Topic Brief: Transition of Care Tools for Childhood Cancer Survivors

Date: 1/5/2024
Nomination Number: 1055

Purpose: This document summarizes the information addressing a nomination submitted on June 3, 2023, through the Effective Health Care Website (link to nomination). 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: As survivors of childhood cancer are living longer, they often face unique, life-long health challenges in adulthood that require ongoing surveillance. As these patients transition from pediatric oncology to primary care, the importance of information transfer between different doctors, and between doctors and patients, is paramount. Using electronic health records and related digital tools as part of these processes may improve the care transitions, thus improving patient outcomes over time. For this reason, the nominator is interested in receiving an environmental scan of eHealth and other tools that are used for childhood cancer survivors care planning and transitions to primary care.

Findings: The scope of this topic met all EHC Program selection criteria and was considered for a technical brief. However, it was not selected.

───

Background

In 2022, there were an estimated 18.1 million cancer survivors in the United States, and as of 2020 nearly 496,000 were first diagnosed when they were younger than 20 years old.[1] While more information is needed regarding the financial impact for childhood cancer survivors and their families, this population is particularly vulnerable to the financial burden of cancer care.[2] A recent analysis found that the economic and human costs of cancer in adolescent and young adults was substantial, corresponding to $259,324 per person over their lifetime – and most of these costs were borne by childhood cancer survivors in the form of lost productivity, loss of well-being, and loss of life.[3] As a result of improvements in care in recent decades, children with cancer are living longer lives.[4] As they age, this population may face harms due to treatment, including premature or accelerated aging due to chemotherapy, radiation-induced second cancers, infertility and other reproductive health issues, and various psychological issues.[5]

A 2023 guideline update from the Children's Oncology Group (COG),[6] previous versions of which have been endorsed by the American Academy of Pediatrics,[7] maintains that individualized, consistent follow-up care for childhood cancer survivors, should be clear and transparent communication between doctors and patients as the transition from oncology care to primary care occurs. Despite this, many still do not receive adequate survivorship care. A recent

report from the COG found that, while most COG institutions surveyed transfer adult-aged survivors of childhood cancer elsewhere for survivor care, "few programs report delivering recognized standards for quality healthcare transition programming to support survivors."[8] The use of electronic health records (EHR), which are digital versions of a patient's medical chart,[9] and related digital tools have been proposed as a strategy to improve survivorship care. Some qualitative research has found that young patients and their parents are open to the use of electronic tools,[10] and that they can be an effective component of a structured healthcare transition for young people with specialized healthcare needs.[11]

Additionally, AHRQ produced two recent reports that are relevant to this subject area. The first is a 2021 technical brief on disparities and barriers to pediatric cancer survivorship care,[12] and the second is a 2022 comparative effectiveness review on transitions of care from pediatric to adult services for children with special healthcare needs.[13] In 2022 the Childhood Cancer STAR Reauthorization Act was passed into law, authorizing the Department of Health and Human Services to award grants to entities that can "design tools to support the secure electronic transfer of treatment information and care summaries between health care providers…"[14] Considering this, the nominator is interested in the formulation of a "comprehensive list of such tools through an environmental scan" of electronic record keeping tools used for survivors of childhood cancer.

Scope

Guiding Question 1. Description of Information Transfer for Transitioning Cancer Survivors
   a. How is patient information currently transferred from oncologists to primary care providers for childhood cancer survivors?
      - Is it predominately electronic, paper-based, etc.?
      - When is the information transferred (e.g., prior to/following end of oncologic care)?
      - How do transfer characteristics vary by payer (e.g., public vs. private payer)?
      - How does cost vary across different forms of information transfer types?
   b. When electronic forms are used, how are the electronic tools/EHR set up for transferring this information?
      - What electronic transfer tools are used/available and what are their features/characteristics?
         o Which clinical information is transferred?
         o What is the business model for electronic tools (e.g., ownership, marketing)?
            ▪ Who are the consumers (e.g., clinicians, hospitals)?
      - How do costs vary across different electronic transfer tool types?

Guiding Question 2. Patient/Provider Experience with Information Transfer
   a. What is the provider's experience with different information transfer systems?
      a. How is information shared with the patient/patient's family?
   b. What is the patient's experience with transition of care as it relates to information transfer?

Guiding Question 3. Description of the Existing Evidence
   a. What patient groups/cancer types are represented in studies of information transfer for childhood cancer survivors?

b. What is the range of electronic transfer tools represented in studies and how does this compare to the range of electronic transfer tools that are used for childhood cancer survivors?
c. What outcomes are measured in studies of information transfer tools for childhood cancer survivors?

Guiding Question 4. Innovation and Future Research
a. What are predicted trends for adoption of different types of information transfer tools for childhood cancer survivors?
b. What are predicted trends in innovation of information transfer tools for childhood cancer survivors?
c. What is the predicted trend in studies of information transfer tools for childhood cancer survivors?
d. Which transfer tools for childhood cancer survivors seem most promising?

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

Summary of Literature Findings
We conducted a targeted search of the literature (see Appendix A below for search details) and found a variety of evidence sources which describe the methods and tools currently in use for the transition from pediatric oncology to primary care for childhood cancer survivors (CCS). These tools and methods are designed to aid communication between providers, patients, and family members to facilitate appropriate long-term follow-up (LTFU) care and surveillance of possible late effects from childhood cancer treatments. Table 1 provides a summary of the literature identified for each guiding question.

We found one systematic review which assessed transition practices, readiness tools, barriers and facilitators and addressed at least one of the guiding questions.[15] We also found two narrative reviews which addressed at least one of the guiding questions. One of the narrative reviews was focused on a shared care model which involves primary care practitioners[16] and one focused on successful elements of the transition process in the three primary models (specialty cancer center, community-based care, and hybrid models) of LTFU for survivorship care.[17]

In addition, we found eight primary studies that addressed at least one of the guiding questions. Five studies were randomized trials[18-22] and three were non-randomized trials.[23-25] Of these eight primary studies, three were focused on survivor care plans,[19, 21, 25] two were focused on a shared care model,[20, 23] two were focused on the Survivor Healthcare Passport,[18, 22] and one study looked at the Cancer SurvivorLink™ tool.[24]

We also found 34 observational/qualitative studies which varied in size and scope and addressed at least one of the guiding questions. Twelve studies focused on survivor care plans,[26-37] three studies focused on shared care models,[38-40] and six studies focused on some version of a paper or electronic survivorship "passport."[41-46] The remaining thirteen studies looked at multiple methods and tools including shared care models, survivorship passports, electronic personal health records (ePHR) and web-based tools.[10, 47-58]

Table 1. Identified studies by key question.

