Proposal to the Agency for Healthcare Research and Quality Effective Health Care Program (submitted via online form June 5)

1. What is the decision or change (e.g., clinical topic, practice guideline, system design, delivery of care) you are facing or struggling with where a summary of the evidence would be helpful?

Electronic health records and related tools (eHealth) are used routinely for survivors of childhood cancer. These tools are a critical component of survivorship care planning and inform patients, caregivers, primary care physicians and other healthcare specialists. Cost-effective and high-quality electronic and mobile health tools have the potential to substantially improve long-term survivorship care because their systems are dynamic to allow current display, updating, and rapid access. As noted in a recent article by Marchak, et al.[1], both the National Academy of Medicine and Children's Oncology Group (COG) recommended that survivors participate in continuous, risk-based survivor care across the lifespan to monitor for late effects of their previous cancer treatments.[2],[3] The Marchak article also pointed out that "Facilitating healthcare transition and eventual transfer of risk-based survivor care from pediatric to adult settings is critical to the long-term health of childhood cancer survivors since their morbidity and mortality risks increase significantly over time and do not reach a plateau."[4] [5] [6] In addition, a literature review in the *Journal of Pediatric Nursing* concluded that there is "evidence that a structured [health care transitions] process for

[1] Marchak JG, Sadak KT, Effinger KE, Haardörfer R, et al. Transition practices for survivors of childhood cancer: A report from the Children's Oncology Group. Research Square (preprint). 2022 Nov 4. https://doi.org/10.21203/rs.3.rs-2042808/v1.

[2] Children's Oncology Group. (October 2018). Long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancers. Version 5.0. Monrovia, CA.

[3] Institute of Medicine and the National Research Council. From cancer patient to cancer survivor: lost in transition. Hewitt M, Greenfield, S., Stovall E., eds., editor. Washington, DC: National Academies Press; 2006.

[4] Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Friedman DL, Marina N, Hobbie W, Kadan-Lottick NS, Schwartz CL, Leisenring W, Robison LL. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med. 2006;355(15):1572-82. doi:10.1056/NEJMsa060185. PubMed PMID: 17035650; PMCID: Unavailable.

[5] Hudson MM, Ness KK, Gurney JG, Mulrooney DA, Chemaitilly W, Krull KR, Green DM, Armstrong GT, Nottage KA, Jones KE, Sklar CA, Srivastava DK, Robison LL. Clinical ascertainment of health outcomes among adults treated for childhood cancer. JAMA. 2013;309(22):2371-81. doi: 10.1001/jama.2013.6296. PubMed PMID: 23757085; PMCID: PMC3771083.

[6] Mertens AC, Liu Q, Neglia JP, Wasilewski K, Leisenring W, Armstrong GT, Robison LL, Yasui Y. Cause specific late mortality among 5-year survivors of childhood cancer: the Childhood Cancer Survivor Study. J Natl Cancer Inst. 2008;100(19):1368-79. doi: 10.1093/jnci/djn310. PubMed PMID: 18812549; PMCID: 2556702.

youth with special health care needs can show improvements in adherence to care, disease-specific measures, quality of life, self-care skills, satisfaction with care, health care utilization, and HCT process of care."[7]

There is a growing interest in using digital technologies to mitigate late effects in childhood cancer survivors. Cancer patients and survivors report positive attitudes towards eHealth tools for care management, preferring eHealth tools that enable active and frequent self-monitoring and more convenient survivorship care delivery. The Children's Cancer Cause is proposing that AHRQ produce an environmental scan of eHealth tools that providers use to collect the information needed for the successful transition from oncology to primary care. An accessible, comprehensive list of eHealth summaries and tools for patients, their caregivers, and providers will enable health professionals to streamline care coordination as patients move through the continuum of care.

The Childhood Cancer STAR Reauthorization Act[8], passed into law in late 2022, authorizes funding to the Department of Health and Human Services to award grants to entities for reviewing childhood cancer survivorship and to "design tools to support the secure electronic transfer of treatment information and care summaries between health care providers." AHRQ should supplement this effort by producing a comprehensive list of such tools through an environmental scan.

The AHRQ environmental scan would collect and catalogue data on active electronic record keeping tools used for survivors of childhood cancer, including a characterization of those programs by factors such as sponsoring entity, target audience, program objectives, delivery method, duration, scalability, and cost. Recommendations for revised or additional tools might be included. The ultimate goal is a comprehensive report that would form the basis of a user-friendly database and resource for patients and caregivers.

In summary, the Children's Cancer Cause requests that the environmental scan examine the barriers and challenges survivors face in receiving appropriate and timely electronic information regarding survivorship issues following the conclusion of their active oncological care. Included would be primary care-based strategies aimed at providing evidence-based survivorship care through electronic means. Further, the environmental scan would conclude with suggestions for future investigation and a discussion of implications for policymakers. The proposed scan would include a review of relevant published literature as well as "gray" literature on efforts that may not be found in the peer-reviewed articles. Finally, AHRQ should highlight existing model health care practices that are promising and scalable.

