# PAPERWORK REDUCTION ACT STATEMENT

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| --- | --- |
| **SESSION OVERVIEW**  | **Stimuli** |
| Housekeeping and Background (4 minutes)  |  |
| Participant Introductions (3 minutes) |  |
| Questions about Parents Taking Surveys About their Teens (18 minutes) | ABCD Parent Survey question topics about teensExample questions (as requested by participants) |
| Whole Genome Sequencing Results (12 minutes) | Whole Genome Results Consent Form  |
| Gun Access Questions (8 minutes) | Gun Access Questions |
| Teen Driving Experiences (10 minutes) | Driving Questions |
| Conclusion (4 minutes) |  |

# MODERATOR’S GUIDE

## HOUSEKEEPING [3 minutes]

*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 Development StudySM, 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 [1 minute]

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 [3 minutes]

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. An activity you’re involved in this year (such as a sport, club, or hobby).

Okay, let’s get started on our questions.

## PARENTS AND CAREGIVERS ANSWERING SURVEYS ABOUT THEIR TEENS [18 minutes]

Today I have some questions about how well parents or other people who care for teens answer questions about their teens’ lives.

In the ABCD Study, researchers ask survey questions to parents and caregivers (someone who isn’t a parent but takes care of someone like a parent does, like a grandparent, foster parent, or aunt/uncle). These questions cover topics like health, activities, emotions, and behaviors of their teenager or young adult.

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. Which topics would be easy for your parent (or someone in your life who is like a parent) to accurately answer questions about you in a survey?

*[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, not living with the parent]*

1. What topics do you think parents or caregivers are more knowledgeable about than you? On what topics are you more knowledgeable than your parents?

*[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?]*

## WHOLE GENOME SEQUENCING CONSENT [12 minutes]

Now I’m going to switch topics a bit. Let’s talk about genes and DNA. The ABCD Study looks at genetic information from people in the study and wants to give teens and their families the option of learning more about the results of genetic tests. In the survey activity you completed before this discussion, we asked you to look at the sample consent form.

First, I want to have everyone review this description of the 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. After reading this slide, 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. What might be a better way to describe “risk of getting a disease because of your DNA”? How well does “hereditary disease risk” describe that?
2. 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 pros and cons—or 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. What pros or benefits would you add to the slide about benefits? What cons or risks would you add to the slide about risks?
2. How involved would you want your parents or family to be in the decision to learn about the results of your genetic tests?
3. Which option would you prefer, and why?
* You could get the results of your genetic test before you turned 18 but would need to get permission from a parent or legal guardian and your parent/guardian would see the results;

OR

You would have to wait until you turned 18 but you could get the results yourself without a parent’s or guardian’s permission or your parent/guardian seeing the results.

1. Would you want to get your results back if they 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: What would you want to know before getting your results? What about after?]*

## ACCESS TO GUNS [8 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. If you were taking this survey, how comfortable or uncomfortable would you be answering questions about firearms?
2. We don’t need to know your answers, but in general, would you have enough knowledge about firearms in or around your home to answer these questions? Why or why not?
3. What changes would you make to any of these questions to make them clearer?

*[Probe: Word choices like “firearm” or “gun,” definitions for “loaded,” “unlocked,” “in or around your home,” etc.]*

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

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

## TEEN DRIVING QUESTIONS [10 minutes]

Switching topics, I want to get your feedback on questions about driving behaviors.

[STIMULI: Driving Behaviors Questions]

|  |
| --- |
| Do you have (or did you have) a provisional driver’s license?* No
* Yes

If YES, how old were you when you got your provisional driver’s license? (Years, Months) \_\_\_\_\_\_  |
| Do you have a driver’s license with full privileges?* No
* Yes

If YES, how old were you when you got your driver’s license? (Years, Months) \_\_\_\_\_\_  |
| In the last 12 months how often did you do each of the following:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Never** | **Rarely** | **Sometimes** | **Often** | **Always** |
| Drove with passengers my age without having someone 25 years or older present, such as a parent or relative? |  |  |  |  |  |
| Drove between the hours of 11pm and 5am without having a guardian 25 years or older present. |  |  |  |  |  |
| Read, ate, talked on a cell phone, put on makeup, horsed around with passengers, or other such activities while driving. |  |  |  |  |  |
| Drove 20 or more miles per hour over the speed limit. |  |  |  |  |  |
| Drove after drinking alcohol or using other drugs not as prescribed. |  |  |  |  |  |
| During the last 12 months, how many times have you ever ridden in a vehicle driven by someone else who had been drinking alcohol or using other drugs not as prescribed? |  |  |  |  |  |

 |

1. If you saw these questions in a survey, how easy or hard would it be to answer them? Are there any that are tricky, confusing, or uncomfortable?

*[Probe about comfort disclosing risky/illegal behaviors, what would make them more comfortable with disclosure.]*

1. Looking at the list of driving behaviors (that starts with “In the last 12 month….”). What do these things have in common? What else should we add to this list?

*[Probe: Relevancy of the term “horsing around,” other examples of distracted driving like texting other examples of risky behaviors like driving by while being sleepy.]*

1. Let’s look at the terms “provisional license” and “full license.”

We know each state has different rules about driver’s licenses for new drivers. If you were answering this survey, how would you define a “provisional license” and how would you define a “full license?”

*[Probe: Differences between learner’s permits vs. provisional license vs. license with no restrictions, other terms for provisional license like “graduated driver’s license,” being able to answer the questions about age.]*

## CONCLUSION AND OBSERVER QUESTIONS [4 minutes]

Many things influence our health, from what we like to do in our free time to our social experiences and even the communities we grow up in.

20. What things do you think influence your health most? Which ones are you most curious about?

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.

We talked about some topics today that may have brought up negative memories or emotions for you. If you’re having a hard time after this discussion or later this week, I encourage you to talk to your parent or guardian, your school counselor or social worker, or to reach out to the study team at abcdresearch@iqsolutions.com.

