



Rainbow Health Ontario

Fact Sheet

Because LGBT health **matters**

DESIGNING SURVEYS AND QUESTIONNAIRES

In recent years health ministries across Canada have emphasized health equity and access, leading to the need for data on lesbian, gay, bisexual and trans (LGBT) health. Researchers in universities and in the community are now adding measures of sexual orientation and gender identity to surveys on a wide variety of health issues.

Those who are new to the field are often looking for the perfect question to capture information about sexuality and gender. However, no single question can adequately account for the diversity of attractions, identities and behaviours found within LGBT communities. Rather, there are a number of possible options, depending on the research questions being asked and the population being researched.

This fact sheet is best used as an overview of issues to consider when developing your study measures. Since no single measure is perfect, and our knowledge of sexual orientation and gender identity is always developing, take the examples as starting points, adjusting them as needed.

SEXUAL ORIENTATION MEASURES

- Sexual orientation is traditionally assessed by measures of sexual attraction, sexual behaviour, or sexual identity. Population figures for sexual minority people will vary, with measures of attraction garnering the largest number of sexual minority members, behaviour the next largest, and sexual identity the fewest.
- Ask yourself, what do you need to know? Are you trying to capture data on as many sexual minority people as possible? If so, you might measure attraction. Do you need to know about STI risk? Then sexual behaviour might be your focus. Do you need data on people who belong to specific communities? In that case identity may be more salient. Perhaps you need information about all of these (and more)?
- Researchers are often concerned that their respondents will not answer questions about sexual orientation. An analysis of responses to a state-wide US survey over five years found that non-response to sexual orientation questions varied between 5.7% in the first year of the study to 3% in subsequent years. Moving questions about sexual orientation from the section on human immunodeficiency virus (HIV) risk to the demographics section may have helped increase the response rate. By contrast, 5.6% of respondents refused to supply information about their annual income (1).
- The Williams Institute, a think tank of scholars at the University of California, Los Angeles, recommends that researchers avoid placing questions about sexual orientation with questions about sexual violence or sexual abuse, as this has been found to increase non-response rates (2-3).
- Avoid using warnings, apologies or other caveats before questions about sexuality as this may decrease the response rate or reinforce sexual shame. Best practice is to include sexual questions alongside other demographic questions (3).



MEASURING SEXUAL ATTRACTION

- Sexual attraction has been defined by some researchers as forming the very foundation of sexual orientation (4-5) Asking about attraction can identify those sexual minority people who choose not to identify as LGBT, and is useful when surveying youth populations who may have limited sexual experience, or may lack a fully developed sexual identity (15).
- The Williams Institute recommends measuring sexual attraction using the question developed by the National Study of Family Growth: (NSFG) (3):

People are different in their sexual attraction to other people. Which best describes your feelings? Are you:
<input type="checkbox"/> Only attracted to females?
<input type="checkbox"/> Mostly attracted to females?
<input type="checkbox"/> Equally attracted to females and males?
<input type="checkbox"/> Mostly attracted to males?
<input type="checkbox"/> Only attracted to males?
<input type="checkbox"/> Not sure?

- To facilitate honest responses and reduce social desirability bias (selecting the answer they think will be most acceptable to others), questions about sexual orientation should be included on self-administered portions of a survey, rather than on portions administered by an interviewer (3).
- For the ease of your participants, you may wish to list the most common options first. For example, if surveying men in the LGBT population, the majority of whom will be primarily attracted to other men, you might list “only attracted to males” as the first option. Be aware, however, that the order you select may unintentionally send a message about which answers are most acceptable.
- The drawback to the NSFG question is that it does not account for attractions to people who do not fall easily into the categories of male or female, and it does not offer an option for people who experience no attractions at all. Moreover, some respondents may be unsure whether “Equally attracted to females and males” is describing frequency of attractions (equally split between men and women) or intensity of attractions (equally attracted to men and women).
- An alternative is to ask questions with yes/no options:



Are you sexually attracted to women? Yes No

Questions of this type can be designed to identify people attracted to transgender, transsexual, or genderqueer people, and if the questions are comprehensive, the analysis stage can identify asexual people (who will answer no to each question). However, yes/no questions cannot identify gradations of attraction, as does the NSFG question.

