# Using Implementation Science to Improve Transition for Adolescents and Young Adults with Sickle Cell Disease

Cecelia Calhoun[1], Lingzi Luo[2], Ana Baumann[3], Anna Bauer[2], Virginia McKay[3], Cole Hooley[4], Aimee James[2], and Allison King[2]

[1]Washington University in Saint Louis School of Medicine
[2]Washington University School of Medicine in Saint Louis
[3]Washington University in St. Louis
[4]Brigham Young University College of Family Home and Social Sciences

June 4, 2020

## Abstract

Background The adolescent and young adult (AYA) period is a time of high morbidity and mortality for persons with sickle cell disease (SCD). The goal of this study was to use implementation science combined with qualitative methods to understand the determinants of an optimal transition to adult care for AYA with SCD. Methods Sixty participants were purposefully recruited from a large hospital system and the community for 16 focus groups or semi-structured interviews. Patient-caregiver dyads and health care providers shared experiences in the health care and academic settings. Data were coded and analyzed by paired coders using an inductive coding approach in combination with an implementation research framework, the Consolidated Framework for Implementation Research (CFIR). Results At the Individual Characteristics level, AYA patients expressed challenges with adult life experiences, disease self-management, and preparation for the adult health care model. Caregivers and health care providers reported independence and autonomy as facilitators of a successful transition. At the Inner and Outer Setting levels, differences between pediatric and adult health care models were noted barriers, highlighting the gap in patient-centered care. Patient and provider communication was identified as both a barrier and facilitator. A standardized approach to transition planning and coordination was noted as a facilitator. At the Intervention Characteristics level, adaptability, incentive, and perceived attractiveness of the intervention were important components. Conclusion This study highlights which determinants of transition are most amenable to evidence-based interventions. This is imperative for rapidly improving this process for AYA with SCD and, thus, improving overall outcomes.

Cecelia Calhoun MD MPHS[1*], Lingzi Luo MSW MPH[2*], Ana Baumann PhD[4], Anna Bauer BA[2], Virginia McKay PhD[4], Cole Hooley PhD LCSW[4], Aimee James PhD MPH[3], Allison King MD MPH PhD[1,2,3]

Washington University of Medicine [1]Department of Pediatrics and [2]Program in Occupational Therapy,[3]Division of Public Health Sciences[4]; [4]Washington University Brown School of Social Work

*Indicates equal contributions as first authors.

Corresponding Author:

Cecelia L. Calhoun

Washington University School of Medicine

Department of Pediatrics

1

660 S. Euclid

Campus Box 8116

St. Louis, MO 63110

Phone: 314-454-6018

Fax: 314-454-2780

Email: calhounc@wustl.edu

Abstract Word Count: 250/250

Main Text Word Count: 3495/3500

Tables Count: 2

Short Running Title: Implementation Science for SCD Transition

Key Words: sickle cell disease, transition, young adult, education

Abbreviations:

| AAP | American Academy of Pediatrics |
| --- | --- |
| ASH | American Society of Hematology |
| AYA | Adolescents and young adults |
| AYA-SCD | Adolescents and young adults with sickle cell disease |
| CFIR | Consolidated Framework for Implementation Research |
| ED | Emergency department |
| SCD | Sickle cell disease |
| SCDIC | Sickle Cell Disease Implementation Consortium |

## ABSTRACT

### Background

The adolescent and young adult (AYA) period is a time of high morbidity and mortality for persons with sickle cell disease (SCD). The goal of this study was to use implementation science combined with qualitative methods to understand the determinants of an optimal transition to adult care for AYA with SCD.

### Methods

Sixty participants were purposefully recruited from a large hospital system and the community for 16 focus groups or semi-structured interviews. Patient-caregiver dyads and health care providers shared experiences in the health care and academic settings. Data were coded and analyzed by paired coders using an inductive coding approach in combination with an implementation research framework, the Consolidated Framework for Implementation Research (CFIR).

