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Engaging sexual minority adolescents in nationwide at-home HIV prevention research in the U.S

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ABSTRACT

Objectives: This study examined research-related privacy and confidentiality concerns among adolescent sexual minority males (ASMM) and provides lessons learned to inform recruitment and enrollment strategies for this population.
Methods: Participants were a 2017–2018 internet-based U.S. national sample of sexual minority adolescents who responded to self-report measures of privacy and confidentiality concerns. Results: Bivariate chi-square tests were used to identify participants' mean differences in worry and likelihood of privacy breach occurrences. Many participants reported privacy-related concerns within remote HIV prevention research.
Conclusions: Study protocols were designed to ensure participants felt safe participating in online HIV prevention research. However, there are challenges to enroll participants with rigorous protocols for ensuring safety and privacy.

1. Introduction

Despite a slight decline in HIV incidence over the past decade, adolescent sexual minority males (ASMM) are disproportionately impacted by the HIV epidemic in the United States (US). In 2021, 19 % of new HIV diagnoses were among youth aged 13–24, most of whom identified as a sexual minority (CDC, 2021). Factors perpetuating the HIV epidemic among adolescents are rooted in systemic injustices, including poverty, racism, homophobia, and lack of access to healthcare and education (Allan-Blitz et al., 2021). ASMM also undergo psychological, social, physical, and cognitive transitions (e.g., more independent and self-aware, advanced problem-solving skills, and may struggle with issues such as self-esteem) during adolescence that impact HIV risk. Yet opportunities to participate in prevention research during this pivotal developmental stage remain scarce due to a confluence of societal, political, and institutional barriers (e.g., stigma and discrimination, access to care, legal and ethical issues, socio-economic factors) (Steinberg, 2008; Mustanski et al., 2011).

Mobile technology, including the Internet and mobile phone applications ("apps"), have become important venues for information gathering, communication, and social networking among adolescents. It is therefore a strategic method for health researchers and providers to access and engage adolescents using a person-centered approach. Likewise, mobile technology studies are one of several approaches to conduct online assessments and deliver interventions (Hall et al., 2015). Prior research indicates that ASMM not only use mobile technology to access sexual health information, but they also find mobile phone–based HIV prevention interventions acceptable (Gilbey et al., 2022). These findings support prior research that has found high rates of Internet use among ASMM, partially due to interest specific online resources and social support for lesbian, gay, bisexual and transgender populations (Craig et al., 2021). Researchers are, therefore, in the unique position to leverage mobile technologies to engage ASMM in HIV prevention studies.

Ethical and legal factors, such as adolescent vulnerability, capacity for research-related decision-making, confidentiality and privacy

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concerns, and minor consent laws, may deter researchers and ultimately hinder efforts to end the HIV epidemic. Understanding the unique human subjects' protections issues in online and mobile research that differ from those encountered in traditional in-person research among ASMM is imperative. Given the limited focus on ASMM participation in remote, online HIV prevention research, this paper examines ASMM privacy and confidentiality concerns to inform future recruitment and enrollment protocols for this highly important, yet often excluded, research population. The steps used to help protect ASMM privacy and confidentiality are illustrated in Fig. 1.

2. Methods

The study sample of ASMM draws from the screening and baseline data of Understanding New Infections Through Targeted Epidemiology (UNITE), a national longitudinal cohort study prospectively following SMM to better understand risk factors for HIV infection (Rendina et al., 2021). Data were collected between November 2017 and September 2018. Online strategies across a range of venues were used during recruitment, including geosocial networking apps, social media sites, website referrals, and email blasts. Interested respondents completed a brief online screener that assessed eligibility criteria including: (1) being at least 16 years old; (2) identifying as male (including transmen); (3) not reporting heterosexual identity; (4) reporting HIV negative or unknown status; (5) reporting using any app to find a potential sex partner in the past six months; and (6) reporting sexual HIV risk in the past six months. Additional information on eligibility criteria can be found in the UNITE enrollment manuscript (Rendina et al., 2021).

