BEST PRACTICES FOR IDENTIFYING AND INCLUDING TRANSGENDER AND NONBINARY PARTICIPANTS IN RESEARCH

2022

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Transgender/Nonbinary Community Advisory Board (TCAB)

ACKNOWLEDGEMENTS

Transgender/Nonbinary Community Advisory Boards (TCAB)

The UC San Diego Center for AIDS Research Transgender/Nonbinary Community Advisory Board (TCAB) was established to improve and sustain the health and well-being of the transgender and nonbinary community. The TCAB helps to build bridges between the transgender and nonbinary community and key health initiatives that benefit the community through fostering inclusion in health research, conducting community events, and increasing community education and advocacy.

REPORT DETAILS

About this report

This report has been developed by members of the TCAB in conjunction with members of the transgender and nonbinary community. The purpose of this report is to present best practices for inclusion of transgender and non-binary individuals in research, provide recommendations on how to address and record participant gender identity information, and develop pathways for implementation in current practice.

Considerations

Throughout this report, the phrasing "transgender and nonbinary" will be used, with the shortened form being "trans/nonbinary." It is important to note that transgender and non-binary identities are not mutually exclusive. The purpose of using this phrasing is to provide explicit visibility to nonbinary identities and increase recognition that nonbinary identities may also be transgender identities.

This report provides recommendations for obtaining full sexual orientation/gender identity (SO/GI) data from participants. The trans/nonbinary community is diverse with multiple perspectives on what questions are appropriate, and how to ask question appropriately. There is no one correct way to collect SO/GI data that will garner the approval of all persons. Language used within the trans/nonbinary community may change over time, so what is recommended now may change in the future. Thus, the following recommendations have been crafted by and with trans/nonbinary community members as the best option at this time. Additionally, staff should provide ongoing opportunities for participants to provide feedback and make necessary changes to increase participant satisfaction.

COLLECTION SEXUAL ORIENTATION & GENDER IDENTITY (SO/GI) DATA

WHY ASK?

When engaging with research participants, it is necessary to know *who* a participant is in order to establish their specific needs. Trans/nonbinary individuals are significantly likely to encounter profound discrimination and violence in healthcare, health insurance, employment, housing, education, and in social settings [1,2,3]. Trans/nonbinary individuals often experience discrimination by healthcare providers and insurance companies, resulting in the refusal of care or denial of coverage for needed services, in addition to limited inclusion in health research and educational efforts [4,5,6,7,8]. As a result, trans/nonbinary individuals may lack access to stable healthcare and social supports or feel uncomfortable accessing resources due to past discrimination or incompetence from providers.

Despite these known barriers to care, service providers often do not talk with their participants about gender identity, and offices may not even collect this information [2,5,6,9,10,11]. Due to the lack of efforts taken to identify transgender and nonbinary individuals, the participants are largely invisible in research data. Staff cannot assume a participant's identity by outward appearance because a participant's gender expression does not dictate their identity. Thus, it is imperative to ask participants about gender identity. Taking time to discuss gender identity, pronouns, and sexual orientation in a respectful manner can encourage communication between participants and providers. Doing so will allow for a more accurate understanding of an individual's specific needs and the provision of thorough care [7].

RECOMMENDED QUESTIONS

WHAT TO ASK, WHERE TO ASK, AND HOW TO ASK

Collecting gender identity information is crucial to identifying and addressing the needs of the trans/nonbinary community. It is recommended that name (specifically chosen name) and pronoun information be completed at the initial point of contact so that staff knows how to address the individual appropriately [2,6,12]. Gender identity, pronouns and sexual orientation information should then be recorded when a participant is completing registration/intake forms. It is also important to pair SOGI questions with other necessary demographic information such as age, race/ethnicity, languages spoken, housing, employment, education, etc. as identities are complex and not mutually exclusive. How a person prefers to be addressed, when/where transition happens, and what transition (if undertaken) looks like may be influenced by these other aspects of their identity. Information about an individual's various identities will give information about how best to provide culturally competent care. It is also important to provide participants with verbal and written explanations of any confidential agreements and address any concerns a participant may have about maintaining confidentiality in terms of their identity.

