Electronic Health Reporting and Cancer Surveillance in the U.S.

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Presentation Overview

- President’s Health Initiative
- Electronic Health Records (EHR)
- National Initiatives
- Examples of e-Reporting Projects in Cancer Surveillance
- Final thoughts…
“By computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care.”

--President George W. Bush, State of the Union Address, January 20, 2004
President’s Health Initiative

• 10 years – Most Americans will have access to their EHR at any time and place, no matter where it originates

• Voluntary patient participation

• EHR to share information privately and securely among health care providers - when authorized by the patient
President’s Health IT Plan

- Adopt Health Information Standards
- Increase funding for demonstration Projects on Health Care IT
- Use Federal Government to foster adoption of Health IT
- Create a new Office of the National Coordinator for Health IT
Public Health Challenges with EHR

• Understand public health organization:
  – Domain/programs fragmentations
  – Organizational hierarchy
• Understand commonalities among PH domains/programs and PH settings in terms of data sources, users, public health goals and functions
• Define the role of the EHR in integrating primary care and PH practices
• Define the processes for involving the various PH stakeholders in the national effort for the standardization of health care data via the EHR
• Develop PH vocabulary
The 2003 IOM Letter Report, *Key Capabilities of an EHR System*, defined the EHR System as including:

- Longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual,
- Immediate electronic access to person- and population-level information by authorized users,
- Provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care,
- Support of efficient processes for health care delivery (reduce duplication of effort and redundancies).
Introduction to the EHR

EHR Lifetime

PCP: Primary Care Physician
Radiologist
Surgeon
Radiation Center
Oncologist

Physical
Needle Bx
Lumpectomy
Axillary Dissection
Radiation
Hormonal Rx
Follow-up Visit

PCP: Primary Care Physician
The Electronic Health Record?

• Talking about EHR for 20+ Years
• All or most hospitals have some type of electronic systems
  – Billing
  – Disease Index
  – Physician Dictation
• Today – Hybrid EHR
• Today - New emphasis on EHR
EHR Standards to HL7

• Charge to HL7 – Accelerate Development of EHR Standards
• Who and what is HL7?
  – Standards setting organization - ANSI
  – A tool for clinical data transfer
• EHR-S Functional Model and Standard
  – Summary of Functions
  – Describes Behavior of a System from Functional Perspective
National Initiatives
Federal Participation in President’s Health IT Plan

The Community (AHIC)
Federal Health Architecture
Federal Agencies

Private

Federal

Input
Implementation
Accountability

Private

Federal
Nationwide Health Information Network

Nationwide Health Information Network…

“ …widely available services that facilitate the accurate, appropriate, timely, and secure exchange health information.”

Nationwide Health Information Network will…

– Specify information exchanges and interoperability architectures necessary to realize the President’s vision for health care IT

– Interconnect health records

– Transport electronic health information to inform clinicians and follow the consumer
“NHIN” is a Part of the Solution

Practices and Policy

What are the requirements of care provision, privacy, etc.?  
What are acceptable constraints and costs of operating electronically?

NHIN Architecture

What are the requirements for information exchange and interoperability?  
What are the minimal constraints that can be implemented?

Standards

Certification
# NHIN Iterative Development

## Phase I (2006)
- Form Consortia
- Develop Use Cases
- Develop High Level Standards
- Develop Harmonization Requests
- Develop Business Models
- Develop Prototypes

## Future (2007- )
- Develop a shared architecture with best elements
- Produce operational implementations
- Establish environment for sustainability
NHIN Participants

• Broad Participation
  • Public, Private, Federal
  • Providers, Payers, Researchers, Regulators, Population Health Monitors
  • Domain and Technical Experts

• Collaboration
  • Functional Requirements
  • Interoperability Specification
  • Privacy and Security Approaches
  • Revenue and Cost Model
NHIN Functional Requirements

Purpose

• Identify minimal set of functions needed to interconnect systems and provide interoperable exchange of health information
• Focus attention on capabilities needed to support use cases emanating from the American Health Information Community (AHIC)
• Provide specifications for steps of NHIN process
• Inform CCHIT’s certification criteria
• Inform HITSP’s process
Regional Health Information Organizations (RHIOs) or Health Information Exchange (HIE)

- A group of organizations with a business stake in improving the quality, safety and efficiency of healthcare delivery
- Purpose of a RHIO is to electronically exchange health information in a secure format so that the receiver can use the information
- Local/state level development of interoperable health records must happen first to build a national network
- Building blocks of the NHIN initiative
- Currently over 100 RHIOs exist
- Robert Wood Johnson Foundation studying interoperability of RHIOs
HIMSS RHIO Federation

- Goal is to foster the RHIO/HIE industry through education, outreach and advocacy activities at the local, state and federal level

