

**TABLE 1—Hypothetical Population and Sampling Percentages, and Creation and Application of Weights**

Variable	Straight	LGBT
Population, %	96	4
Sample, %	80	20
Weight	1.2 (96/80)	0.2 (4/20)
Weight × sample n	96 (1.2 × 80)	4 (0.2 × 20)

Note. LGBT = lesbian, gay, bisexual, or transgender.

decide to oversample in those areas first until we selected, for example, 17 people who identified as LGBT. We would then choose the remaining 83 people randomly from the population (assuming that population proportions would result in about 80 people who say that they are straight and about three who say that they are LGBT<sup>2</sup>) to keep our sample size at 100. We are now much more confident about characterizing the hypertension rates of LGBT individuals on the basis of our

sample of 20 people as opposed to four.

What we would not do is say that the prevalence of LGBT individuals in the population is 20% (20/100), because we purposefully sampled 20 such individuals to better describe their hypertension rates. When doing prevalence analyses, we would statistically “down-weight” those 20 observations to equal four, so the prevalence would not change (i.e., the true prevalence would still be four per 100, or 4%). But now we have used

oversampling to learn something about a perhaps hard-to-reach or low-prevalence group.

Table 1 illustrates this process numerically; the first data row provides the estimated population prevalence for the two groups, and the second row shows the percentage of each group in our sample after oversampling (note that the “amount” of oversampling would be determined by the research team). The “weights” are calculated by taking the ratio of the population prevalence to the sample percentage, and one can see that when those weights are “applied” to the data, the rates return to the correct population proportions. Clearly, this example is simplified; the process of oversampling and calculation and application of weights is complex and a discipline unto itself, but the principle is the same.

## WHEN TO OVERSAMPLE?

There are readily available sampling and statistical tools that can help one learn more about lower-prevalence populations without inducing bias in calculating prevalence rates. Therefore, the decision of whether to oversample in an LGBT health survey depends on the answer to a simple question: “Is learning about the health of LGBT individuals important or not?” *AJPH*

Roger Vaughan, DrPH, MS

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# Recording Sexual Orientation in the UK: Pooling Data for Statistical Power

We know that sexual minority health disparities exist, but in the United Kingdom, the research demonstrating disparities in sexual minority health has been dominated by small convenience samples that do not represent clearly defined populations. Recently, UK population health surveys began to include a question on sexual orientation identity that makes available high-quality data. However, very few studies collect sexual orientation within their demographic data.<sup>1</sup> There need to be more, as it is this important, high-quality evidence that can be used to make

a political impact and determine policy change.

Studies that collect data on sexual orientation and on health outcomes or behaviors and therefore allow prevalence of to be captured are the United Kingdom national longitudinal cohort study called “Understanding Society” ([bit.ly/259UCLb](http://bit.ly/259UCLb)) and several population cross-sectional studies. Data sets can be accessed through the UK Data Service ([bit.ly/1Nz5cl3](http://bit.ly/1Nz5cl3)). Participant recruitment by the surveys is through random or stratified random sampling of their target population, which establishes generalizability of findings.

## IDENTITY, ATTRACTION, BEHAVIOR

Sexual orientation was recorded in all of these included health surveys, using the standardized wording to capture sexual orientation identity that has been developed by the UK Office of National Statistics.<sup>2</sup> The sexual orientation identity

question asks, “Which of the following options best describes how you think of yourself?” Participants can respond “heterosexual or straight,” “gay or lesbian,” “bisexual,” or “other,” or they can refuse to respond. This question does not measure sexual attraction or sexual behavior. These are different concepts well described in other literature.<sup>3</sup> A test of the impact of including the sexual orientation identity question in the Integrated Household Survey (2009–2010), which had a sample

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size of around 250 000 people, found that overall survey response rates were not affected, demonstrating acceptance of the question.<sup>2</sup> Moreover, refusal rates in current surveys collecting sexual orientation are very low, indicating that people are happy to answer the question.<sup>3</sup> Thus, with the addition of a single question, the health status of lesbian, gay, bisexual, or other (LGBO) people in the United Kingdom is available.

