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## Measuring Discomfort in Health Research Relative to Everyday Events and Routine Care: An Application to Sexual and Gender Minority Youth

Kathryn Macapagal, Ph.D.<sup>a,b,\*</sup>, Emily Bettin<sup>a,b</sup>, Margaret Matson, M.P.H.<sup>a,b</sup>, Ashley Kraus, Ph.D.<sup>a,b</sup>, Celia B. Fisher, Ph.D.<sup>c</sup>, and Brian Mustanski, Ph.D.<sup>a,b</sup>

<sup>a</sup> Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, Illinois

<sup>b</sup> Institute for Sexual and Gender Minority Health and Wellbeing, Northwestern University, Chicago, Illinois

<sup>c</sup> Center for Ethics Education and Department of Psychology, Fordham University, Bronx, New York

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### ABSTRACT

**Purpose:** Understanding how sexual and gender minority (SGM) youth's comfort with research procedures compares to their comfort with everyday experiences and routine health care can help calibrate decisions about whether a study meets minimal risk criteria. We sought to quantify SGM adolescents' comfort with sexual health research relative to everyday events and activities often cited as benchmarks of minimal risk.

**Methods:** A total of 616 SGM adolescents in the United States (mean age = 15.7 years, 41.7% racial/ethnic minority) completed online survey questions assessing sexual behavior, SGM identity, and a 53-item Measure of Adolescent Comfort with Clinical, Research, and Everyday Events that assessed comfort on a 7-point scale (1 = extremely uncomfortable and 7 = extremely comfortable).

**Results:** The Everyday Events for Adolescents domain had the lowest mean comfort score ( $M = 3.49$ , standard deviation [SD] = .58) and was significantly lower than the Routine Medical and Psychological Tests domain ( $M = 4.43$ ,  $SD = .92$ ) and the HIV/Sexual Health Research Procedures domain ( $M = 4.19$ ,  $SD = .94$ ). Eleven of 17 items on the HIV/Sexual Health Research Procedures domain were ranked as more comfortable than a neutral rating of "neither comfortable nor uncomfortable." Higher levels of parental acceptance predicted greater levels of comfort across all four domains of the Measure of Adolescent Comfort with Clinical, Research, and Everyday Events. Participants who were out to their parents expressed greater comfort with both SGM Identity and Sexual Health–related procedures and events as well as HIV/Sexual Health Research Procedures.

**Conclusions:** Overall participants expressed equal or more comfort with research procedures than with everyday life experiences. These findings indicate that common sexual health research procedures may meet minimal risk criteria among SGM adolescent populations.

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### IMPLICATIONS AND CONTRIBUTIONS

This study quantifies sexual and gender minority adolescents' comfort with sexual health research procedures relative to everyday events and routine care. These findings can inform decisions made by researchers and institutional review boards regarding inclusion of sexual and gender minority adolescents in sexual health research.

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\* Address correspondence to: Kathryn Macapagal, Ph.D., Department of Medical Social Sciences, Feinberg School of Medicine, Institute for Sexual and Gender Minority Health and Wellbeing, Northwestern University, 625 N. Michigan Avenue, Suite 14-057, Chicago, IL 60611.

E-mail address: [kathryn.macapagal@northwestern.edu](mailto:kathryn.macapagal@northwestern.edu) (K. Macapagal).

Sexual and gender minority (SGM) adolescents are at disproportionate risk of adverse sexual health and substance use outcomes, including higher rates of sexually transmitted infections (STIs) [1,2], HIV [3], unplanned pregnancy [4,5], and alcohol and substance use [6–8] relative to their heterosexual and cisgender (i.e., not transgender or nonbinary) peers. However, SGM adolescents aged younger than 18 years are underrepresented in research aimed at understanding and improving these health outcomes, which perpetuates health disparities in this population [9]. One obstacle to their inclusion is some investigators' and institutional review boards' (IRBs) belief that certain research procedures may pose greater than minimal risk for adolescents [9–12]—in other words, they exceed the magnitude or probability of risks encountered during everyday life or routine medical or psychological examinations [13]. Case examples from researchers in the United States and Canada have described challenges navigating IRB review for social-behavioral [10–12] and biomedical research with SGM adolescents [14] on “sensitive” topics, and IRB application of risk/benefit standards in health research with minors can be variable [15,16]. Subjective judgments about the risks of adolescent health research may lead IRBs to deny parental permission waivers, which can lead to critical sampling biases [17] or the exclusion of minors from a research protocol [12,14]. Thus, the ability to quantify common risks, such as the potential for discomfort in social-behavioral and biomedical research, can promote consistency in IRB decisions about minimal risk. To facilitate evidence-based decision-making regarding SGM adolescents' inclusion in health research, we sought to measure youth's comfort with sexual health and risk behavior research procedures relative to everyday events (e.g., taking a test) and clinical activities often cited as benchmarks of minimal risk (e.g., blood draws).

