

Sickle Cell Disease in South
Carolina
Stakeholder and Advocacy Meeting
January 28, 2016

Julie Kanter, MD
Director of Sickle Cell Disease Research
Assistant Professor
Medical University of South Carolina

Agenda

- What is happening now in South Carolina?
- Current plans to develop a comprehensive state (SC) sickle cell disease plan
- How can we improve the development of a coordinated case management state plan?
- Time Line for year 1
- Initiate plans for a bundled/shared savings program for patients and partners of the SC network

What is Sickle Cell Disease?

- Sickle Cell Disease (SCD) is the most common inherited blood disorder in the United States
- Affects approximately 100,000 individuals
- More than 98% of affected persons in the US are African-American, African or Black American
- Highest cause of 30-day readmission in many hospitals in South Carolina

Why is Sickle Cell Disease hard?

- Patients are living longer with SCD
- Adults are highly underserved and often live in rural areas where they do not have access to specialized care
- There are not enough physicians trained to care for persons with SCD
- The majority of primary care and emergency department physicians have not received education in SCD management.
- PCPs are often unwilling or uncomfortable with SCD patients
- **As a result of these systemic issues, adults with SCD are often forced to rely on urgent care treatment, which is not disease or patient-focused.**



What is happening in South Carolina?

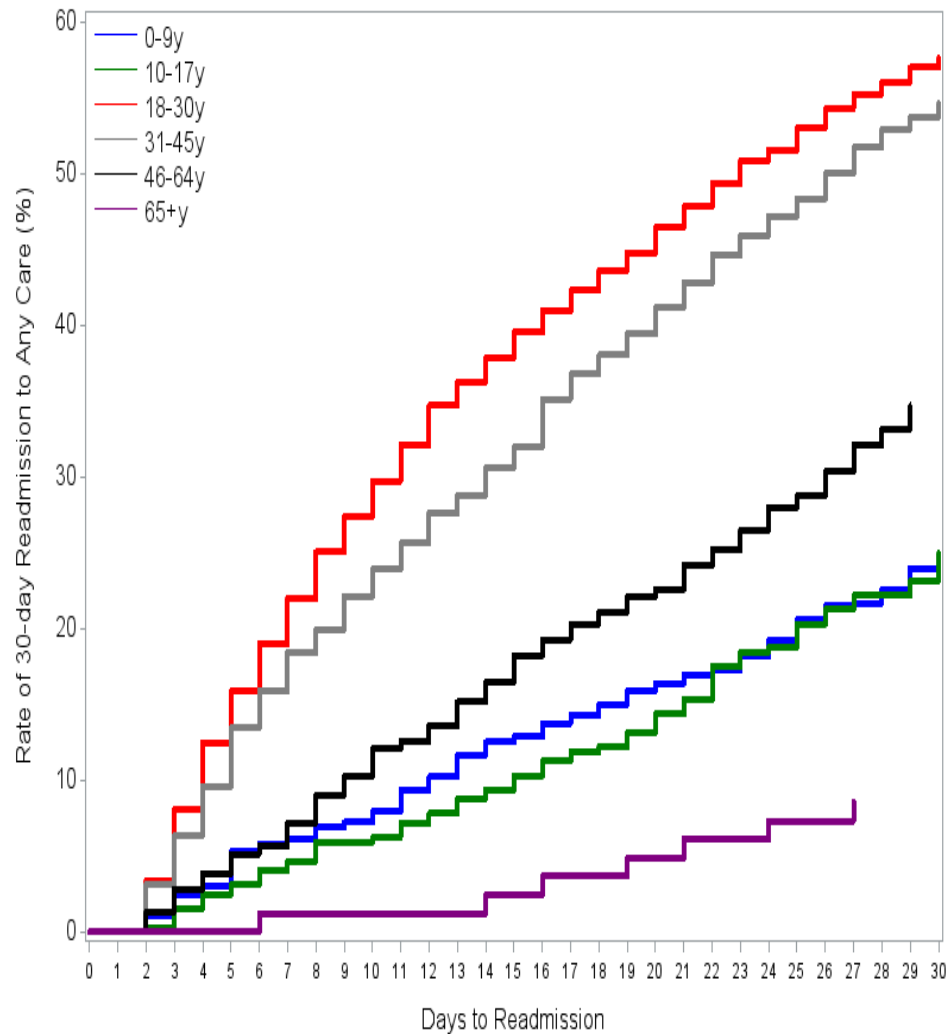
- Sickle Cell Disease is highly prevalent in SC
 - Recent data estimate up to 4500 persons with SCD
- Very few providers willing/able to take patients with SCD >18
- Lack of care coordination for all patients with sickle cell disease (of all ages)
- Limited post-acute care services, follow-up for patients of all ages
- Lack of quality improvement in SCD
- Lack of statewide protocols
- Pharmacy/Prescription ordering is poorly coordinated and often works against the patient to improve care
- Care coordinators/Case Managers are not coordinated and likely underutilized

