




## Attachment 7b - Public Comments

## Document Details

<b>Docket ID:</b>	CDC-2016-0069 <a href="#">↕</a>
<b>Docket Title:</b>	National Health Interview Survey 0920-0214 * <a href="#">↕</a>
<b>Document File:</b>	 HTML
<b>Docket Phase:</b>	Notice
<b>Phase Sequence:</b>	1
<b>Original Document ID:</b>	CDC-2016-0069-DRAFT-0002
<b>Current Document ID:</b>	CDC-2016-0069-0002
<b>Title:</b>	National Health Interview Survey Comment from (name) <a href="#">↕</a>
<b>Number of Attachments:</b>	0
<b>Document Type:</b>	PUBLIC SUBMISSIONS * <a href="#">↕</a>
<b>Document Subtype:</b>	<a href="#">↕</a>
<b>Comment on Document ID:</b>	CDC-2016-0069-0001 <a href="#">↕</a>
<b>Comment on Document Title:</b>	National Health Interview Survey 0920-0214 <a href="#">↕</a>
<b>Status:</b>	Posted <a href="#">↕</a>
<b>Received Date:</b>	09/02/2016 * <a href="#">↕</a>
<b>Date Posted:</b>	09/02/2016 <a href="#">↕</a>
<b>Posting Restriction:</b>	No restrictions <a href="#">↕</a>
<b>Submission Type:</b>	API
<b>Number of Submissions:</b>	1 *

## Document Optional Details

<b>Status Set Date:</b>	09/02/2016
<b>Current Assignee:</b>	NA
<b>Status Set By:</b>	Burroughs-Stokes, Kenya LaTrice (CDC)
<b>Comment Start Date:</b>	07/26/2016 <a href="#">↕</a>
<b>Comment Due Date:</b>	09/26/2016 <a href="#">↕</a>
<b>Tracking Number:</b>	1k0-8rob-oui0 <a href="#">↕</a>
<b>Page Count:</b>	1 <a href="#">↕</a>
<b>Total Page Count Including Attachments:</b>	1

## Submitter Info

**Comment:** I don't agree with the data collection. It's intrusive and not necessary. Government needs to step back, not in each further on our personal liberties and information. \*🌐


**First Name:** Lisa 🌐

**Last Name:** Imerman 🌐

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**Organization Name:** 🌐

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## Document Details

<b>Docket ID:</b>	CDC-2016-0069 <a href="#">🔗</a>
<b>Docket Title:</b>	National Health Interview Survey 0920-0214 * <a href="#">🔗</a>
<b>Document File:</b>	 <a href="#">HTML</a>
<b>Docket Phase:</b>	Notice
<b>Phase Sequence:</b>	1
<b>Original Document ID:</b>	CDC-2016-0069-DRAFT-0003
<b>Current Document ID:</b>	CDC-2016-0069-0003
<b>Title:</b>	National Health Interview Survey 0920-0214 Comment from (name) <a href="#">🔗</a>
<b>Number of Attachments:</b>	1
<b>Document Type:</b>	PUBLIC SUBMISSIONS * <a href="#">🔗</a>
<b>Document Subtype:</b>	<a href="#">🔗</a>
<b>Comment on Document ID:</b>	CDC-2016-0069-0001 <a href="#">🔗</a>
<b>Comment on Document Title:</b>	National Health Interview Survey 0920-0214 <a href="#">🔗</a>
<b>Status:</b>	Posted <a href="#">🔗</a>
<b>Received Date:</b>	09/09/2016 * <a href="#">🔗</a>
<b>Date Posted:</b>	09/12/2016 <a href="#">🔗</a>
<b>Posting Restriction:</b>	No restrictions <a href="#">🔗</a>
<b>Submission Type:</b>	API
<b>Number of Submissions:</b>	1 *


