

University of Vermont Consent to Participate in Research

Title of Research Protocol:	SOCKS B3 – Healing, Empowering, and Resilience Through Text
Lead Investigator:	Matthew Price, PhD
Sites Where Research is Being Conducted:	University of Vermont
Sponsor:	National Science Foundation

Introduction

You are invited to take part in this research study because you are an **adult** who owns a smartphone and has retained your text message history over the past 3 years and have denied having unwanted sexual contact in the last 10 years. This study is being conducted by the University of Vermont.

Your participation in this research study is optional. We encourage you to ask questions and take the opportunity to discuss the study with anybody you think can help you make this decision.

Key Information to Help You Decide Whether or Not This Study Is Right for You

The purpose of this study is determine how the words we use may be indicative of our mental and physical health. By participating in this study, you will help us better learn how people respond to difficult experiences. As part of this study, you will be asked to do the following:

- Participate in two clinical interviews. The interviews will focus on how you are doing. We will ask about past difficult experiences as part of these interviews.
- Share your story by talking about your experiences in the past few years. You will share your story of positive experiences and negative experiences.
- Fill out self-report surveys about your thoughts and feelings.
- Perform tasks that are similar to games.
- Use a machine (similar to a scale at a doctor's office) that will tell us about how strong your body is, including your muscles and weight, and have your blood pressure taken
- Share data from your phone, including:
 - **Text messages** from a pre-selected period of 7 months over the past 3 years and the last month.
 - **Screen time information** from the past week.

The primary risks of the study are feeling discomfort when talking about prior difficult experiences and the loss of confidentiality.

The information above is only a summary of the study. If you are interested in learning more, it is important to read the following pages for additional detailed information about the study. If you decide to take part in the research, you will be asked to provide written consent at the end of this document.

Why is This Research Study Being Conducted?

The purpose of this study is to learn more about how people recover after difficult experiences, such as unwanted sexual experiences, and how their use of language might give clues about their recovery. The way we have done this in the past requires a lot of effort and misses important information, so this study looks at using things like text messages to understand mental health. The goal is to find patterns in how people heal and create better ways to help those in need. We are recruiting a group of individuals who have not had one of these experiences in a very long time to serve as a comparison to those who have such experiences recently.

What Is Involved in The Study?

Study participation will take a total of 3 hours today.

For the 3 hour visit that will take place today, you will be asked to do several tasks.

The first task we will do is an interview. For the interviews, we will ask how you are doing. Some of the questions will ask about personal topics, such as traumatic events you have experienced, how you feel about it, and how anxious or depressed you feel. You may be as detailed or as brief as you like in your responses. With your permission, we will audio record the interview. You may decline to have your interview audio recorded and still participate in the study. The interview is expected to take 1 hour.

The second task is a story telling task. We will ask you to tell us three stories. Each story will be for 5 minutes. The first will be about a happy event from the past year. The second will be about a sad event from the past year. The third story will be about the most difficult experience you had in the past year. These stories will be audio recorded. These audio stories must be recorded. If you decline to have your stories recorded, we will not be able to have you tell your stories. You can still participate in the study if you decline to participate in this portion of the study.

The third task is completing surveys. The surveys will ask you questions about how you are doing. For example, we will ask questions like “in the past 2 weeks, have you felt down or depressed?” We will ask about how you are doing with regard to past potentially traumatic experiences. We will ask questions like, “Have you had repeated, disturbing dreams of the stressful experience?”. We will also ask about your use of substances in the past year, including marijuana. It is expected that it will take 25 minutes to complete these surveys.

The fourth task involves collecting information about how you have used your phone in the past week. These will be collected via screenshots of your “ScreenTime” data that will be either on your Android or iOS device. You will take the screenshots yourself via your own device and then transfer them to us via “AirDrop” or via a USB Cable. We will ask you to crop the photos so that we only obtain screentime data and no identifying information, such as your name or the name of your phone (e.g., “Casey’s iPhone”).

We will also collect a sample of your text messages from your primary texting application, including texts from the last month and a seven-month period over the past three years. The period we will choose will correspond to the period of another participant selected at random to serve as a fair comparison. Here are several important points about what data we will collect and how we will collect it.

- The period that is chosen from the past 3 years is based on other participants in the study, which means that you do not get to choose and we do not get choose.
- For these text messages, we will retain the following pieces of information:
 - The content of the messages that you have sent. We are only interested in your messages because we want to know how your language is associated with how you are doing. We will not retain the content of any messages you have received.
 - The dates and times that you sent messages.
 - An anonymized contact to whom you sent messages. For example, you sent messages to Natalie, Johanna, and Ella. We will anonymize these names to Person_1, Person_2, and Person_3. Thus,

