



Sexual Orientation and Gender Identity Measures for Global Survey Research:

A Primer for Improving Data Quality

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ABBREVIATIONS

ART	antiretroviral therapy
GenIUSS	Gender Identity in the U.S. Surveillance Group
HPP	Health Policy Plus
LGBT	lesbian, gay, bisexual, and transgender
LGBTQ	lesbian, gay, bisexual, transgender, and queer
LGBTQI	lesbian, gay, bisexual, transgender, queer, and intersex
LINKAGES	Linkages across the Continuum of HIV Services for Key Populations Affected by HIV
MINSA	Ministry of Health, Nicaragua
MSM	men who have sex with men
NGO	nongovernmental organization
NIH	National Institutes of Health
PEPFAR	United States President’s Emergency Plan for AIDS Relief
SMART	Sexual Minority Assessment Research Team
SOGI	sexual orientation and gender identity
SGM	sexual and gender minority
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNC	University of North Carolina
USAID	United States Agency for International Development
WHO	World Health Organization

INTRODUCTION

Everywhere in the world, people of diverse sexual orientations and gender identities make important contributions to the social and economic development of their families, communities, and countries. However, the experience of sexual and gender minorities globally has been mostly invisible because of a lack of quality data specific to these populations. As a consequence, little is understood about their contribution to health, education, and governance sectors. Moreover, their needs in these areas go largely unmet.

Increasingly, in the field of public health, there is recognition that sexual orientation (Logie, 2012) and gender identity (Reisner, et al., 2016) are important determinants of health. This has been documented across a range of health issues, including for HIV, mental health, substance use, and violence, where sexual and gender minorities¹ (SGMs)—people who do not identify as heterosexual or whose gender identity differs from their sex assigned at birth—experience substantially worse health outcomes, primarily as a result of stigma and social marginalization (Mayer, et al., 2008; Beyrer, et al., 2016; Logie, 2012; Poteat, Sheim, Xavier, Reisner, & Baral, 2016).

A major barrier to improved health and well-being of SGM populations is the lack of quality health-related data at a global-level. Most global research about how to improve the availability of health-related data has focused exclusively on how to access and recruit SGM populations. Less attention has been given to how to accurately identify and classify individuals in a way that is meaningful and respectful to them, while also serving the need to understand their particular health problems, their causes, and their consequences. Unlike sampling and recruitment strategies, this additional issue of meaningful classification is particularly complex when considered across a global context with diverse sexual cultures.

There are very few things that can be generalized about sexuality and gender across the human experience (Hardley, 2003; Horley & Clarke, 2016), and it can be challenging to capture these characteristics appropriately using closed-ended questions typical of forms used in health surveillance and survey research. One of the major health problems faced by SGMs globally is HIV, and so this is also the health area where most information about these populations has been documented. How HIV programs collect information about SGM populations is critical to ensure effective evidence-based HIV programs and policies. It is also important because the way HIV programs collect and report on SGM populations has a wider social influence on knowledge construction for these populations. The public health response to complexity in obtaining information on SGMs has been to revert to a biomedical lens, focusing on the specific behavior that transmits HIV—hence the umbrella term “men who have sex with men”—to categorize individuals. But this perspective can miss important

Failure to give attention to how boxes for HIV key populations get filled in can result in misclassification and poor data quality.

¹ The definition of sexual and gender minority (SGM) populations used in this report is based on the definition used by the National Institutes of Health, Sexual and Gender Minority Research Office (see: <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-19-139.html>). SGM populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, two-spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with a difference in sex development are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.

variance and negates the substantial body of evidence that demonstrates that it is the lived experience of SGMs that puts them at increased risk for HIV. As noted in a recent policy brief by the Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES)—a project funded by the United States Agency for International Development (USAID) and the United States President’s Emergency Plan for AIDS Relief (PEPFAR)—a common refrain among transgender activists is, “I am not a high-risk person; I am a member of a community that is put at high risk” (LINKAGES, 2015, p. 2). Ignoring complexity and context in the sorting and counting of individuals would miss important information for program design that illustrates how sexual orientation and gender identity are determinants of HIV risk and service use in each particular context.

Purpose of This Report

Without existing standards for asking questions, data collectors or interviewers may rely on their own perceptions of clients to categorize people as members of an SGM population (usually as either MSM or a transgender person in HIV research). This practice can lower the validity (truthfulness) of data. When self-report of sexual orientation or gender identity is elicited, using categories and terminology that align with the client’s or research participant’s perspective is critical. It is important to understand categories from the “lens,” or perspective, of sexual and gender minorities in each context, rather than universally applying a fixed global set of questions and responses.

The purpose of this report is to provide recommendations on how to develop closed-ended survey questions to measure sexual orientation and gender identity (SOGI) that are context specific, while, to the degree possible, also fulfilling global data reporting needs for HIV key populations. The report is written for all actors involved in the design of data-collection activities, including for surveillance, monitoring, evaluation, and broader research purposes. It begins with an overview of the current state of SOGI measurement in HIV programs. Next, it describes an inductive process for generating SOGI questions. The first step is to ensure a good understanding of SOGI concepts and **review context-specific literature** related to gender and sexuality. The second step is to review **existing survey questions** and assess their utility for the particular context and HIV-related issue under study. In some cases, a third step of **conducting qualitative research** may be warranted. The fourth and final step is to assess the potential questions through piloting and **cognitive interviewing**. The report provides instruction on each recommended step, and guidance on where to access additional information when necessary.

How to Use This Report

This report should be used to design research questions and data collection forms prior to the implementation of any new data collection planned for SGM clients or research participants. It may also be used to adapt existing instruments for SOGI data collection. The information presented is specific to SOGI, but it also outlines important principles for enhancing data quality related to survey question design more generally. Once SOGI questions are developed and tested, it is important to work with the direct service providers or interviewers who will interact with clients to elicit SOGI information. To support optimal implementation of SOGI data collection, online training about SOGI developed by the MEASURE Evaluation project is also available. This online training reviews important SOGI concepts and can be used to assess a team’s personal values and readiness to work with SGM clients. It can be accessed here:

<https://www.measureevaluation.org/resources/training/online-courses-and-resources/non-certificate-courses-and-mini-tutorials/sogi/sogi>

The Need for SOGI Data to Reach Global HIV Prevention and Treatment Targets

Achievement of the PEPFAR HIV “95 targets” for SGM populations is critically important given the substantial burden of HIV experienced by these groups across global contexts. These targets are that by 2020, 95 percent of people with HIV know their status, 95 percent of all those diagnosed with HIV will receive sustained antiretroviral therapy (ART), and 95 percent of all those receiving ART will have viral suppression. Designing appropriate patient-centered HIV programs for SGM populations and meet the PEPFAR targets requires accurate SOGI data about clients.

In a seminal study conducted among MSM globally in 2012, HIV services were described as “a treatment cascade that leaks.” This study was based on responses from 6,095 men in the Global Men’s Health and Right’s survey who identified as MSM across the regions of North, South, and Central America; South and Southeast Asia; and sub-Saharan Africa (Ayala, et al., 2014). Only 57 percent of participants reported ever having tested for HIV; of those aware of their HIV-positive status and eligible for ART, 76 percent were currently on ART (using standards at the time of the survey), 79 percent were retained in care, and 65 percent were virally suppressed (Ayala, et al., 2014). Discrimination from healthcare providers, homophobia, and fear of other’s reaction to one’s sexuality were associated with lower access to HIV prevention and testing services, as reported by participants (Ayala, et al., 2014).

Apart from this study, limited data exist on HIV cascade outcomes from ongoing HIV programs. These data are necessary to appropriately target, design, monitor, and evaluate HIV programs for MSM and transgender people. In a recent global review,² quality data able to support analysis of the HIV care continuum were available in only 12 countries for MSM, and none were available for transgender people (Gupta & Granich, 2017). Only four of the 12 countries with HIV cascade data for MSM were within 20 percent of achieving the 90-90-90 targets, and all were in high-income countries (Denmark, France, the Netherlands, and the United Kingdom). Estimates for the targets varied widely across the 12 countries, from 5 percent to 85 percent for MSM living with HIV knowing their status, 2 percent to 73 percent for MSM diagnosed with HIV on ART, and 1 percent to 72 percent of MSM on ART achieving viral suppression (Gupta & Granich, 2017).

Consequences of Misclassification for Transgender Populations

In no uncertain terms, there must be significant improvements in the availability of HIV care continuum data for transgender populations. The lack of global data for transgender populations as compared to MSM is, in part, a result of historical use of the term “MSM” as a broad category under which trans feminine gender variance was subsumed and erroneously conflated with sexual behavior. Global data for HIV among transgender populations is almost wholly limited to either HIV prevalence data, or, to a lesser degree, HIV testing uptake (Baral, et al., 2013; Reisner, et al., 2016). Few data exist from around the world to appropriately document factors relevant to HIV vulnerability among transgender people; those that do, note complex “syndemic” conditions including substance use, mental health, violence, and stigma as increasing risk for HIV acquisition (Poteat, et al., 2016). Globally, information on improving quality HIV services for transgender

² This review encompassed a wide range of sources, including published studies and conference abstracts, as well as surveillance reports, UNAIDS country reports, and PEPFAR country and regional operational plans.

populations is sorely lacking, with a review of quality of HIV care conducted in 2013 yielding only 20 of the 137 documents identified as focused specifically on designing quality services for transgender people (Andrinopoulos, Do, Wares, & Scholl, 2016).

Casting the net more widely, there remains a scant amount of empirical data on the health of transgender populations, inclusive of HIV, in addition to other health issues. In a landmark series on this issue in *The Lancet* (2016), authors note: “Transgender people and their needs remain little understood, not only by health-care providers but also more generally in society (including legislators and policy makers). An absence of appropriate information, together with ubiquitous misinformation breeds stigma, prejudice, and consequent discrimination, harassment and abuse, with alarming consequences for transgender people’s health and wellbeing” (Winter, et al., 2016, p.1). In a review published in the series by Reisner and colleagues, only 116 studies on transgender populations in global settings were identified, with some countries reporting no information on transgender health at all.

Current Global Guidance on SOGI Data Collection

Across leading global health agencies—the Joint United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO), Global Fund, and PEPFAR, among others—there is consensus on the need for quality data related to HIV prevention and care for SGMs, including data about HIV service uptake and factors influencing success or failure at each step of the HIV prevention and care continuum. To this end, a number of guidance documents are available to assist in programmatic and policy decision making, but none that focuses on meaningful classification of SGM populations across cultural contexts.

“To achieve universal health coverage for all, we need to know who the so-called ‘all’ are, and measure the risks to their health.” (Lo & Horton, 2016, p.1313)

There is guidance on what interventions should be implemented to mitigate HIV provided in the WHO *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations* (WHO, 2014), and companion documents on how to engage MSM and transgender communities to plan for the implementation of HIV interventions—the *Implementing Comprehensive HIV and STI Programmes with Men Who Have Sex With Men (MSMIT)* (UNFPA, et al., 2015) and *Implementing Comprehensive HIV and STI Programmes with Transgender People (TRANSIT)* (UNDP, et al., 2016) guidance documents. Online modules to support training in the implementation of these guidelines, and broader issues related to service provision, are also available through the Global Forum for MSM (<http://msmgf.org/learn-online/cpr-video-gallery/>).

Important technical guidance exists on measuring the size of key populations, including MSM and transgender people, as outlined in the UNAIDS/WHO document, *Guidelines on Estimating the Size of Populations Most at Risk to HIV* (2010) (WHO & UNAIDS, 2010). Additionally, the “PLACE” method—Priorities for Local AIDS Control Efforts—a rapid assessment tool that can be used to estimate the size of key populations, evaluate intervention effectiveness, and estimate the prevalence of HIV among key populations, has been implemented in more than 29 countries (<http://www.cpc.unc.edu/measure/tools/hiv-aids/place>).

Monitoring and evaluation tools for key populations, national HIV programs, and HIV program managers are also available, including *Operational Guidelines for Monitoring and Evaluation of HIV Programmes for Sex Workers, Men who Have Sex with Men and Transgender People Volumes I and II* (MEASURE Evaluation, 2013).

A number of useful technical guides have also been produced by the LINKAGES project. The manuals are written specifically for organizations implementing HIV programs globally, including program managers at the frontlines of designing HIV programs, and for data collection among key populations. They include, among others: *Integrated Technical Organizational Capacity Assessment (ITOCA) and Action Planning* (LINKAGES, 2016a); *Monitoring Guide and Toolkit for Key Population HIV Prevention, Care, and Treatment Programmes* (LINKAGES, 2016b); *Programmatic Mapping Readiness Assessment for Use with Key Populations* (LINKAGES, 2017b), and the *Gender Analysis Toolkit for Key Population HIV Prevention, Care, and Treatment Programs* (LINKAGES, 2017a). As noted in the LINKAGES' monitoring guide, "Many sites operate without routine data other than clinic registers or an Excel spreadsheet that tracks outreach and is kept at the NGO [nongovernmental organization] office" (LINKAGES 2016b, p.8). In response, the guide provides useful tools, including mapping tools, facility monitoring tools, and client registers.

Many of the guidance documents cited above rely on closed-ended survey questions to count each of the UNAIDS and PEPFAR stated key populations, including MSM and transgender people. The survey questions result in "boxes" that capture data about each group to be aggregated-up into the *a priori* fixed parameters of populations the global HIV community has determined to be at increased risk for HIV. The consistency of these boxes serve an important purpose—to allow for the determination of global trends, needs, and reach of programs towards key populations. **But how individuals are sorted into these boxes is undocumented, without universal guidance, and can differ vastly from one context to the next. This variance in elicitation and interpretation of data can greatly influence data quality.**

Noting the inherent complexity in sexuality, and the challenge of "unpacking" related concepts globally that would allow for the "repacking" of individuals into key population categories, USAID has supported trainings on gender and sexual diversity across PEPFAR programs to begin a dialogue about these concepts with global partners. In 2015, the Health Policy Project (HPP) developed gender and sexual diversity trainings, a related training guide, and a slide deck for implementers (<https://www.healthpolicyproject.com/index.cfm?id=GSDTraining>). This training reviews differences in sexual orientation and gender identity, although it is based primarily on a western understanding of these concepts. It also provides examples of how and why understanding gender and sexual diversity is important to HIV program design (HPP, 2015).

