

New Guidelines Nudge Doctors on Giving Patients Access to Medical Records

By ROBERT PEAR

WASHINGTON — The Obama administration is tearing down barriers that make it difficult for patients to get access to their own medical records, telling doctors and hospitals that in most cases they must provide copies of these records within 30 days of receiving a request.

In theory, patients have long had a right to obtain copies of their records, but federal officials say they receive large numbers of complaints from consumers frustrated in trying to exercise that right.

In new guidelines, issued this month, the administration says doctors and hospitals cannot require patients to state a reason for requesting their records, and cannot deny access out of a general concern that patients might be upset by the information.

"Based on recent studies and our own enforcement experience, far too often individuals face obstacles to accessing their health information," said Jocelyn Samuels, the director of the Office for Civil Rights at the Department of Health and Human Services, which enforces federal health privacy standards. "This must change."

When patients can see their medical records, the administration said, it is easier for them to participate in their

health care. They can, for example, review what they were told by their doctors and, perhaps, consider other options for care.

Christopher S. Moore of Alpharetta, Ga., said he had great difficulty obtaining hospital records for his 4-year-old son, Oliver, who has a rare genetic disorder and has seen at least eight medical specialists in Atlanta, Cincinnati and Boston.

"The hospital in Atlanta was very slow to respond," Mr. Moore said. "We had to escalate our request to the hospital leadership to get the records."

Mr. Moore said insurers had spent \$800,000 on care for his son, generating several thousand pages of medical records.

"Some doctors seem to believe that medical records are intended only for doctor-to-doctor communication, and that patients would not understand those records," Mr. Moore said. "We want the records so we have control over them — so we can provide them to any doctor who sees our son."

Under the new guidelines, a health care provider cannot require patients to pick up their records in person if they ask that the records be sent by mail or email. A health care provider cannot deny a request for access to health information because a patient has failed

to pay medical bills. A doctor or a hospital may charge a fee to cover the cost of copying, but cannot charge for the cost of searching for data and retrieving it.

Dr. Francis S. Collins, the director of the National Institutes of Health, said consumers needed access to their

records so they could "take more control over decisions regarding their health," follow treatment plans and correct errors in the files.

In addition, Dr. Collins said, some people want access to their records so they can contribute information to bio-

medical research projects like President Obama's "precision medicine" initiative.

Researchers working on the project will collect data on the health, genetic characteristics and lifestyle habits of a million or more volunteers.

The same rules that protect the privacy of medical records also give patients a right to see a broad array of health information about themselves. The rules were issued under the Health Insurance Portability and Accountability Act of 1996.

Doctors and hospitals are supposed to provide consumers with access to personal health information within 30 days and, in some cases, can extend the deadline by 30 days. But, the administration said, most requests should be fulfilled in fewer than 30 days.

Melinda R. Hatton, a senior vice president of the American Hospital Association, said the guidelines were "a helpful reminder." Hospitals, she said, "strongly support patients' access to their medical records," and many have web portals that let patients view information about their care.

But Deven McGraw, a deputy director of the Office for Civil Rights, said complaints about access to medical records were one of the top five issues



MELISSA GOLDEN FOR THE NEW YORK TIMES

Christopher S. Moore with his son, Oliver, 4, who has a rare genetic disorder. Mr. Moore said he had difficulty getting Oliver's full medical records.

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investigated by her agency.

Megan O'Boyle of Arlington, Va., whose 15-year-old daughter has intellectual disabilities, autism and epilepsy, said, "It burns me up that I had to jump through hoops to get her records."

She said she wanted copies so new doctors could see the history of her daughter's illness and would not have to repeat medical tests and imaging procedures.

"It's empowering when you get all this information," Ms. O'Boyle said. "You can be a much better advocate for the patient. More information is better. It means better services for my daughter."

For patients with chronic illnesses, the fees charged by doctors and hospitals for providing medical records can add up. "Why should I have to pay 25 cents to 50 cents a page for what really belongs to me in the first place?" Ms. O'Boyle asked.

Joy L. Pritts, a former privacy officer at the Department of Health and Human Services, said that "many health care providers still don't understand that patients have a right to get their medical records," and she sug-

gested a possible reason.

"It may be contrary to the financial interests of health care providers to give patients broad access to their medical records," Ms. Pritts said. "Once patients have that information, they can share it with competing health care providers."

Under the rules, doctors and

An obligation to produce files within 30 days.

hospitals do not have to disclose psychotherapy notes that are kept separate from the rest of a patient's medical record.

Health care providers may also deny requests if the disclosure of personal health information is "reasonably likely to endanger the life or physical safety" of a patient or another person. Thus, certain information might be denied to a suicidal patient.

But, the administration said, this exception is to be narrowly construed.