For the Record —
The Case for Managing Medical Records

Diligent patients attend to numerous aspects of their medical care. But one thing they may never have thought about doing is taking charge of their medical records.

By Dana Henry

DOCTOR AND POET William Carlos Williams once wrote that so much depends on a red wheelbarrow. Though not nearly as idyllic, in the world of modern healthcare, so much depends on medical records. Despite their importance, many people never even think about their medical records. And it's no wonder, given the way providers have traditionally viewed these documents. "In medical school, we learn that medical records exist so that doctors can communicate with other doctors," says Leana Wen, MD, an emergency room physician. "No one told us about the benefits they could bring when shared with patients."[1]

Like providers, patients tend to see medical records as doctors' property for use by doctors, whether for ongoing care within a doctor's office, allowing doctors to communicate with each other about their patients or reporting medical information to health insurance companies. When patients walk into a provider's office with a health concern — especially an urgent or serious one — medical records are probably the last thing on their mind. Those records can remain an invisible element of the healthcare transaction, at least from patients' perspectives. Yet, in many ways, medical records are all that count in healthcare. What's included in them serves as the basis for covering or denying care, conveying information from one specialist to another and making healthcare decisions down the line, even years later. Incomplete, inaccurate and outdated information can linger in medical records without anyone noticing — especially not the patients, who probably aren't even aware such mistakes exist.

Fortunately, patients have rights with regard to their records. Passed in 1996, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule explicitly gives patients the right to inspect, review and receive a copy of their medical and billing records that are held by health plans and healthcare providers covered by the Privacy Rule.[2] Covered health plans include health insurance companies, company health plans, HMOs and government programs that pay for healthcare such as Medicare and Medicaid. Covered providers include doctors, clinics, psychiatrists, dentists, chiropractors, pharmacies and nursing homes, but only if they transmit any information in an electronic form in connection with a transaction for which the Department of Health and Human Services has adopted a standard.[3] In simpler terms, almost all entities patients deal with are covered by HIPAA.

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Better Records, Better Care

Information professionals recommend patients obtain and keep a copy of their medical records for numerous reasons: 1) to ensure new providers receive all the information needed and no health information falls through the cracks; 2) to protect against accidental loss of them by the provider, which can happen; and 3) to allow patients to keep records past the date providers must legally keep them.[2]

Possessing records can also be a way for patients to learn more about their medical conditions.[2] Records may reveal information patients might not otherwise see such as lab work anomalies that have been flagged but never communicated directly to patients, or blood pressure levels that have been inching up over time, maybe even at different doctors' offices. Records can also be a valuable tool for helping family members better understand patients' conditions. And, if patients work with an advocate, records can be an important part of that relationship.

Errors are another reason people should be vigilant about obtaining and reviewing their records. The Joint Commission, a nonprofit that provides accreditation to healthcare organizations, found that communication failure was at the root of more than 70 percent of serious adverse health outcomes in hospitals.[4] Medical records are one place that errors may stem from due to poor communication that can be recorded and take on a life of their own. Simple transcription and entry errors, for example, can result in a wrong diagnosis or medication being added to

