate resources to deliver needed care or respond to needs (PCP or specialist)
Szalda, 2016 ¹²⁶ Szalda, 2017 ¹²⁵ Cancer Survivorship Program at the Children's Hospital of Philadelphia (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; Dependence/independence in decision-making; Cultural, language, and literacy difficulties; Trust in providers/medical community
Van Laar, 2013 ¹³⁰ 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
Warner, 2014 ¹³¹ 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; Lack of adequate financial or employment resources (money to spend on co-pays or coinsurance, time off work, childcare); Trust in providers/medical community Provider, health system, or payer barrier type: Lack of knowledge or comfort in ability to provide survivorship care

Table D3. GQ4: Evaluated Strategies

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
Bashore, 2016 ¹⁸ N/A Observational	Multiple cancer origin CCS: 100%	Strategy: Care plan, Model of care Intervention category: Education	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

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
USA		Evaluation regarding the usefulness of a workbook to assist survivors to become ready to transition to adult care Primary target: Patient	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, 2012 ²² N/A Observational Multiple countries	Multiple cancer origin CCS: 100%	Strategy: Care plan Intervention category: Given tools for empowerment Web-based survivorship care plan given to CCS to sent to primary care provider to initiate surveillance and long-term follow-up Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care plan Authors' conclusion: The vast majority of survivors and providers accessed the website and found the SCP user-friendly for both the online and the printed version. The majority of survivors thought their knowledge of late effects had improved through the SCP and nearly all survivors had become more aware of the benefits of follow-up.
Casillas, 2017 ²⁶ N/A Observational USA	Multiple cancer origin CCS: 100%	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 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 also shared the texting messaging system 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.
Casillas, 2019 ³⁰ N/A Experimental	Multiple cancer origin CCS: 100%	Strategy: Survivorship care service, Care plan Intervention category: Education Evaluation of text-messaging and peer navigation interventions were compared to standard-of-care	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Knowledge of survivorship care among survivors

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
USA		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	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 ³¹ N/A Experimental USA	Multiple cancer origin CCS: 100%	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. 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.
Costello, 2017 ³⁶ N/A Observational USA	Multiple cancer origin CCS: 100%	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: The 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 ³⁸	Multiple cancer origin	Strategy: Other : Knowledge of late effects	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
Klosky, 2008 ⁷⁸ ; Hudson, 2002 ⁶¹ After Completion of Therapy (ACT) Clinic Experimental USA	CCS: 100%	Intervention category: Education Assess the efficacy of an educational intervention targeting survivorship clinic attendees to assess health knowledge about cancer treatment and risks, health perceptions, and health behavior practice at baseline and follow-up one year later Primary target: Patient	care: Attenders vs. 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: In comparison, to the standard of care, at the one-year follow-up assessment female survivors in the intervention group (standard of care plus the educational intervention) reported higher health knowledge than male survivors.
de Moor, 2011 ⁴³ Emmons, 2013 ⁴⁹ NCT00588107 Observational USA	Multiple cancer origin CCS: NR	Strategy: Other: Access to survivorship care/primary care providers were included as covariates Intervention category: Education Web site and print materials intervention for smoking intervention for childhood, adolescent, and young adult cancer survivors Primary target: Patient	Outcomes: Biomedical: Late effects and morbidity; Health services/Economics: Primary care, specialty care, or other care utilization: smoking rate, nicotine dependence, quit attempts Authors' conclusion: Encouragement to quit smoking by one's regular doctor or oncologist was associated with a making more quit attempts.
Devine, 2020 ⁴⁵ NCT02699996 Experimental USA	Multiple cancer origin CCS: 100%	Strategy: Survivorship care service Intervention category: Education Self-management and peer mentoring intervention to promote self-management of follow-up care; the main target was the CCS 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; Psychosocial: Psychological; Health services/Economics: Primary care, specialty care, or other care utilization: Barriers to care, transition readiness; Health services/Economics: Quality of life/satisfaction with care; Health services/Economics: Financial hardship, costs, and resource utilization 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).

