The Substance Use Resistance (SUR) in Twins Study Phase One Info Page

Your insights & opinions can help shape research!

Thank you for your interest in learning more about the SUR Study! This research has two main Phases and you are being invited to Phase One of the study.

Prior research about substance (drugs & alcohol) use has been focused on collecting information on behaviors and reducing risk related to using substances. **This study is unique in wanting to identify factors that help individuals resist developing a substance use problem altogether!** To do this, they must first identify factors (resistance factors) that have helped individuals not use or reduce their use of substances. These types of factors are unique to each individual's experiences. **This is where participants like you come in.** The **study wants to know your opinions and personal insights** about any resistance factors that may have helped you decrease your use of substances or prevented your use altogether. The study needs participants with a variety of experiences related to substance use so whether you do not use substances now (or ever) or if you are currently using substances, then you would qualify for this study.

What's involved in study participation?
All the study procedures can be completed online or virtually and some can be done by phone. The study events are separated into three steps. Each step would be completed on separate days. **Currently, all participants are invited to complete Step 1, but only some participants might get invitations to Steps 2 & 3. The first two steps involve participants creating group concept maps.**

> **Step 1** – (Consent + Survey + Brainstorming session) This will take 25 to 40 minutes, but generally, it is likely to only take 25 minutes. Step 1 involves completing the consent and then a short survey that asks demographic and substance use questions. Following the survey, you will be given instructions to create a de-identified account on a platform called groupwisdom. Once on groupwisdom, you will participate in an interactive brainstorming session about your experiences with resistance factors. Brainstorming is the first step in helping to create a group concept map about resistance factors.
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> **Step 2** – (Sorting + Rating concepts) Approximately two to six weeks after you complete step 1, you *may* be invited to re-enter your groupwisdom account and complete an interactive session where you sort and rate the ideas gathered from step 1 to help create a group concept map. For example, you might rate the importance of different resistance factors. The time spent on this depends on the individual, but it's estimated to be between 20 – 30 minutes.
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> **Step 3** – (Consent + Virtual Focus Group) Approximately two to six weeks after you complete step 2, you *may* be invited to participate in a virtual focus group done using Zoom. This is not required to be part of the overall study. There is a separate consent for this part of the study that will tell you more about confidentiality (e.g., you do not have to have your camera on) and other important details related to the focus group so you can agree or decline the focus group at that time.

At the end of steps 1 and 2, the study needs to take the information participants have provided and help organize it before asking participants to carryon to the next step. That's why you see it takes 2 to 6 weeks before participants receive invitations to steps 2 and 3. Because of this, your overall timeframe of involvement could be up to 2 to 3 months, but you would only be doing tasks on three separate days over that timeframe.

Will I get paid for being in the study & how do I receive payments?
Yes! If you complete the all the study elements (and provide info (name, address) that VCU requires us to collect to send payments, then you would qualify for up to $80 in e-gift cards (Mastercard, Amazon, Walmart, Lowes – your choice!). The breakdown of compensation is:
Step 1 - $15 e-gift card
Step 2 - $20 e-gift card
Step 3 - $45 e-gift card
The e-gift cards are sent to you by email using an online vendor (Rybbon/BHN Rewards). The email will contain a link that takes you to your own compensation page where you can "claim" your choice of e-gift card. *Generally*, payments are made within one to two weeks of completing the step but due to circumstances outside our control (e.g., delay in VCU fiscal offices providing approvals and payments to the vendor), it could take several weeks before you would receive compensation. **IMPORTANT** - Once the email is sent, you have approximately a year to "claim" the compensation if you

select a retail card (like from Amazon). If you choose a MasterCard e-gift card, you may only have six months to claim the payment so please make sure you read the details provided on the emails and claim pages.

Who is in charge of this study?
While the MATR is helping with recruitment and some of the initial study steps, Dr. Elizabeth Prom-Wormley is the study Principal Investigator (PI). Dr. Prom-Wormley is an Assistant Professor with VCU's Department of Family Medicine & Epidemiology. She is also affiliated with the Departments of Psychiatry and Human & Molecular Genetics. Dr. Prom-Wormley studied under Dr. Lindon Eaves and is well versed in twin research and genetic epidemiology.

Who do I contact if I have questions? At this stage, if you have questions, it's best to contact the MATR by leaving a voicemail on our toll-free number (1-800-URA-TWIN) or emailing us at matr@vcu.edu. If you go on to participate, you will have the study's contact information for questions related to the study steps.

What types of questions will be asked in the short survey from Step 1 and why are they being asked?
The survey will ask demographic questions (sex, race, age) as well as questions about past and current substance use. In this instance the word 'substance' refers to tobacco, alcohol, and other drugs like marijuana, opiates, amphetamines, etc., and 'use' refers to ever trying the substance (even if just a small amount once). This information is **kept confidential**. The study knows this information is sensitive and would not request that we ask about it if it was not necessary for the research. Since the study needs participants that represent all the different types of people in our population, they need folks with a variety of substance use experiences - from those that have never used anything to those currently using substances. If they don't have this representative range, then the resistance factors that are identified will be very limited and it will be hard for the study to determine which resistance factors might work better than others. The only way they can be sure of having this range of use-experiences is by asking these questions. When the study receives the data related to substance use experiences, it is fully de-identified – which means that it does NOT have your name or other personally identifying information. Due to the sensitive nature of this information, the study has additional steps to help keep it confidential by obtaining a **Certificate of Confidentiality** (see below).

What is a Certificate of Confidentiality?
A Certificate of Confidentiality is provided by the National Institutes of Health (NIH) and is an extra measure of protection. It helps the researchers keep your information private. For example, we 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.

