

Expanding capacity for the measurement of sexual orientation and gender identity in federal surveys: Discussion

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Abstract

Under the leadership of President Obama, the federal government has made dramatic advances in adding sexual orientation and gender identity (SO/GI) questions to federally-led and –funded health surveys. Systematic collection of such data will allow us to better understand health disparities affecting LGBT people and the extent to which they are able to access important human and social services. Improvements in the quality of data on same-sex couple households will increase our knowledge of gender and racial/ethnic differences among same-sex couple households. Developing SO/GI questions that work for older adults and Spanish-speakers is key to improving quality of data and understanding health disparities affecting LGBT older adults. Collection of SO/GI data on crime surveys is important due to the disproportionate impact of hate violence and intimate partner violence on LGBT people, and the fact that so many LGBT people live in urban areas. Expanded collection of SO/GI data will eventually allow for analysis of racial/ethnic differences in LGBT samples, as has been done with the LGB sample of the Massachusetts Youth Risk Behavior Survey.

Key Words: sexual orientation, gender identity, survey data, LGBT

1. A dam-burst of dreams and an end to invisibility

As someone who has promoted sexual orientation and gender identity (SO/GI) data collection on federally-funded and led surveys since the late 1990s starting at the National Gay and Lesbian Task Force Policy Institute, it is very gratifying to see the dramatic expansion of SO/GI data collection on surveys. At the outset I want to acknowledge Randall Sell, now at Drexel University; Urvashi Vaid, then at the Task Force Policy Institute and now at Columbia University Law School; and David Winters, then at the Ford Foundation and now at the Global Fund to Fight AIDS, Tuberculosis and Malaria. Randall, Urvashi and David were visionaries who helped found and fund the Sexual Minority Assessment Research Team (SMART), a group of researchers and advocates promoting sexual orientation (SO) data collection on government-led surveys with whom I had the honor of working from 2000 to 2007. SMART issued recommendations for SO data collection in a 2009 report published by the Williams

Institute at UCLA Law School.¹ Five years later, an analogous group working on gender identity measures published a report on this subject, also by the Williams Institute.²

In my enthusiasm for the recent advances in SO/GI data collection described by today's panel, I am reminded of a powerful metaphor created by Irish poet Christopher Nolan: a dam-burst of dreams. Nolan was an Irish poet who was born mute and quadriplegic due to oxygen deprivation during a difficult delivery. As a result, he struggled to communicate with his family. At age 11, supplied with a new medication to relax his neck muscles and a "unicorn stick" strapped to his forehead, Nolan was able to type one letter at a time on a typewriter. At age 15 Nolan published an award-winning book of poems titled *Dam-burst of dreams*, and later published a novel and autobiography. "My mind is like a spin-dryer at full speed, my thoughts fly around my skull while millions of beautiful words cascade down my lap," Nolan told *The Observer of London* in 1987. "Images gunfire across my consciousness and while trying to discipline them I jump in awe at the soul-filled bounty of my mind's expanse."³

In addition to feeling that many years of research, advocacy and pent-up demand have been actualized under the Obama-Biden Administration, I am also reminded of the message of early homophile activists like Barbara Gittings, Frank Kameny, Harry Hay, Del Martin and Phyllis Lyon. These brave lesbian and gay pioneers stressed the importance of breaking the silence and ending the invisibility of gay people in American culture and political life in the 1950s and 1960s.⁴ The federal government researchers and those outside of government working with them who have organized and presented research on today's panel are continuing this important work of breaking the silence and ending the invisibility of lesbian, gay, bisexual and transgender (LGBT) people. By breaking this silence and ending this invisibility, the work that you are all doing will allow us to identify disparities in accessing social services and health care, and the disparate impact of systems and policies on LGBT people. The expansion of SO/GI data collection on surveys and in clinical settings may be one of the most impactful and lasting legacies of the Obama-Biden Administration for LGBT health and wellness.

