

# TEACHERS COLLEGE

COLUMBIA UNIVERSITY

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## INFORMED CONSENT

**Protocol Title:** In Pursuit of Healthful Narratives: Black Women and Gender Expansive Citizens Creating and Performing Art and Cultural Work in Service of “Good Health”

**Principal Researcher:** Shanaé Burch, Ed.M, Teachers College  
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**INTRODUCTION** You are invited to participate in this research study called “In Pursuit of Healthful Narratives: Black Women and Gender Expansive Citizens Creating and Performing Art and Cultural Work in Service of “Good Health”. You may qualify to take part in this research study because you self-identify as Black; a woman and/or as gender-expansive (an umbrella term for those who expand notions of gender which includes but is not limited to trans, genderqueer, nonbinary, as well as persons who identify as gender non-conforming); work professionally as an artist and/or culture worker, and be 18 or older. Approximately 10 people will participate in this study, and it will take approximately 2.5-3 hours of your time to complete over the course of two days that are within 5-7 days of one-another.

The purpose of this dissertation study I am conducting to complete my doctoral degree is to practice narrative research where the stories of participants could be elevated to inform future priorities and policies of the arts in public health field concerning health promotion, civic participation, and cultivating a sense of community that identify Black artists and culture workers as informal public health educators. Working from the definition of racism by Ruth Wilson Gilmore who describes it as “state-sanctioned vulnerability to premature death”, I am centering Black creatives in hopes my anti-racist, culturally driven approach will offer insights for new cultural pathways for this work. I especially hope to use my dissertation research to help build a Culture of Health in the U.S but also beyond in our transcontinental relationships (specifically across the Black Diaspora). Such relationships have weathered many storms and yet reflect crucial bonds to not only overcoming cultural trauma, but identifying cultural inheritances such as wisdom, resilience, possibility, pleasure, and hope.

My dissertation emphasizes changing the order of business as usual. While I am unable to prove the connection between the amplification of Matthew Shephard’s murder in “The Laramie Project” and the U.S. Supreme Court’s 2015 landmark decision to legalize same-sex marriage, I know the world was made better by it — specifically with the “Matthew Shepard and James Byrd Jr. Hate Crimes Prevention Act”.

There are no randomized controlled trials or longitudinal studies tracking the experience, accomplishments, and wellbeing of Black women after experiencing “For Colored Girls Who Have Considered Suicide/When The Rainbow Is Enuf.” But even in 1975, Ntozake Shange

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showed concern for what would become the future CROWN Act’s mission: “Creating a Respectful and Open World for Natural Hair” when she had lady in orange say to a room of Black women, “hold yr head like it was ruby sapphire.”

Last year, many states passed “Breonna’s Law,” banning “no—knock” search warrants. Among many initiatives, there were performances of #SayHerName by Kimberlé Crenshaw. This dissertation is rooted in a life-history approach and will explore what ways the arts and cultural workers can further usher in inspiration for legislation to actualize — if not ever for Breonna — other Black people’s dreams while we are still alive to see it.

When I think of my research’s relevance with health policy in the U.S., I must access a part of my dreams that believes in a future time when we might get closer to establishing health policy not solely in memory of lives cut short by injustice. Inherent in its design, my dissertation research posits that equitable policy recommendations can be legislated in the name of the living by the sharing of stories because Black health, Black citizenship, and Black belonging are central to building healthy communities.

The Robert Wood Johnson Foundation has provided funding for this study.

**WHY IS THIS STUDY BEING DONE?** This study is being done to further develop the anti-racist social and cultural pathways that identify arts and cultural work as informal public health education. The purpose of the study is to have narrative research and stories inform future priorities and policies of the field concerning health promotion, civic participation, and cultivating a sense of community that Identify Black artists and culture workers as Informal public health educators.

