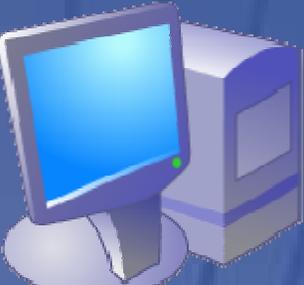


# Clinical Informatics: A Focus on Data Standards and Family History

Thomas G. Savel, MD  
Senior Informatics Advisor & Medical Officer  
NCBDDD, CDC

Pediatric Family History WG  
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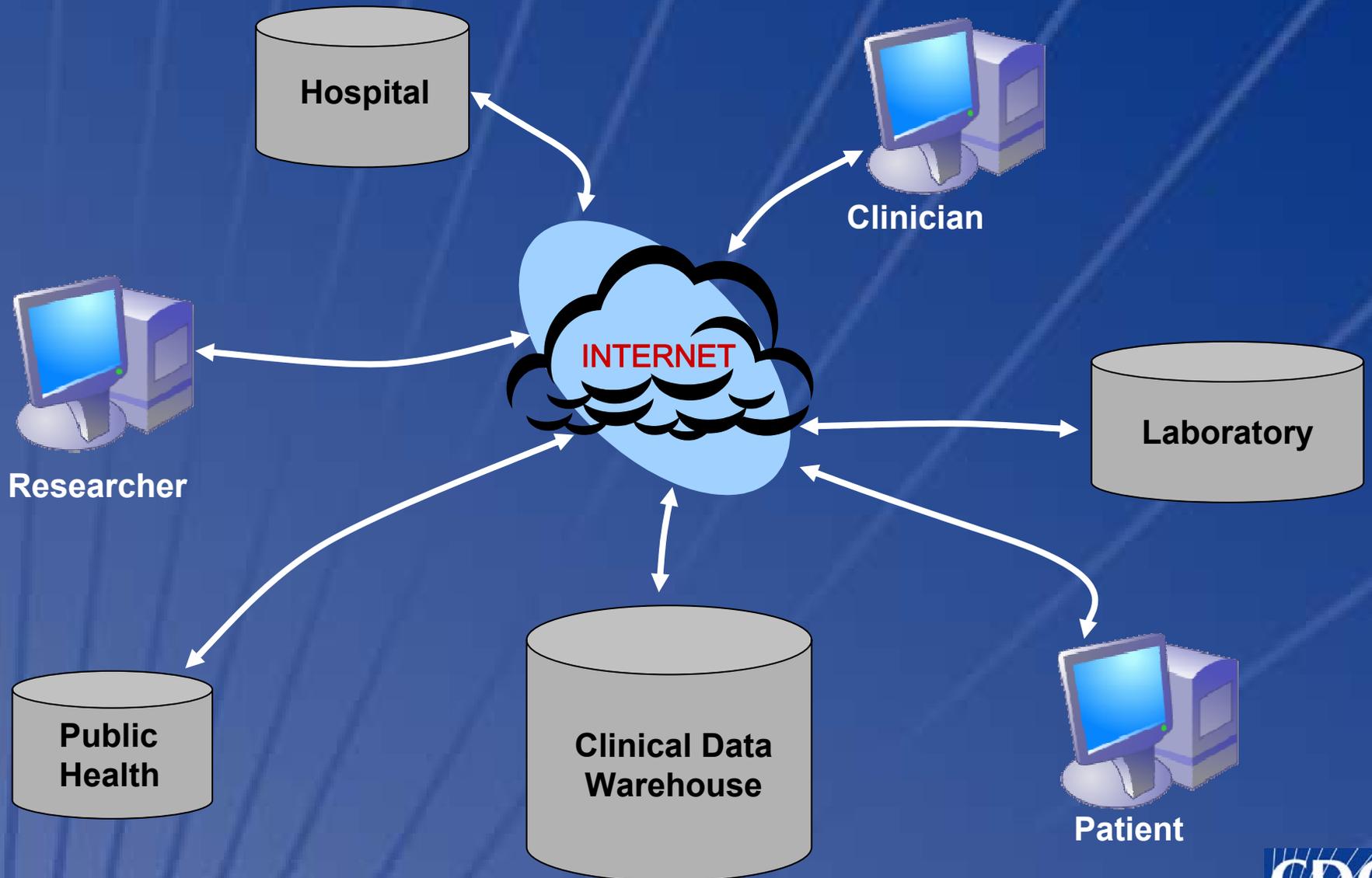


The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.

