

Community Forum on Future Directions for Sickle Cell Disease Treatment Demonstration Program (SCDTDP)

Thursday, December 12th, 2013
3:00-4:30pm ET

Who we are



Suzette Oyeku



Tricia Finnerty



Elissa Faro



Avery Seefeld



Donnell Ivy



Nancy Settle-Murphy

Meeting Objectives

- Share with the community HRSA's vision for the future direction for SCDTDP
- Address community questions about the future direction of SCDTDP
- Solicit input and ideas from the community

Agenda

- Setting the stage
- Summarize Registration Responses
- Current SCDTDP
- Future Direction of SCDTDP
 - Rationale
 - Components

REMINDER!

Questions are encouraged throughout the presentation, please use the chat box.

Meeting Norms

- All phone lines are muted
- Chat in any questions
 - NICHQ team will be monitoring chat and will read your questions at designated times
 - We may not get to all of them, but we will summarize and send to HRSA
- Do not place your phone on hold
- Contact Elisa (617-391-2699) for technical assistance

Registration Questions and Responses



What would be the highest leverage action that would improve care for individuals with sickle cell disease and their families?

- Developing an expanded network of knowledgeable sickle cell providers
- Coordinated system of care
- Increased access to care/services
- Establishment of Sickle Cell Centers
- Research

What do you see as the greatest barrier to obtaining comprehensive care for individuals with sickle cell disease?

- Finances
- Lack of knowledgeable providers
- Lack of care coordination

Thinking about this barrier, what change do you think would be most effective in addressing it?

- Care coordination/medical homes
- Expanded availability of knowledgeable providers and dedicated facilities for SCD patients
- Registry/Database

Focusing now on the next round of the SCDTDP, what factors do we have to keep in mind to ensure a successful project?

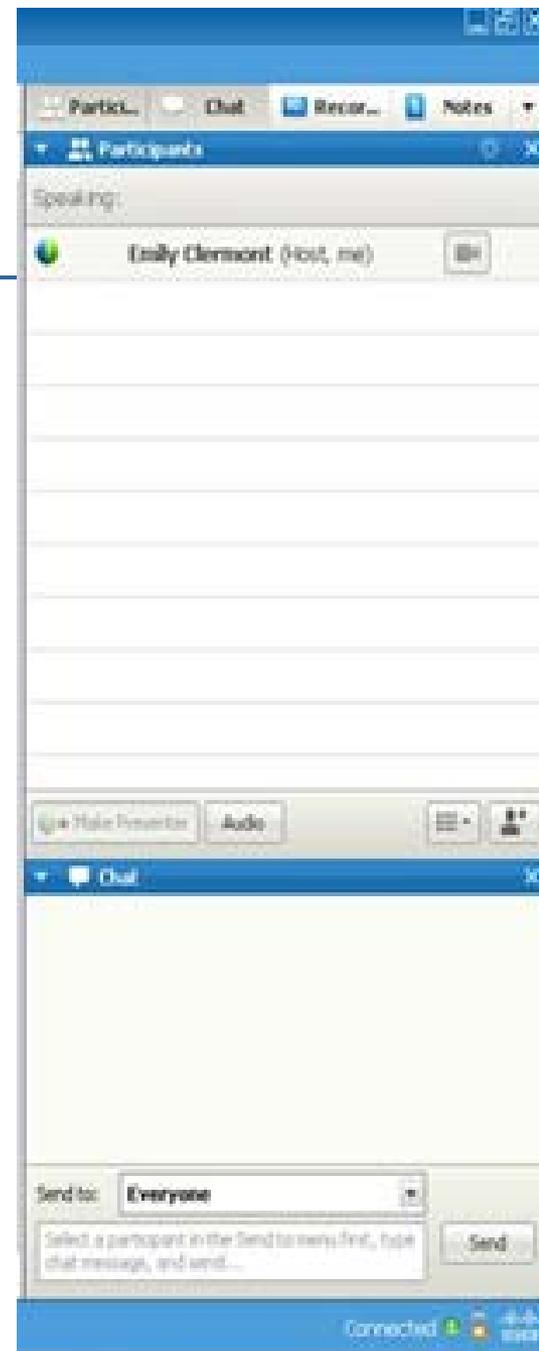
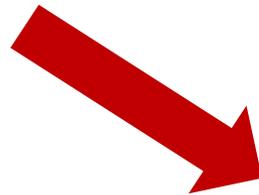
- Demonstration of improved outcomes with provision of services
- Funding/Resources

Thank you!

- Thank you for your feedback, we appreciate your time and thoughtful responses!

Reminder!

- Please remember to share your questions throughout the presentation in the chat box



HRSA's Vision for the SCD Treatment Demonstration Program

Edward Donnell Ivy, MD, MPH

Medical Officer, Genetics Services Branch

Division of Services for Children with Special Health Needs

Maternal and Child Health Bureau

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Goals of SCDTDP Grant

- Identify individuals with sickle cell disease and sickle cell trait
- Ensure individuals with sickle cell disease have access to medical home approach to care which provide coordinated, comprehensive, evidence-based care
- Medical home approach to care effectively monitor, prevent and treat complications of disease
- Collect data on sickle cell population to determine access is improved and care is provided in a medical home

