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## Improving the Lives of People with Sickle Cell Disease: Community Organizations and Epidemiologists Working Together

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## Abstract

**Background:** CDC's Sickle Cell Data Collection program comprises multidisciplinary teams, which include community-based organizations. Partnering with CBOs is a novel approach to ensure that SCDC data is actionable.

**Objective:** To better understand areas for mutual capacity building, we explored the relationships and dynamics between CBO and data teams within the SCDC program in 10 states.

**Methods:** We conducted semi-structured interviews with CBO (n=13) and SCDC (n=10) participants and then categorized and compared text from each interview and across states. Six themes emerged.

**Lessons Learned:** Transparency and trust are essential. Early CBO engagement and leadership are needed for trust and agreed upon priorities.

**Conclusions:** Participants contextualized trust, the most prominent theme, within discussions of racism and health inequities. Relationships between the CBO and data teams bring hard data and human experience together for advocacy, education, improved care, and a platform for the SCD voice.

## Keywords

Sickle Cell Disease; Communication; Community-Based Participatory Research; Centers for Disease Control and Prevention; Community Based Organizations; Collaboration; Ethics; Health Care Quality; Access; Evaluation

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## Introduction

Sickle cell disease (SCD), one of the most common genetic disorders in the United States, is a group of red blood cell disorders that affect about 100,000 Americans,<sup>1</sup> over 90% of whom are Black<sup>1</sup>. The SCD community includes patients, caregivers, healthcare providers, researchers, public health practitioners, and advocates like SCD community-based organizations (CBOs). Here, we examine the interactions between CBOs and state Sickle Cell Data Collection (SCDC) programs. State SCDC programs leverage existing data sources to compile health information about people with SCD to better understand and raise awareness of long-term trends in SCD diagnosis, treatment, and healthcare use.

## Background

Underlying SCD is the malformation of red blood cells. These long, stiff RBCs damage and block blood vessels, leading to anemia, infections, multiorgan damage, stroke, excruciating pain, and shortened lifespan.<sup>2</sup> Many people with SCD experience co-occurring health complications, limited access to SCD-trained providers, inconsistent care coordination, and

lack of support at home, work, and school. The stress and stigma associated with these experiences make life difficult.<sup>6,7</sup> Currently, the number of individuals living with SCD, where they live, and their experience is not well understood. This knowledge gap creates challenges to improving access to and delivery of quality comprehensive care, services, and support.

### **Sickle Cell Data Collection Program**

In 2015, the CDC launched a pilot project in California and Georgia to understand how many people have SCD, their demographics, and their patterns of health care use.<sup>8</sup> This pilot established the foundation for 11 CDC-funded state SCDC programs in October, 2020. These SCDC programs, led by state government agencies or academic institutions, were funded to establish statewide SCD monitoring systems based on established public health practices. Each state SCDC has an advisory multidisciplinary team (MDT) that includes health care providers, researchers, CBOs, people living with SCD or their caregivers, public health practitioners, policy-and decision-makers, and other interested partners. At the national level, the CDC convenes, coordinates, and provides technical assistance to support state level SCD data collection, analysis, and reporting within and across the 11 state SCDC programs.

### **The CBO and SCDC Data Team Partnership**

In this exploratory project, community is defined as a group of people with a shared identity, with common concerns and challenges, who work toward community identified goals – in this case improving the lives of people living with SCD. In each state, CBOs bridge the SCD community and the SCDC data teams, striving to ensure the community's voice is heard and needs are addressed, especially in the context of historical medical mistreatment and ongoing health inequities.<sup>5,7</sup> In February 2021, the CDC organized and convened the SCDC/CBO Community Outreach Workgroup, which includes SCDC and CBO representatives from each of the 11 states. To foster collaboration, each state SCDC/CBO team designed communication and dissemination plans to share SCDC information using accessible and engaging language for audiences that the CBOs determined as important. During this process, it became clear that relationships between SCDCs and CBOs were unique across the states, with each having different strengths and challenges. In some states, the institutional partnerships were long-standing, with established programs and projects. However, in most states, with the advent of the CDC funding, the partnerships were very new. As members of the Community Outreach Workgroup and the overall SCDC project, we undertook this quality improvement assessment to examine the status of CBO and data team relationships, their perspectives, experiences, challenges, potential opportunities, and lessons learned in these unique multi-state collaborative approaches. The primary objective is to provide a baseline to guide and strengthen these collaborative partnerships and, ultimately, improve the health and well-being of individuals living with SCD.

