

Title: Improving Data on LGBTQ Health: Addressing Sexual Orientation & Gender Identity (SOGI)

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Executive Summary

Introduction. The past few decades have seen major changes in the societal perceptions, visibility, and civil liberties of the gay, bisexual, transgender, queer, and questioning (LGBTQ) population in the United States. Despite these changes and the large number of individuals who identify as LGBTQ today, scientific knowledge on the health of this population remains limited due to a lack of widespread and consistent collection of relevant data.

Background. Myriad perceived challenges, which are sometimes based in fact but often exaggerated, have prevented more mainstream incorporation of sexual orientation and gender identity (SOGI) questions in scientific research and major public health surveys. This is true despite consensus that the limited data that does exist clearly shows serious and wide-ranging disparities for LGBTQ individuals. While uptake of SOGI questions has increased in recent years, inconsistency in the way that questions are asked means limited comparability of data, and also reinforces the perception that there remains too much doubt on how to ask SOGI questions for their inclusion in research to be successful. Some are also concerned that SOGI questions might be too personal and therefore offend those being asked; however, research has demonstrated an overwhelming acceptance of these questions by the public.

Analysis. Consensus has emerged among experts that measuring SOGI requires at least two separate questions to measure the distinct concepts of sexual orientation and gender identity individually. Additionally, whenever sex assigned at birth is needed in addition to current gender identity, that also should be assessed in a separate question. It may be valuable, when possible, to explore these concepts further with questions that distinguish between sexual orientation as an identity, behavior, and attraction, and with questions that assess the complexities of gender identity and expression. However, the structure of three questions to separately assess sexual orientation, gender identity, and sex assigned at birth has emerged as a minimum standard. Major surveys demonstrating this structure include the national standard questions for the Behavioral Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS) as administered in states such as Massachusetts. This general structure has also been adopted by LGBTQ experts at the Fenway Institute, Williams Institute, and PRIDE Study. Furthermore, LGBT HealthLink's own experience in crafting surveys demonstrates the development and benefits of this structure. In contrast, alternative approaches that attempt to combine the constructs of gender identity and sexual orientation into one measure, solicit incomplete information on gender identity, or omit gender identity questions altogether demonstrate shortcomings when compared to the emerging best practices as observed herein.

Recommendations. Based on its analysis of emerging best practices, the authors recommend three questions (at a minimum) to assess SOGI and sex assigned at birth. The first question should assess sexual orientation as a current identity; the second question should assess gender identity, with options of male, female, transgender, none of the above, or (if possible) an open field for "other;" and the final question should assess "sex assigned at birth."

Conclusion. Understanding variations in health related to SOGI is key to identifying and reducing health disparities facing the LGBTQ community. It is therefore key that SOGI data collection is increased in a manner that, if not entirely uniform, is consistent with best practices and relatively comparable between studies. These recommendations aim to provide guidance on how this goal can be achieved.

Introduction

Lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ) health has been largely ignored as a key part of health disparities work until recently. A 2014 study, for example, found that only one-half of one

percent of studies funded by the National Institutes of Health between 1989 and 2011 pertained to LGBTQ health issues, with most focused on sexual minority men and relating to sexual health (Coulter, Kenst & Bowen, 2014). While there has been a recent push for inclusion of sexual orientation and gender identity (SOGI) questions in scientific and national studies, full inclusion remains a distant goal (Sell, 2017). While some of the commonly-cited challenges to collecting SOGI data may have a basis in reality, many have been exaggerated or reflect a lack of prioritization rather than a lack of practicality (Sell & Holliday, 2014). Furthermore, although a lack of consensus over how to ask SOGI questions has also been an oft-cited challenge, the research summarized herein indicates that there is a sufficient, emerging consensus around best practices to negate this once legitimate concern. Regardless of the reasons for which SOGI questions have not been more universally included in research, the result is significant gaps in our knowledge of LGBTQ health (Wolff, 2016). The limited nature of the available data and lack of inclusion in large and diverse studies makes it difficult to demonstrate conclusively where and how LGBTQ health disparities should be addressed and is especially harmful for our understanding of subpopulations within the LGBTQ community, such as LGBTQ people of color, for whom there is often not statistically-significant data to fully understand disparities (Gates, 2017; Durso, 2017).

