DO NO HARM GUIDE

COLLECTING, ANALYZING, AND REPORTING GENDER AND SEXUAL ORIENTATION DATA

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DECEMBER 2023

GLOSSARY

The below sexual orientation and gender identity categorizations and definitions are intended to be broad and capture what these words mean to most people in 2023. Labels are not diagnostic but a way for sexual and gender minorities to find community and communicate aspects of their personhood and experiences in the world. Rather than smoothing over differences in how sexual and gender minorities describe themselves, it is important to recognize that they are not a monolith and have a range of experiences and ways of understanding their identities. By providing this list, we do not mean to imply that there is consensus around what they mean and how they are used. Furthermore, these terms are likely to evolve and change.

Asexual. Often called "ace" for short. A person with a complete or partial lack of sexual attraction or lack of interest in sexual activity with others. Asexuality exists on a spectrum, and asexual people may experience no, little, or conditional sexual attraction.

Bisexual. A person emotionally, romantically, or sexually attracted to more than one sex, gender, or gender identity, though not necessarily simultaneously, in the same way, or to the same degree.

Cisgender. A term used to refer to people whose gender identities align with the cultural expectations based on the sex they were assigned at birth, or who do not question or disagree with the gender society has expected them to present since they were born.

Gay. A person who is emotionally, romantically, or sexually attracted to members of the same gender. Men, women, and nonbinary people may use this term to describe themselves, but it is most often used by men who are attracted to other men.

Gender. The social and cultural categorization of people, such as "man" or "woman," based on their identity, behavior, self-expression, and interaction with others. Gender varies across societies and contexts and can change over time.

Gender expression. The external manifestations of gender, expressed through a person's name, personal pronouns, clothing, behavior, body characteristics, and more. Gender expression is not static.

Gender identity. A person's internal psychological identification as a man, woman, another gender, or no gender. This identification may or may not align with the sex the individual was assigned at birth.

Heterosexual. A person who is emotionally, romantically, or sexually attracted only to people who present on the opposite end of the gender spectrum; the term typically refers to cisgender men attracted to cisgender women and vice versa.

Homophobia. Negative and often hateful—and sometimes violent—attitudes toward people who are LGBTQIA+ or are thought to be LGBTQIA+ based on misguided assumptions and beliefs.

Intersex. A term used to refer to people who are born with a variety of differences in their sex traits and reproductive anatomy that together exist outside the normative biological sex categories of male or female subjectively assigned at birth by doctors based on visible anatomy or X and Y chromosomes alone. Intersex variations include differences in genitalia, chromosomes, gonads, internal sex organs, hormone production, hormone response, and/or secondary sex traits.

Lesbian. A woman who is emotionally, romantically, or sexually attracted to other women or nonbinary people. Women and nonbinary people may use this term to describe themselves.

LGBTQ+ or LGBTQIA+. An acronym for "lesbian, gay, bisexual, transgender, and queer," with a "+" sign to recognize the limitless sexual orientations and gender identities. The LGBTQIA+ includes "intersex and asexual" identities. We use the LGBTQIA+ acronym in this guide, though we recognize that the identities the term encompasses are separate, and sometimes they are intersectional identities that can refer to distinct persons, communities, and contexts.

Nonbinary. Some people may have a gender that blends elements of masculinity and femininity, some people do not identify as either male or female, and some people's gender changes over time. People whose gender is not captured by manhood or womanhood may use different terms to describe themselves, including *nonbinary*, but also *genderqueer, agender, bigender, genderfluid*, and others.

Pronouns/personal pronouns. Terms used in place of a proper noun, usually a name, when referring to a person. Examples include *they/them/theirs, she/her/hers, he/him/his*, and *ze/hir/hirs*. Pronoun choice is highly personal, and pronouns should not be assigned to someone based on assumptions about their perceived gender.

Queer. A term people use to express a spectrum of identities and orientations that are counter to the mainstream. It is often used as a catchall for many people, including those who do not identify as exclusively straight and/or those who have nonbinary or gender-expansive identities. This term was previously used as a slur but has been reclaimed by many LGBTQIA+ communities and people. It should not be used to describe someone unless they explicitly indicate that they are comfortable being labeled that way.

Questioning. A term used to describe people who are exploring their sexual orientation or gender identity.

Sex or sex assigned at birth. The classification of a person as male, female, or intersex as assigned at birth by doctors based on hormones, chromosomes, and the appearance of external anatomy. Sex, gender, and gender identity are not interchangeable, they are spectrums that have traditionally been divided into binary categories.

Sexual and gender minority. A term used to describe people who do not conform to traditional societal norms and expectations regarding sexual orientation and gender identity. It can refer to a diverse group of people who may identify as lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual, or any other nonheteronormative or noncisnormative identity. The term recognizes the fluidity and complexity of human sexuality and gender beyond the dominant binary narratives.

Sexual orientation. A term used to refer to a person's pattern of emotional, romantic, or sexual attraction to other people.

SOGI, SOGIE, or SOGIESC. Variations of an acronym for "sexual orientation, gender identity, gender expression, and sex characteristics." SOGIESC encompasses "sex characteristics" to include intersex people. We use the SOGI acronym in this guide because our focus is on sexual orientation and gender identity, not necessarily on how people express their gender. Again, we recognize there are separate and sometimes intersectional identities that can refer to distinct persons, communities, and contexts.

Transgender. An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Someone could be a transgender man, a transgender woman, transgender nonbinary, or otherwise gender nonconforming. Being transgender does not imply any specific sexual orientation, and transgender people may identify as straight, gay, lesbian, bisexual, and so on.

Two-Spirit. A term used by many Indigenous people in North America to describe those who have both a masculine and a feminine spirit. It may also be used to describe a person's sexual, gender, and/or spiritual identity. The term was coined in 1990 by Myra Laramee (Cree) and is intended to be an umbrella term, not to replace tribal-specific names or traditions nations may have, such as *winkte* (Lakota) and *nadleeh* (Navajo).[1]

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Every day, millions of people provide data about their gender or sexual orientation. They supply data about themselves or their families, even if they are not fully aware of it, by using their cell phones or shopping online, for example; or they may answer questions in a formal survey. And with so much (and increasing) technological power at our disposal, researchers, analysts, and social scientists have started to think more carefully about how we collect, analyze, communicate, and respond to data around demographic characteristics and identities.

These data, when disaggregated by demographics or identities, can offer insight into and understanding about disparities across health, income, housing, and other areas—and ultimately inform policy and funding decisions. For example, we know from the Centers for Disease Control and Prevention's (CDC's) Youth Risk Behavior Survey that LGBTQIA+ youth (students in grades 9–12) are at a higher risk of suicide relative to their non-LGBTQIA+ peers. Federal, state, and local governments can use these data to better allocate budget resources and select hospital locations.[2] But these data also have a significant capacity to cause harm if misused.

The long arc of the fight to recognize and respect the dignity and rights of LGBTQIA+ people has raised the visibility of multiple dimensions of gender and sexual orientation, expanding our conception of these identities beyond the binary definitions of man or woman, straight or gay. But recently, we have seen an increasing and targeted backlash against LGBTQIA+ people, particularly transgender and gender-nonconforming people. As of September 2023, more than 560 anti-LGBTQIA+ bills were introduced across the country.[3] These bills—more than 80 of which have already passed—seek to prohibit a number of identity- or gender-affirming practices, including the use of a person's correct pronoun in schools, access to evidence-based and medically necessary care, treatment of gender dysphoria in minors, and the provision of accurate identification documents. Each of these pieces of legislation demonstrates that data regarding gender and sexual orientation can be used for harm—to restrict rights, health care, and freedoms and to further disparage vulnerable, marginalized persons as "other."

In this fifth guide of the Urban Institute's Do No Harm project, we explore the current state of data around gender, gender identity, and sexual orientation. The collection of demographic (or identity-based) data is often complicated by the evolution and nuance of language; words or phrases that we used yesterday may not be the words or phrases that we use today or will use tomorrow. By understanding these changes and employing data best practices, researchers, analysts, and other stakeholders can help ensure that such data are used for good—to help address disparities and inequities faced by LGBTQIA+ people and to assess the effects of policies, interventions, and societal attitudes on their lives. Making purposeful and thoughtful decisions about these kinds of data in inclusive and equitable ways can result in recommendations to policymakers that are more likely to be embraced and implemented without risking the safety and privacy of the people whose data are collected.

Our goal with this guide is to provide a series of considerations and, in some cases, recommendations regarding collecting, analyzing, and communicating quantitative data on gender, gender identity, and sexual orientation. We focus on quantitative (i.e., countable) data, mostly in the context of social science research, because that is where our expertise lies. But this focus should not suggest that qualitative data are not important or valuable—in fact, we have argued elsewhere that quantitative research needs to add more qualitative dimensions (Schwabish and Feng 2021). We hope this omission leaves the door open for further work on how to best collect and analyze data relating to gender, gender identity, and sexual orientation.

LGBTQIA+ experience is not a monolith. Historic and current realities faced by LGBTQIA+ people of color include intersecting dynamics of structural racism, overcriminalization, and violence that impact how they engage with researchers. Recognizing these intersections is essential to ensure that efforts to bring about positive change are comprehensive, just,

and transformative. However, data collection for the Do No Harm project takes a more general lens, and this guide does not attempt to address specific data collection considerations that may be prompted by the intersections of gender, sexual orientation, race, ethnicity, disability status, age, economic status, and other components of individual identity.

The findings reported here focus mainly on larger surveys, such as those conducted by the US Census Bureau, the Bureau of Labor Statistics, and other federal agencies. But the lessons can be extended to smaller surveys or surveys addressing specific themes and soliciting specific types of data—for example, data that are collected by (and for) advocacy groups working on behalf of LGBTQIA+ issues. Similarly, large surveys can adopt practices, strategies, and language from these other types of surveys. In any case, there is still more work to be done, and we list a set of possible future research opportunities in **box 1**.

For this guide, we identified and interviewed more than 20 scholars and advocates with expertise in collecting, analyzing, and communicating data on sexual orientation and gender identity, otherwise known as "SOGI" data (see the glossary for definitions). Our interview protocol and informed-consent documents for the interviews are included in the appendixes. In addition to the interviews, we conducted a literature scan of dozens of reports, academic articles, and books to understand the current landscape of recommendations. We also presented our preliminary findings and sought feedback in open conversations with representatives from LGBTQIA+ service and advocacy organizations across the country. These participants provided feedback based on their personal and professional lived experiences, which we have incorporated into our understanding of these issues and the findings reported below.

We have organized this guide according to each step in the data process: collection, analysis, and communication. The following are five key points to keep in mind when working with SOGI data:

1. **Researchers must tell people why their data are being collected.** Survey data collection, especially for large government surveys, has traditionally reflected the nation's historical structures and institutions that placed certain people—typically white cisgender men—in positions of power. As a result, researchers have created data that have long minimized and overlooked people from other groups, leading to distrust of government and research. Making clear why a person's data will help answer important research and policy questions is fundamental for building trust, which will ultimately result in better-quality data. This task may be easier for certain data, such as personal health data, or for surveys aimed at capturing the experiences of particular groups or communities. But for large, nationally representative surveys—such as those often conducted by the US Census Bureau—it can be a bigger challenge.

2. **Doing SOGI research is just like doing any good research.** Although existing SOGI data are intermittent and sometimes of dubious quality, the process of collecting and analyzing those data—both qualitative and quantitative—should be similar to the process of collecting and analyzing any data. Before thinking about the best and safest way to conduct an interview about SOGI topics, the research team should understand how to conduct a qualitative interview. Before designing a survey to collect SOGI information, the research team should understand how to implement sound survey design. Before conducting surveys or interviews with groups that have experienced discrimination and violence, the research team should receive trauma-informed interview training. No matter the type of research, researchers should be clear about the questions they are asking, what data they need to answer those questions, and why.

3. **There is no one way to collect SOGI data.** As both our interviews and literature review showed, there is no universal agreement on the best way to collect SOGI data. Some experts argue that asking questions about a person's transgender status should be accomplished by asking two separate, consecutive questions, whereas others say a single question with a list of options or even an open-ended (i.e., write-in) option is a better approach. But everyone we spoke with agreed that continued research is necessary to understand how to more accurately capture people's identities and experiences, which echoes existing research literature.

4. **Language-to-language translation can be complicated.** Most of this guide focuses on the words and phrases used in US surveys and research reports to describe LGBTQIA+ people. Making surveys and data collection efforts as well as final dissemination of products available to people who do not speak English, however, can pose additional concerns. Different language structures and the lack of equivalent terms or phrases are just two of the challenges researchers face.

5. **Privacy and safety are real and serious concerns.** Especially with the rise of hate speech and violence against transgender people, asking (or requiring) people to reveal their identity can put them at risk for discrimination and harm. Any organization collecting, storing, and analyzing SOGI data needs to take data privacy seriously to adequately protect research participants. These precautions can extend from safely storing digital files to using an institutional review board (IRB) to ensure compliance with applicable regulations, accepted ethical standards, and institutional policies.

As with previous *Do No Harm Guides*, the importance of approaching these data efforts with empathy and nuance clearly emerged in our interviews. Our interviewees noted how excluding marginalized groups from data collection and analysis undercuts policy solutions and negatively affects the lives of people and communities. Collecting, analyzing, and communicating these data are crucial to provide evidence, shape public discourse, and guide decisionmaking to protect LGBTQIA+ people's rights and improve their well-being. But none of this data work can be done without considering the ramifications for people's physical and mental health, their ability to live and work, and the threats to their personal freedoms.

Here, we extend the concept of empathy to consider how, when people provide their data for research, they give a part of themselves to the researcher. Researchers incorporating this lens of empathy in their work have an obligation to safeguard and use those data responsibly. As Kevin Guyan wrote in *Queer Data*:

> When people participate in research related to EDI [equity, diversity, and inclusion] they give a piece of themselves to the work. They grant you access into their world. There is therefore an onus on the researcher to do something meaningful with the data collected. When data shared is not used for action, or even worse left unanalyzed on a hard drive or cloud server, it benefits nobody and risks discouraging future participation in research projects (Guyan 2022, 62).

BOX 1: OPPORTUNITIES FOR FUTURE RESEARCH

Many aspects of SOGI data collection, analysis, and communication are not covered in detail in this guide. The following issues should be explored in future work:

- **Qualitative data collection and communication.** Our focus on quantitative data in this guide leaves more to be said about the importance and value of qualitative data, which include interviews, observations, case studies, focus groups, and open-ended text. Qualitative data collection is important not only as a way to capture a wider range of opinions and experiences but also as a way to help readers and users better connect with research—but we do not go into great detail about how to conduct qualitative research here. Using qualitative data to help open the door to better understand the experiences and perspectives of survey respondents throughout the data collection process can yield more representative and more accurate data. But it can also be a challenge for many researchers, who are not trained in qualitative methods, and for research funding organizations, which are more likely to fund quantitative research than qualitative research (see, for example, Carey and Swanson [2003] and Bourgeault [2012]). Sociologist Tey Meadow, whose work is often centered around using qualitative data, told us that the challenge for quantitative researchers is to take a qualitative data perspective: "Qualitative researchers have a kind of dense curiosity and an ability to sit with nuance, which makes us question not merely how people in different categories experience the world, but how the categories into which they sort them should be constructed. While some survey researchers interrogate the assumptions behind their categories, others merely reproduce normative assumptions by using old metrics."

- **Gender expression and gendered behaviors.** Unlike race or nationality, gender is a component of one's personal identity that is both conveyed through and reified by performed physical, social, and aesthetic behavior. Our research did not elicit sufficient information on best practices for or innovative examples of research seeking to understand how an individual expresses their authentic gender identity or how an individual perceives gendered behaviors of others. However, this is a crucial field for future research.

- **Intersex people.** There are many questions to explore around data relating to intersex people, some of which go beyond the scope of our work. For example, what does someone's sex at birth really tell us, and are researchers using it as a proxy for how a person is socialized? Is a person's sex a proxy for how the world sees them? What are the risks of this kind of assumption in research and analysis?

- **Asking about pronouns.** Most data collection issues we focus on in this guide relate to specific categories of gender and sexual orientation. While pronouns should never be used to infer a person's gender identity, sharing pronouns is a common component of personal introductions and can be a sufficient and more appropriate alternative to collecting gender identity data formally, especially in more informal contexts, such as a conference registration form or a classroom survey, where the intent is to accurately address people.

