

Measuring Sexual and Gender Minority Populations in Health Surveillance

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Abstract

Purpose: Sexual and gender minorities (SGMs) are underrepresented and information about SGMs is difficult to locate in national health surveillance data, and this limits identification and resolution of SGM health disparities. It is also not known how measures of sexual orientation and transgender-inclusive gender identity in health surveillance compare with best practice recommendations. This article reviews and summarizes the publicly available, English language, large-scale, rigorously sampled, national, international, and regional data sources that include sexual orientation or transgender-inclusive gender identity and compares measures with best practice guidelines.

Methods: A systematic review was undertaken of national, international, state, and regional health surveillance data sources. Data sources that measured sexual orientation or transgender-inclusive gender identity and met seven inclusion criteria were included.

Results: Forty-three publicly accessible national, international, and regional data sources included measures of sexual orientation and transgender-inclusive gender identity and health. For each data source, sampling design, sample characteristics, study years, survey questions, contact persons, and data access links are provided. Few data sources met best practice recommendations for SGM measurement: 14% measured all three dimensions of sexual orientation (identity, behavior, attraction) as recommended by the Sexual Minority Assessment Research Team. No data sources measured transgender-inclusive gender identity according to the Gender Identity in U.S. Surveillance-recommended two-step method of measuring sex assigned at birth and current gender identity.

Conclusions: This article provides a much needed detailed summary of extant health surveillance data sources that can be used to inform research about health risks and disparities among SGM populations. Future recommendations are for more rigorous measurement and oversampling to advance what is known about SGM health disparities and guide development of interventions to reduce disparities.

Keywords: gender identity, public health surveillance, population health, quantitative data sources, sexual orientation, transgender

Introduction

THE 2011 INSTITUTE OF MEDICINE (IOM) report on The Health of Lesbian, Gay, Bisexual, and Transgender People summarized growing and consistent evidence of health disparities among sexual and gender minority (SGM) people.¹ The landmark report called for the use of rigorous, population-based, observational, and cohort studies of health, among these groups, to expand what is known about SGM health disparities and guide policies and interventions to reduce disparities.¹

Rigorous, large-scale data sources regarding SGM health are in relative short supply,^{1,2} and several national public health surveillance programs do not contain questions regarding respondents' SGM status. For example, the Surveil-

lance, Epidemiology, and End Results (SEER) program, the nation's comprehensive source of cancer incidence and survival data, does not include sexual orientation or transgender-inclusive gender identity measures.² General health surveys designed to sample and chart the health status of specific populations, including the Behavioral Risk Factor Surveillance System (BRFSS)³ and National Survey on Drug Use and Health (NSDUH),⁴ have not always measured sexual orientation or transgender-inclusive gender identity. In addition, despite their importance for identifying predictors of disease, few population-based, observational, and cohort studies recruit specifically for SGM participants, nor do they include questions regarding participants' SGM status. These omissions make analyses by sexual minority and/or gender minority characteristics impossible.

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Excluding demographic questions regarding sexual orientation and transgender-inclusive gender identity from public health surveillance perpetuates the status quo, whereby SGM groups are underserved and knowledge about their physical and mental health is lacking. The relative paucity of knowledge from rigorous, large-scale health surveillance regarding the health of SGM individuals marginalizes these populations by masking potential disparities in health and health behaviors, making it difficult to secure funding for health-enhancing programs, and impossible to develop quality solutions that can reduce or eliminate costly health disparities.

A few national and regional data sources, including some federally funded surveillance programs, measure sexual orientation and transgender-inclusive gender identity: these data sources have played an important role in advancing SGM health research.¹ However, there is no comprehensive, scholarly published resource that allows researchers to easily determine which data sources contain information on SGM people. This is problematic. Without a detailed summary of available SGM population health surveillance, it is time-consuming and challenging to locate quality pre-existing data sources to inform research on SGM health and health disparities.

A detailed report would add to existing listings of sexual minority-inclusive datasets⁵ by providing a summary of publicly available, large-scale health surveillance resources that measure sexual orientation or transgender-inclusive gender identity as well as those that measure both sexual orientation and transgender-inclusive gender identity, from which researchers can easily (1) find available SGM-inclusive health surveillance systems, (2) identify gaps and opportunities for future SGM health surveillance, and (3) track future progress in the collection of SGM health surveillance data.

While best practice recommendations for measuring sexual orientation and transgender-inclusive gender identity have been published,^{1,6,7} there is no published scholarly resource that allows researchers to see how sexual orientation or transgender-inclusive gender identity is measured across data sources.

To measure sexual orientation, the Williams Institute Sexual Minority Assessment Research Team (SMART) considered three dimensions: sexual identity, sexual behavior, and attraction.⁶ Measuring any one or all of these dimensions captures different subgroups of individuals, each with potentially different levels of and mechanisms for health risk related to sexual orientation. Therefore, SMART recommends including sexual orientation measures according to study aims. Sexual orientation measures of identity, behavior, and attraction should be selected specifically to capture the individual subgroups of interest.⁶ For example, health surveillance surveys used to estimate population health may include questions that capture all three dimensions of sexual orientation to explore the relationships between multiple aspects of sexual orientation and physical, sexual, and mental health in the population.⁶

To measure transgender-inclusive gender identity, the Williams Institute Gender Identity in U.S. Surveillance (GenIUSS) group recommends a two-step approach. The two-step approach includes measuring self-reported assigned sex at birth (sex recorded on the original birth certificate) and current gender identity (at time of survey).⁷ When a two-step method cannot be used, a single demographic item that mea-

sures self-reported gender identity (at time of survey) is recommended. This measure should include multiple, specific response options for transgender-inclusive gender identity; that is, transgender, male to female; transgender, female to male; transgender, gender nonconforming; and not transgender.⁷

This article reviews and presents the publicly available, rigorously sampled data sources that include sexual orientation or transgender-inclusive gender identity. In the interest of presenting a comprehensive picture of the state of SGM health surveillance, international, national, and regional data sources are included. We compare specific measures of sexual orientation and transgender-inclusive gender identity with best practice recommendations^{6,7} to determine how data sources differ from each other and best practice.

It is important to note that while SMART⁶ and GenIUSS⁷ recommendations were developed in English by SGM researchers and experts in the United States, they represent the best available, comprehensive published guidelines for SGM measurement domestically and internationally. Thus, assessing international and domestic health surveillance data sources published and distributed in the English language by these standards is a logical first step toward documenting and assessing data sources that measure SGM status. All data sources presented here include sexual orientation measures, but not all data sources measure transgender-inclusive gender identity. Therefore, information regarding specific SGM measures is presented separately.

Methods

Search strategy

Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines were followed for this systematic review.⁸ A twofold approach was used to identify SGM-inclusive data sources. First, data sources were identified through a comprehensive online search of electronic data warehouses. Warehouses to be searched were determined a priori based on their focus on either SGM health or large-scale health surveillance and included the Population Research in Sexual Minority Health data archive at the Inter-university Consortium for Political and Social Research,⁹ LGBTData.com by Dr. Randall Sell at Drexel University,⁵ and the U.S. Government's open data site, Data.gov.¹⁰

Second, a literature search was performed on August 16, 2016, using the National Library of Medicine's PubMed database (National Center for Biotechnology Information, U.S. National Library of Medicine, USA). Publication dates were limited to January 1, 1990, through December 31, 2015. After determining our inclusion and exclusion criteria, we conducted a broad preliminary search of articles on SGM health to identify key search terms that described said inclusion and exclusion criteria. Specifically, we searched on pairs of terms that defined SGM (including LGBT, GLBT, lesbian, gay, bisexual, transgender, sexual minority, and gender minority) and health ($N=13,191$), SGM and disparities ($N=1184$), and SGM and health behavior ($N=4654$).

Through this preliminary search, we identified key terms that described our inclusion and exclusion criteria. We specified that LGB*, GLB*, gay, lesbian, bisexual*, transgender, transsexual*, homo*, gender minority, or sexual minority appear in the title and/or abstract and specifically did not include certain terms unrelated to large-scale health surveillance or

the objective of this review to obtain only the most relevant articles (search strategy available upon request). For example, we excluded articles including the terms “systematic review,” “meta-analysis,” “case study,” “case series,” and “clinical trial” in their title and/or abstract. The search was restricted to English language articles for which full text was available and that included human subjects.

Inclusion criteria. Data sources selected for inclusion in this search met the following criteria: (1) measured sexual or gender minority status, including a measure of at least one dimension of sexual orientation (identity, behavior, or attraction), a transgender-inclusive gender identity measure, or a mechanism to enable identification of same-sex household partnerships; (2) focused upon health or household demography; (3) had publicly available data source documentation and survey questionnaires; (4) had data sources that were available to researchers for reanalysis; (5) were conducted between 1990 and 2015; (6) had a sample size of at least 1000; and (7) were conducted and published in the English language. In addition to U.S. national and regional data sources, international data sources meeting selection criteria were included.

SGM measurement

We defined sexual orientation according to best practices for survey development.⁶ Three categories comprised sexual minority orientation: identity, those who identify as homosexual, lesbian, gay, or bisexual; behavior, those who have engaged in same-gender sexual behavior in their lives; and attraction, those who have experienced same-gender attraction. While not recommended as a best practice for measuring sexual orientation,⁶ we defined same-sex-inclusive partner status as a measure of sexual minority cohabitation/marital status. Gender minority status was defined according to best practice recommendations as those who identify as transgender as well as those who endorse another nonbinary gender identity, but do not identify as transgender.⁷

To assess inclusion of SGM measures, survey questionnaires were collected for each data source. Counts and percentages of surveys that included SGM measures were calculated. For all data sources, the specific SGM measurement type(s) used—as defined by inclusion criteria—and total number of SGM measures were counted.

The specific SGM measures included in each survey were compared qualitatively with SMART and GenIUSS best practice recommendations. Counts and percentages of surveys that met specific SGM measurement recommendations were calculated.

All data sources and surveys were publicly accessible as of December 1, 2015. This project did not involve human subjects and did not require approval by the University of Tennessee Institutional Review Board.

Results

Figure 1 presents the flow-diagram for our targeted Web and PubMed searches to identify potential SGM-inclusive public health surveillance data sources. Our Web search identified 28 data sources for inclusion; 3 were international sources; and 25 were U.S. specific. Of U.S.-specific data sources, 16 were nationally representative in scope and 9 were not. The

PubMed search identified 3237 articles. Through title and abstract review provided by coauthors (J.P., J.J.), 2752 of the original 3237 articles were identified as not meeting inclusion criteria.

Full-text review of the remaining 485 articles identified 20 articles, representing 15 data sources that were eligible for inclusion. Reasons for exclusion were (1) not publicly available (337 articles), (2) not conducted and published in English (63 articles), (3) did not measure SGMs specifically (42 articles), or (4) data sources were identified previously in the Web search (23 articles). Of the 15 eligible data sources identified in the literature review, 4 were international and 11 were U.S. specific. Of U.S. data sources, 5 were nationally representative and 6 were not. Combining results from the Web and PubMed searches, a total of 7 international and 36 U.S.-specific (21 national and 15 regional) data sources were identified.

Summary of data source measures

Tables 1^{3,4,11-60} and 2^{3,14,21,23,29,31-33,42,45,59} summarize the 43 data sources identified by this review. Table 1 presents data sources that include sexual orientation measures and Table 2 presents data sources that include transgender-inclusive gender identity measures. Numerous measures were used to assess sexual orientation, including sexual identity, sexual behavior, attraction, and partner status, utilizing varied question formats (e.g., 5-year versus lifetime sexual behavior). Transgender-inclusive gender identity was most commonly evaluated using a single transgender-inclusive gender identity item.

