ATTACHMENT 3A

NPCR Program Evaluation Instrument (previously approved (0920-0706) and currently in use)

[Expiration date to be updated Upon receipt of OMB approval]

Form Approved OMB NO. _0920-0706_ Exp. Date _12-31-2008_



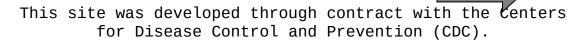
National Program of Cancer Registries

Program Evaluation Instrument

Registry Status As of June 30, 2007

To visit the National Program of Cancer Registries' Web site please click <u>here.</u>

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



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The National Program of Cancer Registries (NPCR) Program Evaluation Instrument (PEI)

PURPOSE STATEMENT

The NPCR Program Evaluation Instrument (PEI) is a web-based survey instrument designed to evaluate NPCR-funded registries' operational attributes and their progress towards meeting program standards. The APEI also provides information about advanced activities and "success stories" that highlight ways registry data are used.

Based on CDC's Updated Guidelines for Evaluating Public Surveillance Systems, the PEI monitors integration of surveillance and health information systems, the utilization of established data standards, and the electronic exchange of health data. Data provided by this report can be used for public health action, program and formulating planning evaluation, and research hypotheses.

Specific knowledge about operational activities NPCR registries are engaged in is used to provide valuable to CDC regarding insiaht programmatic efficiencies/deficiencies that have contributed to success/challenges of the NPCR. The results of instrument inform CDC and NPCR Program Consultants where technical assistance is most needed in order to continue to improve and enhance the NPCR.

Many of the questions in the 2007 PEI provide baseline data that will be used when measuring future progress with the NPCR Program Standards expected to be implemented this year. These questions, and the standard they reference, are noted throughout the instrument (e.g., "Program Standard I.a.")

Using all available information as of **June 30, 2007**, the appropriate Central Cancer Registry (CCR) staff should complete the PEI.

ADMINISTRATIVE DATA

State / Territory	
NPCR reference year	
Registry reference year	
Registry Program Director	
Cooperative Agreement #	U58/DP000
Most Current Grant Award	\$

Amount	
CDC Program Consultant	
Your name	
Title	
Phone number	
Date completed	

STAFFING

The following questions use the concept of a "Full-time Equivalent" also known as an "FTE". In each question you will be asked to report the total number of FTEs (FTE count). 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 1.0 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 the CTR works 35 hours a week and another CTR works 25 hours a week, the combined hours for the CTR positions = 60 hours = 1.5 FTEs.

1. On **June 30, 2007**, how many total FTE central cancer registry (CCR) staff positions were **funded**? In this table, you may include positions outside the registry, **ONLY IF the registry pays a portion of the salary**. Remember to use the calculation method above when computing partial FTEs.

	Total Count FTES		
Funding Category	Filled	Vacant	
Number of NPCR-funded (non-contracted) FTE			
positions			
Number of NPCR-funded, Contracted FTE positions			
Number of State-funded (non-contracted) FTE			
positions			
Number of State-funded , Contracted FTE positions			

Number of non-contracted FTE positions funded by other sources	
Number of Contracted FTE positions funded by other sources	
TOTALS	

2. Please complete this table with the number of FTEs who work in the capacity of the position titles listed. In this table, include both filled and vacant, as well as access to these staff (outside the registry), regardless of funding, in your total FTE count. So, if a position is vacant, it still counts as a position. Remember to use the same FTE calculation method as described above. Please note CTR credentials may be held by several registry positions and should be counted accordingly.

Total Count FTEs			
Position (FTE or percentage of FTE)	Non- Contractor	Contractor	
Principle Investigator			
Program Director			
Registry Administrator			
Program Manager			
Budget Analyst			
CTR Quality Control Staff			
Non-CTR Quality Control Staff			
CTR Education/Training Staff			
Epidemiologists			
Statisticians			
Computer/IT/GIS Specialists			
Other staff, specify:			
	Total Count CTRs Non-Contracted Contracted		
Total Number CTRs (may overlap with above categories)			

St	affing Sec	tio	n Co	mments	(You	may	add	comments	s regardir	١g
your	responses	in	the	"Staff	ing"	sect	ion	above)		