The limited literature on SGM adolescents' perspectives on research participation shows that they generally feel comfortable participating in health-related research [11,18–21]. In a study of 181 SGM youth, 90% felt comfortable with answering survey questions about sexual behavior, mental health, and substance and alcohol abuse, and only 2%–3% felt very uncomfortable across these domains [11]. Another study found SGM adolescents felt low levels of distress after completing survey questions about their sexual behavior and that this distress was not significantly different from that reported by adult participants [19]. Likewise, a survey and focus group study of 74 SGM adolescents aged 14–17 years found that the majority felt comfortable answering survey questions about sexual behavior (67%) and drug and alcohol use (61%) [20]. These studies lend evidence to the argument that certain sexual health and risk behavior research procedures pose relatively little risk.

Limited research has quantified individuals' comfort during everyday events and routine care and compared them with social-behavioral or biomedical research procedures although such work can help calibrate decisions about whether a study meets minimal risk criteria. For example, Petrie et al. [22] asked university students and community members to rate their anticipated distress associated with common health research procedures (e.g., sexual behavior surveys and health interviews) and everyday events; ethics committee members were asked to rate their perceptions of how distressing the public would find these same activities. Community members and students rated their distress regarding research procedures lower than did ethics committee members and similar to or less than their distress regarding everyday events (e.g., waiter forgetting order

[22]). This study indicates that common health research procedures are perceived to be relatively low in risk but also that ethics committee members systematically overestimated potential participants' perceived distress. However, this work was conducted with adults, and comfort with health-related research procedures may differ among adolescents. To our knowledge, the only study that has directly compared routine health care with research participation in SGM adolescents involved young sexual minority men who were interviewed about their sexual behavior; afterward, participants reported feeling equally or more comfortable in the study than in a routine medical visit [18]. To build on this work, larger-scale quantitative studies are needed to better situate the discomforts of a variety of adolescent health research procedures relative to exemplars of minimal risk events.

Among SGM adolescents, anticipated discomfort associated with sexual health and risk behavior research participation could be related to certain sociodemographic and behavioral factors. For example, transgender youth or SGM youth of color may experience greater discomfort with research procedures because of mistrust stemming from historical mistreatment of their communities in research contexts [23,24]. In addition, youth who are not out to their parents about their SGM identity, whose parents may be unaccepting of their SGM identity, or who are sexually active may have heightened concerns about research participation because of fears of parental discovery of and punishment for their SGM identity or same-gender sexual behavior [25,26].

Understanding adolescents' perspectives on research that can affect their health and well-being is a cornerstone of ethical practice and can prevent IRBs and investigators from identifying research as harmful or distressing when participants perceive it otherwise [27]. To guide evidence-informed decision making by researchers and IRBs, following Petrie et al. [22], we measured SGM adolescents' discomfort with sexual health and risk behavior research procedures and compared these items with everyday events and routine medical and psychological tests. As identifying predictors of increased discomfort in research can draw IRBs' and researchers' attention to participant groups who may benefit from additional protective mechanisms to mitigate the risk of harm, we also explored how comfort differed by sociodemographic and behavioral characteristics [20,21].

## Methods

### *Participants and recruitment*

Participants were recruited to complete an online survey on ethical issues in adolescent sexual health research as part of a larger study [20,21,28]. Eligible participants were aged 14–17 years; identified as a sexual minority (e.g., lesbian, gay, bisexual, queer, and questioning) and/or transgender or gender nonconforming or were romantically interested in or had sex with partners of the same gender; lived in the United States; could read English at an eighth grade level; and were HIV negative or did not know their status. All procedures were IRB approved. A waiver of parental permission was granted on the grounds that it was not a reasonable requirement to protect the participants, the research could not practicably be carried out without a waiver, and study procedures were determined to be no more than minimal risk [13]. A Certificate of Confidentiality from the National Institutes of Health was issued to protect the

identities of participants in the event of subpoenas requesting identifiable study data.

Participants were recruited through paid Facebook, Instagram, and Twitter advertisements in spring 2017. Advertisements targeted adolescents who indicated they were romantically interested in people of the same gender on their profile and/or listed interests relevant to SGM youth (e.g., pop culture figures popular with SGM youth). Clicking on the advertisement directed individuals to an online eligibility survey. Eligible participants were presented with an online consent form and were automatically directed to the survey. No financial incentives were offered for participation.

### Measures

*Demographics, sexual behavior, and SGM identity.* Participants completed items assessing age, race and ethnicity, sex assigned at birth, current gender identity and sexual orientation, and disclosure of sexual orientation to parents (out to one, all, and none). Participants were then asked about sexual orientation disclosure to their mother or guardian most like a mother and their father or guardian most like a father (1 = definitely knows and we have talked about it and 4 = does not know or suspect) and the extent to which these individuals were accepting or would be accepting of their sexual orientation if disclosed (1 = very rejecting and 5 = very accepting) [26]. Disclosure to parents was dichotomized to being not out versus being out to at least one parent. Responses to a closed-ended item assessing participants' sexual activity were dichotomized to reflect whether participants ever had sex (yes or no).

