A Paradigm Shift in Cancer Informatics

Leading the Pack to Going with the Information Flow

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Christopher G. Chute, M.D., Dr.P.H.

Professor and Chair, Medical Informatics

Mayo Clinic

Informatics
Long Tradition of Leadership and Innovation

- Standard Representation of Cancer Patient Data – ACS 1920s
- Formalization of Histopathologies
  - Manual of Tumor Nomenclature and Coding (MONTAC), 1951
- Formalization of Extent of Disease

Health Care *Is* An Information Intensive Industry

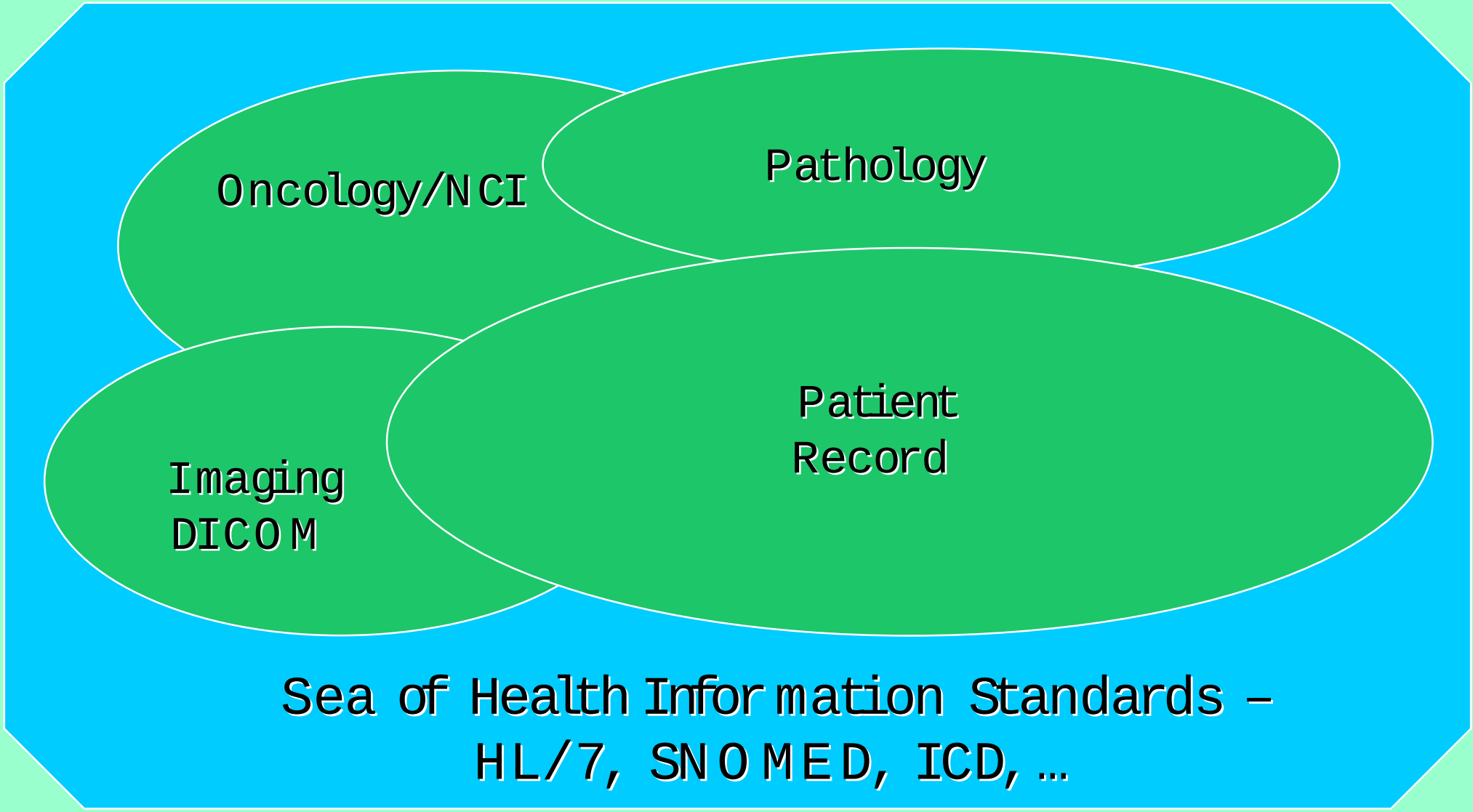
- Control of Health Care Costs ...
- Improved Quality of Care ...
- Improved Health Outcomes ...
- Appropriate Use of Health Technology...
- Compassionate Resource Management...

