



Sexual and Gender Minority Youth's Perspectives on Sharing De-identified Data in Sexual Health and HIV Prevention Research

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Abstract

Funding agencies encourage and sometimes require data sharing. However, there is limited empirical research on participant perspectives on sharing de-identified data from research on sensitive topics (e.g., HIV, sexual health) with other researchers, and virtually none from adolescents or sexual and gender minority (SGM) participants. SGM teens ($N = 197$) ages 14–17 completed an online survey with multiple-choice and open-ended items assessing perspectives toward sharing survey responses and blood samples from sexual health and HIV testing studies with other researchers. SGM youth were willing to share data but frequently cited confidentiality and privacy concerns, including fears about parents finding out about their identities even after de-identification was explained. Researchers need to ensure youth understand explanations of data security protections in order to make well-informed decisions about participating in research.

Keywords Data sharing · Adolescents · Participant perspectives · HIV prevention · Research ethics · Sexual orientation · Gender identity

Data sharing is the practice of making data collected from a previous study available for other researchers or members of the community to use. Data sharing provides opportunities to validate findings and to explore new research questions in a way that conserves funding and helps avoid duplication of efforts. Funders, such as the National Institutes of Health, increasingly encourage and sometimes require researchers to share de-identified data (National Institutes of Health 2003, 2018). De-identification is the removal of identifiable information (e.g., names, birth dates, street address) from responses and samples collected in research, and is a practice commonly used to protect participants' privacy and confidentiality when data are shared with other researchers or members of the community. Despite

increased attention among researchers on concerns about re-identification, de-identification remains a best practice to minimize risks to participants' privacy when sharing data (Meyer 2018), and a majority of institutional review boards (IRBs) do not require a review for researchers interested in sharing de-identified biological samples and data with other researchers at other institutions (Goldenberg et al. 2015). However, some participants, such as those from populations historically mistreated in research and/or who participate in health research on sensitive topics, may still be wary about the prospect of having their de-identified responses and samples shared with other investigators. This includes sexual and gender minority (SGM) adolescents, who have unique concerns about research participation related to their SGM identities and sexual health behaviors (Fisher et al. 2016, 2017; Macapagal et al. 2017; Mustanski et al. 2017) and whose voices have been underrepresented in health and ethics research (Fisher and Mustanski 2014; Mustanski 2011; Mustanski and Fisher 2016). Drawing on a framework for involving participants in the creation of ethical research practices (Fisher and Mustanski 2014), we sought to explore SGM youth's perspectives toward sharing de-identified data collected in sexual health and HIV prevention studies.

The majority of studies on participants' perspectives about data sharing focus on attitudes toward sharing blood samples or DNA data for genetic research due to the potentially

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identifiable nature of DNA data. Studies commonly cite two concerns. First, participants identify loss of privacy as a risk (e.g., if de-identified data are released and DNA data are traced back to them) (Oliver et al. 2012). Second, concern about the use of DNA data (e.g., unapproved use, genetic discrimination) is a reason for apprehension (Burststein et al. 2014; D. Kaufman et al. 2008; Kaufman et al. 2009; Lemke et al. 2010; Oliver et al. 2012), and participants may be less willing to share data if concerned about how it will be used (D. J. Kaufman et al. 2009; Lemke et al. 2010). One study surveyed adolescents about their perspectives on bio-banking their blood samples and similarly found that adolescents were willing to share their blood samples, but worried about privacy and wanted to know how other types of research studies would use their blood samples (Kong et al. 2016). Additional research is needed to obtain a better understanding of specific adolescent populations' attitudes toward sharing different types of behavioral data and biomedical samples within health and behavioral risk research.

Certain demographic and attitudinal factors may impact SGM youth's perspectives toward data sharing. For example, the history of exploitation and abuse involving SGM medical research participants has fostered mistrust toward research (Fisher et al. 2016; Hoyt et al. 2012), which may impact willingness to share data among SGM populations. In studies with non-SGM populations, trust and credibility were identified as important factors with regard to willingness to share data (Lemke et al. 2010; Manhas et al. 2016). In addition, among participants with greater trust in researchers, the potential benefits or utility of data sharing outweighed privacy risks, which influenced data sharing decisions (Oliver et al. 2012). Similarly, participants of color have been historically mistreated in research (Corbie-Smith et al. 1999; Freimuth et al. 2001; Hoyt et al. 2012), generating research mistrust among adult and adolescent populations (Fisher 2010; Fisher et al. 2008; Fisher and Wallace 2000), which may similarly affect data sharing perspectives among SGM youth of color. For example, in some studies, when compared to participants of color, non-Hispanic White participants were more likely to pick less restrictive data sharing options and consent to share their own DNA data or samples (Kaufman et al. 2009; McGuire et al. 2011). In another study, adolescent and parents from diverse ethnic backgrounds were uneasy with the potential future misuse by other researchers or policymakers of genetic data related to adolescent risk (Fisher and Wallace 2000). It is possible that factors such as research trust and credibility and demographic characteristics like race and ethnicity would impact SGM participants' perspectives toward data sharing as well.

