Attachment 3A

NPCR Program Evaluation Instrument

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 PEI also provides information about advanced activities and "Survey Feedback" assists CDC in improving the survey instrument.

Based on CDC's Updated Guidelines for Evaluating Public Health Surveillance Systems, the PEI monitors the integration of surveillance, registry operations 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 planning and evaluation, and research hypothesis formulation.

Specific knowledge about operational activities in which NPCR registries are engaged is used to provide valuable insight to CDC regarding programmatic efficiencies/deficiencies that have contributed to the success/challenges of the NPCR. The results of this 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 2022 PEI provide baseline data that can be used to measure compliance with the NPCR Program Standards. Using all available information as of December 31, 2021, the appropriate Central Cancer Registry (CCR) staff should complete the PEI.

Burden Statement

Public reporting burden of this collection of information varies from 1.5 to 2.5 hours with an estimated average of 2 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-741, Atlanta, Georgia 30333; ATTN: PRA (0920-0706).

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

Note: Please update to reflect Registry Status as of December 31, 2021.

	ns require an answer with the exception of comments, estions and those indicated as optional.
0	Indicates user can select only one answer. Indicates user can select more than one answer. Indicates user may enter text/number.
Large Box Response	Indicates long description as response.

ADMINISTRATIVE DATA

State / Territory	
NPCR reference year	
TW Civicience year	
Registry reference year	
Registry Program Director	
Cooperative Agreement # 17-1701	
Most Current Grant Award Amount	
CDC Program Consultant	
Your name	
Title	
Phone number	
Date completed	
Email	

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.

1. On December 31, 20XX, how many total FTE central cancer registry (CCR) staff positions were funded? 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 FT	Es
Funding Category	Filled	Vacant
Number of NPCR-funded (non-contracted) FTE positions		
Number of NPCR-funded, FTE positions		
Number of State-funded (non-contracted) FTE positions		
Number of State-funded, FTE positions		
Number of non-contracted FTE positions funded by other sources		
Number of Contracted FTE positions funded by other sources		
TOTALS		

2. Please Indicate number of FTEs in the positions listed below. Please include both <u>filled and vacant</u>, as well as time contributed by non-registry staff (e.g. chronic disease epidemiologist), regardless of funding, in your total FTE count. **Use the FTE calculation method as described previously. 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)	Filled	Vacant
Principal Investigator		
Program Director		
Program Manager		
Budget Analyst		
CTR Quality Control Staff		
Non-CTR Quality Control Staff		
CTR Education/Training Staff		
Epidemiologists		
Statisticians		
Computer/ IT		
GIS Specialist		
Other staff, specify:	_	
Total Number of Staff		
Total Number CTRs (of total number of staff)		

Staffing Section section above.)	n Comments (Yo	u may add comr	ments regarding	your responses i	n the "Staffing

LEGISLATIVE AUTHORITY

3. Have an	y law/regulations been revised to address cancer reporting in the past two years?
0	Yes; please describe:No
If there are	plans for revisions in the next two years, please provide comment in box below.
•	Section Comments (You may add comments regarding your responses and/or any legislative barriers related to the "Legislation" section above.)

ADMINISTRATION

- 4. Does your CCR maintain an operational manual describing registry operations, policies and procedures that, at a minimum, contains the following? 1. Registry collects and submits data for all reportable cancers and benign neoplasms, including at a minimum, primary site, histology, behavior, date of diagnosis, race and ethnicity, age at diagnosis, gender, stage at diagnosis, and first course of treatment, according to CDC specifications and other information required by CDC. 2. For all CDC-required reportable cases, the registry collects/derives all required data items using standard codes prescribed by CDC.
- 3. Registry participates in all analytic datasets and Web-based data query systems, according to the annual NPCR CSS Data Release Policy.

Check all that apply.

	Yes	No
Reporting laws/regulations	•	•
List of reportable diagnoses	•	•
List of required data items	•	•
Data processing operational procedures for (Check all that apply):		
a. Monitoring timeliness of reporting	•	•
b. Receipt of data	•	•
 Database management including a description of the registry operating system (software) 	•	•
d. Conducting death certificate clearance	•	•
Procedures for Implementing and maintaining a quality assurance/control program including (check all that apply, e-h):		
e. Conducting follow-back to reporting facilities on quality assurance issues	•	•
f. Conducting record consolidation	•	•
g. Maintaining detailed documentation of all quality assurance operations	•	•
h. Education and training	•	•
Procedures for conducting data exchange including a list of states with which case- sharing agreements are in place	•	•
Procedures for conducting data linkages	•	•
Procedures for ensuring confidentiality and data security including disaster planning	•	•
Procedures for data release including access to and disclosure of information	•	•
Procedures for maintaining and updating the operational manual	•	•