## Document Optional Details


<b>Status Set Date:</b>	09/12/2016
<b>Current Assignee:</b>	NA
<b>Status Set By:</b>	Burroughs-Stokes, Kenya LaTrice (CDC)
<b>Comment Start Date:</b>	07/26/2016 <a href="#">🔗</a>
<b>Comment Due Date:</b>	09/26/2016 <a href="#">🔗</a>
<b>Tracking Number:</b>	1k0-8rt6-jagx <a href="#">🔗</a>
<b>Page Count:</b>	1 <a href="#">🔗</a>


**Total Page Count  
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1

## Submitter Info


**Comment:** See attached file(s) \* 


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**Last Name:** Penner 

**ZIP/Postal Code:** 20002

**Email Address:** mweir@NASTAD.org

**Organization Name:** NASTAD 

**Cover Page:** 

September 9, 2016

Information Collection Review Office  
Centers for Disease Control and Prevention  
1600 Clifton Road NE., MS-D74  
Atlanta, Georgia 30329

Docket Number: CDC-2016-0069

To Whom It May Concern:

On behalf of the National Alliance of State & Territorial AIDS Directors (NASTAD), which represents public health officials who administer HIV and hepatitis health care, prevention, education, and supportive service programs funded by state and federal governments, I am writing to express the importance of maintaining questions pertaining to hepatitis B and C screening on the National Health Interview Survey (NHIS).

In the United States, there are approximately 5.3 million people living with chronic hepatitis B (HBV) and/or hepatitis C (HCV), with at least 18,000 deaths annually attributed to hepatitis-related liver disease or liver cancer. Worse, of the estimated two million people living with chronic HBV and three million people living with chronic HCV, 65-75% do not know their diagnosis and are not receiving the appropriate care and treatment. Without appropriate screening, individuals living with hepatitis are unlikely to be diagnosed, linked to and retained in care, increasing their risk of developing liver cirrhosis and/or hepatocellular carcinoma.

Both the Centers for Disease Control and Prevention (CDC) and the U.S. Preventive Services Task Force (USPSTF) released new HBV and HCV screening guidelines. These aligned recommendations from the CDC and USPSTF send a clear signal to health care professionals, policy makers, and the public that screening for HBV and HCV is essential. Even with these recommendations, there are screening disparities among populations that are disproportionately impacted by hepatitis. For this reason, NHIS should continue to include HBV and HCV screening questions on their surveys. NHIS data on HBV/HCV screening will allow stakeholders (states, health departments, policy makers, and providers) to monitor trends and information that is critical to understanding the impacts of the hepatitis

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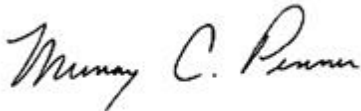
Murray C. Penner (ex officio)  
Executive Director

epidemics. Additionally, these data will allow stakeholders to track progress towards achieving national health objectives, including screening for HBV/HCV, and help determine where best to target resources among communities most impacted.

Collecting data on HBV/HCV screening directly aligns with key actions in the *Action Plan for the Prevention, Care, and Treatment of Viral Hepatitis (the Action Plan)* that is being led by the U.S. Department of Health and Human Services. CDC's leadership is urgently needed to ensure the goals of the Action Plan are realized and that pertinent data is available to stakeholders. Expanded federal investment to support outreach, prevention, and care services for people living with and impacted by hepatitis is paramount to the work of NASTAD and its members, and improving the NHIS is just one of the many avenues to improve our nation's public health and promote the health of our most vulnerable communities.

We appreciate your attention and consideration of these comments. Please do not hesitate to contact me at (202) 434-8090 or by email at [mpenner@NASTAD.org](mailto:mpenner@NASTAD.org) if you have questions related to these comments.


Sincerely,

A handwritten signature in black ink that reads "Murray C. Penner". The signature is written in a cursive, flowing style.

