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

@insarkar

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

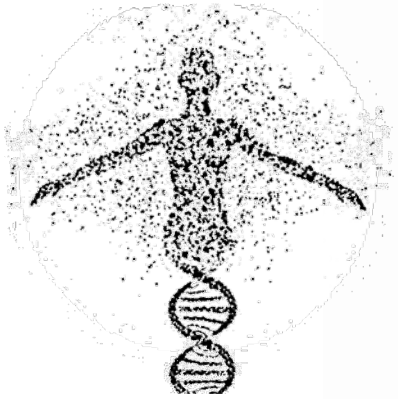
Outline

- Setting the Stage
- Exploring Clinical and Genomic Data
- Thinking about Big Data
- Bridging the Divide
- Addressing Clinical Needs

The Promised Future…

Biomedical Informatics

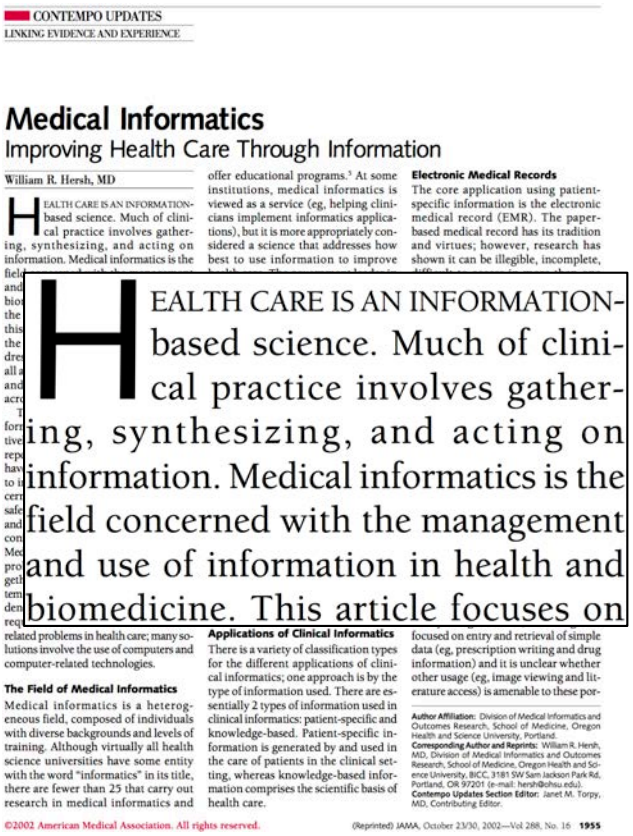
“He is programmed with the medical knowledge of 47 of Starfleet's finest physicians and the collected medical information of three thousand cultures.”



Genomic Data

Clinical Data

Transforming Health Care



CONTEMPO UPDATES
LINKING EVIDENCE AND EXPERIENCE

Medical Informatics
Improving Health Care Through Information

William R. Hersh, MD

HEALTH CARE IS AN INFORMATION-based science. Much of clinical practice involves gathering, synthesizing, and acting on information. Medical informatics is the field concerned with the management and use of information in health and biomedicine. This article focuses on

related problems in health care; many solutions involve the use of computers and computer-related technologies.

The Field of Medical Informatics

Medical informatics is a heterogeneous field, composed of individuals with diverse backgrounds and levels of training. Although virtually all health science universities have some entity with the word "informatics" in its title, there are fewer than 25 that carry out research in medical informatics and offer educational programs.[3] At some institutions, medical informatics is viewed as a service (eg, helping clinicians implement informatics applications), but it is more appropriately considered a science that addresses how best to use information to improve

Applications of Clinical Informatics

There is a variety of classification types for the different applications of clinical informatics; one approach is by the type of information used. There are essentially 2 types of information used in clinical informatics: patient-specific and knowledge-based. Patient-specific information is generated by and used in the care of patients in the clinical setting, whereas knowledge-based information comprises the scientific basis of health care.

Electronic Medical Records

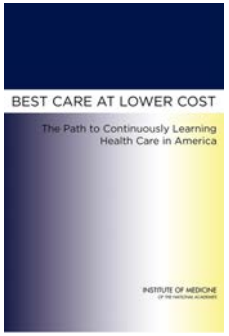
The core application using patient-specific information is the electronic medical record (EMR). The paper-based medical record has its tradition and virtues; however, research has shown it can be illegible, incomplete,

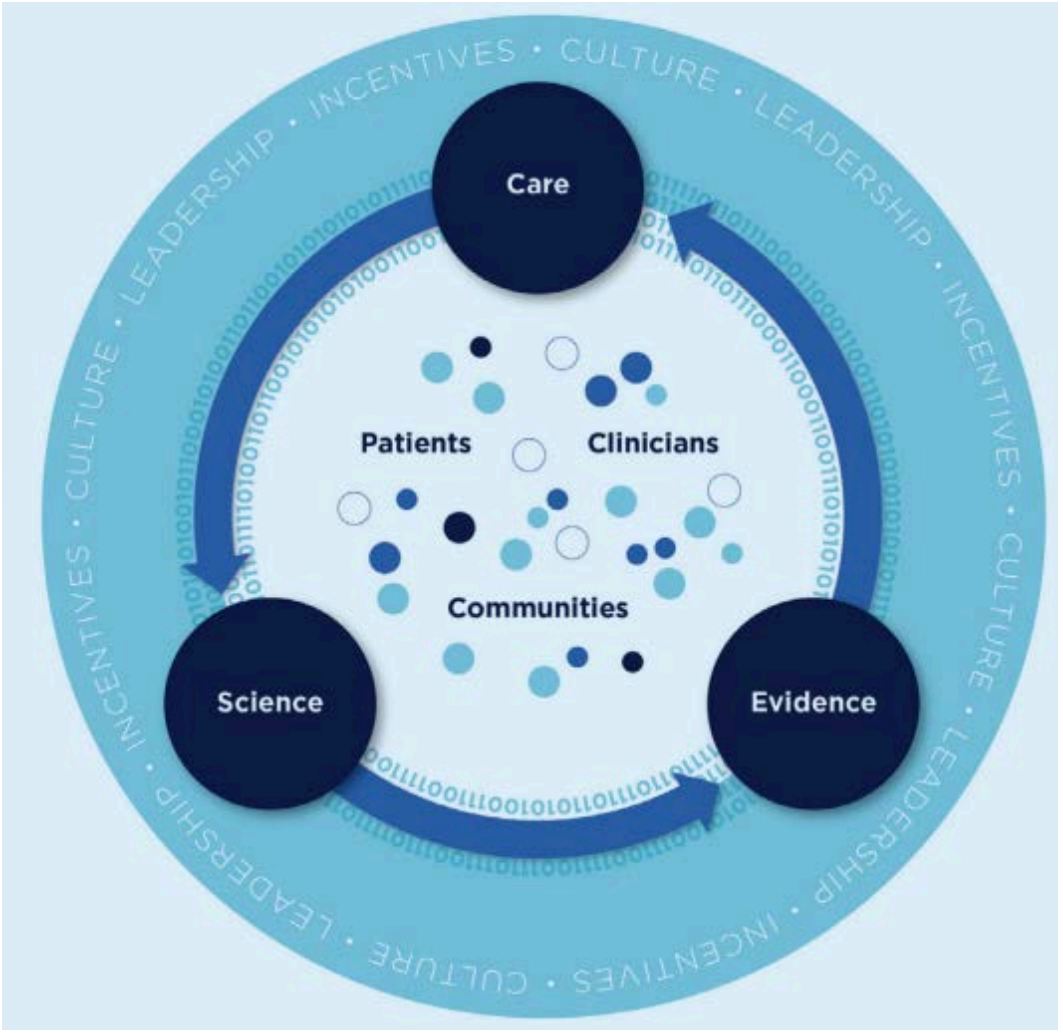
focused on entry and retrieval of simple data (eg, prescription writing and drug information) and it is unclear whether other usage (eg, image viewing and literature access) is amenable to these por-

Author Affiliation: Division of Medical Informatics and Outcomes Research, School of Medicine, Oregon Health and Science University, Portland.
Corresponding Author and Reprints: William R. Hersh, MD, Division of Medical Informatics and Outcomes Research, School of Medicine, Oregon Health and Science University, BICC, 3181 SW Sam Jackson Park Rd, Portland, OR 97201 (e-mail: hersh@ohsu.edu).
Contempo Updates Section Editor: Janet M. Torpy, MD, Contributing Editor.

