NAACCR Interoperability Activities and the Electronic Health Record

August 4, 2011

Presented by the NAACCR Ad Hoc Interoperability Committee

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Questions

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

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Fabulous Prizes!!!

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For the best question and tip

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

NAACCR Webinar

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Webinar Purpose

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

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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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Wikipedia: image source

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NAACCR Interoperability Ad Hoc Committee 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 …….

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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

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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

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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.

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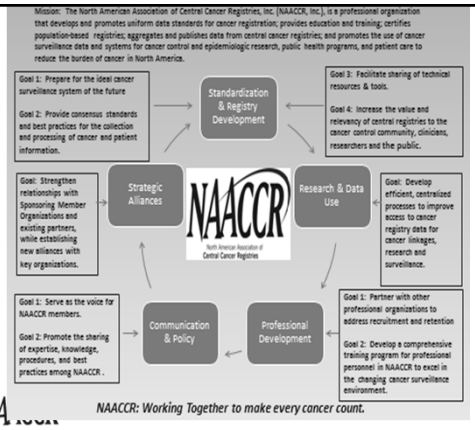

Meaningful Use Overview

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

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

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."[1]**

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

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

ONC Health Information Technology Federal Advisory Committees

- **HIT Policy Committee**
  - Meaningful Use
  - Certification and Adoption
  - Information Exchange
  - NHIN
  - Strategic Plan
  - Privacy & Security Policy
  - Enrollment
  - Governance
  - PCAST Report
  - Quality Measures
- **HIT Standards Committee**
  - Clinical Operations
  - Clinical Quality
  - Privacy & Security
  - Implementation
  - Vocabulary Task Force

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

MEDICARE EP Incentive Payment - Based on First Calendar Year EP receives					
Calendar Year	CY 2011	CY 2012	CY 2013	CY 2014	CY 2015 and later
2011	$18,000				
2012	$12,000	$18,000			
2013	$8,000	$12,000	$15,000		
2014	$4,000	$8,000	$12,000	$12,000	
2015	$2,000	$4,000	$8,000	$8,000	0
2016		$2,000	$4,000	$4,000	0
TOTAL	$44,000	$44,000	$39,000	$24,000	0

Medicaid Incentives for Providers

MEDICAID EP Incentive Payment - Based on First Calendar Year EP receives						
Calendar Year	CY 2011	CY 2012	CY 2013	CY 2014	CY 2015	CY2016
2011	$21,250					
2012	$8,500	$21,250				
2013	$8,500	$8,500	$21,250			
2014	$8,500	$8,500	$8,500	$21,250		
2015	$8,500	$8,500	$8,500	$8,500	$21,250	
2016	$8,500	$8,500	$8,500	$8,500	$8,500	$21,250
2017		$8,500	$8,500	$8,500	$8,500	$8,500
2018			$8,500	$8,500	$8,500	$8,500
2019				$8,500	$8,500	$8,500
2020					$8,500	$8,500
2021						$8,500
TOTAL	$63,750	$63,750	$63,750	$63,750	$63,750	$63,750

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!

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National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

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

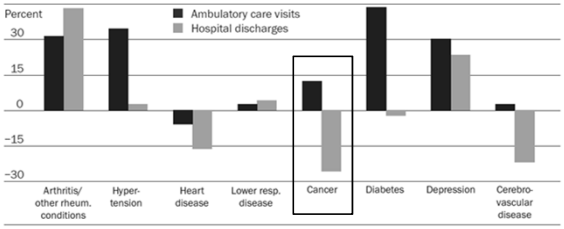
Treatment Information Captured in Central Registries

Treatment/Service	Sensitivity of Registry Data
Mastectomy	95.0%
Lumpectomy	94.9%
Lymph Node Dissection	95.9%
Biopsy	9.8%
Radiation Therapy	72.2%
Chemotherapy	55.6%
Hormone Therapy	36.2%

Malin JL, Kahn KL, Adams J, Kwan L, Laouri M, Ganz PA. Validity of Cancer Registry Data for Measuring the Quality of Breast Cancer Care. Journal of the National Cancer Institute 2002;94(11):835-844.

Shifts in Cancer Treatment Settings

Percentage Change In Age-Adjusted Ambulatory Care Visit (1995–96 And 2005–06) And Hospital Discharge (1996 And 2006) Rates



SOURCE: National Ambulatory Medical Care Survey and National Hospital Ambulatory Medical Care Survey, 1995–96 and 2005–06; and National Hospital Discharge Survey, 1996 and 2006.

Decker SL, Schappert SM, Sisk JE. Use Of Medical Care For Chronic Conditions. *Health Affairs.* Jan-Feb 2009;28(1):26-35,492.

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.

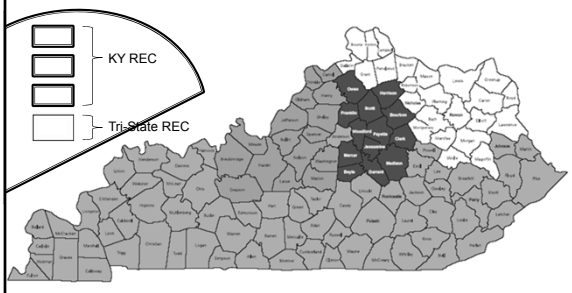
Health Information Exchanges

- 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

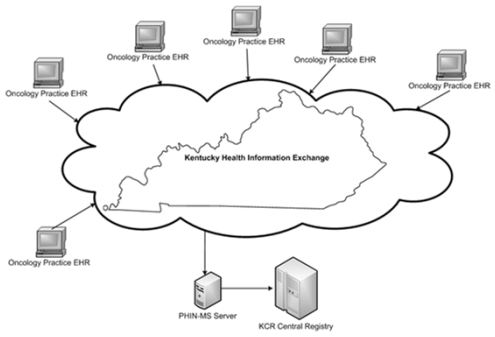
RECs in Kentucky



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."[1]

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

[1]Jaro MA. Prob Probabilistic linkage of large public health data files. Statistics in Medicine. 1995;14(5-7):491-8.

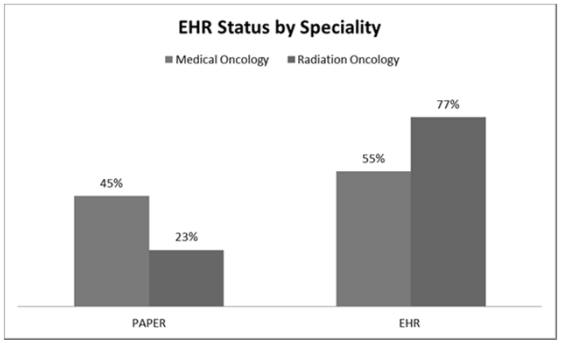
EHR Repository

- 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

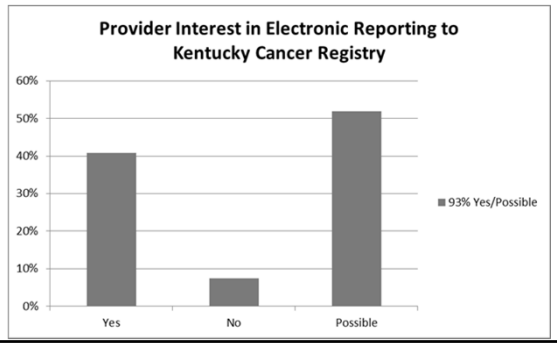
2011 Kentucky Oncology Provider Survey

- 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



Provider Interest in Participating



Early Successes and Challenges

- 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

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.

