The National Program of Cancer Registries (NPCR)

Annual Program Evaluation Instrument (APEI)

PURPOSE STATEMENT

The NPCR Annual Program Evaluation Instrument (APEI) is a web-based survey instrument designed to evaluate NPCR-funded registries' operational attributes and their progress towards meeting program standards. The APEI also provides information about advanced activities and "success stories" that highlight ways registry data is being used.

Based on *CDC's Updated Guidelines for Evaluating Public Health Surveillance Systems*, the APEI monitors the integration of surveillance 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 formulating research hypotheses.

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 2007 APEI provide baseline data that will be used when measuring future progress with the NPCR Program Standards expected to be implemented this year. 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, 2006**, the appropriate Central Cancer Registry (CCR) staff should complete the APEI.

State / Territory	
NPCR reference year	
Registry reference year	
Registry Program Director	
Cooperative Agreement #	U55/CCU -
Most Current Grant Award Amount	\$
CDC Program Consultant	
Your name	
Title	
Phone number	

ADMINISTRATIVE DATA

Date completed	

STAFFING

The following questions use the concept of a "Full-time Equivalent" also known as an "FTE". In each question you will be asked to report the total number of FTEs (FTE count). To do this, please convert each position to the appropriate FTE using the guidelines below, rounding each position to the nearest quarter of an FTE (e.g., 34 hrs/week would convert to 0.75 FTE, whereas 35 hrs/week would convert to 1.0 FTE):

0.25 FTE = 10 hrs/week

0.50 FTE = 20 hrs/week

0.75 FTE = 30 hrs/week

1.00 FTE = 40 hrs/week

Then add each converted position for the total number of FTEs. For example, if the CTR works 35 hours a week and another CTR works 25 hours a week, the combined hours for the CTR positions = 60 hours = 1.5 FTEs.

1. On **December 31, 2006,** 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.

		unt 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 Contracted FTE positions funded by other sources		
Number of non-contracted FTE positions funded by other sources		
TOTALS		

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 **access to these staff (outside the registry), 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
Principle 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 Count CTRs	
	Non-Contracted	Contracted
Total Number CTRs (may overlap with above categories)		

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

LEGISLATIVE AUTHORITY

3. Does your state/territory have a current law authorizing a populationbased central cancer registry? (*Program Standard I.a.*)

Yes
No

4. 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

5a. Are there any penalties in place regarding reporting compliance as mandated by current legislation or regulations?



- 5b. 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
- 5c. If "Yes," have you had to impose the penalty?
 - Yes
- 6a. 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

6b. 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?

Specify			

7. Does your State or Territory have legislation or regulations prohibiting you from reporting county level data?

Yes
No

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

Yes
No

9a. Does your state law/regulations protect your cancer registry data from subpoena?



- 9b.
- 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)

ADMINISTRATION

10. 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:

	YES	NO
Reporting laws/regulations		
List of reportable diagnoses		
List of required data items		
Data processing operational procedures for (check all that apply):		
a. Monitoring timeliness of reporting		
b. Receipt of data		
c. Database management including a description of		
the Registry Operating System (software)		
d. Conducting death certificate clearance		
Procedures for Implementing and maintaining a quality assurance/control		
program including (check all that apply, f-h)		
f. Conducting follow-back to reporting facilities on quality		
assurance issues		
g. Conducting record consolidation		
h. Maintaining detailed documentation of all quality		
assurance operations		
Procedures for insuring 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		
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11. Do you believe that your CCR policies and procedures are sufficient and clear as to what data may and may not be disclosed and how this should occur?



12. Do you believe that your CCR policies and procedures are sufficient and clear for protection of confidentiality for all routine registry activities?

Yes
No

13. Do you believe that your CCR staff possesses sufficient knowledge and resources to meet risk-appropriate threats to security and confidentiality?

Yes
No

14. 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 Other, specify

None of the above

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



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

REPORTING COMPLETENESS

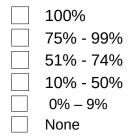
16. What types of facilities and health care providers report to your CCR? Please list the percentage of facilities, by type, that actually reported in the past year (2006) (do not record the percentage reporting according to your CCR's timeliness schedule), and calculate what percentage of the reports, by facility type, are received electronically. *Note:* "Hospital cancer registry" is defined as one (single or joint institution) who collects data to be used internally and who would continue to do so regardless of the central cancer registry requirements to collect and report cancer data. Provide the number of facilities required to report and, where indicated, use your best estimate if the exact number is not available. For those facilities which are not applicable to your state/territory (e.g., IHS Hospitals), record zero (0) in 'Number Required to Report' and 100 in 'Percent Compliant with Reporting'. In these instances, 'Percent Reports Received Electronically' is to be left blank and will be validated against the 'Number Required to Report'. (Program Standards III.a-c)

