

ATTACHMENT 4

**NPCR Program Evaluation
Results Web Display**

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National Program of Cancer Registries (NPCR) Program Evaluation Results 2006

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Staffing

1. FTE staff positions funded at CCR

	National	Filled	Vacant
NPCR-funded FTE positions		88.93% (381.10)	11.07% (47.45)
State-funded FTE positions		91.69% (316.75)	8.31% (28.70)
FTE positions funded by other sources		96.16% (142.65)	3.84% (5.70)

2. Percentage of FTEs with the following qualifications:

	National
FTE Certified Tumor Registrars (CTR)	42.02% (387.95)
FTE Epidemiologists (Ph.D., Dr.P.H., or Sc.D.)	4.36% (40.25)
FTE Epidemiologists (M.P.H.)	5.84% (53.90)
FTE Medical Doctors (M.D.)	1.79% (16.51)

FTE Statisticians (masters or doctoral level)	4.40% (40.60)
Other (B.A., B.S., no degree)	41.59% (383.95)

Legislation

3a. With the passing of Public Law 107-260 (the Benign Brain Tumor Cancer Registry Amendment Act), NPCR-funded registries are required to collect data on benign brain tumors beginning in diagnosis year 2004. Do regulations or legislation in your State or territory authorize you to collect data on benign brain tumors?

National
91.49%
(43)

3b. If No, what are your plans, including timeframes, to modify your State or territory's legislation or regulations to allow you to collect benign brain tumor data?

	National
Modification of legislation or regulations in process	75%
Plan to be addressed after key position is filled	25%

4. Does your State or Territory have legislation or regulations prohibiting you from reporting county level data?

National
10.64% (5)

Data Quality And Completeness

5. Does your CCR have at least one staff member responsible for QC?

National

97.87%
(46)

6. Does your CCR have at least one CTR who performs abstract review?

National
95.74%
(45)

7. Does your CCR analyze information from edit procedures on a regular basis to identify trouble spots?

National
100.00%
(47)

8. Has your CCR included reportable hematopoietic diseases in any case finding and quality control skills?

National
80.85%
(38)

9. Does your CCR perform any of the following methods of acceptance sampling?

	National
Automated edit checks	91.49% (43)
Duplicate data entry	34.04% (16)
Duplicate coding	36.17% (17)
Duplicate abstracting	34.04% (16)
None	6.38% (3)

Total Respondents: 47

10. When abstracts are corrected or changed at your CCR, is information about the changes returned to the abstractor for review?

National
63.83%
(30)

11. Does your CCR match all cancer causes of death against your registry data?

National
97.87%
(46)

12a. Do you update your CCR database following death clearance matching?

National
97.87%
(46)

12b. If "yes", by which method do you perform this update?

	National
Manual	19.15% (9)
Electronic	78.72% (37)

Total Respondents: 47

13. Does your CCR perform follow back to or on the following sources of death clearance?

	National
Hospitals	97.87% (46)
Physician(s) / Medical Examiner	93.62%

	(44)
	76.60%
Nursing Homes	(36)
	59.57%
Hospices	(28)
	46.81%
Coroner	(22)
	31.91%
Resident, died out of state	(15)
Non-resident, died in state	8.51% (4)
Next of kin	2.13% (1)
None	
Total Respondents: 47	

14. Does your CCR receive cases from:

	National
	91.49%
All bordering States	(43)
Some bordering States	6.38% (3)
	46.81%
Out-of-State facilities	(22)
Total Respondents: 47	

Computer Infrastructure

15. Listed below are commonly used software systems for central cancer registries. What is the primary software system used to process and manage cancer data in your CCR?

	National
	42.55%
RMCDS (Rocky Mountain Cancer Data System)	(20)
ELM (Premier) (IMPAC Medical	

Systems, Inc.)	
CansurFacs (IMPAC Medical Systems, Inc.)	
IMPAC (IMPAC Medical Systems, Inc.)	4.26% (2)
MRS (Medical Registry Services, Inc.)	4.26% (2)
OncoLog (Onco, Inc.)	
ERS (Electronic Registry Systems, Inc.)	
Registry Plus Products	14.89% (7)
In-house software (developed specifically for your State)	23.40% (11)
Other	10.64% (5)
None	

Total Respondents: 47

15a. Please indicate which Registry Plus Products software are used primarily to process and manage cancer data in your CCR?

