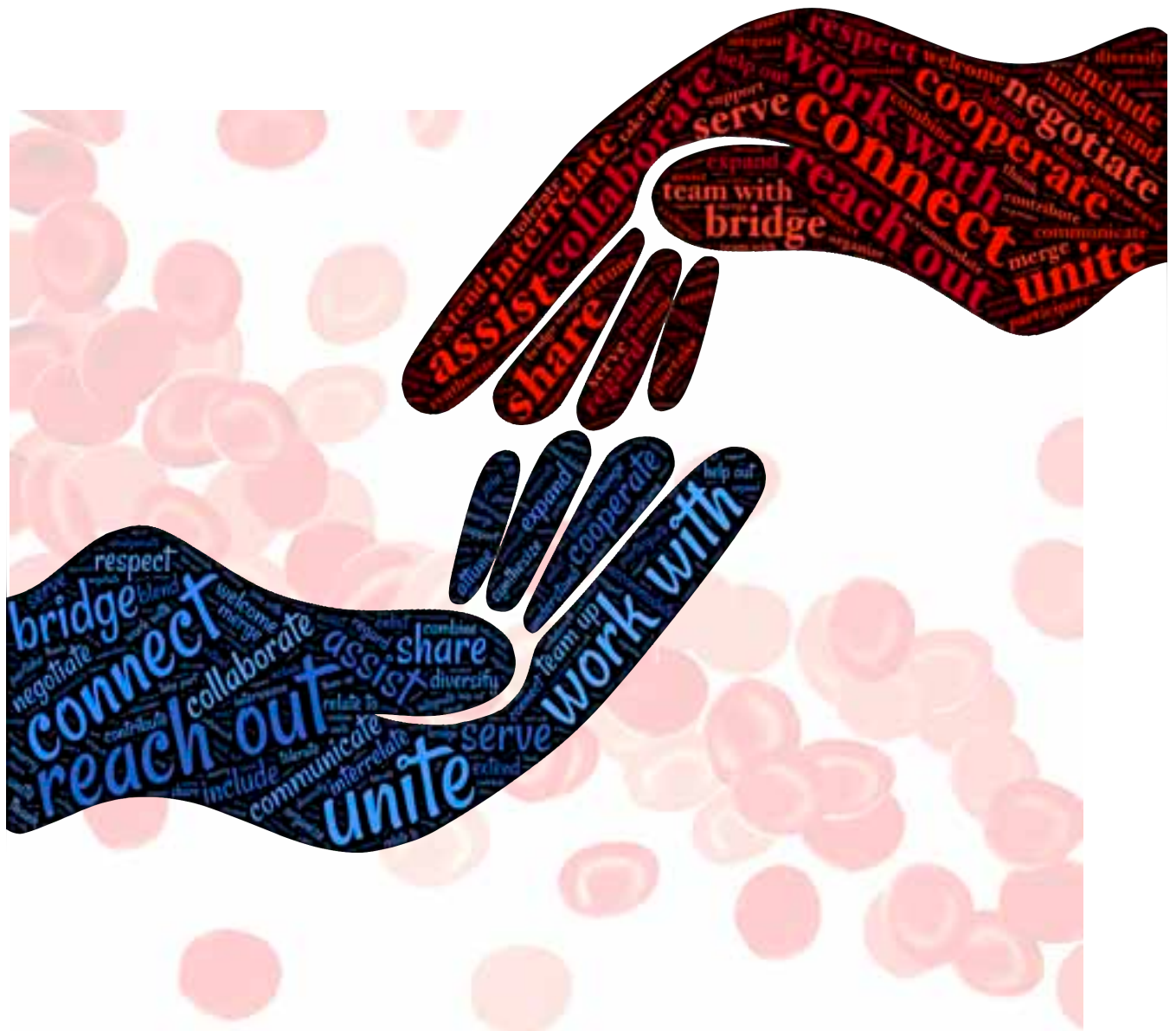


A microscopic view of numerous red blood cells, which are biconcave discs, scattered across the frame. The cells are a light pink color with a darker pink center, set against a light yellow background.

# **SICKLE CELL DISEASE**

## **Collaborative Conversations: Breaking Down Silos**



By: Sam Trenner & The Sickle Cell  
Foundation of Tennessee



Supported from an Accel Grant by Global Blood Therapeutics 2021-2022.



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# COLLABORATIVE CONVERSATIONS: BREAKING DOWN SILOS

## PURPOSE:

The purpose of Collaborative Conversations: Breaking Down Silos to Improve Care for People with Sickle Cell Disease (CC:BDSCDS) is to use unconventional partnerships to help improve care for people with SCD by building a collaborative provider/community network and developing an actionable strategic plan. The environment has long been recognized as having an impact upon health - social determinants of health. People with SCD have complex medical and social needs, and according to the CDC “people with SCD experience worse health outcomes compared to other diseases and have access to fewer health resources”.

## INTRODUCTIONS:

**The Importance of Community Based Participatory Research for Sickle Cell Disease:** Sickle cell disease is a rare blood disorder affecting an estimated 100,000 individuals in the United States (Hassell, 2010). Sickle cell disease affects the shape of red blood cells which can cause many complications including vaso-occlusive pain crises, decreased immune protection, stroke, and premature red blood cell death (Rees et al., 2010). While sickle cell disease was first discovered over 100 years ago, there are currently few therapies and treatments available for those with sickle cell disease. More options are currently being developed, however many individuals with sickle cell disease face a multitude of other challenges such as poor healthcare access and low quality of care (Lee et al., 2019). For any treatment and therapy to be successful, the social determinants of health must be addressed to ensure equitable treatment access and health outcomes for all people. Improvements to the physical and social environments for individuals with sickle cell disease can have immediate and lasting beneficial effects.

Individuals and populations with sickle cell disease are left vulnerable to the social determinants of health. The long-lasting effects of structural racism coupled with a painful chronic disease causes many individuals with sickle cell disease to experience large health disparities (Bailey et al., 2021) (Power-Hays and McGann., 2020). Notable socioeconomic burdens of these individuals include the lack of employment, education, transportation, healthy food access, and affordable



housing. Universal screening of the social determinants of health showed that 66% of screened patients with sickle cell disease had at least one unmet socioeconomic need (Power-Hayes et al. 2019). These unmet needs can be addressed by empowering the community and providing resources that can improve overall health and wellbeing.

Community based participatory research (CBPR) is a collaborative approach that ties together all invested researchers, community members, and community partners to enhance the research process (Israel et al., 1999). In this process, each diverse group shares their own insights and strengths to improve the quality and efficacy of the research. This method allows real people with real experiences and understandings of the issue to participate with the research and community groups. Feedback from all involved groups is vital to build upon current systems that need improvement. Through this bottom-up process, research and interventions are less generalized and more focused on creating an engaging and in-depth discussion centered on the specific needs of the community. The goals of CBPR are to improve and strengthen community resources while building long lasting collaborative partnerships between groups. With strong partnerships, CBPR can facilitate substantial beneficial changes that can both improve the health outcomes of a community and reduce health disparities (Israel et al., 1999).

