

Data Altruism: Honoring Patients' Expectations for Continuous Learning

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Ninety-four percent of U.S. adult social media users with health conditions agree with use of their health data, shared anonymously, to help clinicians improve care, according to a discussion paper available today from the Institute of Medicine (IOM). This strongly prevailing perspective was reinforced by answers to different survey questions with similar intents, which found that 92 percent of respondents supported sharing their health data to help research and 94 percent to help other patients.

These survey results—presented by participants in IOM's Evidence Communication Innovation Collaborative (ECIC)—offer a refreshing counterpoint to the dominant narrative of data sharing and electronic health records as a source of potential risk to patients through the erosion of privacy. Although patients do expect their privacy to be protected, they also expect their health data to be put to use in improving care for themselves, their families, and for future patients. These findings also echo results found by Consumer Reports' National Research Center when it queried the general public: 9 in 10 people agreed that their health data should be used to help improve the care of future patients.

This altruistic vision of clinical data as a shared resource—embraced by U.S. social media users with health conditions—is an essential building block for achieving a continuously learning health system, in which data from every health care interaction are leveraged to inform future practices. As

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Health Affairs Blog noted previously, patients place “significant emphasis” on the latest medical evidence as they make health care decisions (“An Evidence-Based Approach to Communicating Health Care Evidence to Patients,” September 25, 2012).

When privacy is protected, learning can be profound. Kaiser Permanente recently found that timely administration of a statin to patients hospitalized after suffering strokes dramatically reduced mortality rates. That finding—powered by access to de-identified data—came about because patients gave permission in advance for the research to be conducted. We need a world in which more research like this can be done. The learning that can result from that research will save many lives.

The new book *Don't Let Health Care Bankrupt America*, released in January 2014, demonstrates explicitly how that kind of patient-centered data can be used to make care better and more affordable. Significant reform in the practice of research and the delivery of health care will be needed to make patients' vision a reality, and as the nation moves toward an emphasis on value and coordination in health care, investment in resources for data sharing and analysis will become increasingly

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critical to success. The provision in the Patient Protection and Affordable Care Act that patients cannot be denied coverage because of pre-existing conditions represents a major advance in the health data space, because it assuages one of most frequently reported concerns about data sharing: the possibility that it could imperil health benefits.

With the rise of social media sites as a potential source of health data—for example, the rapidly growing PatientsLikeMe site—comes not only new opportunity, but also the need to develop assurances that support patient privacy and trust in a research context. The regulatory protections provided for data from traditional medical and research settings do not extend to other platforms, and some systematic approach is likely necessary to sustain an altruistic national attitude toward continuous learning from health data provided through social media platforms.

Today, to an unprecedented extent, patients and families hold the keys to the pace of health care progress, both in their direct contributions to better understanding of the patient experience and in their insistence that their experience be captured and applied on behalf of improving care. Health care

providers have an obligation to respond to patients' expectations for data sharing, and by extension, to achieve the potential that real-time, accessible data can impart to the American medical enterprise.

Achieving this promise in a connected, data-driven world will require a new formulation of health care, centered on strong patient–clinician partnerships in the delivery and improvement of clinical practice. Success will require changes in the culture, standards, and recording of the care experience, so that clinicians and patients both become active stewards in the learning process, facilitated by the incentives and regulatory streamlining that make change possible.

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