The Importance of Context-Specific Survey Measures for SOGI

Sorting people into discrete key population boxes across global contexts is challenging, because many characteristics related to sexuality are socially constructed and therefore context specific. Categories and conceptualizations of SOGI vary widely in their interpretation from one culture to another. This is true when considering comparison of cultures from one continent to another, as well as distinctions between subcultures in the same geographic region. These understandings also shift from generational groups, ethnic groups, and various other subcultures and subpopulations. For this reason, it is imperative to use caution when determining how to conceptualize and quantify these groups, as instituting a uniform model may miss

important nuances of the population, force people into categories that are not true or comfortable, and erase or negate people's experience and aspects of culture.

Western identity categories for SOGI have widely been based on the biological sex of one's sexual partners. This may be neither appropriate nor adequate to study sexuality in other settings. For example, a study looking at sexual orientation in Eastern Europe noted, "The men in our sample failed to recognize and uniformly apply western sexual identity labels such as 'gay', 'straight', 'bisexual' or even 'MSM'. Rather, these men used their own locally meaningful terms to describe themselves, placing elements of sexual practice in relation to other, non-sexual demographic and personal factors." Locally meaningful terms cited include circus MSM/ *cirk'is emesemi*, bisexual MSM/ *bisexuali emesemi*, true/genuine MSM/ *namdvili emesemi*, and so on (Meyer, Costenbader, Zule, Otiashvili, & Kirtadze, 2010). These varied terms take on unique meanings that are often rooted in institutional and group culture and reflect diverse understandings of sexuality. For example, the term "same gender loving" is frequently used among African American males and is rooted in Afro-centric traditions. The identity exists in opposition to the term gay/homosexual and has explicit anti-colonial nuances. African American community members advocate for its inclusion in a lexicon, because it holds socio-political importance and allows for self-definition and self-determination. This underscores the complexity and weight of these identity categories and a potential disconnect between what might be asked by researchers and how community members understand and respond to items in questionnaires (Martin-Green, 2014).

Blending Western and Indigenous Conceptualizations of SOGI

A common way of understanding gender is based on a binary conception of gender, including man and woman, and sometimes an "other" category. However, it is important to move forward with an understanding that for many cultures across the globe, historically and in the present day, gender is understood differently. In some instances, gender is understood on a spectrum, while in others, multiple gender identities are acknowledged and integral to the way people understand each other.

While today throughout the world sexual and gender minorities often face discrimination and stigma, in many cultural contexts, people with nonbinary genders were revered and celebrated. Prior to the exportation of western concepts through colonization, these cultures had their own, often more fluid understanding of sexuality and gender. In modern times, these indigenous concepts are often blended with concepts from other parts of the world, imported through health and development programs as well as social media. Because of the global footprint of HIV programs, it is important to take these local conceptualizations into account when designing SOGI questions.

"Knowledge construction is a cyclical process: Beliefs about the world shape how surveys are designed and data are collected; survey research findings, in turn, shape beliefs about the world and the cycle repeats." (Westbrook & Saperstein, 2015, p.536)

Increasing Visibility through Data

What is clear from existing research is that SGM face rampant discrimination in many parts of the world, which negatively affects their overall health and wellness and access to healthcare services. It is also important

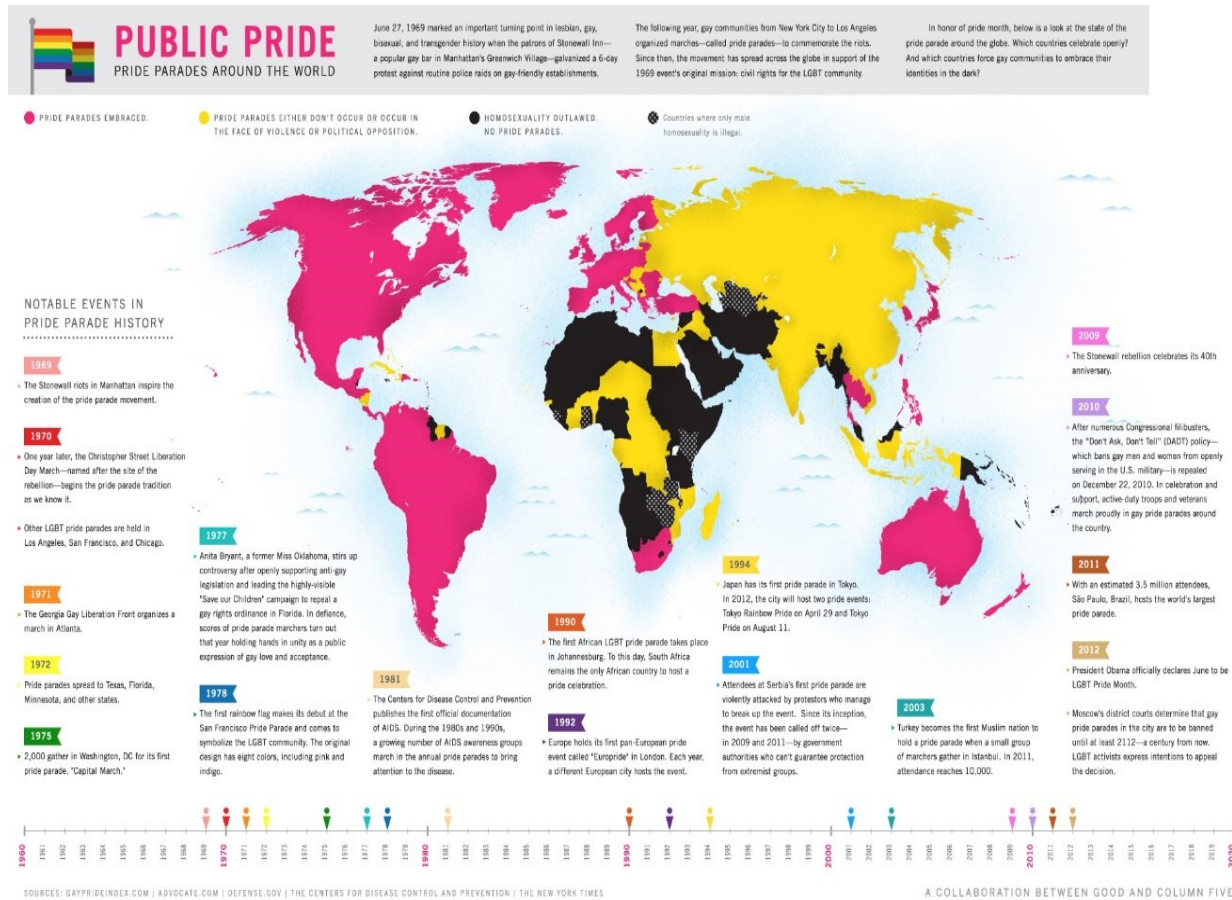
to remember that while SGM groups are frequently discussed as a whole, there is great diversity within that umbrella group, with various subgroups facing different health challenges. Given the threat of violence experienced by these groups, there are important ethical dilemmas in how information about these populations is documented and used. At the same time, increased visibility of these groups is needed to build an understanding of how to support their human rights, health, and well-being.

The global adoption of “coming out” and “pride” events indicates the enormous power and empowerment that is associated with becoming visible. Further, it is important to note that even in countries where homosexuality is illegal and governments are actively increasing anti-homosexual legislation and sentiment, being visible can be all the more empowering. Recognition and visibility in formal and informal settings become ever important for anti-stigma work, self-empowerment, and other reasons. The invisibility of SGMs in overall existing data is a major obstacle in advancing the healthcare needs of these key populations. The overwhelming majority of large-scale data collection endeavors have utilized a binary model for understanding and querying about gender, and sexual orientation has been historically unexamined. The public health community understands the importance of evidence-based decision making when it comes to resource allocation, intervention choices, and monitoring and evaluation. Without including meaningful and sophisticated measurements for SGM populations in data-gathering endeavors, these populations remain invisible in the public health arena, and their needs cannot be adequately addressed. It becomes an ethical imperative to engage in this important work, and to do so well.

In Focus: Pride Events in Uganda

Take, for example, pride events and anti-homosexuality laws in Uganda. In August 2012, the first Ugandan pride parade was held in Entebbe to protest the government's treatment of its lesbian, gay, bisexual, transgender, and queer (LGBTQ) citizens and the attempts by the Ugandan Parliament to adopt harsher sodomy laws, which would include life imprisonment for aggravated homosexuality (Okeowo, 2012). Pride events occurred in the following years, particularly to celebrate the overturning of the nation's anti-homosexuality bill in 2014. Increasing turnout numbers for Pride events have been reported, even amidst the political uncertainty and societal violence towards LGBTQ people (Sirin, 2016).

Figure 1. Pride parades around the world



Source: <https://www.columnfivemedia.com/work-items/infographic-pride-parades-around-the-world>

The endeavor to measure SOGI is an important one, and there is no easy answer. As described below, there are many nuances and dilemmas in this endeavor (Glick, Theall, Andrinopoulos & Kendall, 2018). Many great minds the world over are currently pondering this dilemma, thinking creatively about solutions, discussing possibilities, and testing theories.

The following process aims to support practitioners in understanding the constructs of sexual orientation and gender identity from both a broad standpoint and in the cultural contexts where they work, among the target populations with whom they work. We resist the desire to highlight a single-one-size-fits-all “best practice” when we understand that this will be an iterative process. A higher aim is to continuously strive for “better practices” to meet the developing needs of SGMs.

Asking Questions from the Lens of the Respondent

Tapping into the memory banks of respondents to retrieve the most accurate responses to survey questions requires an understanding of the “cognitive response process”—the way people think when they are asked a question and give a response. A common model used to describe cognitive processing of questions was

developed by Tourangeau in 1984 and has since been applied in many settings (Tourangeau, 1984). It involves the four steps noted in Box 1.

- The first step in the response process is *comprehension*, which refers to the degree of understanding of the question by the respondent. To increase comprehension, the survey questions should include familiar categories or domains and terminology that respondents will understand. Using everyday terms will increase comprehension and accurate responses.
- The second step is *retrieval*, during which the participant searches their memory banks to find information they understand to be pertinent to the question they were asked. Recall of an event or information is important to retrieval; questions that include information to prompt recall will improve accuracy.
- The third step is *judgment*, an evaluation of the information found during retrieval as well as an assessment of the degree of certainty the respondent feels about their answer. The judgment step is particularly important for questions about attitudes and those that involve the consideration of one's emotions in relation to a response. For SOGI questions, the judgment step may be complicated for respondents with a liminal development of their sense of self in relation to their sexuality or gender. This is another reason why asking about multiple dimensions of a domain in the same survey can be important (for example, sexual behavior, sexual orientation identity, sexual attraction, sex assigned at birth, and gender identity).
- The fourth step is *response*, which is the point where the respondent maps the answer they've developed to the possible response categories provided with the question. Similar to comprehension, providing familiar response categories that are logical to the respondent is important to ensure the most accurate matching of the true answer to an available response.

Box 1. Respondent's four-step cognitive response process

1. **Comprehension:** understanding of the question
2. **Retrieval:** recall necessary information
3. **Judgment:** assess completeness of memory, make estimate based on retrieval
4. **Response:** map judgment onto response category; potential editing based on social desirability

(Tourangeau, 1984; Tourangeau & Yan, 2007)

During the final response step, respondents weigh the social costs and benefits of sharing their true answer to a question with the interviewer. This can lead to *social desirability bias* if the respondent perceives their answer to go against an accepted social norm or to be a cause for embarrassment (Tourangeau & Yan, 2007). In this case, the respondent may give a false answer to prevent the interviewer from learning something about them that they consider defamatory. In research studies, it may be possible to administer sensitive questions without an interviewer (for example, through a sealed envelope or computerized self-interviews), but this is difficult to accomplish in a health delivery setting. Further, respondents may still fear that a third party will learn their answer even if not given directly to an interviewer (for example, a government agency or insurance provider).

Several techniques can reduce potential social desirability bias. Using wording that suggests social acceptance regardless of the participant's response in a preamble to the question or the question itself is one strategy. For

example, a preamble may state that “there are many different types of sexual attraction that a person may have” to communicate that one type of sexual orientation is not valued over another by the research team or data collector (Sudman & Bradburn, 1982).³ It is also important to reinforce that responses are confidential and to maintain practices that will ensure confidentiality (Tourangeau and Yan, 2007).

Matching respondents with interviewers perceived as sympathetic rather than judgmental can also reduce misreporting based on social desirability. Collecting the information in a private location or where bystanders are perceived to be more accepting of the sensitive information can also reduce social desirability bias. Here, meaningful engagement of sexual and gender minority individuals and organizations in the research process can help improve data quality, in addition to being a sound ethical principal in the conduct of research. Finally, some evidence shows that priming the cognitive process to elicit honest responses may reduce misreporting (Rasinski, Visser, Zagatsky, & Rickett, 2005), for example, by reinforcing how the information will be used and why it is important to obtain the most accurate and honest answers possible. Again, this can be reinforced through preambles such as, “The information you report will assist me in providing the best care possible,” or those that note that “there are no right or wrong answers, so please answer the questions as honestly as possible.”

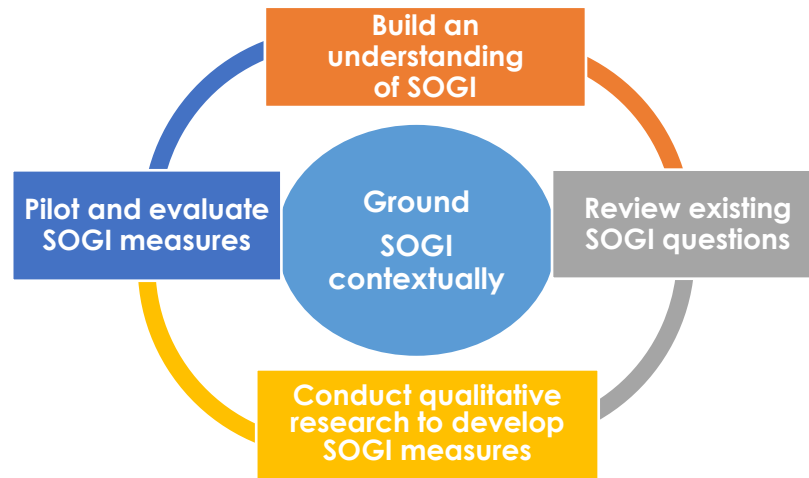
It is important to monitor that the perceived intrusiveness and sensitivity of the information being collected do not lead to a decline in HIV care seeking for potential clients. Frequent check-ins with frontline HIV service providers should be made to ensure that SOGI data collection is not serving as a deterrent to care seeking. In the context of a research study, investigators should monitor the number of refusals or instances where participants stop answering survey questions before the end of the survey to track if the nature of questions may lead to missing data and lack of generalizability.