During the phone-based screening, staff described the sensitive nature of survey topics, consisting of a range of questions about sociodemographic characteristics, relationships, sexual behaviors, substance use, HIV and sexually transmitted infections (STI) testing behaviors, and HIV prevention and care. Study staff asked participants about their own practices related to privacy (e.g., access to password-protected phone). Participants were asked to respond affirmatively that they understood the risks of participating, including that their parents might learn of their participation. Study staff informed all those reached by phone that if they were to experience an adverse event due to their study

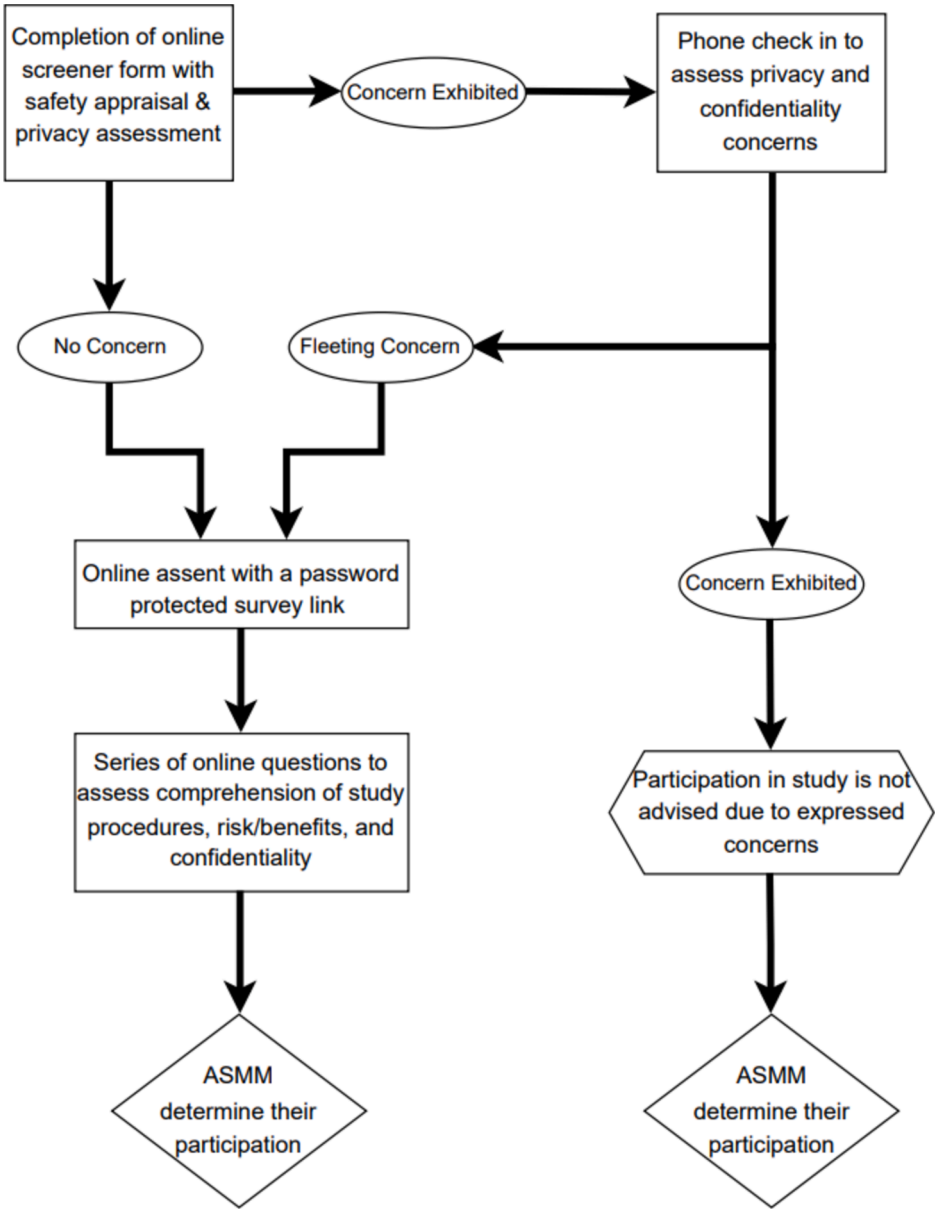

Fig. 1. Overview of Safety Appraisal & Privacy Assessment in a 2018 U.S HIV Prevention Study of ASMM. Abbreviation: ASMM, Adolescent Sexual Minority Males.

participation, staff would assist them in obtaining resources.

Upon receiving a call from our staff and before initiating the phone-based screening, 15 participants (6.3 %) indicated that they were not interested in participating in the study. Although privacy concerns were not cited during the conversation, we were unable to determine why these participants were no longer interested. After completing phone-based screening, one participant indicated major concerns about privacy and withdrew his participation for fear of being kicked out of his house.

During the phone-based screening, participants were informed that they would receive an HIV testing kit and, for half (based on randomization), a swab for testing rectal gonorrhea and chlamydia (Rendina et al., 2021). If participants indicated worry or were concerned about their participation, the study staff would discuss options for receiving their test kits at an address other than their home (e.g., local health center). The study staff prepared scripts for coordinating with such organizations to facilitate this process. In total, five participants requested that their package be sent to an alternate address, yet study staff were unable to confirm a different address upon follow-up.

