A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs

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Moderator

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Today's Speakers

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Ask Questions!

We look forward to a lively discussion with our audience.
Submit your questions through the Q&A.

National Health Systems Research Agenda for CYSHCN

- Developed as a major part of CYSHCNet's initial 5-year Cooperative Agreement with the Maternal and Child Health Bureau, Health Resources and Services Administration

- Rationale:
  - Number of CYSHCN is increasing, as is research on how to improve systems of care
  - Outcomes are not improving, and research is not always well coordinated
  - Needs of families are not always explicitly included in research priorities
  - Core Outcomes (MCHB) and System Standards (AMCHP/NASHP) are well articulated
  - Research needs to be aligned with outcomes, and efforts need to be coordinated

Development of National Research Agenda

- Began in 2018 with multistakeholder priority-setting process: RAND Appropriateness Method (RAM) and published in 2020 (Coller et al., Pediatrics, March 2020)

- Additional stakeholder input to include more/diverse families, provider groups

- Six major areas identified, with research questions prioritized within each area:
    - Transitions of Care
    - Caregiving at Home/Caregiving Processes
    - Principles of Care
    - Child Healthcare
    - Family Health
    - Financing

Improving Health Care Transitions for Children and Youth with Special Health Care Needs

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Improving Health Care Transitions for Children and Youth With Special Health Care Needs

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The authors have nothing to report.
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ABSTRACT

Health care transitions (HCT) from pediatric to adult health care remain a challenge for children and youth with special health care needs (CYSHCN), their families and their clinicians. While the HCT literature has expanded, gaps remain in how to improve health outcomes during transitions. HCTs broadly encompass three key domain areas: transition planning, transfer to adult health care clinicians or an adult model of care, and integration into an adult care/model of care.
The CYSHCNet national research agenda development process, described in a previous article, prioritized several key research areas to address deficiencies in the HCT process. The highest priority questions identified were *"What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (eg, to new clinicians, new settings, new schools, etc.)?"* and *"How do gaps in insurance and community supports during early adulthood effect CYSHCN health outcomes, and how can they be reduced?"*. Based upon these priorities, we describe the current state of transition research and recommendations for future investigation.
Recommendations: The authors recommend 3 primary areas of investigation: 1) Understanding the optimal development and implementation of HCT service models in partnership with youth and families to improve transition readiness and transfer 2) Defining the process and outcome measures that capture adequacy of transition-related activities and 3) Evaluating fiscal policies that incentivize the processes of transition readiness development, transfer to adult health care services, and continuity of care within an adult health care setting. This article explores approaches within each research domain.

KEYWORDS: Transition from Pediatric to Adult Health Care; research agenda; stakeholder engagement; families; patients

ACADEMIC PEDIATRICS 2021;XXX:1−7

WHAT'S NEW

We add to the literature key areas for future transition research based on a RAM process of stakeholder engagement. Health care providers

SUMMARY OF EXISTING KNOWLEDGE ON HEALTH CARE TRANSITIONS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

1. Barriers to health care transitions (HCT) experienced by CYSHCN are well studied and include patient-level barriers (insufficient preparedness, poor self-management skills), clinician-level barriers (lack of time in practice, lack of familiarity of disease) and system-level barriers (lack of infrastructure resources on the adult health care system including care coordination or developmentally appropriate resources for youth/young adults and families).
2. There has been guidance from numerous professional organizations, most recently the American Academy of Pediatrics/American Academy of Family Practitioners and American College of Physicians (AAP/AAFP/ACP) in the 2018 Clinical Report.[1] This guideline includes a literature review, a framework called the Six Core Element approach, and clinical recommendations in infrastructure, education, payment and research.
3. Several clinical models have been investigated, but these studies are limited to single targets rather than comprehensive approaches using available frameworks. Disease-specific outcomes have improved with some clinical models. Unfortunately, these interventions lacked descriptions of the theoretical target/mechanism for the desired outcomes as there is a

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Background

- The transition and transfer from pediatric to adult care is a vulnerable time for adolescents and young adults with special health care needs

- Adolescents experience lower continuity of care and higher morbidity

    - High attrition rates post-transfer
    - Higher Hba1c

- Well-developed research describes numerous barriers experienced on patient, provider, system, and policy levels

    - Developmental concerns for young adults
    - Provider access and knowledge
    - System barriers to knowledge transfer and follow up
    - Insurance and reimbursement practices that does not support health care transition (HCT)

Background

- To address barriers to HCT, multiple academic societies, such as the American Academy of Pediatrics, American College of Physicians, Adolescent Medicine, and subspeciality groups have advocated for improving the transition process

- Health systems have been working on trying to improve this “transition process” to improve quality of care delivery to these adolescents and young adults

- Unfortunately, there is not a clear evidence on how to ensure optimal HCT outcomes

Stakeholder Questions

"What are the best models to accomplish youth-adult transition planning? How might this translate to other transitions (e.g., to new providers, new settings, new schools, etc)?"

"How do gaps in insurance and community supports during early adulthood effect CYSHCN health outcomes, and how can they be reduced?"

The Gap: “Fixing” HCT

- Barriers to HCT are complex and the way to address barriers to HCT requires a multi-modal approach with input from patients and families
- No single “magic bullet” that addresses all the barriers identified
- There continues to be significant research gaps in HCT that we address in the paper

Recommendations

- Understanding the optimal development and implementation of HCT service models
- Defining the process and outcome measures that capture adequacy of transition-related activities
- Evaluating fiscal policies that incentivize the processes of transition readiness development, transfer to adult health care services, and continuity of care within an adult health care setting

Addressing the Gap: Include Patients and Families

- Most studies do not engage families or youth in the research process
- Disconnect between family/youth goals and provider goals for HCT serves as a source of continuing failure to improve HCT
- Aligning the goals of families, youth, and providers provides opportunities to advance the field by defining appropriate process and outcome measures and generating creative solutions

Addressing the Gap: Look Beyond Healthcare

- Many interventions focus on clinic-based interventions, and yet young adults and their families don't live their lives in the clinics

- Strategies that work with community engagement, schools, and outside programs that fulfill needs of youth (e.g., vocational attainment) will likely allow youth to grow and develop their health care management skills

- Working with community programs will also facilitate additional barriers to healthcare, and bring cultural and social competencies

Addressing the Gap: Rigor and Real World

- Greater use of randomized controlled trials and quasi-experimental methods that would help evaluate measurement and outcomes are needed
- Currently much of the research has been driven by single academic center pilots but do not use theoretically driven models or evaluations that allow for greater generalizability
- Using implementation science strategies to see what “works” is critical to change health systems nationally