Technical Brief:	Reviews	Trials	Observational/Qualitative studies
Question 1 Description of info transfer	Total: 0 • Cochrane: 0 • AHRQ: 0 • Other: 0	Total: 4 • RCT (1) [19] • nRCT (3) [23-25]	Total: 7 • Observational (5) [28, 42-44, 53] • Qualitative (2) [37, 56]
Question 2 Pt/provider experience with info transfer	Total: 1 • Cochrane: 0 • AHRQ: 0 • Other: 1 [16] Focus of Review: • Description of models that involve primary care providers in follow-up care	Total: 3 • RCT (3) [18, 20, 22]	Total: 21 • Observational (11) [28, 29, 32, 33, 39, 42, 43, 45, 50, 53, 57] • Qualitative (10) [10, 26, 27, 30, 31, 36, 37, 47, 48, 56]
Question 3 Description of existing evidence	Total: 1 • Cochrane: 0 • AHRQ: 0 • Other: 1 [15] Focus of Review: • Assesses transition practices, readiness tools, barriers, and facilitators	Total: 1 • RCT (1) [21]	Total: 7 • Observational (3) [34, 35, 44] • Qualitative (4) [37, 47, 54, 56]
Question 4 Innovation & future research	Total: 1 • Cochrane: 0 • AHRQ: 0 • Other: 1 [17] Focus of Review: • Innovative approaches for transition of follow-up care	Total: 0	Total: 15 • Observational (3) [41, 35, 49] • Qualitative (11) [10, 31, 37, 38, 40, 46, 51, 52, 54-56] • Other (1) [58]

Abbreviations: AHRQ=Agency for Health Research and Quality; RCT=randomized controlled trial; nRCT=non-randomized controlled trial.

Summary of Selection Criteria Assessment

Childhood Cancer Survivors can suffer from significant health complications related to long-term effects from their treatments. The Children's Cancer Cause, a non-profit advocacy and research organization is interested in an environmental scan of eHealth tools that providers use to collect the information needed for the successful transition from oncology to primary care. Patients, caregivers, and providers will be able to use this information to enable health professionals to streamline care coordination for this unique group of youth and adults. We found three systematic reviews, eight primary studies and 34 observational/qualitative studies which addressed one or more of the guiding questions that could contribute to the development of a technical brief. We estimate a potential technical brief would be medium size.

This topic was initially submitted in November 2022; however, the nominator chose to withdraw their nomination and re-submit it with a greater focus on transition practices. This topic brief addresses the second nomination submitted June 3, 2023.

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

References

1. National Cancer Institute. Childhood Cancer Survivor Study: An Overview. 2023. https://www.cancer.gov/types/childhood-cancers/ccss. Accessed on December 20 2023.
2. 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://dx.doi.org/10.1002/cncr.33559. PMID: 33849081.
3. Parsons SK, Keegan THM, Kirchhoff AC, et al. Cost of Cancer in Adolescents and Young Adults in the United States: Results of the 2021 Report by Deloitte Access Economics, Commissioned by Teen Cancer America. J Clin Oncol. 2023 Jun 10;41(17):3260-8. doi: https://dx.doi.org/10.1200/JCO.22.01985. PMID: 36827624.
4. Yeh JM, Ward ZJ, Chaudhry A, et al. Life Expectancy of Adult Survivors of Childhood Cancer Over 3 Decades. JAMA Oncol. 2020 Mar 1;6(3):350-7. doi: https://dx.doi.org/10.1001/jamaoncol.2019.5582. PMID: 31895405.
5. Shapiro CL. Cancer Survivorship. N Engl J Med. 2018 Dec 20;379(25):2438-50. doi: https://dx.doi.org/10.1056/NEJMra1712502. PMID: 30575480.
6. Children's Oncology Group. Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. 2023. http://www.survivorshipguidelines.org/pdf/2023/COG_LTFU_Guidelines_Comprehensive_v6.pdf
7. Hudson MM, Bhatia S, Casillas J, et al. Long-term Follow-up Care for Childhood, Adolescent, and Young Adult Cancer Survivors. Pediatrics. 2021 Sep;148(3). doi: https://dx.doi.org/10.1542/peds.2021-053127. PMID: 34462344.
8. Marchak JG, Sadak KT, Effinger KE, et al. Transition practices for survivors of childhood cancer: a report from the Children's Oncology Group. J Cancer Surviv. 2023 Apr;17(2):342-50. doi: https://dx.doi.org/10.1007/s11764-023-01351-y. PMID: 36870037.
9. HealthIT.gov. What is an Electronic Health Record (EHR)? The Office of the National Coordinator for Health Information Technology. https://www.healthit.gov/faq/what-electronic-health-record-ehr#:~:text=An%20electronic%20health%20record%20%28EHR%29%20is%20a%20digital,information%20available%20instantly%20and%20securely%20to%20authorized%20users. Accessed on December 20 2023.

10. Schaffer M, McLoone JK, Wakefield CE, et al. eHealth tools for childhood cancer survivorship care: A qualitative analysis of survivors', parents', and general practitioners' views. PEC Innov. 2022 Dec;1:100010. doi: https://dx.doi.org/10.1016/j.pecinn.2021.100010. PMID: 37364028.
11. Schmidt A, Ilango SM, McManus MA, et al. Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review. J Pediatr Nurs. 2020 Mar-Apr;51:92-107. doi: https://dx.doi.org/10.1016/j.pedn.2020.01.002. PMID: 31981969.
12. Mobley EM, Moke DJ, Milam J, et al. Disparities and Barriers to Pediatric Cancer Survivorship Care. Disparities and Barriers to Pediatric Cancer Survivorship Care. Rockville (MD); 2021. https://www.ncbi.nlm.nih.gov/pubmed/33724748.
13. Parsons HM, Abdi HI, Nelson VA, et al. Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs. Rockville (MD); 2022. https://www.ncbi.nlm.nih.gov/pubmed/37184175.

14. United States Congress. Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Reauthorization Act of 2022. 2022. https://www.congress.gov/bill/117th-congress/senate-bill/4120/text.

15. Otth M, Denzler S, Koenig C, et al. Transition from pediatric to adult follow-up care in childhood cancer survivors—a systematic review. J. 2021;15(1):151-62. doi: https://dx.doi.org/10.1007/s11764-020-00920-9. PMID: 151915563.

16. Singer S, Gianinazzi ME, Hohn A, et al. General practitioner involvement in follow-up of childhood cancer survivors: a systematic review. Pediatr Blood Cancer. 2013 Oct;60(10):1565-73. doi: https://dx.doi.org/10.1002/pbc.24586. PMID: 23813795.

17. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. J Clin Oncol. 2010 Nov 10;28(32):4810-8. doi: https://dx.doi.org/10.1200/jco.2009.23.4278. PMID: 20351333.

18. Murphy P, Levine A, Lerma T, et al. A portable survivorship care plan: a tool that helps educate and improve knowledge in childhood cancer survivors. Support Care Cancer. 2021 Jan;29(1):169-77. doi: https://dx.doi.org/10.1007/s00520-020-05422-z. PMID: 32328773.

