Technical Brief Disposition of Comments Report

Research Review Title: *Disparities and Barriers to Pediatric Cancer Survivorship Care*

Draft report available for public comment from October 7, 2020 to November 4, 2020.

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Comments to Draft Report

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Comments on draft reports and the authors' responses to the comments are posted for public viewing on the website approximately 3 months after the final report is published. Comments are not edited for spelling, grammar, or other content errors. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments.

This document includes the responses by the authors of the report to comments that were submitted for this draft report. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Quality	Good	Thank you.
Key Informant (KI) Reviewer #1	Quality	Superior	Thank you.
KI Reviewer #2	Quality	Good	Thank you.
Peer Reviewer #2	Quality	Superior	Thank you.
Peer Reviewer #3	Quality	Good	Thank you.
KI Reviewer #3	Quality	Superior	Thank you.
Peer Reviewer #4	Quality	Superior	Thank you.
KI Reviewer #4	Quality	Superior	Thank you.
Peer Reviewer #1	General	Thank you for the opportunity to review this report. It is a thoroughly researched and well-written document. The literature review is appropriately detailed and well supplemented by grey literature and expert opinion. The five guiding questions are well framed and capture the key issues in addressing disparities and barriers. I have no critical concerns. Some minor comments/suggestions are documented in the individual sections below.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	General	Thank you for the opportunity to review this technical report. I appreciate the efforts being made to examine disparities and interventions to overcome disparities as related to survivorship care for childhood cancer survivors. Reducing and eliminating disparities is a necessary step toward achieving equity and justice in health care; however, eliminating disparities is not the same as achieving equity and justice. Eliminating barriers to care for patients and families is certainly an important first step; yet, studies are still required to determine the extent to which equity is achieved once the barriers are removed. Health equity refers to a state characterized by the "absence of systematic inequalities in health" (Farrer et al., 2015, p. 394). Therefore, interventions that reduce or dismantle barriers should result in equitable outcomes across sub-populations as defined by race, ethnicity, sexual orientation, gender and gender identification, age, religion, nationality, etc. I encourage the authors to consider and at least comment on the need for future research that examines interventions that explicitly aim to achieve equity by intervening on institutional structures and practices that systematically reinforce inequities.	Thank you for this important feedback. We have added a sentence to address this concern and reference the Farrer citation to emphasize the importance of achieving health equity in the outcomes section of Next Steps.
KI Reviewer #1	General	Objectives of the report are clearly delineated in context of concise background. The technical brief succeeds in providing a framework to guide future intervention research.	Thank you.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #2	General	Throughout the brief, there are statements that mention that biomedical and psychosocial outcomes were less frequently examined in reference to disparities. There are lots of papers examining outcomes in the biomedical and psychosocial domain (many of them listed in the Excluded papers of Appendix B) that show results by sex, racial/ethnic status, other SES factors. However, if this statement is being made because the literature search was limited to papers that focus on survivorship care as an outcome, then expecting many of those papers to also cover biomedical / psychosocial outcomes is not entirely realistic given the breadth of those topics and the constrained nature of most scientific papers. However, I think what you are trying to say perhaps is that we haven't demonstrated that decreasing barriers to survivorship care can actually translate to improved biomedical and/or psychosocial outcomes, which I agree is a major limitation in survivorship research.	Thank you for making this important point. We have added clarifying text throughout the report to explain that survivorship care needed to be part of the study or model for these outcomes (and to meet our overall inclusion criteria).
Peer Reviewer #3	General	Comments on each section included below.	Thank you.
KI Reviewer #3	General	This is well written and I have no specific critiques to offer.	Thank you.
Peer Reviewer #4	General	This technical brief is very well researched, well written and provides an outstanding objective description of the state of the science in disparities and barriers to pediatric cancer survivorship care.	Thank you.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #4	General	While I have never read a technical brief before, I appreciated the breakdown and explanation of the research and studies written and with the diagrams. That is very useful for people with different learning techniques. This is a great technical brief because as a CCS myself I have been invested in my communities CCS's and seen firsthand MANY of the disparities and barriers discussed in this brief.	Thank you for providing this important feedback and for your insight into the disparities and barriers faced by Childhood Cancer Survivors (CCS).
Francisco Espinoza (Public Reviewer)	General	Great draft report. The conclusion could have been longer and more detailed describing the impact of these findings on how the healthcare system or other fields can offer assistance in mediating this problem.	Thank you for your important and helpful comment. We have added more text to the conclusion to help the reader. However, the Technical Brief wants to provide an overview of the content and the volume of the existing research, so recommendations for healthcare systems are beyond the scope of the project.

Commentator & Affiliation	Section	Comment	Response
George Dahlman-Children's Cancer Cause (Public Reviewer)	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." The final draft should indicate where a study included survivors who were diagnosed with cancer as a child vs. diagnosed as an adult. Additionally, the final draft should note where studies include both pediatric and adult onset cancers (if the childhood cancer survivor population composes <20% of the overall study population). The report should address this issue both broadly and study by study. Reported studies regarding childhood cancer survivors are lacking, however survivorship needs vary based on cancer onset by age. Thus, the report should clearly identify the study cohorts since the objective is to describe disparities experienced by childhood cancer survivors.	All included studies were among CCS diagnosed prior to age 21; however, studies could have used samples of CCS who were well into their adult years. Studies that included < 50% of their sample that were CCS (diagnosed prior to age 21) were excluded. We have added language to the Background section (last paragraph) regarding the scope of the technical brief report.

