

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

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DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION

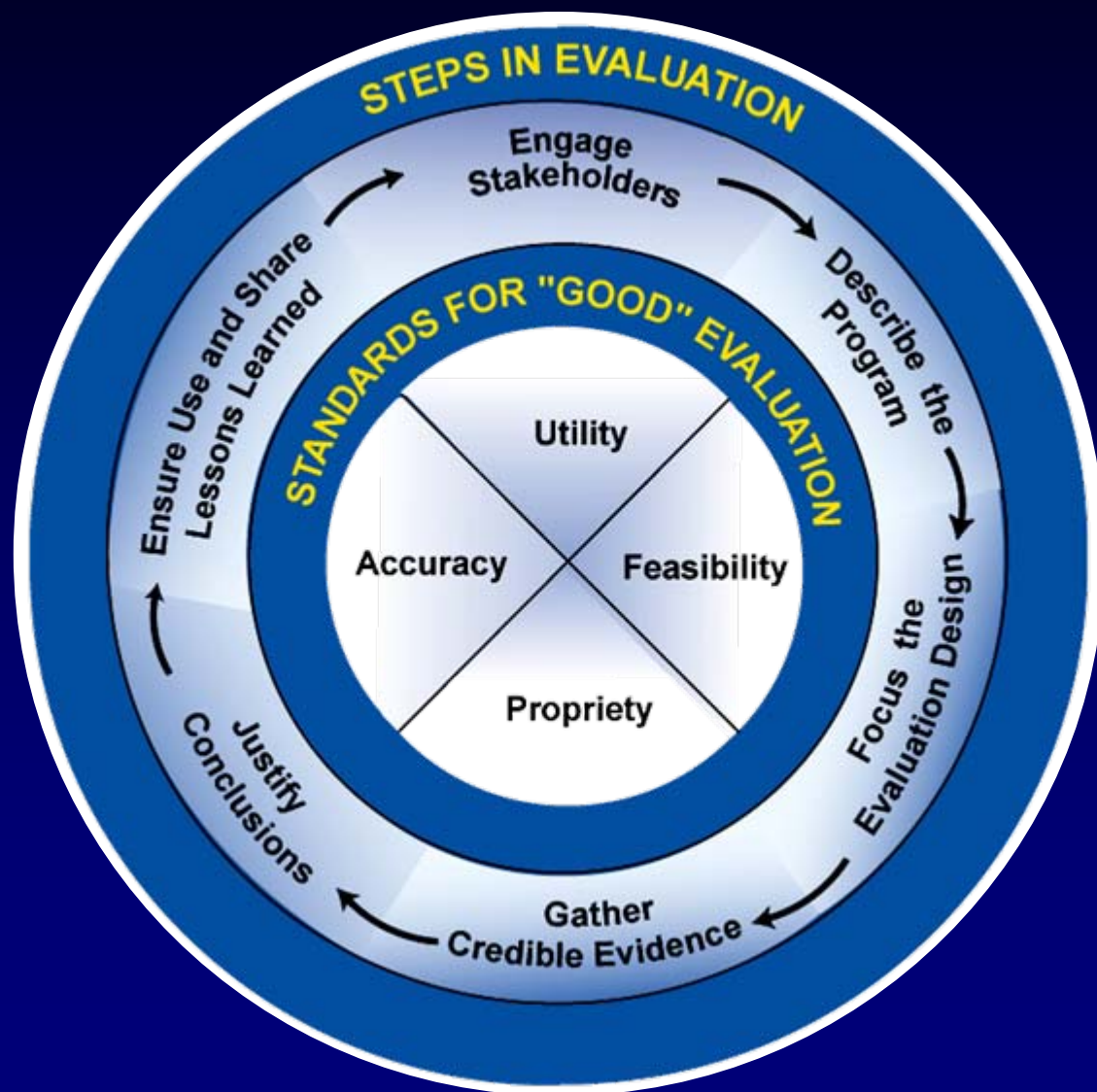
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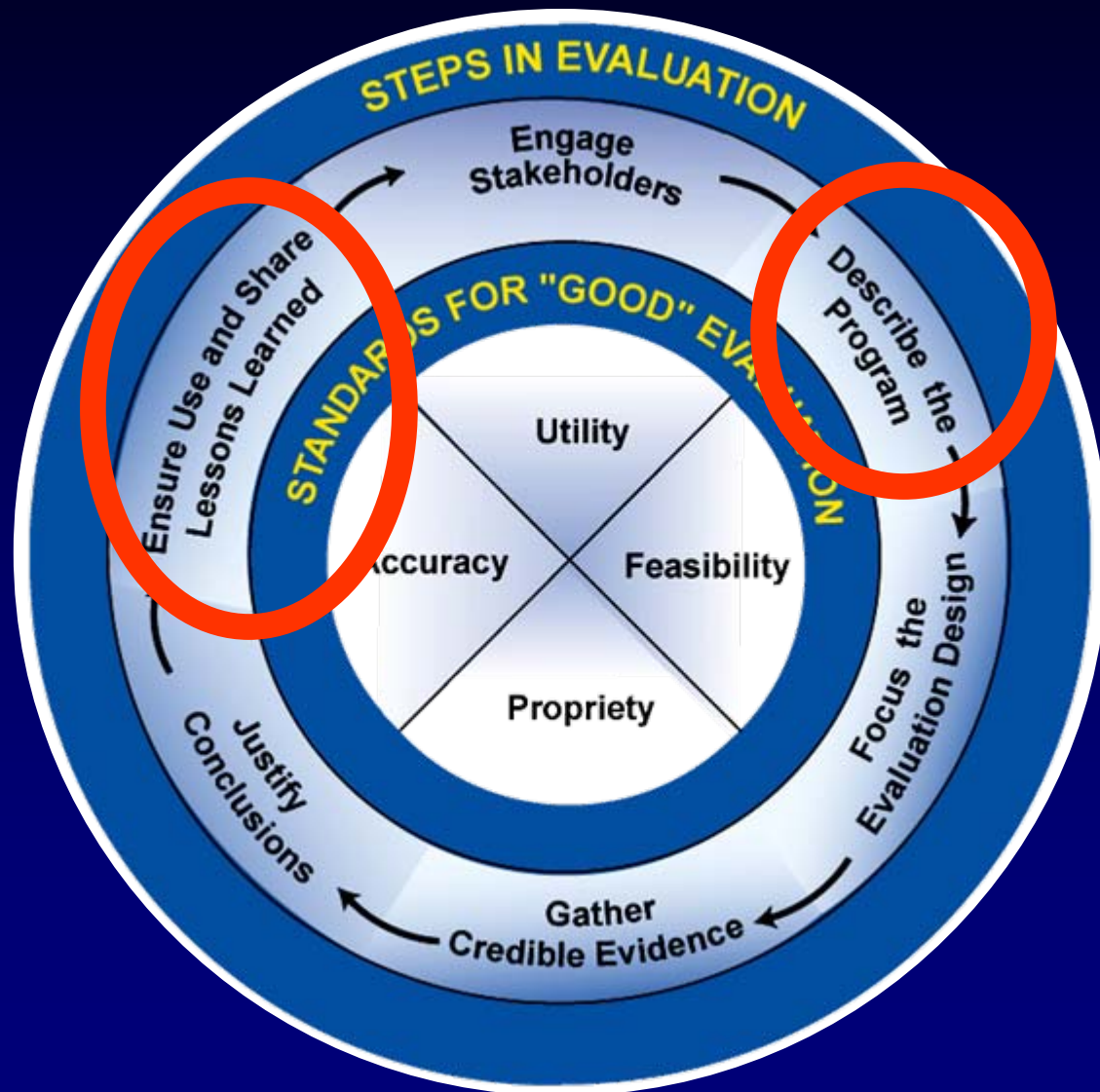
What is Program Evaluation?