Re-envisioned SCDTDP

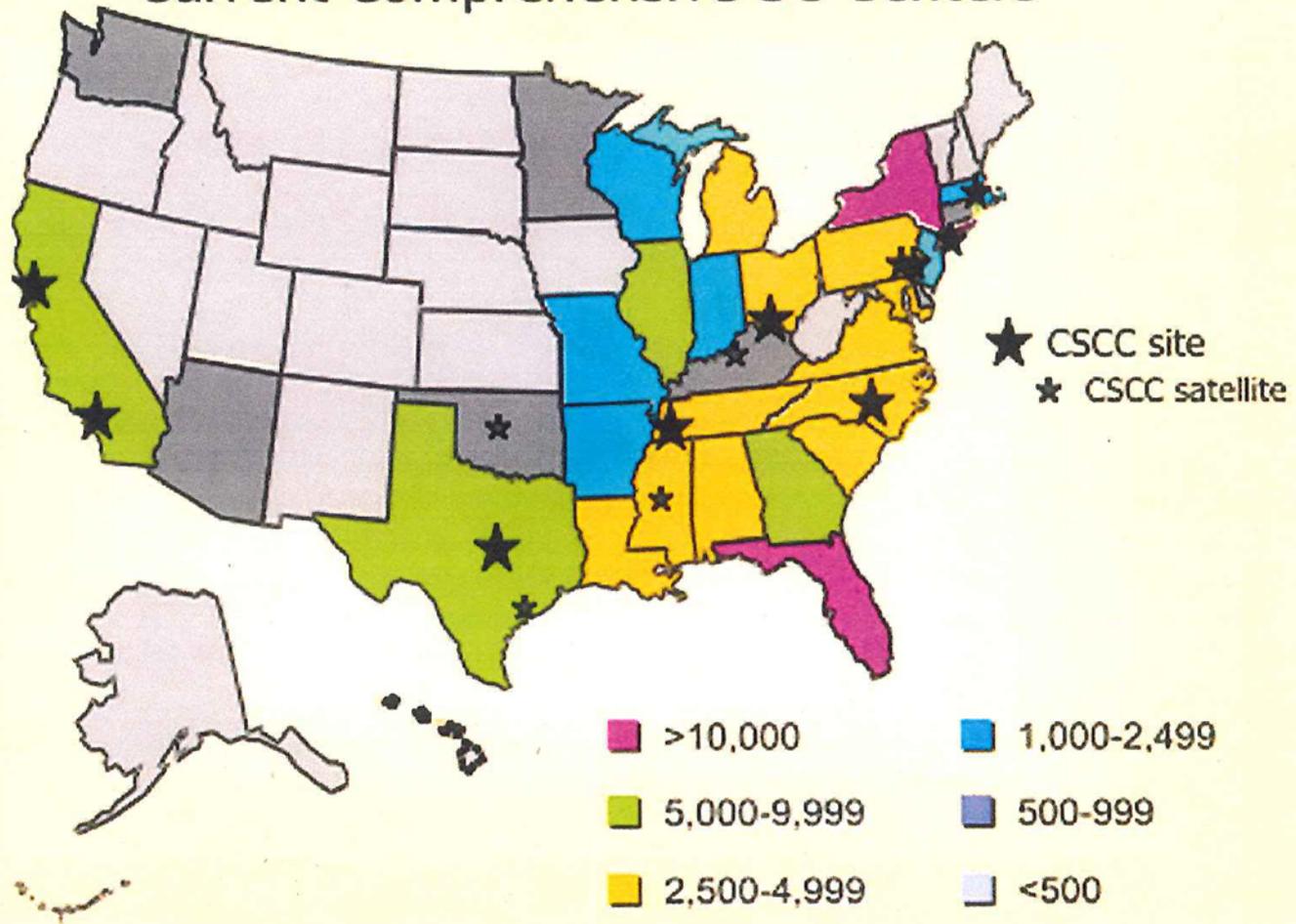
- Use the **Collective Impact model** to create a regional network with stakeholder in multiple states
- Use **Regional Networks** to expand use of sickle cell medical home approach to care
- Use **quality improvement strategies** to improve the use of disease modifying therapies, such as improving **hydroxyurea** utilization, and to improve use of care coordination in sickle cell medical homes
- Use a **National Coordinating Center** to help disseminate strategies of the networks and provide technical assistance to the networks
- Use Regional Networks to improve **data collection and evaluation** of the program efforts

Definitions

- Medical Home Approach to Care - a model of care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety.¹
- Collective Impact Strategies - commitment of a group of stakeholders from different sectors to work together on a common agenda for solving a specific problem.²
- Primary Care Extension Community Healthcare Outcomes (ECHO) - innovative health care program that uses technology to expand access to specialty health care in rural and medically underserved communities by allowing specialists to work with and educate primary care providers.³

