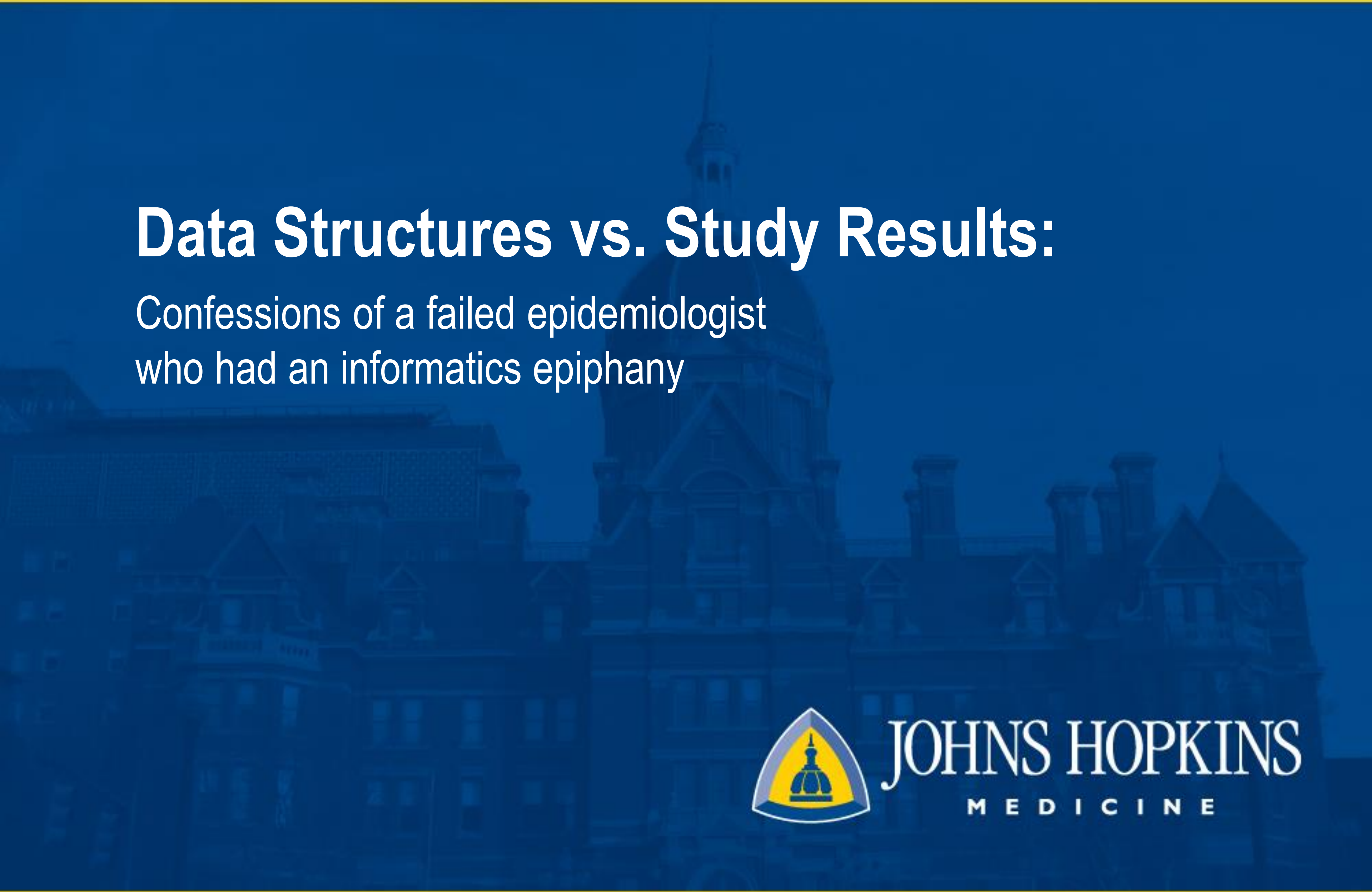


Data Structures vs. Study Results:

Confessions of a failed epidemiologist who had an informatics epiphany

JOHNS HOPKINS
MEDICINE

CG Chute, MD DrPH, Bloomberg Distinguished Professor of Health Informatics

April 7, 2015

Chris's story

- Recognized clinical training as apprenticeship
  - Folklore and anecdote
- Sought methodology training for outcomes research
  - Had not yet heard of "evidence-based medicine"
- DrPH in epidemiology and biostatistics—but no data
- Sought informatics; discovered that data was junk
  - No comparability or consistency, no standards
- Established career in clinical data representation

Where did my training go wrong?

