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Surveying Sexual and Gender Minorities

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23.1 Introduction

Lesbian, gay, and bisexual (LGB) individuals are often referred to as *sexual minorities*, and *transgender* (T) individuals are referred to as *gender minorities*. These labels are determined based on sexual orientation and gender identity designations. This chapter provides an overview of considerations for health-related survey research with sexual and gender minorities and is divided into three sections. The first section provides definitions of sexual orientation and gender identity, describes challenges in the measurement of sexual and gender minority status, and presents examples of questions for measuring sexual orientation and gender identity. The second section presents a summary of the probability and nonprobability

sampling methods that have been used most frequently in research with sexual and gender minorities with a description of the major strengths and limitations of each approach for sampling and recruiting sexual and gender minorities. The third section provides an overview of data-collection methods that have been used in research with sexual and gender minorities. While many of the methodological issues are relevant for any medical, psychological, or social science research study, the examples in this chapter emphasize the medical and public health literatures.

23.1.1 DEFINITION OF SEXUAL ORIENTATION

Sexual orientation is a relational construct that refers to the biological sex of an individual and the sex of one's potential or actual sexual and/or romantic relationships relative to each other (Institute of Medicine 2011); this does not include isolated sexual encounters or experimentation (Peplau and Garnets 2000, Herek 2006). The most recent and generally accepted conceptualization of sexual orientation includes three components: identity, behavior, and attraction (Laumann et al. 1994, Solarz 1999, McCabe et al. 2005, Institute of Medicine 2011). Sexual orientation *identity* is generally defined as self-identification as heterosexual (e.g., straight), homosexual (e.g., gay or lesbian) or bisexual (e.g., bi). The meaning of the identity terms *homosexual*, *heterosexual*, and *bisexual* changes with cultural, social, economic, political, and historic circumstances (Lesbian Gay and Bisexual (LGB) Youth Sexual Orientation Measurement Work Group 2003). *Behavior* encompasses engagement in sexual contact with a person or people of the same sex, opposite sex, or both sexes over time. *Attraction* refers to a person's tendency to be attracted to individuals of the same sex, opposite sex, or both. Several studies have shown that engagement in same-sex sexual behaviors and/or same-sex attractions is much more common than identification as homosexual or bisexual (Laumann et al. 1994, Smith et al. 2003, Friedman et al. 2004, Mosher et al. 2005, Kerker et al. 2006, McNair et al. 2006).

Sexual orientation as a continuum was first introduced in the United States by Kinsey and colleagues (1948, 1953) and has been supported through ongoing research (Weinrich and Klein 2002, Worthington and Moreno 2005, Herek et al. 2010). The fact that sexual orientation is a multifaceted construct that operates along a continuum makes it difficult to measure sexual orientation by identity alone. For instance, because the behavior and attraction components of sexual orientation exist on a spectrum, individuals may not easily classify themselves into one of the identity categories. An individual who has engaged in sexual contact with individuals of both sexes and reports being somewhat attracted to individuals of both sexes may identify in any of the sexual identity classifications. Dissonance between the various dimensions of sexual orientation has been widely acknowledged (Ross et al. 2003, Friedman et al. 2004, McCabe et al. 2005, Savin-Williams and Ream 2007, Bauer and Jairam 2008); many more individuals report same-sex behavior or attraction than those who identify as homosexual or bisexual. Sexual orientation has also been found to change over time, adding

even more of a challenge to its measurement (Diamond 2000, Diamond 2003, Kinnish et al. 2005, Savin-Williams and Ream 2007, Bauer and Jairam 2008).

To date, there have not been standard, generally accepted measures of sexual orientation. Many different measures of sexual orientation have been used over time. The Kinsey scale (Kinsey et al. 1948, 1953) was one of the first measures developed and has continued to be used in more recent studies (Rahman et al. 2008, Zietsch et al. 2008, Rubinstein 2010). This measure is typically used as a scale from 0 to 6, where 0 means exclusively heterosexual and 6 means exclusively homosexual. Values 1 through 5 represent varying degrees of bisexuality (Kinsey et al. 1948, 1953). Another older measure that has been used in recent studies is the Klein sexual orientation grid (Klein et al. 1985), a measure that views sexual orientation as a multivariable dynamic process (de Rooij et al. 2009, Colzato et al. 2010). This grid includes 21 items, each of which can be rated 1 through 7, similar to the Kinsey scale. The 21 items comprise seven dimensions of sexual orientation with three time references: lifetime history, past 12 months, and ideal preference. The seven dimensions include: attraction, behavior, fantasy, emotion, social preference, lifestyle preference, and identity (Klein et al. 1985). The Sell assessment of sexual orientation (Sell 1996, 1997) is another assessment of sexual orientation that has been used in at least one recent study (Alanko et al. 2010). This assessment considers various dimensions of sexual orientation, and consists of 12 questions about attractions, behavior, and identity. Many other multiitem measures of sexual orientation have been proposed, but none have garnered widespread support (e.g., Shively and De Cecco (1977), Storms (1980), Friedman et al. (2004), Worthington and Moreno (2005)).

Depending on the research topic, different dimensions of sexual orientation are more salient. For example, same-sex behavior is more relevant than identity for studies of HIV risk behaviors, while sexual orientation identity may be the important dimension in studies of stress or discrimination experiences. Several recent nationally representative surveys and large-scale studies, which have limited space to devote to particular constructs, have included a single measure of sexual orientation identity, with a fewer studies including questions about attraction and/or behavior. Examples of single questions used in recent large-scale surveys to measure sexual orientation dimensions are included in Table 23.1.

23.1.2 DEFINITION OF GENDER IDENTITY

Gender identity is usually defined as a person's sense of gender; being a man, woman, or another gender. *Transgender* refers to an individual whose gender identity differs from the sex originally assigned at birth, whose gender expression varies from what is traditionally associated with that sex, or who varies from or rejects traditional cultural conceptualizations of gender in terms of the male–female dichotomy (Institute of Medicine 2011). Transgender women, often referred to as *male-to-female* (MTF), are individuals who were assigned at birth as male and who self-identity as female or express their gender as female. Transgender men, often referred to as *female-to-male* (FTM), are individuals who were assigned at birth as female and who self-identify as male or express their gender as male.

