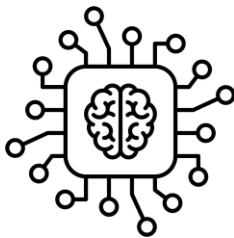


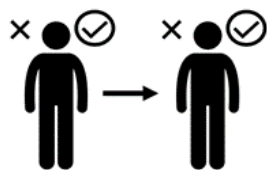
Research Words



Adverse event: When someone is hurt in research in a way you weren't expecting them to be hurt.



Artificial intelligence (AI) is a type of technology that uses a lot of information to create new things. For example, AI can create a summary of information or write an email.

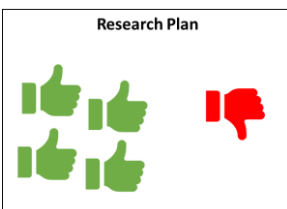


Guardian Participant

Assent: Someone with a legally authorized representative (LAR) saying or showing with their body that they want to be in a research study.



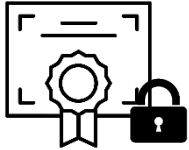
Authors: People who share about a research study and are responsible for the research.



Beneficence: Making research have as many good outcomes as possible and keeping people as safe as possible.



A **biobank** is a safe place to store people's samples collected for a research study. Samples could include spit and blood, hair, or something else from their body.



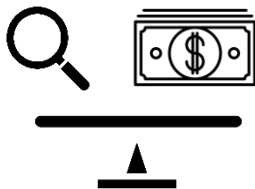
A **Certificate of Confidentiality** says that private research information can't be used in any federal, state, or local court case or legal action.



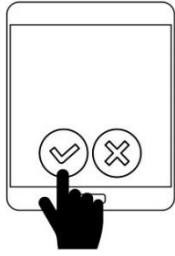
Clinical trials are research on treatments, medicines or programs. In clinical trials, people try the treatment, medicine or program and researchers see if it improves their health.



Community-engaged research: When people who work at universities and people from the community do research together.



Conflict of interest: When someone doing the research has circumstances that might change how they do the research in bad ways

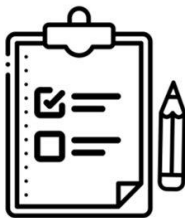


Consent: When someone says yes to being in the study.



Consent capacity: Someone's ability to make their own decision about being in a research study.

Data: Information researchers collect to answer a research question.



Examples of data are:

- Information about people on surveys or in interviews (for example, what they like to eat, how they exercise)
- Blood, urine or saliva samples so that genes can be studied
- Lab tests done to check signs of health like cholesterol and blood sugar levels
- Medical records (information about health conditions or medical treatments)



A **data repository** is a safe place to electronically store research data.

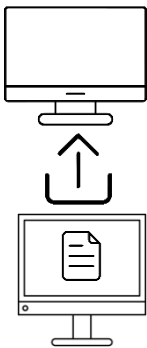


Data Safety Monitoring Board or Data Safety Monitoring Committee is a group of people who are not part of the research team that checks how a study is going.

The Board of Committee checks to make sure the participants are staying safe.

Data Safety Monitoring Board is also called the DSMB.

The Data Safety Monitoring Committee is also called the DSMC.



Data sharing is sharing research information with other researchers so they can use the information to answer new research questions.



Dissent: When someone decides they do not want to be in a research study.



DNA are the instructions for building your body.



Educational records are information schools keep about students, like their grades, test scores, and services.



Eligibility criteria: A list of experiences and characteristics that people need to be in a research study.

Eligibility criteria might include age, where someone lives, or having a specific health condition.



Exclusion criteria: The experiences and characteristics of people who can **not** be in a study.



The Food and Drug Administration or FDA has rules about doing research on new things that could impact bodies and improve health.

FDA rules are about what to do in emergency situations, what people need to be told about a research study, and what information about the study must be shared with the FDA.



FERPA is a law in the United States.

FERPA is about keeping student's educational records confidential.

FERPA has rules about what schools can or can't share from educational records.



GINA is a law in the United States.