**WHAT WILL I BE ASKED TO DO IF I AGREE TO TAKE PART IN THIS STUDY?** If you are invited after completing a screener questionnaire and decide to participate, the primary researcher will individually interview you over the course of two virtual meetings within 5-7 days of one another and ask that you complete a demographic questionnaire.

During the first individual interview you will be asked to provide an overview of your life history and discuss your identity as it relates to your race as a Black person, as well as your gender and sexuality. The interview will then transition into a collage activity related to your beliefs and ideas about health. This interview will be audio and video recorded. After the audio recording is written down (transcribed) and reviewed (analyzed), the recording will be deleted. If you do not wish to be recorded, you will not be able to participate. The first interview will take approximately 1.5 hours. At your request, you can be given a pseudonym or false name to keep your identity confidential.

You will then be asked to participate in a second individual interview by the primary researcher where the same Black artists and culture workers will discuss their experience in the first individual interview, revisit their mosaic (collage), as well as participate in a writing activity.

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This will also be audio and video recorded. After the audio recording is written down (transcribed) and reviewed (analyzed), the recording will be deleted. If you do not wish to be recorded, you will not be able to participate. The second interview will take approximately 1 hour.

Finally, you will be asked to fill out a demographic questionnaire/ survey. This will take about five minutes.

All these procedures will be done remotely using an online platform such as Zoom. To reiterate, the interviews will be recorded, and the researcher will notify you when the recording is started and stopped.

## **WHAT POSSIBLE RISKS OR DISCOMFORTS CAN I EXPECT FROM TAKING PART IN THIS STUDY?**

This is a minimal risk study, which means the harms or discomforts that you may experience are not greater than you would ordinarily encounter in daily life while taking routine physical or psychological examinations or tests. However, there are some risks to consider. You might feel strong emotions in response to prompts to discuss problems that you experience(d) as a person who is Black and whose gender has historically (and/or currently) exists on the margins in or outside the arts and culture industry. You do not have to answer any questions or share anything you do not want to talk about. You can stop participating in the study at any time without penalty. Your information will be kept confidential.

The primary researcher is taking precautions to keep your information confidential and prevent anyone from discovering or guessing your identity, such as using a pseudonym instead of your name and keeping all information on a password protected computer and locked in a file drawer.

Due to the evolving nature of the COVID-19 pandemic, there are inherent risks with in-person research. Therefore, the researcher is forgoing in-person research activities and will be conducting the studying entirely remote.

## **WHAT POSSIBLE BENEFITS CAN I EXPECT FROM TAKING PART IN THIS STUDY?**

There is no direct benefit to you for participating in this study, however Sonke & Golden's Arts & Culture in Public Health Framework identifies the direct health benefits and evidence-based outcomes of arts and culture in public health. This dissertation builds upon their previous work that identifies mechanisms of arts and culture that provide and facilitate health and wellbeing such as: self-efficacy, personal and cultural resonance, aesthetic experience, emotional engagement and empathy, expression and being heard, and meaning making and self-transcendence (Sonke & Golden, 2020).

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Participation may benefit the field of arts in public health to better understand how racial, gendered capitalism manifest itself for Black women and gender- expansive people when creating or performing art and cultural work in relationship to health promotion goals.

**WILL I BE PAID FOR BEING IN THIS STUDY?** You will be paid an \$150 USD honorarium for your participation at the end of the study. There are no costs to you for taking part in this study.

**WHEN IS THE STUDY OVER? CAN I LEAVE THE STUDY BEFORE IT ENDS?** The study is over when you have completed the screener questionnaire, two individual interviews, and a demographic questionnaire. However, you can leave the study at any time even if you have not finished. *If you leave the study early, or do not complete all study tasks, you will* still be paid for your time at a pro-rated fee.