Addressing the Gap: Addressing Policy

- Funding and funding strategies are key to implement sustainable transition programs
- Projects describing cost effectiveness and strategic funding strategies have not been performed
- State and federal demonstration projects would help advance how best to fund incentives and programs to ensure high quality HCT

Conclusion

- Funding agencies are now increasingly prioritizing HCT research
  - National Institute of Mental Health
  - National Institute of Child Health and Human Development
  - Patient-Centered Outcomes Research Institute

- Robust development of transition measures and key outcomes are still needed

- Theory-driven interventions that are disease agnostic and rigorously tested are critical to changing the way we go about the HCT process

Faculty disclosures

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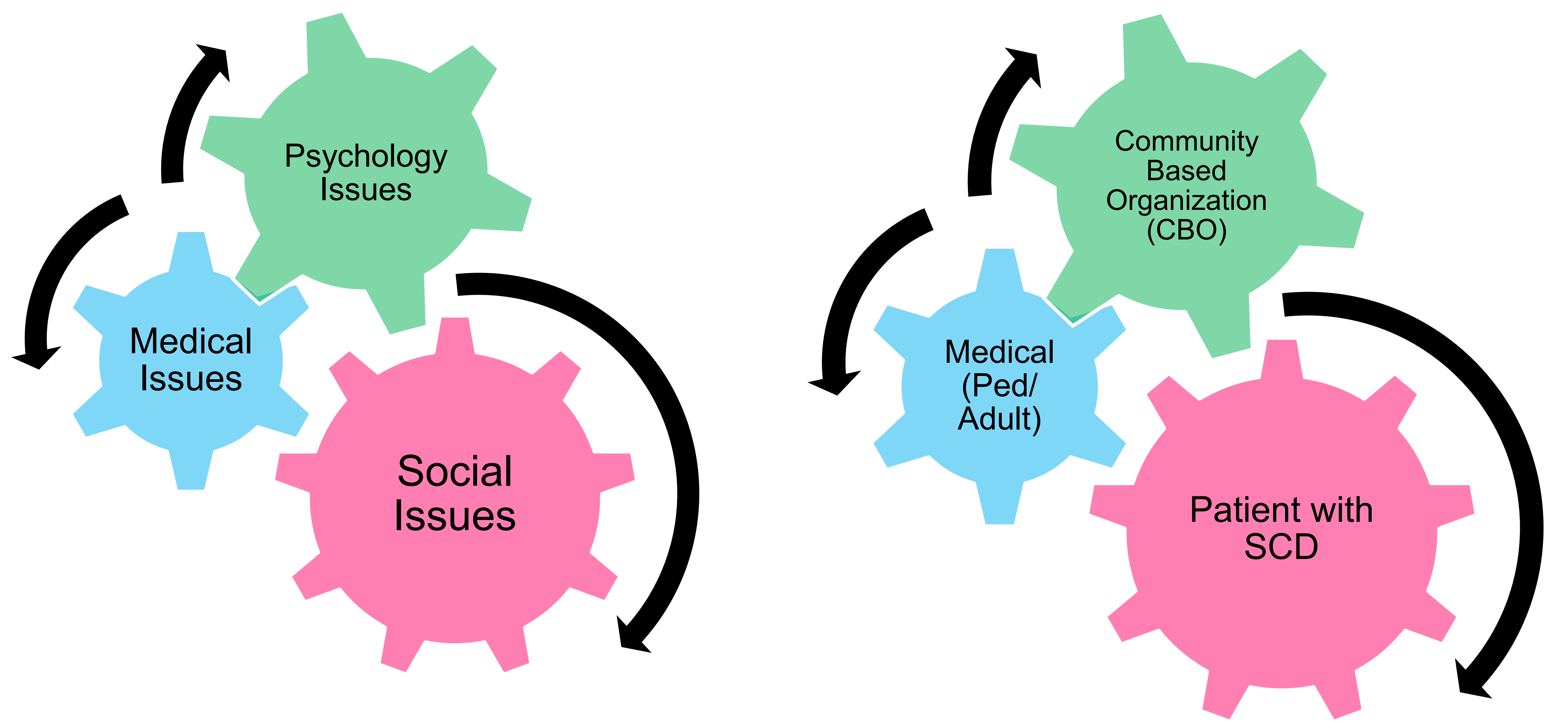
[SCD] Transition is Complex; The TRIAD Approach is Critical



Community Input Should [MUST] Guide Research Agenda

1 Care Standardization

- **Consistency**
- Pathways
- Communication
- **SCD Action Plan**

2 Provider Education

- Understanding Patient Pain
- **Building Partnerships**
- Comfort and Confidence

3 Community Engagement

- Education
- **Partnering with Schools, Healthcare, Employers**

4 Patient-Provider Relationship

- Improved Communication
- Skilled Listening
- **Patient Navigation/ Peer Mentor**

5 Patient Education and Resources

- Understanding Self-Care
- **Support Resources**
- Networks of Care

ST3P- UP Sickle Cell Trevor Thompson Transition Project

Jan 05, 1968 - Nov 10, 2016

- A PCORI-sponsored $9.8m prospective, double arm, unblinded, cluster randomized study of a structured education-based transition program **+/- virtual peer mentoring**
- 14 sites (peds +adult program + community-based organizations)
- **Standard arm**
  - Structured transition process
  - Implementation using quality improvement (QI)
    - Change across pediatric and adult clinics and CBO

