FINAL REPORT

Development, Assessment, and Implementation of an Evaluation for CDC's National Program of Cancer Registries (NPCR)

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Executive Summary

TITLE:	Development, Assessment, and Implementation of an Evaluation for CDC's National Program of Cancer Registries (NPCR)
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I. Statement of the Problem

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The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) has been providing funding to state and territorial central cancer registries since 1994 to establish or enhance existing registries to reduce cancer mortality as part of a national disease prevention strategy. During NPCR's first five years, an Evaluation Working Group was convened within the Cancer Surveillance Branch (CSB) in CDC's Division of Cancer Prevention and Control — the agency charged with implementing this national program — to develop an evaluation strategy and tools for the program. As NPCR looks ahead to its second five years of funding, the CSB is reviewing and revising the evaluation tools used to assess progress towards program goals and objectives. The CSB contracted with Battelle Centers for Public Health Research and Evaluation to help with this review.

Congress established the National Program of Cancer Registries in 1992 by enacting the Cancer Registries Amendment Act (Public Law 102-5 15). This legislation and its 1998 reauthorization (1998 code) authorizes the CDC to provide funds to states and territories

- to improve existing cancer registries;
- to plan and implement registries where they do not exist;
- to develop model legislation and regulations for states to enhance the viability of registry operations;

- to set standards for data completeness, timeliness, and quality;
- to provide training for registry personnel; and
- to help establish a computerized reporting and data-processing system.

The CSB was given the responsibility for implementing a program to meet the requirements of this legislation. Significant progress has been made in each of these areas. With fiscal year 1998 appropriations of $24.2 million, CDC will continue to support the development and enhancement of these programs. These resources will better equip states to meet CDC's standards for timeliness, completeness, and quality of cancer registry data. Improvements in these areas, in turn, will advance state cancer registries as critical components of a national cancer prevention and control strategy. These new appropriations will also enable CDC to work with state partners and national organizations toward developing an aggregated and centralized database of cancer incidence in the United States. This type of database can provide an opportunity for analyzing the cancer burden in the United States on a regional and national basis. CDC will also begin to explore ways to enhance state capacity to respond to inquiries through development of model cancer inquiry response systems.

II. Evaluative Objectives

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The purpose of this project was to help the Cancer Surveillance Branch (CSB) articulate program goals and objectives for NPCR's second five years and to provide the CSB with the capacity to assess progress toward these new goals and objectives. At this critical juncture in the program's history, it was an ideal time to revisit program goals and to improve the tools for evaluating progress in keeping with these new goals and directions, building upon the strengths of past approaches. Specifically, the purpose of the project was to:

- refine program goals and objectives,
- revise evaluation criteria,
- revise the evaluation instrument, and
- recommend the most effective and efficient method of data collection for program evaluation.

III. Methodology

Goals and Objectives

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The first step towards revising the evaluation approach was to discuss the goals and objectives for the National Program of Cancer Registries (NPCR) during its second five years and to discuss the role of evaluation activities with respect to this future direction. Three central themes emerged from this discussion and served as guiding principles for revising both program goals and objectives and the evaluation tools used to assess progress:

- *Increase the focus onprogram outcomes.* Focus increasingly on outcomes rather than processes, using objective measures where possible.

- *Provide a mechanism for program monitoring.* Enable the program to monitor progress and to identify registries not making sufficient progress that can then be the focus of further diagnostic inquiry.
- *Emphasize the use of registry data.* Increase the emphasis on using cancer registry data to support cancer control objectives through additional monitoring and financial support.

The program goal and purpose statement that had been used in previous program announcements was reviewed in light of these new program priorities and "guiding themes." The most significant change in the proposed new statement is the program's commitment to helping states that excel in meeting program standards to pursue various kinds of advanced activities. The program intends to provide funds to support advanced activities for states whose registries have met minimum standards for completeness, timeliness, quality, and use. These advanced activities are focused on putting registry data to use to support public health objectives.

To support this revised statement of goal and purpose, the program objectives were also revised. The proposed objectives set performance targets for the year 2005 for the program as a whole. New objectives were added relating to use (greater use of data for achievement of cancer control objectives), advanced activities (activities beyond the minimum program standards), and data submission (reporting of data to NPCR to construct an aggregate data set) for the purpose of enhancing program monitoring. Through these additions, the capacity of the program to analyze cancer incidence and mortality in the United States and to contribute to meeting public health objectives for cancer control and prevention will be greatly enhanced.

Measuring Progress

Pp. 13-19

Evaluation questions were proposed to help focus discussion on what topics should be included in the evaluation instrument. Evaluation questions were developed to address two important, complementary purposes:

- assess compliance with program requirements and standards, and
- enhance program insight and program improvement.

This distinction reflects the dual mandate of the CSB in implementing this national program. The first mandate is to implement the program in compliance with its enabling legislation, and to be accountable to the legislature for the expenditure of funds for this purpose. The second mandate is to provide technical assistance to the funded registries to help them achieve and even exceed program goals and objectives. To support the CSB in this latter role, it is imperative to continually seek to understand registry activities beyond those that are required by the program. This is particularly important in areas that are not well understood, and where individual registries may be "pushing the envelope" in developing innovative approaches from which other registries and the program as a whole may benefit.

Based on the discussion of evaluation questions and the revised program goals and objectives, a revised evaluation instrument was developed. To support the use of the evaluation instrument for program monitoring, evaluation criteria were developed for each program objective and the proposed questions in the instrument were "mapped" against these. That is, each question in the instrument was matched to one or more objective and criterion. This was intended to provide a check to make sure that the objectives could be measured with

the instrument and, conversely, that the questions included in the instrument contributed to an understanding of progress towards each of the objectives. The evaluation instrument, as before, is designed for annual administration.

Pp. 19-21 Six states participated in a pilot test of the revised instrument. The states were selected to represent a range of experience and sophistication with respect to registry operations. Participants in the pilot test were asked to complete the instrument and provide comments directly on the instrument and at the end of each section. They were asked to address the following questions in providing their feedback:

- Are the right topics included in the instrument?
- Are these the best questions to address each topic?
- Can the wording or phrasing of the questions or response categories be improved?
- Do you have the information needed to answer these questions?
- Is the level of effort required to answer the questions reasonable?

The feedback received, especially those comments related to the clarity of questions and response categories, was used to revise the instrument.

Implementation

Pp. 22-23 CDC is committed to finding ways to implement the revised evaluation instrument so as to reduce the burden on program and registry staff. Towards this end, Battelle reviewed and assessed five data collection methods in light of program needs and the primary attributes of the revised evaluation instrument: (1) mail survey, (2) telephone survey, (3) electronic-mail survey, (4) free-standing application, and (5) World Wide Web-based system. A full report of these methods and our recommendations is included in Appendix D of this report.

IV. Major Findings and Recommendations

Goals and Objectives

Pp. 10-12 Program goals were established for the next five years and used as the basis for revising program objectives and the evaluation instrument. Program goals and program objectives are provided in Sections 3.2 and 3.3 of this report, respectively. They remain subject to change as the Cancer Surveillance Branch at CDC continues to plan for the next request for proposals from states and territories for new and continued funding.

Evaluation Instrument

Pp. 15-19 The revised evaluation instrument and evaluation criteria reflect the new program goals and objectives. The evaluation instrument, as before, is designed for annual administration. A key feature of the revised instrument is the adoption of a modular format. The first module (Part A) focuses on infrastructure and processes, the second (Part B) focuses on outcome measures, and the final module (Part C) focuses on advanced activities. The modular format serves two purposes. First, it allows for the separate administration of Part B: In a major departure from previous years, CDC, via an independent contractor, will request data submissions from states and independently and uniformly calculate outcome measures across

the state registries related to completeness, timeliness, and quality of the data. Second, the modular format allows CDC to specifically focus attention on advanced activities (Part C). This is a new and appropriate focus for the program as it enters its second five years of funding and it is important that CDC monitor, understand, and support the efforts of states to move beyond minimum program requirements.

App. C The revised instrument, modified to reflect the feedback received during the pilot test, is included in Appendix C of this report.