**PROTECTION OF YOUR CONFIDENTIALITY** Any electronic or digital information (including audio (and video) recordings) will be stored on a computer that is password protected. What is on the audio and video recording will be written down and the audio recording will then be destroyed. There will be no record matching your real name with your pseudonym. Some researchers hire professional transcriptionists, to transcribe audio-recorded interviews. The professional transcriptionists will be signing a “*non-disclosure agreement for transcriptionist*” form with your protocol. Data will be kept for at least 3 years.

For quality assurance, the study team, the study sponsor (grant agency), and/or members of the Teachers College Institutional Review Board (IRB) may review the data collected from you as part of this study. Otherwise, all information obtained from your participation in this study will be held strictly confidential and will be disclosed only with your permission or as required by U.S. or State law.

**HOW WILL THE RESULTS BE USED?** The results of this study will be published in journals and presented at academic conferences. This includes the art works, so you can be identified with the art pieces which would identify you as a participant in the study. However, your identity can be removed from any data you provide before publication or use for educational purposes. Your name or any identifying information about you will not be published without your consent given the nature of your work. This study is being conducted as part of the dissertation of the primary researcher.

\_\_\_\_\_ I want to be identified with any publication of my art work.

\_\_\_\_\_  
Signature

\_\_\_\_\_ I **do not** want to be identified with any publication of my art work.

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Signature

**CONSENT FOR AUDIO AND OR VIDEO RECORDING** Audio recording (and/or video recording is part of this research study. You can choose whether to give permission to be recorded. If you decide that you don't wish to be recorded, **you will not be able to participate** in this research study.

\_\_\_\_\_ I give my consent to be recorded

\_\_\_\_\_  
Signature

\_\_\_\_\_ I **do not** consent to be recorded

\_\_\_\_\_  
Signature

**WHO MAY VIEW MY PARTICIPATION IN THIS STUDY?**

\_\_\_ I consent to allow written, video and/or audio-recorded materials viewed at an educational setting or at a conference outside of Teachers College, Columbia University

\_\_\_\_\_  
Signature

\_\_\_ I **do not** consent to allow written, video and/or audio-recorded materials viewed outside of Teachers College, Columbia University

\_\_\_\_\_  
Signature

**OPTIONAL CONSENT FOR FUTURE CONTACT**

The primary researcher may wish to contact you in the future. Please initial below to indicate whether you give permission for future contact.

The researcher may contact me in the future for information relating to this current study:

Yes \_\_\_\_\_  
Initial

No \_\_\_\_\_  
Initial

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## **WHO CAN ANSWER MY QUESTIONS ABOUT THIS STUDY?**

**If you have any questions about taking part in this research study, you should contact the primary researcher, Shanaé Burch, at 856-3322-2922 or at [sb4003@tc.columbia.edu](mailto:sb4003@tc.columbia.edu) . You can also contact the faculty advisor, Dr. John Allegrante at 212-678-3960.**

If you have questions or concerns about your rights as a research subject, you should contact the Institutional Review Board (IRB) (the human research ethics committee) at 212-678-4105 or email [IRB@tc.edu](mailto:IRB@tc.edu) or you can write to the IRB at Teachers College, Columbia University, 525 W. 120<sup>th</sup> Street, New York, NY 10027, Box 151. The IRB is the committee that oversees human research protection for Teachers College, Columbia University.

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## **PARTICIPANT'S RIGHTS**

- I have read the Informed Consent Form and have been offered the opportunity to discuss the form with the researcher.
- I have had ample opportunity to ask questions about the purposes, procedures, risks, and benefits regarding this research study.
- I understand that my participation is voluntary. I may refuse to participate or withdraw participation at any time without penalty.
- The researcher may withdraw me from the research at the researcher's professional discretion.
- If, during the study, significant new information that has been developed becomes available which may relate to my willingness to continue my participation, the researcher will provide this information to me.
- Any information derived from the research study that personally identifies me will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- Your data will not be used in further research studies.
- I should receive a copy of the Informed Consent Form document.

## **My signature means that I agree to participate in this study:**

**Print name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature:**

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