

# The Power of Choice

Respecting your right to choose is fundamental in ethical research. The International Council for Harmonization's Good Clinical Practice (ICH GCP) guidelines and the Office for Human Research Protections (OHRP) emphasize the importance of informed consent and voluntary participation.



## Informed Consent

Informed consent means that you fully understand what joining a study involves. Before making a decision, researchers will provide you with detailed information about the study's purpose, procedures, risks, and benefits. This information should be clear and easy to understand, and you are encouraged to ask questions to help you decide. You can also request more time to think about whether the study is right for you.



## Voluntary Participation

Your participation is entirely voluntary. You have the right to decide whether to join, and you can leave at any time without any penalty or loss of benefits. Your decision to join, stay, or leave will always be respected and honored. Both ICH GCP and OHRP guidelines highlight the importance of respecting your decision.

## The Power of Choice

The impact of your choice extends beyond the study itself. Your participation can lead to breakthroughs in medical treatments and improve the quality of life for others with similar conditions. Each participant provides valuable information that helps researchers better understand diseases and develop more effective treatments. Your decision to participate can truly make a difference.

The power of choice in clinical research lies in your hands. Understanding your rights and the potential impact of your participation can help you make an informed decision.

## 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.

