Comparative Effectiveness Review Disposition of Comments Report

Title: Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs

Draft report available for public comment from September 3, 2021, to September 24, 2021.

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Comments to Draft Report

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This document includes the responses by the authors of the report to comments that were submitted for this draft report. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Peer Reviewer, Technical Expert, and Public Comments and Author Response

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Evidence Summary	At the top of page ES-3, the authors state that "None is available specific for CSHCN". Consider clarifying the thought a bit to include language from page 62. Presumably the "none" refer to cultural and linguistic competence trainings.	We have clarified the statement on ES-3 to more directly reference the availability of cultural and linguistic competence trainings. The last sentence now states: CSHCN, their caregivers, providers, and other stakeholders may initially draw from evidence and best practices outside of this population by using a few systematic reviews and organizational trainings that inform culturally and linguistically competent healthcare in general healthcare populations and settings, but recognize that they are not specific to CSHCN.
Peer (TEP) Reviewer #8	Evidence Summary	In the section on Implications and Conclusions on page ES-3, the authors state "the lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, and funders and policy makers." As previously noted, HCT is complex and multi-dimensional and the HCT research field is emerging, is it realistic to expect clear answers from this study.	We have added additional language to the Implications and conclusions section on ES-3 to recognize the complex nature and emerging field of HCT and state: While we recognize that healthcare transitions are complex and multi-dimensional, 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 as this field is emerging.
Peer (TEP) Reviewer #8	Evidence Summary	The statement on Page ES-3 that "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" and again on page 73 fails to acknowledge policy statements, clinical and evidence reports from a number of health professional organizations as well as the guidance provided by HRSA/MCHB. In addition to previously cited clinical reports, the Society for Adolescent Health and Medicine released a position statement in 2020, https://www.jahonline.org/article/S1054-139X(20)30075-6/fulltext. It's not that organizations and stakeholder groups disagree on the definition of healthcare transition; rather, it's the definition of effective HCT as noted on page 72.	We acknowledge that several health profession organizations have released policy statements and have clarified this in the evidence summary and have added the suggested citation. While these statements exist, our systematic review highlights gaps in the current evidence (similarly to previous AHRQ reviews on this topic), providing future opportunities to more rigorously evaluate future interventions. We also note that this field is emerging. We have revised the statement to say: While we recognize that healthcare transitions are complex and multi-dimensional, stakeholders must rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings as this field is emerging.
Peer (TEP) Reviewer #1	Introduction	Well written and compelling.	Thank you for the comment.

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Peer (TEP) Reviewer #2	Introduction	The Introduction aptly describes the report and provides the appropriate context for the report findings.	Thank you for the comment.
Peer (TEP) Reviewer #4	Introduction	Solid	Thank you for the comment.
Peer (TEP) Reviewer #6	Introduction	PDF pg. 17 table- and throughout this section, the language: " Adolescents and young adults (diagnosed with cancer or other special healthcare condition before 21 years old) with a chronic physical or mental illness or physical, intellectual, or developmental disability." is confusing and repetitive. Could you just say "adolescents and young adults with a chronic physical or mental illness or physical, intellectual, or developmental disability diagnosed before age 21"	Thank you for the suggestion. The table of population, intervention, comparator, outcomes, timing, and settings, established during an extensive topic refinement period. Likewise, the inclusion and exclusion criteria and definitions were set a priori after input from a panel of technical experts, and remained consistent throughout the review process. Both the original language and suggested language would allow for inclusion of the same population so we have kept the original language posted in the protocol.
Peer (TEP) Reviewer #6	Introduction	same table and throughout: concerns about use of the term "sex" instead of "gender identity" and lumping it with sexual identity which has a quite different meaning and implication. This page may be a useful reference and provide sample, appropriate language.https://dpcpsi.nih.gov/sgmro/measurement	Thank you for highlighting the importance of ensuring that sexual and gender minority status is adequately measured and described in the context of the report. We have highlighted our inclusive meaning of sex and gender identity in the context of NIH suggested literature on the topic, but chose to use a consistent term throughout. We now state in the methods: These fields included subject inclusion and exclusion criteria, intervention and comparison characteristics, study funding source and special subpopulations (e.g., sex/sexual identity, race/ethnicity, socioeconomic status), if reported. In the report, we use the term sex/sexual identity as a broader umbrella to encompass an individual's sexual or gender identity which may include sexual orientation, gender identity or expression. We also recognize that, while important, information on important sub-populations were often not included or reported by stating in the results that: Many important sub-populations (e.g., race, socio-economic status, sex/sexual identify) reported in these studies were either not included as subjects of study or results were not separately reported the context of these interventions.

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Peer (TEP) Reviewer #6	Introduction	pg. 18 table of outcomes- listing "intervention" as an implementation outcome is confusing. Assuming it means features of the intervention or something like that? perhaps clarify.	We have clarified that we meant intervention adoption, fidelity, sustainability, feasibility, acceptability and/or satisfaction.
Peer (TEP) Reviewer #6	Introduction	same table/page- the distinction between wellness screenings and psychosocial outcomes is not clear-certain things like mental health outcomes are listed as examples of both.	We have clarified that for wellness screenings we mean that providers would screen for conditions such as depression, anxiety, etc. This is distinct from a psychosocial outcome of a diagnosis of depression or anxiety.
Peer (TEP) Reviewer #6	Introduction	disease specific clinical outcomes, morbidity, etc. are listed as an implementation outcome but typically patient level clinical outcomes are NOT considered to be implementation outcomes and are in fact used to screen out studies to be labeled as implementation if they only have such outcomes. please clarify.	In our PICOT, we included studies that evaluated the outcomes of implementation strategies for CSHCN. We purposely included a broad range of outcomes that included both traditional implementation evaluation metrics (e.g., intervention sustainability, feasibility, etc.); however, we did not want to exclude studies that may have also evaluated clinical outcomes in this context to allow for a more robust evaluation of the literature in this area.
Peer (TEP) Reviewer #6	Introduction	same comment as above regarding the parentheses and confusing definition of the patient population.	We have clarified that the language around the intervention includes adoption, fidelity, etc. and have edited the parentheses for clarity. After descriptions of the intervention outcomes, we describe satisfaction as including physician and other formal caregiver satisfaction.
Peer (TEP) Reviewer #6	Introduction	Also multidisciplinary care is defined well on the following page but listing it in the figure alone without clarification makes it sound as though you are talking about health care, education, social services integration.	We added a note in Table 1.1 to point the readers to Table 1.2 for a definition of multidisciplinary care providers.
Peer (TEP) Reviewer #6	Introduction	Finally, here and elsewhere sometimes using health care setting and other times using medical care is confusing. suggest including one or the other throughout report.	We have edited the text throughout and now use the term medical care consistently.
Peer (TEP) Reviewer #7	Introduction	The introduction sets the context for the review. Introduction to 'Got Transition' and the Six Core Elements is important. … Table 1.1 is helpful.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #7	Introduction	Additional text explaining the Key Questions and Contextual Questions might be helpful to the reader, i.e. additional explanation regarding why the Contextual Questions were added, the importance of these questions, etc.	The Key and Contextual questions were refined, clarified, and established during an extensive topic refinement including conversations with key informants. We recognize the importance of understanding the importance of the questions as well as the motivation. We made a slight revision, moving the motivation to the introduction of the research questions and now state: KQs and CQs were developed based on National Cancer Institute priorities and input from technical experts, with further feedback and refinement received during a public comment period.
Peer (TEP) Reviewer #7	Introduction	The sub-questions under each Key Question are repetitious and perhaps could be organized in another way to simplify.	The Key and Contextual questions were established during an extensive topic refinement period with conversations with key informants, and were posted for public comment. They have since remained consistent throughout the review process.
Peer (TEP) Reviewer #8	Introduction	It would be useful to define health care transition up front using the definitions on page 50-51.	We have added a definition of healthcare transitions in the introduction and note that no globally accepted definition of an effective healthcare transition exists. We use the definition from the AAP, AAFP and ACP defined as "maximizing lifelong functioning and well-being…[thereby] ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood"
Peer (TEP) Reviewer #8	Introduction	The rationale for undertaking the study that is provided is inadequate (page 1, para 1). Suggest expanding on the significance of improving healthcare transition for CYSHCN.	We agree that highlighting the significance of improving the healthcare transition for CSHCN is critical. We have added the follow sentence to the introduction: Therefore, identifying the most effective interventions to improve healthcare transitions for CSHCN and outcomes in this population is critical.
Peer (TEP) Reviewer #8	Introduction	Consider acknowledging that HCT is a Healthy People 2030 research objective: • HP 2030 research objective https://health.gov/healthypeople/objectives-and-data/browse-objectives/adolescents/increase-proportion-adolescents-who-get-support-their-transition-adult-health-care-ah-r01	We have added additional context to highlight the importance of HCT as a priority for Healthy People 2030 in the introduction and now state: 'Therefore, identifying the most effective interventions to improve healthcare transitions for CSHCN and outcomes in this population is critical, as evidenced by prioritization of healthcare transitions as a Healthy People 2030 research objective.'

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Introduction	Further, HCT is one of 15 Maternal and Child Health (MCH) National Performance Measures (NPMs) for the State Title V MCH Services Block Grant to States program. The goal of NPM 12: Transition is to increase the percent of adolescents with or without special health care needs (SHCN) who have received services to prepare for the transition from pediatric to adult health care. As part of a HRSA/MCHB funded initiative to Strengthen the Evidence Base for MCH Programs and support states in their development of strategies, an evidence review was conducted. The full report and supplemental implementation resources can be found at: www.mchevidence.org/documents/reviews/npm-12-transition.pdf and www.mchevidence.org/tools/npm/we-transiton.php.	Thank you for highlighting these additional resources which are now included as references in our introduction. As noted in the results of the evidence review, the rating of scientifically rigorous was not given to any included studies, highlighting the opportunity for further evidence synthesis using a broader range of inclusion criteria and research questions. We now state in the introduction: While CSHCN often experience significant barriers to effectively transitioning from pediatric to adult medical care, the lack of rigorous evaluation of interventions and strategies to reduce these barriers may hinder widespread development and dissemination of policies and programs for this population, as has been highlighted in previous evidence reviews.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Introduction	Consider expanding the statement on page 1, paragraph 2 about the 2011 clinical report to note that the published framework is to aid clinicians in the implementation of care transition into their patient/family-centered medical home practice. Regarding the Six Core Elements of Health Care Transition, it should be noted that it is a structural quality improvement process that can be customized to apply to many different types of transition care models. It also should be noted that the description only includes elements applicable to pediatric clinicians. There are elements applicable to adult practices as well as those practices where the youth doesn't need to transfer. What is the meaning of the sentence: "However, the broad spectrum of the Six Core Elements has raised questions about the best transition intervention designs, implementation tools, and strategies"? The 2018 Clinical Report from the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians recommended the implementation of the Six Core Elements for improving the transition process. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics. 2018; 142(5):e20182587	We expanded the sentence about the 2011 clinical framework to acknowledge that the goal was to 'aid clinicians in transition within their medical home. We have clarified the description of the Six Core Elements and state that it is 'a structured clinical quality improvement approach for transitioning patients from pediatric to adult medical care customizable across many transition care models.' For the statement about the broad spectrum of Six core elements, we have clarified that it is not the elements themselves, but the broad spectrum of included components and now state: the broad spectrum of included components targeted within the Six Core Elements has raised questions about the best transition intervention designs, implementation tools, and strategies to address these complex transitions.
Peer (TEP) Reviewer #8	Introduction	The citation for the data on the number of youth transitioning between 2011-2017 is from 2013 (Page 1, para 1). Please revise as appropriate.	The citation is correct and is an estimate based on the 2009-2010 National Survey of Children with Special Health Care Needs. We now clarify that this is an estimate.

