

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 2016 PEI provide baseline data that can be used to measure compliance with the NPCR Program Standards. Using all available information as of December 31, 2016, 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, 2016.

Notes: All questions require an answer with the exception of comments, questions and those indicated as optional.

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	_____
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	_____

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, 2016, 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.

Funding Category	Total Count FTEs	
	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 Indicate number of FTEs in the positions listed below. Please include both filled and vacant, 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.**

Position (FTE or percentage of FTE)	Total Count FTEs	
	Non-Contractor	Contractor
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 Specialists	_____	_____
Other staff, specify: _____	_____	_____
Total Number of Staff	_____	_____
Total Number CTRs (of total number of staff)	_____	_____

Staffing Section Comments (You may add comments regarding your responses in the “Staffing” section above.)

LEGISLATIVE AUTHORITY

3. Have any law/regulations been revised to address cancer reporting in the past two years?

- Yes; please describe: _____
- No

Legislation Section Comments (You may add comments regarding your responses and/or any anticipated 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? **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	•	•
c. 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?

- Yes
- 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 2016. 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 2016	Number Reporting Electronically **
HOSPITALS			
Hospitals with a cancer registry (non-federal)			
Hospitals without a cancer registry (non-federal)			
CoC hospitals #			
VA hospitals #			
IHS hospitals #			
Tribal Hospitals #			
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

****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 require that non-analytic (classes 30-38) cases be reported to your CCR?

- Yes
 No

9. Do you receive data from the **Department of Defense's** Automated Central Tumor Registry (ACTUR) dataset? **(If No, please skip to Question 12)**

- Yes
- No

10. If Yes, how often? **Check only one.**

- Quarterly
- Every 6 months
- Annually
- Other, specify: _____

11. If Yes, have these data proven to be helpful in finding new incident cases?

- Yes
- No

12. If No, why not? **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: _____

13a. Do you receive data directly from the **Veteran's Administration's** central cancer registries in your state?

- Yes
- No

13b. How many VA facilities currently report to your CCR indirectly from the VA Central Cancer Registry in Washington, DC? _____

14. Based on historical data, how many cases per diagnosis year do you estimate are missed (i.e. never received) by your CCR because of non-reporting by VA facilities?

Number of cases missed: _____

15a. Industrial or Occupational History Data

From what sources are you able to **ROUTINELY** collect information on industrial or occupational history (without seeking additional data sources for only these variables)? **Check all that apply.**

- Administrative records (e.g., billing or claims databases, or patient forms that are not part of the medical record)
- Medical records
- Death certificate linkages
- Other _____
- Do not 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?

- No
- Yes, please describe _____

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

DATA EXCHANGE

16. Does your CCR use and require the following standardized, CDC-recommended data formats for the electronic 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)?
 - Yes
 - No

- b. Pathology reports (NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting)?
 - Yes
 - No
 - 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)?
 - Yes
 - No
 - Not Applicable, not receiving Ambulatory healthcare provider reports

17. Do your interstate data exchange procedures meet the following minimum criteria?

- a. Within 12 months of the close of the diagnosis year, your CCR exchanges that year's data with other central cancer registries where a data-exchange agreement is in place:
 - Yes
 - 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**:
 - Yes
 - No

- c. The recommended frequency of data exchange is at least two times per year. Your CCR exchanges data at the following frequency:
 - Annually
 - Biannually (two times per year)
 - 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
 - No, no exchange agreements in place with neighboring states, but some are in place with non-neighboring states
 - No, no exchange agreements in placeList 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. Are NPCR core data items included in the dataset submitted to other states?
- Yes
- No
- g. Do 99% of data submitted to other states passes an NPCR-prescribed set of standard edits?
- Yes
- No
- h. Are exchanged data transmitted via a secure encrypted Internet-based system?
- Yes
- No
- i. Is the standardized, NPCR-recommended data exchange format used to transmit data reports (The current NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary):
- Yes
- No

18. What type(s) of secure encrypted Internet-based system is used for interstate data exchange?

Check all that apply.