*Comfort with research, everyday events, and routine medical/psychological tests.* Items assessing comfort with research participation were based on a 15-item questionnaire developed by the authors [20]. Items were added that reflected activities deemed to pose no more than minimal risk by most IRB standards (e.g., finger stick), common sexual health research procedures (e.g., sexual behavior interviews) and HIV prevention studies that are underway or are anticipated in the future (e.g., investigational trials for injectable and implantable pre-exposure prophylaxis, a medication to prevent HIV) [29]. Several everyday events experienced by adolescents were taken from previous research (e.g., caught in rain [22] and taking a test [30]) or adapted to reflect adolescent experiences (e.g., standing in long line at a bank [22] changed to standing in a long line at a store). Additional items were developed in consultation with SGM youth to ensure the everyday events reflected a range of adolescent experiences that varied widely in their comfort levels (e.g., coming out and using social media) and piloted; see [Supplementary Material](#) for the initial and final item sets. Items were rated on a scale ranging from extremely uncomfortable (1) to extremely comfortable (7).

The Measure of Adolescent Comfort with Clinical, Research, and Everyday Events (MACCREE; [Table 1](#)) reported in the present study included 53 items reflecting four domains. Three domains assessed comfort with *Everyday Events for Adolescents* (e.g., "Taking a test at school"; 21 items); *Routine Medical and Psychological Tests* (e.g., "Having your vision checked at the doctor's office"; 11 items); and events related to *SGM Identity and Sexual Health* (e.g., "Coming out to a parent or guardian"; 4 items). Another domain assessed comfort with *HIV/Sexual Health Research Procedures* (e.g., "Having your finger pricked to test your blood for HIV during a research study"; 17 items) including some

procedures that would require parental consent. Mean ratings for items in each domain were computed [22].

### Procedure

After providing informed assent, participants completed a 20-minute survey that included the MACCREE and items on condom attitudes and perspectives on research incentives; results from the latter two topics are not reported here. The MACCREE was positioned toward the middle of the survey following questions about condom attitudes, and items were randomized (i.e., not grouped by domain) and presented in a matrix. Instructions for the MACCREE were as follows: "In this section, we'd like to understand how uncomfortable or comfortable you would feel with different types of life events, health related tests, and procedures used in research studies on sexual health. This is so we can compare how you might feel about different research procedures relative to other events you experience in your everyday life. The content or order of items may at times seem strange, but please answer as best you can. Please indicate how uncomfortable or comfortable you would be with each event on a scale from extremely uncomfortable to extremely comfortable."

### Data analysis

Statistical analyses were run in SPSS 24 (IBM SPSS Statistics for Windows, version 24 IBM Corp., Armonk, NY). Frequencies were run for all demographic variables, and descriptive statistics were computed for individual items as well as the four domains. Item means were rank-ordered in a bar chart to better visualize how individual items compared with each other. To test for differences between the mean scores of the MACCREE domains, we used repeated measures analysis of variance and post-hoc tests with Bonferroni corrections were run to discover which specific means differed.

Several tests assessed demographic differences in MACCREE domain means. Independent samples *t*-tests compared the ratings of domains between dichotomous variables (assigned male at birth [AMAB] vs. assigned female at birth [AFAB]; sexually active vs. not). Simple linear regression compared continuous variables (age; parental acceptance of SGM identity) and dummy-coded variables (race/ethnicity: black, Latino, and Other, with white as reference group; gender identity: transgender, genderqueer, and gender nonconforming, with cisgender as reference group). Finally, to test the unique influence of demographic characteristics, variables that were significant at  $p < .05$  were included in multiple linear regression models for each domain.

### Results

The sample ([Table 2](#)) included 616 participants ( $M = 15.69$ ,  $SD = 1.01$ ). Participants' racial/ethnic backgrounds were diverse (41.7% youth of color). More than half (54.7%) were AFAB. Cisgender men (43.2%) and women (28.6%) made up most of the sample. Of the transgender (12.2%), genderqueer (8.0%), and gender nonconforming (8.1%) youth in the sample, 89.5% were AFAB. Gay (37.0%), bisexual (23.2%), and pansexual youth (20.3%) made up the largest sexual orientation groups. More than half (62.8%) were out to at least one parent, and 60.1% reported their mothers were somewhat to very accepting of their sexual orientation, whereas