☞ ***... depend upon information***

Cancer Information is *No* Exception

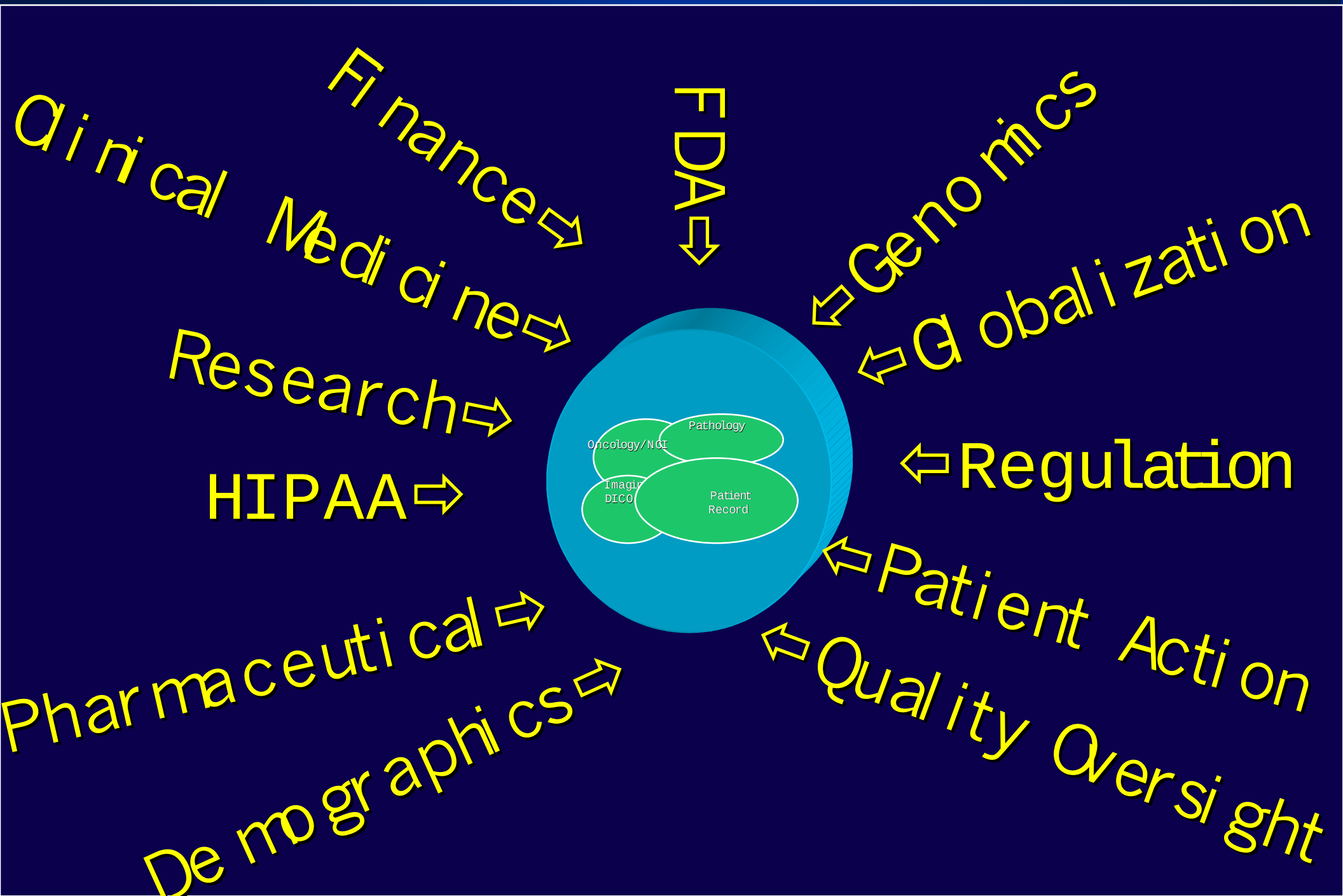
- Cancer Patient Data is a subset of a Patient Record (electronic or otherwise)
- Cancer Information Spans the Spectrum of Scientific Understanding
  - From Molecule to Society
  - Genomics to Social Work