Since gender identity is complex and informed by many aspects of a person's life, questions about gender identity should always provide space for a participant to offer an answer that may be different from the options that are provided. This also holds true for pronouns and sexual orientation. Below are recommendations for how to ask about gender identity and sexual orientation. Various research about the best methods to identify trans/nonbinary individuals has concluded that a two-question approach should be taken [2,6,12,14,15,16]. Some trans/nonbinary individuals may not explicitly define their gender identity as transgender, so asking both a person's gender identity and sex assigned at birth allows for staff to see if an individual's gender matches the sex that they were assigned at birth or not. In addition to asking about an individual's gender identity, staff should ask what the person's pronouns are and clarify when the participant would like staff to address them as such. Some individuals may be not be comfortable going by their chosen name and pronouns in a public setting and request use of pronouns or chosen names be used in private. For example, these situations may occur with minors or those being accompanied by a caregiver to whom the person has not come out to. Asking when to use chosen name and pronouns, allows the participant to maintain confidentiality in terms of their gender identity.

INTAKE FORM QUESTIONNAIRES

Regardless of the format chosen to record SO/GI data, participant's will be asked about their name, pronouns, current gender identity, sex assigned at birth, sexual orientation, and when/how staff should address the participant using provided pronouns and chosen name. Given the sensitivity and invasiveness of some questions, it is paramount that the first question should be to ask the participant for their name (chosen name), followed by pronouns and gender identity. Asking for the participant's pronouns and gender identity before other questions shows individuals that staff understand the importance of properly addressing individuals and respecting the participant's identities.

On intake forms, provide space for participants to dictate their name (chosen name). If it is necessary to know an individual's legal name (if different from chosen name) in order to provide care, include space to record the legal name. However, if the legal name is not necessary for care, then the legal name does not need to be recorded.

After obtaining the participant's name and pronouns, the intake form layout can vary depending on the purpose for collecting data, and participant population. Since some of these questions are sensitive in nature, we also recommend providing a small explanation of why they study is collecting these data. An example may be:

> *The following questions about gender and sex assigned at birth are asked to offer individuals freedom in identifying themselves while attempting to capture the most accurate representation of those who have lived a transgender experience. These questions are optional and do not need to be answered if you do not wish to do so."

Knowing a participant's sex assigned at birth and what organs a participant has may be necessary for laboratory testing and to provide appropriate medical preventative and treatment measures. If asking sex assigned at birth is mandatory, it is best to explain why this is being asked. Ann example explanation may be:

> *The following question about sex assigned at birth is asked to provide the most accurate laboratory testing. Unfortunately, some laboratory results are calculated based on sex assigned at birth."

Additionally, inclusion of the question "when would you like staff to use your name and/or pronouns?" will be most applicable to research or care providing practices where and individual will have regular face-to-face interactions with staff, particularly where staff may address a participant in the presence of others (such as calling for a participant in a waiting room). However, for research projects that are limited to either a single visit, completion of

surveys/interviews without extended participant-staff interaction, or interactions where only the staff and participant are present at all times, this final question may be omitted.

MULTIPLE-CHOICE ONLY

In most cases, multiple-choice only questions may be the preferred method for documentation purposes. Multiple-choice only questions may be helpful when the demographic of participants is quite diverse. Some individuals may be unfamiliar with these questions and not understand what is being asked [7, 16]. The multiple-choice format provides context for those individuals and makes it easier to select the answers appropriate for them. In terms of collecting data, having multiple-choice answers makes categorization easier. Multiple-choice questions may also decrease the amount of time needed to complete paperwork or questionnaires.

Model 1: Multiple Choice Only

What are your pronouns? (check all that apply)

- She/ her/ hers
- He/ him/ his
- They/ them/ theirs
- Other, specify: _____

What is your current gender identity? (check all that apply)

- Female/ Woman OR Cisgender female/ Cisgender woman
- Male/ Man OR Cisgender male/ Cisgender man
- Transgender female/ Transgender woman
- Transgender male/ Transgender man
- Nonbinary
- Choose not to disclose
- Prefer to self-describe: _____

How would you define your sexual orientation? (check all that apply)

- o Straight/ heterosexual
- o Gay/ Lesbian/ homosexual
- o Bisexual
- o Pansexual
- o Choose not to disclose
- o Prefer to self-describe:_____

When would you like staff to use your pronouns and chosen name?

- o Always
- o In private only
- o Other, specify:_____

What sex were you assigned at birth?

- o Female
- o Male
- o Intersex
- o Choose not to disclose

MULTIPLE CHOICE & WRITE-IN

Having questionnaires that provide multiple choice answers and write in options allows individuals to define themselves more freely. Since the questions are open ended, participants may feel less pressure to adhere to a category provided for simplicity or perceived better understanding or familiarity on the part of the provider. However, some individuals may not be familiar with some of the terminology in the questions. Thus, some people may not understand open-ended questions. The mixed option of multiple-choice and write-in questions would best be used in populations that are familiar with the terminology or where it is important for the research study or data collection to provide participants with the freedom to answer using their own language.

