

## Letter to the Editor

### Why patients shouldn't "own" their medical records

The commentary by Kish and Topol<sup>1</sup> listed a number of possible benefits of personal health data ownership by patients pointing out the number of obstacles to sharing of health data that may be overcome by patient ownership. The authors rightly point out a number of 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 there are a number of problems that patient ownership of health data creates. Firstly, 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*.<sup>2</sup> There are property rights in a database as a thing in action, but these relate to intellectual property or *sui generis* database rights (that apply in the EU).

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 anonymised 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 anonymised or pseudonymised (that is reversible anonymisation by means of key or similar) data. Patient "ownership" of data would have the potential to make access to aggregated data more difficult and thus to hinder research.<sup>3</sup>

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 a nation-wide public healthcare system which is common in the EU and of which the UK's National Health Service is typical.

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<sup>1</sup>Kish LJ, Topol EJ. Unpatients – why patients should own their medical data. *Nature Biotechnology*. 2015 33(9): 921-24.

<sup>2</sup> Feist Publications, Inc., v. Rural Telephone Service Co., 499 U.S. 340 (1991)

<sup>3</sup> Lowrance WW. *Privacy, Confidentiality, and Health Research*. Cambridge: Cambridge University Press; 2012