Where are SCD patients receiving acute care?

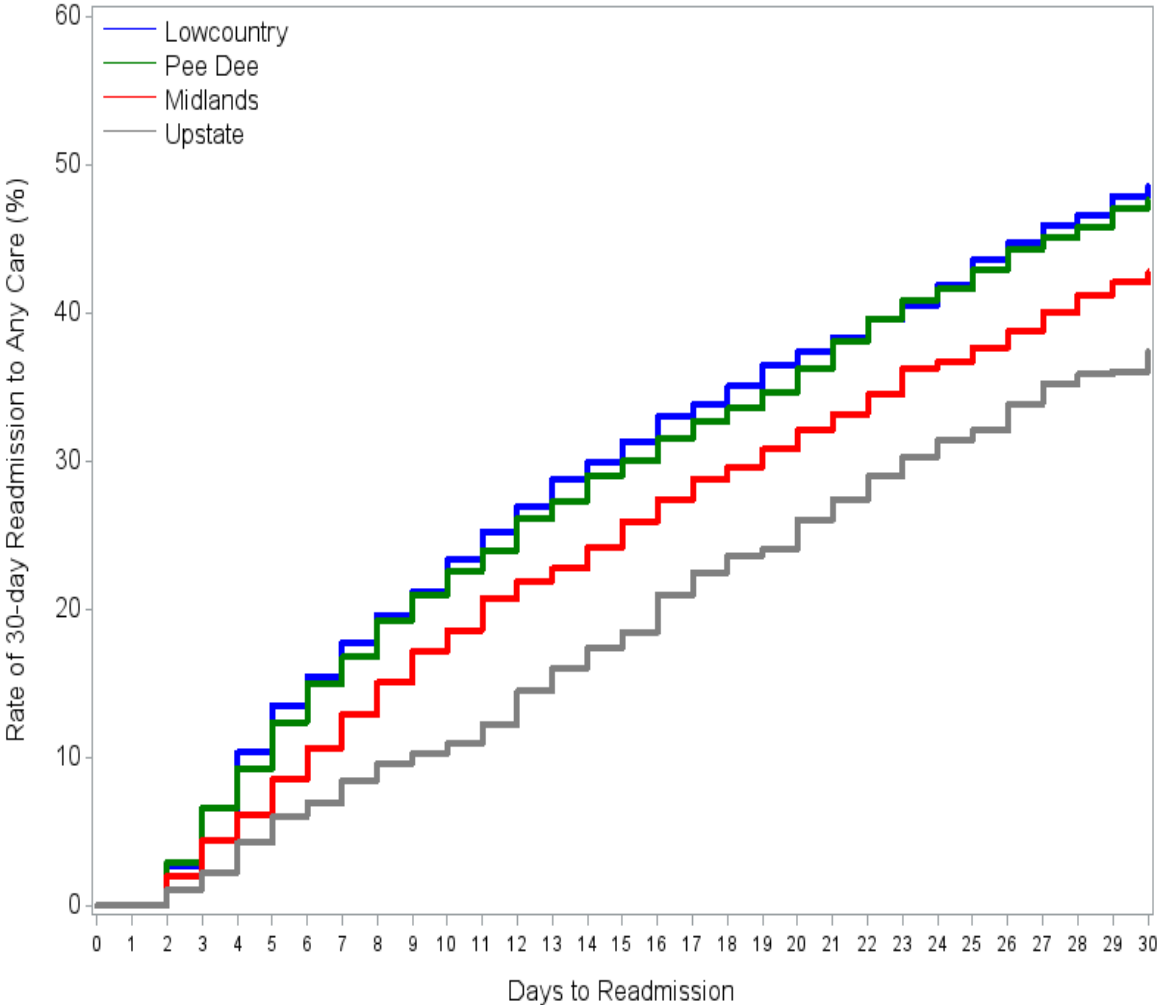


	Patients, No.	Encounters per Patient, No. (95% CI)		
		ED	IP	Total
Total	2313	2.90 (2.63-3.17)	1.74 (1.62-1.85)	4.64 (4.30-4.97)
Age, y				
0-9	473	1.08 (0.97-1.18)	1.33 (1.17-1.49)	2.41 (2.22-2.59)
10-17	272	1.31 (1.12-1.50)	1.28 (1.08-1.49)	2.59 (2.28-2.90)
18-30	713	4.92 (4.24-5.60)	2.25 (1.99-2.50)	7.17 (6.34-7.99)
31-45	478	3.77 (3.05-4.84)	1.94 (1.65-2.23)	5.71 (4.82-6.60)
46-64	290	1.75 (1.33-2.17)	1.46 (1.20-1.72)	3.21 (2.64-3.78)
≥65	87	0.30 (0.19-0.41)	1.03 (0.84-1.23)	1.33 (1.17-1.50)
Region				
Lowcountry	808	3.83 (3.23-4.44)	1.82 (1.62-2.01)	5.64 (4.94-6.35)
Midlands	613	2.44 (2.08-2.80)	1.48 (1.29-1.68)	3.92 (3.44-4.40)
Pee Dee	541	2.74 (2.20-3.28)	2.14 (1.87-2.41)	4.89 (4.17-5.60)
Upstate	351	1.80 (1.39-2.21)	1.38 (1.15-1.61)	3.18 (2.66-3.71)
Expected payer				
Medicaid	1057	2.84 (2.46-3.22)	1.95 (1.78-2.13)	4.79 (4.31-5.27)
Medicare	559	4.57 (3.77-5.36)	2.46 (2.18-2.74)	7.03 (6.09-7.96)
Private	486	1.62 (1.30-1.94)	1.05 (0.90-1.20)	2.67 (2.27-3.08)
Self-pay/uninsured	211	1.74 (1.44-2.05)	0.33 (0.24-0.42)	2.07 (1.76-2.38)

Are patients in South Carolina getting appropriate post-acute follow up?



Are patients in South Carolina getting appropriate post-acute follow up?



Current improvement process plans

- National Maternal and Child Health Workforce Development Grant
 - CO-Leads: Dr. Kanter and Jessica Drennan MSW
- SC2 Pilot funding (Duke Endowment)
 - PI: Dr. Julie Kanter
 - Project Coordinator: Katherine Williams
- State Sickle Cell Disease Study Committee
 - Representative John King, Co-Chairman

National MCH Workforce Development Grant

- CO-Leads: Dr. Kanter and Jessica Drennon DHEC
- Goals:
 - Improving **access to care**,
 - Using **quality improvement** tools to drive health transformation,
 - Fostering **systems integration** and harmonization within public health and across organizational boundaries
 - Furthering effective **change management**, collective action and individual leadership skills that will lead to health improvement of specific populations.

