

Topic 4.2.3: Privacy and Confidentiality when sharing about research

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.