



Research Ethics for All:

Accessible Research Ethics Education for

Community Research Partners

Taking Care of People in Patient-Centered Research:

Ethical Issues in Social, Behavioral, and Biomedical Research

Add-On Activities

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Unit 1: Community-Engaged Scientific Research



Discussion Questions

1. What is your team's research question?
 - What is your team trying to learn about or find an answer to?
 - What problem do you want to know more about or solve?
2. What good things do you hope will come from answering your research question?



Unit 1 Rights and Responsibilities Agreement

Pages 1-2

1. Write or draw your research question.

Our Research Team

List all the people on your research team and their roles or titles.

Picture	Name	Role or title

Unit 2: History of Scientific Research with People and Rules

Topic 2.3: Vulnerability



Discussion Questions

1. Does your team have any concerns that some people who you will invite to be in your research study may be easily hurt if they are in the study or will have a hard time understanding information about your study or making a decision about being in your study?
 - If you have them, what are your concerns?

 - How can you pay extra attention to these people's rights and safety?



Unit 2 Rights and Responsibilities Agreement

Page 3

Who do I talk to if I have questions about rules we need to follow in my research study?

Name



Email



Phone

Unit 3: Getting People Involved in Research

Topic 3.1: Recruitment: Finding People to Be in a Research Study



Discussion Questions

1. Think about all the types of people you want to include in your study. Think about the different ages, races, cultures, disabilities, other characteristics of people or different experiences people may have. Why is it important for your study to include these different types of people?

Unit 3 Rights and Responsibilities Agreement

Page 4

Write your study's eligibility criteria.

- Talk about why these characteristics and experiences are important for your research study.



Inclusion criteria-the experiences and characteristics people need to be in our study



Exclusion criteria- the experiences and characteristics of people who can **not** be in our study



Discussion Questions

2. Look at your study's recruitment plan.

- How does it show respect to people?
- How will you help build trust with people?
- How does it help people understand what your study is about?
- How does it help people know they can make their own choice?
- How will you help make sure people know they can say no?



Role Play

1. Write a script for what you will tell people if they are not eligible for your study.

2. Act it out!

Topic 3.2: Finding Research Participants through Other People



Discussion Questions

1. If your recruitment plan involves working with people who provide support to people with disabilities, like family members or service providers, how will you talk to these people so they understand:

- The importance of letting people know about the opportunity to be in a research study and making their own decision
- The things you will do to keep participants safe
- The good things (benefits) that can happen from people being in research studies



Discussion Questions

2. What may be some challenges of working with people who support people with disabilities?

- How can you work well with people who support people with disabilities?



Role Play

If any people you invite to be part of your research study will be children or have a guardian, write scripts to practice talking to the parents and guardians about the study:

1. Write a script for how you will talk about the study to parents and guardians.
 - Remember to think about how you will support the rights of children and adults with guardians.

2. Act it out!

Topic 3.3: Consent: Working with People as they Make Decisions about Being in Research



Discussion Questions

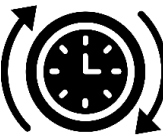
1. Review your team's consent and assent document(s).
 - Underline where people's choices to say yes (consent) or no (dissent) are explained.
 - Circle information about who is doing the study and how to contact the researcher.
 - **Highlight** information about why the research study is being done
 - Put a **box** around the parts of the form that tells people what they will do if they are in the study.
 - **Highlight** information about risks and benefits of the research study.

2. How will your team help people understand information about the study and their rights?

Unit 3 Rights and Responsibilities Agreement



Describe how your team will work with people when they are making a decision about being in your research study.

Consent Requirements	How we will do it
 Informed: people have all the information they need about the study	
 Voluntary: people making a choice without pressure from other people	
 Ongoing: people can say no at any time during the study	



Role Play

1. Role Play doing a consent or assent meeting. Use the checklist below to make sure you do everything you can to support the person to make their own decision. You can also use the checklist to reflect on how a meeting went and think about ways to make it better next time.

- ☐ Use the right consent and/or assent document
- ☐ Use IRB-approved materials
- ☐ Share all the information the person needs to make a decision about being in the research study
- ☐ Explain the risks (bad things) and benefits (good things) that could happen.
- ☐ If the person seems confused, try another way to share the information in ways that made it easier to understand
- ☐ Leave time for questions
- ☐ Do consent and assent in a private place
- ☐ Share where people can get more information about the study
- ☐ Pay attention to signs of dissent, including body language
- ☐ Make sure that other people aren't pressuring the person to be in the study
- ☐ Explain what will happen when the study ends

Topic 3.5: Research with Children



Discussion Questions

1. Talk with your team about how to keep children safe and respect children's rights when children are invited to be in research.

Think about what to do if:

- The child is pressured to be in a research study
- The child's parent thinks the research study is too hard for them
- The child needs help understanding the research study and the decision they are making
- How to make information about the research study easy to understand for the child



Role Play

Write a script for what researchers can say to a parent if their child is showing signs they don't want to do the research study.

- What will you explain about assent?
- If your research team has script for this already, give your feedback on the script.

