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ORIGINAL PAPER

“I Won’t Out Myself Just to Do a Survey”: Sexual and Gender Minority Adolescents’ Perspectives on the Risks and Benefits of Sex Research

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Abstract Sexual and gender minority (SGM) adolescents under age 18 are underrepresented in sexual health research. Exclusion of SGM minors from these studies has resulted in a lack of knowledge about the risks and benefits youth experience from sexual health research participation. Institutional Review Boards’ (IRB) overprotective stances toward research risks and requirements for guardian consent for SGM research are significant barriers to participation, though few have investigated SGM youth’s perspectives on these topics. This study aimed to empirically inform decisions about guardian consent for sexuality survey studies involving SGM youth. A total of 74 SGM youth aged 14–17 completed an online survey of sexual behavior and SGM identity, and a new measure that compared the discomfort of sexual health survey completion to everyday events and exemplars of minimal risk research (e.g., behavioral observation). Youth described survey benefits and drawbacks and perspectives on guardian permission during an online focus group. Participants felt about the same as or more comfortable completing the survey compared to other research procedures, and indicated that direct and indirect participation benefits outweighed concerns about privacy and emotional discomfort. Most would not have participated if guardian permission was required, citing negative parental attitudes about adolescent sexuality and SGM issues and not being “out” about their SGM identity. Findings suggest that sexual health survey studies meet minimal risk criteria, are appropriate for SGM youth, and that recruitment would not be possible without waivers of guardian consent. Decreasing barriers to research participation would dramatically improve our understanding of sexual health among SGM youth.

Keywords Sexual behavior · Sexual orientation · Adolescence · Research ethics · Parental consent

Introduction

Sexual and gender minority (SGM)[1] adolescents in the United States are at elevated risk for adverse sexual and reproductive health outcomes relative to their cisgender and heterosexual peers, including sexually transmitted infections (STIs) (CDC, 2015a), HIV (CDC, 2013, 2015b), and unplanned pregnancy (Lindley & Walsemann, 2015; Saewyc, Bearinger, Blum, & Resnick, 1999; Tornello, Riskind, & Patterson, 2014). Despite these health disparities, relative to heterosexual youth, SGM adolescents under age 18 are underrepresented in research surveying their sexual health, behavior, and experiences (Fisher & Mustanski, 2014; Mustanski, 2011). This is detrimental to our basic understanding of SGM youth’s sexual development and a barrier to designing sexual health education and interventions tailored for the unique needs of this population.

A significant barrier to SGM youth’s involvement in sexual health survey research is institutional review boards’ (IRBs) concern that the distress or discomfort caused by such questions may exceed the “minimal risk” standard—in other words, that asking questions about sexual behavior and experiences might cause more discomfort than ordinarily encountered in daily life

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[1] The terms “sexual and gender minority” and “SGM” are used here instead of “lesbian, gay, bisexual, and transgender” or “LGBT” to be more inclusive of other identities that fall outside the LGBT umbrella.

or in routine physical or psychological examinations (Department of Health and Human Services, 2009). Research on adult samples has indicated that ethics committee members overestimated the level of distress that participants may experience in sexual behavior surveys, while participants' perceived levels of distress were comparable to other common research procedures (e.g., health interviews) and lower than everyday events (e.g., waiting in traffic) (Petrie, Faasse, Notman, & O'Carroll, 2013). IRB overestimations of risk are due in large part to a lack of knowledge regarding the risks and benefits of SGM youth's participation in survey research on their sexual behavior and experiences. Without this information, IRBs must rely on subjective judgments when making decisions about SGM youth's involvement in sexual health research, which can lead to misestimations of the harms of answering questions about sexual behavior and experiences (Fisher, 1999; Fisher, Kornetsky, & Prentice, 2007; Institute of Medicine, 2011; Mustanski, 2011; National Human Research Protections Advisory Committee, 2001; Secretary's Advisory Committee for Human Research Protections, 2005). For example, one common concern is that answering such questions may cause youth undue psychological distress, though the limited available evidence suggests otherwise. To date, the lone study of SGM youth's experiences in survey research found that 90 % felt "comfortable" to "very comfortable" answering questions about sexual behaviors, experiences, and other sensitive topics (i.e., mental health and substance/alcohol use), and no more than 3 % were "very uncomfortable" (Mustanski, 2011). Similarly, a Dutch study that included, but did not explicitly focus on, SGM youth revealed that adolescents experienced low levels of distress after answering survey questions about their sexual behavior, that the distress was not significantly different from that felt by adult participants, and that adolescents rated the benefits of participating greater than the distress experienced during the study (Kuyper, de Wit, Adam, & Woertman, 2012; Kuyper, Wijsen, & de Wit, 2014). This initial evidence indicates that youth, including SGM youth, feel comfortable in and perceive modest risks to participating in sexual health survey studies.

Additional research is needed to shed light on nuanced aspects of harms and benefits that may result from SGM youth's study participation and offer suggestions for study protections to reduce the risks of harms. Involving the target population in this research is critical in identifying benefits, risks, and adequate protections that are not easily identified through investigators or IRBs' logic or scientific inference (Fisher, 2002, 2004). For example, qualitative methods may illuminate factors specific to SGM youth that raise distinct concerns about privacy and confidentiality, such as whether they are "out" about their sexual orientation and/or gender identity to family or friends. Moreover, as most attention to date has focused on potential harms associated with sexual health research, a better understanding of how anticipated benefits may inform SGM youth's decisions to participate, and how actual benefits of participation compare to its harms, can guide decisions about involving SGM youth in sexual health survey research. Participant perspectives can also help prevent investigators and IRBs from rejecting research procedures as harmful when participants perceive them to be low risk and outweighed by benefits (Fisher, 2002, 2004). Further research is needed to examine how SGM youth feel about potential harms of having answered different types of sexuality survey questions (e.g., sexual experiences and risk behavior vs. sexual and gender identities) relative to other minimal risk research procedures and in comparison to everyday events. As such, development of a quantitative measure like that described in Petrie et al. (2013) could facilitate cross-study comparisons of SGM (and non-SGM) adolescents' level of discomfort in sexual health survey research.

Research is also needed on a second critical barrier to sexual health research involving SGM youth, namely, IRBs' reluctance to grant waivers of guardian consent for research that is neither feasible nor reasonable if guardian permission is required and therefore meet federal regulations for such waivers (Department of Health and Human Services, 2009). For example, parents may be less inclined to grant consent for adolescent sexual health research if they hold more conservative attitudes toward sexuality, whether or not their adolescent is sexually active or has the maturity to provide informed, voluntary, and rational consent (Moilanen, 2015, 2016). Moreover, SGM youth may be less likely than non-SGM youth to participate in studies that require guardian permission, especially those who are not open about their sexual orientation or gender identity, lack support from their parents or guardians, or fear being victimized by their families following disclosure of their sexual orientation or gender identity (D'Augelli, Grossman, & Starks, 2008; D'Augelli, Hershberger, & Pilkington, 1998; Mustanski, Newcomb, & Garofalo, 2011; Ryan, Russell, Huebner, Diaz, & Sanchez, 2010). Indeed, we found that 68 % of SGM youth who were not out would refuse to participate in a biomedical HIV prevention study that required guardian permission for these reasons (Fisher, Arbeit, Dumont, Macapagal, & Mustanski, 2016). In both cases, investigators attempting to increase SGM youth's representation in sexual health survey research may face challenges recruiting unbiased samples of youth if guardian permission is not waived, thereby limiting the generalizability of findings to SGM youth whose parents are accepting of their sexuality and gender identity (Fisher & Mustanski, 2014; Mustanski, 2011; Tufford, Newman, Brennan, Craig, & Woodford, 2012). In addition, investigators may be more inclined to exclude SGM adolescents from sexual health research due to anticipated or actual difficulties obtaining IRB approval or waivers of guardian permission (Miller, Forte, Wilson, & Greene, 2006; Mustanski, 2011). Only including SGM youth who can obtain parental permission in sexual health research poses a problem especially for basic or epidemiological studies, whose results may not be generalizable to the larger population of SGM youth (Fisher & Mustanski, 2014;

Mustanski & Fisher, 2016). Moreover, implementation of public health policies based on such results may perpetuate sexual health inequities among the SGM population.

SGM youth are underrepresented in sexual health research that ultimately could improve their health and that of their community. However, our knowledge of the risks and benefits SGM youth experience from completing sexual health surveys, as well as their perceptions regarding guardian permission for these studies, remains relatively limited. This hinders the ability of IRBs and investigators to make informed and ethical decisions about including these youth in sexual health research. As it is critical to consider youth's perspectives when making research ethics decisions that can affect their well-being (United Nations General Assembly, 1989), the present study used online focus groups to investigate SGM adolescents' appraisals of risks and benefits of sexual health survey research and their attitudes toward requiring guardian permission for this research. We also designed a quantitative measure to assess participants' level of discomfort after completing a survey on sexual behavior and other sensitive topics relative to everyday events and research activities considered to be minimal risk. Ultimately, such a measure could be used by other investigators to yield concrete information on potential risks experienced by SGM youth when completing sexual health survey research, which in turn can guide IRB and investigator decisions on inclusion of these youth and other adolescents in similar studies.