- Three focus areas:
  - Business Rules
  - Harmonization
  - Chain of Trust
Agency for Healthcare Research and Quality (AHRQ) Health IT Grants

• HHS Awarded $139 million for Health IT in 2004
• In Oct 2005, over $22.3 million awarded to 16 grantees to implement Health IT systems – selected from 2004 grant recipients for planning Health IT systems
• 11 of 16 grants awarded to small/rural communities
• Focus on sharing health information between providers, labs, pharmacies, and patients and help ensure safer patient transitions between health care settings
• Promoting adoption of health IT by local communities/health care providers and working with states to develop RHIOs
Consolidated Health Informatics (CHI)

- Office of Management and Budget’s (OMB) eGov Initiative and is part of the FHA in the ONC
- Collaborative effort to adopt health IT standards for implementation in federal gov’t systems (particularly vocab and messaging standards)
- Participation of 20 department/agencies in governance process
- Adopted 20 uniform standards for electronic exchange of clinical information to be used in the federal gov’t – Published in Federal Register Dec 2005
- Currently in Phase II – implementation, maintenance, and identify/adopt new standards
Public Health Information Network (PHIN)

Will enable consistent exchange of response, health, and disease tracking data between public health partners through:

- defined data and vocabulary standards
- architectural standards
- strong collaborative relationships
Public Health Information Network

- Early Event Detection
  - BioSense
- Outbreak Management
  - Outbreak Management System, lab result reporting
- Surveillance
  - NEDSS
- Secure Communications
  - Epi-X
- Analysis & Interpretation
  - BioIntelligence analytic technology
- Information Dissemination & KM
  - CDC Website
  - Health alerting
- PH Response
  - Countermeasure administration; isolation, vaccine, prophylaxis

Federal Health Architecture, NHIN & Consolidated Health Informatics
National Electronic Disease Surveillance System (NEDSS)

- NEDSS is the surveillance component of PHIN

- NEDSS includes the PHIN data and architecture standards necessary for interoperable state and local surveillance systems

- The NEDSS Base System (NBS) and NEDSS Program Area Module (PAM) Platform (NPP) are a specific instance of a NEDSS compatible system
NEDSS PAM Platform (NPP)

TB Surveillance PAM
- SVOT Form
- Surveillance
- TB Specific Vocabulary
- Vocabulary

Varicella PAM
- Investigate
- Investigation Management
- Varicella EHR Message Implementation Guide
- Varicella Specific Vocabulary
- Vocabulary/Message

LEAD PAM
- Environmental Investigation
- Environmental
- Individual Case Management
- Case Management
- Varicella EHR Message Implementation Guide
- Varicella Specific Vocabulary
- Vocabulary/Message

STD PAM
- Morbidity Reports
- Fluid Records
- Intervene Records
- Investigation Management
- STD EHR Message Implementation Guide
- STD Specific Vocabulary
- Vocabulary/Message

NEDSS Base System
- VPD
- EHR
- ID

LEAD PAM
- Patient
- Organization
- Provider
- Lab Report
- Investigation
- Morbidity Report
- Treatment
- Vaccination

“COMMON” PAM PLATFORM SERVICES
- Patient
- Addresses
- Employee
- Provider Medical Group
- Manufacturer
- Treatment
- Vaccination
- Case Data Entry Elements

Messaging Subsystem
- Message Mapping
- Message Management
- Subscription Management
- Vocabulary Validation
- Message Activity Monitor
- Messaging Services

Note: Subcomponents included with the PAM Platform are Onion Rhapsody, PHIN VADS, G1 GeoStat, ChoiceMaker Deduplication, SAS

Cancer Registry
- NEDSS Reports
- NEDSS Data

Reporting Database (RDB)
- NPP Data
- NPP Program Specific Reports (Secured by Program Access)

SAS
- Multi-Disease/Condition Analysis Reports

Program Specific Features & Requirements

Future Release PAM Functionality
How does PHIN/NEDSS improve local and state capacity?

- **Web entry**: case information available to local & state health departments immediately on entry (no paper, no mail)
- Electronic connectivity with local providers
  - Communication, alerting
  - Case reporting via web
- Standardized data sent electronically to CDC
- Same application for over 140 diseases, replacing disease specific “stovepipe” applications
How does NEDSS deliver value to local & state health?