### **Methods**

Our exploratory assessment proposal to examine the unique partnerships in each state was discussed with the CBO and SCDC representatives at a monthly Community Outreach

Workgroup meeting. The group endorsed moving forward with the proposal, and then a core research team emerged. Led by JD, our study team ultimately included three CBO members (who live with or support family members with SCD), nine data team members, two graduate students (public health and communication), and one CDC Foundation field employee. CDC was available to provide subject matter expertise upon request. The general goals, methods, and assessment protocol for the project were decided within the monthly workgroup meeting, with the core team refining the ideas. The interview protocol was developed through group discussions about priorities to explore, and then individual questions framed by AM, AY, and JD. The entire authorship team then used Zoom meetings and emails to discuss and revise those questions through five iterations until 11 focus areas were finalized:

1. Funding history
2. Partnership expectations
3. Partnership goals
4. Shared activities
5. How CBOs and data teams strengthened each other
6. Opportunities that CBOs and data teams opened for each other
7. Challenges
8. Goals
9. Lessons Learned
10. Success stories
11. Overall impressions of the partnership

The unit of analysis for the project was the partnering organization (either CBOs or data teams) within each of the 11 states. We emailed the director of each CBO and the contact person for each data team, inviting them to designate 1–3 people to represent their group in semi-structured Zoom interviews. We conducted 23 virtual interviews lasting 30–60 minutes; some were with individuals and others with groups of two to three people representing their organization. In total, we interviewed 13 data team leaders and staff across 10 of the SCDC projects, and 16 directors and staff of 13 CBOs. In one state we interviewed 3 of 6 CBOs and in another state, we were unable to coordinate a CBO interview. One state did not identify any partnering CBOs. AY, AM, JD, and two graduate students (RA and LS) conducted the interviews in teams of two, with one person leading and the other taking notes in lieu of recording. We used the 11 question categories as an a priori coding scheme to organize notes from participants' responses, direct quotes, and our reflections. On a spreadsheet, we then collated the responses from all states for each category, which allowed us to compare responses to each question within and across states. We then inductively identified themes that ran throughout the data and captured exemplars from the transcripts that illustrate and support the themes. Trustworthiness and credibility of the data were established by discussing our notes after the interviews, checking our entries in the analytic template against our notes, and incorporating the insights of our diverse study

team as we passed the analysis draft among the team. For member checking, we presented the entire project to the SCDC/CBO Community Outreach Workgroup for discussion and questions, and then made revisions accordingly. Figure 1 is a flow chart of the project. Table 1 shows the contributions of the CBOs and the data teams to their own SCDC project, as our interviewees described them.

The University of Memphis' Institutional Review Board determined our project was standard public health practice and exempt from review.

## Lessons Learned

Six major themes emerged from the data: trust between the CBOs and the SCDC data teams, communication among these entities, expectations of the CBOs and data teams, goals of these same entities, mutual benefits for the CBOs and data teams, and new insights to strengthen the ongoing partnerships and work of the SCDC project. Table 2 shows exemplars from each of the themes.

### Lesson 1: Trust Between the CBOs and Data Teams

Our findings show that trust is foundational to CBO and data team collaborations and that a history of mistrust continues to challenge relationships with medical, public health, and academic institutions. One barrier to trust cited by CBO respondents was skepticism, an expected and reasonable mindset considering the deep inequities in healthcare, as well as lived experiences of SCD patients and families. Yet, according to one CBO leader, “when the community describes itself as skeptical, it’s meant as a good thing. We’ve learned to not accept the status quo and to hold people accountable. We say it with pride.” Several participants noted that some of the skepticism is waning. One data team member said: “We’re building trust, building relationships. We’re still involved. We did not come into the community and just leave... We’re still around and that has built our credibility.”

