

Research With LGBTQ2IA+ Populations Guidance

Purpose

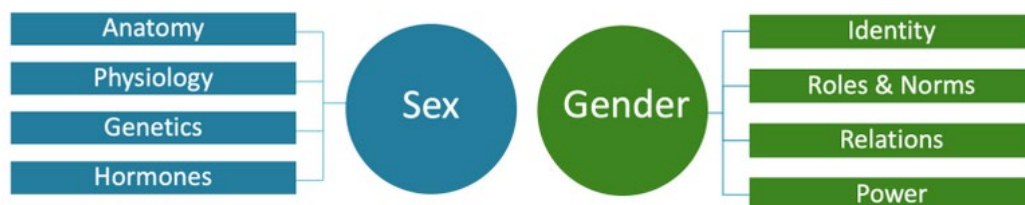
This document provides best practices as well as guidance for researchers who will be asking questions about sexuality, sexual orientation, sex variance, gender identity and/or gender expression. Much of this document has been informed by the University of Wisconsin-Milwaukee and their Chancellor's Advisory Committee for LGBTQ+ Advocacy with additional guidance from Washington State University's Commission for Gender Identity/Expression and Sexual Orientation (GEISO).

Definitions

- **AFAB:** Assigned female at birth.
- **AMAB:** Assigned male at birth.
- **Female:** Biological term for an organism that produces ova.
- **Gender:** Gender includes the social, psychological, cultural, and behavioral aspects of being a man, woman, or other gender identity. Depending on the context, this may include sex-based social structures and gender expression. Gender is self-identified and may change during the course of a person's life.
- **Intersex:** A biological term to describe bodies that fall outside the male/female binary. This is a naturally occurring variation, and there are many ways a person can be intersex.
- **Male:** Biological term for an organism that produces sperm.
- **Non-Binary:** A term to describe gender identities and gender expressions that exist outside of the binary gender categories of "man" and "woman".
- **Sex:** Typically assigned at birth based on physiological characteristics like genitalia or chromosome composition, also referred to as "natal sex." Sex assigned at birth is typically either male, female, or intersex.
- **Transgender:** A term used to describe people whose gender identity differs from their sex assigned at birth.

The following table, courtesy of the National Institutes of Health, gives a visual example of the differences between "sex" and "gender."

Dimensions of Sex (Biological Variable) & Gender (Social and Cultural Variable)



Best Practices for The Ethical Collection of Data About Sex and Gender

It is a common practice for researchers engaging in the study of human subjects to collect data about sex and gender. Often, researchers structure this demographic question as a dichotomous variable, often in the checkbox format supplying “Male” and “Female” as the options. While it remains common, this practice has been subjected to multiple critiques, and should not be considered a best practice.

Physical Sex

Physical sex is, empirically speaking, not binary, but manifests in a complex spectrum of physical traits. Today in the United States, approximately 1 in 150 infants is diagnosed at birth as being intersex, with one of a variety of “DSDs” (differences of sex development). This diagnosis is made based on genital intermediacy. Because other sex characteristics (gonads, chromosomes, and hormones) are not obvious at birth, many more Americans discover later in life that they are intersex.

Unfortunately, in the latter half of the 20th century, it became a common medical practice to try to erase physical sex variance to avoid stigma. But in recent decades, intersex individuals have formed advocacy groups to protest surgical interventions performed without consent upon the genitalia of young children. Intersex people are now much more likely to be open about their intermediate sex status, and to demand that it not be erased by dichotomous sex variables in data collection.

Consider that approximately 2% of the U.S. population is born intersex, which is equal to the population of Chicago, Illinois. In collecting demographic data about location, it would be considered poor practice not to include an option for subjects to identify Chicago as where they live. Similarly, it is not appropriate to deny intersex research subjects the right to identify their physical sex status at birth.