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



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

Goal	1995 (N=37)	2001 (N=49)	2006 (N=49)
Data Submission Year # NPCR Registries			
100% of US jurisdictions have central cancer registry (Includes SEER registries)	72%	100%	100%
Collected all NPCR required data items in standardized format	43%	100%	100%

RESULTS:

Progress Towards NPCR Goals (Cont'd)

Data Submission Year # Submissions Goal	1995 (N=37)	2001 (N=43)	2006 (N=46)
Met all NPCR 24-mo. data standards for completeness, timeliness, and quality	16%	65%	80%
Produced annual report using 12-month data (file or report available)	0%	15%	20%
Produced annual report using 24-Month Data	N/A	70%	94%

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

Year (# Responders)	1995 (N=37)	2001 (N=47)	2006 (N=47)
Avg. # filled FTEs (all funding sources)	6	7	8
Average # CTRs per CCR (all funding sources)	N/A	5	6
% Filled FTEs = CTR (all funding sources)	N/A	71%	75%
% CCRs with \geq 1 CTR (all funding sources)	89%	91%	96%

Results (Cont'd): Staffing

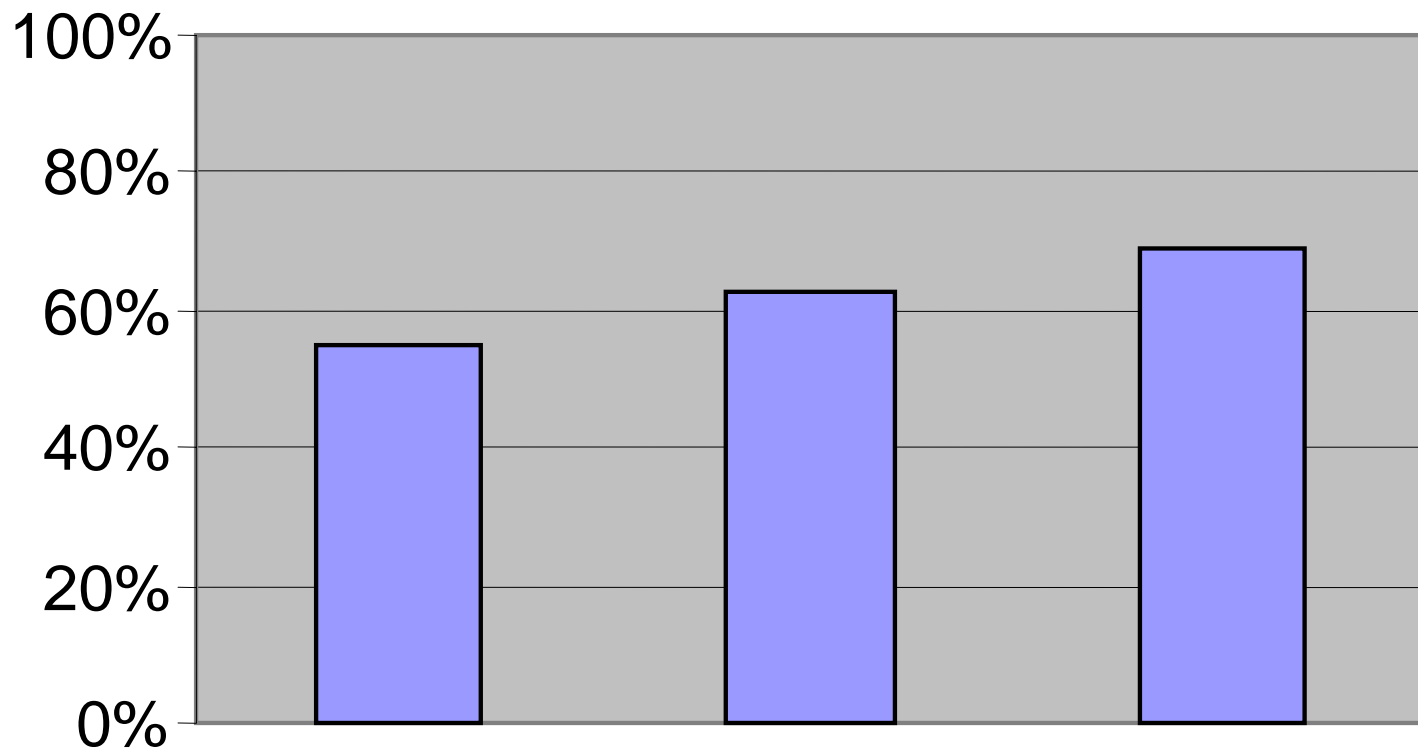
Year (# APEI Responders)	1995 (N=37)	2001 (N=47)	2006 (N=47)
% CCRs with NO CTR (all funding sources)	11%	8%	4%
% CCRs with No Statistician (all funding sources)	N/A	50%	49%
% CCRs with No Epidemiologist (all funding sources)	N/A	39%	38%