Murray C. Penner  
Executive Director



## Document Details

<b>Docket ID:</b>	CDC-2016-0069 <a href="#">🔗</a>
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<b>Document File:</b>	 <a href="#">HTML</a>
<b>Docket Phase:</b>	Notice
<b>Phase Sequence:</b>	1
<b>Original Document ID:</b>	CDC-2016-0069-DRAFT-0004
<b>Current Document ID:</b>	CDC-2016-0069-0004
<b>Title:</b>	National Health Interview Survey 0920-0214 Comment from (name) <a href="#">🔗</a>
<b>Number of Attachments:</b>	1
<b>Document Type:</b>	PUBLIC SUBMISSIONS * <a href="#">🔗</a>
<b>Document Subtype:</b>	<a href="#">🔗</a>
<b>Comment on Document ID:</b>	CDC-2016-0069-0001 <a href="#">🔗</a>
<b>Comment on Document Title:</b>	National Health Interview Survey 0920-0214 <a href="#">🔗</a>
<b>Status:</b>	Posted <a href="#">🔗</a>
<b>Received Date:</b>	09/10/2016 * <a href="#">🔗</a>
<b>Date Posted:</b>	09/12/2016 <a href="#">🔗</a>
<b>Posting Restriction:</b>	No restrictions <a href="#">🔗</a>
<b>Submission Type:</b>	Web
<b>Number of Submissions:</b>	1 *

## Document Optional Details

<b>Status Set Date:</b>	09/12/2016
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<b>Status Set By:</b>	Burroughs-Stokes, Kenya LaTrice (CDC)
<b>Comment Start Date:</b>	07/26/2016 <a href="#">🔗</a>
<b>Comment Due Date:</b>	09/26/2016 <a href="#">🔗</a>
<b>Tracking Number:</b>	1k0-8rtq-m91k <a href="#">🔗</a>
<b>Page Count:</b>	1 <a href="#">🔗</a>
<b>Total Page Count Including Attachments:</b>	1

## Submitter Info

**Comment:** Interesting and useful website. Good luck! \* 🌐

**First Name:** Anna 🌐

**Last Name:** YALE 🌐

**ZIP/Postal Code:**

**Email Address:**

**Organization Name:** 🌐

**Cover Page:** 



Dear Fundraiser,

I've got good news. If your fundraising results have been something less than dramatic, and the thought of the next fundraiser is driving you up the wall, then this could be the most eye-opening letter you will ever read.

You see, I have spent many months of long hours, late nights and weekends collecting more than 150 of the jealously-guarded secrets professional fundraisers use to create a flood of donations. I read books. I interviewed experts. I hunted high and low for the best, most up-to-date information. I've put what I learned into an ebook, Stress-Free (& Profitable) Fundraising.

My purpose? To take the stress out of your fundraising, and make it much more profitable at the same time.

I know what it's like trying to take time out from your crazy schedule to raise funds. You pull your hair out trying to get ready. Or...you dread the thought of having to come up with another direct mail letter. And trying to corral volunteers? That's like trying to round up a herd of stampeding cattle after a lightning strike. Nobody's available and all you hear is excuses. A lot of the time, you end up doing most or all of the work yourself.

Not to mention all the decisions you have to make. Do we sell the same products we did last year? How do I replace (Judy or Jack) who used to organize all of this for me, but who has moved to another city? Where did I put that folder with the results from last year's fundraiser? And on and on.

You run around like a chicken with its head cut off trying to keep everybody motivated and making sure everything gets done right. And what does it get you? Frazzled nerves and an Extra Strength Excedrin headache. And not always the appreciation you deserve.

Introducing Stress-Free (And Profitable) Fundraising... [good fundraising ideas](#)

There's got to be another way. And there is. A simple solution. A stress-free solution. A much more profitable solution: Stress-Free (And Profitable) Fundraising.

Picture for a moment the way things could be: You use the notes from your last fundraiser to correct past mistakes. You outline a new plan and things go like clockwork. Volunteers happily perform their assigned tasks, without all the in-fighting. Sure, glitches happen. They almost always do. But you handle them smoothly. And thankfully, funds flow in even better than you expected.