	National
Abstract Plus	77.78% (7)
Prep Plus	77.78% (7)
CRS Plus	66.67% (6)
TLC Plus	66.67% (6)
Link Plus	66.67% (6)
NAACCR Record Conversion Utility	66.67% (6)
Registry Plus Online Help	77.78% (7)

Total Respondents: 47

16. Listed below are commonly used registry software systems. What software systems are used by most of your reporting sources as the primary software for managing cancer data?

	National
RMCDs (Rocky Mountain Cancer Data System)	51.06% (24)
Abstract Plus	27.66% (13)
Registry Plus Online Help	12.77% (6)
Precis Central (IMPAC Medical Systems, Inc.)	19.15% (9)
IMPAC (IMPAC Medical Systems, Inc.)	82.98% (39)
SHACRS (Scotts Hill Associates Cancer Registry Systems)	4.26% (2)
ERS (Electronic Registry Systems, Inc.)	53.19% (25)
MRS (Medical Registry Services, Inc.)	61.70% (29)
In-house software (developed specifically for your State)	21.28% (10)
Other	48.94% (23)
Total Respondents: 47	

17. Is your CCR able to receive encrypted cancer abstract data from reporting sources via the Internet?

	National
Yes	65.96% (31)
Currently being developed and/or implemented	23.40% (11)
No, not able to receive encrypted data via Internet from reporting	10.64% (5)

sources

Total Respondents: 47

18. Which edit programs are used by your CCR to check cases?

National

	93.62%
CDC EDITS (batch)	(44)
	61.70%
CDC EDITS (interactive)	(29)
	51.06%
Other in-house	(24)
	59.57%
Other vendor	(28)
None	

Total Respondents: 47

19. On which edit sets are your edits based?

Percentages do not equal 100

National

	100.00%
NPCR - Required	(47)
	78.72%
NPCR - Supplemental	(37)
State Example with NPCR RX	10.64% (5)
	42.55%
CoC (any CoC sets)	(20)
	95.74%
NAACCR call-for-data	(45)
Extent of disease	14.89% (7)
	42.55%
Verify ICD-0-2 to 3 conversion	(20)

Recodes	8.51% (4)
	40.43%
SEER	(19)
TEXT	17.02% (8)
	21.28%
Staging	(10)
	29.79%
In-house	(14)
	23.40%
Other	(11)
Total Respondents: 47	

20. How are edits applied at your CCR?

	National
Source records	4.26% (2)
Consolidated records	4.26% (2)
Both source and consolidated records	91.49% (43)
Total Respondents: 47	

21a. Do you perform record consolidation on your data?

National
97.87%
(46)

21b. If "yes", do you perform record consolidation on the following:

	National	Electronic	Manual	Both
Patient	12.77% (6)		10.64% (5)	74.47% (35)
Treatment	8.51% (4)		27.66% (13)	57.45% (27)

Follow-up 14.89% (7) 6.38% (3) 61.70% (29)

22a. Do you provide a registry-specific edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR?

National
46.81%
(22)

22b If yes, do you require facilities to run registry-specific edits prior to their data submission to your CCR?

National
29.79%
(14)

Reporting Completeness

23. Types of facilities and healthcare providers reporting:

	National	No. required to report	Total reporting	Reporting electronically	Reporting by paper
Non-Federal Hospital Cancer Registries		1582	98.74%	99.87%	0.13%
Non-federal Hospitals with no cancer registry		2769	97.87%	76.05%	23.95%
CoC Approved Hospital Registries		1327	100.00%	99.70%	0.30%
In-State Reference Pathology Laboratories		1973	53.47%	49.00%	51.00%
Out-of-State Reference Pathology Laboratories		406	70.44%	62.59%	37.41%
Radiation Therapy Centers		798	66.79%	78.05%	21.95%
Dermatologists		4855	50.26%	35.37%	64.63%
Urologists		4910	34.28%	33.04%	66.96%