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Peer (TEP) Reviewer #8	Introduction	Some of the citations for the background section are dated. There are more current publications, including a few systematic reviews. For example, • Otth, M., Denzler, S., Koenig, C. et al. Transition from pediatric to adult follow-up care in childhood cancer survivors—a systematic review. J Cancer Surviv 15, 151–162 (2021). https://doi.org/10.1007/s11764-020-00920-9 • Annie Schmidt, Samhita M. Ilango, Margaret A. McManus, Katherine K. Rogers, Patience H. White, Outcomes of Pediatric to Adult Health Care Transition Interventions: An Updated Systematic Review, Journal of Pediatric Nursing, 51, 2020, 92-107, ISSN 0882-5963, https://doi.org/10.1016/j.pedn.2020.01.002.	We have added the additional citations to the background of the introduction.
Peer (TEP) Reviewer #9	Introduction	The key and contextual questions are important and relevant. I think it would be important to address this issue of how self-management outcomes fit into evaluating transition outcomes and the Key questions.	We agree that self-management is an important component that can affect transition outcomes and have added this as a key factor in the introduction.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #9	Introduction	The Got Transition 6 core elements framework is appropriately mentioned frequently and used as a way to categorize interventions. However, although the 6 core elements provide a nice framework for QI and implementation work, they may not necessarily provide a comprehensive framework for evaluating all the potential factors that may impact transition outcomes and require interventions. As the authors note, a clear definition of successful transition and agreed upon outcome measures are needed, along with potentially multicomponent interventions. To appropriately evaluate multicomponent interventions, describing the impact of these interventions within a broader context of the individuals overall transition to adult life (including education/vocational outcomes, community participation, etc.) might facilitate agreement on the healthcare-related outcomes to measure effectiveness, as well as other characteristics/factors to adjust for. A discussion of other conceptual models for health care transition and transition interventions may be helpful. For example some use an ecological model (Wang et al, J Pediatr Nurs. 2010 December ; 25(6): 505–550; Betz et al. Pediatr Rehabil Med. 2014;7(1):3-15). to describe how various factors may relate to transition outcomes.	We completely agree with the reviewer that there is no globally agreed upon definition for an effective healthcare transition as highlighted in our report. In consultation with our technical expert panel during the topic refinement period, we chose to use the Six Core Elements as a framework for understanding how interventions address the wide range of components that may be required for successful transition. However, we recognize that other models exist and may provide frameworks in other contexts. We have added clarification that this is only one model and now cite this framework as well.
Peer (TEP) Reviewer #9	Introduction	Table 1.1 comments Population: Patient subgroups - Some potential other patient factors/characteristics that have been identified as potentially impacting transition readiness or transition outcomes include the patient/family health literacy status and particularly prior health care utilization /visit attendance. Multidisciplinary Care Providers - Think RNs and Social workers would be important to include here.	We have added these additional important patient subgroups to the introduction and now state: Characteristics that might affect transition outcomes include patient demographics (e.g., age, ethnicity), capacity for self-management (e.g., health literacy, prior healthcare attendance), condition type and severity, provider/hospital features (e.g., access to specialty services, specialty training) and care setting (e.g., specialty center, telemedicine). We have additionally clarified in table 1.2 that social workers and RNs are included under the umbrella of multidisciplinary care providers.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #9	Introduction	Outcomes: Not sure where provider satisfaction or burden/burnout will be included here?	We have clarified in the outcomes in table 1.1 that provider burden would be included as an example of an unintended consequence.
Peer (TEP) Reviewer #9	Introduction	Timing: 6 months post transition - Just want to clarify if this means that interventions that didn't measure actual transfer (such as disease knowledge or patient activation prior to transfer) were excluded?	To clarify, we included a broader set of studies that included outcomes in the population listed in table 1.1.
Peer (TEP) Reviewer #9	Introduction	Figure 1: where do systems interventions - such as improved access to health insurance, payment for transition planning seem fit here?	These could be included as components under KQ2, Implementation Strategies.
Peer Reviewer #10	Introduction	p.3: Table 1.1 confusing. Unclear if referring to general content.. or summary of studies	We have clarified that Table 1.1 is an overview of our PICOT and now state: Table 1.1 provides detailed information on the populations, interventions, comparators, outcomes, timing, and settings (PICOTS) and include criteria used for inclusion of studies in the review based on Key Questions
Peer Reviewer #10	Introduction	p.7: define adol/YA. Is there an age range?	We included a broad age range for adolescents up to age 21 to allow for a comprehensive review of available studies. This included studies if they evaluated healthcare transitions for adolescents and young adults age 10-21 as defined by the World Health Organization.
Peer Reviewer #11	Introduction	Introduction line 12-14: approximately 4.5 million children ages 12 – 18 with special healthcare needs (CSHCN) transitioned from pediatric to adult healthcare providers. Those who are 12-18 are not transitioned, usually they are preparing for transition and over 18 have been transitioned.	We agree with the reviewer that individuals may be in various stages of the transition process during this age range and have clarified that: Between 2011 and 2017, an estimated 4.5 million children ages 12 – 18 with special healthcare needs (CSHCN) transitioned or prepared to transition from pediatric to adult healthcare providers
Peer Reviewer #11	Introduction	Introduction nicely lays out key questions and sub-questions	Thank you for the comment.
Peer Reviewer #11	Introduction	Glossary of terms. I wonder if under multidisciplinary providers we should list out social workers, nurse navigators, community health workers since these groups are increasingly being used for transition.	Thank you. We have added these providers to the glossary of terms.
Peer Reviewer #11	Introduction	Could risk of bias be flushed out more in this section. I know it links to the source and there is an Appendix, but I think more content in the text might be worthwhile (here or methods)	Thank you. The Methods section does contain more information on risk of bias assessment, and points readers to the appendix as well, which contains detailed decision rules for the assessment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #1	Methods	The methods seem clear as do the search strategies used. Clearly there was an abundance of abstracts and articles that were examined and the type of eligible studies allowed for a good sample of studies that included the important groups, (CSHCN, families, caregivers, and health care professionals)	Thank you for the comment.
Peer (TEP) Reviewer #2	Methods	The methods for the report are appropriate and rigorously defined and delineated for the audience. The methods are in line with systematic reviews. Inclusion and exclusion criteria are justifiable, such that findings could be easily reproduced. The accompanying appendices thoroughly describe the definitions, flow-charts and outcomes for the report.	Thank you for the comment.
Peer (TEP) Reviewer #4	Methods	Very clear	Thank you for the comment.
Peer (TEP) Reviewer #6	Methods	No additional comments or concerns with the methods. Appropriately defined and described (with the one note above about exclusion of autism and related conditions by the nature of health care focus). Some of the comments in introduction section for the tables may be categorized as needing more clarity on definition of outcome measures.	Thank you for the opportunity to clarify. We did not specifically exclude studies addressing transition for children with intellectual/physical disabilities. However, as we focused on healthcare transitions this did exclude many studies within these populations as they tended to focus on work/school transitions. We have clarified this in the strengths and limitations section stating: However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #7	Methods	The methodology is nicely outlined. Eligible studies are explained, and the strategy is outlined in table format. Search criteria and databases examined are provided in the Appendix. The addition of a grey literature search is a strength, given that many of the studies informing this topic may not be published in the expected peer-reviewed journals or many have been discussed/presented in other forums. Table 8.2 is a useful addition. Note typo in Appendix A, p. A-2, 'We searched for grey literature using Google, Google Scholar…'.	Thank you for the comment.
Peer (TEP) Reviewer #7	Methods	A potential overlooked variable is immigration status. This may/may not have been addressed in any of the studies but could impact healthcare transitions.	We agree that immigration status can significantly influence access to healthcare and effective healthcare transitions. We added this as an example in the introduction stating: Characteristics that might affect transition outcomes include patient demographics (e.g., age, ethnicity, immigration status), capacity for self-management (e.g., health literacy, prior healthcare attendance), condition type and severity, provider/hospital features (e.g., access to specialty services, specialty training) and care setting (e.g., specialty center, telemedicine). We also now note this in our discussion of populations studied in the included literature: Additionally, stakeholders noted the importance of understanding the variation in effectiveness of interventions across characteristics of CSHCN (e.g., age at diagnosis, sex/sexual orientation, race/ethnicity, religion, socioeconomic status, immigration status adverse childhood events such as trauma, and care setting). While the included literature may have enrolled individuals from these important subpopulations, studies rarely reported results according to these characteristics.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Methods	It seems after review of the literature and finding a lack of comparative effectiveness studies, the authors may have considered adjusting the methodology and broadening the analysis, perhaps to include other types of studies as well as quality improvement research.	We included a broad population and set of included interventions that fell under the broader umbrella of healthcare transitions (as included in the Got Transitions® framework). As we note in the review in the discussion: We broadly defined care interventions, implementation strategies, and trainings to enlarge the scope of studies and thus better understand the range of relevant interventions. This included quality improvement research. However, we note that the majority of included studies are in Stage I of the National Institutes of Health Stage Model. Stage I encompasses the generation of new behavioral interventions as well as feasibility and pilot test of these interventions. Few studies evaluated interventions focused on later stages of the model such as efficacy (Stages II and III), effectiveness (Stage IV), or implementation and dissemination of interventions in community settings (Stage V).
Peer (TEP) Reviewer #8	Methods	Should studies conducted outside of the United States be distinguished from those that were in the US given the variability in health care systems?	We completely agree it is important to distinguish the setting of these interventions as the application may vary in US versus non-US settings. For readers interested in the location of the study, we have included information on location (e.g., United States) in Appendix D.
Peer (TEP) Reviewer #9	Methods	Would like to see the search strategy specifics in the text of the Methods.	Due to space limitations and readability concerns, the search strategy is presented in Appendix A. A brief overview of our search strategy is included on page 8.
Peer (TEP) Reviewer #9	Methods	I realize it might be out of the scope of this review, but I would recommend commenting on the fact that it is possible other studies evaluating interventions for self-management of chronic conditions, that one could argue are relevant to transition readiness or an important transition outcome itself), may not be captured in the current search strategy. For example, there are no studies identified on self-management in those with DM.	We completely agree that studies such as self-management of chronic conditions may provide important context for broader, successful healthcare transition interventions; However, these studies were beyond the scope of our review. We now note this in the limitations of our discussion stating: Further, studies that focused exclusively on self-management of conditions (among CSHCN) in the absence of a healthcare transition were beyond the scope of our review, although evaluation of this literature may provide important insights for components of a broader healthcare transition intervention.
Peer (TEP) Reviewer #9	Methods	Figure 3.1 - It appears only 173 of the 270 studies that were excluded b/c didn't describe care transition interventions are listed in Appendix C	We have updated Appendix C to now include the full list of 270 studies.