South Carolina Sickle Cell Disease Access to Care Pilot Program (SC²): Building a statewide program through collective impact

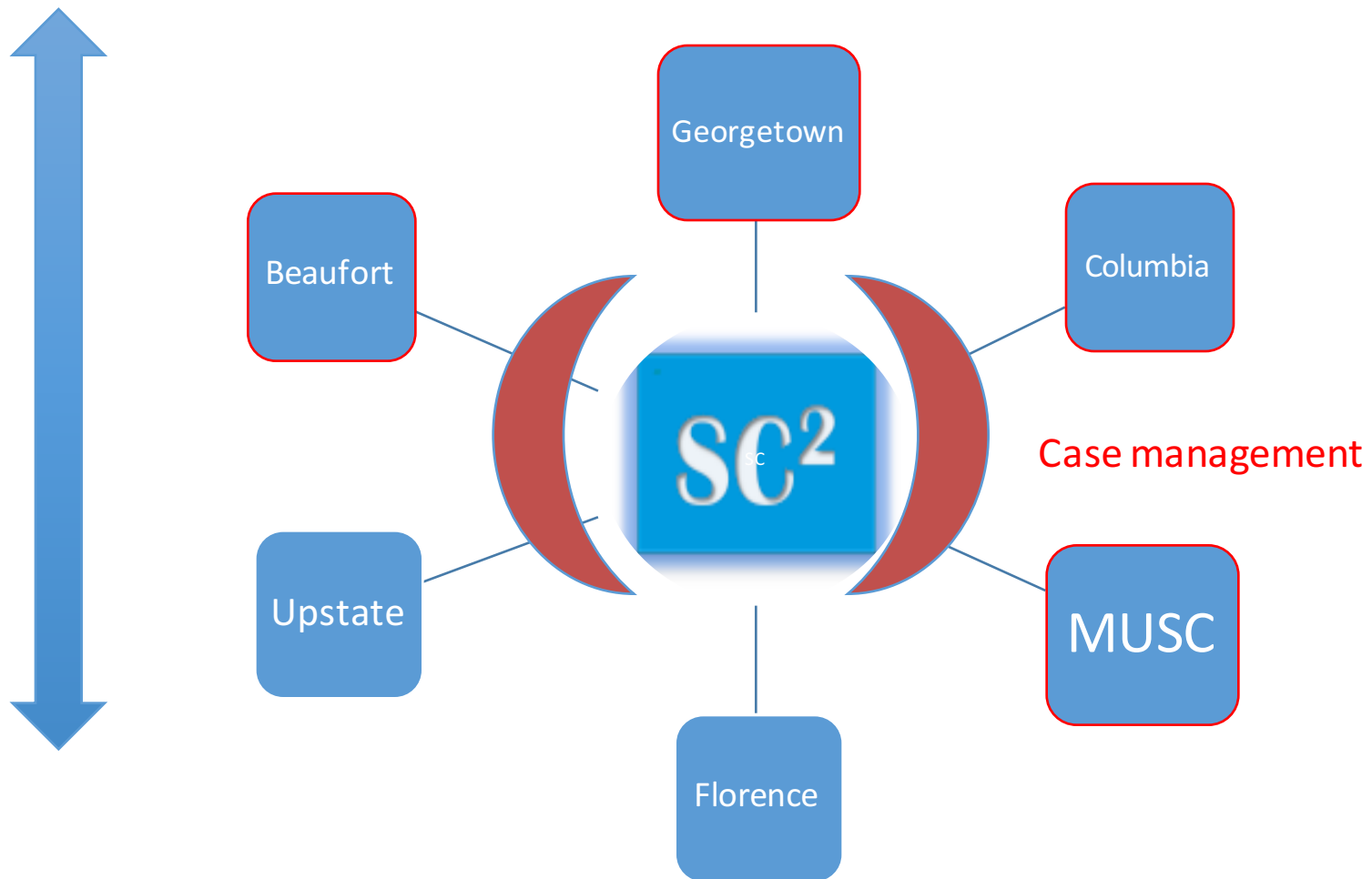
- The SC² program is designed to increase access to care for all persons with SCD in South Carolina
- SC² includes both specialty and primary care
- Uses a hub-and-spokes care delivery model using a collective impact approach.
 - In-person clinics
 - Telehealth clinics
- This approach will both harness the resources of the state to approach SCD and will also use a technology-based approach to increase education of providers