Cancer Patient Data: Island Continents in Sea of Health Standards



Ocean of Information Standards – TCP, XML, Corba…

Influences on Cancer World



Premise: Cancer Information Shares General Structure of EMR Standards

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- Content (Vocabulary)
  - Consistent and Comparable Ways to Represent Concepts and Relations
- Structure (Models)
  - Consistently and Predictably Organized
- Messaging (Interoperability)

Information Beyond Practice Secondary Re-use as Primary A Interest

- Data Collected for Clinical Care Forms the Basis for Patient Experience Repositories
- The Importance of a Well Characterized, High Quality Patient Experience Repository May Exceed the Value of the Primary Information Many Fold

Aggregate Data Uses Core of Improvement and Excellence

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Patient Data Repository

- Disease Natural History
- Treatment Response
- Outcomes Research
- Best Practice Modeling
- **Efficient and Effective Care Delivery**

Prospective Clinical Trials vs Patient Data Repository

- Still Require Consistent and Comparable Information
- Most Reliable if Captured *in and for* the Process of Care
  - Requires Terminology Services Integrated into Record System
- Efficiencies from *Non* Boutique Approach

Terminology as Crucial Requirement

Without Terminology Standards...

- Health Data is *non*-comparable
- Health Systems *cannot* Interchange Data
- Secondary Uses (Research, Efficiency) are *not* possible
- Linkage to Decision Support Resources *not* Possible

Continuum from Nomenclature to Classification

- Patient Data is Highly Detailed
  - Modifiers: Anatomy, Stage, Severity, Extent
  - Qualifiers: Probability, Temporal Status
- Aggregate Uses Require Categorization
  - Granularity of Classifiers

Familiar Points Along Continuum Modern Health Vocabularies

- Nomenclature – Highly Detailed Descriptions (SNOMED)
- Classification – Organized Aggregation of Descriptions into a Rubric (ICDs)
- Groupings – High Level Categories of Rubrics (DRGs)

Disease Severity .:. Co-Morbidity What Cancer can teach Hospital IS/IT

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- Should be Directly Measurable or Categorized
  - Cancer Stage
  - Systolic Ejection Fraction in CHF
- *Not* a Function of Co-morbidity
  - If you have this other disease, the first one must be really bad….