At the Fenway Institute we work with partners across Massachusetts and across the U.S. to help them collect SO/GI data from clients and patients. For example, we are currently working with our state Executive Office of Elder Affairs (EOEA) to help them implement SO/GI data collection in elder services across the Commonwealth. We are also working with health centers across the U.S. to collect and use SO/GI data from patients to improve quality of care. In this work with EOEA and Massachusetts elder service providers we stress that LGBT people live everywhere—not only in the gay enclaves like greater Boston, Provincetown and Northampton, Massachusetts, but throughout the Commonwealth. Data from the U.S. Census on same-sex couple

¹ Sexual Minority Assessment Research Team. 2009. *Best Practices for Asking Questions about Sexual Orientation on Surveys*. Los Angeles, CA: Williams Institute. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>.

² Gender Identity United States Surveillance Group (GenIUSS). 2014. *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*. Los Angeles, CA: Williams Institute. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.

³ Grimes W. 2009, February 23. Christopher Nolan, Irish author, dies at 43. *New York Times*. Books. http://www.nytimes.com/2009/02/24/books/24nolan.html?_r=0

⁴ D'Emilio, J. 1998. *Sexual Politics, Sexual Communities: The Making of a Homosexual Minority in the United States, 1940–1970*. Chicago, IL: University of Chicago Press.

households, which Williams Institute scholars Gates and Cooke have mapped onto the Commonwealth's 351 towns and cities⁵—demonstrate this and the need for LGBT-targeted congregate meal programs across Massachusetts.⁶ Similarly, data on LGBT people from the Gallup Poll also show that fair numbers of us live not only in liberal coastal states like California and Massachusetts, but also in Nevada, South Dakota, Kansas, Indiana, Georgia and North Carolina.⁷

2. Responses to each paper

2.1 Jennifer Park, Office of Management and Budget

As for the presentation by Jennifer Park from the Office of Management and Budget (OMB), it is heartening to hear that six federal surveys are now testing or asking gender identity questions. I don't think that this is widely known in the LGBT community. We are aware of advances with sexual orientation questions—which have been added to the National Health Interview Survey,⁸ and to the core Youth Risk Behavior Questionnaire⁹—but less aware of these positive developments with gender identity questions. The December 2015 U.S. Department of Health and Human Services LGBT Issues Coordinating Committee report described more modest progress on the Healthy People 2020 data objectives related to SO/GI data collection: six data systems collecting SO data, and two collecting GI data.¹⁰ The higher number for GI data collection is welcome news.

One question I have for Jennifer Park of OMB and other federal government leaders is, how will these important new data be communicated to the communities that they represent, in order to improve policies and services. For example, data presented at the International AIDS Conference by Laura Kann of CDC's Division of Adolescent and School Health showed strikingly high rates of injection drug use, cocaine use,

⁵ Gates GJ, Cooke AM. No date. *Massachusetts Census Snapshot, 2010*. Los Angeles: Williams, Institute, UCLA Law School. http://williamsinstitute.law.ucla.edu/wp-content/uploads/Census2010Snapshot_Massachusetts_v2.pdf

⁶ Porter, K., and S. Cahill. 2014. A State-Level Review of Diversity Initiatives in Congregate Meal Programs Established under the Older Americans Act. *Research on Aging*. doi:10.1177/0164027514552330.

⁷ Gates GJ, Newport F. 2013. *Gallup Special Report: New Estimates of the LGBT Population in the United States*. Los Angeles: Williams, Institute, UCLA Law School. <http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/gallup-lgbt-pop-feb-2013/>

⁸ Cahill S, Bradford J, Makadon H. 2014. New CDC data on lesbian, gay and bisexual health demonstrate resiliency, disparities. *Huffington Post*. http://www.huffingtonpost.com/sean-cahill/new-cdc-data-on-lesbian-gay-and-bisexual-health-demonstrate-disparities-resiliencies_b_5596445.html