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
Ducassou, 2017 ⁴⁷ N/A Experimental France	Multiple cancer origin CCS: 100%	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 proved to be very useful in helping survivors to adhere to follow-up care.
Eilertsen, 2004 ⁴⁸ N/A Observational Norway	Multiple cancer origin CCS: 100%	Strategy: Model of care Intervention category: Education Hold 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	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.
Ford, 2013 ⁵³ N/A Observational USA	Multiple cancer origin CCS: 100%	Strategy: Other : Knowledge of the need for life-long survivorship care Intervention category: Education Long term survivorship clinic 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 Authors' conclusion: There were 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.
Iyer, 2017 ⁶⁵ N/A Observational USA	Multiple cancer origin CCS: 50% or more	Strategy: Care plan, Model of care Intervention category: Access to care Survivorship care plans 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

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
			care plan and providing survivorship care, the biggest barrier was lack of knowledge.
Kadan-Lottick, 2018 ⁷⁰ Yale University, 2010 ¹²⁹ NCT02816866 Experimental USA	Multiple cancer origin CCS: 100%	Strategy: Care plan Intervention category: Access to care Upfront distribution of survivorship care plans to be implemented by 1) primary care physicians or 2) survivorship clinic 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 PCPs is not sufficient to meet consensus follow-up recommendations compared to those who attend survivorship clinic. CCS who had SCP and attend up 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 ⁸² NCT01593618 Experimental USA	Multiple cancer origin CCS: 100%	Strategy: Care plan Intervention category: Education Web-based informational intervention for adolescent and young adult survivors of childhood cancer to improve cancer 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; Health services/Economics: Quality of life/satisfaction with care Authors' conclusion: Post-treatment, the web-based intervention was not statistically better in improving cancer knowledge, anxiety of health beliefs compared to the standard of care. Among those randomized to the web-based intervention there was low utilization of the website. However, the most visited part of the website was the treatment summary followed by links to other outside sites for cancer survivors and then links to specific health-related information.

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
Landier, 2015 ⁸⁴ N/A Observational USA	Multiple cancer origin CCS: 100%	Strategy: Care plan Intervention category: Access to care, Education Survivorship clinic and tailored education of 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.
Oeffinger, 2019 ¹⁰⁷ NCT01579552 (EMPOWER Study) Experimental Multiple countries	Multiple cancer origin CCS: 100%	Strategy: Survivorship care service Intervention category: Education Randomized control trial where some female childhood cancer survivors were mailed an information packet and received a motivational interview from trained counselors; the measured outcome was 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. The intervention was more successful among women age 25 to 39 years than among those age 40 to 50 years.
Reynolds, 2019 ¹¹⁴ N/A Observational Canada	Multiple cancer origin CCS: 100%	Strategy: Model of care Intervention category: Access to care Follow up care at specialized care facilities versus at a primary-care facility Primary target: Patient	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care at oncologist vs. PCP; Health services/Economics: Primary care, specialty care, or other care utilization: survivorship care at oncologist vs. PCP Authors' conclusion: Cancer-center based models reported higher rates of all COG-recommended follow-up tests than the community-based model.
Rose-Felker, 2019 ¹¹⁵ N/A Observational USA	Other (specify) : not specified CCS: NR	Strategy: Other: Intervention targeting pediatric cardiologists Intervention category: Education Educational intervention targeting pediatric cardiologists; used pre/post test with a web-based survey to assess knowledge of surveillance needs for CCS among pediatric cardiologists	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 CCS surveillance, treatment related risk, risk of cardiac dysfunction with time since treatment, the role of dexrazoxane in cardioprotection, that