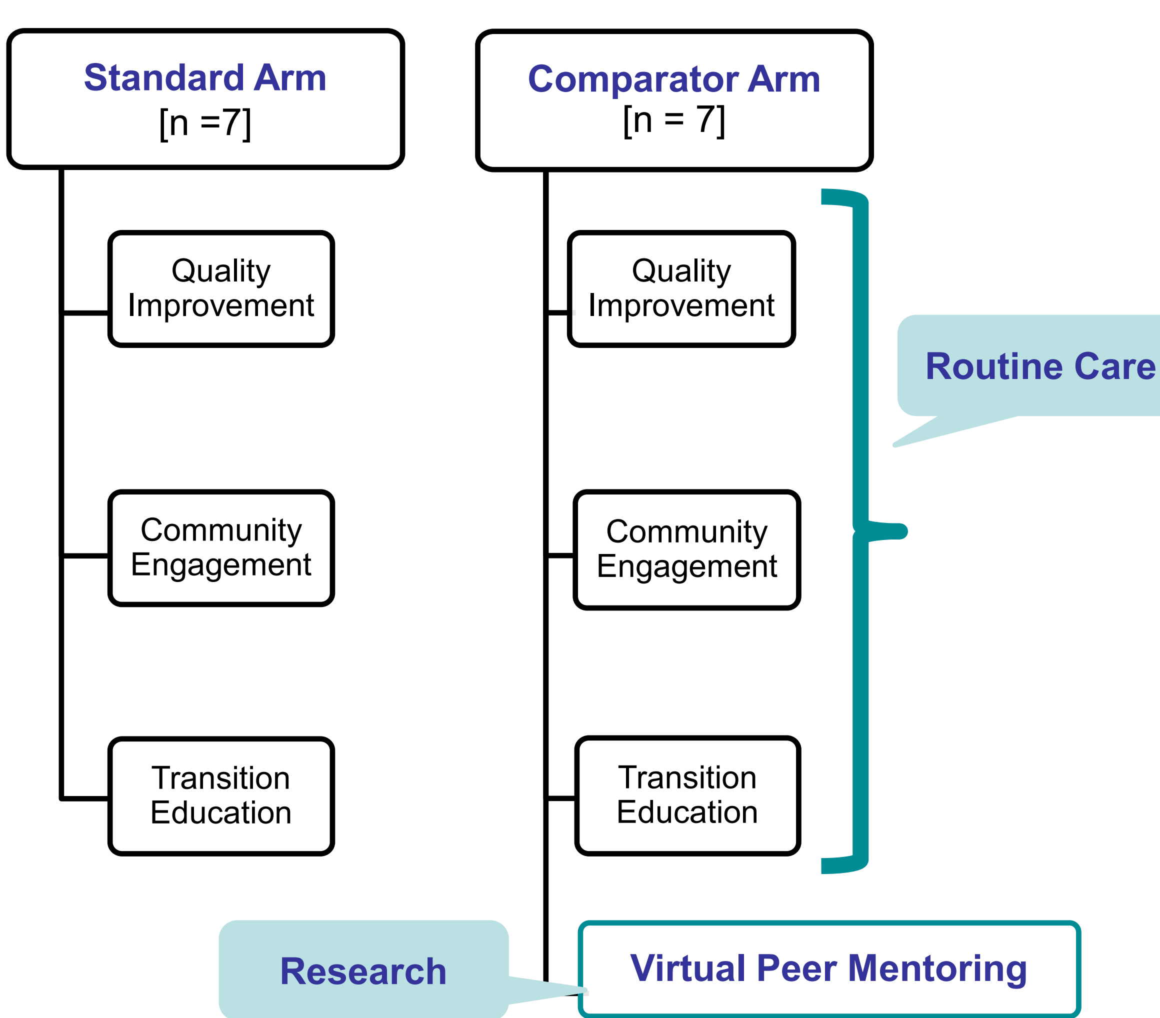
ST3P-UP Study Design Informed by TRIAD

Standardize Process of Transition Planning and Education

- Use www.gottransition.org model
- QI Model for Improvement, implement practice change
- QI Coach to oversee work with each site
- **Transition Coordinator = Transition Quarterback**
- Work in a TRIAD along with CBO
- Every patient in practice benefits

Addition of peer mentors will improve outcomes

- Acute Care Reliance = Acute care utilization / All healthcare encounters
- **Quality of Life Self Efficacy**
- Remaining in adult care for 1 year or more (regular visits)
- Process and Outcomes (QI, patient engagement, etc)



Transition QI Collaborative (SMART) Aim Statement

Sickle cell disease (SCD) is a complex chronic disease that results in significant morbidity, mortality, and poor quality of life for teens and young adults.

A successful transition from pediatric care to adult care has great impact on the health and lives of these patients.

We aim to improve the health of teens and young adults with SCD by implementing an evidence-based transition program in pediatric and adult SCD programs.

We will accomplish this by December 30, 2021, using the Model for Improvement and the Got Transition Six Core Elements.

Approaches to Quality Improvement. Content last reviewed May 2013. Agency for Healthcare Research and Quality, Rockville, MD. https://www.ahrq.gov/ncepcr/tools/pf-handbook/mod4.html

SCD Transition QI Measures – Patient Centered

Outcome Measures

Standardized Transition Readiness Assessment [TIP-RFT]

- Standardized assessment
- Helps identify gaps in readiness
- Focus **intervention and support**
- **Update annually**
- Goal 75%

Provide Detailed Transition Specific Medical Summary

- Address medical & psychosocial factors
- Personal info relevant to care
- Update, share with patient, caregiver, adult provider
- Goal 100%

Individualized Emergency Care Plan / Disease Management Pan

- Plan for managing SCD plus Pain
- Acute care Emergency Department / Hospital
- Plan for home pain management
- Update regularly (annually)
- Goal 75%

Process Measure

SCD Transition Process Measurement Tool [6CE]

- Transition Policy
- Tracking/Monitoring
- Readiness and Orientation
- Planning/Integration
- Transfer/Initial visit
- Transfer Completion /Ongoing care
- Goal 90%

QI Process Measurement Tool (PMT) Peds & Adult

Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers

Each of the Six Core Elements can be scored according to whether some or all of the implementation steps have been completed. Possible scores for each step vary depending on complexity or importance. For example, developing a written transition policy has a possible score of 5; that is, if this step is completed (yes), a practice or network would receive a score of 5. If it is not completed (no), the score is 0. Educating staff about transition policy has a possible score of 4 (yes), and similarly, not posting it would be a 0 (no). No partial scores.

