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Authors

Cicero, Ethan C
Lunn, Mitchell R
Obedin-Maliver, Juno
et al.

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Acceptability of Biospecimen Collection Among Sexual and/or Gender Minority Adults in the United States

Ethan C. Cicero[a,b], **Mitchell R. Lunn**[b,c,d], **Juno Obedin-Maliver**[b,d,e], **Gowri Sunder**[f], **Micah E. Lubensky**[b,f], **Matthew R. Capriotti**[b,g], **Annesa Flentje**[b,f,h]

[a]Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia

[b]The PRIDE Study/PRIDEnet, Stanford University School of Medicine, Stanford, California, USA

[c]Division of Nephrology, Department of Medicine, Stanford University School of Medicine, Stanford, California, USA

[d]Department of Epidemiology and Population Health, Stanford University School of Medicine, Stanford, California, USA

[e]Department of Obstetrics and Gynecology, Stanford University School of Medicine, Stanford, California, USA

[f]Department of Community Health Systems, School of Nursing, University of California, San Francisco, California, USA

[g]Department of Psychology, San Jose State University, San Jose, California, USA

[h]Alliance Health Project, Department of Psychiatry, School of Medicine, University of California, San Francisco, California, USA

Abstract

Health studies using biospecimens have an underrepresentation of sexual and/or gender minority (SGM) participants, making it difficult to use data to advance SGM health knowledge. This study examined: 1) the willingness of SGM adults to provide research biospecimens, 2) if SGM groups differ in their willingness, 3) the relationship of demographic characteristics with willingness, and 4) the ideas/concerns of SGM adults toward providing research biospecimens. Data collected in 2018–2019 from The Population Research in Identity and Disparities for Equality Study were analyzed. Regressions examined willingness to provide biospecimens (blood, buccal swab, hair, saliva, and urine) across SGM groups (cisgender sexual minority [SM] men, cisgender SM women, gender-expansive, transfeminine, and transmasculine adults; N = 4,982) and the relationship of demographics with a willingness to provide each biospecimen type. A thematic analysis of an open-ended item elucidated SGM adults' (N = 776) perspective toward providing biospecimens. Most SGM adults were willing to provide biospecimens. Cisgender SM women

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Correspondence regarding this article should be directed to Ethan C. Cicero, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia. ethan.cicero@emory.edu.

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were less willing to provide some types (blood 54% and urine 63%) than the other groups. Cisgender SM men were most willing to provide all types. Older age, identifying as pansexual, and income >$50,000/year were associated with increased odds of providing biospecimen(s). Gender identity was a significant predictor for all biospecimen types. A gender identity other than cisgender man was associated with 1.6–2.4× lower odds of providing biospecimen(s). Participants expressed concerns about data confidentiality and privacy, data access and misuse, research purposes, and inadvertent disclosure of SGM status. SGM adults' concerns about donating biospecimens can be used to create an affirming and inclusive methodology.

Keywords

ethics; health disparities; LGBTQ health; methodology; SOGI

INTRODUCTION

Sexual and gender minority (SGM) adults are individuals who self-identify as bisexual, gay, intersex, lesbian, queer, transgender, and others whose sexual orientation, gender identity, or gender expression varies from those associated with heterosexual and cisgender experience (eg, gender-expansive, nonbinary, and Two-Spirit).[1] SGM adults are more likely to experience poorer physical and mental health, a greater number of chronic health conditions, and higher levels of psychological distress compared with their non-SGM counterparts.[2–5] The disparate health status of SGM people is associated with exposure to stressful and adverse social conditions (ie, stigma, discrimination, and violence targeting SGM people) where they age, live, learn, work, and seek healthcare.[2,6]

For the second time since its inception, *Healthy People*, a U.S. health initiative aimed at health promotion and disease prevention, established national goals and measurable objectives to improve the health and well-being of the more than 18 million SGM adults living in the United States.[6–9] Health-related research and population-based studies have increasingly used biological samples (eg, saliva, urine, hair, and blood; biospecimens) to study population health.[10–13] These studies often have an underrepresentation of SGM people[6] or lack sexual orientation and/or gender identity (SOGI),[10–12,14,15] making it difficult to use these biospecimen data to advance knowledge about SGM health.

Biospecimens are used for many purposes in clinical and research settings, including the development and implementation of precision healthcare initiatives and understanding of physiological adaptations to chronic exposure to adverse social conditions that increase stress and may predispose an individual to disease.[16] Researchers using blood and saliva samples from SGM people found that greater exposure to SGM-related discrimination and stressors was associated with physiological dysregulation (eg, elevated levels of cortisol and systemic inflammation),[17–21] conditions that can lead to higher rates of chronic health conditions, such as cardiovascular disease, Alzheimer's disease, depression, cancer, and diabetes.[16] Biospecimens have also been used as a predictor of early morbidity and mortality. Data illuminating the relationships between social factors and health outcomes using biospecimens from SGM people remain limited.[6,22,23] The knowledge gained by understanding the physiological and biological consequences of exposure to adverse social conditions will facilitate the development of clinical interventions, guide current and future public health initiatives, and shape policies to improve the health and well-being of SGM people.[24,25]

SGM people remain underrepresented in health research, and advances in knowledge about SGM health are hindered by the lack of SOGI measures in health-related research and population-based studies.[6] Data repositories from National Institutes of Health (NIH)-funded research catalog the vast amount of biospecimen data accessible for analyses.[26] Despite these data-rich repositories, SGM participant data cannot be identified because SOGI measures have not been systematically considered key demographic variables that must be accounted for in NIH-funded studies.[27] By failing to account for SGM group membership, research findings do not provide accurate and useful information to identify modifiable pathways to improve the health, well-being, and quality of life of SGM people. New studies, such as the NIH's *All of Us* Research Program,[28] are making concerted efforts to include SGM people by including SGM community engagement teams to reach and advise on research with these populations.[29] Little is known, however, about the willingness and concerns of SGM people related to providing biospecimens for research purposes.

The purpose of this study was to examine the willingness of SGM adults to provide certain biospecimens (ie, blood, buccal swab, hair, saliva, and urine) for research purposes. We examined 1) the willingness of SGM adults to provide certain biospecimens for research purposes, 2) if SGM groups (cisgender sexual minority [SM] men, cisgender SM women, gender-expansive, transfeminine, and transmasculine individuals) differ in their willingness to provide biospecimens, 3) the relationship of demographic characteristics (age, education, gender identity, income, race/ethnicity, and sexual orientation) with a willingness to submit biospecimens, and 4) the ideas/concerns of SGM adults regarding providing biospecimen. These findings will inform future efforts to include SGM people in research studies involving biospecimens and other biological measures. Furthermore, it will allow consideration of SGM people's concerns to guide the design of future studies.

METHODS

We used a modified, embedded, mixed methods study design to analyze data from The Population Research in Identity and Disparities for Equality (PRIDE) Study. This design was chosen because a single type of data was not sufficient to answer our research questions.[30] Data were collected online between June 2018 and May 2019 from the 2018 Annual Questionnaire and Supplement within The PRIDE Study. The Institutional Review Boards of the University of California, San Francisco and Stanford University approved this study.

Launched in 2017, The PRIDE Study is a national online longitudinal cohort study of SGM adults 18 years old and older living within the United States, described in detail elsewhere.[31] Study participants are recruited using multiple strategies, including advertising on social media and in person at LGBTQ+ community events and through PRIDEnet Community Partners, a national network of health, community, and other LGBTQ+ organizations.[32]

Eligible participants visit The PRIDE Study's online study platform to enroll in the study and complete surveys that examine their social, mental, and physical health as well as surveys that focused on specific health topics.[33]

Participants

These analyses included individuals who provided data to demographic measures and items pertaining to providing research biospecimens (five categorical items and one open-ended question). Based on their self-reported gender identity and sex assigned at birth, participants were categorized into five mutually exclusive study groups that were used to differentiate cisgender sexual minority participants from gender minority participants of all sexual orientations: cisgender SM men, cisgender SM women, gender-expansive, transfeminine, and transmasculine individuals.[34] All cisgender participants self-identified with at least one sexual orientation that indicated they were members of an SM community. Participants categorized within one of the gender minority study groups were also not required to endorse being a member of an SM community. These groups were chosen because health disparities and social disadvantages experienced by SGM adults vary based on gender identity and sex assigned at birth.[6,35] Demographic information about these groups is found in Table 1. Individuals who did not provide adequate information about their current gender identity or sex assigned at birth for study group classification were excluded from these analyses (ie, current gender identity = woman, sex assigned at birth not provided).

Measures

Demographic Characteristics.—Demographic measures included gender identity, sex assigned at birth, sexual orientation, birthdate (used to calculate age at the time of survey start), race/ethnicity, annual individual income, the highest level of education completed, and intersex identity. Participants could self-identify with more than one race/ethnicity, gender identity, and sexual orientation category, and they also had an opportunity to write in a response. We report the number of people who endorsed each race/ethnicity and sexual orientation category, allowing for a more comprehensive understanding of these nonfixed, multidimensional social constructs.

