



FAQ: Collecting Sexual Orientation and Gender Identity Data

Kellan Baker and Andrew Cray October 16, 2012

Health insurance exchanges, established under the Affordable Care Act, are new state-based marketplaces for uninsured individuals and small businesses to shop for affordable health insurance products. The exchanges will also provide valuable new data on the health care needs of people across the United States, including historically underserved groups such as the LGBT population.

Exchanges will have the opportunity to collect these data through optional demographic questions on exchange application forms, as well as through their oversight of insurance carriers offering plans in the exchange marketplaces. If done well, data collection will help policymakers and advocates better understand and address health disparities affecting the LGBT community, while also protecting the confidentiality of those who volunteer information on their sexual orientation and gender identity.

This FAQ explains why collecting sexual orientation and gender identity data is important, how these data can be collected, and the protections in place for LGBT people who respond to these questions.

Why collect data on sexual orientation and gender identity?

Public health practitioners and health care providers know that the future of health and health care is built on data. Data collection is indispensable to efforts to achieve better health for all by identifying, tracking, and eventually eliminating health disparities. Data help policymakers, advocates, researchers, and community members better collaborate in understanding where disparities exist, directing resources to where they are most needed, and tailoring health programs to the specific needs of diverse communities.

Sexual orientation and gender identity data will facilitate numerous activities of the health insurance exchanges, including measuring the effectiveness of health plan initiatives to promote cultural competency and quality improvement, assessing the insurance coverage

needs of LGBT communities, and designing effective outreach policies and programs for connecting LGBT people and their families with affordable, high-quality coverage.

While sexual orientation and gender identity data may not initially be sufficiently robust to facilitate stratification or other detailed analysis, initiating collection of these data is vital to establishing a baseline and, over time, identifying patterns of practice that point to opportunities for the exchanges to improve efforts to serve their diverse consumer populations.

Most importantly, asking questions about sexual orientation and gender identity communicates to LGBT consumers that the exchanges are truly dedicated to fostering inclusivity and promoting insurance access for all.

What kind of questions can exchanges use to collect information about sexual orientation and gender identity?

Sexual orientation and gender identity have several different components related to demographics and legal relationship status, all of which have relevance to the exchanges' activities. Because everyone has a sexual orientation and a gender identity, these questions will be relevant to all people who apply for coverage through exchanges.

- **Sexual orientation:** the respondent's identity with regard to romantic and/or sexual attraction
- **Sex:** the respondent's assigned sex at birth, which is the sex listed on the original birth certificate
- **Gender identity:** the respondent's current gender identity, which is the respondent's internal sense of being male, female, or another gender; for transgender people, gender identity may differ from the sex they were assigned at birth
- **Relationship status:** the respondent's legally recognized relationship status with a same- or different-sex partner

Administrative data collection efforts by federally supported health programs under agencies such as the Health Resources and Services Administration and the Substance Abuse and Mental Health Services Administration currently include sexual orientation and gender identity questions.¹ Several federal and state surveys, such as the Behavioral Risk Factor Surveillance System and the Youth Risk Behavior Survey, also include these demographic variables.²

The primary developers of sexual orientation and gender identity questions have included the Sexual Minority Research Team, or SMART, group at the Williams Institute—a national sexual orientation and gender identity law and policy think tank at the UCLA School of Law—and the Centers for Disease Control and Prevention.³ The National Center for Health Statistics is also developing a sexual orientation measure that will be added to the National Health Interview Survey in 2013.⁴ Though the administrative and population survey data collection contexts are different, there is substantial overlap in research exploring how best to collect sexual orientation and gender identity data under various circumstances.

Is it legal to ask questions about sexual orientation and gender identity?

Yes. Federal regulations clarify that the Affordable Care Act permits exchanges to collect any demographic data using optional questions.⁵ Reflecting this standard, both the proposed single streamlined application and Small Business Health Options Program, or SHOP, Exchange employee/employer applications developed by the Centers for Medicare and Medicaid Services include optional data elements for race and ethnicity information.⁶ Data elements on sexual orientation and gender identity can similarly be included as optional questions on exchange applications.

Will people answer questions about this sort of sensitive information?

Yes. As with questions on race, ethnicity, and primary language, respondents may be uncomfortable sharing personal information due to concerns about privacy or potential discrimination. Accepted practice, however, reflects the recognition that the usefulness of race, ethnicity, and language data justifies the inclusion of these optional questions on enrollment forms and for health plan quality and performance measures. Sexual orientation and gender identity data are no different.

