ADMINISTRATIVE DATA

State/Territory:

NPCR reference year:

Year registry began:

Registry Program Director:

Cooperative Agreement #:

Most Current Grant Award Amount:

CDC Program Consultant:

Date first funded in NPCR:

Type of current funding from NPCR:

- ☐ Enhancement
- ☐ Planning

Your name:

Title:

Phone number:

Date completed:

STAFFING

The questions below use the concept of a "Full-time Equivalent" also known as an "FTE". In each question you will be asked to report the number of FTEs. To do this, please convert each position to the appropriate FTE using the guidelines below, rounding each position to the nearest quarter of an FTE (e.g., 34 hrs/week would convert to 0.75 FTE, whereas 35 hrs/week would convert to 1 FTE):

0.25 FTE = 10 hrs/week
0.50 FTE = 20 hrs/week
0.75 FTE = 30 hrs/week
1.00 FTE = 40 hrs/week

Then add each converted position for the total number of FTEs. For example, if you have one epidemiologist working 35 hours and one working 20 hours, together they are 1.5 FTEs.

1. On **January 1, 2006,** how many FTE staff positions were funded at the CCR? Enter the number of filled and vacant **NPCR-funded FTE** the first row, and the number of filled and vacant **non-NPCR funded FTEs** in the second and third rows. **(Please include contractors in you totals but do not include positions outside the registry, even if those people sometimes engage in registry activities.)**

	Filled	**Vacant**
Number of **NPCR-funded** FTE positions:		
Number of **State-funded** FTE positions:		
Number of FTE positions funded by **other sources**:		

2. How many of the FTEs counted in Question 1 had the following qualifications? **(Please include contractors in your totals.)**

Number of filled FTE Certified Tumor Registrars (CTR):

Number of filled FTE Epidemiologists (Ph.D., Dr.P.H., or Sc.D.):

Number of filled FTE Epidemiologists (M.P.H.):

Number of filled FTE Medical Doctors (M.D.):

Number of filled FTE Statisticians (master's or doctoral level):

Number of filled Other (B.A., B.S., no degree):

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?

☐ Yes

☐ No

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?

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

☐ Yes

☐ No

DATA QUALITY AND COMPLETENESS

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

☐ Yes

☐ No

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

☐ Yes

☐ No

7. Does your CCR analyze information from edit procedures on a regular basis to identify trouble spots (e.g., with data sources, coders, item code structure, or interpretation of instructions in manuals)?

☐ Yes

☐ No

8. Has your CCR included reportable hematopoietic diseases in any casefinding and quality control audits?

☐ Yes

☐ No

9. Does your CCR perform any of the following methods of acceptance sampling? **Please check all that apply** (See NAACCR Standards Vol III, Section IIB. for a definition of acceptance sampling)

☐ Automated edit checks

☐ Duplicate data entry

☐ Duplicate coding

☐ Duplicate Abstracting

☐ None

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

☐ Yes

☐ No

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

☐ Yes

☐ No

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

☐ Yes

☐ No

12b. If "yes", what is your primary method to perform this update?

☐ Manual

☐ Electronic

13. Does your CCR perform follow back to or on the following sources of death clearance? **(Please check all that apply)**

☐ Hospitals

☐ Physician(s) / Medical Examiner

☐ Nursing Homes

☐ Hospices

☐ Coroner

☐ Resident, died out of state

☐ Non-resident, died in state

☐ Next of kin

☐ None

14. Does your CCR receive cases from **(Please check all that apply):**

All bordering States	☐ Yes	☐ No
Some bordering States	☐ Yes	☐ No
Out-of-State Facilities	☐ Yes	☐ No

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? **Please check only one.**

☐ RMCDS (Rocky Mountain Cancer Data System)

☐ ELM (Premier) (IMPAC Medical Systems, Inc.)

☐ CansurFacs (IMPAC Medical Systems, Inc.)

☐ IMPAC (IMPAC Medical Systems, Inc.)

