The Sickle Cell Trevor Thompson Transition Study (ST3P-UP)
ST3P-UP Study Principal Investigators

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# Data Coordinating Site Staff

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Email</th>
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<tbody>
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<td>Jennifer Cornette</td>
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</tr>
</tbody>
</table>
### Participating Sites and Partner CBO’s

<table>
<thead>
<tr>
<th>Site</th>
<th>Pediatric PI</th>
<th>Adult PI</th>
<th>CBO Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atrium Health</td>
<td>Kristina Harrell</td>
<td>Padmaja Veeramreddy</td>
<td>Piedmont Health Services</td>
</tr>
<tr>
<td>Wake Forest</td>
<td>Natalia Dixon</td>
<td>Andrew Farlan</td>
<td>Piedmont Health Services</td>
</tr>
<tr>
<td>Duke University</td>
<td>Nirmish Shah</td>
<td>Nirmish Shah</td>
<td>Wake County SCD Support Grp</td>
</tr>
<tr>
<td>East Carolina university</td>
<td>Darla Liles</td>
<td>Sarah Leonard</td>
<td>Piedmont Health Services</td>
</tr>
<tr>
<td>Novant Health System</td>
<td>Paulette Bryant</td>
<td>Jennifer Dallas</td>
<td>Piedmont Health Services</td>
</tr>
<tr>
<td>Greenville Health System</td>
<td>Alan Anderson</td>
<td>Alan Anderson</td>
<td>Louvenia D. Barksdale Sickle Cell Foundation</td>
</tr>
<tr>
<td>Univ of Louisville/Norton HealthCare</td>
<td>Ashok Raj</td>
<td>Shawn Glisson</td>
<td>Sickle Cell Association of Kentukiana</td>
</tr>
<tr>
<td>University of Alabama Birmingham</td>
<td>Jeff Lebensberger</td>
<td>Julie Kanter</td>
<td>SCDAAD Central Alabama Chapter</td>
</tr>
<tr>
<td>University of South Alabama</td>
<td>Felicia Wilson</td>
<td>Johnson Haynes MD</td>
<td>SCDAAD Mobile Chapter</td>
</tr>
<tr>
<td>CHOA/ Emory University</td>
<td>Maa-Ohui Quarmyne</td>
<td>Ross Fasano</td>
<td>Sickle Cell Foundation of GA</td>
</tr>
<tr>
<td>Virginia Commonwealth University</td>
<td>India Sissler</td>
<td>Wally Smith</td>
<td>Living with Sickle Cell RVA</td>
</tr>
<tr>
<td>Montefiore Hospital and Medical Center</td>
<td>Deepa Manwani</td>
<td>Caterina Minniti</td>
<td>Sickle Cell Thal Patients Network</td>
</tr>
<tr>
<td>John’s Hopkins All Children's</td>
<td>Leila Clay</td>
<td>Leila Clay</td>
<td>SCDAAD St. Petersburg Chapter</td>
</tr>
<tr>
<td>University of Miami</td>
<td>Ofelia Alvarez MD</td>
<td>Thomas Harrington</td>
<td>SCDAAD Miami Chapter</td>
</tr>
</tbody>
</table>
An EA-SCD with an **UNPLANNED** Transition...

Pediatric Support System
“The Bath Water”

EA - SCD (or any chronic disease)
“The Baby”

Pediatric Care

Adult Care
EVERYONE Will Eventually Transition
An EA-SCD with a PLANNED Transition...
“Transition in health care for young adults with special health care needs is a **dynamic lifelong** process that seeks to meet their **individual needs** as they move from childhood to adulthood. The goal is to **maximize lifelong functioning and potential** through the provision of high quality, **developmentally appropriate** health care services that **continue uninterrupted** as the individual moves from adolescence to adulthood.”

The Goals of Optimal Transition

• REDUCE the 3X higher mortality among 15-24 year olds with SCD
• REDUCE the annual acute care utilization rates among 18 – 30 year olds of 3.61 /year) compared to 10 – 17 years olds (2.04 /year)
• REDUCE the 30-day readmission rate of 48.9% compared to 27.4% among younger children
• REDUCE school absenteeism that ranges between 20-40 days/year
• IMPROVE standardized test scores
• INCREASE school attainment, job/financial security
• IMPROVE overall Quantity and Quality of life
What Are The Barriers to Optimal Transition?

Why is transition important?

