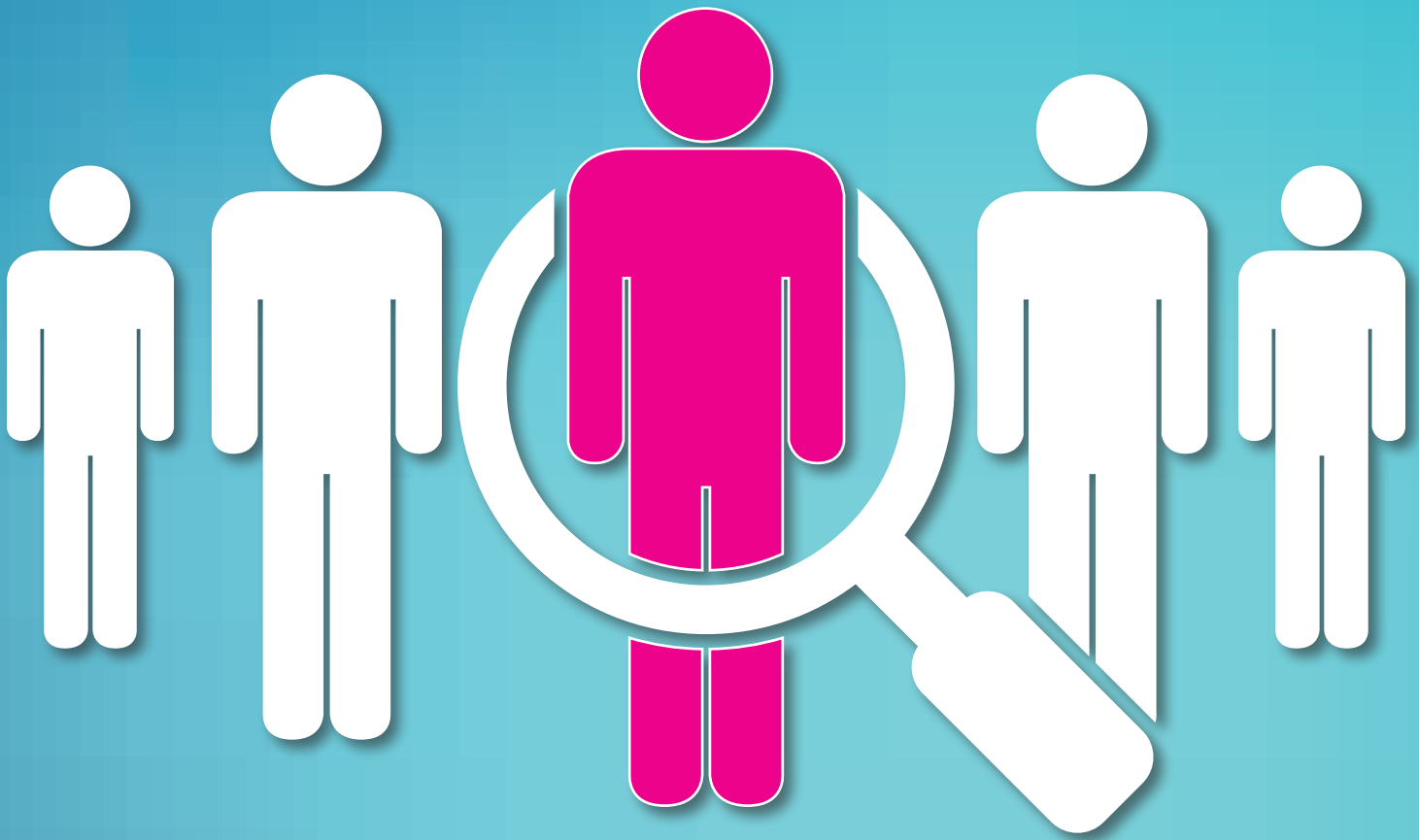




Equitas Health
Institute



**Transgender, Gender Non-conforming
and Non-binary (TGNCNB) Research
Protocol Guide**

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Purpose of Guide

- Transgender, Gender non-conforming, and Non-binary (TGNCNB) communities have historically not been explored in research. While TGNCNB people have always existed, the research community is now taking notice. This research must be done right to ensure that this community is supported and uplifted.
- For important political and social reasons, it is paramount that research counter the social erasure and negative legislation targeting TGNCNB people. Anti-Trans legislation, such as bathroom bills, anti-DEI in schools legislation, and bans on gender affirming care, have proliferated exponentially, putting TGNCNB folk in harm's way. Research is not divorced from social and political environments and must counter these harmful trends.
- There must be standards in place to conduct TGNCNB research. This guide's intention is to offer a roadmap and asset-based approach to strengthen research involving TGNCNB communities.
- Research can do good by illuminating health issues and offering solutions to these disparities. But the research must get it right to be useful and not do further harm.
- This guide is not fully exhaustive but offers general guidance to academic researchers and people interested in learning about TGNCNB research. This guide also be of interest to members of government, universities and LGBTQIA2S+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, Two-Spirit Plus) community members, allies and co-conspirators.

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Disclosures

- The purpose is to guide researchers and interested others in fostering safer research spaces for Transgender, Gender non-conforming, and Non-binary (TGNCNB) folks and lead to much-needed advancement in TGNCNB research.
- Transgender, Gender non-conforming, and Non-binary (TGNCNB), and Gender minority (GM) populations are used interchangeably in this guide.
- In this guide, we will discuss the research needs of the TGNCNB community using affirming current terminology.

Common Gender Affirming Terms (which may not be mutually exclusive):