Consistent with recommendations from the Society of Adolescent Medicine, the Department of Health and Human Services, and empirical research, a waiver of parental permission was obtained for this study (Bauman et al., 2020; Mustanski, 2011; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; Sigman et al., 1997). To aid participants in making the best decision for themselves about adolescent participation during the assent process, all eligible ASMM were informed about specific situations that necessitate breaks in confidentiality and to whom their identifying information may be disclosed, including mandated reporting to service providers (e.g., suicidality), welfare agencies (e.g., child abuse), or the health department (e.g., new diagnosis of certain STIs). During the assent process, participants were asked true/false questions designed to assess their capacity to understand, appreciate, reason with, and express a choice about participation in the study. If a participant selected the incorrect response, the correct answer would be displayed with an explanation. After assent, participants could access a link providing information about their participation, which they could give to a parent or guardian.

Following the screener, participants provided online consent or assent and completed an online questionnaire survey capturing sociodemographic characteristics, elements of the syndemics and minority stress models (e.g., depression, stigma) (Meyer, 1995; Stall et al., 2003) as well as HIV and STI testing and prevention practices. Upon completion of the survey, participants were directed to a follow-up survey that was designed to re-confirm their previously collected contact information and gather mailing address information for the purposes of HIV and STI home-based testing. Following submission of this contact information and before being sent an at-home testing kit, participants were required to respond to an automated text message to verify their phone number and prevent multiple attempts at participation. Participants were compensated with a $25 Amazon e-gift card at baseline. The City University of New York Institutional Review Board approved all study procedures.

Using features within the Qualtrics platform, participants were required to create and use a unique password along with their email address to access the baseline online survey. All subsequent study-related links sent required participants' unique password to open, ensuring the confidentiality of their information. The password-protection process continued for participants until they reached 18 years of age; those who reported being 16 at the time of enrollment were required to set up a new password for links related to the first year of follow-up. All safeguards were executed according to the study protocol. None of the participants expressed any issue with study participation once enrolled.

2.1. Participants

There were 113,874 potential participants who completed the screener, of which 27, 364 were eligible for contact. Of those, 1319 ASMM (16–17 years of age) completed the screener, which included an assessment of both the likelihood of and concern about whether their parent(s)/guardian(s) might read their text messages or emails from our team or open mail addressed to them; phone contact was made to participants who endorsed at least some degree of worry and likelihood of concern to initiate a phone-based screening protocol that included follow-up questions to assess potential safety and privacy concerns.

2.2. Measures

2.2.1. Sociodemographics

Participants reported sociodemographic information including age, ethnic and racial self-identification, sexual identity, zip code (which was converted to regions), living situation, relationship status, and health insurance status. Participants who had health insurance were asked if it was their own private insurance, or through their parent/guardian, or partner.

2.2.2. Sexual history and HIV/STI risk

Participants were provided with the following prompt before answering the question on Pre-Exposure Prophylaxis (PrEP). PrEP use: "PrEP (pre-exposure prophylaxis) is a biomedical strategy to prevent HIV infection. PrEP involves HIV-negative guys taking anti-HIV medications (for example, Truvada™ (tenofovir disoproxil fumarate/emtricitabine (TDF/FTC)) once a day, every day to reduce the likelihood of HIV infection if they were exposed to the virus." Individuals reported current PrEP use by responding to the question "Have you ever been prescribed HIV medication (e.g., Truvada™) for use as PrEP (HIV pre-exposure prophylaxis)?" Response options were, "Yes, I am currently prescribed PrEP," "Yes, but I am no longer prescribed PrEP," and "No, I have never been prescribed PrEP."

Participants reported their most recent HIV test by responding to the question "When was the last time you received an HIV test?" Response options were "Within the last month," "About one–three months ago," "About three–six months ago," "About six–12 months ago," "About one to two years ago," "More than twp years ago," and "I have never been tested." Participants reported whether they had received a positive STI diagnosis in the previous six months, with responses coded as "yes" or "no."

Participants reported if they had used 14 different drugs (alcohol, cocaine, crystal meth, ecstasy, gamma-hydroxybutyrate/gamma-butyrolactone, heroin/opiates, ketamine, marijuana, crack, poppers, Viagra® (Sildenafil Citrate), Levitra® (Vardenafil), Cialis® (Tadalafil), prescription stimulants, prescription sedatives, prescription pain killers) in the past six months. For prescription drugs, participants were instructed to respond with instances of using them without a prescription, using more than prescribed, and/or using them for a recreational purpose. Those who reported any drug use were coded as "yes," and those who reported no drug use were coded as "no."