19. Kadan-Lottick NS, Ross WL, Mitchell HR, et al. Randomized Trial of the Impact of Empowering Childhood Cancer Survivors With Survivorship Care Plans. J Natl Cancer Inst. 2018 12 01;110(12):1352-9. doi: https://dx.doi.org/10.1093/jnci/djy057. PMID: 29771337.

20. Nielsen JD, Palshof T, Mainz J, et al. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. Qual Saf Health Care. 2003 Aug;12(4):263-72. doi: https://dx.doi.org/10.1136/qhc.12.4.263. PMID: 12897359.

21. Gross CP, Ross WL, Rotatori JL, et al. Randomized trial assessing the impact of survivorship care plans on the quality of care for childhood cancer survivors. J Clin Oncol. 2016;34.

22. Goldsby R, Raber S, Li L, et al. Survivor healthcare passport: a tool to educate and enhance the care of survivors of childhood cancer. Pediatr Blood Cancer. 2012;59(6):1107. doi: https://doi.org/10.1002/pbc.24295.

23. Ducassou S, Chipi M, Pouyade A, et al. Impact of shared care program in follow-up of childhood cancer survivors: An intervention study. Pediatr Blood Cancer. 2017 Nov;64(11). doi: https://dx.doi.org/10.1002/pbc.26541. PMID: 28371178.

24. Williamson R, Meacham L, Cherven B, et al. Predictors of successful use of a web-based healthcare document storage and sharing system for pediatric cancer survivors: Cancer SurvivorLink TM. J. 2014 Sep;8(3):355-63. doi: https://dx.doi.org/10.1007/s11764-014-0346-6. PMID: 24535124.

25. Oeffinger KC, Hudson MM, Mertens AC, et al. Increasing rates of breast cancer and cardiac surveillance among high-risk survivors of childhood Hodgkin lymphoma following a mailed, one-page survivorship care plan. Pediatr Blood Cancer. 2011 May;56(5):818-24. doi: https://dx.doi.org/10.1002/pbc.22696. PMID: 21370417.

26. Cai CR, Cornelius S, Demedis J, et al. Experiences of adult survivors of childhood cancer in a randomized cardiovascular health promotion trial: a qualitative report from the Childhood Cancer Survivor Study. J. 2023 May 30;30:30. doi: https://dx.doi.org/10.1007/s11764-023-01406-0. PMID: 37253902.

27. Ross LW, Townsend JS, Rohan EA. Still Lost in Transition? Perspectives of Ongoing Cancer Survivorship Care Needs from Comprehensive Cancer Control Programs, Survivors, and Health Care Providers. Int J Environ Res Public Health. 2022 03 04;19(5):04. doi: https://dx.doi.org/10.3390/ijerph19053037. PMID: 35270729.

28. Hamilton SN, Howard F, Afghari N, et al. The impact of survivorship care plans on adolescent and young adult head and neck cancer survivors and their primary care providers. Support Care Cancer. 2023 Jul 07;31(7):448. doi: https://dx.doi.org/10.1007/s00520-023-07860-x. PMID: 37418030.

29. Pannier ST, Mann K, Warner EL, et al. Survivorship care plan experiences among childhood acute lymphoblastic leukemia patients and their families. BMC Pediatr. 2019 04 13;19(1):111. doi: https://dx.doi.org/10.1186/s12887-019-1464-0. PMID: 30979365.

30. Keats MR, Shea K, Parker L, et al. After Childhood Cancer: a Qualitative Study of Family Physician, Parent/Guardian, and Survivor Information Needs and Perspectives on Long-Term Follow-up and Survivorship Care Plans. J Cancer Educ. 2019 Aug;34(4):638-46. doi: https://dx.doi.org/10.1007/s13187-018-1349-1. PMID: 29552704.

31. Signorelli C, Wakefield CE, McLoone JK, et al. Models of childhood cancer survivorship care in Australia and New Zealand: Strengths and challenges. Asia Pac J Clin Oncol. 2017 Dec;13(6):407-15. doi: https://dx.doi.org/10.1111/ajco.12700. PMID: 28670761.

32. Shay LA, Parsons HM, Vernon SW. Survivorship Care Planning and Unmet Information and Service Needs Among Adolescent and Young Adult Cancer Survivors. J Adolesc Young Adult Oncol. 2017 Jun;6(2):327-32. doi: https://dx.doi.org/10.1089/jayao.2016.0053. PMID: 28103126.

33. Szalda D, Schwartz L, Schapira MM, et al. Internet-Based Survivorship Care Plans for Adult Survivors of Childhood Cancer: A Pilot Study. J Adolesc Young Adult Oncol. 2016 12;5(4):351-4. doi: https://dx.doi.org/10.1089/jayao.2016.0026. PMID: 27258823.

34. Jabson JM. Treatment summaries, follow-up care instructions, and patient navigation: could they be combined to improve cancer survivor's receipt of follow-up care? J. 2015 Dec;9(4):692-8. doi: https://dx.doi.org/10.1007/s11764-015-0444-0. PMID: 25764272.

35. Glaser A, Levitt G, Morris P, et al. Enhanced quality and productivity of long-term aftercare of cancer in young people. Arch Dis Child. 2013 Oct;98(10):818-24. doi: https://dx.doi.org/10.1136/archdischild-2013-304348. PMID: 23966026.

36. Mayer DK, Gerstel A, Leak AN, et al. Patient and provider preferences for survivorship care plans. J Oncol Pract. 2012 Jul;8(4):e80-6. doi: https://dx.doi.org/10.1200/JOP.2011.000401. PMID: 23181005.

37. Baird H, Patterson P, Medlow S, et al. Understanding and Improving Survivorship Care for Adolescents and Young Adults with Cancer. J Adolesc Young Adult Oncol. 2019 10;8(5):581-6. doi: https://dx.doi.org/10.1089/jayao.2019.0031. PMID: 31268400.

38. Hahn EE, Munoz-Plaza CE, Schottinger JE, et al. Developing innovative models of care for cancer survivors: use of implementation science to guide evaluation of appropriateness and feasibility. Support Care Cancer. 2019 May;27(5):1737-45. doi: https://dx.doi.org/10.1007/s00520-018-4425-5. PMID: 30143893.

39. Costello AG, Nugent BD, Conover N, et al. Shared Care of Childhood Cancer Survivors: A Telemedicine Feasibility Study. J Adolesc Young Adult Oncol. 2017 Dec;6(4):535-41. doi: https://dx.doi.org/10.1089/jayao.2017.0013. PMID: 28657408.

40. Kinahan KE, Kircher S, Altman J, et al. Promoting the Shared-Care Model for Adolescent and Young Adults With Cancer: Optimizing Referrals and Care Coordination With Primary Care Providers. Journal of the National Comprehensive Cancer Network. 2017 01;15(1):38-44. doi: https://dx.doi.org/10.6004/jnccn.2017.0005. PMID: 28040718.