A community-based process can be especially useful for sickle cell communities because it gives individuals with sickle cell disease a chance to finally join the conversation and put a voice to their own ideas and concerns. Through collaborative conversations, researchers can understand the specific problems faced by the sickle cell community. Following the constructive conversations, partnerships with community organizations can be initiated to specifically target and strengthen the sickle cell community. These partnerships can help improve the health and wellbeing of individuals with sickle cell disease by providing resources to meet their currently unmet needs. For example, many individuals with sickle cell disease struggle to find employment that can be accommodating and structured around their chronic disease. However, those with sickle cell disease who are employed have better health outcomes and fewer hospitalizations compared to those who are unemployed (Williams et al., 2019). By providing resources such as employment accommodation options, researchers and community partners can directly impact the sickle cell community and provide more stable employment for sickle cell individuals. Employment would not only give those with sickle cell disease a reliable income, but it could also decrease socioeconomic burdens and improve quality of life.

Improvements to just one socioeconomic factor can prove to have massive benefits to those in the sickle cell community. However, CBPR can be used to improve all aspects of life for individuals with sickle cell disease. There is currently a vast number of resources available to people with sickle cell disease, however these resources are greatly underutilized because they are not well-known. Methods to improve the awareness of these underused resources to the sickle cell communities could show tremendous health improvements. Resources that could prove to be exceedingly beneficial for individuals with sickle cell disease include affordable transportation, internet assistance, childcare, housing and utility assistance, caregiver respite, financial literacy, mental healthcare, and food access. A well-known and accessible local resource bank can increase the use of these helpful resources leading to an improvement of the social determinants of health for sickle cell communities.

## PROJECT OBJECTIVES:

Establish Project Objective. Make sure your objectives are SMART objectives: Specific, measurable, achievable, reasonable, and time-based.

All SCFT project objectives were based on an end date of June 30, 2022. The timeline later in the project provides more detailed information on timing of each objective.

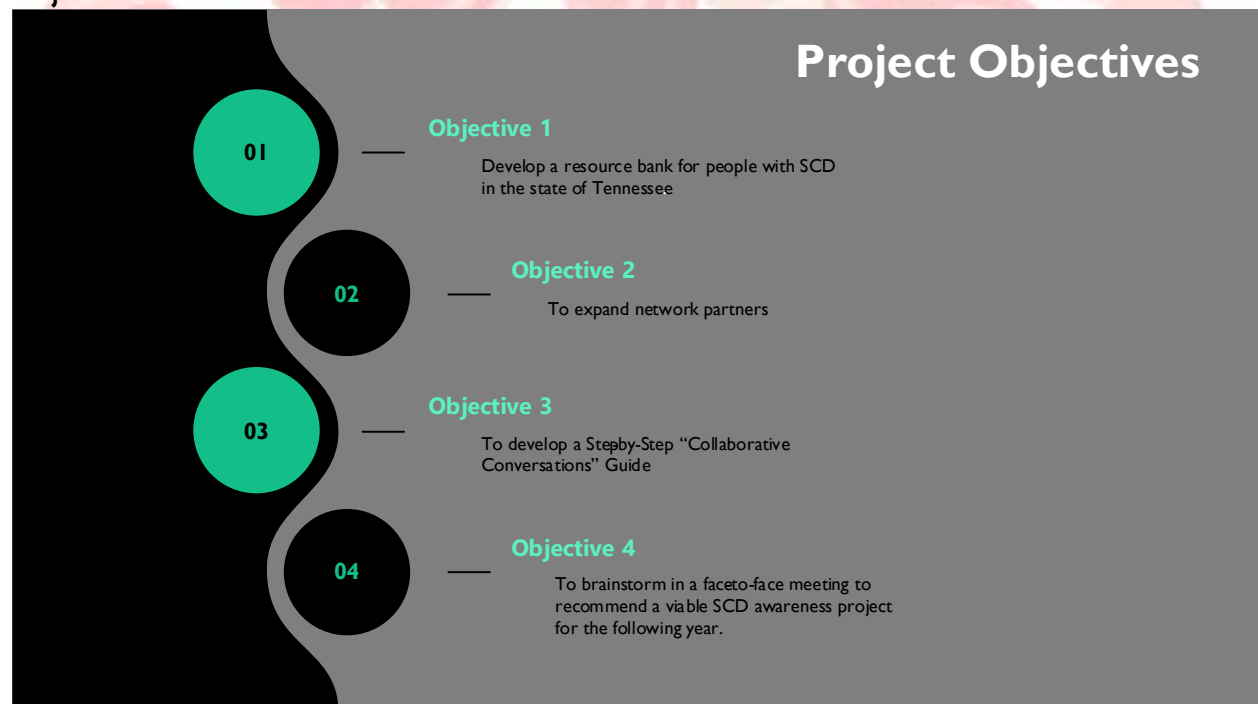


Figure 1 SCFT abbreviated project objectives

## TIMELINE

All objectives should have a timeline. The Advisory Council should refer to the timeline at least once a month to ensure the objectives are being met.