Moreover, while some individuals will refuse to answer questions they consider too personal, research has shown that survey respondents are twice as likely to refuse to answer questions about income as about sexual orientation.⁷ Other research has demonstrated that including sexual orientation and gender identity questions does not cause respondents to refuse to continue the survey.⁸

For exchange applicants who are either unfamiliar with these questions or unsure how to respond, navigators—entities that will assist consumers with enrolling in coverage through the exchanges—and other consumer-assistance personnel should be appropriately trained to alleviate confusion and help individuals proceed through the application process with minimal difficulty.

Will respondents be protected from discrimination if they answer questions about sexual orientation and gender identity?

Yes. Several protections will help assure respondents that they will not suffer discrimination if they choose to disclose that they are gay, lesbian, bisexual, and/or transgender.

- Federal regulations require exchange staff and contractors, including brokers and navigators, to provide equal services to every individual regardless of sexual orientation or gender identity.⁹
- Section 1557 of the Affordable Care Act extends the protections of several federal nondiscrimination laws to the exchanges, and the Department of Health and Human Services has clarified that these protections include gender identity and sex stereotyping.¹⁰
- Many states have LGBT-inclusive nondiscrimination protections in public accommodations that prohibit unequal treatment on the basis of sexual orientation or gender identity.¹¹ These laws provide additional protections against the improper use of this information by exchange employees.

As is also the case with race, ethnicity, and primary language data, as well as all confidential health information, these nondiscrimination protections must be paired with strong privacy and confidentiality standards. This will prevent the inappropriate disclosure or misuse of personal data by any person or entity with access to sensitive sexual orientation or gender identity data information.

Kellan Baker is a Health Policy Analyst with the LGBT Research and Communications project at the Center for American Progress and Andrew Cray is a Research Associate for LGBT Progress at the Center.

Endnotes

- 1 See e.g. Health Resources and Services Administration, "Annual Ryan White HIV/AIDS Program Services Report (RSR) Instruction Manual" (2012), available at <http://hab.hrsa.gov/manageyourgrant/files/rsrmanual.pdf>; U.S. Substance Abuse and Mental Health Services Administration, "Government Performance and Results Act (GPRA): Client Outcome Measures for Discretionary Programs Question-By-Question Instruction Guide" (2012), available at https://www.samhsa-gpra.samhsa.gov/CSAT/view/docs/SAIS_GPRA_Services_Tool_QxQ_final.pdf.
- 2 See California Health Interview Survey, "CHIS 2009 Adult Questionnaire Version 3.4" (2011), available at <http://www.chis.ucla.edu/pdf/CHIS2009adultquestionnaire.pdf>; Massachusetts Department of Health and Human Services, "2012 Behavioral Risk Factor Surveillance System Questionnaire - Massachusetts" (2011), available at <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-12.pdf>. See also Scout, "LGBT Surveillance and Data Collection Briefing Paper" (2008), available at http://www.lgbttobacco.org/files/09FCH_DataCollection.pdf.
- 3 Sexual Minority Assessment Research Team, "Best Practices for Asking Questions about Sexual Orientation on Surveys" (The Williams Institute, UCLA School of Law, 2009), available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>.
- 4 "Improving Data Collection for the LGBT Community," available at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=209&id=9004>.
- 5 45 CFR 155.315
- 6 See CMS-10438, CMS-10439 and CMS-10440
- 7 BH Carlini, "What does this have to do with quitting smoking? Push & Pull of Asking Sensitive Questions to Callers Seeking Tobacco Treatment Through Quitlines" (National Conference on Tobacco or Health, 2006).
- 8 S Landers, K Conron, and R Sell, "Developing Data for Advocacy," (Philadelphia: National LGBTI Health Summit, 2007); Patricia Case, "Disclosure of sexual orientation and behavior in the Nurses' Health Study II: results from a pilot study," *J Homosex* 51 (1) (2006):13-31.
- 9 45 C.F.R. §155.120(c)(2)
- 10 Letter from Leon Rodriguez to Maya Rupert, July 12, 2012, available at <http://www.scribd.com/doc/102491874/HHS-Response-1557-7-12-12>.
- 11 National Gay and Lesbian Task Force, "State Nondiscrimination Laws in the U.S" (2012), available at http://www.thetaskforce.org/downloads/reports/issue_maps/non_discrimination_1_12_color.pdf.