- Transgender
- Non-binary
- Gender non-conforming
- Gender fluid
- Genderqueer
- Two-Spirit
- Agender
- Please note that everyone is unique, particularly those that identify as TGNCNB. TGNCNB people choose and use descriptive terms that reflect their identity, which can vary widely. Additionally, some may have differing opinions on the appropriateness of this list. If you are unsure about what terminology to use, it's best to ask respectfully, showing your willingness to understand and support them individually.

Acronyms used in the guide

Acronym	Full Term	Definition/More Information
TGNCNB	Transgender, Gender non-conforming, and Non-binary	This is an acronym used in this guide as an umbrella for gender minorities.
SGM	Sexual and Gender Minority	This is a term, created by the National Institutes of Health, to describe LGBTQIA2S+ folk.
GM	Gender Minority	This is an offshoot of the SGM acronym, used to describe transgender, gender non-conforming and non-binary folk.
SOGI	Sexual Orientation and Gender Identity	Often used to describe data, this term is used in research to describe demographic information.
NIH	The National Institutes of Health	This is a United States governmental agency tasked with ensuring the health of the nation.
LGBTQ+/ LGBTQIA2S+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual and Two-Spirit Plus	These are acronyms used as an umbrella to describe certain common sexual orientations and gender identities.
SDOH	Social Determinants of Health	Social Determinants of Health are non-medical factors that influence our health.
No acronym	Biological Determinism	The biology of a person are fixed and unchangeable therefore one's gender is determined at birth.
CFR	United States Code of Federal Regulations	This is a list of U.S. general and permanent rules published by agencies of the U.S. Federal Government.
IRB	Institutional Review Board	This is a body established to protect human subjects in research. It is most commonly found at universities and colleges.
HHS	United States Department of Health and Human Services	This is a U.S. Federal agency tasked with overseeing the general welfare of the nation.

Part One – Introduction to Sexual and Gender Minority Populations

Who are sexual and gender minority (SGM) populations?

