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Making Personal Health Records Personal

No one debates the benefits of a complete and accurate medical history. However there is an intense tug-o-war between the federal government, large corporations, and patients over where those medical records are stored and who has access to them.

From the moment of birth - and even before - our medical records begin. They follow the paths of our lives, scattered among our various health providers. From prenatal care, to childhood physicians, from annual checkups, to hospice care, medical information is gathered, analyzed, re-gathered, and, eventually, lost to the passage of time.

As American society has become more health-conscious, interest in and the need for medical record-keeping has also grown. Medical records have real and positive impacts on our health care and on the health care of our families as well. (For example, when your doctor is trying to diagnose a problem you are having, knowledge of your parents' and grandparents' medical histories can be invaluable in the diagnostic process.) These medical records – often called Personal Health Records (PHRs) – include information on:

- Medication prescription history
- Surgeries and procedures
- Vaccinations
- Allergies
- Illnesses
- Hospitalizations
- Laboratory test results
- Adverse drug reactions
- Family history

Even today, more than fifty years after computers began their conquest of the economy, most personal health records are paper-based. The most meticulous health care consumers collect copies of their records from their physicians and file the paper documents; most Americans don't even do that much, hoping and trusting that their doctors and hospitals will do the recordkeeping for them.

However, there is hope for an electronic future. Medical records are increasingly created in an electronic format. According to the latest information from the National Ambulatory Medical Care Survey (NAMCS), 25 percent of office-based physicians report using fully or partially electronic medical record systems (EMR) in 2005, a 31% increase from the 18.2 percent reported in the 2001 survey. The percentage will continue to increase as computer-savvy physicians raised on Nintendo in a world of ubiquitous personal computers come into the workplace and embrace (or demand) EMR systems.

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As the medical industry creeps slowly into the digital age and the availability of electronic PHRs increases, it is likely that health care consumers will take advantage of the increased interactivity that electronic PHRs make possible. According to a report published by the Markle Foundation, over 70 percent of the patients would use electronic PHRs to:

- Track immunizations
- Note mistakes with a medical record
- Transfer information to new doctors
- Get and track test results
- Email a doctor

Some of these functions, of course, do not require electronic PHRs; you can e-mail your doctor whether she keeps your records on a computer or on paper, assuming she has a computer. However, electronic PHRs are likely to make even basic tasks easier and quicker, and thus more likely to actually happen.

Once the health records are in an electronic format, the information becomes easily transmitted, distributed, and searched. As the ease of access to this data increases, so must the level of security provided. The primary legal assurance of privacy is the federal Health Insurance Portability and Accountability Act (HIPAA). This law allows patients to view, request changes to, and receive copies of, PHR information and documents. HIPAA also provides protections against healthcare providers misusing medical information – for example, by drawing on PHR databases to create marketing mailing lists for specific drugs or treatments.

Getting PHRs into electronic form is, of course, only the first step. Once PHRs are digitized, the question becomes what to do with them. One option is to store the electronic PHRs in a centralized system that can be accessed via the internet or via internal networks at a hospital or health care provider. Several corporations have embraced this centralized approach. In 2006, companies like Wal-Mart, Intel, and Applied Materials began sponsoring the Dossia project. According to the Dossia website (www.dossia.org), Dossia is “an independent secure, non-profit infrastructure for gathering and securely storing information for lifelong health records”. Other large corporations are offering or will be offering similar services. In October of 2007, Microsoft announced its HealthVault system, and Google is expected to release its Google Health service in 2008.

Storing records in a centralized system has many benefits, not least among them reduced costs and universal accessibility. However, centralizing the recordkeeping also raises many legitimate concerns, including:

- How secure is the information?

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- Who has access to it?
- How will it be used?
- Who is paying the costs?
- Which centralized service to use?
- Do records replicate from one service to another if a patient changes physicians or providers?
- How is the information loaded from clinics and hospitals?
- How is the integrity of the data maintained?