1			
1			
1			

LEGISLATIVE AUTHORITY

 Does your state/territory have a current law authorizing a population-based central cancer registry? (Program Standard I.a.) 	J
Yes No	
4. Does your state/territory have current legislation or regulations in support of all 8 criteria of the Public Law authorizing the NPCR? (Program Standard I.b.)	
Yes No	
5a. Are there any penalties in place regarding reporting compliance as mandated by current legislation compliations?	ng or
Yes No	
5b. If "Yes", in which law/regulations are the penalticincluded? (check only one):	es:
Cancer-specific reporting law/regulations General public health law/regulations Both None of the above	
5c. If "Yes," have you had to impose the penalty?	
Yes No	
6a. With passage of Public Law 107-260 (the Benign Brain Tumor Cancer Registry Amendment Act), NPCR-funded registries are required to collect data on benign brai tumors beginning in diagnosis year 2004. Do regulations or legislation in your State or territory authorize you to collect data on benign brain tumors?	.n
Yes No	

6b. 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?
Specify
7. Does your State or Territory have legislation or regulations prohibiting you from reporting county level data?
Yes No
8. Does your state law/regulations protect your cancer registry data from the Freedom of Information Act (FOIA)?
Yes No
9a. Does your state law/regulations protect your cancer registry data from subpoena?
Yes No
9b. If no, are data received through interstate data exchange protected from subpoena?
Yes No
Legislation Section Comments (You may add comments regarding your responses in the "Legislation" section above)

ADMINISTRATION

10. Does your CCR maintain an operational manual that describes registry operations, policies and procedures that, at a minimum, contains the following? (Program Standard II.a.) Check all that apply:

	_
YES	NO
	YES

11.		CCR policies and procedures as to what data may and may this should occur?
	Yes No	

12. Do you believe that your CCR policies and procedures are sufficient and clear for protection of confidentiality for all routine registry activities?

	Yes No
13.	Do you believe that your CCR staff possesses sufficient knowledge and resources to meet risk-appropriate threats to security and confidentiality?
	Yes No
14.	Does your CCR produce reports that are used to monitor the registry operations and database, including processes and activities? (Program Standard II.b.) Check all that apply:
	Quality control report (central registry) Quality control reports for each facility Data completeness report for each facility Timeliness of data report for each facility Data workflow report Other, specify
	None of the above
that	Does your CCR have an abstracting and coding manual is provided for use by all reporting sources? (Program dard II.c.)
	Yes No
	nistration Section Comments (You may add comments rding your responses in the "Administration" section e)

REPORTING COMPLETENESS

16. What types of facilities and health care providers report to your CCR? Please list the percentage of

facilities, by type, that actually reported in the past year (do not record the percentage reporting according to your CCR's timeliness schedule), and calculate what percentage of the reports, by facility type, are received electronically.

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 regardless of the central cancer registry requirements to collect and report cancer data.
- Provide the number of facilities required to report and, where indicated, use your best estimate if the exact number is not available.
- For those facilities which are not applicable to your state/territory (e.g., IHS Hospitals), record zero (0) in 'Number Required to Report' and 100 in 'Percent Compliant with Reporting'. In these instances, 'Percent Reports Received Electronically' is to be left blank and will be validated against the 'Number Required to Report'. (Program Standards III.a-c)

Facilities Required to Report Cancer Cases by Type	Number Required to Report (Denominator)	Percent Compliant by Reporting**	Percent Reports Received Electronically
Hospitals with a cancer			
registry (non-federal)			
Hospitals without a cancer			
registry (non-federal)			
VA Hospitals			
IHS Hospitals			
Tribally Owned Hospitals			
Health Centers (IHS,			
Tribal)			
Surgery Centers			
Independent Radiation			
Therapy Centers			
In-State Independent			
Pathology Laboratories			
Out-of-State Independent			
Pathology Laboratories*			
Dermatologists*			

11				I
Urolog				
	gists*/Hematologists* Physicians*			
Other	FilySicialis			
Other	facilities, specify:			
	vide best estimate ** those reporting in a	Those facilitie timely manner	es who report	rather
17.	Within 24 months of the what percentage of phealth care practition treatment for cancer cases to your CCR? Exercited to report capreviously admitted to ther facility provide the the capeutic services State/Territory? (Propone:	nysicians, surge oners diagnosing patients submit exception: Physic ases directly re to, and reported ling screening, to patients in	eons, and all g or providin all reporta icians are no eferred or d by, a hospi diagnostic o that	other g ble ot tal or
	100% 75% - 99% 51% - 74% 10% - 50% 1% - 9% None			
18.	Of the pathology lab percentage are in the (CAP) cancer protocol estimate)	College of Ame	erican Pathol	ogists.
	100% 75% - 99% 51% - 74% 10% - 50% 1% - 9% None			
	Do you require that s be reported to your		(classes 3	and 4)
	Yes			

20a. Do you receive data from the Department of D Automated Central Tumor Registry (ACTUR) dataset? skip 20b - 20d)	
Yes No	
20b. If yes, how often? Please check only one.	
<pre>Every quarter Every 6 months Once a year Other, specify</pre>	
20c. If yes, have these data proven to be helpful finding new incident cases?	Lin
Yes No	
20d. If not, why not? (Please check all that appl	Ly)
☐ Data are incomplete.	
 Data are not in the proper format for us to cowith existing records. We don't have time to deal with it. Other, specify: 	nsolidate
21. To how many VA facilities do you currently send central registry staff for data collection/abstracting? 22. At how many VA facilities are data collected by a combination of VA facility staff and central registry staff?	Number of Facilities
23. How many VA facilities currently report to your CCR indirectly from the VA central cancer registry in Washington, DC?	

