EDM Forum: Connect, Collaborate, Communicate

Margo Edmunds, Ph.D.
Vice President, AcademyHealth

Concordium
Washington, DC
November 17, 2017
About Today’s Presentation

→ No COI or financial disclosures

→ Learning objectives:
  – Become familiar with a model for collaborative research: CER, informatics, PROs
  – Consider value and implications of open science model for public-private collaboration and dissemination
  – Assess sustainability models for EDM Forum: Why should you care?
our data is our future

The EDM Forum drives rapid collaboration among researchers & diverse stakeholders who create data, methods & evidence to shape the next generation of learning health systems.

eGEMs publications do not reflect the official views of AHRQ or the United States Department of Health and Human Services.

AcademyHealth’s EDM forum was created through a cooperative agreement from the Agency for Healthcare Research and Quality (AHRQ) grant U13 HS20249. Ongoing support for the EDM forum comes from AHRQ grant U38 HS022715.
“How can we talk about patient safety when patients live in dangerous communities? You will not have a healthy patient if you don’t have a healthy community. How can we have quality without equity; patient safety without community safety?“

- Gilbert Salinas, M.P.A., Patient Advocate
Growth of the EDM Forum Network

2010
EDM Forum launched with 11 ARRA-funded AHRQ Grantees

2011
600 members
19 published products

2012
1,700 members
47 published products
eGEMs launched
23,000 downloads

2013
2,000 members
162 published products

2014
3,000 members
294 products
56,000 downloads

2015
3,700 members
411 products
92,000 downloads

2016-2017
4,000+ members
469 total products
160,000+ downloads

Learn more at
www.academyhealth.org/edmforum
Concordium brings together the best and brightest in the fields of **health data and delivery system transformation**.

The meeting showcases innovation and emerging science, **promoting collaboration** in an effort to improve health.

**2017 Concordium**
November 17, 2017
AcademyHealth
COLLABORATE

Data-Sharing Platform
CIELO

Community of Practice
DALHS

Online Resource
PRO Toolkit
Toward Greater
Health Information Interoperability
in the United States Health System

EXECUTIVE SUMMARY

The 2015 EDM Forum hosted AcademyHealth’s newest national conference, Consortium 2015: Strategic Uses of Evidence to Transform Delivery Systems. The theme of the conference was “Toward Greater Health Information Interoperability in the United States Health System.”

The conference focused on the importance of interoperability in the health care system, and the challenges and opportunities it presents. The conference aimed to address the need for better data exchange and sharing to improve patient care and outcomes.

Attendees discussed the latest developments in health information technology and data sharing, and shared insights and experiences from their own work. The conference featured keynote speeches, panel discussions, and networking opportunities to promote collaboration and innovation in the field of health information technology.

The conference concluded with a focus on the future of health information interoperability, and the steps needed to achieve greater interoperability and data sharing in the health care system. Attendees left with a better understanding of the challenges and opportunities in the field, and a commitment to working towards a more interoperable health care system.

COMMUNICATE
The Global Reach of eGEMs

Launched in 2013, eGEMs has published over 160 papers with more than 160,000 downloads from readers across the globe. This map shows download data from eGEMs’ Google Analytics.
Challenges and Lessons Learned

**Challenges**

- Communicating value of participation
- Creating a culture of collaboration and trust
- Meaningfully engaging stakeholders on their own terms: mutual benefit
- Doing real-world implementation and evaluation
- Learning to right-size funding for network and special projects (“three bears”)
- How to execute together, rather than separately

**Lessons Learned**

- Engage the right people: doers with multiple hats and entrepreneurial spirit
- Cultivate a safe space that allows diverse stakeholders to tell their stories and engage with one another
- Be a learning organization: *Listen first, understand needs, then build*
- Flexibility is key. Expect plans to change, and don’t lose sight of the vision
- Adapt as new opportunities arise
Thank you!

To learn more about the EDM Forum:

➔ Visit
  www.academyhealth.org/edmforum

➔ Contact
  Margo.Edmunds@academyhealth.org
The EDM Forum
Data Quality Collaborative

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AcademyHealth Concordium
Panel: Learning from Experience: The EDM Forum
17 November 2017
EDM-F picks up a recurring pain point……

• April 2011: EDM Forum solicits papers for special issue in Medical Care
  – Erin Holve comments: “Everybody is concerned about EHR data quality”

A Pragmatic Framework for Single-site and Multisite Data Quality Assessment in Electronic Health Record-based Clinical Research

Michael G. Kahn, MD, PhD,*† Marsha A. Raebel, PharmD,‡§ Jason M. Glanz, PhD, MS,‡||
Karen Riedlinger, MPH, MT (ASCP),¶ and John F. Steiner, MD, MPH‡

Introduction: Answers to clinical and public health research questions increasingly require aggregated data from multiple sites. Data from electronic health records and other clinical sources are useful for such studies, but require stringent quality assessment. Data quality assessment is particularly important in multisite studies to distinguish true variations in care from data quality problems.