Results: Quality Control (2006)

Quality Control Measure	(# Responders)	Percent (N = 47)
CCRs with at least 1 staff member responsible for quality control		98%
CCRs with at least 1 CTR who performs abstract review		96%
Abstracts that are corrected at CCR are <i>returned to facility abstractors for review</i>		64%
CCR includes hematopoietic diseases in casefinding and QC audits		81%

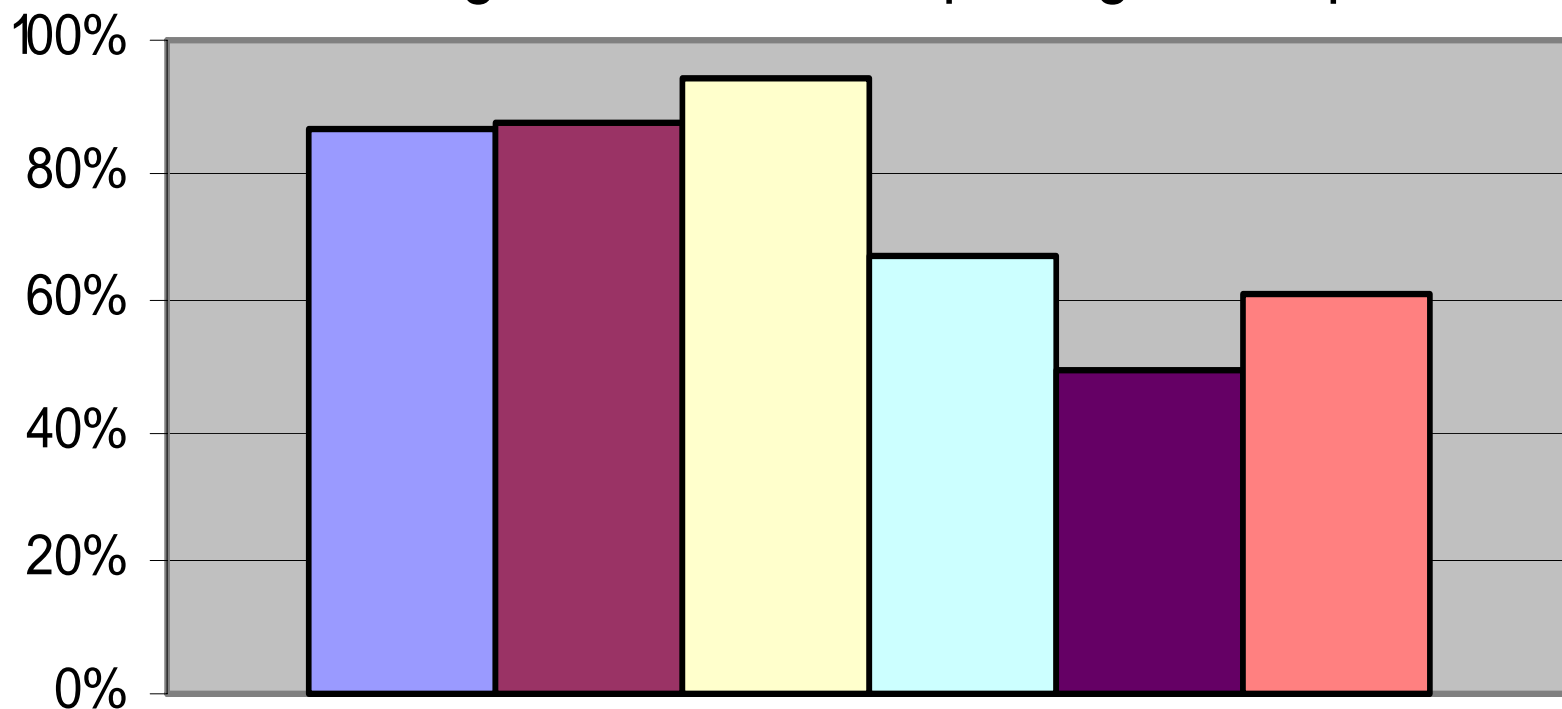
Results: Electronic Data Reporting by Hospitals (2006)

