NPCR Program Evaluation Instrument (NPCR PEI)

Summary of Proposed Changes for 2017-2019

(numbers correspond to the question number in the survey instrument)

Staff in the Cancer Surveillance Branch (CSB) of DCPC worked collaboratively to review results from the 2015 PEI. Updates to the PEI were made based on these results, release of the new FOA (DP17-107) and changes to the Program Standards. In addition, determination was made from the Applications, Statistics, and Informatics Support Team that questions pertaining to Physician Reporting and Meaningful Use will be removed from the PEI and added to a separate questionnaire that will require separate OMB clearance. It is expected that some questions below will be deleted or revised. New questions have also been proposed based on the need for information from awardees to CSB and FOA DP17-1707 requirements.

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 20XX PEI provide baseline data that can be used to measure compliance with the NPCR Program Standards. These questions, and the standard they reference, are noted throughout the instrument (e.g., "Program Standard I. a.") Using all available information as of December 31, 20XX, the appropriate Central Cancer Registry (CCR) staff should complete the PEI.

Survey Changes:

Staffing Section –

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 time contributed by non-registry staff (e.g. chronic disease epidemiologist), 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**
Principal Investigator	_____	_____
Program Director	_____	_____
Removed Row: Registry Manager		
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)	_____	_____

Legislative Authority Section – All except one question under this section was deleted because 100% of the awardees meet this standard.

3. **Delete**
4a. **Delete**
4b. **Delete**
4c. **Delete**
4e. Consolidated with question 4d to make one question (#3) in this section
5a. **Delete**
5b. **Delete**

6. **Delete**
7. **Delete**
8a. **Delete**
8b. **Delete**

Administrative Data Section – no changes

Reporting Completeness Section –

12a. **Revised question in table and reworded disclaimer for clarity**

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

* **ALL facilities that report -- not only those reporting in a timely manner**. ~~Those facilities that report -not only those reporting in a timely manner~~

12b. **Delete Physician Reporting table. This table will be included in a separate survey.**

14c. **Removed to reference to question 14a** - If Yes~~" for 14a,~~ have these data proven to be helpful in finding new incident cases?

17. **Delete**

15a. **New Question:** 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.**New Question:** 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_____

Data Exchange Section –

19d. **Revised Answer Choices**: Exchange agreements are in place with all bordering 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 place

List all existing CCR agreements here: _____

19f. **Reworded for clarity**: Are NPCR core data items are included in the dataset submitted to other states?

- ○ Yes
- ○ No

19g. **Reworded for clarity**: Do 99% of data submitted to other states passes an NPCR-prescribed set of standard edits?

- ○ Yes
- ○ No

19h. **Reworded for clarity**: Are Exchanged data are transmitted via a secure encrypted Internet-based system?

- ○ Yes

- ○ No

19i. **Reworded for clarity**: Is the standardized, NPCR-recommended data exchange format is 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

Data Content and Format Section –

21. **Delete**

21. Renumbered Question and Added another answer choice: 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 Quality Assurance Section –

26. **Removed Yes/No for each answer choice to reflect a simpler selection method and added additional answer options -** 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)_____

27a. **Reworded for clarity**: 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

29e. **New Question**: 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 Use Section –

34a. **Delete**

33. **Reworded an answer choice**: 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: _____	_____

Collaborative Relationships Section –

38a. **Delete**

38b. **Delete**

40. **Added another answer option and removed example behind "Data linkages" for clarity-** 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 departmental staff
- ☐ Provides training/technical assistance to NBCCEDP staff
- ☐ Provides data to NBCCEDP
- ☐ Provides technical material for publications to NBCCED P
- ☐ Provides subject matter expertise to NBCCEDP
- ☐ Data linkages ~~(NBCCEDP database, Minimum Data Elements (MDE) Study~~
- ☐ Partner on collaborative projects
- ☐ All of the above
- ☐ Other, specify: _____
- ☐ None of the above, Explain: _____

41. **Added other answer options** - With which chronic disease programs does your CCR collaborate?