Kentucky Cancer Registry

Semantic Data Work Group Crosswalk Tables

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

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Presentation Overview

- Definition
- Crosswalk Development Process
- Crosswalk Usages
- Currently Available Crosswalks
- Review of Crosswalks
- Future Crosswalks

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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.

Wikipedia: http://en.wikipedia.org/wiki/Schema_crosswalk

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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

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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)

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Currently Available Crosswalks

- Gender
- Race
- Ethnicity
- Marital Status

http://www.naaccr.org/StandardsandRegistryOperations/InteropInfo.aspx

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Review of Crosswalks

http://www.naaccr.org/StandardsandRegistryOperations/InteropInfo.aspx

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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

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Thank You

Questions?

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

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Discharge Data WG

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

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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 of 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

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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

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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

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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 web site: *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*

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NAHDO

- http://www.nahdo.org

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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

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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

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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

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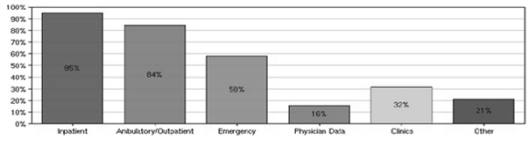
Survey Results

- Discharge data come from a variety of sources



- On average it took six months to a year for the registry to receive the data

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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

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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

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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

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NAHDO Recommendations

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

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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

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NAHDO Joint Statements

- NAHDO-proposed joint statements with NAACCR
- 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

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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

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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

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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

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Break Time

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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

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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**

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2

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

Jovanka Harrison, PhD (Chair)	**Gemma Lee**	**Robin Rossi****
New York State Cancer Registry	Cancer Care Ontario	Cancer Care Ontario
Mayra Alvarez, RHIT, CTR	**Lori A. Havener, CTR**	**Mark Rudolph**
Florida Cancer Data Systems	NAACCR	Florida Cancer Data Systems
Victor Brunka	**Leon Sun**	**Wendy Scharber, RHIT, CTR**
AIM	NCI SEER	Registry Widgets
Wendy Aldinger, RHIA, CTR**	**Carol Kosary, MS**	**Beth Schmidt, MSPH**
Northern Calif. Cancer Center	NCI SEER	Louisiana Tumor Registry
Eric B. Durbin, MS	**Keith Laubham, MS**	**Wendy Blumenthal, MP**
Kentucky Cancer Registry	Arizona Cancer Registry	CDC/NPCR
Ken Gerlach, MPH, CTR	**Andrea MacLean****	**Dan Curran**
CDC/NPCR	CPAC	California Cancer Registry
Barry Gordon, PhD	**Varun Mediratta**	**Kevin Zhao**
C/Net Solutions	Cancer Care Ontario	Greater Bay Cancer Registry
Catherine Grafel-Anderson	**Richard Moldwin, MD, PhD**	**Ted Klein**
Hawaii Tumor Registry	CAP DIHIT	Klein Consulting
David Lyalin, PhD*	**Lalin Perera***	
	CDC/NPCR	Cancer Care Ontario

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** Co-Chair of NAACCR Path Data CAP Checklist WG;
*Member of NAACCR Path Data CAP Checklist WG

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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.

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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

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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.

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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/**

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A 'Brief' on Health Level Seven (HL7)

- **The HL7 Standard**
  - **An HL7 2.x message is comprised of a group of segments ordered in a *hierarchical* and defined sequence.**

Example (HL7 snippet):

PID|1||123456789^^^^SS|000039^^^^LR|McMuffin^Candy^^^Ms.|…<CR>

PV1|N||||594110NY^Attending^Doctor^^^DR|…<CR>

OBR|1||97865|11529-5^SURG PATH REPORT^LN^^PATH REPORT^L|…<CR>

OBX|1|TX|22636-5^CLIN HISTORY^LN||white F with (L) UOQ breast mass|…<CR>

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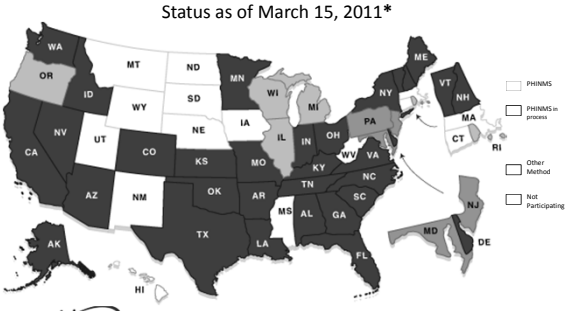
Volume V, Version 2.2-- A Success

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



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*Adapted from http://www.cdc.gov/cancer/npcr/informatics/aerro/activities/epath.htm

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".

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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".**

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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.**

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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.

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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.

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Thank You!

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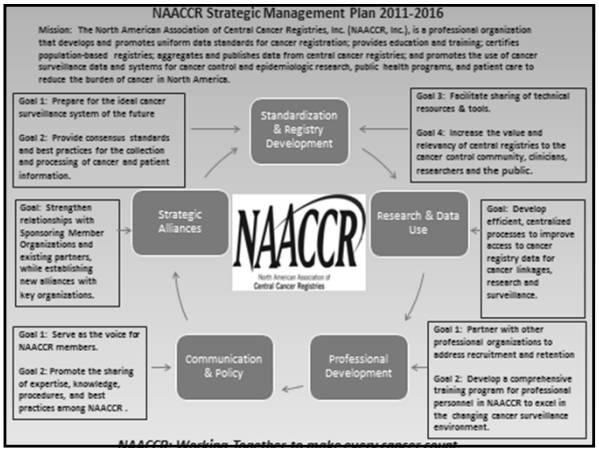

The Ontario Pathology Reporting Project
Overview, Key Success Factors, Lessons Learned

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

Gemma Lee

NAACCR

Proposed Agenda

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

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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)

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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

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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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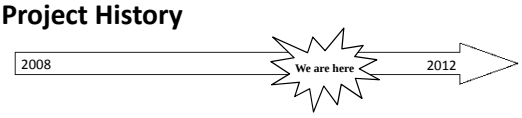
Project History



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

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Implementation Overview

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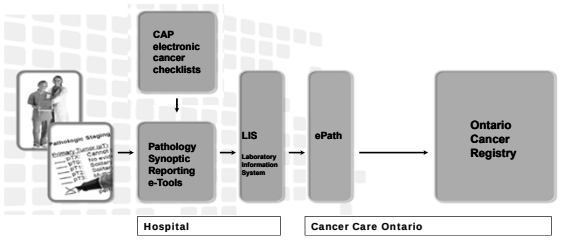
Enabling Synoptic Reporting at Hospitals



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.

