



September 24, 2021

David Meyers, MD
Acting Director
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Meyers:

On behalf of Children's Cancer Cause, we are pleased to offer comments on the Agency for Healthcare Research and Quality (AHRQ) draft report, "Transitions of Care From Pediatric to Adult Services For Children With Special Healthcare Needs." Children's Cancer Cause (CCC) is the leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families. Our comments focus specifically on the needs of childhood cancer survivors as they transition to adult care.

The number of childhood cancer survivors is now estimated to be 500,000 and continues to grow as more children survive their cancers. However, 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age as a result of their cancer or their treatment. The standards of care for follow-up and surveillance of late effects are established by the Children's Oncology Group (COG) evidence-based guidelines (Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers). We believe that these guidelines and their adherence offer the best evidence basis for the development and adoption of childhood cancer survivorship care plans. Such plans are a critical tool for survivors transitioning from pediatric to adult care. Unfortunately, childhood cancer survivors and their families as well as their primary care providers do not routinely receive survivorship care plans when active treatment ends.

Defining the Transition of Care: Guidelines and Models of Care

As stated in the report, there is no globally accepted definition for effective transition of care from pediatric to adult services for children with special health care needs (CSHCN). This is compounded by the differences among the conditions included in the review in which clinical needs may vary significantly. Because children with cancer have unique and life-long health challenges, the effective transition to adult care should be specific to the unique and complex needs of survivors whose risk of potential of multiple late effects are often life-threatening, including the risk of second cancers. The COG Long-Term Follow-Up Guidelines provide specific recommendations for the types of monitoring needed depending on the cancer treatment exposures. However, a recent GAO report cited a study where a majority of primary care providers reported that they had never utilized the COG guidelines. The AHRQ report should specifically acknowledge the need for healthcare professionals to actively follow the COG Guidelines in their evaluation and treatment of childhood cancer survivors' late effects.

We also believe the AHRQ report ought to cite model, real-world programs that used by many childhood cancer survivors and their families. Such programs provide care for childhood cancer survivors that can serve as models for other settings attempting to transition survivors from pediatric to adult care. For example, the Passport for Care model is widely used in over 50% of Children's Oncology Group (COG) institutions, and by over 45,000 childhood cancer survivors across the nation. Passport for Care uses the COG consensus guidelines for long-term follow-up care to provide guidance to clinicians regarding exposure-based risk for late effects, generating a personalized Survivorship Care Plan that details the treatment summary, potential late-effects, and recommended surveillance. Passport for Care also provides the Survivorship Care Plan to survivors in lay language, together with related COG-developed educational handouts. By providing web-based access to the Survivorship Care Plan, Passport for Care serves as a mobile electronic health record guide to survivorship care that follows the survivor regardless of medical provider, treating clinic, or institution, and may be shared with any member of the medical team.

Another model worth mentioning in the report is SurvivorLink™ (www.cancersurvivorlink.org). Focused on the young adult cancer survivor, SurvivorLink is a patient-controlled electronic personal health record (ePHR) where users can upload and store their important health documents and electronically share their health record with their healthcare providers who are registered on SurvivorLink. Educational materials about survivor care and late effects of cancer therapy are also available for patients/parents and providers.

We provided detailed comments in June 2021 on the ARHQ's "Models of Care that Include Primary Care for Adult Survivors of Childhood Cancer: A Realist Review," stressing the importance of developing model programs for childhood cancer survivorship care plans. We believe that it is important to highlight the development and dissemination of care plan models such as Passport for Care and SurvivorLink in the AHRQ report to demonstrate that childhood cancer survivors' effective transitions to adult care are possible through careful planning and implementation.

Measuring Effectiveness

The AHRQ review also found there is also no single measure or set of measures consistently used to evaluate effectiveness of transitions of care. A limited number of available training and other implementation strategies have been identified through the literature, generally focused on specific clinical specialties in targeted settings. As with other conditions included in the review, the unique and complex nature of the long term health needs of childhood cancer survivors require definitions that consider the clinical characteristics for the transition process as well as to measure effectiveness.