2.2.3. Privacy and confidentiality concerns

Using a 3-point scale ranging from "not at all worried" to "very worried", participants responded to "How worried would you be if a parent/caregiver read a text message or email to you that we sent?" and "How worried would you be if a parent/caregiver opened a package addressed to you with an HIV test inside?" Participants who responded "somewhat worried" or "very worried" received a follow-up question "How likely is it that a parent/caregiver would read your text messages or emails in the next year?" or "How likely is it that a parent/caregiver would open a package addressed to you in the next year?" Participants were provided the response options "not at all likely" "somewhat likely" and "very likely."

2.3. Analysis plan

We first ran descriptive statistics to characterize the sample in terms of worry and likelihood of privacy breach occurrences. We then used bivariate chi-square tests of independence to examine differences in these indicators by race and ethnicity (Black, Latino, White, Multiracial, 'Other'), sexual identity (gay, bisexual, queer), health insurance (yes on parent's, yes on my own/partner's, no insurance), relationship status (partnered, single), living situation (lives with parents, does not live with parents) geographic region determined by zip code (South, Northeast, Midwest, West, Puerto Rico, military overseas), recent STI diagnosis, recent illicit drug use and recent heavy drinking. Participants in the "Other" race category were those who identified as Asian, Native American or Alaskan Native, Native Hawaiian or Pacific Islander, due to insufficient sample sizes of each group. Analyses were conducted using SPSS, version 27.

3. Results

Overall, the participants were diverse across a range of

Table 1
Sociodemographic and behavioral differences in privacy concerns related to text/email communication among a U.S study sample of ASMM in 2018.

	Overall sample of screened ASMM ($n = 1319$		**Not at all worried (n = 384)**		**Somewhat or very worried (n = 935)**		**Not at all likely (n = 576)**		**Somewhat or very likely(n = 359)**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Race/Ethnicity			$\chi^2(4) = 7.035$ p = 0.134				$\chi^2(4) = 18.080$ p < 0.001			
Black	183	13.87	60	32.79	123	67.21	84	68.29	39	31.71
Latino	389	29.49	100	25.71	289	74.29	199	68.86	90	31.14
White	466	35.33	140	30.04	326	69.96	175	53.68	151	46.32
Multiracial	218	16.53	71	32.57	147	67.43	90	61.22	57	38.78
Other	63	4.78	13	20.63	50	79.37	28	56.00	22	44.00
Region			$\chi^2(5) = 3.384$ p = 0.641				$\chi^2(5) = 4.979$ p = 0.418			
Northeast	201	15.24	58	28.86	143	71.14	92	64.34	51	35.66
Midwest	248	18.80	67	27.02	181	72.98	105	58.01	76	41.99
South	491	37.23	154	31.36	337	68.64	201	59.64	136	40.36
West	371	28.13	104	28.03	267	71.97	175	65.54	92	34.46
Puerto Rico	5	0.38	1	20.00	3	80.00	2	66.67	1	33.33
Military/Other	3	0.23	0	0.00	3	100.00	1	33.33	2	66.67
Sexual identity			$\chi^2(2) = 6.229$ p < 0.05				$\chi^2(2) = 5.071$ p = 0.079			
Gay	929	70.43	287	30.89	642	69.11	411	64.02	231	35.98
Queer	29	2.20	10	34.48	19	65.52	11	57.89	8	42.11
Bisexual	361	27.37	87	24.10	274	75.90	154	56.20	120	43.80
Relationship status			$\chi^2(4) = 6.164$ p < 0.05				$\chi^2(4) = 0.640$ p = 0.424			
Single	1100	83.40	305	27.73	795	72.27	494	62.14	301	37.86
Partnered	219	16.60	79	36.07	140	63.93	82	58.57	58	41.43
Living situation			$\chi^2(1) = 20.412$ p < 0.001				$\chi^2(1) = 0.102$ p = 0.750			
Without parents	119	9.02	56	47.06	63	52.94	40	63.49	23	36.51
With parents	1200	90.98	328	27.33	872	72.67	536	61.47	336	38.53
Insurance status			$\chi^2(2) = 22.486$ p < 0.001				$\chi^2(2) = 10.262$ p < 0.01			
No insurance	204	15.47	59	28.92	144	71.08	84	58.33	60	41.67
Own insurance	505	38.29	183	36.24	322	63.76	221	68.63	101	31.37
Parent insurance	610	46.25	142	23.28	468	76.72	271	57.91	197	42.09
PrEP status			$\chi^2(2) = 10.68$ p < 0.001				$\chi^2(2) = 2.105$ p = 0.349			
Currently on PrEP	16	1.21	10	62.50	6	37.50	2	33.33	4	66.67
Previously on PrEP	13	0.99	6	46.15	7	53.85	4	57.14	3	42.86
Never taken PrEP	1290	97.80	368	28.53	922	71.47	570	61.82	352	38.18
Most recent HIV test			$\chi^2(3) = 57.72$ p < 0.001				$\chi^2(3) = 2.319$ p = 0.509			
Past 6 months	288	21.83	127	44.10	161	55.90	95	59.01	66	40.99
Past 7–12 months	50	3.79	19	38.00	31	62.00	17	54.84	14	45.16
Over a year ago	63	4.78	28	44.44	35	55.56	19	54.29	16	45.71
Never been tested	918	69.60	210	22.88	708	77.12	445	62.85	263	37.15
STI recency			$\chi^2(1) = 6.43$ p < 0.01				$\chi^2(1) = 2.942$ p = 0.087			
No	1265	95.91	360	28.46	905	71.54	562	62.10	343	37.90
Yes	54	4.09	24	44.44	30	55.56	14	46.67	16	53.33
Drug use last 6 months			$\chi^2(1) = 11.252$ p < 0.001				$\chi^2(1) = 1.353$ p = 0.245			
No	1259	95.50	355	28.20	904	71.80	560	61.95	344	38.05
Yes	60	4.50	29	48.33	31	51.67	16	51.61	15	48.39

