Research Ethics for All:
Accessible Research Ethics Education for Community Research Partners

Certification Checklist

After completing the training, work with each training participant individually to check their understanding of essential information required for certification by completing the certification activities in the workbook.

You can use these certification activities to reinforce learning and provide clarifications. As training participants complete the certification activities, you can prompt recall by asking guiding questions or referring training participants to their workbook materials or specific conversations or experiences your team has had.
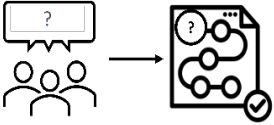
The Certification Checklist includes prompts that may support training participants and the content that should be included in responses to demonstrate understanding. The checklist can be used to document training participant's understanding. On the checklist you can also check off the prompts used to support the training participant to complete each activity.

When you are satisfied that the training participant has a basic understanding of the content, you can download a certificate template to provide to the training participant, save in your files, and submit to your IRB.

The completed full checklist and/or the summary form can be provided to document completion of certification activities should this be requested by your IRB or another entity.

1. **Describe, write, draw, or act out a definition of scientific research.**

Key content required in response:	Met criteria?
• Research is about answering questions • Research follows a plan	Y N
Prompts: • Why do we do scientific research? • What does this picture show? [point to image on page] • What do people learn from doing scientific research? • Look in your Research Words list. What is scientific research?	

2. **Describe, draw, write, or act out 3 ways community research partners can help with research studies.**

Key content required in response:	Met criteria?

• Any 3 of the following:
  o Help identify research questions
  o Share what it is like to be a person with a disability
  o Make sure research participants stay safe
  o Share ideas
  o Share opinions
  o Collect data
  o Interpret data
  o Share findings
  o Make sure research is respectful
  o Any other role/responsibility relevant to the community research partner
	Y N

Prompts: ❑ What do you do on your research team? ❑ What did the community research partners on the Mental Health for All team do? ❑ Why is it important for people with disabilities to be involved in research?	

3. **Describe, write, draw, or act out 1 or 2 reasons why we have rules for research.**

Key content required in response:	Met criteria?

• Any 1-2 of the following:
    ○ Keep people safe
    ○ Make sure people's rights are respected
    ○ Make sure people are respected
    ○ Help people trust research
    ○ Make sure research helps people and does not hurt them
    ○ Make sure researchers do the right thing
	Y N

Prompts: ❑ What would happen if there were not rules for research? ❑ How can rules help people be treated well? ❑ Why do you have rules at [school/work/setting relevant to community research partner] ❑ Look at the summary for Topic 2.1. What does it say about why we need rules for research?	

4. **Describe 1 way you can respect people's rights in research.**

Key content required in response:	Met criteria?

• Any of the following:
    ○ Keep their information private or confidential
    ○ Give them choices about being in research (voluntary consent)
    ○ Make sure they have the information they need to make a research participation decision (informed consent)
    ○ Talk to them directly about their decision to be in the research study
    ○ Make sure participants know they can stop at any time (ongoing consent)
    ○ Make information/processes accessible so people can make their own decisions.
    ○ Assume people have consent capacity until they show that they do not
	Y N

Prompts: ❑ What helps you feel respected? ❑ What are some rights people have in research? ❑ How can you make sure people know they can make their own choice? ❑ [If applicable]: Look at your Community Research Partner Rights and Responsibilities document. What did we agree to do to respect people's rights?	

5. Describe 2 ways you can keep people safe in research.

Key content required in response:	Met criteria?

• Any 2 of the following:
  ○ Keep their information private (they can name any approach to keeping information private, such as using ID numbers, passwords, or doing research in private locations).
  ○ Tell people what to expect about the research relationship
  ○ Make sure you don't talk about topics that are upsetting unless you really need to for the research
  ○ Have someone available in case a participant gets upset or needs help
  ○ Make sure the research activities happen in a safe place
  ○ Don't ask people to do anything that you know will hurt them
  ○ Have a plan in case someone gets hurt
	Y N

Example prompts: ❑ What helps you feel safe? ❑ What are some harms, or risks in research? How can you stop them from happening or make sure they aren't so bad? ❑ [If applicable]: Look at your Community Research Partner Rights and Responsibilities document. What did we agree to do to keep people safe?	

6. **If someone is considered vulnerable, we need to pay extra attention to how we do research with them. What are 2 things you can do to help respect someone who is vulnerable in research and keep them safe?**
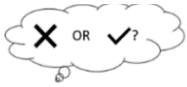
Key content required in response:	Met criteria?

• Any 2 of the following:
    ○ Give them extra time to make a decision.
    ○ Give them a chance to have someone help them make a decision.
    ○ Make sure they can understand the information you share.
    ○ Make sure they don't feel pressured by other people (for example, by talking to them alone, by letting them know all of their choices, by giving extra time, etc.).
	Y N

Example prompts: ❑ What does it mean for someone to be vulnerable? How can you help them? ○ Look at your Research Words list to help you find the definition for "vulnerable." ❑ Look at page 23 of your workbook. What ideas did you have to keep people who are vulnerable safe and respect them?	

7. **Review the Mental Health for All team's eligibility criteria. Decide if each person can be in their study.**

Circle the parts that match the eligibility criteria.

