

Interoperability between the EHR and Public Health Disease Surveillance – The Cancer Registry Use Case

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Almost two million cancers are diagnosed each year in the United States

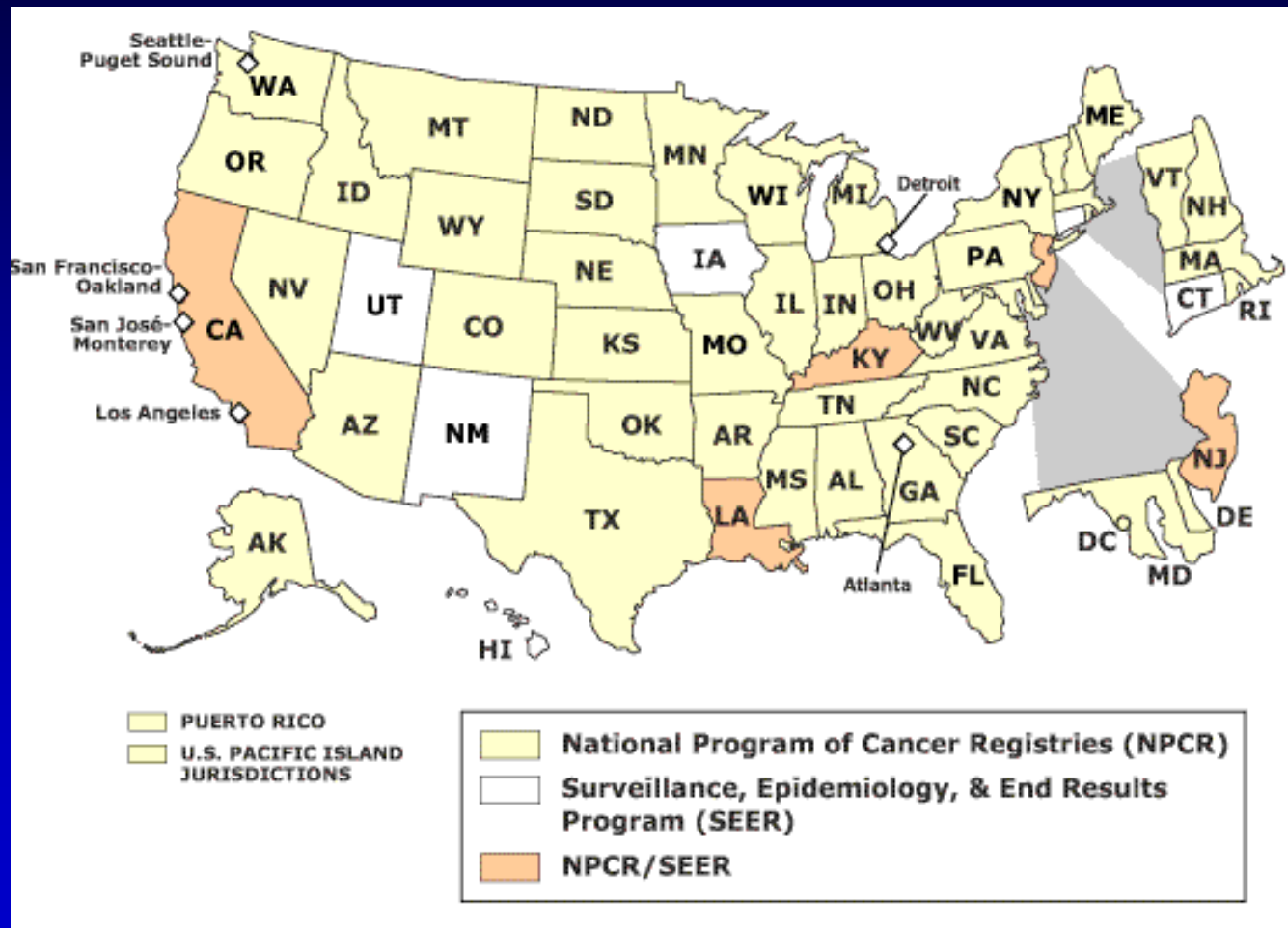
Cancer surveillance serves as the “foundation for a national comprehensive strategy to reduce illness and death from cancer. Such surveillance is the indispensable tool that enables public health professionals at all levels to better understand and tackle the cancer burden while advancing clinical, epidemiologic, and health services research”.

UICC: International Union against Cancer

There are 241 cancer surveillance systems (registries) on all 6 continents participating in the International Association of Cancer Registries (part of the World Health Organization).