- How do we get back to Childrens services?
- That's NOT what the Paediatric team said!!
- If only I knew what the Paediatric team said!
- Semi-intelligent comment about patients care
- Who is this person? Do they know anything? Doubt I'll be back....
Barriers to Successful Transition

- Systems
- Health
- Patients
- Pediatric Provider
- Community
- Adult Providers
HOW Do we get to “PERFECT Transition?"

The biopsychosocial model of disease

My long-term health conditions are biological in origin, but the impact has been felt physically, psychologically and socially. My long-term health condition can’t be treated just through the biological medical model alone.

“The medical support keeps me alive, but it is the psychological and social support that enables me to live.”

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www.thepatientpatient2011.blogspot.co.uk
HOW Do we get to “PERFECT Transition?"
Addressing Transition with a Multi-Pronged Approach

- Individual- & Interpersonal-Level Interventions
- Community Engagement
- Systems-Level Interventions

Health Care Transition:
- Transition from Childhood to Early Adulthood
- Assumption of Responsibility for Self-Management of a Chronic Disorder

Child with FH
- Active, Engaged Family
- Pediatric Care

Active, Engaged Young Adult with FH
- Family
- Peers
- Adult Care
EA-SCD require additional **individualized and system** based SUPPORT to transition successfully.

There is **NO STANDARD** “healthcare transition program” for EA-SCD.

Transition should be **TARGETED, STRUCTURED AND PLANNED**.

EA-SCD need **EDUCATION** about their condition and **SKILLS** to survive adulting.

EA-SCD also need to **REPEATEDLY PRACTICE** the skills they learn before it sticks (**TIME**).

Whatever you do, **EVERYONE** should benefit.

Whatever you do, make it **SUSTAINABLE, PRACTICAL, REPRODUCIBLE**.
ST3P-UP Objectives and Endpoints

• Primary Objective:
  • Compare the Effectiveness of a Structured Education Based Transition Program + / - Peer Mentoring in decreasing the number of acute care visits per year over a 24-month period among EA-SCD

• Primary Outcome Measure
  • Average number of acute care visits per year over a minimum of 24 months

• Patient Reported Outcomes
  • ASCQ-ME Quality of Care
  • PedsQL- SCD Quality of Life
  • MOS-SSS – Social Support Score,
  • Transition Readiness (TIP)
  • Satisfaction with Health Care Transition Feedback (patient and provider)
ST3P-UP Objectives and Endpoints

• Additional Secondary Outcomes:
  • Number of acute care & ambulatory visits per year
  • Number of visits with adult providers
  • Number of hospitalization days
  • 14 day and 30 day readmissions

• Evaluate the feasibility of adoption of and adherence to the six core elements of transition practice
  • Health Care Transition Process Measurement Tool score
  • Every 6mo throughout study.

• Identify patient / stakeholder determined optimal outcome(s) of transition
  • Provider satisfaction with transition services
  • Qualitative feedback throughout study
  • Modified Delphi survey of patients and caregivers
## Study Design Overview

### Study Schema

Practices with Emerging Adults with SCD (EA-SCD) aged 16 – 25y Randomized at the Practice Level

<table>
<thead>
<tr>
<th>Small Sized Program [≤ 80 EA-SCD]</th>
<th>Large Sized Program [&gt; 80 EA-SCD]</th>
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</thead>
<tbody>
<tr>
<td>Arm 1-A</td>
<td>Arm 1-B</td>
</tr>
<tr>
<td>Structured Education Based Transition Program [STE]</td>
<td>Structured Education Based Transition Program [STE] + Peer Mentoring [STE+PM]</td>
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<tr>
<td>Arm 2-A</td>
<td>Arm 2-B</td>
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<tr>
<td>Structured Education Based Transition Program [STE]</td>
<td>Structured Education Based Transition Program [STE] + Peer Mentoring [STE+PM]</td>
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</table>

### Outcome Measures at 24 months

**Primary Outcome:** change in number of acute care visits [ED visits, Admissions, Readmissions at 14d, 30d, Total Hospital Days]

**Secondary Outcome:** Change in patient reported outcomes [MOS-SS, TIP-RFT, PedsQL-SCD, ASCQ-Me QOC], Satisfaction with Transition Process, Change in Ambulatory Care visits

**Process Outcome:** Change in Adherence to Standard Transition process, Transition Feedback survey
This is a prospective, double-arm, unblinded, cluster randomized study of Structured Education Based Transition Program + / - Peer Mentoring to reduce acute care visits among EA-SCD

**Sample Size:** 14 sites with 700 evaluable participants
- Expected dropout or withdrawal rate is 10%

**Randomization: by Site**
- 7 sites will get Peer Mentoring PLUS Structured Education
- 7 sites will get Structured Education alone

