

Sexual and Gender Minority Adolescents' Views On HIV Research Participation and Parental Permission: A Mixed-Methods Study

CONTEXT: Sexual and gender minority adolescents are underrepresented in HIV research, partly because institutional review boards (IRBs) are reluctant to waive parental permission requirements for these studies. Understanding teenagers' perspectives on parental permission and the risks and benefits of participating in HIV research is critical to informing evidence-based IRB decisions.

METHODS: Data from 74 sexual and gender minority adolescents aged 14–17 who participated in an online focus group in 2015 were used to examine perspectives on the risks and benefits of participation in a hypothetical HIV surveillance study and the need for parental permission and adequate protections. Data were analyzed thematically; mixed methods analyses examined whether concerns about parental permission differed by whether teenagers were out to their parents.

RESULTS: Most adolescents, especially those who were not out to their parents, would be unwilling to participate in an HIV study if parental permission were required. Perceived benefits of participation included overcoming barriers to HIV testing and contributing to the health of sexual and gender minority youth. Few risks of participation were identified. Adolescents suggested steps that researchers could take to facilitate informed decision making about research participation and ensure minors' safety in the absence of parental permission; these included incorporating multimedia presentations into the consent process and explaining researchers' motivations for conducting the study.

CONCLUSIONS: Respondents believed that the benefits of HIV surveillance research outweighed the risks. Requiring parental permission may exclude many sexual and gender minority teenagers from taking part in HIV research, especially if they are not out.

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Sexual and gender minority adolescents in the United States are at heightened risk for adverse sexual health outcomes, including HIV.^{1–6} Adolescent men who have sex with men are disproportionately affected, accounting for three quarters of the nearly 1,900 new HIV cases each year among youth aged 13–19;⁷ however, this is likely an underestimate, as adolescents report extremely low rates of HIV testing.^{8,9} Although studies are scarce,^{10,11} research on transgender adults¹² and women who have sex with men and women^{13–15} suggest that these groups are also at increased risk of HIV infection.

Research is needed to improve our understanding of HIV epidemiology and identify strategies for increasing testing rates among sexual and gender minority adolescents. However, although the literature offers guidelines on navigating ethical and regulatory issues in adolescent sexual health research,^{16–20} researchers face challenges in obtaining approval from institutional review boards (IRBs).¹⁶ One key obstacle is that IRB decisions about sexual and gender minority adolescents' involvement in sexual health research are often based on personal judgment rather than on empirical data, in part because few studies have examined ethical issues surrounding these adolescents' participation in such research.^{21,22} We believe it is critical to involve adolescents when making ethical decisions about research that can affect their well-being.²³

Thus, in this study, we elicited sexual and gender minority adolescents' perspectives on participation in HIV surveillance research, on requirements that parents consent to adolescents' participation and on what constitutes adequate protections when parental consent requirements are waived.*

BACKGROUND

Barriers to HIV Research Inclusion

Guidelines issued by the U.S. government's Office for Human Research Protections state that if adolescents can legally consent to the treatment or procedure involved in a research study, they do not meet the regulatory definition of "children" and should not be required to have parental permission to participate.¹⁶ Many scholars have interpreted this to mean that in jurisdictions where adolescents can legally consent to HIV testing, they may consent to participate in research involving such testing, and that depriving them of this right would be unjust.^{16,17,19,24} However, IRBs apply these regulations to adolescent sexual health research unevenly; consequently, some study protocols require parental permission even though permission is not required for the same procedures outside of a research context.^{16,25,26}

*In this article, the word "parent" should be understood to refer both to biological parents and to legal guardians.

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Unfortunately, requiring parental permission is a major obstacle to sexual and gender minority adolescents' involvement in sexual health surveys,²¹ HIV prevention research²² and, likely, HIV surveillance studies. One survey found that sexual and gender minority adolescents, especially those of color and those with relatively little familial support, had negative attitudes toward requirements of parental permission for participation in sexual health research.²¹ Another study found that most parents of sexual and gender minority children supported waiving permission requirements for such youth to take part in HIV surveillance research.²⁷ Although these requirements are intended to protect adolescents from potential risks of research,²⁸ they might have the opposite effect for sexual and gender minority adolescents, who may be outed to unsupportive parents^{29–31} and subsequently abused or kicked out of their homes because of their identity.^{29,30} IRBs can approve waivers of parental permission requirements when studies are not otherwise feasible or when parental permission may not protect the adolescents.³² Adolescents' perspectives represent a critical lens through which to examine these issues.