Table 1 presents the specific items used to assess sexual orientation. All three dimensions of sexual orientation (sexual identity, sexual behavior, and attraction)⁶ were measured in 14% of data sources^{4,11,38,40,44,47}; 37% measured only two of these dimensions.^{15-17,20,21,24,30-36,39,42,43,48-50,52,53,60} Of data sources measuring only two dimensions of sexual orientation, the most frequent pair of measures used were sexual identity and sexual behavior—present in 35% of data sources.^{15-17,20,24,30-36,39,42,43,48-50,52,53,60}

Forty percent of data sources measured a single dimension of sexual orientation.^{3,13,14,18,22,23,25-29,37,41,45,46,54-56,58,59} Of those measuring a single dimension, 12 data sources (28% of all sources) measured sexual identity.^{3,13,14,18,22,23,25-29,37,41,45,54,55}

Overall, sexual identity was the most common sexual orientation measure and was included in 33 (77%) of the 43 data sources.^{3,4,11,13-18,20,22-27,29-45,47-50,52-55,60} Sexual behavior was the next most common measure, included in 25 (58%) of the 43 data sources.^{4,11,15-17,20,21,24,28,30-36,38-40,42-44,46-50,52,53,58,60}

The language used by each of the specific items measuring sexual behavior varied greatly between data sources. Most data sources measuring sexual behavior included 12-month^{4,11,15-17,20,24,28,31-33,39,40,43,44,47,52} or lifetime^{11,17,20,21,38-40,42,44,47-50,53,58,60} same-sex sexual behavior items. Of the 25 data sources measuring sexual behavior,^{4,11,15-17,20,21,24,28,30-36,38-40,42-44,46-50,52,53,58,60} only 9 (36%) used at least two sexual behavior items and thus captured sexual behavior over multiple time periods.^{11,15,17,20,39,40,44,47,58}

Partner status was measured in 13 (30%) data sources.^{12,13,19,21,25-27,34-36,40,41,44,46,47,51,57} Four sources

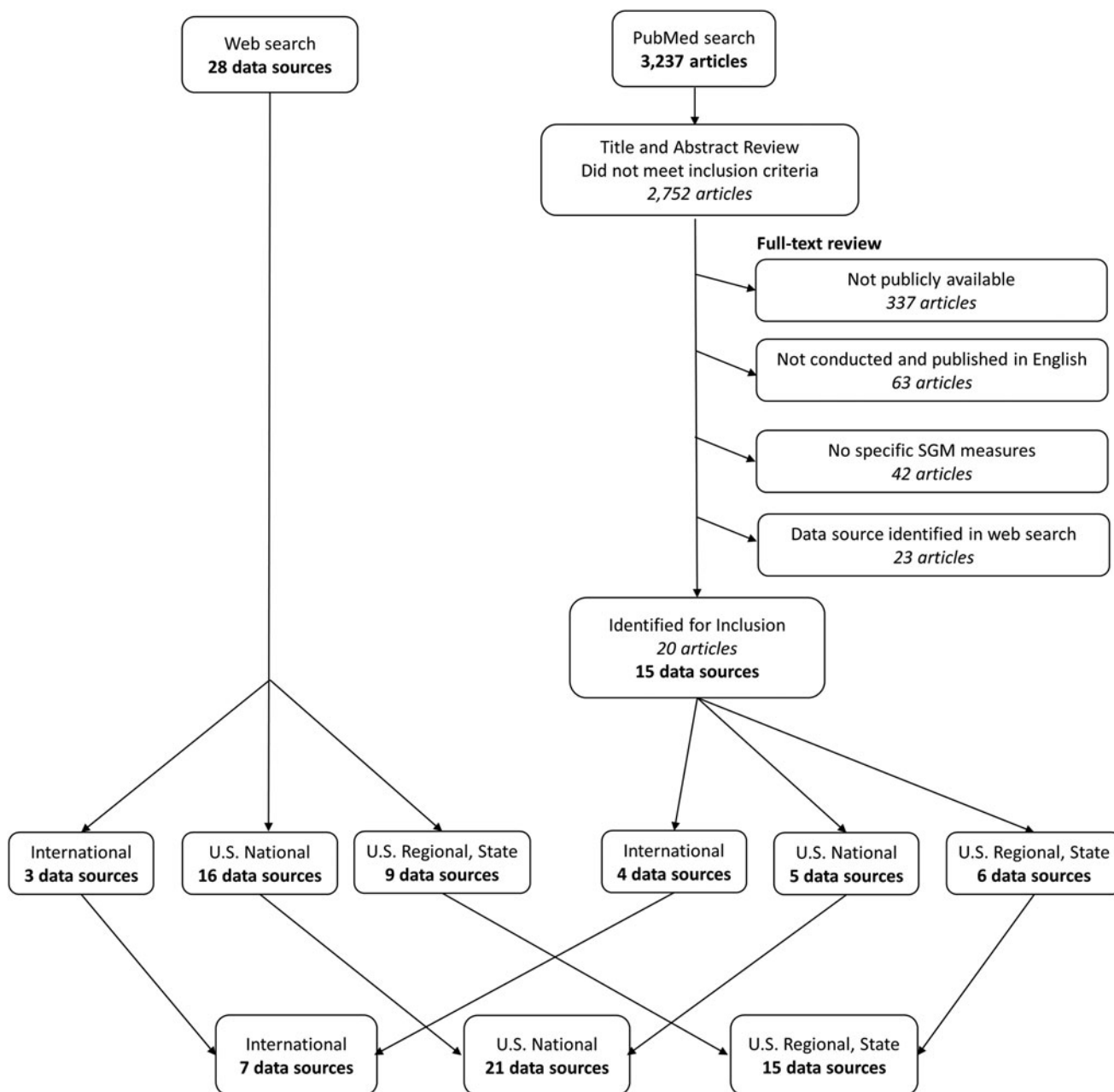


FIG. 1. Exclusion cascade for targeted Web and PubMed search.

solely measured partner status^{12,19,51,57}; three of these used U.S. census data for their sampling frame.^{12,19,57}

Table 2 presents specific questions used to assess respondent gender identity. Transgender-inclusive gender identity questions were present in 8 (19%) of the 43 data sources.^{3,14,21,23,29,31–33,42,45,59} Most of these data sources used a single item to measure transgender-inclusive gender identity (e.g., Do you identify as male, female, or transgender?).^{3,14,21,23,29,42,45,59} One data source used two items to measure gender minority identity.³³ No data sources followed best practice recommendations for a two-step approach to gender minority measurement; that is, measuring sex assigned at birth and current gender identity. One data source followed best practice recommendations for single-item gender minority measurement.^{3,14}

Detailed descriptions of data source methods and measures

Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing. The Adult Psychiatric Morbidity Survey¹¹ was commissioned by England's National Health Service Information Centre for Health and Social Care. This survey was representative of the population residing in households (not communal establishments) in England. Interviews were collected from a population-based sample of ~7500 adults aged 16 years or older. Core topics included in the survey were anxiety, depression, psychosis, substance use disorders, eating disorders, post-traumatic stress disorder, and hyperactivity disorder. Sexual orientation measures changed in 2014 and sexual minority status was measured

TABLE 1. SEXUAL MINORITY-INCLUSIVE HEALTH SURVEILLANCE DATA SOURCES

Name/study website	Sampling design		Sample characteristics	Study years	Question type				Partner status	PI/contact and data access	
	Probability	Nonprobability			Sexual identity	Sexual behavior (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (past 5 years)			Sexual behavior (lifetime)
Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England ¹¹ http://coment.digital.nhs.uk/article/5739/National-Wellbeing			Population: noninstitutionalized British residents; Age: ≥16years Size: varies 2014: 7500	2000, 2007, 2014						2014: Which of the following options best describes how you think of yourself? Heterosexual or Straight, Gay or Lesbian, Bisexual, Other Altogether, in the last 5 years, how many same sex partners have you had sex with? Altogether, in the last year, how many same-sex partners have you had sexual intercourse with? 2007: Which statement best describes your sexual orientation? This means sexual feelings, whether or not you have had any sexual partners: Entirely heterosexual (attracted to persons of the opposite sex); Mostly heterosexual, some homosexual feelings; Bisexual (equally attracted to men and women); Mostly homosexual, some heterosexual feelings; Entirely homosexual (attracted to persons of the same sex) Have your sexual partners been...? only opposite sex; mainly opposite sex, but some same-sex partners; mainly same-sex, but some opposite sex, partners; only same sex. I have not had a sexual partner Please choose the answer below that best describes how you think of yourself: completely heterosexual, mainly heterosexual, bisexual, mainly gay or lesbian, completely gay or lesbian	PI: National Centre for Social Research, and the Department of Health Sciences, University of Leicester. E-mail: enquiries@nhsdigital.nhs.uk Phone: +44-(0)-0300-303-5678 Data access: https://discover.ukdataservice.ac.uk/series/?sn=2000044
American Community Survey ² census.gov/acs			Population: noninstitutionalized U.S. residents; Age: all ages Size: varies	Annually 2000–present						How is this person [Person 2] related to Person 1? Husband or wife, Unmarried partner What is Person 2's sex? Male Female	PI: U.S. Department of Commerce, U.S. Census Bureau Phone: 1-800-923-8282 Data access: www.census.gov/programs-surveys/acs
Australian Longitudinal Study on Women's Health ¹³ alswh.org.au			Population: female, Australian Medicare recipients Age: 18–23, 45–50, 70–75 in 1996 Size: 41,600	1996–present Longitudinal						1946–1951 cohort-specific questions: What is your present marital status? (Mark one only) Married (registered), De facto relationship (opposite sex), De facto relationship (same sex), Separated, Divorced, Widowed, Never married (2013, 2010, 2007) 1973–1978 cohort-specific questions: Which of these most closely describes your sexual orientation? (Mark one only) I am exclusively heterosexual, I am mainly heterosexual, I am bisexual, I am mainly homosexual (lesbian), I am exclusively homosexual (lesbian), I don't know, I don't want to answer (2014, 2012) What is your present marital status? (Mark one only) Never married, Married, De facto (opposite sex), De facto (same sex), Separated, Divorced, Widowed (2015, 2012, 2009) What are your living arrangements? (Mark all that apply) I live alone, I live with one or both parents, I live with other adults, I live with my male partner, I live with my female partner (2014)	E-mail: a.dobson@sph.uq.edu.au Data access: requires application and study team review More information: http://alswh.org.au/how-to-access-the-data/alswh-data

(continued)

TABLE 1. (CONTINUED)

