

# BMJ Open Integrating primary care and childhood cancer survivorship care: a scoping review protocol

Sarah E Piombo <sup>1</sup>, Julia Stal <sup>1</sup>, Dalia Kagramanov,<sup>1</sup> Lynn Kysh,<sup>2</sup> David R Freyer,<sup>1,3,4,5</sup> Barbara J Turner,<sup>6,7</sup> Kimberly A Miller<sup>1,8</sup>

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SEP and JS contributed equally.

SEP and JS are joint first authors.

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For numbered affiliations see end of article.

## Correspondence to

Julia Stal; [jstal@usc.edu](mailto:jstal@usc.edu)

## ABSTRACT

**Introduction** Improved treatment regimens have led to increased survival rates among childhood cancer survivors (CCS), and more than 84% of all children diagnosed with cancer will experience long-term survival or cure. Survivors are susceptible to late effects of cancer treatment often requiring lifelong follow-up care, as many of these conditions can be prevented or mitigated with surveillance. Integrating primary care (PC) and childhood cancer survivorship care can improve follow-up for survivors, however, little integrative research exists. This scoping review aims to: identify and describe existing models of care that integrate PC and childhood cancer survivorship care, examine the effectiveness of these models of care, and characterise the barriers and facilitators for the integration of PC for CCS.

**Methods and analysis** A comprehensive empirical literature search of three electronic databases (PubMed, CINAHL, and Embase) was employed to identify potentially relevant citations on 1 October 2020. The population, independent variables/intervention, comparator, outcomes, timing, setting and study design/other limiters (PICOTSS) framework was used to inform protocol development. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist and explanation will be used to report study findings. The search strategy will be completed again prior to publication to ensure recent empirical research is accounted for.

**Ethics and dissemination** This research is exempt from Institutional Review Board (IRB) review. Approval from a research ethics board for this study was not required as it does not involve human participants or unpublished secondary data. The findings from this scoping review will be disseminated through peer-reviewed scientific manuscripts, clinical conference presentations, professional networks and digital communications using social media platforms such as Twitter. This study has been registered with Open Science Framework: <https://osf.io/92xbg>.

## INTRODUCTION

More than 84% of all children diagnosed with cancer will experience long-term survival or cure.<sup>1</sup> In the USA, there are over 500 000 childhood cancer survivors (CCS), with estimates that 1 in every 500 young adults is a

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Knowledge gaps surrounding the role of primary care providers (PCPs) in childhood cancer survivorship care exist; therefore, the present review will provide a detailed synopsis of the international empirical literature surrounding models of care that integrate primary care (PC) and childhood cancer survivorship care, will examine the effectiveness of these models of care, and will characterise barriers and facilitators associated with integrating PC among childhood cancer survivorship care.
- ⇒ Models of care and measures of effectiveness identified will be used to provide recommendations for providers and healthcare systems regarding which patients are most likely to benefit from which model of care and in which care setting.
- ⇒ Rigorous research methods, expert medical research librarian services, three electronic databases, comprehensive and controlled search terms, and strict adherence to protocol will be used.
- ⇒ The population, independent variables/intervention, comparator, outcomes, timing, setting and study design/other limiters (PICOTSS) framework was used for protocol development, and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist and explanation will be used to report study findings.
- ⇒ Given the international inclusion criteria and a focus on existing, empirical research, it will not be feasible to perform a grey literature search from all of the included Commonwealth Fund high-income countries, preventing a characterisation of ongoing, unpublished research.

