Principles for Collecting, Coding, and Reporting Identity Data

SEXUAL ORIENTATION GUIDELINES

Purpose

To promote widespread San Francisco Department of Public Health (SFDPH) collection of sexual orientation information, with accuracy, transparency, and consistency, so that the SFDPH collects, codes, and reports categories that are meaningful for identifying differences in health outcomes, conditions that impact health, and delivery of health services.

Background

Scientific research, as well as provider and community experience, indicate that sexual orientation has important implications for health. It is associated with differences in (1) access to and use of health care treatment, (2) health-related behavior and experiences, and (3) health outcomes. The California Health Interview Survey data show that lesbian, gay, and bisexual (LGB) adults have significantly higher rates of delaying or not seeking medical care and of receiving health care in emergency rooms than straight/heterosexual adults. Survey results also show that LGB adults have higher rates of diagnosed cancer but proportionately receive fewer mammograms, LGB youth have higher rates of physical fights that require medical treatment, and both LGB youth and adults have higher rates of cigarette-smoking. Persons with same-gender attractions are five to six times more likely than heterosexuals to engage in self-harming behaviors, including non-suicidal self-injury (e.g., cutting) as well as suicide attempts.

Additional analysis by sexual orientation and ethnicity revealed additional vulnerabilities and health disparities. For example, while LGB women are less likely to have had a mammogram in the past two years than straight women, the gap is the greatest between LGB and heterosexual African-American women—only 35% of LGB African-American women had mammograms in the past two years, compared to 69% of heterosexual African-American women. While LGB adults are more likely to report alcohol abuse overall, alcohol abuse rates vary by ethnic group; Asian or Pacific Islander LGB adults are less likely to abuse alcohol than heterosexual Asian or Pacific Islander adults, while African-American and Latino LGB adults are nearly twice as likely to abuse alcohol as heterosexual African-American adults. Latino LGB adults are significantly more likely to abuse alcohol than other LGBs or heterosexual African-Americans, Asian/Pacific Islanders, Latino and White adults.

These findings suggest that from the perspectives of both clinical health care and public health monitoring, it is important to identify sexual orientation in the populations we monitor and serve. SFDPH's goal is to have all divisions and sites collect this information routinely, although it is recognized that the adoption will happen in phases, and that the process in which it is collected may vary between sites. This document provides the language and rationale for how and when data on sexual orientation should be collected.

While the U.S. government has not yet recommended a way of collecting data about sexual orientation in health care settings or for public health purposes, gathering these data is consistent with key recommendations in Healthy People 2020, the 2011 Institute of Medicine report on LGBT health issues and research gaps, the recent California Department of Mental Health Reducing LGBTQ Disparities Population Report, and the federal government's implementation of the Patient Protection and Affordable Care Act.
The U.S. Department of Health and Human Services is currently field-testing a question about sexual orientation identity to be used on the National Health Interview Survey.9 Healthy People 2020 explicitly identifies this data collection as a priority:

"Increase the number of population-based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set of questions that identify lesbian, gay, and bisexual populations."10

Among the SFDPH programs that already collect data relevant to sexual orientation, their methodologies are inconsistent; programs assess sexual orientation with different questions or with variability in response items. Some SFDPH programs do not ask individuals about their sexual orientation, but do collect data on the gender/sex of clients’ sexual partners.

These guidelines are a first attempt by SFDPH to systematically expand and improve consistency in sexual orientation data collection, to better understand the factors influencing the risk of all of San Franciscans and all sexual orientation identities. They were developed in consultation with internal SFDPH experts, academics at SF State University whose work focuses on sexual orientation and LGB populations, and community members.

The language recommended in the questions reflects the Department of Public Health’s multiple efforts to (1) enable all individuals to identify their sexual orientation, (2) limit the possible answers in order to maximize SFDPH’s ability to analyze risks and trends, and (3) obtain answers readily and accurately from all populations in all programs.

These guidelines are meant to be used for any individual who seeks services from DPH and DPH-funded programs. In the event an individual is at least 12 years old but not yet 18 years old, the DPH Minor Consent Policy should be followed, including specification of where sexual orientation information for LGBT-identified minors is coded and collected. Moreover, because children and adolescents have unique developmental processes with understanding gender identity and identification,[i] SFDPH with its expert partners will continue to research and explore appropriate methods, models and age criteria for capturing sex and gender identity for children and adolescents.

**SFDPH Policy**

All new data collection systems purchased or designed for or by the Department of Public Health that will be used for patients, clients, participants, or other cohorts must have the ability to track sexual orientation in accordance with these guidelines. Reporting of collected data should also adhere to these guidelines whenever possible, recognizing third party reporting requirements may be in conflict.

