

The Healing Power of Your Own Medical Records

By [STEVE LOHR](#)

Steven Keating, a doctoral student at M.I.T.'s Media Lab, collected and researched his own patient data, which led to the discovery of a brain tumor. He is shown in front of an image of radiation backscatter from his brain during therapy. Credit Erik Jacobs for The New York Times

Steven Keating's doctors and medical experts view him as a citizen of the future.



A scan of his brain eight years ago revealed a slight abnormality — nothing to worry about, he was told, but worth monitoring. And monitor he did, reading and studying about brain structure, function and wayward cells, and obtaining a follow-up scan in 2010, which showed no trouble.

But he knew from his research that his abnormality was near the brain's olfactory center. So when he started smelling whiffs of vinegar last summer, he suspected they might be “smell [seizures](#).”

He pushed doctors to conduct an [M.R.I.](#), and three weeks later, surgeons in Boston removed a cancerous tumor the size of a tennis ball from his brain.

(See below: *News Analysis: Medical Records: Top Secret*)

At every stage, Mr. Keating, a 26-year-old doctoral student at the Massachusetts Institute of Technology's Media Lab, has pushed and prodded to get his medical information, collecting an estimated 70 gigabytes of his own patient data by now. His case points to what medical experts say could be gained if patients had full and easier access to their medical information. Better-informed patients, they say, are more likely to take better care of themselves, comply with prescription drug regimens and even detect early-warning signals of illness, as Mr. Keating did.

Mr. Keating with a 3-D-printed copy of his brain tumor. Credit Erik Jacobs



“Today he is a big exception, but he is also a glimpse of what people will want: more and more information,” said Dr. David W. Bates, chief innovation officer at Brigham and Women’s Hospital.

Some of the most advanced medical centers are starting to make medical information more available to patients. Brigham and Women’s, where Mr. Keating had his surgery, is part of the Partners HealthCare Group, which now has 500,000 patients with web access to some of the information in their health records including conditions, medications and test results.

Other medical groups are beginning to allow patients online access to the notes taken by physicians about them, in [an initiative called OpenNotes](#). In a yearlong evaluation project at medical groups in three states, more than two-thirds of the patients reported having a better understanding of their health and medical conditions, adopting healthier habits and taking their medications as prescribed more regularly.

The medical groups with OpenNotes programs include Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in Pennsylvania, Harborview Medical Center in Seattle, the Mayo Clinic, the Cleveland Clinic and the Veterans Affairs department. By now, nearly five million patients in America have been given online access to their notes.

As an articulate young scientist who had studied his condition, Mr. Keating had a big advantage over most patients in obtaining his data. He knew what information to request, spoke the language of medicine and did not need help. The information he collected includes the video of his 10-hour surgery, dozens of medical images, genetic sequencing data and 300 pages of clinical documents. [Much of it is on his website](#), and he has made his medical data available for research.

Still, he said he encountered a medical culture resistant to sharing data, owing to tradition, business practices and legal concerns.

“The person with the least access to data in the system is the patient,” he said. “You can get it, but the burden is always on the patient. And it is scattered across many different silos of patient data.”

Since his diagnosis last summer, Mr. Keating has become a passionate advocate for giving patients all the medical data they ask for. He has given talks at M.I.T., where he studies mechanical engineering, he has met with doctors, hospital administrators and researchers, and he has been invited to the White House.

<http://www.nytimes.com/2015/04/01/technology/the-healing-power-of-your-own-medical-data.html>

He knows that what he is pushing goes against convention.

To a hospital, a patient is a revenue-generating asset, said Ben Shneiderman, a professor at the University of Maryland who is a health technology expert. Hold onto the patient's information, and you are more likely to keep the patient. Health software suppliers have traditionally sold closed, proprietary systems, which tend to lock in customers.

“The problem is that you have institutions whose business models do not favor sharing information, either with other hospitals or patients,” said Mr. Shneiderman.

Yet the economic incentives for data-sharing, some medical experts say, are beginning to fall into place. Increasingly, providers will be paid a set amount of money for a population of patients, an approach called accountable care, and a departure from fee-for-service reimbursement in which doctors and hospitals are paid for each test and treatment.

Photo



A 3-D print of Mr. Keating's M.R.I. data showing his large brain tumor, the white mass in the right front section of the brain. Credit Erik Jacobs for The New York Times

Accountable care reimbursement is a critical ingredient in the Obama administration's [health care overhaul](#).

