Connected Health: A Case Study on Creating a Learning Health System

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Conflict of Interest

Thomas W. Carton, PhD, MS,
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have no real or apparent conflicts of interest to report.
Agenda

• Overview
• Learning Health Systems
• Introduction to CER, PCORnet, REACHnet
• Data Infrastructure
  – Common Data Model
  – Global Patient Identifier
  – Data Linkages
• Patient Engagement Infrastructure
  – REACHnet’s Pragmatic Trial App Suite
  – Health in Our Hands Patient Network
• Learning Health Systems
• Lessons Learned from Pilot Site: Ochsner Health System
• Conclusion
Learning Objectives

1. Illustrate the value of intersecting informatics, research, patient engagement, and operations for creating a learning health system
2. Explain the connected and interoperable principles utilized
3. Discuss the importance and effects of patient engagement and pragmatic research
Applying the HIMSS STEPS Framework

E  ELECTRONIC SECURE DATA

P  PATIENT ENGAGEMENT
A learning health system is one where knowledge is derived from practice and used to drive the cycle of continuous improvement (Johnson et al, 2015).

**Patient Engagement**
- Patient-centered care
- Results of interest to patients

**Operations**
- Alignment of research with organizational strategy
- Buy-in from health systems leaders

**Data**
- To answer research questions
- Integrated into routine healthcare delivery
- To measure outcomes
Pragmatic Research as Basis for Learning Health System

1. Comparative Effectiveness Research
   - Compares outcomes and effectiveness, risks/harms, and benefits of two or more treatments or services

2. Pragmatic research
   - Clinical research embedded in healthcare delivery systems rather than controlled conditions; effectiveness vs. efficacy

3. Multi-site trials
   - Trials implemented across health systems and sites for broad recruitment
The Challenge: A Tale of Two Studies

Two dosing trials for coronary heart disease patients

PCORI ADAPTABLE

- Aspirin maintenance dosage comparison
- $10,000,000
- 20,000 patients

NIH INVESTED

- Flu vaccine—high vs. standard dose
- $20,000,000
- 10,000 patients

CER
Pragmatic
Multi-site
The Solution: Enhanced Efficiencies

- Clinical data infrastructure
- Data linkages
- Patient recruitment
- Trial management
PCORnet
National Patient Centered Clinical Research Network

We face many important, unanswered questions about health care.

- "What type of diabetes is best for a breast cancer patient diagnosed at age 52?"
- "What are my treatment options to reduce readmission rates?"
- "How can I help my patient with chronic kidney pain decide on the best treatment?"
- "What can I learn from my patients to improve their health care?"

But our current research system is not set up to answer these questions in the most useful and efficient way.

Together, partners can decide what questions to study and how to use the data.

And harness health data to foster knowledge that can lead to better care.

A collaborative national resource using the power of partnerships and health data for better research.

That’s the vision of
PCORnet
The National Patient-Centered Clinical Research Network

With sites and partners in every state...

...And protection of patients’ privacy and data security.
REACHnet
REACHnet is a network of health systems containing clinical records for more than 3 million patients in Louisiana and Texas, facilitating patient-centered comparative effectiveness research (CER).

Resources and Services
- Pragmatic Trial App Suite
- Prep-to-Research Querying & Common Data Model
- Collection of Patient-Generated Data
- Stakeholder Engagement
- Streamlined IRB and Contracting
- Health in Our Hands (HiOH) Patient Network
- REACHnet Coordinating Center

Funded by the Patient-Centered Outcomes Research Institute (PCORI) and made possible with these partners:
Data Infrastructure

1. PCORnet Common Data Model
   - Standardized clinical data prepared for retrospective/prospective research and prep-to-research queries

2. Global patient identifier (GPID)
   - Allows for deduplication and matching of patient records

3. Data linkages
   - Ability to link data from other sources with clinical data (i.e., claims, patient-generated data)
PCORnet CDM Domains, v3.0

CONDITION v2.0
A condition represents a patient's diagnosed and self-reported health conditions and diseases. The patient's medical history and current state may both be represented.

DEATH v3.0
Reported mortality information for patients.

DEATH_CAUSE v3.0
The individual causes associated with a reported death.

DEMOGRAPHIC v1.0
Demographics record the direct attributes of individual patients.

DIAGNOSIS v1.0
Diagnosis codes indicate the results of diagnostic processes and medical coding within healthcare delivery.