### Results

At the Individual Characteristics level, AYA patients expressed challenges with adult life experiences, disease self-management, and preparation for the adult health care model. Caregivers and health care providers reported independence and autonomy as facilitators of a successful transition. At the Inner and Outer Setting levels, differences between pediatric and adult health care models were noted barriers, highlighting the gap in patient-centered care. Patient and provider communication was identified as both a barrier and facilitator. A standardized approach to transition planning and coordination was noted as a facilitator. At the Intervention Characteristics level, adaptability, incentive, and perceived attractiveness of the intervention were important components.

**Conclusion**

This study highlights which determinants of transition are most amenable to evidence-based interventions. This is imperative for rapidly improving this process for AYA with SCD and, thus, improving overall outcomes.

**INTRODUCTION**

Sickle cell disease (SCD) is an inherited hemolytic anemia that affects over 100,000 people, primarily African Americans, in the United States.[1,2] Clinical manifestations include debilitating pain, severe anemia, and end organ damage. With the successful implementation of evidence-based interventions such as pneumococcal vaccination and penicillin prophylaxis, over 95% of children with SCD live into adulthood.[3] With increased longevity, transition from pediatric to adult care is an emerging field fraught with challenges.

Adolescent and young adults with SCD (AYA-SCD) experience more hospitalizations, readmissions, and acute care utilization compared to others with SCD.[1,4] Transition is multilayered and complex in nature. The transition process represents the intersection of the emotional, social, psychological, and physical development of normal adolescence; changes in health care access; and increased manifestations of end organ damage of SCD.[5] Compounding these challenges are the socioeconomic disparities faced by the majority of AYA-SCD.[3]

To improve health care transition for AYA, especially those with special health care needs, the American Academy of Pediatrics (AAP) updated its guideline in 2018: *Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home* .[6] The guideline includes structured guidance centered around the "six core elements of health care transition," which define the basic components of health care transition support.[7] It also includes an SCD-specific toolkit for transition from pediatric to adult hematologic care developed in collaboration with the American Society of Hematology (ASH) to assess transition readiness and concisely document each patients health history.[6]

Implementing evidence-based guidelines in practice settings is challenging.[8,9] Implementation research, an emerging field that addresses the gap between current knowledge and practice to provide structured guidance and more rapid implementation of evidence-based interventions, provides a novel approach.[10,11] Informed by the AAP transition guideline, the goal of this project was to identify the multilevel barriers and facilitators of transitioning care for AYA-SCD for implementation of a future structured local transition program.

**METHODS**

**Framework and a Deductive-Inductive Coding Approach**

Our work was informed by the Consolidated Framework for Implementation Research (CFIR), an overarching framework composed of 5 domains: Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals Involved, and Process Of Implementation.[12] The framework has been widely used to evaluate pre, post, and ongoing implementation processes.[13,14] It has been used across a wide variety of studies, settings, and units of analysis.[15]

While the CFIR framework offers a comprehensive taxonomy of factors influencing intervention planning and implementation, a mixed deductive-inductive approach has been used to address the challenge that CFIR domains and constructs may not capture all emergent themes in qualitative assessment.[16] The deductive-inductive approach integrates inductive, data-driven codes with deductive, theory-driven codes using an a priori code template and has proven rigor within qualitative research.[17] This approach expedites data analysis while providing comprehensive themes that otherwise would not be captured by CFIR constructs.

**Study Setting and Participants**

The Sickle Cell Disease Implementation Consortium (SCDIC) is a multi-institutional cooperative funded by the National Institutes of Health's National Heart, Lung, and Blood Institute. The SCDIC was established in 2016 to improve "the health and well-being of adolescents and adults with SCD in the US through the development of multi-modal, multi-sector interventions aimed at improving the rate at which patients with

SCD receive routine primary care."[18] Eight academic sites and a Data Coordinating Center comprise the SCDIC. This study involved 1 site.