Key Words: data quality, data quality assessment, single-site studies, multisite studies

(Med Care 2012;50: S21–S29)
EDM Forum Funds The Data Quality Collaborative

Data Quality Collaborative (DQC): Strategies for Assessing Data Quality

Project Lead: Michael Kahn, University of Colorado Denver Anschutz Medical Campus

Project Period: October 2012 - September 2013

The Data Quality Collaborative (DQC) is a working group of leading experts from teams using electronic clinical data to address the need to ensure that CER and PCOR findings derived from diverse and distributed data sources are based on credible, high-quality data; and that the methods used to assess and report data quality are consistent, comprehensive, and available to data consumers. The major aim of the collaboration is to develop a comprehensive data quality assessment framework and guidelines for the CER community, including draft recommendations that can guide the development of new analytic and reporting methods specifically directed to data quality assessment and reporting for CER studies.

Visit the DQC community to access recent publications and discussions related to this work.
Convening stakeholders to create a community
DQC work products

TRANSPARENT REPORTING OF DATA QUALITY: DISTRIBUTED PLATFORMS

Abstract

Introduction: Poor data quality can hinder the availability of electronic administrative data for observational research and has implications for the quality and reproducibility of research results that would enable informed decision making and development of evidence-based policies and interventions.

Model and Methods: We describe and share our experience in developing distributed platforms for sharing data across research networks. Our efforts have included the design of an interoperability framework and a recommendation for data collection and sharing. To support the implementation of these recommendations, we develop an implementation guide, a data dictionary, and an online wiki.

Recommendations: Our recommendations focus on building a distributed data platform that can be used for observational research across multiple networks. This platform will support data sharing and quality improvement, and enable researchers to access and analyze data from multiple sources.

Project Cover Sheet

FOR LETTERS OF INTENT AND APPLICATIONS

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Principal Investigator: Kahn, Michael
Organization: UNIVERSITY OF COLORADO DENVER
Project Title: Building PCOR Value and Integrity with Data Quality and Transparency Standards
Easygrants ID: 5581
Date Submitted: EST
Reporting Data Quality Assessment Results: Identifying Individual and Organizational Barriers and Solutions

Tiffany Callahan, MPH; Juliana Barnard, MA; Laura Helmkamp, MS; Julie Maertens, PhD; Michael Kahn, MD, PhD

ABSTRACT

Introduction: Electronic health record (EHR) data are known to have significant data quality issues, yet the practice and frequency of assessing EHR data is unknown. We sought to understand current practices and attitudes towards reporting data quality assessment (DQA) results by data professionals.

Methods: The project was conducted in four Phases: (1) examined current DQA practices among informatics/CER stakeholders via engagement meeting (07/2014); (2) characterized organizations conducting DQA by interviewing key personnel and data management professionals (07-08/2014); (3) developed and administered an anonymous survey to data professionals (03-06/2015); and (4) validated survey results during a follow-up informatics/CER stakeholder engagement meeting (06/2016).

Results: The first engagement meeting identified the theme of unintended consequences as a primary barrier to conducting DQA. The survey revealed that data professionals in the field of informatics had varying levels of knowledge about DQA, with some reporting that they were not aware of the practice at all. The follow-up meeting provided insights into the challenges and strategies for improving DQA processes.
What did the EDM Forum do for the Data Quality Collaborative?

1. Highlighted a recurring complaint/need
2. Solicited input via open-access publication
3. Supported establishment of a new community via collaborative grant
   • Collaboration support
   • Relationships to new communities
4. Organized/hosted workshops
5. Supported open-access publications
6. Partnered in follow-up PCORI funding

Continued engagement in PCORI DQ project
The CIELO Project: Creating and Sustaining an Open Data Platform for Healthcare Researchers and Data Scientists

Philip R.O. Payne, PhD, FACMI
Robert J. Terry Professor and Director, Institute for Informatics
Washington University School of Medicine
Professor of Computer Science and Engineering
Washington University School of Engineering and Applied Science
CIELO: An Open Science Platform for Healthcare Researchers and Data Scientists

Project Objectives:

1) Provide members of the healthcare research community with access to an easy to use and highly flexible data commons platform
2) Reduce time and cost of research while enhancing the reproducibility and cumulative benefit of data analyses
3) Evolve and meet emerging community needs

Blue-Sky: not grounded in the realities of the present: visionary <blue–sky thinking> (Merriam Webster Dictionary)
Community-Defined Requirements:

- Integration with analogous platforms and tools
  - Ex. Sage Bionetworks Synapse
- Incorporation of data security/confidentiality controls
  - Particularly in the context of analyses involving PHI or similarly privileged data sets
- Convergence towards common data model for submission and reuse of data sets
  - Ex. OMOP
- Multi-tiered sharing model
  - Open access
  - Limited access
  - Private (for defined collaborators)
- Semantic search and discovery of code and data
- Connectivity to linked open data sets
- Social networking at a project and individual level

Collected via interaction with members of the EDM Forum Community:
- ✓ Academia
- ✓ Industry
- ✓ Government
- ✓ Influencers
Technical Requirements: Extending and Enhancing Existing Technologies and Platforms

Sharing of Software and Data Sets

- Github/Gitlab
  - Partitioning of access
  - Bundling code and data
  - Data model harmonization
  - Cross-linkage (URIs/APIs)

Discovery and Reuse

- Folksonomy
- Semantic Search
  - Current ontologies
  - Linkage to social functions

Social Engagement

- Activity Feeds Discussion Forums
  - Project-level feeds
  - Linkage to metadata
5 Lessons Learned from the CIELO Project To-Date:

1) It is important to allow users to bundle data and code in variable ways (e.g., mapping multiple versions of code to multiple versions of data, as opposed to a one-to-one mapping of such artifacts).

