



Detailed Summary of Information Covered During the MATR Recruitment Phone Call for the Adolescent & Young Adult Twin Study (AYATS)

The information in this document 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:

In the past few decades there have been many advances in our understanding of human emotions and psychology. These advances have led to improvements in how doctors treat internalizing disorders like depression and anxiety. Internalizing disorders have a significant impact on the quality of life of individuals as well as on society. Though we have made many advances, there is still a great deal more to learn about these conditions and their causes. Improved scientific techniques now offer researchers opportunities for an even deeper level of understanding about internalizing disorders.

This study is being conducted to learn more about the genes and other factors that could influence the likelihood of someone developing an internalizing disorder. To help accomplish this, the researchers are inviting parents (or legal guardians) and their adolescent/young adults twins, currently 15 through 20 years old, to participate in this study. This age group of twins is key to the study because it allows the researchers to observe behaviors and collect basic data during a time of significant adolescent development. It's also typically a time just before a major life change in which older adolescents, who still live at home with their parent(s), transition into young adults preparing to move out of their parent's home. Because capturing the transition time frame is important, adult twin participants (twins 18 and older) will still need to be leaving at home with their parents as much as possible. For example, if an adult twin has already started college but comes home for the majority of the holidays and summers then that twin will likely still be eligible to participate.

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

The MATR recruitment phone call will vary slightly depending upon if we are contacting a family with juvenile twins (twins under 18 years old) or young adult twins (generally twins 18 or 19 years old, though if we started calling when the twins were 18 or 19, we may continue to call until just before their 21st birthday and study participation can continue until 23). *The main difference is that we call and carryout our phone conversations with adult twins directly since legally they have to provide their own consent. For families with juvenile twins, all the MATR contact is conducted with a parent(s)/legal guardian(s) of the twins* (though we strongly recommend that the parents discuss this with their twins to make sure the twins are interested). The other difference is that adult twins do not have to have a parent participate in the appointment day because they do not need parental consent to participate in the study; juvenile twins do need parental consent so at least one parent/legal guardian must be available during the appointment day to provide their consent as well as answer some questions about the twins. For both groups of twins, the study will also invite one or both parent(s) to participate in tasks for that parent to complete about themselves (this is optional and in the case of parents of adult twins, parents that are willing can complete their items online; furthermore, adult twins can participate even if their parents choose not to).

The study staff reviews information you provide during the MATR recruitment phone call to determine eligibility (if you give your permission to us to share this information; otherwise, the study does not receive information from the MATR about you or your family). If twin pairs are eligible, the study will contact you (typically first by letter and then by phone). You can review a copy of the consent (and juvenile assent) and other information prior to scheduling an appointment. All levels of participation are voluntary throughout the course of the study. Even if an appointment is scheduled, you can cancel the appointment.

The study day appointment occurs at Virginia Commonwealth University in Richmond, VA. For parents and for adult twins, participation starts with completing the consent process; juvenile twins complete a similar process called an assent—for juvenile twins to participate, both parental consent and twin assent is required. During your study day appointment, the parent or parents that accompany juvenile twins will be asked to complete a few questionnaires about the twins; adult twins will complete these items about themselves and do not need parents to answer for them. Parents of juvenile twins should know that if juvenile twins turn 18 prior to their study day appointment, they will need to be enrolled in the study as adults and would provide their own consent.

The rest of the study appointment deals with twins completing research tasks. Parents are welcome to be with each child throughout the process, but twin pairs cannot complete these items together. Study tasks for twins involve a range of events such

as viewing images and faces on a computer screen that display different emotions like happiness, anger, fear, or neutral expressions (to see how well each twin assesses emotional states) and one that measures startle-responses using a minor shock sensation (similar to static). There are tasks that will examine responses to stressful stimuli including one that requires twins to speak in front of a small audience and perform certain math questions, like serial subtraction, and one that examines their response to breathing air with increased levels of carbon dioxide, which is already in the air we all breathe every day. During some of the tasks, the researchers will collect saliva samples so that they can measure certain stress-related hormones. They will also collect some physiological measures such as heart and respiratory rates. Overall these tests and measurements are meant to help the researchers assess how easily each twin recognizes different emotions and to gauge their tolerance for stressful situations.

Each twin will also be asked to answer a series of questionnaires about themselves and to provide an optional DNA sample, which will be obtained from blood samples. If providing the study DNA samples, twins will also be asked if they are willing to provide a sample for the MATR to keep in our repository for future twin-related research. This is completely optional and not required for study participation.

Approximately a year or more after participating in this study appointment, the researchers will invite the twin pairs to participate in a second wave of the study. During this second wave of participation, most of the twins will be adults (18 or over). For some this may only be a web-based survey while others will be randomly selected to receive a request for a return visit to VCU. Participation in this second request is not required to participate in the first appointment.

There is no cost to your family to participate, other than the time you spend completing the study. The study will take about 4 to 5 hours to complete and all participants are compensated for their time. Each study-related task has a separate compensation level. Amounts range from 20 to 100 dollars and vary depending upon the study tasks completed. Generally though, if all or most tasks are completed, compensation could add *up to* 170 dollars for each twin and *up to* 20 to 70 dollars for parent(s). Families that travel more than 30 miles to the research site will also be reimbursed mileage to help offset travel costs. Generally, the study will **not** have the funding to cover other travel-related costs, such as hotels, dining, or gas.