- **Expanding to an international view.** While questions regarding the collection and use of SOGI data span the globe, we have focused on the experience of US data collection agencies, US-based advocates, and other people conducting research in the US. Important work is being carried out in this area at organizations around the world, including the World Bank, for example, with its *Equality of Opportunity for Sexual and Gender Minorities* report; the International Lesbian, Gay, Bisexual, Trans and Intersex Association; and the United Nations, to name just a few.
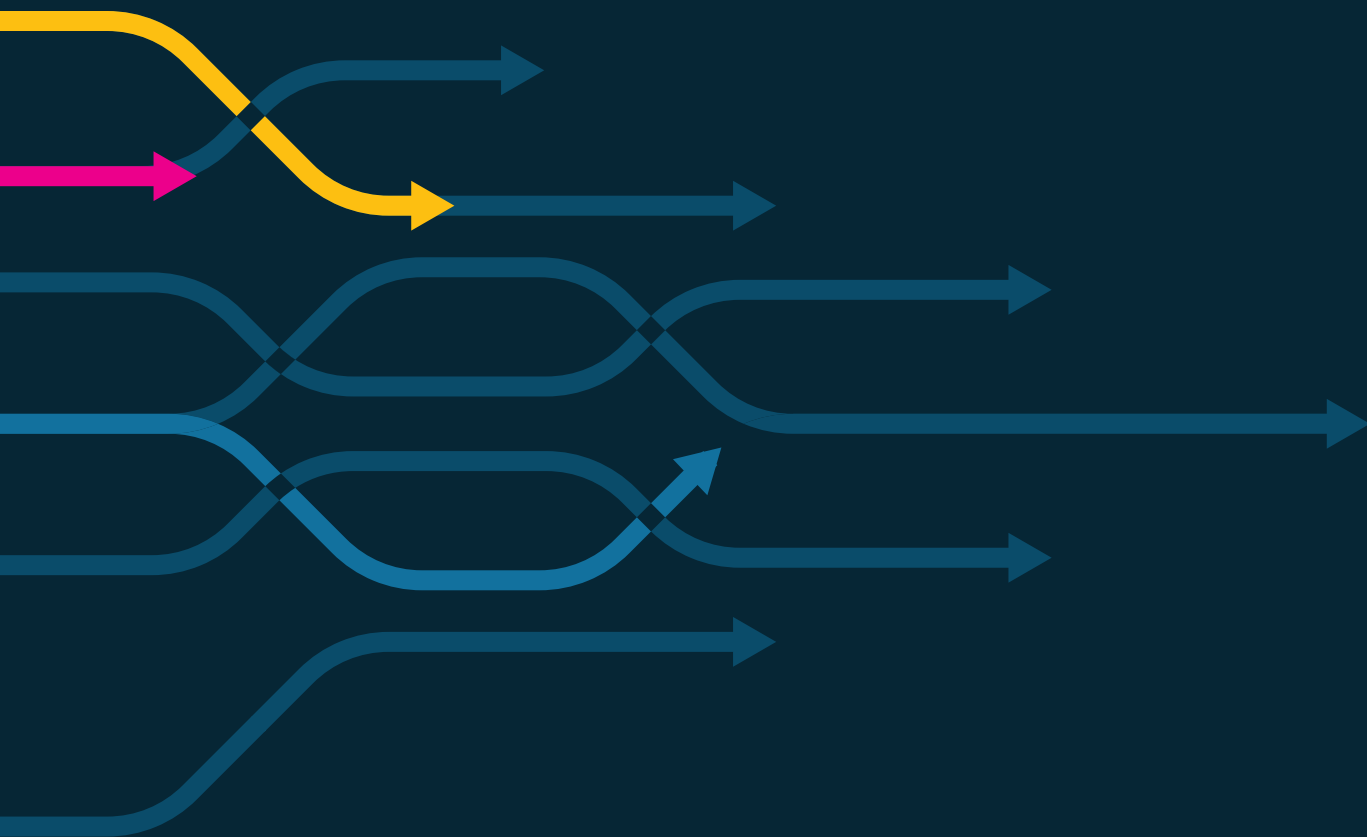
Part Two

Historical Context for
SOGI Data Collection

Historical Context for SOGI Data Collection

Collecting data about sexual orientation and gender identity and expression allows for a better understanding of sexual and gender minority populations, enabling researchers, policymakers, and advocates to understand differences between these populations and other population groups or the general population across policy areas. Insight from these data highlight important areas for interventions that may improve the lives of members of sexual and gender minority groups.

Historically, however, this information has not always been used to improve the lives of LGBTQIA+ people. Throughout US history, public disclosure of one's sexual orientation has often led to disastrous consequences, including jail time; police violence; and discrimination in employment, health, and other areas. For example, many gay men and lesbians served openly during World War II, but as demand for troops declined toward the end of the war, many were dishonorably discharged (Berube 1990). This forcible outing prevented them from receiving benefits under the GI Bill of Rights and often hindered their ability to secure employment. Additionally, in 1953, President Eisenhower issued an executive order barring all homosexuals from federal employment because of fear that communist sympathizers would blackmail them because of their sexuality (Cervini 2020; Johnson 2004).

Here, we hope to provide an overview of modern SOGI data collection efforts. Much of this history is summarized in and informed by *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (National Academy of Medicine 2011, chapter 2). We cover some important events in American LGBTQIA+ history, but we do not seek to detail the long and complex history of LGBTQIA+ people or the disparate and discriminatory treatment they have often experienced.

Early SOGI Data Collection Efforts

After World War II, scientific research that collected sexual orientation information helped improve conditions for LGBTQIA+ people. The publication of Alfred Kinsey's *Sexual Behavior in the Human Male* (1948) and *Sexual Behavior in the Human Female*

(1953)—also called the Kinsey Reports—was a watershed moment in SOGI data collection, because the reports did not treat same-sex attraction and sexual behavior as categorically different from any other form of sexual attraction or behavior. Compared with previous research, which took for granted that "homosexual practice" was inherently "deviant," the Kinsey Reports, and the Kinsey Scale in particular, "implied that homosexuality was just another form of sexual activity" (Bullough 1998, 130). Though now considered overestimates, the reports' assessments of the frequency of same-sex attraction and behavior were among the earliest attempts at measuring the size of the sexual or gender population in the US.

Kinsey's work—along with other contemporaneously published work from Evelyn Hooker, Clellan Ford, and Frank Beach—presented a new avenue for research to address discrimination against LGBTQIA+ people. A 2011 report from the National Academy of Medicine said that this era of research "challenged widespread assumptions that homosexuality was a rare and pathological form of sexuality, practiced only by a small number of social misfits" (National Academy of Medicine 2011, 37). This scholarship also bolstered the work of activists, who began to work to end harassment and discrimination.

Despite some success in protecting the rights of gay people during the 1960s, anti-LGBTQIA+ persecution was still common.[4] Among other forms of discrimination, police still routinely raided spaces where sexual and gender minorities congregated to arrest and brutalize people (Boyd 2003; Johnson 2004). During one such raid on the Stonewall Inn, a gay bar in New York City, patrons and their allies resisted the police for several nights (Adam 1995). Known today as the Stonewall rebellion, this confrontation—which was planned, led, and supported by transgender, lesbian, and gay people—marked the beginning of the contemporary movement for LGBTQIA+ rights.

After the Stonewall rebellion, many people became empowered to publicly reveal their sexual orientation. Gay and lesbian communities as well as LGBTQIA+ organizations, groups, and businesses grew across the US throughout the 1970s (Faderman 1991; Levine 1979). The LGBTQIA+ activists notched another important victory with the removal of homosexuality from the American Psychological Association's *Diagnostic and Statistical Manual of Mental Disorders* in 1973 (Drescher 2015). Still, the social, legal, and political backlash against this movement and gay and transgender people continued.

The beginning of the HIV/AIDS epidemic in the 1980s marked one of the darkest chapters in LGBTQIA+ history. In June 1981, the first cases of the disease, which would eventually be called AIDS, were reported in the CDC's *Morbidity and Mortality Weekly Report*. By 1995, as many as 1 in 15 gay men in the US had died of AIDS.[5] Driven by overwhelming inaction on the part of the federal government—exemplified by then president Ronald Reagan's refusal to use the word *AIDS* until September 1985, after more than 8,000 Americans had died—the HIV/AIDS epidemic marked a turning point in LGBTQ organizing efforts.[6] LGBTQ people formed groups, such as Gay Men's Health Crisis and the AIDS Coalition to Unleash Power (commonly known as ACT UP), to provide peer-to-peer support and advocate on behalf of those affected by AIDS.[7] This infrastructure created the foundation for many current LGBTQ services and groups interested in collecting SOGI information.[8]

Although these decades brought more visibility for LGBTQIA+ people, that progress was not felt equally. Often, white cisgender gay men were at the forefront of these groups—with disproportionate shares of leadership roles and media attention—to the exclusion of Black, Hispanic/Latine/Latinx, and Indigenous people; transgender people; and people with other intersecting identities. The consequences of that inequality within the LGBTQIA+ community reverberate to this day, with Black and Latina transgender women experiencing disproportionate rates of violence, homelessness, and discrimination.

Federal (and Other Large-Scale) SOGI Data Collection Efforts

The early 1990s saw a marked increase in the statistical rigor of sexual behavior research—in large part because of the compelling public health interest created by HIV/AIDS. Not only did the epidemic reveal the need for robust data on sexual behavior, but "researchers in the United States, many of them lesbian, gay, or bisexual themselves … started to argue for the collection of sexual orientation data in publicly funded data sets" (Sell and Holliday 2014, 967).

One of the first large-scale SOGI data collection efforts was the 1992 National Health and Social Life Survey (NHSLS), which was originally intended to be a pretest survey for the larger Survey of Health and AIDS-Related Practices. Although funding for the larger project was blocked in Congress, the NHSLS still proved massively influential. According to a 1995 retrospective on the NHSLS: "The National Health and Social Life Survey is a singular event in the history of survey research, not because it pioneered new methods, but because it demonstrated that sound, traditional survey approaches can be applied to the study of sexual behavior" (Miller 1995, 418).

The publication of the findings from the NHSLS—along with the 1988 introduction of sexual behavior questions in the National Opinion Research Center (NORC) General Social Survey, one of the longest-running social surveys in the US—marked a turning point in LGBTQIA+ data collection.

In 1996, four years after the NHSLS was conducted, the National Institute of Mental Health funded the one-time National Sexual Health Survey, which was one of the earliest federal surveys to include questions about sexual behavior and sexual identity. Other early federal efforts included the National Longitudinal Study of Adolescent to Adult Health (Westbrook, Budnick, and Saperstein 2022), which incorporated sexual orientation questions into its 2001 panel, and the National Survey of Family Growth, which added the full spectrum of sexual

orientation questions as part of a suite of changes to the survey in 2002 (Saperstein and Westbrook 2021).

Through the rest of the 1990s and into the 2000s, other federal surveys began adding questions about sexual orientation. As we discuss later in this guide, sexual orientation is a multifaceted construct that is typically divided into three dimensions: sexual identity, sexual behavior, and sexual attraction (National Academy of Medicine 2011). While some surveys, such as the NHSLS, addressed all three dimensions of sexual orientation, many others included only one or two of the dimensions.

This period also marked the first time that same-sex couples were recognized in the US Census. In 1990, the Census Bureau added an "unmarried partner" category to the "relationship to householder" question to capture the increasing number of couples living together without getting married. However, in data files available to the public, the bureau recoded the gender of individuals who indicated that they were same-sex couples, treating them as an error. In 2000, the National LGBTQ Task Force and other organizations pressed the bureau to stop recoding the gender of same-sex partners in public-use data, and the bureau agreed (National LGBTQ Task Force 2017; Smith and Gates 2001).

Since these first instances of federal SOGI data collection, best practices started to emerge for the burgeoning field. Researchers at the UCLA Williams Institute convened the Sexual Minority Assessment Research Team, which authored *Best Practices for Asking Questions about Sexual Orientation on Surveys* in 2009 (SMART 2009). This report, along with the Williams Institute's 2013 report *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys* (GenIUSS Group 2014), would later guide the creation of the CDC's optional SOGI module for the Behavioral Risk Factor Surveillance System (BRFSS) (Baker and Hughes 2016). The latter report, also called the GenIUSS report, was especially timely, as

states began asking questions about gender identity in the BRFSS as early as 2007 (Baker and Hughes 2016). This period also saw the publication of the National Academy of Medicine's influential *The Health of Lesbian, Gay, Bisexual, and Transgender People* report (National Academy of Medicine 2011). Although not focused on SOGI data collection, the report, which is considered one of the first comprehensive overviews of the field, included guidance for federal surveys collecting SOGI data and called for the collection of these data across federal agencies. These three reports came at a critical time in federal data collection, and by 2016 "there [were] eleven federal surveys and one federal study that collect data on sexual orientation, including identity, attraction, and behavior, and gender identity" (Federal Committee on Statistical Methodology 2016, 4).

But collecting SOGI data remains a contentious political issue. In 2017, the Trump administration removed questions about sexual orientation and gender identity from the National Survey of Older Americans Act Participants and the annual program performance report for Centers for Independent Living[9] (Cahill and Makadon 2017). The administration also curtailed the Census Bureau from adding sexual orientation and gender as potential question topics to the American Community Survey.[10]

The Biden administration, however, has resumed the federal SOGI data collection efforts. In 2021, the Census Bureau added questions about sexual orientation and gender identity to its Household Pulse Survey,[11] marking the first time a Census Bureau–sponsored survey has included SOGI questions.[12] In 2022, President Biden signed the Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals. One section of the executive order focused on "promoting inclusive and responsible federal data collection" to help policymakers identify, understand, and address disparities experienced by LGBTQIA+ people. The executive order also required federal agencies to submit a "SOGI Data Action Plan" to explain how they will use data to advance equity for LGBTQIA+ people.[13] In fiscal year 2023, Congress appropriated $10 million to the Census Bureau to support research on asking SOGI questions in the American Community Survey, which is one of the largest demographic surveys administered by the federal government.[14]

Yet, concerns about data privacy and potential misuse of data abound, no matter who is in the Oval Office, given the current charged political environment. In the next section, we discuss these concerns in more detail, including safety and security measures researchers should consider when collecting SOGI data.
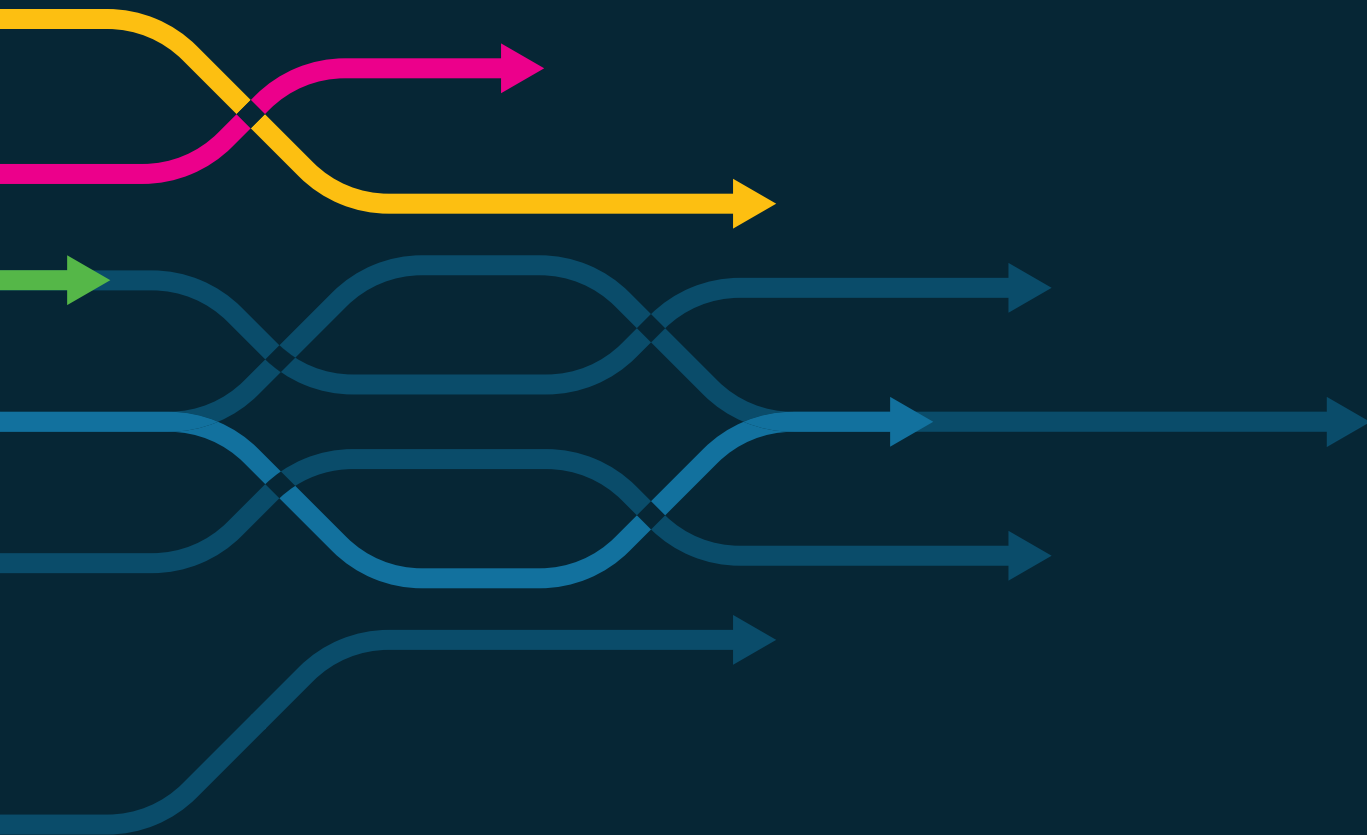
Part Three
Data Collection

Data Collection

There are two sides to survey data collection: the experience of the participant and the experience of the researcher. Thus, building trust between the participant and the researcher is key to generating high-quality data. Communicating to people why their personal information is necessary and gaining their formal consent can lead to greater collaboration and, ultimately, allow for more inclusive survey methods.

No data collection effort is entirely without social implications. Collecting data on LGBTQIA+ people in particular entails special considerations, especially with the recent rise in anti-LGBTQIA+ (most notably anti-transgender) violence and legislation. SOGI data collection efforts are essential for understanding different LGBTQIA+ groups in the US and providing an evidence base for programs and services (Office of Management and Budget 2021). Although aspects of data privacy are encoded in federal law—such as Titles 13 and 26 of the US Code, which lay out regulations and requirements for collecting and storing personally identifiable information (PII)[15]—anyone collecting, analyzing, and communicating SOGI data needs to be cognizant of the importance of data privacy stewardship.