The US requires reporting of cancer to the national cancer programs



Time Period	Number of New Registries
1930	2
1940	2
1960	6
1970	14
1980	14
1990-1995	5
1996-2000	8
2001+	2

From: NAACCR CINA: 2001-2005

Purpose of Cancer Surveillance

- ◆ Advance clinical, epidemiologic, and health services research
 - Provide information on efficacy of treatment options
 - Monitor cancer trends over time
 - Determine cancer patterns in various populations
 - Provide complete national cancer incidence
- ◆ Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference)
- ◆ Help set priorities for allocating health resources



Quick Profiles

Area

Cancer

Generate Profile

Comparison Tables



[Rate/Trend Comparisons](#)

set higher priority for cancer control when rates are high or rising
[learn more...](#)

- [Prioritize cancer sites](#) for a specific state or county
- [Prioritize states or counties](#) for a specific cancer site



[Death Rates](#)

for states or for counties in a state
[learn more...](#)



[Incidence Rates](#)

for states with high quality cancer registries
[learn more...](#)

Graphs and Maps



[5-Year Rate Changes](#)

in cancer mortality or incidence for all major cancer sites by user selectable criteria
[learn more...](#)



[Historical Trends](#)

compare trends in cancer mortality and incidence by user selectable criteria
[learn more...](#)



[Comparative Data Display \(Micromaps\)](#)

explore relationships across geography of mortality, incidence, demographics, or risk factors
[learn more...](#)



[Interactive Maps](#)

for states or for counties in a state - mortality and incidence maps
[learn more...](#)

Support Data



[Screening and Risk Factors](#)

prevalence percents by state from behavioral surveys
[learn more...](#)



[Demographic Data](#)



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New Releases

2005 SEER Incidence Data (also released in the [Cancer Statistics Review](#))

[2005 Mortality Data](#)

[2004 USCS Incidence Data](#)

[2005 & 2006 Screening and Risk Factors](#)

[Download State Cancer Profiles brochure \(PDF\)](#)

[Revision History \(Updated: 8/16/2007\)](#)

[Release Schedule](#)

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Full Public Health Cancer Registry Use Case (1)

- ◆ Patient has a mammogram for a suspicious lump in her breast
- ◆ Pathologist in the pathology laboratory analyzes the specimen and dictates findings
 - Anatomic pathology laboratory information system (LIS) identifies diagnosis of cancer (reportable event) and transmits data to Hospital Cancer Registry and State Cancer Registry using standards
- ◆ State Cancer Registry creates a record of patient's cancer automatically populating the appropriate data elements in the cancer registry record



Full Public Health Cancer Registry Use Case (2)

- ◆ **In the hospital, the Patient has a lumpectomy**
 - Pathologist in the pathology laboratory analyzes specimen and dictates findings
 - Anatomic pathology LIS identifies diagnosis of cancer (reportable event) and transmits data to Hospital Cancer Registry and State Cancer Registry using standards
 - Hospital cancer registrar creates comprehensive abstract of patient's cancer information and transmits event report to Hospital EHR and to State Cancer Registry
- ◆ **Patient discharged with instructions and an appointment to see an oncologist**



Full Public Health Cancer Registry Use Case (3)

- ◆ State Cancer Registry links the hospital cancer registry event report to the electronic pathology report and possibly other electronic reports and consolidates them into a comprehensive unique analyzable record of the patient's cancer

This record can be used to provide incidence data to monitor trends and to identify patients for clinical trials.

- With EHR transmissions, data is available much sooner



Full Public Health Cancer Registry Use Case (4)

- ◆ Physician and patient decide on course of radiation and then continues treatment with recommended chemotherapy regimen
 - Physician uses cancer registry and EHR information to help identify the appropriate treatment plan
- ◆ Patient receives 6 weeks of radiation at hospital radiation therapy clinic
 - Radiation Therapy Clinic EHR transmits information to Hospital Cancer Registry and State Cancer Registry
 - Both registries update their systems

Provide more complete treatment information to clinicians and researchers.



Full Public Health Cancer Registry Use Case (5)

- ◆ Patient begins chemotherapy at the oncology clinic. Patient can't tolerate chemotherapy, so treatment plan is altered to provide a different chemotherapy course.
 - Oncology Clinic EHR transmits the revised information to Hospital Cancer Registry and State Cancer Registry
 - Both Registries update their systems

Provide more complete treatment information to clinicians and researchers.



Full Public Health Cancer Registry Use Case (6)

- ◆ Patient continues to see medical oncologist at yearly intervals for five years, at which time her care is transferred to her family physician.
 - Medical oncology clinic software transmits an event report to the State Cancer Registry providing the patient's vital status and cancer status.
 - State Cancer Registry transmits this information to the Hospital Cancer Registry.