- Set up “Health Professionals’ Follow-up Study” as graduate student
  - Did thesis on Nurses’ Health Study
- Became far more interested in process, data collection, methods, meaning, and data quality
  - Latent informaticist, though I did not know the word
- Rather indifferent to “results” as inferences
  - Not a good sign for a junior epidemiologist

Why did my training go wrong?

- Exposed to 256-byte programmable calculator in HS
- Became an English major in college
- Imbued in computer science
  - All undergrads had computer accounts
  - Daily user of email (campus) since 1973
  - Lots of CS and applied math courses
  - Directed undergraduate computer consulting program
- It was in the water…
  - Musen, Cimino, Lipman, Butte, Kohane, …

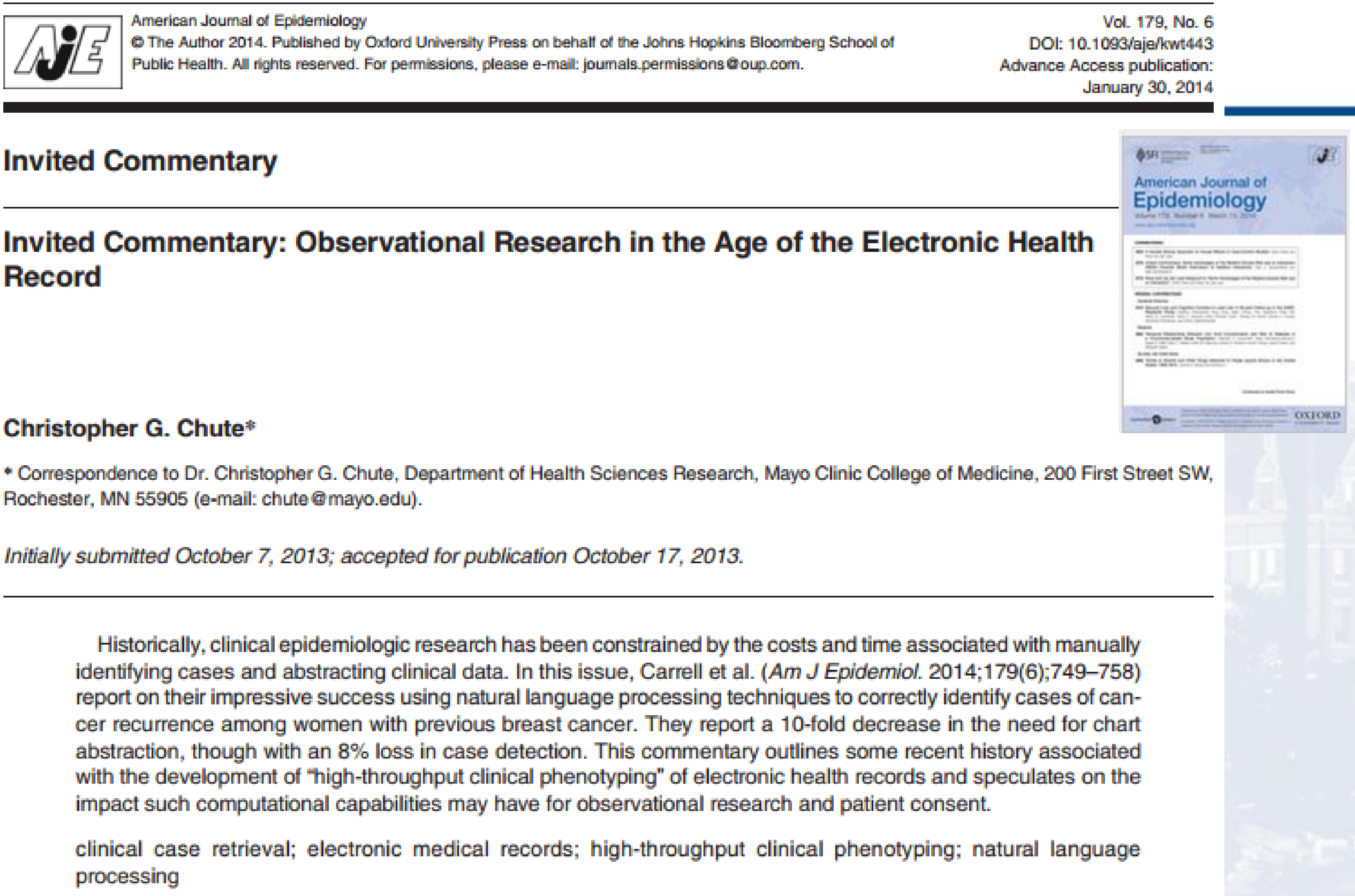
How many boats did I miss?