HCFA Mortality Model Medicare Hospital Information

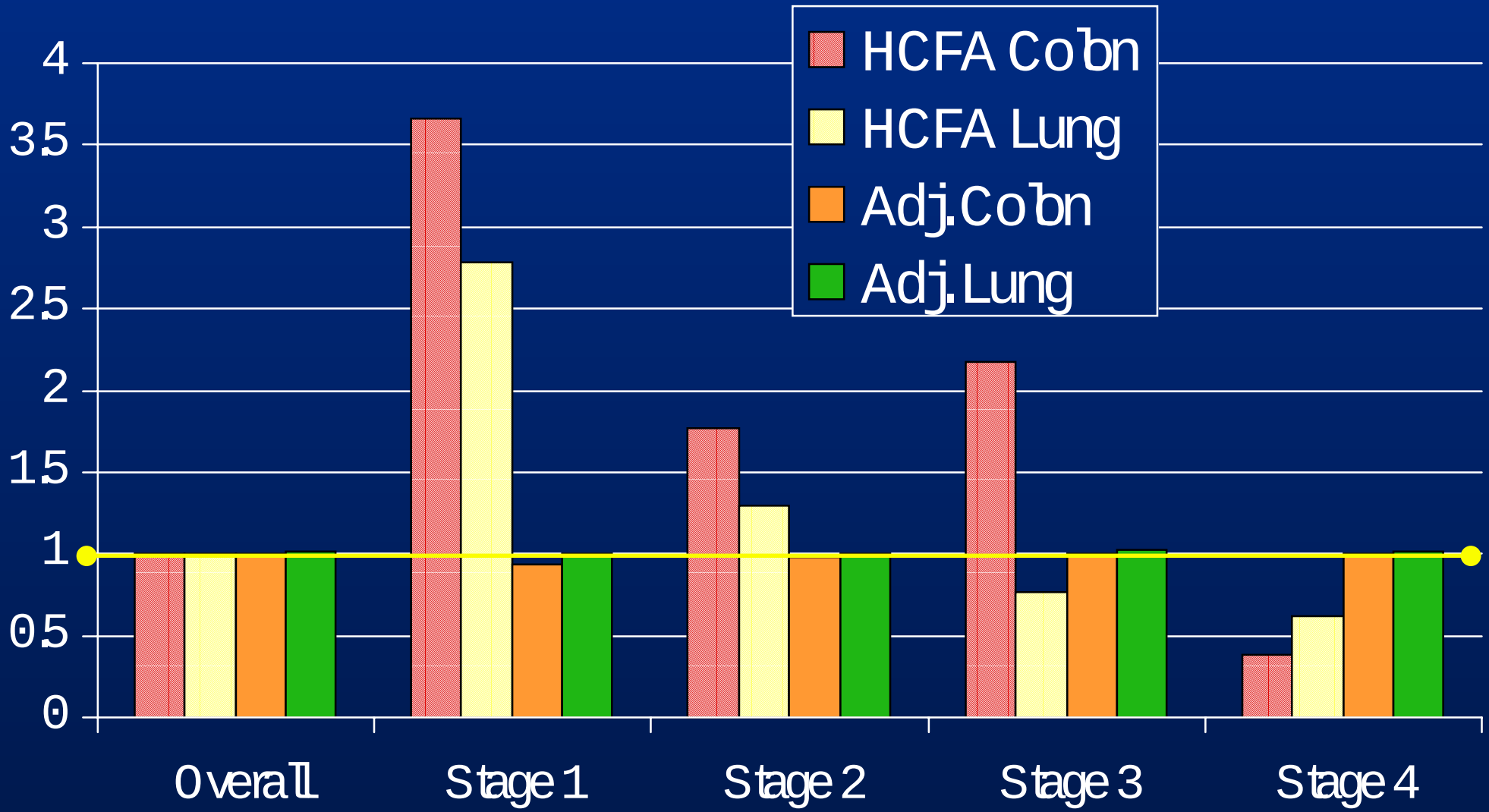
- Formerly Used to Benchmark Hospitals
- Invokes Co-morbidity From Admin. Data
- Approximated on Mayo Cancer Cohorts
- Computed +/- Extent of Disease
- Distorted Survival Prediction

Cohort Mayo Cancer Patients

- 3,000 Cancer Registry Patients
- Three year period
- Followed for Survival 180 days
- Data resources
  - Cancer Registry Detail (high resolution data)
  - Medicare Discharge Summary (UB82)