Name/study website	Sampling design		Study years	Sample characteristics	Question type				PI/contact and data access
	Probability	Nonprobability			Sexual behavior (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (lifetime)	Attraction	
Behavioral Risk Factor Surveillance System ¹⁴ cdc.gov/brfss			Annual	Population: noninstitutionalized U.S. residents; Age: ≥18 years Size: varies					1989–1995 cohort-specific questions: Which of these most closely describes your sexual orientation? (Mark one only) I am exclusively heterosexual, I am mainly heterosexual, I am bisexual, I am mainly homosexual (lesbian), I am exclusively homosexual (lesbian), I don't know, I don't want to answer. What are your living arrangements? (Mark all that apply) I live alone, I live with one or both parents, I live with other adults, I live with my male partner, I live with my female partner (2015) We ask this question to better understand the health and healthcare needs of people with different sexual orientations. Do you consider yourself to be Straight, Lesbian or Gay, Bisexual, Other, Don't Know/Not sure Do you think of yourself as straight or heterosexual, gay/lesbian or homosexual, or bisexual? Is that partner (if sexually active) male or female? (Referring to past 30 days) In the past 12 months, have your sexual partners been male, female, or both male and female? Which of the following best describes you? Would you say...: Heterosexual (straight), Gay or Lesbian, Bisexual, Not sure, Don't know Which response best describes whom you have had sex with in the past 12 months? Would you say...: Sex only with a woman (or with women), Sex only with a man (or with men), Sex with both men and women, Did not have sex, Don't know Do you consider yourself to be...? Heterosexual (sexual relations with people of the opposite sex), Homosexual, that is, lesbian or gay (sexual relations with people of your own sex), Bisexual (sexual relations with people of both sexes) In the past 12 months, have you had sex with a male? In the past 12 months, have you had sex with a female? During your lifetime, have you had sex with...? Males only, Females only, Both males and females Do you consider yourself to be Heterosexual, that is, straight; Homosexual, that is, gay or lesbian; Bisexual, or something else? How is [Person 2] related to you? Opposite-sex spouse (Husband/Wife), Opposite-sex unmarried partner, Same-sex spouse (Husband/Wife), Same-sex unmarried partner
California Health Interview Survey ¹⁵ chis.ucla.edu			Biennially	Population: California residents; Age: ≥18 years Size: 50,000					
California Women's Health Survey ¹⁶ www.dhcs.ca.gov/dataandstate/Pages/CWHS.aspx			Annually since 1997	Population: California adult women living in households with telephones Age: ≥18 years Size: ~4000					
Canadian Community Health Survey ¹⁷ statcan.gc.ca/indb-bmd/3226-eng.htm			Biennially 1991–2007 Annually 2008–present	Population: noninstitutionalized Canadian residents; Age: ≥12 years Size: 65,000					
Colorado Tobacco Attitudes and Behaviors Survey ¹⁸ www.ucdenver.edu/academics/colleges/healthcommunity/CEPEG/TABS/Pages/CEPEG/TABS.aspx			2001, 2005, 2008, 2012, 2015	Population: English- or Spanish-speaking Colorado residents Household sampling based on landline or cell phone Age: ≥18 years Size: 12,000–18,000					
Current Population Survey ¹⁹ census.gov/cps/			Monthly	Population: civilian, noninstitutionalized U.S. residents; Age: ≥16 years Size: 50,000					

(continued)

TABLE 1. (CONTINUED)

Name/Study website	Sampling design		Study years	Question type				PI/contact and data access
	Probability	Nonprobability		Sexual identity (30 days)	Sexual behavior (12 months)	Sexual behavior (5 years)	Sexual behavior (lifetime)	
			Sample characteristics				Specific questions	
General Social Survey ²⁰ gss.norc.umd.edu			Population: noninstitutionalized U.S. residents; Age: ≥18 years; Size: 2000	Annually until 1994 Biennially since 1994			Which of the following best describes you? Gay, lesbian, or homosexual; Bisexual; Heterosexual or Straight; Don't Know Have your sex partners in the last 12 months been... Exclusively male, Both male and female, Exclusively female, Don't know Have your sex partners in the last 5 years been... Exclusively male, Both male and female, Exclusively female, Don't know Now, thinking about the time since your 18th birthday (again, including the recent past that you have already told us about) how many female partners have you ever had sex with? Again thinking about the time since your 18th birthday (again, including the recent past that you have already told us about) how many male partners have you ever had sex with? During your life, the person(s) with whom you have had sexual contact (however you define it) is (are): I have not had sexual contact with anyone, Female(s), Male(s), Female(s) and Male(s) Which of the following best describes your feelings? Completely heterosexual (attracted to persons of the opposite sex), Mostly heterosexual, Bisexual (equally attracted to men and women), Mostly homosexual, Completely homosexual (gay/lesbian, attracted to persons of the same sex), Not sure Is your partner in your current relationship: Male, Female	PI: Tom W. Smith E-mail: GSS@norc.umd.edu Phone: 733-256-6288 Data access: available for download at http://gss.norc.umd.edu/Ges-The-Data or through gsdataexplorer.norc.umd.edu
Growing Up Today Study ²¹ gutsweb.org			Population: Children of Nurses' Health Study participants in 2004 Age: 9–14 in 1996 and 10–17 in 2004 Size: GUTS-16,700 GUTS2-10,900	Annually since 1996 Longitudinal				Contact: Xenia Kumph, Project Manager E-mail: gutsadmin@channing.harvard.edu Data access: investigators who are interested in using GUTS data or surveys should e-mail the Project Manager.
Healthy Youth Survey ²² www.doh.wa.gov/DataandStatisticalReports/DataSystems/HealthyYouthSurvey			Population: Students from schools randomly sampled at the state level Age: grades 6, 8, 10, and 12 Size: varies	2002, 2004, 2006, 2008, 2010, 2012, 2014			Which of the following best describes you? Heterosexual (straight), Gay or lesbian, Bisexual, Not sure	Contact: Jennifer Sabel at Washington State Department of Health E-mail: Jennifer.Sabel@doh.wa.gov Phone: 360-236-4248 Data request: www.doh.wa.gov/DataandStatisticalReports/DataSystems/HealthyYouthSurvey
Kaiser Permanente Member Health Survey ²³ DORexternal/mhs/index.aspx			Population: northern California Kaiser health plan members; Age: ≥20 years Size: 42,000	1993–ongoing, every 3 years			Are you bisexual or [lesbian/gay]? No; yes, bisexual; yes, [lesbian/gay].	Nancy P. Gordon, ScD, Study Director, Research Investigator, Division of Research Phone: 510-891-3587 E-mail: nancy.gordon@kp.org dor.kaiser.org/external/Nancy_Gordon
Los Angeles County Health Survey ²⁴ publichealth.org/ha/hu_surveyintro.htm			Population: Los Angeles county residents Age: ≥18 years Size: 7200	1997, 1999–2000, 2002–2003, 2005, 2007, 2011			Now I'll read a list of terms people sometimes use to describe themselves. As I read the list, please stop me when I get to the term that best describes how you think of yourself: Heterosexual/Straight, Homosexual/Gay/Lesbian, Bisexual, Don't Know Over the past 12 months, with how many [women/men] have you had sex?	PI: Los Angeles County Department of Public Health Phone: 213-240-7785 Data access: requires submission of a proposal and documentation of data security. More information on data access: publichealth.org/ha/HA_DATA.htm

(continued)

TABLE 1. (CONTINUED)

Name/Study website	Sampling design		Study years	Question type			Partner status	PI/contact and data access	
	Probability	Nonprobability		Sexual behavior 30 (days)	Sexual behavior (months)	Sexual behavior (lifetime)			Attraction
Midlife Development in the United States ^{28,29} midus.wisc.edu			Wave 1: 1995–1996 Wave 2: 2004–2006 Wave 3: 2013–2014 Longitudinal	Sexual identity	Sexual behavior (months)	Sexual behavior (lifetime)		MIDUS 1: How would you describe your sexual orientation? Would you say you are heterosexual (sexually attracted only to the opposite sex), homosexual (sexually attracted only to your own sex), or bisexual (sexually attracted to both men and women)? MIDUS 2: How would you describe your sexual orientation? Would you say you are primarily heterosexual (sexually attracted only to the opposite sex), homosexual (sexually attracted only to your own sex), or bisexual (sexually attracted to both men and women)? MIDUS 2: Is [KHNAME] a male or a female? Male, Female, Don't Know/Not sure MIDUS 2: How is [KHNAME] related to you? Husband or wife, lover/partner, same-sex lover/partner MIDUS 3: How would you describe your sexual orientation? Would you say you are primarily heterosexual (sexually attracted only to the opposite sex), homosexual (sexually attracted only to your own sex), or bisexual (sexually attracted to both men and women)? MIDUS 3: Is [KHNAME] a male or a female? Male, Female, Don't Know/Not sure MIDUS 3: How is [KHNAME] related to you? Husband or wife, lover/partner, same-sex lover/partner	PI: Carol Ryff, PhD Phone: 608-262-2056 Data and documentation available for download: dx.doi.org/10.3886/ICPSR04652
Minnesota Student Survey ²⁸ www.health.state.mn.us/divs/chs/mss			Conducted every 3 years; 1992–2013					Contact: Ann Kinney E-mail: ann.kinney@state.mn.us Phone: 651-201-5946 Data access: E-mail to request data use and agreement forms	
National Adult Tobacco Survey ²⁹ www.cdc.gov/tobacco/data_statistics/surveys/nats			2009–2010, 2012–2013					PI: CDC Phone: 800-CDC-INFO Data access: www.cdc.gov/tobacco/data_statistics/surveys/nats	
National Alcohol Survey ³⁰ arg.org/center/national-alcohol-surveys			2005, every 5 years					PI: Alcohol Epidemiologic Data System E-mail: AEDSinfo@esrincorporated.com	
National College Health Assessment ^{31,33} achacha.org			Biannually 2000–present					PI: American College Health Association E-mail: mhoban@acha.org Phone: 410-859-1500 Data access: requires application More information on data access: achacha.org/research.html	

(continued)

TABLE 1. (CONTINUED)

