NAACCR Interoperability Activities and the Electronic Health Record

August 4, 2011

Presented by the NAACCR Ad Hoc Interoperability Committee

Questions

• Please submit questions about today’s presentation through the Q&A (?) panel

Fabulous Prizes!!!

For the best question and tip

NAACCR
**Webinar Agenda**

- Overview – Ken Gerlach
- Meaningful Use – Sandy Jones & Eric Durbin
- Semantic Crosswalks – Gary Levin
- Discharge Data – Dan Curran
- Break
- Volume V – Jovanka Harrison, Gemma Lee, & Rich Moldwin
- NAACCR XML – Isaac Hands
- Conclusions – Ken Gerlach

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**NAACCR Interoperability Webinar Overview**

Ken Gerlach, Chair  
NAACCR Interoperability Ad Hoc Committee  
August 4, 2011

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**Webinar Purpose**

- Educate NAACCR membership on the activities, work, and challenges of the NAACCR Interoperability Ad Hoc Committee
Interoperability

- Definition – Wikipedia
  “a property referring to the ability of diverse systems and organizations to work together (inter-operate)”

- Definition – IEEE Glossary
  “the ability of two or more systems or components to exchange and to use information.”

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NAACCR History of Interoperability

- Standards Volumes I and II
  - Starting in ~1994
    - (UDSC Convened 1987)
    - Data Dictionary: definitions & codes
    - Data exchange record layout – column format
- Electronic Reporting - Cancer Abstracts
  - National Standards for transmission

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Interoperability and EHR

Why?

- Shift in diagnostic and treatment from hospitals
- Changes in healthcare information technology
- Initiative to establish national health IT standards
- Recent legislation promoting adoption and use of electronic medical records
- At the table

Interoperability Ad Hoc Committee Work Groups (WG)

- Semantic Data WG
- Discharge Data WG
- Pathology Data WG
  - Volume V WG
- Clinical Data WG

- Plus monitor national health information technology initiatives

National Health IT Initiatives

- Integrating the Healthcare Enterprise (IHE)
- Health Level Seven (HL7)
- College of American Pathologists (CAP) Cancer Committee
- CAP Pathology Electronic Reporting Taskforce (PERT)
- ONC HIT Policy Committee and the HIT Standards Committee
- caBIG
Strategic Management Plan (2011 – 2016)
June 2011 Version
• Priority Area 2: Standardization and Registry Development
• Goal 1: Prepare for the ideal cancer surveillance system of the future – a system that is more timely and adaptable to change.
  – Objective 1: Explore how cancer surveillance systems will interface with electronic health records and continue to assess semantic interoperability issues.
  – Objective 2: Stay engaged and remain current with national/international efforts regarding electronic health records and enhance efforts to include cancer in the “meaningful use” case for public health reporting.

Meaningful Use Overview

Sandy Jones
Public Health Advisor
Cancer Surveillance Branch
Division of Cancer Prevention and Control
National Center for Chronic Disease Prevention and Health Promotion

August 4, 2011
NAACCR Interoperability Webinar
National Center for Chronic Disease Prevention and Health Promotion Division of Cancer Prevention and Control
Interoperability and EHR

Meaningful Use of Electronic Health Records

Established by American Recovery and Reinvestment Act (ARRA) of 2009
- Health Information Technology for Economic and Clinical Health (HITECH)
- Comparative Effectiveness Research (CER)

Providing significant funding for healthcare IT infrastructure development
- Health Information Exchanges
- Regional Extension Centers
- CDC Special Registries and Special Projects

Meaningful Use

Centers for Medicare and Medicaid Services (CMS)
- Incentive Program for EHRs
- Guidelines for how EHR should be used by health care providers and hospitals
- Final rule defines the minimum requirements for Clinical Quality Measures and MU Criteria that eligible providers and hospitals must meet through their use of certified EHRs

Office of National Coordinator for Health Information Technology (ONC)
- Standards and certification criteria for EHR functionality
- Final rule identifies the standards and certification criteria for the certification of EHR

What is Meaningful Use?

“Simply put, ‘meaningful use’ means providers need to show they’re using certified EHR technology in ways that can be measured significantly in quality and in quantity.”

1Centers for Medicare and Medicaid Services: https://www.cms.gov/EHRIncentivePrograms/30_Meaningful_Use.asp#BOOKMARK1

Meaningful Use

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Incentive Program for EHRs
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Meaningful Use Criteria
Criteria for meaningful use will be staged in three steps over the course of five years:
Stage 1 Final Rule (2011 and 2012) sets the baseline for electronic data capture and information sharing – July 2010
Stages 2 and 3 will continue to expand on this baseline and be developed through future rule making
Timeline under consideration for possible changes

Stage 1 Meaningful Use Provisions
Eligible providers must comply with 20 objectives to reach meaningful use.
- Providers must attest to 15 core objectives along with another 5 objectives chosen from a menu list of 10 objectives.
Stage 1 Core Set (All Required)

- Use computerized order entry for medication orders.
- Implement drug-drug, drug-allergy checks.
- Generate and transmit permissible prescriptions electronically.
- Record demographics.
- Maintain an up-to-date problem list of current and active diagnoses.
- Maintain active medication list.
- Maintain active medication allergy list.
- Record and chart changes in vital signs.
- Record smoking status for patients 13 years old or older.

Stage 1 Core Set (All Required)

- Implement one clinical decision support rule.
- Report ambulatory quality measures to CMS or the States.
- Provide patients with an electronic copy of their health information upon request.
- Provide clinical summaries to patients for each office visit.
- Capability to exchange key clinical information electronically among providers and patient authorized entities.
- Protect electronic health information (privacy & security)

Stage 1 Menu Set (Choose 5)

- Implement drug-formulary checks.
- Incorporate clinical lab-test results into certified EHR as structured data.
- Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, and outreach.
- Send reminders to patients per patient preference for preventive/ follow-up care.
- Provide patients with timely electronic access to their health information (including lab results, problem list, medication lists, allergies)

*Must choose one as part of 5 selected Menu measures.
Stage 1 Menu Set (Choose 5)
Use certified EHR to identify patient-specific education resources and provide to patient if appropriate.
Perform medication reconciliation as relevant
Provide summary care record for transitions in care or referrals.
*Capability to submit electronic data to immunization registries and actual submission.
*Capability to provide electronic syndromic surveillance data to public health agencies and actual transmissions

*Must choose one as part of 5 selected Menu measures.

Stage 2 Meaningful Use
Health Information Technology Policy Committee (HITPC)
Public meeting held June 8, 2011 to make recommendations to ONC for Stage 2 criteria
Several registries lobbied for cancer registry reporting

Stage 2 Meaningful Use
Recommendations sent to CMS
Eligible Provider: Submit cancer registry reporting added as a menu item!
Signal to Health Information Technology Standards Committee: Possible use of IHE cancer reporting implementation guide
Timeline: Delay Stage 2 provisions until 2014
CMS now deciding
Medicare Incentives for Providers

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Medicaid Incentives for Providers

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Meaningful Use (MU) and Public Health

MU provides important opportunity for public health to exchange data with hospitals and providers.

3 public health criteria in Stage 1

Relevant to cancer community: electronic laboratory reporting requirement

Clinical hospital laboratories only; does not include pathology laboratories or stand-alone, independent laboratories.
Uses ELR implementation guide as standard, which NAACCR Volume V is based on.
NPCR has requested inclusion of pathology laboratory reporting for future stages.
Cancer and Meaningful Use

Improve cancer surveillance, cancer prevention and control efforts, health care quality, and public health outcomes
Improve timeliness of cancer surveillance information such that it can be used to impact patient care and clinical decision making

Meaningful Use: Why Cancer?