# Agenda

- **Overview**
  - **The Role of Biomedical / Health Informatics in healthcare**
- **Health Informatics Standards**
  - **The information itself**
  - **How the information is structured**
- **Challenges for the future**
- **Questions...**

# Sharing Healthcare Data: Vision for the Future...



# Overview

**Q: What can facilitate this integration?**

**A: Biomedical / Health Informatics**

# Biomedical & Health Informatics: A Definition...

**“The systematic application of information and computer science and technology to the biological sciences and healthcare domains”**

# Key Requirement: Health Informatics Standards

- What is a “Standard”?
  - A basis for comparison
  - A reference point against which other things can be evaluated
- What can a standard do?
  - Facilitate the sharing of information (e.g., family history data) among disparate systems (e.g., hospitals, clinics, labs, Biobanks, clinical data warehouses)...
- For success, there must be the development & usage of Informatics Standards!

# Health Informatics Standards

- What informatics standards (federal, industry, international), are involved in the storage and transmission of clinical data?
  - For the information itself:
    - Controlled vocabularies / Coding Systems
      - ICD-9, CPT, SNOMED
  - For the transmission of data:
    - Messaging standards
      - HL7 & ASTM

# U.S. Health Informatics Standards

## U.S. (Federal) Initiatives to note:

- Consolidated Health Informatics (CHI) - part of eGov
- National Health Information Infrastructure (NHII)
- Public Health Information Network (PHIN)
- Federal Health Architecture

# Informatics Standards: Controlled Vocabularies

- A “controlled vocabulary”:
  - Coding System
  - National / Internationally Accepted
  - Continually Maintained / Updated
  - Content has unique identifiers

# Informatics Standards: Controlled Vocabularies

- **Examples**
  - **ICD-9/10 - Used for diagnosis / billing**
    - International Classification of Diseases (WHO)
  - **LOINC – For Laboratory Test Orders**
    - Logical Observation Identifiers Names and Codes
  - **SNOMED CT – Detailed Clinical descriptions (an ontology)**
    - Systemized Nomenclature of Medicine – Clinical Terms

# Standards: Controlled Vocabularies

- Why the vocabularies?
- 2 Family History Examples:
  - “Mother with history of heart disease”
    - (cardiovascular disease, coronary artery disease)
      - Different text, same concept...
      - Human vs. Machine readable...

# Standards: Controlled Vocabularies

- Why the vocabularies?
- 2 Family History Examples:
  - “Father diagnosed with diabetes at age of 50”
    - Type I, Type II, etc.?
    - Isn’t this all semantics? YES!
  - “Semantic Interoperability”

# Standards: Controlled Vocabularies: ICD-9 example

## 250 Diabetes mellitus

Excludes: gestational diabetes (648.8)

hyperglycemia NOS (790.6)

neonatal diabetes mellitus (775.1)

Non-clinical diabetes (790.2)

that complicating pregnancy, childbirth, or the puerperium (648.0)

The following fifth-digit sub-classification is for use with category 250:

0- type II [non-insulin dependent type] [NIDDM type] [adult-onset type] or unspecified type, not stated as

uncontrolled

1- type I [insulin dependent type] [IDDM] [juvenile type], not stated as uncontrolled

2- type II [non-insulin dependent type] [NIDDM type] [adult-onset type] or unspecified type, uncontrolled