2) There is a need to support multi-level sharing permissions that can evolve gracefully over the lifecycle of a project or bundle (from private collaborative or enclaves to fully open releases of data and code).

3) Flexible and dynamic metadata management functionality can assist in responding to the ongoing evolution of standards and requirements.

4) Cross-linkage to external data and code resources where contribution to a centralized repository is not possible, due diverse data and code stewardship, ownership, and technical requirements, is highly desirable.

5) Support for provisioning of durable resource identifiers, such as digital object identifiers (DOIs), can increase uptake and impact. DOIs enable attribution of work and create a value proposition for both the contribution and subsequent reuse, adaptation, and recontributing of data and analytics bundles, particularly for scholars.
Deploying CIELO to the National CTSA Consortium: National Center for Digital Health Innovation (CD2H)

- We will deploy, optimize, and support the use of a collaborative “storefront” for CD2H data and software products, originating from either collaborative projects that are catalyzed by the center or through efforts undertaken at individual CTSA hubs or collaborative partners.
- This “storefront” will emphasize systematic product lifecycle management and the provision of both content-driven and social resource discovery and interaction surrounding such products.
How to get involved:

- Join the community
- Contribute bundles
- Adopt and adapt bundles
- Provide feedback
- Incorporate into your projects

Public bundles:

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<thead>
<tr>
<th>Name</th>
<th>Description</th>
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<th>Contributor</th>
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<td>Interoperability brief</td>
<td>Toward Greater Health Information Interoperability in the United States Health System</td>
<td>Electronic Health Records; Interoperability</td>
<td>2016-06-21</td>
<td>David Padgham</td>
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<td>ResearchIQ Resource Ontology</td>
<td>Research Integrative Query (ResearchIQ) tool is a semantically anchored resource discovery</td>
<td>Semantic Web; Semantics; ontology</td>
<td>2016-05-20</td>
<td>Omkar Lele</td>
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<td>DQE-v</td>
<td>An Open Source Database-Agnostic Tool for Exploring Variability in EHR Data</td>
<td>Data Quality; Electronic Health Records; Variability</td>
<td>2016-04-11</td>
<td>Hossein Estiri</td>
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http://cielo.edm-forum.org
Questions or Comments?

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EDM Forum’s eGEMS: Generating Evidence and Methods

Adam Wilcox, PhD
University of Washington
Early Efforts and Lessons Learned

- Need for methods dissemination
- Lack of journals that were structured to focus on methods
- Need for incentives to contribute methods
> Focus on methods
> Peer-reviewed
> Open access
> Special issues on topics of identified need
eGEMS Results

Yearly Downloads

- > 14 issues
  - 9 special issues
- > 201 papers
  - 20+/general issue
  - 10/special issue
- > Leading papers in various methods areas
Cognitive Computing and Innovative Analytics: Concordium’s Past Work and Potential Future Directions

Gurvaneet Randhawa, MD, MPH

Medical Officer,
Health Systems and Interventions Research Branch,
Health Care Delivery Research Program,
Division of Cancer Control and Population Sciences
Context

- Rapidly increasing use of IT in healthcare delivery
- Big data is transforming research (and may transform healthcare)
- Communication revolution has changed patient’s expectations
- Shift towards patient-centeredness and value-based care

Disclaimer: The views expressed are not necessarily those of NIH or HHS
EDM Forum’s Accomplishments

- Created a learning network for scientists building large clinical data networks for CER
  - Many were either largest or first in the nation (J Comp Eff Res. 3:562; 2014)
- Support of open and collaborative science
  - Dissemination and engagement: EGEMS, issue briefs, meetings
  - Collaborative projects: Participant-centered consent toolkit, CIELO
- Issue brief on informatics tools: 31 spanning the data cycle (collection, access, exchange, aggregation, analysis, and decision support)
  - Distributed analytics: GLORE, OCEANS (SCANNER)
  - Query/Explorer: RedX (WICER), SHRINE Custom workbench (Ped IBD)
Distributed Research

- Well-suited for healthcare delivery research
  - Addresses many concerns: privacy, proprietary, cyber-security
  - Leverages existing data infrastructure

- Challenges:
  - Harmonizing data to a common data model
  - Variable data quality
  - Care delivery constraints on data collection
  - Time lag for administrative claims data
Large-Scale Treatment Research

- Observational Health Data Sciences and Informatics (OHDSI) collaborative analyzed information from 250 million patients from four countries (PNAS.113:7329-36; 2016)
- 11 data sources (EHRs and claims) mapped to OMOP CDM
- Used distributed analytics to elucidate treatment pathways over 3 years after diagnosis for diabetes, depression and hypertension
- Less variation in first drug for diabetes compared to other two
- Unique treatment pathways for 10% of diabetes and depression patients and nearly 25% for hypertension patients
  - 1.1 million HTN patients, about 300,000 DM & depression patients
Large-Scale Cancer Treatment Research

- Goal: Harness big data-based infrastructure and methods to understand the cancer treatment pathways, the extent of variations in these pathways, and their impact on patient outcomes.