**Accrual period:** 18 - 24 months

**Duration on Study:** Minimum 24 months (6-12mo in Pediatrics; 12mo + in Adult care)
Structured Education Based Transition Model (Standard Arm)

• Transition Quality Improvement Collaborative
  • Occurs in the Pediatric AND Adult Sickle Cell Clinic
  • Collaboration between **CBO, providers, clinic staff and patients** to **IMPROVE THE SYSTEM OF CARE FOR EA-SCD**
  • Follow the 6 Core Elements of Transition Model per [www.gottransition.org](http://www.gottransition.org) (change package)
  • Use **The Model for Improvement** QI methodology to implement the change package (6CE) into Pediatric and Adult Clinic
    • Track process and outcome measures
    • Every patient, Every visit

• Targeted Education
  • **Assess Transition Readiness** Gaps using standard tool (TIP) as part of ongoing transition process for EA-SCD
  • Use **targeted education to address gaps** in knowledge and skills identified by TIP
  • **Repeatedly reinforce** areas of gaps to make sure that it sticks
  • Continues “**uninterrupted**” in both Pediatrics and Adult clinic
Engage mentors/advisors to telephonically support and guide EA-SCD through adaptive behavioral changes specific to SCD transition

- Mentors/Advisors will be trained (virtual and in-person at CBOs)
- Virtual 1:1 mentor meetings ONLY (phone calls via web-based platform or text)
- HIPPA Compliant virtual mentoring platform called Mentor1to1™
- Mentoring protocol structured to follow a systematic curriculum
  - Mentor : Mentee ratio 1:3 max
  - Advisor : Mentor ratio 1:5 max

Comparator: +/- Peer Mentoring (Virtual)
The Village Mentoring Concept

Advisor

Mentor

Mentor

Mentor

Mentor

Mentee

Mentee

Mentee

Mentee

Mentee
Mentor consented and enrolled in adult clinic.

Once enrolled, they receive email from platform vendor for background check.

If cleared → virtual mentor training starts.

8 – 10 hours of virtual training on how to be a good mentor, HIPPA, motivational interviewing and sickle cell disease basics.

Certificate of Completion given once training is complete.

Platform will match mentor to available mentee (availability; gender preference).

Mentor reaches out to mentee to schedule first call.

ALL interaction is via platform ONLY.

Call cadence is weekly x 3 months then every 2 weeks thereafter.

Advisor call cadence is monthly.
Key Inclusion Criteria – EA-SCD

- Age $\geq 16$ and < 25 years at the time of consent AND currently in a PEDIATRIC SICKLE CELL PROGRAM
- ANY Sickle Cell Genotype
- Subject is planned to be transferred to an adult sickle cell program within 6 -12 months of consent
- Can read and understand the English language
- Not known to be currently pregnant
- Signed Informed Assent (and HIPAA authorization) by EA-SCD** and Informed Consent Signed by parent/guardian
- Signed Informed Consent (and HIPAA authorization) by EA-SCD if over 18y and still in pediatrics

** EA-SCD will need to sign Informed Consent once they turn 18y
Key Inclusion Criteria – Mentors / Advisors

• Age $\geq 26$ years (Mentor) and $\geq 36$ years (Advisor) at the time of consent AND being cared for by an ADULT SICKLE CELL PROGRAM
• ANY Sickle Cell Genotype
• Readily available access to a computer with internet
• Can read and understand the English language
• Have completed and passed a background check
• Legally able to work in the United States
• Signed Informed Consent (and HIPAA authorization)
• Has successfully transitioned to adult care (defined as having had at least 3 visits and/or a year of continuous care with an adult sickle cell provider)
• Endorsed by their healthcare provider as reliable and able to meet the physical, psychological and cognitive requirements for serving as a mentor
Transition QI Collaborative
Changing Your Clinic Practice to Support Every Patient, Every Visit
Purpose: To help teams generate *specific changes* to improve transition processes in their clinics.