Training and Professional Knowledge

While the review consistently acknowledges the role of psychosocial care in survivors' transition to adult care, we recommend that social workers, psychologists, or other relevant mental health providers be included among the multi-disciplinary care providers (Table 1.1, populations, interventions, comparators, outcomes, timing, and settings, KQ2, Implementation Strategies). These providers are essential to ensuring that survivors' social and emotional needs associated with the late effects of treatment are fully integrated into the transition of care.

The review found considerable variability in transition care training, and care interventions to prepare pediatric patients and their families for transitioning to adult care. The report notes that Got Transitions™ offers a sound structural framework for the successful transition to adult care. However, as noted in the review, the broad scope of the Got Transitions Six Core Elements does not account for the interventions best suited for specific participant characteristics and complex needs in making a successful transition to adult care, as is the case for with childhood cancer survivors. The review notes that the “majority of trainings addressed a specific disease” and “targeted providers of various clinical backgrounds, often relative to the setting in which they practiced.” Other training programs for transitioning patients from pediatric to adult care as identified by AHRQ were those developed by professional medical organizations. Of note, none of the studies identified by the Agency measured the effectiveness of providing linguistic and culturally competent healthcare care for children with special healthcare needs (CSHCN). There is clearly a need for more provider training and ongoing education for more effective care transitions for CSHCN, as well as increasing the number of providers available to these populations. The September draft review also stresses that more needs to be done to assist patients and families in the transition to adult care. Such assistance is especially critical for the childhood cancer population due to the unique, complex, and long term health care needs resulting from cancer treatment.

The June 2021 draft report, “Models of Care,” found that if care is delivered outside of a specialty care setting, there must be effective knowledge transfer about treatment history to survivors and families as well as to and PCPs. The AHRQ report identified several ways this knowledge could be shared, including a range of resources (e.g., guidelines, survivorship care plans) and contexts (e.g., survivor confidence in PCPs, shared care with oncologists). As noted in the June AHRQ report, studies showing that knowledge transfer did not always result in survivorship care planning and that more work is needed to make sure the knowledge is available, accessible and the provider knows about it and is reminded where to get it. The report found -- and we agree -- that further research is required to explore the above knowledge transfer strategies and contexts for effective implementation.

Implementation Barriers and Reimbursement

As pointed out in the Introduction, “persistent uncertainty about effective programs and practices, as well uncertainty or inconsistency about incentives to engage in transition care (e.g., reimbursement, capacity, training) across settings and specialties (e.g., primary care)” is a significant barrier to effective care transitions. Payers and other relevant stakeholders need to recognize the time and resources required to provide the necessary transition services by establishing reimbursement policies. The review noted that some transition approaches “include dedicating time and resources to support transition planning, developing a workforce trained to care for the needs of this population, and creating structured processes and tools to facilitate the transition process.” Initiatives are needed to determine the scope of the work involved in transition care planning and implementation and develop reimbursement policies that offer reasonable incentives to provide such services.

The review’s conclusions state, “Little rigorous evidence is available to inform care interventions and implementation strategies. Significant barriers exist to implement effective interventions, tools, and trainings to transition CSHCN. This review highlights the lack of sufficient evidence and need for more-rigorous studies

across the diverse populations of CSHCN to provide clearer answers for CSHCN, their families, caregivers, providers, funders, and policymakers.”

The lack of sufficient evidence to support widespread dissemination of interventions and implementation strategies for effective transitions for CSHCN analyzed in this review provide no clear answers for CSHCN, their families, caregivers and providers, funders, and policymakers. Currently, stakeholders have little to rely on beyond local and institutional policies to determine whether to disseminate or implement these interventions in their populations or care settings.