Throughout this section, we try to balance research and survey methodological considerations with the importance of being inclusive of survey participants' identities and protecting their safety and privacy. Unfortunately, these factors often are in tension with one another. Therefore, we recognize that a survey is *not meant* to capture all the nuances of someone's story. But, when constructed thoughtfully, it can still be a powerful tool for giving visibility and agency to historically marginalized groups. In all cases, researchers have a responsibility to be ethical and empathetic stewards of these data.

Safety and Security Measures to Consider in SOGI Data Collection

Throughout history, marginalized groups have been repeatedly harmed by research. From the Tuskegee syphilis study, in which 400 Black men with syphilis were purposely untreated; to Henrietta Lacks, whose cancer cells were extracted and used

without her permission; to the Havasupai Tribe in Arizona, whose blood samples were used without their permission for genetic research—history has no shortage of examples of exploitative and extractive research practice.

It is not surprising, then, that many people today may feel wary about providing their information to institutions or individuals, whether doctors, the federal government, or political pollsters. This lack of trust can result in lower survey response rates and less accurate information. Data scientist Kelsey Campbell summarized this challenge in our conversation: "There is that tension between wanting representation and wanting more inclusive measures on surveys or in systems, but also not having trust in a system to use that data appropriately and not use it in an exploitative way."

Creating inclusive and representative surveys that benefit people and communities can therefore be key to generating the knowledge needed to pursue better policy and community outcomes. We do not endeavor to summarize every necessary step of a research project in this guide, but we want to stress that collecting data on LGBTQIA+ identities or experiences must include foundational security measures. No survey effort should put people at risk.

Although SOGI data are essential to understanding where LGBTQIA+ people live and work, what benefits and services they receive, and many other types of information, such data can be used to both promote and restrict access to rights and services. Collecting and using SOGI data to locate—and potentially punish—people who identify as LGBTQIA+ is a real concern, especially at the government level. Data on how many or few LGBTQIA+ people live in a given area, for example, can demonstrate the need for services, just as it can be used to target service reductions. In late 2022, the *Washington Post* reported that the Texas attorney general's office requested a list of individuals who had changed the gender on their driver's license and other records. The head of the Texas Department of Public Safety Driver

License Division had emailed colleagues: "Need total number of changes from male to female and female to male for the last 24 months, broken down by month. We won't need DL/ID numbers at first but may need to have them later if we are required to manually look up documents."[16]

With LGBTQIA+ identities so intensely politicized, data on the prevalence and experiences of LGBTQIA+ people can be used to advance anti-LGBTQIA+ legislation, which presents safety challenges for researchers. As of September 2023, the Trans Legislation Tracker[17] had recorded more than 560 anti-transgender bills introduced across the country that seek to limit medical care, bathroom access, and accurate identification for transgender people (**figure 1**).[18] According to the 2022 Trevor Project survey, 86 percent of transgender and/or nonbinary young people (ages 13 to 24) reported that the political debates around these issues had a negative effect on their mental health (The Trevor Project 2022).

FIGURE 1

More than 560 Anti-LGBTQ Bills Were Introduced across the US between January and September 2023
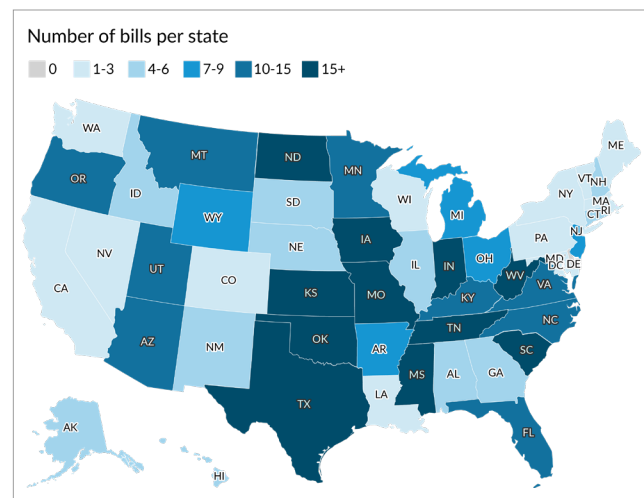
Source: "2023 Anti-Trans Bills Tracker," Trans Legislation Tracker, accessed September 12, 2023, https://translegislation.com.

In light of all these challenges, protecting LGBTQIA+ people's identity must be a top priority in data collection and data analysis efforts, in large-scale representative surveys and smaller-scale local surveys alike (Flores et al. 2021).

For data collectors, protecting people's privacy and preserving their safety comes with potential trade-offs in terms of both data quality and group wishes. In the 2023 *Do No Harm Guide: Applying Equity Awareness in Data Privacy Methods*, our colleagues Claire Bowen and Joshua Snoke summarized these concerns:

> An underrepresented group might be less concerned about their privacy and would rather have more accurate representation in the data. For instance, a university might suppress the number of transgender students attending their law schools for privacy purposes. Some students might support this decision while others may want to be accurately represented to allow other transgender students to reach out to them or to know that the law school is welcoming toward transgender students. The outcome depends on the group representatives influencing these decisions, and in either case, the trade-offs and privacy limitations should be acknowledged and communicated to group representatives. (Bowen and Snoke 2023, 12)

As our colleagues note, fears about how data collection may be weaponized for harm must be weighed against the importance of having representation. For many people, the balance will depend on their specific intersectional identities. As in the above example, a transgender law student may prefer visibility over privacy to lift up others with their identity. Similarly, a Black transgender woman who has experienced systemic discrimination may trade some privacy for more awareness of these harms. However, these circumstances can just as easily be flipped. If the same law student attends school in a state that is stripping transgender protections, they may prefer their data be suppressed. And if the same Black transgender woman fears retaliation for their participation in a survey, they may prefer privacy to visibility.

Ultimately, existing power structures have always made some identities safer than others in society. There is little research—likely because of lack of representative data—for example, on the denial of employment opportunities to transgender and nonbinary people, much less on how such discrimination varies by race and ethnicity (see Sears et al. [2021] and Badgett, Baumle, and Boutcher [2018]). Thus, while the balance between data collection and data privacy is important on its own at an aggregate level, it becomes even more important as we consider intersections of identities.

Data Privacy and Collecting Personally Identifiable Information

For researchers who routinely conduct surveys, the process of developing security measures for PII may be familiar. The US Department of Labor defines PII as data "(i) that directly identifies an individual (e.g., name, address, social security number or other identifying number or code, telephone number, email address, etc.) or (ii) by which an agency intends to identify specific individuals in conjunction with other data elements, i.e., indirect identification."[19] Demographic information, such as race, ethnicity, annual income, and sex at birth, is not generally considered PII for large-scale survey efforts. But the risk of "indirect identification" is particularly high when researchers are working with data from marginalized groups, including LGBTQIA+ people, and even higher for specific subpopulations, such as transgender people.

Survey scope and size can also influence how data may put people at risk of identification. A national survey is usually too large to put individuals at risk, but a school-based survey asking about gender might generate a dataset that highlights just one respondent as nonbinary—a number so low that administrators and readers may know exactly which student reported that information. For these reasons, it is a good practice to treat all instruments asking about SOGI information like they are collecting PII.

Any US research project seeking to collect data from marginalized groups, including LGBTQIA+ people, should seek approval from an IRB before beginning data collection. Some smaller-scale survey research teams—including those at service organizations or advocacy groups, which may not have immediate

access to an in-house IRB—could explore partnering with IRBs at nearby universities or larger organizations.

To secure IRB approval and conduct data collection as ethically as possible, research teams need to develop specific plans for assuring anonymity and storing survey data in ways that minimize the risk of linking specific survey responses (e.g., reported gender identity) to respondents' full names, addresses, or birthdays. Researchers should be prepared to detail what digital tools they will use for storage, how video or audio files will be stored safely and securely, how that storage may update or change over time, and what steps are needed if the data are combined or merged with other data. Large-scale survey efforts seeking to release datasets for future research should be particularly careful about how demographic data are both stored and published. Obviously, qualitative data collection raises privacy considerations to an entirely new level, owing to smaller sample sizes and the possibility of identifying a person, their location, or their occupation from their quotes or comments. Additional security measures should be undertaken by researchers and institutions storing video or audio files, transcriptions, and related qualitative materials.

In addition to building careful measures for data security, storage, and sharing in the research design phase, organizations that ask SOGI-related questions should consider ways to minimize potential harm experienced by respondents. Researchers should prepare transparent and detailed informed-consent statements outlining who the research team is, where the funding comes from, and what data are being collected and how they will be used. More information about ethical research principles and trauma-responsive survey design can be found in the "Incorporating Trauma-Informed Care in Survey Response" section below.

Researchers interested in collecting SOGI data should answer four key questions before designing a survey instrument. We derived the following questions and considerations from our interviews and review of existing literature:

- **Does the research have a legitimate and defensible purpose for collecting the information (i.e., does the researcher need this information)?** Researchers often believe that more data are better, no matter the research question or final product. But if the SOGI data are not going to be used, especially if they are not even relevant to the research question, then they do not need to be collected. Researchers should evaluate whether the benefits of collecting sensitive information are worth the risk to participants and the potential unintended consequences of data collection and storage. As University of Chicago sociologist Kristin Schilt told us, "You should ask yourself, why am I collecting this data if I am not planning to use it in my project?"

- **How is the researcher guaranteeing safety and confidentiality?** Especially for smaller organizations that may not have official data security protocols in place, leaving PII lying around on a desk or on an unsecure computer risks the privacy and safety of survey respondents. Bobby Jefferson, the global head of diversity, equity, engagement, and inclusion at the development firm DAI Global, told us that he provides survey respondents with specific statements regarding data privacy, security, and storage, which he believes helps increase survey response rates and the overall accuracy of the data collected.

- **Has the research proposal undergone an IRB review?** IRBs are designed to protect research study participants and act as a third-party review for the research team to ensure that sufficient protections are in place for data collection and data communication. If the researcher does not have access to an IRB within their organization, it may be worth seeking an outside IRB or partnering with an organization that has an internal IRB.

- **Is the researcher making promises they cannot keep?** In our interviews, we heard how important it is to tell survey participants why their data matter for the research project. But what happens when the research strategy, goals, or storage plans change? For large national surveys, it can be particularly hard to ensure that the data will be used for their intended purpose. Surveys are often used for many purposes and shared with other organizations. And administration changes mean that the survey conducted under one set of privacy and storage rules or priorities could be under different rules in a new administration.[20] When conducting surveys, it is important to clearly inform participants of all the possible ways in which their data may be used. For smaller-scale surveys, in particular, researchers may have more latitude for when certain data fields are necessary and how they might revise their data collection to maximize respondent protection.

Building Inclusive Data Collection Methods

Although several representative surveys in the US currently collect SOGI data, most still collect gender data in the binary (i.e., man/woman), and if they collect sexual orientation data at all, they do so along a binary division (i.e., straight/gay). Of course, other surveys and data collection efforts have included a wider array of identities, such as the National Transgender Discrimination Survey (Grant et al. 2011), the 2022 US Transgender Survey,[21] and the 2023 KFF/Washington Post Trans Survey[22] (all of which were offered in English and Spanish). These more inclusive surveys provide lessons for how to better frame questions around identity.

In this section, we draw from existing surveys and our interviews with SOGI data experts and advocates to outline some principles for inclusive, thoughtful data collection methods, including survey mode, question response options, language choices, trauma-informed design, and proxy reporting. Because data collection efforts and use cases vary so widely, we hesitate to make blanket recommendations for all SOGI data work. With these principles, we try to balance the tension between offering marginalized groups visibility and remaining cognizant that a survey cannot capture every part of a person's identity.

Survey Mode

There are many ways to conduct a survey: in person, over the phone, via text, or online. Each survey can be self-administered (i.e., the respondent answers the questions on their own) or administered during an interview, and each method has its own challenges with regard to time, cost, and accuracy.

- **Paper-and-pencil interviewing.** This is the traditional survey method, in which a respondent or interviewer fills out a paper form.

- **Computer-assisted personal interviewing.** In this survey method, the interviewer sits with the respondent and records the answers using a mobile phone, tablet, or computer.

- **Audio computer-assisted self-interviewing.** A respondent listens to prerecorded questions through headphones and responds to the questions by selecting their answers on a screen or touch pad (Morrison-Beedy, Carey, and Tu 2006).

- **Self-administered questionnaire.** A respondent completes the survey on their own, without an interviewer present. This method can be efficient and inexpensive, but it can also result in missing data because of skipped questions (Morrison-Beedy, Carey, and Tu 2006).

A large amount of evidence suggests that the number of people who stop taking a survey altogether (typically called survey termination or survey breakoff) when they encounter SOGI questions is low (see Atrostic and Kalenkoski [2002] and references therein). The evidence suggests that nonresponse to individual SOGI questions is also low, ranging from less than 1 percent to about 6 percent (see, for example, NASEM [2020]). By comparison, survey questions about income can have nonresponse rates exceeding 20 percent (Atrostic and Kalenkoski 2002).

In a 2019 paper that used the National Health Interview Survey (NHIS), Dahlhamer, Galinsky, and Joestl (2019) found statistically—and meaningfully— similar rates of survey nonresponse to SOGI questions

under computer-assisted personal interviewing and audio computer-assisted self-interviewing survey modes. And other research has shown that nonresponse rates in self-administered surveys are lower than in interview-administered surveys (see Dahlhamer, Galinsky, and Joestl [2019]; and Jesdale [2021b]).

Asking Questions about Gender

There is no universal agreement on the best way to collect SOGI data. Large-scale survey strategies to collect gender data are rapidly evolving as research needs, community understanding, and language change. At the time of this writing, there are three common approaches to asking questions about gender: (1) directly asking respondents about their current gender in a single question or measure, (2) using a two-step approach to indirectly capture gender and transgender status across two consecutive questions, and (3) using an open-ended (i.e., write-in) question. We discuss the first two options, which are more common in large-scale surveys, in detail below.

Single-Measure Approach for Current Categorical Gender

A single question with limited yet inclusive options can often be sufficient to record gender for research needs without being taxing on survey respondents. The 2021 Australian Census is an example of this approach (**figure 2**). In this measure, respondents are asked about their current gender and are provided binary (man/woman), nonbinary, and write-in options.

FIGURE 2
Sample Gender Question from 2021 Australian Census

How [do/does] [you/Person's name/they] describe [your/their] gender?

Gender refers to current gender, which may be different to sex recorded at birth and may be different to what is indicated on legal documents.

Please [tick/mark/select] one box:

☐ Man or male

☐ Woman or female

☐ Non-binary

☐ [I/They] use a different term (please specify)

☐ Prefer not to answer

Source: Australian Bureau of Statistics, *Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables* (Belconnen, AUS: ABS, 2020), https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release#gender.

The single gender question combines both cisgender and transgender men/women as men/women and gives decent representation to those outside the gender binary through the nonbinary umbrella option. Transgender status, however, is not explicitly captured (except for respondents selecting the nonbinary option) with the single gender measure, which may be insufficient for some use cases.

The most recent 2023 NHIS (CDC 2023) offers an important view into how large surveys are experimenting with SOGI questions, particularly in terms of the single-measure approach. It introduces a significant change from previous NHIS and other major surveys in the US.[23] In the new NHIS, respondents are asked how they currently describe their gender, and they are able to select one or more of seven possible answers (see the simplified survey text in **table 1,** next page). This is the first time the NHIS has allowed users to select multiple gender options, and the first time it has explicitly offered "transgender" and "nonbinary" as answer options. In follow-up questions, respondents are asked about their assigned sex at birth, and to confirm if it differs from the previous answer. NHIS data are collected throughout the year, so information on how this revised survey worked and how respondents answered the questions will not be available until 2024.

Two-Step-Measure Approach for Transgender Status and Current Categorical Gender

A two-step approach is commonly used to collect data on gender. Two questions are used in this approach, with the first asking the respondent about their reported sex at birth and the second asking about their current gender. The first question typically limits options to male or female, aligning with how sex is and has been assigned at birth. When this response is combined with the response to the second question—the respondent's current gender identity—the two measures can be used to infer transgender status. For example, the Australian Census uses the gender measure in conjunction with the sex assigned at birth measure, as shown in **figure 3** (next page). The two measures are combined to derive transgender status, as illustrated in **figure 4** (next page).

TABLE 1

Summary Reconstruction of the 2023 National Health Interview Survey Questions

QUESTION TEXT	VARIABLE NAME	RESPONSES	INTERVIEW NOTES
For this next question you may select more than one answer. Do you currently describe yourself as male, female, transgender, nonbinary, or another gender?	GENDER_A	1 Male 2 Female 3 Transgender 4 Nonbinary 5 Another gender 7 Refused 9 Don't Know	
If the respondent selects option 1 (Male) or 2 (Female) only, they are asked the following question:			
Is [GENDER_A] the sex you were assigned at birth, on your original birth certificate?	ASATB1_A	1 Yes 2 No 3 Refused 4 Don't know	
If the person selects more than one answer or selects option 3 (Transgender), 4 (Nonbinary), 7 (Refused), or 9 (Don't know), they are asked the following question:			
What sex were you assigned at birth, on your original birth certificate?	ASATB2_A	1 Male 2 Female 3 Refused 9 Don't know	
If the person selects option 5 (Another gender), they are asked to write in their gender:			
What term do you use to describe your gender?	GENDSPEC_A	Verbatim 97 Refused 99 Don't know	
In all three cases, if the answers to the questions do not match, the respondent is asked to confirm the discrepancy, and the data are recorded as the respondent answered.			
Just to confirm, your sex assigned at birth is [GENDER_A] and [ASATB1_A/ ASATB2_A/GENDSPEC_A]. Is that correct?	GICHECK_A	1 Yes 2 No 7 Refused 9 Don't know	(For brevity, *we* only include one of the more than 25 options included in the NHIS codebook.) If [GENDER _A] IN (2,3,4), fill "you describe yourself as female, transgender, and nonbinary"

Source: "National Health Interview Survey: 2023 NHIS," Centers for Disease Control and Prevention, National Center for Health Statistics, last reviewed July 5, 2023, https://www.cdc.gov/nchs/nhis/2023nhis.htm.