Method

Participants

As part of a larger study, participants were enrolled in online focus groups on ethical issues in HIV prevention research among SGM adolescents. Eligible participants were between 14 and 17 years old; identified their sexual orientation as lesbian, gay, bisexual, queer, questioning, and/or reported a transgender or non-binary gender identity; indicated they were romantically interested in or had sex with male partners (the behavioral profile among SGM youth that has the greatest risk for HIV transmission); had reliable access to a phone and Internet; and lived in the United States.

Participants were recruited nationally through paid advertisements on Facebook from January to April 2015. Advertisements were targeted to 14–17 year olds who indicated a romantic interest in the same sex on their Facebook profile, or who listed interests that were expected to be relevant to SGM youth. These interests were identified by the study team's research assistants and included SGM-focused organizations; actors, musicians, and other public figures; and movies and television shows popular among SGM youth. Targeting advertisements by interests, rather than sexual orientation, was intended to increase the likelihood that advertisements would reach youth who were not out about their sexual orientation or gender identity on their profile. In addition, to increase racial and ethnic diversity of the study sample, Facebook's Multicultural Affinity Targeting feature was used to reach youth who engaged with, or would likely engage with, content relevant to racial or ethnic minority individuals. Clicking on the study advertisement directed the individual to an online eligibility survey. Those who appeared eligible based on their survey responses were then contacted by a study staff member via telephone to confirm eligibility, provide more information about the study, assess understanding of study procedures and decisional capacity (Moser et al., 2002; UCSD Task Force on Decisional Capacity, 2003), and obtain verbal informed assent.

Procedure

Online focus groups were chosen for this study to overcome challenges to youth's participation, such as transportation, concerns about meeting strangers in an unfamiliar place, as well as publicly identifying oneself as part of a stigmatized group (Fox, Morris, & Rumsey, 2007). In addition, the group format was expected to facilitate research participation among SGM youth by providing a sense of support, belonging, and community (Greene, Fisher, Kuper, Andrews, & Mustanski, 2015; Ybarra, DuBois, Parsons, Prescott, & Mustanski, 2014).

Six focus groups were conducted from February to April 2015 using a secure website accessed via a login with a pseudonym and unique password created by the participant. Four groups were stratified by age and gender, and transgender participants were offered the opportunity to participate in the focus group of their choice based on their age. This resulted in groups that predominantly consisted of 14–15 year old male youth, 14–15 year old female youth, 16–17 year old male youth, and 16–17 year old female youth. As these groups largely consisted of youth who were out to their families, two additional groups were conducted with 14–17 year old participants who were not out about their sexual orientation and/or gender identity. These two groups were heterogeneous with respect to age- and gender given challenges in recruiting younger adolescents who were not out, a preliminary content analysis indicating that focus group responses did not appear to differ by these characteristics, as well as past work indicating that youth's age and gender may not adversely impact the quality of online focus group interactions (Fox et al., 2007).

Focus groups were moderated by two members of the research team. Given the online nature and diverse composition of the focus groups, moderators were not race- and gender-matched to the participants (Fox et al., 2007), and consisted of a lead moderator (an Asian, female clinical psychologist) and one of two co-moderators (a Latina, female, master's level counselor, and a White, male clinical psychologist). Focus groups consisted of 7–13 participants (Krueger, 2009) and took place over three consecutive days. Questions were posted each morning, and participants were permitted to answer at their convenience, rather than at a specified time. Moderators prompted participants who did not respond to each question. Participants who were fully engaged in the focus groups (defined as posting in the focus group at least once on each day, or at least three times over the course of 2 days) were sent a link to a post-focus group survey after the focus groups ended. Participants who were fully engaged in the groups and who completed both the baseline and post-focus group surveys received a $30 USD Visa gift card for their participation.

All study procedures were approved by the Northwestern University and Fordham University IRBs. Parental permission was waived on grounds that it was not a reasonable requirement to protect the participants and appropriate protective mechanisms were in place (Mustanski, 2011). These included a decisional capacity assessment, a discussion with each participant regarding the privacy measures taken by both the study team (e.g., limiting study staff's access to participant identifying information) and the participant (e.g., password protecting computer or smartphone, using computer at library instead of at home) during the study, and obtaining a Certificate of Confidentiality from the National Institutes of Health to protect the identities of participants in the event of subpoenas requesting identifiable study data.

Measures

Demographics, sex and sexuality, and health behaviors

Demographic, sexual health data (e.g., history of STI and HIV testing, STI status), and information about youth's sexual behaviors and alcohol/drug use were collected during the baseline surveys. In addition, several items assessed the extent to which participants had disclosed their sexual orientation and/or gender identity to others (i.e., "outness"). Participants were first asked whether they were out to "everyone," to "most people," to "some people," or out to "no one." Those who were out to at least some were then asked if they were out to their mother or the woman who raised them, and their father or the man who raised them, and the extent to which these individuals were accepting of the youth's sexual or gender identity. Participants who were not out to either guardian or their only guardian at the time of baseline survey completion were considered "not out" for the purposes of the study; those who were out to at least one guardian were considered "out."

Assessing levels of risk

A Minimal Risk Assessment informed by Petrie et al. (2013) was developed by the study team and included at the end of the baseline survey. Instructions were as follows: "In this survey we asked you about your gender/sexual identity, sexual behavior, and use of alcohol and drugs. To help us improve our surveys in the future we'd like to know how you felt answering these questions compared to other events. Did answering these questions for our research study make you feel more comfortable, about the same, or more uncomfortable than…" Three subscales assessed the extent to which completing the baseline survey was "more comfortable" (1), "about the same" (2), or "more uncomfortable" (3) than procedures designated by guidelines from the US Office for the Protection of Research Participants to be *minimal risk* (e.g., blood draws) and *events in everyday life* (e.g., taking a test) (8 items), situations posing potential *informational risks* (e.g., if counselor asked the same questions, if private diary was discovered) (3 items), and events related to *SGM identity and sexual health* (e.g., talking about sex, coming out to a parent) (4 items). The final four items on SGM identity and sexual health can be dropped from the scale for use with non-SGM adolescent populations. Sum scores on the 15-item version of the scale range from 15 to 45, while the 11-item scale ranges from 11 to 33.

A separate set of three items administered during the post-focus group survey assessed participants' level of comfort answering survey questions on (1) drug and alcohol use, (2) sexual behavior, and (3) sexual orientation and gender identity. Responses were made on a 5-point scale ranging from "very uncomfortable" to "very comfortable."

Concerns about privacy and research trust

Three items near the end of the baseline survey assessed participant concerns about privacy during survey completion: "When you filled out this survey, were you worried that other people might be looking over your shoulder and seeing your answers?" (response options: yes/no), "Please describe any other privacy concerns you had while you were filling out the survey" (open ended response), and "Now think about filling out a form at the doctor's office that asks about your sexual orientation, drug use, and other personal information. In terms of your worries about privacy, how does filling out our online survey compare?" (response options: worry more at the doctor's office [1], about the same level of worry [2], worry more in this study [3]).

Another three items at the end of the post-focus group survey assessed participants' trust in the research team to maintain their privacy and confidentiality: "How confident do you feel that the researchers who are conducting this study will keep what you told them in the surveys and focus group private?" (response options: completely confident [1], somewhat confident [2], not at all confident [3]). The remaining two items asked about trust in researchers relative to healthcare providers: "Compared to your [regular doctor/school counselor or psychotherapist], how much do you trust that the researchers who are conducting this study will keep what you told them in the surveys and focus group private?" (response options: trust researchers more [1], about the same [2], trust researchers less [3]).

Focus Group Guide

The focus group guide covered a range of topics relevant to the larger project, which was focused on SGM adolescents' perceptions of different ethical issues for sexual health survey research, HIV testing studies, and a pre-exposure prophylaxis (PrEP) adherence trial (Fisher et al., 2016). The current article focuses on analyses of responses to survey and focus group questions pertaining to sexual health survey research. Focus group questions included: (1) Would you have agreed to fill out our survey if we had to get your parent's or guardian's permission? Why or why not, (2) Did answering the survey questions benefit or help you in some way? If so, can you describe, and (3) Were there certain types of survey questions that made you feel uncomfortable? For those of you who felt uncomfortable at any point, discuss what it was about the questions that made you feel that way.

Coding and Analysis

Each participant's transcript was imported into Dedoose (2015) for analyses. Analyses focused on individual-level transcripts, rather than group narratives (Carey & Smith, 1994), which enabled us to examine individual responses to our research questions and to conduct mixed-methods analyses across different groups of participants. First, root codes were applied to each transcript to identify excerpts broadly representing each key topic covered during the focus group. For this article, root codes of interest included "survey risks and benefits" and "parent/guardian permission." Second, open coding identified themes within these two root codes using the constant comparison method (Glaser & Strauss, 1967). One coder independently reviewed the excerpts and generated a list of potential themes, or any topic the coder perceived to be a significant or recurring pattern in the data. Then, another coder reviewed these themes alongside the excerpts and generated additional emergent themes. Coders then combined their lists, which were refined and reduced via comparison, discussion, and consensus. Third, the reduced list of codes was then applied to the excerpts, and coders continued to iteratively refine and reduce the codes until arriving at a final set of 9 discrete axial codes reflecting survey risks and benefits, and 9 reflecting parent/guardian permission (see Table 1). Reliability coding was performed by a third coder. A pooled kappa of .85 for the survey risks and benefits codes, and .87 for the guardian permission codes, indicated excellent intercoder reliability (Dedoose, 2015; Fleiss, 1971).