Commentator & Affiliation	Section	Comment	Response
George Dahlman-Children's Cancer Cause (Public Reviewer)	Key Messages	"Fifteen organizations have proposed strategies to address barriers to survivorship care." Children's Cancer Cause has developed a comprehensive legislative and regulatory proposal around addressing barriers to survivorship care for childhood cancer survivors. Our proposal would serve children and adolescents under a Medicaid demonstration program, providing care for at least a six-month period following their active cancer treatment. Every childhood cancer survivor would have a comprehensive care summary and follow up plan in the survivor's native language to account for disparities. The plan would specify their treatment history and address individual post treatment needs based on Children's Oncology Group recommendations. Attached is a short and long version of the proposal. The report should include the proposal in the strategies to address barriers to survivorship care.	Thank you very much for bringing the Children's Cancer Cause (CCC) to our attention. We have thoroughly reviewed your website and included additional applicable CCC-endorsed proposals as part of GQ3.

Commentator & Affiliation	Section	Comment	Response
George Dahlman-Children's Cancer Cause (Public Reviewer)	Key Messages	"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 strategies to alleviate barriers that lead to disparities to improve the survivorship care for pediatric cancer survivors." -The report acknowledges research limitations, namely, that barriers exist and that little has changed over the past 20 years. The report would benefit from more explicit recommendations on how to address research gaps. Specifically, a funding opportunity that addressed barriers and reduced disparities is critically important. We do not have comprehensive solutions on how to reduce barriers and we struggle with widespread implementation and adoption where we do have those strategies. In sum, highly diverse survivor cohorts are needed that are more representative of underserved communities.	We appreciate this excellent example of addressing research gaps, notably a lack of funding opportunities. We have incorporated this specific recommendation into the key messages, including the need for funding a diverse cohort of survivors that are representative of disparate subgroups of survivors.

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George Dahlman-Children's Cancer Cause (Public Reviewer)	Key Messages	"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 strategies to alleviate barriers that lead to disparities to improve the survivorship care for pediatric cancer survivors." -Most experts and stakeholders agree regarding the problems that plague survivors – insurance and access barriers, lack of primary care knowledge about how to treat survivors and lack of patient knowledge about their status and individual needs as a childhood cancer survivor.	We agree with this statement and this is aligned with what our study found. We have added a sentence to the last bullet of the key messages explaining this.

Commentator & Affiliation	Section	Comment	Response
George Dahlman-Children's Cancer Cause (Public Reviewer)	Key Messages	"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 strategies to alleviate barriers that lead to disparities to improve the survivorship care for pediatric cancer survivors." -Additional information is needed regarding how policy solutions might be structured with particular attention to insurance and reimbursement issues. Key screenings are strongly supported by evidence as both cost effective and beneficial to survivors when the risk is exceptionally high, the screening is relatively low cost, and early identification is critical to improving survival. For example, health plans should cover breast cancer screening - both mammograms and breast MRIs - for young women who are childhood cancer survivors -- previously exposed to chest radiation. In general, more data are needed to show how childhood cancer survivors are not getting this recommended screening due to lack of insurance coverage, and as a result, there may be added healthcare costs and resulting morbidity from a diagnosis due to a failure in secondary prevention.	Thank you for providing this feedback. We have added additional text to the Next Steps section under the "Independent variables/interventions and comparators" sub-section to clarify that these next steps need viable solutions due to insurance and reimbursement barriers.

Commentator & Affiliation	Section	Comment	Response
George Dahlman-Children's Cancer Cause (Public Reviewer)	Key Messages	"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 strategies to alleviate barriers that lead to disparities to improve the survivorship care for pediatric cancer survivors." -Given the static nature of the research and policy limitations, the Section on Interventions and Comparators should include explicit language about conducting pilot projects to implement model programs to develop a standard of care.	We thank the reviewer for pointing out the usefulness of explicitly noting pilot projects for model program implementation. We have changed the wording in the second paragraph of interventions and comparators in Next Steps.
Peer Reviewer #1	Background	Page 9, first paragraph: improvement in survival is also due to better risk stratification and improvements in supportive care. This should be acknowledged here.	Thank you for pointing this out; we have added language to clarify this.
Peer Reviewer #1	Background	Page 9, line 27: Would be useful to define the term “risk-based”. Unless defined later, I would suggest alluding to how risk is defined and by who, perhaps with reference to existing guidelines (e.g COG)	We appreciate this suggestion to improve the background section and have added text to clarify that risk- and exposure-based methods should be utilized.
KI Reviewer #1	Background	The background appropriately sets the stage for the importance of the work. The diversity of cancer/treatment-related late effects is highlighted. The background fails to convey the high prevalence of multimorbidity experienced by childhood cancer survivors, further emphasizing importance of addressing survivorship care disparities.	Great point; we have added text to clarify that late effects typically co-occur.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #2	Background	P9, L9: Age "21" is mentioned earlier in the abstract so use of age "20" here seems inconsistent.	Thank you for pointing this out; we have edited the age to make this clear.