Average Percentage of Hospitals with Abstracts Reported Electronically



Results: Reporting Compliance (2006)

Percentage of Facilities Reporting as Required



■ Non-Fed Hospitals

■ Military Hospitals

■ Path Labs

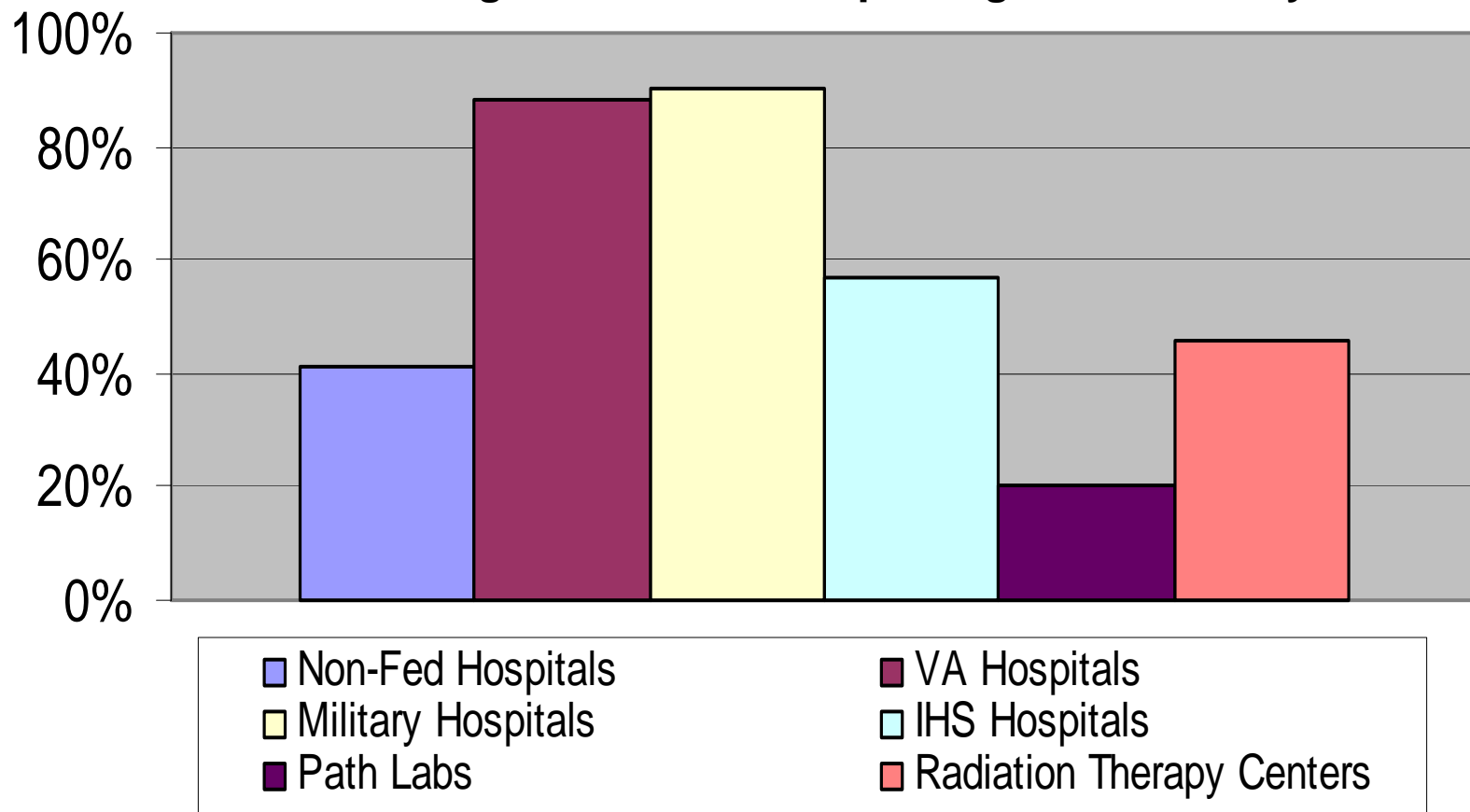
■ VA Hospitals

