

Best Practices for the ethical conduct of research involving Sex, Gender and Sexual Orientation Minorities

Before conducting studies about or that involve members who self-identify as sex, gender or sexual orientation minorities, we urge researchers to familiarize themselves with the following foundational principles, definitions and suggested best practices. Bear in mind that the duty to protect human subjects includes the duty to uphold antidiscrimination guarantees, which at UWM include protections on the basis of sex, sexual orientation, and gender identity.

I. Foundational Principles

Institutions which commit themselves to protecting against discrimination on the basis of sex and of gender identity or expression (GIE) must give individuals the right to self-identify their sex/gender.

Whenever data are gathered about sex/gender, the rights of GIE minorities (intersex individuals, trans men, trans women, and individuals with alternative gender identities) must be protected.

Whenever data are gathered about sexuality, the rights of sexual minorities must be protected, including the right to identify as lesbian, gay, bisexual, pansexual, asexual, or with some other sexual identity.

II. Definitions

“GIE minorities” include intersex individuals, transgender individuals (trans men, trans women, and individuals with alternative gender identities), and people with variant gender expression.

Intersex Persons

While it is common to believe that sex is binary—that is, that all people are born either male or female—in fact, sexual characteristics exist as a spectrum. There is a great deal of variation in chromosomes (XX, XY, XXY, XYY, etc.), hormones (relative levels of estrogen, progesterone and testosterone), secondary sexual characteristics (breasts, hair distribution, etc.) genital configurations, and gonads (ovaries, ovotestes, testes). Intersex people are individuals whose sexual characteristics fall toward the middle of the spectrum. Approximately 1 in 150 people in the U.S. are diagnosed by doctors as intersex at birth, and more find out they are physically sex-variant later in life. 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.

Transgender Individuals

Individuals whose gender identity does not match the sex they were assigned at birth are

deemed transgender. A trans man was assigned female at birth but identifies as man; a trans woman was assigned male at birth but identifies as a woman; a person with a nonbinary gender identity identifies as neither a man nor a woman. Trans men and women often transition to their gender of identification, though they may do so in different ways. Some transition socially by changing name, pronoun, and dress. Others also take hormones (testosterone or estrogen/progesterone) to alter their bodies. In addition, some get surgery to change their chests or genitalia. Because surgery is quite expensive, may not be covered by insurance, and because it carries serious risks, many transgender individuals in the U.S. do not seek or are unable to access surgical transition services. And for people with nonbinary gender identities, transition is highly complicated by the lack of legal recognition of their identified genders in many locales, and the lack of an established medical best practice for facilitating nonbinary gender transitions. Researchers interacting with transgender subjects must respect their identified genders regardless of their legal or medical transition status.

Variant Gender Expression

People of any sex or gender may have an atypical gender presentation—being masculine women, feminine men, or androgynous. Individuals often experience discrimination based on their variant gender expression, which makes it an important issue to account for in studies in which gender experience or gender discrimination are relevant.

Sexual Orientation Minorities

Sexual orientation minorities include people whose attractions are those to the same gender, other genders, or who are asexual. Common sexual orientation minorities include lesbians, gay men, bisexuals, pansexuals, and asexual people (including those who identify as demisexual and gray-area asexuals, who experience sexual attractions intermittently, or only under certain limited circumstances).

III. Best Practices

Whenever possible, eliminate the unnecessary requirement of declaring sex/gender from participants.

There are many institutional contexts in which people are routinely asked to identify their sex/gender based on common marketing practices or institutional tradition rather than an intent to protect the individuals from discrimination on the basis of their sex/gender. (For example, this is a common requirement in registering to use website services.) Therefore, we recommend that researchers seriously consider if they need to collect such data at all.

Utilize Appropriate Language For Collection Of Sex Or Gender Identity Data In Human Subjects Research.

Researchers should avoid poor practices which undermine individuals' identities instead of protecting them. For best practices regarding the collection of generic demographic information about subjects' gender, see the guidance ""Best Practices for the Ethical Collection

of Data about Sex and Gender."

Gender Identity

When collecting information about gender identity, a common poor practice is to use a single additional checkbox: "Male___, Female___, Transgender___." This is inappropriate for several reasons.

- First, it does not allow intersex individuals a way to identify themselves.
- Secondly, it discriminates against trans men and trans women by framing transgender identification as not really men or women. "Transgender" is a term that describes a life trajectory, not a gender identity. (An analogy would be that it is equivalent to requesting subjects' identify their religion, providing three checkboxes, "A. Christian, B. Jewish, C. Convert." Such a question not only offends human subjects whose identities are not listed, but also produces invalid data for the researcher.)
- And thirdly, it does not allow for recognition of the distinct needs and identities of individuals who identify as neither men nor women.

In contexts in which data are collected order to ensure equal treatment and respect for all, information about sex/gender should be collected in a manner that protects gender identity and expression (GIE) minorities. In cases where the researcher wishes to collect information beyond identified gender, with the research inquiring into an individual's status as cisgender or transgender, the best practice would be the following format:

1. Gender identity: Woman __, Man __, Alternate Self-identification (please write in) _____.
2. Are you transgender? Yes___, No___.

Sexual Orientation

In contexts in which the researcher wishes demographic information about subjects' identified sexual orientation, the best practiced would be the following format:

Sexual orientation: Heterosexual __, Lesbian___, Gay___, Bisexual___, Queer___, Pansexual___, Asexual___, Alternate Self-identification (please write in) _____.