CCS.<sup>2</sup> Improved survival has been achieved through complex and often toxic treatment regimens. As a result, many CCS are at risk for developing late effects over their lifetime such as heart failure, infertility, second malignancies, neurocognitive deficits, early mortality, and adverse quality of life.<sup>3</sup> For example, after 30 years of follow-up, 73% of adult CCS have reported having a chronic health condition and 43% have reported a severe or life-threatening health condition.<sup>4,5</sup>

These complications of cancer treatment often necessitate lifelong follow-up medical care, as many of these conditions can be prevented or mitigated with surveillance.<sup>6</sup> Components of cancer survivorship care include risk reduction and prevention; detection and surveillance of new and recurrent cancer; interventions for both short-term and long-term late effects from cancer and its treatment; psychosocial services; and coordination between specialists and primary care providers (PCPs).<sup>7</sup> CCS face challenges surrounding follow-up care and the management of late effects, such as the transition both from paediatric to adult-focused care and from the oncology to primary care (PC) setting.<sup>8</sup>

Existing models of long-term follow-up care for survivors of all ages have been categorised into eight broad categories by the American Society of Clinical Oncology (ASCO).<sup>9–10</sup> While some research has explored the integration of PC into models of follow-up care for adult survivors,<sup>11</sup> little research has focused on the integration of PC and childhood cancer survivorship care.<sup>12</sup> CCS experience distinct obstacles in obtaining follow-up care, such as a challenging transition from paediatric to adult care settings, compared with adult survivors.<sup>13</sup> While this transition can be within oncology, PC, or a combination of both, it is often unstandardised, particularly within the transition to PC from oncological care. Attrition from a cancer-focused survivorship care setting is the norm for this population.<sup>13</sup> After completing cancer treatment, many CCS receive their general healthcare from PCPs and report using PC more than the general population.<sup>14–15</sup> In addition, older CCS are less likely to report a general health examination, a cancer-related health visit or a visit to a cancer centre than younger CCS.<sup>16</sup> As such, the unique survivorship care needs among this population warrant distinct CCS-specific survivorship research.

Evidence suggests that survivorship care models that incorporate PC may reduce demand on oncologists, increase care accessibility, and offer more comprehensive patient care.<sup>17–18</sup> However, the successful implementation of these models is dependent on whether PCPs are equipped to deliver proper care that adequately addresses CCS's complex healthcare needs. One challenge is that many PCPs lack formal training in childhood cancer survivorship care and therefore lack the knowledge to successfully manage their long-term follow-up care.<sup>19–20</sup> While PCPs express a willingness to care for CCS with regard to the management of late effects, the majority do not feel prepared to deliver complex survivorship care related to patients' specific cancer type.<sup>20–23</sup> Therefore, more research on models of survivorship care that integrate PC among CCS is needed to address these barriers and facilitate the implementation of high-quality, guideline-concordant care for CCS.<sup>14</sup>

## Rationale

Specialised oncology clinics have been viewed as the 'gold standard' for CCS,<sup>24</sup> however, little is known about PC-specific barriers and facilitators for follow-up care

among CCS who transition to a PC setting. Initial database searches from 1 October 2020 did not identify any scoping reviews that specifically address the implementation of PC within childhood cancer survivorship care. Further research is needed to describe and evaluate existing models of care, and to identify PC-specific factors that facilitate or hinder access, and continuity and transition of care. Therefore, we propose a scoping review that will identify and describe existing models of care that integrate PC and childhood cancer survivorship care; examine the effectiveness of these models of care; and characterise the barriers and facilitators for the integration of PC for CCS. The findings from this review will characterise existing PC-integrated childhood cancer survivorship care models and identify gaps in the literature for stakeholders and healthcare systems to effectively allocate resources to needed areas (ie, medical training).

The Agency for Healthcare Research and Quality (AHRQ) recently published a research protocol focused on models of care that include PC for adult survivors of childhood cancer.<sup>25</sup> While similar to the present review, multiple differences should be noted. First, the present review will use scoping review methodology while the AHRQ plans to use realist synthesis. Next, the AHRQ aims include a focus on programme theories. By contrast, the present review will detail barriers and facilitators for the integration of PC for childhood cancer survivorship care. Finally, the AHRQ review focuses on adult survivors of childhood cancer, while the present review does not require eligible studies to include exclusively adult CCS. Rather, we will not define the age range of participants beyond the requirement that they are diagnosed as children. The present study will also include providers part of the multidisciplinary cancer care team that may not be captured by the AHRQ review. We believe these respective reviews will collectively and in complementary fashion contribute to a broader characterisation of the integration of PC in childhood cancer survivorship care.

