The National Committee on Vital and Health Statistics

The Public Advisory Body to the Secretary of Health and Human Services

Privacy, Confidentiality and Security Sub-committee

Recent Activities and Future Directions

2011 Inventory and Findings from April 2012 Hearing

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- Key Themes and Stakeholders:
    - Patients/consumers
    - Providers
    - Plans (public and private)
    - Policy makers
    - Regulators (OCR, ONC, states)
    - EHR/PHR vendors, other IT services
    - Exchanges
    - Congress

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- patient control improves trust
- Consumer education
- not impeding innovation
- Expansion of use of health info to non-health
- Secondary uses, complementary to community uses
- Web 2.0/Cloud technology
- Rules follow the custodian v. the data
- International issues

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- Identifiable health data that's not in medical records
  - Health industry
  - Non-health industry
- Secondary uses of data
  - Community uses
  - Updating the Data Stewardship report
  - AMIA work in this area
  - public health selling data for use in research
  - Relationship to contextual access criteria
  - Marketing
  - Non-health insurance
  - Employment

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- Recourse in the case of inappropriate secondary uses
  - Legal recourse, but there is more
  - Culture, education ethics
  - Medical circles –
    - employment discrimination,
    - you’ve let people bring a case that’s hard to prove
    - usually “mixed motive,”
    - the person has already been dismissed
    - Merely shifted the burden?

- New business arrangements
  - Business associate agreements
  - Web 2.0, the cloud, and health data
  - Exchanges – jurisdiction, audit, enforcement
  - Outsourcing data to Philippines or India
- International ideas in health data privacy
  - What are other nations doing?
  - Learning from their experience
  - Best practices

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- De-identified data
  - matching with other dbases
  - Mosaic effect
- Governance of exchanges
  - Accreditation
  - Mechanism for conformance
- Surveillance systems
  - Sentinal at FDA others?
  - Biosense at CDC

- Extend the Community Health Data Report
  - Best practices for privacy
- Lessons from GINA?
  - GINA relies on bringing suit
  - After-the-fact kind of problem
- Public Health Emergencies
  - What kind of privacy issues are there?
  - What kind of data is needed?
  - How to manage it?

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- Breach notification
  - Remedies for breach are inadequate
- Creation of a unique patient ID
  - Recommendations?

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- Privacy is not an individual issue only, it’s societal and family
- Chain of trust involving the whole process from collaboration through use of data
- Participatory Governance and special obligations of data stewards to the community
- Spectrum of consent

“Trust is our Most Important Resource….and Trustworthy practices require attention to relationships and accountability.”

Kelly Edwards, PhD, Department of Bioethics and Humanities University of Washington School of Medicine

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- April Hearing
  - Educating community members and leaders about data use and benefits
  - Involving community members in decisions about data use and more
  - Trust-building among organizations and agencies that are data sources
  - Governance fosters a sense of ownership and control

“…further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country.”

The Community as a Learning System for Health, NCVHS, December 2011, p. 19

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1. Facilitate the development and promulgation of models for stewardship of community health data. HHS might facilitate this development through pilot projects, demonstration projects, grants, case studies, and the like.
2. Support the development of dynamic guidance resources that compile best practices that experts, communities, and other data users are learning about stewardship.. NCVHS has identified the following high priority areas for resource development:
    - How-to examples and case studies about de-identified data;
    - Data use agreements and their enforcement;
    - Risks of disclosure and data reporting, including information about risks of data aggregation and methods for protecting small groups when data are analyzed in small cells;
    - Methods and best practices for openness and transparency;
    - Community engagement and closing the loop with communities.
3. Compile case studies of results that communities achieve through their uses of data so other communities might learn and be inspired.
4. Promote the creation of training materials for researchers who collect and use community health data.