³ At the same time, the use of long preambles that over-emphasize the potential sensitivity of a question should be avoided, as this may reinforce stigma related to the concept (SMART, 2009).

A PROCESS FOR DEVELOPING SOGI SURVEY QUESTIONS

In the remainder of this report, we present an inductive process for generating SOGI questions. As shown in Figure 2, these steps include a review of SOGI literature, a review of existing SOGI questions, qualitative research to create or adapt SOGI questions, and piloting of SOGI questions using cognitive interviewing. It may not be necessary to complete each step, based on the existing knowledge of the team or program. However, it is recommended that teams consider each step, as the field of sexual and gender studies is rapidly evolving, and new, useful information is constantly emerging. Teams should move from one step to the next sequentially, although it may be necessary to circle back to previous steps based on the outcomes of each one. Table 1 provides a brief definition of each step. The sections that follow provide information needed to complete each step and a summary of where to find useful resources.

Figure 2. Four-step process for SOGI survey development



Build an understanding of SOGI	Review existing SOGI questions	Conduct qualitative research to develop SOGI measures	Pilot and evaluate SOGI measures
<ul style="list-style-type: none"> • Develop an understanding of basic concepts related to sexual orientation and gender identity • Gather and review resources related to the health of SGM populations in your context • Gather and review resources about SOGI from fields adjacent to public health, including gender and sexuality studies, sociology, and anthropology 	<ul style="list-style-type: none"> • Develop an understanding of the various domains of sexual orientation (behavior, identity, and attraction) and gender identity • Decide which domains are most critical for your data needs • Consider the strengths and weaknesses of survey questions and their applicability to your research question and context • Identify areas needing further research to adapt existing measure or develop new ones 	<ul style="list-style-type: none"> • Conduct exploratory research to better understand SOGI constructs • Develop a folk taxonomy related to sexual orientation • Develop a folk taxonomy related to gender identity 	<ul style="list-style-type: none"> • Apply survey questions with a purposefully selected sample of participants • Use cognitive interviewing to evaluate the performance of survey items and refine them

Step 1: Build a Context-Specific Understanding of SOGI

The first step in the process is to ensure that members of the project team have a good understanding of important concepts related to sexuality and gender. In the ideal case, key members of the team would be members of the SGM population under study, following the principle of “nothing about us, without us” (UNDP, et al., 2016). As noted above, through the MEASURE Evaluation project, there is a free online course that explains important components of holistic sexuality, including sexual orientation identity and the distinction between gender identity, expression, and sex assigned at birth. Other useful training material is noted in Box 2. It is important for the project team to take time to explore these concepts and that all people who will be involved in the design, collection, use, and dissemination of data on SGM populations approach this work in an informed and respectful way.

A few important points to remember are:

- Sexual orientation and gender identity are aspects of the human experience that ALL people experience. Everyone experiences gender and everyone experiences sexuality.
- Humans are naturally diverse. We have a wide variety of hair and eye colors, skin tones, heights, shapes, voices, temperaments, and personalities. When we talk about gender and sexual diversity, we are talking about a few of a person’s many facets—biological sex, gender identity and expression, and sexuality—and recognize human diversity across these dimensions.
- By deepening one’s understanding of sexual and gender minorities in the context of all possible gender and sexual orientations, we increase the likelihood of reducing stigma for experiences that may be different from mainstream understanding.
- Diversity in sexuality and gender exists throughout the world. Scientific studies and historical accounts provide evidence of such diversity in nearly every culture and society since ancient times. So, although the terms and concepts may seem new to many people, it is neither a new phenomenon nor something isolated to certain societies.
- Sexuality and gender are culturally constructed, which means that they are concepts that are “constructed” through cultural or social practice. And as culture shifts from one context to another, the ways sexual orientations and gender identities are understood and experienced also shift.

Box 2. Sexual orientation and gender identity training resources

Affiliated with USAID

- A Facilitator's Guide for Public Health and HIV Programs: Gender & Sexual Diversity Training:
<http://www.healthpolicyproject.com/index.cfm?id=publications&get=pubID&pubID=398>
- Broadening Our Understanding of Diversity: Sexual Health and Sexual Diversity Training Manual for Primary Healthcare Professionals:
<https://aidsfree.usaid.gov/resources/broadening-our-understanding-diversity-sexual-health-and-sexual-diversity-training-manual>

Other

- Diversity Training on Gender Identity and Gender Expression:
<http://www.hrc.org/resources/diversity-training-on-gender-identity-and-gender-expression>
- Do Ask, Do Tell! Collecting Data on Sexual Orientation and Gender Identity in Health Centers: <http://www.lgbthealtheducation.org/webinar/sogi-collection-in-chcs/>
- Training Frontline Staff to Collect Data on Sexual Orientation and Gender Identity: <http://www.lgbthealtheducation.org/webinar/training-frontline-staff/>
- Reexamining LGBT Healthcare: http://www.cancer-network.org/reexamining_lgbt_healthcare/
- LGBT Local Projects in a Box: <http://www.amsa.org/advocacy/action-committees/gender-sexuality/lgbt-local-projects-in-a-box/>
- The Safe Zone Project: <http://thesafezoneproject.com/>

In addition to general concepts related to sexuality and gender noted in the resources above, it is also important to review context-specific literature related to these topics conducted by local experts. A literature review can draw on a range of different types of sources, including academic and professional journal articles, books, films, zines and other self-published media, social media, and web-based resources. Search engines can be used to search web resources and bibliographic databases. It is important to evaluate all sources for their authenticity and to use information gained through a lens of the origin of the data (Rowley & Slack, 2004).

Academic Databases

Academic search engines that may be helpful include the following: JSTOR, Sociological Abstracts, Web of Science, and PsycINFO. Some anthropology-specific resources include: Anthropological Index Online (AIO), Anthropological Literature (AL), and Abstracts in Anthropology (AIA). As these topics are currently emerging in academia as hot topics, beyond traditional sources like books and journal articles one might look for papers in conference proceedings, reports, and dissertations.

Note #1: In certain settings, for example, low-income countries, it may be harder to access academic search engines due to financial and technological constraints. There are some initiatives, like the WHO-supported Health InterNetwork Research Initiative (HINARI) (Swartz, 2013), or the Open-Access (OA) movement (Liesegang, 2013), which have aimed to increase accessibility to healthcare literature within low-income countries. However, these are not without their problems (Villafuerte-Gálvez, Curioso, & Gayoso, 2007). If you are working in a low-income country context or otherwise have issues accessing academic databases, these above options may be helpful.

Note #2: Be careful when accessing older anthropological and other academic texts. While these fields have made and continue to make great contributions to this topic, earlier anthropological treatments of SGM populations have been critiqued for analyzing their data using a western lens and therefore promulgating western cultural imperialism. This critique of certain anthropological trends is not limited to SGMs but includes the way the discipline has handled women and many other marginalized groups. Certainly, anthropology has made significant and important contributions to this field, but be cautioned to keep a sharp eye for this issue. Consider utilizing resources by non-western anthropologists and anthropologists coming from a post-modern, feminist, or critical standpoint when learning about a specific cultural context.

Public Databases and Search Engines

Many articles can also be accessed through public search engines, including Google (www.google.com) and Google Scholar searches (<https://scholar.google.com>). In Box 3, illustrative search terms are presented. Reports and professional documents about SOGI or SGM communities will likely have information about these concepts in the local area in an early part of the report. In Appendix A, additional global resources related to SGM populations is presented.

Box 3. Illustrative search terms

Search terms to try include:

Your geographic context
Your target population
Sexual orientation
Gender identity

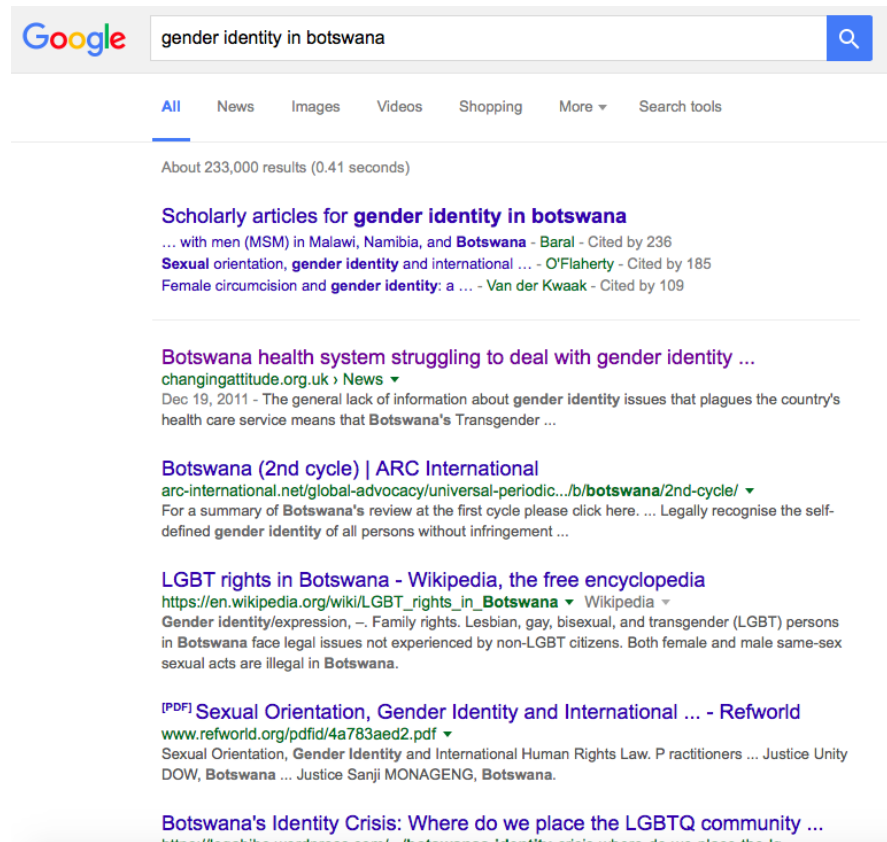
Possible search phrases include:

Gender Identity in "COUNTRY X"
Sexual Orientation in "COUNTRY X"
Gender Identity in "REGION X"
Sexual Orientation in "REGION X"

Case Example: Exploring Gender in Botswana

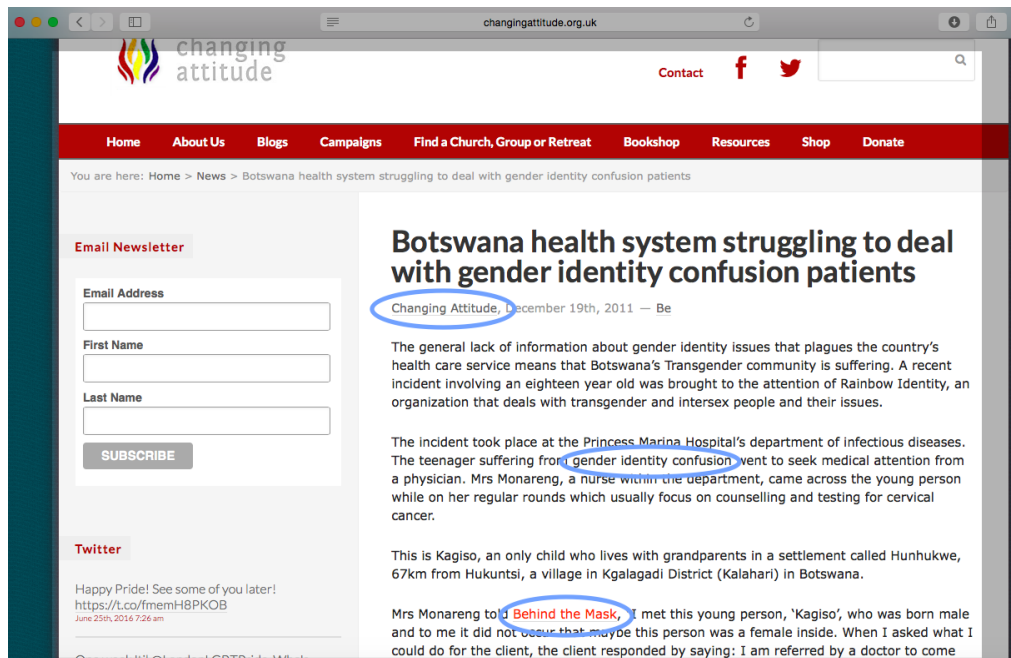
You can see in Figure 3 that the search term “gender identity in Botswana” was used in a standard Google.com search and turned up many possible resources, including scholarly articles and professional documents, and news stories.

Figure 3. Google search for “gender identity in Botswana”



To illustrate, the first link was selected (see Figure 4). A quick review of the article revealed three key pieces of information. First, that there is an organization called “Changing Attitude” that covers news stories of lesbian, gay, bisexual, and transgender (LGBT) issues in Botswana, likely among other topics. Searching on the “Changing Attitude” website by entering “Botswana” in the search bar on their webpage could reveal more information about SGM populations in Botswana, local organizations, and local terminology. Second, the journalist uses the term “gender identity confusion.” This terminology might be new to the project team. They could take a note of this language and either search the Internet for other uses of the phrase in Botswana or keep it as a term to ask about when discussing with local experts. It could be language that would be recognizable in a survey item in this context, or it could be language unique to the journalist. This is something the team should investigate more. Third, “Behind the Mask,” seems to be an organization of some sort that has an interest in SGM issues in Botswana. It is hyperlinked and may lead to further resources, such as potential community partners.