KI Reviewer #2	Background	P1, L16-17: "Many challenges are still poorly understood or unknown" seems awkwardly phrased - it was not clear to me what is meant.	We have removed this statement from the text.
KI Reviewer #2	Background	P1, L20-21: "liver disease" doesn't come up for me as a major organ toxicity that needs to be highlighted in contrast to the other problems listed.	Thank you for pointing this out; we have removed liver disease from this list.
KI Reviewer #2	Background	P1, L25: should perhaps be "... income, and greater burden of mental health disorders."	Agree; we have made this change.
Peer Reviewer #2	Background	Very clear	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Background	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. Effective and efficient access to survivorship 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. While disparities in accessing survivorship care are increasingly recognized in the pediatric survivorship field, practitioners often are at a loss for how to mitigate 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 guidance for future research.	Thank you.
Peer Reviewer #3	Background	In the background, it would be helpful to clarified that this technical brief not only addresses research relevant to disparities and barriers for pediatric cancer survivorship care, but also disparities in outcomes among CCS as a presumed result of barriers to care, including biomedical, psychosocial, and health services/economics.	Thank you for this important point; we have added text to clarify this in the purpose and scope section of the introduction.
KI Reviewer #3	Background	The background was comprehensive.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Background	Page 1 Line 13: Consider including an additional treatment: hematopoietic stem-cell transplantation. This has also been an important contextual factor in improved treatment that has increased survival.	We agree and have added this to include hematopoietic stem-cell transplantation as a reason for improved survival.
Peer Reviewer #4	Background	Page 1 Line 18: Functional outcomes are often overlooked as risks for CCS. This may be included in the psychosocial umbrella of risks but calling this out in this sentence could highlight an important part of medical practice when caring for CCS that relates to disparities in or barriers to care.	Thank you for bringing this important point up. We have added functional outcomes to this sentence.
Peer Reviewer #4	Background	Page 1 Line 25: Could an additional word or two be added to clarify what the exact disparity is with mental health disorders (e.g. …lower income, and increased rates of mental health disorders.)?	We agree with this and have added "greater burden" to clarify this statement.
Peer Reviewer #4	Background	Page 1 Line 30-31: Two additional references (and sentinel literature) that provide primary data to support this statement are: 1) Nathan PC, Greenberg ML, Ness KK, et al. Medical Care in Long-Term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. J Clin Oncol 2008;26:4401-4409. 2) Oeffinger KC, Mertens AC, Hudson MM et al. Health Care of Young Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Ann Fam Med 2004;2:61-70.	Both references met inclusion criteria and are documented in detail in the report, but we tried to avoid singling out individual studies from the study set in the introduction.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Background	Page 1 Line 34: The unique challenges are not only seen for research but also clinical care and education/advocacy. It may be worth adding this to give the reader a broader understanding of this unique challenge for research and would set up the next sentence/paragraph nicely.	We agree and have added language clarifying this.
KI Reviewer #4	Background	It explains well the point of this technical brief and why researching these barriers of CCS's is so important. CCS's do not often realize how many late effects they may face after surviving cancer. Taken from Background- 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.	Thank you.
Francisco Espinoza (Public Reviewer)	Background	Detailed information on background of topic and introduction to barriers such as psychosocial, physical and behavioral factors that are preventing childhood cancer survivors from fully recovering from the long-term effects of cancer. The guiding questions ask good open ended questions that can lead to a plethora of information in the literature.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Guiding Questions	Appropriate and thorough. No concerns	Thank you.
KI Reviewer #1	Guiding Questions	Guiding questions are appropriate. The section does not note if any changes were made.	No changes were made.
KI Reviewer #2	Guiding Questions	No comments	Thank you.
Peer Reviewer #2	Guiding Questions	Re CG 2: I believe important to examine both barriers and facilitators. Focus on the negative precludes learning from conditions or strategies that are oriented to achieving strengths. As an analogy, enhanced quality of life is not solely a function of reducing physical or psychiatric symptoms but also partly attributable to promoting coping behaviors and enhancing social relationships. Similarly, future investigations should be guided by questions about factors that mitigate barriers and disparities but also promote facilitators and equity.	We cannot change the pre-specified guiding questions, but note that both barriers and facilitators were included in this review (in the independent variables/interventions section for guiding question 2 in table 1). We have added language to indicate this important distinction throughout the report.
Peer Reviewer #3	Guiding Questions	The guiding questions were clearly stated and appear to have remained the same over the completion of the draft technical brief.	Thank you.
KI Reviewer #3	Guiding Questions	The guiding questions were appropriately put forth.	Thank you.
Peer Reviewer #4	Guiding Questions	Page 2 Line 6: There is no note if any changes were made to the guiding questions and if so, why?	We cannot change the pre-specified guiding questions.
KI Reviewer #4	Guiding Questions	The guiding questions were helpful to bring the discussion of the barriers and how to address them. I hope this brief will bring more research and advocacy to long term care for CCS's.	Thank you.
