Research Ethics for All:
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?

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1. Write or draw your **research question**

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**?

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1. 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

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

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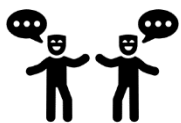
Topic 3.1 Role Play

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

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**.
  - o Remember to think about **how you will support** the **rights** of **children and adults with guardians**.
  - o Act it out.

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 children** and **adults with guardians**.
    - o 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**?

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1. Write how your team will make sure you work with people when they are making a decision about being in your research study in a way that is

- **Informed**

- **Voluntary**

- **Ongoing**

Topic 3.3 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 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 does not want 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** t**he 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?

   a. **What experiences** or **feelings** might be **hard to talk about**?

   b. **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**?

    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 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 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 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.**

Unit 5: Community Research Partner Rights

Topic 5.1: Keeping Community Research Partners Safe

Topic 5.1 Discussion questions

1. **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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1. 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**.

Unit 6: Wrap up and Check Out

Unit 6 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?

Unit 6 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)