

GENDER-RELATED MEASURES OVERVIEW



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The GenIUSS Group
a collaboration of scientists, scholars, and transgender leaders

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INTRODUCTION

Transgender people, like any group of people, come from a wide range of backgrounds. They live in cities and rural areas; are young, elderly, and middle-aged; began to live as their true gender when they were children, young adults, or much later in life; and live in families of all varieties. Transgender people, and the communities they live in, are diverse in terms of factors such as race, income, and sexual orientation.

Unfortunately, transgender people from all backgrounds face discrimination in a wide array of settings. Transgender people across the United States today frequently encounter prejudice, violence, and institutionalized discrimination in areas of everyday life such as health care, housing, employment, education, and legal recognition in their true gender. These disparities are exacerbated for transgender people who are also members of other disadvantaged groups, such as transgender people of color and transgender women.

The consequences of discrimination are deadly: According to the 2011 *National Healthcare Disparities Report*, transgender people are disproportionately likely to experience violence in the home, on the street, and even in health care settings.¹ They are twice as likely as the general population to live in extreme poverty, defined as an annual income under \$10,000, and more likely to be uninsured.² Sources such as the Institute of Medicine and Healthy People 2020 report that transgender people are also more likely to contract HIV, to go without preventive care, and to attempt suicide.³ In a recent study of more than 6,400 transgender people in the United States, 41% of trans people reported attempting suicide—a rate 25 times higher than the general population.⁴

While the existing body of research has helped policymakers, researchers, providers, and advocates begin to address these concerns, many aspects of the needs and experiences of transgender people remain unexplored. Collecting more high-quality data on the disparities associated with a transgender identity and other social, economic, and health concerns of transgender communities is essential if federal, state, local, and nonprofit agencies are to adequately serve transgender people. Improved data are also necessary to allow researchers to better understand the backgrounds and needs of transgender people and to help transgender advocates and their allies develop effective strategies for improving the circumstances of transgender people's lives.

The GenIUSS group (Gender Identity in U.S. Surveillance), convened by the Williams Institute, is a collaboration of scientists, scholars, and transgender leaders dedicated to increasing knowledge about gender-related measurement and promoting the inclusion of these measures on population-based surveys, with particular consideration for publicly-funded data collection efforts. GenIUSS group efforts will result in the creation of recommendations and best practices for gender identity questions and data collection in the near future.

The crucial first step in building the knowledge we need is adding questions that allow us to characterize the needs of transgender respondents, as well as questions about sexual orientation, to federally supported surveys.⁵ The GenIUSS group has identified six large-scale federally-supported surveys across the fields of health, demographics, education, employment, and justice that should add gender-related measures: The National Health Interview Survey, the Behavioral Risk Factor Surveillance System, the American Community Survey, the Current Population Survey, the Survey of Income and Program Participation, and the National Crime Victimization Survey.⁶ Furthermore, research studies and privately-funded surveys in areas such as employee diversity and patient experiences in health care settings should consider including validated measures that provide an accurate picture of transgender lives. The field of health information technology, which relies heavily on data captured in electronic health records, also has much to learn from population survey research about how to accurately reflect the identities and lived experiences of transgender people.⁷ This brief describes the current state of gender-related measurement for adult populations.⁸

CURRENT STATE OF GENDER-RELATED MEASUREMENT IN SURVEYS

Numerous tested or applied examples of how to collect information about the transgender population already exist. This brief draws on the expertise of numerous scholars and researchers to provide an overview of four of the most promising tested or applied gender identity measurement models. Each has undergone question development testing, usually cognitive testing, and has evidence from field application available as well. The GenIUSS group urges federal authorities to conduct additional testing on one or more of these models.

FOUR CURRENT GENDER-RELATED MEASURES

1) A two-step method of assessing current gender identity and assigned sex and birth

Source: Center of Excellence for Transgender Health at University of California – San Francisco

Year developed: 1997

Since 2007, the Center of Excellence for Transgender Health at the University of California at San Francisco (UCSF) has advocated the use of a two-step question that captures a transgender

person's current gender identity as well as their assigned sex at birth.⁹ This protocol involves first querying the patient's current gender identity, followed by a query of the sex assigned at birth. Together, these two variables accurately reflect the current gender in which the individual is living and functioning socially, and when used in a health care setting, also alerting health care providers about potential physiological considerations of which they should be aware in order to provide appropriate health care such as preventive screenings.