DISPENSING v2.0
Outpatient pharmacy dispensing, such as prescriptions filled through a neighborhood pharmacy with a claim paid by an insurer. Outpatient dispensing is not commonly captured within healthcare systems.

ENROLLMENT v1.0
Enrollment is a concept that defines a period of time during which all medically-attended events are expected to be observed. This concept is often insurance-based, but other methods of defining enrollment are possible.

ENCOUNTER v1.0
Encounters are interactions between patients and providers within the context of healthcare delivery.

HARVEST v3.0
Attributes associated with the specific PCORnet datamart implementation.

LAB_RESULT_CM v2.0
Laboratory result Common Measures (CM) use specific types of quantitative and qualitative measurements from blood and other body specimens. These standardized measures are defined in the same way across all PCORnet networks.

PCORNET_TRIAL v3.0
Patients who are enrolled in PCORnet clinical trials.

PRESCRIBING v3.0
Provider orders for medication dispensing and/or administration.

PRO_CM v2.0
Patient-Reported Outcome (PRO) Common Measures (CM) are standardized measures that are defined in the same way across all PCORnet networks. Each measure is recorded at the individual item level: an individual question/statement, paired with its standardized response options.

PROCEDURES v1.0
Procedure codes indicate the discreet medical interventions and diagnostic testing, such as surgical procedures, administered within healthcare delivery.

VITAL v1.0
Vital signs (such as height, weight, and blood pressure) directly measure an individual's current state of attributes.
Informatics Solution

GPID Hashing

Longitudinal Data Sources (claims, vital records, hospital discharge data, etc.)

Health System Partner A

Health System Partner B

Health System Partner C

Tablets

Sync App

I2b2

Live CDM

SAS CDM Datamart

Secure Environment

GPID Matching

Study Specific DataMarts (aggregated clinical and other data types)

Combined CDM (Longitudinal patient records linked by GPID)

Data cleaning, Derivations, Transformations

Condition Specific Cohort A

I2b2 & analysis tools

Condition Specific Cohort B

Condition Specific Cohort C

Secure Connections

Data Lake

Quality Checks

Live CDM

SAS CDM Datamart

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Matching Across Clinical Sites

Partner A (hashing_output)
- PatID, HashBundle
  - PTA12300, lksjdfkljweoiru
  - PTA00321, oiwrwoud,nvs
  - PTA45600, z,mcnvhweonc
  - PTA00654, ncokwe9asjdneof

1. Partner A furnishes hashing_output file

2. Matching Tool reads record from hashing_output file

3. Matching Tool matches hashes read with hashes stored in GID_table

4. If a match is not found a new record is created with a new GID for the PatID read from the hashing_output file. If a match is found a new record is created using the GID found and the PatID read from the hashing_output file.

Partner B (hashing_output)
- PatID, HashBundle
  - PTH88800, oiwrwoud,nvs
  - PTH00444, oi1wrw#06wd,
  - PTH33300, z,c@nvh3wo9
  - PTH00222, ncokwe9asjdneof

5. Partner B furnishes hashing_output file and steps 2 - 4 are repeated.

GID_table
- GID, PatID, HashBundle
  - G0001, PTA12300, lksjdfkljweoiru
  - G0002, PTA00321, oiwrwoud,nvs
  - G0003, PTA45600, z,mcnvhweonc
  - G0004, PTA00654, ncokwe9asjdneof
  - G0002, PTB88800, oiwrwoud,nvs
  - G0005, PTB00444, oi1wrw#06wd,
  - G0006, PTB33300, z,c@nvh3wo9
  - G0004, PTB00222, ncokwe9asjdneof

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Matching Across Clinical and Claims Data

- **Tulane** (hashing_output)
  - PatID, HashBundle

- **BSWH** (hashing_output)
  - PatID, HashBundle

- **BCBS** (hashing_output)
  - PatID, HashBundle

- **Medicaid** (hashing_output)
  - PatID, HashBundle

- **PATH** (hashing_output)
  - PatID, HashBundle

- **Ochsner** (hashing_output)
  - PatID, HashBundle

- **LSU** (hashing_output)
  - PatID, HashBundle

**GPID_table**
- GPID, PatID, HashBundle
  - G0001, PTH12300, lksdjflkjweoiru
  - G0002, PTH00321, oiwruowd,nvs
  - G0003, PTH45600, zmcn lhsweon
  - G0004, PTH6545, nccokwe9asjdhn
  - G0002, OCH888800, oiwruowd,nvs
  - G0005, OCH00444, o1wr668686w,
  - G0006, OCH333300, z,c@nvh3w9e9
  - G0004, OCH00222, nccokwe9asjdhn
  - G0007, BCBS11111, jhjkjikhsas1d
  - G0002, MC00222, oiwruowd,nvs
  - G0002, BCBS88999, oiwruowd,nvs