Six Core Elements

1. Establish a Transition policy
2. Develop a process for tracking, transition, and monitoring
3. Formalize a process for transition preparation and orientation to adult practice
4. Conduct transition planning and integration into an adult practice
5. Transfer care with initial adult care visit
6. Complete transition/ongoing care
# Study Procedures – QI Process Measurement Tool (Peds Clinic)

## 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

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Yes or No</th>
<th>Possible</th>
<th>Actual</th>
<th>Possible Documentation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a written transition policy/statement that describes the practice’s approach to transition with input from youth and family</td>
<td>Yes = 5</td>
<td>Transition policy/Number of consumer reviewers</td>
<td></td>
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</tr>
<tr>
<td>Included information in policy/statement about privacy and consent at age 18 and expected age of transition</td>
<td>Yes = 5</td>
<td>Transition policy</td>
<td></td>
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</tr>
<tr>
<td>Displayed policy/statement about privacy and consent at age 18 and expected age of transition in public clinic spaces, practice websites, etc.</td>
<td>Yes = 5</td>
<td>Photo/Screenshot</td>
<td></td>
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</tr>
<tr>
<td>Educated staff about transition policy/statement and delineated staff’s role in transition process</td>
<td>Yes = 4</td>
<td>Dates of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a process to share policy/statement with youth and family during first conversation about transition to an adult provider</td>
<td>Yes = 5</td>
<td>Description of process used</td>
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<td><strong>Transition Policy Implementation Subtotal</strong></td>
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<tr>
<td><strong>2. Transition Tracking and Monitoring</strong></td>
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<tr>
<td>Established criteria and process for identifying transitioning target population</td>
<td>Yes = 4</td>
<td>Description of population and process used</td>
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<tr>
<td>Developed a transition registry that tracks progress through and completion of all Six Core Elements</td>
<td>Yes = 5</td>
<td>Registry screenshot</td>
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<td><strong>3. Transition Readiness</strong></td>
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<tr>
<td>Adopted readiness assessment tool for use in practice</td>
<td>Yes = 5</td>
<td>Readiness assessment</td>
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<tr>
<td>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)</td>
<td>Yes = 5</td>
<td>Description of clinic process used</td>
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<tr>
<td>Developed a process to track the completion of readiness assessments during at least two visits prior to transfer</td>
<td>Yes = 5</td>
<td>Description of process used</td>
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<tr>
<td>Created an educational process to address readiness assessment needs (e.g. discussion/philosophy/educational groups)</td>
<td>Yes = 5</td>
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<td><strong>4. Transition Planning</strong></td>
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<tr>
<td>Developed plan of care template that includes the youth and family’s goals and prioritized actions related to health care transition</td>
<td>Yes = 4</td>
<td>Plan of care template</td>
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</tr>
<tr>
<td>Incorporated patient’s readiness assessment in plan of care</td>
<td>Yes = 5</td>
<td>Plan of care template</td>
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<tr>
<td>Established clinical process to assess need for decision-making support before age 18</td>
<td>Yes = 4</td>
<td>Description of clinic process used</td>
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<tr>
<td>Developed a medical summary and emergency care plan (ECP) with youth and family</td>
<td>Yes = 5</td>
<td>Medical summary/ECP template</td>
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</tr>
<tr>
<td>Established process to identify and communicate with adult clinician</td>
<td>Yes = 5</td>
<td>Vetted list of adult clinicians</td>
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<td><strong>Transition Planning Implementation Subtotal</strong></td>
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<tr>
<td><strong>5. Transfer of Care</strong></td>
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<tr>
<td>Have mechanism to send medical records to adult clinician for transferring youth</td>
<td>Yes = 4</td>
<td>Description of mechanism used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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</td>
<td>Yes = 5</td>
<td>Transfer package checklist/Description of mechanism used</td>
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<td></td>
</tr>
<tr>
<td>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</td>
<td>Yes = 5</td>
<td>Registry screenshot</td>
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<td><strong>Transfer of Care Implementation Subtotal</strong></td>
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<td><strong>6. Transfer Completion</strong></td>
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<tr>
<td>Developed mechanism to systematically obtain anonymous feedback from young adults about transition process</td>
<td>Yes = 5</td>
<td>Survey or interview questions</td>
<td></td>
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<tr>
<td>Documented first appointment with adult clinician in medical record</td>
<td>Yes = 5</td>
<td>Registry screenshot</td>
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<tr>
<td><strong>Transfer Completion Implementation Subtotal</strong></td>
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</table>
# Study Procedures – QI Process Measurement Tool (Adult Clinic)