Name/study website	Sampling design		Sample characteristics	Study years	Question type			PI/contact and data access	
	Probability	Nonprobability			Sexual identity	Sexual behavior (past 30 days)	Sexual behavior (past 12 months)		Sexual behavior (lifetime)
National Comorbidity Survey ³⁴⁻³⁶ hep.med.harvard.edu/ncs			Population: noninstitutionalized U.S. residents; Age: ≥18 years old Size: NCS-1: 8000 NCS-2: 5000 NCS-R: 10,000	NCS-1: 1990–1992 NCS-2: 2001–2002 NCS-R: 2001–2003				NCHA II: What is your sexual orientation? Heterosexual, Gay/Lesbian, Bisexual, Unsure Within the last 12 months, did you have sexual partner(s) who were (Please mark the appropriate column [Yes/No] for each row) Female, Male, Transgender NCHA IIc: What term best describes your sexual orientation? Asexual, Bisexual, Gay, Lesbian, Pansexual, Queer, Questioning, Some Gender, Straight/Heterosexual Another identity (Please specify) Within the past 12 months, did you have sexual partner(s) who were Women, Men, Trans women, Trans men, Genderqueer, Persons with another identity	PI: Ronald Kessler E-mail: NCS@hep.med.harvard.edu Data access: data are publicly available for NCS and NCS-R. However, NCS-R sexual minority measures are restricted and require a restricted use dataset application. NCS-2 data are restricted and require application for access: www.hep.med.harvard.edu/ncs
National Drug Strategy Household Survey ³⁷ www.aihw.gov.au/alcohol-and-other-drugs/data-sources/about-ndshs			Australian population Age: ≥12 years Size: varies 2013: 24,000	Every 3 years 1998–present				Do you think of yourself as...? Heterosexual or straight; homosexual (gay or lesbian); bisexual; not sure, undecided; something else	PI: Australian Institute of Health and Welfare E-mail: Open.data@aihw.gov.au Data access: http://data.aihw.gov.au/dataset/aa3cb47f-b3b4-492a-8f98-c6013beeb814e
National Epidemiologic Survey on Alcohol and Related Conditions ³⁸ niaaa.nih.gov/research/nesarc-iii			Population: noninstitutionalized U.S. residents; Age: ≥18 years Size: Wave 1: 43,100 Wave 2: 34,700 Wave 3: 36,300	Wave 1: 2001–2002 Wave 2: 2004–2005 Wave 3: 2012–2013 Longitudinal				Which of the categories on the card best describes you? Heterosexual (straight), gay or lesbian, bisexual, not sure In your entire life, have you had sex with only males, only females, both males and females, or have you never had sex? People are different in their sexual attraction to other people. Which category on the card best describes your feelings? Only attracted to females, mostly attracted to females, equally attracted to males and females, mostly attracted to males, only attracted to males	PI: National Institute on Alcohol Abuse and Alcoholism Contact: Nekisha Lakins, CSR Incorporated E-mail: nlakins@csrincorporated.com Phone: 703-741-7157 Data access: researchers interested in accessing NESARC datasets should contact Aaron White, PhD, at aaron.white@mh.gov or 301-451-5943
National Health and Nutrition Examination Study ³⁹ cdc.gov/nchs/nhanes.htm			Population: civilian, noninstitutionalized U.S. residents; Age: all ages Size: 5000	Annually 1999–present				Do you think of yourself as heterosexual or straight (i.e., sexually attracted only to men/women); homosexual or gay (i.e., sexually attracted to only women/men); bisexual (i.e., sexually attracted to men and women); something else? In the past 12 months, with how many [men/women] have you had sex? In your lifetime, with how many [men/women] have you had sex?	PI: CDC Phone: 800-232-4636 Data access: series available for download at cdc.gov/nchs/nhanes/ nhanes_questionnaires.htm More information about data access: can be pooled across survey years to create large sample sizes; CDC provides guidance at cdc.gov/nchs/tutorials/Nhanes/index_continuum.htm
National Health and Social Life Survey ⁴⁰ popcenter.uchicago.edu/data/nhsis.shtml			Population: U.S. residents of two metropolitan areas Age: 18–59 years old Size: 3400	1992				Do you think of yourself as... Heterosexual, Homosexual, Bisexual, Something else, Normal/Straight, Don't know Have your sex partners in the last 12 months been exclusively male; both male and female; or female?	PI: Edward Laumann, PhD E-mail: sscs-data-archiv@lshost.uchicago.edu Data access: available for download at study website or dx.doi.org/10.3886/ICPSR060647

(continued)

TABLE 1. (CONTINUED)

Name/study website	Sampling design		Sample characteristics	Study years	Question type				PI/contact and data access		
	Probability	Nonprobability			Sexual identity (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (past 5 years)	Sexual behavior (lifetime)		Attraction	Partner status
National Health Interview Survey ⁴¹ cdc.gov/nchs/nhis.htm			Population: civilian, noninstitutionalized U.S. residents; Age: all ages Size: 87,500	1972–1993 Annually 1994–2014 Even-numbered years						Have your sex partners in the last 5 years been exclusively male; both male and female; or female? Now thinking about the time since your 18th birthday (including the recent past you've already told us about) how many (female/male) partners have you had sex with? Now thinking about the time since your 18th birthday and during the time before you started living with (S)partner(s) (resident), how many people, including men and women, did you begin having sex with, even if only one time? If one, was this partner a male or female? If two or more, how many of these partners were (a) male or (b) female? Now, I am going to ask you some questions about any other sexual partners you may have had during the time you were living with (1st S/C)... On a scale of 1 to 4, where 1 is very appealing and 4 is not at all appealing, how would you rate each of these activities: a) having sex with someone of the same sex. In general, you are sexually attracted to (1) only men, (2) mostly men, (3) both men and women, (4) mostly women, (5) only women Relationship roster includes relationship to respondent and sex	PI: CDC Phone: 800-432-4636 Data access: series available for download at cdc.gov/nchs/nhis/nhis_questionnaires.htm
National Intimate Partner and Sexual Violence Survey ⁴² www.icpsr.umich.edu/icpsrweb/NACJD/studies/34305			Population: U.S. men and women Age: ≥18 years Size: 18,000	2010						Which of the following best represents how you think of yourself? Gay; Straight, that is, not gay; Bisexual; Something else; I don't know the answer [Are you/IS ALIAS] male or female? What is [ALIAS]'s relationship to [you]? Spouse (husband/wife); Unmarried partner Do you consider yourself to be...? Heterosexual or straight, Gay or lesbian, Bisexual, Transgendered During your lifetime, have you had sex with only men, only women, or both men and women? Only men, Only women, Both men and women, Other (specify), Neither	PI: Margaret Alegria Data access: www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240 Phone: 800-999-0960 E-mail: nacjd@icpsr.umich.edu Data access: www.icpsr.umich.edu/icpsrweb/NACJD/studies/34305
National Latino and Asian American Study ⁴³ www.icpsr.umich.edu/icpsrweb/ICPSR/studies/00191#dbcite			Population: national U.S. community and household sample of adults Age: ≥18 years Size: 4600	2002–2003						We would like to ask you some questions about your sexual preference. We would like to know how you best describe yourself. Please read the question and tell me the letter corresponding to your answer: heterosexual; homosexual; lesbian, gay; bisexual; something else; not sure Thinking back on the past 12 months, have your sexual experiences been with... females only, mostly females, about equal numbers of males and females, mostly males, all mates	PI: Margarita Alegria Data access: www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240
National Longitudinal Study of Adolescent to Adult Health (Add Health) ⁴⁴ cpc.unc.edu/projects/addhealth			Population: U.S. in-school adolescents Age: grades 7–12 Size: 14,400	1994–2008 Longitudinal						Choose the description that best fits how you think about yourself: 100% heterosexual (straight); Mostly heterosexual (straight), but somewhat attracted to people of your own sex;	PI: Add Health Study Team E-mail: addhealth@unc.edu Data access: Sexual minority data require restricted use application, IRB approval, data security plan, \$850 fee.

(continued)

TABLE 1. (CONTINUED)

Name/study website	Sampling design		Study years	Question type					PI/contact and data access	
	Probability	Nonprobability		Sexual identity	Sexual behavior (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (lifetime)	Attraction		Partner status
National Research Consortium of Counseling Centers in Higher Education ³ www.cmhc.utexas.edu/rc_datasets.html			Population: stratified random sample of students from 70 U.S. institutions of higher education Age: ≥18 years Size: 108,500						Bisexual that is, attracted to men and women equally; mostly homosexual (gay), but somewhat attracted to people of the opposite sex; 100% homosexual (gay); Not sexually attracted to males or females; Not sure. Considering all types of sexual activity, with how many [females/males] have you had sex over the most 12 months, even if only one time? Considering all types of sexual activity, with how many [female/male] partners have you ever had sex? Are you romantically attracted to [females/males]? Identify romantic and sexual partners, including their gender, in a partnership roster	More information on data access: www.icpsr.umich.edu/icpsrweb/DSDR/studies/21600
National Social Life, Health, and Aging Project ⁶ norc.ORG/nshap			Population: community-residing U.S. adults Age: 57–85 years Size: 3,000 Wave 1: 3,000 Wave 2: 3,400						First, in what month and year did you first have sexual activity with (CURRENT OR MOST RECENT SPOUSE/COHAB THAT BEGAN WITHIN LAST 5 YEARS, OR CURRENT ROMANTIC PARTNER'S NAME)? Is this person male or female? Thinking about the most recent person you had sexual activity within the last 5 years, in what month and year did you first have sexual activity with that person, even if it was more than 5 years ago? Is this person male or female? Thinking about the (most recent/second most recent/third most recent) person you had sexual activity within the last 5 years. In what month and year did you first have sexual activity with that person, even if that first time was more than 5 years ago? Is this person male or female? Which of the following best describes (name's) relationship to you? Spouse, Romantic/Sexual Partner	Contact: University of Texas Counseling and Mental Health Center Data access: www.cmhc.utexas.edu/rc_datasets.html PI: Linda Waite, PhD Phone: 773-256-6333 E-mail: l.waite@uchicago.edu Data access: requires restricted use application and IRB approval More information on data access: dx.doi.org/10.3886/ICPSR20541
National Survey of Family Growth ⁹ cdc.gov/nchs/nsfg.htm			Population: noninstitutionalized U.S. residents; Age: 15–44 years Size: 12,600						Do you think of yourself as...Heterosexual or straight; Homosexual, gay, or lesbian; or Bisexual Thinking about the last 12 months, how many [male/female] sex partners have you had in the 12 months since (INTERVIEW MONTH)? Please count every partner, even those you had sex with only once in those 12 months. Have you ever had any sexual experience of any kind with another [male/female]? People are different in their sexual attraction to other people. Which best describes your feelings? A re you...only attracted to females, mostly attracted to females, equally attracted to males and females, mostly attracted to males, only attracted to males What is X's relationship to you? Husband, Male partner, Wife, Female partner	PI: National Center for Health Statistics Data access: Sexual minority data restricted and require a data request and user agreement More information: cdc.gov/nchs/nsfg/nsfg_questionnaires.htm

(continued)

TABLE 1. (CONTINUED)

