

## 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 this discussion group 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 feedback teams will be making posts and answering 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

For this activity, we are going to look at: [Example stimuli] a draft consent form for learning about genetic results. This is a draft, so the final graphics and text are not finished yet.

For each page, I am going to ask some questions about whether what is on that page is clear, your thoughts on the visuals and text, 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: INTRODUCTION]

The ABCD Study looks at genetic information people in the study provide. ABCD Study wants to give teens and their families the option of learning more about the results of tests that look at your genes for those risks. This form will be addressed to the teens in the study, but we are also interested in hearing feedback on it from parents and caregivers.

1. In your own words, what is this page saying?
2. [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?

3. 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.
4. What questions do you have after reading this page?

[STIMULI: "What will my Hereditary Disease Risk results tell me?"]

5. In your own words, what is this page saying?
6. [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?

7. 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.
8. What questions do you have after reading this page?

[STIMULI: "How will I get my results?"]

9. [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?

10. 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.
11. What questions do you have after reading this page?

[STIMULI: "What are the risks of getting my Heredity Disease Risk results?"]

12. [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?

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.

14. What questions do you have after reading this page?

[STIMULI: "Could learning about my heredity disease risk affect my insurance?"]

15. [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?

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 after reading this page?

[STIMULI: "How could learning about my hereditary disease risk affect me emotionally?"]

18. [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?

19. 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.

20. What questions or thoughts do you have about talking with family about hereditary disease risk?

[STIMULI: "What are the benefits of learning about my hereditary disease risk?"]

21. [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?

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 page?

[STIMULI: "What are the limits of my Hereditary Disease Risk results from the ABCD Study?"]

24. [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?

25. 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.

26. What questions do you have after reading this page?

[STIMULI: "What are my choices?"]

27. [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?

28. 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.

29. What questions do you have after reading this page?

## WRAP UP

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

- a. What was it about that information that made it stand out to you?

## CLOSE

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