

Research Ethics for All:

RE4ALL Accessible Research Ethics Education for Community **Research Partners**

Research Ethics for All: Add-On Activities

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How to use add-on discussion questions and learning activities

Research Ethics for All offers optional add-on discussion questions and learning activities for teams who are working together on a research study. We encourage project leaders to use these additional educational materials as needed.

These include:



1. **Discussion questions about your research study and research team:**Use these discussion questions to support application of *Research Ethics for All* educational material to your research study and team.
Sometimes these questions will ask about your team's research materials.



2. Community Research Partner Rights and Responsibilities Agreement:
Use the Add-On activity workbook to draft and brainstorm the
information that you will put in the Community Research Partner
Rights and Responsibilities Agreement. Creating this agreement will
help your team apply what you learned from Research Ethics for All to
your research study. The agreement can serve as a one-stop reference
for how your team will apply ethical principles to a specific research
study. Project Leaders can work with their teams to make a final
version of this document.



3. **Role plays:** Role plays provide opportunities for your team to put ideas into practice. You may want to consider selecting role plays based on the responsibilities of community researchers in your study.

The add-on discussion questions and learning activities are linked to learning units and can be used alongside each learning unit or following the full *Research Ethics for All* training, as a bridge to the research protocol-specific training you also provide to each team member.

Unit 1: Community-Engaged Scientific Research



Unit 1 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?



Pages 1-2

2. **Describe your job, role** or **title** on your research study.

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

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** or **making decisions**?
 - If you have them, what are your concerns?

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

Unit 3: Getting People Involved in Research

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



Topic 3.1 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?



Topic 3.1 Discussion questions

- 2. Look at your study's recruitment plan.
 - a. How does it **show respect** to people?
 - b. How will you help build trust with people?
 - c. How does it help people understand what your study is about?
 - d. How does it help people know they can make their own choice?
 - e. How will you help make sure people know they can say no?



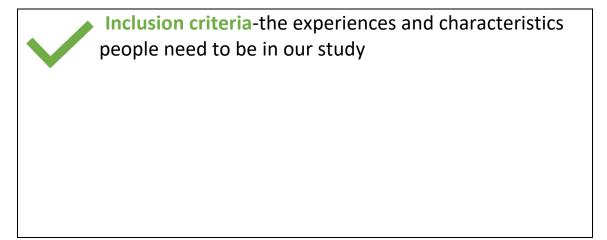
Topic 3.1 Role play

1. Write a **script** for what you will **tell people** if they are **not eligible** for your study. Then, act out your script.



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- 1. Write your study's eligibility criteria.
 - Talk about why these characteristics and experiences are important for your research study.





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

Topic 3.2: Finding Research Participants through Other People



Topic 3.2 Discussion questions

- 3. 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



Topic 3.2 Discussion questions

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

• How you can you avoid these challenges?



Topic 3.2 Role play

- 2. 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 them about the study**:
 - 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.
 - o Act it out.

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

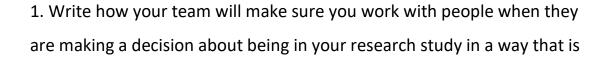


Topic 3.3 Discussion questions

- 1. Review your team's consent and assent documents.
 - <u>Underline</u> 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**?



Page 4



Informed

Voluntary

Ongoing



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 consent 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, share the information in ways that made it
	easier to understand
	Leave enough time for questions
	Do consent and assent in a private place
	Share where people can get more information
	Pay attention to signs of dissent, including body language
	Make sure that other people didn't pressure the person to be in the study
	Explain what will happen when the study ends

Topic 3.5: 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?



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1. Write how your team will show respect for decisions made by people with guardians, or LARs



Topic 3.5 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



Topic 3.5 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 research.
 - Act it out

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

Who can you share information about the research study with?
 Circle 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	People on the research team
research study but did not have all the eligibility criteria	People not 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 cannot 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
	confid	dential:
	•	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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 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.

Unit 5: Community Research Partner Rights

Topic 5.1: Keeping Community Research Partners Safe



Topic 5.1 Discussion questions

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



Topic 5.1 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.



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

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

Topic 5.2: Being an Author and Sharing Findings



Topic 5.2 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).



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1. Make a plan for how your team will share information about your study.

2. Make a plan for **how** your team will **decide who** is an **author**.

Topic 5.3: Wrap Up



Topic 5.3 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?



Topic 5.3 Discussion questions

3. What are some things related to **research ethics** that you **still want to practice**?

4. How you will your team **make sure** you are **respecting research** participants' rights?



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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)