Implementation

Pp. 22-25 App. D Battelle recommends (and CDC concurs) that CDC develop a **World Wide Web-based survey system.** Our recommendation is based on the many strengths and advantages this option provides over the alternative options. We consider the Web-based option to be the best match between data collection mode and long-term program needs. To summarize, the following characteristics of the Web-based option lie at the heart of our recommendation in its favor:

- Data entry and data transfer are both accomplished automatically as each section of the instrument is completed.
- The system can be accessed with any common Web browser application.
- Changes to the instrument can be made easily from a central site. This advantage is important for providing flexibility in the instrument content over time.
- Respondents can easily review their responses from the previous year (or the previous day).
- Many data editing and quality control functions can be programmed into the system.
- Context-specific on-line help systems can be developed so that respondents can click on a question or response category for clarification or additional information.
- Providing reminders and feedback to respondents is easy and straightforward.

,CDC has adopted this recommendation and is moving forward with its plans to place the instrument on the Web. Funded registries will be asked to voluntarily complete the instrument on an annual basis in lieu of one of the quarterly reports that they currently complete.

1.0 Introduction

The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) has been providing funding to state and territorial central cancer registries since 1994 to establish or enhance existing registries to reduce cancer mortality as part of a national disease prevention strategy. A cancer registry is a fundamental tool for cancer surveillance. Data collected through statewide cancer registries can be used to identify trends over time, to discover cancer patterns among various populations, and to show whether screening and other prevention measures are making a difference. This information is essential to states in directing effective cancer prevention and control efforts.

As NPCR looks ahead to its second five years of funding, the Cancer Surveillance Branch (CSB) in CDC's Division of Cancer Prevention and Control — the agency charged with implementing this national program — is reviewing and revising the evaluation tools used to assess progress towards program goals and objectives. The CSB contracted with Battelle Centers for Public Health Research and Evaluation to help with this review.

This report describes the process that was used to review and revise existing evaluation tools and summarizes the revisions that have been made to date to program goals and objectives, evaluation criteria, and the evaluation instrument. The report also provides recommendations about how to implement the instrument, and discusses the challenges that lie ahead for NPCR as the new tools and recommendations are implemented.

1.1 Background

Congress established the National Program of Cancer Registries in 1992 by enacting the Cancer Registries Amendment Act (Public Law 102-5 15). This legislation and its 1998 reauthorization (1998 code) authorizes the CDC to provide funds to states and territories

- to improve existing cancer registries;
- to plan and implement registries where they do not exist;
- to develop model legislation and regulations for states to enhance the viability of registry operations;

- to set standards for data completeness, timeliness, and quality;
- to provide training for registry personnel; and
- to help establish a computerized reporting and data-processing system.

The CSB was given the responsibility for implementing a program to meet the requirements of this legislation. Significant progress has been made in each of these areas. The number of states with their own legislation authorizing a cancer registry increased from 8 before the NPCR was established to 40 in 1998. Twenty-six states have established all eight of the regulations specified in PL 102-5 15. CDC has set national standards for completeness, timeliness, and quality of state cancer registries, and has collaborated with the North American Association of Central Cancer Registries (NAACCR) to provide technical assistance and support to data quality assurance activities by states. By maintaining ongoing liaisons with federal agencies and private organizations, NPCR staff have helped to encourage reporting of cancer cases to state registries. CDC has provided computer expertise to states in building improved electronic systems to support state cancer registries.

In fiscal year 1997, CDC supported 45 states, three territories, and the District of Columbia: 37 for enhancing established registries and 12 for developing registries where none had been organized previously. With fiscal year 1998 appropriations of $24.2 million, CDC will continue to support the development and enhancement of these programs. These resources will better equip states to meet CDC's standards for timeliness, completeness, and quality of cancer registry data. Improvements in these areas, in turn, will advance state cancer registries as critical components of a national cancer prevention and control strategy. These new appropriations will also enable CDC to work with state partners and national organizations toward developing an aggregated and centralized database of cancer incidence in the United States. This type of database can provide an opportunity for analyzing the cancer burden in the United States on a regional and national basis. CDC will also begin to explore ways to enhance state capacity to respond to inquiries through development of model cancer inquiry response systems.

1.2 Evaluation During NPCR's First Five Years

During NPCR's first five years, an Evaluation Working Group (EWG) was convened within the CSB to develop an evaluation strategy and tools for the program. During this period, evaluation criteria were established to measure progress toward program goals and objectives and a survey instrument was developed and implemented to collect annual data about funded central cancer registries.

Baseline data on program status was collected as of January 1, 1994. Annual progress was first assessed on October 1, 1995 and each year thereafter. The Year 1 evaluation instrument was relatively short, focusing on seven program goals. The goals used to assess progress in this first year were:

Goal 1. 95% of states will have a population-based central registry,

Goal 2. 100% of funded states will have legislation and regulations in place-that meet all 8 criteria specified in the law,

Goal 3. 100% of funded states will collect uniform data elements in a standardized format,

Goal 4. 90% of funded states will comply with standards for completeness of data collection,

Goal 5. 90% of funded states will comply with standards for timeliness of data collection,

Goal 6. 90% of funded states will comply with standards for quality of data collection, and

Goal 7. 90% of funded states will have provided an annual report within 12 months of the end of the diagnosis year.

Over time, the instrument expanded to include additional questions. The evaluation instrument used in Year 3 of the program (implemented September 1997) contained 67 questions organized by program objective.

The instructions to the instrument were that the CDC project officer for each funded state should complete the instrument using "published information, state applications, quarterly reports, and discussion with state staff." Each project officer would complete the instrument and

send it to the state to verify and correct. The information was recorded in paper and pencil format and data entry was done by the EWG. Data collected via this instrument were used to prepare presentations on progress toward meeting program objectives.

Annual data collection served the purpose of documenting progress in meeting some of the program goals and objectives. By collecting information at baseline and at one-year intervals, the program was able to demonstrate advances in the funded states and territories. A strength of the instrument was that it was clearly focused on the program goals and objectives that were established for the program during its first five years.

However, accurate measurement of many of these objectives has been a continual challenge for NPCR and the EWG. Over time, the wording of questions has been changed to improve the quality of the data collected and new questions have been added to the instrument to more effectively measure program objectives, but accurate measurement has continued to be a major issue.

One source of difficulty has been responsibility for completing the instrument. Although responsibility was assigned to project officers, they lacked the information to answer many of the questions and had to turn to their state contacts for help. The quality of the data was dependent on the conscientious follow through of individual project officers.

Clarity of questions has been another source of difficulty. Some questions were vague and ill-defined, and subject to interpretation. Those with responsibility for analyzing the data have therefore been unsure about how to interpret the responses. A few questions have also suffered from a lack of well-defined response categories, making the information collected hard to use.

'But perhaps most importantly, the instrument was necessarily (and appropriately) focused on the early years of the national program and the goals and objectives established for those first five years. As the program has matured, it has become important to not only improve individual questions to make the information collected more accurate and useful, but also to examine the scope of the instrument and revise it to better reflect the goals and priorities of NPCR during its second five years.

1.3 Project Purpose

The purpose of this project was to help the CSB articulate program goals and objectives for NPCR's second five years and to provide the CSB with the capacity to assess progress toward these objectives. At this critical juncture in the program's history, it was an ideal time to revisit program goals and to improve the tools for evaluating progress in keeping with these new goals and directions, building upon the strengths of past approaches. Specifically, the purpose of the project was to:

- Refine program goals and objectives,
- Revise evaluation criteria,
- Revise the evaluation instrument, and
- Recommend the- most effective and efficient method of data collection for program evaluation.

1.4 Organization of Report

Section 2 describes the methods used to conduct this project. Section 3 presents the program goals and objectives for the second five-year program period. Section 4 discusses the revised tools for evaluating progress toward these objectives. Section 5 recommends the best data collection option for implementing the evaluation. Section 6 concludes with a discussion of next steps, including some thoughts about supplemental tools that could be developed and used to increase the CSB's capacity to understand progress towards program goals and to increase the effectiveness of the technical assistance provided to states and territories.

At the conclusion of the report, more detailed information is provided about the content and results of the pilot test of the instrument (Appendices A and B). Also provided are a copy of the revised instrument (Appendix C) and a more detailed report on data collection options and the basis for our recommendations (Appendix D).

2.0 Methods

The process used to review and revise the instrument was iterative, but generally followed a sequence from discussion of broad program goals and the purpose of the program, to specific evaluation criteria, concluding with the development of a revised evaluation instrument and recommendations for implementation.