3- type I [insulin dependent type] [IDDM] [juvenile type], uncontrolled

250.0 Diabetes mellitus without mention of complication

# Informatics Standards: Data Structure

- We've talked about the content...but how about the structure?
  - We have the words, now we need the sentence... [the syntax]
  - “Syntactic Interoperability”

This is my first homepage. **This text is bold**

# Informatics Standards: Data Structure - XML

Review: HTML

- Hypertext Markup Language
  - Structure to view (and transmit) web page information

SAMPLE: “<tag>”

```
<html>
  <head>
    <title>Title of page</title>
  </head>
  <body>
    This is my first homepage. <b>This text is bold</b>
  </body>
</html>
```

# Standards: XML

- **XML**
  - **Extensible Markup Language (Meta-Language)**
    - **Customized to create (build your own “tags”):**
      - **HTML – Hypertext Markup Language**
      - **WSDL – Web Services Description Language**
      - **BSML – Bioinformatic Sequence Markup Language**
      - **CDL – Choreography Description Language**

# Standards: XML

## Review:

- XML is not:

- A database
- A programming language (Java, C, Visual Basic)
- A tool to store data

- It is:

- A tool to structure and transmit data
- Completely Hardware and software independent

# Standards: XML

Sample XML message:

```
<note>  
  <to>Jack</to>  
  <from>Jill</from>  
  <heading>Warning</heading>  
  <body>Watch out for that hill!</body>  
</note>
```

\*A separate document must be created that defines these non-changing terms (in brackets) – not the content in document: An XML SCHEMA

# Healthcare Specific XML Standards: Health Level Seven (HL7)

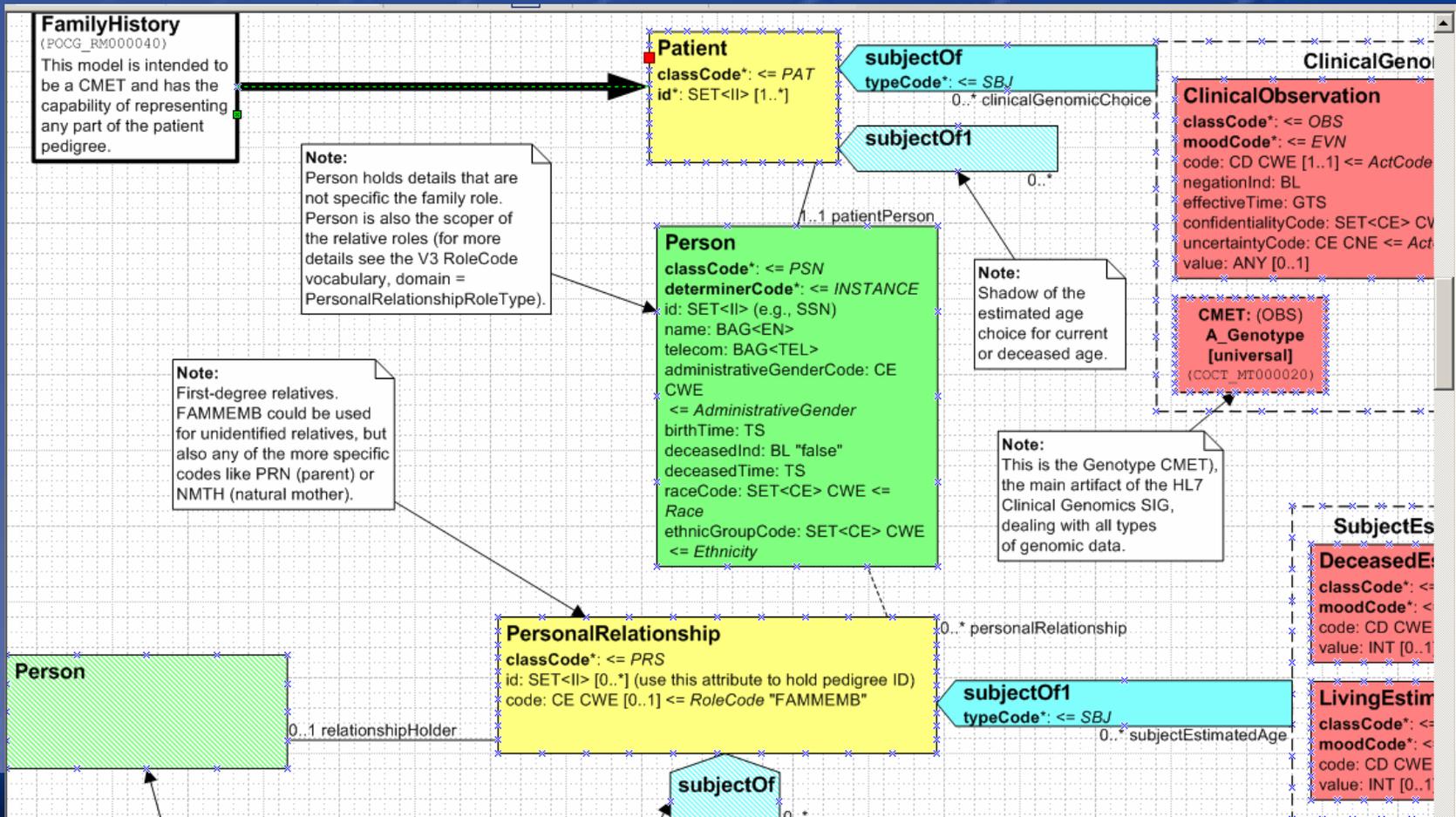
- Founded in 1987
- American National Standards Institute (ANSI) – Accredited Standards Developing Organization (SDO)
- 2,200 health industry members
- Affiliate organization in 18 other countries
- Focus:
  - Electronic interchange of clinical, financial, and administrative information in healthcare organizations

