



HHS Public Access

Author manuscript

Health Psychol. Author manuscript; available in PMC 2021 January 01.

Published in final edited form as:

Health Psychol. 2020 January ; 39(1): 21–28. doi:10.1037/hea0000804.

Surveillance Studies Involving HIV Testing Are Needed: Will At-Risk Youth Participate?

Aaliyah Gray

Department of Psychology, Fordham University

Kathryn Macapagal, Brian Mustanski

Feinberg School of Medicine, Northwestern University

Celia B. Fisher

Department of Psychology, Fordham University

Abstract

Objectives.—Adolescent males who have sex with males (AMSM) account for high numbers of new HIV diagnoses. To date, surveillance data have been limited to diagnosed cases of HIV, resulting in an underestimation of risk and burden among AMSM unwilling or unable to access HIV testing. This study identified facilitators and barriers to AMSM’s participation in future surveillance studies involving HIV testing.

Methods.—198 AMSM 14 – 17 years participated. The majority identified as non-Hispanic white or Latinx, had a least 1 male sex partner, and self-reported HIV negative. Participants read an online survey that began with a vignette describing a hypothetical HIV surveillance study requiring HIV testing. They then completed questions assessing likelihood to participate, perceived research benefits and risks, attitudes toward HIV risk, prior HIV health services, and parental awareness of sexual orientation.

Results.—Approximately 40% indicated strong willingness to participate. Willingness was positively related to perceived HIV risk, free access to HIV testing, counseling and referral if testing positive, confidentiality protections, and lack of access to a trusted physician. Having to tell others if one tested positive for HIV and requirements for guardian permission were significant participation barriers.

Conclusions.—Inclusion of HIV testing in surveillance studies is essential for accurate estimation of HIV incidence and prevalence among AMSM. Successful recruitment of sexual minority youth into sexual health surveillance research will require procedures tailored to youth’s perceived healthcare needs and concerns, including adequate HIV counseling, referral to treatment if seropositive, and attention to AMSM concerns regarding guardian permission.

Correspondence should be addressed to: Aaliyah Gray, Department of Psychology, Fordham University, Bronx, NY 10458. agray11@fordham.edu.

Related presentations include Gray, A., Macapagal, K., Mustanski, B., & Fisher, CB (2019). “Surveillance Studies Involving HIV Testing Are Needed: Will Sexual Minority Adolescent Males Participate?” Society for Research in Child Development, Baltimore, MD, March 21 – 23; and, Gray, A., Macapagal, K., Mustanski, B., & Fisher, CB (2019). “Motivation to Participate in HIV Testing Research Among Adolescent Males who have Sex with Males.” American Psychological Association, Chicago, IL, August 8 – 11.

Keywords

Adolescents; LGBT youth; HIV testing; surveillance; health disparities

Historically, HIV surveillance research has helped to identify trends in HIV prevalence and behaviors among at-risk groups including men who have sex with men, ethnic minority men and women, and persons who use intravenous drugs (Family Health International, 2000). To date, surveillance studies have been predominantly utilized in research assessing populations of adults previously identified as seropositive, although intervention efforts for individuals at behavioral risk for HIV such as adolescent males who have sex with males (AMSM) would also benefit from this methodological approach.

In addition to increased risk for sexually transmitted infection (STI) (Centers for Disease Control and Prevention, 2018b), AMSM between 13 and 24 years of age account for disproportionately high numbers of new HIV diagnoses. According to the Centers for Disease Control and Prevention, AMSM accounted for 64% of HIV diagnoses among men who have sex with men (MSM) in 2016 (2018b) and 83% of new HIV diagnoses among 13 to 24 year olds in 2017 (2018a). Younger MSM, however, are less likely than older MSM to receive HIV testing and, in general, the least likely to be linked to HIV care (Centers for Disease Control and Prevention, 2018a; Phillips, Ybarra, Prescott, Parsons, & Mustanski, 2015). For these reasons, statistics on HIV prevalence among AMSM may actually underestimate the level of infection within this population since, with few exceptions (Balaji et al., 2018), surveillance research has been largely limited to medical records of those who have been tested for HIV or diagnosed as seropositive (Conron, Landers, Reisner, & Sell, 2014; Mahle Gray et al., 2013; Matthews & Lee, 2014).

In addition, current estimates of HIV risk may not be representative of young, untested adolescents who often are newly initiated to sexual activity or may not have the opportunity or desire to be tested, and consequently, remain undiagnosed. Thus, the integration of HIV testing within surveillance and other population-based studies is needed to ensure that prevention and treatment services are appropriately tailored to the needs of AMSM with and without access to HIV testing. To date, however, little is known about factors that will influence youths' motivations and decision to participate in such studies. Drawing on previous research, the current study sought to identify facilitators and barriers to AMSM participation in surveillance studies involving HIV testing.