2.1 Participants

Reviewing and revising program goals, objectives, and evaluation tools involved the concerted effort of a number of people, both internal and external to the CDC. The primary groups involved in this process are described below.

The Evaluation Working Group (EWG) within CSB was charged with overseeing the development of a revised evaluation instrument. To this end, the members of the EWG developed proposed changes to the program goals, objectives, and evaluation criteria as early as September 1998. This group continued to be involved in reviewing, recommending, and approving changes to the instrument.

Cancer Surveillance Branch (CSB) staff participated in a facilitated discussion regarding proposed changes to the program goals, objectives, and evaluation criteria. This discussion was held in October 1998. Several staff also provided written feedback following the meeting on the proposed changes. CSB managers continued to provide critical review as the revision process continued.

Domain Working Groups' were established within the CSB expressly for the purpose of providing input regarding individual program domains. The volunteer members of each group provided input on program goals and registry performance in their respective domains and discussed ideas about how to monitor progress.

[1] Working groups were established to address the following 8 domains: registry status, legislative authority, content and format, completeness, timeliness, quality, use, and "other." Later, the "other" domain was subdivided into separate new objectives for "advanced activities" and "data submission."

Central Cancer Registries helped to improve the evaluation instrument by participating in a pilot test. Six funded registries completed the instrument and provided written (and oral) feedback on the content and clarity of an earlier draft of the instrument.

Battelle Centers for Public Health Research and Evaluation was charged with bringing its evaluation expertise to this project. Battelle staff worked with the EWG to revise program goals, objectives, and criteria. Battelle also revised the evaluation instrument to improve the measurement of progress towards these goals and recommended a data collection approach to implementing the instrument.

2.2 Data Sources and Collection

Several data sources and data collection activities supported the development process. The key sources and activities are summarized below.

Discussions with CSB staff. The involvement of CSB staff was critical to revising program goals and objectives and developing the tools to measure progress. Program staff were the primary source of expertise on the registry program, and were thus critical to establishing new directions for the program and for generating ideas about measuring progress. The entire Branch participated in these discussions. In particular, the members of the Domain Working Groups, the Evaluation Working Group, and senior managers within the Branch provided invaluable insights, substantive contributions, and important review comments.

Attendance at program meetings. Program meetings were another valuable source of data. The first annual NPCR Program Directors' Meeting was held in Atlanta on December 2-4, 1998 and an Ad Hoc Advisory Working Group met in Atlanta on December 7, 1998. Both of these meetings provided an opportunity for Battelle to hear first hand some of the ideas and concerns of state cancer registrars and registry experts regarding the future direction of NPCR. These meetings also provided an opportunity to hear informed discussion about program standards and evaluation criteria, both those currently in use and those that have been proposed.

Review of previous evaluation data collected. A third activity undertaken was a review of the data collected during the previous year's evaluation. This provided important information about the quality of the responses and the appropriateness of response categories. It also allowed

for the development of closed-ended response categories for some questions that had previously been open-ended.

Pilot test of revised instrument. Once a revised instrument was prepared, a pilot test provided important feedback on the clarity and content of the instrument. The instrument was revised in response to the feedback received from participating states.

Published documents and product information. Published documents and product information were the primary data sources used to develop recommendations for implementing the revised evaluation instrument.

3.0 Goals and Objectives for the Second Five Years

A critical first step towards revising the evaluation approach was to discuss the goals and objectives proposed by the EWG for NPCR during its second five years and to discuss the role of evaluation activities with respect to this future direction. Once an understanding of these broad directions and approaches had been reached, it would then be possible to address evaluation criteria and the best approach to measurement and instrumentation.

3.1 Guiding Themes

In October 1998, Battelle facilitated a discussion with CSB staff regarding the future direction of NPCR and the role of evaluation with respect to this direction. Three central themes emerged from this discussion and have served as guiding principles for revising both program goals and objectives and the evaluation tools used to assess progress:

- **Theme 1: Increase the focus on program outcomes.** The program would like to see an increased focus on program outcomes, with a concurrent decrease in program processes. A corollary to this is that the program would like to move toward objective measures of these outcomes and to reduce the historical reliance on self-reported measures of performance.

- **Theme 2: Provide a mechanism for program monitoring.** The evaluation instrument should serve as a mechanism for *monitoring* registries to identify those that are failing to make expected progress toward desired outcomes. Towards this end, the instrument should enable the program to obtain an annual snapshot of progress toward program objectives, and to differentiate between registries making sufficient progress and those that are not. Registries failing to make satisfactory progress should then be the focus of further *diagnostic* inquiry, to identify the reasons behind the observed difficulties.

- **Theme 3: Emphasize the use of registry data.** As more central cancer registries reach minimum levels of performance, the program would like to see an increased emphasis on the use of cancer registry data to support cancer control objectives. The program is planning to set aside funds, available on a competitive basis, to support these advanced cancer control activities. The evaluation instrument (as well as program objectives) must therefore increase its emphasis on data use.

3.2 Program Goal and Purpose

The program goal and purpose statement that had been used in previous program announcements was reviewed in light of these new program priorities and "guiding themes." It has been modified as presented below but it remains subject to change as the CSB continues to plan for the next request for proposals from states and territories for new and continued funding.

The national goals of this program are to rapidly establish and standardize the reporting of cancer among the States in order to:

(1) monitor the cancer burden in the nation;

(2) evaluate progress toward achieving cancer-control objectives;

(3) provide data to identify cancer incidence variation for ethnic groups and for regions within a State, between States, and between regions;

(4) provide guidance for health resource allocation;

(5) provide data to evaluate State cancer-control activities;

(6) provide information to improve planning for future health care needs;

(7) provide data for research; and

(8) better respond to public concern and inquiries about cancer in communities.

The purpose of funds awarded for the program's second five year funding period is to maintain and expand the national program of cancer registries by supporting States in their efforts to:

(1) Plan and implement statewide, population-based cancer registries to meet minimum standards for data completeness, timeliness, quality, and data use, where a statewide registry does not currently exist. (Part II Planning/Implementation);

(2) Enhance statewide, population-based cancer registries to meet minimum standards for data completeness, timeliness, quality, and data use. (Part I Enhancement);

(3) Conduct advanced activities as part of a comprehensive cancer prevention and control program, including but not limited to: quality of care studies, clinical studies, detailed survival analyses, implementation of a cancer inquiry response system, and etiologic and applied research, where the cancer registry demonstrates an ongoing capacity to excel in meeting minimum standards.

The most significant change in this proposed statement from the statement that guided the program's first five years is the program's commitment to helping states that excel in meeting

program standards to pursue various kinds of advanced activities. As stated, the program intends to provide funds to support advanced activities for states whose registries have met minimum standards for completeness, timeliness, quality, and use. These advanced activities are focused on putting registry data to use to support public health objectives.

3.3 Program Objectives

To support this revised statement of goal and purpose, the program objectives have also been revised. All of the proposed objectives shown in Table 1 set performance targets for the year 2005 for the program as a whole. The proposed objectives differ from those for the first five years in several significant ways. In part, the difference reflects the higher percentage of state registries that can be expected to meet performance objectives by 2005 as compared to program expectations for the year 1999. But the most substantial change is the addition of four new objectives.

New objectives have been added relating to registry status, use, advanced activities, and data submission. These additions add the following concepts:

- Data Use. Two new objectives focus on using data for cancer control objectives and making data available to outside researchers in the form of an analytic data set.

- Advanced Activities. One objective emphasizes that registries should seek to move beyond minimum standards by undertaking "advanced" activities designed to improve the completeness, timeliness, quality and use of registry data.

- Data Submission. A final new objective focuses on plans to request that funded states report data to NPCR on an annual basis. This would enable the program to construct an aggregate data set to examine regional and national trends in cancer incidence and mortality and to improve the assessment of program outcomes.

Table 1. Propose

Domain	B
Registry status	progra
Legislative authority	By th autho criteri
Content and format	By the derive standa

4.0 Evaluating Progress During NPCR's Second Five Years

Once agreement had been reached about program goals and objectives, attention turned to measurement of progress towards these objectives. First, evaluation questions were developed to focus discussion on the scope and content of the instrument. Then evaluation criteria and a revised instrument were prepared to monitor progress. The revised instrument provided in Appendix C incorporates the results of a pilot test conducted with six funded states.