SGM adolescents participating in sexual health survey research or biomedical HIV surveillance or prevention research may have additional concerns about privacy and

confidentiality related to how their data will be used. Privacy and confidentiality concerns may be heightened for SGM youth participating in behavioral or biomedical studies on sensitive topics such as sexual behavior or HIV (DiClemente et al. 2010; Fisher et al. 2016; Fisher et al. 2018), which may impact their willingness to participate in studies where sharing de-identified survey responses or blood samples is required. Even though sharing de-identified data may be generally perceived as low risk by the researchers and IRBs, it might not be perceived in the same way by SGM youth who may or may not understand the protections in place to mitigate privacy and confidentiality breaches. Furthermore, SGM youth may be concerned about sharing data on sensitive topics with other researchers if they are worried about the prospect of research findings misrepresenting the SGM community at large (Gonsiorek 1991; Herek 1998), and if consent forms only specify the types of future studies de-identified data may be used for, participants cannot personally verify the motives or credibility of researchers who may have access to their de-identified data (Fisher and Layman 2018). Other situational factors relevant to SGM youth's perspectives about the privacy and confidentiality of data sharing are worth exploring, such as not being out to one's parents about their sexual orientation or gender identity, and concern that disclosure of stigmatized behaviors, such as same-sex sexual behavior or high-risk sexual behavior, might lead to negative repercussions like rejection or emotional and physical abuse (Fisher et al. 2016; Fisher et al. 2017; Macapagal et al. 2017; Mustanski et al. 2017). Together, factors such as SGM identity, race and ethnicity, and engagement in potentially stigmatized or risky behaviors may influence SGM youth's perceptions and concerns about data sharing.

Although research on sexual health and HIV prevention in SGM minor adolescents has increased in recent years (Mustanski et al. 2011; Rhodes and Wong 2016), SGM adolescent participants' perspectives on sharing de-identified data from these studies have not been examined. Shedding light on this topic can inform researchers' and IRBs' decision-making around data sharing practices in sexual health and HIV prevention research with SGM adolescent participants, including how to best communicate with adolescents about the parameters of data sharing. This paper explored SGM youth's perspectives on sharing de-identified survey responses from sexual health studies and blood samples from HIV testing studies and youth's recommendations to help protect adolescent participants when these data are shared with other researchers. We also examined whether attitudes toward sharing de-identified data from sexual health and HIV testing studies differed by (1) socio-demographic characteristics, (2) sexual behavior and engagement in HIV risk behavior, and (3) attitudes toward research and researchers.

Method

Participants and Recruitment

As part of a larger study (Fisher et al. 2016; Macapagal et al. 2017; Mustanski et al. 2017) SGM youth were recruited to complete an online survey on ethical issues in adolescent sexual health and HIV prevention research. Eligibility criteria for the larger study included (1) ages 14–17 years; (2) sexual minority (e.g., lesbian, gay, bisexual, queer, questioning) and/or gender minority (e.g., transgender or gender non-conforming) identity; (3) romantic/sexual interest in cisgender males; (4) residence in the USA; (5) ability to read English at an 8th grade level; and (6) HIV negative or never tested for HIV. All procedures were approved by the Northwestern University and Fordham University Institutional Review Boards. A waiver of parental permission was granted in accordance with 45 CFR 46.116(c) and (d), as it was not a reasonable requirement to protect the participants, the research could not practicably be carried out without a waiver, and study procedures were determined to be no more than minimal risk (Department of Health and Human Services 2009). A Certificate of Confidentiality from the National Institutes of Health was issued to protect the identities of participants in the event of subpoenas requesting identifiable study data.

SGM youth were recruited through paid advertisements on Facebook from September to October 2016. Advertisements targeted adolescents whose Facebook profile indicated they were romantically interested in people of the same or multiple genders and/or listed interests that were expected to be relevant to SGM youth. Clicking on the advertisement linked to an online eligibility screener. Eligible participants were presented with an online consent form with the option to download a PDF version. After agreeing to the study, participants were automatically directed to the survey. Participants who completed the survey and whose data passed the study's validation protocol received a \$30 electronic Visa gift card.

Measures

Demographics Participants reported their age, race, ethnicity, assigned sex at birth, current gender identity, and sexual orientation. Participants reported disclosure of their SGM identity to parents on three levels: out to all parent(s), out to only one parent, not out. For analytic purposes, we dichotomized disclosure of SGM identity (0 = “not out,” 1 = “out to at least one parent”).