**Table 1**

Means and standard deviations of all items on the Measure of Adolescent Comfort with Clinical, Research, and Everyday Experiences

| Question  | N   | Mean | SD   |
|---|-----|------|------|
| Routine Medical and Psychological Tests (M = 4.43, SD = .92)  |     |      |      |
| Having your vision checked at the doctor's office   | 616 | 5.59 | 1.32 |
| A doctor asking you about the types of foods you usually eat and drink  | 616 | 5.43 | 1.52 |
| Answering a questionnaire about your future career or job interests at your school counselor's or psychotherapist's office                      | 615 | 5.40 | 1.59 |
| Getting an X-ray to check your bones at the doctor's office   | 616 | 5.38 | 1.40 |
| A doctor asking you about your alcohol and drug use   | 614 | 4.79 | 1.84 |
| Providing a urine sample at the doctor's office to be tested for sexually transmitted infections.   | 614 | 4.79 | 1.63 |
| Answering a questionnaire about your mood at your school counselor's or psychotherapist's office  | 615 | 4.25 | 1.74 |
| Having your blood drawn at the doctor's office  | 615 | 3.99 | 1.94 |
| A doctor asking you about your sexual behavior  | 616 | 3.50 | 1.68 |
| Having a doctor do a full-body skin examination for spots that could be cancerous   | 616 | 2.92 | 1.69 |
| Providing a sample of your poop at the doctor's office  | 614 | 2.66 | 1.55 |
| Everyday Events for Adolescents (M = 3.49, SD = .58)  |     |      |      |
| Sending a text message to your friend   | 616 | 6.30 | 1.09 |
| Talking to your classmates about an after-school activity   | 616 | 6.18 | 1.13 |
| Posting a picture on social media   | 616 | 5.27 | 1.55 |
| Getting drug tested at school to participate in a sport or extracurricular activity   | 612 | 4.75 | 1.94 |
| Getting caught in the rain  | 615 | 4.69 | 1.63 |
| Taking a test at school   | 616 | 4.63 | 1.64 |
| Having the principal of your school observe your class  | 615 | 4.37 | 1.63 |
| Doing homework  | 615 | 4.11 | 1.61 |
| Getting called on in class  | 616 | 3.82 | 1.89 |
| Being asked to donate money or sign a petition on the street  | 616 | 3.76 | 1.62 |
| Standing in a long line at a store  | 616 | 3.47 | 1.37 |
| Being grounded for something you did  | 616 | 2.98 | 1.35 |
| Picking up dog poop   | 614 | 2.85 | 1.47 |
| Forgetting to do your homework  | 616 | 2.69 | 1.52 |
| Getting a detention   | 615 | 2.52 | 1.37 |
| Getting into an argument with a friend  | 615 | 2.34 | 1.07 |
| Finding out a friend was talking about you behind your back   | 616 | 1.98 | 1.03 |
| Sending an embarrassing text message to the wrong person  | 615 | 1.95 | 1.10 |
| Having your partner break up with you   | 604 | 1.65 | .90  |
| Having someone read your private blog or journal who was not supposed to see it   | 614 | 1.64 | .93  |
| Having your cell phone stolen   | 615 | 1.25 | .59  |
| SGM Identity and Sexual Health (M = 3.57, SD = 1.08)  |     |      |      |
| Talking about sex with your friends   | 615 | 5.37 | 1.67 |
| Discussing sexual issues in a health class  | 615 | 4.33 | 1.71 |
| Talking about sex with your parent or guardian  | 616 | 2.44 | 1.47 |
| Coming out to a parent or guardian  | 615 | 2.13 | 1.47 |
| HIV/Sexual Health Research Procedures (M = 4.19, SD = .94)  |     |      |      |
| Filling out survey questions about your sexual orientation or gender identity for a research study  | 616 | 6.02 | 1.23 |
| Having the inside of your mouth swabbed with a Q-tip to test your saliva for HIV during a research study  | 615 | 5.34 | 1.47 |
| Filling out survey questions about your sexual behavior for a research study  | 615 | 5.14 | 1.52 |
| Talking to a researcher about your alcohol or drug use  | 613 | 4.97 | 1.63 |
| Taking a pill that can help you prevent HIV every day for a year-long research study  | 616 | 4.84 | 1.70 |
| Getting your urine tested for STIs during a research study  | 614 | 4.81 | 1.64 |
| Having your finger pricked to test your blood for HIV during a research study   | 616 | 4.60 | 1.68 |
| Being interviewed with a group of other teenagers about sexual issues for a research study  | 613 | 4.53 | 1.70 |
| Getting your urine tested for drugs during a research study   | 613 | 4.48 | 1.80 |
| Getting an injection (a shot) of medication every three months that can help you prevent HIV for a research study                               | 616 | 4.38 | 1.87 |
| Talking to a researcher about your sexual behaviors   | 615 | 4.05 | 1.73 |
| Having to ask your parents for permission to participate in a research study about your alcohol and drug use                                    | 612 | 3.65 | 1.91 |
| Being in a study where you do not know, and do not get to decide, whether you get an HIV prevention pill or a placebo                           | 609 | 3.32 | 1.78 |
| Having a matchstick-sized implant containing medication inserted in your upper arm that can help you prevent HIV for a year in a research study | 615 | 3.32 | 1.76 |
| Having to ask your parents for permission to participate in a research study for LGBT teens   | 614 | 3.12 | 2.01 |
| Having to ask your parents for permission to participate in a research study about your sexual behavior   | 615 | 2.56 | 1.57 |
| Having the inside of your butt swabbed to test for STIs during a research study   | 615 | 2.07 | 1.40 |

Items were rated on a 7-point scale ranging from extremely uncomfortable (1) to extremely comfortable (7).