4.1 Evaluation Questions

Evaluation questions were proposed to help focus discussion on what topics should be included in the evaluation instrument. Two sets of evaluation questions were developed to reflect two important, complementary purposes:

- *assess compliance* with program requirements and standards, and
- *enhance program insight* and program improvement.

This distinction reflects the dual mandate of the CSB in implementing this national program. The first mandate is to implement the program in compliance with its enabling legislation, and to be accountable to the legislature for the expenditure of funds for this purpose. The second mandate is to provide technical assistance to the funded registries to-help them achieve and even exceed program goals and objectives. To support the CSB in this latter role, it is imperative to continually seek to understand registry activities beyond those that are required by the program. This is particularly important in areas that are not well understood, and where individual registries may be "pushing the envelope" in developing innovative approaches from which other registries and the program as a whole may benefit. The evaluation questions presented to the EWG and the domain working groups are listed in Table 2.

Table 2: Proposed Evaluation Questions

Domain	Compliance	Program Insight
Registry Status	Does the State have core staff for the central registry? How is that staff configured? Does the CCR have written central cancer registry operational policies and procedures? For which years does the CCR have data that meet minimum standards for completeness, timeliness, and quality? What type of funding does the registry receive?	For what purpose(s) have supplemental funds been used?
Legal Authority	Does the State have a law authorizing formation of a statewide registry? Does the State have legislation or regulations in support of all 8 criteria specified in PL 102-5 15?	What type of facilities and health care providers are reporting to the central cancer registry?
Zontent and Format	Are all required minimum data elements collected? Are the recommended data elements collected? Can registry data be mapped to the national standard?	What other data items-does the CCR routinely collect? Does the CCR link its records with other databases to improve case follow up?
Completeness and Timeliness	What percentage of expected cases were registered at 12 months after the close of the diagnosis year? What method was used to assess completeness? What percentage of expected cases were registered at 24 months after the close of the diagnosis year? What percentage of cases were reported by a death certificate only at 24 months after the close of the diagnosis year? How many duplicate cases per 1,000 cases were there at 24 months after the close of the diagnosis year?	How does case sharing affect the completeness of the data? What activities does the CCR engage in to facilitate reporting? What infrastructure does the CCR have to support timely reporting? How confident is the CCR hat the registered cases are valid cases?
Quality	What were the results of standard quality checks at 12 months? What were the results of standard quality checks at 24 months? How complete are 1996 records for sentinel variables?	Nhat methods are used by he CCR for quality control? Nhat infrastructure is available to support quality control? Iave independent quality hecks been performed? Yhat were the results of adependent quality checks?
Use	Has an annual report been produced within 12 months of the end of the diagnosis year?	Iave cancer registry data een linked with data in

	How are registry data being used? In what ways, in addition to the annual report, have the registry data been published? Is an analytic data set available for research?	other systems? What infrastructure is there to support the use of registry data? How has the CCR responded to requests for data and information?
Other	Did the State provide an analytic data set to NPCR 24 months following the end of the diagnosis year?	

In developing the evaluation questions, but particularly in operationalizing those questions for the evaluation instrument, the three guiding themes — increase the focus on program outcomes, provide mechanism for program monitoring, emphasize use of registry data — were taken into consideration. Proposed questions focused as much as possible on program outcomes, monitoring of performance, and using registry data to meet cancer control- objectives. Process questions were included if they served to interpret outcome data or in areas where outcome measures were difficult to establish.

4.2 Criteria and Instrumentation

Initial drafts of the revised evaluation instrument itself relied on the guiding themes, discussion of the evaluation questions, and a review of the quality of responses to the existing evaluation instrument. A key feature of the revised instrument was the adoption 'Of a modular format. The first module (Part A) focused on infrastructure and processes, the second (Part B) focused on outcome measures, and the final module (Part C) focused on advanced activities.

The modular format serves two purposes. First, it allows for the separate administration of Part B in the near future when data are submitted to CDC by the state registry programs. This development, which marks a major departure from previous years, will allow CDC, via an independent contractor, to request data submissions from states and independently and uniformly calculate outcome measures across the state registries related to completeness, timeliness, and quality of the data. Second, the modular format allows CDC to specifically focus attention on advanced activities (Part C). This is a new and appropriate focus for the program as it enters its second five years of funding and it is important that CDC monitor, understand, and support the

efforts of states to move beyond minimum program requirements. This module represents one tool to support that effort.

Concurrent with the development of the instrument, considerable discussion was devoted to the evaluation criteria that should be used to measure progress. Criteria provide a standard of comparison, whether that standard reflects minimum performance expectations or some loftier performance goal. Furthermore, to effectively use an evaluation instrument to evaluate performance, it is necessary to identify which questions in the instrument are needed to assess performance relative to each objective and criterion. Therefore, criteria were developed for each program objective and the proposed questions in the instrument were "mapped" against these. That is, each question in the instrument was matched to one or more objective and criterion (Table 3). This was intended to provide a check to make sure that the objectives could be measured with the instrument and, conversely, that the questions included in the instrument contributed to an understanding of progress towards each of the objectives.

In Table 3, the criteria that have been developed for each program objective are specified. Where both outcome and process criteria have been specified, these are listed. Also specified in Table 3 are the specific questions from the revised instrument that address each objective, organized by instrument module. For example, if two questions from Part A and two questions from Part C directly address the objective, these are listed. In addition, supporting questions are listed. These are questions that provide information about infrastructure and processes that are believed to be directly relevant to meeting that objective.

Table 3. Criteria and Instrumentation

I. REGISTRY STATUS: By the year 2005, 75 percent of funded States will meet all program criteria. *A. Outcome Criterion:* The State meets program criteria for legislative authority, content and format, completeness, timeliness, quality, and use. *B. Instrumentation:* Achievement of this objective is determined analytically by combining answers to questions addressing program objectives for legislative authority, content and format, completeness, timeliness, quality, and use.
II. LEGISLATIVE AUTHORITY: By the year 2005, 100 percent of funded States will have authorizing legislation and all 8 reporting regulations that meet criteria specified in Public Law 102-515 (PL 102-515). *A. Outcome Criteria:*

1. The State has a law authorizing a statewide cancer registry.
2. The State has legislation or regulations in support of all 8 criteria specified in PL 102-5 15.
3. The State provides documentation to CDC from the highest ranking State legal officer certifying the extent to which the State has laws and regulations in compliance with PL 102-5 15.

B. Instrumentation:

Part A: Questions 4-6.

III. CONTENT AND FORMAT: By the year 2005, 95 percent of funded States will collect or derive, for reportable cancer cases, uniform data elements in a standardized format as prescribed by NPCR pursuant to PL 102-515.

A. Outcome Criteria:

1. The information collected or derived on cancer cases includes all data elements required by the NPCR.
2. The data codes for all required and recommended data elements are consistent with those prescribed by NPCR.
3. The State central registry uses a standardized, NPCR-recommended data exchange record layout for the exchange of data.

B. Instrumentation:

Part A: Questions 17-2 1.
Part B: Questions l-3.

IV. COMPLETENESS: By the year 2005, 95 percent of funded States will comply with NPCR standards for completeness of data collection.

A. Outcome Criteria:

1. Within 12 months of the close of the diagnosis year, 90% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.
2. Within 24 months of the close of the diagnosis year, 95% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.
3. Within 24 months of the close of the diagnosis year, the State has performed death clearance and 3% or fewer of cases in the database are reported by death certificate only at the central cancer registry.
4. Within 24 months of the close of the diagnosis year, 1 or fewer duplicate cases per-l ,000 are present in the database at the central cancer registry.

B. Process Criteria.

1. The CCR conducts case sharing with all bordering states.
2. The CCR receives case reports from all facilities providing cancer screening, diagnosis, and therapeutic services.
3. The CCR performs case finding audits.
4. The CCR performs death clearance and followback.

C. Instrumentation:

Part A: Questions 8-9, 15-16, 24-26.
Part B: Questions 4-5, 6-8.
Supporting questions: Al-3,7, 10-l 1, 38

V. TIMELINESS: By the year 2005, 95 percent of funded States will comply with NPCR standards for timeliness of data collection.