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Initiate, engage and coordinate hospital implementations with the vendor community

Vendor Engagement

Vendor Initiation	Hospital Scheduling
• 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 comment	• 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

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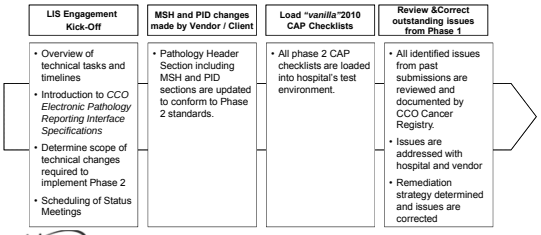
Commence the technical upgrade modifications required for phase 2 and load the 2010 CAP checklist into the test environment

Technical Engagement



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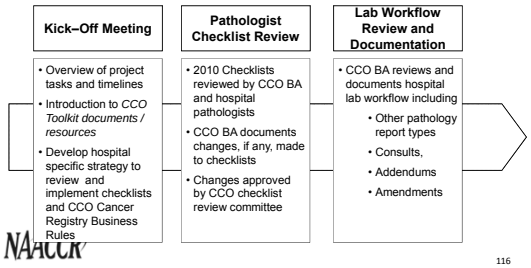
Engagement of the entire hospital team & checklist review includes providing the scope and timelines of the project and reviewing the checklists and workflow with the pathologist(s).

Pathologist Engagement & CAP Checklist Review



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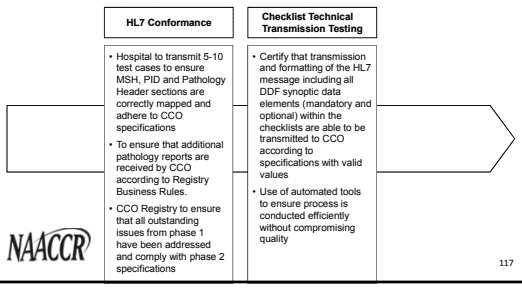
Technical and Registry Compliance Testing are important to the success of the project and require coordination between CCO and hospital resources

HL7 Conformance and CAP Checklist Transmission Testing



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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	Closure & Disbursement	CCO Pathology Reporting
• 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	• 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 resumes creation and distribution of provincial, LHIN and hospital-based reports • Reports can be accessed through iPort™, CCO's web-based business intelligence tool

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Current Status

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Current Synoptic Pathology Reporting Capability

LHIN	Number of hospitals implemented synoptic DDF reporting	Number of hospitals	% of hospitals
All	90	110	82%
1	5	5	100%
2	14	16	88%
3	6	6	100%
4	9	9	100%
5	1	2	50%
6	3	3	100%
7	6	7	86%
8	6	6	100%
9	7	7	100%
10	5	6	83%
11	9	13	69%
12	5	5	100%
13	13	19	68%
14	1	6	17%

Over 90% of all electronic reporting PIMS hospitals have enabled synoptic reporting capability

LHIN	Number with DDF reporting	Number of hospitals	%
All	89	97	92%
1	5	5	100%
2	14	16	88%
3	6	6	100%
4	9	9	100%
5	1	2	50%
6	3	3	100%
7	6	7	86%
8	6	6	100%
9	7	7	100%
10	5	5	100%
11	9	9	100%
12	5	5	100%
13	12	16	75%
14	1	1	100%

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Ontario Pathology reports in Transition

Proportion of Ontario hospitals reporting cancer pathology to CCO, by level of standardization from narrative to synoptic

Reporting Level	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6
Description	• Narrative • No CAP content • Single text field data	• Narrative • CAP content • Single text field data	• Level 2 + • Synoptic-like structured format	• Level 3 + • Electronic reporting tools using drop -down menus	• Level 4 + • Standardized reporting language • Data elements stored in discrete data fields	• Level 5 + • Common data and messaging standards with C-Keys, SNOMED CT or other encoding
% Ontario Hospitals 2004-05	5%	40%	50%	5%	0%	0%
% Ontario Hospitals 2006-07	0%	5%	70%	25%	0%	0%
% Ontario Hospitals 2008-09	0%	0%	65%	17%	18%	0%
% Ontario Hospitals 2009-10	0%	0%	20%	2%	78%	0%
% Ontario Hospitals Mar 2011	0%	0%	16%	2%	50%	32%
% Ontario Hospitals 2011-12 projection	0%	0%	≤10%	0%	0%	90%+

82% with discrete synoptic reporting

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

Ontario hospitals includes 110 acute care facilities - 59 primary and 51 secondary. Primary sites submit cancer pathology reports directly to the Ontario Cancer Registry through Ontario's Path Information Management System (PIMS) or via fax/mail (6 sites). Primary sites may also report cancer pathology for secondary hospitals. Private labs and paediatric facilities are not included.

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

Overall Satisfaction Score (Scale 1-5; with 5 = significantly better than narrative reports)	Clinicians Mean (SD)	Pathologists Mean (SD)
Your overall satisfaction with synoptic pathology reporting process	4.52 (.991)	4.08 (1.34)
Your overall satisfaction l level with the information provided by synoptic reports.	4.85 (.901)	4.08 (1.44)

Sample size = 27 Hospitals; 970 Clinicians	
Speciality Area	**Response Rate**
Pathologist	68%
Surgeon	39%
Medical Oncologist	45%
Radiation Oncologist	55%
Overall	51%

Correlation between overall satisfactions with the level of information provided by standardized synoptic reports.	Clinician	Pathologist
Reports are complete for the purpose of clinical decision making	.750**	NA
Ease of finding information required for clinical decision making	.663**	.510**
Facilitates consistent approach to diagnostic and prognostic factors	.717**	.638**
** Correlation is significant at the 0.01 level (2-tailed)		

Key Success Factors, Challenges and Lessons Learned

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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 HL-7 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

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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 teams understand system capabilities, features and limitations

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Questions?

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cap

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**
  - **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**
  - **Current Problems, Coordinating Data Elements**
- **Describe how the eCC is evolving to interface with vendor systems (now and future plans)**
  - **Driving eCC Adoption**

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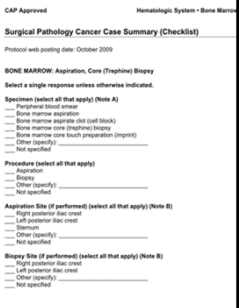
Definitions 1

- **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)**



CAP Approved Hematologic System • Bone Marrow

Surgical Pathology Cancer Case Summary (Checklist)

Protocol web posting date: October 2009

BONE MARROW: Aspiration, Core (Trephine) Biopsy

Select a single response unless otherwise indicated.

Specimen (select all that apply) (Note A)
___ Peripheral blood smear
___ Bone marrow aspiration
___ Bone marrow aspirate clot (cell block)
___ Bone marrow core (trephine) biopsy
___ Bone marrow core touch preparation (imprint)
___ Other (specify): _____
___ Not specified

Procedure (select all that apply)
___ Aspiration
___ Biopsy
___ Other (specify): _____
___ Not specified

Aspiration Site (if performed) (select all that apply) (Note B)
___ Right posterior iliac crest
___ Left posterior iliac crest
___ Sternum
___ Other (specify): _____
___ Not specified

Biopsy Site (if performed) (select all that apply) (Note B)
___ Right posterior iliac crest
___ Left posterior iliac crest
___ Other (specify): _____
___ Not specified

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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")**
- **XML Document Template (XDT) – The XML representation of a Template.**

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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**

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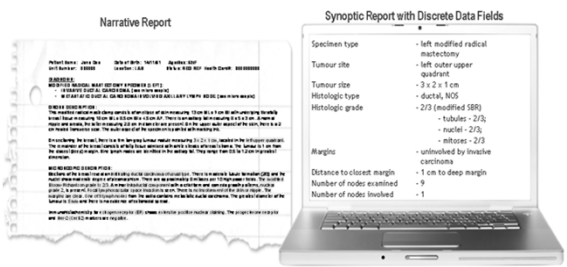
Definitions 4
Narrative vs. "Synoptic-like" Reports



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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

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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."

