



July 15, 2020

RE: Response to 60-Day Federal Registry Notice Comment on the National Death Reporting System Proposed Data Collection for Public Comment and Recommendations (0920-0607)

Dear [REDACTED] request [REDACTED]

[REDACTED] Thank you very much for your comments and recommendations regarding our Federal Registry Notice. The National Violent Death Reporting System (NVDRS) team at CDC is always glad to receive feedback about our system from organizations and institutions such as yours that do critically important work to promote lesbian, gay, bisexual, transgender, and questioning (LGBTQ) health and wellness. The NVDRS team seeks to continually improve our system to achieve the most accurate, inclusive, and representative surveillance data possible to inform prevention efforts and serve our partners and data users. [REDACTED]

We recognize that LGBTQ persons are an historically underserved population, and really appreciate your suggestions to improve and enhance the collection of information for these decedents within NVDRS. Accurate and representative data will also allow for describing the circumstances surrounding such deaths and the risk factors that disproportionately affect LGBTQ persons. The NVDRS team at CDC has made capturing sexual orientation and gender identity (SOGI) data about individuals who experience violence in the United States a priority, and we have undertaken several activities to be able to better capture information for LGBTQ decedents.

Responses to the specific points you raised are found below.

Suggested Changes to NVDRS Coding

Sexual Orientation

Thank you for bringing up the constraints of the sexual orientation variable. Sexual orientation is currently defined in NVDRS as whether the victim self-identified as heterosexual, gay, lesbian, or bisexual based on interviews of friends, family or acquaintances. As you know, NVDRS uses information from three sources (death certificates, coroner/medical examiner reports, and law enforcement reports). The coroner/medical examiner reports and the law enforcement report are used by trained abstractors to compose narratives for the system that describe the incident. The data abstractors are asked to only code this sexual orientation variable if the information is reported in the source documents. Eyewitnesses or key informants who provide



information that is reported in the documents may or may not be aware of a decedent's sexual orientation.

Given the challenges with capturing SOGI status, CDC is exploring adding another value to the sexual orientation variable that will capture decedents who were other sexual minorities. 'Unspecified or Other sexual minority' would be added, to include all other sexual minorities that may not fit into the categories of gay, lesbian, or bisexual. Some examples might include; queer and questioning. By expanding the variable in this way, CDC may be able to better identify and describe sexual minorities. However, it is unknown as to how often VDRS abstractors may see this information in reports.

Sex of Partner

Thank you for suggesting that the variable 'sex of partner' be modified to provide a more complete picture of victims' behavior, by indicating whether victims' partners were same-sex only, different-sex only, or both same- and different-sex.

We agree that expanding this variable would be of great benefit. As a first step, we would like to discuss this with the CDC NVDRS team and the VDRS abstractors to find out if and how often they see this in source documents (coroner/medical examiner reports and law enforcement reports). We agree that modification to capture behavioral evidence of sexual orientation would be useful if this is available.

Sex and Transgender Status

Thank you for your suggestions about how to capture sex and transgender status. The information regarding sex comes from the U.S. Standard Death Certificate, and sex at birth is not a variable that is readily available. In doing analysis on these variables, CDC found that there were inconsistencies in how sex is captured on the death certificate. Currently, information regarding transgender status comes from either the coroner/medical examiner report or law enforcement report, or comparing the sex as noted on the death certificate to information that is provided by a friend/family member, or other informant. Per the NVDRS guidance, an individual is identified as transgender if he or she identified as transgender or family, friends, physician or other acquaintances identified the individual as transgender. Additionally, if the victim was undergoing or had undergone sex reassignment surgery, hormone therapy to support a sex reassignment surgery, or some other mention of gender transition, the person would be considered transgender. Next steps address the challenge of adequately identifying LGBTQ individuals may include expanding on the transgender variable or creating a new variable to better capture other gender minorities who may not be represented in NVDRS. This would be done in collaboration with our partners and VDRS jurisdictions.



Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30341-3724

Additionally, we recommend that researchers using NVDRS data should examine the law enforcement and coroner/medical examiner narratives for keywords that might indicate that the victim was LGBTQ. This would be done in addition to using the sexual orientation, transgender, and sex of partner variables.

Partnerships

We are also working with national partners on the issue of capturing SOGI status in NVDRS. In recent years, CDC NVDRS has reinvigorated and strengthened its partnerships with various organizations, including the Trevor Project, National Association of Medical Examiners (NAME), the National Association for Public Health Statistics and Information Systems (NAPHSIS), and more recently, the International Association of Coroners and Medical Examiners (IACM&E). Our colleagues at CDC's National Center for Health Statistics (NCHS) are also our partners, and we engage in discussions with them about issues regarding how to better capture information among this population in the National Vital Statistics System (NVSS). We are using these ongoing partnerships as an opportunity to enhance SOGI data collection.

In May of 2019, at the NVDRS Reverse Site Visit Annual Meeting, CDC convened a panel of experts from NAME, SAVE (Suicide Awareness Voices of Education), and the Trevor Project. There were presentations from each of the organizations and a discussion with the audience of VDRS state staff and other NVDRS partners about how best to ascertain the sexual orientation/gender identity of decedents, and how to address potential barriers to gathering such information. The recommendation was made to further expand our SOGI variables to be more inclusive of other sexual and gender minorities not currently being captured by the NVDRS. This led CDC to explore revisions to the system to make this possible. Additional next steps include collaborating with NAME and the Trevor Project on training and education for coroner and medical examiners on the routine and systematic collection of SOGI data.

Once again, thank you for your interest in NVDRS. We appreciate your suggested improvements to our variables and response categories to enhance the capacity of NVDRS to capture information among LGBTQ persons. Your suggestions are noted and will be discussed with the CDC NVDRS Team, VDRS Principal Investigators, and VDRS abstractors as we modify and improve our data collection fields. We have monthly NVDRS Coding Workgroup calls and will use these as an opportunity to explore these options. These are all good points, and we truly appreciate your perspective.

If you have any additional questions or comments, please feel free to contact me at (770) 488-0049 or JBlair@cdc.gov

Sincerely,



Centers for Disease Control
and Prevention (CDC)
Atlanta, GA 30341-3724



Janet M. Blair, PhD MPH
Team Lead, Mortality Surveillance Team
Surveillance Branch
Division of Violence Prevention
National Center for Injury Prevention and Control
Centers for Disease Control and Prevention