The authors put forward that a major goal for the public health community today should be to move the research forward in a way that is meaningful to both LGBTQ populations and those interested in reducing health and social disparities for LGBTQ identifying individuals. All levels of government as well as private actors can play a role in implementing policies and practices in which data collection can be improved and consensus can be built over time. Given the decentralized nature of key surveillance instruments such as the Youth Risk Behavior Surveillance System (YRBSS) and Behavioral Risk Factor Surveillance System (BRFSS), action from the states in particular may be key to building momentum towards more and better collection of SOGI data.

This article first identifies the current gaps and challenges in the collection of SOGI data, and then explores best and promising practices that are developing from major surveys, studies, and expert consensus, which can serve as a guide for those working on implementing data collection measures in various capacities. The authors then recommend questions on sexual orientation, sex, and gender identity that reflect the emerging expert consensus. The article concludes by summarizing the authors’ recommendations for increasing the inclusiveness and quality of data.

Background: Gaps & Challenges in the Collection of SOGI Data

SOGI measurement guidelines are still evolving, which may be daunting for researchers, public health personnel, and for policy makers interested in or tasked with implementing LGBTQ-inclusive data collection measures (Flentje, Bacca, & Cochran, 2015). One study found a variety of actual and perceived challenges to collecting SOGI health data, as shown in Table 1 (Sell & Holliday, 2014) (Table 1). Understanding these perceptions can help to inform how those interested in improving SOGI data collection frame this as an issue of relevance.

Table 1. Perceived challenges (and responses) to collecting SOGI data

Perceived challenges as identified by Sell & Holliday (2014)	Responses to perceived challenges
Sexual orientation data are not relevant to their survey	If this data is not collected, it is impossible to know if SOGI are relevant to the issue being studied

Adding a variable to their survey would be costly or require another question to be deleted (because of survey length)	There is also a cost to public health and to the strength of the data collected when SOGI is not included
A valid and reliable measure of sexual orientation does not exist	There is emerging consensus on how to collect SOGI data, and further consensus can only be reached when more researchers include SOGI questions
Respondents would refuse to answer sexual orientation questions or break off interviews when asked their sexual orientation	Research has consistently shown that the vast majority of people, both LGBTQ and otherwise, are willing to answer SOGI questions
Lesbians, gays, and bisexuals would be so rare there would not be enough power to analyze data related to sexual orientation	The number of people who self-identify as LGBTQ is growing due to cultural and generational changes, and inclusion in more surveys and studies will mean greater ability to compare studies and detect statistically significant findings
Sexual orientation variable is really a proxy for other variables that should be measured instead (e.g., stigma and discrimination)	Measuring for variables like stigma and discrimination alone is of limited use without also knowing the source of that bias
If LGB people are found to be at greater risk for certain health concerns, this could be used to further stigmatize these populations or even be used to argue for the curing of homosexuality	LGBTQ people already face high levels of stigma, and to fully address this stigma, LGBTQ health disparities and their origins and solutions must be better understood

Despite these perceived challenges, measurable advances in health for LGBTQ individuals will be difficult to achieve without adequate information, and this is especially relevant for vulnerable subpopulations (e.g. bisexual women, LGBTQ people of color, etc). Federal, state, and local governments all have a role to play in identifying and recognizing the serious gaps in SOGI data within their information systems and databases. For example, the federal Department of Health and Human Services (DHHS) is charged with monitoring the health of the U.S. population and eliminating health disparities between different segments of the population, including, according to Healthy People:

"groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion" (2017, para. 5).

Although Healthy People 2020 requires the collection of SOGI data in order to monitor specific objectives, the Centers for Disease Control and Prevention (CDC) does not currently require this and has only recently begun to recommend the collection of SOGI data on surveys (Sell & Holliday, 2014). A core set of survey variables are required on local, state, territorial, and tribal survey instruments to receive CDC funding and data, and at the local level survey administrators can add variables in addition to the core required variables.

Some state survey administrators have chosen to use this opportunity to collect SOGI data. For example, sexual orientation data collection first occurred in Massachusetts in 1993, with other states cautiously following suit (Sell & Holliday, 2014). As of 2015, 25 states and 19 large urban school districts had collected

sexual orientation data by variously assessing sexual orientation identity, sexual behavior, or sexual attraction, as well as bullying because of perceived sexual orientation (Kann, 2016). It is encouraging that a number of states have collected sexual orientation data. However, there has been tremendous variation in the types of questions utilized as well as the wording of SOGI assessments, both across and within states and localities. This variation makes comparing data across states and localities challenging and imprecise. The CDC currently provides sites with a list of optional questions, including one question regarding sexual orientation identity and one question assessing the sex of sexual contacts (Sell & Holliday, 2014). The CDC has yet, however, to issue such a standard question with respect to gender identity (CDC, "Questionnaires," 2018).