Abbreviations: PrEP, Pre-Exposure Prophylaxis; STI, Sexually transmitted infection; ASMM, adolescent sexual minority males.

demographics. A majority of the sample identified as an adolescent of color, with 13.9 % identifying as Black, 29.5 % as Latino, 16.5 % as Multiracial and 4.8 % as Other. A majority of the sample identified as gay (70.4 %) and there was diversity in terms of geographic location, including 37.2 % residing in the South, 28.1 % in the West, 18.8 % in the Midwest and 15.2 % in the Northeast. Many participants reported privacy-related concerns with the present remote HIV prevention research. Specifically, 70.8 % of participants indicated worry ("somewhat worried" or "very worried") if their parent or caregiver were to discover communications from study staff involved in HIV research. Among those who indicated some level of worry, more than one-third (38.3 %) suggested that this type of privacy breach was either "somewhat" or "very likely" to occur. Similarly, approximately three-quarters (76.1 %) of participants expressed worry ("somewhat worried" or "very worried") if their caregiver were to open mail connected to a study about HIV. Among those who indicated some level of worry, a majority (72.3 %) thought this type of privacy breach was "somewhat" or "very likely" to occur.

Demographic differences were observed for concern about potential breaches of privacy and confidentiality by parents or caregivers, as well as the likelihood of occurrence. Table 1 highlights the demographic differences in participants' level of worry and concern about receiving a

Table 2
Sociodemographic and behavioral differences in privacy concerns related to packages among a U.S study sample of ASMM in 2018.