LGBT = lesbian, gay, bisexual, and transgender; SD = standard deviation; STI = sexually transmitted infection.

40.9% reported their fathers were somewhat to very accepting. Nearly two-thirds (65.6%) had previously had sex.

#### Measure of Adolescent Comfort with Clinical, Research, and Everyday Events domains and items

Routine Medical and Psychological Tests had the highest mean score (M = 4.43, SD = .92), indicating the greatest levels of

comfort, followed by HIV/Sexual Health Research Procedures (M = 4.19, SD = .94) and SGM Identity and Sexual Health (M = 3.57, SD = 1.08). The domain with the lowest mean score was Everyday Events for Adolescents (M = 3.49, SD = .58). A repeated measures analysis of variance with a Greenhouse-Geisser correction showed a significant difference between the means ( $F(2.45, 1505.43) = 342.74, p < .001$ ). Post-hoc tests showed that all domain means differed significantly from each



**Table 2**  
Demographic characteristics (N = 616)

|  | n (%)      |
|--|------------|
| Age (M = 15.69; SD = 1.01)                                   |            |
| 14   | 86 (14.0)  |
| 15   | 178 (28.9) |
| 16   | 191 (31.0) |
| 17   | 161 (26.1) |
| Race/ethnicity   |            |
| White  | 359 (58.3) |
| Black/African American                                       | 28 (4.5)   |
| Hispanic or Latino   | 164 (26.6) |
| Asian  | 16 (2.6)   |
| Native Hawaiian/Pacific Islander                             | 6 (1.0)    |
| American Indian/Alaska Native                                | 3 (0.5)    |
| More than one race   | 31 (5.0)   |
| Other  | 4 (0.6)    |
| Prefer not to answer   | 5 (0.8)    |
| Sex assigned at birth  |            |
| Male   | 279 (45.3) |
| Female   | 337 (54.7) |
| Gender identity  |            |
| Man  | 266 (43.2) |
| Woman  | 176 (28.6) |
| Transgender man  | 70 (11.4)  |
| Transgender woman  | 5 (0.8)    |
| Genderqueer  | 49 (8.0)   |
| Gender nonconforming   | 50 (8.1)   |
| Cisgender  |            |
| Cisgender  | 435 (70.6) |
| Transgender or nonbinary                                     | 181 (29.4) |
| Sexual orientation   |            |
| Gay  | 228 (37.0) |
| Lesbian  | 44 (7.1)   |
| Bisexual   | 143 (23.2) |
| Pansexual  | 125 (20.3) |
| Asexual  | 15 (2.4)   |
| Heterosexual   | 4 (0.6)    |
| Queer  | 34 (5.5)   |
| Questioning/unsure   | 23 (3.7)   |
| Outness to parents/guardians                                 |            |
| Not out to any   | 222 (36.0) |
| Out to at least one (but not all)                            | 150 (24.4) |
| Out to all   | 237 (38.5) |
| Prefer not to answer   | 7 (1.1)    |
| Mom's acceptance of sexual orientation (M = 3.60, SD = 1.42) |            |
| Very rejecting   | 67 (10.9)  |
| Somewhat rejecting   | 103 (16.7) |
| Neither rejecting nor accepting                              | 61 (9.9)   |
| Somewhat accepting   | 142 (23.1) |
| Very accepting   | 228 (37.0) |
| Prefer not to answer or not applicable                       | 15 (2.4)   |
| Dad's acceptance of sexual orientation (M = 3.10, SD = 1.43) |            |
| Very rejecting   | 100 (16.2) |
| Somewhat rejecting   | 122 (19.8) |
| Neither rejecting nor accepting                              | 89 (14.4)  |
| Somewhat accepting   | 128 (20.8) |
| Very accepting   | 124 (20.1) |
| Prefer not to answer or not applicable                       | 53 (8.6)   |
| Sexual partners  |            |
| Only guys  | 225 (36.5) |
| Mostly guys but some girls                                   | 43 (7.0)   |
| Guys and girls equally                                       | 58 (9.4)   |
| Mostly girls but some guys                                   | 53 (8.6)   |
| Only girls   | 25 (4.1)   |
| None—never had sex   | 212 (34.4) |

M = mean; SD = standard deviation.

other ( $p < .001$ ), with the exception of SGM Identity and Sexual Health and Everyday Events for Adolescents ( $p = .295$ ).