- The National Institutes of Health (NIH) defines sexual and gender minority (SGM) people as: “Individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with a difference in sex development are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex” (NIH, 2023).
- Each group represented via the LGBTQIA2S+ acronym is associated with a different population and each person and group’s experiences have unique health concerns (Institute of Medicine, 2011). In other words, there is no “one size fits all” when conducting this research.
- It is estimated that there are 1.3 million transgender adults and an additional 300,000 youth (Herman et al., 2022).
- 11% of LGBTQ+ adults ages 18-60 identify as non-binary, translating to 1.2 million people (Wilson & Meyer, 2021).
- More people than ever are seeking gender-affirming care and supportive medical treatment (Coleman et al., 2022).

Trailblazing Calls for SGM Research

- The Institute of Medicine (2011) report, “The Health of Lesbian, Gay, Bisexual and Transgender People- Building a Foundation for Better Understanding” identified several priority research areas, including transgender-specific health needs. The Institute of Medicine is respected and the report advocated for a shift in research to include SGM people as a priority.
- The Institute of Medicine (2011) report called for sexual orientation and gender identity (SOGI) data to be collected in the electronic health record and on federally funded surveys. You cannot study what you do not measure.
- The Institute of Medicine report (2011) called for research involving the LGBTQ+ community to be funded by the NIH (Institute of Medicine, 2011).
- In October 2016, The National Institute on Minority Health and Health Disparities announced SGM as an officially designated health disparity population for NIH (National Institutes of Health, 2016). A health disparity population is one that is experiencing a disproportionate burden of negative health outcomes. This indicates that formally SGM research is in need of targeted study. Formal declarations do not guarantee adequate funding or affirming research.

Barriers to Health Care for TGNCNB Individuals

- Evidence indicates that SGM populations have higher disease burdens and decreased access to care when compared to hetero/cis folk (Pérez-Stable, 2016). The implications of such burden of disease and reduced access to care are linked to worsening SGM health outcomes. Hetero stands for anyone who self-identifies as straight. Cis stands for cisgender, which means that the person identifies with gender given at birth.
- Transgender individuals often delay seeking care due to a fear of discrimination and stigma or that they will be mistreated for their gender (Vasudevan et al., 2022). Delaying care can lead to health being compromised leading to worse health.
- Both transgender and gender-nonconforming individuals were found to have lower levels of healthcare access (Ferrucci et al., 2022). This study highlighted gender-conforming folk’s health which is not a common population of study and remains so.

- The lack of access to providers knowledgeable on TGNCNB health needs is a major barrier to care (Safer et al., 2017; Mayer et al., 2008).
- Medical education of physicians, nurses, and other healthcare professionals has little dedicated time to transgender health in the curriculum (Vasudevan et al., 2022; Safer et al., 2017; Lane, 2020). This lack of education for health professionals leads to clinicians that do not provide gender-affirming care to their patients.
- Although a survey by Vasudevan et al. (2022) showed that a majority of students reported high levels of personal comfort caring for transgender patients, students reported low levels of knowledge and skills when it comes to transgender health. Comfort with TGNCNB folk does not translate to proper knowledge and skills.
- The burden of teaching medical providers about TGNCNB people often falls on that community due to the severe lack of education (Coleman et al., 2022). Often TGNCNB educate the clinicians which is unacceptable.
- The 2015 United States Transgender Survey found that at least one-third of those surveyed who had seen a healthcare provider in the past year reported one or more negative experiences related to their transgender identity (James et al., 2016). Transphobia is at play and places the responsibility of seeking and getting care on the TGNCNB patient.
- In a 2010 nationwide survey of transgender adults, over 70% of people surveyed reported experiencing stigma and adverse reactions to a healthcare provider at some point in their life (Kosenko et al., 2013). Stigma is negative attitudes and practices that do not support proper, ethical care.
- Gender-nonconforming people were the least likely to report being very satisfied with their healthcare (Ferrucci et al., 2022). Data often does not include gender-nonconforming people so this study is important to understand their experiences.
- Gender non-conforming people were less likely to have had a routine healthcare visit in the last 12 months. (Ferrucci et al., 2022). Not seeing a clinician that offers gender affirming care impacts one's health and makes staying healthy more difficult.

