Who Owns Health Information?

Ownership of health information depends on a variety of factors, including the source, custody, and form of the information and legal rights, such as rights created by contracts or under state law. In the case of medical records, healthcare providers like physicians and hospitals usually own the medical records in their custody, which represent part of the business records of their organization or practice. Prior to HIPAA, individuals may not have had any rights with respect to those records, depending on state law. The HIPAA Privacy Rule gives individuals who are the subject of a medical record (held by a covered entity such as a healthcare provider) the right to access their record, amend the record, obtain a copy, and direct that the record be provided to other healthcare providers. However, while the HIPAA Privacy Rule protects the privacy of individually identifiable information, individuals do not "own" the record and cannot take it from the provider or have it destroyed. The same principles apply to information contained in a provider's electronic medical record (EMR). Like the HIPAA Privacy Rule, many state laws give individuals certain rights of access and control with respect to their medical records and the information contained in those records (and in the case of New Hampshire, patients own the information in their record under state law), but ownership of the record remains with the provider who created or has custody of the record.

If the health information in question is not part of a provider's medical record, ownership of information generally belongs to the individual or company who created or authored the information. Beyond that, a variety of laws and contractual relationships may determine ownership. For example, intellectual property laws protect "original works of authorship" and trade secret laws may protect confidential information that provides a competitive advantage. Copyright laws and patents may protect proprietary formats for information, such electronic record software, programming code, applications, and databases that contain aggregated information. The collection of information into a database can also change the information into something new that may be subject to legal protections independent of the original source material. New forms of health records, such as personal health records (PHRs) provided by a health care provider, health plan, or web-based service, can pose complex questions of ownership and control. Individuals should carefully read terms of use to be sure of their rights and responsibilities before providing personal information.

Finally, note that de-identified information (which is no longer protected health information under the HIPAA Privacy Rule) may be used for a number of purposes, including aggregation into a data set that may be "owned" by the creator of the data set. The recent emphasis on tracking cost and quality has increased interest in large sets of data that include information about patient treatment and outcomes, with identifying patient information removed. These data sets may become valuable commodities to be bought or sold.

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See our 50 State Comparative Map of state medical record ownership laws here: http://www.healthinfolaw.org/comparative-analysis/who-owns-medical-records-50-state-comparison. For more information on Medical Records Collection, Retention, and Access, see our resources here: http://www.healthinfolaw.org/topics/60.

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