National Committee on Vital and Health Statistics

**Virtual Hearing on Privacy, Confidentiality and Security
Considerations for Data Collection and Use during a
Public Health Emergency**

**Final Agenda
September 14, 2020**

Purpose of the Hearing

To clearly define the challenges and identify potential approaches to address them, NCVHS is seeking input from public health practitioners and other experts to explore data privacy and security in light of the COVID-19 Public Health Emergency (PHE). The Committee will use this input to inform the development and dissemination of a toolkit outlining methods and approaches to collect, use, protect, and share data responsibly during a pandemic or long-term nationwide PHE.

Objectives of this meeting are to:
- Understand current policies and practices involving data collection and use with respect to privacy and security during the COVID-19 PHE;
- Understand challenges and potential areas of clarification in light of these practices, new and emerging technology developments, and new and evolving policy directions;
- Identify best practices and areas where additional technical assistance or guidance may be useful.

Monday, September 14, 2020

9:30 – 9:35 a.m.   Welcome and Roll Call – Rebecca Hines, NCVHS Designated Federal Official

9:35 – 9:45 a.m.   Opening Remarks – Frank Pasquale, Chair, PCS Subcommittee

9:45 – 10:00 a.m.   Overview and Framing of Current Issues

10:00 – 11:30 a.m.   **Panel I – 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]

11:30 – 12:30 p.m.   **Break**

12:30 – 2:00 p.m.   **Panel II – 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 Service**

2:00 – 2:15 p.m.   **Break**

2:15 – 3:45 p.m.   **Panel III — 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 I JAMA]

3:45 – 4:00 p.m.   **Public Comment**

4:00 – 4:15 p.m.   **Break**

4:15 – 5:15 p.m.   **Subcommittee Discussion: Review themes, identify potential recommendations and additional information needs**

5:15 p.m.   **Adjourn**

Upcoming NCVHS Meetings
- November 18-19, 2020, Full Committee