Estimating Research Risks and Benefits

IRB review of a research protocol is best informed by accurate estimates of the risks of participation. Without ethics research to calibrate those estimates, IRBs may overestimate research risks.³³ In one study, IRB members' estimates of discomfort associated with study participation and everyday events were significantly greater than those of students and community members.³⁴ Empirical data on study participants' perceived and experienced discomfort is particularly useful in guiding IRB decision making when the primary risk of research is psychological discomfort. Furthermore, ethics research can help determine adolescents' capacity to consent to various research methodologies. Without such evidence to guide their decisions, IRBs must rely on subjective judgments,^{17,21,35} if they believe that study-related discomfort will be greater than discomfort encountered in everyday life or during routine physical or psychological examinations, the study is considered to pose "greater than minimal risk."³² Ethics research can assess the extent of research risks and help identify appropriate safeguards (e.g., having an adult serve as a youth advocate when parental permission requirements are waived).

While the anticipated benefits of research participation often receive less attention than the risks, investigators and IRBs need to ensure that such benefits are conveyed clearly to participants during the consent process. Benefits fall into two categories: those that directly help participants (e.g., diagnostic tests) and those that help society (e.g., increased knowledge). Ethics research can help identify direct benefits, particularly those that may be subjectively experienced; these include the opportunity for participants to voice their opinions, improved personal sexual health outcomes, feeling relief from telling researchers about their experiences, and feeling a sense of community from having participated in a study with other people like them.^{21,36–38}

METHODS

Sample, Recruitment and Enrollment

Participants were enrolled in a larger study on ethical issues in adolescent sexual health research.^{22,38} Youth were eligible to participate if they were aged 14–17; identified as a sexual minority (e.g., lesbian, gay, bisexual, queer, questioning) or a gender minority (e.g., transgender, nonbinary, genderqueer); were romantically interested in or had sex with cisgender male partners (i.e., they might engage in sexual behaviors associated with increased risk for HIV); had reliable access to a phone and the Internet; and lived in the United States. Participants were recruited through paid Facebook advertisements. Clicking on the advertisement directed individuals to an eligibility survey hosted on a Northwestern University website. Study staff called potential participants to confirm eligibility, review the consent form and answer any questions about the study. Then, study staff assessed participants' understanding of study procedures and decisional capacity by asking a series of questions about study procedures and possible risks, and of what they should do if they felt uncomfortable answering study questions or wanted to withdraw from the study.^{39,40} Youth were also asked questions to determine their safety and privacy while taking part in the study (e.g., whether they had access to a computer in a private place; whether their smartphone was password-protected). After participants demonstrated their understanding of the research procedures and confirmed that they were able to participate safely, study staff obtained verbal informed consent.

Procedures and Measures

Six online focus groups were conducted between February and April 2015 using a password-protected website. Four groups were stratified by age (14–15-year-olds and 16–17-year-olds) and gender identity. As these groups consisted predominantly of teenagers who were out to their parents, youth who were not out to their parents were recruited for two additional groups, which were otherwise identical. Each group consisted of 10–15 participants, in accordance with sample size guidelines for mixed-methods research,⁴¹ and took place over three consecutive days; two research team members served as moderators. Questions were posted each morning, and participants answered at their convenience. Moderators prompted participant responses as necessary. Participants received a \$30 gift card for their time.

Study procedures were approved by the Northwestern University and Fordham University IRBs. The parental permission requirement was waived on the grounds that it was not needed to protect the participants, and that appropriate protective mechanisms were in place; justification of such waivers has been described elsewhere.²¹ A certificate of confidentiality from the National Institutes of Health was obtained to protect the identities of participants in the event of legal or administrative actions requiring the release of study data.

Before taking part in the focus groups, participants completed a survey assessing their sociodemographic characteristics (e.g., age, birth sex, race and ethnicity) and their disclosure of their sexual orientation and gender identity to

others (i.e., whether they were out to “everyone,” to “most people,” to “some people” or to “no one”). Participants who were out to at least some people were asked if they were out to their parents; only those who were out to at least one parent were considered “out.” Other items assessed whether participants had sought sexual health services and STD testing and treatment in the past year, and whether they perceived that parental permission was required for these services.⁴²

Participants who posted in the focus group at least once daily, or at least three times in two days, were sent a post-focus group survey. Items assessed participants’ likelihood of participating in a hypothetical HIV testing study if parent permission were required; reasons why adolescents would or would not participate under such circumstances; reasons why researchers should or should not obtain parental permission for teenagers to be in an HIV testing study; adolescents’ perceptions of how difficult it would be to decline to be take part in such a study, measured on a scale from 1 (“very hard”) to 5 (“very easy”); whether adolescents thought it was more, less or equally likely that they would be tested for HIV if they were enrolled in a research study as opposed to on their own; whether adolescents’ concerns about confidentiality of HIV test results varied by setting (i.e., a doctor’s office or a study); and whether adolescents would have other privacy concerns if they were tested for HIV in a research study. Responses to open-ended survey items were included in qualitative analyses.