- 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 CONTENT AND FORMAT

19. 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

20. What is the **primary** software system used to process and manage cancer data in your CCR? **Check only one.**

- Commercial Vendor
- In-House Software
- CRS Plus

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

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

DATA QUALITY ASSURANCE

22. Please respond to each of the following statements to describe your CCR's quality assurance program:

	Yes	No
A designated CTR is responsible for the quality assurance program	<input type="radio"/>	<input type="radio"/>
Qualified, experienced CTRs conduct quality assurance activities	<input type="radio"/>	<input type="radio"/>
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)	<input type="radio"/>	<input type="radio"/>
Data consolidation procedures are performed consistently from all source records	<input type="radio"/>	<input type="radio"/>
Procedures are in place for follow-back to reporting facilities on quality issues	<input type="radio"/>	<input type="radio"/>

23. Does your CCR have a designated **CTR** education/training coordinator, to provide training to CCR staff and reporting sources to ensure high quality data?

- Yes
- No

24. In the past year, which of the following type of quality control audits or activities did your CCR conduct? **Check all that apply.**

- Case finding
- Re-abstracting
- Re-coding
- Visual editing
- Data Item Consolidation
- Other: (specify) _____

25. Although required to match on all underlying causes of death, does your CCR match all causes of death against your registry data to identify a reportable cancer?

- Yes
- No

26. Does your CCR match by tumor (site/histology) and not just by patient identifying information?

- Yes
- No

27a. Does your CCR update the CCR database following death certificate matching within 3 months of linkage?

	Yes	No
Death information	<input type="radio"/>	<input type="radio"/>
Missing demographic information	<input type="radio"/>	<input type="radio"/>

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.)

	Manually (%)	Electronically (%)
Death information:	_____	_____
Demographic information:	_____	_____

28. Does your CCR perform record consolidation on the following?

Data Group	Electronic	Manual		Both	Neither
Patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow-up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29a. Does your CCR provide an edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR?

- Yes
- No

29b. If Yes, are facilities required to run prescribed edits prior to their data submission to your CCR?

- Yes
- No

29c. Does your CCR have an established threshold for percent of records passing edits on incoming submissions?

- Yes
- No

29d. If Yes, what is the threshold?

- 100%
- 90% or greater
- 80% or greater
- Less than 80%

29e. How often does your CCR provide feedback to reporting facilities on the quality, completeness, and timeliness of their data?

- Quarterly
- Every six months
- Annually
- Other, describe: _____

Data Quality Assurance Section Comments (You may add comments regarding your responses in 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 or rates in an electronic data file or report 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?

- Yes
- No

31a. Within 24 months of the end of the diagnosis year with data that are 95% complete, did your CCR calculate incidence rates and counts in an electronic data file or report? (The report should include, at a

minimum, age-adjusted incidence rates and age-adjusted mortality rates for the diagnosis year by sex for

SEER site groups, and, where applicable, by sex, race, ethnicity, and geographic area).

- Yes
- No

31b. Within 24 months of the end of the diagnosis year with data that are 95% complete, does 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).

- Yes
- 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 cancers
- All the above
- Other, describe _____

32a. What is the **most current** diagnosis year a data file or report is available to the public?

Year: _____

32b. In what format is this report available? **Check all that apply.**

- Hard (paper) copy
- 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: _____	_____

34a. Have any of the above uses of data been included in a journal publication in the last two years?
 Yes
 No

34b. If yes, please list the citation(s) in the space provided:

35. 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? **Check all that apply.**

- 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
- Other, specify _____

36. Does your CCR use United States Cancer Statistics (USCS) data when performing comparative analyses?

- Yes
- No, explain _____

Data Use Section Comments (You may add comments regarding your responses in the “Data Use” 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).