Model 2: Multiple Choice & Write-In

> ### What are your pronouns? (check all that apply)
>
> o   She/ her/ hers
> o   He/ him/ his
> o   They/ them/ theirs
> o   Other, specify: _____

> ### When would you like staff to use your pronouns and chosen name?
>
> o   Always
> o   In private only
> o   Other, specify:_____

WRITE-IN ONLY

Write-in only questionnaires are most beneficial for allowing participants to identify with their own language. These questions are best when working with individuals who are familiar with the language and questions since there are no sample answers to provide guidance.

> ### What sex were you assigned at birth?
>
> _____

> ### What are your pronouns?
>
> _____

How would you define your sexual orientation?

_____

What is your current gender identity?

_____

How would you define your sexual orientation?

_____

When would you like staff to use your pronouns and chosen name?
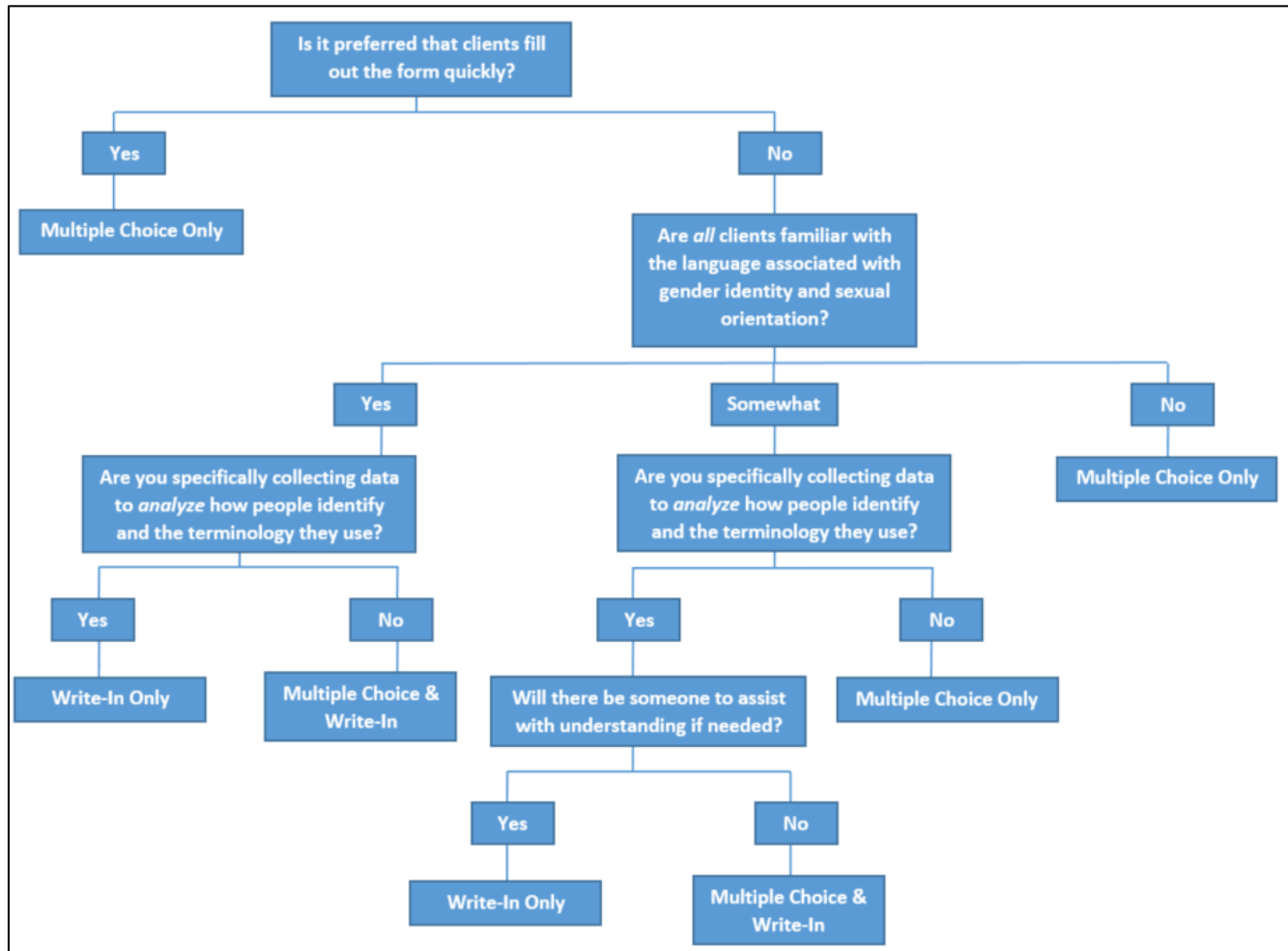
_____
_____

DECISION TREE

The following decision tree serves as a guide to determine which approach is best when collecting SO/GI information. The decision tree is a guideline only. Staff should consider the specific needs of participants and the purpose of collecting data when selecting an approach.