☐ MRS (Medical Registry Services, Inc.)

☐ OncoLog (Onco, Inc.)

☐ ERS (Electronic Registry Systems, Inc.)

☐ Registry Plus Products

15a. Please indicate which Registry Plus Products software are used primarily to process and manage cancer data in your CCR? Please check all that apply.**reporting sources** as the **primary** software for managing cancer data? **Please check all that apply**

☐ Abstract Plus

☐ Prep Plus

☐ CRS Plus

☐ TLC Plus

- ☐ In-house software (developed specifically for your State), specify:
- ☐ Other, specify:
- ☐ None
- ☐ Link Plus
- ☐ NAACCR Record Conversion Utility
- ☐ Registry Plus Online Help

In-House, specify:

Other, specify:

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? **Please check all that apply.**

- ☐ RMCDS (Rocky Mountain Cancer Data System)
- ☐ Abstract Plus
- ☐ Registry Plus Online Help
- ☐ Precis Central (IMPAC Medical Systems, Inc.)
- ☐ IMPAC (IMPAC Medical Systems, Inc.)
- ☐ SHACRS (Scotts Hill Associates Cancer Registry Systems)
- ☐ ERS (Electronic Registry Systems, Inc.)
- ☐ MRS (Medical Registry Services, Inc.)
- ☐ In-house software (developed specifically for your State), specify:
- ☐ Other, specify:

17. Is your CCR able to receive encrypted cancer abstract data from reporting sources via the Internet? **Please check only one**.

- ☐ Yes
- ☐ Currently being developed and/or implemented
- ☐ No, not able to receive/able but not using encrypted data via the Internet.

18. Which edit programs are used by your CCR to check cases? **Please check all that apply.**

- ☐ CDC EDITS (batch)
- ☐ CDC EDITS (interactive)
- ☐ Other in-house, specify:
- ☐ Other vendor, specify:
- ☐ None

19. On which edit sets are your edits based? **Please check all that apply.**

- ☐ NPCR - Required
- ☐ NPCR - Supplemental
- ☐ State Example with NPCR RX
- ☐ CoC (any CoC sets)
- ☐ NAACCR call-for-data
- ☐ Extent of disease
- ☐ Verify ICD-0-2 to 3 conversion
- ☐ Recodes
- ☐ SEER
- ☐ TEXT
- ☐ Staging

☐ In-house

☐ Other, specify:

20. How are edits applied at your CCR? **Please check only one.**

☐ Source records

☐ Consolidated records

☐ Both source and consolidated records

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

☐ Yes

☐ No

21b. If "yes", do you perform record consolidation on the following: **Check all that apply.**

Data Group	Electronic	Manual	Both
Patient	☐	☐	☐
Treatment	☐	☐	☐
Follow-up	☐	☐	☐

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?

☐ Yes

☐ No

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

☐ Yes

☐ No

REPORTING COMPLETENESS

23. What types of facilities and health care providers report to your CCR?

Please list the number of sources in the State that should be reporting, the total number that actually reported in the past year (2004), and indicate how many report electronically and by paper. ***Note****: "Hospital cancer registry" is defined as one (single or joint institution) who collects data to be used internally and who would continue to do so irregardless of the central cancer registry requirements to collect and report cancer data.* ***(*Provide best estimate **Free-standing or independent, where the medical records are owned by the reporting source.)***

Type of facility	Number required to report	Number actually reporting		
		Total reporting	Reporting electronically	Reporting by paper
Non-Federal Hospital Cancer Registries				
Non-Federal Hospitals with No Cancer Registry				
CoC Approved Hospital Registries				
In-State Reference Pathology Laboratories**				
Out-of-State Reference Pathology Laboratories *				
Radiation Therapy Centers**				
Dermatologists*				
Urologists*				

Oncologists*				
Hematologists*				
Other Physicians*				
VA Hospitals				
Military Hospitals				
Indian Health Services (IHS) Hospitals				
IHS Health Centers				
Tribally Owned Hospitals				
Tribally Owned Health Centers				
Surgery Centers**				
Other, specify:				

