

NPCR-AERRO'S CANCER CONTROL AND DATA USE (CC&DU) PROJECT

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BACKGROUND

NPCR-AERRO

- **Develop best practices, guidelines, and recommendations for an ideal cancer surveillance informatics infrastructure**
- **Use a collaborative, consensus-building framework to construct a comprehensive model to demonstrate the potential of electronic cancer registry reporting and automated registration**

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

CANCER CONTROL AND DATA USE WORKGROUP

Cancer Control and Data Use Workgroup

- ❑ Purpose: To evaluate how electronic reporting of cancer data and adoption of the Electronic Health Record (EHR) can impact use of cancer surveillance data, such as improved timeliness and data quality for better trend analysis.**
- ❑ Convened first meeting in October, 2007**
- ❑ Participants include state central cancer registry programs, state comprehensive cancer control programs, and NPCR.**
- ❑ Monthly conference calls**

CC & DU Goals

- ❑ Model how cancer data are used for current and future needs**
- ❑ Identify data sources and/or data elements not previously available**
- ❑ Model feedback mechanisms between data use and cancer surveillance**

CC & DU Core Activities—Modeling

- ❑ Develop business use case diagram**
- ❑ Classify current and potential users of cancer surveillance data**
- ❑ Describe the benefits EHR can offer to cancer control**
- ❑ Examine short- and long-term data needs**
 - types of data used
 - purpose of the data
 - how the data are used
 - data sources
 - challenges to data collection and/or use
- ❑ Identify existing and new knowledge products (such as state profiles)**

Benefits of EHR

Benefit	Effects
Increase completeness of reporting	<ul style="list-style-type: none">• More data for research and evaluation• More sources for data, e.g., Health Information Exchanges (HIEs)• Better data for evaluation by cancer registries
Decrease lag time of reporting	<ul style="list-style-type: none">• Faster evaluation of screening, detection, and treatment• Quicker access to data on aggressive cancers

Benefits of EHR (cont'd)

Benefit	Effects
Reduce cost of obtaining data	<ul style="list-style-type: none">• Ability to obtain more data with existing funds and resources
Provide more data elements	<ul style="list-style-type: none">• Broader and deeper picture of individual cancer cases and aggregate effects• Access to risk factors, e.g., lifestyle factors such as Body Mass Index (BMI) based on height and weight• Access to screening data for particular cancers, e.g., date and risk code for mammography• Possibility of tracking post-diagnosis data, e.g., treatment, survivorship, quality of life, recurrence, end-of-life treatment

Knowledge Products

Product	Audience	Purpose	Possible Enhancements with EHR
State cancer plan	Grant writers Researchers Cancer programs Cancer coalitions Community organizations Decision makers/ Congressional staffers Media	Comp Cancer strategy	Increased ability to provide more complete and timely information for developing cancer plan strategies. Able to track cancer plan objectives better. Assist in prioritizing cancer plan objectives.
State cancer profile	Grant writers Researchers Cancer programs Cancer coalitions Community organizations Congressional staffers Media	Program planning Justification for funding Research Education Evaluation	Expansion of information contained in profile, updated more often, more comprehensive and timely data

Examine short- and long-term data needs

Types of Data Used	Purpose	How Used	Data Sources	Challenges
Disparities				
Geographic (current and past residence)	Develop targeted interventions Conduct cancer cluster reviews Identify variation by geographic region	Look for disparities in terms of urban vs. rural communities. Look at geographic access to cancer care .	Cancer Registries	For rural communities, address is not very helpful. PO boxes skew cluster analyses.
Socioeconomic status (SES)	Assess access to care	Used with geographic data (location at diagnosis) to refine disparities research	Census, tax commission, hospital data	Need to define disparities at individual level.

Examine short- and long-term data needs

Types of Data Used	Purpose	How Used	Data Sources	Challenges
Prevention and Early Detection				
Screening Behavior	To evaluate screening behaviors and interventions	Trends over time of screening types	BRFSS, NHIS, NHANES, patient medical record, pathology reports, screening programs	Medical records may not give complete or accurate information about screening tests
Vaccination History	Measure the efficacy of the HPV vaccine in reducing incidence of disease	Measure use of HPV vaccine	Immunization Registry, patient medical records, BRFSS (optional modules)	Education of population on use of vaccine

CC & DU Core Activities—Analysis and Design

- ❑ Review data items currently available in the EHR, and identify other data items to be included based on cancer data gaps**
- ❑ Form an action plan to further potential uses of cancer surveillance data**
- ❑ Recommend improvements to the format of the Electronic Health Record, Personal Health Record (PHR), and/or data collection and dissemination standards to aid in the use of cancer-related statistical data**

Mapping to EHR data items

Types of Data Used	EHR	HITSP Public Health Case Reporting Data Elements	HITSP Continuity of Care (C32) Data Elements
Family History	Future development of EHR will include data on family history	<p>Present: none</p> <p>Absent: Degree or type of relative Type of cancer (primary site and histology) Vital Status Cause of Death Age at diagnosis</p>	<p>Present: none</p> <p>Absent: Degree or type of relative Type of cancer (primary site and histology) Vital Status Cause of Death Age at diagnosis</p>
Lifestyle Factors	EHR could provide BMI and occupation Could EHR help provide greater consistency to lifestyle factor data elements?	<p>Present: weight, occupation, occupational risk factors</p> <p>Absent: Height, socio-behavioral risk factors</p>	<p>Present: Height, weight</p> <p>Absent: Occupation, occupational risk factors, socio-behavioral risk factors</p>

Mapping to EHR data items—Part 2

Data Type	Cancer Concept	PHCR Data Element	PHCR Definition	PHCR Standards
Family History	Type of cancer for family member	No Mapping		
	Degree/Type of relative	No Mapping		
Lifestyle Factors	Tobacco use	No Mapping		
	Height	No Mapping		
	Dietary Habits	No Mapping		
	Patient's Usual Occupation	Occupation	The occupation of subject of the case report. Enter as much detail as possible.	North American Industry Classification System
	Weight	Weight	The weight of the patient at the time of the report	UCUM units

Next Steps

- ❑ **Complete mapping to EHR data elements**
- ❑ **Based on mapping/gap analysis, develop document with recommendations for improvements and new data items to be added to EHRs**
- ❑ **Develop tool that identifies different data sources for cancer data elements, including:**
 - **Sorting functionality**
 - **Query functionality**
 - **Map to NAACCR Volume II data elements**

Thank you!

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