
# 2013 - NPCR Program Evaluation Instrument

**Form Approved**

**OMB NO. 0920-0706**

**Exp. Date: XX/XX/XXXX**

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National Program of Cancer Registries
Cancer Surveillance System

NPCR NATIONAL PROGRAM OF CANCER REGISTRIES

# Program Evaluation Instrument

Form Approved
OMB No. 0920-0706
Exp. Date XX/XX/XXXX

**Purpose Statement**

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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 hypotheses formulation.

Specific knowledge about operational activities NPCR registries are engaged in 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 2013 PEI provide baseline data that can be used to measure compliance with the NPCR Program Standard. 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, 2012**, the appropriate Central Cancer Registry (CCR) staff should complete the PEI.

Deadline for completion: October 31, 2013

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, 2012.**

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

# 2013 - Program Evaluation Instrument

Survey | Questionnaire | Glossary

**Survey** Survey Progress:

- Administrative Data
- Staffing
- Legislation
- Administration
- Reporting Completeness
- Data Exchange
- Data Content
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- Data Use
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- Survey Feedback
- Optional
- Validation
- Review
- Save and Logout

## Administrative Data

| | |
|---|---|
| State/Territory | SA |
| NPCR reference year | 2000 |
| Registry reference year | 1995 |
| Registry Program Director | Joe Smith |
| Cooperative Agreement # | DP12-1205- 205454 |
| Most Current Grant Award Amount | $ 999999 |
| CDC Program Consultant | Netta Apedoe |
| Your name | Joe Smith |
| Title | Principal Investigator |
| Phone number | (999) 999-9999 |
| Status | In Progress |
| Date Completed | 3/13/2013 |

Cancel | Save & Continue

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**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, 2012, how many total FTE central cancer registry (CCR) staff positions were funded? In this table, you may include positions outside the registry; ONLY IF the registry pays a portion of the salary. Remember to use the calculation method above when computing partial FTEs.

| | Total Count FTEs | |
|---|---|---|
| **Funding Category** | **Filled** | **Vacant** |
| Number of NPCR-funded (non-contracted) FTE positions | | |
| Number of NPCR-funded, Contracted FTE positions | | |
| Number of State-funded (non-contracted) FTE positions | | |
| Number of State-funded, Contracted FTE positions | | |
| Number of non-contracted FTE positions funded by other sources | | |
| Number of Contracted FTE positions funded by other sources | | |
| Totals | | |

Cancel | Save & Continue

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**Staffing 2 of 2**

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 | | |
| Registry Administrator | | |
| Program Manager | | |
| Budget Analyst | | |
| CTR Quality Control Staff | | |
| Non-CTR Quality Control Staff | | |
| CTR Education /Training Staff | | |
| Epidemiologists | | |
| Statisticians | | |
| Computer / IT / GIS Specialists | | |
| Other staff, specify | | |
| Total 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.)

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**Legislation 1 of 2**

3. Does your state/territory have current legislation or regulations in support of all 8 criteria of the Public Law authorizing the NPCR? (Program Standard I.b.)

- Yes
- No

4a. Does your state/territory's current law/regulation include any penalties regarding reporting compliance as mandated by current legislation or regulations? (Program Standard I. a.)

- Yes
- No

4b. If "Yes", in which law/regulations are the penalties included? (Check only one ):

- Cancer-specific reporting law/regulations
- General public health law/regulations
- Both
- None of the above

4c. If "Yes" to 4a, have you had to impose the penalty?

- Yes
- No

4d. Have any law/regulations been revised to address cancer reporting in the past two years?

- Yes
- No

4e. If "Yes" please describe:

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**Legislation 2 of 2**

5a. With passage of Public Law 107-260 (the Benign Brain Tumor Cancer Registry Amendment Act), NPCR-funded registries are required to collect data on benign brain tumors beginning in diagnosis year 2004. Do regulations or legislation in your state or territory authorize you to collect data on benign brain tumors?

- Yes
- No

5b. If "No", what are your plans, including timeframes, to modify your state or territory's legislation or regulations to allow you to collect benign brain tumor data?