The researchers hope that information gained by your participation will provide groundbreaking insights into how and why some individuals develop internalizing disorders. They ultimately hope to use this information to improve treatment programs and potentially develop early interventions to prevent or minimize the severity of internalizing disorders, like depression and panic attacks. So, while your family may not benefit directly from participating in the study, you and your twins may experience satisfaction in knowing that your efforts might possibly improve the emotional well-being of future generations.

We will request information the study will use to help determine twin pair eligibility:

During the phone call we need to complete an eligibility screener questionnaire (parents will complete the items about their juvenile twins and adult twins will complete the items about themselves). If you give us your permission, we share the answers with the study so that they can determine twin pair eligibility. The questions will include some items related to health conditions, learning styles, and mental well-being. Adult twins will also be asked if they and their cotwin still predominantly live at home in their parent's house (though some can also be in college; this can be discussed more during the phone call). If you are eligible, the study will send you a 'heads-up' letter letting you know to expect their call. If you are not currently eligible to participate, we may call you back at a later date to see if your eligibility might have changed. Full pairs are needed for the study so both members of the twin pair need to be willing and eligible to participate.

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. For those that are willing, we tape record the consent. You do not have to be tape recorded to complete the consent.

Description of what the screener questions cover:

The screener questions will include questions about general health (asthma, diabetes, heart condition, gastrointestinal disorders, psychological, medications, etc); learning (Autism, educational accommodations like an IEP, 504 plans, etc); and diagnosed mental health conditions and certain medications. Answers to these questions are used by the study staff to determine if there is a medical condition or learning or social interaction disability that would make the twin pair ineligible for study participation.

The Consent Statement for Parents of Juvenile Twins:

The following is the consent that will be read to you. Prior to reading the consent we will ask you if we can record it (this recording will not have your name). You can still provide consent whether it is recorded or not. The choice is yours.

[If yes to recorded—start here] Alright, I've turned on the tape recorder and I'm speaking with contact ID _____. This number is used for our purposes to identify this recording rather than using your name.

[If no to being recorded—start here] 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 the genetic and environmental factors that influence the development of internalizing disorders.

We will ask you a set of screener questions about each of your twins. These questions will be about your twins' moods, anxiety levels, and other personality traits. There will also be some questions to make sure neither twin has a health condition or takes a medication that would prevent them from participating.

You may not get any direct benefit from participating in these screener questions but your answers will help the researchers determine your and your twins' eligibility for participation. The questions will take approximately ten minutes.

We take your privacy very seriously and will make every effort to keep the information you provide confidential. 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 and contact information will be shared with the researchers. The MATR may also 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.

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 and zygosity.

If you have allowed us to record this consent, the consent recording will be saved in a secure computer file and will only be identified by a number. Information from this call and the taped 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).

You can choose not to complete the screener questions, but this may mean that you and your twins will not be eligible to participate in the study. You are welcome to stop your participation at any time or to only answer items you're comfortable answering.

We will ask you if you have any questions and then we will ask the following:

Do we have your permission to share yours and your twin's names, contact information, eligibility data, dates of birth, genders, race, and your twin's zygosity with the study?

- If you say yes, we proceed with the rest of the call which includes the screener questions and verifying contact information.
- 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 your contact information and in the case of the adult twins, yours and your twin's contact information and collecting the best number and days/times for the study to attempt to contact you.

The Consent Statement for Adult Twins:

The following is the consent that will be read to you. Prior to reading the consent we will ask you if we can record it (this recording will not have your name). You can still provide consent whether it is recorded or not. The choice is yours.

[If yes to recorded—start here] Alright, I've turned on the tape recorder and I'm speaking with contact ID _____.

This number is used for our purposes to identify this recording rather than using your name.

[If no to being recorded—start here] 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 the genetic and environmental factors that influence the development of internalizing disorders.

We will ask you a set of screener questions about yourself. These questions will be about your moods, anxiety levels, and other personality traits. There will also be some questions to make sure you don't have a health condition or take a medication that would prevent you from participating.

You may not get any direct benefit from participating in these screener questions but your answers will help the researchers determine your eligibility for participation. The questions will take approximately ten minutes.

We take your privacy very seriously and will make every effort to keep the information you provide confidential. 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. One thing to keep in mind, is that since this study requires full twin pairs, if both you and your twin agree to participate and are contacted by the study, then you each will be made aware that you are both part of the MATR and participating in this study.

If you give us your permission to do so, then the data you provide during this call as well as your date of birth, gender, race, zygosity and contact information will be shared with the researchers. The MATR may also 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.

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 and zygosity.

If you have allowed us to record this consent, the consent recording will be saved in a secure computer file and will only be identified by a number. Information from this call and the taped 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).

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We will ask you if you have any questions and then we will ask the following:

Do we have your permission to share your contact information, eligibility data, date of birth, gender, race, and zygosity with the study?

- If you say yes, we proceed with the rest of the call which includes the screener questions and verifying contact information.
- 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 your contact information and in the case of the adult twins, yours and your twin's contact information and collecting the best number and days/times for the study to attempt to contact you.