A convenience sample of patients, caregivers, and providers was recruited from the pediatric and adult SCD clinics affiliated with a university in the Midwest and from an SCD community-based organization. The study was approved by the university's Institutional Review Board.

Eligible patients were between ages 15 and 26 years and had SCD of any genotype. Caregivers were eligible if they were caring for AYA-SCD. Sickle cell providers were defined as physicians, nurse practitioners, or clinic staff who provide medical care to patients with SCD. Emergency department (ED) providers were recruited via an email list of faculty and staff who serve the medical school and affiliated hospitals. All participants provided informed consent or assent and received a $50 gift card for their participation.

### Measures

Interview guides

The SCDIC developed 3 semi-structured interview guides for patients and caregivers, SCD providers, and ED providers. The guides addressed the following domains: access to primary and specialized care, beliefs and practices related to hydroxyurea and pain control, transition from pediatric to adult care, and patients' experiences in the ED.

### Data Collection

A co-investigator (CC) conducted focus groups and interviews until thematic saturation was reached. Each focus group lasted between 45 and 80 minutes. Each interview lasted between 20 and 40 minutes and was audio-recorded and transcribed verbatim.

### Data Analysis

The research team used a combined inductive and deductive approach to code and analyze data. The deductive approach used the CFIR as a coding framework. A leading coder (LL) with experience in implementation research created the codes using the CFIR domains, developed the codebook, and reviewed each transcript to increase familiarity with the data. The inductive approach entailed open coding to identify emerging themes from the transcriptions.[19] A team of graduate research assistants, led by the co-investigator (CC) and the leading coder (LL) developed the inductive codebook. The inductive codebook was then revised considering the addition of the deductive codebook to avoid duplicity of codes. The team met to compare codes, discussed definitions of each code until consensus was reached, grouped codes into categories, and finalized the codebook.

Two research assistants (AB, ES) were paired with the leading coder (LL) and coded transcripts with the inductive codebook and deductive codebook separately. The leading coder cross-checked coding and discussed differences in coding with research assistants. Although inter-coder reliability was not calculated, the simplicity of the deductive codebook and the operational definitions of the inductive codes led to high-level agreement, and consensus was reached for coding discrepancies. Codes were entered to NVIVO software. Data were analyzed through direct content analysis using the inductive and deductive codebooks, and the results were organized based on CFIR domains.

### RESULTS

Sixty participants (21 patients, 17 caregivers, 9 pediatric SCD providers, 6 adult SCD providers, 6 ED providers) completed a total of 16 focus groups. These included 8 patient-caregiver focus groups (see Table 1 for patient demographics), 2 pediatric SCD provider focus groups, 1 adult SCD provider focus group, and 5 semi-structured interviews with ED providers between July 2016 and November 2017.

Four CFIR domains were used for the CFIR deductive codebook: Intervention Characteristics, Outer Setting, Inner Setting, and Individual Characteristics. Five domains emerged from the inductive coding process: Healthcare Access, Healthcare Delivery and Use, Social/Emotional Considerations, Disease Education, and

Disease Management. Table 2 reports sample quotes of each CFIR domain, with themes from inductive coding. Below, we report data specifically related to transitioning care for AYA-SCD.

**Outer Setting**

In this study, *Outer Setting* refers to the factors outside of the hospital that may influence care during the transition period. As the quotes in Table 2 demonstrate, lack of understanding and support from the community and employers was a major theme reported by all stakeholders. The stigma surrounding opioid use, particularly in the current policy context, was also reported as a challenge. In terms of AYA transition, stakeholders reported the lack of access to subspecialty care in the region as a major challenge. Patients and caregivers mentioned the struggle to find an adult SCD doctor:

*"As she [SCD patient] got older, I come to find out that it was plenty of sickle cell doctors for children, but she's an adult now. As big as [place] is, how could you only have 1 adult sickle cell doctor? It's, it's still just blowing my mind on that one right there." – Caregiver*