FIGURE 3

Sample Sex Recorded at Birth Question from 2021 Australian Census

What was [your/Person's name/their] sex recorded at birth?

Please [tick/mark/select] one box.

☐ Male

☐ Female

☐ Another term (please specify)

Source: Australian Bureau of Statistics, *Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables* (Belconnen, AUS: ABS, 2020), https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release#gender.

FIGURE 4

The Cisgender and Trans and Gender Diverse Derivation Matrix, Two-Step Method from the Australian Bureau of Statistics

Gender question response	Sex recorded at birth question response		
	Male	**Female**	**Another Term***
Man or male	Cis	Trans	Inadequately described
Woman or female	Trans	Cis	Inadequately described
Non-binary	Trans	Trans	Inadequately described
Different term	Trans	Trans	Inadequately described
Prefer not to answer	Inadequately described	Inadequately described	Inadequately described

*Responses to the sex recorded at birth question of 'Another term' provides insufficient information to enable accurate derivation of cis or trans. Where a person has preferred not to answer a gender question, an accurate cis or trans derivation is also not possible.

Source: Australian Bureau of Statistics, *Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables* (Belconnen, AUS: ABS, 2020), table 8, https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release#gender.

When the two-step approach uses a gender measure that is inclusive of nonbinary people, as in the Australian Census example, it can be an efficient and accurate way to capture transgender status and gender identity. However, the research design principles discussed above should still be considered. Some transgender people, for example, consider it offensive to be asked about sex assigned at birth, resulting in lower response rates or inaccurate data collection. Transparency about data use, research goals, and why transgender status is needed can help encourage representative participation.

The two-step approach has been adopted by several large-scale survey efforts in the US, but there is still ample room for improvement in the language used, the design of the questions, and the definitions of identities. In the US, available options in the first question are typically male or female. The respondents are then asked their current gender identity, with options often limited to male, female, and transgender. If an individual selects male or female in response to the second question, and this differs from the response to the first question on sex at birth, the interviewer may ask a follow-up question to confirm that the person's sex at birth and current gender identity are different. The National Crime Victimization Survey (**figure 5**) and the Census Bureau's Household Pulse Survey (**figure 6**) are examples of this two-step approach (see also UCLA Center for Health Policy Research [2018] and NIAID [2023]).

FIGURE 5
The National Crime Victimization Survey, Two-Step Approach

Source: US Department of Justice, Bureau of Justice Statistics, "National Crime Victimization Survey: NCVS-1 Basic Screen Questionnaire," implementation date July 1, 2019, https://bjs.ojp.gov/content/pub/pdf/ncvs20_bsq.pdf.

FIGURE 6
Census Bureau's Household Pulse Survey, Two-Step Approach

Source: Thom File and Jason-Harold Lee, "Phase 3.2 of Census Bureau Survey Questions Now Include SOGI, Child Tax Credit, COVID Vaccination of Children," US Census Bureau, August 5, 2021, https://www.census.gov/library/stories/2021/08/household-pulse-survey-updates-sex-question-now-asks-sexual-orientation-and-gender-identity.html.

FIGURE 7

National Academies of Sciences, Engineering, and Medicine's Recommendation for Asking Questions about Sex and Gender Identity

RECOMMENDATION 4: The panel recommends that the National Institutes of Health use the following pair of questions for assessing sex assigned at birth and gender identity:

Q1: What sex were you assigned at birth, on your original birth certificate?
○ Female
○ Male
(Don't know)
(Prefer not to answer)

Q2: What is your current gender? [Mark only one]
○ Female
○ Male
○ Transgender
○ [If respondent is AIAN:] Two-Spirit
○ I use a different term: [free text]
(Don't know)
(Prefer not to answer)

Source: National Academies of Sciences, Engineering, and Medicine, *Measuring Sex, Gender Identity, and Sexual Orientation* (Washington, DC: National Academies Press, 2022).

FIGURE 8

Biden Administration's Recommendation for Asking Questions about Sex and Gender Identity

Q1. What sex were you assigned at birth, on your original birth certificate?
☐ Female
☐ Male

Q2. How do you currently describe yourself (mark all that apply)?
☐ Female
☐ Male
☐ Transgender
☐ I use a different term [free-text]

Q3. Just to confirm, you were assigned {FILL} at birth and now you describe yourself as {FILL}. Is that correct?[8]
☐ Yes
☐ No <skip back to Q1 and/or Q2 to correct>

Source: White House, "Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys" (Washington, DC: White House, 2023), https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf.

NASEM (**figure 7**) and the Biden administration both recommend following a two-step approach when asking about gender identity (**figure 8**). The NASEM report also recommends breaking out a separate "Two-Spirit" option for people who identify as American Indian or Alaska Native earlier in the survey.

The Behavioral Risk Factor Surveillance System (BRFSS),[24] an annual survey conducted by the CDC, first asks the respondents their sex at birth and provides four options: "Male," "Female," "Don't know/ Not sure," and "Refused." If the respondent chooses the "Don't know/Not sure" or "Refused" option, they are offered a follow-up question that asks whether the respondent considers themself transgender, with six separate options (see **table 2,** next page).[25]

Many of these US examples offer "transgender" as a survey response option to the gender question. However, it is important to note that the word *transgender* is an adjective, not a noun; in other words, the word itself does not describe a gender but a person whose gender assignment at birth does not match their current gender identity (as illustrated in figure 4). Thus, a transgender woman *is* a woman, a transgender man *is* a man, and some transgender people who fall outside this binary may want to be identified only as a transgender person. Transgender

psychologist Devon Price offers an analogy (which they self-described as "flawed") of asking survey respondents about their religious affiliation.[26] Price offers the following list of possible responses to such a question:

1. Protestant   3. Muslim   5. I converted to
2. Catholic   4. Jewish   my religion

Price notes: "Listing 'I converted to my religion' as a religious identity option is like listing 'Transgender' as a gender option. In this context, 'Transgender' *is an answer to a question that hasn't been asked*."[27]

Gender questions that offer three options—male, female, transgender—are conflating gender assignment and a limited aspect of current gender identity. Many of these types of survey questions also conflate biological sex and gender terminology. The terms *male* and *female* refer to sex, while the terms *man* and *woman* refer to gender. But, as NASEM notes, "most people do not recognize a conceptional distinction between sex terminology and gender terminology, which is likely both a cause and consequence of continued conceptual conflation and inconsistent use of terminology in data collection and everyday life" (NASEM 2022, 39). In general, data users should seek to apply the terms as precisely as possible and to make clear what data are being collected and why.

TABLE 2
2021 BRFSS Survey Questions about Gender Identity

QUESTION NUMBER	QUESTION TEXT	VARIABLE NAME	RESPONSES	INTERVIEW NOTES
MSAB.01	What was your sex at birth? Was it male or female?	BIRTHSEX	1 Male 2 Female 7 Don't know/Not sure 9 Refused	This question refers to the original birth certificate of the respondent. It does not refer to amended birth certificates.
If BIRTHSEX does not equal 1 (Male) or 2 (Female), continue to question MSOGI.02				
MSOGI.02	Do you consider yourself to be transgender?	TRNSGNDR	1 Yes, Transgender, male-to-female 2 Yes, Transgender, female to male 3 Yes, Transgender, gender nonconforming 4 No 7 Don't know/Not sure 9 Refused	Read if necessary: Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels woman would be transgender. Some transgender people change their physical appearance so that it matches their internal gender identity. Some transgender people take hormones and some have surgery. A transgender person may be of any sexual orientation—straight, gay, lesbian, or bisexual. If asked about definition of gender non-conforming: Some people think of themselves as gender non-conforming when they do not identify only as a man or only as a woman. If yes, ask Do you consider yourself to be 1. male-to-female, 2. female-to-male, or 3. gender non-conforming? Please say the number before the text response. Respondent can answer with either the number or the text/word.

Source: Centers for Disease Control and Prevention, "2021 BRFSS Questionnaire" (Atlanta: CDC, 2022), https://www.cdc.gov/brfss/questionnaires/pdf-ques/2021-BRFSS-Questionnaire-1-19-2022-508.pdf.

Note: Questionnaires dating back to 1984 can be found on the CDC website at https://www.cdc.gov/brfss/questionnaires/. Also see Centers for Medicare & Medicaid Services, "Behavioral Risk Factor Surveillance Systems (BRFSS)," accessed September 21, 2023, https://www.cms.gov/files/document/sgm-clearinghouse-brfss-updated.pdf.

Overall, compared with the Australian Census measure and the new NHIS, most large-scale US surveys do not capture a complete and accurate picture of the transgender population. Some binary transgender people may choose a male or female gender or the transgender option, and some nonbinary people may or may not self-identify as transgender. These results illustrate the importance of using terms precisely and correctly.

Even when the two-step approach is implemented appropriately, several challenges may affect data collection in the near and long term. Some people may be transitioning (though not necessarily physically), meaning that the gender option they choose today may not be the same one they choose tomorrow. In surveys that use a limited set of options—particularly with no write-in option— people with genderfluid identities are erased.

Additionally, none of the methods mentioned may make sense in the future as states' policies around gender continues to diverge (**figure 9**). As of early 2023, 13 states plus the District of Columbia allowed people to put a third gender category or *X* marker on their birth certificates,[28] which will make the first question in the two-step approach moot when those children reach survey age. California and New Jersey, for example, adopted a third gender category for birth certificates in 2019. By comparison, in April 2022, Oklahoma passed a law that forbids nonbinary gender markers on birth certificates.[29]

Nonbinary Birth Certificate Laws by State
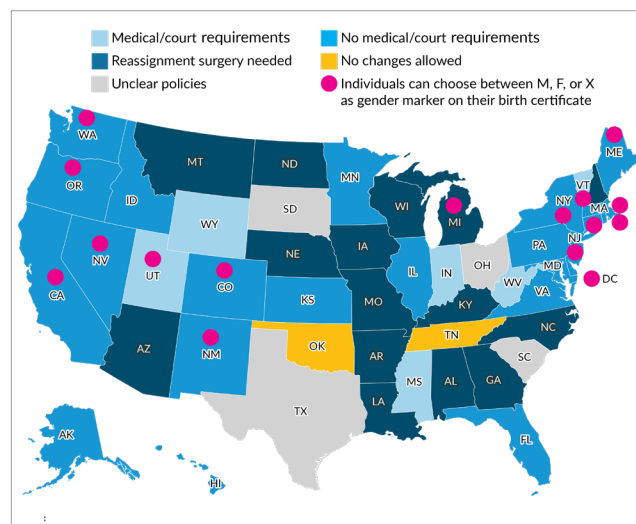
Source: "Non-Binary Birth Certificates and State IDs: Full Guide," US Birth Certificates, accessed September 21, 2023, https://www.usbirthcertificates.com/articles/gender-neutral-birth-certificates-states.

In any case, Nancy Bates, a retired US Census Bureau senior research methodologist, explained that despite these challenges, data practitioners should still go forward with asking questions about gender: "The reason 'they are not perfect' is not a reason not to use them." Multiple people we spoke with supported the idea that additional survey testing and experimentation are needed to identify the best ways to ask SOGI questions, to process the data, and, ultimately, to communicate the results.

Surveys Specific to Transgender People

We close this section by looking at two of the larger US surveys directed specifically to people who are transgender to see how questions about gender are framed and what lessons they can offer large surveys designed for a general audience. At this time, the 2015 US Transgender Survey (USTS) is the largest survey to examine the experience of transgender people in the US, with nearly 28,000 respondents (**figure 10,** next page). The 2011 National Transgender Discrimination Survey (NTDS) included more than 6,000 transgender and gender-nonconforming study participants across the country (**figure 11,** next page).

Both surveys started with a straightforward question: "Do you think of yourself as transgender?" (USTS) and "Do you consider yourself to be transgender/gender non-conforming in any way?" (NTDS). The USTS then asked respondents eight additional questions about their gender identity to include anyone who may fit within the survey criteria but may have responded "No" to the initial question. Any respondent who also answered "No" to all the subsequent questions was excluded from the sample. The NTDS took a more straightforward route: respondents who answered "No" to the first question were excluded from the resulting sample, though there were some allowances (based on follow-up questions) for people who did not answer the question. Both surveys then implemented some form of a two-step gender question, first asking about sex assigned at birth and then about current gender identity. The USTS offered a long multiple-selection list of 25 identity labels, spanning gender identity, gender expression, sex characteristics, and other labels, as well as a write-in option.[30] The NTDS opted for a shorter list with binary options, a part-time category, and a free-text option to express nonbinary gender identities.

In these community-specific cases, the direct screening questions and expanded/write-in identity options provide researchers and other groups unparalleled insight into gender diversity within the transgender community. In seeking to collect data about the

transgender and gender-nonconforming population, these survey questions assume a level of familiarity with terms relating to gender and sexual orientation that the general population may lack. Furthermore, words and phrases used to describe people and communities change over time—both in specific areas and across the nation (or world)—for a wide variety of reasons. While not a panacea for addressing these trends and changes in conventions, consulting and working with advocacy groups and specific communities more generally can help researchers develop better surveys, resulting in more accurate data.

The 2015 US Transgender Survey

PLEASE READ AND RESPOND CAREFULLY TO THE FOLLOWING QUESTIONS.

This is a survey for people who are transgender, trans, or non-binary. It doesn't matter if you have transitioned gender or if you plan to. To see if this survey is for you, please answer the following questions.

1.10 Do you think of yourself as transgender? *[Must answer to continue.]*

No

Yes

1.11 Do you identify as more than one gender or as no gender (such as genderqueer or non-binary)? *[Must answer to continue.]*

No

Yes

1.12 Do you currently live full-time in a gender that is different from the one assigned to you at birth? *[Must answer to continue.]*

No *[Skip to 1.14]*

Yes

1.13 How old were you when you started to live full-time in a gender that is different from the one assigned to you at birth? *[Only respondents who selected "Yes" in response to 1.12 received this question.]*

[Drop-down list of all ages from "1" through "99," and "100 and above" as final response choice]

1.14 Someday do you want to live full-time in a gender that is different from the one assigned to you at birth? *[Respondents who selected "No" in response to 1.12 must answer to continue.]*

No *[Skip to 1.16]*

Yes

Not sure

Source: S. E. James, J. L. Herman, S. Rankin, M. Keisling, L. Mottet, and M. Anafi, *The Report of the 2015 U.S. Transgender Survey* (Washington, DC: National Center for Transgender Equality, 2016).

The 2011 National Transgender Discrimination Survey

The Questionnaire

"Transgender/gender non-conforming" describes people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth.

1. Do you consider yourself to be transgender/gender non-conforming in any way?

❍ Yes
❍ No. If no, do NOT continue.

Anyone who answered "No" to this first question was excluded from our sample. Anyone who left this question blank was included or excluded based on their answers to other questions. We intentionally included respondents in the sample who did not identify as transgender because we wanted to include gender non-conforming people. We understood that by gathering data on gender identity/expression across a broad spectrum, and posing questions in a manner that would make it possible to distinguish transgender and gender non-conforming respondents for analysis, we could discover and report on differences across the spectrum when considerable or relevant.

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

❍ Male
❍ Female

See note after question 3.

3. What is your primary gender identity today?

❍ Male/Man
❍ Female/Woman
❍ Part time as one gender, part time as another
❍ A gender not listed here, please specify _____

Source: Jaime M. Grant, Lisa A. Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling, *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey* (Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011), https://transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf.

Asking Questions about Sexual Orientation

Sexual orientation consists of three dimensions:

- **sexual identification:** the sexual orientation that one identifies with or uses to describe themself
- **sexual behavior:** the sex or gender of one's sexual partners
- **sexual attraction:** the sex or gender of the individuals one feels emotionally, romantically, or physically attracted to

While these dimensions are interconnected, they are not always perfectly aligned, and the level of overlap or alignment can vary. Sexual identification, for example, can evolve over time, and an individual's sexual behavior can fluctuate or be influenced by various factors. When conducting a survey (or using survey data more generally), it is important for researchers to know which dimension(s) they are interested in measuring when asking questions about sexual orientation. Knowing which dimension(s)

of sexual orientation they are seeking to better understand can result in better data collection and, ultimately, better analysis and recommendations.

Many existing large-scale surveys that ask about gender identity also ask about sexual identity. The BRFSS, National Crime Victimization Survey, NHIS, and Census Bureau's Household Pulse Survey all ask the same kind of questions, split separately for people who identify as men and who identify as women. In the National Crime Victimization Survey, for example, people who identify as men are provided with three specific sexual orientation options ("Gay"; "Straight, that is, not gay"; and "Bisexual") and three other catchall options ("Something else"; "I don't know the answer"; and "Refused"); people who identify as women are asked a very similar question, though the first option is listed as "Lesbian or Gay." In both cases, *straight* is the only term explicitly defined in the question, and it is defined as the negation of being gay (**figure 12**).

FIGURE 12

The National Crime Victimization Survey Question about Sexual Identity

Source: US Department of Justice, Bureau of Justice Statistics, "National Crime Victimization Survey: NCVS-1 Basic Screen Questionnaire," implementation date July 1, 2019, https://bjs.ojp.gov/content/pub/pdf/ncvs20_bsq.pdf.