- Attraction alone cannot present an entire picture of everyone’s sexual context. A bisexual woman, who reports that she is primarily attracted to men, may in fact have a same-sex partner and spend most of her time in the lesbian community.

MEASURING SEXUAL BEHAVIOUR

- Measuring sexual behaviour is useful when a respondent's sexual activity is more relevant than their attraction or identity, such as when assessing sexually transmitted infection (STI) risk factors. One scale, pioneered by Kinsey and colleagues in the 1940s, is still used today (6-7). The Kinsey scale asks participants to report their sexual behaviour on a continuum:

What is your sexual orientation?	
Rating	Description
0	Exclusively heterosexual
1	Predominantly heterosexual, only incidentally homosexual
2	Predominantly heterosexual, but more than incidentally homosexual
3	Bisexual
4	Predominantly homosexual, but more than incidentally heterosexual
5	Predominantly homosexual, only incidentally heterosexual
6	Exclusively homosexual
7	Other (please tell us how you identify here)_____

Some researchers add another category to the Kinsey scale to represent asexuality (8).



- Some researchers prefer the Kinsey scale because not all people who have sex with individuals of the same sex identify as gay or lesbian. It may also translate more easily as some languages will lack equivalent terms for gay, lesbian, or bisexual, but may have a term for homosexual. Other researchers avoid terms like homosexual, which has a history of pathologization, and prefer to use the terms gay or lesbian.
- Measuring sexual behaviour will count some people as sexual minority members who identify themselves with the sexual majority. In a New York study from 2006, 9.4% of men who identified as straight reported same-sex activity in the past year (9). To include men such as this, many researchers avoid referring to participants by identity labels such as gay and instead use behavioural labels such as “men who have sex with men” (MSM).
- Some researchers have criticized the use of behavioural labels, such as MSM, and WSW (women who have sex with women), suggesting that they erase social identities such as gay or lesbian, that are important to many people (10-11).
- When asking about sexual behaviour, focusing on a specific time frame helps ensure accurate data by reducing the length of time you ask participants to recall:

In the past five years, whom have you had sex with?
<input type="checkbox"/> Men only
<input type="checkbox"/> Women only
<input type="checkbox"/> Both men and women
<input type="checkbox"/> I have not had sex in the past five years

- By asking about behaviour without applying a sexual identity label this question solves a problem encountered by the Kinsey scale, in which some respondents are hesitant to label their same-sex experiences as homosexual.
- Since sexual activity varies, best practices are to use terms such as “sex” or “sexual experience,” and allow participants to define these terms for themselves. Be aware however, that respondents may have very different ideas as to what constitutes sex.
- When you need data about particular sexual acts associated with STI risk it is best practice to ask about those acts specifically. You may need to use street terms such as “blowjob” instead of “oral sex” in order to ensure that respondents understand the question. For instance, a question such as “have you had oral sex in the past five months” may confuse respondents who aren’t sure if the question is asking about receiving oral sex *from* a partner or performing oral sex *on* a partner.
- For the ease of respondents, you may want to place the most common or expected response first. For example, if surveying lesbians and bisexual women, you may want “women only” and “both men and women” to be at the top of the list of options. Be aware,



however, that the order in which options are presented can influence how participants respond. This is called “response order bias,” and can be reduced by varying the order of response options.

- The time interval you choose (one year, five years, ten years, etc.) will depend on the focus of your research. For example, if you are assessing the impact of a particular health campaign, you may want to measure behaviour before and after the campaign launch.
- Be aware that the time frame you choose may affect your results. For example, a man who has been in a six year monogamous relationship with another man might select “men only” if asked to describe his sexual activity during the past five years. However, the same man might select “both men and women” if the time period was ten years. Keep in mind that respondents may have difficulty remembering details of their sexual history when responding to questions about longer timeframes.
- You may want to ask about different time periods throughout a respondent's life rather than having one question about lifetime sexual experience. Asking about different time periods enables a researcher to distinguish between sex that was part of adolescent sexual exploration and sex that is part of a participant's current practice. In a longitudinal study, be sure to use the same measure of sexual behaviour in each wave of the project.
- Some sexual activities, such as group sex, casual sex in a bathhouse, some BDSM activities (bondage, discipline, domination, submission, sadism, & masochism), or blackout parties (sex in a darkened room with many partners) may be more difficult to quantify in terms of number of partners (or indeed, in what counts as sex).
- Researchers can also measure sexual behaviour using yes/no questions:

Have any of your sexual partners been trans men? <input type="checkbox"/> Yes <input type="checkbox"/> No

Yes/no questions avoid erroneous responses caused when participants anticipate the location of the option that relates to them, and answer without thoroughly reading the question.