Act it out!

Topic 3.6: Assent: Working with Guardians and Parents of Children



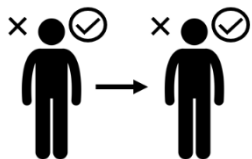
Discussion Question

1. How will your team get assent from children and people with guardians appointed by a court or judge?



Unit 3 Rights and Responsibilities Agreement

Page 6



Some people can only be in research if someone else makes the decision for them. Write how your team will show respect for decisions made by people with guardians, or legally authorized representatives.



Role Play

1. A person is saying they do not want to be in your research study, but their guardian wants them to be in your study.
 - Write a script for what you can say to the guardian.
 - Write a script for what you can say to the person who does not want to be in research.

Act it out!



Role Play

2. A person wants to be in research, but their guardian does not want them to be in research. Write a script for what you can say.
 - Write a script for what you can say to the guardian.
 - Write a script for what you can say to the person who wants to be in the research study.

Act it out!

Unit 4: Keeping Research Participants Safe

Topic 4.1: Risks and Safeguards



Discussion Questions

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



Discussion Questions

2. It is possible you might know people who you are inviting 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 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?



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?



Discussion Question

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

Topic 4.1.6 More information about risks and safeguards

Research-related financial conflict of interest form



What is a research-related conflict of interest?

A **conflict of interest** is when someone doing the research has **circumstances that might change how they do the research in bad ways.**

The worry is that a person with a conflict of interest might:

- make up information,
- only share information that makes them look good, or
- pressure people to be in the research study

Conflicts of interest are **usually about money.**

A conflict of interest can be **actual**—you are sure it is there.

Sometimes conflicts of interest are not really there, even though it might seem like the conflict is there. This is called a “**perceived**” **conflict of interest**. You might worry it might change things or it makes other people think the research is not as good.

Examples of conflicts of interest are:

- If someone doing the research works at another organization, and if the research study has good findings, they may earn more money at their job.
- If someone who made a new healthcare app is doing the research, they might want the research to say the app helps people so they can sell the app and make money.

Anyone who is part of the planning, doing or sharing of a research project must **report any conflict of interests:**

- **once a year AND**
- **no more than 30 days after the conflict of interest starts**

Do you think because of anything in your personal life, work life, family life, or volunteer work, you might have a conflict of interest?

Do you think the conflict might change how this research project is done or make other people worry about how the research is done?

Check off if you have any of the potential conflicts of interest:

- ☐ I own a business that is involved in the research study
- ☐ I have a family member who owns a business that is involved in the research study
- ☐ I work for an organization involved in or affected by the research study
- ☐ I have a family member who works for an organization involved in or affected by the research study
- ☐ I might earn more than \$5,000 in income or interest because of this research that is separate from my payment for being a researcher.
- ☐ I am not sure

Talk about what you think might be a conflict of interest with your project leader:

- How do you think this conflict of interest might have a bad impact on you being part of the research?
- How do you think this conflict of interest might make other people think the research is bad because you are a part of it?

If there is a research-related conflict of interest, your project leader will work on a plan to address it.

1. Do you have any financial conflicts of interest?
2. What did you decide to do about the conflict of interest?



Unit 4 Rights and Responsibilities Agreement



Keeping Research Participants Safe

Think about the possible bad things (harms) that could happen in your study.

Then think about the ways you can try to stop them from happening.

Write or draw your ideas in the table.

Possible bad thing in our research	How we will try to stop this bad thing from happening (safeguard)



Unit 4 Rights and Responsibilities Agreement

Adverse Events

Write the adverse events that could happen in your research study.

Write how you will try to keep people safe from adverse events.

Adverse events that could happen in our research study	How we will try to keep people safe

Topic 4.2.1: Privacy and Confidentiality



Discussion Question

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



Topic 4.2.1 Add-on activity: Sharing Research Information

Sort different types of research information that you can share with different people.

[Sharing information link](#)



Google Slides

Copy document

Would you like to make a copy of **Sharing information about research?**

Make a copy





Unit 4 Rights and Responsibilities Agreement

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Talk about who you can share different types of research information with.

- What information can you only share with people on your research team?
- What information is ok to share with people not on your research team?



Role Play

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

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

2. Act it out!



Role Play

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

1. Write a script for how you will tell them that you cannot share this information.

2. Act it out!



Role Play

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!

Topic 4.2.3 Privacy and Confidentiality when using Artificial Intelligence (AI)

Add-on Activity

Fill in the table about how you want to use AI in your research study.

After you fill in steps 1-3, talk with your project leader to finish steps 4 and 5.

Step 1 How do you want to use AI in the research study?	Step 2 What AI do you want to use?	Step 3 What information do you want to put in to the AI?	Step 4 Will the information you put into the AI be kept confidential?	Step 5 Does the project leader say it is ok to use AI this way?

