Promoting Patient and Researcher Engagement with Distributed Data Research Networks through Hurdle Free Tools

pSCANNER All Hands Symposium 2016

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Data QUEST: Improving Health in Rural Populations
funded by NIH, AHRQ, CDC, PCORI, AHRQ, CMMS, and industry

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<th>Research Studies</th>
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<td>• Team-based Safe Opioid Prescribing</td>
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<td>• Integrated Behavioral Health</td>
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<td>• MOSAIC: Meaningful Outcomes and Science to Advance Innovations Center of Excellence</td>
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<td>• Establishing the Priority Clinical Areas for Use of Handheld Ultrasound In Family Medicine</td>
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<td>• Acute Pain in Primary Care</td>
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<td>• Integrating Behavioral Health and Primary Care</td>
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<td>• Chronic kidney disease</td>
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<td>• Colorectal cancer screening</td>
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<td>• Acute Pain</td>
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<td>• Lung cancer screening</td>
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<th>Network Participation</th>
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<td>• Clinical Trials Network: Pacific Northwest Node</td>
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<td>• Accelerating Change and Transformation in Organization and Networks III (ACTION III) partnership, The Quality Commons</td>
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<td>• WWAMI Practice Transformation Network</td>
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<td>• Diabetes Prevention Registry</td>
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<td>• PCORNet’s Patient-Centered Scalable National Network for Effectiveness Research (pSCANNER)</td>
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<td>• Northwest Pharmacogenomic Research Network</td>
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<td>• DARTNet Practice Benchmarking Registry</td>
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Profiling Electronic Health Records Data

• EHR data networks are growing and offer huge promise for research.
• But there are not many tools to offer KNOWLEDGE about data.
Addressing researchers’ barriers...

Answering the question... Ways to share the depth and breadth of data, going beyond a data dictionary

- What’s there?
- How do I use it?
- What algorithms do I use? (e.g., the best way to identify diabetics, Coumadin adverse events)

So what data do you have in your system??

2014
CTSA funded us and we set to launch FindIT

2015
FindIT 1.0 launched

2016
pSCANNER → FindIT 2.0 and patient/family stakeholder visualizations
Building FindIT

- Human centered design process
- Needs assessment study
- Multidisciplinary participatory design process
- Incorporating data visualization

FindIT 2.0
Building FindIT

http://dataquest.iths.org

Human Centered Design Approach

Observe / Ideate  Design  Build  Evaluate
Patient counts using standard EHR categories

### Browse Data Types
Explore counts of patient lives by different categories of data found in Data QUEST partners' electronic health record systems.*

- **Patient Demographics**
- **Medications**
- **Vital Signs**
- **Procedures**
- **Communications**

### Browse By Diagnosis
Explore counts of patient lives by different diagnosis categories, driven by ICD-9 codes.*

* e.g., 154.3,154.2

- **Common Conditions (in alphabetical order)**

### Data Dictionary
Explore our data dictionary.

- **Appointments**
- **Diagnoses**
- **Encounters**
- **Immunizations**
- **Insurances**
- **Labs**
- **Medications**
- **Past Medical History**
- **Patients**
- **Patient Address**
- **Procedures**
- **Providers**
- **Referrals**
- **Vitals**

Diagnosis record status: 1 = active, 0 and -1 = inactive

### Counts by ICD-9 Code
<table>
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<tr>
<th>ICD-9 Code</th>
<th>Number of Patients: 2012</th>
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<tr>
<td>414.00</td>
<td>1725</td>
</tr>
<tr>
<td>413.9</td>
<td>141</td>
</tr>
<tr>
<td>414.01</td>
<td>139</td>
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Researcher Needs Assessment Studies

Themes driving design considerations

- 32 participants, 66% female
- 3 studies
  - 2 qualitative interviews
  - 1 user test
- residents, postdoctoral fellows, junior and senior faculty, research scientists

Study 1 & 2
- Access to clear process for receiving data sets
- Good usability
- Expertise in data content
- Contextual and specific knowledge about datasets (data provenance, quality, trustworthiness)
- Expertise in discovering and accessing data
- Confidence and trust in data quality
- Detailed descriptions of data
- Usable data search tools
- Ability to view patterns at different scales
- Easy ability to search for appropriate cohorts
- Training on data tools
- Correct and clear description of tool’s functions

Study 3
- Process and Status
- Data Expertise
- Informed Data Utility
- Tools to Explore/Discover Data
- Orient Researchers