During the focus groups, the participants viewed a 5.5-minute video developed by the study team.⁴³ The video covered several topics: what HIV is, the risk of HIV infection among sexual and gender minority teenagers, rapid HIV tests, and procedures for a hypothetical HIV behavioral surveillance study of sexual and gender minority teenagers. Participants then responded to several questions and prompts. Youth were asked whether they would want to be in a study that included getting tested for HIV, and to explain why or why not. They were also asked to discuss with one another whether and how they could benefit from—or be harmed by—getting an HIV test in a research study. Finally, they were asked what researchers could do to help them decide if they wanted to be in an HIV testing study, if their parents were not involved in the decision.

Analysis

Focus group transcripts and open-ended survey responses were imported into the Dedoose software application. Analyses focused on individual-level transcripts, rather than on group narratives, to enable comparisons across individuals.⁴⁴ To identify excerpts that broadly represented each key topic covered during the focus group discussions, three root codes were applied to each transcript: HIV testing risks and benefits, parental permission, and informed consent for HIV testing. Next, we performed open coding to identify themes within these root codes. One coder reviewed the excerpts, generated a list of potential themes and noted any significant patterns of topics in the data. Another coder then identified additional emergent themes. These codes were refined

and in some case combined via comparison, discussion and consensus. The codes were applied to the excerpts, and coders continued to iteratively refine and reduce the number of codes. A third coder performed reliability testing on a subset of the excerpts. The pooled kappas were 0.80 for the codes concerning the risks and benefits of HIV testing (14 excerpts), 1.00 for the parental permission codes (19 excerpts) and 1.00 for the informed consent codes (10 excerpts), indicating excellent intercoder reliability.⁴⁵

We also conducted mixed-methods analyses to explore whether endorsement of the parental permission codes differed according to whether participants were out to their parents, which is relevant to the likelihood of seeking parental permission. In accordance with prior studies,^{46,47} we performed these analyses only on codes endorsed by at least five participants, and considered differences in code application rates of at least 20% to be meaningful. We present group differences as normalized percentages calculated by Dedoose, which account for differences in group size.⁴⁸ The normalization function operates by assigning a weight of 1 to the larger group and then assigning a weight to the other group as a function of the numeric relation between the number of members in the two groups. These weights are then used to adjust the number of raw counts of the relevant code to accomplish ratio equivalence across groups; the weighted percentage is calculated using these adjusted counts. Fisher’s exact test was used to identify differences in participants’ experiences with sexual health services.

RESULTS

Sample Characteristics

Eighty-two youth enrolled in the study. Eight withdrew before participating in the focus groups; some attributed their withdrawal to family reasons or to being too busy, while others gave no reason. The analytic sample consisted of 74

TABLE 1. Percentage distribution of sexual and gender minority adolescents aged 14–17 who took part in an online focus group examining participation in a hypothetical HIV testing study, by gender identity, 2015

Characteristic	All (N=74)	Cisgender female (N=39)	Cisgender male (N=29)	Transgender/nonbinary (N=6)
Age				
14–15	40.5	41.0	41.4	33.3
16–17	59.5	59.0	58.6	66.7
Birth sex				
Male	39.2	0.0	100.0	0.0
Female	60.8	100.0	0.0	100.0
Sexual orientation				
Gay/lesbian	35.1	12.8	72.4	0.0
Bisexual	58.1	76.9	27.6	83.3
Queer/questioning	6.8	10.3	0.0	16.7
Race				
White	68.9	76.9	58.6	66.7
Black	6.8	2.6	13.8	0.0
Asian	2.7	2.6	3.4	0.0
Multiracial/other	20.3	15.4	24.1	33.3
Missing	1.4	2.6	0.0	0.0

Table continues

TABLE 1 (continued)

Characteristic	All (N=74)	Cisgender female (N=39)	Cisgender male (N=29)	Transgender/nonbinary (N=6)
Ethnicity				
Hispanic/Latino	23.0	20.5	24.1	66.7
Other	77.0	79.5	75.9	33.3
Housing				
Lives with parents/family members	97.3	97.4	96.6	100.0
Other type of housing	2.7	2.6	3.4	0.0
Primary guardian*				
Parent	95.9	97.4	93.1	100.0
Extended family	29.7	25.6	34.5	50.0
Other	6.8	7.7	6.9	33.3
Father's education				
<high school	14.9	12.8	20.7	0.0
High school	25.7	20.5	34.5	16.7
>high school	43.2	48.7	34.5	50.0
Does not know	14.9	18.0	6.9	33.3
Missing	1.4	0.0	3.4	0.0
Mother's education				
<high school	13.5	12.8	17.2	0.0
High school	25.7	25.6	20.7	50.0
>high school	54.1	56.4	51.7	50.0
Does not know	5.4	5.1	6.9	0.0
Missing	1.4	0.0	3.4	0.0
Out to one or both parents				
Yes	52.7	35.9	69.0	100.0
No	45.9	61.5	31.0	0.0
Missing	1.4	2.6	0.0	0.0
Female parent accepts adolescent's sexual orientation†				
Yes	86.1	78.6	94.7	33.3
No	13.9	21.4	5.3	16.7
Male parent accepts adolescent's sexual orientation†				
Yes	85.2	90.0	86.7	50.0
No	14.8	10.0	13.3	50.0
Had HIV test in past six months				
Yes	12.2	7.7	17.2	16.7
No	86.5	92.3	79.3	83.3
Missing	1.4	0.0	3.4	0.0
Ever tested for STDs				
Yes	35.1	41.0	31.0	16.7
No	63.5	59.0	65.5	83.3
Missing	1.4	0.0	3.4	0.0
Prior STD diagnosis				
Yes	2.7	5.1	0.0	0.0
No	95.9	94.9	96.6	100.0
Missing	1.4	0.0	3.4	0.0
Total	100.0	100.0	100.0	100.0

