



Topic Brief: Childhood Cancer Care Transition: Implementation of the Children's Oncology Group Long- Term Follow-Up Guidelines

Date: 5/5/2023

Nomination Number: 1030

Purpose: This document summarizes the information addressing a nomination submitted on December 16, 2022 ([link to nomination](#)) through the Effective Health Care Website. This information was used to inform the Evidence-based Practice Center (EPC) Program decisions about whether to produce an evidence report on the topic, and if so, what type of evidence report would be most suitable.

Issue: The nominator is concerned about difficulties in implementing the Children's Oncology Group (COG) Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers and the impact on health outcomes. For this reason, they are requesting a review on strategies to promote guideline implementation.

Program Decision: We identified too few studies to inform a new systematic review. The program will not consider this nomination further.

Findings

We identified four relevant studies on implementing portions of the COG Long-term Follow-up Guidelines.

Background

Childhood cancer survivors (CCS) face many challenges regarding long-term health outcomes, many of which are poorly understood or unknown.¹ Despite gains in survival, CCS are at risk for adverse physical, psychosocial, and behavioral outcomes. These late effects could 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. Follow-up and surveillance are key components of care after the treatment of cancer.

In 2018, the COG developed Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers.² These are designed for use in asymptomatic childhood, adolescent, and young adult survivors presenting for routine health maintenance at least 2 years after completion of cancer-directed therapy (e.g., surgery, chemotherapy, radiation, immunotherapy), whether the survivor is receiving care in a pediatric cancer center, a specialized adolescent-young adult program, an adult-focused oncology program, a long-term follow-up program, or community primary care practice. The guidelines are not designed for primary cancer-related surveillance.

In a recent Agency for Healthcare Research and Quality (AHRQ) technical brief, one of the barriers to pediatric cancer survivorship care included a lack of knowledge or comfort regarding follow-up care guidelines and/or recommended care.¹ A recent retrospective analysis at a healthcare organization found that adherence was 50 percent.³ For this reason the nominator is interested in ways to increase implementation of the guideline recommendations in practice.

The nominator is an advocacy group for pediatric cancer. Their original nomination was around development of guidelines for long-term follow-up for survivors of pediatric cancer. After discussion with the nominator around the scope of AHRQ and the EPC Program, they felt that a review focused on implementation of the widely known COG’s Long-term Follow-up Guidelines would be useful.

Scope

Contextual question: To what extent are the 2018 Children’s Oncology Group (COG) Long-term Follow-up guidelines followed in the primary care setting, including patients receiving recommended follow-up screenings, particularly for secondary cancers, cardiac late effects, and hearing loss?

Question 1: What implementation strategies and tools (i.e., a treatment summary, survivorship care plan, follow-up visits, and other recommended surveillance) have been used to implement the COG long-term follow-up guidelines for pediatric cancer?

- Does implementation of the guidelines vary depending on patient factors such as geography, socioeconomic status, race, or healthcare delivery factors?

Assessment Methods

See Appendix A.

Summary of Literature Findings

We identified one in-progress systematic review though it was not specific to guidelines for long-term follow-up.⁴ We found 2 studies the evaluated adherence to the COG long-term follow-up guidelines.^{5,6} We identified 4 studies on different strategies to implement specific recommendations in the COG long-term follow-up guidelines. Recommendations included colorectal cancer screening,⁷ surveillance generally,⁸⁻¹⁰ and surveillance for cardiac dysfunction.¹¹ Strategies included mHealth,⁷ web-based CDS,¹⁰ models of care,⁸ electronic personal health record,⁹ and survivorship care clinic.¹¹

Key question	Systematic reviews (February 2020-February 2023)	Study publications (February 2020-February 2023)
1. Implementation strategies	Total - 1 <ul style="list-style-type: none"> • AHRQ - 0 • Cochrane – 0 • Pubmed - 0 • PROSPERO - 1⁴ 	Total-5 <ul style="list-style-type: none"> • RCT⁹ • hybrid type II effectiveness and implementation⁷ • retrospective cohort^{8, 11} • Cross-sectional¹⁰

See Appendix B for detailed assessments of all EPC selection criteria.

Summary of Selection Criteria Assessment

While this is an important topic, we found too few studies to inform a new systematic review.

Please see Appendix B for detailed assessments of individual EPC Program selection criteria.