There are national surveys in the United Kingdom that collect data based on sexual behavior, and these find that greater numbers of people select same-sex behavior than a nonheterosexual identity. Ideally, surveys that measure populations across behavior, attraction, and identity would give the best data.<sup>4</sup>

## POOLING DATA

By adopting the same standardized sexual orientation identity question in a range of surveys, it is possible to combine data across years or across data collection efforts. This is important, because the proportion of people that respond as LGBO in the surveys that collect sexual orientation is relatively small. In a recent pooling of 12 UK surveys, with a resulting sample of 94 818 participants, 1.1% identified as lesbian or gay, 0.9% as bisexual, 0.8% as “other,” and 97.2% as heterosexual<sup>1</sup>; these are similar to rates found by the Integrated Household Survey.<sup>2</sup> Pooling data across surveys allows for greater numbers of participants in each sexual orientation identity category.<sup>5</sup> Moreover, it is possible, through larger sample sizes, to carry out subgroup analysis. The statistical technique adopted—that is, logistic regression with a random

effect—acknowledges that data are drawn from different studies. The analytic sample for pooled meta-analysis comprises the study population, with available data on health outcome or behavior (harmonized across studies to ensure comparability), sexual orientation, and covariates associated with sexual orientation identity. Similar analyses have been carried out, for example, on data pooled from the California Health Interview Survey (2001, 2003, 2005, and 2007) and from the Youth Risk Behavior Survey (2005 and 2007). This technique of pooling different study samples addresses the problems of low statistical power frequently seen in studies using sexual orientation identity categories.

Larger sample sizes can increase reliability in estimate reporting and allow greater power in analyses, making it possible to look at subgroup comparisons among sexual minorities and intersections within the data set, such as differences by ethnicity, socioeconomic status, educational attainment, or age. Commonly, because of low response rates, studies are forced to combine response categories, forming a “non-heterosexual” grouping to provide greater statistical power to detect differences compared with a heterosexual reference group. However, LGBO people are not one homogenous group, and a nonheterosexual grouping can conceal meaningful differences in these groups. We know that gay and bisexual men have a higher risk of suicide than lesbian and bisexual women,<sup>6</sup> that lesbian and bisexual women have higher substance misuse than gay and bisexual men,<sup>6</sup> and that bisexual women have higher depressive symptoms and perceived stress than women

reporting only same-sex attraction. Moreover, this grouping eradicates any separate understanding of LGBO health and prevents any analysis of the category of sex in this group. Finally, we do not know if “other” is selected as a gender identity category or as a political rejection of sexual orientation categories.

## COLLECTING SEXUAL ORIENTATION IDENTITY

Nondisclosure of sexual orientation within health care settings is well documented, resulting in reduced well-being and delayed presentation for treatment. Disclosure has been shown to be related to improved well-being. Population surveys that treat all respondents as heterosexual will not only tell us nothing about LGBO people but will be less likely to engage LGBO respondents. Low response rates to this question reflect understandable anxieties about misuse of data and fear of homophobia as a result of disclosure. The routine collection of sexual orientation identity in population surveys would make such data available as part of existing, regularly collected demographics; this would lead to increased confidence and engagement by participants in sexual orientation identity data provision and would provide a more representative data set.

## BEYOND SMALL CONVENIENCE SAMPLES

The importance of recording sexual orientation cannot be overstated. Mental and physical

health disparities continue to be experienced by this population, often manifested by internalization of chronic stress as a result of structural stigma, prejudice, and discrimination.<sup>7</sup> The need to monitor health outcomes and health (risk) behaviors in this population is crucial as health disparities persist over time, which is demonstrated by recent studies showing the same effects as older research. Moreover, such disparities not only emerge early in adolescence, but they persist into adulthood. Routine data collection allows the possibility of early detection of health issues, a fulsome understanding of health disparities in this population, a better-informed, deeper engagement with assessment of life-course risks, and the possibility for health patterns to be explored.