A. Outcome Criteria:

1. Within 12 months of the close of the diagnosis year, 90% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.
2. Within 24 months of the close of the diagnosis year, 95% of expected, unduplicated cases are available to be counted as incident cases at the central cancer registry.

3. Within 24 months of the close of the diagnosis year, the State has performed death clearance and 3% or fewer of cases in the database are reported by death certificate only at the central cancer registry.
4. Within 24 months of the close of the diagnosis year, 1 or fewer duplicate cases per 1,000 are present in the database at the central cancer registry.

B. Instrumentation:

Part B: Questions 4-5, 6-8.

Supporting questions: A1-3, 7, 39

VI. QUALITY: By the year 2005, 95 percent of funded States will comply with NPCR standards for data quality.

A. Outcome Criteria:

1. Within 12 months of the close of the diagnosis year, 97% of cases pass a prescribed set of standard data edits according to NPCR established overrides.
2. Within 24 months of the close of the diagnosis year, 99% of cases pass a prescribed set of standard data edits according to NPCR established overrides.

B. Process Criteria:

1. The CCR performs reabstracting audits.
2. The CCR collects text information that supports coded data from reporting sources,.
3. The CCR maintains allinformation, including supporting text, from source records.
4. The CCR employs at least 1 CTR (defined as 1 FTE).
5. The CCR has written quality assurance policies and procedures.

C. Instrumentation:

Part A: Questions 2, 7, 22-23, 27-30.

Supporting questions: Al, 3, 10-14, 40; B12-14.

[Note: Questions aimed at addressing the outcome criteria are not presently included in the instrument. This is an area requiring further development.]

VII. USE: By the year 2005, 95 percent of funded States will produce an annual report of cancer incidence that meets the standards established by NPCR pursuant to PL 102-5 15.

A. Outcome Criterion:

Within 12 months of the end of the diagnosis year (and with data at least 90% complete), the State produces an annual report (hardcopy or electronic). The annual report includes, at minimum, age-adjusted incidence rates and age-adjusted mortality rates for the diagnosis year by sex for selected cancer sites and, where appropriate, by sex and race and ethnicity for selected cancer sites.

B. Instrumentation:

Part A: Questions 3 l-33.

Supporting questions: Al-3, 7, 41.

VIII. USE: By the year 2005, 90 percent of funded States will use central cancer registry data for planning and evaluating achievement of cancer control objectives.

A. Outcome Criterion:

The State used registry data for planning and evaluation of cancer control objectives in at least one of the following ways in the past year: incidence/mortality estimates; linkage with a statewide cancer screening program to improve follow-up of screened patients; health event investigations; response to inquiries/data requests; needs assessment/program planning; program evaluation; clinical studies; quality of care studies; epidemiologic studies.

B. Instrumentation:

Part A: Questions 34-3 5.

Supporting questions: A1-3, 7, 4 1

IX. USE: By the year 2005, 90 percent of funded States will make an analytic data set available for research.

A. Outcome Criterion:
Within 24 months after the completion of the diagnosis year, an analytic data set that meets NPCR standards for completeness and quality is available for research purposes.

B. Instrumentation:
Part A: Questions 36-37.
Supporting questions: A1-3, 7, 41

X. ADVANCED ACTIVITIES: By the year 2005, 50 percent of funded States will engage in at least one advanced activity.

A. Outcome Criterion:
The State conducted at least one of the following advanced activities in the past year: receipt of encrypted case reports via the Internet or other source; automated case finding via linkage with pathology reports, disease indices, or other data sources in addition to vital records; survival analysis; linkage with the National Death Index for survival analysis; quality of care studies; clinical studies; publication of research studies using registry data; other innovative uses of registry data.

B. Instrumentation:
Part A: Questions 34.
Part C: Questions 1-1 1.
Supporting questions: A 1-3, 7, 4 1.

XI. DATA SUBMISSION: By the year 2005, 90 percent of funded States will report data to CDC for program monitoring and to meet national cancer surveillance objectives.

A. Outcome Criterion:
Within 12 months after the completion of the diagnosis year, the State submits an analytic data file to CDC with individual records containing all requested data elements.

B. Instrumentation:
Achievement of this objective is determined by CDC Program Data.

4.3 Pilot Testing the Instrument

After several iterations between Battelle and CDC, the instrument was ready for pilot testing. Six states were asked to participate in the pilot test. The states were selected to represent-a range of experience and sophistication with respect to registry operations. Two of the states received funding from NPCR to plan a registry (none had previously existed) in 1994 and had recently begun to collect data; the other four received funding to enhance existing registry operations and had been collecting data for several years. Of these four, two were considered by NPCR to be "advanced" in that they were top performing registries that were engaged in advanced cancer control activities designed to increase the completeness, timeliness, quality, and use of registry data beyond the minimum program standards.

Participants in the pilot test were asked to complete the instrument and provide comments directly on the instrument and at the end of each section. They were asked to address the following questions in providing their feedback:

- Are the right topics included in the instrument?
- Are these the best questions to address each topic?
- Can the wording or phrasing of the questions or response categories be improved?
- Do you have the information needed to answer these questions?
- Is the level of effort required to answer the questions reasonable?

The pilot instrument was sent via Fed Ex to each participant in hardcopy format with a cover letter and a return Fed Ex envelope. Copies of the cover letter, pilot evaluation instrument, and feedback questions sent to participants are included in Appendix A.

Participants were informed in the cover letter that NPCR is committed to exploring electronic methods for implementing the instrument. Therefore, they were asked to focus their feedback on the content and clarity of the questions, and not on the pencil and paper format. CDC fully expects that the burden of providing this information on an annual basis will be substantially reduced with electronic implementation (states will then be able to update previous responses rather than having to resupply information provided the previous year). Nevertheless, participants were also asked to provide comments on the degree of difficulty and to estimate the level of burden to complete the pilot test?

A detailed report on the results of the pilot test is included in Appendix B. The feedback received, especially those comments related to the clarity of questions and response categories, was used to revise the instrument. The revised instrument is presented in Appendix C.

To summarize briefly, a few new topic areas were suggested for inclusion in the instrument, most notably the topic of training. The current version of the instrument still excludes this topic, but future versions may be modified to include questions such as the following: Are CCR staff being trained? Are CCR staff conducting ongoing training for reporting facilities? Are the training activities adequate to meet existing needs?

Overall, the dominant suggestions for improving the instrument were to

- shorten the instrument by eliminating any questions that NPCR does not really need to know or does not have plans to use, and
- increase the level of coordination with other ongoing data collection activities (NAACCR, progress reports) to reduce the level of burden.

[2] The exception to our request was that respondents need not estimate the burden in Part B. These items will be answered by CDC or a third-party contractor when the registries provide CDC with data.

The instrument was not shortened in response to these comments because all data will be used to monitor progress and improve the national program. However, increasing the level of coordination received a great deal of discussion. In particular, current plans are to integrate this data collection activity with the quarterly progress reports, thereby reducing to a large degree the extra burden placed on both state and territorial registries and on CDC program officers.

Other suggestions included providing an instruction supplement to ensure that questions are interpreted and answered as similarly as possible, and providing more space for writing in comments. Participants agreed that data collection will be easier when the instrument is electronically implemented. An instruction supplement has not yet been prepared, but program staff agree that electronic implementation will lend itself well to embedded instructions and are giving consideration to its development.

Most of the written feedback received related to the clarity of the questions and the response categories. Most of the questions and responses were clear and easy for participants to understand with a few notable exceptions. In Part A, questions related to staffing were subsequently modified to clarify which staff should be counted. Changes were also made to the question on case sharing, a question about computerized edits, the questions on reporting sources, and questions regarding the availability of analytic files for research purposes. Response categories to the self-assessment questions were also modified.

Part B was the most difficult and confusing portion of the instrument for participants to complete. A major reason for the difficulty is that many of the questions ask for-outcomes computed at specific points in time. Registries typically do not "freeze" their databases in time. As new data are received databases are continually updated. Thus registry staff are not able (or find it difficult) to recreate numbers or percentages at a specific date in the past. This was very important feedback to receive because it emphasizes the importance of timing. CDC plans to request data annually from the states and to use these data submissions to complete questions in Part B. The results of the pilot test make it clear that the data submissions must be timed to match the wording of the questions in Part B (outcomes requested as of January 1st) or it will not be feasible to answer many of the questions. The pilot test also made it clear that Part B questions will have limited utility in the absence of data submissions. That is, the module is clearly designed to be compatible with a data submission and is not well suited to retrospective self reporting.

