

## PAPERWORK REDUCTION ACT STATEMENT

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### Parent or Caregiver Consent Form

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

Thank you for your interest in participating in our feedback teams! We are talking with parents and caregivers of teens who are aged 17 to 19 to get their perspectives on parts of a research study with other parents and caregivers of teens.

**You will need to electronically sign, date, and return this form to [RECRUITER] before joining any 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 ABCD Study, a study managed by the National Institutes of Health. The ABCD Study 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 and parent/caregivers who are at the same stage of life as the individuals in the ABCD Study (such as being teens or parents/caregivers of teens) 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?

- You will join a feedback team made up of other parents/caregivers of teens, for a total of 15 team members. Feedback team members will receive invitations to participate in feedback 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 one-on-one interviews
  - Online bulletin boards
- **If you take a survey:** You will be asked for your feedback on questions about health, life experiences, activities, and parts of your identities. Surveys will take no longer than 30 minutes to complete. You will have several days to complete the survey.
- **If you join an interview:** You and a moderator will have a 30-minute live, video-recorded, virtual discussion on Zoom. In the discussion, you will be asked to share your 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 for research with parents and caregivers of teens.
- **If you join an online bulletin board:** You and other parents and caregivers will be invited to give 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 live interviews on Zoom will be recorded for reporting purposes. If you do not want to be recorded, you cannot take part in that activity.
  - Only the moderator and project staff will know what you say during the interview.
  - To protect your 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 your full name for three purposes:
  - 1) Scheduling and reminders.
  - 2) Documenting that you agree to participate.
  - 3) Recording that you received a payment.
- Only first names will be used during the interviews 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 child's school, we will censor that word or phrase in the transcripts.

#### **How will my/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 or other information that identifies you.

- 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 (your 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 for being part of the feedback teams. However, your thoughts and opinions may help researchers improve questions for future research with parents 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:
  - Parent/caregiver “at home” material review: \$15
  - Parent/caregiver survey activity: \$40
  - Parent/caregiver interview: \$50
  - Parent/caregiver online bulletin board: \$100
- The token of appreciation for participating in a feedback activity will be sent shortly after the close of the activity.
- Team members may be eligible for a continuing participation bonus for feedback activities after the first year.
- You do not have to answer any questions that you do not want to and will still receive the token of appreciation.
- There is no cost to you for taking part in the feedback team. 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 can ask the project leads or discussion moderators any questions.
- These activities do not try to embarrass or upset you. If any of the questions *do* upset you, you can choose not to answer them. **You can stop answering questions and leave the activity at any time.**
- You will not be asked to answer any sensitive questions about personal life experiences. However, it is possible during these conversations that you 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 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.

**Do I have to take part in the feedback teams? What if I change my mind or no longer want to be part of a feedback team?**

- Joining the feedback teams and taking part in any activity is completely voluntary. **You can choose whether or not to join the feedback team and whether or not to join or complete any individual feedback activity.**
- You can agree to join the feedback teams now and change your mind later with no penalty. You can also choose to stop participating in the feedback teams at any time.
- You can always choose whether or not to join any individual feedback activity.
- When participating in a feedback activity, you do not have to answer any questions that you do not want to.
- You can join an activity and decide to stop early without penalty or loss of benefits to which you are otherwise entitled. This means:
  - You will still receive the token of appreciation for participating in the activity even if you choose not to answer some questions or leave the activity before it ends.
  - You 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.
- We may reach out to confirm your interest in being part of the feedback team based on level of participation in activities or response to invitations.

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

If you have any questions about the feedback teams, would like to offer input, or if you feel that you may have been harmed by participating in the project, 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 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: XXXXX.

**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.**

**Consent to Join the Feedback Team:**

- Your consent indicates that you have read the information about the feedback team and agree to take part. By providing electronic consent to participate in this study, you do not give up any legal rights.
- Do YOU agree to join the feedback team and take part in feedback activities, some of which may be recorded?

**Yes, I agree to participate in the feedback team MYSELF, 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 consent form.**

**No, I do not agree to participate in the feedback team MYSELF. I have read and had time to consider all of the information above. My questions have been answered and I have no further questions.**

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Adult Participant Consent Signature

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Date