24. Of the anatomical pathology lab reports your CCR receives, what percent of these reports is in the College of American Pathologists (CAP) cancer protocol checklist format? ***(Provide best estimate)***

- ☐ 100%
- ☐ 75%-99%
- ☐ 50%-74%
- ☐ 10%-50%
- ☐ None

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

- ☐ Yes
- ☐ No

26. Do you require historical cases (history of) be reported to your CCR?

- ☐ Yes
- ☐ No

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?

- ☐ Yes
- ☐ No

28a. Will an electronic data file or report be produced this year of cancer incidence in your central registry?**Please check all that apply.**

- ☐ Yes, using 12-month-old data
- ☐ Yes, using 24-month data
- ☐ No Annual Report will be produced this year (Skip to Q28)

28b. If "Yes", in which format(s) is the most recent "report" available? **Please check all that apply.**

- ☐ Hardcopy
- ☐ Electronic word-processed or pdf file
- ☐ Web page or query system
- ☐ Other, specify:

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

- ☐ 2000 U.S. standard

☐ Other, specify:

29. Has your central registry or its designee used registry data for planning and evaluation of cancer control objectives in at least three of the following ways in the past year: 1) additional detailed incidence/mortality estimates; 2) linkage with a statewide cancer screening program to improve follow-up of screened patients; 3) health event investigations; 4) needs assessment/program planning; 5) program evaluation; or 6) epidemiologic studies?'

☐ Yes
☐ No

Please select in which ways. **Please check all that apply**.

☐ Additional detailed incidence/mortality estimates
☐ Linkage with a statewide cancer screening program to improve follow-up of screened patients
☐ Health event investigations
☐ Needs assessment/program planning
☐ Program evaluation
☐ Epidemiologic studies

30. Does the CCR maintain a log of data requests made for the use of registry data?

☐ Yes

☐ No

Choose ONE below if answered "Yes" to Q 30

☐ Less than 10 per year

☐ 11-49 per year

☐ 50-99 per year

☐ 100-199 per year

☐ 200-299 per year

☐ 299 or greater per year

SELF ASSESSMENT

31. Which of the following reasons are responsible for any difficulties your CCR experiences in meeting NPCR program objectives for data completeness, quality, and timeliness.
Score each of the reasons below as follows:
2 = very important/critical
1 = relevant but not critically important
0 = not currently relative/important
OR
Select only the last response, "none of the above".

RATING

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

State data exchange not happening

Reporting facilities lack adequate staff

Other, specify:

None of the above, our CCR does not have difficulty meeting this objective.

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

Score each of the reasons below as follows:
2 = very important/critical
1 = relevant but not critically important
0 = not currently relative/important

OR
Select only the last response, "none of the above".

RATING

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify:

None of the above, our CCR does not have difficulty meeting this objective.

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?
☐ Yes
☐ No

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

Item Name	Item #	Yes	Item Name	Item #	Yes
RX Summ - Surg Primary Site	1290	☐	RX Summ-Horm	1400	☐
RX Summ - Scope Reg LN Sur	1292	☐	RX Summ-BRM	1410	☐
RX Summ - Surg Oth Reg/Dis	1294	☐	RX Summ-Other	1420	☐
Reason for No Surgery	1340	☐	Rad-Regional RX Modality	1570	☐
RX-Summ-Surg/Rad Seq	1380	☐	RX Summ-Trans; Int/Endocr	3250	☐
RX Summ-Chemo	1390	☐	Primary Payer at DX	630	☐

35. Does your CCR collect treatment data from: **Please check all that apply.**

☐ Non-CoC approved facilities
☐ Freestanding treatment facilities
☐ Ambulatory surgery centers
☐ Physicians offices
☐ None of the above
- ☐ due to lack of resources
- ☐ due to lack of training

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

Advanced directives? (Living Will)

☐ Yes ☐ No

Quality of survival (#1780)?