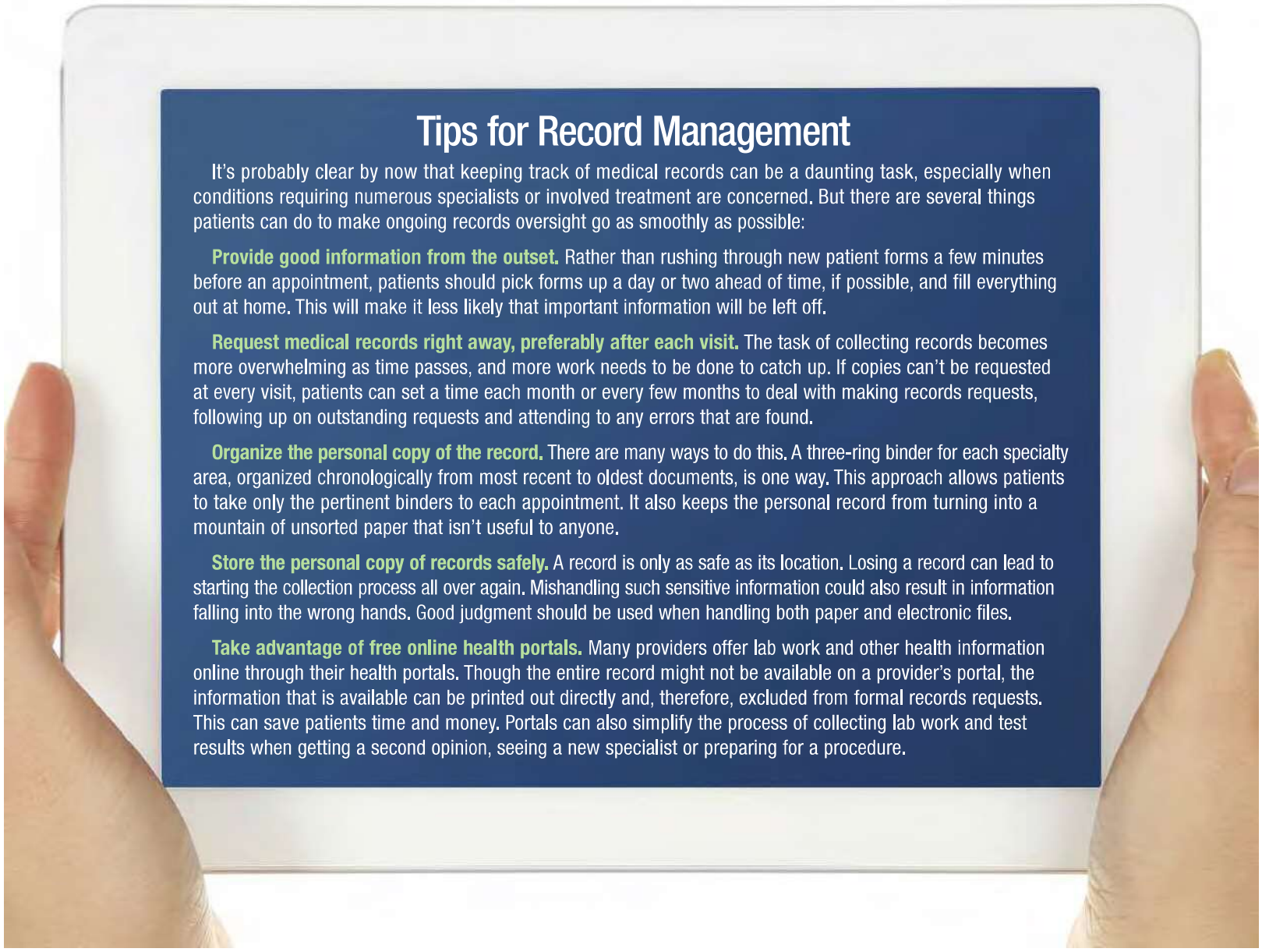
records. Larger errors can also occur such as those that arise when patients are discussing complicated medical histories with providers. Some details may get lost or be misconstrued, and those mistakes can make their way into records. Any error can have serious consequences, either immediately or down the line.

Dr. Wen recounts a time when a patient came to the emergency room with abdominal pain, and the patient asked if she could look at her record as Dr. Wen was updating it. "[The patient] began pointing out changes [to her chart]," Dr. Wen says. "She'd said that her pain had started three weeks ago, not last week. Her chart mentioned alcohol abuse in the past; she admitted that she was under a lot of stress and had returned to heavy drinking a couple of months ago." According to Dr. Wen, the patient's diagnosis became clear because she had been able to look at her record and help fill in the blanks. The woman was suffering from inflammation of the pancreas caused by alcohol use.[1]

This story illustrates just how important it is for patients to take an active part in reviewing and discussing their records. Health stories can unfold very differently when patients have the ability to contribute to and help manage their narratives.

Accessing and Amending Medical Records

To access medical records, the first step is requesting them from each provider. Most providers have a section on their website where medical record request forms can be downloaded. Provider offices can also send a copy of the request forms through the mail.