HCFA Mortality Model

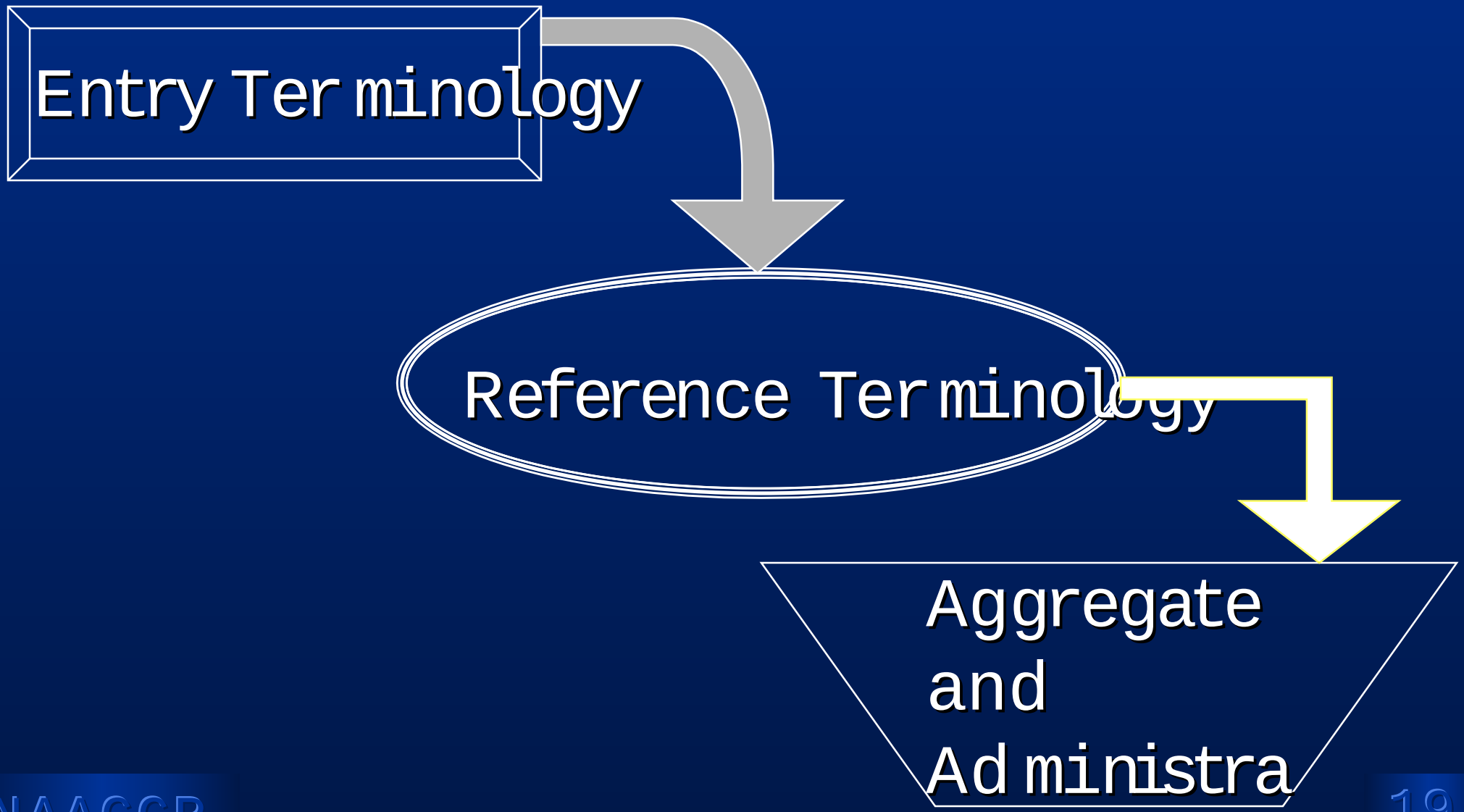
Cancer Survival at 180 Days: Ratio Obs./Pred.



Grand Unified Model of Terminology?

- Smooth Transition from Nomenclature to Classification
- Explicit Data Representation and Structure
- Distinguish Entry Terms and Pre-coordinated Convenience Phrases
- Accommodate Rules and Logic

Terminology Systems Relationships Engineering Map



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Content vs. Structure Contest or Synergy? Computer Equivalent?

- Family History of Breast Cancer
- Family History of Heart Disease
- Family History of Stroke

vs.

