



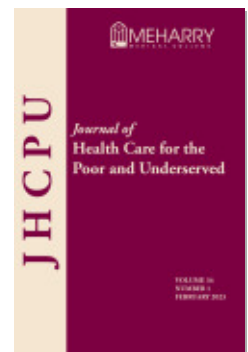
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Journal of Health Care for the Poor and Underserved, Volume 34, Number 1, February 2023, pp. 74-101 (Article)

Published by Johns Hopkins University Press
DOI: <https://doi.org/10.1353/hpu.2023.0006>



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Recruitment and Feasibility of Hair Cortisol Collection in a Sample of Ethnically and Sexually Diverse, Low-Income Adults: A Qualitative Community-Partnered Participatory Research Study

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Abstract: The current study describes how a community-partnered participatory research (CPPR) model was used to enhance hair cortisol research engagement among low-income adults of diverse ethnicities and sexual and gender identities. Participants' reported motivations and concerns surrounding providing a hair sample are also described. Participants from a larger longitudinal study were invited to provide a hair sample and/or complete acceptability interviews. Results indicated that 71% of all persons (N=133) contacted participated in the current study, of whom 82% provided hair samples. Several themes emerged from the interviews indicating that participants were motivated to provide a hair sample due to internal and external factors; however, concerns about mistrust of research remained. Thus, collecting biospecimens in research with underserved groups requires careful consideration of benefits and risks to the individual and their communities. Our results provide guidelines for engaging low-income racially/ethnically and sexually diverse community members in biospecimen research to understand stress-health relationships.

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Key words: Community-based participatory research, sexual minority, people of color, research subject recruitment, hair cortisol.

A major challenge for biomedical research in the United States is the effective translation of science to reduce racial/ethnic health disparities and improving the representation of historically understudied groups in research, which includes sexual and gender minority people of color (SGM-POC) and people from lower-income backgrounds.¹⁻⁴ The National Institute of Health (NIH) and the Institute of Medicine have outlined that biospecimen research can help promote advances in basic science into new public health approaches through deeper understanding of the physiological mechanisms implicated with health disparities.^{2,5,6} However, people of color (POC), including Black and Latinx individuals, and sexual and gender minority people (SGM; e.g., who traditionally identify as lesbian, gay, bisexual, transgender, and queer)—particularly those with lower-incomes—are underrepresented in biospecimen studies, due to multiple facets related to institutional racism, which influence methods, recruitment strategies, and participant mistrust towards researchers as a result of historical racism and misconduct.^{7,8,9,10} Mistrust towards science, rooted in a history of structural racism and misconduct, can undermine well-intentioned efforts to address health equity.^{8,11,12} Culturally-informed study methods that bridge these issues and renegotiate power structures can improve representation and participation in biomedical research and facilitate urgently needed developments in basic science to better understand illness and health.^{13,14}

Increasing representation of vulnerable groups, such as minorities and people from lower-income backgrounds, is an NIH priority.⁴ Despite these commitments to health equity, disparities continue to grow and innovative methods are needed to renegotiate power structures in science, in part by re-examining scientific methods that build trust and address underrepresentation in research that has resulted from historical racism and exclusionary structures.³ The underrepresentation of diverse groups, such as low-income POC, SGM, and SGM-POC,^{15,16} in biospecimen research is a result of prejudiced structures, rooted in historical racism and heterosexism, that yielded scientific barriers for both researchers and participants.⁸⁻¹⁰ For researchers, since past studies have predominantly been conducted by and focused on White and heterosexual gender-conforming persons, the current standards for research conduct may be culturally insensitive or ineffective for recruiting and engaging participants from diverse and lower-income backgrounds.^{9,18} For participants, people from underserved communities may face numerous barriers in participating, including learned mistrust towards researchers due to an extensive history of scientific abuses.^{9,19} We provide a few illustrative examples of these abuses (see brief overview¹²). First, the 1932 Tuskegee experiment failed to obtain clear informed consent among Black male participants, who were deceptively left with untreated syphilis.¹² Second, in California, low-income Latina women were disproportionately at risk of being sterilized under the state's forced sterilization laws, which were aimed at preventing the reproduction of individuals thought to be "feble-minded" or having undesirable hereditary conditions.¹³ Similarly, the connection between eugenics and heterosexism has been well established.¹⁰ Additionally,

homosexuality and transgender experiences were classified as mental illnesses until 1973 and 2013, respectively.^{20,21} This history has generated mistrust of the medical and research community and, in combination with methodological barriers, contribute to underrepresentation of these communities across biomedical studies.

Yet, enhanced representation of diverse groups, such as POC and SGM people, in research is important for the development of higher-quality science. Adequate representation of diverse groups has been shown to contribute to generalizability of study findings, the accuracy of subgroup analyses, and health equity and reduction of disparities.^{14,19,22-24} Therefore, improving representation of under-resourced groups across multiple social locations is an urgent matter for the development of high-quality science that can be applied. However, limited attention and solutions related to underrepresentation have been generated in psychological basic science and biomarker research, despite the promise of these methods to further understanding about illness and disparities.¹⁴ It is essential to develop study methods that can bridge the issue of mistrust to produce biomarker studies that include diverse populations experiencing health disparities.

Some researchers have begun to describe methods that can be used to enhance engagement with under-studied populations. For example, some work has shown feasibility of using less invasive biospecimen collection methods, such as hair clippings for assay of cortisol (a stress hormone²⁵) among low-income families,²⁶ racially/ethnically diverse pregnant women,²⁷ and racially/ethnically diverse adults.²⁸ Relying on a low-burden biomarker such as hair cortisol may facilitate research engagement among underrepresented populations. Furthermore, hair cortisol can be used to disentangle contributors to health disparities, such as by examining the associations between discrimination and hair cortisol among Black adults^{29,30} and racially/ethnically diverse young adults.³¹

The National Academy of Medicine and NIH have published recommendations for conducting research with underrepresented groups, underlining the need for community engagement.^{2,5} Community-partnered participatory research (CPPR) models, which rely on community partnerships of shared power and community engagement, have been shown to increase research engagement and trust, partly through the development of culturally-responsive research methods.³² Community-partnered participatory research includes ongoing consultation and involvement of community partners in all phases of the research process, with community partners treated as co-investigators. Although several CPPR studies have been conducted with POC, little is known about how to employ a CPPR framework for biospecimen collection among low-income, SGM, POC and SGM-POC.³² Furthermore, even less is known about how study participants view participating in a CPPR biomarker study, including motivations or concerns towards participating.^{9,19} This information may be useful for studies aiming to enhance recruitment by incorporating clear motivators and addressing concerns within a tailored protocol. Additionally, existing research on barriers and facilitators has focused primarily on POC or SGM, with only a few studies focused on SGM-POC. Understanding the views of SGM-POC who participate in research is important and can help inform future research methods.

Therefore, the current study used a CPPR model to learn how to engage predomi-

nantly low-income, SGM, POC, and SGM-POC in biospecimen research. The study also aimed to use qualitative interviews to examine participants' views to understand why they were or were not motivated to participate in biospecimen research. The study relied on consultation with community partners and study participants to develop and pilot a cortisol study protocol. Considering the dearth of information about POC, SGM, and SGM-POC in biospecimen research, the study also descriptively explored racial and sexual orientation subgroup patterns at the intersection of visible (race and ethnicity) and concealable (sexual orientation or low income) social group statuses³³ in their reported barriers and facilitators to participating in the current study. This study is not intended as a comparative study of the diverse subgroups represented in the sample.

Methods

Study overview and participants. The current study was conducted as a follow-up to the Resilience Against Depression Disparities (RADD) study.³⁴ The current paper describes our recruitment and study engagement methodology. All participants who completed the RADD study and were based in Los Angeles were allowed to participate in the current follow-up study. The RADD study employed a CPPR model to conduct a longitudinal comparative effectiveness depression trial for low-income, predominantly SGM and POC adults (see full study description²⁶). Inclusion criteria for the RADD study involved meeting a clinical cut-off based on a depression screener (PHQ-8³⁵ ≥ 10). Although the parent trial was established to reduce depression disparities in SGM communities that were predominantly of color, there were no exclusion criteria based on identity due to community partner recommendations and empirical support³⁶ that SGM POC may not identify as traditionally LGBTQ or SGM. Therefore, recruitment for the RADD study occurred at sites that predominantly served low-income SGM POC, and anyone meeting the study criteria, regardless of identity, was able to enroll. Only participants who were recruited at the study sites and met study criteria were allowed to enroll in the RADD study.