The inclusion of a sexual orientation question in some national health surveys was a huge advance. To gain a comprehensive understanding of LGBO health, it is important that collection of sexual orientation be continued. Furthermore, the measurement of gender identity also needs to be adopted within these studies. Inclusion of sexual orientation and gender identity across the research and health surveillance landscape would allow significant improvement in our understanding, increase our knowledge about the health needs of sexual and gender minorities, and allow targeted interventions to address the health disparities experienced. Efforts to remove sexual orientation from surveys that currently collect it, such as the 2017 National Survey of Older Americans Act Participants (NSOAAP), would be a significant backward step. Indeed, to remove sexual orientation data from the few health surveys that

collect it would be oppression by omission. **AJPH**

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# Erasing LGBT People From Federal Data Collection: A Need for Vigilance

On March 13, 2017, the Administration for Community Living (ACL) of the US Department of Health and Human Services published a request for comments in the *Federal Register* on the latest draft of the National Survey of Older Americans Act Participants (NSOAAP). The notice claimed that it sought comments “on a proposed extension with no changes of a currently approved collection,” but in fact this latest version of the tool used to assess program performance of recipients of funding under the Older Americans Act omitted a critical piece of data collection. During the three previous years, the NSOAAP had asked about participants’ sexual orientation. The newest draft does not.

The removal of this inquiry is extremely troubling. The federal data in the NSOAAP are critical for evaluating whether federally funded aging programs, including nutrition, transportation, case management, homemaker, and caregiver support services for seniors, accurately reflect the demographics of the United States. Failing to document whether these programs are meeting the needs of lesbian, gay, bisexual, and transgender (LGBT) seniors will result in

ill-informed decisions about how to use limited public resources to meet the needs of older adults across the country. High-quality, accurate data that capture the diversity of the older adult community are essential to ensuring that LGBT older adults “count,” both in a literal sense and in terms of fundamental protections for a vulnerable population.

## UNIQUE NEEDS

Failing to include LGBT seniors in the ACL’s appraisal of the efficacy of the federally funded aging network is particularly problematic because LGBT people face substantial barriers to successful aging. First, LGBT older adults experience higher rates of social isolation and have more precarious support networks than their non-LGBT counterparts. They are more likely to live alone, less likely to have children, and more likely to be alienated from their families of origin, the predominant source of informal caregiving in this country. As a result, LGBT seniors often look to peer-based support networks, which can leave them without needed care as these peers face their own

health and aging challenges or die.<sup>1</sup>

Second, LGBT older adults have experienced a lifetime of discrimination, social exclusion, stigmatization, and the need to conceal their identities, resulting in diminished health outcomes and diminished resources to support them as they age.<sup>2</sup> More specifically, LGBT seniors have faced greater financial instability and have had fewer opportunities to build savings as a result of employment discrimination and exclusion from programs designed to provide financial assistance to older adults, resulting in higher poverty rates than their non-LGBT peers.<sup>1</sup>

Third, and relatedly, LGBT older adults face dramatic health disparities along with high levels of discrimination in provision of health care, substandard health care, and obstacles to accessing health care. Studies show that LGBT older adults have higher rates of disability, mental health challenges, and chronic health

problems including asthma, diabetes, HIV/AIDS, obesity, and illnesses such as cancer. These conditions are exacerbated by the tendency of LGBT older adults to withhold information about their identities from providers and to delay screening for fear of discrimination.<sup>3,4</sup> This fear is warranted. In 2009, A Legal’s national Health Care Fairness Campaign revealed that LGBT people and people living with HIV, and particularly people of color, experience widespread discrimination in health care, ranging from outright refusals to provide care to harsh verbal and physical treatment by health care providers. The results were particularly pronounced for LGBT seniors, who are significantly more likely to have faced health care discrimination than their younger counterparts.<sup>5</sup>

Finally, and most critically with regard to the NSOAAP, LGBT older adults lack access to culturally competent aging programs and services. This is particularly alarming in light of their increased need for these services given their limited support networks. Having confronted discrimination from entities

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