■ IHS Hospitals

■ Radiation Therapy Centers

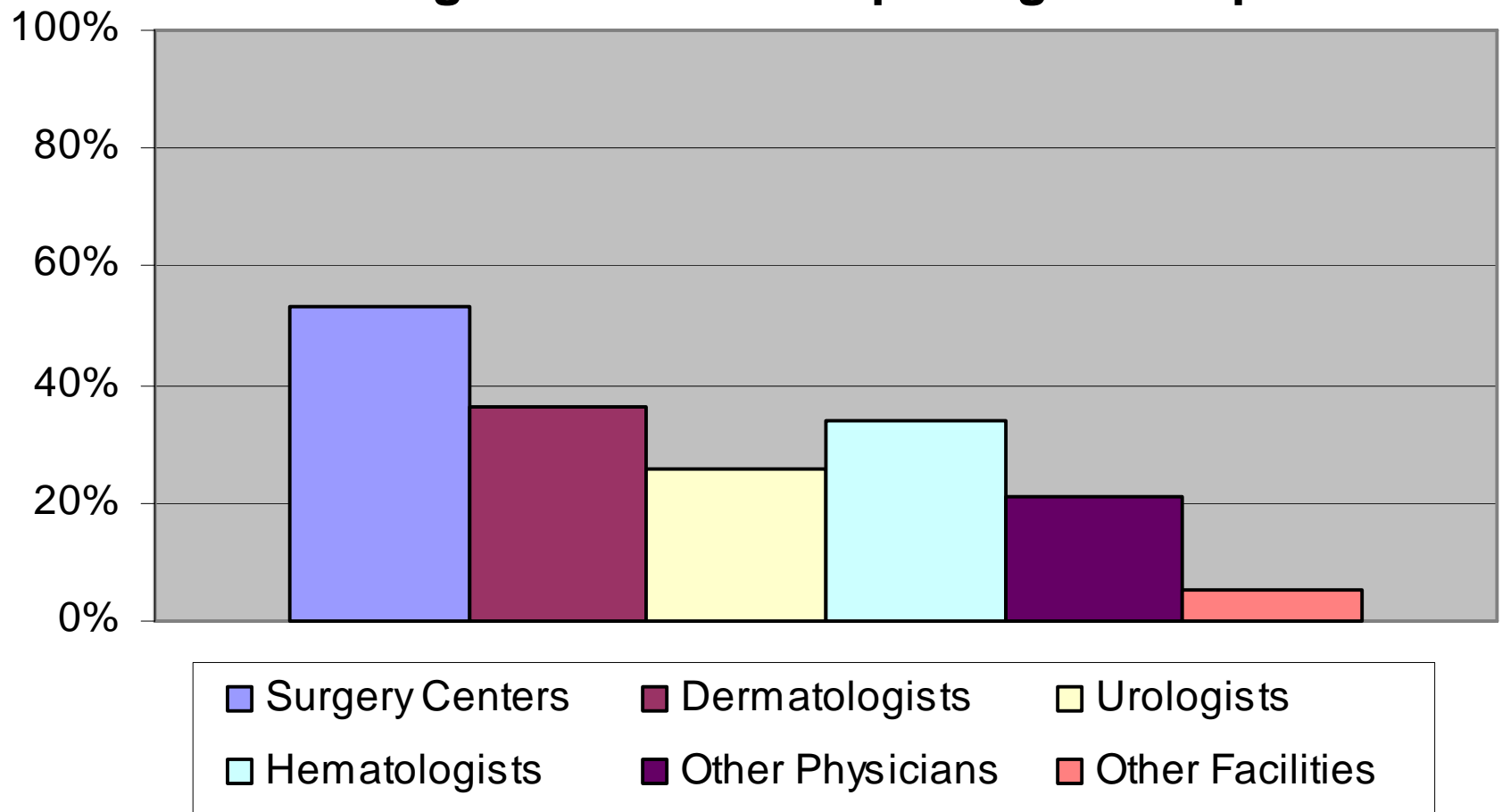
Results: Electronic Reporting (2006)

Percentage of Facilities Reporting Electronically



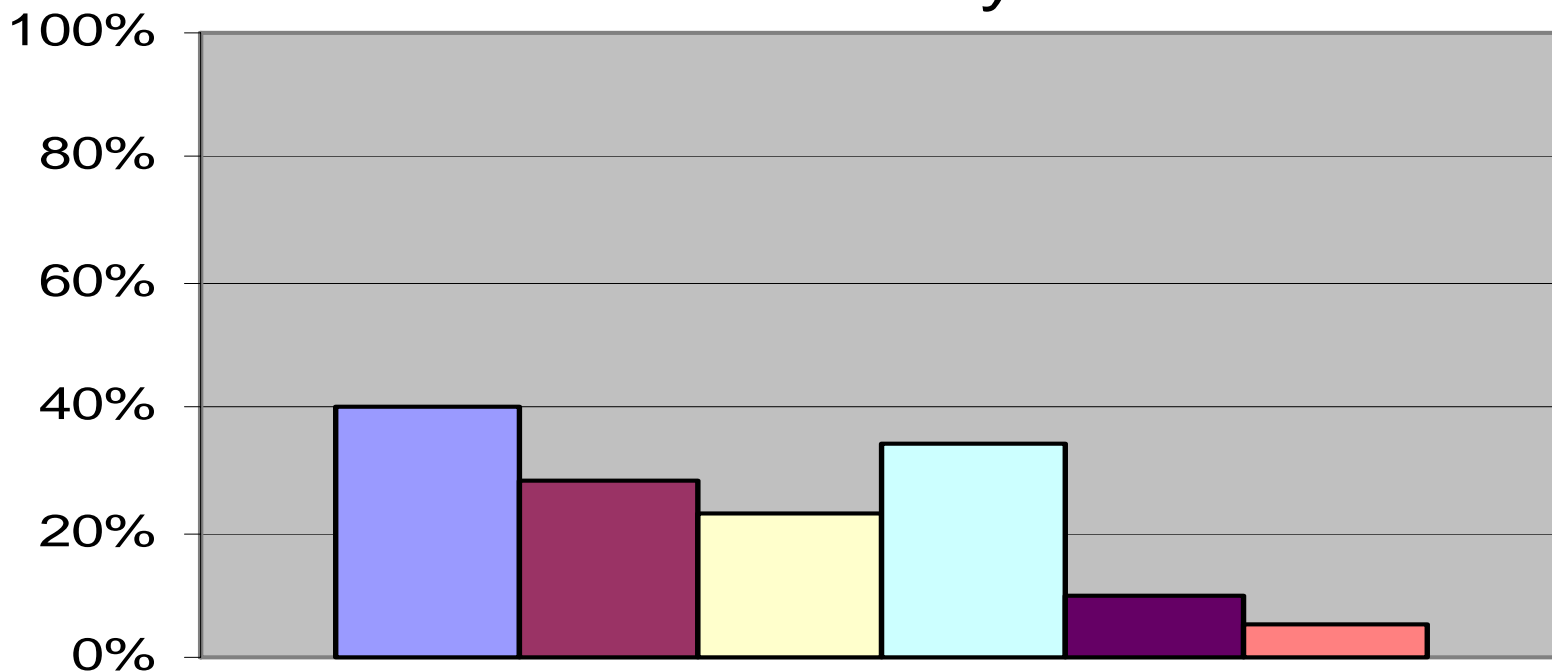
Results (Cont'd): Reporting Compliance (2006)

