

**Patient Ownership – creating the business environment to build the Learning Health System**  
**Our Health Data Cooperative**  
**<http://www.ourhdc.com>**

Helping USA Residents understand they have rights to their health data and structuring the organization which can hold the key to accessing the accumulation of the patients' data so their rights are protected are two main precepts of Our Health Data Cooperative (OHDC).

Formed as a cooperative business under Minnesota Cooperative law and owned by people who are or someday will be patients, Our Health Data Cooperative is attempting to build an anonymous set of 50 million health records to provide a more efficient way to help health research institutions assess outcomes from treatments of various diseases.

### **The problem**

Big Data in Health is an emerging market. Competitors including Private Search Engine Companies, Social Media Companies, Treatment Companies, Payers of Insurance, Provider Companies and Vendors are holding their data so there is no sharing. The identification of any patient across the various silos of data is difficult to guarantee because there are rules against a national identification number for assignment to each patient that is guaranteed to be accurate. The cost of development of new drugs, or solutions to disease, is going up: delays in research and lack of dissemination about treatments with negative effects prevent patients from getting the information they need. A study currently may have 250 patients being tested for a new drug and the conclusion from that study is being sold by the owner of the drug as a solution which may not have all the negative effects known when it is provided to a population of hundreds of millions of people.

Health researchers spend an estimated \$80 billion annually in the US to obtain patient information to support 800,000 peer-reviewed annually published medical journal articles. Unfortunately, many of these studies cannot be duplicated, and the results cannot be assimilated by patients or providers of health care due to the overwhelming amount of information.

The current siloed structure of US health data repositories requires researchers to access a variety of proprietary databases, controlled by individual healthcare systems providers or to request access to health providers' patients for randomized double-blind samples.

This system is inefficient and results in unreliable studies which frequently allow vested interests to push agendas supporting their assets or withholding information that may be detrimental to patients' health.

*“Patients are going to change the world. Our Health Data Cooperative is attempting to bring together 50 million patients who agree to share their data anonymously to provide a better way to provide health researchers with a better method of collecting valid, non-biased and non-confounded data. In turn, this will result in better treatments, lower healthcare costs and reduce nationwide healthcare expenditures by \$hundreds of billions. We estimate that OHDC will result in better treatments, cut the cost of healthcare in the US by up to \$400 billion annually and help drop the price of achieving research studies from a per patient cost of around \$10,000, to around \$100.*

*”*  
*-Patrick J Grant, Chairman, OHDC*

## **Impacting – Outcome medicine lowers costs and improves patient care**

Our Health Data Cooperative (<http://www.ourhdc.com/>) expands the opportunity for patients to receive outcomes based medicine that diagnosis disease more precisely than is possible today through either intuitive medicine or empirical based medicine alone, so that care may move from more expensive care centers and care givers toward decentralized and distributed rules based medicine.

This disruptive organizational design, through a patient owned cooperative model, is more sustainable and inclusionary than the alternative “Federal Reserve Bank” model being promoted by private drug manufacturers in that:

- 1) OHDC owners, the patients, will be assigned a Personal Identification Number of Cooperative Members (PINOCM™) which allows, by their assignment of this number to each health record point of care, to securely search data bases by OHDC for longitudinal gathering of their record regardless of geographic areas of the care. (as a side note, the trend toward concierge care where operations may occur outside the US system due to cost savings makes this tracking capability very unique to OHDC and important to both outcome medicine and care flexibility).
- 2) All stakeholders can join OHDC through either direct membership, which only requires their consent to share their health records anonymously in exchange for a share of OHDC Stock (no cash cost to join therefore open to all socio-economic groups), or as a company, through Associate Membership in OHDC, which is non-voting but allows access to the **Associate Member Combined Understood Research E-Records (AMCURE™)** data search engine.
- 3) Ownership of the organization that is allowing access to a data set that represents 50 Million aggregated anonymous longitudinal records is important as OHDC will be the “honest broker” model which distributes the info found from studies that represents all outcomes, regardless of their reflection on drug or a manufacturer’s desire for suppressing the results, because OHDC is owned by the patients who will benefit most from knowledge that is gained by information gathered.
- 4) A cooperative private company model, where by patient/owners agree to give up their data and share their records, presents the only model which allows better sharing by providers, (those that allow OHDC access to member records) , so that by participating, providers who allow their data to be searched for PINOCM™ related fields of data are also able to gather the OHDC member records from the AMCURE™ system, which can reduce costs for providers (fees associated with HIE membership can range from \$40,000 to \$150,00 per year and the HIE model is failing).

**An effort to build a Learning Health System, which allows sharing between holders of patient data, is underway in the United States.**

OHDC cooperative business model differs from Private Company or Government models, by its effort to create a patient-controlled Learning Health System, using a secure, cloud-based search and retrieval technology to access multiple databases, regardless of data format, that will anonymously bring millions of patient records together.

