



Summary of Information Covered During the MATR Recruitment Phone Call for the *Adolescent Brain Cognitive Development (ABCD) Study*

This information is being provided to give you an idea of what will be discussed during the MATR recruitment phone call. Please keep in mind that giving the MATR your permission to share your contact information with the study does not obligate you to participate. If you agree to be contacted by the study and the research staff determines that your family might be eligible for participation, they will provide with you with more detailed information prior to your appointment day.

During our phone call with you...

→We will provide information on the study background and why the study is being done:

Environmental, social, genetic, and other biological factors all play a role influencing the dramatic brain development occurring during adolescence. This has a profound impact on physical and mental health, behavioral choices, and life achievements throughout childhood and well into adulthood. However, scientists have a very limited understanding of how all of these influencing factors interact with each other to boost or undermine brain development and its associated outcomes. Because of this, the National Institutes of Health or NIH asked researchers to develop a comprehensive study, unlike any other, to address this need.

To help meet this challenge, nineteen distinguished academic institutions, including VCU, have come together to establish this landmark study on brain development. Each ABCD study site will invite families with 9 & 10 year olds to be part of this vital research and altogether they hope to have at least 10,000 participants join these efforts! While most of the research sites will recruit singleton or non-twin children, VCU's MATR was chosen as one of only four sites that will invite twin families to take part. The twin sites play a valuable role because twin participants will help provide the unique insight needed to unravel important gene-environment interactions influencing brain development.

→We will provide information generally covering what participation in the study will involve:

During the rest of this call, I'd like to provide you with some basic information about study participation and to see if you might be interested in learning more from the study staff.

The first, baseline study visit involves at least one parent along with the twins traveling to Virginia Commonwealth University in Richmond, VA to complete the consent process and study tasks. There are surveys for the parents to complete, but the bulk of the study is carried out by the twins. Questions for the parents include items about their twins' behaviors, personalities, medical histories, mental health, birth and development. There may also be questions about the parent's personality & habits. Since the researchers need to capture as much information as possible about all the factors in the twins' lives that may be impacting their brain development, the twins will be asked questions pinpointing many different areas—this includes but is not limited to: personality & moods; peer groups & relationships; substances, such as cigarettes, alcohol, and other drugs they may have tried or that they have seen others try; pubertal assessments, mental health, and sleep habits.

The twins will also complete tasks checking their memory, attention, and thinking. These are a lot like playing a game, or solving puzzles or brainteasers. Some of these tasks will need to be completed in a Magnetic Resonance Imaging or MRI machine, which looks like a big tube and uses magnetic fields to produce 3-D pictures. This is crucial because the researchers need 3-D pictures of the brain to help see what areas are more active during different tasks. MRIs are non-invasive and safe ways of looking at the brain and how it functions. To make sure they are getting accurate brain pictures, the researchers need to confirm that participants are substance-free for the MRI so they will use samples, such as saliva to double check. Female twins may have some other tests and questions, related to being a female. The twins will also be asked to provide some samples, such as saliva or blood to help the researchers get DNA for the genetics portion of the study.

Altogether, this appointment, with its study tasks and built-in breaks, meals, and snack times, will take about 8 hours. Participants may choose whether they want to do all of this in one day or divide it between two days.

Depending upon the distance traveled, the study may provide hotel accommodations. Most of the tasks are voluntary, but there are some, such as the MRI, that are necessary for study participation.

→We will provide information generally covering possible compensation for participation and travel:

Families will be compensated for their time participating in the study. For completing the baseline appointment, parents/guardians that participate in the study day are compensated up to 200 dollars total and twins are compensated up to 100 dollars each. Furthermore, if the study notices something that could be clinically relevant to the twins' mental or physical health, study staff will let the parent(s) know about it and provide suggestions for follow up with physicians.

→We will provide information about the option of being a long-term participating family:

One of the things that makes this a landmark, groundbreaking research effort, is that the study hopes to follow as many of the participants as possible over a period of time, for up to ten years. Because of this, the research group will retain your contact information and data in their own NIH-consortium database. They will contact families that completed the baseline appointment to ask them to take part in additional surveys and study visits over the course of the full study time frame. Although the researchers hope you will be able to be a part of the whole study, it is always your decision whether or not you want to continue in the study and you can withdraw at any time.

→We will request information the study will use to help determine how and if they will contact you:

This will include questions whose answers will help the study staff determine your twins' eligibility for participation. These questions will include items about their birth health, their current general health, learning, and other items related to qualifying for completing an MRI.

→We will request your verbal consent to share information with the study staff:

Just prior to starting the eligibility questions, we have to read a consent statement (copied below) and get your permission to share your information and answers with the study staff. This statement also covers what information gets returned to the MATR.

The Consent Statement:

If I say something you do not understand, please stop me and ask me to explain what I said. This telephone call is the first step for participating in a study which hopes to advance understanding on childhood, adolescent, and young adult brain and cognitive development.

We will ask you a set of screener questions about your twins and a few socio-demographic questions about you at the time of the twins' birth. The questions will be about your twins will be about their functioning, general health, and birth. Since some individuals may feel uncomfortable answering questions like this, please know that this is completely voluntary. This will take approximately ten minutes.

Also, while you may not get any direct benefit from answering these screener questions, your answers will help the researchers determine your and your twins' eligibility for participation. You can choose not to complete the questions or to only answer items you are comfortable answering, but this may mean that you and your twins will not be eligible to participate in the study. You are welcome to refuse or stop your participation at any time without penalty or disadvantage to you.

We take your privacy very seriously and will make every effort to keep the information you provide confidential. The MATR may retain any information you provide in this phone call in order to select you for contact regarding future studies, to possibly match this data with other data to answer general scientific questions, and in the administration of the registry. Your answers to these questions will be identified with a number. Only very select MATR personnel have the authorization and access needed to match this number and data to your name.

If you give us your permission to do so, then the data you provide during this call as well as your date of birth, your twins' date of birth, genders, race, zygosity data and contact information and preferences will be shared with the

researchers. Furthermore, the researchers will retain this information and any data you and your twins provide to them in their own NIH-consortium database.

Information the study will share back to the MATR will be related to your participation status in the study, such as the date of your study enrollment and any changes in your participation status. The MATR will also be informed of any updates to your contact information or your twins' zygosity.

Information from this call and about the consent may be looked at or copied for research or legal purposes by the sponsor or people who ensure that the rights of research participants are protected. This may include people at the Department of Health and Human Services or people at Virginia Commonwealth University. It's normal for these people to be able to review information from research studies. If you have questions about your rights as a research participant please call VCU's Office of Research at (804) 827-2157, but if your questions are about your eligibility status for the study or other study-related topics, please call 1-800-URA-TWIN (1-800-872-8946).

We will ask you if you have any questions and answer them to the best of our ability or track down the answers for you before proceeding.

We will ask the following:

Do we have your permission to share your contact information & preferences, eligibility data, date of birth and twins' date of birth, genders, race, and zygosity data with the study?

- If you say yes, we proceed with the rest of the call which includes the screener questions and verifying contact information & preferences.
- If you say yes, we will also ask you if you want a copy of the consent statement sent to you for your records.
- If you say no, we end the call.

The rest of the phone call deals with verifying yours and your twins' information and collecting contact details, such as the best number and days/times for the study to attempt to contact you if they need to reach you by phone.