Protocol for the Examination of Specimens from Patients with Primary Carcinoma of the Colon and Rectum

Well-differentiated neuroendocrine neoplasms (carcinoid tumors) are not included.

Based on AJCC/UICC TNM, 7th edition
Protocol web posting date: October 2009

Procedures
- Excisional Biopsy (Polypectomy)
- Local Excision (Transanal Disk Excision)
- Colectomy (Total, Partial, or Segmental Resection)
- Rectal Resection (Low Anterior Resection or Abdominoperineal Resection)

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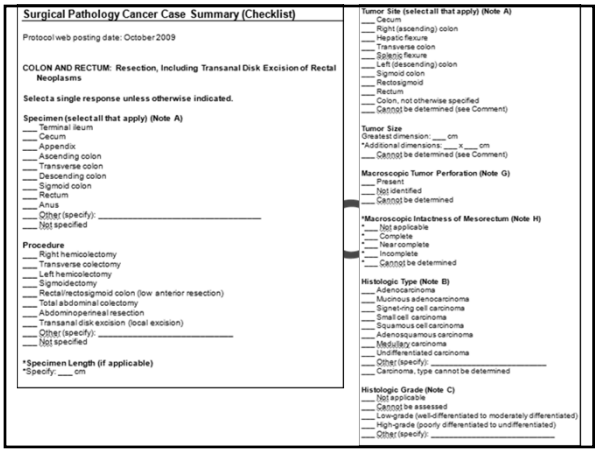

Surgical Pathology Cancer Case Summary (Checklist)

Protocol web posting date: October 2009

COLON AND RECTUM: Resection, Including Transanal Disk Excision of Rectal Neoplasms

Select a single response unless otherwise indicated.

Specimen (select all that apply) (Note A)
___ Terminal ileum
___ Cecum
___ Appendix
___ Ascending colon
___ Transverse colon
___ Descending colon
___ Sigmoid colon
___ Rectum
___ Anus
___ Other (specify): _____
___ Not specified

Procedure
___ Right hemicolectomy
___ Transverse colectomy
___ Left hemicolectomy
___ Sigmoidectomy
___ Rectal/rectosigmoid colon (low anterior resection)
___ Total abdominal colectomy
___ Abdominoperineal resection
___ Transanal disk excision (local excision)
___ Other (specify): _____
___ Not specified

***Specimen Length (if applicable)**
*Specify: ___ cm

Tumor Site (select all that apply) (Note A)
___ Cecum
___ Right (ascending) colon
___ Hepatic flexure
___ Transverse colon
___ Splenic flexure
___ Left (descending) colon
___ Sigmoid colon
___ Rectosigmoid
___ Rectum
___ Colon, not otherwise specified
___ Cannot be determined (see Comment)

Tumor Size
Greatest dimension: ___ cm
*Additional dimensions: ___ x ___ cm
___ Cannot be determined (see Comment)

Macroscopic Tumor Perforation (Note G)
___ Present
___ Not identified
___ Cannot be determined

***Macroscopic Intactness of Mesorectum (Note H)**
*___ Not applicable
*___ Complete
*___ Near complete
*___ Incomplete
*___ Cannot be determined

Histologic Type (Note B)
___ Adenocarcinoma
___ Mucinous adenocarcinoma
___ Signet-ring cell carcinoma
___ Small cell carcinoma
___ Squamous cell carcinoma
___ Adenosquamous carcinoma
___ Medullary carcinoma
___ Undifferentiated carcinoma
___ Other (specify): _____
___ Carcinoma, type cannot be determined

Histologic Grade (Note C)
___ Not applicable
___ Cannot be assessed
___ Low-grade (well-differentiated to moderately differentiated)
___ High-grade (poorly differentiated to undifferentiated)
___ Other (specify): _____

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"

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Brief History 2

Table 1. The College of American Pathologists (CAP) Cancer Protocols—Journey From Guidelines to Standards

1986	"Guidelines for Data to Be Included in Consultation Reports on Breast Cancer, Bladder Cancer, and Hodgkin's Disease" was the first set of cancer protocols published in a CAP publication.
1992	Richard L. Kempson, MD, published "The time is now: checklists for surgical pathology reports" in *Archives of Pathology & Laboratory Medicine.*
1994–1998	Protocols for gastrointestinal lymphoma and carcinomas of the prostate, colon, lung, ovary, breast, head and neck, ampulla of Vater, esophagus, stomach, exocrine pancreas, and bladder were published in *Archives of Pathology & Laboratory Medicine.*
1998–2000	CAP published 32 protocols in the manual *Reporting on Cancer Specimens: Protocols and Case Summaries* (1st and 2nd editions).
2001	American College of Surgeons Commission on Cancer (COC) develops Standard 4.6 that requires for COC accreditation the reporting of the scientifically validated elements listed in the CAP cancer protocols. Implementation of Standard 4.6 gets deferred to 2004 to allow institutions time to integrate these elements into their reporting informatics systems.
2003	2003 edition of *Reporting on Cancer Specimens: Case Summaries and Background Documentation* 3rd edition (Carolyn Compton, MD, PhD, editor) contained 42 protocols. Protocols were updated in conjunction with the 6th edition of American Joint Committee on Cancer (AJCC) *Cancer Staging Manual.* First version of the SNOMED CT (Systematic Nomenclature of Medicine—Clinical Terms)-encoded cancer checklists (paper-based version only).
2004	COC Standard 4.6 is in effect requiring COC-accredited institutions to report the scientifically validated elements listed in the CAP cancer protocols. CAP Laboratory Accreditation Program (LAP) revises accreditation checklist question ANP.12350 recommending that laboratories include all the scientifically validated elements listed in the CAP cancer protocols in definitive cancer reports (phase 2). This is a recommendation in the note not a requirement.