## 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.

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<th>Possible Documentation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Young Adult Transition and Care Policy</strong></td>
<td>Yes = 5</td>
<td>Transition policy/Number of consumer reviewers</td>
<td>Transition policy</td>
<td>Photo/Screenshot</td>
</tr>
<tr>
<td>Developed a written transition policy/statement that describes the practices’ approach to transition with input from young adults</td>
<td>Yes = 4</td>
<td></td>
<td>Transition policy</td>
<td></td>
</tr>
<tr>
<td>Included information about privacy and consent at age 18</td>
<td>Yes = 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Displayed policy/statement (public clinic spaces, practice websites, etc.)</td>
<td>Yes = 4</td>
<td>Photo/Screenshot</td>
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<tr>
<td>Educated staff about transition policy/statement and delineated staff’s role in transition process</td>
<td>Yes = 4</td>
<td>Dates of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a process to share policy/statement with young adult during first</td>
<td>Yes = 5</td>
<td>Description of process used</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Young Adult Transition and Care Policy Implementation Subtotal</strong></td>
<td></td>
<td>22</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **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 | | |
| **Integration into Adult Practice Implementation Subtotal** | | 9 | | |

| **5. Initial Visits** | | | | |
| Adopted 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 = 4 | 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/Imprint | | |
| **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 | | |
The PDSA Cycle

**Act**
- What changes are to be made?
- Next cycle?

**Plan**
- Objective
- Questions and predictions
- Plan to carry out the cycle (who, what, where, when)

**Study**
- Complete the analysis of the data
- Compare data to predictions
- Summarize what was learned

**Do**
- Carry out the plan
- Document problems and unexpected observations

SMART AIM: Give Transition Policy to 100% 12y+ by Jan 31 2019

PLAN: Which process do I tackle first? HOW?

ACT: How about we give policy upon check in?

STUDY: Ok, that process did not work on the last 3 pts...

DO: We will give policy to ALL pts in clinic during depart

Slide courtesy LCH QI Coaching Conference
## Sickle Cell Transition Intervention Program (TIP)

### Personal Information Table

<table>
<thead>
<tr>
<th>First and Last Names:</th>
<th>Date of Birth:</th>
<th>Today's Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Which best describes your racial/ethnic background?
- □ Black/African-American
- □ Black/Hispanic
- □ Black/Non-Hispanic
- □ White/Hispanic
- □ White/Nom-Hispanic
- □ American Indian, Alaska Native
- □ Asian
- □ Other: __________________________

Marital Status:
- □ Married
- □ Single
- □ Divorced/Separated

What type of health insurance do you have?
- □ Private Health Insurance
- □ Medi-Cal
- □ No health insurance (self-pay)
- □ I am under my parent's insurance
- □ CCS/GHIPP
- □ Other: __________________________

Don't know/Not Sure

What type of sickle cell disease do you have?
- □ S/S (Sickle Cell Anemia)
- □ Sickle Beta Zero Thalassemia
- □ S/C (Sickle Cell Disease SC)
- □ Sickle Beta Plus Thalassemia
- □ Other: (please indicate) __________________________

Don't know/Not Sure

Education: What is the highest grade you have completed? (Please circle one)

<table>
<thead>
<tr>
<th>Grade School</th>
<th>Middle School</th>
<th>High School</th>
<th>College/Technical</th>
<th>College Grad/Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td>6 7 8 9</td>
<td>10 11 12</td>
<td>1 2 3 4</td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

### Employment & Educational Checklist

If you are currently employed, please check one of the following:
- □ Full-Time
- □ Part-Time

How many hours per week: __________________________

### Living Arrangements

What best describes your current living arrangement?
- □ I live independently in my own apartment, dorm or private residence
- □ I live with my parents
- □ I live with other family members
- □ I have other living arrangements. (Please describe) __________________________

### Health Care Knowledge and Skills - Medical Skill Set

How much do you know about sickle cell? Do you know how to manage your own health care? How to talk to doctors? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree or Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:

- □ I understand behaviors that can cause a pain episode.

Comments:

- □ I can answer my doctor's questions during my clinic visits.

Comments:

- □ I keep track of my medical appointments.

Comments:

- □ I know how to take my medicines (time, dosage, and frequency) without help.

Comments:

- □ I am aware of what hydroxyurea is and how it affects sickle cell disease. (If you are not taking this medicine, please check: Not Applicable)

Comments:

- □ I understand how drugs, alcohol and tobacco usage affect sickle cell disease.

Comments:

### Education and Vocation Planning - Educational/Vocational Skill Set

Are you ready for your future? Do you have a 504 plan or IEP? Take a few minutes to identify your areas of strength and highlight where there is room to grow!

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree or Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:

- □ I have a vision for my future.

Comments:

- □ I plan to attend college or obtain post high school training.

Comments:

- □ I know the types of work situations that could cause problems related to sickle cell disease.

Comments:

- □ I have talked to my parents about my hopes for the future.

Comments:

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TRANSITION READINESS ASSESSMENT TOOL

After TIP readiness assessment survey completed by a study patient, please **print pdf** and share with **clinical team** to guide clinical care.