If the study in question enquires into sexual behavior, this identification scale may not be sufficient. It is well established that there is a difference between how many people identify their sexual orientation and the sexual activities in which they actually engage. This may be addressed through questions such as the following:

1. On a scale of zero to 10, how sexually attracted are you to men? Zero means not at all attracted, and 10 means greatly attracted. [Insert Likert scale]
2. On a scale of zero to 10, how sexually attracted are you to women? Zero means not at

all attracted, and 10 means greatly attracted. [Insert Likert scale]

3. On a scale of zero to 10, how sexually attracted are you to individuals who identify as neither men nor women (for example, people who say their gender identity is nonbinary, agender, genderqueer, etc)? Zero means not at all attracted, and 10 means greatly attracted. [Insert Likert scale]
4. On a scale of zero to 10, what proportion of your sexual partners have been men? Zero means you have never had a sexual partner who is a man, and 10 means all of your sexual partners have been men. [Insert Likert scale]
5. On a scale of zero to 10, what proportion of your sexual partners have been women? Zero means you have never had a sexual partner who is a woman, and 10 means all of your sexual partners have been women. [Insert Likert scale]
6. On a scale of zero to 10, what proportion of your sexual partners have been people who identify as neither men nor women? Zero means you have never had a sexual partner who identifies as neither a man nor a woman, and 10 means all of your sexual partners have been people who identify as neither men nor women. [Insert Likert scale]
7. Are the people to whom you are attracted (1) very masculine, (2) moderately masculine, (3) a bit masculine, (4) androgynous, (5) a bit feminine, (6) moderately feminine, (7) very feminine.

Gender Expression

There will be research contexts in which the subjects' gender expression is also relevant. For example, any study considering gender experience or gender discrimination should consider the subjects' gender expression. The best practice format for such a question is:

1. Please indicate how masculine or feminine you are in your dress and manner on the following scale: (1) very masculine, (2) moderately masculine, (3) a bit masculine, (4) androgynous, (5) a bit feminine, (6) moderately feminine, (7) very feminine.

In situations in which the research wishes to inquire as to physical sex characteristics because those are relevant to the research question, the best practice would be to ask a 3-stage question:

1. What is your identified gender?
 - Man
 - Woman
 - Another gender identity not listed here (please specify _____)
1. When you were born, what sex was listed on your birth certificate?
 - Male
 - Female

2. To the best of your knowledge, are you physically intersex? That is, do you have a difference of sex development (“DSD”)?
- Yes
 - No

Another possible option is to ask the question using a two-step approach recommended by the Gender Identity in U.S. Surveillance (GenIUSS) group⁷. The Institute of Medicine and The Joint Commission have also recommended this data collection method for general use in U.S. health records. Studies have found the two-step approach is acceptable and understandable for diverse samples of patients in the general population⁸. But note that this approach has been criticized by advocates for transgender populations and intersex groups. It conflates sex and gender identity, does not acknowledge intersex status, and undermines the legitimacy of trans people’s identified genders by the opposition of men versus trans men, and women versus trans women. However, since it is in common use, it is presented here:

Assigned sex at birth:

Male

Female

Current gender identity:

Male/Man

Female/Woman

Trans male/Trans man

Trans female/Trans woman

Genderqueer/Gender non-conforming/Gender non-binary

Different identity (please state): _____

IV. Incorporate Gender Affirming Practices Throughout Human Subjects Research Activities.

Researchers who choose specifically to study GIE and/or sexual orientation minorities should consider them a vulnerable subject pool for IRB human subject protection purposes. In cases of studies recruiting intersex, transgender, or gender-variant subjects, procedures should be set in place to protect these vulnerable subjects, and the questions asked about sex and gender carefully designed to accord all subjects with full respect for persons.

Gender affirming practices include validation of an individual’s gender identity and/or expression. Validation occurs in the form of:

- asking for and utilizing an individual’s name and pronouns,
- providing access to gender neutral or safe bathrooms or changing areas, and
- conducting research that has the overall rights and well-being of the individual in mind.

Gender affirming research also takes into consideration how increased visibility and attention from researchers can become burdensome for the relatively small number of transgender, intersex, or gender nonbinary individuals in comparison to the general population (especially

students within our UWM community). Therefore, care should be taken in the conceptualization and implementation of research:

- Researchers should take care to conduct studies that have a likelihood of contributing to the knowledge base about these populations.
- Student projects in classes that are only for educational purposes should be carefully considered in terms of their potential “load” on these populations and how aligned the work is with classroom content.

Finally, researchers working with transgender, intersex, or gender nonbinary people should take into consideration the very high levels of stigma and discrimination they face in society, and consider precautions as necessary for protecting their safety and privacy that may be compromised through participation in research. For example,

- Confidentiality should be strictly protected, data collected in a location where subjects will not be at risk of having others see or overhear their responses, and information sheets listing appropriate support groups and links to mental health resources distributed to those recruited to participate.
- Making sure that participants have a safe place to participate in the research without fear of negative consequences on their personal lives.
- Researchers should be sensitive to their own potentially offensive behaviors (e.g., using language that is no longer considered acceptable such as using the term same and different-gendered couples vs. same and opposite sex or heterosexual and homosexual couples).

Further information about best practices can be found in the American Psychological Association Guidelines for Practice with Transgender and Gender Nonconforming People⁵.