Biospecimen Questions.—We examined differences in self-reported willingness to provide five different types of research biospecimens: blood, buccal swab, hair, saliva, and urine. Across five survey items, participants were asked: "Would you be willing to participate in research studies that request you to submit a (biospecimen type) sample?" Response choices were: "yes," "no," and "I don't know." In our analyses, "yes" or "no" answer choices were used to describe being willing vs. unwilling to participate in research studies that request a particular biospecimen. This series of five survey items were used to operationalize participant willingness to provide one of five different types of biospecimens for research. We analyzed data from one open-ended response item to elicit the ideas/ concerns that participants had regarding providing biospecimens: "If you have any specific ideas or concerns that you would like to share with us about giving biological samples to The PRIDE Study, please describe them here." This question followed the survey items asking about participants' willingness to provide biospecimens. Analyzed comments were those in which participants provided at least one phrase written in English that went beyond an affirmative or negative response.

Analytic Plan

Quantitative Analysis.—Chi-square and one-way analysis of variance tested differences between study groups in demographic characteristics and willingness to provide each type of biospecimen. Multivariable logistic regression models examined the association of demographic characteristics (race/ethnicity, SOGI, annual individual income, and education) on willingness to provide a biospecimen. Separate analyses were conducted for the total sample and each SGM group for each biospecimen to provide specific information for researchers interested in a specific SGM group. To better understand the perspective of the participants who endorsed being intersex, bivariate and multivariable models were fit to examine the association of intersex identity on each biospecimen outcome. Indicator variables were used as dependent variables in the multivariable models and represented each race/ethnicity and sexual orientation categories (eg, Asian [1 = yes, 0 = no], asexual [1 = yes, 0 = no]), multiracial identities, and the use of multiple terms to describe one’s sexual orientation. Analyses conducted for the total sample used cisgender men as the reference category for gender identity because the majority of NIH-funded research on SGM health topics has focused on cisgender SM men.[36,37] Reference categories for annual individual income ($0–$20,000) and education (college degree; all models except for cisgender SM men group analyses, where graduate degree was used) were based on the largest number of SGM participants within each category. Due to convergence issues within models, race/ethnicity and sexual orientation were treated as mutually exclusive categorical variables in our multivariable models that fit data from our transfeminine and transmasculine participants. *A priori*, we determined that if race/ethnicity or sexual orientation were significantly associated with willingness, we would discuss the potential historical and social underpinnings that contextualize these findings.[38,39] Adjusted odds ratios (aOR) and their 99% confidence interval (CI) are reported to estimate effect size. Given our inclusion of group analyses, we chose a more conservative α level of .01 for each test. Quantitative analyses were conducted using Stata SE version 16.[40]

Thematic Analysis of the Open-Ended Question.—Thematic analysis was conducted using responses to the open-ended item.[41] These data provided insight into the ideas/concerns that SGM adults had about participating in research studies that involve collecting biospecimens from participants. We implemented an inductive approach to identifying data-driven themes.[41]

To ensure the rigor of the analysis, two researchers (ECC and GS) independently reviewed all responses and generated initial codes. Together, the researchers established a coding structure that was used separately by each researcher. Coding differences that occurred were resolved by discussion. Codes were then organized into categories and ultimately into broader themes. The themes reflected data from the entire participant sample and each SGM group. To avoid sample size-driven exclusion of underrepresented communities, when there were any differences between the entire sample and any one individual study group or between the entire sample and a minoritized ethnoracial group, we report this in our discussion within each theme.

RESULTS

Willingness to Provide Biospecimens for Research

Descriptive statistics for demographic characteristics and willingness to provide biospecimens are summarized in Tables 2 and 3, respectively. Within the total sample (*N* = 4,982), 27.6% (*n* = 1,376) were cisgender SM men; 35.5% (*n* = 1,770) were cisgender SM women; 24.2% (*n* = 1,206) were gender-expansive individuals; 4.5% (*n* = 226) were transfeminine individuals; and 8.1% (*n* = 404) were transmasculine individuals. Among the gender-expansive individuals, 86.2% (*n* = 1,035) were assigned female at birth. Approximately, 1.1% (*n* = 54) of the sample endorsed being intersex. Although 10.5% of the sample identified with more than one race/ethnicity category, the majority endorsed being White only (82%). The groups differed significantly in all demographic characteristics (Table 2).

Bivariate Results

The majority of SGM adults were willing to provide research biospecimens (Table 3). SGM adults indicated that they were most willing to provide saliva (78.4%, *n* = 3,347), followed by buccal swabs (77.7%, *n* = 3,301), hair (77.3%, *n* = 3,299), urine (69.5%, *n* = 2,944), and blood (61.4%, *n* = 2,470). Across all biospecimen types, there were no differences in willingness for participants who endorsed being intersex.

The proportion of participants who indicated they were willing to provide a biospecimen varied by biospecimen type and SGM group (Table 3). Among cisgender SM men, cisgender SM women, and transfeminine individuals, the greatest proportion of participants were willing to provide saliva (86.9%–69.2%). Among gender-expansive individuals, the greatest proportion of participants were willing to provide hair (76.5%, *n* = 767), and among transmasculine individuals, the greatest proportion of participants were willing to provide a buccal swab (76.8%, *n* = 265). Across groups, urine and blood were ranked as the two least desired biospecimen types.

Demographic Correlates of Willingness to Provide Biospecimens

There were differences in the willingness to provide each type of biospecimen for all SGM adults. Correlates varied by biospecimen type and included age, gender identity, sexual orientation, and annual individual income (Table 4). Race/ethnicity, education, and intersex status were not predictors for any biospecimen outcome, whereas gender identity was a significant predictor for all biospecimen types.

Blood.—Age, gender identity, sexual orientation, and annual individual income were predictors of willingness to provide blood. For each one-year age increase, the odds of SGM adults providing blood increased by 2%. Cisgender SM women (aOR = 0.47, 99% CI: 0.36–0.62), gender-expansive (aOR = 0.60, 99% CI: 0.46–0.80), and transfeminine individuals (aOR = 0.53, 99% CI: 0.35–0.79) were less likely to provide blood when compared with cisgender SM men. Pansexual SGM individuals (aOR = 1.37, 99% CI: 1.09–1.72) were more likely to provide blood when compared with nonpansexual SGM adults. SGM adults earning $20,001–$50,000 (aOR = 1.36, 99% CI: 1.14–1.62) were more likely to provide blood than those earning $20,000 or less.

Buccal Swab.—Gender identity, sexual orientation, and annual individual income were predictors of willingness to provide buccal swab specimens. Cisgender SM women (aOR = 0.60, 99% CI: 0.44–0.82) and transfeminine individuals (aOR = 0.43, 99% CI: 0.28–0.67) reported lower odds when compared with cisgender SM men. SGM individuals who endorsed being pansexual (aOR = 1.51, 99% CI: 1.16–1.96) compared with those not were more likely to provide a buccal swab. SGM adults earning $20,001–$50,000 annually were more likely to provide a buccal swab (aOR = 1.36, 99% CI: 1.12–1.67) than those earning $20,000 or less.

Hair.—Age and gender identity were predictors of willingness to provide hair specimens. For each one-year age increase, the odds of SGM adults providing hair increased by 1%. Cisgender SM women (aOR = 0.60, 99% CI: 0.44–0.82) and transfeminine individuals (aOR = 0.43, 99% CI: 0.28–0.67) were less likely to provide hair when compared with cisgender SM men.

Saliva.—Age, gender identity, sexual orientation, and annual individual income were predictors of willingness to provide saliva specimens. For each one-year age increase, the odds of SGM adults providing saliva increased by 1%. Cisgender SM women (aOR = 0.54, 99% CI: 0.39–0.75), gender-expansive (aOR = 0.64, 99% CI: 0.46–0.89), transfeminine (aOR = 0.41, 99% CI: 0.27–0.65), and transmasculine individuals (aOR = 0.62, 99% CI: 0.43–0.88) were less likely to provide saliva when compared with cisgender SM men. SGM adults who endorsed being pansexual were more likely to provide saliva (aOR = 1.51, 99% CI: 1.16–1.97) than those who did not. SGM adults earning $20,001–$50,000 annually were more likely to provide saliva (aOR = 1.44, 99% CI: 1.17–1.77) than those earning $20,000 or less.

Urine.—Age, gender identity, sexual orientation, and annual individual income were predictors of willingness to provide urine specimens. For each one-year age increase, the odds of SGM adults providing urine specimens increased by 2%. Cisgender SM women (aOR = 0.42, 99% CI: 0.19–0.57), gender-expansive (aOR = 0.51, 99% CI: 0.38–0.68), transfeminine (aOR = 0.42, 99% CI: 0.28–0.63), and transmasculine individuals (aOR = 0.59, 99% CI: 0.43–0.83) reported lower odds of providing urine specimens when compared with cisgender SM men. Individuals who endorsed being pansexual were more likely to provide urine specimens (aOR = 1.50, 99% CI: 1.19–1.89) when compared with nonpansexual adults. SGM adults earning $20,001–$50,000 annually (aOR = 1.48, 99% CI: 1.23–1.79) were more likely to provide urine specimens than those earning $20,000 or less.