Cancer community has a well-established SINGLE national data standard for case reporting that has been agreed upon and used by all state cancer registries for over fifteen years (NAACCR Vol. II)
State Cancer Registries ready to receive and process data from physician offices by early 2012 or sooner
eMaRC Plus, CDC-developed, freely available software, receives and processes CDA documents from EMRs

Meaningful Use: Why Cancer?

Cancer reporting requirements are part of capture of information related to cancer diagnosis and treatment, fit in normal clinical workflow
State Cancer Registries are CURRENTLY receiving electronic pathology reports (HL7 2.3.1 and 2.5.1)
Meaningful Use (MU) Activities in Cancer Community

Provided public testimony to HIT Policy Committee through CDC Chronic Center Medical Officer
Continued advocacy for cancer within CDC and communications with HIT MU WG member
Monitoring of ONC HIT Policy Committee and MU WG meetings

Meaningful Use (MU) Activities in Cancer Community
Support and public comments from Central Cancer Registries
Developed IHE PRPH-Ca profile; tested/demonstrated with vendors at IHE
Implementation of physician reporting using the IHE PRPH-Ca profile within CER funded States (KY and MO)

Thank you!

Sandy Jones
Public Health Advisor
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sft1@cdc.gov
Electronic Physician Reporting and Meaningful Use

Eric B. Durbin, MS
Director of Cancer Informatics
Kentucky Cancer Registry
NAACCR Interoperability Webinar
August 4, 2011
Louisville, Kentucky

Overview

Problems associated with capturing complete treatment data in central cancer registries
Leveraging ARRA funded healthcare IT initiatives and Meaningful Use (MU) to address problem
Kentucky physician EHR reporting project
Early successes, challenges and recommendations

The Problem: Incomplete Treatment Data in Central Registries

Complete treatment data difficult to collect in central registries
Most surgeries performed in hospital settings
Chemo, radiation, hormonal, immuno and other treatments often performed in ambulatory settings
Non-surgical treatment not as well represented in central cancer registries
Interoperability and EHR

Treatment Information Captured in Central Registries

<table>
<thead>
<tr>
<th>Treatment/Service</th>
<th>Sensitivity of Registry Data</th>
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<td>Mastectomy</td>
<td>95.0%</td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>94.9%</td>
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<tr>
<td>Lymph Node Dissection</td>
<td>95.9%</td>
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<tr>
<td>Biopsy</td>
<td>9.8%</td>
</tr>
<tr>
<td>Radiation Therapy</td>
<td>72.2%</td>
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<tr>
<td>Chemotherapy</td>
<td>55.6%</td>
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<tr>
<td>Hormone Therapy</td>
<td>36.2%</td>
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Shifts in Cancer Treatment Settings


Can EHRs Provide Automated Treatment Data?

Hypothesis: Advances in Electronic Health Records will facilitate automated capture of treatment data directly from ambulatory settings.

- May be more feasible and reliable than physician office data entry.
- May be more efficient and cost effective than physician office record abstraction by registry staff.
- May produce more complete, accurate and timely data.
Health Information Exchanges

Provide backbone for the meaningful use of health information technologies
Funded by grants through State HIE Exchange Cooperative Agreement Program
Funded in all states, DC, and several territories
Provide network infrastructure for the secure exchange of health information

Regional Extension Centers

Help health care providers implement and achieve meaningful use of EHR systems
Offer information and guidance
Provide training and support
Provide direct technical assistance
Assist in certification process
62 centers across U.S.
Initially funded to support primary care providers only

RECs in Kentucky
A Strategy to Leverage Meaningful Use

Leverage MU incentives and infrastructures to achieve direct electronic reporting from medical and radiation oncology practices in Kentucky

Connectivity and secure data transmissions through the Kentucky HIE

Sponsor MU technical support from the Kentucky REC for oncology providers in exchange for cancer reporting

Building the Electronic Data Transmission Infrastructure

Data Transmissions Standards:

Health Level Seven (HL7)

HL7 V3 Clinical Document Architecture (CDA)

Continuity of Care Documents (CCD) supported by the Kentucky HIE and Meaningful Use

CDC NPCR-AERRO group leading development of an Integrating the Healthcare Enterprise (IHE) Profile

Potential challenges with HL7 V3

CDA did not work well in NAACCR data exchange pilot

HL7 V3 highly criticized over complexities
**HL7 V2 as Backup**

Works very well for E-Path and current EHR feeds  
ORU messages for E-Path  
ADT messages for discharge data from Norton Healthcare in Kentucky  
Likely already supported by vendors  
More simple and straightforward  
Kentucky HIE will support HL7 V2 and V3  
CDA/CCD for KCR

**Vendor Support?**

How quickly can vendors support IHE Physician Reporting to a Public Health Repository – Cancer (PRPH-Ca) profile?  
Can existing billing data provide meaningful cancer registry data?  
Registry community may need to be creative in seeking immediate returns.

**Record Linkage Engine**

“Probabilistic linkage technology makes it feasible and efficient to link large public health datasets in a statistically justifiable manner.”

CDC Link Plus  
Collaborating with CDC in development of a LinkPlus API  
Will allow fully automated record linkage integration into various software applications

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Interoperability and EHR

EHR Repository

- Physician EHR records
  - Demographics
  - Diagnosis
  - TNM Staging
  - Treatment
  - Notes/Text
- Repository resides at registry
- Evaluating CDC’s eMaRCPlus as application to receive and process EHR messages

2011 Kentucky Oncology Provider Survey

- Practices (55)
  - 61 offices
  - 27 cities
- Office Specialties
  - 23 radiation and medical oncology
  - 25 medical oncology
  - 13 radiation oncology
- Providers (216)
  - 155 medical oncologists
  - 61 radiation oncologists
- Survey response rate
  - 24/55 (44%)

EHR Adoption in Kentucky

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<tr>
<th>EHR Status by Speciality</th>
<th>Medical Oncology</th>
<th>Radiation Oncology</th>
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<tr>
<td>Paper</td>
<td>43%</td>
<td>23%</td>
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<tr>
<td>EHR</td>
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Provider Interest in Participating

Provider Interest in Electronic Reporting to Kentucky Cancer Registry

- **Successes**
  - Oncology providers well aware of MU
  - Widespread interest among providers
  - Willing to push data to registry
  - 9 practices ready to commit

- **Challenges**
  - Bleeding edge
  - Relationship between oncology practices, hospitals, and EHR systems difficult to assess
  - Requires EHR vendor support
  - Requires extensive coordination among many parties

**Early Successes and Challenges**

**Successes**
- Oncology providers well aware of MU
- Widespread interest among providers
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- 9 practices ready to commit

**Challenges**
- Bleeding edge
- Relationship between oncology practices, hospitals, and EHR systems difficult to assess
- Requires EHR vendor support
- Requires extensive coordination among many parties

**Recommendations**

**Meaningful Use Stage 2 Call to Action**
- CMS MUST include reporting to cancer registries
- What can you do to help?

Establish contact with state Health Information Exchange(s) and Regional Extension Centers

Reach out to providers now

Participate in NPCR-AERRO physician reporting group
Acknowledgements

Sheena Batts, CTR
Tamas Gal, MS
Isaac Hands
David Rust, MS
This project was funded as part of the American Recovery and Reinvestment Act (ARRA) Comparative Effectiveness Research activities through the CDC.

