

Data Collection

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Summary

Although the data showing health, economic, violence, employment and other disparities faced by bisexuals¹ continue to mount, serious problems with data collection remain. Many studies of sexual minorities report the results of their research in an aggregated fashion that does not distinguish the outcomes of bisexual people from those of lesbian and gay people. In the realm of sexual and gender minority behavioral health risk analysis, federally funded research studies and reports often conflate gay and bisexual men and transgender women under the umbrella of “men who have sex with men,” ignoring the unique disparities and needs of men who have sex with people of more than one sex or gender and of transgender women. These studies also often fail to account for both sexual orientation and gender identity, rendering transgender people who have sex with people of more than one sex or gender invisible. These practices result in commingled data that do not facilitate setting targeted research priorities or tailoring interventions to improve outcomes for all bisexual people. LGBT data-collection leaders such as The Fenway Institute and The Williams Institute agree that disaggregated data analysis that reports research results of self-identified and behaviorally bisexual people separately from gay, lesbian, and MSM and WSW is a best practice for LGBT health research.

Evidence

As of 2015, the Healthy People 2020 objectives state an explicit strategy for improving data collection on LGBT populations: “LGBT-1 -- Increase the number of population-based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set

¹ For the purposes of this paper, the term bisexual is used as an umbrella term for people who have the potential for sexual, emotional, and/or romantic attraction to more than one gender. This includes people who may identify as bisexual, pansexual, fluid, queer, and questioning as well as people who do not but whose emotions, desires and/or actions have the capacity to occur across more than one point along the gender spectrum. Some studies cited here may use the term bisexual to refer to people who have been sexually active with more than one gender, but who may not identify as bisexual. Research reflects there are serious disparities connected both to bisexual identity and bisexual behavior.

of questions that identify lesbian, gay, bisexual, and transgender populations” **Source:** Office of Disease Prevention and Health Promotion, “Healthy People 2020: Lesbian, Gay, Bisexual, and Transgender Health Objectives,”

<http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives>

The Fenway Institute warns against the dangers of lumping all sexual minority people together when performing data analyses of the LGB community: “Collapsing all sexual minorities into one ‘LGB’ category assumes lesbians, gay men and bisexuals have the same health-related experiences and needs. For example, lesbian women may face different barriers to receiving routine Pap smears than bisexual women. Lumping lesbians and bisexual women together in analyzing cervical cancer screening data may hinder the exploration of such important differences.” **Source:** Leigh Evans, Kelsey Lawler, and Sammy Sass, “Gathering Sexual Orientation Data on Statewide Behavioral Risk Factor Surveillance Surveys: A Call to Action for States,” *The Fenway Institute*, 2014,

http://fenwayhealth.org/documents/the-fenway-institute/policy-briefs/COM484_BRFSS_Brief.pdf

The National LGBT Health Education Center recommends that clinicians should capture sexual orientation and gender identity in electronic health records as a standard part of providing high-quality, patient-centered care to LGBT individuals. Implementation of this recommendation would also facilitate future research about the health outcomes of LGBT patients. **Source:** National LGBT Health Education Center, “Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Taking the Next Steps,” *The Fenway Institute*, 2015, <http://www.lgbthealtheducation.org/wp-content/uploads/Collecting-SOGI-Data-in-EHRs-COM2111.pdf>

Bisexuality researchers have published best practices guidelines for conducting research about bisexuality. These recommendations include not lumping bisexuals in with gay and lesbian people during data analysis, not assuming heterogeneity of the bisexual community when interpreting research results, and incorporating bisexual community input when formulating research questions to study bisexuality. **Source:** Meg Barker et al., “Guidelines for researching and writing about bisexuality,” *Journal of Bisexuality*, 2012,

http://oro.open.ac.uk/31195/2/Guidelines_for_researching_and_writing_about_bisexuality.pdf

Recommendations

Developing Survey Questions

Federal agencies should consult with bisexually identified researchers who are studying bisexual populations, including members of the Bisexual Research Collaborative on Health, when crafting surveys that examine sexual orientation and/or sexual behavior.

Federal agencies should consult with transgender research professional associations including the Williams Institute and the Fenway Health Institute, and transgender advocacy organizations including the National Center for Transgender Equality, when crafting surveys that include questions about sexual and gender minorities.

Federal agencies should consult with asexual organizations including Asexual Awareness Week and the Asexual Visibility and Education Network, when crafting surveys that include questions about sexual and gender minorities.

Health Data

In accordance with the Healthy People 2020 objectives for Lesbian, Gay, Bisexual and Transgender health, the federal government should include and/or retain standardized questions to capture sexual orientation and gender identity in all health and demographics surveys, including but not limited to the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Surveillance System (YRBS), the Census, and the National Health Interview Survey (NHIS).

The Centers for Disease Control and Prevention (CDC) should urge all states to adopt the and use the optional BRFSS and YRBS modules of sexual orientation measures, using the following questions:

Do you consider yourself to be:

- Straight
- Lesbian or gay
- Bisexual
- Other (please specify): _____
- Don't know/not sure
- Refused

Do you think of yourself as:

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional gender category/(or Other), please specify: _____
- Something else
- Decline to Answer

What sex were you assigned at birth on your original birth certificate? (Check one):

Male

Female

Decline to Answer

[If respondent reports sex in past 12 months]

During the past 12 months, please indicate if you have had sex with people of any of the following genders (select all that are applicable):

Male

Female

Female-to-Male (FTM)/Transgender Male/Trans Man

Male-to-Female (MTF)/Transgender Female/Trans Woman

Genderqueer, neither exclusively male nor female

Additional gender category/(or Other), please specify: _____

Something else

Decline to Answer

Do you consider yourself to be:

Asexual (someone who does not experience sexual attraction)

Grey-asexual (someone who experiences sexual attraction infrequently and/or not very strongly)

Demisexual (someone who experiences sexual attraction only after experiencing emotional/romantic attraction)

Other (write in): _____

None of the above

Don't know/not sure

Refused

The National Institutes of Health (NIH) and the CDC should fund studies to determine best survey design practices to measure sexual orientation, sex, gender identity and sexual behavior in health surveys.

For all freely posted public data sets that include sexual orientation and sexual behavior, NIH and CDC should fund studies examining disparities for bisexual-identified, bisexual-behaving, and otherwise non-monosexual² participants. Studies should also analyze data for participants selecting "other" or "unsure."

² For the purposes of this paper, the term "monosexual" refers to people who have the potential for sexual, emotional, and/or romantic attraction to only one sex or gender, whether similar to or different than their own. "Non-monosexual" refers to people who are not monosexual.

Supporting Research

Federal agencies should include sexual and gender minorities among the groups of people who are considered eligible for diversity related federal grantmaking programs.

Federal agencies conducting, reporting and funding research on sexual minority populations should discontinue the practice of collapsing sexual minority populations into monolithic categories such as “MSM” and “gay, lesbian, and bisexual (LGB)”, that mask issues specific and unique to individual sub-groups (particularly bisexual individuals). Agencies should recommend researchers separately analyze MSM, MSMW, WSW, and WSWM populations and/or gay, lesbian, bisexual, heterosexual, and unsure/questioning respondents, respectively. Researchers must clarify participants’ gender identity; for example, researchers must not conflate transgender women who have sex with men with men who have sex with men.

Administration-wide Review

The White House should order all agencies to review their programs, services, and regulations for areas that can be amended to be more supportive of bisexual people. This includes, but is not limited to, all health programs and services including mental health programs and services, all LGBT-inclusive data collections, all violence prevention programs and services, and services and programs for youth and students.