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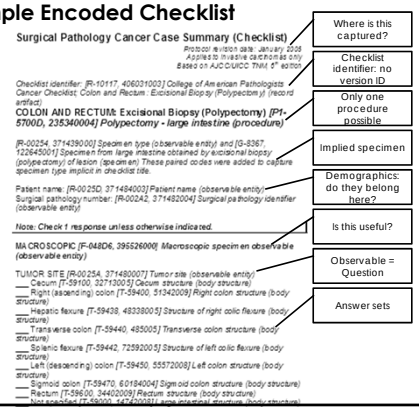
Sample Encoded Checklist



2005	CAP Cancer Committee forms 11 cancer review panels encompassing the major subspecialties of surgical pathology. These panels contain 10 to 20 multidisciplinary members who review existing and develop new CAP cancer protocols. Centers for Disease Control and Prevention (CDC) releases *Report on the Reporting Pathology Protocols for Colon and Rectum Cancers Project*. Atlanta, GA: Department of Health and Human Services (HHS), CDC, National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP); 2005. This project focused on implementing and improving the reporting of information from the SNOMED CT–encoded CAP colon and rectum cancer checklists.
2006	The Centers for Medicare and Medicaid Services (CMS) accepts the complete reporting of cancer based on the CAP breast and colon protocols as the bases for newly developed pay for performance initiatives. The AJCC includes members of the CAP cancer review panels on its disease-site task forces to develop the elements of the 7th edition of the AJCC *Cancer Staging Manual*.
2007	First release of an electronic version of the SNOMED CT–encoded cancer checklists in an Access database.
2008	CAP establishes the Diagnostic Intelligence and Health Information Technology (DIHIT) Committee and also forms under it the Pathology Electronic Reporting Taskforce (PERT) with a mission to "advance the implementation of the CAP Cancer Checklists using health information technology."
2009	CAP updates 55 protocols for the 2009 edition of *Reporting on Cancer Specimens* (Mahul B. Amin, MD, and M. Kay Washington, MD, PhD, editors) in conjunction with the release of the AJCC *Cancer Staging Manual* 7th edition. CAP cancer protocol review panel (CPRP) lead pathologists are actively engaged in the formulation of AJCC staging systems. The entire body of the CAP cancer protocols are available on cap.org, and additionally, the breast, colon, prostate, lung, and melanoma protocols are published in *Archives of Pathology & Laboratory Medicine*. CAP LAP releases 2 new accreditation checklist questions requiring a self-audit for the completeness of cancer reports based on the CAP cancer protocols (phase 1) and the inclusion of a synoptic section with the staging elements (phase 0). COC offers commendation for COC-accredited institutions that include a synoptic section in definitive cancer reports with the scientifically validated elements listed in the CAP cancer protocols. First release of the XML version of the CAP electronic cancer checklists (eCCs), which includes SNOMED CT codes. The Canadian Association of Pathology endorses the use of the CAP cancer protocols for reporting cancer in Canada. The CAP creates the Pathology & Laboratory Quality Center that will assist with the development and distribution of CAP guidelines and white papers.
2010	The 7th edition of the AJCC *Cancer Staging Manual* and the 2009 CAP cancer protocols take effect for patient reporting. CAP releases 10 new protocols for a total of 65 protocols.

81 checklists

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What's in the XML? QAS and Ckeys

```
<template-body xmlns="">
  <header-group header-group-id="15360.100004300" sort-order="100">
    <required>true</required>
    <title>SPECIMEN</title>
    <header-group-items>
      <question question-id="15497.100004300" sort-order="200" question-fillin="false" locked="false"
        <required>true</required>
        <title>Specimen (Note A)</title>
        <authority-required>
          <authority-id>PERT: Pathology Electronic Reporting Taskforce(CAP)</authority-id>
        </authority-required>
        <fixed-list-answer allow-multiple-selection="true">
          <fixed-list-item answer-id="15498.100004300" sort-order="300">
            <title>Terminal ileum</title>
          </fixed-list-item>
          <fixed-list-item answer-id="15499.100004300" sort-order="400">
            <title>Cecum</title>
          </fixed-list-item>
          <fixed-list-item answer-id="15500.100004300" sort-order="500">
            <title>Appendix</title>
          </fixed-list-item>
          <fixed-list-item answer-id="15501.100004300" sort-order="600">
            <title>Ascending colon</title>
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          <fixed-list-item answer-id="15502.100004300" sort-order="700">
            <title>Transverse colon</title>
          </fixed-list-item>
```
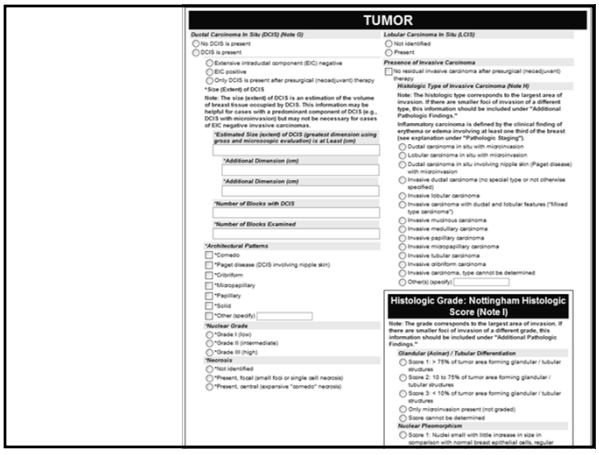
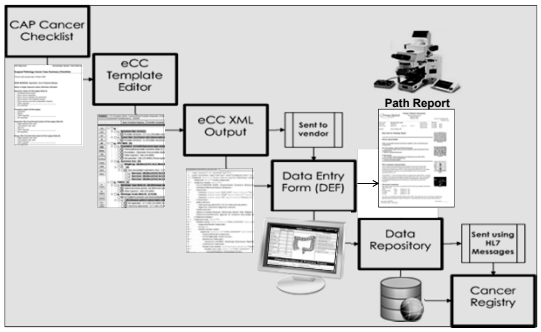



eCC Components - Current Status



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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

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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?

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Coordinating Data Elements
Solving the Problems

Examples: Multiple Primaries, and related issues

A detailed peek inside…

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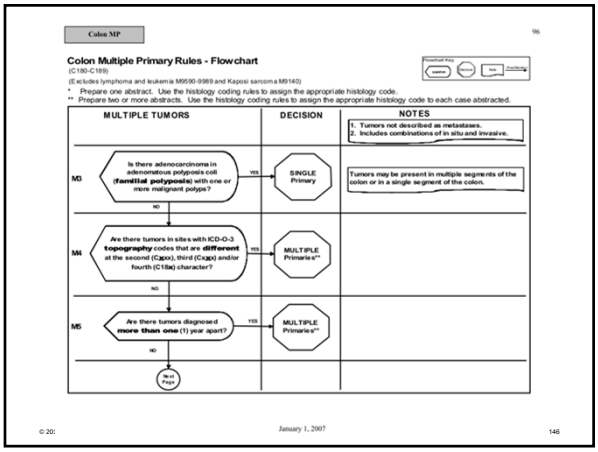

Colon MP

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Colon Multiple Primary Rules - Flowchart

(C180-C189)

(Excludes lymphoma and leukemia M9590-9989 and Kaposi sarcoma M9140)

* Prepare one abstract. Use the histology coding rules to assign the appropriate histology code.

** Prepare two or more abstracts. Use the histology coding rules to assign the appropriate histology code to each case abstracted.

