Consent Information Sheet (Online)

Key information: We invite you to participate in a research study being conducted by investigators from Washington University in St. Louis. This is a research study conducted by Dr. Nancy Saccone having to do with cannabis use. You should carefully consider the information in this consent document. You may discuss this information with the research team. You should understand why you might want to participate, or why you might not want to participate. You may choose to participate or not.

If you consent to this study, you will be volunteering to participate in the research study. As a voluntary participant, you will be asked to spend an estimated 10-15 minutes to answer an online survey and upload consumer genetic test results through a secure process. The main risk to you if you participate is accidental breach of confidentiality. Your confidentiality will be protected with multiple safeguards as detailed below.

This study is not expected to benefit you directly, but it will help us understand cannabis use and its medically relevant effects. By volunteering you may help someone else in the future. There is no cost to you and you will not be paid for being a volunteer participant. All of this information will be explained in more detail in this consent document. We recommend you print a copy of this document for your records.

Detailed information: The purpose of the study is to better understand factors that influence cannabis use and related risks and benefits of cannabis use. You are being asked to participate in this study because you have visited our study website and may have received genetic testing from a commercial genetic testing company such as 23andMe®.

If you agree to participate, we would like you to complete two participation steps.

1. Online survey: You will be presented with an online survey with questions on demographics (e.g. sex, age) and your use of cannabis, nicotine, and alcohol. You may skip any questions that you prefer not to answer. The survey will take approximately 5 minutes or less. To protect your confidentiality, no identifying information will be stored with your survey. We will not ask for or store your name. Your survey will be assigned an arbitrary study ID to track the information.

2. Upload consumer genetic test results: If you have received commercial genetic testing, we will provide a secure online process for you to transfer a copy of your genetic test results (the "raw" data) to our study computer, which is password protected and behind a secure firewall. To protect your confidentiality, your genetic data file will be renamed using your arbitrary study ID.

We will ask whether you are willing to be re-contacted for future research studies including research related to the current study. You may choose not to participate in any

future study. If you agree to be re-contacted, we will ask you to provide an email address. Providing this information for future re-contact is completely voluntary. Email addresses are considered identifiable and will be stored separately from the other information you provide (survey and genetic data). Only research staff will have access to your email address.

We might remove identifiers (email address) from your study information and then use the de-identified information for future research studies or share them with other researchers for their future research. If this occurs we will not ask you for additional consent for these uses of your information. This future research may be in areas similar to this research or in other unrelated areas.

One way in which we may share your de-identified data with other researchers is by putting it into a large database of information, called a data repository. If your individual data is placed in one of these repositories only qualified researchers, who have received prior approval from individuals who monitor the use of the data, will be able to look at your information. Your data will be coded to protect your confidentiality. Even though these data will not have your name or other identifying information associated with it, it is still possible that someone may be able to trace these data back to you because genetic information is unique.

Approximately 30,000 people are expected to take part in this research study.

Risks and benefits of this study: There is a minimal risk of accidental breach of confidentiality in participating. We use multiple safeguards and procedures to keep the information about you secure, as described below. You will not benefit personally from being in this research study. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. You will not be paid for being in this research study.

How we protect your confidentiality: We will keep the information you provide confidential. First, we will assign an arbitrary study ID code to all the information we collect from you. This ID code will be used to track your data, instead of using any identifying information. Your survey data and genetic data will be labeled with the ID code only and will be stored on a password protected, encrypted server behind Washington University's private, firewall protected network. The only identifying information we may collect from you is your email address, if you voluntarily provide it for future re-contact, and this email address will be stored by the research team separately from your survey and genetic data. Only the research team will be able to access your email address or link it to your study ID. Any report or article that we write will not include information that can directly identify you. The journals that publish these reports or articles may require that we share your information that was collected for this study

with others to make sure the results of this study are correct and help develop new ideas for research. Your information will be shared in a way that cannot directly identify you.

Federal regulatory agencies and Washington University, including the Washington University Institutional Review Board (a committee that reviews and approves research studies) and the Human Research Protection Office may inspect and copy records pertaining to this research. If we write a report about this study we will do so in such a way that you cannot be identified.

Additional protections for your health information: As part of this study we will generate Protected Health Information, or PHI. PHI is health information that identifies you and is protected by law under HIPAA (the Health Insurance Portability and Accountability Act). To take part in this study you must give the research team permission to use and disclose your PHI as explained in this letter. The research team will follow state and federal laws and it is possible that other people may become aware of your participation in this study and may inspect records pertaining to the research. This could include university representatives, to complete university responsibilities, and government representatives (including the Office for Human Research Protections and the Food and Drug Administration), to complete federal or state responsibilities, and the National Institute on Drug Abuse.

Once your health information is shared with someone outside of the research team, it may no longer be protected by HIPAA.

The research team will only use and share your information as talked about in this letter. When possible, the research team will make sure information cannot be linked to you (de-identified). Once information is de-identified, it may be used and shared for other purposes not discussed in this letter. If you have questions or concerns about your privacy and the use of your PHI, please contact the University's Privacy Officer at 866-747-4975.

Although you will not be allowed to see the study information, you may be given access to your health care records by contacting your health care provider.

If you do not provide authorization for us to use your PHI it will not affect your treatment or the care given by your health provider, insurance payments or enrollment in any health plans, or any benefits to which you are entitled. However, it will not be possible for you to take part in the study. If you agree, you authorize the use of your PHI for this research, and your authorization will not expire. You may later change your mind and not let the research team use or share your information.

In order to revoke your authorization, you will need to complete a withdrawal letter. Please contact the Human Research Protection Office for more information on how to

revoke your authorization or contact the research team to request the withdrawal letter. If you revoke your authorization, the research team may only use and share information already collected for the study. Your information may still be used and shared as necessary to maintain the integrity of the research, for example, to account for a participant's withdrawal from the research study or for safety reasons. You will not be allowed to continue to participate in the study.

This study is voluntary: Your participation in this study is completely voluntary. You may choose not to take part. If you decide to participate in the study you may stop participating at any time. Any data that was collected as part of this study will remain as part of the study records and cannot be removed. If you decide not to take part in the study or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

23andMe displays the following message to users who visit their "Download Raw Data" page: "If you upload your raw data to a third party application or service, keep in mind that your raw data is not validated for accuracy and the interpretation, reports or other claims that the third party makes may not be accurate. Your data also may not be maintained in a secure or private manner by third parties."

By consenting to this research study, you are indicating that you understand the limitations and risks associated with uploading your information, and you are authorizing our study to use your data for research. As described in this informed consent letter, this study protects your data with stringent security and privacy measures.

If you do not wish to participate in this study or want to end your participation in the study, please close your internet browser at this time.

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Nancy Saccone, Ph.D., Associate Professor of Genetics, 314-747-3263**.** If you feel you have been harmed from being in the study, please contact: Nancy Saccone, Ph.D. at 314-747-3263. If you have questions, concerns, or complaints about your rights as a research participant, please contact the Human Research Protection Office at 660 South Euclid Avenue, Campus Box 8089, St. Louis, MO 63110, 1-(800)-438-0445 or email hrpo@wustl.edu. General information about being a research participant can be found on the Human Research Protection Office web site, http://hrpo.wustl.edu. To offer input about your experiences as a research participant or to speak to someone other than the research staff, call the Human Research Protection Office at the number above.

Thank you very much for your consideration of this research study.