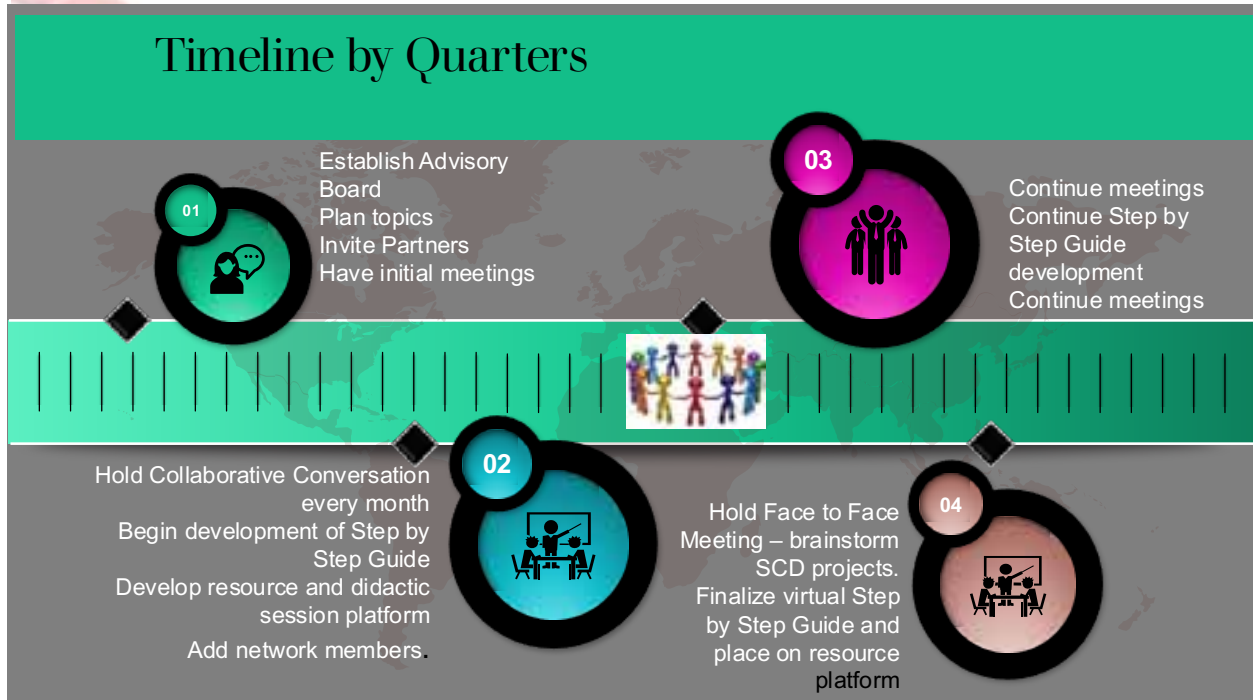


Figure 2: Example of SCFT timeline

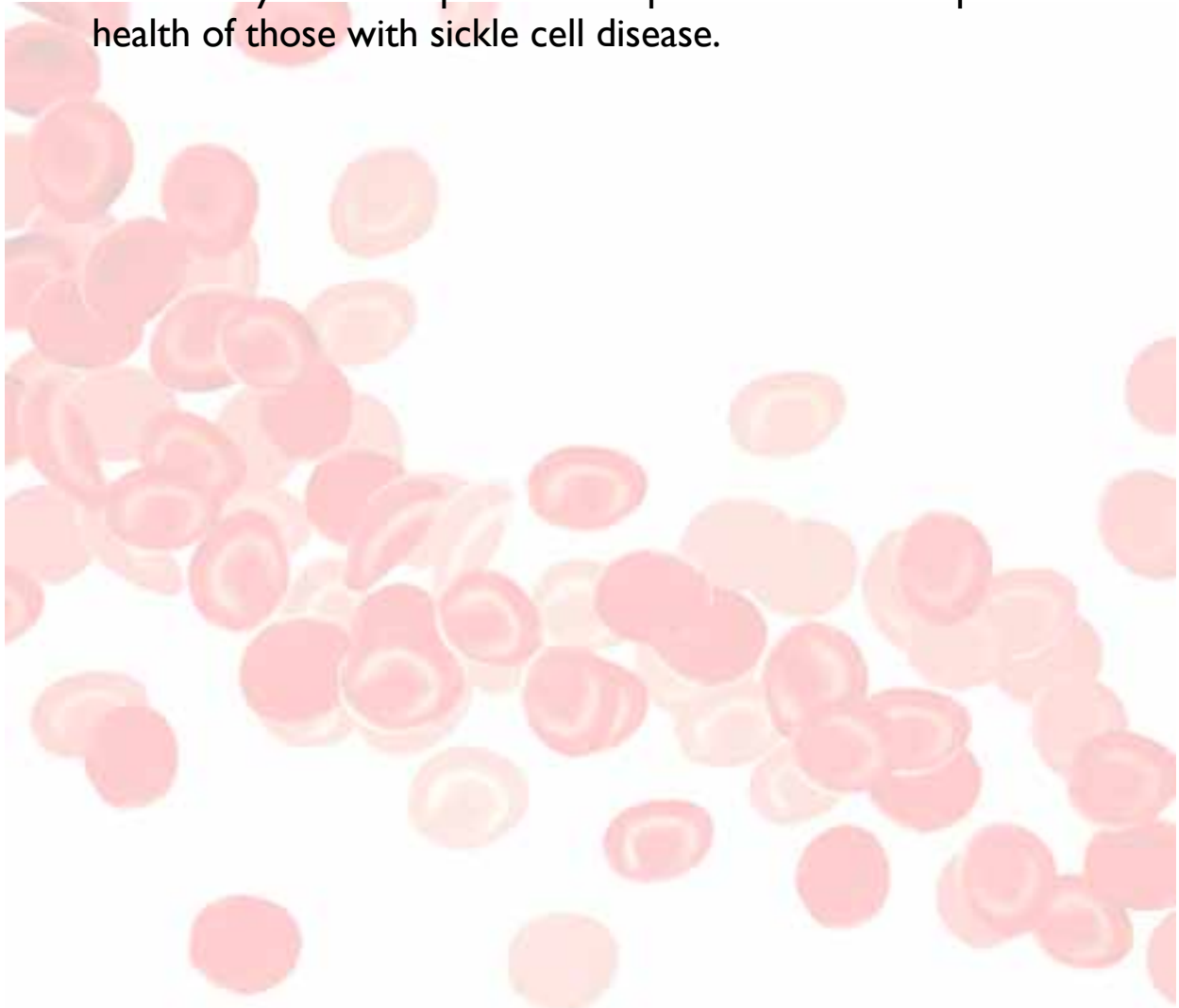


## WHY IS IT IMPORTANT?



- This booklet serves as a guide for sickle cell disease researchers and providers to start collaborative community network in their own communities.
- The booklet was created and organized by the Sickle Cell Foundation of Tennessee to instruct other groups how to initiate and plan sickle cell disease collaborative conversations.
- A step-by-step guide is available for those who wish to emulate this process to serve the specific needs of their sickle cell community

- This guide describes an accessible learning process where each involved member is invited to share their experiences and learn from the experiences of others.
- The end goal of this process is to create partnerships with the community to develop actionable plans that could improve the health of those with sickle cell disease.



## OUTLINE FOR BUILDING A SICKLE CELL DISEASE COLLABORATIVE CONVERSATIONS NETWORK

The way to get started is to quit talking and begin doing.

