

## LGBTQ RESEARCH WITH SECONDARY DATA

Researchers who wish to study lesbian, gay, bisexual, trans and queer (LGBTQ) populations have three options for obtaining raw data:

1. Gathering original data: This takes time and money to do well, but provides maximum flexibility in terms of framing questions specific to a project.
2. Working with data already collected by other researchers: Research data is rarely maximized, and researchers may welcome the opportunity to share their data sets with colleagues. Research teams may already have a process for applying to use their data sets, and this will usually include applying to the relevant research ethics board (REB) for approval of the new study.
3. Using a governmental or administrative data set: LGBTQ people are a small portion of the population, but in a national study a substantial number of respondents will be LGBTQ. There are established protocols for accessing these data.

## ASKING ABOUT SEXUAL ORIENTATION IN NATIONAL CANADIAN SURVEYS

- People often expect that there will be Canadian data on LGBTQ people and their health, yet such data are not always collected or readily available. Data that are available, even when collected from population-based surveys, may not accurately reflect the LGB population since many people are hesitant to identify themselves as LGB to the government or its researchers (1). While data on the trans population have not yet been collected in national Canadian surveys, the same concerns will likely apply.
- The 2003 Canadian Community Health Survey (CCHS) was the first Statistics Canada survey to include a question on sexual orientation. In that study, 1% of Canadians age 18 to 59 identified as gay or lesbian, and 0.7% identified as bisexual. Among men, 1.3% identified as gay, and 0.6% identified as bisexual. Among women, 0.7% identified as lesbian, 0.9% identified as bisexual (2). LGBTQ health information broken down by geographic region (city, region or Local Health Integration Networks) or by ethno-cultural community is often unavailable and this lack of regional data is a barrier to local health planning.
- The Canadian Census included information on same-sex households in 2001 and 2006. In 2001, 68,400 people (34,200 couples) reported living in a same-sex common-law relationship, and this figure increased to 75,770 (37,885 couples) by 2006. Data on married same-sex couples were collected with limited success via write-in in 2006 (1). With the discontinuation of the mandatory long-form census in 2010, detailed information about LGB Canadians may become even more scarce, and trans people have yet to be explicitly included in either the census or Statistics Canada surveys.

## IDENTIFYING LGBTQ DATA

- A single standardized measure of sexual orientation is contained in most recent Statistics Canada data sets, including the Canadian Community Health Survey, the General Social Survey, and others (3). The Canadian Census (through 2006), and the new National Household Survey (begun in 2011) that has replaced the mandatory long-form census, do not include this measure. However, they do identify same-sex households. All Canadian federal databases have documentation available in both French and English.
- In the U.S., multiple measures of sexual orientation (e.g. behaviour, identity) are often present in data sets from the National Center for Health Statistics, such as the National Survey of Family Growth and the National Health and Nutrition Examination Survey (4).
- Provincial and state surveys vary in terms of whether measures of sexual orientation are included. A number of large adolescent health surveys, including the British Columbia Adolescent Health Survey, contain multiple measures of sexual orientation.
- Outside of Canada and the U.S., population data sources are available for some countries and regions, though there are still many countries for which there are no population data on sexual or gender minorities.
- While the number of population health surveys that include items on sexual orientation has increased dramatically in recent years, studies are only beginning to identify participants who are transgender, transsexual or transitioned (trans). Currently, only a handful of studies contain such measures, including the Ontario Health Study (5) and the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) (6).

## TYPES OF AVAILABLE DATA

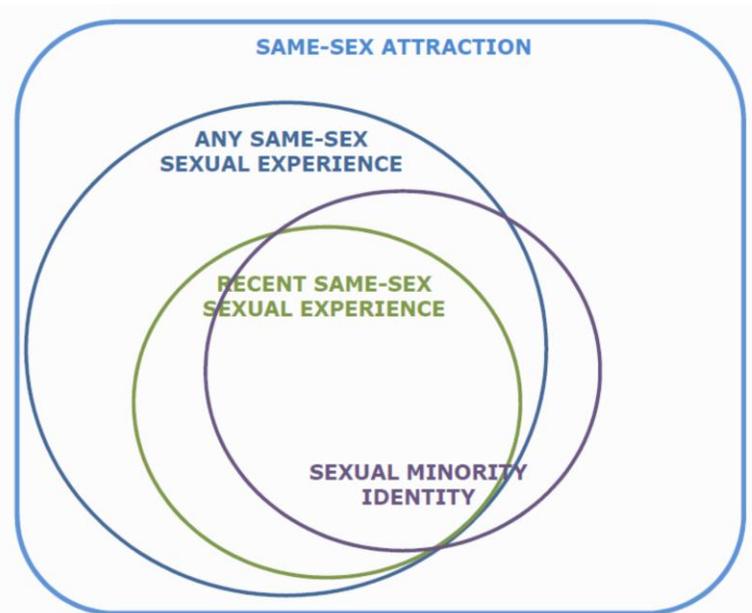
- Sexual Identity is commonly considered one of three dimension of sexual orientation, along with sexual behaviour and attraction. Statistics Canada data sets each contain a single item on sexual orientation, which is as follows:

<b>Do you consider yourself to be:</b>
• heterosexual? (sexual relations with people of the opposite sex)
• homosexual, that is lesbian or gay? (sexual relations with people of your own sex)
• bisexual? (sexual relations with people of both sexes)

This item assesses sexual orientation identity (how one considers or labels themselves) though terms are defined behaviourally.

