



The purpose of the Sickle Cell Disease Implementation Consortium (SCDIC) is to use implementation science to **identify and address barriers to quality care in sickle cell disease (SCD)**.

The SCDIC seeks to understand **how and why individuals with SCD become unaffiliated** from SCD care. We hope to figure out strategies to connect with individuals to help them find a specialty doctor. We used a Delphi consensus process to develop a definition of someone with SCD who is “unaffiliated” from SCD care.



An individual with sickle cell disease who is unaffiliated from care is someone who has not been seen by any sickle cell specialist in at least a year.

A sickle cell specialist

is someone who meets the following criteria:

- is knowledgeable of the 2014 NIH Guidelines, “Evidence-Based Management of SCD”
- is trained in hydroxyurea management and transfusions
- is trained on screening for organ damage in SCD
- is aware of psychosocial and cognitive issues in SCD
- has experience working with SCD patients
- has received training in pain management and on SCD emergencies
- attends SCD conferences regularly
- has been mentored by an SCD specialist
- obtains continuing medical education on SCD every 2 years

Delphi Study Participants

Our results were based on the expertise of SCD practitioners. The Delphi process is a process of arriving at consensus by providing participants with rounds of questionnaires, as well as the group response before each subsequent round.



65%
SCD-focused researchers



60%
providers



30%
worked on developing SCD care guidelines



68%
spent more than 50% of their time caring for patients with SCD

For more information, please check out <https://scdic.rti.org/>.

The SCDIC, which has been funded by the National Heart, Lung, and Blood Institute since 2016, includes the Data Coordinating Center at RTI International and 8 participating centers: Augusta University, Duke University, Icahn School of Medicine at Mt. Sinai, Medical University of South Carolina, St. Jude Children’s Research Hospital, UCSF Benioff Children’s Hospital Oakland, University of Illinois at Chicago, and Washington University School of Medicine in St. Louis.

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