Name/Study website	Sampling design Probability	Nonprobability	Sample characteristics	Study years	Question type				Partner status	Specific questions	PI/contact and data access
					Sexual identity	Sexual behavior (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (past 5 years)			
National Survey on Drug Use and Health ⁴⁸ samhsa.gov/data/population-data-nsduh/reports			Population: noninstitutionalized U.S. residents; Age: ≥12 years Size: 70,000	1971–present					Which of the following do you consider yourself to be? Heterosexual, that is, Straight; Lesbian, or Gay; Bisexual During the past 12 months, have you had sex with only males, only females, or with both males and females? Remember: by sex we mean only vaginal, oral or anal. Please only mark one box for the best answer. People are different in their sexual attraction to other people. Which statement best describes your feelings? I am only attracted to females. I am mostly attracted to females. I am equally attracted to females and males. I am mostly attracted to males. I am only attracted to males. I am not sure.	PI: Substance Abuse and Mental Health Services Administration Data access: 1996 data and documentation available for download: dx.doi.org/10.3886/CPSR02391 For more information about NSDUH data, see www.samhsa.gov/data/population-data-nsduh/reports?tab=38 or contact samhsa-support@samhsa.hhs.gov	
National Survey of Sexual Attitudes and Lifestyles ⁴⁹⁻⁵⁰ www.natsal.ac.uk/home.aspx			General population survey in the United Kingdom Natsal-1: Age: 16–59 years Size: 18,900 Natsal-2: Age: 16–44 years Size: 12,110 Natsal-3: Age: 16–74 years Size: 15,000 U.S. sample of adults Age: ≥18 years Size: 8000 men and 8000 women	Natsal-1: 1990–1991 Natsal-2: 1999–2000 Natsal-3: 2010–2012					Which of the options on this card best describes how you think of yourself? Response options: Just tell me the letter next to the description on this card: Heterosexual/straight, gay/lesbian, bisexual, other. Altogether, in your life so far, how many (men/women—same sex) have you had sex with (that is, oral or anal, or other forms of genital contact)? Are you currently living as a couple with a woman/man? Have you ever lived as a couple with a woman/man? How many women/men have you lived with as a couple?	PI: Bob Erens E-mail: c.mercer@ucl.ac.uk Phone: 0800-783-5890	
National Violence Against Women Survey ⁵¹ www.icpsr.umich.edu/icpsrweb/NACJD/studies/2566			U.S. sample of adults Age: ≥18 years Size: 8000 men and 8000 women	1994–1996					Are you currently living as a couple with a woman/man? Have you ever lived as a couple with a woman/man? How many women/men have you lived with as a couple?	PI: Patricia Tjaden Data access: www.icpsr.umich.edu/icpsrweb/NACJD/studies/2566	
New York City Community Health Survey ⁵² www1.nyc.gov/site/doh/data/data-sets/community-health-survey.page			Cross-sectional NYC residents from the five boroughs; adults Age: ≥18 years Size: 8500	Annually 2002–2014					Now I'll read a list of terms people sometimes use to describe themselves...heterosexual or straight, homosexual, gay or lesbian, and bisexual. As I read the list again, please stop me when I get to the term that best describes how you think of yourself. Heterosexual or straight; Homosexual, gay or lesbian; Bisexual. Don't know/not sure For women: During the past 12 months, with how many women have you had sex? READ IF NEEDED: By sex, we mean oral, vaginal, or anal sex, but not masturbation. For men: During the past 12 months, with how many men have you had sex? READ IF NEEDED: By sex, we mean oral or anal sex, but not masturbation.	Contact: CHS coordinator, NYC Department of Health and Mental Hygiene E-mail: survey@health.nyc.gov Data access: www1.nyc.gov/site/doh/data/data-sets/community-health-survey-public-use-data.page	
New York City Health and Nutrition Examination Survey ⁵³ http://nychanes.org/data			Cross-sectional noninstitutionalized sample of NYC residents; Age: ≥20 years Size: 1500	2013–2014					Do you think of yourself as... Response options: Heterosexual/straight, homosexual, gay/lesbian, bisexual, don't know, not sure. In your lifetime have you had any type of sex with man/woman (same sex)?	E-mail: info@nychanes.org Phone: 347-396-4171 Data access: http://nychanes.org/data	
Nurses' Health Study II ⁵⁴ channing.harvard.edu/nhs			Population: nurses from CA, CT, IN, IA, KY, MA, MI, MO, NY, NC, OH, PA, SC, and TX in 1989 Age: 25–42 years Size: 116,700	Biennially 1989–present Longitudinal					Whether or not you are currently sexually active, what is your sexual orientation or identity (please choose one answer): heterosexual; lesbian, gay or homosexual; bisexual; none of these; prefer not to answer.	PI: Nurses' Health Study Phone: 617-525-2279 E-mail: nhs2@channing.harvard.edu Data access: requires proposal, identification of a study team collaborator, and approval of advisory committee; data requester responsible for paying the data production and statistical analysis costs.	

(continued)

TABLE 1. (CONTINUED)

Name/study website	Sampling design		Sample characteristics	Study years	Question type				Partner status	Specific questions	PI/contact and data access
	Probability	Nonprobability			Sexual behavior (past 30 days)	Sexual behavior (past 12 months)	Sexual behavior (past 5 years)	Sexual behavior (lifetime)			
					Sexual identity	Attraction	Partner status				
Personality & Teen Health Through Life ⁵⁵ crainv.anu.edu.au/research/projects/personality-total-health-path-through-life			Population: Canberra and Queensland, Australia residents Age: 20–24, 40–44, and 60–64 at baseline Size: 20+ cohort: 2400 40+ cohort: 2500 60+ cohort: 2500 Population: adolescents, children, and their caregivers from randomly sampled neighborhoods in Chicago, Illinois; longitudinal Size: 6200	1999–present Longitudinal					Would you currently consider yourself to be predominantly heterosexual, homosexual, bisexual, Don't know	PI: Kaarin Anstey, PhD Phone: +61 2-6125 8410 E-mail: kaarin.anstey@anu.edu.au Information on data access: http://crainv.anu.edu.au/research/projects/personality-total-health-path-through-life/ data	
Project on Human Development in Chicago Neighborhoods ⁵⁶ www.icpsr.umich.edu/icpsrweb/PHDCN/about.jsp			Population: noninstitutionalized U.S. residents; Age: all ages Size: varies Population: women from 40 U.S. clinical centers; Age: 50–79 years Observational: 161,800	1994–1997, 1997–1999, 2000–2001 Longitudinal					Which of the following best describes your feelings? 100% heterosexual (only attracted to person of the opposite sex); mostly heterosexual (attracted to both, but mostly persons of the opposite sex); bisexual (pretty much equally attracted to both men and women); mostly homosexual (attracted to both, but mostly persons of the same sex); 100% homosexual (gay/lesbian; only attracted to persons of the same sex); not sure	PI: Felton Earls E-mail: phdcn@cpsr.umich.edu Data access: www.icpsr.umich.edu/icpsrweb/PHDCN/daa.jsp	
U.S. Census ⁵⁷ census.gov			Population: secondary school students from New Zealand; schools randomly selected throughout the country; cross-sectional Age: 9–13 years Size: 28,000	1990, 2000, 2010 Longitudinal					How is this person (Person 2) related to Person 1? Husband or wife, Unmarried partner What is Person 2's sex? Male Female Which response best describes who you have had sex with after 45 years of age? Never had sex, Sex with a woman or with women, Sex with a man or with men, Sex with both men and women Regardless of whether you are currently sexually active, which response best describes who you have had sex with over your adult lifetime? Have never had sex, Sex with a woman or with women, Sex with a man or with men, Sex with both men and women, Prefer not to answer.	PI: U.S. Department of Commerce, U.S. Census Bureau Phone: 1-800-923-8282 Data access: factfinder.census.gov PI: WHI Phone: 301-402-2900 E-mail: helpdesk@whi.org Data access: requires request and IRB approval. More information: www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/study.cgi?study_id=phs000200.v10.p3	
Women's Health Initiative ⁵⁸ nhlbi.nih.gov/whi			Population: secondary school students from New Zealand; schools randomly selected throughout the country; cross-sectional Age: 9–13 years Size: 28,000	2001, 2007, 2012 Longitudinal					Who are you sexually attracted to...? The opposite sex (e.g. I am a male attracted to females; I am a female attracted to males); The same sex (e.g. I am a male attracted to males; or I am a female attracted to females); Both sexes (e.g. I am attracted to males and females); I'm not sure; Neither; I don't understand this question	PI: Terryann Clark E-mail: t.clark@aukland.ac.nz Phone: +64-9-923-7670 or +64-21-294-8354 Data access: www.fmhs.auckland.ac.nz/en/faculty/adolescent-health-research-group/collaborations-and-access-to-datasets.html#2c2c836f06923183b0e0884a0f954	
Youth2000 ⁵⁹ www.fmhs.auckland.ac.nz/en/faculty/adolescent-health-research-group/youth2000-national-youth-health-survey-series.html			Population: U.S. public and private school students Age: grades 9–12 Size: varies	Biennially					Which of the following best describes you? Heterosexual (straight), Gay or lesbian, Bisexual, Not sure During your life, with whom have you had sexual contact? I have never had sexual contact, Females, Males, Females and Males	E-mail: cdcinfo@cdc.gov Data access: combined dataset 1991–2013 available at www.cdc.gov/healthyouth/data/yrbbs/data.htm CDC will provide information on how to request data from jurisdictions where survey was conducted and in some cases can provide the data. More information on data access: cdc.gov/HealthyYouth/yrbbs/contactyrbbs.htm	
Youth Risk Behavior Surveillance System ⁶⁰ cdc.gov/HealthyYouth/yrbbs											

Column shading is used to indicate the following for each data source: 1) type of sampling design, and 2) specific types of sexual orientation and transgender-inclusive gender identity questions. BRFS, Behavioral Risk Factor Surveillance System; CA, California; CDC, Centers for Disease Control and Prevention; CT, Connecticut; GUTS, Growing Up Today Study; IA, Iowa; IN, Indiana; IRB, Institutional Review Board; KY, Kentucky; MA, Massachusetts; MI, Michigan; MIDUS, Midlife Development in the United States; MO, Missouri; N/A, not applicable; NCS, National Survey of Sexual Attitudes and Lifestyles; NC, North Carolina; NCHA, National College Health Assessment; NCS, National Comorbidity Survey; NESARC, National Epidemiologic Survey on Alcohol and Related Conditions; NSDUH, National Survey on Drug Use and Health; NYC, New York City; NYC CHS, New York City Community Health Survey; OH, Ohio; PA, Pennsylvania; SC, South Carolina; TX, Texas; WHI, Women's Health Initiative; YRBSS, Youth Risk Behavior Surveillance System.

TABLE 2. GENDER MINORITY-INCLUSIVE HEALTH SURVEILLANCE DATA SOURCES

Name/study website	Sampling design		Study years	Question type			PI/contact and data access
	Probability	Nonprobability		Single-item, general	Single item, specific with probe	Two-item	
Behavioral Risk Factor Surveillance System ^{3,14} cdc.gov/brfss			Annual				PI: CDC Behavioral Survey Branch Data access: contact state-by-state project officers (www.cdc.gov/brfss/state_info/coordinators.htm) More information: see BRFSS state-added question database (www.cdc.gov/brfss/questionnaires/index.htm) Contact: Xenia Kumph, Project Manager E-mail: gutschmidt@channing.harvard.edu Data access: investigators who are interested in using GUTS data or surveys should e-mail the Project Manager.
Growing Up Today Study ²¹ gutsweb.org			Annually, since 1996 Longitudinal				How do you describe yourself? (Mark one answer) Female, Male, Transgender, Do not identify as female, male, or transgender
Kaiser Permanente Member Health Survey ²² dor.kaiser.org/external/DORExternal/mhs/index.aspx			1993–ongoing, every 3 years				What is your sex? Male, Female, Transgender (describe)
National Adult Tobacco Survey ²³ www.cdc.gov/tobacco/data_statistics/surveys/nats			2009–2010, 2012–2013				If answers “something else” to sexual orientation question (see Table 1 above): By something else, do you mean that... identify with another label, such as queer, bisexual, omnisexual, or pan-sexual, “you are transgender, transsexual, or gender variant,” “you have not yet figured out your sexuality, or in the process of figuring it out,” “you do not think of yourself as having a sexuality,” “you do not use labels to identify yourself,” “you made a mistake and did not mean to pick this answer,” and “you mean something else.”
National College Health Assessment ³¹⁻³³ achancea.org			Biannually 2000–present				NCHA I: Which of the following best describes you? Heterosexual, Gay/Lesbian, Bisexual, Transgendered, and Unsure NCHA II: What is your gender? Female, Male, Transgender NCHA IIC: Do you identify as transgender? No, Yes NCHA IIC: Which terms do you use to describe your gender identity: Woman, Man, Trans woman, Trans man, Genderqueer, Another identity
National Intimate Partner and Sexual Violence Survey ³⁴ www.icpsr.umich.edu/tepsrweb/NACJD/studies/34305			2010				Do you consider yourself to be Heterosexual or straight, Gay or lesbian, Bisexual, Transgendered, or DON'T KNOW
National Research Consortium of Counseling Education ³⁵ www.cmhc.utexas.edu/rc_datasets.html			2001, 2007, 2012				How do you identify? Female, Male, Transgender
Youth2000 ³⁹ www.fmhs.auckland.ac.nz/en/faculty/adolescent-health-research-research-group/youth2000-national-youth-health-survey-series.html			2001, 2007, 2012				Do you think you are transgender? This is a girl who feels like she should have been a boy, or a boy who feels like he should have been a girl. (e.g., Trans, Queen, Fa'afine, Whakawahine, Tangata ira Tane, Genderqueer) Yes, No, I'm not sure, I don't understand this question

Column shading is used to indicate the following for each data source: 1) type of sampling design, and 2) specific types of sexual orientation and transgender-inclusive gender identity questions.

with three questions concerning identity and behavior. Prior to 2014, sexual orientation was measured with three questions concerning identity, behavior, and attraction. Transgender-inclusive gender identity was not measured.