Research involving sexual and gender minority (SGM) adolescents and young adults indicates many postpone or avoid HIV testing and do not request sexual health information from primary care providers (PCPs) because of anticipated stigma, institutional mistrust, fear of being outed, and a general belief that sexual and gender minorities do not receive equitable health services (Fisher, Fried, Desmond, Macapagal, & Mustanski, 2018; Fisher, Fried, Macapagal, & Mustanski, 2018; Macapagal, Greene, & Bhatia, 2016; Meanley et al., 2015). Along with research on SGM youth's attitudes toward participation in safety and efficacy trials testing pre-exposure prophylaxis (PrEP), the literature also suggests that for youth who have avoided, do not have independent health insurance, or cannot afford sexual minority affirming health care, research-provided access to free HIV testing and other sexual

health services may increase willingness to participate in surveillance research providing HIV testing (Fisher, Fried, Desmond, et al., 2018; Fisher, Fried, Ibrahim Puri, Macapagal, & Mustanski, 2018).

Fear of parental involvement may also influence AMSM willingness to participate in research providing HIV testing. Research indicates that requirements for guardian permission to obtain sexual health services are a barrier to accessing these services among AMSM and other adolescents. For example, Guttmacher Institute reports that 18% of 15–17 year olds and 7% of 18–19 years olds between 2013 and 2015 reported that they would not access sexual or reproductive health care such as pregnancy and STI testing because they did not want their parents to find out about obtaining such services (Guttmacher Institute, 2018). Specific to AMSM, prior research also suggests that fear of HIV stigma and guardian disclosure may be barriers to youth participation in surveillance studies involving HIV testing. For example, studies have documented SGM adolescents' reluctance to seek sexual health care or to participate in online sexual health surveys or biomedical prevention trials if guardian permission is required (Fisher, Arbeit, Dumont, Macapagal, & Mustanski, 2016; Macapagal, Coventry, Arbeit, Fisher, & Mustanski, 2016; Mustanski, Coventry, Macapagal, Arbeit, & Fisher, 2017; Nelson, Carey, & Fisher, 2018).

Increasing the integration of HIV testing in studies is necessary for more accurate estimates of HIV incidence and prevalence among AMSM and to facilitate direct links to care for youth who test seropositive (Geanuracos et al., 2007; Hood et al., 2017). The primary aim of the present study was to identify facilitators and barriers to participation in surveillance and other population risk-based studies involving HIV testing among AMSM. Based on prior research, we hypothesized that access to free HIV testing and related sexual health services, including referrals for youth testing seropositive, would positively motivate participation, especially for AMSM who had not discussed their sexual behavior with their primary care provider. We also hypothesized that guardian permission requirements and concerns regarding disclosure of HIV status would emerge as barriers to participation, especially for youth whose guardians were unaware of their sexual activity with male partners.

Methods

Participants

The sample of 198 AMSM ages 14–17 was drawn from a nationally administered Internet-based survey on sexual behavior, social stigma and acceptance, healthcare experiences and attitudes toward participation in HIV-related studies among sexual and gender minority youth (Fisher, Fried, Ibrahim Puri, et al., 2018; Fisher, Fried, Macapagal, et al., 2018). Recruitment occurred over a 4-week period in early 2017 using paid Facebook advertisements and a screener and survey created using LimeSurvey software. Interested participants completed an 11-item screening questionnaire to determine eligibility: age 14–17, having a male sex assigned at birth, at least one lifetime male anal sex partner, and self-reported HIV negative.

A total of 1,351 individuals completed the online screener. Of this total, 959 individuals were ineligible, a majority of whom were over 18 or did not report anal sexual activity with

another male; 392 individuals met inclusion criteria but 178 did not complete the survey; 14 youth failed attention checks (e.g., “To be sure you are still reading the content of these questions, please select “neither agree nor disagree” from the list of responses below”) and consistency validation (e.g., consistency between self-reported age in years provided as an open text box response and birthdate provided as drop-down response); and, lastly, 2 female participants were not included, leaving a final sample of 198 youth. Youth who completed the survey received a \$30 virtual, online gift card for participation which was emailed to them within 2–3 weeks. The email provided for compensation was not attached to participant responses. All study procedures were approved and guardian permission requirements were waived by the institutional review boards (IRB) at both Fordham University and Northwestern University.

Sample Considerations

A G* Power analysis for a binomial logistic regression yielded a requirement for 107 participants to achieve an effect size (OR; odds ratio) of 1.8, a power of .80, and alpha of .05. With a total sample size of 198, sufficient statistical power was achieved. Further, there were no significant differences between individuals who did and did not complete the survey on any demographic or sexual behavior/risk variables included in the screener. Additionally, the sample was geographically representative; participants were drawn from 42 states representing four regions of the United States including the Northeast ($n = 33$, 18.5%), Midwest ($n = 29$, 16.3%), South ($n = 58$, 32.6%), and West ($n = 58$, 32.6%).

Survey Items

Demographics, disclosure to guardians, HIV risk behaviors, and HIV testing.—Table 1 provides demographic information for the sample. Participants completed self-report questions about age, race/ethnicity, sexual orientation, education level, employment status, living situation, and socioeconomic status (SES) measured by primary guardian education. Likert-type items with ordinal response options were used to assess the degree to which AMSM agreed with statements regarding sexual orientation and sexual health experiences and their personal attitudes toward participation in a HIV surveillance study requiring HIV testing.

