

# Special populations in human research: Sexual and gender minorities

Kathryn Macapagal, PhD  
Research Assistant Professor  
Department of Medical Social Sciences, Feinberg School of Medicine  
Institute for Sexual and Gender Minority Health and Wellbeing  
Northwestern University  
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Institute for Sexual  
and Gender Minority  
Health and Wellbeing

# Overview

- About ISGMH & my experience
- Historical perspective & LGBTQ community viewpoints on research
- Best practices for research associated with SGM/LGBTQ populations
- Considerations for minor populations
- IRB review considerations for researchers and IRBs
- Resources

**About ISGMH & me**

**Audience check!**



**Setting the stage: Why is research on SGM populations important?**

# What do LGBT and SGM acronyms mean?

“Sexual and gender minority” [SGM] is an umbrella term that encompasses lesbian, gay, bisexual, and transgender [LGBT] populations as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional, societal, cultural, or physiological norms.

–NIH Sexual and Gender Minority Research Office



# How many adults identify as SGMs?

## U.S. Adults Identifying as LGBT, 2012-2016

Do you, personally, identify as lesbian, gay, bisexual or transgender?

	2012	2013	2014	2015	2016
	%	%	%	%	%
% LGBT	3.5	3.6	3.7	3.9	4.1
Estimated number of LGBT	8.3 million	8.673 million	9.18 million	9.652 million	10.052 million

GALLUP DAILY TRACKING

8% same-sex behavior  
11% same-sex attraction

10 million adult Americans ≈ **population of Chicagoland area**

# Adolescents more likely to identify as SGM

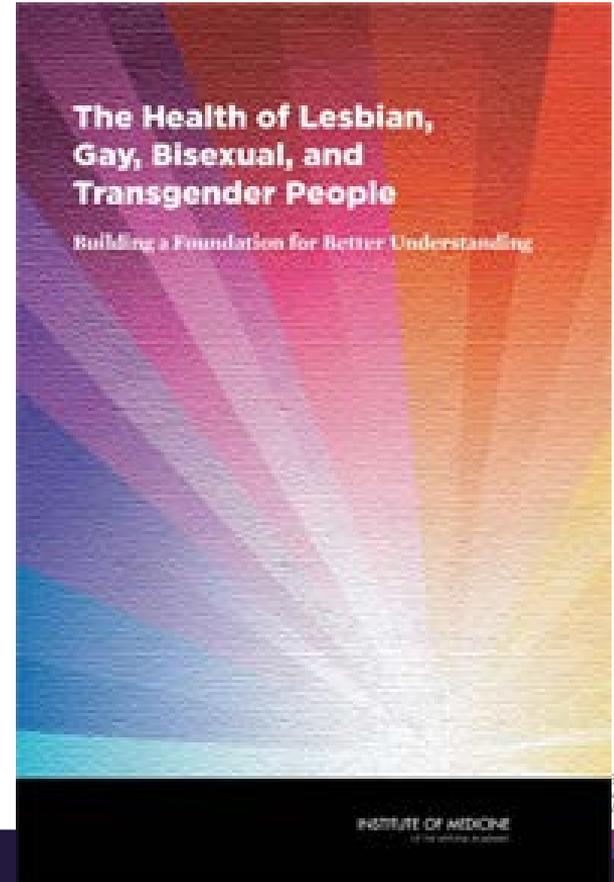


- 2015 CDC Youth Risk Behavior Survey – 11% sexual minority high schoolers (1.3 million)
- CDC Behavioral Risk Factor Surveillance Survey – 0.7% adolescents identify as transgender (vs. 0.3% adults)
- Why?

# SGMs experience numerous health disparities

Compared to non-SGM/general populations:

- Tobacco use (32% vs 21% past month)
- Alcohol use (64% vs 56% past month)
- Illicit drug use (>2x past year)
- Mood & anxiety disorders (>2-3x lifetime)
- Suicide attempts (>2x past year)
- Physical health problems (cancer, obesity, HIV – 70% gay/bi men, >4x trans)
  
- Disparities begin to emerge in adolescence



## Violence-Related Health Risks

	Lesbian, Gay, and Bisexual Students	Heterosexual Students	Increased Risk for Lesbian, Gay, and Bisexual Students
Ever physically forced to have sexual intercourse	17.8%	5.4%	>3 times
Experienced sexual dating violence	22.7%	9.1%	>2 times
Experienced physical dating violence	17.5%	8.3%	>2 times
Were bullied on school property	34.2%	18.8%	~2 times
Were electronically bullied	28.0%	14.2%	~2 times
Did not go to school because they felt unsafe at school or on their way to or from school	12.5%	4.6%	>2 times
<b>Felt sad or hopeless</b>	<b>60.4%</b>	<b>26.4%</b>	<b>&gt;2 times</b>
<b>Seriously considered attempting suicide</b>	<b>42.8%</b>	<b>14.8%</b>	<b>~3 times</b>
<b>Attempted suicide</b>	<b>29.4%</b>	<b>6.4%</b>	<b>&gt;4 times</b>