Percentage of Facilities Reporting as Required



Results (Cont'd): Electronic Reporting (2006)

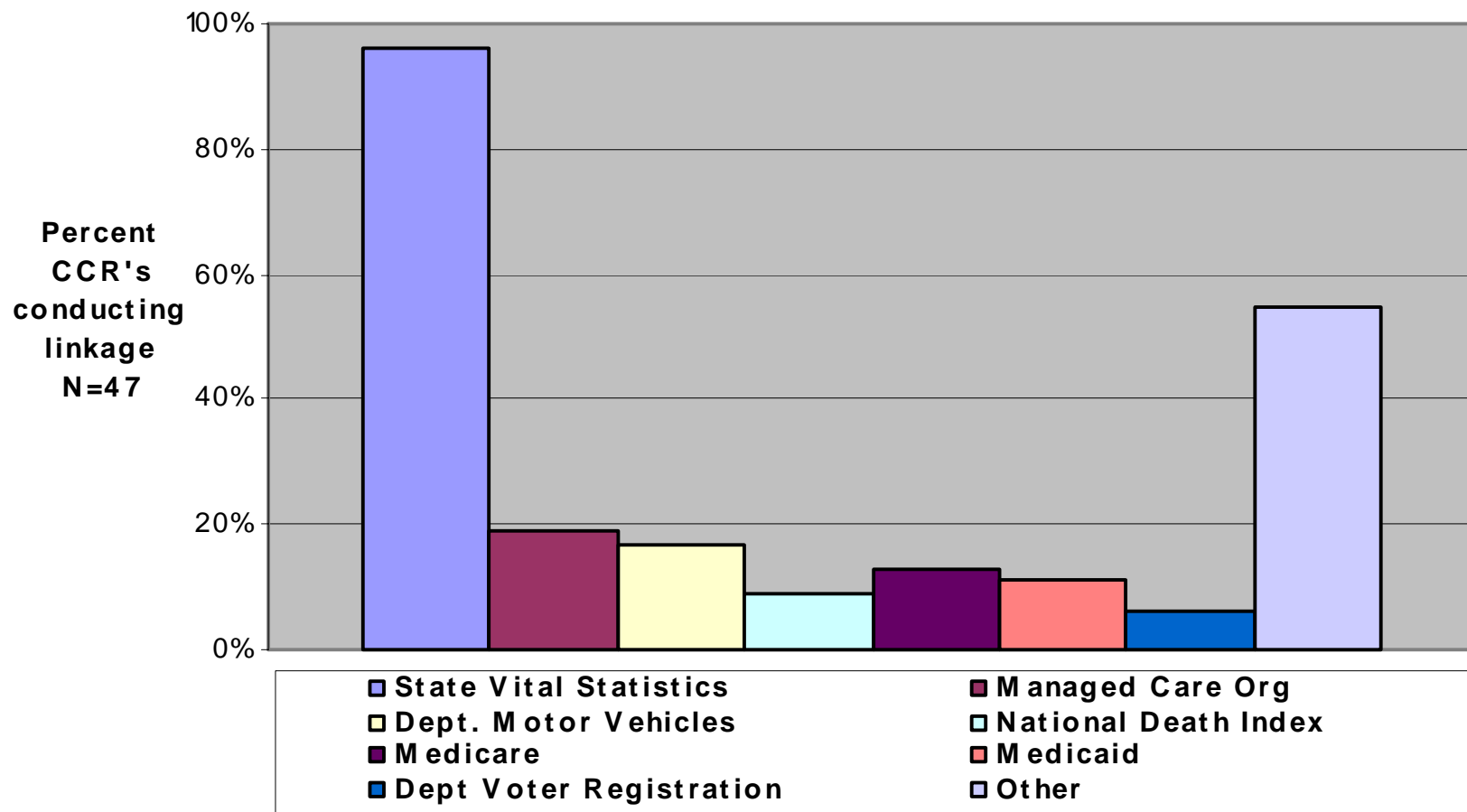
Percentage of Facilities Reporting Electronically



