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Our Needs Have Been Ignored for a Long Time: Factors Affecting the Willingness of Black and Hispanic/Latinx Sexual and Gender Minority Communities to Donate Biospecimens

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Abstract

The study aimed to document factors affecting willingness to engage in biospecimen donation for substance use research among Black and Hispanic/Latinx sexual and gender minority (SGM) people. From May to July 2022, we interviewed 22 Black and Hispanic/Latinx SGM people from The PRIDE Study, a cohort of SGM people in the United States and its territories, using Zoom videoconferencing software. Fourteen participants were sexual minority people, and eight participants were gender minority people. We took an inductive, collaborative qualitative analytic approach to identify themes. Themes included: (1) community benefits, (2) personal benefits, (3) community exploitation, (4) personal risks, (5) convenience, (6) trustworthiness of the research team, (7) perceived value in donating, and (8) normalization of biospecimen collection. Participants were generally motivated to engage in biospecimen donation for altruistic purposes. The most cited concerns were related to data security, misuse, and privacy. Researchers must be proactive in building trust with Black and Hispanic/Latinx SGM communities to increase engagement, diversify biospecimen repositories and reduce health inequities. Future research involving biospecimens should provide biospecimen education during the consent process and prioritize participant convenience.

Public health significance: Black and Hispanic/Latinx SGM communities are significantly underrepresented in biospecimen repositories. This work describes factors that impact their willingness to engage in substance use research involving biospecimens. Information from this work can be used to increase engagement from Black and Hispanic/Latinx SGM communities.

Keywords: LGBTQ health, Substance Use, Black or African American, Latinx, Ethics

Introduction

The minority stress model postulates that members of historically marginalized and oppressed communities including sexual minority (SM; those who do not exclusively identify their sexual orientation as heterosexual) and gender minority (GM; individuals whose gender identity does not align with that often associated with their sex assigned at birth, abbreviated collectively as SGM) people have poorer health outcomes (*e.g.*, higher rates of substance use disorder^{1,2}) than non-SGM populations due to minority, or identity-based, stressors.³ Minority stressors consist of internal stress processes (*e.g.*, internalized stigma) and external events in the environment (*e.g.*, discriminatory experiences). Minority stressors may decrease coping resources (*e.g.*, social support and community connectedness), which may lead to maladaptive or avoidant coping mechanisms such as substance use.^{3,4} Disproportionally higher substance use rates have been documented among SGM people who identify as Black and Hispanic/Latinx relative to their heterosexual and/or cisgender peers.⁵⁻⁷ This may partially be explained by the minority stress model and the concept of “double or triple jeopardy” – referring to the various, intersecting forms of oppression experienced by people with multiple, marginalized identities.⁸

Biospecimens (*i.e.*, biological samples) may be used in substance use research to examine the neurobiological and long-term effects of substance use, to identify risk factors associated with substance use, and to develop treatment strategies and medications for substance use disorder. Despite facing elevated rates of substance use, Black and Hispanic/Latinx SGM people have been underrepresented in substance use research;⁹ this may be attributed to the dearth of studies measuring sexual orientation and gender identity.¹⁰ Moreover, Black and Hispanic/Latinx

SGM people may be less likely to donate their biospecimens than their White counterparts¹¹ due to several factors including limited knowledge about biospecimens and their critical role in substance use research, lack of transparency about biospecimen utilization in biomedical research, and the historical and ongoing exploitation and mistreatment of their communities in research (*e.g.*, the Tuskegee Syphilis Study¹² and forced sterilization of Black,¹³ Mexican,¹⁴ and Puerto Rican¹⁵ women).^{16,17} Unsurprisingly, these populations may have distrust and mistrust in substance use research impacting their willingness to donate their biospecimens, although meager research have documented these factors. Substance use research, particularly studies involving biospecimens, must be representative of Black and Hispanic/Latinx SGM people to increase generalizability of study findings and to reduce health inequities rooted in cisheteronormativity and systemic and structural racism. The aim of the study was to identify factors affecting willingness to participate in biospecimen donation for substance use research among Black and Hispanic/Latinx SGM people through qualitative analysis of individual interviews with community members in a longitudinal cohort study.