Walt Disney

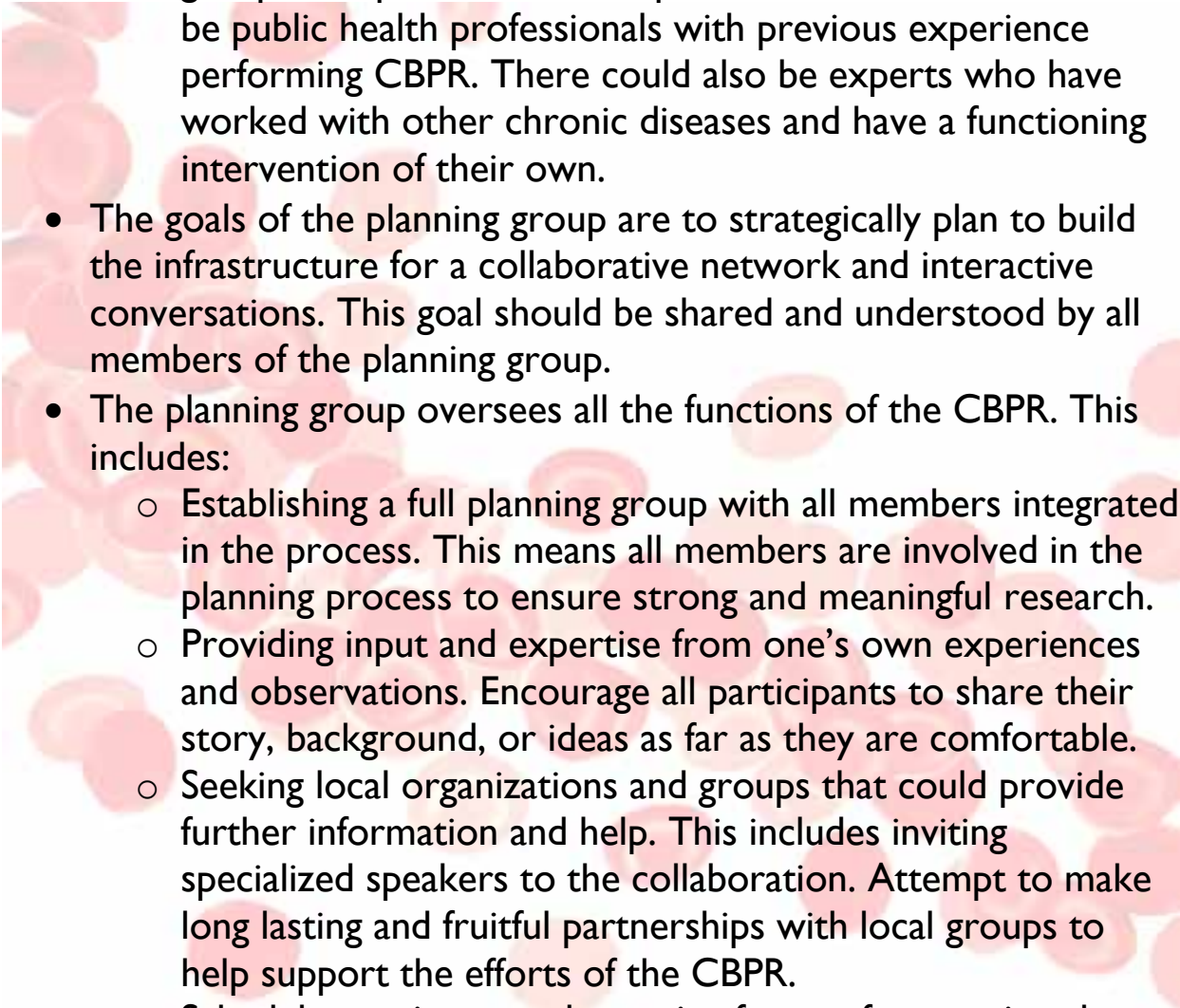


1. Establish a planning group or advisory board for the region/community. The group should contain a mixture of health professionals, invested individuals, and community members with sickle cell disease or those who care for loved ones with sickle cell disease.
2. Prepare to build a collaborative network of local providers and community organizations to assist in the process.
3. Schedule face-to-face or virtual meetings and invite collaborative network participants to share their experiences and ideas to the group.
4. Conduct and maintain consistent collaborative conversations throughout the process.
5. Wrap up the process through reflection of the project. Create actionable plans and share all insights with the community.

## ESTABLISHING AN ADVISORY GROUP



- The planning group is the foundation of a sickle cell disease collaborative network, and it sets up the CBPR for success.
- The planning group consists of invested individuals driven to improve the quality of care and wellness for those with sickle cell disease. Members of the group should include community members who care for or have sickle cell disease, a sponsoring organization, local sickle cell disease providers, and any other community experts.
  - The sponsoring organization can be any group already dedicated to improving the lives of those with sickle cell disease in their community. This organization typically starts the planning group, and it recruits members from their specific community.
  - Community members with sickle cell disease or those who care for those with sickle cell disease are vital to the development of the planning group. Input from these members is highly valued as they represent the group that will eventually benefit from the CBPR. These members have the greatest understanding of what needs to improve in their community to accommodate for sickle cell disease.

- 
- Local sickle cell disease providers also have immense knowledge of the effects of sickle cell disease in their community.
  - Various community experts can be included in the planning group to improve the CBPR process. These individuals could be public health professionals with previous experience performing CBPR. There could also be experts who have worked with other chronic diseases and have a functioning intervention of their own.
  - The goals of the planning group are to strategically plan to build the infrastructure for a collaborative network and interactive conversations. This goal should be shared and understood by all members of the planning group.
  - The planning group oversees all the functions of the CBPR. This includes:
    - Establishing a full planning group with all members integrated in the process. This means all members are involved in the planning process to ensure strong and meaningful research.
    - Providing input and expertise from one's own experiences and observations. Encourage all participants to share their story, background, or ideas as far as they are comfortable.
    - Seeking local organizations and groups that could provide further information and help. This includes inviting specialized speakers to the collaboration. Attempt to make long lasting and fruitful partnerships with local groups to help support the efforts of the CBPR.
    - Schedule consistent and engaging face-to-face or virtual meetings to facilitate the sharing of ideas and plans.
    - Finding ways to ensure attendance at the collaborations. Discover any barriers that could prevent group members from attending. For example, participants might struggle attending face-to-face meetings without transportation.