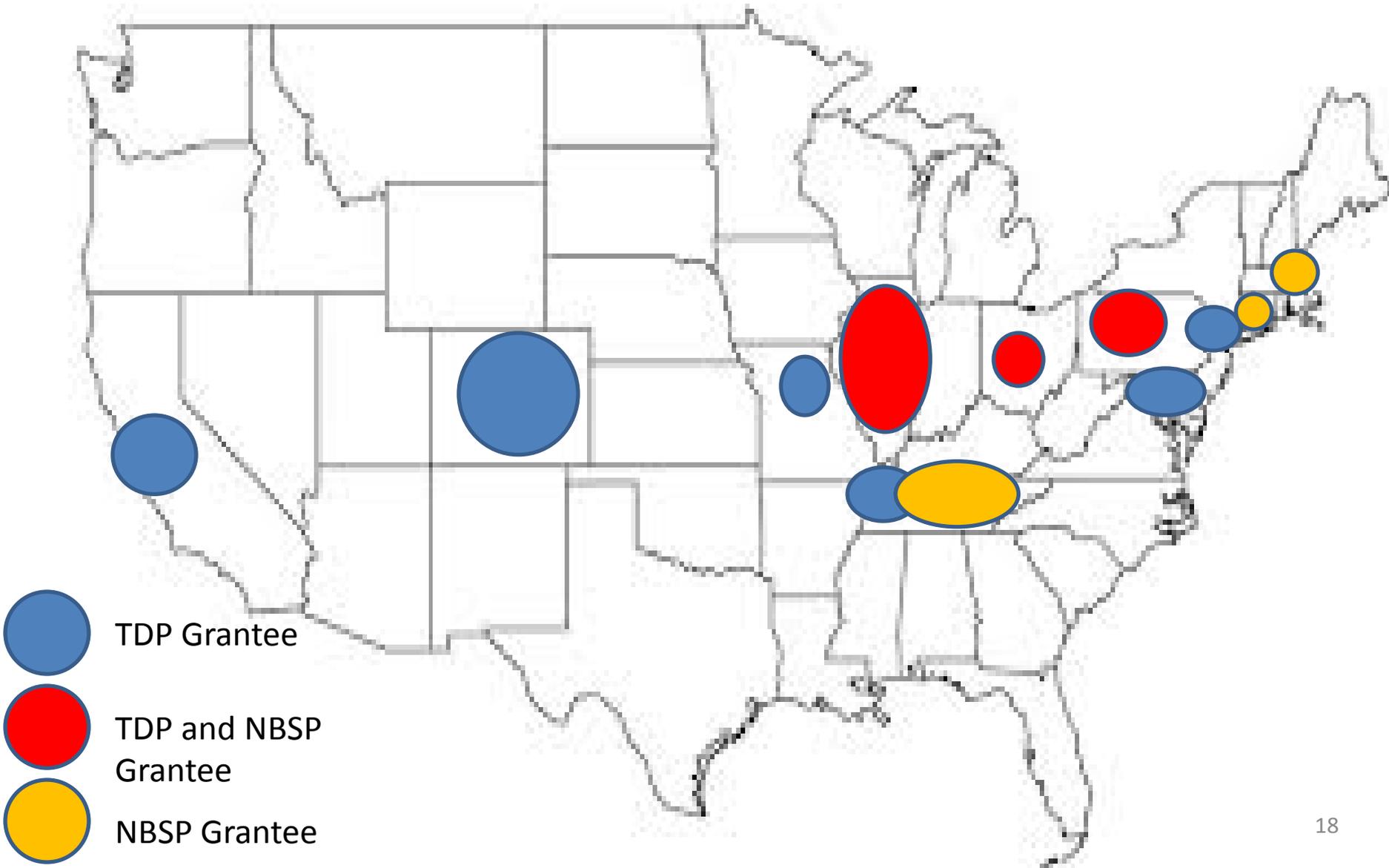
1. Patient Centered Primary Care Collaborative: <http://www.pcpcc.org/about/medical-home>
2. Stanford Social Innovative Review: Collective Impact: http://www.ssireview.org/articles/entry/collective_impact
3. Project ECHO: <http://echo.unm.edu/echocare/index.html>

Current Comprehensive SC Centers

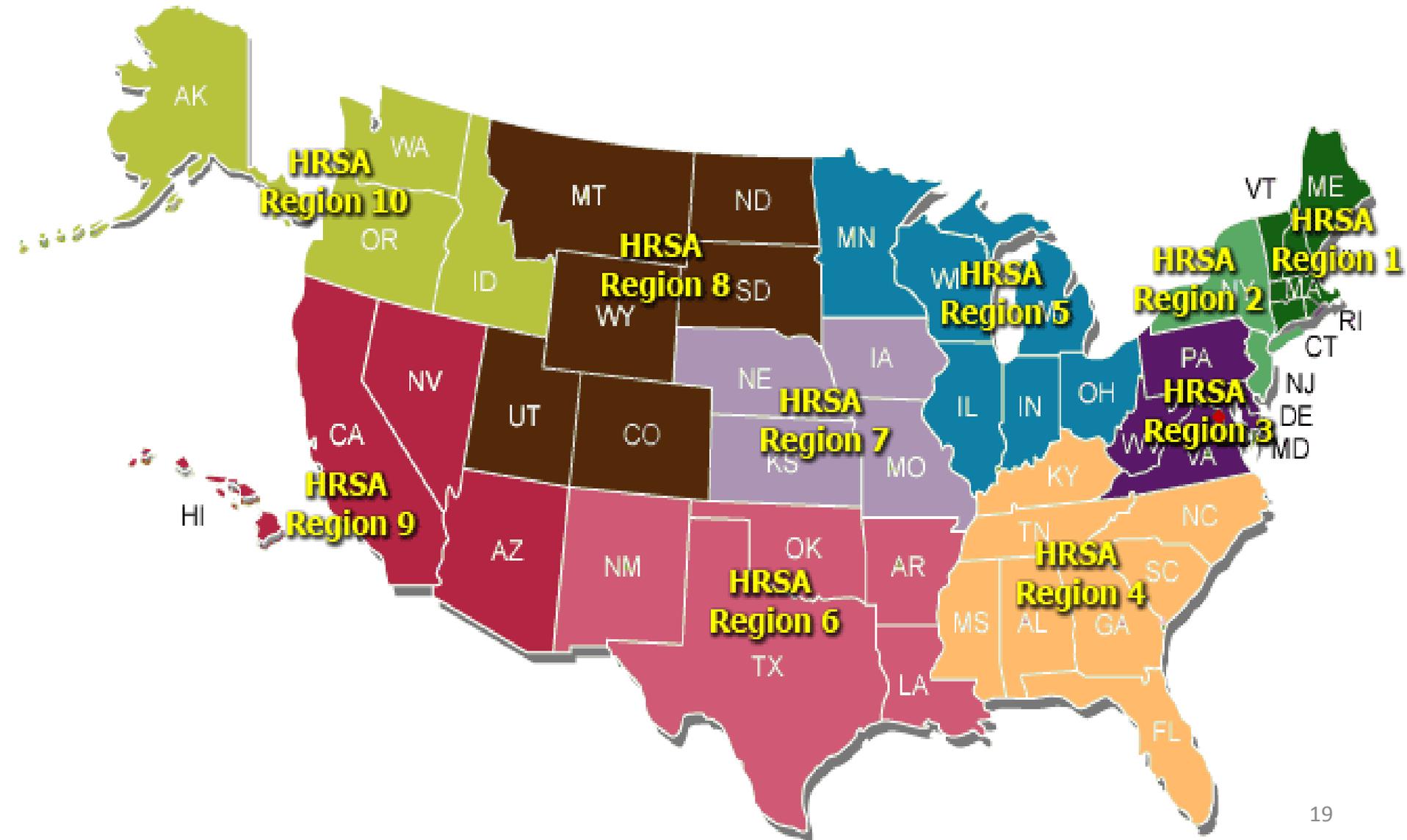


Hospitalizations for SCD by state and location of federally funded Comprehensive Centers before 2007. Funding has expired and centers “dissolved”. (Hassell, 2007)