41. van den Oever SR, de Beijer IAE, Kremer LCM, et al. Barriers and facilitators to implementation of the interoperable Survivorship Passport (SurPass) v2.0 in 6 European countries: a PanCareSurPass online survey study. J. 2023 Feb 20;20:20. doi: https://dx.doi.org/10.1007/s11764-023-01335-y. PMID: 36808389.

42. Valencia MC, Hang L, Schmidt D, et al. Next Steps: Survivor Healthcare Passport - A Novel Form of Survivorship Care Plan in the Pediatric Population. J Pediatr Hematol Oncol. 2023 Jul 01;45(5):e573-e7. doi: https://dx.doi.org/10.1097/MPH.0000000000002651. PMID: 36898042.

43. 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 01;70(1):e30070. doi: https://dx.doi.org/10.1002/pbc.30070. PMID: 36326111.

44. Williamson RS, Cherven BO, Gilleland Marchak J, et al. Meaningful Use of an Electronic Personal Health Record (ePHR) among Pediatric Cancer Survivors. Appl Clin Inform. 2017 03 15;8(1):250-64. doi: https://dx.doi.org/10.4338/ACI-2016-11-RA-0189. PMID: 28293684.

45. Poplack DG, Fordis M, Landier W, et al. Childhood cancer survivor care: development of the Passport for Care. Nat Rev Clin Oncol. 2014 12;11(12):740-50. doi: https://dx.doi.org/10.1038/nrclinonc.2014.175. PMID: 25348788.

46. Chronaki C, Charalambous E, Cangioli G, et al. Factors Influencing Implementation of the Survivorship Passport: The IT Perspective. Stud Health Technol Inform. 2022 05 16;293:161-8. doi: https://dx.doi.org/10.3233/SHTI220363. PMID: 35592976.

47. Marchak JG, Cherven B, Williamson Lewis R, et al. User-centered design and enhancement of an electronic personal health record to support survivors of pediatric cancers. Support Care Cancer. 2020 Aug;28(8):3905-14. doi: https://dx.doi.org/10.1007/s00520-019-05199-w. PMID: 31853699.

48. Sadak KT, Gemeda M, Grafelman MC, et al. Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative interview study of parents. Cancer Med. 2021 09;10(18):6239-48. doi: https://dx.doi.org/10.1002/cam4.4164. PMID: 34355520.

49. Haupt R, Essiaf S, Dellacasa C, et al. The 'Survivorship Passport' for childhood cancer survivors. Eur J Cancer. 2018 Oct;102:69-81. doi: https://dx.doi.org/10.1016/j.ejca.2018.07.006. PMID: 30138773.

50. Gramatges MM, Bonaduce de Nigris F, King J, et al. Improving Childhood Cancer Survivor Care Through Web-Based Platforms. Oncology (Williston). 2018 01 15;32(1):e1-e10. PMID: 29447422.

51. Berg CJ, Stratton E, Esiashvili N, et al. Young Adult Cancer Survivors' Experience with Cancer Treatment and Follow-Up Care and Perceptions of Barriers to Engaging in Recommended Care. J Cancer Educ. 2016 09;31(3):430-42. doi: https://dx.doi.org/10.1007/s13187-015-0853-9. PMID: 25948413.

52. Berg C, Stratton E, Esiashvili N, et al. Providers' Perspectives of Survivorship Care for Young Adult Survivors of Childhood Cancer. J Cancer Educ. 2016 Mar;31(1):31-8. doi: https://dx.doi.org/10.1007/s13187-015-0848-6. PMID: 25943901.

53. Meacham LR, Edwards PJ, Cherven BO, et al. Primary care providers as partners in long-term follow-up of pediatric cancer survivors. J. 2012 Sep;6(3):270-7. doi: https://dx.doi.org/10.1007/s11764-012-0224-z. PMID: 22562474.

54. Tonorezos ES, Barnea D, Cohn RJ, et al. Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade. J Clin Oncol. 2018 07 20;36(21):2223-30. doi: https://dx.doi.org/10.1200/JCO.2017.76.5180. PMID: 29874138.

55. Sharp LK, Carvalho P, Southward M, et al. Electronic Personal Health Records for Childhood Cancer Survivors: An Exploratory Study. J Adolesc Young Adult Oncol. 2014 Sep 01;3(3):117-22. doi: https://dx.doi.org/10.1089/jayao.2013.0039. PMID: 25276495.

56. Eshelman-Kent D, Gilger E, Gallagher M. Transitioning survivors of central nervous system tumors: challenges for patients, families, and health care providers. J Pediatr Oncol Nurs. 2009 Sep-Oct;26(5):280-94. doi: https://dx.doi.org/10.1177/1043454209343209. PMID: 19837958.

57. Meacham LR, Williamson RS, Forehand RL, et al. University Health Centers and Young Adult Survivors of Pediatric Cancer: Changes in Providers' Familiarity with and Practice of Survivor Care. J Adolesc Young Adult Oncol. 2014;3(1):12-9. doi: https://dx.doi.org/10.1089/jayao.2013.0029. PMID: 103896896.

58. Ellenbogen Y, Yang K, Ajani O. Transition of Care for Children with High-Grade Central Nervous System Tumors. Journal of Pediatric Neurology. 2020;18(6):301-6. doi: https://dx.doi.org/10.1055/s-0040-1716909. PMID: 146847707.

Author
Cathy Gordon
Charli Armstrong
Lisa Winterbottom
Robin Paynter

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

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
Due to the unique nature of this technical review search, a modified search strategy was deemed appropriate, and the duplication search for systematic reviews was combined with the feasibility search for all other literature. Please see Feasibility of New Evidence Review for additional details.

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
The search strategy was designed and conducted by an experienced systematic review/medical reference librarian with input from the investigators. To find additional relevant studies, reference lists of included articles were manually screened.

We applied the following limits or filters to the database searches:
- Language: publications were excluded if they were written in a language other than English. This was due to resource constraints.
- Publication status: we searched for published, unpublished, and ongoing studies.
- Age limit: children and young adults.
- Please note study design filters were used to organize the results for ease of screening only. All records were ultimately screened.