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
		Primary target: Provider	there is a web-based risk-assessment tool to estimate the risk of congestive heart failure in survivors by age 40, and that African-Americans CCS are at increased risk for late cardiotoxicity.
Santacroce, 2010 ⁶⁸ HEROS PLUS AYA Experimental USA	Multiple cancer origin CCS: 100%	Strategy: Survivorship care service,Care plan Intervention category: Psychosocial A coping skills training intervention via telephone and discussed plans for future monitoring with survivors (main target) and parents (secondary) Primary target: Patient	Outcomes: Psychosocial: Psychological,Other : Psychosocial outcomes for survivors and parent Authors' conclusion: HEROS PLUS CST has clinical relevance and that inperson long-term follow-up plus telephone-delivered psychosocial care is a practical way to deliver integrated care to adolescent–young adult childhood cancer survivors and their parents. 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.
Schwartz, 2018 ¹²⁰ N/A Observational USA	Multiple cancer origin CCS: NR	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 ¹¹⁹ AYA STEPS (AYA Self-management via Texting, Education, and Plans for Survivorship) Experimental	Multiple cancer origin CCS: 100%	Strategy: Survivorship care service Intervention category: Education AYA STEPS (AYA Self-management via Texting, Education, and Plans for Survivorship) mobile app creation	Outcomes: Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: Mobile app to encourage use of survivorship care plan Authors' conclusion: AYA survivors reported that the app and the embedded tailored messages related to

ID Study ID Design Country	Cancer origin Proportion of CCS	Strategy and intervention approach Description of survivorship care strategy	Assessed outcome domain and measure
USA		Primary target: Patient	their health and SCP were easy to use and generally satisfying and beneficial.
Williamson, 2014 ¹³³ SurvivorLink Observational USA	Multiple cancer origin CCS: 100%	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 survivor clinic is the biggest 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, vs versus

Table D4. GQ5: Ongoing Studies

ID Study ID Design Country Expected completion	Cancer origin Proportion of CCS	Intervention type Description of survivorship care strategy	Assessed outcome domain and measure
Chow, 2020 ³⁵ NCT03104543 [Communicating Health Information and Improving Coordination With Primary Care (CHIIP)] Experimental USA Expected completion: 03/01/2022	Multiple cancer origin CCS: 100%	Survivorship care service Educational materials provided to CCS	Biomedical: Late effects and morbidity, Psychosocial: Psychological, Health services/Economics: Primary care, specialty care, or other care utilization

ID Study ID Design Country Expected completion	Cancer origin Proportion of CCS	Intervention type Description of survivorship care strategy	Assessed outcome domain and measure
Daniel, 2015 ⁴⁰ NCT02046811 Experimental USA Expected completion: 01/01/2018	Multiple cancer origin CCS: 100%	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
Devine, 2019 ⁴⁶ NCT04075734 Experimental USA Expected completion: 09/30/2020	Multiple cancer origin CCS: 100%	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 primary care provider Other: Responsibility, self-efficacy, health insurance self-efficacy
Escoffery, 2019 ⁵¹ Emory University, 2020 ¹²⁸ ; SurvivorLink, 2020 ²³ NCT03543852	Multiple cancer origin CCS: 100%	Survivorship care service,Care plan	Survivorship Care Domain: Utilization of survivorship care services, care plans, or models of care: survivorship care plan

ID Study ID Design Country Expected completion	Cancer origin Proportion of CCS	Intervention type Description of survivorship care strategy	Assessed outcome domain and measure
Experimental USA Expected completion: 05/01/2023		Patient-controlled electronic personal health record and system (SurvivorLink)	
Hill-Kayser, 2020 ⁵⁹ SmartALACC; NCT02559219 Experimental USA Expected completion: NR	Leukemia,Lymphoma CCS: 100%	Care plan Test the feasibility and acceptability of use 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 ⁹⁰ NCT04257058 Experimental USA Expected completion: 04/01/2023	Multiple cancer origin CCS: 100%	Survivorship care service,Care plan Electronic educational materials on CCS' (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
McClellan, 2015 ⁹⁴ N/A Observational USA Expected completion: NR	Multiple cancer origin CCS: NR	Model of care Follow-up with a primary care physician in the adult setting who is knowledgeable about late effects of childhood cancer treatment and transition support/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