The current follow-up study recruited participants who completed the RADD study, were based in Los Angeles, and had agreed to be contacted about future research opportunities ($n=133$). Only former participants from the RADD study were allowed to participate. Participants were contacted by the research team and asked whether they would be interested in participating in a follow-up study examining the connection between experiencing multiple types of discrimination (e.g., racism, heterosexism), hair cortisol, and mental health outcomes. The cortisol study was developed using a CPPR framework, which involved integrating feedback from community members to write the study's aims and to adapt the study protocol to the community's needs. Those interested in the cortisol study were offered an in-person visit at which research staff conducted a brief interview, administered questionnaires, and collected hair samples. Participants who were unable to attend in-person visits or who did not wish/ were unable to provide a hair sample (≥ 1.5 cm of hair length on head or body) were able to complete the interview and questionnaires by phone. Participants were compensated, in cash, \$35 for providing a hair sample and \$15 for completing the interview and questionnaire. The in-person visits lasted 30–60 minutes and were conducted by student

(two graduate, two undergraduate) research team members who shared one or more minority identities with participants.

Protocol adaptation using multiple stakeholder input. Adaptations to the protocol were iterative and developed in consultation with community partners and based on initial study participants' input. The main steps of the adaptation process included the following: The cortisol study idea was developed because of conversations with community partners during the RADD study, with the goal to examine the role of biological stress in the relationship between discrimination and depression. An initial protocol for collecting hair samples was developed based on existing cortisol study protocols and then presented to partners who provided feedback on community needs and cultural sensitivity.^{25,30,37} Based on these recommendations and study feasibility, the protocol was adapted, and pilot-tested. As part of the research aims, participants were interviewed about their perspectives on the current research to determine study acceptability. During the piloting phase of the study, participants' feedback was integrated into further protocol adaptations. Details regarding the community partner and participant feedback received, and adaptations developed, are provided in Box 1.

Community partners were identified through their involvement in the implementation of the RADD study. They did not participate in the cortisol study but were representatives of their communities. Based on partners' recommendations and a literature review, hair cortisol was identified as a low-burden method for collecting a marker of chronic stress because it would not require participants to complete daily diaries or ask participants to adhere to self-administered sampling and storage procedures such as is required with other methods (e.g., saliva).²⁵

Participant recruitment and engagement. Several techniques were identified through the iterative protocol adaptation process and employed to enhance recruitment for the cortisol study (see Box 1). These included a flexible and persistent contact and scheduling approach, which took into consideration logistical and socioeconomic barriers to participating. For example, participants were contacted at different times of the day, week, and month to account for varying work schedules and variability in telephone access. All efforts were made to see any participants who arrived in person for a study visit, regardless of whether they arrived at their scheduled appointment time or date. For this reason, study visits were staggered throughout the day to allow time for participants who arrived late. Participants whose head hair was too short for hair sampling were given the option to complete part of the study and return when their hair had grown 1.5cm or more, or to provide a sample of body hair of the required length (e.g., underarm).³⁷ Participants who missed appointments were actively rescheduled.

Although the beginning of the study visit involved formal consent documents, consent was considered an ongoing process throughout the visit.¹⁶ Participants were provided a clear explanation of how their hair samples would be handled and assurances that their samples would only be assayed for cortisol. Research staff then collected hair samples that would later be sent for off-site cortisol assay. Next, participants completed a brief feasibility/acceptability interview and questionnaires. Participants' feedback was integrated into an adapted study protocol until saturation based on participants' feedback was reached. For example, during the piloting of the protocol, participants requested concrete recommendations for managing stress. Therefore, the research team developed

Box 1.
STUDY PROTOCOL ADAPTATION

| Design component | Original goal or issue | Community feedback | Final solution |
|----------------------|---|---|--|
| Study Goals | Examine the biological underpinnings of the discrimination- depression relationship. | Given multiple logistical barriers experienced by under-resourced communities participating in research, study should rely on a low-burden, single time-point biospecimen sample. | Study collected hair samples in person, to be assayed for cumulative cortisol during the past 3 months. ²⁸ |
| Study Staff Training | Study staff must be culturally informed and sensitive to unique needs and stressors faced by the communities participating in research. | Staff should be trained on community stressors, including homelessness, poverty, immigration stress, and prejudice such as racism, heterosexism, and transphobia. Staff should also be familiar with and respect norms regarding not assuming sexual orientation, gender identity, or pronouns. | Staff belonged to the same diverse communities as participants. Staff received cultural sensitivity training regarding race/ethnic diversity and prejudice, psychoeducation about sexual orientation and gender identity, and norms. All staff were held accountable and supportively corrected one another when mistakes or assumptions were made regarding a participants' identity or experience. Regular team discussions were held to promote awareness of sociocultural issues affecting participants and their communities. |

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Box 1. (continued)

| Design component | Original goal or issue | Community feedback | Final solution |
|-------------------------------------|--|--|--|
| Participant Recruitment and Contact | <p>Difficulty getting in contact with participants or frequently disconnected phones.</p> | <p>Many participants may want to participate but have non-traditional work schedules and many life stressors that make it difficult to get in contact. Participants may have inconsistent access to a telephone.</p> <p>Study staff should be persistent and respectful in contacting participants at different times of the day, week, and month to account for work schedules and when participants' phone credit was most likely recharged. Multiple methods of contact should be used.</p> | <p>Staff called or texted from a study cell phone at different times of the day (e.g., mornings, afternoons, evenings) during different days of the week, and different times of the month (e.g., start, middle, and end). Participants who did not respond to phone contact were sent an email or letter about the study. If study staff were still unable to reach participants, staff relied on the contact information participants had provided the RADD study for a relative or friend, to reach the participant. Participants who agreed were texted the appointment information immediately after the call. All participants received a reminder call or text before appointments. Participants were notified that study compensation would be provided in cash.</p> |
| Scheduling visits | <p>High number of missed appointments or participants showed up at different times than scheduled.</p> | <p>Given the numerous life stressors and logistic issues faced by under-resourced communities, flexibility is necessary with scheduling. Participants may require multiple scheduled appointments. Visits should be held at convenient times and locations.</p> | <p>All visits were scheduled at times that were convenient for the participants, within the student research staffs' availability. Participants who missed appointments were re-contacted and rescheduled. Participants were scheduled with time buffers in between appointments to allow late attendance. Visits were offered in several locations in Los Angeles, but most were conducted in a university office with convenient access to public transport and parking.</p> |

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Box 1. (continued)

| Design component | Original goal or issue | Community feedback | Final solution |
|---|---|--|---|
| Participant Engagement throughout the Study | <p>While all participants were recruited from the RADD study, the research staff conducting the cortisol study visits was primarily new and had no past contact with participants.</p> | <p>The cortisol study should be explained as a follow up to the RADD study. Efforts should be made to maintain consistency in research staff contacting participants and develop rapport to increase participant comfort.</p> | <p>During initial contact, participants were invited to participate in a follow-up study to the RADD project. To enhance consistency, staff were assigned to call specific participants. Every effort was made for the same staff who called and scheduled the participant's appointment to also conduct the study visit. When this was not possible, the team relied on warm handoffs, which included providing the participant the name and work cellphone number of the staff member who would conduct the study visit, which participants could call or text before or during the study visit in case of scheduling issues or questions.³⁶ Staff used warm interpersonal styles to help build rapport and comfort throughout the research process, and snacks were provided during the visit.¹²</p> |
| Consent Process | <p>Engaging underrepresented participants in a hair cortisol study (throughout the research process) given history of structural racism and homophobia, and current community mistrust.</p> | <p>Extreme care should be taken to preserve the safety and limit the use of hair samples. Given community mistrust, staff should be explicit about how hair will be analyzed. Staff should use visuals to demonstrate amount of hair sample to be collected.</p> | <p>Consent was ongoing, avoided the use of jargon, and included a clear justification (e.g., "When you are stressed, your body produces a hormone called cortisol.¹⁶ This is stored in your new hair for up to 3 months"). False hair samples were used to demonstrate the amount which would be collected. During initial phone contact, descriptive language in relation to everyday objects was used (e.g. "the sample will be the thickness of half the diameter of a pencil"). Throughout the study, staff attended to and elicited concerns about mistrust, including by explaining that hair samples were for cortisol assay only, and providing details (verbally and on paper) about how hair samples would be confidentially handled and securely stored and disposed of. Staff were extensively trained in the study protocol, through a process of observing others and receiving feedback on how they obtained study consent.</p> |