---

**Sickle Cell Transition Intervention Program (TIP)**

### Feelings, Stress and Strengths – Stress Checklist

Does having sickle cell disease cause you to have stress? Please rate the extent to which you agree or disagree with the following statements using the scale: *There are no “right or wrong” answers, we just want to know what you think.*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Neither Agree or Disagree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I worry that my pain medication won’t control my pain.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about being hospitalized for long periods of time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death is always on the back of my mind.</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry that my sickle cell disease will keep me from doing the things I enjoy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry that some doctors don’t trust me with pain narcotics.</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about not having enough pain medication or running out of my medications.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I worry that I won’t be able to get insurance because of my sickle cell disease.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about being too much of a burden on my parents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wonder if my brothers and/or sisters are bothered by my illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about being able to take care of myself when I get older.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about my illness getting in the way of schoolwork and/or job.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

This checklist is used by permission: “Pain in Sickle Cell Epidemiology Study (PISCEIS)”, Wally R. Smith, M.D., NIMH, 2002.
MEDICAL SUMMARY AND SCD TREATMENT PLAN

American Society of Hematology
Sickle Cell Disease Clinical Summary

Contact Information and Demographics
Name: [Blank]
DOB: [Blank]
Address: [Blank]
Cell #: [Blank]
Home #: [Blank]
E-Mail: [Blank]
Health Insurance Plan: [Blank]

Health Care Providers (clinical and emergency information)
Specialty: [Blank]
Name: [Blank]
Clinic or Hospital: [Blank]
Phone # (daytime clinic # and after hours paging #): [Blank]
Fax or E-mail Address: [Blank]
Hematologist: [Blank]
Primary Care: [Blank]

Name and number of Medical Records Department: [Blank]
Allergy Information: [Blank]

Emergency Care Plan
Emergency Contact: [Blank]
Relationship: [Blank]
Preferred Emergency Care Location: [Blank]

Educational and Employment Information
Educational Status / Current Grade Level: [Blank]
Name of School: [Blank]
Contact Person: [Blank]
Phone: [Blank]
Special Accommodations (i.e. Individualized Education Program): [Blank]

Employment Status: [Blank]
Name of Employer: [Blank]
Contact Person: [Blank]
Phone: [Blank]

Sickle Cell History
Diagnosis: SS / SC / SBeta-thal / SBeta-thal / other: [Blank]
Notes: [Blank]
Has HLA Typing Been Performed? YES / NO: [Blank]
If yes, please specify type.

Baseline Values
Baseline Vital Signs: [Blank]
Hemoglobin: g/dL
Reticulocyte Count: %
White Blood Cell Count: 10³/mm³
Total bilirubin: mg/dL
Oxygen Saturation: %

Sickle Cell Complications (Explanation if yes)
ACS: YES or NO
Aplastic Crisis: YES or NO
Dactylitis: YES or NO
Retinopathy: YES or NO
Spleen sequestration: YES or NO
AVN: YES or NO
Pain: YES or NO
Strokes: YES or NO
Abdominal TCD: YES or NO
ICU admissions: YES or NO
Pulmonary hypertension: YES or NO
Asthma: YES or NO
Bacteremia: YES or NO
Nephropathy: YES or NO

Please attach individual care plan (if available) or fill out the form below:
SC Genotype:
# ED visits for pain in past year:
# hospitalizations for pain in past year:
Pain Plan (i.e. suggested test, treatment, preferred opioid dosing, number of pain episodes per year, other considerations):
Home Pain Plan:
ED/Patient pain plan:
Preferred opioid:
Dronages:
PCA: YES or NO
Notes: [Blank]
## MEDICAL SUMMARY AND SCD TREATMENT PLAN

### Medications

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Frequency</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hydroxyurea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes/No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior Myelosuppression</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Prior Surgeries, Procedures, and Most Recent Hospitalizations

- Splenectomy: Yes/No
- Colonoscopy: Yes/No
- Cholecystectomy: Yes/No
- Port: Yes/No
- Most recent pain admission: Date
- Most recent admission for ACS: Date

### Transfusion History

(Please specify chronic transfusion or chronic exchange)

(Please note, known antibodies, reaction, and need for pre-medication)

### Health Maintenance

- Cardiologist/Echo
- Pulmonary/PFTs
- Dilated eye exam
- UA/Urinary Microalbumin
- MRI/MRA

### Common Emergent Presenting Problems

- Suggested Tests
- Treatment Considerations

### Immunization Summary

- PPSV23 #1
- PPSV23 #2
- Last meningococcal vaccine
- Last influenza vaccine

---

Please attach the immunization record to this form.
## SAMPLE SCD EMERGENCY CARE PLAN