Correlates of Demographic Characteristics Within SGM Groups

When examining the five SGM groups separately, there were differences in which demographic characteristics were associated with the odds of providing a biospecimen. Results are available upon request/included as supplemental tables.

Cisgender SM Men and Transfeminine and Transmasculine Individuals.—The demographic characteristics of cisgender SM men, transfeminine, and transmasculine individuals were not significantly associated with their willingness to provide any research biospecimen.

Cisgender SM Women.—Age, sexual orientation, and education were predictors of willingness to provide biospecimens. For each one-year age increase, the odds of cisgender SM women providing blood and hair specimens increased by 2%. Cisgender pansexual women were more likely to provide blood (aOR = 1.79, 99% CI: 1.20–2.67), a buccal swab (aOR = 1.94, 99% CI: 1.19–3.15), saliva (aOR = 1.90, 99% CI: 1.17–3.10), and urine (aOR = 1.87, 99% CI: 1.23–2.83) when compared with those who did not endorse being pansexual. Among cisgenderSM women, those with a high school diploma or some college education were less likely to provide blood (aOR = 0.67, 99% CI: 0.41–0.80) compared with those with a college degree.

Gender-Expansive Individuals.—Age and annual individual income were predictors of willingness to provide biospecimens. For each one-year age increase, the odds of gender-expansive individuals providing blood, saliva, and urine increased by 3%. When compared with gender-expansive individuals earning \$20,000 or less annually, those earning \$20,001–\$50,000 (aOR = 1.59, 99% CI: 1.12–2.27) and those earning more than \$50,000 (aOR = 1.88, 99% CI: 1.16–3.04) were more likely to provide urine.

Thoughts About Providing Biospecimens for Research

After data cleaning, there were 776 participants who provided a response to the open-ended question. Within the sample, 23.3% (*n* = 181) were cisgender SM men; 34.0% (*n* = 264) were cisgender SM women; 28.7% (*n* = 223) were gender-expansive individuals; 5.4% (*n* = 42) were transfeminine individuals; and 8.5% (*n* = 66) were transmasculine individuals. Among the gender-expansive individuals, 89.1% (*n* = 197) were assigned female at birth (Table 5). Approximately, 1.2% (*n* = 9) of the participants who provided a response to the open-ended question endorsed being intersex. These groups differed on all demographic variables. Gender minority (GM) individuals were more likely to provide a response to the open-ended item than cisgender SM participants (18.0% vs. 14.1%). Although 9% of the sample identified with more than one race/ethnicity category, the majority endorsed being White only (84%).

There were differences in age, study group distribution, and sexual orientation of the participants who answered the open-ended question compared with those who did not. Participants who provided an open-ended response were older, more likely to identify as a GM, and more likely to endorse being queer or use multiple terms when describing their sexual orientation.

Five themes were identified from participants' responses: security (*n* = 441), scope of study (*n* = 335), logistics (*n* = 202), dissemination (*n* = 43), and health concerns (*n* = 28). Each quote is accompanied by the demographic characteristics that participants selected and, at times, wrote in to specify their race/ethnicity and SOGI. To distinguish quotes from SM participants and those provided by GM participants, we included additional bracketed gender identity details.

Security

Nearly 60% (*n* = 441) of SGM adults in our sample expressed concerns regarding the safety and security of their demographic and biospecimen data. These concerns relate to confidentiality and privacy and biospecimen storage.

The majority of participants articulated apprehension regarding the anonymity of their information and its affiliation with their biospecimen sample, as well as if their identities and/or biospecimen data would be accessible to others. Many commented specifically about the privacy of their information.

> "I suppose I'd want to be assured that my samples could never be matched with my real-life identity" (65-year-old, White, bisexual and lesbian, transgender woman) and "Will the information derived from these samples be kept confidential? How am I to trust you?"
>
> (68-year-old, Black, African American, or African; gay and same-gender loving [cisgender] man).

Over 50 participants addressed confidentiality concerns regarding their personal and biospecimen data being accessible to other researchers and that their data would be used without their consent in future research:

> "Black people have historically been used as medical guinea pigs. Our specimens have been used for purposes we never agreed to"
>
> (27-year-old; Black, African American or African and White; asexual, pansexual, and queer; genderqueer and agender person),

> "Native people have our genetic information stolen, and a lot of genetic research is eugenicist"
>
> (43-year-old; American Indian or Alaska Native; Black, African American or African and White; queer; Two-Spirit person),

> and "My concern as a Black child of immigrant Latinx parents is about having my DNA and cells held by some organization to be used without my informed consent later on à la Henrietta Lacks. My body is the only thing that's mine, and many people, institutions, (and) governments still don't agree that I should be free!"
>
> (30-year-old; Black, African American, or African; Hispanic, Latino, or Spanish; bisexual and queer [cisgender] woman).

SGM adults were fearful about who can access their personal and biospecimen data and how those data may be used against them. Over 10% (n = 47) of SGM adults with security concerns explicitly named the U.S. government as their number one concern. Participants articulated life safety concerns because of the U.S. government having knowledge of their SGM status:

> "How do I know this isn't the government compiling a list of queers so you can holocaust us?" (41-year-old, White, queer, genderqueer person) and "It's unsafe for queer folk to be biologically identifiable. If we were to be targeted by the government, samples such as you've requested could be seized and used to locate us"
>
> (23-year-old; White; bisexual, gay, and queer; genderqueer, nonbinary, and transgender man).

SGM adults voiced concerns about how their personal and biospecimen data may be shared with third parties (eg, law enforcement and health insurance). Many asserted that they did not want any *"biological data released to any private or third-party companies" (27-year-old; White; asexual, queer, and demisexual; genderqueer and nonbinary transgender person*).

Participants communicated anxiety regarding the possibility of their data being used to oppress SGM people (eg, "*misuse or misinterpreting of data by anti-LGBTQ groups"* [*34-year-old, White, queer, genderqueer, and transgender man*]). Participants inquired if law enforcement would have access to their information; some expressed fear as to what may happen if their data were *"legally confiscated and used for eugenics" (35-year-old, White, queer, genderqueer, and transmasculine person*). Numerous SGM adults referenced the practice of law enforcement, leveraging existing DNA databases to solve crimes. Others suggested they would not participate in studies where DNA was sequenced and results shared with law enforcement.

"I do not wish to be entered into a DNA database" (29-year-old; Hispanic, Latino, or Spanish and White; gay and lesbian [cisgender] woman). Participants also disclosed concerns that their data would be shared with or sold to health insurance companies and *"used to prove pre-existing conditions to deny health insurance" (36-year-old; White; asexual, lesbian, and queer; transgender woman*).

SGM adults articulated concerns about storing their genetic data within a biospecimen repository. Participants expressed general discontent:

> "I'm concerned about having my DNA in a database"
>
> (36-year-old; American Indian or Alaska Native, Middle Eastern or North African, and White; lesbian [cisgender] woman)

and unease:

> "having known LGBT members DNA on file, even if anonymous, seems dangerous to me"
>
> (39-year-old, White, bisexual [cisgender] woman).

The monetization of personal and biospecimen data was discussed by many SGM adults. Participants explained that they would not want their data or biospecimens to *"be used for for-profit research" (41-year-old, Asian and White, lesbian and queer, transgender woman*) or sold for profit *"to biobanks or other researchers" (33-year-old, White, bisexual [cisgender] woman), and "as long as you don't sell it for profit and my biological samples are used only for research, then it's fine" (33-year-old; White; asexual, pansexual, and queer; nonbinary person*).

When examining the confidentiality and privacy concerns of each SGM group, consent was the topic most frequently discussed by all SGM groups except gender-expansive individuals who more frequently discussed concerns about the U.S. government. The majority of participants from a minoritized ethnoracial group discussed confidentiality and privacy concerns regarding their biospecimen data being accessible to others.

Nearly one-third of participants with security concerns cited trepidation about the storage and retention of their biospecimen samples. Participants inquired about how long their biospecimens would be kept once the study was completed, and others wanted *"assurance the samples would not be retained" (39-year-old, White, gay [cisgender] man*) because they did *"not consent to indefinite storage of biological samples" (29-year-old; White; gay, lesbian, and queer; genderqueer person*). Ten participants mentioned the possibility that their data would be hacked:

> "I am concerned…about the storage of my biological information, who has the rights to access this information, and general security in this age of hackers and data breaches"
>
> (25-year-old; Black, African American, or African; queer; androgynous person).

Scope of Study

The scope of the study is important to SGM adults, considering participating in biospecimen-based research. Nearly 45% (n = 335) of the participants provided input about the study objectives, research question, methods utilized, and genetic material.

Study Aim.—

Most participants, including those from minoritized ethnoracial groups, commented that they needed more information about the study, why it was being conducted, and its significance. Along with the study purpose, participants wanted to know more about the research team conducting the study:

> "I'm not interested in having my samples used for foolhardy science dreamed up by someone with uninformed or biased notions about queer folks"
>
> (36-year-old, White, asexual and queer, genderqueer person).