Sexual Behavior and Substance Use Before Sexual Contact

Participants reported a number of lifetime vaginal and anal sex partners of any gender. Due to low endorsement of multiple sexual partners, we dichotomized responses into a measure of sexual experience (0 = “never engaged in vaginal or anal

sex,” 1 = “engaged in vaginal or anal sex”). Parental knowledge of participants' sexual history was assessed via a single item: “Do your parents/guardians know that you have had sex before?” Responses were dichotomized into 0 = “no/unsure” and 1 = “yes.” Participants reported how often in the past 12 months they engaged in alcohol or drug use before sexual contact (1 = never, 2 = sometimes, 3 = about half the time, 4 = most of the time, 5 = always).

Comfort with HIV Research Procedures Participants' comfort with procedures used in HIV and sexual health studies was measured with a 14-item scale informed by previous work (Macapagal et al. 2017; Petrie et al. 2013). Items assess comfort with sexual health and HIV research study procedures such as, “Having your finger pricked to test your blood for HIV” and “Talking to a researcher about your sexual behaviors.” Participants rated items on a 7-point Likert scale (1 = “extremely uncomfortable,” 7 = “extremely comfortable”) and responses were averaged to create a composite score ($\alpha = .90$).

Attitudes Toward Sexual Health Survey Three closed-ended items created by the study team and adapted from Fisher (2003) assessed whether the results of the current survey might increase prejudice against lesbian, bisexual, transgender, and queer (LGBTQ) teens; whether answering questions on the survey about sexual behaviors, sexual orientation, and gender identity felt like an invasion of privacy; and satisfaction derived from helping other SGM youth by participating in research (e.g., “I feel good about contributing to research that might help other LGBTQ teens”); (1 = strongly disagree; 5 = strongly agree). These three items were analyzed separately.

Trust in Researchers A six-item composite score was used to measure participants' trust in researchers. Four statements about researchers' integrity and process were adapted from Hall et al. (2006) and two additional items were created by the study team (“I trust the motives of the researchers conducting the study” and “I trust the researcher to keep my answers confidential”). Participants rated their agreement with each statement on a scale from 1 = “strongly disagree” to 5 = “strongly agree.” Negatively worded items were recoded so that higher ratings reflected more trust, and responses to all six items were averaged ($\alpha = .75$).

Data Sharing Eight items developed by the study team asked participants to share their thoughts about sharing survey responses and blood samples with other researchers (Table 1). These questions were preceded by a brief description about data sharing, why researchers might share data from surveys and blood samples with other researchers, and privacy and confidentiality protections when data are shared. Four closed-ended items assessed perceptions about the helpfulness

Table 1 Items assessing attitudes toward, concerns about, and recommendations for data sharing

A researcher is a person who uses science to understand different problems. After a study is over, researchers are often asked to share participants' responses on survey or interview questions so that other researchers and even doctors can use this information to do more research to help people. To protect your privacy, when responses are shared, information that can identify you, like your name or date of birth, is NOT included. In this study, we are not sharing any information that can identify you with other researchers. We are interested in what you think about sharing results in studies on LGBTQ teens.

1. As long as your identity was protected, do you think it would be helpful to share your responses to an LGBTQ sexual health survey with other researchers?^a
2. What concerns would you have if your survey responses were shared with other researchers?
3. If researchers shared your survey responses with other researchers, what would you want the researchers to do in order to protect you?
4. As long as your identity was protected, would you agree to sign a form agreeing to let the researcher share your responses to an LGBTQ sexual health survey with other researchers?^a

Now imagine you were participating in an HIV testing study where the researchers took a sample of your blood. The blood would be used for medical research trying to understand why some people are at higher risk for HIV or why some people get sick more quickly if they are HIV positive.

1. As long as your identity was protected, do you think it would be helpful to share your blood sample with other researchers?^a
2. What concerns would you have if your blood sample was shared with other researchers?
3. If researchers shared your blood sample with other researchers, what would you want the researchers to do in order to protect you?
4. As long as your identity was protected, would you agree to sign a form agreeing to let the researcher share your blood sample with other researchers?^a

^a Items scored on a scale of 1–5 (1 = definitely not; 5 = definitely yes), all other items were open-ended ($N = 197$)

of and willingness to share survey responses and blood samples (1 = definitely not; 5 = definitely yes). Cronbach's α for these items was .78. Participants were also asked four open-ended questions on concerns about and recommendations for sharing survey responses and blood samples with other researchers. Data are available on request from the corresponding author.

Data Analysis

Descriptive statistics were computed for all variables. A simple linear regression was calculated to examine associations between race/ethnicity and perceived helpfulness of and willingness to share data. Mann-Whitney tests were used to identify other group differences in socio-demographic characteristics (e.g., assigned sex at birth, gender identity, outness), and sexual experiences (e.g., previous anal or vaginal sex, and parental knowledge of the respondent having sex) in

responses to closed-ended data sharing items. Spearman's correlations were used to look for relationships between responses to closed-ended data sharing items and age, frequency of alcohol or drug use, attitudes toward sexual health research, and trust in researchers. Significant correlates were entered into multiple linear regressions to examine the impact of socio-demographic, experiential, and attitudinal variables on participants' willingness to share data and perceived helpfulness of sharing data.