- You may also choose to measure sexual behaviour on a scale:

During the past five years, with how many different partners have you had sex?	
<input type="checkbox"/> None	<input type="checkbox"/> 16-20
<input type="checkbox"/> 1-5	<input type="checkbox"/> 21-25
<input type="checkbox"/> 6-10	<input type="checkbox"/> 26-30



<input type="checkbox"/> 11-15	<input type="checkbox"/> 31 or more
--------------------------------	-------------------------------------

The options you provide for categorical scales will vary, depending on the participants. If surveying adolescents, for example, you may want to use smaller gradations such as 1-3, 4-5, etc., to account for their limited sexual history. A review of data from the US and Canada found that less than half the adolescents surveyed were sexually experienced (2).

- The disadvantage of using categorical scales is that, depending on your research question, you may want to know exactly how many partners a participant had, or exactly how many times a participant had a certain type of sex. Another option is to allow participants to report themselves how many partners or acts they had:

During the past five years, with how many different partners have you had sex? Please indicate the number of partners here: _____

The disadvantage of using this method is that some participants may not know this information, especially if they have had a lot of partners or sexual activity.

- While it can be helpful to ask how many partners participants have had, when measuring STI risk you may also want to ask about frequency of sex. A person who reports sex without a condom, for example, will be exposed to differing levels of risk depending on whether they had unprotected sex once, or hundreds of times with the same partner (12).

MEASURING SEXUAL IDENTITY

- If your goal is to understand how people label themselves, you will be measuring sexual identity. This can be relevant to studying health-related topics for which social isolation, victimization, or social support may play a role.
- The Williams Institute recommends a question that has been developed and tested by U.S. National Center for Health Statistics (3):

Do you consider yourself to be
<input type="checkbox"/> Heterosexual
<input type="checkbox"/> Bisexual
<input type="checkbox"/> Gay/lesbian



- In measures of sexual identity, bisexuals tend to appear in equal numbers to gays and lesbians, with more women reporting a bisexual identity than a lesbian identity (13).
- Sexual identity labels vary by culture. For example, many Aboriginal people who have same-sex attraction identify as two-spirited. Some racialized people may identify as same-gender loving, homosexual, or on the down low rather than as gay, lesbian or bisexual (3).
- If your survey addresses a specific population you may want to offer options that are more common among that group. The Bisexual Mental Health Study included identity categories used primarily by people attracted to more than one gender, such as ambisexual, biaffectionate, bisensual, fluid, heteroflexible, homoflexible, omnisexual, and pansexual.
- Sexual identity, like attraction and behaviour, can change over time. Depending on your research question, you may need to ask how people have identified at particular time periods in their lives.
- Avoid defining terms in ways that exclude people who use that identity label. Do not, for example, define bisexuals as “attracted to both sexes,” or as “attracted to both men and women,” since many bisexuals will also be attracted to people such as genderqueers, who fall outside of these categories. Instead, use inclusive descriptions such as “attracted to more than one gender” (14).
- Avoid making assumptions about the sexual behaviour of people based on their sexual identity. Not all women who identify as lesbian, for example, will report an exclusively same-sex history.
- When reporting data on sexual identity, be precise, and avoid using sexual identity terms interchangeably. Not everyone who identifies as queer, for example, will identify as LGB, and vice versa.
- Be aware that a question about sexual identity will not capture everyone who engages in same-sex behaviour (indeed, it will capture some who do not). As well, it will represent only a fraction of those with same-sex attractions, as this diagram shows:

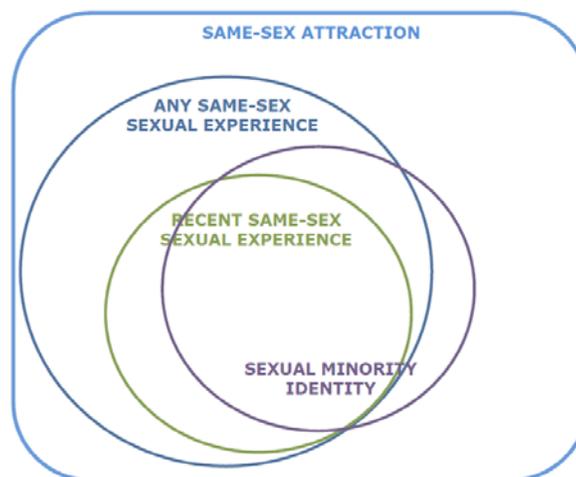


Diagram provided by Dr. Greta Bauer



- Knowing how participants identify their own sexuality is useful when studying aspects of health affected by social factors, such as community belonging and support. However, do not assume that all participants who indicate an LGB identity are necessarily out as lesbian, gay or bisexual to others. If degree of outness is a factor in your study you will need to ask about that specifically.

OFFERING OTHER OPTIONS

- Using the “Other—please specify” option can help researchers collect data that would otherwise be missed. Enabling respondents to specify a less common identity also prevents them from choosing a category that describes them inaccurately, and skewing your data. Researchers can use write-in responses to become aware of emerging sexual or gender categories. Several resources are available to help researchers familiarize themselves with sexual identity categories specific to various groups (15-16).
- Participants may find it offensive or dehumanizing to be included in an “other” category. To reduce this effect, researchers may wish to acknowledge that the shortcoming lies in the study options, not the participant and their identity, e.g.: “You don’t have an option that applies to me. I identify as _____.”
- Some studies offer a “not sure” option when asking about sexual or gender identity. This option can be particularly useful for youth, for whom sexual and gender identity may not yet be clear. However, studies suggest that most people who choose “not sure” did not understand the question (17). In addition, participants who select “not sure” may be selecting that category for every question (called response set bias).
- To distinguish between respondents who are not sure of their sexual or gender identity and those who are not sure what the question means, the Williams Institute recommends including two separate options, such as “I am not yet sure of my sexual identity,” and “I am not sure what this question means” (3).
- Some surveys offer a “prefer not to answer” category for some questions. Including this option on questions related to sexual identity or gender is not recommended as it singles these questions out as particularly sensitive and may bias responses (3).

ASKING ABOUT GENDER IDENTITY

- Gender identity refers to a person’s perception of themselves as male, female or intersex; masculine, feminine, trans, transgender, or transsexual. Not everyone identifies with the gender associated with the sex they were assigned at birth.
- Be aware that not everyone will identify as male, female, or trans. Some participants may identify as genderqueer or as two-spirited (which is a gender identity as well as a sexual identity). Be aware, however, that not everyone uses these terms in the same way. Some butch lesbians, for example, may consider themselves to be genderqueer while others may define genderqueer as more androgynous.



- People who identify with the gender associated with their assigned birth sex are called “cisgender.” However, most cisgender people will not recognize the term. To distinguish between trans and cisgender participants you may wish to ask a yes/no question such as “Do you identify as transgender or transsexual?” Avoid using terms such as “biological” male or female to describe cisgender people as this is othering to trans people, whose bodies are just as biological as those of cisgender people.
- Since many people will hold more than one gender identity it is common to ask participants to “check all that apply.”
- Your participants’ familiarity with gender terms may vary considerably as terms that are common in some LGBT populations are virtually unknown in others. Below is a question about gender identity included in a provincial study of bisexual people:

Which of the following describes your present gender identity?
<input type="checkbox"/> 2-spirited
<input type="checkbox"/> Bigendered
<input type="checkbox"/> Crossdresser
<input type="checkbox"/> Genderqueer
<input type="checkbox"/> Man
<input type="checkbox"/> Trans man
<input type="checkbox"/> Trans woman
<input type="checkbox"/> Woman
You don't have an option that applies to me. I identify as (<i>Please specify</i>) _____

- Asking separate questions about the sex that participants were assigned at birth, their currently lived gender, and whether or not they identify as trans will better enable researchers to analyze data sets that include trans participants.
- Asking trans participants about their use of hormones and their location on the male-to-female or female-to-male spectrum is also important since these factors may have an impact on their health.
- Some research has asked participants to rate themselves on a scale from masculine to feminine. However, participants have expressed confusion as to whether they were being asked about their own identity, or others perception of them, and whether they were expected to base their response on their physical appearance, mannerisms, or personality traits (18).



