National Program of Cancer Registries – Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO)

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Centers for Disease Control and Prevention
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Cancer Reporting in the United States

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number of New Registries</th>
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<tbody>
<tr>
<td>1930</td>
<td>2</td>
</tr>
<tr>
<td>1940</td>
<td>2</td>
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<tr>
<td>1960</td>
<td>6</td>
</tr>
<tr>
<td>1970</td>
<td>14</td>
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<tr>
<td>1980</td>
<td>14</td>
</tr>
<tr>
<td>1990-1995</td>
<td>5</td>
</tr>
<tr>
<td>1996-2000</td>
<td>8</td>
</tr>
<tr>
<td>2001+</td>
<td>2</td>
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From: NAACCR CINA: 2001-2005
Registry Challenges

• Resources for Collecting Data
  – Process of identifying and collecting cancer data is resource intensive, time consuming, and creates risk of errors in transcription

• Delay in Availability of Data
  – Time gap between diagnosis of cancer and availability of data for analysis is a significant problem for cancer surveillance
  – National cancer information is published more than two years after end of diagnosis year
Registry Challenges

• Completeness of Reporting
  – Non-hospital sources do not consistently report cases

• Standardized Data Exchange for Non-Hospital Data Sources
  – No standards for data collection, transmission, and reporting have been implemented for non-hospital sources

• Limited data set
  – Cancer surveillance has had to limit its data set due to the expense of manually collecting and processing large amounts of data
The Solution

- Re-engineer data collection process to make use of EHR
- Harmonize existing cancer registry standards with Integrating the Healthcare Enterprise (IHE) and Healthcare Information Technology Standards Panel (HITSP) to connect the cancer surveillance workspace to National Health IT efforts
- Introduce and adopt IHE and HITSP use cases, profiles and transactions
- Certify electronic health systems by Certification Commission for Healthcare Information Technology (CCHIT) to ensure that standards are implemented
National Program of Cancer Registries – Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO)**

- CDC funded project to collaboratively develop an electronic reporting model for cancer surveillance
  - recommendations, guidelines, and diagrams
- Promote the utilization of the EHR
- Increase electronic reporting and automated processing
- Standardize electronic data exchange

** Previously known as NPCR-Modeling Electronic Reporting Project (NPCR-MERP)
NPCR-AERRO Approach

**Modeling:** Develop consensus best practice models for automating processes and electronic reporting

**Analysis and Design:** Analyze current technology and infrastructure surrounding registry operations and develop products supporting automation and electronic reporting

**Implementation:** Coordinate, lead, and support software vendors, hospitals, and state cancer registries pilot testing NPCR-AERRO models and products
Scope of Cancer Surveillance Data Reporting

NPCR–MERP includes cancer data sources and the lines drawn to the Central Cancer Registries and the National Cancer Programs

*Pathology Laboratories–Freestanding and Hospital–send data to both the Hospital Registries and the Central Cancer Registries
**CoC receives data directly from hospitals.
Activities to explore use of EHR/EMR

- **Cancer Control and Data Use Workgroup**
  - Evaluates how electronic reporting of cancer data and adoption of EHR can impact use of cancer surveillance data

- **Claims projects**
  - Link cancer registry and insurance claims data
  - Link cancer registry and state “all-payers” claims data
  - Hospital discharge data
  - Provider office billing data

- **Clinical Care Provider projects**
  - Test implementation of electronic reporting from provider offices to registries
  - Move cancer registry community forward in using consistent standards for electronic provider reporting to improve completeness, timeliness, and quality of cancer registry data
HealthCare Information Technology Standards Panel (HITSP) and Integrating the HealthCare Enterprise (IHE)

• **HITSP**
  – Partnership between public and private sectors in the United States
  – Harmonize and integrate standards that will meet clinical and business needs for sharing information among organizations and systems
  – Respond to requests from the Secretary of the Department of Health and Human Services

• **IHE**
  – Collaboration among national and international health care professionals and industry to identify ways to improve the way health care systems share information
  – Promote the use of established standards such as Health Level Seven (HL7) that have been identified and adopted by HITSP to address specific clinical needs in support of optimal patient care
HealthCare Information Technology Standards Panel (HITSP) and Integrating the HealthCare Enterprise (IHE)