According to the National LGBT Cancer Network (2017), none of the large national cancer registries and surveys of cancer incidence collect SOGI data, leaving LGBTQ cancer survivors embedded and invisible among the vast wealth of information these surveys provide to other groups. For example, much of what is known about cancer incidence and mortality in the U.S. comes from data collected by the National Cancer Institute through its Surveillance, Epidemiology, and End Results (SEER) program. Health policy makers use SEER data to identify and address disparities in cancer risk - for instance, those that exist among different ethnic, geographic, or socioeconomic groups. Yet SEER does not collect information on LGBTQ identities, which means that many basic questions about cancer in the LGBTQ community have no clear answers (Tontonoz, 2016). If the ultimate goal of LGBTQ health advocates is to have uniform SOGI questions included in major national programs such as SEER, the most realistic first steps are likely greater consensus among experts and policy makers as to how to ask these questions, and inclusion in state and other surveys using the best practices currently available.

While obtaining data through population surveys is important for identifying and addressing health disparities, collecting data in a patient's electronic health record (EHR) provides another benefit: enabling clinicians to provide more complete care on an individual level (Daniel & Butkus, 2015; Alper, Feit, & Sanders, 2013). Although the Institute of Medicine and the Joint Commission recommend routine documentation of patients' sexual orientation in healthcare settings, currently very few health care systems collect these data (Haider et al., 2017). The Centers for Medicare & Medicaid Services released guidelines effective in 2016 that require all certified EHR systems to have the *capacity* to record sexual orientation data (Office of the National Coordinator for Health Information Technology, 2015), with few health systems or hospitals at that time routinely collecting such data (Alper, Feit, & Sanders, 2013). Limited research suggests that many healthcare providers have yet to take advantage of the new capacity available in EHR systems to collect this data, despite their key potential role in helping to build consensus and improve the available data on disparities.

For example, Haider et al. (2017) found that routine collection of data on sexual orientation in the emergency departments (ED) setting remains rare, despite the feasibility and importance of collecting this data. That study used nationally representative survey data and in-depth qualitative interviews to identify the optimal patient-centered approach to collect sexual orientation data in the ED. It found that although most clinicians believe that patients will refuse to provide sexual orientation information, few patients reported that they would refuse to provide such information, and that most Americans would be willing to disclose their sexual orientation in the ED setting. Another study by Maragh-Bass et al. (2017) surveyed LGBTQ and non-LGBTQ patients and providers on their views of SOGI collection. While eighty percent of providers felt that collecting SO data would offend patients, only 11% of patients reported that they would be offended. Patients perceived individualized care as a benefit of SOGI disclosure, while providers perceived improved patient-provider interaction as the main benefit. Similarly, Bjarnadottir, Bockting, and Dowding (2017) conducted an integrative review examining patients' perceptions of being asked SOGI questions in the healthcare setting. Of the 21 studies examined, a majority indicated patients' recognition of the importance of SOGI questions and a willingness to respond to these questions. Therefore, while the collection of this data is currently lacking, the openness of patients to respond if asked is promising and puts the onus on those with the power to collect SOGI data to do so.

Analysis: Current Best and Promising Practices for LGBTQ Data Collection

The current state of best and promising practices for collecting data on SOGI is complex, but approaching consensus that at a minimum, there is a necessity for three separate questions to assess three distinct concepts: sexual orientation, sex assigned at birth, and gender identity. Many recommend using two or potentially three questions to measure only gender identity, and up to three questions to measure different constructs relating to for sexual orientation. There is also debate about the usefulness of including open-ended “other” response options which would allow individuals to self-identify as something other than the pre-designated categories provided within the survey framework. While experts differ on these details, there is consensus that sex, sexual orientation, and gender identity are all important and distinct, and therefore should be screened separately.

