

Spit for Science (S4S): The VCU Student Survey Consent

(IRB Protocol # HMI3352)

Thank you for your interest in Spit for Science: The VCU Student Survey, a research project directed by Dr. Karen Chartier. Your participation in this research is completely voluntary. You may decide not to participate in this study. If you do participate, you may withdraw from the study or registry at any time. Your decision not to take part or to withdraw will involve no penalty or loss of benefits to which you are otherwise entitled. The university will not know if you have participated or not, nor what your responses to any of the questions are. Your participation will not affect your class work.

Purpose & Background: Research is an important part of all universities and the Spit for Science project is an opportunity for VCU students to get involved in the research process. One of the things that researchers here at VCU are interested in is what factors contribute to how well students do during their college years and beyond. As you are well aware, starting college is a major milestone, associated with a lot of big life transitions. For many students, college is an exciting time, filled with new opportunities. But the college years are harder for some students. For some individuals, this period can be a high risk time for the development of problems associated with alcohol use, other substances, and emotional health. We want to understand what factors contribute to these outcomes, so that we can ultimately use this information to improve the quality of life for our VCU students.

Your Involvement: This survey primarily contains questions about your personality and behavior, as well as your family and friends. It covers topics including your living situation; cultural experiences; family history; experience of stressful life events; social support; alcohol, nicotine, and drug use; emotional health, including depression and anxiety; friends' behavior; food access, COVID-related questions, and resilience. We will also ask you for your updated contact information, V# (optional), and alternate points of contact. The survey will take approximately 15-30 minutes to complete. You may skip any question that you don't want to answer. If you want to skip a question, please select 'I choose not to answer'. Survey answers are completely confidential – no names or other personally identifying information is shared with researchers.

Compensation: You will receive a \$15 e-gift card (Amazon, MasterCard, Target – your choice) for your completion of this survey. In addition, if you have not already provided a DNA (saliva) sample to the S4S project, you will have the opportunity to receive another \$20 by providing a sample at one of our on-campus events or by mail. We provide more details at the end of this survey about the saliva sample; however, it is not required for participation in this survey. After the main survey, there will be a section you need to complete in order to receive compensation. VCU requires that we document payments made to participants. If total payments within one calendar year exceed \$600, the University will need to report these payments to the IRS and you. This may require you to claim the compensation you receive for participation in this study as taxable income. VCU is required by federal law to track these payments using your V number or social security (optional) and/or contact information. If provided, your social security number will be kept confidential and will only be used by the necessary staff and VCU financial departments to process payment. No copy of your social security number will be retained by S4S for use beyond documentation of payments.

S4S Registry: As part of this project, we will keep this information (which includes full and partial survey responses) in a registry/repository to be available for other research studies. You are considered part of the registry until such time as you withdraw. As part of the registry, Spit for Science may contact you periodically by email, mail, phone, or text to ask that you complete additional S4S follow-up surveys or other

requests. For example, there may be requests in the future for samples, like “spit” (saliva) to obtain your DNA/genetic material. Materials you provide from these requests would be added to your existing data. You can always decline these additional invitations. Your de-identified survey responses also may be used to select you for future “spin-off” studies. If that is to occur, you will be contacted by Spit for Science registry staff about the future spin-off studies and you can decline the study at that time. No identifiable information will be shared with future spin-off studies unless you consent for us to do so. Information from spin-off studies may be supplied back to the registry and added to your existing data. Your information may be matched with other databases, agencies, or records for research purposes such as census records, national search databases, or other internet sources. S4S may obtain and use this information, as well as information you share with S4S, to administer the registry (e.g., updating contact info) and to create anonymized or de-identified datasets for research purposes without asking you for additional consent. Your name and other identifiable information will not be shared with researchers in this process.

Risks & Discomforts: There are no more than minimal risks involved in this survey/registry; however, with all research participation, there is a risk that participant confidentiality or privacy could be compromised. Standard practices will be used to protect participant confidentiality and personal information, including removing identifiers from all data collected, using only numbers to identify participant data, and keeping all data files securely stored. This study will ask you questions about personal topics that might be embarrassing to talk about and that could affect your family relationships if this information were to become known outside of the study. You will also be asked about illegal activities, which could have legal and financial consequences if this information were to become known outside of the study. This survey may also contain questions that are personal in nature. You may refuse to answer any question that makes you feel uncomfortable. The researchers will let you know about any significant new findings (such as additional risks or discomforts) that might make you change your mind about participating in the study.