Facilities Required to Report Cancer Cases by Type	Number Required to Report (Denominator)	Percent Compliant by Reporting**	Percent Reports Received Electronically
Hospitals with a cancer registry (non-federal)			
Hospitals without a cancer registry (non-federal)			
VA Hospitals			
IHS Hospitals			
Tribally Owned Hospitals			
Health Centers (IHS, Tribal)			
Surgery Centers			
Independent Radiation Therapy Centers			
In-State Independent Pathology Laboratories			
Out-of-State Independent Pathology Laboratories*			
Dermatologists*			
Urologists*			
Oncologists*/Hematologists*			
Other Physicians*			
Other facilities, specify:			

*Provide best estimate **Those facilities who report rather than those reporting in a timely manner

17. Within 24 months of the close of the diagnosis year, what percentage of physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients submit all reportable cases to your CCR? *Exception:* Physicians are not required to report cases directly referred or previously admitted to, and reported by, a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State/Territory?

(Program Standard V.a.) Check only one:



- 18. Of the pathology lab reports your CCR receives, what percentage are in the College of American Pathologists (CAP) cancer protocol checklist format? *(Provide best estimate)*
 - 100%
 75% 99%
 51% 74%
 10% 50%
 0% 9%
 None
- 19. Do you require that non-analytic (classes 3 and 4) cases be reported to your CCR?
 - Yes
- 20a. Do you receive data from the **Department of Defense's** Automated Central Tumor Registry (ACTUR) dataset? (If "No," skip 15b –

15d)



20b. If yes, how often? Please check only one.

	Every quarter
20c.	Every 6 months If yes, have these data proven to be helpful in finding new incident cases? Other, specify
	Yes
	No

20d. If not, why not? (Please check all that apply)

Data are incomplete.	
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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:	
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	Number of Facilities	
21. To how many VA facilities do you currently send central registry staff for data collection/abstracting?		
22. At how many VA facilities are data collected by a combination of VA facility staff and central registry staff?		
23. How many VA facilities currently report to your CCR indirectly from the VA central cancer registry in Washington, DC?		
24. If there are VA facilities not reporting, please explain why in the s provided below:	pace	
25. Based on historical data, how many cases per diagnosis y estimate are missed (i.e., not ever received) by your CCR becareporting by VA facilities?	•	
Number of cases missed:		

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

DATA EXCHANGE

and

- 26. Does your CCR use and require the standardized, NPCR-recommended data exchange record layout for the electronic exchange of cancer data for (*Program Standards III.a.*):
 - a. Abstract reports (The NAACCR record layout version specified in Standards for Cancer Registries Volume II: Data Standards Data Dictionary)?

Yes
No

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

Yes
No

- 27. Does your exchanged data meet the following minimum criteria? (*Program Standards V.d.*) (Check all that apply):
 - a. Within 12 months of the close of the diagnosis year, your CCR exchanges data with other central cancer registries where a dataexchange agreement is in place (the data file includes all cases not previously exchanged):

Yes
No

Regardless of residency, your CCR collects data on all patients diagnosed and/or receiving first course of treatment in the state/territory:

regi	stry's
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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 Bi-annually Other, explain
d.	Exchange agreements are in place with all bordering central cancer registries:
	Yes, with all bordering CCRs No, <i>not all</i> List existing agreements here:
e.	Exchanged data includes a dataset that consists of NPCR core data items
	Yes No
f.	99% of exchanged data passes an NPCR-prescribed set of standard edits
	Yes No
g.	Exchanged data are transmitted via a secure encrypted Internet- based system
	Yes No
h. version II: Data	The standardized, NPCR-recommended data exchange format is used to transmit data reports (<i>The NAACCR record layout</i> <i>specified in Standards for Cancer Registries Volume</i> <i>Standards and Data Dictionary</i>)
	Yes No
	nge Section Comments (You may add comments regarding your e "Data Exchange" section above)
DATA	

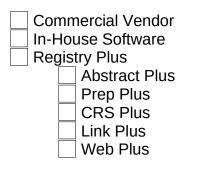
28. Does your CCR collect or derive all required data items using standard codes as prescribed by NPCR?



