

Building a health care information economy based on patients' control of data

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The time is right for a broad range of stakeholders to push for a health care information economy founded on the basic principle that patients should have control over their data, Boston Children's Hospital informatics researchers say in a Perspective article in *The New England Journal of Medicine*. The technologies, demand and benefits are there, they note; what remains are the incentives and will to make it happen.

In the piece, Kenneth Mandl, MD, MPH, director of Boston Children's Computational Health Informatics Program (CHIP), and Isaac Kohane, MD, PhD, CHIP faculty and chair of the Department of Biomedical Informatics at Harvard Medical School, briefly recount the history of the movement to develop personally-controlled health records (PCHRs)—repositories in which patients can store, track and manage their own health data. They also point out barriers that have stymied PCHRs' widespread adoption, including the industry move to provider-based electronic health records (EHRs) and associated patient portals.

"EHRs are limiting in two ways," Kohane explained. "First, they only show the data from one hospital or provider, which is not a complete picture if you see multiple providers at multiple hospitals. Second, the data stay with that hospital, such that patients can't want to share their data elsewhere, easily seek second opinions or contribute their data to clinical studies."

"Since 1996, federal regulation defining a patient's right to health data have failed to ensure access," said Mandl. "Further, hospitals in general

do not see having complete patient records as a business priority. We believe the Meaningful Use program would have been more successful if it had rewarded clinicians for storing data in patient-controlled repositories rather than in EHRs that fragment data across the [health care](#) system."

The pair notes several reasons for pursuing a patient-controlled health data economy, including:

- enabling patients to gather all data from all health care encounters in one place, providing a more complete picture of a patient's health
- fostering greater coordination in the care multiple providers deliver to each patient
- allowing patients to easily donate their data for research purposes
- empowering patients to augment their data and correct errors in their health records
- feeding the development of intelligent health care software or health care apps

Mandl and Kohane outline four steps could fuel the creation of a patient-drive information economy in health care:

1. strong incentives from the Centers for Medicare and Medicaid Services and private insurers for [health care organizations](#) to provide data to patients
2. development, backed by federal health care IT policy and demand from purchasers of health systems, of uniform, standard, public application programming interfaces (APIs) to catalyze the development of an ecosystem of health data apps for providers and patients
3. creation of tools by which [patients](#) can set permissions and consents

for who can access their [health data](#) and for what purposes

4. adoption of rigorous authentication frameworks akin to those in the e-commerce industry to provide data security and accountability

"It's time to re-evaluate what the fundamental architecture of the health care system should look like," Mandl said. A patient controlled record allows each patient to become a health information exchange of one; as data accumulate in a patient controlled repository, a complete picture of the patient emerges."

"EHRs and patient portals were plan B," Kohane added. "We should go back to plan A, which was to create patient-controlled data stores that compiles all pertinent [data](#) across a patient's lifetime and is the patient's to share as they see fit."

Provided by Boston Children's Hospital

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