- Measures of attraction are used primarily in youth studies, such as the British Columbia Adolescent Health Survey, Seattle Teen Health Risk Survey, National American Indian Adolescent Health Survey, and Minnesota Adolescent Health Survey (7). The Minnesota and BC survey asked, “People have different feelings about themselves when it comes to questions of being attracted to other people. Which of the following best describes your feelings?” Options offered were: 100% heterosexual (attracted to persons of the opposite sex); Mostly heterosexual; Bisexual (equally attracted to men and women); Mostly homosexual; 100% homosexual (“gay/lesbian”; attracted to persons of the same sex); and Not sure.

- Many data sets include both an identity measure and behaviour measures over multiple timeframes (e.g. one year and lifetime). However, as the diagram below shows, not every measure will capture the same pool of participants, since more people have same-sex attractions, for example, than identify as LGB.



- Which type of measure will provide the data needed will depend on the research questions. Identity may be an important contributor to health behaviours and outcomes in some ways, while sexual behaviour may contribute in other ways. Some studies will need to combine data across dimensions to assess, for example, heterosexually identified men who have had sex with men. What is important is that the research question is well defined, and that the data source used provides the most appropriate type of data to address that question.
- Be aware that not all sexual minorities will adopt an identity such as gay or bisexual. Moreover, some people may identify in ways that are more creative than the limited options available in a survey. Culturally specific sexual identity terms, such as two-spirit or same-gender-loving will get missed in national databases, which categorize people only as gay, lesbian, or bisexual.
- Though everyone has a gender identity (often simply male or female), few studies differentiate social gender from biological sex, distinguish different aspects of each, or use measures that allow for identification of trans participants. Even among those that do, the measure used may not be adequate for most analyses. For example, the question in the Massachusetts BRFSS did not allow researchers to identify whether a participant was on the male-to-female (MTF) or female-to-male (FTM) spectrum, what their sex assigned at birth was, which gender they were currently living in, or what their hormonal exposure might be (6). Conflating data in this way can obscure key disparities and prevent detailed analysis of trans health.
- Be aware also that not all trans people personally identify as trans, transgender or transsexual, and may identify as simply men or women with a medical history that involves transitioning. Unless a question incorporates a broad definition for trans people,

or asks detailed questions, it may not identify all trans participants (8). The Ontario Health Study contains multiple dimensions of transgenderism and transsexualism, and additional research is underway to determine how best to improve survey measures for trans participants (5).

- Some data sets may have been top coded, changing responses that may be identifiable in order to protect respondent privacy. A participant living in a small region who reports having 13 children, for example, may be represented as having 6+ children. Other information, such as records of abortion access, may also be removed from raw data available to the public.
- Be aware that not all questions in a survey may be asked of all respondents. Questions about sexual orientation are usually not asked of children, and are often not asked of people over the age of 59.

## ACCESSING LGBTQ DATA SETS

- Statistics Canada has a series of Research Data Centres (RDCs) in universities across Canada, where raw data on population health and social surveys can be accessed and analyzed on site. These data are available to both researchers with an academic affiliation and those from non-profit organizations. Researchers wishing to access data must submit a proposal of their research to a review committee. The application process generally takes at least one month. Data use through the RDC is free for members of the RDC network, and at a fee for others. There are also guidelines as to how the findings of the research must be published (9).
- The U.S. National Center for Health Statistics makes de-identified data sets available from low-risk groups for free through their website (4). There is no cost for off-site data use. Access to more sensitive data sets (e.g. data on children or adolescents, data on abortions and sexually transmitted infections) may be restricted to on-site access, or to pre-approved researchers only.
- For other sources of data, access varies widely. Research access in advance, so that time is available to complete application materials, security checks, or other requirements. Keep records of materials submitted for approval, as well as any waived requirements (e.g., e-mails indicating that REB approval is not needed).
- In some cases, it may be possible to link data from a survey that identifies participants as L, G, B, and/or T with other databases, to gain additional data. For example, linkage with Ontario data from the Institute for Clinical Evaluative Sciences, a non-profit Canadian health research institute, can allow for a safely anonymized analysis that links data on LGBTQ individuals from health surveys to administrative databases (e.g., OHIP records) containing information on health service use (10-11). Database linkage can be complex, and needs to be considered well in advance with regard to both feasibility and cost.

## RECOMMENDATIONS FOR FUTURE DIRECTIONS

- LGB research with secondary data would be facilitated by adding multiple measures of sexual orientation to the Statistics Canada data sets, to allow for analysis of a wider range of research questions.

- Adding measures to identify trans participants to all large studies would enable researchers to produce information on trans health, including health inequities.
- More work needs to be done on developing and promoting best practices for measuring biological sex and social gender in order to better reflect the range of sexual and gender diversity, and explicitly include trans people in research.

## REFERENCES

- (1) Statistics Canada. 2006. Census information on same-sex common-law and married couples. [http://www12.statcan.ca/census-recensement/2006/ref/info/same\\_sex-meme\\_sexe-eng.cfm](http://www12.statcan.ca/census-recensement/2006/ref/info/same_sex-meme_sexe-eng.cfm) .
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- (11) Institute for Clinical Evaluative Sciences. Available at: <http://www.ices.on.ca/index.html>.

## Acknowledgements

This fact sheet was co-written by staff at Rainbow Health Ontario and Dr. Greta Bauer, who is an Associate Professor in Epidemiology & Biostatistics at Western University. Dr. Bauer has extensive experience working in LGBTQ health research in the U.S. and Canada.

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Last updated: August 2012