Making EHR Data More Available for Research and Public Health (MedMorph)

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Agenda

• Broad Aims for MedMorph
  • The Data Lifecycle & Impacts to the Public’s Health
  • Transforming the clinical data landscape with FHIR
• Project Overview
• Cancer Use Case
• MedMorph Team at CDC
The Data Lifecycle & Impacts to the Public’s Health

**Data Science**
- Analytics
- Data Linkages
- Data Visualization

**Updating Scientific Evidence**

**Knowledge**
- Guidelines
- Recommendations
- Guidance
- Public Health Policies or Mandates

**Analyzing data to advance evidence**

**Fast Healthcare Interoperability Resources (FHIR)**

**Delivering actionable knowledge**

**Action**
- Point of Care
- Emergency Response
- Public Health Departments
- Community Services

**Health Impacts & Outcomes**

**Data**
- EHRs
- Registries
- Public Health Info Systems
- Community Info Systems
- ...many potential sources

**Updating Scientific Evidence**

**Information**
- Data Science
- Analytics
- Data Linkages
- Data Visualization

Guidelines
Recommendations
Guidance
Public Health Policies or Mandates
Transforming the clinical data landscape with FHIR

Slide courtesy of Dr. Ken Gersing, artwork by Julie McMurry (National Center for Advancing Translational Sciences (NCATS))
Project Overview

• Funded by the Patient-Centered Outcomes Research Trust Fund (PCORTF) via the Department of Health and Human Services (HHS) Assistant Secretary for Planning and Evaluation (ASPE)
  – Total project timeline: 3 years

• **PROBLEM:** Patient-centered outcomes researchers and public health professionals need better ways to get data from different electronic health record (EHR) systems without posing additional burden on health care providers

• **GOAL:** Create a reliable, scalable, generalizable, configurable, interoperable method to get EHR data for multiple public health and research use cases

• **OBJECTIVE:** Develop a reference architecture and demonstrate a reference implementation (including implementation guides)
Guiding Principles for Technical Approach

Leverage FHIR

Automate

Limit proliferation of IGs for public health

Promote configuration over proprietary implementation

Account for implementation variability
Making EHR Data More Available for Research and Public Health

Technical Expert Panel:
End Users, Data Recipients, Stakeholders – Including representatives of additional use cases

Foundation of standards supported by health IT certification (CCDS/USCDI, APIs, FHIR)

Fully Modeled Use Cases
Hepatitis C, Cancer, Healthcare Surveys

Implementation Guides
For general use and for each use case

Technological Strategies
To develop scalable and extensible architecture

Agile Development: Iterative Design-Build-Test Cycles (test case: Hepatitis C)

National Test Collaborative
Including a variety of clinical organizations and their EHR platforms

PRODUCTS:
Reference Architecture, Reference Implementation Guides, Balloted Implementation Guides, Roadmap for Scalability and Sustainability

Evaluation Planning
Measure and Evaluate

Software
Clinical organization
EHR platform
Other testing partners (e.g., public health departments, registries, health IT developers, etc.)
MedMorph Workgroups

TIME

Use Cases (incl. Research)
- SMEs: Hepatitis C
  - Technical Experts
- SMEs: Cancer
  - Technical Experts
- SMEs: Healthcare Surveys
  - Technical Experts

Evaluation Planning
- Data Flows & Clinical Workflows
  - SMEs: All use cases
- Data Standards
  - SMEs: All use cases
- Reference Architecture/Authorities/Policies
  - SMEs: All use cases

Evaluation
- Data Flows & Clinical Workflows
  - SMEs: All use cases
- Data Standards
  - SMEs: All use cases
- Reference Architecture/Authorities/Policies
  - SMEs: All use cases

Technical Requirements
Cancer Use Case
Cancer Surveillance Overview

- Cancer is a reportable disease
  - Every state has public health law/regulation requiring information to be reported to Central Cancer Registry (CCR) about all cancers diagnosed or treated within that state
- Collect standardized data on all cancers diagnosed
  - All reporting sources – physician, hospital, laboratory
  - Captures ALL cancers (census) – not a sample
- Involves longitudinal data collection
  - Diagnosis → Staging → Initial Treatment → Death
- Is complex
  - Heterogeneous disease (100s of different types of cancer)
  - Many diagnostic and prognostic factors (100+ variables)
  - Multiple medical encounters
Cancer Surveillance in the U.S.

Covers 100% of U.S. population
Current Reporting Structure

- Hospitals
- Laboratories
- Physicians
- Radiation Therapy Centers & Medical Oncology Facilities
- Outpatient Centers

Central Cancer Registry
- Follow back
- Clean
- Edit
- Link
- Consolidate
- Analyze

De-identified
Cancer Registry Information Flow

• Data are reported to each individual CCR from multiple data sources, including: hospitals, labs, physicians, radiation or oncology facilities, and other outpatient centers.

• Traditionally, hospitals have been the primary data source for cancer reporting, using a well-established SINGLE national data standard.

• There are an increasing number of pathology reports from independent pathology labs that are submitted to each individual CCR from independent pathology labs; these are paper-based, narrative reports. Some, but not all, use standard HL7 (Version 2.X) format.

• Diagnosis and treatment of certain cancers has moved from the acute care setting to the physician/clinic office. Some, but not all, use standard HL7 (CDA) format.