- ☐ 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: _____

Advanced Activities Section –

43. **Delete**

49. **Delete**

47. **New Question –** Based on the most recent year of data received, please list the top 5 independent laboratories that do NOT report according to the NAACCR Volume V standard by volume of % total reports received:

1. _____: _____%
2. _____: _____%
3. _____: _____%

4. _____: _____%
5. _____: _____%.

Survey Feedback Section – no changes

Optional Section –
49. **Reworded answer choices**: I would like to participate in discussions regarding the 2019 evaluation instrument.
☐ Yes; add name and best contact info here: _____
☐ No

2017 - NPCR Program Evaluation Instrument

Form Approved

OMB NO. 0920-0706

Exp. Date: 05/31/2018

Login

User Name:

Password:

Login

Forget your user ID or password?

Please call the NPCR-CSS Helpline (301) 572-0502 between 8AM and 4:30PM ET Monday through Friday except holidays. Passwords cannot be sent via email

Survey Question?

Please contact your CDC Program Consultant
or
Netta Apedoe

Other Question

Please email support@npcrcss.org

Program Evaluation Instrument

Form Approved
OMB No. 0920-0706
Exp. Date 05/31/2018

Purpose Statement change my password

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 2017 PEI provide baseline data that can be used to measure compliance with the NPCR Program Standard. Using all available information as of **December 31, 2016**, the appropriate Central Cancer Registry (CCR) staff should complete the PEI.

Deadline for completion: July 24, 2017

Enter The Survey

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).

Note: Please update to reflect Registry Status as of December 31, 2016.

This site was developed through a contract with the Centers for Disease Control and Prevention (CDC).

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey | Survey Progress: | Export & Print

- Administrative Data
- Staffing
- Legislative Authority
- Administration
- Reporting Completeness
- Data Exchange
- Data Content And Format
- Data Quality Assurance
- Data Use
- Collaboration
- Advanced Activities
- Survey Feedback
- Optional
- Validation
- Review
- Save and Logout

Administrative Data

State/Territory	SA
NPCR reference year	1995
Registry reference year	1981
Registry Program Director	
Cooperative Agreement #	17-1701-
Most Current Grant Award Amount	$
CDC Program Consultant	Paran Pordell
Your name	
Title	
Phone number	
Status	In Progress
Date Completed	12/23/2016

Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Staffing 1 of 2

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.

Page 1 Staffing

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		

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Staffing 2 of 2

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.**

Page 2 Staffing

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.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

- Administrative Data
- Staffing
- Legislative Authority
- Administration
- Reporting Completeness
- Data Exchange
- Data Content And Format
- Data Quality Assurance
- Data Use
- Collaboration
- Advanced Activities
- Survey Feedback
- Optional
- Validation
- Review
- Save and Logout

Legislation

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

- ○ Yes
- ○ No

Please describe:

Legislation Section Comments (You may add comments regarding your responses and/or any anticipated legislative barriers related to the "Legislation" section above.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Administration 1 of 2

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.**

Page 4 Administration

Reporting laws/regulations	○ Yes ○ No
List of reportable diagnoses	○ Yes ○ No
List of required data items	○ Yes ○ No
Data processing operational procedure for (Check all that apply):	
a. Monitoring timeliness of reporting	○ Yes ○ No
b. Receipt of data	○ Yes ○ No
c. Database management including a description of the registry operating system (software)	○ Yes ○ No
d. Conducting death certificate clearance	○ Yes ○ No
Procedure 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	○ Yes ○ No
f. Conducting record consolidation	○ Yes ○ No
g. Maintaining detailed documentation of all quality assurance operations	○ Yes ○ No
h. Education and Training	○ Yes ○ No
Procedures for conducting data exchange including a list of states with which case-sharing agreements are in place	○ Yes ○ No
Procedures for conducting data linkages	○ Yes ○ No
Procedures for ensuring confidentiality and data security including disaster planning	○ Yes ○ No

