

## 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.

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.

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

- 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 Development<sup>SM</sup> 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

- 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.
- 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."]**

## 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 [season].

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:]* These questions ask how much someone worked in the last 12 months and how much they earned from work.

How many months out of the year did you work?	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4 <input type="radio"/> 5 <input type="radio"/> 6 <input type="radio"/> 7 <input type="radio"/> 8 <input type="radio"/> 9 <input type="radio"/> 10 <input type="radio"/> 11 <input type="radio"/> 12 <input type="radio"/> Don't know <input type="radio"/> Decline to answer
During the past 12 months, how much did you yourself earn before taxes?  (Include only pay for work, such as salary, wages, tips, commissions, etc.)	<input type="radio"/> \$0 <input type="radio"/> \$1 - \$2499 <input type="radio"/> \$2500 - \$4,999 <input type="radio"/> \$5,000 - \$11,999 <input type="radio"/> \$12,000 - \$15,999 <input type="radio"/> \$16,000 - \$24,999 <input type="radio"/> \$25,000 - \$34,999 <input type="radio"/> \$35,000 - \$49,999 <input type="radio"/> \$50,000 - \$74,999 <input type="radio"/> \$75,000 - \$99,999 <input type="radio"/> \$100,000 - \$199,999 <input type="radio"/> \$200,000 - \$299,999 <input type="radio"/> \$300,000 or more <input type="radio"/> Don't know <input type="radio"/> Decline to answer

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]*


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

In the past 12 months, when did you work (e.g., including jobs, internships, volunteer work)?	<input type="radio"/> Seasonal (summer, holidays) <input type="radio"/> While you were enrolled in school/taking classes <input type="radio"/> Year-round <input type="radio"/> Other <input type="radio"/> Don't know <input type="radio"/> Decline to answer
How many hours per week did you typically spend working in the last 12 months? (If more than one work experience, answer for the position that took the most time)	<input type="radio"/> 5 hours or less <input type="radio"/> 6-10 hours <input type="radio"/> 11-20 hours <input type="radio"/> 21-35 hours <input type="radio"/> 36-40 hours <input type="radio"/> More than 40 hours <input type="radio"/> Don't know <input type="radio"/> Decline to answer
About how much did you earn PER HOUR on the average? (Answer for your most important job and include all earnings before deductions. If not sure, guess.)	<input type="radio"/> Did not get paid <input type="radio"/> Less than \$12 <input type="radio"/> \$12 - \$14.99 <input type="radio"/> \$15 - \$19.99 <input type="radio"/> \$20 - \$24.99 <input type="radio"/> \$25 - \$29.99 <input type="radio"/> \$30 - \$39.99 <input type="radio"/> \$40 - \$80 <input type="radio"/> More than \$80

4. How would you think about answering this question?

*[Probe on definitions, examples, confusing areas]*

*[Stimuli description:]* This question asks about how people see themselves doing in life.

<p>At the top of the ladder are the people who are the best off, those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off, those who have the least money, least education, worst jobs, or no job. Please place an 'X' on the rung that best represents where you think you stand on the ladder.</p>	
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5. How would you think about answering this question?

*[Probe on definitions, instructions, confusing areas or wording that makes it hard to answer]*

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

Think of this ladder as showing where people stand in the United States. At the top of the ladder are the people who are best off – those who have the most money, the best education, and the most respected jobs. At the bottom are the people who are worst off – those who have the least money, the least education, and the least respected job or no job. The higher up you are on this ladder, the closer you are to the people at the top; the lower you are, the closer you are to the people at the bottom. Where would you place yourself on this ladder? Place an “X” on the rung where you think you stand at this time of your life relative to other people in the United States.



6. How would you think about answering this question?

*[Probe on definitions, instructions, 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 ABCD Study participants to share their electronic health records. I would like to get your feedback on some of those pages today.

### **What are EHRs?**

Health records are the information collected about you when you get health care. They include information about the care you get. Electronic health records, or EHRs, are when this information is kept in secure electronic systems.

### **Why is this study being done?**

Your EHRs contain important information about your health. They are a way for researchers to get a picture of your health over a long period of time.

We will add your EHRs to your ABCD Study data we have already collected. This will allow researchers to use these health records alongside your other ABCD Study data to better understand adolescent and young adult development. Information from your record will be part of the ABCD Study database. Information that directly identifies you, like your name or address, will **not** be part of this database, like with the rest of your ABCD data. Before researchers will be allowed to see your data, they will have to sign a contract agreeing they will not try to find out who you are. This contract also says how they can and cannot use your data. Researchers will use this database to make discoveries about health. You can learn more about the research being done at <https://abcdstudy.org/publications/>.

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 in my EHRs?**

The information in your EHRs depends on what kinds of health care providers you see. Your EHRs tell about any health problems you have seen a health care provider about. They tell about care you have received. They may list the medicines you take. They may have laboratory/test results. They may have images, like X-rays. If you have had a medical procedure, notes about it will likely be in your EHRs. Any time you see or have any interaction with a health care provider that uses EHRs, a note is created.

Your EHRs may also tell how much you were billed and how much you paid for your care.

### **Is there sensitive information in my EHRs?**

There may be sensitive information in your EHRs. For example, there may be information about your use of alcohol or drugs. Or about tests and treatments for sexually transmitted infections, like HIV. They may have results from genetic (DNA) tests. We will be able to see this information.

If you have seen healthcare providers such as doctors, nurses, social workers, medical technicians or counselors, information about your diagnosis and treatment may be in your EHRs. For example, if you have seen counselors or doctors who treat

- addictions (also known as substance use disorders);
- mental health conditions, like depression or bipolar disorder; or
- trauma, from things like domestic violence and sexual assault.

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?

**How will my confidentiality and privacy be protected? Is there anyone else who will see my EHRs?**

Like with the rest of your ABCD Study data, we will add your EHRs to the ABCD Study data resource that is broadly available to researchers. It will not include your name or other information that directly identifies you, like your address or other identifiers. Access to this database is strictly controlled. Before researchers will be allowed to access the data, they will have to sign a contract agreeing they will not try to find out who you or other participants are. This contract also says how they can and cannot use your data. These researchers may be from anywhere in the world. They may work for commercial companies, like drug companies. Their research may be on nearly any topic.

Your information may no longer be protected by patient privacy rules (like "HIPAA") once you share it with ABCD. This is because ABCD does not provide medical care. The patient privacy rules that apply to health care providers do not apply to ABCD. The copies of your EHRs that are with your health care providers will still be covered by HIPAA. The copies that are shared with ABCD will be protected by other privacy rules and agreements like those described in this consent form and your main ABCD Study consent form. These include the rules and agreements that researchers must follow to use the ABCD Study database.

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 if I don't want ABCD to have my EHRs? What if I change my mind?**

Sharing your EHRs with ABCD is voluntary. You get to choose. No matter what you decide, it will not affect your medical care. It will not affect your treatment, payment, enrollment, or eligibility for any health care benefits. It will not affect your ability to continue in the ABCD Study.

If you decide to authorize ABCD to get your EHRs, you can change your mind at any time. If you decide you want to stop allowing us to get this information, you need to tell us. You can use the contact information at the end of this form to call or write to us.

If you tell us to, we will stop getting your EHRs. Data from your EHRs will not be used for new studies. But, if researchers have already used data from your EHRs for their studies, ABCD cannot get it back. Also, we will let researchers check the results of past studies. If they need your old data to do this work, it will be given to them.

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?

## CONCLUSION AND OBSERVER QUESTIONS

I have one last question:

23. What is one thing that researchers should be asking young adults questions about, to better understand this time in their lives?

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.