

## PAPERWORK REDUCTION ACT STATEMENT

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### Parent/Guardian Permission Form for Teen Participants

Project Title: Feedback Activities with Parents and Teens to Inform the Adolescent Brain Cognitive Development (ABCD) Study<sup>SM</sup>

We are thrilled that your child is interested in participating in the upcoming feedback team! Your child is being asked to join the feedback team because they are aged 17 to 19 years old.

We ask that you please read this form carefully. If you agree for your child to take part, you will use this form to give your permission for your child to be contacted. **If your child is under age 18**, you will also use this form to give consent for your child to participate. (Teens who are age 18 or older will provide their own consent.)

**You will need to electronically sign, date, and return this form to [RECRUITER] before the first feedback team activity. Please email the completed form to [NAME] at [EMAIL ADDRESS]. If you have any questions, please feel free to contact the project lead at the below email address:**

**Project Lead:** Rachael Picard

**Email Address:** [rpicard@iqsolutions.com](mailto:rpicard@iqsolutions.com)

#### About this project:

- The goal of this project is to get feedback on parts of a research study like survey questions on life and health, documents explaining what happens in the Study, and materials that communicate Study findings.
- These materials are for the Adolescent Brain Cognitive Development (ABCD) Study, a study managed by the National Institutes of Health. The ABCD Study<sup>®</sup> is run by researchers from universities and hospitals across the country to help understand how children's life experiences affect the brain as they grow. For more information on the ABCD Study, please visit: [www.abcdstudy.org](http://www.abcdstudy.org).
- We are inviting teens who are at the same stage of life as the individuals in the ABCD Study to join feedback teams.
- The feedback teams are groups of people who provide their thoughts and opinions through surveys, interviews, or bulletin board discussions. The input from these feedback teams will help the ABCD Study researchers ask questions about life experiences in the best way possible.
- Feedback teams will run for up to three years. Team members will be invited to at least one but no more than three feedback activities per year.

### What will happen?

- Your child will join a feedback team made up of other teens the same ages (17-18), for a total of 36 team members. Feedback team members will receive invitations to activities where they can provide their opinions on questions, instructions, and other forms that are used in the ABCD Study.
- These activities include:
  - Online surveys
  - Virtual discussion groups
  - Online bulletin boards
- **If your child takes a survey:** Your child will be asked for their feedback on questions about health, life experiences, activities, and parts of their identities. Surveys will take no longer than 30 minutes to complete. Your child will have several days to complete the survey.
- **If your child joins a virtual discussion group:** Your child will join two or three other teens for a 60-minute live, video-recorded, virtual discussion on Zoom. In the discussion, we will ask your child to share their thoughts and opinions on things like survey questions or instructions for being part of a research study, so that these are written in the best way possible in future research with other teens.
- **If your child joins an online bulletin board:** Your child will join other teens to comment with their feedback on questions, images, or instructions. This feedback includes things like polls or short-answer questions. Team members can see and comment on each other's responses and a moderator may ask some follow-up questions in the discussion. These questions are longer than a survey but you can participate on your own time (no more than 60 minutes) over a 2 to 3 day period.

### Who will see the information that I and/or my child provide?

- Only project staff will have access to feedback team activity responses. When summarizing the feedback for our report, we will communicate general themes and patterns and will not identify any individual team member.
- The discussions on Zoom will be recorded for reporting purposes. If you or your child do not want to be recorded, they cannot take part in virtual discussion groups.
  - Only the other participants in that group, the moderator, and project staff watching the discussion will know what your child said during the discussion.
  - To protect your child's privacy, we will only use the recording to create an accurate written record of the conversation (a transcript).
  - All recordings will be deleted 30 days after completing the last discussion.
- We will ONLY collect contact information and full name for you and your child for three purposes:
  - 1) Scheduling and reminders.
  - 2) Documenting that you and/or your child agree to participate.
  - 3) Recording that you or your child received a payment.
- Only first names will be used during the discussion and on the recording/transcripts. Any full names will not be shared with the moderator or other feedback team members. If someone mentions something specific to them during a discussion, such as the name of their town or school, we will censor that word or phrase in the transcripts.

### **How will my child's information be protected?**

- Signed consent forms will be stored in a secured, password-protected file only as a record that all participants agreed to be part of the study. Only the lead researcher and one back-up researcher will have that password.
- All activity data, any recordings, and all transcript files from the feedback teams will be stored on a password-protected cloud server. Only the project staff will be able to access them.
- The research team will summarize everyone's thoughts and opinions in a final report. The report will not have your name, your child's name, or other information that identifies you or your child.
- The research team will share the report with the researchers who are managing the ABCD Study.
- Summarized information from the feedback teams may be published in professional journals or at scientific conferences, but you or your child will not be identified or linked to the results.
- Your information and your child's information will be kept as confidential as possible according to all local, state, and federal laws. The National Institutes of Health and the Institutional Review Board (IRB)—a team of reviewers that makes sure your rights and welfare as a research participant are protected—may also have access to records for monitoring purposes, but names and information will not be used in any way that would help someone outside of the research team identify you or your child.
- All study data (answers to feedback activity questions) will be stored for no longer than 36 months. No information that could identify an individual person will be included in any of these data sets.

### **What are the benefits of being part of the feedback teams?**

- There is no direct benefit to you or your child for being part of the feedback teams. However, your and your child's thoughts and opinions may help researchers improve questions for future research with other teens and parents or caregivers of teens from across the country. The alternative is to not participate.