6. Does your state or territory have legislation or regulations prohibiting you from reporting county level data?

- Yes
- No

7. Does your state law/regulations protect your cancer registry data from the Freedom of Information Act (FOIA)?

- Yes
- No

8a. Does your state law/regulations protect your cancer registry data from subpoena?

- Yes
- No

8b. If "No", are data received through interstate data exchange protected from subpoena?

- Yes
- No

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

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**Administration 1 of 2**

| 9. Does your CCR maintain an operational manual that describes registry operations, policies and procedures that, at a minimum, contains the following? (Program Standard II.a.) Check all that apply | |
|---|---|
| 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 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 |

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**Administration 2 of 2**

10. Does your CCR produce reports that are used to monitor the registry operations and database, including processes and activities? (Program standard II. b) **(Check all that apply)**

- [ ] Quality control report (central registry)
- [ ] Quality control reports for each facility
- [ ] Data completeness report for each facility
- [ ] Timeliness of data report for each facility
- [ ] Data workflow report
- [ ] All of the above
- [ ] Other, specify:
- [ ] None of the above

11. Does your CCR have an abstracting and coding manual that is provided for use by all reporting sources? (Program Standard II.c)

- ( ) Yes
- ( ) No

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

Cancel | Save & Continue

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**Reporting Completeness 1 of 3**

12a. **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 2012. 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). (Program Standards V c-d, IV b-c)

| | Number Required to Report (Denominator ) | Number Compliant with Reporting* at the end of 2012 | Number Reporting Electronically** |
|---|---|---|---|
| **HOSPITALS** | | | |
| Hospitals with a cancer registry (non-federal) | | | |
| Hospitals without a cancer registry (non-federal) | | | |
| VA Hospitals# | | | |
| IHS Hospitals# | | | |
| Tribally Hospitals (Tribal Hospitals) | | | |
| In-state independent labs# | | | |
| Out-of-state independent labs | | | |
| Other | | | |
| TOTAL | | | |

*Those 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.

Cancel | Save & Continue

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**Reporting Completeness 2 of 3**

12b. **Physician Reporting:**

The NPCR Program Standard for physician reporting focuses on annually increasing the number reporting to the CCR. The NPCR Physician Reporting document provides guidance on how to count physician reporting. In the table below, please provide the baseline number of physician specialties that were reporting at the end of 2012 (column b.). In column d. record the number of physician specialties from column b. that are reporting electronically.
CCRs may use the Practice Method, Physician Method or a combination of the two (see definition below). For example, you may count Hematology using the Practice Method (2 practices) but for Dermatology use the Physician Method (10 physicians). **However you may not count the Hematology Practice (2 practices) and then count the physicians in those practices again in the Individual Physician section.**
Counting physician reporting is not an exact science; however, CCRs should use a consistent methodology. If the CCR is unable to determine whether a physician is reporting on behalf of a practice, count the reporting source as an individual physician. If the type of physician is unknown, group the physician into an "Other" category

| **Physician Group (Centers/Clinics/Practices) - Use this top section to report specialty physicians counted using the Practice Method****** | | | |
|---|---|---|---|
| **a. Physician Specialty** | **b. Number reporting** at the end of 2012** | **c. Number currently reporting**** | **d. Number reporting electronically***** |
| Independent Surgery Centers* | | | |
| Independent Radiation Therapy Centers | | | |
| Hematology | | | |
| Medical Oncology | | | |
| Urology | | | |
| Dermatology | | | |
| Gastroenterology | | | |
| Other | | | |
| **Individual Physicians - Use this lower section to report specialty physicians counted using the Individual Physician Method****** | | | |
| **a. Physician Specialty** | **b. Number reporting at the end of 2012** | **c. Number currently reporting** | **d. Number reporting electronically** |
| Surgeons* | | | |
| Radiation Oncologists | | | |
| Hematology | | | |
| Medical Oncologists | | | |
| Urologists | | | |
| Dermatologists | | | |
| Gastroenterologists | | | |
| Other | | | |
| TOTAL | | | |

*Surgeons that diagnose or treat patients in the office
**Those 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.
****Practice Method:** Each specialty practice is counted as a single reporting source without consideration for the number of physicians in the practice.
****Individual Physician Method:** Each individual specialty physicians is counted as a single reporting source without consideration for the number of locations where she/he works.

