

Predictive Modeling Integrated in Healthcare, Toward the Learning Health System

Jonathan Silverstein, MD, MS, FACS, FACMI
Chief Medical Informatics Officer
Kanter Health Foundation

U.S. healthcare challenges in a slide?

- People are dying of preventable causes.
- Cost is out of control.
- Quality can't be measured.
- Variability is local and widespread.
- New technology is exponentiating.
- Decision-making is maximally distributed.
- Data is not available routinely for learning.

Informatics and Predictive Analytics has fundamentally changed our world!

- Credit card fraud detection
- Target can predict when you are pregnant
- Traffic monitoring and prediction
- SPAM filters
- Smart meters and utility grids
- Weather forecasting
- Netflix and Amazon predict your tastes
- Mobile phones become interactive assistants
- Science's third pillar of data and computation!

- WHAT ABOUT BIOMEDICINE?!

Universe of Biomedical Data

LIFESTYLE

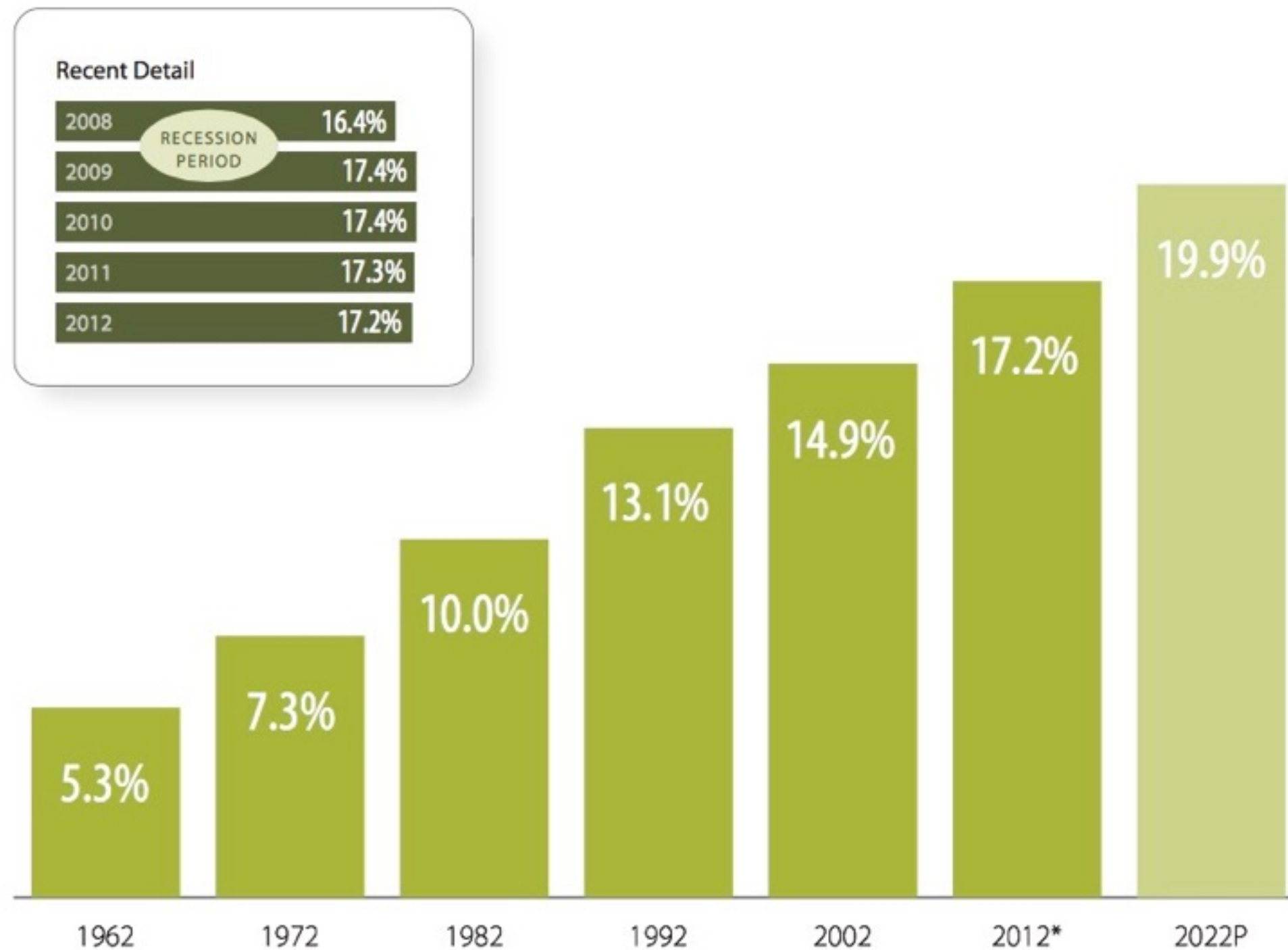
ENVIRONMENT

CLINICAL

GENOMIC

Health Spending as a Share of GDP

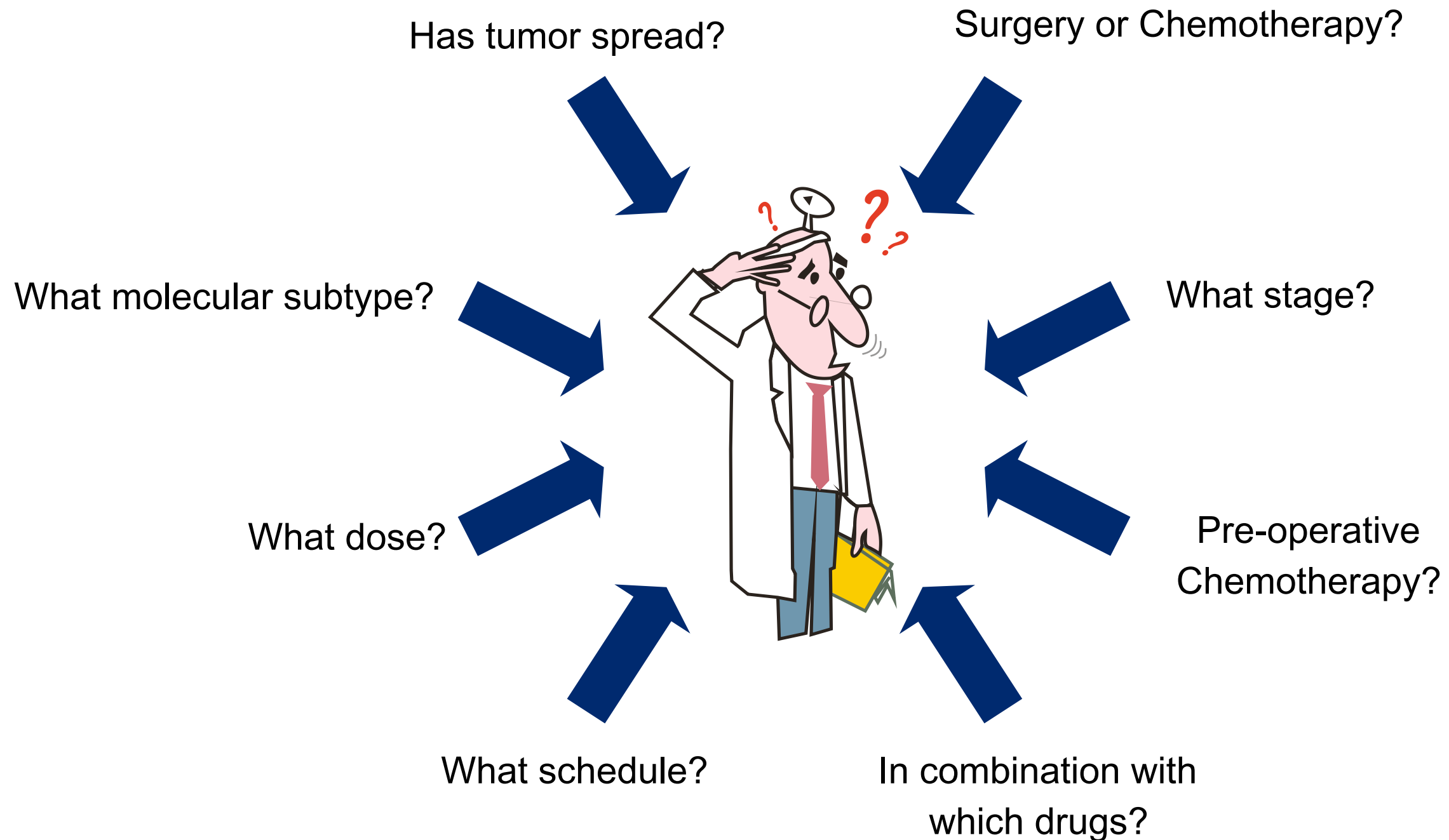
United States, 1962 to 2022, Selected Years

