

eHEALTH: Putting Patients First



Imagine...

- Arriving from out of town to care for your elderly mother after a serious fall and finding all of her medical records—including x-rays and prescriptions—are available electronically to share with care providers.
- Being displaced by a disaster such as Hurricane Katrina and having the ability to access your medical records at an out-of-town clinic or emergency room.
- Battling a chronic illness such as multiple sclerosis or AIDS and having all of your health information—clinical history, prescriptions, lab results—available electronically to you and your providers.
- Having an automatic email alert delivered to your pharmacist or physician if a new prescription will have an adverse interaction with a drug you are already taking.

The Promise of eHealth

eHealth has the potential to improve health care quality, safety, and access. To deliver on that promise, patient and consumer advocates must press for policies that put patients first and encourage people to be informed and active participants in their own care.

We must ensure that all eHealth initiatives:

- Grant patients and providers real-time access to secure medical records;
- Provide medical histories inexpensively and in electronic form for patients to share with new health care providers or others;
- Empower individuals to better manage their own and their family's health by:
 - Checking lab results online
 - Downloading medication histories
 - Exchanging secure email with healthcare professionals
 - Managing chronic and acute illnesses;
- Improve health care safety and quality by reducing medical errors;

- Allow clinicians to electronically send prescriptions to pharmacies;
- Incorporate legal and technical solutions that rigorously protect sensitive data, such as genetic, mental health, alcohol and drug treatment, and HIV/AIDS-related information;
- Make available non-identifiable patient information for research and public health; and
- Reduce health care costs by streamlining billing and reimbursement, and avoiding duplicate tests.

eHealth Momentum Is Building, but Challenges Persist

President Bush has called for most Americans to have an electronic health care record by 2014. The U.S. Congress and state legislatures are considering a number of eHealth proposals. And many government and private sector initiatives are under way to create information networks to store and transmit patient records:

- The U.S. Department of Health and Human Services has funded prototypes for health information exchange and chartered a federal advisory body to make recommendations for accelerating the adoption of eHealth.
- Public/private collaborations in many states are developing linked health networks (known as Regional Health Information Organizations, or RHIOs) to share information among providers and payers.

Most of these initiatives are driven and funded by providers, insurers, technology companies, and the government, with little involvement from consumers or health advocacy groups.

The federal health privacy law mandated by HIPAA gives people important new rights, but gaps and weaknesses in the law leave many critical consumer issues unresolved.

Improving health care quality, safety, and access includes building strong eHealth privacy protections right from the start.

Fear of Privacy Breaches: Strong and Growing

Many patients fear privacy breaches that could expose them to stigma, discrimination, and loss of jobs and health benefits.

According to a 2005 study, two-thirds of Americans have concerns about the privacy of their personal medical records. A rapidly growing number of Americans—now more than half—are concerned that insurance claims information might be used by their employer to limit job opportunities.

As a result of these fears, nearly 20% of people are engaging in “privacy-protective behaviors,” such as avoiding medical tests, asking doctors not to record health problems, or going to another provider to avoid telling their regular doctor about a health issue. Studies have shown that the chronically ill and racial and ethnic minorities are more likely to put their health at risk by engaging in these behaviors.

The magnitude of risk to patients’ privacy increases dramatically with the creation of large, interconnected databases that can be breached at the malicious or inadvertent push of a button.

Just recently:

- *The birth dates, Social Security numbers, and, in some cases, disability ratings and other medical information of 26.5 million veterans were stolen from a laptop in the home of a Department of Veterans Affairs employee.*
- *A hacker downloaded the medical records and Social Security numbers of more than 5,000 patients at the University of Washington Medical Center.*
- *A 30-year FBI employee was forced into early retirement when the FBI learned he had sought mental health treatment after obtaining his prescription records during a fraud investigation of his therapist.*

Making eHealth Work

Consumer and patient advocates must press for:

- Consumer access to one’s own records, in electronic form;
- Control over one’s own health information—choosing who has access to information and under what circumstances;

- Easy-to-read notices about how one’s health information will be used and disclosed;
- Strong privacy and data security protections; and
- Strong penalties and meaningful remedies for privacy breaches and harms.

What You Can Do

- Stay informed about ongoing eHealth developments. Understand how they impact health care access and quality and empower patients to better manage their care.
- Visit the Health Privacy Project’s site—www.healthprivacy.org, the most comprehensive resource for medical privacy information—and join the Consumer Coalition for Health Privacy. You will receive updates about the latest eHealth developments and information about how to make your voice heard.
- Visit the California HealthCare Foundation’s site—www.chcf.org—for research about electronic health records, data standards, and eHealth policy issues.
- Make eHealth part of your organization’s mission, agenda, and activities. Talk about eHealth with policymakers and community leaders, and train your constituents to do the same.
- Advocate preserving strong state-level privacy protections. Federal rules must continue to be a floor, not the final word.
- Urge patients to take advantage of their legal right to get a copy of their medical records—in electronic format if possible.



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