(continued on p. 82)

Box 1. (continued)

| Design component | Original goal or issue | Community feedback | Final solution |
|------------------|---|---|---|
| Hair collection | Some participants are unwilling or unable to provide head hair samples. | Hair carries different meanings in diverse communities sampled for the study. Participants who do not wish to provide a head hair sample should be provided alternative options to participating in the study. Participants wanted more personalized information about the hair collection process. | While studies traditionally rely on head hair samples, participants in the current study were allowed to provide head or body hair samples. Participants who did not want to provide a hair sample were still allowed to participate over the phone or in person for the study interview and survey portions. Participants were provided details about how hair sampling collection may vary for them based on their hair type (e.g., thin, curly, short, or balding hair). Many participants opted to have several smaller samples collected from different nearby locations on their head. Although this method introduced greater variability in the sample, this option was offered in response to participants' concerns about leaving a noticeable bald spot. |

Analysis and Dissemination of Results

| | | | |
|----------------------------|---|---|---|
| Study Wrap up and Analysis | Giving back to the community and disseminating results. | Participants wanted to receive information about stress and their own assay results. Results should be presented to the community and analyzed and interpreted with input from the community. | Participants received a tip sheet for managing stress, based on CBT and mindfulness principles. Research should be done in a collaborative fashion, such that community partners are involved in the analysis and publication of study results. At the end of the study, participants will receive a summary of the study findings and personal results about their hair sample. While hair cortisol does not yet have any established clinical cutoffs, participants will receive a clear explanation that describes their cortisol level in comparison to prior population studies or the rest of the study sample. ²⁸ Results will continue to be shared through community conferences. |
|----------------------------|---|---|---|

a tip sheet document for managing stress, which staff reviewed with participants at the end of the study visit. These tips were based on cognitive behavioral therapy (CBT) and mindfulness principles and were developed by a clinical psychology doctoral candidate in collaboration with clinical psychologists on the team.^{38,39} Once the study analyses are finalized, participants will receive an additional copy of the tip sheet, along with a summary of the study findings.

Measures. *Demographics.* During the RADD study, participants were asked to report the following demographic characteristics: age, household income, current health insurance coverage, gender identity, sexual orientation, current marital status, U.S.-born status, current living situation, educational background, and race/ethnicity (re-coded, given the small sample size, as Hispanic, non-Hispanic Black, non-Hispanic White, or racially/ethnically diverse subgroup*). Participants were also asked about their sexual behavior. Given that POC may vary in how they identify with the LGBTQ community, those who reported having sex with people of their same sex or gender were considered to belong to a sexual minority group.³⁶ Information was collected using the HIPAA-compliant online platform, CHORUS.⁴⁰ Further details about RADD data collection are provided elsewhere.²⁶

Interview. The qualitative acceptability interview consisted of nine open-ended questions concerning perceptions of biospecimen research (including hair, saliva, and blood specimens), although for purposes of the current study only the responses regarding hair samples were used.²¹ Interviews lasted an average of 15 minutes. Interviews were conducted in Spanish or English, depending on participant preference. Participants were asked about their motivations and concerns related to participating in a hair cortisol study (e.g., *What motivated you to provide a hair sample?*). Interviews were audio recorded.

Qualitative analysis. Participants' responses during the acceptability interview were coded to systematically capture the presence of different types of responses. The initial codebook was developed by the first author who conducted most of the study interviews (SMV). The codebook was informed by grounded theory and was developed using an inductive approach and open coding.⁴¹ During the coder training and reliability phase, the codebook was considered a living document that could be refined. Once coder reliability was established, the codebook was finalized.

Four coders (LAP, WAR, SP, & RM) rated the 90 interviews included in the analysis. Coder training involved independently coding 15 interviews and discussing consensus. Reliability was then established based on 25 interviews, which all four raters coded (see Table 1 for kappas). Two bilingual Spanish-speaking coders coded 6 additional Spanish interviews to ensure the codebook reflected both Spanish and English cases. Coders then independently coded the remaining cases ($n=59$; 14–15 cases per coder), including the first 15 coding training cases. All coding was conducted using interview audio recordings, and ratings were entered in Excel. Reliability was analyzed using SPSS to yield a kappa statistic.

*Given the smaller proportions of a wide array of racial group options, and efforts to retain the full sample, we grouped participants who did not identify with the larger racial/ethnic group categories into a single subgroup.

Table 1.
RATER AGREEMENT ACROSS THEMES

| Theme | Kappa ^a value | Strength of agreement |
|--|--------------------------|-----------------------|
| Facilitators of participation in the hair cortisol study | | |
| Internal motivators for participating | | |
| Curiosity about their own health and stress | .56 | Moderate |
| Desire to contribute to research | .67 | Substantial |
| Prior experience participating in research | .85 | Almost perfect |
| External motivators for participating | | |
| Monetary incentive | .65 | Substantial |
| Study convenience | .67 | Substantial |
| Clear explanation about the study | .57 | Moderate |
| Perception of receiving a service in return | .31 | Fair |
| Barriers to participation in the hair cortisol study | | |
| Mistrust | .36 | Fair |
| Stigma | .38 | Fair |
| Aesthetic concerns regarding quantity of hair clippings | .91 | Almost perfect |

Note

^aAll kappa's refer to averaged Cohen's Kappa, based on pairs using all four coders.

Results

Indicators of recruitment success. *Study engagement and recruitment.* The study team attempted to contact 133 people (Figure 1). Of those who scheduled an appointment ($n=104$), 94 participated in the study. Participants who ultimately enrolled were contacted on the telephone an average of 5.74 times ($SD=4.22$). Nine ($n=9$) were additionally mailed a letter or contacted via e-mail, and two ($n=2$) were contacted via a relative or friend. Through our recruitment strategy, the research staff was able to engage 71% ($n=94$) of participants in the current study. Of those who participated in the study, 82% ($n=77$) completed the hair sampling, brief interview, and survey portion of the study. These participants were scheduled an average of 1.62 times ($SD=1.23$). Additionally, seven ($n=7$) of the 77 participants did not have long enough hair during their visit and provided a hair sample during a follow-up appointment. On average, the participants who scheduled a follow-up appointment did so 2.29 times ($SD=2.05$). An additional 17 participants only completed the interview portion of the study. Therefore, a total of 94 participants completed an interview, but only 90 audio recordings were analyzed due to participants not consenting to record ($n=1$) or technical failures with the recorder ($n=3$).

Participants. Participants ($N=94$) were English or Spanish ($n=6$) speaking adults ($M=43.29$ years; $SD=13.47$; Table 2). Most participants identified as men (76.4%) and had low incomes, with 69.6% of participants earning \$20,000 or less annually. Most participants were Hispanic (43.7%), followed by non-Hispanic Black (referred to as

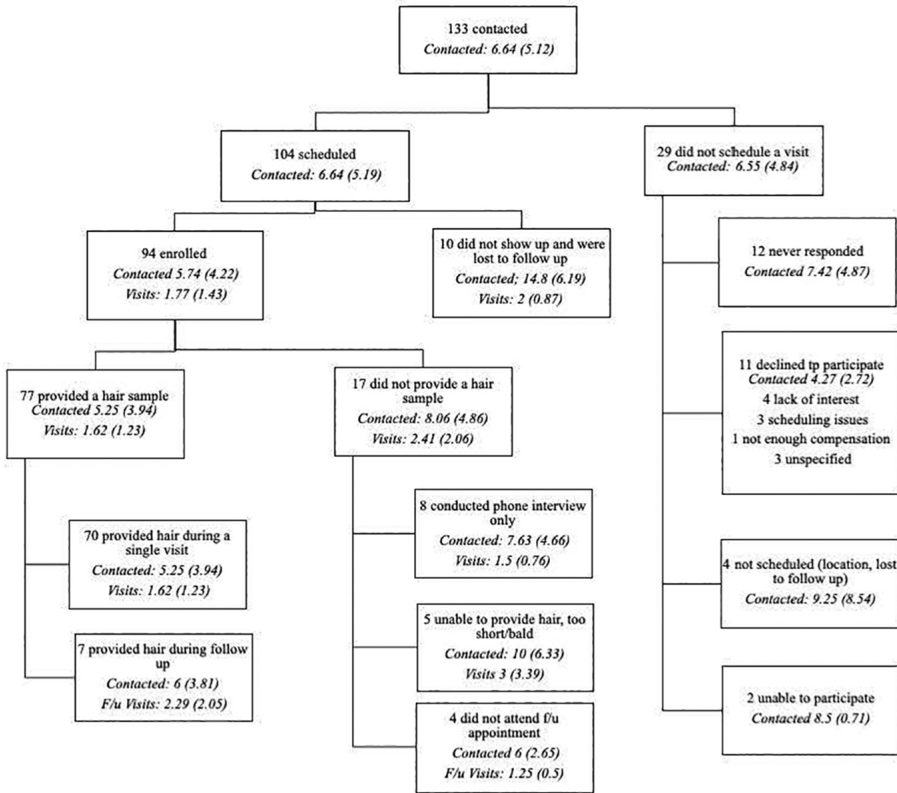


Figure 1. Study engagement and recruitment flow chart.

