Transforming Health Data into Clinical Actions

Neil Sarkar, PhD, MLIS, FACMI
President & CEO
Rhode Island Quality Institute

Associate Professor of Medical Science
Associate Professor of Health Services, Policy and Practice
Brown University
Commercial Conflict(s) Of Interest

None to report.
Learning Objectives

• Understand the concepts of “Big Data” in the context of health
• Identify the challenges of interoperability, resulting in the “data chasm”
• Describe the core elements of enabling a Learning Healthcare System
• Formulate how health data can be transformed into clinically actionable knowledge
Outline

• Setting the Stage
• Exploring Clinical and Genomic Data
• Thinking about Big Data
• Bridging the Divide
• Addressing Clinical Needs
The Promised Future...
Biomedical Informatics

“He is programmed with the medical knowledge of 47 of Starfleet's finest physicians and the collected medical information of three thousand cultures.”
Transforming Health Care

- Cost of Care
- Sharing Knowledge
- Involving Patients
- Personalizing Care
- Coordinating Care
- Improving Outcomes
Managing Expectations
The Five “Rights” of CDS

• The right **information** (what)
• To the right **person** (who)
• In the right intervention **format** (how)
• Through the right **channel** (where)
• At the right time in **workflow** (when)
21st Century Cures

Defines how the healthcare ecosystem:

1. Enables the secure exchange and use of electronic health information *without special effort* on the part of the user
2. Allows for complete access, exchange, and use of all electronically accessible health information for authorized use under applicable State or Federal law; and
3. Does not constitute *information blocking*

Defined in Section 4003 of the Cures
**USCDI v1**

<table>
<thead>
<tr>
<th>Assessment and Plan of Treatment</th>
<th>Laboratory</th>
<th>Provenance *NEW</th>
<th>Smoking Status</th>
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<tr>
<td>Care Team Members</td>
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<td>Author Time Stamp</td>
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<td>Laboratory</td>
<td>Values/Results</td>
<td>Author Organization</td>
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<td>Medications</td>
<td>Medications</td>
<td>Medication Allergies</td>
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<td>Medication Allergies</td>
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<td>Laboratory Report Narrative</td>
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<td>Pathology Report Narrative</td>
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<td>Progress Note</td>
<td>Medications</td>
<td>Medication Allergies</td>
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<td>Patient Demographics</td>
<td>Date of Birth</td>
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<tr>
<td>First Name</td>
<td>Race</td>
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<tr>
<td>Last Name</td>
<td>Ethnicity</td>
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</tr>
<tr>
<td>Previous Name</td>
<td>Preferred Language</td>
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<td></td>
</tr>
<tr>
<td>Middle Name (including middle initial)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Suffix</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Birth Sex</td>
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</tr>
<tr>
<td>Problems</td>
<td>Address *NEW</td>
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<tr>
<td>Vital Signs</td>
<td>Phone Number *NEW</td>
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<tr>
<td>Diastolic Blood Pressure</td>
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<td>Systolic Blood Pressure</td>
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<td>Body Height</td>
<td></td>
<td></td>
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<tr>
<td>Body Weight</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Heart Rate</td>
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<tr>
<td>Respiratory rate</td>
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<tr>
<td>Body Temperature</td>
<td></td>
<td></td>
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<td>Unique Device Identifier(s) for a Patient’s Implantable Device(s)</td>
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<td>Smoking Status</td>
<td>Pulse oximetry</td>
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<td></td>
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<tr>
<td></td>
<td>Inhaled oxygen concentration</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Pediatric Vital Signs *NEW</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>- BMI percentile per age and sex for youth 2-20</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Weight for age per length and sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Occipital-frontal circumference for children &gt;3 years old</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**The proposed EHI Export certification requirement requires that:**

1. All EHI produced and electronically managed by a developer’s health IT must be readily available to export for:
   - a single patient upon request for their health data, and
   - all patients when a provider seeks to change health IT systems.

2. The export file must:
   - be computable, and
   - include documentation to allow for interpretation and use of EHI. The documentation must be made publically available via a hyperlink.

Note: Health IT developers would have the flexibility to determine their products’ export standards.
In the Clinic

Electronic Health Data
Uses of an EHR

• **Primary Uses**
  – Patient Care
    • Delivery
    • Management
    • Support
  – Billing and Reimbursement

• **Secondary Uses**
  – Decision support (development)
  – Quality
  – Research
  – Education
  – Public Health
  – Regulation
  – …
In 2015 over 4 in 5 of all non-federal acute care hospitals had adopted a Basic EHR with clinician notes, whereas, 80 percent of small hospitals with less than 100 beds, rural hospitals, and critical access hospitals had adopted a Basic EHR with clinician notes. Nearly all non-federal acute care hospitals have possession of an EHR certified by HHS.