Methods

Participants

Recruitment and sampling method

Participants must have been enrolled in The Population Research in Identity and Disparities for Equality (PRIDE) Study, a longitudinal cohort of SGM people aged 18 years or older who reside in the United States and its territories and are able to read and understand English. Recruitment for The PRIDE Study occurs through the the PRIDEnet Community Partners (*i.e.*, community centers, clinics, and organizations), in-person events, social media

advertisement, and by word-of-mouth.¹⁸ The PRIDE Study received approval from the institutional review boards of the University of California, San Francisco, Stanford University, and the WIRB-Copernicus Group (WCG). Participants enroll in The PRIDE Study through a digital research platform¹⁸ and are encouraged to complete their profile and annual surveys exploring various health constructs. Data collection is ongoing with annual surveys administered from approximately June to May.

Participants in the current substudy within The PRIDE Study were selected because they identified as Black and/or Hispanic/Latinx and were selected irrespective of their past or current substance use status. Eligible participants were stratified into 3 groups based on the completion status of their 2021 annual survey, to ensure representation across levels of engagement: (1) completed the survey, (2) started but did not complete the survey, and (3) did not start or complete the survey. Purposeful sampling was used to ensure sample diversity related to age, gender identity, sexual orientation, and completion status of the 2021 survey. Interviews were conducted from May to July 2022 until thematic saturation was reached.¹⁹ IRB approval was received from the WCG.

Interview Protocol

Semi-structured interviews were conducted to understand Black and Hispanic/Latinx SGM participants' thoughts on completing health surveys and donating their biospecimens (*i.e.*, blood, hair, saliva, and urine) for substance use research. The interviewer was a post-baccalaureate researcher with 3 years of research experience who identified as Latina/e/o/x. Interview questions were open-ended and generated based on feedback from SGM health experts including The PRIDE Study's Participant Advisory Committee. Interview questions assessed

past engagement in biospecimen donation for research, perceived benefits and risks in donating, and thoughts on donating different types of biospecimen during the COVID-19 pandemic. Each interview was prefaced with a brief description and definition of biospecimens to ensure participant understanding. Participants chose whether to participate in a video or audio-only interview using Zoom videoconferencing software. Interviews were approximately 20- to 30-minutes and were audio-recorded and transcribed. Participants received a \$20 gift card as compensation.

Demographics

Demographics included age, gender identity, race and ethnicity, sexual orientation, education, income, and geographic region; all are described in Table 1. Participants could select multiple options for gender identity, sexual orientation, and race and ethnicity. Data were obtained from participants' most recently completed survey (2019-2021) or participants' profiles in The PRIDE Study's platform.

Among the sample ($N = 22$), 12 (54.55%) identified as Black, African American, or African; 11 (50%) identified as Hispanic, Latino, or Spanish; 9 (40.91%) identified as White; 1 participant (4.55%) identified as American Indian or Alaska Native; 1 participant (4.55%) identified as Native Hawaiian or other Pacific Islander; 1 participant (4.55%) identified as Middle Eastern or North African; and 1 participant (4.55%) selected that none of the racial and ethnic categories fully described [them]. Our sample consisted of 7 cisgender men (*i.e.*, participants who identified within the masculine binary and were assigned male sex at birth), 7 cisgender women (*i.e.*, participants who identified within the feminine binary and were assigned female sex at birth), 4 gender expansive people (*i.e.*, participants who identified beyond the gender binary),

1 transgender woman (*i.e.*, participant who identified within the feminine binary and was assigned male sex at birth), and 3 transgender men (*i.e.*, participants who identified within the masculine binary and were assigned female sex at birth). Participants' ages ranged from 22-80 ($M_{age} = 39.97$). Of the participants who provided alcohol use data ($n = 19$), 84.21% ($n = 16$) were at low risk and 15.79% ($n = 3$) were at hazardous risk for alcohol use. All participants who provided other substance use data were at low risk ($n = 18$) for other substance use. Half of our sample ($n = 11$) reported that they had been given the opportunity at least once in their life to donate biospecimens for research; most (90.91%, $n = 10$) resulted in actual biospecimen donation.