☐ Yes ☐ No

Pain (or other symptom) management?

☐ Yes ☐ No

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

☐ Yes ☐ No

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

☐ Yes ☐ No

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

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

☐ Yes ☐ No

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?

☐ Yes ☐ No ☐ Not Applicable

41a. Do you receive data from the **Department of Defense's** Automated Central Tumor Registry (ACTUR) dataset? **(If no, skip to Q42)**

☐ Yes ☐ No

41b. If yes, how often? **Please check only one.**

☐ Every quarter

☐ Every 6 months

☐ Once a year

☐ Other, specify:

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

☐ Yes ☐ No

41d. If not, why not? **Please check all that apply.**

☐ Data are incomplete

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

☐ We don't have time to deal with it

☐ Other, specify:

42. To how many VA facilities do you currently send central registry staff for data collection/abstracting?

Number of facilities:

43. At how many VA facilities are data collected by a combination of VA facility staff and central registry staff?

Number of facilities:

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

Number of facilities:

45. If there are VA facilities not reporting, please explain why in the space provided below:

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?

Number of cases missed:

Skip to Question 54. (Questions 47-53 will be downloaded from NPCR-CSS data)

47. What was the percentage of expected 2003 cases reported to the CCR by **January 1, 2005**?

Numerator (# cases registered):

Denominator (# expected cases):

Percentage (use single decimal):

48. What data were used to calculate the expected number of cases listed above? **Please check only one.**

- ☐ NAACCR
- ☐ ACS Estimates
- ☐ SEER incidence rates
- ☐ Historical State data
- ☐ Other, specify:

49. What was the percentage of expected 2003 cases reported to the CCR by **January 1, 2006**?

Numerator (# cases registered):

Denominator (# expected cases):

Percentage (use single decimal):

50. What method was used to calculate the expected number of **2003** cases listed above? **Please check only one.**

- ☐ NAACCR
- ☐ ACS Estimates
- ☐ SEER incidence rates
- ☐ Historical State data
- ☐ Other, specify:

51. What was the percentage of **2003** cases reported by a death certificate only as of **January 1, 2006**?

Numerator (# cases death certificate only):

Denominator (# registered):

Percentage (use single decimal):

52. What percentage of **2003** cases had **missing** or **unknown** values for the following variables? **Values are missing if any part is missing (i.e. month or year for dates).**

Age at diagnosis (item # 230):

Race 1 (item # 160):

Sex (item # 220):

Address at DX - State (item # 80):

County at DX (item # 90):

Primary Site (item # 400):

Date of DX (item # 390):

Diagnostic Confirmation (item # 490):

Summary Stage (item # 760 for cases prior to January 1, 2001):

Summary Stage (item # 759 for DX2001 and DX2002):

53. What percentage of unduplicated **2003** cases were microscopically confirmed?

Numerator (# cases confirmed):

Denominator (# registered):

Percentage (use single decimal):

ADVANCED ACTIVITIES

As the capacity of central cancer registries to collect and maintain population-based cancer data increases, so does their ability to engage in new activities designed to improve the completeness, timeliness, quality, and use of their data. In this section, we are interested in learning more about your "advanced activities".

54. Does your central registry conduct at least one of the following advanced activities: 1) receipt of encrypted case reports, 2) automated casefinding via interfacing with pathology reports, disease indices, or other data sources in addition to vital records; 3) survival analysis; 4) linkage with the National Death Index for survival analysis; 5) quality of care studies; 6) clinical studies; 7) publication of research studies using registry data; 8) geocoding to latitude and longitude; or 9) other innovative uses of registry data as determined by CDC?'

☐ Yes ☐ No

Which activities? Please check all that apply.