## Review objective

The objective of this scoping review is to describe the state of the current, empirical, international PC-based childhood cancer survivorship literature using three guiding questions (GQs): *GQ1*. What models of cancer survivorship care that integrate PC exist for childhood cancer survivors? *GQ2*. What is the effectiveness of models of survivorship care that integrate PC for CCS? *GQ3*. What are the barriers and facilitators to the integration of PC into childhood cancer survivorship care?

## METHODOLOGY

This manuscript details the protocol for a scoping review that is currently in progress. Scoping review methodology was identified to broadly characterise the state of the empirical literature surrounding the integration of PC and childhood cancer survivorship care to identify gaps in the literature and inform future, more detailed, research

on the topic.<sup>26</sup> The GQs were used to inform both the methods and search strategy for this scoping review. The protocol development was guided by the population, independent variables/intervention, comparator, outcomes, timing, setting and study design/other limiters (PICOTSS) framework. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist and explanation will be used for reporting study findings.

### Eligibility criteria

The PICOTSS framework was used to inform eligibility criteria to guide the inclusion of empirical research.<sup>27</sup> The *population* includes CCS who are off treatment (diagnosed before age 21)<sup>28</sup> and/or healthcare providers including general or PC practitioners (eg, PCPs, family practice physicians, gynaecologists) as well as various disciplines from the multidisciplinary cancer survivorship care team (eg, oncologists, nurse practitioners, physician assistants, oncology nurses, etc). The *independent variables and interventions* include studies that incorporate both PC and childhood cancer survivorship care. *Comparators* include comparing CCS across different models of care to the general population and/or comparing PCPs to oncologists or other healthcare providers. *Outcomes* include reporting on the integration of PC for childhood cancer survivorship care, the effectiveness of this integration, and/or barriers and facilitators to integrate PC in childhood cancer survivorship care (ie, the GQ). *Timing* restrictions will not be used; therefore, studies may be published at any date and may include CCS who are either short-term or long-term survivors. The *setting* of included studies will be limited to those conducted in the Commonwealth Fund's high-income country list, because the healthcare systems of these countries are often compared with the USA and is in accordance with prior research on a similar topic.<sup>28 29</sup> In reporting our study findings, we will take each of these settings into account, considering varying resources, structures, and barriers that may be present in each of the healthcare settings from which relevant studies emerge. We will also consider the setting when reporting the implications of our findings for providers and healthcare systems alike. *Study design and other limiters* represent an inclusion of English-only publications and quantitative and/or qualitative studies. Additional details for inclusion and exclusion criteria are described in [table 1](#).

Only empirical studies will be included in the present review. While literature reviews are not eligible for inclusion, they will be retained for reference mining. (*GQ1*) Studies that are descriptive in nature and do not empirically address PC-integrative models of childhood cancer survivorship care will not be included. (*GQ2*) Studies that are determined to satisfy GQ1 will be subsequently screened for satisfaction of GQ2 (ie, providing an empirical measure of effectiveness of models of care). The author's definition of an effective model of care will be accepted and no limitations regarding the outcome

measure will be employed. Therefore, outcomes used by studies to determine model of care effectiveness may include, but are not limited to, the utilisation of follow-up care, adherence to screening guidelines, and patient and/or provider satisfaction, among others. (*GQ3*) Only PC-specific barriers and facilitators to childhood cancer survivorship care will be considered for inclusion in the present review. Studies do not have to satisfy GQ1 or GQ2 to be considered for GQ3. Each study can contribute to more than one GQ but is only required to satisfy one to meet inclusion criteria for this scoping review.