We conducted a literature search in July 2023. We searched the following databases:
- Ovid MEDLINE ALL (1946 to July 11, 2023) Date searched: July 12, 2023
- Embase.com (1967 to July 12, 2023) Date searched: July 13, 2023
- Ovid EBM Reviews - Cochrane Central Register of Controlled Trials (June 2023) Date searched: July 12, 2023
- EBSCOHost CINAHL Plus with Full Text (inception to July 18, 2023) Date searched: July 19, 2023

We conducted a grey literature search in July 2023 that included the following resources:
- Conference proceedings. To locate unpublished studies, we searched Embase.com for
  conference proceedings since 2000.
- Trial register
  - ClinicalTrials.gov

- Websites:
  - US National Cancer Institute/ Children's Oncology Group
  - American Society of Clinical Oncology
  - American Society of Pediatric Hematology/Oncology

Ovid MEDLINE ALL 1946 to July 11, 2023

Date searched: July 12, 2023

1 Cancer Survivors/ or ((Aftercare/ or Continuity of Patient Care/ or Survival/ or Survivors/ or Survivorship/) and (chemotherapy.hw. or exp Neoplasms/ or Radiotherapy/ or radiotherapy.hw. or (cancer* or carcinoma$1 or leukemia$1 or lymphoma$1 or neoplas* or neuroblastom* or onco* or osteosarcom* or retinoblastom* or sarcoma$1 or tumor$1 or tumour$1).ti,ab,kf.)) (28619)

2 ((cancer* or carcinoma$1 or leukemia$1 or lymphoma$1 or neoplas* or neuroblastom* or onco* or osteosarcom* or retinoblastom* or sarcoma$1 or tumor$1 or tumour$1) adj5 ("after-care" or aftercare or surviv*)).ti,ab,kf. (192649)

3 or/1-2 (201309)

4 Family Practice/ or General Practitioners/ or Oncologists/ or Patient Care Team/ or Pediatricians/ or Physicians/ or Physicians, Family/ or Physicians, Primary Care/ or Primary Health Care/ or Radiation Oncologists/ or Transition to Adult Care/ or Transitional Care/ (342968)

5 (clinician$1 or doctor$1 or ((family or general) adj (medicine or practice)) or oncologist$1 or paediatrics or paediatrician$1 or pediatrics or pediatrician$1 or physician$1 or practitioner$1 or "primary care" or "primary health care" or "primary healthcare" or provider$1 or specialist$1 or team$1).ti,kf. (453036)

6 (clinic or clinician$1 or doctor$1 or "general practice" or oncologist$1 or paediatrics or paediatrician$1 or pediatrics or pediatrician$1 or physician$1 or practitioner$1 or "primary care" or provider$1 or specialist$1 or team$1).ti,ab,kf. (1799985)

7 or/4-5 (615770)

8 or/4,6 (1913618)

9 Adolescent/ or Child/ or Child, Preschool/ or Infant/ or Infant, Newborn/ or Parents/ or Young Adult/ (4418454)

10 (AYA$1 or CCS$1 or CTYA$1 or YAC$1 or adolescen* or baby or babies or boy$1 or child or childhood or children or girl$1 or infan* or juvenile* or minors or neonate$1 or neonatal$2 or newborn$1 or paediatric or parent$1 or pediatric or preadolescen* or preschool* or preteen* or school* or teen* or toddler$1 or transfer* or transition* or young* or youth*).ti,kf. (2344281)

11 (AYA$1 or CCS$1 or CTYA$1 or YAC$1 or adolescen* or baby or babies or child or childhood or children or infan* or juvenile* or minors or neonate$1 or neonatal$2 or newborn$1 or paediatric or parent$1 or pediatric or preschool* or school* or teen* or toddler$1 or transfer* or transition* or young or youth*).ti,ab,kf. (4570326)

12 or/9-10 (5192133)

13 or/9,11 (6840963)

14 Ambulatory Care Information Systems/ or exp Communication/ or exp Computing Methodologies/ or Data Display/ or Documentation/ or Electronic Health Records/ or Health Information Exchange/ or Health Information Systems/ or Health Records, Personal/ or Hospital Information Systems/ or Informatics/ or Information Dissemination/ or exp Information Systems/ or Information Technology/ or Interdisciplinary Communication/ or Medical Informatics/ or Medical Record Linkage/ or Medical Records/ or Medical Records Systems, Computerized/ or Patient Discharge Summaries/ or Software/ or Software Design/ or Systems Integration/ or User-Computer Interface/ (1795304)

15 (EHR$1 or eMR$1 or ePHR$1 or PHR$1 or (care adj3 (coordinat* or integrated or model$1 or plan$1 or planning or shared)) or collaborat* or communicat$3 or computer* or cooperative* or data or digital$2 or ehealth or "e-health" or electronic* or groupware or "health record$1" or information* or informatics or interface$1 or integrat* or internet or interoperab* or "medical record$1" or online or platform$1 or portal$1 or software or system$1 or technolog$3 or tool$1 or web-based).ti,kf. (2105718)

16 or/14-15 (3463271)

17 and/3,7,11,16 (224)

18 and/3,8,12,16 (689)

19 (LIVESTRONG$2 or athenaOne$2 or CareAware$2 or CareView$2 or Cerner$2 or ChartLogic$2 or DrChrono$2 or EPIC$2 or HealtheReferrals$2 or Kareo$2 or MedPointe$2 or NextGen$2 or PowerChart$2 or Sevocity$2 or SurPass$2 or RXNT$2).ti,ab,kf. (20810)

20 and/3,12,19 (56)

21 ("Life After Childhood Cancer" or PanCareSurPass$2 or "Passport for Care" or "Survivorship Passport" or "Survivor Healthcare Passport" or SurvivorLink$2).ti,ab,kf. (48)

22 or/17-18,20-21 (852)

23 limit 22 to english language (833)

24 23 and ((meta-analysis or systematic review).pt. or (meta-anal* or metaanal* or ((evidence or review or scoping or systematic or umbrella) adj3 (review or synthesis))).ti.) (43)

25 (((integrative or interpretive or "mixed method" or "mixed methods" or qualitative or realist or thematic) adj3 (synthes* or review*)) or ((framework or narrative) adj2 synthes*)).ti,ab,kf. (29808)

26 (mega-ethnograph* or megaethnograph* or meta-aggregat* or metaaggregat* or meta-ethnograph* or metaethnograph* or meta-interpret* or metainterpret* or meta-method* or metamethod* or meta-narrative* or metanarrative* or meta-study or metastudy or meta-synthe* or metasynthe* or meta-summary or metasummary or meta-triangulat* or metatriangulat*).ti,ab,kf. (3563)

27 ((qualitative adj2 (literature or paper or papers or research or study or studies)) and (synthes* or "systematic review" or "systematic reviews")).ti,ab,kf. (8578)

28 ((qualitative adj2 (literature or paper or papers or research or study or studies)) and ("literature search" or "literature searching" or "literature searches")).ti,ab,kf. (921)

29 ((qualitative adj2 (literature or paper or papers or research or study or studies)) and ("quality assessment" or "critical appraisal" or checklist*)).ti,ab,kf. (2780)

30 (((mixed or integrative) adj2 (method* or research or study or studies)) and (synthes* or "systematic review" or "systematic reviews")).ti,ab,kf. (6178)

31 (((mixed or integrative) adj2 (method* or research or study or studies)) and ("literature search" or "literature searching" or "literature searches")).ti,ab,kf. (662)