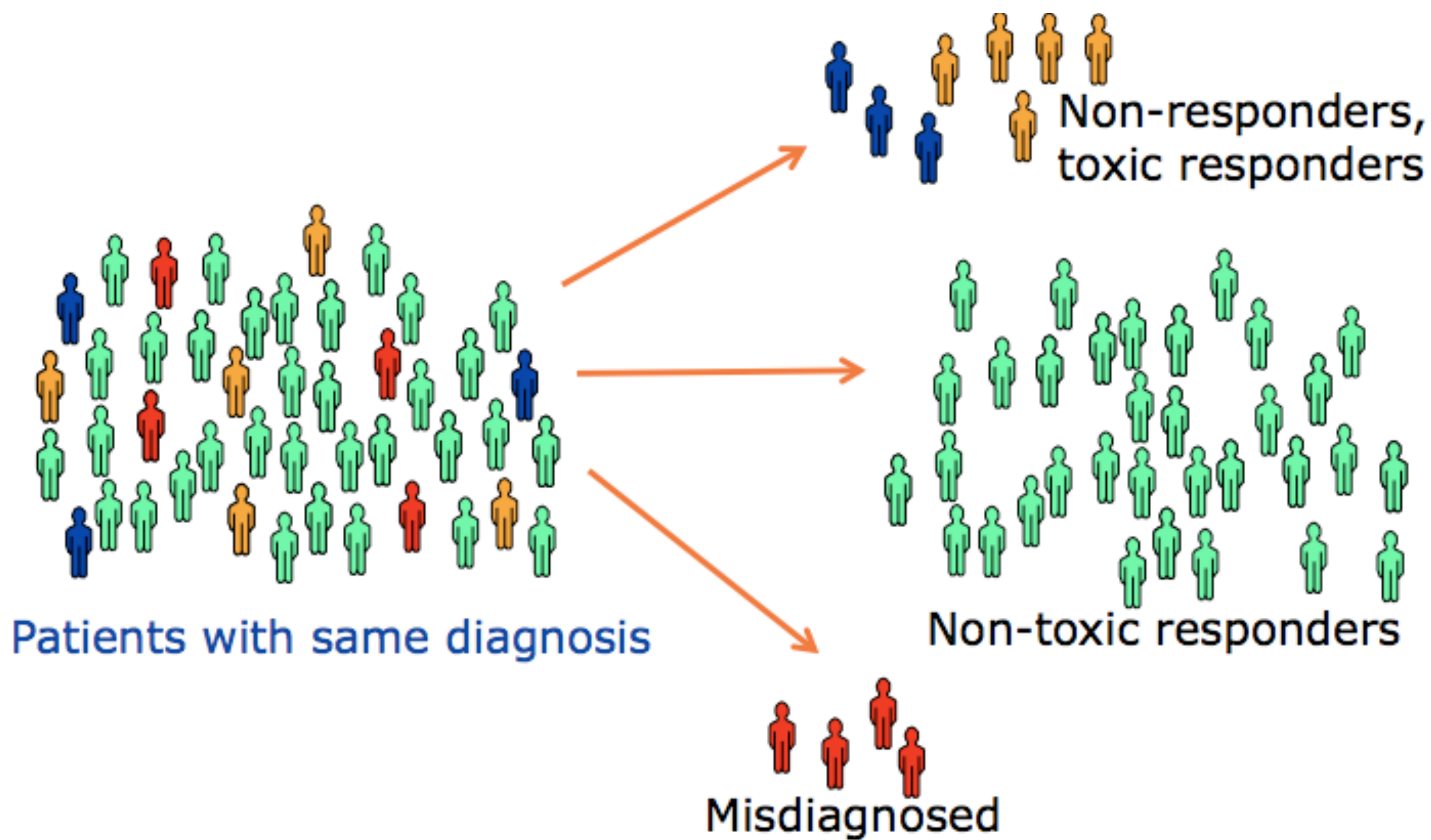


Notes: Health spending refers to National Health Expenditures. Projections (P) include the impact of the Affordable Care Act.

Source: Centers for Medicare & Medicaid Services (CMS), National Health Expenditures, 2014 release (historical) and 2013 release (projections), www.cms.gov.

Provider, Patient & Payor Faced With Bewildering Choices: The Current Practice of “Qualitative” Medicine



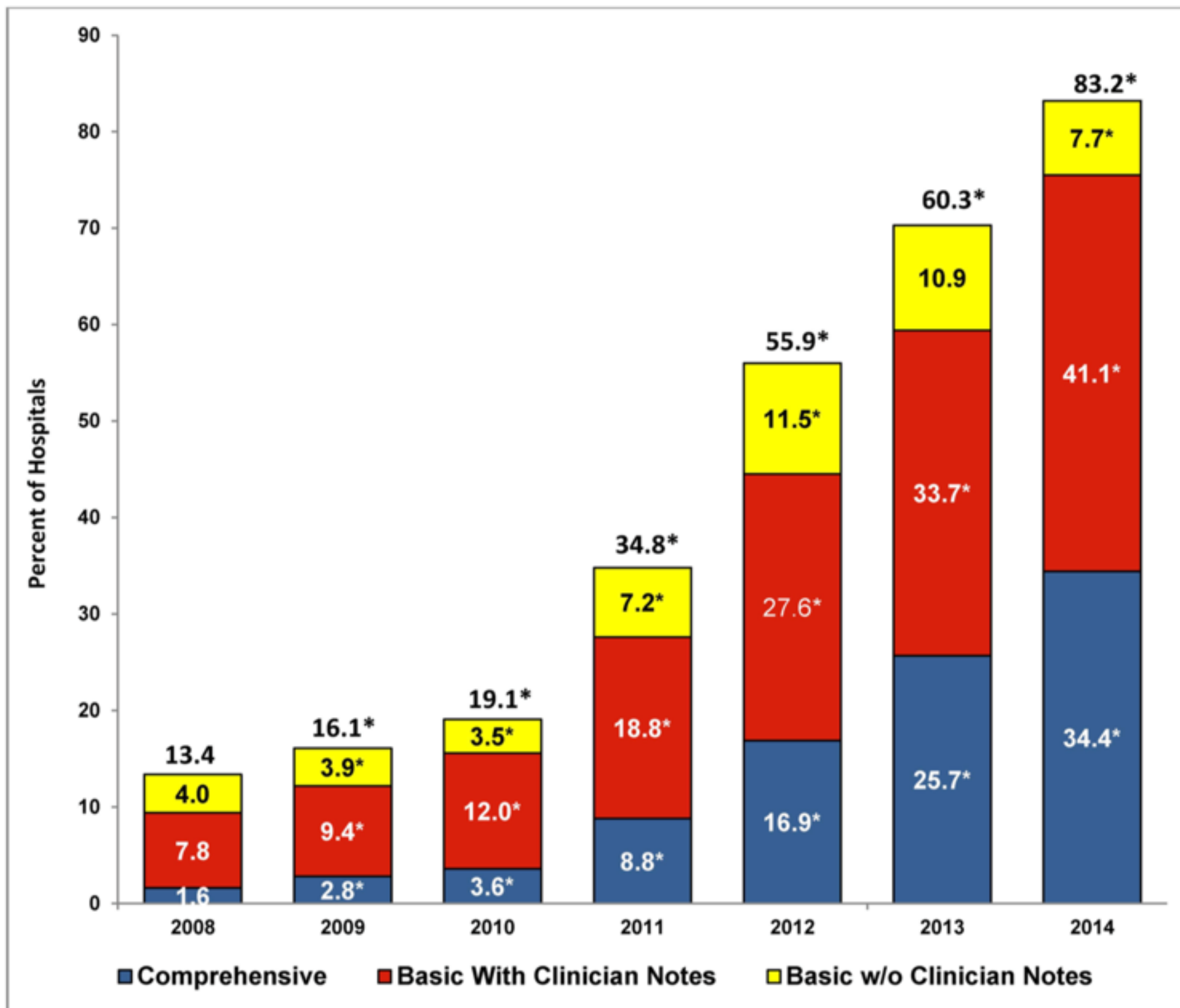


The Future of Medicine is:

- Evidence based (data driven)
- Practice based (generation of data)
- Targeted and precise (ER+ Breast Cancer vs. Triple Negative Breast Cancer)
 - Personalization to individual mutations
 - Genomics for biomarkers and gene therapy
- A Learning Health System
 - “...gets the right care to people when they need it and then captures the results for improvement...” – Institute of Medicine

Trends in EHR adoption show increasing use of advanced functionality.

Figure 3: Percent of non-federal acute care hospitals with adoption of EHR systems by level of functionality: 2008-2014.



NOTES: Definitions of Basic EHR and Comprehensive EHR systems are reported in [Table A1](#).

*Significantly different from previous year ($p < 0.05$).

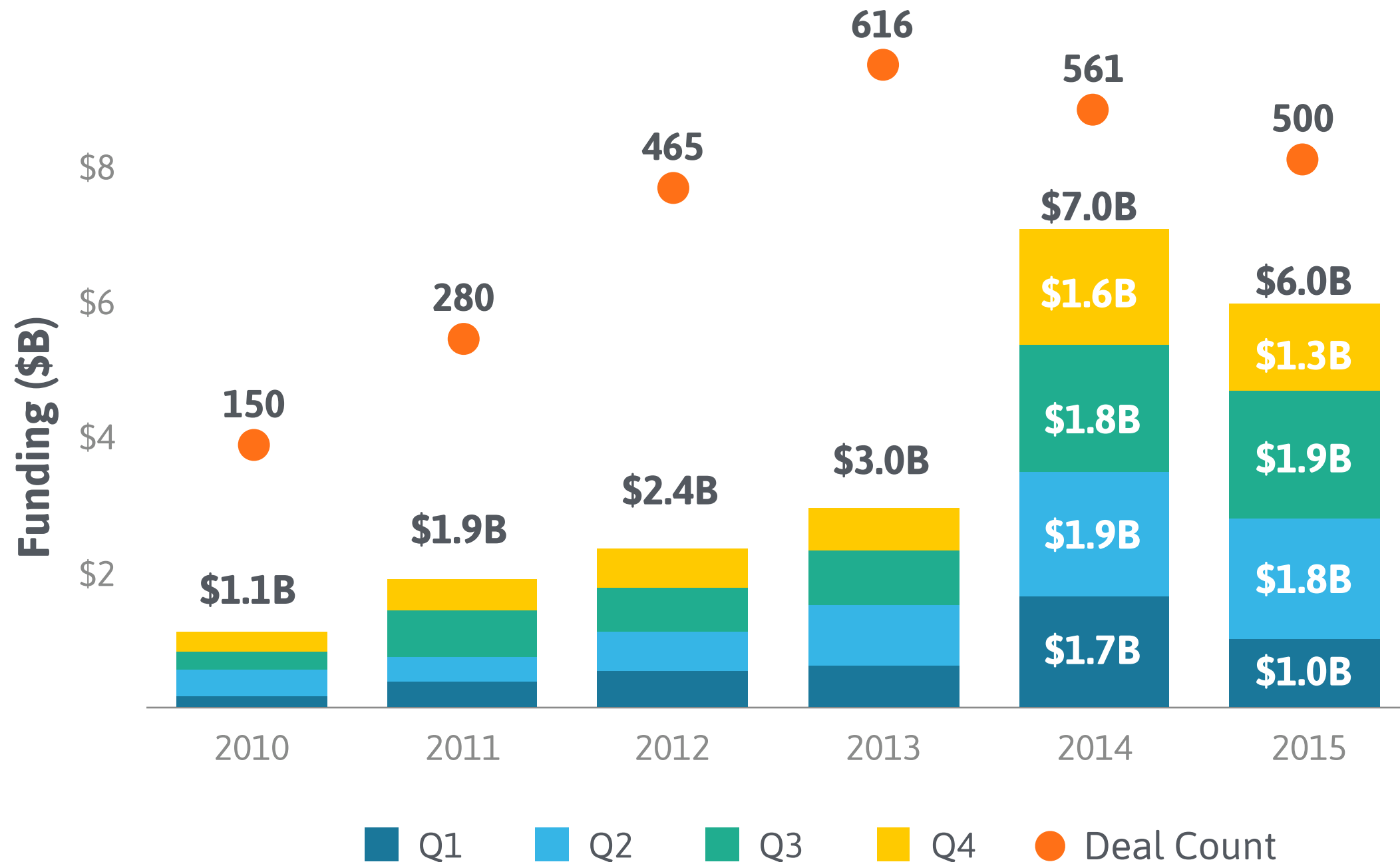
SOURCE: ONC/AHA, AHA Annual Survey Information Technology Supplement.