TABLE 23.1 Examples of Sexual Orientation and Gender Identity Questions Used in State and National Surveys by Dimension

Dimension	Question	Example Survey
Sexual orientation-identity	Do you consider yourself to be: [ ] Heterosexual or straight, [ ] Gay or lesbian, or [ ] Bisexual?	Behavioral Risk Factor Surveillance Survey (state of Vermont) (www2a.cdc.gov/nccdphp/brfss2/coordinator.asp) HIV/AIDS Surveillance System (www.cdc.gov/hiv/stats/hasrlink.HTM) National Survey of Family Growth[a] (www.cdc.gov/nchs/nsfg.htm) National Epidemiologic Survey on Alcohol and Related Conditions[b] (http://www.niaaa.nih.gov/Resources/DatabaseResources/Pages/default.aspx) California Health Interview Survey[c] (www.chis.ucla.edu/)
	Which of the following best describes you? [ ] Heterosexual (straight) [ ] Gay or lesbian [ ] Bisexual [ ] Not sure	Youth Risk Behavior Surveillance Survey (selected states) (www.cdc.gov/HealthyYouth/yrbs/index.htm)
	Do you think of yourself as … [ ] Heterosexual or straight (that is, sexually attract only to [opposite sex]) [ ] Homosexual or gay (that is, sexual attracted only to [same sex]) [ ] Bisexual (that is, sexually attracted to men and women) [ ] Something else, or [ ] Not sure?	National Health and Nutrition Examination Survey[c] (www.cdc.gov/nchs/nhanes.htm)
Sexual orientation-behavior	During the past 12 months, have you had sex with [ ] only males [ ] only females, or [ ] both males and females?	Behavioral Risk Factor Surveillance Survey (states of Vermont, Massachusetts) (www2a.cdc.gov/nccdphp/brfss2/coordinator.asp)
	During the past 12 months, have your sexual partners been [ ] male [ ] female, or [ ] both male and female?	California Health Interview Survey (www.chis.ucla.edu/)
	During your life, the person(s) with whom you have had sexual contact is (are): [ ] I have not had sexual contact with anyone [ ] Female(s) [ ] Male(s) [ ] Female(s) and male(s)	Youth Risk Behavior Surveillance Survey (selected states) (www.cdc.gov/HealthyYouth/yrbs/index.htm) National Epidemiologic Survey on Alcohol and Related Conditions[b] (http://www.niaaa.nih.gov/Resources/DatabaseResources/Pages/default.aspx)

(continued)

TABLE 23.1 (*Continued*)

Dimension	Question	Example Survey
	Thinking of the last 5 years, that is since (season) of (year), has the partner or partners in your sexual relationships been: [ ] only men [ ] mostly men [ ] about the same number of men and women [ ] mostly women [ ] only women, or [ ] have you not had a sexual relationship in the last five years?	National Alcohol Survey (www.arg.org/address.html)
Sexual orientation-attraction	People are different in their sexual attraction to other people. Which best describes your feelings? Are you [ ] only attracted to females [ ] mostly attracted to females [ ] equally attracted to females and males [ ] mostly attracted to males [ ] only attracted to males, or [ ] not sure?	National Survey of Family Growth (www.cdc.gov/nchs/nsfg.htm) National Epidemiologic Survey on Alcohol and Related Conditions[b] (http://www.niaaa.nih.gov/Resources/DatabaseResources/Pages/default.aspx)
Gender identity	Which of the following best describes you? [ ] Male [ ] Female [ ] Transgendered [ ] Not sure	Youth Risk Behavior Surveillance Survey (Washington, DC) (www.cdc.gov/HealthyYouth/yrbs/index.htm)
	People describe themselves as transgender when they need to express themselves, or enjoy expressing themselves in the gender role of the opposite sex. For example, this could include cross dressing, transvestitism, being transsexual, or doing drag. Do you consider yourself to be transgender? [ ] Yes-Male to female (MTF) [ ] Yes-Female to male (FTM) [ ] No	Behavioral Risk Factor Surveillance Survey (state of Vermont) (www2a.cdc.gov/nccdphp/brfss2/coordinator.asp)

[a]Includes additional response of "or something else?"
[b]Question wording varies slightly by year of administration.
[c]Second category phrased gay (lesbian) or homosexual.

Similar to sexual orientation, there have not been standard, generally accepted measures of gender identity. Some studies have included a single question to assess respondents' transgender status using a yes–no response (Almeida et al. 2009). Conron and colleagues (2008) conducted cognitive-based testing of a more complex gender identity measure with youth. Response options for this measure included (i) female; (ii) male; (iii) transgender, male to female, (iv) transgender, female to male, (v) transgender, do not identify as exclusively male or female; and (vi) not sure. The National lesbian, gay, bisexual, transgender (LGBT) Tobacco Control Network conducted cognitive-based testing of a single question that combined sexual orientation and gender identity, asking adult respondents, "Do you consider yourself to be one or more of the following," providing the answer categories: (i) straight; (ii) gay or lesbian; (iii) bisexual; (iv) transgender (Scout 2008). There have been very few large-scale surveys to date that have included items about gender identity. Examples of single items used in large-scale surveys are shown in Table 23.1. More methodological studies are needed to determine the measures of gender identity that ultimately facilitate the most valid and reliable survey responses from gender variant populations.

23.2 Prevalence Estimates of Sexual and Gender Minorities

23.2.1 SEXUAL ORIENTATION

Prevalence estimates of homosexuality and bisexuality among United States adults have ranged from 1 to 7%, increasing considerably after the 1990s (Laumann et al. 1994, Gates 2006, 2010, Herbenick et al. 2010, Gates and Cook 2011). These estimates include only adults who identify as homosexual, gay, lesbian, or bisexual. However, prevalence estimates of adults reporting same-sex partners are much higher, ranging from 4% to 12% since 1994 (Laumann et al. 1994, Mosher et al. 2005, Gates 2010, Herbenick et al. 2010). In addition to lack of consistency in definition and measurement of sexual orientation, the large variation in prevalence estimates may be due to differences in studies based on the time period of data collection, sampling methods, sample age, survey instruments used, and mode of data collection.

