UNIVERSITY OF PENNSYLVANIA
RESEARCH PARTICIPANT
INFORMED CONSENT FORM

Protocol Title:	Sexual and Gender Minority Emerging Adults Eliciting Narratives (SEEN)
Principal Investigator:	Jennifer Tran, PhD & José Bauermeister, MPH, PhD 418 Curie Blvd., Philadelphia, PA 19104 215-898-3616
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Research Study Summary for Potential Participants

You are being invited to participate in a research study. Your participation is voluntary, and you should only participate if you completely understand what the study requires and what the risks of participation are. You should ask the study team any questions you have related to participating before agreeing to join the study. If you have any questions about your rights as a human research participant at any time before, during or after participation, please contact the Institutional Review Board (IRB) at (215) 898-2614 for assistance.

The research study is being conducted to see if telling your story through photographs of video can improve mental health and well-being of emerging adults that identify as a member of a sexual and/or gender minority and a racial and/or ethnic minority.

If you agree to join the study, you will be asked to complete the following research procedures:

1. You will first be asked to take a survey online (about 20-30 minutes). Then, you will be asked to participate in an interview with study staff members about your everyday experiences as sexual/gender minority of color and your experiences in seeking out mental health services.
2. After the interview, you have one month to tell your story answer two prompts “Tell us a time you have felt seen” and “Tell us a time when you have felt unseen” either by taking photographs or making two short videos.
3. At the one-month time frame, you will be asked to fill out another survey (about 20-30 minutes) and then complete an interview with a study staff member about your photos or videos you created.

Your participation will last for one month starting today. Your personal identifiable information will be kept for 5 years. Your deidentified data will be kept indefinitely.

You may not get any direct benefit from being in this research study. It is possible you may benefit by learning skills of photography and creating videos.
The findings of this study may also help develop interventions and support resources for other people in the future. The main risks of participating in this study are loss of confidentiality despite the security and privacy controls put in place for the study and that study topics may raise potentially distressing memories, thoughts, and feelings.

Please note that there are other factors to consider before agreeing to participate such as additional procedures, use of your personal information, costs, and other possible risks not discussed here. If you are interested in participating, a member of the study team will review the full information with you. You are free to decline or stop participation at any time during or after the initial consenting process.

Why am I being asked to volunteer?

You are being asked to take part in a research study because you filled out an interest survey. Your participation is voluntary which means you can choose whether to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you decide, you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if you decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to decide now; you can take the consent document home and share it with friends, family, and your treatment team.

If you do not understand what you are reading, do not provide your electronic consent. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to check a box. A copy will of the form will be given to you so that you can find contact information and answers to questions about the study. You may ask to have this form read to you.

What is the purpose of the study?

The purpose of the study is to learn more about how creating your own story with photography or videos can impact and support sexual and gender minority emerging adults of color's mental health and well-being. This research study is asking participants to answer two prompts, "Share an experience of when you have felt seen as an SGM Person of Color in Philadelphia." AND "Share an experience of when you have felt unseen as an SGM person of color in Philadelphia." Half of the participants will be asked to answer these prompts by taking photographs and the other by creating a short (1-3 minute) video.

Why was I asked to participate in this study?

You are being asked to join this study because you have indicated that:
- You are between the ages of 18 and 24,
- You live in the Philadelphia Metropolitan Area
- You identify as a member of a sexual and/or gender minority
- You identify as a member of a racial and/or ethnic minority, and
- You have access to a smartphone and or laptop with internet access.

How long will I be in the study?

The study will take place over a period of up to a month (about 4 weeks). This means for the next month we will ask you to spend 2 days participating in study surveys and interviews. Each survey will take approximately 20 minutes to complete. Interviews will take an additional 30-45 minutes.

What am I being asked to do?

During your participation you will be asked to do the following:
- Day 1: Participate in an interview and complete a survey virtually. This will take approximately 90 minutes. You will then be given a manual and instructions to either take photographs or create videos.
- Day 2-29: Take your photographs or create your videos answering the prompts with guidance from the manual.
- Day 30: Share your photographs/videos. Participate in a survey and remote interview. This will take approximately 90 minutes in total.

What are possible risks or discomforts?

