



# HHS Public Access

Author manuscript

*Am J Public Health*. Author manuscript; available in PMC 2019 March 20.

Published in final edited form as:

*Am J Public Health*. 2019 February ; 109(2): 192–194. doi:10.2105/AJPH.2018.304891.

## Challenges and Opportunities for Modernizing the National Violent Death Reporting System

**Vickie M. Mays, PhD, MSPH<sup>#</sup>** and

Department of Psychology, University of California Los Angeles, CA.

Department of Health Policy and Management, UCLA Fielding School of Public Health, Los Angeles, CA.

**Susan D. Cochran, PhD, MS<sup>#</sup>**

Department of Epidemiology, UCLA Fielding School of Public Health, Los Angeles.

Department of Statistics, University of California Los Angeles.

<sup>#</sup> These authors contributed equally to this work.

---

In this issue of *AJPH*, Haas et al. (p. 255) describe an effort to improve the coding of self-identified sexual orientation and gender identity (SOGI) status among decedents in the National Violent Death Reporting System (NVDRS). As they illustrate, this is no easy task. Unlike most public health surveys for which living respondents can be queried, the NVDRS reporting process begins at death. Vital registrants at the local level are dependent on reports from law enforcement, coroners or medical examiners, social media and newspapers, and interviews with proxy reporters to piece together the victim's SOGI status at the time of death.

We heartedly agree with the authors that the public health need for this information cannot be underestimated.<sup>1,2</sup> Over the past two decades, numerous studies have documented elevated risk for violent death among SOGI minorities arising from suicide attempts, depression, and antigay and antitransgender violence and victimization. But, as they note, linking the greater risk to reveal the burden of violent deaths in the SOGI-minority population is greatly hampered by our current data systems.<sup>3,4</sup>

Although the NVDRS offers a different route to obtain this information, compiling individual records in the NVDRS is both labor-intensive and prone to difficulties in data collection in part because of differences in state approaches. As one example, some public health departments code gender status in the NVDRS for transgender decedents as birth sex while others use gender at time of death. Furthermore, many SOGI-minority victims are undetectable if the circumstances surrounding their deaths do not include SOGI-related themes.

---

Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

Correspondence should be sent to Susan D. Cochran, PhD, MS, Department of Epidemiology, UCLA Fielding School of Public Health, 650 Charles E Young South, Los Angeles, CA 90095-1772 (cochran@ucla.edu).

CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

Improved SOGI data collection can occur with enhanced ability of the National Center for Health Statistics to modernize the National Vital Statistics System. This can be done by focusing on six areas of transformation:

1. facilitating interoperability,
2. employing advanced technology,
3. developing standards,
4. achieving federation of the system,
5. expanding the reach of the NVDRS to all 50 states and the District of Columbia, and
6. harmonizing vital registration jurisdictional laws and statutes.<sup>5,6</sup>

Although training funeral directors, medical examiners, and coroner groups to code SOGI-related information is useful, it cannot match the gains that would come from developing an electronic data collection system that electronically populates the death report with information from electronic health records (EHRs) and other databases. This would serve to reduce human error, improve the precision of medical histories feeding into the death record, and reduce reluctance or inability to ask and code SOGI-related questions. Furthermore, it would provide a mechanism for individuals to share self-identification of SOGI status regardless of the ultimate circumstances of their deaths. Including SOGI status ascertainment in the EHR and along with increased interoperability among the medical examiners, law enforcement investigators, funeral home systems, and coroners' case management systems would decrease staff burden, assist with the timeliness of completing the data record, and enhance the accuracy of identifying risk factors for violent death more generally.

But interoperability will only work well if there are standards and procedures that both protect confidentiality and enhance accuracy when capturing and sharing SOGI status in the mortality record. Standards are needed to address classification systems, terminologies, and data interchange among localities, states, and the Centers for Disease Control and Prevention. In addition, standards will require establishing a fixed set of core questions for ascertaining SOGI status and the circumstances of the death. Standards ensure that the documentation in the death record will be transportable and a bridge for the different professions involved in the collection and use of the data. Most importantly, development of standards for privacy, confidentiality, and security of the SOGI data that meet the requirements of local jurisdictions and statutes is critical. This will be difficult but not impossible.