Data were analyzed thematically across transcripts and blind to participant characteristics (Braun & Clarke, 2006). For the parent/guardian permission codes, mixed-methods analyses (Axinn & Pearce, 2006) were also used to explore group differences in code application rates by whether or not a participant was out to their parents/guardians. These analyses were performed on codes endorsed by a minimum of five participants, and group differences for a given code were considered meaningful if the number of times that code was applied differed by at least 20 % between groups (Greene, Andrews, Kuper, & Mustanski, 2014; Magee, Bigelow, Dehaan, & Mustanski, 2012). These differences are presented in terms of weighted percentages that account for varying sample sizes across groups (Dedoose, 2015). There were no consistent differences in the risk and benefit codes by outness; as such, mixed-methods findings are not reported for these themes.

Results

The analytic sample comprised 74 participants (M age = 15.9 years, $SD = .97$), 53 % of whom identified as cisgender female, 39 % cisgender male, and 8 % transgender and/or non-binary gender. Most of the sample was White (69 %) and non-Hispanic or Latino (77 %). Bisexual sexual orientation was the largest group (58 %), with 79 % of cisgender females identifying as bisexual and 28 % of cisgender males. This gender difference reflects sex with a cisgender male partner as an inclusion criterion. Approximately half were out to their parents or guardians (53 %), and almost all listed a parent as their primary legal guardian (96 %). Of those who were out to their parents or guardians, most reported that their guardians were accepting (female guardian: 86 %, male guardian: 85 %). Youth who were out were more likely to be White, $\chi^2(1, N = 74) = 5.72, p = .017$ and in the 14–15 age group, $\chi^2(1, N = 74) = 5.62, p = .018$. In addition, 42 % of youth had ever participated in a research study that asked them questions about sensitive topics (i.e., SGM identity, sexual behavior, drug/alcohol use), with most having done so at school. Additional sample characteristics are shown in Table 2.

Quantitative Surveys

Minimal Risk Assessment and Comfort with Survey Topics

Table 3 shows participants' responses to the Minimal Risk Assessment, which was administered at the end of the baseline survey. Overall, completing the survey was rated about the same to more comfortable than minimal risk research procedures, everyday events, and events related to SGM identity and sexual health, with item means ranging from 1.49 to 1.95. Sum scores for the 15-item scale ranged from 16 to 41 with a

Table 1 Themes, sub-themes, and application frequencies

	Participants		Number of excerpts
	n	%	
Risks of sexual health surveys			
Privacy/confidentiality concerns	10	13.5	11
Discomfort reflecting on past behaviors	8	10.8	9
Concern about disclosing illegal activity	7	9.5	7
Benefits of sexual health surveys			
No specific benefits	28	37.8	28
Emotional or psychological benefits	18	24.3	19
Identified gaps in knowledge	11	14.9	11
Made a contribution	9	12.2	9
Reasons why surveys pose little risk			
Comfortable with survey topics	44	59.5	47
Privacy and trustworthiness of study	17	23.0	19
Would get parent/guardian permission?			
No	34	45.9	34
Yes	24	32.4	24
Yes if required	4	5.4	4
Reasons against asking guardian permission			
SGM-related issues	30	40.5	30
Discomfort asking permission	6	8.1	6
Teen autonomy	4	5.4	4
Reasons in favor of guardian involvement			
Guardian is supportive	22	29.7	22
Would circumvent guardian permission	8	10.8	8
Guardian would say yes	5	6.8	5

mean of 25.45 ($SD = 6.12$), and internal consistency was good ($\alpha = .84$). Sum scores for the 11-item scale ranged from 11 to 30 with a mean of 19.37 ($SD = 4.81$); this version also had good internal consistency ($\alpha = .81$). The scale scores did not differ by outness, gender, age group, race and ethnicity, or prior experience as a research participant.

During the post-focus group survey, participants were asked about their comfort level answering certain types of questions in the baseline survey (Table 4). Overall, most were somewhat to very comfortable answering items related to drug and alcohol use, sexual behavior, and sexual orientation and gender identity. A small minority endorsed these questions as "very uncomfortable," and comfort levels did not significantly differ by outness, gender, age group, race and ethnicity, or prior experience as a research participant.

Privacy and Research Trust

Table 4 includes items from the baseline and post-focus group surveys regarding participants' sense of privacy and trust in the research team during the study. The majority of participants (78 %) felt about the same as or more comfortable completing the survey questions than if their regular doctor was asking the same questions; 54 % felt about the same as or more comfortable than if their school counselor or psychotherapist was asking the same questions. The vast majority were not worried that others would be able to see their answers while completing the online survey, and the only participants who indicated this concern were not out, $\chi^2(1, N = 77) = 6.68, p = .01$. In addition, most were more likely to worry about completing similar questions on a form at their doctor's office.

While most participants felt somewhat to completely confident that the researchers would keep their responses during the survey and focus group private, youth who were not out were somewhat less confident ($M = 1.32$, $SD = .48$) than out participants ($M = 1.07$, $SD = .26$), $F(1, 58) = 6.128$, $p = .016$. Overall, most youth trusted the researchers in the study about the same as or more than their school counselor/psychotherapist and regular doctor, though relative to White participants ($M = 1.43, SD = .56$), racial and ethnic minority participants trusted the researchers less than their doctor ($M = 1.92$, $SD = .50$),

Table 2 Sample characteristics by gender identity

	All participants ($N = 74$) n (%)	Cisgender female ($n = 39$) n (%)	Cisgender male ($n = 29$) n (%)	Transgender or non-binary ($n = 6$) n (%)
Mean age (*SD*)	15.9 (0.97)	15.9 (1.02)	15.9 (0.92)	15.7 (1.03)
Birth sex				
Male	29 (39.2)	0 (0.0)	29 (100.0)	0 (0.0)
Female	45 (60.8)	39 (100.0)	0 (0.0)	6 (100.0)
Race				
White	51 (68.9)	30 (76.9)	17 (58.6)	4 (66.7)
Black	5 (6.8)	1 (2.6)	4 (13.8)	0 (0)
Asian	2 (2.7)	1 (2.6)	1 (3.4)	0 (0)
Multiracial/other	15 (20.3)	6 (15.4)	7 (24.1)	2 (33.3)
Declined to answer	1 (1.4)	1 (2.6)	0 (0)	0 (0)
Ethnicity				
Hispanic/Latino	17 (23.0)	8 (20.5)	7 (24.1)	2 (66.7)
Not Hispanic/Latino	57 (77.0)	31 (79.5)	22 (75.9)	4 (33.3)
Sexual orientation				
Gay/lesbian	26 (35.1)	5 (13.2)	21 (72.4)	0 (0.0)
Bisexual	43 (58.1)	30 (78.9)	8 (27.6)	5 (83.3)
Queer/questioning	5 (6.8)	3 (7.9)	0 (0.0)	1 (16.7)
Outness				
Not out	34 (46.6)	24 (63.2)	9 (31.0)	0 (0.0)
Out	39 (53.4)	14 (36.8)	20 (69.0)	5 (100.0)
Primary guardian(s)[a]				
Parent	71 (95.9)	38 (97.4)	27 (93.1)	6 (100.0)
Extended family	22 (29.7)	10 (25.6)	10 (34.5)	3 (50.0)
Other	5 (6.8)	3 (7.7)	2 (6.9)	2 (33.3)
Mother's education				
More than HS	40 (54.8)	22 (56.4)	15 (53.6)	3 (50.0)
High school	19 (26.0)	10 (25.6)	6 (21.4)	3 (50.0)
Partial HS or less	10 (13.7)	5 (12.8)	5 (17.9)	0 (0.0)
Do not know	4 (5.5)	2 (5.1)	2 (7.1)	0 (0.0)
Father's education				
More than HS	32 (51.6)	19 (59.4)	10 (38.5)	3 (50.0)
High school	19 (30.6)	8 (25.0)	10 (38.5)	1 (16.7)
Partial HS or less	11 (17.7)	5 (15.6)	6 (23.1)	0 (0.0)
Do not know	11 (17.7)	7 (21.9)	2 (7.7)	2 (33.3)
Mother acceptance of sexual orientation[b]				
Accepting	31 (86.1)	11 (78.6)	18 (94.7)	2 (33.3)
Rejecting	5 (13.9)	3 (21.4)	1 (5.3)	1 (16.7)
Father acceptance of sexual orientation[b]				
Accepting	23 (85.2)	9 (90.0)	13 (86.7)	1 (50.0)
Rejecting	4 (14.8)	1 (10.0)	2 (13.3)	1 (50.0)
Housing				
Stable	72 (97.3)	38 (97.4)	28 (96.6)	6 (100.0)
Unstable	2 (2.7)	1 (2.6)	1 (3.4)	0 (0.0)
STI tested in lifetime				
Tested	26 (35.6)	16 (41.0)	9 (32.1)	1 (16.7)