Figure 1 illustrates the items rank-ordered from most to least comfortable and enables direct comparisons between individual

research procedures, routine care, and everyday events. Of all items, “having your cell phone stolen” (M = 1.25, SD = .59) ranked as the most uncomfortable event, and “sending a text message to your friend” (M = 6.30, SD = 1.09) ranked as the most comfortable (Figure 1). The item “having your blood drawn at the doctor’s office” was rated closest to the median (M = 3.99, SD = 1.37) reflecting a neutral rating of “neither comfortable nor uncomfortable.”

Items in the HIV/Sexual Health Research Procedures domain tended to cluster higher on the comfort scale, with 11 of 17 items ranking as more comfortable than “having your blood drawn at the doctor’s office” (Figure 1). These items included study procedures involving HIV testing, urine drug screening, talking to a researcher about sexual behavior, and talking about sexual behavior in a focus group with other teenagers. One of the biomedical HIV prevention research procedures, “getting an injection (a shot) of medication every three months that can help you prevent HIV for a research study,” was rated similarly to these items. Only two items in the HIV/Sexual Health Research Procedures domain had a mean score of less than 3 (somewhat uncomfortable): “having to ask your parents for permission to participate in a research study about your sexual behavior” and “having the inside of your butt swabbed to test for STIs during a research study.”

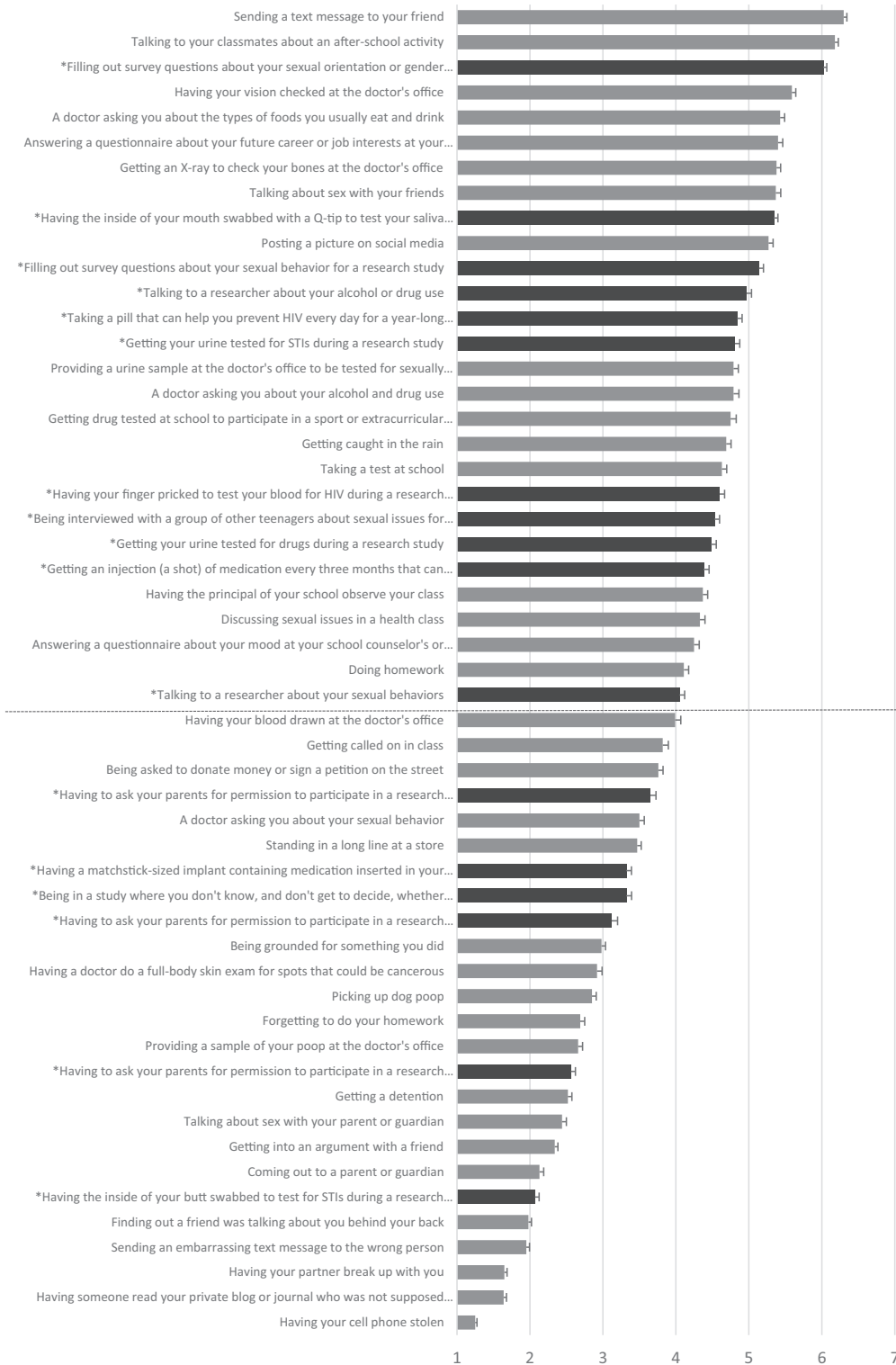
#### Group differences

Results of multiple regression tests are in Table 3. Significant predictors were found across all four MACCREE domains, even while controlling for other demographic covariates. Regarding outness to parents and parental attitudes, higher levels of parental acceptance predicted significantly greater levels of comfort across all four domains. Participants who were out to their parents or guardians expressed significantly greater comfort with both SGM Identity and Sexual Health–related procedures and events and HIV/Sexual Health Research Procedures.