American Community Survey. An ongoing survey conducted by the U.S. Census Bureau, the American Community Survey (ACS),¹² produced annually updated data for census tracts and block groups formerly surveyed through the decennial census long-form sample. The initial sample was ~3.5 million housing unit addresses and group quarters in the United States selected from all counties and county equivalents. The ACS collected data regarding 165,000 respondents' marital and spousal relationships, household characteristics, health insurance, and disabilities. Sexual orientation was measured by partner status; household demographic questions included sex of partner and relationship status. Transgender-inclusive gender identity was not measured.

Australian Longitudinal Study on Women's Health. Initiated in 1996, the Australian Longitudinal Study on Women's Health (ALSWH)¹³ was an ongoing population-based study of over 40,000 women in three age-specific cohorts randomly sampled from the Australian Medicare database. Women from rural and remote areas were sampled at twice the rate of urban women. The study produced health information related to spiritual, behavioral, physical, oral, and sexual health. The ALSWH was linked with Australia's Medicare Benefits data and Pharmaceutical Benefits Scheme. Sexual orientation was measured by sexual identity and partner status. Transgender-inclusive gender identity was not measured.

Behavioral Risk Factor Surveillance System. BRFSS^{3,14} assessed information on risk behaviors, preventive health practices, and healthcare utilization for over 400,000 respondents sampled from residents of the 50 states of United States, the District of Columbia, and three U.S. territories by random digit dialing through landlines and cell phones. Inclusion of sexual orientation and transgender-inclusive gender identity questions varied by year and state. Sexual orientation was measured by sexual identity. Transgender-inclusive gender identity was captured by a four-category measure.

California Health Interview Survey. California Health Interview Survey¹⁵ was a biennial, population-based telephone survey of 50,000 Californian residents ≥18 years old. Sexual orientation was measured by sexual identity and 30-day and 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

California Women's Health Survey. Established in 1997, the California Women's Health Survey (CWHHS)¹⁶ was an annual random digit dialing telephone survey of ~4000 California women ≥18 years old. CWHHS collected information on health indicators and health-related knowledge, behaviors, and attitudes. Sexual orientation was measured by sexual identity and 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

Canadian Community Health Survey. A yearly cross-sectional survey, the Canadian Community Health Survey (CCHS),¹⁷ collected information on health status, healthcare

utilization, and health determinants for 65,000 Canadian residents ≥12 years old living in private residences. To capture local health data, the survey contained a core module and optional modules that changed every 2 years. Sexual orientation was measured by sexual identity, 12-month sexual behavior, and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

Colorado Tobacco Attitudes and Behaviors Survey. Colorado Tobacco Attitudes and Behaviors Survey¹⁸ was conducted in 2001, 2005, 2008, 2012, and 2015 and was a population-level, weighted telephone survey of Colorado adults aged 18 and older. The telephone survey covered landlines and cellular telephone numbers. The survey included general demographic characteristics, smoking and cessation history, quit line use, and attitudes about tobacco-related policies. Response rates varied by year. Sexual orientation was assessed by sexual identity. Transgender-inclusive gender identity was not measured.

Current Population Survey. Conducted by the Census Bureau for the Bureau of Labor Statistics, the Current Population Survey¹⁹ provided estimates of employment, earnings, hours of work, and other labor force characteristics for noninstitutionalized, civilian U.S. residents ≥16 years old in ~50,000 households. Sexual orientation was assessed by household roster questions about partner status. Transgender-inclusive gender identity was not measured.

General Social Survey. An annual, multistage area probability study, the General Social Survey,²⁰ assessed 2000 English- and Spanish-speaking adults ≥18 years old residing in households. Measures included a standard core of demographic, behavioral, and attitudinal questions plus special interest topics. Sexual orientation was measured by sexual identity, 12-month, 5-year, and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

Growing Up Today Study. Since 1996, the Growing Up Today Study (GUTS)²¹ followed a national cohort of 16,700 children of Nurses' Health Study participants aged 9–14 years. In 2004, a second cohort of 10,900 children aged 10–17 years was recruited for GUTS2. Health topics included alcohol, tobacco, and other drug use; sexual behaviors; body image, weight, activity, and nutrition; health status; and contextual factors. Sexual orientation was measured by lifetime sexual behavior, attraction, and partner status; items varied by survey year. Transgender-inclusive gender identity was captured in the 2010 survey with a single four-category measure.

Healthy Youth Survey. The Healthy Youth Survey²² was a cross-sectional cohort study collected from Washington State public schools, grades 6–12 ($N=27,752$). The Healthy Youth Survey used a cluster sampling design, in which schools were randomly selected and all students at participating schools were invited to complete the surveys. Topics covered in this survey included health, relationships, behavioral risks such as use of tobacco, alcohol, and other substances, as well as experiences with victimization and bullying. Sexual orientation was assessed with one question about sexual identity. Transgender-inclusive gender identity was not measured.

Kaiser Permanente Member Health Survey. Kaiser Permanente Member Health Survey (KPMHS)²³ was distributed to independent, stratified random samples of ~40,000 adult health plan members ≥20 years old in northern California. Conducted every 3 years, the survey assessed self-reported behavioral health risks, health conditions, and health status. Sexual orientation was assessed by a single sexual identity measure in both men's and women's surveys. Transgender-inclusive gender identity was assessed by a single self-identified sex measure in both men's and women's surveys.

Los Angeles County Health Survey. A population-based sample of 7200 adults ≥18 years old, the Los Angeles County Health Survey (LACHS),²⁴ used telephone surveys and interviews to assess health-related needs of Los Angeles county residents. Health indicators, including health knowledge, behaviors, and conditions, and healthcare access were measured. Sexual orientation was assessed by sexual identity and 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

Midlife Development in the United States. Midlife Development in the United States (MIDUS)^{25–27} was a longitudinal survey of major biomedical, psychological, and social factors known to contribute to good health, psychological well-being, and social responsibility. MIDUS 1²⁵ data were collected from 7100 noninstitutionalized U.S. adults aged 25–74 years in 1995–1996. MIDUS 2²⁶ follow-up data were collected in 2004–2006. MIDUS 3 follow-up data were collected in 2013–2014.²⁷ MIDUS 1 assessed sexual orientation by sexual identity.²⁵ MIDUS 2 assessed sexual orientation by sexual identity and partner status.²⁶ MIDUS 3 assessed sexual orientation by sexual identity and partner status.²⁷ Transgender-inclusive gender identity was not measured.

Minnesota Student Survey. The Minnesota Student Survey (MSS)²⁸ was conducted every 3 years with three groups of students in Minnesota public schools: students in regular schools, students in alternative schools, and students in juvenile correctional facilities. The MSS asked questions about student activities, experiences, and behaviors, including tobacco, alcohol, and drug use, school climate, physical activity, connections with family and school, and health. Sexual orientation was measured by 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

National Adult Tobacco Survey. National Adult Tobacco Survey (NATS)²⁹ was a random digit-dialed, landline and cellular telephone survey conducted with noninstitutionalized U.S. adults aged 18 and older. The population-based sample was drawn from households in the 50 U.S. states and District of Columbia. The sample included 60,192 interviews and the survey covered topics concerning cigarette and tobacco use patterns across the United States. Sexual orientation was measured by sexual identity. Gender identity was measured with one question. If participants selected “something else” from the sexual orientation question, participants were then asked a follow-up question concerning transgender-inclusive gender identity and sexual identity.

National Alcohol Survey. National Alcohol Survey (NAS)³⁰ was a representative sample of 7000 U.S. adults

≥18 years old. Health measures included information on drinking patterns, alcohol-related health behaviors, and outcomes. Sexual orientation was measured by sexual identity and 5-year sexual behavior. Transgender-inclusive gender identity was not measured.

National College Health Assessment. National College Health Assessment (NCHA) I³¹ and NCHA II³² were non-probability samples of students attending self-selected universities in the United States. NCHA collected data twice per academic year from randomly selected students ≥18 years old to assess alcohol and drug use; sexual health, weight, nutrition, and exercise; mental health; personal safety; and violence. Sexual orientation was measured by sexual identity and 12-month sexual behavior.^{31,32}

Transgender-inclusive gender identity was assessed in the NCHA I with a single measure that combined sexual identity and gender identity items.³¹ The NCHA II measured transgender-inclusive gender identity with a three-category gender identity measure.³² In fall of 2015, the NCHA IIc expanded transgender-inclusive gender identity measures to describe participants' gender identities more broadly.³³

National Comorbidity Survey. A nationally representative survey, the National Comorbidity Survey (NCS),^{34–36} measured mental health outcomes of 8000 noninstitutionalized U.S. residents ≥18 years old. Baseline data were collected from 1990 to 1992³⁴ and followed up in the NCS-2 during the period 2001 to 2002.³⁵ From 2001 to 2003, the NCS-R, a replication survey of 10,000 new participants, was conducted.³⁶ Sexual orientation was measured by sexual identity,³⁶ 5-year sexual behavior,^{34,35} and partner status.^{34,35} Transgender-inclusive gender identity was not measured.

National Drug Strategy Household Survey. The National Drug Strategy Household Survey (NDSHS)³⁷ targeted the Australian population age 12 and over. Participants were recruited using a multistage, stratified area, random sample design. The sample included 26,648 respondents, of whom 24,858 responded to sexual orientation questions. The survey covered topics, including, but not limited to, use of alcohol, tobacco, and illicit drugs, victimization arising from use of alcohol or illicit drugs, and demographic characteristics. Sexual orientation was measured by sexual identity. Access to sexual orientation data required additional permissions granted through request and with assurances and protocols to protect respondent confidentiality. Transgender-inclusive gender identity was not measured.

National Epidemiologic Survey on Alcohol and Related Conditions. A cross-sectional national survey, National Epidemiologic Survey on Alcohol and Related Conditions (NESARC),³⁸ surveyed ~43,000 U.S. residents ≥18 years old. Health topics included alcohol and drug use, abuse, and dependence and associated comorbidities. Sexual orientation was assessed by sexual identity, lifetime sexual behavior, and attraction. Transgender-inclusive gender identity was not measured.

National Health and Nutrition Examination Survey. National Health and Nutrition Examination Survey

(NHANES)³⁹ was a cross-sectional probability survey that assessed nutrition and health of civilian noninstitutionalized children and adults in the United States. NHANES included socioeconomic, demographic, dietary, and health-related questions, physiological measurements, and laboratory tests. NHANES assessed sexual orientation by sexual identity and 12-month and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

National Health and Social Life Survey. The National Health and Social Life Survey (NHSLs)⁴⁰ assessed a national probability sample of U.S. noninstitutionalized English-speaking individuals 18–59 years old from two middle-sized metropolitan areas. Topics included sexual experiences and social, demographic, and health-related characteristics. Sexual orientation was assessed by sexual identity, 12-month, 5-year, and lifetime sexual behavior, attraction, and partner status. Transgender-inclusive gender identity was not measured.