Sickle Cell Disease State Committee

- Sickle Cell Disease State Committee: created and charged with better serving adults with sickle cell disease (SCD), health care providers, and the public about State care and treatment.
- The committee is to examine existing services and resources available to children with the disease as well as adults with the disease.
- Additionally, the committee is to establish partnerships with institutions, and communities, a statewide network of service providers for adults with the disease; a comprehensive education and treatment program for adults, as well as establish standardized treatment and emergency room protocols.

SC²

designed to connect the dots and fill in the gaps in care



Concrete Plans:

- 1. Develop a statewide sickle cell disease protocol for treatment based on the national NHLBI sickle cell disease care guidelines
- 2. Work with our CMS partners to obtain approval for this protocol
 - What does this mean?
 - How can we make this happen?
- 3. Discuss how we can improve and coordinate a case management program
 - MCO
 - Foundations
 - Hospitals
- 4. Discuss how we can build a shared savings program
- 5. Develop/utilize a sickle cell disease registry for individualized care plans for patients seeking acute care (scdcare.com)

Methods:

People:

- SC² program coordinator to lead patient navigation, outreach clinic scheduling, coordinate meetings and educational symposiums
- SC² social worker to identify resources, provide social service support, insurance management, and address disease specific concerns.
- MD will initiate weekly outreach clinics at identified sites to increase patient access to specialized SCD specific care and develop individualized education and treatment plans for affected patients

Information Technology

- Utilize an SC² SCD registry to enhance access to patient-specific individualized treatment plans for providers throughout the state
- Data assessment for quality improvement (*Care Coordination Institute*)
- Use telehealth for acute care needs at the individual medical homes
- ECHO program for educational conferences

Methods:

Education

- Initiate monthly teleconferences based on the ECHO model to bring the interdisciplinary expertise of specialists to the local providers DHEC-funded quarterly symposiums for statewide provider education
- Quality Assessment with feedback

YEAR 1:

- Hire personnel and Initiate work in 2 outside sites (already in process)
- Initiate stakeholder/advocacy meetings
- Begin to develop and register patients with individualized plans
- Continue symposiums
- Quality tracking
- Website
- Begin monthly education conferences in June using ECHO model

Measurable Outcomes:

- Hydroxyurea: Enhanced access to disease modifying medications:
Hydroxyurea (HU) is currently the only FDA-approved disease-modifying drug for SCD.
 - Recent data demonstrates that we can expect an annual decrease in cost of \$6,000/patient who take the medication.
- Improving transfusion utilization:
 - Stroke is one of the biggest complications seen in SCD. Blood transfusions are indicated for stroke prevention in those at-risk with SCD or for acute treatment of severe organ dysfunction
 - Providers without SCD training/knowledge often transfuse unnecessarily
 - Unnecessary transfusions cause complications and unnecessary expense.
 - Each unit not transfused saves up to \$500 per event and decreasing the risk of blood exposure
- Decreasing hospitalizations and ER visits

SC² Sustainability

- Work with the centers for CMS and the state MCOs to develop a sustainable, reimbursable model for care in SCD
- Utilize the current payment structure to demonstrate that the SC² clinical program will generate sufficient revenue at individual outreach clinic locations and save on urgent care costs -- sufficient to support the continued efforts of the program
- Education of local providers
 - Previous programs have demonstrated that situated learning and practice are supported by collaborative learning, coaching, and mentoring which will be part of SC²
 - The ECHO initiative also showed that disease specific education can be accomplished through iterative practice, feedback, modeling, and mentoring and consultation with interdisciplinary experts and peers.
- Improvement in care of patients with SCD will also lead to the success and sustainability of the project