FIGURE 13

National Academies of Sciences, Engineering, and Medicine Recommended Sexual Identity Question

> Which of the following best represents how you think of yourself? [Select ONE]:
> ○ Lesbian or gay
> ○ Straight, that is, not gay or lesbian
> ○ Bisexual
> ○ [If respondent is AIAN:] Two-Spirit
> ○ I use a different term [free-text]
> (Don't know)
> (Prefer not to answer)

Source: National Academies of Sciences, Engineering, and Medicine, *Measuring Sex, Gender Identity, and Sexual Orientation* (Washington, DC: National Academies Press, 2022), https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation.

FIGURE 14

The White House Recommended Sexual Identity Question

> SEXUAL ORIENTATION
>
> Q1. Which of the following best represents how you think of yourself?
> ☐ Gay or lesbian
> ☐ Straight, that is not gay or lesbian
> ☐ Bisexual
> ☐ I use a different term [free-text]
> ☐ I don't know

Source: White House, "Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys" (Washington, DC: White House, 2023), https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf.

The official recommendations from the NASEM report (**figure 13**) and the White House (**figure 14**) collapse these two questions into a single question, with the first option listed as "Lesbian or gay" or "Gay or lesbian." Both provide a write-in category, but instead of the diminishing "Other" label, they use a more affirming "I use a different term [free-text]" label for that option. The NASEM report also includes the "Two-Spirit" option for those who identify as American Indian or Alaska Native in an earlier question on race.

When we spoke to Nancy Bates about providing a recommendation for ordering the options in the NASEM report, she said there is not enough research to suggest a specific best practice, but a lack of general knowledge about some of these sexual identities would make alphabetical ordering—where *bisexual* would appear at the top of the list—confusing for many survey respondents.[31] Kevin Guyan reinforces this sentiment in his book *Queer Data:* "Several scholars have noted a lack of familiarity or identification with terms such as 'heterosexual' and 'straight' among heterosexual/straight survey respondents" (Guyan 2022, 56). Again, survey size and scope may be a helpful guidepost here; a small-scale survey for LGBTQIA+ people may not have the same kind of language considerations, and an alphabetic ordering of response options may be sufficient.

Short Lists, Long Lists, and Open-Ended Survey Questions

The list of response options presented is the core component of survey design and affects both what data the researcher can collect and how respondents approach completing the survey. Multiple methodological strategies can be used to enable researchers to capture a wider range of responses, with the two most common being a long list of options (e.g., offered as multiple-selection checkboxes or single-selection radio buttons) and an open-ended option that allows respondents to write out their response. Another strategy is providing a short list of options. Consequently, a trade-off exists: a long list of identities or an open-ended option can be more representative, whereas a short list can decrease response time, increase the response rate, and make analyzing the data easier.

Our interviews with experts suggest that, in most cases, shorter lists are preferred. Although longer lists can offer more representation, they also generate the following four primary issues:

1. **Increased possibility of error.** Additional subcategories within questions can lead to misclassification and increased statistical noise. Members of the majority population may not be familiar with the more specific response options and misinterpret them, resulting in "false positives"

that bias results (Guyan 2022; Michaels et al. 2017; Ridolfo, Miller, and Maitland 2012). Sexual identity questions are particularly susceptible to false positives when the respondent is unable to select multiple categories. In smaller surveys or surveys directed toward specific communities or groups, however, longer lists may allow for a wider range of responses and provide the nuance that often exists in sociodemographic survey data.

2. **Aggregation of results into larger categories.** To protect privacy and ensure a large enough sample size, smaller groups of gender and sexual orientation identities are often aggregated into larger categories. People who select specific gender identities such as "agender" or "genderqueer" in a survey, for example, are often subsequently collapsed into a "nonbinary/gender-nonconforming" or even "other" category in later analysis. In practice, this erases people who originally had the opportunity to select their unique identity from being represented, even if their privacy is not always guaranteed (NASEM 2022). That being said, aggregating people into groups that have been traditionally discriminated against may help support efforts to pursue equity and equality for those groups and give them a magnified voice. In his book *Queer Data*, in a section based on Weinrich and colleagues (1993), Guyan argues, "Depending on the spread of responses, analysis can find a middle ground between the crude binary of heterosexual/homosexual and a potentially unwieldy list of twenty response options" (Guyan 2022, 117).

3. **Failure to provide additional insight.** Research suggests that when presented with long lists of sexual identities, the vast majority of respondents choose "Straight," "Lesbian," "Gay," or "Bisexual" (see, for example, Bates, García Trejo, and Vines [2019] and Virgile et al. [2022]). Thus, additional categories can make the survey longer and more difficult to answer, without resulting in significantly more variation in responses. We also heard in our interviews that, anecdotally,

some survey respondents may choose the larger, more "majority" categories to ensure that their responses are not omitted from analysis because of inadequate number of responses. Although a longer list of options can provide more representation opportunities, longer surveys mean longer response times, which can result in lower response rates and smaller datasets[32] (see, for example, Rolstad, Adler, and Rydén [2011]). For groups that are already small, losing survey respondents reduces the sample size and thus analysts' ability to draw statistically meaningful conclusions. But best practices likely depend on the person or group conducting the survey: a survey from a local LGBTQIA+ advocacy organization may be perceived differently than a survey from the US Census Bureau.

4. **Question refusal.** In our interview, Marcus Berzofsky of RTI International wondered how people perceive lists of different lengths: "From the respondent's perspective, is it worse if I had seen a list of 20 and still didn't see how I identify? Or if I saw a list of four and didn't see it?" With a long list, Berzofsky noted, a respondent may be offended if their identity is not listed, as it suggests the survey made an effort but still excluded them. This erasure could lead respondents to refuse to answer the questions. Stuart Michael, senior research scientist at NORC at the University of Chicago, summarized this discussion, noting that "in survey research, you don't really need to have every single nuanced category that people use within their everyday life and community."

When implementing a short list, researchers should consider how the response options are ordered. Here again, there are trade-offs, and the best course of action may depend on the survey and the target audience. Placing a "straight/heterosexual" option at the top of the list of responses to a question about sexual identity, for example, may suggest a hierarchy or norm, while alphabetically ordered options may be easier to navigate.

When adding an "other" category, researchers should consider alternative words or phrases that do not reinforce the idea that identities *not* represented in the list of options are less accepted or normal. Instead, an open-ended text box with a prompt, such as "I identify as," "I use a different term," or "I am," offers more inclusive options, explicitly eliminating the connotation that a person's identity is a choice.

Open-ended questions can sometimes seem like a compromise between a long and a short list because they provide a write-in option, but this approach still comes with trade-offs. On the one hand, open-ended questions offer respondents the ability to be as detailed as they wish; on the other hand, they require more time and energy on the part of analysts to parse and categorize the responses.

For specific target audiences who may not be familiar with certain terms, open-ended questions can offer more comfort. Kristin Schilt told us that in her research with older adults, the team often opts for an open-ended question on sexual orientation, because they think that people over 70 have less familiarity with response categories such as queer or asexual. According to Schilt, "Those categories haven't been in circulation on mainstream survey instruments for very long." She then added, "But we don't know if our assumption will be correct—we will find out." The process of wading through open-ended responses, however, can be onerous. Amy O'Hara, formerly of the US Census Bureau and now a research professor at the Georgetown University Massive Data Institute, expressed some apprehension about the open-ended option in our conversation: "As a data person, having those write-ins means that you're going to have somebody or some algorithm try to code them, and that's only going to be as good as what you put into it."

Research suggests that answers to open-ended questions—particularly for questions around sexual identity—can yield extraneous responses. In their analysis of the 2020 Census Barriers, Attitudes, and Motivators Survey, Bates, García Trejo, and Vines

(2019) found that of the more than 200 nonblank write-in answers, only 16 percent represented sexual minority groups, such as "queer," "pansexual," or "asexual." The rest included write-ins, such as "normal," "not your business," or "Christian male." Similarly, using pooled data from three separate US Census surveys, Virgile and colleagues (2022) found that 21 percent of open-ended responses were sexual minority identities; 14 percent were variations on "straight" or "heterosexual"; 17 percent were blank or vague; and 20 percent were considered protest or hard refusal–type answers, such as "Christian," "child of God," "womanizer," or "human" (see also Otero Class, Meyers, and Berger [2022]).

By comparison, the Pew Research Center found that changing a survey question about gender from "Were you born male or female?" to "Do you describe yourself as a man, a woman, or in some other way?" yielded extremely few of these extraneous responses—only 4 out of more than 2,600 responses, or less than 0.2 percent of the sample.[33] Similarly, the 2023 National LGBTQ+ Women's Community Survey,[34] which specifically sought LGBTQ+ women and femmes[35] for the survey sample, found very few of these kinds of responses to the open-ended questions about gender identity. As LGBTQIA+ identities face further politicization and vilification in the current political culture, it is possible that protest or hard-refusal answers will increase.

No matter the type of question—whether a long list, a short list, or open ended—how people select options should also be considered. A survey might enable respondents to select a single option (usually presented as a radio button or an item on a drop-down menu) or multiple options (usually presented as a set of checkboxes). Some LGBTQIA+ people may feel strongly that they fall within a specifically defined identity, such as a "gay man" or a "bisexual woman." But for many others, particularly queer-identifying individuals and gender-nonconforming people, categorical labels are not a good fit.

The very ethos of discrete data collection conflicts with the non-normative and nonbinary frames through which many LGBTQIA+ people identify and live their lives. Researchers should understand that discrete labels cannot capture the full breadth and variety of LGBTQIA+ identity and experience. Surveys could provide a multiple-category option; the Census Bureau, for example, derives a "more than one race" category by combining answers for people who choose more than one race in its surveys.[36] In any case, categorical labels can have consequences, whether intentional or not, so researchers must recognize that the trade-offs between offering a wider range of response options and optimizing survey response rates may depend on the type and purpose of the survey.

There are clear trade-offs between short lists, long lists, and open-ended questions. How people see themselves in the survey or final data, how the questions affect survey response time and rates, how those data will ultimately be used, and what type of survey is conducted are all factors to be considered when designing question formats. In the end, more research and testing are needed across different groups and communities to better inform survey practice.

Language Shifts and Translation

When thinking about large-scale or cross-national research, understanding differences in meaning and semantics both within and across languages can be especially important. Over recent decades, several words related to LGBTQIA+ identities have shifted in meaning even within the English language. The word *queer*, for example, was used as a slur to attack homosexual identity as unusual, wrong, or inferior through much of the 20th century. But when the word was reclaimed, as "a term of power" in the early 1990s, as linguist Gregory Coles writes, it became a "category term" rather than a "derogatory term" (Coles 2016).[37] That being said, not everyone who identifies

as queer in the modern parlance necessarily prefers the term. In deciding to use the word *queer* in its reporting, NPR explicitly noted that older generations may find the word painful, pejorative, or insulting while younger generations are more likely to embrace it.[38]

Translating survey questions about sexuality from English to other languages also presents unique challenges because of the inherent cultural and linguistic nuances involved. Terms, expressions, attitudes, and cultural context related to sexual orientation, gender identity, and sexual practices may differ between English-speaking and non-English-speaking communities, requiring careful consideration to ensure accurate translation.[39] Some concepts may not have direct English equivalents in other languages, which necessitates the adaptation and contextualization of questions to capture the intended meaning. Additionally, language structures and syntax can differ, making it crucial to ensure that questions are linguistically appropriate, clear, and comprehensible to respondents. As Chloe Schwenke, president and founder of the Center for Values in International Development, said: "We're not trying to impose a Western definition of what is LGBTQ … but just to be able to find commonalities is an important piece of the work that needs to be done."

In English, pronouns (e.g., he/him/she/her) are associated with different genders. Other languages, such as Spanish and French, classify nouns as masculine or feminine (e.g., "el sol" and "la luna") and traditionally indicate people's gender by ending a word in either -a for women or -o for men (e.g., Latina and Latino). When describing a mixed-gender group, these languages tend to ascribe the masculine plural form, but the use of the -e or -x suffix for nonbinary people (e.g., Latine and Latinx) or to neutrally address a mixed-gender group has increased in the last several years. Further complicating matters, words that are masculine in one language may be feminine in another language.

Other languages similarly have different approaches to gender. In Urdu, for example, gender is indicated in the verb, not the pronoun: "he walks" is "who chalta hai" and "she walks" is "who chalti hai." The pronoun "who" is genderless. And in some Indigenous communities, the term *Two Spirit* refers to "a person who identifies as having both a masculine and a feminine spirit, and it is used by some Indigenous people to describe their sexual, gender and/or spiritual identity."[40] Chrystos, a Two-Spirit poet from the Menominee nation, told author Leslie Feinberg: "Most of the nations that I know of traditionally had more than two genders. It varies from tribe to tribe. The concept of Two-Spiritedness is a rather rough translation into English of that idea. I think the English language is rigid, and the thought patterns that form it are rigid, so that gender also becomes rigid" (Feinberg 1996, 27).

When translating surveys into another language, it is worth taking the time to understand how that language treats gender identities and sexual orientations. Translation from English to Spanish, for example, is not necessarily a one-to-one transformation. In their survey, Stuart Michaels and colleagues (2017) used different terms for sexual identity questions in English and Spanish. For English-speaking respondents, they used the phrase "Straight, that is, not (lesbian or) gay." For Spanish-speaking respondents, they translated the word *straight* to *heterosexual* ("Heterosexual, o sea, no gay o lesbiana"). While the vast majority of English speakers in their sample were able to answer this sexual identity question correctly, almost 60 percent of the non-LGBTQIA+ Spanish speakers did not select the

"heterosexual" option. Following further discussions with survey participants, the authors found that the Spanish-speaking respondents had "difficulties understanding the term 'heterosexual,' leading to their choosing 'something else' or saying that they didn't know how to answer."[41]

As languages continue to evolve, words and phrases could change to incorporate different identities. The increased use of the words *Latinx* and *Latine* as alternatives to *Latino/Latina*, for example, avoids the nonbinary gender suffix[42] (Schwabish and Feng 2021), as does the shift in Latin America from the word *queer* to *cuir*.[43]

Generally, in large government-led surveys, the terms used reflect the nation's structures and institutions that have placed white people (typically cisgender men) in positions of power and decisionmaking. Overcoming these challenges in translating may require using open-ended options to allow survey respondents to self-identify. Federal survey organizations like the Census Bureau are not likely to use separate question structures for different languages, but a smaller survey or a community-based organization conducting a local survey could create tailored questions in different languages.

Language is complicated, nuanced, and forever evolving. There are no objective solutions for finding the right words or phrases to describe people and their identities. Although we do not focus on qualitative data collection or research methods here, engaging with people and communities can help researchers better understand what questions to ask and how (**box 2**).

BOX 2: STRENGTHENING RESEARCH BY ENGAGING COMMUNITY

Community engagement can take many forms, but at a high level, it is the explicit inclusion of community members as collaborators, reviewers, or participants in the research process (Sankofa, Daly, and Falkenburger 2021). Incorporating community engagement in the research process for SOGI data collection can ground the data in the lived realities of those communities.

Community engagement can take place in four main phases: contextualizing the research questions (e.g., understanding the issues and how to engage communities of interest); survey design (e.g., knowing what questions to ask and how); survey implementation (e.g., outreach and survey administration); and data analysis and dissemination (e.g., interpreting and sharing results) (Harrison et al. 2021).

Connecting with advocacy groups, nonprofit organizations, or other community-based organizations offers one way to tap into people's knowledge and experience. Community advisory boards—groups composed of community members who share an identity, geography, history, or other characteristics or experiences—can also become an integral part of a project team (Arnos et al. 2021). Building and promoting a diverse research team or workforce is another way to bring a variety of perspectives and lived experiences directly into the work.

For SOGI data, community engagement can be particularly useful in *interpreting* survey results and ensuring that there is proper expertise and cultural competency to understand their nuance. As Meghan Maury at the Office of Science and Technology Policy highlighted in our interview, "Having regular, consistent communications with community members about their priorities for how data is collected and disseminated" can help make findings accessible for that group and expand the impact of the research.

The appropriate level of community engagement will depend on the project's goals, scale, capacity, and limitations. Community engagement requires time and resources to build trust and create a sustainable partnership. This additional time can pay dividends by ensuring that the data collected are robust, accurate, and effective. For more information about community engagement, we recommend the Urban Institute report *Community-Engaged Surveys: From Research Design to Analysis and Dissemination*.

Incorporating Trauma-Informed Care in Survey Response

Trauma may be defined as "a response to anything that's overwhelming, that happens too much, too fast, too soon, or too long—coupled with a lack of protection or support."[44] Unfortunately, much of the general population has experienced some form of trauma, either as one-time events or through cumulative harms over time. In the US, groups that have been subjected to systemic discrimination and marginality have a uniquely traumatizing experience (Carter, Gibbons, and Beach 2021; Estrada et al. 2022; Green, Price, and Dorison 2022; Peterson et al. 2021). As the American Psychiatric Association notes, "LGBTQ populations have unique lived experiences partly defined by adversity and discrimination,"[45] and many of these experiences may be directly traumatic, including experiences of familial rejection. Incorporating *trauma-informed research practices*

can help LGBTQIA+ people to more willingly engage with survey instruments and minimize the potential for harm (Jaffe et al. 2015). The Center of Excellence on LGBTQ+ Behavioral Health Equity defines six key principles of trauma-informed care for LGBTQ+ people: safety, peer support, empowerment, trustworthiness and transparency, collaboration, and cultural responsiveness (Levenson, Craig, and Austin 2021). These principles translate well to the four key assumptions of applying trauma-informed care to research, as defined by Voith and colleagues (2020): realizing trauma impacts, recognizing signs of or potential for trauma among those involved in a research study, responding by integrating trauma knowledge, and resisting the possibility of retraumatization.

