A Paradigm Shift in Cancer Informatics

Leading the Pack to Going with the Information Flow

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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

Ultimately: Patient Data
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

- Sea of Health Information Standards – HL7, SNOMED, ICD, ...
- Ocean of Information Standards – TCP, XML, Corba...
Influences on Cancer World

Finance
Clinical Medicine
Research
HIPAA
Pharmaceutical
Demographics

FD
Genomics
Globalization
Regulation
Patient Action
Quality Oversight
Premise: Cancer Information Shares General Structure of EMR Standards

- **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

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 Nomencalature 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)

[Diagram showing the continuum of nomenclature, classification, and groupings]
Disease Severity: Co-Morbidity

What Cancer can teach Hospital IS/IT

- 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.

- HCFA Colon
- HCFA Lung
- Adj Colon
- Adj Lung

Graph showing survival ratios for different stages.
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
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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
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 Data
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 Subset of Clinical Data
Future Concerns: The New Medicine
Organizationally Play Well or Die

- 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?

- 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 Differentiation
- Further Elucidation of Etiology and Risk
- Informed Assessment of Treatment Effects
  - Pharmacogenomics
Formulate the role of the National Cancer Institute in the national standards
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.
Include in the approach dynamic processes for content management and configuration control for the entire lifecycle of standards.
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
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