Part C was generally found to be easy to complete. Modest changes were made to this module in response to feedback in order to clarify the intent of several questions and to provide more satisfactory response categories to several other questions.

5.0 Implementation of the Instrument

CDC is committed to finding ways to implement the revised evaluation instrument so as to reduce the burden on program and registry staff. One way to reduce the burden is to substitute the instrument, or portions of the instrument, for the quarterly progress reports that programs are currently required to submit. Another way to reduce the burden is by adopting new implementation strategies, particularly electronic implementation modes. To help CSB determine the most effective implementation approach, Battelle was asked to identify implementation options and recommend the best approach. A detailed report is included in Appendix D. A brief summary of the options addressed and the recommendations is provided here.

5.1 Data Collection Options

Every data collection method has its advantages and disadvantages. The best method of data collection for any given program evaluation depends upon the program being evaluated and the attributes of the evaluation tools designed to evaluate that program. Selecting the best method involves assessing the strengths and weaknesses of the method against the particular needs of the evaluation to find the best match between data collection method and the attributes of the evaluation tool.

Five data collection methods were reviewed:

- Mail survey
- Telephone survey
- Electronic-mail survey
- Free-standing application
- World Wide Web-based system

Each of these five options was assessed in light of program needs and the primary attributes of the revised evaluation instrument. These primary attributes are summarized as follows:

- *Basic administration requirements.* The evaluation instrument will be implemented annually in all states and territories receiving funding under NPCR, which means that the respondents are highly motivated and can be expected to cooperate. All funded programs (49 registries were funded in fiscal year 1997) will be required to complete the instrument (a 100% response rate is required).

- *Modular structure.* The instrument is comprised of three modules. The questions in the first module (Part A) will remain fixed over time. Answers to these questions, which relate to infrastructure to support registry activities, may change little from year to year for some states. Therefore, respondents need to be able to see and modify their previous year's answers. Part B will be completed by all funded registries only until CDC has a system in place to receive data sets from the states. The questions in the third module (Part C) may vary in content from year to year. This module is designed as a way for NPCR staff to gain understanding about the activities that funded registries are engaged in that are not required by the program but that enhance the ability of the states to effectively engage in cancer-prevention and control activities.

- *Complexity of instrument design.* The questions are primarily closed-ended and responses can be easily precoded. There is no complicated skip logic.

- *Complexity of instrument content.* Many of the questions are complex and are potentially subject to variations in interpretation. Respondents will need access to instructions and definitions. This includes clarification of questions, instructions for how to perform calculations, and detailed descriptions of response categories. Respondents will also need to locate and collect information and perform calculations to be able to complete the instrument.

- *Centralized data processing and analysis.* CDC will need to compile all responses from all central cancer registries into a single database for analysis. To monitor responses and respond to inquiries, CDC will want to have ready access to evaluation data. Trends over time will be of interest, so the database should be cumulative. In addition to responses to the evaluation instrument, CDC will also request **registry data set submissions** from each respondent. Datasets received from states will be managed by a third-party contractor and used to answer questions in one of the modules (Part B). This information will need to be integrated with the responses received from states to questions in Parts A and C.

5.2 Implementation Recommendations

Each of the five data collection options reviewed has its own set of requirements and its strengths and weaknesses in light of the features of the revised instrument. All are viable options

but some are more ideally suited than others to the needs of NPCR. Based on our review of these options, Battelle recommended that CDC seriously consider developing a **World Wide Web-based survey system.** Our recommendation is based on the many strengths and advantages this option provides over alternative options. We consider the Web-based option to be the best match between data collection mode and long-term program needs.

The self-administered, paper-based questionnaire and the telephone interview are the least suited to this evaluation. Although both have the advantage of low front-end costs to develop the instrument (this advantage would disappear with the telephone option if CAT1 technology were used), the back-end functions and costs — data entry and quality control — would be assumed by CDC. Nor do these options lend themselves well to the automated help and support functions that can be integrated into the other systems. Furthermore, the telephone option is poorly suited to an instrument that requires respondents to gather information or make calculations prior to responding to a question.

While the e-mail questionnaire may offer better help and support functions, depending on the software selected, the state-of-the-art technology limits the format in which responses can be received and aggregating the responses into a database suitable for analysis is not a trivial task.

The free-standing application option, modeled on the NBCCEDP's STAR system, has considerable advantages over the other three systems previously discussed: quality control functions (editing/error trapping) and technical support (help screens) can be integrated into a free-standing system; respondents can access previous answers for easy updating; and no separate data entry is required at the receiving end. The major disadvantages of the system are technical difficulties associated with installation and maintenance of the free-standing system in multiple sites, and the costs and difficulties associated with implementing future modifications to the instrument.

The World Wide Web-based option, in contrast, provides many of the same advantages of the free-standing option without its limitations. That is, the Web-based evaluation instrument can be accessed via any common Web browser application, and changes to the instrument can be easily implemented from a centralized location. Access to the various modules of an instrument can also be controlled centrally if not all respondents need access to all modules.

Web-based applications have gained popularity in recent years and are fast becoming an industry standard. All of the major software companies have developed packages to help individuals design and implement Web-based applications, including Microsoft (with InterDev), Oracle (with Enterprise Developer Suite), Inprise (formerly Borland, with IntraBuilder), and Sun (with NetDynamics), among others.[3]

To summarize, the following characteristics of the Web-based option lie at the heart of our recommendation in its favor:

- Data entry and data transfer are both accomplished automatically as each section of the instrument is completed.
- The system can be accessed with any common Web browser application.
- Changes to the instrument can be made easily from a central location. This advantage is important for providing flexibility in the instrument content over time.
- Respondents can easily review their responses from the previous year (or the previous day).
- Many data editing and quality control functions can be programmed into the system.
- Context-specific on-line help systems can be developed so that respondents can click on a question or response category for clarification or additional information.
- Providing reminders and feedback to respondents is easy and straightforward.

We believe that a Web-based questionnaire is the best match between data collection mode and long-term program needs. The disadvantages and security concerns associated with this option are outweighed by the considerable advantages it has over other options. The primary disadvantage of a Web-based system is that it requires access to the Internet and to a Web browser. While this is not expected to be a problem at University-based registries nor at many health department-based registries, it may be a serious limitation for a few states and territories. We believe, however, that this disadvantage will rapidly disappear for most registries in the next few years and that a Web approach will prepare NPCR well for the future. We furthermore believe that the current state-of-the-technology is sufficiently advanced to adequately protect the security of the data. In short, we recommend this option as the most effective and efficient method of data collection for NPCR's annual evaluation instrument.

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[3] Web sites for the companies and their products:
Oracle Developer, http://www.oracle.com/tools/wds/award.html
MS InterDev, http://msdn.microsoft.com/vinterdev/News/default.asp
Borland IntraBuilder, http://www.borland.com/jbuilder
Sun NetDynamics, http://netdynamics.com

6.0 Next Steps

The revised tools developed in this project and presented in this report provide a good foundation for NPCR as it enters its second five years of program funding. Some work remains to be done, however, to see these efforts brought to fruition. In particular, the CSB is currently working to put in place the infrastructure to support data submissions by the funded registries. The centralized database of cancer incidence that this will create will be a powerful tool for analyzing the cancer burden in the United States on a regional and national basis. It will also allow the CSB to implement Part B of the revised evaluation instrument as it has been designed.

Development of an electronic method of data collection is another important next step. Recommendations for this are included in this report. As the CSB moves forward with these recommendations, it will be an ideal time to develop some built-in instruction supplements to enhance consistent and thorough completion of the evaluation instrument by funded states and territories.

Another important development will be explicit instructions for using the instrument to evaluate progress. The foundation for this has been laid in the "mapping" of questions against evaluation criteria and program objectives (see Table 3). The next logical step is to explicitly describe how responses to each question will be used to analytically measure and report on progress. Multiple questions correspond to each program objective, thus requiring an analytic approach that uses responses to multiple questions to assess progress towards each objective. Development of an analysis plan could be accomplished internally by the CSB. Alternatively, an analysis plan and progress report could be developed by an outside contractor based on data from the first annual implementation of the revised instrument.