What's in a Health System Enterprise Data Warehouse?

- Extreme granularity of data capture - Terabytes of transactions of who did what to whom for millions patients
- Demographics
- Medical history
- Orders
- Meds
- Procedures (e.g. details about implants)
- Test results (including molecular markers?)
- Vital signs, detailed characteristics (e.g. pain)
- Text of all notes
- Perhaps charges, Perhaps imaging, ...

Digital Health Funding Snapshot Year Over Year

2015 saw a significant shift towards validated innovation. Today's capital is supporting companies with proven leadership, strategy, business models and demonstrated outcomes. Although total funding is down from last year, there is more market impact per invested dollar than ever.



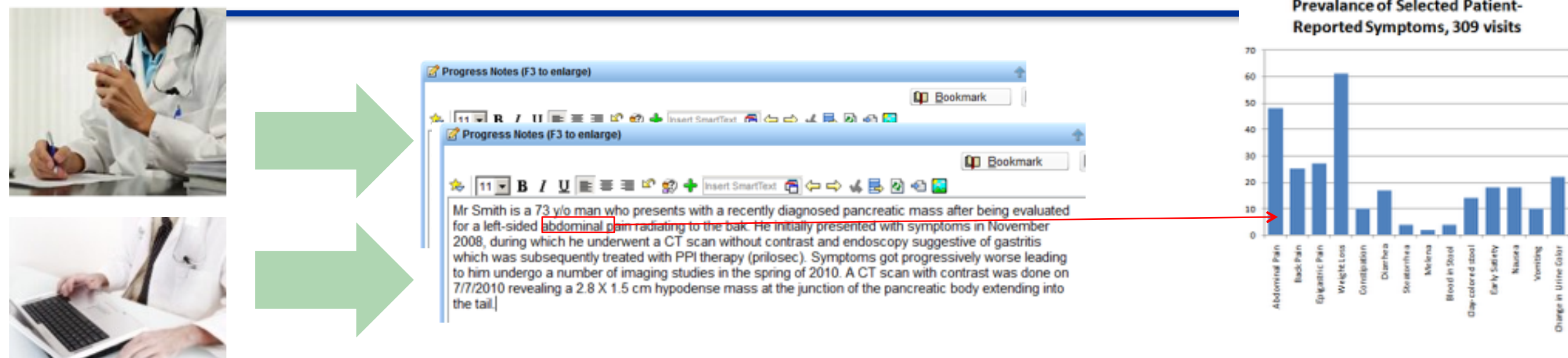
A “Fundamental Theorem” of Biomedical Informatics



Data Collection, Modeling, Integration, and Learning Opportunities

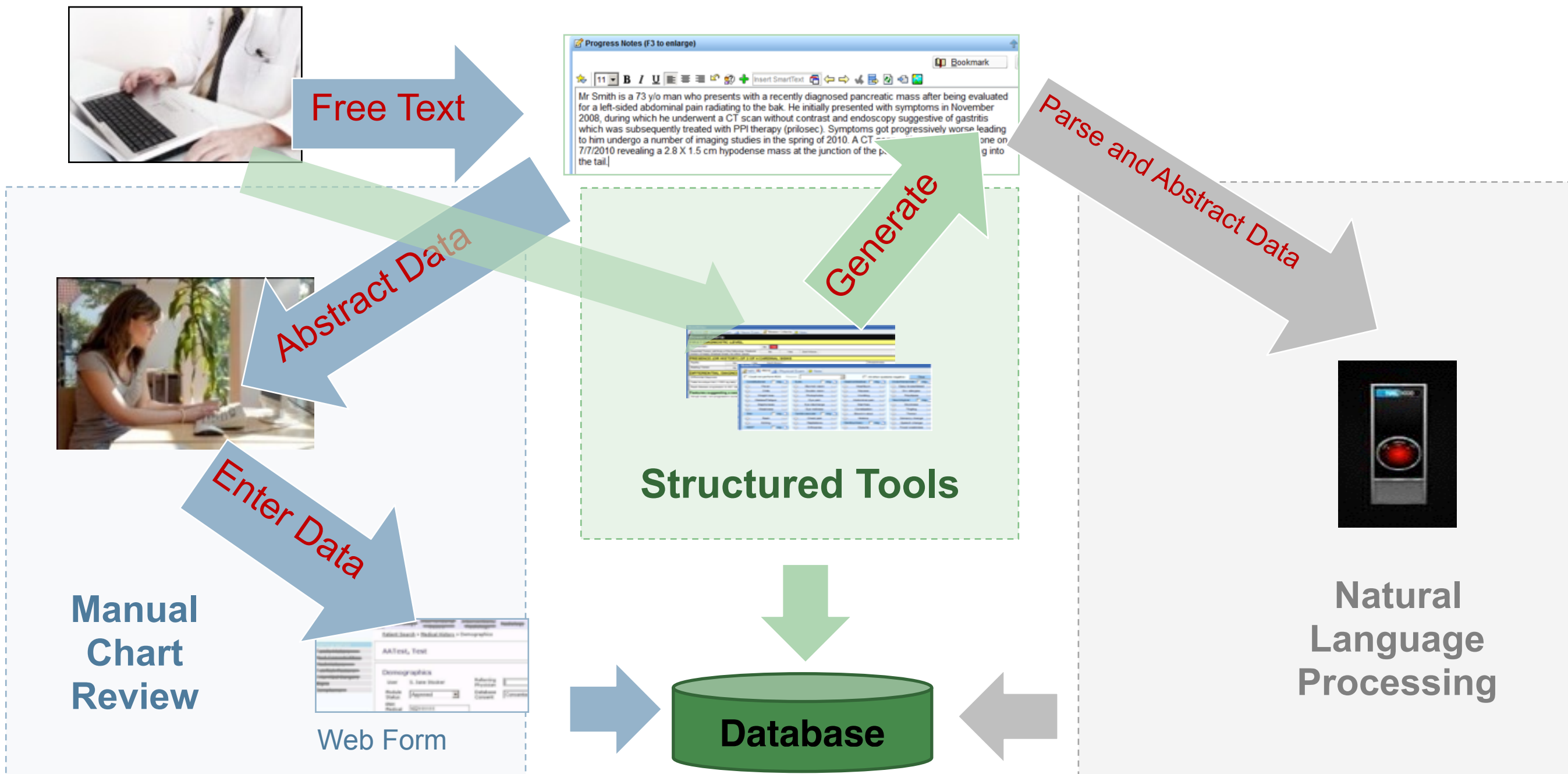
- Collection of Discrete Clinical Data
 - System collects data in context-specific EHR workflows for research and quality improvement.
- Integration of EMR/EDW & External Systems
 - System exchanges data and extends workflow.
- Surveillance Algorithms
 - System monitors and recommends specific intervention for patients who meet known criteria.
- Predictive Algorithms
 - System recommends specific intervention for patients by analyzing thousands of similar patients' data.

Statement of Problem



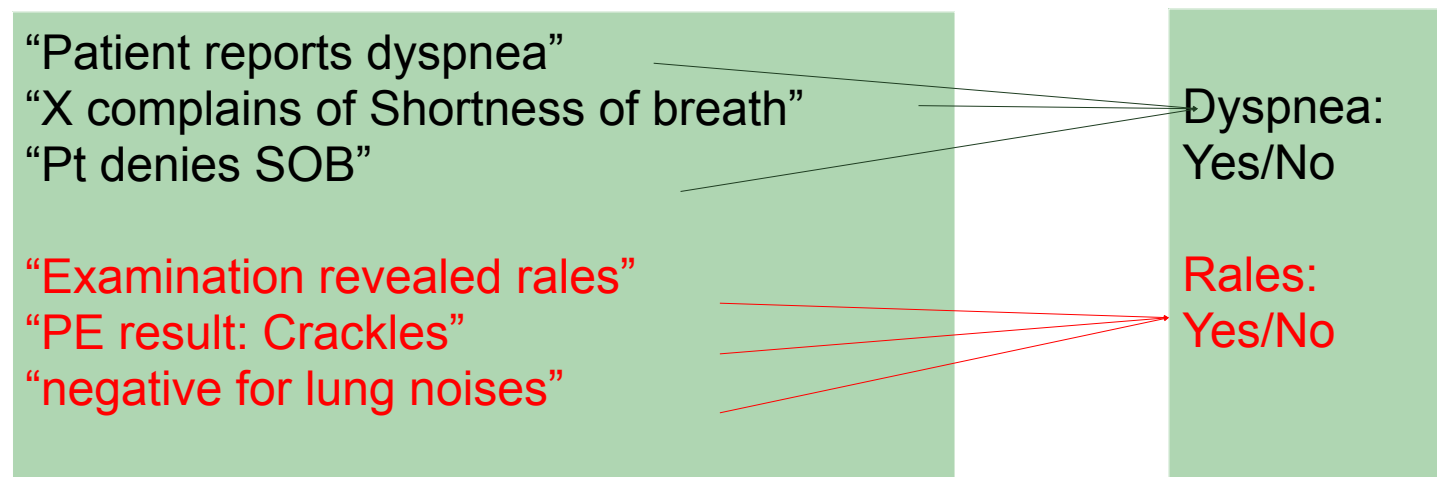
- Clinical documentation is a rich source of information on interactions between the health system and individual patients.
- Question: How can we capture this information **Consistently and Completely** for analysis—especially the interesting parts of progress notes?
- Answer: Tools Balance Expressivity and Workflow