⁹ Centers for Disease Control and Prevention (CDC). 2016, August 11. First National Study of Lesbian, Gay and Bisexual Students' Health Finds Higher Levels of Physical/Sexual Violence and Bullying Than Peers; Accelerated action needed to protect vulnerable youth. Atlanta: CDC. <http://www.cdc.gov/nchhstp/newsroom/2016/lgb-youth-report-press-release.html>

¹⁰ U.S. Department of Health and Human Services *LGBT health and well-being; 2015 HHS LGBT Issues Coordinating Committee Report*. Washington, DC: Department of Health and Human Services. <http://www.hhs.gov/programs/topic-sites/lgb/reports/health-objectives-2015.html>

methamphetamine use among sexual minority male high school students.¹¹ How will the interagency working groups disseminate these findings to the public, to public health officials, and to medical and behavioral health providers? How will they translate them into interventions to reduce these striking disparities in risk behaviors affecting young gay and bisexual men?

2.2 Kreider, Bates, Lofquist, U.S. Census Bureau

As for the presentation by Rose Kreider, Nancy Bates, and Daphne Lofquist of the U.S. Census Bureau, the U.S. Census Bureau's data on same-sex cohabiting couples have been incredibly important in documenting that gay and lesbian couples live everywhere.¹² Analysis of demographic differences between male and female same-sex couples, and of racial and ethnic differences—in terms of parenting races, income, and home ownership—have been important in understanding the differential impact of pro- and anti-gay family recognition and parenting policies.¹³

The fact that nearly three-quarters of the married same-sex cohabiting households reported on the 2010 Census were misclassified heterosexual couples is a major concern. Most of these were heterosexual married couples who misclassified themselves as same-sex couples. Nancy, why do you think the misclassification rate was so much lower for unmarried same-sex couples versus for married couples?

As of April 2010, when the last U.S. decennial Census was conducted, only five states (Massachusetts, New Hampshire, Vermont, Connecticut, and Iowa) allowed same-sex couple to legally marry. In addition, one jurisdiction—New York state—recognized marriages from other jurisdictions. Given that marriage equality is now legal in all 50 states, how might this affect misclassification rates in 2020?

Why was the same-sex married misclassification rate lower on the 2010 American Community Survey compared with the 2010 Census (58% versus 73%)? Was the question asked the same or differently?

The fact that the automated check questions reduce the percentage of opposite-sex couples who likely misreported sex from 0.5% to 0.03%—a decline of 263,200 (from 280,000 heterosexual couples misclassified as same-sex couples to only 16,800)—is “quite significant” and a welcome improvement in data quality. Before the automated check questions, there were almost as many miscategorized heterosexual couples as actual same-sex couples. Increasing the percentage of households that respond via the internet should lead to a further reduction in misclassification. The U.S. Census bureau should also consider running a public education campaign in the months leading up to Census 2020 to educate all couples and households how to answer this question, to explain why we collect data on same-sex couple households, and how they can help us collect accurate data. The Institute for Gay and Lesbian Strategic Studies, the National Gay and Lesbian Task Force Policy Institute, and other LGBT organizations ran a social

¹¹ CDC. 2016, August 11.

¹² Bradford J, Barrett K., Honnold J. 2002. *The 2000 Census and Same-Sex Households: A User's Guide*. New York: National Gay and Lesbian Task Force Policy Institute, Fenway Institute. http://www.thetaskforce.org/static_html/downloads/reports/reports/2000Census.pdf

¹³ Cahill S. 2009. The Disproportionate Impact of Anti-Gay Family Policies on Black and Latino Same-Sex Couple Households. *Journal of African American Studies*. 13(3), 219-250.

marketing campaign in the gay press and elsewhere in the months leading up to the 2000 Census encouraging same-sex couples to self-identify on the 2000 Census titled “Same-sex couples: Make your family count!” The highly successful campaign helped increase the number of same-sex couples from about 150,000 on the 1990 Census to more than 600,000 on the 2000 Census.¹⁴

