



June 29, 2017

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RE: National Mental Health Study Field Test Comment Request (2017-08993)

Dear Ms. King:

The Trevor Project is pleased to have the opportunity to deliver comments regarding the proposed National Mental Health Study (NMHS) Field Test. We applaud the Substance Abuse and Mental Health Services Administration (SAMHSA) for dedicating its time to creating and implementing surveys concerning mental health issues and for seeking comments to further enhance the quality and clarity of information being collected. We write to advocate for the inclusion of a two-part gender identity question and a sexual orientation question to adolescent and adult questionnaires. We will also detail several critical changes that are needed regarding the sections on suicidality. Adding sexual orientation and gender identity (SOGI) questions will provide a better understanding of the mental health challenges facing lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) youth and adults, a population we already know experiences great health disparities. Making our suggested edits to the suicide section will bring the survey in alignment with proper messages on suicide and will ultimately help respondents better understand the questions without feeling stigmatized.

Importance of Data Collection

The Trevor Project is the leading national nonprofit organization providing crisis intervention and suicide prevention services to LGBTQ young people 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. A leader and innovator in suicide prevention, Trevor focuses on an important, at-risk population: LGBTQ youth. LGBTQ people experience significant health disparities, including increased

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suicidality. Suicide is the second leading cause of death among young people ages 10 to 24¹, and LGB youth are four times more likely and questioning youth are three times more likely than their heterosexual counterparts to attempt suicide.² 40% of transgender adults report having made a suicide attempt, and 92% of these individuals report having made a suicide attempt before the age of 25.³ In addition, LGBTQ individuals are more likely than non-LGBTQ people to experience a mental health condition such as generalized anxiety disorder or major depression.⁴ Collecting data about the LGBTQ population, including LGBTQ youth, in the NMHS Field Test is crucial to better understanding and addressing the link between this vulnerable group, mental illness, and suicide.

Data from the proposed NMHS would inform prevention programs, treatment facilities, and the distribution of relevant resources on a state, federal, and local level. LGBTQ youth especially suffer disparately high rates of mental illness, and are six times more likely than their non-LGBTQ peers to experience symptoms of depression.⁵ Therefore, collecting sexual orientation and gender identity data on youth under 18 is critical to best provide the appropriate resources for at-risk youth.

Federal Surveys: Sexual Orientation and Gender Identity Questions

During the past several years there has been a trend towards adding SOGI demographic questions to publicly administered surveys. This movement reflects the clear and considerable research indicating the LGBTQ population faces a disproportionately high risk of experiencing a variety of negative health outcomes. And yet, the majority of population-based surveys and surveillance systems fail to include basic demographic questions such as SOGI measures. SAMHSA and several other federal government agencies, as well as numerous state and local governments, have made considerable efforts to respond to the calls from advocates and researchers to include SOGI questions in regularly occurring surveys, but a great deal of work remains. Some surveys that do include SOGI questions include: the National Crime Victimization Survey and related School Crime Supplement; School Survey on Crime & Safety; School Associated Violent Death Survey, and the Behavioral Risk Factor Surveillance System (BRFSS). While we greatly appreciate these efforts, there is, however, still a striking lack of information collected on transgender people and on LGBTQ youth. This serious omission is at odds with research indicating that transgender people and LGBTQ youth are vulnerable to a variety of health disparities, and that gender non-conforming LGBTQ youth may be even more at risk for mental illnesses than their gender conforming LGBTQ peers. What little research we do have on transgender people and LGBTQ

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youth underscores the grave need for more data collection on these populations. The time has come for all federal surveys to measure the gender identity and sexual orientation of youth and adult respondents.

One barrier to addressing this lack of SOGI data collection is the ill-informed opinion that it is not age-appropriate to ask minors about their sexual orientation or gender identity. There is no evidence that mentioning sexuality-related topics to children and adolescents (in an age-appropriate manner) will cause them to engage in sexual behavior, or somehow influence their sexual orientation or gender identity. According to the American Psychological Association, becoming aware of sexual feelings, including questioning one's sexuality, is a normal developmental task of adolescence.⁶ Asking youth about their sexual orientation and gender identity is crucial to understanding and addressing the disproportionate negative health outcomes that LGBTQ youth face and does not affect their perception of their own sexual orientation and/or gender identity. Large-scale school-based surveys around the world have been asking adolescents about their sexual orientations since the 1980s with no negative impacts reported.⁷ Similarly, according to Pew Research most transgender respondents reported that they first felt their gender was different from their birth sex before puberty and that 12 is the median age at which LGB adults first felt they might have a sexual orientation other than heterosexual.⁸ Therefore we recommend SOGI questions to be asked of youth ages 12-18.

Adoption of Best Practices for Gender Identity and Sexual Orientation Demographic Questions

The American Institute for Research, The Williams Institute, The Gay, Lesbian & Straight Education Network, The National Center for Transgender Equality, and other LGBTQ organizations have spent years researching and testing appropriate language for survey questions designed to obtain demographic data on sexual orientation and gender identity. Research suggests that the “two step” approach to asking about sex assigned at birth and gender identity, recommended below, yields the most accurate results and is recognized as the gold standard question to determine gender identity.⁹ 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 NMHS are as follows:

(1) In Attachment A-1, “Adult and Adolescent Questionnaire Specifications”, QD01 of the Core Demographics section asks the interviewer to “record respondent’s

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gender.” It is unclear whether this question is asking about the person’s sex assigned at birth or current gender identity. Given the confusion, we recommend the question be removed. A better question to include in the beginning of the survey when the respondent’s gender identity is trying to be ascertained is a question asking about the respondent’s “current gender identity” with the following responses:

1. Male
2. Female
3. Trans male/Trans man
4. Trans female/Trans woman
5. Genderqueer/Gender non-conforming
6. Different identify (please specify): _____
7. Prefer not to answer

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 BRFSS:

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 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.