- Cost of Care
- Sharing Knowledge
- Involving Patients
- Personalizing Care
- Coordinating Care
- Improving Outcomes

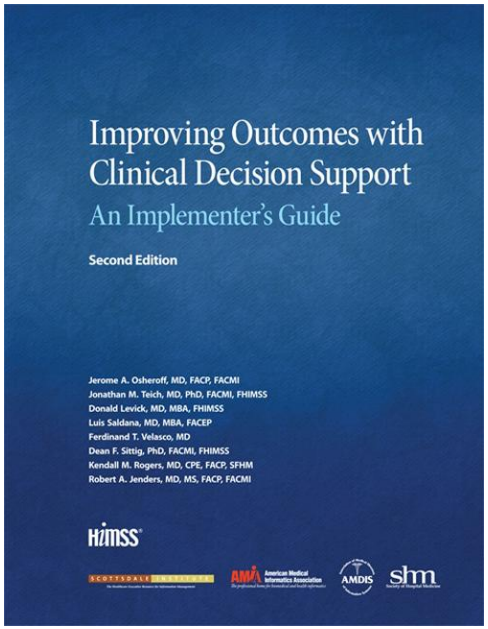
Managing Expectations


BEST CARE AT LOWER COST
The Path to Continuously Learning Health Care in America
INSTITUTE OF MEDICINE


INCENTIVES • CULTURE • LEADERSHIP • INCENTIVES • CULTURE • LEADERSHIP • INCENTIVES • CULTURE • LEADERSHIP • INCENTIVES • CULTURE • LEADERSHIP •
Care
Patients
Clinicians
Communities
Science
Evidence

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

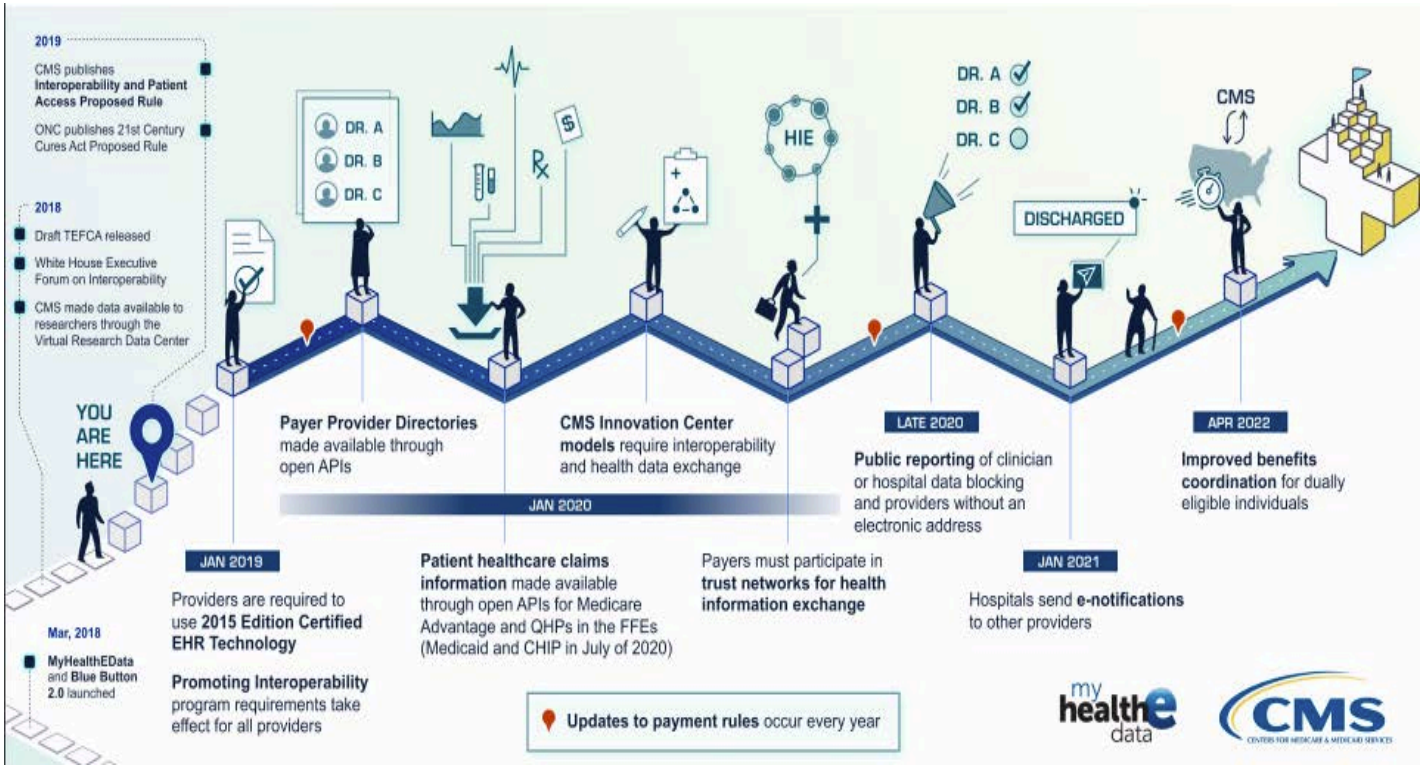
Defines how the healthcare ecosystem:

(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


2019
CMS publishes Interoperability and Patient Access Proposed Rule
ONC publishes 21st Century Cures Act Proposed Rule
2018
Draft TEFCA released
White House Executive Forum on Interoperability
CMS made data available to researchers through the Virtual Research Data Center
Mar, 2018
MyHealthEData and Blue Button 2.0 launched
YOU ARE HERE
DR. A
DR. B
DR. C
HIE
DISCHARGED
CMS
JAN 2019
Providers are required to use 2015 Edition Certified EHR Technology
Promoting Interoperability program requirements take effect for all providers
Payer Provider Directories made available through open APIs
JAN 2020
Patient healthcare claims information made available through open APIs for Medicare Advantage and QHPs in the FFEs (Medicaid and CHIP in July of 2020)
CMS Innovation Center models require interoperability and health data exchange
Payers must participate in trust networks for health information exchange
LATE 2020
Public reporting of clinician or hospital data blocking and providers without an electronic address
JAN 2021
Hospitals send e-notifications to other providers
APR 2022
Improved benefits coordination for dually eligible individuals
Updates to payment rules occur every year
my healthe data
CMS

USCDI v1

Assessment and Plan of Treatment

Care Team Members

Clinical Notes *NEW
- Consultation Note
- Discharge Summary Note
- History & Physical
- Imaging Narrative
- Laboratory Report Narrative
- Pathology Report Narrative
- Procedure Note
- Progress Note

Goals
- Patient Goals

Health Concerns

Immunizations

Laboratory
- Tests
- Values/Results

Medications
- Medications
- Medication Allergies

Patient Demographics
- First Name
- Last Name
- Previous Name
- Middle Name (including middle initial)
- Suffix
- Birth Sex
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Address *NEW
- Phone Number *NEW

Problems

Procedures

Provenance *NEW
- Author
- Author Time Stamp
- Author Organization

Smoking Status

Unique Device Identifier(s) for a Patient's Implantable Device(s)

Vital Signs
- Diastolic Blood Pressure
- Systolic Blood Pressure
- Body Height
- Body Weight
- Heart Rate
- Respiratory rate
- Body Temperature
- Pulse oximetry
- Inhaled oxygen concentration
- Pediatric Vital Signs *NEW
  - BMI percentile per age and sex for youth 2-20
  - Weight for age per length and sex
  - Occipital-frontal circumference for children >3 years old

The Office of the National Coordinator for Health Information Technology

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. a single patient upon request for their health data, and

B. all patients when a provider seeks to change health IT systems.

2

The export file must:

A. be computable, and

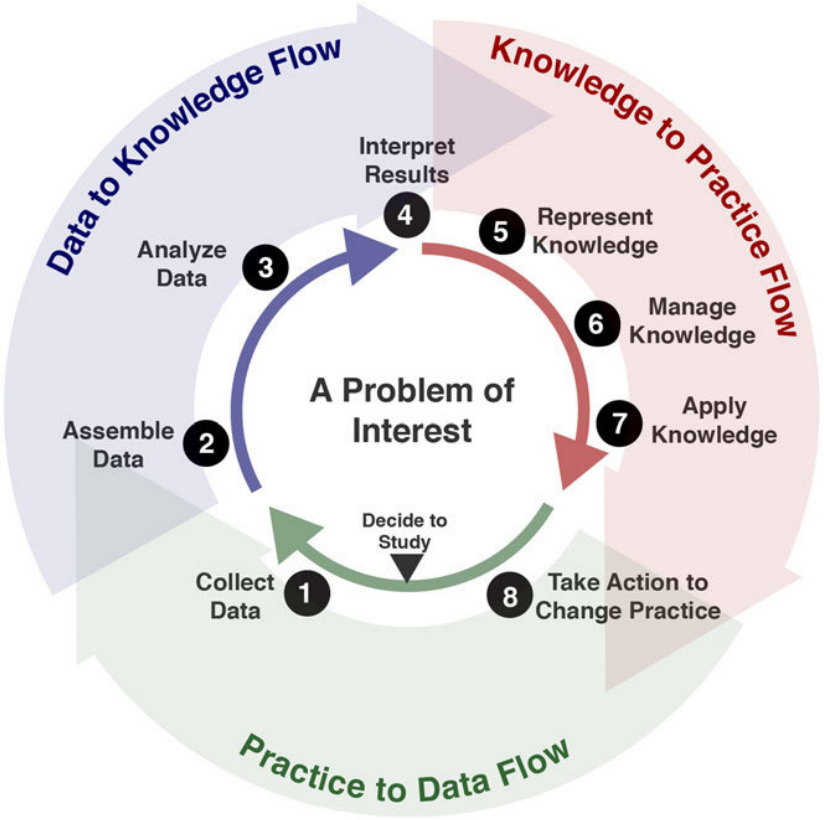
B. include documentation to allow for interpretation and use of EHI. The documentation must be made publically available via a hyperlink.

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

Rhode Island Quality Institute

BROWN Center for Biomedical Informatics

@insarkar



Flynn AJ, Friedman CP, Boisvert P, Landis-Lewis Z, Lagoze C. The Knowledge Object Reference Ontology (KORO): A formalism to support management and sharing of computable biomedical knowledge for learning health systems. Learning Health Systems. 2018 Apr;2(2):e10054.

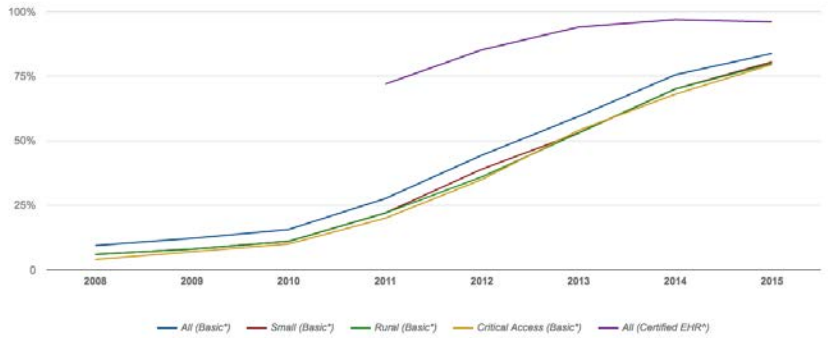
In the Clinic

Electronic Health Data

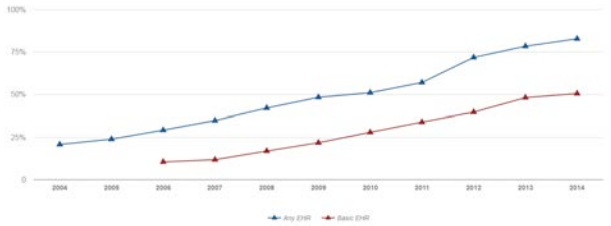
Uses of an EHR

- **Primary** Uses
  - Patient Care
    - Delivery
    - Management
    - Support
  - Billing and Reimbursement
- **Secondary** Uses
  - Decision support (development)
  - Quality
  - Research
  - Education
  - Public Health
  - Regulation
  - …

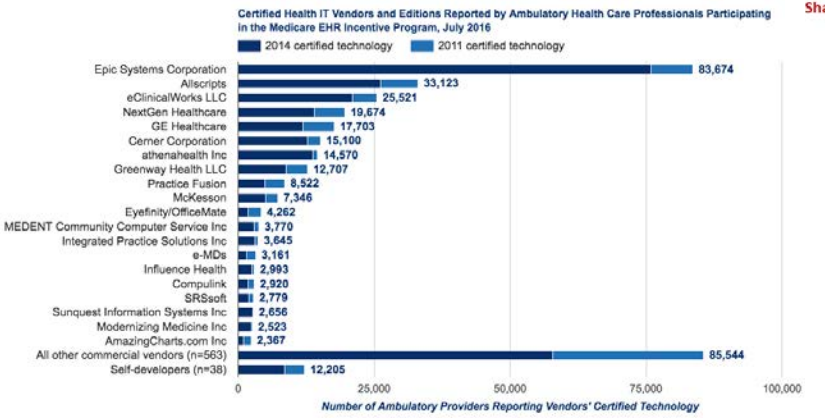
Institute of Medicine (U.S.). Committee on Improving the Patient Record., Dick RS, Steen EB, Detmer DE. The computer-based patient record : an essential technology for health care. Rev. ed. Washington, D.C.: National Academy Press; 1997.
Bloomrosen M, Detmer D. Advancing the framework: use of health data--a report of a working conference of the American Medical Informatics
Association. J Am Med Inform Assoc. 2008 Nov-Dec;15(6):715-22.

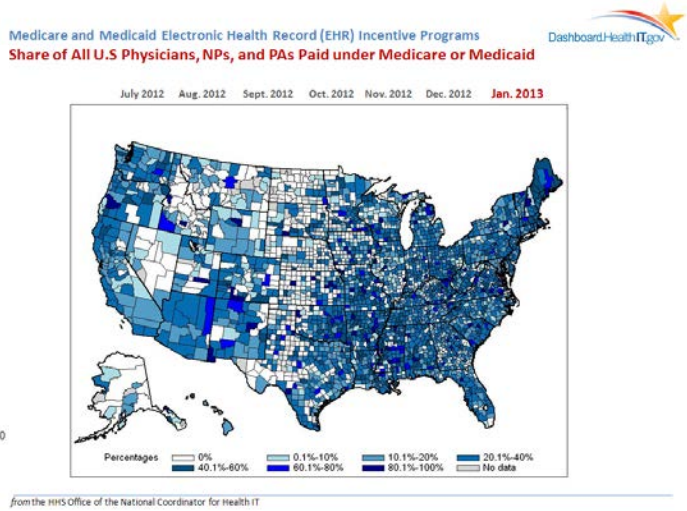


In 2015 over 4 in 5 of all non-federal acute care hospitals had adopted a Basic EHR with clinician notes, whereas, 80 percent of small hospitals with less than 100 beds, rural hospitals, and critical access hospitals had adopted a Basic EHR with clinician notes. Nearly all non-federal acute care hospitals 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%.





