Data Standards: Updating, Changing and Implementing

Andrew K. Stewart - American College of Surgeons

NAACCR Annual Meeting
Salt Lake City, UT
June 10, 2004
NAACCR Data Standards (+)

• NAACCR vol. II provides the cancer surveillance community of North America with a standardized description of:
  – Item definitions
  – Data record layout specifications

• Data exchange layout provides standard parameters for transmission of registry data between facilities and central registries or among central registries.
NAACCR Data Standards (-)

• The presence of a data item in NAACCR vol. II does not represent a NAACCR mandate for the collection, reporting or exchange of the item.

• NAACCR does not establish requirements describing how data collectors (hospital or central) must maintain and organize data systems.
<table>
<thead>
<tr>
<th>Year</th>
<th>Version #</th>
<th>Coding Guideline Changes</th>
</tr>
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<tbody>
<tr>
<td>1995</td>
<td>v4</td>
<td></td>
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<tr>
<td>1996</td>
<td>v5</td>
<td>ROADS 96</td>
</tr>
<tr>
<td>1997</td>
<td>...</td>
<td></td>
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<tr>
<td>1999</td>
<td>v7</td>
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<td>2001</td>
<td>v9</td>
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<td>v10</td>
<td>FORDS / SEER ed. 3.1 / AJCC 6th ed.</td>
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<td>2006</td>
<td>v11</td>
<td>?</td>
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</table>
• 1997 NAACCR policy allowed:
  – Updates no more frequently than once annually
  – A minimum of six months provided for vendors and registries to implement new standards, perform conversions, and conduct necessary training.
NAACCR Policy and the Pace of Change

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NAACCR Policy and the Pace of Change

• 1997 NAACCR policy allowed:
  – Updates no more frequently than once annually
  – A minimum of six months provided for vendors and registries to implement new standards, perform conversions, and conduct necessary training.

  – Recognized existing NAACCR policy as inadequate
  – Defined time-lines and assigned responsibilities for the establishment of major and minor changes to NAACCR data standards.
Implementing Data Standards

• Stakeholders
  – Standard Setters
  – Central Cancer Registries
  – Reporting Facilities
  – Vendors

• Heuristic view of responsibilities

• Synthesis of interdependencies
Implementation Issues: Standard Setters

- Time line for development of materials
- Education
- Conversion rules and codes
- EDITS
- Establish clear timing rules
- Clearly defined reporting requirements
- Adopt to potential delays
Implementation Issues: Central Cancer Registries

- Comply with requirements of standard setter(s)
- Recognize differential reporting requirements of hospitals
- How to interpret and use conversion rules and codes
- Dependent on availability of EDITS
- Adopt to potential delays
- NOT educators
Implementation Issues: Reporting Facilities

- Comply with requirements of standard setters
- Comply with CCR requirements
- Depend on SS for education
- Constrained by vendor production time line
- Reluctant to support multiple abstracting schemes
- Want time-lines from SS
- Want data conversion
  - ‘Continuous’ data for internal analysis/reporting
Implementation Issues: Vendors

• Comply with Standard Setter Requirements
  – Differing reporting requirements of hospitals
  – Differing reporting requirements of CCRs
• Commercial concerns need to “maximize” lead time
• Reluctant to support multiple abstracting schemes
• How to interpret and use conversion rules and codes
• Adopt to potential delays
• NOT educators
A Structural Composition

- Standard Setters
- APIs
- EDITS
- Vendors
- Central Registries
- Reporting Facilities
A Standard Setter’s View

Develop and communicate new STDs, provide education, and feedback to CCRs and RFs
Comply with SS requirements and recognize RFs variable reporting requirements
A Reporting Facility’s View

Comply with SS and CCR reporting requirements, desire analytic continuity, are dependent on Vendors for registry software.
A Vendor’s View

Standard Setters

APIs

EDITS

Vendors

Central Registries

Reporting Facilities

Comply with SS and CCR reporting requirements, continue product development and enhancements
**Bringing it Together**

- **Standard Setters**
  - SS develop and communicate new standards, provide education, direction & feedback to CCRs
  - SS develop and communicate new standards, provide education, direction & feedback to RFs

- **APIs**

- **EDITS**
  - CCRs submit data back to SS according to standards

- **Vendors**
  - RFs provide case reports to SSs according to standards
  - CCRs communicate new standards, provide education, direction and feedback to RFs

- **Central Registries**
  - CCRs communicate new standards, provide education, direction and feedback to RFs

- **Reporting Facilities**
  - RFs provide case reports to CCRs according to standards

Goal

Standard Setters

APIs

EDITS

Vendors

Central Registries

Reporting Facilities

Transparency of reporting
Implementing Data Standards: Future Challenges

• NAACCR is not structurally equipped to assess the establishment of proposed new data elements.
  – Definition of the entity being measured
  – Uneven registry infrastructure
Implementing Data Standards: Future Challenges

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  - Definition of the entity being measured
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- Potential criteria:
  - Availability
  - Reliability
  - Guidelines
  - Application
  - Cost
  - Maintenance
Thank You