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

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being male, female, or another gender. This may be different or the same than a person's assigned sex at birth.

The recognized best practice before asking about a respondent's current gender identity is to ask about the respondent's "sex assigned at birth". We recognize this question is asked in a later section which should suffice.

(2) We understand that the NMHS has a similar gender identity question, U1c, later on in the survey; however, the introductory phrasing is confusing (i.e. "how do you think of yourself?") and the responses are not aligned with current recommend best practices. Therefore, we recommend that question U1c as currently written be eliminated in favor of the above question and phrasing. In addition, it will not be necessary to ask this question again later on in the interview.

(3) Questions regarding the respondent's sexual orientation and sex assigned at birth, QU1a and U1b, are aligned with best practice standards and we applaud SAMHSA for including them.

(4) We strongly urge SAMHSA to include the same questions (sex assigned at birth, current gender identity and sexual orientation) for adolescents. As discussed above, it is perfectly developmentally appropriate to ask these questions of young people beginning at age thirteen. Additionally, the data is sorely needed to help prevent LGBTQ youth suicide as well as other negative health outcomes.

Risk Management and Best Practices When Asking Questions On Suicide

Unfortunately, death by suicide is very common; it is the tenth leading cause of death in the United States.¹⁰ As a result, many people have been personally impacted by suicide, whether they have experienced the suicide attempt of a friend or family member, or have attempted suicide themselves. While asking people questions about suicide does not directly cause someone to become suicidal, it is important to recognize that discussing suicide can be emotional and even distressing, to individuals affected by suicide. Cheryl King, a leading expert on research pertaining to suicide and Director of the University of Michigan Youth Depression and Suicide Prevention Research Program, recommends that for studies of which the primary aim is not related to suicide risk, and respondents are not known to be at a generally high-risk for suicide (such as this survey), researchers should, at a minimum, have a system in place to provide subjects with mental health

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resource information.¹¹ Considering the relatively low suicide risk of the average participant in the NMHS and the nationally standardized nature of the survey, we recommend the inclusion of the National Suicide Prevention Lifeline (1-800-273-TALK) before and after question sections pertaining to suicide, for all respondents including adults and adolescents. Clearly including this information in the survey is critical so that in the event a respondent does experience suicidal thoughts when asked about their history of suicide, they will have easy and immediate access to the Lifeline's trained crisis counselors. Although the survey does mention in some sections that the respondent will receive information regarding a suicide hotline, there is no such information listed at the end of the suicide section.

(5) The following suggested language should be included at the end of each section on suicide:

If you are considering suicide, please call the National Suicide Prevention Lifeline number (1-800-273-8255) to speak with a trained counselor. If you are a lesbian, gay, bisexual, transgender, queer or questioning young person under the age of 25 and are having thoughts of suicide please call The Trevor Project (1-866-488-7386) to speak with a trained counselor.

The introductory paragraph contained in the "suicidality" section of attachment A-1 needs to be edited to improve the clarity and consistency of the survey. The question is listed below with the suggested tracked changes:

The next few questions are about thoughts of ~~hurting~~ **killing** yourself. At the end of this interview you will receive a hotline number you can call if you ever feel you need to talk to someone about ~~mental health issues~~ **these thoughts**.

(6) The word "hurting" should be removed and instead replaced with the word "killing" because the first nineteen questions (SD15 - SD290th) are about suicide and not about self-directed non-suicidal harm of one's self. The last four questions of the "suicidality" section do ask about non-suicidal, self-direct harm and may benefit from similar introductory language such as "the next few questions are about actions taken to hurt one's self without wanting to die."

(7) The phrase "mental health issues" should be removed and replaced with the phrase "these thoughts" because there are certainly individuals who may need to talk to someone about thoughts of suicide but who may not believe or equate that with needing to talk about "mental health" issues. Working in the field of suicide

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prevention, we know that our language choices matter and we wouldn't want to unknowingly put up a barrier to someone receiving necessary care.

Our final recommended edits apply to questions SD22 and SD27, which differ only in asking about the first time and the last time something happened. The question is listed below with the suggested tracked changes:

Which of the three statements below best describes your situation when you tried to kill yourself the first time?

1. You made a serious attempt to kill yourself and it was only luck that you did not ~~succeed~~-die.
2. You tried to kill yourself but knew, ~~or suspected~~, that the method was not foolproof.
3. Your attempt was a cry for help, that is, you did not intend to die.

(8) The word "succeed" must be replaced with the word "die" to comply with safe messaging guidelines. Although we are sure this is an oversight by SAMHSA we do insist for obvious reasons that suicide not be discussed in terms of being "successful" or not.

(9) One of the basic concepts of survey methodology is that the responses to each question should be exhaustive, meaning that the responses must account for every possible answer. Without inserting the words "or suspected" in option two of the above question, the question does not meet the exhaustive criteria. This is especially important given that there may be a sizable number of individuals who hoped but didn't truly know if the method they choose to attempt suicide was "foolproof."

Conclusion

We appreciate this opportunity to comment on the quality, utility, and clarity of information collected in the National Mental Health Study Field Test. Inclusion of sexual orientation and gender identity demographic questions across all ages in this questionnaire will contribute greatly to the knowledge and understanding on mental health and treatment, and allow for more informed prevention and intervention efforts. Upon accepting our suggested edits regarding the suicidality section we are confident that the survey will be administered in the safest and most appropriate way. We greatly anticipate the results of this important field test and hope that it may lead to a landmark new federal survey on the mental health of Americans. If you should have any questions regarding these comments, please contact Amy

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Sincerely,



Amit Paley
CEO & Executive Director

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