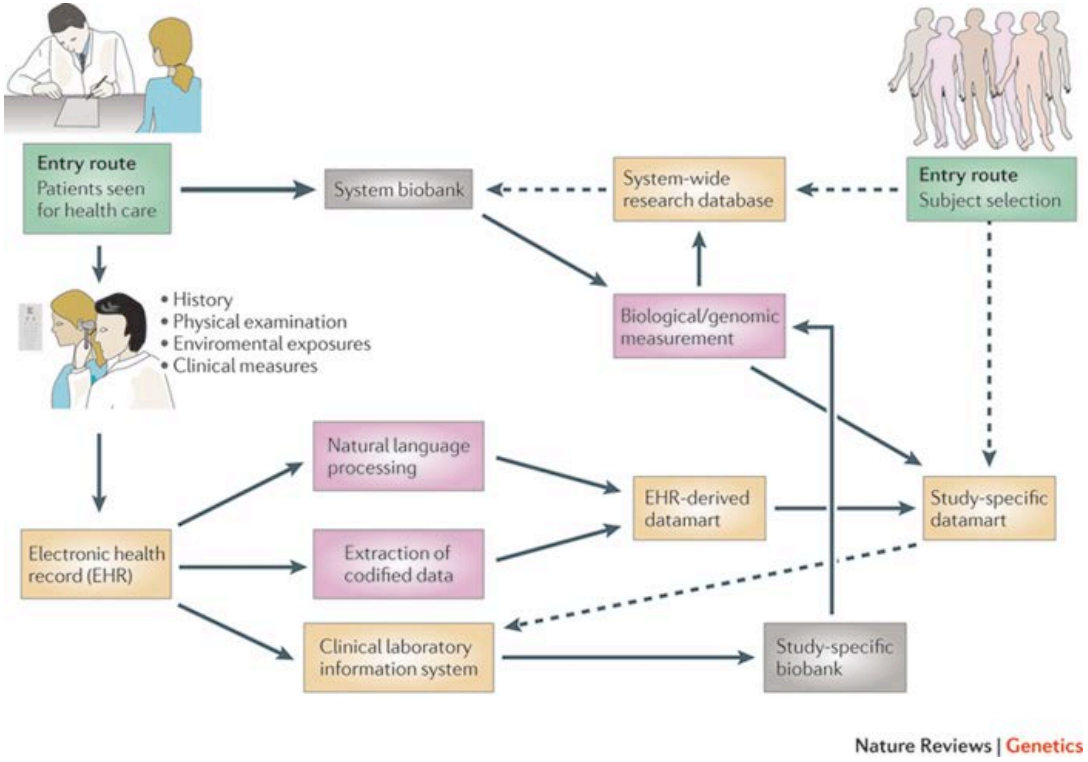
http://dashboard.healthit.gov/quickstats/quickstats.php

The Molecular Promise

Genomics, Proteomics &
Metabolomics


ggttcacctcagtc
tggaagatactgataag
gcaggtcaacatgtat
ttattataattcctat
atggatcgagttcaga
gtgttaagtggc
taaaacag
aggat

EHR-driven Genomics Research



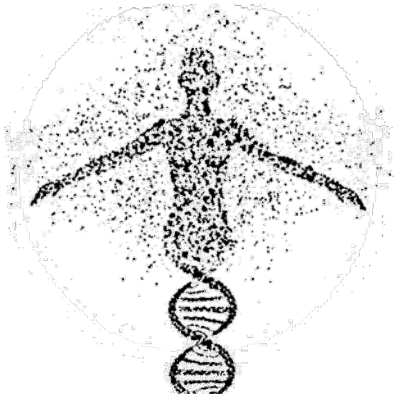
Workflow #2: Phenotypic augmentation

Workflow #1: Phenotyping, selection and sample acquisition

Kohane IS. **Using electronic health records to drive discovery in disease genomics**. Nat Rev Genet. 2011 Jun;12(6):417-28. doi: 10.1038/nrg2999. Epub 2011 May 18. Review. PubMed PMID: 21587298

Personalized Medicine

(Typical Interpretation)



Genomic Data

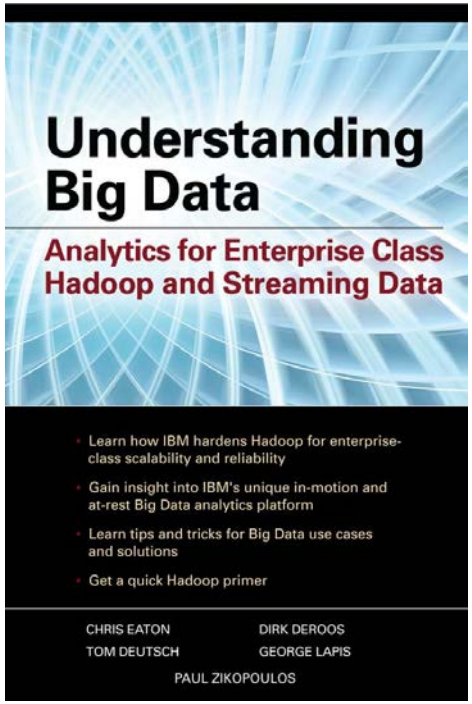
+

Clinical Data

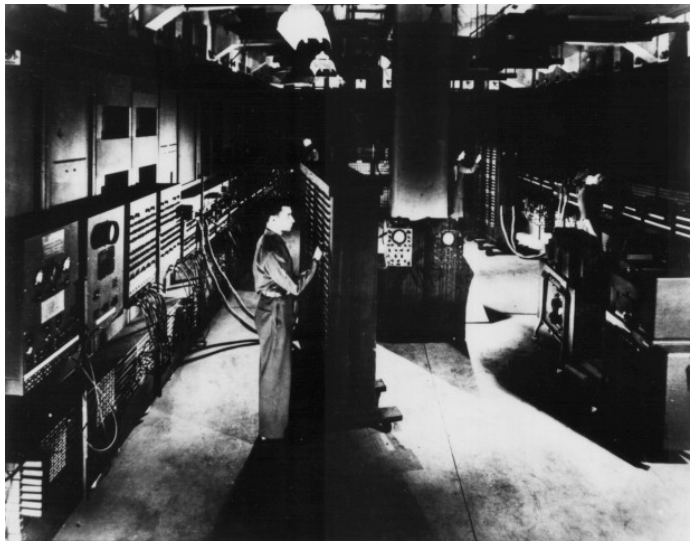
Big Data, Big Opportunities

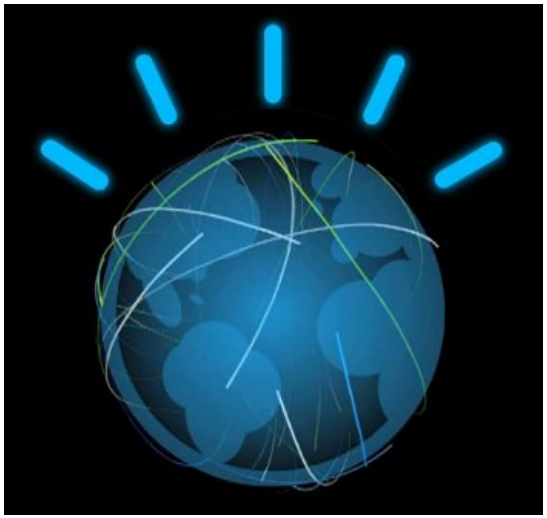
“Big Data”