CBOs want to trust that their expertise is valued. Several CBOs described feeling minimized in the past but that their sense of being valued has grown with the SCDC relationship. This growth comes with increased trust; however, one CBO director stated bluntly that “trust is always an issue.” Foremost, the timing of CBOs becoming part of the SCDC project is important to ensure trust and value. Some CBOs felt they were not invited to the table early enough, which contributed to their feeling undervalued. One CBO explained: “I don’t want to just be invited to the table. I want to be in the grocery store deciding on the menu.” An area of concern described by an SCDC was the administration of grant money, which necessitates high levels of trust and transparent expectations of how SCDC funding can be used. Finally, both CBOs and SCDCs discussed the need for trust in deciding how data from the SCDC project would be used, whether for advocacy, policy, education, program planning, grant reporting or funding opportunities. One CBO participant said that when gathering data, “building trust in a community relationship requires balance between community interests, such as honoring existing relationships, and meeting institutional interests.” Some CBOs expressed frustration with a perceived lack of respect: “Because we don’t have PhDs, somehow we’re minimized.” Citing consistent struggles with communication and messaging, CBOs want to make certain that data are

used for “real world impact.” CBOs also expressed their expectations that they have a voice in deciding what data should be collected and what studies should be done by the SCDC program. Data teams recommended CBOs be proactive in initiating these conversations.

## **Lesson 2: Communication between CBOs and Data Teams**

One data team said, “Effective communication can only happen in a trust-based relationship.” CBOs and data teams described the need for transparency and clear communication regarding priorities, goals, and expectations. They identified cultural differences as one barrier to communication, particularly in comparing the cultures of the SCD community and public health organizations. Attributes of SCD culture that shape communication include passion for advocacy and narratives of struggle and resilience. Data teams, public health organizations, and academic departments also have a distinct culture that shapes their communicative practices. They value scientific analysis and report data through formal research reports and grant applications. CBO agendas are driven by their focus on specific needs in their areas. In contrast, data team agendas are driven by the larger goals of the SCDC program and legislative priorities. In some cases, these differences have become barriers to communication and challenges in collaboration. However, sometimes these differences aligned in pragmatic ways. One CBO described the elegance and effectiveness of communication when data and cultural attributes of community narrative are woven together to educate legislators.

CBOs explained that their organizations are diverse in purpose and scope. Some work mostly in advocacy, whereas others focus on education, community services, or access to care. A common challenge CBOs described was communicating how their organizations’ focus areas align with the data teams’. CBOs with long-standing relationships with the data teams described more satisfying and effective communication than those who had fewer substantive relationships, underscoring the claim that trust is built over time.

## **Lesson 3: Expectations**

A consistent expectation was that the CBO and data team relationships would continue to grow. One CBO said, “SCDC is a treasure trove. They help us get data and stats that we can then share with the public in a way that can be understood.” Another CBOs member described their work with the state’s data team as an ongoing journey. When asked if they had specific expectations, several CBOs said they had none for this relationship. Others said CDC’s expectations and goals of this relationship were unclear. Many who did express specific expectations said it was too early in the project to know if they were being met. An expectation shared by several participants was that CBOs would use SCDC data to educate the SCD community. One data team expected that by using the data they supplied, the CBO would “bridge the gap between patients, providers, and specialists.”

## **Lesson 4: Goals**

The foundational goal of the CBOs and data teams was to use SCDC data to improve the lives of people living with SCD and ensure the SCD community’s voice is included in every aspect. Also described frequently was a desire to share goals early in the relationship. A few CBOs and data teams felt that their goals were not aligned with each other, and almost all

of them expressed the need to be more transparent and intentional about sharing goals from the beginning. One CBO said that their goal was connection: “Just the connection, meeting Mary from CDC. Sharing my connections to the disease and what I’ve been doing at the CBO. It was very personally satisfying for me, being a mom to a child with sickle cell – feeling that my voice is part of something bigger.”

Some CBOs and data teams defined specific goals. One data team wants to strengthen their CBO relationship by “meshing their goals more specifically” in jointly writing papers and creating multimedia tools. They also want to leverage the CBO’s relationship with legislators. Other goals included exploring the incidence of SCD in prison systems, developing mental health interventions, supporting adolescents transitioning to adult care, developing a training program for emergency departments, and improving access to health care in remote areas.