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Peer (TEP) Reviewer #9	Methods	The methodology for how studies were identified/included for Barriers/Facilitators was less clear to me. There are a plethora of studies in transition describing barriers to transition and besides the 147 intervention studies, it wasn't clear how other studies were chosen to inform this discussion.	We have clarified our methodology to be more clear about how we identified the studied evaluated to examine barriers and facilitators to implementing interventions and tools. In Chapter 6 we state: We identified barriers and facilitators from included studies (N=147) that evaluated 1) care interventions for transitioning CSHCN and their families/caregivers, 2) implementation strategies for care interventions for transition, and 3) tools to facilitate communication between pediatric and adult providers. These 147 studies were supplemented by literature (identified from our broader search strategy) that specifically examined barriers and facilitators to successful transitions, but not in the context of an intervention. Themes were abstracted until saturation, at which point no additional themes were found from reviewing successive studies. Additionally, in the methods section we have clarified: To examine KQ1-3c (barriers and facilitators to implementation), we abstracted examples from articles included in KQ1-3 as well as additional articles identified through our primary search strategy that specifically examined barriers and facilitators to successful transitions until themes were saturated.
Peer Reviewer #10	Methods	P. 9: This statement and process seems underspecified: Additional identified articles of either quantitative or qualitative design not used for KQs might still have contributed data toward barriers and facilitators extraction, if they provided particularly clear examples. We also assessed these articles for further usefulness for addressing the CQs. If studies seemed useful, we abstracted data into tables.	We have clarified our strategy for including studies evaluated for barriers and facilitators of successful transitions and now state: To examine KQ1-3c (barriers and facilitators to implementation), we abstracted examples from articles included in KQ1-3 as well as additional articles identified through our primary search strategy that specifically examined barriers and facilitators to successful transitions until themes were saturated.
Peer Reviewer #11	Methods	Inclusion and exclusion criteria are justifiable. Would be very explicit that interventions aimed at transition to school or work vs. adult medical care were excluded. It says this in one location, but just to be consistent.	We clarify in the study selection that: As this review focused on healthcare transitions, studies evaluating transitions to school or work were beyond the scope of this review.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #11	Methods	Search strategies are clear. I had a question about the Grey literature search. I see you used google, I was wondering specifically about Med Ed Portal since that might have some relevant items for specifically the education question.	General education in the context of medical school was excluded as this was outside the scope of the review. The review focused on trainings provided to multidisclinary providers in the context of providing clinical care. We have clarified this in the methods, but encourage the inclusion and development of more educational programming in the context of medical education to support knowledge of CSHCN and their healthcare needs.
Peer Reviewer #11	Methods	Risk of bias: Would be nice to expand upon how this determination was made/graded (as above) even though I know it is in appendix. I think it made sense to try and organize/ground by Six Core Elements as stated.	Due to space constraints and readability concerns, detailed information on the approach for risk of bias assessments are included in the Appendix only.
Peer Reviewer #11	Methods	Grading Strength of Evidence: Makes sense	Thank you for the comment.
Peer Reviewer #11	Methods	The way the studies ended up in the evidence map studies is confusing to me. This may just be me. But a more detailed description could be useful. Why were those studies excluded before risk of bias assessment and put in this section.	The risk for biased outcomes, not being able to infer if an observed change was due to the intervention or to some other factors, is highest when a study does not include the ability to compare to situations where the intervention was not present. Because of this, studies without a comparison of some fashion are by definition high risk of bias. Removing these studies from the review process at this point reserves resources which can be more usefully spent on better quality studies or other synthesis processes.
Peer (TEP) Reviewer #1	Results	As stated there was a large body of literature which led to 147 references describing or examining a care transition intervention with good detail pg 12 The paragraph starting with "significant barriers impede..." summarized the report very well.	Thank you for the comment.
Peer (TEP) Reviewer #2	Results	The results section utilizes a formulaic approach such that the amount of detail can appear overwhelming at times. Nonetheless, as the results are outlined by disease/condition, the audience may focus on separate sections, as appropriate for their own work.	Thank you for the comment.
Peer (TEP) Reviewer #2	Results	I do not believe any studies were overlooked (e.g., in the filed of HIV).	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #4	Results	I think it helpful to have included the level of detail offered in the report, including stratification of results by disease type.	Thank you for the comment.
Peer (TEP) Reviewer #6	Results	table on page 26 using terms "other conditions" and "chronic conditions" is confusing since they have not yet been defined (on the next page).	We now provide examples of other conditions on page 12 and in table 4.1 stating:(e.g., hemophilia, endocrine conditions) to introduce the reader prior to this point.
Peer (TEP) Reviewer #6	Results	pg. 56 some confusion about how an implementation study can be stage 1	In the NIH stages model, Stage I encompasses the generation of new behavioral interventions as well as feasibility and pilot test of these interventions. This was the purpose of many of this implementation studies.
Peer (TEP) Reviewer #6	Results	overall results easy to follow with appropriate level of detail	Thank you for the comment.
Peer (TEP) Reviewer #7	Results	The results are presented in a consistent format. The tables are helpful.	Thank you for the comment.
Peer (TEP) Reviewer #7	Results	The arrows in Table 4.2 are not defined, not clear what they mean.	We have added the following note to the table: Note: Up arrows signify results favor the intervention; down arrows signify results favor usual care; horizontal double-headed arrows signify no difference between groups.
Peer (TEP) Reviewer #7	Results	The description by disease condition is helpful. However, the description of 'CSHCN with cancer' is not clear. This literature is explicitly concerning cancer survivors, not children 'with' cancer. Would be helpful to be clearer in this section.	We have now clarified that this literature set includes CSHCN with a history of cancer
Peer (TEP) Reviewer #7	Results	The exclusion of studies addressing transition for children with intellectual/physical disabilities is not clear (no genetic syndromes, Trisomy 21, etc. were included). It seems this might be a significant proportion of the population of CSHCNs, and they have long-term healthcare needs, aside from just vocational needs.	Thank you for the opportunity to clarify. We did not specifically exclude studies addressing transition for children with intellectual/physical disabilities. However, as we focused on healthcare transitions this did exclude many studies within these populations as they tended to focus on work/school transitions. We have clarified this in the strengths and limitations section stating: However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly such as school or work transitions. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Results	I did not find the studies clearly described and at time, confusing. Consider having a table of the analytic set that would include the "interventions", measures, and outcomes. Be specific about the components of the "intervention".	We agree that it is important to understand many of the elements of individual included studies that were part of the analytic set. For a further evaluation of the components you describe, we have provided detailed information by study on the interventions (including components of the intervention), outcome measures in Appendix D. The Results tables are a summary of the individual studies to allow for evaluation at a high level of where interventions and outcomes were focused.
Peer (TEP) Reviewer #9	Results	Results are overall comprehensive and given the variety of interventions and outcomes and overall heterogeneity of studies, well organized.	Thank you for the comment.
Peer (TEP) Reviewer #9	Results	Table 4.6 - Outcomes Evaluated: is Time to Transition consider a Transition Readiness outcome or more of an Engagement in Care?	After consideration, we have moved this outcome to engagement in care as we agree it more closely aligns with this element.
Peer (TEP) Reviewer #9	Results	Page 37, Line 43-44 - think should read CSHCN with Spina bifida	Thank you we have added the dropped language and now state: Evidence was insufficient to draw conclusions about the effects of interventions for care transitions for CSHCN with spina bifida.
Peer (TEP) Reviewer #9	Results	For other examples of potential other transition/self-management interventions for spina bifida: Sawin KJ, Margolis RHF, Ridosh MM, Bellin MH, Woodward J, Brei TJ, Logan LR. Self-management and spina bifida: A systematic review of the literature. Disabil Health J. 2021 Jan;14(1):100940.	Thank you for highlighting this important literature set. We note the importance of self-management of individual conditions to promote readiness for transition and reduce adverse outcomes after transition. However, studies that focused on self-management in the absence of a transition intervention were beyond the scope of the review. We now state in the discussion: Further, studies that focused exclusively on self-management of conditions (among CSHCN) in the absence of a healthcare transition intervention were beyond the scope of our review, although evaluation of this literature may provide important insights for components of a broader healthcare transition intervention.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #9	Results	Figure 6.1: 2 major barriers that are described in literature and quite common in my experience are difficulty addressing 1) the impact of the strong patient-pediatric provider relationship (both for provider and patient/family) and 2) the fear/anxiety of the unknown for patient and caregivers. These appear missing from the list here and both can impact letting Go and effectiveness of interventions such as Transition Policies and Transition Readiness.	We agree that these are important barriers and had considered them more broadly in the discussion of outer setting and characteristics of the individual. However, to more explicitly state these barriers, we have clarified two sentences: Unfortunately, many CSHCN are reluctant to disclose their need for support, and report feelings of disruption and abandonment around the transition from pediatric to adult services due to the strong patient-pediatric provider relationship. Additionally, we now state: Notably, patients and caregivers feel uncertain about where to find appropriate medical care, overwhelmed by the steps to seek services, and frustrated by the lack of comprehensive information about the healthcare transition process and fear/anxiety of the unknown.
Peer (TEP) Reviewer #9	Results	Table 7.1 I would consider including Got Transitions' "Current Assessment of Healthcare Transition Activities" in this table may be appropriate since it seems to be one of few ones representative of assessments of the process outcomes of transition, such as having a transition policy	Thank you for the suggestion. We have elected to leave the table focused on patient-important outcomes, rather than process measures.
Peer Reviewer #10	Results	p. 15 table 4.2: unclear what the arrows mean	We have added the following note to the table: Note: Up arrows signify results favor the intervention; down arrows signify results favor usual care; horizontal double-headed arrows signify no difference between groups.
Peer Reviewer #10	Results	p. 52 Table 7.1: would be helpful to note what were primary outcomes.	In the context of this table, the measures are meant as examples of measuring effectiveness of transitions of care. In this respect they may be used as primary or secondary outcomes in different contexts or study designs.
Peer Reviewer #10	Results	p. 63: Given chap 10 providers details of interventions and strategies from those identified in KQ1, it is unclear why It doesn't come sooner in the report. Seems odd for it to come in the end.	While we include studies evaluating implementation strategies and communication tools based on our PICOTS criteria in Chapter 5, Chapter 10 examines in further detail our contextual questions. We have structured the report by examining the Key Questions followed by Contextual Questions so this information is included later in the report.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #10	Results	Overall, justification could be better for including general training, QI materials, etc, some of which seemed pulled from websites.	In Chapter 9, we have added additional justification for our included resources, stating: We examined studies included in Key Questions 1 – 3, and, due to the lack of culturally and linguistically competent training specific to CSHCN, supplemented this literature with a grey literature search in Google Scholar and a scan of organizational websites for information about linguistic and cultural competency training and guidance.
Peer Reviewer #11	Results	Chapter 4: I do think it makes sense to break out by disease condition in more detail as this will be of interest for planning future studies. Table 4.1 and 4.2 are a nice summary of initial results of key questions Going through each section by disease process was the most useful for me. I think that representing outcomes in chart form and then written are nice to describe studies in some detail and as a group.	Thank you for the comment.
Peer Reviewer #11	Results	In intervention type: Define difference between transition clinic and transition program just to be clear	We included the intervention type based on the author's description as a transition program or clinic, under a single umbrella. Many programs were embedded within a clinic and included services and supports to promote transition either through direct or indirect medical care within a clinic. We include these now as one group of intervention type: Transition program or clinic.
Peer Reviewer #11	Results	I am wondering about rationale to break up JIA vs. other rheumatologic diseases. Just for space, could combine these	Thank you for the suggestion. Based on our discussion with our technical expert panel, they had suggested the categories and we would like to keep them separate to allow for individual or combined evaluation.
Peer Reviewer #11	Results	Page 61 Line 33 When you mention work force, I think it would be relevant to mention Med-Peds trained providers as well as shared support staff when possible (social work and nursing for example)	Thanks for suggestion. We have added these important examples to page 61 which now states: Specifically, studies note the importance of building a workforce of practitioners (e.g., family medicine nurse practitioners, Med-Peds trained providers and shared adult and pediatric support staff) specifically trained to provide healthcare across the lifespan
Peer Reviewer #11	Results	I was a little concerned about another list of barriers and facilitators of transition if there are no evidenced based interventions but I think this list was productive. I think Table 6.1 is particularly a nice overview.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #11	Results	Table 7.1 on measures, I am wondering if there is a way to break this down more into available questionnaires, health-related measures, utilization measures.	Thank you for the suggestion. We have detailed the domains in further detail in the appendix accompanying this table, Appendix G, which outlines several of the domains identified by the reviewer (e.g., utilization, health-related measures).
Peer Reviewer #11	Results	For training section: Did "Grey literature" search included Med Ed Portal. I wonder about items that would be useful in this section there. It is really a wealth of available trainings though that could be useful.	General education in the context of medical school was excluded as this was outside the scope of the review. The review focused on trainings provided to multidisclinary providers in the context of providing clinical care. We have clarified this in the methods, but encourage the inclusion and development of more educational programming in the context of medical education to support knowledge of CSHCN and their healthcare needs.
Peer Reviewer #11	Results	Table 10.1/Section on patient training. Just to be clean I wonder if this section should exclude transition clinic/programs/navigators and focus more on other interventions like the computer and other trainings. (Same comment as above in key/context questions).	We agree it is important to distinguish between direct patient trainings (e.g., computer modules) versus clinics. We do include the strategy as a column to help the reader distinguish between these approaches for preparing patients and families, but based on the scope of contextual questions 4 and 5 we needed to include a broader set of trainings, implementation strategies and interventions.
Peer (TEP) Reviewer #1	Discussion and Conclusions	The conclusion on pg 88 clearly states and recaps much of the information stated in the text. It is clear that more comprehensive evaluations in future research are needed to have attainable goals for CSHCN using the best interventions. Also mentioned in the conclusion is the need for effective interventions that support adaptability across diverse disease conditions, social determinants of health and a variety of health care settings.	Thank you for the comment.
Peer (TEP) Reviewer #2	Discussion and Conclusions	Though the findings are not conclusive with respect to evidential interventions for successful pediatric to adult healthcare, the preliminary findings from the studies lend support for needed research and gaps. As such, the future research section clearly makes the case for needed research in this area.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #4	Discussion and Conclusions	In both the evidence summary and body of the report, the authors suggest that significant barriers exist to implement effective interventions. However, the authors also suggest that they cannot conclude anything about the effectiveness of interventions to promote transition, and that the one study that stood the test of scientific rigor suggested that a transition clinic did NOT improve outcomes for young people. So, to state that barriers exist to implement "effective" interventions begs the question that "effective" interventions exist. I also appreciate that the authors suggest that there may be approaches to promoting implementation of "effective" interventions, such as dedicating time and resources, developing a workforce, and creating structured processes and tools; however, the utility or effectiveness of these approaches can only be speculative. It's not clear to me that the study derived data from which to suggest these implementation strategies would be useful or grounded in evidence.	The reviewer makes an important point that reducing barriers may be premature before we know which interventions are most effective. However, we also acknowledge the importance of incorporating known barriers into the development, testing and implementation of new interventions. We have modified our statements in the abstract stating: Significant barriers impede implementation of interventions, tools, and trainings to transition CSHCN that may be reduced in future intervention development. In the main points we now state: While significant barriers impede implementation of interventions, some approaches to reduce these barriers in future interventions 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. Finally, we have removed language referring to barriers to implementing effective interventions throughout and now just state that they are barriers to implementing interventions.
Peer (TEP) Reviewer #4	Discussion and Conclusions	In my opinion, the conclusion about there being no globally accepted definition for effective care transitions is critical. Defining a consensus-drive and agreed upon outcome seems critical prior to developing calls for research; otherwise, future investigators will define their own outcomes. One could argue that transitions to primary care that result in equal access to care or equity in terms of risks for morbidity or mortality are or should be a globally-defined and desired outcomes.	Thank you for the comment. We agree that having no globally accepted definition for effective care transitions is a critical point we hope to emphasize with this report. Specifically in the conclusions we now state: Namely, the literature lacks a clear, consistent definition of an effective transition is critical.
Peer (TEP) Reviewer #4	Discussion and Conclusions	The lack of rigorous studies in this regard is also a critical finding, suggesting need for greater investments in examining models of care and implementation strategies as they relate to transition.	We agree with the reviewer and highlight this point in the conclusions stating: Importantly, study designs in this literature set lack the necessary rigor to provide evidence on the best interventions (or components) that most effectively support care transitions for CSHCN.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #6	Discussion and Conclusions	The overall conclusions and implications are clearly stated. however, a few suggestions to potentially make the future research section more clear and useful to guide new research.	Thank you for the comment.
Peer (TEP) Reviewer #6	Discussion and Conclusions	1) pg. 85 last paragraph of section on rigor, consider an explicit call for hybrid effectiveness/implementation designs. the stage model of efficacy, effectiveness, implementation is somewhat outdated and increasingly there are calls to consider implementation in the initial intervention development work. This is particularly needed in this area with so much real world action but limited rigorous evidence for specific interventions.	Thank you for highlighting additional approaches to future study designs that may aid in reducing the timeline from study testing to implementation in healthcare settings. We have added this additional approach into the discussion on study rigor and now state: Other approaches may include the optimization of intervention components through frameworks such as the Multiphase Optimization Strategy (MOST) that allow for optimizing and rigorously evaluating multi-component interventions as well as hybrid effectiveness-implementation designs that blend design components of clinical effectiveness and implementation research.
Peer (TEP) Reviewer #6	Discussion and Conclusions	2) pg. 86/87- sentence about future research on subpopulations could be expanded- while specific subgroups may be needed in some case, aiming for a middle ground that is beyond disease specific but groups by important categories of care needed would be enormously helpful to the field.	We agree that disease agnostic approaches to understanding the effects of interventions is critical. We have expanded the discussion of future research needs in the discussion by stating: Future research should examine the effects of interventions and implementation strategies across these important subpopulations and settings as well as disease agnostic approaches that focus on important categories of needed care (e.g., healthcare literacy, care coordination).
Peer (TEP) Reviewer #6	Discussion and Conclusions	3) pg. 87- focus on consistent and consolidated measures. consider referencing NIH PhenX and PROMIS both of which DO have recommended measures for some outcomes such as quality of life.	We have incorporated these additional recommendations into discussion of a consolidated measure set and now state:
Peer (TEP) Reviewer #6	Discussion and Conclusions	4) pg. 88 in limitations section (or elsewhere) when issue of educational or vocational interventions comes up perhaps make the point that future research needs to actually be more inclusive of all of these transitions. you can't separate them out, ESPECIALLY for kids with such conditions. We need a holistic, developmental approach to transition.	Thank you. We have added: Also helpful would be consolidated measures of transition effectiveness focused on key social, psychological, and health outcomes broadly applicable to the diverse population of CSHCN such as incorporating recommended measures from NIH PhenX or PROMIS into a consolidated measure set.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #7	Discussion and Conclusions	The discussion is helpful and nicely summarizes the findings. As above, additional detail in the strength/limitations regarding why some studies, particularly those that included children with intellectual and physical disabilities, were excluded would be helpful.	We have added further clarification and now state: However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly such as school or work transitions. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria.
Peer (TEP) Reviewer #7	Discussion and Conclusions	It appears studies that addressed 'interventions to support CSHCN transitioning to adulthood' were excluded. Were these studies that focused only on educational/vocational interventions? While excluding those studies may be appropriate, it seems that it overlooks healthcare services for children with intellectual and physical disabilities. Were no studies identified addressing this need? Might be helpful to elaborate in the text.	We are sorry for the confusion. In our evaluation we focused on studies that evaluated the healthcare transition from pediatric to adult services in CSHCN. We did excluded studies that focused exclusively on the transition from pediatric to adulthood in the educational or vocational setting as this was beyond the scope of the review. We have clarified this in the discussion and why studies in some populations may have been excluded for this reason, stating: However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly such as school or work transitions. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Discussion and Conclusions	One of the main points the authors made is that except for one study, they found insufficient evidence to draw conclusions. Consider adding to the point their observation on page ES-2 that "insufficient evidence does not mean that the intervention is of no value to CSHCN. Rather, it means that, due to the uncertainty of the evidence, we cannot draw meaningful conclusions at this time."	We now highlight a number of ways in the Implications and conclusions ways that future research can build upon the current evidence base. Specifically in the discussion section we now further highlight: While we recognize that healthcare transitions are complex and multi-dimensional, stakeholders must rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings as this field is emerging AND Importantly, we found that study designs used in this literature lacked the necessary rigor to provide a solid evidence base. Future research for this population is crucial to generate quality evidence—not only to understand the most effective interventions, but also to understand how these interventions support adaptability across diverse disease conditions and sub-populations (e.g., race/ethnicity, sex/sexual orientation, socioeconomic status, and care setting).
Peer (TEP) Reviewer #8	Discussion and Conclusions	Perhaps more can be said about the main point that there are approaches for implementing effective transitions. Given there are significant barriers, have any of the approaches been successful?	We are sorry for the confusion. In the discussion our main point was to highlight that: The lack of sufficient evidence to support widespread dissemination of interventions and implementation strategies for effective transitions for CSHCN analyzed in this review provides no clear answers for CSHCN, their families and caregivers and providers, or for funders and policymakers. We additionally recognize that to develop and implement future effective interventions, researchers need to be mindful of incorporating known barriers into the development. We have added the following to the abstract and discussion: Significant barriers impede implementation of interventions, tools, and trainings to transition CSHCN that may be reduced in future intervention development.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	Discussion and Conclusions	The future research section could be further developed to provide clearer guidance. For instance, are there specific components that should be included in an intervention study? Should there be considerations for mixed method research designs in HCT? As for outcomes to be considered, should future studies incorporate quality of life and wellbeing measures?	The author makes an important point that unfortunately cannot be identified given the availability of rigorous evidence. We have highlighted this challenge by clarifying in the conclusions that: While ideally the current set of evidence could provide a foundation for proposing specific components that should be included in future interventions and a defined set of outcome measures to evaluate effectiveness, the lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, or for funders and policymakers. We do additionally note potential study designs future research may employ to allow for more robust evidence in the discussion by stating: Other approaches may include the optimization of intervention components through frameworks such as the Multiphase Optimization Strategy (MOST) that allow for optimizing and rigorously evaluating multi-component interventions as well as hybrid effectiveness-implementation designs that blend design components of clinical effectiveness and implementation research.
Peer (TEP) Reviewer #9	Discussion and Conclusions	The implications of the major findings are clearly stated.	Thank you for the comment.
Peer (TEP) Reviewer #9	Discussion and Conclusions	I would recommend address the limitation of some transition relevant interventions - such as other interventions for continuity of care or self-management - not being fully captured in this report. This may have limited studies of this with IDD or autism as well.	We now highlight this point based on the scope of our review by stating in the limitations: However, we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly such as school or work transitions. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria. Educational or vocational interventions may provide an important component of successful transition for CSHCN, but these were beyond the scope of our review. Further, studies that focused exclusively on self-management of conditions (among CSHCN) in the absence of a healthcare transition were beyond the scope of our review, although evaluation of this literature may provide important insights for components of a broader healthcare transition intervention.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #9	Discussion and Conclusions	I think the authors point about the need to identify universal definitions of effective transition interventions and general agreement on relevant outcomes across conditions is well made. At the same time, it is also I think important to discuss that it is expected that the interventions, some of the measured outcomes, and maybe even some effectiveness definitions may vary by condition, given the complexities the authors describe.	We agree with this important point and now further highlight that there must be a balance between universal definitions and a recognition of the complexity and diversity of CSHCN. We now state in the discussion: While we recognize that effectiveness measures may necessarily vary due to the complexities of conditions among CSHCN, this field would benefit from a consistent definition of healthcare transition supported or endorsed across the diverse patient populations, specialty societies, and federal agencies that develop and support research in transitions for CSHCN.
Peer (TEP) Reviewer #9	Discussion and Conclusions	The topic of health insurance impact and potential for intervention and study seemed lacking given my experience of it's impact on implementing health care transition planning and ensuring access to care.	We completely agree that lack of insurance contributes significant challenges to implementing healthcare transitions in this population. While we highlight this important barrier in the barriers chapter, we again further highlight this important challenge in the discussion by stating: Other challenges to implementation include complexity and diversity of care settings for CSCHCN, the lack of adult providers for this population and the ongoing challenges with insurance coverage for healthcare transitions and underinsurance in this population.
Peer (TEP) Reviewer #9	Discussion and Conclusions	I think it is important that the authors did recognize the significant progress on the number of studies evaluating interventions over the last 5 to 10 years.	Thank you for the comment.
Peer Reviewer #10	Discussion and Conclusions	Fairly straightforward given the lack of evidence.	Thank you for the comment.
Peer Reviewer #11	Discussion and Conclusions	I think the future sections segment is the part I was most excited about reading in this report. I was looking for very concrete recommendations – not just generalities. I do think this report did a nice job at that listing the items to improve studies is valuable.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #11	Discussion and Conclusions	I think a few items could be expanded if you all feel they are within the scope of this report. Specifically, 1) We all know we need more methodically rigorous studies, but specific examples – like the MOST framework (page 86, line 33) are useful.	We agree that more methodologically rigorous studies are important to continue building the evidence base in this population. We have added an additional example to ways future research might build this more rigorous literature base using hybrid effectiveness-implementation designs as well as the MOST framework stating: Other approaches may include the optimization of intervention components through frameworks such as the Multiphase Optimization Strategy (MOST) that allow for optimizing and rigorously evaluating multi-component interventions as well as hybrid effectiveness-implementation designs that blend design components of clinical effectiveness and implementation research.
Peer Reviewer #11	Discussion and Conclusions	2) How do clinicians decrease risk of bias when they are trying to publish their clinical work (maybe they should not be and it should all be research designed, but a lot of this work is trying to study what is already happening).	We agree this can be a challenging task and now highlight the opportunity to build on work already underway in the clinical setting and couple this with more robust research networks and infrastructure dedicated to this area, stating: Strategies may include the adoption of more rigorous study designs in early-stage feasibility and pilot tests of new interventions, many of which may be built into current clinical work and care pathways already underway in the clinical setting through the further development of research networks and infrastructure dedicated to this population (e.g., Got Transitions).
Peer Reviewer #11	Discussion and Conclusions	3) Page 87 18: certainly there are have been papers that have called for specific definitions and agreed upon outcome measures (Fair et al JAMA Peds 2016). I don't know it it is out of the scope of this report but it would be nice to use the reviewed literature to suggest a starting point for both definition and outcome measure.	We agree that suggesting a starting point for effectiveness definitions and outcome measures is an ideal next step, but is beyond the scope of this review. Our goal is to identify and highlight prior definitions in this space to examine future opportunities in the research agenda to improve healthcare transitions for CSHCN.
Peer (TEP) Reviewer #1	General	This paper is extremely thorough and detailed. I appreciated the way care interventions by disease condition were highlighted. This will allow the reader to focus on topics of interest more efficiently (pg 30). Figure 67.1 (pf 63) is clearly written and easy to understand. pg. 11 I like the bullets with the main points listed out. This helps the reader anticipate what the paper is going to outline. Overall, excellent work!	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #1	General	A key sentence on page 5 " Contextually, no globally accepted definition for effective transition of care from pediatric to adult services for CSHCN exists" sums up the report. We have a lot of work to do. Unfortunately the pandemic makes these issues worse as healthcare providers are adversely impacted. The inevitably will make resources available to serve this population harder to obtain and effect their transitions.	Thank you for the comment.
Peer (TEP) Reviewer #2	General	The report provides a comprehensive and clinically meaningful contribution to the field of pediatric to adult healthcare transition with respect to several important populations. The key questions are appropriate and explicitly stated.	Thank you for the comment
Peer (TEP) Reviewer #2	General	The report is dense (appropriately so) so its clarity and usability will depend on the audience's needs. The Table of Contents appropriately guides the audience is they are not able to read the entire report.	Thank you for the comment.
Peer (TEP) Reviewer #4	General	This is an important report because of the implications of the findings. The dearth of scientific rigorous studies is rationale for investment in this work.	Thank you for the comment.
Peer (TEP) Reviewer #6	General	Overall the report is extremely well done and will be an important resource to the field in documenting the limited research in this critical area and identifying potential gaps and opportunities. I anticipate the report will be useful for researchers and clinicians. They key questions, framework methods and summary of findings were all clear.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #6	General	A few points: 1) while I agree with the decision to frame the review around health care transition specifically, this does exclude a substantial portion of the literature on transition, much of which has occurred in the context of autism and educational/vocational supports. This point is raised in the limitations but perhaps should be more clearly stated up front and perhaps noted in future directions for research to be more integrated around outcomes, given the importance of a holistic, developmental view.	We agree that it is important to highlight up front what studies were within the scope of the review. We now that in the methods: As this review focused on healthcare transitions, studies evaluating transitions to school or work were beyond the scope of this review. Additionally, in the discussion we now state: we focused on health services and did not include interventions used to support CSHCN transitioning to adulthood more broadly such as school or work transitions. This decision resulted in excluding the majority of the literature addressing autism and other intellectual and physical disabilities as many of these studies of these populations evaluated transitions in other contexts (e.g., work, school) and did not meet the review inclusion criteria. Educational or vocational interventions may provide an important component of successful transition for CSHCN, but these were beyond the scope of our review and may be examined in future studies as a component of integrated developmental transitions in this population
Peer (TEP) Reviewer #6	General	2) The summary statements up front about clinicians not having anything to rely on is somewhat misleading, though it is an accurate statement of the state of the evidence for specific interventions. However, as is appropriately detailed later in the report, the Got Transition core elements and the range of trainings offered across the country and virtually do provide some guidance to practitioners. The issue is that there are no agreed upon consistent interventions or measures to share. Perhaps this point could be made up front as well.	We have clarified our statement in the evidence summary to highlight that resources exist but consensus around measures and intervention rigor is lacking. We now state: The lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, or for funders and policymakers. While we recognize that healthcare transitions are complex and multi-dimensional, stakeholders must rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings as this field is emerging.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #6	General	3) Finally, many of the included studies appear to be global. Perhaps this should be stated up front given real differences in health care financing and structure in different countries this seems important to note or call out.	We agree it is important to highlight that we did include a broad literature base in both US and non-US settings that may have different implications for implementation. In the methods we now state: We selected studies based on the PICOTS framework outlined above in Table 1.1 if they were published in English in a peer-reviewed journal in both US and non-US settings. In the discussion we now state: We additionally note the diverse geographic settings where interventions were implemented (e.g., US vs. non-US settings), which vary significantly in healthcare financing and infrastructure.
Peer (TEP) Reviewer #7	General	The authors have conducted a systematic review of care interventions, implementation strategies, and provider communication tools for children with special healthcare needs transitioning from pediatric to adult healthcare services. The review is timely, and the problem/issues nicely outlined in the background. The methodology is detailed and focused on intervention strategies and programs as outlined in three Key Questions and supplemented by several Contextual Questions. The tables and figures are helpful. Oddly, the clinical significance of the review is in its lack of findings; disappointing that so little evidence has been generated but important to identify the need and challenges for future studies.	Thank you for the comment.
Peer (TEP) Reviewer #7	General	The authors do not explicitly identify a target audience for their review and adding this would be a strength to ensure wider uptake by researchers, physician investigators, and clinical stakeholders.	We agree it is important to highlight the intended audience and have added this to the main points and background of the report stating: The target audience for this review includes CSHCN, their families, caregivers, providers, and policymakers to examine the current evidence for interventions to support healthcare transitions for CSHCN.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #8	General	It's unclear what information this review adds to the small but expanding knowledge base on health care transition (HCT) except to indicate there were few studies that met the study's rigorous review criteria. It would be helpful to stakeholders and decision makers to have a more detailed discussion on the basis for this review's findings given that a number of recent systematic reviews have revealed benefits of health care transition interventions.	Thank you for the comment. We included a broad range of interventions across settings and populations within CSHCN in our review. We agree that this is a small but expanding evidence base and note this in our main points by further clarifying that 'this field is emerging'. We look forward to new evidence the reviewer notes has identified benefits of new healthcare transition interventions.
Peer (TEP) Reviewer #8	General	Further, should more be said about how the complexities of HCT may limit the number of rigorous studies using traditional study designs?	We agree that the complexities of healthcare transitions may create challenges for developing rigorous designs and note in the main points and discussion: While we recognize that healthcare transitions are complex and multi-dimensional, stakeholders must rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings as this field is emerging.
Peer (TEP) Reviewer #8	General	As for the target population, presumably the focus is on the pediatric population (12-18 years); however, to fully discuss HCT, one needs to take into consideration the young adults populations, particularly when looking at outcomes of HCT.	In our study, we included studies of adolescents and young adults (diagnosed with cancer or other special healthcare condition before 21 years old) which would encompass this young adult population.
Peer (TEP) Reviewer #8	General	Also, there's little attention given to youth and young adults and their families as key audiences.	We highlight our target audience in the main points and background stating: The target audience for this review includes CSHCN, their families, caregivers, providers, and policymakers to examine the current evidence for interventions to support healthcare transitions for CSHCN. In this review this included adolescents and young adults (diagnosed with cancer or other special healthcare condition before 21 years old)
Peer (TEP) Reviewer #8	General	The key questions are appropriate and explicitly stated.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer (TEP) Reviewer #9	General	The report is clinically meaningful and addresses key questions related to effectiveness of health care transition interventions for transition from pediatric to adult healthcare. The Key questions are clearly stated. While I agree communication between pediatric and adult providers is worthy of being a separate Key question, I think another Key question related to transition interventions that could be a separate topic is what is the effectiveness, comparative effectiveness, harms, and costs of self-management support interventions for care transitions. This is related/overlaps conceptually with Transition readiness, at least as measured by many of the mentioned transition readiness tools, but self-management and self-efficacy interventions have often been assessed on their own outside the context of Transition. I think this is somewhat related to Contextual Question #4. Despite the complexity of transition and measuring outcomes of interventions, I think the report is overall very clearly written, organized, and easy to follow	Thank you for the comment.
Peer Reviewer #9	General	Overall, well organized and clear.	Thank you for the comment.
Peer Reviewer #11	General	This is obviously a document that took a lot of time to create and organize. I think it is a stellar overview of where transition work is currently. The target populations are clearly defined, and I think the authors did a nice job of describing the complicated groupings of all children with special health care needs vs. subsets and the groupings they chose (see few specific comments below).	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #11	General	I think the key questions were clearly defined as well. However, I was less convinced about key question 3. I could have seen another way to organize is to make key question 3 a contextual question, since I believe we all think increased communication between providers would improve transition outcomes, but as we see in this report and others I am not sure that is truly the case based on the literature.	Thank you for your comment. Our key and contextual questions for the review were set by topic refinement based on the priorities of NCI and input from our technical expert panel and are set after the topic refinement period.
Peer Reviewer #11	General	On contextual question #4: When I read this here and in the later description, I again thought much of this is covered in key question 1 and 2. I wonder if it would be more specific if it was focused on non-transition program/clinic interventions such as mobile health, modules, etc.	Thank you for your comment. Our key and contextual questions for the review were set by topic refinement based on the priorities of NCI and input from our technical expert panel and are set after the topic refinement period.
Peer Reviewer #11	General	On the contextual questions: #5 seems a bit duplicative to me to things that may already be covered fully in the key questions 1 and 2.	Thank you for your comment. Our key and contextual questions for the review were set by topic refinement based on the priorities of NCI and input from our technical expert panel and are set after the topic refinement period.
Peer Reviewer #11	General	I think the overview is useful to understand how the report is laid out.	Thank you for the comment