- High Volume
- High Velocity
- High Variety
- High Veracity

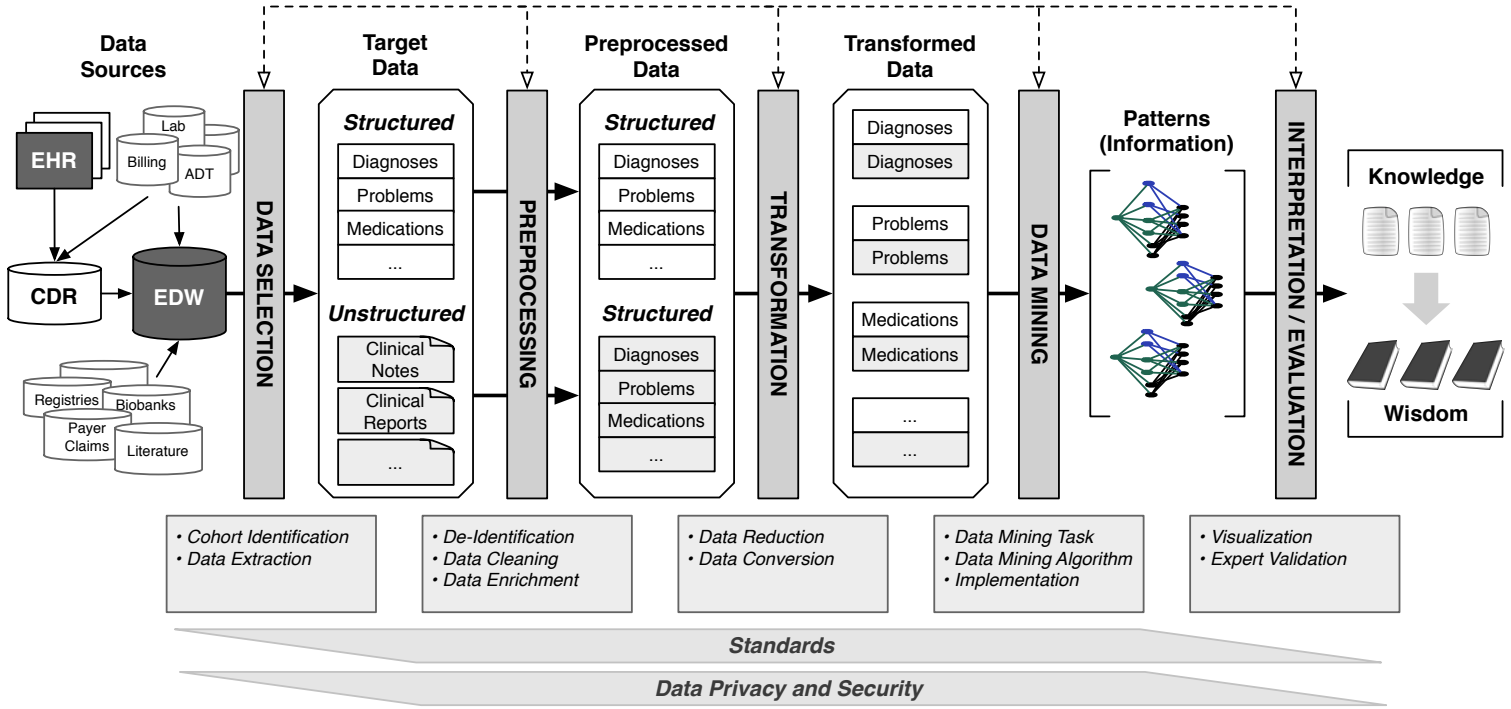


Addressing the Challenge of “Big”



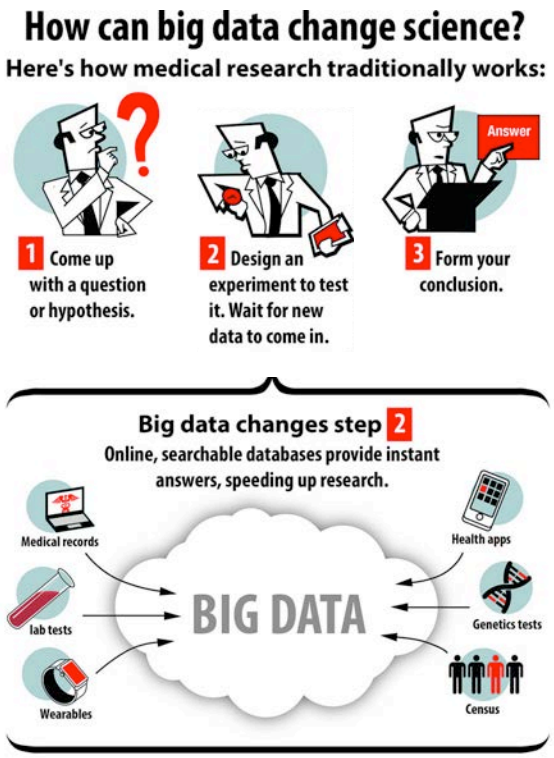


Disease Knowledge Discovery

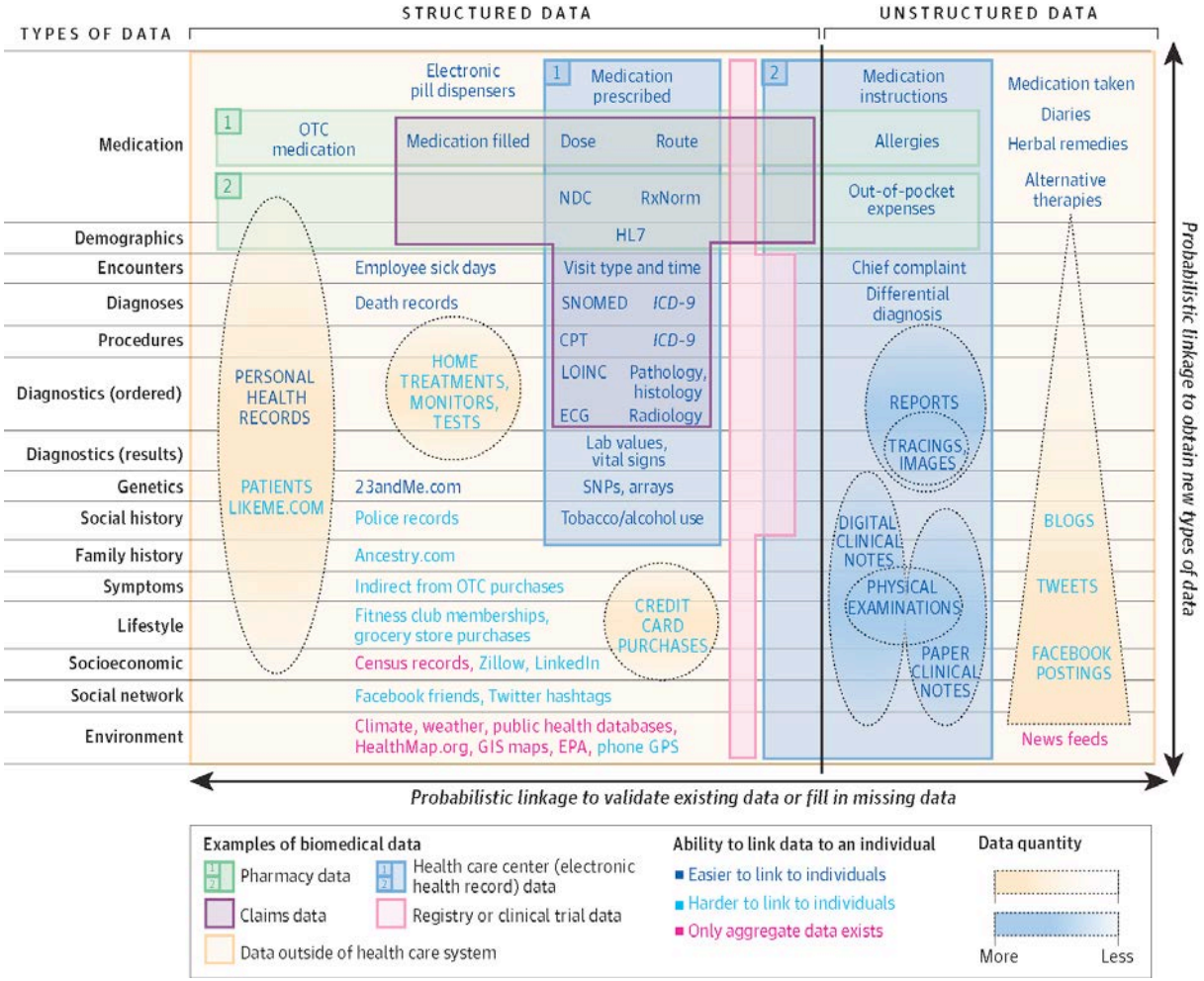


Chen ES, Sarkar IN. Mining the electronic health record for disease knowledge. Methods Mol Biol. 2014;1159:269-86.

The Right Data at the Right Time



http://ww2.kqed.org/futureofyou/2014/09/29/how-big-data-is-changing-medicine/



Weber GM, Mandl KD, Kohane IS. Finding the missing link for big biomedical data. *JAMA*. 2014 Jun 25;311(24):2479-80.