Figure 1: Decision Tree for Deciding SO/GI Question Model

PARTICIPANT REGISTRATION FORM

The following form is provided as an example of what the first part of a registration form may look like (adapted from Fenway SO/GI Guidelines 2018).

PARTICIPANT REGISTRATION

Client Chosen Name:	Last	First	Middle initial

Name on Legal Documents: *(if different from above)*	Last	First	Middle initial

What are your pronouns? *(e.g. he/him, she/her, they/them, etc.)*

The following questions about gender and sex assigned at birth are asked to offer individuals freedom in identifying themselves while attempting to capture the most accurate representation of those who have lived a transgender experience. These questions are optional and do not need to be answered if you do not wish to do so."

What is your current gender identity? (select all that apply)

☐ Female/Woman   ☐ Male/Man   ☐ Trans female/ Trans Woman   ☐ Trans male/ Trans Man   ☐ Nonbinary
☐ Choose not to disclose   ☐ Other: _____

What sex were you assigned at birth?   ☐ Female   ☐ Male   ☐ Intersex

Staff will refer to you by your chosen name and the pronouns provided. Are there any instances where you would like staff to refer to you in a different way? *(e.g. "only use pronouns in private", "use last name in public areas")*

IMPORTANT CONSIDERATIONS

SEX ASSIGNED AT BIRTH QUESTION

Currently, research shows that asking only gender identity can result in the invisibility of many transgender individuals and that the two-question method is the most accurate [2,6,12,14,15,16]. However, we recognize that the sex assigned at birth question is extremely personal and can be uncomfortable for transgender/nonbinary participants. Given the sensitivity of this question, staff should always provide an explanation of why the question is asked. Furthermore, participants should be provided the option of "choose not to disclose" when answering the sex assigned at birth question, unless this information is necessary for the study (e.g., laboratory testing, preventative screening).

Since perspectives related to the sex assigned at birth question vary widely in the community, researchers should provide participants with an opportunity to provide feedback about the questions they were asked and how they were asked them. Doing so can give researchers an idea of what may be best for the community in which they are conducting research.

While we recommend asking the sex assigned at birth question, depending on the needs and data collection for the research, an alternative question may be preferable. Some proposed solutions to address the concerns about the sex assigned at birth question are to instead ask questions such as:

- Have you lived a transgender experience? (your gender identity is **not** the same as the sex you were assigned at birth)
    - o Yes
    - o No
    - o Choose not to answer
- Do you identify as any of the following? (select all that apply)
    - o Transgender
    - o Nonbinary/gender non-conforming
    - o Cisgender (your gender identity is the same as the sex you were assigned at birth)
    - o Prefer to self-describe:_____
    - o Choose not to answer

Either of these questions would replace the sex assigned at birth question and used in conjunction with the question about gender identity. It is important to note that with these two questions, some individuals may not identify as transgender or having lived a transgender experience even if their gender identity is different from the sex they were assigned at birth. Additionally, in consideration for the later question, some nonbinary individuals may also identify as transgender, while some nonbinary individuals may not identify as transgender.

Finally, at this time there is no research to investigate the accuracy or acceptability of alternative methods for assessing gender identity. These are suggestions from the trans/nonbinary community. Thus, we continue to recommend the two-question method based on what we know but strongly urge that more research be conducted to assess alternative questions.

MINORS/ELDERS/PERSONS WITH DISABILITIES

In the case of working with minors, elders, or persons with disabilities, it is important to note that caregivers may have completed documentation and identification. Thus, the information may not accurately reflect the participant's preference. Where possible, providers should ask these questions in person, not just on paper, especially if caregivers do not remain present for the point of care/study visits. If an individual discloses name, gender, pronouns, etc., different from those provided on paperwork, it is particularly important to ask when and how the provider should address the participant to prevent outing the individual.

TERMINOLOGY/ LANGUAGE

Terminology used to describe sexual orientation and gender identity is vast and constantly in flux. Certain descriptors may be of great value to some while offensive to others (e.g., the word "queer"). Age, race/ethnicity, social culture, religion/spirituality, language spoken, family dynamics, socioeconomic status, and other factors can influence these differences in preferences. Thus, staff need to be thoroughly educated on how to handle SO/GI data with respect, sensitivity, and without making assumptions.