Table 2 continued

	All participants ($N = 74$) n (%)	Cisgender female ($n = 39$) n (%)	Cisgender male ($n = 29$) n (%)	Transgender or non-binary ($n = 6$) n (%)
Not tested	47 (64.4)	23 (59.0)	19 (67.9)	5 (83.3)
STI positive				
No	71 (97.3)	37 (94.9)	28 (100.0)	6 (100.0)
Yes	2 (2.7)	2 (5.1)	0 (0.0)	0 (0.0)
HIV test within past 6 months				
No	64 (87.7)	36 (92.3)	23 (82.1)	5 (83.3)
Yes	9 (12.3)	3 (7.7)	5 (17.9)	1 (16.7)
Ever participated in research study asking about SGM identity, sexual behavior, or drug/alcohol use				
No	42 (57.5)	22 (56.4)	14 (50.0)	6 (100.0)
Yes, at school	19 (26.0)	14 (35.9)	5 (17.9)	0 (0.0)
Yes, at community or health center	6 (8.2)	2 (5.1)	4 (14.3)	0 (0.0)
Yes, on the Internet	6 (8.2)	1 (2.6)	5 (17.9)	0 (0.0)

*N*s in cells may vary due to participants who chose not to respond to the question

[a] Participants could select multiple options; as such columns may add up to greater than 100 %

[b] Of participants who had disclosed their sexual orientation to their parents

$F(1, 58) = 11.785$, $p = .001$. There were no other differences in the privacy and research trust questions by outness or race, and no differences by age, gender identity, or prior experience as a research participant.

Qualitative Analyses

Risks of Sexual Health Survey Participation

In response to the focus group question "Were there certain types of survey questions that made you feel uncomfortable?" and the survey question "Please describe any other privacy concerns you had while you were filling out the survey," overall, participants described few risks. The most commonly identified risks included *privacy or confidentiality concerns* (11 applications), which likely reflects the fact that participants were specifically asked to report on them. Some were concerned that their personal information or responses might be shared with authorities, particularly if they reported any illicit alcohol or drug use in the survey: "I felt uncomfortable answering questions about my drug/alcohol use, just because it is like part of me is saying, 'They won't tell' but another part is like, 'But they might'" (#911, 16 year old queer transgender male, not out). Others were concerned that their guardians would find out they were participating in the study, or that they would be inadvertently outed by participating. These latter concerns were most commonly referenced in the context of not being open about one's sexual orientation:

> I believe it could harm some [teens] because the risk of being let out of the closest. I know some people whose family would not approve of any other sexuality [other than heterosexuality]. Such as my own, my mother would turn on me for not being her perfect image (#581, 15 year old bisexual female, out).

Discomfort reflecting on past behaviors (9 applications). A small number of participants experienced some discomfort when certain survey questions led them to reflect on their past behaviors. These excerpts mostly described regret or embarrassment about past sexual behaviors, as explained by this participant: "The questions asking about past sexual partners made me a bit uncomfortable because I'm a bit ashamed of how promiscuous I have been in the past, and sharing my number of sexual partners made me feel a bit embarrassed" (#2154, 15 year old bisexual female, not out).

Benefits of Sexual Health Survey Participation

In response to the focus group question "Did answering the survey questions benefit or help you in some way?" participants most frequently endorsed *emotional or psychological benefits* (19 applications) to completing the surveys. Common sub-themes included the ability to reflect positively on one's behavior: "The questions helped… I was able to use them as a tool for retrospection, I was able to look back on my life and think about my past experiences" (#1273, 16 year old bisexual male, not out). In addition, other participants described how

Table 3 Responses to Minimal Risk Assessment and item and scale descriptives (*N* = 73)

	More comfortable *N* (%)	Neither comfortable nor uncomfortable *N* (%)	More uncomfortable *N* (%)	*M* (*SD*)
Informational risk				
Having someone find and read your private blog or diary who was not supposed to see it	34 (46.6)	8 (11.0)	31 (42.5)	1.95 (.95)
If your school counselor or psychotherapist was asking the same questions	32 (43.8)	24 (32.9)	17 (23.3)	1.78 (.80)
If your regular doctor was asking the same questions	29 (39.7)	29 (39.7)	15 (20.6)	1.80 (.76)
Minimal risk research and everyday events				
Having a sore throat	38 (52.8)	24 (33.3)	10 (13.9)	1.59 (.70)
Getting a flu shot	36 (49.3)	27 (37.0)	10 (13.7)	1.62 (.70)
Getting weighed at the doctor's office	35 (47.9)	23 (31.5)	15 (20.6)	1.77 (.77)
Getting a physical from your doctor	34 (46.6)	29 (39.7)	10 (13.7)	1.65 (.69)
Having a researcher sit in your classroom and watch what you and the other students are doing	32 (43.8)	31 (42.5)	10 (13.7)	1.73 (.69)
A doctor taking a blood sample	27 (37.0)	32 (43.8)	14 (19.2)	1.80 (.72)
Spitting into a small bottle so researchers could test your saliva	23 (31.9)	33 (45.8)	16 (22.2)	1.88 (.72)
Taking a test in a health class	23 (31.5)	43 (58.9)	7 (9.6)	1.82 (.58)
SGM identity and sexual health				
Coming out to a parent or guardian	51 (70.8)	8 (11.1)	13 (18.1)	1.50 (.80)
Talking about sex with your parents or guardians	47 (64.4)	11 (15.1)	15 (20.5)	1.58 (.81)
Coming out to a friend	40 (55.6)	27 (37.5)	5 (6.9)	1.49 (.60)
Going to a store to buy sex-related products (like condoms or lube)	39 (53.4)	26 (35.6)	8 (11.0)	1.58 (.66)
11-item scale score	–	–	–	19.37 (4.81)
15-item scale score	–	–	–	25.45 (6.12)

One participant did not complete this scale. Means reflect the extent to which completing the baseline survey was "more comfortable" (1), "about the same" (2), or "more uncomfortable" (3) than the events listed

answering the survey questions helped them feel more comfortable with their sexual identity: "[The survey] did help me… the more I think about my sexual orientation, the more confident I am about myself" (#288, 15 year old gay male, out).

Identified gaps in knowledge (11 applications). For some, completion of the surveys brought to participants' attention their own lack of knowledge surrounding HIV and STI prevention and transmission risks: "It definitely opened my eyes to the fact that I haven't been given any education on HIV prevention" (#167, 17 year old bisexual female, out). Relatedly, several described how their study participation made them feel more empowered to discuss sexual health, STIs, and HIV with their doctors: "After taking the survey, I realized that HIV prevention is something I really need to focus on and [it] helped me realize that I can go to my doctor for tests and information" (#178, 17 year old bisexual female, out).

Made a contribution (9 applications). Several youth expressed that their study participation meaningfully contributed to the health of the SGM community or to scientific research. "[Answering] the survey questions… made me feel like I was making a difference in this targeted [SGM] community" (#1177, 17 year old bisexual male, not out).

Finally, a number of participants perceived *no specific personal benefits* (28 excerpts) to their study participation, but many acknowledged that their participation may contribute to society: "I don't believe [the survey] benefited me, but I believe that the answer will benefit others" (#583, 14 year old bisexual non-binary youth, out).

Reasons Why Survey Research Poses Little Risk

Within the discussion of risks and benefits, a number of participants spontaneously expressed reasons why they felt the surveys posed relatively little risk overall. The most frequently endorsed reason was that participants felt *comfortable with survey topics* (47 applications) and were open about discussing their sexuality and sexual behavior, provided that it was not with their parents: "I felt very comfortable with these questions because I'm very open about my sexuality and it wasn't anything too personal" (#277, 15 year old gay male, out). Other participants indicated that study involvement was low risk because it was similar to previous experiences they had: "Not particularly, I've answered surveys with similar questions for

Table 4 Participants' comfort level and privacy concerns when completing survey by gender identity ($N = 74$)