Implementation Requirement	Yes or No	Possible	Actual	Possible Documentation
1. Transition Policy				
Developed a written transition policy/statement that describes the practices' approach to transition with input from youth and family		Yes = 5		Transition policy/Number of consumer reviewers
Included information in policy/statement about privacy and consent at age 18 and expected age of transfer		Yes = 5		Transition policy
Displayed policy/statement (public clinic spaces, practice websites, etc.)		Yes = 5		Photo/Screenshot
Educated staff about transition policy/statement and delineated staff's role in transition process		Yes = 4		Dates of education
Developed a process to share policy/statement with youth and family during first conversation about transition to an adult provider		Yes = 5		Description of process used
Transition Policy Implementation Subtotal		24		
2. Transition Tracking and Monitoring				
Established criteria and process for identifying transitioning target population		Yes = 4		Description of population and process used
Developed a transition registry that tracks progress through and completion of all Six Core Elements		Yes = 5		Registry screenshot
Transition Tracking and Monitoring Implementation Subtotal		9		
3. Transition Readiness				
Adopted readiness assessment tool for use in practice		Yes = 5		Readiness assessment
Incorporated readiness assessment into clinical processes (a clear process for how the readiness assessment is given to youth and how results are incorporated into patient medical record)		Yes = 5		Description of clinic process used
Developed a process to track the completion of readiness assessments during at least two visits prior to transfer		Yes = 5		Description of process used
Created an educational process to address readiness assessment needs (e.g. discussion/pamphlets/educational groups)		Yes = 5		Registry screenshot
Transition Readiness Implementation Subtotal		20		
4. Transition Planning				
Developed plan of care template that includes the youth's and family's goals and prioritized actions related to health care transition		Yes = 4		Plan of care template
Incorporated patient's readiness assessment needs in plan of care		Yes = 5		Plan of care template
Established clinical process to assess need for decision-making support before age 18		Yes = 4		Description of clinic process used
Developed a medical summary and emergency care plan (ECP) with youth and family		Yes = 5		Medical summary/ECP template
Established process to identify and communicate with adult clinician		Yes = 5		Vetted list of adult clinicians
Transition Planning Implementation Subtotal		23		
5. Transfer of Care				
Have mechanism to send medical records to adult clinician for transferring youth		Yes = 4		Description of mechanism used
Have mechanism to collect and send transfer package (with introduction letter, medical summary, emergency care plan, latest readiness assessment, transition goals, and if needed, legal documents) to adult clinician prior to first visit		Yes = 5		Transfer package checklist/ Description of mechanism used
Practice staff communicated directly with adult clinician (e.g. letter, email) confirming the pediatric clinician's responsibility for care until youth is seen in the adult practice		Yes = 5		Registry screenshot
Transfer of Care Implementation Subtotal		14		
6. Transfer Completion				
Developed mechanism to systematically obtain anonymous feedback from young adults about transition process		Yes = 5		Survey or interview questions
Documented first appointment with adult clinician in medical record		Yes = 5		Registry screenshot
Transfer Completion Implementation Subtotal		10		

Health Care Transition Process Measurement Tool for Integrating Young Adult to Adult Health Care Providers

Each of the Six Core Elements can be scored according to whether some or all of the implementation steps have been completed. Possible scores for each step vary depending on complexity or importance. For example, developing a written transition policy has a possible score of 5; that is, if this step is completed (yes), a practice or network would receive a score of 5. If it is not completed (no), the score is 0. Educating staff about transition policy has a possible score of 4 (yes), and similarly, not posting it would be a 0 (no). No partial scores.

Implementation Requirement	Yes or No	Possible	Actual	Possible Documentation
1. Young Adult Transition and Care Policy				
Developed a written transition policy/statement that describes the practices' approach to transition with input from young adults		Yes = 5		Transition policy/Number of consumer reviewers
Included information about privacy and consent at age 18		Yes = 4		Transition policy
Displayed policy/statement (public clinic spaces, practice websites, etc.)		Yes = 4		Photo/Screenshot
Educated staff about transition policy/statement and delineated staff's role in transition process		Yes = 4		Dates of education
Developed a process to share policy/statement with young adult during first		Yes = 5		Description of process used
Young Adult Transition and Care Policy Implementation Subtotal		22		
2. Transition Tracking and Monitoring				
Established criteria and process for identifying transitioning target population		Yes = 4		Description of population and process used
Developed transition registry that tracks progress through and completion of all Six Core Elements		Yes = 5		Registry screenshot
Transition Tracking and Monitoring Implementation Subtotal		9		
3. Orientation to Adult Practice				
Developed welcome materials (e.g. letter, FAQs, transitioned adult policy) with input from young adults		Yes = 5		Welcome materials/Number of consumer reviewers
Established a process to provide welcome materials to new young adults coming into the practice		Yes = 5		Description of process
Identified clinicians in practice who are interested and available to care for young adults		Yes = 4		Vetted list of adult clinicians
Orientation to Adult Practice Implementation Subtotal		14		
4. Integration into Adult Practice				
Established a process to ensure receipt of transfer package from pediatric clinicians before first visit (with introduction letter, medical summary, emergency care plan, latest readiness assessment, transition goals, and if needed, legal documents) to adult clinician prior to first visit		Yes = 5		Registry screenshot
Have capability to send digital appointment reminders (e.g. text, email)		Yes = 4		Text/email template
Integration into Adult Practice Implementation Subtotal		9		
5. Initial Visit(s)				
Adopted a self-care assessment tool for use in practice		Yes = 4		Self-care assessment
Developed a process to track the completion of self-care assessment(s) within first year in adult practice		Yes = 5		Description of process used
Developed and/or updated plan of care with patient's goals and prioritized actions related to health care transition		Yes = 4		Registry screenshot
Incorporated young adult's self-care assessment needs in plan of care		Yes = 4		Plan of care template
Developed content for first visit (e.g. review aspects of adult health care, discuss young adult's concerns about changes from pediatric care) with input from young adults		Yes = 5		Description of content/ Number of consumer reviewers
Developed and/or reviewed a medical summary and emergency care plan with young adult		Yes = 5		Medical summary/ECP template
An educational process is in place around self-care assessment needs (e.g. discussion/pamphlets/educational groups)		Yes = 5		Registry screenshot/materials
Initial Visits Implementation Subtotal		32		
6. Ongoing Care				
Linked young adult with adult specialists or PCP (e.g. OB/GYN, behavioral health provider) if needed		Yes = 5		Registry screenshot
Made available list of community support resources		Yes = 4		Resource list
Developed mechanism to systematically obtain anonymous feedback from young adults about transition process		Yes = 5		Survey or interview questions
Ongoing Care Implementation Subtotal		14		

Emergency Care Plan Tool - Home & Acute Care

Carolinas HealthCare System
SCD Pain Action Plan

Name:	
MRN #:	DOB:
Tier:	Date:
Diagnoses:	

Break-Through Pain Medicines	How Much to Take	How Often	Other Instructions
			If this medicine is needed often (_____ Times per week), call physician
			If this medicine is needed often (_____ Times per week), call physician
			If this medicine is needed often (_____ Times per week), call physician
Long Acting Control Medicines *(Use Every Day to Control Pain)*	**How Much to Take**	**How Often**	**Other Instructions**

CHECK TEMPERATURE BEFORE TAKING PAIN MEDS. IF TEMP > 101F (38.3C), Go to ED

GREEN ZONE

Pain Under Control (VAS 0 – 3)
No pain to minimal pain
Mild Pain to Uncomfortable

Can do all activities without pain. Hardly notices pain at all. Feels low level of pain when pays attention. Pain there but can ignore most of the time

PREVENT Symptoms/Avoid Triggers:
1) Take long acting control medications **EVERY DAY:**