Semantic Data Work Group Crosswalk Tables

• Gary M. Levin, BA, CTR
• Florida Cancer Data System
• Interoperability Webinar
• August 4th, 2011

Presentation Overview

• Definition
• Crosswalk Development Process
• Crosswalk Usages
• Currently Available Crosswalks
• Review of Crosswalks
• Future Crosswalks
**Definition**

- A crosswalk is a table that shows equivalent elements (or “fields”) in more than one database schema. It maps the elements in one schema to the equivalent elements in another schema.


**Crosswalk Development Process**

- Select Standard Setters to Review
- Gather Coding Systems for each Standard Setter
- Map each code to NAACCR code
- Review Mapping (Semantic, IO Ad Hoc, Board)
- If need to modify an existing Volume II value set, make Recommendations to IO Ad Hoc UDS
- Publish Crosswalk on NAACCR Web Site

**Crosswalk Usages**

- Defines method of importing various data streams and coding systems into a NAACCR Coded Field
  - Using Census Data and linking to Census Race Codes to NAACCR Race Codes
  - Using National Health Information Survey data and linking to NAACCR Marital Status Codes
- Make recommendations to enhance codes of data items in NAACCR Volume II
  - Marital Status (Code 6 - Domestic Partner)
Currently Available Crosswalks

- Gender
- Race
- Ethnicity
- Marital Status


Review of Crosswalks


Future Crosswalks

- Country Codes
  - Address at Diagnosis - Country
  - Address Current - Country
  - Birthplace - Country
  - Follow Up Contact - Country
  - Place of Death - Country
- Primary Payer at Diagnosis
  - Reviewing Coding Provided by Public Health Data Consortium
- Primary Language
- Occupation
- Industry
Interoperability and EHR

Thank You
Questions?
Gary M. Levin, BA, CTR
Florida Cancer Data System
glevin@med.miami.edu

PLEASE Volunteer for a NAACCR Committee
We Need YOUR Help!!
Especially Semantic Interoperability

Thank You
Questions?
Gary M. Levin, BA, CTR
Florida Cancer Data System
glevin@med.miami.edu

Discharge Data WG
Dan Curran, MS, CTR
C/NET Solutions
Interoperability Town Hall
August 4, 2011

Overview
• WG Origin
• Definitions
• WG Goal, Objectives and Activities
• Member Survey and Follow-up
• Overview of NAHDO Reports
• Joint Statements Recommended by NAHDO
• Call for Members

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WG Origin

- Information Technology (IT) Committee initiated a discharge data project
- NPCR-AERRO staff inventoried existing discharge data transmission formats; defined data items; identified national healthcare information technology organizations responsible for standards
- Responsibility for the discharge data domain moved from to the Interoperability Ad Hoc Committee
- Discharge Data WG was formed in spring 2010 and its goals and objectives approved by Interoperability in Summer 2010

Definitions

- **Discharge data** - defined set of data compiled after a hospital discharge or subsequent to a medical encounter that gives a minimum description of the events
- **Claims data** – record of the fees or costs for health care services provided to a covered person submitted by a health care provider
- **Billing data** - used in the Canadian context to refer to claims data paid for by the provincial or territorial health system
- More definitions – see page 8 of the Spring 2011 Narrative

WG Goal

- Explore opportunities with existing discharge data sets and work with appropriate organizations responsible for those data sets to facilitate transmissions and to include additional data items for cancer surveillance, as appropriate
  - needed information and expert guidance to achieve the goal
NAHDO Expertise

- Met with staff and consultants from the National Association of Health Data Organizations (NAHDO); contract with NPCR-AERRO
- NAHDO made a presentation to the WG explaining their expertise and mission
- From their website: NAHDO provides leadership in health care information management and analysis, promotes the availability of and access to health care data, and the use of these data to make informed decisions and guide the development of health care policy

NAHDO

- http://www.nahdo.org

NPCR-AERRO Expertise

- WG learned about the technical aspects of the ANSI X12 standard from a presentation by Minal Agrawal, authored by Minal and Sandy Jones from NPCR-AERRO
- ANSI X12 is widely used in the health care field
Objective - Survey

• Continue to collaborate with NPCR-AERRO to explore existing transmission standards for discharge data
  – survey central cancer registries to identify if anyone is receiving discharge data and the format they are receiving it in
• Activities – survey sent out at the end of 2010; results published in Summer 2011 Narrative

Survey Results

• Discharge and claims survey sent to all U.S. and Canadian registries – 38 responses
• Discharge data: About half of the respondents used discharge data
• Discharge data used mostly for casefinding and as a follow-up resource
• Problems include SSN not included and limited resources at the registry

Survey Results

• Discharge data come from a variety of sources

• On average it took six months to a year for the registry to receive the data
Survey Results

- **Claims data**: used by only 20% of respondents
- Medicare or Medicaid data supplements information from private payers
- Medicare lag > one year; Medicaid within 60 days
- Common uses of claims/billing data are casefinding and gaining treatment and diagnosis date information
- At least half of respondents who do not use discharge or claims data intend to do so in the future

Survey Results

- Data formats received by registries vary greatly; a minority mentioned X12 format
- **Response to survey**: the group is proposing a concurrent session featuring the uses of discharge and claims data at the 2012 NAACCR annual conference
- Understand discharge data delays better by developing a process flow diagram and identifying bottlenecks
- Look into follow-up questions, such as asking which discharge data fields are most useful

Objective – Recommended File Format

- Recommend a discharge data set and file format
- WG is considering X12 as the proposed standard
  - already established industry standard
  - at a June 2011 Town Hall meeting NAHDO staff presented a gap analysis between discharge and cancer registry data and developed prioritized recommendations to harmonize the two
- Semantic Data WG will consider these recommendations
**NAHDO Recommendations**

- Link to recommendations
- Types of recommendations
  - joint workgroup
  - joint statements
  - format changes
  - education
  - no action

**Examples**

- Physician identifiers
  - workgroup to work on standardizing definitions, numbers of identifiers collected, field length
  - joint statement issued regarding the need for a both a unique and stable physician identifier
- Patient identifiers
  - privacy concerns and need for unique patient identifiers addressed in a joint statement
  - NAACCR to increase SSN field length to match X12 standard
  - discharge systems to change Name field length to 40 to match NAACCR

**NAHDO Joint Statements**

- NAHDO-proposed joint statements with NAACC
- Physician identifier statement
  - addressed to the Centers for Medicare and Medicaid Services (CMS)
  - points out inadequacies of NPI
  - identifies need for single stable identifier for a physician
  - identifier should not imply information about the practice group, billing hospital, or location
NAHDO Joint Statements

- Patient demographics statement
  - addressed to members of both organizations
  - emphasizes the importance of harmonized demographic fields while using a standard format
  - addresses privacy and confidentiality concerns
  - urges developing common definition for Personal Health Information (PHI)
- Joint statements are being reviewed by NAACCR committees

Additional Objectives

- Identify existing software or software requirements for cancer registries to successfully receive discharge data – action pending; will work with IT Committee
- Recommend transmission format standard for use between healthcare facilities or health data organizations, and cancer registries – action pending
- Provide guidance for the implementation of discharge data set reporting – action pending
- Educate the NAACCR community about the existing discharge data sets, related transmission standards, and responsible entities – articles will continue to be published in the Narrative; annual conference presentations

Call for Members

- Lots of work to be done – we need you!
- WG meets the first Wednesday of each month at noon eastern time
- Contact Dan Curran, dcurran@ccr.ca.gov, (916) 779-0362
Break Time

Introducing Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting, Version 4.0
NAACCR Interoperability Webinar
August 4, 2011

Jovanka N. Harrison, PhD
New York State Cancer Registry; Chair of NAACCR Path Data WG

Outline
• Development Team
• Volume V – Background & History
  • Definition of Synoptic Reporting
  • A ‘brief’ on Health Level Seven (HL7)
  • Version 2.2 – A Success Story
• Volume V, Version 4.0 Highlights
  • Synoptic Reporting: A (Canadian) reality
Interoperability and EHR

NAACCR Pathology Data WG 2010-2011
A Collaboration between Canada and the U.S.