Figure 4. Internet search for “gender identity in Botswana”



Develop Relationships with Community Partners and Stakeholders

Working with community partners, program stakeholders, and data end users will be integral to ensuring that survey items and language are appropriate for the local context and will yield meaningful and applicable data. Well beyond developing an effective survey item, building relationships with community partners can help ensure the overall quality, relevance, and utility of research products and any associated program or interventions. It is also very important to recall that community organizations are often the frontline responders to many of the crises facing SGM communities. These organizations are frequently composed of people reflecting the target populations and living the day-to-day of discrimination, barriers to health access and other concerns HIV programs set out to address.

Step 2: Review Existing SOGI Questions

In the past 10 years, there have been several major projects to improve SOGI measurement in survey research. These include three expert reviews that produced guidance documents on SOGI measures (Sexual Minority Assessment Research Team [SMART], 2009; Gender Identity in the U.S. Surveillance Group [GenIUSS], 2014; Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys [FWG], 2016a; FWG, 2016b) and workshops on SOGI measurement facilitated by the National Institutes of Health (NIH) in the United States (Sexual and Gender Minority Research Office at the National Institutes of Health [SGMRO], 2018). Further, the SGMRO hosts an online compilation of resources about SOGI measurement that includes seminal work by leading scientists and institutes in the United States, and a compendium of survey questions from federal surveys and other research (<https://dpcpsi.nih.gov/sgmro/measurement>).

Recommendations across these resources are that three domains of sexual orientation be measured: **sexual orientation identity**,⁴ **sexual behavior**, and **sexual attraction** (Sell & Petrulio, 1996; SMART, 2009; FWG 2016a). Questions about **gender identity** should be distinct from those about sexual orientation and different than a person's assigned sex at birth (SMART, 2009; FWG 2016a). Given that these resources were developed in the United States, it is important to consider findings in relation to a western cultural lens. Nevertheless, the compendium of SOGI questions is a good starting point for project teams. In the sections below, selected questions for each SOGI domain are presented, along with a rationale for their selection above others in the compendiums. There is no one "right" answer for which question is best. Question selection ultimately depends on the specific needs of each project.

Sexual Orientation Identity

An individual's **sexual orientation identity** is constructed based on emotional and physical desire, actions with other individuals, and how a person perceives and labels their own sexuality (SMART, 2009; FWG, 2016b). **Sexual orientation identity** refers to how an individual thinks about their own sexual orientation and the labels that they feel apply to them. As one component of a person's overall sense of self and identity, sexual orientation identity is based on how a person sees themselves, and their ideals about the type of person they accept themselves to be (SMART, 2009). It is also based on a person's sexual desire and sexual behavior with people of the same or opposite gender, and how they understand this to be relevant to their sexual identity (Dailey, 1981; National Resource Center on LGBT Aging, 2016; Talley & Stevens, 2017).

Box 4. Sexual orientation identity question

Do you think of yourself as:

- Straight or heterosexual, that is, not gay or lesbian
- Lesbian, gay, or homosexual
- Bisexual

In Box 4, one approach for measuring sexual orientation identity is presented (National Resource Center on LGBT Aging, 2016). There are several reasons this question and set of responses was selected from the multitude of those listed in the above-named reviews.

- By wording the question stem as, "Do you think of yourself as..." the respondent's personal perception is highlighted as the key information needed for their response.
- The number of response options is within the recommended range (three to five) for survey research (Aday, 1996).
- The terminology "straight or heterosexual" has been tested among cross-cultural contexts and has performed better than using only "heterosexual," at least in English-to-Spanish translation (Ridolfo, Miller, & Maitland, 2012).

⁴ Various sources use different terms for the dimension we refer to as "sexual orientation identity." The SMART 2009 recommendations use the term "self-labeling," while the U.S. Federal Working Group on SOGI measurement uses the term "sexual identity." However "sexual identity" is also a term used in the field of sexual health under the commonly accepted framework of "holistic sexuality" (Dailey, 1981). In the holistic sexuality framework, sexual identity refers to a more complex set of constructs (biological gender, gender identity, gender role, sexual orientation). For this reason we use the term "sexual orientation identity."

There are several adaptations to this question that project teams might consider:

- One option is to add a short definition for each response option, for example: lesbian, gay, or homosexual (attracted to people of the same sex); straight or heterosexual (attracted to people of the opposite sex); bisexual (attracted to men and women).
- Project teams may adapt the question to be inclusive of transgender partners, for example omnisexual or pansexual (attracted to men, women, and transgender people).
- Another common adaptation is to present response options on a continuum, for example, completely heterosexual, mostly heterosexual, bisexual, mostly homosexual, or completely homosexual. This latter adaptation adds complexity to question administration and analysis but may be a worthwhile tradeoff for a project needing this level of detail.
- Project teams might include a “Not listed above. Please specify_____” response option that would allow respondents to include their own identity category. This will allow important but less frequent categories to be captured, and new categories can emerge. However, this category could be very small and, therefore, may ultimately be discarded during analysis. Re-coding of open-ended questions is also labor intensive (SMART, 2009), and requires the researcher to make decisions about the respondent’s self-identification, which may not be accurate.
- Project teams might include a “not sure” option to avoid forcing respondents to select a category that is not authentic or true when they are not yet able to select an identity category. In this case, the interviewer should ask if they are “not sure” because they are questioning their sexuality, or if they did not understand the question. The tradeoff with including this response option, similar to that of “Not listed above. Please specify_____” is that it may ultimately end up being a small category and could divert respondents that might select another SGM category if they were restricted (SMART, 2009). It also makes the data less straightforward for the analyst to code and interpret, and therefore potentially less likely to use.

Compared to other domains of sexual orientation (behavior and attraction), sexual orientation identity is the most difficult to standardize across cultural contexts. This is because identity formation is an interpersonal process and is greatly influenced by the interaction of an individual with others and by messages received about broader cultural and social norms. The terminology used for identity categories are also more likely to differ across cultural settings than those for the other domains. For this reason, project teams may need to consider qualitative research methods (presented in Step 3) to adapt their question for sexual orientation identity.

Sexual Behavior

Sexual behavior refers to the relationship between a person’s gender and the gender of the individuals with whom they engage in sexual activity (for example, the same gender, opposite gender, or both) (SMART, 2009; FWG, 2016b). This is the most commonly used measure in HIV programs, because transmission of HIV can occur through unprotected sexual activity. In Box 5, one approach for measuring sexual behavior is presented (National Resource Center on LGBT Aging, 2016). There are several important aspects of this question to consider. First, it uses a set time frame for asking about a person’s sexual activity. This is important because recent sexual activity is the most relevant for providing individualized sexual health counseling. The time

period should be neither too short (since sexual activity may not be an ongoing occurrence) nor too long (to avoid problems of recall). Including a time period would also allow the project team to measure changes in sexual behavior if data about a client are captured at multiple time points. Other commonly used recall time periods in sexual health surveys include three months and 12 months.

Another important aspect of the question is that the respondent can “choose all that apply.” This keeps the number of response options manageable, but it still allows data analysts to code respondents who have bisexual, pansexual, or omnisexual activity, meaning sexual relations across gender categories including those that are non-binary. A newer aspect of the question compared to others listed in available compendia is the inclusion of “transgender man” and “transgender women,” as potential partners. Without these, the respondent would face the impossible task of guessing whether the question means to categorize partners based on their partner’s sex assigned at birth or gender. Depending on the specific research needs, the project team may choose to adapt the question so that it is more specific about the type of sexual activity (for example, sexual intercourse). Response options may be condensed to “transgender person” or could be expanded to include other trans identities (for example, transqueer), again based on the goals of the specific research.

Sexual Attraction

Sexual attraction refers to sexual desire one feels towards another person, which may or may not result in sexual activity. This is a particularly important domain of sexual orientation to measure when conducting surveys among youth and other people who may not currently be sexually active. It may also help identify people who are bisexual but have only had sexual contact with someone of the same or different gender during the reporting period. A person may be attracted to someone of the same gender, different gender, both, or no one.

Fewer questions have been examined and piloted related to sexual attraction compared to the other sexual orientation domains. The example question and response options in Box 6 are different from questions included in the compendia referenced above in several ways. First, they include response options for transgender men and transgender women, in addition to men and women. The

Box 5. Sexual behavior question

In the past six months with whom have you engaged in sexual activity? Choose all that apply:

- Men
- Women
- Transgender men
- Transgender women
- I have not engaged in sexual activity with a partner

Many cultures promote the assumption of a dominant heterosexual identity that is static. But identities, including for sexual orientation and gender, may differ over the course of an individual's life.

Box 6. Sexual attraction question

People are different in their sexual attraction to other people. Which best describes your feelings? Choose all that apply:

- Attracted to men
- Attracted to women
- Attracted to transgender men
- Attracted to transgender women
- No sexual attraction to others

question also includes an option for no sexual attraction, to correctly identify people who are asexual. Similar to questions for other domains, it includes an option to “choose all that apply” to accurately identify people with attraction across gender categories. It is important to combine this question with those of the respondent’s own sex and gender identity (described in more detail below).

Gender Identity

To understand **gender identity**, it is first important to review the key concepts of sex and gender, including how they are distinct and where they overlap. Sex refers to a person’s biological status (chromosomal, hormonal, gonadal, and genital) that is labeled male or female. This labeling of sex is typically termed **sex assigned at birth** and is usually based on the appearance of external reproductive anatomy by those present at birth (e.g., doctor, midwife) (FWG, 2016b; Institute of Medicine of the National Academies, Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, 2011). Gender is a core sense of person’s identity in relation to cultural and social aspects of being masculine, feminine, or elsewhere along this continuum (for example, genderqueer). Gender norms are the attitudes, feelings, and behaviors that a given culture associates with a person’s biological sex. It is a social construct that varies across culture and time.

Gender identity is the personal experience of oneself as a boy or man, girl or woman, as a mix of the two, as neither, or as a gender beyond man or woman (Winter, et al., 2016). All people are assigned a sex at birth and develop a gender identity. For some people, their sex assigned at birth is consistent with their gender identity, and for others it is not. Gender nonconformity refers to the extent to which a person’s gender identity differs from the social norms and expectations traditionally associated with their sex assigned at birth. The term transgender is one of the most commonly used terms to describe a person whose sex assigned at birth and true gender identity do not match (Smalley, Warren, & Barefoot, 2018). Additional ways used to describe gender-nonconformity include genderqueer, non-binary, androgynous, and two-spirit, among others (Smalley, et al., 2018). In contrast, the term “cisgender” refers to people whose sex assignment at birth corresponds to their gender identity. The prefix “cis” is derived from the words “consistent in sex” (Winter, et al., 2016).

A “two-step method” for measuring gender identity is recommended by leading organizations in transgender health, including the World Professional Association for Transgender Health, the Center for Excellence for Transgender Health, and the Gender Identity in U.S. Surveillance Research Group (Sausa, Sevelius, Keatley, Iniguez, & Reyes, 2009; SMART, 2009; GenIUSS, 2014; FWG, 2016b). This method involves asking respondents two separate questions about their sex assigned at birth and their gender identity, as illustrated in Box 7.

The first question measures gender identity. Response options include transgender woman and transgender man rather than a broader transgender category because of the increased risk for HIV among transgender women, specifically, that is important for HIV programming. There are many ways these response categories

Box 7. Questions to measure gender identity and sex assigned at birth

1. *What is your gender identity?*

- Man
- Woman
- Transgender man
- Transgender woman

2. *What sex were you assigned at birth?*

- Male
- Female

could be expanded given the diversity in types of trans identities. This should be explored by the project team and considered in relation to the ways the data will be used. “Transgender” is selected here since it is currently one of the more commonly used gender non-conforming identities (Smalley, et al., 2018). Some past surveys have used the categories of “transgender male-to-female” or “transgender female-to-male,” but this does not align with commonly used terminology for self-identification among trans communities. To measure sex assigned at birth, the second question uses the response options of “male” and “female” to refer to biologically defined sex.

SOGI Questions and PEPFAR Reporting

Many project teams working globally in the field of HIV are funded by PEPFAR and will want to use their SOGI data to classify clients as members of the HIV key populations of MSM and transgender people. In PEPFAR’s 2017 *Monitoring Evaluation and Reporting 2.0 Indicator Reference Guide (MER 2.0)*, recommendations are made on the classification of key populations (PEPFAR, 2017). The information is then used to calculate several key population-specific indicators. The questions and response categories recommended above can be used to complete this classification. For example, the first question in Figure 5, “Do you consider yourself: male, female, transgender or other?” aligns with the proposed questions for gender identity, “What is your gender identity?” The proposed question has the advantage of using gender (man, woman) rather than sex (male, female) terminology and uses terms that correspond with how a person might truly identify (e.g., transgender woman) rather than using an etic and more biomedical term (e.g., transgender male-to-female). The second question in Figure 5, “What was your sex at birth?” aligns with the proposed question related to sex assigned at birth, “What sex were you assigned at birth?” However, the latter has the advantage of correctly highlighting that sex categories are assigned rather than wholly innate characteristics (Kelly, 2016; FWG 2016b). Finally, the third question in Figure 5, “Do you have sex with: men, women or both?” aligns with the proposed question for sexual behavior, “In the past six months, with whom have you engaged in sexual activity?” The proposed question has the advantage of including the categories of transgender man and transgender woman as response options, as well as including a fixed-time parameter for recall of the behavior.