Many participants asked general questions related to the scope of the study. Some explicitly voiced their opposition in providing their biospecimens to researchers exploring the etiology of SOGI. Numerous participants stated they would not participate in a study or provide biospecimens if their data could be used to *"cure or prevent LGBTQness" (29-year-old,* *White, queer; genderqueer and nonbinary person*). Others expressed concerns that their biospecimens might be used to support eugenic practices to eliminate SGM people:

> "I would not like to participate in any studies that try to determine a genetic 'cause' or 'link' to being gay or transgender. I don't believe that we live in a society that could be trusted to act appropriately with that information"
>
> (28-year-old; White; bisexual, gay, and queer; transgender man)
>
> and "I'm especially not keen on the idea of trying to find if there's any biological reason WHY we're queer, because that could very well lead to eugenics and people trying to 'fix' the issue of our existence"
>
> (18-year-old; White; asexual, bisexual, and queer; genderqueer and transgender man).

Genetic Material.—Over 10% (*n* = 94) of the participants and nearly 30% of SGM adults who provided input for the "Scope of Study" theme referenced genetic materials. Participants inquired about which biospecimens are needed and the type of testing being conducted. SGM adults asked if their DNA will be sequenced and stated that they have concerns about DNA sequencing. Some explicitly asked for assurance that their samples will not be "DNA-tested." Several cited that they would not share their DNA with anyone who was not their healthcare provider. Although many SGM adults only expressed unease with providing their genetic material, others explained that they would need to understand more about the study before providing their biospecimen:

> "I would consider giving up body matter which contains my DNA, if I felt it was more beneficial than harmful to me and I knew how exactly how it would be used to help the LGBT+ community"
>
> (37-year-old, American Indian or Alaska Native and White, gay and heterosexual [transmasculine] man).

Broadly, participants expressed apprehension about providing their DNA to researchers. Several comments suggest that some SGM adults lack an understanding that biospecimens contain their DNA:

> "I am happy to provide any biological sample that does not include my DNA"
>
> (33-year-old, American Indian or Alaska Native, gay, Two-Spirit person).

Similarly, some participants indicated that they would only be willing to provide urine and/or hair samples, but not blood, indicating that they may not understand that DNA could be accessed through hair and urine samples.

At the SGM group level, the proportion that discussed genetic material was highest among transmasculine individuals and more than double that of cisgender SM men, which represented the lowest proportion of individuals that discussed genetic material across groups.

Logistics

Logistics associated with collecting biospecimens covered a wide range of topics associated with biospecimen collection. More than 25% (*n* = 202) of participants' responses touched on this theme, reflecting ideas about the collection, data sharing, and compensation.

Collection.—Nearly all participants within this theme provided input about collecting research biospecimens. Participants indicated that they wanted to know more about the collection process and asked for *"a clear description of the process for obtaining the sample and sending it in" (21-year-old; White; asexual, gay, lesbian, and queer; agender person*). Numerous participants asked specifically about the handling of biohazards and safe practices in collecting blood samples, and others asked for clarification about hair samples because they are bald, or their hair is dyed or shaved.

The equipment needed to collect biospecimens is a topic many broached. Participants anticipated needing equipment or devices and commented that these supplies should be provided by the researchers. SGM adults inquired about the collection expenses, and many disclosed that they "*wouldn't participate if it cost (them) to get these biological samples (themselves)" (38-year-old; American Indian or Alaska Native, Black, African American or African; Hispanic, Latino, or Spanish, and White; lesbian [cisgender] woman*).

SGM adults discussed concerns about receiving supplies or sending biospecimens through the mail. Beyond shipping procedures, many participants described what they would not send through the mail, with most opposing blood and urine samples. Many described a personal barrier related to using mailing services:

> "I am very bad at actually going to the post office to mail things"
>
> (29-year-old; White; bisexual, pansexual, and queer; agender, genderqueer, nonbinary, and transgender person),
>
> and that would "not send anything through the mail"
>
> (26-year-old; American Indian or Alaska Native, Black, African American or African, and White; pansexual; nonbinary, man, and woman).

SGM adults under the age of 35 years described concerns about how biospecimen collection materials are shipped to their home. These concerns centered on inadvertent disclosure of their SOGI to individuals within their household, a fear that precludes some from providing biospecimens:

> "I live with my parents, and I'm not out to them, so I'm unable to participate in any part of the study that requires mail or anything offline"
>
> (33-year-old; White; asexual, lesbian, queer, and neptunic [lesbian and enbian]; nonbinary person).

In a way to prevent accidental disclosure of their SGM status, numerous GM participants requested discreet packaging and for researchers to verify, prior to mailing supplies, the participant's name and shipping address:

> "The packaging would also have to be INCREDIBLY discreet if anything was mailed to me because my parents don't approve of my identity, and I'm trying very hard not to upset them"
>
> (21-year-old, White, bisexual, genderqueer person),

> and "If you do these studies, PLEASE have an option of 'what name would you like this to be sent to' or something for people who aren't out under their chosen name yet."
>
> (26-year-old; Black, African American, or African; bisexual and queer; agender, genderqueer, gendervoid, and transneutral person).

Mail was the top collection concern for both the gender-expansive and transmasculine groups.

SGM adults expressed opposing views about where they would like their biospecimen collected. Participants who expressed a preference to perform home collection provided varying rationale, including transportation challenges, discomfort, and time constraints. Whereas others desired a lab or clinic:

> "I would be totally willing to provide biological samples if there was a participating clinic near me"
>
> (30-year-old; Asian and White; gay, queer, and gray-asexual; man and transgender man)

> and inquired if they "may use any lab or only a specific one that may be difficult to access?"
>
> (28-year-old, White, asexual and queer, agender and genderqueer person).

Although most commented about their location preference, some participants referenced apprehension about disclosing their SGM status if their biospecimens were collected outside of their home.

SGM adults were interested in knowing who would be collecting their sample. The majority alluded to blood samples when explaining that they would want collection by a licensed professional, and some expressed concerns that they would have a hard time using devices on themselves, such as fingerstick/lancet devices.

Data Sharing.—Nearly 10% (*n* = 18) of SGM adults with logistical concerns discussed ways they could leverage their existing health-related data. Participants *"participate in multiple clinical studies and clinical trials…and would be happy to authorize (researchers) to have access to (their) medical records and biological samples…" (56-year-old, White,* *gay [cisgender] man*). Others suggested sharing their existing health data from wearable technology (eg, Fitbit and Apple Watch) or genetic results (eg, 23andMe and Ancestry).

Compensation.—SGM adults ($n = 20$) considering providing research biospecimens wanted compensation for their biological contributions. Some wanted to know how they would be compensated. Others explained that they *"would only be willing to do (it) if (they were) being compensated" (20-year-old; Hispanic, Latino, or Spanish; lesbian [cisgender] woman*).

Dissemination

Dissemination represented the fourth most discussed theme ($n = 44$). Participants were interested in learning the results from any testing conducted using their biospecimen, particularly if clinical or health concerns were identified. If any adverse condition was discovered, participants requested researchers provide them with appropriate resources to address their health:

> "On discovery of some pathology or risk of pathology, whether life-threatening or nonlife threatening, I would like to be informed"
>
> (45-year-old; White; gay, queer, and same-gender loving; genderqueer man).

However, a desired notification mechanism was not articulated. Participants also expressed concern about how the results would be communicated:

> "Will the results of the studies be available to view for anyone, or will they be behind a paywall where they're of no use to anyone?"
>
> (34-year-old; White; pansexual and queer; genderqueer, man, and transgender man).

SGM adults disclosed the importance of researchers disseminating the knowledge gained from their contributions:

> "I would like to know what you have found from them and when/how this information is being shared with others"
>
> (25-year-old; Asian, White, and biracial; gay, lesbian, and queer; genderqueer and nonbinary woman).

Health Concerns

Health concerns, the fifth most discussed theme, represented SGM adults who reflected upon their health when considering if they would provide biospecimens. Participants expressed concerns about not being able to provide biospecimens because of pre-existing health conditions, such as living with anemia. Having either a needle or blood phobia was a salient concern impeding participation:

> "I'm just scared of needles, I wouldn't mind giving blood, but I have a very bad phobia of needles and cannot even look at them"

(20-year-old, White, demisexual and panromantic, nonbinary person).

DISCUSSION

To our knowledge, this is one of the first studies to assess the acceptability among SGM adults in providing research biospecimens. These findings illustrate relatively high rates of acceptability for all SGM individuals (61.4%–78.4%) and individual SGM groups (54.0%–86.9%) across all biospecimen types. These results can be used to increase research representation of specific SGM groups by providing information about groups that may be less likely to participate in biospecimen research. The specific concerns, noted by SGM participants, may be used to design better studies that overcome the problems. Demographic characteristics were associated with willingness to provide biospecimens for all SGM adults and each SGM group. For all SGM adults, older age, identifying as pansexual, and earning $20,000–$50,000 annually were associated with increased odds of providing biospecimen(s) for research. Additionally, gender identity was a significant characteristic with cisgender men, having 1.6–2.4 times higher odds of providing all biospecimen types when compared with other SGM groups.

