



Resources

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 (2nd Draft), De-Identifying Government Datasets (2016), available at http://csrc.nist.gov/publications/drafts/800-188/sp800_188_draft2.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. Letter to HHS Secretary with recommendations at <http://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/2017-Ltr-Privacy-DeIdentification-Feb-23-Final-w-sig.pdf>.

- Open Data Privacy: A risk-benefit, process-oriented approach to sharing and protecting municipal data (February 2017), available at <https://cyber.harvard.edu/publications/2017/02/opendataprivacyplaybook>.
 - 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.
 - Nelson S. "Practical Implications of Sharing Data: A Primer on Data Privacy, Anonymization, and De-Identification." 2015. Available at <https://support.sas.com/resources/papers/proceedings15/1884-2015.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:
- California Open Data Handbook <https://chhsdata.github.io/opendatahandbook/> and Data Playbook <https://chhsdata.github.io/dataplaybook/>.
 - Colorado Health Information Dataset, Guidelines for Working with Small Numbers, available at <http://www.cohid.dphe.state.co.us/smnumguidelines.html>.
 - Missouri Department of Health & Senior Services, Data Release Policies, Procedures and Guidelines, available at <http://health.mo.gov/data/policies.php>.
 - 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>.
 - Ohio Department of Health, Data Methodology Standards for Public Health Practice, available at <http://www.odh.ohio.gov/-/media/ODH/ASSETS/Files/data-statistics/standards/methodological-standards/disclimit.pdf?la=en>.
 - Washington State Department of Health, Guidelines for Working with Small Numbers, available at <http://www.doh.wa.gov/portals/1/documents/1500/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 DEClDE 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 Policy Surveillance Program: A Law Atlas Project identifies state statutes and regulations that address health departments' ability to release and use personally identifiable information to promote public health and coordinate care. This interactive map is available at <http://lawatlas.org/datasets/public-health-departments-and-state-patient-confidentiality-laws>.

8. 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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This resource list was compiled by Denise Chrysler, JD, Director, with the Network for Public Health Law – Mid-States Region at the University of Michigan School of Public Health and by its contractor, Trust Matters, LLC. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.