

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**?



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**?



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



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**?





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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

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



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.



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**.
 - Act it out.



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**.
 - Remember to think about **how you will support the rights of children and adults with guardians**.
 - 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 documents.
 - 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**?



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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**



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



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 does not want to be** in research.
 - **Act it out**