• CCRs go through several steps to clean, edit, link, consolidate, and analyze the data reported from these different sources to create a longitudinal record for every cancer diagnosed.
### Cancer Reporting Challenges

<table>
<thead>
<tr>
<th>General</th>
<th>Data Flow</th>
<th>Physician Reporting (from EHRs using HL7 CDA IG)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Data availability to public and planners takes at least 30 months</td>
<td>• Electronic reporting systems are costly</td>
<td>• Limited uptake by EHRs</td>
</tr>
<tr>
<td>• Labor Intensive (manual data entry)</td>
<td>• Lack of will or incentive to switch from paper-based reporting</td>
<td>• Limited implementation by providers</td>
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<tr>
<td>• Duplication of Effort</td>
<td>• Delayed identification can lead to cancer-related death and disability</td>
<td>• No common way to disseminate knowledge artifacts (e.g., reportability trigger codes and cancer-specific value sets) to all implementers</td>
</tr>
<tr>
<td>• Missed cases and/or missed treatment</td>
<td></td>
<td>• Workflow triggers implemented partially and inconsistently</td>
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Cancer Use Case Purpose, Goals and Scope

Purpose

• Transmit cancer case information to state Central Cancer Registries
• Provide access to data not currently available, or available through non-standard and/or manual methods
• Address gaps in current processes related to workflow and triggers

Goals

• Identify missed cases and treatment
• Provide incidence data faster for research and public health
• Identify data standards that allow for collection, transmission, and aggregation of cancer data electronically from EHRs automatically

Scope

• Collect standardized data on all types of reportable cancers diagnosed
• Define when a cancer report must be created and transmitted to the central cancer registry
• Identify the standard data elements to be retrieved from the EHR to produce the cancer report
  • Use NAACCR Volume II data dictionary for standardized data collection
Use Case Sections

• Description
  • Problem Statement
• Goals
• User Stories
• Scope
  • In Scope
  • Out of Scope
• Actors
• Abstract Model
• Use Case Flow and Diagrams
  • Preconditions
  • Main Flow (table)
  • Postconditions
• Use Case Flow and Diagrams (cont’d)
  • Alternate Flow
  • Use Case Diagram
  • Activity Diagram
  • Sequence Diagram
• Dataset Requirements
• Policy Considerations
• Non-Technical Considerations
• Appendices
  • Related Use Cases
  • Previous Work Efforts
  • References
Patient is seen by provider and diagnosed with or treated for cancer

EHR system determines patient has been diagnosed with a cancer that meets the criteria for reporting to the CCR, as defined by national standard Cancer Reportability List.

A standard report with the required data elements is sent to the central cancer registry in the state in which the patient resides, as required by state law.
Questions?

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DRIVERS

• Public health needs **span** surveillance, monitoring, quality measurement, research, population health management, and “secondary uses” of healthcare data

• Collaboratively establishing a common framework helps **increase the likelihood of success** rather than trying multiple separate approaches for research and public health

• **Closing the loop** (e.g., through bidirectional data exchange) can deliver more public health **value** to healthcare

• Leveraging existing efforts offers a **foundation** and lessons learned to build on
Technical Expert Panel (TEP): Participating Stakeholder Groups

- Federal Partners
- Health IT developers
- Clinicians/Healthcare Organizations
- Medical Societies
- Public Health Organizations
- Evaluation experts
- Laboratory Professional Groups

- Standards experts
- Clinical decision support developers
- Clinical quality measure developers
- Policy or technical support for implementation
MedMorph Team at CDC

Maria Michaels – Lead
Wendy Blumenthal – Co-lead, Cancer SME
Arun Srinivasan – Technical Lead
Brian Gugerty – Healthcare Surveys SME
Aaron Harris – Hepatitis C SME
Abigail Viall – Hepatitis C SME
Laura Conn – eCR SME
Sameemuddin Syed – ORISE Fellow
Current Data Flow

Challenges

- Electronic reporting systems are costly
- Cancer registrars do not trust the security of electronic reporting systems
- Lack of will or incentive to switch from paper-based reporting
What Information Do Central Cancer Registries Collect?

• High level overview
  • Patient identification, demographics, social history
  • Cancer identification, including: diagnosis date, body site, histologic type (cell type), behavior (benign or malignant), grade
  • Stage and prognostic factors
  • First course of treatment (e.g., surgery, chemotherapy, radiation, etc.)
  • Facility information
  • Follow up and vital status

• See NAACCR Standards for Cancer Registries Volume II: http://datadictionary.naaccr.org/?c=1
National Standards for Cancer Surveillance

Formats

• North American Association of Central Cancer Registries (NAACCR)
  • Hospitals: NAACCR Volume II (ASCII Fixed-Length Flat File --> XML)
  • Anatomic Pathology Laboratories: NAACCR Volume V (HL7 ORU v.2.5.1)

Terminologies/Coding Systems

• International Classification of Diseases for Oncology (ICD-O-3)
  • Used principally in tumor or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms, usually obtained from a pathology report.
  • Administered by WHO
  • ICD-10-CM
  • American Joint Committee on Cancer (AJCC) TNM Staging
Resources/Useful Links

• NPCR Website: https://www.cdc.gov/cancer/npcr/index.htm
• NCI SEER Website: https://seer.cancer.gov/
• NAACCR Website: https://www.naaccr.org/
• NAACCR Version 18 Data Standards and Data Dictionary
• Pathology Laboratory Electronic Reporting Version 4.0