With respect to gender identity, Bauer, Braimoh, Al, and Dharma (2017) recently published recommendations for transgender-inclusive measures of sex and gender for population surveys; they propose asking for the “sex were you assigned at birth, meaning on your original birth certificate,” and “your current gender identity.” A third question (to be asked only of those who indicated a gender identity different than their birth-assigned sex) asks for the gender “you currently live as in your day-to-day life” (Bauer et al., 2017). The Center of Excellence for Transgender Health at University of California, San Francisco, advocates for the use of a two-step question that captures a person’s gender identity as well as their assigned sex at birth. This two-step process first queries “current gender identity,” and then follows with a question querying “assigned sex at birth” (Sausa, Sevelius, Keatley, Iniguez, & Reyes, 2009). It has been found that a two-question technique for assessing sex assigned at birth and gender identity provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single question asking respondents’ gender with choices of “male,” “female,” “transgender,” or “other” (Tate, Ledbetter, & Youssef, 2012). The two-step approach to measuring sex and gender identity has been recommended by professional groups since at least 1997 (Cahill & Makadon, 2014b).

Sexual orientation can also be challenging to measure, as it is a multi-dimensional construct and its measurement has varied considerably over time (Sell, 1997). The measurement of sexual orientation within public health research can be fairly summarized as having the three components of identity, attraction, and behavior, each of which provides unique insights that are not directly comparable (Wolff, Wells, Ventura-diPersia, Renon, & Gov, 2016). While a measure of identity (i.e., the category of sexual orientation with which one identifies, such as heterosexual, lesbian, gay, or bisexual) is perhaps most commonly thought of as a minimum, it is important to consider that sexual orientation can also include behavioral and attraction domains, which can be incongruent with one another (Korchmaros, Powell, & Stevens, 2013). Whether identity, behavior, or attraction is used in a survey can have important implications on the resulting data, and when all cannot be independently assessed, care should be taken as to which is selected (Geary, Tanton, Erens, Citton, Prah, Wellings, et al., 2018). For example, among youth, sexual attraction may capture many young people who do not yet identify as gay, lesbian, or bisexual (and thus would be missed in an identity question) but who also may not yet be sexually active (and thus would be missed by a sexual behavior question); for data collection primarily aimed at addressing sexual health questions, knowing the sexual behavior of participants may prove equally or even more valuable than knowing their sexual orientation as an identity (hence the frequent use in HIV-related literature of the phrase “men who have sex with men,” i.e. those whose sexual behavior rather than identity or attraction has included them in the identified group). While each of the three measures of sexual orientation identity, attraction, and behavior may have something unique to offer, the inability of many data gathering instruments to account for all three should not prevent the significant progress made when at least one is adapted, with identity being the most common.

The following analysis looks first at major government surveys and how they have approached SOGI data, followed by how major LGBTQ organizations and studies have recommended that this data be collected, and ending with examples from LGBT HealthLink’s own experience in this evolving field. An examination of these sources is useful both to understand the context in which the authors issue the recommendations herein and to see the current strengths and limitations of the data currently being collected on SOGI identities. A summary of these sources is presented in **Table 2**.

Table 2. Overview of SOGI Questions from Key Sources

Major Surveys				
Source	Sexual Orientation	Gender Identity	Sex	Current Best Practice
BRFSS: Standard Survey	The next two questions are about sexual orientation and gender identity. Do you consider yourself to be: straight; lesbian or gay; bisexual; other; don’t know/not sure; [or] refused.	Do you consider yourself to be transgender? Yes, Transgender, male-to-female; Yes, Transgender, female-to-male; Yes, Transgender, gender non-conforming; No; Don’t know/not sure; [or] Refused	<i>Format 1:</i> What is your sex? <i>Format 2:</i> What was your sex at birth? Was it: male; female; don’t know/not sure; [or] refused.	✓
BRFSS: Michigan	Next, I’m going to ask you a question about sexual orientation. Do you consider yourself to be: A - Heterosexual, that is straight; B - Homosexual, that is [if male insert “gay,” if female insert “lesbian”]; C - Bisexual, D - Transgender, or E - Something else?	[Gender identity question is combined with sexual orientation]	What is your sex: male; female; [not read, but available as response] don’t know / not sure; [or] refused	
YRBSS: Standard High School Survey	<i>Sexual Orientation Question 1:</i> During your life, with whom have you had sexual contact? I have never had sexual contact; Females; Males; [or] Females and males <i>Sexual Orientation Question 2:</i> Which of the following best describes you?	[No gender identity question]	What is your sex? Female; [or] Male	