Differences in self-reported sexual orientation have been identified by gender, race/ethnicity, culture, age, education, income, and geography. In the first national probability survey to examine adult sexual behaviors in the United States, 2.8% of men and 1.4% of women identified as homosexual or bisexual (Laumann et al. 1994). In the 2010 National Survey of Sexual Health and Behavior, 6.8% of men identified as homosexual or bisexual, whereas only 4.5% of women did so (Herbenick et al. 2010). However, in the 2008 General Social Survey, 4.6% of women identified as homosexual or bisexual compared to only 2.9% of men (Gates 2010). These differences may be due to a large margin of error, changes over time, or differences in the sampled populations.

Self-reports of sexual orientation also differ by culture, race, and ethnicity. There is some evidence that racial/ethnic minorities who engage in same-sex behaviors are less likely to identify as gay because they fear being stigmatized by their community (Ross et al. 2003). For example, Ford and colleagues (2007) describe a culture of secret same-sex behaviors referred to as *the down low* among some African-American males that does not involve identifying as homosexual. Cultural differences in the concept of community membership, traditional gender roles, and religiosity are also known to affect reported sexual orientation identity (Institute of Medicine 2011).

Sexual orientation also differs across age groups. Among studies that have included individuals across the adult lifespan, homosexual identification is highest among young and middle-aged adults (Herek et al. 2010, Boehmer et al. 2012). Some recent data suggest that adults who identify as bisexual may be younger on average than the U.S. adult population and significantly younger than lesbians and gay men (Herek et al. 2010). Youth, despite being aware of same-sex attractions, may be less likely to self-identify as homosexual to avoid bullying and abuse (D'Augelli 2003). There is a paucity of data about older adults because only a few of the large-scale surveys that include questions about sexual orientation ask these questions of adults over age 50 years. The best projections suggest that there are 2–7 million sexual minority elders in the United States (Grant et al. 2010).

Sexual orientation differences have also been observed by socioeconomic characteristics. A 1995 study using data from the General Social Survey found that gay and bisexual male workers earned from 11 to 27% less than heterosexual counterparts with equal experience, education, marital status, and region of residence (Badgett 1995). More recent data have also documented lower incomes among gay men compared to their heterosexual counterparts (Allegretto and Arthur 2001, Black et al. 2003, Carpenter 2007). Much of this disparity has been attributed to work place discrimination. Finally, a systematic review by Black and colleagues in 2000 (Black et al. 2000) found that gay and lesbian individuals report higher average education levels than their heterosexual counterparts. However, the authors caution that this finding may be due to well-educated people being more willing to identify as homosexual.

Sexual orientation differences have also been noted across regions of the United States. The most geographically robust data on the sexual minority population is from the U.S. Census. While the Census does not measure sexual orientation directly, it includes information on same-sex partnered households, which has been used as a surrogate measure of sexual orientation (Ost and Gates 2005, Gates 2006, Carpenter and Gates 2008). Data from the 2000 Census showed that Midwestern states had disproportionately fewer same-sex couples compared to other regions of the United States (Gates 2006). However, the largest percentage increase of same-sex couples between 2000 and 2005 occurred in the Midwest region. Recent data from the 2010 Census indicate that the states with the largest numbers of same-sex couples per 1000 households include: Vermont, Massachusetts, California, Oregon, as well as the District of Columbia (Gates and Cook 2011). Congressional districts with the highest percentage of same-sex couples also tend to be more urban (Gates 2006).

There have been limited recent large-scale population-based state and national surveys that have included items about sexual orientation. Examples of these surveys are shown in Table 23.2. In general, prevalence estimates of individuals identifying as homosexual or bisexual from these surveys were consistent with other published literature. Prevalence of homosexuality ranged from 1 to 5% with men being more likely than women to identify as homosexual. Prevalence of bisexuality ranged from 1 to 3% with less consistent differences between men and women. Prevalence estimates by age and race/ethnicity varied considerably by the survey.

23.2.2 GENDER IDENTITY

One approach to obtain prevalence estimates of transgender or gender nonconforming individuals has been the use of medical record data. This approach includes the subgroup of transgender individuals who presented at medical clinics and received a diagnosis of gender dysphoria, a diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, or who presented for medical services for gender-related surgery (The World Professional Association for Transgender Health 2011). Using international data, mostly from European countries, prevalence estimates range from 1:11,900 to 1:45,000 for MTF individuals and 1:30,400 to 1:200,000 for FTM individuals (The World Professional Association for Transgender Health 2011). These prevalence estimates have been criticized as underestimates, derived from biased methodology (Conway 2002). Furthermore, recent data suggest that the number of individuals seeking medical treatment to masculinize or feminize their bodies is increasing and that the prevalence of individuals identifying as transgender is likely to increase over time (Zucker and Lawrence 2009).

Very little survey research has been conducted to determine the size of the transgender population. However, the Vermont and Massachusetts Behavioral Risk Factor Surveillance Surveys (BRFSS) included a question about transgender identity, which was endorsed by 0.5% and 0.9% of Massachusetts and Vermont respondents, respectively (Conron et al. 2012). Unfortunately, there are a number of limitations with estimating the prevalence of transgender identity using population-based surveys. Household-based surveys such as the BRFSS reach only the most socially integrated transgender individuals, who have stable housing and a telephone, thereby omitting transgender individuals who are severely impoverished, homeless, or marginally housed (Conron et al. 2012). Therefore, prevalence estimates of less than 1% are likely an underestimate of the transgender population.

Differences in self-reported gender identity have been identified by sociodemographic characteristics. In a study of more than 6000 transgender adults from across the United States, Grant and colleagues (2011) found that the adult transgender population was younger and more likely to be living in poverty than the general U.S. population in the American Community Survey. These data are consistent with those from the Massachusetts BRFSS (Conron et al. 2012) and those from an Internet-based study comparing an adult transgender population to the

TABLE 23.2 Prevalence Estimates (%) and Mode of Data Collection for Self-Reported Sexual Orientation Identity from Selected Population-Based Surveys