The Importance of Language

- Language is constantly evolving, and it must be acknowledged that the terms being used today, while considered to be the most inclusive and appropriate, may not be considered inclusive or appropriate in the future.
- Researchers should be cautious in their language as it may impact the way that individuals view themselves. TGNCNB folk can experience shame, exclusion, and stigma based on the language used in research.
- Involving the TGNCNB community in the research process ensures that terms are inclusive and appropriate (Coleman et al., 2022).
- Scientific language affects transgender-focused policy directly and is therefore closely related to the struggle for transgender equality (Miyagi, 2021).
- If multiple choice gender options in studies are not inclusive, this leads to anyone who falls outside of the gender binary as an “other” thus making them less comfortable in the research setting (Lewis & Reynolds, 2021).
- Avoid the terms, incidence and prevalence, as they can be pathologizing (Adams et al., 2017). Pathologizing means treating someone as abnormal. Incidence is a way of measuring the rate of disease over a time period. Prevalence measures the number of people with disease over a time period

Intersectionality: What is it and how should we consider it in research?

- Intersectionality was first described by a Black feminist scholar, Kimberlé Crenshaw, who emphasized thinking about relationships between and within the social categories of race and gender (Crenshaw, 1991).

- In healthcare, addressing health disparities based on socially created roles and identities gives a complete picture of the state of public health.
- An intersectional analysis is important because it reveals the intersecting structure of power and domination including cisgenderism, white supremacy, and heteropatriarchy (Wesp et al., 2020). In research, the context is seen as secondary or not necessary at the expense of the data. Cisgenderism is an ideology that prejudices that presumes gender at birth is correct at the expense of diverse gender identities. White supremacy is defined as the belief that white people are erroneously deemed superior to other races. Heteropatriarchy is the social systems that puts white, hetero males over others.
- Applying an intersectional framework to the methodology requires researchers to ask other questions and explore other identities and relationships. Questions for research include “How do you describe yourself?”, “What is your current gender identity?” (The GeniUSS Group, 2014).
- Multiple social identities work together to explain experiences and multiple social identities reveal interlocking systems of oppression (Parmenter et al., 2021). Applying intersectionality shows that the researcher acknowledges the overlapping identities of the TGNCNB people. For instance, a Black transgender person’s experience will be different from a white transgender person’s.
- It is acknowledged that many other possible intersecting combinations not discussed here, but they are no less important.

Part Two – The Benefits of Research

What is Research with Community Involvement?

- Research is “a structured inquiry that utilizes acceptable scientific methodology to solve problems and create new knowledge that is generally applicable” (Gupta & Gupta, 2022).
- Research should ideally be done in partnership with the community and not merely about the community without community involvement. “Nothing about us without us” is true here.
- Engaging the community in the research ensures that research is culturally specific and that the research is gender-affirming (Reisner et al., 2016).

Considerations for doing TGNCNB/ GM Research During Study Preplanning

- To make GM folk as comfortable as possible and to do the much-needed research on this underserved community, researchers must take extra precautions in all study stages.
- Partner with and involve LGBTQ+ community-based organizations and TGNCNB stakeholders and allies as investigators before starting the study.
- Consider forming a Community Advisory Board (CAB) comprised of representative GM community members. A CAB is a group of folk from the community being studied who consult the researchers throughout the research process.
- Determine an agreed-upon vocabulary, population definitions, study design, sampling methods, measurement, outcome ascertainment, and sample size before embarking on SGM research (Reisner et al., 2017).
- Vocabulary is constantly changing and evolving in the GM community. It is important to use the most inclusive and current language in your research. This act affirms the person as they are, not as the study labels them.
- Though one might include outdated language in their literature reviews to capture all of the work done in the past, introduce affirming terms.