**General Guiding Principles**

1. **Sexual orientation is an identity that typically indicates the gender(s) to whom a person is sexually or romantically attracted.**11
Public health researchers have defined sexual orientation in many ways, recognizing the inter-related but not exchangeable concepts of sexual attraction, self-identification, and sexual behavior (including the gender of one’s sexual partners).12

2. **Sexual orientation is not a medical condition.**
   Though some studies indicate a biological foundation for sexual orientation, these have not been demonstrated to result in health disparities (whereas sex assigned at birth is sometimes a reason for some health disparities related to anatomy or hormone levels). Some of the health risks for LGB individuals stem from social stigmatization of their sexual orientation.

3. **Sexual orientation may be an important marker of health differences but should not be assumed to be the source of health differences.**
   Health disparities related to sexual orientation stem from discrimination and social stigma, which have health effects in both everyday life and within healthcare settings. In a community survey of 3,023 LGB Californians reached via a snowball design, more than 80% reported experiencing discrimination more than 1-3 times each year. Additionally, 72%-82% reported having “experienced emotional difficulties (e.g. stress, depression, anxiety) due to sexual orientation or gender identity/expression.”13 In a study of 1,248 young adult gay and bisexual men living in Southwestern cities, 37% reported experiencing anti-gay verbal harassment in the previous 6 months and 4.8% reported physical violence in the previous 6 months.14

4. **Sexual orientation identity does not restrict sexual behavior.** The gender(s) of a patient’s sexual partners and sexual behavior data should not be assumed from reported sexual orientation identity but rather should be gathered through other specific questions as needed.
   Sexual orientation identities should not be assumed from the gender(s) of people’s sexual partners, and the gender(s) of people’s sexual partners should not be assumed based on their identified sexual orientation.15 Data collected for an individual—on either their sexual orientation or the gender of their sexual partners—should not be “corrected” based on a perceived “mismatch,” as people’s sexual identity and sexual behaviors may not be consistent.16 See endnote 15 for how to collect data on the gender(s) of people’s sexual partners.

5. **Naming of sexual orientations should allow for both consistency and relevance.**
   Response options should be both recognizable to respondents and translatable into minimum reporting categories.

6. **Categorization of sexual orientations should allow for compliance and comparability.**
   While some programs collect information about sexual orientation in a completely open-ended forum (i.e., anything that someone provides via a blank line or box), this method requires intensive data cleaning and a rigorous coding scheme rendering data analysis extremely time consuming and difficult. Also, while reports to some government contractors do not currently require data about sexual orientation, SFDPH data collection protocols should be reviewed periodically to remain in compliance with governmental contracts once those categories are established.
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Data Collection Principles

7. **Sexual orientation should be self-identified.**

8. **Sexual orientation data should be collected for all adults (18 years and older).**
   Sexual orientation data collection should be normalized by being asked of all adults. However, as with all identity demographic data, it should be optional for patients/clients to provide this information. When feasible, sexual orientation data should be collected as a part of the standard demographic information in a self-completed form. When intake information is gathered in other ways (registration by phone or in face-to-face interviews, electronically, or by the clinician in the course of the visit), care should be taken to assure privacy. Sexual orientation should not be in the general demographic information included at the top of medical records that is viewable by non-clinical staff.

9. **Sexual orientation data should be collected for minors where appropriate starting at age 12 years in accordance with the minor consent policy.** These data should be coded with caution and care. The SFDPH Minor Consent Policy states that minors may consent to health care services beginning at age 12 years. Research has shown that youth report an awareness of same-gender sexual attractions at varying ages, but on average as early as age 10 (median age 11). Therefore, consistent with both the empirical research and the SFDPH Minor Consent Policy, it is appropriate to begin collecting sexual orientation information from youth starting at age 12 years. When sexual orientation information is discussed with people younger than 18 years of age, documenting their identity should be done with sensitivity and caution knowing that legal guardians may access their child’s medical record, including demographic information and all service records (excluding those requiring minor consent). This data collection should only be done by providers when legal guardians are not present. When sexual orientation data are collected for minors, it should be recorded in fields that are not releasable to legal guardians without the consent of the minor. Ideally, this field should be able to be included in statistical aggregate analysis. Providers should follow the Minor Consent Policy’s confidentiality-related procedures when serving LGBT-identified youth.