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Background: NAACCR Pathology Data Work Group’s Goal and Aims

- Goal: to develop messaging standards for electronic transmission of reports (anatomic pathology, cytology, hematology) from pathology laboratories to central cancer registries.

- Aims: to improve efficiency, reduce costs and provide a structure for future electronic pathology initiatives.

Recent History of Volume V

- Version 2.2 provides guidance using HL7 v.2.3.1
  (February 2009)
  - A continued success story - widely used in the U.S.
- Version 3.1 provides guidance using HL7 v.2.5.1
  (October 2009)
  - Limited synoptic guidance
- Version 4.0 provides guidance using HL7 v.2.5.1
  (April 2011)
  - Expanded synoptic reporting guidance
Definition of Synoptic

- The standardized and structured documentation of a Cancer Pathology Report, with common definitions, data items, and data item values.
- Synoptic is a term which typically refers to checklists designed to ensure that key data fields are not omitted.
- "Affording a general view of a whole; manifesting or characterized by comprehensiveness or breadth of view" (from Greek synoptikos), Merriam-Webster Dictionary.

A ‘Brief’ on Health Level Seven (HL7)

- Organization – Standards for Development Organization (SDO) for transmission of healthcare/clinical information
- Over 20 years old
- http://www.hl7.org/

Example (HL7 snippet):

```
PID|1||123456789^^^^SS|000039^^^^LR|McMuffin^Candy^^^Ms.|...<CR>
PV1[N]|1||594110NY^Attending^Doctor^^^DR|...<CR>
OBR[1]|1||97865|115295^SURG PATH REPORT^LN^^PATH REPORT^L|...<CR>
OBX|1|TX|226365^CLIN HISTORY^LN||white F with (L) UOQ breast mass|...<CR>
```
Volume V, Version 2.2-- A Success

NPCCR/AERRO E-path Participating States -- Users of Volume V,
Status as of March 15, 2011*

*Adapted from

Volume V, Version 4.0 -- Highlights

- Version 4.0, ~ 300 pages
  - Moved material to the "E-Path Reporting Guidelines" document (forthcoming)
  - Removed the 1998 Pipe-Delimited format
  - Expanded Chapter 3: Synoptic Reporting -- includes rules for constructing the HL7 message for CAP electronic Cancer Checklist (eCC) synoptic reporting.
  - Available on the NAACCR web site, under "Standards".

Volume V, Version 4.0 -- Highlights Cont’d.
A Paradigm Shift

- Styles of Pathology Reporting
- Traditional Narrative Reporting
  - Broad Section Headings (e.g., microscopic, final diagnosis, etc.)
- Synoptically Structured (aka synoptic like)
- Synoptic – fully structured and encoded; e.g., the electronic College of American Pathologists' (site-specific) Cancer Checklists, the so called "eCCs".
- Q & A pairs, where the question would be “Surgical margin involvement”, and the answer would be “All surgical margins free of tumor”.
Volume V, Version 4.0 -- Highlights Cont’d.
A Paradigm Shift

- Kinds of Pathology Reports
- Primary Reports
  - Supplemental Reports; Addenda; Amendments; Consultation notes (consults); Autopsy Reports.

Volume V, Version 4.0 -- Highlights Cont’d.
Synoptic Reporting: A (Canadian) Reality

- In Canada, Volume V, ver. 4.0 has successfully been implemented in the province of Ontario, by Cancer Care Ontario (CCO), as will be illustrated by the next presenter -- Gemma Lee from CCO.
- Many of the examples shown in the new Volume V specifically targeted the HL7 message encoding of completed eCCs, based on Canadian (sample) cancer cases.

Volume V, Version 4.0 -- Highlights Cont’d.
Synoptic Reporting: A (Canadian) Reality

- Work with other provinces is underway-- please see the Canadian Partnership Against Cancer (CPAC) initiative for more details on the Canadian experience.
  - http://www.partnershipagainstcancer.ca/priorities/surveillance/
- At this time there are no central cancer registries in the U.S. which have implemented Volume V, version 4.0.
The Ontario Pathology Reporting Project
Overview, Key Success Factors, Lessons Learned

NAACCR
Interoperability Ad Hoc Committee
Interoperability Webinar
August 4, 2011
(9:00 am ET and 2:00 pm ET)

Gemma Lee
Proposed Agenda

- Project Background
- Implementation Overview
- Current Status
- Key Success Factors, Challenges and Lessons Learned

Diagnosing the cancer stage is the start of the cancer care journey for the patient

- Almost all cancer patients begin their involvement with the cancer system through a series of diagnostic tests. Some of these involve removing tissue or cells to be examined.
  - Pathology is the medical specialty that deals with the examination of tissues and cells under the microscope to arrive at a diagnosis.
- Pathologists make decisions that determine diagnosis, extent of disease and also interpret test results affecting cancer treatment and recovery. (i.e. diagnostic oncologists)

Cancer pathology reporting in Ontario

Some facts and figures:

- About 400 pathologist submit cancer pathology reports to CCO from 100 cancer treating hospitals
- 90% of cancer pathology reports are electronically sent by Ontario labs and hospitals
- Over 100,000 electronic cancer pathology reports are received each year at CCO
College of American Pathologists (CAP) cancer checklists endorsed as the cancer pathology report content standard in Ontario and Canada

- Endorsed as Ontario standard in 2004 by CCO and the Ontario Association of Pathologists
- Endorsed as pan-Canadian standard July 2009 by the Canadian Association of Pathologists

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**Project History**

![Timeline](image)

**PHASE 1**

- Engage hospitals to implement synoptic reporting e-Tools:
  - ALL pathology reporting hospitals have implemented synoptic reporting e-Tools and are reporting synoptic pathology reports for the 5 most common cancer resections
  - Aligned to CCO CAP/CS Data Standard

**PHASE 2**

- Partner with hospitals to update existing 5 checklists and expand synoptic reporting to ALL cancers with a mandated 2010/11 CAP checklists
- Update pathology reporting standards to align with: NAACCR and Canada Health Infoway (CHI) data messaging standards

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**Pathology Reporting Project - Goals**

- Receive synoptic cancer pathology reports in discrete data field format from 90/110 electronically submitting hospitals
- Pathology Reports standardized according to the College of American Pathologists (CAP) cancer reporting checklist standard
- Report Format standardized to the North American Association of Central Cancer Registries (NAACCR) standard
Synoptic reports use discrete data field format (DDF), standardized against the CAP checklists to allow for easier transmission, storage, retrieval, and sharing of data between clinical information systems.