National Health Interview Survey. Initiated in 1957, the National Health Interview Survey (NHIS)⁴¹ surveyed ~87,500 civilian noninstitutionalized children and adults in the United States in over 35,000 U.S. households. The Family Core Questionnaire assessed demographics, socioeconomic status, healthcare coverage, health status, and healthcare utilization of adult respondents. Historically, sexual orientation was assessed by partner status in the household roster. In 2013, a sexual identity measure was added. Transgender-inclusive gender identity was not measured.

National Intimate Partner and Sexual Violence Survey. National Intimate Partner and Sexual Violence Survey (NISVS)⁴² was an ongoing nationally representative survey that assessed the experiences of sexual violence, stalking, and intimate partner violence among adult men and women, aged 18 years and older, in the United States. Sexual orientation was measured by sexual identity and lifetime sexual behavior. Transgender-inclusive gender identity was measured not with a distinct question, but as a possible response to the sexual identity question.

National Latino and Asian American Study. National Latino and Asian American Study (NLAAS)⁴³ was a complex, multistage, household probability survey of noninstitutionalized U.S. Latino and Asian American adults aged 18 and older. Participants ($N=4649$) were administered a face-to-face interview concerning mental health and psychiatric disorders based on the World Mental Health Survey Initiative. Sexual orientation was measured by sexual identity and 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

National Longitudinal Study of Adolescent to Adult Health. A longitudinal cohort study, the National Longitudinal Study of Adolescent to Adult Health (Add Health),⁴⁴ followed a nationally representative sample ($N=14,400$) of U.S. adolescents in grades 7 through 12 in the 1994 to 1995 school year. Four waves of data collection were completed. Sexual orientation was assessed by sexual identity, 12-month sexual behavior, lifetime sexual behavior, attrac-

tion, and partner status. Transgender-inclusive gender identity was not measured.

National Research Consortium of Counseling Centers in Higher Education. This data source surveyed a stratified random sample of 108,536 students from 70 U.S. institutions of higher education. Surveys were administered through a Web-based questionnaire to undergraduate and graduate students. The survey assessed topics including suicidal ideation and severity, psychological distress, coping, and other mental health concerns. Sexual orientation was measured by sexual identity. Transgender-inclusive gender identity was measured with a single gender identity question.⁴⁵

National Social Life, Health, and Aging Project. A population-based, household probability sample, the National Social Life, Health, and Aging Project (NSHAP),⁴⁶ assessed community-residing U.S. adults aged 57–85 years. Topics included social networks, social and cultural activity, physical and mental health, and sexual history. Sexual orientation was measured using 5-year sexual behavior and a household roster to assess partner status. Transgender-inclusive gender identity was not measured.

National Survey of Family Growth. National Survey of Family Growth⁴⁷ interviewed over 12,000 noninstitutionalized U.S. women (Cycles I–VI) and men (beginning in Cycle VI), 15–44 years old. General topics included family life, marriage and divorce, pregnancy, infertility, use of contraception, and health. Sexual orientation was assessed by sexual identity, 12-month sexual behavior, lifetime sexual behavior, attraction, and partner status. Transgender-inclusive gender identity was not measured.

National Survey on Drug Use and Health. The National Survey on Drug Use and Health (NSDUH)⁴ began in 1971 and was conducted annually with a random sample of 70,000 non-institutionalized, U.S. residents ≥ 12 years old. Topics included trends in alcohol, tobacco, and illicit drug use; demographics; mental health; and related topics. Historically, NSDUH assessed sexual orientation with a single sexual behavior measure. Beginning in 2015, measures of sexual identity and attraction were added. Transgender-inclusive gender identity was not measured.

National Survey of Sexual Attitudes and Lifestyles. National Survey of Sexual Attitudes and Lifestyles (Natsal)^{48–50} began in 1990 as the first nationally representative survey of sexual behavior and attitudes in Britain. The goal of this program was to describe patterns of sexual behavior in Britain, provide data for HIV/AIDS projections, assess changes in sexual attitudes and behavior, and determine the prevalence of sexually transmitted infections. Sexual orientation was measured with questions about sexual identity and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

National Violence Against Women Survey. The National Violence Against Women Survey (NVAW)⁵¹ was a nationally representative probability sample of 8000 women and 8000 men aged 18 years and older. The survey assessed violence against women, including victimization

in childhood and subsequent victimization, physical assault, forcible rape and stalking, injury rates, and use of medical services as a result of violence against women. NVAW measured sexual orientation by partner status. Transgender-inclusive gender identity was not measured.

New York City Community Health Survey. The New York City Community Health Survey (NYC CHS)⁵² was an annual survey that sampled noninstitutionalized adults aged 18 years and older who lived in NYC and had either a landline or cellular telephone. Topics included the health of New Yorkers including chronic disease and behavioral risk factors. Sexual orientation was measured by sexual identity and 12-month sexual behavior. Transgender-inclusive gender identity was not measured.

New York City Health and Nutrition Examination Survey. New York City Health and Nutrition Examination Survey (NYC HANES)⁵³ was a population-based cross-sectional survey of the NYC noninstitutionalized adult population 20 years and older and was modeled after the NHANES.⁶¹ Respondents provided an in-depth health interview, physical examination, and laboratory tests. Sexual orientation was assessed with sexual identity and lifetime sexual behavior questions. Transgender-inclusive gender identity was not measured.

Nurses' Health Study II. Beginning in 1989, the Nurses' Health Study II (NHS II)⁵⁴ was a prospective survey mailed every 2 years to 116,700 female nurses 25–42 years old at baseline in California, Connecticut, Indiana, Iowa, Kentucky, Massachusetts, Michigan, Missouri, New York, North Carolina, Ohio, Pennsylvania, South Carolina, and Texas. NHS II focused on oral contraceptives, diet, and lifestyle risk. Sexual orientation was assessed with a sexual identity measure. Transgender-inclusive gender identity was not measured.

Personality & Total Health Through Life. A 20-year longitudinal study, Personality & Total Health,⁵⁵ surveyed over 7000 community residents randomly selected from the electoral rolls of Canberra and Queanbeyan in Australia. Each study wave consisted of (at baseline) three cohorts: 20–24 years old, 40–44 years old, and 60–64 years old. Health topics included depression and anxiety, alcohol and drug addiction, and cognitive functioning and dementia. Each survey measured sexual orientation by sexual identity. Transgender-inclusive gender identity was not measured.

Project on Human Development in Chicago Neighborhoods. Project on Human Development in Chicago Neighborhoods (PHDCN)⁵⁶ was a multilevel, prospective cohort study of 6226 adolescents and children, their caregivers, and neighborhoods randomly sampled from neighborhood clusters in Chicago, Illinois. The full project involved households with children in one of seven age groups (in utero, 3, 6, 9, 12, 15, and 18 years old). PHDCN used a comprehensive in-person interview and self-report questionnaire to assess sexual orientation, sexual risk indicators, and sexual abuse victimization. Sexual orientation was assessed by attraction. Transgender-inclusive gender identity was not measured.

U.S. Census. Conducted by the Census Bureau⁵⁷ for the Bureau of Labor Statistics, the census provided decennial es-

timates of disability, birth rates, employment and economic indicators, and household characteristics for persons dwelling in U.S. households, including citizens, noncitizen legal residents, noncitizen long-term visitors, and undocumented immigrants. Sexual orientation was assessed by household roster questions about partner status. Transgender-inclusive gender identity was not measured.

Women's Health Initiative. A longitudinal, randomized, controlled comparison trial and observational study, the Women's Health Initiative (WHI),⁵⁸ assessed 161,800 postmenopausal women, aged 50–79 years beginning in 1993. In 2005, the WHI Extension Study (2005–2010, 2010–2015) continued follow-up of all consenting participants. Topics included demographic, psychosocial factors, and physical and mental health issues, including cancer and cardiovascular disease prevention. Sexual orientation was measured by sexual behavior after age 45 and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

Youth2000. The Youth2000⁵⁹ survey was a cross-sectional self-administered questionnaire concerning the health and well-being of secondary school students conducted in 2001, 2007, and 2012. It included a representative sample of secondary students in New Zealand. Surveys were completed anonymously by students enrolled at a secondary school using computer-assisted self-interviewing technology. Sexual orientation was measured by attraction. In 2012, transgender-inclusive gender identity was measured with a single gender identity question.

Youth Risk Behavior Surveillance System. A national, state, and regional system of school-based probability surveys, the Youth Risk Behavior Surveillance System (YRBSS),⁶⁰ assessed U.S. public and private school students aged 12–18 years. Inclusion of sexual orientation questions varied by year and state until 2015 when the national YRBSS measured sexual orientation by identity and lifetime sexual behavior. Transgender-inclusive gender identity was not measured.

Discussion

With this work, we provided a review of data sources that included SGM measures. We have also identified the limitations in best practice measurement of SGM populations in these data sources as compared to best practice recommendations. Our findings point to opportunities to improve large-scale collection of SGM data. This is especially important in light of the 2011 IOM report, which calls for standards to revise SGM measures across health surveillance resources to improve measurement precision with the intent to meaningfully compare data across surveys and achieve nationally representative data sources.¹

This article's purpose rested on the philosophical tenet that public health data sources including sexual orientation and transgender-inclusive gender identity measures should be readily accessible, yet these data can be difficult to locate and no single scholarly resource documented their location. Using published recommendations for measurement of sexual orientation⁶ and transgender-inclusive gender identity⁷ as inclusion criteria, we filled this gap by identifying large-

scale, publicly available, health surveillance resources that included sexual orientation or transgender-inclusive gender identity measures; increasing their accessibility to maximize value for SGM health research. Furthermore, by comparing data sources with these recommendations, we identified how available health surveillance data sources differed from each other and best practice.

Limitations in SGM health surveillance

SGM measurement. A growing number of health surveillance data sources measured sexual orientation or transgender-inclusive gender identity, as evidenced by the data sources identified and summarized herein. Very few of the data sources measured sexual orientation and transgender-inclusive gender identity consistently across data sources, within data sources across time, or according to recommended guidelines.

Just over half of the 43 data sources assessed sexual minority status with two or more dimensions of sexual orientation, with most measuring sexual identity and behavior at minimum.^{4,11,15–17,20,24,30–36,38–40,42–44,47–50,52,53,60} Yet, only 14% followed best practice recommendations to measure sexual identity, sexual behavior, and attraction to assess sexual orientation.^{4,11,38,40,44,47}

Notably, 40% of data sources measured a single dimension of sexual orientation.^{3,13,14,18,22,23,25–29,37,41,45,46,54–56,58,59} This is in direct contrast to published recommendations to measure multiple dimensions of sexual orientation.⁶ Single-item sexual orientation measures limit what can be known about sexual orientation and health because sexual identity, behavior, and attraction are not always concordant and do not all confer the same type and degree of health risk. Therefore, it is important that multiple sexual orientation measures be used to capture sexual minority persons accurately and understand population-level risk and health.⁶

Data sources also varied in the type of measure used to assess sexual behavior as a dimension of sexual orientation; specifically, sexual behavior measurement included same-sex sexual behavior in the past 30 days, 12 months, 5 years, and lifetime. Discordance in measurement across health surveillance resources limits our ability to conduct meaningful comparisons across data and surveys. Public health surveillance must employ standard measures of sexual orientation dimensions across data sources to reliably assess and quantify health disparities experienced by sexual minorities.^{1,6}

Only 19% of data sources measured transgender-inclusive gender identity and most sources included only a single transgender-inclusive gender identity measure.^{3,14,21,23,29,42,45,59} Single-item measurement is problematic because some transgender individuals identify their gender as male or female and not as transgender,⁶² thereby occluding the presence and experiences of these transgender individuals. This significantly limits what can be known about health, risks, and disparities and curtails the development of optimal disparity-reducing interventions for the diverse group of individuals who identify on the spectrum of transgender identities.

