

## PAPERWORK REDUCTION ACT STATEMENT

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## BACKGROUND AND INSTRUCTIONS

Thank you for participating in this online bulletin board discussion! We're interested in your thoughts and opinions on some materials that have been created for the Adolescent Brain Cognitive Development (ABCD) Study<sup>SM</sup> —the largest long-term study of brain development and child health in the United States.

Over the next two days, we want to get your feedback on anything that isn't clear, anything that might be offensive, or anything that might make someone feel like their life experiences aren't included. We will post some starting questions, but a moderator will also respond to your answers with some follow-up questions for you. You can also respond to other people's comments, and they can respond to yours.

Before you get started, here are some "ground rules" for the discussion:

- Your **total time** spent on this Bulletin Board Forum will be approximately **60 minutes** (across two days). It is up to you how you spend your time answering questions, but we encourage you to check in on Day 1 and Day 2 to respond to any follow-up questions from our moderator and to see what others have posted.
- *After* you answer each question, you will be able to see how others answered the same question. You will be able to react to comments from other participants in the Bulletin Board Forum as well as interact with the moderator.
- We want to hear all opinions and perspectives—there are no right or wrong answers to these questions. Please be respectful of all opinions and perspectives.
- This activity can be completed on a computer (desktop or laptop) or using a smartphone/tablet, whichever you prefer. You can choose to type your answers or record a video.

- At the end of the discussion, we will download everyone's feedback for the purposes of our report. If you choose to record video answers, these will be transcribed and the videos deleted after the close of the Bulletin Board Forum.
- All information and opinions you give us will be kept **private**. Your identity will not be shared with anyone outside of the feedback team or project staff. Please do not share any information which could be used to identify you or someone else, such as full names, the name of your town, or your school's name.
- Project staff may read responses, but only the moderator and other people on the teen feedback team will be post and answer questions during our discussion.
- Your feedback will only be used to help make sure that questions and instructions for the ABCD Study® are written in the best way possible. This means we may share some comments with people who work on the ABCD Study but without any information that could identify who you are.

Thank you for reading our "ground rules." Now, let's get started!

## PARTICIPANT INTRODUCTIONS

Let's start by introducing ourselves! Please share your name (first name only) and something you like to do for fun.

[SUBSEQUENT ACTIVITIES: If this is your first time joining a feedback team activity, please introduce yourself using your first name only (no last names). If you are returning feedback team member, welcome back! Please share your first name for any new members in this bulletin board activity.]

## MATERIAL TESTING

Today we are going to look at something called a "visual consent form." First, I wanted to ask some discussion questions to get us all thinking about why the ABCD Study team created this and how you can help them make it better.

1. Think about a time when you signed up for something, and you had to sign or check a box showing you understood what that agreement meant. This could be something like agreeing to the rules for joining a group or signing up for a new app. (This could even be the agreement to join the feedback team!)

What are three words you would use to describe that process?

The ABCD Study team created a consent form that uses pictures to explain what people in the study can expect if they agree to participate. For each page, I am going to ask some questions about whether what is on that page is clear, what you think about the visuals, and if there is anything you would change. Some of these questions might repeat, and that's because it is important for us to know that information for each page.

[STIMULI 1: COVER PAGE] Here is what the first (or cover) page will look like. As a reminder, this is a form used by people who are currently part of the ABCD Study. They will be using this form to agree to keep participating in the study, since they will be part of it for many years.

2. What is one part of this image that grabbed your attention and why? (Was it surprising, confusing, eye-catching, or something else?)
3. What questions do you have after reading the cover page?

[STIMULI 2: STUDY GOALS PAGE] Let's look at the page titled "Goals of the ABCD Study."

4. In your own words, what is this page saying?
5. [Poll]: Overall, how clear is this page?
  - Very clear – I understand it completely
  - Somewhat clear – I understand at least half of it
  - Somewhat unclear – I understand some of it (less than half)
  - Not very clear – I don't understand much or any of it

Tell me more about your choice. What made it clear? Unclear?

6. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.
7. What questions do you have after reading this page?

[STIMULI 3: TIMELINE] This page explains the timeline of the ABCD Study.

