



De-Identification & Uses of Anonymized Data under HIPAA

Deven McGraw

The Health Privacy Project at CDT

- Health IT has tremendous potential to improve health care quality, reduce costs, and save lives.
- But consumers have significant privacy concerns about the sharing of their health information on-line.
- Project's aim: Develop and promote workable privacy and security policy solutions for electronic personal health information.
 - Includes more in-depth exploration of more challenging issues

De-identification of Health Data

- Is it still possible?
- What are the common uses of de-identified data?
- Is the HIPAA standard sufficiently “rigorous”? (safe harbor)
- Are policies governing de-identification still sound?
 - When qualifies as de-identified not protected by HIPAA
 - Insufficient legal mechanisms to ensure accountability for re-identification

Workshop on De-identification

- September 26, 2008
- Panels of leading experts
- Invitees
 - CDT's informal health IT working group (vendors, employers, consumers, provider groups, academics);
 - Hill and Administration staff
- Closed to press and not recorded to encourage free flow of dialogue

Summary: Issues Raised at Workshop

- ❑ De-identification – in particular the “safe harbor” method” – should be reviewed on an ongoing basis
- ❑ Uses of de-identified data should still be permitted, at least for those uses that generate public benefit
- ❑ We need better methods for holding data recipients accountable
- ❑ Current de-identification standard has limited utility for many data uses – same is true for limited data set
- ❑ HIPAA should require – or at least encourage – greater use of “anonymized data”

Workshop Panels & Participants

- Moderator: Peter Swire, J.D., Ohio State University (formerly Clinton Administration)
- Panels
 - Current De-Identification Practices:
 - IMS Health (Mark Kohan & Sylvia Plotzker)
 - Latanya Sweeney, Ph.D. (Carnegie Mellon)
 - Cynthia Dwork, Ph.D. (Microsoft)

Workshop Panels (cont.)

- Common uses of de-identified data:
 - Justine Carr, M.D., Caritas Christi Health System and NCVHS
 - Linda Goodwin, R.N., Ph.D., Duke Univ. School of Nursing
 - Stanley W. Crosley, M.D., Eli Lilly
 - Shaun Grannis, M.D., M.S., Regenstrief Institute

Workshop Panels (cont.)

□ Policy Implications

- Bill Braithwaite, M.D., Anakam Inc.
- Mark Rothstein, J.D., University of Louisville School of Medicine
- Kenneth Goodman, Ph.D., University of Miami Bioethics Program

Workshop Outcomes – De-identification

- ❑ Wide variety of common uses of HIPAA de-identified data
 - ❑ Quality improvement efforts
 - ❑ Public Health
 - ❑ Research (clinical and epidemiological)
 - ❑ Commercial
- ❑ Because data not regulated or required to be tracked, complete universe of uses is unknown

Outcomes of De-identification

Discussion (cont.)

- ❑ Ensuring low risk of re-identification is getting more difficult – increased availability of data
- ❑ Statistical method for de-identification is meant to be flexible over time
- ❑ However, safe harbor (removal of 18 specific data elements) may lose its potency over time
 - ❑ Never intended to be set in stone

Outcomes of De-identification

Discussion (cont.)

- ❑ Does it still make sense to allow de-identified data to be used for any purpose
 - ❑ If so, increased transparency to public of uses?
 - ❑ Tracking/monitoring?
 - ❑ Role for data stewardship entities?
- ❑ How to ensure accountability for “misuse” of data or re-identification – data use agreements?
- ❑ Ongoing review of safe harbor
- ❑ Ensuring rigor for statistical method?

Workshop Outcomes – Need More Data Anonymization Options?

- ❑ De-identified data is often not useful for research, public health, and quality purposes because too much data is removed
 - ❑ Fully-identifiable data can be used for these purposes (in many circumstances)
- ❑ Limited data set preserves more data – but still rigid and may not be useful for many important purposes

More Options? (cont.)

- Requirement to use “least identifiable data possible” for many purposes under HIPAA
 - Accomplish through minimum necessary standard?
- ARRA 2009 Opportunities:
 - HHS Secretary required to examine several areas of HIPAA
 - HHS study on “deidentification”
 - HHS guidance on minimum necessary
 - Requirement that new HIT advisory committees consider recommendations of NCVHS

CDT Follow-up

- Paper on De-identification Workshop – release in Spring 2009
 - Paper released first to Workshop participants for review
- Contribute to regulatory/guidance process
- Continue to work with NCVHS on this issue