### Carolinas HealthCare System

#### SCD Pain Action Plan

<table>
<thead>
<tr>
<th>Break-Through Pain Medicines</th>
<th>How Much to Take</th>
<th>How Often</th>
<th>Other instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Long Acting Control Medicines (Use Every Day to Control Pain)</th>
<th>How Much to Take</th>
<th>How Often</th>
<th>Other instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

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

### 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

### 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

### 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.

**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

---

**Patient Signature:**

**Date / Time:**

**Hematologist/Sickle Cell Provider Clinic Number:**

**Primary Care Provider Clinic Number:**

**Provider Signature:**

**Date / Time Revised:**
**SAMPLE SCD EMERGENCY CARE PLAN**

---

**Carolinan HealthCare System**

**SCD Inpatient Pain Action Plan**

<table>
<thead>
<tr>
<th>Break-Through Pain Medicines</th>
<th>How Much to Take</th>
<th>How Often</th>
<th>Other Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Long Acting Control Medicines (Use Every Day to Control Pain)</th>
<th>How Much to Take</th>
<th>How Often</th>
<th>Other Instructions</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

---

**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

---

**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

---

**GREEN ZONE**

- **Pain Under Control (VAS <4)**
  - No pain to minimal pain
  - 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
2. 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
3. If the patient has been on IV opioid for > 1 week:
   - Start oral long acting medication taper over 2 weeks after discharge by decreasing dose by 25% every 3 days
4. Set follow up appointment with PCP and Hematologist

---

**Name:**

**MRN #:**

**DOB:**

**Tier:**

**Diagnoses:**

---

**Patient Signature:**

**Provider Signature:**

**Date / Time:**

**Hematologists/Sickle Cell Provider Clinic Number:**

**Expiration Date:**

**Primary Care Provider Clinic Number:**

---

(Atrium Health Logo)
• Administer Readiness Assessment (TIP-RFT) at baseline then every 6 months thereafter
• Identify GAPS in READINESS
• Address these gaps with education module provided and additional individualized support from clinical team
• Goal is to PREPARE EA-SCD for life after leaving Pediatrics and KEEP them in HEALTHCARE
• At EACH Clinic visit every 3 months Provider Team will
  • Review TIP-RFT results and gaps in readiness with patient
  • Provide targeted education to address gaps identified
  • Develop an action plan for EA-SCD and support them to practice new self care / independent life skills
  • Review action items provided at last visit to help build independent skills
  • Review previously attained milestones and ensure EA-SCD is still competent in this area
  • Review anticipated changes to expect after transfer to adult care or Review how EA-SCD is coping with the changes since arrival into adult care and address concerns
  • Ensure EA-SCD is connected with community resources (CBO partnership)
  • Address emerging medical needs as well - specifically any acute care visits (obtain records), visit to PCP (if no PCP facilitate EA-SCD getting a PCP)
  • Ensure SCD Treatment Plan is up to date, review with patient
  • Ensure Emergency Care Plan is Completed, review with patient

EA-SCD Study Visit EVERY 3 MONTHS +/- 2 weeks
<table>
<thead>
<tr>
<th>Milestone Due Date</th>
<th>Actual Date Achieved</th>
<th>Deliverable</th>
<th>Patient Enrollment Required</th>
<th>% of Total Enrollment</th>
</tr>
</thead>
<tbody>
<tr>
<td>9/30/2018</td>
<td>1/12/2019</td>
<td>Begin Recruitment</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>10/31/2018</td>
<td>1/18/2018</td>
<td>Enroll First Patient</td>
<td>1</td>
<td>0.14%</td>
</tr>
<tr>
<td>12/31/2018</td>
<td></td>
<td>Recruit 10% of Patients</td>
<td>70</td>
<td>10.00%</td>
</tr>
<tr>
<td>4/30/2019</td>
<td></td>
<td>Recruit 25% of Patients</td>
<td>175</td>
<td>25.00%</td>
</tr>
<tr>
<td>11/30/2019</td>
<td></td>
<td>Recruit 50% of Patients</td>
<td>350</td>
<td>50.00%</td>
</tr>
<tr>
<td>4/30/2020</td>
<td></td>
<td>Recruit 75% of Patients</td>
<td>525</td>
<td>75.00%</td>
</tr>
<tr>
<td>11/30/2020</td>
<td></td>
<td>Recruit 100% of Patients</td>
<td>700</td>
<td>100.00%</td>
</tr>
</tbody>
</table>
ST3P-UP Study Enrollment and Retention**

• We have enrolled 5 EA-SCD at STE Sites
• We have enrolled 0 EA-SCD at PM Sites
• We have enrolled 2 Mentors
• We have enrolled 1 Advisors

** enrollment numbers were as of 1/28/2019
ST3P-UP Study Engagement – *Its WHAT WE DO!*

Raymona Lawrence
“Community Based Participatory Research” enhances collaborative efforts among community members, academic, clinicians and other stakeholders who use research to build on the strengths and priorities of the community for multi level strategies to improve health and social equity.”