- NCI has funded Columbia U. (OHDSI coordinating center) to ascertain the feasibility of using the OHDSI approach to cancer care
  - Aim 1: Conduct similar analysis in cancer patients
  - Aim 2: Understand feasibility of conducting cancer treatment and outcomes research
Cancer Care Delivery Challenges

- Delivering high-quality cancer care: Charting a new course for a system in crisis (NAM, 2013)
  - 18 million cancer survivors by 2022
  - Survivors are living longer and getting older
  - Provider shortages
  - Care is fragmented and poorly coordinated
  - Few tools to improve quality of cancer care
- Provider frustration with poorly-designed EHRs
- Care needs to be knowledge-based, patient-centered, and systems-minded (Berwick, 2002)
Distributed Cognition (DC)

- Conceptual framework to understand goal-directed, information-rich, complex collaborative work
  - Unit of analysis is an *activity system* oriented around specific goals
  - Analyze the propagation of information in the system
  - Analyze social and material context that shapes activity in a system
- Activity system: Set of actors, their goals, *information-bearing media*, and physical and social structures that influence the activity
- Well studied in aviation: Cognition is distributed over personnel, sensors and machinery in the plane and on the ground.
Principles of DC Applied to Care Coordination
NCI-commissioned (Draft) White Paper by Hazlehurst, Xiao, Gorman

- Patients and care-givers co-produce care with providers
- People actively manage their environment to reduce need for effortful and error-prone mental processing
- Human-technology interfaces play a primary role in cognitive work
- Information curation (e.g. pulling data from different sources, validating data, prioritizing information, presenting information in a timely manner) is a cognitive task
- Coordination devices (e.g. checklists, patient monitoring routines) are needed – hard to use when actors are dispersed
- Study not only what people know but how they go about using what they know to do what they do
DC: Next Steps

- Synthesize existing literature on methods and frameworks used to study distributed cognition in healthcare
- Identify gaps and a research agenda to advance the methods to study distributed cognition
Achieving System-minded Care Delivery

- Harness big data (e.g. AI approaches)
- Better understanding of how delivery systems think and act (e.g. DC)
- Evaluate interventions that improve system performance
- Quality measures for system performance
- Incentives to improve system performance
- Need better-designed IT
Data Commons
Increased Need to Share Data Has Caused Rapid Changes in Market Trends

Complex data sharing platforms can change how and who performs research, enables new engagement models, and accelerates time to insights.

Insights from Multiple Datasets
Access to integrated clinical trial data, clinical data, biosamples, and omics data

Patient and Provider Engagement
Patient enrollment and engagement platform allowing for capture of patient reported data

Data Governance and Provisioning
Approval processes and toolkits in place for data governance and automated data provisioning

Data Information Exchange
Automated capabilities to select and provision data to share with research, clinical, and patient partners in a common format

Intuitive and Flexible Research Tools
Easy to use research tools for creating cohorts and analyzing the data

HPC Needs On Demand
Ability to have private secure High Performance Computing (HPC) environments provisioned on demand for a fee

Data Information Exchange
Automated capabilities to select and provision data to share with research, clinical, and patient partners in a common format
Patient Registries Are a Key Output of This Trend and Market Need

The number of patient registries has grown from 17 per year in 2000 to 547 per year in 2016. Please provide a source to support all statistical/factual representations on this slide.

Based on current rates, by 2020, 606 additional registries will be developed each year.

Source: ClinicalTrials.gov using keyword “Registry” in search field “Other Terms”
Approach: Search performed on 4/12/17. All countries included. “First Submitted” date determined year. Five registries without date were excluded. Linear extrapolation to 2020.
Organizations Use Registries in Multiple, Valuable Ways

- Identify patient risk, enabling better prediction of outcomes
- Examine factors that influence prognosis in disease groups
- Describe care patterns such as care quality and delivery disparities
- Inform regulatory decision-making
- Determine treatment or drug effectiveness

Institutions leverage data stored in registries to promote patient care and research initiatives
Patient Registries have proven benefits and Outcomes

Registries have resulted in proven clinical and scientific successes, including publications, trial recruitment, and outcomes

- Improved Health Outcomes
- Publication of scientific articles
- Enhanced clinical trial recruitment
- Augmented real world outcome monitoring

Scientific Publications Citing Registry Data

Source: NCBI PubMed using keyword “Registry”
Approach: Search performed on 4/11/17. PubMed file “Results by Year” was used to determine number of studies per year.
Many Different Registry Types Exist, But Their Information Exists in Silos