For general population surveys that only engage with LGBTQIA+ topics when collecting demographic data, considerations for how to respond to and support

possible trauma histories among individual respondents are minimal. In these surveys, it is more important to recognize systemic trauma (e.g., institutional discrimination, regular omission of nonbinary identities from demographic forms, etc.) that may affect how LGBTQIA+ people interact with questions about their identities. Targeted surveys that ask about specific experiences of harm among LGBTQIA+ people demand more robust application of trauma-informed principles. Qualitative and mixed-methods research incorporating trauma-informed practices are more expansive and emphasize the need for partnership,[46] but they are beyond the scope of this guide.

Trauma-informed survey research practices can respond to participants' fears of submitting data about their identity and then not being involved in the rest of the process. By actively incorporating plans for community-engaged data dissemination as part of a research approach that prioritizes participant trust and researcher transparency, researchers can start to address some of these anxieties (Edelman 2023). To ensure that data instruments are as conscientious as possible, research teams should participate in trauma-informed research training. Researchers should also consider team supports and minimizing trauma for researchers, especially if a survey instrument asks about violence or discrimination.

Ultimately, maximizing respondent comfort maximizes the likelihood of full participation, which strengthens the data (Saleh and Bista 2017). When conducting a survey instrument with LGBTQIA+ populations, researchers should keep the following four best practices in mind:

1. transparent and robust informed consent
2. disclaimers for sensitive or potentially upsetting questions, with reiteration that participation is voluntary
3. provision of support resources as needed at the end of survey administration
4. culturally competent, representative question response options and survey administration practices

For detailed examples of how to implement these practices, we recommend *Trauma-Informed Socially Just Research Framework*, developed by Voith and colleagues (2022).

Proxy Reporting

For many large-scale surveys, proxy response—having one person respond for all eligible members of the family, household, or community—offers a useful way to reduce costs and time (Mathiowetz and Groves 1985). However, proxy responses can impair the quality of the data, depending on what is being collected and the complexity of the response options (Fulton et al. 2020). In the context of SOGI questions, there is little research on the effect of proxy reporting, including how sensitive or difficult respondents find the questions and whether proxies have the knowledge or even the willingness to answer the survey questions.

In a thorough report on proxy reporting, Holzberg and colleagues conducted 132 interviews in four cities in the US. They found that most proxy respondents did not have difficulty or sensitivity when reporting SOGI information. Respondents were willing to report SOGI information for themselves and other members of their household, with only one respondent refusing to answer. There was also a high level of agreement in responses when interviews were conducted in pairs. Overall, the authors suggest that "asking SOGI by proxy may be feasible in large-scale, general population surveys" (Holzberg et al. 2019, 904).

Their conclusion, however, comes with an important caveat. In the qualitative interviews and focus groups, some respondents noted that the questions might be sensitive for other survey respondents in the household—for example, "[My husband] would find the gay and lesbian, the transgender, and the [disability questions] sensitive ... He was

raised in Alabama as a Baptist." Others noted that they were unsure of the correct term or category to use—for example, one proxy respondent living in an LGBTQIA+ household reported that "they [others in the household] see sexuality [as] more fluid. They might answer it 'lesbian,' might answer 'bisexual.'" Altogether, quantitative results suggest little difference with using proxy reports, whereas qualitative results suggest that proxies could provide incorrect or misleading information.

When working with proxies, researchers should be aware that revealing information to or from the proxy may put the safety of another household member at risk. Interviewers and interview teams should be vigilant about the level of risk involved in asking sensitive identity questions and should use trauma-informed surveying methods if possible.
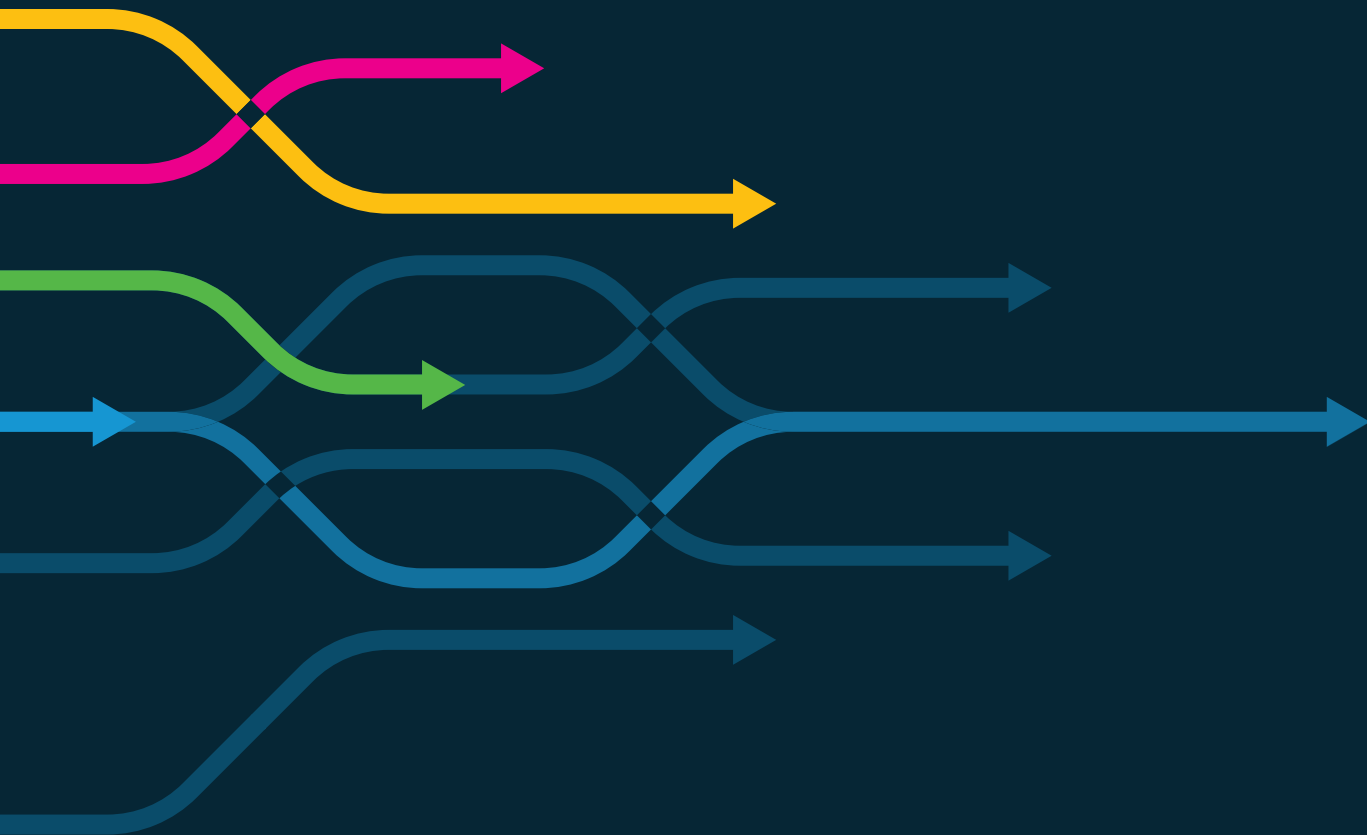
Data Analysis

Data Analysis

Analyzing SOGI data is like analyzing any other data. Researchers will need to make some key considerations and judgments, just as they would with any type of data they analyze. Our goal for this section is not to prescribe a set of instructions for different types of analysis but to highlight additional considerations that may be necessary when analyzing SOGI-specific data in different contexts.

Although we primarily focus on quantitative data in this guide, qualitative data should be incorporated into research when possible to complement the quantitative analysis. Qualitative data can help researchers understand the "cracks" in the quantitative data—the things that are not captured in the checklist of survey options. Qualitative data can also instill a greater sense of empathy by allowing both the researchers and stakeholders to better connect with the people and communities in question. Especially in the case of SOGI data collection, where existing survey categories may not be sufficient to capture the expansiveness of gender and sexual orientation, qualitative data can humanize the quantitative data and help provide additional perspective and representation.

Demographic Survey Data

SOGI data can often produce small sample sizes for gender minorities, which can pose many challenges to researchers' data analysis. Researchers may need to combine groups into larger categories to retain an appropriate sample size (e.g., collapsing response options to "cisgender" and "transgender and/or nonbinary" or "heterosexual" and "not heterosexual"), but they should be aware that variation may be lost in the process and should note it in the final analysis.

It is incumbent on researchers to read the survey codebook and understand exactly what questions were asked. Shortcutting or summarizing answers to survey questions should be done with care. If a survey asks respondents, "Do you or have you ever had sex with someone of your same sex?" reporting a single answer as "homosexual" may be incorrect, as the measure only asked about sexual behavior and not sexual identity. Researchers should be explicit about what the question asks, acknowledge the specific

language, and state any summary or proxy words/phrases used. This consideration is especially important when merging different datasets in which questions about gender or sexual orientation are asked differently and may have different implications.

Gender and sex are separate variables, and researchers should not conflate the two. Terms like *man* and *woman* refer to gender, while terms like *male* and *female* refer to sex. If the survey uses the terms *male* and *female*, the analysis results should be reported as such, instead of using terms like *man* and *woman*. Surveys often ask about gender but include "male" and "female" as response options.

Lastly, any question that results in missing data for gender minorities can have a greater effect on these groups during the imputation process, because imputations for small samples can distort aggregate summary statistics, such as means, medians, and variances (see, for example, Little and Rubin [2019]). William Jesdale at the UMass Chan Medical School found that *more than half* of respondents in the July–October 2021 Census Household Pulse survey who identified as transgender were attributable to the imputation method of sex at birth. Although nearly 4,000 people out of more than 300,000 survey respondents had their sex at birth imputed—accounting for 1 percent of the entire sample—the imputation overly affected estimates of the transgender population (Jesdale 2021a; Herman and O'Neill 2022). The analysis therefore suggests that the resulting counts of the transgender population in the Pulse survey were overestimated, and that more accurate estimates can be obtained using known data rather than data that relies on imputed sex at birth. Until additional research can be conducted on these surveys and imputation methodologies for SOGI data, Jesdale recommends restricting imputation to people with known sex at birth in analyses (for surveys that use that approach).[47]

Cleaning SOGI Survey Data

Data cleaning is the process of fixing or removing incorrect, corrupted, incorrectly formatted, duplicate, or incomplete data within a dataset. Several challenges can make cleaning SOGI data more difficult than cleaning other types of data:

- **Intersecting identities.** There are multiple components of sexual orientation (e.g., identity, sexual desire, emotional attraction, and behavior) and gender (e.g., identity and expression). The data should match the actual question—meaning the researcher may need to reframe the analysis or the communication of the analysis to accurately reflect the identities measured in the data.

- **The "other" category.** Many SOGI survey questions include an open-ended or "other" response option. Researchers need to be aware that using such data can be time consuming. Additionally, interpretation of these responses may be subjective, especially if aggregating them into larger groups. One strategy to increase the reliability of the open-ended response option is to have multiple people work independently to code the responses, and then create a consistent set of outcomes by working together (see, for example, O'Connor and Joffe [2020] and Braun and Clarke [2012]).

- **Splitting and lumping.** Splitting (disaggregating) or lumping (aggregating) identity groups can be difficult, because the process may require certain interpretation of identities. Again, there is no perfect answer to the question of when to split or lump responses; it will depend on the individual use case. Is the research seeking to make specific, statistically meaningful comparisons? If so, it may need larger groups. Is the research seeking to better understand the makeup of a local area or different gender/sexual orientation populations? If so, it may need smaller groups, while recognizing that, from a purely statistical perspective, drawing conclusions may not be possible. The NASEM report explicitly identifies these practices as

potentially problematic: "When this [lumping] occurs, although respondents may have initially had the opportunity to express their unique identity in data collection, the end result is that their voice is erased" (NASEM 2022, 67).

- **Evolution of language.** As survey language evolves over time to reflect current trends, groups, and understanding, researchers may need to consider how a new term relates to a past term. As we mentioned earlier, the word *queer* is a good example—although the word was reclaimed from being used as a slur in the early 1990s, because of its history, it is still not a preferred word for many people.

- **Cultural considerations.** In some cultures, there is no distinction between sex and gender, so respondents may interpret questions on gender differently. It also may not be possible to fully explain these differences within a survey. It is therefore worth considering how survey options may be interpreted differently in different languages. Most large-scale surveys in the US will be translated into Spanish, and researchers should include considerations to that effect. For smaller-scale surveys—especially those focusing on SOGI data—researchers should be aware to whom the survey is geared and how it may be translated into other languages.
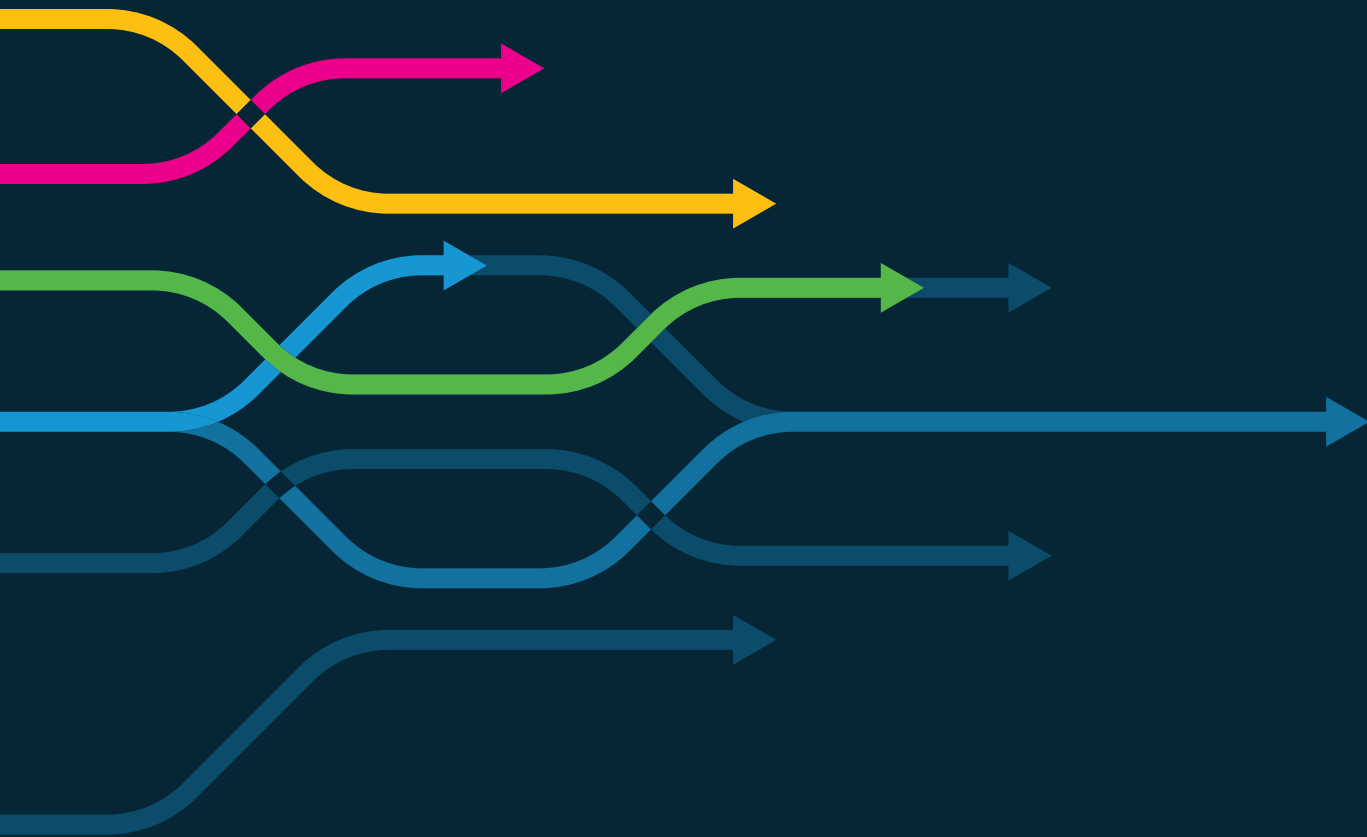
Part Five

Communication and Data Visualization

Communication and Data Visualization

With the collection and analysis completed, the final step is to visualize and communicate the work. There are five main considerations when communicating data, all of which are similar to those outlined in the other *Do No Harm Guide*s. However, unlike the data on race and ethnicity discussed in *Do No Harm Guide: Applying Equity Awareness in Data Visualization*, there is less evidence on how people are presenting broader SOGI categories—for better or for worse—likely because there is simply not enough data to be visualized. Here, we provide some general guidelines for each of the five considerations.

Color

Color is one of the most powerful pieces in the data visualization toolkit. It can be used to enhance and clarify while respecting and recognizing the different identities of the people represented in the charts and the people reading them.[48] As SOGI data collection improves and more data become available, we will likely see how language and culture coincide with the data, and how the two evolve together through data visualization and other products (Kay and McDaniel 1978; Setlur and Stone 2016).

