

## LGBTQ Health Surveillance: Data = Power

Despite decades of research and advocacy, sexual and gender minorities are still not equitably included in health research and surveillance in the United States. In 1990, as I was beginning graduate school, I wrote on a piece of paper “Data = Power.” This was my take on ACT UP’s (AIDS Coalition to Unleash Power) “Silence = Death.” I created this personal motto because I had been working in the late 1980s on evaluations of some of the earliest federally funded HIV/AIDS prevention programs while attending ACT UP’s first demonstration at the Food and Drug Administration in 1988 and attending its action to “Storm the NIH” (National Institutes of Health) in 1990. What struck me more than anything during this period was that nothing could be said with confidence about sexual and gender minorities. Fundamental and excruciatingly simple questions were unanswerable and factual statements elusive.

The few pioneering sexual and gender minority health researchers were attempting to study the health of these populations in the 1980s without any significant funding or access to government-controlled data sources and surveillance systems. The convenience samples they created were remarkable illustrations of a community struggling to understand itself. Unfortunately, mainstream journals and conferences would

not accept articles based on these samples.

### NO DATA, WHY NOT?

In 1989, I listened to a presentation about the prevalence of cancer risk behaviors among African American women. What struck me was the confidence with which the presenter was revealing facts about African American women and the uncritical audience acceptance of the findings on the basis of National Health Interview Survey data. I realized as I sat there that, just as ACT UP was beginning to make demands of the Food and Drug Administration and NIH, we needed to demand that major government data sources be able to examine the health concerns of sexual minorities.

Knowing the speaker would not be able to answer my question, I raised my hand and asked it anyway. I wanted to know the prevalence of cancer risk behaviors among lesbians. The speaker responded that she could not answer my question because she did not know which women in the data set were lesbians. I followed up by asking, “Why not?” I made it a habit for more than a decade after that to ask about lesbians and gay men to anyone giving a conference presentation using data from any large government survey. I always made sure to ask my follow-up question, “Why not?” I targeted

presentations given by people who worked at government agencies that controlled survey content. Over the years, audience members recognized me from previous conferences and anticipated my questions. On rare occasions I made a presenter angry, or I heard boos from other scientists in the audience. But the survey administrators began to recognize me and answer my questions before they were asked, and some became good friends.

What I wanted to accomplish by asking these questions was to make people think about the relationship between sexual orientations and health outcomes, and to think about how ongoing surveillance systems could be used to answer these questions. Only now, almost 30 years after first approaching that speaker, are a handful of government surveys starting to collect sexual orientation data. And yes, the National Health Interview Survey has started to collect sexual orientation data, allowing researchers to report cancer-related behaviors among lesbians as I requested so long ago.<sup>1</sup>

Unfortunately, only a tiny fraction of surveys used to monitor the health of the US population currently collect sexual

orientation data, and an even smaller number collect gender identity data.<sup>2</sup> Furthermore, because of the lack of guidance on the collection of these data, there are notable differences between surveys in the questions used to assess these constructs. For example, when assessing sexual orientation, some surveys include questions about sexual orientation identity, some ask about sexual behaviors, and a handful even ask about sexual attractions.

### PUBLIC HEALTH MALPRACTICE

We are, therefore, a long way from where we need to be, and progress has been painfully slow. I have labeled government’s inaction “public health malpractice”<sup>3</sup>; this malpractice clearly continues. At some point, the secretary of Health and Human Services needs to require the collection of sexual orientation and gender identity data in every survey they have jurisdiction over, just as a previous secretary required for race and ethnicity.