The pediatric SCD providers agreed with this challenge and offered potential solutions:

*"In the community, instead of having 1 hematologist, can we not set up some type of education where you getting these [medical school] doctors in, and seek them out to actually, um, train them to be a hematologist, that way our kids can get the care that they need when they get to be older." – Pediatric SCD provider*

**Inner Setting**

In this study, the *Inner Setting* refers to the factors within the hospital and clinic setting. Stakeholders mentioned differences in the pediatric and adult care models, which result in different expectations from patients, caregivers, and providers, as well as communication challenges both between the patient and provider and among providers. Coordinated care or a structured transition program is needed:

*"We need to have some sort of common expectation amongst the providers on the pediatric side and the providers on the adult side about, like, things like hydroxyurea, things like opioid, you know, how are we refilling people's opioids. Fortunately, that is less of a problem than it used to be, but, you know, like, so that we're not, so that we're not telling the patients one thing and then they get to the adult side and that's a completely different, you know, situation." – Pediatric SCD provider "From a pediatric standpoint, they can give you awareness with what you faced... what you are going to be up against when you are going through that transition, instead of you being...blindsided through it." – Patient*

Other themes in this domain included lack of timely care, need of structured disease education for providers and patients, and stigma within the hospital system, particularly in the ED where providers may not be familiar with SCD treatment.

**Individual Characteristics**

*Individual Characteristics* refer to individual-level challenges centered on patients with SCD and characteristics of providers that could facilitate the transition process. Patients discussed challenges with self-management and disease-specific management barriers to optimal care. New life experiences, such as pregnancy or drinking alcohol, necessitate disease education and self-management skills around how these young adult experiences may affect SCD:

*"By me turning 21, I found out that alcohol affects my sickle cell because it's taking the water basically from my body.... And, um, that affects me. Instead of having a hangover, I can have a sickle cell attack. So, I think that's something that I wasn't prepared for, but I understand that now. And I understand that if I feel a little pain, I am not going out and drinking this weekend. But you don't know that until it happens to you." – Patient*

Providers sometimes find it difficult to communicate adult-specific challenges with patients or caregivers:

*"Sometimes when we take literature in for the patients. . . about pregnancy and sickle cell, a lot of the parents [say], 'Oh, no, we don't need that.' They don't want it. They don't want you to give that to their daughter. They'll stop you." – Pediatric SCD provider*

Advocacy from providers was identified by patients and caregivers as a facilitator to care. Advocacy manifests in multiple settings, including schools, health care settings, the workplace, and in the community in general.

**Intervention Characteristics**

*Intervention Characteristics* refer to the features of an intervention that may influence intervention implementation or outcomes. We asked participants to think about solutions to mitigate the challenges that they perceived surrounding AYA-SCD transition. Major themes that emerged in this domain were: (1) starting the transition process at an early age, (2) building transition readiness for both patients and caregivers, and (3) care coordination that builds the patient-provider relationship and ensures consistency.

Starting the transition process at an early age

Acknowledging that many AYA-SCD patients are not well prepared for the transition process, providers expressed that starting the transition and providing educational programming at an early age may help the process:

*"I think starting education from a young age is huge. And talking about transitioning when they're a young adult, even at like 12, could be optimized a little better. I think. . . a co-nurse practitioner does a good job of kicking parents out sometimes and making sure that the patient can kind of describe their symptoms on their own, and their medications on their own, and revealing their complications and what kind of disease they have, and I think that does help foster independence" – Pediatric SCD provider*

Building transition readiness for both patients and caregivers

As the pediatric and adult care models are dramatically different, patients, caregivers, and providers acknowledge that building the patient's autonomy and independence is vital to successful transition:

