The National Program of Cancer Registries’ (NPCR) Annual Program Evaluation: Ten Years of Partnership and Progress

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The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.
What is Program Evaluation?

The systematic collection of information about the activities, characteristics, and outcomes of programs to make judgements about the program, improve program effectiveness, and make informed decisions about future program development.
Framework for Program Evaluation in Public Health

STANDARDS FOR "GOOD" EVALUATION

Accuracy  Feasibility  Propriety  Utility

Gather Credible Evidence  Focus the Evaluation Design  Describe the Program  Engage Stakeholders  Ensure Use and Share Lessons Learned  Justify Conclusions

STEPS IN EVALUATION
Framework for Program Evaluation in Public Health
Purpose of the Evaluation

- Identify characteristics, activities, and program needs of the NPCR
- Monitor program activities and progress in meeting national cancer surveillance needs
- Determine technical assistance needs of central registries
- Monitor progress, successes, and challenges of the CCRs
Unique Utility of the NPCR Annual Program Evaluation Instrument (APEI)

- Web-based instrument
- Responses retained from year to year
  - Allows for simple updating
- Built-in validation checks
  - Eliminates non-responses
  - Greatly improves validity of responses
  - Minimizes/eliminates errors
Updates to the 2006 APEI

◆ New or revised questions regarding:
  ● Data quality and completeness
  ● Record consolidation
  ● Registry-specific edits requirement
  ● Data use
  ● Collection of treatment data items
  ● ePath reporting/format
  ● PHIN/NEDSS capability
  ● Use of SNOMED tools

◆ Provides Program Consultants with current information
Using the Results

- Measure Progress with NPCR Program Standards
- Update NPCR Program Standards
- Determine Technical Assistance Needs
  - Database Linkages
    - National Death Index Database
  - Electronic Reporting
    - ePath
    - HL7 Format
    - WebPlus for Physician Reporting
- Determine Education and Training Needs
  - SNOMED Tools
  - Multiple Histology Coding
## RESULTS:
### Progress Towards NPCR Goals

<table>
<thead>
<tr>
<th>Goal</th>
<th>1995 (N=37)</th>
<th>2001 (N=49)</th>
<th>2006 (N=49)</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% of US jurisdictions have central cancer registry (Includes SEER registries)</td>
<td>72%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Collected all NPCR required data items in standardized format</td>
<td>43%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
### RESULTS: Progress Towards NPCR Goals (Cont’d)

<table>
<thead>
<tr>
<th>Goal</th>
<th>1995 (N=37)</th>
<th>2001 (N=43)</th>
<th>2006 (N=46)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Met all NPCR 24-mo. data standards for completeness, timeliness, and quality</td>
<td>16%</td>
<td>65%</td>
<td>80%</td>
</tr>
<tr>
<td>Produced annual report using 12-month data (file or report available)</td>
<td>0%</td>
<td>15%</td>
<td>20%</td>
</tr>
<tr>
<td>Produced annual report using 24-Month Data</td>
<td>N/A</td>
<td>70%</td>
<td>94%</td>
</tr>
</tbody>
</table>
Results: Benign Brain Tumor Legislation

◆ PL 107-260 requires NPCR Funded Programs to collect Benign Brain Tumor cases starting 2004
  - In 2004, 78% of NPCR funded programs had regs or legs in place
  - By 2006, 92% had regs or legs
### Results: Staffing

<table>
<thead>
<tr>
<th>Year (# Responders)</th>
<th>1995 (N=37)</th>
<th>2001 (N=47)</th>
<th>2006 (N=47)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avg. # filled FTEs (all funding sources)</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Average # CTRs per CCR (all funding sources)</td>
<td>N/A</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>% Filled FTEs = CTR (all funding sources)</td>
<td>N/A</td>
<td>71%</td>
<td>75%</td>
</tr>
<tr>
<td>% CCRs with &gt;= 1 CTR (all funding sources)</td>
<td>89%</td>
<td>91%</td>
<td>96%</td>
</tr>
</tbody>
</table>
### Results (Cont’d): Staffing

<table>
<thead>
<tr>
<th>Year (# APEI Responders)</th>
<th>1995 (N=37)</th>
<th>2001 (N=47)</th>
<th>2006 (N=47)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% CCRs with NO CTR (all funding sources)</td>
<td>11%</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>% CCRs with No Statistician (all funding sources)</td>
<td>N/A</td>
<td>50%</td>
<td>49%</td>
</tr>
<tr>
<td>% CCRs with No Epidemiologist (all funding sources)</td>
<td>N/A</td>
<td>39%</td>
<td>38%</td>
</tr>
<tr>
<td>Quality Control Measure</td>
<td>(# Responders)</td>
<td>Percent (N = 47)</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>CCRs with at least 1 staff member responsible for quality control</td>
<td>98%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCRs with at least 1 CTR who performs abstract review</td>
<td>96%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abstracts that are corrected at CCR are returned to facility abstractors for review</td>
<td>64%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCR includes hematopoietic diseases in casefinding and QC audits</td>
<td>81%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Results:
Electronic Data Reporting by Hospitals (2006)

Average Percentage of Hospitals with Abstracts Reported Electronically

0% 20% 40% 60% 80% 100%
Results: Reporting Compliance (2006)

Percentage of Facilities Reporting as Required

- Non-Fed Hospitals
- Military Hospitals
- Path Labs
- VA Hospitals
- IHS Hospitals
- Radiation Therapy Centers

0% 20% 40% 60% 80% 100%
Results: Electronic Reporting (2006)