Black; 29.9%), and non-Hispanic White (referred to as White; 19.5%). The remainder (6.9%) comprised racially/ethnically diverse groups, which we collapsed into a single category due to efforts to retain the sample size. Additionally, 42.0% identified as gay or lesbian, 37.5% as heterosexual, 11.4% as bisexual, and 9.1% as queer/questioning. Given the intersectional nature of the sample, participant racial subgroup breakdowns are provided by sexual orientation in Table 2. Based on their reported sexual behavior, in combination with self-reported identity, it was determined that 64.5% of participants were members of sexual minorities. Nearly half of participants reported at least some college. The average hair cortisol level in the sample was 18.30 pg/mg, which was based on a hair sample 1 cm in length.

Interview findings. Results from the interviews are separated into two sections: 1) facilitators and 2) barriers to participation in the hair cortisol study. Code descriptions and exemplary quotations are provided below, as well as descriptive statistics reflecting the endorsement of each code by racial and sexual orientation subgroups. All codes are presented in Table 3.

Facilitators of participation in the hair cortisol study. Participants who provided a hair sample ($n=77$) described several factors that facilitated their participation in the hair cortisol study. These broadly fell under two themes: internal motivations, and external motivations.

Table 2.
PARTICIPANT CHARACTERISTICS^a

| Variable | Total N = 94 |
|---|-----------------|
| Age, mean (SD) | 43.29 (13.47) |
| Work-related income in U.S. Dollars | |
| 0–10,000 | 31 (44.9) |
| 10,001–20,000 | 17 (24.6) |
| 20,001–25,000 | 9 (13.0) |
| 25,001–30,000 | 3 (4.3) |
| 30,001–35-000 | 3 (4.3) |
| 35,001–40,000 | 6 (8.7) |
| Current health insurance coverage | |
| Yes | 73 (89.3) |
| Current Gender | |
| Woman | 17 (19.1) |
| Man | 68 (76.4) |
| Transgender man/transgender male/female-to-male | 1 (1.1) |
| Transgender woman/transgender female/male-to-female | 0 (0) |
| Genderqueer/Gender non-conforming | 3 (3.4) |
| Race ^b | |
| Hispanic | 38 (43.7) |
| Black | 26 (29.9) |
| White | 17 (19.5) |
| Racially/ethnically diverse group | 6 (6.9) |
| Sexual Orientation x race | |
| Straight or heterosexual | 32 (37.5) |
| Hispanic | 12 (37.5) |
| Black | 10 (31.3) |
| White | 6 (18.8) |
| Racially/ethnically diverse group | 4 (12.5) |
| Gay (lesbian) or homosexual | 38 (42.0) |
| Hispanic | 18 (47.4) |
| Black | 11 (28.9) |
| White | 7 (18.4) |
| Racially/ethnically diverse group | 2 (5.3) |
| Bisexual | 10 (11.4) |
| Hispanic | 6 (60) |
| Black | 2 (20) |
| White | 1 (10) |
| Racially/ethnically diverse group | 1 (10) |
| Queer/questioning | 9 (9.1) |
| Hispanic | 2 (22.2) |
| Black | 4 (44.4) |
| White | 3 (33.3) |
| Racially/ethnically diverse group | 0 |

(continued on p. 87)

Table 2. (continued)

| Variable | Total N = 94 |
|--|-----------------|
| Sexual minority (based on sexual behavior) | 55 (64.5) |
| Marital Status | |
| Now married | 10 (11.4) |
| Widowed | 2 (2.3) |
| Divorced or separated | 10 (11.4) |
| Single, never married | 60 (68.2) |
| Living with someone as though married | 6 (6.8) |
| Born in U.S. | |
| Yes | 56 (65.9) |
| Current Living Situation | |
| Own home or apartment | 3 (3.4) |
| Rent home or apartment | 49 (55.7) |
| Living with friends or family | 25 (28.4) |
| Living in a supported housing program | 5 (5.7) |
| Living in an emergency shelter | 0 (0) |
| Homeless | 6 (6.8) |
| Educational Background | |
| Less than high school | 17 (18.5) |
| High school graduate | 25 (27.2) |
| Some college | 29 (31.5) |
| College or higher | 21 (22.8) |

Notes

^aResults are n(%) unless otherwise specified. Percentages in italics represent nested percentages.

^bMissing demographic data not shown.

Internal motivations for participating. Participants described several personal reasons for participating in our study, including: (1) curiosity about their own health and stress, (2) desire to contribute to research, and (3) prior experience participating in research studies. Overall, 73% of Hispanic, 81.2% of Black, 73.3% of White, and 80% of people from racially/ethnically diverse backgrounds endorsed some internal motivation that contributed to their decision to provide a hair sample. A majority (91.7%) of heterosexual, 87.9% of lesbian/gay (LG), 100% of bisexual and queer people endorsed internal motivations.

Curiosity about their own health and stress. Most participants (66.3%) stated that they provided a hair sample because they wished to learn about their personal stress and the impact stress had on their health. Seventy-three percent of Hispanic, 62.5% of Black, 60% of White, and 60% of people from racially/ethnically diverse backgrounds endorsed this as a motivating factor for providing a hair sample. Sixty-four percent (63.6%) of LG, 62.5% of bisexual, and 57.1% of queer people reported this as a reason for participation, whereas 75% of heterosexual people identified this motivating factor. Several participants described wanting to learn whether they experienced too

Table 3.

THEMES ACROSS STUDY: FACILITATORS FOR PARTICIPATING IN A HAIR CORTISOL STUDY

| Theme | Sample quote | Frequency (%) | | | | | | | | |
|--|--|---------------|-----------|---------|---------|---------|----------|--------------------|------|------|
| | | Overall | Hisp (40) | BI (27) | Wh (17) | R/E (7) | HET (33) | Sexual orientation | | |
| | | | | | | | | | | |
| Internal motivators for participating | | | | | | | | | | |
| Curiosity about own health and stress | "I see this study as more of a benefit to me. If there's an answer to how high my levels of stress are, right?" (Cisgender man, Bisexual, Hispanic) | 66.3 | 73 | 62.5 | 60 | 60 | 75 | 63.6 | 62.5 | 57.1 |
| Desire to contribute to research | "That's good they have these research studies. Then they could help, you know, find a cure for different things." (Cisgender man, Gay, Black) | 55 | 48.6 | 43.8 | 73.3 | 60 | 50 | 60.6 | 62.5 | 71.4 |
| Prior experience participating in research | "At first, I was hesitant. But because I've heard of the **** study and I've worked with ya'll before, I was like, 'Ok, might as well check it out.' And here I am." (Cisgender man, Bisexual, Hispanic) | 25 | 18.9 | 12.5 | 46.7 | 40 | 25 | 21.2 | 25 | 42.9 |

(continued on p. 89)