Current Hemoglobinopathy Program Grantees

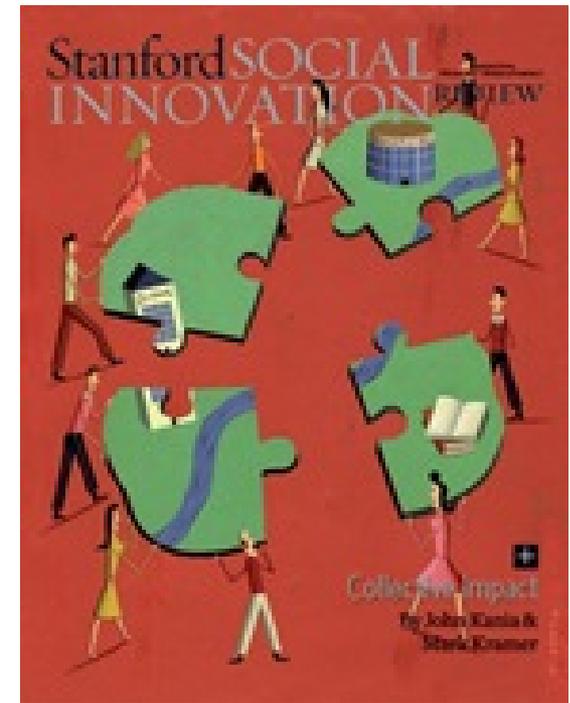


HRSA Regions



Collective Impact

- Collective impact is an approach to use collective efforts of multiple organizations to achieve improved outcomes
- Five conditions
 - Common agenda
 - Shared Measurement System
 - Mutually Reinforcing Activities
 - Continuous Communication
 - Backbone Support Organization



Use of Primary and Secondary Grantees

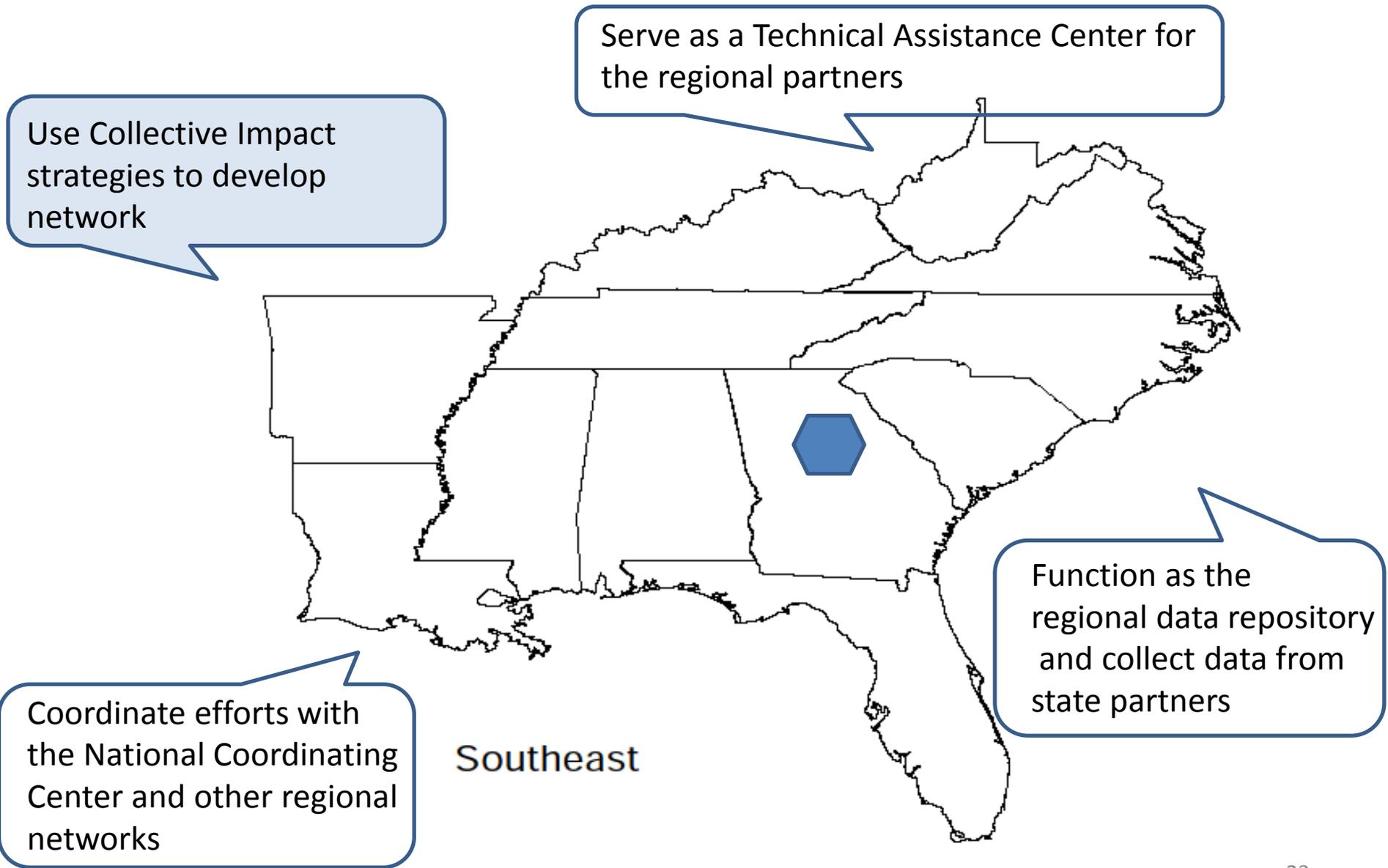
- The SCDTDP will fund both a Primary Grantee and Secondary Grantees to conduct the activities of the grant
- The program will seek to accomplish goals on both regional and state levels
- Program implementation will be the responsibility of Primary and Secondary Grantees