MULTIPLE TUMORS	DECISION	NOTES
		1. Tumors not described as metastases. 2. Includes combinations of in situ and invasive.
M3 Is there adenocarcinoma in adenomatous polyposis coli (**familial polyposis**) with one or more malignant polyps? — YES	SINGLE Primary	Tumors may be present in multiple segments of the colon or in a single segment of the colon.
NO		
M4 Are there tumors in sites with ICD-O-3 **topography** codes that are **different** at the second (C**x**xx), third (C0**x**x) and/or fourth (C18**x**) character? — YES	MULTIPLE Primaries**	
NO		
M5 Are there tumors diagnosed **more than one** (1) year apart? — YES	MULTIPLE Primaries**	
NO		
M-01 Page		

© 20

January 1, 2007

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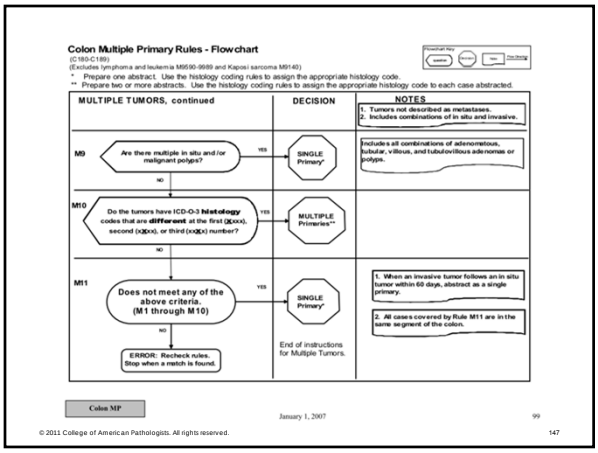

Colon Multiple Primary Rules - Flowchart

(C180-C189)

(Excludes lymphoma and leukemia M9590-9989 and Kaposi sarcoma M9140)

* Prepare one abstract. Use the histology coding rules to assign the appropriate histology code.

** Prepare two or more abstracts. Use the histology coding rules to assign the appropriate histology code to each case abstracted.

MULTIPLE TUMORS, continued	DECISION	NOTES
		1. Tumors not described as metastases. 2. Includes combinations of in situ and invasive.
M9 Are there multiple in situ and/or malignant polyps? — YES	SINGLE Primary*	Includes all combinations of adenomatous, tubular, villous, and tubulovillous adenomas or polyps.
NO		
M10 Do the tumors have ICD-O-3 **histology** codes that are **different** at the first (**x**xxx), second (x**x**xx), or third (xx**x**x) number? — YES	MULTIPLE Primaries**	
NO		
M11 Does not meet any of the above criteria. (M1 through M10) — YES	SINGLE Primary*	1. When an invasive tumor follows an in situ tumor within 60 days, abstract as a single primary. 2. All cases covered by Rule M11 are in the same segment of the colon.
NO		
ERROR: Recheck rules. Stop when a match is found.	End of instructions for Multiple Tumors.	

Colon MP

January 1, 2007

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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.

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Remodeled Tumor Sites: Support MP Rules

SPECIMEN

Specimen (Note A)
- Terminal ileum
- Cecum
- Appendix
- Ascending colon
- Transverse colon
- Descending colon
- Sigmoid colon
- Rectum
- Anus
- Other (specify)
- Not specified

Procedure
- Right hemicolec
- Transverse colec
- Left hemicolecto
- Sigmoidectomy
- Rectal / rectosig
- Total abdominal
- Abdominoperine
- Transanal disk e
- Other (specify)
- Not specified

**Specify Specimen Length (cm) (if applicable)*

Primary Tumor Site (Note A)
- Cecum
- Right (ascending) colon
- Hepatic flexure
- Transverse colon
- Splenic flexure
- Left (descending) colon
- Sigmoid colon
- Rectosigmoid
- Rectum
- Colon, not otherwise specified
- Cannot be determined (explain)

Additional Sites Involved by Tumor (Note A)
- Cecum
- Right (ascending) colon
- Hepatic flexure
- Transverse colon
- Splenic flexure
- Left (descending) colon
- Sigmoid colon
- Rectosigmoid
- Rectum
- Colon, not otherwise specified
- Cannot be determined (explain)
- None identified

Multiple Primary Sites (e.g., hepatic flexure and transverse colon)
- Additional primary site(s) present

Please complete a separate checklist for each primary site

Macroscopic Tumor Perforation (Note G)
- Present
- Not Identified
- Cannot be determined

Tumor Site (select all that apply) (Note A)
- ___ Cecum
- ___ Right (ascending) colon
- ___ Hepatic flexure
- ___ Transverse colon
- ___ Splenic flexure
- ___ Left (descending) colon
- ___ Sigmoid colon
- ___ Rectosigmoid
- ___ Rectum
- ___ Colon, not otherwise specified
- ___ Cannot be determined (see Comment)

Colon

C18.0-C18.9 Excluding Appendix (C18.1)

- C18.0 Cecum
- C18.2 Ascending colon
- C18.3 Hepatic flexure of colon
- C18.4 Transverse colon
- C18.5 Splenic flexure of colon
- C18.6 Descending colon
- C18.7 Sigmoid colon
- C18.8 Overlapping lesion of colon
- C18.9 Colon, NOS

An example schema-

Often, these items do not line up well with checklist questions and answer choices

eCC now matches CS Site Codes

CS Tumor Size
CS Extension
CS Tumor Size/Ext Eval
CS Lymph Nodes
CS Lymph Nodes Eval
Reg LN Pos
Reg LN Exam
CS Mets at DX
CS Mets Eval
CS Site-Specific Factor 1
Carcinoembryonic Antigen (CEA)
CS Site-Specific Factor 2
Clinical Assessment of Regional Lymph Nodes
CS Site-Specific Factor 3
Carcinoembryonic Antigen (CEA) Lab Value
CS Site-Specific Factor 4
Tumor Deposits
CS Site-Specific Factor 5
Tumor Regression Grade
CS Site-Specific Factor 6
Circumferential Resection Margin (CRM)

Note new SSFs that now match the CAP checklists

CS Site-Specific Factor 7
Microsatellite Instability
CS Site-Specific Factor 8
Perineural Invasion
CS Site-Specific Factor 9
KRAS
CS Site-Specific Factor 10
18q Loss of Heterozygosity (LOH)
CS Site-Specific Factor 11 = 988
CS Site-Specific Factor 12 = 988
CS Site-Specific Factor 13 = 988
CS Site-Specific Factor 14 = 988
CS Site-Specific Factor 15 = 988
CS Site-Specific Factor 16 = 988
CS Site-Specific Factor 17 = 988
CS Site-Specific Factor 18 = 988
CS Site-Specific Factor 19 = 988
CS Site-Specific Factor 20 = 988
CS Site-Specific Factor 21 = 988
CS Site-Specific Factor 22 = 988
CS Site-Specific Factor 23 = 988
CS Site-Specific Factor 24 = 988

Coordinating Data Elements
Colon: CS Extension

CS Notes – illustrates the complexity of mapping to the eCC

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.

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.**

Coordinating Data Elements

Quick Fixes? – Mapping

CS Variables	(And/OR)	IF Field	IF Value	Then	Target Table (Variable)	Target Value	Final Value
							Final value is Target Value in the following order: Exact 989, if value X 10, 990, 999
CSTumorSize		Tumor Size:Greatest Dimension	≤ 0.1		CSTumorSize	990	
CSTumorSize		Tumor Size	Cannot be determined		CSTumorSize	999	
CSTumorSize		Tumor Size:Greatest Dimension	>0 and <98.9		CSTumorSize	x10	
CSTumorSize		Tumor Size:Greatest Dimension	>=98.9		CSTumorSize	989	

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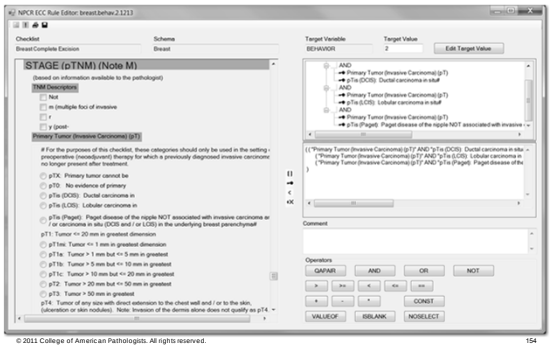
Coordinating Data Elements
Better Fixes - Rules



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Coordinating Data Elements
Mapping eCC to CS – The ERE Tool

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 VolV (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.

