# PAPERWORK REDUCTION ACT STATEMENT

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| --- | --- |
| **SESSION OVERVIEW**  | **Stimuli** |
| Housekeeping and Background (2 minutes)  |  |
| Whole Genome Sequencing Consent Form (10 minutes) | Consent Form Slides |
| Gun Access Questions (6 minutes)  | Gun Access Questions  |
| Answering Survey Questions for Teens (10 minutes) | Sample Question Topics |
| Conclusion (1 minute) |  |

# MODERATOR’S GUIDE

## HOUSEKEEPING [1 minute]

*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 Development StudySM, 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 [1 minute]

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.

## ICEBREAKER [1 minute]

For our first question:

1. What is one thing you have always wanted to know about how teenagers’ brains work?

## WHOLE GENOME SEQUENCING CONSENT [10 minutes]

We’re going to start by discussing genes and DNA. The ABCD Study looks at genetic information from the samples people in the study provide. The ABCD Study wants to give teens and their families the option of learning more about the results of genetic tests for diseases.

First, I want to have everyone take a look at this description of the results of genetic tests, also known as “Hereditary Disease Risk results.”

[STIMULI: “What will my Hereditary Disease Risk results tell me?” slide]

1. After reading this slide, can you tell me in your own words what “hereditary disease risk” means?

This next slide describes the limits of the test.

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

1. Can you tell me, in your own words, what the limits of the test are—what the results CANNOT tell someone about disease risks related to their DNA changes?

*[Probe: diagnosis/treatment options, current disease status, limits of current knowledge about DNA risk, knowing/not knowing about diseases that can’t currently be treated]*

1. In your opinion, what are the pros (or benefits) and cons (or risks) of learning about hereditary disease risk?

Now I want to show you some slides that the ABCD Study team has created to talk with people about the risks and benefits of learning about the results of tests for diseases linked to genes.

[STIMULI: “What are the risks of getting my Hereditary Disease Risk results?” and “What are the benefits of learning about my hereditary disease risk?” slides]

1. How well does this slide describe the benefits? What “pros” or benefits would you add to the slide?

*[Probe based on the pros/cons discussed in previous question.]*

1. How well does this slide describe the risks? What “cons” or risks would you add to the slide?

*[Probe based on the pros/cons discussed in previous question.]*

1. How involved would you want yourself or other family members to be in the decision to learn about the results of your teen’s genetic tests?

1. Which option would you prefer, and why? Which do you think your teen would prefer?

*[Read options:]*

Your teenager could get the results of their genetic test before they turn 18 but would need to get permission from a parent or legal guardian;

OR

They would have to wait until they turn 18 but they could get the results without a parent or guardian’s permission.

1. Would you want to get your teen’s results back if the study found one of the DNA changes related to disease risk? Would you want them back even if there weren’t any DNA changes related to disease risk?
2. The ABCD Study will have genetic counselors available to talk about the results of the genetic tests. Genetic counselors are medical professionals who specialize in understanding and talking with people about the results of genetic tests. Would you want to speak to one before deciding whether to get genetic test results back? What kinds of questions might you ask?

*[Probes: For example, what if you were learning the results of a test for risk of breast cancer? What would you want to know before getting your results? What about after?]*

## ACCESS TO GUNS [6 minutes]

Now I have some questions that ask about access to guns or firearms.

[STIMULI: Access to Guns Measure]

|  | Yes | No | Don’t Know | Decline to Answer |
| --- | --- | --- | --- | --- |
| Are any firearms now kept in or around your home? |  |  |  |  |
| Are any of these firearms now loaded? |  |  |  |  |
| Are any of these loaded firearms also unlocked? |  |  |  |  |

1. Would any of these questions be hard or uncomfortable to answer? For example: not having the information, not wanting to say, being uncomfortable talking about it, or something else.
2. What changes would you make to any of these questions to make them clearer?

*[Probe: Word choices like “firearm” or “gun,” definitions for “loaded” and “locked,” etc.]*

1. What other questions are important to ask about access to guns or firearms?

*[Probe: access to ammunition, access to guns outside of home]*

## PARENTS AND CAREGIVERS ANSWERING SURVEYS ABOUT THEIR TEENS [10 minutes]

In the ABCD Study, researchers ask survey questions of parents and caregivers about their children. These questions cover topics like health, extracurricular activities, emotions, and behaviors of their child.

Here is a slide showing a summary of the topic areas. If you want to see an example question for one of those topics, let us know and we can pull it up.

[STIMULI: ABCD PARENT SURVEY TOPICS]

|  |
| --- |
| * Moods, Emotions, Mental Health
* School Attendance, Grades, Behavior in School, Focusing on Tasks
* Major Life Events
* Medications, Health Problems, Doctors’ or Hospital Visits
* Social Skills, Friendships
* Access to and Use of Alcohol, Cigarettes, and Drugs
 |

Looking at this list of topics…

1. If you had to answer survey questions about your teen: which topics from this list would be easy for you to accurately answer?

*[As needed: If you want us to show you an example of what one of those questions looks like for any topics, let us know!]*

1. Which topics would be difficult? Why is that?

*[Probe on: difference in opinion, privacy or sharing less with parents/caregivers, parents/caregivers not current on what is happening in their teen/young adult’s lives]*

1. What topics do you think parents or caregivers are more knowledgeable about? On what topics are teens more knowledgeable about themselves and their experiences?

*[Probe: What topics are more appropriate to ask parents about? What topics are more*  *appropriate for teens and young adults to answer on their own?]*

CONCLUSION AND OBSERVER QUESTIONS [1 minute]

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.