29. 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

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



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

DATA QUALITY ASSURANCE

31. Does your CCR's quality assurance program consist of, but is not limited to: (*Program Standard VI.a.*) **Check all that apply:**

	YES	NO
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, and may include external audits (NPCR/SEER)	
Data consolidation procedures are performed according to an accepted protocol	
Procedures are performed for follow-back to reporting facilities on quality issues	

32. Does your CCR have a designated education/training coordinator, who is a CTR, to provide training to CCR staff and reporting sources to assure high quality data? (*Program Standard VI.b.*)

Yes
No

Patient Treatment

33. <u>In the past year, wh</u>ich of the following type of quality control audits_or activities <u>did</u> your CCR <u>conduct? **Check all that apply**</u>:

	Yes	No
Casefinding		
<u>Re-abstracting</u>		
<u>Re</u> - <u>coding</u>		
<u>Visual editing</u>		

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



35a. Does your CCR update the CCR database following death certificate matching:

Death information	
Missing demographic information	

res	INO	
Yes	No	

35b. If "Yes", what percentage(s) is updated manually or electronically?: (Provide best estimate; may be some overlap between automation and manual review)

Death information:	Manually	%	Electronically	%
Demographic information:	Manually	%	Electronically	%

36. Does your CCR perform record consolidation on the following **(check all that apply)**: Data Group Electronic Manual Both

Follow-up			
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37a. Does your CCR provide a registry-specific edit set to your reporting facilities and/or vendors for use prior to data submissions to your CCR?



37b. If "Yes," are facilities **required** to run registry-specific edits prior to their data submission to your CCR?



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

DATA USE

38. Within 12 months of the end of the diagnosis year with data that are 90% complete, did your CCR produce pre-calculated data in tables in an electronic data file or report of incidence rates, counts, or proportions 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 VII.a.*)



39a. Within 24 months of the end of the diagnosis year with data that are 95% complete, did your CCR produce pre-calculated data in tables 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, and ethnicity). (Program Standard VII.b.)

Yes
No

39b. What is the most current diagnosis year a data file or report is available?

Year _____

39c. In what format is this report available?

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

40a. 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:** Comprehensive cancer control detailed incidence/mortality estimates, linkage with a statewide cancer screening program to improve follow-up of screened patients, health event investigation(s), needs assessment/program planning, program evaluation, or epidemiologic studies? (Program Standard VII.c.)

Yes
No

40b. 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	
Linkage with a statewide cancer screening program	
Health event investigation(s)	
Needs assessment/program planning	
Program evaluation	
Epidemiologic studies	
Other, describe:	

41a. Have any of the above uses of data been included in a journal publication?



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- 41b. If "yes," please list the citation(s) in the space provided:
- 42. 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
- 43. Does your CCR use *United States Cancer Statistics* (USCS) data when performing comparative analyses?

Requests for proposals, bid solicitations

Yes			
No, explain: _	 	 	

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

COLLABORATIVE RELATIONSHIPS

44. 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 IX.a.,b.*)



Please check all of the ways you collaborate:

Member of our state/territory's comprehensive cancer control (CCC)

	planning group (coalition, committee, or workgroup)
	Provide data for CCC planning
ſ	Provide data for CCC Activities
	Provide technical assistance and collaborate on data analyses for
	CCC program publications
Γ	Data linkages
ſ	Other, specify
Γ	None, Explain

45. Has your CCR established and regularly convened an advisory committee to assist in building consensus, cooperation, and planning for the registry? (Representation should include key organizations and individuals both within and outside the program. Advisory committees may be structured to meet the needs of the state/territory such as the CCC Program committee structure, an advocacy group, or a focus group). (*Program Standard IX.c.*)



The Advisory Committee includes representation from (check all that apply):

Representatives from all cancer prevention and control components Vital Statistics

Bospital cancer registrars

American Cancer Society

- Clinical-laboratory personnel
- Pathologists
- Clinicians
- Researchers
- Other, specify _
- 46. If you have an Advisory Committee, how often does this group convene, including in-person and teleconferences? *Please check only one:*

Quarterly	
Annually	
Biannually	
Other, specify	

47. In what ways does your CCR collaborate with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the National Comprehensive Cancer Control Program (NCCCP)?

Please check all that apply:

Regular meetings with NBCCEDP and/or NCCCP departmental staff

Provides assistance in staging NBCCEDP cases

Provides training/technical assistance to NBCCEDP and/or NCCCP staff

Provides data to NBCCEDP and/or NCCCP

Provides technical material for publications

Provides subject matter expertise to NBCCEDP and/or NCCCP

Data linkages	(NBCCEDP	database,	Minimum	Data	Elements	(MDE)	Study
Other, specify							

None of the above, explain _____

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

ADVANCED ACTIVITIES

As the capacity of central cancer registries to collect and maintain populationbased 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."

48. Please complete the table below regarding CCR receipt of electronic records from the reporting sources listed. Check "Yes" next to the facility type and then enter the format, as text, in which the electronic records are received. Please check "Yes" and enter the format or "No" for each facility type. No line should be left blank.