Oncologists	3642	48.90%	39.02%	60.98%
Hematologists	1974	54.00%	33.21%	66.79%
Other Physicians	252484	6.86%	5.57%	94.43%
VA Hospitals	132	88.64%	94.02%	5.98%
Military Hospitals	80	96.25%	96.10%	3.90%
Indian Health Services (IHS) Hospitals	25	76.00%	73.68%	26.32%
IHS Health Centers	33	9.09%	0.00%	100.00%
Tribally Owned Hospitals	12	66.67%	62.50%	37.50%
Tribally Owned Health Centers	63	30.16%	0.00%	100.00%
Surgery Centers	2134	47.70%	63.65%	36.35%
Other	832	84.13%	16.86%	83.14%

24. Of the anatomical pathology lab reports your CCR receives, what percentage of these reports is in the CAP cancer protocol checklist format?

	National
100%	2.13% (1)
75% - 99%	6.38% (3)
50% - 74%	8.51% (4)
	21.28%
10% - 50%	(10)
	61.70%
None	(29)

Total Respondents: 47

25. Do you require non-analytic (classes 3 and 4) cases be reported to your CCR?

National
82.98%
(39)

26. Do you require historical cases to be reported to your CCR?

National
27.66%
(13)

Use of Registry Data

27. Is an analytic data set that meets NPCR standards for data completeness and quality available for research within 24 months after the completion of the diagnosis year?

National
93.62%
(44)

28a. Will an electronic data file or report be produced this year of cancer incidence in your central registry?

	National
Yes, using 12-month-old data	19.15% (9)
Yes, using 24-month data	93.62% (44)
No Annual Report will be produced this year (Skip to Q28)	

Total Respondents: 47

28b. If "Yes", in which format(s) is the most recent "report" available?

	National
Hardcopy	53.19% (25)
Electronic word-processed or pdf file	85.11% (40)
Web page or query system	63.83% (30)
Other	4.26% (2)

Total Respondents: 47

28c. Also, to which population were most recent incidence rates standardized?

	National
	97.87%
2000 U.S. standard population	(46)
Other	4.26% (2)
	Total Respondents: 47

29a. Registry data used for planning and evaluation of cancer control objectives in at least three ways in the past on year:

	National
	95.74%
	(45)

29b. If "yes", methods selected:

	National
Additional detailed incidence/mortality estimates	78.72% (37)
Linkage with a statewide cancer screening program to improve follow-up of screened patients	70.21% (33)
Health event investigations	82.98% (39)
Needs assessment/program planning	82.98% (39)
Program evaluation	70.21% (33)
Epidemiologic studies	87.23% (41)
	Total Respondents: 47

30a. CCR's maintaining a log of data requests made for the use of registry data

National

100.00%

(47)

30b. If "yes", how many requests per year?

National

Less than 10 per year	4.26% (2)
11 - 49 per year	31.91% (15)
50 - 99 per year	36.17% (17)
100 - 199 per year	12.77% (6)
200 - 299 per year	8.51% (4)
299 or greater per year	6.38% (3)

Total Respondents: 47

Self Assessment

31. Reasons for any difficulties your CCR experiences in meeting NPCR program objectives for data completeness, quality, and timeliness.

	National	Important/ Critical	Relevant	Not Relevant/ Important
Not enough staff		14.89% (7)	27.66% (13)	44.68% (21)
Not enough staff with the necessary qualifications		23.40% (11)	25.53% (12)	34.04% (16)
Software inadequate		44.68% (21)	34.04% (16)	4.26% (2)
Hardware inadequate		65.96% (31)	17.02% (8)	0.00% (0)
State data exchange not happening		44.68% (21)	25.53% (12)	12.77% (6)

Reporting facilities lack adequate staff	4.26% (2)	21.28% (10)	59.57% (28)
Other	2.13% (1)	10.64% (5)	19.15% (9)
None of the above, our CCR does not have difficulty meeting this objective	8.51% (4)	0.00% (0)	2.13% (1)

32. Which of the following reasons are responsible for any difficulties your CCR experiences in meeting NPCR program objectives for data use.