For most patients, the greatest concern involves the security of private medical information. Despite extensive safeguards, processes, and procedures at companies and institutions handling electronic PHRs, many breaches of medical information privacy and security have occurred in the recent years. There are documented cases of unauthorized personnel viewing celebrities' medical records. Other cases have involved the theft of laptop computers which contained vast quantities of sensitive medical information. No useful computer system is totally secure and no data within a system is totally protected; solutions have to be found which maintain adequate safeguards of patient information without making the records so inconvenient to access that we'd be better off just sticking with paper.

In a recent roundtable hosted by the American Health Information Management Association (AHIMA), medical information experts discussed concerns related to personal health record security. The most alarming topic of discussion was the revelation that some of the organizations hosting centralized systems are vendors and are not covered under HIPAA, which is limited to regulating direct health care providers. Patients who have their records stored with a vendor's service may not have the same protections under the HIPAA laws as they would if the office or hospital was maintaining its own record system – yet the benefits of electronic PHRs are only fully realized when systems are uniform across providers. Having each doctor's office maintain its own little slice of the electronic record pool would be inefficient and would lead to the same problems that plague paper records.

There is, however, an alternative to the centralized record system which nonetheless maintains record portability and patient security – private records. Privatized records consolidate a patient's PHRs but leave the information in the physical possession of the patient. Only the patient has access to the files, and only the patient can give out copies of the file to health care providers. In this model, a patient receives medical treatment or consults a physician, and the information from his treatment is entered into his personal electronic medical record. The patient, and only the patient, has the complete medical history. The patient is in complete control and may share the information, or part of it, as he wishes.

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There are several different software programs that manage personal health records. Software applications such as EMRy Stick, CheckUp, and others allow users to enter and track their medical records on their personal computers. Some products can store these records on a USB drive device, allowing patients to transport the information easily via key rings, wrist bracelets, necklaces, etc. Medical information is thus readily available regardless of the patient's location – ideal for patients who are traveling or who do not have a regular health care provider.

Privatization of records faces two major challenges: the initial acquisition of existing medical information (which can be voluminous, stored in a dozen different places, and which may have inconsistencies and contradictions that should be resolved before a unitary record is created), and the ongoing entry of new information as the patient receives treatment. To start a private electronic PHR, the records must first be obtained from the patient's health providers, clinics, and hospitals, and then digitized if they are not already electronic. To cover the extra costs of retrieving and copying the records, these organizations typically charge the patients a fee. Once the historical information is in the electronic PHR, the patient must continue to have updates made, and will have to pay each time a request is made. If a patient visits her health care provider frequently, the cumulative cost of the records for each visit can become substantial. For ongoing data entry, most software applications today require manual entry of the information. This can be a tedious, time consuming – and thus, expensive - activity.

To overcome the challenges of manually obtaining and maintaining medical information, Drs. Jeff and Paige Turk of Timberview Clinic in Aurora, Colorado offer a unique and innovative solution. Their clinic has teamed with the Blue Goose Corporation to provide automated, secure retrieval, delivery, and entry of patient medical information. This solution uses Blue Goose's EMRy Stick, an electronic medical record application that allows a user to enter, view, and track medical information.

From a patient's perspective, the Timberview service is very easy to use and straightforward in its application. The patient downloads a free version of the EMRy Stick program and signs up for the service with the clinic. After each visit to the clinic, the patient will receive a secure email that can be loaded automatically into the EMRy Stick application. No manual entry or additional steps by the patient are required.

For the clinic, the only extra effort needed is the initial setup of the patient with the service. All retrieval and delivery tasks are completely automated. Dr. Jeff Turk believes that not only will the automated process provide his patients with updated medical information, but it will also save his clinic time and money by automating record retrieval and delivery. The project is currently in final testing and will be available to patients of Timberview in the near future. There will be a minimal annual fee for each patient who subscribes to the service.

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In the future, regardless of whether centralized or privatized medical records end winning in the marketplace, every patient will have access to all of their personal medical records. There are costs and obstacles in the way of this future, but the enormous benefits of an accurate and complete medical history being available for all patients will override all political, financial, and technical objections. The question will then no longer be whether a patient has access to his files. It will instead be a matter of who *else* has access, and who controls the information in question.