As of 2014, a majority of office-based physicians have adopted electronic health records (EHRs). By the end of 2014, about 8 in 10 (83%) of office-based physicians had adopted any EHR and about half (51%) adopted a 'Basic EHR'. Since 2008, office-based physician adoption of any EHRs has nearly doubled, from 42% to 83%, while adoption of Basic EHRs has nearly tripled from 17% to 51%. Between 2013 and 2014, adoption of any EHR grew by 6% and Basic EHR adoption grew by 5%.

http://dashboard.healthit.gov/quickstats/quickstats.php
The Molecular Promise

Genomics, Proteomics & Metabolomics
Workflow #1: Phenotyping, selection and sample acquisition

Workflow #2: Phenotypic augmentation

Personalized Medicine
(Typical Interpretation)

Genomic Data + Clinical Data
Big Data, Big Opportunities
“Big Data”

• High Volume
• High Velocity
• High Variety
• High Veracity
Addressing the Challenge of “Big”
Disease Knowledge Discovery

The Right Data at the Right Time

How can big data change science?
Here's how medical research traditionally works:

1. Come up with a question or hypothesis.
2. Design an experiment to test it. Wait for new data to come in.
3. Form your conclusion.

Big data changes step 2
Online, searchable databases provide instant answers, speeding up research.

https://www.mobifilia.com/iot-for-healthcare/
Interoperability
The future of health will be driven by digital transformation enabled by radically interoperable data and open, secure platforms.

Always-on sensors that capture data and platforms that aggregate, store, and derive insights from individual, institutional, population, and environmental data will catalyze the transformation.

The **catalyst for change**: Radically interoperable data will empower hyper-engaged consumers to sustain well-being and receive care only in the instances where well-being fails.

Two **jobs to be done** for consumers to holistically address their health (overall state of well-being encompassing mental, social, emotional, physical, and spiritual health).

Five **enablers** for consumers to accomplish their jobs to be done.

Five **tasks** that ecosystem players will perform on behalf of consumers.

Three categories of **business archetypes** in the future of health environment.

Source: Deloitte analysis.

Deloitte Insights | deloitte.com/insights
Ten winning business archetypes in the future of health

Data + platforms
- Data convener
- Science and insights engine
- Data/platform infrastructure builder

Well-being + care delivery
- Health products developer
- Consumer-centric health “virtual home + community”
- Specialty care operator
- Localized health hub

Care enablement
- Connectors and intermediaries
- Individualized financer
- Regulator

Powered by radically interoperable data for a personalized and seamless consumer experience

Source: Deloitte analysis.

Deloitte Insights | deloitte.com/insights
The Health Interoperability Ecosystem

Where do you fit in?

The health interoperability ecosystem comprises individuals, systems and processes that want to share, exchange and access all forms of health information, including discrete, narrative and multimedia. Individuals, patients, providers, hospitals/health systems, researchers, payors, suppliers and systems are potential stakeholders within this ecosystem. Each is involved in the creation, exchange and use of health information and/or data.

An efficient health interoperability ecosystem provides an information infrastructure that uses technical standards, policies and protocols to enable seamless and secure capture, discovery, exchange and utilization of health information.

- “Foundational” interoperability develops the building blocks of information exchange between disparate systems by establishing the inter-connectivity requirements needed for one system or application to share data with and receive data from another. It does not outline the ability for the receiving information technology system to interpret the data without interventions from the end user or other technologies.

- “Structural” interoperability defines the structure or format of data exchange (i.e., the message format standards) where there is uniform movement of healthcare data from one system to another such that the clinical or operational purpose and meaning of the data is preserved and unaltered. Structural interoperability defines the syntax of the data exchange. It ensures that data exchanges between information technology systems can be interpreted at the data field level.

- “Semantic” interoperability is the ability of two or more systems to exchange information and to interpret and use that information. Semantic interoperability takes advantage of both the structuring of the data exchange and the codification of the data, including standard, publicly available vocabulary, so that the receiving information management systems can interpret the data. Semantic interoperability supports the electronic exchange of patient data and information among authorized parties via potentially disparate health information and technology systems and products to improve quality, costs, safety, efficiency, experience and efficacy of healthcare delivery.