Three Studies Twelve Themes Five Design Considerations
Researcher Needs Assessment Studies

Themes driving design considerations

- **Process and Status**
  - process easy to understand
  - user friendly with a simple design

- **Data Expertise**
  - researchers have varying levels of tech expertise
  - easy access to expertise when needed
  - quick linking of relevant data to a preferred topic

- **Informed Data Utility**
  - confidence and trust in the data
  - detailed descriptions

- **Tools to Explore/Discover Data**
  - usable data search tools
  - viewing patterns at different scales
  - quick / easy cohort discovery

- **Orient Researchers**
  - quick lay of the land – a good / fast user experience
Innovations + Collaborations Workshops

RESULTS

12 teams

44 recommendations

15 Features/characteristics

3 objectives

5 properties
Key Questions

*Question 1* – What kind of data exist in the network (i.e., primary care data generated in the EHR data, coded data elements across a set of specified domains)?

*Question 2* – Where are the data from (i.e., geography, number of clinics, type of clinics (primarily community health clinics), type of patients served (high need patients from rural areas))?  

*Question 3* – How much data are there (i.e., across how many patient lives, across how much of the system of care for those patients)?  

*Question 4* – When do the data come from (i.e., how many years of care does the network involve, how often is it updated/kept up to date)?
FindIT 2.0
Preliminary Wireframe

Demographics
- Gender
- Ethnicity
- Language
- Race
- Age
- Insurance

Primary Care Patient
- Health Behaviors
  - Tobacco
  - Alcohol
  - Drugs
  - STDs
- Diagnoses
- Vital Signs
- Immunizations
- Labs
- Medications
- Procedures
- Screening Tests

DataQUEST
- CONTENT
- MAP
- NEWS ITEM DATA VIZ
  - Visuals
  - News
  - More News
  - Contact

Visualizing data reflecting primary care research opportunities (e.g., diagnoses)
Shifting focus to patient and family stakeholders...

Creating a health communication bridge using data visualization

Human Centered Design Approach

Observe / Ideate ➔ Design ➔ Build ➔ Evaluate
Patient / Family Member Needs Assessment

Goals were to understand:

- participant’s role and motivation for taking part in pSCANNER
- the participant’s perception of themselves as a researcher and to discover how they articulate their curious questions and seek answers to them
- how the participant currently looks up health information, and what this experience has been like
- participant’s attitudes toward technology, and what they’re comfortable using

- participant’s mental model of pSCANNER EHR data, and to discover if they see value in that data
- participant’s attitudes toward a pSCANNER data visualization tool and how they might use it
- what kinds of health information the participant thinks are important for patient groups to have access to via a pSCANNER data visualization tool
Patient and Family Member Needs Assessment Study

- 13 participants, 62% female
- 1-hr qualitative interview
- Patients, patient advocates, patient family members
- Obesity, CHF, KD

Emerging motivations for participating in pSCANNER

- educate themselves and others about health research
- seek better treatment options for themselves and others
- to be the voice of patients
Patient and Family Member Needs Assessment Study

**Emerging Themes**

- Patients actively educate themselves about their health
- Patients want access to their own health information and electronic health record
- Patients want health research to be accessible to the layman
- Patients want reliable health information
- Patients want to work together as a team with doctors and caregivers
- Patients no longer regard what their doctor says as the end all be all
- Patients often seek out health information after a health crisis of some kind
- Patients have very specific medical questions about their condition
- Patients unanimously turn to Google to seek health answers

**Emerging Design Considerations**

- Want information that's current and relevant to their needs
  - Want to analyze their own health data and make use of it
- Must have content and design that's simple, easy to use, and understandable
- Need to see where the data comes from and how it came to be
  - Want to be able to use the health information as a means of educating and collaborating with their care team
- Design and content must evoke trust and aid in their search for second opinions
- Content must easily digestible in high stress situations
- Needs to allow adequate content and data filtering to suit their needs
  - Health questions must be properly indexed by Google
Next Steps: delivering visualizations to the pSCANNER Stakeholder Engagement Team

Patient / Family Member Stakeholders
• Complete the interviews
• Analyze data – define design considerations
• Design visualizations
• Build prototype
• Test
• Launch with pSCANNER data

Clinicians / Researchers
• Finish FindIT 2.0 design
• Test
• Launch with pSCANNER data