Three Different Approaches



Discretization

the translation of continuous information into discrete data



Analogies:

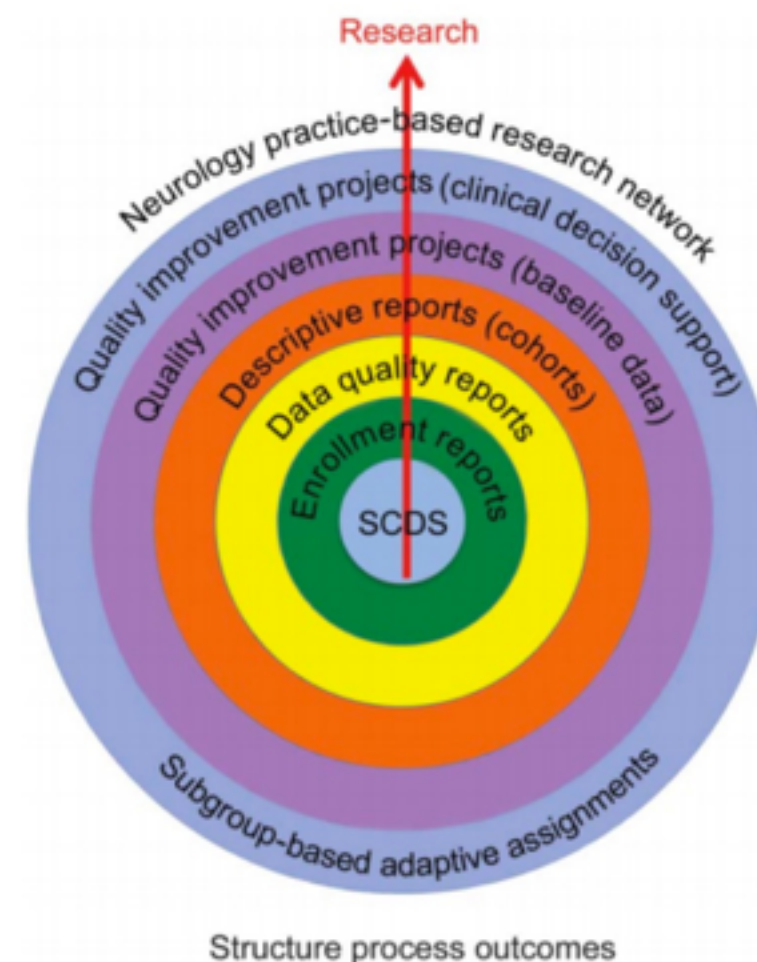
- analog signals vs. discrete waveforms
- film vs. JPG

Quality improvement and practice-based research in neurology using the electronic medical record

Demetrius M. Maraganore, MD
Roberta Frigerio, MD
Nazia Kazmi, MS
Steven L. Meyers, MD
Meredith Sefa, MS
Shaun A. Walters, MS
Jonathan C. Silverstein, MD, MS

Abstract

We describe quality improvement and practice-based research using the electronic medical record (EMR) in a community health system-based department of neurology. Our care transformation initiative targets 10 neurologic disorders (brain tumors, epilepsy, migraine, memory disorders, mild traumatic brain injury, multiple sclerosis, neuropathy, Parkinson disease, restless legs syndrome, and stroke) and brain health (risk assessments and interventions to prevent Alzheimer disease and related disorders in targeted populations). Our informatics methods include building and implementing structured clinical documentation support tools in the EMR; electronic data capture; enrollment, data quality, and descriptive reports; quality improvement projects; clinical decision support tools; subgroup-based adaptive assignments and pragmatic trials; and DNA biobanking. We are sharing EMR tools and deidentified data with other departments toward the creation of a Neurology Practice-Based Research Network. We discuss practical points to assist other clinical practices to make quality improvements and practice-based research in neurology using the EMR a reality. **Neurol Clin Pract** 2015;5:1-11



Genomic Health Initiative (efficient research)



Enrollment/ consenting at pre- existing medical contact points

- Fully electronic through patient portal
- At routine blood draws



Multi-purpose consent

- Bio-sample collection
- Research
- Options for return of clinical data, & patient re-contacting



Biological specimens

- Consenting patients are 'flagged' for bulk ordering
- At next routine blood test, we collect the specimen



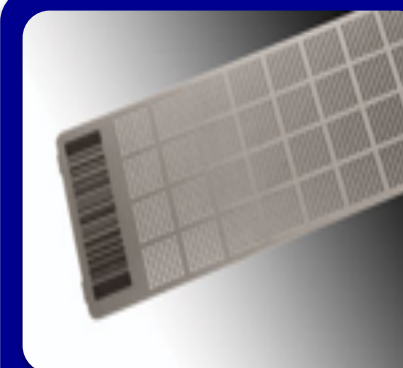
Processing of blood specimens

- Robotized methods
- Transfer of DNA aliquot to genomics lab



Integration with NS EHRs warehouse

- Fully identified protected linkage inside the health system



Genomics

- Results not part of EPIC
- Sharing of de-identified samples/data
- Back to patient is defined in consent
- Alignment with NS business plans

Health Monitors for Chronic Disease by Gait Analysis with Mobile Phones

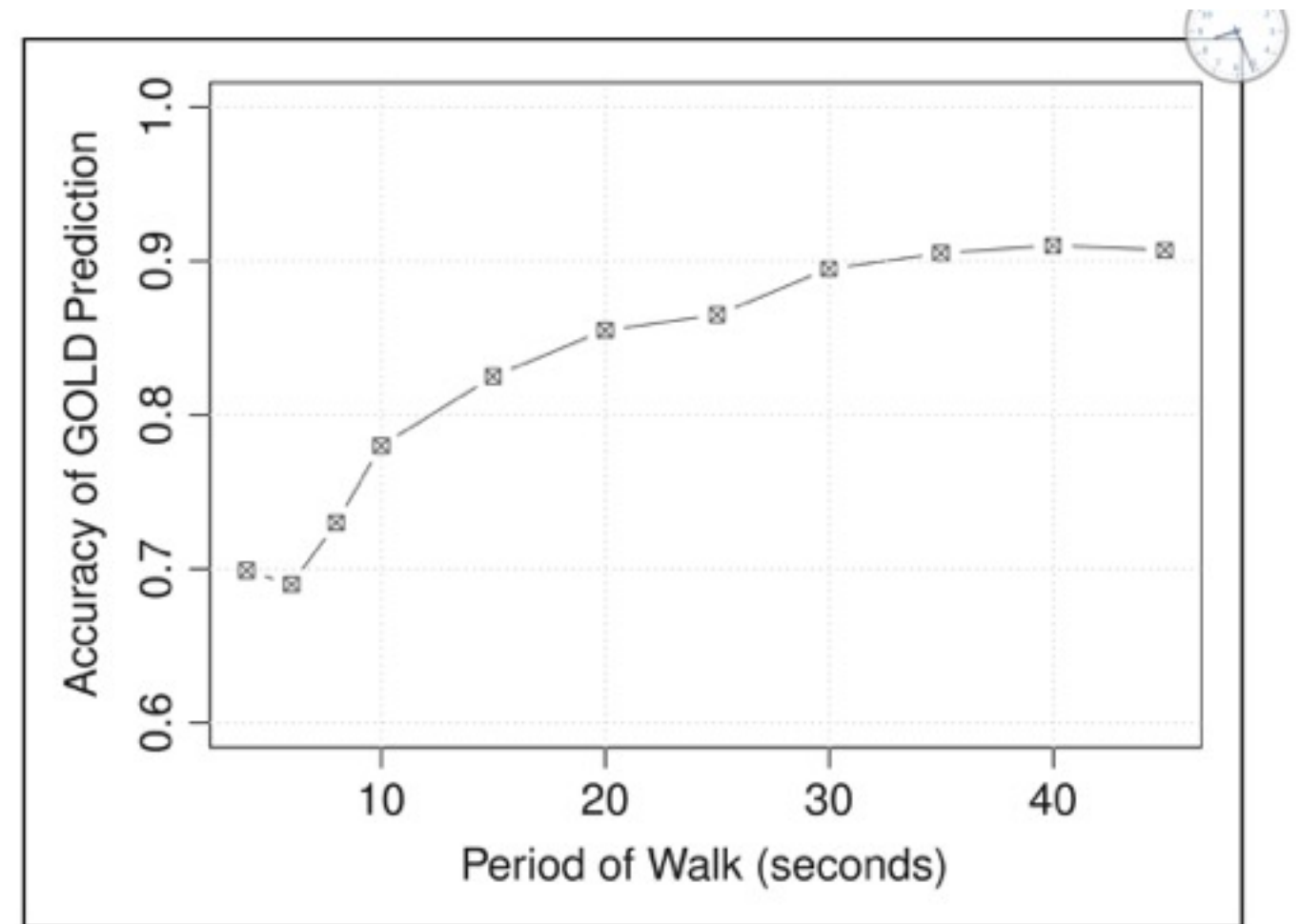
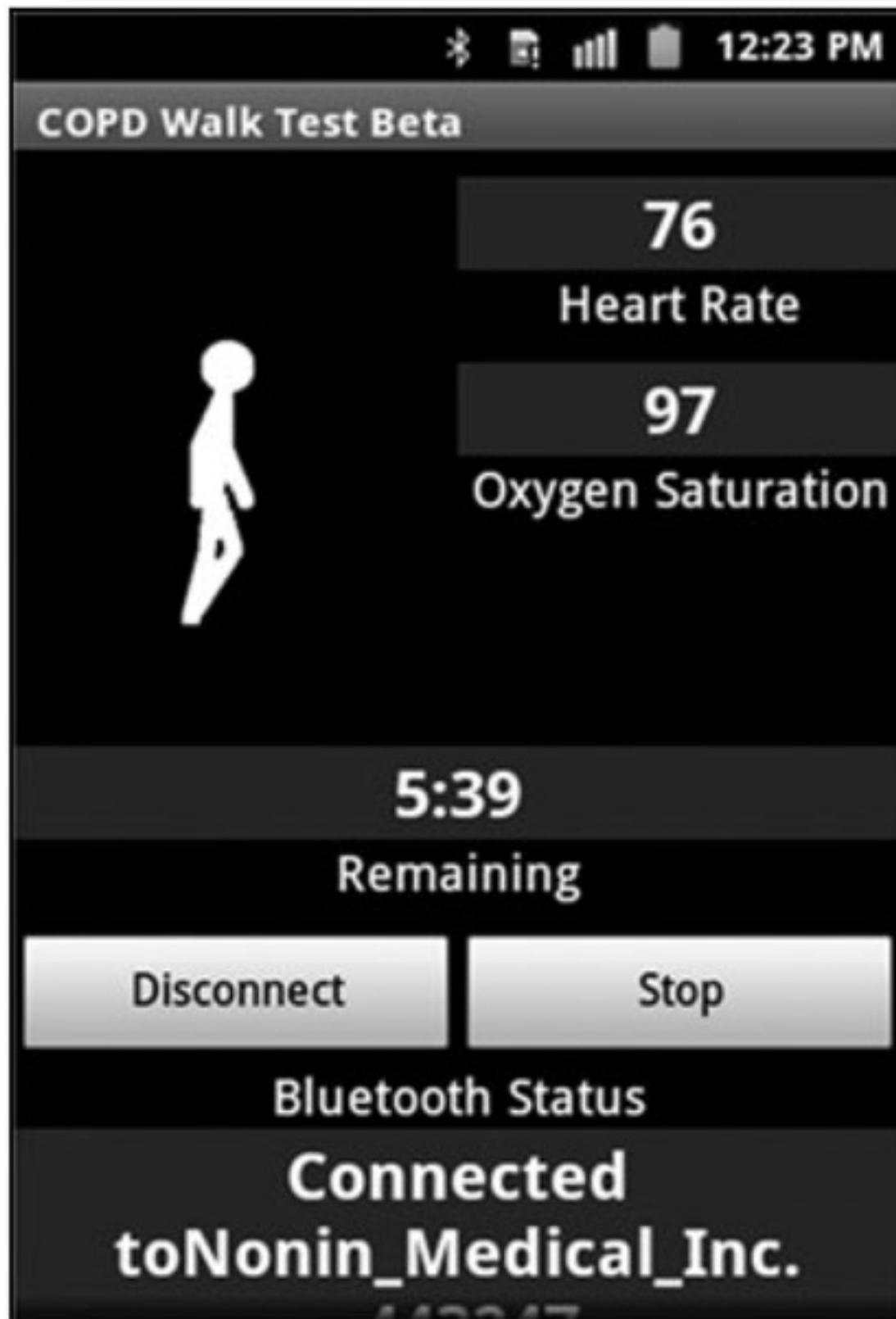


