Research with Pride: Considerations for Research with LGBTQ Participants

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About ISGMH

Based at Northwestern, the Institute for Sexual and Gender Minority Health and Wellbeing (ISGMH) is the nation's first university-wide institute to focus exclusively on improving the health and wellbeing of sexual and gender minority populations.

ISGMH is the largest LGBTQ health research institute in the world, connecting scholars from numerous disciplines with the sexual and gender minority community in order to foster collaboration and stimulate new research.



Why do we need to consider how we conduct research with LGBT participants?

- Prior research has either ignored LGBT populations or further stigmatized them
- Accurate data are needed to identify disparities
 - \circ We already know disparities exist in:
 - Suicide
 - Depression
 - Uptake of HIV prevention interventions
 - \circ Prior research has ignored the needs of LGBT populations
 - HIV prevention interventions have excluded transgender men (Descovy for PrEP)
 - Unclear whether transgender women need gynecological care after surgery
 - Long term impacts of hormone replacement therapy remain unclear

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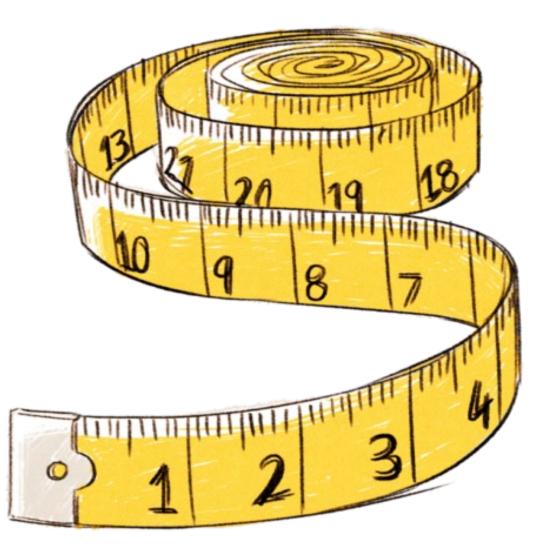
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- Experiences of discrimination lead to heightened concern about demographic questions

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 - Male, Female

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 - Woman, Man, Nonbinary

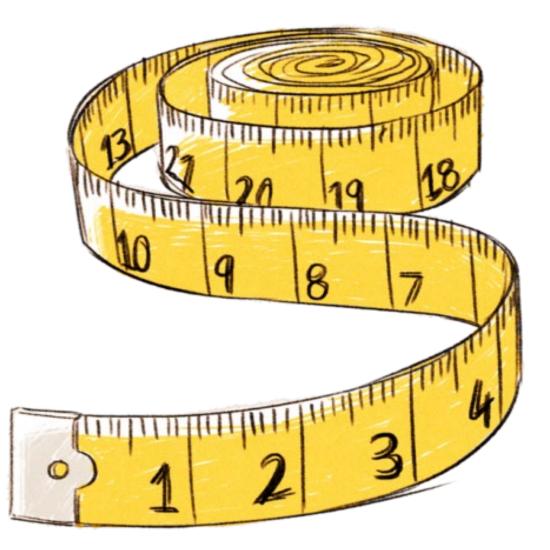
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- Intersex: individuals who are born with sex characteristics outside the male/female binary
- Sexual Orientation: how someone describes their sexual and romantic desires
 - Gay, lesbian, straight, queer, asexual



