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Why patients shouldn't "own" their medical records

To the Editor:

The Commentary in your September issue by Kish and Topol¹ listed several possible benefits of personal health data ownership by patients. The authors rightly point out several problems that are caused by the lack of data sharing. There is a substantial body of literature on patients' attitudes to data sharing, their desire for control of their health data, and their expectations of and concerns about healthcare professionals sharing data safely and appropriately. This notwithstanding, we believe that patient ownership of health data creates several problems.

First, it must be stated for clarity that there is no property in data. If something is not property, it cannot be owned nor stolen. Thus, the proposed benefits of ownership described cannot accrue to patients in that way. This fundamental understanding is crucial to any argument about providing patients with the right to access their own healthcare data, given that they are appealing for legally enforceable rights. Plain lists of facts do not constitute intellectual property, as per *Feist Publications v. Rural Telephone Service*² and the *Fixtures Marketing* cases³. There are property rights in a database as a thing in action, but these relate to intellectual property or *sui generis* database rights (which apply in the European Union, (EU), Brussels). There are also philosophical objections to the assertion that "without ownership, there can be no trusted exchange." It is the ability to enforce contracts that is the basis for trusted exchange, not the concept of a thing in possession. A contractual *right in personam* overrides a *right in rem*; therefore, this is a better basis for protection of data rights.

The rights over personal data largely relate to issues of privacy and confidentiality, and can be contrasted with the rights over

anonymized data. The authors promote the benefits of aggregated health data from a communal bank of health data. Much of the research on aggregated health data can be performed with anonymized or pseudonymized (i.e., reversibly anonymized through the use of a key or similar means) data. Patient 'ownership' of data would have the potential to make access to aggregated data more difficult and thus to hinder research⁴.

Their proposed solution might be optimal for the US situation—the lack of interoperability of health IT systems, the payment of fees by healthcare providers to access their patients' data held by other providers and the disincentives in a fee-for-service system to reduce repeat testing of no medical value—but it would prove an impediment in nationwide public healthcare systems such as are common in the EU and of which the UK's National Health Service is typical.

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The authors declare no competing financial interests.

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Topol and Kish reply:

Technology has far outpaced our legal system's ability to establish new forms of data property, both in the United States and worldwide. There are many inconsistencies, but the lack of clarity should highlight the need for us to pursue new definitions of data property, not to resign ourselves to the belief that constructing new rules will be too difficult. The potential value is vast. New approaches to medical data ownership, implemented via technological solutions and legislative action, must be advanced in order for individualized medicine to achieve its potential.

The point raised by Rumbold—that there "is no property in data"—is in many circumstances false. Although intellectual property (IP) is a matter of national law and can vary by nation, research data are often considered IP and are covered as a trade secret, or copyrighted.

This raises an interesting point as to whether an individual's data, say from a medical device, constitute a new kind of research and could be considered IP of the individual, or whether they are just a set of facts. As we move toward precision medicine, personal data will take on much greater value, and we expect that laws will need to adjust.

In addition, in the United States, many states have determined that medical records are property, mostly that of the providers who collect them. In New Hampshire, however, "Medical information contained in the medical records at any facility licensed under this chapter shall be deemed to be the property of the patient"¹.

Finally, several states have considered bills asserting that genetic data not only is property, but should be considered 'real property' of the individual from whom it came. Real property normally requires a verified signature in order to be transferred. In other contexts, our identities have recognized value, and there are laws that protect the use of our likeness, our image, our voice and other information derived from us. The bottom line is that personal data are already viewed as property in a variety of contexts.

Doing nothing about ownership has had the effect of encouraging unwanted behavior, as we saw last year with over 100 million data breaches in the United States². The high value of the data is increasing, promoting incentives for acquiring them, but apparently not enough incentives to protect them. Laws are generated and rights