	Heterosexual; Gay or lesbian; Bisexual; [or] Not sure			
YRBSS: Massachusetts	<p><i>Sexual Orientation Question 1:</i> During your life, with whom have you had sexual contact? I have never had sexual contact; Females; Males; [or] Females and males</p> <p><i>Sexual Orientation Question 2:</i> Which of the following best describes you? Heterosexual; Gay or lesbian; Bisexual; [or] Not sure</p>	A transgender person is someone whose biological sex at birth does not match the way they think or feel about themselves. Are you transgender?: no, I am not transgender; yes, I am transgender and I think of myself as really a boy or man; yes, I am transgender and I think of myself as really a girl or woman; yes, I am transgender and I think of myself in some other way; I do not know if I am transgender; [or] I do not know what this question is asking.	What is your sex? Female; [or] Male	✓
YRBSS: Washington, D.C.	<p><i>Sexual Orientation Question 1:</i> During your life, with whom have you had sexual contact? I have never had sexual contact; Females; Males; [or] Females and males</p> <p><i>Sexual Orientation Question 2:</i> Which of the following best describes you? Heterosexual; Gay or lesbian; Bisexual; [or] Not sure</p>	Some people describe themselves as transgender when their sex at birth does not match the way they think or feel about their gender. Are you transgender?: no, I am not transgender; yes, I am transgender; I am not sure if I am transgender; [or] I do not know what this question is asking.	What is your sex? Female; [or] Male	
LGBTQ Organization Expert Opinions				
Source	Sexual Orientation	Gender Identity	Sex	Current Best Practice
Williams Institute	<i>Sexual Orientation Question 1:</i> Do you consider yourself to be:	<i>Principal Gender Identity Recommendation:</i> How do you describe	What sex were you assigned at birth, on your original birth	✓

	<p>heterosexual or straight; gay or lesbian; or bisexual?</p> <p><i>Sexual Orientation Question 2:</i> In the past (time period e.g. year) who have you had sex with?: men only; women only; both men and women; [or] I have not had sex.</p> <p><i>Sexual Orientation Question 3:</i> People are different in their sexual attraction to other people. Which best describes your feelings? Are you: only attracted to females; mostly attracted to females; equally attracted to females and males; mostly attracted to males; only attracted to males; [or] not sure?</p>	<p>yourself? (check one): male; female; transgender; [or] do not identify as female, male, or transgender</p> <p><i>Gender Identity Alternative A:</i> What is your current gender identity? (Check all that apply): male; female; trans male/trans man; trans female/trans woman; genderqueer/ gender non-conforming; different identity (please state): [open response form]</p> <p><i>Gender Identity Alternative B:</i> Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?: yes, transgender, male to female; yes, transgender, female to male; yes, transgender, gender non-conforming; [or] no</p>	<p>certificate?: male; [or] female</p>	
Fenway Institute	<p>Do you think of yourself as (Check one): straight or heterosexual; lesbian, gay, or homosexual; bisexual; something else; don't know; [or] choose not to disclose</p>	<p>What is your current gender identity? (Check one): male; female; transgender male/trans man/ female-to-male (FTM); transgender female/trans woman/ male-to-female (MTF); genderqueer, neither exclusively male nor</p>	<p>What sex were you assigned at birth? (Check one): male; female; [or] choose not to disclose</p>	✓

		female; additional gender category, please specify: [open field]; [or] choose not to disclose		
Pride Study	Current Sexual Orientation (Check All That Apply): asexual; bisexual; gay; lesbian; pansexual; queer; questioning; same-gender loving; straight/heterosexual; [or] another sexual orientation	Current gender identity (check all that apply): genderqueer; man; transgender man; transgender woman; woman; [or] another gender identity	Sex Assigned at Birth on Your Original Birth Certificate: [open response form]	✓
LGBT HealthLink's Experience				
Source	Sexual Orientation	Gender Identity	Sex	Current Best Practice
North American Quitline Consortium	<i>Combined SOGI Question, Part 1:</i> Do you consider yourself to be gay, lesbian, bisexual, and/or transgender?: yes; no; [or] refuse <i>If Yes, Part 2:</i> Thank you, please indicate all of the following which apply to you: bisexual; gay or (for a woman) lesbian; queer; [or] transgender or gender variant	[Combined with sexual orientation question]	N/A	
LGBT HealthLink Needs Assessment	Currently, do you consider yourself to be: lesbian; gay; bisexual; straight; [or] other (please specify): [open field]	How do you describe yourself: male; female; transgender; do not identify as male, female, or transgender; [or] other (please specify): [open field]	What sex were you assigned at birth?: male; [or] female	✓

