# NCVHS - Terminologies for Healthcare Reporting

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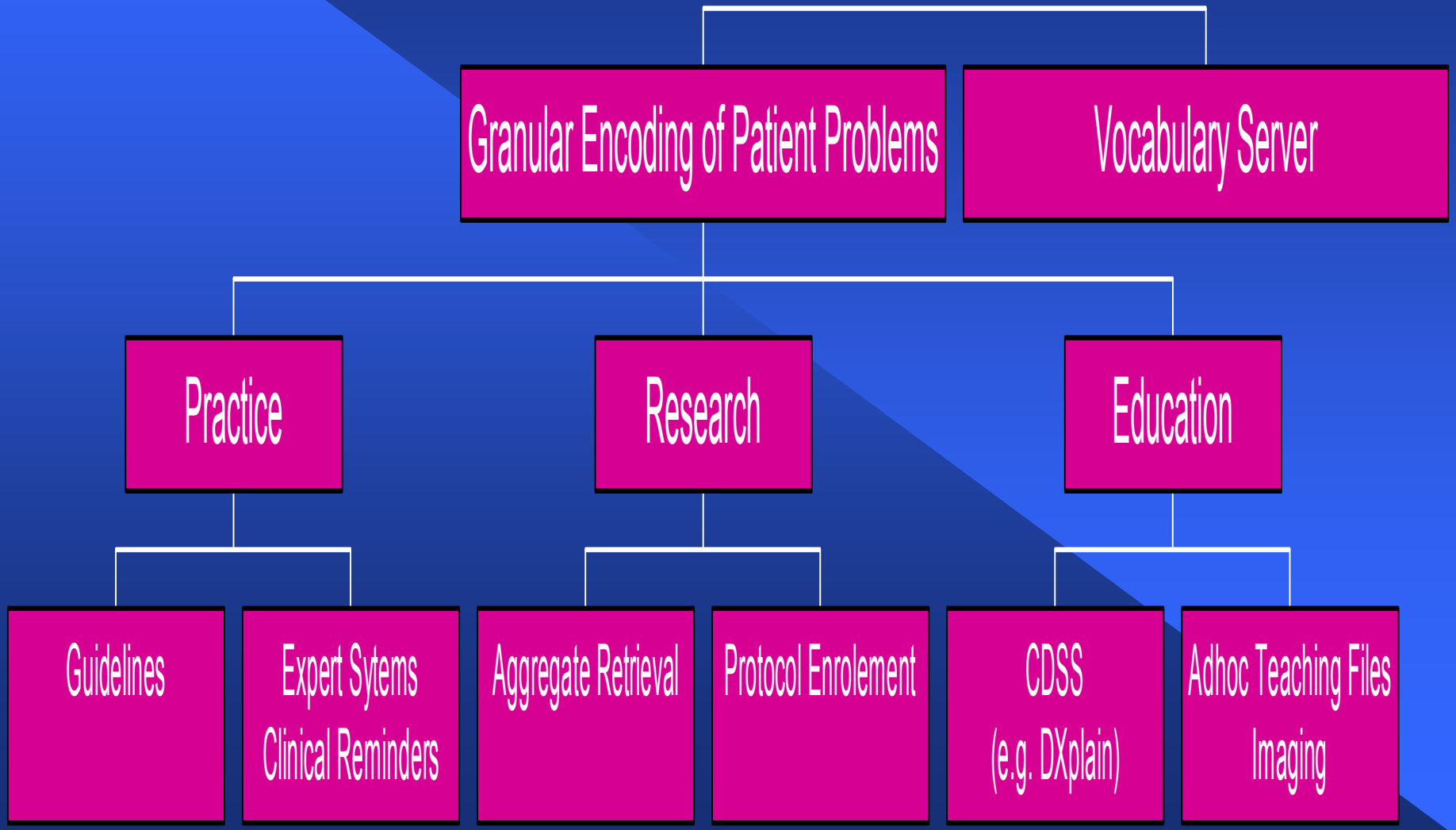
"In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison."