Four 4-point Likert-type items (1 = does not know or suspect, 4 = knows and we have talked about it) assessed whether youth’s primary guardian and PCP were aware of their sexual orientation and sexual activity with male partners. HIV risk questions included number of lifetime sexual partners, lifetime condomless anal sex occurrences, and recent (in the past 12 months) alcohol and drug use before sexual contact. Two items assessed lifetime HIV testing and HIV testing in the past year. Two 5-point Likert-type items (1 = none of the time, 5 = all of the time) assessed the extent to which youth perceived themselves at risk for HIV and worried about getting infected with HIV (Napper, Fisher, & Reynolds, 2012). An additional item (1 = never, 5 = always) asked whether youth had avoided getting an HIV or STI test because they were worried about being outed or criticized for being LGBTQ.

Vignette of a hypothetical surveillance study involving HIV testing.—A text vignette described a hypothetical HIV surveillance study that required HIV testing designed

to assess prevalence of HIV and its relationship to attitudes and behaviors related to HIV acquisition among teenagers. The vignette stated that the hypothetical study included pre-test counseling, HIV testing using either an oral swab or a finger stick, and a questionnaire to help researchers understand attitudes and behaviors that decrease or increase HIV risk among LGBTQ teens. Investigators would provide teens who tested positive with a list of options for community-based medical treatment sensitive to the needs of LGBTQ teens and would keep the results confidential unless the teen asked them to share results with a guardian or doctor. A similar vignette approach was successfully employed with a sample of sexual and gender minority youth to assess youth's ability to self-consent and their attitudes toward guardian permission requirements for a hypothetical pre-exposure prophylaxis (PrEP) adherence trial (Fisher et al., 2016).

Items assessing attitudes toward participation.—Following the description of the hypothetical surveillance study, youth responded to 18 Likert-type questions (1 = strongly disagree, 5 = strongly agree) assessing the likelihood of and motivations for participation in that study. These items were developed and refined from items in our prior research on healthcare experiences and attitudes toward HIV prevention research among adolescent and young adult MSM, review by a youth advisory council, and online piloting with a sample of 30 AMSM (Fisher et al., 2016; Fisher, Fried, Ibrahim Puri, et al., 2018). Table 2 provides wording of each item.

The first question assessed youth's willingness to participate followed by eight items assessing positive (e.g. free HIV testing, confidentiality protections, LGBTQ-sensitive counseling and sexual health education) and negative (learning and having to disclose to others seropositive HIV status) attitudes toward research-provided HIV testing. Four items assessed attitudes toward HIV testing from PCPs including whether they had a trusted doctor for HIV testing, were more comfortable and had less confidentiality concerns being tested by a doctor than a researcher, or more likely to get an HIV test through research than on their own. Two additional items asked whether youth would agree to participate if guardian permission was required and whether they believed this was important so that guardians would help if youth tested positive for HIV. The last 3 Likert-type items assessed the perceived benefits of referrals if youth tested positive and whether youth wanted researchers to facilitate communication of positive results to guardians through advice or direct communication.

Analytic Plan

Descriptive statistics were calculated for all variables. Pearson product-moment correlations, t-tests, and chi-squares assessed relationships among demographic factors, sexual history, facilitators and barriers toward participation, and attitudes toward referrals. Binary logistic regressions assessed the extent to which disclosure to primary care providers and guardians about sexual activity with males influenced research participation attitudes.

Results

Demographics, Sexual and HIV Testing History, and Sexual Orientation Disclosure to Primary Care Providers and Guardians

Demographics, sexual history, and disclosure of sexual orientation and sexual behavior to guardians and PCPs are reported in Table 1. Most participants were between 16 and 17 years, identified as non-Hispanic white or Hispanic/Latino, were in high school, unemployed, and lived with a guardian/parent. The majority of primary guardians were reported to have at least some college education.

Sexual and HIV testing history.—Overall, 34.8% of the sample had been tested for HIV in their lifetime. Participants reported a median of 2 male anal sex partners and 36.4% reported one lifetime condomless anal sex experience. Older youth reported significantly more male sexual partners ($r = .16, p < .05$), but age of youth was not significantly related to number of condomless events. Number of sexual partners and condomless sexual events were significantly related ($r = .88, p < .001$). About a third indicated they had consumed alcohol and a quarter indicated drug use before sexual contact in the past 12 months. A minority (14.6%) believed they were likely to become infected with HIV, but twice as many (28.3%) worried about HIV infection.

Disclosures.—Less than half of respondents (42.9%) had spoken to their PCP about their sexual orientation and only 31.3% reported their PCP knew they were sexually active with male partners. Over one-third (37.4%) of all youth had avoided HIV/STI testing due to concern about being outed or criticized for being LGBTQ. Sixty-six percent of youth indicated their primary guardian definitely knew about their sexual orientation, although only 29.8% indicated their primary guardian knew they were sexually active with male partners.

Willingness to Participate in Surveillance Research Involving HIV Testing

As illustrated in Table 1, a little less than half the respondents would strongly agree to participate in the study, while close to a third would somewhat agree. Demographic and sexual health items were not significantly associated with willingness to participate with one exception: The more likely youth believed they might become infected with HIV the more likely they were to participate ($r = .16, p < .05$).