Qualitative Analysis and Positionality

Using Dedoose software,²⁰ we took an inductive approach to collaborative qualitative analysis, grounded in thematic analysis¹⁹ and constant comparative method,²¹ to identify themes and patterns among the transcribed interviews.²² This approach was taken to integrate the diverse perspectives of our coding team,²³ which consisted of one post-baccalaureate and four undergraduate researchers; all are based in California. Members of our coding team identified with the following races and ethnicities: Latina/e/o/x, Middle Eastern, and Southeast Asian. The gender identities that were represented within the team included cisgender woman, man, non-binary person, and woman. The sexual orientations of the coding team included bisexual, gay, pansexual, and queer. We developed the codebook collaboratively and modified it across iterations using consensus coding. Two researchers coded the same transcripts and resolved discrepancies through discussion. The codebook included definitions of the themes and example

excerpts to ensure consistency among coders. Our research team met regularly to discuss emergent themes and to identify the excerpts that best illustrated each theme.

Results

Eight themes emerged: (1) community benefits, (2) personal benefits (subdivided into tangible and intangible benefits), (3) community exploitation, (4) personal risks, (5) convenience, (6) trustworthiness of the research team, (7) perceived value in donating, and (8) normalization of biospecimen collection. Participants were asked about their thoughts on donating their biospecimens for substance use research specifically, although this was often extended to related topics (*e.g.*, HIV research).

Community benefits

Most participants' willingness to donate their biospecimens was based on altruistic motives. Biospecimen donation was described by one participant as "providing a wider, deeper knowledge base that doesn't currently exist and it normalizes the importance of knowing about some communities" (45-64, Hispanic/Latinx, White, cisgender man, gay). Participants hoped that their biospecimen donation could contribute to the expansion of current knowledge about the needs and health of their communities: one participant reflected, "I'm the demographic that doesn't necessarily get attention in research literature" (18-34, Black, cisgender woman, woman, bisexual, pansexual, queer). Many participants specifically referenced their desire for the study findings to be disseminated broadly (*e.g.*, to their communities, health care specialists, and the public) and in multiple languages. One participant voiced frustration with the lack of knowledge from health care specialists about their communities' health: "I'm tired of the excuse being used that they don't have enough information to make an informed decision, so we have to put up

with the way that things are right now. So, get what you can from us right now so that we can make things better for all of us in the future including myself, I hope” (35-44, Hispanic/Latinx, White, transgender woman, woman, lesbian, queer). Some participants expressed a willingness to donate their biospecimens for the improvement of healthcare policy, treatment, and infrastructure for future generations as communicated succinctly by this participant: “The more information that we have about our community and the more research that's done, the better that health care in the future can be tailored to our specific needs. It's been ignored for a long, long time and it's important that that information be out there” (45-64, Hispanic/Latinx, White, cisgender woman, lesbian).

Personal benefits

Tangible

Beyond their altruistic motivations, several participants mentioned financial compensation as a motive for biospecimen donation. One participant declared, “I'm 99% sure that I wouldn't have been interested at all [in engaging in prior biospecimen donation] if I didn't think I was going to be compensated fairly” (45-64, Black, cisgender woman, bisexual). Despite variability in desired compensation for biospecimen donation, participants asserted that they should receive greater compensation for donation of their blood biospecimen than the other types of biospecimen because it requires more effort, is more invasive, and is associated with greater risk for experiencing discomfort. Participants wanted to be compensated around \$30-\$100 for blood biospecimen donation and around \$15-\$50 for donation of the other types of biospecimens. In addition to greater compensation for blood biospecimen donation, one participant stated that “[biomedical companies] should pay more [for biospecimen donation] than

at a university” (35-44, Hispanic/Latinx, cisgender man, man, gay). Despite the common assertion that people should be compensated for biospecimen donation, one participant revealed, “Even if I wasn't paid, I'd still probably do it, because this is something that matters to me ... and I know it'll also be helping other queer people” (18-34, Hispanic/Latinx, White, transgender man, gay).