All CBOs and data teams described their goal to honor the expertise of everyone involved in the project and ensure the community’s voice is incorporated into decisions. One CBO summed up the goals of everyone we spoke to: “We’ll do a better job of this together than if we were to do it separately.”

### **Lesson 5: Mutual Benefit**

The consensus among the data teams was that the CBOs bring vital components to the SCDCs, most importantly the patients’ voice and cultural perspective. Both groups discussed funding for CBOs and how data teams can collaborate, support, and enhance CBO funding opportunities. Data teams noted some CBOs’ networks have given them access to policy makers. When speaking to such audiences, CBOs and data teams have presented a collective narrative. One data team noted that the relationship has given CBOs more access to clinicians and epidemiologists, with CBOs providing cultural insights that are impossible to gain without connection to the SCD community. One CBO summarized the connections like this: “No data, no dollars. No dollars, no research. No research, no cure.” A data team summarized the connection by saying: “Their participation is vital. I can’t imagine doing this work without them.”

When asked about opportunities that each group provided, two CBOs mentioned funding and grant writing opportunities that had come about through their relationship with the data team. Many CBOs, however, felt the relationship was not well enough developed to see specific opportunities. In contrast, the data teams readily described opportunities that the CBOs were providing. First was the opportunity to connect with the SCD community, allowing them to hear the patient’s voice, connect data to lived experience, and have more credibility in speaking to other agencies. Data team members described opportunities they were providing for the CBOs, such as networking; likewise, they expressed gratitude for the CBOs bringing their voice to the table. One person said, “It’s a perspective that goes above the numbers, having them be at the table to explain the numbers.”

### **Lesson 6: New Insights**

Our final question to participants was about the lessons learned in relation to the SCDC project. Answers tended to fall in three categories: collaboration and relationship,

perspective, and timing. Participants reiterated the value of collaboration and relationship, but with caveats.

In discussing collaboration, one CBO cautioned other CBOs to “know their realms” and “just because we work with them [the data team] doesn’t mean that we are them.” They reminded CBOs to “remember your mission.” Both data teams and CBOs advised CBOs to know their strengths, while one data team advised colleagues to “not take the CBOs for granted.” Both CBOs and data teams acknowledged that challenges exist, but one data team said, “it’s worth the work,” and a CBO said, “partnering with the SCDC is worth it.”

CBOs and data teams offered advice on how to build and maintain trust: be transparent, reach out to members of the community, leverage existing partnerships, and, as one CBO said, “don’t try to reinvent the wheel.” They emphasized that trust is broken if either party fails to fulfill a promise. One data team suggested making time to meet informally with CBOs and members of the SCD community to better understand of the realities of living with SCD.

Many responses to the “lessons learned” question provided advice on valuing and seeking out alternative perspectives. One CBO said, “Be open to learning and changing. You can’t be successful if you say, ‘We’ve been doing it like this since the 70s.’” Another CBO suggested broadening their CBO advisory council to develop more diverse partnerships and perspectives.

## Summary of Findings

Trust, communication, and collaboration were the most salient concepts from our conversations. Across all respondents, the most important goal was to improve the lives of those living with SCD. Our findings suggest that collaboration is the process through which this goal can be accomplished, and that trust is how this collaboration can succeed. Our findings also suggest that neither trust nor collaboration can exist without intentional, effective, and transparent communication.

## Discussion

An extensive literature review on community-based participatory research shows that projects are often time- and resource-limited, 9–14 hindering what Calloway et al.<sup>15</sup> define as authentic community engagement. Guidance for equitable and sustained partnerships between CBOs and public health surveillance programs is limited. This study examined these novel partnerships emerging across multiple states. The most salient findings focused on the need for transparency and engagement with all stakeholders from the conception of the program, to build and sustain trust.