Peer Reviewer #1	Methods	Search strategy seems appropriately broad and deep.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Methods	Page 13, Table 1: What is meant by the criterion: "eligible to receive survivorship care services…"? Since a CCS has already been defined, it was not clear what the meaning of this added inclusion was.	The original intention was to be inclusive and we have added "*currently receiving or* eligible to receive survivorship care…" to this criteria to make this more clear.
Peer Reviewer #1	Methods	PICOTSS are thorough and well-constructed. I have no substantive concerns.	Thank you.
KI Reviewer #1	Methods	The methods provide a comprehensive overview of the data sources, collection, abstraction, and integration process. The types and numbers of Key Informants are described. How such informants were identified is not stated, rather the expertise that was solicited. Excellent summary tables detail the contributions of Key Informants.	We have added language explaining how individual key informants were selected and approached.
KI Reviewer #2	Methods	No comments	Thank you.
Peer Reviewer #2	Methods	Clear and rigorous	Thank you.
Peer Reviewer #3	Methods	The types and numbers of key informants were clearly stated and the questions and sub-questions posed to the key informants were listed.	Thank you.
Peer Reviewer #3	Methods	The grey and published literature searches were concisely described and appropriately detailed in Appendix B.	Thank you.
Peer Reviewer #3	Methods	On page 5, lines 5-6, it would be helpful to expand on the definitions of the populations that experience health disparities for underserved, socioeconomic status and educational attainment. Does underserved refer just to rural populations?	We did not limit our search to only these disparity groups; we conducted our search to be inclusive of any disparity or synonym of disparity, as defined by the citation.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Methods	Page 7, lines 51-52: Should quality of life, which is currently noted as one of the health services/economics outcomes, be a psychosocial outcome instead? In addition, there appears to be overlap with health services and survivorship care, particularly with primary care, specialty care, or other care utilization. How were these distinguished?	The text has been revised to clarify that health-related quality of life was captured within psychosocial and quality and satisfaction with care captured in health services/ economic outcome domains.
KI Reviewer #3	Methods	The methods were rigorous.	Thank you.
Peer Reviewer #4	Methods	Page 4 Line 30: My pdf version of the report makes it look like the words “above” and “mentioned” are not separated by a space.	Yes, this is correctly stated.
Peer Reviewer #4	Methods	Page 4 Line 43: I think Appendix “B” is listed as a type-o; it looked to me that Appendix “A” covered these details. Also, upon review of the professional organization list in Appendix A, I would hesitate to call them all “professional organizations” and recommend consideration of adding a term such as “non-profit organizations” or “fund raising organization” or “advocacy groups” to “professional organizations.”	Thank you for noting the mistake in the reference to the appendix; we have corrected this. We have revised the language used to reference the organizations as “relevant organizations.”
Peer Reviewer #4	Methods	Page 4 Line 50/51: I think Appendix “B” might actually be referencing Appendix “A.”	Thank you for noting the mistake in the reference to the appendix; we have corrected this.
KI Reviewer #4	Methods	Figure 2. on page 17 showed a great representation through each domain and the visuals were easy to interpret.	Thank you.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #4	Methods	I found figure 4 confusing but the information below was useful to understanding: 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.	Thank you for pointing this out. We have edited the titles of the figures to make them more clear and added more detail to the text explaining each of the figures.
Francisco Espinoza (Public Reviewer)	Methods	Extensive research completed in searching for a variety of articles that included many different cultures and ethnicities. Inclusion and exclusion criteria described including steps taken to include and exclude certain literature.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Findings	Under disparities, the section lays out the volume of literature addressing each disparity category but doesn't summarize the findings. For example, it is not clear what the relationship is between race/ethnicity and CCS care. I worry about assuming that minority race/ethnicity is associated with poorer care since that has not been the finding of all studies. Is it beyond the scope of this report to articulate what the included studies actually showed (or, is this detail only to be shown in the appendices)?	Yes, a valid synthesis would require a formal systematic review of the presence and absence of associations. Most variables of interest have been addressed in multiple studies and results vary across studies, requiring a thorough analysis of the evidence. We have made the constraints of the technical brief clearer in the Purpose and Scope section.
Peer Reviewer #1	Findings	Also, the number of studies does not necessarily equate to the strength of association between a disparity type and outcome in a specific domain (Figure 3). So, interpretation of these findings is not possible. The challenge is similar for Figures 4 and 5 as well.	Yes, we agree. In order to fully articulate the findings of these studies, a critical appraisal is needed to assess the risk of bias and fully evaluate the quality of evidence.
Peer Reviewer #1	Findings	Table 4: The International Guideline Harmonization Group is an international initiative, not exclusively US (it is actually led out of the Netherlands). I think that the Late Effects Taskforce of the Dutch Childhood Oncology Group is Dutch (not multiple countries) – can you verify this?	Thank you for pointing these out; we have made these corrections.
Peer Reviewer #1	Findings	The section on Guiding Question 4 (studies that assess strategies) is a lot stronger than the section on Guiding Question 2 (barriers) since it actually presents the findings so goes beyond just "counting" the literature.	The intervention studies are briefly summarized while the GQ1 and GQ2 studies are much more complex, we have tried to characterize the existing research.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #1	Findings	Overview of findings is well organized in context of Guiding Questions. The summary tables and figures are helpful in highlighting themes and limitations (scope and focus) of available literature/data. Several sections provide context from Key Informants that support relevance of findings or real-world experience that impact implementation/contributes to disparities. The results presented clearly highlight knowledge gaps that can guide research. Note -- there are other interventions through the Childhood Cancer Survivor Study that evaluated survivorship care service in context of specific outcomes (breast cancer cardiomyopathy, skin cancer) but are not mentioned (PMID: 21370417, PMID: 25366684. PMID: 25873142).	Thank you for bringing these studies to our attention, all have been added during the update search.