### Information sources and search strategy

Detailed support from a skilled medical research librarian (LK) was leveraged to develop an inclusive and all-encompassing research strategy through controlled vocabulary terms (MeSH, Emtree, or CINAHL Headings) that includes topics of cancer, PC-based survivorship care, and childhood cancer survivorship. Online supplemental appendix 1 details this developed search strategy. Three electronic databases were used: PubMed (National Library of Medicine), CINAHL (EBSCO), and Embase (Elsevier). The searches were first completed on 1 October 2020, and all citations were exported into an EndNote X9 (Clarivate Analytics, Philadelphia, USA) library. This search will be completed once more prior to publication of the scoping review to ensure recent publications are included.

Due to both feasibility and a primary focus on characterising the state of the empirical, academic literature, a grey literature search will be excluded from the present study. The Commonwealth Fund's high-income countries inclusion criteria employed broadens our understanding of the existing empirical literature but hinders our ability to satisfy this criterion while performing a comprehensive grey literature search across international healthcare settings. While a grey literature search will not be performed, references of included studies will be scanned to identify any empirical research satisfying inclusion criteria that may be missed by the search strategy.

### Methods limitations

While the methods are strengthened due to the international inclusion criteria, they may be limited as only studies in English will be included due to challenges associated with translating non-English articles. Similarly, grey literature, while valuable for combating biases in publication, will not be included due to feasibility. Further, the present study does not provide an evaluation of the quality of the empirical research identified, but rather characterises the literature to describe the existing state of PC-integrative models of childhood cancer survivorship care.

### Selection of sources of evidence

The search strategy identified a total of 4522 records. After importing into Covidence (Melbourne, Australia), an online software for managing systematic reviews, 30 duplicate records were identified and were subsequently

**Table 1** Criteria for inclusion/exclusion of studies

PICOTSS	Inclusion	Exclusion
Population	<ul style="list-style-type: none"> <li>▶ Paediatric/childhood survivors diagnosed at or before age 21.</li> <li>▶ The author's definition of a CCS will also be accepted.</li> <li>▶ Samples that include at least 50% CCS or include a subgroup analysis will be included.</li> <li>▶ Survivors must have completed active cancer treatment.               <ul style="list-style-type: none"> <li>– PCPs of various disciplines and titles including, but not limited to, general practitioners, family medicine practitioners, and/or gynaecologists.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▶ Not diagnosed with cancer at or before age 21.</li> <li>▶ The author does not otherwise define CCS.</li> <li>▶ Study sample is not over 50% CCS and does not include subgroup analyses.</li> <li>▶ Survivors on active cancer treatment, in hospice, or receiving palliative care services.</li> <li>▶ Providers who are not directly involved with primary healthcare service.</li> </ul>
Independent variables and interventions	<ul style="list-style-type: none"> <li>▶ Studies must include both cancer survivorship care and PC for CCS.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Studies that mention only cancer survivorship care or only PC and are not focused on CCS.</li> </ul>
Comparators	<ul style="list-style-type: none"> <li>▶ Studies may compare CCS to the general population using any variables in addition to PC care models.</li> <li>▶ Studies may compare oncologists to PCPs, or any combination of healthcare providers.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Studies not addressing PC models of survivorship care among CCS.</li> </ul>
Outcomes	<ul style="list-style-type: none"> <li>▶ Integration of PC in CCS survivorship care.</li> <li>▶ Barriers and facilitators to PC integration in paediatric survivorship care.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Studies that do not relate to PCPs and CCS survivorship care.</li> </ul>
Timing	<ul style="list-style-type: none"> <li>▶ Studies may include long-term CCS or recently diagnosed, off treatment CCS.</li> </ul>	<ul style="list-style-type: none"> <li>▶ No time constraints will be applied.</li> </ul>
Setting	<ul style="list-style-type: none"> <li>▶ Studies from countries in the Commonwealth Fund's high-income country list: Australia, Canada, France, Germany, the Netherlands, Japan, New Zealand, Norway, Sweden, Switzerland, the UK, and the USA.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Studies from countries <i>not</i> on the Commonwealth Fund high-income country list.</li> </ul>
Study design and other limiters	<ul style="list-style-type: none"> <li>▶ English-language publications.</li> <li>▶ Quantitative or qualitative empirical studies.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Studies exclusively reported in non-English publications.</li> <li>▶ Case report or case study.</li> <li>▶ Psychometric study.</li> <li>▶ Systematic and literature reviews will be retained for manuscript development but are not eligible for inclusion.</li> </ul>

