

## Topic 3.4: Consent Capacity

In this unit you will learn about people’s abilities to make their own decisions and how sometimes people need help to make research decisions.



Having the ability to make your own research decision is called **consent capacity**. Often, we assume people can make their own choice—and have consent capacity.



Sometimes researchers check to see if the person understands the important information about a research study like the good and bad things that might happen, what they will be asked to do, and their right to say no to being in the study.

Researchers may check for someone’s ability to make a decision when a research study has a higher chance of hurting someone or includes people or groups who may be more likely to be hurt in research. How much researchers need a person to understand about the study may depend on what kind of good and bad things might happen if they are in the study. It is important to have a good reason to check consent capacity. Remember what we said before that a label alone may not be a good reason!



For example, we know that people with developmental disabilities are able to say no to being in a research study, especially when it involves things that might hurt them or feels too personal.

We also know they can understand information about a research study and that they may be harmed if they are excluded or if someone else makes a decision for them.

And we know we can improve consent capacity by helping people understand information and removing pressure. Consent capacity can change depending on how someone feels, where someone is, or who is around.

For example, if someone is not feeling well, they may have a hard time understanding all of the information researchers share. They might want to make a quick decision, because they are so overwhelmed with the information. On another day, they might be able to make a better decision for themselves.

Another example is if there are people around who make the person feel pressured. For example, it might be easier for some people to make their own decisions if they aren't worried about disappointing the people who are there.