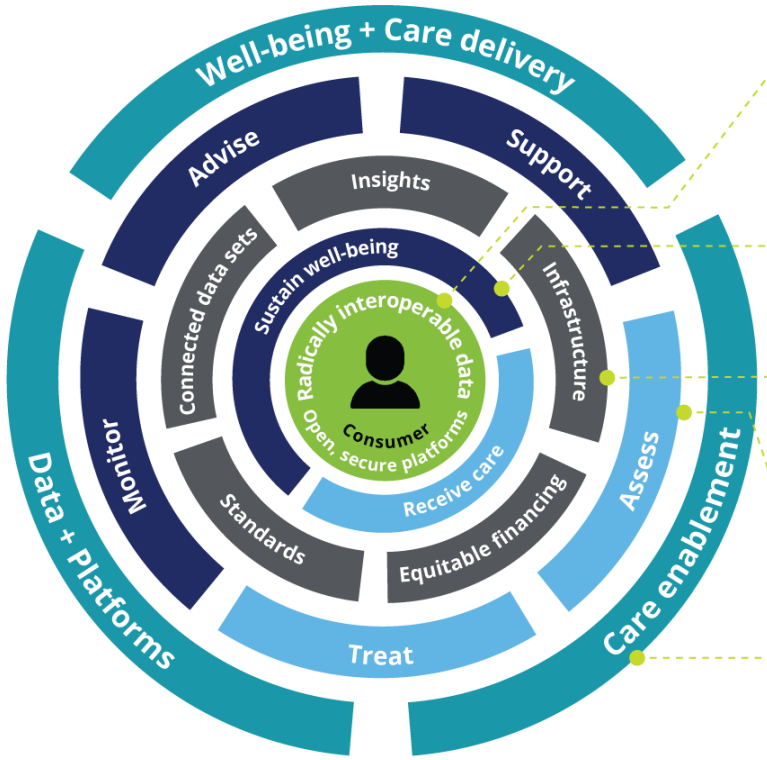
https://www.mobifilia.com/iot-for-healthcare/

Interoperability

FIGURE 3

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.

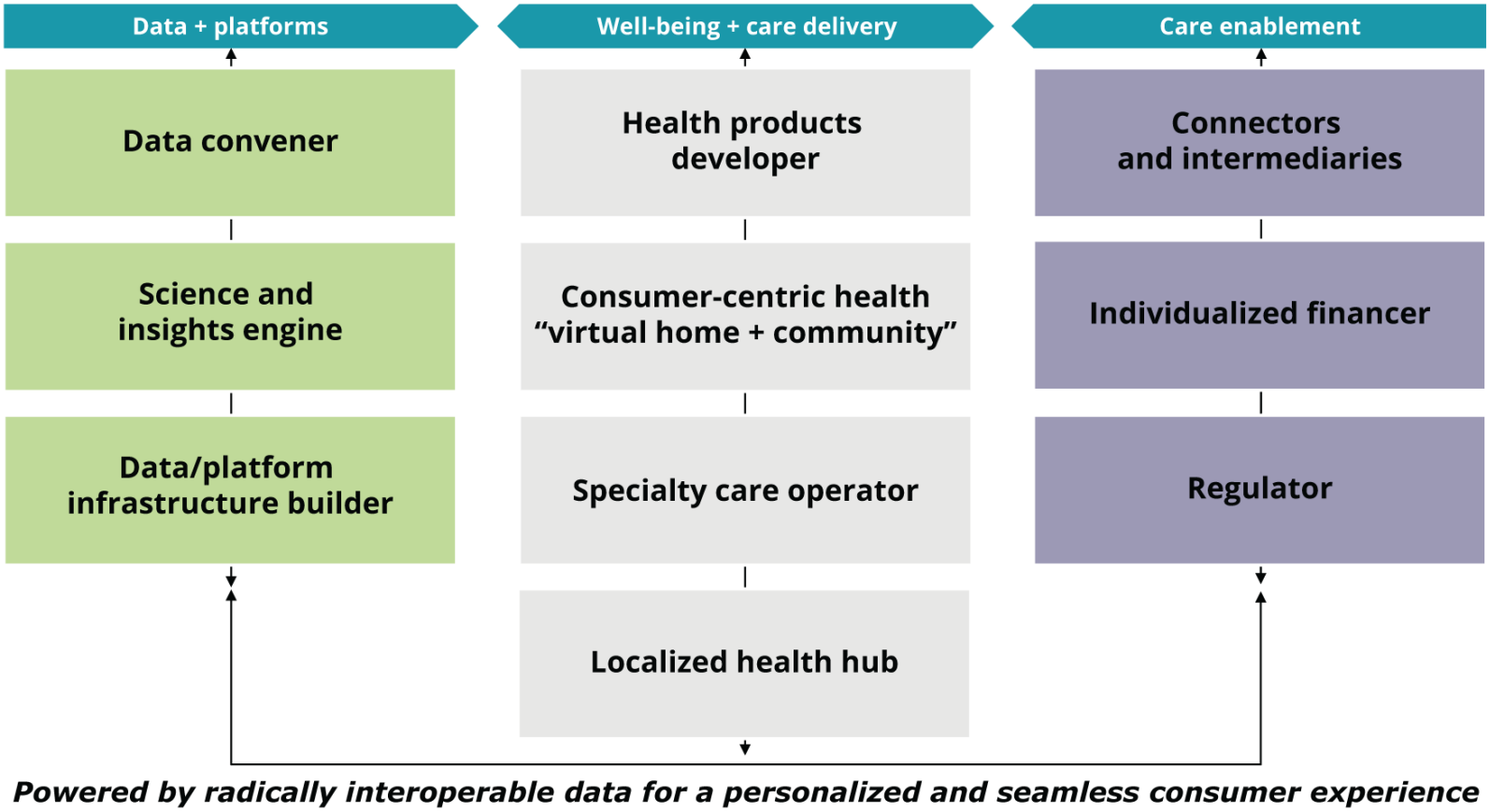
Five **tasks** that ecosystem players will perform on behalf of consumers.

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

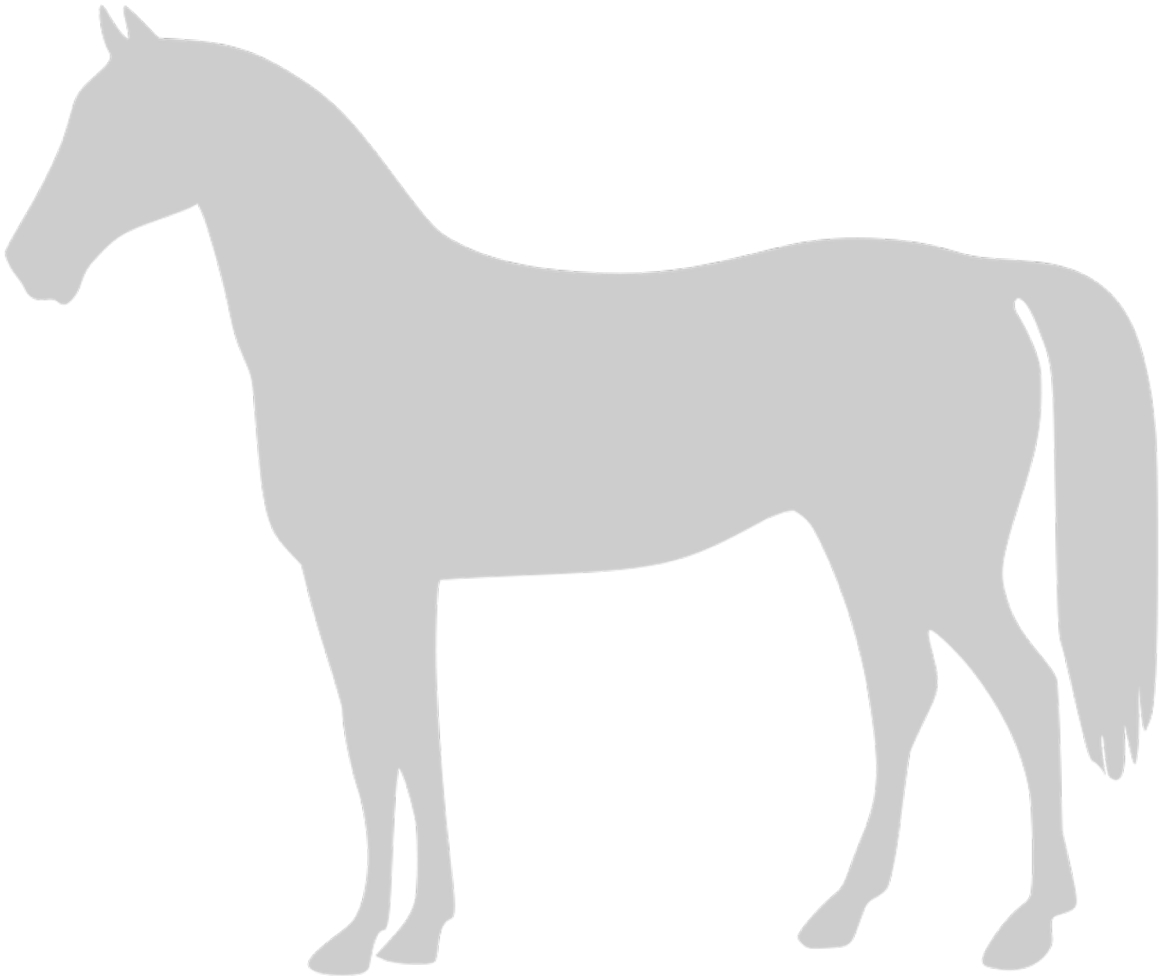
Source: Deloitte analysis.