Motivations to participate.—Table 2 provides descriptive data on attitudes toward participation in surveillance research involving HIV testing and Pearson correlations with the item assessing likelihood to participate. Reasons to participate including access to free HIV testing, wanting to know one's HIV status, trust that researchers would protect their confidentiality, research-provided LGBTQ-sensitive counseling and information referrals if they tested positive were endorsed by a majority of youth and significantly and positively correlated with likelihood to participate. Although only 7.6% did not want to know their HIV status, for over half the youth, having to tell other people if they were HIV positive was a significant barrier to participation that was significantly and negatively related to participation.

Medical mistrust.—Only 18.7% of AM SM indicated they already had doctors they trust for HIV testing, and approximately one-third of youth indicated they would be more comfortable getting an HIV test from a doctor than in a research study. Although both these items were negatively correlated with participation, only the former association yielded significance. A little over one-third of youth would be more worried about confidentiality in a doctor’s office than in research, and 65.7% indicated it would be easier to get tested if they participated in a research study than on their own. Both items were positively correlated with participation, although only the latter was significant. Youth who had never spoken to a PCP about sexual relationships with other males ($n = 136, 69\%$) were more likely to endorse statements indicating it would be easier to get tested in a study than in a doctor’s office ($OR = .73, 95\% CI = .56 - .95, p < .05$) and they would be more worried about HIV test confidentiality in a doctor’s office than in a research study ($OR = .71, 95\% CI = .57 - .90, p < .01$) compared to youth who had spoken to a PCP ($n = 62, 31\%$).

Guardian permission.—Less than 25% of youth would agree to be in a surveillance study involving HIV testing if guardian permission was required. However, the odds of agreeing with this statement were higher for AM SM whose guardian knew about their sexual activity with males ($n = 59, 30\%$) compared to those whose guardian did not know ($n = 139, 70\%$) ($OR = 1.74, 95\% CI = 1.40 - 2.16, p < .001$). Similarly, 23.7% agreed permission was important so that guardians could assist youth if they tested positive; although this item was not significantly related to willingness to participate. The odds of agreeing with this statement was also significantly greater for youth who had disclosed their sexual activity with males to guardians compared to those who had not ($OR = 1.56, 95\% CI = 1.23 - 1.99, p < .001$).

Testing positive for HIV.—The majority of youth believed they would benefit from getting referrals if they tested positive during the course of the study and this response was significantly correlated with likelihood of participation. The majority also wanted researchers to help them figure out how to communicate results of their HIV test to guardians. However, few wanted the researcher to be the one to tell their guardian that they tested positive for HIV. Neither item was significantly correlated with likelihood to participate.

Discussion

Meeting the National HIV/AIDS Strategy for 2020 to reduce the number of new HIV infections by 25% will require accurate estimations of the incidence and prevalence of HIV infection among AM SM, who account for disproportionately high numbers of new HIV diagnoses and are among at-risk populations least likely to be tested (Centers for Disease Control and Prevention, 2018a, 2018b). The accuracy of these estimates requires integrating HIV testing into current national surveillance strategies to reach untested AM SM who are often newly initiated to sexual activity or may not have the opportunity or desire to be tested, and consequently, remain undiagnosed.

Consistent with estimates of HIV testing among adolescents and young adults (Koenig, Hoyer, Purcell, Zaza, & Mermin, 2016) and lower estimates of testing among AM SM

(Phillips et al., 2015), in the present study only a third of the sexually active MSM respondents in our study had been tested. Although frequency of high-risk sexual encounters increased the likelihood that youth were tested, fear of testing positive emerged as an impediment to participation for some. Further, only 14% believed they were likely to be at HIV risk although a third indicated they often worried about their HIV risk. At the same time, however, almost two-thirds of youth indicated they would agree to participate, suggesting a majority of our sample would be motivated to participate in a surveillance study if HIV testing was offered. Past studies demonstrate that cognitive appraisals of personal HIV risk influence sexual risk taking and are related to health-promoting behavioral intentions (Gladis, Michela, Walter, & Vaughan, 1992). However, intention to be tested does not necessarily predict whether individuals obtain HIV testing in the future (McGarrity & Huebner, 2014). This underscores the importance of examining the psychosocial and institutional obstacles to HIV testing discussed below.

Medical mistrust.

One reason for low HIV testing rates among sexual and gender minority youth and young adults is anticipated bias and lack of trust in primary care providers (Hoyt et al., 2012; Macapagal, Greene, et al., 2016; Meanley et al., 2015). Over one-third of youth in the present study indicated they avoided HIV testing because of concern they would be “outed” or criticized for being LGBTQ. Anticipated bias and confidentiality concerns may thus be the reason why two-thirds of respondents believed it would be easier to get an HIV test if they participated in a research study than if they got tested on their own. As predicted, this belief was significantly greater in youth who had not discussed their sexual activity with male partners with a PCP. Across all respondents, endorsement of this item was positively related to the decision to participate in a surveillance study. Moreover, the majority were motivated to participate by a desire to know their HIV status, free access to HIV testing, and research-provided HIV counseling. These findings indicate a desire among sexually active MSM for access to HIV testing and provides support for the integration of HIV testing into surveillance studies.

Guardian permission.

The majority of respondents would not participate in a surveillance study involving HIV testing if guardian permission was required. These findings are consistent with prior research identifying guardian permission as a significant barrier to participation in HIV-related survey and biomedical prevention research for sexual and gender minority youth (Fisher et al., 2016; Macapagal, Coventry, et al., 2016; Mustanski et al., 2017). As predicted, youth whose guardians were unaware of their sexual activity with male partners were less likely to participate if guardian permission were required and less likely to believe their guardians would be supportive of their participation.