24. If there are VA facilities not reporting, please explain why in the space

No

provided below:				
year do yo your CCR b	on historical data, how many cases per diagnosis ou estimate are missed (i.e., not ever received) by because of non-reporting by VA facilities?			
Reporting comments r	Completeness Section Comments (You may add regarding your responses in the "Reporting ess" section above)			
DATA EXCH	ANGE			
recommende	your CCR use and require the standardized, NPCR-ed data exchange record layout for the electronic of cancer data for (Program Standards III.a.):			
a.	Abstract reports (The NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary)?			
	Yes No			
b.	Pathology reports (NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting)?			
pathology	Yes No Not Applicable, not receiving electronic reports			

	your exchanged data meet the following minimum (<i>Program Standards V.d.</i>):
ca is	Within 12 months of the close of the diagnosis ar, your CCR exchanges data with other central ncer registries where a data- exchange agreement in place (the data file includes all cases not eviously exchanged):
	Yes No
	Regardless of residency, your CCR collects data on its diagnosed and/or receiving first course of in the registry's state/territory:
	Yes No
	The recommended frequency of data exchange is at times per year. Your CCR exchanges data at the frequency:
	Annually Biannually (two times per year) Other, explain
	Exchange agreements are in place with all central cancer registries:
	Yes, with all bordering CCRs No, not all
List exist	ing agreements here:
	Exchanged data includes a dataset that consists of data items:
	Yes No
f. set of sta	99% of exchanged data passes an NPCR-prescribed andard edits:

Yes No
g. Exchanged data are transmitted via a secure encrypted Internet-based system:
Yes No
h. The standardized, NPCR-recommended data exchange format is used to transmit data reports (<i>The NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary</i>):
Yes No
Data Exchange Section Comments (You may add comments regarding your responses in the "Data Exchange" section above)
DATA CONTENT AND FORMAT
28. Does your CCR collect or derive all required data items using standard codes as prescribed by NPCR?
Yes No
29. Is your CCR able to receive secure, encrypted cancer abstract data from reporting sources via the Internet?
Yes Currently being developed and/or implemented No, not able to receive No, able to receive, but not receiving

30. What is the primary software system used to process and

manage cancer data in your CCR? Please check only one:
Commercial Vendor In-House Software Registry Plus Abstract Plus Prep Plus CRS Plus Link Plus Web Plus
Data Content and Format Section Comments (You may add comments regarding your responses in the "Data Content and Format" section above)

DATA QUALITY ASSURANCE

31. Does your CCR's quality assurance program consist of, but is not limited to: (Program Standard VI.a.)

	YES	NO
A designated CTR is responsible for the quality		
assurance program		
Qualified, experienced CTRs conduct quality		
assurance activities		
At least once every 5 years, case-finding and/or		
re-abstracting audits from a sampling of source		
documents are conducted for each hospital-based		
reporting facility, and may include external		
audits (NPCR/SEER)		
Data consolidation procedures are performed		
according to an accepted protocol		
Procedures are performed for follow-back to		
reporting facilities on quality issues		

32. Does your CCR have a designated education/training coordinator, who is a CTR, to provide training to CCR staff and reporting sources to assure high quality data? (*Program Standard VI.b.*)

	Yes No				
qu		st year, which rol audits or			
	Casefindir Re-abstrac Re-coding Visual edi	cting	No		
		CCR match <i>al</i> oidentify a			inst your
		Yes No			
35a.	•	CCR update te matching:	he CCR data	base follow	ving death
	Death info Missing de	ormation emographic inf	ormation	Yes Yes	No No
elect	ronically?	what percent P: (<i>Provide b</i> n automation a	est estimat	e; may be s	-
	Death info	ormation: Manually Lc information Manually	:	ectronicall.	
36.	Does your following:	CCR perform r	ecord consc	lidation or	ı the
Data Patie Treat Follo	ment	Electronic	Manual 	Both	Neither

37a. Does your CCR provide a registry-specific edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR?