Engagement of the TGNCNB community

- Each community within the TGNCNB population may have its own differences within groups and between groups. The TGNCNB community is not a group without its distinctions based on orientations and identities.
- Researchers must evaluate their reasons for wanting to do this research. Research on marginalized populations should be done within the community, and not merely in and about the community.
- It is important for researchers to remember that just because you want to do the research does not mean that the GM community wants the research done. There should be consent and buy-in from the TGNCNB community being studied,
- Use positionality statements to acknowledge privilege and power of the researchers. A positionality statement lists out the researchers’ privileges in full disclosure and explain how they might influence their research.

Conducting the Study

- Researchers must make clear the purpose of the study and how this will add to the literature.
- Research fatigue could become an issue in the SGM community if constant research has seemingly little benefit to the community or its members (Henrickson et al., 2020; Lewis & Reynolds, 2021). TGNCNB research is of increased interest but this new research must give back to those who are studied.

- Additionally, stigmatization and lack of trust in the medical and research community may make individuals wary of participating in government-sponsored research, especially in the current political and social environment (Henderson, 2019),
- Additionally, we must call for gender identity questions to be assessed in the U.S. Census to provide information about the oversampling and weighting of LGBTQ+ populations in national samples (Henderson, 2019). Oversampling and weighting evens the playing field when LGBTQ+ subjects are fewer in number.
- Additionally gender exists on a spectrum. Gender and sex are not synonymous. Many people using the biological determinism model which assumes that the sex assigned at birth is correct and fixed. However, for TGNCNB individuals, the sex assigned at birth does not align with their gender. Their gender may change throughout their lives and they may never fall into the traditional binary of man or woman (Henrickson et al., 2020; Mayer et al., 2008).
- When conducting a longitudinal study, be sure to ask the gender question regularly to ensure that participants still identify in the same way and respect the gender spectrum.
- The social norm and often the norm in research is being cisgender and heterosexual. There is a bias in research that privileges the cisgender social experience as the dominant gold standard. In addition, the incorrect perception of gender as fixed and unchangeable is false.
- Others, such as parents vested by society with power to make such determinations, act under the biological determinism and social strictness of gender.
- In research studies, the assumption that heterosexuality is the social norm and masks the diversity of sexualities present in society.
- No researcher is truly objective, meaning they must account for their own biases and positionality in the development and interpretation of SGM research.
- When added to research papers, positionality statements acknowledge the social positions and power enjoyed by the authors. Inclusion in health articles is new but no less important.

Data Invisibility

- SOGI status is an important social determinant of health that is rarely measured. Many national surveys fail to collect SOGI data. This forces researchers to work with suboptimal data and often make concessions in their research methodology based on the availability of data. Ultimately, this omission leaves the SGM community behind and prevents health equity. Collecting SOGI data must be intentional.
- When this information is collected, due to sampling procedures they are often collapsed into an “other” category due to a small sample size. This choice may create a situation of harmful “othering” and increase the probability of non-response. Non-response means that a person may skip a question and not complete the full survey or not complete the survey at all.
- If researching the overall population, it may be important to consider oversampling members of the SGM community to ensure that there is an accurate representation of this population.
- The NIH recommends routine collection of SOGI data in the electronic medical record, however, some clinics provide pushback because they are afraid that it will offend their conservative patients or make them uncomfortable (Rosser et al., 2021).
- However, studies have shown that item non-response regarding sexual orientation are lower than item non-response about income. Yet questions about income are still commonly asked and used in data analysis, while measures about SGM status are often left out (Fredricksen-Goldsen, 2015).
- In fact, only 5% of the population in a feasibility study declined to answer the question about sexual orientation and gender identity (Rosser et al., 2021).

Examples of SOGI Data Collection

- According to Jones (2023), the Phenx Social Determinants of Health Assessment Collection created social and structural-based questions to gather information about SOGI among other items. These guides are meaningful because there is a new to standardize measurement of SOGI data.
- As of the publication of this guide, current guidelines on gender identity data collection are available from the All of Us Research Program (2018). The All of Us questions are highlighted in Phenx. It is important to acknowledge that language and community-accepted terms are constantly evolving so check often.