10. **Sexual orientation data should be accessible for statistical aggregate analysis, regardless of how and where different clinics or programs may collect these data.**

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A **Minor Consent Policy**, Section II, 1, iv, c & d: Collecting basic demographic information on clients is an important part of a first visit to a primary care or behavioral health clinic. For LGBT youth however, questions about gender or sexual orientation may be anxiety producing if parent/guardian is unaware that they identify as transgender, gay, etc. When asking youth questions about their gender and/or sexual orientation at registration or through health history, it is important to assure the youth that this information will be kept confidential when collected under minor consent, and that this information cannot be disclosed to parent/guardian or other outside person or agency without the youth’s express permission. Included in the basic demographic information are the following questions: what is your gender, what was your sex at birth, what pronoun should we use in addressing you, and how do you describe your sexual orientation or sexual identity. For transgender identified youth, it is extremely important that there be good communication among the health care team (from registration to discharge) particularly related to chosen gender, name and appropriate pronoun use.
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Regardless of how the data are collected, they should be consistently coded and collected in a format that allows aggregation and analysis and as outlined in these guidelines.

11. When collecting data on sexual orientation, the following format should be followed:

Selection of sexual orientation identity should be limited to one answer choice.

How do you describe your sexual orientation or sexual identity? (Check one)
   a. Straight / Heterosexual
   b. Bisexual
   c. Gay / Lesbian / Same-Gender Loving
   d. Questioning / Unsure
   e. Not listed. Please specify: ________________________
   f. Decline to answer

And for internal use only (not to be listed as an option to the individual):
   g. Not Asked
   h. Incomplete / Missing data

There are identities that are not included in the above list (e.g., Queer). Although Queer was considered as an option for the list, stakeholders agreed that the definition for Queer varies considerably and it remains unclear in the literature how Queer is different (or not) from lesbian, gay, or bisexual as a sexual orientation. For example, "Queer" is often used as an umbrella term to capture the potential combinations of gender identity, sexual orientation, and sexual practice that violate existing social norms. Therefore, because the term “queer” can overlap and is not mutually exclusive with other categories already listed, it was not included as an independent option at this time. To address the fact that some people may not see a description for themselves in the choices provided the option “Not listed. Please specify” is included in the list.

12. Programs adopting this method should consider how to keep sexual orientation information up-to-date.

Sexual orientation identity may fluctuate over time. Therefore, programs should develop and adopt best practices that allow for sexual orientation data to be updated as often as feasible and appropriate. Programs that collect data on the gender of people’s sexual partners should also allow for information updates.

Coding and Reporting Principles

13. Data reports by sexual orientation should present these categories:
   a. Straight / Heterosexual
   b. Bisexual
   c. Gay / Lesbian / Same-Gender Loving
   d. Questioning / Unsure
   e. Not listed
   f. Asked, Declined to Answer
g. Not Asked

While individual divisions and sites may find it useful to combine multiple categories, all categories should first be analyzed separately for any unique trends. This is in line with the advice of the San Francisco’s Commission on Human Rights, which recommended that data on bisexuals not be combined with data on gays and lesbians, as these populations often have significantly different experiences and health outcomes.  

Recommendations

- **DPH Programs should incorporate these principles** into their current data collection and reporting as feasible, and attempt to apply them further in any system, data collection, and reporting (re)designs.

- **DPH should develop and make available implementation materials**, including question and response options, best practices, community recommendations, and data coding and reporting programs that have been developed.

- **DPH should assess training, technical assistance, and implementation needs of SFDPH, agencies, and community service providers**. Since the model will be new to most community service providers and programs, it will need an implementation plan, with technical assistance if possible. All staff and public health practitioners should receive LGBT cultural competency training and should be able to ask questions about sexuality and gender identity correctly and consistently.

- **DPH should develop a policy** that each data system designed must articulate how questions will be asked, when they will be asked, and by whom. Each program should make available documentation of its implementation of this policy.

Endnotes

5. Citations:
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15 Programs that collect data on the gender of people's sexual partners should acquire that information from the following question. There should not be a limit on data collected about the gender of people's sexual partners.

What is/are the gender(s) of your sexual partners over the past 12 months? (Check all that apply)

a. Male
b. Female
c. Transgender Male (FTM)
d. Transgender Female (MTF)
e. Other - Please specify: ________________________
f. Unknown
g. Not applicable – no sexual partners in past 12 months

And for internal use only (not to be listed as an option):
h. Not specified

16 A 2006 study from the New York Department of Mental Health that found 9.4% of men who identified as heterosexual had had sex with a man in the previous year. (Source: Pathela P, Hajat A, Schilling J, Blank S, Sell R, Mostashari F. Discordance between sexual behavior and self-reported sexual identity: a population-based survey of