ONLINE SURVEY PROGRAMS

- Some online surveys programs, such as SurveyMonkey, store their data in the United States. Data stored in the U.S. are subject to the Patriot Act, which allows the U.S. government access to these data if a threat to the U.S. government or its citizens is identified. However, since most surveys do not ask participants to report their name, address, phone number, or other identifying information, the chance of identifying a participant is low. For the perspective of SurveyMonkey's representatives on this issue, please see <http://blog.surveymonkey.com/2011/05/patriot-act/>.
- Alternatives exist for researchers who would prefer not to store data in the United States. For example, FluidSurveys has a similar program: <http://fluidsurveys.com/alternative/to-surveymonkey-canadian>, as does LimeSurvey <http://www.limesurvey.org/en>. However, the authors of this document and Rainbow Health Ontario do not endorse any particular product or company, and recommend that researchers search for all available options, which may include programs not mentioned in this fact sheet.
- Depending on the kinds of data analysis you plan to do, you may use a spreadsheet program, such as Microsoft Excel, or a statistics program, such as IBM's SPSS. The U.S. Centre for Disease Control provides a set of software tools called Epi-Info to enable health workers to collect, analyze, visualize, and report data: <http://wwwn.cdc.gov/epiinfo/>.

ANALYZING SEXUAL ORIENTATION & GENDER IDENTITY DATA

- Whether or not a statistical analysis program is necessary depends on the research questions being asked. For example, if a researcher only wants to know the distribution of responses (e.g., "How many people identify as trans?"), a spreadsheet program may be appropriate. However, if a researcher wants to know how transgender and cisgender people differ in quality of life and access to health care, a statistical program would be more useful.
- Research has found significant health differences across sex and sexual orientation. Whenever possible, data should be separated by sex and by sexual orientation, enabling comparisons between categories (e.g., between men and women, and between bisexuals and gays or lesbians). Avoid collapsing data groups in ways that disrespect their self-identity. Do not, for example, fold bisexual women into the lesbian category, or include trans women in the male category. Likewise, participants who select "other," "unsure," or "I don't know" for sexual orientation should not be considered LGB (3).
- The majority of people who participate in studies of LGBT populations have tended to be white. Be aware that conclusions drawn from data on white LGBT people may not be generalizable to racialized LGBT people.



OTHER CONSIDERATIONS

- The order in which options appear in a survey may be interpreted as an order of researcher preference, thereby affecting how participants respond. If, for example, straight/heterosexual always appears first, sexual minority respondents may feel marginalized by the research. Alphabetizing or varying the order of selection options can avoid this effect.
- Questions about marital status should account for variations in equity across geographic boundaries. Not all LGBT people will have access to same-sex marriage, for example. The Williams Institute suggests including an option for “living with a partner,” and recommends that follow-up data be gathered regarding the number and age of adults and children in the household (3).
- While using measures that have been included in other surveys enables data comparisons, be aware that not all scales have been validated for use with LGBT populations. Read potential questions carefully for language bias. If you are unsure as to whether the language of the scale is offensive or irrelevant to LGBT people consider having an LGBT advisory committee or focus group examine the questions.
- All research projects that are affiliated with a university need to undergo an ethics review, which can add considerable time to the research process. Non-university affiliated projects that are not intended to be published in a research journal may not need to undergo such a process. Volunteering to sit on a research ethics board is one way of ensuring that LGBT research receives an equitable review.
- Rainbow Health Ontario has a list of affiliated researchers with experience working on projects that assess sexual orientation and gender identity. Rainbow Health Ontario can put you in touch with a researcher whose expertise can help you to design a survey. For more information, please see <http://www.rainbowhealthontario.ca/research/find.cfm> or contact Lorelee Gillis, RHO's Research and Policy Coordinator, at lgillis@rainbowhealthontario.ca.

