### 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. <b>W</b>	/ho can y	you <b>share information</b>	about the	research study	/ with?
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Check the people who you can share the different types of information with.

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



### Topic 4.2.1 Role play

 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

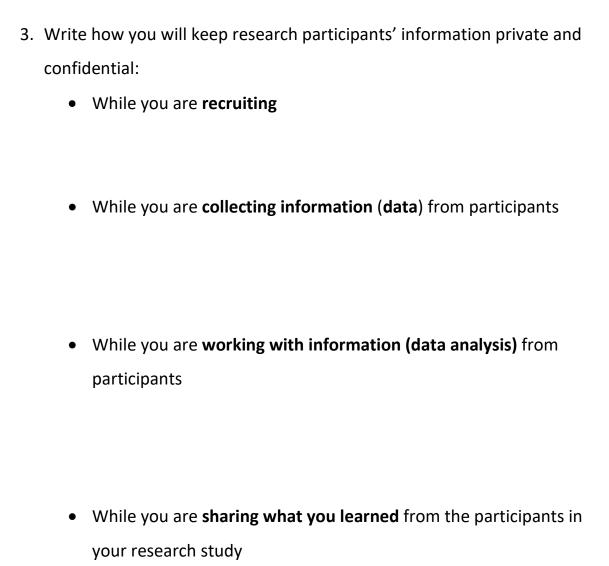


### Topic 4.2.1 Role Play

- 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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- 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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 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.