KI Reviewer #2	Findings	Findings: P8, L46: "A total of 88 citations from 127 publications..." should this be restated as "A total of 127 publications from 88 studies"?	This change has been made.
KI Reviewer #2	Findings	P10: General comment about discussion around GQ1: This section just seems to be counting up the # of studies without really commenting on what the findings were? Also, number of studies assumes all studies are of equal quality, weight, when one very large, well done study, may have much more significance than multiple smaller, less rigorous studies?	See comment above about the scope of a technical brief. We added text to the Next Steps (under population) regarding corroboration of the examination of disparities in smaller studies in comparison to the Childhood Cancer Survivor Study (CCSS).
KI Reviewer #2	Findings	P15-16: Ref 33 and 34 in Table 4 are about the same guideline / strategy (i.e., Children's Oncology Group LTFU Guidelines).	Although these citations are very similar, they are distinct so we have kept these separate for the purposes of GQ3.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #2	Findings	P20: Table 6's Ref 35 has a published paper that reviews what the study is about: https://urldefense.proofpoint.com/v2/url?u=https-3A__pubmed.ncbi.nlm.nih.gov_31862436_&d=DwICaQ&c=iLFkktpbVJiqSz07OUNw8-PWtGGtHBTxbUB7zsE1fFk&r=MnX-oEwwQQffF7oeSHII5GDUh9Iy9ecJ1kks7D9kEEY&m=wwm2Mg2led-CnGF7sm-CspQQMydb26b4N3KCVXYNX2g&s=Kp8Y-n71DxCylYOnQRHpMypYJ8v73ZNX8uCG19IjCs8&e=	Thank you. We have added the paper to the ref 35 and have abstracted the relevant information from it to the included study.
KI Reviewer #2	Findings	P23, L35/36: "However, many of the types of barriers faced by patients are not by any fault of their own." I think you should not even imply that some of these barriers could be the "fault" of the patient. Assigning fault/blame I think is not a good approach here.	Thank you for making this important point; we have removed this sentence.
Peer Reviewer #2	Findings	Clear and concise. Important findings.	Thank you.
Peer Reviewer #3	Findings	Page 8, lines 22/23 (Figure 1): Will the current exclusion of “waiting on pdf’s” be resolved in the final report?	Yes, this has been removed from the final report.
Peer Reviewer #3	Findings	Page 9, lines 37-44: Suggest revising the sentence on the primary themes of disparities to more clearly articulate the disparities that the Key Informants identified. In particular, what are the “issues related to racial/ethnic, sexual/gender and underserved minorities or groups”?	Thank you for this important feedback. We have addressed this comment on page 10 by revising the language used slightly to make what our KIs told us more clear.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Findings	Pages 10-11 and Figure 3: Throughout the findings from Guiding Question 1, recommend discussing the direction of the disparities so that it is clear what groups are experiencing disparities (e.g., minority race/ethnicity or specific race/ethnicity, specific biological sex, low socioeconomic status, low/lack of employment or insurance).	We agree that it would be helpful to discuss the direction of the disparity; however, that would require a formal systematic review of the presence and absence of associations. Most variables of interest have been addressed in multiple studies and results vary across studies, requiring a thorough analysis of the evidence. We have made the constraints of the technical brief clearer in the Purpose and Scope section.
Peer Reviewer #3	Findings	Page 11, line 48: What is meant by "a patient's dependence or independence in decision-making"?	This refers to patient autonomy. We have changed this term to make it more clear.
Peer Reviewer #3	Findings	Page 12, lines 30-34 and Figure 4: Were the barriers to care that impacted the health services and economic domain "lack of" knowledge of the need for life-long survivorship care, "lack of" trust in providers or medical community and "lack of" prioritization of survivorship care? Suggest specifying this in the text and figure.	No, these were not all barriers; they could have been facilitators depending on the study.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Findings	Page 13, lines 28-38 and Figure 5: This paragraph provides a nice overview of the Key Informant interviews. Figure 5 also notes the direction of the barriers as is recommended above for Figures 3 and 4.	We agree that it would be helpful to discuss the direction and magnitude of the disparity and barrier; however, that would require a formal systematic review of the presence and absence of associations. Most variables of interest have been addressed in multiple studies and results vary across studies, requiring a thorough analysis of the evidence. We have made the constraints of the technical brief clearer in the Purpose and Scope section
Peer Reviewer #3	Findings	Page 16, lines 14-16: Enhanced funding for pediatric cancer survivors, including the Childhood Cancer STAR Act and the Childhood Cancer Data Initiative, while important, doesn't present a more specific strategy to reduce barriers to care similar to the rest of the strategies in Table 4. Suggest just presenting this in the text of the technical report.	Thank you for alerting us to this, we have removed the reference.
