

Understanding Gender Identity, Sex Assigned at Birth, and Sexual Orientation

A GUIDE FOR RESEARCHERS

Introduction and Importance

Many people from populations that are underrepresented in biomedical research (UBR) do not participate in research due to historical experiences with and ongoing fear of discrimination and stigmatization. The *All of Us* Research Program collects data elements to better include, welcome, and affirm the health and experiences of people from UBR populations. Because *All of Us* collects these data elements, the assessment of “common” demographics may be different in *All of Us* than in other studies. Researchers who do not have a special interest in UBR populations may not think about these demographics to ensure appropriate analyses. Additionally, failing to understand the data elements, the constructs measured, and how the data were collected may affect analyses and may result in misclassification and erroneous interpretations.

The *All of Us* Research Program collects gender identity, sex assigned at birth, and sexual orientation from all participants. This will help improve understanding of the health, well-being, and health disparities of UBR communities including sexual and gender minority (SGM) people. Because researchers may not have experience with these data elements, this resource was created to ensure that researchers understand each data element to effectively use them in their research project.



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Data Elements

Because *All of Us* collects gender identity, sex assigned at birth, and sexual orientation, researchers and analysts must understand each of these terms, the constructs being measured, and how the data were collected. We present each of these data elements below.

GENDER IDENTITY

Let's start by discussing "gender" and "sex." Gender is frequently conflated with sex (i.e., these terms are often used interchangeably). In actuality, these are two different concepts. Gender refers to the socially constructed roles, behaviors, activities, and attributes that society has defined. Gender can change over time. We typically use the terms "woman" and "man" when discussing gender. However, there are more than two genders. Non-binary genders include "genderfluid" and "genderqueer" among others. Sex, on the other hand, refers to biological, anatomical, and physiological characteristics that describe phenotype of a species. We typically use the terms "female" and "male" when discussing sex.

Within gender, there are two primary constructs: gender identity and gender expression. Gender identity is our internal sense of gender. For many, this is "woman" or "man." Some people, however, identify outside of this typical binary of "woman" or "man" and use terms such as "gender non-binary" and "genderqueer." Some people may not identify with a gender at all. Someone's gender identity cannot be known without asking them. When someone's gender identity does not match the sex that they were assigned at birth, they may identify as "transgender." The term "cisgender" refers to someone whose gender identity aligns with the sex that they were assigned at birth. Gender expression is the way in which a person expresses their gender identity; this includes their clothing, hairstyle, cosmetic use, jewelry, and mannerisms/behaviors, among others.

Gender identity is assessed with the following question:

What terms best express how you describe your current gender identity? (Check all that apply.)

- Man
- Woman
- Non-binary*
- Transgender*
- None of these describe me, and I'd like to consider additional options*
- Prefer not to answer

[The following question is shown if any answer choices marked by * are selected.]

Are any of these a closer description to your gender identity? (Check all that apply.)

- Transman/Transgender Man/FTM
- Transwoman/Transgender Woman/MTF
- Genderqueer
- Genderfluid
- Gender variant
- Two-Spirit
- Questioning or unsure of your gender identity
- None of these describe me, and I want to specify (optional free-text field)



SEX ASSIGNED AT BIRTH

As noted above, sex refers to biological, anatomic, and physiological characteristics that primarily describe phenotype. This is typically determined by health care providers who look at a person's reproductive organs and genitalia at birth. We typically use the terms "female" and "male" when discussing sex. Occasionally, genetic or hormonal assessments may influence the sex that is assigned to a particular person. Like gender identity, sex assigned at birth is also non-binary. Intersex people are those with a difference of sex development (i.e., they may not fit traditional conceptions of "female" or "male"). This may include differences in chromosomes, genitalia, and/or internal organs. Not all people with a difference of sex development identify as intersex and instead may identify as female or male.

Sex assigned at birth is assessed in "The Basics" Participant-Provided Information (PPI) module.

Sex assigned at birth is assessed with the following question:

What was your biological sex assigned at birth? (Select one.)

- Female
- Male
- Intersex
- None of these describe me (optional free-text field)

SEXUAL ORIENTATION

Sexual orientation is composed of three different constructs: identity, attraction, and behavior. Identity refers to the sexuality with which someone identifies; attraction refers to the gender(s) to which someone is romantically, sexually, or emotionally attracted; behavior refers to the gender(s) with

which someone has sex. All constructs of sexual orientation can change over time. Additionally, all constructs may not necessarily be aligned. For example, a man may identify as straight (heterosexual), be attracted to people of any gender, and have sex with other men only.

The *All of Us* Research Program only assesses the identity construct of sexual orientation in "The Basics" Participant-Provided Information (PPI) module. Sexual attraction and sexual behavior are not assessed.

Sexual orientation is assessed with the following question:

Which of the following best represents how you think of yourself? (Check all that apply.)

- Gay
- Lesbian
- Straight; that is, not gay or lesbian, etc.
- Bisexual
- None of these describe me, and I'd like to see additional options*
- Prefer not to answer

[The following question is shown if the answer choice marked by * is selected.]

Are any of these a closer description of how you think of yourself? (Check all that apply.)

- Queer
- Polysexual, omnisexual, sapiosexual, or pansexual
- Asexual
- Two-spirit
- Have not figured out or are in the process of figuring out your sexuality
- Mostly straight, but sometimes attracted to people of your own sex
- Do not use labels to identify yourself
- Don't know the answer
- No, I mean something else (optional free-text field)

Example Scenarios

SCENARIO 1

A researcher is interested in studying cisgender (i.e., not transgender) men who have sex with men (MSM). To do this, the researcher creates a cohort of *All of Us* participants who (i) have a gender identity as “man,” (ii) were assigned “male” sex at birth, and (iii) have a sexual orientation of “gay,” “bisexual,” “queer,” or “polysexual, omnisexual, sapiosexual, or pansexual.”

This is not correct because *All of Us* does not assess sexual behavior, it only assesses identity. It is not appropriate for researchers to assume that because men identify as “gay,” “bisexual,” “queer,” or “polysexual, omnisexual, sapiosexual, or pansexual” that they are having sex with other men.

SCENARIO 2

A researcher is interested in studying women with chronic kidney disease who are aged 40–69. To do this, the researcher creates a cohort of *All of Us* participants in the Researcher Workbench who have a gender identity as “woman” (along with the desired condition and age range). When analyzing the data, the researcher notes that some women in the

cohort have high hemoglobin levels—levels that are most commonly associated with men. Upon deeper inspection, the researcher notices that some of the women in the cohort were assigned male sex at birth.

In this scenario, the researcher selected participants for the cohort using gender identity instead of sex assigned at birth. Because some transgender and gender-diverse people may not identify with the minority labels (e.g., “transgender,” “non-binary,” “genderqueer”), they may select majority labels (e.g., “woman,” “man”) that align with their current gender identity.

It is inclusive and affirming to include all people who have a current gender identity as a “woman” regardless of the sex assigned to them at birth. While it may be easier and quicker to select a cohort of, in this scenario, cisgender women (i.e., people who were assigned “female” sex at birth and currently identify as “women”), researchers can help increase the visibility of communities that are underrepresented in biomedical research (UBR) by not excluding them while also generating scientific results to improve the health of these communities. These are key tenets of the *All of Us* Research Program.

Additional Assistance

The *All of Us* Research Program has a national community engagement partner focusing on SGM communities. This partner—based at Stanford University—is available to provide assistance about cohort selection, data interpretation, and correct language usage.

The SGM team at Stanford can be reached by contacting **(888) 410-LGBT** or **(888) 410-5428**.

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