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**Reporting Completeness 3 of 3**

13. Do you require that non-analytic (classes 30-37) cases be reported to your CCR?
- Yes
- No

14a. Do you receive data from the Department of Defense's Automated Central Tumor Registry (ACTUR) dataset? (If "No," skip to 14d):
- Yes
- No

14b. If "Yes", how often? Please check only one.
- Every quarter
- Every 6 months
- Once a year
- Other, specify

14c. If "Yes" for 14a, have these data proven to be helpful in finding new incident cases?
- Yes
- No

14d. If "No" for 14a, 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:

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

**Number of facilities:**

16. Based on historical data, how many cases per diagnosis year do you estimate are missed (i.e., not ever received) by your CCR because of non-reporting by VA facilities?

**Number of cases missed:**

17. How many providers have contacted you regarding meaningful use?

a. Of those who have contacted you, how many have signed on/initiated* the Meaningful Use process with your registry?

b. Of those who have contacted you, how many are reporting** data to you?

*This would include:
1) Providers that have indicated plans to report to you once the Stage 2 MU reporting period begins in 2014; and
2) Providers that have begun working with you to test their data submissions (also known as "on-boarding")
**This number should represent providers that are reporting live, production level data to you for MU (i.e., they are in "ongoing submission" as defined by MU).

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

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**Data Exchange**

18. Does your CCR use and require the following standardized, CDC-recommended data formats for the electronic exchange of cancer data from reporting sources (Program Standards IV a.):

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

19. Do your exchanged data meet the following minimum criteria? (Program Standards V.d.):

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
- ○ No, not all

List all existing agreements here:

e. What type of records do you transmit for interstate exchange?
- ○ Consolidated cases
- ○ Source records with text
- ○ Source records without text

f. NPCR core data items are included in the dataset submitted to other states:
- ○ Yes
- ○ No

g. 99% of data submitted to other states passes an NPCR-prescribed set of standard edits:
- ○ Yes
- ○ No

h. Exchanged data are transmitted via a secure encrypted Internet-based system:
- ○ Yes
- ○ No

i. 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

20. What type of secure encrypted Internet-based system is used?
- ☐ PHINMS
- ☐ Secure FTP
- ☐ WebPlus
- ☐ HTTPS
- ☐ N-IDEAS
- ☐ Secure encryped e-mail
- ☐ Other, specify:

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

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## Data Content And Format

21. Does your CCR collect or derive all required data items using standard codes as prescribed by NPCR? (See Chapter VIII, Required Status, NAACCR, vol 2, http://www.naaccr.org/LinkClick.aspx?fileticket=EEnPpGkO0Jc%3d&tabid=133&mid=473)

- ○ Yes
- ○ No

22. 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

23a. What is the **primary** software system used to process and manage cancer data in your CCR? Please check only one:

- ○ Commercial Vendor
- ○ In-House Software
- ○ CRS Plus

23b. 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
- ☐ 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.)

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**Data Quality Assurance 1 of 2**

| 24. Please respond to each of the following statements to describe your CCR's quality assurance program: (Program Standard VII a) | |
|---|---|
| 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 following general coding principles | Yes No |
| Procedures are performed for follow-back to reporting facilities on quality issues | Yes No |

25. Does your CCR have a designated education/training coordinator, who is a CTR, to provide training to CCR staff and reporting sources to ensure high quality data? (Program Standard VII.b 2.)

- Yes
- No

| 26. In the past year, which of the following type of quality control audits or activities did your CCR conduct? | |
|---|---|
| Casefinding | Yes No |
| Re-abstracting | Yes No |
| Re-coding | Yes No |
| Visual editing | Yes No |

27a. Does your CCR match all causes of death against your registry data to identify a reportable cancer?

- Yes
- No

27b. Does your CCR match by tumor (site/histology) and not just by patient identifying information?