Fig. 2. Prediction accuracy of Global Initiative for Chronic Obstructive Lung Disease (GOLD) status for different walk periods. For the continuous model, the spatiotemporal gait parameters are calculated over discrete periods of time. Thirty seconds of walking is selected as the optimal walk period to balance prediction accuracy with practicality.

What's Going Around

Syndromic Surveillance Across the NorthShore Population

[Influenza](#)

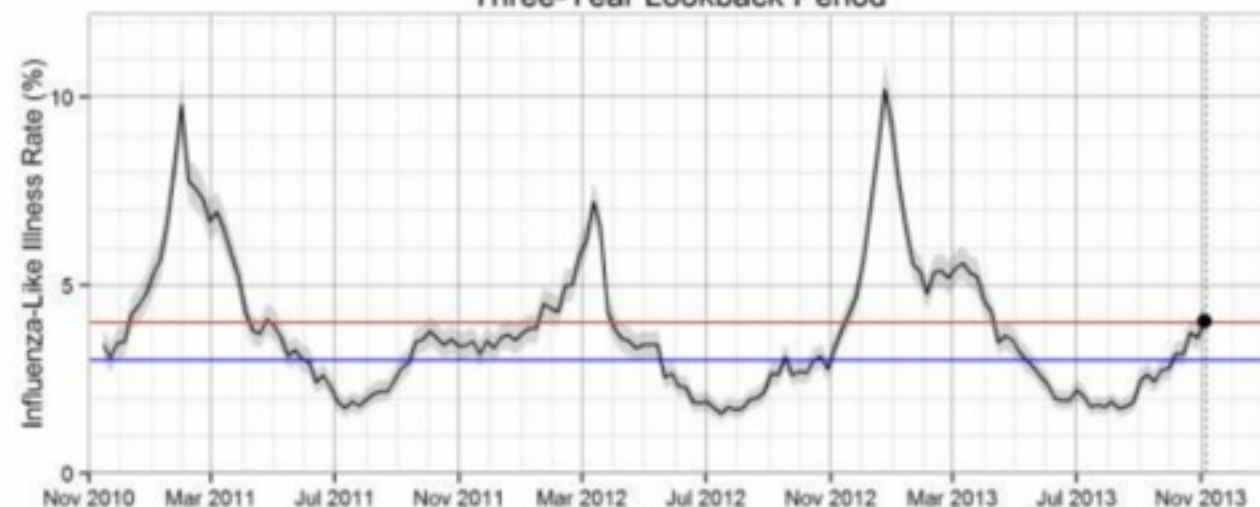
[Strep Throat](#)

[Pertussis](#)

[Pediatric Asthma](#)

[Gastroenteritis](#)

Influenza-Like Illness as of November 06, 2013
Three-Year Lookback Period



[Sample Maps](#)

[Change Location](#)

[How WGA Works](#)

[Feedback](#)

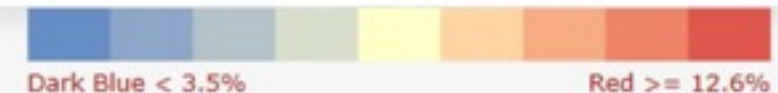
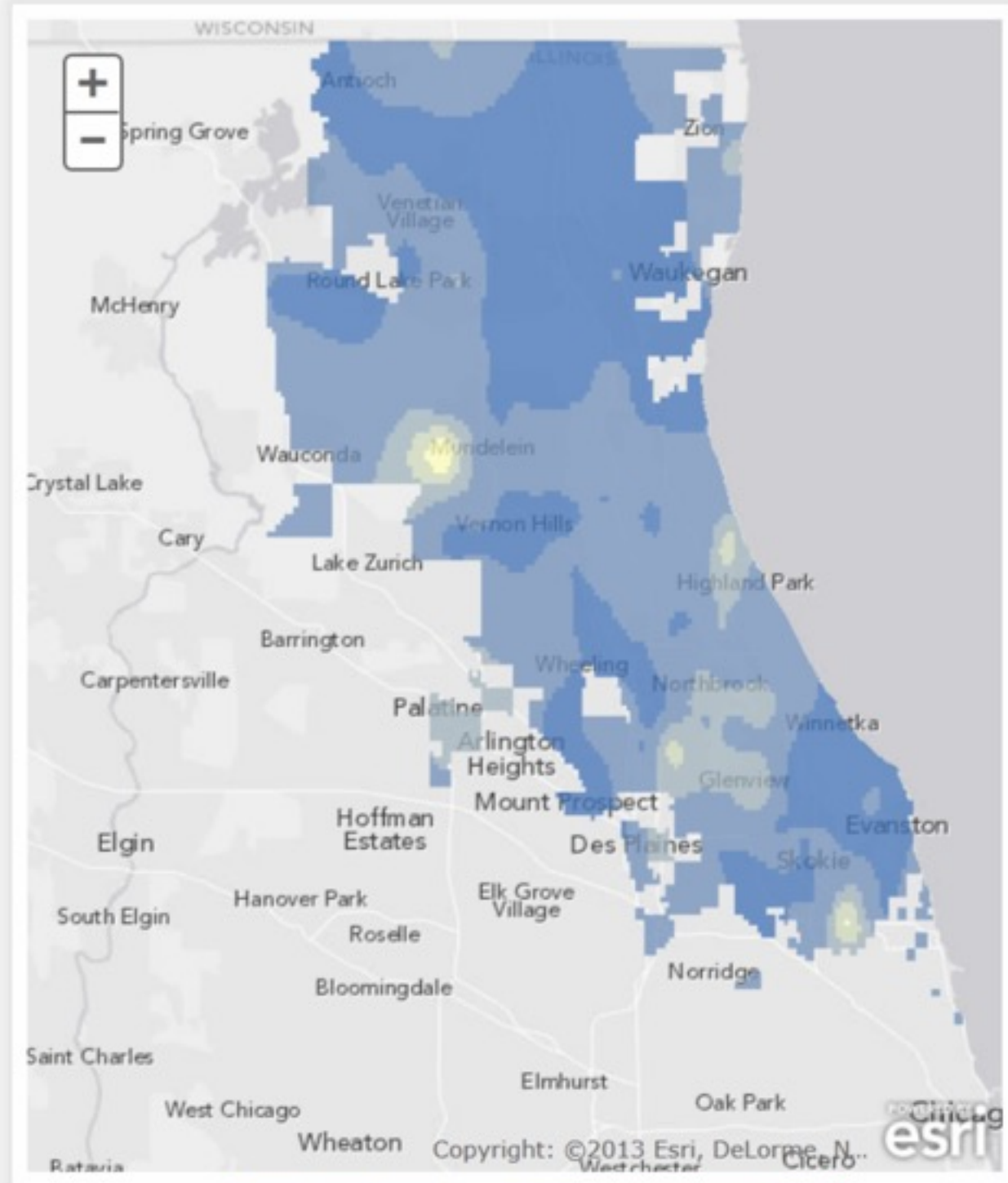
How What's Going Around Works.

'What's Going Around' (WGA) demonstrates a new way in which an Electronic Medical Record system can benefit providers and patients. We believe WGA is the first platform in the world to translate EMR-based data into up-to-date local epidemiological information, and provide this information to clinicians at the point-of-care, in a patient-specific manner.