In the case of childhood cancer, this lack of evidence is even more stark; the AHRQ review notes that only one study addressing Key Question 1 within the population of cancer survivors was included. While we highlight two models for survivorship care planning for childhood cancer survivors, the draft report concludes that evidence-based interventions for the transition from pediatric to adult care are limited. Both because of the limited number of studies and because real-world examples exist, the report should acknowledge the Passport for Care and SurvivorLink models referenced above. In addition, there is a clear need to validate current models being used for this purpose and these should be evaluated with specific considerations to the unique needs of childhood cancer survivors.

CCC agrees that better evidence is needed to support new payment models for transitioning to adult care, as well as for the care necessary for childhood cancer survivors once they complete their cancer treatment. We have shared with AHRQ in previous comments there is an ongoing and unmet need to develop and test new healthcare payment and service delivery models that have a real-world application. This is relevant to services for effective transitioning to adult care. Specifically, the CCC supports the authorization of a Center for Medicare and Medicaid (CMMI) demonstration program to develop standards of care for survivors of childhood cancer with a focus on potentially scalable models based on the COG guidelines across the United States. The CCC's legislative and regulatory proposal would serve children and adolescents under a Medicaid demonstration program, providing care for at least a six-month period following their active cancer treatment. Attached is a CCC proposal for such a demonstration entitled the Child and Adolescent Cancer Survivorship Transition (CAST) Model. We recommend that the report as an example of a model that could generate evidence to be tested by CMMI.

Research Gaps

The AHRQ review acknowledges research limitations on answering questions of which interventions work best and under what circumstances. This is especially acute for the childhood cancer survivor population, in particular addressing questions on models that include differences for diverse and underserved populations. The report stresses that “specific implementation of interventions must reflect the substantial heterogeneity of the population, which includes diverse social, behavioral and medical needs.” We agree that for the childhood cancer population, a different clinical approach is needed for a survivor who develops cardiotoxic late effects than a child with a congenital heart condition. The report offers another example on the difference “between supporting the transition of a child that has lived with developmental delays their entire life versus one who acquired a development delay after treatment for a brain tumor.” Adult survivors of childhood cancer may

require lifelong from adult primary care providers as well as care from specialists in tertiary care centers. Due to the paucity of research studies, we understand the need to address a variety of conditions among CSHCN; however, the review understates of the need to conduct research on transition care models that is specific to the complex and varying needs of childhood cancer survivors.

Conclusion

As with previous AHRQ reports, this review provides further evidence of the significant gaps in survivorship care, including the development, evaluation, and implementation of effective interventions to address the needs of childhood cancer survivors as they transition from childhood cancer care to adult care. We are grateful for your careful review of the evidence on transitions from pediatric to adult care for CSHCN. This latest AHRQ review notes several important areas that can markedly advance understanding of how to improve childhood cancer survivors' transitions from pediatric to adult care:

- There should be a clear definition of "transition" to adult care, and we would encourage the definition to include the unique and complex needs of particular populations of CSHCN, such as childhood cancer survivors.
- The effectiveness of any transitions in care model should be fully evaluated; real world evaluations such as CMI demonstrations may be particularly effective.
- Transition to adult care for childhood cancer survivors (as well as other CSHCN conditions reviewed) require additional efforts to improve education and training of multiple care providers – both primary and specialty – to ensure improved uptake and adherence to the evidence-based guidelines for long-term follow-up care for childhood cancer survivors.
- Barriers to implementation of transition care need to be addressed through reimbursement and other incentives to address providers' dedicated time and resources required for transition care planning.
- All these factors point to the need for additional research on the "what" and "how" to best ensure effective transitions from pediatric to adult care for children with special health care needs.

We look forward to working with you on these issues and others related to improving care for childhood cancer survivors. If you should have questions, please contact Julie Taylor at jtaylor@childrencancercause.org.

Sincerely,

A handwritten signature in blue ink that reads "Steve Wosahla".

Steve Wosahla
Chief Executive Officer
Children's Cancer Cause