Table 3. (continued)

| Theme | Sample quote | Frequency (%) | | | | | | | | |
|--|---|---------------|-----------|---------|---------|--------------------|----------|---------|--------|-------|
| | | Race | | | | Sexual orientation | | | | |
| | | Overall | Hisp (40) | BI (27) | Wh (17) | R/E (7) | HET (33) | LG (39) | B (10) | Q (9) |
| External motivators for participating | | | | | | | | | | |
| Monetary incentive | “The compensation was a good incentive.” (Cisgender man, Gay, Hispanic) | 52.2 | 48.6 | 62.5 | 46.7 | 80 | 58.3 | 48.5 | 50 | 57.1 |
| Study convenience | “I said, ‘It’s good. If it’s close by, I’ll go.’” (Cisgender woman, Straight, Hispanic) | 25 | 29.7 | 12.5 | 20 | 40 | 20.8 | 33.3 | 12.5 | 14.3 |
| Clear explanation about the study | “Once explained I understood the purpose and once knowing the purpose made for being okay with assisting technology and to find out reasons why to help—the research” (Cisgender man, Gay, Black) | 17.5 | 10.8 | 25 | 20 | 40 | 12.5 | 12.1 | 37.5 | 42.9 |
| Perception of receiving a service in return | “I’m curious to know what my levels are—I mean free testing, why not?” (Cisgender man, Gay, Hispanic) | 18.8 | 13.5 | 37.5 | 13.3 | 0 | 20.8 | 18.2 | 12.5 | 14.3 |

(continued on p. 90)

Table 3. (continued)

| Theme | Sample quote | Frequency (%) | | | | | | | | |
|---|---|---------------|-----------|---------|---------|--------------------|----------|---------|--------|-------|
| | | Race | | | | Sexual orientation | | | | |
| | | Overall | Hisp (40) | BI (27) | Wh (17) | R/E (7) | HET (33) | LG (39) | B (10) | Q (9) |
| <i>Completed interview (regardless of hair sample donation; N=94)</i> | | | | | | | | | | |
| Barriers to participating in hair cortisol study | | | | | | | | | | |
| Mistrust regarding hair | “What are they going to do with that sample of hair? And now, with this president [Trump] that says he’s going to collect DNA samples on immigrants” (Cisgender man, Gay, Hispanic). | 33.3 | 38.5 | 38.5 | 23.5 | 14.3 | 26.7 | 42.1 | 30 | 33.3 |
| Stigma | “I don’t want people to be concerned about me, that’s why. I don’t want them to say like, ‘oh are you depressed is that you’re doing this?’ I don’t want people to judge me for doing this.” (Cisgender man, Straight, racially/ethnically diverse) | 3.3 | 0 | 3.8 | 0 | 28.6 | 3.3 | 2.6 | 10 | 0 |
| Aesthetic concerns regarding quantity of hair clippings | “The only concern would be like leaving a noticeable spot, but it seems it didn’t happen.” (Cisgender man, Gay, racially/ethnically diverse) | 7.8 | 5.1 | 3.8 | 17.6 | 14.3 | 10 | 2.6 | 20 | 0 |
| <i>Notes</i> | | | | | | | | | | |
| Hisp=Hispanic; BI=Black; Wh=White; R/E=Racially/Ethnically Diverse; HET=Heterosexual; LG=Lesbian Gay; B=Bisexual; Q=Queer | | | | | | | | | | |
| ****= MASKED FOR REVIEW | | | | | | | | | | |

much stress, or to understand how events in their lives might be impacting their stress level. For example, one participant stated that he participated “Because I was curious about how stressed I am or how I can stress less and maybe my hair will grow back” (Cisgender man, Gay, Black).

Desire to contribute to research. Over half (55%) of participants reported providing a hair sample because they wanted to contribute to research or knowledge. Nearly half of Hispanic (48.6%) and Black (43.8%), three-quarters (73.3%) of White, and nearly two-thirds (60%) of people from racially/ethnically diverse backgrounds described this reason for participating. Fifty percent of heterosexual, 60.6% of LG, 62.5% of bisexual, and 71.4% of queer people reported this as a motivating factor for providing a hair sample. While some described personally enjoying participating in research (“Research generally . . . is all for the purpose of education and enlightenment”, Cisgender man, Gay, Black), others stated that they participated to help other members of their community. For example, one participant stated that he participated because, “. . . [of] wanting to help . . . out. Give something back in a way” (Cisgender man, Gay, Hispanic).

Prior experience participating in research. Several participants (25%) cited their prior experience participating in research studies, particularly participation in the RADD study, as a motivation. A small proportion of Hispanic (18.9%) and Black (12.5%) participants endorsed this reason for providing hair samples, whereas a larger percentage of White (46.7%) and people from diverse racial/ethnic backgrounds (40%) described this as a rationale. Twenty-five percent of heterosexual, 21.2% of LG, 25% of bisexual, and 42.9% of queer people reported this as a reason for participating. For example, one woman stated that “. . . I really like the way that they conducted the study with the follow-ups and making sure that after the interviews everyone was okay. If they needed any sort of help contacting [mental health] resources [they would help link people to care]. I thought that was great” (Cisgender woman, Queer, Black). Many others similarly expressed willingness to provide a hair sample due to their appreciation that they were being continuously followed up with and linked to resources by the RADD study, suggesting that they experienced a personal benefit from participating in prior clinical assessment research.

External motivators for participating. Participants described several external reasons for participating in the hair cortisol study, with most involving factors related to the research team or study. These include: 1) monetary incentives, 2) study convenience, 3) clear explanations concerning the research study, and 4) perceptions of receiving a service in return from the study. Given that many of these factors are well documented in prior work, we elaborate below only on a few, but all codes are described in Table 3.³⁸ A majority of Hispanic (89.2%) and White (86.7%), and all Black and racially/ethnically diverse participants endorsed some external factor that motivated them to provide a hair sample. A majority of heterosexual (83.3%), LG (72.7%), bisexual (75%), and queer (71.4%) people described external motivators associated with their participation in the study.

Monetary incentives. Approximately half of participants (52.2%) shared that financial incentives motivated them to provide a hair sample. Nearly half of Hispanic (48.6%) and White (46.7%), and most Black (62.5%) and racially/ethnically diverse (80%) participants described this as a motivator to participate. Forty-nine percent (48.5%) of

LG, 50% of bisexual, and 57.1% of queer participants discussed monetary incentives. For example, one participant explicitly stated,

That [the monetary incentive] was one of the factors that affected me too, honestly. I said, "Well, it's a little help." Currently, I haven't worked in a few months. I said, "Well, it's a little benefit that the community is offering. Why shouldn't I take it?" (Cisgender man, Gay, Hispanic).

Study convenience. Some participants (25%) stated that the location and scheduling flexibility of where and when the study took place encouraged their participation. Fewer Black (12.5%) and White (20%) participants endorsed study convenience as a motivating factor for participating in the study. Over a quarter of Hispanic (29.7%) and racially/ethnically diverse (40%) participants described study convenience as a reason for participating. Similarly, 12.5% of bisexual, 14.3% of queer, and 33.3% of LG participants mentioned study convenience. One participant stated, "Because you guys [study staff] were willing to work with me and my schedule." (Cisgender man, Gay, Hispanic).

Clear explanation about the study. Some participants (17.5%) noted their initial hesitation to participate was eased by the clear and ongoing consent process that included an explanation about the purpose of the study and clarity on how samples would be handled. Few Hispanic (10.8%), some White (20%), and a quarter of Black (25%) and 40% of racially/ethnically diverse participants described this as a motivation to participate. Similarly, few heterosexual (12.5%) and LG (12.1%), vs. over a third of bisexual (37.5%) and queer (42.9%) participants reported this as a motivating factor.

Perception of receiving a service in return. Some participants (18.8%) perceived the current study as a clinical service that would provide cost-free information and testing about stress and stress management. Few Hispanic (13.5%), White (13.3%), and participants from the racially/ethnically diverse subgroup (0%) endorsed this reason, whereas over a third (37.5%) of Black participants reported this was a motivating factor. Some heterosexual (20.8%), LG (18.2%), bisexual (12.5%), and queer (14.3%) people endorsed this reason for participating. Several participants expressed a desire to acquire this information to improve their health. For example, one participant stated that he provided a hair sample to receive feedback that might help improve the quality of his current medical care: "I came here for answers to things that I don't think people [like my physician] are taking a look at. So, I'm hoping that it'll reveal something that I can take with me to show someone. You know, to advocate for myself." (Cisgender man, Heterosexual, Black).

Barriers to participation in the hair cortisol study. All participants ($N=94$) described concerns and barriers to participating. For some, these concerns remained throughout the study visit, whereas others reported that their concerns were assuaged during the visit. Overall, participants reported three types of engagement-related barriers: (1) mistrust, (2) stigma, and (3) aesthetics.