Intangible

Participants identified that acquiring new knowledge about their individual health was a reason they would be motivated to provide biospecimens for research. One participant said they would like “more access and awareness to my own genetic risks for specific kinds of diseases, so I can make informed decisions about my own health care” (18-34, Hispanic/Latinx, White, man, gay). Another participant discussed a potential benefit of obtaining information about their individual health from research: “They're giving me all these results which otherwise I wouldn't be able to get for free. I would have to pay a lot of money” (35-44, Hispanic/Latinx, cisgender man, man, gay). However, one participant was concerned that by donating their biospecimens they may “find out something I did not want to know” (65+, Black, woman, lesbian).

Community exploitation

Several participants identified the continued exploitation of racial minority and SGM communities in biomedical research as a community-wide risk in biospecimen donation. Several participants worried that their biospecimens may be given to institutions that would profit from the exploitation of their communities: “I don't want us to be seen as nothing more than just something to be experimented on. That's something I do fear” (35-44, Hispanic/Latinx, White, transgender woman, woman, lesbian, queer). Some participants specifically referenced past

examples in which researchers had engaged in unethical practices with members from their communities. One participant reflected: “As a Latina I’m aware that it was Brown and Black bodies that were used for medical experiments ... So, I’m kind of wary about things when I think about the Tuskegee experiments, the forced sterilization of Indigenous people, the testing and sterilizing of Latina women in Puerto Rico, and the throwing of pesticides on my gente in the Rio Grande Valley” (35-44, Hispanic/Latinx, White, transgender woman, woman, lesbian, queer). Another participant shared that they were grappling between past exploitation of members of their communities and the potential benefits of biospecimen donation for their communities: “Henrietta Lacks’s cell line now has sort of helped capitalism. It’s healed a lot of people, but it made a lot of White folks rich. What is that balance between public good and corporate profit? I think [it] is a personal balance I’m trying to figure out my head” (45-64, Black, man, gay).

Personal risks

Many participants identified individual-level concerns including those pertaining to data security, misuse, and privacy. Participants were concerned that their data could be used for unethical practices such as data sharing with external research or groups (*e.g.*, law enforcement) without their knowledge. This sentiment was illustrated by this participant’s response: “I think my biggest fear is that the data or specimens could be used for some outside research that I have no idea that I’m involved in” (18-34, Black, genderqueer, non-binary, bisexual, queer). One participant explained how data sharing with external parties could impact their health and well-being: “There’s the risk of biological information being shared with health insurance companies that can then be used to deny health insurance claims based on pre-existing conditions. Things

like that are very worrying to me when it comes to the sharing of biological information and data” (18-34, Hispanic/Latinx, White, man, gay). Another participant worried about the potential for experiencing “discrimination based on genetic material” if data privacy policies were not followed (18-34, Black, man, transgender man, gay, queer). One participant summarized, “When someone has a part of you, you want to have the best practices and you want to have the proper handles” (18-34, Black, White, cisgender woman, woman, pansexual).

Participants were also concerned about the potential for experiencing discomfort and adverse reactions due to biospecimen donation with several referencing past donation experiences. One participant shared, “When I'm getting blood drawn, I might get dizzy. It's happened a couple of times and that's a risk” (35-44, Hispanic/Latinx, cisgender man, man, gay). Another participant discussed their heightened risk for experiencing an adverse health reaction during the COVID-19 pandemic: “I have a narrow airway, so I have breathing issues and COVID exacerbates everything. If I got COVID it would affect my breathing even more and I don't really need that” (18-34, Black, White, non-binary, woman, asexual).

Convenience

Participants expressed a willingness to donate if the donation process was easy, convenient, and accessible. Several participants spoke about time as a challenge of donating their biospecimens in-person: “I think for me personally, I would not have an ethical problem donating biospecimen but it's more like well, do I have time to do this?” (35-44, Hispanic/Latinx, White, cisgender man, gay). In contrast, other participants thought less effort was required of them if they donated their biospecimens in-person: “I don't like pricking myself ... I would much prefer if someone else would collect my blood instead of me because I don't like the act of

hurting myself” (18-34, Hispanic/Latinx, White, transgender man, gay). These sentiments were related to past negative experiences of donating at home and with specific collection methods (*i.e.*, lancets). Another participant highlighted the importance in offering a variety of collection modalities: “If there's an option to collect it at home, I can do that. If there's an option to go to an office, I can also do that. I know a lot of people ... may not have steady work hours or work standard 9-5 jobs and so having that flexibility I think is important” (18-34, Hispanic/Latinx, White, man, gay).

