

**Sexual Orientation and Gender Identity (SOGI)   
Guidance on Data Collection**

In the recent IRB community 2023 survey, UMCP investigators requested guidance on best practices for collecting data that includes sexual orientation and gender identity (SOGI) demographics. This request from UMCP researchers is evidence that, *"sex, gender, and sexual orientation are core aspects of identity that shape people’s opportunities… and the outcomes through their life courses"* *(The National Academies of Science, Engineering, and Medicine (2022)).*

This document has two objectives: 1) Provide a short-list of recent and objective scientific resources that IRB staff and UMCP investigators have found to be instructive when collecting SOGI data; 2) Show examples of how to apply the IRB guidance in research materials. Please note that a comprehensive review of the literature and best practices regarding SOGI data is outside the scope of this guide.*The UMCP Human Research Protection Program produced this guide in consultation with voting members of the UMCP IRB, individuals who identified as LGBTQIA+, and research professionals in the areas of sexual and gender diversity. If you have any questions or feedback regarding this material, please contact us at irb@umd.edu.*

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# Where to Start

1) Obtain Community Input.  
Seeking and implementing feedback directly from communities of interest (e.g., sexual and/or gender minorities) is a hallmark of rigorous SOGI data collection. This practice helps to differentiate between research "on" a minority group (i.e., a collection of test subjects) and research "for" that minority group (i.e., a collection of active participants). The IRB Office recommends obtaining peer-reviewed, scientific resources whose authors and/or research participants identify as members of the group in which you intend to explore. When in doubt, consider establishing an advisory board composed of a diverse group of community members from the population you intend to represent with your research. Present your methods for collecting SOGI data to the advisory board to ask them what works, and if any adjustments are needed.  
  
2) Source Recent References.  
Scientists want to utilize the most valid SOGI terminology and measurements, yet SOGI labels can be inherently fluid and are rapidly evolving. In light of this, check for the most recent version of any resource you locate (e.g., a 2022 version of resource, versus its 2012 iteration). An expert tip: If a resource has been revised, identify what changes were implemented to elucidate if certain verbiage has become stigmatized or pejorative over time. In some instances, the opposite may be true (e.g., the word "queer" is commonly used and widely accepted today among SOGI groups, although it was considered broadly offensive in past decades.)

3) Recognize That One Modality Does Not Fit All.  
Personal preferences, culture, world location, and other variables may influence how individuals or groups describe themselves. Both scientists and SOGI groups acknowledge that there is no "gold standard" for SOGI terminology, or data collection, due to the vast heterogeneity present in human sexual orientation and gender identity. Therefore, the IRB Office suggests that investigators employ best practices with a willingness to evolve with the scientific community as the measurement and description of these unique identities improves.

4) Collect Only The Necessary Data.  
Investigators must respect an individual's right to privacy whether or not they agree to be in a study. One way to support this is to only ask for the data which is required to answer your research question(s). Investigators should carefully determine if collecting data regarding sexual orientation and/or gender identity supports the validity of the research results, or other applicable reporting requirements (e.g., NIH). Tip: It can be helpful to explain to participants why you are asking them to report sensitive information (e.g., to address a disparity within a group, etc.)

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**How to Apply Best Practices**

## **Gendered Language versus Gender-Neutral Language:**

In many studies, sex and gender are not inclusion criteria (i.e., one's sex assigned at birth and/or gender identity/expression does not affect their ability to participate). Nonetheless, researchers may still unnecessarily or unintentionally employ gendered language in their research materials, which can disenfranchise and inadvertently exclude gender minority participants.  
Example: Gendered Language in a Recruitment Material:   
*"You are eligible for this study if you are a man or woman above the age of 18."*  
Although it may be unintentional, this language implicitly suggests that only persons who identify as men or women are eligible (i.e., non-binary, transgender, intersex, or other gender diverse persons are not eligible).

Recommendation: Gender-Neutral Language in a Recruitment Material:   
*"You are eligible for this study if you are an individual above the age of 18."* or simply, *"You are eligible for this study if you are above the age of 18."*  
This description removes the ambiguity of who is excluded based on gender and/or sex, while still maintaining the scientific integrity of a sample wherein sex/gender are not eligibility requirements.  
  
Example: Gendered Language in a Recruitment Material (Parent of a Child):   
*"Your child is eligible because he or she attends XYC Elementary School."*

Recommendation: Gender-Neutral Language in a Recruitment Material (Parent of a Child):   
*"Your child is eligible because they attend XYC Elementary School."*

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Individuals who are pregnant, and/or who are capable of becoming pregnant, include persons who do not identify as female/woman (e.g., transgender persons, non-binary persons, etc.) Therefore, unless the investigators are specifically targeting pregnant "women" only as their research subjects, the IRB recommends describing pregnant participants as individuals.  
  