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Evidence Summary	1. (Pages vi and ES-1) The results of this systematic review are too broad and should be narrowed in the main points and elsewhere in the report to accurately reflect the stringent criteria used for study inclusion and bias assessment. The reviewers suggest the following summary of the findings: Health care transition evidence using randomized and non-randomized controlled trials, cohort studies with comparator arms, and single arm pre/post design is insufficient to draw meaningful conclusions. The reviewers also suggest that the authors add a comment to the main points stating, as they did on page ES-2, that "insufficient evidence does not mean that the intervention is of no value to CYSHCN. Rather it means that one cannot draw conclusions at this time."	Thank you for the comment. Several reviewers noted the review was well organized and clear and appropriate. Due to space constraints we have left the criteria for study inclusion embedded within the methods section, but have added the reviewers point into the main points that: insufficient evidence does not mean that the intervention is of no value to CYSHCN.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Evidence Summary	(ES-3) The implication and conclusion statement the "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" is misleading and potentially harmful to future progress in this field. This statement fails to consider the 2018 AAP/AAFP/ACP professional recommendations on how to conceptualize a HCT approach to assist transition-aged youth and young adults while a more rigorous evidence based approach is created with different methodologies, such as observational studies, RCTs, and approaches used in complex interventions. This statement also fails to take into account an extensive and growing body of HCT quality improvement studies and two past systematic reviews that found statistically significant positive outcomes associated with a structured HCT process.	We have clarified this statement recognizing the emerging field and more diverse policy and professional organization recommendations, stating: While we recognize that healthcare transitions are complex and multi-dimensional, stakeholders must rely on institutional policies and professional organization position statements to determine whether to disseminate or implement these interventions in their populations or care settings as this field is emerging.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	(Page 1) Data on the number of 12-18 year old children with special health care needs who transitioned to adult care between 2011 and 2017 are incorrect; the number referenced is an estimate of the total number in that 6-year age group. The article cited for this data was published in 2013, which is an obvious error.	The citation is correct and is an estimate based on the 2009-2010 National Survey of Children with Special Health Care Needs. We now clarify that this is an estimate.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	Background on the 2018 AAP/AAFP/ACP Clinical Report should be more prominent in this review as that represents the professional consensus about what constitutes a recommended transition approach. Without this, there is no context from which to look at the key questions for the systematic review or even to understand what transition includes. It is hard to define effectiveness, when transition is not adequately described. Further, the Clinical Report calls for all youths and young adults, including those with special needs, to receive transition preparation, assistance with transfer to an adult-model of care (with or without changing providers), and facilitated integration into adult care. The authors should make clearer that they elected to focus only on those with special needs.	We recognize the importance of this report as is evidenced by the inclusion of its framework in the background and motivation for the review. We have further clarified the definition of transition in the background and now state: In 2011, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians sought to address this issue by publishing a framework for implementing care transitions for youth (starting in early adolescence) to aid clinicians in transition within their medical home.[6] In this report, they define the goal of healthcare transition as "maximizing lifelong functioning and well-being…[thereby] ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	The Description of the Six Core Elements on page 1 is incomplete. What is referenced is only the Six Core Elements from the Transitioning Youth to an Adult Health Care Clinician package (for pediatricians). There are two additional Six Core Elements packages that are not mentioned in this report: Transitioning to an Adult Approach to Health Care Without Changing Clinicians (for family medicine clinicians) and Integrating Young Adults into Adult Health Care (for adult clinicians). All three are available on Got Transition's website at https://gottransition.org/six-core-elements/. This report should include more description about the Six Core Elements approach that was recommended in the 2018 Clinical Report, including the implementation guide and QI primer that is associated with this along with the various measurement tools. Since the authors write about implementation strategies, the absence of complete information about the Six Core Elements is problematic. As noted in general comments, HCT is a complex intervention that needs much more specificity in this report. It is unclear why the authors (in lines 32-33) raise questions about the "broad design" of the Six Core Elements: "raising questions about the best transition intervention designs, implementation tools, and strategies."	The use of the Six Core element was incorporated as a way to frame the literature and further understand which components were targeted within specific interventions. We recognize that transitions are complex and that there are modified packages that apply to different settings and approaches. We now note: Got Transitions® (a federally funded national resource center on healthcare transitions) developed a structured clinical quality improvement approach for transitioning patients from pediatric to adult medical care customizable across many transition care models. However, as other reviewers have noted this is only one of several models for understanding a framework for categorizing interventions evaluated within this review. We have additionally added a discussion of the definition of transitions and note the complex nature in the background. Finally, the broad design does not refer to the Six Core Elements, but rather the included components. We now clarify: the broad spectrum of included components targeted within the Six Core Elements has raised questions about the best transition intervention designs, implementation tools, and strategies to address these complex transitions
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	The authors should have included a synthesis of past systematic reviews on transition, which are available on Got Transition's website here. It is not clear what this review adds in terms of past syntheses.	We have added reference to prior reviews on healthcare transition in CSHCN. Specifically, we highlight previous work by the AHRQ EPC program on this topic stating: Previous reviews of literature on interventions for healthcare transition in CSHCN have identified a need for further attention to rigorously examining the effectiveness of programs or services, noting that among the few evaluating studies the majority did not include rigorous study designs leading to a lack of a robust evidence base.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	This introduction could have incorporated current national data on HCT from the National Survey of Children's Health and acknowledgement that HCT is a national performance measure for the Maternal and Child Health Bureau and its state Title V programs across the country.	Thank you for this comment. Study designs using data like these make it very difficult/preclude the ability to draw inferences for how HCT is delivered, or what the actual intervention is. However, we do use information from the National Survey of Children with Special Health Care Needs to describe the current population and identify the number of individuals transitioning from pediatric to adult services. In addition, we highlight the use as a performance measure by stating: Therefore, identifying the most effective interventions to improve healthcare transitions for CSHCN and outcomes in this population is critical, as evidenced by prioritization of healthcare transitions as a Healthy People 2030 research objective and inclusion as a performance measures in state and federal programs.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	(Page 3, Table 1.1) The description of what is included under intervention is inadequately defined ("any single or multi-component intervention that addresses the Six Core Elements, such as educational materials, patient care documents, processes, etc.") There are a set of HCT interventions that are part of planning, transfer, and integration into adult care that are not specifically pulled out, resulting in weak characterizations of what is a HCT intervention. Also, the section on timing only refers to "at least 6 months post transition for tests of results."	Our intention with the description is to indicate we included a broad definition and were not intending to be exhaustive in the examples. We do indicate that an intervention is included if it addresses the Six Core Elements which would encompass the examples indicated.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Introduction	(Page 6, Figure 1.1). The analytic framework is insufficient. The box on care providers does not specify pediatric and adult health care providers; it only notes multidisciplinary care providers. The box on care transition intervention has no specificity. The box on care transition interventions setting & context is connected to nothing. There have been many transition frameworks that the authors could have relied on.	Thank you for the comment. The analytic framework is not meant to be all inclusive or to replace existing conceptual models but to demonstrate at a high level how the concepts covered in the systematic review relate to the KQ and CQs. Full inclusion/exclusion is provided in tables and text.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	Additional comments on methods can be found above under general comments.	Thank you.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	The authors use strict inclusion criteria and risk of bias assessments described on pages 8-9, however these criteria seem premature to apply to health care transition research since the field is so new and in development. Appendix A was not made available to be able to review each decision rule, but based on the text, the reviewers think the existing methods used were not entirely applicable. The inclusion of a rigorous review of previously published systematic literature reviews in this section would allow readers to understand the early stages of this field and lack of effectiveness studies to date. This should also be highlighted under Main Points on page ES-1.	Thank you. These comments support the main findings of our report. As the reviewer mentions, if a study is "too new" for risk of bias rigor, the evidence is not yet to a level to support strength of evidence assessment, but rather to generate hypotheses for future rigorous assessment. We do now note in our evidence summary that 'this field is emerging'. We also note in the background that: 'the lack of rigorous evaluation of interventions and strategies to reduce these barriers may hinder widespread development and dissemination of policies and programs for this population, as has been highlighted in previous evidence.' Our methodological approach along with the study inclusion and exclusion criteria was discussed with a technical expert panel prior to initiating the review. Other reviews may use different criteria and therefore include a different literature set in their assessment.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	The authors early on note "the lack of rigorous evaluation of interventions" (page 1) which serves as a reason to modify methodology to adjust for the limited research. It begs into question why an extensive and restrictive analysis was conducted when the foundation of literature is weak.	The goal of the review was to evaluate current literature recognizing that previous reviews have identified a need for further attention to rigorously examining the effectiveness of programs or services for HCT for CSHCN. Our review set a broad definition for included studies to identify literature in this field since the publication of prior reviews. However, we still continue to find a lack of a robust evidence base for which interventions work for effectively transitioning CSHCN from pediatric to adult medical care. We note the motivation based on prior reviews in the background stating: Previous reviews of literature on interventions for healthcare transition in CSHCN have identified a need for further attention to rigorously examining the effectiveness of programs or services, noting that among the few evaluating studies the majority did not include rigorous study designs leading to a lack of a robust evidence base.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	The Key Questions (KQs) used to drive the search strategies do not take into account the current landscape of health care transition literature. The methods also do not describe how the KQs were developed. This would be helpful to understand.	The KQs underwent a development process and received input from a wide range of stakeholders to help frame the final published list of key questions that were used in the review. We now state in the research questions: KQs and CQs were developed based on National Cancer Institute priorities and input from technical experts, with further feedback and refinement received during a public comment period.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	(Page 8) The authors mention that they "supplemented our search strategies with backward and forward citation searches of recent relevant systematic reviews." However, they do not cite which relevant systematic reviews were looked at. This would be useful for readers to know.	For a full list of included studies that were identified, we direct the reviewers to Appendix C. These studies included articles that were identified through or primary search strategy or through systematic reviews.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	(Page 8) Please disclose the time period of publication for searched articles.	The full search strategy can be found in Appendix A, but we have added the time period to the methods of the main document stating: We conducted a comprehensive literature search in September 2020 (updated May 2021) searching Ovid Medline®, Ovid Embase®, the Cochrane Central Register of Controlled Trials, and CINAHL databases that included literature published prior to May 2021.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	The Methods section should include definitions for "analytic set" as well as a definition for what is meant by "studies that underwent synthesis." While these are mentioned in Table 1.2, these additions would be most useful in this section.	The definition of analytic set can be found in the glossary of terms in Table 1.2. It states: For the purposes of this review, the **analytic set** is the set of studies that underwent synthesis. It consists of the studies not judged to be pilots or have a high potential for bias that might have interfered with the ability of the study to answer its research question
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Methods	Please provide justification for why measures for process and efficacy were not included in the data abstraction. Literature suggests that where there is a lack of measures for evaluative effectiveness and outcomes, it is important to look at quantitative process measures to analyze mixed-methods study.	Our final protocol for conducting the review was developed based on input from a wide range of stakeholders and technical experts to help frame the final published list of included outcomes. Many of the measures may be classified as process measures (e.g., screenings for depression) as well as efficacy (e.g., transition readiness, disease-specific clinical outcomes). While these were included in our protocol, many studies did not report or evaluate these outcomes and were therefore not abstracted.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 4	(Page 14, Table 4.1) The listing under intervention type is inadequate: "transition programs and clinics, transition skill-based training or education, transition workbook or toolkit, EMR transition tool, summer program, music therapy." These are methods not intervention types. Without the authors' understanding of what HCT intervention includes, this analysis of the intervention research context is impossible to use. Take, for example, the write up on page 29 of juvenile idiopathic arthritis. The authors write "All interventions included components of the Six Core Elements which include transition readiness while two studies in addition incorporated transition and care policy/guide and one incorporated transition planning and transition of care." Again, what is referenced as the Six Core Elements is incomplete. The Six Core Elements listed is the pediatric set of core elements; the reader has no idea what the HCT intervention is related to transfer or integration into adult care. Moreover, it appears that only a transition readiness assessment was done in all 5 studies; it is not a useful description to state, "All interventions included components of the Six Core Elements." This significant criticism can be made for each of the disease write-ups.	The goal of the basic characteristics table is to provide an overview of the populations, study designs, key components of the intervention and outcomes studied, among other characteristics. As implied by the title, it is not meant to be a comprehensive examination of each individual study and the nuances therein. The intervention types describe the approach that was taken in the intervention, which included many of the components the reviewer references at a high level to understand the overall literature base. As noted by other reviewers, they believed the disease specific sections provide nice summary of initial results of key questions.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 5	Past systematic reviews4,5, found that with a structured HCT process in place – with components for planning, transfer, and integration, positive benefits result.	Thank you for the comment. Other reviews may use different criteria and inclusion/exclusion criteria set by our protocol and, as a result, include a distinct literature set. We encourage more work in this space to continue rigorous evaluation of interventions for healthcare transition for CSHCN.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 5	Chapter 6, page 45. The authors would benefit from looking at the literature on studies that have implemented the Six Core Elements, available at www.gottransiton.org. It is not true that "no model of HCT or group of services is consistently or widely used in pediatrics."	The use of the term model was not in reference to the Six Core Elements or other QI framework but rather a set of interventions or set of services that are consistently used, as noted in previous literature. We now state: This barrier is compounded by the fact that no consistent group of services or interventions for healthcare transition are consistently or widely used in pediatrics
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 6	The Consolidated Framework for Implementation Research was used to organize barriers and facilitators. However, the choice of what was addressed under intervention characteristics, outer setting, inner setting, and process was weak. Though the authors mention that 147 studies plus additional articles were reviewed for this section, there were few citations in this section. The 2018 AAP/AAFP/ACP Clinical Report has a detailed summary of barriers from the perspective of youth/young adults/families and from pediatric and adult clinicians. The authors should look at these barriers to improve Figure 6.1 (page 49).	As we note in the methods, We identified barriers and facilitators from included studies (N=147) that evaluated 1) care interventions for transitioning CSHCN and their families/caregivers, 2) implementation strategies for care interventions for transition, and 3) tools to facilitate communication between pediatric and adult providers. These 147 studies were supplemented by literature (identified from our broader search strategy) that specifically examined barriers and facilitators to successful transitions, but not in the context of an intervention. Themes were abstracted until saturation from the 147 studies. While this chapter presents a high level overview of the noted barriers and facilitators, the reviewers may find specific examples and citations from the source articles within Appendix F. Many of the barriers noted in the 2018 report are acknowledged in this chapter.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 7	The reviewers suggest starting with the definition of transition in the 2018 Clinical Report, which you have listed as the 3rd example (page 50). You could also use the HCT definition and goals used by Got Transition: "Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care. The goals of health care transition are: 1) To improve the ability of youth and young adults with and without special health care needs to manage their own health care and effectively use health services, and; 2) To ensure an organized process in pediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into adult-centered health care."	The definitions are listed in no particular hierarchy as we acknowledge no globally accepted definition. Providing examples of definitions is meant as a way to demonstrate the range of information included in the definition of an effective transition and not to prioritize or rank the merits of the definitions themselves.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 7	Rather than stating that there is "no globally accepted definition for effective transition," the authors could convey that often transition was thought to be just transition preparation on the pediatric side or just the actual transfer between pediatric and adult care. With the 2018 Clinical Report, professional recommendations make clear that HCT includes transition preparation, transfer of care, and integration into adult care. These critical aspects of transition start in early adolescence and continue into young adulthood, and they are reflected in the Six Core Elements of HCT.	As can be seen in the list of example definitions cited in Chapter 10, many experts in this field have a widely varying approach to the definition of an effective healthcare transition. We recognize the importance of the 2018 report noted by the reviewer and do include the definition in this report as an example.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 7	There are three articles written by Got Transition that lay out existing measures used to evaluate HCT.4,5,7 Were these articles referenced or only those in the 9 included studies? It might be helpful to reference those studies and also consider organizing Table 7.1 (pages 52-54) using the Triple Aim Framework.	The full list of eligible studies include in our review can be found in Appendix C, with a listing of all reported measures of effectiveness and accompanying studies where they were evaluated in Appendix G. If the articles were included in this list, they were evaluated. Table 7.1 was developed as an overview of example measures used to evaluate the effectiveness of interventions. It was not meant to be exhaustive but provide context to the range of available measures used in the literature along with important contextual information to understand what the measure is, the measure target, whether it was validated and which studies evaluated the measure. The goal was not to evaluate the measure in the context of other frameworks, which may be considered in future evaluations.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 7	There should be some discussion about the importance of measuring the transition process to better understand the scope of the HCT intervention that influenced outcomes. The Six Core Elements includes two different ways to measure process (HCT Process Measurement Tool and the Current Assessment of HCT Activities). There are also measurement tools available for youth/young adult/parent/caregiver and clinician feedback on HCT. All of these measurement tools are available on Got Transition's website at https://gottransition.org/six-core-elements/measurement.cfm.	We agree that measuring the transition process is an important component of the transition process. This chapter reports on definitions of outcomes evaluated in studies included as part of KQ 1-3. While the evaluation is not meant to be exhaustive, it does provide an overview of how others have measured transition effectiveness. We now note this in the beginning of the chapter as other measure, like those identified by the reviewers, exist. We now state: This review of definitions of healthcare transition intervention outcomes is not meant to be exhaustive, but provide context for how studies evaluate the impact of their interventions across diverse populations. We recognize that other definitions outside of this literature set exist and may be included as measures of healthcare transition effectiveness in future studies. Additionally, in the discussion, we note: We also recognize the importance of outcomes that may not have been evaluated in the context of this review, but provide additional insights into the impact of interventions (e.,g,Got Transitions Current Assessment of Healthcare Transitions Activities) that may be included in future studies in this population.