In terms of language, the questions recommended in the guidelines use popular terms from the United States in the English language. Participants may prefer identity descriptors that are popular in other geographic locations or in languages other than English. It is important to

note that these identity descriptors may not have an English language equivalent. Thus, staff should only use the language/terms that the participant provides and *not* assign any participant an identity category in English for ease of use. If a term is unknown, staff may simply ask a participant to explain what that term means to the participant.

FEEDBACK

Given the various perspectives on identity, it may be useful to include space where participants may provide feedback specific to their comfortability with any forms and interactions with staff. Collecting feedback can aid staff in making any necessary changes for given populations and serve as a tool for continued informed care. Additionally, providing participants with an opportunity to voice opinions can influence and improve participant-provider interactions and trust.

INTEGRATION INTO ELECTRONIC SYSTEMS

The report thus far has discussed how to make changes to paperwork; however, modifications may also need to be made within electronic systems for research. Recommendations include making systematic changes to allow for participant-centered, knowledgeable care and the use of appropriate terminology. However, we recognize that changes to a system can be challenging and require dedicated personnel and funding. Thus, the following will address possible options for working within a current system as well as recommended changes to the system itself.

PARTICIPANT NAME

In electronic systems, the participant's chosen name should appear first and foremost in cases where the legal name is different. In many systems, the participant's legal name is listed in larger print with a chosen name in small print below. However, with this set up, most staff will only see the name that shows first and use the participant's legal name. Staff should be trained to always check for a chosen name before interacting with a participant. The listed chosen name should always be used to address the participant unless they ask for their legal name to be used instead.

In cases where systems do not have spaces to record chosen names, the chosen name can be recorded in the main name space. Ideally, the participant's name is recorded as: **Surname, Chosen first name (Legal first name)**. This method is preferred to recording the name as: **Surname, Legal first name (Chosen first name)**, because it shows acknowledgment that the person's chosen name is their true name and that the legal name-- by being in parentheses-- is a side note.

PRONOUNS

To date, many systems do not have a space for pronouns. For systems that do, record the participant's pronouns in the provided space. If no space is provided, and the system allows, pronouns may be recorded after a participant's name [e.g.; John (**pronouns: they/them/theirs)**].

SO/GI DATA

When addressing a participant's sex and gender, electronic systems typically only have "sex" as a main record section. A person's sex is not the same as their gender. Staff should be fully informed that a participant's recorded "sex" may not reflect how the participant identifies. Additionally, the category of "sex" does not disclose any accurate information about a participant's anatomy. As an example, if a participant file lists "female" in the sex field, it should not be assumed that the participant has a uterus or is capable of becoming pregnant.

We strongly recommend that staff record both gender identity and sex assigned at birth. The methods used to record this information is dependent on the capabilities of the electronic record system. Some systems may only provide the selection options of "male" or "female" under "sex" designation. In this case, staff should be aware that "sex" means "sex assigned at birth" and that this system does not provided gender identity information.

If the system allows for written answers under "sex", it should be written "sex assigned at birth:…." If space allows, a participant's gender identity can also be added in the write-in section. An example might look like:

Sex: SAB: male, GI: nonbinary

Here SAB is the shorthand for "sex assigned at birth", and "GI" is a shorthand for gender identity.

Anatomical Inventory

If information regarding sexual organs/genitalia is necessary for providing research-related medical care, staff should take great care to gather this information appropriately and respectfully. An anatomical inventory would ask each person to indicate the organs that they have from a list that is not gender- or sex-specific (e.g., penis, testes, prostate, breasts, vagina, cervix, uterus, ovaries). Staff should explain to participants that questions will be asked about a participant's anatomy to ensure proper care is provided.

IMPLEMENTATION IN PRACTICE

STAFF TRAINING/COMPETENCY

Research settings can undertake steps to improve staff/participant interactions and create a more welcoming environment. For any clinical practices or research projects that primarily serve or focus on trans/nonbinary participants, great effort should be taken to hire staff that identifies as a part of the community. Additionally, any research about trans/nonbinary persons should always include the community in constructing and conducting the research, wherever possible, to assist in ensuring the quality of the research project and adequate care of participants. Staff should work to engage with the community by presenting projects and asking for feedback at regular intervals.

Staff should receive mandatory SO/GI training upon hire and at regular intervals throughout employment. Staff should be trained to be familiar with sexual orientation and gender identity and how to respectfully interact with participants, such as using properly worded questions as stated previously. This training can include asking staff to introduce themselves by name and pronouns when greeting a participant. Starting a conversation by giving pronouns lets participants know that the staff is familiar with gender identity, and it may create an environment where participants feel more comfortable disclosing their gender identity.