Peer Reviewer #3	Findings	Page 16, lines 42-43: Suggest briefly noting strategies that the NCCN support to minimize the burden of disparities and alleviate barriers to care for CCS.	We have noted the barriers to care limitations of the NCCN Guidelines.
Peer Reviewer #3	Findings	Page 17, lines 40-41: How are these studies observational if they evaluated interventions?	We have revised the text to read that the observational studies were evaluating specific programs.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Findings	Page 17-18, Table 5/Figure 6: Given the focus on the survivorship care domain in Table 5, Figure 6 and Guiding Question 4, recommend adding some example strategies under each of the sub-domain headings in Table 5 or Figure 6. Also, it appears that studies additionally considered the other outcome domains: health services and economics (N = 10) and biomedical and psychosocial domains (N = 3, respectively); therefore, for consistency with other sections, shouldn't these outcomes be added to Table 5 and Figure 6?	Thank you for pointing this out. We have edited the figures for GQs 4 and 5 so that they fully map to the outcome domains.
Peer Reviewer #3	Findings	Pages 18-20: The section summarizing the findings of the studies evaluating strategies seems at odds with the goal of technical briefs to review and describe relevant studies, but not synthesize study results or often not even report the studies results at all. With the study details provided in more detail and referenced in Table D3 (please note that 'evaluated' is misspelled in the title of Table D3), I recommend revising this section to focus on a summary of the types of interventions undertaken to date. It would be helpful if the specific Appendix D Table was referenced here.	We have provided a synthesis of the studies reporting evaluating strategies to reduce disparities and barriers and describe the intervention. We wanted to provide helpful context about each of these strategies without going into too much detail.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Findings	Knowledge of late effects/health and/or survivorship care is an outcome in a number of the studies evaluating strategies, but is not included under any of the outcome domains considered in the technical brief (it is noted as a barrier). Should it be included as an intermediate outcome in the survivorship care domain?	For GQs 1 and 2, knowledge of survivorship care was included as part of the Survivorship Outcome Domain. For GQs 4 and 5, knowledge of survivorship care was included as 'other' because it did not fit well under the care domains of survivorship care plan, model of care, or survivorship care service. There were only two studies in GQ4 that examined this as the primary outcome, which is another reason it is categorized under other.
Peer Reviewer #3	Findings	Pages 20-21, Guiding Question 5: Were literature searches conducted to identify ongoing studies assessing strategies that targeted reducing disparities and barriers to the other outcome domains (biomedical, psychosocial or health services/economics)?	Yes, we were inclusive as possible. We searched research registries for ongoing studies but because researchers sometimes do not register their work, it can be difficult to locate.
Peer Reviewer #3	Findings	Page 22. It would be helpful if the specific Appendix D Table was referenced here.	We have added this.
KI Reviewer #3	Findings	Well laid out.	Thank you.
Peer Reviewer #4	Findings	This is excellent and effectively and concisely shares the findings of this great work. My only comment is regarding Figures 3-7. These figures have a lot of great information but it was not completely clear to this reader how to approach these figures to get the most out this information.	Thank you. We have added more information to the notes section of the figures.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #4	Findings	The findings were not surprising as we are aware that childhood cancer has been understudied and underserved. Though survival rates have gone up but more research and follow up as CCS adults need to conduct more research and findings for future generations.	Noted, thank you.
Francisco Espinoza (Public Reviewer)	Findings	Findings demonstrate a good emphasis on the disparities in survivorship care. Findings are tied back to the guiding questions which asked why are there disparities to adequate care and what strategies can be proposed to address these barriers. One field that would be benefit pediatric cancer survivors would be occupational therapy. Occupational therapy can offer a lot of support during treatment as well as after so that the children are properly taken care of in their recovery and long after. Sahin, Akel & Zarif (2017) give a good description of what occupational therapy has to offer including training in activities of daily living, education on energy conservation techniques, assistive technology and many more occupations. - Sahin, S., Akel, S., & Zarif, M. (2017). Occupational Therapy in Oncology and Palliative Care.D93 Occupational Therapy - Occupation Focused Holistic Practice in Rehabilitation. doi:10.5772/intechopen.68463	Thank you for making this important point. We have added text to state that occupational therapy can be used to promote desired outcomes.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Summary and Implications	Focus seems to be more on the number of studies identified rather than a synthesis of the findings. Some of this is addressed in section g (next steps), but there is an opportunity to enhance this section.	A valid synthesis would require a formal systematic review of the presence and absence of associations. Most variables of interest have been addressed in multiple studies and results vary across studies, requiring a thorough analysis of the evidence. We have made the constraints of the technical brief clearer in the Purpose and Scope section.