## Drug-Related Health Risks

Ever used hallucinogenic drugs	11.5%	5.5%	>2 times
Ever used ecstasy	10.1%	4.1%	>2 times
Ever used heroin	6.0%	1.3%	>4 times
Ever used methamphetamines	8.2%	2.1%	~4 times
Ever took steroids without a doctor's prescription	9.7%	2.6%	>3 times
Ever used inhalants	17.3%	5.6%	>3 times
Ever injected any illegal drug	5.4%	1.1%	~5 times

Sexual minority adolescents at increased risk relative to heterosexual peers

# Sexual/reproductive health among SGM teens

Compared to non-SGM teens, SGM teens:

- More likely to have had sex
- Less likely to use contraception during sex
- Less likely to use condoms at last sexual intercourse
- More likely to be involved in unplanned pregnancy
- Have higher rates of HIV/STIs

Transgender teens

- Medical needs related to gender affirming treatments (e.g., hormone therapy, puberty blockers, fertility preservation)

# State of research on SGM populations

- Compared to other minority groups, there is less research on SGM populations
- Researchers often able to study broader issues affecting SGM populations by focusing on health issue that disproportionately impacts them (e.g., HIV)
  - More research on gay men/MSM; less research on women, youth, transgender individuals, bisexual people
- In 2016, SGM designated a health disparity population by NIH – increased research attention on issues broader than specific diseases or disorders

**Sexual and gender minorities are comprising a larger, more visible part of our population.**

**Research is sorely needed to understand & improve their health and well-being.**



# **Historical perspective & LGBTQ community viewpoints on research**

# Historical and current issues impacting SGM research

- LGBT populations have historically been mistreated in research
- Misrepresentation of research results has contributed to negative perceptions of LGBT individuals
- Heightened concerns about privacy and confidentiality (being outed, health status, risk behaviors)
- Despite improvements in social/cultural attitudes toward LGBT individuals, these factors can make people wary of research involvement
  - Increased sensitivity on the part of some IRBs

# What do our participants think?

- Many enthusiastic about being in research, motivated to give back to the community
- Vast majority of participants feel comfortable with research participation even on sensitive topics
- Research participation can have added benefit of providing support, resources, affirmation

# What our teens have said

- I would say this was a very comfortable survey. It was very lengthy but I feel you have received a lot of useful research. I felt uncomfortable at first when asked what material I look up on the web but I realized my parents won't ever find out about this and all of this is for research so its best to be honest and informative.
- I think this survey hit all of the aspects that I was expecting to answer, and it opened my eyes more to HIV testing (since I was already considering getting tested). I also realized that I am more comfortable answering questions about my sexuality and sexual activity.

# That said...

- Mistrust in research may be greater in some subgroups of the LGBT community
  - Transgender or nonbinary individuals
  - LGBT people of color
- Mistrust can be mitigated by conducting research that is informed by community voices & takes their needs and perspectives into consideration



# **Best practices for research with SGM populations**

# Best Practices: Informed consent process

- Consider potential barriers to informed consent process & take additional measures that optimize consent with SGM populations
  - E.g., is written documentation of consent necessary?
- Address negative experiences with / negative perceptions about research
  - Foster trust – be transparent about researcher experiences, motivations
  - Ensure team is culturally responsive, includes members of the community
  - Be aware of your institution's reputation in the SGM research space
- What is your participants' level of education, reading ability, SES?
  - Ensure consent materials in accessible and affirming language, use multimedia
  - Are your incentives potentially coercive?

# Best Practices: Privacy & confidentiality

- A major concern of SGM research participants. Be explicit and detailed about how you are protecting their privacy/confidentiality and limits.
- Are participants outing themselves or having to disclose sensitive information by expressing interest in or participating in the study, or signing a consent form?
  - Consider discretion in advertising, recruitment, study location if necessary
  - Obtain waiver of written documentation of consent; use pseudonyms
- Health and risk behavior research can trigger mandated/health department reporting. Be explicit about the situations that require breaking confidentiality
- Even in a big city, the SGM community is small! Avoid or mitigate dual relationships and initiating contact with participants in public

# Best Practices: Mitigating discomfort & harm

- Our studies investigate sex, discrimination, violence and victimization, substances, mental health, HIV, families/social support
  - May lead to discomfort/harm to participant and SGM community at large
- Ensure content and process of research is culturally sensitive
  - Consult with a community advisory board, seasoned researchers in the area
  - Environment, research team, research materials
  - Carefully frame results to minimize possibility of misinterpretation or misuse
- Give participants space to share concerns, feelings
  - Ask about (dis)comfort following certain procedures (and collect this data!)
  - Have trained mental health providers on team / on-call
  - Have up-to-date SGM-inclusive resource list at hand