Despite support by scientific organizations to waive guardian permission requirements (American Psychological Association, 2018; Santelli et al., 2003), IRBs fail to do so because of confusion regarding the relationship between state mature minor laws and federal regulations permitting waiver of guardian permission, over-estimation of youth’s consent vulnerability, and lack of attention to data indicating that guardian permission risks

disclosing SGM youth's sexual orientation to guardians potentially resulting in family rejection, stigmatization or punishment (D'Amico & Julien, 2012; Fisher et al., 2016; Mustanski & Fisher, 2016). As documented in the current study and prior research, guardian permission requirements is likely to lower recruitment and may result in non-representative, biased samples in research involving minors in sexual health research (American Psychological Association, 2018; Fisher & Mustanski, 2014; Moore, Paul, McGuire, & Majumder, 2016; Mustanski & Fisher, 2016).

Prior research demonstrates that when developmentally-appropriate consent procedures are applied, youth as young as 14 years of age achieve adult levels for understanding the key elements of informed consent to HIV prevention research (Fisher et al., 2016). IRBs, however, are often reluctant to waive guardian permission for research in states that permit youth independent access to HIV testing (Moore et al., 2016). To ensure the representation of AMSM needed to accurately inform HIV prevention and treatment policy, federal funding agencies and investigators will need to work together to encourage states to interpret adolescent access to sexual health preventions more broadly and IRBs to apply federal regulations permitting youth to independently consent to surveillance research involving HIV testing.

Referrals for youth testing positive.

Integrating HIV testing into surveillance research will include an obligation to provide counseling, return of results, and referrals for youth testing HIV positive. For the majority of our respondents, referrals for treatment if they tested positive during the course of the study and advice on how to communicate the results to guardians were perceived as a benefit of participation. However, such obligations present challenges for national surveillance studies in terms of time, costs, and competencies required for staff training and identification of local referral sources (Office of Adolescent Health, 2018). The immediacy of results from rapid screening tests effectively used in non-clinical settings (Centers for Disease Control and Prevention, 2018c) can allow research staff to more readily connect youth testing positive to local referral sources. However, investigators will need to develop procedures that encourage participants to wait to receive results (Mollen, Lavelle, Hawkins, Ambrose, & Ruby, 2008) and although highly reliable, rapid tests require confirmatory follow-up testing with healthcare providers. Most youth will not be aware of the nature of follow-up assessments nor where to seek free or affordable HIV treatment, increasing the responsibility of researchers to ensure adequate pre-and post-testing counseling.

Strengths and Limitations

Our online data collection and recruitment methods yielded a national sample of sexually active AMSM. Nevertheless, this methodology does not allow for absolute certainty inclusion criteria were met and also limits participation to those who use the Internet, mobile phones, and social media. Additionally, our knowledge of HIV testing history was limited to youth self-report. Still, the confidential nature of the study may have increased comfort and honesty of responding, an opportunity critical to capture the views and concerns of hidden, socially vulnerable populations. Second, our study benefitted from adequate participation of youth who identified as Hispanic and non-Hispanic white; however, there was insufficient

representation of other racial/ethnic minority groups. Additional research is needed on how the intersections of ethnic and social minority status influence AMSM's motivations to participate (Macapagal, Greene, et al., 2016; Smalley, Warren, & Barefoot, 2016).

Conclusion

HIV sero-surveillance data is critical for the accurate estimation of HIV prevalence rates among AMSM that can assist local and national efforts to set HIV policy and priorities, design developmentally-appropriate prevention and treatment programs, and evaluate the effectiveness of government responses to the epidemic (UNAIDS/WHO Working Group in Global HIV/AIDS/STI Surveillance, 2001). To date, surveillance research relying on medical records of those who have been tested for HIV or diagnosed as seropositive are not representative of untested AMSM who often are newly initiated to sexual activity, refrain from HIV testing for fear of bias or confidentiality concerns, or may not have the opportunity or desire to be tested. Surveillance research involving HIV testing is thus needed to ensure prevention and treatment services are appropriately tailored to the needs of AMSM with and without access to HIV testing.

Integration of HIV testing within surveillance studies will face considerable economic and implementation challenges (Mahle Gray et al., 2013; Matthews & Lee, 2014; Myers et al., 2018). However, the findings of the present study strongly suggest these efforts will be rewarded by the participation of high numbers of AMSM who perceive such research as a means of learning their HIV status and benefiting from HIV counseling and referral services to which they would otherwise not have access. Successful recruitment for these studies will also depend on the ability of funding agencies, investigators, and AMSM advocates to successfully overcome IRB and statutory impediments to the right of youth to provide independent consent to research directly related to their health and the future health of other sexual minority youth.

Acknowledgments

This research was supported by NIMHD grant R01MD009561 to principal investigators Celia B. Fisher and Brian Mustanski.