32 (((mixed or integrative) adj2 (method* or research or study or studies)) and ("quality assessment" or "critical appraisal" or checklist*)).ti,ab,kf. (1686)

33 (CERQUAL or CONQUAL or JBI-QARI or QualSys or "Mixed Methods Appraisal Tool" or MMAT).ti,ab,kf. (1615)

34 (Noblit and Hare).ab. (98)

35 or/25-34 (39541)

36 and/23,35 (15)

37 36 not 24 (3)

38 23 and ((controlled clinical trial or randomized controlled trial).pt. or (control or controls or controlled or random* or trial*).ti,ab,kf.) (180)

39 38 not (24 or 36) (173)

40 23 and (Cohort Studies/ or Cross-Sectional Studies/ or exp Evaluation Studies as Topic/ or Follow-Up Studies/ or Observational Study/ or Prospective Studies/ or Retrospective Studies/ or

(cohort$1 or evaluation or cross-sectional or follow-up or observational or prospective$2 or retrospective$2).ti,ab,kf.) (507)
41 40 not (24 or 36 or 38) (376)
42 exp Attitude/ or Focus Groups/ or Grounded Theory/ or "Interviews as Topic"/ or Narration/ or exp Qualitative Research/ or exp "Surveys and Questionnaires"/ or px.fs. (2479831)
43 ("critical interpretive" or "critical race" or "critical realism" or "critical realist" or emic or etic or ethnograph* or ethnolog* or hermeneutic* or heuristic* or "grounded theory" or phenomenolog* or semiotic*).ti,ab,kf,kw. (83457)
44 (((content or conversation or discourse or narrative or thematic) adj2 analy*) or ((cluster or purposive or theoretical) adj2 (sample* or sampling)) or "constant comparative" or descriptive or ethnonursing or ethno-nursing or (field adj1 (study or studies or work)) or fieldwork or "focus group" or "focus groups" or "key informant" or "key informants" or interview* or "mixed design" or "mixed methods" or qualitative or ((semi-structured or semistructured or unstructured or informal or in-depth or indepth or face-to-face or structured or guided) adj3 (discussion* or questionnaire*)) or survey* or thematic or triangulat*).ti,ab,kf,kw. (1641797)
45 (attitud* or barrier* or benefit* or context* or emotion* or facilitator* or experienc* or narratives or opinion* or perception* or perspective* or preference* or react* or theme or themes or value* or valuing or viewpoint* or view or views).ti,ab. (8097673)
46 or/42-45 (10096008)
47 and/23,46 (626)
48 47 not (24 or 36 or 38 or 41) (194)
49 23 not (36 or 38 or 41 or 48) (69)

EBM Reviews - Cochrane Central Register of Controlled Trials June 2023
Date searched: July 12, 2023
1 Cancer Survivors/ or ((Aftercare/ or Continuity of Patient Care/ or Survival/ or Survivors/ or Survivorship/) and (chemotherapy.hw. or exp Neoplasms/ or Radiotherapy/ or radiotherapy.hw. or (cancer* or carcinoma$1 or leukemia$1 or lymphoma$1 or neoplas* or neuroblastom* or onco* or osteosarcom* or retinoblastom* or sarcoma$1 or tumor$1 or tumour$1).ti,ab.)) (3687)
2 ((cancer* or carcinoma$1 or leukemia$1 or lymphoma$1 or neoplas* or neuroblastom* or onco* or osteosarcom* or retinoblastom* or sarcoma$1 or tumor$1 or tumour$1) adj5 ("after-care" or aftercare or surviv*)).ti,ab. (15645)
3 or/1-2 (17511)
4 Family Practice/ or General Practitioners/ or Oncologists/ or Patient Care Team/ or Pediatricians/ or Physicians/ or Physicians, Family/ or Physicians, Primary Care/ or Primary Health Care/ or Radiation Oncologists/ or Transition to Adult Care/ or Transitional Care/ (11569)
5 (clinician$1 or doctor$1 or ((family or general) adj (medicine or practice)) or oncologist$1 or paediatrics or paediatrician$1 or pediatrics or pediatrician$1 or physician$1 or practitioner$1 or "primary care" or "primary health care" or "primary healthcare" or provider$1 or specialist$1 or team$1).ti. (22853)
6 (clinic or clinician$1 or doctor$1 or "general practice" or oncologist$1 or paediatrics or paediatrician$1 or pediatrics or pediatrician$1 or physician$1 or practitioner$1 or "primary care" or provider$1 or specialist$1 or team$1).ti,ab. (185648)
7 or/4-5 (27565)
8 or/4,6 (187124)
9 Adolescent/ or Child/ or Child, Preschool/ or Infant/ or Infant, Newborn/ or Parents/ or Young Adult/ (230079)
10 (AYA$1 or CCS$1 or CTYA$1 or YAC$1 or adolescen* or baby or babies or boy$1 or child or childhood or children or girl$1 or infan* or juvenile* or minors or neonate$1 or neonatal$2 or

newborn$1 or paediatric or parent$1 or pediatric or preadolescen* or preschool* or preteen* or school* or teen* or toddler$1 or transfer* or transition* or young* or youth*).ti. (178875)
11 (AYA$1 or CCS$1 or CTYA$1 or YAC$1 or adolescen* or baby or babies or child or childhood or children or infan* or juvenile* or minors or neonate$1 or neonatal$2 or newborn$1 or paediatric or parent$1 or pediatric or preschool* or school* or teen* or toddler$1 or transfer* or transition* or young or youth*).ti,ab. (299712)
12 or/9-10 (335450)
13 or/9,11 (426478)
14 Ambulatory Care Information Systems/ or exp Communication/ or exp Computing Methodologies/ or Data Display/ or Documentation/ or Electronic Health Records/ or Health Information Exchange/ or Health Information Systems/ or Health Records, Personal/ or Hospital Information Systems/ or Informatics/ or Information Dissemination/ or exp Information Systems/ or Information Technology/ or Interdisciplinary Communication/ or Medical Informatics/ or Medical Record Linkage/ or Medical Records/ or Medical Records Systems, Computerized/ or Patient Discharge Summaries/ or Software/ or Software Design/ or Systems Integration/ or User-Computer Interface/ (43464)
15 (EHR$1 or eMR$1 or ePHR$1 or PHR$1 or (care adj3 (coordinat* or integrated or model$1 or plan$1 or planning or shared)) or collaborat* or communicat$3 or computer* or cooperative* or data or digital$2 or ehealth or "e-health" or electronic* or groupware or "health record$1" or information* or informatics or interface$1 or integrat* or internet or interoperab* or "medical record$1" or online or platform$1 or portal$1 or software or system$1 or technolog$3 or tool$1 or web-based).ti. (92350)
16 or/14-15 (123646)
17 and/3,7,11,16 (14)
18 and/3,8,12,16 (58)
19 (LIVESTRONG$2 or athenaOne$2 or CareAware$2 or CareView$2 or Cerner$2 or ChartLogic$2 or DrChrono$2 or EPIC$2 or HealtheReferrals$2 or Kareo$2 or MedPointe$2 or NextGen$2 or PowerChart$2 or Sevocity$2 or SurPass$2 or RXNT$2).ti,ab. (2013)
20 and/3,12,19 (3)
21 ("Life After Childhood Cancer" or PanCareSurPass$2 or "Passport for Care" or "Survivorship Passport" or "Survivor Healthcare Passport" or SurvivorLink$2).ti,ab. (10)
22 or/17-18,20-21 (79)
23 limit 22 to english language (79)