Our findings from this cross-sectional formative assessment are similar to those of Calloway et al.<sup>15</sup> who identified trust, shared power, funding objectives, differences in CBO capacities, and inherent differences in perspective and communication as key themes driving relationships between CBOs and public health entities. Calloway’s themes are further underscored with our CBO and SCDC data team partnerships where public health



practitioners who want to build partnerships with historically marginalized, minoritized people must respect the historical underpinnings of distrust.<sup>16, 17, 18</sup> The onus is on practitioners and researchers to engage, share power, and be transparent in intent and strategy, recognizing that early, effective dialogue honors the humanity and lived experience of all.

### Strengths and Limitations

A key strength of our study is the intentional collaboration between SCDC data teams and CBOs in designing, implementing, analyzing, writing, and sharing results of this effort, which everyone recognized as a self-assessment of the project we are all committed to. Our study is limited in that our assessment took place at one moment in time. An important extension of this work would be to longitudinally re-evaluate the CBO and data team relationships. Another limitation is that this was an exploratory assessment conducted at the organizational level which limits more sophisticated, individual-level assessments across and within participating organizations. This is an important consideration for follow-up assessments. Finally, this was an ‘internal’ assessment which may positively bias findings. While there may be potential for this, core team members did not conduct interviews with their own state CBO and SCDC teams, did not know CBO staff from other states, and had limited contact with other state SCDC staff, thus minimizing potential bias. Furthermore, the findings do present strengths and weaknesses of the SCDC/CBO partnerships. Future work should include focus groups and surveys to capture a broader assessment.

### Recommendations for Next Steps

Our study and the overall SCDC program reflect the impetus of the CDC to improve and extend the lives of people with SCD by studying trends in diagnosis, treatment, and healthcare use to inform policy and practices that improve health. Along with epidemiologic and clinical studies, a deliberative effort is required to share leadership, prioritize goals, improve effective communication, and sustain and grow CBO and data team partnerships. Purposeful attention, training, and facilitation are needed. This effort will require additional qualitative assessments to explore:

1. How to have equitable collaboration among partners with different capacity, expertise, and experience
2. How to build capacity that positively impacts all stakeholders and builds on strengths
3. How to improve communication, trust, and collaboration, and discern what frameworks can serve as a guide
4. How to highlight the uniqueness of the SCDC collaborations within and across states
5. How to capture and share the personal passion of CBOs

Addressing these concerns will be an ongoing focus of each SCDC and CBO, as well as the Community Outreach Workgroup, to leverage CBO experiences and develop approaches to share SCDC data findings with the SCD community. This study serves as a critical step

in exploring and documenting the mechanisms that can build and maintain trust in the SCD community, thereby improving the SCDC program's impact on the SCD's community health. Additional assessment of the SCDC model on SCD surveillance, communication, and patient outcomes will be important to inform existing and new state SCDC programs and their CBO partners.