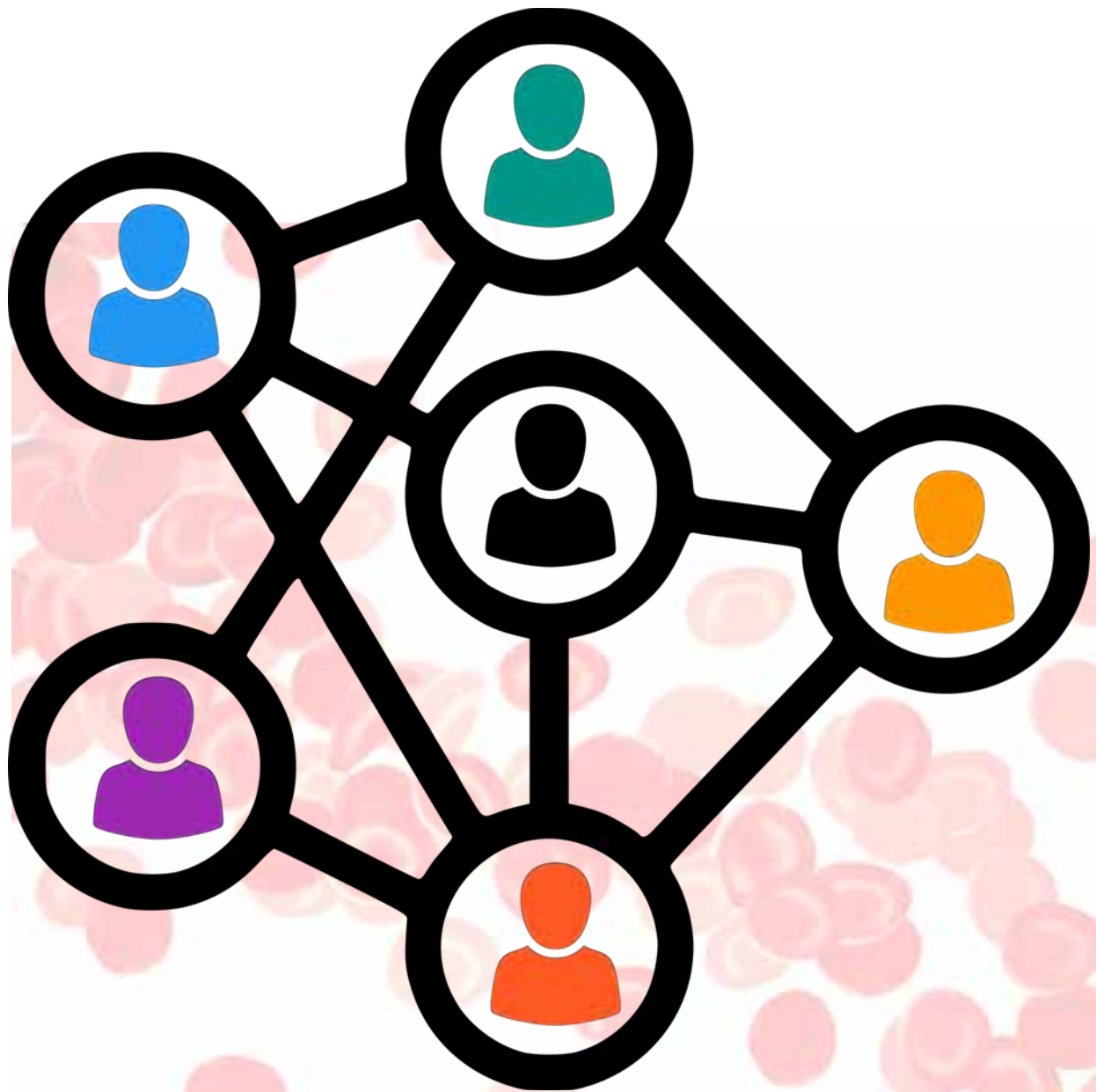
- Steps:

1. Start with the sponsoring organization. They will serve as the foundational leadership for the planning group.
2. Select invested members from the community to join the planning group. Delegate responsibilities to group members based on their areas of expertise.
3. Create consistent and accessible meetings for the planning group members to discuss and plan for the collaborative conversations. The use of timely and regular communication between planning group member can help to avoid scheduling conflicts
4. Create a realistic and adjustable timetable for the project. Scheduled meetings should occur routinely with plenty of notice. During meetings, plan or discuss the upcoming meetings to ensure all members are aware and prepared to meet again.
5. Consistently discuss and document the goals and objectives. Ensure that all members of the planning group understand the importance of the work and how it could benefit those with sickle cell disease in the community.



## **PREPARING AND BUILDING A COLLABORATIVE NETWORK**

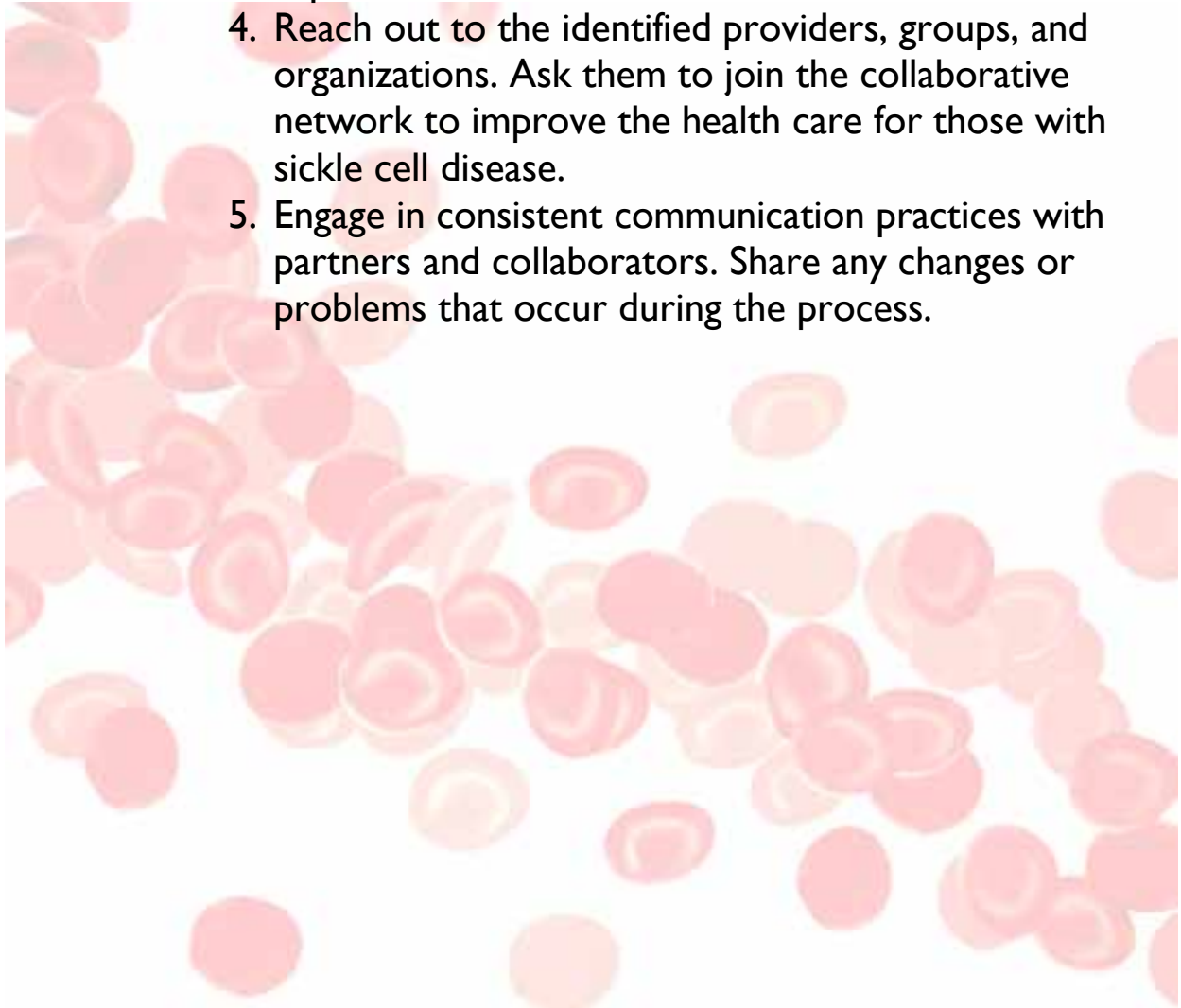
- The collaborative network provides a larger extension of community partners that can work to improve the lives of those with sickle cell disease.
- The planning group invites partners to join the collaborative network. Members of the collaborative network are invited to participate in the collaborative conversations and share their knowledge and experiences.
- Community partners could include local businesses, churches, government officials, hospitals/providers, schools/colleges, or any other organizations. These partners could provide further insights during the collaborative conversations and perhaps unconventional collaborations with these groups could improve the health and healthcare for those with sickle cell disease.
- These unconventional partnerships will hopefully identify and address the physical, social, and mental factors that effect of the health of those with sickle cell disease.
- The overall goals of a collaborative network include:
  - Increased communication and cooperation between groups and organizations.
  - The sharing of local resources designed to help the sickle cell community.
  - Improved sickle cell knowledge base in the community to dispel biases of sickle cell disease.
  - The creation of long-lasting and beneficial partnerships between local groups and organizations.



