Data Sharing: Patient Care and Research Data

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President Obama's Priority

- Patient's health record (medical records) will be electronic. Utilization of electronic health records (EHR) will be the standard of health care in the U.S.
  - Definition: A longitudinal electronic record of patient health or medical information generated by one or more encounters in any care delivery setting.

Electronic Health Records: Why?

- Rationale: Patients receive care in numerous settings. Quality and cost-effective care is best delivered with longitudinal records.
- Advantages
  - evidenced-based decision support
  - reduction in unnecessary expenses
  - improvement in quality and safety of patient care
  - better analysis of medical outcomes

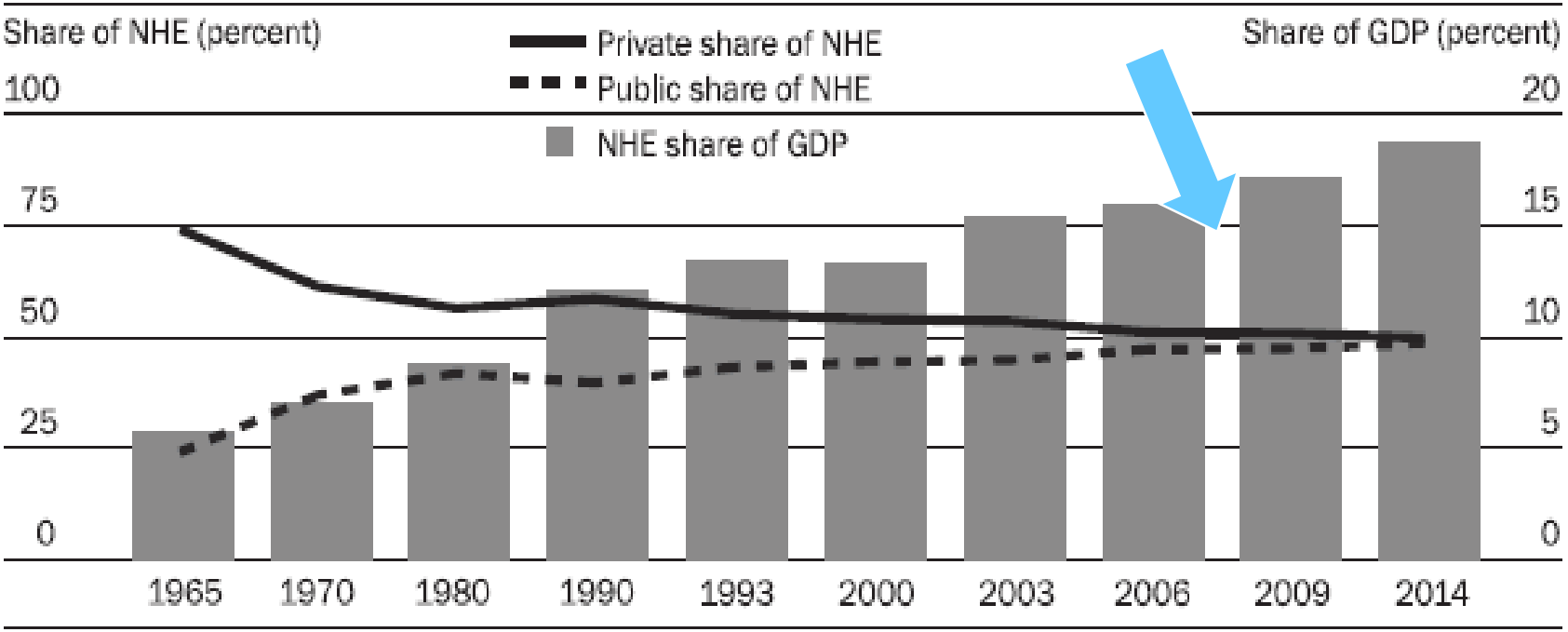
Current Status of EHR Implementation

- Records contain: medications, lab data, medical summary documents
- What is missing?
  - Imaging examination data which are primary diagnostic tools
- What is needed?
  - Security policies
  - Interoperable security technologies

Health Care Spending as a Share of U.S. Economic Output Rising Steadily

EXHIBIT 3

National Health Expenditures (NHE) Share Of Gross Domestic Product (GDP) And Private And Public Shares Of NHE, Selected Years 1965–2014



SOURCE: Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group.