### **Will I or my child be paid for taking part in this study? Are there any costs?**

- You or your child will receive a token of appreciation in the form of check or electronic payment (such as a prepaid gift card) for participating in feedback activities:
  - Teen survey activity: \$20
  - Teen discussion group or online bulletin board: \$50
- The token of appreciation for participating in a feedback activity will be sent shortly after the close of the activity.
- Team may be eligible for a bonus for feedback activities after the first year.
- Your child does not have to answer any questions that they do not want to and will still receive the token of appreciation.
- There is no cost to you or your child for taking part in the feedback teams. However, your usual internet access costs may still apply.

### **What are the risks?**

- The risks for taking part in the feedback teams are low. You or your child can ask the project leads or discussion moderators any questions.

- These activities do not try to embarrass or upset you or your child. If any of the questions *do* upset your child, they can choose not to answer them. **Your child can stop answering questions and leave the activity at any time.**
- Your child will not be asked to answer any sensitive questions about personal life experiences. However, it is possible during these conversations that they could disclose information during the discussion that would require the research team to share your/your child's private information with federal, state, or local authorities ONLY IF someone is at risk of being harmed.
- If someone is at risk of being harmed, we are required to try to keep them safe. If we learn you plan to harm yourself or others, or if a child or elder is being abused, we may need to tell someone (such as the authorities) to make sure people are safe.
- No computer system is 100 percent secure, so there is some risk that your/your child's information could be part of a data breach. We will do our best to protect against this unauthorized access to private information by keeping information password-protected, enabling two-factor authentication on all staff devices, limiting access to ONLY the people who need it, and using services like ZoomGov that have enhanced security and privacy protections.

**Does my child have to take part in the feedback teams? What if they change their mind or no longer want to be part of the feedback team?**

- Joining the feedback teams and taking part in any activity is completely voluntary. **You can also choose whether or not to give permission for your child to join the team or join any feedback activity, and your child can also choose whether or not to join a team or complete any individual feedback activity.**
- Your child can agree to join the feedback team now and change their mind later with no penalty. Your child can also choose to stop participating in the feedback team at any time.
- Your child can always choose whether or not to join any individual feedback activity.
- When participating in a feedback activity, your child does not have to answer any questions that they do not want to.
- Your child can join an activity and decide to stop early without penalty or loss of benefits to which they are otherwise entitled. This means:
  - You or your child will still receive the token of appreciation for participating in the activity even if they choose not to answer some questions or leave the activity before it ends.
  - Your child will still be invited to participate in future activities.
  - We expect all team members to make a good faith effort to participate in an activity; otherwise, we may award a partial token of appreciation.
- Please note, if any participant makes inappropriate comments, repeatedly responds off-topic, or is otherwise inappropriate in a feedback activity, they will receive a warning. If inappropriate behavior continues, they may be removed from the activity.

**Whom do my child and I contact if we have questions?**

If you or your child have any questions about the feedback teams, would like to offer input, or if you/they feel that you/they may have been harmed by participating in the feedback team, you should contact the project lead, Rachael Picard at [rpicard@iqsolutions.com](mailto:rpicard@iqsolutions.com) or 240-221-4336.

If you or your child have questions about your rights or your child's rights as a research participant or if you have questions, concerns, or complaints about the research, you may contact Salus IRB at 1-800-472-3241, or by email at [subject@salusirb.com](mailto:subject@salusirb.com). You may also contact Salus IRB if the research staff cannot be reached or if you wish to talk to someone other than the research staff. Reference study number: 24032.

**Please keep a copy of this form for your records. If you would like an additional blank copy of this form, you can print or save a copy.**

**Permission for Teens:**

Please complete either the left **OR** right section below:

<b>My Child is UNDER Age 18</b>	<b>My Child is Age 18 or Older</b>
<p>You give CONSENT for your child to be contacted and take part in feedback activities. Your consent indicates that you read the information about the feedback teams and agree to YOUR CHILD taking part. By providing electronic consent for your child to participate in this study, your child does not give up any of their legal rights.</p> <p>Do you agree for YOUR CHILD to join the feedback team and take part in feedback activities, some of which may be recorded?</p> <p><input type="checkbox"/> <b>MY CHILD IS UNDER 18: Yes, I agree FOR MY CHILD to participate in the feedback team, which will include recording. I have read and had time to consider all of the information above. My questions have been answered and I have no further questions. By checking this box and typing my name on the signature line below, I am electronically signing this permission form.</b></p> <p><input type="checkbox"/> <b>No, I do not agree FOR MY CHILD to be contacted or participate in the feedback team. I have read and had time to consider all of the information above. My questions have been answered and I have no further questions.</b></p>	<p>You give PERMISSION for your child to be contacted and take part in feedback activities, but since your child is 18, they will provide their own consent to participate. By providing permission for your child to be contacted and to participate in this study, your child does not give up any of their legal rights.</p> <p>Do you give PERMISSION for your child to be contacted about joining the feedback team and taking part in feedback activities, some of which may be recorded?</p> <p><input type="checkbox"/> <b>MY CHILD IS AT LEAST 18 YEARS OLD: Yes, I agree FOR MY CHILD to be contacted and participate in the feedback team, which will include recording. SINCE THEY ARE 18, THEY WILL PROVIDE THEIR OWN CONSENT TO PARTICIPATE. I have read and had time to consider all of the information above. My questions have been answered and I have no further questions. By checking this box and typing my name on the signature line below, I am electronically signing this permission form.</b></p> <p><input type="checkbox"/> <b>No, I do not agree FOR MY CHILD to be contacted or participate in the feedback team. I have read and had time to consider all of the information above. My questions have been answered and I have no further questions.</b></p>

\_\_\_\_\_  
Parent or Legal Guardian Permission Signature

\_\_\_\_\_  
Date