Figure 5. PEPFAR MER 2.0 key population classification (PEPFAR, 2017, p.166)

<p>1. Do you consider yourself: male, female, transgender or other?</p> <p style="text-align: right;"><input type="checkbox"/> MALE</p> <p style="text-align: right;"><input type="checkbox"/> FEMALE</p> <p style="text-align: right;"><input type="checkbox"/> TRANSGENDER (male to) FEMALE</p> <p style="text-align: right;"><input type="checkbox"/> TRANSGENDER (female to) MALE</p> <p style="text-align: right;"><input type="checkbox"/> _____ OTHER</p> <p style="text-align: right;"><input type="checkbox"/> REFUSE TO ANSWER</p>	<p><i>If TRANSGENDER (male to) FEMALE: client was born a boy, but identifies as a woman</i></p> <p><i>If TRANSGENDER (female to) MALE: client was born a girl, but identifies as a man</i></p>
<p>2. What was your sex at birth: male or female?</p> <p style="text-align: right;"><input type="checkbox"/> MALE</p> <p style="text-align: right;"><input type="checkbox"/> FEMALE</p> <p style="text-align: right;"><input type="checkbox"/> _____ OTHER</p> <p style="text-align: right;"><input type="checkbox"/> REFUSE TO ANSWER</p>	
<p>3. Do you have sex with: men, women or both?</p> <p style="text-align: right;"><input type="checkbox"/> MEN ONLY</p> <p style="text-align: right;"><input type="checkbox"/> WOMEN ONLY</p> <p style="text-align: right;"><input type="checkbox"/> BOTH MEN AND WOMEN</p> <p style="text-align: right;"><input type="checkbox"/> REFUSE TO ANSWER</p>	

Comparing SOGI Questions: An Example from Nicaragua

In this section, data from an ongoing HIV program in Nicaragua is presented to demonstrate the way that the wording of survey questions can influence what we understand about clients of HIV services.⁵ In Nicaragua, the HIV epidemic is concentrated in key populations, with HIV prevalence estimated at 7.5 percent among MSM and 13.8 percent among transgender women, but only 0.003 percent in the general population (Jarquin, Ochoa, Larios, & Hernandez, 2013). The *Centro Para la Educación y Prevención del SIDA* (CEPRESI) is an NGO located in Managua, Nicaragua with more than 25 years of experience providing HIV prevention, HIV counseling and testing, and HIV treatment support services to the MSM and transgender communities. CEPRESI provides services to support the human rights of MSM and other sexual minorities, sexual and reproductive health, masculinity, and human sexuality. The organization is large in size, and well networked with other civil society groups serving SGM. CEPRESI works together with the Ministry of Health in Nicaragua (MINSa) to facilitate access to ART for HIV-positive clients. Clients of CEPRESI are able to obtain CD4 tests on site, and they also have access to an in-house social worker who provides psychological support for treatment adherence. Clients access ART through MINSa.

CEPRESI uses two main forms to collect data about their clients—MINSa’s standard “Epidemiological Surveillance” form and its own, more in-depth “Clinical and Social History” form. Data from these forms are used to report to multiple donors including PEPFAR and Global Fund. For the present analysis, data for all clients from 2014 through 2018 and HIV-positive clients through the first quarter of 2019 were included. Complete MINSa forms were available for 560 clients, and a complete Clinical and Social History form was available for 510 clients. Each form includes a different **sexual behavior** question, as follows:

Have you had sex with someone of the same sex?

Yes No (MINSa Epidemiological Surveillance form)

Any time in your life, have you had sex with someone of the same sex?

Men Both Women (Clinical and Social History form)

The phrasing of the response options for the first question resulted in little useful variance to understand differences in clients, as all but one of the 560 respondents reported, “Yes.” In contrast, the second question which was from the “Clinical and Social History” form captured more variance, with 255 clients reporting “Men,” 254 clients reporting “Both,” and only one reporting “Women.” This enabled the distinction between clients having sex only with men, only women, or both men and women. A limitation of both questions is the absence of a time period to bound when the sexual behavior occurred. On average, clients were 28 years old (range 16–63 years) and had had their first sexual experience at 16 years old (range 6–27). They may have had sex with someone of the same sex only once at 16, throughout their life, or only very recently. Without a fixed recall period for sexual behavior, it is difficult to use the information to understand current sexual risk.

Fortunately,

⁵ The proposed analysis was reviewed by Tulane University’s Biomedical Institutional Review Board for Human Subjects Research. This secondary analysis was approved as exempt.

both forms also captured information about sexual orientation identity so that there is an additional way of understanding the sexual orientation of clients. The **sexual orientation identity** questions included are:

How do you identify?

Heterosexual Bisexual MSM Transgender Other (MINSA Epidemiological Surveillance form)

How do you self-identify your sexuality?

Gay Travesti Transgender Transsexual Homosexual Heterosexual Bisexual Other (Clinical and Social History form)

A major drawback of both questions is that response options to capture gender identity (travesti, transgender, and transsexual) are mixed in with options relating to sexual orientation. Clients were coded only with one response option (rather than “all that apply”). This means that a transgender person would have to choose to report either on their gender identity or their sexual orientation. In some contexts, response options might be designed that way because sexual orientation and gender identity are not conceptually distinct, but this is not the case in Nicaragua. Neither form contains a question about sex assigned at birth, although the MINSA form includes a question about “sex” with the response options of “male” or “female.” The only “trans” response selected was “transgender” by 36 respondents. Future versions of the question may consider collapsing travesti, transsexual, and transgender as one response option.

A comparison of the two sexual orientation identity questions showed incongruence in the responses, mostly related to the MSM category. Because the response categories on the Clinical and Social History form align better with locally used terminology and more nuanced identities (compared to MSM), we used this question in further analysis. The categories “gay” and “homosexual” were combined. Respondents were classified based on gender identity (36 transgender respondents, 474 MSM). Since it was not possible to know transgender respondents’ sexual orientation identity, only cisgender respondents were able to be classified based on their sexual orientation identity.

Table 1 presents a comparison of clients’ reported sexual behavior and sexual identity orientation. In total, 253 clients self-identified as gay/homosexual, 108 as bisexual, and 109 as heterosexual. Most clients who reported only having sex with men also reported that they were gay or homosexual (95%). There was greater diversity in identity for clients who reported their sexual behavior as having had sex with both men and women—40 percent identified as bisexual, and 42 percent identified as heterosexual. This is an example of where, without information about clients’ sexual orientation identity, heterosexual MSM may have been misclassified as bisexual based on their reported behavior. The incongruence between behavior and identity may be a result of mismatched time periods, with clients’ identity more linked to recent behavior, whereas the behavior question spans the respondent’s lifetime. Or it may be that clients who identify as heterosexual are not accepting of a gay, homosexual, or bisexual label despite their sexual activity. The major value added of having both the sexual orientation identity and sexual behavior questions is that we can examine difference in HIV risk behavior and HIV outcomes for each group when discordance in classification arises.

Table 1. Comparison of cisgender clients' reported sexual behavior and sexual orientation identity (n=470)

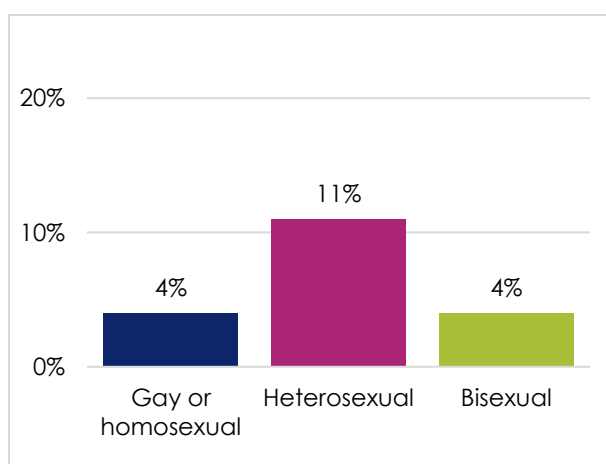
Sexual Orientation Identity	Sexual Behavior			
	Men	Both	Women	Total
Gay/homosexual	208	44	1	253
Bisexual	9	99	0	108
Heterosexual	2	107	0	109
Total	219	250	1	470

The forms used by CEPRESI also collected information on HIV status, HIV treatment and care, and HIV risk behavior. In terms of HIV prevalence, we see similar results for clients reporting sexual behavior only with other men (31% HIV positive) and clients reporting their identity as gay or homosexual (32% HIV positive). Among clients who report sexual behavior with men and women, the HIV prevalence was 19 percent. Comparing this to identity categories, we see the same HIV prevalence among heterosexually identified clients (19%) and those reporting sexual behavior with both men and women, but a much lower prevalence among clients who identify as bisexual (only 9%). Without the information about identity, we would not have been able to observe this lower HIV prevalence among bisexually identified clients.

Moving across the HIV treatment cascade, there was little variability—all 146⁶ HIV-positive clients were retained in care, referred for clinical services, and were on ART. All but five HIV-positive clients (4%), had their first follow-up consultation within one month of being diagnosed with HIV. Thirty-two clients had information on CD4 counts, and only eight had CD4 counts under 200 cells/ μ L. This level of variability and the small number with CD4 data prohibited a treatment cascade analysis disaggregated by sexual orientation or gender identity.

In terms of HIV risk behavior, however, we continue to see the importance of categorizing clients as heterosexual and bisexual using the identity question. For example, drug use in the last 12 months was reported by 11 percent of clients who identified as heterosexual but only 4 percent of gay or homosexual men and bisexually identified men (see Figure 6). Using only sexual behavior would have masked this difference among heterosexual MSM—only 5 percent of clients reporting sex with men and 7 percent of clients reporting sex with both men and women used drugs in the last 12 months. Condom use at last sex was also lower among heterosexually identified men (25%), compared to 44 percent among gay or homosexual men and 41 percent among bisexually identified men. Again,

Figure 6. Percentage of clients reporting drug use in the last 30 days by sexual orientation identity



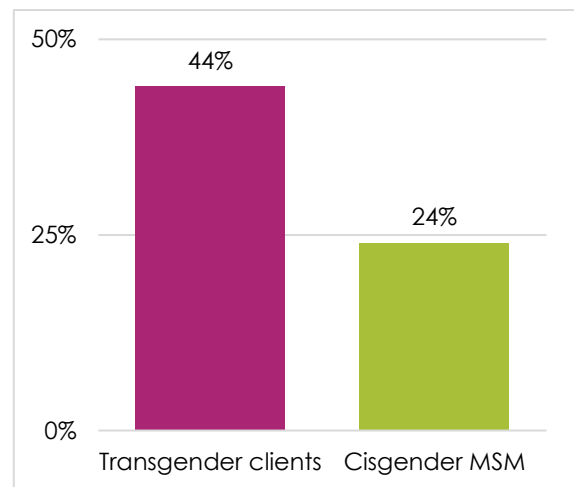
⁶ Two HIV-positive clients had missing data for retention variables.

using only sexual behavior would have masked this difference—48 percent of clients who reported sex only with men and 34 percent of clients who reported sex with both men and women used a condom at last sex.

Data on gender identity were also examined to understand potential differences between transgender clients and cisgender MSM. However, it should be noted that only 36 clients identified as transgender, and it is possible that a substantial number may be misclassified as cisgender because of the combination of response options for gender identity and sexual orientation. The HIV prevalence was higher among transgender clients (44%) compared to cisgender MSM (24%) (Figure 7). Several risk behaviors were also higher, including sex work in the last 12 months (50% among transgender clients vs. 3% among cisgender MSM), drug use in the last 30 days (14% among transgender clients vs. 5% for cisgender MSM), having an STI in the last 12 months (29% among transgender clients vs. 10% for cisgender MSM), and receptive anal sex in the last 30 days (67% among transgender clients vs. 21% for cisgender MSM). However, transgender clients were more likely to use a condom at last sex (66% among transgender clients vs. 59% for cisgender MSM).

Moving forward, there are several way the questions to capture SOGI data might be adapted by CEPRESI. Most notable is the need to use the two-step method for measuring gender identity. Adding a specific time period for sexual behavior would also be helpful. However, using these data, we can still see the importance of triangulating information for domains of sexual orientation. Having *both* the questions on sexual behavior and sexual orientation, we were able to capture the increased HIV risk behavior for MSM who identify as heterosexual in terms of drug use and condom use. This information can be used to inform differentiated HIV prevention programs.

Figure 7. HIV prevalence by gender identity



Step 3: Qualitative Research to Develop or Adapt SOGI Questions

In public health, qualitative methods with open-ended question formats are often used to obtain descriptive data to inform program design (Gittleson, et al., 2006). Therefore, most readers of this report will likely be familiar with general concepts of exploratory qualitative inquiry. Perhaps less familiar to public health practitioners, however, are specific qualitative methods used to elicit and construct classificatory systems of social constructs, including those related to sexuality and gender. In this section, an overview of these techniques is provided along with illustrative open-ended questions that might be used to construct domains.

Classification underlies the basic cognitive process of data reduction necessary to function in our everyday world. Cognitively, all humans use symbols to represent “bounded sets of meaning.” In social science research these bounded sets of meaning are commonly referred to as “domains.” Put another way, domains represent coherently defined concepts. These concepts are composed of items that are interrelated and mutually reinforcing. Items within a domain also represent something unique about that concept.

The concept of color is an example of a common conceptual domain across cultures.⁷ Within this domain, items include different types of colors, such as red, blue, pink, and purple. They are similar, but also different. In some contexts, red and blue might be further grouped into the subdomain of primary colors. In contrast, pink and purple might be grouped into the subdomain of secondary colors—those created by the blending of two or more primary colors. However, across cultures, the colors included in this conceptual domain are known to differ (Berlin & Kay, 1969) and to hold different meanings (for example, “red” symbolizes a life stage in some cultures, while it symbolizes danger in others). In some contexts, it is argued that there are no words related to color, because people do not form conceptual groups by this domain (Jones, 2017) but rather may define domains based on the function, size, or texture of objects.

The complexity and cross-cultural differences illustrated by the simple domain of color grow exponentially when considering social constructions like sexuality and gender. For this reason, an understanding of the cultural domains related to sexuality and gender is needed to ensure the construction of appropriate survey measures. By reviewing context-specific literature on sexuality and gender, project teams may have developed a good understanding of these cultural domains. Eliciting the perspective of members of the community can help to make sure these domains are up-to-date.

Qualitative methods that can help construct classificatory systems include in-depth interviews, focus groups, free lists, and pile sorts. Strategic use of open-ended questions through each method can help identify appropriate and familiar categories and terminology that will increase a respondent’s comprehension of questions and ability to provide accurate responses. These types of methods are used in a field of study known as “folk taxonomy” that focuses on how a culture names, identifies, and classifies groups (Bernard, 2011). Used together, these techniques can help gather useful information to:

- Understand boundaries of culturally appropriate groups for classification of sexual orientation and gender categories
- Describe important characteristics used to determine membership in the defined groups
- Identify culturally appropriate terminology that can be used to ask participants about their membership in the defined groups

Individual Interviews and Focus Groups

There are many different styles of interviews, including informal interviews, in-depth interviews, structured interviews, and expert interviews. Each one provides an opportunity to learn more about sexual orientation and gender identity.