	Cisgender female participants ($n = 39$) *n* (%)	Cisgender male participants ($n = 29$) *n* (%)	Trans/Non-binary participants ($n = 6$) *n* (%)	All participants ($N = 74$) *n* (%)
Comfort answering survey questions about drug and alcohol use				
Very uncomfortable	3 (9.4)	1 (8.3)	0 (0.0)	4 (8.2)
Somewhat uncomfortable	3 (9.4)	2 (16.7)	3 (60.0)	8 (16.3)
Neither uncomfortable nor comfortable	5 (15.6)	1 (8.3)	1 (20.0)	7 (14.3)
Somewhat comfortable	4 (12.5)	0 (0.0)	0 (0.0)	4 (8.2)
Very comfortable	17 (53.1)	8 (66.7)	1 (20.0)	26 (53.1)
Comfort answering survey questions about sexual behavior				
Very uncomfortable	3 (9.4)	1 (8.3)	0 (0.0)	4 (8.2)
Somewhat uncomfortable	6 (18.8)	1 (8.3)	1 (20.0)	8 (16.3)
Neither uncomfortable nor comfortable	4 (12.5)	0 (0.0)	0 (0.0)	4 (8.2)
Somewhat comfortable	6 (18.8)	4 (33.3)	2 (40.0)	12 (24.5)
Very comfortable	13 (40.6)	6 (50.0)	2 (40.0)	21 (42.9)
Comfort answering survey questions about sexual orientation and gender identity				
Very uncomfortable	3 (9.4)	1 (8.3)	0 (0.0)	4 (8.2)
Somewhat uncomfortable	2 (6.3)	0 (0.0)	0 (0.0)	2 (4.1)
Neither uncomfortable nor comfortable	5 (15.6)	1 (8.3)	0 (0.0)	6 (12.2)
Somewhat comfortable	6 (18.8)	0 (0.0)	2 (40.0)	8 (16.3)
Very comfortable	16 (50.0)	10 (83.3)	3 (60.0)	29 (59.2)
Did you worry that other people might look over shoulder and see answers when filling out survey				
Yes	4 (10.3)	1 (3.6)	1 (16.7)	6 (8.2)
No	35 (89.7)	27 (96.4)	5 (83.3)	67 (91.8)
Filling out online survey compared to filling out a form at doctor's office that asks about sexual orientation, drug use, and other personal information				
I worry more about my privacy filling out a form at the doctor's office.	31 (79.5)	20 (71.4)	6 (100.0)	57 (78.1)
About the same level of worry	7 (17.9)	8 (28.6)	0 (0.0)	15 (20.5)
I worry more about my privacy filling out an online survey in this study	1 (2.6)	0 (0.0)	0 (0.0)	1 (1.4)
Confident that researchers will keep survey and focus group responses private?				
Completely confident	24 (75.0)	19 (86.4)	4 (80.0)	47 (79.7)
Somewhat confident	8 (25.0)	3 (13.6)	1 (20.0)	12 (20.3)
Not at all confident	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Compared to regular doctor, how much do you trust researchers to keep survey and focus group responses private?				
I trust the researchers in this study more	18 (56.3)	6 (27.3)	1 (20.0)	25 (42.4)
I trust the researchers in this study about the same as my doctor	12 (37.5)	15 (68.2)	4 (80.0)	31 (52.5)
I trust the researchers in this study less	2 (6.3)	1 (4.5)	0 (0.0)	3 (5.1)
Compared to school counselor or psychotherapist, how much do you trust researchers to keep survey and focus group responses private?				
I trust the researchers in this study more	20 (62.5)	13 (59.1)	4 (80.0)	37 (62.7)
I trust the researchers in this study about the same as my school counselor or psychotherapist	9 (28.1)	9 (40.9)	1 (20.0)	19 (32.2)
I trust the researchers in this study less	3 (9.4)	0 (0.0)	0 (0.0)	3 (5.1)

*N*s in cells may vary as some items were asked at baseline and others asked during the post-focus group survey, the latter of which was administered only to participants who completed the focus group anonymous school health surveys" (#167, 17 year old bisexual female, out).

Privacy and trustworthiness of study (19 applications). Participants also perceived the study to be private and trustworthy, and consequently low risk. Some related this sense of confidentiality to their ability to complete the survey "in the privacy of [their] own room" (#293, 15 year old gay male, out) or online, while others cited the anonymity of the survey questions: "None of the survey questions made me feel uncomfortable because I knew my answers were confidential and it's only for the benefit of research. I'm comfortable and happy with myself, so being forthcoming isn't an issue" (#317, 15 year old gay male, out).

Willingness to Obtain Guardian Permission

Participant responses to the question "Would you have agreed to fill out our survey if we had to get your parent's or guardian's permission?" were coded for their overall willingness to obtain permission for the present study (i.e., yes/no). Participants were then asked to elaborate on reasons they were or were not willing. In the following sections, we describe both thematic analyses and mixed-methods analyses that examined whether the frequency with which participants endorsed the parent/guardian permission codes differed by self-reported outness at baseline.

Participants frequently stated that they were not willing to obtain guardian permission had it been required for the present study (34 excerpts). Others indicated that they would be willing (24 excerpts), or would do so only if absolutely necessary (4 excerpts). Participants who were not out more frequently discussed a lack of willingness to obtain guardian permission than those who were out (75 vs. 25 %).

Reasons Against Asking Guardian Permission for Survey Research

Participants described several reasons for their reluctance to ask for guardian permission for sexual health survey research. These mostly reflected *SGM-related issues* (30 applications). Among these excerpts, numerous participants stated that they were not out to their guardian(s), and that asking for permission would likely out themselves given the study's focus on SGM adolescents. Participants often expressed that one or both of their guardians had negative attitudes toward SGM individuals, or that their guardians disagreed with each other about SGM issues, which were additional barriers to requesting permission.

> I don't think I would have been comfortable filling out the survey and joining [the study] if I needed parental consent. My mom is mostly supportive of my sexuality, but I haven't told my dad, who I can assume from previous experience would be against my sexuality. If I needed their permission to fulfill this study, I'd probably not be able to help, especially if my dad stepped in (#22, 17 year old bisexual male, out).

One participant, who said she would "absolutely not" participate if she had to ask for her parents' permission, elaborated on this point:

> My father is a very religious person and has told me in the past that 'gays have chosen the wrong path in life'… My mother…is much more accepting, but not accepting to the point that I would be able to tell them. I'm not out to either of them and I definitely wouldn't out myself just to do a survey (#1688, 16 year old bisexual female, not out).

Even among participants who were out, several still would not have requested permission due to lack of guardian support for their SGM identity and/or guardian disapproval of SGM-related study content:

> I would have not participated because my parents would not approve of me participating in studies that pertain to the LGBT community… I… came out to them after I had already signed up [for the study], but if they had known before, I still would not have participated because my parents are not a big fan of me being gay (#1423, 17 year old gay male, not out).

Of particular importance, these descriptions were not about parents seeking to protect their child against harms related to research participation (i.e., the purpose of parental permission in the federal regulations), rather, they focused on parents being unsupportive of their children engaging in SGM-related activities of any type. Participants who were not out (74 vs. 26 %) were more likely to endorse this code.

Discomfort asking for permission (6 applications). Talking to parents or guardians about sex, sexual health, or HIV was uncomfortable for youth and posed an additional barrier to asking for permission: "No I wouldn't have took the survey. I would've felt pretty uncomfortable and awkward asking my mom for permission, and she would probably be very disapproving of the survey" (#1211, female, 15 year old, bisexual, not out). Others indicated that asking for permission would feel uncomfortable in general. This theme was referenced more often by participants who were not out (68 vs. 32 %).

An additional code that did not meet criteria for our mixed-methods analyses ($\geq$5 excerpts) is worth mentioning here. *Teen autonomy* (4 applications) was applied to any references where youth's ability to make independent decisions about their lives was a reason against obtaining guardian permission. "I would have done the survey anyway regardless of what my parents would tell me. Mainly because it is my sexuality and my life… [it] would benefit me more than them"

(#62, 17 year old gay male, out). Youth also expressed that their parents or guardians should not be aware of their "business" especially as it pertained to sex and sexuality.

Reasons in Favor of Guardian Involvement in Survey Research

Though participants more frequently described their concerns about obtaining guardian permission for this study, others were willing to involve their guardians in very specific circumstances.

Guardian is supportive (22 applications). Guardian support of youth's sexual or gender identity or the SGM community more broadly was the primary reason why some youth would have been willing to seek permission: "HIV prevention is very important to me and [my parents] know how important it is to me. They are cool with me being gay and celebrate me whenever I try to better the community" (#232, 17 year old lesbian female, out). Other excerpts reflected a general sense of support, but did not mention support about their sexual orientation or gender identity specifically: "I am lucky enough to have thoughtful and open minded parents. I even told them about this project anyways because I am excited to be helping" (#428, female, 15-years old, bisexual, out). This theme was discussed more frequently by those who were out to their parents (75 vs. 25 %).

Guardian would say yes (5 applications). Several youth stated that their guardian(s) would have agreed to or would not have cared whether they participated, without explicitly mentioning that their parents or guardians were supportive: "My mom is aware of [the study] and thinks it's interesting, but she doesn't particularly care either way. My dad would be fine with it if he knew. It just hasn't come up yet" (#659, 15 year old queer female, out). In other words, this theme reflected the perspective that youth who know their parents would say yes were more likely to ask permission. This theme was discussed exclusively by participants who were out.

Finally, it is important to note that several youth described ways to *circumvent guardian permission* (8 excerpts) regardless of whether they were willing to obtain it or not. Some youth indicated that they would be willing to obtain permission by asking one guardian but not the other: "If parents' permission was needed…I would have waited…until I was at my father's house" (#140, 16 year old queer female, out). Others who were unwilling to seek guardian permission were open to informing their parents about their study involvement by sharing certain details (e.g., that the study was for teenagers, conducted by a reputable university) and omitting others (e.g., that it was about sexual health and HIV in SGM youth). This theme did not differ by participant outness (56 % out vs. 44 % not out).