CCS, childhood cancer survivors; PC, primary care; PCP, primary care provider.

removed. Therefore, a total of 4492 records will be screened against the inclusion criteria (PubMed (n=1799); Embase (n=1410), and CINAHL (n=1253)). Initially, four independent literature reviewers (SEP, JS, DK, and KAM) will screen all records for satisfaction of the PICOTSS inclusion criteria based on both their titles and abstracts. Any records that are determined to potentially satisfy inclusion criteria by two reviewers will be included at this stage. Next, two independent literature reviewers (SEP and JS) will screen each of the previously identified records to determine final inclusion in the scoping review and reasons for exclusion will be documented. Any disagreements will be resolved through both group discussion and group consensus (SEP, JS, DK, and KAM). The search strategy will be re-ran prior to manuscript submission to capture recent studies.

### Data charting process

References will be managed using EndNote X9 (Clarivate Analytics), a citation management software. Data from studies selected for inclusion in the present study will be charted using a standardised data charting form

developed in accordance with prior research on a similar topic<sup>28</sup> (table 2).

Data will be abstracted from published studies using Qualtrics (Qualtrics XM, Seattle, USA), a web-based survey tool. Data charting will be conducted by one literature reviewer and will be subsequently verified for accuracy by a different independent reviewer not previously involved in screening. Any disagreements that may arise will be resolved through group discussion and group consensus (SEP, JS, DK, and KAM)

### Synthesis of results

The PRISMA-ScR checklist and explanation will be used to report study findings.<sup>30</sup> Several figures and tables will be used to report scoping review findings upon manuscript completion (note: only tables 1 and 2 are complete and thus presented in the current protocol as data collection is not yet complete). An online supplemental appendix will detail each of the studies selected for inclusion in the present review and will include first author name, title, year of publication, country of study location, sample, study design, and an overview of the main



**Table 2** Data charting form

Characteristics	Components
<i>General information</i>	
Citation information	1. Study title 2. Year of publication 3. Type of publication (eg, peer-reviewed article, conference presentation, book chapter, thesis/dissertation) 4. Publication sub-type (eg, editorial, commentary, review), and author first and last name
Study demographics	5. Country of study location (eg, commonwealth country list) 6. Employment of authors (eg, university, industry, hospital, academic medical centre)
Intervention characteristics	7. Study setting (eg, inpatient, home, university, community medical setting) 8. Number of sites 9. Target of intervention (eg, patient, caregiver, provider, policy)
<i>Study information</i>	
Research methods	10. Research design (eg, observation, experimental, non-research) 11. Detailed research design (eg, randomised control trial, cohort study, cross-sectional study, qualitative study) 12. Control group (yes/no) 13. Data collection method (eg, survey, interview, electronic medical record)
Study characteristics	14. Duration of study 15. Source of data (eg, CCS survivor, caregiver, provider)
Sample characteristics	16. Sample size 17. Provider included in study (eg, PCP, nurse practitioner, physician assistant, nurse) 18. Age at diagnosis 19. Age at time of study 20. Years since diagnosis 21. Cancer type 22. Race/ethnicity 23. Language 24. Socioeconomic status 25. Setting (eg, urban, rural)
<i>Clinical information</i>	
Model of care characteristics	26. Detail reimbursement structure of care model 27. Model of care (eg, PCP, shared care, survivorship clinic) 28. Evaluation of care coordination and communication among providers (yes/no) 29. Cost assessment and cost analysis (yes/no)
Clinical characteristics	30. Symptom tracking (eg, late effects) 31. Survivorship care guideline adherence (yes/no) 32. Specification of guideline
Barriers	33. Barriers to PC delivered survivorship care
Facilitators	34. Facilitators to PC delivered survivorship care
Additional survivorship concerns	35. Adherence to prevention care, preventive screenings, psychosocial or general health outcomes, comorbid conditions
CCS, childhood cancer survivors; PC, primary care; PCP, primary care provider.	