**Benefits of adapting the OHDC model for the patient when compared to Private Company or Government ownership of health data models include:**

- A) Patient realizes an Economic Benefit of anonymously sharing, and aggregating their health data with other members
- B) Outcomes of various treatment options for diseases can be more quickly dispersed to patients
- C) Probabilities of adverse complications from treatments for each disease can be listed so as to inform patients of risks of treatment options before agreeing to the treatments (OHDC is the "honest broker" of treatment products' effects on patients)
- D) Health Providers and Patients in all areas of the country can have access to the best scientific, valid, non-biased and non-confounded outcomes for each disease treatment, regardless of socio-economic background
- E) The OHDC cooperative model can be expanded to other countries (India/Latin America in process)

Specific goals of OHDC include improving health of our patient members by aggregation of sufficient anonymous health records to: allow researchers to assess various treatments; oversee revenue optimization of the members' data; save the US hundreds of billions of dollars a year through identification of new and alternative treatments; and rapid sharing of effective and/or dangerous procedures.

**A Share for a Share**

An Equity Stake for Membership in OHDC requires members to agree to allow their health data to be anonymously used for research, but does not require any cash cost by the member. This allows all to join OHDC regardless of their socio-economic status.

*“There is a dire need to improve access to patient outcomes so the patient knows what treatment works best for their disease. OHDC protects the patients’ rights to that data through a cooperative ownership model. We want to get the word out now, and that is why we are tapping the best minds in the country to find effective ways to expand membership.” –*

**We want this to happen faster**

Currently, healthcare data is controlled, not by patients, but by thousands of healthcare systems and healthcare providers. Accessing this data to answer the question “what treatment works best for my disease?” is expensive, costing \$80 Billion each year. Worse, it results in conclusions that cannot be replicated 65% of the time according to a study in Nature. But most tragically, this lack of cooperation results in 100,000 deaths annually, while adding about \$400 billion annually to the cost of providing healthcare in the US.

If the outcome of each treatment for each patient is gathered together with 50 Million other patients anonymously, health researchers can analyze this data to find out what works best, safer, quicker and cheaper. This means you could just "**press best treatment for me**" from your smart phone as you sit in your doctor's office and both you and your doctor would see the percent of outcomes that had successes, and their respective risks, for the treatments that your doctor may be recommending.

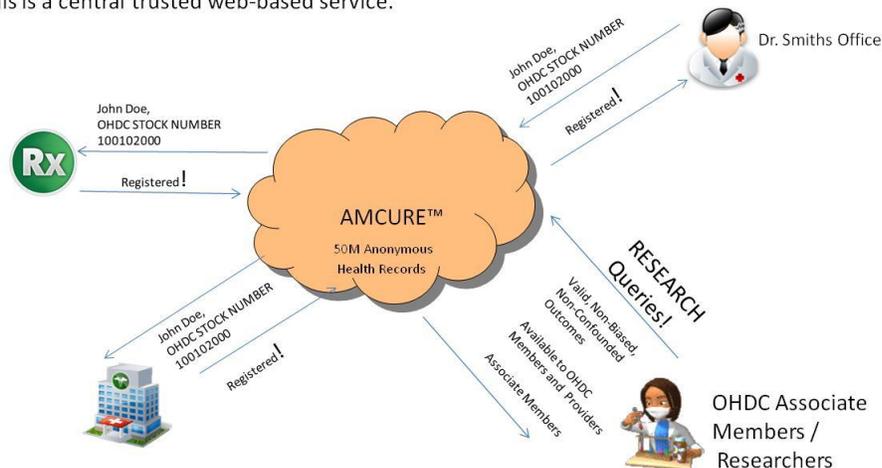
## Recognition

Recently, Our Health Data Cooperative was selected by the White House as one of twenty six partnerships in the United States that showed innovation in the way Big Data can be gathered. OHDC will be highlighted November 12, 2013. Here are some of the highlights of that recognition.

### Novel Ideas

- Patient Owned, Free Membership** – Patient Receives Economic Benefits
- Membership Stock Number** – Provides PIN for All US Residents – Reduces Risks of Errors
- Anonymous Aggregated Health Records** – Creates Big Data For Research
- All Stakeholders Can Join** - Associate Members
- Reduces Administrative Cost for Providers** – Search for patient info by OHDC Stock Number

When a patient is entered into a participating system the OHDC Stock Number is registered with the AMCURE™ Locator. This is a central trusted web-based service.



### Associate Member Combined Understood Research E-Records (AMCURE™)

- ❖ **Simple: Providers register their OHDC patients basic information**
- ❖ **Affordable: No cost or low cost model**
- ❖ **Inclusive: Works with all EHR systems**
- ❖ **Efficient: The right information available where needed when needed**
- ❖ **Practical: Can be built with available technologies**
- ❖ **Secure: Limited to trusted participants**

## **Data to Knowledge to Action Partners**

### **Our Health Data Cooperative**

- Transparent Platform
- Membership Free to All US Residents
- Each Member has an OHDC Share of Stock
- Each Member's OHDC Stock Number Unique
- OHDC Stock Number Identifies Patient's Records
- Gathering of health Records is done Anonymously with OHDC Stock Number as Locator

### **Touchstone Energy**

- Existing 30 Million Members in Cooperative introduced to Our Health Data Cooperative who understand Cooperative Principles

### **UNC/RTI\***

- Builds the evidence-based educational infrastructure for OHDC members that will help them understand use of the OHDC research and create the structure for accessing the results of the database efficiently.

\* UNC/RTI The School of Information and Library Science at the University of North Carolina at Chapel Hill and the Center for the Advancement of Health Information Technology at RTI International

## **Our Health Data Cooperative Mission**

Create a transparent organization owned by 50 million members that agree to share anonymously their health records so a valid comprehensive evidence-based clinical research database is created to answer: "What is the best treatment for my disease?"