- *Florence Nightingale, 1893*

# Granular Encoding



# Categorizations of Terminologies

- By Level of Detail
  - Aggregation for Billing Group or Category (e.g. DRGs)
  - Classification for Administrative Morbidity and Mortality coding (e.g. ICD)
  - Detailed Reference Terminology for specifying the exact clinical details of a Healthcare event or service (Within a Scope and Purpose).
- Compositional Systems (To be or Not to be? That is the *Question.*)
  - Expressivity vs. Decreased Complexity

# Other Terminologies to Consider

- Foundation Model of Anatomy (University of Washington)
- Dermatology Lexicon (NIAMS / NIH – University of Rochester)
- Patient Safety Coding System (Currently be contracted for by AHRQ)
- Gene Ontology (Gene Ontology Consortium)

# Controlled Health Vocabularies – Vocabulary Structure and High-Level Quality Indicators (ASTM E2087), (ISO-TS17117) So What?

- Clinical Terminologies are becoming robust enough for Clinical Use
- There are many competing philosophies
- Commonly there is a cost for purchase of these Vocabularies
- Always, there is a cost to the use of these Terminologies
- Quality Directly effects their Usefulness

# Controlled Health Vocabularies – Vocabulary Structure and High-Level Quality Indicators (ASTM E2087), (ISO-TS17117) Who Cares?

- Terminology Developers
  - Stipulates the features associated with Quality
  - Gives direction for performing High Quality Evaluations
- Terminology Users / Purchasers (Caveat Emptor)
  - Assists Users in Evaluating Terminologies
  - Assists Users in Evaluating the Strength of Evidence that they are presented by Third Parties
- Governments faced with Selecting a Standardized Clinical Terminology

# Controlled Health Vocabularies – Vocabulary Structure and High-Level Quality Indicators (ASTM E2087), (ISO-TS17117)

## What's in it for you?

- More Granular (Better) Understanding of your clinical practice toward improved Clinical Care
- Improved Datasets for Administering the practice of medicine
- Linking Decision Support to the practice at the Point-of-Care (Just-in-time)
- Higher Quality -> Controlled Health Vocabularies

# Implementation Guide

- 1 **General** - Basic characteristics of a terminology influence its utility and appropriateness in clinical applications.
  - **1.1 Concept Orientation 7 – Is the terminology concept oriented? To how many meanings can one identifier correspond? This must be the case.**
    - 1.1.1Non-redundancy – Can concepts be redundantly instantiated within the terminology? This must not be the case.
    - 1.1.2Non-Ambiguity – Can concepts be ambiguous? This must not be the case.
    - 1.1.3Non-Vagueness – Are concept definitions independent of their context? This must be the case.
    - 1.1.4Internal Consistency – Are the relationships used in the terminology applied consistently? This must be the case.

# Implementation Guide

- 1.2 Purpose and Scope – What is the purpose of the terminology? What is the scope of the terminology? Please state these in operational terms (what functions is the terminology intended to serve?).
  - 1.2.1Coverage – What is the intended coverage of the terminology?
  - 1.2.2Comprehensiveness – What is the degree of comprehensiveness (expressed in percent completion) of the terminology within the intended area of coverage? What studies can be referenced to support this assertion (Use the criteria under section #4 for assess the validity and generalizability of the study referenced)?

# Implementation Guide

- 1.3 Mapping – Is the terminology mappable to classifications or other terminologies? If so, which ones? If it is partially mappable to some classifications or other terminologies, to what extent is this true (expressed in percent completion)? Use the criteria under section #4 for assess the validity and generalizability of the study referenced?
- 1.4 Systematic Definitions Are the meanings of each specific concept within the terminology made available for the users? These should be provided.
- 1.5 Formal Definitions– Does your terminology support formal definitions? If so, to what extent (expressed in percent completion) is it fully defined? What studies can be referenced to support this assertion (Use the criteria under section #4 for assess the validity and generalizability of the study referenced)? It is essential that reference terminologies support formal definitions.

# Implementation Guide

- *1.6* Explicitness of Relations – Does your terminology support formal subsumption? To what extent are the hierarchies automatically generated by the description logic (expressed as a percentage of all the concepts contained in the terminology)? This is a desirable characteristic.
- 1.7 Reference Terminologies – Is the terminology intended to be used as a reference terminology?
  - 1.7.1Atomic Reference Terminologies – Is there an explicit mechanism for identifying the atomic portion of the reference terminology? Is it intended that pre-coordinated terms can be used within compositional expressions? This should be a goal of all reference terminologies.
- 1.8 Colloquial Terminologies – Specifically, what is the association between the colloquial terms and the reference terminology? How are these two terminologies maintained so as not to create ambiguous or redundant instantiation of data? This is necessary for all reference terminologies intended to be used clinically.