Procedures for data release including access to and disclosure of information	○ Yes ○ No
Procedures for maintaining and updating the operational manual	○ Yes ○ No

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | **Questionnaire** | **Glossary**

Survey Survey Progress: Export & Print

- Administrative Data
- Staffing
- Legislative Authority
- Administration
- Reporting Completeness
- Data Exchange
- Data Content And Format
- Data Quality Assurance
- Data Use
- Collaboration
- Advanced Activities
- Survey Feedback
- Optional
- Validation
- Review
- Save and Logout

Administration 2 of 2

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 reports 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.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Reporting Completeness 1 of 3

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).

Page 6 Reporting Completeness

	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#			
Tribally Hospitals#			
PATHOLOGY LABORATORIES			
In-state independent labs			
Out-of-state independent labs			
Other			
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.

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Reporting Completeness 2 of 3

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, describe

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 **Veterans Administration's** central cancer registries in your state?
- ○ Yes
- ○ No

13b. How many VA facilities currently report your CCR indirectly from the VA central cancer registry in Washington, DC?

Number of facilities:

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:

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Reporting Completeness 3 of 3

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, specify:
- ☐ 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?

- ○ Yes
- ○ No

Please describe:

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

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

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 all bordering 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 place

List all existing CCR agreements here:

e. What type of records do you transmit for interstate exchange? **Check all that apply.**

☐ 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 pass 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
☐ WebPlus
☐ HTTPS
☐ N-IDEAS
☐ Secure encrypted e-mail
☐ Other, specify:

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

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

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.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Data Quality Assurance 1 of 3

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

Page 11 Data Quality Assurance

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

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

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Data Quality Assurance 2 of 3

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

Death information	○ Yes ○ No
Missing demographic information	○ Yes ○ No

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.)

Page 12 Data Quality Assurance

	Manually (%)	**Electronically (%)**
Death information		
Demographic Information		

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

Patient data group	○ Electronic	○ Manual	○ Both	○ Neither
Treatment data group	○ Electronic	○ Manual	○ Both	○ Neither
Follow-up data group	○ Electronic	○ Manual	○ Both	○ Neither

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Data Quality Assurance 3 of 3

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 6 months
- ○ Annually
- ○ Other, describe

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

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Data Use 1 of 3

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

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

Most current diagnosis year:

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

- [ ] Hard (paper) copy
- [ ] Electronic word-processed file
- [ ] Web page/query system

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Data Use 2 of 3

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:

Page 15 Data Use

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:

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Data Use 3 of 3

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.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | **Questionnaire** | **Glossary**

Survey Survey Progress: Export & Print

Collaborative Relationships 1 of 2

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:

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Collaborative Relationships 2 of 2

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, specify:

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

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Advanced Activities 1 of 3

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
- ☐ 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:

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Advanced Activities 2 of 3

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
- ○ Never
- ○ Other, specify

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
- [ ] Hospital Radiation Therapy Dept.
- [ ] Hospital Disease Indices
- [ ] Other, specify:

- [ ] None

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

Advanced Activities 3 of 3

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.)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | **Questionnaire** | **Glossary**

Survey Survey Progress:

Export & Print

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 are collected in this instrument.
- ○ Agree
- ○ Disagree

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

Survey Survey Progress: Export & Print

- Administrative Data
- Staffing
- Legislative Authority
- Administration
- Reporting Completeness
- Data Exchange
- Data Content And Format
- Data Quality Assurance
- Data Use
- Collaboration
- Advanced Activities
- Survey Feedback
- Optional
- Validation
- Review
- Save and Logout

Optional

49. I would like to participate in discussions regarding the 2019 evaluation instrument.

- ○ Yes
- ○ No

Add name and best contact info here:

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)

Save & Previous | Cancel | Save | Save & Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

Survey | **Questionnaire** | **Glossary**

Survey Survey Progress:

Export & Print

The following questions have missing responses. Please use the navigation menu to find the question and provide a response.