	General Social Survey (2010)[a] n = 2044			National Health and Nutrition Examination Survey (2007–2008)[b, a] n = 3265			National Study of Family Growth (2002)[c, d] n = 12,571			California Health Interview Survey (2007)[a] n = 41,157			Behavioral Risk Factor Surveillance System: Washington, DC (2005 and 2007 combined)[e] n = 6218		
	Homo	Bi	Ref	Homo	Bi[f]	Ref	Homo	Bi[f]	Ref	Homo	Bi	Ref	Homo	Bi[f]	Ref
Prevalence estimates															
Overall	1.2	1.4	1.4	1.5	2.8	0.1	1.7	2.4	1.8	2.2	1.2	—	4.9	2.3	3.2
Gender															
Male	1.3	0.5	0.9	1.9	1.4	0.0	2.3	1.8	1.8	3.2	1.1	—	8.3	2.4	—
Female	1.2	2.1	1.4	1.1	4.2	0.2	1.3	2.8	1.8	1.5	1.3	—	2.0	2.2	—
Age (years)															
18–24	2.4	1.9	1.5	0.7	6.9	0.2	—	—	—	1.5	2.2	—	3.7	3.7	—
25–34	0.9	2.6	0.8	2.1	3.2	0.2	—	—	—	1.7	1.8	—	5.7	1.9	—
35–44	1.9	1.6	0.8	1.9	3.0	0.1	—	—	—	2.4	1.4	—	6.2	3.7	—
45–53	1.2	1.4	0.7	1.0	1.6	0.2	—	—	—	2.9	1.1	—	6.7	1.8	—
55–64	1.4	0.8	0.8	1.3	1.3	0.0	—	—	—	2.1	0.9	—	4.3	0.8	—
≥65	0.0	0.0	2.9	—	—	—	—	—	—	1.4	0.9	—	1.0	1.7	—
Race/ethnicity															
White	1.4	1.4	1.2	1.1	2.8	0.0	—	—	—	2.6	1.3	—	9.0	2.0	—

(continued)

TABLE 23.2 (*Continued*)

	General Social Survey (2010)[a] n=2044			National Health and Nutrition Examination Survey (2007–2008)[b,a] n=3265			National Study of Family Growth (2002)[c,d] n=12,571			California Health Interview Survey (2007)[a] n=41,157			Behavioral Risk Factor Surveillance System: Washington, DC (2005 and 2007 combined)[e] n=6218		
	Homo	Bi	Ref	Homo	Bi[f]	Ref	Homo	Bi[f]	Ref	Homo	Bi	Ref	Homo	Bi[f]	Ref
Black	0.9	1.5	1.9	2.2	4.2	0.0	—	—	—	2.0	1.2	—	2.0	2.2	—
Hispanic/Latino	—	—	—	2.1	2.4	0.8	—	—	—	1.3	1.0	—	5.3	4.8	—
Asian	—	—	—	—	—	—	—	—	—	0.9	0.9	—	—	—	—
Other	0.5	1.3	0.5	2.9	1.5	0.0	—	—	—	2.3	1.3	—	5.2	1.3	—
Mode of data collection for sexual orientation questions	Computer-assisted personal interviews			Audio computer-assisted self-interviews			Audio computer-assisted self-interviews			Computer-assisted telephone interviews			Computer-assisted telephone interviews		

—, Data not available.

Homo, self-reported homosexual orientation; Bi, self-reported bisexual orientation; Ref, refused question about sexual orientation.

[a] Analysis computed for this chapter.

[b] Includes only ages 20–59.

[c] Includes only ages 15–44.

[d] Data from Mosher et al. (2005).

[e] Data from Dyer et al. (2010).

[f] Bisexual includes individuals reporting "other."

[g] Includes only ages 18–70.

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general U.S. population using Census data (Rosser et al. 2007). These studies also suggest that transgender individuals were more educated than the general U.S. population (Rosser et al. 2007, Grant et al. 2011). Transgender individuals are also more likely to be unemployed than the general population. For example, in the national survey by Grant and colleagues (2011), transgender individuals were twice as likely to be unemployed as the general population, while Conron and colleagues (2012) found that the odds of being unemployed were three times higher for transgender compared to nontransgender adults in the Massachusetts BRFSS. In addition, 15–57% of transgender individuals in a sample of sexual and gender minorities reported experiencing employment discrimination with 19% reporting that they were denied a promotion based on their gender identity (Badgett et al. 2007).

Ethnicity and culture also likely influence self-identification as transgender. For example, transgender individuals were more likely to report Hispanic ethnicity in the Massachusetts BRFSS (Conron et al. 2012). Although small sample sizes have precluded specific subgroup analyses in most studies to date, many Asian and American Indian communities recognize transgender individuals as part of traditional society, unlike the dichotomous constructions of gender common in Western culture (Mayer et al. 2008), therefore, likely increasing the rates of transgender identity in those cultures.

23.3 Sampling and Recruitment

There are important considerations for sampling sexual and gender minority research participants that ultimately may affect the internal and external validity of study results. Sampling refers to the way in which research participants, a subset of individuals from the population of interest, are selected. Sampling methodologies in research with sexual and gender minorities have included probability and nonprobability approaches. Probability samples are ones from which a subset of individuals are selected from a population of interest with every person having a known nonzero probability of being included (Meyer and Wilson 2009). Nonprobability samples are ones in which a subset of individuals are selected from a population in which the probability of being selected is unknown; this is typically referred to as a *convenience* sample. To date, nonprobability sampling has been much more common than probability sampling in research with sexual and gender minorities.

There are inherent challenges in all sampling methodologies when attempting to extrapolate study findings to a broader population. However, it is even more challenging when the population of interest is considered a "hidden population." Sexual and gender minorities have frequently been referred to as a *hidden* community (Sudman et al. 1988, Watters and Biernacki 1989, Solarz 1999, Bochmer 2002). This is because LGBT individuals are not easily identifiable from any sampling frame and may be unwilling to identify as members of this population due to the sensitive nature and potential social discrimination of such an identity.

These same factors also have the potential, regardless of sampling methodology, to cause low response rates. In addition, how sexual minority status is defined may influence the sampling approach (e.g., those who identify as sexual minorities versus those who meet a behaviorally defined criterion for being a sexual minority) (Binson et al. 2007).

There are many considerations for determining a sampling method for research with sexual and gender minorities including cost, time, feasibility, generalizability, accessibility of the population, and the over-arching objective of the study. In Table 23.3, we provide an overview of the major different sampling methods that have been used in research with sexual and gender minorities and document the major strengths and limitations of each method.

23.3.1 PROBABILITY SAMPLING METHODS

In general, probability sampling is the gold standard for survey research because study findings can be extrapolated to the population from which participants were drawn (Meyer and Wilson 2009; see also Chapter 2). Probability sampling includes many different techniques including simple random sampling, stratified, and cluster sampling approaches. Unfortunately, probability sampling for studies of the sexual and gender minority population is particularly challenging due to the low prevalence of LGBT identity.