Tips for Record Management

It's probably clear by now that keeping track of medical records can be a daunting task, especially when conditions requiring numerous specialists or involved treatment are concerned. But there are several things patients can do to make ongoing records oversight go as smoothly as possible:

Provide good information from the outset. Rather than rushing through new patient forms a few minutes before an appointment, patients should pick forms up a day or two ahead of time, if possible, and fill everything out at home. This will make it less likely that important information will be left off.

Request medical records right away, preferably after each visit. The task of collecting records becomes more overwhelming as time passes, and more work needs to be done to catch up. If copies can't be requested at every visit, patients can set a time each month or every few months to deal with making records requests, following up on outstanding requests and attending to any errors that are found.

Organize the personal copy of the record. There are many ways to do this. A three-ring binder for each specialty area, organized chronologically from most recent to oldest documents, is one way. This approach allows patients to take only the pertinent binders to each appointment. It also keeps the personal record from turning into a mountain of unsorted paper that isn't useful to anyone.

Store the personal copy of records safely. A record is only as safe as its location. Losing a record can lead to starting the collection process all over again. Mishandling such sensitive information could also result in information falling into the wrong hands. Good judgment should be used when handling both paper and electronic files.

Take advantage of free online health portals. Many providers offer lab work and other health information online through their health portals. Though the entire record might not be available on a provider's portal, the information that is available can be printed out directly and, therefore, excluded from formal records requests. This can save patients time and money. Portals can also simplify the process of collecting lab work and test results when getting a second opinion, seeing a new specialist or preparing for a procedure.

State laws vary, but charges are typically based on the page count for the records being requested. After the initial request for records is made, fees are assessed and typically must be paid before records are released. Being specific about what records are requested can help minimize the fees involved. For instance, the request can be limited to certain types of records such as lab work, or to a specific date range. In many cases, electronic records are less expensive than paper records.[5] It's worth asking if an electronic version is available and if the cost is the same as or less than printed records. Whether requesting either, be prepared to wait a month or more before receiving them, says the Center for Democracy and Technology (CDT).

Legally, patients have the right to ask for corrections to their records. To do so, they should ask providers what forms need to be filled out when requesting corrections and how they need to be submitted. Small changes can be written on records themselves. (A copy of the records should be made first so patients can retain a copy.) Larger errors may require a letter explaining how records need to be corrected.[5] "Try to be as specific as you can," the CDT recommends. "If possible, include dates of treatment and the names of the healthcare providers involved."

Not all requests for changes are guaranteed. Requests can be denied if providers believe records are accurate and complete or if they did not create the records in question. If a request is denied, patients can file what is called a statement of disagreement with a provider. This statement must be added to the records and included in future disclosures of them.[5,6]

Opening Up the Record

Healthcare providers are increasingly adopting an approach in which they share notes with patients in real time, just as Dr. Wen describes in her story. Doctors who work in this vein may dictate a patient's records during the appointment so the patient can weigh in, right there on the spot. This evolution has everything to do with trust, namely between the provider and the patient.

One man, who encountered numerous difficulties when he attempted to get his medical records for a second opinion, was left with a feeling of distrust in the medical system. "It's like they and the hospital were doing everything they could to make it harder for me," he says.[7] Understandably, his experience made him lose confidence in his doctor and the hospital. The fabric of his relationship with healthcare itself was fraying. More than anything, trust is what had been eroded.

A 2010 study called OpenNotes, which allowed patients to read what their primary care providers wrote about them, showed that most patients who had access knew more about their medical condition, were better at taking their medicine and felt like they were in better control of their health. Participants also reported feeling more trust in their relationships with providers. An impressive 99 percent of participants wanted to see OpenNotes continue.[1,8]

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"When patients see their records, there's more trust and more accuracy," Dr. Wen says, adding that in her years of using an open approach to the medical record, she has been able to create better records, period. "The medical record becomes a collaborative tool *for* patients, not just a record of what we doctors do *to* patients."

Today, OpenNotes says more than 10 million patients have easy access to their clinicians' notes.[8] But, even in areas where this movement hasn't caught on, patients can still enhance their healthcare by tracking their records and helping to shape their healthcare stories. To learn more about OpenNotes and see areas in which clinicians are using this approach, visit www.opennotes.org/who-is-sharing-notes.

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