



Health Record Banking Alliance

Organizing Health Data Around the Patient Using New 21st Century Cures Act Interoperability Rules

Health Data Bank National Systems Design Overview

A **Health Data Bank (HDB)**, also called a Health Record Bank) is an **integrated patient information services institution**. As a **trusted agent**, it offers a **secure repository** for each individual to collect and compile their “**interoperable**” digital health information in a **smart Personal Health Record (PHR)**. Individuals own and control their Personal Health Records, as in a bank checking account. With these **new information flows**, consumers will:

- exchange medical records and other health data in their Personal Health Records conveniently with doctors’ offices and hospitals for better, faster care; improve patient safety; and reduce information burden on physicians by supplying an aggregated, lifetime, searchable medical record for easy and immediate reference.
- control Personal Health Record access for doctors and hospitals; family, friends, and health coaches; medical researchers; members of the press; and others as they wish.
- use their Personal Health Records to help manage their health and healthcare, and to help shop for doctors, hospitals, and health insurance.
- view their Personal Health Records on smartphones, tablets, and other computers.

Health Data Banks and Efficiency: Integrating health information around each patient via HDBs is the most efficient way to aggregate and use “**interoperable**” health data under 21st Century Cures Act regulations. It is far more efficient and useful than a collection of “apps.”

HRBA’s Education and Policy Advocacy: HRBA advocates government policies promoting Health Data Banks as a **major new structural sector in U.S. health care**. This systems design includes a **national regulatory framework for Health Data Banks**.

Health Data Banks and Health Equity: Health Data Banks will promote **health equity** because **everyone can have a Personal Health Record**.

Health Data Banks as Medical Research Clearinghouses: Medical researchers cannot get enough patient data to make fast or sufficient progress. HDBs can be clearinghouses between patients and researchers. Patients can **voluntarily** list themselves with their HDBs to be informed of research projects they are interested in, and to which they want to **contribute or sell their data**. This also is a path to developing **national federated diagnostic and research databases** while respecting **patients’ privacy rights** (because patients are in control). Better research will improve treatment for acute, chronic, and orphan diseases.

Health Data Banks, Security, and Patient Matching: Security, credentialing, and patient authentication and efficient matching are systems design features of HDBs

Advanced Features of Smart Personal Health Records: Systems design features such as artificial intelligence (AI) and search capabilities, robust family history, and genomic analytics will deliver **problem-oriented data and analysis** to **mesh** with clinicians’ Electronic Health Record (EHR) systems **at the point of care**. Availability of this aggregated **reference record** will reduce burdens on clinicians while improving diagnosis, treatment, and patient outcomes.



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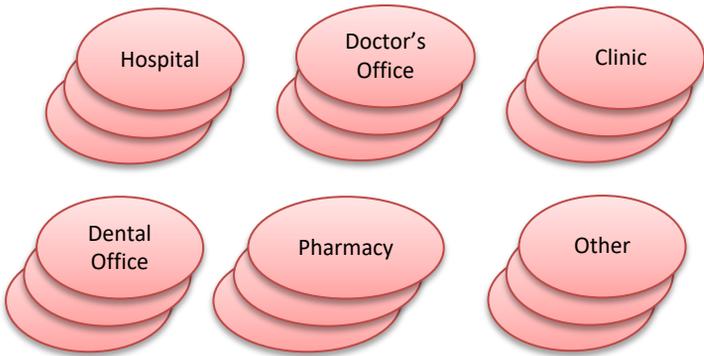
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Health Data Bank National Systems Design Overview Schematic

All data exchange, both sending and receiving, follows the 21st Century Cures Act interoperability rules (the United States Core Data for Interoperability Standard) in 45 C.F.R. Part 170, and the Trusted Exchange Framework and Common Agreement (currently in development).

Any two or more nodes can exchange data directly using the United States Core Data for Interoperability standard.

Electronic Health Record Systems



Iterative data exchange between clinicians and researchers.

Biomedical Researchers

Health Data Banks will maintain lists of PHR account holders (patients) who voluntarily ask to be notified about research projects in areas that interest them. An HDB will be a clearinghouse for these research opportunities.

Patients may elect to furnish a researcher with all or selected parts of the data in their PHRs. The data can be fully identified (which is the most useful to researchers) or anonymized, as the patient decides.

Patients (or other consumers) who supply data to researchers fall under the Federal Policy for the Protection of Human Subjects.

Mandatory reports by providers under existing public health reporting statutes and regulations, normalized to the extent attainable under the interoperability rules.

Doctors, other clinicians, and hospitals transmit standardized encounter reports, images, laboratory and other data to the patient's PHR.

Patients grant full or partial PHR access to clinicians at the point of care or transmit selected information to the clinician.

Patients can transmit data from their PHRs to researchers whom they support.

Federal, State,
Local Public
Health Authorities

Personal Health Record (PHR)

- ❖ Secure repository for encrypted PHR storage.
- ❖ Patients can collect, aggregate, and compile their medical data from various doctors and hospitals into one lifetime health record.
- ❖ Patients own and control access to their lifetime health record.
- ❖ Patients can add data from personal or home devices to their record.
- ❖ The "smart" lifetime health record is *problem-oriented* to assist doctors at the point of care. The smart record has search, artificial intelligence, error identification, and other analytics.
- ❖ Social Determinants of Health (SDOH) are included.
- ❖ Health coaches can help patients understand and use their smart PHRs, genomics, and family history.
- ❖ Anyone can have a smart PHR – promotes health equity.
- ❖ Treatment chronology helps coordinate insurance claims.

Sequestered archive so patients can restrict access to particularly sensitive information.

Separate area for patient's notes and articles of interest (such as medical literature).

Researchers notify HDB clearinghouses of research opportunities that may interest patients.

As Health Data Banks become a significant industrial sector in U.S. healthcare, they will promote health equity, improve public health reporting and response, and engage patients as never before to improve their health.

Health Data Bank (HDB)
Patient's Trusted Agent

Security, credentialing, and PHR access authentication are HDB services.

Health Data Bank's list of PHR account holders who want to be notified of research projects in areas of their interest.