☐ Receipt of encrypted case reports
☐ Automated casefinding via interfacing with pathology reports, disease indices, or other data sources in addition to vital records
☐ Survival analysis
☐ Linkage with the National Death Index for survival analysis
☐ Quality of care studies
☐ Clinical Studies
☐ Publication of research studies using registry data
☐ Geocoding to latitude and longitude
☐ Other innovative uses of registry data as determined by CDC

55. Do you receive electronic records from any of the following? **Please check all that apply.**

☐ Anatomical pathology labs
☐ Hospital radiology departments
☐ Physician offices
☐ State-wide disease index
☐ Freestanding radiology centers
☐ Hospital disease indices
☐ Nuclear medicine facilities
☐ Other (specify):
☐ None

56. If you receive electronic pathology laboratory reports, in which format do you receive them? **Please check all that apply.**

☐ NAACCR format for pathology reporting (NAACCR Vol. II, Version 10, Chapter VI)
☐ HL7, Version 2.X
☐ HL7, Version 3.0
☐ Other **Please Specify**:
☐ None

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

☐ Anatomical pathology laboratory reporting

☐ Physician disease reporting

☐ Other healthcare data reporting

☐ None of the above

58. Does your CCR geocode cancer cases by latitude/longitude to enable mapping or reporting of cancer cases? **Please check yes or no.**

☐ Yes ☐ No

59. How often does your CCR link to the National Death Index (NDI)? **Please check only one**.

☐ Every year ☐ Other Specify

☐ Every other year

☐ Every 3-5 years

☐ Never (skip to Q64)

60. For which of the following has your NDI linkage proven to be useful? **Please check all that apply.**

☐ Casefinding

☐ Survivorship

☐ Data quality

☐ Research

☐ Other, please specify:

61. Do you update your database following NDI linkage?

☐ Yes ☐ No

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

☐ State Vital Statistics

☐ National Death Index

☐ Department of Motor Vehicles

☐ Department of Voter Registration

☐ Medicare (Health Care Financing Administration)

☐ Medicaid

☐ Managed Care Organizations

☐ Breast and Cervical Cancer

☐ Blue Cross/Blue Shield

☐ Hospital Discharge

☐ Other, specify:

☐ None

63a. As noted in an August 13, 2004 e-mail, CDC-NPCR has negotiated an agreement with SNOMED International for several tools for us by NPCR registries. Has your registry downloaded any of these tools (the SNOMED CT CLUE Browser, the SNOMED CT Technical Reference Guide, the ICD-O 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)?

63b. Does your registry use any of these

☐ Yes ☐ No

If "No":

63c. Do you have plans to use them in the next

☐ Yes ☐ No

Do you need additional information or training on these tools?

☐ Yes ☐ No

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?

☐ Yes ☐ No

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? **Please check all that apply.**

☐ Comprehensive Cancer Control Planning or Implementation

☐ Breast and Cervical Cancer Program (Planning or Implementation

☐ Other Cancer Program Planning or Implementation

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

☐ Yes ☐ No

67. Please summarize additional activities not yet mentioned (i.e., advanced data security, implementation of cancer inquiry response system) your CCR has been engaged in this past year. **Please describe in the space provided below (*limit 4,000 characters*).**

SUCCESS STORIES

68. Please provide a summary of ways in which cancer registry data has been used in the past year in the format suggested below:

Suggested format:

The data-use highlight should fit on one page, front side only, in 12-point font and single-spaced. Information needs to be in simple language and should avoid public health jargon and scientific language

Suggested components:

1. The name of the NPCR registry program.
2. Contact name, phone number, and e-mail address for further information
3. Title of the initiative, project, or type of data use
4. General timeframe (year(s) or month(s) during which the initiative/project/data use occurred)
5. A statement of the public health issue, concern, or problem
6. Evidence that the use of registry data was effective in addressing the issue, concern, or problem
7. Implications regarding this successful use of cancer registry data

Please contact your NPCR Program Consultant (or Mary Kaeser (770) 488-3231, mkaeser@cdc.gov) if you need more detailed information about the submission of cancer registry "success stories".