National Committee on Vital and Health Statistics
Subcommittee on Privacy, Confidentiality & Security

September 2020 Hearing:

Data Collection and Use
During a Public Health Emergency

September 9, 2021

Context

- Need for support of public health contact tracing activities at all levels of government

- Variability in data collection and use activities by Federal government v. state activities v. local practices

- What tools might we use for public health surveillance in a public health emergency?

- How is privacy implicated?
  - Exposure notification apps such as Apple/Google/State-sponsored/Others?

Objectives of Sept 2020 Hearing

1. Understand current policies and practices for data collection and use with regard to privacy and security of <u>identifiable</u> COVID data

2. Identify best practices in public health emergency situations. What worked?

3. Consider additional technical assistance needed. What did not work?

4. Consider building on prior Committee work:
   - 2015 "Toolkit" for Communities Using Health Data ([2015 Toolkit](#))
   - 2019 "Health Information Privacy Beyond HIPAA" ([2019 Beyond HIPAA Framework](#))

5. Consider developing recommendations on values and opportunities in data collection and use in public health emergencies

Themes expressed by panelists

- **Need for a data collection and use framework**
    - Overarching
    - Integrated
    - Well-funded
    - Socially supported at Federal, state, and local levels
    - Specific to public health emergencies

- **Address health disparities and improve health equity**

Themes expressed by panelists

- **Technology and ethics goals**
  - Health data infrastructure for new forms of data collection and sharing in a public health emergency
  - Removal of data silos across public health and healthcare entities
  - Development of standardized data use agreements
  - Collection and sharing of complete race and ethnicity data
  - Potential data commons — combine data and computing infrastructure
  - Embed privacy and security guidelines
  - Data sharing within communities in a privacy appropriate environment

Themes expressed by panelists

- **Difficulty of multiplicity, patchwork, variety of laws**
  - Develop national legal/policy standards?
- **Definition of HIPAA "covered entity"**
  - Develop broader definition? How to approach practices of non-covered entities.
- **Reconsideration of de-identification/De-identification as backbone of use of administrative data**
  - Development of a new term (instead of "de-identification")?
  - Importance of assessing and communicating risks and opportunities in redacting different identifiers
  - New models for de-identification?
  - Explore new ways to bridge HIPAA/non-HIPAA gap for de-identification

After the Hearing

- Evolution of COVID-19 pandemic and technological tools, changes in priorities
- US did not widely adopt apps for exposure notification/contact tracing
- Lessons learned?
- Potential next steps?

Potential Topics

- **How can we be better prepared for the next public health emergency?**
  - Exposure notification v. contact tracing
  - Relevance of registries
  - Apps that share vaccine status
  - Contact tracing – how to measure attitudes?

Potential Topics

- **Data collection and use in health care/public health/research**
  - CDC V-safe app (after vaccination health checker) – not widely used
  - Vaccine status/"passports" – standards for information sharing and privacy
  - Relationship to Foundations for Evidence-Based Policymaking Act of 2018 (Evidence Act)
    - Law requires Federal agency data to be accessible and requires agencies to plan to develop statistical evidence to support policymaking
    - Privacy issues when linking general data sets with COVID data
  - Long-term maintenance and use of data
  - Life cycle of public health data collected in emergency: best practices
  - Public/consumer education

Potential Topics

- **Analysis of Federal program waivers**
  - USDA flexibilities in Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) (e.g., remote contact with eligible families to meet demands while protecting health of participants and staff)
  - Waivers granted to mail drug-related supplies
  - Waivers for telehealth access
  - Notices of Enforcement Discretion of various HIPAA rules

Potential Topics

- **Strengthening Immunization Information Systems (IIS)**
  - Reduce health inequities
  - Conduct rigorous evaluations of vaccine campaigns
  - Comprehensive coverage of vaccine administration
  - Gather complete demographic information
  - Increased linkage between IIS and electronic health records

- **Challenges of conducting intrastate/interstate policy surveillance**

Contextual Issues

- **Policy/Legal Waivers**
  - Timing, sunset, reapplication
  - Evaluation and accountability
  - Tracking collection/use of data even under waivers

- **Data Collection and Vital Records**
  - States not sharing timely data on cases or deaths
    - Move from weekly to monthly
  - Avoidance of perception of a "bad" record of cases
    - No standards for detail on data or timing
  - Clinical, lab work, hospitalization data, etc.

Potential Next Steps

- **Transmittal letter to Secretary**
  - Include hearing summary?
  - Other?
- **Potential focus on current HHS activities**
- **Gaps in Federal/state/local data collection and use work**
  - How can the Committee contribute to existing work?
- **Possible hearings on new topics**
  - Emerging COVID-related (and/or public health emergency) security & privacy issues?

Potential Next Steps

Return to Data Stewardship theme?

1. Build on the 2019 Beyond HIPAA work and the 2015 NCVHS Toolkit.

2. Linking case studies presented in September 2020 hearing

3. Additional topics
    *   Community outreach on data collection, use, sharing
    *   Communication
    *   Transparency
    *   Focus on secondary use
    *   Public trust