	National	Important/ Critical	Relevant	Not Relevant/ Important
Not enough staff			19.15% (9)	31.91% (15)
Not enough staff with the necessary qualifications		10.64% (5)	12.77% (6)	31.91% (15)
Software inadequate		17.02% (8)	6.38% (3)	4.26% (2)
Hardware inadequate		44.68% (21)	51.06% (24)	0.00% (0)
Other		0.00% (0)	6.38% (3)	14.89% (7)
None of the above, our CCR does not have difficulty meeting this objective.		23.40% (11)	4.26% (2)	8.51% (4)

Outcome Measures - Data Items/Format

33. Does your central registry collect or derive information on cancer cases that includes all data elements currently required by the NPCR?

National
100.00%
(47)

34. Were the following NPCR recommended data items collected for 2003 cases? Refer to NAACCR standards, Vol II, for description of 2003 data items.

	National
	97.87%
RX Summ - Surg Primary Site	(46)
	97.87%
RX Summ - Scope Reg LN Sur	(46)
	95.74%
RX Summ - Surg Oth Reg/Dis	(45)
	85.11%
Reason for No Surgery	(40)
	78.72%
RX-Summ-Surg/Rad Seq	(37)
	89.36%
RX Summ-Chemo	(42)
	87.23%
RX Summ-Horm	(41)
	87.23%
RX Summ-BRM	(41)
	87.23%
RX Summ-Other	(41)
	82.98%
Rad-Regional RX Modality	(39)
	80.85%
RX Summ-Transplnt/Endocr	(38)
	65.96%
Primary Payer at DX	(31)
Total Respondents: 47	

35. Does your CCR collect treatment data from:

	National
Non-CoC approved facilities	97.87% (46)
Freestanding treatment facilities	87.23% (41)
Ambulatory surgery centers	78.72% (37)
Physicians offices	85.11% (40)
None of the above due to lack of resources due to lack of training	

Total Respondents: 47

36. Does your CCR currently have the ability to collect data on:

	National
Advanced directives	4.26% (2)
Quality of survival (#1780)	14.89% (7)
Pain (or other symptom) management	4.26% (2)

Total Respondents: 47

37. Does your CCR collect data on family history of cancer, NAACCR data item # 360?

National
42.55%
(20)

38a. Does your CCR have the ability to collect site-specific data on chemotherapy agents used?

National
44.68%
(21)

38b. If "YES", how are you able to collect these data?

	National
	66.67%
Text	(14)
Database Field	14.28% (3)
Other	19.05% (4)

39. Does your CCR submit census tract data to NPCR as required?

National
70.21%
(33)

40. If you cannot submit census tract data to NPCR because of existing legislation in your State, are steps being taken to change this legislation?

National

41 a. Receives data from DOD's ACTUR data set

National
70.21%
(33)

41 b. If yes, frequency

	National
Every quarter	7.69% (3)
	33.33%
Every 6 months	(13)
	35.90%
Once/year	(14)
Other	7.69% (3)

Total Respondents: 47

41 c. If yes, have these data proven to be helpful in finding new incident cases?

National

76.92%

(30)

41 d. If not, why not?

National

Data are incomplete

5.71% (2)

Data are not in the proper format
for us to consolidate with existing
records

We don't have time to deal with it

Other

5.71% (2)

Total Respondents: 47

42. Number of VA facilities being sent staff for data collection/abstracting

National

6

43. Number of VA facilities where data collected by combo of VA staff and CRR staff

National

25

44. How many VA facilities currently report to the central registry indirectly from the VA central cancer registry?

National

15

45. If there are VA facilities not reporting, please explain why?

	National
No VA registry	2.13%
VA data rejected due to poor quality	2.13%
VA registry backlog	2.13%
No VA registry staff	4.26%
VA resources and priority	2.13%
VA HIPAA concerns	6.38%
Lack of VA cooperation	8.51%

46. Based on historical data, how many cases per diagnosis year do you estimate are missed (i.e., not ever received) by your CCR because of non-reporting by VA facilities?

National
10211

Advanced Activities

54 a. Does your central registry conduct at least one of the following advanced activities:

National
91.49%
(43)

54 b. If Yes, which activities?