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# THE GEORGE WASHINGTON UNIVERSITY

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WASHINGTON, DC

September 23, 2016

Leroy A. Richardson  
Information Collection Review Office  
Centers for Disease Control and Prevention  
1600 Clifton Road NE., MS-D74  
Atlanta, Georgia 30329

Via: Regulations.gov

Re: National Health Interview Survey (OMB Control Number 3501-3520)

Dear Mr. Richardson,

I am pleased to respond to the *Federal Register* notice of July 26, 2016 concerning the National Center for Health Statistics' planned information collection request (ICR) to OMB to conduct the National Health Interview Survey (NHIS) in 2017 through 2019. As a research professor at the George Washington Institute of Public Policy, I provide staff support to the Economic Statistics Committee of the American Economic Association (AEA). Several AEA members have described to NCHS staff their appreciation for and reliance on NHIS data and their support for the survey's continuation.

The NCHS notice in the *Federal Register* says that the 2017 NHIS may include "short, web-based methodological and cognitive testing activities that will inform the upcoming 2018 NHIS questionnaire redesign." From conversations with NCHS staff, I understand the ICR will not specify the nature of these testing activities, that NCHS will submit the specifics of such tests for OMB approval at a later date, and that these subsequent submissions will be considered a "non-material change" to the collection request and so not require public notice.

In light of the importance of the NHIS for economic research, AEA members wish to have an opportunity to provide input on the 2018 redesign, including the design of 2017 tests. Consequently, I ask that the NHIS ICR indicate that 60 days before NCHS submits any 2017 tests for OMB review, it will allow interested AEA members to provide input on the test designs. I would be pleased to facilitate such an exchange.

I appreciate the chance to comment on the importance of the NHIS for economic research and wish NCHS all the best in preparing the ICR.

Sincerely,



Andrew Reamer  
Research Professor

September 26, 2016

Leroy A. Richardson  
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*Re: National Health Interview Survey (NHIS) Revision (OMB No. 0920-0214)*

Dear Mr. Richardson,

The Academy of Nutrition and Dietetics (the “Academy”) appreciates the opportunity to submit comments to the Centers for Disease Control and Prevention (CDC) related to its July 26, 2016 information collection, “*National Health Interview Survey (NHIS) Revision.*” Representing more than 100,000 registered dietitian nutritionists (RDNs),<sup>1</sup> nutrition and dietetic technicians, registered (NDTRs), and advanced-degree nutritionists, the Academy is the largest association of food and nutrition professionals in the United States and is committed to improving the nation’s health through food and nutrition across the lifecycle.

The Academy supports the NHIS as necessary for the proper performance of the functions of the CDC and will have significant practical utility. We agree with the CDC that the NHIS is “instrumental in providing data to track health status, health care access, and progress toward achieving national health objectives.”<sup>2</sup> As the information collection notes, the NHIS is “the single most important source of statistics to track progress toward the National Health Promotion and Disease Prevention Objectives [and] ‘Healthy People 2020,’” two vitally important government initiatives.

The Academy supports the inclusion of the proposed supplemental questions for 2017 and the continued and enhanced supplemental topics from 2016. Specifically, we applaud the focus on topics in which nutrition plays a fundamental role in preventing and treating. Many of these topics have been included: alternative and integrative medicine, cognitive disability, and receipt of culturally and linguistically appropriate health care services, epilepsy, Crohn’s disease and colitis, diabetes, disability and functioning, family food security, heart disease and stroke treatment and prevention, and children’s mental health. These are critical topics and the importance of good nutrition in their prevention and amelioration cannot be overstated.

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<sup>1</sup> The Academy recently approved the optional use of the credential “registered dietitian nutritionist (RDN)” by “registered dietitians (RDs)” to more accurately convey who they are and what they do as the nation’s food and nutrition experts. The RD and RDN credentials have identical meanings and legal trademark definitions.

<sup>2</sup> National Health Interview Survey. National Center for Health Statistics website, updated September 13, 2016. Available at <http://www.cdc.gov/nchs/nhis/index.htm>. Accessed September 22, 2016.