Mistrust. One third (33.3%) of participants reported worrying about the safety and confidentiality of their hair sample. Nearly forty percent (38.5%) of Hispanic and Black, a quarter (23.5%) of White, and few (14.3%) participants of racially/ethnically diverse subgroups endorsed concerns around mistrust. Twenty-six percent (26.7%) of

heterosexual, 30% of bisexual, 33.3% of queer described this concern, whereas 42.1% of LG people discussed mistrust. For example, some participants described concerns about what would happen with their data, citing recent news stories about companies sharing or selling customer's data. "I was a little worried about, like, confidentiality stuff . . . part of me that is just like totally weirded out by companies like 23andMe, who . . . can sell [your data] or they can analyze certain portions . . . and you would never know" (Cisgender man, Bisexual, racially/ethnically diverse). Others described concerns that their data could be mishandled and used to implicate people in crimes, "If somebody tries to frame you for a crime or something. But then they got your hair, so . . . you know, it's their word against yours but they got a sample of your hair" (Cisgender man, Gay, Black).

Stigma. Very few (3.3%) participants voiced concerns about social stigma surrounding participating in mental health research. No Hispanic or White, 3.8% Black, and 28.6% of participants from racially/ethnically diverse groups discussed worries about stigma. Few heterosexual (3.3%), LG (2.6%), bisexual (10%), and no queer people reported this concern.

Aesthetic concerns regarding the quantity of hair clippings. Very few (7.8%) participants expressed concern that the amount of hair collected might leave a visible collection spot. Five percent (5.1%) of Hispanic, 3.8% of Black, 17.6% of White, and 14.3% of participants from diverse racial/ethnic groups endorsed this concern. Few heterosexual (10%), LG (2.6%), bisexual (20%), and no queer people described this concern.

Discussion

The current study relied on a community-partnered participatory research model to develop a protocol for collecting hair samples among low-income, racially/ethnically, and sexually diverse adults.⁴² We used a variety of recruitment techniques to explore how to engage participants in biomarker research and interviewed participants to understand their motivations and concerns surrounding providing a hair sample. Through a CPPR model, community partners informed the research team of the existing stress and health concerns, helped to design research questions and methodology, and critically reviewed the themes that emerged from thematic analysis. Given discussions with community partners, a wide net of recruitment strategies was used. These included persistent, flexible, and respectful scheduling; attention to relationship rapport and offering support to participants; staff availability; and transparency about the study's aims.

Participants who provided a hair sample reported several internal and external factors that motivated them to provide a hair sample, such as wanting to learn more about their own stress and health. All participants described barriers to providing biospecimens, such as concerns about potential violations to their rights to privacy and confidentiality. Despite those concerns, 82% of participants who enrolled in the study provided a hair sample. This high rate of participation may suggest that participants perceived the benefits of this research as outweighing the potential risks, which is a fundamental component of community-partnered work.³² In the current study, some participants described providing a hair sample to help improve knowledge about health in their community. It is also possible that participants' concerns may

have been mitigated through the research team's ability to work with the community to clearly establish how the research might benefit participants and their community. For example, throughout the study, our team established a mutual relationship with participants, where the research team was not merely extracting information from the community without providing resources in return. To do this, our study relied on a process of consultation with community partners and study participants.

Across participants' interviews, participants who did and did not provide a hair sample discussed several concerns about biological samples, including worries related to trust, confidentiality, and sample use/storage. Some participants discussed concerns about potential data breaches that were reflected in current events. For example, several Black participants reported concerns that the data extracted from their hair samples might be used to implicate them or someone they know in a crime. At the time the current study took place, several news stories reported that ancestry testing companies had shared customer data with law enforcement. This linked customers' relatives, who had not provided a biospecimen sample, to crime scenes.⁴³ Participants who reported this concern about the study were gently reminded that confidentiality limits would not allow the research team to share their data, but when participants persisted with this concern, their worries were validated as a reflection of broader historical systemic mistrust. Interviewers therefore articulated this concern as a point to further investigate participants' motivation to participate.

In general, the qualitative findings suggest that biospecimen research with underserved communities requires commitment to developing relationships as part of a collective effort to conduct research. Throughout their interviews, participants described a desire to receive a service for their participation. For example, during the piloting phase, several participants expressed enthusiasm about receiving individualized results about their stress levels. While at first the research team interpreted these comments as an opportunity for clarification about the limited interpretability of individual cortisol scores, eventually this was understood as a study adaptation to maximize researcher responsiveness. Through discussions with community partners and consultation with other biomarker CPPR researchers, the decision was made to provide individual raw cortisol scores in letters that will be sent to participants at the end of study analysis. Consistent with CPPR dissemination goals,³² the team will send a summary of study findings to participants. Per this study protocol adaptation, the summary will also include a description of the individual participant's cortisol score, along with a qualitative comparison with the study sample and prior study sample cortisol averages.^{30,44} Participants will be reminded that this information is descriptive and not clinically significant.

Additionally, to be responsive to participants' concern regarding their stress levels and some explicit requests for information about how to manage stress, a brief CBT tip sheet was developed and shared with participants during the study visit. Furthermore, some participants described experiencing a mutual relationship during their prior participation with the RADD study, in which participants provided data and the research team provided resources including linking them to mental health services as needed. In both examples, participants described a desire for immediate personal benefit from participating in the study.

Another engagement approach focused on technical recruitment strategies that had

been used in past studies by our CPPR team to facilitate participation for minoritized groups.^{23,45} These strategies included systematic participant outreach, flexibility in scheduling, and specific efforts to establish rapport and build trust. Overall, the contact and scheduling approach used in the current study aimed to be culturally informed by adopting a method that places accountability on research staff. For example, rather than expecting participants to follow up, the research team employed several strategies to make sure participants who had been called or scheduled were not unintentionally forgotten. Given that many participants had nontraditional work schedules, numerous life stressors, and variability in access to a telephone, research staff repeatedly attempted to contact participants about the study. These recruitment efforts have proven efficacious in enrolling and retaining people of color in research studies.⁴⁶

At the same time, we weighed ethical considerations about unintentional coercion or participant discomfort related to repeated calls.⁴⁷ Therefore, research team-initiated contact was spaced out and a system was developed to transition to participant-initiated contact through alternative means of communication (e.g., sending emails or letters asking participants to contact the research team). Similar considerations were adopted when participants missed a scheduled appointment, and research staff was responsible for contacting participants to reschedule. Flexibility and accessibility were emphasized throughout the recruitment process, such as by allowing participants to arrive late if necessary, using study cell phones which could be used for texting or speaking with participants who got lost or needed support arriving to the study location, and issuing appointment reminders.

Several participants noted that different efforts by the research team contributed to their decision to provide a hair sample. Guided by best practices for facilitating research participation among POC,¹⁸ research staff received extensive training on how to clearly explain the study and obtain ongoing consent from participants, with the goal of demonstrating transparency and clarity about the study process. Several participants remarked on the critical role this consent process played in their decision to provide a hair sample. Participants' narratives suggested that they were searching for signs of legitimacy (e.g., specific rationale for hair samples and the role cortisol plays in stress) and of specificity about the parameters of the study (e.g., only cortisol, but not DNA, would be measured; safe disposal of hair samples).

Through the acceptability interviews, participants discussed how the different recruitment strategies described above contributed to their participation in the study, as well as their broader view about hair cortisol research. Given the dearth of data on SGM-POC, a group whose social status is both visible (race and ethnicity) and invisible (sexual orientation or low income), these results provide important initial data about an understudied population. Overall, participants endorsed multiple reasons for providing hair samples.¹⁶ Participants most often discussed wishing to learn about their health and stress. Statistical comparisons by race and/or sexual orientation were not possible in this study due to small subsamples yielding insufficient power. However, some descriptive patterns can be observed based on the frequencies. For example, a greater proportion of White participants in our sample than Black and Hispanic participants described that contributing to research motivated them to provide a hair sample for the current study. This may reflect differences in attitudes and valence associated with

research, given the history of misconduct and abuse targeted at underserved communities such as Black and Hispanic groups.^{7,8,12,19} Additionally, a greater proportion of LG participants expressed concerns regarding mistrust than did heterosexual participants. These findings are unsurprising given the extant harm experienced by sexual minority persons caused by the research community.^{10,18}

Future studies with larger samples should examine mistrust and other subgroup patterns in perceived motivators and barriers to participation in biomarker research. For example, larger studies that employ stratified sampling approaches to recruit adequate numbers of Black, Latinx, and Asian gay, bisexual, and queer women, men, and transgender people could allow for inter-categorical intersectionality approaches.⁴⁸ Such an approach could generate group sizes large enough to detect meaningful results to better understand the heterogeneity of motivators and barriers to participation in biomarker research among multiply minoritized groups of people.