We should also demand that all research funded by the NIH collect sexual orientation and gender identity data or justify its exclusion. We need legislation like Public Law 103–43, the NIH Revitalization Act of 1993, which put this requirement

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This editorial was accepted March 16, 2017.

doi: 10.2105/AJPH.2017.303798

in place for women and racial/ethnic minorities.<sup>4</sup>

## PLANNED ENROLLMENT REPORT

Anyone who has submitted a research proposal to NIH in the past 20 years that includes human participants is aware of the consequences of this act. All proposals are required to include a “planned enrollment report,” which involves enumerating the numbers of women and racial/ethnic minorities included in the proposed research. Proposals also require a discussion about the inclusion of women and minorities. Although this legislation has been far from perfect (e.g., it has not eliminated racial/ethnic health disparities, and women are still not equally included in research studies), it has had an immense impact on our understanding of the health of women and racial/ethnic minorities.<sup>5,6</sup>

There was a time when common sense told us, without convincing evidence, that sexual and gender minorities had health disparities. With vigilance, we will never go back to that dark time, but we also cannot let ourselves be satisfied with the modest gains that have been made. We need to continue to demand that every survey under the purview of the secretary of Health and Human Services collect sexual orientation and gender identity data or be required to publicly justify their exclusion. And we need to fight for legislation that ensures that sexual and gender minorities are included in all research studies funded by our taxpayer dollars through the NIH.

## KEEP ASKING

Considering recent changes in government leadership, making such demands may

seem poorly timed. However, knowing LGBTQ (lesbian, gay, bisexual, transgender, and queer or questioning) people and their history, I know that the more impossible a challenge seems, the more likely they are to stand up and fight. Although one recent US president (George W. Bush) supported a constitutional amendment banning same-sex marriage and used that position in part to get elected, a little more than a decade later the ability of same-sex couples to marry was legal everywhere in the United States. I want this editorial to serve as a reminder to sexual and gender minorities and their supporters that at this particular moment in history we need to continue to ask for things that may seem impossible to achieve, because we need to be thinking of a time not just four but 40 years from now. **AJPH**

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## REFERENCES

- Gonzales G, Przedworski J, Henning-Smith C. Comparison of health and health risk factors between lesbian, gay, and bisexual adults and heterosexual adults in the United States: results from the National Health Interview Survey. *JAMA Intern Med.* 2016;176(9):1344–1351.
- Landers S, Kapadia F. The health of the transgender community: out, proud, and coming into their own. *Am J Public Health.* 2017;107(2):205–206.
- Sell RL, Holliday ML. Sexual orientation data collection policy in the United States: public health malpractice. *Am J Public Health.* 2014;104(6):967–969.
- Rothstein MA. Ethical research and minorities. *Am J Public Health.* 2013;103(12):2118.
- Kwiatkowski K, Coe K, Bailar JC, Swanson GM. Inclusion of minorities and women in cancer clinical trials, a decade later: have we improved? *Cancer.* 2013;119(16):2956–2963.
- Chen MS Jr, Lara PN, Dang JH, Patemiti DA, Kelly K. Twenty years post-NIH Revitalization Act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual. *Cancer.* 2014;120(suppl 7):1091–1096.

# Note From the Editor-in-Chief: Who Wants to Exclude Older LGBT Persons From Public Health Surveillance?

It is sobering to publish Sell’s call for every federal survey to include questions about sexual orientation and gender identity precisely when the Trump Administration excludes such questions from the proposed 2017 National Survey of Older Americans Act Participants (NSOAAP) conducted by the Administration for Community Living (ACL) in the Department of Health and Human Services.

In particular, NSOAAP question DE1a, introduced in

2014, asked “Which of the following best represents how you think of yourself? Lesbian or Gay; Straight, that is, not lesbian or gay; Bisexual; Something else; Refused; Don’t know.” The ACL has invoked the Paperwork Reduction Act to justify excluding this question.

DE1a was allegedly being pilot tested but “unfortunately, because extremely few people identified themselves as LGBT [lesbian, gay, bisexual, or transgender], there were not enough respondents for the data to be statistically

reliable or reportable” (see the Appendix, available as a supplement to the online version of this article at <http://www.ajph.org>). For this same reason, the 2014 and 2015 data “are not available for viewing or downloading at this time” ([bit.ly/2ntXyXl](http://bit.ly/2ntXyXl)).

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This editorial was accepted April 12, 2017.

doi: 10.2105/AJPH.2017.303851

This explanation is surprising. The act has tremendous public health implications for the LGBT community, particularly those in the older adult sub-population. It has caught the broader research and community interest groups off guard because the ACL did not actively seek their input before publishing the proposed 2017 NSOAAP with the deletion in the Federal Register for public comment. On March 13, 2017, written or electronic comments were invited by