



# Topic Brief: Electronic Health Records for Childhood Cancer Survivors

**Date:** 3/2/2023

**Nomination Number:** 1031

**Purpose:** This document summarizes the information addressing a nomination submitted on November 15, 2022, 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:** Childhood cancer survivors have specific care needs and often do not receive a plan for care following cancer treatment. Electronic Health Records (EHRs) could be a way to communicate information for the successful transition from oncology to primary care. The nominators are interested in the best practices for using EHRs to communicate information to facilitate the care transition. [Nomination](#).

**Findings:** The program will not develop an evidence synthesis product because the nominator is no longer requesting the product.

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## Background

In 2019, there were an estimated 16.9 million cancer survivors in the United States, and, in 2018, at least 483,000 were first diagnosed when they were younger than 20 years old.<sup>1</sup> From 2008 to 2010, the annual cost of care for cancer survivors ages 18 to 64 was \$16,213 per survivor.<sup>2</sup> While little evaluation of the financial impact on young adults and their families has been conducted, this population is particularly vulnerable to the financial burden of cancer care.<sup>3</sup> Additional burdens for young adult cancer survivors may include anxiety about cancer recurrence, fatigue, depression,<sup>4</sup> fertility issues,<sup>5</sup> and difficulties securing assistance to address their health and supportive care needs.<sup>4</sup> Harms due to treatment may also include premature or accelerated aging due to chemotherapy, and radiation-induced second cancers and cardiovascular disease.<sup>6</sup>

Despite the specialized needs of this population, many do not receive long-term follow-up for the screening, prevention, and treatment of late effects.<sup>7</sup> Electronic health records (EHRs) could potentially facilitate the transfer of information from oncologist to primary care provider that could aid in the provision of follow-up care. An EHR is a digital version of a patient's paper chart that contains the medical and treatment histories of a patients and can provide a broad view of a patient's care. Advantages include providing access to evidence-based tools that providers can use to make decisions about a patient's care, and allowing for automation and streamlining of provider workflow.<sup>8</sup> In 2021, nearly 88% of office-based physicians in the United States were using EHRs.<sup>9</sup> The nominators are interested in best practices for using EHRs to facilitate the effective transfer of information to ensure follow-up care for childhood cancer survivors.

## Nominator Engagement

We reached out to the nominator to discuss their concerns and rationale for the nomination. The nominators plan to resubmit a nomination taking into account an AHRQ/NIDDK study: [Implementation of an Electronic Care Plan for People with Multiple Chronic Conditions Digital Healthcare Research \(ahrq.gov\)](#). For this reason, they have withdrawn this nomination from further consideration.

## Assessment Methods

We assessed nomination for priority for a systematic review or other AHRQ EHC report with a hierarchical process using established selection criteria. Assessment of each criteria determined the need to evaluate the next one.

1. Determine the *appropriateness* of the nominated topic for inclusion in the EHC program.
2. Establish the overall *importance* of a potential topic as representing a health or healthcare issue in the United States.
3. Determine the *desirability of new evidence review* by examining whether a new systematic review or other AHRQ product would be duplicative.
4. Assess the *potential impact* a new systematic review or other AHRQ product.
5. Assess whether the *current state of the evidence* allows for a systematic review or other AHRQ product (feasibility).
6. Determine the *potential value* of a new systematic review or other AHRQ product.

## References

1. Childhood Cancer Survivor Study: An Overview. National Cancer Institute. doi: <https://www.cancer.gov/types/childhood-cancers/ccss>.
2. Guy GP, Jr., Ekwueme DU, Yabroff KR, et al. Economic burden of cancer survivorship among adults in the United States. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2013;31(30):3749-57. doi: <https://doi.org/10.1200/JCO.2013.49.1241>. PMID: 24043731.
3. Salsman JM, Danhauer SC, Moore JB, et al. Systematic review of financial burden assessment in cancer: Evaluation of measures and utility among adolescents and young adults and caregivers. *Cancer*. 2021 Jun 1;127(11):1739-48. doi: <https://doi.org/10.1002/ncr.33559>. PMID: 33849081.
4. Jones JM, Fitch M, Bongard J, et al. The Needs and Experiences of Post-Treatment Adolescent and Young Adult Cancer Survivors. *Journal of clinical medicine*. 2020;9(5):1444. doi: <https://doi.org/10.3390/jcm9051444>. PMID: 32413981.
5. Hydeman JA, Uwazurike OC, Adeyemi EI, et al. Survivorship needs of adolescent and young adult cancer survivors: a concept mapping analysis. *J Cancer Surviv*. 2019 Feb;13(1):34-42. doi: <https://doi.org/10.1007/s11764-018-0725-5>. PMID: 30604138.
6. Shapiro CL. Cancer Survivorship. *N Engl J Med*. 2018 Dec 20;379(25):2438-50. doi: <https://doi.org/10.1056/NEJMra1712502>. PMID: 30575480.
7. Mouw MS, Wertman EA, Barrington C, et al. Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *J Adolesc Young Adult Oncol*. 2017 Mar;6(1):111-9. doi: 10.1089/jayao.2016.0035. PMID: 27486707.
8. HealthIT.gov. doi: <https://www.healthit.gov/faq/what-electronic-health-record-ehr>.
9. Quick Stats. HealthIT.gov. doi: <https://www.healthit.gov/data/quickstats#:~:text=As%20of%202021%2C%20nearly%209,office%2Dbased%20physician%20adoption%20of%E2%80%A6>.

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**Conflict of Interest:** None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

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