This program involves increasing understanding about some of your difficulties and your suicidal thoughts and behaviors. This may cause you to experience other emotions or distress, but the long-term effects from this are expected to be minimal. We will make every effort to minimize any discomfort you may feel during this process. If you feel any discomfort during the study, please inform a researcher. We will do everything that we can to make you feel better. This may include taking breaks between questionnaires or having a brief check-in with the investigators or, if you prefer, another clinician to make sure that you are doing okay. You have the right to stop participating in the study at any time, and there are no penalties or negative consequences to you if you choose to stop your participation.

The main risk is loss of confidentiality or private information despite the security and privacy controls put in place for the study. Several steps will be taken to protect your privacy as described in the section below labeled “How will my personal information be protected?” We will take careful precautions to protect your privacy, but complete privacy can never be guaranteed.

What if new information becomes available about the study?

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind

about being in the study. We will notify you as soon as possible if such information becomes available.

How will I benefit from the study?

You may not receive any direct benefit from participating in this study. It is possible that you may benefit by learning skills of photography or creating videos.
Additionally, your participation could help us understand how to better support the mental health and well-being of SGM young adults of color, which can benefit you indirectly. In the future, this may help other people to develop treatments for other SGM populations.

What other choices do I have if I do not participate?

Your alternative to being in the study is to not be in the study.

Will I be paid for being in this study?

You will receive up to $75 for participating in the study via an electronic Greenphire ClinCard. The breakdown of these incentives is as follows:

- Baseline Visit: $30
- Follow-Up Visit (within 4 weeks): $45
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Please note: In order to be compensated for your participation in this study, you must provide your email. Additionally, please note that the University of Pennsylvania is required to report to the IRS any cumulative payments for participation in research studies that exceed a total of $600 in a calendar year.

Will I have to pay for anything?

You will not be expected to pay anything to participate in this study. All study visits are virtual.

What happens if I am injured from being in the study?

We will offer you the care needed to treat injuries directly resulting from taking part in this research. We may bill your insurance company or other third parties, if appropriate, for the costs of the care you get for the injury, but you may also be responsible for some of them.

There are no plans for the University of Pennsylvania to pay you or give you other compensation for the injury. If you feel this injury was caused by medical error on the part of the study doctors or others involved in the study, you have the legal right to seek payment, even though you are in a study. You do not give up your legal rights by signing this form.

If you think you have been injured as a result of taking part in this research study, tell the person in charge of the research study as soon as possible. The researcher's name and phone number are listed in the consent form.

When is the Study over? Can I leave the Study before it ends?

This study is expected to end after all participants have completed all visits, and all information has been collected. This study may also be stopped at any time because:

- The Primary Investigator feels it is necessary for the welfare, rights, or safety of participants. Such an action would not require your consent, but you will be informed if such a decision is made and the reason for this decision.
- The Sponsor or the study Principal Investigator has decided to stop the study.

If you decide to participate, you are free to leave the study at any time. You may do this by contacting the investigator noted on page one of this form.

How will my personal information be protected during the study?

We will do our best to make sure that the personal information obtained during the course of this research study will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. The Institutional Review Board (IRB) at the University of Pennsylvania will have access to your records.

What may happen, in the future, to my information collected on this study?

Your information will be de-identified prior to storage for future use. De-identified means that all identifiers have been removed. The information could be stored and shared for future research in this de-identified fashion. The information may be shared with other researchers within Penn or other research institutions as well as pharmaceutical, device, or biotechnology companies. It would not be possible for future researchers to identify you as we would not share any identifiable information about you with future researchers. This can be done without again seeking your consent in the future, as permitted by law. The future use of your information only applies to the information collected on this study. If you change your mind, we will not be able to destroy or withdraw your information that was shared because all identifiers would have already been removed.

Who can I call with questions, complaints or if I'm concerned about my rights as a research participant?

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research participant, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the IRB at the number on page one of this form.

When you sign this form electronically you are agreeing to take part in this research study. This means that you have read the consent form, your questions have been answered, and you have decided to volunteer. Your signature also means that you are permitting the University of Pennsylvania to use your personal information collected about you for research purposes within our institution. You are also allowing the University of Pennsylvania to disclose that personal information to outside organizations or people involved with the operations of this study.

A copy of this consent form will be emailed to you.

Please check one of the following boxes:

☐ I DO consent to take part in this study

☐ I DO NOT consent to take part in this study

_____	_____	_____
Name of Participant	Signature of Participant	Date
_____	_____	_____
Name of Person Obtaining Consent	Signature	Date