

Electronic Data Exchange... Moving Forward

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2004 State of the Union Address

- President Bush addressed the need for computerized health records.
- President Bush stated that most Americans should have electronic medical records within 10 years.

Health Care Technology Advancements

Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)

- SNOMED CT is a dynamic, scientifically validated clinical health care terminology and infrastructure that makes health care knowledge more usable and accessible.

Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)

- SNOMED CT core terminology provides a common language that enables a consistent way of capturing, sharing, and aggregating health data across specialties and sites of care.

Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)

- Applications for SNOMED CT:
 - ◆ Electronic medical records
 - ◆ Medical research studies
 - ◆ Clinical trials
 - ◆ Disease surveillance
 - ◆ Etc.

Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)

- SNOMED CT core content is now available, free of charge, through the National Library of Medicine's (NLM) Unified Medical Language System® (UMLS®) Metathesaurus®

Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)

- For more information about SNOMED CT:
<http://www.snomed.org/snomedct>

Health Level Seven (HL7)

- Develops standards for exchange, management and integration of data that supports clinical patient care and the management, delivery, and evaluation of healthcare services. Specifically, to create flexible, cost effective approaches, standards, guidelines, methodologies, and related services for interoperability between healthcare information services.

HL7

- In 2001, HL7 established an Electronic Health Record (EHR) technical committee to begin efforts on EHR systems.
- In 2003, the EHR technical committee began development of a functional model of the EHR system (the Center for Medicare and Medicaid Services was the catalyst for accelerating the development of this model).

HL7

- **Two year contract with the National Library of Medicine (NLM) to provide government agencies and the private sector with an implementation guide for the transmission of patient information between disparate EHR systems.**

HL7

- **Three year contract with NLM:**
 - ◆ **Make HL7 vocabularies available from within the Universal Medical Language System (UMLS)**
 - ◆ **Replace HL7 vocabularies with designated Consolidated Health Initiative (CHI) vocabularies, where possible**
 - ◆ **Describe how vocabulary bindings from specific HL7 messages to the UMLS will occur.**

HL7

- For more information about HL7:
<http://www.hl7.org>

Cancer Biomedical Informatics Grid (caBIG)

- The National Cancer Institute (NCI) provides coordinating supervision of caBIG and works in collaboration with partners in the public, private, and academic sectors.

caBIG

- **An informatics infrastructure that will connect teams of cancer and biomedical researchers together to enable them to better develop and share tools and data in an open environment with common standards.**

caBIG

- **Three domain workspaces**
 - ◆ **Clinical trial management systems**
 - ◆ **Integrative cancer research**
 - ◆ **Tissue banks and pathology tools**
- **Two cross-cutting workspaces**
 - ◆ **Architecture workspace**
 - ◆ **Vocabularies and common data elements workspace**

caBIG

- **Strategic Level Working Groups**
 - ◆ **Training**
 - ◆ **Strategic Planning**
 - ◆ **Data Sharing and Intellectual Capital**

caBIG

- For more information about caBIG
<http://caBIG.nci.nih.gov>

Public Health Information Network (PHIN)

- The Centers for Disease Control and Prevention (CDC) developed PHIN to improve public health communications by using and promoting health data and technology standards.

PHIN

- Enables consistent exchange of response, health, and disease tracking data between public health partners.

PHIN

- **Five key components:**
 - ◆ **Detection and monitoring**
 - ◆ **Data analysis**
 - ◆ **Knowledge management**
 - ◆ **Alerting and communications**
 - ◆ **Response**

PHIN

- Includes a number of component systems including the National Electronic Disease Surveillance Systems (NEDSS).

NEDSS

- A public health initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state, and local levels.

PHIN/NEDSS

- For more information about PHIN:
<http://www.cdc.gov/phinf/>
- For more information about NEDSS:
<http://www.cdc.gov/nedss/>

Modeling Electronic Reporting Project

- The purpose of this National Program of Cancer Registries (NPCR) project is to develop a model using the Unified Modeling Language (UML) to transmit data within the hospital's electronic medical record and hospital database system to both the hospital and central cancer registries.