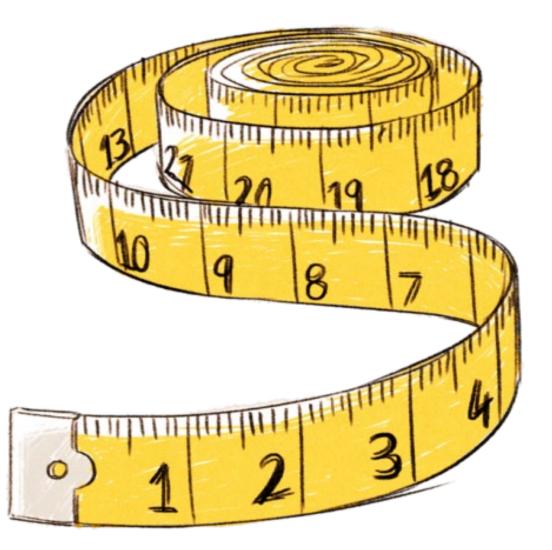
Sex

- What is your sex as listed on your birth certificate?
 - Male
 - Female



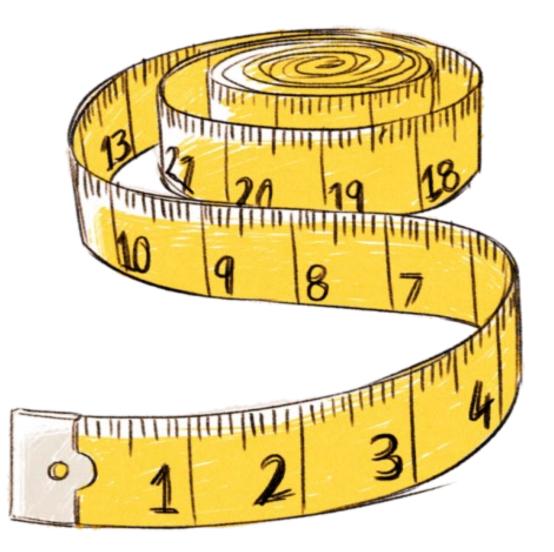
Gender

- What is your current gender identity?
 - Cisgenderman
 - Cisgender woman
 - Nonbinary
 - Genderqueer
 - Gender nonconforming
 - Transgender man
 - Transgender woman
 - Agender
 - An identity not listed here



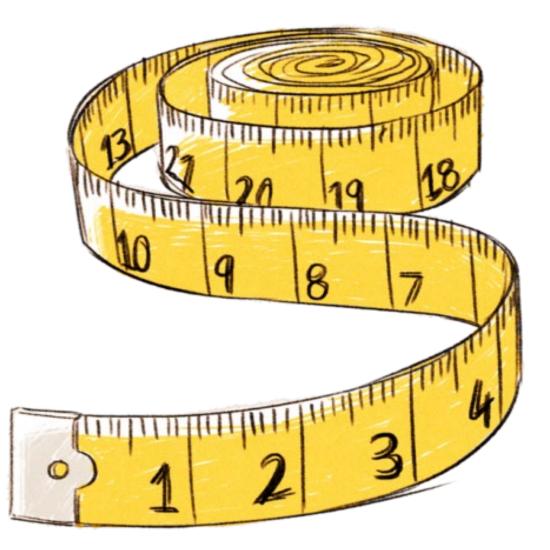
Gender: Two-Step

- What is your current gender identity?
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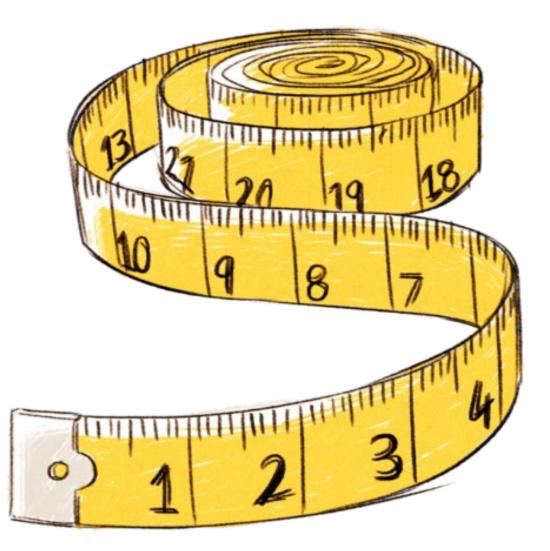
Intersex

- Are you intersex?
 - Yes
 - No
 - Unsure



Sexual Orientation

- How do you describe your sexual orientation?
 - Gay/lesbian
 - Straight
 - Bisexual
 - Queer
 - Asexual
 - Pansexual
 - Another option not listed here



Sexual Attraction

- Which individuals are you attracted to?
 - Only men
 - Only women
 - Only nonbinary people
 - Men and women
 - Men and nonbinary people
 - Women and nonbinary people
 - Men, women, and nonbinary people
 - I'm not physically attracted to anyone

Why might it matter whether you measure sexual orientation or sexual attraction?



Sampling

Sexual Orientation

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- Are you interested in how people identify?

