



## DE-IDENTIFICATION Fact Sheet

# De-identification is an Important Tool to Make Data Available to Communities.

Generally, once public health removes or obscures personal identifying information within a data set, law does not constrain the use or disclosure of the remaining data. De-identification enables public health to collect and share data without violating individuals' privacy or law.


Public health has evolved to an expanded scope of practice, called Public Health 3.0, which recognizes that “[p]ublic health is what we do together as a society to ensure the conditions in which everyone can be healthy.”<sup>1</sup> Today, communities partner with public health and others to address important issues, often focusing on environmental and social determinants of health, with the goal of achieving health equity. A modern information infrastructure, built with health and non-health data that are locally relevant, is critical to both public health and its community partners. To help support this infrastructure, public health should more widely use de-identification to make more timely, reliable, sub-county and actionable data available. Understanding the benefits of utilizing de-identified data and the mechanics of disclosing it are matters of national priority.

## **Health happens in communities; it is where we live, learn, work and play.**

Many communities across the country have become learning health systems and are actively collaborating with local, state and national public health and others to ensure conditions in which everyone can be healthy. This toolkit highlights success stories where using and sharing de-identified data occurred and made a difference. Project Tycho illustrates the power of the use of de-identified data to quantify the impact that vaccine licensure has on the spread of disease. Mobile, Alabama, a Robert Wood Johnson Foundation Culture of Health Sentinel Community, effectively uses de-identified multi-sectoral data to improve health and well-being. The Memphis Community Health Record is spotlighted as a framework and tool for the community to simultaneously use, aggregate and integrate data and information. Importantly, this project's leadership understood that privacy is a balance and that collaboration is essential for data sharing; it also provides lessons learned and models for building trust and data governance.

## **Public Health 3.0 requires a sea change.**

A health official, in the role of Chief Health Strategist, provides the leadership required to champion the cultural shift within public health to legally and safely make more data available. Public health practitioners, privacy



officers, data managers and their attorneys need tools, resources and training to carry out this expanded data disclosure mission. This toolkit is intended for a broad audience of health officials, privacy officers, public health practitioners, data managers and their attorneys.

**This toolkit highlights traditional, non-traditional and emerging data sources that provide useful and actionable data regarding local health and well-being.**

These de-identified data may be freely published on the internet or disclosed to a trusted data recipient. It also provides public health practitioners and others with the tools and resources to better understand de-identification for improved collection and use activities, and to more freely, safely and legally disclose de-identified data needed for the community's information infrastructure. As de-identification is a delicate process involving a variety of statistical and scientific methods to balance data utility against the risk of breaching an individual's privacy, leadership should both govern and manage data disclosure, and ensure that it is performed by appropriately trained and experienced individuals.

The toolkit below contains an issue brief which provides an overview of the importance of access to timely and relevant health and non-health de-identified data, de-identification and the law, de-identification methods, re-identification studies, risks of bad de-identification and a four-step approach to analyzing de-identified data sharing. It also provides a range of tools and resources to assist public health practitioners, privacy officers, data managers and their attorneys share de-identified data legally and safely.

- Issue Brief
- Case Studies Where Data Sharing Makes a Difference
- Table of Statutes
- Table of Cases
- HIPAA Safe Harbor Tool
- HIPAA Expert Method Tool
- Statistical De-Identification Fact Sheet
- Checklist of Factual Information
- Checklist of Review Criteria
- Resources

**SUPPORTERS**



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**This document was developed by Sallie Milam, JD, CIPP/US/G, Deputy Director, Network for Public Health Law – Mid-States Region Office, and reviewed by Denise Chrysler, JD, Director, Network for Public Health Law – Mid-States Region Office. 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.**



<sup>1</sup> Public Health 3.0 - A Call to Action to Create a 21st Century Public Health Infrastructure, p. 4, Retrieved from <https://www.healthypeople.gov/sites/default/files/Public-Health-3.0-White-Paper.pdf>

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