Initiate, engage and coordinate hospital implementations with the vendor community

Vendor Engagement

Vendor Initiation
- Conduct quarterly Vendor Communities of Practice calls outlining the anticipated release of new CAP eCCs
- Provide vendors with CCO electronic specifications and venue to seek clarifications and comments

Hospital Scheduling
- Identify all client hospitals and their preferred implementation dates
- Coordinate a mutually agreed upon schedule with the vendor to ensure availability and support extended throughout the implementation and warranty
Commence the technical upgrade modifications required for phase 2 and load the 2010 CAP checklist into the test environment

**Technical Engagement**

- **Lab Engagement Kick-Off**
  - Overview of project tasks and timelines
  - Introduction to CCO Toolkit documents / resources
  - Development of a specific strategy to review and implement checklists and CCO Cancer Registry Business Rules

- **Technical Checklist Evaluation**
  - Pathology Header Section in CCO CAP checklist: MSH and PID sections are updated to conform to Phase 2 standards
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- **Load Kick-Off**
  - Load the 2010 CAP checklist into the test environment

- **Technical Checklist Transmission Testing**
  - Load Kick-Off
  - Load the 2010 CAP checklist into the test environment

**Engagement of the entire hospital team & checklist review** includes providing the scope and timelines of the project and reviewing the checklists and workflow with the pathologist(s).

**Pathologist Engagement & CAP Checklist Review**

- **Kick-Off Meeting**
  - Overview of project tasks and timelines
  - Introduction to CCO Toolkit documents / resources
  - Development of a specific strategy to review and implement checklists and CCO Cancer Registry Business Rules

- **Pathologist Checklist Review**
  - 2010 Checklists reviewed by CCO BA and hospital pathologists
  - CCO BA documents changes, if any, made to checklists
  - Changes approved by CCO checklist review committee

- **Lab Workflow Review and Documentation**
  - CCO BA reviews and documents hospital lab workflow including:
    - Other pathology report types
    - Addendums
    - Amendments

**Technical and Registry Compliance Testing** are important to the success of the project and require coordination between CCO and hospital resources

**HL7 Conformance and CAP Checklist Transmission Testing**

- **HL7 Conformance**
  - Hospital to transmit 5-10 test cases to ensure MSH, PID and Pathology Header sections are correctly mapped and adhere to CCO specifications
  - To ensure that all pathology reports are received by CCO according to Registry Business Rules
  - CCO Registry to ensure that all outstanding issues from phase 1 have been addressed and comply with phase 2 specifications

- **Checklist Technical Transmission Testing**
  - Checklist Technical Transmission Testing
  - Checklist Technical Transmission Testing
  - Certification testing is conducted to ensure compliance with valid values
  - Use of automation tools to ensure process is conducted efficiently without compromising quality
Once live, the hospital’s submissions continue to be checked for alignment to the CCO standard for a period of 30 to 60 days. Reports are generated the following month and reviewed to ensure hospital meets CCO Registry’s Warranty Requirements.

**Go Live, Warranty Period & Closure**

**Go Live and Warranty Period**
- Pathologists use new checklists in production
- Data is monitored for a full 1-2 full calendar months to ensure proper formatting and receipt of data
- Reports are generated at the completion of the warranty months to ensure compliance with warranty rules

**Closure & Disbursement**
- Upon completion of the Warranty Review period, phase 2 is completed
- Hospital to document and submit incurred expenses to CCO to ensure payment is received
- All future changes to checklists must abide by CCO’s Change Control Process

**CCO Pathology Reporting**
- CCO resumes creation and distribution of provincial, LHIN and hospital-based reports
- Reports can be accessed through iPark™, CCO’s web-based business intelligence tool

**Current Status**

**Current Synoptic Pathology Reporting Capability**

<table>
<thead>
<tr>
<th>LHIIN</th>
<th>Number of hospitals implementing synoptic reporting</th>
<th>Number of hospitals</th>
<th>% of hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>90</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>5</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>14</td>
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<td>3</td>
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<td>100</td>
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</tr>
<tr>
<td>14</td>
<td>1</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

Over 90% of all electronic reporting PMGs hospitals have enabled synoptic reporting capability.
Ontario Pathology reports in Transition

<table>
<thead>
<tr>
<th>Reporting Level</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
<th>Level 5</th>
<th>Level 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Narrative</td>
<td>No CAP content</td>
<td>Single text field data</td>
<td>Narrative</td>
<td>CAP content</td>
<td>Single text field data</td>
</tr>
<tr>
<td>Description</td>
<td>Level 2+</td>
<td>Synoptic-like structured format</td>
<td>Level 3+</td>
<td>Electronic reporting tools using drop-down menus</td>
<td>Level 4+</td>
<td>Standardized reporting language</td>
</tr>
<tr>
<td>Ontario Hospitals, 2004-05</td>
<td>0%</td>
<td>0%</td>
<td>65%</td>
<td>17%</td>
<td>18%</td>
<td>0%</td>
</tr>
<tr>
<td>Ontario Hospitals, 2006-07</td>
<td>0%</td>
<td>0%</td>
<td>20%</td>
<td>2%</td>
<td>78%</td>
<td>0%</td>
</tr>
<tr>
<td>Ontario Hospitals, 2008-09</td>
<td>0%</td>
<td>0%</td>
<td>14%</td>
<td>2%</td>
<td>10%</td>
<td>52%</td>
</tr>
<tr>
<td>Ontario Hospitals, 2009-10</td>
<td>0%</td>
<td>0%</td>
<td>16%</td>
<td>2%</td>
<td>78%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Data Source: CCO PIMS ePath Database; As of Apr 13, 2011.

Synoptic reporting format overwhelmingly preferred by 97% of Ontario surgeons and oncologists who are the primary users of cancer pathology reports

<table>
<thead>
<tr>
<th>Overall Satisfaction Score</th>
<th>Clinicians Mean (SD)</th>
<th>Pathologists Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process is complete for the purpose of clinical decision making</td>
<td>4.85 (1.35)</td>
<td>4.08 (1.44)</td>
</tr>
<tr>
<td>Ease of finding information required for clinical decision making</td>
<td>4.94 (1.45)</td>
<td>4.04 (1.42)</td>
</tr>
<tr>
<td>Facilitates consistent approach to diagnostic and prognostic factors</td>
<td>4.95 (1.45)</td>
<td>4.04 (1.42)</td>
</tr>
</tbody>
</table>

Correlation between overall satisfaction with the level of information provided by standardized synoptic reports

<table>
<thead>
<tr>
<th>Clinicians</th>
<th>Pathologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process is complete for the purpose of clinical decision making</td>
<td>0.70**</td>
</tr>
<tr>
<td>Ease of finding information required for clinical decision making</td>
<td>0.60**</td>
</tr>
<tr>
<td>Facilitates consistent approach to diagnostic and prognostic factors</td>
<td>0.77**</td>
</tr>
</tbody>
</table>

*Correlation is significant at the 0.01 level (2-tailed)

Key Success Factors, Challenges and Lessons Learned
Success Factors enabling project success

Direct Hospital & Vendor Engagement
- Secured two dedicated teams to coordinate and manage project implementations with hospital partners

Employ automated Checklist Testing Tools
- Developed in-house software tools to automatically validate HL7 messages for completion, structure, format and valid values

Availability and adherence to the CAP Data Standard
- Utilized the CAP electronic data standard with c-key encoding as opposed to a "home-grown" standard

CCO Liaisons with NAACCR & CAP
- Facilitated feedback and corrections from hospitals and vendors for both standards through dedicated channels

Challenges and Lessons Learned

Encourage adoption of an unaltered CAP checklists
- Strongly encourage checklists to be used in "vanilla" form without additions/modifications