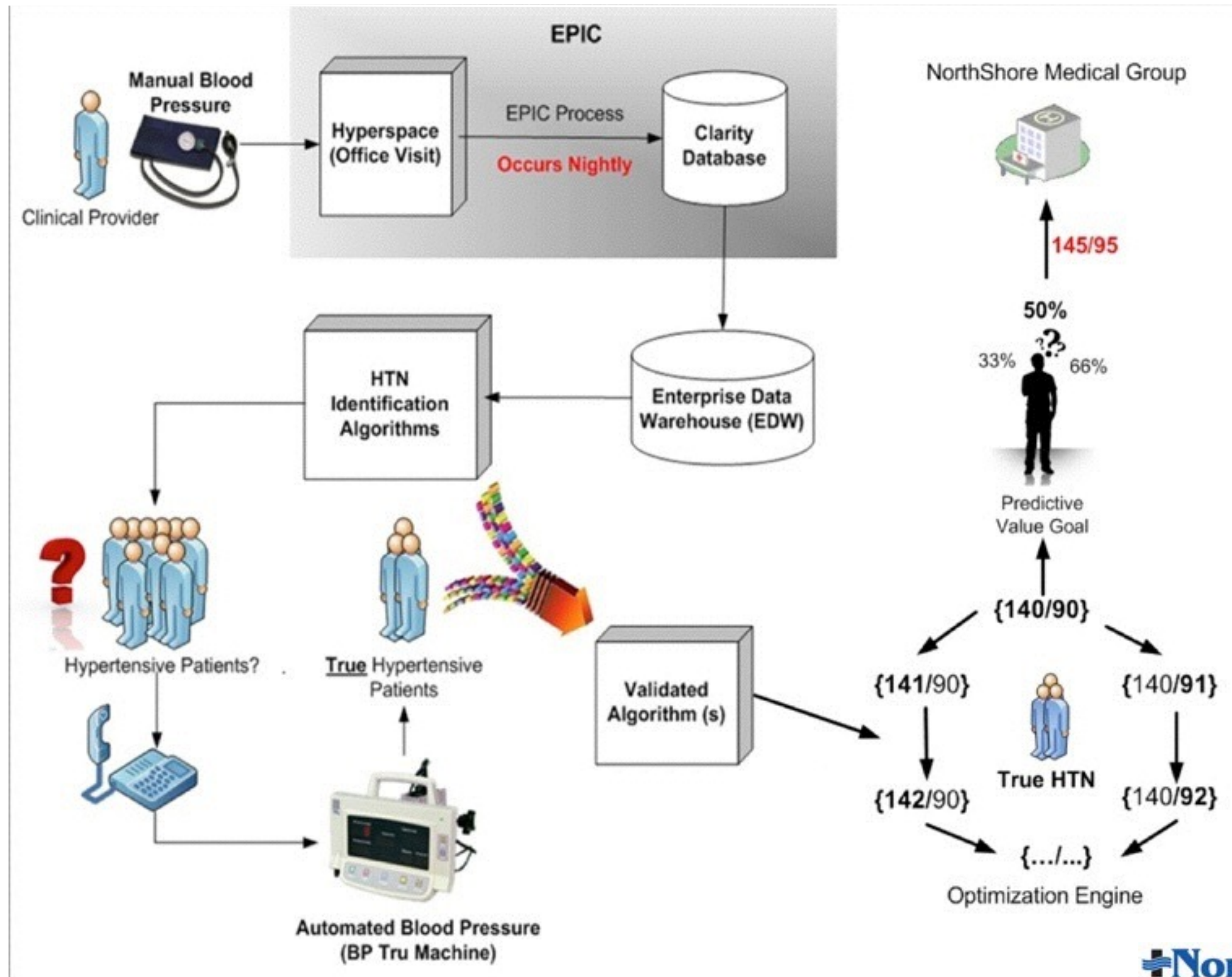
Click [here](#) for full description.



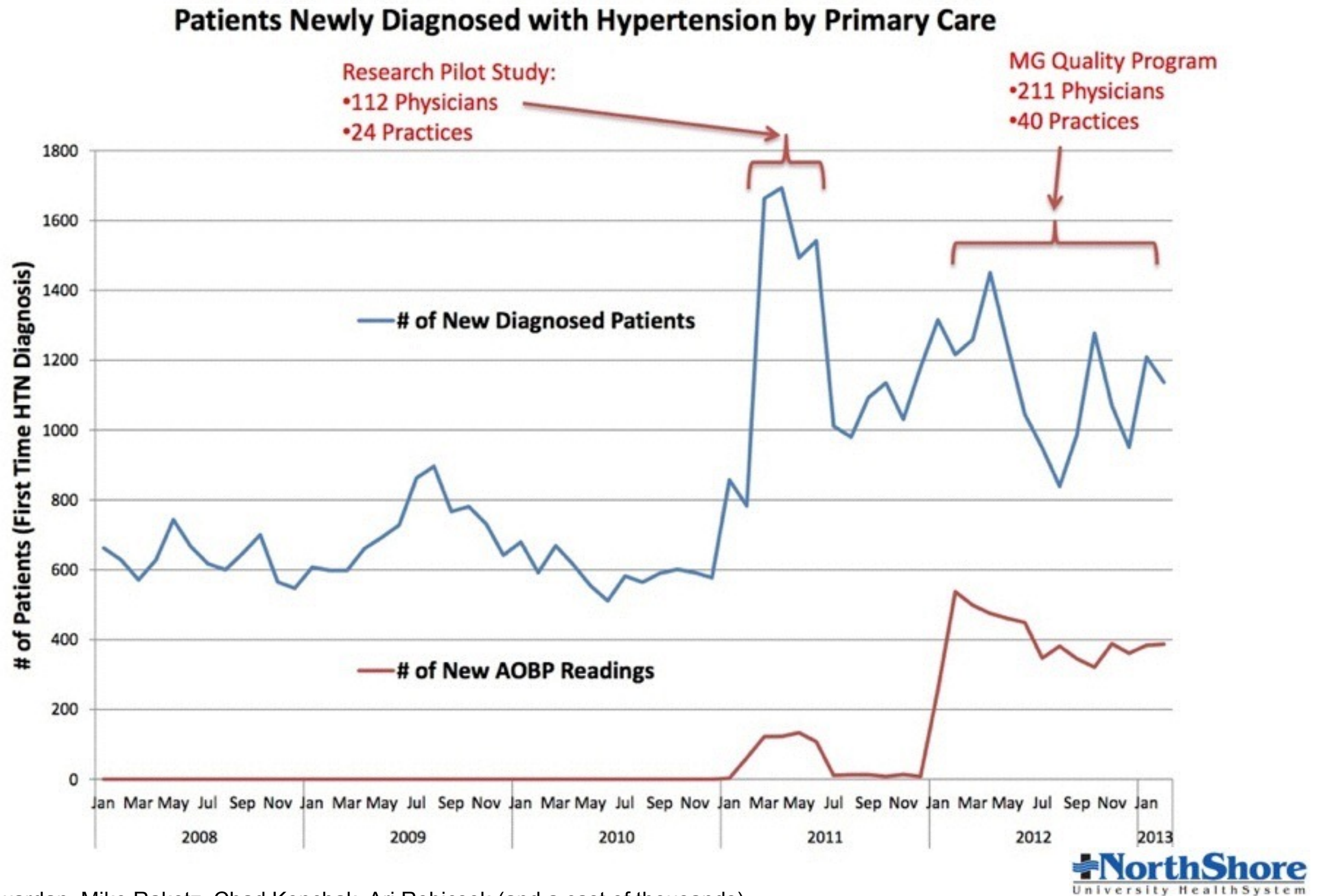
Colors represent the *proportion of all patients seen in the Medical Group who had the syndrome of interest*. Areas with insufficient data for accurate estimates are not colored.



Eliminating Undiagnosed HTN 2010-2012



Eliminating Undiagnosed HTN 2010-2012





THE LEARNING HEALTH SYSTEM SERIES

ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE

DIGITAL INFRASTRUCTURE FOR THE LEARNING HEALTH SYSTEM

The Foundation for Continuous Improvement
in Health and Health Care

Workshop Series Summary

"We seek the development of **a learning health system** that is designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; **to drive the process of discovery as a natural outgrowth of patient care**; and to ensure innovation, quality, safety, and value in health care."

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

JOSEPH H. KANTER FAMILY FOUNDATION
YOUR LIFE YOUR HEALTH
EX-37
DAY-1234
REF-45678
Z-1234
E-1234

Your Life, Your Health

*Sharing your digital health
data could save your life*

PH-1234
DATE-5/15/20
FIL-123456
QBS-WIDE-EX-1234



JOSEPH H. KANTER

Kanter Health Foundation

- MISSION

- To mobilize diverse organizations and people to collaboratively advance human health

- VISION

- Every decision affecting health is informed by knowledge of *what works best*

The Learning Health System

*Health systems--at any level of scale--become **learning health systems** when they can continuously study and improve themselves*



The NEW ENGLAND
JOURNAL of MEDICINE

Perspective: Jan 3, 2013

"Code Red and Blue — Safely Limiting Health Care's GDP Footprint"

