



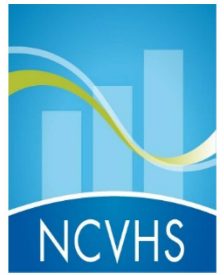
National Committee on Vital and Health Statistics
Advising the HHS Secretary on National Health Information Policy

PSC Subcommittee Report: September Hearing on Data Use in Public Health Emergencies, and Potential Projects Going Forward

**NCVHS Subcommittee on Privacy,
Confidentiality and Security**

Nov. 19, 2020

Today's agenda



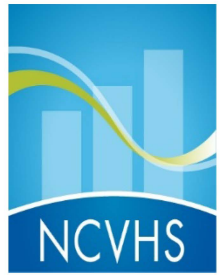
11:45 - 12:05 p.m.: Review of Issues and Hearing Report

12:05 – 12:25 p.m.: Takeaways from Hearing Report and Discussion

12:25 – 12:30 p.m.: Longer Term PCS Priorities

12:30 to 12:45 p.m.: Discussion of Longer Term Priorities

Review of Data Use in Public Health Emergency Topics



- What are fair information principles for a pandemic?
- What data should we be collecting?
- What rules are all right to override to advance public health, and what should remain in force, and perhaps inalienable?
- What level of identification of data is appropriate for which purposes?
 - When is there a need for identifiable data?
 - When is aggregate data more appropriate?
 - Is case-level data without identifiers an adequate compromise?
- How do our standards differ at the local / state / federal levels?

September Hearing: Panel 1, Data Collection and Use



- Ashkan Soltani, Independent researcher and technologist specializing in privacy, security, and technology policy. Former Senior Advisor to the U.S. Chief Technology Officer in the White House Office of Science and Technology Policy and as Chief Technologist for the Federal Trade Commission. [For the record: Contact-tracing apps are not a solution to the COVID-19 crisis]
- Commissioner Allison Arwady, Chicago Department of Public Health [Recommended viewing: <https://www.nbcchicago.com/top-videos-home/arwady-explains-new-contact-tracing-efforts-in-chicago/2278204/>]
- Robert Grossman, Co-Chief, Section of Computational Biomedicine and Biomedical Data Science, Dept. of Medicine; and Chief Research Informatics Officer (CRIO), Biological Sciences Division at the University of Chicago. [Recommended Reading: Rockefeller Foundation COVID-19 Testing Action Plan]

September Hearing: Panel 2, Technology and Ethics



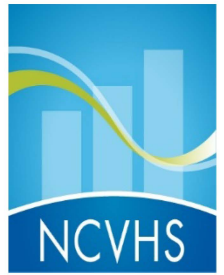
- Professor Danielle Allen, Harvard University, Edmond J. Safra Center for Ethics [Recommended reading: Roadmap to Pandemic Resilience: Massive Scale Testing, Tracing, and Supported Isolation (TTSI) as the Path to Pandemic Resilience for a Free Society]
- John W. Loonsk, MD, Johns Hopkins University, Bloomberg School of Public Health and consulting chief medical informatics officer for the Association of Public Health Laboratories (APHL) [Recommended reading: Pandemic Reveals Public Health Data Infrastructure Shortcomings]
- Kate Goodin, Director, Surveillance Systems and Informatics Program, Communicable and Environmental Diseases and Emergency Preparedness, Tennessee Department of Health
- Stacey Mondschein Katz, Esq., Director of Healthcare Privacy and Human Protections Administrator, Maine Department of Health and Human Services

September Hearing: Panel 3, Bias and Discrimination

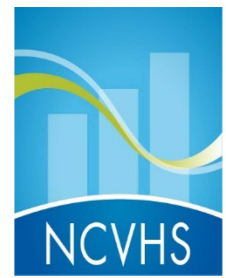


- Bryant Thomas Karras, M.D. Chief Informatics Officer, Office of the State Health Officer/Chief Science Officer, Washington State Department of Health
- Mary L. Gray, Senior Principal Researcher, Microsoft Research [Recommended reading: Mary Gray Urges COVID-19 Technology to Focus on Equity]
- Sean Martin McDonald, Senior Fellow, Centre for International Governance Innovation; Waterloo, Ontario, Canada [In the news: Contact-Tracing Apps Fail to Deliver on Tech Boosters' Promises]
- C. Jason Wang, MD, PhD, Director, Center for Policy, Outcomes and Prevention (CPOP), Stanford University [Recommended reading: Response to COVID-19 in Taiwan Big Data Analytics, New Technology, and Proactive Testing | JAMA]

