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Our specific comments below are on behalf of Children's Cancer Cause regarding the Agency for Healthcare Research and Quality (AHRQ) technical brief that 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. Our comments are presented in bold.

- 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.**
- 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.**
- 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.**
 - **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.**
 - **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.**
 - **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 appreciate your work to develop a thorough and comprehensive report which will help move the childhood cancer survivorship policy agenda forward. We look forward to working with you on these issues and others related to improving care for childhood cancer survivors. If you should have questions please contact Susan Emmer at sue@emmerconsultinginc.com.

Best –

A handwritten signature in black ink that reads "George Dahlman".

George Dahlman