MRCT CENTER
THE MULTI-REGIONAL CLINICAL TRIALS CENTER OF BRIGHAM AND WOMEN'S HOSPITAL AND HARVARD

What is... Data Sharing and Data Privacy?

Researchers have a responsibility to **protect your privacy** when you participate in research.

Let's look at what researchers *can* and *can't* do with your data.

Privacy means ***protecting*** participants' information.

Know Your Vocab!
click here to open the cheat sheet

So, how do researchers protect my privacy?

Researchers separate your data– like your temperature taken at a study visit or survey answers– from the specific information that identifies you, like your name and home address.

Some studies ***share data*** with other researchers, but they won't share who you are, your "identity."

Why do researchers share data?

When researchers share their data, other scientists can **double-check their findings**, **build on their work** (and not have to start from the beginning), and **make discoveries** that no individual research team could make on their own.

They are only allowed to share your data with **specific people** for **specific reasons**.

What can *those* researchers do with my data?

All researchers who have access to your data follow the same rules to protect your privacy.

This means they only **share** your data with others who have permission to see or use your data.

They should also only **use** your data in the specific way they said they would.

Talk to the research team if you think someone has seen or used your data without the proper permission.

You should feel comfortable asking researchers any other **questions** you might have, like:

- Who will see my data?
- How will I know if someone has seen my data?
- Who will you share my data with?
- Why is it helpful to share my data with other researchers?
- How will you protect my privacy?

Ask any questions you have!

Questions?

You have the right to know!

You can learn more at:

mrctcenter.org/for-kids

www.icanresearch.org
ICAN Approved
International Children's Advisory Network

© 2026 MRCT Center CC BY-NC-SA 4.0 license