

What's so special about the Caregiver PHR?

Caregiver Alliance Web Services™ is the only consumer-controlled, interoperable personal health record system (PHR) with the security of online banking.

Health care providers, who have long maintained paper records for their patients, began adopting electronic records in the 1990s. About 20% of medical providers now employ electronic health record systems (EHRs) to manage patients' records. Perhaps 1% of non-medical providers employ EHRs to manage patients' records. Few EHRs are interoperable--capable of exchanging data about shared patients—so that each doctor can get a holistic view of a patient's health history.

Americans' health records are scattered in fragments across the paper and electronic record systems of all the providers, hospitals, health plans, and pharmacies they have visited. Fragmented health records have been blamed for medical mistakes and for impeding recovery from complex illness and long-term care of chronic illnesses and disabilities.

The Markle Foundation, in 2003, envisioned that improvements in long-term care could result from a personal health record (PHR) “an electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment... an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”

While there are standards that regulate providers' EHRs (such as HIPAA), there are, as yet, no standards that regulate consumers' PHRs. As a result, the PHR label is applied to various electronic record products. PHRs products vary in *consumer control*—whether consumers determine who may access which data in their PHR records for what time periods. PHR products vary in *interoperability*—whether consumers have options for automated data exchange data between their PHRs and multiple doctors' EHRs. A PHR that is both consumer-controlled and interoperable has been called the *holy grail* because of its potential for remedying dilemmas that confront health care consumers and providers every day.

There are four major types of PHRs: (1) view, (2) tethered, (3) freestanding, and (4) consumer-controlled, interoperable.

View PHRs offer neither consumer control nor interoperability. View PHRs give individuals glimpses of selected information in their records in an EHR system. View PHRs may allow individuals to enter and update information related to emergency contacts, allergies, and current health problems. View PHRs do not: inform individuals about all the information in their EHR system records; permit them to control access to information in their EHR system records; or allow them to exchange data between their records in one EHR system and their records in other EHR and PHR systems.

Freestanding PHRs offer consumer control but not interoperability. Freestanding PHRs allow individuals to enter information into Web-accessible medical summary

What's so special about the Caregiver PHR?

forms, print hard copies of the completed forms, and download the completed forms to a USB stick or other storage device. Individuals may share completed forms with trusted others by giving them passwords for Web access, hard copies, or storage devices. Freestanding PHRs do not allow individuals to exchange data with their records in other EHR and PHR systems.

Tethered PHRs offer some interoperability but no consumer control. Tethered PHRs give individuals glimpses of selected information in their records in a health plan or regional health information organization (RHIO) network database. Data exchange among the EHR systems of in-network providers creates one integrated, cross-EHR record for each individual. Tethered PHRs give individuals selective glimpses into their integrated records and make their updates immediately available to in-network EHR systems. Tethered PHRs do not: inform individuals about all the information in their cross-EHR or EHR-specific records; permit them to control access to information in their records; or, allow them to exchange data with out-of-network EHR and PHR systems.

A consumer-controlled/interoperable PHR system offers two truly consumer-empowering capabilities. Individuals control who has access to what information in their PHR system records; they also control the exchange of information between their PHR system records and their records in other EHR and PHR systems. The patent-pending Caregiver PHR system is the only consumer-controlled, interoperable PHR system and it is operated with the security of online banking.

The patent-pending Caregiver PHR system is the first and only consumer-controlled, interoperable PHR system and it is operated with the security of online banking. The Caregiver PHR system gives consumers a centralized storage system, like a bank vault, for all their personal information and records. Individuals control who has access to what information in their PHR system records; they also control the exchange of information between their PHR system records and their records in other EHR and PHR systems.

References

- Aspden P, Wolcott J, Bootman JL, Cronenwett LR. Preventing medication errors: quality chasm series. Committee on identifying and preventing medication errors. Washington (DC): National Academy Press. In press 2007.[Q12]
- Blechman EA, Bopp JM, King R, Qualls S, Mabry H, Robinson C, et al. Health information technology for long-term caregivers. In: Talley RC, editor. Building community caregiving capacity. Oxford University Press. In press.
- Brailer DJ. Interoperability: the key to the future health care system [Web exclusives]. Health Aff (Millwood). Epub 2005 Jan-Jun;Suppl:W5-19-21.
- Bush GW. Executive Order: Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator. Washington (DC): The White House, Office of the Press Secretary; April 27, 2004. Available from: <https://www.whitehouse.gov/news/releases/2004/04/print/20040427-4.html>

What's so special about the Caregiver PHR?

- California HealthCare Foundation. Medical privacy and confidentiality survey: summary and overview. January 28, 1999. Oakland (CA) [cited 2006 Jul 18]. Available from: <http://www.chcf.org/documents/ihealth/survey.pdf>
- Dick RS, Steen EB. The computer-based patient record: an essential technology for health care. Committee on improving the patient record, Division of the Health Care Services, Institute of Medicine. Washington (DC): National Academy Press; 1991.
- Donelan K, Hill CA, Hoffman C, Scoles K, Feldman PH, Levine C, et al. Challenged to care: informal caregivers in a changing health system. *Health Aff (Millwood)*. 2002;21:222-31.
- Halamka J, Aranow M, Ascenzo C, Bates D, Debor G, Glaser J, et al. Health care IT collaboration in Massachusetts: the experience of creating regional connectivity. *J Am Med Inform Assoc*. 2005 Nov-Dec;12:596-601. Epub 2005 Jul 27.
- Health Insurance Portability and Accountability Act (HIPAA): Public Law 104-191. 104th Congress. August 21, 1996. Available from: <http://aspe.hhs.gov/admnsimp/pl104191.htm>
- Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Committee on cancer survivorship: improving care and quality of life, National Cancer Policy Board. Washington (DC): National Academies Press; 2006.
- Kaiser Commission on Medicaid and the Uninsured. The uninsured: a primer: key facts about Americans without health insurance. Menlo Park (CA): Henry J. Kaiser Family Foundation; 2006.
- Key capabilities of an electronic health record system. Letter report. Committee on data standards for patient safety: Institute of Medicine. Washington (DC): National Academies Press; 2003.
- Kohn LT, Corrigan JM, Donaldson MS. To err is human: building a safer health system. Washington (DC): National Academy Press; 2000.
- Markle Foundation. Connecting for health: a public-private collaborative. The Personal Health Working Group: final report. July 1, 2003. Available from: http://www.markle.org/downloadable_assets/final_phwg_report1.pdf
- Rothstein MA, Talbott MK. Compelled disclosure of health information: protecting against the greatest potential threat to privacy. *JAMA*. 2006;295:2882-5.
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc*. 2006 Mar-Apr;13:121-6. Epub 2005 Dec 15.
- Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. *Health Aff (Millwood)*. 2005;24:1290-5.
- United States Department of Health and Human Services: Office for Civil Rights. Standards for privacy of individually identifiable health information: 45 CFR parts 160 and 164: final rule. December 28, 2000[Q13]. Available from: <http://www.hhs.gov/ocr/hipaa/finalmaster.html>