

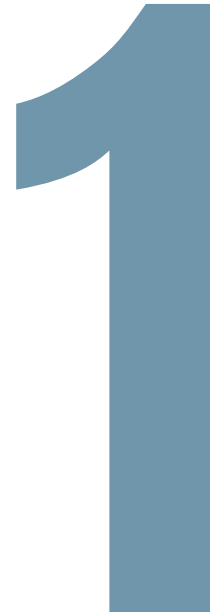
# Privacy in Research

Joining clinical research can improve care, help people living with sickle cell disease, and lead to new treatments. Privacy and confidentiality are guided by health agencies like the U.S. Department of Health and Human Services (HHS), the National Institutes of Health (NIH), and the International Council for Harmonization (ICH). These agencies set rules and provide guidance on protecting human subjects and research design.

These are some key points about your privacy protection:



**Your choice to join is always voluntary, and you can leave at any time without losing benefits.**



## **Informed Consent**

Before research starts, the study team creates an informed consent document that explains the purpose of the research, how long it lasts, risks and benefits, study procedures, who to contact, and any compensation. An ethics committee or institutional review board (IRB) reviews and approves this document to meet ethical and legal standards. Researchers will explain how your personal information and research results will be collected and used. You will sign a consent form to show you understand and agree.

# Protecting Your Identity

Researchers take steps to protect your identity by removing or hiding personal details from your data—a process known as de-identification, data masking, or anonymization. These are some ways your identity is protected

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## Removal of Personal Details

Personal details like your name, address, phone number, and social security number are removed from the data.

## Data Masking

Your data is given a unique code instead of personal identifiers like your social security number, making it difficult to trace back to you.

## Combining Data

Data points are combined into larger categories or groups. For instance, instead of showing an exact age, data might indicate an age range.

## Generalization of Information

Detailed information is made more general. For example, exact dates might become time frames, or specific locations could be reported as regions.

## 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.

Interested in joining a local CAB in our Network? [Contact us](#)

As a member of one of our local CABs, you'll join a supportive group of people who understand what it's like to live with and care for someone with SCD. We invite you to share your experiences and discover the innovative clinical research being conducted in our Network that's transforming SCD care. Together, we can improve lives of those most affected by SCD.



## Securing Your Data

Your data is protected using different types of security measures, such as encryption, which converts your data into a secure code that requires special access. Federal guidelines require researchers to secure your data to prevent unauthorized access. Regular inspections and security checks help ensure that data remains safe throughout the research process.



## Transparency in Research

Your privacy matters. Your clinical care team and researchers are committed to protecting the confidentiality of your health information and data. As a participant, you have the right to know what data is collected, how it will be used, and who will have access to it. You can ask questions at any time about your data protection. If you feel uncomfortable or change your mind about participating, you can leave the study without affecting your regular medical care.

Privacy is key to ethical clinical research and builds trust. Ensuring research participants are well-informed, respected, and protected is essential for successful research. Knowing your data is handled with care can give you confidence in your decision to participate.