# Best Practices: Build in benefits/resources

- Participant time is so valuable. Without them, we cannot do our science. Consider how the study can be helpful or useful to them
- Give back, provide something tangible: SGM-affirming resources, referrals, food, transportation (if allowable)
- Inform past participants of findings & concrete products, request feedback
- Acknowledge them: publications, birthdays, swag
- All these measures help build trust & credibility with the community

# Considerations for minor adolescent populations

# Teens can independently consent to healthcare

- ‘Mature minor’ laws: parental permission can be an obstacle to certain health services
- In Illinois, anyone 12 or older may independently consent to
  - outpatient counseling or psychotherapy
  - medical care or counseling related to substance/alcohol use disorders
  - medical care or counseling related to sexually transmitted infections
  - HIV testing with no duty or obligation to notify parents of the results



# Teens aren't always permitted to consent to health research



“...an adolescent who by state law has the right to consent to... reproductive and sexual health medical care without parental permission should also have the right to autonomously consent to research *[in these areas]*.

Failure of IRBs to *[waive parental consent]* ... unjustly deprives them of research critical to their health and wellbeing.”



sharing child and youth development knowledge  
volume 27, number 1  
2013



AMERICAN PSYCHOLOGICAL ASSOCIATION  
**COUNCIL OF REPRESENTATIVES RESOLUTION  
SUPPORT FOR THE EXPANSION OF MATURE MINORS' ABILITY TO  
PARTICIPATE IN RESEARCH (Adopted by the APA Council of  
Representatives on August 8, 2018)**

*“Therefore Be It Further Resolved,* in accordance with current regulations, APA asks IRBs to waive the parental permission requirement when it potentially could harm the mature minor and when alternative and appropriate research protections are in place;”



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# Research suggests that most risks of social/behavioral research with LGBT adolescents are minimal

- Minimal risk research = discomfort/harms no greater than those in everyday life
- Youth feel comfortable answering questions about sexual behavior, sexual orientation/gender identity, mental health, substance/alcohol use
- Risks similar to adult sexual health studies
- No evidence sexual health / risk behavior research promotes adverse outcomes



# Why are SGM teens underrepresented in health research?

- Consent waivers for minimal risk research aren't always granted
  - Meta-analysis on effects of parental permission in research
  - SGM youth – fear of disclosure to parents, consequences
- Researchers & IRB members may have concerns (e.g., that adolescents may be uncomfortable with research or fail to comprehend it; lack knowledge about special populations; believe that parents have a right to decide)
- Researchers may avoid doing this work altogether concerned it is “too hard”; may anticipate or experience pushback from IRBs

**These factors contribute to a lack of research on SGM adolescents & perpetuate health disparities.**

# What do 200 LGBT adolescents think about being in a sexual health/risk behavior survey?

Question	Higher = More Agreement			STD
	Min	Max	Mean	
The results of the survey study may increase prejudice against LGBTQ teens.	1	5	2.03	1.01
I was afraid to answer questions about my sexual orientation/gender identity honestly.	1	5	1.62	1.13
Taking this survey has made me more likely to have sex.	1	5	1.99	1.04
Taking this survey has encouraged me to use condoms or other forms of protection against HIV/STIs.	1	5	3.85	1.00
Taking this survey has encouraged me to get tested for HIV/STIs.	1	5	3.40	1.06
Answering these questions made me feel that someone is paying attention to problems faced by LGBTQ teens.	1	5	4.66	0.59
I feel good about contributing to research that might help other LGBTQ teens.	1	5	4.81	0.50
Answering questions about sex helped me reflect on my past behaviors.	1	5	3.63	1.05
I trust the motives of the researchers conducting the study.	1	5	4.37	0.73
I trust the researcher to keep my answers confidential.	1	5	4.32	0.82
Answering questions about my sexual behaviors, sexual orientation, and gender identity felt like an invasion of privacy.	1	5	1.69	0.88
I feel more comfortable answering research questions about my sexual behavior than when I talk to my regular doctor.	1	5	3.97	1.31
I feel more comfortable answering research questions about my sexual orientation/gender identity than when I talk to my regular doctor.	1	5	3.88	1.24
I was concerned that my parents would see my answers to the survey questions.	1	5	2.51	1.49
Getting my parents' or guardians' permission to participate would protect me from being harmed during the survey.	1	5	2.10	1.07

# Sometimes the answers are not what you expect...

- In a recent study, more youth were uncomfortable answering questions about body image than about their use of sex/dating applications to meet partners (but rates of discomfort still low)

**How comfortable did you feel answering the questions about your body image and how you feel about your body?**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very uncomfortable	11	3.6	3.8	3.8
	Somewhat uncomfortable	28	9.3	9.7	13.5
	Neither uncomfortable nor comfortable	52	17.2	18.1	31.6
	Somewhat comfortable	72	23.8	25.0	56.6
	Very comfortable	125	41.4	43.4	100.0
	Total	288	95.4	100.0	