“The accountable care world is based on wellness rather than episodic illness,” said Dr. John Halamka, chief information officer at Beth Israel Deaconess. “In the fee-for-service world, the incentives for

data-sharing were not there. But with accountable care, providers cannot survive unless they share data,” to help improve care and eliminate unnecessary tests.

The medical groups, Dr. Halamka said, will insist that their technology suppliers open up their software for automated data handoffs, which are a fixture of Internet technology but not health care technology.

Dr. Halamka is part of an effort to accelerate the adoption of open technology standards in health care, the Argonaut Project, which began in December. It has representatives from a few large medical groups, but also from leading suppliers of electronic health records, including Epic, Cerner and McKesson.

The Argonaut project, said Claudia Williams, a senior adviser for health innovation and technology policy in the White House, is a “very hopeful sign” that “incentives are beginning to line up in a powerful way” to encourage more openness and sharing of data among providers and with patients.

Opening data to patients raises questions. Will worried patients inundate physicians with time-consuming questions? Will sharing patient data add to legal risks? One detail in the yearlong study of OpenNotes underlines doctors’ concerns; 105 primary physicians completed the study, but 143 declined to participate.

Still, the experience of the doctors in the evaluation seemed reassuring. Only 3 percent said they spent more time answering patient questions outside of visits. Yet knowing that patients could read the notes, one-fifth of the physicians said they changed the way they wrote about certain conditions, like [substance abuse](#) and [obesity](#).

Evidence of the benefit to individuals from sharing information rests mainly on a few studies so far. For example, 55 percent of the members of the [epilepsy](#) community [on PatientsLikeMe](#), a patient network, [reported that](#) sharing information and experiences with others helped them learn about [seizures](#), and 27 percent said it helped them be more adherent to their medications.

Mr. Keating has no doubts. “Data can heal,” he said. “There is a huge healing power to patients understanding and seeing the effects of treatments and medications.”

Health information, by its very nature, is personal. So even when names and other identifiers are stripped off, sharing personal health data more freely with patients, health care providers and researchers raises thorny privacy issues.

Mr. Keating says he is a strong believer in privacy, but he personally believes that the benefits outweigh the risks — and whether to share data or not should be an individual’s choice and an individual responsibility.

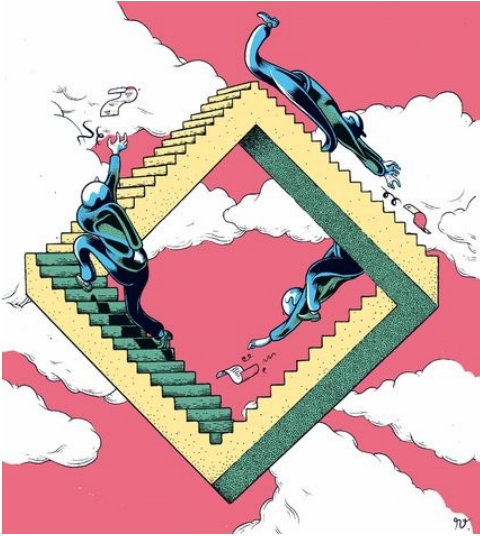
Not everyone, surely, would be as comfortable as Mr. Keating is sharing all his medical information. But he says he believes that people will increasingly want access to their medical data and will share it, especially younger people reared on social networks and smartphones.

<http://www.nytimes.com/2015/04/01/technology/the-healing-power-of-your-own-medical-data.html>

“This is what the next generation, which lives on data, is going to want,” Mr. Keating said.

A version of this article appears in print on April 1, 2015, on page B1 of the New York edition with the headline: Healed by His Own Data.

Medical Records: Top Secret.



Credit Renaud Vigourt

MANY readers were shocked by my recent article about [Peter Drier](#), who received a surprise bill of \$117,000 from an out-of-network assistant surgeon who helped out during his back operation. But almost as surprising was how difficult it was during my reporting for Mr. Drier to extract his own records from the hospital.

He wanted a copy because he enjoys adventurous travel and he needed a record of the surgery in case of injury; I wanted to see the chart to make sure nothing unusual had occurred in the operating room that might justify the enormous bill. Hospitals are computerized, and patients have a right to their own records, so I assumed getting the chart would be easy.

I was wrong. The six-week ordeal included requests that needed to be made via regular mail, numerous phone calls, consent forms and an estimate for copying fees that totaled \$100. This was topped off by an actual visit to the hospital by Mr. Drier, who sat in an office until he had paper documents in hand.

In a digital age when we can transfer money to purchase a house online or view a college transcript by logging on to a secure website, why is it so often difficult for patients to gain access to their medical data? And who controls our health information?

