**Guidance regarding questions on sex, gender and sexuality**

**Purpose**

The goal of this document is to provide general guidance and example questionnaires for collecting data on sex, gender and sexuality in epidemiologic studies.

**Why do we need guidance about this?**

When collecting data about any aspect of human experience of health, asking questions consistently across studies allows for better interpretability, and asking questions in a way that is respectful and comprehensible to the subject allows for better data quality. This is especially true for questions about sex, gender, sexuality and sexual behavior, because:

1. In most cultures, sexuality and sexual behavior are considered private and intimate, so asking questions about them can make people uncomfortable.
2. In most cultures, gender and sexual behavior are closely connected with power and oppression, with some identities being socially accepted and centered in cultural narratives, while others are excluded or criminalized. Answering questions about these topics in ways that do not adequately reflect subjects’ lived experiences can be traumatizing for people with marginalized identities – especially if the subject sees no clear link between the purpose of the research and the data being collected about them. As researchers we have a responsibility not to cause harm to subjects by asking questions in inappropriate ways or asking questions that are not necessary to our research.
3. Gender and sexuality are complex and highly contextual. This presents logistical challenges for researchers, because our instruments likely need to be adapted for each new research question, cultural and linguistic context, and time period.

**Definitions**

*Disclaimers:*

* *These concepts and language about them are complex and changing. This is a basic primer based on a certain set of resources. It will likely change and not everyone will agree with these definitions. It’s encouraged to read additional resources, especially those relevant to your context.*
* *These definitions apply in US English, but in different settings words, concepts, and their implications may be different. We recommend pilot-testing your instruments in your specific context, and welcome input from people working in other contexts about what language is used in your context.*

*Sex*

**Sex:** the anatomy and physiology of an individual's reproductive system and secondary sexual characteristics. 3 sexes are typically thought of: Female, Male and Intersex (having both male and female characteristics)

**Sex assigned at birth:** the sex someone was assigned by a medical provider at the time they were born based on genitals and/or chromosomes. This is usually listed on a birth certificate. In many places, only 2 sexes can be listed on a birth certificate: male and female. Some places (including WA state) allow a third sex, X, to be listed.

Gender

**Gender:** A LOT has been written about what gender is. At its simplest, it is a set of social experiences associated with a person’s internal identity and how they are perceived externally. Some people conceptualize a few gender categories (most commonly man/boy and woman/girl); others hold that there are many genders that can be approximately categorized, but that people’s genders are not fixed and that gender is as fluid and unique as any human behavior. The most important difference between sex and gender is that gender cannot clearly be categorized based on external morphology or measurable variables – self-report is the only way to asses someone’s gender.

**Gender identity:** A person’s internal concept of themselves and what they call themselves. One's gender identity can be the same or different from sex assigned at birth.

**Gender expression:** Externalization of a person’s gender identity, usually expressed through behavior, clothing, haircut or voice. This may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.

**Cisgender:** A term for people whose gender identity and/or expression matches the sex they were assigned at birth.

**Transgender:** An umbrella term for people whose gender identity and/or expression is different from the gender they were assumed to be at birth based on their assigned sex. Trans-man refers to someone who identifies as a man and whose sex assigned at birth was not male. Trans-woman refers to someone who identifies as a women and whose sex assigned at birth was not female.

**Gender non-binary / gender non-conforming / genderqueer:** A term for people who do not identify with a binary gender of man or woman or who reject gender as a binary construct.

Sexuality & sexual behavior

### Sexuality / sexual orientation: A term reflecting the gender(s) a person is attracted to sexually and romantically. Terms to describe sexuality include:

### Heterosexual: a person who is attracted to people whose gender is the opposite of theirs (assuming binary gender man/woman)

### Homosexual: a person who is attracted to people whose gender is the same as theirs (assuming binary gender man/woman)

### Bisexual: a person who is attracted to men and women (assuming binary gender man/woman)

### Pansexual: a person who is attracted to people with multiple genders and/or conceives of gender as non-binary

### Asexual: a person who does not feel sexual or romantic attraction to anyone

### Queer: an umbrella term for sexual and gender minorities who are not heterosexual and cisgender (ie can refer to sexuality and/or gender)

**Sexual behavior:** Physical acts that constitute sexual expression. When talking about sexual behavior, note that sexual acts can be consensual or non-consensual, and that when a person sells sex to another person they may or may not think of their client as a sexual partner.

**Guidance and considerations**

1. The most important question to ask yourself when designing a questionnaire on this topic (or any topic) is precisely what information do you need and why? Which questions and which possible responses are relevant? Some examples:

* You are conducting a study on cervicitis. Only people who have a cervix can experience cervicitis. Their gender identity isn’t relevant to this research question but their anatomy (sex) is.
* You are conducting a study on disparities in heart disease outcomes. Health disparities may be influenced by social context and power structures, which may be related to gender (among other things). The natural history of heart disease may also differ between people with high levels of testosterone and people with high levels of estrogen, and furthermore between people with endogenous hormone production vs. hormonal supplementation. Gender, sex, and sex assigned at birth may be relevant to this question.
* You are conducting a study of contraception use. Contraception is mostly relevant to people whose sexual behavior puts them or their partner at risk of pregnancy, and the type of contraception they use depends on what type of gametes they make. Their sex, fertility and sexual behavior are relevant but not their gender or sexual orientation.