Responses to open-ended items were imported into Dedoose and data were analyzed thematically (Braun and Clarke 2006). Four root codes reflecting each open-ended item were applied to each transcript: *Concerns about sharing survey responses*, *Concerns about sharing blood samples*, *Recommendations for sharing survey responses*, and *Recommendations for sharing blood samples*. Next, we performed open coding to identify themes within responses to each open-ended item. One coder reviewed the excerpts, generated a list of potential themes, and noted any significant patterns of topics in the data. A second coder then reviewed and identified additional emergent themes. These codes were refined via comparison, discussion, and consensus. The codes were applied to the excerpts, and coders continued to iteratively refine codes and definitions. The second coder performed a series of reliability tests on a subset of the excerpts from each code. The pooled Kappas were 0.95 for survey response sharing concerns (12 excerpts), 1.00 for blood sample sharing concerns (18 excerpts), 1.00 for survey response sharing recommendations (15 excerpts), and 0.86 for blood sample sharing recommendations (21 excerpts), indicating excellent inter-coder reliability (Braun and Clarke 2006).

Results

Sample Characteristics

The analytic sample (Table 2) included 197 participants (M age = 16.5 years, SD = 1.01). A majority (60.4%) were assigned female at birth and 64.0% identified as youth of color. Most participants identified as cisgender, with 33% identifying as transgender, genderqueer, or gender non-conforming. Bisexual youth (38.1%) and gay youth (27.4%) made up the largest sexual orientation groups. Most (73.1%) were out to at least one parent or guardian about their sexual orientation or gender identity. A majority of participants (58.4%) had never had anal or vaginal sex. Only 14.2% of participants believed that their parents/guardians were aware that they were sexually active. A majority had not used alcohol (50.8%) or drugs (51.3%) before sexual contact in the past 12 months.

Table 2 also shows descriptive statistics for items assessing attitudes toward research, trust in researchers, and perspectives on data sharing. Participants had positive attitudes

Table 2 Sample characteristics ($N = 197$) and descriptive statistics for trust in researchers, attitudes toward research, and perspectives on data sharing

Variable	n (%)	
Birth-assigned sex		
Male	78 (39.6)	
Female	119 (60.4)	
Gender identity		
Man	67 (34.0)	
Woman	67 (34.0)	
Transgender man (FTM)	21 (10.7)	
Transgender woman (MTF)	1 (0.5)	
Genderqueer/gender non-conforming	41 (20.8)	
Race		
White	103 (52.3)	
Black or African American	18 (9.1)	
Asian	20 (10.2)	
Multiracial/Other	49 (24.8)	
Prefer not to answer	7 (3.6)	
Ethnicity		
Hispanic/Latino	64 (32.5)	
Not Hispanic/Latino	132 (67.0)	
Prefer not to answer	1 (0.5)	
Sexual orientation		
Gay/lesbian	63 (32.0)	
Bisexual	75 (38.1)	
Pansexual	34 (17.3)	
Queer/questioning	13 (6.6)	
Other	11 (5.6)	
Prefer not to answer	1 (0.5)	
Outness		
Not out	52 (26.4)	
Out	144 (73.1)	
Prefer not to answer	1 (0.5)	
Ever had anal or vaginal sex		
Yes	82 (41.6)	
No	115 (58.4) ^a	
Parental knowledge of respondent having sex		
Yes	28 (14.2)	
No/unsure	69 (35.0)	
Not applicable, never had sex before	100 (50.8) ^a	
	M (SD)	<i>Range</i>
Frequency of use before sex in past 12 months		
Alcohol use	1.20 (0.46)	1.0–3.0
Drug use	1.23 (0.56)	1.0–4.0
Trust in researchers	3.80 (0.60)	2.0–5.0
Attitudes toward research		
Comfort with sexual health/HIV research procedures ^b	4.59 (1.07)	2.3–6.9
Feels good contributing to research that may help other LGBTQ teens	4.82 (0.48)	1.0–5.0
Survey results may increase prejudice against LGBTQ teens	2.04 (1.02)	1.0–5.0
Sexual behavior and SGM identity questions an invasion of privacy	1.68 (0.87)	1.0–5.0
Perspectives on data sharing		
Helpfulness of sharing survey responses	4.49 (0.76)	1.0–5.0
Willingness to share survey responses	4.50 (0.71)	1.0–5.0
Helpfulness of sharing blood samples	3.85 (1.23)	1.0–5.0
Willingness to share blood samples	3.76 (1.29)	1.0–5.0

^a We did not define “having sex” in the item assessing parental knowledge of respondent having sex which likely accounts for the discrepancy between these two numbers. ^b Items scored on a scale of 1–7, all other items with means given scored on a scale of 1–5

toward sexual health research in general with most agreeing that it felt good to help other LGBTQ teens by participating in research (98.5%) and only a few endorsing beliefs that the current survey’s results would create prejudice against LGBTQ teens (7.1%) or thoughts that answering questions about sexual behavior and SGM identity felt like an invasion

of privacy (2.5%). Mean scores indicated general trust in researchers and comfort with sexual health and HIV research procedures. Regarding perspectives on data sharing, the vast majority of participants were willing (92.9%) to share survey responses and thought it would be helpful (89.8%) to do so. Fewer (though still a majority of) participants were willing

(68.0%) to share blood samples with other researchers and thought it would be helpful (69.1%) to do so.