Topic 4.2.4 Privacy and Confidentiality of Online Information



Discussion Questions

1. What type of online information will your research study use?
 - Where are you getting the online information?



Discussion Questions

2. How do you think people will feel about you using this information for your research study?

3. What rules are there for using this type of information?

Topic 4.2.7 Sharing data with other researchers: Biobanks and data repositories



Discussion Questions

Think about data sharing in your study.

1. Where will you share the data?
2. Who will you share data with?
3. How will you share the data?
4. How will you keep people's identifies confidential when you share their data?



Discussion Questions

Think about data sharing in your study.

5. Who will be able to use the data for new studies?
6. What will they be able to use the data for?
7. What questions or concerns do you have about data sharing in your research study?
8. What can your research study do to make you and research participants less concerned?



Role Play: Explaining how we will share data

1. Write a script explaining the data that will be shared and what will happen with it to people invited to be in your research study.

Use the prompts to write a script to help you talk to the participant.

- We are asking your agreement to share your data because:

- The data we will share includes:

- The data we will share does not include:

- We will do our best to keep your data safe by:

- The people who can use your data are:

- They will use your data to:

- Some of the risks of sharing your data are:

2. Act it out!

Unit 4 Rights and Responsibilities Agreement



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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 with other people.



Unit 4 Rights and Responsibilities Agreement

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Review and sign the confidentiality agreement on page 9 of your Rights and Responsibilities Agreement.

Topic 4.3: Breaking Confidentiality: Mandatory Reporting



Discussion Questions

1. Find information about mandatory reporting on your consent form.
2. In the video, you 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.

Unit 4 Rights and Responsibilities Agreement

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What should you do if you learn 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.

Unit 5: Trying out new treatments, medicines, and programs

Topic 5.2: Risks in clinical trials



Discussion Question

1. What are the risks in your clinical trial related to the treatment or treatments you are studying?

- What questions do you think people will have about those risks?

Topic 5.3. Taking care of participants in clinical trials



Discussion Questions

1. What parts of your research study might be hard to understand for the people you invite to be in your research study?
 - How can you help people understand these parts of your research study?

2. What risks do you think are most important for people you invite to be in your research study to understand?
 - How can you help people understand these risks?

Unit 5 Rights and Responsibilities Agreement



Side Effects

Write the side effects that could happen in your research study.

Write how you will try to keep people safe from the side effects.

Side effects that could happen in our research study	How we will try to keep people safe from the side effects

Topic 5.4 Return of personal health results to participants



Discussion Questions

1. What type of information are you sharing with research participants about their health?
 - What might be good about learning this information with research participants?
 - What might be scary about learning this information for research participants?
 - How can you support research participants when they learn this information?



Discussion Questions

2. If you are not returning results to research participants, why not?

- How do you feel about not returning this information?

Topic 5.5 Keeping People Safe in Clinical Trials: Data Safety Monitoring Boards or Committees



Add-On Activity: Data Safety Monitoring Boards

Ask your project leader if you have a Data Safety Monitoring Board or Committee.

If your research study has a board or committee, find out:

- Why did they pick the people to be on the committee or board? Do they have special knowledge or experience?
- What kind of risks is the committee or board looking for?
- How often does the committee or board meet?
- Does the committee or board have rules about if they will recommend stopping the research study?

If your research study doesn't have a Data Safety Monitoring Board or Committee, find out why.

Unit 6: Community Research Partner Rights

Topic 6.1: Keeping Community Research Partners Safe



Discussion Questions

1. Talk with your project lead privately about things that might happen during the research study that would make you feel unsafe, uncomfortable, or not respected. Make a plan with your project leader for what you will do if those things happen.



Discussion Questions

2. Talk about different ways your team can support each other.
 - Think about when you might need support during research. Think about what that support might look like.
 - Think about who you can talk to if you are having a hard time. This could be someone on your team or a professional.



Unit 6 Rights and Responsibilities Agreement

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Talk with your team about how you will get support while you are doing the research study.

How will you support other team members while you are doing the research study?

Topic 6.2: Being an Author and Sharing Findings



Discussion Questions

1. Talk about how your team will decide authorship.
 - Talk about if authorship will be different for different things you create, like podcasts or academic papers.

2. Talk about if your team will ask permission from participants to use their words (quotes).



Unit 6 Rights and Responsibilities Agreement

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Our team will share information about our research by:

To be an author I will:

- 1.
- 2.
- 3.
4. Approve the final version of anything my name is on to make sure I agree with what we are sharing.

Topic 6.2.1: Using artificial intelligence, authorship, and sharing findings



Unit 6 Rights and Responsibilities Agreement

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I have my project leader's permission to use AI to do the research project

☐ Yes

☐ No

AI will help me with:

The AI I will use is:

The rules I have for using this AI are:

If I want to use another AI app or use AI for another reason I will talk to my project leader and get permission before using the new AI or using the AI for a new purpose.

Wrap Up



Discussion Questions

1. What will help you and your team think about how you can do your best to respect research participants' rights and safety?
2. What are some things related to research ethics that you still want to learn more about?



Discussion Questions

3. What are some things related to research ethics that you still want to practice?
4. How will your team make sure you are respecting research participants' rights?