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Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 7	In the beginning of this chapter, the authors could make some reference to how the federal government measures HCT preparation in the National Survey of Children's Health and also note how there is no corresponding data source for measuring transfer of care and integration into adult care from the perspective of the young adult.	This chapter reports on definitions of outcomes evaluated in studies included as part of KQ 1-3. While the evaluation is not meant to be exhaustive, it does provide an overview of how others have measured transition effectiveness. However, in the discussion we now note: We recognize that other definitions outside of this literature set exist (e.g., performance measures from state and federal programs and national surveys) and may be included as measures of healthcare transition effectiveness in future studies.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 8&9	What is included in Table 8.1 (pages 56-60) is a disorganized list of training and implementation strategies. The authors should separate out specific training strategies from implementation strategies and do a better job summarizing the implementation strategies. For example, the first article by Jones is an implementation strategy, not a training strategy, designed to implement the Six Core Elements in pediatric and adult primary and specialty clinics; it went on over 18 months. The authors should add the Nagra et al. (2015) paper on Implementing Ready Steady Go (current reference 34).	To clarify, this table was not meant to be an exhaustive list of available trainings and implementation strategies. We drew from those studies that met our inclusion criteria and were included as part of KQ2 and supplemented by a grey literature set to provide additional examples. We recognize that there is a larger set of implementation strategies, as the reviewers note; however, the purpose of the studied cited was to provide an overview of the strategy and evaluate the effectiveness of the implementation so it was not included as part of this literature set. We now note that these are examples and not exhaustive and have added the ready, steady go example to the grey literature search set.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 8&9	The headers used in Table 8.1 are not very helpful (e.g., disease specific vs general). The authors should split training for disease knowledge from training on HCT, as this is supposed to be a review of HCT training.	To clarify, this column is meant to distinguish between disease specific implementation strategies versus general transitions of CSHCN. Our key informants highlighted the importance of acknowledging these distinctions as they help providers to understand whether a tool or implementation strategy would require adaptation for the population they care for.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 8&9	Got Transition, under its policy and research page, has an up-to-date list of quality improvement studies using the Six Core Elements (see here). Did the authors review these studies?	Thank you for highlighting this resource, which was used to identity additional examples of training and implementation strategies as part of the initial study search of the grey literature. Again, this chapter of the report was not meant to be an exhaustive list of all programs but provide (as a contextual question) examples of common or readily available trainings available.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 8&9	The authors failed to include the Six Core Elements Implementation Guides and Quality Improvement Primer. This was completed in 2020, with QI expert consultation from Atrium Health. These are available at https://gottransition.org/six-core-elements/implementation.cfm.	We have added this additional resource as part of Table 8.2. Please note that some of the literature included as part of our analytic set in table 8.1 used components of these primers as part of their program design and would additionally direct readers to this resource.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 8&9	If the authors want to list all training opportunities for clinicians, as implied, the list did not appear to be complete given what the reviewers were allowed to review in the table (Note: the reviewers did not receive the appendices). If there is a more complete list in the appendix, the authors should explain why they chose what they did for the table or put all the information into the appropriate appendix and refer the reader to it.	This is not meant to be an exhaustive list but an example of the types of programs available for providers. We have clarified this in the title of the table. We also now note: This review of trainings and implementation strategies is not meant to be exhaustive, but provide context for resources stakeholders can examine for use in future research and practice implementation.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 10	This section appears to be about training only on the pediatric part of HCT. What about self-advocacy training on the adult side post-transfer. Did the authors look at the training in young adult clinics referred to in the prior sections?	The goal of this contextual question, which was set during the topic refinement period, was to examine examples of transition care training, implementation strategies, and care interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care. We encourage future research to examine self-advocacy and training once CSHCN on the adult side post-transfer in future research. As the reviewers correctly note, examples of these trainings and implementation strategy are noted in Chapters 9 & 10 and can be referenced by readers in that specific aspect of training.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 10	It was unclear how the authors separated HCT training and care interventions. Is the latter training about disease knowledge as opposed to training about HCT self-advocacy?	We included a broad range of training, implementation strategies, and care interventions as part of this contextual question. It was not meant to be exhaustive but provide examples that may not have been captured in the systematic review. The descriptions were drawn from the authors or publishers discussion about their own programs and how they self- classified as training or care interventions.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 10	Table 10.1 appears to be a random list of patient training tools and programs. The authors should consider listing common strategies, such as a tool (eg, workbook) or a formal curriculum taught be clinicians or a navigator assisting with HCT activities (eg, scheduling appointments) and indicate what was the HCT activity offered.	This review was not meant to serve as an education primer or exhaustive list of available programs, but provide examples of tools and programs that may not have been included in the systematic review. We also now note: This review of trainings and implementation strategies is not meant to be exhaustive, but provide context for resources stakeholders can examine for use in future research and practice implementation.