When we examined each SGM group separately, notable differences (compared with entire sample) were discovered. Among cisgender SM women, less education was associated with less willingness to provide blood. This association was most notable because education was significant only among cisgender SM women. This indicates the importance of considering the SGM group(s) involved in a research study—and how specific communities within that group (eg, cisgender SM women with less education) may be systematically less likely to agree to participate in research, thereby being less represented.

Cisgender SM men are most willing to provide biospecimens. This finding may reflect the trustworthiness between cisgender SM men, researchers, and research institutions, a possible byproduct of the centering of cisgender SM men and their health concerns within SGM-related research.[6,36] Although SGM people are underrepresented in health research overall, cisgender gay men have been the predominant SGM group represented in health research.[6,36,42] NIH-funded, SGM health research has historically focused on HIV/AIDS among cisgender SM men and cisgender men who have sex with men (MSM).[36,42] Conversely, these conditions may have negatively impacted trust between transgender people and researchers. As researchers explored HIV/AIDS in cisgender SM men, transgender women and transfeminine individuals were erroneously and harmfully classified as MSM (making their identities invisible in research) or excluded altogether from HIV studies; methods used to identify transgender men/transmasculine participants were largely not used.[43,44] Despite years of transgender community leaders advocating for change and a growing body of evidence documenting the disproportionate risk for HIV acquisition and transmission among transgender women/transfeminine people,[45] the Centers for Disease Control and Prevention did not issue an HIV surveillance report that included disaggregated data for transgender persons until 2020.[46]

With the centering of cisgender gay men in SGM health research, many other SGM groups are overlooked. Less inclusive, SOGI-related research methods may also render some groups invisible, particularly, more emerging and less studied SGM groups (ie, asexual and pansexual).[6] Recognizing this, The PRIDE Study sought to recruit and engage a diverse cohort of SGM people, including less represented SGM groups, by using community-engaged research methods (eg, including collecting iterative feedback from participants, conducting community listening sessions, and tabling at community events of underrepresented groups).[33] This approach can improve trust and willingness to participate in research and increase the number of participants from less studied SGM groups,[47] which may explain our finding—pansexual adults were approximately 1.5 times more likely to provide each biospecimen type when compared with participants who did not endorse being pansexual. Despite representing different sexual orientations, pansexual people are often grouped under the bisexual umbrella, which may obscure relevant research findings about the pansexual community. In conjunction with community engagement efforts, providing a more expansive list of SOGI identities,[48] along with the ability to select multiple terms to describe one's gender identity and sexual orientation, The PRIDE Study created a platform that acknowledges the diversity of SGM groups. In this case, we were able to identify a difference among pansexual adults, which was not present among bisexual participants. Additional research is needed to understand factors that contribute toward an increased willingness of pansexual adults in providing biospecimens.

Focused attention on cisgender gay men largely mirrors that of the LGBTQ+ civil rights movement in the United States, a movement started by Black and Latinx cisgender and transgender lesbian and queer women during the 1969 Stonewall riots.[49] The role that Black and Latinx cisgender and transgender women played in jumpstarting the LGBTQ+ civil rights movement is downplayed, often excluded, and re-envisioned with White gay cisgender men as champions in historic accounts.[50] Nearly 40 years after the riots, many LGBTQ rights organizations focused their attention on marriage equality and supporting a version of the Employment Non-Discrimination Act that excluded protections for transgender and other GM people.[51] Taken together, the findings in this present study and sociopolitical context suggest that in society and compared with other SGM subgroups, cisgender gay men have the most privilege, which may contribute toward their willingness to provide research biospecimens as well as engender research mistrust among other SGM groups. This interpretation is consistent with findings among members of marginalized groups that have shown research participation and trust are influenced by historical and socially structured privilege and inequality.[52–54] SGM people experience stigma and inequities in society, and some SGM groups experience it from within the SGM community; these factors may affect their willingness to provide research biospecimens and represent an area for further examination.

Building and establishing trusting relationships with SGM communities to encourage research participation will require researchers to acknowledge the long-standing stigma, oppression, and marginalization that SGM people have endured and continue to experience.[52,55] Participants in the current study alluded to mistrusting both the research team as well as other entities (ie, government, health insurance companies, and law enforcement) that may gain access to their data. Despite decades of advocacy, legislative advancements in civil rights, and growing cultural acceptance for SGM people, the historical, organized, and ongoing patterns of mistreatment targeting SGM people can influence their trust in and willingness to participate in research.[52,54,55] Participants shared their fears about the U.S. government using shared data to generate lists of SGM people to target with oppression and violence. Indeed, the U.S. government has previously taken specific oppressive actions against SGM people. In 1953, after many years of arresting and punishing people who were suspected of being gay or lesbian, the U.S. government issued an executive order supporting the systematic removal of gay and lesbian people from the federal government.[56] This period, known as the Lavender Scare, was grounded in baseless claims that gay and lesbian people posed a security threat because they may not be mentally stable or loyal enough to hold a government job.[56–58] Nearly 40 years later, two executive orders banned discrimination based on sexual orientation when granting security clearances (1995) or when hiring government employees (1998).[59] Gender identity-related protections were not established until 2020 when the Supreme Court clarified that the Civil Rights Act of 1964 also provides protection against employment discrimination based on one's gender identity.[60] The data analyzed in this study were collected during the Trump administration, and it is probable that the discriminatory actions and beliefs of the administration may have contributed to SGM adults' hypervigilance about their safety when providing biospecimens. During the Trump administration, many previously issued SGM-protective executive orders and federal guidelines were revoked, thereby stripping SGM adults of their civil rights.[61] The actions of the Trump administration were discussed by many participants and were cited as reasons for not wanting to provide biospecimens. Although investigators of previous studies have documented safety concerns among SGM adults related to actions by the Trump administration,[62] additional research is needed to examine the longitudinal effects of SGM adults on willingness to provide research biospecimens.

Research mistrust was implicitly and explicitly disclosed by participants in the current study as barrier to participating in research studies that collect biospecimens. SGM adults overwhelmingly stated that their willingness to provide biospecimens was contingent upon the purpose and perceived usefulness of the study and the composition of the research team, with many worried that their biospecimens will be used to *"cure or prevent LGBTQness," "support eugenic practices to eliminate SGM people,"* or *"misuse[d] or misinterpret[ed]…by anti-LGBTQ groups."* Numerous individuals discussed how the history and ongoing abuses of racism perpetuated by researchers and healthcare professionals against Black and other minoritized ethnoracial communities contributed to their hesitancy to provide biospecimens. These findings closely match those obtained in other studies with SGM people and other marginalized communities.[52,53,63–66] This mistrust may be a result of a long history of pathologizing, insensitive, and unethical practices in research involving SGM people, approaches that continue today.[67–70] The stigma and discrimination experienced by SGM people in healthcare environments and by healthcare professionals can also lead to research mistrust.[54,64] Given the amount of discrimination that SGM people face in healthcare,[6] these findings are not surprising. These findings provide an important perspective for researchers to consider and address as they recruit and consent SGM adults for research.

Our thematic analyses can directly inform researchers' planning studies, involving biospecimen collection. For example, study materials should not unnecessarily reference the individual’s SGM status. This may mean making study materials and references to study names neutral and not having SGM-related imagery on materials that would be seen by outside parties. Clear information about how the data will be used and by whom can help to put participants at ease and make informed decisions about their participation. Our results have already informed decisions about current biospecimen collection in The PRIDE Study. For example, participants discussed wanting to be able to determine for which studies their biospecimens would be used. In The PRIDE Study’s consent procedures for biospecimen studies, participants allow their biospecimens to be used for research on a specific topic or future topics reviewed by The PRIDE Study Participant and Research Advisory Committees. Participants indicate if they desire to be recontacted about future studies on topics that have not yet been determined. Specific concerns have been integrated into The PRIDE Study’s consent processes, including videos to let participants know about the research team conducting the research. The PRIDE Study also created explicit biospecimen collection instructions and information about and the ability to decide about data sharing with government organizations.

Results from this study are applicable to other research studies that include SGM people. This includes SGM-specific health research, either at the population or subgroup level, or more broadly, research that examines health-related outcomes, such as the NIH’s *All of Us* Research Program, which will be collecting blood and urine specimens for biochemical assays and will be performing whole-genome sequencing on all 1 million participants (approximately 10% of current enrollees are SGM people). Findings from this study and the initiatives planned by *All of Us* may provide the needed pressure to develop community engagement efforts to build trust as well as methods and privacy safeguards to support biospecimen donation from SGM participants and other participants from communities that are underrepresented and/or historically excluded in biomedical research.