(Wallerstein et al, 2018, modifications in Italics)
“To ensure that we collaboratively empower, motivate and contribute to the quality of life of emerging adults with sickle cell disease (EA-SCD) to create a foundation for **successful transition.** This study will provide them with the comprehensive tools to be **effective advocates, leaders, and champions** for their **individual well-being and community engagement.**”
Patient Centered Outcomes Research Institute (PCORI)

Principal Investigators: Osunkwo/Lawrence

Data Coordinating Center (DCC)

Scientific Oversight Group (SOG)

Data Safety Monitoring Board (DSMB)

ST3P-UP Study Team (SST)

Study Advisory Council (SAC)

Quality Improvement Team (QI)

Peer Mentoring Intervention
- Mentor Recruitment and Training
- Mentor-Mentee-Advisor Pairing
- Mentor program tracking

Community Advisory Board (CAB)

Standard Transitioning Programming
- Implementation of 6 core Elements
- SCD Education
- Community Engagement
- Self Management Support

The DCC communicates with every aspect of the study. All data/communication flows back to the DCC.
Engagement Goal 1: To establish a study advisory council (SAC) comprised of key patient, provider, and community stakeholders to provide insight and guidance on the project protocol development, refinement and implementation.

• Meetings: Monthly, every 2nd Wednesday

Engagement Goal 2: To establish effective, sustainable partnerships within the study site triad (Pediatric/Adult Providers, Community Based Organizations, and Patients).

These partnerships will help us meet our recruitment goals for the study and ensure that sites move along with implementing the STANDARD transition process.
Engagement Strategies

“A 3-Strand Chord is not easily Broken” - Ecclesiastes 4:12;

“Coming together is a beginning; Keeping together is progress; working together is success.”-Henry Ford

-Strong Triad Development/Implementation

“The [community engaged study] is one place where a doctor ought to forget that he’s a doctor. The [community engaged study] is the one place where a PhD ought to forget that he’s a PhD. The [community engaged study] is the one place that the school teacher ought to forget the degree she has behind her name.” adapted from Martin Luther King’s “The Drum Major Instinct”

-Eliminate Titles; Every one is an Engaged Sickle Cell Advocate, E-SCA

“Health is the first wealth, the second one is the happy marriage.”-Unknown

-Make engagement fun
Engagement Photos

TEAM DCC!
Engagement Photos – ST3P-UP Consultants
Engagement Photos – Certificate and all!
Engagement Photos – Certificate and all!
ST3P-UP Investigators Welcome Dinner

Thank You for Engaging in the ST3P-UP Study
Learning From Our Consultants
Patient Panel Discussion
“Before you marry a person, you should first make them use a computer with slow Internet to see who they really are.” - Will Ferrell

• Adjust to Communities/Partners’ pace....with a smile

“The goal in marriage is not to think alike, but to think together.”-Robert C. Dodds

• Help partners recognize the partnership as the solution to any issues they might face

“I got gaps; you got gaps; we fill each other’s gaps.”-Rocky

• EVERY partner is valued when you are working to fill complex issues related to transition in SCD

“My wife tells me that if I ever decide to leave, she is coming with me.”-Jon Bon Jovi

• Consistently remind partners WHY we are engaged and that we have a common purpose.
OK....Now Lets Have Some FUN!!😊😊😊

BEFORE YOU SAY “I DO”...
Engagement

Tell me....I Forget
Show me....I remember
Involve me....I understand
Engage me....I own it

*Chinese Proverb (modified)*
• Why are we here? To **CHANGE** systems and support **EA-SCD** to be successful well into adulthood.

• What will we be doing? Use **quality improvement** methods to implement the 6 core elements of transition into pediatric and adult clinics. We will also **provide targeted and individualized education and support to EA-SCD** during the continuum of transition.

• How will we do this? By working **TOGETHER**, being fully **ENGAGED** in this project and **OPEN** to doing things **DIFFERENTLY**.
Questions & Discussion