

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

“De-Identification and the Health Insurance Portability and Accountability Act (HIPAA)”

**May 24-25, 2016
Hubert H. Humphrey Building
U.S. Department of Health and Human Services
Washington, D.C.**

PURPOSE OF THE MEETING

HIPAA sets forth methodologies for de-identifying protected health information (PHI). Once PHI is de-identified, it is no longer subject to the HIPAA rules and can be used for any purpose. The U.S. Department of Health and Human (HHS) Services Office for Civil Rights (OCR) issued guidance in 2012, specifying two ways through which a covered entity can determine that health information is de-identified: (1) the Expert Determination Method and (2) the Safe Harbor Method. Much has changed in the health care landscape since that time, including greater availability and use of big data. Concerns have been raised about the sufficiency of the HIPAA de-identification methodologies, the lack of oversight for unauthorized re-identification of de-identified data, and the absence of public transparency about the uses of de-identified data. The purpose of this hearing is to gather industry input on existing guidance and possible limitations of the de-identification methodologies for making recommendations to the Secretary of HHS.

The objectives of this meeting are as follows:

- Increase awareness of current and anticipated practices involving de-identified health information, such as the sale of such information to data brokers and other data-mining companies for marketing and/or risk mitigation;
- Understand HIPAA’s de-identification requirements in light of these practices, and
- Identify areas where outreach, education, technical assistance, a policy change, or guidance may be useful.

AGENDA - Tuesday, May 24, 2016

- 9:00 to 9:15 a.m. Introductions and Opening Remarks – *Linda Kloss, Chair*
- 9:15 - 10:00 a.m. Overview and framing of current issues – Dr. Simson Garfinkel, Information Access Division, National Institute of Standards and Technology
- 10:00 - 11:15 a.m. **Panel I – Policy Interpretations of HIPAA’s De-identification Guidance**
- Ira Rubinstein, JD, Senior Fellow, Information Law Institute; Adjunct

Professor, New York University School of Law

Bradley Malin, PhD, Vice Chair for Research, Department of Biomedical Informatics. School of Medicine; Director, Health Information Privacy Laboratory; Vanderbilt University

Daniel Barth-Jones, MPH, PhD; Assistant Professor of Clinical Epidemiology; Mailman School of Public Health; Columbia University

11:15 – 11:30 a.m. Break

11:30 – 12:45 p.m. **Panel I — Policy Interpretations, cont’d**

12:45 – 1:45 p.m. Lunch

1:45 – 3:15 p.m. **Panel II — De-Identification Challenges**

Michelle De Mooy, Deputy Director, Privacy and Data Project, Center for Democracy & Technology; Washington, D.C.

Jules Polonetsky, JD; CEO, Future of Privacy Forum; Washington, D.C.

Ashley Predith, PhD; Executive Director. President's Council of Advisors on Science and Technology; White House Office of Science and Technology Policy; Washington, D.C.

Cora Tung Han, JD; Federal Trade Commission, Bureau of Consumer Protection; Washington, D.C.

3:15 - 3:30 p.m. Break

3:30 – 4:45 p.m. **Panel II — De-Identification Challenges, cont.**

4:45 - 5:15 p.m. Public Comment period

5:15- 5:30 p.m. Framing of Issues by Subcommittee Members

5:30 p.m. Adjourn

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TENTATIVE AGENDA – Wednesday, May 25, 2016

9:00 to 9:15 a.m. Opening Remarks – *Linda Kloss, Chair*

9:15 – 11:15 a.m. **Panel III - Approaches for De-Identifying and Re-Identifying Data**

Vitaly Shmatikov, PhD; Professor of Computer Science; Cornell; New York, NY

Jacki Monson, JD; Chief Privacy Officer; Sutter Health; Sacramento, CA

Jeptha Curtis, MD, FACC; American College of Cardiology

11:15 – 11:30 a.m. Break

11:30 – 12:45 p.m. **Panel IV - Models for Privacy-Preserving and Use of Private Information**

Micah Altman, PhD; Director of Research, MIT Libraries; Head/Scientist, Program on Information Science; Non-Resident Senior Fellow, Brookings Institution; Boston, MA

Sheila.Colclasure, MA, Privacy Officer, Axiom; Little Rock, AR

Kim Gray, JD: Chief Privacy Officer, Global, IMS Health

12:45 – 1:00 p.m. Public Comment period

1:00-2:00 p.m. Lunch

2:00 – 3:00 p.m. Subcommittee Discussion: Review themes, identify potential recommendations and additional information needs

3:00 - 3:15pm Break

3:15 – 5:15 a.m. Subcommittee Discussion: Frame letter to the Secretary, reach consensus on the timeline and next steps, if any

5:15 p.m. Adjourn