- **Informal interviews** frequently happen in the context of observations and are spontaneous, and often opportunistic. Questions are not planned ahead of time but arise organically based on the context. An example of an informal interview might be that the researcher identifies an employee of an AIDS service organization in a meeting about another topic and asks that employee what they know about the LGBT community in the particular context.
- **In-depth interviews** are often semi-structured, do not occur spontaneously but instead are scheduled, and are directed by a topic guide prepared in advance. Topic guides cover the study’s key domains and

⁷ See the world color survey at <http://www1.icsi.berkeley.edu/wcs/>.

have possible questions and prompts, but they do not get administered like a script. The interviewer works from the topic guide but improvises based on the responses elicited.

- **Structured interviews** expose all respondents to the same set of questions and prompts. This often looks like an interviewer-administered survey (Bernard, 2011).
- **Expert interviews** may target highly regarded practitioners (for example, the executive director of an LGBT NGO), policymakers, or public figures who can add an insider perspective. Such interviews need to be highly planned. These are people who often have little extra time and a reputation that can be tarnished if the interview/research should misrepresent them. Questions are usually tailored specifically to the respondent to maximize efficiency and collect the unique information that the respondent has to share (Padgett, 2012).

In-depth interviews are one of the most commonly used types of individual interviews. In Box 8, a sample interview guide for an in-depth interview is provided to explore sexual orientation and gender identity domains. Separate questions are included to accomplish the three objectives noted above—to bound concepts, describe inclusion/exclusion criteria, and elicit appropriate terminology.

Focus groups are a style of group interview that was originally developed for marketing and polling. They are designed to query people of similar backgrounds who do not know each other, with the idea that familiarity encourages people to open up. Focus groups are conducted by a moderator who asks open-ended questions, and they often have a note taker to record participants' comments. Aside from asking the questions and follow-up prompts, the moderator guides and manages the conversation so that no one dominates the group and everyone has an opportunity to share their input (Padgett, 2012). Similar open-ended questions as listed in Box 8, could be used to facilitate a focus group discussion aimed at generating sexual orientation and gender identity domains.

Box 8. Sample in-depth interview topic guide

I. Sexual Orientation

- How would you define sexual orientation?
- What are some examples of the different types of sexual orientations?
- Tell me about each of these types of sexual orientations—how are people similar and different in each group?
- Are certain sexual orientations more or less stigmatized or discriminated against?
- What terms are commonly associated with the different types of sexual orientation?

II. Gender Identity

- How would you define gender identity?
- What are some examples of the different types of gender identities?
- Tell me about people whose gender identity is different from the sex they were assigned at birth.
- Tell me about each of these types of gender identity—how are people similar or different in each group?
- Are there certain gender identities more or less stigmatized or discriminated against?
- What are common terms associated with gender identities?

III. Existing Resources

- Do you know of any organizations, groups, or community leaders that do work around these issues?
- Do you know anyone who collects data or conducts surveys with this community?

The broad questions used to define a cultural domain will yield narrative data that should be analyzed using textual analysis. In both individual interviews and focus groups, responses should be recorded verbatim when possible and transcribed to facilitate analysis. Otherwise, interviewers should make detailed notes during and after the discussion. This is because it is important to document details in the language used by participants to inform phrasing in subsequent free lists and pile sort exercises, as well as in the final survey questions developed. In this report we will not review the details of textual data analysis. However, we provide the following general guidelines:

- Data should be reviewed as they are collected so that what is learned in earlier interviews can be applied to adjust questions and probing in subsequent interviews. Completion of summary forms after each interview and review of audio recordings while transcriptions are being prepared should be done concurrently with data collection.
- Once data collection and transcription are complete, the coding of the data to represent key ideas and concepts related to domains of sexual orientation and gender identity should be conducted. Coding is only the first stage of analysis that allows you to sort segments of text.

- The coded text should be reviewed to determine where there is—and is not—consensus. The results of this analysis should guide subsequent pile sorts and free lists.
- If focus groups are used, it is important to note that the unit of analysis is the group discussion, not each person participating in the group.

Project teams may consider hiring a qualitative research consultant to provide additional guidance on sampling and textual data analysis. Additional resources about how to conduct qualitative research are also available through the MEASURE Evaluation project (<https://bit.ly/2mrqtv1>).

Free Lists and Pile Sorts

Free lists and pile sorts are two examples of qualitative research methods used to help identify local understandings of cultural domains. Free lists are a simple yet powerful research method. The goal is to get respondents to list all the items within a domain (Weller & Romney, 1988; Bernard, 2011). Free lists are usually conducted as part of an individual interview. Some examples of leading questions are:

What are names for different genders?

What are names for different sexual orientations?

What are names for different types of sexual relationships?

What are words associated with these issues?

The interviewer would start with a few questions and use prepared question probes to encourage respondents to think of more responses. One probing strategy is to repeat the question and shift the respondent's language, for example:

You mentioned _____. Can you think of any additional names for different gender identities? Please keep trying to think of additional names for gender identities.

Another probing strategy is to use semantic clues, for example:

You said X is a gender identity. What other gender identities are similar to X? Is there another word that some people might use for X? You also mentioned Y. What other gender identities are similar to Y? Is there another word that some people might use for Y? (Continue with each term offered.)

Once the initial list of terms is generated, the interviewer should prompt respondents with additional questions related to the saliency and meaning of terms. For example, in many contexts, both affirming and pejorative terms for sexual and gender minorities exist, and sometimes terms can be used both ways. The interviewer might ask about using questions such as:

Now let's go back and you can tell me which terms are kind terms, and which ones are negative. Some might be both or neither, and you can explain that to me as well.

You mentioned that X can be used both ways. Are there certain groups that use it one way versus another? How would you describe those groups? (i.e., older people vs. younger, or SGMs use it in an affirming way, or men who are not SGMs use it negatively but women who are SGM use it lovingly, etc.)

The free-listing activity should be repeated with multiple respondents and ultimately create a master list of terms for each prompt. In some cases, depending on the cultural context, sexual orientation terms and gender identity terms will overlap, while in others these will be separate and distinct groups. A pile sort activity can help project teams figure this out, as described below.

Once the project team has a list of terms, the next task is to figure out how the terms relate to each other. The project team should first review the free lists from various respondents and then go back to participants with a combined list that includes the most commonly reported terms. Participants in the first stage of the research could be invited back, or new people could be asked to participate. Each term should be written on its own card.

There are various types of pile sorts. A good one for these purposes is the free pile sort. In a free pile sort, the interviewer will give the cards to the respondent and ask them to arrange the cards according to which ones belong together. The respondent should be assured that there are no right or wrong answers and that the project team just wants to know what they think. Respondents can make as many piles as they like, as long as there is more than one pile and less than the number of cards (i.e., each card in its own pile). Keep in mind that some people will tend toward “lumping,” that is, putting most cards together and having few piles, while others will tend toward “splitting,” recognizing each card’s uniqueness and having many piles. After the respondent is finished the interviewer should ask the respondent to describe their process for sorting and how they would describe each pile. Respondents could also be asked to sort again within a specific pile, if that will be of interest (Weller & Romney, 1988; Bernard, 2011).

Another technique which can be used with respondents is known as frame elicitation. Using this technique, the interviewer would craft open-ended questions in a different way. For example:

What kinds of _____ are there?

*What kinds of **sexual minorities** are there?*

*What kinds of **gender minorities** are there?*

Once an initial list of sexual minorities is generated, the interviewer can review each item with the respondent to elicit more nuances in a category. Respondents may have more categories for some of these terms but not for others. For example, if someone was interviewed in the United States about sexual minorities, the exchange might go like this:

What kinds of sexual minorities are there?

Gays, lesbians, bisexuals, and queers

What kinds of gays are there?

MSM, gay men, bears, twinkles.

What kinds of MSM are there?

All of the others are MSM.

Are there other kinds of MSM?

Yes, also some men who identify as heterosexual also have sex with men so would be considered MSM.

What kinds of bears are there?

I don't know.

What kinds of lesbians are there?

Butch, femme, switches, lipstick lesbians, that's all I know.

What kinds of butches are there?

I don't know.

Of course, there may be some overlap; for example, the term queer can be used by sexual and gender minorities. When creating folk taxonomies, there are multiple points of which to be aware:

The first is inter-informant variability. Not everyone will know the same terms or use them in the same way. That is inherently part of what the project team is trying to figure out. Part of the complexity of the endeavor is reckoning with the levels of contrast that are found. These are the terms that are most likely to be misunderstood if used in a survey with a wide range of respondents (Bernard, 2011).

In many parts of the world, information obtained in this initial phase of research will support the separation of sexual orientation and gender identity constructs as categories that are correlated, yet distinct. However, in some parts of the world, it would be conceptually confusing to participants to separate these constructs in survey questions. (One example of this is in Nepal, as described in the next section.) This may be because distinct conceptual domains truly do not exist in the culture being studied. However, it may also be because of the highly stigmatized nature of certain gender identities or sexual orientations that limit common knowledge and development of language to articulate distinctions in groups. In some settings, previous experiences of colonialism and other forms of imperialism may have layered a binary concept of gender and sexuality on top of richer fluidity that existed in native cultural groups. In this case, "scratching beneath the surface" with open-ended questions may reveal deeper connections among concepts.

Development of categories that correspond to the local taxonomy will yield more valid data from participants. At the same time, researchers should strongly consider using separate categories for gender identities and sexual orientations when possible and appropriate. For many years, epidemiological and programmatic data for HIV were reported under the umbrella term MSM, mistakenly clustering transgender people under this group and limiting their visibility and unique health needs. In many contexts, including the United States and other western cultures, this classification system did not match cultural domains, and it slowed the development of an effective and evidence-based response to the HIV epidemic among transgender populations. This same mistake should be avoided in the future.

Using Research to Understand Sexual Orientation and Gender Identity in Nepal

In this section, the case of Nepal and research conducted by the Williams Institute and Blue Diamond Society are presented to demonstrate the potential for overlap in sexual and gender categories and how research can help uncover this (Knight, 2014). A 2007 Supreme Court case in Nepal ordered the government to create a legal category for people who identify as neither male nor female. The judgment dictated that the ability to get documents bearing a third gender should be based on “self-feeling” and not external tests or “expert opinions.” While attempts to put this policy into practice have had their struggles, in 2011, Nepal included a third gender in its census. “Third gender” is sometimes used as an umbrella term to refer to sexual and gender minorities in Nepal, though many other terms are also used to express sexual orientation and gender identity. In addition to English-language terms that roughly correspond with the “LGBTI” acronym, Nepal employs terms for identities that are unique to the Nepali experience, and these terms do not fall discretely or solely under legal or conceptual headings of either sexual orientation or gender identity. Any attempts to collect data about people who identify with these terms need to incorporate these terms and concepts meaningfully (Knight, 2014).

The following terms were identified and operationalized in various health studies in Nepal. Note the use of both Nepali terms and English-language terminology.

- *Meti*: Effeminate men attracted to the same sex, who sometimes cross-dress and have a receptive role during anal sex
- *Ta*: Masculine-appearing men and sexual partners of *meti*
- *Kothi/panthi*: The *kothi* perceives himself and his desire for other males in the context of gender roles in South Asia, i.e., the “penetrated” partner. *Kothis*, identifying as feminized males, construct their social roles, mannerisms, and behaviors to attract what they call *panthis*—“real men.” In this context, *kothis* are usually the visible MSM in a range of public environments and neighborhoods, but *panthis* are not, for they could potentially be any “manly” male (Cohen, 2005).
- *Fulumulu*: A term that commonly corresponds closely with *meti*. It is attributed to languages spoken in Nepal’s eastern hills and mountains.
- Bisexual: Men who are sexually attracted to both men and women.
- Homosexual/gay: This is a broader term representing sexual orientation (attraction to the same sex). In Nepal, some upper- and middle-class men, especially educated ones, use this term to describe their sexual orientation (Oli & Onta, 2012; Deuba, et al., 2013; Knight, 2014).

A 2014 study, “Surveying Nepal’s Sexual and Gender Minorities: An Inclusive Approach” was a joint effort of the United Nations Development Programme, the Williams Institute, and Blue Diamond Society (BDS) (Knight, 2014). In this study, 1,200 respondents wrote in 21 different terms to describe their primary gender and/or sexual identity. Notably, 51.4 percent of the sample used third gender, third gender woman, or third gender man (the language used in the 2011 census), indicating that approximately half of the gender minority population would not be accurately captured in the census. By adding *meti* and gay, lesbian, bisexual, heterosexual, and MSM, the census would provide over 92 percent of the sample with terms they would choose themselves to describe their primary sexual or gender identity. Adding an additional seven terms (*kothi*, *mangiyaya*, *natuwa*, *hijara*, *dburanji*, *nechani*, and intersex) would have provided the entire sample with terms

they would choose themselves to describe their primary identity. It is also worth mentioning that respondents identified with multiple identity terms, some of which refer to sexual behavior as well as to sexual orientation and gender identity (Knight, 2014).

These identity categories do not necessarily fall under a sexuality or gender heading discretely and can simultaneously inhabit and challenge both categories in various ways. In a study by Bochenek and Knight (2012), a third gender-identified Nepali who had been assigned male at birth expressed, “I am biologically male, but I am not a man. I do not desire women sexually. Men in my culture desire women sexually. Therefore I am third gender” (Bochenek & Knight, 2012). This testimony is an example of sexual desire defining gender identity rather than sexual orientation. Another example is hijaras who “could be men who cross-dress, castrated men, or intersexed individuals. Hijara is not a sexual identity but more to do with gender, the ‘third sex’ as it is sometimes called, neither man nor woman. A Hijara’s sexual acts (for instance, with men) therefore defy understanding of both heterosexual and homosexual” (Baudh, 2008).