The different types and designs of registries results in additional challenges and demands when using the data

1. **Product Registries**
   Include patients exposed to a given health care product such as a drug or device

2. **Disease or Condition Registries**
   Disease state or condition used as the inclusion criteria

3. **Research Patient Registries**
   Include patients included in clinical trials

4. **Health Services Registries**
   Include patients based on clinical encounters such as hospital visits, procedures, and office visits

5. **Mortality Registries**
   Record cause of death

6. **Care Coordination Registries**
   Record data on referring Physicians and Primary Physicians

Different registry types are designed with different outputs in mind, so data in one registry cannot always be combined with data from another registry
The Solution to These Challenges Could be a Universal Health Registry Platform

A single Universal Health Registry solution would enable multiple users to access and utilize data that is constantly updated, integrated and standardized.
A Universal Platform Would Allow Multiple, Distinct Users to Maximize the Utility of Collected Data

Users have distinct needs and uses for data, but collective utilization of available data can lead to efficient and effective development of new treatments and therapies.
A Proposed Stack that Provides the Foundation for a Universal Registry Platform

The platform architecture is designed to provide capabilities to power research and analytics within a registry platform.

<table>
<thead>
<tr>
<th>Contributor Data Types</th>
<th>Data Integration (Secure Zone)</th>
<th>Data Lake (Protected Zone)</th>
<th>Collaboration Zone</th>
<th>Application Zone</th>
<th>User Portal</th>
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<tbody>
<tr>
<td>CLinical Trial (SDTM)</td>
<td>Secure Encrypted Channel</td>
<td>Data Metadata</td>
<td>Subscriber Data Assets</td>
<td>Analysis Tools &amp; Utilities</td>
<td>Public</td>
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<tr>
<td>Clinical Trial (other)</td>
<td>Raw data storage</td>
<td>Data Categorization</td>
<td>Metadata Catalog (Publicly Searchable)</td>
<td>Subscriber Workspace</td>
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<td>Data Sharing Platform</td>
<td>Staging Zone</td>
<td>Reference Data &amp; Ontologies</td>
<td>Document, Publication and Code Base Repository</td>
<td>Subscriber Data Browser (Tier one)</td>
<td>Admin/Report</td>
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<tr>
<td>Research Data Analytic Code</td>
<td>Secure Zone</td>
<td>Semantic Data Integration</td>
<td>Analytic Data Mart (Tier One Data)</td>
<td>Subscriber Request Workflow</td>
<td>Super Admin</td>
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<td>Data Dictionary</td>
<td>Central Normalized Repository (Tier One &amp; Two)</td>
<td>Central Normalized Repository (Tier One &amp; Two)</td>
<td>Other Data Stores (Tier One Data)</td>
<td>Reports &amp; Dynamic Dashboards</td>
<td>IRP Admin</td>
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<td>Data Provisioning</td>
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<td>Research Zone</td>
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<td>Secure External Collaboration Environment</td>
<td>SAS/Strata/R/Python</td>
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<td>SNP Data</td>
<td>NLP Training Library</td>
<td>Central Normalized Repository (Tier One &amp; Two)</td>
<td>Secure External Collaboration Environment</td>
<td>Cloud Infrastructure Management</td>
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</table>

Cloud Infrastructure Management
(Security, Scalability, Elastic Capabilities, HW Virtualization, Logging, Backup D/R, High Availability, VPN Capabilities)

Information Management
Metadata, Master Data, Auditing, Data Provenance, Data Quality, Anonymization

Governance
(e.g., IPD, Policies and Procedures, DUA, Organization, Processes, Tools & Technology, Security)
Focus at the Core of a Universal Registry Platform Stack

*Deloitte’s Research Trust implements and extends multiple standards*
Research Trust Standards

Deloitte’s Research Trust is compatible and extends OHDSI’s OMOP model
IBD Plexus is an Existing, Successful Registry Platform Based on Research Trust Stack

The IBD Plexus platform was designed to support multiple activities, and the design of this platform can be leveraged and expanded to additional organizations and diseases.

**Discovery**
- Drug target discovery
- Biomarker identification
- Hypothesis validation
- Evidence generation

**Clinical Development**
- Study feasibility
- Protocol development & refinement
- Clinical trial support: stratifying patients & site selection

**Outcomes Research**
- Comparative effectiveness
- Healthcare utilization
- Cost effectiveness (future phase)

**Safety Surveillance**
- Pharmacovigilance
- Post marketing safety studies, including electronic support for AE & SAE reporting
Integrates clinical, socioeconomic, radiological, and genomic data from six international clinical sites, with little extension to accommodate the variety of multi-modal data sets.

