

SHARING YOUR INFORMATION (DATA) IN RESEARCH

A guide for young people.

Researchers collect information about you when you are in a research study.

Researchers may ask questions, look at medical records, get test results from a blood sample, look at patient information from journals or apps, or gather information in other ways. Researchers may call your information **'data.'**

Data is just another word for information. Your height, temperature, blood test results, and answers to a survey are examples of data.



Will I benefit from sharing my data with researchers?

Researchers use data to learn new things and help people in the future. You may not directly benefit, but others might.



Why do researchers collect data?

Researchers use data to answer questions about health and illness. They often combine your data with other people's data to answer their questions.

Some research studies share data with other researchers. They will not share who you are, your "identity."



What are the risks of sharing my data?

There is a small risk that:

- someone sees your data when they aren't supposed to.
- someone connects your data with you when they aren't supposed to.

Researchers follow rules to make sure this is unlikely to happen.

How do researchers protect my privacy?

Researchers separate your data from the specific information that identifies you, like your name and home address.

Talk to the research team if you are worried that someone has seen or used your data when they aren't supposed to.

Can I see my data?

Each research study is different. It might depend on the type of data that's collected. You can always ask the researchers.

We hope this information has been helpful. You should feel comfortable asking researchers any other questions you might have, like:

What information are you collecting from me?

Will I see my data and study results?

Who will see my data?

How long will you keep my data?

Will I benefit from sharing my data?

How will I know if someone has seen my data?



Scan this QR code to view your rights as a research participant