- Yes
- No

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**Data Quality Assurance 2 of 2**

| 28a. Does your CCR update the CCR database following death certificate matching: | |
|---|---|
| Death information | ○ Yes ○ No |
| Missing demographic information | ○ Yes ○ No |

28b. 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 | | |

| 29. 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 |

30a. 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

30b. If "Yes", are facilities **required** to run prescribed edits prior to their data submission to your CCR?

○ Yes
○ No

30c. Does your CCR have an established threshold for percent of records passing edits on incoming submissions?

○ Yes
○ No

30d. If "Yes" what is the threshold?

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

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

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**Data Use 1 of 3**

31. Within 12 months of the end of the diagnosis year with data that are 90% complete, did your CCR calculate incidence count 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? (Program Standard VIII.a.)

- Yes
- No

32a. 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). (Program Standard VIII.b.)

- Yes
- No

32b. 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

32c. If yes, indicate what information was included in the report.

- Screening-amenable Cancers
- Tobacco-related Cancers
- Obesity-related Cancers
- HPV-related Cancers
- All the above
- Other

33a. What is the most current diagnosis year a data file or report is available to the public?

**Most current diagnosis year:**

33b. In what format is this report available? (Check all that apply)

- Hard copy
- Electronic word-processed file
- Web page/query system

Cancel | Save & Continue

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**Data Use 2 of 3**

34a. Has the CCR, state health department, or its designee used registry data for planning and evaluation of cancer control objectives in **at least three of the following ways in the past year?** (Program Standard VIII.c.)

- Comprehensive cancer control detailed incidence/mortality estimates
- Detailed incidence/mortality by stage and geographic area
- Collaboration with cancer screening programs for breast, colorectal, or cervical cancer
- Health event investigation(s)
- Needs assessment/program planning (e.g., Community Cancer Profiles)
- Program evaluation
- Epidemiologic studies

○ Yes
○ No

34b. If "Yes", indicate the number of times data was used 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 with cancer screening programs for breast, colorectal, or cervical cancer | |
| Health event investigation(s) | |
| Needs assessment/program planning | |
| Program evaluation | |
| Epidemiologic studies | |
| Other, describe | |

35a. Have any of the above uses of data been included in a journal publication in the last two years (1/1/11-12/31/12)?

○ Yes
○ No

35b. If "Yes", please list the citation(s) in the space provided:

Cancel | Save & Continue

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**Data Use 3 of 3**

36. 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:

37. 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.)

Cancel | Save & Continue

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**Collaborative Relationships 1 of 3**

38a. Does your CCR actively collaborate with your state/territory's comprehensive cancer prevention and control (CCC) planning efforts, including establishing a working relationship to ensure the use of registry data to assess and implement cancer control activities? (Program Standards X.a-c.)

- ◉ Yes
- ◉ No

38b. If "Yes", please check all of the ways you collaborate with CCC:

- ☐ Member of the Program Management, Leadership, and Coordination Team (Component 1)
- ☐ Member of our state/territory's comprehensive cancer control (CCC) planning group (coalition, committee, or workgroup)
- ☐ Provide data for CCC planning and/or
- ☐ Provide data for CCC activities
- ☐ Provide technical assistance and collaborate on data analyses for CCC program publications
- ☐ Regular meetings with CCC departmental staff
- ☐ Provides subject matter expertise to CCC
- ☐ Data linkages

- ☐ All of the above
- ☐ Other, specify:
- ☐ None, Explain:

Cancel | Save & Continue

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**Collaborative Relationships 2 of 3**

39a. 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). (Program Standard X.c.)

- ○ Yes
- ○ No

39b. 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:

39c. 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:

Cancel | Save & Continue

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**Collaborative Relationships 3 of 3**

40. 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 NBCCEDP
- ☐ Provides subject matter expertise to NBCCEDP
- ☐ Data linkages (NBCCEDP database, Minimum Data Elements (MDE) Study
- ☐ All of the above
- ☐ Other, specify:

- ☐ None of the above, explain

41. With which chronic disease programs does your CCR collaborate?

- ☐ Tobacco Control
- ☐ Oral Health
- ☐ Diabetes
- ☐ Physical Activity and Nutrition/Obesity
- ☐ Radiation Control
- ☐ Environmental Health
- ☐ Infectious disease (HIV/AIDS, HPV, hepatitis)
- ☐ All of the above
- ☐ Other, specify:

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

Cancel | Save & Continue

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**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."

