

## Los Angeles Times

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From the Los Angeles Times

### Building a personal medical database

New products help patients take charge of their health and medical history by organizing their records, but there are privacy concerns.

By Jan Greene  
Special to The Times

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Cathy Barnes of Bakersfield was traveling on business in Philadelphia a few years ago when she developed a terrible pain in her abdomen. Doctors at a major medical center there kept her overnight and carried out a battery of tests on her heart. The tests came up negative.

When she got home, Barnes went to her regular doctor, and an ultrasound exam found a mass in her kidney. A CT scan showed a kidney tumor, and she was immediately scheduled for surgery to remove it before the cancer spread.

Barnes believes she saved precious time in her treatment because she knew enough to ask for a copy of her medical records from the Philadelphia hospital and show them to her doctor at home -- eliminating the need to repeat all those tests. "Having copies of my cardiac tests saved all that time," she says.

Barnes, a database specialist, is unusual -- long before the tumor, she'd gotten in the habit of asking for copies of her records and meticulously tracking her vital signs on a spreadsheet to share with her doctor, who monitors her high blood pressure.

Although not every doctor would want that much detail, nor does every patient have the patience to accrue it, most people could benefit from routinely asking for a copy of their lab results and doctor's reports, says David Lansky, senior director of the health program for the Markle Foundation, a nonprofit that promotes application of technology to health problems.

Such a personal health record, kept either on paper or electronically, can help patients stay aware of their health, particularly if they have a chronic illness such as diabetes or hypertension. It can help a person weed out mistakes in the information, avoid unnecessary repeats of tests and ease the move to a new town or doctor's office.

And anyone who takes care of another person, such as an elderly relative or child with a health problem, can use the records to help advocate for the patient.

Health insurers such as Aetna have helped drive this trend in hopes that patients would pay closer attention to their health. They were among the first to offer some online access to medical claims. Kaiser Permanente -- unique in being an insurance company and a healthcare provider -- is probably the furthest along, offering members not only access to an abbreviated version of their medical records but other services too, such as the ability to e-mail physicians and set up appointments online.

Companies such as Wal-Mart are starting to offer their employees the option of saving personal health records as well.

Many people don't have such access, however -- and there's a downside, in any case, to using an online personal health record provided by an employer or insurer, even though it's free: If you leave that job, you may not be able to maintain access to the site. So people wanting a more detailed record may seek out a solution on their own, and today, they have a wide array of options.

Over the last few years, dozens of personal health record models have hit the market. Some include software that allows people to track their health on their own computers at home or to put it on a thumb drive to give to a doctor. Others are based online, using a secure server that a patient, or a relative or doctor with permission, can sign on to from any Internet-connected computer.

Before taking the time to type a lot of personal history into a product, consumers should think a bit about what they want from a personal health record.

They should also think about how private their records will remain.

#### The products:

With at least 200 personal health record products on the market, there's a wide array of designs. Many of them simply allow the user to fill in information by answering questions, such as: What chronic illnesses do you have? What medications are you on? What are the doses? Do you have any allergies to medications or other things?

Others are focused more specifically on people with a particular chronic illness or an interest in making a particular behavior change, such as diet or exercise. These would allow the user to regularly fill in information such as a blood pressure reading or number of minutes walking that day. Some products allow you to plug in an electronic device and download the information. Most sell for less than \$50 or involve a small monthly fee.

HealthFrame, for example, is a \$40 software product that allows the user to insert information on medical history, expenses, charts on tabbed pages. It has a calendar to track appointments, a format that can be shared with some doctors' electronic systems and a sync for an iPod to keep key medical information with you so it can be accessed in an emergency ( [www.recordsforliving.com/HealthFrame](http://www.recordsforliving.com/HealthFrame)).

There are also some free online products, such as one available at WebMD's site. Using pull-down menus, it allows a consumer to answer questions about illnesses, medications and surgeries, and maintain that information on the site at no cost. It is, however, less detailed than some other products.

