

Video: Ethical Code and Data Privacy - Transcript

0:21: Welcome to our short introductory video about “Ethical standards and data privacy issues when interviewing neurodiverse individuals.”

0:33: Interviewing people for research is always a sensitive thing to do. The people you are interviewing are opening themselves up to you, in what may be some very personal ways.

0:46: This video will describe the things you do to protect the privacy and dignity of the people you interview, and how you also protect yourself within the scope of this project – both ethically (because it’s the right thing to do) and legally (so you don’t violate any laws).

1:09: The first issue is one of ethical standards. Universities hold researchers to high standards that require them to follow a code of conduct when they carry out research on human (or animal) subjects. Some parts of the ethical code are unwritten, or require you to promise something that cannot be easily checked or tested.

1:35: For example, we ask that you treat the people you interview well. It is important that you speak and act respectfully by, for example, reminding them they only have to answer questions they want to answer, not taking too much of their time, offering them breaks if they seem like they might want one, and by using an appropriate tone and the correct forms of address.

2:04: After the interview, you will be discussing what they said and reflecting on it with other students. Here, too, we ask you to be very respectful. Some things to remember are to avoid a deficit perspective and to validate the interviewee’s point of view. Sometimes it can be difficult to value an interviewee’s perspective and still critique it meaningfully. A good researcher will undertake extreme efforts to do this sensitively.

2:37: A good rule to keep in mind is this: Imagine your interviewee is sitting in front of you. Would you say to them what you say about them? Some parts of the ethical code are written down. Our ethical code requires you to get informed consent from the people you are interviewing or, if they are children or have a legal representative, from their guardians. The informed consent is a document you give to your interviewee.

3:10: The informed consent tells your interviewee how their information is going to be used. It also tells them how their information (that is their personal data) is going to be collected, stored, kept secure, and what will happen to it after the project.

3:29: Please do not simply hand the informed consent to the interviewee. Talk to them about its content. Assure them that you take their privacy seriously. Remind them that they do not have to do the interview, and that they can change their mind in the middle. They can also decide afterwards if they don’t want the interview used.

3:53: You need to tell the interviewee that you are recording them! For many people, this is a significant invasion of their privacy. You must make sure your interviewee knows that they will be recorded before the interview, and before you actually start recording.

4:12: The informed consent tells the interviewee what their rights are if they are unhappy with how their data is collected, used, or stored. They need to agree to the informed consent by signing it.

4:27: If you think the interview partner does not understand what they are signing, or that they feel pressured to do so, you have an ethical obligation to report this to the person in charge of the research project.

4:42: The second issue deals with data privacy, and especially, making sure you comply with General Data Protection Regulations (GDPR for short). You may be more familiar with the German abbreviation: DSGVO.

5:00: The GDPR goes hand in hand with the ethical standards – you cannot have ethical standards without following laws about how to handle personal data. In our case, the relevant GDPR requirements for the interviewee are found in the informed consent document that they sign. The parts of the informed consent that have to do with the GDPR involve informing the interviewee about how their data will be collected and used, and what rights they have regarding their data.

5:32: There are additional GDPR elements that you, as the interviewer, have to agree to. This includes agreeing to submit some files and delete other files at specific times after they are no longer needed. For example, you need to delete the audio file and any files that might reveal the identity of your interviewee when you are done with the transcription.

5:59: You also have to commit to keeping the data secure by, for example, not leaving it on shared computers or unsecured networks. Finally, you agree to not discuss your interviewee by name outside of your work group. As a researcher, you also have rights to your data.

6:19: We hope that this brief video gives you some insight into the several pages that we are asking you to sign, share with your interviewee, and return to us. We hope that, by viewing this video, we have explained both the “why” and “how” of ensuring ethical and legal standards of work with interviewees in research settings.

6:41: This brief summary cannot cover everything there is to know on the topics. If you have questions about these issues, please speak to your professor or professors!

Thank you!