The questionnaire will ask some questions about difficulties that various people experience, be it past experiences that were hard, or difficulties with substances or other mental health problems. If you are experiencing any challenges in these areas, you can contact University Counseling Services at 828-6200. If it is an emergency or after business hours you can call VCU police at 828-1234 and ask to speak to a counselor. There is someone on call all day, every day, all year long.

Protecting Confidentiality & Privacy: All responses to this survey will be kept strictly confidential. VCU and the VCU Health System have established secure research databases and computer systems to store information and to help with monitoring and oversight of research. Your information may be kept in these databases but are only accessible to individuals working on this study or authorized individuals who have access for specific research related tasks. Identifiable information in these databases are not released outside VCU unless stated in this consent or required by law. You can also help protect your own privacy and confidentiality by: completing surveys in a location you are comfortable in; limiting the use of shared devices or computers; not sharing access to your email account or survey links; exiting and closing surveys as well as your browser when finished or taking a break.

Certain organizations are in charge of making sure researchers do what they say they will do. Some of these organizations are part of VCU, VCU Health System, and the U.S. Department of Health and Human Services. When people from these organizations review the research, they may see or copy information that the researcher collected. It is unlikely these people or organizations will know who the information is about because the researcher stores your personal information (like name and email address) separate from your

survey responses.

The people who have access to the names of participants (necessary for reimbursement) will not have access to your survey responses, and the investigators who will be analyzing the data from the survey responses will not have access to your names or any other identifying information. Although results of this research may be presented at meetings or in publications, identifiable personal information about participants will not be disclosed.

Additional Protections: The study has a **Certificate of Confidentiality** issued by the National Institutes of Health. A Certificate of Confidentiality helps the researchers keep your information private. For example, S4S may not give out your information in a civil proceeding or court case. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects. The Certificate cannot be used to refuse a request for information from personnel of the United States federal or state government agency sponsoring the project that is needed for auditing or program evaluation by the organization funding this project or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research.

How to decline or withdraw from participation: To decline participation, just select the “No...” option in the ‘Consent to Participate’ question [insert location of question] and follow the prompts. Although your consent for this survey and registry does not expire, you can withdraw your consent for the survey or the registry at any time by contacting the research team at spit4science@vcu.edu. However, information that has been shared with other researchers will continue to be used.

Benefits: You will not get any direct benefit from completing this survey, but the information we learn from people in this study will help us understand why some people are more likely than others to develop problems associated with alcohol use, other substances, and emotional health. Findings from the study will be included in educational materials provided to VCU students through a variety of outlets (e.g., flyers and information from Recreation and Well-Being (RecWell)) and be used to help direct VCU programming toward student needs. In general, we will not give you any individual results from the study.

Questions: If you have any questions:

- **about the Study** – contact **Dr. Karen Chartier or the S4S staff at spit4science@vcu.edu or 804-628-4645** (Spit for Science phone line devoted solely to the study; rings through to Project Staff)
- **about your rights as a research subject or general concerns** you may contact:

Office of Research
Virginia Commonwealth University
800 East Leigh Street, Suite 3000
PO Box 980568
Richmond, VA 23298
(804) 827-2157

By participating in Spit for Science: The VCU Student Survey, you acknowledge that:

- Your answers will be recorded.
- You will be contacted again in the future for follow-up surveys. You will have the opportunity to decline to participate at that time. The information you provide may be used to select students to invite them to participate in future studies. You will be contacted about future studies and can decline to participate in any of those studies at that time.
- You agree that your data will be stored and used for future research as described above.
- Coded data (i.e., de-identified data that is not connected to your name or any other identifying information about you) may be shared with other researchers and other individuals at the university, and linked to other university data.
- In the future, your de-identified data could be used for other research studies by this study team or another researcher without asking you for additional consent.
- Should you choose to provide a DNA sample, your survey answers will be associated with that sample using a coded number, but not your name or other identifying information. In the future DNA data and associated survey answers may be included in the National Institutes of Health Genome Wide Association Study (GWAS) database. This is a de-identified and confidential national database that allows approved scientists to work together to advance genetic science. More information about this will be provided in the DNA consent form (and is available on-line at www.spit4science.vcu.edu). If you choose not to participate in the DNA component, this will not apply to you.

Consent to participate. If you select the “Yes...” option then you are indicating the following: You have read and you understand this consent and any questions you may have had were answered to your satisfaction. ***You freely consent to participate in this survey and the Spit for Science Registry and give your permission to have your data and information used as described in this consent document.***

[Online Consent Options Provided]

- Yes, I understand this and want to participate in Spit for Science: The VCU Student Survey.
- I want to think about it more before making a decision about participation. Please exit by closing your browser.
- No, I do not want to participate in the study.