- Steps:
  1. Once the planning group is mostly complete and organized, the process of creating a collaborative network can begin.
  2. Consult with the planning group to determine topics to discuss during collaborative conversations. Focus on topics that are currently unaddressed or underutilized in the sickle cell community. Topics could include

mental health, education, employment, disability benefits, bias, vaccination, etc.

3. Consider community providers, groups, or organizations that might be able to address the above topics.
4. Reach out to the identified providers, groups, and organizations. Ask them to join the collaborative network to improve the health care for those with sickle cell disease.
5. Engage in consistent communication practices with partners and collaborators. Share any changes or problems that occur during the process.



## **COLLABORATIVE CONVERSATIONS MEETINGS**





- Following extensive preparations by the planning group to build the collaborative network, the collaborative conversations process can begin.
- The collaborative conversations are an opportunity to connect invested community members and the community partners. All involved members of the collaborative conversations are invited to share their experiences and learn from the experiences of others from their community.
- The goals of the collaborative conversations:
  - Increased awareness of sickle cell disease in the community.
  - Understanding the social, physical, and environmental factors that affect those with sickle cell disease in the specific community. Each of these factors can have a large impact on the health and wellbeing of those with sickle cell disease.
  - Giving a voice to those with sickle cell disease to share their story. Chronic conditions can sometimes make one feel powerless, but this process gives those with sickle cell disease an opportunity to voice their story to help others with sickle cell disease. In a way, this process helps them to have more control over how sickle cell disease affects their community.
  - Gaining insights from different perspectives in the community. All communities cannot be generalized together. What affects one community may not affect all communities. This community learning process allows for a specific understanding of the problems and perspectives of an individual sickle cell community.
  - Be further educated on topics centered on sickle cell disease. Community experts on topics such as mental health or employment can share their knowledge of programs and resources that could benefit those with sickle cell disease.

- Steps:

1. After a collaborative network has been created, the planning group can start preparing for collaborative conversations meetings. Determine whether the collaborative conversations meetings will occur face-to-face, virtually, or a mixture of the two.
2. Contact community partners from the collaborative network to determine availability for collaborative conversations.
3. Use the list of topics that was created to find community partners. Select the most important topics from the list and dedicate a collaborative conversation meeting to each topic.
4. Invite community partners to present on a topic that they know well. For example, if a selected topic is mental health, select a community partner that has experience dealing with mental health issues.
5. Invite community members who have sickle cell disease or who care for those with sickle cell disease. Encourage them to share their experiences at the collaborative conversations meetings.
6. Schedule collaborative conversations meetings monthly for a predetermined time. 12-18 months are recommended. Each monthly meeting will have the testimonial of someone with sickle cell disease and it will cover one identified topic or issue.
7. Inform all member of the collaborative network about the collaborative conversations meetings and invite them to join.
8. Work with members of the collaborative network to ensure most members can participate and attend meetings. For face-to-face meetings, arrange timely transportation for members. For virtual meetings,

ensure internet connectivity and help set up devices that can be used for a virtual meeting.

9. Format collaborative conversations meetings. Typical meeting format in order includes an introduction, overview of the agenda for meeting, speaker living with sickle cell disease describes their experiences, community partner speaker discusses the identified topic or issue, questions for speakers, and finally a quick conclusion detailing the time and place of the next collaborative conversations meeting.
10. Each month, assist the invited speakers prepare for their part in the collaborative conversation.
11. Hold the meetings and help to smoothly guide participants through each item on the agenda.
12. Ask for feedback from participants at the end of each meeting. This can help improve the planning and structure for following meetings. For example, feedback might show that some participants felt uncomfortable joining the conversation. Thus, some changes might be needed in future meetings to facilitate conversations between all participants.

## Wrapping Up and Sustainability



- For this project, sustainability is the process of keeping collaborative partners and members continually invested and informed throughout the process. Any changes or unexpected problems encountered during the project should be communicated to every member.
- Meeting reminders and overall progress updates should be consistently sent to all members.
- Meeting feedback should be taken very seriously. This can help to ensure all meeting participants understand the material presented during meetings. Important topics can be revisited if there is still confusion. The overall goal of feedback is to improve the collaborative conversations process so that all participants can be involved at every stage of the process.
- The collaborative conversations meetings were a way to engage and involve the community on improving care for sickle cell disease. The wrapping up process involves the creation of actionable plans based on the experiences of community members

and the guidance of community experts. Information gained through these collaborative conversations can provide a great foundational base for potential interventions and programs targeting sickle cell disease.