- 1a. What terms best express how you describe your gender identity? (Check all that apply)
 - Man
 - Woman
 - Non-binary
 - Transgender
 - None of these describe me, and I'd like to consider additional options
 - Prefer not to answer
- ✓ • Branching logic: If 'non-binary', 'transgender,' or 'none of these describe me and I'd like to consider additional options' selected:
 - 1b. Are any of these a closer description to your gender identity?
 - Trans man/Transgender Man/FTM
 - Trans woman/Transgender Woman/MTF
 - Gender queer
 - Gender fluid
 - Gender variant
 - Questioning or unsure of your gender identity
 - None of these describe me, and I want to specify

Centering Social Justice in TGNCNB Research

- Public health research should be a tool toward social justice and it requires methodological rigor, intent, and conviction. According to the National Association of Social Workers (n.d.), "social justice is the view that everyone deserves equal economic, political and social rights and opportunities."
- Utilizing an intersectional approach in research is an excellent way to work towards social justice and push for transformation in health equity.
- To create a socially just environment, we must evaluate the structures of power and policy and the effects of policy on health outcomes.
- It is important to ensure that suggested policy changes are empowering the minoritized populations and improving their social determinants of health as a way that reduces health inequities.
- Researchers can center social justice in the research questions that are investigated and the involvement of TGNCNB folk in the research process.

Role of Stigma in TGNCNB Research

- The fear of stigmatization and privacy concerns may lead to individuals concealing their LGBTQIA2S+ status. Recognizing potential reporting bias is important to any SGM research because it is likely that participants will conceal or underreport their own identities or lived experiences (Henrickson et al., 2020). This becomes especially true when participants do not feel safe.
- Ways to ensure safety and acceptance in the research environment include asking the communities what they need from researchers to feel safe.
- A group who conceals their status is likely different from those who do not conceal their status, possibly leading to further bias (Institute of Medicine, 2011).

Part Three – Creating a Trauma-Informed and Gender Identity-Affirming Research Environment

Why use a trauma-informed approach?

- It is necessary to utilize a trauma-informed approach in research with the TGNCNB communities.
- A trauma-sensitive environment considers the vulnerabilities and lived experiences of individuals in all planning stages. Trauma-sensitive research allows vulnerable populations to control how their story is shared and gives them autonomy.
- Trauma-informed care approach is to recognize individual trauma and offer different interventions that may be needed to increase participant comfort (Morenz et al., 2020).
- Being mindful of previous trauma in the research setting protects participants from re-traumatization (Ruff et al., 2019). It is imperative that research protects the participants and prevents harm to the participants whenever possible. This is another stage where working with the community, rather than in the community, becomes essential to the success of SGM research.
- Ask community members what makes them comfortable and what they need in a research study to feel safe.
- A trauma-sensitive environment for the TGNCNB populations can range from the utilization of inclusive language to ensuring that they have access to appropriate gender-neutral restroom facilities on site.
- Trauma requires acknowledgement of the possibility of resilience (Edelman, 2022).

How does trauma-informed affect the community?

- According to Edelman (2022), there are Trauma and Resilience Informed Research Principles and Practice (TRIRPP) aims. They are:
 1. Attend to the “adversity context” lived by the people studied;
 2. Open the research to scrutiny by the populations being studied;
 3. Recognize the existence of trauma;
 4. Acknowledge resilience in the populations studied (Edelman, 2022).
- The research being done must be used to give back to the community and improve their health, rather than simply analyze it.
- Involve community members to find out exactly what they feel needs to be done to keep them safe and comfortable.
- Regardless of the study design, researchers must take care to ensure that the survey items or research questions do not perpetuate further harm against the community. This goes back to ensuring inclusive language is used throughout the study and making TGNCNB researchers and TGNCNB people active members of the research design process.