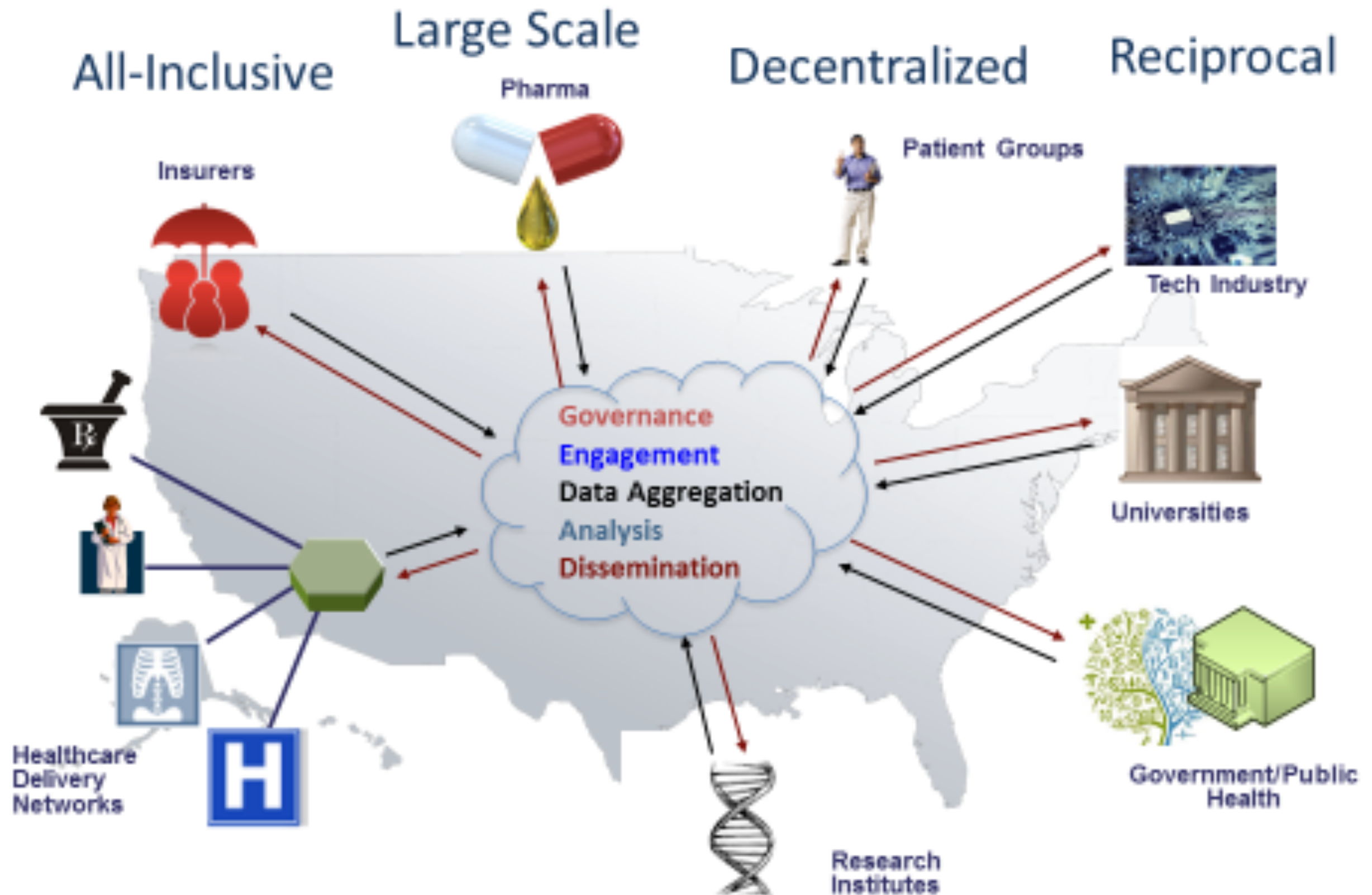
Arnold Milstein, M.D., M.P.H.

...U.S. health care needs to adopt new work methods, outlined in the Institute of Medicine's vision for a learning health system...

Checklist View: A Health System That Can Learn

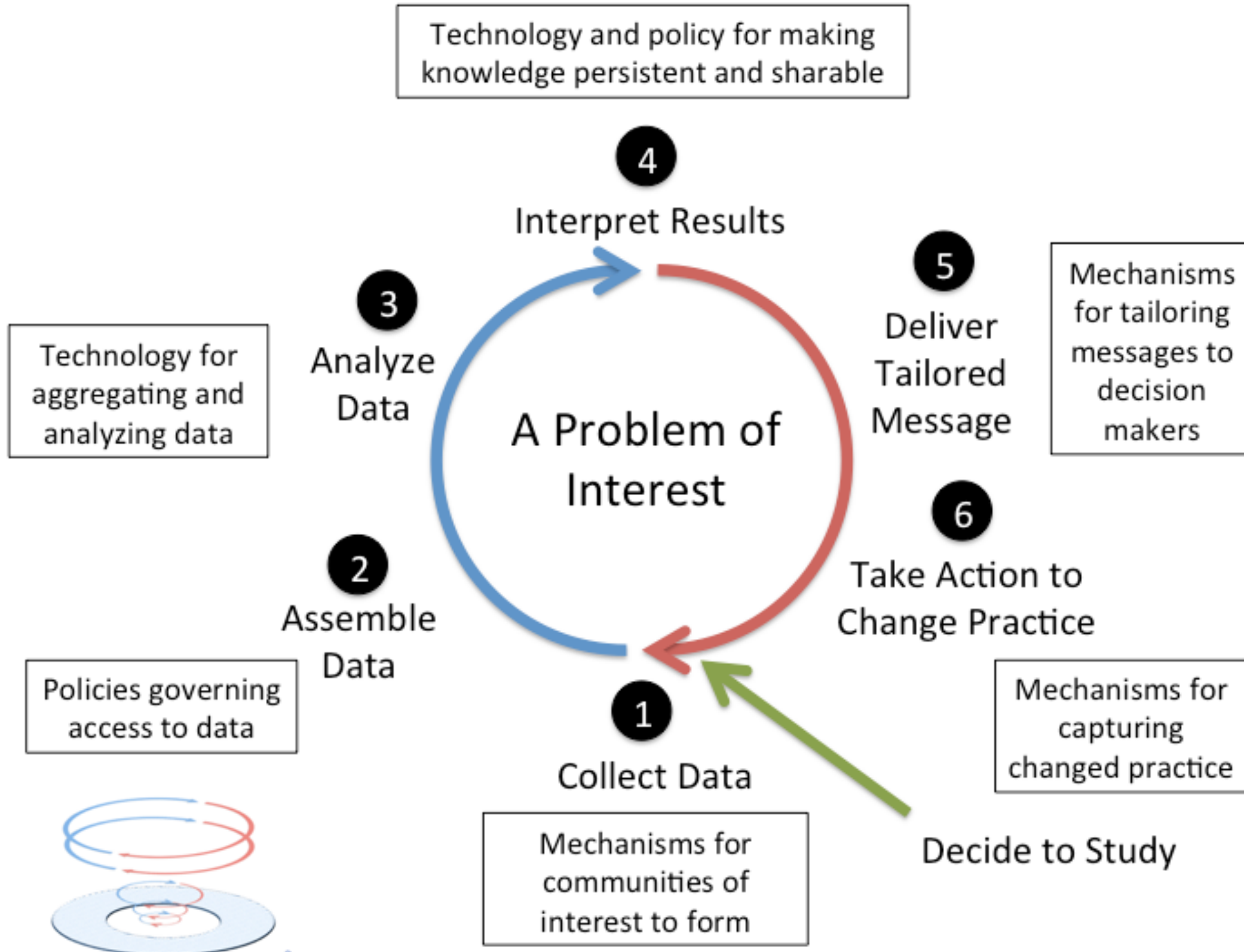
- ✓ Every **consenting** patient's characteristics and experience are available to **learn** from
- ✓ Best practice knowledge is **immediately available** to support decisions
- ✓ Improvement is **continuous** through ongoing study
- ✓ This happens **routinely, economically** and almost invisibly
- ✓ All of this is part of the **culture**

A Nationwide Learning Health System: A System of Health Learners Across Our Nation



Micro View: How Learning Happens

“Virtuous Cycles” of Study and Change



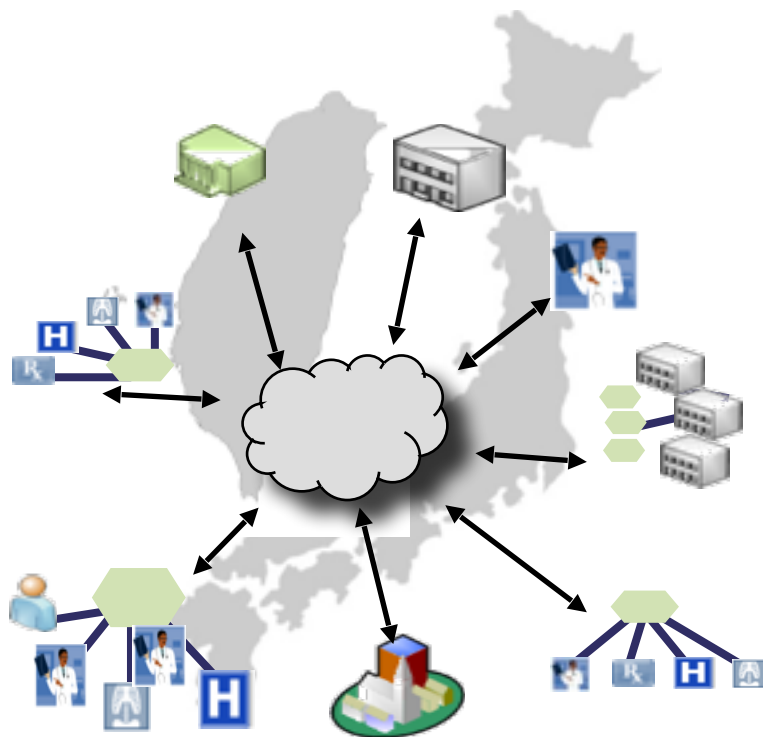
Learning Systems Can Exist at Any Level of Scale



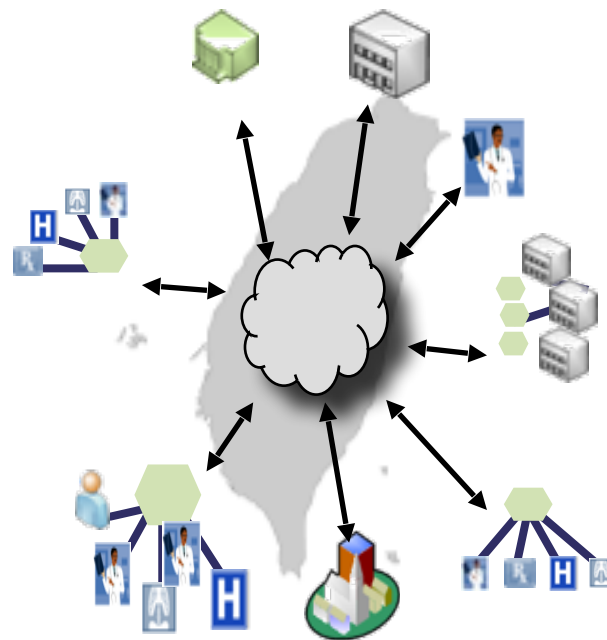
One organization



Many organizations



Several countries



A region or country



The world

Many “Use Cases”...

A Learning System Routinely Enables:

- **Pursuit of Best and Safer Care at Lower Cost:** Communities of interest discover what interventions are most cost-effective and are supported in implementing them.
- **Enhanced Public Health:** During an epidemic, new cases are reported directly from EHRs, the spread of the disease is predicted, and clinicians are alerted.
- **Consumer Empowerment:** Patients facing difficult medical decisions discover the experiences of other patients like them.
- **Enhanced Research:** Data of many types (all –omics) can be rapidly aggregated and analyzed.