- 5. Does your CCR produce reports that are used to monitor the registry operations and database, including processes and activities? **Check all that apply.**
 - Quality control report (central registry)
 - Quality control report for each facility
 - Data completeness report for each facility
 - Timeliness of data report for each facility

 Data workflow report All of the above Other, specify None of the above
6. Does your CCR have an abstracting and coding manual that is provided for use by all reporting sources
O Yes O No
Administration Section Comments (You may add comments regarding your responses in the "Administration" section above.)

REPORTING COMPLETENESS

7. Hospital and Pathology Laboratory Reporting:

Please list the number, by type, that are required to report and the number that were compliant with reporting at the end of 20XX. Also report the number reporting electronically (e.g. in a standardized format that minimizes the need for manual data entry.)

- "Hospital cancer registry" is defined as one (single or joint institution) that collects data to be used internally and that would continue to do so regardless of the central cancer registry requirements to collect and report cancer data.
- For those types of Hospitals and Pathology Labs which are not applicable to your state/territory (e.g., IHS Hospitals), record zero (0) in "Number Required to Report" and record zero (0) in "Number Compliant with Reporting." In these instances, "Number Reporting Electronically" should also be recorded as zero (0).

	Number Required to Report (Denominator)	Number Compliant with Reporting* at the end of 20XX	Number Reporting Electronically **
HOSPITALS & OFFICES			
Hospitals with a cancer registry (non-federal)			
Hospitals without a cancer registry (non-federal)			
CoC hospitals #			
VA hospitals #			
IHS hospitals #			
Tribal Hospitals #			
Physician offices #			
PATHOLOGY LABORATORIES			
In-state independent labs			
Out-of-state independent labs			
Other, specify			
TOTAL			

^{*}ALL facilities that report -- not only those reporting in a timely manner

O No

**Electronic Reporting is the collection and transfer of data from source documents by hospitals, physician offices, clinics or laboratories in a standardized, coded format that does not require manual data entry at the Central Cancer Registry (CCR) level to create an abstracted record.

#Although these groups are not "required" to report in accordance with state law, please indicate the number of known facilities that diagnose or treat cancer for residents of your state.

8.	Do you i	require that non-analytic (classes 30-38) cases be reported to your CCR?
	0	Yes

9. Do you receive data from the **Department of Defense's** Automated Central Tumor Registry

(ACTUR) data	aset? (If No, please skip to Question 12)
0 Y	
0 N	
TO. If Yes, no	ow often? Check only one.
0 Q	puarterly
	very 6 months
	nnually other, specify:
0 0	Mici, Specify
11. If Yes, ha	ave these data proven to be helpful in finding new incident cases?
O Y	es
O N	0
12. If No, wh	ny not? Check all that apply.
• D	ata are incomplete.
• D	ata are not in the proper format for us to consolidate with existing records.
	Ve don't have time to deal with it.
• 0	other, specify:
_	receive data directly from the Veteran's Administration's central cancer registries in your
state? O Y	res
0 N	
	ny VA facilities currently report to your CCR indirectly from the VA Central Cancer Registry
ın vvasnıngtor	n, DC?
	n historical data, how many cases per diagnosis year do you estimate are missed (i.e. d) by your CCR because of non-reporting by VA facilities?
Number of ca	ses missed:
15a. Industri a	al or Occupational History Data
From what so	ources are you able to ROUTINELY collect information on industrial or occupational history
	ring additional data sources for only these variables)? Check all that apply.
	nistrative records (e.g., billing or claims databases, or patient forms that are not part of the
	cal record)
	cal records
DeathOther	n certificate linkages
	 ot collect information on industrial or occupational history

15b. Do you conduct any **ADDITIONAL** activities (e.g. linkages with external databases) to collect or improve upon industrial or occupational history information?