8. What do you like about the visual? What do you dislike? For example: the symbols, the images of people, colors, or anything else you like or dislike.
9. What parts of the visual, if any, raise questions for you?
10. In your own words, explain what you think will happen during the timeline of the study.
11. What questions do you have after looking at this page?

[STIMULI 4: STUDY PROCEDURES 1] This is the first page that describes the activities that will take place during the study.

12. [Poll]: How clear are the descriptions of the study procedures on this page?
  - Very clear – I understand them completely
  - Somewhat clear – I understand at least half
  - Somewhat unclear – I understand some (less than half)
  - Not very clear – I don't understand much or any of them

Tell me more about your choice. What made it clear? Unclear?

13. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.

[STIMULI 5: STUDY PROCEDURES 2] This page explains some of the study procedures where researchers need to take a measurement or collect a small amount of blood, urine, hair, or saliva from someone.

14. What do you like about the visuals on this page? What do you dislike?
15. [Poll]: How clear is this page about what samples will be taken and why?
- Very clear – I understand it completely
  - Somewhat clear – I understand at least half of it
  - Somewhat unclear – I understand some (less than half)
  - Not very clear – I don't understand much or any of it

Tell me more about your choice. What made it clear? Unclear?

16. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.

17. What questions do you have about the samples and measurements described on this page?

[STIMULI 6: MRI BRAIN SCAN] This page explains the MRI part of the study, which is used to take a picture of someone's brain.

18. Before you read this page today, how much did you know about MRI? (For example: have heard of it, know someone who had one, or even had one yourself.)
19. How well does this page explain what MRI is and what someone could expect during the brain scan?
20. What do you like about the visuals on this page? What do you dislike?

[STIMULI 7: TECH DATA COLLECTION] This page explains some studies that use technology to collect information.

21. [Poll]: How clear is the description of the sub-studies on this page?
- Very clear – I understand it completely
  - Somewhat clear – I understand at least half of it
  - Somewhat unclear – I understand some (less than half)
  - Not very clear – I don't understand much or any of it

Tell me more about your choice. What made it clear? Unclear?

22. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.

23. What questions do you have about this part of the study?

24. What thoughts do you have about using technology to track your screen time or sleep?

[STIMULI 8: CONFIDENTIALITY] This page talks about some important concepts related to being part of the ABCD Study.

25. In your own words, how would you describe what the page means by “confidentiality”?
26. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.
27. What questions do you have about how the ABCD Study keeps people’s answers confidential, including times when the study team may need to tell someone about something they learn?

[STIMULI 9: VOLUNTARY RESEARCH] This page talks about another important concept related to being part of the ABCD Study.

28. This page has some examples of what they mean when they say the research activities in the ABCD Study are “voluntary.” What does “voluntary” mean to you?
29. In your own words, what is this page trying to say?

30. [Poll]: How clear is this page?
  - Very clear – I understand it completely
  - Somewhat clear – I understand at least half of it
  - Somewhat unclear – I understand some (less than half)
  - Not very clear – I don’t understand much or any of it

Tell me more about your choice. What made it clear? Unclear?

[STIMULI 10: STUDY COMPENSATION] This last page explains the compensation that someone in the ABCD Study could receive.

31. [Poll]: How clear is this page?
  - Very clear – I understand it completely
  - Somewhat clear – I understand at least half of it
  - Somewhat unclear – I understand some of it (less than half)
  - Not very clear – I don’t understand much or any of it

Tell me more about your choice. What made it clear? Unclear?

32. Is there anything on this page that is confusing or not how you would say it? What would be a better way to phrase it? You can type or copy and paste any words or phrases into your answer.
33. What questions do you have after reading this page? (Note: We understand that this page refers to another form that we didn’t show you today.)

## WRAP UP

34. Which ONE piece of information do you remember MOST clearly?

- a. What was it about that information that made it stand out to you?
- b. What do you remember about the wording of that information? What about the visuals?
- c. What do you feel the main idea of that information was trying to communicate?
- d. What is one new thing you learned from that information?

35. Is there anything else that the ABCD Study team should add to, change, or take out of this form to improve it?

**CLOSE**

Those are all the questions we have for you today. Thank you very much for sharing your thoughts and for being part of our feedback team!