Color perceptions and usage already differ by culture, which will influence how colors assigned to SOGI data are perceived. In Western cultures, for instance, red is often used to show errors or negative values, while in Eastern cultures, red is often used for prosperity and good luck. Since the mid-20th century, the blue-pink color pair is instantly identifiable as representing men and women in Western cultures. But this color scheme is also rooted in sexism, with many societies traditionally assigning less value to feminine-coded colors and products. It does not have to be this way, and other color pairs should be considered.[49]

When using a color palette to represent a broader range of SOGI data (e.g., men/women, straight/gay), any color combinations could be candidates. If we draw color palettes from LGBTQIA+ movement pride flags, then there are essentially endless choices (**figure 15**). The iconic pride rainbow flag typically includes six colors that span the rainbow.[50] The transgender flag, which debuted in 1999, consists of baby blue, baby pink, and white. And the progress pride flag uses blue, pink, and white from the transgender pride flag, with brown and black to represent people of color and the unique challenges that queer people of color face accessing the same rights as white and heterosexual people.

Whatever colors are chosen, avoid using sequential color palettes when presenting data along a continuous spectrum. Sometimes referred to as a color ramp or color gradient, the sequential palette uses a single hue (e.g., blue) that ranges from a light color for small numbers to a dark color for large numbers. The sequential blue color palette used in the pie chart in **figure 16**, for example, suggests a hierarchical ordering—from gay/lesbian/same-gender (29 percent) to bisexual (31 percent) to heterosexual (23 percent) and so on—that is not reflected in the data (Grant et al. 2011). A sequential color palette should refer to data values, not to category names.

Terminology in Data Visualization

We addressed the evolution of language and translation earlier in this guide, but when it comes to communicating SOGI data, there are a few other considerations to keep in mind. First, keep language consistent with what is asked in the survey, but balance that continuity with using more equitable and inclusive terminology. If the survey collected sex data using the terms *man/woman*, for example, a researcher can choose to change them to *male/female* to be more accurate. A similar change can be made when using race/ethnicity data. If a survey uses the term *Latinx*, but a researcher recognizes that their audience prefers alternative terms, such as *Hispanic* or *Latino*, they can choose to make the change (Schwabish and Feng 2021). Whenever terms are changed from the original survey, it is best practice to acknowledge the original language used—the respondent did, after all, select the box for "man/woman"—and note that the visualization or text uses a different term, word, or phrase. Endnotes or footnotes can also recognize data collection limitations—for example, a footnote might say, "Nonbinary genders were not available for this analysis and are a limitation."
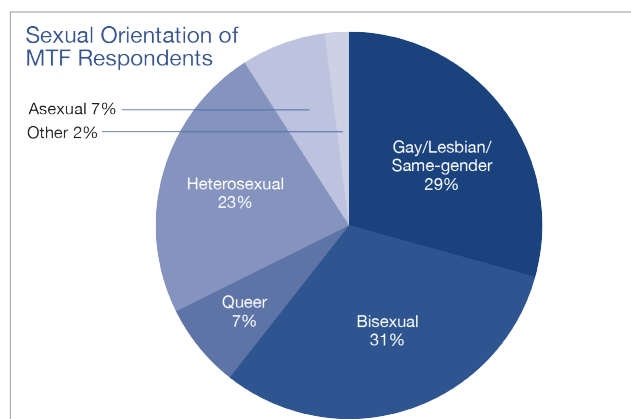

FIGURE 15
Flags for the SOGI Community

Source: Authors created the images based on "Flags of the LGBTIQ Community," Outright International, accessed September 21, 2023.

Note: A. LGBTQIA+ movement pride flag; B. transgender flag; C. progress pride flag.

FIGURE 16
Sequential Color Palette that Does Not Match the Data

Source: Jaime M. Grant, Lisa A. Mottet, Justin Tanis, Jack Harrison, Jody L. Herman, and Mara Keisling, *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey* (Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011), 29, https://transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf.

Second, the term *other* is common in data visualization, but it literally "others" individuals by emphasizing how they are different from some perceived norm.[51] We propose several alternatives to the "other" label:

- another gender/sexual orientation
- additional groups
- all other self-descriptions
- people identifying as other or multiple genders/sexual identities
- identity not listed
- identity not listed in the survey

In general, consider how the language could misrepresent the issue, be misconstrued or misunderstood, or be used for harm.[52] Are the data being presented proportional to the issue? There are more than 1.3 million adults (ages 18 and older) and about 300,000 younger people (ages 13 to 17) who identify as transgender in the US (Herman, Flores, and O'Neill 2022). Is it necessary for data visualization, especially within a larger argument, to focus on the transgender community? Does it treat all people equally or does it minimize the experiences or challenges certain people or groups face? These questions have answers, and they likely can be addressed by including people with lived experience of the topic being discussed or visualized.

Icons

Instead of using an abstract shape, such as a bar or a circle, to represent a data value, it is sometimes better to use icons, which enable readers to see themselves in the data and connect directly with the person or community underlying the data. By offering readers a way to see themselves in the data, researchers can help them feel more empathy toward the people the data represent.

But icons also can be problematic, especially given the various intersections and complexities of human beings and identities. No single icon will be able to capture all that complexity. **Figure 17**, for example, shows 4 icons (out of nearly 250 options) found under the search term *transgender*

from the Noun Project, an online resource for icons. Which icon (if any) feels as if it completely captures the complexity of being transgender?

FIGURE 17
Examples of Icons Representing the Term "Transgender"
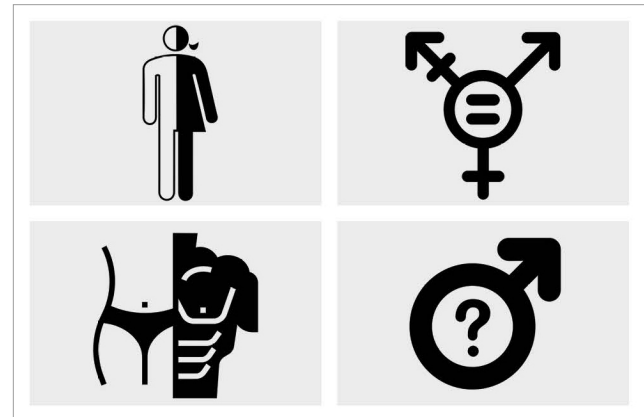
Source: Noun Project, s.v., "transgender," accessed September 21, 2023, https://thenounproject.com/search/icons/?q=transgender.

Again, the use case is important here. Using an icon in a graphic that explores violence against transgender people will look and feel very different from using an icon in a sign on the bathroom door. In the latter case, a reader just needs to know where the restroom is and whether it is wheelchair accessible, which could be simply symbolized by a wheelchair and toilet. That being said, it is worth asking whether icons like those shown in **figure 18** are even necessary. Information that expresses the gender of the people who most often use the bathroom may not be especially important. (It is worth noting that some may perceive these icons as comparing people who do not fit into the binary gender norm with mythical or imaginary things.[53])

FIGURE 18
Example of Icons Representing Nonbinary Genders

Source: Photo taken by author.

At their core, icons are just representations of people. Although they can do harm, we should be less concerned with their total accuracy in depicting every characteristic and identity, and instead use them as they are intended—as representations of people. In his book *Joyful Infographics*, Nigel Holmes suggests the following: "When making icons of people for *Isotype*-like charts, consider making them all blue. Using a blue [or, presumably, any single color] figure of a person is not a way to avoid questions of difference or inequality, it simply makes everyone equal, whereas showing people in precisely-color-calibrated, almost-realistic pictures amplifies the differences—that's the intention, of course—but it does not promote equality" (Holmes 2023, 106).

Showing Small Numbers

As we have demonstrated throughout this guide, one of the challenges in using SOGI data is the issue of small sample sizes. With an estimated 0.5 percent of US adults (ages 18 and older) identifying as transgender (Herman, Flores, and O'Neill 2022), any sample of transgender respondents, especially when disaggregated by race, ethnicity, geography, or something else, will be quite small.

These small-sample-size issues require data visualization creators to be conscientious and careful about using levels or growth rates. Characterizing the change in a variable that increases from 3 units to 12 units as an increase of 300 percent is factually true, but it can also distort the actual meaning of that increase.[54] Such distortion can be especially harmful when reporting about health care for transgender children, which can be intentionally misleading and risk the health and safety of transgender children and their families.

Ordering

Finally, as with all identities, think carefully about how to order the results in the table, graph, or chart. Simply because the survey codes man as 1, woman as 2, and transgender as 3—which we have noted above may be problematic because the word *transgender* does not describe a gender—does not mean the results need to be shown in that order.

As with equity in race and ethnicity data, consider whether sorting the reults by population size, sample size (weighted or unweighted), or magnitude makes more sense than the data default (Schwabish and Feng 2021). Alphabetical ordering of SOGI data can be more difficult, because many people may not be familiar with certain terms like *asexual, intersex*, or *genderqueer*. However the results are ordered, as long as the decision is made, *conscientiously and purposefully*, the work will be the better for it.
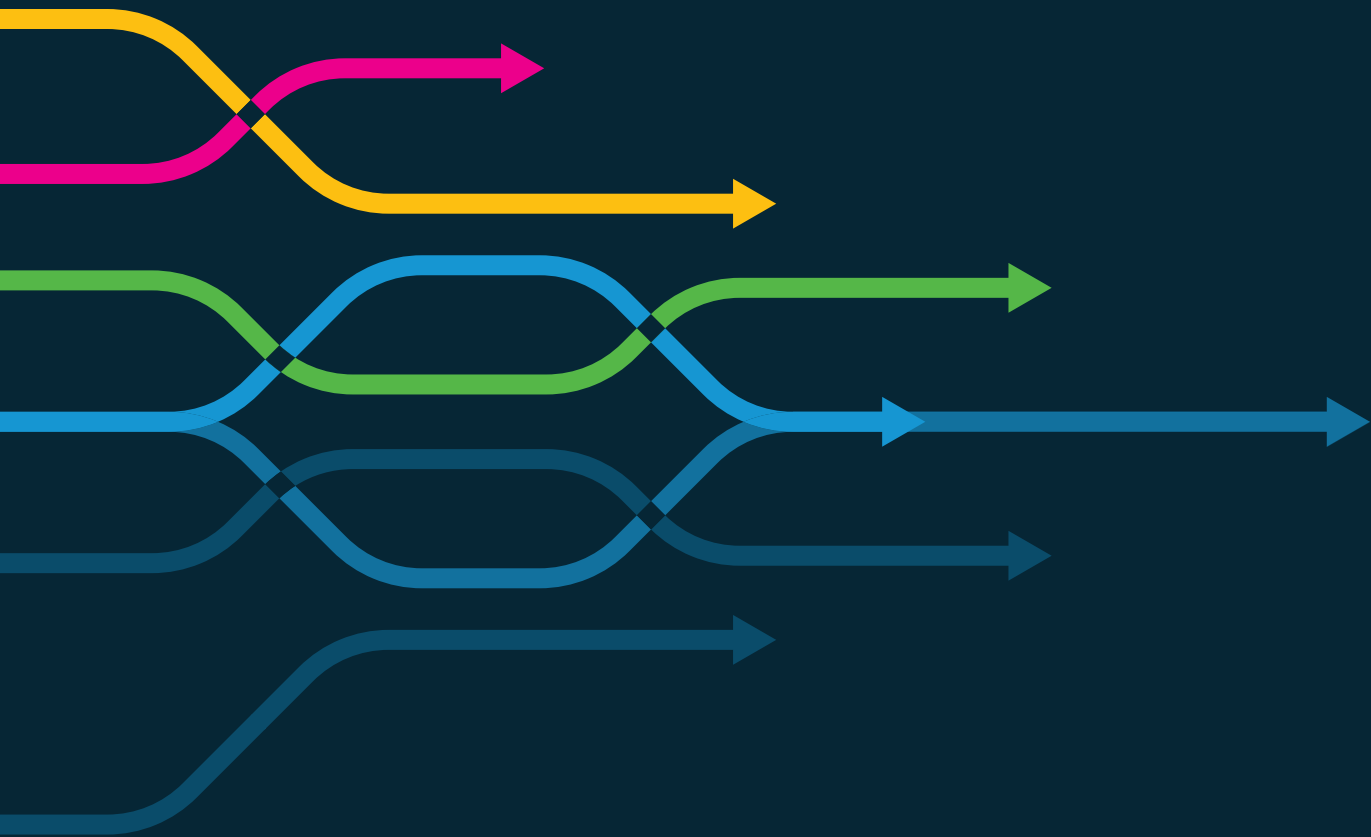
Conclusion

Conclusion

Despite recent efforts to expand and improve SOGI data practices, there is still much work to be done. And with many trying to strip LGBTQIA+ people of their rights, these data can help improve policy and inform perspectives. The work of collecting, using, analyzing, and communicating SOGI data—and all data that represent people and communities, for that matter—should be carried out carefully, respectfully, and through the lens of equity and inclusivity.

We have presented many recommendations and guidelines that people working with data should consider when presenting data relating to gender and sexual orientation. The issues we have highlighted here are not static and do not necessarily have concrete right or wrong approaches. But the principles we have outlined can help people and organizations think more critically about how to work with SOGI data. We urge analysts and researchers to be aware of how decisions made at each step in the pipeline may not only affect data accuracy and representation but also potentially put vulnerable populations at risk.

Many issues discussed in this guide and that our interviewees and advisers brought to our attention will continue to evolve and change with society, culture, and norms. By applying SOGI data best practices, experts in data and research fields are in a unique position to improve how people view and understand data relating to gender and sexual orientation, and to help governments, organizations, and other groups implement strategies, programs, and policies that address disparities and inequities—and to use data for good.
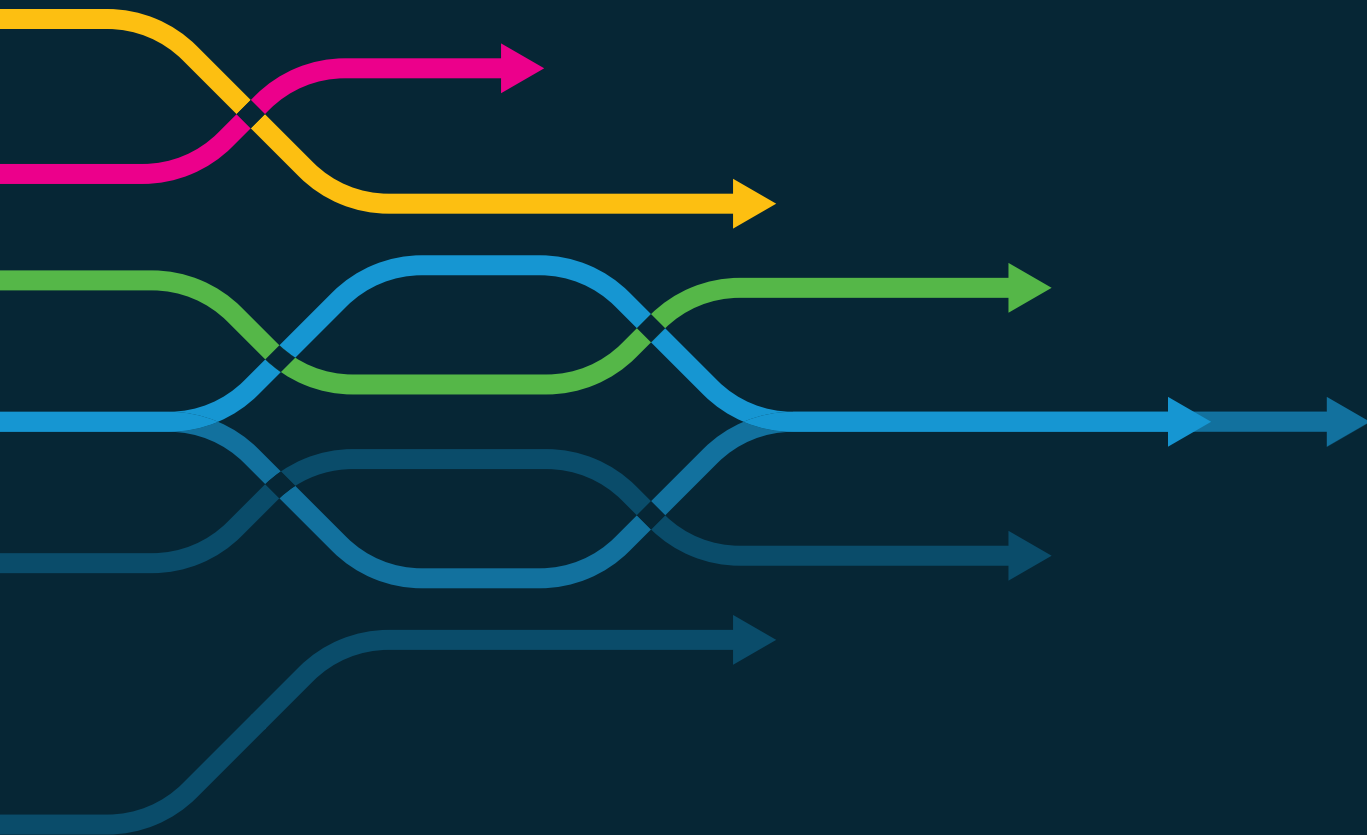
Appendix

APPENDIX A: PROTOCOL FOR INTERVIEW

Confidentiality Statement and Conversation Guide: Interview Introduction and Consent

Hello, my name is [*insert name*] and I'm joined by my colleague [*insert name*]. We are researchers with the Urban Institute, a nonprofit research organization based in Washington, D.C.