References

- American Psychological Association. (2018). APA resolution on support for the expansions of mature minors' ability to participation in research. Retrieved January 13, 2019 from <https://www.apa.org/about/policy/resolution-minors-research.pdf>
- Centers for Disease Control and Prevention. (2018a, 4 20). HIV among youth. Retrieved January 13, 2019
- Centers for Disease Control and Prevention. (2018b, 9 26). HIV and gay and bisexual men. Retrieved January 13, 2019 from <https://www.cdc.gov/hiv/group/msm/index.html>
- Centers for Disease Control and Prevention. (2018c, 10 31). Testing. Retrieved January 13, 2019 from <https://www.cdc.gov/hiv/basics/testing.html#>
- Conron KJ, Landers SJ, Reisner SL, & Sell RL (2014). Sex and gender in the US health surveillance system: A call to action. *American Journal of Preventive Medicine*, 104(6), 970–976. doi: 10.2105/AJPH.2013.301831

- D'Amico E, & Julien D (2012). Disclosure of sexual orientation and gay, lesbian, and bisexual youths' adjustment: Associations with past and current parental acceptance and rejection. *Journal of GLBT Family Studies*, 8(3), 215–242. doi: 10.1080/1550428X.2012.677232
- Family Health International. (2000). Behavioral surveillance surveys: Guidelines for repeated behavioral surveys in populations at risk hiv. Retrieved from http://www.who.int/hiv/strategic/en/bss_fhi2000.pdf
- Fisher CB, Arbeit M, Dumont M, 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*, 11(1), 3–14. doi: 10.1177/1556264616633963 [PubMed: 26956988]
- Fisher CB, Fried AL, Desmond M, Macapagal K, & Mustanski B (2018). Perceived barriers to HIV prevention services for transgender youth. *LGBT Health*, 5(6), 350–358. 10.1089/lgbt.2017.0098 [PubMed: 30070960]
- Fisher CB, Fried AL, Ibrahim Puri L, Macapagal K, & Mustanski B (2018). “Free testing and PrEP without outing myself to parents:” Motivation to participate in oral and injectable PrEP clinical trials among adolescent men who have sex with men. *PLOS ONE*, 13(7), 1–19.
- Fisher CB, Fried AL, Macapagal K, & Mustanski B (2018). Patient-provider communication barriers and facilitators to HIV and STI preventive services for adolescent MSM. *AIDS Behavior*, 22(10), 3417–3428. [PubMed: 29546468]
- Fisher CB, & Mustanski B (2014). Reducing health disparities and enhancing the responsible conduct of research involving LGBT youth. *Hastings Cent Rep*, 44 Suppl 4(0 4), S28–S31.
- Geanuracos CG, Cunningham SD, Weiss G, Forte D, Reid LM, & Ellen JM (2007). Use of geographic information systems for planning HIV prevention interventions for high-risk youths. *American Journal of Preventive Medicine*, 97(11), 1974–1981. doi: 10.2105/AJPH.2005.076851
- Gladis MM, Michela JL, Walter HJ, & Vaughan RD (1992). High school students' perceptions of AIDS risk: Realistic appraisal or motivated denial? *Health Psychology*, 11(5), 307–316. [PubMed: 1425548]
- Guttmacher Institute. (2018, February 1). Minors' access to STI services. Retrieved January 13, 2019 from <https://www.guttmacher.org/state-policy/explore/minors-access-sti-services>
- Hood JE, Katz DA, Bennett AB, Buskin SE, Dombrowski SE, Hawe SE, & Golden MR (2017). Integrating HIV surveillance and field services: Data quality and care continuum in King County, Washington, 2010–2015. *American Journal of Preventive Medicine*, 107(12), 1938–1943. doi: 10.2105/AJPH.2017.304069
- Hoyt MA, Rubin LR, Nemeroff CJ, Lee J, Huebner DM, & Proeschold-Bell RJ (2012). HIV/AIDS-related institutional mistrust among multiethnic men who have sex with men: Effects on HIV testing and risk behaviors. *Health Psychology*, 31(3), 269–277. doi: 10.1037/a0025953 [PubMed: 22059617]
- Koenig LJ, Hoyer D, Purcell DW, Zaza S, & Mermin J (2016). Young people and HIV: A call to action. *American Journal of Preventive Medicine*, 106(3), 402–405. doi: 10.2105/AJPH.2015.302979
- Macapagal K, Coventry R, Arbeit MR, Fisher CB, & Mustanski B (2016). “I won't out myself just to do a survey:” Sexual and gender minority adolescents' perspectives on the risks and benefits of sex research. *Archives of Sexual Behavior*, 46(5), 1393–1409. [PubMed: 27469352]
- Macapagal K, Greene GJ, & Bhatia R (2016). Differences in healthcare access, use, and experiences within a community sample of racially diverse lesbian, gay, bisexual, transgender, and questioning emerging adults. *LGBT Health*, 3(6), 434–442. doi: 10.1089/lgbt.2015.0124 [PubMed: 27726496]
- Mahle Gray K, Tang T, Shouse L, Li J, Mermin J, & Hall HI (2013). Using the HIV surveillance system to monitor the National HIV/AIDS Strategy. *American Journal of Preventive Medicine*, 103(1), 141–147. doi: 10.2105/AJPH.2012.300859
- Matthews DD, & Lee JGL (2014). A profile of North Carolina lesbian, gay, and bisexual health disparities, 2011. *American Journal of Preventive Medicine*, 104(6), e98–e105. doi: 10.2105/AJPH.2013.301751