Some nationally representative surveys using probability sampling approaches have included measures of sexual orientation, including the National Health and Nutrition Examination Survey (www.cdc.gov/nchs/nhanes.htm) and the National Survey of Family Growth (www.cdc.gov/nchs/nsfg.htm). Despite their large sizes, these surveys have yielded a very small number of participants that identify as LGBT, documenting the high costs of using probability-based approaches for a population with prevalence estimates as low as 1%.

In a recent study, Herek and colleagues (2010) sampled sexual minority individuals from the Knowledge Networks panel, which is large probability sample of U.S. residents who were recruited through random-digit dialing methods. A probability sample of English-speaking adults was drawn from the subset of all panel members who had previously responded to being gay, lesbian, or bisexual. Each sampled individual then received an email invitation to complete an online survey.

A few studies have used stratified or cluster sampling to obtain probability samples of members of the LGBT community (Bowen et al. 2004, Gruskin et al. 2007, Mackesy-Amiti et al. 2008). For example, study investigators have identified neighborhoods with large numbers of sexual minorities (e.g., high gay density) and then used probability-based approaches for participant recruitment in those areas to reduce cost and increase efficiency. The use of these high gay density neighborhoods reduces the number of households that require screening to identify sexual minorities compared to other population-based approaches. For example, Gruskin and colleagues (2007) used national data to identify the California zip codes with the highest proportion of sexual minorities. Using a two-stage sampling approach with *random-digit-dialing* within the selected zip

TABLE 23.3   Strengths and Limitations of Sampling Methods Used in Studies with Sexual and Gender Minorities

Sampling Method	Strengths	Limitations	Example Studies that have Used Method
Probability sampling			
Random-digit dialing	Estimates can be extrapolated to the population from which study subjects were drawn	High costs due to low prevalence of sexual and gender minorities Low coverage of individuals with no or sporadic telephone availability	(Gruskin et al. (2007), Herek et al. (2010)
Household-based sampling	Estimates can be extrapolated to the population from which study subjects were drawn	High costs due to low prevalence of sexual minorities Potential bias toward individuals living in areas with higher densities of sexual minorities	Bowen et al. (2004)
Nonprobability sampling			
List-based sampling	Provides an easy and accessible sampling frame	Can only generalize findings to others in the list population Lists of sexual and gender minorities are generally unavailable Quality of available lists must be carefully assessed for incorrect, incomplete, and duplicate information	Solomon et al. (2004)

TABLE 23.3 (*Continued*)

Sampling Method	Strengths	Limitations	Example Studies that have Used Method
Time-location sampling	Can help to increase sample size when recruiting sexual minorities. If all relevant venues are included and all segments of population visit these venues, this can be considered a probability sampling	Appropriate venues for recruitment may change over time and must be reevaluated continually. Venues and times selected for data collection may not include certain segments of the population. Nonresponse may be a problem at stigmatized venues	MacKellar et al. (1996), Muhib et al. (2001), Cai et al. (2010)
Snowball sampling	Can help to increase sample size when recruiting sexual minorities. May be able to better recruit hard-to-reach individuals not enrolled through other sampling schemes	Members of the same social network are likely to be more socially connected and thus more similar than the broader sexual and gender minority population	Warner et al. (2004), Browne (2005), Kendall et al. (2008), Balsam et al. (2010), Feng et al. (2010), Lehavot and Simoni (2011), Prado Cortez et al. (2011)
Respondent-driven sampling	Can help to increase sample size when recruiting sexual minorities. Associated with lower costs than time-location sampling. Can be used to derive valid, unbiased population estimates	Assumptions of the methodology must be met. May not be able to reach an adequate sampling size in subgroups of sexual and gender minority population with limited social connections	Ramirez-Valles et al. (2005), Johnston et al. (2008), Kendall et al. (2008), Lauby et al. (2008), Ramirez-Valles et al. (2008) Richards et al. (2008), Wheeler et al. (2008), Evans et al. (2011)
Web-based sampling	Can help to increase sample size when recruiting sexual minorities. May be particularly effective for recruiting younger populations	Samples are not likely representative of the broader sexual and gender minority population	Rosser et al. (2007), Johnston et al. (2008), Chesir-Teran and Hughes (2009), Evans et al. (2011)
Advertising	Can help to increase sample size when recruiting sexual minorities	Samples are not likely representative of the broader sexual and gender minority population	Silvestre et al. (2006), Chesir-Teran and Hughes (2009)

codes, they recruited participants who identified as sexual minorities. Next, using prevalence rates of LGB individuals, the average numbers of LGB adults per household, and the numbers of households per zip code from the 2000 census data, they constructed weights to account for the unequal probabilities of selection. Similarly, a study by Bowen and colleagues (2004) identified zip codes in Massachusetts with high proportions of female same-sex partnered households using census data. They then conducted *door-to-door household sampling* in those zip codes to screen for female participants. Finally, Mackesy-Amiti and colleagues (2008) identified two zip codes in Chicago, Illinois with known high concentrations of gay men and then used face-to-face screening to select eligible respondents.

Boehmer and colleagues (2010) used a similar approach to obtain representative samples of sexual minority and heterosexual individuals with a particular health condition. Using Census data, they defined areas in Massachusetts with the highest density of sexual minority women and then obtained data on female cancer cases in those areas from the Massachusetts Cancer Registry. Next, they used telephone screening of the cancer cases from the Cancer Registry to identify a sample of sexual minority women and a comparison sample of heterosexual women. Another recent novel approach by Boehmer and colleagues (2011) was to combine the geographic density of sexual minorities identified by the Census with cancer incidence and mortality data from the Surveillance, Epidemiology, and End Results (SEER) Program. Combining these data allowed for ecological analyses of differences in cancer incidence and mortality by county, resulting in county-level prevalence estimates of cancer disparities by sexual orientation.

Focusing on areas with a high density of sexual minorities has the advantage of reducing costs and increasing efficiency of sampling small or hidden populations. However, potential biases with this approach remain. For example, sexual minorities living in high density LGB areas may be different than those that do not live in such areas. In addition, these high density areas are most likely to be in large, urban metropolitan areas, leaving substantial challenges for probability-based sampling in nonmetropolitan areas. Finally, potential biases remain if there are differential response rates by sexual orientation or within the sexual minority population.