Surveys indicate that patients are most comfortable with a product offered by their doctors. One, called iHealthRecord, is offered on 100,000 physician websites, according to Medem, the organization that developed it. Medem, which is supported by the American Medical Assn. and other doctors' groups, says the benefit of iHealthRecord is that it is secure, but a patient can give online access to anyone, including family members, doctors and emergency personnel.

At this point in tech history, patients will have to enter much of this information by hand or scan doctors' reports into their computers. But some day, medical information experts hope, doctors and hospitals will use compatible systems that will allow lab results and doctors' reports to be automatically added to patients' online records.

With this prospect in mind, Microsoft has unveiled its free HealthVault online service, which can hold different types of medical records in different formats. However, many doctors and hospitals are not quite ready to provide that information, because of technical barriers and the simple cost of doing it.

#### **Why keep your records?**

Knowing why you are collecting the information will help determine what kind of personal health record you choose: Someone with diabetes will want one that can easily track blood sugar readings and offer the doctor easy access to them, whereas someone simply wanting to collect the family's medical records on the home computer might want software that tracks multiple people's health records.

"An electronic PHR is basically just a better shoe box," says Stephen Downs, a personal health record researcher for the Robert Wood Johnson Foundation. "If, right now, you have a shoe box of copies of bills and various records, this is a way to have it organized in a much more manageable way."

#### **What to get and how:**

First, gather your medical information. The American Health Information Management Assn., a professional organization for people who maintain medical records in the healthcare industry, recommends that at a minimum consumers keep names and addresses of physicians, health insurance information, dates of significant illnesses and surgical procedures, current medications and dosages, allergies and sensitivities to drugs or materials such as latex, results from a recent physical exam, and eye and dental records.

That may not be as straightforward as it seems. Doctors' offices and hospitals aren't used to consumers wanting such information routinely and may balk at the time involved in copying a large chart. One strategy suggested by the health information association is to do it piecemeal: The next time you see the optometrist or your primary care doctor, ask for your most recent records.

In fact, federal law guarantees individuals the right to get a copy of their medical record, although it might require a written request. The doctor or hospital can charge a reasonable fee for copies, such as 10 cents per page.

There are other places you should check when compiling your medical information. The Medical Information Bureau, an arm of the insurance industry, maintains a database of information about people who have applied for health or disability insurance in the previous seven years. The bureau, in accordance with a federal law, allows consumers free access to their file once a year; call toll-free (866) 692-6901 to request it.

#### **Keeping records safe:**

Consumers should know that there are serious limitations and privacy concerns when considering handing over their medical history, says Dr. Deborah Peel, who heads a consumer group called Patient Privacy Rights in Austin, Texas. For example, some websites offer to maintain an individual's data for free but will then sell the information to marketers who want to advertise to people with certain health conditions.

Privacy advocates also worry that with spotty federal safeguards on Americans' health data, personal information could easily be used against them in a hiring situation or application for health insurance.

"For 30 years, I've been listening to my patients tell me about the ways they are harmed when employers get a hold of their sensitive medical records," says Peel, a psychiatrist. She recommends that consumers not use an online personal health record offered by an insurer or employer: "It's impossible to tell how many times your records have been disclosed or to whom."

Insurance companies argue that they are simply giving easy access to information they already possess and protect, in hopes that members will use the information to improve their health. Legislation is pending in Congress that would give consumers more ability to control how their information is used.

Keeping medical records at home in a file makes it simpler to ensure their security, and maintaining a spreadsheet or other records on your computer just requires periodic backup.

But as soon as medical information gets shared through a website, a thumb drive or a magnetized card, security becomes a concern.

Health record experts say consumers should treat their medical information with the care they use with their banking records. It's vital to read the fine print when considering a vendor's offer of an online health record. "Know what they can do with your data," Downs says.

Even if you don't go online, Lansky says, you can begin to compile medical information on paper or on your computer and take more responsibility for your own medical history -- which, after all, is languishing in paper records at doctors' offices and hospitals.

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