Characteristics	Overall sample of screened ASMM ($n = 1319$)		Not at all worried (n = 315)		Somewhat or very worried (n = 1004)		Not at all likely (n = 278)		Somewhat or very likely (n = 726)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Race/Ethnicity			$\chi^2(4) = 3.900\ p = 0.419$				$\chi^2(4) = 10.247\ p < 0.05$			
Black	183	13.87	50	27.32	133	72.68	50	37.59	83	62.41
Latino	389	29.49	82	21.08	307	78.92	70	22.80	237	77.20
White	466	35.33	109	23.39	357	76.61	101	28.29	256	71.71
Multiracial	218	16.53	58	26.61	160	73.39	44	27.50	116	72.50
Other	63	4.78	16	25.40	47	74.60	13	27.66	34	72.34
Region			$\chi^2(5) = 2.562\ p = 0.767$				$\chi^2(5) = 11.099\ p < 0.05$			
Northeast	201	15.24	49	24.38	152	75.62	48	31.58	104	68.42
Midwest	248	18.80	56	22.58	192	77.42	49	25.52	143	74.48
South	491	37.23	126	25.66	365	74.34	117	32.05	248	67.95
West	371	28.13	83	22.37	288	77.63	63	21.88	225	78.13
Puerto Rico	5	0.38	1	20.00	4	80.00	1	25.00	3	75.00
Military overseas	3	0.23	0	0.00	3	100.00	0	0.00	3	100.00
Sexual identity			$\chi^2(2) = 12.406\ p < 0.01$				$\chi^2(2) = 0.512\ p = 0.774$			
Gay	929	70.43	242	26.05	687	73.95	193	28.09	494	71.91
Queer	29	2.20	10	34.48	19	65.52	4	21.05	15	78.95
Bisexual	361	27.37	63	17.45	298	82.55	81	27.18	217	72.82
Relationship status			$\chi^2(1) = 0.412\ p = 0.521$				$\chi^2(1) = 1.725\ p = 0.189$			
Single	1100	83.40	259	23.55	841	76.45	226	26.87	615	73.13
Partnered	219	16.60	56	25.57	163	74.43	52	31.90	111	68.10
Living situation			$\chi^2(1) = 21.522\ p < 0.001$				$\chi^2(1) = 4.450\ p < 0.05$			
Without parents	119	9.02	49	41.18	70	58.82	27	38.57	43	61.43
With parents	1200	90.98	266	22.17	934	77.83	251	26.87	683	73.13
Insurance status			$\chi^2(2) = 28.887\ p < 0.001$				$\chi^2(2) = 2.221\ p = 0.329$			
No insurance	204	15.47	48	23.53	156	76.47	36	23.08	120	76.92
Own insurance	505	38.29	159	31.49	346	68.51	102	29.48	244	70.52
Parent insurance	610	46.25	108	17.70	502	82.30	140	27.89	362	72.11
PrEP status			$\chi^2(2) = 7.682\ p < 0.05$				$\chi^2(2) = 1.307\ p = 0.520$			
Currently on PrEP	16	1.21	8	50.00	8	50.00	1	12.50	7	87.50
Previously on PrEP	13	0.99	5	38.46	8	61.54	3	37.50	5	62.50
Never taken PrEP	1290	97.80	302	23.41	988	76.59	274	27.73	714	72.27
Most recent HIV test			$\chi^2(3) = 60.155\ p < 0.001$				$\chi^2(3) = 11.054\ p < 0.05$			
Past 6 months	288	21.83	105	36.46	183	63.54	63	34.43	120	65.57
Past 7–12 months	50	3.79	17	34.00	33	66.00	6	18.18	27	81.82
Over a year ago	63	4.78	28	44.44	35	55.56	15	42.86	20	57.14
Never been tested	918	69.60	165	17.97	753	82.03	194	25.76	559	74.24
STI recency			$\chi^2(1) = 10.844\ p < 0.001$				$\chi^2(1) = 0.029\ p = 0.865$			
No	1265	95.91	292	23.08	973	76.92	269	27.65	704	72.35
Yes	54	4.09	23	42.59	31	57.41	9	29.03	22	70.97
Drug use last 6 months			$\chi^2(1) = 13.084\ p < 0.001$				$\chi^2(1) = 0.026\ p = 0.872$			
No	1259	95.5	289	22.95	970	77.05	269	27.73	701	72.27
Yes	60	4.5	26	43.33	34	56.67	9	26.47	25	73.53

Abbreviations: PrEP, Pre-Exposure Prophylaxis; STI, Sexually transmitted infection; ASMM, adolescent sexual minority males.

text message or email from a staff member involved in HIV research. We observed comparatively higher rates of worry and concern among participants who identify as bisexual (75.9 %) compared with those who identify as queer (65.5 %) or gay (69.1 %). Participants who lived with their parents or guardians were also more likely to express worry (72.7 %) compared with those who did not (63.9 %). Participants who were on their parent's insurance plan were also more likely to express worry (76.7 %) compared with those who had their own insurance (71.1 %) or had no insurance (63.8 %). Additionally, compared to their counterparts, there were greater proportions of concern among participants who have never been tested for HIV (77.1 %), have no recent STI diagnosis (71.5 %), have not used drugs in past six months (71.8 %), and have never taken PrEP (71.5 %).

Among participants who expressed worry or concern about receiving a text message or email from an HIV research staff member, participants who identified as White (46.3 %) or 'Other' (44.0 %) were more likely to think this breach in privacy was "somewhat" or "very likely" to occur compared with participants who identify as Black (31.7 %), Latino (31.1 %) or multiracial (38.8 %). Participants with their own insurance were less likely (31.4 %) than those with no insurance (41.7 %) or their parent's insurance (42.1 %) to think that a breach in privacy was "somewhat" or "very likely" to occur.