23.3.2 NONPROBABILITY SAMPLING

Using nonprobability samples, it is not possible to estimate population measures such as the prevalence of sexual and gender minorities. However, it is possible to examine factors within a specific target group. In fact, Boehmer and colleagues (2008, 2010) demonstrated that characteristics and experiences of participants from nonprobability samples were representative of the sexual minority communities of interest when carefully selected inclusion criteria were applied.

Many different types of nonprobability methods have been used in research with sexual and gender minorities. The most commonly used methods include: list-based sampling, time-location sampling (TLS), snowball sampling,

respondent-driven sampling (RDS), web-based sampling, and advertising. A general discussion of several of these techniques is also provided in Chapter 4.

List-Based Sampling. List-based sampling involves the use of a preexisting list of members of the population of interest to select potential study participants. This sampling method may be very efficient when information about individuals is in the public record such as drivers' licenses, marriage licenses, and birth and death certificates. However, there are very few lists of individuals in the LGBT community from which to sample. In addition, the quality of the lists must be carefully assessed due to the potential for incorrect, incomplete, and duplicate information in available lists (Kalton and Anderson 1986). In one novel study, Solomon and colleagues (2004) used a list of all civil union certificates from the Vermont Office of Vital Records to select adults in same-sex civil unions for research about their experiences during the first year after civil union legislation passed in Vermont. Unfortunately, this approach is limited to states that have same-sex civil union and marriage legislation. Furthermore, study findings cannot be generalized beyond individuals in legally recognized relationships in the limited number of states for which same-sex relationships have been officially sanctioned.

Time-Location Sampling. TLS, also known as *time-space sampling, venue-based* or *venue-day-time* sampling, is another nonprobability sampling method (MacKellar et al. 1996, Muhib et al. 2001) that has been used in research with sexual minorities. Using TLS, study investigators recruit from venues (e.g., sites) where the population of interest tends to gather. Prior to study implementation, venues are enumerated and used as a sampling frame. A probability sample of venues is selected from the sampling frame and data collection is implemented at all or some of the sites. Data are collected at a predetermined time period at each site. In a study by Cai and colleagues (2010) examining HIV risk behaviors among male sex workers in China, TLS was used to sample 32 venue-date-times from 43 venues, yielding a total sample size of 456 individuals. The analysis included a weighting scheme that adjusted for the probability of selection of venue-date-times and the homogeneity of participants sampled at each venue-date-time. TLS approximates a random cluster sampling method, so unlike other nonprobability methods, it provides somewhat known probabilities of selection and is considered by some to be a probability sampling method (Magnani et al. 2005). Others argue, however, that while the probability of selection can be determined for each venue-date-time, the probability of selection for a specific individual cannot necessarily be established. In addition, nonresponse bias may be particularly problematic at venues that have stigma associated with them.

Snowball Sampling. Snowball sampling, also referred to as *chain sampling, chain-referral sampling,* or *referral sampling* is another nonprobability method that has been used in studies of sexual and gender minorities. In this method, participants are not recruited from a sampling frame. Rather, study eligibility is

defined, several eligible individuals are approached for participation, and each is asked to recruit other individuals in his/her social network that also meet the study eligibility criteria. The additionally recruited participants are then asked to recruit other individuals in their social network, and this referral approach continues until the designated sample size is met. For example, Kendall and colleagues (2008) used snowball sampling to recruit men who have sex with men (MSM) in Fortaleza, Brazil. Initial recruits were recruited from venues around the city where MSM were likely to meet. Snowball sampling can result in samples of participants who are similar to one another given their connectedness in a broader social network, and as a result, the sample is not necessarily representative of the broader target population. Therefore, snowball sampling may be a useful way to increase the sample size in studies of sexual and gender minorities, but caution should be used in making generalizations about study findings.

Respondent-Driven Sampling. RDS is a method that is similar to snowball sampling. The approach, initially used for research on HIV/AIDS and injection drug use, is becoming increasingly more common among studies of other topics in the LGBT community (Ramirez-Valles et al. 2005, Abdul-Quader et al. 2006, Frost et al. 2006, Robinson et al. 2006, Lauby et al. 2008, Ramirez-Valles et al. 2008, Richards et al. 2008, Wheeler et al. 2008, Abramovitz et al. 2009, Townsend et al. 2010). Unlike snowball sampling, RDS provides the opportunity to derive valid, unbiased population estimates, as well as measures of precision around those estimates (Heckathorn 1997, 2002). In RDS, respondents recruit their peers and study investigators monitor who recruited whom and the numbers of each participant's social contacts. Then, using a mathematical model to apply weights to the sample, a weighting scheme is applied to compensate for the nonrandom sampling approach. RDS is useful because it allows for the calculation of selection probabilities and therefore is considered by some to be a probability sampling method. It also has more external validity than other nonprobability sampling methods because it is not limited to subgroup members who access venues such as is necessary for TLS. In a comparison of snowball sampling, TLS, and RDS to recruit MSM, Kendall and colleagues (2008) found that RDS produced a sample with greater inclusion of individuals of lower socioeconomic status than snowball sampling or TLS. RDS also achieved the sample size faster and at lower cost. In addition, RDS can contribute to a more inclusive sample and strengthen community participation in research (Tiffany 2006).

Unfortunately, there are a number of limitations of RDS. RDS can be challenging due to small network sizes, lack of ties among members of the target population, and high levels of perceived stigma and fear of participation in studies. In addition, there are inherent assumptions that must be met for RDS to be used in deriving valid and unbiased population estimates: (i) the number of people that each person is associated with in the target population is measured accurately; (ii) relationships are reciprocal; (iii) sampling is with replacement, that is, each person in the population may be included in the sampling more than once; (iv) seeds (e.g., recruiters) choose who to recruit randomly from their

associates within the target population; (v) a sufficient number of waves of data collection can be collected such that seeds are independent of the subsequent waves of recruits; and (vi) each person in the population is connected to every other person in the population through a chain of associations. In order to best use RDS, these assumptions must be tested and/or addressed in implementation. For example, in a study examining recruitment methods of central and eastern European migrant MSM in London, study investigators found that RDS was ineffective due to small sample size and/or little connectedness of this population (Evans et al. 2011). A similar study conducted in Estonia found that RDS did not adequately recruit a large enough sample, and the sample recruited was fairly homogenous by demographics (Johnston et al. 2009).