In addition to preferences for specific methods of collection, some participants preferred to donate certain biospecimen types based on their perceptions of what the donation process could entail. For instance, one participant said, “I'd have to go down to the doctor's office and make an appointment and they would have to draw blood and everything. It seems kind of like a hassle if I could just collect my saliva at home” (18-34, Black, White, non-binary, woman, asexual). Relatedly, another participant commented, “The more invasive it gets and the longer it takes, the less I'm interested I think” (45-64, Black, man, gay). Generally, blood biospecimen was perceived to be the most difficult to donate and there were varying perspectives on which biospecimen was the easiest to donate.

Trustworthiness of the research team

Participants discussed the importance of knowing who is conducting the research and of assessing the credibility of the research team prior to deciding whether to donate their biospecimens. Credibility was equated with familiarity with and trust in the research team as exemplified by this participant’s response: “Having been a graduate student at [university] before I kind of know how the clinical trials team does things and so there's a level of trust there. I think

if it was from another entity, I would probably have a lot questions” (18-34, Black, White, man, gay). Similarly, another participant expressed concern about donating to a research group that they were unfamiliar with because of uncertainty about their intentions: “I can donate this to XYZ study that I don't know about, but then how do I know that they're not going to turn around and use that data for marketing or for a sobriety program or something that I didn't initially sign up for?” (35-44, Hispanic/Latinx, White, cisgender man, gay). A few participants felt more comfortable donating if the research team was from a university than a biomedical company because “universities have a lot of ethical standards that they have to abide by” (35-44, American Indian/Alaska Native, Black, Hispanic/Latinx, White, genderqueer, non-binary, queer). With a credible research group, participants stated that they would not be concerned about the study’s fidelity, for example, falsification of results.

Participants were willing to donate their biospecimens if the research team was transparent in communicating about the collection and storage processes prior to donation. Information they stated they would need to know included: the aim of the study, the reason for donation, potential research outcomes, the potential level of discomfort they may experience, and why biospecimens are specifically needed from people in their communities. In addition, participants stated that they would need to be guaranteed that their data were secure, held anonymously, and only used for the purposes specified in the informed consent. One participant highlighted the historical significance of obtaining transparency in biomedical research as a racial minority: “As a Black person, the last thing I want is to be in an experimental trial, which makes me really sick or in a non-trial, where I get sick, and they knew there was a drug” (45-64, Black, man, gay).

Perceived value in donating

Participants with no self-reported substance use questioned the value of their biospecimens for substance use research. For instance, one participant stated, “I’m sure it’s important for non-substance users to give their sample for various reasons, but I feel like it just wouldn’t be relevant for me to give” (18-34, Black, White, cisgender woman, woman, pansexual). Another participant indicated that their perceived value in donating would, in part, be influenced by whether they were currently involved in a study with the research team requesting biospecimen donation: “I probably wouldn’t volunteer unless I could see a real reason that my samples will add value. Partly, I know that The PRIDE Study has a lot of information about my demographics so if they reached out to me, I know they think I’m going to add something valuable to the study by donating my samples. I’d do it. I don’t know if I saw a flyer, I’d do it” (18-34, Hispanic/Latinx, White, cisgender woman, bisexual, queer).

Normalization of biospecimen collection

Many participants indicated that they would be willing to donate their biospecimens in person during the COVID-19 pandemic if safety protocols (*e.g.*, social distancing) were followed. Several participants reflected on the normalization of biospecimen collection during the COVID-19 pandemic due to the frequency of biospecimen testing and donation in health care and research settings. One participant commented, “Because the pandemic it really doesn’t seem like a big deal anymore. Just seems normal” (45-64, Black, White, none of the racial/ethnic categories fully describe me, genderqueer, man, non-binary, woman, bisexual, pansexual, queer, same-gender loving). Another participant shared, “I do this literally like every week now ... It

made it easier ... It really has shifted in some instances the specialness of it because you just do it so much now. You're specimen-ing all the time” (45-64, Black, man, gay).