Table 2 highlights the differences in participants' worry and concern about receiving study-related packages by mail. Participants who identified as bisexual were more likely to express worry (82.5 %) compared with those who identified as queer (65.5 %) or gay (74.0 %). Participants who lived with their parents were also more likely to express worry if their caregiver were to discover a package from a HIV research study (77.8 %) compared with those who did not (58.8 %). Participants who had their own insurance were less likely to express worry if their caregiver were to discover a package from a HIV research study (68.5 %) compared with those who had no insurance (76.5 %) or who were on their parent's insurance plan (82.3 %). Additionally, compared to their counterparts, there were greater proportions of concern among those who have never been tested for HIV (82.0 %), those without a recent STI diagnosis (76.9 %), and those who have not used drugs in the past six months (77.1 %).

Among participants who expressed worry or concern about receiving study-related packages by mail, Latino participants (77.2 %), participants who live with their parents (73.1 %), those who are on their parent's insurance (76.7 %), those who have never been tested for HIV (74.2 %) orwere tested 7–12 months ago (81.8 %), and those who live in the West (78.1 %) and Midwest (74.5 %) were more likely than their counterparts to think this breach in privacy was somewhat or very likely to occur.

In total, 237 participants endorsed some degree of privacy-related concerns that warranted further phone-based screening before study enrollment. Study staff were able to reach by phone, and then carry out, the predetermined protocol with 47 participants (19.8 %) who ultimately expressed interest in continuing their participation. Among those who completed the protocol, 12 participants (25.5 %) completed all baseline components to enroll in the cohort. The complete enrollment cascade for participants is presented in Fig. 2.

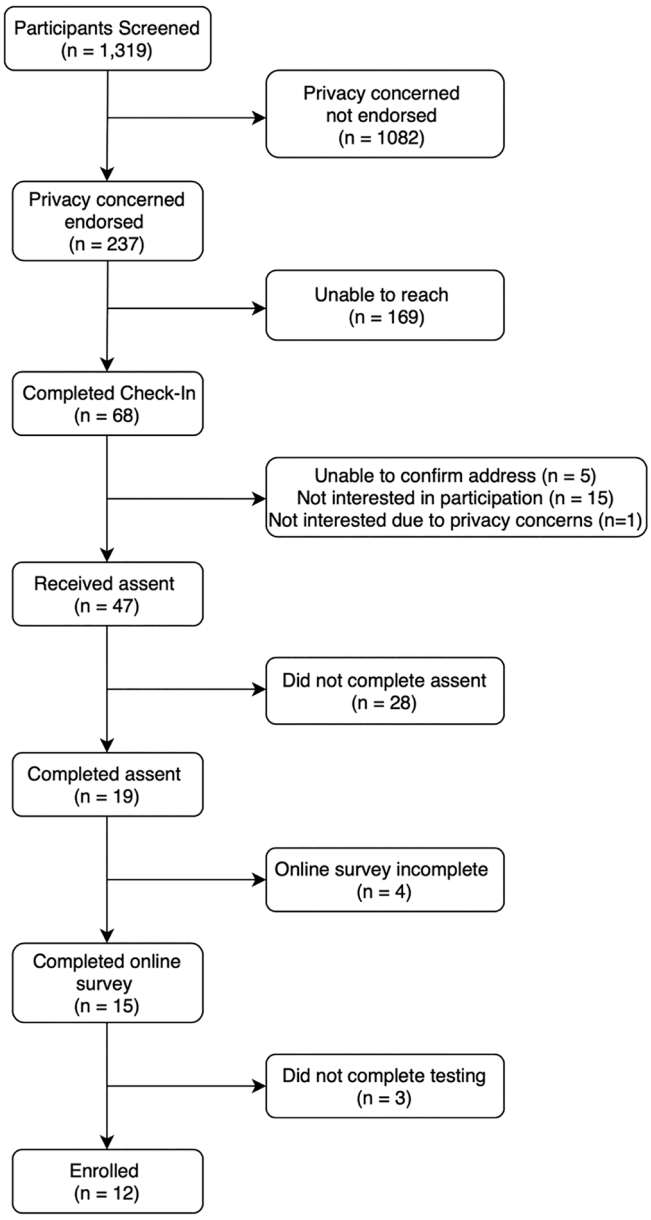

Fig. 2. Enrollment Cascade of a 2018 U.S HIV Prevention Study of ASMM. Abbreviation: ASMM, Adolescent Sexual Minority Males.