FIGURE 4

Ten winning business archetypes in the future of health



Source: Deloitte analysis.



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.

Rhode Island Quality Institute

BROWN Center for Biomedical Informatics

HIMSS transforming health through information and technology

@insarkar

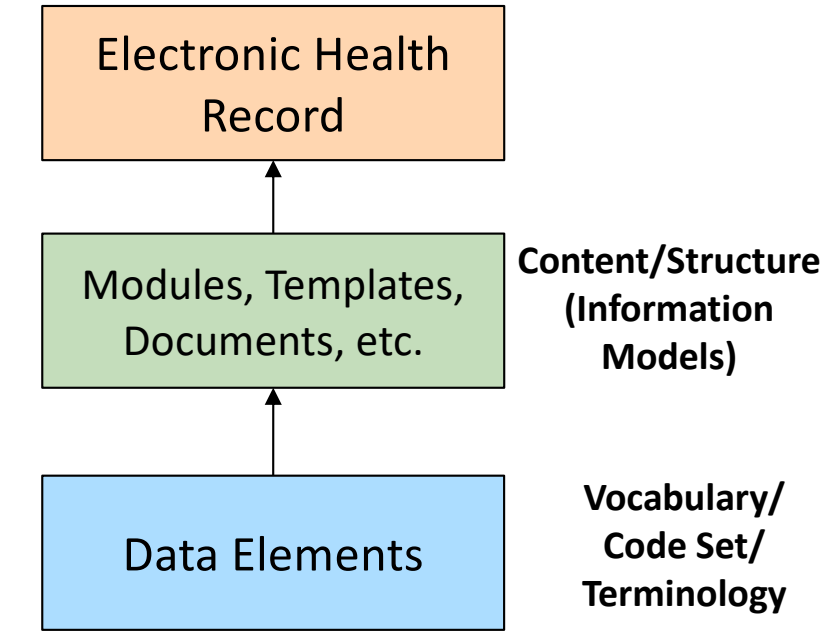
CATEGORIES OF STANDARDS	FUNCTIONS OF STANDARDS	EXAMPLES OF REAL WORLD USE OF THE STANDARDS
VOCABULARY & CODE SETS (SEMANTICS)	The information is universally understood	RxNorm Code for Ibuprofen is 5640
FORMAT, CONTENT & STRUCTURE (SYNTAX)	Information is in the appropriate format	C-CDA packages up data in the appropriate format
TRANSPORT	The information moves from point A to point B	SMTP and S/MIME to send the C-CDA from one setting to another
SECURITY	The information is securely accessed and moved	X.509: to ensure it is securely transmitted to the intended recipient
SERVICES	Provides additional functionality so that information exchange can occur	DNS+LDAP: to find the recipient's X.509 certificate to encrypt a message

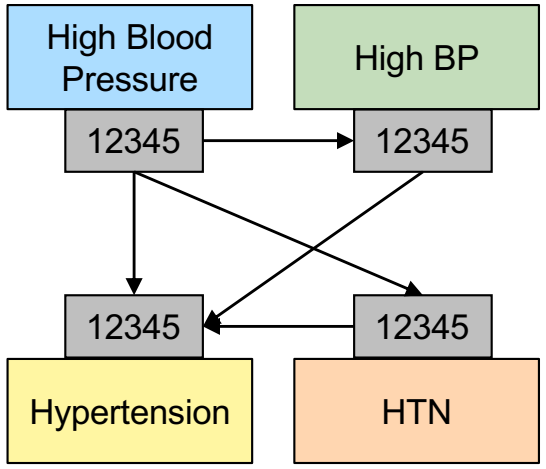
Standards and Interoperability

"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, BA[1], Indra Neil Sarkar, PhD, MLIS[1,2], Elizabeth Chen, PhD[1,2], Elaine Fontaine, BS[3], Gregory Walker, PhD[3], Megan Ranney, MD, MPH[1,4]

[1]The Warren Alpert Medical School of Brown University, Providence RI, [2]Center for Biomedical Informatics, Brown University, Providence RI, [3]Rhode Island Quality Institute, Providence RI, [4]Emergency 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

RESULTS

(see Table 1 for preliminary results). Disposition, race, and ethnicity were the most challenging to map to a standard. 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 identified in the hospital network data and 40 non-standard values 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.

networks, use CurrentCare (comprised of 442 data sources). Fifty percent of statewide ED visits in Rhode Island occur at a single hospital network.

- 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.
- The content of the CurrentCare HIE data fields of interest were compared to terminology standards (e.g., those defined for the HL7 Continuity of Care Document [CCD]).
- This study was deemed exempt by the IRB.

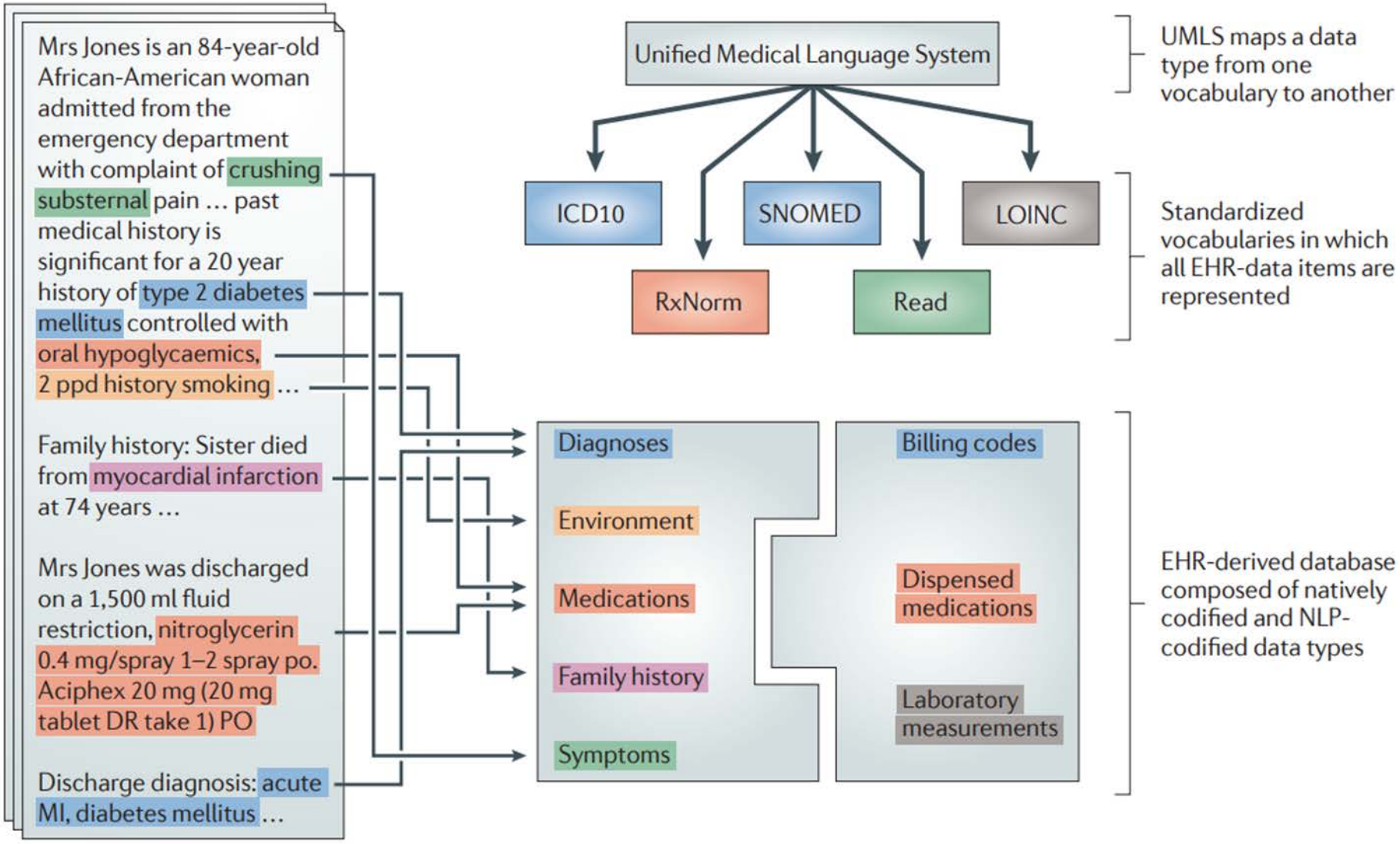
References

1. Pacific Northwest Evidence-based Practice Center. *Evidence Report/ Technology Assessment: Health Information Exchange.* Portland, OR; 2015.
2. Parker C, Weiner M, Reeves M. Health Information Exchanges – Unfulfilled Promise as a Data Source for Clinical Research. *Int J Med Inform.* 2016;87:1-9.
3. Johnson K, Unertl K, Chen Q, Lorenzi N, Nian H, Bailey J, Frisse M. Health information exchange usage in emergency departments and clinics: the who, what, and why. J Am Med Inform Assoc. 2011;18(5): 690–697.