The State Cancer Registry produces survival rates.



Full Public Health Cancer Registry Use Case (7)

Twelve (12) years later....

Patient sees family practitioner because she is not feeling well. Physician orders a series of tests, the results of which diagnose *metastatic breast cancer*.

Currently: Physician records the patient's statements regarding her cancer experience; requests and receives paper medical records from hospital and medical oncologist's office to find specific detailed medical information and treatment of patient's breast cancer

Physician electronically retrieves consolidated cancer information from Cancer Registry. Patient and physician decide on treatment based on the amount of radiation she has had previously and her inability to tolerate one of the components of the chemotherapy regimen.



Intra-community standardization is NOT a problem

A standard case definition, core data set, transmission methods and data validation have been developed by consensus and fully implemented to ensure semantic and syntactic interoperability *within the cancer workspace*

(North America)



Department of Health and Human Services

Centers for Disease Control and Prevention



National Cancer Institute



The North American Association of Central Cancer Registries



National
Cancer Institute
of Canada

Institut national
du cancer
du Canada



College of American Pathologists



Commission
on Cancer

A MULTIDISCIPLINARY
PROGRAM OF THE
AMERICAN COLLEGE OF SURGEONS



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Challenges

Resources for Collecting Data

- ◆ ***The process of identifying and collecting cancer data is resource intensive, time consuming, and creates a risk of errors in transcription.***

Delay in Availability of Data

- ◆ ***The time gap between a diagnosis of cancer and the availability of data for analysis is a significant problem for cancer surveillance. National cancer information is published more than two years after the end of a diagnosis year.***



Challenges

Completeness of Reporting

- ◆ ***Non-hospital sources, such as physician offices and radiation therapy centers, do not consistently report cases***

Standardized Data Exchange for Non-Cancer Registry 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 to reduce the financial and staff resources required to meet the federal mandate and improve the timeliness of reporting**
 - **Applies to both clinical and registry settings**
- ◆ **Harmonize existing cancer registry standards with IHE and HITSP to connect the cancer surveillance workspace to National Health IT efforts**
- ◆ **Adopt IHE and HITSP use cases, profiles and transactions to leverage the expertise and work of those in the primary healthcare setting for population-health activities**
- ◆ **Certify electronic health systems by CCHIT to ensure that standards are implemented**



Implementation

- ◆ Real-time reporting of basic incidence information from hospital and clinician Electronic Medical Records (EMRs) to cancer registries
- ◆ Real-time data transmission of more complex data from hospital EMR to hospital cancer registry (stage and treatment)
- ◆ Implemented by:
 - Leveraging transaction standards for exchanging data between hospital and clinical EMRs
 - IHE forms processing
 - CDA transmission



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

- ◆ Collaborative project to 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)