KI Reviewer #1	Summary and Implications	The summary underscores the existence disparities in survivorship care, contributors to disparities, and the dearth of research that has addressed/identified strategies to overcome disparities. While not specifically stated in a conceptual framework figure, the summary does identify the key barriers to address to overcome disparities at patient, provider, health care system, payer, family/caregiver level.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Summary and Implications	Authors concluded that they found evidence of disparities and barriers to survivorship care. I wonder if they would have found evidence of equity and studies of interventions aimed at achieving equity in survivorship care (as evidenced by an absence of differences in service utilization or health outcomes) if they had also conceived of "equity" as a viable construct for literature search. It is one thing to identify and evaluate studies demonstrating differences across groups; it is a different thing to look for studies in which absence of differences in desired outcomes are hypothesized to occur as a result of interventions intended to remove barriers. For example, could there be studies, now or in the future, demonstrating equity (no Black v White race differences in morbidities or mortality) when both groups received guideline concordant care at similar rates? The report is strong in terms of reporting on what the investigative team was looking for -- differences and barriers contributing to those differences – even though available studies were few and far between. However, reporting on or investing in studies of interventions that when applied equally across population sub-groups achieved NO DIFFERENCES in desired outcomes could also be enlightening, if in fact they exist.	We acknowledge and agree that reducing risk factors (and/or barriers) can be distinct from promoting protective factors (and/or facilitating factors). Each strategy can yield positive outcomes. We carefully reviewed report to ensure that we do not overstate that we have found evidence of disparities/barriers, have found research assessing disparities/barriers. It is worth noting that there are very few interventions focused on CCS. This goes beyond disparities among population groups, as care is inadequate for everyone.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Summary and Implications	Page 23, lines 14-25. Suggest noting both the direction of disparities and the consistency of findings.	A full systematic review of tracing each assessed disparity and the results of the findings across all studies was outside the scope of this Technical Brief but we have added more detail to the text.
Peer Reviewer #3	Summary and Implications	Page 23, line 45: Can the authors expand upon the following conclusion: "Most significant are barriers at the level of the provider"? Is this in comparison to the health system level?	We added examples to clarify this.
Peer Reviewer #3	Summary and Implications	Pages 23-24: The paragraph on proposed strategies for addressing those barriers nicely summarizes the important findings in this area. Suggest adding a similar level of detail to the paragraph discussing studies that have assessed these strategies (lines 19-25). For example, in addition to noting the number of studies and the level of barriers assessed, it would be helpful to summarize the strategies assessed (e.g., education).	We have added language to describe assessment of strategies.
Peer Reviewer #3	Summary and Implications	Page 24, lines 31-34: The authors should more specifically state what the imbalance refers to in the following sentence: "An imbalance was observed between the studies identifying disparities and barriers and studies aimed at overcoming these barriers and lessening disparities."	We edited this sentence to make it clearer.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Summary and Implications	Page 24, lines 43-48: As funding and the Childhood Cancer Star Act was mentioned earlier in the paragraph and at the beginning to of the report under Purpose of review, recommend removing the following sentences at the end of the paragraph ("-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"). In addition, recommend replacing "…and many other opportunities" (line 43) with more of the summarized recommendations of the key informants.	Thank you for pointing this out. We have made the suggested edits.
Peer Reviewer #3	Summary and Implications	Page 24, In addition to discussing ongoing studies, could the gaps in the published and unpublished studies that have assessed these strategies also be summarized in the future directions for research in addressing barriers to survivorship care section?	Yes, we have added more text to make this clearer.
Peer Reviewer #3	Summary and Implications	The PICOS (population, intervention, comparator, outcomes, and study design) framework is not discussed in this section.	Yes, it is part of the Next Steps section.
KI Reviewer #3	Summary and Implications	Well summarized.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Summary and Implications	Page 23 Line 19: Throughout the report, the "health services" and "economic" domains are mentioned frequently. To ensure that the reader clearly understands the implications of the summary and the most important issues, repeated clarification of what exactly do the authors mean with these terms could be helpful here.	Thank you for pointing this out. We have added text defining the categories and headings included in the figures.
Peer Reviewer #4	Summary and Implications	Page 23 Line 39-42: Please consider additional text in this sentence that illustrates how these two barriers were just as large in the literature as the lack of knowledge on their need for life-long survivorship care (which is emphasized as "one of the largest barriers" in the prior sentence but according to Figure 4 lack of adequate financial or employment resources was just as large of a barrier).	We have clarified this text to make this clearer.
KI Reviewer #4	Summary and Implications	The technical brief did a good job of showing the evidence and research described to showcase how CCS are being underserved and forgotten about. CCS's should have a better transition into adult survivorship and they should have better access to tools that can assist them to live a "normal life".	Thank you.
Francisco Espinoza (Public Reviewer)	Summary and Implications	Great summary of all the key points and answers to the guiding questions. Several studies are mentioned that answer the guiding questions.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Next Steps	This is the strongest section. I think it does a very good job of assessing the opportunities for improving the care of survivors. It provides a synthesis that is stronger than what is available in section (f).	Thank you.