Rigorous, population-based health surveillance should measure transgender-inclusive gender identity through a two-step approach with items that capture sex assigned at birth and current gender identity.^{7,62} No data sources identified in this search utilized this two-step approach to capture

gender minority identity. To fully capture the diversity of the transgender community, experts also suggest expanding measurement of transgender-inclusive gender identity questions and response options to include genderqueer/gender nonconforming and other identities.⁷ Only two data sources included genderqueer or gender nonconforming as response items.^{3,14,33}

Age. There appears to be a difference in how sexual orientation is measured depending on the age of participants that may be problematic for older adults. This review identified 15 data sources that included sexual orientation measures for youth below the age of 18.^{4,11,17,21,22,28,37,39,41,44,47–50,56,59,60} Of these data sources, 27% ($N=4$) asked questions concerning all three aspects of sexual orientation.^{4,11,44,47} Comparatively, of the 28 data sources that included sexual orientation measures only for respondents aged 18 or older,^{3,12–16,18–20,23–27,29–36,38,40,42,43,45,46,51–55,57,58} only 7% ($N=2$) asked questions concerning all three aspects of sexual orientation.^{38,40}

Variation in measurement by age is problematic because risk for health and health-related problems differs depending on how sexual orientation is measured. By limiting the range of questions concerning sexual orientation to younger ages only, what can be known about health and health risk as it pertains to behavior, attraction, and identity among adults is systematically limited. Similarly, in some data sources, participants over the age of 59 are asked only specific sexual orientation questions. For example, NHANES includes sexual behavior questions for adults up to age 69; however, the survey includes sexual identity questions only for adults aged 59 and younger.³⁹ We believe this is problematic because it is probable that one's sexual orientation remains salient after age 59, some or all aspects of sexual orientation are not static and may change over time, and that the multiple aspects of sexual orientation remain relevant to health after age 59.¹

Data linkages. A strength of health surveillance programs is the capacity to link health surveillance data with healthcare administrative data to better investigate complex health-related issues. In the United States, the National Center for Health Statistics has linked both the NHIS and the NHANES to specific administrative datasets, including the National Death Index (NDI) as well as Centers for Medicare and Medicaid Services (CMS), Social Security Administration (SSA), and U.S. Housing and Urban Development (HUD) administrative files.⁶³ However, information on SGM populations that can be drawn through these data linkages is extremely limited.

Specifically, as NHIS only began collecting information on sexual identity as part of the 2013 survey, no additional data linkages are yet available.⁶³ NHANES, which began collecting data on sexual identity in 2001 and same-sex sexual behavior in 1999, offers more opportunity for analysis of administrative datasets: NDI, CMS, SSA, and HUD data are currently available for 1994–2004 surveys, and NDI data are also available from 2005 to 2010.⁶³ However, sexual orientation questions asked of NHANES participants are age restricted. Sexual identity is asked of participants 18–59 years of age and sexual behavior is asked of participants 18–69 years of age.³⁹ Yet, sexual orientation remains salient and could possibly change after ages 59 and 69.^{1,64,65} This limits the utility of linked data sources because little information on older sexual minority adults (age 65+) can be drawn from linked data sources.

In addition, while evidence suggests that sexual minorities are more likely to engage in risky health behaviors (e.g., tobacco use and heavy alcohol use) and experience chronic disease,¹ we are less able to examine connections between these variables and mortality due to age-restricted sampling. This problem is not restricted to the United States; the CCHS,¹⁷ while linked with datasets measuring mortality, hospital admissions, and finances,⁶⁶ measures sexual identity only for respondents of age 18–59 and sexual behavior for respondents of age 18–49. Such restrictions compromise our capacity to understand sexual minority health.

Only KPMHS measures transgender-inclusive gender identity and offers linked information to administrative and clinical data, thus offering an opportunity to explore health-care utilization among this group.^{23,67} However, similar to NHANES³⁹ and CCHS,¹⁷ the KPMHS is age-restricted to respondents 20–60 years old and thus limits our understanding of aging and health among SGMs.²³ No national data sources exist that include transgender-inclusive gender identity measures and are linked with administrative or clinical data. These omissions severely limit our capacity to understand gender minority health.

Sampling. The reviewed data sources also suffered from another limitation. None of the reviewed data sources oversampled for SGM populations. This is problematic because SGMs exist in small proportion relative to the general population. Under optimal population-based sampling strategies, very few (~3%–5%) samples will include SGM persons. These very small sample sizes significantly restrict empirical investigation of health, health disparities, and health needs among these groups. This problem is similar to that of underrepresentation of racial/ethnic minority persons in population-based data sources, which has previously been resolved with oversampling strategies. Oversampling SGM groups could decrease underrepresentation in health surveillance data sources and ensure reliable estimates of population demographics and health.

Opportunities for future SGM health surveillance

Despite the limitations of the data sources reviewed and summarized herein, this article complements existing listings of sexual minority-inclusive data sources⁵ in two ways. First, it provides scholarly documentation and review of publicly available, large-scale, health surveillance data sources that include measures of transgender-inclusive gender identity as well as sources that include both sexual orientation and transgender-inclusive gender identity measures. Second, it provides meaningful comparison of SGM measures included in health surveillance with the published recommended best practices.

Although the measures included in public health surveillance are constantly changing, and some new data sources may become publicly accessible in the future (i.e., The PRIDE Study) and others may begin to include SGM measures (i.e., Health Information National Trends Survey), this detailed review of the publicly available, large-scale health surveillance resources that measure SGMs provides a peer-reviewed scholarly reference from which researchers can build upon and evaluate limitations, identify opportuni-

ties for future growth, and chart progress over time in SGM data collection.

SGM measurement. Our results suggest that current public health surveillance resources are greatly limited in their measurement of sexual orientation and transgender-inclusive gender identity. Too few large-scale, publicly available, rigorously sampled data sources measure SGMs. Those that do include SGM measures do so inconsistently within and across data sources and in relation to best practice recommendations. In addition to increasing the number of SGM-inclusive data sources, we recommend modifications to SGM measures currently included across public health surveillance, cohort, and observational data sources to close the gap between current measurement and best practice recommendations.

To improve sexual orientation measurement, we encourage researchers to include, at minimum, two dimensions of sexual orientation: sexual identity and sexual behavior. This practice standard is being met by a majority of large-scale, public health surveillance resources and can be built upon to achieve consistency across data sources. In addition, while study aims dictate survey measures to ensure precision across data sources, sexual behavior measures should include lifetime same-sex sexual behavior and, ideally, two time periods (i.e., in addition, a 5-year or 12-month item dependent on study aims).

To capture gender minority identity, we encourage researchers to, at minimum, add a single-item transgender identity question to surveys so that we may begin to gather national representative data for this group.

For all SGM measures, we encourage health surveillance administrators and researchers to use language outlined in best practices set forth by the Williams Institute.^{6,7} These changes could improve investigations of SGM health and the ability to identify disparities by allowing for comparisons across data sources. Such comparisons could result in new or extended findings and increase the potential for developing health-promoting and disparity-eliminating solutions for SGM groups.

Age. The substantial gaps in SGM measurement of older adults among existing health surveillance data sources greatly limit our understanding of this growing and vulnerable group. An estimated 2.4 million LGBT adults, age 60 and older, currently reside in the United States, and that number is expected to grow to over 5 million by 2030.⁶⁸

Current evidence suggests that SGM older adults are at risk for experiencing victimization, higher alcohol and tobacco use, poor mental and physical health, and disability.^{69,70} However, existing studies of SGM older adults have mostly used community-based nonprobability sampling and small sample sizes because population-based health surveillance data sources are largely unavailable. To date, no studies have examined response rates among older adults for transgender-inclusive gender identity measures. Considering this evidence, and given the rising number of SGM older adults, health surveillance surveys must include SGM measures for older adults. Only then can researchers, policy makers, and practitioners best develop targeted cost-effective solutions for addressing the health needs of this vulnerable group.

Data sources. Our review highlights critical gaps in SGM-inclusive data sources that must be filled to advance comprehensive health surveillance for this population. A significant concern is that no accurate census count of SGM people exists. Without direct questions about sexual orientation and transgender-inclusive gender identity, national estimates of SGM populations are aggregated from multiple surveys, thus creating variability in percentage estimates for these groups. Without SGM census counts, we are unable to clearly articulate who SGM people are and what needs they have. Subgroups of SGM people are significantly underrepresented (e.g., racial/ethnic minorities, older adults, and immigrants) and this severely limits our understanding of health and health disparities within the SGM community.

In addition, without federal SGM census data, we cannot determine correct statistical weighting for SGMs represented in national probability surveys. This gap may cause researchers using existing weighting to make inaccurate population-based estimates of SGM health-related outcomes. Using unweighted data is also problematic because it may limit the utility of existing probability sampling health surveillance to nongeneralizable estimates of SGM sample characteristics. With these limitations in mind, we strongly advocate for including SGM measures beyond those capturing partner status in the federal census as a priority for advancing future SGM health research.

Several data sources are notably absent from our review. For example, despite the disproportionate prevalence of cancer risk factors among SGMs,¹ cancer incidence and mortality are largely unmonitored for this group. National cancer surveillance data sources, specifically SEER and the American Cancer Society's Cancer Prevention Studies (CPS), have not included SGM measures historically.² The CPS-3, which began recruitment in 2013, now includes a sexual orientation measure⁷¹; however, these data are not publicly available. Future SGM-inclusive cancer surveillance is essential for understanding the cancer burden among SGMs and developing disparity-reducing prevention and treatment programs for this population.

Public dissemination. As previously discussed, this article provides a systematic review of publicly available, large-scale health surveillance data sources that measure SGMs. Given the IOM recommendation to expand SGM health surveillance,¹ it is imperative that researchers, practitioners, and policy makers continue to monitor and track improvements in SGM measurement within existing and newly developed health surveillance programs.

As a central body tasked with leveraging resources to support SGM health research, the National Institutes of Health's Sexual and Gender Minority Research Office (SGMRO) is uniquely positioned to track and disseminate information on SGM-inclusive health surveillance. To this end, we suggest that the SGMRO conduct ongoing review and publication of SGM-inclusive health surveillance data sources, including specific SGM measures, as well as a summary of the state of SGM-inclusive health surveillance. These efforts

may be leveraged to track progress in SGM measurement, identify gaps in SGM health surveillance, and set national priorities for SGM health research.

Conclusion

With this work, we intended to contribute to the collective, peer-reviewed, scholarly knowledge base about data sources that include SGM measures and can be used to inform research about health risks and disparities among SGM populations. Future recommendations are for increased SGM-inclusive data sources, more rigorous measurement of sexual orientation and transgender-inclusive gender identity concordant with best practice recommendations, and oversampling of SGM populations. Only then can needs be identified, solutions developed, tested, and disseminated toward the overarching aim: to develop programs and policies that best serve the unique health needs of and eliminate health disparities experienced by lesbian, gay, bisexual, and transgender communities.

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