Yes No
37b. If "Yes," are facilities required to run registry-specific edits prior to their data submission to your CCR?
Yes No
Data Quality Assurance Section Comments (You may add comments regarding your responses in the "Data Quality Assurance" section above)
DATA USE
38. Within 12 months of the end of the diagnosis year with data that are 90% complete, did your CCR produce precalculated data in tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year for Surveillance Epidemiology and End Results (SEER) site groups as a preliminary monitor of the top cancer sites within your state/territory? (Program Standard VII.a.)
Yes No
39a. Within 24 months of the end of the diagnosis year with data that are 95% complete, did your CCR produce precalculated data in tables in an electronic data file or report? (The report should include, at a minimum, ageadjusted incidence rates and age-adjusted mortality rates for the diagnosis year by sex for SEER site groups, and, where applicable, by sex, race, and ethnicity). (Program Standard VII.b.)
Yes

□ No	
39b. What is the most current diagnosis year a da report is available?	ata file or
Year	
39c. In what format is this report available?	
Hard copyElectronic word-processed fileWeb page/query system	
40a. Has the CCR, state health department, or its used registry data for planning and evaluation control objectives in at least three of the followin the past year: Comprehensive cancer control coincidence/mortality estimates, linkage with a statement of screening program to improve follow-up of patients, health event investigation(s), needs assessment/program planning, program evaluation, epidemiologic studies? (Program Standard VII.c.)	of cancer owing ways detailed atewide screened or
Yes No	
40b. If "yes," indicate the number of times data for each category in the table below:	was used
Data Use Category	Number pe Year
Comprehensive cancer control	1 222
Detailed incidence/mortality estimates	+

Data Use Category	Number Year	per
Comprehensive cancer control		
Detailed incidence/mortality estimates		
Linkage with a statewide cancer screening		
program		
Health event investigation(s)		
Needs assessment/program planning		
Program evaluation		
Epidemiologic studies		
Other, describe:		

41a. Have any of the above uses of data been included in a journal publication?

a L	publication?		
	Yes		

	□ No
	If "yes," please list the citation(s) in the space ided:
42.	During the past year, for which areas of registry data utilization did your CCR acknowledge CDC-NPCR funding, as required in the Notice of Cooperative Agreement Award? <i>Check all that apply:</i>
othe	Publications (e.g.; journal articles, annual report, reports) Web site Presentations, posters Release of data Education meeting, training program, conference Press releases, statements Requests for proposals, bid solicitations None
	Does your CCR use <i>United States Cancer Statistics</i> S) data when performing comparative analyses? Yes No, explain:
	Use Section Comments (You may add comments regarding responses in the "Data Use" section above)

COLLABORATIVE RELATIONSHIPS

44. Does your CCR actively collaborate with your state/territory's comprehensive cancer prevention and control (CCC) planning efforts, including establishing a working relationship to ensure the use of registry data to

assess and implement cancer control activities? (<i>Program Standards IX.a.,b.</i>)
Yes No
<pre>Please check all of the ways you collaborate:</pre>
Provide technical assistance and collaborate on data analyses for CCC program publications Data linkages Other, specify None, Explain
45. Has your CCR established and regularly convened an advisory committee to assist in building consensus, cooperation, and planning for the registry? (Representation should include key organizations and individuals both within and outside the program. Advisory committees may be structured to meet the needs of the state/territory such as the CCC Program committee structure, an advocacy group, or a focus group). (Program Standard IX.c.)
Yes No
The Advisory Committee includes representation from (check all that apply): Representatives from all cancer prevention and control components Vital Statistics Hospital cancer registrars American Cancer Society Clinical-laboratory personnel Pathologists Clinicians Researchers Other, specify

group	If you have an Advisory Committee, how often does this convene, including in-person and teleconferences? Se check only one:
	Quarterly Annually Biannually Other, specify
	In what ways does your CCR collaborate with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the National Comprehensive Cancer Control Program (NCCCP)?
	Please check all that apply: ☐ Regular meetings with NBCCEDP and/or NCCCP tmental staff
and/o	Provides assistance in staging NBCCEDP cases Provides training/technical assistance to NBCCEDP NCCCP staff Provides data to NBCCEDP and/or NCCCP Provides technical material for publications Provides subject matter expertise to NBCCEDP and/or
NCCCP	Data linkages (NBCCEDP database, Minimum Data Elements Study Other, specify
	☐ None of the above, explain
comme	aborative Relationship Section Comments (You may addents regarding your responses in the "Collaborative ionship" section above)

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."