Avoid Scope Creep
- Additional reporting types, data elements were not well defined from initial outset and lack of applying consistent rules hampered credibility and success initially

Define Go-Live Monitoring Process
- Lack of reporting tools required an intensive manual process of reviewing live reports to ensure compliance and data quality

Manage & understand the complexities and nuances of vendor systems
- Certain system limitations hampered hospitals to adhere to CCO electronic standards. Significant learning curve to ensure implementation meets understood system capabilities, features and limitations

Questions?
The Evolution of CAP’s electronic Cancer Checklists (eCC)

Richard Moldwin, MD, PhD
NAACCR Interoperability Webinar, Aug 4, 2011

Topic Description

• Describe the Checklist to eCC process
  o Definitions, Brief History, Checklist to eCC Process

• Review how the PERT issues vetting is helping to adjust the Checklists (paper) and the eCC to be more consistent with cancer registry concerns
  o Current Problems, Coordinating Data Elements

• Describe how the eCC is evolving to interface with vendor systems (now and future plans)
  o Driving eCC Adoption

Definitions 1

• CCC- CAP Cancer Committee
• CCP - CAP Cancer Protocols (a.k.a. “Protocols,” checklists”)
• PERT – Pathology Electronic Reporting Taskforce, a CAP committee
• CAP Checklists – contained in each CCP (a.k.a. “Checklists”)
• CAP eCC – electronic Cancer Checklist(s)
Definitions 2

- QAS – Question-Answer Set(s)
- Checklist Template – a single version of a checklist, in a structured data format, such as a database or XML file (a.k.a. “Template”)

Definitions 3

Structured Data Set
- Representation of report data (the eCC answer set) in a standardized and interoperable computer-readable format that can be exchanged between computer systems (e.g., labs and cancer registries)
- Can be transformed into a synoptic report

Synoptic Report
- Human-readable presentation of each required checklist item followed by an answer; inapplicable QAS omitted
- Used directly by treating physicians

Definitions 4

Narrative vs. “Synoptic-like” Reports
Definitions 5

Pathology Electronic Reporting Taskforce (PERT)
- Composed of pathologists and other physicians, cancer registrars, and informaticians
- CAP/CDC-sponsored group to address computerization and standards convergence for the checklist project
- Technical and non-technical issues are addressed
- Address issues related to the eCC, and coordination with AJCC, CS, and the CCP
  - Technical and non-technical issues are addressed
- Receives, tests and implements suggestions from vendors, cancer registrars, programmers and physicians
- Restructure the CCP to meet the needs of cancer registries

The CAP Cancer Protocols
- The CAP publishes cancer protocols as a resource to pathologists in effectively delivering the information necessary to provide quality patient care.
- The “Protocols” consist of cancer case summaries (“checklists”) accompanied by background documentation.
- These widely-used case summaries are sometimes called “synoptic reports.”
**Interoperability and EHR**

**Brief History 1**

The 2009 Version of the Cancer Protocols of the College of American Pathologists
A Continuing Journey From “Guidelines for Pathologists” to “Standards for Multidisciplinary Comprehensive Cancer Care”

**Brief History 2**

<table>
<thead>
<tr>
<th>Table 1. The College of American Pathologists (CAP) Cancer Protocols—Journey From Guidelines to Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td>1986</td>
</tr>
<tr>
<td>1994</td>
</tr>
<tr>
<td>1998</td>
</tr>
<tr>
<td>2001</td>
</tr>
</tbody>
</table>

**Sample Encoded Checklist**

Surgical Pathology Cancer Case Summary (Checklist)