*"Give them exactly what they need so when they get to see [an adult SCD provider], they will have everything in place for them as far as a teenager. Knowing their medications. Knowing how to get the medications filled. How to set up an appointment. How to call if you need transportation, if mom's sick or something, you need to be able to get on that phone and call your Medicaid transportation." – Pediatric SCD provider*

As caregivers play an important role in most AYA-SCD patients' transition processes, programs need to involve caregivers while building patients' transition readiness:

*"My biggest challenge was being so overprotective because from two-and-a-half up until 10 and 11, I mean we STAYED in the hospital. So, I was so overprotective that I didn't want him to get out there and play football, do anything, because I really thought he was going to hurt himself. So, I think that was my biggest thing because the doctor used to say, let him do as a kid would do. He knows his limitations, but I think it was more me. And now, it's like okay you grown, so it's a big difference from when I was taking care of you. And now that you grown, it's a big difference." – Caregiver"I think we need to do better education of parents at different developmental stages of their kid, to not be the helicopter, because I think that's the natural parent response. I do not fault parents for that at all, but I do think maybe they should go every 6 months and 1 of those visits is strictly for some type of education." – Pediatric SCD provider*

Patient-centered care coordination

Patients, caregivers, and providers acknowledged the importance of care coordination and patient-centered care during transition. Trust between providers and patients is a crucial facilitator of health care access and utilization. Participants mentioned 2 approaches that would be helpful: introducing patients to the adult team before actual transition or having a provider help patients go through transition at both the pediatric and adult side:

6

*"I think having a consistent team, that's good. I think that that's helpful. . . You know, like, seeing the same faces and having that relationship is helpful with the teenager." – Adult SCD provider "Maybe if he could have the doctors from [the adult hospital] come over to [the children's hospital] and meet with him before he transitions over to the adult care, that would help some." – Caregiver*

Ensuring provider-provider communication and the consistency of care transitioning from pediatric to adult care is also important:

*"I think we need. . . to have some common expectation amongst the providers on the pediatric side and the providers on the adult side about, like, things like hydroxyurea,. . . opioids. . . so that we're not telling the patients one thing and then they get to the adult side and that's a completely different situation. I think that's a very important component." – Pediatric SCD provider*

Other health care services and models were brought up by patients and caregivers that could improve services for SCD patients, including co-location of care. One caregiver thought that outpatient services, such as SCD nurse home visitations, would be helpful. A few patients and caregivers mentioned establishing a sickle cell center to provide a more holistic health care approach to treat patients with SCD.

*"Just strictly a sickle cell center, that they already know you come there, just like a clinic that you can go to. . . for health care. You don't have to feel ashamed because everybody is in there for the same thing." – Caregiver*

ED providers mentioned challenges of treating SCD patients in the ED. The adult ED needs a more standardized treatment approach that could better utilize the Electronic Medical System.

*"I think a national care path, where the hematologist manages accessible to everybody in health care, would be ideal, whether it's through Cerner or Epic or through the sharer program. That would be ideal, to be able to provide comprehensive care to the patients, rather than this, um, kind of variable care that sometimes we provide now." – Adult ED provider*

## DISCUSSION

This pilot qualitative study aimed to explore multilevel barriers and facilitators associated with transition of SCD pediatric to adult care. Perspectives of adolescents, caregivers, and providers endorsed the need for better preparation, communication, and coordination.

By organizing the findings into the main components of CFIR, we can consider the multilevel approaches needed. For example, barriers in the Outer Setting domain reiterated the need for more adult hematology providers and showed how this shortfall compromises access to care. An investment in training classical hematologists, mid-level providers, and adult primary care providers with a focus on SCD is needed to meet this shortfall. This domain also highlighted the external factors to the health care system, such as employment, that affect AYA-SCD in their ability to matriculate into adulthood. Interventions targeting modifiable factors at the individual and inner organizational levels still need to acknowledge the outer context to adapt their programs to be effective.