Several study limitations exist. First, the study recruited participants who were previously engaged in a research study. Although the specific members of the research team during the follow-up study were not the same as for the larger study, participants reported that their relationship with the RADD team motivated their engagement with the current study. It is not clear how the current engagement strategies would work for people who are unfamiliar with research. Second, while the racial and sexual orientation diversity of the sample provided a breadth of perspectives, subgroup differences may have been missed, particularly given that most participants identified as cisgender men. Future studies may benefit from providing greater in-depth assessment of differences across subgroups. Third, participants in the current study were previously or currently depressed. The perspectives of people without a history of depression may be different. Fourth, some codes in the current analysis reflected fair or moderate interrater reliability. When we reviewed these data, it appeared the low base rate of codes might have contributed to overestimating the few instances when raters did not agree. We opted to include these codes in our analysis given that the focus of our paper is on describing qualitative findings rather than establishing reliable codes for generalizable use in the future. However, this may reflect a need for greater precision in future studies examining the presence of such factors. Furthermore, the current study focused on participants' views about hair cortisol. Views about other types of biomarkers (e.g., blood cortisol, urine, saliva) may differ, a question future research should examine. Additionally, while efforts were made to meet participants in community settings that were convenient to them, most visits were conducted at a university office that was centrally located and accessible by public transit. The location, along with the composition of the research team as mostly students, may have influenced participants' responses. Finally, other demographic factors, such as education level, prior experience with research, and gender may affect engagement with research. Future studies should examine these issues.

Given that SGM-POC are largely missing from biospecimen research, greater culturally informed efforts are needed to mitigate reluctance to participate in biospecimen research by increasing the benefits and minimizing risks. Taking such approaches is critical to making basic science more inclusive and diverse to better understand illness and health and to address health inequities among underserved populations. General

recommendations, based on this study's findings, are provided below. First, researchers should develop longstanding relationships with community partners, which may enhance participant trust, identify potential concerns, and develop appropriate procedures based on community needs, cultural sensitivity, and feasibility. Second, participant and community benefit for the study should be clearly stated (see Box 1 for examples). Third, since logistical barriers can keep underserved people from participating in research, recruitment efforts should be informed by participants' realities and adapted to facilitate study engagement (see Box 1 for examples). Fourth, the consent process should begin when participants are first contacted about the study and should continue throughout the scheduled visit (see Box 1 for examples). Finally, offering cash payment and notifying participants that payments are in cash is an effective recruitment tool (see Box 1 for examples).⁴⁴ Aside from cash incentives, future studies may benefit from paying separately for cost of transportation. Using these recommendations may support research engagement among under-represented groups in biomarker research and facilitate greater attention to important processes that underlie disparities and their connection with minority stressors such as discrimination and stigma.

Acknowledgements:

The authors would like to thank the RADD study participants; RADD Executive Committee; RADD Community Advisory Board; the County of Los Angeles Department of Mental Health; Mariah Williams, BA; Jeremy Goldbach, PhD; Darby Saxbe, PhD; Richard John, PhD; and countless others whose involvement were essential to completing this study.

Conflicts of interest and source of funding:

No conflicts of interest. This study was supported by the American Psychological Foundation and Council of Graduate Departments of Psychology (2017 Ruth G. and Joseph D. Matarazzo Scholarship), the Patient-Centered Outcomes Research Institute (PCORI, www.pcori.org), grant number: PPRND-1507-32173, and the University of Southern California Department of Psychology and Graduate School. SMV was supported through a Ford Foundation Predoctoral Fellowship. JM was partly supported through a Substance Abuse and Mental Health Services Administration grant (SM080041-01) and a National Institute of Mental Health grant (P30MH058107-21). BC was also supported by the UCLA Clinical and Translational Science Institute/ National Center for Advancing Translational Sciences grant (UL1TR001881).

References

1. Smedley BD, Stith AY, Nelson AR, eds, et al. *Unequal treatment: confronting racial and ethnic disparities in health care*. Washington, DC: National Academies Press, 2003.
2. Shner AI, Terry SE, Schultz AM, et al, eds. *The CTSA Program at NIH: opportunities for advancing clinical and translational research*. Washington, DC: National Academies Press, 2013.

3. Jackson CS, Gracia JN. Addressing health and health-care disparities: the role of a diverse workforce and the social determinants of health. *Public Health Reports*. 2014;129 (1_Suppl2):57–61.
<https://doi.org/10.1177/00333549141291S211>
PMid:24385666 PMCID:PMC3863703
4. Oh SS, Galanter J, Thakur N, et al. Diversity in clinical and biomedical research: a promise yet to be fulfilled. *PLOS Med*. 2015 Dec 15;12(12):e1001918.
<https://doi.org/10.1371/journal.pmed.1001918>
PMid:26671224 PMCID:PMC4679830
5. CTSA Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. *Principles of community engagement (2nd ed.)*. Washington, DC: Department of Health and Human Services, 2011. Available at: https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf.
6. National Institutes of Health (NIH). Institutional clinical and translational science award (U54). Washington, DC: Department of Health and Human Services, 2013. Available at: <https://grants.nih.gov/grants/guide/rfa-files/RFA-TR-12-006.html>.
7. Lick DJ, Durso LE, Johnson KL. Minority stress and physical health among sexual minorities. *Perspect Psychol Sci*. 2013 Sep;8(5):521–48.
<https://doi.org/10.1177/1745691613497965>
PMid:26173210
8. Bassett MT, Graves JD. Uprooting institutionalized racism as public health practice. *Am J Public Health*. 2018;108(4):457–8.
<https://doi.org/10.2105/AJPH.2018.304314>
PMid:29513591 PMCID:PMC5844417
9. George S, Duran N, Norris K. 2014. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):e16–31.
<https://doi.org/10.2105/AJPH.2013.301706>
PMid:24328648 PMCID:PMC3935672
10. Kline W. 2001. *Building a better race: gender, sexuality, and eugenics from the turn of the century to the baby boom*. Berkeley, CA: University of California Press, 2001.
11. Rusoja EA, Thomas BA. 2021. The COVID-19 pandemic, Black mistrust, and a path forward. *EclinicalMedicine*. 2021 May 6;35:100868.
<https://doi.org/10.1016/j.eclinm.2021.100868>
PMid:33977258 PMCID:PMC8102042
12. Layman EJ. Human experimentation: historical perspective of breaches of ethics in US health care. *The Health Care Manager*. 2009;28(4):354–74.
<https://doi.org/10.1097/HCM.0b013e3181bddbc2>
PMid:19910712
13. Novak NL, Lira N, O'Connor KE, et al. 2018. Disproportionate sterilization of Latinos under California's Eugenic Sterilization Program, 1920–1945. *Am J Public Health*. 2018;108(5): 611–13.
<https://doi.org/10.2105/AJPH.2018.304369>
PMid:29565671 PMCID:PMC5888070
14. Ford JL, Boch SJ, McCarthy DO. Feasibility of hair collection for cortisol measurement in population research on adolescent health. *Nurs Res*. 2016 May–Jun;65(3):249–55.
<https://doi.org/10.1097/NNR.0000000000000154>
PMid:27124260 PMCID:PMC4852400
15. Institute of Medicine. *The Health of lesbian, gay, bisexual, and transgender people:*