- we will know that you sent and received messages from Person_1 – but we will not know the identity of Person_1.
- The dates and times that you received messages. However, we will not collect the content of those messages – only the dates and times that they were sent.
 - For these text messages, we will NOT retain the following pieces of information:
 - Actual names of contacts. For example, you sent messages to Natalie, Johanna, and Ella. We will anonymize these names to Person_1, Person_2, and Person_3. Thus, we will know that you sent and received messages from Person_1 – but we will not know the identity of Person_1.
 - Phone numbers, locations, or email addresses. This includes contact information or information included in a text. For example, a text that said “call me at 802-656-9196” will be stored as “call me at Phonenumner”.
 - Messages you have received from other people.
 - Attachments sent via text, including photographs, GIFs, and files.
 - Before we save your data, you will have a chance to remove any conversations that you do not want us to have. Conversations are text threads between you and a group of other individuals.
 - For iPhone owners, we will connect your phone to our computer and use a program to obtain your texts. This program will create a backup of your text messages on our lab computer and store it locally on our computer. During this process, we will ask you to unlock your phone and “trust” our computer to grant the program access to your phone. The program does not install any data on your device. We will remove all files created by the program on our computer when this data collection process is complete.
 - For Android owners, we will ask you to download an app to your phone through your personal Google Play account called “SMS Backup & Restore”. This app is free to use and does not collect any user data. According to the terms of service, the app may share your Device ID and app performance data with the company. The app will make a backup on your texts on your phone that you will transfer to our computer via USB cable. You can delete the app from your phone after you have transferred the file to our computer. We will delete the file that was created from your phone during the transfer process.
 - Once we have the file of your texts on our computer, you and the research assistant will conduct an anonymization and review process. This process involves:
 - Selecting the 7-month period and the last month’s texts. All other texts, both sent and received, will be deleted automatically by the computer. The research team will not see these texts.
 - Review the conversations that are included in the dataset. You will be shown a list of conversations that will be included. You will be able to tell us any conversations that you want to remove from the dataset. These conversations will be deleted automatically by the computer. The research team will not see these texts.
 - The computer will then automatically anonymize the texts. For example, lets say you sent messages to Natalie, Johanna, and Ella. We will anonymize these names to Person_1, Person_2, and Person_3. Thus, we will know that you sent and received messages with Person_1, but we will not be able to identify Person_1. This is done using software designed to anonymize such information.
 - The computer will show you and the research team a sample of the anonymized data to make sure it is anonymized. If there are errors in the anonymization process, we will fix them.
 - Finally, the research team will export this new anonymized text message list. We will delete any information we have collected from your phone on our computers and will save the anonymized texts at UVM.

The phone collection tasks are expected to take 30 minutes.

The fifth task will be to measure how much muscle is in your body. This will require you to stand on a machine and remove your socks and shoes, similar to a scale at a doctor’s office. This machine also collects your weight. We will cover the display where information is shown during this process. You may ask to see your weight and

muscle information. You cannot complete this with an implanted device such as a pacemaker. We will also collect your blood pressure. These tasks are expected to take 5 minutes.

Your participation is completely voluntary, and you may skip any question that you would rather not answer. These surveys will also contain questions about your possible use of substances.

All study procedures for the in-person visit will take place at the University of Vermont. The phone follow-up will take place on your mobile device.

The collected data may be de-identified and used for future research or be given to another investigator for future research without additional informed consent.

What Are the Risks and Discomforts of The Study?

Participation in this study may involve some risks or discomforts. Some questions and tasks may make you feel upset or distressed, especially when discussing personal experiences or feelings. If you feel overwhelmed at any point, the study team will be available to provide support and assess your needs. Additionally, you will be provided with referrals to local mental health resources if necessary.

The study will include questions about thoughts of self-harm or suicide. If you express significant distress or suicidal thoughts, the study team will take immediate steps to ensure your safety. This may include a licensed psychologist conducting a further assessment and providing crisis intervention if needed. Your well-being is the highest priority, and all concerns will be handled with care and professionalism.

If you have any concerns about these risks, please speak with the research team before deciding to participate.

If you are a student or UVM employee, your decision whether or not to participate in this research study will not affect your class standing, grades, status on an athletic team, or job standing.

What Are the Benefits of Participating in The Study?

There is no direct benefit to you anticipated from participating in this study. However, it is hoped that the information gained from the study will help people in the future.

What Other Options Are There?

There are no other options to participating in the study.

Are There Any Costs?

You may be asked to pay for parking during your visit if you drove to the appointment. Please notify the research staff if you incurred a parking or travel expense.

What Is the Compensation?

You will be provided compensation for your time associated with the study. For your time in the in-person visit, you will receive \$100 in cash at the end of the in-person session.

You will be required to provide your name and address each time you receive payment. You will also be requested to provide your social security number if the amount of the payment is \$100 or if the total payments from UVM are equal to or greater than \$600 in a calendar year. If you are not a US Citizen or Permanent Resident you will be required to complete additional paperwork including your immigration status for payment. This information will be strictly confidential and will be used for tax withholding and reporting purposes only and will allow the University to determine your US residency for federal income tax purposes.

Can You Withdraw or Be Withdrawn From This Study?

You may discontinue your participation in this study at any time. Any data that is collected up to the point of your withdrawal will be retained. You may request to have your data destroyed if you or the researcher decide to discontinue the study.

