Building Public Trust in De-Identified Health Data

May 31, 2013
Tags: Array

Supporting Documents

The aim of this paper is to summarize concerns with the de-identification standard and methodologies established under the Health Insurance Portability and Accountability Act (HIPAA) regulations, and report some potential policies to address those concerns that were discussed at a recent workshop attended by industry, consumer, academic and research stakeholders.

HIPAA sets forth methodologies for de-identifying health data; once such data are de-identified, they are no longer subject to HIPAA regulations and can be used for any purpose. Concerns have been raised about the sufficiency of HIPAA de-identification methodologies, the lack of legal accountability for unauthorized reidentification of de-identified data, and insufficient public transparency about de-identified data uses. Although there is little published evidence of the re-identification of properly de-identified datasets, such concerns appear to be increasing.

This article discusses policy proposals intended to address de-identification concerns while maintaining de-identification as an effective tool for protecting privacy and preserving the ability to leverage health data for secondary purposes.

*This article was first published online in the **Journal of American Medical Informatics Association**, June 26, 2012*

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- HIPAA
- de-identification

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