Networking and Health Information Exchange

Unit 4d

Basic Health Data Standards

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Unit 4d Objectives

- Understand data elements; attributes of data elements

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Why data elements?

- The level at which data is created and collected
  - Level that is necessary to define clinical models and input for clinical decision making
  - Level at which data elements can be precisely, uniquely and unambiguously defined that is independent of use, location and circumstance.
- Simplifies achieving semantic interoperability
- Essential for computer understandability
Data elements and terminology

- What is a data element and what is a terminology?
- Is diagnosis a data element or a terminology?
- Any and every concept is a data element

Data elements

- Each data element assigned a unique code for identification purposes.
- Each data element will be derived to a level of precision to prevent any ambiguity in its meaning and use.
- If uniform agreement cannot be reached for an element, an element will be defined for each agreement with precise definitions to distinguish. Experience in use might ultimately resolve these disagreements.

Data element set

- Defines at the lowest level the structured components that are contained and used in health care.
- If all data is derived from this master data element set, data can be shared and understood independent of the interchange mechanism.
- Can be harmonized across clinical domains.
- Permits sites to define the data they collect.
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Master data element set

• Enables sites to define what data elements are collected and stored as part of the EHR.
• From this master, minimum data sets may be derived for various purposes, for example, a minimum data set defining decision support inputs, reporting quality measures or to a clinical data registry.
• Becomes the basis for interoperability in the interchange of data.

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Master data element set

• The MDE set will include categorical terms from high to lower levels. The level of defining these levels will be a development issue. It is most likely that these will be hierarchical.
• Class examples include:
  – Demographic
  – Studies
  – Therapies
  – Problems
  – Physical Examination

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Other uses

• It is likely that most data exchanges between various sites of care will be in a query response mode. A site’s database of the data elements collected with make it much easier to define what is available and what is desired.
• Query profiles can be defined from the site’s data element set.
• Permits local, dynamic classification sets for various purposes, including medical specialties.
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Attributes
- Unique code
- Short name or acronym
- Long name
- Synonyms
- Definition
- Use and purpose, including context
- Category
- Units
- Data type
- Value set
- Mood (state)
- RIM Class
- Linkages to representation sets

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List of attributes (1)
- Code
  - numeric without meaning
  - OID hierarchically assigned
- Name
  - As used in clinical setting
  - Preferred
  - Short name or display name
- Definition
  - Textual
  - Structured

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List of attributes (2)
- Data type
  - Chosen from ISO/HL7/CEN standard
  - Simple or complex
- Units
  - Scientific; ISO
- Value set
  - A set of permissible values
  - Single or multiple
- Synonyms
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List of attributes (3)

- Relationship to other data elements
  - Hierarchical relationships
  - Bidirectional (parent, children)
  - Other linkages (equivalent, opposite)
  - Flags: top level; leaf level
- Classifications (Antihistamine, beta blocker)
- Language

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Administrative attributes

- Owner/caretaker/steward/responsible organization
- Submitting organization
- Registration authority
- Status (active/inactive or deprecated)
- Version
- Date

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Potential issues

- Data elements should not be controversial, since they represent a master set, not a required set.
- Categories and groupings of data elements subject to discussion and debate
- Attribute sets subject to discussion and debate
- Tool sets might evolve in functionality provided
- Early user would be essential to define issues, gaps, unforeseen consequences
- Permanent support, including maintenance and distribution must be defined, including funding
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What is ISO/IEC 11179?

- ISO/IEC 11179 Parts 1-6: Information technology – Specification and Standardization of data elements
  - A metamodel for ‘data element’ metadata
  - Standard by which to convey semantic, syntactic and lexical meaning
  - Human and machine understandable
  - Unambiguous

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ISO 11179

- Part 1: Framework for the Specification and Standardization of Data Elements
- Part 2: Classification for Data Elements
- Part 3: Basic Attributes of Data Elements
- Part 4: Rules and Guidelines for the Formulation of Data Definitions
- Part 5: Naming and Identification Principles for Data Elements
- Part 6: Registration of Data Elements
National Cancer Institute

- Cancer Data Standard Repository (caDSR) – registry of common data elements
- Enterprise Vocabulary Service (EVS) – registry of terminology used by CDSR
  - Includes SNOMED CT, MedDRA, VA_NDF-RT, LOINC, HL7, NCI Thesaurus
- Based on ISO 11179
- Tools available
  - CDE Browser, UML Browser, free style search, CDE curation tool, form maker, others
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cabIG

- Vocabularies & Common Data Elements
- Evaluate and integrate systems for vocabulary and ontology content development used throughout cabIG system
- Review process classifies vocabulary into bronze, silver, gold categories with rigid rules for definition
- Stores in caDSR, EVS

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CDISC

- Study Data Tabulation Model – data elements used for clinical trials
- Uses NCI’s caDSR
- Operational Data Model (ODM)

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How we use the result

Master Data Element Set

Value sets

Attributes Include definitions, terms, units, ...
Summary

- Necessary part of semantic interoperability
- Importance of fully defined set of characteristics
- Use 11179 standard as base
- Need global commitment