

PAPERWORK REDUCTION ACT STATEMENT

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MODERATOR'S GUIDE

HOUSEKEEPING

Please note: Participants have been asked to log in a few minutes prior to the scheduled start time of the group discussion to begin on time. 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, can anyone NOT see the shared screen? If you cannot, please let me know now.

A few housekeeping items to review before joining today's call:

- 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. **Does anyone object to this discussion being recorded? [Moderator to dismiss anyone who objects to the recording. Notetaker to press "record."]**
- We will use first names only during today's discussion, and I will report all findings from our conversation in summary form, never connecting an individual comment with an individual name. This means that I will acknowledge that *someone* in this group made a comment but not anything about who you are (like your name, town, or school).
- To maintain everyone's privacy, please do not share any specific comments other participants say during the discussion with anyone. You can talk about your experience participating in this project, but please do not share anything someone else says about their identities or experiences.
- 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 mute your microphone when you are not speaking to minimize background noise.
- 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 anything you'll see on the screen.
- It is valuable for me to hear all points of view, so please talk respectfully, one at a time, and let other participants finish what they're saying before speaking.
- 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], I use [XXXX] pronouns, 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 of the questions, graphics, and instructions that will be asked of other people in the study later this year.
- When we ask for your feedback on questions, we don't need to know what your answers to the questions would be—just your reactions to how the questions are written.
- We want to make sure the questions or instructions don't leave anyone confused, uncomfortable, offended, or feeling like their experiences aren't included.

PARTICIPANT INTRODUCTIONS

Thank you all for joining our discussion today. I am now going to go around the virtual "table" and call your first name. Please introduce yourself **briefly** by letting us know:

1. The name that you would like me to use during this discussion—remember, no last names—and the pronouns you use, if you would like.
2. Something you are looking forward to this school year.

Okay, let's get started on our questions.

FEEDBACK ON SURVEY QUESTIONS

We would like to get your feedback on some survey questions that the ABCD Study would like to use later this year. Thank you for the feedback you shared in the pre-discussion survey! In this part of the discussion, we want to ask some more questions to make sure the questions are written in the best way possible.

[Stimuli description:] This question asks about difficulties someone might experience with doing activities.

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

3. In your own words, what do you think this question is asking about?
4. 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]

5. What other questions are important to ask on this topic?

[Stimuli description:] Here is another version of the question.

Do you experience difficulty in doing certain activities and interacting with the world around you because of a physical, mental, emotional, or behavioral condition?

- Yes
- No
- Decline to answer

6. How would you think about answering this question?

[Probe on definitions, examples, confusing areas]

FEEDBACK ON STUDY MATERIALS

Now I'm going to switch topics a bit. I would like your feedback on some materials or instructions that will be used in the ABCD Study later this year.

[Stimuli description:] I'd like to get your feedback on some of the pages from a consent form for getting results from a genetic test for health risks. You might remember seeing the consent form during the discussion in the spring. Some of these pages were revised based on what youth and parents in the feedback teams shared in the last discussions—if you participated, thank you for your feedback. I would like to get your feedback on some of those pages today.

What will my results tell me?

Genetics can influence risk across a large number of diseases in different ways; however, we will only share results on a restricted set of DNA differences that are on a list developed by the [American College of Medical Genetics \(ACMG\)](#). Not all serious diseases caused by genetics are included on this list. The ACMG list was specially designed by a group of experts to include DNA differences that are very likely to increase your risk of getting certain diseases or health conditions, like some cancers and types of heart disease, and are also substantially treatable or preventable. About 97% of people DO NOT carry these disease risk DNA differences on the ACMG list.

We only want to give you test results that may be useful to your future health decisions.

For that reason, the results we will share include health conditions where:

- Medical treatment is available.
- Early diagnosis is helpful for treatment.
- A DNA test is the main way you would learn that you are at increased risk for that condition.

The results will **not** include conditions that:

- Do not have a medical treatment option.
- Would be treated with lifestyle change, like not using tobacco products.
- Would typically be diagnosed by a doctor.

The reason we only provide test results for DNA differences that meet these criteria is to reduce unnecessary anxiety that could arise from finding out about disease risk for which no treatment exists.

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?

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.

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?

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.

15. What did you find surprising on this page?

16. What, if anything, did you find confusing on this page?

17. How would you summarize this page in your own words?

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

What are the possible benefits of getting my genetic risk results?

Your results could help you make decisions about your health care that reduce your risk of getting disease in the future.

- If you learn that you have a DNA difference related to diseases on the ACMG list, you may be able to work with your health care provider to prevent the disease from developing or to detect it and start treatment early.
- We will only tell you about DNA results from the ACMG list where there is a proven medical treatment to help. In some cases, knowing this information can be lifesaving.

You could discover something that helps explain the history of a health condition in your family.

- If you have certain DNA differences, your blood relatives might have them too.
 - "Blood relatives" are people who you typically share DNA with, such as your parents and siblings.
 - Twins, triplets, and other siblings may share a lot of DNA, including DNA differences related to disease.
 - Because the genetic test results might impact your blood relatives, you should discuss with your family whether **you** want to learn about your results and whether **they** would also want to learn about **your** results.
- Having this information could help you talk with your family about their health. Everyone's DNA is different, but sharing your results with your blood relatives can help them think about their own risks. They can decide if they want to get tested themselves. This could end up helping them stay healthy for longer.

19. What did you find surprising on this page?

20. What, if anything, did you find confusing on this page?

21. How would you summarize this page in your own words?

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

FEEDBACK ON LIFE EXPERIENCES

For this part of the discussion, we are interested in your experiences with certain topics that the questions writers may want to include in the ABCD Study.

[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.

23. What are the most important mental health topics that the ABCD Study should be asking people your age about?

24. How do people your age get mental health services or treatments?

[Stimuli description:] The ABCD Study would like to give the people participating in the study some options for providing feedback on being part of the study.

25. 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:

26. 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 as a group. The sponsors of this project will appreciate your honest feedback and reactions.