*Participants could select multiple options. †Among respondents who were out to the parent. Notes: Percentages may not total 100.0 because of rounding.

adolescents (mean age, 15.9) who participated in at least one day of the focus groups; 39 identified as cisgender female, 29 as cisgender male and six as transgender or nonbinary (Table 1). The most common sexual orientation was bisexual, reported by 58% of all participants, 77% of cisgender females and 28% of cisgender males. Most participants were white (69%) and were not Hispanic or Latino (77%); nearly

all reported that they lived with their parents or other family members and that their primary guardian was a parent. Approximately half were out to at least one parent; of those, the vast majority reported that their parents accepted their sexuality. Most participants had not had an HIV test in the past six months (87%) and had never been tested for any STD (64%); only 3% of all participants had ever received a positive diagnosis for an STD.

Qualitative Findings

We identified 10 subcodes related to risks or benefits of HIV testing, five related to parental permission and five related to informed consent about HIV testing (Table 2).

• **Study risks.** While participants described several potential risks of HIV testing, relatively few mentioned risks related to testing in the context of a research study. In fact, 19 stated that testing during a research study presents no risk. Among participants who cited risks, the most commonly specified concern, cited by 31 youth, was loss of privacy and confidentiality, including the possibility that parents would discover that their child was taking part in a testing study without their approval and would become upset. For example, one participant commented:

“I don't see how getting tested for a study would bring you any harm....I guess the only way you could be harmed is if someone like a parent was unsupportive of your decision to participate in the study and found out about it.”
—Bisexual female, age 17, out

A minority of teenagers articulated concerns about the research team's knowledge of their HIV test results. For example, a 15-year-old bisexual youth, who was nonbinary and out, noted that “since it is a research study, [the] findings are going to be pored through and analyzed....I don't know if my privacy is going to be safe with all of those people.”

Twenty-five participants described emotional risks, in particular stress related to the testing process, such as waiting for results and the possibility of a positive HIV test. For example, a 15-year-old male, who was gay and out, said that “the only way you would be harmed from the testing is if it comes back positive, because then you would be worried with loads of questions, and you would even probably experience depression.” Less commonly, participants expressed concern that test results would cause shame or that doctors would make judgmental comments.

Nine participants would have other concerns if they learned they were HIV-positive, mostly reflecting the difficulty of disclosure. A 17-year-old bisexual female, who was not out, said, “I would mainly be worried about telling my mom and boyfriend, and maybe my previous partner. My parents probably would be super upset, and it'd hurt knowing I gave HIV to my best friend and my boyfriend.”

Six adolescents expressed concern that HIV testing would have unpleasant or harmful physical effects, such as pain from the blood draw or finger stick and infection resulting from an unsanitary testing environment. For example,

TABLE 2. Codes and subcodes, and number of sexual and gender minority adolescents who expressed related ideas and beliefs

Code/subcode	No. of adolescents
RISKS AND BENEFITS OF HIV TESTING RESEARCH	
No risks	19
Risks	53
Loss of privacy/confidentiality	31
Emotional harm	25
Effects of learning HIV-positive status	9
Physical harm	6
Hard to get treatment	2
Benefits	51
Knowing one's HIV status	39
Access to HIV testing, information and care	32
Contribution to research/society	21
Promotes safer sex	7
PARENTAL PERMISSION	
Reasons not to ask permission	34
Teenager might not want to talk to parent about sex/sexuality/HIV	14
Parent might have concerns about research participation	7
Teenager might be uncomfortable asking for permission	7
Teenager should have autonomy	6
Reason to ask permission	8
Parents would be supportive/agreeable	8
WAYS TO FACILITATE INFORMED CONSENT	
Any suggested	49
Present study details in transparent, age-appropriate manner	40
Explain pros/cons	20
Emphasize confidentiality	14
Build relationship/trust	8
Encourage consultation with person outside study	2

a 17-year-old gay, out male expressed concern that “if the person [doing the] testing was careless, I could be harmed or infected with the virus due to unclean tools....My cousin was infected [in this way].” Finally, two participants worried that it would be hard to get treatment for HIV, though this concern arose only when focus group moderators probed the issue.