Modeling Electronic Reporting Project

- The Division of Quality Health Care of the Virginia Commonwealth University Hospital system is developing an electronic medical record system and has systems in place to glean cancer related information.

NAACCR Advancements



NAACCR Data Exchange Record Layout

- ASCII, fixed length, flat file format
- Common language for cancer registry systems
- 397 data items, 6694 characters
- OUTDATED

Electronic Data Exchange ...Moving Forward

- Review current data exchange layout and discuss alternative electronic data transmissions.

NAACCR Overarching Goals and Tasks

- The need to move toward electronic, real time case reporting from all reporting sources that includes demographic information, disease codes, and pathology results. (Highest Priority)

Electronic Data Exchange ...Moving Forward

- Real Time Reporting Work Group
 - ◆ Develop a report summarizing the past, current, and future of real time reporting efforts.
 - ◆ Provide recommendations to NAACCR Board steps needed to keep involved in national efforts to develop interoperable EHRs.

Electronic Data Exchange ...Moving Forward

- **Develop NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting.**

Electronic Data Exchange ...Moving Forward

- NAACCR staff participate in HL7 trainings and work group meetings.
 - ◆ EHR Technical Committee
 - ◆ PHER Special Interest Group

Electronic Data Exchange ...Moving Forward

- NAACCR staff participate in SNOMED meetings.
 - ◆ Surgical Pathology Working Group

How do we bring all of these technological advancements together to move the cancer community forward?



C-Change

- C-Change is comprised of the nation's key cancer leaders from government, business, and nonprofit sectors.

C-Change

- The mission of C-Change is to leverage the combined expertise and resources of its members to eliminate cancer as a (major) public health problem at the earliest possible time.

C-Change

- In 2004, C-Change sponsored a Cancer Surveillance and Information Summit that brought together 86 experts from the broad field of cancer surveillance.
 - ◆ Purpose: to seek ways to reduce the burden from cancer through the full application of information.

C-Change

- The future will bring some fundamental changes in cancer surveillance that will be advanced by information technology, the increased use of the Internet, and new regulations governing personal privacy.

C-Change

- The future holds the promise of addressing the demands of clinicians eager for information, by researchers increasing the depth and breath of information, and by the public seeking to better understand the risks of cancer and the options available to them.

C-Change Summit Conference Recommendations

- **Seven primary recommendations:**
 - ◆ **Data Standards:** the recent agreement by major registries and coding systems on common stage specifications is a model for future action in data standardization.

C-Change Summit Conference Recommendations

- ◆ **Expanded Scope for Cancer Surveillance:** an expanded vision for cancer surveillance goes beyond cancer registration to include, risk factor data, pre-neoplastic events, quality indicators, and patient-centered outcomes.

C-Change Summit Conference Recommendations

- ◆ **Leadership: the activity of collecting and disseminating cancer surveillance information requires leadership and financial support. Central leadership is needed to guide activities by individual agencies and organizations.**

C-Change Summit Conference Recommendations

- ◆ **Incentives:** needed for participation in expanded surveillance activities.
- ◆ **Health Disparities:** need to be addressed across the spectrum of cancer surveillance by adopting measures of SES as well as age, gender, race and ethnicity into national dataset and medical record systems.

C-Change Summit Conference Recommendations

- ◆ **Surveillance Tools:** surveillance data must be more readily available for clinical and public health practice.
- ◆ **Legislative Mandate:** may be needed to authorize the collection of patient-centered data and other data elements under an expanded scope of surveillance.

C-Change Summit Conference Recommendations

- The next step is to engage critical players in implementing the top priority, that of achieving standards across the cancer surveillance enterprise including coding, data collection, procedures, and information dissemination.

C-Change Summit Conference Recommendations

- **Access to Quality Cancer Care Team** has taken on this task and is proceeding with a major planning effort in the current year for a meeting to address the critical issues involved in setting standards for cancer surveillance and information.

Electronic Data Exchange ...Moving Forward

- What will be the next steps for NAACCR members and committees?
- Where do we go from here?