Advanced Analytics Tool for TB Portals' Data

Multiple and Extensively Drug-Resistant Tuberculosis Data Exploration Portal MXDR-TB DEPOT has been created for working with cohorts that one can analyze across the four types of data.
Towards a Data Commons

**NIH Definition**

- A data commons is a shared virtual space where scientists can work with the digital objects of biomedical research such as data and analytical tools.
- The NIH Data Commons Pilot will test ways to store, access, and share biomedical data and associated tools in the cloud so that they are FAIR (Findable, Accessible, Interoperable, Reusable).
- The goal of the NIH Data Commons is to accelerate new biomedical discoveries by providing a cloud-based platform where investigators can store, share, access, and compute on digital objects (data, software, etc.) generated from biomedical research and perform novel scientific research including hypothesis generation, discovery, and validation.

**Potential Commons Framework**

*Source: https://datascience.nih.gov/thecommons*
Blockchain – A Method to Enable Universal Data Sharing: Data as a Valuable Asset, a Currency

To overcome barriers of data sharing, new concepts need to be explored that can ascertain that credit is given where credit is due

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Health organizations direct information to the blockchain. Health organizations provide services to patients. Clinical data is tracked in existing health IT systems. Standard data fields and a patient’s public ID are redirected to the blockchain via APIs.</td>
</tr>
<tr>
<td>2</td>
<td>Transactions are completed and uniquely identified. Each transaction is stored on the blockchain, containing the patient’s public (non-identifiable) ID. Smart contract processes incoming transactions.</td>
</tr>
<tr>
<td>3</td>
<td>Health organizations and institutions can directly query the blockchain. Health organizations and institutions submit their queries via APIs. Non-identifiable patient information (e.g., age, gender, illness) is viewable. Data can be analyzed to uncover new insights.</td>
</tr>
<tr>
<td>4</td>
<td>Patients can share their identity with health organizations. The patient’s private key links their identity to blockchain data. The private key can be shared with new health organizations. With the key, organizations can then uncover the patient’s data. Data remains non-identifiable to those without the key.</td>
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</table>
Conclusion

Developing a framework for a data-driven biomedical ecosystem is not just a technology challenge – we need governance principles and an economic model to incentivize users to share data.
Jose Morey, M.D.
Senior Medical Scientist
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Medical Technology and Artificial Intelligence Adviser
Visiting Assistant Professor – University of Virginia
@DrMorey1

Healthcare in the New Machine Age
Academy Health
10th Annual Conference on the Science of Dissemination and Implementation in Health
Source: Gartner (August 2016)
Thank You
Life Changing Innovation

@RasuShrestha
Chief Innovation Officer, UPMC | EVP, UPMC Enterprises

#UPMCInnovates
#1 Most Livable City (The Economist, 2014)
#1 Best Places to Live (Money Magazine, Aug. 2015)
Pittsburgh Is The New Cool (Forbes, Feb. 2016)
#4 Best Places to Travel in 2017 (Harpers Bazaar, Jan. 2017)
Ford invests $1 billion in Pittsburgh-based Argo

Yelp acquires Pittsburgh startup Nowait for $40 M

10 Pittsburgh startups paint the tech world yellow + black
Integrated Delivery & Finance System

$16B annual revenue in 2016

80K employees - largest private employer in PA

39 hospitals

3.2M Health Plan members
Our DNA as an Academic Hub

• Aligned with University of Pittsburgh’s School of Medicine

• #5 in NIH funding with $475 million for clinical research

• One of largest programs in US with 1,800 residents and fellows
As an organization dedicated to Life Changing Medicine, UPMC has defined a bold mission: to shape the future of health care through innovation. At UPMC Enterprises, we help bring this mission to life by turning innovative ideas into growing, thriving businesses.
Key Focus Areas

**Translational Science:**
Accelerate the application of discoveries to deliver new models of care, narrowing the gap between bench science and bedside practice.

**Improving Outcomes:**
Connect and coordinate the health system to empower clinicians to provide high-quality care in any setting.

**Consumer:**
Develop solutions that allow consumers to access medical services and information anytime, anywhere, and to engage in all steps in their health care journey.

**Infrastructure and Efficiencies:**
Deliver health care with fewer resources in a fiscally sound manner.
## Portfolio Companies

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<th>Company Name</th>
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<td>vincent</td>
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<td>Vivifyhealth™</td>
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Thank you.

@RasuShrestha
What does it take to stay healthy?
To understand Social and non-medical determinants and how to address them, *Out in the Rural* is a must read.

Highly relevant to contemporary discussions of social inequality and health care reform combining social and political history. The first historical account of America's first rural community health center.

- Tufts-Delta Health Center, Founded by Dr. H. Jack Geiger, opened in 1967 in Mound Bayou in the Mississippi Delta, to become the first rural community health center in the United States- represents birth of the nation’s community health care program--50th anniversary in 2017
- *Its goal was simple:* to provide health care and outreach to the region's thousands of rural poor, most of them black sharecroppers who had lived without any medical resources for generations.
- Worked upstream to address the fundamental determinants of health---factors such as education, poverty, nutrition, and the environment,(e.g., unsafe drinking water, poor sewage, hunger)-and asks the question, "What does it take to stay healthy?"