# Healthcare Specific XML Standards: Health Level Seven (HL7)

- Defining how to organize XML to work with Healthcare data (HL7 V3)
  - Lab Data, History Data, Physical Exam data, Radiology Data, Pharmacy Data, Orders Data
- Examples:
  - Clinical Document Architecture (CDA)
  - Family History (Pedigree) Shared Model (next slide...)

# Healthcare Specific XML Standards: Health Level Seven (HL7)

## Partial diagram of the Family History (Pedigree) Shared Model



# Healthcare Specific XML Standards: Health Level Seven (HL7)

```
- <patientPerson>
  <administrativeGenderCode code="F" />
  <birthTime value="1957" />
  <!-- MOTHER -->
- <relationshipHolder>
  <id extension="555.002-SUBJ" />
  <id extension="555.004-NMTH" />
  <id extension="555.005-NFTH" />
  <code code="NMTH" />
- <relationshipHolder>
  <!-- The value 'true' means that this person is dead. Default value is 'false' -->
  <deceasedInd value="true" />
</relationshipHolder>
- <subjectOf>
- <clinicalGenomicChoiceClinicalObservation>
  <!-- Ovarian Cancer observation of the patient's mother -->
  <code code="V1043" codeSystemName="ICD" displayName="HX OF OVARIAN MALIGNANCY" />
  <!-- The following construct represents the estimated age at which the above diagnosis was made -->
- <subject>
  - <estimatedAge>
    <value value="40" />
  </estimatedAge>
</subject>
</clinicalGenomicChoiceClinicalObservation>
</subjectOf>
  <!-- The following construct represents the estimated deceased age (72) -->
- <subjectOf>
  - <clinicalGenomicChoiceEstimatedDeceasedAge>
    <value value="72" />
  </clinicalGenomicChoiceEstimatedDeceasedAge>
</subjectOf>
</relationshipHolder>
  <!-- end of MOTHER data -->
  <!-- FATHER -->
- <relationshipHolder>
  <id extension="555.003-SUBJ" />
  <id extension="555.006-NMTH" />
```

**Sample XML document  
generated from the HL7 v3  
Family History (Pedigree)  
Shared Model**

# Healthcare Specific XML Standards: ASTM

- **American Society for Testing Materials**
  - 30,000 ASTM members
  - Over 100 countries
    - **ASTM Committee E31 on Healthcare Informatics** develops standards related to the architecture, content, storage, security...and communication of information used within healthcare...