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

Results: Database Linkages

Percentages of Secondary Linkages in 2005



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

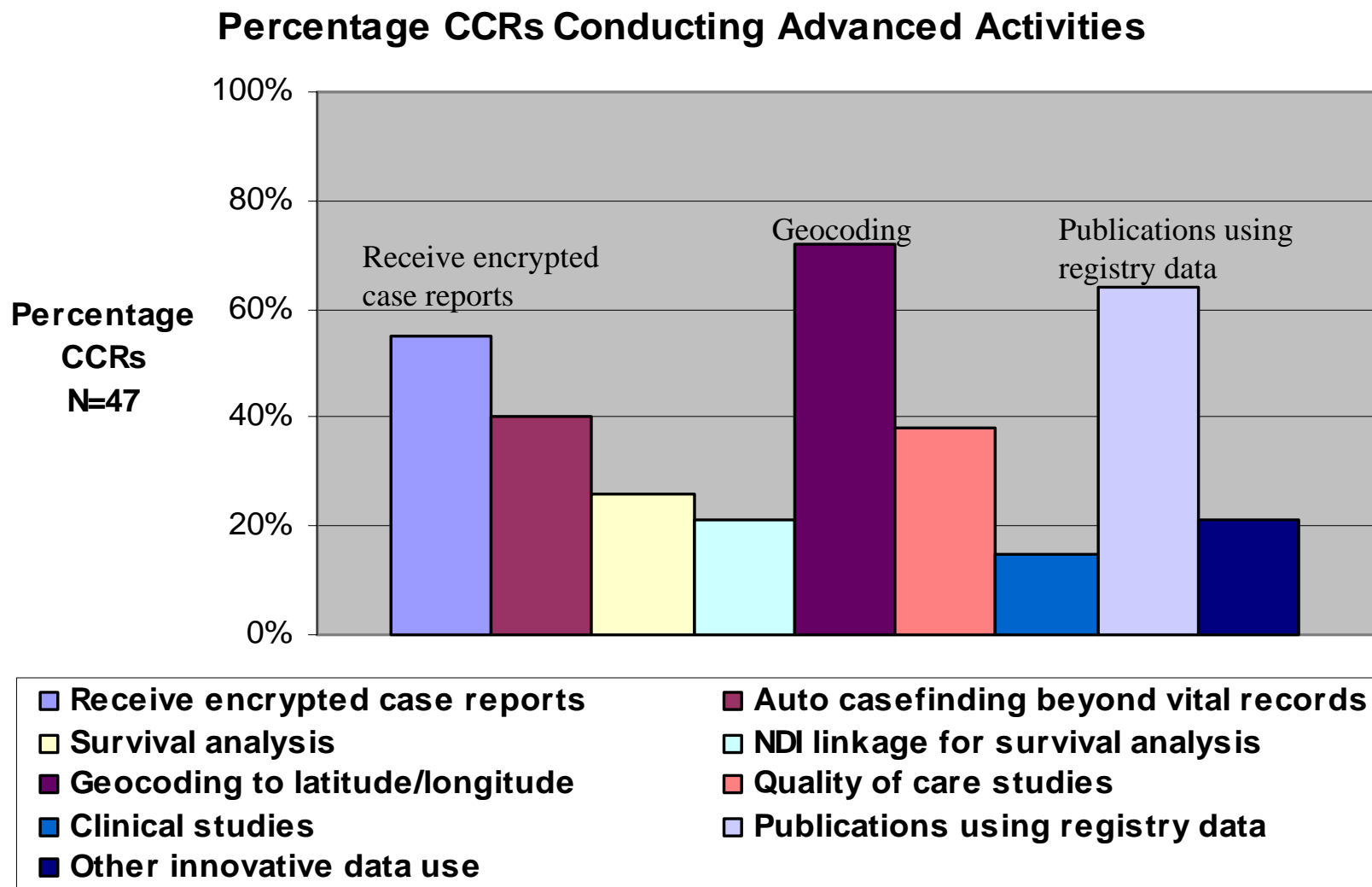
Results: Data Use

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)



Results (Cont'd): Advanced Activities (2006)

Type of ePath Report Format	Percent CCRs Receiving
NAACCR ePath format	43%
HL7 format	30%
Other: MS Excel, MS Access, text, MS SQL, tab delimited	5%
No path reports received in electronic format	22%

Results: PHIN and NEDDS (2006)

Data Collection and PHIN/NEDDS	Percent CCRs Contacted PHIN/NEDDS
Integration of cancer data collection system for PHIN compatibility	26%
Anatomical path lab reporting	57%
Physician reporting	23%
Other healthcare facility reporting	6%
None of the above	38%

Results: SNOMED Tools

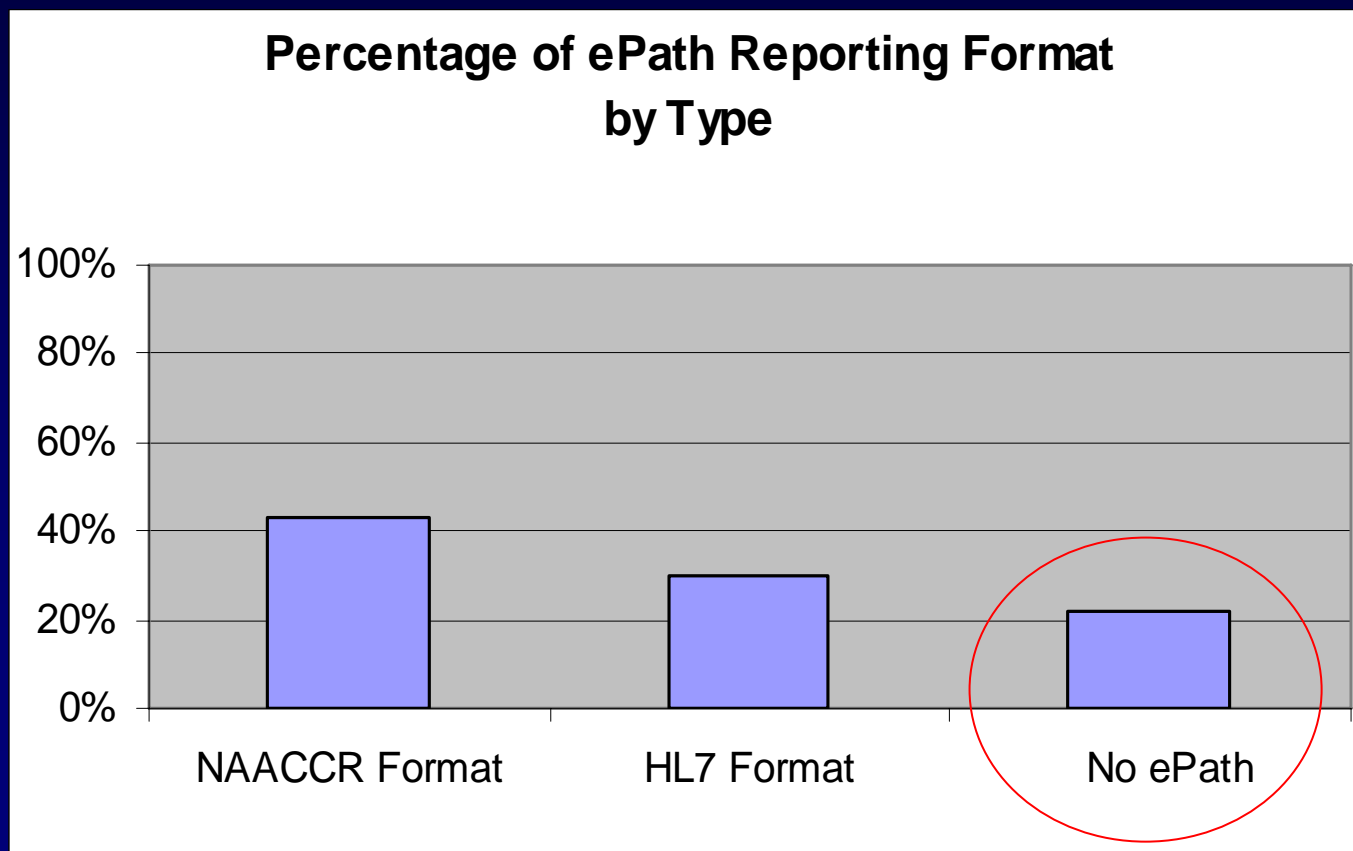
From 2006 APEI: Training/Education Need Identified	Percentage of CCRs
CCRs used SNOMED tools in 2005 that CDC made available	17%
“No,” but CCR plans to use in 2006 - 2007	23%
Additional information or training on tools is needed	66%