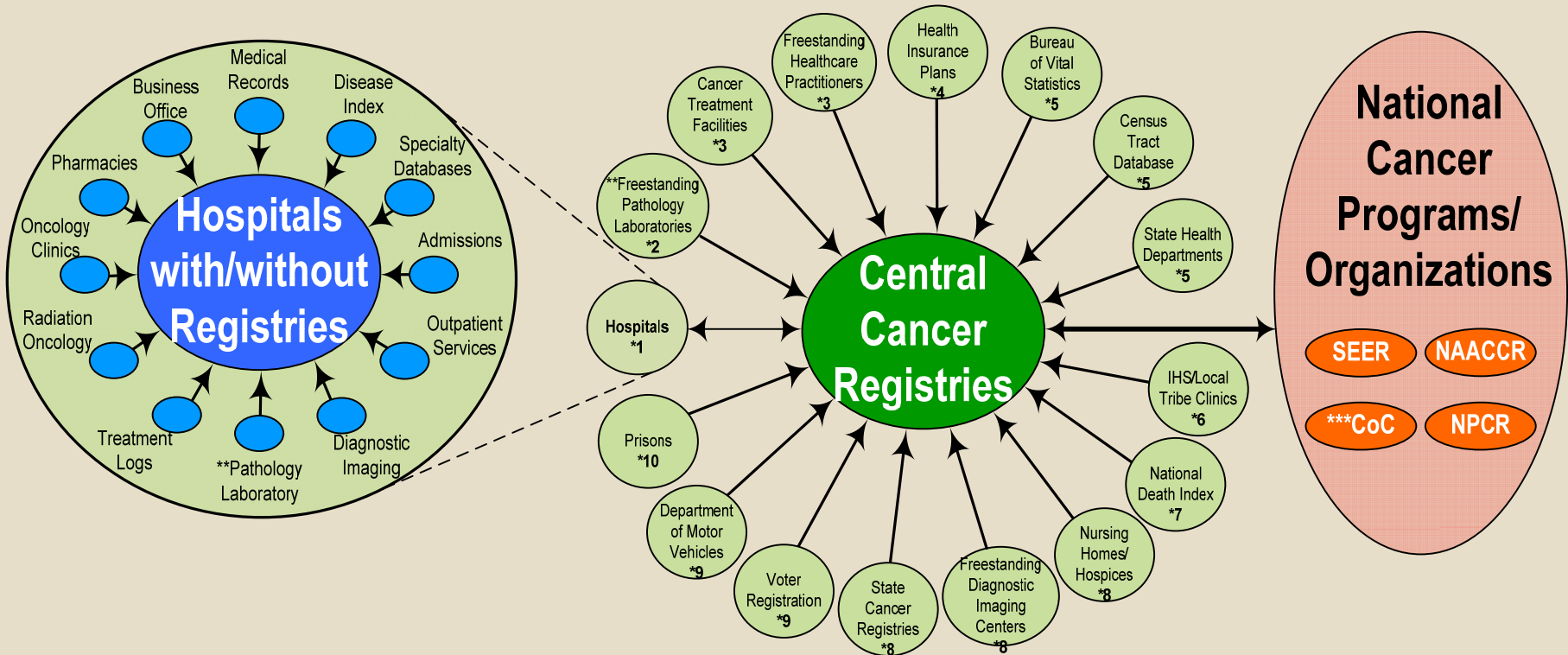


NPCR-AERRO Objectives

- ◆ Identify new capabilities offered by electronic capture of patient information
- ◆ Identify opportunities to automate manual processes for data capture
- ◆ Incorporate national standards
- ◆ Reflect current industry best practices
- ◆ Use iterative process to develop and assess models, design specifications, and implementation at multiple levels of granularity and specificity



Scope of Cancer Surveillance Data Reporting



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

*Numbers rank the data sources on the quality of useful data available on a scale of 1 being the most useful and 10 being the least useful.

**Pathology Laboratories–Freestanding and Hospital–send data to both the Hospital Registries and the Central Cancer Registries

***CoC receives data directly from hospitals.

Electronic Pathology Laboratory Reporting to Cancer Registries

Implement messaging standards to electronically transmit electronic pathology reports anatomical pathology laboratories to cancer registries

- ◆ Implementation guide for HL7 version 2.5.1
- ◆ Messaging Workbench (MWB) profile
- ◆ CDC's Public Health Information Network's Messaging system (PHIN-MS)
- ◆ Encourage LIS and registry vendors to implement



Electronic Pathology Laboratory Reporting to Cancer Registries

Harmonize North American Association of Central Cancer Registries (NAACCR) Standards for Cancer Reporting with IHE Anatomic Pathology Technical Framework

- ◆ **New Profile for 2009: Reporting Anatomic Pathology to Registries or Public Health Repositories**
- ◆ **Determine US-Realm specific standards**



Computer-assisted processing of Pathology Data

Map College of American Pathologists (CAP) electronic Cancer Checklist (eCC) data to cancer registry data elements and values

Text mine pathology reports to identify those with a diagnosis of cancer



Align Cancer Registry With National Health IT Standards

- ◆ Implement national data exchange mechanisms for cancer registry data
 - HL7 Clinical Document Architecture (CDA) for reporting cancer abstracted data to State Cancer Registry
- ◆ Achieve semantic interoperability of cancer registry data items with national standards
- ◆ Adopt national standards for security and privacy
- ◆ Update National Notifiable Diseases data set with federal regulations for use in HITSP IS11
[Public Health Case Reporting Interoperability Specification]



Collaborate with National/International Initiatives

IHE

- ◆ *Patient Care Coordination (PCC)*
 - *Retrieve Form for Data capture (RFD)*
- ◆ *Quality, Public Health and Research (QPHR)*
 - *Retrieve Profile for Execution (RPE)*
- ◆ *Anatomical Pathology*

HL7

- ◆ *Orders and Observations*
- ◆ *Clinical Documents*
- ◆ *Anatomic Pathology*
- ◆ *Public Health and Emergency Response*

HITSP

- ◆ *Population Health Technical Committee*

Public Health Data Standards Consortium (PHDSC)



Websites

NPCR: www.cdc.cancer.gov/cancer/npcr

Cyberview:

www.cdc.gov./cancer/npcr/informatics/merp2

www.cdc.gov/cancer/npcr/informatics/merp

NAACCR: www.naacr.org

SEER: 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