At the Inner Setting level, the difference between the pediatric care model, where pediatric patients are closely guided, and the adult care model, where patients are expected to be independent, is well acknowledged by previous literature.[20-22] There is a clear need for a structured transition program to bridge the gap between these systems, which requires better care coordination and improved provider-provider and patient-provider communication. There was previously only 1 adult hematologist focused on SCD care in our metropolitan area. In an effort to address this shortage and the gap in systems of care, pediatric SCD providers have been extending their care to AYA-SCD patients in an adult setting. The transition program links pediatric patients to the adult team, but these efforts need to be more structured with greater visibility in the organizations.

At the Individual Characteristics level, previous literature has highlighted the importance of patient transition readiness,[23,24] and our data suggest that caregivers also need to be prepared for patient transition,

7

especially when addressing adult-specific challenges, and that promoting patient and provider advocacy is an important component for successful transition.

One of the most positive findings of the study was that the majority of the emerging themes captured by the Intervention Characteristics domain reflected the "six core elements" of transition.[7] These include discussion of the transition policy at an early age, preparing both patients and caregivers for transition, and careful planning and integration into adult care. Many of these intervention characteristics directly address or incorporate factors identified by the other 3 CFIR domains, especially at the Individual Characteristics level. Some stakeholders acknowledged the efforts made at the institutional and individual levels to help with patient transition. A structured transition program with defined transition policy, practice, and a strong presence is needed to incorporate these intervention characteristics.

A deductive-inductive analysis approach allowed for a comprehensive, structured understanding of the rich data from multiple stakeholder perspectives. The CFIR domain specifies which level the factor manifests, and the themes identified through inductive coding specified challenges. This organization of data can help local teams identify and target amendable factors and design specific implementation strategies to address these challenges while acknowledging other multi-level factors that will not be directly addressed by the designed intervention. Our data describe issues around stigma, access, and communication—highly relevant to people in vulnerable contexts. Further work needs to be done in the field of implementation science to explicitly recognize aspects of health care disparities[25] and develop comprehensive strategies aimed to address these multiple levels to maximize equity and health care impact. This work focuses on using the contextual insights gained from CFIR to develop implementation strategies that address these determinants for guideline implementation.

This study is not without inherent limitations. Our interview guide was not developed based on a specific implementation research framework but sought to focus on a broad cadre of factors affecting transition. The field of implementation research is evolving, and future research may integrate the CFIR into data collection efforts early on, which will strengthen applicable findings for intervention design and evaluation. Additionally, this was a single-site study, which may limit generalizability. However, its setting was a large, urban center that likely has similar characteristics to other academic centers. Future explorations will examine what themes are salient across other sites in the SCDIC to understand how to best adapt evidence-based interventions in the AYA-SCD population.

Conclusions

This pre-implementation study highlights barriers and facilitators for AYA patients with SCD transitioning from pediatric care to adult care. The CFIR is a helpful framework to aid researchers and practitioners to understand barriers and facilitators from a multi-level perspective that not only considers the role of the individual patient or caregiver and the individual provider, but also suggests that system-level interventions are imperative. Future studies should use implementation science to further examine systems-level barriers to guideline implementation in order to expedite the development of structured transition programs for AYA-SCD.

**Conflict of Interest Statement**

The authors have no conflicts of interest to declare.

**Acknowledgements**

**Data Availability Statement**

The data that supports the findings of this study are available in the supplementary material of this article

References

1. Hassell KL. Population estimates of sickle cell disease in the U.S. Am J Prev Med 2010;38(4 Suppl):S512-521.

2. Piel FB, Steinberg MH, Rees DC. Sickle cell disease. New Engl J Med 2017;376(16):1561-1573.

3. Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. Blood 2010;115(17):3447-3452.

4. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. JAMA 2010;303(13):1288-1294.

