

MYTH: All patient-generated health data has the same privacy and security protections.

FACT: The privacy and security protections of patient-generated health data varies depending on the type of entity collecting or storing the information.

Patients generate health data using a variety of sources, including patient portals (online applications where patients and providers can share health information remotely, such as BlueButton), patient-powered research networks (e.g., PatientsLikeMe), and even social media networks (e.g., Facebook). This is distinct from more traditional methods of patient health data collection, where healthcare providers collect information from the patient and store it on site. Patient-generated health data (PGHD) has many benefits; however, not all PGHD is protected in the same way, and patients should be aware of the ways in PGHD can be used depending on where and how it is shared.

While federal laws and regulations govern the use and disclosure of personal health information held by “covered entities” (i.e., physicians, hospitals, and health plans), PGHD that is created and/or shared on patient-powered research networks (e.g., PatientsLikeMe and 23andMe) and registries (e.g., BioBank) may not be protected in the same way. In fact, HIPAA and the Common Rule do not regulate patients, and therefore PGHD enjoys far less legal privacy and security protection as compared to health information contained in a physician’s medical record.

Many websites on which patients share their health information are owned and operated by private companies, and each one sets forth its own privacy

and security parameters for the information contained therein. All patient-participants must agree to the “terms and conditions” of the applicable site, which will detail exactly how any uploaded PGHD will be used and disclosed. In addition, individual states may separately regulate the privacy and security of online information.

In contrast to HIPAA, which prohibits the use and disclosure of protected health information by covered entities (except in certain circumstances), the terms and conditions of a typical website are much more expansive, and thus less protective of health information shared or stored there. In fact, some sites tell the patient that any uploaded information may be used and/or sold to entities such as research institutions, pharmaceutical companies, medical device companies and others. Although PGHD may be subject to different protections than traditional health information, it has many unique benefits as well, such as enabling patients to be active participants in their own health, improving clinician-patient communication, and serving as a rich source of data for health research.

For More Information:

- [Learn](#) more about privacy and confidentiality.

Follow us on Twitter at [@HealthInfoLaw](#)