How Sickle Cell Disease Research Helps Reduce Bias

Within the SCD community, people living with Sickle Cell Disease–also known as Sickle Cell Warriors–often report racism and disease-related stigma in hospitals a nd clinics, because bias exists. They know this reality all too well:

- Being in pain but not being believed.
- Being labeled before being heard.

The Reality for People Living with Sickle Cell Disease (SCD)

Sickle Cell Disease is often misunderstood by healthcare providers, leading to pain being minimized over and over again. This behavior invalidates a person's experience, leaving them feeling unseen and unworthy. When bias overrides clinical judgment, treatment is delayed–and in SCD, delay can mean organ damage, infection, or even death.

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How Bias Can Show Up

- Harmful myths and stereotypes
- Assuming people with SCD exaggerate their symptoms because of their race
- Thinking SCD only affects one racial group, which leads to missed diagnoses in other communities
- Doubting patients' pain, leading providers to not follow approved pain guidelines or an individual's pain care plan
- Seeing SCD Warriors in pain as "drug seekers", or thinking patients don't "look sick enough" to be in pain, leading to their symptoms being ignored or dismissed
- Using research tools, surveys, or questions that don't match people's language, culture, or daily experiences, leading to misunderstandings or missed information
- Overlooking barriers to participation
- Designing studies that don't consider the real barriers people with SCD face, like transportation, time off work, or child care needs
- Not sharing study results with participants or their communities

Bias in healthcare is not just frustrating, it can be life-threatening!

Changing the Story Through Research

Clinical research–when done right–is a powerful tool to uncover and fix these harms. Inclusive and equitable research can change how Warriors are seen and how compassion is needed in their treatment.
By including Sickle Cell Warriors, their guardians, and community health worker advocates as partners, not just participants:

- Data reflects real lives.
- Treatment improves.
- The system changes from the inside out.

Equity Begins with Listening

When people living with SCD are seen, heard, and included in research, we move toward a future where care is informed, compassionate, and built on a healthcare system that truly listens.

A note about this resource

This resource was co-created with members of our SCD National Community Advisory Board (NCAB). Learn more about how the NCAB is shaping the future of SCD research and care across the ASH Research Collaborative® (ASH RC) Network.

The ASH RC created CABs so you can learn about the research happening in Sickle Cell and help shape it. CAB members are individuals living with SCD, parents, partners, caregivers, advocates, and community organizations, each bringing vital perspectives to the table.

As a CAB member, you join a supportive community working to make sure research reflects the needs, voices, and values of those most affected. You'll also be part of something bigger: a movement to center the SCD Community voice in research. Your insights help ensure that research remains grounded in lived experience. Together, we can improve the lives of those most affected by SCD.

Interested in joining a local CAB in our Network?
Contact us

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