The *Do No Harm Guide — Gender* research project, funded by the Tableau Foundation, is centered on identifying promising practices for collecting data around gender identity and sexual orientation that would help move the ideas of equity and inclusivity in the research, data science, and data visualization communities forward. By conducting a landscape scan of the current state of data collection around sexual orientations and gender identities/expressions (SOGIEs), interviewing and engaging in thought partnership with LGBTQ+ data leaders, and developing a series of accessible public products with the support of the Tableau Foundation, Urban intends to continue its partnership with the Tableau Foundation in creating data products for all people and communities. The final deliverable will be a report that includes a review of existing best practices and interviews with experts around the country.

This research will help data communicators create more equitable, inclusive, and accessible data products. While there are increasing conversations around the need to inclusively represent sexual orientations and gender identities/expressions in data collection and visualization, there does not seem to be much agreement or formal resources around best practices. This guide will focus on creating guidelines and best practices to advance equity in data products. The guide will also help researchers and analysts be more forward thinking as they prepare their data collection, analysis, and communication efforts. We are conducting a series of interviews with experts in LGBTQ+ data collection to help guide the development of best-practices as well as to bring a first-person perspective to the challenges—and rewards— of creating more equitable and inclusive data products.

We know that you are busy, so we will be as focused as possible. Your participation in this discussion is completely voluntary. That means you may choose to skip any questions you wish, refuse to participate, or stop the interview at any time.

This interview will last up to 60-90 minutes. My colleague, [*name*], will be taking notes today and we would like to record the interview as well to make sure we capture everything you say accurately.

- We would like permission share what we learn from you today, but we will take precautions to protect your identity during the data collection process.

- We will make every effort to protect your identity; however, there is a small chance your comments and/or descriptions could be attributed to you in the final report.

- We also cannot guarantee the confidentiality of the information you provide given the nature of Zoom. We believe the risk of sharing information is minimal, but you are free to decline to respond to any question that you are not comfortable answering.

- We will not cite your name in the report unless you grant us permission to do so. We ask that you participate in a private setting away from earshot or viewing by unauthorized persons to include family members.

We take all notes on password-protected computers and store them in folders only accessible to researchers working on this project who have signed a confidentiality pledge.

Do you have any questions before we begin?
[*pause for response*]

If you have any questions about this study, you can contact: Jon Schwabish, Principal Investigator, the Urban Institute jschwabish@urban.org

Do you agree to participate in this conversation?
[*if no*] No problem, thank you for your time.
[*if yes*] If it's ok with you, we would like to record this conversation to make sure that we get what you have to say down correctly. It will also help us move through the interview with fewer pauses for the notes. Once the project is over, we will delete the recording. At any time while we talk, we can also stop the recording if you like.

Do you consent to this interview being recorded?
[*if yes, start recording.*] Thanks. We're recording now.
[*if no, do not record.*] No problem, we won't record.

In this interview we are interested in learning about your ideas, experiences, and perspectives. There are no right or wrong answers. Do you have any questions before we begin? If you have any questions during our interview, please do not hesitate to ask.

APPENDIX B: DATA EXPERTS AND AGENCY STAKEHOLDERS INTERVIEW PROTOCOL

Interview teams should first ensure the informed consent is covered, which can be found here: [link]

Setting the Space

Thank you again for speaking with us today. In this conversation, we will use the term "SOGIE" to refer to sexual orientation and/or gender identity and expression data. We want this interview to be only semi-structured and are eager to learn from you as the expert, so please feel free to speak as much as you'd like and we'll probe with questions where needed.

SECTION 1: Respondent and Organization Background

Thank you for agreeing to speak with us today. We look forward to learning more about your perspectives on and experience with collecting SOGIE data in various research efforts. We'd like to start with some basic background questions about you and your work.

1. **Can you tell us about your [institution/agency] and your role?**
   a. What is your title?
   b. How long have you been in this position?
   c. What are your primary responsibilities/what is your primary focus?
2. **Please briefly provide an overview of your or your agency's work as it relates to demographic data collection broadly.**
   a. *[probe]*
3. **In what capacity do you engage with SOGIE data?**
   a. Is it something you ensure is included in any data collection and analysis effort or is it something that only pops up in dedicated projects?
   b. *Use this question to have the interviewee(s) expand on their SOGIE data work or familiarity with the idea of collecting SOGIE data.*
      i. To consider: does their organization have a specific team(s) that work on these issues? Is everyone in the organization tasked with thinking about these issues? Are there distinctions between the technical and content teams?

SECTION 2: Sexual Orientation Data Considerations

4. **Have you ever written a survey/form/census that asked respondents about their sexual orientation?**
   a. *If no, move to section 3.*
   b. *If yes:*
      i. Have you ever designed a survey/project with the explicit goal of learning about sexual orientation of some specific population?
5. **What is your opinion on (or experience with) having respondents report their sexual orientation by selecting from a list of options vs. asking via an open-ended question?**
   a. What trade-offs do you consider when designing how respondents report their sexual orientation (i.e., list of options vs. open-ended questions)?
6. **In your view, what are the tradeoffs between these different data collection methods and survey response rates?**
7. **What is your opinion on (or experience with) reporting respondents' sexual orientation, especially in data sets that include a limited number of options?**

SECTION 3: Gender Identity and Expression Data Considerations

8. **Have you ever written a survey/form/census that asked respondents about their gender identity?**
   a. *If no, move to section 4.*
   b. *If yes:*
      i. Have you ever designed a survey/project with the explicit goal of learning about gender identity among some population?

9. **What is your opinion on (or experience with) having respondents report their gender identity by selecting from a list of options vs. asking via an open-ended question?**

10. **In your view, what are the tradeoffs between these different data collection methods and survey response rates?**

11. **What is your opinion on (or experience with) reporting respondents' gender identity, especially in data sets that include a limited number of options?**

SECTION 4: Current Scholarship and Landscape of SOGIE Work

12. **When working toward collecting SOGIE data, does your institution/agency have its own standard format for these types of questions? Or do you consult any external resources?**

13. **What, if anything, related to updating SOGIE data collection best practices do you see being discussed in your field of work?**
   a. For example, are you aware of any recent scholarship or conversations around how to ask transgender status or pronouns?

14. **Are there any gaps that you see in the current conversation/scholarship around SOGIE data collection?**
   a. What do you see people get wrong most often about collecting SOGIE data?

SECTION 5: Trainings

15. **Are you aware of any training or technical assistance efforts that exist to support research teams in learning more about SOGIE data and equitable data collection practices?**
   a. What content is covered during this training?
   b. Who facilitates the training?

16. **Are there any gaps that you see in the current conversation/scholarship around SOGIE data collection practices?**
   a. What structure of our work do you think would be most helpful?
   b. What materials or resources would you find most useful for your own work or to help others at your organization?

SECTION 6: Miscellaneous

17. **Are there any major institutional or political changes that you anticipate may impact how the field is able to embrace best practices for SOGIE data collection (i.e., elections, legislative changes, lawsuits, system restructuring, university funding, etc.)?**

18. **Is there anything else you'd like us to know that we did not cover today?**

SECTION 7: Conclusion + Referrals

Thank you so much for speaking with us today. We're looking forward to continuing to learn more about best practices around SOGIE data collection. We have one final question for you:

19. **Do you know of anyone else in your field that we should reach out to? If it's a personal connection, could you please share their contact information or otherwise introduce us?**

APPENDIX C: COMMUNITY-BASED PRACTITIONERS AND ADVOCATES INTERVIEW PROTOCOL

Interview teams should first ensure the project background + informed consent is covered, which can be found here: [*link*]

Setting the Space

Thank you again for speaking with us today. In this conversation, we will use the term "SOGIE" to refer to sexual orientation and/or gender identity and expression data. We want this interview to be only semi-structured and are eager to learn from your expertise in working with LGBTQ+ people, so please feel free to speak as much as you'd like and we'll probe with questions where needed.

Warm-up question

When you think about the way that data on sexual orientation and/or gender identity is currently collected in most research efforts, what comes to mind?

SECTION 1: Respondent and Organization Background

We look forward to learning more about your perspectives on how LGBTQ+ people can best be represented in research data collection efforts. We'd like to start with some basic background questions about you and your work.

1. **Can you tell us about your organization and your role?**
    a. What is your organization's mission/focus?
    b. What is your title?
    c. What are your primary responsibilities/what is your primary focus?
    d. In what capacity do you work with LGBTQ people? Or on LGBTQ issues?
2. **Do you have any experience with thinking about SOGIE data or discussing opinions on how identities are asked about in research with your clients/with the LGBTQ people you work with or in your peer network?**

SECTION 2: LGBTQ People and SOGIE Data Considerations

3. **LGBTQ+ people are by no means a monolith and there can be significant variation in language used for defining sexuality or gender from person to person. In your experience, what do you view as the most representative language to capture this information?**
    i. [*probe*]
4. **What do you view as the tradeoffs between asking people to report their sexual orientation on a survey or form by selecting from a list of options versus asking via an open-ended question?**
    a. Do you have any thoughts on any possible tradeoffs between these survey methods and response rates/sample representativeness?
5. **Do you think people feel more included/represented when they report their gender identity on a survey or form by selecting from a list of options, or asking via an open-ended question?**
    a. What about for transgender status? Do you think it's better to ask this in every effort to collect SOGIE data, only if the project has a focus on trans people, etc.?
        i. If a trans person was taking a survey, do you think they'd prefer to identify as "trans woman" or "woman" and select 'yes I am transgender' in a follow up question?

SECTION 3: Current Scholarship and Landscape of SOGIE Work

6. **What, if anything, related to updating SOGIE data collection best practices do think we should consider or explore in this project?**
    a. For example, are you aware of any recent scholarship or conversations around how to ask transgender status or pronouns?

7. **What materials or resources would you find most useful for your own work or to help others at your organization? In other words, how can we make this report as useful as possible?**

SECTION 4: Miscellaneous

8. **Is there anything else you'd like us to know that we did not cover today?**

SECTION 5: Conclusion + Referrals

Thank you so much for speaking with us today. We're looking forward to continuing to learn more about best practices around SOGIE data collection. We have one final question for you:

9. **Do you know of anyone else in your field that we should reach out to? If it's a personal connection, could you please share their contact information or otherwise introduce us?**

APPENDIX D: INTERNAL EXPERTS INTERVIEW PROTOCOL

Setting the Space

Thank you again for speaking with us today. In this conversation, we will use the term "SOGIE" to refer to sexual orientation and/or gender identity and expression data. We want this interview to be only semi-structured and are eager to learn from you as the expert, so please feel free to speak as much as you'd like and we'll probe with questions where needed.

1. **In what capacity do you engage with SOGIE data?**
   a. Is it something you ensure is included in any data collection effort, something that only pops up in dedicated projects, etc.?
   b. *Use this question to have the interviewee(s) expand on their SOGIE data work or familiarity with the idea of collecting SOGIE data.*

2. **What is your opinion on (or experience with) having respondents report their sexual orientation by selecting from a list of options vs. asking via an open-ended question?**
   a. What tradeoffs do you consider when designing how respondents report their sexual orientation (i.e., list of options vs. open-ended questions)?

3. **What is your opinion on (or experience with) having respondents report their gender identity by selecting from a list of options vs. asking via an open-ended question?**

4. **What, if anything, related to updating SOGIE data collection best practices do you see being discussed in your field of work?**
   a. For example, are you aware of any recent scholarship or conversations around how to ask transgender status or pronouns?

5. **Are there any gaps that you see in the current conversation/scholarship around SOGIE data collection?**
   a. What do you see people get wrong most often about collecting SOGIE data?

6. **Are you aware of any training or technical assistance efforts that exist to support research teams in learning more about SOGIE data and equitable data collection practices? Or that should exist?**

7. **Is there anything else you'd like us to know that we did not cover today?**

8. **Do you know of anyone else in your field that we should reach out to? If it's a personal connection, could you please share their contact information or otherwise introduce us?**
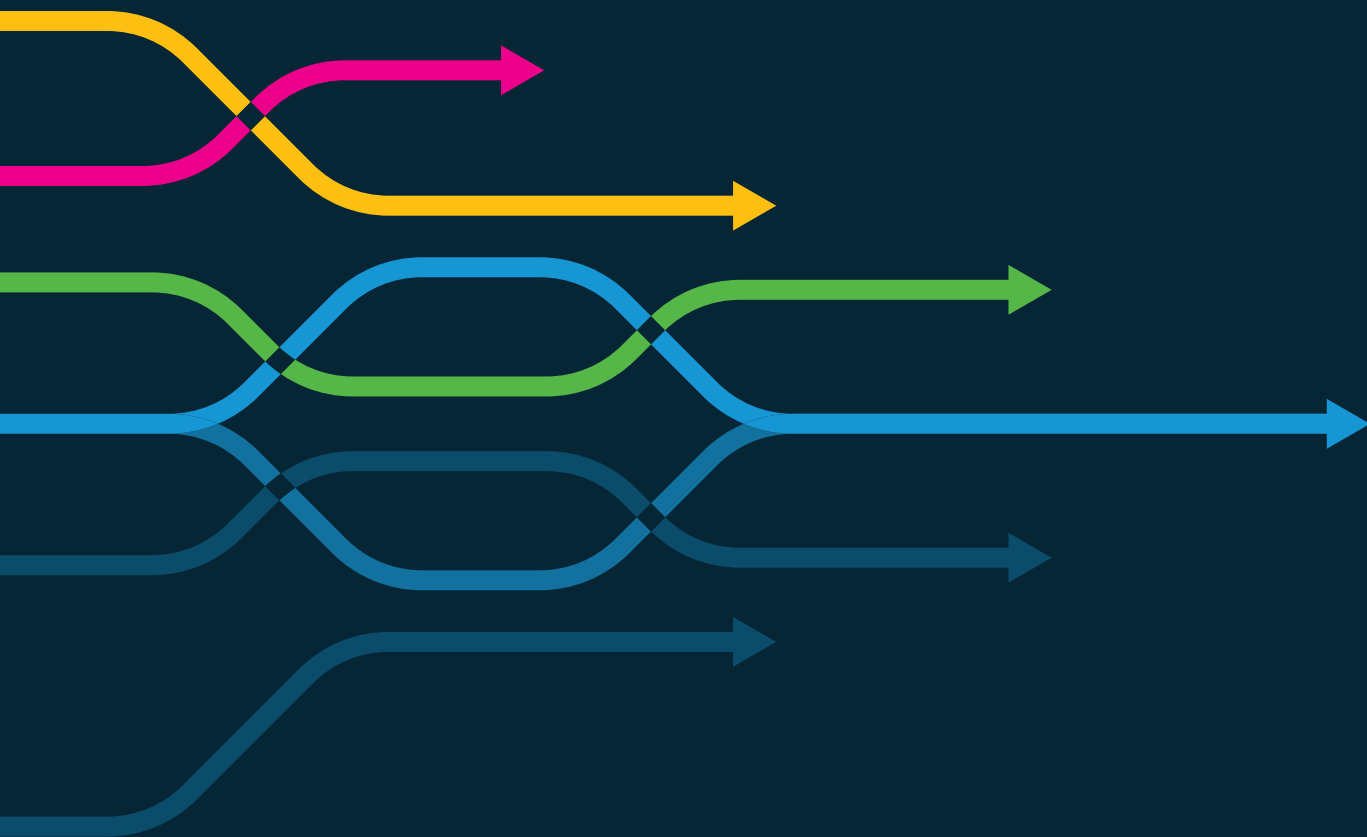
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3. The more than 560 anti-LGBTQIA+ bills introduced, as of early September 2023, include 535 bills at the state level and 32 at the federal level. "2023 Anti-Trans Bills Tracker," Trans Legislation Tracker, accessed September 12, 2023, https://translegislation.com.

4. Many transgender people are also part of gay communities and have played a key role in advancing gay rights. However, the history of transgender communities and transgender acceptance is in many ways distinct from the history of gay communities, and we try to make this distinction apparent as necessary in this section.

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8. We use the acronym "LGBTQ" instead of "LGBTQIA+" in this paragraph because, while intersex and asexual individuals were undoubtedly affected by the HIV/AIDS epidemic, neither group was the primary focus of the advocacy or organizing efforts in this period.

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39. In our interview, Kristen Schilt explained that regional and cultural terminology in the US can also be potentially challenging in survey design. She brought up the work of Ilan Meyer, who found in one of his surveys on sexual and gender identity that "same-gender-loving" was often selected as an identity by Black men who had sexual and romantic relationships with other men, but also by Southern heterosexual white women who imagined this response to mean having close platonic female friendships (Young and Meyer 2005). In a 2004 focus group study of 81 Black men living in New York state and Atlanta, Georgia, researchers found that 10 participants (12 percent of the sample) identified as "same-gender-loving" (Malebranche et al. 2004).

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ACKNOWLEDGMENTS

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NORC at the University
of Chicago

CHLOE SCHWENKE
Pronouns: she/her
President,
Center for Values in
International Development

POSITIONALITY STATEMENT

This project was led by Jonathan Schwabish (he/him), who directs the Urban Institute's *Do No Harm* project, in collaboration with Urban Institute researchers holding various LGBTQIA+ identities. Our work draws on our interdisciplinary backgrounds in topics related to economics, public health, public policy, social work, transformative justice, housing justice, and community-based participatory methods. We work at a relatively well-resourced and predominately white research organization based in Washington, DC. We acknowledge the extensive history of intentional and unintentional harm that research organizations have caused to structurally marginalized communities, including LGBTQIA+ people of all identities.

ABOUT THE PROJECT

ABOUT THE URBAN INSTITUTE

The Urban Institute is a nonprofit research organization that provides data and evidence to help advance upward mobility and equity. We are a trusted source for changemakers who seek to strengthen decisionmaking, create inclusive economic growth, and improve the well-being of families and communities. For more than 50 years, Urban has delivered facts that inspire solutions—and this remains our charge today.