Limitations

Our study has limitations. How we classified participants into study groups may not accurately reflect how they self-identify. Our categorization may have inadvertently obscured meaningful patterns in the data about SGM groups and communities within that group that are less represented in research. Future research could consider how intersecting identities, particularly, the intersection of multiple marginalized identities, creates overlapping and unique forms of discrimination and their impacts on willingness to provide biospecimens. Our operationalization of participants’ willingness to provide research biospecimens may not align with how participants interpreted the original survey items. Participants were asked if they would be willing to participate in research studies that request them to submit a biospecimen. This may have been understood as willingness to participate in a research study and not necessarily about providing a biospecimen, particularly because providing a biospecimen was not explicitly stated as a study requisite. Another limitation of this study is the predominantly White sample (n = 3,839; 91.27%), despite The PRIDE Study’s ongoing efforts to increase the representation of SGM participants of color. This may explain why race was not associated with willingness, which is contrary to previous work that indicates higher levels of research and healthcare mistrust stemming from systemic racism, among Black communities and other minoritized ethnoracial communities.[71] The findings from our thematic analysis may not adequately amplify the voices of individuals from minoritized ethnoracial communities about providing biospecimens for research. For this reason, The PRIDE Study is currently conducting in-depth qualitative interviews to further explore the willingness of ethnic and racial minoritized SGM people to donate biospecimens. Numerous White and multiracial individuals alluded to the history and ongoing abuse, maltreatment, and racist approaches used by researchers and healthcare professionals against Black and other minoritized ethnoracial communities in the United States. Eugenic programs, forced sterilization, medical experimentation, and the Tuskegee syphilis study were a few examples participants cited as contributing toward their hesitancy to provide biospecimens. Our study limitations highlight the importance of continuing these lines of inquiry and conducting more extensive investigations into concerns of underrepresented SGM people.

CONCLUSION

Our study indicates that most SGM people in this sample were willing to provide biospecimens for research. We found that SGM research participants have specific concerns about donating biospecimens. Researchers can use this information to create protocols that take SGM community concerns into account. Understanding how SGM groups have been marginalized and at times excluded, can help researchers better understand the concerns of SGM people and build rapport with SGM communities to increase SGM representation in biospecimen-based health research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Statement of Public Health Significance:

Health studies using biospecimens often have an underrepresentation of sexual and/or gender minority (SGM) people or lack measures to identify SGM participants, making it difficult to use data to advance SGM health knowledge. Little is known about the willingness and concerns of SGM people related to providing research biospecimens.

TABLE 1.

Attributes Characterizing the Five Mutually Exclusive Study Groups

Study group	**Current gender identity**	**Sex assigned at birth**	**Sexual orientation**
Cisgender sexual minority men	Man or within the gender binary on the masculine spectrum	Male	Self-identified with at least one sexual orientation that indicated they were a member of a sexual minority community
Cisgender sexual minority women	Woman or within the gender binary on the feminine spectrum	Female	Self-identified with at least one sexual orientation that indicated they were a member of a sexual minority community
Gender-expansive individuals	Genderqueer and/or another gender identity outside of a gender binary (eg, agender and nonbinary) or selected more than one option for their current gender identity not reflective of the same gender binary (eg, man and woman)	Any	Any
Transfeminine individuals[a]	Transgender woman, woman, or within the gender binary on the feminine spectrum	Male	Any
Transmasculine individuals[a]	Transgender man, man, or within the gender binary on the masculine spectrum	Female	Any

Note. Based on their self-reported current gender identity and sex assigned at birth, participants were categorized into five mutually exclusive study groups that were used to differentiate cisgender sexual minority participants from gender minority participants of all sexual orientations.

[a] Participants who indicated they were a transgender man or transgender woman but did not select sex assigned at birth were categorized into the respective transmasculine or transfeminine group.

TABLE 2.

Total Sample Characteristics by Sexual and Gender Minority Study Group ($N = 4{,}982$)

Variable	**Total quantitative sample** (**N = 4,982**) **n (%)**	**Cisgender sexual minority men** (**N = 1,376**) **n (%)**	**Cisgender sexual minority women** (**N = 1,770**) **n (%)**	**Gender-expansive individuals** (**N = 1,206**) **n (%)**	**Transfeminine individuals** (**N = 226**) **n (%)**	**Transmasculine individuals** (**N = 404**) **n (%)**	***P***
Personal characteristics							
Age, in years[a]	30.2 (24.7, 40.6)	38.3 (28.9, 54.1)	30.0 (24.8, 38.2)	26.8 (22.8, 32.7)	38.7 (28.6, 53.2)	27.6 (22.9, 35.4)	**< .0001**
Median (Q1, Q3) (range)	(18.0–90.9)	(18.0–90.4)	(18.0–90.9)	(18.0–76.2)	(18.3–73.8)	(18.0–78.0)	
Race/ethnicity[b]							
American Indian or Alaska Native	104 (2.5)	28 (2.0)	36 (2.0)	50 (4.2)	7 (3.1)	11 (2.7)	**.004**
Asian	208 (5.0)	65 (4.7)	79 (4.5)	68 (5.6)	4 (1.8)	17 (4.2)	.13
Black, African American, or African	129 (3.1)	45 (3.3)	54 (3.1)	41 (3.4)	3 (1.3)	17 (4.2)	.38
Hispanic, Latino, or Spanish	271 (6.4)	98 (7.1)	113 (6.4)	61 (5.1)	9 (4.0)	22 (5.5)	.13
Middle Eastern or North African	65 (1.6)	18 (1.3)	25 (1.4)	23 (1.9)	3 (1.3)	5 (1.2)	.73
Multiracial[c]	441 (10.5)	98 (7.1)	193 (10.9)	161 (13.4)	16 (7.1)	46 (11.4)	**< .0001**
Native Hawaiian or other Pacific Islander	22 (0.5)	4 (0.3)	8 (0.5)	9 (0.8)	1 (0.4)	0 (0)	.28
None of these fully describe me	74 (1.8)	13 (0.9)	34 (1.9)	32 (2.7)	8 (3.5)	6 (1.5)	**.007**
White	3,839 (91.3)	1,218 (88.5)	1,641 (92.7)	1,119 (92.8)	210 (92.9)	375 (92.8)	**< .0001**
Sex assigned at birth	4,206	1,376	1,770	1,201	224	402	**< .0001**
Female	2,681 (63.8)	0 (0)	1,770 (100.0)	1,035 (86.2)	3 (1.3)	401 (99.8)	
Male	1,519 (36.2)	1,376 (100.0)	0 (0)	166 (13.8)	221 (98.7)	1 (0.3)	
Intersex	4,200	1,375	1,768	1,202	226	404	**< .0001**
Yes	45 (1.1)	1 (0.1)	2 (0.1)	30 (2.5)	11 (4.9)	10 (2.5)	
Sexual orientation[b]		1,376	1,770	1,206	226	404	
Asexual	410 (9.8)	21 (1.5)	137 (7.7)	276 (22.9)	27 (12.0)	43 (10.6)	**< .0001**
Bisexual	1,175 (27.9)	145 (10.5)	707 (39.9)	400 (33.2)	52 (23.0)	115 (28.5)	**< .0001**
Gay	1,498 (35.6)	1,228 (89.2)	202 (11.4)	199 (16.5)	15 (6.6)	116 (28.7)	**< .0001**

Variable	Total quantitative sample (*N* = 4,982) *n* (%)	Cisgender sexual minority men (*N* = 1,376) *n* (%)	Cisgender sexual minority women (*N* = 1,770) *n* (%)	Gender-expansive individuals (*N* = 1,206) *n* (%)	Transfeminine individuals (*N* = 226) *n* (%)	Transmasculine individuals (*N* = 404) *n* (%)	*P*
Lesbian	934 (22.2)	0 (0)	807 (45.6)	189 (15.7)	102 (45.1)	2 (0.5)	**< .0001**
Pansexual	664 (15.8)	46 (3.3)	298 (16.8)	327 (27.1)	55 (24.3)	76 (18.8)	**< .0001**
Queer	1,595 (37.9)	149 (10.8)	677 (38.3)	871 (72.2)	52 (23.0)	194 (48.0)	**< .0001**
Questioning	105 (2.5)	16 (1.2)	39 (2.2)	44 (3.7)	18 (8.0)	15 (3.7)	**< .0001**
Same-gender loving	195 (4.6)	44 (3.2)	69 (3.9)	92 (7.6)	17 (7.5)	22 (5.5)	**< .0001**
Straight/heterosexual	78 (1.9)	5 (0.4)	8 (0.5)	8 (0.7)	16 (7.1)	56 (13.9)	**< .0001**
Another sexual orientation	142 (3.4)	11 (0.8)	39 (2.2)	106 (8.8)	12 (5.3)	11 (2.7)	**< .0001**
More than one sexual orientation	1,648 (39.2)	201 (14.6)	797 (45.0)	770 (63.9)	79 (35.0)	165 (40.8)	**< .0001**
Socioeconomic position							
Annual individual income	3,997	1,307	1,666	1,158	218	390	**< .0001**
$0–$20,000	1,478 (37.0)	276 (21.2)	586 (35.2)	623 (53.8)	80 (36.7)	201 (51.5)	
$20,001–$50,000	1,198 (30.0)	376 (28.8)	522 (31.3)	343 (29.6)	57 (26.2)	114 (29.2)	
$50,001+	1,321 (33.1)	655 (50.1)	558 (33.5)	192 (16.6)	81 (37.2)	75 (19.2)	
Education	4,075	1,331	1,703	1,177	224	397	**< .0001**
No high school diploma	26 (0.7)	2 (0.2)	5 (0.3)	12 (1.0)	2 (0.9)	9 (2.3)	
High school/GED graduate or some college[d]	963 (23.6)	228 (17.1)	303 (17.8)	384 (32.6)	72 (32.1)	135 (34.0)	
College degree (two or four y)	1,587 (38.9)	522 (39.2)	673 (39.5)	473 (40.2)	96 (42.9)	150 (37.8)	
Graduate degree[e]	1,499 (36.8)	579 (43.5)	722 (42.4)	308 (26.2)	54 (24.1)	103 (25.9)	
Provided response to an open-ended question about biospecimen collection							.014
Yes	776 (18.5)	218 (15.8)	279 (15.8)	234 (19.4)	50 (22.1)	72 (17.8)	

Note. The number of participants in a study group with data available (*n*) and percent (%) of *n* reported for each variable. Bold *P* values indicate statistical significance at the .01 level.