- Where is this captured?
- What is this banner?
- Case number: no version ID
- OPD code: no version ID
- Observed presence: determined, do they belong here?
What’s in the XML? QAS and Ckeys

```xml
<checklist-group header-group-id="10360.100903907" sort-order="100"/>

<title>Interoperability and EHR</title>

8/4/2011

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81 checklists

TUMOR

<table>
<thead>
<tr>
<th>Title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Type</td>
<td>Carcinoma of the breast</td>
</tr>
<tr>
<td>Organ Site</td>
<td>Breast</td>
</tr>
<tr>
<td>Organ Site Code</td>
<td>B200</td>
</tr>
</tbody>
</table>

NAACCR 2010-2011 Webinar Series
Problems 1

- Data element mismatch between AJCC, CCP/eCC, and NAACCR/CS
  - Complex rules needed for data conversion
  - Rolling Releases Chaos?
  - CS lacks data elements for information collected by eCC
  - eCC lacks discrete data elements needed to match all CS elements

Problems 2

- Current eCC XML model too complex; does not adequately represent QAS behavior for vendor implementation

- Suboptimal uptake in the U.S.
  - How can we encourage greater use of eCC?
Coordinating Data Elements
Solving the Problems

Examples: Multiple Primaries, and related issues
A detailed peek inside…

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Coordinating Data Elements – Solving SEER Multiple Primaries (MPs)

Complex Rules, generally involving Tumor Sites and Histologic Types

PERT Phase I – Tumor Sites remodeled in eCC, sometimes involving large additions to the CCP version. MP fixes mostly complete as of Feb. 2011 eCC release.

PERT Phase II – Allow selection of multiple histologic types when needed for SEER MP designation.

PERT Phase III – Allow use of repeating sections for multiple excisions from same patient.

Remodeled Tumor Sites: Support MP Rules

An example schema... Often, these items do not line up well with checklist questions and answer choices

Note new SSFs that now match the CAP checklists...
Coordinating Data Elements

Colon: CS Extension

**Note 1:** Ignore intraluminal extension to adjacent segment(s) of colon/rectum or to the ileum from the cecum; code depth of invasion or extracolonic spread as indicated.

**Note 2:** Codes 600-800 are used for contiguous extension from the site of origin. Discontinuous involvement is coded in CS Mets at DX.

**Note 3:** Tumor that is adherent to other organs or structures, macroscopically, is classified T4b. However, if no tumor is present in the adhesion, microscopically, the classification should be pT3.

**Note 4:** High grade dysplasia and severe dysplasia are generally not reportable in cancer registries, but if a registry does collect it, code 000 should be used.

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Coordinating Data Elements
Harmonizing the Checklists with Collaborative Staging

- Sometimes, we can alter the checklists to produce 1:1 maps with CS questions and answers
- Sometimes, mapping the checklist to CS will require computer logic to assign CS codes: e.g. *=`* relationships
- The CDC already produces software to turn sets of CS responses into AJCC cancer staging output (TNM stage).
- Currently, we are working on ways to help map eCC data to NAACCR and CS codes for eventual incorporation into the NPCR and SEER data sets.
- In the future, native eCC data items could be included in cancer registry data sets.

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Coordinating Data Elements
Quick Fixes? – Mapping

<table>
<thead>
<tr>
<th>CS Variable</th>
<th>Code Options</th>
<th>Value</th>
<th>Target Table</th>
<th>Target Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor Size</td>
<td>≤ 0.1</td>
<td>CSTumorSize 990</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumor Size</td>
<td>&gt;0 and &lt;98.9</td>
<td>CSTumorSize x10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumor Size</td>
<td>≥98.9</td>
<td>CSTumorSize 989</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Connecting the eCC to the cancer registry world requires a tool that can automatically map or convert data from eCC data sets to NAACCR (CS) data elements.

The version-sensitive mapping rules must be created centrally by domain experts, and then distributed as packaged software (a DLL module) for incorporation into cancer registry software. This module is usually referred to as the “conversion dll”.

The tool used to produce the mapping rules is called the Electronic Rules Editor (ERE).

The conversion dll receives eCC input in NAACCR VoV (v4) HL7 format, and exports sets of CS codes. This functionality can be supported by vendor tools, and will also be supported by the CDC’s eMaRC Plus tool.

The general goals for ERE:

- Create and organize rules generated by subject matter experts by checklist, schema, and NAACCR data element
- Expose a standard vocabulary for creating rules
- Implement user interface features for easing the construction/modification/reuse of rules
- Handle the transition from one eCC or CS release to another
Interoperability and EHR

Coordinating Data Elements
Solving the Problems

• Mismatch between CCP and CS schemas

CS Schemata—Note that they don’t match the checklists.

81 Checklists Currently Available

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NAACCR 2010-2011 Webinar Series 53
Coordinating Data Elements

**eCC & CS: Checklist/Schema Mismatches**

- Protocol Mismatch:
  - CAP: Lip & Oral Cavity, Major Salivary Glands, Larynx, Pharynx

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**Coordinating Data Elements**

**Comprehensive Fixes**

- AJCC, CAP, CDC, CS and NAACCR will investigate ways to coordinate efforts
- The goal is to enable “rolling releases” of state-of-the-art cancer diagnosis and data standards
- The work is just beginning...

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**Coordinating Data Elements**

**Future, Improved eCC Data Standards**

New eCC XML (XDT) schema will provide missing functionality
- Streamlined structure
- Data validation
- Repeating checklist sections
- Selection-dependant actions, Rules, calculations, help links, and more
- Improved ability to map to NAACCR/CS codes
- Room for growth

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Source: uhaweb.hartford.edu/CHAWKINS
Driving eCC Adoption

Barriers to eCC uptake in U.S.

- Cost and complexity of Anatomic Pathology (AP) computer systems
  - Need for installation, training, ongoing support
- Resistance from pathologists
  - Resistance to change
  - Concern about loss of “art of pathology”
  - Concern about time to enter cases
- No “stick” to encourage adoption, as in Canada. What kind of carrot can we offer?

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Driving eCC Adoption

How can we give carrots to everyone? For vendors, pathologists, CTRs...

- Driving pathologist uptake of eCC is key:
  - Will drive sales for AP system vendors
  - Automated NAACCR/CS coding via eCC will allow CTRs to focus on data quality, data completeness, additional data sources, and followup activities.
  - Data reaching central cancer registries will be more timely and complete.

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Driving eCC Adoption

Future

The future electronic Form and Reporting Module (eFRM) from CAP:

- Simple, user friendly application to allow pathologists and allied health workers to quickly enter checklist data into computer in eCC format.
- Will allow storage of patient’s structured data files in XML format on user’s desktop
- Will generate simple synoptic reports
- No database, no advanced functionality...

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Driving eCC Adoption

Future

eFRM data files will be designed for importing into vendor AP and cancer registry computer systems.

Search, analysis, and other functionality will not be included in eFRM, in order to encourage users to adopt more advanced vendor solutions.

In addition to encouraging uptake by pathologists, eFRM could provide an approach for manually-assisted conversion of current narrative or paper-checklist pathology reports into eCC format. CTRs could be involved in this activity.

The CAP eCC Production Team

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The CAP eCC Extended Family

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- Andrea Maclean
- Josh Mazuryk
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- Robin Rossi
- Jennifer Seiffert
- Jim Sorace, MD
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- and more on the way...

Any Questions?

NAACCR XML
A New Data Exchange Standard

Clinical Data Workgroup
Isaac Hands (isaac@kcr.uky.edu)
Kentucky Cancer Registry
Overview

• Current Data Exchange Standard
• Why Change?
• Why XML (eXtensible Markup Language)?
• XML Pilot 1
• Current XML Draft Standard
• Next Steps

Current Data Exchange Standard

<table>
<thead>
<tr>
<th>Name</th>
<th>Size (characters)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Update</td>
<td>1543</td>
</tr>
<tr>
<td>Incidence</td>
<td>3339</td>
</tr>
<tr>
<td>Confidential</td>
<td>5564</td>
</tr>
<tr>
<td>Full case abstract</td>
<td>22824</td>
</tr>
<tr>
<td>Modified record</td>
<td>22824</td>
</tr>
</tbody>
</table>

Robust, since 1995 (?)
Simple to implement and communicate
Maintained within NAACCR community
Interoperability and EHR

Current Data Exchange Standard

Data Item Count by Section

<table>
<thead>
<tr>
<th>Section</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Identification</td>
<td>50</td>
</tr>
<tr>
<td>Demographic</td>
<td>55</td>
</tr>
<tr>
<td>Follow-up</td>
