

Topic 4.2.2: Privacy and Confidentiality when other people are present

Sometimes when we do research, there are other people around. In this unit we'll talk about privacy when there are other people around during the research.



You might also need to think about **privacy and confidentiality** when participants bring someone else with them. This could include a family member or guardian, or someone who is supporting them. For example, some participants need help getting to the place where the research is or need help from other people to use email or video chat.

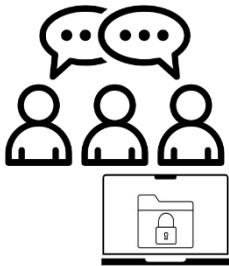


It is important to think about collecting information in ways that their supporter can't overhear if the participant doesn't want them to. You can also talk to the supporter and remind them they shouldn't share what they learn with anyone else.

You can also think about if the support person should sign an agreement saying they won't share the participant's information with other people.

When there is a supporter helping the participant, make sure you still talk directly to the participant. Supporters can sometimes help you figure out the best way to communicate with the participant.

Remember, their job is to help, not to speak for the participant. If you are ever worried about what's happening, take a break or stop the research and talk to your project leader.



If you are gathering information in a group, like a focus group, it is important to tell everyone that the information shared should be kept confidential and not shared with other people outside of the group.

Unfortunately, you can't promise everyone will keep the information confidential.

You also want to be sure you use devices that have passwords and keep paper copies in locked files and locked drawers. If you are bringing information somewhere, your team will make a plan to keep it safe while you travel.

You also need to keep confidentiality and privacy in mind when you share about research. A lot of times, people with disabilities know the other people with disabilities who live near them. That's because they went to school together or have done the same programs or are in the same self-advocacy groups. This can make keeping confidentiality and privacy harder.

For example, if you share information about a specific experience someone had, or name a specific school or workplace, other people might be able to figure out who you are talking about, even if you don't say their name.



When you think this might happen, you can talk to the participants in your research study and ask them for permission to use their exact words, or quotes, and explain that there is a chance that their exact words will make it possible for people reading about the research to figure out who they are. This is one reason it can be a good idea to give participants a chance to review the information they shared and let them take out anything they don't want shared.

Sometimes people will be proud of the contributions they made to research and want their name included with their quotes. It is your job to talk to them about what could happen if you use their name when you share about the research. Your team might also have a rule that you don't ever use participant's names. If your team has this rule, some people might feel like they are not getting credit for what they shared. You can talk to them about why you have this rule, so they understand that your team wants to protect everyone's privacy and confidentiality.

That's a lot! Ok, one more thing that you can do to protect privacy and confidentiality. Your research study may include other ways to keep people safe like a Certificate of Confidentiality. Your project leader will talk to you more about these if you have one.



Mental Health for All Team Talks About Confidentiality



Brendan: We knew from our work at our self-advocacy group how important it is to keep people's information private and confidential. We spent a lot of time talking about how to do that.



Ariel: We sure did! We also had some situations while we were collecting information that made things hard for us.



Micah: First, we worked on our plan to keep information from study participants private and confidential. Once we had our plan, we each signed a piece of paper saying we would follow the plan. I kept this with me to remember all my responsibilities.

Brendan: We also practiced what to do if we saw someone that had been our study. We even practiced ignoring them! That felt a little weird, but we got used to it.

Micah: We also practiced using participant ID numbers on all our forms and we made sure any device we used, like our computers, had a password.

Brendan: One time, I was collecting information from a person and their guardian was there. I was talking to them about their experiences with mental health treatment and they didn't seem very comfortable sharing because their guardian could hear. I took a break and called Ariel for help. Ariel helped me figure out the right words to use to ask the guardian to sit outside for the rest of the research study.

Micah: Another time I had just finished collecting information from a focus group and I heard some of the participants talking about something someone else had said during the group. I reminded them they had agreed to keep that information private and confidential.

Brendan: There was also a time when I was talking to someone about where to do the interview. They said their group home would be a good spot. But I talked to them about whether there would be any privacy there. We decided it would be better to meet in a private room in the library.