Pause for Questions



Primary Grantee Regional Activities

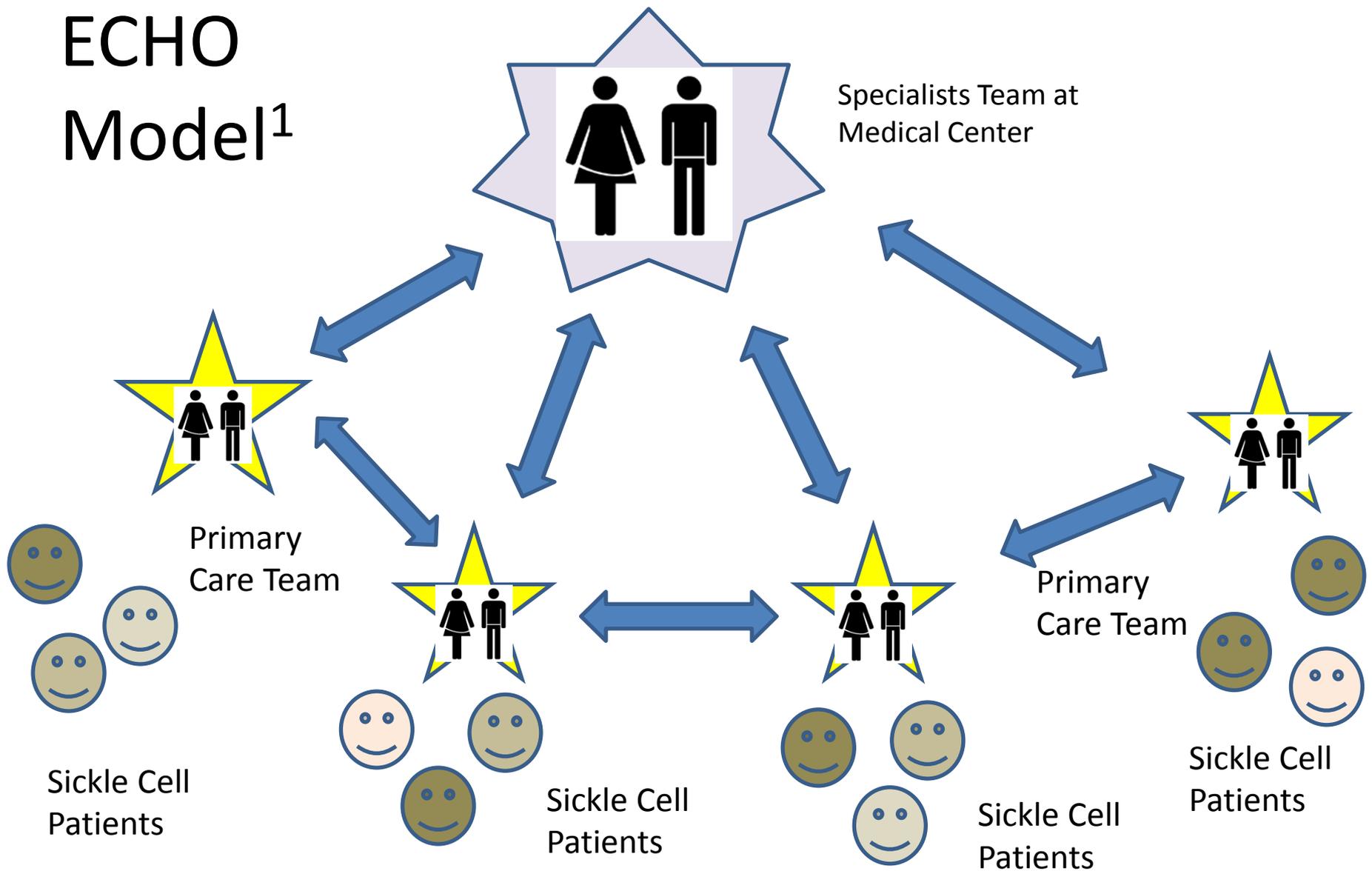


Extension for Community Healthcare Outcomes¹

- Links community care clinicians with specialist care teams at AMCs to manage patients with chronic conditions who require complex care.
- Connects multiple clinics with specialists via videoconferencing to conduct virtual grand rounds.
- Expands the technical expertise and medical knowledge of primary clinicians to deliver specialized care in rural or underserved areas.

1. Project ECHO: <http://www.rwjf.org/en/research-publications/find-rwjf-research/2013/11/demonopolizing-medical-knowledge.html>

