

Online Tool May Help Revive Family History

BY HEIDI SPLETE

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A revised high-tech tool from the Department of Health and Human Services may make filling out a pre-exam checklist in the doctor's office obsolete, if doctors and patients will use it.

"We know that a large percentage of our risk for developing certain diseases is related to genetics and related to our family histories," acting Surgeon General Steven Galson said in an interview.

In the future, providers will predict risk and plan therapy based on information obtained from a drop of blood, but that future is still far off, Dr. Galson said.

"We know that today, by using family history, we can get a lot of information that can help clinicians," he emphasized. The online tool, called My Family Health Portrait, collects information in a standard way that's easy for family members to share and for providers to use, he said.

"We'd like to see every single American have the opportunity to input their data into this tool and enable their physicians to treat them with a better understanding of family history," he added.

"Family history can provide important insights into future risk of developing a wide variety of serious medical conditions like cardiovascular disease, diabetes, and many types of cancers," Dr. Greg Feero, a senior adviser for genomic medicine at the National Institutes of Health, said in an interview.

But many time-strapped clinicians fail to collect family history during an office visit.

"The tool offers doctors and patients a convenient way to collect and organize an expanded range of family history information outside of the time constraints and pressures of the office visit," Dr. Feero said.

My Family Health Portrait was introduced in 2004 as a form that patients could print and take to their medical appointments. But the revised version (available at

<https://familyhistory.hhs.gov>), lets individuals input, save, and download their information. One person can share the file with other family members and allow them to add their own information if they choose, and they can send it to their physicians via a secure connection. Call it "wiki history"—and it has potential benefits for both doctors and patients.

For example, if you create a file with your own history, you are prompted to note the dates when you had certain diseases (if any) or to add diseases not on the default list. You can also add health information about your immediate family members (siblings, parents, children, aunts, and uncles) with options to add more family members. If you give your brother the file, it asks him whether he is a family member and reorients the data around him. This prevents the duplication of data; your brother would only need to input health data that are unique to him.

According to the Department of Health and Human Services, building the basics of a family health history should take about 15-20 minutes. Beyond that, the more family members someone includes, the longer it takes. The history may be downloaded onto a patient's own computer, and it is not automatically accessible by the government or by any health care provider without the patient's permission.

Doctors who start an exam with an accurate family history at hand can spend their time reviewing and interpreting the information, rather than collecting it, Dr. Feero said.

"Importantly, the new tool is designed using accepted data standards, so that the data file it creates has the potential to be shared electronically with electronic health record and personalized health record systems," Dr. Feero noted. "Ultimately, this same standards-based design should allow the development of automated tools to help clinicians interpret the information the patients provide them."

But how easy is it for clinicians to promote the tool

to patients, and use it in practice? "If the clinician currently uses a paper-based patient family history intake form for new patients, or for yearly physicals, the provider could simply ask patients to complete the new tool online and supply them either with the data file or a paper version," Dr. Feero explained. "If secure e-mail systems are available to the patient and provider, this might be another option for transferring the information."

Alternatively, the entire program is available for downloading and customizing at no charge. Providers can install the My Family Health Portrait software as part of their health information technology system. Patients could complete the information at a kiosk or laptop in the waiting room, and have the electronic file sent directly to their physicians for review.

An electronic family history is potentially useful, Dr. Charles Scott, a pediatrician in private practice in Medford, N.J., said in an interview. But it would have to be reviewed and incorporated carefully, so that patients would not be able to access medical files other than their own if they completed the history in a doctor's office, he said. Software compatibility could be a problem in some practices, he added.

And it's important to remember the personal touch, no matter how much electronic media become part of medical practice. "My fear is that we may get so involved with our data entry in the e-chart that we will forget to warmly interact face to face with our patients," Dr. Scott said.

Clinicians can continue to remind patients to provide as much family history as possible, but it may take time to resolve technical and privacy issues before an electronic family health history becomes a seamless part of an electronic medical record, he said.

Dr. Scott had no financial conflicts to disclose. Dr. Feero is an employee of the National Institutes of Health, which is part of the Department of Health and Human Services. ■

THE OFFICE

Protect Your Data!

All too often, our office computers are disasters waiting to happen. We store huge amounts of important information on them and risk losing it all by neglecting to back up the data. No amount of casualty insurance will recoup the loss of the data on stolen or destroyed computers.

Industry statistics show that fully 10% of hard drives fail in any given year and that 43% of computer users lose one or more files every year in the form of clinical data, financial records, photos, e-mail, documents, and other important information. Recovery of lost data, when it's possible at all, can be very expensive.

Yet a Harris Interactive study last year found that 35% of Americans admitted they never back up their computers. And amazingly, many people who have lost important data in a crash still refuse to do regular backups. Why do so many of us neglect such a basic precaution? Because it's inconvenient and time-consuming. Clearly, the only way to get many people to back up their data regularly is to make the process automatic.

Some computer companies have taken steps in that direction. Apple, for example, has a feature called Time Machine that backs up Macs to an external drive automatically. But that does you no good if, for example, a fire destroys the computers and also incinerates the backup drives.



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So, the first rule is to store your backup drives in a different location from your computers. Unfortunately, that's a pain, too, and external drives can be lost or stolen, creating a HIPAA nightmare. So an increasingly popular alternative is automatic remote backup.

Several companies offer this service: two of the most popular are Mozy (www.mozy.com) and Carbonite (www.carbonite.com). (I have no financial interest in any product or service discussed here.)

The cost is very reasonable for individual computers. In fact, Mozy lets you store up to two gigabytes of data for free. Its basic package, which includes unlimited storage, costs \$4.95 a month per computer. Carbonite is a bit cheaper (\$49.95 per year, also for unlimited ca-

capacity), but Mozy is a little more customizable, and you can specify the files you want regularly backed up and when it will be done. Backing up an entire office costs more, depending on how many computers and/or servers you have, but it's still very reasonable and includes other services such as operating system and network share support.

The procedure is simple: You create an account and tell the service which files to copy. Your first backup can take a long time, often days, depending on how much data you are sending and the speed of your Internet connection. After that, the program runs in the background, copying only files that have changed since the previous backup. Files are encrypted before leaving your computer, and they remain encrypted at the service's data center, making them HIPAA compliant and, theoretically, accessible only to you.

To restore files, you open a sort of virtual representation of your backed-up files and click on what you want restored. You also can log into the Web site from any other computer and pick any file or folder to retrieve. If your computer is stolen or the hard drive is destroyed, you can go to a site to initiate a

full restore to a new computer. Remote backups might even help you recover a lost or stolen machine: If the finder or thief opens new files, they will be backed up to your new machine, which could allow you (or the police) to trace the original computer's whereabouts.

If you ever decide to terminate the service or simply want a hard copy of your data, Mozy will send you a DVD of all your files, for a fee. (Carbonite does not mention this service on its site.)

Soon, though, you might be able to use these services for a lot more than simply storing and retrieving files. Mozy's parent company, EMC, has announced a new subsidiary called Decho (www.decho.com), which it says will soon offer the same services for information that banks offer for money. Not only will you be able to store your data, you'll also be able to share it, move it around, put it to work, and access it no matter where you are. Such a centralized "information bank in the sky" could change the way we perceive and use computers. ■

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