2.3 Michaels, Stern, Haffer, Guerino, Reed-Gillette, CMS

As for the paper by Stuart Michaels, Michael Stern, Samuel Christopher Haffer, Paul Guerino, and Debra Reed-Gillette, this is a very important contribution to the research on how to ask SO/GI questions in English and Spanish to older adults. It is important because previous research has found higher rates of missing responses to sexual orientation questions among Spanish speakers compared with English speakers.¹⁵ We also see higher rates of missing responses to sexual orientation questions among respondents age 65 and older,¹⁶ and lower rates of LGBT identity among older age cohorts.¹⁷

That 58% of Spanish-speaking respondents chose an inconsistent sexual identity category gives pause. Michaels et al. also found that Spanish-speaking respondents struggled with the gender identity question as well. Some Spanish-speakers conflated sexual orientation with gender identity. It is good to see that flipping the order of the heterosexual response dramatically increased the consistency of the response (from “Heterosexual, o sea, no gay (o lesbiana)” to “No gay (o lesbiana), o sea, heterosexual”). What about defining the terms when asking the question, as follows?

- Usted se considera? (Marque uno):
- For man:
 - Heterosexual, sea, un hombre quien tiene relaciones sexuales con mujeres solamente
- For woman
 - Heterosexual, sea, un mujer quien tiene relaciones sexuales con hombres solamente
- Similar language for “gay,” “lesbiana o gay,” “bisexual”

The cognitive testing of SO/GI questions for the Medicare Current Beneficiaries Survey is highly significant. The 2015 Centers for Medicare and Medicaid Services *Equity Plan for Medicare Beneficiaries* encourages SO/GI data collection by health care providers:

¹⁴ Bradford, Barrett, Honnold, 2002.

¹⁵ Miller K, Ryan JM. 2011. *Design, Development and Testing of the NHIS Sexual Identity Question*. Hyattsville, Maryland: Questionnaire Design Research Laboratory, Office of Research and Methodology, National Center for Health Statistics October 2011.
http://www.cdc.gov/qbank/report/Miller_NCHS_2011_NHIS%20Sexual%20Identity.pdf

¹⁶ Fredriksen-Goldsen, KI, Kim, H-J. 2015. Count Me In – Response to Sexual Orientation Measures Among Older Adults. *Research on Aging*, 37(5), 464-480. doi: 10.1177/0164027514542109.

¹⁷ Gates, Newport. 2013.

Comprehensive patient data, including...sexual orientation, gender identity...are required to plan for quality improvements, and to address changes among the target populations over time.¹⁸

Collecting SO/GI data from older adults is important because LGBT people experience myriad health disparities, and may be more likely to have comorbidities in older adulthood than heterosexuals.¹⁹ LGBT older adults are more likely to report a physical disability, and to experience mental distress.²⁰ They are more likely than heterosexual elders to be single and/or live alone,²¹ are less likely to have children and grandchildren,²² are more likely to be estranged from family,²³ and may be more in need of formal caregiving support.²⁴

The Medicare Current Beneficiaries Survey is a goldmine of morbidity and mortality data on elderly and disabled Americans. If survey data were accessible in a way such that cause of death could be analyzed by SO/GI, it could be enormously valuable for exploring how and when elderly and disabled sexual and gender minorities die. This is a critical step in understanding how LGBT health disparities play out over the life course.

2.4 Jenna Truman, Bureau of Justice Statistics

It is great that the Bureau of Justice Statistics is adding SO/GI questions to the National Crime Victimization Survey this summer, and that the questions it tested were found acceptable. There are many reasons this is important to LGBT people. Anti-LGBT hate violence disproportionately burdens gay men and transgender women, especially people of color.²⁵ LGBT people concentrate in cities, and are a disproportionately urban population.²⁶ As such, they may be disproportionately burdened by violent crime.

¹⁸ Centers for Medicare and Medicaid Services (CMS). 2015. *The CMS Equity Plan for Improving Quality in Medicare*. https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

¹⁹ Grossman A. 2006. Physical and Mental Health of Older Lesbian, Gay and Bisexual Adults. In *Lesbian, Gay, Bisexual, and Transgender Aging: Research and Clinical Perspectives*. D. Kimmel, T. Rose, and S. David (eds.). New York: Columbia University Press.