Module	Question	Variable Name	Error
User Data Edit			Response is missing
User Data Edit			Response is missing
User Data Edit			Response is missing
User Data Edit			Response is missing
User Data Edit			Response is missing
User Data Edit			Response is missing
Staffing Edit	1	Number of NPCR-funded (non-contracted) FTE positions: Filled	Response is missing
Staffing	1	Number of NPCR-funded (non-contracted) FTE positions: Vacant	Response is missing

Edit				
Staffing	1	Number of NPCR-funded, contracted FTE positions: Filled	Response is missing	
Edit				
Staffing	1	Number of NPCR-funded, contracted FTE positions: Vacant	Response is missing	
Edit				
Staffing	1	Number of State-funded (non-contracted) FTE positions: Filled	Response is missing	
Edit				
Staffing	1	Number of State-funded (non-contracted) FTE positions: Vacant	Response is missing	
Edit				
Staffing	1	Number of State-funded, contracted FTE positions: Filled	Response is missing	
Edit				
Staffing	1	Number of State-funded, contracted FTE positions: Vacant	Response is missing	
Edit				
Staffing	1	Number of non-contracted FTE positions funded by other sources: Filled	Response is missing	
Edit				
Staffing	1	Number of non-contracted FTE positions funded by other sources: Vacant	Response is missing	
Edit				
Staffing	1	Number of contracted FTE positions funded by other sources: Filled	Response is missing	
Edit				
Staffing	1	Number of contracted FTE positions funded by other sources: Vacant	Response is missing	

Edit				
Staffing	2	Principal Investigator: Non-Contractor	Response is missing	
Edit				
Staffing	2	Principal Investigator: Contractor	Response is missing	
Edit				
Staffing	2	Program Director: Non-Contractor	Response is missing	
Edit				
Staffing	2	Program Director: Contractor	Response is missing	
Edit				
Staffing	2	Program Manager: Non-Contractor	Response is missing	
Edit				
Staffing	2	Program Manager: Contractor	Response is missing	
Edit				
Staffing	2	Budget Analyst: Non-Contractor	Response is missing	
Edit				
Staffing	2	Budget Analyst: Contractor	Response is missing	
Edit				
Staffing	2	CTR Quality Control Staff: Non-Contractor	Response is missing	
Edit				
Staffing	2	CTR Quality Control Staff: Contractor	Response is missing	
Edit				
Staffing	2	Non-CTR Quality Control Staff: Non-Contractor	Response is missing	
Edit				
Staffing	2	Non-CTR Quality Control Staff: Contractor	Response is missing	
Edit				

Staffing Edit	2	CTR Education /Training Staff: Non-Contractor	Response is missing
Staffing Edit	2	CTR Education /Training Staff: Contractor	Response is missing
Staffing Edit	2	Epidemiologists: Non-Contracted	Response is missing
Staffing Edit	2	Epidemiologists: Contracted	Response is missing
Staffing Edit	2	Statisticians: Non-Contracted	Response is missing
Staffing Edit	2	Statisticians: Contracted	Response is missing
Staffing Edit	2	Computer / IT / GIS Specialists: Non-Contracted	Response is missing
Staffing Edit	2	Computer / IT / GIS Specialists: Contracted	Response is missing
Staffing Edit	2	Total Number CTRs (may overlap with above categories)	Response is missing
Staffing Edit	2	Total Number CTRs (may overlap with above categories)	Response is missing
Legislation Edit	3		Must select one
Administration	4	Reporting laws/regulations	Must select one