- building a foundation for better understanding. Washington, DC: National Academies Press, 2011.
16. Parra LA, Hastings PD. Integrating the neurobiology of minority stress with an intersectionality framework for LGBTQ-Latinx populations: integrating the neurobiology of minority stress. *New Directions for Child and Adolescent Development*. 2018 Jul;2018(161):91–108.
<https://doi.org/10.1002/cad.20244>
PMid:29978937 PMCID:PMC6320723
 17. Barnett AP, del Río-González AM, Parchem B, et al. 2019. Content analysis of psychological research with lesbian, gay, bisexual, and transgender people of color in the United States: 1969–2018. *Am Psychol*. 2019;74(8):898–911.
<https://doi.org/10.1037/amp0000562>
PMid:31697126 PMCID:PMC8243565
 18. Logie CH. 2015. (Where) do queer women belong? Theorizing intersectional and compulsory heterosexism in HIV research. *Critical Public Health*. 2015;25(5):527–38.
<https://doi.org/10.1080/09581596.2014.938612>
 19. Hussain-Gambles M, Atkin K, Leese B. 2004. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health Soc Care Community*. 2004;12(5):382–8.
<https://doi.org/10.1111/j.1365-2524.2004.00507.x>
PMid:15373816
 20. Pandya A. 2014. Mental health as an advocacy priority in the lesbian, gay, bisexual, and transgender communities. *J Psychiatr Pract*. 2014;20(3):225–7.
<https://doi.org/10.1097/01.pra.0000450322.06612.a1>
PMid:24847996
 21. Rodríguez Madera SL, Varas Díaz N, Pibernus AR, et al. Exploring the feasibility and acceptability of biomarker collection for HIV infection and chronic stress among transwomen in Puerto Rico. *Revista Puertorriquena De Psicología*. 2017;28(2):268–81.
 22. Yancey AK, Ortega AN, Kumanyika SK. 2006. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27(1):1–28.
<https://doi.org/10.1146/annurev.publhealth.27.021405.102113>
PMid:16533107
 23. Miranda J, Nakamura R, Bernal G. 2003. Including ethnic minorities in mental health intervention research: a practical approach to a long-standing problem. *Cult Med Psychiatry*. 2003;27(4):467–86.
<https://doi.org/10.1023/B:MEDI.0000005484.26741.79>
PMid:14727681
 24. Office of the Surgeon General, Center for Mental Health Services, National Institute of Mental Health. 2001. *Mental health: culture, race, and ethnicity: a supplement to mental health: a report of the Surgeon General*. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2001. Available at: <http://www.ncbi.nlm.nih.gov/books/NBK44243/>.
 25. Russell E, Koren G, Rieder M, et al. Hair cortisol as a biological marker of chronic stress: current status, future directions and unanswered questions. *Psychoneuroendocrinology*. 2012;37(5):589–601.
<https://doi.org/10.1016/j.psyneuen.2011.09.009>
PMid:21974976
 26. Bates RA, Salsberry PJ, Ford JL, et al. Hair sampling for cortisol analysis with mother-toddler dyads living in low-income homes. *Infant Behav Dev*. 2020;61:101499.

- <https://doi.org/10.1016/j.infbeh.2020.101499>
PMid:33068954 PMCID:PMC7736194
27. Schreier HMC, Enlow MB, Ritz T, et al. Lifetime exposure to traumatic and other stressful life events and hair cortisol in a multi-racial/ethnic sample of pregnant women. *Stress*. 2016;19(1):45–52.
<https://doi.org/10.3109/10253890.2015.1117447>
PMid:26551892 PMCID:PMC4766015
 28. Palmer-Bacon J, Willis-Esqueda C, Spaulding WD. Stress, trauma, racial/ethnic group membership, and HPA function: utility of hair cortisol. *Am J Orthopsychiatry*. 2020;90(2):193–200.
<https://doi.org/10.1037/ort0000424>
PMid:31566392
 29. Lehrer HM, Goosby BJ, Dubois SK, et al. Race moderates the association of perceived everyday discrimination and hair cortisol concentration. *Stress*. 2020;23(5):529–37.
<https://doi.org/10.1080/10253890.2019.1710487>
PMid:31888404 PMCID:PMC7769195
 30. O'Brien KM, Tronick EZ, Moore CL. Relationship between hair cortisol and perceived chronic stress in a diverse sample. *Stress Health*. 2013;29(4):337–44.
<https://doi.org/10.1002/smi.2475>
PMid:23225553
 31. Yip T, Smith P, Tynes M, et al. Discrimination and hair cortisol concentration among Asian, Latinx and White young adults. *Compr Psychoneuroendocrinol*. 2021;6:100047.
<https://doi.org/10.1016/j.cpnec.2021.100047>
PMid:35757364 PMCID:PMC9216324
 32. Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*. 2007;297(4):407.
<https://doi.org/10.1001/jama.297.4.407>
PMid:17244838
 33. Potter L, Zawadzki MJ, Eccleston CP, et al. The intersections of race, gender, age, and socioeconomic status: implications for reporting discrimination and attributions to discrimination. *Stigma and Health*. 2019;4(3):264–81.
<https://doi.org/10.1037/sah0000099>
PMid:31517056 PMCID:PMC6741774
 34. Vargas SM, Wennerstrom A, Alfaro N, et al. Resilience Against Depression Disparities (RADD): a protocol for a randomised comparative effectiveness trial for depression among predominantly low-income, racial/ethnic, sexual and gender minorities. *BMJ Open*. 2019;9(10): e031099.
<https://doi.org/10.1136/bmjopen-2019-031099>
PMid:31641001 PMCID:PMC6830623
 35. Kroenke K, Strine TW, Spitzer RL, et al. The PHQ-8 as a measure of current depression in the general population. *J Affect Disord*. 2009;114(1–3):163–73.
<https://doi.org/10.1016/j.jad.2008.06.026>
PMid:18752852
 36. Bilodeau BL, Renn KA. Analysis of LGBT identity development models and implications for practice. *New Directions for Student Services*. 2005(111):25–39.
<https://doi.org/10.1002/ss.171>
 37. Jackson SE, Kirschbaum C, Steptoe A. Perceived weight discrimination and chronic biochemical stress: a population-based study using cortisol in scalp hair: perceived weight discrimination and chronic stress. *Obesity*. 2016;24(12):2515–21.

- <https://doi.org/10.1002/oby.21657>
PMid:27740706 PMCID:PMC5132135
38. Wenzel A, Dobson KS, Hays PA. Cognitive behavioral therapy techniques and strategies. Washington, DC: American Psychological Association, 2016.
<https://doi.org/10.1037/14936-000>
 39. Wolf C, Serpa GJ. A clinician's guide to teaching mindfulness: the comprehensive session-by-session program for mental health professionals and health care providers. Oakland, CA: New Harbinger Publications, 2015.
 40. Arevian AC, O'Hora J, Jones F, et al. Participatory technology development to enhance community resilience. *Ethn Dis*. 2018;28(Supp 2):493–502.
<https://doi.org/10.18865/ed.28.S2.493>
PMid:30202203 PMCID:PMC6128332
 41. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Sessions Lincoln Y, eds. *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications Inc., 1994:273–85.
 42. Friedman DB, Foster C, Bergeron CD, et al. A qualitative study of recruitment barriers, motivators, and community-based strategies for increasing clinical trials participation among rural and urban populations. *Am J Health Promot*. 2015 May–Jun;29(5):332–8.
<https://doi.org/10.4278/ajhp.130514-QUAL-247>
PMid:24670073
 43. Jacey F. In serial rape case that stumped police, genealogy database leads to arrest. New York, NY: New York Times, 2018.
 44. O'Brien KM, Meyer J, Tronick E, et al. Hair cortisol and lifetime discrimination: moderation by subjective social status. *Health Psychol Open*. 2017;4(1):205510291769517.
<https://doi.org/10.1177/2055102917695176>
PMid:28491342 PMCID:PMC5405887
 45. Chung B, Jones L, Dixon EL, et al. Using a community partnered participatory research approach to implement a randomized controlled trial: planning community partners in care. *J Health Care Poor Underserved*. 2010;21(3):780–95.
<https://doi.org/10.1353/hpu.0.0345>
PMid:20693725 PMCID:PMC2962454
 46. Dilworth-Anderson P, Williams SW. Recruitment and retention strategies for longitudinal African American caregiving research: the Family Caregiving Project. *J Aging Health*. 2004;16(5 Suppl):137–56.
<https://doi.org/10.1177/0898264304269725>
PMid:15448291
 47. Garza MA, Quinn SC, Li Y, et al. 2017. The influence of race and ethnicity on becoming a human subject: factors associated with participation in research. *Contemp Clin Trials Commun*. 2017;7:57–63.
<https://doi.org/10.1016/j.conctc.2017.05.009>
PMid:29226266 PMCID:PMC5716487
 48. McCall L. The complexity of intersectionality. *Signs: Journal of Women in Culture and Society*. 2005;30(3):1771–1800.
<https://doi.org/10.1086/426800>