•**Study benefits.** Participants described both direct and indirect benefits of HIV testing, including several specific to testing within a research study. The most frequently endorsed benefit, cited by 39 participants, was knowing one’s HIV status. Some noted that although this information could be obtained by seeking testing on one’s own, getting tested as part of a study would offer additional benefits or would otherwise be preferable; for example, a 15-year-old bisexual, out female confessed that she “would be too scared” to get tested on her own. Participants acknowledged that knowing their status could benefit their partners’ health and increase opportunities for HIV testing. A 17-year-old gay male noted that “If I...contracted [HIV], then all of my future partners could be affected.... It’s important for people to know if they’re infected or not, so the disease doesn’t spread any further.” Similarly, three teenagers mentioned that knowing they were HIV-negative

would reassure them that they were making good choices to reduce their HIV risk.

Another benefit, cited by 32 teenagers, was that study participation would facilitate access to HIV testing, information and care; many of the adolescents had never been tested, had encountered barriers to being tested on their own or both. Taking part in a study, they said, would enable them to get information about HIV and sexual health that they would not receive otherwise. For example, a 16-year-old female, who was queer and out, said that she would participate in the hypothetical study because after getting tested, “whether the answer is positive or negative, you will have gained more knowledge on HIV and how to prevent it.” Other participants noted that if they were to test positive, being in a research study would facilitate linkage to care and result in better health outcomes. A 15-year-old female, who was bisexual and out, commented:

“There’s a lot of pros to getting tested for HIV [in a study], because...you’d probably catch it early on if you didn’t go in for a test on your own....That could make it easier to deal with.”

Twenty-one teenagers highlighted how study participation could contribute to research and society. Some specifically mentioned that it could help to improve the health of the sexual and gender minority community. For example, a 17-year-old gay, out male said, “Even if I test negative, my test results...could help other LGBTQ [lesbian, gay, bisexual, transgender and queer] youth down the road.”

Finally, seven participants described how getting an HIV test could promote safer sex by increasing their motivation to change their sexual behaviors. As one teenager said:

“Many people can benefit from getting an HIV test just because the pressure and anxiety of waiting for your test result to come back can be a wakeup call to many people, and may influence them to take up better practices when having sexual intercourse.”—*Gay male, age 17, not out*

•**Reasons not to ask permission.** When participants were asked about their willingness to participate in HIV testing studies requiring parental permission, their responses reflected both concerns that seemed broadly applicable to all teenagers and ones specific to being a sexual or gender minority teenager.

The most frequent response was that teenagers would not want to talk to parents about sex, sexuality or HIV (14 participants). Most would not want to ask for permission because they would want to avoid revealing that they were sexually active; typically, such comments were made in conjunction with expressing reluctance to disclose sexual orientation or gender identity to parents. For example, a 17-year-old bisexual female who was not out said, “My parents don’t know about my sexual life or orientation, and HIV would be a somewhat connected topic that I wouldn’t feel comfortable talking to them about.” Most references to this theme (93%) were made by participants who were not out.

Seven teenagers expressed general emotional discomfort with the notion of asking for permission that was not

TABLE 3. Percentage distribution of sexual and gender minority adolescents, by reports of selected experiences with sexual health services, according to gender identity

Experience	All	Cisgender female	Cisgender male	Transgender/nonbinary
Received sexual health services in past year				
Yes	59.5	66.7	44.8	83.3
No	39.2	33.3	51.7	16.7
No response	1.3	0.0	3.5	0.0
Parental permission required for these services*				
Yes	20.5	30.8	7.7	0.0
No	72.7	61.5	84.6	100.0
Does not know	6.8	7.7	7.7	0.0
Received HIV/STD testing or treatment in past year				
Yes	27.0	30.8	24.1	16.7
No	71.6	69.2	72.4	83.3
No response	1.4	0.0	3.5	0.0
Parental permission required for these services*				
Yes	35.0	33.3	28.6	100.0
No	45.0	41.7	57.1	0.0
Does not know	10.0	16.7	0.0	0.0
No response	10.0	8.3	14.3	0.0
Total	100.0	100.0	100.0	100.0

*Among participants who had received such services in the past year. Note: Response patterns did not differ by adolescents' gender identity.

specific to being sexual or gender minority. For example, a 15-year-old bisexual, out male said, "My parents would ask me too many questions, and I wouldn't want to tell them [about the study] because they might get suspicious." Again, participants who expressed this theme generally were not out (86%).

Another barrier, also reported by seven participants, was that their parents might have concerns about their participation in research. Some respondents thought that their parents would be skeptical about the legitimacy of research studies and believed that their parents would not support or would simply forbid their participation. To a lesser degree, teenagers mentioned parental concerns about the study topic (e.g., that it was related to sex); for instance, a 15-year-old bisexual teenager who was not out said that his parents "wouldn't want me to get testing for HIV because they'd think it would encourage me to have sex." Endorsement of this theme did not differ by whether participants were out.

