



## **Unit 3: Written Training**

### Unit 3: Getting People Involved in Research

#### Topic 3.1.1: Recruitment: Finding People to be in a Research Study

We have talked about what research is and how to treat people well in research.

In the next several units, we will talk about specific ways we can treat people well when they are in research.

We'll start first with talking about getting people involved in research. Getting people involved in research is all about finding people to be in your study and working with them as they make their decision about being in your study.

This unit is about recruitment, or finding people to be in a research study.

You are learning about doing research with people. Before you can start the research, you need to find people to be in the research study and help them make a decision about whether or not they want to do it.



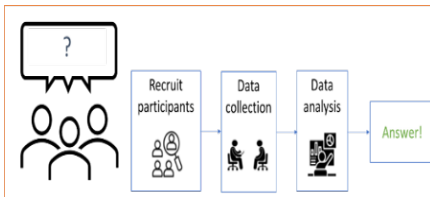
The first part in deciding about being in a research study—whether the person agrees or says no—starts with learning about a new study. **Recruitment** is the thing researchers do to find people and invite them to be in a research study.

**Research participants** are the people who agree to be in a research study.

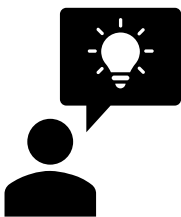
You can find people to be in your studies in different ways. You can use flyers, social media, email, or letters to tell people about a new research study.



Remember, the IRB will review your recruitment materials to make sure they support everyone’s rights. The IRB will make sure your recruitment materials have required information. This includes that you are doing research, why the study is being done, how long the study will take to do and who to contact for more information. It’s important that you use the materials the IRB approves. It is also important to follow the research plan for how you will recruit people.



It is important to show respect and build trust with the people you are recruiting, or asking to be in your research study. There are a few different ways to demonstrate respect and build trust—we’ll hear from the Mental Health for All team about their ideas.



You may have ideas about how to do recruitment with people with disabilities that is accessible, respectful, and earns their trust—this is an important role you have on a research team!

It is also important to think about who people will feel comfortable learning about the study from. It's also important to think about who people trust and who they will feel comfortable saying no to.

Some people with disabilities want to be recruited by the people who are doing the research themselves. Other people with disabilities feel more comfortable being recruited by someone they know and trust. For other people, it might be harder to say no to someone they know already.

When you are the person sharing information about the research study, you might feel like it is sometimes easy to earn the trust of people you are recruiting and sometimes it is hard. It can help to take extra time to talk to the person and get to know them a little bit.



They might also ask you questions to make sure that your research project is real and not a scam— sharing information like who is doing the study and where they work or volunteer and who is paying for the study might help them understand your study is real.

When you are finding people to be in your research study, be sure to talk to them in a way that does not make them feel pressured to be in the study. Let people know that they don't have to be in the study. You should make sure that they know that you will not be upset if they say no, and that no one else will be mad if they say no.

### Topic 3.1.2: Eligibility criteria

In the last section you learned about being inclusive when you think about recruitment. In this section, we will talk about eligibility criteria, or the experiences and backgrounds people may need to be in a study.



Remember when we talked about the Belmont principle of **Justice**? The Belmont principle of Justice and the Disability Rights principle of inclusion remind us how important it is to invite lots of different people to be in a research study.

For example, when people of different ages and races or ethnicities, people with disabilities, and people who do and do not get developmental disabilities services are included, what you learn from the study represents more types of people.



It's also important to know who to invite to each study based on what the team is trying to learn. You need to make sure you only include people who are eligible or meet eligibility criteria. **Eligibility criteria** are a list of the are a list of characteristics that people need to be in a research study.

Eligibility criteria are important for a few different reasons:

Sometimes researchers have eligibility criteria for **scientific reasons**. Researchers need to make sure people can get information that helps answer their research question. For example, to be in a study about what it's like to be autistic and interact with healthcare providers, everyone in the study has to be autistic.

Sometimes researchers have eligibility criteria for **safety reasons**. Sometimes, people can get hurt if they are in the study, so researchers make sure they aren't in the study. For example, if you are researching a new medicine to treat diabetes, that medicine might hurt someone who also takes medicine for a heart condition. The researchers would exclude people who take those medicines so they don't get hurt.



