Attachment 3C

NPCR Program Evaluation Instrument (NPCR PEI)

Summary of Proposed Changes for 2022-2024

(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 2018 PEI. Updates to the PEI were made based on these results, release of the current NOFO (DP17-1707) and updates to the Program Standards. In addition, determination was made to edit, add and clarify various questions as a result of feedback from awardees as well as CDC staff. 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: (Indicated in Red)

Administrative Data Section

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	
Email (Inserted row to request **Email** info)	

Staffing Section –

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.**

	Total Count FTEs	
Position (FTE or percentage of FTE)	**Filled (deleted Non-Contractor)**	**Vacant (deleted 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 (inserted this position)		
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. Have any law/regulations been revised to address cancer reporting in the past two years?

- O Yes; please describe: _____
- O No

If there are plans for revisions in the next two years, please provide comment in box below. **(additional details requested if Question 3 is answered "Yes")**

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

Administrative Data Section – (Directions for Section edited to clarify)

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

Check all that apply.

Reporting Completeness Section – (Hospital and Pathology Laboratory Reporting table was edited to include a Row to insert Physician Offices)

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 2021. Also report the number reporting electronically (e.g. in a standardized format that minimizes the need for manual data entry.)

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

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

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_____

Please indicate how the following factors influenced the completeness and timeliness of your CCR's 12-month data submission:

	Contributing Factor	**Negative Factor**	**Both Contributing and Negative Factor**
Laws and Rules			

Fines and Penalties			
Outsourcing and contracting			
Interstate data exchange			
Other factors, specify			

17. Do your interstate data exchange procedures meet the following minimum criteria? (Several Edits to Question 17 -d, g, and j are reflected below in Red)

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

- O Yes, with all bordering CCRs plus other non-adjacent CCRs
- O Yes, with all bordering CCRs but no others
- O Yes, with some bordering CCRs
- O Yes, Includes National Interstate Data Exchange Agreement
- O No, no exchange agreements in place with neighboring states, but some are in place with non-neighboring states
- O No, no exchange agreements in place

List all existing CCR agreements here: _____

_____

e. What type of records do you transmit for interstate exchange?

- Consolidated cases
- Source records with text
- Source records without text

f. Does it include all cases not exchanged previously?

Yes

No

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

- O Yes
- O No

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

- O Yes
- O No

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

- O Yes
- O No

j. Is the standardized, NPCR-recommended data exchange format used to transmit data to other central cancer registries and CDC (The current NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary):

- O Yes
- O No

Data Exchange Section – (Question 19 was edited slightly to align with the current Program Standards)

19. Is your CCR able to receive secure, encrypted cancer abstract data from reporting sources via the internet, FTP, email, etc ?

Data Quality Assurance Section –

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: _____	_____

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

- O Yes
- O No

26. During the death certificate linkage, does your CCR match by tumor (site/histology) and not just by patient identifying information?

- O Yes
- O No

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

	Yes	**No**
Death information (vital status and cause of death)	O	O
Missing demographic information	O	O

27 b. 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:	_____	_____

30. Within 12 months of the end of the diagnosis year with data that are 90% complete, did your CCR calculate incidence counts, rates, or proportions in an electronic data file or report for the diagnosis year for Surveillance Epidemiology and End Results (SEER) site groups to monitor the top cancer sites within your state/territory?

- O Yes
- O No

31a. Within 24 months of the end of the diagnosis year with data that are 95% complete, did your CCR calculate incidence rates, counts or proportions in an electronic data file or report? (The report should include, at a minimum, age-adjusted incidence rates, age-adjusted mortality rates, and stage at diagnosis for the diagnosis year for SEER site groups, and, where applicable, stratified by sex, race, ethnicity, and geographic area.

- Yes
- No

Collaborative Relationships Section –

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: _____

43b. If yes, within what time frame are cases reported?" Selections could be "30 days, 60 days, other specify, study dependent specify"

- ○ 30 days
- ○ 60 days _____
- ○ Study dependent specify
- ○ Other, specify; _____

44b. Does your CCR update your database with vital status and cause of death following NDI linkage?

- ○ Yes
- ○ No
- ○ Not applicable

Advanced Activities Section –

45. With which databases did your CCR link its records in 2020-2021 for follow-up or some other purpose?

Check all that apply.

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

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