Mental Health for All

Mental Health for All Team Talks About Consent



Brendan: One of our jobs was to help figure out how to make sure that people in our study were informed. This means they understood the information about our study.

We also had to help make sure people felt comfortable saying no and could make their own choice—this is voluntary consent. We learned that making sure consent is voluntary and informed starts with recruitment.



Micah: We talked and came up with a lot of good ideas. Here are some of our tips!

Think about where you recruit people. You might want to recruit in places people know and are comfortable in. Think about the sensory environment, like lights and noise.

Brendan: We also talked about how to share all the information people need to know to make their decision. When we talked about the study, we made the information accessible by using pictures, easy to understand everyday words, and talking slowly. We also repeated the most important information. Remember everyone might need something different to understand.

When we did recruitment, we learned that sometimes we needed to learn a more individualized way to communicate with someone. We talked as a team and decided in these types of situations to create a list of ways to communicate and understand each other.

Micah: We talked with people and their supporters about what it looks like when they are saying yes and no. We wanted to make sure we didn't misunderstand what they were telling us.

Brendan: When we recruited people to be in our study, we gave them time to make a decision. One way to do this is by telling them all about the study and then letting them know they can decide later.

When they decide later they get more time to think and it is easier for them to say no. It might be really important to take extra time for studies that might hurt people or for studies where participants need to do a lot of things.



Katie: We practiced ways to act friendly, show we believe in people's abilities to make decisions, and help people know they can ask questions. When someone shared a worry, we gave them the information they needed to feel more comfortable.

Micah: We didn't pressure them to say yes to being in our study and we reminded them that we wouldn't be upset if they said no.



Ariel: We reminded them that even though their group home provider was excited about the study, they could still say no to being in the study and we wouldn't tell their service provider.

We knew how important it is to make it easy for people to say no, even when we were first telling them about the study. We used these communication cards so they could just point to their choice. We also included choices of telling us they needed a break or wanted to keep going.

Brendan: Ariel and Katie told us that it may be hard for people to understand that we are studying an experimental way to help them get better mental health services and that we don't know if it will work. We made sure to tell people that we didn't know if the study would help them a few times so they would understand.

Ariel and Katie also said sometimes it is hard for people to understand how the bad things that might happen can impact them. As part of the consent meeting, we helped people by making a card sort of reasons they would or would not want to be in the study. We helped them do the card sort and think about all the things that could happen in the study.





Consent information can look different for different studies. But usually consent forms have the most important information about a study, like why it is being done, what you will need to do if you are in it, the good and bad things that could happen, who is doing the research, and how the researchers will keep your information safe. Check out your workbook to see our consent form.