# Healthcare Specific XML Standards: ATSM & The Continuity of Care Record (CCR)

Other sponsoring organizations include:

- Massachusetts Medical Society
- HIMSS
- American Academy of Family Physicians
- American Academy of Pediatrics
- American Medical Association
- and others...

# Healthcare Specific XML Standards: ASTM: CCR

- The “Continuity of Care Record” (CCR)
  - Data summary
  - Aggregated data from multiple sources
  - Transmit “snapshot” of patient-between disparate healthcare entities

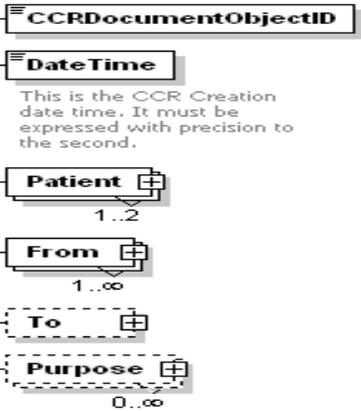
# Healthcare Specific XML Standards: What's in the CCR?

- Insurance
- Advance Directives
- Support
- Functional Status
- Problems
- Family History
- Social History
- Alerts
- Medications
- Medical Equipment
- Immunizations
- Vital Signs
- Results
- Procedures
- Encounters
- Plan of Care
- Healthcare Providers

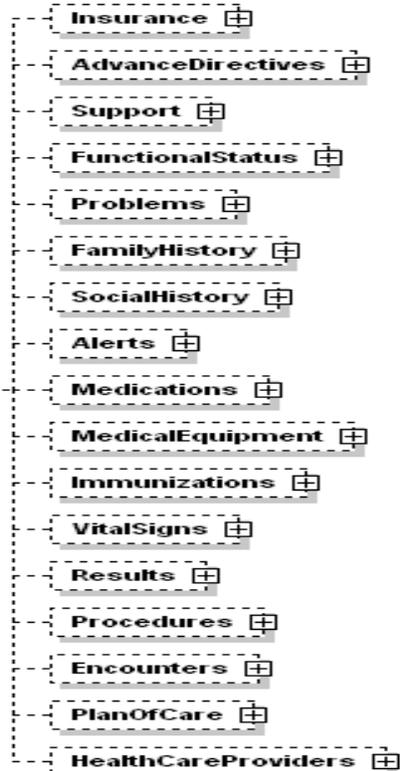
# Healthcare Specific XML Standards: What's in the CCR?

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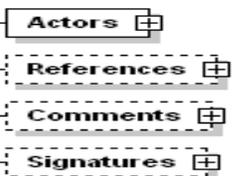
## CCR HEADER