Medication	How Much to Take	Directions

2) Good Fluid Intake at least 64oz or 8 cups (8oz)
3) Weather precautions
4) Good rest/light exercise
5) Practice positive thinking
6) Contact with friends/social support
7) Monitor stress level
8) Practice Mind-Body/ relaxation Strategies (Deep breathing and Listen to Music)
9) Other distracting activities________________

YELLOW ZONE

Pain Uncomfortable (VAS 4 - 6)
Not feeling well, Moderate / Distracting/ Distressing

Always have pain but can still do normal activities. Can work through the pain but must rest or give up some activities. Have to give up many activities and can't sleep

CAUTION! Take Action! CONTINUE ALL ACTIVITIES FROM (GREEN ZONE)
1) Start taking break-through medication for pain:

Medication	How Much to Take	Directions

2) Increase Fluid Intake at least 128oz or 16 cups (8oz)
3) Warm bath/heat compress
4) Gentle activity – walk activity, stretches
5) Incentive Spirometer
6) Practice Mind-Body/ relaxation Strategies (Deep breathing and Listen to Music)
7) Other enjoyable activity

If pain does not improve (is not in the Green Zone) and still has symptoms after 24-48hrs then, call Provider Office to review meds – see numbers below

RED ZONE

Pain Unmanageable! (VAS 7- 10)
Unmanageable, intense, Severe, Immobilizing

Cannot sleep, do activities, work, or do hobbies. Unable to think about anything else, or even talk. Unable to move, must rest or give up, go to the ER, cannot get out of bed.

Warning Signs May Include:
- **FEVER ≥ 101°F or 38.3°C**
- CHEST PAIN
- SHORTNESS OF BREATH
- SUDDEN WEAKNESS ON ONE SIDE
- SEIZURE

MEDICAL ALERT! Get help
1) GO to the nearest Emergency Department
2) If you go to the emergency room, call to notify your provider during office hours

Danger! Get help immediately! **Call 9-1-1 if: Unable to arouse**

Patient Signature: ____________ **Provider signature:** ____________
Date / Time: ____________ **Date/ Time Revised:** ____________
Hematologist/Sickle Cell Provider Clinic Number: ____________
Primary Care Provider Clinic Number: ____________

Carolinas HealthCare System
SCD Pain Action Plan

Name:	
MRN #:	DOB:
Tier:	Date:
Diagnoses:	

Break-Through Pain Medicines	How Much to Take	How Often	Other Instructions
			If this medicine is needed often (_____ Times per week), call physician
			If this medicine is needed often (_____ Times per week), call physician
			If this medicine is needed often (_____ Times per week), call physician
Long Acting Control Medicines *(Use Every Day to Control Pain)*	**How Much to Take**	**How Often**	**Other Instructions**

Other: ____________

RED ZONE

Pain Unmanageable! (VAS 7- 10)
Unmanageable, intense, Severe, Immobilizing
Cannot sleep, do activities, work or do hobbies; Unable to think about anything else, or even talk; unable to move, must go to the ER, cannot get out of bed.
- **Continue until pain VAS is ≤ 6 for 24 hours then initiate Yellow Zone Plan**

ED:
1) IV Dilaudid/Morphine ____ mg q20-30 min, up to 3 doses. If > 3 doses needed, please admit for further IV pain management.
2) IV Toradol _____ mg X 1 dose
3) IVF Hydration with D5 ½ NS at rate _____ ml/hr.

IP:
1) ATC Dilaudid/Morphine/Other, IV/PCA, ____________ ____ mg/___ hr or PCA (Basal ___ mg, Bolus ___ mg q ___ min, with max lock out ___ mg/4hrs)
2) ATC IV Toradol ____ mg q8hrs for 72hrs
3) For itching: Benadryl/Atarax/Sarna lotion/other
4) For nausea: Zofran/Phenergan/Reglan
5) Continuous IVF Hydration with D5 ½ NS at rate _____ ml/hr.
6) Continue home long acting medications (For example Fentanyl patch / Methadone / Oxycontin / MS Contin, etc….)
7) Initiate incentive spirometry and constipation prevention
8) Early ambulation

YELLOW ZONE

Pain Uncomfortable (VAS 4 - 6)
Not feeling well, Moderate / Distracting/ Distressing
Always have pain but can still do normal activities; can work through the pain but must rest or give up some activities; have to give up many activities and can't sleep
- **Continue until off of IV pain medications for 24hrs then initiate Green Zone Plan**

Initiate Pain Weaning Protocol:
1) Start home oral pain regiment ATC. After the second dose of oral medication, start reduction protocol of IV medications.
2) Reduce IV Dilaudid/Morphine dose by 25% every 12 hrs until IV is completely discontinued. For PCA, discontinue basal dose. Reduce the demand dose by 25% every 12 hrs.
3) Continue home long acting medications (For example Fentanyl patch / Methadone / Oxycontin / MS Contin, etc….)
4) Once tolerating PO, wean IVF to KVO
5) Continue constipation prevention, ambulation, and incentive spirometry

GREEN ZONE

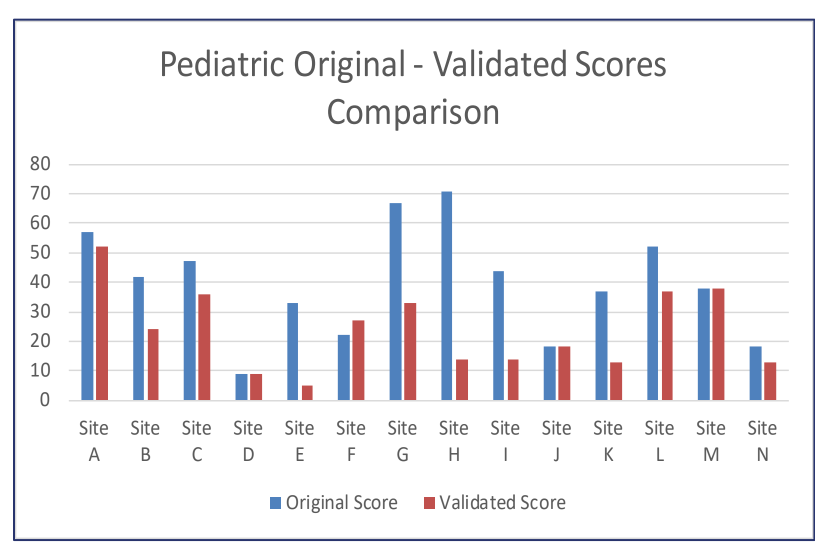
Pain Under Control (VAS <4)
No pain to minimal pain
Mild Pain to Uncomfortable