It is also imperative that staff be trained to appropriately handle situations where they make a mistake by misgendering a participant, using a wrong name or where a participant is asked a question that makes them uncomfortable.

In situations where staff makes a mistake, staff can use tool of "ACAM."

Apologize- Apologize for making a mistake.

Correct- Restate the question or sentence using the correct information.

And

Move on- Do no dwell on the mistake, move on with the visit. Do not continue to apologize or plead with the participant.

It is important that staff be honest if they are unfamiliar with something and apologize for any mistakes made but should not draw attention to the staff themselves. Under no circumstances should staff make excuses, even if they are true to the staff's experience.

IMPROVING ENVIRONMENT

Research projects can also make efforts to improve the environment where research is conducted. The goal should be to create an environment where trans/nonbinary participants feel welcome and safe and their needs are met. Ensuring that there are gender-neutral restrooms for participants to use is of utmost importance. Staff may also include trans-friendly magazines or have a trans flag in the waiting room. These small actions can signal to participants that the staff is trans friendly and knowledgeable. However, it is important that these changes always be proceeded by necessary staff training and improvements to the research projects.

CONDUCTING/PRESENTING RESEARCH

Staff should use the information above to conduct research that is trans/nonbinary friendly and informed about SO/GI information. It is critical to use trans-friendly language in writing protocols and project descriptions as well as presenting research projects. Many projects use gender binary language to describe participants and should adjust wording to be more accurate and specific. For example, if a project only engages with participants that were assigned male at birth and also identify as male, many projects would describe the participants as "men". However, if the project did not accept trans men as participants, the label of "men" is inaccurate and incomplete. When discussing the project, staff should also be clear that the participants were cisgender men (or cismen).

RESEARCH WRITING

Research protocols, recruitment materials, manuscripts and presentations should always use the terms "cisgender" and "transgender" when describing the gender of participants in binary terms ("women"/"men"). Additionally, it should be clarified if nonbinary individuals were included in the study. This recommendation includes study titles. If the title describes the population using gender, the title should always clarify if the population is "cisgender" and/or "transgender", as well as "nonbinary." If the research does not define the population by gender, then these specifications are not needed.

Clarifying gender identity of the study population is of utmost importance for any promotional or recruitment material. If a project produces recruitment materials asking for "men" and/or "women" to join the study, the lack of specificity may lead to problems in the screening

process. To use an example, a transgender individual may be interested and scheduled for a study screening. However, since the project is only recruiting cisgender individuals, the interested participant would be deemed ineligible. Turning away the transgender participant may invalidate their identity as a "woman" or "man." Without the explicit clarification that the study is recruiting "cisgender men" and/or "cisgender women," the study risks damaging relationships with the community and undermining the research because the study is not accurately presented. Thus, any studies with eligibility criteria that includes gender must clarify the population they are recruiting by using the terms "cisgender" and/or "transgender". Studies should also make clear if individuals that identify as nonbinary are also eligible.

While clarification in the title, recruitment materials, and first introduction in any papers may suffice, we recognize that future research may also quote published writing. Thus, we recommend that this clarification of cisgender and/or transgender take place wherever gender is mentioned to avoid misquotation and providing consistent visibility of transgender and nonbinary participants. This recommendation extends to studies where gender identity was used to define populations and trans identity was not an exclusion criteria. For example, if a study recruited "men," including cisgender and transgender men, the study should clarify that cis and trans men were included since when most people read "men" or "women" they think cisgender. In this example, detailing that "men" included both cisgender and transgender men provides visibility for transgender participants.

> When describing a population by gender, the terms "cisgender," "transgender" and/or "nonbinary should be included in:

- Descriptions of gender of participants (including research title, papers, and presentations, data charts, etc.)
- Any and all study advertising
- Listing of eligibility criteria

OBTAINING TRAINING

To obtain staff training, please contact TCAB at: cfar@ucsd.edu

CONCLUSION

Inclusion of transgender and nonbinary individuals in research is crucial to identifying and addressing healthcare needs of the population. Trans/nonbinary individuals need to be identified so that data are recorded accurately. We recommend that the two-step method be used in research settings, as it is the most precise measure known at this time. We continue to advocate for more research to investigate the validity and acceptability of questions that ask about SOGI. Participants' chosen names should be the name used when providing care and conducting research. If information regarding sexual organs/genitalia is necessary for conducting research, staff should take great care to gather this information appropriately and respectfully through an organ inventory. Researchers should use this information to guide the development and facilitation of projects so that research is inclusive and mindful of the trans/nonbinary community. Using these best practices can help improve how we conduct research and inform and address health disparities in the community.