Finally, the evaluation instrument will help NPCR monitor progress and document changes over time in program outcomes, including the completeness, timeliness, quality, and use of registry data. However, other evaluation tools are needed to diagnose the problems -to understand why some states may fail to make sufficient progress or why others have shown exceptional progress. The development of supplemental diagnostic tools was beyond the scope

of this project. Nevertheless, several ideas were generated during project discussions that merit mention here.

Efforts to better understand why states are having problems in particular areas, or how states have successfully overcome problems they have faced could be accomplished in a variety of ways. Some of these could complement other activities already taking place, including ongoing technical assistance activities. Ideas discussed include:

- Site visits
- Audits
- Best practice studies
- Case studies of registries that were expected to perform well but did not (a lot can be learned from the surprises) or of top performers and/or low performers to identify sentinel indicators of performance
- Special surveys (to obtain more in-depth information about an area that many states seem to be struggling with)

The annual evaluation tool revised as part of this project can be used, in part, to identify opportunities for implementing these additional evaluation approaches.

Appendix A Pilot Test Materials

August 19, 1999

Name

Dear Pilot Test Participant:

Thank you for agreeing to participate in the pilot test of this draft revised evaluation instrument for the National Program of Cancer Registries (NPCR). We will use the feedback we receive from you to work with CDC to improve the instrument. Revisions will also occur as program goals and objectives for the next five years are finalized. After revisions have been made, the instrument is scheduled to be implemented during NPCR's second five-year project period.

The evaluation instrument is divided into 3 parts. Part A contains core questions about the infrastructure, processes, and operations of your central cancer registry. Part B focuses on outcome measures. Part C addresses advanced activities. We ask that you complete all three parts of the instrument.

We also ask that you take the time to provide feedback by answering the questions we have included at the end of each section and by marking comments or suggestions directly on the instrument. In providing your feedback, please think about the following questions:

- Are the right topics included in the instrument?
- Are these the best questions to address each topic?
- Can the wording or phrasing of the questions or response categories be improved?
- Do you have the information needed to answer these questions?
- Is the level of effort required to answer the questions reasonable?

Please note that NPCR is committed to exploring electronic methods for implementing this instrument. Therefore, your feedback should be focused on the content and clarity of the questions, and not on the pencil and paper format. CDC fully expects that the burden of providing this information on an annual basis will be substantially reduced with electronic implementation, as you will then be able to update your previous responses rather than repeating information you provided the previous year. Furthermore, in the not-too-distant future CDC expects that central cancer registries will only need to update

and/or answer the questions in Parts A and C. Part B questions will be answered by CDC from the data that each central cancer registry will be asked to submit to CDC.

We need to receive your completed responses **by September 3rd.** Send your completed instruments and feedback to Carlyn Orians using the enclosed self-addressed FedEx envelope. Please keep a copy of your responses so that we can follow up by phone to ask you to clarify questions and/or provide additional feedback. All your answers will be treated confidentially and will not be shared with anyone who is not directly involved in the revision process.

Thank you again for agreeing to participate. If you have any questions about completing this pilot test, please contact Carlyn Orians by e-mail (orians@battelle.org) or by phone (206-528-3320).

Sincerely,

Carlyn E. Orians
Principal Research Scientist
Battelle Centers for Public Health Research and Evaluation
4500 Sand Point Way N.E.
Seattle, Washington 98 105

Revised Evaluation Instrument

CDC's National Program of Cancer Registries (NPCR)

Pilot Test Draft

August 1999

Prepared *for:*

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1600 Clifton Road, NE
Atlanta, Georgia 30333

Prepared by:

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Battelle
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and Evaluation

NPCR REVISED EVALUATION INSTRUMENT

PILOT TEST DRAFT PREPARED 8/19/99

ADMINISTRATIVE DATA

To be completed by project officer

NPCR reference year _____

State _____

State program director _____

CDC project officer _____

Date first funded in NPCR
Please check (✓) only one
___ September 1994
___ May 1995
September 1997
Other, specify: _____

Type of current funding from NPCR
Please check (✓) only one
___ Enhancement
Planning

To be completed by State registry staff completing instrument

Your name _____

Title _____

Phone number (____) _____-_____

Date completed (mm/yyyy) ____/_____

Supplementary materials requested by CDC project officer

The materials listed below will help your CDC project officer serve you better. It is important that you keep ydur project officer informed about new developments or changes in operations so that he or she can provide you with sound and appropriate technical assistance.

The tables below are designed to help you make sure that your project officer has the most recent versions of each of these important materials and is kept abreast of the latest publications resulting from your registry. Please use the first table to indicate when each document last updated, whether you have already provided your project officer with this version, whether you are sending it now under separate cover, or whether you are unable to provide it at this time. If unable to provide a given document, please explain why and indicate when it can be made available.

Materials *(please send most recent versions only)*	**Date** of most recent version	**Previously provided** (✓)	**Sending now** (✓)	**Unable to provide** (please explain)
Letter from State attorney general				
State legislation and regulations				
Written policies and procedures				
Annual report (hardcopy and/or electronic)				

New publications

Please use this table to list new publications and presentations by registry staff OR check (✓) here _____ if a list will be sent under separate cover with the above materials.

Author(s)	**Title**	**Publication forum (journal name, conference, etc.)**	**Date of publication**

PART A:
INFRASTRUCTURE AND PROCESSES

Part A contains core questions about the infrastructure and operations of your central cancer registry. These questions should be answered by appropriate registry staff.

STAFFING

INSTRUCTIONS:

The first three questions use the concept of a "Full-time Equivalent" also known as an "FTE." In each question you will be asked to report the number of FTEs. To do this, please convert each position to the appropriate FTE equivalent using the guidelines below, rounding each position to the nearest quarter of an FTE (e.g., 34 hrs/week would convert to 0.75 FTEs, whereas 35 hrs/week would convert to 1.O FTE):

0.25 FTE = 10 hr/week
0.50 FTE = 20 hr/week
0.75 FTE = 30 hr/week
1 .OO FTE = 40 hrs/week.

Then add each converted position for the total number of FTEs. For example, if you have 1 epidemiologist working 35 hours and one working 20 hours, together they are 1.5 FTEs).

1 . **On January 1, 1999,** how many full-time equivalent (FTEs) staff positions were funded at the CCR? Enter the number of filled and vacant **federally funded** FTEs in the first row, and the number of filled and vacant **non-federally funded** FTEs in the second row. (***Please include contractors in your totals.)***

	filled	**vacant**
Number of **federally funded** FTE positions:	_____	_____
Number of **non-federally funded** FTE positions:	_____	_____

2. **On January 1, 1999** how many filled FTEs were on staff at the CCR with the following qualifications? (***Please include contractors in your totals.)***

Number of filled FTE Certified Tumor Registrars (CTR) _____

Number of tilled FTE Epidemiologists (Ph.D. or Dr. PH) _____

Number of filled FTE Epidemiologists (M.P.H.) _____

Number of filled FTE Medical Doctors (M.D.) _____

3. We would like to know more about the staff who work in your CCR. ***In the first column, please list the filled staff positions (all funding sources) in your CCR, including contractors. Then, for each position, list the number of full time equivalents (FTEs) and place a check (✓) under the primary activities (up to 4) persons in that position are responsible for***

		Primary Activities											
Position Title	Total Number of FTEs	Registry Management	Data Management	Data Analysis	Computer Support	Public Inquiries/ Requests	Quality Control - Edits	Quality Control- Audits	Clerical Support	Death Certificate Clearance	Case Abstraction	Other, specify_____	Other, specify_____
Example 1 Director	*1.0*	✓											
Example 2 Epidemiologist	*1.25*		✓	✓									

LEGISLATION

4. Does your State have a law authorizing formation of a statewide registry? ***please check (✓) yes or no and, if yes, enter date.***

___ Yes ➡ Enter date enacted (mm/dd/yyyy) _ / _/ -

___ No

5. Does your State have legislation or regulations to support the following 8 criteria specified in Public Law 102-5 15? ***Please check (✓) yes or no for each criterion.***

	Criteria	Yes	No
1	a means to assure **complete reporting** of cancer cases to the statewide cancer registry **by hospitals** and other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer; T - l -		
2	a means to assure the **complete reporting** of cancer cases to the statewide cancer registry **by physicians, surgeons, and all other health care practitioners** diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;		
3	a means for the statewide cancer registry to **access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals,** or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;		
4	for the **reporting** of cancer case data to the Statewide cancer registry in such a format, with such data elements, and in accordance with such standards of **quality, timeliness and completeness, as may be established by the Secretary;**		
5	for the **protection** of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;		
6	for a means by which confidential case data may in accordance with State law be **disclosed to cancer researchers** for the purposes of cancer prevention, control and research;		
7	for the **authorization or the conduct,** by the statewide cancer registry or other persons and organizations, of **studies utilizing statewide cancer registry data,** including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and		
8	for protection for individuals complying with the law, including provisions specifying that no **person shall** be **held liable** in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.		