Sometimes when people are not eligible for a study it can be disappointing. People might even feel upset. You'll learn how the Mental Health for All team handled this.



You will probably ask a lot of people to be in the study. Many may not want to or not be able to be in your research study. That is ok. In fact, having some people say no means you are doing a good job!





## Mental Health for All Team Talks About Eligibility

### Criteria



**Brendan:** Hello again! Ariel and Katie shared with us their list of our eligibility criteria. They said we needed to look for people who:

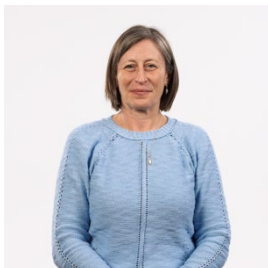
- have a developmental disability
- are at least 18 years old,
- live in a group home in the US.

I had questions—does it matter how many people live in the group home? Does it matter how long the person has lived in the group home?



**Micah:** I also wanted to know if we could include people who live with a roommate and have staff come and help them. We talked about what mattered for our study based on what we wanted to learn.

**Brendan:** We agreed we wanted to talk to anyone who lived in a group home and had an individualized service plan. We also talked about making sure we reached out to group homes in neighborhoods with people from different racial and ethnic groups and group homes with older people.



**Katie:** Once we had agreed on the type of people we would invite to participate, we had to think about how we would find people to be in our studies in ways that felt respectful and trustworthy.

**Brendan:** I suggested we share information in ways that are understandable. This might mean using simple, everyday words, instead of the big research words you use with your research team, slowing down when you talk, and using pictures or another form of communication like writing that is better for some people.

**Micah:** I also suggested that when there is another person there, we be sure to talk directly to the person with the disability since it's their choice to be in the study or not.

**Brendan:** I reminded everyone to not make people feel pressured to say yes. For example, we can remind people that they have a choice to be in the study and that they can stop at any time.



**Ariel:** We also made sure to tell them that no one would be mad if they said no or changed their mind. We made sure to not say things like “If you don’t do this, you won’t get the gift card at the end” so the people didn’t feel pressured to be in the study.

**Micah:** We also realized some people might feel a little suspicious about who we are and what we were doing. We told people we were a team of people from the state self-advocacy association and the local university.

**Katie:** We shared that we had money from the government to do our project. To help people feel comfortable with us, we also spent a little time getting to know each other.

**Micah:** Because of all the work we did before we started looking for people to be in our study, we felt ready. Some things went well but we also had to handle some tricky situations!

**Brendan:** While we were recruiting participants, we felt like our ideas to use simple words, pictures, talk slowly, and give time for people to think and ask questions worked really well. It seemed like people understood based on the questions they asked!

**Micah:** But sometimes we ended up talking mostly to the person providing support and not the person with a disability.

**Katie:** We worked together and decided to make some information about why we're doing the study easier to understand. We also reminded the person giving support that we wanted to hear from the person with a disability.

**Brendan:** If we didn't know what to do in a situation, we knew we could ask Katie and Ariel for help. We also talked to some people who ended up not having the characteristics we were looking for. Once we talked to someone who had a brain injury from an accident when they were 37. Another time we talked to someone who was not an adult yet.

**Brendan:** It worked out, because we knew what to do. We had to tell the person with a brain injury that the study was only for people with developmental disabilities. It felt hard to say no to them. We did share information about a brain injury support group since we knew it might help them.

**Micah:** They understood and thanked us for sharing information. The person who was too young was really disappointed. I explained why they can't be in our study, and I worked with Katie and Ariel to find a program they might be able to be in through their school. I also told them they could keep our information and reach out when they turn 18 in case we have any studies in the future they can be in.

**Brendan:** I also remember some people saying they didn't want to talk to someone they didn't know. They had a bad experience the last time they did research, and they didn't want to talk about their mental health. I was so happy we had practiced what to do in these types of situations!

**Katie:** We also noticed that we didn't have many people yet who used a communication device and we didn't have many people from our local refugee community. When we realized this, we developed relationships to find people with these characteristics.

**Brendan:** We learned that you need to tell a lot of people about a study to find enough people. We always felt disappointed when someone said no to being in our study, but Katie and Ariel told us that meant we were doing a good job since people felt they could say no to us.