Discussion

SGM adolescents are underrepresented in research on sexual behavior, development, and health in part due to IRB overestimations of risk and requirements for guardian permission that render their participation in these studies difficult. Unfortunately, these obstacles contribute to our lack of understanding about sex and sexuality among this understudied group and in turn widen the sexual health disparities they experience. To guide investigators and IRBs toward evidence-based decision making when evaluating SGM youth's involvement in sexual health research, this study examined SGM youth's perceptions of participation risks and benefits after completing a survey on their sexual behaviors, SGM identity, and other sensitive health behaviors. In addition, we collected data addressing the extent to which youth felt comfortable completing this survey compared to routine events and procedures identified in federal regulations as minimal risk, as well as their reasoning regarding guardian permission requirements for sexual health survey studies.

Overall, focus group responses indicated that participants felt the survey posed little risk of harm. Results from the Minimal Risk Assessment revealed that youth felt equally or more comfortable completing the survey relative to everyday events and procedures meeting the minimal risk regulatory definition. In addition, when asked to rate the different types of questions asked in the survey, participants were more comfortable answering questions about sexual behavior and SGM identity than questions about drug and alcohol use. Participants attributed their comfort with survey participation to the various privacy measures in place for the study and the fact that questions were asked anonymously and online. This finding suggests that investigators working with SGM adolescents implement the Goodness-of-Fit Ethics model for informed consent, which calls for the consent process to match the developmental and educational status of prospective participants to minimize research risks (Fisher & Masty, 2006; Fisher & Ragsdale, 2006; Fisher & Vacanti-Shova, 2012). For sexual health studies involving SGM minors, who may be at different stages of sexual and gender identity development and disclosure, as well as different stages of development in general, a goodness-of-fit approach could involve implementing several strategies to ensure that protections are in place to compensate for waivers of guardian permission. These could include additional privacy protections to minimize the risk of confidentiality breaches that may place youth at risk for harm or inadvertently out the youth to their families or social networks, or utilizing a peer advocate who also identifies as SGM and could help youth navigate the consent process (Fisher et al., 2016). However, more research is needed to investigate alternative means of protecting youth when guardian permission is waived and ways to ensure consent procedures are inclusive of adolescents' developmental level and SGM identity.

In addition, although youth reported some emotional discomfort, which is not uncommon in psychosocial survey research (Labott, Johnson, Fendrich, & Feeny, 2013), the benefits of participating appeared to outweigh the costs. For instance, reflecting on one's past sexual behavior during the survey was evaluated as somewhat uncomfortable for a minority of youth, but was also perceived as leading youth to recognize that they could make more positive decisions about their sexual health. Relatedly, while several youth felt that the survey highlighted gaps in knowledge about their sexual health, they also felt encouraged to seek further information from their healthcare providers. The fact that youth described such adaptive responses to the survey, including health seeking behaviors, contrasts with the common (yet unsubstantiated) concern that such questions may encourage youth to engage in risky sexual behaviors (Santelli et al., 2003).

Results also indicated that most youth would have been unwilling to participate in this survey study had guardian consent been required. This is consistent with SGM youth's perspectives on guardian permission for HIV prevention research participation (Fisher et al., 2016). Many reported that asking parents for permission to participate would have outed them before they were ready, which could potentially increase risk of physical or emotional harm from their families (D'Augelli et al., 2008, 1998; Mustanski et al., 2011; Ryan et al., 2010). Parents' negative attitudes about SGM people and disapproval of the youth's SGM identity posed another major obstacle to asking for permission. Unsurprisingly, youth who were more accepting of guardian permission requirements reported having supportive or permissive parents, and some youth who were unwilling to seek permission remained open to informing their parents about their study participation, albeit with limited details. These data strongly support concerns that requiring guardian permission for sexuality research on SGM youth poses a threat to research validity by yielding samples that overrepresent youth who are out and/or who have affirming or communicative relationships with their guardians. As SGM youth who lack family support are at greater risk for adverse sexual health outcomes, including elevated rates of HIV risk behavior (Garofalo, Wolf, Kessel, Palfrey, & DuRant, 1998; Glick & Golden, 2014; Ryan, Huebner, Diaz, & Sanchez, 2009), exclusion of these youth from sexual health research will continue to undermine empirically informed understanding of factors that contribute to HIV risk and underscores the need to reduce these barriers to their research participation. Moreover, although guardian permission requirements assume that parental participation decisions reflect the best interests of the child, youth responses indicated that for many of their parents, decisions regarding youth's research participation would more likely be based on parental values concerning sexuality and gender identity, rather than focused on the minimal level of risk and opportunities for informational benefits that sexual health research provides. However, as we only obtained youth's perspectives on this issue, research is needed to assess parents' concerns regarding inclusion of SGM adolescents in sexual health research and the factors informing their decisions to grant or deny permission, which can further inform investigator and IRB decision making.

The remaining reasons against seeking guardian permission reflected concerns that likely generalize across adolescents regardless of sexual orientation or gender identity, such as discomfort at the prospect of talking to parents about sex, and the belief that teenagers should be able to make autonomous decisions about sexual health research participation since they make similar decisions in other aspects of their sex lives (e.g., having sex, purchasing condoms, HIV/STI testing). Although adolescents may tend to take more risks with their health behavior than adults (Steinberg, 2008), this does not necessarily mean that they are inclined to make risky or impulsive decisions when deciding to participate in research. By age 14, adolescents' understanding of the nature of health research and participant rights in general are similar to those of adults (e.g., Bruzzese & Fisher, 2003; Gibson, Stasiulis, Gutfreund, McDonald, & Dade, 2011; Koelch et al., 2009; Masty & Fisher, 2008; Miller, Drotar, & Kodish, 2004; Santelli et al., 2003); consistent with these studies, our work has shown that SGM adolescents can adequately understand and self-consent to sexual health research (Fisher et al., 2016). Many states have minor consent laws that recognize this autonomy and permit adolescents as young as 12 to independently consent to sexual and reproductive healthcare (Guttmacher Institute, 2015). As these services routinely involve assessment of patients' sexual history, SGM adolescents should also be able to independently consent to survey research studies aimed at understanding their sexual experiences and sexual and gender identity development (Fisher et al., 2013; Fisher & Mustanski, 2014; Institute of Medicine, 2004; Mustanski, 2011; Society for Adolescent Medicine, 2004).

Implications for Investigators and IRBs

Our findings indicate that the majority of SGM youth perceive risks of participation in survey research on sexuality and sexual behaviors as minimal, value the informational benefits of participating, and believe that requiring guardian permission poses a substantial barrier to research involvement, and in some cases increases participation risk. In addition, our Minimal Risk Assessment indicated that the survey questions caused little discomfort relative to everyday life and routine research procedures, and thus may be a useful tool for future researchers or IRBs interested in assessing the extent of discomfort participants experience from different types of survey questions on "sensitive" topics. These findings add to the mounting evidence that survey research on sensitive topics such as sexuality, sexual behavior, and drug use should be considered minimal risk (Kuyper et al., 2012, 2014; Langhinrichsen-Rohling, Arata, O'Brien, Bowers, & Klibert, 2006; Mustanski, 2011; Yeater, Miller, Rinehart, & Nason, 2012).

While our participants described few risks and discomforts associated with their involvement in our study, this does not diminish the importance of continuing to mitigate potential participation risks for SGM youth. For example, simply because youth may not feel their privacy to be at risk does not mean that adequate privacy protections are necessarily in place. Investigators should consider taking additional measures beyond the minimum required by their IRBs to ensure youth's privacy and comfort, such as obtaining a Certificate of Confidentiality for federally funded research, which permit researchers to refuse to disclose identifiable data in response to a subpoena (US Department of Health and Human Services, 2015). While such cases might be rare, youth might feel protected from the possibility that custody or other family law cases might involve parents taking legal recourse to identify their child's sexual orientation or gender identity. Other measures could include taking additional time to explain the privacy protections in place for the study, and collaborating with youth to identify ways to protect their own privacy during research studies (e.g., enabling password protection on their computers and phones for online research). Further research should investigate youth's preferences for mitigating participation risks in sexuality research studies where guardian permission is waived.

Strengths and Limitations

This study had several strengths. First, compared to previous studies that examined ethical issues in sexuality research using quantitative surveys (Kuyper et al., 2012, 2014; Langhinrichsen-Rohling et al., 2006; Mustanski, 2011; Yeater et al., 2012), using a combination of surveys and focus groups enabled us to elicit nuanced data that enriched our understanding of youth's reasoning regarding sexuality research participation. Second, we were able to enroll a national sample of SGM youth under age 18 using online recruitment, whereas traditional recruitment methods for an in-person focus group would have yielded a more geographically restricted sample. Last, SGM youth were likely more willing to participate due to the relative anonymity afforded by the online focus groups (Fox et al., 2007). Though one may argue that online methods may lack the richness of in-person exchanges, our participants often provided support for each other during the focus groups and expressed their feelings through emoticons, abbreviations, and font styles (e.g., using bold text or all capital letters) (Fox et al., 2007). Our online approach likely also overcame the need to match the moderators and participants based on appearance (e.g., race, gender) as in traditional face-to-face methods (Fox et al., 2007).

