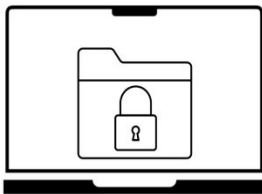


Topic 4.2: Privacy and Confidentiality

In the last units we talked about a lot of different types of risks. In this unit we will focus on privacy and confidentiality and how we can keep it.

One of the things researchers worry about in every research study is that someone's privacy or confidentiality will be lost.



Privacy and confidentiality are about keeping research participants' information safe. Researchers make sure that they keep information, or data, safe so other people don't get research participants' information.

You will work really hard to not let this happen!

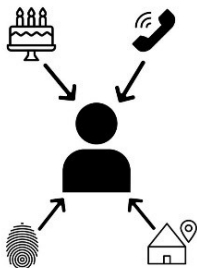
Everyone who is on a research team has a job of helping keep participants' information private and confidential.



When the IRB approved your study, they agreed you had a good plan for keeping information private and confidential. Following that plan is one of the most important jobs you have.

None of the information you learn about participants in your research study should be shared with anyone who is not part of your research team! There are some times you won't follow this rule—we'll get back to that idea in another unit.

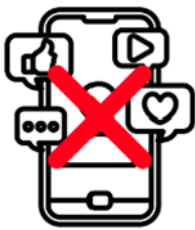
By being on a research team, you agree not to tell people outside of your research team anything about the participants in your research study. This even includes not saying that they are in your research study.



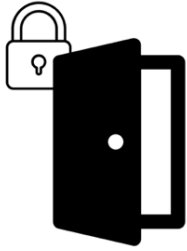
Some information is called **individually identifiable data** information. Individually identifiable data is information you collect about a person who is in your research study that can be used to know who they are. You have to work extra hard to keep this information safe.

You also cannot tell anyone who is in your research study or share anything they shared with us publicly. That means if you see someone at a store, you should pretend not to know them unless they say hi to you first. If they say hi to you, don't talk about anything they shared with you when they were in your research study. It is ok if the person says something about what they shared.

If you know a participant's support provider, you also shouldn't share what they shared with you during the research study. Letting people know that their information is private is really important to build trust.



You also can't share any pictures you take of people in research on social media unless you have permission to share them.



You also want to think about privacy and confidentiality when you ask people to be in your research study.

Sometimes research studies are about topics that are personal, or sensitive. This is why it is important to make sure you do recruitment as privately as possible. For example, try to talk to people one-on-one about your research study.



Your team might also want to talk about what to say in recruitment flyers or social media posts, especially if you are studying something very private or personal.

Someone might have a disability or a medical condition that not everyone knows about. Some people with disabilities are proud of their disability and happy to be part of the disability community.

But some people feel like their disability is private. To make sure you respect everyone, make sure that you don't tell anyone about someone's disability or medical condition.

When you collect information from people, there are lots of things you can do to keep their information private and safe. Like we talked about before, you might want to not ask about information if it would really hurt participants if someone else learned about it. If you have papers or electronic forms you use to collect information, you should write a participant ID number instead of their name.

You can also think about where you can collect the information. It should be a place where everyone feels safe and that no one else can hear what the participant shares.

Usually, you will collect information from participants in private places, but sometimes a public place, like a private room at a library or a private place at work might work, especially if the research project isn't about a very personal topic.

Talk with the participant about privacy—help them understand what might happen if someone overhears what they share. It is always ok to reschedule or to remind the person they can say no to being in the research study if the space doesn't feel good to them.

One last thing to remember—you can't always control how private information is. You need to tell participants about the ways their information might not stay private. For example, you might use video chat and the company that makes the video chat software might get broken into.

If that happens, participants might lose privacy in a way that you couldn't control. This doesn't happen very often, but it is important to talk to people about the risks of losing their privacy because of technology trouble.