- Successes and insights from the collaborative conversations should be shared with the community.
- Steps for the final stages of the project:
  1. Following the final collaborative conversation meeting, begin to reflect on the experience and the knowledge that was learned during the meetings.
  2. Ask for feedback from all participants. Feedback can ensure that the whole collaborative conversations process went as intended. This information can also be helpful when designing and implementing future collaborative projects.
  3. Schedule meeting(s) with all members of the collaborative network. The final meeting(s) involves a brainstorming session where members will discuss what they learned during the collaborative conversations.
  4. Encourage meeting attendance and work to accommodate all participants. As with earlier meetings, communicate with members to ensure all transportation or technology needs are met to join the meeting.
  5. Invite a keynote speaker to discuss the importance of this process. This speaker should be someone intimately familiar with the collaborative conversations process.
  6. During the meeting(s), discuss potential actionable plans or projects that could benefit those with sickle cell disease in the community. These actionable plans should be based on the recommendations and



experiences of the collaborative network and community members.

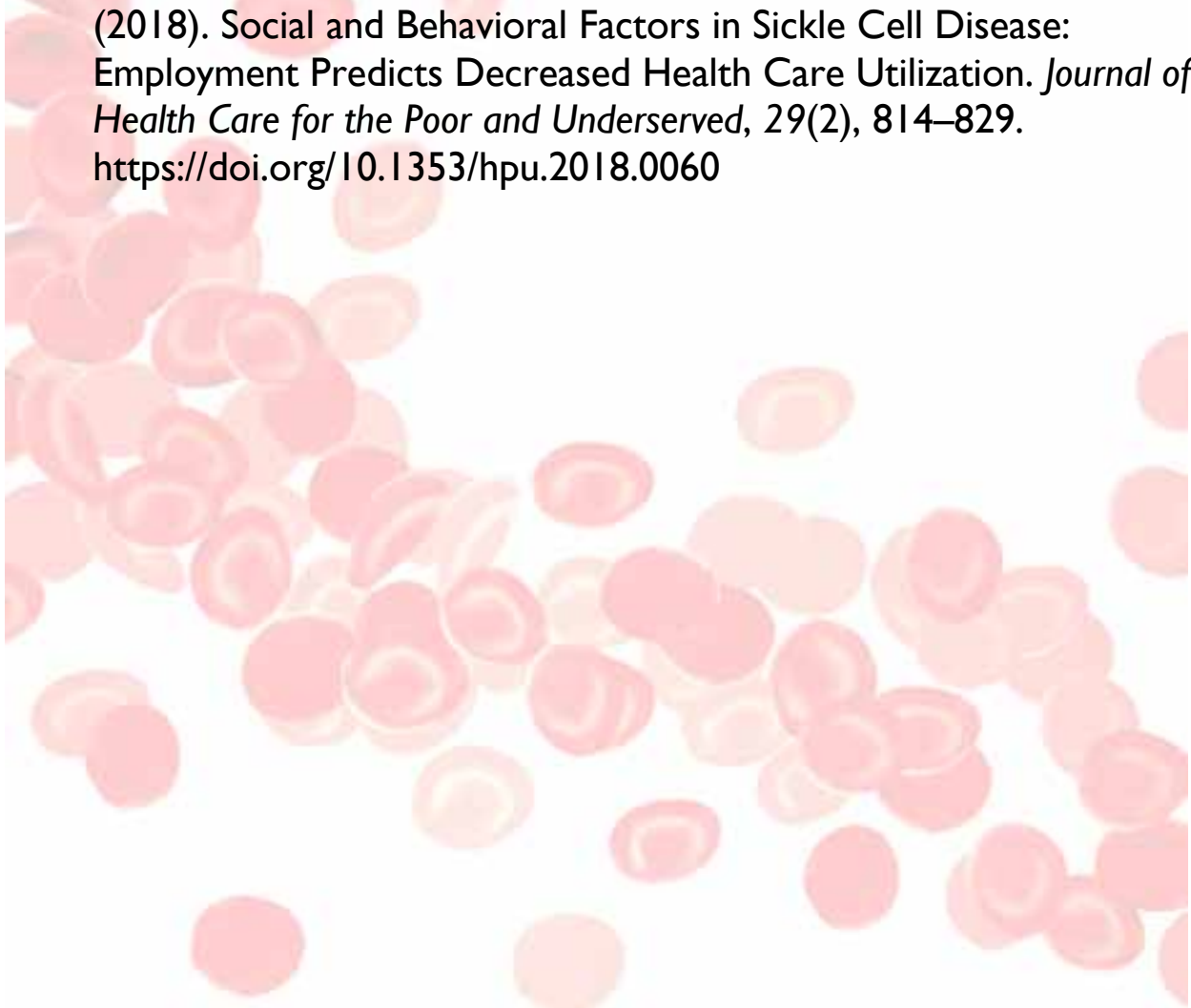
7. Work with the collaborative network to initiate the community plans and projects discussed.
8. Share all accomplishments and new insights with the community