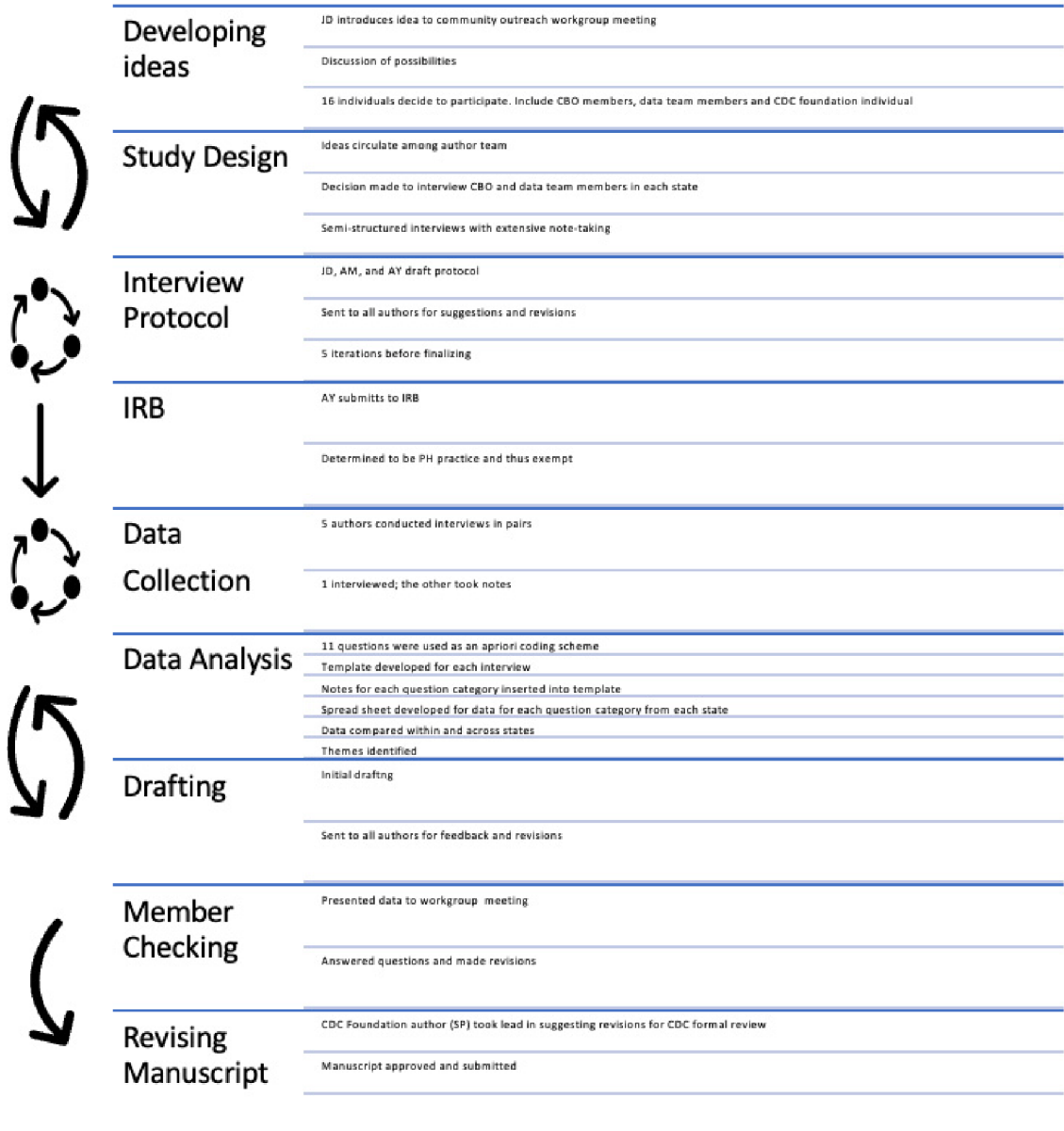
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**Figure 1.**  
Process

Contributions of the CBOs and data teams in each state, paraphrased from their own words.