**How comfortable did you feel answering the questions about your use of apps and websites to meet male partners for sex and dating?**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I do not want to answer	1	.3	.4	.4
	Very uncomfortable	5	1.7	1.9	2.3
	Somewhat uncomfortable	17	5.6	6.6	8.9
	Neither uncomfortable nor comfortable	51	16.9	19.8	28.8
	Somewhat comfortable	68	22.5	26.5	55.3
	Very comfortable	115	38.1	44.7	100.0
Total	257	85.1	100.0		

# What do SGM adolescents think about health research?

- **N=616 SGM adolescents rated most research procedures similar to or more comfortable than everyday events, routine medical procedures**
- Most comfortable
  - Everyday event – Sending a text message
  - Research – Filling out survey questions about sexual orientation/gender identity
  - Routine healthcare – Having your vision checked at the doctor's office
- Most uncomfortable
  - Everyday event – Providing a sample of poop at doctor's office
  - Research – Rectal STI swab for research study
  - Routine healthcare - Having cell phone stolen

1 (most uncomfortable)

7 (most comfortable)

Most comfortable everyday event

Most comfortable research

Most comfortable routine care



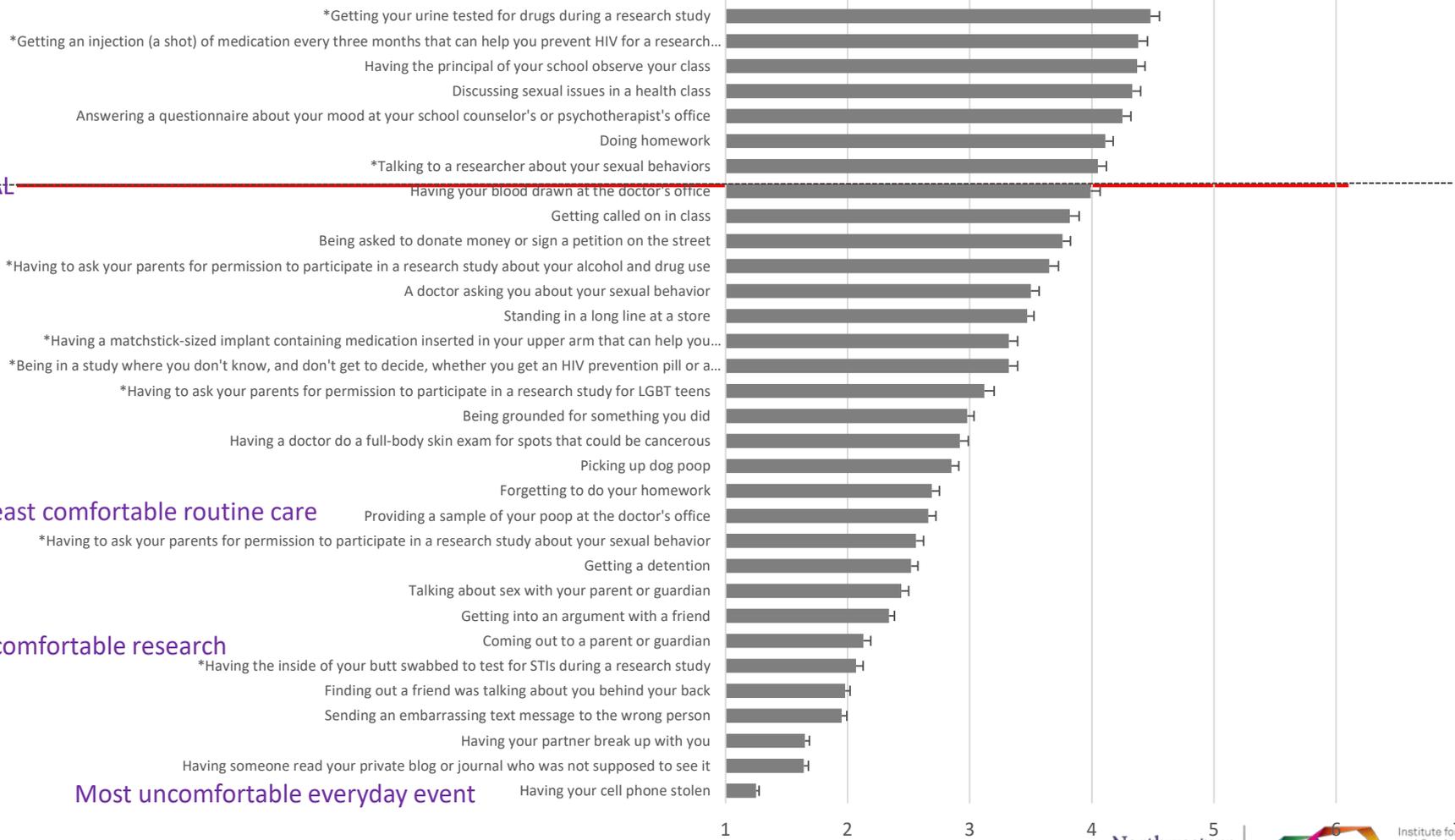
NEUTRAL

NEUTRAL

Least comfortable routine care

Most uncomfortable research

Most uncomfortable everyday event



# Best Practices: Adolescents

- SGM adolescents face unique issues related to their developmental stage & SGM identity/behavior that may impact their research participation
- Consider whether parental permission is the best protection for the specific research study at hand
- Be transparent about researcher experiences with community, motivations for research
- Form community advisory board of LGBT adolescents, young adults (online!)
- Tailor study materials, considering adolescents' education and attention level
- Appropriate incentives for adolescents – how much is too much? Tough to say.
- Use decisional capacity measures