KI Reviewer #1	Next Steps	I found the Next Steps section to be more of a summary of findings previously presented and generalities of the research needed to advance the field – evaluation of more diverse populations, evaluation of provider, healthcare system and payer barriers, etc.. Perhaps this is appropriate considering the limited data available to guide more specific recommendations.	Thank you for pointing this out. We have summarized the Summary and Implications section and enhanced the Next Steps.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #2	Next Steps	P25, L17-19: "More specifically, the CCSS has had historically low representation of racial or ethnic minorities." I'm not sure this statement is entirely accurate, and is easily misinterpreted. The representation of minorities in CCSS reflects the less diverse composition of children in the US from the 1970s-90s vs. now (https://urldefense.proofpoint.com/v2/url?u=https-3A__pubmed.ncbi.nlm.nih.gov_27253866_&d=DwICaQ&c=iLFkktpbVJiqSz07OUNw8-PWtGGtHBTxbUB7zsE1fFk&r=MnX-oEwwQQffF7oeSHII5GDUh9Iy9ecJ1kks7D9kEEY&m=wwm2Mg2led-CnGF7sm-CspQQMydb26b4N3KCVXYNX2g&s=B5udx0ouh1wL5DznID-TiaVt6xcpLpcEIwLPJbC3KdY&e=). I think it may be more accurate to say that "More specifically, the proportion of racial or ethnic minorities in the CCSS reflects the composition of the US population from the 1970s-1990s, and that population has greatly diversified in the past 20 years."	Thank you for suggesting clarification to this statement; we have adopted the suggested changes and cited the Bhatia, 2016 position paper from the CCSS.
KI Reviewer #2	Next Steps	P26, L40-41: "assessment of alleviating or decreasing..." this seems awkwardly phrased. Is "assessment of" needed?	Agree, this is awkwardly phrased; we have edited this to make it clearer.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Next Steps	Finally, with regard to Next Steps, the authors suggest the importance of investing in and testing interventions that address barriers. I would argue that we also need to invest in and test interventions that promote conditions that are known or expected to achieve desired outcomes. For example, emerging literature on peer support and its positive effect on outcomes could also be a viable next step. By focusing only on barriers and strategies to reverse negative outcomes (e.g., disparities) we might miss the opportunity to further enhance and promote strategies that advance equity.	This is an excellent point. We have added a paragraph to the end of the outcomes section of Next Steps.
Peer Reviewer #3	Next Steps	Page 25, line 12: Define CCSS.	We have made this correction.
Peer Reviewer #3	Next Steps	Page 25, line 19: Suggest stating what types of survivorship care are represented in the CCSS.	We have examples of the scope of survivorship care that has been represented in the CCSS publications.
Peer Reviewer #3	Next Steps	Page 25, lines 45-47: In the last paragraph of the population section, the authors state that: "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." Recommend that the authors expand this paragraph to discuss what should be done to move knowledge forward in this area.	This is an excellent point; we have added this content at the end of the Population section of Next Steps.
Peer Reviewer #3	Next Steps	Page 26, line 30: Please specify the alternative models that merit examination.	We have added an example of an alternative model that may be useful to study in the future.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Next Steps	Page 26, lines 30-37: Given that it is difficult to decipher the best approach for comparator groups across all studies, what do the authors recommend in terms of next steps and over-coming these challenges? For example, should comparators be considered both within and across different healthcare delivery systems?	Thank you for pointing out this shortcoming. We have added some language to clarify the ideal comparator groups.
Peer Reviewer #3	Next Steps	Page 26, lines 41-44: In the discussion of outcomes, the authors state that alleviating or decreasing some of the more practical or logistic aspects of barriers to care warrant further investigation. Which outcome(s) is this next step recommended for?	This could affect multiple outcomes.
Peer Reviewer #3	Next Steps	Page 26, lines 49-50: Suggest that the authors be more specific in their recommendation that "further investigation may be warranted." What should be done to move knowledge forward in this area.	Thank you; we have incorporated some clarifying language to explain this more.
KI Reviewer #3	Next Steps	Well elaborated	Thank you.
Peer Reviewer #4	Next Steps	Page 26 Line 29-37: This is an excellent point about the complexities of the typical health care system and how this impacts future research. Exploration of the benefits of using health systems science and related expertise may align nicely with the next step of interventions.	Thank you.

Commentator & Affiliation	Section	Comment	Response
KI Reviewer #4	Next Steps	Interventions into disparities would be helpful so that CCS can have a better quality of life and access to healthcare as needed. Having a child with cancer survive is wonderful, but if life is forever altered and they are left in the dark or without the necessary resources, they may not be able to rejoin society and their peers on the level deserved.	Thank you for pointing this out. We have added text in the next steps to make the importance of designing studies with careful attention paid to comparator groups and intervention design.
Francisco Espinoza (Public Reviewer)	Next Steps	There is a good description of how survivorship is impacted by the social determinants of health. However, there is still more research needed that represents ethnic minorities so that we can get a more accurate picture of why the disparities exist.	This is a good point, especially since most of the research has taken place within the CCSS, a largely white, non-Hispanic cohort. We have added a sentence and clarified some of the language used in the second paragraph of the population section (in Next Steps) to highlight racial/ethnic disparities.
Francisco Espinoza (Public Reviewer)	Did you find this report unnecessarily difficult to read?	Not at all.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Francisco Espinoza (Public Reviewer)	Could you find and understand the results and conclusions ?	The results and conclusions were clear and easy to understand.	Thank you.
Peer Reviewer #4	Clarity and Usability	The only thing I would request the authors clarify further is how Figures 3-7 work (eg. how best a reader should approach these Figures to get the most out of them).	Thank you, we have added descriptive text to explain the figures throughout the findings section.
KI Reviewer #4	Clarity and Usability	For someone who is in communication and writing, it was easier to read the report and findings and harder to understand the diagrams showing research studies. They did a good job explaining the formulas but unless your brain operates like that, it is hard to follow.	Thank you.