We offer the below suggestions for improvement and clarification as the final survey is developed:

- Family Questionnaire
  - Module 4, Section Name “Health Status and Limitation of Activities:”
    - Question ID “FHS.270,” Page 39: Include answer code related to swallowing or chewing difficulty.<sup>3</sup>
    - Question ID “FHS.350,” Page 73: Include answer code related to swallowing or chewing difficulty.<sup>4</sup>
- Child Questionnaire
  - Module 11, Section Name “Child Conditions, Limitation, Health Status:”
    - Question ID “CHS.115\_10.000,” Page 70: The question text may be made more clear if were to read “During the past 12 months, has [fill: S.C. name] had any difficulty speaking, such as the following conditions...”
    - Question ID “CHS.270\_00.000,” Page 77: By revising the question to ascertain whether there is difficulty (or not) seeing at certain times of the day, the question could help capture conditions such as severe vitamin A deficiency.<sup>5</sup>
- In questions related to family food security, the Academy understands that the tool has been validated by the USDA ERS without the incorporation of religious or cultural reasons, but we encourage an option to clarify that a limitation of meals or restriction of consumption may be for religious or cultural reasons (*e.g.*, Ramadan).
- Recognizing the efforts to develop the questionnaire in multiple languages, the Academy encourages the CDC to ensure the design of the NHIS accounts for differences in health literacy and clarity among multicultural respondents.
- Although it is difficult to ascertain the extent to which new technologies will be utilized in the NHIS, the Academy suggests the burden of collection could be minimized through the use of computer kiosks, handheld devices, and the use of pictorial formats.

The Academy sincerely appreciates the opportunity to offer comments regarding the NHIS and is grateful for the important work the CDC is undertaking. Please contact either Jeanne Blankenship by telephone at 312-899-1730 or by email at [jblankenship@eatright.org](mailto:jblankenship@eatright.org) or

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<sup>3</sup> See, Heiss CJ, Goldberg L, Dzarnoski M. Registered dietitians and speech-language pathologists: an important partnership in Dysphagia management. *J Am Diet Assoc.* 2010;110(9):1290, 1292-3.

<sup>4</sup> *Ibid.*

<sup>5</sup> See, Nordin SM, Boyle M, Kemmer TM. Position of the academy of nutrition and dietetics: nutrition security in developing nations: sustainable food, water, and health. *J Acad Nutr Diet.* 2013;113(4):581-95.

Pepin Tuma by telephone at 202-775-8277 ext. 6001 or by email at [ptuma@eatright.org](mailto:ptuma@eatright.org) with any questions or requests for additional information.

Sincerely,



Jeanne Blankenship, MS RDN  
Vice President  
Policy Initiatives and Advocacy  
Academy of Nutrition and Dietetics



Pepin Andrew Tuma, Esq.  
Senior Director  
Government & Regulatory Affairs  
Academy of Nutrition and Dietetics



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September 26, 2016

Jeffrey M. Zirger  
Information Collection Review Office  
Centers for Disease Control and Prevention  
1600 Clifton Road NE., MS-D74  
Atlanta, GA 30329

**RE: Comment Request for Project: National Health Interview Survey (NHIS)  
Docket No. CDC-2016-0069**

The Trevor Project is pleased to have the opportunity to deliver comments regarding the National Health Interview Survey (NHIS). The Trevor Project is the leading national nonprofit organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth through age 24. We work to save young lives through our accredited free and confidential lifeline; our secure instant messaging services which provide live help and intervention; our social networking community for LGBTQ youth; and our in-school workshops, educational materials, online resources, and advocacy. Our comments will focus on three main recommendations: the need to add a suicide screening tool to the survey; the need to include sexual orientation and gender identity questions; and privacy concerns for youth. Implementing these recommended changes will allow the Centers for Disease Control and Prevention (CDC) to get a more accurate and comprehensive understanding of the public health experiences of the United States population.