# Using consent capacity questions for adolescent research

PrEP 4 The Future Project  
SGM adolescents' perspectives on novel biomedical HIV prevention  
Northwestern University IRB# STU00207525  
Principal Investigator: Dr. Kathryn Macapagal

Please read through the consent form on the next few pages carefully. In between some of the pages you'll be asked questions to confirm that you understand what you just read. You must answer these questions to join the study. If you get any of the questions wrong, you will have to reread parts of the consent form again and will be asked the questions you missed a second time.

If you want some more time to decide about whether or not to participate after reading the form and answering the questions, just click "save" and you will receive a return code.

Take all the time you need and don't hesitate to reach out if you have any questions along the way! You can email us at [prep4thefuture@northwestern.edu](mailto:prep4thefuture@northwestern.edu)

Will being in this study help me in any way?

We don't know if you'll benefit from participating in this research, but you will receive information on the daily PrEP pill, which is currently approved to prevent HIV, as well as information about other HIV prevention options currently being tested by researchers. Researchers will also learn new things that will help with developing and improving PrEP options for teens. So, you being in the study can help teens like you in the future.

Is there any way being in this study could be bad for me?

Your privacy might be broken. For example, if someone sees your computer/tablet/smartphone screen, this person may see that you are answering questions about your sexual orientation and gender identity or HIV. It's very important that you use a computer/tablet/smartphone in a private place.

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**Please answer the question based on the information you just read.**

When watching study videos and answering survey questions, I should make sure:

- My friends are around
- My homework is done
- No one is around (especially people who you don't want to know that you're in the study)
- I am in a public place

What happens if I do not want to be in this research?

It is your choice to take part in the study or not. You can drop out of the study at any time and nothing bad will happen to you.

What happens if I say "Yes", but I change my mind later?

You can drop out of the study at any time and it will not be held against you. If you decide to withdraw from the study, please let us know. If you end your participation mid-study, we will keep your data unless you tell us you don't want us to.

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**Please answer the question based on the information you just read.**

If I no longer wish to participate in the study:

- I don't get to decide whether or not to leave
- I can leave the study at any time and nothing bad will happen to me
- No matter what I have to stay in the study until I complete it
- I should keep participating because the researchers will be mad at me if I leave

# Do 14-17 year old minors differ from 18-19 year old adults in consent capacity for HIV/sexual health research?

**No significant age differences in understanding, appreciation, or reasoning:**

- Purpose of study
- Inclusion criteria
- Side effects
- Key study procedures
- Random assignment
- Confidentiality
- Voluntarism
- Contacting IRB if questions, concerns
- Liability in case of needed medical care
- Decision to participate based on weighing risks and benefits

Minor adolescents able to make reasoned decisions about research participation without parental involvement with developmentally appropriate consent procedures

What I've learned in doing this work:

**We underestimate teens' abilities and capacity. The assumption that we (adults) always know better leaves LGBT youth without a say in research and decisions that affect their health and wellbeing.**

**Teens are not uniformly risky or impulsive decision makers. Such decisions often happen in the context of peers rather than important decisions they are making on their own.**

Wait... what about the parents??



# Parent views on permission waivers for sexual health research

**Parents we have talked to generally recognize the value of research participation and parental permission waivers if you provide them with enough context.**

**Benefits:** reduce participation barriers among SGM who are not out, youth of color

*There's a history of... minorities not wanting to participate in research [and] if you have children who are not out to their parents... or whose parents just have a fundamental opposition to research or have a huge distrust of the medical community, then they could participate without worrying about their parents.*

**Concerns:** perception that teens too immature to make informed decisions

# What are parents' suggestions for substitute protections?

## Confidentiality, informed consent, easy access to healthcare professionals

*I: what do you think researchers need to do in order to ensure [teen's name]'s safety and wellbeing if he were to participate in this study?*

*P: Making sure that things stay **confidential and that there's resources available to him... making sure that everything is explained very well... the ability to call somebody or email someone if he has additional questions***

*\*These are standard protections that IRBs require*

## Reinforcing study information throughout study, using multiple formats

*“...If he hears something verbally he doesn’t get all the details and especially not with one time through. So if he brings a message home from school... I’ll always ask him to get it in writing, bring home the papers that describes it because he misses a lot of information if it’s just verbal input and it’s not more than one time through.*

***So having multiple inputs of the information like written and saying it verbally, even watching a video or having something to go back to or refer to...”***

# Example of parent information sheet



## Information for Parents

Below we answer questions commonly asked by parents about the SMART Project.