Acknowledgments

This work was funded in part by the Summer Research Assistantship in Emergency Medicine Program at Brown University and National Institutes of Health grant K23MH095866. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors thank Mete Tunca and Dennis Ferrante for their assistance with local data extraction and data transfer.

From Unstructured to Structured Data



Rhode Island Quality Institute · BROWN Center for Biomedical Informatics

Kohane IS. Using electronic health records to drive discovery in disease genomics. Nat Rev Genet. 2011 Jun;12(6):417-28. doi: 10.1038/nrg2999. Epub 2011 May 18. Review. PubMed PMID: 21587298

@insarkar

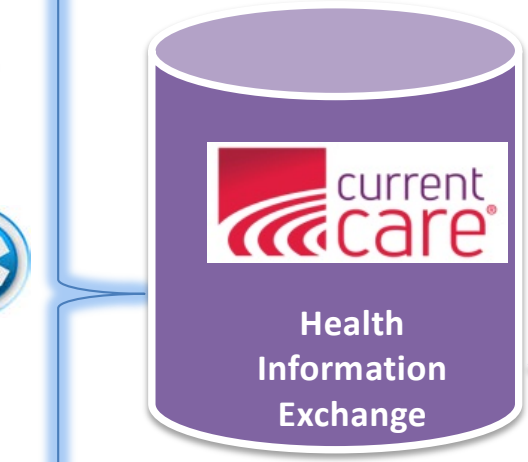
Supporting Clinical Needs

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")

@insarkar

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

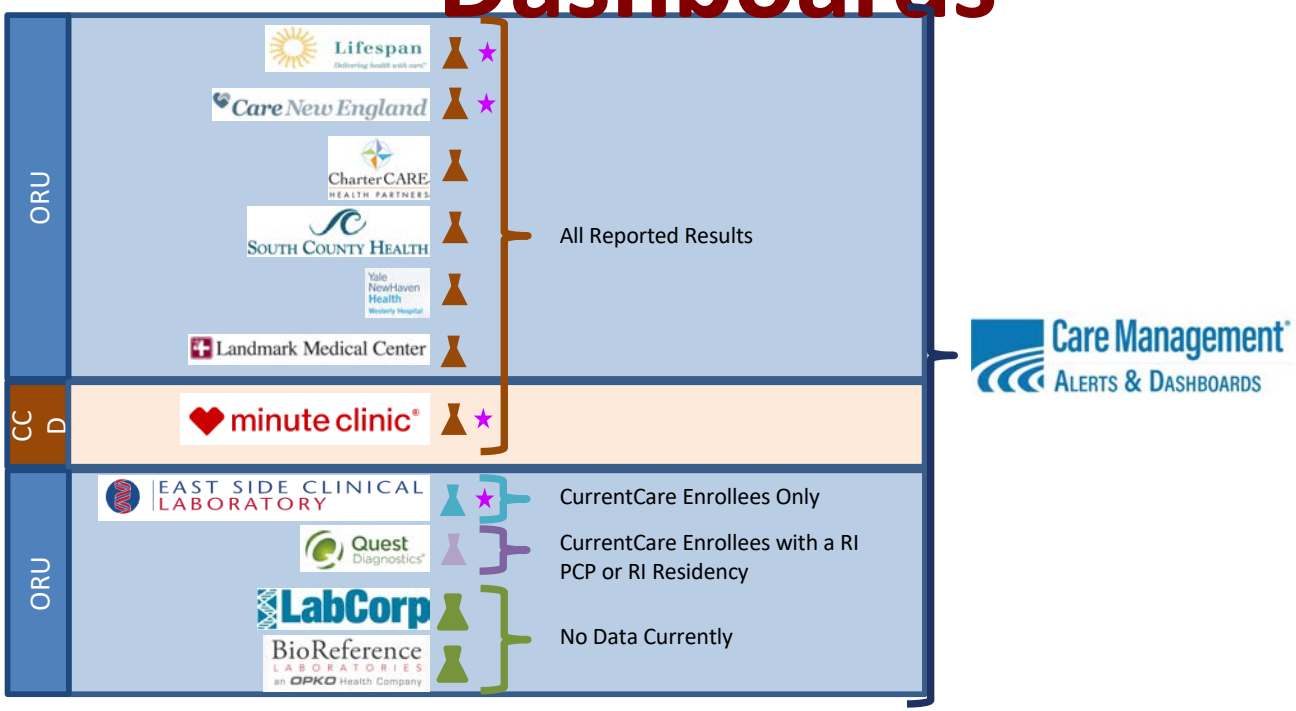
- *Over 520 data sources from:*
  - Hospital Admissions, Discharges, and Transfers (ADTs)
  - Labs
  - Imaging facilities
  - Pharmacies
  - Pharmacy benefit managers
  - Providers' EHRs
  - Urgent Care Facilities
  - Skilled Nursing Facilities

  – www.currentcareri.org/guidebook

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



Identifying Possible COVID-19 Encounters

Possible COVID-19 Encounter	Admission Reason
	Painful Urination
	alcohol withdrawal uncomplicated
Yes	Low back pain fever
	RASH
	Chest Pain
	Sprain
Yes	Flu Like symptoms
	Vertigo
Yes	Shortness of breath
	DA/IOL 38.6wks gest diab

COVID-19 Lab Test Results for Patient Panels

MPIID	First Name	Middle Name	Last Name	COVID-19 Risk Factors	COVID-19 Result	ResultTime	Test Source	Test Code	Test Description	Ordered By
100001	Joe		Patient	1	Positive	2020/04/10 18:36	CVSMC	94534-5	Covid-19 Result	Provider, Test
100002	Mike	A	Test	1	Positive	2020/04/16 08:05	CHARTERCARE	5099-7	Coronavirus Ab Ser-aCnc	Provider, Test
100003	Bill		Patient	3	Negative	2020/04/17 13:45	LIFESPAN	94309-2	SARS-CoV-2	Provider, Test
100004	Harry	R	Patient	0	Positive	2020/04/18 10:35	LMK	1230170102	SARS-COV-2 BY PCR	Provider, Test
100005	Mary		Test	0	Negative	2020/04/13 09:46	CVSMC	94534-5	Covid-19 Result	Provider, Test
100006	Jan	A	Sample	5	Negative	2020/04/20 15:55	CVSMC	94534-5	Covid-19 Result	Provider, Test
100007	Nancy	A	Test	2	Negative	2020/04/20 20:15	LIFESPAN	94309-2	DOH SARS-CoV-2 rRT-PCR	Provider, Test
100008	Dylan		Patient	6	Negative	2020/04/17 16:33	CARENE	Special Pathogen Result	Special Pathogen Result	Provider, Test
100009	Sam	N	Sample	5	Positive	2020/04/20 17:12	CARENE	Special Pathogen Result	Special Pathogen Result	Provider, Test
100010	Alex	A	Person	4	Negative	2020/04/19 01:05	LIFESPAN	94309-2	SARS-CoV-2	Provider, Test

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

Rhode Island Quality Institute
BROWN Center for Biomedical Informatics

@insarkar