

Unit 4: Keeping Research Participants Safe

Topic 4.1: Risks and Safeguards



Topic 4.1 Discussion questions

1. What are some **risks**, or possible harms **in your** research **study**?



Topic 4.1 Discussion questions

2. It is possible you **might know people** who you are recruiting to be in your study. **Sometimes** it is **ok to know people in your research study** and **sometimes** it will make things hard and should be avoided. **How** would **you feel** about **being** in a research **study** with someone **you already know**?

- **How** do you think **other people will feel** about **being in** your research **study with people they know**?

- Do you think it is **ok** for you to **know people in your team's study**?
Think about the **topic** you are studying and **possible harms** from **learning** this **information** about someone you know.

- **What** do you think you should **do when you know the people you are recruiting**?



Topic 4.1 Discussion Questions

3. **Who** may have a **difficult experience** with **your** research **study** because of the **topic** you are studying?

- **What experiences** or **feelings** might be **hard to talk about**?
- **How** can you **help people** who **have a hard time** with your research topic?



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1. What **you will do** if there is an **adverse event**, or something that doesn't go as expected during your research and might hurt someone?

Topic 4.2.1: Privacy and Confidentiality



Topic 4.2.1 Discussion questions

1. **How** will your team **keep** people's **information private** and **confidential**?

Topic 4.2.1 Add-on activity

2. **Who can you share information** about the research study **with**?

Check the people **who you can share** the different types of information with.

What the project is about	People on the research team People not on the research team
What I do for the research project	People on the research team People not on the research team
Who is in the research study	People on the research team People not on the research team
The things people in the study tell us	People on the research team People not on the research team
Who has a legal guardian	People on the research team People not on the research team
The people who wanted to be in the research study but did not have all the eligibility criteria	People on the research team People not on the research team



Topic 4.2.1 Role play

1. Your **family member wants to know who you interviewed** for your research study.

Write a **script** for **how you will tell them that you can not share information** about who is in the research study.

- **Act it out**



Topic 4.2.1 Role play

2. **Your friend asks about what participants said** about your self-advocacy group **during the interviews** you did.

Write a script for how you will **tell them that you can not share** this information.

- **Act it out**



Topic 4.2.1 Role Play

3. You **see a research participant at the grocery store** a week after doing an interview with them.
 - Role play **ignoring** them.
 - The research participants says hi to you. **What will you do or say** to make sure **you don't share information** about the research in **public? Act it out.**



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3. Write how you will keep research participants' information private and confidential:
- While you are **recruiting**
 - While you are **collecting information (data)** from participants
 - While you are **working with information (data analysis)** from participants
 - While you are **sharing what you learned** from the participants in your research study



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4. Talk about **who you can share different types** of research **information** with.
- You can share **some information only** with **people** on **your research team**.
 - **Other information is ok to share** with people not on your research team.



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5. Review and sign the confidentiality agreement on page 7 of your Community Research Partner Rights and Responsibilities document.

Topic 4.3: Breaking Confidentiality: Mandatory Reporting



Topic 4.3 Discussion questions

1. **Find information** about **mandatory reporting** on **your consent form**.

2. In the video, we learned that sometimes you learn **information** that you **have to share**, because **someone is being hurt**. Make a list of the information that you need to talk to your Project Leader about if you hear.



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1. What **you should do** if you **learned something that concerns** you about the safety or well-being of a research participant and might mean **you can't keep it confidential**? For example, if you learn that a participant is being **hurt or abused or hurting someone else**.