105 Endorsements of the LHS Core Values*

(As of 6/7/2016)



*To be included on the www.LearningHealth.org website.

Core Values of the Learning Health System



1) Person Focused



2) Privacy

3) Inclusiveness



4) Transparency



5) Accessibility



6) Adaptability

7) Governance



8) Cooperative & Participatory Leadership



9) Scientific Integrity



10) Value

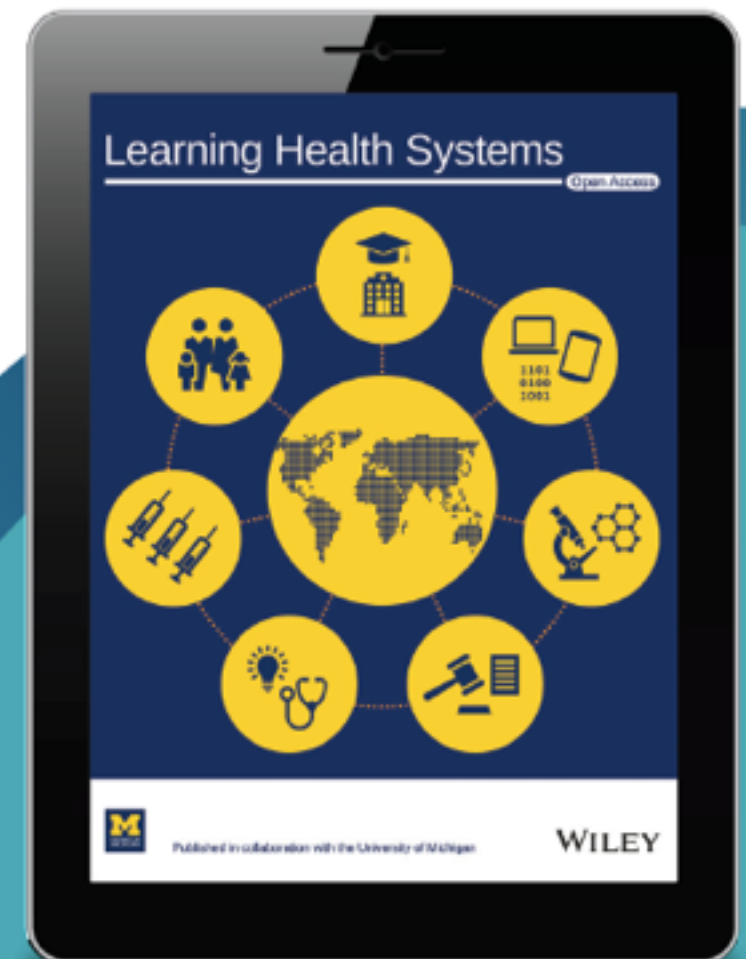
A New International Journal

Learning Health Systems

Open Access

**A new open access journal
dedicated to improved
individual and population health**

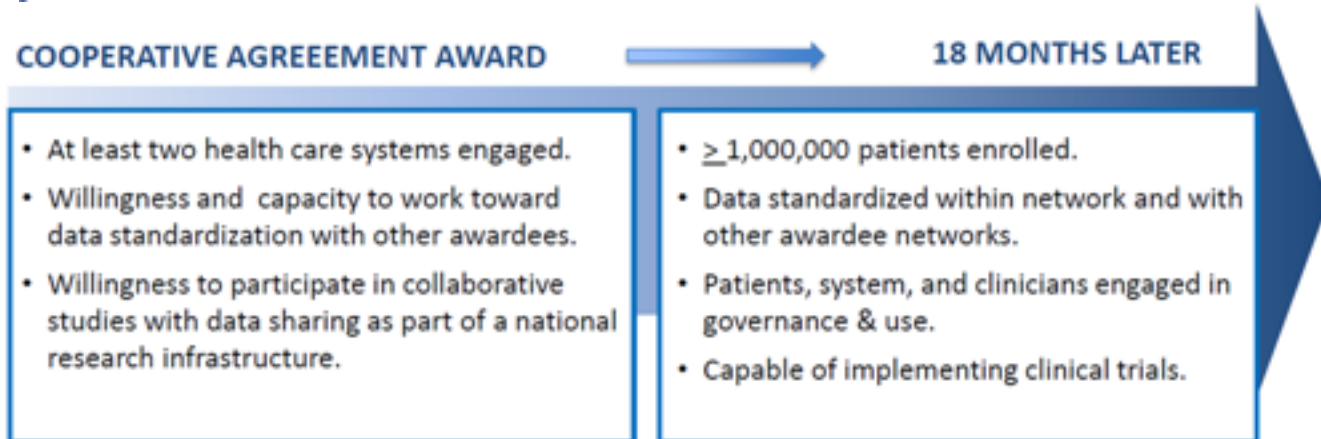
All articles are freely
available to read,
download and share



www.lhsjournal.com

WILEY

Chicago Area Patient Centered Outcomes Research Network



The mission of CAPriCORN is to provide a data and informatics infrastructure to support collaboration among Chicago area scientists in conducting patient-centered outcomes research.

NORTHWESTERN
UNIVERSITY



UNIVERSITY OF ILLINOIS
Hospital & Health Sciences System
Changing medicine. For good.



THE UNIVERSITY OF CHICAGO
MEDICINE



RUSH UNIVERSITY
MEDICAL CENTER



ALLIANCE OF CHICAGO
Community Health Services, LLC

NorthShore
University HealthSystem

CCHHS

Cook County Health & Hospitals System



LOYOLA
MEDICINE

We also treat the human spirit.®



Tufts



MRAIA
Midwest Research
Analytics and
Informatics Alliance



CAPRICORN HOSPITALS, HEALTH CENTERS AND HEALTH SYSTEMS:

ALLIANCE OF CHICAGO'S FEDERALLY QUALIFIED HEALTH CENTERS • COOK COUNTY HEALTH AND HOSPITALS SYSTEM
• LOYOLA UNIVERSITY HEALTH SYSTEM • NORTHSORE UNIVERSITY HEALTHSYSTEM • NORTHWESTERN MEDICINE
• RUSH UNIVERSITY MEDICAL CENTER • UNIVERSITY OF CHICAGO MEDICINE • UNIVERSITY OF ILLINOIS HOSPITAL & HEALTH SCIENCES SYSTEM • VETERANS ADMINISTRATION HOSPITALS (HINES, JESSE BROWN)

CAPRICORN PARTNERS:

BLUE CROSS BLUE SHIELD OF ILLINOIS • CENTER FOR MEDICAL TECHNOLOGY POLICY • CHICAGO ASTHMA CONSORTIUM
• CHICAGO HEALTH IT REGIONAL EXTENSION CENTER (CHITREC) • CLINICAL DIRECTORS NETWORK • COMER CHILDREN'S HOSPITAL • HAVE A HEART FOR SICKLE CELL ANEMIA FOUNDATION • ILLINOIS HOSPITAL ASSOCIATION • ILLINOIS MEDICAL DISTRICT COMMISSION • LURIE CHILDREN'S HOSPITAL • MEDICAL RESEARCH ANALYTICS AND INFORMATICS ALLIANCE • NEXT STEP/STRIVE • OFFICE OF HEALTH INFORMATION TECHNOLOGY • RAND • RESPIRATORY HEALTH ASSOCIATION • SICKLE CELL DISEASE ASSOCIATION OF ILLINOIS • THE CHICAGO COMMUNITY TRUST • THE PEGGY LILLIS MEMORIAL FOUNDATION • TUFTS UNIVERSITY CTSI • UNIVERSITY HEALTHSYSTEM CONSORTIUM (UHC)
• UNIVERSITY OF ILLINOIS AT CHICAGO • VANDERBILT UNIVERSITY

Research Data Network

Epic



...to provide software applications and appropriate governance to facilitate the sharing of EHR data among healthcare organizations for research purposes



INCLUSIVENESS

COLLABORATION

TRANSPARENCY

PRIVACY

**COMMUNITY
DISSEMINATION**

**GOOD
CITIZENSHIP**



Collaborative data sets for specific studies

Specialty-focused data sets for ongoing research (e.g., consortium data sharing)

De-identified queries across entire community



LHS.network cohort

LHS.network is building a cohort of millions of patients' full electronic medical records with the objective of answering the following question:

Among patients with my diagnosis and *similar* to me, what treatments did they choose and what were the outcomes?

Achieving our objective will proceed along two parallel projects:

- Assembling base set of millions of full electronic medical records from dead people (decedents)
 - Key mechanism: non-human subjects research can progress rapidly
- Building a living cohort of altruists who will both contribute their data and benefit directly
 - Key mechanism: Touching millions of people will be achieved by an efficient scalable consent

decedent subject data repository

Research informatics platform aggregating decedent subject data from health systems and transforming it for use in generating hypotheses and piloting informatics methods.

The HITECH Act modified HIPAA to enable research access to decedent records under all circumstances with no method for patients or their representatives to opt-out.

PHI of Decedents {45 CFR 164.512(i)(1)(iii)}

§ 164.512 Uses and disclosures for which consent, an authorization, or opportunity to agree or object is not required.

(iii) Research on decedent's information. The covered entity obtains from the researcher:

- **(A) Representation that the use or disclosure is sought is solely for research on the protected health information of decedents;**
- **(B) Documentation, at the request of the covered entity, of the death of such individuals; and**
- **(C) Representation that the protected health information for which use or disclosure is sought is necessary for the research purposes.**

why do we need patient identifiers?

- Precise verification of records for any findings (e.g. Chart Review) and source verification is impossible with de-identified records without re-identification.
- We need to know the context of time and location in order to optimize the similarity metric between patients.
- Project goals are totally dependent on a similarity metric among people, so it is essential to de-duplicate all records before analysis.
- EMRs do not account for behavior and other social determinants of disease, so if we can determine with precise identification that one person lives in the same house as another, then we can assert with high confidence that many of the same social determinants of disease are similar without knowing what they are precisely.

Two Questions to Consider*



1. What can the LHS do for me?
2. What can I do for the LHS?



*In your role as a healthcare professional, as a patient/caregiver, as a citizen, and in other roles.