The researcher may discontinue your participation in this study at any time. Possible reasons for discontinuing your participation include becoming very distressed. You will be compensated based on the amount of the study that you have completed at the time of withdrawal.

What About Confidentiality?

There is a risk that confidentiality may be breached, including that of your contacts. To protect your confidentiality, we will store data securely at the University of Vermont. Your confidentiality will be protected by storing paper records in a locked filing cabinet, and by using password protection for electronic data. Research data will be stored securely using ID numbers instead of names, and personal details will be kept separate and encrypted. Data will be stored on secure, password-protected university servers to minimize the chance of unauthorized access.

Audio recordings and images that are collected as part of the study will be stored on electronic databases that are maintained and supported by UVM. To protect your confidentiality, these audio files will be stored in a separate location from other data. Recordings will be transcribed to learn more about how the language that is used and the way in which people speak are associated with well-being. Recordings will be maintained for a minimum of 5 years as is consistent with UVM research policy.

To protect your phone data, we will conduct all phone data collection locally at UVM. This means we will not knowingly transmit identifiable data over the internet or to external servers.

There is a chance that when we anonymize your text message data, the automatic anonymizer may miss an identifying piece of information (e.g., name). To protect against this, we will review all text message data before we begin to analyze it. We will do so in a way that protects your confidentiality by looking only at the unique words that are present in the texts as opposed to them in the message. For example, we would view a list of words like: The: 10, smile: 4, a: 7, David: 1. We would then be able to identify names (e.g., David) and anonymize those names before we proceed. Thus, we will reduce the chances of a confidentiality breach.

When the research is completed, our research team may save the data and audio recordings for use in future research done by myself or others. The same measures described above will be taken to protect confidentiality of this study data.

If results of this study are published or presented, individual names and other personally identifiable information will not be used.

The sponsor(s), the National Science Foundation, or their appointed designees as well as the Institutional Review Board and regulatory authorities will be granted direct access to your original research records for verification of research procedures and/or data.

Any communications through email and social media are not considered private or secure. Though we are taking precautions to protect your privacy, you should be aware that information sent electronically through these methods could be read by a third party.

If your record is used or disseminated for government purposes, it will be done under conditions that will protect your privacy to the fullest extent possible consistent with laws relating to public disclosure of information and the law-enforcement responsibilities of the agency.

We will keep your study data as confidential as possible, with the exception of certain information that we must report for legal or ethical reasons, such as child abuse, elder abuse, or intent to harm yourself or others.

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. This means that the researchers cannot release or use information, documents, or samples that may identify you in any action or suit unless you say it is okay. They also cannot provide them as evidence unless you have agreed. This protection includes federal, state, or local civil, criminal, administrative, legislative, or other proceedings. An example would be a court subpoena.

There are some important things that you need to know. The Certificate does not stop reporting that federal, state or local laws require. Some examples are laws that require reporting of child or elder abuse, some communicable diseases, and threats to harm yourself or others. The Certificate cannot be used to stop a sponsoring United States federal or state government agency from checking records or evaluating programs. The Certificate does stop disclosures required by the federal Food and Drug Administration (FDA). The Certificate also does not prevent your information from being used for other research if allowed by federal regulations.

Researchers may release information about you when you say it is okay. For example, you may give them permission to release information to insurers, medical providers or any other persons not connected with the research. The Certificate of Confidentiality does not stop you from willingly releasing information about your involvement in this research. It also does not prevent you from having access to your own information.

Risks associated with terms of use

As part of this research, you will be required to use one or more of the following: a phone and an app if you are using an Android device. While using these, information about you may be collected and shared with researchers or people outside of the study. This data might include personal health information, location, call logs, text message history, web browsing history, or social media use. A complete description of the data collection and sharing for an app or device can commonly be found in the Terms of Use, End User License Agreement, or Privacy Policy associated with the device. You will be required to agree to the Terms of Use, End User License Agreement, or Privacy Policy prior to using the associated software or device.

While the Terms of Use, End User License Agreement, or Privacy Policy may include statements limiting your rights if you are harmed because of your use of the app or device in this study, you do not release the study researcher, sponsor, institution, or agents for responsibilities from mistakes. You also do not waive any of your rights as a research participant.

Contact Information

You may contact Dr. Matthew Price, the Investigator in charge of this study, at 802-656-9196, for more information about this study. If you have any questions about your rights as a participant in a research project or for more information on how to proceed should you believe that you have been harmed as a result of your participation in this study, you should contact the Director of the Research Protections Office at the University of Vermont at irb@uvm.edu or 802-656-5040.

Statement of Consent

You have been given and have read or have read to you a summary of this research study. Should you have any further questions about the research, you may contact the person conducting the study at the address and telephone number given below. Your participation is voluntary, and you may refuse to participate or withdraw at any time without penalty or prejudice.

You agree to participate in this study, and you understand that you will receive a copy of this form.

Signature of Participant

Date

Name of Participant Printed

Signature of Principal Investigator or Designee

Date

Name of Principal Investigator or Designee Printed

Name of Principal Investigator: Matthew Price
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