Two-step assigned sex and gender identity protocol:

1. What is your current gender identity?

- Male
- Female
- Trans male/Trans man
- Trans female/Trans woman
- Genderqueer/Gender non-conforming
- Different identity (please state): _____

2. What sex were you assigned at birth, meaning on your original birth certificate?

- Male
- Female

The two-step method was first developed in 1997 by the Transgender Health Advocacy Coalition, a community-based organization, for use in a survey of transgender people in Philadelphia.¹⁰ The measure was then adapted for use in the Washington Transgender Needs Assessment Survey and the Virginia Transgender Health Information Study.¹¹ In 2011, the U.S. Centers for Disease Control and Prevention (CDC) adopted this question protocol for use in its Adult Case Report Form as well as its electronic surveillance system, the Enhanced HIV/AIDS Reporting System (eHARS).¹²

Asking gender identity first emphasizes that this parameter tends to be much more important than assigned sex at birth for transgender people. A 2012 study by Tate, Ledbetter, and Youssef has shown that this technique provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single-item method (i.e., a single question asking respondents' gender with choices of "male," "female," "transgender," or "other" only).¹³ It also minimizes confusion among and misclassification of non-transgender people, who may be unfamiliar with the concept of gender identity.

2) A single-item method of assessing transgender status

Source: Massachusetts Behavioral Risk Factor Surveillance System

Year developed: 2007

The Behavioral Risk Factor Surveillance System (BRFSS) is a collaborative health surveillance effort between the CDC and state departments of public health. Each year, a household sample of adults who can be reached by telephone is drawn using random digit dial methods. Topics such as health insurance coverage, cancer screening, and sexual behavior are assessed with core questions provided by the CDC. States may add supplemental questions to their own state survey. In 2007, the Massachusetts (MA) Department of Public Health added a single-item transgender status question to the MA-BRFSS survey.

Transgender status single-item protocol:

Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?

- Yes, transgender, male to female
- Yes, transgender, female to male
- Yes, transgender, gender non-conforming
- No

Note—Additional information for telephone interviewer if asked about definition of transgender:

Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman would be transgender. Some transgender people change their physical appearance so that it matches their internal gender identity. Some transgender people take hormones and some have surgery. A transgender person may be of any sexual orientation – straight, gay, lesbian, or bisexual.

Note—Additional information for interviewer if asked about definition of gender non-conforming: Some people think of themselves as gender non-conforming when they do not identify only as a man or only as a woman.

A single Yes/No response option was provided between 2007 and 2012, before the question was modified to reflect the original question developed for inclusion on the Boston Public Health Commission’s Boston BRFSS survey in 2000 by transgender leaders and allies. The original proposed question included three “yes” response options (transgender, male to female; transgender, female to male; and transgender, gender-variant).

This measure is a stand-alone question that does not require valid data about assigned sex at birth to classify respondents as transgender or gender non-conforming.¹⁴ This item was answered by a heterogeneous group of adults on a large, population-based survey. The non-response rate (1.4%) was very low; in fact, it was lower than the non-response rate for sexual orientation, and much lower than the non-response rate for income on the same survey. Analyses of MA-BRFSS data collected between 2007-2009 indicate that 0.5% of 18-64 year old adults answered yes to this question and were classified as transgender.¹⁵ This population prevalence of transgender adults is consistent with population-based estimates from two other states (California and Vermont).¹⁶

This question has not yet been cognitively tested with adults; however, a simplified version of this item performed very well with adolescents.¹⁷

3) A two-item method of assessing socially assigned gender expression

Source: Wylie SA, Corliss HL, Boulanger V, Prokop LA, Austin SB. 2010. Socially assigned gender nonconformity: A brief measure for use in surveillance and investigation of health disparities. *Sex Roles* 63(3-4): 264-276.