Discussion

The current study explored factors affecting willingness to participate in biospecimen donation for substance use research among 22 Black and Hispanic/Latinx SGM people. Contrary to other work showing that participants who identify as Black and Hispanic/Latinx report fewer opportunities to engage in studies involving biospecimens,^{24,25} almost half of our sample were offered the opportunity to donate their biospecimens for research at least once in their lifetime. High rates of inclusion in research studies collecting biospecimens were observed among our sample and may be due to participants' involvement with The PRIDE Study and other studies working with PRIDEnet. Consistent with prior work in SGM communities,^{26,27} we observed high acceptability of biospecimen donation among Black and Hispanic/Latinx SGM people. The most salient motive for engaging in biospecimen donation was altruism, confirming previous findings in non-SGM samples of people who identify as Black and Hispanic/Latinx.^{28,29} Participants hoped that, by providing their biospecimens, they could contribute to the advancement of scientific knowledge about their communities and the improvement of healthcare policy, treatment, and infrastructure. Other frequently discussed motives included financial incentives and gaining knowledge about their individual health.

Participants voiced concerns about participating in studies involving biospecimens, most of which were related to data security, privacy, and misuse, and transparency of the research team about the processes and anticipated level of discomfort involved. Some participants specifically cited concerns about potential mistreatment and exploitation in biomedical research,

including experiences of minority stressors (*e.g.*, discrimination), which is supported by prior work in non-SGM samples of people who identify as Black^{17,24} and Hispanic/Latinx.²⁹ Another factor that was discussed was the credibility or trustworthiness of the research team. Some participants specifically expressed greater willingness to donate their biospecimens for research conducted at educational institutions and through projects and ongoing research they are familiar with compared to biomedical companies, which aligns with prior research findings.³⁰

Many participants cited convenience as a major factor influencing their decision to donate their biospecimens, although participants generally expressed willingness to donate in person if COVID-19 safety protocols were followed. National, longitudinal studies such as The PRIDE Study¹⁸ and The *All of Us* Research Program³¹ could enhance the participation of underrepresented groups such as Black and Hispanic/Latinx SGM people by embracing methods that prioritize participant convenience. In a recent report, the *All of Us* Research Program described modifying their methodologies to continue biospecimen collection during the pandemic, for example, by allowing participants to donate saliva biospecimen at home instead of requiring in-person donation of blood biospecimen.³² These types of changes are consistent with the concerns of participants in our sample about biospecimen convenience and donation during the COVID-19 pandemic. Interestingly, some participants conveyed that biospecimen donation has been normalized during the COVID-19 pandemic due to frequent biospecimen collection in health care and research settings.

Our sample offered several recommendations for improving studies involving biospecimens. These recommendations include disseminating the research findings in multiple languages, providing compensation for biospecimens, offering both in-person and at-home

collection options, and sharing individual health results with participants. Participants emphasized the significance of addressing the injustices that Black and Hispanic/Latinx SGM communities have endured in health care and biomedical research. To build trust with these communities, researchers should acknowledge these injustices and work to disrupt structural and systemic cisheteronormativity and racism that contribute to health inequities among these communities. Researchers should inform participants of their efforts to conduct ethical research, for example, by demonstrating transparency in communicating about the processes involved in biospecimen donation through educational components. Providing education about biospecimens can increase participant knowledge and facilitate trust building, leading to high levels of research engagement.³³ Education about biospecimens should be a component of the informed consent process to ensure participant understanding.

Limitations

Although our study extended existing knowledge of factors affecting willingness to provide biospecimens among Black and Hispanic/Latinx SGM people, it was not without limitations. We had relatively low representation from transgender men and transgender women, yet our sample was diverse in terms of sexual orientation, geographic region, and age. Researchers may need to communicate the importance and value of engaging in substance use studies involving biospecimens to people who report no current substance use. The scope of our study did not allow for assessment of actual willingness to engage in biospecimen donation. Future work should investigate whether desired study practices and procedures stemming from participant recommendations result in changes in actual donation of their biospecimens. Our sample was at low risk for substance use and may not reflect the diversity in substance use status

of people asked to participate in substance use studies involving biospecimens. For example, in samples with greater substance use, there may be concerns about privacy specifically related to substance use that were not concerns raised by our sample. Although all interviews were conducted via Zoom, participants were given the option to choose between an audio-only or video interview. As a result, some participants chose an audio-only interview and therefore did not see and/or perceive the interviewer's physical attributes.