Issues Raised

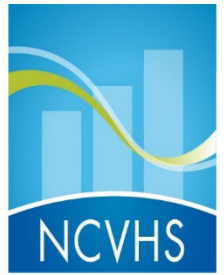


- Data and data stewardship
- Coverage gaps
- Public trust
- Laws and policies



Data and Data Stewardship

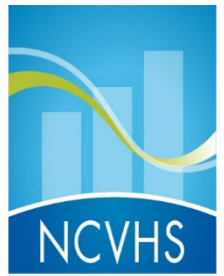
- There is a need to consider data stewardship in the age of COVID-19 and how case examples can be applied to the gaps and needs.
- “Deidentification” is the backbone of much of the current public health data collection process. Terminology may need to change to accurately reflect the process of repackaging data for various purposes.
 - The field could also provide alternative models for promoting privacy.
- While a master patient index would be helpful, it is not a realistic goal as a focus for current efforts.
- There is need to consider how the field can increase the liquidity of data and the collection of key data—including better means of assessing and communicating the risks of different forms of data collection. Rapid response is critical in the context of emergencies.
- Often public health data are more secure than other public data because of the dedication of the individuals working with the data to the betterment of the public at large.
- Many smartphone apps require sign-up and download, providing a form of consent; however, there are concerns about secondary uses that are not anticipated by users.
- Prohibition of secondary use of data may help build public trust, if well enforced.
- NCVHS’ Subcommittee on Standards has a project under way about the convergence of clinical and administrative data—revisiting the fundamental premise of health care data between providers and payers—including public health data needs and the intersection of public health with the clinical and payer workflows.



Coverage Gaps

- Lack of payment coverage for testing
- Gaps in HIPAA privacy protection coverage
- The disparate impact on individuals partially caused by misidentification of individuals due to missing data in the analytical models.

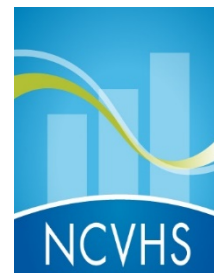
Public Trust



- Without public trust, no interventions or data collection efforts implemented in the public health field will be successful.
- When building a data trust, there is a need to consider the different responses to opt-in versus opt-out options and the balance between collecting the amount of data needed and maintaining public trust—for short-term and long-term data needs.
- Building public trust requires better ways to communicate the complex processes of data collection and storage so that the public can understand—with the person responsible sometimes likened to a data counselor.
 - Creation of this role will be challenging because the health care financial realm is encouraging hospitals to do more with less resources.
- Opt-in for all data use is complicated, and increased transparency is a complex lift for the field.
- Public distrust has been a longstanding, gradually worsening issue that cannot be addressed completely in the short term.
- Transparency is key to trust; however, speed is an important aspect of data, particularly related to vital statistics—quicker access to the data can help move along projects to address needs and build trust.
- Effective and clear emergency response with a sound scientific basis is the cornerstone on which public trust can be built.

Laws and Policies

- Efforts should be made to create policies to address the inconsistent, patchwork coverage across the nation by different state and local laws.
- National-level guidance may foster more consistency at the state and local levels.
- Laws should balance the need for privacy and protection of the individual with the need to collect data.
- The work recently completed by the NCVHS on Next Generation Vital Statistics could be used as a model to consider how working parts are being forced into an incomplete whole and how federal leadership can be supported to create a structure that can hold the disparate pieces together.



Potential Future Work Topics

- A. Deep dive on Beyond HIPAA expanding to include apps/Data Use and Service Agreements for Wearables, M-health.
- B. Health information security – especially in light of recent HHS/FBI memo on ransomware/malware in healthcare
- C. Data linkage stewardship
- D. Further HIPAA guidance related to accounting for disclosures
- E. Approaches for dealing with civil monetary penalties resulting from HIPAA enforcement
- F. NPRM on the HIPAA Privacy Rule: Changes To Support, and Remove Barriers to, Coordinated Care and Individual Engagement