	Contributing Factor	Negative Factor	Both Contributing and Negative Factor
Laws and Rules			
Fines and Penalties			
Outsourcing and contracting			
Interstate data exchange			
Other factors, specify			
ing Completeness S	ection Comments (You " section above.)	may add comments	regarding your responses

O No

DATA EXCHANGE

	CCR use and require the following standardized, CDC-recommended data formats for exchange of cancer data from reporting sources:	
a.	Hospital Reports (The NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary)?	
	O Yes O No	
b.	Pathology reports (NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting)?	
	O Yes O No O Not Applicable, not receiving electronic pathology reports	
C.	Ambulatory healthcare providers using electronic health records (Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries)?	
	O Yes O No O Not Applicable, not receiving Ambulatory healthcare provider reports	
17. Do your in	terstate data exchange procedures meet the following minimum criteria?	
a. Within 12 months of the close of the diagnosis year, your CCR exchanges that ye data with other central cancer registries where a data-exchange agreement is in p		
	O Yes O No	
b.	Your CCR collects data on all patients diagnosed and/or receiving first course of treatment in your registry's state/territory regardless of residency :	
	O Yes O No	
c.	The recommended frequency of data exchange is at least two times per year. Your CCR exchanges data at the following frequency:	
	O Annually O Biannually (two times per year) O Other, specify:	
d.	Exchange agreements are in place with other central cancer registries:	
	 Yes, with all bordering CCRs plus other non-adjacent CCRs Yes, with all bordering CCRs but no others Yes, with some bordering CCRs Yes, Includes National Interstate Data Exchange Agreement No, no exchange agreements in place with neighboring states, but some are in place with non-neighboring states No, no exchange agreements in place List all existing CCR agreements here: 	

e.	What type of records do you transmit for interstate exchange? Consolidated cases Source records with text Source records without text
f.	Does it include all cases not exchanged previously? Yes No
g.	Are NPCR core data items included in the dataset submitted to other states?
	O Yes O No
h.	Do 99% of data submitted to other states passes an NPCR-prescribed set of standard edits?
	O Yes O No
i.	Are exchanged data transmitted via a secure encrypted Internet-based system?
	O Yes O No
j.	Is the standardized, NPCR-recommended data exchange format used to transmit data to other central cancer registries and CDC (The current NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary):
	O Yes O No
18. What typ	e(s) of secure encrypted Internet-based system is used for interstate data exchange? at apply.
• (S	PHINMS Secure FTP Web Plus HTTPS N-IDEAS Secure encrypted e-mail Other:

Data Exchange Section Comments (You may add comments regarding your responses in the "Data Exchange" section above.)

DATA COI	NTENT AND FORMAT
19. Is you Internet?	r CCR able to receive secure, encrypted cancer abstract data from reporting sources via the
0	Yes Currently being developed and/or implemented No, not able to receive No, able to receive, but not receiving
	is the primary software system used to process and manage cancer data in your CCR? neck only one.
0	Commercial Vendor In-House Software CRS Plus SEER DMS
21. Which	of the following Registry Plus programs do you use? Check all that apply.
•	Abstract Plus Prep Plus CRS Plus Link Plus Web Plus eMaRC Plus CDA Validation Plus All of the above None of the above
	cent and Format Section Comments (You may add comments regarding your responses in Content and Format" section above.)

DATA QUALITY ASSURANCE

22. Please respond to each of the following statements to describe your CCR's querogram:	ality assu	ırance
program.	Yes	No
A designated CTR is responsible for the quality assurance program	0	0
Qualified, experienced CTRs conduct quality assurance activities	0	0
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. This may include external audits (NPCR/SEER)	0	0
Data consolidation procedures are performed consistently from all source records	0	0
Procedures are in place for follow-back to reporting facilities on quality issues	0	0
O No 24. In the past year, which of the following type of quality control audits or activiti conduct? Check all that apply.	es did yo	ur CCR
 Case finding Re-abstracting Re-coding Visual editing Data Item Consolidation Other: (specify) 		
25. Although death certificate processes require matches on all underlying caus CCR match all causes of death against your registry data to identify a reportable ca		th, does you
O Yes O No		
26. During the death certificate linkage, does your CCR match by tumor (site/his patient identifying information?	stology) a	nd not just b
O Yes O No		

27a. Do linkage?	es your CCR update th	e CCR databas	e followi	ng death certific	ate matching	within 3 month	s of
			Yes	No			
	Death information (vital	status and caus	se of dea	ıth)	0	0	
	Missing demographic in	nformation	0	0			
	27b. If yes, what percentage(s) of the updates are performed manually or electronically? (Provide best estimate; may be some overlap between automation and manual review.)						
			Manua	lly (%)	Electronic	cally (%)	
	Death information:					-	
	Demographic informa	tion:				_	
28. Do	es your CCR perform re	ecord consolidat	tion on th	ne following?			
	Data Group	Electronic	Manua	ıl	Both	Neither	
	Patient	0	0	0	0		
	Treatment Follow-up	0	0	0	0		
	rollow-up	O	O	O	O		
 29a. Does your CCR provide an edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR? O Yes O No 29b. If Yes, are facilities required to run prescribed edits prior to their data submission to your CCR? O Yes O No 							
	es your CCR have an e	established thre	shold for	percent of reco	rds passing e	edits on incomin	ıg
submiss	ons? O Yes						
	O No						
	0 110						
	Yes, what is the threshold 100% O 90% or greater O 80% or greater O Less than 80%	old?					
	w often does your CCR ss of their data?	provide feedba	ck to rep	orting facilities o	n the quality,	completeness,	and
	O Quarterly O Every six months O Annually O Other, describe:						