ECHO Model¹



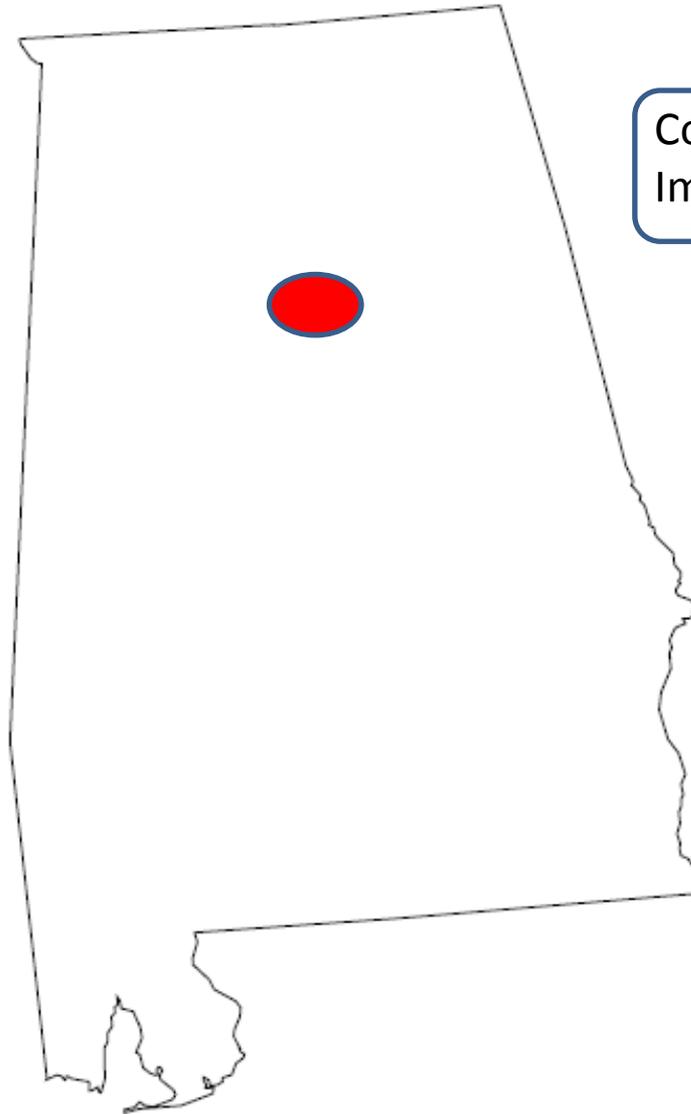
1. Project ECHO: <http://www.rwjf.org/en/research-publications/find-rwjf-research/2013/11/demonopolizing-medical-knowledge.html>

Secondary Grantees State Activities

Use Collective Impact Strategies to create state network

Partner with primary care organizations and develop Sickle Cell ECHOs

Develop materials, tools and strategies for sickle cell medical home approach to care



Conduct Quality Improvement Activities

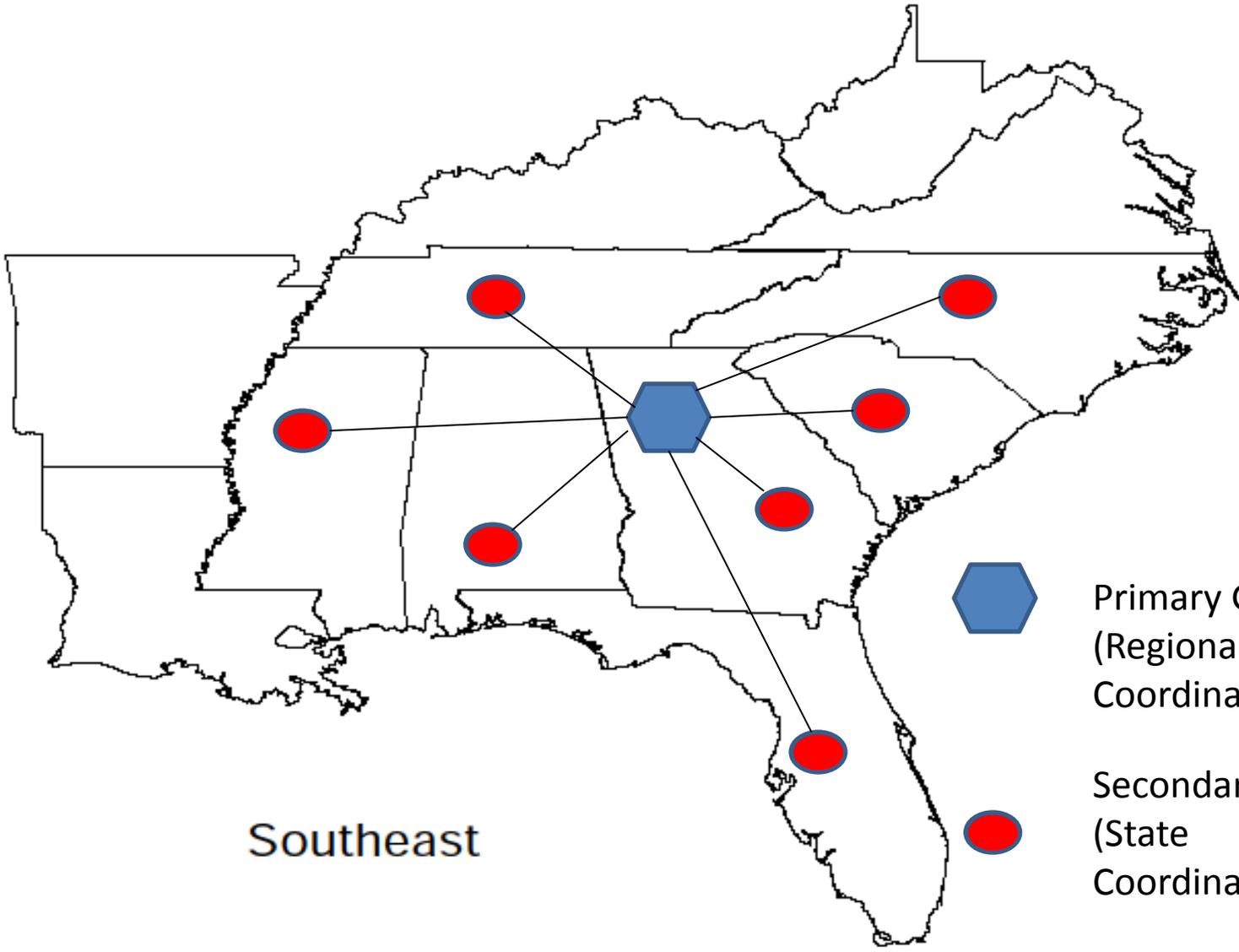
Perform data collection and evaluation activities at the state level