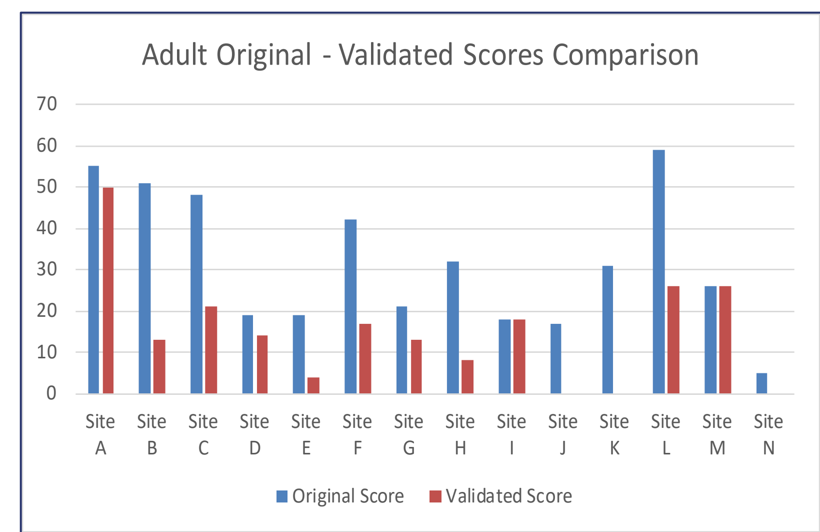
Patient is ambulating
Patient is tolerating PO meds

Assess for discharge readiness:
1) If the patient on long acting opioid at home:
   - Continue long acting at home
   - Take break-through medications with NSAIDs ATC X 3 days. Then as needed after
2) If the patient has been on IV opioid for < 7 days:
   - Take break-through medications with NSAIDs ATC X 24-48hrs. Then as needed after.
3) If the patient has been on IV opioid for > 7 days:
   - Start oral long acting medication, taper over 2 weeks after discharge by decreasing dose by 25% every 3 days
   - Take break-through medications ATC alternating with NSAIDS.
4) Set follow up appointment with PCP and Hematologist:
   - Tier I: W/I 2 weeks with PCP; Hematologist appointment as previously scheduled
   - Tier II: W/I 2 weeks with PCP; Hematologist W/I 4-6 weeks
   - Tier III: W/I 3-7 days with PCP; Hematologist W/I 2-4 weeks

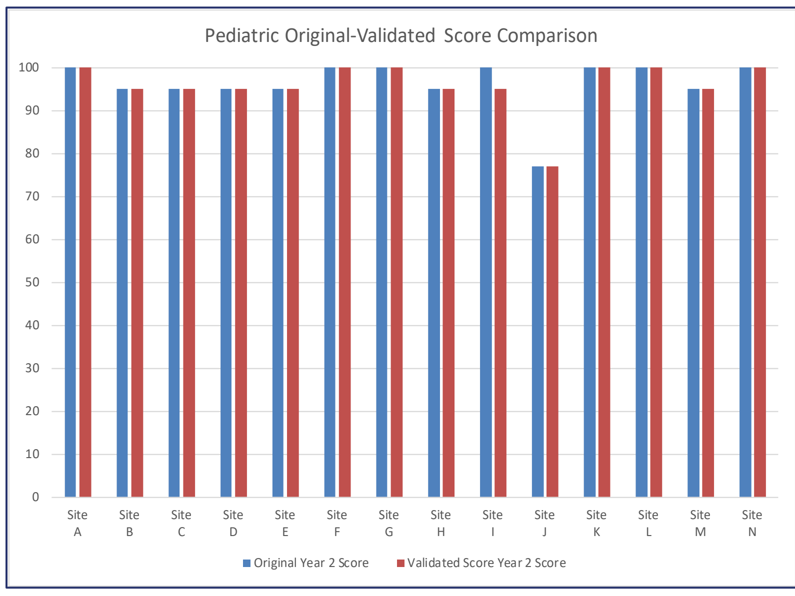
Patient Signature: ____________ **Provider signature:** ____________
Date / Time: ____________ **Date/ Time Revised:** ____________
Hematologist/Sickle Cell Provider Clinic Number: ____________
Primary Care Provider Clinic Number: ____________

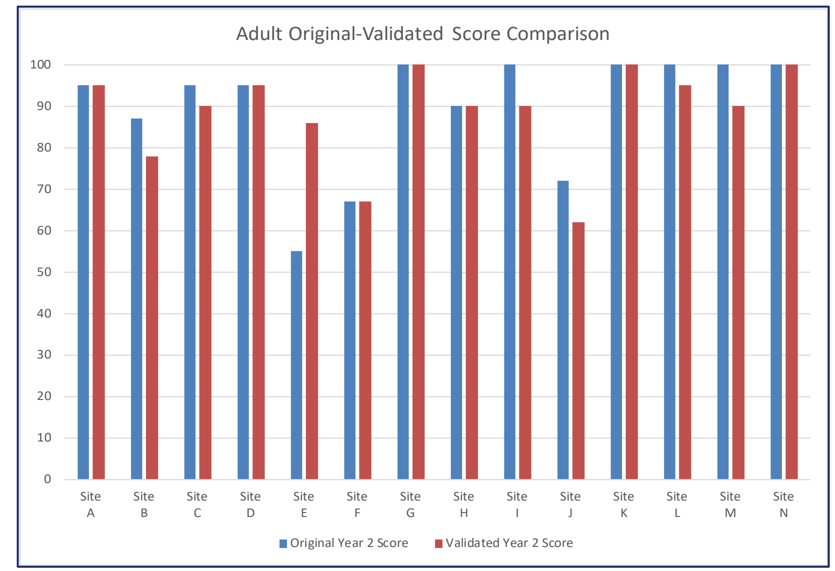
Self vs Validated Score for Process Measurement Tool Score