Example: Pregnant People are "Women" Only:  
*"We are seeking pregnant women to participate in a survey…; When a woman discovers she is pregnant…"*

Recommendation: Pregnant People are Individuals:

*"We are seeking pregnant people/persons/individuals to participate in a survey…; When a person/individual discovers they are pregnant…"*

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Scientists, diversity advocates, and individuals with gender minority identities, often recommend measuring gender identity with the Two-Step method\*. This includes sex assigned at birth (Step 1) followed by current gender identity (Step 2)*(Source: GenIUSS group (2014)).*

**Step 1: ASSIGNED SEX AT BIRTH**  
What sex were you assigned at birth, on your original birth certificate?

* Male
* Female

**Step 2: PROMISING MEASURE FOR THE "CURRENT GENDER IDENTITY" STEP IN THE "TWO STEP" APPROACH (RECOMMENDED FOR FURTHER TESTING):**Current gender identity  
What is your current gender identity? (Check all that apply)

* Male
* Female
* Trans male/Trans man
* Trans female/Trans woman
* Genderqueer/Gender non-conforming
* Different identity (please state): \_\_\_\_\_\_\_

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##### **Gender Identity Data Collection - Self Reported (For Youth):**

The Trevor Project (2021) provides the following example of the Two-Step method for youth participants:

**Recommended Two-Stage Questions for Youth Gender Identity**

**Open Response Lead-in Option:**Gender identity is how someone feels about their own gender. There are many ways a person can describe their gender identity and many labels a person can use. How would you describe your current gender identity in your own words? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Thank you for telling us about your gender identity in your own words. Sometimes we have to create categories to make it easier to present our findings and we want to make sure you are represented in the best category. Which of the following terms **best** describes your current gender identity? We understand that there are many different ways you may identify, please pick the one that **best** describes you.

Girl or woman

Boy or man

Nonbinary, genderfluid, or genderqueer

I am not sure or questioning

I don't know what this question means

Decline to answer  
  
 **AND**

What sex were you assigned at birth, on *your original birth certificate?*

Male

Female

Decline to answer

**OR**

**Without Open Response Lead-in:**

Gender identity is how someone feels about their own gender. There are many ways a person can describe their gender identity and many labels a person can use. Which of the following terms **best** describes your current gender identity?

Girl or woman

Boy or man

Nonbinary, genderfluid, or genderqueer

I am not sure or questioning

I don't know what this question means

Decline to answer  
  
 **AND**

What sex were you assigned at birth, on *your original birth certificate?*

Male

Female

Decline to answer

### *\*For more information on alternatives to the Two-Step method, see: Felt, D., Beach, L. B., Ashley, F., & Phillips, G. (2023). An exploratory comparison and evaluation of two two-step measures to identify transgender people in survey datasets. Transgender Health.* [*https://doi.org/10.1089/trgh.2023.0010*](https://doi.org/10.1089/trgh.2023.0010)

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###### **Sex/Sex Assigned At Birth - Including Intersex:**

It is estimated that Intersex traits occur in 1 in 2,000 births; however Intersex is often not provided as an option for sex, sex assigned at birth, or gender identity in participant-facing materials. Here is an example of a survey item for assessing Intersex identity (*Source: Measuring Sex, Gender Identity, and Sexual Orientation - A Consensus Study Report of The National Academies of Science, Engineering, and Medicine (2022)*):

**Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?**

* **Yes**
* **No**
* **Don't know**
* **Prefer not to answer**

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**Sexual Orientation Data Collection - Self-Reported:**

Research has demonstrated that participants who see their SOGI described in a demographic measurement report feelings of affirmation. Alternatively, participants may experience a sense of erasure when their SOGI is omitted from a measure.

Measure for Sexual Orientation Data Collection With "Other"/Write-In: (*Source: Measuring Sex, Gender Identity, and Sexual Orientation - A Consensus Study Report of The National Academies of Science, Engineering, and Medicine (2022)*)

**RECOMMENDATION 2: The panel recommends that the National Institutes of Health use the following question for assessing sexual orientation identity:**

Which of the following best represents how you think of yourself?

[Select ONE]:

* Lesbian or gay
* Straight, that is, not gay or lesbian
* Bisexual
* [If respondent is AIAN:] Two-Spirit
* I use a different term [free-text]
* Don't know
* Prefer not to answer

Measure for Sexual Orientation Data Collection (Expanded): *(Source: The Trevor Project 2021)*

**Single item:**

Sexual orientation is a person's emotional, romantic, and/or sexual attractions to another person. There are many ways a person can describe their sexual orientation and many labels a person can use. Which of these options **best** describes your sexual orientation?