• **Electronic laboratory results** reporting (ELR) from clinical diagnostic laboratories
  - For pre-defined results of public health importance, electronic message to health department **automatically sent**
  - Message includes structured data including test, result, provider ID, patient age, sex
  - Multi-jurisdiction labs, public health labs, some local labs
ELR and Public Health

Nebraska Interim Report – 2/04

Parallel evaluation of ELR vs. usual paper-based LabCorp notifiable disease reports, January - June, 2003

Reporting Completeness:

• 280% increase in cases reported (1044 ELR vs 373 paper)

Reporting Timeliness:

• mean interval to receive results 3 days vs. 24 days (ELR vs. paper)
Messaging Subsystem: A Conceptual View
Data flow of messages in ePath Reporting Pilot Project with LabCorp

Pathology Lab

PHIN-MS

Secure/encrypted

Central cancer registry

PHIN-MS

Send queue (All cases for the state)

Receive queue (All cases for the state)

HL7 Mapper

Read messages and extract data elements of interest to the state

Search for cancer terms in text field (OBX-5) (this module can be bypassed optionally)

Path Reports database

Central registry database

Depending upon the user preference HL7 Mapper will either write all reports to the database without searching for cancer terms or write only the reports that have cancer terms or write all the reports to the database after marking the ones that have cancer terms.
Participating State Cancer Registries in ePath Pilot Project with LabCorp

- AL, AZ, CA, CO, FL, GA, MD, MI, MO, NV, NH, NJ, NY, NC, OH, OK, PA, TN, TX, VA

Washington D.C.

Participating States – 20
Objectives

- Test and document the implementation of ePath reporting from a national laboratory to central cancer registries
- Adopt and/or develop software needed to successfully implement ePath reporting
- Provide guidance to central cancer registries and path labs on implementation requirements for ePath reporting – tools and lessons learned will be distributed to all
Examples of E-Reporting Projects in Cancer Surveillance

• NAACCR Workgroups:
  – NAACCR Vol V - Pathology Laboratory Electronic Reporting, Version 2.0
  – Work underway on E-Path Process Guide
  – Explore/test use of HL7 CDA format for submission of NAACCR Vol II data (Cancer Abstract)
  – UML Modeling of Death Clearance and NAACCR Hispanic Algorithm

• NCI/SEER:
  – E-Path Project with AIM
  – SEER Data Management System (SEER*DMS)
Examples of E-Reporting Projects in Cancer Surveillance (con’t)

- CDC/NPCR
  - Reporting Pathology Protocols - CAP Cancer Checklists
  - VA Project
  - NPCR-Modeling Electronic Reporting Project
  - ePath Pilot Project with LabCorp

- State Projects
  - Web Plus Urology Project
  - E-Path Implementation

- Others
  - Radiological Society of North America: RadLex – Lexicon for uniform capture/index/retrieval of Radiology Information Resources
Reporting Pathology Protocols (RPP)

• Demonstration projects funded by CDC NPCR
• Implement SNOMED CT Encoded CAP Cancer Checklists
• In 2001
  – California and Ohio
  – Cancers of the colon and rectum
• In 2004
  – California, Maine, and Pennsylvania
  – Cancers of the breast, prostate, and melanoma of the skin
VA Project

• Drs. V. J. Varma and Theresa W. Gillespie at the Atlanta VAMC proposed to implement
  – A two year project
  – Template-based reporting
  – Using SNOMED CT Encoded CAP Checklists
  – Top 5 cancers
    • Lung, breast, prostate, colon and rectum, pancreas
  – Store values in a database in the pathology lab
NPCR-MERP

• Collaborative project to develop an electronic reporting model (recommendations, guidelines, and diagrams) for cancer surveillance to:
  – Promote the utilization of the EHR
  – Standardize electronic data exchange from:
    • data sources to the Central Cancer Registries (CCR)
    • CCR to the National Cancer Surveillance Programs (i.e. NPCR, SEER, CoC, NAACCR)

• Complete a formal Needs and Capabilities Assessment to provide an up-to-date view of cancer registration
NPCR-MERP Scope
NPCR-MERP includes items 1–8 and the lines drawn to the Central Registries
*Numbers rank the data sources as to the quantity of useful data available
Hospital Level

Data Sources
- Internal
- External

Information Sharing
- NCDB
- Clinical Trial
- General Cancer Information

Cancer Case

Hospital Cancer Registry

State Level

Central Cancer Registry

Reporting Facility
- Healthcare
- Non-Healthcare
- Multiple Hospitals

Consolidate

Electronic Cancer Abstract

State Level

Reference Path Lab

Private Physician

Electronic Data Format File

Summarize

Electronic

Summarize

Consolidate

Consolidate

National Level

Information Sharing
- CDC
- NPCR
- SEER
- NAACCR
- Patient/Public/Statistician

Consolidate

Consolidate

Consolidate
Final Thoughts…

• Cancer Surveillance is doing a lot of great work in the area of electronic reporting
• Need to work together more within and outside of our cancer community
• Better utilization of resources
• CDC-NPCR and NCI-SEER will work together to form a National “Oversight” Committee