4. Discussion

In the present study, we examined privacy and confidentiality concerns among ASMM from a large U.S. national sample. Our findings suggest that potential concerns are prevalent and likely serve as a barrier to adolescents' participation in HIV research. Furthermore, our findings suggest that concerns affecting participation in HIV prevention research extend beyond logistical barriers (e.g., time, transportation, space) and vary based on socio-demographic characteristics.

We hypothesize that one of the major drivers of experiencing privacy concerns is connected to the fear of coming out to others, including parents and family members. If ASMM come from unsupportive or hostile family environments, the fear of being outed can be particularly intense (Katz-Wise et al., 2016). Participating in research that could potentially disclose their sexual orientation might jeopardize their safety and well-being within their families. Our findings suggest that participants identifying as bisexual reported higher rates of privacy concerns in research compared with their counterparts. It is possible that those who identified as bisexual were less likely to be out to their parents and family members compared to those who identifed as gay or queer in our sample. Studies from the past decade support the idea that invalidating responses remain common during the coming out process (Mustanski and Liu, 2013), and further complicating the coming out process, adolescents who identify as bisexual can experience rejection and exclusion from both gay and straight communities (Serpe et al., 2020).

Most of the limited research on parental acceptance and rejection has focused on sociodemographic characteristics differences by race and ethnicity or sexual identity. Researchers have highlighted the need to examine the role of religion, urbanicity/rurality, and geographic region (Newcomb et al., 2019). Our findings suggest that region did not impact

the level of privacy concern across our variables of interest. Yet it did contribute to the likelihood of our ASMM sample to think a breach in privacy relating to study-related packages by mail was somewhat or very likely to occur among those who reside in the West and Midwest. Further exploration is needed to understand how region contributes to cultural norms around family practices as it relates to privacy among adolescents.

Participants with less experience with HIV prevention services (e.g., never been tested for HIV, have no recent STI diagnosis) reported more privacy concerns as well. We hypothesize that adolescents who are less familiar or engaged in systems of care that are inclusive of HIV prevention services are less likely to have had conversations with their parents about safer sex practices, HIV testing, and PrEP. On the other hand, it is possible that ASMM with more experience with HIV prevention services would feel more comfortable sharing their participation in an HIV prevention study with their parents or family because they have the language and lived experience to have a conversation to explain their decision to participate. Unsurprisingly, participants who were not on their parents' insurance plan, or live separately, reported fewer overall concerns related to participation in HIV research. Future studies should consider how these concerns manifest in both recruitment and retention of participants in HIV research.

Well-planned strategies can mitigate the risks of study participation among sexual minority adolescents. That said, enrolling participants with rigorous protocols for ensuring safety and privacy presented challenges. Our study staff was unable to reach 169 participants (71.3 %) after three telephone-based contact attempts to follow up on the reported privacy concerns identified in the screener. Alternate, age-appropriate means of contact should be considered in future research – for example, including free-response, open-ended questions to contextualize responses, using text messaging, or an interactive web-based platform. Such methods would facilitate the gathering of additional data, including their perceived anticipated barriers to completing research tasks. Hearing from participants about their preferred contact method could better address their their privacy concerns and increase engagement. It is unknown why many participants could not be reached conduct phone-based screening. Future research exploring the effectiveness of protocols that use text-based platforms would be beneficial. In addition, future research that is inclusive of sexual minority adolescent females is necessary to understand the nuanced differences of how adolescents engage in research by gender identity.

5. Implications and contribution

Although there were successes, there are also challenges that must be addressed. We reached but had more difficulty screening ASMM with several important features, including ASMM who were not gay identified. Additional strategies to recruit ASMM with bisexual and queer identities is vital for future efforts. Furthermore, a larger sample size would have allowed for more nuanced investigation into the range of drivers and motivators of privacy concerns. That said, most ASMM reported the potential for privacy-related issues within remote HIV prevention research. Well-planned strategies can mitigate risks, but enrolling youth in research with rigorous protocols for ensuring safety and privacy is challenging. In total, 237 (38 %) sexual minority participants endorsed some degree of privacy-related concerns that warranted further phone-based screening prior to consent. A majority (75 %) of the participants who indicated a privacy concern did not ultimately enroll because study staff were unable to reach them to complete the pre-enrollment check-in. Future research should examine alternative mechanisms to complete privacy and safety checks.

CRediT authorship contribution statement

Ali J. Talan: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Carly Wolfer:** Writing – original draft, Project administration. **Nicola Tavella:** Writing – original draft, Project administration. **Cynthia Cabral:** Writing – review & editing, Methodology. **Ricardo Despradel:** Writing – review & editing, Methodology. **H. Jonathon Rendina:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

Data will be made available on request.

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