Finally, six participants, 85% of whom were out, discussed the notion of adolescent autonomy. These youth believed that they should have the freedom to make independent decisions about their sexual health. A 17-year-old out, bisexual male explained:

"I don't think that [HIV testing] is a topic where a teen should need special permission to participate....To me, it falls under the category of personal wellness, and that's just not something I should need my parents' consent for."

Another 17-year-old male, who was gay and out, offered another perspective on autonomy:

"If you can buy condoms without parent permission and have sex without going, 'Hey, Mommy, I'm gonna go have sex! Be back in two hours!' then you should be able to get confidential, free HIV testing without parent consent."

•**Reasons to ask permission.** Only eight participants described situations in which they would be willing to seek parental permission to participate in HIV testing research. These teenagers described their parents as being generally agreeable or characterized their relationship with their parents as supportive and caring. For example, a 17-year-old lesbian who was not out said, "I think my parents would value my safety over my sexuality." Seventy percent of participants who mentioned this theme were out.

•**Facilitating informed consent.** Participants were also asked how researchers could ensure that teenagers make informed, rational and voluntary decisions when parental permission requirements for a study are waived. Forty participants suggested that researchers present study details in a transparent, age-appropriate manner. In particular, they recommended providing clear and thorough explanations of study procedures, and supplementing standard informed consent forms with multimedia presentations to promote teenagers' understanding of and interest in the study. As one teenager explained:

"It would help if [researchers would] show videos and more information because...it can be more appealing, and [teenagers], especially more sexually active teenagers, would feel like they want to know more about the risks of HIV and contribute to the study."—*Bisexual female, age 17, not out*

In recommending a transparent, age-appropriate approach, some respondents cited aspects of the present study's recruitment and consent process that they felt enabled them to make informed decisions about participating: demonstrating the researchers' legitimacy (e.g., by having an informative, professional-looking study website); checking teenagers' understanding by quizzing them about the informed consent form and study procedures; and reminding teenagers of the ongoing nature of consent. IRBs commonly suggest the use of a youth advocate when parental permission requirements are waived; because this approach did not emerge from teenagers' discussions about preferred research protections, we asked participants for their thoughts about the idea. Only two participants thought that consulting with a person outside the study who was not a parent would be helpful in making sense of the study procedures, and one of them explained that speaking with a sibling would be the best option for her:

"My sister...knows I'm bisexual, and respects that because her best friend is a lesbian. She is over 26, so she is an adult. I would prefer to have researchers talk with her and not my mother. Just for safety."—*Bisexual female, age 15, out*

Another approach for enhancing the consent process, suggested by 20 participants, was explaining in more detail the pros and cons of study participation. Although teenagers wanted to know the risks, they also had a great deal of interest in learning how their involvement might benefit

TABLE 4. Percentage of sexual and gender minority adolescents who endorsed selected perspectives concerning research studies involving HIV testing, by gender identity

Perspective	All (N=59)	Cisgender female (N=32)	Cisgender male (N=22)	Transgender/nonbinary (N=5)
Would participate in HIV testing study if parental permission required				
No	44.1	53.1	31.8	40.0
Not sure	33.9	21.9	45.5	60.0
Yes	22.0	25.0	22.7	0.0
Perceived difficulty of declining to participate in HIV testing study				
Very easy	40.7	43.8	40.9	20.0
Somewhat easy	22.0	18.8	22.7	40.0
Neither hard nor easy	27.1	31.3	18.2	40.0
Somewhat hard	8.5	3.1	18.2	0.0
Very hard	1.7	3.1	0.0	0.0
Parental permission should be required for youth to participate in HIV testing study				
No	66.1	62.5	72.7	60.0
Not sure	22.0	25.0	13.6	40.0
Yes	11.9	12.5	13.6	0.0
Reasons parental permission should not be required*				
Parent might ask questions about my sexual behavior	59.3	53.1	68.1	60.0
Parent might punish me	39.0	37.5	40.9	40.0
Parent might find out I am LGBTQ	35.6	40.6	36.4	0.0
Parent might kick me out of my home	11.9	12.5	13.6	0.0
Other	11.9	12.5	9.1	20.0
Reasons parental permission should be required*				
Parent could help me if test results were positive	8.5	9.4	9.1	0.0
Parent could help explain risks and benefits of HIV testing	3.4	6.3	0.0	0.0
Parent could help me decline participation if I was not comfortable	3.4	6.3	0.0	0.0
Other	6.8	9.4	4.5	0.0
Likelihood of getting tested for HIV				
More likely to get tested if part of research study	59.3	75.0	36.4	60.0
Equally likely to get tested in a study and on my own	37.3	25.0	54.5	40.0
More likely to get tested on my own	3.4	0.0	9.1	0.0
Concern about confidentiality of HIV test				
More worried about confidentiality if tested at doctor's office	39.0	37.5	40.9	40.0
Not worried about confidentiality	47.5	50.0	50.0	20.0
More worried about confidentiality if part of research study	13.6	12.5	9.1	40.0
Concern about accuracy of HIV test				
More worried about accuracy if tested at doctor's office	6.8	3.1	9.1	20.0
Not worried about accuracy	79.7	75.0	86.4	80.0
More worried about accuracy if part of research study	13.6	21.9	4.5	0.0

*Participants were asked to "check all that apply." Note: LGBTQ=lesbian, gay, bisexual, transgender or queer.

other sexual and gender minority teenagers. For example, one 15-year-old female who was bisexual and out suggested that researchers "explain the positive outcome a study like this can evoke. They can explain that [teenagers] would be taking part in a program that can get [sexual and gender minority individuals] the proper education [about HIV]."