Regarding demographic characteristics and sexual history, compared with white participants, black participants reported significantly greater comfort levels with both Routine Medical and Psychological Tests and HIV/Sexual Health Research Procedures, whereas participants who identified as other racial or ethnic minorities reported significantly less comfort with Everyday Events for Adolescents. Cisgender participants were significantly more comfortable than their transgender or nonbinary peers with Everyday Events for Adolescents. AFAB youth were less comfortable than AMAB youth across three of the four domains: Routine Medical and Psychological Tests, Everyday Events for Adolescents, and HIV/Sexual Health Research Procedures. The older participants were, the greater comfort they expressed with both Routine Medical and Psychological Tests and HIV/Sexual Health Research Procedures. Finally, sexually active youth reported greater comfort with HIV/Sexual Health Research Procedures.

#### Discussion

Empirical studies focused on SGM adolescents’ comfort with health-related research procedures have the potential to shape decisions regarding their inclusion in research and inform practices that might mitigate risks. In this study, we quantitatively measured SGM youth’s comfort with sexual health, HIV prevention, and risk behavior research procedures relative to



**Figure 1.** Rank-ordered MACCREE items reflecting adolescents' level of comfort with everyday events, routine medical and psychological tests, SGM Identity and Sexual Health topics, and HIV/Sexual Health Research Procedures (denoted in black with \*). Dotted line indicates "line of neutrality" (score of 4 = "neither comfortable nor uncomfortable"). MACCREE = Measure of Adolescent Comfort with Clinical, Research, and Everyday Events; SGM = sexual and gender minority.

**Table 3**  
Multiple regression results for demographic predictors of MACCREE domain scores

|                         | RMPT                 |         | EEA                  |         | SGM                 |         | HRP                  |         |
|-------------------------|----------------------|---------|----------------------|---------|---------------------|---------|----------------------|---------|
|                         | B                    | p value | B                    | p value | B                   | p value | B                    | p value |
| Outness                 | .163 (–.003, .328)   | .054    | .035 (–.070, .140)   | .512    | .239 (.049, .429)   | .014    | .240 (.072, .407)    | .005    |
| Parental acceptance     | .100 (.038, .161)    | .002    | .067 (.028, .106)    | .001    | .276 (.205, .347)   | .000    | .146 (.084, .208)    | .000    |
| Race                    |                      |         |                      |         |                     |         |                      |         |
| Black                   | .533 (.209, .898)    | .002    | .058 (–.160, .276)   | .602    | .198 (–.198, .594)  | .327    | .405 (.056, .754)    | .023    |
| Latino                  | –.069 (–.236, .098)  | .418    | –.085 (–.191, .021)  | .115    | .088 (–.104, .281)  | .366    | .023 (–.146, .192)   | .790    |
| Other                   | –.105 (–.349, .138)  | .396    | –.169 (–.323, –.015) | .032    | –.124 (–.404, .157) | .387    | –.120 (–.367, .126)  | .338    |
| Cisgender               | .070 (–.105, .245)   | .431    | .141 (.030, .252)    | .013    | –.082 (–.284, .119) | .423    | –.096 (–.274, .081)  | .287    |
| AFAB                    | –.368 (–.530, –.207) | .000    | –.273 (–.375, –.170) | .000    | –.078 (–.264, .108) | .410    | –.238 (–.401, –.074) | .004    |
| Age                     | .115 (.042, .188)    | .002    | .029 (–.017, .075)   | .223    | .023 (–.061, .106)  | .591    | .096 (.022, .169)    | .011    |
| Sexually Active         | .115 (–.038, .268)   | .141    | .035 (–.062, .132)   | .484    | .157 (–.019, .334)  | .080    | .270 (.114, .425)    | .001    |
| Adjusted R <sup>2</sup> | .124                 |         | .114                 |         | .144                |         | .131                 |         |

AFAB = assigned female at birth; EEA = Everyday Events for Adolescents; HRP = HIV/Sexual Health Research Procedures; MACCREE = Measure of Adolescent Comfort with Clinical, Research, and Everyday Events; RMPT = Routine Medical and Psychological Tests; SGM = SGM Identity and Sexual Health.

everyday life events and routine medical care using the MACCREE, a questionnaire based on the framework described in Petrie et al. [22].

