MYTH: Patients own their health information and medical records. FACT: The person or organization holding the information, such as a physician or hospital, generally owns the information.

Patients who disclose sensitive information about their health history and personal information such as their social security number may continue to think of that information as "theirs" even if they give it to a provider for the purpose of receiving healthcare services. In fact, once a patient discloses information that becomes part of a healthcare provider's medical record, the information is now owned by the provider. The HIPAA Privacy Rule gives individuals who are the subject of a medical record (held by a covered entity such as a physician or hospital) the right to access their record, amend the record, obtain a copy, and direct that the record be provided to other health care providers, and protect the privacy of individually identifiable information, but the individuals do not "own" the record and cannot take it from the provider or have it destroyed. The same principle applies to information contained in a provider's electronic medical record (EMR). Like the HIPAA Privacy Rule, some state laws give individuals certain rights of access and control with respect to their medical records and the information contained in those records, but ownership remains with the provider who created or has custody of the record. (One exception is in New Hampshire, where the state Patients' Bill of Rights statute deems the medical

information in medical records to be the property of the patient.¹)

In the case of repositories other than a provider's medical record, ownership of information generally belongs to the individual or company who created or authored the information. HIPAA does not apply to information that is not held by a covered entity (health care provider, plan, or clearinghouse), so individuals may not have rights to control information contained in records such as disease registries or public health databases. That information is most likely owned by the owner of the database. For other types of health information that are not medical records of individuals, and derivatives of that information, a variety of laws and contractual relationships may determine ownership. The information may be considered intellectual property, trade secrets, copyrighted, or protected by a patent, and a variety of state and federal laws would determine "ownership" in those cases. 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. De-identified information, in particular, is likely to be used in large data sets that may be bought and sold.

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¹ N.H. Rev. Stat. Ann. § 151:21.

New forms of personal health records (PHRs) can pose complex questions of ownership and control. In general, when a person creates a PHR, he or she retains ownership of it. When the information from a PHR is given to a provider, it becomes part of the medical record owned by the provider. However, when the information is put into a web-based program that stores the information for the individual, there may be portions of the information that become the property of the software developer or service provider, depending on the contract between the individual and the program. In the case of PHRs sponsored or provided by health plans, the information put into the PHR may become the property of the health plan. Individuals should carefully read terms of use to be sure of their rights and responsibilities.

For More Information:

- <u>See</u> our 50 state map of medical record ownership laws.
- <u>See</u> our 50 state map of individual access to medical records laws.
- Learn more about HIPAA.
- <u>Explore</u> state and federal laws related to Medical Records Collection, Retention, and Access.

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