GINA says you can't be treated differently by employers and health insurance companies based on your genetic information.

Health records are information doctor's keep about a patient's health and medical history.



Health records include information like a patient's height, health conditions, treatments and test results.

Health records are also called medical records.

HIPAA is a law in the United States.



HIPAA is about keeping people's health records confidential.

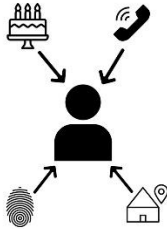
HIPAA has rules for who can see health records and how health records can be used.



Impaired decision-making capacity is when someone can't understand information well enough to make a certain decision.

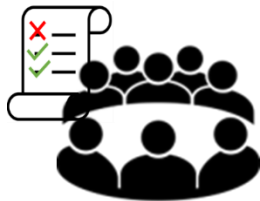


Inclusion criteria: The experiences and characteristics people need to be in a study.



Individually identifiable data: Information researchers collect during research about a participant that can tell them who a person is.

Examples: Name, Address, Birthday



Institutional Review Boards (IRBs): Groups of people who make sure researchers protect people's rights and well-being.



Justice: Making sure all types of people can be in research and that everyone shares the good and bad things that can happen in research.

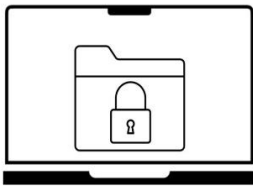


Mandatory reporting: If researchers learn that a research participant is being hurt or abused, they have to share the information with authorities (people who can stop other people from being hurt). Researchers also have to share information if they find out a research participant is hurting or abusing someone else.



Plagiarism is taking someone else's words and ideas without giving them credit.

Plagiarism is not ok because it is stealing someone else's ideas and words.



Privacy and confidentiality: Keeping research participants' information (data) safe so other people don't have research participants' information.



Recruitment: Finding people to be in a research study.



Research benefits: Good things that come from research studies. Research benefits can be for the person in the research study or for other people in the future.



Research Ethics: The rules researchers follow to do the right thing, take care of people, and respect people's rights.



Research harms and risks: Something bad that can happen during research to people who are in

research. Examples include hurting someone's body or feeling sad.

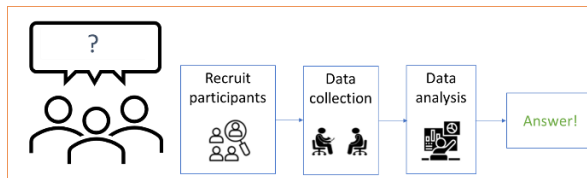


Respect for persons: Believing that everyone can make decisions on their own or with support.

Respect for persons also means taking extra care of people who have a hard time making decisions.



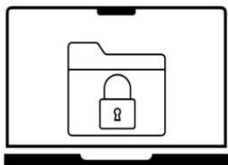
Research participants: The people in a research study.



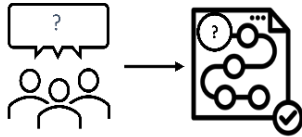
Research protocol: A plan for how to do a research study.



Return of results is when research participants learn new information about their health or health problems they might have in the future.



Safeguards: The things researchers do or use to keep people safe in research.



Scientific research: Asking a question and using a step by step process to collect information to answer the question.



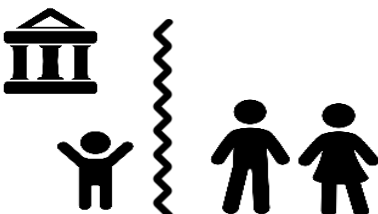
People who are **vulnerable** may not be able to make their own decision because:

- They can't understand the information
- They might not be able to tell someone their decision
- Other people might influence their decisions

They also might get hurt by research more easily than other people.



Voluntary: Making a choice, without anyone pressuring you.



Children who do not have their parents or family as their guardians are **wards of the state**.

Citation: McDonald, K. & Schwartz, A. (2026). *Research Ethics for All: Accessible Research Ethics Education for Community Research Partners*. Syracuse University, Institute on Disability: University of New Hampshire. [www.re4all.org]

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