



Consent to Participate in Research

Investigating how U.S. Latinas Anticipate and Experience Racism

Key Information

- You are being invited to participate in a research study. Participation in research is completely voluntary.
- The purpose of the study is to understand how Latinas experience racism in America.
- The study will take a total of one hour and thirty minutes and you will be a part of a small virtual focus group with other American Latinas.
- Risks and/or discomforts may include experiencing emotional discomfort or distress given the sensitive nature of discussing personal experiences with racism as well as the potential for breach of confidentiality.
- There is no direct benefit to you. The results from the study will shed light on the experiences of U.S. Latinas as they navigate racism in various facets of their lives.

Introduction and Purpose

My name is Amanda Perez. I am a Postdoctoral Researcher at the University of California, Berkeley in the School of Public Health. I am working under Dr. Amani Allen, a faculty member in UC Berkeley's School of Public Health. I would like to invite you to take part in my research study about the lived experiences of Latina Americans. In particular, we are interested in your experiences of racism including any discrimination you may or may not experience as a Latina.

Procedures

If you agree to participate in my research, you will participate in a virtual focus group through the Zoom platform. The interview will involve questions about your experiences with racism. It should last about 90 minutes. **The virtual focus group will be video and audio recorded.** The recordings are to accurately record the information you provide and will be used for transcription purposes. If you agree to being audio/videotaped but feel uncomfortable or change your mind for any reason during the focus group, you may stop your participation at any time and leave the focus group session. In this scenario, your face would be blurred in any future video clips. After the focus group session ends, you will be sent a link to complete an online exit survey which will ask you for demographic information.

Benefits

There is no direct benefit to you from taking part in this study. However, your invaluable contribution will shed light on the experiences of U.S. Latinas as they navigate racism in various facets of their lives. By participating, you are amplifying the voices of Latinas, fostering deeper societal understanding, and assisting researchers and policymakers in identifying areas of needed intervention or support.

Risks/Discomforts

Participants in this study may encounter emotional discomfort or distress given the sensitive nature of discussing personal experiences with racism. Recounting these experiences may evoke strong emotions, memories of unpleasant incidents, or feelings of vulnerability.

To minimize and address these risks:

1. **Voluntary Participation:** Your participation is entirely voluntary. You are free to decline to answer any specific questions that make you feel uncomfortable or choose to pause or stop the focus group discussion at any time without any repercussions.
2. **Safe Environment:** We will foster a respectful and empathetic environment during the focus groups. Ground rules will be set to ensure that all participants are treated with dignity, respect, and sensitivity by both the facilitators and fellow participants.
3. **Referrals:** While we will not have a licensed mental health professional on call, we will provide participants with a list of local mental health resources and hotlines. Should any participant feel the need for support or counseling following the discussion, they can use these resources.
4. **Debriefing Session:** At the end of each focus group, a brief debriefing session will be conducted to provide participants with an opportunity to discuss and process their feelings, and to ensure they are leaving in a positive or neutral emotional state.
5. **Confidentiality:** Emphasizing the strict confidentiality measures in place will hopefully reduce any anxiety related to potential breaches of privacy or misuse of shared experiences.
6. **Follow-up:** We will offer participants an optional follow-up contact, in case they wish to discuss any subsequent feelings or concerns related to the study.
By recognizing and addressing these potential emotional challenges proactively, we aim to ensure the well-being of our participants throughout the research process.

Confidentiality

Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

To minimize the risks to confidentiality we will employ the following data security measures:

1. **Secure Storage:** All digital recordings, transcripts, and any other data will be stored on a secure, password-protected server.
2. **Coding:** To further ensure confidentiality, participants' names and any other identifiable information will be removed from the recordings and transcriptions. Instead, each participant will be assigned a unique identification code. A separate, password-protected document will link participants' names to their respective codes, and only the principal investigators will have access to this document.
3. **Encryption:** Digital recordings and other electronic data files will be encrypted using state-of-the-art encryption protocols. This ensures that even if unauthorized access is attempted, the data remains protected and unreadable.
4. **Limited Access:** Access to study records, recordings, and transcriptions will be limited strictly to the research team.
5. **Secure Data Transmission:** If data needs to be shared among the research team or transferred for any reason, it will be done through encrypted channels, ensuring the data's security during transmission.
6. **Regular Backups:** Data will be backed up regularly on encrypted drives to prevent data loss, ensuring that multiple security measures protect each copy.

We will keep all the information provided during the focus groups as confidential as possible, and strongly encourage all participants to do likewise. However, we cannot guarantee that your data will not be shared after this focus group is over so, please do not discuss anything that you do not wish to be made public.

Your personal information may be released if required by law. Authorized representatives from the following organizations may review your research data for purposes such as monitoring or managing the conduct of this study:

- National Institutes of Health
- University of California

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 NOT 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.

We will transcribe the digital recordings as soon as possible after the interview. When the research is completed, I will save the transcriptions and other study data for possible use in future research done by myself or others. I will retain these records indefinitely after the study is over. The same measures described above will be taken to protect confidentiality of this study data. Identifiers might be removed from identifiable private information. After such removal, the information could be used for future research studies or distributed to other investigators for future research studies without additional informed consent from the subject or the legally authorized representative. In addition to the transcribed data, we propose to retain the original audio/video recordings beyond the transcription process. We recognize the paramount importance of participant confidentiality. Therefore, all digital recordings will be stored securely, with access limited strictly to the research team. Identifiable information, such as names or other personal details mentioned during the focus group, will be removed in both the transcriptions and any subsequent use of the recordings.

Compensation

To thank you for participating in this study, you will receive a \$50 digital gift card for your participation immediately after you complete the exit survey. Compensation is contingent upon completion of both the focus group session and the online exit survey. There is no partial payment for this study and compensation will not be given if you choose to leave the focus group session at any time.

Rights

Participation in research is completely voluntary. You are free to decline to take part in the project. You can decline to answer any questions and are free to stop taking part in the project at any time. Whether or not you choose to participate in the research and whether or not you choose to answer any

questions or continue participating in the project, there will be no penalty to you or loss of benefits to which you are otherwise entitled.

Questions

If you have any questions about this research, please feel free to contact me at adpc@berkeley.edu.

If you have any questions about your rights or treatment as a research participant in this study, please contact the University of California at Berkeley's Committee for Protection of Human Subjects at 510-642-7461, or e-mail subjects@berkeley.edu.

CONSENT

If you agree to take part in the research, please, please print or save a copy of this pae to keep for future reference, then click on the “Accept” button below.

Accept

Decline