**Table 1:**

| State          | CBO contributions to SCDC project   | Data Team contributions to SCDC project  | Challenges of partnership  |
|----------------|---|--|--|
| <b>State 1</b> | Ability to share data in a culturally appropriate manner.<br>Established paths for dissemination  | Educational presentations<br>Data informs grant writing for CBO.   | Perception that some CBOs don't see the value in the data<br>Collaborating earlier would be helpful.<br>CBO feels they come from a "listening mode" only and must stay in their lane.<br>Distance across state is a challenge.<br>More collaboration in disseminating the data and developing the messaging is needed. |
| <b>State 2</b> | Connecting with people "on the ground" doing the work, who understand what the issues are, what's on the horizon  | Brings grant writing opportunities to CBO. CBO brings most up to date information<br>Shared leadership between CBO and data team   |  |
| <b>STATE 3</b> | CBO attends data teams advisory meetings and provides important insight.  | Committed to improving access to care, especially for warriors in remote areas   | Most warriors are in a rural area and hard to reach.<br>Relationship building has been difficult because of a lack of trust.   |
| <b>STATE 4</b> | Collected data on why PCPs are hesitant to provide SCD care.<br>Taught the data member about the challenges of living with SCD and running a CBO.   | Share data, papers and videos and helps them to disseminate information to the community   | Longstanding, successful relationship that has evolved organically<br>See the relationship as a way to increase funding.   |
| <b>STATE 5</b> | CBO provides the patient voice.   | Project has given CBO access to epidemiologists and clinicians.<br>Working jointly to communicate data to warriors   | They don't expect many challenges except to help CBO understand how federal grant money is used.   |
| <b>STATE 6</b> | Participates in designing messaging<br>Identifies gaps that need to be addressed  | Hired a communications director as a liaison between data team and CBO   | Expectations not being met from SCDC perspective. Want CBO to take lead in driving the message<br>Would benefit from a better explanation of the CBOs role and purpose, what the CDC is expecting the states do with their CBOs, ongoing as more data comes in   |
| <b>STATE 7</b> | Building trust in the community<br>Insight into the hierarchy of needs in the SCD community<br>"Legacy relationships" that build trust<br>Introduced to new initiatives, positions, partnerships, etc.<br>Demonstrates sustainability<br>Provides feedback on communication interventions | Provides data that can be used to seek funding and inform policy makers<br>Keeps CBO informed about related government activities  | CBO has limited capacity.  |
| <b>STATE 8</b> | Provides the patient perspective  | SCDC data will lead to allocation of more SCD resources to improve client treatment, provider education, and improved quality of care for patients living with SCD.<br>Providing data and help to write grants<br>Helps CBO state connected to the state health department | CBO felt the partnership was not established early enough and felt CBO was engaged only when required.<br>CBO is spread thin.  |
| <b>STATE 9</b> | The link to getting the information into the right hands<br>Teaches the SCDC what is important to the SCD community   | The CBO can use that data to write for grants or to help tell their story.   | Consistent struggle with communication and messaging in the SC community<br>The CBO is stretched thin, lack of capacity.   |

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| <b>State</b><br><b>STATE 10</b> | <b>CBO contributions to SCDC project</b><br>Provides the voice of the community<br>Helps identify gaps in the community for the data team. | <b>Data Team contributions to SCDC project</b><br>Provides some funding for information dissemination<br>Provides expertise in marketing materials developed with the data | <b>Challenges of partnership</b><br>Consensus the CBO and data team need to meet more often to identify goals and expectations. |
|---------------------------------|--|--|---|

**Table 2:**

Exemplars from each theme

| Theme           | Quote   |
|-----------------|---|
| Trust           | <p>“Because we don’t have PhDs, somehow we’re minimized.”</p> <p>“CBOs have to trust each other and work together even though they are competing for the same resources.”</p> <p>“Trust is always an issue.”</p>  |
| Communication   | <p>“Our goal is to be the communication conduit between the SCDC and the SCD community. It’s been very slow going in [our state].”</p>  |
| Expectations    | <p>The idea of partnership working parallel, they were not on the same page about that. . . . Miscommunication happened. Some questioned why even partner with them.</p> <p>If we had had a meeting about success and expectations at the beginning of the project, it would have improved communication.</p> <p>The CBO meetings could be better. Making it very clear what the expectations are for the CBOs, having a general meeting, seems confusing for many CBOs right now.</p>  |
| Goals           | <p>“When states are asked to share their own plans, there were differences in goals, info, etc. Where ever you are in your journey.”</p> <p>“The goal of partnership is to make the CBO feel included.”</p> <p>“We want to know if we’re not helping, because we don’t want to do a disservice to their community, make them feel we’re changing the narrative in a detrimental way.”</p> <p>“Ultimately to work with the partnership to help gather data that help patients. They don’t have a lot of care in the state so people drive long to get help.”</p> |
| Mutual Benefits | <p>“SCDC provides an opportunity for bringing the voice of the community to the table.”</p> <p>“The idea is that with the data, hopefully more opportunities open up for the CBO.”</p> <p>“Their participation is vital. I can’t imagine doing this work without them.”</p> <p>“SCDC is a treasure trove.”</p>  |
| New Insights    | <p>For a CBO that’s been around for a long time, don’t forget your mission. Embrace funding and contracts/MOUs that are part of the work that you’re already doing. Don’t go in a different direction just because there is funding available.</p> <p>CBOs have to trust each other and work together even though they are competing for the same resources.</p> <p>Be transparent, reach out to members of the community, leverage existing partnerships first, not always re-inventing the wheel.</p>   |