Results should be interpreted within the context of several limitations related to our sample and methodology. Perhaps most importantly, the views of our sample are not necessarily representative of all SGM youth. The majority of participants who completed the study were White, non-Hispanic (77.0 %), sexual minority youth in the United States who had regular access to the Internet and often were able to participate in the study in the privacy of their own room. Racial and ethnic minority youth and youth from different socioeconomic groups or countries may have had additional barriers to participation not evident among our participants. Future studies should consider how to facilitate sexual health survey research involvement among SGM youth who come may come from countries or cultural backgrounds with more conservative attitudes toward sexuality and SGM issues, as well as those who may have more limited access to technology. In addition, our sample included relatively few transgender participants, who may have different perspectives on the risks and benefits of sexual health survey research and guardian permission. It is possible that by advertising our study to "LGBT youth" rather than "transgender youth" specifically, gender minority youth may have been less inclined to participate. Research is needed to assist investigators who desire to increase representation of transgender individuals in sexual health research studies to ensure that study materials ranging from recruitment advertisements to sexual behavior and experience surveys use respectful language that does not assume a cisgender, binary gender identity, and does not conflate sex and gender (e.g., assuming sex with a male partner means penile-vaginal intercourse). Moreover, although we made efforts to recruit youth who were not out about their SGM identity, it is possible that some of these youth may have refrained from clicking on our online advertisements because of their explicit focus on SGM issues or their affiliation with an SGM research institute. In addition, as participants' responses may have been based on assumptions about their parents' attitudes and behaviors surrounding sexuality research, including the voices of both parents and SGM children in future research would provide even richer information to guide IRB decision making.

Regarding potential methodological limitations, we quantified the number of times a theme appeared in the focus groups, which may suggest that some themes are more noteworthy than others. It is possible that some participants had important thoughts, feelings, or experiences that differed from the most common themes reported in this article, but chose not to share them for a number of reasons. For example, social desirability and group norms may have produced responses that predominantly reflect negative attitudes toward parental involvement in research. However, these potential limitations may have been mitigated given the anonymity of online participation, as well as the fact that it was not uncommon for youth to describe positive reasons for and situations in which they would seek their parents' involvement. Finally, the majority of questions on our survey reflected sexual health issues that are relevant to cisgender and heterosexual youth. However, the conduct of sexual health research for these populations also suffers from popular biases regarding the vulnerability of youth in general and unsupported assumptions that simply asking youth questions about sex or high risk behaviors encourages such activities (Fisher et al., 2013).

Thus, the extent to which the ethically relevant attitudes and experiences of SGM youth are similar to or distinct from other adolescent research participants remains an important area for future study.

Conclusion

Taken together, the present study adds to the accumulating knowledge that can inform ethically responsible decision making regarding both SGM and other youth's involvement in sexuality research. Investigators should consider including questions about participants' comfort with research participation, negative consequences, and direct and indirect benefits experienced in adolescent sexual health research studies, as publishing these findings can build a corpus of evidence that can guide investigators and IRBs toward data-driven decision making when reviewing sexuality-related protocols involving minor adolescents (Mustanski, 2011). Using the Minimal Risk Assessment in particular may help facilitate comparisons of research risks across socially sensitive topics and methodologies with both SGM youth and general samples of adolescents. In addition, research is needed to investigate the perspectives of parents and more diverse groups of SGM youth on these ethical topics in hopes of reducing barriers to SGM adolescents' participation in sexuality research that can improve their health. However, addressing disparities in health research involving SGM youth also requires recognition that the subjective nature of IRB decisions not only reflects the absence of empirical data to inform protocol review, but in some cases, pervasive ignorance about different sexualities and gender identities and persistent negative biases against SGM persons that continue to haunt the United States and other nations. Investigators should not shy away from conducting research on the larger issues shaping our national research agenda and public health policies.

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Compliance with Ethical Standards

Conflict of interest Kathryn Macapagal, Ryan Coventry, Miriam Arbeit, Celia Fisher, and Brian Mustanski have no conflicts of interest to disclose.

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References

Axinn, W. G., & Pearce, L. D. (2006). *Mixed method data collection strategies*. New York: Cambridge University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–102.

Bruzzese, J., & Fisher, C. B. (2003). Assessing and enhancing the research consent capacity of children and youth. *Applied Developmental Science, 7*, 13–26. Retrieved from http://dx.doi.org/10.1207/S1532480XADS0701_2

Carey, M. A., & Smith, M. W. (1994). Capturing the group effect in focus groups: A special concern in analysis. *Qualitative Health Research, 4*, 123–127. doi:10.1177/104973239400400108.

CDC. (2013). *HIV among transgender people in the United States*. Retrieved from http://www.cdc.gov/hiv/pdf/risk_transgender.pdf.

CDC. (2015a). *2015 Sexually Transmitted Diseases Treatment Guidelines: Special Populations*. Retrieved from http://www.cdc.gov/std/tg2015/specialpops.htm.

CDC. (2015b). *HIV among youth*. Retrieved from http://www.cdc.gov/hiv/group/age/youth/index.html.

D'Augelli, A. R., Grossman, A. H., & Starks, M. T. (2008). Families of gay, lesbian, and bisexual youth: What do parents and siblings know and how do they react? *Journal of GLBT Family Studies, 4*, 95–115. doi:10.1080/15504280802084506.

D'Augelli, A. R., Hershberger, S. L., & Pilkington, N. W. (1998). Lesbian, gay, and bisexual youth and their families: Disclosure of sexual orientation and its consequences. *American Journal of Orthopsychiatry, 68*, 361–371.

Dedoose. (2015). Web application for managing, analyzing, and presenting qualitative and mixed method data (Version 4.5.91). Los Angeles, CA: SocioCultural Research Consultants, LLC.

Department of Health and Human Services. (2009). *Title 45 Public Welfare, Part 46, Code of Federal Regulations, Protection of Human Subjects*. Retrieved from http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html.

Fisher, C. B. (1999). *Relational ethics and research with vulnerable populations*. Retrieved from Rockville, MD: http://www.bioethics.gov/reports/past_commissions/nbac_mental2.pdf.

Fisher, C. B. (2002). Participant consultation: Ethical insights into parental permission and confidentiality procedures for policy relevant research with youth. In R. M. Lerner, F. Jacobs, & D. Wertlieb (Eds.), *Handbook of applied developmental science: promoting positive child, adolescent, and family development through research, policies, and programs* (Vol. 4, pp. 371–396). Thousand Oaks, CA: Sage.

Fisher, C. B. (2004). Ethics in drug abuse and related HIV risk research. *Applied Developmental Science, 8*, 91–103.

Fisher, C. B., Arbeit, M. R., Dumont, M. S., Macapagal, K., & Mustanski, B. (2016). Self-consent for HIV prevention research involving sexual and gender minority youth: Reducing barriers through evidence-based ethics. *Journal of Empirical Research on Human Research Ethics*. doi:10.1177/1556264616633963.

Fisher, C. B., Brunnquell, D. J., Hughes, D. L., Liben, L. S., Maholmes, V., Plattner, S., … Sussman, E. J. (2013). Preserving and enhancing the responsible conduct of research involving children and youth: A response to proposed changes in federal regulations. *Social Policy Report, 27*, 3–15.

Fisher, C. B., Kornetsky, S. Z., & Prentice, E. D. (2007). Determining risk in pediatric research with no prospect of direct benefit: Time for a national consensus on the interpretation of federal regulations. *American Journal of Bioethics, 7*, 5–10. doi:10.1080/15265160601171572.

Fisher, C. B., & Masty, J. K. (2006). A goodness-of-fit ethic for informed consent to pediatric cancer research. In R. T. Brown (Ed.), *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach* (pp. 205–217). New York: Oxford University Press.

Fisher, C. B., & Mustanski, B. (2014). Reducing health disparities and enhancing the responsible conduct of research involving LGBT youth. *Hastings Center Report, 44*(Suppl. 4), S28–31. doi:10.1002/hast.367.

Fisher, C. B., & Ragsdale, K. (2006). A goodness-of-fit ethics for multicultural research. In J. E. Trimble & C. B. Fisher (Eds.), *The handbook of ethical research with ethnocultural populations and communities* (pp. 3–26). Thousand Oaks, CA: Sage.

Fisher, C. B., & Vacanti-Shova, K. (2012). The responsible conduct of psychological research: An overview of ethical principles, APA Ethics Code standards, and federal regulations. In S. J. Knapp (Ed.), *APA handbook of ethics in psychology* (1st ed., Vol. 2, pp. 335–370). Washington, DC: American Psychological Association.

Fleiss, J. L. (1971). Measuring nominal scale agreement among many raters. *Psychological Bulletin, 76*, 378–382. doi:10.1037/h0031619.

Fox, F. E., Morris, M., & Rumsey, N. (2007). Doing synchronous online focus groups with young people: Methodological reflections. *Qualitative Health Research, 17*, 539–547. doi:10.1177/1049732306298754.

Garofalo, R., Wolf, C. R., Kessel, S., Palfrey, J., & DuRant, R. H. (1998). The association between health risk behaviors and sexual orientation among a school-based sample of adolescents. *Pediatrics, 101*, 895–902.