What is groupwisdom?
This web-based application is a tool that researchers can use that allows participants to provide interactive feedback while remaining anonymous to one another on the platform. For example, when you provide your brainstorming ideas, as you add them to the platform, you will also get to see the ideas that others are contributing. Overall, the activities on groupwisdom will help create a group concept map about substance use resistance factors.

How do I create an account on groupwisdom?
So that you do not have to use any of your personal details or own email addresses to create your accounts, we will assign a username for you. You will have to use this username to create your account. This username will not be based on any of your personal details. It will be made up of letters and number or unrelated combinations of words. If you go on to participate in the study, you will receive instructions on creating the account. These instructions will include your username and temporary password.

Can you tell me more about the focus groups?
We will provide an overview here since not all participants will be asked to participate in the focus group. Those asked to participate will be given more information about this at the time of the invitation. For example, confidentiality is very

important so, though it's encouraged to have your camera on, you are not required to do so to be part of the focus group. These focus groups will discuss the resistance factor concepts that are developed, sorted, and rated in steps 1 & 2. The study wants to have deeper insights into participant experiences around the resistance factors as well as gaining knowledge about how accessible these factors are to different groups of people. You would not be asked about your individual substance use during these sessions, but rather about things that helped prevent you (or those you know) from using substances as well as how important you think those factors are and how much access you had to some of the resistance factors identified.

If you are selected for the focus group, there is a separate consent for this and you always decline the focus group and still be part of steps 1 and 2. It is very important to the research team that everyone feels respected and safe to share their viewpoints so as part of the consent process for the focus group, participants will have to agree to abide by rules. Examples of the rules include:

1. Be respectful of all members of the focus group including moderators.
2. Provide honest responses.
3. Respect and maintain the confidentiality of information shared in the focus group. This includes making sure you are alone in a private location for the focus group.
4. Do not disclose or discuss any information about participants in the focus group.
5. **Failure to follow the rules could result in an expulsion from the focus group and loss of eligibility for compensation.**

What will the study do with the information collected from the groupwisdom concept maps and the focus group discussions?

As mentioned, this research project is divided into two main parts – Phase One and Phase Two. The groupwisdom activities and focus groups are all part of Phase One. One of the main goals of this study is to identify resistance factors that help individuals choose not to use certain substances or to decrease their use of those substances. Phase One helps accomplish this goal. The information gathered from Phase One will be used to help develop a survey that will include items related to the resistance factors participants helped identify in Phase One. The survey that gets developed will be used for Phase Two of the research. During Phase Two, a completely different pool of participants will be asked to complete the survey that your (and others that completed Phase One) feedback helped develop.

Are there substance use prevention and support resources you can tell me about?

Yes - The research team put together a list of resources some participants may find helpful. You will see that there are items specific to substance use as well as items that address other needs.

Please note that these are provided for informational purposes only and not as a medical care recommendation. *We encourage all that might need it, to see appropriate medical professionals if more is needed to support mental health.*

Organization	Support Offered	Contact
988 Suicide & Crisis Lifeline	Confidential emotional support for people considering suicide or are in emotional distress (or their family members)	Call or Text: 988 Text Messaging: Text 'HOME' to 741741
Alcohol Treatment Navigator	Explains how different alcohol treatment options work, how to choose a quality program, and how to get support for yourself or for a loved one through the recovery process.	https://alcoholtreatment.niaaa.nih.gov/
National Alliance on Mental Illness Helpline	Free peer-support services with information, resource referrals, and support for people living with a mental health condition, their family members and caregivers, and mental health providers. Monday-Friday, 10am-10pm ET	Call: 1-800-950-6264

National Mental Health & Substance Use Hub	Central resource to find mental health, alcohol, substance use support	https://www.usa.gov/mental-health-substance-abuse
National Treatment Referral Routing Service	Free referrals to substance use treatment facilities, support groups, and community-based organizations in your area. Free. Available 24 hours/day, 7 days/week in English and Spanish.	Call: 1-800-662-HELP (4357) Visit Online: https://findtreatment.samhsa.gov/
SMART Recovery	Find support for alcohol or other substance use dependence through group therapy sessions (in-person or online) in English and Spanish.	https://meetings.smartrecovery.org/meetings/
The Trevor Project	Confidential support for people who identify as LGBTQ+ and are experiencing a mental health crisis.	Call: 1-866-488-7386 Text Messaging: Text 'START' to 678-678 Visit Online: https://www.thetrevorproject.org/get-help/
National Health Insurance Marketplace (Healthcare.gov)	Find an agent or broker in your area and set up a time to talk about Medicaid or Children's Health Insurance Program (CHIP)	https://localhelp.healthcare.gov/
	Find price estimates for available healthcare plans in your area	https://www.healthcare.gov/see-plans/#/
Feeding America	Locate the closest food bank in your area via zip code	https://www.feedingamerica.org/find-your-local-foodbank
Food Distribution Program on Indian Reservations (FDPIR)	Food to income-eligible households on Indian reservations and Native American households in certain regions.	https://www.fns.usda.gov/fns-regional-offices
Supplemental Nutrition Assistance Program (SNAP)	Financial assistance for financially-eligible families to buy certain food products	https://www.fns.usda.gov/snap/state-directory
American Job Centers	Find employment opportunities	https://www.careeronestop.org/LocalHelp/AmericanJobCenters/american-job-centers.aspx
Career One Stop	Informational hub for job-seeking resources and opportunities	Call: 1-877-872-5627 Visit Online: https://www.careeronestop.org/
Workforce Development Board Finder	Programs to help seek employment information, training, and networking opportunities	https://www.careeronestop.org/LocalHelp/WorkforceDevelopment/workforce-development.aspx