- McGarrity LA, & Huebner DM (2014). Behavioral intentions to HIV test and subsequent testing: The moderating role of sociodemographic characteristics. *Health Psychology, 33*(4), 396–400. 10.1037/a0033072 [PubMed: 23795706]
- Meanley S, Gale A, Harmell C, Jadwin-Cakmak L, Pingel E, & Bauermeister JA (2015). The role of provider interactions on comprehensive sexual healthcare among young men who have sex with men. *AIDS Education and Prevention, 27*(1), 15–26. doi: 10.1521/aeap.2015.27.1.15 [PubMed: 25646727]
- Mollen C, Lavelle J, Hawkins L, Ambrose C, & Ruby B (2008). Description of a novel pediatric emergency department-based HIV screening program for adolescents. *AIDS Patient Care and STDs, 22*(6), 505–512. [PubMed: 18462077]
- Moore QL, Paul ME, McGuire AL, & Majumder MA (2016). Legal barriers to adolescent participation in research about HIV and other sexually transmitted infections. *American Journal of Preventive Medicine, 106*(1), 40–44. doi: 10.2105/AJPH.2015.302940
- Mustanski B, Coventry R, Macapagal K, Arbeit MR, & Fisher CB (2017). Sexual and gender minority adolescents' views on HIV research participation and parent permission: A mixed-methods study. *Perspectives on Sexual Reproductive Health, 49*(2), 111–121. doi: 10.1363/psrh.12027 [PubMed: 28445608]
- Mustanski B, & Fisher CB (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, 51*(2), 249–252. [PubMed: 27061893]
- Myers JE, Edelstein ZR, Daskalakis DC, Gandhi AD, Misra K, Rivera AV, ... Braunstein SL (2018). Preexposure Prophylaxis Monitoring in New York City: A Public Health Approach. *American Journal of Public Health, 108*(S4), S251–S257. doi: 10.2105/AJPH.2018.304729 [PubMed: 30383427]
- Napper LE, Fisher DG, & Reynolds GL (2012). Development of the perceived risk of HIV scale. *AIDS Behav, 16*(4), 1074–1083. 10.1007/s10461-011-0003-2
- Nelson KM, Carey MP, & Fisher CB (2018). Is guardian permission a barrier to online sexual health research among adolescent males interested in sex with males? *Journal of Sex Research, 1*–11.
- Office of Adolescent Health. (2018). Linkages and referrals to services. Retrieved January 13, 2019 from <https://www.hhs.gov/ash/oah/resources-and-training/tpp-and-paf-resources/linkages-and-referrals-to-services/index.html>
- Phillips G, Ybarra ML, Prescott TL, Parsons JT, & Mustanski B (2015). Low rates of human immunodeficiency virus testing among adolescent gay, bisexual, and queer men. *Journal of Adolescent Health, 57*(4), 407–412. [PubMed: 26318671]
- Santelli JS, Smith Rogers A, Rosenfeld WD, DuRant RH, 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*(5), 396–409. doi: 10.1016/j.jadohealth.2003.06.009 [PubMed: 14596961]
- Smalley KB, Warren JC, & Barefoot KN (2016). Differences in health risk behaviors across understudied LGBT subgroups. *Health Psychology, 35*(2), 103–114. [PubMed: 26375040]
- UNAIDS/WHO Working Group in Global HIV/AIDS/STI Surveillance. (2001). Guidelines for using HIV testing technologies in surveillance. Retrieved January 13, 2019 from https://www.who.int/hiv/pub/surveillance/en/guidelinesforUsingHIVTestingTechs_E.pdf

Table 1:

Frequency of Responses and Percent Agreement for Demographic Characteristics, Guardian and PCP Disclosure, HIV Risk and Testing Items, and Willingness to Participate

General Demographics	Frequency and Percent (N= 198)	
Age	<i>M</i> = 16.20, <i>SD</i> = .82	
14	8 (4.0%)	
15	27 (13.6%)	
16	80 (40.4%)	
17	83 (41.9%)	
Race/ethnicity		
Black or African American	9 (4.5%)	
Asian/Pacific Islander	10 (5.1%)	
White	100 (50.5%)	
Hispanic/Latino	68 (34.3%)	
More than one race	8 (4.0%)	
Other	1 (0.5%)	
Sexual Orientation		
Gay	164 (82.8%)	
Bisexual	26 (13.1%)	
Pansexual	5 (2.5%)	
Other	3 (1.5%)	
Education level		
High school	195 (98.5%)	
College	1 (.5%)	
Not in school	1 (.5%)	
Employment status		
Working part-time	72 (36.4%)	
Not working	124 (62.6%)	
Living with guardian	194 (98.0%)	
Highest education level of primary guardian		
High school or less	60 (30.8%)	
Some college	40 (20.2%)	
College degree	29 (14.6%)	
Graduate degree	64 (32.3%)	
HIV Testing History		
Has been tested for HIV (lifetime)	69 (34.8%)	
Has been tested for HIV (in the past year)	64 (32.3%)	
HIV Risk Behaviors	<i>M</i> (<i>SD</i>)	<i>N</i> (%)
Lifetime number of male (whose birth sex and gender identity are male) anal sex partners	3.36 (4.58) Median = 2	Range=1–35 Mode=1