the "Data Quality Assurance" section above.)
DATA USE
30. Within 12 months of the end of the diagnosis year with data that are 90% complete, did your CCR calculate incidence counts, rates, or proportions in an electronic data file or report for the diagnosis year for Surveillance
Epidemiology and End Results (SEER) site groups to monitor the top cancer sites within your state/territory?
O Yes
O No
31a. Within 24 months of the end of the diagnosis year with data that are 95% complete, did your CCR calculate incidence rates, counts or proportions in an electronic data file or report? (The report should include, at a
minimum, age-adjusted incidence rates, age-adjusted mortality rates, and stage at diagnosis for the diagnosis year for
SEER site groups, and, where applicable, stratified by sex, race, ethnicity, and geographic area. O Yes O No
31b. Within 24 months of the end of the diagnosis year with data that are 95% complete, did the CCR create biennial reports providing data on stage and incidence by geographic area with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors (e.g., tobacco obesity, HPV). O Yes
O No
 31c. If Yes, indicate what information was included in the report: Check all that apply. Screening-amenable cancers Tobacco-related cancers
Obesity- related cancers
HPV-related cancersAll the above
Other, describe
32a. What is the most current diagnosis year a data file or report is available to the public?
Year:
32h In what format is this report available? Check all that apply .

 Hard (paper) c 	vgo
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- Electronic word-processed file
- Web page/query system
- 33. Indicate the number of times the CCR, state health department, or its designee used registry data for planning and evaluation of cancer control objectives for each category in the table below:

Data Use Category	Number per Year
Comprehensive cancer control detailed incidence/mortality estimates	
Detailed incidence/mortality by stage and geographic area	
Collaboration, as defined in DP17-1701, with cancer screening programs for breast, colorectal, and cervical cancer	
Health event investigation(s)	
Needs assessment/program planning (e. g. Community Cancer Profiles)	
Program evaluation	
Epidemiologic studies	
Other, describe:	

	Collaboration, as defined in DP17-1701, with cancer screening programs for breast, colorectal, and cervical cancer		
	Health event investigation(s)		
	Needs assessment/program planning (e. g. Community Cancer Profiles)		
	Program evaluation		
	Epidemiologic studies		
	Other, describe:		
34a. Ha	ave any of the above uses of data been included in a journal publicati O Yes O No	on in the last two years?	
34b. If	yes, please list the citation(s) in the space provided:		
	ring the past year, for which areas of registry data utilization did your funding, as required in the Notice of Cooperative Agreement Award?	_	
	 Publications (e.g.; journal articles, annual report, other reports) Web site Presentations, posters Release of data Education meeting, training program, conference Press releases, statements Requests for proposals, bid solicitations None Data System Other, specify 		
36. Do	es your CCR use U.S. Cancer Statistics data when performing compa O Yes O No, explain	rative analyses?	
Data U	se Section Comments (You may add comments regarding your re	esponses in the "Data Use	e"

section above.)

COLLABORATIVE RELATIONSHIPS
37a. Has your CCR established and regularly convened an advisory committee to assist in building consensus, cooperation, and planning for the registry? (Advisory committee structures may include a CCC Program committee or an advocacy group). O Yes O No
37b. If Yes, the Advisory Committee includes representation from: Check all that apply.
 American Cancer Society American College of Surgeons Clinicians Clinical-laboratory personnel Hospital Cancer Registrars Oncologist Representatives from all cancer prevention and control components Researchers Oncologist Pathologist Vital Statistics All the above Other, specify:
37c. If you have an Advisory Committee, how often does this group convene, including in-person and teleconferences? Check only one.
O Quarterly O Annually O Biannually O Other, specify:
38. In what ways does your CCR collaborate with your state's National Breast and Cervical Cancer Early
Detection Program (NBCCEDP), National Comprehensive Cancer Control Program (NCCCP) and other chronic disease programs? Check
all that apply.
 Provides assistance in staging NBCCEDP cases Regular meetings with NBCCEDP, NCCCP and chronic disease departmental staff Provides training/technical assistance to NBCCEDP, NCCCP and chronic disease staff Provides data to NBCCEDP, NCCCP and chronic disease Provides technical material for publications to NBCCEDP, NCCCP and chronic disease Provides subject matter expertise to NBCCEDP, NCCCP and chronic disease Data linkage Partner on collaborative projects All of the above Other, specify: None of the above, Explain:

39. With which other Department of Health programs does your CCR collaborate? Check all that upply.	
 Asthma Diabetes Environmental Health Heart Disease and stroke prevention Infectious Disease (HIV, AIDS, HPV, hepatitis) Immunization Oral Health Physical Activity and Nutrition/ Obesity Radiation Control Tobacco Control All the above Other: 	
Collaborative Relationships Section Comments (You may add comments regarding your responses in the "Collaborative Relationship" 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."

40. If your CCR receives electronic pathology reports, in which format are these received? **Check all that**

apply.

- NAACCR, HL7 Format (Volume V), Version 2.x
- NAACCR, Pipe Delimited Format (Volume V), Version 2.x
- NAACCR, HL7 Format (NAACCR Volume II, Version 11, Chapter VI)
- NAACCR, Pipe Delimited Format (NAACCR Volume II, Version 10, Chapter VI)
- Other, specify: ______
- Not applicable

Department's PHIN/ NEDSS staff? Check all that apply.	
 Pathology laboratory reporting Physician disease reporting Other healthcare data reporting. Describe None of the above 	
42. Does your CCR conduct at least one of the following advanced activities? Check all that apply.	
 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. Describe: Other innovative uses of registry data such as Survivorship Care Plan. o Describe: 	
None of the above	
43. Does your registry have a system in place for early case capture (rapid case ascertainment)?O YesO No	
43a. If Yes, is early case capture performed for:	
O All cases O Subset of cases (e. g. Pediatric Cancer): O Special Studies O Other, specify;	
43b. If yes, within what time frame are cases reported?" Selections could be "30 days, 6 days, other specify, study dependent specify".	iO
O 30 days O 60 days O Study dependent specify O Other, specify;	
44. How often does your CCR link to the National Death Index (NDI)? Please check only one. never,skip to question 46.)O Every year	(lf
O Every other year O Every 3-5 years O Other, specify: O Never	
44a. For which of the following has the NDI linkage proven to be useful? Check all that apply.Survivorship	

41. For which of the following cancer surveillance needs has your CCR been in contact with your Health

Data qualityResearch
Other, specify:Not applicable
 44b. Does your CCR update your database with vital status and cause of death following NDI linkage? O Yes O No O Not applicable
45. With which databases did your CCR link its records in 20XX-20XX for follow-up or some other purpose?
Check all that apply.
 CDC's National Breast and Cervical Cancer and Early Detection Program CDC's National Colorectal Cancer Screening Program Department of Motor Vehicles Department of Voter Registration Hospital Disease Indices Hospital Discharge Database Hospital Radiation Therapy Dept. Indian Health Service Insurance Claim Databases (E.G. BC&BS, Kaiser, Managed Care Organization, fee for service) Medicaid Medicare (Health Care Financing Administration) Medicare Physician Identification and Eligibility Registry National Death Index State Vital Statistics Other, specify: None
46. Based on the most recent year of data received from independent (i.e., not hospital-affiliated) pathology laboratories, please list the top five independent laboratories that do NOT report according to the NAACCR Volume V standard. List them in descending order by the percent each represents of the total volume of independent pathology reports received in the most recent year. 1
Advanced Activities Section Comments (You may add comments regarding your responses in the "Advanced Activities" section above.):

		lease comment below about your experience completing the bice which best represents your thoughts and experience:	is evaluation instrument by selecting
		 a. All or most of the questions are clearly stated. O Agree O Disagree 	
		 b. I understand the importance of all or most of the quest O Agree O Disagree 	ions.
		c. For the most part, I found the web technology of the inO AgreeO Disagree	strument to be user-friendly.
		 d. For the most part, I consider the time spent completing contribution to NPCR and the cancer surveillance com O Agree O Disagree 	
		 e. Our Central Registry uses data that is collected in this O Agree O Disagree 	instrument.
		<u>OPTIONAL</u>	
48	8.	I would like to participate in discussions regarding the 2022 evaluation instrument. O Yes; add name and best contact info here: O No	
49. I have the following suggestions/revisions for the PEI questions or web formattin next year's evaluation instrument (please comment in the space provided below):			

Thank you for participating in the NPCR Program Evaluation!