- “Organizational” interoperability encompasses the technical components as well as clear policy, social and organizational components. These components facilitate the secure, seamless and timely communication and use of data within and between organizations and individuals. Inclusion of these non-technical considerations enables interoperability that is integrated into end-user processes and workflows in a manner that supports efficiencies, relationships and overall health and wellness through cooperative use of shared data both across and within organizational boundaries.

HIMSS
transforming health through information and technology

@insarkar
<table>
<thead>
<tr>
<th>Categories of Standards</th>
<th>Functions of Standards</th>
<th>Examples of Real World Use of the Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocabulary &amp; Code Sets (Semantics)</td>
<td>The information is universally understood</td>
<td>RxNorm Code for Ibuprofen is 5640</td>
</tr>
<tr>
<td>Format, Content &amp; Structure (Syntax)</td>
<td>Information is in the appropriate format</td>
<td>C-CDA packages up data in the appropriate format</td>
</tr>
<tr>
<td>Transport</td>
<td>The information moves from point A to point B</td>
<td>SMTP and S/MIME to send the C-CDA from one setting to another</td>
</tr>
<tr>
<td>Security</td>
<td>The information is securely accessed and moved</td>
<td>X.509: to ensure it is securely transmitted to the intended recipient</td>
</tr>
<tr>
<td>Services</td>
<td>Provides additional functionality so that information exchange can occur</td>
<td>DNS+LDAP: to find the recipient’s X.509 certificate to encrypt a message</td>
</tr>
</tbody>
</table>
Standards and Interoperability

“Too many ways to say the same thing”

• Common data elements, terminology, structures, and organization
• Seamless exchange and interpretation of data across systems and institutions
• Interoperability
  – Content and structure *(syntactic)*
  – Vocabulary/code set/terminology *(semantic)*
Assessing Data Quality within Health Information Exchanges: A Case Study for Supporting Emergency Department Research

Margaret M Thorsen, BA1, Indra Neil Sarkar, PhD, MLIS2,1, Elizabeth Chen, PhD2,3, Elaine Fontaine, BS1, Gregory Walker, PhD1, Megan Ranney, MD, MPH1,4

1The Warren Alpert Medical School of Brown University, Providence RI, 2Center for Biomedical Informatics, Brown University, Providence RI, 3Rhode Island Quality Institute, Providence RI, 4Emergency Digital Health Innovation Program, Department of Emergency Medicine, Brown University

ABSTRACT

This study characterizes data quality within a state-based Health Information Exchange (HIE) for supporting subsequent research. This study was deemed exempt by the IRB.

METHODS

De-identified data from the hospital network EHR and CurrentCare were analyzed in aggregate for all patients who had visited an ED in the hospital system between August 1, 2015 and March 31, 2016 focusing on: age, gender, race/ethnicity, diagnosis codes, problem list, primary care provider (PCP) status, and disposition.

RESULTS

Sample Size: n 28117 130847

Patients who have a PCP: n (%) 28047 (99.75%) 92246 (70.50%)

Female: n (%) 16751 (59.58%) 68356 (52.24%)

Discharged from ED: n (%) 27079 (96.31%) 88743 (67.82%)

DISCUSSION

HIE data makes it difficult to verify meaning of these variables. Preliminary disposition data showed a larger than expected discrepancy between HIE and hospital network datasets for unclear reasons. In addition, more than 60 variations of race were found in the HIE data for race. For instance, HIE output for “White” race included “1,” “2106-3,” and “WHITE.” Several additional output may represent “White” (e.g., “W” and “WH”), but the loss of mapping scheme in aggregate analysis of HIE data makes it difficult to verify meaning of these variables.

REFERENCES


ACKNOWLEDGMENTS

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(see Table 1 for preliminary results).
From Unstructured to Structured Data

Supporting Clinical Needs
HIE - CurrentCare

- Rhode Island’s state-wide Health Information Exchange (HIE)
- Operated by the Rhode Island Quality Institute (RIQI)
- A secure repository - protected under HIPAA and the RI Health Information Exchange Act of 2008
- Available to HIPAA-covered organizations; no cost to providers or patients
- Patients must enroll (“Opt-in”)

© 2020, Rhode Island Quality Institute
HIE - CurrentCare

Care team can see patient data using CurrentCare Viewer

Patients can view and download their record using CurrentCare for Me
Patients Decide to Enroll...