Gibson, B. E., Stasiulis, E., Gutfreund, S., McDonald, M., & Dade, L. (2011). Assessment of children's capacity to consent for research: A descriptive qualitative study of researchers' practices. *Journal of Medical Ethics, 37*, 504–509.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing Company.

Glick, S. N., & Golden, M. R. (2014). Early male partnership patterns, social support, and sexual risk behavior among young men who have sex with men. *AIDS and Behavior, 18*, 1466–1475. doi:10.1007/s10461-013-0678-7.

Greene, G. J., Andrews, R., Kuper, L., & Mustanski, B. (2014). Intimacy, monogamy, and condom problems drive unprotected sex among young men in serious relationships with other men: A mixed methods dyadic study. *Archives of Sexual Behavior, 43*, 73–87. doi:10.1007/s10508-013-0210-1.

Greene, G. J., Fisher, K. A., Kuper, L., Andrews, R., & Mustanski, B. (2015). "Is this normal? Is this not normal? There's no set example": Sexual health intervention preferences of LGBT youth in romantic relationships. *Sexuality Research and Social Policy, 12*, 1–14. doi:10.1007/s13178-014-0169-2.

Guttmacher Institute. (2015). *State policies in brief: An overview of minors' consent law*. Retrieved from http://www.guttmacher.org/statecenter/spibs/spib_OMCL.pdf.

Institute of Medicine. (2004). *Ethical conduct of clinical research involving children*. Washington, DC: National Academies Press.

Institute of Medicine. (2011). *The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding*. Washington, DC: National Academies Press.

Koelch, M., Singer, H., Prestel, A., Burkert, J., Schulze, U., & Fegert, J. M. (2009). "…because I am something special" or "I think I will be something like a guinea pig": Information and assent of legal minors in clinical trials–assessment of understanding, appreciation and reasoning. *Child and Adolescent Psychiatry and Mental Health, 3*, 2.

Krueger, R. A. (2009). *Focus groups: A practical guide for applied research* (4th ed.). Los Angeles: Sage.

Kuyper, L., de Wit, J., Adam, P., & Woertman, L. (2012). Doing more good than harm? The effects of participation in sex research on young people in the Netherlands. *Archives of Sexual Behavior, 41*, 497–506. doi:10.1007/s10508-011-9780-y.

Kuyper, L., Wijsen, C., & de Wit, J. (2014). Distress, need for help, and positive feelings derived from participation in sex research: Findings of a population study in the Netherlands. *Journal of Sex Research, 51*, 351–358. doi:10.1080/00224499.2012.736092.

Labott, S. M., Johnson, T. P., Fendrich, M., & Feeny, N. C. (2013). Emotional risks to respondents in survey research: Some empirical evidence. *Journal of Empirical Research on Human Research Ethics, 8*, 53–66. doi:10.1525/jer.2013.8.4.53.

Langhinrichsen-Rohling, J., Arata, C., O'Brien, N., Bowers, D., & Klibert, J. (2006). Sensitive research with adolescents: Just how upsetting are self-report surveys anyway? *Violence and Victims, 21*, 425–444.

Lindley, L. L., & Walsemann, K. M. (2015). Sexual orientation and risk of pregnancy among New York City high-school students. *American Journal of Public Health, 105*, 1379–1386. doi:10.2105/AJPH.2015.302553.

Magee, J. C., Bigelow, L., Dehaan, S., & Mustanski, B. S. (2012). Sexual health information seeking online: A mixed-methods study among lesbian, gay, bisexual, and transgender young people. *Health Education and Behavior, 39*, 276–289. doi:10.1177/1090198111401384.

Masty, J., & Fisher, C. B. (2008). A goodness-of-fit approach to informed consent for pediatric intervention research. *Ethics and Behavior, 18*, 139–160.

Miller, V. A., Drotar, D., & Kodish, E. (2004). Children's competence for assent and consent: A review of empirical findings. *Ethics and Behavior, 14*, 255–295.

Miller, R. L., Forte, D., Wilson, B. D., & Greene, G. J. (2006). Protecting sexual minority youth from research risks: Conflicting perspectives. *American Journal of Community Psychology, 37*, 341–348.

Moilanen, K. L. (2015). Predictors of parental consent for adolescent participation in sexual health–related research. *Journal of Empirical Research on Human Research Ethics, 10*, 157–168. doi:10.1177/1556264615575510.

Moilanen, K. L. (2016). Why do parents grant or deny consent for adolescent participation in sexuality research? *Journal of Youth and Adolescence, 45*, 1020–1036. doi:10.1007/s10964-016-0445-y.

Moser, D. J., Schultz, S. K., Arndt, S., Benjamin, M. L., Fleming, F. W., Brems, C. S., … Andreasen, N. C. (2002). Capacity to provide informed consent for participation in schizophrenia and HIV research. *American Journal of Psychiatry, 159*, 1201–1207.

Mustanski, B. (2011). Ethical and regulatory issues with conducting sexuality research with LGBT adolescents: A call to action for a scientifically informed approach. *Archives of Sexual Behavior, 40*, 673–686. doi:10.1007/s10508-011-9745-1.

Mustanski, B., & Fisher, C. B. (2016). HIV rates are increasing in gay/bisexual teens: IRB barriers to research must be resolved to bend the curve. *American Journal of Preventive Medicine*. doi:10.1016/j.amepre.2016.02.026.

Mustanski, B., Newcomb, M., & Garofalo, R. (2011). Mental health of lesbian, gay, and bisexual youth: A developmental resiliency perspective. *Journal of Gay & Lesbian Social Services, 23*, 204–225. doi:10.1080/10538720.2011.561474.

National Human Research Protections Advisory Committee. (2001). *Children's workgroup report: April 2001 meeting*. Retrieved from http://www.hhs.gov/ohrp/nhrpac/mtg04-01/childworkgroup4-5-01.pdf.

Petrie, K. J., Faasse, K., Notman, T. A., & O'Carroll, R. (2013). How distressing is it to participate in medical research? A calibration study using an Everyday Events questionnaire. *JRSM Short Reports*. doi:10.1177/2042533313493271.

Ryan, C., Huebner, D., Diaz, R. M., & Sanchez, J. (2009). Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Pediatrics, 123*, 346–352.

Ryan, C., Russell, S., Huebner, D., Diaz, R., & Sanchez, J. (2010). Family acceptance in adolescents and the health of LGBT young adults. *Journal of Child and Adolescent Psychiatric Nursing, 23*, 205–213.

Saewyc, E. M., Bearinger, L. H., Blum, R. W., & Resnick, M. D. (1999). Sexual intercourse, abuse and pregnancy among adolescent women: Does sexual orientation make a difference? *Family Planning Perspectives, 31*, 127–132.

Santelli, J. S., Smith Rogers, A., Rosenfeld, W. D., DuRant, R. H., Dubler, N., Morreale, M., … Schissel, A. (2003). Guidelines for adolescent health research. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 33*, 396–409.

Secretary's Advisory Committee for Human Research Protections. (2005). Meeting presentations and reports (April 18–19, November 1). Retrieved from http://www.hhs.gov/ohrp/archive/sachrp/mtgings/mtg04-05/mtg04-05.htm.

Society for Adolescent Medicine. (2004). Confidential health care for adolescents: Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 35*, 160–167.

Steinberg, L. (2008). A social neuroscience perspective on adolescent risk-taking. *Developmental Review, 28*, 78–106. doi:10.1016/j.dr.2007.08.002.

Tornello, S. L., Riskind, R. G., & Patterson, C. J. (2014). Sexual orientation and sexual and reproductive health among adolescent young women in the United States. *Journal of Adolescent Health, 54*, 160–168. doi:10.1016/j.jadohealth.2013.08.018.

Tufford, L., Newman, P. A., Brennan, D. J., Craig, S. L., & Woodford, M. R. (2012). Conducting research with lesbian, gay, and bisexual populations: Navigating research ethics board reviews. *Journal of Gay & Lesbian Social Services, 24*, 221–240. doi:10.1080/10538720.2012.697039.

UCSD Task Force on Decisional Capacity. (2003). *Procedures for determination of decisional capacity in persons participating in research protocols*. Retrieved from http://irb.ucsd.edu/decisional.shtml

United Nations General Assembly. (1989). *Convention on the Rights of the Child* (A/RES/44/25). Retrieved from http://www.un.org/documents/ga/res/44/a44r025.htm

US Department of Health and Human Services. (2015). *Certificates of confidentiality*. Retrieved from https://grants.nih.gov/grants/policy/coc/index.htm.

Ybarra, M. L., DuBois, L. Z., Parsons, J. T., Prescott, T. L., & Mustanski, B. (2014). Online focus groups as an HIV prevention program for gay, bisexual, and queer adolescent males. *AIDS Education and Prevention, 26*, 554–564. doi:10.1521/aeap.2014.26.6.554.

Yeater, E., Miller, G., Rinehart, J., & Nason, E. (2012). Trauma and sex surveys meet minimal risk standards: Implications for Institutional Review Boards. *Psychological Science, 23*, 780–787. doi:10.1177/0956797611435131.