### **How much will this cost me?**

This program is provided to your child at no cost.

### **Why is this only for guys? Why can't my daughter participate?**

We've tailored this study to only focus on health issues facing teen guys. As I'm sure you're aware, young men and young women have many different concerns and behaviors relevant to their health, so it makes sense to tailor programs to their own unique needs.

### **How can my child be in a study without my permission?**

The SMART Project has been classified as a minimal risk study, meaning ethics experts have decided being in this study presents no more risks than experienced in everyday life or a typical doctor's visit. Some teens may feel uncomfortable talking to their parents about enrolling in health-related research. In addition, our previous research has shown that teens have the capacity to understand the benefits and risks of participating in a study and make an informed decision about their participation. Allowing teens to make their own decision about participation ensures that all eligible teens are able to participate in our study, including those who may feel uncomfortable talking to a parent or may not be in contact with a parent.

### **How is my child's information used?**

The information your child provides will help us understand how online programs can improve teens' health.

### **Will my child's data be kept confidential?**

Participant data is kept completely confidential. Participant names will never be used in any reports of this research, and only select members of the study staff will have access to participant data. Any identifying information will be changed to protect teens' confidentiality. The federal government has given us a certificate to help us protect against disclosing your child's information.

# Summary of our ethics research

- SGM teens perceive adolescent sexual health research procedures to be low-risk & high-benefit
- SGM teens under 18 have the ability to make reasonable, informed, voluntary decisions about participation in sexual health research
- Parental permission waivers are critical in order to conduct sexual health research that is inclusive of and representative of SGM youth
  - But: still gaps in our knowledge about parents who may be less accepting, from different cultures/backgrounds



# **IRB review considerations for researchers & IRB members**

# How has empirical ethics data informed our research practice with SGM adolescents?

- Build trust and credibility starting with recruitment process
- Integrate decisional capacity questions into consent process
- Provide easy-to-digest visual and written consent information
- (Over)explain data security, privacy, confidentiality, specify reporting situations
- (Over)explain rationale for each research procedure
- Ask about discomfort/concerns during novel survey topics or research procedures
- Provide resources, clinician-on-call
- Consult with standing youth advisory councils, outside experts in ethics and SGM adolescent health

# Recommendations for researchers

- Familiarize self w/literature, guidelines, regulations in SGM research ethics
  - Published case examples – in references section
  - Your profession's ethics code regarding research
  - HHS/OHRP regulations relevant to consent waivers
- Ensure research team is culturally responsive to needs of LGBT participants
- Develop a community advisory board, consult with colleagues
  - Enhances validity, buy-in, maximizes benefits and minimizes harms
- Work with your IRB from the beginning
  - Consult with them while preparing proposal
  - Attend meetings if possible, brainstorm appropriate protections and risk reduction procedures w/board members
  - Provide information about risks and benefits of the kinds of research you conduct

# Recommendations for researchers

- Get involved in ethics research, publish the results, share this information with your IRB coordinator, integrate participant suggestions into your work
- It's easier than it seems! Can just add a couple of questions...
  - Rationale for nonparticipation during screening process
  - Comfort/discomfort
  - Opinions on adequate protections (for youth/other vulnerable populations)
  - When testing novel procedures or questions
  - When conducting research on an understudied population (e.g., transgender teens)

# Recommendations for IRB members

- Balance getting the science done with minimal selection bias + ensuring adequate protections for research participants
- Research suggests that standard practices for human research protections are what LGBT teens and parents feel is appropriate
  - Greater emphasis on privacy and confidentiality, resource provision
- If a study has an opportunity to build in research ethics questions consider suggesting that researchers do so
  - Taking survey made me likely to have Sec
  - Discomfort w body questions

# Recommendations for IRB members

- Share successful templates for IRB protocols with LGBT populations
- **What are your experiences? What knowledge/advice do you have to share?**
  - Investigators new to working with LGBT populations
  - Seasoned investigators

# Researcher and IRB partnerships

- IRBs can play an important role in ensuring that scientific knowledge reflects all populations while ensuring safeguards to protect the populations in those studies
- Important for us to work collaboratively – what are the channels in which we can do that the best?
  - Brown bag
  - IRB retreat
  - Ad hoc conversations with IRB coordinators
  - Other ideas? LGBT consultant/committee to review protocols?

