

PAPERWORK REDUCTION ACT STATEMENT

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MODERATOR'S GUIDE

HOUSEKEEPING

Please note: Participants have been asked to log in 5 to 10 minutes prior to the start of the discussion. During this time, the moderator will ensure that each participant can see the shared screen, is in a private space with no other individuals present, and knows how to mute their microphone when not speaking.

Before we begin, I just want to make sure that you're able to see the shared screen and are able to minimize background noise (either by using headphones or being in a quiet room).

A few housekeeping items to review:

- Our discussion will be recorded so that I can refer to the recording as needed for my report writing, and my colleague is also on the line to take notes. In addition, other project staff are on the line listening to today's discussion. **Are you okay with this discussion being recorded? [Moderator to dismiss anyone who objects to the recording. Notetaker to press "record."]**
- We will use the findings from today's discussion only to inform the development of questions asked in the Adolescent Brain Cognitive DevelopmentSM Study, also called the ABCD Study[®].
- Please put your smartphone or tablet on Do Not Disturb mode while we are in this discussion. I want to make the most of our time together.

In terms of your feedback:

- There are no right or wrong answers to any of the questions I will be asking. Please be honest.
- If something feels uncomfortable or unclear, we want to know. Please don't worry about being polite, or holding back. I didn't write any of the questions we're going to be looking at together.
- You are not required to answer every question. You can "pass" if any question makes you uncomfortable. You are also free to stop participating at any time.

BACKGROUND

Good [evening/afternoon]. Thank you for taking the time to participate in this discussion. My name is [XXXX], and I am going to facilitate our conversation.

- I am a trained moderator with IQ Solutions, a company that is holding these discussions to help the National Institute on Drug Abuse (or NIDA).
- NIDA manages the Adolescent Brain Cognitive Development (ABCD) Study—the largest long-term study of brain development and child health in the United States.
- We're looking for your feedback on some materials the Study uses to give people an idea of research activities related that are part of the ABCD Study.
- We want to make sure any questions/instructions don't leave anyone confused, uncomfortable, offended, or feeling like their experiences aren't included.

INTRODUCTION

For our first question:

1. What is one thing you are looking forward to this [season]?

FEEDBACK ON SURVEY QUESTIONS

I would like to get your feedback on some survey questions that the ABCD Study would like to use later this year. I don't need to know what your answers would be to these questions. Instead, I am interested in hearing your feedback on how these questions are written.

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

2. In your own words, what do you think this question is asking about?
3. How would you think about answering this question? As a reminder, I don't need to know your answer—rather, I want to hear you talk me through how you would get to the answer.
[Probe on definitions, examples, confusing areas]
4. What other questions are important to ask on this topic?

[Stimuli description:] One topic important to the ABCD Study is mental health. The question writers want to make sure they are asking questions about mental health that are up-to-date and relevant.

5. What are the most important mental health topics that the ABCD Study should be asking older teens and young adults about?
6. How do teens and young adults get mental health services or treatments?

FEEDBACK ON STUDY MATERIALS

Now I'm going to switch topics a bit. In the survey activity you completed before this discussion, we asked you to look at some materials or instructions that will be used in the ABCD Study later this year.

What is the process? How do I get my results?

We are only returning results from the ACMG list. Most people (about 97 out of 100 people) will get a report that says ABCD did not find DNA differences related to diseases in the ACMG list. If we find a DNA difference from the ACMG list on our initial test, someone from the ABCD Study team will try to contact you directly to get another DNA sample to confirm the results. If the confirmation test is positive, an ABCD Study genetic counselor will reach out to you to discuss the results.

- There is no charge to talk with a genetic counselor.
- They will send you a report, tell you what your results mean, and answer your questions.
- They can send a report to your health care provider, who will help you decide what medical treatment or tests you might need.



What is a genetic counselor?
A genetic counselor is a health care professional trained to talk with people about how the differences in their DNA may affect their health. They help people understand information about their DNA differences and the options available for genetic testing, but they do not provide treatment.

Watch a [video](#) to learn more about genetic counselors.

It may take a few years to get your results. If you have not heard from anyone in the ABCD Study, your sample may not have been studied yet.

7. What did you find surprising on this page?
8. What, if anything, did you find confusing on this page?
9. How would you summarize this page in your own words?
10. What questions do you have after reading this page?

Could learning about my genetic risk affect my employment or insurance?

Most of the time, your health insurance and employment opportunities will not be affected. Under Federal law (as of 2024):

- Health insurers **cannot** use DNA information to decide if they will add you to an insurance plan ("cover" you), change or cancel your coverage, or charge you more for insurance.
- Employers **cannot** use DNA information in decisions like hiring, firing, promotions, pay, and job assignments.

The federal law does not apply to the military or employers with fewer than 15 employees. They are permitted to use DNA information obtained from your medical record to make employment decisions.

Other types of insurance are different

- In most places, companies that offer disability insurance, life insurance, or long-term care insurance **can** use DNA information to decide if they will cover you and how much to charge you.

Employers and insurers can ONLY get this information from your medical record.

- Getting your results back from us **does not** automatically add them to your medical record.
- If you end up with a medical diagnosis or get treatment based on your results, that **will** become part of your medical record.



Life insurance pays money to people you specify (like a spouse or children) if you die.

Disability insurance gives you some income if you lose the ability to work due to a disability.

Long-term care insurance helps pay for the cost of care to help with daily living, like in-home nurses, nursing home care, or end of life care.

11. What did you find surprising on this page?
12. What, if anything, did you find confusing on this page?
13. How would you summarize this page in your own words?
14. What questions do you have after reading this page?

[Stimulus Description:] Now I would like to ask about giving feedback. The ABCD Study would like to give the people participating in the study some options for providing feedback on being part of the study.

15. Can you tell me about a time you gave feedback to a company, a business, or an organization? Just to clarify: we're looking for an experience outside of being part of our audience feedback team.

CONCLUSION AND OBSERVER QUESTIONS

I have one last question:

16. What is one thing you read or heard about in this discussion that was new to you?

Now I'd like to ask the observers if they have any additional questions or need clarification on any of the issues we've discussed. *[Moderator will review any questions from observers via a private communication channel and pose those to the participants, as time allows.]*

Thank you so much for taking the time today to discuss these topics with me. The sponsors of this project appreciate your honest feedback and reactions.