NOTES: The left axis (public and private spending's share of NHE) relates to the two line graphs. The right axis (NHE's share of GDP) relates to the gray-shaded bars. Data for 2006, 2009, and 2014 are projections.

Image Data Sharing: Reduce Health Care Costs

- Eliminate unnecessary imaging
  - About 20% of hospital radiology tests are duplicates
  - Represents $20 billion/year of wasted health care spending
- Reduce patient exposure to radiation
  - Chest computed tomography (CT) exposes a patient to 80-400X radiation than a chest x-ray
- Promote appropriate use of radiological services
- Promote cost-effectiveness

Image Data Sharing

- Goal:

  Make available image examinations to authorized providers with the consent of patient

Image Data Sharing

- Approach: Internet-based exchange of radiological examinations and reports in a secure, efficient, cost-effective fashion.
- Patient-controlled Personal Health Records
- A common platform for effective exchange of research-related imaging examinations
- DICOM, universally adopted standards for images
- Picture archiving and communication systems (PACS)

Example of Image Data Sharing

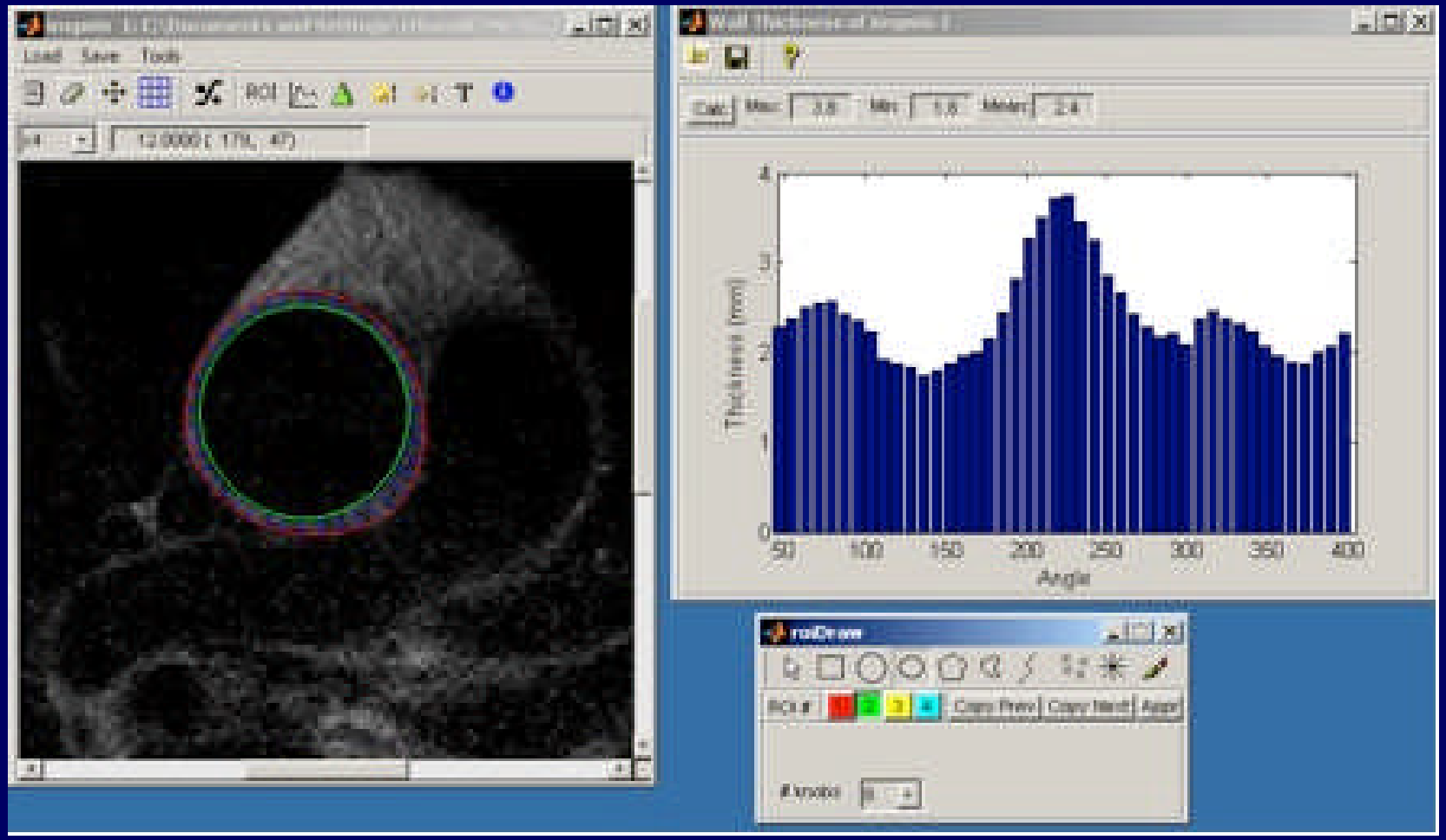
Jackson Heart Study

- A large, longitudinal, observational study to investigate genetic risk factors for high blood pressure, heart disease, strokes, and diabetes in African Americans.
- Estimate of 400,000-460,000 Americans die in an emergency department each year.

Cardiac MRI Examination Components

- LV Function, myocardial mass
  - Cardiac cycle
  - Myocardial segments
- Myocardial Strain
- Aortic Compliance
- Aortic wall thickness

Subclinical Atherosclerosis Aortic Wall thickness



J. Jeffrey Carr, MD

Informatics: Critical Need

- Improve data management
  - Expensive, precious and vast amount of data stored in disparate locations, formats and media
  - Much will be lost!!!!

  Improve knowledge management
  - Important analysis results and findings represented in data dictionaries and publications that vary across studies
  - Substantial amount of knowledge locked inside researcher's head
- Improve knowledge discovery
  - Difficult to ensure the integrity of myriads of complex findings within genomic and phenomic data
  - Difficult to go beyond hypotheses about single variables and simple associations

Ontology is the key!

- Formal and precise representation of concepts and their relationships
  - Clear and consistent representation of existing data and knowledge
    - Standard concepts that connect variables from different studies
    - Standard terminologies to capture future data and analysis results
  - Continued assessment of knowledge and knowledge integrity
  - Automated analysis of complex data and high order associations