Family History

Breast Cancer
Heart Disease
Stroke

Data Model Standards
The HL7 Reference Information Model

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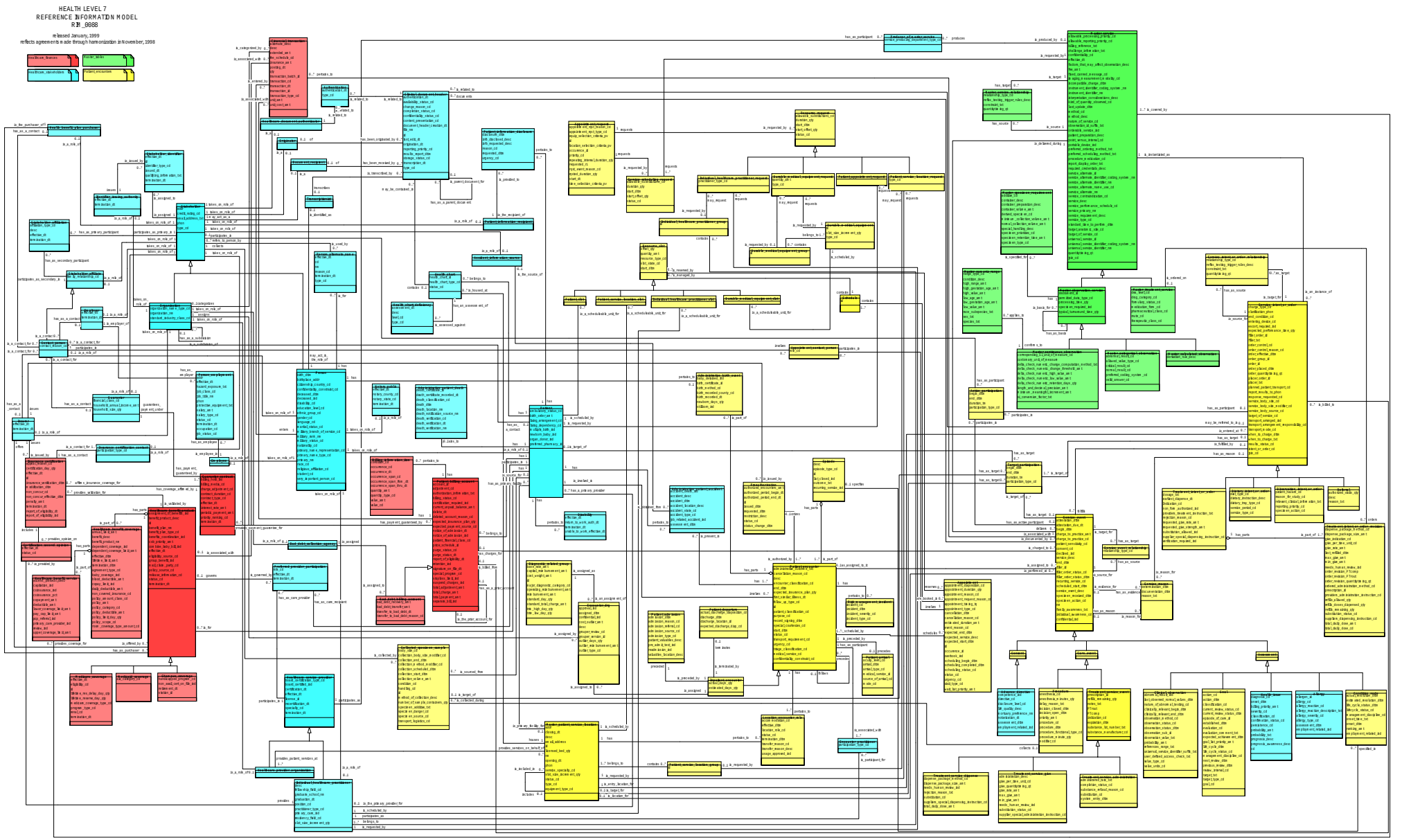

Relevance for Cancer Information?