- Myopic focus on clinical data generated during the process of care
  - Discount survey data
  - Discount reimbursement data
  - Discount vital statistics
  - Discount environment and exposure
  - Discount occupational health

What do I think was going on?

- Healthcare benefits from analyses
- Inferencing methodology is not sufficient
- It’s all about the [clinical] DATA
  - Assume universal healthcare
  - Assume complete data capture and availability
- Data remained heterogeneous, non-comparable
- *Informatics emerged as the only path to truth!*

One of my least-cited articles….



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Invited Commentary

Invited Commentary: Observational Research in the Age of the Electronic Health Record

Christopher G. Chute*

* Correspondence to Dr. Christopher G. Chute, Department of Health Sciences Research, Mayo Clinic College of Medicine, 200 First Street SW, Rochester, MN 55905 (e-mail: chute@mayo.edu).

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Historically, clinical epidemiologic research has been constrained by the costs and time associated with manually identifying cases and abstracting clinical data. In this issue, Carrell et al. (*Am J Epidemiol.* 2014;179(6);749–758) report on their impressive success using natural language processing techniques to correctly identify cases of cancer recurrence among women with previous breast cancer. They report a 10-fold decrease in the need for chart abstraction, though with an 8% loss in case detection. This commentary outlines some recent history associated with the development of "high-throughput clinical phenotyping" of electronic health records and speculates on the impact such computational capabilities may have for observational research and patient consent.

clinical case retrieval; electronic medical records; high-throughput clinical phenotyping; natural language processing

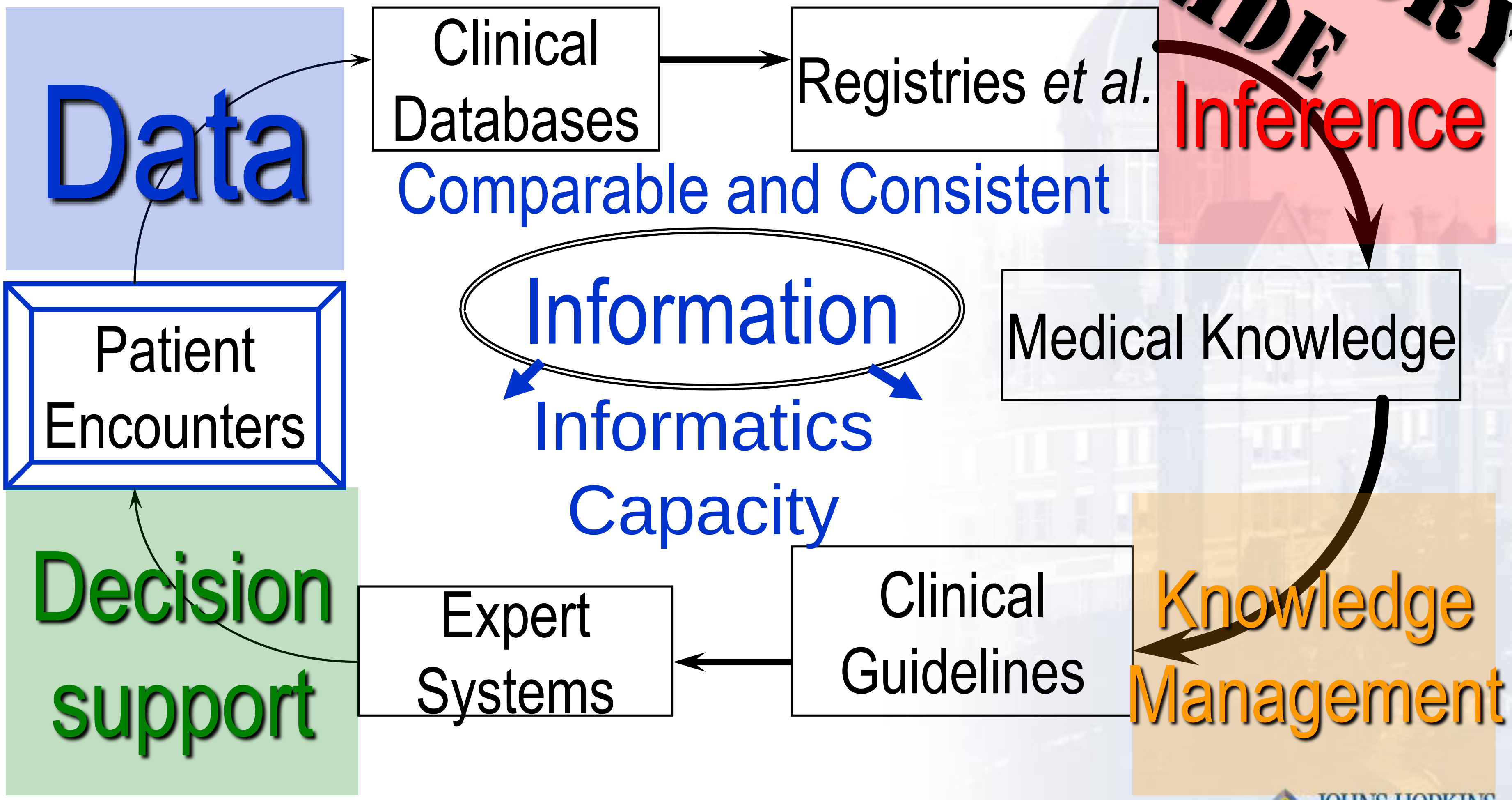
So, what was the epiphany?
What are epiphanati?