REFERENCES

- (1) Conron KJ, Mimiaga M, and Landers S. 2008. A Health Profile of Massachusetts Adults by Sexual Orientation Identity: Findings from the 2001-2006 Massachusetts Behavioral Risk Factor Surveillance System Surveys. Report prepared for the Massachusetts Department of Public Health. Available at http://www.mass.gov/Eehhs2/docs/dph/health_equity/sexual_orientation_disparities_report.pdf.
- (2) Saewyc E, Bauer G, Skay C, Bearinger L, Resnick M, Reis E, et al. 2004. Measuring sexual orientation in adolescent health surveys: Evaluation of eight school-based surveys. *Journal of Adolescent Health* 35(4):345.E1-345.E15.
- (3) Badgett M. 2009. Best Practices for Asking Questions about Sexual Orientation on Surveys. Los Angeles: The Williams Institute, UCLA School of Law. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>
- (4) Cochran S, Mays V. 2000. Relation between psychiatric syndromes and behaviorally defined sexual orientation in a sample of the US population. *American Journal of Epidemiology* 151 (5): 516-523.
- (5) Russell S, Joyner K. 2001. Adolescent sexual orientation and suicide risk: evidence from a national study. *American Journal of Public Health* 91 (8): 1276-1281.
- (6) Kinsey A, Pomeroy W, Martin C. *Sexual Behavior in the Human Male*. Philadelphia: W.B. Saunders; 1948
- (7). Kinsey A, Pomeroy W, Martin C, Gebhard P. *Sexual Behavior in the Human Female*. Philadelphia: W.B. Saunders.; 1953.



- (8) Jones RL. 2010. Troubles with bisexuality in health and social care. In: Jones R, Ward R, editors. *LGBT issues: Looking beyond categories*. Edinburgh: Dunedin Academic Press, pp 42-55.
- (9) Pathela P, Hajat A, Schillinger J, Blank S, Sell R, Mostashari F. 2006. Discordance between sexual behavior and self-reported sexual identity: a population- based survey of New York City men. *Annals of Internal Medicine* 145: 416-425.
- (10) Young R, Meyer I. 2005. The Trouble With “MSM” and “WSW”: Erasure of the Sexual-Minority Person in Public Health Discourse. *American Journal of Public Health* 95 (7): 1144-1149.
- (11) Bauer G. 2012. Making sure everyone counts: considerations for inclusion, identification and analysis of transgender and transsexual participants in health surveys. In: Canadian Institutes of Health Research, Institute of Gender and Health., editor. *What a Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook*, pp. 59-67.
- (12) Sell R. 1996. The Sell Assessment of Sexual Orientation: Background and Scoring. *Journal of Lesbian, Gay and Bisexual Identity* 1 (4): 295-310.
- (13) Bradford J, Cahill S, Grasso C, Makadon H. 2012. Why Gather Data On Sexual Orientation And Gender Identity In Clinical Settings? Fenway Health Institute. Boston. http://www.fenwayhealth.org/site/DocServer/Policy_Brief_WhyGather..._v6_01.09.12.pdf?docID=9141
- (14) Barker M, Richards C, Jones R, Bowes-Catton H, Plowman T, Yockney J, et al. 2012. The Bisexuality Report: Bisexual inclusion in LGBT equality and diversity Centre for Citizenship, Identities and Governance and Faculty of Health and Social Care.
- (15) Adams H, Phillips L. 2009. Ethnic related variations from the Cass model of homosexual identity formation: the experiences of two-spirit, lesbian and gay Native Americans. *Journal of Homosexuality* 56 (7): 959-976.
- (16) Ford C, Whetten K, Hall S, Kaufman J, Thrasher A. 2007. Black Sexuality, Social Construction, and Research Targeting ‘The Down Low’ (‘The DL’). *Annals of Epidemiology* 17 (3): 209-216.
- (17) Sell R, Wells J, Wypij D. 1995. The Prevalence of Homosexuality in the United States, the United Kingdom, and France: Results of Population-Based Surveys. *Archives of Sexual Behavior* 24 (3): 235-248.
- (18) Clark M, Armstrong G, Bonacore L. 2005. Measuring sexual orientation and gender expression among middle-aged and older women in a cancer screening study. *Journal of Cancer Education* 20 (2): 108-112.

This fact sheet was co-written by staff at Rainbow Health Ontario and Dr. Trevor Hart, a Clinical Psychologist and Associate Professor at Ryerson University who uses clinical trial and community-based research methods in studies on HIV prevention and care.



RHO Factsheet: Designing Surveys and Questionnaires is licensed under a [Creative Commons Attribution-noncommercial-sharealike 3.0 Unported License](https://creativecommons.org/licenses/by-nc-sa/3.0/).

Last updated: August 2012