Edit			
Administration	4	List of reportable diagnoses	Must select one
Edit			
Administration	4	List of required data items	Must select one
Edit			
Administration	4	a. Monitoring timeliness of reporting	Must select one
Edit			
Administration	4	b. Receipt of data	Must select one
Edit			
Administration	4	c. Database management including a description of the registry operating system(software)	Must select one
Edit			
Administration	4	d. Conducting death certificate clearance	Must select one
Edit			
Administration	4	e. Conducting follow-back to reporting facilities on quality assurance issues	Must select one
Edit			
Administration	4	f. Conducting record consolidation	Must select one
Edit			
Administration	4	g. Maintaining detailed documentation of all quality assurance operations	Must select one
Edit			
Administration	4	h. Education and Training	Must select one

Edit			
Administration	4	Procedures for conducting data exchange including a list of states with which case-sharing agreements are in place	Must select one
Edit			
Administration	4	Procedures for conducting data linkages	Must select one
Edit			
Administration	4	Procedures for ensuring confidentiality and data security including disaster planning	Must select one
Edit			
Administration	4	Procedures for data release including access to and disclosure of information	Must select one
Edit			
Administration	4	Procedures for maintaining and updating the operational manual	Must select one
Edit			
Administration	5		Must select at least one
Edit			
Administration	6		Must select one
Edit			
Reporting Completeness	7	Hospitals with a cancer registry (non-federal): Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	Hospitals with a cancer registry (non-federal): Number Compliant with reporting at the end 2016	Response is missing

Edit			
Reporting Completeness	7	Hospitals with a cancer registry (non-federal): Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	Hospitals without a cancer registry (non-federal): Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	Hospitals without a cancer registry (non-federal): Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	Hospitals without a cancer registry (non-federal): Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	CoC Hospitals: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	CoC Hospitals: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	CoC Hospitals: Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	VA Hospitals: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	VA Hospitals: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			

Reporting Completeness	7	VA Hospitals: Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	IHS Hospitals: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	IHS Hospitals: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	IHS Hospitals: Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	Tribally Owned Hospitals: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	Tribally Owned Hospitals: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	Tribally Owned Hospitals: Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	7	In-State Independent Pathology Laboratories: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	In-State Independent Pathology Laboratories: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	In-State Independent Pathology Laboratories: Number Reporting Electronically	Response is missing

Edit			
Reporting Completeness	7	Out-of-State Independent Pathology Laboratories: Number Required to Report (Denominator)	Response is missing
Edit			
Reporting Completeness	7	Out-of-State Independent Pathology Laboratories: Number Compliant with Reporting at the end of 2016	Response is missing
Edit			
Reporting Completeness	7	Out-of-State Independent Pathology Laboratories: Number Reporting Electronically	Response is missing
Edit			
Reporting Completeness	8		Must select one
Edit			
Reporting Completeness	9		Must select one
Edit			
Reporting Completeness	13a		Must select one
Edit			
Reporting Completeness	13b	Number of facilities:	Response is missing
Edit			
Reporting Completeness	14	Number of cases missed:	Response is missing
Edit			
Reporting Completeness	15a		Must select at least one
Edit			
Reporting Completeness	15b		Must select one

Edit		
Data Exchange	16a	Must select one
Edit		
Data Exchange	16b	Must select one
Edit		
Data Exchange	16c	Must select one
Edit		
Data Exchange	17a	Must select one
Edit		
Data Exchange	17b	Must select one
Edit		
Data Exchange	17c	Must select one
Edit		
Data Exchange	17d	Must select one
Edit		
Data Exchange	17e	Must select at least one
Edit		
Data Exchange	17f	Must select one
Edit		
Data Exchange	17g	Must select one
Edit		
Data Exchange	17h	