Quantitative Analyses

Among outcomes of interest, the only demographic differences were greater perceived helpfulness of sharing blood samples was associated with older age (Table 3), Asian race ($\beta = 0.208, p < .01$), and other non-White races/ethnicities ($\beta = 0.201, p < .01$). Asian race was also associated with greater perceived helpfulness of ($\beta = 0.171, p < .05$) and willingness to share survey responses ($\beta = 0.160, p < .05$). There were no significant associations between assigned sex at birth or gender identity and data sharing items.

Table 3 shows results of Spearman's correlations; results of Mann-Whitney tests are reported in the text. Regarding attitudinal associations (Table 3), greater perceived helpfulness of sharing survey responses and blood samples was associated with higher trust in researchers, feeling good about helping other SGM teens by participating in research, and comfort with HIV research procedures. Those reporting greater trust in researchers, feeling good about helping other SGM teens by participating in research, and comfort with HIV research procedures were also significantly more willing to share survey responses and blood samples. Perceptions that survey results would increase prejudice toward LGBTQ teens and thoughts that questions on sexual behavior and SGM identity were an invasion of privacy were significantly associated with lower levels of perceived helpfulness of and willingness to share survey responses and blood samples (Table 3).

Regarding associations with sexual behavior, Mann-Whitney tests revealed that perceived helpfulness of sharing blood samples was higher for participants who ever had anal or vaginal sex (Mdn = 4.50) $U = 3837.0, p = .020$ and those were out to their parents about their SGM identity (Mdn = 4.00) $U = 3020.5, p = .031$ compared to their counterparts (Mdn = 4.00). Participants who ever had anal or vaginal sex were also more willing to share survey responses (Mdn = 5.00) $U = 3662.0, p = .002$ and blood samples (Mdn = 4.00) $U = 3797.0, p = .015$. There were no other significant associations between socio-demographic or sexual behavior and HIV risk variables and the closed-ended data sharing items.

Associations with Data Sharing Table 4 shows the results of multiple linear regressions examining socio-demographic characteristics, sexual experience, attitudes toward sexual health research, and trust in researcher associations with participants' perspectives on data sharing. Asian race and greater comfort with sexual health and HIV research procedures were significantly associated with perceived helpfulness of sharing survey responses and willingness to share survey responses. In addition, sexual experience and feeling good about helping other SGM teens by participating in research was associated with willingness to share survey responses.

Regarding the items about blood sample sharing, older age, Asian or Other race, sexual experience, greater comfort with sexual health research procedures, and feeling good about contributing to research was associated with greater perceived helpfulness of sharing blood samples. Black race and the feeling that answering questions about sexual behavior and SGM identity was an invasion of privacy was associated with lower

Table 3 Results of Spearman's correlations looking at relationships between demographic, attitudinal, and behavioral factors and data sharing items

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Age	–										
2. Alcohol use	– .011	–									
3. Drug use	– .029	.429***	–								
4. Trust in researchers	– .016	– .006	– .056	–							
5. Comfort with HIV research procedures	.048	– .037	– .070	.314***	–						
6. Feels good helping LGBTQ teens	.030	– .073	– .018	.311***	.238**	–					
7. Survey results increase LGBTQ prejudice	– .052	.024	– .068	– .353***	– .189*	– .214**	–				
8. Questions an invasion of privacy	.039	.063	.102	– .213**	– .261***	– .158*	.321***	–			
9. Helpful sharing survey responses	– .012	– .157	– .157	.225**	.299***	.258***	– .197**	– .145*	–		
10. Willing to share survey responses	.100	.041	.047	.243**	.363***	.337***	– .221**	– .166*	.497***	–	
11. Helpful sharing blood sample	.211**	.078	– .051	.292***	.401***	.203**	– .229**	– .191**	.344***	.462***	–
12. Willing to share blood sample	.129	.033	.071	.255***	.372***	.166*	– .249***	– .192**	.323***	.517***	.818***

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 4 Results of multiple linear regressions examining demographic, behavioral, comfort with research procedures, attitudes toward the sexual health survey, and trust in researcher associations with perceived helpfulness of and willingness to share survey responses and blood samples