Step 4: Pilot Test SOGI Survey Questions

Once an initial set of questions and response categories for gender identity and the three domains of sexual orientation have been drafted, it is critically important that the questions be piloted. Oftentimes, project teams are working under constrained timelines to begin data collection. As a result, piloting may be skipped altogether or conducted in a hurried manner. However, thorough piloting can avoid costly errors and poor-quality data. It is important to pilot all aspects of survey administration, including matching of interviewers with respondents, method of survey administration (e.g., computer-based vs. paper), and place of administration. At a minimum the pilot should determine whether the words and phrases in a question mean the same thing to the respondents as to the survey designer (Aday, 1996). One way to accomplish this latter goal is through cognitive interviewing.

Cognitive interviewing is an open-ended elicitation method used to understand respondents’ reasoning process for answering survey questions, what they interpret a survey question to mean, and any potential difficulties they may experience while answering the questions. It is informed by the four-step cognitive response process presented earlier in this report, and it aims to mitigate any challenges to respondent’s understanding of what is being asked, retrieving the relevant information, and providing their response within the categories available on the survey.

Similar to other qualitative methods, the number of people interviewed is based on the principle of saturation, where data collection continues until little new knowledge is gained by completing additional interviews. Participants in the interviews should include *all potential survey respondents*. It is especially important that projects collecting general population data (for example, HIV and other health programs) pilot the survey with SGM populations and cisgender heterosexual people who are not part of an SGM population. This is because even small levels of error in response from a larger population can substantially skew important data for subpopulations represented in the survey population. It is recommended that several rounds of cognitive interviews be conducted with five to 15 participants. The findings of these interviews should be used to adapt the survey questions. The process should be repeated until little new information of value is learned (Willis, 1999; Beatty & Willis, 2007).

Traditionally, cognitive interviewing methods have relied on the “think aloud” method; however, active probing is now a more common practice (Beatty & Willis, 2007). First, the respondent is presented with the survey question. Then, they are probed to elicit information about what they understood from the question and the “thinking” process they went through to deliver their response. In addition to general probing techniques (e.g., “tell me more about that”), it is useful for project teams to develop a set of structured probes to follow each question that will be tested during the cognitive interview. In Table 2, illustrative questions for basic cognitive probes are presented that relate to the proposed questions in Section 2.

Table 2. Illustrative cognitive probes for sexual orientation and gender identity questions

	Sexual Orientation Identity	Sexual Behavior	Sexual Attraction	Gender Identity
Comprehension/ interpretation probe	What does the term “lesbian” mean to you? <i>Repeat for other response options</i>	What does the term “sexual activity” mean to you?	What does the term “sexual attraction” mean to you? <i>Repeat for feelings</i>	What does the term “gender identity” mean to you?
Paraphrasing	Can you repeat the question I just asked you in your own words?			
Confidence judgment	How sure are you about the identity category you selected?	How sure are you about who you had sex with in the last six months?	How sure are you about the feelings you described?	How sure are you about the gender identity you reported?
Recall probe		How did you remember all the people you had sex with in the past six months?		
Specific probe	Why did you select ____ over the other response options?			
General probes	<ul style="list-style-type: none"> • How did you arrive at that answer? • Was that easy or hard to answer? • I noticed that you hesitated—tell me what you are thinking. 			

Adapted from Willis, 1999, p.6

In addition to the verbal responses provided by participants, interviewers should also observe instances where the respondent takes a long time to answer a question or seems to struggle with their response. During this process, key terminology used by participants should be highlighted and considered in the adaptation of question response categories. In addition to modifying terminology, findings from the cognitive interviewing may lead project teams to use different recall periods (for sexual behavior), or add specificity to terms like “sexual activity” and “sexual attraction” based on respondent interpretation and the intended use of the data by the project team.

CONCLUSIONS

Increasing the health and well-being of SGM populations is fundamental to achieving global development and human rights goals, and a better and just world. Health and development researchers and program implementers have a major role to play in documenting the current challenges faced by SGM populations and finding solutions. The historic invisibility of these populations is pervasive in society in general and in health-related data, and this is a major ethical issue in current public health practice. A key obstacle to obtaining data on SGM populations is that sexual orientation and gender identity are multi-faceted concepts, and defining them operationally for research and surveillance is a difficult task. These concepts are context specific and tied to broader social, cultural, and sexual norms, which prohibits the direct transfer of existing measures from one setting to another without taking steps to examine their appropriateness, and, if necessary, develop new ones.

In this report, current challenges for measuring SOGI and existing research were summarized, as well as the critical importance of gathering quality SOGI data to reach global targets to mitigate the HIV epidemic. The following four-step process for adapting SOGI questions was presented: (1) building a context-specific understanding of SOGI concepts, (2) reviewing existing SOGI survey questions, (3) conducting qualitative research to adapt SOGI questions, and (4) piloting SOGI questions using cognitive interviewing. The importance of gaining high-quality, valid data about SGM populations merits the resources, time, and effort required to construct SOGI questions. The immense scale of information collected and reported by HIV programs and HIV research globally about SGM populations plays a major role in the progress toward achieving HIV targets. These data also have a powerful influence on wider social, sexual, and gender norms, and knowledge construction about SGM populations. There is a broader ethical imperative to get it right. By following the recommendations in this report, it is intended that SOGI data generated by project teams will be high quality and valuable to HIV programs, as well as respectful and meaningful to the SGM populations the data are meant to serve.

REFERENCES

- Aday, L. A. (1996). Chapter 8: General principles for formulating questions. *Designing and conducting health surveys: A comprehensive guide* (pp.177–199). San Francisco, CA, USA: Jossey-Bass Publishers.
- Andrinopoulos, K., Do, M., Wares, K., & Scholl, A. D. (2016). *Defining quality of HIV services for MSM and transgender women*. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina. Retrieved from <https://www.measureevaluation.org/resources/publications/tr-16-133>.
- Ayala, G., Makofane, K., Santos, G. M., Arreola, S., Hebert, P., Thomann, M., . . . Do, T. D. (2014). HIV treatment cascades that leak: Correlates of drop-off from the HIV care continuum among men who have sex with men worldwide. *AIDS Clinical Research*, 5(8), 331. Retrieved from <https://www.omicsonline.org/open-access/hiv-treatment-cascades-that-leak-correlates-of-dropoff-from-the-hiv-care-continuum-among-men-who-have-sex-with-men-worldwide-2155-6113.1000331.php?aid=30623>.
- Baral S., Poteat, T., Stromdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. (2013). Worldwide burden of HIV in transgender women: A systematic review and meta-analysis. *The Lancet Infectious Diseases*, 13(3), 214–22. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/23260128>.
- Baudh, S. (2008). Human rights interrupted: An illustration from India. In Cornwall, A., Correa, S., & Jolly, S. (Eds.), *Development with a body: Sexuality, human rights & development*. New York, NY: Zed Books.
- Beatty, P. & Willis, G. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, 71(2), 287–311. Retrieved from <https://academic.oup.com/poq/article/71/2/287/1928986>.
- Beyrer, C., Baral, S., Collins, C., Richardson, E. T., Sullivan, P. S., Sanchez, J., . . . Mayer, K. (2016). The global response to HIV in men who have sex with men. *The Lancet*, 388, 198–206.
- Berlin, B. & Kay, P. (1969). *Basic color terms: Their universality and evolution*. Berkeley, CA, USA: University of California Press.
- Bochenek, M. & Knight, K. (2012). Establishing a third gender category in Nepal: Process and prognosis. *Emory International Law Review*, 26 (11). Retrieved from <http://law.emory.edu/eilr/documents/volumes/26/1/recent-developments/bochenek-knight.pdf>.
- Cohen, L. (2005). The Kothi wars: AIDS cosmopolitanism and the morality of classification. In Adams, V. & Pigg, S. (Eds.), *Sex in development: Science, sexuality, and morality in global perspective* (pp.269–304). Durham, NC, USA: Duke University Press.
- Bernard, H. R. (2011). *Research methods in anthropology: Qualitative and quantitative approaches*: Lanham, MD: Rowman Altamira Press.
- Dailey, D. (1981). Sexual expression and ageing. In Berghorn, F. & Schafer, D. (Eds.), *The dynamics of ageing*, (pp.311–333). Boulder, CO, USA: Westview Press.
- Deuba, K., Ekström, A. M., Shrestha, R., Ionita, G., Bhatta, L., & Karki, D. K. (2013). Psychosocial health problems associated with increased HIV risk behavior among men who have sex with men in Nepal: A cross-sectional survey. *PloS One*, 8(3). Retrieved from <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0058099>.

Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys (FWG). (2016a). *Current measures of sexual orientation and gender identity in federal surveys*. Washington, DC, USA: Federal Committee on Statistical Methodology. Retrieved from <https://nces.ed.gov/FCSM/pdf/buda5.pdf>.

Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys (FWG). (2016b). *Evaluations of sexual orientation and gender identity survey measures: What have we learned?* Washington, DC: Federal Committee on Statistical Methodology. Retrieved from https://nces.ed.gov/FCSM/pdf/Evaluations_of_SOGI_Questions_20160923.pdf.

Gender Identity in the U.S. Surveillance Group (GenIUSS). (2014). *Best practices for asking questions to identify transgender and other gender minority respondents on population-based surveys*. Los Angeles, CA, USA: The Williams Institute. Retrieved from <https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.

Gittleson, J., Steckler, A., Johnson, C., Pratt, C., Grieser, M., Pickrel, J., . . . Staten, L. (2006). Formative research in school and community-based health programs and studies: “State of the art” and the TAAG approach. *Health Education and Behavior*, 33(1), 25–39. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2475675/>.

Glick, J. L., Theall, K., Andrinopolous, K., & Kendall, C. (2018). For Data’s Sake: Dilemmas in the Measurement of Gender Minorities. *Culture, Health & Sexuality*, 20(12), 1362–1377. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/29533145>.

Gupta, S. & Granich, R., (2017). National HIV care continua for key populations: 2010–2016. *Journal of the International Association of Providers of AIDS Care*, 16(2), 125–132. Retrieved from <https://journals.sagepub.com/doi/full/10.1177/2325957416686195>.

Harding, J. (2003). Investigating sex: Essentialism and constructionism. In LaFont, S. (Ed.), *Constructing Sexualities* (pp.6–17). Upper Saddle River, NJ, USA: Prentice Hall.

Health Policy Project (HPP). (2015). *A facilitator’s guide for public health and HIV programs: Gender and sexual diversity training*. Washington, DC. Retrieved from http://www.healthpolicyproject.com/pubs/398_GSDGuide.pdf.

Horley, J. & Clarke, J. (2016). Constructing sexuality: A theory of stability and fluidity. *Sexuality & Culture*, 20(4), 906–922. Retrieved from <https://link.springer.com/article/10.1007/s12119-016-9364-z>.

Institute of Medicine of the National Academies, Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities (IOM). (2011). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. National Academies Press, March 31. <http://www.nationalacademies.org/hmd/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>.

Jarquín, Y., Ochoa, J. F., Larios, L. M., & Hernández, C. (2013). *USAID Nicaragua HIV bilateral program mid-term performance*. Managua, Nicaragua: United States Agency for International Development (USAID). Retrieved from <https://www.semanticscholar.org/paper/USAID-Nicaragua-HIV-Bilateral-Program-mid-term-Hern%C3%A1ndez-Jarqu%C3%ADn/02ab3f17730d59f5af5ca2a91ab68fa3c44b4f2c>.

Jones, N. (2017). Do you see what I see? Retrieved from <https://www.sapiens.org/language/color-perception/>.

- Kelly, M. (2016). Sex versus gender categorization. *The Wiley Blackwell Encyclopedia of Gender and Sexuality Studies* (1–3). Retrieved from <https://onlinelibrary.wiley.com/doi/pdf/10.1002/9781118663219.wbegss028>.
- Knight, K. (2014). *Surveying Nepal's sexual and gender minorities: An inclusive approach*. Los Angeles, CA: The Williams Institute. Retrieved from <https://williamsinstitute.law.ucla.edu/research/international/surveying-nepals-sexual-and-gender-minorities/>.
- Liesegang, T. J. (2013). The continued movement for open access to peer-reviewed literature. *American Journal of Ophthalmology*, 156(3), 423–432. Retrieved from <https://www.sciencedirect.com/science/article/pii/S0002939413003097>.
- Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES). (2015). *Rights in action: Transgender health and HIV*. Durham, NC, USA: FHI 360. Retrieved from https://aidsfree.usaid.gov/sites/default/files/aidsfree_linkages_transgender_brief.pdf.
- Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES). (2016a). *Integrated Technical Organizational Capacity Assessment (ITOCA) and action planning*. Durham, NC, USA: FHI 360. Retrieved from <https://www.fhi360.org/sites/default/files/media/documents/linkages-facilitators-guide-itoca.pdf>.
- Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES). (2016b). *Monitoring guide and toolkit for key population HIV prevention, care, and treatment programmes*. Durham, NC, USA: FHI 360. Retrieved from <https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-monitoring-tools.pdf>.
- Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES). (2017a). *Gender analysis toolkit for key population HIV prevention, care, and treatment programs*. Durham, NC: FHI 360. Retrieved from <https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-gendertoolkit-2017.pdf>.
- Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES). (2017b). *Programmatic mapping readiness assessment for use with key populations*. Durham, NC: FHI 360. Retrieved from <https://www.fhi360.org/sites/default/files/media/documents/resource-mapping-readiness-assessment.pdf>.
- Lo, S. & Horton, R. (2016). Everyone counts – so count everyone. *The Lancet*, 388, 1313–121417. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/25971219>.
- Logie, C. (2012). The case for the World Health Organization's Commission on the Social Determinants of Health to Address Sexual Orientation. *American Journal of Public Health*, 102(7), 1243–1246. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/22594723>.
- Mayer, K., Bradford, J., Makadon, H., Stall, R., Goldhammer, H., & Landers, S. (2008). Sexual and gender minority health: What we know and what needs to be done. *American Journal of Public Health*, 98 (6), 989–995. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2377288/>.
- Martin-Green, J. (2014). *Mental and spiritual health and LGBT communities*. Paper presented at the LGBT Health Workforce Conference, Hunter College: CUNY, New York City.