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Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 10	The authors do not comment if any of the trainings evaluated outcomes, such as knowledge gained, satisfaction, etc. Perhaps adding a column on evaluation strategies might be helpful since this falls in a systematic review that is using rigorous methods to evaluate other aspects of the review.	These were meant as guiding questions to provide additional context for available trainings and implementation strategies and not a formal evaluation of their effectiveness which was the focus of the systematic review.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 11	This chapter suffers from a lack of focus. The authors suggest referencing the gray literature – for example, see attached poster (see here), which helps to identify areas of needed support by adult health care providers. We also suggest referencing the recommendations in the 2018 Clinical Report for additional suggestions. The authors should consider highlighting for which populations finding an adult doctor is harder and then discuss strategies related to training, infrastructure supports, and payment. There are several additional The National Alliance/Got Transition reports that could be referenced – in addition to the Medicaid MCO report – including Coding and Payment Tip Sheet (see here), Value-Based Payment Report (see here), and Health Policy Open article (see here)	This contextual question, which was set during the topic refinement period, was not meant to serve as an education primer or exhaustive list of available programs, but provide examples of strategies for increasing availability of adult providers.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Results – Chapter 11	This section seems to imply that payment is the main reason adult providers would not take young adults with pediatric-onset conditions. The reviewers want to underscore the significance of needed infrastructure supports and also the fact that there not adult enough PCPs and many have full practices.	As others have highlighted challenges with reimbursement, particularly reimbursement of activities supporting transition (e.g., infrastructure, nursing support, records transfer and alignment) influence the capacity of adult providers to take on CSHCN. We do not imply that payment is the main reason adult providers would not take CSHCN. As we note in this chapter, based on previously published literature on the barriers to care in this population, there are 'limited resources and reimbursement for coordinating and conducting care to transition CSHCN'
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Discussion and Conclusions	Because of the inherent problems noted above – with respect to understanding HCT interventions, we recommend a very careful revision of the discussion to clarify what can be said about the 9 studies that met comparator criteria and the measures used. The rest of the report on training, implementation, and communication is not well organized and complete.	Other reviewers have noted implications of the major findings are clearly stated and provide important context and recommendations for future studies. They also noted the report is overall very clearly written, organized, and easy to follow. Therefore, we elected to leave the present report organization. We clarify in the discussion that 'Among the studies included in our review, the lack of sufficient evidence to support widespread dissemination of interventions and implementation strategies for effective transitions for CSHCN analyzed in this review provides no clear answers for CSHCN, their families and caregivers and providers, or for funders and policymakers.'
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Discussion and Conclusions	When mentioning "evidence," please clarify whether this is of the 9 studies from the analytic set or the broader group of literature.	This includes all studies included in our review. The studies not included in the analytic set were, by definition, high risk of bias due to their study design (as we note in the methods) and would not provide additional rigorous evidence beyond the 9 studies in the analytic set. As we note in future directions within the discussion, this provides an opportunity for future research, where more rigorous research designs are implemented to study this important interventions.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	Discussion and Conclusions	The authors should consider having a discussion comparing their systematic review to others, and why their comparator criteria and using ROB-2 to look at bias may have focused this review too narrowly, as other systematic reviews have found evidence for HCT interventions.	We identify in our methods the approach to inclusion and exclusion as well as risk of bias that were set based on topic refinement and input from technical experts and a public comment period. Other reviews may use their own criteria that would necessarily include a distinct literature set. The goal of our study was to identify rigorously conducted research to examine the current evidence base.
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you for highlighting this model, which has been added to chapter 8 in the table results for the grey literature search. We would also like to highlight a complementary realist review that was conducted through the AHRQ EPC in parallel to our review that specifically focuses on models of care for adult survivors of pediatric cancer that can be found here: https://effectivehealthcare.ahrq.gov/products/pediatric-adolescent-cancer-survivorship/protocol
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you for this additional resource, which has been added to the resources in Chapter 8. We would also like to highlight a complementary realist review that was conducted through the AHRQ EPC in parallel to our review that specifically focuses on models of care for adult survivors of pediatric cancer that can be found here: https://effectivehealthcare.ahrq.gov/products/pediatric-adolescent-cancer-survivorship/protocol