Conclusions

Taken together, our findings illustrate that Black and Hispanic/Latinx SGM people are willing to donate biospecimens primarily for altruistic motives. The COVID-19 pandemic did not appear to negatively impact willingness to donate. For a subset of the sample, the biospecimen collection process has been normalized during the pandemic. Concerns about data security, privacy, and misuse were heavily emphasized among the sample. Therefore, it is critical for researchers to build trust with Black and Hispanic/Latinx SGM communities and engage in trustworthy research practices, which can subsequently increase community participation in studies involving biospecimens.

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Table 1. Sample demographic characteristics ($N = 22$).

Variable	Total
Age, in years (Mean, Median, SD)	39.97 (34.75, 14.60)
Gender identity ^a (n , %)	
Cisgender man	4 (18.18)
Cisgender woman	6 (27.27)
Genderqueer	3 (13.64)
Man	7 (31.82)
Non-binary	4 (18.18)
Transgender man	3 (13.64)
Transgender woman	1 (4.55)
Woman	7 (31.82)
Reported more than one gender identity	11 (50)
Race and ethnicity ^b (n , %)	
American Indian or Alaska Native	1 (4.55)
Black, African American, or African	12 (54.55)
Hispanic, Latino, or Spanish	11 (50)
Middle Eastern or North African	1 (4.55)
Native Hawaiian or other Pacific Islander	1 (4.55)
White	9 (40.91)
None of these fully describe me	1 (4.55)
Reported more than one race and/or ethnicity	10 (45.45)
Sexual orientation ^c (n , %)	
Asexual	1 (4.55)
Bisexual	6 (27.27)
Gay	10 (45.45)
Lesbian	4 (18.18)
Pansexual	3 (13.64)
Queer	8 (36.36)
Same-gender loving	2 (9.09)
Reported more than one sexual orientation	8 (36.36)
Annual individual income ^d (n , %)	
\leq \$20,000	7 (36.84)
\$20,001 to \$40,000	5 (26.32)

\$40,001 to \$60,000	2 (10.53)
³ \$60,001	5 (26.32)
Education level ^e (<i>n</i> , %)	
No high school diploma	1 (5.26)
High school/GED graduate or some college	3 (15.79)
2- or 4-year college degree	6 (31.58)
Graduate degree	9 (47.37)
Geographic region ^f (<i>n</i> , %)	
Midwest	5 (23.81)
South	7 (33.33)
West	9 (42.86)
Donated biospecimen(s) for research in the past ^g (<i>n</i> , %)	10 (45.45)

- ^a. Participants could select multiple responses from options (*i.e.*, agender, cisgender man, cisgender woman, genderqueer, man, non-binary, questioning, transgender man, transgender woman, Two-spirit, woman, and another gender identity (please specify)) to describe their current gender identity.
- ^b. Participants could select multiple responses from options (*i.e.*, American Indian or Alaska Native; Asian; Black, African American, or African; Hispanic, Latino, or Spanish; Middle Eastern or North African; Native Hawaiian or other Pacific Islander; White, and none of these fully describe me (please specify)). Please note all participants selected either Black, African American, or African *or* Hispanic, Latino, or Spanish to be eligible for the study.
- ^c. Participants were asked to describe their current sexual orientation from options (*i.e.*, asexual, bisexual, gay, lesbian, pansexual, queer, questioning, same-gender loving, straight/heterosexual, Two-spirit, and another sexual orientation (please specify)).
- ^d. Participants were asked the amount of money they earned from all their sources of income before taxes and deductions in the prior tax year with 18 options ranging from \$0 to over \$200,001.
- ^e. Participants reported the highest level of education they completed from options (*i.e.*, no schooling, nursery school to high school (no diploma), high school graduate or equivalent (*e.g.*, GED), trade/technical/vocational training, some college, 2-year college degree, 4-year college degree, master's degree, doctoral degree, and professional degree (*e.g.*, M.D., J.D., and M.B.A.)).
- ^f. Identified from participants' ZIP codes.
- ^g. Not exclusive to substance use research.