Gender Identity

It is quite clear in the 21st century that physical sex characteristics do not determine gender identity. In other words, a significant number of people are transgender. Of those transgender individuals, a significant percentage have nonbinary gender identities, and identify as neither women nor men. The terms “male” and “female” describe sex characteristics; the terms “man,” “woman,” and “nonbinary” refer to gender categories.

In order to treat transgender human subjects with respect, the following are necessary:

- Gender identity must be respected. Unless physical sex characteristics are a topic of a research project, the appropriate language to be used in collecting demographic data is that of gender (man/woman/another gender identity) not sex (male/female/intersex).
- People who are intersex or who have nonbinary gender identities must be respected. Thus, dichotomous identification options are not appropriate.

Best Practices for Collecting Information About Gender

Depending on the research question being asked, it may be more appropriate to ask about gender identity in demographic questions or to screen participants based on certain characteristics (for example, social psych research often examines gender differences, and in these cases, it may be more appropriate to ask about gender identity and include anyone who identifies as that group).

The preferred format for a generic demographic gender question is:

What is your gender?

- *Man*
- *Woman*
- *Non-Binary*
- *A gender identity not listed here (please specify _____)*
- *Prefer not to answer*

However, if your study is examining subjects' biological characteristics, you will need to be specific about the reasons why certain people are eligible to participate (e.g., do participants need a uterus specifically?) and provide a justification why others are excluded that align with the stated purpose and goals of the research. It is the researcher's ethical responsibility to be familiar with the population they are studying. When researchers are using medical records or chart data, the same expectations exist for the justification of inclusion and exclusion of certain fields.

If the study's purpose and goals require information about participant's sex characteristics, researchers should use a 3- step process, in which gender and sex characteristic information is collected separately:

What is your gender?

- *Man*
- *Woman*
- *Non-Binary*
- *Another gender identity not listed here (please specify _____)*
- *Prefer not to answer*

When you were born, what sex was listed on your original birth certificate?

- *Male*
- *Female*
- *Another sex identity not listed here (please specify _____)*
- *Prefer not to answer*

To the best of your knowledge, are you physically intersex? That is, do you have a difference of sex development ("DSD")?

- *Yes*
- *No*
- *Prefer not to answer*

Best Practices for Analyzing Information About Gender

When human subjects volunteer to take part in a study, they do so in substantial part out of a laudable desire to contribute to knowledge. It is therefore ethically problematic for researchers to systematically exclude data from specific subject populations in analyzing their data, as it disrespects the subjects' donation of their time and effort.

This is a problem that extends beyond the arena of sex and gender, and applies in the case of all underrepresented and small subject populations who may be excluded from an analysis. In the case of sex/gender, this issue comes up when subjects who are intersex, transgender, and/or report any nonbinary gender identities that are excluded from the analysis. If it is the expectation of researchers that subjects with certain demographic characteristics will not be included in the analysis, this should either be incorporated into exclusion criteria for study volunteers or should be disclosed in the consent form.

Risks

With any population in a study, there are typically risks to participating in the study, even if they are minimal. For vulnerable populations, along with a participation risk there can also be a risk to not participating or being purposefully excluded in a study.

The primary risk facing LGBTQ2IA+ participants is a breach of confidentiality, since the release of private data can lead to many downstream consequences that are either unique or greater than those experiences by non LGBTQ2IA+ people.

Risks of Breach of confidentiality:

- **Employment:** While many states have protections for government employees against discrimination due to sexual orientation, this protection isn't available in every state, or for people with non-government jobs.
- **Economic (employment or insurability):** A breach of confidentiality could lead to participants losing their jobs.
- **Legal:** The legal landscape for laws affecting LGBTQ2IA+ folks is constantly changing. Being outed can affect people drastically depending on the country, state, county, or town the person lives in. For individuals seeking gender affirmative care - especially for minors and their parents/guardians - a breach could result in legal action, including the minors being removed from their homes. Several advocacy groups have resources tracking legislative and policy changes in the United States. Both the Human Rights Campaign and the Trevor Project have interactive maps showing laws and policies in different states.
- **Social Stigmatization:** Sexual orientation outside of being straight has become less stigmatized in general, but social standing can still be adversely affected by a data breach.