REFERENCES

1. Boisvert, S. (2018, February 7). *Addressing Transgender Invisibility in Healthcare*. American Society for Health Care Risk Management. https://forum.ashrm.org/2018/02/07/addressing-transgender-invisibility-in-healthcare/

2. The GenIUSS Group. (2014). *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute. http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf

3. Weibel, S.G. (2019, January 11). PrEP in the Transgender Population New Study to Examine Effects, *Infectious Disease Advisor*. http://infectiousdiseaseadvisor.com/home/topics/hiv-aids/prep-in-the-transgender-population-new-study-to-examine-effects/

4. Durso, L. E., Baker, K., & Cray, A. (2013, October 10). *LGBT Communities and the Affordable Care Act: Findings from a national survey*. Washington DC: Center for American Progress. https://cdn.americanprogress.org/wp-content/uploads/2013/10/LGBT-ACAsurvey-brief1.pdf

5. HealthyPeople 2020 (ND). *Lesbian, Gay, Bisexual, and Transgender Health*. Healthy People 2020: Office of Disease Prevention and Health Promotion. https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health?topicid=25

6. National LGBT Health Education Center (2016). Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records. Fenway Health Institute. https://www.lgbthealtheducation.org/wp-content/uploads/Collecting-Sexual-Orientation-and-Gender-Identity-Data-in-EHRs-2016.pdf

7. Cahill, S. R., Baker, K., Deutsch, M. B., Keatley, J., & Makadon, H. J. (2016). Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health. *LGBT Health, 3*(2), 100-102. doi:10.1089/lgbt.2015.0136 https://www.liebertpub.com/doi/10.1089/lgbt.2015.0136

8. Makadon, H. J. (2011). Ending LGBT invisibility in health care: The first step in ensuring equitable care. *Cleveland Clinic Journal of Medicine, 78* (4), 220-224. doi:10.3949/ccjm.78gr.10006 https://mdedge-files-live.s3.us-east-2.amazonaws.com/files/s3fs-public/issues/articles/media_425bec3_220.pdf

9. Cahill, S. R., & Makadon, H. J. (2017). If They Don't Count Us, We Don't Count: Trump Administration Rolls Back Sexual Orientation and Gender Identity Data Collection. *LGBT Health, 4*(3), 171-173. doi:10.1089/lgbt.2017.0073 https://www.liebertpub.com/doi/pdfplus/10.1089/lgbt.2017.0073

10. Mayer, K.H., Bradford, J.B., Makadon, H.J., Stall, R., Goldhammer, H., & Landers, S. (2008). Sexual and Gender Minority Health: What We Know and What Needs to Be Done. American Journal of Public Health, 98(6). 989-995. Doi:10.2105/AJHP.2007.127811
https://ajph.aphapublications.org/doi/10.2105/AJPH.2007.127811

11. Alencar Albuquerque, G., de Lima Garcia, C., da Silva Quirino, G., Juscinaide Henrique Alves, M., Moreira Belém, J., Winter dos Santos Figueiredo, F., da Silva Paiva, L., Barbosa do Nascimento, V., da Silva Maciel, E., Engrácia Valenti, V., Carlos de Abreu, L. & Adami, F. (2016). Access to health services by lesbian, gay, bisexual, and transgender persons: systematic literature review. BMC International Health and Human Rights, 16(2), NP. Doi: 10.1186/s12914-015-0072-9

12. National LGBT Health Education Center (2015). Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records. Fenway Health Institute.
http://www.lgbthealtheducation.org/wp-content/uploads/Collecting-SOGI-Data-in-EHRs-COM2111.pdf

13. National LGBT Health Education Center. Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity. Boston: The Fenway Institute; 2018. www.lgbthealtheducation.org/publication/ready-set-go-guidelines-tips-collecting-patient-data-sexual-orientation-gender-identity.