42. 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

43. What method is used to identify reportable conditions from pathology lab reports:

- ○ Manual Review
- ○ Search routine based on NAACCR search term list
- ○ Both manual and search routine
- ○ Other, specify

44. 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

45. 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

46a. Does your registry have a system in place for early case capture (rapid case ascertainment)?

- ○ Yes
- ○ No

46b. If 'Yes" is early case capture performed for:

- ☐ All cases
- ☐ Subset of cases (eg. Pedidatric)
- ☐ Special Studies
- ☐ Other, specify:

Cancel | Save & Continue

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**Advanced Activities 2 of 3**

47a. How often does your CCR link to the National Death Index (NDI)? Please check only one. (If Never, skip to question 48.):

- ○ Every Year
- ○ Every Other Year
- ○ Every 3-5 Years
- ○ Never
- ○ Other, specify

47b. 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

47c. Does your CCR update your database following NDI linkage?

- ○ Yes
- ○ No
- ○ Not applicable

48. With which databases did your CCR link its records in 2012 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

Cancel | Save & Continue

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**Advanced Activities 3 of 3**

| 49. In a given calendar year, what percentage of your total pathology reports (both electronic and paper) received was sent by the following independent laboratories? (Estimates acceptable if exact % not available, must add up to 100%) | |
|---|---|
| Laboratory Corporation of America (LabCorp): | % |
| Quest Diagnostics: | % |
| Bostwick Laboratories: | % |
| Mayo Laboratories: | % |
| Bioreference | % |
| GI Pathology | % |
| AmeriPath | % |
| Clarent | % |
| Miraca Labs | % |
| CBL Path | % |
| Other | % |

| Other: Please list the top 5 additional independent laboratory names by volume and of % total reports received: | |
|---|---|
| 1. | % |
| 2. | % |
| 3. | % |
| 4. | % |
| 5. | % |

| In the same calendar year, what percentage of your total pathology reports received were sent by local (in-state) independent labs, excluding any listed under "other" above? | |
|---|---|
| Local: | % |

**Advanced Activities Section Comments** (You may add comments regarding your responses in the "Advanced Activities" section above.)

Cancel | Save & Continue

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**Survey Feedback**

50. 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

Cancel | Save & Continue

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**Optional**

51. I would like to participate in discussions regarding next year's evaluation instrument

- Yes
- No

Please enter your name and phone number here:

52. 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)

Cancel | Save & Continue

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

| Module | Question | Variable Name | Error |
|---|---|---|---|
| Data Exchange | 19c | Other, explain | You have selected other as an option, specify other |
| Data Use | 32c | Other | You have selected other as an option, specify other |

Edit

Edit

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**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

## Staffing

1. On December 31, 2012, how many total FTE central cancer registry (CCR) staff positions were funded? In this table, you may include positions outside the registry; ONLY IF the registry pays a portion of the salary. Remember to use the calculation method above when computing partial FTEs.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.

| **On December 31, 2012, how many total FTE central cancer registry (CCR) staff positions were funded? In this table, you may include positions outside the registry; ONLY IF the registry pays a portion of the salary. Remember to use the calculation method above when computing partial FTEs.** | **Filled** | **Vacant** |
|---|---|---|
| Number of NPCR-funded (non-contracted) FTE positions | 2.50 | 5.00 |
| Number of NPCR-funded, Contracted FTE positions | 0.75 | 0.75 |
| Number of State-funded (non-contracted) FTE positions | 1.00 | 1.00 |
| Number of State-funded, Contracted FTE positions | 1.00 | 1.00 |
| Number of non-contracted FTE positions funded by other sources | 2.00 | 0 |
| Number of Contracted FTE positions funded by other sources | 0.50 | 0.75 |
| Totals | 7.75 | 8.50 |