Major Surveys

Behavioral Risk Factor Surveillance System (BRFSS): The BRFSS is a telephone-based health survey that explores risk behaviors among the US population, implemented by the Centers for Disease Control and Prevention. SOGI questions have been included as optional modules in the national BRFSS questionnaire since 2014 (CDC, 2018a). As of 2016, 25 states and Guam were using the optional SOGI model in conducting the BRFSS (CDC, 2017). These questions were based on best practices recommendations of the expert Sexual Minority Assessment and Research Team (SMART) and the Gender Identity in U.S. Surveillance (GenIUSS) Group (The GenIUSS Group, 2014). The 2018 questionnaire continues use of these questions, including two options for biological sex (one with more transgender-inclusive language of “what was your sex at birth”), a single question on sexual orientation as an identity, and a single question on gender identity (CDC, 2018a).

Importantly, states have flexibility and do not have to follow the model offered by the CDC. This can lead to variations that are sometimes counterproductive. For example, the state of Michigan was an early adopter of including SOGI data collection in the administration of their statewide BRFSS survey, which certainly marked a positive step forward. However, they took a different path than the main CDC version of the survey and combined questions about sexual orientation and gender identity into one measure (MDHHS, 2018). While the question informs respondents that the question will be about sexual identity, the responses include “transgender” as among the options. This is problematic for several reasons. First, it means that results on sexual orientation and gender identity in Michigan will not be directly comparable with other states’ BRFSS results, and furthermore will unlikely be comparable with other surveys and studies that following the emerging best practice of asking these questions separately. Second, the question may confuse respondents, since the survey prompts them to answer a question about sexual orientation but then includes a measure about gender identity, as well. Finally, whether or not transgender respondents are confused as to how to reply, they will inevitably have to choose between sharing their gender identity or sharing their sexual orientation. As a result, data on transgender respondents will not include their sexual orientation, and some transgender respondents - who choose to select their sexual orientation (as the prompt asks) and not their transgender identity - will not be included in the results. Therefore, while Michigan made a significant step forward by including a SOGI question in their survey, both the inherent problems with the question and its lack of comparability with other surveys highlight the need for revised best practices that are more widely adopted. States like Michigan can continue to be leaders on advancing LGBT equity by continuing to evolve their SOGI questions.

The Youth Risk Behavior Surveillance System (YRBSS): The YRBSS was developed in 1990 to monitor youth risk behaviors such as tobacco use, alcohol and other substance use, unhealthy diet, and exercise behaviors, and is administered in middle and high schools by either the states or local entities, such as large school districts (CDC, 2018c). Sexual attraction and sexual orientation questions were added to the standard high school survey in 2015, but as of the 2019 survey, there is not yet a question on gender identity, only sex (presumably that assigned at birth) (CDC, 2018b).

But while the national YRBSS survey does not include a gender identity question, some states and school districts do include such questions. For example, the 2015 Massachusetts Youth Risk Behavior Survey included the following single question on gender identity that establishes both if a person identifies as transgender, and if so, if they are a transgender man, a transgender woman, or something else (Massachusetts Department of Elementary and Secondary Education, 2017).

The District of Columbia asked a similar, though somewhat simpler, single question on gender identity which established if a person was or was not transgender, but not if they were a transgender man, transgender woman, or transgender and gender-nonconforming (District of Columbia, 2017). This survey also asks for sex assigned at birth, which may lead some to believe that the combination of these two questions - sex assigned at birth, and whether or not a person is transgender - is enough to know their full gender identity. However, a respondent could be assigned male at birth and identify as transgender, but not as a transgender woman; they could instead be gender-nonconforming, or still consider themselves to be male, while recognizing that

internally they identify as transgender. Therefore, while the District of Columbia question is close to best practice, it could be improved by offering more than just a binary status of whether or not someone was transgender.

LGBTQ Organization Expert Opinions

The Williams Institute (WI) - In November of 2009, the Williams Institute published Best and Promising Practices for Asking Questions about Sexual Orientation on Surveys. In September of 2014, the Williams Institute followed up with a report Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS Group, 2014). Their recommendation was to ask three questions about sexual orientation: identity, behavior, and attraction.