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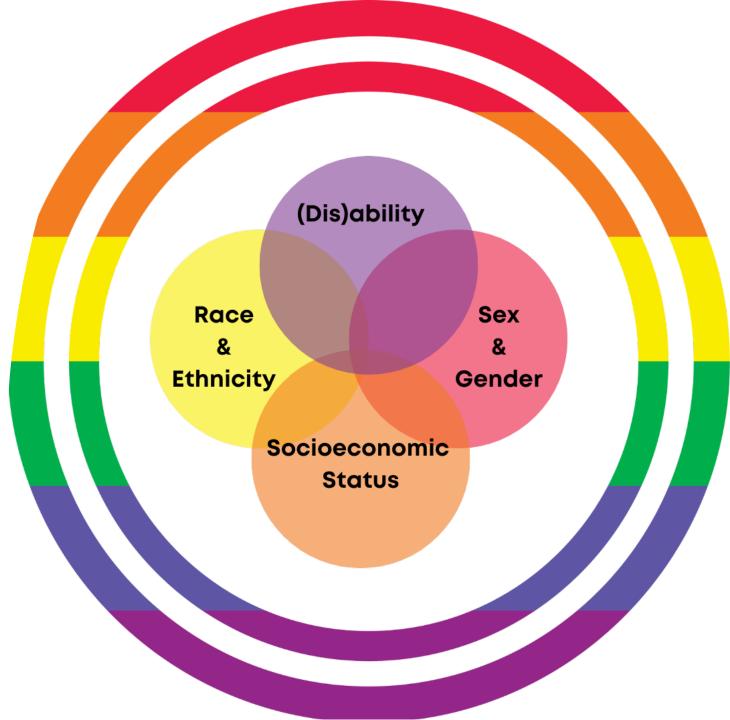
Sexual Attraction

- Are you interested in people's behavior?
- Are you interested in sexual "risk"?

Considerations for the Recruitment and Retention of LGBTQ Populations

Recruiting from LGBTQ Populations

- Define your sub-population
 - The LGBTQ+ community is diverse. Identify what sub-group you need to recruit.



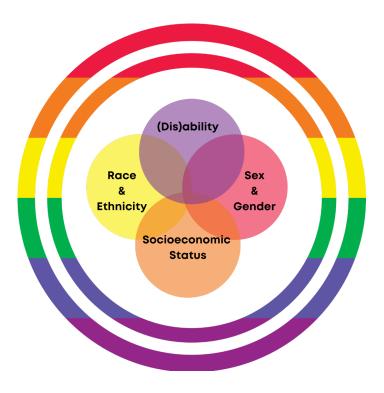
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 - Recruitment for Black LGBTQ individuals might look different than recruiting White LGBTQ individuals.





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- Consider intersecting identities
 - Recruitment for Black LGBTQ individuals might look different than recruiting White LGBTQ individuals.
- Use a multi-pronged approach
 - Meet your population where they are at while considering multiple strategies (e.g., in person, online, Respondent-driven sampling).



Strategies for the Recruitment and Retention of LGBTQ Populations

2GETHER Couples Project

Workshops to help strengthen your relationship and free at-home STI testing



REDCAP.NUBIC NORTHWESTERN LEARN MORE **Paid Couples Research** Northwestern Univ. Couples Study 4 Comments Andrey Canones and 4. Share Comment



Make a difference & get paid!

Earn up to \$125 in an online sex ed p

SIGN UP

-

Online sex ed program for gay, bi, & queer teens

Earn up to \$125 by taking part







answers!



Outreach & Recruitment

- Tailor your outreach procedures and materials to meet the needs of your target population
 - Graphics and language need to be be inclusive.
 - Ensure content and research process is culturally sensitive and accessible.
 - In recruitment advertisements and outreach, ensure discretion to accommodate participants who are not out of the closet.

Intentionality & Transparency

- Acknowledge past harms done to minoritized communities
 - Historically (and currently) LGBTQ have been excluded from research.
- Foster trust through transparency
 - Share motives for research with this community.
 - Create a culturally responsive team.
 - Consider and acknowledge institutional harms.
 - Be aware of how LGBTQ+perceive your institution.
- Be explicit about privacy and confidentiality
 - Be detailed about the steps that are taken to protect participant information and why you are collection certain data (e.g., sexual orientation).



Inclusivity Matters

- Lean on the lived experience of your target population
 - Hire a team who represent the identities of your research population.
 - Consult with community members & compensate them for their expertise.
- Acknowledge your participants in ways that are inclusive & intentional
 - Create LGBTQ affirming resources.
 - Send out birthday cards.
 - Give out swag items or snacks for study visits.
 - Request feedback and implement changes.



Best Practices

Summary of Best Practices

Informed Consent Process

- Consider potential barriers to informed consent with LGBTQ populations, optimizing the process and evaluating if written documentation or parental consent may hinder participation or bias findings.
- Acknowledge your institution's/department's reputation in LGBTQ research, including any history of equity tourism or discriminatory actions.
- Ensure your recruitment materials including consent use inclusive language and are at the appropriate reading level.

Privacy & Confidentiality

- Clearly detail how you will protect LGBTQ participants' privacy and confidentiality, addressing any limits.
- Ensure participants aren't outing themselves or disclosing sensitive information by joining the study; use discretion in advertising, recruitment, and study locations. Obtain a waiver of written consent and use pseudonyms.
- Clearly state situations where confidentiality must be broken due to mandated or health department reporting.



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