


# AJPH Dossier on the Erasure of the Sexual Orientation Question From the National Survey of Older Americans Act Participants

 See also Curran, p. 1196; Greenlee, p. 1211; Sell, p. 1212; Vaughan, p. 1214; Semlyen, p. 1215; Loewy, p. 1217; Durso, p. 1219; and Gates, p. 1220.

In March 2017, the Administration for Community Living (ACL) in the Department of Health and Human Services (USDHHS) announced that it would exclude the single question about sexual orientation (SO) that had been introduced at the federal level in 2014 in the National Survey of Older Americans Act Participants (NSOAAP). The Older Americans Act provides, among other services, meals, transportation, and financial support to people older than 60 years who need them the most. The national survey identifies health needs and services for the recipients of Older Americans Act services. The SO question simply asks whether the respondents identify themselves as lesbian, gay, bisexual, or straight.<sup>1</sup>

The ACL argues that it is struggling with the small number of participants who identify themselves as lesbian, gay, or bisexual (LGB), and has not even released the data collected over the past three years ([bit.ly/2ntXyXl](http://bit.ly/2ntXyXl)). The ACL has asked for public comments. This dossier is *AJPH's* contribution on whether, from

scientific and ethical perspectives, a low response from the older LGB community in the NSOAAP justifies the erasure of the question.

## RATIONALE FOR THE QUESTION

Kathy Greenlee (p.1211), who previously served as the US Assistant Secretary for Aging and Administrator of the ACL from 2009 to 2016, under USDHHS Secretary Kathleen Sebelius, opens this dossier by explaining that the SO question of the NSOAAP was carefully tested and implemented to remediate the dearth of data about the existence of older LGB participants. Without these data the administration cannot “accurately and meaningfully” improve their lives and health.

Greenlee, likely the most knowledgeable person about the SO question in the NSOAAP, is opposed to its abrogation (p.1211).

## THE SCIENTIFIC ISSUE

The targeted sample size of NSOAAP is small. One data set I downloaded from its Web site for 2015 had about 1000 participants (Case Management, [bit.ly/2ntXyXl](http://bit.ly/2ntXyXl)). If, say, 5% were lesbian, gay, or bisexual, there would be an expected 50 people per year.

This number is comparable to numbers in race subcategories. For example, in that data set, there were 14 Asians, 35 American Indian and Alaska Natives, five Native Hawaiian or other Pacific Islanders, and 23 of other races.

## THE ETHICAL ISSUE

Government sampling has an important symbolic value. If certain populations are not included, especially when they previously were, it is tantamount to saying these people literally do not count, and that they have no place beside the rest of older Americans. The exclusion also

implies that these individuals are not entitled to appropriately tailored services for older Americans provided or supported by USDHHS.

Specifically, LGB persons who reach the age of 60 to 70 years today were in their mid-20s and 30s in the 1980s, and are survivors of the worst phase of the AIDS epidemic. To revisit this historical period (or if you were too young to have known it), I refer you to the poignant review of David France’s book *Surviving a Plague* by James Curran in this issue (p.1196). Deliberately ignoring this generation of LBG people is terribly unfair.

## SAMPLING LGB PERSONS

Randall Sell (p.1212), who created LGBTData.com, summarizes the challenges (i.e., sample size and statistical power, sensitive questions, validity and reliability, and cost) and solutions (i.e., oversampling and pooling data) related to SO and gender identity (SOGI) questions.

For survey data to be precise, the size of the sample matters more than the size of the population. Oversampling in the present context means recruiting a larger fraction of the LGB

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community into the sample than its proportional representation in the target population.<sup>3,4</sup>(p89–140)

(See *AJPH* Associate Editor Roger Vaughan's tutorial on oversampling [p. 1214].) Oversampling is an option as the NSOAAP is a telephone survey from a small fraction of randomly selected clients of 312 selected area agencies on aging. The SO question should be extended to SOGI and include transgender people.