Straight or heterosexual

Gay

Lesbian

Bisexual

Queer

Pansexual

Asexual

I am not sure

I don't know what this question means

Decline to answer

**Abbreviated single item:**

Sexual orientation is a person's emotional, romantic, and/or sexual attractions to another person. There are many ways a person can describe their sexual orientation and many labels a person can use. Which of these options **best** describes your sexual orientation?

Straight or heterosexual

Gay or lesbian

Bisexual, pansexual, or queer

Asexual

I am not sure

I don't know what this question means

Decline to answer

*\*Note: Respondents may prefer that a "Select All That Apply" option is available.*

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**Sexual Orientation Data Collection - Parents/Caregivers:**

It is possible to collect data that implies a sexual orientation even when this is not the intention of utilizing a measurement. For example, parent/caregiver materials often identify those responsible for a child in heteronormative (i.e., assuming the reader is heterosexual) terms.

Example: Parent/Caregivers in Heteronormative Terms:   
*"Please select the highest education achieved for the father; Please select the highest education achieved for the mother."*

Although this may be unintended by the research team, readers often see this as an implicit sign that the investigators either assume that all caregivers are heterosexual couples, or that only heterosexual couples are welcome to respond. Therefore, unless the investigators are specifically targeting heterosexual couples only as their research subjects, the IRB recommends describing caregivers in non-discriminatory terms.Recommendation: Parent/Caregivers in Non-Discriminatory Terms:   
*"Please select the highest education achieved for the parent/caregiver #1; Please select the highest education achieved for the parent/caregiver #2"*In addition to ensuring that parents/caregivers in any dyad can respond, we recommend providing an *"N/A"* response option to account for individuals with one or no parent/caregiver.

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**General Recommendations**

* **Participants often report that a "select all that apply" option for both sexual orientation and gender identity questions are affirming** because this recognizes the intersectional and dynamic experiences of SOGI.
* It can be helpful to **explain to participants the reason why** certain sensitive questions (i.e., SOGI) are asked of them (e.g., "sex assigned at birth is necessary for [XYZ scientific reason]")
* **Assume that minorities of SOGI are in your sample.** Ultimately, investigators must determine the appropriate sample population, and scientific measures, required to answer their research question. However, when "general population" or "public" samples are pursued, it is recommended to employ measurements, recruitment verbiage, and other research practices that adequately address, and account for, minorities of SOGI.
* **Engage with scholars of SOGI and scientists who identify as SOGI minorities.** Many professionals and scientists (who may or may not identify as an SOGI minority) report gratitude and enthusiasm when they are approached by investigators who are eager to examine SOGI in a comprehensive and culturally sensitive manner.
* Consistent with the principle of Justice as described in The Belmont Report (1979), investigators should be cognizant of properly compensating participants (e.g., research subjects, advisory board members, etc.), and of sharing the results of the research with them so that their community may benefit from their efforts.

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* *RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF*

*SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SURVEYS* **- The Office of the Chief Statistician of the United States** (2023)Link:[**https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practicess.pdf**](https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf)

* *Measuring Sex, Gender Identity, and Sexual Orientation -* **A Consensus Study Report of The National Academies of Science, Engineering, and Medicine** (2022)Link:[**https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation**](https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation)
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Link: <https://www.apa.org/about/policy/data-sexual-orientation>

* *Measuring Youth Sexual Orientation and Gender Identity* - **The Trevor Project** (2021)  
  Link:<https://www.thetrevorproject.org/wp-content/uploads/2021/07/Measuring-Youth-Sexual-Orientation-and-Gender-Identity.pdf>\
* *Understanding the Well-Being of LGBTQI+ Populations.* (2020). **National Academies of Sciences, Engineering, and Medicine.**(2020)
* *Best Practices for asking Questions to identify transgender and other gender Minority respondents on Population-Based surveys* - **The GenIUSS group at Williams Institute - UCLA School of Law** (2014) **Link:**<https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf>
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* The Belmont Report - **US DHHS** (1979)  
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**Resource on Equity**

### *IRB Role Seen as Critical in Promoting Diversity and Equity in Research* (2021)**Link:**<https://compliancecosmos.org/irb-role-seen-critical-promoting-diversity-and-equity-research?authkey=da2039db52606b86a8806f75f255755367abb1088595804ad591ff9af4f01e29>

**Resource on Justice, Diversity, and Research Ethics Review**

* **Link:** https://www.uwindsor.ca/research-ethics-board/sites/uwindsor.ca.research-ethics-board/files/strauss\_white\_bierer\_2021\_justice\_diversity\_and\_research\_ethics\_review\_003.pdf