Pause for Questions





Primary Grantee Regional Partnership Development



Southeast

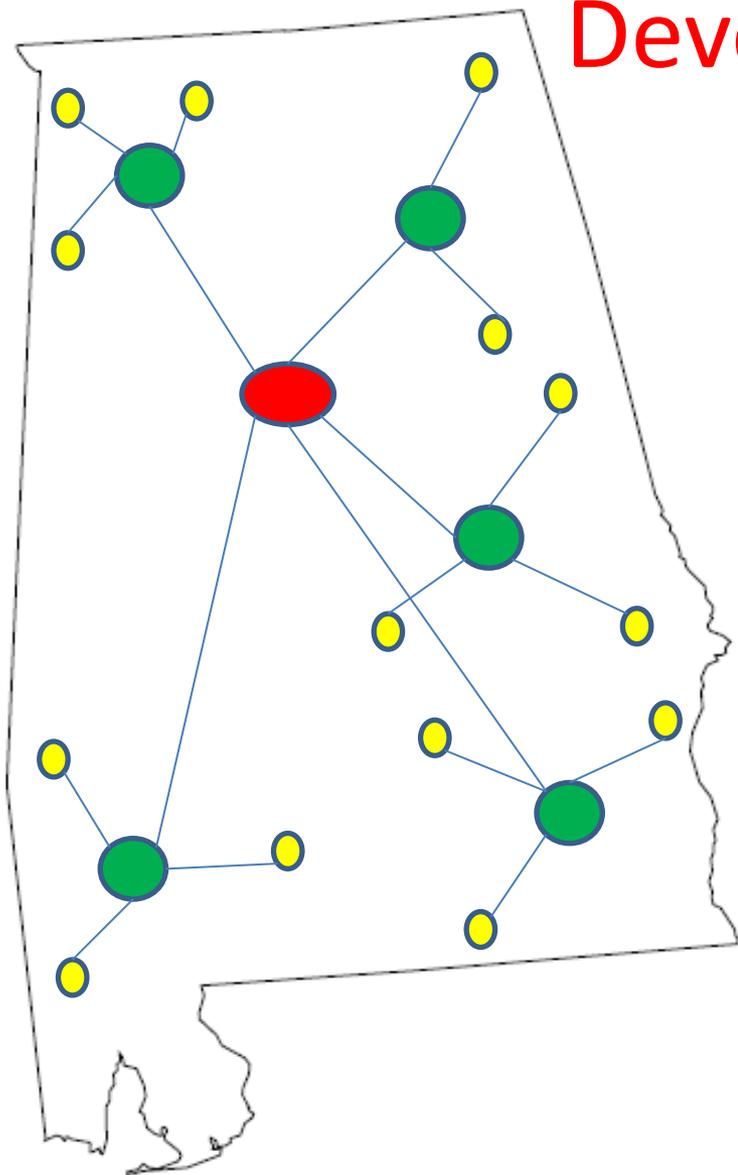


Primary Grantee
(Regional
Coordinator)



Secondary Grantee
(State
Coordinator)

Secondary Grantee State Partnership Development



-  Secondary Grantee (State Coordinator)
-  Hematologists (Medical Center)
-  Primary Care Provider

Pause for Questions



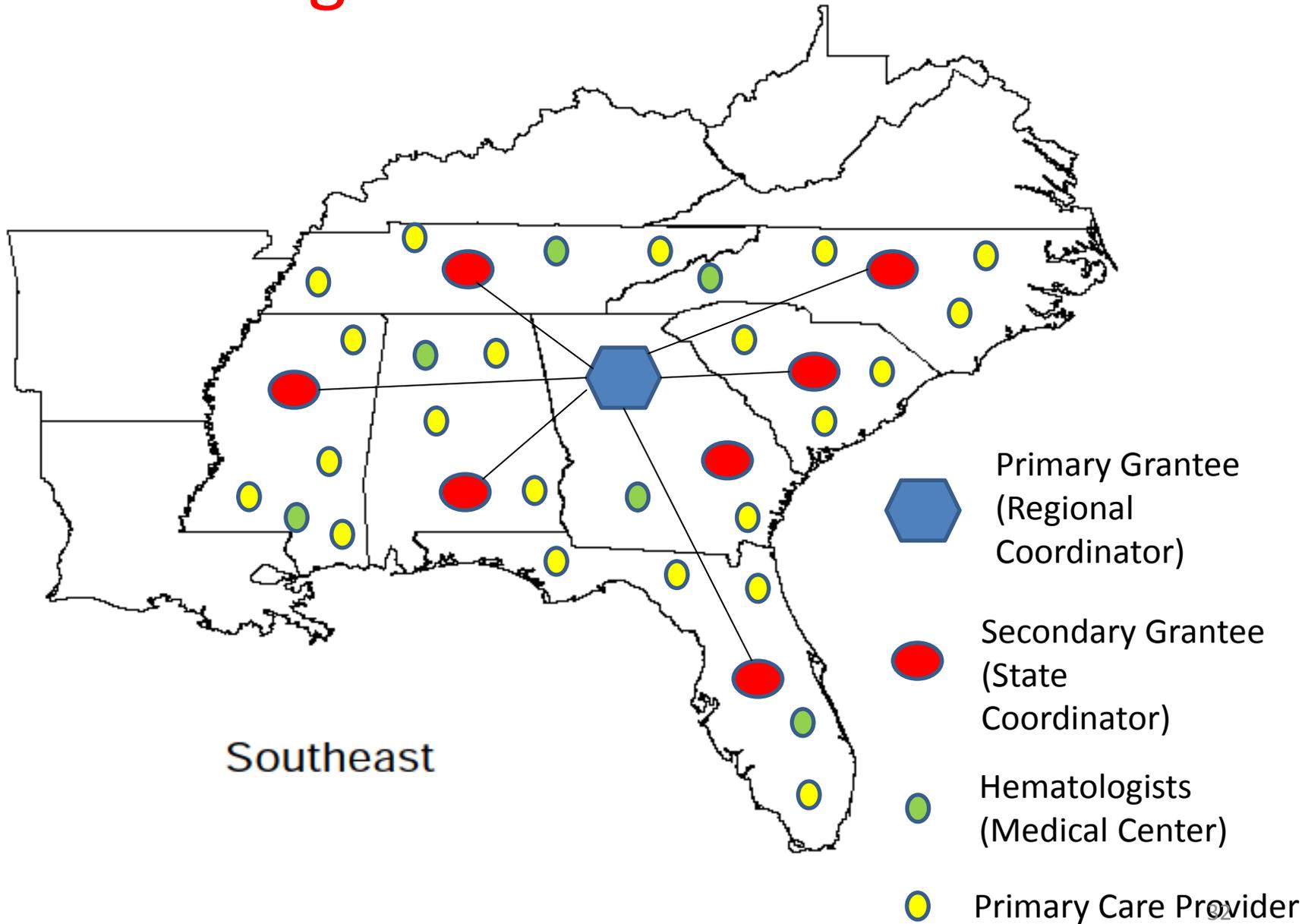
What do you think?