EBSCOHost CINAHL Plus with Full Text
Date searched: July 19, 2023
S1 (MH "Cancer Survivors") or ((MH "After Care") OR (MH "Continuity of Patient Care+") OR (MH "Survival") OR (MH "Disease-Free Survival") OR (MH "Survivors") OR (MH "Survivorship")) and ((MH "Neoplasms+") or (MH "Radiotherapy+")) OR (cancer* or carcinoma* OR chemotherap* OR leukemia* OR lymphoma* OR neoplas* OR neuroblastom* OR onco* OR osteosarcom* OR radiotherap* OR retinoblastom* OR sarcoma* OR tumor* OR tumour*)))
S2 TI ((((cancer* OR carcinoma* OR leukemia* OR lymphoma* OR neoplas* OR neuroblastom* OR onco* OR osteosarcom* OR retinoblastom* OR sarcoma* OR tumor* OR tumour*) W5 ("after-care" OR aftercare OR surviv*))) OR AB ((((cancer* OR carcinoma* OR leukemia* OR lymphoma* OR neoplas* OR neuroblastom* OR onco* OR osteosarcom* OR retinoblastom* OR sarcoma* OR tumor* OR tumour*) W5 ("after-care" OR aftercare OR surviv*)))
S3 S1 OR S2

S4 (MH "Family Practice") OR (MH "Physicians, Family") OR (MH "Multidisciplinary Care Team") OR (MH "Oncology Nurse Practitioners") OR (MH "Primary Care Nurse Practitioners") OR (MH "Pediatric Nurse Practitioners+") OR (MH "Neonatal Nurse Practitioners") OR (MH "Nurse Practitioners+") OR (MH "Family Nurse Practitioners") OR (MH "Oncologists") OR Patient Care Team/ OR (MH "Pediatricians") OR (MH "Physicians") OR (MH "Primary Health Care") OR (MH "Radiation Oncologists") OR (MH "Transitional Care")

S5 TI ((clinician* or doctor* or ((family or general) W1 (medicine or practice)) or nurse* or nursing or oncologist* or paediatrics or paediatrician* or pediatrics or pediatrician* or physician* or practitioner* or "primary care" or "primary health care" or "primary healthcare" or provider* or specialist* or team*)) OR ((clinician* or doctor* or ((family or general) W1 (medicine or practice)) or nurse* or nursing or oncologist* or paediatrics or paediatrician* or pediatrics or pediatrician* or physician* or practitioner* or "primary care" or "primary health care" or "primary healthcare" or provider* or specialist* or team*))

S6 S4 OR S5

S7 (MH "Adolescence") OR (MH "Child") OR (MH "Infant") OR (MH "Infant, Newborn") OR (MH "Minors (Legal)") OR (MH "Child, Preschool") OR (MH "Infant, High Risk")

S8 TI ((AYA* or CCS* or CTYA* or YAC* or adolescen* or baby or babies or boy* or child or childhood or children or girl* or infan* or juvenile* or minors or neonate* or neonatal* or newborn* or paediatric or parent* or pediatric or preadolescen* or preschool* or preteen* or school* or teen* or toddler* or transfer* or transition* or young* or youth*)) OR AB ((AYA* or CCS* or CTYA* or YAC* or adolescen* or baby or babies or boy* or child or childhood or children or girl* or infan* or juvenile* or minors or neonate* or neonatal* or newborn* or paediatric or parent* or pediatric or preadolescen* or preschool* or preteen* or school* or teen* or toddler* or transfer* or transition* or young* or youth*))

S9 S7 OR S8

S10 (MH "Ambulatory Care Information Systems") OR (MH "Clinical Information Systems") OR (MH "Decision Support Systems, Clinical") OR (MH "Documentation") OR (MH "Electronic Health Records") OR (MH "Health Informatics") OR (MH "Health Information Networks") OR (MH "Health Information Systems") OR (MH "Information Systems") OR (MH "Medical Informatics") OR (MH "Medical Records") OR (MH "Medical Record Linkage") OR (MH "Nursing Care Plans, Computerized") OR (MH "Nursing Information Systems") OR (MH "Nursing Informatics") OR (MH "Nursing Records") OR (MH "Patient Record Systems") OR (MH "Practice Management Information Systems") OR (MH "Record Review")ed)) or collaborat* or communicat* or computer* or cooperative* or data or digital* or ehealth or "e-health" or electronic* or groupware or "health record*" or information* or informatics or interface* or integrat* or internet or interoperab* or "medical record" or "medical records" or online or platform* or portal* or software or system* or technolog* or tool* or web-based))

S12 S10 OR S11

S13 S3 AND S6 AND S9 AND S12

S14 TI ((LIVESTRONG* or athenaOne* or CareAware* or CareView* or Cerner* or ChartLogic* or DrChrono* or EPIC* or HealtheReferrals* or Kareo* or MedPointe* or NextGen* or PowerChart* or Sevocity* or SurPass* or RXNT*)) OR AB ((LIVESTRONG* or athenaOne* or CareAware* or CareView* or Cerner* or ChartLogic* or DrChrono* or EPIC* or HealtheReferrals* or Kareo* or MedPointe* or NextGen* or PowerChart* or Sevocity* or SurPass* or RXNT*))

S15 S3 AND S9 AND S14

S16 TI (("Life After Childhood Cancer" or PanCareSurPass* or "Passport for Care" or "Survivorship Passport" or "Survivor Healthcare Passport" or SurvivorLink*)) OR AB (("Life After Childhood Cancer" or PanCareSurPass* or "Passport for Care" or "Survivorship Passport" or "Survivor Healthcare Passport" or SurvivorLink*))

S17 S13 OR S15 OR S16 Limiters - English Language; Exclude MEDLINE records; Human; Publication Type: Meta Analysis, Systematic Review (55)

S18 S13 OR S15 OR S16 Limiters - English Language; Exclude MEDLINE records; Publication Type: Meta Synthesis (2)

S19 S13 OR S15 OR S16 Limiters - English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Randomized Controlled Trial (8)

S20 (S13 OR S15 OR S16) AND (TI (cohort* or evaluation or cross-sectional or follow-up or observational or prospective* or retrospective*) OR AB (cohort* or evaluation or cross-sectional or follow-up or observational or prospective* or retrospective*)) Limiters - English Language; Exclude MEDLINE records (181)