Overall, findings are consistent with research on community samples of adults and college students [22] in that SGM youth rated their discomfort with most research procedures as relatively low. Moreover, their comfort with research procedures was significantly greater than most everyday events, and research procedures were typically rated similarly to or more comfortable than analogous procedures at their doctor's office (e.g., talking to a researcher vs. doctor about substance/alcohol use). The few research procedures that were rated as more uncomfortable (i.e., <4 on a scale of 1–7) involved asking for parental permission to participate in research, and more invasive procedures, such as a rectal swab to test for STIs (done in some of our adolescent research studies considered to have minimal risk) and insertion of a small implant containing HIV prevention medication (a drug delivery system that is in development, similar to a contraceptive implant) [29]. Youth rated the prospect of participating in a study where they could be randomized to an HIV prevention drug or placebo as somewhat more uncomfortable than most everyday events and research procedures ( $M = 3.32$ ), similar in discomfort to being grounded.

Several sociodemographic and behavioral predictors of comfort on the MACCREE emerged. Greater parental acceptance of SGM identity and outness to parents predicted increased comfort with HIV/Sexual Health Research Procedures. These findings substantiate prior qualitative and mixed-methods work showing that outness and parental acceptance were linked with differential willingness to engage in sexual health research among SGM adolescents [20,21,28]. AFAB youth reported lower levels of comfort across HIV/sexual health research procedures, routine care, and everyday events compared with AMAB youth. AFAB youth may have found the HIV prevention research procedures less personally relevant than did AMAB youth; some research suggests sexual minorities AFAB may have worse health care experiences than their AMAB counterparts [31,32]; and several everyday events described experiences related to school or academic achievement, settings in which AFAB adolescents may have lower self-confidence than AMAB adolescents [33]. Unexpectedly, black youth reported higher levels of comfort with HIV prevention research participation and routine care than did non-Hispanic white youth. Nevertheless, as our sample of black youth was relatively small, this finding should be interpreted

with caution. Finally, being older and having had sex was associated with greater comfort with HIV/Sexual Health Research Procedures.

#### Limitations

First, this study assessed youth's discomfort with research and not all possible harms related to research participation. Moreover, we do not know whether participants considered magnitude of discomfort, duration, or both in their ratings. As IRBs need to consider the probability and magnitude of harm to determine whether a study is minimal risk, other frameworks such as those described in the study by Rid et al. [30] may also be useful in their decision making. Second, youth were not given complete details of the research studies, which may have affected their comfort ratings. For example, our experiences in our ongoing research studies indicate that youth express initial discomfort about the concept of a rectal swab to test for STIs, but on learning more details or doing the swab, their discomfort is largely eliminated. Relatedly, generalizability may be limited as we asked participants to anticipate their discomfort in hypothetical research situations, rather than measuring discomfort before and after research participation. Arguably, however, when individuals are considering enrollment in a research study, they are likely taking into account anticipated benefits and risks—including an educated guess about the level of discomfort they may experience—before making a decision. Moreover, many common research procedures are also part of routine care (e.g., health questionnaires) and as such, participants can draw from their experiences there. Generalizability may also be limited by the fact that participants who volunteered for this study may have been more comfortable participating in research. Finally, we did not assess geographic location, which may have impacted participant ratings; for example, youth in rural or more socially conservative areas may be less comfortable with sexual health research participation.

#### Implications and future directions

Here we presented one framework for how adolescent health researchers can assess participants' comfort with novel or existing research procedures in their area of study. As adolescent HIV prevention researchers, the MACCREE enabled us to explore youth's comfort with emerging biomedical prevention methods

(e.g., injectable and implantable pre-exposure prophylaxis) relative to standard HIV behavioral surveillance and prevention research procedures, and it is useful to know how adolescents perceive novel procedures well before they are tested on youth populations. Although it may not be feasible to ask every question because of time constraints and topic relevance (e.g., the SGM items could be dropped for researchers not studying SGM youth), researchers could develop items for procedures specific to their area and compare youth's scores to our items of common clinical procedures and everyday events. In addition, following Petrie et al. [22], future studies could compare SGM youth's levels of comfort to those of cisgender and heterosexual youth, IRB members, and parents, which would shed light on these groups' estimations of research-related discomfort relative to SGM youth.

## Conclusion

Our findings suggest that SGM youth are generally comfortable with a variety of sexual health and risk behavior research procedures. Certain groups of youth (e.g., younger, sexually inexperienced, not out, and lack parental acceptance) and youth in certain types of studies (e.g., those that require parental permission, randomized trials, and more invasive procedures) may benefit from additional measures to increase comfort with participation, such as waiving parental permission, increased privacy protections, developmentally appropriate yet detailed explanations of study procedures and risks/benefits, and access to SGM-specific sexual health information.

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## Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jadohealth.2018.10.293>.

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