**Matching Algorithm**

- REACHnet

**Claims**
- Clinical
Patient Engagement Infrastructure

1. Pragmatic Trial App Suite (PTAS)
   - Web- and tablet-based platform designed to engage patients (patient app) and facilitate pragmatic trials (researcher app)

2. Health in Our Hands (HiOH)
   - Patient network through which patient enrollees are engaged in research activities through the PTAS inside and outside of clinic settings
   - Enrollees receive health information, research results, and opportunities to participate in specific studies
Pragmatic Trial App Suite (PTAS)

- EMR-agnostic tablets installed in exam rooms
- Integrated into clinical workflow
- Quickly sync to data in CDM to push targeted content to patients
- Co-developed among partners

Pilot:
- 16 clinics
- 2 health systems
- 226 tablets

Growing to:
- >= 5 health systems
- 800 tablets

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PTAS Apps, Modes, and Functions

Patient App

- Engagement Mode
- Health in Our Hands Function
- Consumer Health Function

Research Mode

- Recruitment Function
- Trial Management Function
- Trial Participation Function

Researcher App

- Recruitment Function
- Trial Management Function

Web-Based Portals

- HiOH Portal

Web- and Tablet-Based Modes & Functions

HiOH Portal

Researcher Portal
Patient App: Engagement Mode: HiOH Function

Informational Video

Would you like to join the Health in our Hands network?

We’d like you to be part of a new Patient Network called “Health in Our Hands.” Through this Network, Health Care researchers and doctors learn from patients. There is no health risk to you from Health in Our Hands.

What is Health in Our Hands? Health in Our Hands is a network that sees patients as the experts. It gives you the chance to share what is important to you and your health. We will also send you up-to-date news and resources related to your health. Joining Health in Our Hands is up to you. If you choose not to join, it won’t affect your health care.

What happens when I join Health in Our Hands?
1. We will ask for your name and contact information for email or text messages.
2. We may ask you to answer surveys about...

HiOH Consent

Contact Information

An Ochsner representative will answer your questions about Health in Our Hands.

First name: [First name]
Last name: [Last name]
Email me: [youname@email.com]
Text me: +1 [xxx-xxxx-xxxx]

I disagree | Need Help | I agree

PRO Survey

In general, how would you rate your physical health?

Excellent | Very good | Good | Fair | Poor

No response

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Health in Our Hands Patient Network

Patients join HiOH on tablet in exam room at clinic visit

Enrolled patients may be contacted by email or text message

Enrolled patients receive:
- Trial recruitment invitations
- Patient-reported outcomes surveys
- Consumer health information
- Research results
- Opportunities to engage in research processes
Patient App: Engagement Mode: Consumer Health Function

**Women’s Health: Inter-Pregnancy Care**

During any of your previous pregnancies, did you have to see a specialist beside your OB doctor?

- Yes
- No
- Prefer not to respond

**Screening Questions**

**Provider Referral**

Your answers will be shared with your provider for further evaluation.

First name

Last name

Submit
Patient App: Research Mode: Recruitment Function

Informational Video

Pre-screening Questions

Contact Information
You are invited to participate in this survey because you joined the Health in Our Hands patient network in your doctor’s office.

The questions will ask about your personal characteristics and whether you are interested in participating in future health research.

The purpose of the questions is to find out what types of research are of interest to HIOH members.

Participation in this survey is completely voluntary. Choosing to participate or not participate will not affect your medical care. Your survey answers will be stored securely and kept confidential.

Please choose one of the following:

- I would like to continue and answer the survey questions. By answering these questions, you agree to share your responses with the Louisiana Clinical Data Research Network which operates the HIOH patient network.
- I am not interested and would like to quit.

Have you ever been told by a doctor or other health care professional that you have diabetes?