Pooling, which can be done over time, is also an option. It is commonly employed by the federal government for small samples in its data releases: the American Community Survey of the US Census Bureau releases one-year estimates for groups of 65 000 or more, three-year estimates for groups of 20 000 or more, and five-year estimates for groups of fewer than 20 000 ([bit.ly/1M9KAAz](http://bit.ly/1M9KAAz)). Pooling is also feasible across surveys. Joanna Semlyen (p.1215) explains that 12 UK surveys that used a standardized SOGI question yielded a sample of 94 818 participants, 2.8% of whom identified as nonheterosexual: 3% of 100 000 is 3000, a satisfactory sample size.

In terms of question sensitivity, evidence indicates that among US adults aged 65 years and older, the nonresponse rate on SO questions is lower than that of income, and that the nonresponse rates on SO questions have decreased over time and are much lower among younger than older adults ([bit.ly/2rfOval](http://bit.ly/2rfOval), p.19–20; [bit.ly/2rfMxqE](http://bit.ly/2rfMxqE), p.11).<sup>2</sup>

The question to the ACL is, therefore: Why not accrue LGB data in the NSOAAP over more years to pool them?

## DANGERS FOR THE LGBT COMMUNITY

The specific deletion of SO data appears in the context of a series of perturbingly simultaneous attempts to “erase LGBT people.” Karen Loewy (p.1217), Laura Durso (p.1219), and Gary Gates (p.1220) mention that LGBT-related initiatives were abrogated in 2017 in the Centers for Independent Living Program Performance Report at the Department of Housing and Urban Development, and in the 2020 Census and American Community Survey, and LGBT people and issues are no longer mentioned on the White House Web site.

These initiatives seem to have been made stealthily. Loewy (p.1217) notes that the ACL had first attempted to hide its deletion of the SO question by spuriously stating in 82 *Fed Reg* 13457 that the previous version of the NSOAAP had not been altered.

Gary Gates (p.1220) explains that this backtracking jeopardizes the growing evidence-based awareness of the great diversity of the many communities constituting LGBT, and that losing access to these data may hide the ongoing growth, transformation, and representation of LGBT persons in the United States.

## DANGERS FOR SMALL MINORITIES AND NEW IMMIGRANTS

The challenges and solutions of the SO question are similar to those encountered when one is surveying other minority populations.<sup>5</sup> For example, the ACL could invoke small sample sizes to stop collecting or releasing data

on Asian Americans, American Indian and Alaska Natives, Native Hawaiian or Pacific Islanders, and other races.

Admitting that the LGBT community is too small to be analyzed separately can be a potential threat to all minorities in this country, particularly the Arab and Muslim communities along with newly arriving immigrant communities targeted by the Trump Administration.

## SCIENCE OR HOMOPHOBIA?

In my view, at the end of this review, even under the worst methodological scenario invoked by the ACL, there is no obvious, compelling scientific reason for which the SO question in the NSOAAP needs to be erased at this time.

Greenlee's empathic conclusion encapsulates the only scientific and ethically sound attitude:

“Lack of response from the LGBT community is cause for alarm, not an opportunity to stop asking the questions” (p.1212). NSOAAP implemented a 2011 Institute of Medicine recommendation<sup>4</sup>(p9) to collect SOGI data in federally funded surveys administered by the USDHHS. This is work in progress. Now is not the time to be dropping sexual minorities from the survey. If anything, it is an appropriate time to add groups, and the logical group to add would be transgender individuals.

The “lack of statistical significance” justification given by the ACL is unacceptable and leaves us to wonder whether other political reasons are interfering with the activity of the ACL and of other federal

surveillance agencies. If we are witnessing a surge of homophobia, it will not stop there and should be repealed by a large coalition. Means mentioned by Loewy (p.1217) include public comments and policy efforts highlighting gaps in information about the LGBT community.

These missteps can be corrected. I sense in the words of those who have been advocating in favor of the LGBT community for decades that they *will* be corrected. Sell (p.1212) and Durso (p.1219), in their beautifully optimistic articles, seem confident that justice will prevail. *AJPH*

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