Integrating the Healthcare Enterprise (IHE) Structured Data Capture (SDC) Use Case: Cancer Registry Reporting

Sandy Jones  
Public Health Advisor  
Cancer Surveillance Branch, CDC

Vijay Shah  
Director, Health IT Solutions  
JBS International, Inc.

HIMSS National Capital Areas Conference  
May 18, 2017
Central Cancer Registries in the US by Federal Funding Source

- 1992 Cancer Registry Amendment Act, Public Law 102-515, authorized CDC to establish National Program of Cancer Registries (NPCR)
- Nationally reportable disease; required by state law
- Population-based longitudinal data from multiple sources on all diagnosed cancers including diagnosis, treatment and vital status data
- Highly standardized data collection system

*Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI)
CDC’s National Program of Cancer Registries

Hospitals

Laboratories

Physicians

Radiation Therapy Centers & Medical Oncology Facilities

Outpatient Centers

Central Cancer Registry
- Cleaning
- Editing
- Consolidating
- Analyzing
Background and Purpose

- U.S. Laboratories produce narrative pathology and biomarker reports
- Non-standard across labs: test names, terms, results, reference ranges and report formats
- Time-consuming to capture cancer pathology and biomarker data
- Use of the CAP Cancer Protocols and electronic Cancer Checklists (eCC) will enhance data completeness, timeliness, and quality
Cancer Program Accomplishments: Electronic Pathology and Biomarker (ePath) Reporting

- IHE Anatomic Pathology Reporting to Public Health – Cancer Registry (ARPH) profile based on HL7 2 messaging:
  - 46 state cancer registries receive ‘live’ ePath data
  - 25 laboratories reporting to state cancer registries
  - 40+ states use eMaRC Plus ePath Module to receive and process ePath reports

- IHE Structured Data Capture (SDC) Profile to report College of American Pathologists (CAP) Electronic Cancer Checklist (eCC) pathology and biomarker data to cancer registries
  - Implemented in the California Cancer Registry

- Exploring the use of HL7 Fast Healthcare Interoperability Resources (FHIR) SDC to report cancer data to state cancer registries
Structured Data Capture (SDC)

- The Structured Data Capture (SDC) initiative provides an infrastructure for capturing, exchanging and using patient data within electronic health record (EHR) systems for clinical research, and adverse event and public health reporting.

- Standards and Specifications:
  - Integrating the Healthcare Enterprise (IHE)
  - HL7 Fast Healthcare Interoperability Resources (FHIR)

- Develop SDC Form to capture standard data from source (physician EHR, Laboratory, etc.)
  - Utilize College of American Pathologists Cancer Protocols and electronic Cancer Checklist Templates
  - Applicable for any type of data collection

- EHR/Lab systems auto-populate and allow for manual data entry

- Participate in testing and demonstrations with EHRs and other healthcare vendors at IHE, HL7, and HIMSS
Cancer Data Workflow

1. Form Designer
2. InteropX
3. Form Manager & Form Repository
4. Cancer Registry

Request a Form (CCDA)
Receive the Partially filled Form
Submit Completed Form

College of American Pathologist (CAP)
CAP Cancer Protocols

Provider Environment
Epic System

Patient
Doctor

Cancer Registry
State Cancer Registry
Demonstration of IHE Structured Data Capture

- **Past Demonstrations:**
  - HIMSS Interoperability Showcase demonstration at the HIMSS 2017 Annual Conference in Orlando, FL
  - Public Health Informatics Conference 2016 in Atlanta, GA
  - Demonstration participants:
    - Form Manager: JBS International
    - Form Filler: Epic
    - Form Receiver: CDC Cancer Registry
    - Form Designer: College of American Pathologists (CAP)

- **Use Case:** Use of SDC to report cancer pathology and biomarker data from laboratories and EHRs to public health cancer registry systems for cancer surveillance purposes

- **Today’s Demonstration participants:**
  - Form Manager and Form Filler: JBS International
  - Form Receiver: CDC Cancer Registry
  - Form Designer: College of American Pathologists (CAP)
Increase Data Accessibility and Usability

- Data Visualization efforts
- Public Use Data set
Acknowledgements

• Dr. Richard Moldwin, College of American Pathologists
• Shailendra Bajracharya, System Developer, Northrop Grumman
Go to the official source of cancer prevention information: [www.cdc.gov/cancer](http://www.cdc.gov/cancer).

Speaker Contact Information:
Sandy Jones, [sft1@cdc.gov](mailto:sft1@cdc.gov)
Vijay Shah, [vshah@jbsinternational.com](mailto:vshah@jbsinternational.com)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.