INFORMED CONSENT FORM
(For Participants 18+)

WHY ARE YOU BEING INTERVIEWED?

You are being asked to take part in this study because you participated in the South Carolina Project to Learn about Attention Deficit Hyperactivity Disorder (ADHD) in Youth (SC PLAY). The purpose of this study (SC PLAY Follow-Up) is to learn more about the thoughts, feelings and behaviors of young people your age with and without ADHD. We want to better understand how ADHD or other problems are being diagnosed and treated in our community and what difference it makes for the quality of life and behavior of older teens and young adults. This is why we would like to continue to work with you over the next couple of years. The study is planned for 2 more years. This data collection is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241; Attachment A1).

WHAT WILL BE DONE?

Just like the last time we worked together, we will begin with a computer interview: You will wear headphones so only you can hear the questions and see what you answer. Second, we will also ask you to fill out some questionnaires. Our interview will include questions about mental health and behavior. In addition to the computer questions involved with the evaluation for ADHD and other conditions, the questionnaires will ask you about a range of topics about you and your family including: school performance, social support, and family relationships. We will ask you some sensitive questions about tobacco and alcohol, drug use, fighting, and rule breaking, and we will also ask about driving, bullying, dating, and sex.

Your interview will take about 2 hours to complete. If you are still in school, we will also give you forms to have your teacher(s) complete and return to us. This information will not be included in your school record. We believe it is important to respect your privacy. For that reason, we will work with you and your parent separately during the in-person interview, so neither of you can hear what the other says.

Our team includes a psychiatrist who will review the interview results. If a problem is found, we will inform you (and your parent) of our concerns and you and he/she will be given information about where help can be obtained. We are required by law to report any instances of child abuse or neglect that come to our attention.

HOW WILL YOUR PRIVACY BE PROTECTED?

Your answers will be treated in a confidential manner, and we will not reveal those answers to your parents unless you threaten to harm yourself or someone else or there is a serious problem that requires referral such as abuse, neglect, or a major medical condition.

 initials_____

Some of the questions may be of a sensitive nature, but we promise you that all information is being recorded without names. Only code numbers are used. We will make every effort to keep your identity and the information you give us confidential. The key that links a name to a code number is stored in a separate place, under lock and key. Only the key researchers working with this project have access to your information. All reports will use summary data and you can not be identified by anyone outside the research team.

There are organizations that may inspect and/or copy your research records for quality assurance and data analysis. These organizations include the Centers for Disease Control and Prevention (CDC), the organization funding the project, and the USC Institutional Review Board. Data will be reported to CDC without your name or other information that tells who you are.

DO YOU HAVE A CHOICE ABOUT PARTICIPATING?

You do not have to continue in this study; it is your choice. It will not affect how you are treated at school or anywhere else if you say no. You may choose not to take part or may leave the study for any reason at any time. You may also say no to answering any questions or to doing any part of the interview. We will tell your parent/caregiver about any new information that may affect your health, welfare or willingness to stay in this study. You or your parent/caregiver will not be treated any differently if you choose not to participate.

WHAT ARE THE RISKS AND BENEFITS?

There are no known risks for participating in this study. You may benefit from the evaluation, especially if we find a problem that was not known about before. You and your parent/caregiver are helping us learn information that will increase our understanding of ADHD and help children and teens in the future.

WHAT ARE THE COSTS?

There will be no costs to you because of your participation in this study. Because we understand that these interviews take time, we will give you $50 at each annual interview. We will also give your parent/caregiver $75 for participating in each annual interview.

PERMISSION FOR FOLLOW-UP:

☐ Yes, you may contact me again for annual and semi-annual follow-up interviews.
_____ (initials)

The Centers for Disease Control and Prevention (CDC) has funded this study from the beginning and they have been an active partner in the planning and implementation of the project. They are interested in continuing to follow the participants as they become adults. If you would be willing for us to share your contact information with CDC so they can contact you in the future, please check the box below.

☐ Yes, you may provide contact information for me to CDC for possible future data collection.
_____ (initials)

WHAT ABOUT OTHER ADHD STUDIES?

Please mark the box below to indicate your interest to learn about other studies on ADHD. Would you like researchers at USC to contact you with information about other studies on ADHD?

☐ Yes, I am interested in learning about ADHD studies.

☐ No, please to do not contact me about other ADHD studies.

CONTACT FOR QUESTIONS:

If you have any questions about the study or want to withdraw, you may contact the **ADHD Study office at 777-1124** and speak to the Project Director, Ms. Lorie James, or to the Principal Investigator, Robert McKeown, PhD. Or you may write to Dr. McKeown at:

SC PLAY
Department of Epidemiology and Biostatistics
Arnold School of Public Health
University of South Carolina
Columbia, SC 29208

If you have questions about your rights as a research participant or feel you have been harmed from the study, please contact Thomas Coggins, Director of Research Compliance, at 803-777-4456.

A copy of this form is being provided for you to keep.

CONSENT

"I have read and understand the above information. I have received a copy of this form.

☐ I agree to participate in this study with the understanding that I may withdraw at any time.

☐ I do not agree to participate in this study."

Participant Signature:_____ **Date:**_____

Birthdate:_____

ADHD Staff or Investigator:_____ **Date:**_____

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Phone: (803) 777-1124 · Fax: (803) 777-2524

initials_____