Within the biomedical data world:

- Comparable and consistent data is prerequisite
- That rests on semantic coherence
  - Classification, Ontology, Terminology, Value Sets
- Semantics must be bound to context
  - Information models, EHR
- Practice late-binding to application schema

From Practice-based Evidence to Evidence-based Practice

MANDATORY SLIDE



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Coherent semantics

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How do ***you*** say glucose?

Glucose 葡萄糖 Glükoos Glucose Glucose Glucjkose Glukose

LOINC

the ***lingua franca*** of clinical observation exchange

Γλυκόζη Glucosio 포도당 Glicose Glucosa Glucosa Glucosa

Rx NLM Nav

- IHTSDO delivering
- SNOMED CT®
- the global clinical terminology

go Gene Ontology

ICD-11 *alpha*

International Classification of Diseases

Eleventh Revision

World Health Organization
Geneva

THE NATIONAL CENTER FOR BIOMEDICAL ONTOLOGY

ICD-9-CM

International Classification of Diseases, Ninth Revision, Clinical Modification

2010

6

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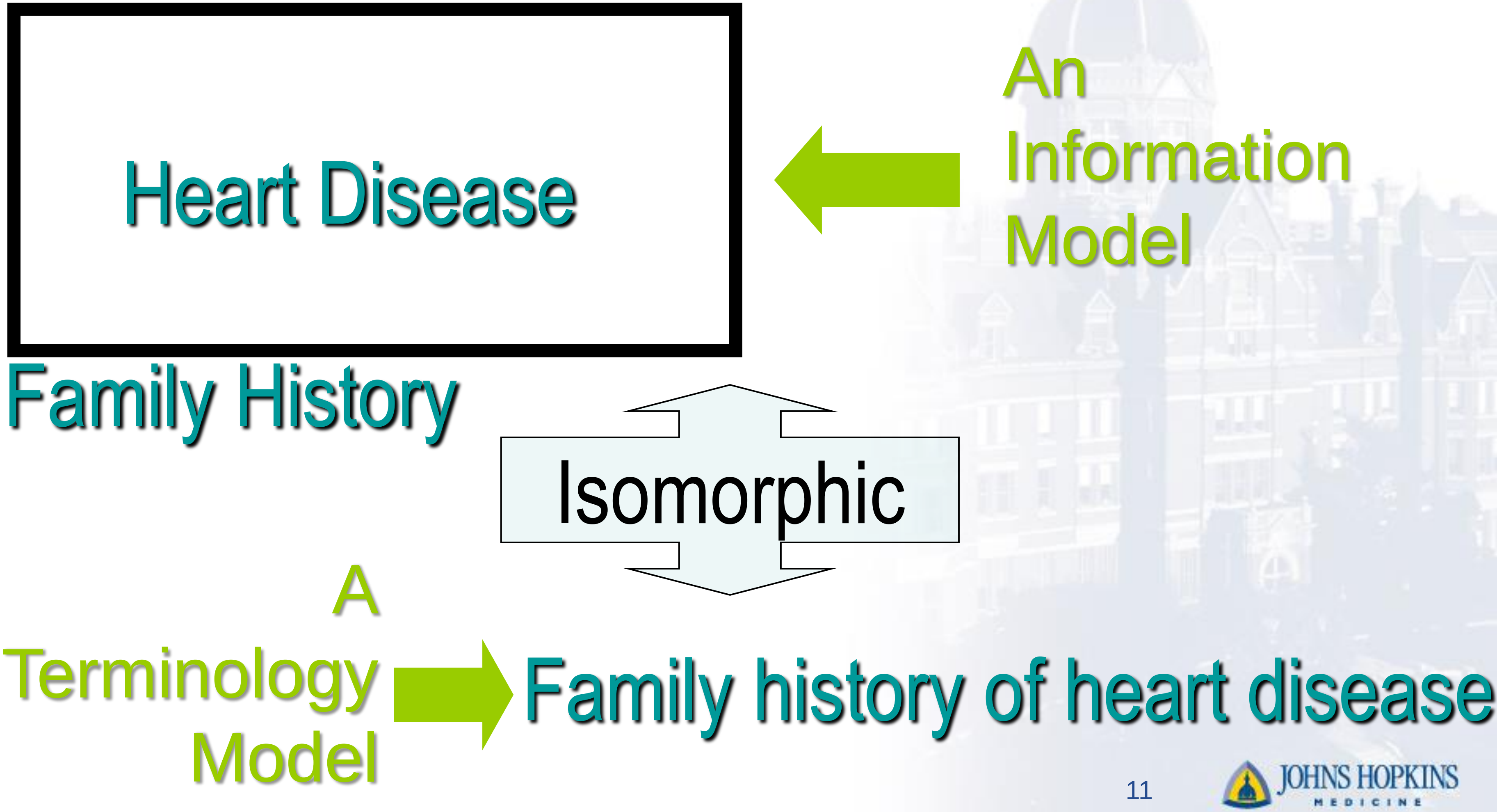
Content vs. Structure
Semantics is intertwined with structure



