

20 September, 2018

Notes for the OMB regarding the SOGI questions on the Young Adult Survey

While the YA survey has allowed for the reporting of same-sex relationships and has included questions about attitudes towards gender roles, gender identity and sexual orientation have not been directly addressed. With growing openness about, and awareness of these issues and how they might affect the lives of our respondents across multiple domains, and in direct response to requests from researchers, we believe these items should be added to the Young Adult survey in 2018/19. Sexual and gender minorities, particularly those transitioning into adulthood, are at a significantly increased risk of mortality and morbidity (e.g. substance use, mental health conditions), and thus understanding the key determinants of health among sexual and gender minorities is a fundamental and imperative research aim for ameliorating health disparities at large.

The grant process works as follows at NIH

Anyone wishing to receive grant money that comes to more than \$500k per year has to request permission to apply for a large grant. This process is started well before the grant proposal is submitted. I worked with NICHD Program Officer, Dr. Regina Bures, to produce a 12 page document that she could submit to the Large Grants Committee at NIH. The Large Grant I wrote went to an NICHD Study Section which is comprised of approximately 20 experts across a variety of fields – PhDs and MDs. Three of these experts are assigned the task of reading through the entire proposal carefully and writing up a report, and giving a preliminary score. Those reports and scores are then made available to all study section members who will read the one page specific aims (abstract and summary) of the proposal and the reviewer comments prior to meeting. Study section meetings generally last 2 days and multiple R1 grant proposals reviewed during this time. Each proposal is given a score between 1 and 9 – the NIH description of scoring is given below:

The NIH grant application scoring system uses a 9-point scale for both overall impact scores and scores for individual review criteria. For both types of score, ratings are in whole numbers only (no decimal ratings). NIH expects that scores of 1 or 9 to be used less frequently than the other scores. For the overall impact score, 5 is considered an average score. The reviewers assigned to review each proposal must evaluate the following: Significance, Investigator(s), Innovation, Approach, Environment - and reviewers consider the strengths and weaknesses within each criterion:

High

1 Exceptional 2 Outstanding 3 Excellent

Medium

4 Very Good 5 Good 6 Satisfactory

Low

7 Fair 8 Marginal 9 Poor

After a question and answer period, ALL study section members (with no conflict of interest) score the overall proposal and scores reported range from a **high of 10 to a low of 90**. The Young Adult grant received an overall score of 12!

The Young Adult survey is being funded by Cooksey's R01 Grant from NICHD, plus money that has passed directly to the BLS by NICHD under an Inter-Agency Agreement. An important addition to this data collection effort that was outlined in the latest Grant Proposal, was to add SOGI questions to the Young Adult survey. Clearly a major emphasis of all NICHD research is upon health, and the manner in which both sexual orientation and gender identity develop, has repercussions for health – especially mental health. A reviewer of the Young Adult Grant proposal explicitly noted that a strength of the grant proposal was that “additional questions about gender identity, sexual orientation, resiliency, social isolation, and social cognition, can lead to novel research that can examine how these factors affect, say, social, economic, behavioral, and health outcomes.” Another reviewer wrote that “The new data collection activities are innovative and will increase the range and appeal of the data and encourage even broader use than currently undertaken in the scholarly community in a number of different social science and public health disciplines.”

Many additional voices have been added to support the need to collect SOGI information through surveys. For example:

- The LGBT companion document to Healthy People 2010 “Gay and Lesbian Medical Association (GLMA). Healthy People 2010: A companion document for LGBT health [Internet]. San Francisco: GLMA” written in 2001
http://www.glma.org/_data/n_0001/resources/live/HealthyCompanionDoc3.pdf [PDF - 2.3 MB) highlighted the need for more research to document, understand, and address the environmental factors that contribute to health disparities in the LGBT community. At the beginning of the decade, the following 6 national data systems collected sexual orientation data:

- Behavioral Risk Factor Surveillance Survey (BRFSS)
- National Health and Nutrition and Examination Survey (NHANES)
- National Survey of Family Growth (NSFG)
- Youth Risk Behavior Survey (YRBS)⁸
- National Crime Victimization Survey (NCVS)
- American Community Survey (ACS)

Since then, 2 additional national surveys have begun collecting sexual orientation data:

- National Health Interview Survey (NHIS) – added in 2013
- National Survey of Drug Use and Health (NSDUH) – added in 2015
- As noted on a recent [healthypeople.gov](https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health) website (<https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>) “In order to effectively address LGBT health issues, we need to securely and consistently collect SOGI information in national surveys and health records. This will allow researchers and policy makers to accurately characterize LGBT health and disparities.
- In a letter to the Office of Minority Health Resource Center written on August 1st, 2011 by the President of the American Heart Association “on behalf of the American Heart Association (AHA), including the American Stroke Association (ASA) and over 22.5 million AHA and ASA volunteers and supporters”, Gordon F. Tomaselli expressed pleasure that the Department on Health and Human Services planned to add additional data collection standards in the future

that would address sexual orientation and gender identity, along with concern that this would not be in place for two more years at least.