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

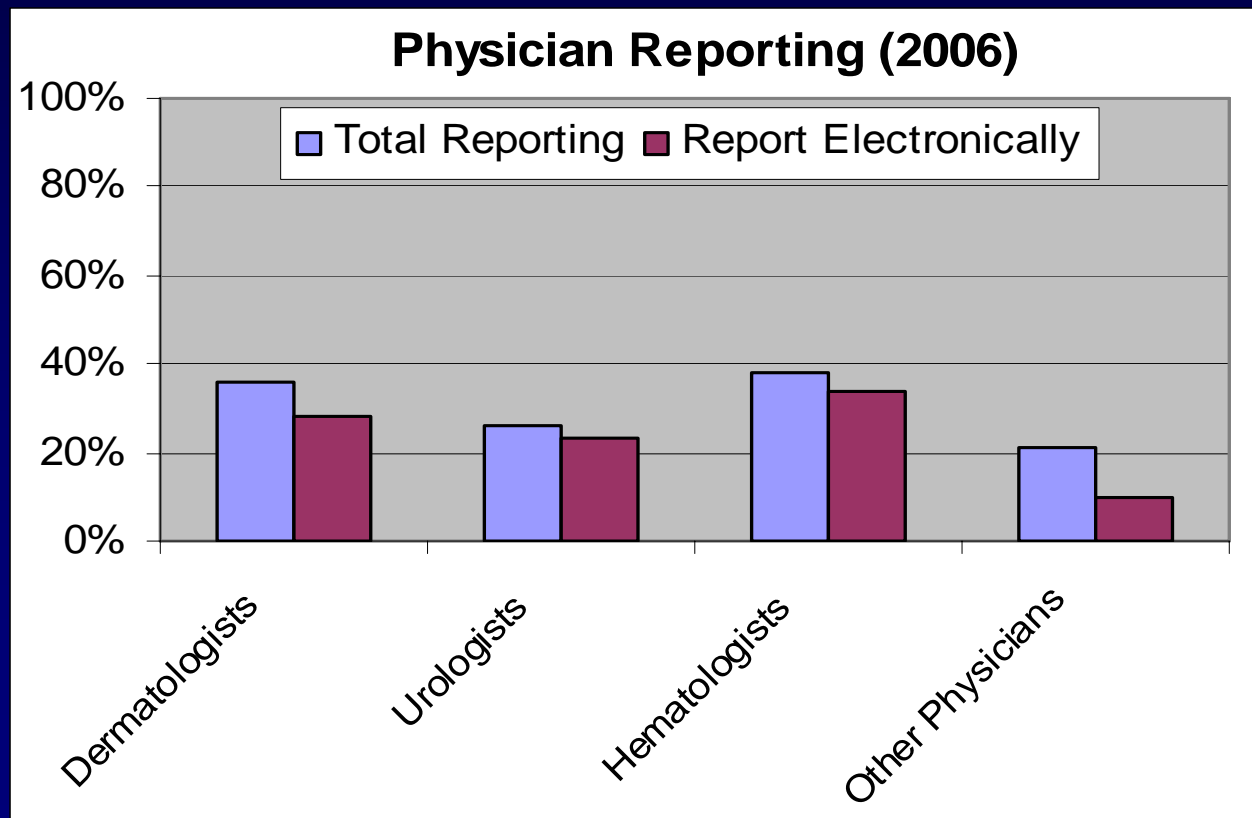
NPCR Responds

- ◆ In 2006, 18% of the CCRs reported they don't receive any path reports electronically
 - CDC Collaborated with LabCorp



NPCR Responds (Cont'd)

- ◆ Only 29% of Physicians Report Electronically
 - CDC's *WebPlus* to Promote Web-based Reporting by Physicians



NPCR Responds (Cont'd)

- ◆ 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**

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