Coordinating Data Elements
Mapping eCC to CS – The ERE 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

Coordinating Data Elements Solving the Problems

- **Mismatch between CCP and CS schemas**

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CS Schemata-

Note that they don't match the checklists.

TNM 7 Schema List

Natural Order • Revision-date Order • **Alphabetical Order** •

AdnexaUterineOther	GISTSmallIntestine	MelanomaLarynxGlottic	PalateSoft
AdrenalGland	GISTStomach	MelanomaLarynxOther	PancreasBodyTail
AmpullaVater	GumLower	MelanomaLarynxSubglottic	PancreasHead
Anus	GumOther	MelanomaLarynxSupraglottic	PancreasOther
Appendix	GumUpper	MelanomaLipLower	ParotidGland
BileDuctsDistal	HeartMediastinum	MelanomaLipOther	Penis
BileDuctsIntraHepat	HemeRetic	MelanomaLipUpper	Peritoneum
BileDuctsPerihilar	Hypopharynx	MelanomaMouthOther	PeritoneumFemaleGen
BiliaryOther	IllDefinedOther	MelanomaNasalCavity	PharyngealTonsil
Bladder	IntracranialGland	MelanomaNasopharynx	PharynxOther
Bone	KaposiSarcoma	MelanomaOropharynx	Placenta
Brain	KidneyParenchyma	MelanomaPalateHard	Pleura
Breast	KidneyRenalPelvis	MelanomaPalateSoft	Prostate
BuccalMucosa	LacrimalGland	MelanomaPharynxOther	Rectum
CarcinoidAppendix	LacrimalSac	MelanomaSinusEthmoid	RespiratoryOther
Cervix	LarynxGlottic	MelanomaSinusMaxillary	Retinoblastoma
CNSOther	LarynxOther	MelanomaSinusOther	RetroperitoneumSalivaryGlandOther
Colon	LarynxSubglottic	MelanomaSkin	Scrotum
Conjunctiva	LarynxSupraglottic	MelanomaTongueAnterior	SinusEthmoid
CorpusAdenosarcoma	LipLower	MelanomaTongueBase	SinusMaxillary
CorpusCarcinoma	LipOther	MerkelCellPenis	SinusOther
CorpusSarcoma	LipUpper	MerkelCellScrotum	Skin
CysticDuct	Liver	MerkelCellSkin	SkinEyelid
DigestiveOther	Lung	MerkelCellVulva	SmallIntestine
EndocrineOther	Lymphoma	MiddleEar	SoftTissue
EpiglottisAnterior	LymphomaOcularAdnexa	MouthOther	Stomach
Esophagus	MelanomaBuccalMucosa	MycosisFungoides	SubmandibularGland
EsophagusGEJunction	MelanomaChoroid	NasalCavity	Testis
EyeOther	MelanomaCiliaryBody	Nasopharynx	Thyroid
FallopianTube	MelanomaConjunctiva	NETAmpulla	TongueAnterior
FloorMouth	MelanomaEpiglottisAnterior	NETColon	TongueBase
Gallbladder	MelanomaEyeOther	NETRectum	Trachea
GenitalFemaleOther	MelanomaFloorMouth	NETSmallIntestine	Urethra
GenitalMaleOther	MelanomaGumLower	NETStomach	UrinaryOther
GISTAppendix	MelanomaGumOther	Orbit	Vagina
GISTColon	MelanomaGumUpper	Oropharynx	Vulva
GISTEsophagus	MelanomaHypopharynx	Ovary	
GISTPeritoneum	MelanomaIris	PalateHard	
GISTRectum			

Coordinating Data Elements 81 Checklists Currently Available

ADRENAL GLAND: Biopsy (Co...	HEPATOCELLULAR CARCINOMA:...	RETINOBLASTOMA: Enucleati...
AMPULLA OF VATER: Ampulle...	HODGKIN LYMPHOMA: Biopsy,...	RHABDOMYOSARCOMA AND RELA...
ANUS: Abdominoperineal Re...	INTRAHEPATIC BILE DUCTS: ...	Small Intestine and Ampul...
ANUS: Excisional Biopsy o...	INVASIVE CARCINOMA OF THE...	SMALL INTESTINE: Segmenta...
Appendix, Neuroendocrine ...	KIDNEY: Biopsy...	SOFT TISSUE: Biopsy...
APPENDIX: Resection (Appe...	KIDNEY: Nephrectomy, Part...	SOFT TISSUE: Resection...
BONE MARROW: Aspiration, ...	KIDNEY: Resection for Ped...	SQUAMOUS CELL CARCINOMA O...
BONE: Biopsy...	LARYNX (SUPRAGLOTTIS, GLO...	Stomach, Neuroendocrine T...
BONE: Resection...	LIP AND ORAL CAVITY: Inci...	STOMACH: Local Resection,...
BRAIN/SPINAL CORD: Biopsy...	LUNG: Resection...	TESTIS: Radical Orchiecto...
Colon and Rectum Neuroend...	MAJOR SALIVARY GLANDS: In...	TESTIS: Retroperitoneal L...
COLON AND RECTUM: Excisio...	MELANOMA OF THE SKIN: Bio...	THYMUS: Resection...
COLON AND RECTUM: Resecti...	Merkel Cell Carcinoma of ...	THYROID GLAND: Resection...
DCIS OF THE BREAST: Comp...	NASAL CAVITY AND PARANASA...	TROPHOBLAST: Dilation and...
DISTAL EXTRAHEPATIC BILE ...	NEUROBLASTOMA: Resection,...	URETER, RENAL PELVIS: Bio...
ENDOMETRIUM: Hysterectomy...	NON-HODGKIN LYMPHOMA/LYMP...	URETER: Resection...
ESOPHAGUS: Endoscopic Res...	Ocular Adnexa: Biopsy, Re...	Urethra: Biopsy (Note A)...
EWING SARCOMA/PRIMITIVE N...	OVARY: Oophorectomy, Salp...	Urethra: Partial or Total...
EWING SARCOMA/PRIMITIVE N...	PANCREAS (ENDOCRINE): Res...	URINARY BLADDER: Biopsy a...
EXTRA-GONADAL GERM CELL...	PANCREAS (EXOCRINE): Rese...	URINARY BLADDER: Cystecto...
FALLOPIAN TUBE: Unilatera...	PERIHILAR BILE DUCTS: Loc...	UTERINE CERVIX: Excision ...
GALLBLADDER: Resection/Ch...	PERITONEUM: Resection...	UTERINE CERVIX: Trachelec...
Gastrointestinal Stromal... Biopsy...	PHARYNX (OROPHARYNX, HYPO...	UVEAL MELANOMA: Resection...
Gastrointestinal Stromal...Resection...	PLEURA: Resection...	*VAGINA: Biopsy (Note:...
HEART: Resection...	PROSTATE GLAND: Needle Bi...	VAGINA: Excisional Biopsy...
HEPATOBLASTOMA (PEDIATRIC...	PROSTATE GLAND: Radical P...	VULVA: Excisional Biopsy,...
	PROSTATE GLAND: Transuret...	...
	RENAL PELVIS: Resection/N...	