~~Cross out~~ the parts that do **not match** the eligibility criteria.

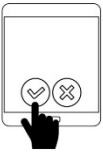| Key content required in response:	Met criteria?

• Correctly identify if 2/3 participants are eligible
  o Eligible: John
  o Not eligible: Sally, Taylor
	Y N

Example prompts: ❑ Refer the learner to eligibility criteria and ask them to match the criteria to each description	

Sally is 19 years old. She has Down syndrome. ~~She just moved to a new group home 2 months ago.~~ She calls you on the phone to say she saw your flyer. She is really interested in learning more about your study.

John is 30 years old. He is autistic and has lived in a group home for 3 years. He loves it there and hopes to live there for a long time. John uses pictures and short phrases to communicate. You meet him at a self-advocacy conference and he says he is interested in knowing more about the study.

Taylor is 42 years old. She has an intellectual disability. She has lived in a group home for 5 years and ~~speaks only Spanish~~.

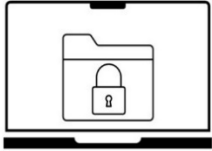8. **Sort the pictures into "it looks like they consent" and "it looks like they do not consent (dissent)."**

Key content required in response:	Met criteria?	
• At least 3 cards correctly sorted into "consent" and "dissent" Completed Card Sort	Y	N
Example prompts: ❑ What looks like someone saying "yes"? ❑ What looks like someone saying "no"? ❑ How do you think [point to picture] feels?		

9. **Describe 3 ways you can keep participants' information (data) private and confidential**

Key content required in response:	Met criteria?	

• Any 3 of the following:
    o Replace names with ID numbers
    o Do research in a private place
    o Change people's names when you write about research
    o Only talk about the information you learn and the people in the study with your research team
    o Use passwords
    o Have a plan for how to keep paper copies of data safe
    o Not saying hi to research participants in public unless they say hi first/not talking about research in public with research participants
    o Any other response related to privacy/confidentiality of data
	Y	N

Example prompts: ❑ How can we make sure people who are not on the research team don't get research participants' information? ❑ How do you keep information private in your personal life? Can you use some of those same ideas/things in research? ❑ Look at the summary in Topic 4.2. What does it help you remember about keeping information private and confidential? ❑ [If applicable]: Look at your Community Research Partner Rights and Responsibilities document. What did we agree to do to keep information private and confidential?		

10. Sort the information about participants into the categories: "confidential" and "not confidential."

Key content required in response:	Met criteria?	

• At a minimum, the following are in the "confidential" category:
      ○ Full name
      ○ Birthdate
      ○ Whether or not someone participated in a study
      ○ Address
 • For other cards sorted as "confidential," if the community research partners has a strong rationale for sorting the cards in a different way, alternatives may be accepted.
 • Competed card sort
	Y	N

Example prompts:
 ❑ What information might "give away" who someone is?
 ❑ Look at the definition for "individually identifiable data."
      ○ What does that mean?
      ○ What do we need to do with information that is "individually identifiable data"?
      ○ What cards show "individually identifiable data"?
 ❑ What information would you not want someone knowing about?		

11. Sometimes we have to break confidentiality to keep participants safe. This is called mandatory reporting. What is 1 thing that participants might talk about that you would have to share with someone else?

Key content required in response:	Met criteria?

• Any of the following
    ○ Abuse
    ○ Neglect
    ○ Hurting someone else
    ○ Wanting to hurt themselves
	Y N

Example prompts: ❑ Look at the definition of "mandatory reporting." What information do we have to share if we find out? ❑ What are some situations when people are not safe and they might need help?	

Facilitator Signature: _____

Summary Score Form

Community Research Partner Name:

Facilitator Name: Facilitator Title and Institution:

Date of Certification:

Certification activity	Met criteria		# Prompts				
1. Describe, write, draw, or act out a definition of scientific research	Y	N	0	1	2	3	4+
2. Describe, draw, write, or act out 3 ways community research partners can help with research studies.	Y	N	0	1	2	3	4+
3. Describe, write, draw, or act out 1 or 2 reasons why we have rules for research	Y	N	0	1	2	3	4+
4. Describe 1 way you can respect people's rights in research.	Y	N	0	1	2	3	4+
5. Describe 2 ways you can keep people safe in research.	Y	N	0	1	2	3	4+
6. What are 2 things you can do to help respect someone who is vulnerable is research and keep them safe?	Y	N	0	1	2	3	4+
7. Review the Mental Health for All team's eligibility criteria. Decide if each person can be in their study.							
Sally	Y	N	0	1	2	3	4+
John	Y	N	0	1	2	3	4+
Taylor	Y	N	0	1	2	3	4+
8. Sort the pictures into "it looks like they consent" and "it looks like they do not consent (dissent)." (at least 3 cards correctly sorted into "consent" and at least 3 cards correctly sorted into "dissent")	Y	N	0	1	2	3	4+
9. Describe 3 ways you can keep participants' information (data) private and confidential	Y	N	0	1	2	3	4+
10. Sort the information about participants into the categories: "confidential" and "not confidential."	Y	N	0	1	2	3	4+
11. What is 1 thing that participants might talk about that you would have to share with someone else? (mandatory reporting)	Y	N	0	1	2	3	4+

Facilitator Signature: _____