Abbreviations: GED = graduate equivalency degree; Q1 = quartile 1 or 25th percentile; Q3 = quartile 2 or 75th percentile.

[a] *P* value based on the Kruskal-Wallis test.

[b] These categories are not mutually exclusive as participants could have selected more than one option.

[c] Multiracial = describes those participants who endorsed multiple races/ethnicities.

[d] Also includes participants with trade, technical, or vocational training.

[e] Graduate degree = Master's, doctoral, or professional (eg, MD, JD, and MBA) degrees.

TABLE 3.

Willingness to Provide Research Biospecimens by Sexual and Gender Minority Study Group ($N = 4{,}982$)

Biospecimen type	ALL SGM individuals (*N* = 4,982) *n* (%)	Cisgender sexual minority men (*N* = 1,376) *n* (%)	Cisgender sexual minority women (*N* = 1,770) *n* (%)	Gender expansive individuals (*N* = 1,206) *n* (%)	Transfeminine individuals (*N* = 226) *n* (%)	Transmasculine individuals (*N* = 404) *n* (%)	*P*
Blood	4,024	1,151	1,428	936	178	331	**< .0001**
Yes	2,470 (61.4)	861 (74.8)	771 (54.0)	536 (57.3)	102 (57.3)	200 (60.4)	
Buccal swab	4,249	1,218	1,494	1,007	185	345	**< .0001**
Yes	3,301 (77.7)	1,045 (85.8)	1,105 (74.0)	762 (75.7)	124 (67.0)	265 (76.8)	
Hair	4,268	1,222	1,503	1,003	189	351	**< .0001**
Yes	3,299 (77.3)	1,035 (84.7)	1,101 (73.3)	767 (76.5)	128 (67.7)	268 (76.4)	
Saliva	4,267	1,225	1,497	1,004	188	353	**< .0001**
Yes	3,347 (78.4)	1,064 (86.9)	1,117 (74.6)	767 (76.4)	130 (69.2)	269 (76.2)	
Urine	4,236	1,216	1,496	988	191	345	**< .0001**
Yes	2,944 (69.5)	1,018 (83.7)	935 (62.5)	634 (64.2)	121 (63.4)	236 (68.4)	

Note. The number of participants in a study group with data available (n) and percent (%) of n reported for each variable. Bold *P* values indicate statistical significance at the .01 level for comparisons across sexual and gender minority subgroups.

Abbreviation: SGM = sexual and/or gender minority.

TABLE 4.

Logistic Regression Modeling of SGM Adult Willingness to Provide Research Biospecimens ($N = 4{,}982$)

Demographic characteristic	Blood ($N = 3{,}831$) aOR (99% CI)	Buccal swab ($N = 4{,}046$) aOR (99% CI)	Hair ($N = 4{,}062$) aOR (99% CI)	Saliva ($N = 4{,}061$) aOR (99% CI)	Urine ($N = 4{,}029$) aOR (99% CI)
Age, in years	1.02 (1.01, 1.03)*	1.01 (1.00, 1.02)	1.01 (1.00, 1.02)*	1.01 (1.00, 1.02)*	1.02 (1.01, 1.03)*
Race/ethnicity^{a}					
American Indian or Alaska Native	1.08 (0.47, 2.47)	0.72 (0.30, 1.74)	0.75 (0.32, 1.77)	0.71 (0.29, 1.72)	0.88 (0.38, 2.03)
Asian	0.91 (0.40, 2.06)	1.05 (0.43, 2.53)	0.99 (0.42, 2.32)	0.99 (0.41, 2.37)	0.90 (0.39, 2.07)
Black, African American, or African	1.06 (0.46, 2.43)	1.11 (0.45, 2.76)	0.65 (0.28, 1.52)	0.82 (0.34, 1.97)	1.00 (0.42, 2.34)
Hispanic, Latino, or Spanish	1.24 (0.56, 2.73)	1.16 (0.49, 2.72)	1.06 (0.47, 2.41)	1.36 (0.58, 3.19)	1.10 (0.49, 2.47)
Middle Eastern or North African	0.94 (0.36, 2.42)	0.81 (0.30, 2.20)	0.63 (0.24, 1.66)	0.76 (0.28, 2.08)	0.87 (0.33, 2.26)
Multiracial Native	1.19 (0.52, 2.76)	1.06 (0.43, 2.60)	1.21 (0.51, 2.89)	1.01 (0.41, 2.48)	1.11 (0.47, 2.61)
Hawaiian or other Pacific Islander	0.60 (0.14, 2.56)	0.52 (0.11, 2.37)	0.37 (0.09, 1.61)	0.59 (0.14, 2.64)	1.07 (0.24, 4.75)
None of these fully describe me	0.90 (0.35, 2.29)	0.85 (0.32, 2.28)	0.87 (0.33, 2.31)	0.92 (0.34, 2.49)	0.68 (0.26, 1.74)
White	1.07 (0.65, 1.29)	1.18 (0.52, 2.70)	1.02 (0.46, 2.26)	1.23 (0.54, 2.81)	0.99 (0.45, 2.17)
Gender identity					
Cisgender men	Ref	Ref	Ref	Ref	Ref
Cisgender women	0.47 (0.32, 0.68)*	0.60 (0.39, 0.90)*	0.60 (0.44, 0.82)*	0.54 (0.36, 0.83)*	0.42 (0.19, 0.57)*
Gender-expansive	0.60 (0.42, 0.87)*	0.68 (0.45, 1.05)	0.77 (0.56, 1.06)	0.64 (0.41, 0.99)*	0.51 (0.38, 0.68)*
Transfeminine	0.53 (0.31, 0.89)*	0.43 (0.24, 0.76)*	0.43 (0.28, 0.67)*	0.41 (0.23, 0.74)*	0.42 (0.28, 0.63)*
Transmasculine	0.74 (0.49, 1.11)	0.69 (0.43, 1.11)	0.75 (0.52, 1.06)	0.62 (0.38, 0.99)*	0.59 (0.43, 0.83)*
Sexual orientation^{a}					
Asexual	0.92 (0.65, 1.29)	0.83 (0.57, 1.21)	0.90 (0.62, 1.31)	0.80 (0.55, 1.17)	0.76 (0.54, 1.07)
Bisexual	0.91 (0.69, 1.20)	0.98 (0.72, 1.34)	0.93 (0.68, 1.26)	0.96 (0.70, 1.32)	0.90 (0.68, 1.20)
Gay	1.15 (0.84, 1.57)	1.22 (0.86, 1.76)	1.12 (0.79, 1.59)	1.20 (0.84, 1.72)	1.22 (0.88, 1.69)
Lesbian	1.07 (0.79, 1.46)	0.90 (0.64, 1.27)	0.96 (0.68, 1.35)	0.97 (0.68, 1.37)	0.97 (0.71, 1.33)
Pansexual	1.37 (1.02, 1.84)*	1.51 (1.07, 2.13)*	1.34 (0.96, 1.88)	1.51 (1.07, 2.14)*	1.50 (1.10, 2.04)*
Queer	0.98 (0.73, 1.31)	0.93 (0.66, 1.30)	0.90 (0.65, 1.26)	0.92 (0.65, 1.28)	1.04 (0.77, 1.40)
Questioning	0.77 (0.44, 1.35)	0.88 (0.46, 1.65)	1.05 (0.55, 2.00)	0.84 (0.45, 1.56)	0.93 (0.52, 1.65)
Same-gender loving	1.03 (0.66, 1.59)	0.93 (0.57, 1.50)	0.92 (0.57, 1.49)	0.93 (0.58, 1.52)	0.99 (0.63, 1.55)