“You should be able to walk into a provider’s office and say, ‘I want a copy’ — you are legally entitled to that,” said I. Glenn Cohen, a professor at Harvard Law School, noting that there were only a few exceptions, such as for prisoners. But the reality is that many hospitals and doctors have created a series of hurdles that must be cleared before patients can get their information. And many of those hurdles, experts say, are based on the economics of medicine.

“The medical record is held hostage,” Professor Cohen said. “The reason is often to keep a customer or keep a patient from leaving the practice.”

Some providers contend that releasing information might somehow compromise patient privacy and confidentiality concerns laid out in Hipaa, the Health Insurance Portability and Accountability Act of 1996. But that legislation was created at the dawn of the Internet era, when there were worries that sensitive health information that could embarrass patients or leave them vulnerable to discrimination would be too freely accessible. Internet security systems have greatly improved, and it is no longer legal for insurers to reject applicants for pre-existing conditions.

“When hospitals talk about Hipaa or charge for releasing records what they’re really saying is, ‘I don’t want to do this and I have to find an excuse,’ ” said Dr. David Blumenthal, president of the Commonwealth Fund, who was previously President Obama’s national health information technology coordinator. “Hipaa is used in all sorts of distorted ways, because ‘protecting privacy’ sounds good.”

This summer, for example, Michael Madrid, 47, a software developer in New York City, saw an orthopedist because of knee pain and was sent for an M.R.I. When he called the office for results he was told he had to come in to get them, to protect his “privacy.” The scan showed a small ligament tear that required no treatment, and Mr. Madrid was billed \$170 for a second visit.

He complained to the doctor and the hospital and on Yelp. He asked the Department of Health and Human Services about Hipaa concerns, which said there were none. “It was a huge inconvenience,” he said. “I had no privacy issues. This was irrelevant. They could have put my M.R.I. on Twitter and Facebook.”

A better flow of information would benefit both patients and the health care system as a whole, Dr. Blumenthal said. If patients possess their records they can choose and move their care at will, picking doctors and testing sites that are cheaper or more to their liking. Likewise, if records can be transmitted with the ease of emails, doctors in different locations can better dispense treatment, avoiding the need to repeat tests. On a larger scale, the release of data that is now trapped in hundreds of hospital systems and thousands of doctors’ offices is crucial for researchers, Dr. Blumenthal said. They could use it to identify trends in overuse or unrealized side effects. (For research purposes, the data can easily be released in a way to protect patients’ identities.) “The nation is on a journey toward more accessibility,” Dr. Blumenthal said, though it still has “a long way to go.”

Linda E. Fishman, senior vice president of the American Hospital Association, said that while the organization supported patients’ rights to their information, providing it was not always simple. “Responding to requests is more difficult than it should be,” she said, because “the entire health care system has one foot in the paper world and the other in the electronic world.” She added that the consequences of violating patient privacy laws were “severe.” Already a few major health systems have been slowly dismantling the firewall between patients and their data. For example, Kaiser Permanente in California, Partners Health in Boston and the Cleveland Clinic allow patients to log on to secure

websites to view their test results and other medical information.

Government mandates, meanwhile, are laying the groundwork for more sharing. Legislation passed in 2009 prods hospitals and doctors' offices to [convert to electronic records](#), a changeover that officials estimate is more than 80 percent complete. But the next step requires health providers to show they are using that capability to begin better sharing medical information with patients and one another. That will begin to phase in next year.

BUT resistance is likely to be fierce from some corners, since sharing data goes against hospitals' and doctors' financial interests when they are jockeying to hold on to patients in a competitive market. The more health care providers restrict the release of records and lab results, the harder it will be for patients to leave. And the companies that design electronic medical record software also don't want patients to leave their orbit, any more than the makers of P.C.s want to facilitate a move to a Mac. In fact, Professor Cohen said, many programs are built so that they cannot share information with one another.

Although doctors and hospitals legally own their medical charts, patients have a right to have access in a timely manner — [Hipaa requires a response](#) within 30 days of a patient request — and at a reasonable processing cost. In the end, Mr. Drier spent six weeks trying to obtain the paper record of his back surgery — though he would have preferred a digital copy. That may or may not have exceeded the 30-day deadline stipulated by law, depending on how the days are counted. But is that “reasonable” in an age when most information is available with the click of a mouse?

Elisabeth Rosenthal is a reporter for The New York Times. For a continuing conversation about health care costs and pricing in the United States, please join our Facebook group, [Paying Till It Hurts](#).

A version of this news analysis appears in print on November 9, 2014, on page SR5 of the New York edition with the headline: **Medical Records: Top Secret.**