Variable	Survey response sharing				Blood sample sharing			
	Helpfulness		Willingness		Helpfulness		Willingness	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
Age	.008	.917	.047	.483	.231	.000***	.103	.117
Race—Black	– .013	.869	– .127	.080	– .179	.007**	– .211	.003**
Race—Latino	.003	.969	.084	.276	.058	.406	.091	.230
Race—Asian	.197	.013*	.215	.003**	.241	.000***	.178	.012*
Race—Other	– .005	.949	– .001	.989	.139	.035*	.053	.457
Outness	.040	.595	.086	.203	.118	.056	.064	.335
Ever had anal or vaginal sex	– .073	.327	.154	.024*	.129	.038*	.174	.010*
Trust in researchers	.108	.195	.055	.468	.099	.151	.034	.647
Comfort with HIV research procedures	.217	.007**	.192	.009**	.207	.002**	.240	.001**
Feel good about helping LGBTQ teens	.123	.109	.284	.000***	.205	.001**	.121	.076
Survey results increase LGBTQ prejudice	– .053	.499	– .098	.168	– .118	.067	– .162	.021*
Questions an invasion of privacy	– .028	.721	– .071	.318	– .149	.021*	– .144	.039*

p* < .05, *p* < .01, ****p* < .001

perceived helpfulness of blood sample sharing. In addition, Black race, the feeling that answering questions about sexual behavior and SGM identity was an invasion of privacy, and the belief that the results of the survey could create prejudice against LGBTQ teens was associated with lower willingness to share blood samples, while Asian race, sexual experience, and greater comfort with sexual health research procedures was associated with greater willingness to share blood samples.

Qualitative Analysis

Concerns About Sharing De-identified Survey Responses and Blood Samples Numbers reported indicate how many excerpts relate to a given theme for each open-ended item. As the codes related to concerns about sharing survey responses and blood samples were very similar, they will be discussed together in the following sections unless otherwise specified. A subset of participants provided codeable responses to the open-ended items on concerns about data sharing (survey responses, *n* = 131; blood samples, *n* = 100). Responses that did not reference data sharing altogether were omitted and not coded (survey responses, *n* = 1; blood samples, *n* = 20); the majority of these responses referenced concerns about the blood draw procedure itself. Roughly a third of those who responded did not identify any concerns about researchers sharing their data (survey responses, *n* = 45; blood samples, *n* = 50) with other researchers. While most responses were brief (e.g., “no

concerns”), three highlighted reasons for their lack of concern, such as trust in researchers (e.g., “N/A. I trust researchers because this information is important to use”—Bisexual transgender man, 15, out), a desire to help the community (e.g., “Not [concerned about] one thing, I am a gay teenage boy. You can throw in my name if you wish, I just want to help my community”—Gay cisgender man, 17, out), and already being out about their SGM identity.

Confidentiality and Loss of Privacy A brief description of privacy protections preceded the questions (e.g., “To protect your privacy, when responses are shared, information that can identify you, like your name or date of birth, is NOT included”); however, the most frequently cited concern about sharing de-identified data (survey responses, *n* = 74; blood samples, *n* = 25) related to *confidentiality and loss of privacy*, which included references to how confidentiality would be maintained, protecting ones’ identity, and sharing or disclosing identifiable information (e.g., “I would just be concerned that personal information like my name, age, and place of residence would be shared”—Bisexual cisgender woman, 16, not out). In addition, questions specified that survey responses and blood samples would be shared with other researchers, but participants (survey responses, *n* = 10; blood samples, *n* = 5) mentioned consequences or fears about parents or family members having knowledge of participants getting an HIV test or finding out about their sexual activity or sexual or gender identity (e.g., “If it were not anon[ymous] I could be outed and that

would be dangerous”—Bisexual transgender man, 17, not out), as well as accessing their survey responses (e.g., “That my father would somehow find out what my answers were and get angry at me”—Asexual cisgender woman, 17, out) or HIV test results (e.g., “My parents would find out if I was positive.”—Gay cisgender man, 16, out). A few participants ($n = 4$) specifically cited the connection between ones’ blood and identity as a reason for concern (e.g., “Blood is identifiable ... I am not comfortable with having my genetic information available where I can’t control where it goes and whose hands it could fall into” - Bisexual genderqueer teen, 15, out).

Use of Survey Responses and Blood Samples Another concern for sharing blood samples related to the *use of data* (survey responses, $n = 14$; blood samples, $n = 21$). With regard to sharing survey responses, concerns about use included curiosity about how survey responses might be used by other researchers as well as fears that responses will be interpreted or used in negative ways if, for example, too little attention is paid to the credibility and cultural competency of the researchers with which they are shared. For example, one 15-year-old pansexual cisgender woman who was not out shared concerns about the misuse of survey responses by saying, “That they would use it as homophobic propaganda and say that queer people (particularly men) pose a health threat due to their higher risk for certain STIs”. Comments also reflected concern about receiving judgment from other researchers or individuals who may see their survey responses (e.g., “I don’t want to be judged for my identity”—Heterosexual transgender man, 16, out).

