Data Mobility and HIPAA: Protect Privacy and Support Research

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The data mobility issues which exacerbated the Covid-19 crisis lay bare the acute need for a health data privacy regime able to protect patients while enabling beneficial aggregation. The existing health data privacy framework is misaligned with reality because it assumes that health data is analogous to physical records, can be governed like property, and can be protected through procedural safeguards that cease to function once data has been “released.” That is, the law understands health data as either protected and immobile or, once released, mobile and unprotected. To build a health data privacy system that supports both data sharing as well as lasting protection for patients, the nation must shift toward a rights-based framework in which health data is recognized as a manifestation of personhood.

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