Edit			Must select one
Data Exchange Edit	17i		Must select one
Data Exchange Edit	18		Must select at least one
Data Content And Format Edit	19		Must select one
Data Content And Format Edit	20		Must select one
Data Content And Format Edit	21		Must select at least one
Data Quality Assurance Edit	22	A designated CTR is responsible for the quality assurance program	Must select one
Data Quality Assurance Edit	22	Qualified, experienced CTRs conduct quality assurance activities	Must select one
Data Quality Assurance Edit	22	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)	Must select one
Data Quality Assurance	22	Data consolidation procedures are	Must select one

		performed according to an accepted protocol	
Edit			
Data Quality Assurance	22	Procedures are performed for follow-back to reporting facilities on quality issues	Must select one
Edit			
Data Quality Assurance	23		Must select one
Edit			
Data Quality Assurance	24		Must select at least one
Edit			
Data Quality Assurance	25		Must select one
Edit			
Data Quality Assurance	26		Must select one
Edit			
Data Quality Assurance	27a	Death information	Must select one
Edit			
Data Quality Assurance	27a	Missing demographic information	Must select one
Edit			
Data Quality Assurance	28	Patient data group	Must select one
Edit			
Data Quality Assurance	28	Treatment data group	Must select one
Edit			
Data Quality Assurance	28	Follow-up data group	Must select one

Edit			
Data Quality Assurance	29a		Must select one
Edit			
Data Quality Assurance	29c		Must select one
Edit			
Data Quality Assurance	29e		Must select one
Edit			
Data Use	30		Must select one
Edit			
Data Use	31a		Must select one
Edit			
Data Use	31b		Must select one
Edit			
Data Use	32a	Most current diagnosis year:	Response is missing
Edit			
Data Use	32b		Must select at least one
Edit			
Data Use	33	Comprehensive cancer control: Number per Year	Response is missing
Edit			
Data Use	33	Detailed incidence/mortality estimates: Number per Year	Response is missing
Edit			
Data Use	33	Collaboration with cancer screening	Response is missing

		programs for breast, colorectal, or cervical cancer	
Edit			
Data Use	33	Health event investigation(s): Number per Year	Response is missing
Edit			
Data Use	33	Needs assessment/program planning: Number per Year	Response is missing
Edit			
Data Use	33	Program evaluation: Number per Year	Response is missing
Edit			
Data Use	33	Epidemiologic studies: Number per Year	Response is missing
Edit			
Data Use	34a		Must select one
Edit			
Data Use	35		Must select at least one
Edit			
Data Use	36		Must select one
Edit			
Advanced Activities	40		Must select at least one
Edit			
Advanced Activities	41		Must select at least one
Edit			
Advanced Activities	42		Must select at least one
Edit			

Advanced Activities	43	Must select one
Edit		
Advanced Activities	45a	Must select one
Edit		
Advanced Activities	46	Must select at least one
Edit		
Collaborative Relationships	37a	Must select one
Edit		
Collaborative Relationships	37c	Must select one
Edit		
Collaborative Relationships	38	Must select at least one
Edit		
Collaborative Relationships	39	Must select at least one
Edit		
Survey Feedback	48a	Must select one
Edit		
Survey Feedback	48b	Must select one
Edit		
Survey Feedback	48c	Must select one
Edit		
Survey Feedback	48d	Must select one

Edit			
Survey Feedback	48e		Must select one
Edit			
Optional	49		Must select one
Edit			

Continue

PEI Help? Please call us at 301.572.0502 or email us at support

2017 - Program Evaluation Instrument

This page can be used to review and revise your responses. If all of your responses are correct, then click the "Submit" button to submit your survey.

Submit your survey Submit

You must address all errors before you can submit the survey! Go to validation page

Staffing

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.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.

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	0	0

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)	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	0	0
Total Number CTRs (of total number of staff)		

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

Edit

Legislation

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

Legislation Section Comments (You may add comments regarding your responses and/or any anticipated legislative barriers related to the “Legislation” section above.)