MEASURE Evaluation. (2013). *Operational guidelines for monitoring and evaluation of HIV programmes for sex workers, men who have sex with men, and transgender people, volumes I and II*. Chapel Hill, NC, USA: MEASURE Evaluation, University of North Carolina. Retrieved from <http://www.cpc.unc.edu/measure/resources/publications/ms-11-49a>.

Meyer, W., Costenbader, E. C., Zule, W. A., Otiashvili, D., & Kirtadze, I. (2010). “We are ordinary men”: MSM identity categories in Tbilisi, Georgia. *Culture, Health, & Sexuality*, 12(8), 955–971. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/20936552>.

National Resource Center on LGBT Aging. (2016). *Inclusive questions for older adults: A practical guide to collecting data on sexual orientation and gender identity*. New York, NY, USA: National Resource Center on LGBT Ageing. Retrieved from https://www.lgbtagingcenter.org/resources/pdfs/Sage_CollDataGuidebook2016.pdf.

Oli, N. & Onta, S. (2012). Self-perception of stigma and discrimination among men having sex with men. *Journal of Nepal Health Research Council*, 10(22), 197–200. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/23281450>.

Sausa, L. A., Sevelius, J., Keatley, J., Iniguez, J. R., & Reyes, M. (2009). *Policy recommendations for inclusive data collection of trans people in HIV prevention, care & services*. San Francisco, CA, USA: Center of Excellence for Transgender Health. Retrieved from <https://prevention.ucsf.edu/transhealth/education/data-recs-long>.

Sell, R. L. & Petruccio, C. (1996). Sampling homosexuals, bisexuals, gays, and lesbians for public health research: A review of the literature from 1990 to 1992. *Journal of Homosexuality*, 30(4), 31–47. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/8738743>.

Sexual & Gender Minority Research Office (SGMRO) & National Institutes of Health. (2018). *Methods and measurement in sexual & gender minority health research: Developing a research agenda and identifying research opportunities*. Paper presented at SGMRO workshop, April 3–4, 2018. Retrieved from https://dpcpsi.nih.gov/sites/default/files/MethodsMeasures_Paper_508_FV.pdf.

Okeowo, A. (2012, August). Gay and proud in Uganda. *The New Yorker*. Retrieved from <http://www.newyorker.com/news/news-desk/gay-and-proud-in-uganda>.

Padgett, D. K. (2012). *Qualitative and mixed methods in public health*. Thousand Oaks, CA, USA: SAGE Publications.

Potat, T., Scheim, A., Xavier, J., Reisner, S., & Baral, S. (2016). Global epidemiology of HIV infection and related syndemics affecting transgender people. *Journal of Acquired Immune Deficiency Syndrome*, 72(Suppl 3), S210–S219. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/27429185>.

Rasinski, K. A., Visser, P. S., Zagatsky, M., & Rickett, E. M. (2005). Using implicit goal priming to improve the quality of self-report data. *Journal of Experimental Social Psychology*, 41, 321–327. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.579.3150&rep=rep1&type=pdf>.

Reisner, S. L., Potat, T., Keatley, J., Cabral, M., Mothopeng, T., Dunham, E., . . . Baral, S. (2016). Global health burden and needs of transgender populations: A review. *The Lancet*, 388, 412–436. Retrieved from [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)00684-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)00684-X/fulltext).

Ridolfo, H., Miller, K., & Maitland, A. (2012). Measuring sexual identity using survey questionnaires: How valid are our measures? *Sexuality Research & Social Policy*, 9(2), 113–124. Retrieved from <https://link.springer.com/article/10.1007/s13178-011-0074-x>.

Rowley, J. & Slack, F. (2004). Conducting a literature review. *Management Research News*, 27(6), 31–39. Retrieved from https://www.researchgate.net/profile/Jennifer_Rowley/publication/41674215_Conducting_a_literature_review/links/00b7d51645445b0a99000000/Conducting-a-literature-review.pdf.

Sexual Minority Assessment Research Team (SMART). (2009). *Best practices for asking questions about sexual orientation on surveys*. Los Angeles, CA, USA: The Williams Institute. Retrieved from <https://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>.

Sirin, K. (2016, April 21). Celebrating gay pride in Uganda. *Dazed*. Retrieved from <http://www.dazeddigital.com/artsandculture/article/30757/1/celebrating-gay-pride-in-uganda>.

Smalley, K., Warren, J., & Barefoot, K. (2018). Gender and sexual minority health history, current state, and terminology. In Smalley, K., Warren, J., & Barefoot, K. (Eds.), *LGBT health: Meeting the needs of gender and sexual minorities* (pp.3–14). New York, NY, USA: Springer Publishing Company.

Sudman, S. & Bradburn, N. (1982). *Asking questions: A practical guide to questionnaire design*. San Francisco, CA: Jossey-Bass.

Swartz, M. K. (2013). HINARI: Providing global access to health care information. *Journal of Pediatric Health Care*, 27(1), 1. Retrieved from [https://www.ipedhc.org/article/S0891-5245\(12\)00193-9/fulltext](https://www.ipedhc.org/article/S0891-5245(12)00193-9/fulltext).

Talley, A. & Stevens, J. (2017). Sexual orientation self-concept ambiguity: Scale adaptation and validation. *Assessment*, 24(5), 632–645. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/26643117>.

Tourangeau, R. (1984). Cognitive science and survey methods. In Jabine, T., Straf, M., Tanur, J., & Tourangeau, R. (Eds.), *Cognitive aspects of survey design: Building a bridge between disciplines* (pp.73–100). Washington, DC, USA: National Academy Press.

Tourangeau, R. & Yan, T. (2007). Sensitive questions in surveys. *Psychological Bulletin*, 133(5), 859–883. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/17723033>.

United Nations Development Programme (UNDP), A Global Network of Transgender Women and HIV, United Nations Population Fund (UNFPA), UCSF Center of Excellence for Transgender Health, Johns Hopkins Bloomberg School of Public Health, World Health Organization, Joint United Nations Programme on HIV/AIDS (UNAIDS), & United States Agency for International Development (USAID). (2016). *Implementing comprehensive HIV and STI programmes with transgender people: Practical guidance for collaborative interventions (TRANSIT)*. New York, NY, USA: United Nations Development Programme (UNDP). Retrieved from https://www.unfpa.org/sites/default/files/pub-pdf/TRANSIT_report_UNFPA.pdf.

United Nations Population Fund (UNFPA), United Nations Development Programme (UNDP), World Health Organization (WHO), United States Agency for International Development (USAID), World Bank, The Global Forum on MSM and HIV, Joint United Nations Programme on HIV/AIDS (UNAIDS), United States President's Emergency Plan for AIDS Relief (PEPFAR), & Bill & Melinda Gates Foundation. (2015). *Implementing comprehensive HIV and STI programmes with men who have sex with men: Practical guidance for collaborative*

interventions (MSMIT). New York, NY, USA: UNFPA. Retrieved from <http://www.unfpa.org/publications/implementingcomprehensive-hiv-and-sti-programmes-men-who-have-sex-men>.

U.S. President's Emergency Plan for AIDS Relief (PEPFAR). (2017). *PEPFAR monitoring, evaluation, and reporting (MER 2.0) indicator reference guide*. Retrieved from <https://www.pepfar.gov/documents/organization/263233.pdf>.

Villafuerte-Gálvez, J., Curioso, W. H., & Gayoso, O. (2007). Biomedical journals and global poverty: Is HINARI a step backwards? *PLoS Med*, 4(6), 220. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/17594171>.

Weller, S. & Romney, A. (1988). *Systematic data collection*. Newbury Park, CA, USA: SAGE Publications.

Westbrook, L. & Saperstein, A. (2015). New categories are not enough: Rethinking the measurement of sex and gender in social surveys. *Gender & Society*, 29(4): 534–560. Retrieved from <https://journals.sagepub.com/doi/full/10.1177/0891243215584758>.

Willis, G. (1999). *Cognitive interviewing: A "how to" guide*. Durham, NC, USA: Research Triangle Institute. Retrieved from <https://www.hkr.se/contentassets/9ed7b1b3997e4bf4baa8d4eceed5cd87/gordonwillis.pdf>.

Winter, S., Diamond, M., Green, J., Karais, D., Reed, T., Whittle, S., & Wylie, K. (2016). Transgender people: Health at the margins of society. *The Lancet*, 388, 390–400. Retrieved from [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)00683-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)00683-8/fulltext).

World Health Organization (WHO). (2014). Consolidated guidelines on HIV prevention, diagnosis, treatment, and care for key populations. Geneva, Switzerland: WHO. Retrieved from <http://www.who.int/hiv/pub/guidelines/keypopulations/en/>

World Health Organization (WHO) & Joint United Nations Programme on HIV/AIDS (UNAIDS). (2010). *Guidelines on estimating the size of populations most at risk to HIV*. Geneva, Switzerland: WHO. Retrieved from http://data.unaids.org/pub/manual/2010/guidelines_popnestimationsize_en.pdf.

Appendix A: Global Resources and Narratives

GLOBAL:

Equaldex: A collaborative knowledge base for the lesbian, gay, bisexual, transgender (LGBT) movement. Equaldex's goal is to become a platform to collect, display, and analyze data about LGBT laws, facts, polls, and opinions. Equaldex's data, which are in a structured and consistent format, are contributed and verified by its users. <https://www.equaldex.com/organizations>

All Out: This organization is bringing people power to the global movement for love and equality. It petitions world leaders and global organizations while using creative tactics—online and offline—to advance the fight for the rights of lesbian, gay, bi, and transgender people. <https://allout.org/en>

AFRICA:

Call Me Kuchu: This film is about how in Uganda, a new bill in 2009 threatened to make homosexuality punishable by death. David Kato, Uganda's first openly gay man, and retired Anglican Bishop Christopher Senyonjo worked against the clock to defeat state-sanctioned homophobia while combatting vicious persecution in their daily lives. But no one was prepared for the brutal murder that shook their movement to its core and sent shock waves around the world. <https://callmekuchu.com/>

Queer African Reader: As homophobia and transphobia threaten to silence the voices of African lesbian, gay, bisexual, transgender, and intersex (LGBTI) people, this account is a testament to the resistance and unrelenting power of these communities across Africa and its diaspora. It brings together academic writings, political analysis, life testimonies, conversations, and artistic works by Africans that engage with the struggle for LGBTI liberation. The book aims to engage the audience from the perspective that various traits of identity—such as gender, race, and class—interact to contribute to social inequality. Including experiences from diverse African contexts, this work breaks away from the homogenization of Africa as the homophobic continent to highlight the complexities of LGBTI lives and experiences through their own voices. <http://fahamubooks.org/book/?GCOI=90638100911630>

Botswana LeGaBiBo (Lesbians, Gays and Bisexuals of Botswana): This was the first LGBTI organization in Botswana. It was founded by Ditshwanelo, the Center for Human Rights, in 1998 as a project. However, due to lack of resources the project could not be implemented and was, therefore, inactive until it resurfaced under BONELA Botswana Network on Ethics, Laws and HIV/AIDS. <https://legabibo.wordpress.com/about/>

Sexual Minorities Uganda [SM-UG]: Formed in March 2004 as a LGBTI nongovernmental network to address human rights emerging issues based on sexual orientation and gender identity or expression. Today, the network comprises 18 LGBTI organizations all working to advocate the rights of LGBTI. The umbrella entity SMUG is entrusted with the responsibility of advocacy for policy reforms as member organizations offer services on economic empowerment, health, counseling and guidance, and other services to the LGBTI community. SMUG works closely with indigenous, regional, and international human rights organizations and people to end discrimination and injustices towards LGBTI people in Uganda. <https://sexualminoritiesuganda.com/>

ASIA:

The Asia Pacific Alliance for Sexual and Reproductive Health and Rights (APA): APA brings together NGOs, donors, and other stakeholders with common goals to build a strong network to ensure everyone's right to health is fully achieved through the promotion and inclusion of sexual and reproductive health rights in development agendas. <https://www.asiapacificalliance.org/>

TARSHI (Talking About Reproductive and Sexual Health Issues): TARSHI works toward expanding sexual and reproductive choices in people's lives in an effort to enable them to enjoy freedom from fear, infection, and reproductive and sexual health problems. TARSHI's work on sexuality is from an affirmative rights-based perspective, a fresh change from perspectives that often restrict sexuality to frameworks of disease prevention, violence against women, or sexual minorities. <http://www.tarshi.net/index.asp>

Utopia Asia: Utopia Asia offers gay, lesbian, bisexual, and transgender resources across Asia, including country-specific sites and message boards. <http://www.utopia-asia.com>

EUROPE:

Council of LGBT-Organizations of Ukraine: This national association unites 19 organizations active in the country. One of the Council's goals is to advocate for the rights, interests, and needs of LGBT people at an international level.

LATIN AMERICA AND THE CARIBBEAN:

Society Against Sexual Orientation Discrimination (SASOD): SASOD is dedicated to the eradication of homophobia in Guyana and throughout the Caribbean. It has worked tirelessly to repeal discriminatory Guyanese laws, change local attitudes about the LGBT community, and end discrimination in the government, workplace, and community. <https://www.sasod.org.gy/>

Fundación Ecuatoriana Equidad: This organization seeks to promote sexual health and reduce prejudice and acts of discrimination based on sexual orientation, gender identity, or HIV/AIDS through communication actions, prevention, awareness, empowerment, visibility, citizen participation, and research; coordinating with private, national, and international civil society and public institutions; and generating resources in order to improve the quality of life for LGBTI populations and those affected by HIV/AIDS. <https://fequidadecuador.org/>

Silueta X Association: The mission of Silueta X Association is to fight for human rights of LGBT people. <https://redsiluetax.wordpress.com/la-institucion/>

Grupo Gay da Bahia (GGB): GGB defends the human and citizenship rights of homosexuals in Brazil. <https://grupogaydabahia.com.br/>

MIDDLE EAST:

The Gay & Lesbian Arab Society (GLAS): This is an international networking organization for gays and lesbians of Arabic descent or those living in Arab countries.

Helem: An LGBT rights organization based in Lebanon.

Meem: An LGBT rights organization based in Lebanon.

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