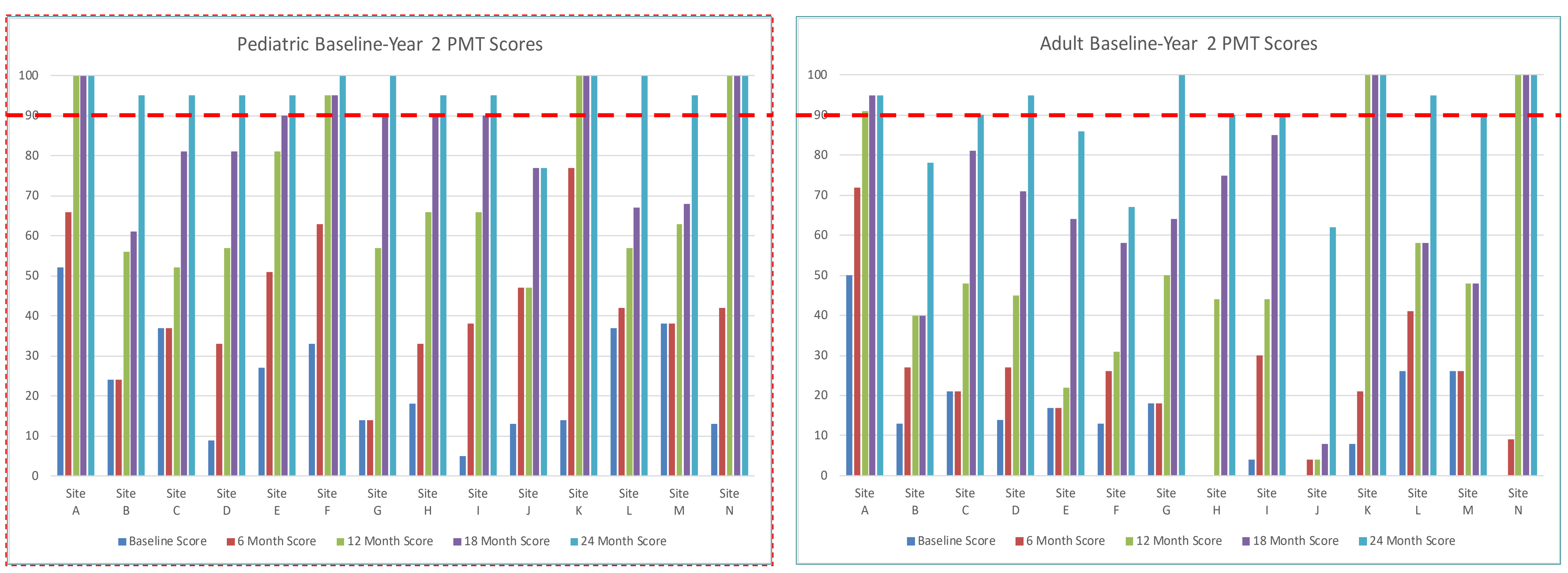
PMT Score at Baseline





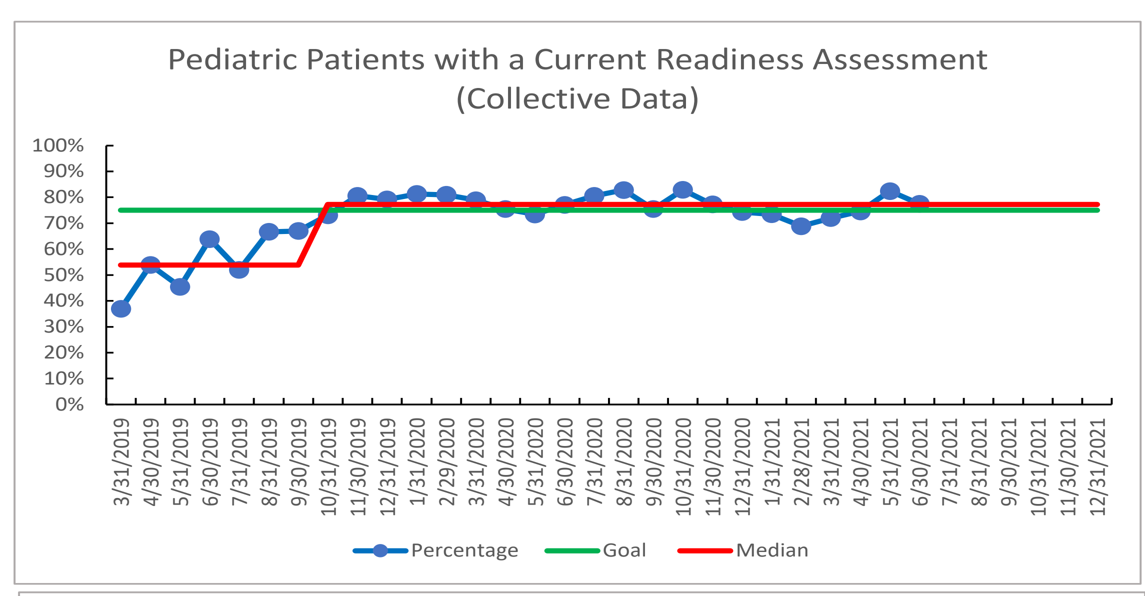
PMT Score at 24 mo

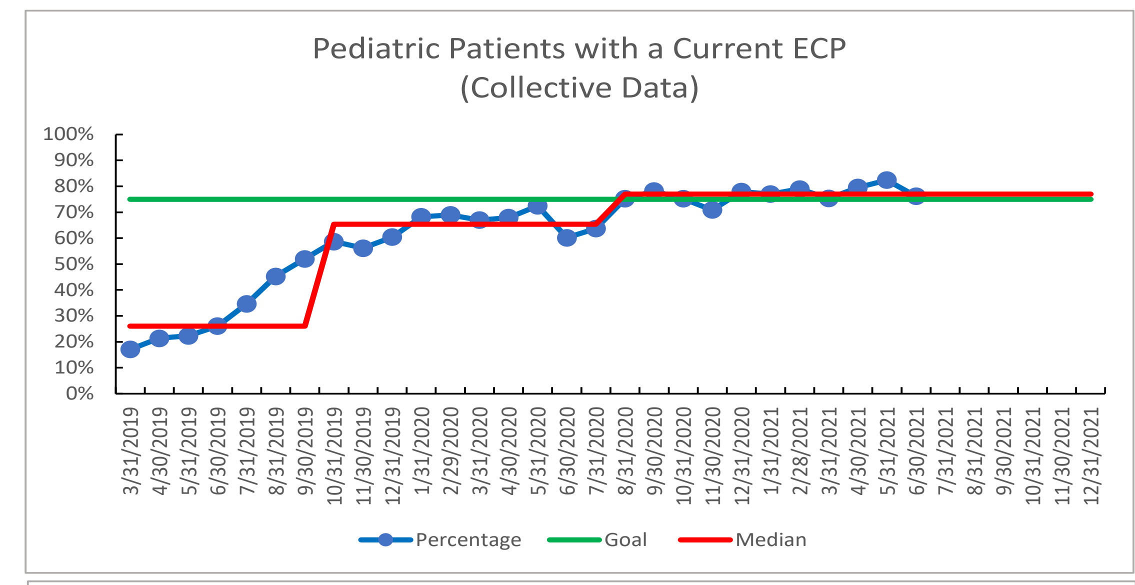
We Did It☺☺☺!! PMT Scores over 24 months