- Housing: Homelessness disproportionately affects LGBTQ2IA+ youth. According to the US Department of Health and Human Services' Substance Abuse and Mental Health Services Administration, youth "are at high risk for family rejection, physical assaults and sexual exploitation in shelters and on the streets, trauma, and mental and substance use disorders."
- Family members/family dynamics: While sexual orientation has some federal protections, relationship status or type does not. For example, polyamory is not a protected orientation, and studies that ask about children in non-monogamous family dynamics may present different risks to individuals and their families in the event of a breach of confidentiality.
- Safety: In approximately 64 countries identifying within the LGBTQ+ community is illegal and punishment in some of these countries is the death penalty.

Risks of Psychological/emotional discomfort or distress:

- Questions about an individual's sexual practices and behaviors (past or current) can be emotionally distressing or uncomfortable for a participant to answer.
- Additionally, research focusing on LGBTQ+ members' experiences with stigma and discrimination may lead to greater harm and re-traumatization.
- It is important to allow participants to disclose only as much as they are comfortable sharing.
- Depending on the types of questions being asked and the format of the survey/interview, it may be beneficial to either provide a debriefing with resources for participants or have a professional on standby (for in-person interviews) should the participant need psychological or counseling services.

Risks of Invasion of privacy:

- This can be a risk to the participant or others. For example, if the research requires the participant to provide information or discuss their experiences with family and friends, those individuals (if identified) may be considered secondary participants. Additionally, recruitment methods such as snowball sampling where an individual is asked to provide the research team with the names and contact information of people they know who meet study inclusion criteria is generally not appropriate. If snowball sampling will be done, it is better to have the researchers provide study pamphlets or flyers for individuals to pass along to others so that only those interested in participating can contact the research team (instead of the research team cold-calling them).
- All risks should be outlined in the application and consent form.

Research With Youth

All research involving children is subject to additional protections outlined in [45 CFR 46 Subpart D](#), since children are considered a vulnerable subject population. When a human subject participant is below the legal age of consent, the researchers must obtain assent from the child. Parental permission from one or both parents (or from a legal guardian) is also required; however, in some instances, it may be appropriate to waive parental permission.

For example, if the focus of the research is on youth who identify as LGBTQ2IA+, and participating in the research would lead to additional risks to the youth (if their parent(s) or guardian(s) are unaware of how they identify) a waiver of parent permission could be requested and approved if criteria for a waiver is

met under [45 CFR 46.116\(f\)\(3\)](#). To request a waiver of parent permission for minimal risk research, submit the [Addendum: Informed Consent – Minimal Risk \(docx\)](#).

Researchers who plan to work with participants who are under the age of 18, particularly in school settings, must be aware that compliance with laws like the Protection of Pupil Rights Amendment (PPRA) could require them to disclose research data to a child's parents or guardians and that this disclosure may increase risk to participants in school settings. Where children are wards of the state, in any state with discriminatory laws against LGBTQIA+ persons, researchers must consider if the risks to these participants could even be made reasonable in relation to the potential benefits given that disclosure of data to the state might not be avoidable or at least might be challenged in state courts.

Legislation Considerations

Within the United States:

A growing number of states have enacted discriminatory legislation impacting LGBTQIA+ individuals and their families/caregivers and seven other states are considering legislation. Legislation, including laws that ban some or all types of gender affirming care up to age 18 (or up to age 26 in a few states), may have a negative impact on research with LGBTQIA+ participants as this type of legislation increases potential legal risk to participants, their families/caregivers and potentially to researchers and medical care providers.