	National
Receipt of encrypted case reports	50.98% (26)
Automated casefinding via interfacing with pathology reports, disease indices, or other data sources in addition to vital	37.25% (19)

records	23.53%
Survival analysis	(12)
Linkage with the National Death	19.61%
Index for survival analysis	(10)
	35.29%
Quality of care studies	(18)
Clinical Studies	13.73% (7)
Publication of research studies	58.82%
using registry data	(30)
	66.67%
Geocoding to latitude and longitude	(34)
Other innovative uses of registry	19.61%
data as determined by CDC	(10)
Total Respondents: 47	

55. Do you receive electronic records from any of the following?

	National
	70.21%
Anatomical pathology labs	(33)
Hospital radiology departments	4.26% (2)
	23.40%
Physician offices	(11)
State-wide disease index	8.51% (4)
	29.79%
Freestanding radiology centers	(14)
	31.91%
Hospital disease indices	(15)
Nuclear medicine facilities	2.13% (1)
Other	12.77% (6)
None	17.02% (8)

Total Respondents: 47

56. If you receive electronic pathology laboratory reports, in which format do you receive them?

	National
NAACCR format for pathology reporting (NAACCR Vol. II, Version 10, Chapter VI)	29.79% (14)
HL7, Version 2.X	14.89% (7)
HL7, Version 3.0	10.64% (5)
Other	40.43% (19)
None	31.91% (15)

Total Respondents: 47

57. For which of the following needs of cancer surveillance have you been in contact with your Health Department's PHIN / NEDSS staff regarding?

	National
Anatomical pathology laboratory reporting	57.45% (27)
Physician disease reporting	23.40% (11)
Other healthcare data reporting	6.38% (3)
None of the above	38.30% (18)

Total Respondents: 47

58. Does your CCR geocode cancer cases by latitude/longitude to enable mapping or reporting of cancer cases?

National

76.60%
(36)

59. How often does your CCR link to the National Death Index (NDI)?

National

Every year	10.64% (5)
Every other year	
Every 3 - 5 years	6.38% (3)
Never	70.21% (33)
Other	12.77% (6)

Total Respondents: 47

60. For which of the following has your NDI linkage proven to be useful?

National

Casefinding	11.76% (2)
Survivorship	58.82% (10)
Data quality	23.53% (4)
Research	41.18% (7)
Other	17.65% (3)

Total Respondents: 47

61. Do you update your database following NDI linkage?

National

58.82%
(10)

62. With which databases has your CCR linked its records in the past year (2005) for follow-up or some other purpose?

National

	95.74%
State Vital Statistics	(45)
National Death Index	19.15% (9)
Department of Motor Vehicles	17.02% (8)
Department of Voter Registration	8.51% (4)
Medicare (Health Care Financing Administration)	12.77% (6)
Medicaid	10.64% (5)
Managed Care Organizations	6.38% (3)
	48.94%
Breast and Cervical Cancer	(23)
Blue Cross/Blue Shield	2.13% (1)
	25.53%
Hospital Discharge	(12)
	55.32%
Other	(26)
None	4.26% (2)
Total Respondents: 47	

63. Has your registry downloaded any of the SNOMED International tools (the SNOMED CT CLUE Browser, the SNOMED CT Technical Reference Guide, the ICD-0 topography to SNOMED CT Map, the SNOMED CT User's Guide, and the full set of the 42 SNOMED CT encoded CAP cancer protocols and checklists)

63a Does your registry use any of these tools?

National
17.02% (8)

63b If no, do you have plans to use them in the next year?

National
28.21%

(11)

63c Do you need additional information or training on these tools?

National

65.96%

(31)

64 Has your CCR planned or developed a cancer data collection system that will be integrated into a Public Health Information Network (PHIN) compatible health surveillance system?

National

25.53%

(12)

65. Has registry data been used in the past year (can be ongoing) for the purpose of comprehensive cancer control planning, breast and cervical cancer programs, or any other cancer program implementation?

National

Comprehensive Cancer Control 95.74%

(Planning or Implementation) (45)

Breast and Cervical Cancer Program 87.23%

(Planning or Implementation) (41)

Other Cancer Program (Planning or 51.06%

Implementation) (24)

Total Respondents: 47

66. Have any of the above uses of data (Q65) been included in a journal publication?

National

21.28%

(10)

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CENTERS FOR DISEASE CONTROL AND PREVENTION
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