Technology

The Healing Power of Your Own Medical Records

By STEVE LOHR, MARCH 31, 2015

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.

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.

“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.
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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.

Mr. Keating with a 3-D-printed copy of his brain tumor. Credit Erik Jacobs for The New York Times

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.

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.

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.
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

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.

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

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