The approach was a radical assault on both the medical and social status quo.
Social Determinants of Health (SDOH)

- Defined by WHO as “the conditions in which people are born, grow, live, work, and age.”
- SDOH is one of the Healthy People 2020 factors of MDOH: interrelationships among… factors that determine individual and population health
- Comprised of 5 key areas:
  - Economic stability
  - Education
  - Social and community context
  - Health and healthcare
  - Neighborhood and built environment
Why are Social Determinants Important?

Most current models treat Bob and Dave the same
(same sex, age, illness burden)

Bob
- 43yo
- Diabetes
- Hypertension
- COPD
- Lives at home with his wife
- Employed with good health insurance
- Good access to supermarkets with healthy food options
- Engineer who uses apps and spreadsheets to manage his conditions

Dave
- 43yo
- Diabetes
- Hypertension
- COPD
- Lives alone
- Occasionally employed, no health insurance
- Nearest supermarket requires a 20 minute drive
- Low literacy
- Unsure how to manage his condition

Unmasking Social Determinants reveals inequity in resource utilization and outcomes.
Current SDoH Measures

- **The National Quality Forum (NQF) partnered with the Aetna Foundation** to create “a large-scale initiative that… would improve healthcare outcomes by addressing the impact of SDoH through efforts designed to influence clinical practice, outcome measurement, and payment.”

- **Connecticut Association of Directors of Health**
  - Created a Health Equity Index which measures 7 SDoH and their relationships with 13 health outcomes

- **Lexis Nexis**
  - Developed a Socioeconomic Health Score to address SDoH
  - Comprised of factors such as personal finances, education, voter registration, law enforcement, and derogatory records

- **North Carolina Institute for Public Health**
  - Partnered with Carolinas HealthCare System to develop an interactive map, which mapped 12 SDoH for a 10-county region

- **Value-Based Payment Programs (VBP)**
  - Social risk factors were measured in association with a VBP, and the study found that dual enrollment (Medicare/Medicaid), as a marker for low income, was the greatest predictor of poor health outcomes
  - A New York Department of Health VBP committee was organized to make recommendations and create interventions in each of the 5 SDoH key areas
How 3M is addressing SDoH

Geographic Data

- Granular geographic SDoH measures relative to state average
- Identify variables driving a particular geography’s score
- Geo-tagging people to impute person-level impact of score on outcomes
- Geographic community needs assessment

Person Level Data

- Identify non-medical risk factors likely to impact outcomes
- Individual action plans to improve outcomes
- Population segmentation layered on top of CRGs
- Feed predictive models (EHN / PHN)
- Risk adjustment models
Link HRA (Health Risk Assessment) to actual claims data to determine costs/outcomes

Using validated NCQA certified Health Risk Assessment (HRA) tool called Assess My Health, with a Midwest Medicaid agency, we linked 50k responses to claims.

FINDINGS:

• We connected the HRA results to claims and followed people over the 12 months post assessment to quantify health care utilization and cost.

• Responses to certain questions predicts concurrent and prospective utilization.
  • We found that a certain set of responses predicted a greater than threefold (3X) increase in ED and/or inpatient hospitalization rate (validated by review of their claims).
    • This includes:
      • Uncontrolled pain
      • Depression/anxiety/stress
      • “Unsure if my meds are helping me”
      • Lack of health confidence to manage health problems

• 55% of this population reported that they lacked money for essentials (food, etc). When compared to the 45% of Medicaid recipients who did not claim they lacked money for essentials
  • Results show very different outcomes in ED utilization, hospitalization, (poorer outcomes for first group).
## SDoH Use Cases

<table>
<thead>
<tr>
<th>Use Case</th>
<th>Users</th>
<th>Description</th>
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<tbody>
<tr>
<td>Action Plan</td>
<td>PCP</td>
<td>Develop a personal action plan based on factors getting between a patient and their best possible outcomes, to address an individual’s needs.</td>
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<tr>
<td></td>
<td>Care Manager</td>
<td></td>
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<td></td>
<td>Health Coach</td>
<td></td>
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<tr>
<td>Priority List</td>
<td>Care Manager</td>
<td>List of people ranked by their geo and self assessment index. Scores can be used in combination with CRG, predictive model scores, and other factors for more nuanced segmentation. Used to prioritize work and outreach.</td>
</tr>
<tr>
<td>Population Profile</td>
<td>Care Managers</td>
<td>Snapshot of aggregate risk factors, lists rates and counts. Can be compared to state or other benchmarks. Used for resource and intervention planning. Might support “Community Needs Assessment” requirement for non-for-profit hospitals.</td>
</tr>
<tr>
<td></td>
<td>Population Health Clinicians</td>
<td></td>
</tr>
<tr>
<td>Risk Adjustment</td>
<td>Data Analysts</td>
<td>Person-level non-medical data feeds a (potential) methodology for enhancing CRG (3M) or other risk-adjustment methodologies; budgets and contracting</td>
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<tr>
<td></td>
<td>Economists</td>
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<td>Researchers</td>
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<td>Finance</td>
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<tr>
<td>Link performance and payment</td>
<td>Medicaid</td>
<td>Incorporate funding for SDoH into MCO contract— housing, food/nutrition, hold accountable for health and social outcome improvements; develop public/private partnerships in at risk communities to address housing, improved environmental issues, food security</td>
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<td></td>
<td>MCOs</td>
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Using Data to Promote Health Equity

Concordium 2017

Brenda Battle
Vice President Urban Health Initiative and Chief Diversity, Inclusion and Equity Officer

November 17, 2017
UChicago Medicine is working on a transformation strategy to integrate the equity lens into foundational process improvement principles.