Coordinating Data Elements
eCC & CS: Checklist/Schema Mismatches

- **Protocol Mismatch:**
  - **CS: LipUpper, LipLower, OthLip, BaseTongue, AntTongue, GumUpper, GumLower, OthGum, FOM, HardPalate, SoftPalate, OthMouth, BuccalMucosa, ParotidGland, SubmandibularGland, OthSalivary, Oropharynx, AntEpiglottis, Nasopharynx, Hypopharynx , OthPharynx**
  - **CAP: Lip & Oral Cavity, Major Salivary Glands, Larynx, Pharynx**

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…**

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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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.

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- Steve DeViney
- Sue Krauser
- Sabrina Krejci
- Candace Robertson
- Monique van Berkum, MD

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- Gemma Lee
- Andrea Maclean
- Josh Mazuryk
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- Robin Rossi
- Jennifer Seiffert
- Jim Sorace, MD
- Vijay Varma, MD
- and more on the way…

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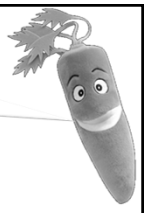

http://carrotcallusculture.blogspot.com/2010/04/preparation-of-carrot-callus-culture.html

NAACCR XML
A New Data Exchange Standard

Clinical Data Workgroup
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Overview

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

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Current Data Exchange Standard

Standards for Cancer Registries Volume II
Data Standards and Data Dictionary
Sixteenth Edition
Record Layout Version 12.2
Implemented January 1, 2012

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Current Data Exchange Standard

- Fixed-width format
- Over 530 data items
- Record Types:

Name	Size (characters)
Update	1543
Incidence	3339
Confidential	5564
Full case abstract	22824
Modified record	22824

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

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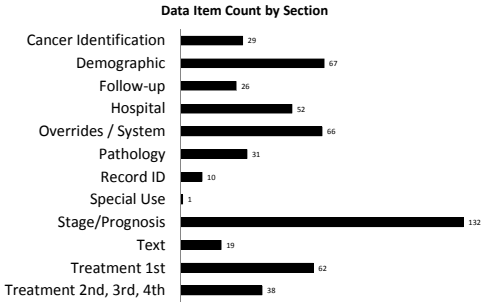
Current Data Exchange Standard



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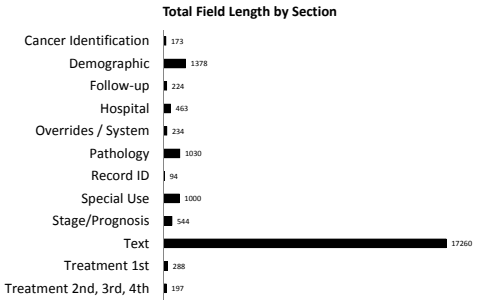
Current Data Exchange Standard



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Why Change ?

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

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Why XML ?

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Why XML ?

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

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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).

(http://en.wikipedia.org/wiki/Clinical_Document_Architecture, July 27, 2011)

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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)

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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

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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

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Current XML Draft Standard

```
<?xml version="1.0" encoding="UTF-8"?>
<Naaccr>
    <RecordVersion item="50"></RecordVersion>
    <RegistryType item="30"></RegistryType>
    ...
    <Patient>
      <RecordType item="10"></RecordType>
      <PatientIdNumber item="20"></PatientIdNumber>
      ...
      <CurrentDemographics>
          <Race item="160"></Race>
          <Race item="161"></Race>
          ...
          <Sex item="220"></Sex>
          <DateOfBirth item="240"></DateOfBirth>
          ...
      </CurrentDemographics>
      ...
      <Cancer>
          <TumorRecordNumber item="60"></TumorRecordNumber>
          <DateOfDiagnosis item="390"></DateOfDiagnosis>
          ...
          <Comorbidities>
              <Comorbidity item="3110"></Comorbidity>
              <Comorbidity item="3120"></Comorbidity>
              ...
          </Comorbidities>
          <Physicians>
              <ManagingPhysician item="2460"></ManagingPhysician>
              <ManagingPhysicianNpi item="2465"></ManagingPhysicianNpi>
              <FollowupPhysician item="2470"></FollowupPhysician>
              <FollowupPhysicianNpi item="2475"></FollowupPhysicianNpi>
              ...
          </Physicians>
          <Prognosis>
              <SeerSummaryStage2000 item="759"></SeerSummaryStage2000>
              <SeerSummaryStage1977 item="760"></SeerSummaryStage1977>
              ...
              <Tnm>
                  <TnmPathT item="880"></TnmPathT>
                  <TnmPathN item="890"></TnmPathN>
                  ...
              </Tnm>
              <CollaborativeStaging>
                  <TumorSize item="2800"></TumorSize>
                  <Extension item="2810"></Extension>
                  ...
                  <SiteSpecificFactor1 item="2880"></SiteSpecificFactor1>
                  <SiteSpecificFactor2 item="2890"></SiteSpecificFactor2>
                  ...
              </CollaborativeStaging>
          </Prognosis>
          <Therapies>
              <TherapySummary>
                  <ReasonNoSurgery item="1340"></ReasonNoSurgery>
                  <SummaryRadiation item="1360"></SummaryRadiation>
                  ...
          <DemographicsAtDiagnosis>
              <City item="70"></City>
              <State item="80"></State>
```

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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

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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

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Next Steps

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

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Questions?

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NAACCR Interoperability Webinar Conclusion & Wrap-up

Ken Gerlach, Chair
NAACCR Interoperability Ad Hoc Committee

August 4, 2011

NAACCR Webinar

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Importance of Interoperability

- Cancer registry operations, primarily based upon paper-based systems, need to evolve and grow
  - changes in the healthcare information technology
  - movement to establish electronic health records
- 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

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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

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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 (S2) 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.

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Sample Tumor Marker Tests by Site

CA 19-9	AmpullaVater, Appendix, PancreasBodyTail, PancreasHead, PancreasOther, Stomach, BileDuctwDistal, BileDuctsIntraHepat, BileDuctsPerihililar
Carbohydrate Antigen 125 (CA-125)	Ovary, PeritoneumFemaleGen
Carcinoembryonic Antigen (CEA)	Rectum, SmallIntestine, Stomach, AmpullaVater, Appendix, Colon, BileDuctsDistal, BileDuctsPerihilar,

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

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

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.

Code	Description
000	0 ng/ml
001	1 - 19 ng/ml
002	20 - 29 ng/ml
003	30 - 39 ng/ml

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**

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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

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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

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Thank you

- Volunteer opportunities
- Contact Lori Havener at Lhavener@naaccr.org

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Coming up…

- September 1, 2011
  - Coding Pitfalls
- Registration is open for the 2011-2012 NAACCR Webinar Series
  - http://www.naaccr.org/EducationandTraining/WebinarSeries.aspx

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