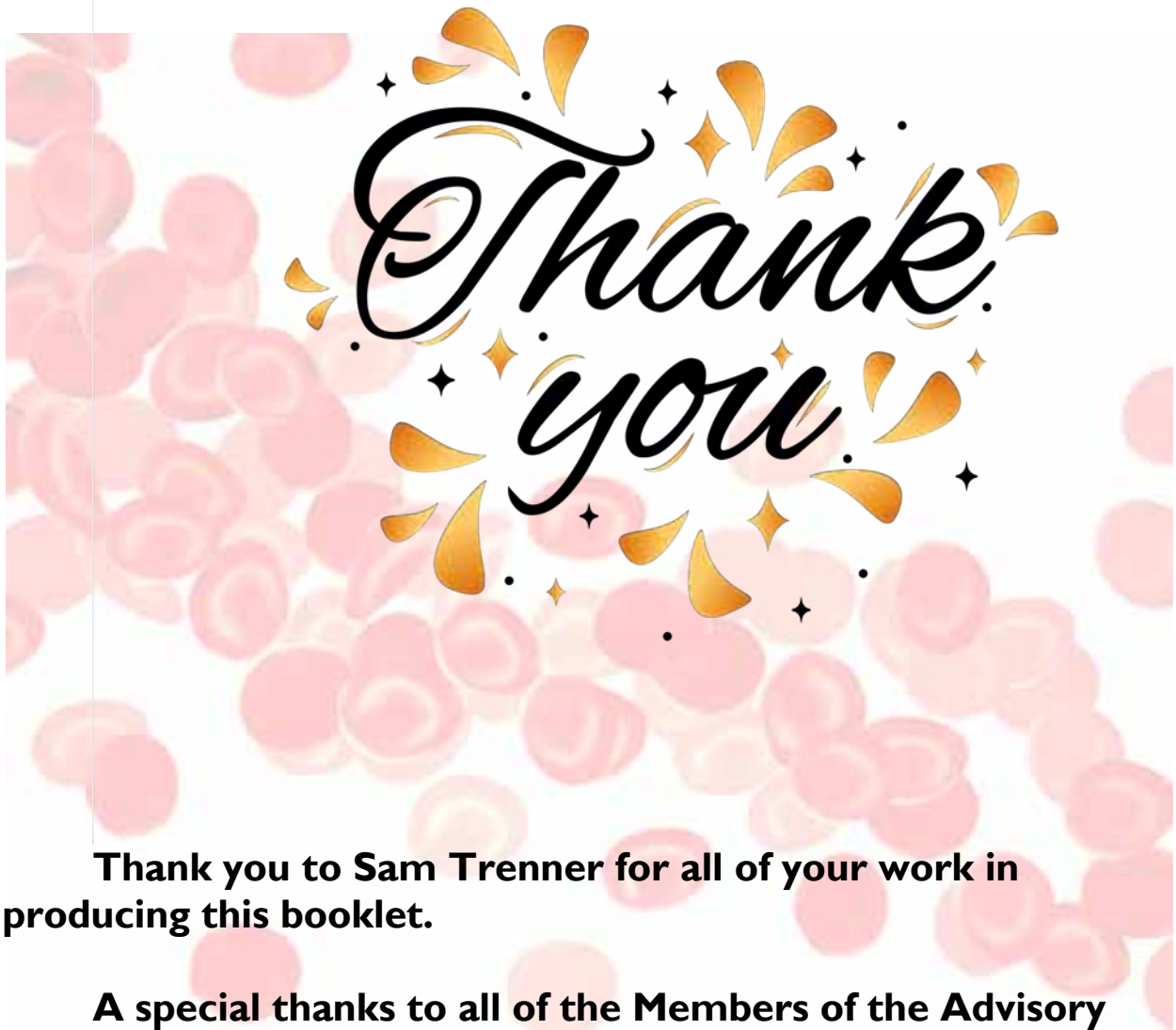


## REFERENCES

- Bailey, Z. D., Feldman, J. M., & Bassett, M. T. (2021). How Structural Racism Works—Racist Policies as a Root Cause of U.S. Racial Health Inequities. *New England Journal of Medicine*, 384(8), 768–773. <https://doi.org/10.1056/NEJMms2025396>
- Hassell, K. L. (2010). Population Estimates of Sickle Cell Disease in the U.S. *American Journal of Preventive Medicine*, 38(4, Supplement), S512–S521. <https://doi.org/10.1016/j.amepre.2009.12.022>
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). REVIEW OF COMMUNITY-BASED RESEARCH: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health*, 19(1), 173–202. <https://doi.org/10.1146/annurev.publhealth.19.1.173>
- Lee, L., Smith-Whitley, K., Banks, S., & Puckrein, G. (2019). Reducing Health Care Disparities in Sickle Cell Disease: A Review. *Public Health Reports*, 134(6), 599–607. <https://doi.org/10.1177/0033354919881438>
- Power-Hays, A., Li, S., Mensah, A., & Sobota, A. (2020). Universal screening for social determinants of health in pediatric sickle cell disease: A quality-improvement initiative. *Pediatric Blood & Cancer*, 67(1), e28006. <https://doi.org/10.1002/pbc.28006>
- Power-Hays, A., & McGann, P. T. (2020). When Actions Speak Louder Than Words—Racism and Sickle Cell Disease. *New England Journal of Medicine*, 383(20), 1902–1903. <https://doi.org/10.1056/NEJMp2022125>

- Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *The Lancet*, 376(9757), 2018–2031.  
[https://doi.org/10.1016/S0140-6736\(10\)61029-X](https://doi.org/10.1016/S0140-6736(10)61029-X)
- Williams, H., Silva, S., Cline, D., Freiermuth, C., & Tanabe, P. (2018). Social and Behavioral Factors in Sickle Cell Disease: Employment Predicts Decreased Health Care Utilization. *Journal of Health Care for the Poor and Underserved*, 29(2), 814–829.  
<https://doi.org/10.1353/hpu.2018.0060>





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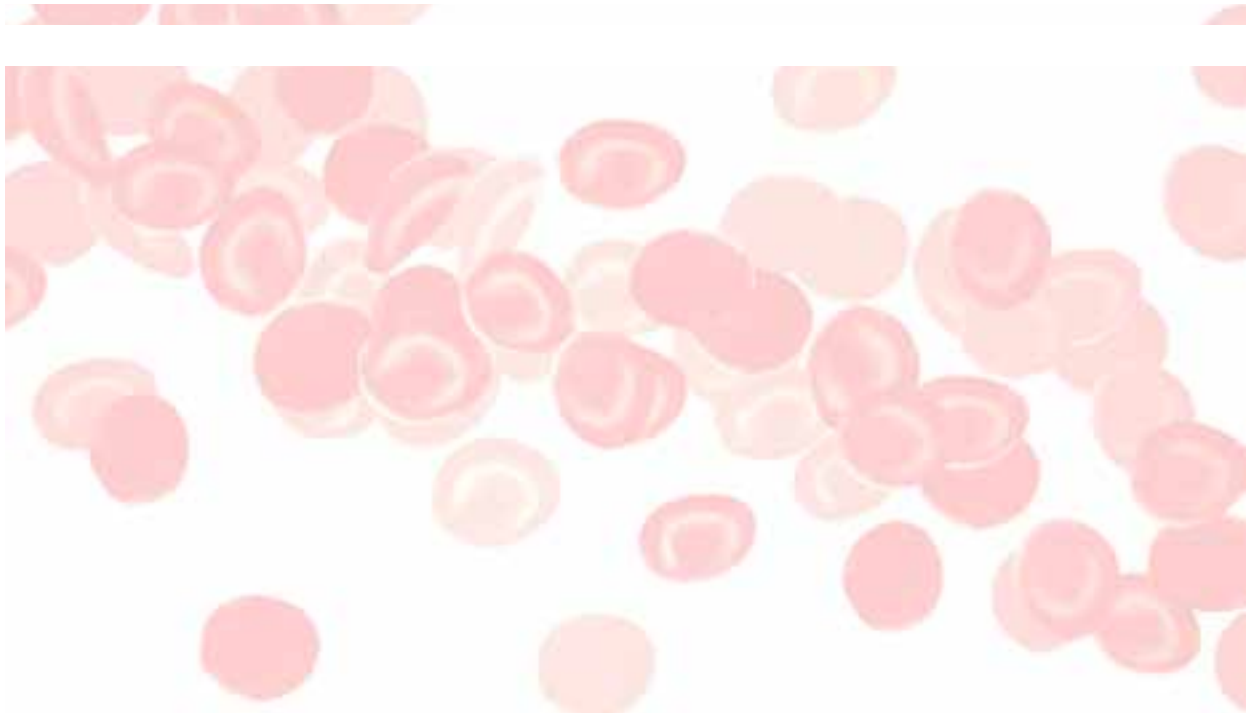
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