DEVELOPING
NPCR Data Quality Indicators to Improve Population-Based Central Cancer Registry Data

Karen Ledford, RHIA, CTR

C Cardinez, G Clutter, R Intlekofer, M Lewis, F Michaud, J Nichols, H Weir, R Wilson
Objective

• **NPCR Goals**
  – High quality data submitted to NPCR-CSS
  – Continuous quality improvement of data
Background

- NPCR Cancer Surveillance System (NPCR-CSS)
  - Annual data submission
  - Critical and non-critical data items and edits
- NPCR-CSS Data Evaluation Reports
  - Feedback to individual registries
  - Completeness, timeliness, quality (edits only)
Methods

• Quality Improvement Workgroup
  – Internal CDC-NPCR
  – Developed NPCR Quality Improvement Plan
    • Evaluated reported data items not included in Data Evaluation Reports
    • Evaluated data items required to be collected but not reported
    • Reviewed quality indicators evaluated by SEER
Results

• NPCR-CSS Annual Data Submission
  – **CORE** Data (changed from Critical)
    • Describes basic cancer incidence
    • Primary site, histology, laterality, age, race/ethnicity, stage
  – **ADVANCED** Data (changed from Non-critical)
    • Identifies and describes high risk populations and survival
    • County, census tract, treatment, vital status
Results

• NPCR Data Quality Indicator Graphs
  – Based on analysis of 24 month data
  – 7 indicators in a set of 11 graphs
  – Comparison across NPCR registries
  – Distributed December 2004
  – Feedback
    • Each state
    • Logistics Workgroup
Data Quality Indicators

- % Other, Ill-defined, and NOS Primary Site
- % Non-specific Morphology
- % Unknown Diagnostic Confirmation or Not Microscopically Confirmed
- % Unknown or Unspecified Laterality for Paired Organs
- % Death Certificate Only
- % Unknown Summary Stage (all sites, breast, colorectal, lung & bronchus, prostate)
Sample DQI Graph

% Other, Ill-defined, and NOS Primary Site [400]
All Sites Combined*, Both Genders
Individual State Registries and NPCR Registries Combined, 2001 diagnosis year

- Red: Other and ill-defined (C76.0-76.8)
- Blue: Unknown primary site (C80.9)

*Invasive cases only, excludes basal and squamous cell carcinomas of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder.
Results

- NPCR-CSS 2005 Data Evaluation Reports
  - Included Data Quality Indicator Report
    - Comparison across years for single registry
    - Table format
    - Core and Advanced data
    - 1998–2002 data years
## Table 2: Advanced Cancer Surveillance Data

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*For quality review only, no NPCR standards at this time. DQI expressed as percent of all invasive cancers and in situ bladder cancers, except as noted.
**SEER Data Extract: Database: Incidence - SF 1H 11 Regs Public Use, released April 2004. Some percentages are based on recoded values.
**NAACCR data item numbers are noted with square brackets "[ ]" and crossed with parentheses ")("
N/A - not applicable for the diagnosis year.
Results

• Reconvened NPCR Logistics Workgroup
  – First convened 1999
    • Forum for NPCR-CSS Implementation
  – Now forum for all NPCR related data issues
Next Steps

- Continue to develop quality improvement plan
- Send additional graphs as topics identified
- Comparison of 2001 to 2003 diagnosis years to assess improvement
Results

- NPCR Priorities for Funded Registries
  - Collect, report, and use high quality **CORE** cancer surveillance data
  - Move toward same for **ADVANCED** cancer surveillance data
DISPLAYING
NPCR Data Quality Indicators to Improve Population-Based Central Cancer Registry Data

Cheryll Cardinez, MSPH

M Lewis, F Michaud, G Clutter, RC Intlekofer, K Ledford, PJ Nichols, H Weir, RJ Wilson
Who Do You See?
Background

• Seven measures for Data Quality Indicator graphs
  – Other, ill-defined primary site
  – Morphology
  – Microscopic confirmation
  – Laterality
  – Race
  – Death clearance only
  – Stage (all cancers combined, female breast, colon and rectum, lung and bronchus, prostate)
Methods

• Analysis on 2001 diagnosis year (24-month data)

• Sorted in ascending order
  – Inherent random order
  – Allowed for de-identification of other registries

• Internal review of data
  – Determination of registries below, within, or higher than NPCR aggregated percentage
Results

% Unknown Summary Stage 2000 [759]
All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder. Death certificate only, pathology laboratory only, and unknown primary site cases were also excluded.
Discussion

• Different data presentation allows for:
  – Identification of training opportunities
  – Improvement in registry operations
  – Incremental improvement of data
Lessons Learned

• Separation of stacked bars in microscopic confirmation graph

• Presentation of two different graphs
  – Unknown
  – Not microscopically confirmed
Lessons Learned

% Unknown Diagnostic Confirmation or Not Microscopically Confirmed [490]
All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder. Death certificate only cases were also excluded.
Lessons Learned

% Unknown Diagnostic Confirmation [490]
All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder. Death certificate only cases were also excluded.
Lessons Learned

% Not Microscopically Confirmed [490]
All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder. Death certificate only cases were also excluded.
Next Steps

• Addition of bar for aggregated SEER data

• Additional data items may be included
  – Unknown age at diagnosis
  – Unknown month of diagnosis
  – Collaborative stage
INTERPRETING & USING
NPCR Data Quality Indicators to
Improve Population-Based Central Cancer Registry Data

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C Cardinez, G Clutter, R Intlekofer, K Ledford, M Lewis, F Michaud, J Nichols, H Weir
Background

- Data quality importance widely recognized
- NPCR committed to continued improvement
Objective

• To utilize indicators documenting data quality for continuous quality improvement and to identify and document training needs.
Methods

• NPCR-CSS data analyzed

• Feedback to CCR to document:
  – Data quality
  – Identify areas for improvement
  – Document training needs
Percent Non-specific Morphology, All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder.
Percent Unknown or Unspecified Laterality
Paired Organs Only, All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder.
Percent Unknown Race
All Sites Combined*, Both Genders
Individual State Registries & NPCR Registries Combined, 2001 Diagnosis Year

*Invasive cases only, excludes basal and squamous cell carcinoma of the skin except when these occur on the skin of the genital organs and in situ cancers except urinary bladder.
Results

• Potential factors affecting data quality
  – Insufficient source documentation
  – Training needs
  – Insufficient non-hospital casefinding
  – Death Clearance
Results

• Importance of Data Quality Indicators
  – Affects incidence rates
  – Quality data necessary for research
Results

• **Additional training required**
  – Reporting sources
    • Review all documentation
    • Review all casefinding sources
  – CCR
    • Data item consolidation
    • Non-hospital casefinding
    • Death clearance
    • Self assessment

• **Reassess data quality each year**
CCR Activities Implemented

• Information sharing
  – Reporting sources
  – Policy makers
  – Advisory groups
  – Department administration
  – Other cancer programs

• New processes
  – CCR policies
  – Feedback to reporting sources

• Site visits by hospital registrars
Conclusions

• Provides means and justification
  – Training
  – Additional resources

• Documents high quality
Next Steps

- NPCR work with grantees
  - Assist with improvement opportunities
  - Establish baselines
  - Determine need for additional standards
Take Home Points

NPCR is dedicated to:

• Quality data collection
• Evaluation
• Documenting quality
• Identifying training needs
Contact Information

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