**The Importance of Suicide Screening**

Suicide is the second leading cause of death among youth nationally<sup>i</sup> and the tenth leading cause of death overall in the United States.<sup>ii</sup> It is a public health issue that is preventable. Indeed, the CDC states in a violence prevention handout that “the economic and human cost of suicidal behaviour to individuals, families, communities and society makes suicide a serious public health problem.”<sup>iii</sup> Given that the NHIS focuses on public health issues, it is imperative that a suicide screening tool is added to the survey for adults and youth. We commend the CDC for including some coverage of mental health issues within the survey. Specifically the survey contains a set of questions for youth and adults that serve as a depression screening tool. While this information is extremely helpful and can be an important component in suicide prevention, it does not measure past or current suicidal ideation or attempts. In order to gain full insight into suicide the NHIS must include suicide screening questions. Obtaining this information on a national scale can build the data we have and greatly increase our ability to study and understand suicide, including minority populations

such as LGBTQ individuals. The NHIS and other national surveys have made great strides in gathering data on mental health issues, however it is crucial that we expand that to specifically focus on suicide. There is a severe lack of research and surveillance on suicide in the LGBTQ community and adding a suicide screening tool (along with sexual orientation and gender identity questions) would help ameliorate this.

### **Federal Surveys: The Importance of Sexual Orientation and Gender Identity Data**

Measuring LGBTQ people in research and large-scale government surveillance systems has received a lot of attention recently. This is largely due to the clear and considerable research that indicates the LGBTQ population faces significant health disparities and has a higher risk of many negative health outcomes, including cancer, obesity and many others. Research shows that LGB youth often suffer from disparate rates of substance abuse, depression, suicidal ideation, harassment, abuse, sexually transmitted diseases, including HIV, and unintended pregnancy.<sup>iv</sup> Yet the majority of population-based surveys and surveillance systems fail to include basic demographic questions such as sexual orientation and gender identity (SOGI) measures. The CDC and several other federal government agencies have recognized this gap and have done considerable work to include SOGI questions in regularly occurring surveys but there is still a significant amount of work to be done, including modifications to the NHIS.

There is great movement occurring to finally recognize the importance of one's sexual orientation and gender identity as basic demographic information, and SOGI questions should be included in all population based surveys. Indeed, the Obama Administration has devoted significant attention to these issues recently with the creation of an inter-agency task force to determine appropriate wording for surveys. Since that task force has ended, we understand that the administration is now pushing federal agencies such as Health & Human Services and the CDC to determine appropriate SOGI question wording to add to the surveys they administer. The Trevor Project would like to reiterate the importance of obtaining this data and normalizing the collection of it by adding SOGI questions to the demographics section of every survey.

With the inclusion of SOGI questions on the NHIS we can obtain far more data and gain a better understanding of the LGBTQ population, including youth and adults. This information will in turn allow for the development of more targeted interventions and better prevention programs and policies.

The Trevor Project

Los Angeles - 8704 Santa Monica Blvd. Suite 200 West Hollywood, CA 90069

New York - 575 8<sup>th</sup> Ave #501 New York, NY 10012

DC - 1200 New Hampshire Ave. NW Suite 300 Washington, DC 20036

p 310.271.8845 | f 310.271.8846 [www.thetrevorproject.org](http://www.thetrevorproject.org)

## **Adoption of Best Practices for Sexual Orientation and Gender Identity Demographic Questions (Adult Survey)**

We thank the CDC for already including a sexual orientation question on the NHIS. The question wording keeps with best practices in obtaining SOGI information. The NHIS does, however, need to add a measure to determine gender identity.

LGBTQ researchers and advocates have spent years researching and testing appropriate question wording to include on surveys to obtain SOGI demographic data. Testing suggests that the “two step” approach to asking about sex assigned at birth and gender identity, recommended below, yields the most accurate results and this is recognized as the gold standard question in determining gender identity.<sup>v</sup> In keeping with best practices in the field, our recommended data collection measures to improve the quality, utility, and clarity of information collected in the NHIS are as follows:

(1) The adult survey should be modified so that the interviewer asks about the respondent’s “sex assigned at birth” rather than recording the interviewee’s “gender.” The question should include the following options:

- a. Male
- b. Female

(2) The adult survey needs to include a follow-up question asking about the respondent’s “current gender identity” and include the following options:

- a. Male
- b. Female
- c. Trans male/Trans man
- d. Trans female/Trans woman
- e. Genderqueer/Gender non-conforming
- f. Different identify (please specify): \_\_\_\_\_
- g. Prefer not to answer<sup>vi</sup>

To provide for situations in which the interviewer is asked about the definition of “trans” or “gender non-conforming,” we recommend the inclusion of interviewer notes with language modeled on the following notes from the gender identity module of the Behavioral Risk Factor Surveillance System:

### **INTERVIEWER NOTE: 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

The Trevor Project

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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.

**INTERVIEWER NOTE: 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.<sup>vii</sup>

To provide for situations in which the interviewer is asked about the definition of “gender identity,” we recommend the inclusion of interview notes with language modeled on the following adaptation from the Gender Identity in U.S. Surveillance group’s best practices:

**INTERVIEWER NOTE: If asked about the definition of gender identity:**

Gender identity refers to a person’s internal sense of themselves (how they feel inside) as being male, female, or another gender. This may be different or the same than a person’s assigned sex at birth.<sup>viii</sup>

It is critical that gender identity and sex assigned at birth be self-reported by clients rather than assumed or guessed by the interviewer. Interviewers’ assumptions about the gender identity and sex assigned at birth of interviewees may be incorrect, particularly for transgender and gender non-conforming clients, overlooking a particularly vulnerable population and compromising the validity of the data. The Gender Identity in U.S. Surveillance (GenIUSS) Group, the authority on current best practices for identifying transgender and gender non-conforming respondents in population-based surveys, recommends self-reporting as the scientifically rigorous procedure for gathering information on sex assigned at birth and gender identity.<sup>ix</sup>

## **Youth Survey**

Research shows that LGBTQ youth, as well as adults, face significant health disparities, but we have very little surveillance data regarding these disparities. We did recently receive some new surveillance data from the CDC’s Youth Risk Behavior Survey (YRBS), which for the first time ever received nationally representative results for sexual minority youth. Analysis from the YRBS found that: LGB youth seriously contemplate suicide at almost *three times* the rate of heterosexual youth; LGB youth are almost *five times* as likely to have actually

The Trevor Project

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attempted suicide; and of all the suicide attempts made by youth that were significant enough to require medical treatment, LGB youth's attempts were almost *five times* as likely to require medical treatment than heterosexual youth.<sup>x</sup> While this data is very useful, the questions asked on the YRBS do not constitute a complete suicide screening instrument and we therefore recommend that the youth survey of the NHIS include suicide screening questions as well.

In order to uncover health disparities in the LGBTQ youth the NHIS must add SOGI questions for youth. We recommend that the sexual orientation question currently asked on the NHIS for adults should be used for youth, including the same wording. The sexual orientation question should read:

- (1). Do you think of yourself as:
1. Gay/Lesbian, that is [not straight]
  2. Straight, that is not [gay/lesbian or gay]
  3. Bisexual
  4. Something else
  5. I don't know the answer
  6. Refused to answer

Because the field of social science research has not yet identified a gender identity question that yields accurate results for youth populations, we recommend the CDC use the most current gender identity question asked on the YRBS. This question is reviewed after each survey is conducted and is consistently tweaked to obtain the most accurate results.

### **Privacy Concerns for Youth**

In order to add SOGI questions for youth the survey administration method *must be altered* in order to ask these questions in a way that will be safe for all youth. The survey is currently administered in the presence of an adult parent or guardian, potentially putting the youth in uncomfortable or unsafe positions to disclose personal information. Even if interviewers ask parents/guardians to step outside the room while youth complete their survey it's highly possible that they may overhear answers. The same may be true if the questions were asked over the phone. We recommend assessing the feasibility of asking youth questions online or in another setting to allow for the greatest privacy for youth. It is of the utmost importance that youth have privacy when answering SOGI questions because there is potential for rejection, psychological harm and even violence when parents/guardians learn that their child is or may be LGBTQ. Despite recent advances towards equal rights for the LGBTQ community, societal attitudes towards LGBTQ youth in particular vary