<td>45</td>
</tr>
<tr>
<td>Hospital</td>
<td>40</td>
</tr>
<tr>
<td>Overrides / System</td>
<td>35</td>
</tr>
<tr>
<td>Pathology</td>
<td>30</td>
</tr>
<tr>
<td>Record ID</td>
<td>25</td>
</tr>
<tr>
<td>Special Use</td>
<td>20</td>
</tr>
<tr>
<td>Stage/Prognosis</td>
<td>15</td>
</tr>
<tr>
<td>Text</td>
<td>10</td>
</tr>
<tr>
<td>Treatment 1st</td>
<td>5</td>
</tr>
<tr>
<td>Treatment 2nd, 3rd, 4th</td>
<td>1</td>
</tr>
</tbody>
</table>

Current Data Exchange Standard

Total Field Length by Section

<table>
<thead>
<tr>
<th>Section</th>
<th>Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Identification</td>
<td>175</td>
</tr>
<tr>
<td>Demographic</td>
<td>170</td>
</tr>
<tr>
<td>Follow-up</td>
<td>165</td>
</tr>
<tr>
<td>Hospital</td>
<td>160</td>
</tr>
<tr>
<td>Overrides / System</td>
<td>155</td>
</tr>
<tr>
<td>Pathology</td>
<td>150</td>
</tr>
<tr>
<td>Record ID</td>
<td>145</td>
</tr>
<tr>
<td>Special Use</td>
<td>140</td>
</tr>
<tr>
<td>Stage/Prognosis</td>
<td>135</td>
</tr>
<tr>
<td>Text</td>
<td>130</td>
</tr>
<tr>
<td>Treatment 1st</td>
<td>125</td>
</tr>
<tr>
<td>Treatment 2nd, 3rd, 4th</td>
<td>120</td>
</tr>
</tbody>
</table>

Why Change?

- Modification Cost
- Extensibility
  - State-Specific Data Items
  - Additional Treatment Data
  - Rapidly Changing Coding Standards
- Readability
- Information Density
- Compatibility
Interoperability and EHR 8/4/2011

Why XML?

- Modification Cost
- Extensibility
  - State-Specific Data Items
  - Additional Treatment Data
  - Rapidly Changing Coding Standards
- Readability
- Data Density
- Compatibility

NAACCR

Why XML?

- Record Type enforcement
  - Helps validation
- Models logical structure of patient record
- Better encoding of text
- Ubiquitous software tools

NAACCR

XML Pilot 1

- In 2006, CDA was chosen as the basis for the new XML format
- CDA
  - Clinical Document Architecture standard is intended to specify the encoding, structure and semantics of clinical documents for exchange
  - The CDA specifies that the content of the document consists of a mandatory textual part (which ensures human interpretation of the document contents) and optional structured parts (for software processing).


NAACCR

NAACCR 2010-2011 Webinar Series
XML Pilot 1

- Fall 2006 – Spring 2009
  - “A Pilot Project to Develop and Deploy the Clinical Document Architecture (CDA) for Cancer Registry Abstract Reporting”
- Results of pilot were reported December 2009 to NAACCR Board:
  “...NAACCR should continue to study and explore CDA and its associated component parts, XML and HL7, as a vehicle to send and receive cancer surveillance information, including the cancer abstract report as defined in Standards Volume II as well as clinical documents from the electronic health record.” (p. 30)

XML Pilot 1

- In 2010, Pilot 2 was proposed:
  Duration: 24 months
  Deliverables:
  1. Documentation of exchange format requirements
  2. Design of NAACCR-specific and CDA XML exchange formats
  3. Specification of Pilot exchange format and development of samples and utilities
  4. Support for the Work Group and participating registries
  5. Analysis and Final Report on Pilot objectives
- Pilot 2 was not pursued

Current XML Draft Standard

- Mid 2010: CDA was re-examined as a requirement
  - Difficult to maintain NAACCR standard based on CDA
  - CDA may not be appropriate for NAACCR data exchange
- New direction:
  - CDA is no longer a primary requirement
  - Compatibility with CDA will be investigated at a later date
  - Focus on overcoming current data exchange limitations
  - Standard should be locally maintainable
Current XML Draft Standard

Current XML Draft Standard

- Direct mapping from current fixed-width format to new XML
- Maintainable by NAACCR committee members
  - Simple to read
  - Simple to communicate
- Simple to parse and process in software
- Unlimited state-specific or custom elements
- Unlimited treatment elements

Current XML Draft Standard

Challenges:

- More participation in WG
- Patient-centered vs. Case-centered
- XML Schema definition
- Identify XML tools for viewing, editing, validating
- Define lowest-cost migration path
Next Steps

- Iterate on XML definition
- Decide on XML Schema Language
- Define transmission standard
  - Compression
  - Encryption
  - Metadata
- Test

Questions?

NAACCR Interoperability Webinar
Conclusion & Wrap-up

Ken Gerlach, Chair
NAACCR Interoperability Ad Hoc Committee

August 4, 2011

NAACCR Webinar
Importance of Interoperability

- Cancer registry operations, primarily based upon paper-based systems, need to evolve and grow
  - changes in the healthcare information technology
- Process underway
- If we can achieve our goal of interoperability of cancer registration standards with national standards, we will facilitate standards for real-time reporting of cancer data which will provide registries with more complete and timely data, enable researchers to perform more timely studies and improve patient care and outcomes

Work in Progress

- Need to continue with existing efforts
  - Electronic Pathology
  - Semantic Data
  - Clinical Data
  - Discharge Data
- Expand scope as necessary
  - Tumor Markers/Molecular Markers

Tumor Markers in CSv2

- Collaborative Stage Version 2 (CSv2) included over 70 tumor marker or molecular marker tests (e.g. HER2, KRAS)
- Many are not required by any of the standard setting organizations
- Some tests include two related data items with two distinct value sets
  - Interpretation data item’s value set includes discrete values (e.g. positive, negative, borderline)
  - Lab value groups the continuous numerical values into discrete codes (e.g. Code 020 equals “Range 2 (52) 1,000 – 10,000 ng/ml”).
- Some of these tests included in College of American Pathologists (CAP) cancer checklists.
- The Canadian standard for units of measure often differs from that used in the U.S.
Sample Tumor Marker Tests by Site

<table>
<thead>
<tr>
<th>Sample Tumor Marker Test</th>
<th>Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA 19-9</td>
<td>AmpullaVater, Appendix, PancreasBodyTail, PancreasHead, PancreasOther, Stomach, BileDuctsDistal, BileDuctsIntrahepatic, BileDuctsPerihilar</td>
</tr>
<tr>
<td>Carbohydrate Antigen 125 (CA-125)</td>
<td>Ovary, PeritoneumFemaleGen</td>
</tr>
<tr>
<td>Carcinembryonic Antigen (CEA)</td>
<td>Rectum, SmallIntestine, Stomach, AmpullaVater, Appendix, Colon, BileDuctsDistal, BileDuctsPerihilar</td>
</tr>
</tbody>
</table>

CS Site-Specific Factor 1
Alpha Fetoprotein (AFP) Interpretation

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>000</td>
<td>Test not done</td>
</tr>
<tr>
<td>010</td>
<td>Positive/elevated</td>
</tr>
<tr>
<td>020</td>
<td>Negative/normal; within normal limits</td>
</tr>
<tr>
<td>030</td>
<td>Borderline; undetermined whether positive or negative</td>
</tr>
<tr>
<td>080</td>
<td>Ordered, but results not in chart</td>
</tr>
<tr>
<td>999</td>
<td>Unknown or no information</td>
</tr>
<tr>
<td></td>
<td>Not documented in patient record</td>
</tr>
</tbody>
</table>

CS Site-Specific Factor 3
Alpha Fetoprotein (AFP) Lab Value

•Note 1: Record the highest value as documented in the patient record in ng/ml PRIOR to treatment in this field. Lab value may be recorded in the lab report, history and physical, or clinical statement in the pathology report, etc. For example, a pretreatment AFP of 20 ng/ml would be recorded as 002. A pretreatment AFP of 11,000 ng/ml would be recorded as 200.
•Note 2: Lab values for SSFs 1 and 2 should be from the same laboratory test.
•Note 3: A lab value expressed in ug/L is equivalent to the same value expressed in ng/ml.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>000</td>
<td>0 ng/ml</td>
</tr>
<tr>
<td>001</td>
<td>1 - 19 ng/ml</td>
</tr>
<tr>
<td>002</td>
<td>20 - 29 ng/ml</td>
</tr>
<tr>
<td>003</td>
<td>30 - 39 ng/ml</td>
</tr>
</tbody>
</table>
Draft - Tumor Markers Data WG Charge

1) Document the potential to capture tumor marker tests
2) Ascertain how electronic transmissions are currently being formatted and transmitted
3) Investigate available international standards
4) Recommend a tumor marker transmission format standard for use between healthcare facilities and cancer registries
5) Develop guidance for the cancer surveillance community related to the capture of tumor marker tests
6) Identify existing software or software requirements for cancer
7) Educate the NAACCR community about the existing tumor marker tests, related transmission standards, and responsible entities
8) Communicate with the Csv2 development team findings to expedite the electronic capture and processing of tumor marker tests
9) Work with international standard setting organizations to promote the needs of the cancer registry community in this domain

Interoperability Ad Hoc Committee Work Groups (WG)

- Semantic Data WG
- Discharge Data WG
- Pathology Data WG
  - Volume V WG
- Clinical Data WG
- Tumor Markers Data WG
- Plus monitor national health information technology initiatives

Acknowledgements

- Eric Durbin, Kentucky Cancer Registry
- Sandy (Thames) Jones, Centers for Disease Control and Prevention
- Gary Levin, Florida Cancer Data System
- Dan Curran, Public Health Institute, California Cancer Registry
- Jovanka Harrison, New York State Cancer Registry
- Gemma Lee, Cancer Care Ontario
- Rich Moldwin, College of American Pathologists
- Isaac Hand, Kentucky Cancer Registry
Thank you

• Volunteer opportunities
• Contact Lori Havener at lhavener@naaccr.org

Coming up...

• September 1, 2011
  – Coding Pitfalls
• Registration is open for the 2011-2012 NAACCR Webinar Series