# Conclusion

- Many ways to ensure research with SGM populations is ethical and responsible
- Researchers and IRBs can do a better job partnering with & learning from each other when navigating research with SGM populations
  - NU is a great example!
- Consider contributing to the development of the SGM research ethics knowledge base by encouraging researchers to include ethics questions in their studies and requesting that feedback

**We can't wait for more ethics  
research in order to do research  
with SGM communities.**

# Resources

- Despite acceleration of research on SGM populations in recent years, relatively little guidance exists on how to conduct this work in an ethical and responsible manner
  - Some commentaries and articles
  - Some empirical research
  - Much knowledge is passed from team to team
- Plans to summarize our ethics research & recommendations in a white paper

IMPLEMENTATION, POLICY AND COMMUNITY ENGAGEMENT  
SPECIAL COMMUNICATION

## White paper from a CTSA workshop series on special and underserved populations: Enhancing investigator readiness to conduct research involving LGBT populations

Alicia K. Matthews<sup>1\*</sup>, Kevin Rak<sup>2</sup>, Emily Anderson<sup>3</sup>, Wendy Bostwick<sup>1</sup>, Jesus  
Ramirez-Valles<sup>4</sup>, Raymond A. Ruiz<sup>2</sup>, Kathryn Macapagal<sup>5</sup>,  
Karriem S. Watson<sup>6</sup>, Rohan D. Jeremiah<sup>4</sup>, Amparo Castillo<sup>7</sup> and Wendy Choure<sup>2</sup>

(full ref in references section)

CCTS Resources

CCTS Grant Programs

Recruitment Toolbox

Community Health Worker  
Training

Recruitment Templates

Target Populations Toolkit

African American

Hispanic & Latino/Latina

**LGBT**

People with Disabilities

## LGBT

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### LGBT Population Overview

This toolkit provides information and resources to researchers working with lesbian, gay, bisexual, and transgender populations.

[Download the LGBT Target Population Toolkit](#)

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### Toolkit Sections

#### I. Historical and Current Issues

A description of the history of research with the population, along with special considerations for working with the LGBT population

**UIC's Center for Clinical and Translational Science – LGBT Population Toolkit**

<http://www.ccts.uic.edu/content/lgbt>

# Diversity and Inclusion

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Feinberg Home > Office of Diversity > Programs and Groups > LGBT Safe Space Training

## Programs and Groups

Mentoring Programs

LGBT Safe Space Training

Northwestern Chicago Out Network

Affinity Groups

LGBT OutList

LGBT AllyList

Offices and Policies

## LGBT Safe Space Training

### LGBT (Lesbian, Gay, Bisexual, Transgender) Safe Space Training

The Feinberg School of Medicine's Safe Space Training has been expanded and updated through a partnership between the Office of Diversity and Inclusion, the Queers and Allies student group, the Gender and Sexuality Curriculum Taskforce, and the Department of Medical Education.

The Safe Space Program is an initiative to educate allies who support LGBT individuals in our campus community. Unlike more visible under-represented groups, LGBT persons cannot be readily identified. Likewise, there is no easy method of finding persons supportive of LGBT people. The Safe Space Training program strives to educate allies and provide a way for allies within the Feinberg community to prominently identify themselves. The program advances Northwestern University's goal of creating a campus community in which everyone is treated with respect and dignity.

A safe space for LGBT people is not about protecting community members from dissenting viewpoints or difficult conversations, but about making sure that everyone functions in an environment of tolerance and mutual respect. This training effort is not trying to create a separate safe space for LGBT individuals, but make the entire Feinberg community safe.

The LGBT Safe Space Training program has two components: [1] An online introductory module and [2] and in-person workshop. Both are approved for *AMA PRA Category 1 Credit*™.



[feinberg.northwestern.edu/diversity/programs-groups/lgbt-safe-space-training.html](https://feinberg.northwestern.edu/diversity/programs-groups/lgbt-safe-space-training.html)



## Resources

For more information on sexual and gender minorities (SGM), including trainings for healthcare providers and other topics related to SGM health and research, the Institute of Sexual and Gender Minority Health and Wellbeing recommends the following websites:

Center of Excellence for Transgender Health

Centers for Disease Control and Prevention: LGBT Health

GLMA: Health Professionals Advancing LGBT Equality

National Institutes of Health: Sexual and Gender Minority Research Office

National LGBT Health Education Center – A Program of the Fenway Institute

The Williams Institute

National Coalition for Sexual Health: "Sexual Health and Your Patients: A Provider's Guide"

Trans-Affirming and Anti-Oppression Trainings with Jes Scheinplug and Kate Harrington Rosen

Northwestern University Institute for  
Sexual and Gender Minority Health and  
Wellbeing (ISGMH)

[ISGMH.northwestern.edu/resources](https://isgmh.northwestern.edu/resources)



