The Network for Public Health Law

Ideas. Experience. Practical answers.

Resources for 2016 Public Health Law Conference Workshop

De-Identification of Health Data: Law and Practice

1. The U.S. Department of Health and Human Services, Office for Civil Rights, hosts a comprehensive website regarding the HIPAA Privacy Rule that includes many useful guidance documents, tools and training materials regarding HIPAA privacy and security regulations. The website is at http://www.hhs.gov/ocr/privacy.
   - Materials focused on public health can be found here: http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/publichealth/index.html.
     - See especially, "HIPAA Privacy Rule and Public Health, Guidance from CDC and the U.S. Department of Health and Human Services" at http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm.
     - See also, FAQs regarding Public Health Uses and Disclosures at http://www.hhs.gov/hipaa/for-professionals/faq/public-health-uses-and-disclosures.
   - For "Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule" go to http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/De-identification/guidance.html.

2. De-identification resources and tools:
   - National Institute of Standards and Technology (NIST) De-Identification Home Page at https://www.nist.gov/itl/iad/deidentificationnistgov. NIST resources include:
     - NISTIR 8053, De-Identification of Personal Information (2015), available at http://nvlpubs.nist.gov/nistpubs/ir/2015/NIST.IR.8053.pdf.
     - DRAFT NIST Special Publication 800-188, De-Identifying Government Datasets (2016), available at http://csrc.nist.gov/publications/drafts/800-188/sp800_188_draft.pdf.
   - Hearing materials, "De-Identification and the Health Insurance Portability and Accountability Act (HIPAA)," Subcommittee on Privacy, Confidentiality & Security, National Committee on Vital and Health Statistics, May 24-25, 2016, available at http://www.ncvhs.hhs.gov/meeting-calendar/agenda-of-the-may-24-25-2016-ncvhs-subcommittee-on-privacy-confidentiality-security-hearing/. Report of hearing at http://www.ncvhs.hhs.gov/wp-content/uploads/2016/04/PCS-Report_June-15-mab.pdf.

- Toolkit for Communities Using Health Data: How to collect, use, protect, and share data responsibly (May 2015), National Committee on Vital and Health Statistics (NCVHS), available at http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/Toolkit-for-Communities.pdf. Section on de-Identification begins on page 39.
- A Visual Guide to Practical De-Identification, produced by the Future of Privacy Forum, available at https://fpf.org/wp-content/uploads/2016/04/FPF_Visual-Guide-to-Practical-Data-DeID.pdf.
- Public Health Data Dissemination Guidelines: NAHDO Working Technical Paper Series (July 2005), available at https://www.nahdo.org/sites/nahdo.org/files/Resources/Data_Release_Access_and_Pricing/PH%20Data%20Dissemination%20Guidelines-2005.pdf. (note: may need to copy and paste link into browser)
- Guidance Document on Creating and Releasing Hospital and Facility Discharge Data Public Use Files (January 2012), available at https://www.nahdo.org/sites/nahdo.org/files/publications/PUF%20Guidance%20Doc%20Final.pdf. (note: may need to copy and paste link into browser)
- De-Identification University, de-identification-related white papers, webinars and other materials developed by Privacy Analytics, a Canadian software company, available at http://www.privacy-analytics.com/de-id-university.
- Rudolph B, Shah G, and Love D. "Small Numbers, Disclosure Risk, Security, and Reliability Issues in Web-based Data Query Systems." J. Public Health Management Practice, 2006, 12(2), 176-183. Abstract at http://journals.lww.com/jphmp/Abstract/2006/03000/Small_Numbers,_Disclosure_Risk,_Security,_and.10.aspx.

3. Sample policies and procedures for release of data that are available on-line:
   - New Hampshire Division of Public Health Services, Health Statistics and Data Management Section, Guidelines for the Public Release of Public Health Data (provisional), available at http://www.dhhs.nh.gov/dphs/hsdm/documents/publichealthdata.pdf.
   - Washington State Department of Health, Guidelines for Working with Small Numbers, available at http://www.doh.wa.gov/portals/1/documents/5500/smallnumbers.pdf.

4. Research resources and tools:
   - Office for Human Research Protections website http://www.hhs.gov/ohrp. See, for example, Guidance on Research Using Coded Private Information or Specimens (2008) available at http://www.hhs.gov/ohrp/regulations-and-policy/guidance/research-involving-coded-private-information.
   - Gliklich R, Dreyer N, Leavy M, eds. Registries for Evaluating Patient Outcomes: A User's Guide. Third edition. Two volumes. (Prepared by the Outcome DEcIDE Center [Outcome Sciences, Inc., a Quintiles company] under Contract No. 290 2005 00351 TO7.) AHRQ Publication No. 13(14)-EHC111. Rockville, MD: Agency for Healthcare Research and Quality. April 2014. Table of contents at http://www.ncbi.nlm.nih.gov/books/NBK208616. Especially see, Section II - Legal and Ethical Considerations for Registries and Section IV - Technical, Legal, and Analytic Considerations for Combining Registry Data With Other Data Sources.

5. Open Records / Freedom of Information Laws (FOI).
   - OCR response to FAQ: How does the HIPAA Privacy Rule relate to state public records or freedom of information laws? Available at http://www.hhs.gov/hipaa/for-professionals/faq/506/how-does-the-hipaa-rule-relate-to-freedom-of-information-laws/index.html.
   - The HIPAA Privacy Rule Preamble in the Federal Register, Vol. 64, No. 250 (Dec. 28, 2000), discusses how the HIPAA Privacy Rule relates to the federal Freedom of Information Act and various other federal laws. Available at https://www.gpo.gov/fdsys/pkg/FR-2000-12-28/pdf/00-32678.pdf. (See pages 82481-82487).
   - The Reporters Committee for Freedom of the Press provides links to open records laws for the federal government and all states and tools to compare FOI laws at http://www.rcfp.org/browse-legal-resources/guides. Especially see, *Open Government Guide* (6th Edition, 2011), a state-by-state guide to open meetings and open records laws, available at http://www.rcfp.org/open-government-guide.
   - The National Freedom of Information Coalition provides materials on federal and state open records laws. http://www.nfoic.org/.
   - U.S. Freedom of Information Act
     - The U.S. Department of Justice provides extensive materials regarding the federal FOIA, including the DOJ Guide to the FOIA, court opinions, and training materials. Available at https://www.justice.gov/oip/foia-resources.
     - Information on each federal agency's FOIA activities, available at www.foia.gov.
   - State Open Records/ Freedom of Information laws. Most state Attorneys General websites provide materials on that state's FOI law. State Privacy offices may also provide materials concerning the intersection of its state's FOI law and privacy laws. See, for example, the materials on the West Virginia State Privacy Office's website at http://www.privacy.wv.gov/FOIAPRIVACY/Pages/default.aspx.

6. Guidance on the release of information concerning deaths, epidemics or emerging diseases was developed by the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO) and the Association of Health Care Journalists (AHCJ) to address the balance between informing the public and protecting privacy. This guidance is at http://www.healthjournalism.org/secondarypage-details.php?id=965.

7. The Network for Public Health Law's health information and data sharing resources are at https://www.networkforphl.org/topics__resources/topics__resources/health_information_and_data_sharing/.
   - A checklist to assist public health practitioners in providing relevant factual information to resolve questions about proposed data collection, access and sharing can be downloaded from https://www.networkforphl.org/resources_collection/2014/01/07/400/tool_checklist_of_information_needed_to_address_proposed_data_collection_access_and_sharing.

SUPPORTERS

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