

Topic 3.3: Consent: Working with people as they make decisions about being in research

Once you have invited people to be in your study and figured out that they are eligible to be in it, you need to work with them on making a decision about being in your research study. This unit is all about how to treat people well when they are making decisions about being in research.

Topic 3.3.1: Main ideas of consent: informed, voluntary, and ongoing.

Like we talked about before, people have the right to know information about a study, make their own choice about being in a research study without pressure from other people, and, if they want, get support when making decisions about being in a research study. We call this decision-making process **consent**.

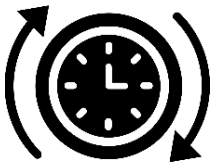
Consent to research participation means a person making an **informed, voluntary, and ongoing choice**.



- **Informed** means that people have all of the information they need to be in a study.



- **Voluntary** means making your own choice without pressure from others.



- **Ongoing** means that researchers check for consent from the beginning to the end of the study.

One of your roles in your research team may be to help plan how your team will ask for consent. You can share your ideas about:

- how to make information easy to understand,
- how to make sure people can make their own choices, and
- what to look for to see if people have changed their mind about being in the study.

This is an important responsibility!



Consent can happen in different ways. Sometimes people will learn about a study on their own (like from a website) and make a decision. Sometimes, researchers give people the choice to be in a study during a consent meeting—a meeting where someone learns more about the research and decides if they want to be in it or not. Sometimes these meetings are one-on-one, and other times they are in a group.

After the meeting, a person may say they want more time to think about their decision. They can:

- Say “yes, I want to be in the study”
- Sign their name to a consent document
- Click “yes I agree to be in the study”
- They may make their “mark” to sign their name. Sometimes not signing a full name is an accommodation for participants.
- They may also decide that they do not want to be in the study and say “no.”



Dissent is when someone decides they do not want to be in a research study.