Furthermore, 14 participants indicated that researchers could facilitate teenagers' decision making by emphasizing confidentiality and privacy protections. Most of these youth would want explicit reassurance that their study participation would not be disclosed to their parents. Teenagers also expressed appreciation for the detailed description of the present study's privacy protections. One noted:

"The most important thing...is how the [researchers] stressed that it would be confidential. Confidentiality is a huge issue for many students and for me as well, and I very much appreciated the lengths gone to ensure my security."—*Bisexual male, age 16, out*

Finally, eight participants suggested that researchers could facilitate the informed consent process by building a trusting relationship with them—for example, by creating a welcoming, adolescent-friendly environment for in-person studies, or conveying a sense of respect and care for participants in online studies. A 16-year-old, out bisexual male suggested that researchers connect with participants on a more personal level to build trust: "for instance, [by explaining] how you got involved in a study like this and why it's important to you."

Quantitative Findings

In the pre-focus group survey, 60% of participants (though only 45% of cisgender males) indicated that they had received a sexual health service in the past year (Table 3). About three-fourths of adolescents who had received such services indicated that permission from a parent had not been required. Twenty-seven percent of participants had

been tested or treated for HIV or other STDs in the past year; a third of these adolescents stated that permission had been required.

Fifty-nine participants completed the post-focus group survey. Findings generally mirrored those of the focus group discussions. Three-fourths of respondents would be unwilling to enroll in an HIV testing study or were unsure of whether they would enroll if parental permission were required (Table 4). Moreover, 63% thought that it would be "somewhat" or "very" easy to decline to participate in a study that did not require a parent's consent, suggesting that most adolescents would not feel a need for a parent to protect them from being pressured to enroll. In fact, 66% believed that a parent's permission should not be required in studies involving HIV testing; only 12% thought that it should. The most frequently endorsed reasons for not requiring parental permission included concerns that parents might inquire about their adolescent's sexual behavior and might discover their adolescent's sexual orientation or gender identity. Although not mentioned in the focus groups, the possibility of being punished also concerned some adolescents.

Relatively few youth endorsed parental permission for an HIV testing study or provided reasons why researchers should obtain it; the most frequently cited reason was that parents could help adolescents who tested positive get connected to care. Finally, more than half of participants reported that they would be more likely to get tested if they were in a research study than if they were on their own, and the vast majority felt that HIV testing in a research study was at least as confidential as a test administered at their doctor's office. Few youth believed the accuracy of an HIV test would differ if it were administered in a doctor's office or as part of a research study.

DISCUSSION

Sexual and gender minority adolescents younger than 18 face a variety of obstacles that contribute to their underrepresentation in HIV prevention and surveillance research that can improve their health. As previous studies did,^{19,22,38} ours found that participants were concerned about privacy loss. In particular, many worried that a parent would learn about their participation in an HIV study and then ask sensitive questions, find out about their sexual or gender identity, or punish them. The risk of such outcomes may be minimized by use of research protocols that help protect adolescents' privacy. For example, as part of the consent process in a text-messaging HIV prevention study for adolescent men who have sex with men, research staff worked with participants to determine the potential consequences of loss of privacy and to identify potential research activities that could inadvertently compromise confidentiality.⁴⁹ The study also provided a "how to" guide that helped participants implement approaches to protecting their privacy in their daily lives, such as creating a password on their phone and clearing their browser history. If the adolescents felt that the potential loss of

privacy was too great or the consequences would place them in an unsafe situation, they were deemed ineligible to participate. Similar approaches could be adapted for studies involving HIV testing; for example, if an HIV testing kit would be sent through the mail, research staff could discuss with participants privacy and safety issues related to receiving the package.

The emotional risks that participants described were tied primarily to the HIV test itself, and not to the research context in which testing would be done. HIV testing is recommended by the Centers for Disease Control and Prevention for adolescents older than 13 as part of routine health care⁵⁰ and by the U.S. Preventive Services Task Force for adolescents older than 15 (and for younger adolescents at increased risk).⁵¹ Although HIV testing should be considered minimal risk and is recommended as part of routine adolescent health care, potential emotional risks can be reduced by ensuring that staff are trained in standard procedures for managing client stress during and after HIV testing and counseling sessions. Moreover, the context of these risks needs to be considered; the youth in our study were more likely to view the possibility of learning that they had HIV as a benefit of research than as a risk of research.