- Simple Data Model Examples
  - ACS or SEER Tumor Registries - Database
  - Clinical Protocol Data – Abstracts and Fields
- Cancer Data Typically Emerges from Clinical Environment
  - Transforming EMR Data to Cancer

Implication for Cancer Information Structure and Model

- Transformations and abstractions are Wasteful
- Goal of Harvesting Clinical Data for Decision Support, Protocol, and Research
- Comparable Terminology Necessary but *not Sufficient*
- Clinical and Cancer Information Model must be Shared

Where Does One Start *or* On the Invention of Wheels

- Build a Cancer Specific Data Model and Variable Set
- Build an Colon Cancer Specific…
- Build a Dukes B2 Colon Cancer Specific…
- Build a Dukes B2, Hepatic Flexure of the ..
- *Or* Leverage Existing Data

How To Leverage What Is, At Least Among Clinical Standards

- Recognize a HUGE Consolidation in the Data Standards' World
  - HL7, SNOMED, ISO TC215
- Assume Your Needs are *Not* Met
- Participate in Standards Process (show up)
  - Ensure Needs and Requirements are Accommodated
  - Increase Likelihood of

Whither Cancer Registries? Paradigm Shift: 1 (of 2)

- Persist as Crucial Aggregation "Views" of Cancer Data
- Evolve from Operations Orientation to Political Consolidation and Data Collection
  - Persuade Constituencies to Harvest and Transport Cancer

Future Concerns: The New Medicine Organizationally Play Well or Die

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- Genomics and Bioinformatics
  - Clinical Correlation
  - Disease Natural History by SNP
  - Treatment Selection and Outcome
- Repositories of Patient Experience
  - Drive Delivery of Efficient and Effective Care
- Require Structured, Detailed

Status and Future of Cancer Information Standards

- Relationships with Existing Cancer Information Standards and Conventions
  - Cancer Registries; SEER; CDC
  - Clinical Trials; CTEP; PDQ; NCI CDE's
- Potential for Strong Synergies with Cancer and Genomics

What can Cancer Community Uniquely Contribute?

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- Dearth of Content (Naming) Standards in Genomics or Proteomics
- We Already Confront Idiosyncratic Naming Conventions, Clinical Confusion
  - GenBank Identifiers as Least Common Denom

Next Grand Informatics Challenge: Linkage Bioinformatics to Medical Informatics

- Leverage Techniques Forged for Consensus Clinical Informatics Standards
- Apply These to Create Consistent and Comparable Genomic Descriptions
- Assure that Standards Communities Broaden Scope to

What would Motivate Linkage of Bioinformatics with Clinical Informatics?

- Understanding Disease Natural History
  - Function of Genomic Differentia
- Further Elucidation of Etiology and Risk
- Informed Assessment of Treatment Effects
  - Pharmacogenomics

Long Range Planning Panel Recommendation 1

- Formulate the role of the National Cancer Institute in the national standards

Long Range Planning Panel Recommendation 1a

- Create a standing review panel for NCI information standards.
  - Coordinate Standards Input
  - Peer Review of Recommendations
  - Stakeholder consensus
  - Liaise with Federal Agencies

Long Range Planning Panel Recommendation 1b

- Ensure that NCI efforts to develop or promote oncology-specific information standards are tightly coordinated with the broader health information standards community.

Long Range Planning Panel Recommendation 1c

- Include in the approach dynamic processes for content management and configuration control for the entire lifecycle of standards.

Patient Data Repository
Obstacle

Confidentiality

Cancer Information Security Standards

- *Sine qua non* Clinical Research
- Basis for Public Confidence
- Obligation to Society

- Emergent Technical Standards
  - Adopted for Health Care Applications

Conclusion

- Clinical Information Standards are Maturing and Have Become Useful
- Cancer Practice and Research will Benefit from Comparable and Consistent Data
- Spectrum of Useful/Required Standards Ranges from Genomics to Social Work
- Cancer Community Should not be

Christopher G. Chute MD, DrPH
Professor and Chair, Medical Informatics
Mayo Clinic
Rochester, MN 55905
Ph: 507 284 5541
Fx: 507 284 0360
Em: chute@Mayo.edu