Year developed: 2010

How a person's gender and gender expression are perceived—or socially assigned—by others is an important health determinant.¹⁸ Furthermore, experiences of prejudice events and discrimination may sometimes be related to one's gender expression.¹⁹ A brief survey measure was developed to assess socially assigned gender expression in adolescents and adults. The measure is composed of two items that were adapted from a single item for assessing appearance conformity, which was first used by Clark et al. in the Cancer Screening Project for Women in 2005.²⁰ In 2010, Wylie et al. evaluated the two-item measure in a cognitive interviewing study with a New England sample of 82 adolescents and young adults of all sexual orientations ages 18 to 30 years who described themselves as female, male, or transgender.²¹ The first item assesses gendered appearance, and the second assesses gendered mannerisms.

Gender expression two-item protocol:

1. A person's appearance, style, or dress may affect the way people think of them. On average, how do you think people would describe your appearance, style, or dress? (Mark one answer)

- Very feminine
- Mostly feminine
- Somewhat feminine
- Equally feminine and masculine
- Somewhat masculine
- Mostly masculine
- Very masculine

2. A person's mannerisms (such as the way they walk or talk) may affect the way people think of them. On average, how do you think people would describe your mannerisms? (Mark one answer)

- Very feminine
- Mostly feminine
- Somewhat feminine
- Equally feminine and masculine
- Somewhat masculine
- Mostly masculine
- Very masculine

Wiley et al. found item clarity, comprehension, and saliency to be high. Other strengths of this measure are that it is brief, easily understood, and provides important detail that would not be captured in only one item. The measure has some limitations to be considered. The measure asks about current socially assigned gender expression and so does not gather information on gender expression at younger ages, which may be different. Also, item performance has not been assessed in depth with regard to race, ethnicity, and education level. Finally, accurate classifications of respondents as gender non-conforming are contingent upon the availability of data about assigned sex at birth.

4) A single-item method of assessing gender identity and sexual orientation

Source: Network for LGBT Health Equity at the Fenway Institute

Year developed: 2008

In 2008, the National Network for LGBT Tobacco Control (now the Network for LGBT Health Equity) developed and tested a single-pass LGBT surveillance question for Blue Cross Blue Shield of Minnesota. This question queries both gender identity and sexual orientation in a format that allows both aspects of identity to be independently addressed.

Gender identity and sexual orientation single-item protocol:

Do you think of yourself as (please check all that apply):

- Straight
- Gay or lesbian
- Bisexual
- Transgender, transsexual, or gender-variant
- Not listed above (please write in): _____

Note—Optional desirable enhancement:

IF yes to transgender, then add this probe.

- Transgender, male to female OR
- Transgender, female to male

While this measure appears to be a single question, this multiple-response question is reported out as a series of Yes/No questions. The data are returned as five responses to five different Yes/No questions: 1) Are you straight? 2) Are you gay or lesbian? 3) Are you bisexual? 4) Are you transgender, transsexual or gender-variant? 5) Are you not listed above?

In 2008, this measure was cognitively tested in a diverse sample (including oversamples of people of color, LGB, and transgender people) in Minnesota and has been fielded as part of the state's surveillance system since then.

This measure demonstrates several important qualities. First, LGBT data collection is complicated by the fact that only two-thirds of transgender people report a distinct sexual orientation identity, one third will skip reporting one or volunteer “transgender” when asked. As desired, this measure provoked some transgender respondents to report a sexual orientation, while allowing others to simply state being transgender.²² Second, in testing, this question successfully steers non-transgender people, including those who do not understand what “transgender” means, away from accidentally saying they are transgender. Testing revealed that when the more familiar terms “gay” and “lesbian” precede the gender identity component, they deter non-transgender heterosexuals from inaccurately selecting transgender as a response option. This measure also offers ease in reporting aggregate LGBT data, which may be desirable for use in surveys with smaller sample sizes due to the relatively small size of the LGBT population.

As originally tested, the primary weakness of this question was that it failed to capture all transgender respondents. Analysis indicated adding the additional verbiage of “*transgender, transsexual or gender-variant*” will address this weakness. The optional enhancement listed above has not been tested, but its addition is highly desirable, since health issues vary widely by whether a transgender individual’s assigned sex at birth was male or female.