Other resources

We found some publications that may be of use to the nominator:

- Mobley EM, et al. Disparities and Barriers to Pediatric Cancer Survivorship Care. Technical Brief No. 39. (Prepared by the Southern California Evidence-based Practice Center under Contract No. 75Q80120D00009.) Rockville, MD: Agency for Healthcare Research and Quality; March 2021.
DOI: <https://www.doi.org/10.23970/AHRQEPCTB39>.
 - [Posted final reports](#) are located on the Effective Health Care Program search page.
- Parsons HM, et al. Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs. Comparative Effectiveness Review No. 255. (Prepared by the Minnesota Evidence-based Practice Center under Contract No. 75Q80120D00008.) AHRQ Publication No. 22-EHC027. Rockville, MD: Agency for Healthcare Research and Quality; May 2022.
DOI: <https://doi.org/10.23970/AHRQEPCCER255>.
 - [Posted final reports](#) are located on the Effective Health Care Program
- van Kalsbeek RJ, et al. The PanCareFollowUp Care Intervention: A European harmonised approach to person-centred guideline-based survivorship care after childhood, adolescent and young adult cancer. *Eur J Cancer*. 2022 Feb;162:34-44.
DOI: <https://doi.org/10.1016/j.ejca.2021.10.035>. Epub 2021 Dec 22. PMID: 34953441.
- Philips. Implementation science in pediatric oncology: A narrative review and future directions. <https://onlinelibrary.wiley.com/doi/10.1002/pbc.29579>

References

1. Mobley EM, Moke DJ, Milam J, et al. Disparities and Barriers to Pediatric Cancer Survivorship Care. Rockville (MD); 2021.
2. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. 2018. <http://www.survivorshipguidelines.org/>
3. Benedict C, Wang J, Reppucci M, et al. Cost of survivorship care and adherence to screening-aligning the priorities of health care systems and survivors. *Transl Behav Med*. 2021 Feb 11;11(1):132-42. doi: 10.1093/tbm/ibz182. PMID: 31907549.
4. Bora A-M PV, Kreuzberger N, Skoetz N. . The effectiveness of clinical guideline implementation strategies in oncology: a systematic review. . 2021.
https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021268593.
5. Yan AP, Chen Y, Henderson TO, et al. Adherence to Surveillance for Second Malignant Neoplasms and Cardiac Dysfunction in Childhood Cancer Survivors: A Childhood Cancer Survivor Study. *J Clin Oncol*. 2020 May 20;38(15):1711-22. doi: 10.1200/jco.19.01825. PMID: 32142393.
6. Reppucci ML, Schleien CL, Fish JD. Looking for trouble: Adherence to late-effects surveillance among childhood cancer survivors. *Pediatr Blood Cancer*. 2017 Feb;64(2):353-7. doi: 10.1002/pbc.26205. PMID: 27578608.

7. Henderson TO, Bardwell JK, Moskowitz CS, et al. Implementing a mHealth intervention to increase colorectal cancer screening among high-risk cancer survivors treated with radiotherapy in the Childhood Cancer Survivor Study (CCSS). *BMC Health Serv Res.* 2022 May 23;22(1):691. doi: 10.1186/s12913-022-08082-3. PMID: 35606736.
 8. Kagramanov D, Sutradhar R, Lau C, et al. Impact of the model of long-term follow-up care on adherence to guideline-recommended surveillance among survivors of adolescent and young adult cancers. *Cancer Med.* 2021 Aug;10(15):5078-87. doi: 10.1002/cam4.4058. PMID: 34128353.
 9. Escoffery C, Gilleland Marchak J, Haardörfer R, et al. Scalability of cancer SurvivorLink™: A cluster randomized trial among pediatric cancer clinics. *Contemp Clin Trials.* 2019 Oct;85:105819. doi: 10.1016/j.cct.2019.105819. PMID: 31400518.
 10. King JE, O'Connor MC, Shohet E, et al. Clinician perceptions of Passport for Care, a web-based clinical decision support tool for survivorship care plan delivery. *Pediatr Blood Cancer.* 2023 Jan;70(1):e30070. doi: 10.1002/pbc.30070. PMID: 36326111.
 11. Marr KC, Agha M, Sutradhar R, et al. Specialized survivor clinic attendance increases adherence to cardiomyopathy screening guidelines in adult survivors of childhood cancer. *J Cancer Surviv.* 2017 Oct;11(5):614-23. doi: 10.1007/s11764-017-0634-z. PMID: 28785871.
 12. Childhood Cancers. Bethesda, MD: National Cancer Institute 2022. <https://www.cancer.gov/types/childhood-cancers#:~:text=Research-Types%20of%20Cancer%20in%20Children,to%20die%20from%20the%20disease>. Accessed on 5/5/2023 2023.
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Author

Christine Chang

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Appendix A: Methods

We assessed nomination for priority for a systematic review or other AHRQ Effective Health Care report with a hierarchical process using established selection criteria. Assessment of each criteria determined the need to evaluate the next one. See Appendix B for detailed description of the criteria.

Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

Desirability of New Review/Absence of Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years February 8, 2020 – February 8, 2023, on the questions of the nomination from these sources:

- AHRQ: Evidence reports and technology assessments
 - AHRQ Evidence Reports <https://www.ahrq.gov/research/findings/evidence-based-reports/index.html>
 - EHC Program <https://effectivehealthcare.ahrq.gov/>
 - US Preventive Services Task Force <https://www.uspreventiveservicestaskforce.org/>
 - AHRQ Technology Assessment Program <https://www.ahrq.gov/research/findings/ta/index.html>
- Cochrane Systematic Reviews <https://www.cochranelibrary.com/>
- PROSPERO Database (international prospective register of systematic reviews and protocols) <http://www.crd.york.ac.uk/prospere/>
- PubMed <https://www.ncbi.nlm.nih.gov/pubmed/>

Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc.).

Feasibility of New Evidence Review

We conducted a limited literature search in PubMed for the last five years February 8, 2018 - February 8, 2023. We reviewed all studies identified titles and abstracts for inclusion.

History and Search Details

Search	Actions	Details	Query	Results	Time
#13			Search: #12 NOT #8	0	17:33:41
#12			Search: #11 AND (2017:2023[pdat])	2	17:33:34
#11			Search: ("Children s Oncology Group"[tiab] OR "Childrens Oncology Group"[tiab]) AND (guidelines OR recommendations) AND (telemedicine OR telehealth)	4	17:32:22
#10			Search: #9 AND ("Children s Oncology Group"[tiab] OR "Childrens Oncology Group"[tiab]) AND (guidelines OR recommendations)	0	17:25:08
#9			Search: "practice facilitation"[tiab] OR "practice improvement"[tiab] OR "increasing utilization"[tiab] OR "increasing adherence"[tiab] OR "practice strategies"[tiab] OR "practice strategy"[tiab]	3,265	17:24:53
#8			Search: #5 OR #7	40	17:10:48
#7			Search: #6 AND (2017:2023[pdat])	17	17:00:23
#6			Search: ("Children s Oncology Group"[tiab] OR "Childrens Oncology Group"[tiab]) AND (guidelines OR recommendations) AND (Implementation Science[mesh] OR Health Plan Implementation[mesh] OR implementation OR tool*[tiab])	32	17:00:10
#5			Search: #2 OR #4	26	16:59:30
#4			Search: #3 AND (2017:2023[pdat])	20	16:59:24
#3			Search: ("Children s Oncology Group"[tiab] OR "Childrens Oncology Group"[tiab]) AND ("use guidelines"[tiab:~3] OR "use recommendations"[tiab:~3] OR "using guidelines"[tiab:~3] OR "using recommendations"[tiab:~3] OR "usage guidelines"[tiab:~3] OR "usage recommendations"[tiab:~3] OR "utilization guidelines"[tiab:~3] OR "utilization recommendations"[tiab:~3] OR "utilizing guidelines"[tiab:~3] OR "utilizing recommendations"[tiab:~3] OR "following guidelines"[tiab:~3] OR "following recommendations"[tiab:~3] OR "follow guidelines"[tiab:~3])	66	16:59:14
#2			Search: #1 AND (2017:2023[pdat])	12	16:59:03
#1			Search: ("Children s Oncology Group"[tiab] OR "Childrens Oncology Group"[tiab]) AND ("follow up"[tiab] OR followup[tiab] OR Aftercare[mesh] OR aftercare OR Cancer Survivors[mesh] OR survivors OR survivorship) AND (adherence OR Guideline Adherence[mesh] OR compliance) AND (guidelines OR recommendations)	25	16:55:53

Appendix B. Selection Criteria Assessment

Selection Criteria	Assessment
1. Appropriateness	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the United States?	Yes.
1b. Is the nomination a request for an evidence report?	Yes.
1c. Is the focus on effectiveness or comparative effectiveness?	Yes
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes.
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	In the United States in 2022, an estimated 10,470 new cases of cancer will be diagnosed among children from birth to 14 years, and about 1,050 children are expected to die from the disease. Although cancer death rates for this age group have declined by 71 percent from 1970 through 2019, cancer remains the leading cause of death from disease among children. The most common types of cancer diagnosed in children ages 0 to 14 years are leukemias, brain and other central nervous system tumors, and lymphomas. ¹²
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the United States population or for a vulnerable population	Yes
2c. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2d. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes
3. Desirability of a New Evidence Review/Absence of Duplication	
3. A recent high-quality systematic review or other evidence review is not available on this topic	We identified no systematic reviews or scoping reviews addressing the nomination question. We identified an in-progress systematic review but it was not specific to COG long-term follow-up guidance.
4. Impact of a New Evidence Review	
4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)?	Yes, it is not clear how best to implement COG guidelines in practice.
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Yes.
5. Primary Research	
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review	We identified five relevant studies, all studying different types of interventions.

- Newly available evidence (particularly for updates or new technologies)	
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Abbreviations: COG=Children's Oncology Group.