Facility Type	YES	Specify Type of Electronic Format	NO
Hospital Radiation Therapy Dept.			
Physician Offices			
State-wide Disease Index			
Freestanding Radiation Centers			
Hospital Disease Indices			
Nuclear Medicine Facilities			
Other, specify			

49. If your CCR receives electronic pathology reports, in which format are these received? (**Please check all that apply**)

NAACCR, HL7 Format (Volume V)
NAACCR, Pipe Delimited Format (Volume V)
NAACCR, HL7 Format (NAACCR Volume II, Version 10, Chapter VI)
NAACCR, Pipe Delimited Format (NAACCR Volume II, Version 10,
Chapter VI)
Other, specify:

Not applicable

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

Manual review
Search routine based on NAACCR search term list
Other, specify

- 51. For which of the following cancer surveillance needs has your CCR been in contact with your Health Department's PHIN / NEDSS staff? Please check all that apply.
 - Pathology laboratory reporting
 - Physician disease reporting
 - Other healthcare data reporting
 - None of the above
- 52. Has your CCR planned or developed a cancer data collection system that will be integrated into a Public Health Information Network (PHIN) compatible health surveillance system?

Yes
No

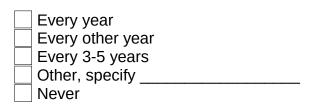
53. Does your CCR conduct at least one of the following advanced activities: *Check all that apply:*

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

Other innovative uses of registry data, describe____

None of the above

54. How often does your CCR link to the National Death Index (NDI)? *Please check only one.*



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

Casefinding
Survivorship
Data quality
Research
Other, please specify:
Not applicable

56. Does your CCR update your database following NDI linkage?

Yes
No
Not applicable

57. With which *databases* has your CCR linked its records in the past year (2006) 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)
Medicaid
Managed Care Organizations
Breast and Cervical Cancer
Blue Cross/Blue Shield
Hospital Discharge
Other, specify:
None

58a. As noted in an August 13, 2004 e-mail, CDC-NPCR has negotiated an agreement with SNOMED International for several tools for use by NPCR registries. Has your CCR downloaded any of these tools (the SNOMED CT CLUE Browser, the SNOMED CT Technical Reference Guide, the ICD-O topography to SNOMED CT Map, the SNOMED CT User's Guide, and the full set of the 42 SNOMED CT encoded CAP cancer protocols and checklists)?

Yes
No

58b. Does your CCR use any of these SNOMED tools?

Yes
No

58c. If "No," does your CCR have plans to use them in the next year?

Yes
No

58d. Does your CCR need additional information or training on these tools?



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

SUCCESS STORIES

59. Please provide a summary, as a separate document, of innovative activities in which your CCR has been engaged within the past year. This can include ways in which cancer registry data has been used, journal citations, as well as other activities that may be of interest to other central registries and to NPCR (e.g., advances in any area of electronic reporting, GIS activities, death clearance activities, automated database activities that have improved data processing efficiencies, any other activities that

have improved data quality, completeness, or timeliness advances in data security, or implementation of cancer inquiry response system, or success in job re-classifications) in the format suggested below:

Suggested format:

The registry highlights should fit on one page, in 12-point font and single-spaced. Information needs to be in simple language and should avoid public health jargon and scientific language.

Suggested components:

1. The name of the NPCR registry program.

- 2. Contact name, phone number, and e-mail address for further information
- 3. Title of the initiative, project, or type of data use

4. General timeframe (year(s) or month(s) during which the initiative/project/data use occurred)

5. A statement of the cancer surveillance issue, concern, or problem

- 6. Evidence that the activity was effective in addressing the above (#5)
- 7. Implications regarding the success of this activity or increased data use.

Please contact your NPCR Program Consultant if you need more detailed information about the submission of your cancer registry "success story".

Success Stories Section Comments (You may add comments regarding the "Success Stories" section above)

- 60. 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

Aaree
, igi cc

Disagree

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

	Agr	ee
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Disagree

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

		Agree	Disagree
cance	d. r	For the most part, I consider the time spent completing the instrument to be a worthwhile contribution to NPCR and the surveillance community	
		Agree	Disagree
	e.	Our central registry uses data that	at is collected in this instrument
		Agree	Disagree
ΟΡΤΙΟ	DNAL		
61.	I would	uld like to participate in discussions regarding next year's evaluation instrument.	
		Yes Please enter your name	and phone number here:
		No	
62.	I have	the following suggestions/revision formatting regarding next year's e comment in the space pro	evaluation instrument (please

Thank you for participating in the NPCR Annual Program Evaluation!