Percentage of Facilities Reporting Electronically

- Non-Fed Hospitals
- Military Hospitals
- Path Labs
- VA Hospitals
- IHS Hospitals
- Radiation Therapy Centers

0% 20% 40% 60% 80% 100%
Results (Cont’d): Reporting Compliance (2006)

Percentage of Facilities Reporting as Required

- Surgery Centers
- Dermatologists
- Urologists
- Hematologists
- Other Physicians
- Other Facilities
Results (Cont’d): Electronic Reporting (2006)

Percentage of Facilities Reporting Electronically

- Surgery Centers
- Dermatologists
- Urologists
- Hematologists
- Other Physicians
- Other Facilities

0% to 100% Percentage Distribution
Results: Database Linkages

Percentages of Secondary Linkages in 2005

- State Vital Statistics
- Dept. Motor Vehicles
- Medicare
- Dept. Voter Registration
- Managed Care Org
- National Death Index
- Medicaid
- Medicaid
- Other

Percent CCR's conducting linkage:
N = 47
Results: Case-Sharing

◆ In 1995, 62% had case-sharing agreements with at least one other jurisdiction

◆ By 2001, 65% reported case-sharing agreements with all bordering jurisdictions

◆ In 2006, 92% case-sharing with all bordering jurisdictions
Results: Data Use

77% in 2001 compared to 96% in 2006

Registries reported data being used for 
at least three 
of the following:

- Detailed incidence/mortality estimates
- Linkage with statewide cancer screening program (to improve follow-up)
- Health event investigations
- Needs assessment/program planning
- Program evaluation
- Epidemiologic studies
Results: Advanced Activities (2006)

Percentage CCRs Conducting Advanced Activities

- Receive encrypted case reports
- Geocoding
- Publications using registry data

Percentage CCRs N=47

- Auto casefinding beyond vital records
- NDI linkage for survival analysis
- Quality of care studies
- Publications using registry data
- Other innovative data use
## Results (Cont’d): Advanced Activities (2006)

<table>
<thead>
<tr>
<th>Type of ePath Report Format</th>
<th>Percent CCRs Receiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAACCR ePath format</td>
<td>43%</td>
</tr>
<tr>
<td>HL7 format</td>
<td>30%</td>
</tr>
<tr>
<td>Other: MS Excel, MS Access, text, MS SQL, tab delimited</td>
<td>5%</td>
</tr>
<tr>
<td>No path reports received in electronic format</td>
<td>22%</td>
</tr>
</tbody>
</table>
## Results: PHIN and NEDDS (2006)

<table>
<thead>
<tr>
<th>Data Collection and PHIN/NEDDS</th>
<th>Percent CCRs Contacted PHIN/NEDDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integration of cancer data collection system for PHIN compatibility</td>
<td>26%</td>
</tr>
<tr>
<td>Anatomical path lab reporting</td>
<td>57%</td>
</tr>
<tr>
<td>Physician reporting</td>
<td>23%</td>
</tr>
<tr>
<td>Other healthcare facility reporting</td>
<td>6%</td>
</tr>
<tr>
<td>None of the above</td>
<td>38%</td>
</tr>
</tbody>
</table>
## Results: SNOMED Tools

<table>
<thead>
<tr>
<th>From 2006 APEI: Training/Education Need Identified</th>
<th>Percentage of CCRs</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCRs used SNOMED tools in 2005 that CDC made available</td>
<td>17%</td>
</tr>
<tr>
<td>“No,” but CCR plans to use in 2006 - 2007</td>
<td>23%</td>
</tr>
<tr>
<td>Additional information or training on tools is needed</td>
<td>66%</td>
</tr>
</tbody>
</table>
But Are The Results Useful to The Registries?

◆ YES!
◆ On the horizon is the new APEI Web Page
  - Queriable web site
  - Compare to aggregate in your Region
  - Compare to US aggregate
  - Print reports
    - Annual Registry Operations Report
      - Your CCR
      - Your CCR compared to Region, US
In 2006, 18% of the CCRs reported they don’t receive any path reports electronically.

- CDC Collaborated with LabCorp

### Percentage of ePath Reporting Format by Type

<table>
<thead>
<tr>
<th>Format</th>
<th>Percentage</th>
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<td>NAACCR Format</td>
<td>40%</td>
</tr>
<tr>
<td>HL7 Format</td>
<td>20%</td>
</tr>
<tr>
<td>No ePath</td>
<td>100%</td>
</tr>
</tbody>
</table>
NPCR Responds (Cont’d)

◆ Only 29% of Physicians Report Electronically
  ● CDC’s WebPlus to Promote

Web-based Reporting by Physicians

![Graph showing physician reporting rates](image-url)

- Total Reporting
- Report Electronically
In 2006, only 19% of registries reported they conducted a database linkage with the National Death Index (NDI) database in the past year.

- CDC recently partnered with NDI
- Facilitated series of technical assistance calls with central registries and NDI
What’s New

◆ Program Evaluation Workgroup
Composed of Volunteers from Central Registries and CSB team members

◆ Commitment to the on-going improvement of APEI data

◆ Promote use of APEI data
What’s Ahead

◆ Questions Align With Program Standards
  ● Enhance Ability to Measure Progress

◆ Continue to Improve Usability of Web Application

◆ New Queriable Web Site
  ● Individual, Regional, US results
  ● Comparative Analyses
  ● Print Program Evaluation Reports
  ● Ad-Hoc Reports as Needed
CONTACT INFORMATION

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