# Personally Controlled Health Records: The US Landscape and the Indivo Project

William Crawford

Office of Policy, Centers for Medicare and Medicaid Services,[i]
200 Independence Avenue SW, Washington, DC 20021, USA
&
MIT Sloan School of Management, Harvard-MIT Division of Health Sciences & Technology,
and the Children's Hospital Informatics Program

## Introduction

This abstract accompanies a talk given at ISePHR on September 28, 2006. It does not represent an official CMS Policy Statement or CMS endorsement of particular research activities.  It is instead intended to catalyze discussion of Personally Controlled Health Records and their role in the future of health care delivery.

## Personal Health Records in the US

Personally Controlled Health Records are an important component of the developing public policy framework for an IT-enabled healthcare system. As the global health agenda increasingly focuses on delivering higher quality care and shifts towards episodic, rather than transactional, methods of assessing the effectiveness of clinical interventions, the tools which place consumers in control of their own healthcare data will become increasingly important.

The term "Personal Health Record" has been applied to a range of software products and related services. While PHRs always contain a collection of basic healthcare data, they range from isolated collections of pure data (which requires additional software to interpret) to paper forms to sophisticated, web-based applications which also incorporate clinical guidance, secure doctor-patient communications, and other features beyond the natural scope of a "medical record."  Merely confirming a shared definition will set the stage for substantial advances.

### Applications and Requirements for PCHRs

Personally Controlled Health Records have a range of current and future applications. In the very short term, PHR technology has been used by individual consumers to track the details of their (or their dependent's) medical histories. In the future other applications will become increasingly important. These include recruitment for

clinical trials, management of patient registries for drugs, emergency care, streamlining of school health record reporting, and other applications which have not yet been envisioned.

Development of future PHR applications will be a collaborative effort between patients, health care providers and software vendors. The establishment of standards for interoperability, translation of data, provisioning of data, and certification of data integrity will all contribute to the creation of "network effects" supporting further adoption of PHR technologies and the development of PHR driven business models.

## PHR Models

There are several widespread approaches to Personal Health Record software. Six major PHR implementation models are described below. The PHR model which requires the most user effort for data collection is listed first; each subsequent model theoretically requires less effort by the patient to populate and maintain the record.

*Paper*: The simplest PHR model is a set of paper forms. In the most primitive model, the PHR is a copy of the doctor's paper record, carried by the patient. Several organizations have developed designated paper PHR forms which collect data in a more structured manner. The primary endpoint of these programs is to streamline patient admissions.

*PC Based*: Several vendors provide desktop applications which allow users to record their own health information. These applications are installed on the user's computer and rely primarily or entirely on self-reported information. The data can be printed out for presentation to a physician. Some applications support exporting data into a standard format called a Continuity of Care Record , but PC based PHRs are primarily "health journaling" tools for individual consumers.

*Portable*: Most often based on a USB "keychain" storage device, a portable PHR contains similar software to a PC based PHR, but resides on a portable storage device. The PHR application can be run on any available computer, allowing data to be viewed or updated at the site of care. The device itself is usually encrypted and requires a password to access the patient's data. Data must be extracted from the PHR before it can be transmitted to a clinician's office. For office visits, the data must still be printed out ahead of time as there is no guarantee that the physician office will have a computer available (or the time, or the security policies in place) to load the portable record.

*Internet (Web) Based*: Similar to a PC based PHR, Internet based PHR companies provide an application interface which allows users to enter their own health information. Internet based PHRs offered by payors and purchasers (usually insurance plans and employers) may also incorporate information from insurance claims and Pharmacy Benefits Managers, reducing the patient's data entry effort. The major

online physician-patient communication platforms (RelayHealth and Medem) both include web based PHRs as key components.

*Internet Portal:* Also known as a "tethered" PHR. Many hospitals and clinics have rolled out patient portals attached to their internal EHR system. Users can log in and are given a view into the data stored within the hospital's clinical information systems. The portal based "PHR" is not, by the definitions above, a Personal Health Record at all, since the data is not owned by the patient unless it is exported. This PHR model requires minimal effort from the patient, but is limited in its ability to integrate data from different providers. We include portal-based PHRs in this document because many vendors have chosen to identify their portal offerings as PHRs.

*Health Bank:* The "Health Bank" model aggregates data from multiple providers (insurance companies, hospitals, PBMs, labs, and the patient) in a centralized, patient-controlled data repository. The health bank is responsible for making the record (or components of the record) available to authorized users, and for giving the patient a mechanism to identify who may access what parts of their record, and under what circumstances. As standards develop, the health bank may or may not provide a direct user interface for manipulating the PHR data. Instead, the health bank provides the data in a standard form via a standard interface to third party software which presents the information in a user-appropriate manner (to a physician via an EHR, to a patient with translations of clinical terms, etc.)

## The Indivo Personal Health Records Platform

At Children's Hospital, Boston, our research group has developed Indivo, a research platform designed to enable the development of personally controlled health record systems. The Principal Investigators of the Indivo system are Dr. Kenneth W. Mandl and Dr. Isaac Kohane of Children's Hospital Boston and HST. William Simons is the lead software architect, and many others have contributed to the system's development.

Indivo is a distributed, web-based, personally controlled electronic medical record system that is ubiquitously accessible to the nomadic user, built to public standards, and distributed under an open-source license. The Indivo system is essentially an inversion of the current approach to medical records, in that the record resides with the patients and the patients grant permissions to institutions, clinicians, researchers, and other users of medical information.

- Electronic medical record systems should be designed so that they can exchange all their stored data according to public standards
- Giving patients control over permissions to view their record (as well as creation, collation, annotation, modification, dissemination, use, and deletion

of the record) is key to ensuring patients' access to their own medical information while protecting their privacy

- Many existing electronic medical record systems fragment medical records by adopting incompatible means of acquiring, processing, storing, and communicating data
- Record systems should be able to accept data (historical, radiological, laboratory, etc) from multiple sources including physician's offices, hospital computer systems, laboratories, and patients' personal computers
- Consumers are managing bank accounts, investments, and purchases on line, and many turn to the web for gathering information about medical conditions; they will expect this level of control to be extended to online medical portfolios

The technical architecture of the system is still evolving; one version was described in a 2005 JAMIA paper.[ii]

---

[i]

[ii] J Am Med Inform Assoc. 2005;12:47−54. DOI 10.1197/jamia.M1592.