Web-Based Sampling and Advertising. Other convenience sampling methods that have been used in LGBT research include web-based sampling and advertising. In web-based sampling, individuals are recruited through the Internet. Advertising is typically done using print ads such as flyers, posters, or magazines. In a Four-City study examining different ways to recruit minority MSM for HIV research, Silvestre and colleagues (2006) used city and minority newspapers, news releases, and magazines to advertise for participation. A study by Chesir-Teran and Hughes (2009) of LGB and questioning high school students used both online and print advertising to sample participants. A study of the transgender community was also conducted by web-based sampling. Rosser and colleagues (2007) used banners on transgender community websites, chat rooms, online mailing lists, journals, and forums to recruit participants for a transgender health survey. In two separate recent studies comparing recruitment of MSM via the Internet to RDS, study investigators found that recruitment via the Internet was the more successful method at recruiting an adequate, more diverse sample (Johnston et al. 2009, Evans et al. 2011). While advertising by print or web can increase samples of sexual and gender minorities, there may be volunteer bias. In addition, individuals frequenting particular websites may not be representative of the broader population of interest.

23.3.3 OTHER RECRUITMENT CONSIDERATIONS

Given the challenges and limitations for recruiting representative samples of sexual and gender minorities, other analytic methods have been proposed to determine prevalence estimates. One analytical method that has been attempted is the capture-recapture method. This method originated to estimate the prevalence of wildlife populations where organisms were captured, marked and released back into the population. Organisms were then captured again by the same procedure. The proportion of marked organisms among those recaptured was assumed to be the same as the proportion of those initially captured among the entire population (Sudnan et al. 1988). Using this method, Aaron and colleagues (2003) attempted to estimate the lesbian population prevalence in Allegheny County, Pennsylvania. A total of 2185 lesbian women were identified from four organizations that served the lesbian and gay population in the county. Using the proportion of overlap of

the lesbian population across the four organizations and log-linear modeling of heterogeneity and dependence across sources, it was estimated that 7031 lesbian women lived in Allegheny County. Bias could result from this type of model if there is a high rate of immigration or emigration into the region or if the probabilities of being sampled by these sources are not equal for all individuals. Assuming these biases are minimal, the capture–recapture method may be a valid alternative to otherwise costly representative probability samples.

In addition to specific challenges with sampling, there are other recruitment considerations for LGBT research. One limitation of many prior health studies among LGB participants has been that there has rarely been a control group with which to compare results. In large-scale national probability studies, there are sufficiently large sample sizes to construct subgroups to compare sexual minorities to majority groups. However, smaller studies directed at particular topic areas must define and recruit the most appropriate control group. One alternative that has been used in studies of risk factors for breast cancer among lesbians has been the use of heterosexual siblings as controls (Rothblum and Factor 2001, Rothblum et al. 2004). Unfortunately, while some research topics are conducive to siblings as controls (i.e., effect of genetic and familial risk factors on health outcomes; relationship of childhood environment on subsequent adult health outcomes), this approach has many limitations for other topics. Another alternative is to compare a sample of sexual minority women recruited through convenience sampling strategies with women from nationally representative samples of adults. In a study of alcohol use behaviors, Wilsnack and colleagues (2008) compared lesbians recruited by convenience sampling to women in the National Study of Health and Life Experiences of Women. Women in the national sample were selected for the study based on age and geographic criteria that maximized comparability with the convenience sample.

23.4 Data Collection

Two questions arise when considering mode of data collection for studies of sexual and gender minorities. One question is the best mode for eliciting information about sexual orientation to determine prevalence estimates and to classify individuals based on identity, behavior, or attraction. A second question is the extent to which there are mode differences in studies specific to sexual and gender minorities and/or with sexual orientation or gender identity specific objectives. To date, more research has been conducted to address the question about methods to elicit sensitive information such as sexual orientation. Results from these studies suggest that self-administered questionnaires (SAQ) are more likely to give participants a sense of anonymity as compared to telephone and face-to-face interviews. However, paper-and-pencil SAQs tend to have more missing data, lower response rates, and are more challenging to use when incorporating skip patterns. Computer-assisted self-interviews (CASIs) have been shown to have better data quality and allow for more complex questionnaire structures relative to

paper-and-pencil SAQs (Tourangeau et al. 2000). Despite these advantages, studies comparing CASI to other modes for reports of sensitive behaviors have had mixed results (Epstein et al. 2001, Gerbert et al. 1999, Hasley 1995, Macalino et al. 2002, Metzger et al. 2000, Newman Jarlais et al. 2002, Saris 1991, Webb et al. 1999, Wright et al. 1998).

There have been a limited number of randomized control trials that have assessed reporting differences in measures of sexual orientation by survey mode. Metzger and colleagues (2000) evaluated audio-CASI (ACASI) versus interviewer-administered assessment for the reporting of sensitive HIV-risk behaviors among gay men and male injection drug users. They found that significantly more men reported engaging in risky sexual behaviors when interviewed by ACASI versus interviewer-administered assessments. They concluded that ACASI can improve data quality of behavioral assessments, particularly when attempting to elicit the disclosure of sensitive and/or risky behaviors. In a similar randomized controlled trial, Macalino and colleagues (2002) compared ACASI and interviewer-administered questionnaires among injection drug users. Participants who were interviewed with ACASI were more likely to report engagement in risky sexual behaviors and HIV-seropositive status. Given that most studies of mode differences in reports of sensitive behaviors, including the randomized control trials were conducted at least 10 years ago, additional research is needed to determine the extent to which these findings are still valid.

As shown in Table 23.2, recent national and state surveys that have included items about sexual orientation have used many different modes, including computer-assisted telephone interviewing (CATI), computer-assisted personal interviewing (CAPI), and audio computer-assisted self-interviewing (ACASI). Unfortunately, it is challenging to compare prevalence and nonresponse estimates from these surveys due to inconsistent ways of measuring sexual orientation and lack of information in the public use data. In addition, some surveys such as the National Health and Examination Survey and the National Study of Family Growth did not ask questions related to sexual orientation of older adults. Regardless, prevalence estimates and nonresponse rates in these surveys do not differ greatly by method of data collection.