48. Please complete the table below regarding CCR receipt of electronic records from the reporting sources listed. For each facility type, either check "Yes" and enter the format, as text, in which the electronic records are received, or check "No". No line is to be left blank.

Facility Type	YES	Specify Type of Electronic Format	NO
Hospital Radiation Therapy			
Dept.			
Physician Offices			
State-wide Disease Index			
Freestanding Radiation			
Centers			
Hospital Disease Indices			
Nuclear Medicine Facilities			
Other, specify			

49.	If your CCR receives electronic pathology reports, in which format are these received? (Please check all that apply)
	NAACCR, HL7 Format (Volume V) NAACCR, Pipe Delimited Format (Volume V) NAACCR, HL7 Format (NAACCR Volume II, Version 10, napter VI) NAACCR, Pipe Delimited Format (NAACCR Volume II, version 10, napter VI) Chapter VI) Other, specify:
	☐Not applicable
50.	What method is used to identify reportable conditions from pathology lab reports:
	Manual reviewSearch routine based on NAACCR search term listOther, specify

51. For which of the following cancer surveillance needs has your CCR been in contact with your Health Department's PHIN / NEDSS staff? Please check all that apply.
Pathology laboratory reporting Physician disease reporting Other healthcare data reporting None of the above
52. 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
53. Does your CCR conduct at least one of the following advanced activities: <i>Check all that apply:</i>
Survival analysis Quality of care studies Clinical Studies Publication of research studies using registry data Geo-coding to latitude and longitude to enable mapping
Other healthcare data reporting Other innovative uses of registry data, describe
☐ None of the above
54. How often does your CCR link to the National Death Index (NDI)? Please check only one. (If Never, skip to question 57.)
Every year Every other year Every 3-5 years Other, specify Never
55. For which of the following has the NDI linkage proven to be useful? <i>Check all that apply:</i>
<pre>Casefinding</pre>

Survivorship Data quality Research Other, please specify: Not applicable
56. Does your CCR update your database following NDI linkage?
Yes No Not applicable
57. With which <i>databases</i> has your CCR linked its records in the past year (2006) for follow-up or some other purpose? <i>Check all that apply:</i>
State Vital Statistics National Death Index Department of Motor Vehicles Department of Voter Registration Indian Health Service Medicare (Health Care Financing Administration) Medicaid Managed Care Organizations Breast and Cervical Cancer Blue Cross/Blue Shield Hospital Discharge Other, specify: None
58a. As noted in an August 13, 2004 e-mail, CDC-NPCR has negotiated an agreement with SNOMED International for several tools for use by NPCR registries. Has your CCR 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)?
Yes No
58b. Does your CCR use any of these SNOMED tools? Yes No

next year?	•	your CCF	R nave	plans	to use	tnem in	tne
Ye							
58d. Does on these t	•	need add	ditiona	al info	ormation	n or tra	ining
Ye	_						
Advanced A regarding section ab	your resp				•	•	omments

SUCCESS STORIES

59. Please provide a summary, as a separate document, of innovative activities in which your CCR has been engaged within the past year. This can include ways in which cancer registry data has been used, journal citations, as well as other activities that may be of interest to other central registries and to NPCR (e.g., advances in any area of electronic reporting, GIS activities, death clearance activities, automated database activities that have improved data processing efficiencies, any other activities that have improved data quality, completeness, or timeliness advances in data security, or implementation of cancer inquiry response system, or success in job re-classifications) in the format suggested below:

Suggested format:

The registry highlights should fit on one page, 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 cancer surveillance issue, concern, or problem
- 6. Evidence that the activity was effective in addressing the above (#5)
- 7. Implications regarding the success of this activity or increased data use.

Please contact your NPCR Program Consultant if you need more detailed information about the submission of your cancer registry "success story".

regai	rding	tories Section Comments the "Success Stories" se ss story in this comment	ction above; do not record
this	evalı	se comment below about yo uation instrument by sele esents your thoughts and	cting the choice which
	a.	All or most of the quest	ions are clearly stated
		Agree	Disagree
quest	b. tions	I understand the import	ance of all or most of the
		Agree	Disagree
	С.	For the most part, I fou	nd the web technology of

the instrument to be user-friendly

	Agree	Disagree
completin	For the most part, I con g the instrument to be a the cancer surveillance c	worthwhile contribution to
	Agree	Disagree
e. in this i		s data that is collected
	Agree	Disagree
OPTIONAL		
	uld like to participate i 's evaluation instrument.	n discussions regarding
here:	Yes Please enter yo	ur name and phone number
	No	
questions	ve the following suggesti or web formatting regard t (please comment in the	ing next year's evaluation

Thank you for participating in the NPCR Annual Program Evaluation!