Any research plan that includes questions about gender identity or that is related to medical care including gender affirming care or mental health services must consider the impact of state laws and when appropriate must obtain a certificate of confidentiality to protect the researcher from being compelled to release data. Researchers must also take care to disclose the potential legal risks to prospective research participants via the informed consent process. Similar to research that may touch on illegal topics, researchers should carefully consider if they should collect any direct identifiers and if requesting a waiver of documentation of consent would further minimize the identifiable information being collected. The [Human Rights Campaign](#) and other similar resources have state by state information, including maps, that can assist researchers in planning out projects in a way that minimizes risks to these vulnerable participants.

Advocacy groups like the Human Rights Campaign and the [Trevor Project](#) have resources available describing legislation affecting LGBTQIA+ people within the United States.

International Legislation Considerations:

Internationally, laws may be much more restrictive than those domestically and researchers should be aware of these if data is collected from other countries. Advocacy groups like the Human Rights Campaign and [Amnesty International](#) are good starting places for international information, but local partners should have a strong understanding of local laws or traditions.

Language In Study Materials

Language is always changing and evolving to meet the needs of its users. While the table below can be a reference, it's the duty of the researcher to use the appropriate term as needed and to avoid sensitive or potentially derogatory language. Many of the words and definitions in the table come from the [American Psychological Association's Equity, Diversity, and Inclusion's Inclusive Language Guidelines](#).

Instead of:	Use:
Wife/Husband	Spouse(s)/partner(s)
Woman (gender)	Girls, women, transwomen
Man (gender)	Boys, men, transmen
Female or male (biological sex)	Use person-first language to describe the biological process or component that is needed for the study. For example, people who menstruate, people with a uterus, people who make sperm, etc.
Birth sex or natal sex	Assigned sex or sex assigned at birth
Born a girl, born female	Assigned female at birth
Born a boy, born male	Assigned male at birth
Hermaphrodite (biological terminology only)	Intersex
Transvestite, transsexual	Transgender
LGTB	LGBTQ+, LGBTQIA+, LGBTQ2IA+

**Consider your audience when using the term "queer" as not everyone receives this word positively; many members of the LGBTQIA+ community have reclaimed it.*

Resources for Researchers

- [President's Commission for Gender Identity/Expression and Sexual Orientation](#)
- [The American Psychological Association's Inclusive Language Guidelines](#)
- [The LGBTQ+ Center at WSU](#)
- [UW Milwaukee's Research with LGBTQ+ Individuals Guidance](#)

Resources for Participants

- [Fenway Health's LGBTQIA+ Aging Project Programs and Support Groups](#)
- [Gender Spectrum Lounge](#): A global online community that facilitates social groups for parents, guardians, grandparents, and other family members and caregivers.
- [LGBT National Help Center](#): A talk line and weekly chatrooms for youth that provide confidential peer-support, information, local resources, and community. Available at 800-246-7743.
- [PFLAG](#): Many PFLAG chapters meet virtually or provide 1:1 virtual support as requested for LGBTQ+ youth or parents/guardians.
[National Resource Center on LGBTQ+ Aging](#): A technical assistance resource center focused on improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults, their families and caregivers.
- [National Suicide & Crisis Lifeline](#): Available 24/7 by calling 988.

- SAGE National LGBTQ+ Elder Hotline: Available at 1-877-360-5428.
- Trans Lifeline Hotline: A peer support service run by trans people located across the US and Canada for trans and questioning callers. Available at 877-565-8860.
- The Trevor Project
- Trevor Lifeline: A crisis intervention and suicide prevention phone service. Available 24/7 at 1-866-488-7386.
- TrevorChat: A confidential online instant messaging with a Trevor counselor, available 24/7.
- TrevorText: A confidential text messaging with a Trevor counselor. Available 24/7 by texting "START" to 678678.
- TrevorSpace: An affirming international community for LGBTQ+ young people ages 13-24.
- Q Chat Space: A bully-free online community of LGBTQ+ teens that can chat with other LGBTQ+ teens and trained staff from LGBTQ+ centers across the country.