Further complicating the process is that SOGI status is not necessarily a fixed identity and where, when, or if a person is willing to disclose such information in the EHR or other databases has yet to be fully determined. As well, standards will need to include flexibility for coders to update terminology and coding standards should evolving language and intersectionality of SOGI-related self-identification create changes in terminology. Improvements in the use of technologies may also ease the burden of data collection, such as

the development of autopopulation of death records or mobile applications to interface with both the EHR and other linked databases.<sup>6</sup>

The ability to employ advanced technology within states will require congressional and Health and Human Services assistance, likely with incentives similar to those used to facilitate the roll out of EHRs nationally. Presently, many vital systems are underfunded and unable to upgrade their reporting capacities without such assistance.<sup>5</sup> While modernization will go a long way in enhancing the accuracy and usability of mortality data, it is also important that reports from all 50 states and the District of Columbia are incorporated into the NVDRS system. Many of the missing states contain significant numbers of racial and ethnic minorities for whom violent death from homicide, suicide, and legal interventions are a significant public health concern. The public health mission demands that the factors associated with these deaths must be better captured.

While incentivizing will help to bring all 50 states and the District of Columbia into alignment in a federation, this goal also requires thoughtful governance approaches. In a recent convening of relevant stakeholders, including one of the authors, the National Committee on Vital and Health Statistics recommended development of business models that could help achieve the transformation of the National Vital Statistics System.<sup>5</sup> Modernization of mortality data means not only fixes to the NVDRS but also enhancing the National Death Index, an important but costly resource for researchers. Although there is much to do here, there are successful models. As an example, California passed the Revitalization of Vitals legislation and Respect After Death Act directing its vital record system to make it easier for individuals to change their sex on their birth certificates and to have their current gender identity on their death certificate. Other states have developed similar legislation but there are also some states that, despite a willingness to make changes, are unable to do so without additional funding to reengineer existing systems.

One of the important lessons learned from the current opioid crisis is that an absence of linked electronic interoperable systems served to blind us to the emerging patterns of homicides and suicides connected to opioids until there were way too many deaths. Modernization of the National Vital Statistics System would also allow it to transition to a near-real-time system of mortality surveillance fulfilling its public health function of being an early detector of emerging public health epidemics, such as the rising suicides and legal interventions in African Americans and homicides in transgender women of color.<sup>2</sup> While we write in response to the matters raised in the article on SOGI measurement in the NVDRS, we note that modernization of the National Vital Statistics System would bring critical public health benefits to many segments of society.

## ACKNOWLEDGMENTS

Work was supported by grants from the National Institute of Mental Health (MH115344) and the National Center for Minority Health and Health Disparities (MD006923).

## REFERENCES

1. Cochran SD. Emerging issues in research on lesbians' and gay men's mental health: does sexual orientation really matter? *Am Psychol.* 2001;56(11): 931–947. [PubMed: 11785169]

2. Clark KA, Mays VM, Cochran SD. Extreme violence and the invisibility of women who murder: the intersectionality of gender, race, ethnicity, sexual orientation, and gender identity equals silence. *Violence Gen.* 2017;4(4):117–120.
3. Cochran SD, Bjorkenstam C, Mays VM. Sexual orientation and all-cause mortality among US adults aged 18 to 59 years, 2001–2011. *Am J Public Health.* 2016;106(5):918–920. [PubMed: 26985610]
4. Haas AP, Lane A. Working Group for Postmortem Identification of SO/GI. Collecting sexual orientation and gender identity data in suicide and other violent deaths: a step towards identifying and addressing LGBT mortality disparities. *LGBT Health.* 2015;2(1):84–87. [PubMed: 26790023]
5. National Committee on Vital and Health Statistics. Next generation vital statistics: a hearing on status, issues and future possibilities. National Committee on Vital and Health Statistics; 2018 Available at: <https://ncvhs.hhs.gov/wp-content/uploads/2018/05/Summary-Report-Next-Generation-Vitals-Sept-2017-Hearing-Final.pdf>. Accessed November 18, 2018.
6. MITRE Corporation. The public health impact of vital statistics. 2017 Available at: <https://www.cdc.gov/nchs/data/nvss/modernization/Newsletter-July-2017.pdf>. Accessed November 18, 2018.