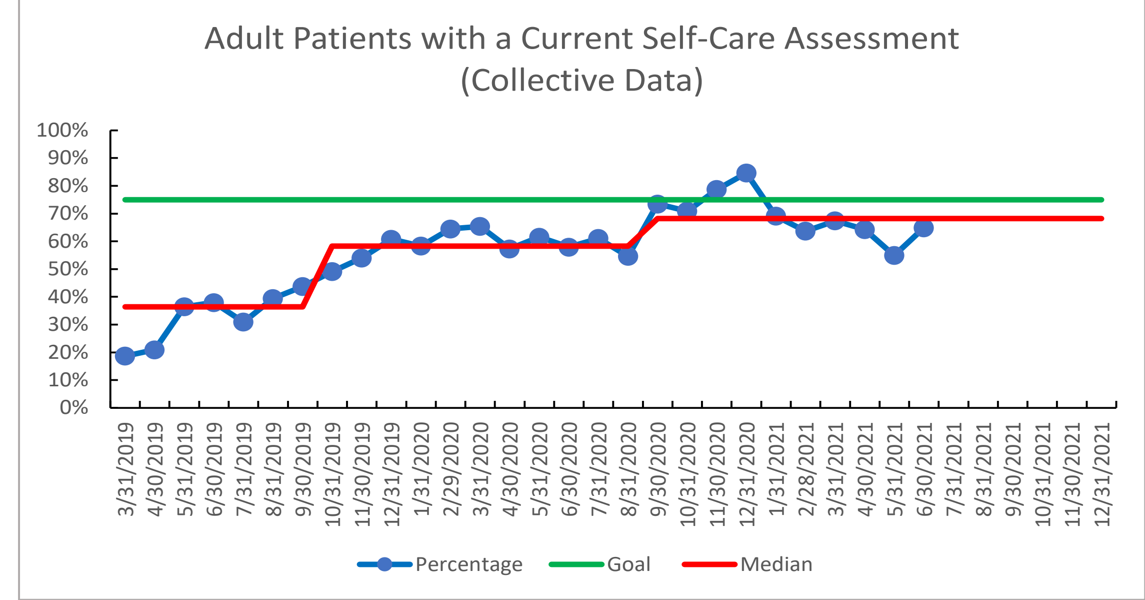


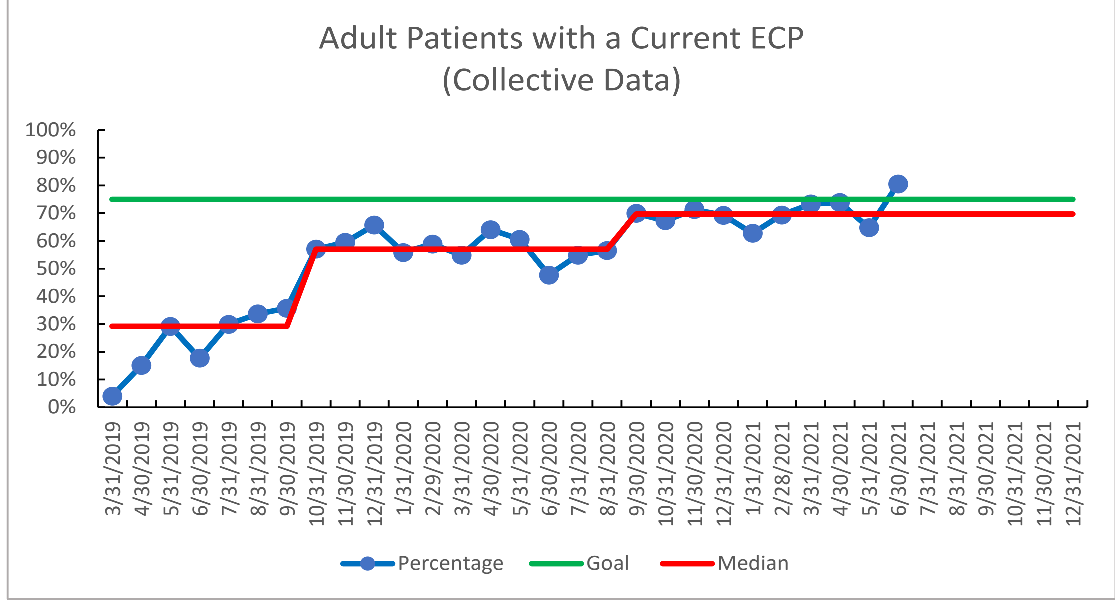
13/14 (92.9%) Pediatric clinics and 10/14 (71.4%) Adult clinics achieved PMT goal of $\geq$90% by 24 mo

Collaborative Aggregate Outcome Measures (June 2021)









Lessons Learned

Transition from pediatric to adult care is a major concern for persons living with sickle cell disease.

A standardized transition program *can and should* be implemented in both pediatric and adult clinics using QI. When using a PMT tool, information received must be **validated for accuracy and consistency.**

All 14 participating **pediatric and adult sites** showed significant progress over two years of implementing a structured HCT process aligned with the Six Core Elements.

Community partnerships are a critical part of the transition process as life happens outside the medical system.

The Transition Coordinator is the most vital "glue" for success.

Mallory Cyr, MPH

Program Manager, Children and Youth with Special Health Care Needs, Association of Maternal and Child Health Programs

- Transition is more than a doctor's appointment. How are we researching what happens outside the clinic, or after the transition discussion is had?
- Remember social determinants - existing research fails to address WHY transition may not occur or be sustained.
- Cultural components - What does “transition” and "family" look like?
- Often transition doesn’t occur because patients cannot be *safely* cared for on the adult side.
- Especially during COVID, “youth” may stay or return to where they have natural supports in place.
- Families and caregivers are more than “parents of CYSHCN.”
- It takes a village - stop the blame game!
- Youth and families can plan and prepare, but there must be something on the other side to support them.

The Truth About Transition…

- 5 Primary Care Physicians in 6 Years
  - Changes in insurance
  - Not responsive to needs
  - I'm not a science experiment

- Moving to a new state as a "transition expert,"…Nobody's interested

- How do we educate and incentivize adult providers to take on medically complex ADULTS as patients?
  - Begin by infusing within education and training

- Involve ADULTS with disabilities and medical complexities to inform the discussion of what is on the other side of the bridge within the adult health care system.

Ask Questions!

We look forward to a lively discussion with our audience.
Submit your questions through the Q&A.

We pursue a system that works for children with special health care needs.

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