- Yes
- No

37b. If Yes, 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
- Oncologists
- American College of Surgeons
- All of 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.**

- Quarterly
- Annually
- Biannually
- Other, specify: _____

38. In what ways does your CCR collaborate with your state's National Breast and Cervical Cancer Early

Detection Program (NBCCEDP) and National Comprehensive Cancer Control Program (NCCCP)?
Check

all that apply.

- Provides assistance in staging NBCCEDP cases
- Regular meetings with NBCCEDP and NCCCP departmental staff
- Provides training/technical assistance to NBCCEDP and NCCCP staff
- Provides data to NBCCEDP and NCCCP
- Provides technical material for publications to NBCCEDP and NCCCP
- Provides subject matter expertise to NBCCEDP and NCCCP
- 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 apply.**

- Tobacco Control
- Oral Health
- Diabetes
- Heart Disease and Stroke Prevention
- Asthma
- Physical Activity and Nutrition/Obesity
- Radiation Control
- Environmental Health
- Infectious disease (HIV AIDS, HPV, hepatitis)
- Immunization
- All of 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

41. For which of the following cancer surveillance needs has your CCR been in contact with your Health 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.
 - Describe: _____
- None of the above

43. Does your registry have a system in place for early case capture (rapid case ascertainment)?

- Yes
- No

44. If Yes, is early case capture performed for:

- All cases
- Subset of cases (e. g. Pediatric Cancer): _____
- Special Studies
- Other, specify; _____

45a. How often does your CCR link to the National Death Index (NDI)? **Please check only one. (If never, skip to question 46.)**

- Every year
- Every other year
- Every 3-5 years
- Other, specify: _____
- Never

45b. For which of the following has the NDI linkage proven to be useful? **Check all that apply.**

- Survivorship
- Data quality
- Research
- Other, specify: _____
- Not applicable

45c. **Does** your CCR update your database following NDI linkage?

- Yes
- No
- Not applicable

46. With which databases did your CCR link its records in 2016 for follow-up or some other purpose?

Check all that apply.

- State Vital Statistics
- National Death Index
- Department of Motor Vehicles
- Department of Voter Registration
- Indian Health Service
- Medicare (Health Care Financing Administration)
- Medicare Physician Identification and Eligibility Registry
- Medicaid
- CDC's National Breast and Cervical Cancer and Early Detection Program
- CDC's National Colorectal Cancer Screening Program
- Insurance Claim Databases (IE: BC&BS, Kaiser, Managed Care Organization, fee for service etc.)
- Hospital Discharge Database
- Hospital Radiation Therapy Dept.
- Hospital Disease Indices
- Other, specify: _____
- None

47. 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.	_____	:	_____	%
2.	_____	:	_____	%
3.	_____	:	_____	%
4.	_____	:	_____	%
5.	_____	:	_____	%

Advanced Activities Section Comments (You may add comments regarding your responses in the “Advanced Activities” section above.):

SURVEY FEEDBACK

48. Please comment below about your experience completing this evaluation instrument by selecting the choice which best represents your thoughts and experience:

- a. All or most of the questions are clearly stated.
 - Agree
 - Disagree

- b. I understand the importance of all or most of the questions.
 - Agree
 - Disagree

- c. For the most part, I found the web technology of the instrument to be user-friendly.
 - Agree
 - Disagree

- d. For the most part, I consider the time spent completing the instrument to be a worthwhile contribution to NPCR and the cancer surveillance community.
 - Agree
 - Disagree

- e. Our Central Registry uses data that is collected in this instrument.
 - Agree
 - Disagree

OPTIONAL

49. I would like to participate in discussions regarding the 2019 evaluation instrument.
 Yes; add name and best contact info here: _____
 No

50. I have the following suggestions/revisions for the PEI questions or web formatting regarding next year’s evaluation instrument (please comment in the space provided below):

Thank you for participating in the NPCR Program Evaluation!