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[7] Schmidt A, Ilango SM, McManus, MA, Rogers KK, White P. Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review. Journal of Pediatric Nursing. https://doi.org/10.1016/j.pedn.2020.01.002.

[8] Childhood Cancer Survivorship, Treatment, Access, and Research Reauthorization Act of 2022 (PL 117-350). https://www.congress.gov/bill/117th-congress/senate-bill/4120/text.

2. Why are you struggling with this issue?

Children are living longer with cancer. According to a 2020 study, there are nearly 500,000 survivors of childhood and adolescent cancer (diagnosed at ages 0 to 19 years) who are alive in the United States today[9]. Despite these advances, pediatric cancer survivors face a lifetime of numerous, complex health issues, which are often severe and potentially life-threatening.[10] [11] However, primary care physicians (pediatricians, internists, family medicine physicians, osteopaths, etc.) often are not knowledgeable about the consequences of cancer and its treatment and the evidence-based follow-up care recommendations of the Children's Oncology Group Long-term Follow-Up Care Guidelines.

In addition, survivors in many instances do not receive explicit guidance – a survivorship care plan – from treating oncologists on how to monitor and manage survivors' late effects. Survivors are often unaware about their ongoing and future needs and lack the information to anticipate and manage their care. While it is becoming more common for survivors to receive a treatment summary and survivorship care plan, providing a plan is not enough to secure quality care since these plans are often static and not easy for survivors, caregivers, and primary care physicians to interpret or act upon. Further, there is typically no formal transition from oncologist to primary care physician, and minimal care coordination even when transitions occur.

A 2020 GAO report found that lack of knowledge was among the key reasons survivors did not receive appropriate follow-up care. The report also highlighted a study suggesting that "receiving reminders about needed care can increase survivors' adherence to appointments."[12] Electronic survivorship tools can deliver these reminders to survivors and help them receive the care they need.

3. What do you want to see changed? How will you know that your issue is improving or has been addressed?

Developing an environmental scan of e-health tools use for survivorship care planning and transitions to primary care will help educate the childhood cancer community - providers and consumers - about the short and long-term needs of survivors. It will also likely improve the implementation of survivorship care services and minimize variations in care. Tools like Passport for Care[13] use the Children's Oncology Group (COG) guidelines to provide information on the type and scope of cancer treatments to the survivor in a secured database. Passport for Care is a clinical decision support tool that

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[9] Howlader N, Noone AM, Krapcho M, et al. (eds). SEER Cancer Statistics Review, 1975–2018, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2018/, based on November 2020 SEER data submission, posted to the SEER web site, April 2021. (also cited here: https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#r1).

[10] https://cac2.org/interest-groups/awareness/childhood-cancer-fact-library/.

[11] Bhakta, Nickhill, et al. "The Cumulative Burden of Surviving Childhood Cancer: An Initial Report from the St Jude Lifetime Cohort Study (SJLIFE)." The Lancet, vol. 390, no. 10112, 2017, pp. 2569–2582. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31610-0/fulltext.

[12] https://www.gao.gov/products/gao-20-636r.

[13] https://www.passportforcare.org/en/.

generates a guidelines-informed Survivorship Care Plan from clinician user-entered treatment exposures. This personalized Survivorship Care Plan (treatment summary, exposure-based risk for late effects, and recommended surveillance) is stored with the treating clinic, automatically updated with each revision to the guidelines, and can be shared with the survivor and his or her family via login access through the dual language Passport for Care Survivor Website portal and subsequently shared with other medical providers. SurvivorLink™[14] serves as a patient-centric tool that provides survivors with a secure repository to upload and organize key health-related documents (test results, imaging, care summaries, etc.) in an online health record, and a mechanism for survivors to share their online health record with providers for their ongoing care. Dissemination and uptake of these available services remains a challenge. For example, despite being used in about half of all Children's Oncology Group Long Term Survivor clinics (~160 clinics and hospitals worldwide), Passport for Care only serves about 10% of survivors living in the U.S. (~50,000 individual survivor accounts).

An environmental scan of such tools by AHRQ will facilitate identification of gaps in the currently available resources for survivors, support augmenting resource accessibility and uptake through potential policy changes and identify opportunities for innovation and collaboration.

4. When do you need the evidence report?

We request the evidence report by the end of 2024.

5. What will you do with the evidence report?

The AHRQ evidence report of an environmental scan will further the Children's Cancer Cause public policy efforts as well as facilitating education efforts among providers. Ultimately, we hope to use the report to encourage and increase the use of electronic tools in survivorship care planning for children and adolescents moving from active oncological care to primary care.

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[14] https://cancersurvivorlink.org/.