- Yes
- No
- No, but I was told I have pre-diabetes or borderline diabetes
- Don't know / Not sure
Researcher App: Recruitment & Trial Management Functions

CRC views and selects enrolled patient

Monitor alerts and progress
Next Step: PTAS Command Center
Examples of Multi-Site Research

- **HiOH Patient Network**
  - Almost 4,000 consents from 2 health systems over 10 months

- **WeighSmart**
  - Text messaging and smart scales for weight loss

- **ADAPTABLE**
  - PCORnet national aspirin dosing trial

- **CHAP**
  - Chronic Hypertension and Pregnancy trial investigating HTN drug therapy

- **PPPRN Partnerships**
  - Co-recruitment with Health eHeart, AR-PoWER, and CPPRN

- **IPC**
  - Facilitation of inter-pregnancy primary care visits

**Consent Rates**
- 30% HiOH Network
- 40% PRO Survey
## Examples of Multi-Site Research (cont.)

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Natural Experiments Network</strong></td>
<td>• Natural experiment of impacts of population-targeted health policies to prevent diabetes</td>
</tr>
<tr>
<td><strong>YMCA Diabetes Prevention Program</strong></td>
<td>• Recruitment of pre-diabetic patients for YMCA’s Diabetes Prevention Program (DPP)</td>
</tr>
<tr>
<td><strong>INVESTED</strong></td>
<td>• Comparative effectiveness of high vs. low dose flu vaccine</td>
</tr>
<tr>
<td><strong>RELIANCE</strong></td>
<td>• Comparative effectiveness of Roflumilast vs. Azithromycin to prevent COPD exacerbations</td>
</tr>
<tr>
<td><strong>Diabetes Medication Decision Tool</strong></td>
<td>• Web-based diabetes medication decision tool for shared-decision making</td>
</tr>
<tr>
<td><strong>Precision Medicine Initiative</strong></td>
<td>• Presidential initiative to build a national, large-scale research participation cohort with cancer</td>
</tr>
</tbody>
</table>
The Goal: A Learning Health System

A learning health system is one where knowledge is derived from practice and used to drive the cycle of continuous improvement (Johnson et al, 2015).

- **Patient Engagement**
  - Patient-centered care
  - Results of interest to patients

- **Operations**
  - Alignment of research with organizational strategy
  - Buy-in from health systems leaders

- **Data**
  - To answer research questions
  - Integrated into routine healthcare delivery
  - To measure outcomes
REACHnet’s Data and Patient Engagement Infrastructures in Practice:

A Success Story from Ochsner Health System
Deploying the PTAS

**Clinic Recruitment**
- Ochsner Leadership and Senior Physicians approached for approval of pilot
- Clinical sites identified by measures including physician research interests, clinical care type, site location

**EMR Integration**
- Tablet launch is initiated through EPIC EMR (hyperlink within MA navigator)
- Data collected via the tablet is sent directly to the REACHnet Data Center
- Select information (e.g. survey responses) is returned to Ochsner EMR in real-time

**Staff Training**
- Nurses and MAs are trained in tablet use through lecture-based and hands-on interactive sessions
- Rooming staff are tasked with tablet activation and hand-off to the patient
Participating Clinical Sites at Ochsner Health System

207 tablets at 17 clinics
Activated over a 7 month period
Clinical areas:
- Primary Care
- Endocrinology
- Cardiology
- Diabetes Management
Patient Response

Health in Our Hands (HiOH):
3,315 patients enrolled (March 18-January 17)
4,222 patients completed PRO survey (March 17-January 17)

Characteristics of HiOH enrollees:
- Gender: 62% Female, 38% Male
- Age Range: 19 to 97
- Race: 64% White, 34% African-American, 2% Other

Patient Interest in HiOH:
- “I would like to stay abreast of my healthcare and keep up with current research as it relates to my health.”
- “It will offer me information about future research studies related to diabetes.”
Physician Testimonials

“I am thrilled about the use of tablet technology for patient education and recruitment to our large PCORI-funded pragmatic trial on heart disease (ADAPTABLE). This study will establish best practices in aspirin dosage to maximum protection with minimum risk to our patients.”

– Eiman Jahangir, MD, Cardiology, Ochsner

“Tablet technology has allowed us to recruit hundreds of patients for future participation in clinical research studies with no negative impact on workflow. I have been very impressed with the rollout.”

– Laura Nicosia, MD, Primary Care, Ochsner
Lessons Learned from Ochsner

This technology presents a promising method for increasing patient engagement in research and incorporating research activities efficiently into the clinic.

**Successes:**
- Increased rate of patient enrollment
- Positive response from patients and physicians
- Technical integration with EMR

**Challenges:**
- Workflow integration; flexibility for clinic-specific needs is key
- Continued front-line staff engagement; physician support is key
Applying the HIMSS STEPS Framework

E  ELECTRONIC SECURE DATA

P  PATIENT ENGAGEMENT
Thank you!

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