14. IOM (Institute of Medicine) (2013). *Collecting sexual orientation and gender identity data in electronic health records: Workshop summary.* Washington, DC: The National Academies Press.
https://www.nap.edu/read/18260/chapter/1

15. Sausa, L.A., Sevelius, J., Keatley, J., Iñiguez, J.R., & Reyes, M. (2009). Policy *Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services*. Center for Excellence for Transgender HIVE Prevention: University of California, San Francisco. Available online at: www.transhealth.ucsf.edu

16. Tate, C.C., Ledbetter, J.N. & Youssef, C.P. (2013) A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences, *Journal of Sex Research*, 50:8, 767-776, doi: 10.1080/00224499.2012.690110

17. German, D., Kodadek, L., Shields, R., Peterson, S., Snyder, C., Schneider, E., Haider, A. (2016). Implementing Sexual Orientation and Gender Identity Data Collection in Emergency Departments: Patient and Staff Perspectives. *LGBT Health, 3*(6), 1-8. doi:10.1089/lgbt.2016.0069

RESOURCES

FENWAY website/videos

https://www.lgbthealtheducation.org/topic/sogi/

FENWAY publications

https://fenwayhealth.org/the-fenway-institute/publications-presentations/

GLOSSARY

The following glossary is provided to give definitions to SOGI related terms, but is by no means exhaustive, and terms may change over time.

AGENDER

A person does not identify with any socially recognized gender.

ASEXUAL

An individual who does not experience sexual attraction to others and/or has no desire to engage sexually. Shorthand forms may include: "ace".

BISEXUAL

A person who experiences sexual/affectional attraction to more than one gender identity. Some individuals may use the term to connote the experience of attraction to all individuals regardless of gender. Shorthand forms may include: "bi".

CISGENDER

A person whose gender identity is congruent with their sex assigned at birth. Shorthand forms may include: "cis" or "cis-".

DEMI-SEXUAL

A person who only experiences sexual/affectional attraction with people that they know very well.

GAY

An individual who experiences sexual/affectional attraction to others of the same gender.

GENDER

Gender is a construction drawing from social expectations, a person's internal feelings, and expressed behaviors. Commonly confused with "sex" or "biological sex", gender in an internal construct and not determined by physical features or expression.

GENDER IDENTITY

Gender identity is how an individual perceives themselves and/or how they feel they align with gender categories.

GENDER EXPRESSION

How an individual presents themselves to the world relative to gender (typically as masculine or feminine or androgynous). This expression may include, clothing, haircut, body language, vocal tone, and behaviors.

GENDERFLUID

A person who does not experience their gender identity in a stagnate form. Their identity shifts between two or more genders.

GENDER NON-CONFORMING

A person whose gender expression and/or gender identity does not match the social expectations of gender. i.e., does not adhere to a category of man/masculine or woman/feminine. Shorthand may include: "GNC".

GENDERQUEER

A person whose gender identity and/or expression falls outside societal expectations.

INTERSEX

A person who has primary and/or secondary sex characteristics that do not fit the conventional categories of male or female. This may include variations in chromosomes, hormones, internal and external characteristics. Historically, most visibly intersex children were forced to undergo surgery in which the child's body was altered.

LESBIAN

A woman who experiences sexual/affectional attraction to people of the same gender. Nonbinary individuals sometimes identify as lesbian because of a connection to womanhood.

NONBINARY

A person whose gender does not solely match the binary construction of man or woman. Nonbinary individuals may experience a mix of gender experiences, identify with a neutral gender identity (androgynous), or align with a gender identity beyond the man/woman binary. Shorthand may include: "NB".

PANSEXUAL

A person who experiences sexual/affectional attraction to another individual regardless of gender identity or sex.

QUEER

"Queer" may be used by individuals who identify as anything other than straight and/or cis-gender. "Queer" was often used as a derogatory term and it not embraced by everyone. But some have reclaimed the term to identify themselves.

SEX ASSIGNED AT BIRTH

The assigned category of sex, given at birth based upon external genitalia. Historically, these categories have been male and female. Shorthand may include "SAAB" for sex assigned at birth, "AMAB" for assigned male at birth, "AFAB" for assigned female at birth.

TRANGENDER/TRANS

A person whose gender identity is not the same as their sex assigned at birth. Some individuals who identify as nonbinary or gender non-conforming may also identify as trans, however some may not.

TRANSGENDER WOMAN/ TRANS WOMAN

A term used by a woman that affirms gender identity and acknowledges lived experience as a transgender person.

TRANSGENDER MAN/ TRANS MAN

A term used by a man that affirms gender identity and acknowledges lived experience as a transgender person.

TRANSITION

A term used to describe the process where a person begins express their true gender identity. Transition may include social changes such as sharing their gender identity with others, changing their name/pronouns, changing their appearance or clothes they wear, and/or medical interventions such as surgery or hormone therapy.

TWO-SPIRIT

A term used in some First Nations/Native American/Indigenous cultures to describe an individual who may experience gender beyond the binary. Two-Spirit may have different meaning depending on the specific culture and may be recognized as a separate gender. Additionally, communities may have terms in their own language to describe these identities. Shorthand may include: "2S".

Transgender/Nonbinary Community Advisory Board (TCAB)