**E3 Leadership + Equity**

- **Engage** in improvement
- **Evolve** in our understanding
- **Excel** in implementing
- Plus **Equity** in execution

**Key Areas**
- Clinical Effectiveness
- Human Resources
- Patient Experience and Engagement
- Diversity, Inclusion and Equity
- Operational Excellence
- Population Health
- Clinical Effectiveness
- Human Resources
We have been redefining our care model to improve population health management.
Through analyzing data derived from our EMR and CHNA, and other sources, interventions are designed to support population health management.

Data determinants include:
- Readmission rate
- ED high utilizer
- Observation data
- CHNA
- Clinical and claims data
UChicago’s Urban Health Initiative provides a conduit for our populations to manage their health and well-being. The Urban Health Initiative provides an umbrella for a wide-ranging research and patient care programs that seek to understand social determinants of health, reduce or eliminate disparities in outcomes to care, and provide residents with tools to manage their health and well-being.

### South Side Fit
- A wellness program that focuses on improving the health and quality of live of adults living with chronic illness such as diabetes and heart disease. The program entails complete health assessments with biometrics, regular exercise, regular health coach with consultations, nutritional and lifestyle seminars, and grocery store tours.

### Improving Diabetes Care and Outcomes on the South Side of Chicago (South Side Diabetes Project)
- A project that engages patients, providers, clinics, and community collaborators to improve the health care and outcomes of African-Americans on the South Side of Chicago. The program engages in a multi-pronged approach patient education and empowerment, provider workshops, quality improvement programs in clinics and community collaborations.

### Community Health Worker Program
- UCMC employs CHWs to help improve management of adult and pediatric chronic conditions, including Diabetes, CHF and Asthma. CHWs educate families on how to recognize the signs and symptoms and triggers, proper use of medications and devices to manage the condition. They conduct in-home environmental assessments to identify common asthma triggers, and connect families with reliable health-related resources available from dozens of community-based agencies.

### South Side Pediatric Asthma Center
- Is a multi-site collaborative focused on reducing the burden of asthma for children and families on the South Side of Chicago by facilitating access to care, promoting standardized treatment, and education through engagement and outreach.

### Diabetes Education and Empowerment Program
- DEEP™ a multi-cultural, bilingual, diabetes self-management curriculum to helping participants take control of their disease and reduce the risk of complications. UChicago Medicine’s CHWs and Community Relations staff are all certified peer educators and deliver in community settings throughout the Southside.
Using Data to Promote Health Equity
Opportunities, Questions, and (Potential) Pitfalls

Philip M. Alberti, PhD
Senior Director, Health Equity Research and Policy

@PM_Alberti

November 17, 2017
Question: What level SDOH data do we need?

Opportunity: Community Health Needs Assessment

**Top 10 Prioritized Community Needs**
Explicitly Addressed Across 97 Implementation Strategies

1. Access to medical care
2. Mental health access and treatment
3. Chronic disease management
4. Obesity
5. Social determinants of health
6. Child health
7. Healthy living
8. Cancer
9. Substance abuse
10. Diabetes

**Social Determinants of Health**
Addressed Across 89 Implementation Strategies in Rank Order of Frequency

1. Food access
2. Social support
3. Poverty
4. Crime
5. Education
6. Transportation
7. Housing
8. Built environment
9. Racism

**Potential Pitfalls:**
1. Less-than-authentic, bidirectional community engagement
2. Less-than-comprehensive community benefit reporting, undercount
Opportunity: SDS-Adjustment for Value Based Purchasing

Conceptual Model
- Transportation
- Neighborhood Deprivation
- Education
- Income
- Social Support
- Food Access
- Racism
- Crime

Empirical Model
- Dual Eligibility
- Black race

Potential Pitfalls:
1. Safety net hospitals unfairly penalized, lose vital resources, exacerbate inequities
Question: What are the “right” adjustors? What’s available *now*?

Potential Pitfall:
1. Pragmatic: Collection and USE
2. Without a national standard, we are no closer to adjustment or to...
Opportunity: Incentivizing Equity through Payment Reform

A Roadmap for Promoting Health Equity and Reducing Disparities

1. Do we incentivize disparity reduction, or the promotion of health equity or both?
2. Given the SDOH, what is our expectation about the % inequity reduction a hospital can truly achieve?
3. National benchmark or self-referent?
• ROCChe
  • SDS data collection in EHRs
  • Health Impact Assessments to inform national advocacy efforts

• AAMC AHEAD
  • “Building a Systems Approach to Health Equity for Academic Medical Centers”

• Monthly Updates and Alerts
  • www.aamc.org/healthequity