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

What is... **Information (Data) in Research?**

Know Your Vocab!
click here to open the cheat sheet

Data is just another word for *information*.

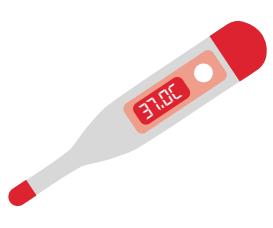


When you agree to participate in a research study, **you are agreeing to share information (data)** with the researcher.

There are many **different types of data**.

Some types of data that researchers might collect about you in a research study include:

Temperature



Survey Answers



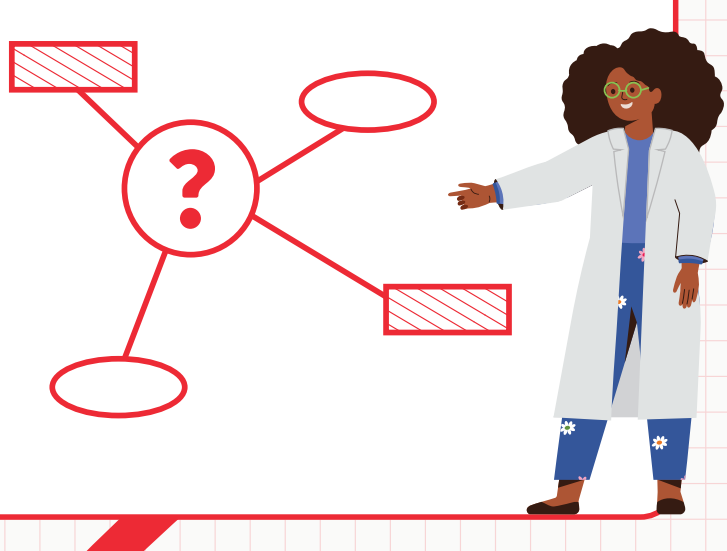
Height



The types of data collected *depend on the study*.

Researchers use data to learn about health, illness, how a new medicine is working, and more.

They often combine your data with other people's to answer their questions.



Will I benefit from sharing my data?

You may or may not benefit directly.

But, researchers use data to learn new things and help people in the future.

What are the risks of sharing my data?

There's a small risk that:

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

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

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.



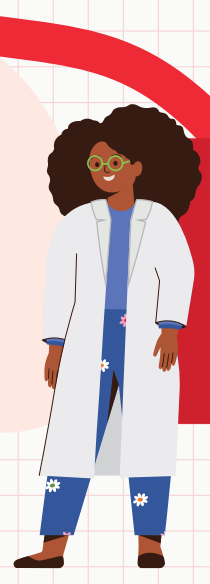
You should feel comfortable asking researchers any other **questions** you might have, like:

- Who will see my data?
- How will I know if someone has seen my data?
- How long will you keep my data?
- What information are you collecting about me?
- Will I see my data and study results?

Ask any questions you have!

Questions?





You have the right to know!

You can learn more at:

mrctcenter.org/for-kids

ICAN Approved
www.icancancer.org
Institute for Cancer Advocacy and Networking

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