As for sharing blood samples, concerns related to use referenced curiosity about the purpose of sharing a blood sample, how other researchers might test the sample, and whether sharing their blood sample could harm themselves or others in the future (e.g., “I have heard of the possibility of using DNA for malicious purposes, such as insurance companies analyzing the DNA to look for preexisting health conditions. If my blood sample were to be shared, I would have concerns about such negative ethical effects”—Gay cisgender man, 17, not out). In addition, participants ($n = 8$) mentioned *general discomfort* with having their blood samples shared (e.g., “I’m not really sure, just feels strange”—Gay cisgender man, 17, out), but *general discomfort* did not emerge as a concern for sharing survey responses.

Recommendations for Sharing De-identified Survey Responses and Blood Samples A subset provided recommendations for protecting participants when sharing data with other researchers (survey responses, $n = 130$; blood samples, $n = 90$). Responses that did not provide recommendations were not coded (survey responses, $n = 11$; blood samples, $n = 22$). A subset of responses ($n = 6$) indicated that they would not

give blood in the first place due to discomfort with getting blood drawn and were also not coded. The vast majority of recommendations for sharing data (survey responses, $n = 122$; blood samples, $n = 76$) related to *protecting confidentiality* with most comments specifically mentioning the need to have names removed from any survey responses and blood samples to protect confidentiality. Other comments that pertained to protecting confidentiality referenced making sure researchers handled data carefully, restricted sharing data to the minimum amount of information necessary for future analysis, and did not disclose participants’ personal information to the public or to their parents.

Other recommendations related to *monitoring use of data* (survey responses $n = 6$; blood samples, $n = 10$) by ensuring that blood samples were used for the purpose agreed upon and survey responses were only shared with LGBTQ affirming researchers. Some participants asked researchers to obtain their *permission* and explain the purpose of and procedures for sharing data (survey responses, $n = 5$; blood samples, $n = 5$) in consent forms. A few ($n = 4$) recommended researchers not share blood samples at all and suggested alternatives such as “Only sharing lab results rather than the blood sample itself” (Gay cisgender man, 17, out).

Discussion

Sharing de-identified data on SGM adolescent sexual health with other investigators can further accelerate research on an understudied population at disproportionate risk for HIV and adverse sexual health outcomes and better understand the health needs and risks of this group. Moreover, as research on the health of SGM populations is rapidly increasing, understanding how data sharing may impact this historically marginalized population is critical. When asked about this issue, the vast majority of participants reported willingness to share de-identified survey responses, and although fewer, a majority were also willing to share de-identified blood samples with other researchers. When participants did express concern, the fear that their parents could gain access to information on sensitive topics such as HIV test results, sexual behavior, or their SGM identity was an emergent theme in our data despite our underscoring the anonymous, de-identified nature of the data. Moreover, certain demographic (e.g., age, race/ethnicity) and behavioral (e.g., sexual activity) characteristics were related to increased perceived helpfulness of sharing, as well as likelihood to share, de-identified survey responses or blood samples with other researchers.

Findings from our qualitative data suggest some similarities between the present study and past quantitative research on adolescents’ and adults’ attitudes and concerns about data sharing. Consistent with findings regarding adults’ and adolescents’ willingness to share DNA data or blood samples

(Burstein et al. 2014; Fisher and Layman 2018; Kong et al. 2016; McGuire et al. 2011), the majority of our participants were willing to share data, and a third of SGM youth who responded to the open-ended items reported no concerns with sharing de-identified survey responses and blood samples with other researchers. A few reasons why participants said they would not have concerns with data sharing involved their trust in researchers and their desire to help the SGM community.

When participants did raise concerns regarding sharing de-identified survey responses in qualitative responses, the most consistent theme was related to concerns about confidentiality and privacy loss even though we described the process of de-identifying data to protect their identity in the prompt preceding questions about sharing survey responses. There has been increased attention on the issue of re-identification of data sets (Meyer 2018), but youth did not explicitly mention other researchers re-identifying their survey responses as the reason for privacy and confidentiality concerns. In addition, although questions specified that survey responses and blood samples would be shared with other researchers, participants were concerned about parents or family members somehow finding out their answers to survey questions or about their study participation. It could be that SGM youth either wanted to reiterate the importance of de-identifying survey responses or did not understand what de-identification entailed, which is important to note as many consent forms include language about “de-identification.” Results indicate the need for future studies to assess youth’s understanding of information in consent forms, especially language around data security procedures, and how that might influence their reasoning around decisions to participate in research studies.

Loss of privacy and confidentiality were also frequently cited as concerns for sharing blood samples with other researchers. New federal regulations expected in January 2019 require specific consent (broad) for secondary use of “identifiable data,” but the definition of “identifiable” includes the term “potentially” identifiable, which recognizes that genomic technology is increasingly able to identify sources of biospecimens (Fisher and Layman 2018). Therefore, concerns regarding re-identification may be more reasonable for biospecimens. However, most participants did not explain their reason for concerns related to loss of privacy and confidentiality in responses to these items either, but a couple referenced the identifiable nature of blood or the connection between their identity and DNA in blood samples. It is also possible youth interpreted “as long as your identity was protected” to mean something other than de-identified in questions about sharing blood samples as the prompt directly preceding these items did not explicitly describe the process of removing identifiable information.

