

Group Title: Patient data ownership

To the Editor:

The Viewpoint by Ms Mikk and colleagues<sup>1</sup> aimed to improve patient engagement and healthcare informatics and recommended technical improvements to electronic healthcare records. The authors proposed a data use agreement (DUA) that relates to data quality, integrity, privacy, and security. Our principal concern is with the use of such a DUA to grant patients control over all uses of health data, including in secondary research. This measure of control is apparently what the authors referred to as “patient data ownership” in their title, although the term was not used in the body of the article.

Individual ownership of data, whether health-related or otherwise, is contrary to well-established legal precedent in the United States, United Kingdom and many other jurisdictions, which for good reasons do not recognize property interests in mere facts or information.<sup>2-3</sup> Instead, the authors would establish property-like rights through contract. Granting individuals a high degree of control over health data may hinder valuable biomedical research, whether this is conferred under a property or contract-based legal regime. For example, giving patients the right to specify that they approve of research relating to cancer but not to HIV, or to change their minds regarding permissions previously granted, could have disruptive and far-reaching consequences for legitimate and potentially lifesaving research.

Thus, while telling patients that they own their data may elicit a short-term, positive response in patients, physicians, and policy makers, it may result in less effective research and flawed health

policy. Accordingly, we caution healthcare systems and informatics providers against expanding the use of DUAs in a manner that gives individuals property-like control over data.

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2. Contreras JL. Genetic Property. *Georgetown L.J.* 2016;105(1):1-54.
3. Evans BJ. Much Ado About Data Ownership, *Harv. J.L. & Tech.* 2011;25(1): 69-130.