## CCR BODY



## CCR FOOTER

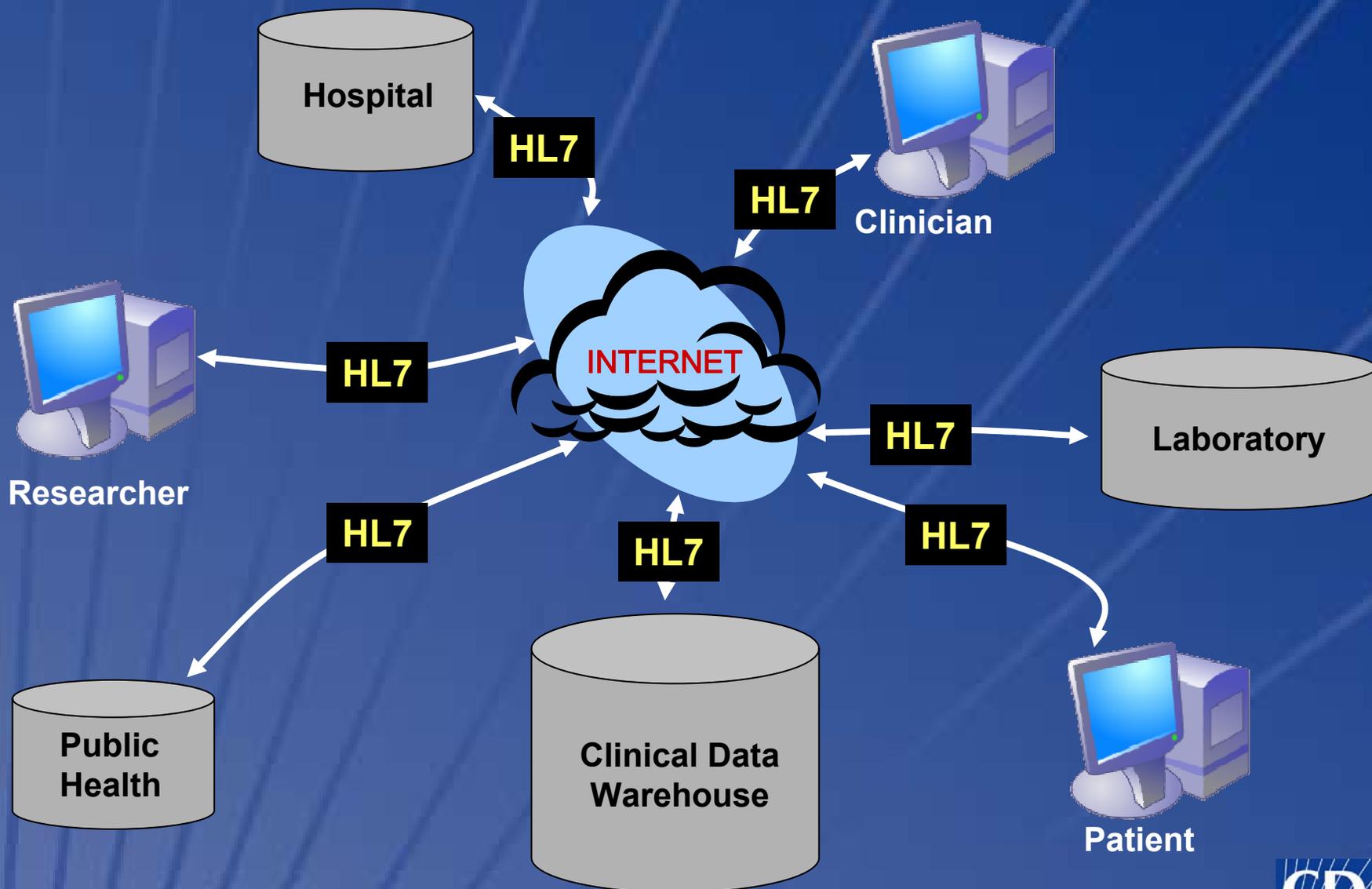


Note: From PPT Presentation on ASTM site  
Author: Claudia Tessier, CAE, RHIA, Co-Chair, ASTM  
E31 CCR Workgroup, Executive Director, MoHCA

# Healthcare Specific XML Standards: HL7 & ASTM

- Memorandum of Understanding is now in place
- 11/2/05 - HL7 to Develop Continuity of Care Record (CCR) Clinical Document Architecture (CDA) Implementation Guide
- Progress....

# Sharing Healthcare Data: Vision for the Future...



# Challenges

- To achieve this **vision for the future:**
  - Awareness of the informatics standards
  - Agreement to use the standards!
- Once foundation in place:
  - Data Sharing ► Information Sharing ► Knowledge Sharing
    - Example...
      - 7 -> HCT 7 -> HCT 7 in an acute GI bleed

**Thank You!**



**Questions?**

[tsavel@cdc.gov](mailto:tsavel@cdc.gov)