Strong partnerships are crucial for this model to work well. What do you see as some of the qualities that will make for a successful partnership, at the regional level, state level or both?

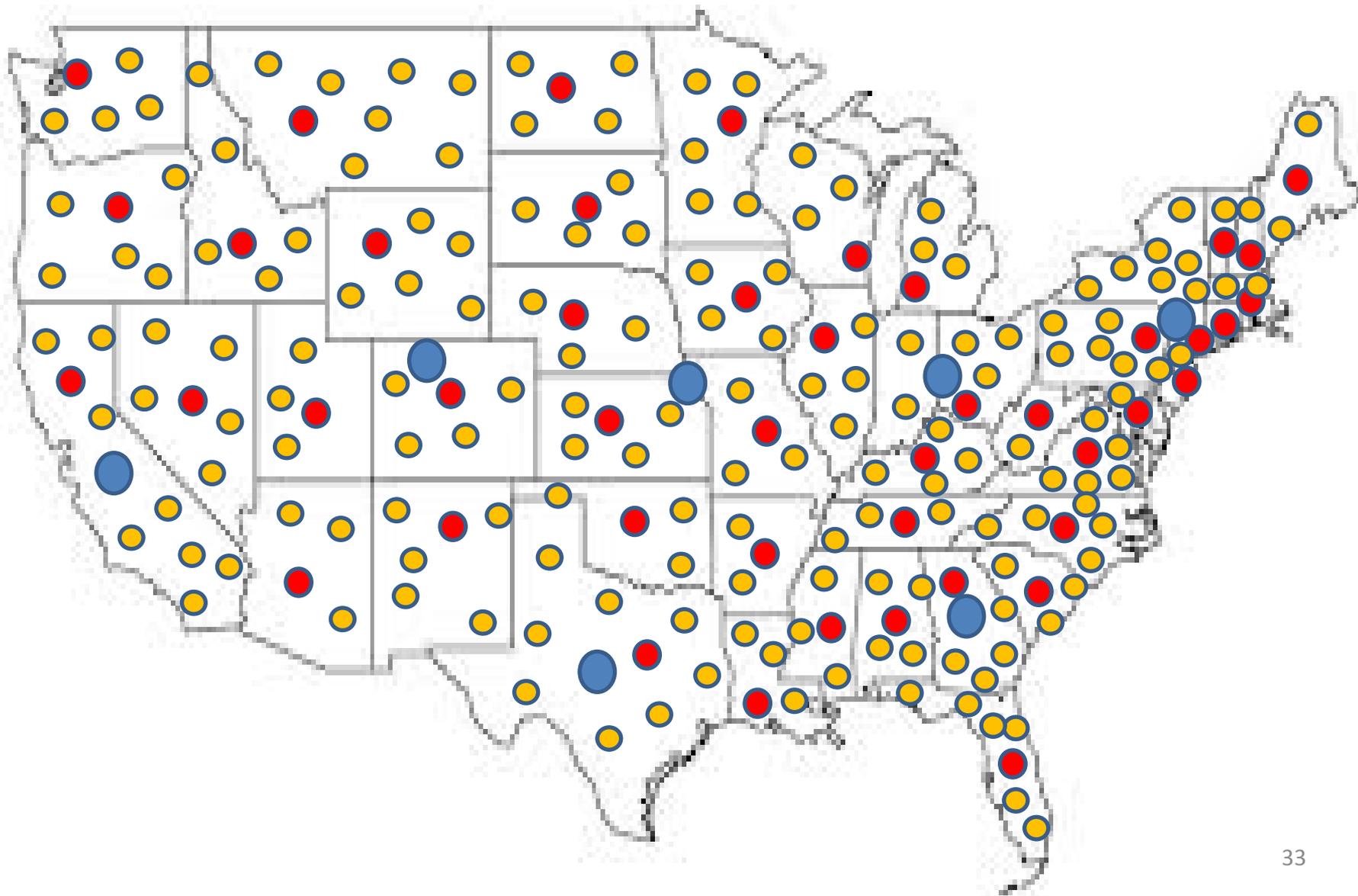
(please chat your answer)



Sickle Cell Regional Collaborative Model



Future Hemoglobinopathy Program



Pause for Questions



Respond to the Poll

- Please respond to the poll on the right hand side of your screen
- If HRSA were able to provide grants to only a few regions to start off, which of these criteria would be most important in selecting which regions to fund?
 - Number of patients with SCD across all the states in a particular region
 - Number of providers (sickle cell and primary care) in the region
 - Strength of current partnerships between health care institutions, community based organizations and public health entities in the region
 - Existing data collection and information technology infrastructure and capacity within a region
 - Other (*please chat in your suggestion*)



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Thank you!

From WISCH

and HRSA

