



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

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Research Studies

- Team-based Safe Opioid Prescribing
- Integrated Behavioral Health
- MOSAIC: Meaningful Outcomes and Science to Advance Innovations Center of Excellence
- Establishing the Priority Clinical Areas for Use of Handheld Ultrasound In Family Medicine
- Acute Pain in Primary Care
- Integrating Behavioral Health and Primary Care
- Chronic kidney disease
- Colorectal cancer screening
- Acute Pain
- Lung cancer screening

Network Participation

- Clinical Trials Network: Pacific Northwest
 Node
- Accelerating Change and Transformation in Organization and Networks III (ACTION III) partnership, The Quality Commons
- WWAMI Practice Transformation Network
- Diabetes Prevention Registry
- PCORNet's Patient-Centered Scalable National Network for Effectiveness Research (pSCANNER)
- Northwest Pharmacogenomic Research Network
- DARTNet Practice Benchmarking Registry

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...

So what data do you have in your system??

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)





Building FindIT

http://dataquest.iths.org

Human Centered Design Approach



Data QUEST ITHS Institute of Translational Health Sciences Accelerating Research, Improving Health. Explore Data Success Stories About Us Home Home > Explore Data FindIT 1.0 Browse Data Discover the breadth and depth of data across the network FindIT, our federated information dictionary tool, can be used to explore the data shared across the Data QUEST network. Data generated in primary care practices via diverse electronic health record systems have been aligned to facilitate research and speed the ability to translate significant research discoveries directly into real world practice settings. Please browse data categories at the bottom of the page to explore what data are available. Distribution of Patient Lives by Race Othe 32.07% Pacific Islander 0.24% American Indian/Alaskan Native 1.14% Asian 1.30% 1.37% Caucasian 58,70% stribution of Patients by Race within Data QUEST data Data QUEST includes data from 3 organizations and 15 primary care clinics across Washington and Idaho that together provide more than 185,000 outpatient visits annually. Browse Data Types Browse By Diagnosis Data Dictionary Explore counts of patient lives by Explore counts of patient lives by Explore our data dictionary different diagnosis categories, different categories of data found in Data QUEST partners' electronic driven by ICD-9 Codes. Patient Demographicshealth record systems Patient Addr / Phone ICD-9 codes (no text) go Patient Demographics Patient Insurance Common Conditions (in Medications Past Medical History alphabetical order) Vital Signs Smoking Status Procedures Family History Immunizations Problem / Diagnoses CPT codes Lab Tests Medications Procedures Immunizations Patient Appts Patient Visit Info Referrals

Patient Finding

Patient counts using standard EHR categories

Browse By Diagnosis Browse Data Types Data Dictionary Explore counts of patient lives by Explore counts of patient lives by Explore our data dictionary. different categories of data found different diagnosis categories, Appointments • driven by ICD-9 codes.* in Data QUEST partners' electronic Diagnoses ٠ health record systems.* Encounters e.g., 154.3,154.2 go Patient Demographics Immunizations • Medications Insurances • Stoprosis data Vital Signs Labs Common Conditions (in ocedures Gender alphabetical order) Medications Diagnosis status **Diagnosis** record nmunizations Past Medical History ٠ status 1 = active, Gender By Age **Diagnosis Code** Race Asthma Patients ٠ 0 and -1 = inactive Chronic Obstructive Pulmonary Disease Gender Age 0-12 Age 13-18 Age 19 Age 2 Diagnosis Type Patient Address ٠ 5,168 Female 5,756 2.690 10.532 Ethnicity Procedures ٠ Diagnosis (7.61%) (8.47%) (3.96%) (15.51%) Description Providers Coronary Artery Disease 6,114 2.593 2,577 7,198 (Language Counts by IDC-9 Code Date diagnosed Referrals (9.00%) (3.82%) (3.79%) Degenerative Joint Disease Number of Patients: 2012 ICD-9 Code Unknown 2 1 0 4 (0.01% Vitals Date resolved (Arthritis) 414.00 1785 413.9 141 Depression Contact Us for More Information 414.01 135 Diabetes V45.81 126 412 122 Hypertension 410.90 81 414.8 73 73 414.9 414.04 37 35 V45.82 26 411.1 410.40 17 w. 15 414.05

Contact Us for More Information

Male

Researcher Needs Assessment Studies

Themes driving design considerations

32 participants, ٠ Access to clear process for receiving data sets 66% female Process and Status Good usability 3 studies • Expertise in data content Data Expertise Contextual and specific knowledge about datasets 2 qualitative (data provenance, quality, trustworthiness) interviews Study 1&2 Expertise in discovering and accessing data Informed Data Utility 1 user test Confidence and trust in data quality Detailed descriptions of data residents, ٠ Study 3 Usable data search tools postdoctoral Tools to Explore/ Ability to view patterns at different scales **Discover** Data fellows, junior and senior Easy ability to search for appropriate cohorts faculty, research Training on data tools **Orient Researchers** scientists Correct and clear description of tool's functions Three **Five Design** Twelve Studies Considerations Themes

Researcher Needs Assessment Studies

Themes driving design considerations





FindIT 2.0 Design

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)?



Shifting focus to patient and family stakeholders...

Creating a health communication bridge using data visualization



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

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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

- \checkmark 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