Sometimes as researchers it’s easier to include a whole bank of questions in a study instrument, but it’s important to remember that for people whose bodies or identities are marginalized, these questions are charged and asking them without any purpose can cause harm.

1. In tension with #1, there is a recent push in the scientific community, including funders such as the NIH to measure sex and gender and disaggregate data. This is due to the history of scientific research focusing on cisgender men and generating findings that were later found not to generalize to people with other sexes and genders. This consideration may provide motivation to record more variables than are directly needed for your analysis, but the guidance to be clear about what you seek to measure and why holds.
2. Explain to the participant why you are asking questions the way you are asking them. This can make questions feel less invasive and help participants answer authentically.
3. Often epidemiologic analyses require a small number of mutually exclusive categories, which do not align well with people’s identities. One approach is to provide response options that resonate for participants (eg more options than you want in your analysis and select-multiple rather than select-one options), and plan to collapse categories in your data cleaning rather than forcing the participant to select a response that does not match their experience. If this approach is not possible, carefully phrase an explanation in the question’s preamble acknowledging the limitation.
4. Gender and sexuality are complex and how people talk about them depends on their context and changes over time. Before you do a study, after you’ve decided which variables are actually relevant to your research question, find out how people in your context talk about sex, gender, sexuality and sexual behavior. What words do they use? Which words are formal/clinical, which are lay, which are derogatory? Which identities and behaviors are socially acceptable, which ones are so taboo that subjects will be confused or offended? Are any of the identities or behaviors you ask about criminalized? If so, can you assure your subjects that their answers will be not lead to their prosecution?
5. If you are interested in specific sexual acts, use very clear language to explain what act you are interested in. “Having sex” can mean different things to different people. E.g. Are you interested in sex that carries a risk of pregnancy, sex that facilitates transmission of a particular STI, any sexual intimacy? Use clear anatomical words to explain what is included in your definition.
6. Check your skip patterns to avoid implicit assumptions of congruence between sex, sex assigned at birth, gender, sexual behavior etc.

**Suggested questions**

1. ***What is your gender identity? (By this I mean your internal concept of yourself.)***

***Select all that apply.***

* man
* woman
* non-binary / genderqueer / gender-fluid
* agender
* questioning
* transwoman / transfeminine
* transman / transmasculine
* two-spirit
* Not listed above (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No answer

***1b. [simplified, for contexts where fewer gender identities are socially acceptable, or where you are unsure of the language] What is your gender identity? (By this I mean your internal concept of yourself.)***

***Select all that apply.***

* man
* woman
* Not listed above (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No answer

1. ***What sex were you assigned at birth? (By this I mean the sex listed on your original birth certificate)***

***Select one***

* Male
* Female
* Intersex *[include/adjust depending on what can be recorded on a birth certificate in the study context]*
* Not listed above (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No answer

1. ***What is your sexual orientation? (By this I mean the genders you are attracted to sexually and romantically. This applies regardless of whether you are sexually active.)***

***Select all that apply.***

* lesbian
* gay
* bisexual
* heterosexual / straight
* queer / pansexual
* questioning
* asexual
* Not listed above (please specify): \_\_\_\_\_\_\_\_\_\_\_\_
* No answer

***3b. [simplified, for contexts where fewer sexual orientations are socially acceptable, or where you are unsure of the language]. What genders you are attracted to sexually and romantically? This applies regardless of whether you are sexually active.***

***Select all that apply.***

* women
* men
* Not listed above (please specify): \_\_\_\_\_\_\_\_\_\_\_\_
* No answer

**Additional resources**

Definitions: <https://www.glaad.org/sites/default/files/GLAAD-Media-Reference-Guide-Tenth-Edition.pdf>

Visual resources on gender, sex and sexuality: <http://www.transhealthsa.com/wp-content/uploads/2017/05/The-Gender-Unicorn.pdf>

Resources on measuring sexuality and gender identity: <https://dpcpsi.nih.gov/sgmro/measurement>

Resources on measuring sexuality and gender identity in global health: <https://www.measureevaluation.org/resources/publications/ms-19-177>

Training on trans health: <https://daidslearningportal.niaid.nih.gov/>

*Resources from Kristjana Asbjornsdottir*

[*https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf*](https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf)

[*https://www.ncbi.nlm.nih.gov/pubmed/25030120*](https://www.ncbi.nlm.nih.gov/pubmed/25030120)

[*https://www.stonewall.org.uk/sites/default/files/do\_ask\_do\_tell\_guide\_2016.pdf*](https://www.stonewall.org.uk/sites/default/files/do_ask_do_tell_guide_2016.pdf)

[*https://www.lgbthealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf*](https://www.lgbthealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf)

[*https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0178043*](https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0178043)