findings. A PRISMA study flow diagram including identified references, stages of screening, reasons for exclusion, and final study selections will be presented. [Table 1](#) displaying the PICOTSS inclusion/exclusion criteria and [table 2](#) displaying the data charting form will be included as shown in the present protocol manuscript. Subsequent tables, corresponding to findings associated with the GQs, will represent models of care that integrate PC for CCS; detail the effectiveness of PC-integrative models of cancer survivorship care for CCS (including metric of effectiveness and subsequent findings); and present barriers

and facilitators for the integration of PC into childhood cancer survivorship care (including whether the barriers and facilitators represent patient-level, provider-level, or system-level factors), respectively. Should additional information become relevant, modifications to the presentation of research findings will be accommodated.

### Patient and public involvement

No patients or participants will be included in the present study due to the nature of exploring secondary data through a scoping review. Our research team includes

two physicians with experience providing both PC and childhood cancer survivorship care (BJT and DRF, respectively), an academic researcher with an extensive history conducting cancer research (KAM), a skilled research librarian with extensive experience synthesising literature (LK), and three advanced doctoral students with a demonstrated focus on cancer survivorship research (SEP, JS, and DK). Each member of the study team has provided detailed guidance and input for the design and development of the study protocol and will continue to help inform our ongoing research efforts.

## ETHICS AND DISSEMINATION

This research is exempt from Institutional Review Board (IRB) review. Approval from a research ethics board was not required as the present study does not involve human participants or unpublished secondary data. Study findings will be interpreted and refined with content experts (DRF, BJT, and KAM) in childhood cancer survivorship care, PC, and evaluating models of healthcare delivery. Our target audiences include healthcare professionals involved with childhood cancer survivorship, specifically oncologists and PCPs, healthcare stakeholders, CCS, and their families. Scoping review findings will be disseminated through peer-reviewed scientific manuscripts, clinical conference presentations, professional networks, and digital communications using social media platforms such as Twitter.

### Author affiliations

<sup>1</sup>Department of Population and Public Health Sciences, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

<sup>2</sup>Institute for Nursing and Interprofessional Research, Children's Hospital of Los Angeles, Los Angeles, California, USA

<sup>3</sup>Cancer and Blood Disease Institute, Children's Hospital of Los Angeles, Los Angeles, California, USA

<sup>4</sup>Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

<sup>5</sup>USC Norris Comprehensive Cancer Center, Los Angeles, California, USA

<sup>6</sup>Department of Medicine, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

<sup>7</sup>Gehr Family Center for Health Systems Research and Innovation, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

<sup>8</sup>Dermatology, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

**Twitter** Julia Stal @JuliaStal1

**Contributors** SEP: conceptualisation, methodology, project administration, supervision, validation, writing-original draft, reviewing and editing. JS: conceptualisation, methodology, project administration, supervision, validation, writing-original draft, reviewing and editing. DK: writing-reviewing and editing. LK: project administration, resources, software, writing-reviewing and editing. DRF: writing-reviewing and editing. BJT: writing-reviewing and editing. KAM: conceptualisation, methodology, supervision, writing-original draft, reviewing and editing.

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### ORCID iDs

Sarah E Piombo <http://orcid.org/0000-0001-5118-7897>

Julia Stal <http://orcid.org/0000-0002-7911-7388>

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