- **IHE Profiles include:**
  - Anatomical Pathology Reporting to Public Health
  - Clinician Reporting to Public Health Repository

- **Constructs used in testing:**
  - IHE Retrieve Form for Data Capture (RFD)
  - IHE Clinical Research Data Capture (CRD)
  - HITSP Components:
    - TP50 (Retrieve Form for Data Capture Transaction Package)
    - C76 (Case Report Pre-populate Component)
  - PHIN Vocabulary Application Distribution System (PHIN VADS)
HealthCare Information Technology Standards Panel (HITSP) and Integrating the HealthCare Enterprise (IHE)

- **IHE Interoperability Testing:**
  - PHIN 2009 Conference
  - IHE U.S. 2010 Connectathon/HIMSS Showcase
  - IHE Europe 2011 Connectathon/Showcase

- **PHDSC-IHE Public Health Task Force:**
  - Building a Roadmap for Health Information System Interoperability for Public Health
Electronic Pathology Reporting:
Pilot Project

- Participants: CDC, North American Association of Central Cancer Registries (NAACCR), LabCorp, 28 State Cancer Registries
- Implement electronic reporting of text based pathology laboratory reports from national laboratories to registries
  - NAACCR Volume V E-Path Implementation Guide (HL7 v.2.3.1) and E-Path Reporting Process Guide
  - Messaging Workbench (MWB) profile
  - CDC’s Public Health Information Network’s Messaging system (PHINMS)
  - Encourage LIS and registry vendors to implement
- Status: 21 states currently receive standardized electronic cancer reports from LabCorp daily
Electronic Synoptic Pathology Reporting

- Reporting Task Force (PERT) College of American Pathologists (CAP) develops Cancer Checklists—transition from text based to synoptic pathology reporting

- CAP Pathology Electronic
  - Mission: Advance implementation of Checklists using health information technology
  - Develop electronic version Checklists
  - Output in XML
  - Use of standard codes (SNOMED CT, LOINC (to be added))
  - Versioning – Unique Item Identifiers
  - Exports to be based on XML: HL7
PHGrid Activities: Goals / Objectives

• Provide a secure, easy-to-use national technical and social infrastructure for solving public health problems
• Develop an extremely low cost grid appliance
• Simplify web services development (drag & drop)
• Simplify data access and data exchange (drag & drop)
• Connect public health grid to other grids, and to other data sources, regardless (in other words, interoperate with everything)
• Recruit local & state health departments, HIEs, RHIOs, academic institutions, national data sources, medical centers, international public health partners, and vendors
PHGrid Conceptual Architecture

Public Health Partner Environment

Grid Viewer

Node

Grid Applications

Partner Applications

See Service Stack Model for Services

Shared Environment*

Collaboration Tools

Wiki

Service Registry

Certificate Authorities

Trust Relationships

Role Based Security

Authentication

Common Security Platform

* Initially hosted by CDC with eventual hosting by community

CDC Environment

Grid Viewer

Node

Grid Applications

CDC Applications

See Service Stack Model for Services

DRAFT
Version 0.5
2009.3.26
Miles, McMullin, Lee, Peng
Proposed Cancer Services for PHGrid

• Build a .NET / Globus bridge service
  – Cancer tools are written in .NET and Globus is java based. This service would be built and generalized for other programs to use.

• Filtering tool for pathology and/or physician reporting that will identify reportable cases for Cancer Registries

• Tool for pathology laboratories to map/create a standard HL7 2.x format message from their local systems

• Test messages for existence of required data items

• Map HL7 data elements to North American Association of Central Cancer Registries (NAACCR) data elements
**Websites**

**NPCR:**  [www.cdc.cancer.gov/cancer/npcr](http://www.cdc.cancer.gov/cancer/npcr)

**AERRO:**  [www.cdc.gov./cancer/npcr/informatics/aerro](http://www.cdc.gov./cancer/npcr/informatics/aerro)

**NAACCR:**  [www.naaccr.org](http://www.naaccr.org)

**SEER:**  [www.seer.cancer.gov](http://www.seer.cancer.gov)
Thank you

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The findings and conclusions in this presentation are those of the author(s) and do not necessarily represent the views of the Centers for Disease Control and Prevention.