Edit

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.**

- Reporting laws/regulations
- List of reportable diagnoses
- List of required data items

Data processing operational procedure 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

Procedure 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.**
6. Does your CCR have an abstracting and coding manual that is provided for use by all reporting sources?
Administration Section Comments (You may add comments regarding your responses in the “Administration” section above.)

Edit

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 2014**	**Number Reporting Electronically****
HOSPITALS			
Hospitals with a cancer registry (non-federal)			
Hospitals without a cancer registry (non-federal)			

CoC Hospitals#			
VA Hospitals#			
IHS Hospitals#			
Tribally Hospitals#			
PATHOLOGY LABORATORIES			
In-state independent labs			
Out-of-state independent labs			
Other			
TOTAL	0	0	0

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

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

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

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

12. If No, why not? **Check all that apply.**

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

13b. How many VA facilities currently report 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?

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.**

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

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

Edit

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)?

b. Pathology reports (NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting)?

c. Ambulatory healthcare providers using electronic health records (Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries)

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:

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**:

c. The recommended frequency of data exchange is at least two times per year. Your CCR exchanges data at the following frequency:

d. Exchange agreements are in place with all bordering central cancer registries:

e. What type of records do you transmit for interstate exchange? **Check all that apply.**

f. Are NPCR core data items included in the dataset submitted to other states?

g. Do 99% of data submitted to other states pass an NPCR-prescribed set of standard edits?

h. Are exchanged data transmitted via a secure encrypted Internet-based system?

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):

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

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

Edit

Data Content And Format

19. Is your CCR able to receive secure, encrypted cancer abstract data from reporting sources via the Internet?
20. What is the **primary** software system used to process and manage cancer data in your CCR? **Check only one.**
21. Which of the following Registry Plus programs do you use? **Check all that apply.**
Data Content and Format Section Comments (You may add comments regarding your responses in the “Data Content and Format” section above.)

Edit

Data Quality Assurance

22. Please respond to each of the following statements to describe your CCR's quality assurance program:	
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. This may include external audits (NPCR/SEER)	
Data consolidation procedures are performed consistently from all source records	
Procedures are in place for follow-back to reporting facilities on quality issues	
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?	
24. In the past year, which of the following type of quality control audits or activities did your CCR conduct? **Check all that apply.**	
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?	
26. Does your CCR match by tumor (site/histology) and not just by patient identifying information?	
27a. Does your CCR update the CCR database following death certificate matching within 3 months of linkage?	
Death information	
Missing demographic information	
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?		
Patient data group		
Treatment data group		
Follow-up data group		
29a. Does your CCR provide an edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR?		
29b. If Yes, are facilities **required** to run prescribed edits prior to their data submission to your CCR?		
29c. Does your CCR have an established threshold for percent of records passing edits on incoming submissions?		
29d. If Yes what is the threshold?		
29e. How often does your CCR provide feedback to reporting facilities on the quality, completeness, and timeliness of their data?		
Data Quality Assurance Section Comments (You may add comments regarding your responses in the “Data Quality Assurance” section above.)		

Edit

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?
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).
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).
31c. If Yes, indicate what information was included in the report: **Check all that apply.**
32a. What is the most current diagnosis year a data file or report is available to the public?
32b. In what format is this report available? **Check all that apply.**

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?

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.**

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

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

Edit

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).

37b. If Yes, the Advisory Committee includes representation from: **Check all that apply.**

37c. If you have an Advisory Committee, how often does this group convene, including in-person and teleconferences? **Check only one.**

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.**

39. With which other Department of Health programs does your CCR collaborate? **Check all that apply.**

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

Edit

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.**

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.**

42. Does your CCR conduct at least one of the following advanced activities? **Check all that apply.**

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

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

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

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

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

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

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.)

Edit

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.

b. I understand the importance of all or most of the questions.

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

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.

e. Our central registry uses data that are collected in this instrument.

Edit

Optional

49. I would like to participate in discussions regarding the 2019 evaluation instrument.

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)

Edit

Submit your survey Submit