General Demographics	Frequency and Percent (N= 198)	
Age	<i>M = 16.20, SD = .82</i>	
Number of times engaging in condomless anal sex with male partners	1.83 (2.96) Median = 1	Range=0–25 Mode=1
Has consumed alcohol before having sexual contact with a male or transgender female partner in the past 12 months	1.65 (1.02)	70 (35.4%)
Has used drugs before having sexual contact with a male or transgender female partner in the past 12 months	1.45 (.87)	50 (25.3%)
Attitudes toward HIV Risk	<i>M (SD)</i>	<i>N (%)</i>
Believes they are extremely or somewhat likely to become infected with HIV	2.14 (1.07)	29 (14.6%)
Worries all or a lot of the time about getting infected with HIV	2.84 (1.12)	56 (28.3%)
Has avoided getting tested for HIV or an STI because “I was worried that I would be ‘outed’ or criticized for being LGBTQ”	1.95 (1.42)	74 (37.4%)
Guardian and Provider Knowledge of Sexual Orientation and Sexual Activity with Males	<i>M (SD)</i>	<i>N (%)</i>
Guardian knows about your sexual orientation	3.07 (1.20)	132 (66.6%)
Guardian knows you are sexually active with male partners	2.08 (1.11)	59 (29.8%)
In the past I have spoken to a doctor, nurse or other healthcare provider about my sexual orientation	1.86 (1.23)	85 (42.9%)
In the past I have spoken to a doctor, nurse or other healthcare provider about having sex with male partners	1.63 (1.10)	62 (31.3%)
I would be willing to participate in a study if it required me to get an HIV test.	3.84 (1.35)	<i>N (%)^a</i>
Strongly disagree		20 (10.3%)
Somewhat disagree		19 (9.7%)
Neither agree nor disagree		18 (9.1%)
Somewhat agree		53 (27.2%)
Strongly agree		85 (43.6%)

^aPercent based on 195 valid responses

Table 2:

Frequency of Responses and Percent Agreement with Willingness to Participate Among Attitudes Toward HIV Testing and Research-Provided Access to Sexual Health Services

Attitudes Toward HIV Testing in Research	<i>M (SD)</i>	<i>N (%)^a</i>	Correlation with Likelihood to Participate in HIV Testing Study
I could get the HIV test for free	4.32 (.98)	151 (76.3%)	$r = .29^{***}$
I would want to know if I have HIV	4.61 (.84)	184 (92.9%)	$r = .18^{**}$
I would trust the researcher to protect my confidentiality	4.20 (1.08)	161 (81.3%)	$r = .42^{***}$
I could benefit from the counseling about sexual health specifically for LGBTQ teens	4.08 (1.05)	148 (74.7%)	$r = .16^*$
I could talk about my sexual orientation with people who know about HIV risk	4.14 (1.05)	159 (80.3%)	$r = .25^{***}$
Being in an HIV testing study would help me learn more about protecting my sexual health	4.07 (1.07)	150 (75.8%)	$r = .43^{***}$
I do not want to know if I have HIV	1.51 (1.02)	15 (7.6%)	$r = -.20^{**}$
If I found out I had HIV, I would have to tell other people	3.41 (1.30)	115 (58.1%)	$r = -.15^*$
Attitudes toward Doctor versus Research-Provided HIV Testing	<i>M (SD)</i>	<i>N (%)^a</i>	
I already have doctors I trust who test me for HIV	1.93 (1.26)	37 (18.7%)	$r = -.17^*$
I would feel more comfortable getting an HIV test from my doctor than from a researcher conducting an HIV testing study	2.99 (1.31)	67 (33.8%)	$r = -.11$
I would be more worried about the confidentiality of an HIV test if I took it at my doctor's office than if I took it as part of an HIV testing study	3.07 (1.37)	77 (38.9%)	$r = .13$
It would be easier for me to get tested if I was in an HIV testing study than if I decided to get tested on my own	3.83 (1.12)	130 (65.7%)	$r = .39^{***}$
Guardian Involvement and Attitudes Toward Research Participation	<i>M (SD)</i>	<i>N (%)^a</i>	
I would agree to participate in the HIV testing study for LGBTQ teens if I had to get my parent's or guardian's signed permission	2.20 (1.47)	49 (24.7%)	$r = .30^{***}$
If I was in a study that involved HIV testing, getting my parent's permission would be important so that they can help me if the test showed I had HIV	2.50 (1.32)	47 (23.7%)	$r = .14$
Attitudes Towards Testing Positive for HIV	<i>M (SD)</i>	<i>N (%)^a</i>	
I could benefit from getting referrals for treatment if I tested positive during the study	4.43 (.87)	168 (84.8%)	$r = .20^{**}$
If I tested positive for HIV during the study, I would want the researchers to help me figure out how to tell my parents, guardians, or another adult I am close to	4.22 (1.27)	161 (81.3%)	$r = .14$
If I tested positive for HIV during the study, I would want the researchers to tell my parents for me	2.18 (1.34)	38 (19.2%)	$r = .03$

^aFrequency and percent agreement based on responses indicating strongly or somewhat agree with item

* $p < .05$

** $p < .01$

*** $p < .001$