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Panelist Statement (HHS Workshop on the HIPAA Privacy Rule's de-identification standard)

Healthcare institutions and health researchers need deidentification methods to exchange, aggregate, and analyze data. Deidentified health records used in medical research or in the development of public policies will ultimately need to be disclosed to the public; otherwise, the quality of the data and the validity of research results, cannot be evaluated.

Currently, some of the methods used to deidentify health data are held by patent or are otherwise encumbered as intellectual property (e.g., licensed software). Healthcare workers and scientists who need to deidentify records often do not know the trusted methods that are freely available to them, and cannot assess whether any particular method is encumbered. I recommend that HHS collect, certify, and make available a variety of public domain algorithms and software implementations that can be used for the common tasks in health record deidentification. These would include free-text scrubbing algorithms, methods to identify and remove safe harbor identifiers, statistically valid ambiguity and obfuscation methods, relevant encryption protocols, and methods to safely reconcile patient identifiers within and across institutions (e.g., zero knowledge protocols).

The most critical task of EHR systems involves assigning a unique code to each patient (sometimes called the patient identifier), that is assigned to every transaction for the patient, and that is not used for any other patient, within a healthcare environment. Reliable methods for creating and assigning unique patient codes require human participation. I strongly suggest that HHS collect a variety of methods for assigning and maintaining unique patient codes. I also suggest that if EHR systems are certified by a federal agency, the key element of review should be the human/computer protocols for assigning and maintaining patient identifiers.

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