



July 27, 2021

Richard Landen, MPH, MBA and Denise E. Love, BSN, MBA  
Chairs  
National Committee on Vital and Health Statistics  
Subcommittee on Standards  
3311 Toledo Road  
Hyattsville, MD 20782

RE: National Committee on Vital and Health Statistics: Notice of Meeting and Request for Public Comment

Dear Chairs Landen and Love:

The Confidentiality Coalition appreciates the opportunity to provide comments to the National Committee on Vital and Health Statistics (NCVHS).

The Confidentiality Coalition is composed of a broad group of hospitals, medical teaching colleges, health plans, pharmaceutical companies, medical device manufacturers, vendors of electronic health records, biotech firms, employers, health product distributors, pharmacies, pharmacy benefit managers, health information and research organizations, patient groups, and others founded to advance effective patient confidentiality protections. The Coalition's mission is to advocate policies and practices that safeguard the privacy of patients and healthcare consumers while, at the same time, enabling the essential flow of patient information that is critical to the timely and effective delivery of healthcare, improvements in quality and safety, and the development of new lifesaving and life-enhancing medical interventions.

The COVID-19 public health emergency (PHE) has highlighted the need to improve data sharing among public and private stakeholders. One of the greatest challenges to data sharing during the PHE has been the lack of a single data standard for health information. Creating harmonization among data standards will allow stakeholders to share information more easily with each other. We encourage NCHVS to evaluate how best to promote harmonization through existing recognized data standards. Leveraging a single standard will significantly improve public health efforts, including surveillance, preparedness, and response for public health threats, such as infectious disease outbreaks, natural disasters and other public health emergencies. Immunization infrastructure systems (IIS), in particular, have struggled with collecting and sharing information due to a lack of harmonized data standards. These systems collect a variety of information about vaccinations for children and adults, such as demographic information as well as more general health information. IIS that are harmonized are able to assist public health officials and healthcare providers in determining vaccination trends that would allow them to make community-level decisions to improve vaccination uptake.

Stakeholders have also had difficulties due to the lack of clear measurement data to collect and report upon during the PHE. Differing health data metrics among federal, state and local reporting requirements created confusion during the reporting period at the height of the COVID-19 pandemic. This lack of harmonized metrics resulted in contradictory and burdensome reporting situations that slowed the sharing of critical information. We encourage NCVHS to examine the data reporting process during the COVID-19 PHE so that the Department of Health and Human Services (HHS) can develop a common measurement framework at all jurisdictional levels. This will enable stakeholders to collect and share information more quickly during future PHEs.

While it is important to develop tools to allow for improved data collection and sharing, HHS must ensure that a baseline of privacy protections is in place before any personal data is shared. While protected health information is governed by the HIPAA framework, additional health data collected by entities outside of the HIPAA framework during PHEs may not be subject to robust protections. The Confidentiality Coalition has developed "[Beyond HIPAA](#)" principles to govern the sharing of information not covered by HIPAA. These principles emphasize the need to obtain patient consent for sharing of their health data not governed by HIPAA as well as prohibitions on the use of data beyond the expressed purpose for which consent was given. We encourage NCVHS to examine how to put robust protections in place before data is collected so that information is properly secured. Providing strong and workable privacy and security protections beyond the HIPAA framework will build patient trust around information sharing, resulting in greater access to important data for future preparedness and response efforts.

The Confidentiality Coalition looks forward to working with you on improving data collection and sharing. Please contact me at [tgrande@hlc.org](mailto:tgrande@hlc.org) or 202-449-3433 with any questions.

Sincerely,

A handwritten signature in black ink that reads "Tina O. Grande". The signature is written in a cursive, flowing style.

Tina O. Grande  
Chair, Confidentiality Coalition and  
Executive VP, Policy, Healthcare Leadership Council