Heart Disease

An Information Model

Family History

Isomorphic

A Terminology Model

Family history of heart disease

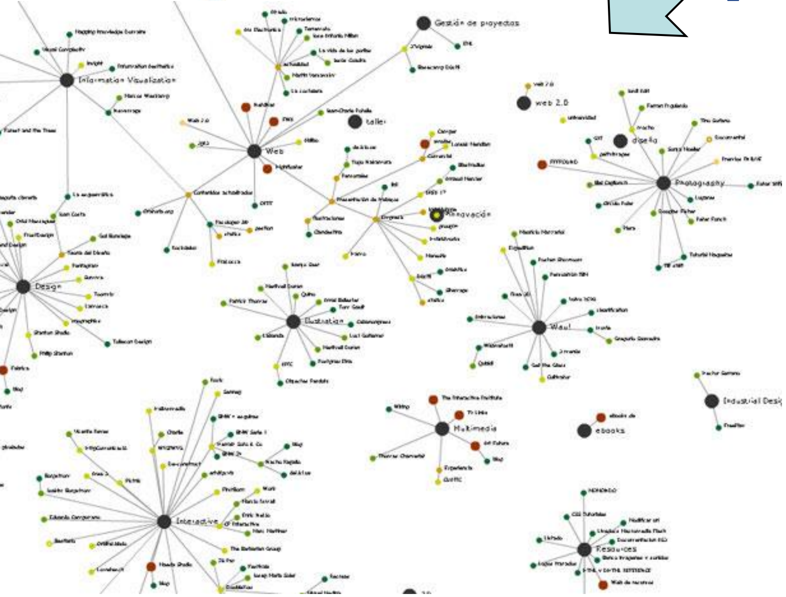
Discrete data elements
Just-in-time model binding

CIMI Archetypes

- Demographics
- Observations
- Medications
- Procedures
- …

Data Marts

- Registries
- Protocols
- Studies
- Cohorts
- …



VS.

What does any of this mean for Hopkins?

- Promote principle of “clinical data as a first-rank resource”
- Pursue the implications
  - Data governance, security, curation
  - Informatics critical mass, development, application
- Propose extension beyond Hopkins to community
  - Population health

The “data lake”

Establish repository of clinical data

- Invoke NOSQL accumulation of data elements
- Leverage Accumulo/Topaz (Armstrong Institute)
- Leverage EPIC data warehouse
- Incorporate departmental data sources
  - Include original content and metadata
  - Capture waveforms and raw signals
  - Integrate claims data
- Incrementally normalize to canonical form

Maryland as a Population Laboratory

Many unique features

- CMS waiver among hospitals
- Successful emergence of CRISP
  - Framework for collaboration
- Goal of federated data repositories
  - Build on “data lake” technologies
  - Participants have secure silos

Where is this going?

- Outstanding opportunity, talent, material
- Hopkins must embrace clinical data
- Collaborate with University resources
- Collaborate with community partners
- Enable unprecedented discovery
- Rewind Chris’s story

Normalized data → Analyses → Evidence → Practice