Demographic characteristic	**Blood (N = 3,831)** **aOR (99% CI)**	**Buccal swab (N = 4,046)** **aOR (99% CI)**	**Hair (N = 4,062)** **aOR (99% CI)**	**Saliva (N = 4,061)** **aOR (99% CI)**	**Urine (N = 4,029)** **aOR (99% CI)**
Straight/heterosexual	1.13 (0.56, 2.30)	1.96 (0.81, 4.76)	1.49 (0.65, 3.46)	1.59 (0.68, 3.70)	1.51 (0.70, 3.24)
Another sexual orientation	1.23 (0.75, 2.01)	1.18 (0.67, 2.06)	1.26 (0.72, 2.24)	1.46 (0.80, 2.66)	1.35 (0.80, 2.30)
More than one sexual orientation	1.06 (0.75, 1.50)	1.18 (0.79, 1.75)	1.11 (0.75, 1.65)	1.11 (0.75, 1.66)	1.01 (0.70, 1.44)
Annual individual income					
$0-$20,000	Ref	Ref	Ref	Ref	Ref
$20,001-$50,000	1.36 (1.08, 1.71)*	1.36 (1.05, 1.78)*	1.21 (0.93, 1.57)	1.44 (1.10, 1.89)*	1.48 (1.16, 1.89)*
$50,001+	1.23 (0.95, 1.59)	1.22 (0.91, 1.63)	1.12 (0.83, 1.49)	1.11 (0.83, 1.49)	1.23 (0.94, 1.61)
Education					
No high school diploma	0.52 (0.17, 1.56)	0.45 (0.15, 1.35)	0.49 (0.16, 1.49)	0.44 (0.15, 1.30)	0.44 (0.15, 1.31)
High school/GED graduate or some college	0.83 (0.66, 1.06)	0.94 (0.72, 1.23)	0.84 (0.65, 1.10)	0.93 (0.71, 1.22)	0.86 (0.67, 1.11)
College degree (two or four y)	Ref	Ref	Ref	Ref	Ref
Graduate degree	0.98 (0.79, 1.22)	1.00 (0.78, 1.28)	0.99 (0.77, 1.26)	1.04 (0.81, 1.34)	1.00 (0.79, 1.26)

Note. Demographic reference categories were based on the largest number of SGM participants. Cisgender men were used as reference categories for gender identity because the majority of NIH-funded research on SGM topics has focused on the health of cisgender sexual minority men.

[*] $P < 0.01$.

Abbreviations: aOR = adjusted odds ratio; GED = graduate equivalency degree; NIH = National Institutes of Health; SGM = sexual and/or gender minority.

[a] Not mutually exclusive categories.

TABLE 5.

Thematic Analysis Sample Characteristics by Sexual and Gender Minority Study Group ($N = 776$)

Variable	Total qualitative sample (*N* = 776) *n* (%)	Cisgender sexual minority men (*N* = 181) *n* (%)	Cisgender sexual minority women (*N* = 264) *n* (%)	Gender-expansive individuals (*N* = 223) *n* (%)	Transfeminine individuals (*N* = 42) *n* (%)	Transmasculine Individuals (*N* = 66) *n* (%)	*P*
Personal characteristics							
Age, in years[a] Median (Q1, Q3) (range)	32.7 (25.8, 43.9) (18.0–81.9)	43.7 (31.2, 57.1) (18.2–81.9)	32.9 (25.7, 42.6) (18.3–75.9)	28.6 (24.3, 33.6) (18.0–66.8)	38.5 (31.2, 57.0) (22.5–70.1)	30.3 (25.8, 40.3) (18.8–59.4)	**< .0001**
Race/ethnicity[b]	776	181	264	223	42	66	
American Indian or Alaska Native	28 (3.6)	8 (4.4)	6 (2.3)	9 (4.0)	1 (2.4)	4 (6.1)	.54
Asian	25 (3.2)	8 (4.4)	8 (3.0)	5 (2.2)	1 (2.4)	3 (4.6)	.73
Black, African American, or African	31 (4.0)	12 (6.6)	6 (2.3)	9 (4.0)	1 (2.4)	3 (4.6)	.23
Hispanic, Latino, or Spanish	32 (4.1)	7 (3.9)	14 (5.3)	7 (3.1)	1 (2.4)	3 (4.6)	.76
Middle Eastern or North African	9 (1.2)	2 (1.1)	3 (1.1)	3 (1.4)	0 (0)	1.5	.96
Multiracial[c]	73 (9.4)	16 (8.8)	22 (8.3)	22 (9.9)	2 (4.8)	11 (16.7)	.23
Native Hawaiian or other Pacific Islander	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	
None of these fully describe me	19 (2.5)	2 (1.1)	4 (1.5)	7 (3.1)	3 (7.1)	3 (4.6)	.10
White	724 (93.3)	161 (89.0)	249 (94.3)	213 (95.5)	39 (92.9)	62 (93.9)	.10
Sex assigned at birth	776	181	264	221	42	65	**< .0001**
Female	528 (68.3)	0 (0)	264 (100.0)	197 (89.1)	2 (4.8)	65 (100.0)	
Male	245 (31.7)	181 (100.0)	0 (0)	24 (10.9)	40 (95.2)	0 (0)	
Intersex	775	207	283	187	44	57	.25
Yes	9 (1.2)	0 (0)	2 (0.8)	5 (2.3)	1 (2.4)	1 (1.5)	
Sexual orientation[b]	776	181	264	223	42	66	
Asexual	94 (12.1)	3 (1–7)	24 (9.1)	57 (25.6)	5 (11.9)	5 (7.6)	**< .0001**
Bisexual	244 (31.4)	22 (12.2)	111 (42.1)	81 (36.3)	7 (16.7)	23 (34.9)	**< .0001**
Gay	262 (33.8)	163 (90.1)	30 (11.4)	39 (17.5)	5 (11.9)	25 (37.9)	**< .0001**
Lesbian	166 (21.4)	0 (0)	117 (44.3)	31 (13.9)	18 (42.9)	0 (0)	**< .0001**

Variable	Total qualitative sample (*N* = 776) *n* (%)	Cisgender sexual minority men (*N* = 181) *n* (%)	Cisgender sexual minority women (*N* = 264) *n* (%)	Gender-expansive individuals (*N* = 223) *n* (%)	Transfeminine individuals (*N* = 42) *n* (%)	Transmasculine Individuals (*N* = 66) *n* (%)	*P*
Pansexual	138 (17.8)	5 (2.8)	47 (17.8)	60 (26.9)	12 (28.6)	14 (21.2)	**< .0001**
Queer	348 (44.9)	24 (13.3)	105 (39.8)	169 (75.8)	15 (35.7)	35 (53.0)	**< .0001**
Questioning	27 (3.5)	3 (1.7)	5 (1.9)	13 (5.8)	4 (9.5)	2 (3.0)	.02
Same-gender loving	49 (6.3)	12 (6.6)	12 (4.6)	16 (7.2)	5 (11.9)	4 (6.1)	.42
Straight/heterosexual	15 (1.9)	1 (0.6)	2 (0.8)	1 (0.5)	3 (7.1)	8 (12.1)	**< .0001**
Another sexual orientation	37 (4.8)	1 (0.6)	4 (1.5)	23 (10.3)	4 (9.5)	5 (7.6)	**< .0001**
More than one sexual orientation	364 (46.9)	35 (19.3)	124 (47.0)	150 (67.3)	20 (47.6)	35 (53.0)	**< .0001**
Socioeconomic position							
Annual individual income	742	171	250	217	40	64	**< .0001**
$0–$20,000	288 (38.8)	42 (24.6)	89 (35.6)	116 (53.5)	16 (40.0)	25 (39.1)	
$20,001–$50,000	214 (28.8)	44 (25.7)	73 (29.2)	59 (27.2)	11 (27.5)	27 (42.2)	
$50,001+	240 (32.4)	85 (49.7)	88 (35.2)	42 (19.4)	13 (32.5)	12 (18.8)	
Education	757	175	256	220	41	65	**< .0001**
No high school diploma	4 (0.5)	0 (0)	1 (0.4)	1 (0.5)	1 (2.4)	1 (1.5)	
High school/GED graduate or some college[d]	159 (21.0)	34 (19.4)	35 (13.7)	60 (27.3)	15 (36.6)	15 (23.1)	
College degree (two or four y)	327 (43.2)	66 (37.7)	109 (42.6)	100 (45.5)	20 (48.8)	32 (49.2)	
Graduate degree[e]	267 (35.3)	75 (42.9)	111 (43.4)	59 (26.8)	5 (12.2)	17 (26.2)	

Note. The number of participants in a study group with data available (n) and percent (%) of n reported for each variable. Bold *P* values indicate statistical significance at the .01 level.

Abbreviations: GED = graduate equivalency degree; Q1 = Quartile 1 or 25th percentile; Q3 = Quartile 2 or 75th percentile.

[a] *P* value based on the Kruskal-Wallis test.

[b] These categories are not mutually exclusive as participants could have selected more than one option.

[c] Multiracial = describes those participants who endorsed multiple races/ethnicities.

[d] Also includes participants with trade, technical, or vocational training.

[e] Graduate degree = Master’s, doctoral, or professional (eg, MD, JD, and MBA) degrees.