Both Sylvia Fisher, Director in the Office of Research and Evaluation in the Office of Planning, Analysis and Evaluation, at the Health Resources and Services Administration (HRSA) and Nancy Bates, Senior Researcher for Survey Methodology at the US Census, reiterated the importance of collecting information on SOGI in a large, national survey such as the NLSY79 Young Adult Study. Fisher and Bates are co-chairs of the the FCSM Measuring Sexual Orientation and Gender Identity Research Group. The Federal Committee on Statistical Methodology (FCSM) is an interagency committee dedicated to improving the quality of Federal statistics. The FCSM was created by the Office of Management and Budget (OMB) to inform and advise OMB and the Interagency Council on Statistical Policy (ICSP) on methodological and statistical issues that affect the quality of Federal data. The purpose of the SOGI research group chaired by Fisher and Bates is “to explore the best practices of the measurement of sexual orientation and gender identity (SOGI) in the context of Federal information collections.” In a telephone conversation with OMB staff members, NLS staff members from the BLS, and Elizabeth Cooksey, PI of the NLSY79 Young Adult Survey from CHRR at The Ohio State University on September 19, 2018, Fisher and Bates noted that there was significant interest from multiple US governmental agencies to collect information on SOGI from adolescents and young adults, especially from younger youth, and that there was a substantial public health rationale for doing so. Both also provided feedback on the questions suggested for inclusion in the NLSY79 Young Adult survey and agreed that these questions (presented below) are both a good match to those asked in other national and regional studies, and possess the capacity to advance research in a number of different areas, most notably within public health. They strongly believed that the Federal community would find these data very useful.

Additionally, the previous Office of Management and Budget’s Interagency Working Group for Measuring Sexual Orientation and Gender Identity published three interagency reports in 2016 which lend support to both the approach we propose to take and the questions we propose to ask: https://nces.ed.gov/FCSM/interagency_reports.asp

We submit that collecting SOGI information from the NLSY79 Young Adult survey respondents will not only add to our nation’s understanding of the very important health disparities faced by LGBTQ individuals, but will be especially valuable given that the YA data are longitudinal and have gathered information across a wide range of topics pertinent to this issue for many years: discrimination; neighborhood characteristics; access to health services; tobacco, drug and alcohol use; mental and physical health etc.

A total of 177 adolescents between the ages of 14 and 17 will be fielded in 2018/19. We believe it is very important to ask youth of these ages about both their sexual orientation and their gender identity as adolescence is the stage in the life course when gender identity forms and solidifies, and when most youth will question their sexual orientation in one way or another. Mental health risks can be significantly higher for youth who do not “conform” to traditional sexual orientations or gender identities. For example, in many ways LGBTQ youth are like all youth. However, they also have unique developmental challenges, and are at higher risk for mental health problems (depression, anxiety, substance abuse, suicide, high risk behaviors and eating disorders) and transgendered youth may experience extreme confusion or conflict during adolescence.

The vast majority of the sample is 18 years or older (N=6010 or 96.25 percent).

Data from the Young Adult survey are either open access to any researchers who wish to analyze and publish from them, or restricted access. Over 2000 publications have used the Child and Young Adult data to date. If a researcher wishes to perform their analyses for specific age groups, they can do so by simply picking the age range they want to work with. For the most part, in order to perform any analyses, collapsing single years of age into wider age ranges is necessary, however.

Any personally identifiable information is suppressed. Only select CHRR and NORC staff have access to the names of respondents and there are severe penalties in place for divulging any personally identifiable information to ANYONE who does not have permission to access these data. No Young Adult respondent has ever been re-identified.

The questions we outline below, are in response to feedback from multiple people, including the chairs of the FCSM Research Group on SOGI

Gender Identity questions: These questions are currently placed at the beginning of the YASR section of the questionnaire

1. Do you consider yourself? (asked of respondents ages 14-17)**

A boy

A girl

Transgender

Something else (please specify): _____

1. Do you consider yourself? (asked of respondents ages 18 and older)**

A man

A woman

Transgender

Something else (please specify): _____

1a. What do you mean by something else? _____ (Note that this question would only be asked if "something else" is checked but then left blank.)

** We will ask these different questions for the different ages with an internal age check.

Note: We think that using "man/boy" and "woman/girl" rather than "male" or "female" is a better option, as we are interested in identity rather than biology, and some younger people are bothered by using male/female when talking about identity. Also, our survey system does not, at current, prevent an "other specify" box from being left blank, but we can check internally if it has been left blank and ask a direct question as follow up if needed.

2. 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?

Very feminine

Mostly feminine

Somewhat feminine

Equally feminine and masculine

Somewhat masculine
Mostly masculine
Very masculine

3. 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?

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

Questions 2 and 3 above are measures of gender expression as perceived by others and have been recommended by Wylie and colleagues (Wylie, SA, Corliss, H.L., Boulanger, V., Prokop, L.A. and S.B. Austin. 2010. "Socially Assigned Gender Nonconformity: A Brief measure for Use in Surveillance and Investigation of Health Disparities, *Sex Roles* 63:264-276) for use on studies of health disparities, including statewide and national public health surveillance tools. Fisher and Bates noted that these questions have primarily been used in clinical studies, but that it would be very beneficial to include them on a national survey, especially in conjunction with the more traditional Gender Identity question (see #1 above) as this would enable new and exciting research to be undertaken addressing the extent to which there is overlap between gender identity and gender expression.

Sexual Orientation questions

1. Which of the following best represents how you think of yourself?

Lesbian or gay
Straight, that is not lesbian or gay
Bisexual
Something else (ask question 2)
I don't know (ask question 3)

2. What do you mean by something else?
(verbatim response)

The SOGI information we propose to collect could be used to answer many **research questions** such as:

Does sexual orientation affect educational attainment and labor force participation?

Do lesbian, gay and transgender individuals differ from straight individuals in their wages and income?
How does perceived discrimination play a role in this relationship?

Is there a relationship between sexual orientation and health during young adulthood and if so, does race/ethnicity moderate the relationship?

To what extent does gender identity overlap with gender expression among adolescents and young adults? Does this differ by gender or race/ethnicity?