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you for the comment.
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	We deliberately left Table 1.1 with the broad term multidisciplinary due to the concern that once listing, readers will expect the list to be exhaustive. However, we have added additional examples to our definition in the glossary of terms in Table 1.2.
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you for the comment

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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.	Thank you. We now highlight in the discussion of Chapter 11 that "Initiatives are needed to determine the scope of the work involved in transition care planning and implementation and develop aligned reimbursement policies to provide such services.'
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	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 evidencebased 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 pediatric cancer survivors.	Thank you for the comment and highlighting these models. Passport for care and SurvivorLink have been added to chapter 8. We agree that rigorous evaluation of these and other models are opportunities for future research.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #1 Children's Cancer Cause (See Appendix X for full letter)	General	The AHRQ review acknowledges research limitations on answering questions of which interventions work best and under what circumstances. This is especially acute for the pediatric 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 pediatric 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 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 1325 G Street, NW | Suite 540 | Washington, DC 20005 | 202.552.7392 | www.childrenscancercause.org 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 CSPHCN; however, the review understates of the need to conduct research on transition care models that is specific to the complex and varying needs of pediatric cancer survivors.	Thank you for this comment.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	The reviewers encourage AHRQ to include observational studies of which there are some in the literature, in addition to the comparator studies. According to a PCORI methodology report, "In particular, the use of observational studies to make causal inference is potentially much stronger than it has been in the past. Many of the standards that we developed address ways to improve the value of observational studies as a substitute for RCTs for questions about comparative clinical effectiveness. Decisions about study design need to take into account these standards, described in Chapters 7 and 8, and the advances in methodology they reflect." Further, PCORI comments that errors in clinical practice can be the result of relying on narrowly focused RTCs. "In addition, nonrandomized studies of subjects with a common feature or condition can be a valid approach." Further, "Subjects are observed to receive specific interventions. Data may be collected and evaluated prospectively or retrospectively. Efficient sampling designs are available for cohort studies, including case-control studies, case-cohort studies, and 2-stage sampling designs."	We did not limit our evaluation to RCTs, but, as noted in the methodology included observational studies that underwent a risk of bias assessment. As we note, many of the studies included in the review did not have a pre- and post-assessment of outcomes or have a comparator arm and were, by definition, subject to a high risk of bias. We agree with and support the PCORI definitions and encourage future research that incorporates these high quality observational designs.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	Descriptions of care interventions for health care transition (HCT) are incomplete throughout this report. What is described, for the most part, has to do with transition preparation activities. Transfer of care and integration into adult care are equally important components of HCT. In the introduction (page 1), the authors refer to the Six Core Elements, and they define them as only what is incorporated in the pediatric package of the Six Core Elements. There is also a Six Core Elements package for practices that serve youth/young adults without changing providers. In addition, there is a Six Core Elements package for practices that integrate young adults into adult care. This incomplete understanding of what is included in the HCT intervention affects the quality of the entire report, including the analytic framework; information collected on intervention type; presentation of outcomes, barriers and facilitators; and descriptions of training, implementation strategies, and interventions.	The information presented in the report is a review of the literature that met the inclusion and exclusion criteria as created during the topic refinement with input and revisions based on key informants and a public posting period. We agree that the elements of healthcare transitions for CSHCN as studied in the published literature that met the inclusion criteria do not include the full range of intervention elements and range out outcomes as presented in the analytic framework. This is noted in the discussion and is an opportunity for future research.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	HCT is a complex intervention. The reviewers suggest that the authors refer to the PCORI methodological approach for analyzing complex interventions. It is important to broaden the methodological perspective in this systematic review. The PCORI paper states, “A complex intervention is a multicomponent intervention that may act independently or interdependently to change patient outcomes (Craig et al. 2013). Examples include various non-pharmacological treatments, behavioral interventions, lifestyle modifications, and reorganization of specific aspects of the delivery system.”1, At this time in the development of HCT research, the reviewers agree that none of the current studies would likely meet their requirements, but the reviewers suggest the authors should at least consider this approach in their methods.	We agree with the reviewers that healthcare interventions for transition in CSHCN may include complex interventions as defined by PCORI. Complex interventions under definitions would have been included based on the PICOTS table that describes our inclusion and exclusion criteria for the systematic review. As we note in the introduction and main points, this literature ‘is emerging’ and may, as the reviewers suggest, contribute to the evidence in the future.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	It is important for the reader to fully understand the limitations of the evidence supporting the authors' conclusion that transition clinics may not improve hemoglobin A1C levels (e.g., the second Main Point bullet on page ES-1). While the authors do indicate that there is only low-strength evidence for this conclusion, it is important to restate the definition of "low-strength," as defined on page 10 to mean there is "Limited confidence that estimate of effect lies close to true effect; major or numerous deficiencies in body of evidence. Additional evidence necessary before concluding that findings are stable or that estimate of effect is close to true effect."	We agree with the reviewers' interpretation of low strength evidence. This section the reviewers refer to is a summary of the evidence and readers may examine exact definitions, including that of low strength evidence, in the definitions of the main report as they remain consistent throughout.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	The absence of a review of existing peer-reviewed systematic reviews on HCT is a flaw. This would have been very helpful to set the stage for this review and to distinguish this report's contributions from other systematic reviews.	We note an overview of findings from prior systematic reviews in the background of the report. Specifically, we now state: Previous reviews of literature on interventions for healthcare transition in CSHCN have identified a need for further attention to rigorously examining the effectiveness of programs or services, noting that among the few evaluating studies the majority did not include rigorous study designs leading to a lack of a robust evidence base. We also note: While CSHCN often experience significant barriers to effectively transitioning from pediatric to adult medical care, the lack of rigorous evaluation of interventions and strategies to reduce these barriers may hinder widespread development and dissemination of policies and programs for this population, as has been highlighted in previous evidence reviews.

Commentator & Affiliation	Section	Comment	Response
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	Despite the very broad set of research questions that this evidence review was intended to answer (pages 2 & 3), the main body of findings pertain to 9 studies that met rigid inclusion criteria. As such, the reviewers suggest eliminating the chapters on implementation and communication tools (5), barriers and facilitators (6), definitions and measures for transition (7), training (8-10), and strategies for increasing availability of adult providers (11). What is included in each of these chapters is not at all well done. Specific comments for these chapters are summarized below.	The chapters on implementation, barriers/facilitators, definitions, training and strategies are guiding questions meant to supplement and provide additional context for the systematic review. They are not meant as an exhaustive review of the literature but to provide additional information on important aspects of interest to stakeholders based on input during the topic refinement period.
Public Commenter #2 Got Transition, National Alliance to Advance Adolescent Health, Peggy McManus, Patience White, Annie Schmidt, and Samhita Ilangos	General	The reviewers also suggest that the authors consider putting all of the disease-specific tables into the appendix.	Thank you. Responses from other reviewers suggest the presentation by disease-conditions was particularly helpful.