# Implementation Guide

## 2. Structure of the Terminology Model

2.1 Compositionality Does your terminology support the creation of compositional expressions? How is a compositional expression created? If this is governed by rules please elaborate them. If so, can you identify equivalence between arbitrary compositional expressions? If so, by what method?

2.1.1 Atomic Concept Do you make explicit which of your concepts are atomic?

2.1.2 Composite Concept – A concept composed as an expression made up of atomic concepts linked by semantic relations (such as roles, attributes or links).

*2.1.2.1* Pre-coordinated Concept Does your terminology make explicit which concepts are pre-coordinated? This must be true for all compositional terminologies.

*2.1.2.2* Post-coordinated Concepts Does your terminology support the creation of post-coordinated expressions?

# Implementation Guide

- 2.1.3Types of Atomic and Pre-coordinated Concepts We can classify unique concept representations within a vocabulary into at least three distinct types, Kernel Concepts, Modifiers, and Qualifiers (which contain Status concepts). This separation allows user interfaces to provide more readable and therefore more useful presentations of composite concepts.
  - 2.1.3.1 Kernel Concept – Does your terminology identify separately kernel concepts? This should be identified by compositional terminologies.
  - 2.1.3.2Terms which refine the meaning of a Kernel Concept – Does your terminology identify modifiers and qualifiers within the terminology? If so, how are they used? This should be identified by compositional terminologies.

# Implementation Guide

- 2.2 Normalization of Content – Is the content of the terminology normalized? What studies can be referenced to support this assertion (Use the criteria under section #4 for assess the validity and generalizability of the study referenced)? This must be accomplished for all compositional terminologies.
- *2.3* Normalization of Semantics – Are the semantics of the terminology normalized? What studies can be referenced to support this assertion (Use the criteria under section #4 for assess the validity and generalizability of the study referenced)? For compositional expressions, is it possible to represent the same concept with different semantics? This must be accomplished for all compositional terminologies.

# Example of Semantic Normalization

- 2 Structure of the Terminology Model
  - 2.4 Normalization of Semantics "Laparoscopic Cholecystectomy"
    - 2.4.1 "Surgical Procedure: Excision"
    - {Has Site Gallbladder},{Has Method Endoscopic}
    - 2.4.2 "Surgical Procedure: Excision"
    - {Has Site Gallbladder},{Uses Devise Endoscope}

# Implementation Guide

- 2.4 Multiple Hierarchies – Are multiple hierarchies supported? Are they present within the current version of the terminology?
  - 2.4.1 Consistency of View – Is a consistency of views into the terminology maintained? This must be the case for terminologies that support multiple hierarchies.
- 2.5 Explicit Uncertainty – Does your terminology support the input of explicit uncertainty and incomplete syndromes? This should be a feature of compositional terminologies.
- 2.6 Representational Form – Does the Representational form of the concept identifier place restrictions on the terminology? If so, what are the restrictions? This must not be the case.

# Implementation Guide

- 3 **Maintenance** - Technical choices can impact the capacity of a terminology to evolve, change, and remain usable over time.
  - 3.1 Context Free Identifiers – Does the terminology support context free identifiers? This must be the case.
  - 3.2 Persistence of Identifiers – Are codes ever reused for different concepts? If so, when can this occur? This must be the case.
  - 3.3 Version Control – Are your codes tied explicitly to the version of the terminology? This must be the case.
    - 3.3.1 Editorial Information - When the terminology is revised, do you record the date of the update and the source or authority of the information leading to the update? This must be the case.
    - 3.3.2 Obsolete Marking – Have you included obsolete marking in your entries? This must be the case.

# Implementation Guide

- 3.4 Recognize Redundancy – Does your terminology recognize redundancy? If so, how is this accomplished? This must be the case.
- 3.5 Language Independence – Is your terminology presently multilingual? If not, does it have the capacity to become multilingual? If so, please explain. This should be the case.
- 3.6 Responsiveness – What is the frequency of updates to the terminology? Is it less than or equal to 12 weeks? This should be the case.

# Implementation Guide

- 4 **Evaluation** – As we seek to understand quality in the controlled vocabularies that we create or use, we need standard criteria for the evaluation of these systems. All evaluations must reflect and specifically identify the purpose and scope of the vocabulary being evaluated. These criteria stipulate the methods for evaluating studies, which make claims regarding controlled terminologies. These criteria are also useful as a guide to individuals or organizations who wish to perform valid and useful evaluations of one or more controlled health terminologies.