Part Four– Ethical Protection and Rights of Participants

Rights of Participants

- Title 45 of the United States Code of Federal Regulations (CFR) is the principal set of rules and regulations issued by federal agencies of the United States regarding public welfare. Research must abide by the most current Federal Regulations pertaining to research integrity and subject protections (45 CFR 46). HHS regulations, 45 CFR part 46, include four subparts: subpart A, also known as the Federal Policy or the “Common Rule”; subpart B, additional protections for pregnant women, human fetuses, and neonates; subpart C, additional protections for prisoners; and subpart D, additional protections for children.

Informed Consent

- Are the subjects fully informed about the benefits and risks of the study? The fundamental purpose of the Institutional Review Board (IRB) review of informed consent is to ensure that the rights and welfare of subjects, not the institution conducting the study are protected.
- A signed informed consent document is evidence that the document has been provided to a prospective subject (and presumably, explained) and that the subject has agreed to participate in the research. IRB review of informed consent documents also ensures that the researchers has complied with applicable regulations.
- In the context of TGNCNB youth research, the topic of informed consent can be difficult. Informed consent is non-negotiable in research. Parental or guardian consent is often required for any research involving minors. However, this may cause a large proportion of TGNCNB youth to not participate. In a study to see who was missing in SGM research, researchers found that more than one-third of youth would not have participated if parental consent had been required (Cwinn et al., 2020).
- Participants must be able to revoke consent at any time.
- These are some basic questions to answer in terms of ethics to participate in a research study:
 - What is the research about?
 - Who is doing the study? Include a positionality statement.
 - Do any of the researchers stand to gain financially or personally from the research?
 - How are psychological, social and physical risks mitigated in the study?
 - What will the participant be asked to do?
 - What are the possible risks and discomforts?
 - Will the participant benefit from taking part? (It may be a no)
 - Does the participant have to take part of the study?
 - What are the financial costs for participation if any?
 - Will the participant receive any payment or reward for taking part in the study?
 - Who will see the information supplied by participants?
 - Can the participants leave the study early?
 - If phone survey, have you established a method of verbal consent to participate?

The Ethical Principles for SGM Research

- Respect the dignity and protect the confidentiality of research participants. SOGI status must be protected from public scrutiny.
- It is essential that we use the language of the community and research participants. Take extra precautions to avoid stigmatization in language and framing of the research. Language changes and must be reflected in the research study.
- Ensure that research includes SGM perspectives. Involve the community in your research early and often, thinking about what is important to the community and how the community views the issues being presented.
- The diversity of the TGNCNB community should be accurately and sensitively reflected.
- Examine your assumptions about who is included in the sample population. SOGI data is self-identified and we as researchers do not have a place to tell people that they are or are not included in the SGM community.
- Informed consent must be meaningful and non-coercive.
- Appropriately compensate participants for their time and involvement in the study.
- Acknowledge the impact that cisnormativity and heteronormativity has had on the SGM community. This can be unwantedly reinforced by your research.
- All research must take positions that are aligned with professional standards refuting conversion therapy and harm to the LGBTQIA2S+ community.
- Disseminate research back to the community, accounting for health literacy.

Part Five - Conclusion

Sexual and gender minorities experience unique challenges in maintaining health. Research has the responsibility to assure that TGNCNB research studies advance knowledge and do not further stigmatize those groups. The intersectional experiences of TGNCNB folk illustrate that one size that fits all approach does not capture diversity in experience. Few studies and surveys capture SOGI data. Positionality of the researchers must be publically acknowledged. Language must mirror what is currently being used by TGNCNB research subjects. Research must not further stigmatize. Trauma-informed research supports ethical research and supports resilience in the subjects. Center social justice. Perform ethical research, accounting for the requirements for informed consent that are unique to TGNCNB folk.

TGNCNB research is lacking. This population cannot be ignored and must be involved in research to not only advance TGNCNB health but advance cisgender and heterosexual health as well. Our biggest recommendation in performing any research with the TGNCNB communities is to involve community members from the TGNCNB community in every step of the research process. In addition, research should mirror the experience of these communities, not create or override it. The hope is that research in this area will create a safer and more affirming world for TGNCNB people.

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