- RI is an “Opt-In” state
- More than 550,000 Rhode Islanders have enrolled
Electronic Health Data Sources

- Over 520 data sources from:
  - Hospital Admissions, Discharges, and Transfers (ADTs)
  - Labs
  - Imaging facilities
  - Pharmacies
  - Pharmacy benefit managers
  - Providers’ EHRs
  - Urgent Care Facilities
  - Skilled Nursing Facilities

  - [www.currentcareri.org/guidebook](http://www.currentcareri.org/guidebook)
Privacy and Security

- Controlled Access
  - RI Health Information Exchange Act of 2008
  - A Data Use Agreement must be executed and in place
  - Training is required before each person is granted access
  - Access levels assigned based on role at the practice
- Audit Processes
  - Checks for user looking up own record, family member, or co-worker
COVID-19 Results in Dashboards

- All Reported Results
- CurrentCare Enrollees Only
- CurrentCare Enrollees with a RI PCP or RI Residency
- No Data Currently
- Landmark Medical Center
- Care New England
- CharterCare Health

ORU

CC

ORU
Identifying Possible COVID-19 Encounters

<table>
<thead>
<tr>
<th>Possible COVID-19 Encounter</th>
<th>Admission Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Low back pain, fever</td>
</tr>
<tr>
<td></td>
<td>RASH</td>
</tr>
<tr>
<td></td>
<td>Chest Pain</td>
</tr>
<tr>
<td></td>
<td>Soreness</td>
</tr>
<tr>
<td>Yes</td>
<td>Flu-like symptoms</td>
</tr>
<tr>
<td></td>
<td>Vertigo</td>
</tr>
<tr>
<td>Yes</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td></td>
<td>DA/IOL 38 wks gest diab</td>
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## COVID-19 Lab Test Results for Patient Panels

<table>
<thead>
<tr>
<th>MPID</th>
<th>First Name</th>
<th>Middle Name</th>
<th>Last Name</th>
<th>COVID-19 Risk Factors</th>
<th>COVID-19 Result</th>
<th>Result Time</th>
<th>Test Source</th>
<th>Test Code</th>
<th>Test Description</th>
<th>Ordered By</th>
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<tbody>
<tr>
<td>100001</td>
<td>Joe</td>
<td>Patient</td>
<td></td>
<td>1</td>
<td>Positive</td>
<td>2020/04/19 18:36</td>
<td>CVSMC</td>
<td>94534-5</td>
<td>Covid-19 Result</td>
<td>Provider, Test</td>
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<tr>
<td>100002</td>
<td>Mike</td>
<td>A</td>
<td>Test</td>
<td>1</td>
<td>Positive</td>
<td>2020/04/19 08:05</td>
<td>CHARTERCARE</td>
<td>5099-7</td>
<td>Coronavirus Ab Ser-aCn</td>
<td>Provider, Test</td>
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<tr>
<td>100003</td>
<td>Bill</td>
<td>Patient</td>
<td>3</td>
<td>Negative</td>
<td></td>
<td>2020/04/17 13:45</td>
<td>LIFESPAN</td>
<td>94309-2</td>
<td>SARS-CoV-2</td>
<td>Provider, Test</td>
</tr>
<tr>
<td>100004</td>
<td>Harry</td>
<td>R</td>
<td>Patient</td>
<td>0</td>
<td>Positive</td>
<td>2020/04/19 10:35</td>
<td>LMK</td>
<td>1230170102</td>
<td>SARS-COV-2 BY PCR</td>
<td>Provider, Test</td>
</tr>
<tr>
<td>100005</td>
<td>Mary</td>
<td>Test</td>
<td>0</td>
<td>Negative</td>
<td></td>
<td>2020/04/13 09:46</td>
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<td>Covid-19 Result</td>
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<tr>
<td>100006</td>
<td>Jan</td>
<td>A</td>
<td>Sample</td>
<td>5</td>
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<td>2020/04/20 15:55</td>
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<td>100007</td>
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<td>100008</td>
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<td>CARENE</td>
<td>Special Pathogen Result</td>
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<td>100009</td>
<td>Sam</td>
<td>N</td>
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<td>5</td>
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<td>100010</td>
<td>Alex</td>
<td>A</td>
<td>Person</td>
<td>4</td>
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<td>2020/04/19 01:05</td>
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<td>SARS-CoV-2</td>
<td>Provider, Test</td>
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Testing Volume Visualization for Patient Panels

Screenshots contained in this document do not contain Protected Health Information (PHI).
All data presented here has been randomly generated from databases of fictitious data.
In Conclusion...
Personalized Medicine
(Modified Interpretation)

Personal Data + Clinical Interpretation
Thank You!

Neil Sarkar, PhD, MLIS, FACMI
President & CEO
Rhode Island Quality Institute
Associate Professor of Medical Science
Associate Professor of Health Services, Policy and Practice
Brown University

neil_sarkar@brown.edu