# Implementation Guide

- *4.1* Purpose and Scope Important dimensions along which scope should be defined include:
  - *4.1.1*Clinical area of use, disease area of patients and expected profession of users – Within what parts of healthcare is it intended to be used and by whom?
  - *4.1.2*Primary use – What is the primary use of the terminology? *Examples Include: reporting for remuneration, management planning, epidemiological research, indexing for bibliographic, Web-based retrieval, recording of clinical details for direct patient care, use for decision support, linking of record to decision support, etc.*

# Implementation Guide

- *4.1.1*Persistence and extent of use – Is the intent of the terminology to persist and evolve? If intended to be persistent, means of updating or change management, etc?
- *4.1.2*Degree of automatic inferencing intended – Is the terminology intended to support automated classification? Is it is intended that validation on input be possible and within what limits? Whether post-coordinated expressions are to be accepted and if so what can be inferred about them and what restrictions must be placed on them?
- *4.1.3*Transformations (mappings) to other vocabularies – What transformations / mappings are supported for what intended purpose – *e.g. transformation for purposes of bibliographic retrieval may require less precision than transformation for clinical usage?* What is the sensitivity and specificity of the mappings?

# Implementation Guide

- *4.1.6*User/Developer extensibility – Is it intended that the vocabulary be extended by users or application developers? If so, within what limits? If not, what mechanisms are available for meeting new needs as they arise?
- *4.1.7*Are Natural language input or output supported? For analysis or input? To what level of accuracy?
- *4.1.8*What other functions are intended? – *e.g. linkage to specific decision support systems, linkage to post-marketing surveillance, etc.*
- 4.1.9Current status – To what extent is the system intended to be 'finished' or work in progress? If different components of the terminology are at different stages of completion how is this indicated?

# Implementation Guide

- 4.2 Measures of Quality - Terminological Tools
  - 4.2.1 Interconnectivity (Mapping)
    - 4.2.1.1 To what extent is the vocabulary mappable to other coding systems or reference terminologies?
    - 4.2.1.2 To what extent can the vocabulary accommodate local terminological enhancements?
    - 4.2.1.3 Can the vocabulary server respond to queries sent over a network (LAN, WAN)?

# Implementation Guide

- 4.2.2Precision and Recall
  - 4.2.2.1What are the vocabulary's precision and recall for mapping Diagnoses, Procedures, Manifestations, Anatomy, Organisms, etc., against an established and nationally recognized standard query test set, using a standard well-principled method? This should be evaluated only within the intended scope and purpose of the vocabulary system.
  - 4.2.2.2Is a standard search engine used in the mapping process?

# Implementation Guide

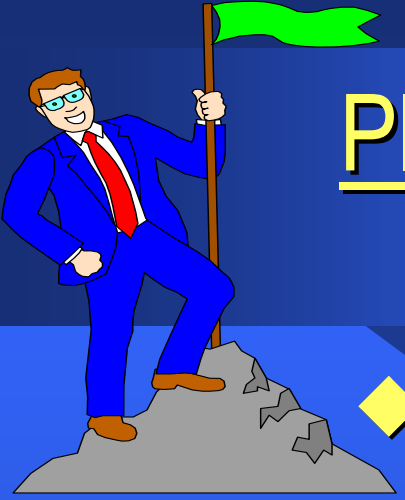
- 4.2.3Usability
  - 4.2.3.1Has the usability of the vocabulary been verified?
  - 4.2.3.2How have interface considerations been separated from vocabulary evaluation?
  - *4.2.3.3*Support for user interfaces. Has an effective user interface been built? Has the vocabulary been shown to have an effective user interface for its intended use? If not, what are the questions or issues outstanding? Evidence for speed of entry, accuracy, comprehensiveness in practice etc. with different approaches? If not, is there a proof of concept?
  - 4.2.3.4Support for computer interfaces and system implementers. Is there a demonstrated proof of concept implementation in software? Can it be shown to be usable for the primary purpose indicated? Have there been failed implementations?

# Implementation Guide

- **4.2.4** Feasibility
  - **4.2.4.1** If it is intended for use in an Electronic Patient Record (EPR), what are the options for information storage? Has feasibility been demonstrated?