CONCLUSION

As this brief outlines, there are several existing examples of gender-related measures in population surveys and other data collection instruments. Aspects of gender measured in the above questions include a two-step measure of current gender identity and sex assigned at birth, two-item measure of socially assigned gender expression, and two single-item measures of transgender status. Importantly, none of the questions presented here should be taken as ideal models or approached from the perspective of “one size fits all.” Survey administrators, researchers, and policymakers should consult with transgender scientists and community members to determine which gender-related measures are most relevant to the circumstances in which data are needed, and thus which question may be most effective in gathering accurate and useful information. Any question selected for use should be subjected to testing in advance, whenever possible, in order to ensure that the measure performs appropriately.

Demographic, health, and other data are crucial markers of social value and inclusion, particularly in our information-rich age. For transgender people, as for other historically marginalized communities, to be counted is to count in important local and national discussions about policy, resource allocations, and other issues that affect transgender lives. The time has come for our country to show transgender people that their lives and concerns matter by routinely including transgender-inclusive gender-related measures in data collection efforts.

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The Williams Institute on Sexual Orientation and Gender Identity Law and Public Policy at UCLA School of Law advances law and public policy through rigorous, independent research and scholarship, and disseminates its work through a variety of education programs and media to judges, legislators, lawyers, other policymakers and the public. These studies can be accessed at the Williams Institute website.

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¹ Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*, available at <http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf>; Grant, J.M., L.A. Mottet, J. Tanis, J. Harrison, J.L. Herman, and M. Keisling. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, available at http://www.thetaskforce.org/reports_and_research/ntds.

² Grant, et al. 2011.

³ See, e.g., Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press; U.S. Department of Health and Human Services. 2010. “Healthy People 2020 LGBT Health Topic Area,” available at www.healthypeople.gov.

⁴ Grant, et al. 2011.

⁵ Sexual orientation and gender identity are different aspects of an individual’s identity. Transgender people, like anyone else, may be gay, straight, or any other sexual orientation. The discriminatory treatment that some transgender people suffer may be based in other’s perceptions and understandings of gender identity or sexual orientation. See, e.g., Gordon, A.R. and I.H. Meyer. 2007. Gender Nonconformity as a Target of Prejudice, Discrimination, and Violence Against LGB Individuals. *Journal of LGBT Health Research*. 3(3): 55-71. Therefore, data should be collected on both gender identity and sexual orientation in order to fully study the disparities transgender people face. For best practices for asking questions related to sexual orientation, see The Williams Institute. 2009. *Best Practices for Asking Questions about Sexual Orientation on Surveys*. Los Angeles: The Williams Institute, available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>.

⁶ The Center for American Progress has also outlined the importance of these federal surveys in informing public policy for LGBT people in the United States. See, e.g., Krehely, J. 2012. “Critical Government Surveys Omit Gay and Transgender People,” available at <http://www.americanprogress.org/issues/lgbt/news/2012/09/06/36134/critical-government-surveys-omit-gay-and-transgender-people/>.

⁷ Institute of Medicine. 2012. *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary*. Washington, DC: National Academies Press.

⁸ This brief focuses on gender-related measurement with adult members of the general U.S. population. While some questions presented in this document have been tested with youth, where noted, special consideration should be given when considering appropriate questions for youth. Organizations, such as GLSEN, are engaged in further testing and refining of gender-related measures developed by GenIUSS researchers for use with youth. See, e.g., GLSEN. 2012. *Assessing Transgender Status in Surveys of Adolescents (Research Brief)*. New York: GLSEN, available at: http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2104-1.pdf.

⁹ Assigned sex at birth refers to the sex entered (male or female) on the original birth certificate.

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¹² CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. 2011. *HIV Infection among Transgender People*. Washington, DC: Centers for Disease Control and Prevention, available at <http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf>.

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- ¹⁴ Participant-reported assigned sex at birth and gender identity are not currently collected on the MA BRFSS.
- ¹⁵ 95% confidence interval [CI]=0.3%, 0.6%; Conron K.J., G. Scott, G.S. Stowell, and S.J. Landers. 2012. Transgender health in Massachusetts: Results from a household probability sample of adults. *American Journal of Public Health*. 102:118-122.
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- ¹⁷ Conron KJ. 2011. *The Massachusetts Gender Measures Project. Final report to the Massachusetts Department of Public Health*. Boston: Institute on Urban Health Research, Northeastern University.
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- ²² Grant, et al. 2011.