5. DeBaun MR, Telfair J. Transition and sickle cell disease. Pediatrics 2012;130(5):926-935.

6. White PH, Cooley WC. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2018;142(5).

7. White P, Cooley WC, McAllister J. S*tarting a transition Improvement Process Using the Six Core Elements of Health Care Transition* . Washington DC: National Alliance to Advance Adolescent Health, 2015. https://www.gottransition.org/resourceGet.cfm?id=331.

8. Davis DA, Taylor-Vaisey A. Translating guidelines into practice. A systematic review of theoretic concepts, practical experience and research evidence in the adoption of clinical practice guidelines. CMAJ 1997;157(4):408-416.

9. Yana R, Jo RM. Getting guidelines into practice: a literature review. Nurs Stand 2004;18(50):33-40.

10. King AA, Baumann AA. Sickle cell disease and implementation science: a partnership to accelerate advances. Pediatr Blood Cancer 2017;64(11).

11. Glasgow RE, Vinson C, Chambers D, Khoury MJ, Kaplan RM, Hunter C. National Institutes of Health approaches to dissemination and implementation science: current and future directions. Am J Public Health 2012;102(7):1274-1281.

12. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci. 2009;4(1):50.

13. VanDevanter N, Kumar P, Nguyen N, et al. Application of the Consolidated Framework for Implementation Research to assess factors that may influence implementation of tobacco use treatment guidelines in the Viet Nam public health care delivery system. Implement Sci 2017;12(1):27.

14. Teeters LA, Heerman WJ, Schlundt D, Harris D, Barkin SL. Community readiness assessment for obesity research: pilot implementation of the Healthier Families programme. *H* ealth Res Policy Syst 2018;16(1):2.

15. Kirk MA, Kelley C, Yankey N, Birken SA, Abadie B, Damschroder L. A systematic review of the use of the consolidated framework for implementation research. Implement Sci 2015;11(1):72.

16. Hill JN, Locatelli SM, Bokhour BG, et al. Evaluating broad-scale system change using the consolidated framework for implementation research: challenges and strategies to overcome them. BMC Res Notes 2018;11(1):560.

17. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. Int J Qual Methods 2006;5(1):80-92.

18. DiMartino LD, Baumann AA, Hsu LL, et al. The sickle cell disease implementation consortium: translating evidence-based guidelines into practice for sickle cell disease. Am J Hematol 2018;93(12):E391.

19. Thomas DR. A general inductive approach for qualitative data analysis. Auckland, New Zealand: School of Population Health, University of Auckland, 2003.

20. Margolis R, Wiener L, Malech HL, Holland SM, Driscoll P. Transition from pediatric to adult care by young adults with chronic granulomatous disease: the patient's viewpoint. J Adolesc Health 2017;61(6):716-721.

21. Crosby LE, Quinn CT, Kalinyak KA. A biopsychosocial model for the management of patients with sickle-cell disease transitioning to adult medical care. Adv Ther 2015;32(4):293-305.

22. Treadwell M, Telfair J, Gibson RW, Johnson S, Osunkwo I. Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. Am J Hematol 2011;86(1):116.

23. Lanzkron S, Sawicki GS, Hassell KL, Konstan MW, Liem RI, McColley SA. Transition to adulthood and adult health care for patients with sickle cell disease or cystic fibrosis: current practices and research priorities. J Clin Transl Sci 2018;2(5):334-342.

24. Kwarteng-Siaw M, Paintsil V, Toboh CK, Owusu-Ansah A, Green NS. Assessment of Transition readiness in adolescents with sickle cell disease and their caretakers, a single institution experience. International J Hematol Res 2017;3(1):171.

25. Baumann AA, Cabassa LJ. Reframing implementation science to address inequities in healthcare delivery. BMC Health Serv Res 2020;20(1):1-9.

**Hosted file**

CFIR_Local_AYA_Table1.docx available at https://authorea.com/users/329729/articles/456660-using-implementation-science-to-improve-transition-for-adolescents-and-young-adults-with-sickle-cell-disease