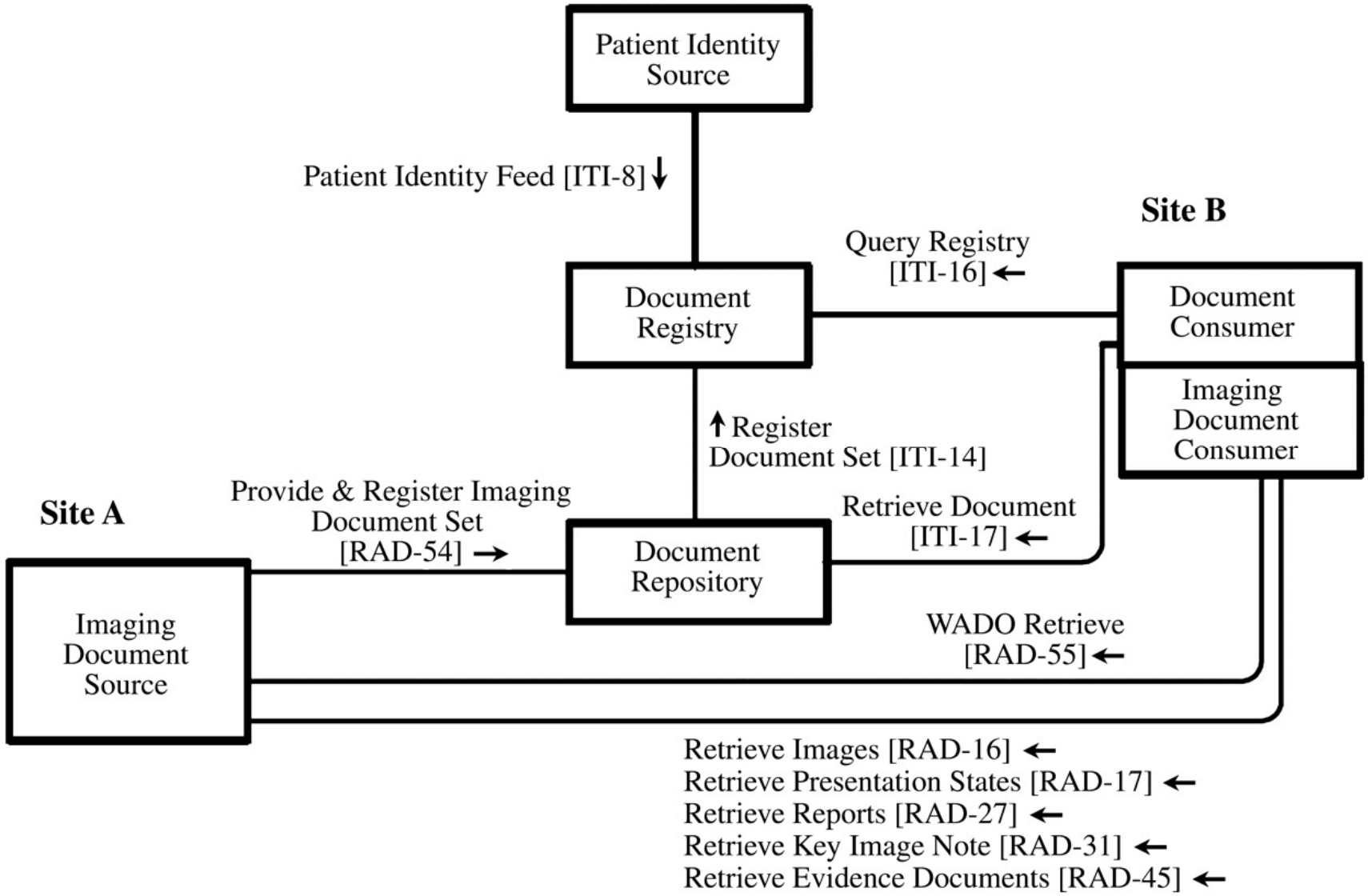
Ontology-driven knowledge discovery

- Semantic query and browsing
  - Linking spreadsheets, databases, and files into the same ontology
  - Natural language user interface
- Continued knowledge discovery and integrity verification
- High-order data analysis and data mining

Grid-based informatics infrastructure

- Trusted network of information systems from multiple research groups and institutions
- Federated query of multiple data sources from multiple studies, locations and data formats using a standard ontology

Web-based Image Data Sharing


Patient Identity Source
Patient Identity Feed [ITI-8]
Site B
Query Registry [ITI-16]
Document Registry
Document Consumer
Imaging Document Consumer
Register Document Set [ITI-14]
Site A
Provide & Register Imaging Document Set [RAD-54]
Retrieve Document [ITI-17]
Document Repository
Imaging Document Source
WADO Retrieve [RAD-55]
Retrieve Images [RAD-16]
Retrieve Presentation States [RAD-17]
Retrieve Reports [RAD-27]
Retrieve Key Image Note [RAD-31]
Retrieve Evidence Documents [RAD-45]

Expected Outcomes from Pilot Studies

- Network-based technologies can effectively provide for image sharing
- An extensible model