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greatly, and many adults still disapprove or do not accept their child's LGBTQ identity; this can have devastating consequences. For example, LGB youth who come from highly rejecting families are over eight times as likely to have attempted suicide than their LGB peers who reported no or low levels of family rejection.<sup>xi</sup> Additionally, 40% of homeless youth are LGBTQ and the number one reason LGBTQ youth cited as the reason for being homeless was family rejection.<sup>xii</sup> While SOGI data for youth is important to obtain, we only recommend that it be gathered if these privacy concerns can be addressed.

### **Conclusion**

The need to implement SOGI questions on the NHIS for youth and adults is paramount and The Trevor Project thanks the CDC for taking steps in the NHIS and other surveys to include SOGI measures. Data is a critical when advocating for programs and policies to meet the needs of youth, and if Trevor is going to achieve its mission of ending LGBTQ youth suicide, the data obtained by the NHIS would be invaluable. The data will also better inform the CDC's and other agencies' prevention efforts. We look forward to more inclusive data collection so we as a society can better address suicide and other major public health concerns. Thank you again for the opportunity to provide comments and we look forward to our continued collaboration.

If you have any questions regarding these comments, please contact Amy Loudermilk, Associate Director of Government Affairs at 202-391-0834 or [Amy.Loudermilk@TheTrevorProject.org](mailto:Amy.Loudermilk@TheTrevorProject.org).

Sincerely,



Abbe Land  
Executive Director & CEO

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<sup>i</sup> CDC, NCIPC. Web-based Injury Statistics Query and Reporting System (WISQARS) [online]. (2010) {2013 Aug. 1}. Available from: [www.cdc.gov/ncipc/wisqars](http://www.cdc.gov/ncipc/wisqars).

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- <sup>ii</sup> American Foundation for Suicide Prevention. Suicide Statistics. Retrieved from: <https://afsp.org/about-suicide/suicide-statistics/>
- <sup>iii</sup> CDC. Suicide Prevention: A Public Health Issue. Retrieved from: [https://www.cdc.gov/violenceprevention/pdf/asap\\_suicide\\_issue2-a.pdf](https://www.cdc.gov/violenceprevention/pdf/asap_suicide_issue2-a.pdf)
- <sup>iv</sup> Hauser, D. (2010). School Environment, Health Risk Behavior and Academic Failure: Linked for LGBT Youth. Washington, DC: Advocates for Youth. Retrieved from: <http://www.advocatesforyouth.org/storage/advfy/documents/yrbs-glb.pdf>
- <sup>v</sup> The GenIUSS Group. (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute.
- <sup>vi</sup> Ibid.
- <sup>vii</sup> Baker, Kellan, and Margaret Hughes. "Sexual Orientation and Gender Identity Data Collection in the Behavioral Risk Factor Surveillance System." Center for American Progress. Center for American Progress, 29 Mar. 2016. Web. 14 June 2016.
- <sup>viii</sup> The GenIUSS Group. (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents.
- <sup>ix</sup> The GenIUSS Group. (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents.
- <sup>x</sup> Kann, Laura. O'Malley Olsen, Emily. McManus, Tim. et al. Sexual Identity, Sex of Sexual Contacts, and Health-Related Behaviors Among Students in Grades 9-12: Youth Risk Behavior Surveillance. *MMWR Surveill. Summ* 2016;65.
- <sup>xi</sup> *Family Acceptance Project™*. (2009). *Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. Pediatrics. 123(1), 346-52.*
- <sup>xii</sup> Durso, L.E., & Gates, G.J. (2012). Serving Our Youth: Findings from a National Survey of Service Providers Working with Lesbian, Gay, Bisexual, and Transgender Youth who are Homeless or At Risk of Becoming Homeless. Los Angeles: The Williams Institute with True Colors Fund and The Palette Fund.

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