Unfortunately, there is less data about mode differences in studies specific to sexual minorities and/or with sexual orientation-specific objectives. Of the available studies, several different survey modes have been used. For example, in a study among high school students that examined emotional distress among LGBT youth, a paper-and-pencil survey was administered in classrooms. Less than 1% of students were prohibited by their parents from participating, and an additional 5.3% of students declined to participate (Almeida et al. 2009). A similar study was conducted nationally among a convenience sample of the same age group and administered only via the Internet. Nonresponse rates could not be computed because all participants volunteered and therefore were self-selected for survey completion (Chesir-Teran and Hughes 2009). A study by McCabe and colleagues (2005) examined associations between sexual identity and substance use among undergraduate students. Half of the participants were randomly assigned to receive mailed SAQ, and the other half were assigned to a web survey. The

response rate was 63% for the web survey, and only 40% for the mailed SAQ. However, identification as homosexual did not differ by survey mode. In 2002, a study was conducted among sexual minority homeless adolescents (Cochran et al. 2002). Private, face-to-face structured interviews were conducted with a response rate of 95%. However, this was a convenience sample with a $25 incentive for participation. In a recent cross-sectional survey, investigators used personal digital assistants to collect information from young adult homosexual males regarding attitudes and behaviors toward sex parties in New York City in an attempt to enumerate ACASI in a venue-based recruitment environment (Solomon et al. 2011). Finally, in a sample of MSM, Fendrich and colleagues (2008) examined agreement between self-reported past month drug use by ACASI and urine and saliva drug testing and found that self-reports among MSM were at least as valid as those provided by a general population sample of men.

Although several modes of data collection have been used to conduct research with younger members of the LGBT community, there have been limited studies that have directly compared response rates and data quality by mode. To date, available data suggests that self-administered computer-assisted technology may optimize response rates among younger adults and result in comparable or higher data quality than other survey modes (McCabe et al. 2003, Turner et al. 1998). However, more research is needed to determine how response rates or data quality might be affected by mode in studies with varying sampling designs, eligibility criteria, and incentives.

Much less research has been done with middle-aged and older LGBT populations, and fewer survey modes have been used. In conducting a perceptions and needs assessment of older LGBT individuals in the greater Chicago area in 2003, mailed SAQs were used. Of approximately 2500 surveys distributed, 11% were received and assessed (Beauchamp et al. 2003). In a 2001 study examining mental health and victimization history of LGB individuals older than 60 years old in the United States, investigators obtained 416 SAQs from a convenience sample of participants recruited through social support groups and social service agencies (D'Augelli and Grossman 2001). In one of the few randomized trials of mode differences among middle-aged and older sexual minorities, Clark and colleagues (2008) randomly assigned 599 heterosexual and sexual minority women aged 40–75 to three different survey modes: self-administered mailed questionnaire (SAMQ), CATI, and the computer-assisted self-interview (CASI) for collecting data about cancer screening behaviors. Response rates were comparable across mode, and method of data collection had little effect on reports of breast, cervical or colorectal cancer screening behaviors.

23.5 Conclusions

With the exception of studies of HIV prevention among MSM, limited numbers of population-based surveys and longitudinal cohort studies of sexual and gender minorities have been conducted. Population-based state-level data about sexual

orientation has increased in the past few years due to surveys such as the California Health Interview Survey (www.chis.ucla.edu/ and state-specific BRFSS (www2a.cdc.gov/nccdphp/brfss2/coordinator.asp). However, population-based data at the national level have been very limited. The consistent inclusion of robust measures of sexual orientation in all state and national population-based surveys is necessary to ultimately determine and address health disparities facing sexual minorities (Institute of Medicine 2011). To date, none of these surveys oversample sexual minorities, resulting in small actual numbers of LGB individuals in these surveys. As a result, subgroup analyses by age and race are essentially impossible unless a survey consistently ask questions about sexual orientation, and researchers wait until they can pool data from several years of the survey (Boehmer et al. 2012). These problems are particularly compounded for gender minorities because only a few surveys include at least one measure of gender identity.

To date, the majority of studies of sexual and gender minorities have used nonprobability sampling methods. While nonprobability sampling can cause biased estimates and prevent generalizations, many early studies that used nonprobability sampling made it possible to learn about disparities in the LGBT population and prepared the field for studies using probability sampling. Unfortunately, the significant effort spent critiquing early studies that used nonprobability methods at times delayed devoting resources to the disparities that were highlighted and later confirmed by more methodologically rigorous studies (Meyer 2001).

The considerable strengths of probability-based methods are well known. However, ultimately, the sampling procedure used when conducting research with sexual and gender minorities should take into account the particular research question. Specifically, consideration should be given to whether the findings are intended to be extrapolated to a larger population or if the intended analyses involve examination of differences between subgroups within the sexual and gender minority population. In addition, feasibility, cost, sample size requirements and time should be considered when choosing a method. Finally, when considering sampling methods that rely on social networks, the likely connectedness of the underlying population of interest should be considered.

To date, no data collection method has been determined to be superior for conducting research with the LGBT population. Rather, the particular research question of interest, the segment of the population, recruitment strategy, and the sensitivity of questions asked must all be considered when determining the most appropriate data collection method for a particular study. Other measures such as efficiency and cost-effectiveness of the method should also be considered in study development.

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ONLINE RESOURCES

A website, created and maintained by Dr. Rondall Sell, serves as an open-access clearinghouse for collection of sexual orientation and gender identity data and measures, including recommendations for how to collect sexual orientation data: www.lgbtdata.com.

Below is the link to the website for the Williams Institute, a national think tank, which conducts independent research on sexual orientation and gender identity law and public policy. Much of the research includes analysis of Census data to estimate prevalence of the lesbian, gay, and bisexual population as well as relevant health and social issues. http://williamsinstitute.law.ucla.edu.

The website below is maintained by the Inter-university Consortium for Political and Social Research. It allows access to data sets that have collected sexual orientation data and allows for comparisons of variables across datasets. www.icpsr.umich.edu/icpsrweb/landing.jsp.

Below is the website for Fenway Health, including the Fenway Institute, which conducts research and evaluation, education and training, and public health advocacy for lesbian, gay, bisexual, and transgender individuals. www.fenwayhealth.org/.