Participants expressed concern about disclosing HIV-positive test results to their parents and sexual partners, which underscores the importance of research teams' being prepared to counsel teenagers on revealing their status, if they choose to do so. Research teams also must be aware of their state's laws regarding disclosure of positive HIV test results to parents. Many states allow providers to disclose test results to parents if they believe such disclosure is in the minor's best interest, but do not require them to do so;²⁵ other states require providers to give minors a chance to tell their parents themselves. Because adolescents who will not or cannot safely disclose their status to their parents are at increased risk of discontinuing care, research is needed to identify the most effective methods of linking HIV-positive minors to services and ensuring that they continue receiving care. That youth are less likely than adults to receive services at every stage of the HIV care continuum underscores the need for such research.⁵²

Participants had much to say about the benefits of study participation. Few had ever had an HIV test, a finding consistent with prior research,^{8,9} and most indicated they would be more likely to get tested for a research study than on their own. Studies that include HIV testing thus provide an important direct benefit to sexual and gender minority adolescents. Participants also described how the testing experience would provide them a chance to reflect on their past HIV risk behaviors. When coupled with information provided by staff, this self-reflection could reinforce existing risk reduction behaviors or motivate safer choices in the future. The direct benefits of self-reflection during sexual health research has been described in the literature,³⁷ and we consider it appropriate to describe this as a possible benefit during the consent process.

Only one in five participants were willing to take part in an HIV testing study requiring parental permission, and many had concerns specific to being a sexual or gender minority. Findings regarding teenagers' privacy concerns and the repercussions of asking their parents for permission to participate in a study involving HIV testing illustrate the reasons underlying legal provisions permitting adolescents to consent to testing.⁵³ Allowing teenagers to seek testing and treatment for STDs without parental permission serves the policy goal of not deterring minors from seeking sexual health care and indicates that adolescents' need for STD testing and treatment overrides parents' interest in determining their children's health care.⁵⁴ The fact that a substantial minority of participants who had received sexual health services in the prior year believed they had needed their parents' consent or were unsure of whether they had needed consent speaks to the need for interventions that inform adolescents about their legal right to consent to STD testing and some other sexual health services.

When parental permission is not required for minors to undergo HIV testing in a research study, it is particularly important for researchers to optimize the consent process to ensure that adolescents' decisions are informed, rational and voluntary. Participants in our focus groups suggested that the consent process include multimedia presentations about the study, quizzes that assess teenagers' understanding of the study, and descriptions of the indirect benefits for other sexual and gender minority teenagers. Researchers should consider integrating such approaches into the consent process of their studies. In addition, several adolescents articulated the need for study staff to build a trusting relationship with participants by making them feel welcome and conveying respect. One suggestion was for research staff to explain their interest in conducting the study and how they became involved in it. These approaches can ensure that teenagers receive comprehensive yet developmentally appropriate study information, and that they feel comfortable communicating their decision to participate or not participate.

The U.S. Office for Human Research Protections' regulations regarding waiving parental permission requirements mandate that appropriate mechanisms be put in place to protect children.¹⁶ The types of mechanisms used depend on the nature of the research and the maturity level of the children; the regulations provide the example of a child advocate. None of the participants in our study spontaneously offered this suggestion, but when probed by the moderator, two agreed that consulting a person outside the study who is not a parent may help teenagers understand study procedures. Prior studies have found that well-trained staff can be effective in helping adolescents determine if research participation is safe and in their best interest.⁴⁹ This suggests that making available an external (i.e., nonstaff) youth advocate for sexual and gender minority adolescents participating in studies involving HIV testing may not be necessary.

Limitations

Recommendations that emerged from this work may not be applicable to other adolescent populations, such as heterosexual teenagers or those who do not have consistent access to the Internet. In addition, our participants may not be representative of all sexual and gender minority youth, as our advertisements targeted adolescents who were willing to indicate in their Facebook profile that they were interested in same-gender partners or sexual and gender minority topics. Finally, our sample included relatively few gender minority teenagers, whose perspectives on participating in sexual health research may differ from those of their cisgender and sexual minority peers.

Conclusion

Research to improve rates of HIV testing and linkage to care for sexual and gender minority adolescents is critically important. The sexual and gender minority adolescents in our sample believed that the benefits of participating in HIV research outweigh its risks, that requiring parental permission creates undue barriers to participation (especially for teenagers who are not out) and that researchers can help teenagers make informed participation decisions when parental permission requirements are waived. While further research—preferably using larger samples of adolescents and also including parents and IRB members—is needed on these topics, investigators and IRBs can begin using these empirical data to inform the inclusion of sexual and gender minority adolescents in research. Such inclusion will ultimately help narrow disparities in sexual health between this vulnerable population and other youth.

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