From Idea to Impact:
The Lifecycle of a Clinical Study

Clinical studies don't just happen–they follow a regulated process designed to protect participants, make research meaningful, and share results that lead to better care.

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It All Starts with a Question

And often, this question comes from the community:

1. A parent notices a problem that isn't being addressed,
2. Individuals living with Sickle Cell Disease raise new concerns,
3. Gaps in treatment become clear.

That's how research begins, when lived experience meets a desire to improve care.

From Question to Study

From there, researchers write what's called a protocol–a detailed plan for how the study will work. Before anything begins, this protocol is reviewed by an Institutional Review Board. This IRB is an independent group of individuals that ensures the study is ethical, fair, and safe. Depending on the type of study, more than one IRB may review the study plan and progress to ensure participants are protected. Only once it's approved, can the study start.

During the Study

People join as participants knowing their rights–and feeling supported every step of the way. That means you can:

- Ask questions whenever you need.
- Get updates along the way.
- Leave the study at any time if you choose.

Meanwhile, data is collected with care, and the research team keeps a close eye on everything, making sure the protocol is followed and safety always stays front and center.

After the Study

Researchers review the data to understand what it says: Did the treatment work? Who did it help? Were there side effects? This takes time to get right.

Results are shared not just in journals or conferences, but also with you. Because if you joined a study, you deserve to know how your contribution made a difference.

The Lasting Impact

Even after a study ends, its impact lives on—shaping future research, guiding new treatments, and improving care for generations. Research isn't just data—it's your story, a partnership, and a path to positive change.

Together, we can make that change and improve lives.

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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