To assess sex and gender identity, they first asked for sex assigned at birth, then current gender identity, which included binary male/female options plus a separate option for transgender and another option for none of the above. But they also put forward two alternative questions that better established if a transgender person was a transgender woman, transgender man, or gender-nonconforming.

Fenway Institute: The National LGBT Health Education Center, part of the Fenway Institute, has issued various guides and webinars on how SOGI data can be collected (National LGBT Health Education Center, 2018a). Most recently, for sexual orientation, the Fenway Institute recommends a single question on how one identifies (National LGBT Health Education Center, 2018b). They also recommend a question on sex assigned at birth that includes male, female, or choose not to disclose, and one additional question on gender identity that includes male and female, transgender male and female, and gender-nonconforming.

The PRIDE Study: The PRIDE study is a national, online, prospective, longitudinal cohort study of LGBTQ communities, that explores the question, "What is the relationship between being sexual or gender minority, which includes but is not limited to being LGBTQ, and health?" (The PRIDE Study, 2018). The PRIDE study provides a wide range of terms for participants to select as their sexual orientation. It also provides an open field for participants to identify their sex as originally noted on their birth certificate, as well as asks for their gender identity, which includes man and woman, transgender man and woman, genderqueer, and something else.

LGBT HealthLink's Experience

North American Quitline Consortium: Beginning in 2014, LGBT HealthLink and National Jewish Health worked with the North American Quitline Consortium (NAQC) to create SOGI questions for tobacco quitline intake protocols, which NAQC released as optional protocols in 2016 (North American Quitline Consortium, 2016). While they did not add or change a question on sex assigned at birth, NAQC implemented a two-part question that combined sexual orientation and gender identity into a single measure. Quitline users are first asked, "Do you consider yourself to be gay, lesbian, bisexual, and/or transgender?" For those who say yes, they are then asked to select all that apply to them from the options of lesbian, gay, bisexual, or transgender or gender variant. While this marked a significant step forward and has surely aided quitlines in gaining initial data on the LGBTQ clients they serve, as the discussion above indicates, the expert consensus has since moved away from combining sexual orientation and gender identity into one question.

LGBT HealthLink Needs Assessment: LGBT HealthLink has twice conducted an LGBT Wellness Needs Assessment with LGBT centers around the country that are part of its parent organization, CenterLink. The 2017 survey followed a 2015 iteration and included questions on sex, gender identity, and sexual orientation. Focus groups and expert review were used to ensure that the questions would be acceptable to those completing the survey and would provide useful data to the individual centers and to the review of the national, compiled data. The sexual orientation question asks about an individual's current identity. The survey also

asks for sex assigned at birth, and asks for gender identity, with the options being male, female, transgender, none, or "other" with an open field to specify. Because of the inclusion of both a "none" and "other" option, when combined with the sex assigned at birth question, this structure allows those collecting the data to understand if someone is a transgender man or woman versus someone who identifies as nonbinary.

Recommendations: LGBT HealthLink’s recommended SOGI questions

Upon review of the options currently in use and expert opinion on the subject, and recognizing the importance of increasing use and uniformity of SOGI questions, the authors recommend the following measures be used as a baseline for assessing SOGI:

Table 3

Recommended question on sexual orientation:	Recommended question on sex assigned at birth:	Recommended question on gender identity:
<i>Currently, do you consider yourself to be: lesbian; gay; bisexual; straight; asexual; [or] other (please specify): [open field]</i>	<i>What sex were you assigned at birth?: male; female; [or] other</i>	<i>How do you describe yourself: male; female; transgender; do not identify as male, female, or transgender; [or] other (please specify): [open field]</i>
Note: If an open field is not possible, consider including examples with "other," such as "queer" or "pansexual"	Note: If it is not necessary to collect data on sex assigned at birth, it may be preferable not to do so.	Note: If an open field is not possible, consider including examples with "other," such as "genderqueer" or "gender-nonconforming"

These recommendations are based on the research presented herein and are designed to balance inclusivity and precision with practical limitations and the need to have greater consistency in research. Implementing SOGI questions into studies and surveys should always reflect the unique circumstances of that scientific endeavor, and be centered around the specific reasons for collecting such data. For example, while in many cases identifying sex assigned at birth is necessary for identifying disparities or collecting necessary data for insurance billing, it can also retraumatize transgender and gender-nonconforming people; therefore, while a recommended question on sex assigned at birth is included herein, if it is not necessary in a given circumstance to ask this question, simply asking for gender identity may be preferable.