S21 (S13 OR S15 OR S16) AND (TI ("critical interpretive" or "critical race" or "critical realism" or "critical realist" or emic or etic or ethnograph* or ethnolog* or hermeneutic* or heuristic* or "grounded theory" or phenomenolog* or semiotic* OR ((content or conversation or discourse or narrative or thematic) W2 analy*) or ((cluster or purposive or theoretical) W2 (sample* or sampling)) or "constant comparative" or descriptive or ethnonursing or ethno-nursing or (field W1 (study or studies or work)) or fieldwork or "focus group" or "focus groups" or "key informant" or "key informants" or interview* or "mixed design" or "mixed methods" or qualitative or ((semi-structured or semistructured or unstructured or informal or in-depth or indepth or face-to-face or structured or guided) W3 (discussion* or questionnaire*)) or survey* or thematic or triangulat* OR attitud* or barrier* or benefit* or context* or emotion* or facilitator* or experienc* or narratives or opinion* or perception* or perspective* or preference* or react* or theme or themes or value* or valuing or viewpoint* or view or views) OR AB ("critical interpretive" or "critical race" or "critical realism" or "critical realist" or emic or etic or ethnograph* or ethnolog* or hermeneutic* or heuristic* or "grounded theory" or phenomenolog* or semiotic* OR ((content or conversation or discourse or narrative or thematic) W2 analy*) or ((cluster or purposive or theoretical) W2 (sample* or sampling)) or "constant comparative" or descriptive or ethnonursing or ethno-nursing or (field W1 (study or studies or work)) or fieldwork or "focus group" or "focus groups" or "key informant" or "key informants" or interview* or "mixed design" or "mixed methods" or qualitative or ((semi-structured or semistructured or unstructured or informal or in-depth or indepth or face-to-face or structured or guided) W3 (discussion* or questionnaire*)) or survey* or thematic or triangulat* OR attitud* or barrier* or benefit* or context* or emotion* or facilitator* or experienc* or narratives or opinion* or perception* or perspective* or preference* or react* or theme or themes or value* or valuing or viewpoint* or view or views))

Limiters - English Language; Exclude MEDLINE records (223)

S22 (S13 OR S15 OR S16) NOT (S17 OR S18 OR S19 OR S20 OR S21) Limiters - English Language; Exclude MEDLINE records (78)

ClinicalTrials.gov
Date searched: July 13, 2023
https://clinicaltrials.gov/search?cond=Childhood%20Cancer%20Survivors&term=EHR%20OR%20eMR%20OR%20ePHR%20OR%20PHR%20OR%20(care%20AND%20(coordinate%20OR%20integrated%20OR%20model%20OR%20plan%20OR%20planning%20OR%20shared))%20OR%20collaborate%20OR%20communication%20OR%20computer%20OR%20cooperative%20OR%20data%20OR%20digital%20OR%20ehealth%20OR%20e-health%20OR%20electronic%20OR%20groupware%20OR%20information*%20OR%20informatics%20OR%20interface%20OR%20integration%20OR%20internet%20OR%20interoperable%20OR%20online%20OR%20platform%20OR%20portal%20OR%20record%20OR%20software%20OR%20system%20OR%20technology%20OR%20tool%20OR%20web-

Value

We assessed the nomination for value. We considered whether the clinical, consumer, or policymaking context had the potential to respond with evidence-based change, if a partner organization would use this evidence review to influence practice, and if the topic supports a priority area of AHRQ or the Department of Health and Human Services.

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. Many of the transition of care tools in use are available in the United States.
1b. Is the nomination a request for an evidence report?	Yes. The nominator is interested in an environmental scan of current tools in use to aid in transitions of care for childhood cancer survivors.
1c. Is the focus on effectiveness or comparative effectiveness?	No.
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. Childhood cancer survivors transition to survivorship care after completing treatments.
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	In 2022, there were an estimated 18.1 million cancer survivors in the United States, and as of 2020 nearly 496,000 were first diagnosed when they were younger than 20 years old.[1]
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	As a result of improvements in care in recent decades, children with cancer are living longer lives.[4] As they age, this population may face harms due to treatment, including premature or accelerated aging due to chemotherapy, radiation-induced second cancers, infertility and other reproductive health issues, and various psychological issues.[5]
2c. Incorporates issues around both clinical benefits and potential clinical harms	Not applicable.
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	While more information is needed regarding the financial impact of cancer on adolescents and AYAs and their families, this population is particularly vulnerable to the financial burden of cancer care.[2] A recent analysis found that the economic and human costs of cancer in AYAs was substantial, corresponding to $259,324 per person over the lifetime – and most of these costs were borne by AYA cancer survivors in the form of lost productivity, loss of well-being, and loss of life.[3]
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 found 1 relevant systematic review and two narrative reviews. However, no one review covered the entire scope of the nomination. These reviews could be incorporated into a technical brief.
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)?	There does not appear to be a single environmental scan of electronic/digital tools that may be used to help transition AYA cancer survivors from specialty to primary care.
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Not applicable.

5. Primary Research	
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies)	Size/scope of review: We found 5 randomized and 3 non-randomized trials of 220 trials identified. We also found 34 observational/qualitative studies that address the guiding questions.
6. Value	
6a. The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change and supports a priority of AHRQ or Department of Health and Human Services	Yes.
6b. Identified partner who will use the systematic review to influence practice (such as a guideline or recommendation)	Yes. This topic was nominated by a group that would use a report to facilitate education efforts among providers and further the nominator's public policy advocacy goals.

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; AYA=adolescent and young adult.

Appendix C. Topic Nomination

1055 Electronic Health Records for Childhood Cancer Survivors (Second Nom) Topic Nomination

A topic nomination was submitted on the EHC website:

Submitted on Saturday, June 3, 2023 – 10:15

Submit a Topic for a New Evidence Review

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., 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. 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." In addition, a literature review in the Journal of Pediatric Nursing concluded that there is "evidence that a structured [health care transitions] process for 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." 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, 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.

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. Despite these advances, pediatric cancer survivors face a lifetime of numerous, complex health issues, which are often severe and potentially life-threatening. 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." 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 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 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™ 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 patient outcomes.

4. When do you need the evidence report?
Tuesday, December 31, 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.

Supporting Documentation

Upload Document
https://effectivehealthcare.ahrq.gov/system/files/webform/topic_nomination_form/1953/AHRQ%20ECR%20Proposal_ehealthtools.2023_Final%20w.%20References.docx

Optional Information About You

What is your role or perspective?
Professional Society

If you are you making a suggestion on behalf of an organization, please state the name of the organization
Children's Cancer Cause

May we contact you if we have questions about your nomination?
Yes

Full Name
Julie Taylor

Email Address
jtaylor@childrenscause.org

Form Type
Topic Nomination