²⁰ Fredriksen-Goldsen, K.I., H.J. Kim, C. Emler et al. 2011. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health.

²¹ deVries, B. 2006. Home at the End of the Rainbow: Supportive Housing for LGBT Elders. *Generations* 29(4):64–9.

²² Gates G, Cooke A. 2011.

²³ Cahill S. 2014. Community resources and government services for LGBT older adults and their families. Orel N, Fruhauf C (eds.). *The Lives of LGBT Older Adults: Understanding Challenges and Resilience*. Washington, DC: American Psychological Association, 2014. 141-170.

²⁴ Cahill S. 2002. Family Caregiving Among Lesbian, Gay, Bisexual, and Transgender Elders in New York City. Third International Conference on Family Care, Washington, DC.

²⁵ Park H, Mykhyalyshyn I. 2016, 16 June. L.G.B.T. People Are More Likely to Be Targets of Hate Crimes Than Any Other Minority Group. *The New York Times*. <http://nyti.ms/1YtDYV8>

²⁶ Bailey RW. 1999. *Gay Politics, Urban Politics: Identity and Economics in the Urban Setting*. New York: Columbia University Press.

Bisexual women and men, and lesbian women, experience intimate partner violence at high rates.²⁷

One question for both Jenna Truman and Stuart Michaels et al.: Are you concerned about transgender people who identify as a man or a woman and who are also transgender being forced to choose one or the other. If someone says “I am a transgender man,” will they be able to choose both “transgender” and “man”? The gender identity question recommended by the Center of Excellence for Transgender Health and adopted by CMS and the Office of Health Information Technology for the Meaningful Use incentive program asks transgender people to “choose all that apply,” allowing people to choose both “man” and “transgender man.”²⁸

3. Conclusion

The collection of SO/GI data and data on same-sex cohabiting households is incredibly important to document the experiences of LGBT Americans and the degree to which we access health care and human services, and experience crime. Thanks to the leadership of the people on this panel today and many others, we have made significant progress in this area over the past seven years. Inclusion of sexual orientation in the 2015 YRBS core questionnaire is especially important to collect enough data to examine racial and ethnic differences among LGB youth. In Massachusetts, our education and health departments have been collecting sexual orientation data since 1995. Researcher Carol Goodenow pooled longitudinal data and found racial/ethnic disparities among LGB youth. Asian Pacific Islander LGB youth in Massachusetts are more likely to feel unsafe at school. Black LGB youth are less likely to smoke cigarettes than other LGB youth, indicating resiliency. White and multiracial LGB youth are the most bullied among LGB youth.²⁹ As we collect more SO/GI data from various populations over time, we will eventually be able to do similar analyses with these data and see if, for example, lesbians who are Black and Latina are less likely to have mammograms than other women. Understanding the intersections of SO/GI and racial/ethnic disparities in health are critical. Thank you all for your leadership and vision in this important work.

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²⁷Brown TNT, Herman JL. 2015, November. *Intimate partner violence and sexual abuse among LGBT people: A review of existing research*. Los Angeles: Williams Institute, UCLA Law School. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Intimate-Partner-Violence-and-Sexual-Abuse-among-LGBT-People.pdf>

²⁸ Department of Health and Human Services, Centers for Medicare and Medicaid Services. 42 CFR Parts 412 and 495 [CMS-3310-FC and CMS-3311-FC], RINs 0938-AS26 and 0938-AS58. Medicare and Medicaid Programs; Electronic Health Record Incentive Program—Stage 3 and Modifications to Meaningful Use in 2015 through 2017. Released October 6, 2015. Available at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25595.pdf> Accessed October 7, 2015.

²⁹ Goodenow, C. 2011. Prevention Needs of Sexual Minority Youth, Massachusetts Youth Risk Behavior Survey 1995–2009. PowerPoint presentation. Malden, MA: Massachusetts Department of Elementary and Secondary Education.

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