These questions also represent a "floor" and not a "ceiling;" for example, while LGBT HealthLink’s recommended sexual orientation question focuses on sexual orientation as an identity, where it is possible for researchers to also include questions on sexual orientation as an attraction or behavior, collecting this additional data may well offer a considerable benefit. Similarly, while these questions do not include a measure for gender expression, including such a question when possible will also expand the available research on LGBTQ health.

Another point to consider is whether or not to include an open field for respondents to select “other,” which can make analysis more difficult and may not be feasible for some studies and surveys, but which has been found to improve participation (Cahill & Makadon, 2014b). Even in the case of sex assigned at birth, where “other” may seem inapplicable if one considers only birth certificates, intersex individuals may well not receive a clear assignment of sex at birth. Furthermore, with nonbinary gender markers being increasingly available on other identification documents, it is feasible that birth certificates may also in the future offer initial or retrospective options for nonbinary identification. Therefore, adding an “other” field to any or all of these questions may be considered by survey and study designers.

Finally, there is the question of the order in which the questions should be asked, particularly those relating to sex and gender identity. As of 2014, the Williams Institute noted the potential significance of this subject, but said that more research was needed (GenIUSS Group, 2014). More recently, the Fenway Institute recommended that a question assessing gender identity come before one assessing sex assigned at birth (National LGBT Health Education Center, 2018b). The authors recommend this order - first gender identity, then sex assigned at birth - because it immediately sends a message of inclusion to transgender individuals, and also because it could reduce confusion. If transgender people are first asked for their sex, they do not know that a gender identity question may be asked next, and therefore might be inclined to share their gender identity instead of their sex assigned at birth. As more surveys and studies include questions regarding SOGI, new knowledge may be gained regarding order bias and the best ordering of SOGI questions, as well as their place within other questions in the instrument.

Conclusion

In the face of clear and serious health disparities facing the LGBTQ community, but also incomplete data on the complexities and depth of those disparities, it is critical that federal, state, local, and private actors take immediate action to increase and improve SOGI data collection. Delays in doing so will lead to exacerbation of existing disparities, especially for the most marginalized subpopulations within the LGBTQ community, as they are most at-risk and least represented by the available data.

As this paper has demonstrated, whereas at one time there was little consensus and SOGI measures had largely not been tested in the field, this is no longer the case, and can no longer be used to justify the exclusion of LGBTQ identities from key public health surveys and studies. Consensus exists in expert opinion and in emerging promising practices from survey instruments that sexual orientation and gender identity should be assessed with at minimum two separate questions assessing them as unique constructs, with sex assigned at birth also assessed separately whenever it is necessary to do so. Many studies have gone beyond only one question for each of gender identity and sexual orientation, and instead use two or three questions to fully assess gender identity and up to three questions to assess not only sexual orientation as an identity, but also as seen in sexual behavior and sexual attraction. These details can provide invaluable added information; for example, multiple questions on both sexual orientation identity and sexual behavior could help parse out disparities for women who identify as bisexual versus women who identify as straight but have sex with both men and women. Therefore, it is clear that more questions can indeed mean better, more complete, and more inclusive data.

Nonetheless, there is also a need for shorter, simpler, and universally-accepted questions to at least ensure that basic measures of SOGI data are being gathered in research, particularly in large, government-conducted surveys. That this is not presently the case means a lack of complete data and also a lack of comparability across studies. When each study addresses these constructs differently, it is unclear if the studies are truly addressing the same constructs, or if the variations are capturing unique constructs that cannot be compared with one another. In this sense, while it may be preferable to observe sexual orientation as an identity,

behavior, *and* attraction, having a mixture of the three between studies - especially when done in an unintentional way - is actually counterproductive to the public health field. Furthermore, while in some ways some data is better than no data, the omission of gender identity questions even when sexual orientation questions are included reinforces the invisibility of the transgender community and reinforces the disparities transgender people face even compared to their lesbian, gay, and bisexual peers.

Therefore, it is essential that all levels of government as well as the scientific, research, and health communities accept the emerging expert consensus on best practices for collecting SOGI data and implement such questions as soon as possible. For this reason, the authors recommend the questions presented herein as a baseline for assessing SOGI in surveys and studies, and to begin to understand and address in earnest the health disparities facing the LGBTQ population.

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