Quantitative analyses also revealed several significant demographic and behavioral associations with youth’s

willingness to and perceived helpfulness of data sharing. Age and sexual activity were associated with more positive attitudes toward data sharing. For example, participants who were older reported a greater perceived helpfulness of sharing blood samples. In addition, participants who ever had anal or vaginal sex reported a higher perceived helpfulness of sharing blood samples and were more willing to share survey responses and blood samples compared to their counterparts. As older participants were more educated, it is possible that they may have learned more about scientific research and can understand the broader benefits of data sharing. Moreover, it is plausible that sexually active youth perceive research on sexual health to be more helpful and personally relevant than those who are not sexually active. Perhaps, as a result of their sexual experience, they are more aware of the risk of STIs and HIV, which may be linked with greater eagerness to contribute to research that might help mitigate these risks.

Participant fear of survey results increasing prejudice toward SGM individuals was associated with a decreased likelihood to share blood samples. De Vries et al. (2016) found that while individuals were happy to share biospecimens for studies focused on disease, they were less likely to want to share biospecimens that would be used for studying the evolution of different ethnic groups, abortion, war, etc., which is consistent with SGM youth’s preference for sharing data with SGM-affirming investigators. Participants worried that their survey responses and blood samples may fall into the hands of researchers who seek to further exploit and/or stigmatize the SGM community and these fears are not unwarranted, as there is a long history of mistreatment of SGM individuals by researchers and medical professionals (Haldeman 1994; Hoyt et al. 2012). Further, the legacy of Tuskegee, associated with collection of blood samples among African Americans (Jones 1981) might also help explain why Black participants reported a significantly lower willingness to share blood samples and were also less likely to perceive sharing blood samples as helpful compared to non-Hispanic White participants, which was similar to the results of previous research (D. J. Kaufman et al. 2009; McGuire et al. 2011). Historically, the Black community has endured mistreatment and neglect at the hands of medical professionals (Corbie-Smith et al. 1999; Freimuth et al. 2001; Hoyt et al. 2012), which has led to low participation rates in medical research. In order to alleviate these concerns, Shavers et al. (2002) suggest that researchers be transparent about the mistreatment of minority participants in the past and explain in detail the protections they have put in place to ensure participants’ safety, as well as engage members of the community in the design of research projects.

Despite the meaningful contribution this study adds to the literature, it is not without limitations. First, we did not assess attitudes toward biomedical research (e.g., whether results of biomedical studies increase prejudice against SGM teens, whether biomedical study procedures feel like an invasion of

privacy, or satisfaction derived from helping other SGM youth by participating in biomedical research), as we only included items that assessed these attitudes toward the current survey study. In addition, as the questions were embedded in the context of a longer survey study, we only briefly introduced the concept of data sharing and obtained participants' initial reactions to sharing de-identified data. Thus, our questions did not necessarily elicit in-depth responses about data sharing. Black participants reported less favorable attitudes toward sharing blood samples, but we only collected data from a small number of Black participants. Future studies should explore attitudes toward data sharing and participation in research in more racially and ethnically diverse samples.

Our findings point to several recommendations for researchers and IRBs related to adolescent research protocols generally and those specific to SGM youth. First, we recommend that consent forms for studies with adolescent participants contain a more extensive explanation of what it means to de-identify data, and adolescents' understanding of data sharing should be assessed after reading the consent form. In addition, IRBs and researchers should ensure youth receive a clear explanation during the consent process of what information, if any, will be reported to parents/guardians in the context of data sharing to help alleviate potential concerns. Research staff should be knowledgeable about the plan for data sharing and be prepared to answer participant questions. As contributing to research that might help SGM youth was associated with perceived helpfulness of sharing blood samples and willingness to share survey data, consent forms for studies that anticipate sharing data for secondary analysis by other investigators should highlight the benefits of data sharing to SGM youth or how it will contribute to research for SGM youth, which may foster increased trust in the research team's motives.

Conclusion

Few studies have explored adolescents' perspectives on data sharing (Kong et al. 2016), and to our knowledge, this is the first study that has focused on SGM adolescents. Future research should explore whether participants are more concerned with certain information being shared than other types of sensitive information. For instance, is it more concerning to share information regarding drug and alcohol use than it is to share information about sexual orientation identity or sexual behaviors, or vice versa? Further, researchers should identify what additional protections, if any, are needed when sharing data on different types of potentially stigmatized identities or health issues, as these should be taken into consideration when creating data sharing plans. Finally, additional research should investigate whether SGM youth are able to understand information about data sharing in consent forms and identify ways

to improve the informed consent process so participants can make a well-informed decision about participation. Findings highlight the need to educate prospective youth participants about the process of de-identifying data as well as other protections put in place in the data sharing process in adolescent research studies. It is our hope that these data encourage increased transparency about data sharing practices between researchers and participants.

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