# Recommended readings

- Bettinger, T. V. (2008). “You know what I’m saying”: Emic and etic considerations in research involving sexual minorities. Adult Education Research Conference, <http://newprairiepress.org/aerc/2008/papers/7/>
- **Bettinger, T. V. (2010). Ethical and methodological complexities in research involving sexual minorities. *New Horizons in Adult Education and Human Resource Development*, 24, 43-58.**
- Dixon, L., Salinas, M., & Marquez, L. (2016). Advances and challenges in conducting research with diverse and vulnerable populations in a healthcare setting : Reducing stigma and increasing cultural sensitivity. In R. Parekh & W. Childs (eds.), *Stigma and Prejudice: Touchstones in Understanding Diversity in Healthcare*.
- LGBT Foundation (2017). Ethical research: Good practice for researching LGBT communities and issues. [http://lgbt.foundation/assets/files/documents/may\\_17/FENT\\_1493809742\\_LGBT\\_Foundation\\_Guide\\_to\\_Ethic.pdf](http://lgbt.foundation/assets/files/documents/may_17/FENT_1493809742_LGBT_Foundation_Guide_to_Ethic.pdf)

# Recommended readings

- Martin, J. I., & Knox, J. (2000). Methodological and ethical issues in research on lesbians and gay men. *Social Work Research*, 24.
- **Martin, J. I., & Meezan, W. (2003). Applying ethical standards to research and evaluations involving lesbian, gay, bisexual, and transgender populations. *Journal of Gay & Lesbian Social Services*, 15, 181-201.**
- Roffee, J. A., & Waling, A. (2017). Resolving ethical challenges when researching with minority and vulnerable populations: LGBTIQ victims of violence, harassment, and bullying. *Research Ethics*, 13, 4-22.
- **Tufford, L., Newman, P. A., Brennan, D. J., Craig, S. L., & Woodford, M. R. (2012). Conducting research with lesbian, gay, and bisexual populations: Navigating research ethics board reviews. *Journal of Gay & Lesbian Social Services*, 24, 221-240.**

## Ethics research & commentaries from our team (LGBT youth & parent focus)

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- Fisher, C. B., Arbeit, M. R., Dumont, M. S., Macapagal, K., & Mustanski, B. (2016). Self-consent for HIV prevention research involving sexual and gender minority youth: Reducing barriers through evidence-based ethics. *Journal of Empirical Research on Human Research Ethics*, **11**, 3-14.  
doi:10.1177/1556264616633963 PMC4842126
- **Matthews, A.K., Rak, K., Anderson, E., Bostwick, W., Ramirez-Valles, J., Ruiz, R.A., Macapagal, K., Watson, K.S., Jeremiah, R.D., Castillo, A., & Choure, W. (2018).** White paper from a CTSA workshop series on special and underserved populations: Enhancing investigator readiness to conduct research involving LGBT populations. *Journal of Clinical and Translational Science*. doi:10.1017/cts.2018.317

- Macapagal, K., Coventry, R., Arbeit, M. R., Fisher, C. B., & Mustanski, B. (2017). “I won’t out myself just to do a survey”: Sexual and gender minority adolescents’ perspectives on the risks and benefits of sex research. Online ahead of print, *Archives of Sexual Behavior*, 46. DOI 10.1007/s10508-016-0784-5 PMC5274602
- Macapagal, K., Bettin, E., Matson, M., Kraus, A., Fisher, C. B., & Mustanski, B. Measuring discomfort in health research relative to everyday events and routine care: An application to sexual and gender minority youth. Online ahead of print, *Journal of Adolescent Health*. doi:10.1016/j.jadohealth.2018.10.293
- **Mustanski, B. (2011). Ethical and regulatory issues with conducting sexuality research with LGBT adolescents: A call to action for a scientifically informed approach. *Archives of sexual behavior*, 40(4), 673.**

- **Mustanski, B., & Fisher, C. B. (2016). HIV Rates Are Increasing in Gay/Bisexual Teens: IRB barriers to research must be resolved to bend the curve. *American journal of preventive medicine*, 51(2), 249-252.**
- Mustanski, B., Macapagal, K., Thomann, M., Feinstein, B. A., Newcomb, M. E., Motley, D., & Fisher, C. B. (2018). Parents' perspectives about adolescent boys' involvement in biomedical HIV prevention research. Online ahead of print, *Archives of Sexual Behavior*. doi: [10.1007/s10508-017-1035-0](https://doi.org/10.1007/s10508-017-1035-0)
- Matson, M., Macapagal, K., Kraus, A., Coventry, R., Bettin, E., Fisher, C. B., & Mustanski, B. Sexual and gender minority youth's perspectives on sharing de-identified data in sexual health and HIV prevention research. Online ahead of print, *Sexuality Research and Social Policy*. doi:10.1007/s13178-018-0372-7
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# Thank you!

📍 Kathryn Macapagal, PhD  
Research Assistant Professor  
Department of Medical Social Sciences  
Institute for Sexual and Gender Minority  
Health and Wellbeing  
Northwestern University

✉️ [kathryn.macapagal@northwestern.edu](mailto:kathryn.macapagal@northwestern.edu)  
[isgmh@northwestern.edu](mailto:isgmh@northwestern.edu)

🐦 @\_karmacap  
@ISGMH



Northwestern