# Implementation Guide

- 4.3 Measures of Quality: Study Design
  - 1) Validity and Generalizability (Applicability)
    - Relevance
    - Gold Standard
    - Blinding
    - Randomization
    - Test Location
    - Sample Size
  - 2) Personnel



# Placing a Stake in the Ground

*by Don Berwick, MD*

- Developers and Evaluators need a comparable mechanism for Selecting Clinical Terminologies and doing Future Evaluations.
- Let's place that stake in the ground where we think it Really Ought To Be!!!

# ASTM E2087 & ISO TC 215 Quality Standard for Terminology:

- So What?
  - While Good Terminologies can be Useful, Bad Terminologies can cause Harm
- Who Cares?
  - Terminology Developers, Consumers, Clinicians and Governments
- What's in it for you?
  - Higher Quality Terminologies
  - The promise of Improved Clinical Care through a better understanding of our practice and increased availability of Decision Support at the Point-of-Care

# ASTM E2087 & ISO TC 215 Quality Standard for Terminology:

- Consensus on Quality
  - All Terminology Developers
  - 19/22 Countries Participating in ISO TC 215
  - ANSI Standard (ASTM E2087) in USA
  - HL7 Criteria for Quality for use of Controlled Vocabularies by their Technical Committees
  - Currently a Technical Specification in ISO TC 215
  - Used by the NIH as Quality Criteria for selection of a Drug Terminology (Kathryn Lesh from the Office of the Director)

| General Quality Metrics | MedDRA | MeSH | SNOmed | nhs (read) | icd | umls |
|---|---|---|---|---|---|---|
| Concept orientation: Non-redundant | | | | | | |
| Concept orientation: non-ambiguous | | | | | | |
| Concept orientation: Non-vague | | | | | | |
| Coverage | | | | | | |
| Comprehensiveness | | | | | | |
| Allowable mappings | | | | | | |
| Systematic definitions | | | | | | |
| Formal definitions | | | | | | |
| Explicitness of relations | | | | | | |

| evaluation of the vocabulary's structure | meddra | mesh | snomed | nhs | icd | umls |
|---|---|---|---|---|---|---|
| Compositional or not: atomic terms | | | | | | |
| Compositional or not: pre-coordinated terms | | | | | | |
| Compositional or not: post-coordinated terms | | | | | | |
| Compositional or not: kernel concepts | | | | | | |
| Compositional or not: modifiers | | | | | | |
| Compositional or not: qualifiers | | | | | | |
| Normalization: content | | | | | | |
| Normalization: semantics | | | | | | |
| Multiple hierarchies | | | | | | |
| Multiple hierarchies: consistency of view | | | | | | |
| Explicit uncertainty | | | | | | |

| Maintainability | meddra | mesh | snomed | nhs | icd | umls |
|---|---|---|---|---|---|---|
| Context free identifiers | | | | | | |
| Persistence of identifiers | | | | | | |
| Version control | | | | | | |
| Version control: editorial information | | | | | | |
| Version control: editorial information: date of entry retained | | | | | | |
| Version control: editorial information<br>Date of update retained | | | | | | |
| Version control: editorial information<br>Old representations available | | | | | | |
| Version control: obsolete marking | | | | | | |
| Recognize redundancy | | | | | | |
| Language independence | | | | | | |
| Responsiveness of update/change | | | | | | |

| Formal evaluation/comparison | meddra | mesh | snomed | nhs | icd | umls |
|---|---|---|---|---|---|---|
| Terminology: precision | | | | | | |
| Terminology: recall | | | | | | |
| Terminology: usability | | | | | | |
| Terminology: positive and negative predictive value of a correct retrieval | | | | | | |
| Terminology: accuracy of mappings to other coding schemes | | | | | | |
| Terminology: validation of heuristics | | | | | | |
| Terminology: normalization of content | | | | | | |
| Terminology: normalization of semantics | | | | | | |
| Studies: what was the gold standard? | | | | | | |
| Studies: was the test set appropriate to the purpose and scope? | | | | | | |
| Studies: was the sample size adequate to form the conclusions stated? | | | | | | |
| Studies: was the data set adequate to form the conclusions stated? | | | | | | |
| Studies: was the number of reviewers (if human verification was employed) adequate to form the conclusions stated? | | | | | | |
| Studies: was the study blinded? | | | | | | |
| Studies: was the study randomized? | | | | | | |
| Studies: was the analysis of the data performed appropriately? | | | | | | |
| Studies: was the study done independently from the terminology developer? | | | | | | |
| Studies: did the terminology developer sponsor the study? | | | | | | |