E-standards for Cancer Registries -- A Status Report

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C/NET Solutions and the California Cancer Registry

Summary of this talk

- Brief history of cancer standards work
- Status of California standards
- Status of National Cancer registry standards
- Four example HL7-based registry projects
- Recap of what we've learned

Brief History of Cancer Standards - California

- PC software used to encourage standard coding
- Created electronic reporting standards
  - Along with software to carry them out
  - to help initiate statewide cancer reporting

Brief History of Cancer Standards - National

- NAACCR founded to support new state registries
- Data standards committee formed.
  - Major task: resolve differences between NCI's SEER and the College of Surgeons
- Data exchange committee formed to agree on single common format for all cancer reports.

Status of California Standards

- Now used by 450 hospitals reporting to state
- California Standards include:
  - A mandated ASCII layout used by all vendors
  - Nationally-agreed-upon code sets + California extensions
  - Online coding manuals with context-specific help
  - A common edit set to enforce validation and completeness rules

California E-Casefinding Standards

- Implementing electronic casefinding is a strong focus in California
- The volume of potential case reports drives an electronic solution
- Many more potential cases must be scanned than end of as reportable cases
- Several Automated casefinding project discussed below

Apparent Source of Casefinding for California Cases Diagnosed in 1999

Source	Count	Percent
Hospital Pathology	69,734	49.4%
Hospital-Initiated NOS	38,099	27.0%
Hospital Disease Index	14,345	10.2%
Private path lab	6,277	4.4%
Hospital Radiation	4,188	3.0%
Death Certificate	2,746	1.9%
Hospital Daily Discharge	2,030	1.4%
Path consultant	1,991	1.4%
Physician Initiated	553	0.4%
Other source	1,119	0.8%
Total	141,082	100.0%

National Standards Within Cancer Surveillance – a Success

- Host standards organization (NAACCR)
- Scope is entire US and Canada
- Key participation by ACoS and SEER, CDC, vendors, and states
- Data harmonization between partners
- Distributable dictionaries, e-manuals, and edits
- States are rated for on their ability to meet data standards and quality

Harmonization Achieved because

- Recognition that data providers reported to disparate parties
- National organizations committed to common definitions
- Federal funding of states contingent on standards use.

Ingredients for Success:

- A commitment to standards
- The tools to encourage them
- The courage to measure and report compliance.

The Edits Tool

- Creates Distributable Edits
- Can be integrated into any Windows app
- Supports a cross-organizational metafile
- Created by CDC with vendor participation
- In California, same edits are in CNExT PC front end and Eureka, the statewide system

Problems

- Little connectivity between registries and data systems
- In spite of success pilots of several HL7 implementations, they are not being used much

Some current projects and what we can learn from them

1. HL7-based cancer case reporting
2. Integrating In-hospital HL7 messaging into cancer reporting
3. Electronic Pathology Reporting using HL7
4. Reporting Pathology Protocols using HL7

1. HL7-based cancer case reporting

- CDC-funded to completely map a cancer report to an HL7 ORU
- Used LOINC to identify new fields
- California pilot implementation was technically successful
- But no real incentives to use it for cancer reporting.

2. Integrating In-hospital HL7 messaging into cancer reporting

- Creating software to capture discharge messages
  - Select those coded with possible cancer diagnoses
  - Bring them into the cancer registry
  - For pre-populating a case report

In-hospital HL7 messaging

- Using both discharge messages and pathology messages will be even better
  - Eliminates manual casefinding
  - Allows rapid identification of cases for special studies
- Most hospitals send standard HL7 discharge messages

3. Electronic Pathology Reporting using HL7

- Big effort in California, especially with standalone path labs
- Using NAACCR HL7 message created with CDC support 2 years ago
- Using a national standard list of phrases for text search identification of potential cases
- These standards have been a big help, but there are problems

Electronic Pathology Reporting Issues

- Schemes that depend on new HL7 formats don't work on outdated platforms
- Takes a long time to get lab buy-in
- HIPAA confusion has labs worried about security sending messages
- No agreement yet on secure protocols that work in mixed B2B and public health environments

4. Reporting Pathology Protocols using HL7

- Builds on CAP new pathology checklists for cancer reports
- We are implementing pilot
  - HL7 messaging of structured synotpic checklists
  - Colorectal cancers
  - Piloted at UC Irvine
- Proposed new report formats must be implemented in real messages before their design is complete

RPP Project recipe for success is participation by:

- National standards-setters (CAP and CDC)
- Standards agencies (SNOMED, HL7, LOINC)
- State registries (California and Ohio)
- software developers (C/NET, Rocky Mountain, and Co-Path)
- Practitioners (pathologists)

Standard Interfaces still needed

- Clinical Lab Electronic-reports
- Hospital Discharges
- Hospital Information Systems
- Radiation Treatment Center systems
- State Vital Status Records
- Clinical Trials Systems
- Rapid Casefinding systems for Interview Studies

To make progress:

- Public health and clinical groups need
  - To value connectivity.
  - To have the courage to measure compliance.
- More pilot ‘glue’ projects are needed
  - to create structured standard interfaces
  - and prove their worth.

To make progress, continued:

- These pilot projects need to be funded well enough to include representatives from all the key players
- Proposed coding and message structures must be implemented in real messages and environments before their design is complete.
- Standards work best when accompanied by portable edits and other tools to implement them.