6. Has your State supplied your CDC project officer with a letter from the highest ranking State Legal Officer certifying the extent to which the State is in full compliance with all criteria specified in PL 102-5 15? ***Please check (✓) yes or no and, if yes, enter date.***

___Yes ➡ Enter date of most recent letter (mm/dd/yyyy) - / -/ -

No

POLICIES AND PROCEDURES

7. For which of the following activities does your CCR have **written** central cancer registry operational policies and procedures? ***Please check (✓) all activities for which there are written policies and procedures as of January I, 1999·***

Reporting from facilities/providers

Data receipt and tracking

Public inquiries/data requests

Data release/confidentiality

Data security

___ Death certificate clearance and follow back

___ Quality assurance

__ Reabstracting audits

__ Casefinding audits

Case consolidation

Other, specify: _____

8. Case sharing with other states and territories is one way to improve the completeness of case reporting. ***For each state and territory listed below, place a check (✓) in the appropriate column to indicate whether or not your CCR has a formal, written case-sharing agreement as of January 1, 1999; has provided cases in the past year (1998); or has received cases from that state or territory in the past year (1998).*** *Exclude vendor software exchange.*

State	Formal agreement	Provided cases	Received cases		State	Formal agreement	Provided cases	Received cases
Alabama					Nevada			
Alaska					New Hampshire			
Arizona					New Jersey			
Arkansas					New Mexico			
California					NewYork			
Colorado					North Carolina			
Connecticut					North Dakota			
Delaware					Ohio			
District of Columbia					Oklahoma			
Florida					Oregon			
Georgia					Pennsylvania			
Hawaii					Rhode Island			
Idaho					South Carolina			
Illinois					South Dakota			
Indiana					Tennessee			
Iowa					Texas			
Kansas					Utah			
Kentucky					Vermont			
Louisiana					Virginia			
Maine					Washington			
Maryland					West Virginia			
Massachusetts					Wisconsin			
Michigan					Wyoming			
Minnesota								
Mississippi					Guam			
Missouri					Puerto Rico			
Montana					Palau			
Nebraska					Virgin Islands			

9. Some central cancer registries engage in case sharing directly with particular facilities or organizations. ***Please list below any other entities that the CCR has a case-sharing agreement with as of January 1, 1999. Then place a check (✓) in the appropriate columns to indicate whether or not your CCR has a formal, written case sharing agreement as of January 1, 1999; has provided cases in the past year (1998); or has received cases in the past year (1998). Exclude vendor software exchange.***

Entity or organization	Formal agreement	Provided cases	Received cases

COMPUTER INFRASTRUCTURE

10. Listed below are commonly used software systems for central cancer registries. What is the PRIMARY software system used to process and manage cancer data in your CCR? ***Please check (✓) only one.***

___ RMCDS (Rocky Mountain Cancer Data System)

___ C/NET

RegistryPlus

In-house software (developed specifically for your state), specify: _____

Other, specify: _____

None

11. Listed below are commonly used registry software systems. Thinking about your reporting sources, what software systems are used by the majority of your reporting sources as the PRIMARY software for managing cancer data? *Please **check (✓) all that apply.***

___ RMCDS (Rocky Mountain Cancer Data System)
___ C/NET
ELM (Premier) (IMPAC Medical Systems, Inc.)
CansurFacs (IMPAC Medical Systems, Inc.)
IMPAC (IMPAC Medical Systems, Inc.)
MRS (Medical Registry Services, Inc.)
OncoLog (Onco, Inc.)
ERS (Electronic Registry Systems, Inc.)
Abstract Plus
In-house software (developed specifically for your state), specify: _____
Other, specify: _____
None

12. What type of edit program is used by your CCR to check cases? *Please **check (✓) all that apply**·*

___ GENEDITS
CDC EDITS (batch)
CDC EDITS (interactive)
Other in-house, specify: _____
Other vendor, specify: _____
None

13. What automated edit checks are used by your CCR? ***Please check (✓) all that apply**·*

___ Unmodified NAACCR
Modified NAACCR
In-house edits
Vendor-supplied edits
SEER Metafile edits
American College of Surgeons (ACOS) edits
Other, specify: _____

14. How are edits applied at your CCR? ***Please check (✓) only one**·*

Source records
Consolidated records
___ Both source and consolidated records

REPORTING COMPLETENESS

15. What types of facilities and health care providers report to your CCR? ***Please list the number of sources in the state that could be reporting, the number that actually reported in the past year (1998), and indicate whether each source reports electronically or by paper.***

Type of Facility	Number of Potential Reporting Sources in the State	Number of Sources Actually Reporting		
		Total	**Electronically**	**By Paper**
ACOS-approved Hospitals (non-federal)				
Non-ACOS approved Hospitals (non-federal)				
Pathology Laboratories (in-state)				
Pathology Laboratories (out-of-state)				
Radiation Centers				
VA Hospitals				
Military Hospitals				
IHS Hospitals				
IHS Health Centers				
Tribally Owned Hospitals				
Tribally Owned Health Centers				
Surgery Centers				
Other, specify:_____				

16. Of the following physician specialties, which actually reported cancer cases to the CCR in the Past year (1998)? ***Please check (✓) all that apply-***

Dermatologist

___ Urologist

Medical Oncologist

Radiation Oncologist

___ Other, specify: _____

DATA CODING

17. What rules are used by your CCR for determining multiple primaries? ***Please check (✓) only one.***

___ SEER
International Agency for Research on Cancer (IARC)
Other, specify: _____
Don't know/ Not sure

18. Which coding system is used by your CCR for topography of incident cases? ***Please check (✓) all that apply.***

___ ICD-O-2
___ ICD-O-3
___ SNOMED
Other, specify: _____
Don't know/ Not sure

19. What coding system is used by your CCR for morphology of incident cases? ***Please check (✓) all that apply.***

___ ICD-O-2/SNOMED
___ ICD-O-3
Other, specify: _____
Don't know/ Not sure

20. From which sources are occupation/industry text data obtained by your CCR? ***Please check (✓) all that apply-***

Reporting facility records throughout the state
Reporting facility records in only certain geographic areas
Death certificates
Other source(s), specify: _____
No sources (not collected)

2 1. Are data on occupation and/or industry being coded by your CCR? ***Please check (✓) only one-***

Yes
No
Not applicable, no data are collected

22. Is text information (beyond simple labeling) to support coded data submitted to your CCR by reporting sources? ***Please check (✓) only one.***

Yes, by all sources

Yes, by most sources ➡ Specify type(s) of facility: _____

_____

No

23. Does your CCR maintain all information, including supporting text, from source records? ***Please check (✓) only one.***

Yes

No

Not applicable, no text is received by CCR

AUDITS

24. Has your CCR performed case finding audits at reporting sources within the past year (1998)? ***Please check (✓) yes or no and, if yes, enter number audited.***

Yes ➡ Enter number reporting sources audited _____

No ➡ Skip to Q. 27

25. Why are case finding audits done? ***Please check (✓) only one.***

Standard QA procedure

When fewer than expected cases are reported

Other specific problem, specify: _____

Other, specify: _____

26. What were the primary outcomes of the case finding audits and how were any problems identified resolved? ***Please describe below.***

_____

_____

_____

_____

_____

_____

27. Has your CCR performed reabstracting audits at reporting sources within the past year (1998)? ***Please check (✓) yes or no and, if yes, enter number audited.***

Yes ➡ Enter number reporting sources audited _____

___ No ➡ Skip to Q. 30

28. Is a standard percentage or number of cases reabstracted at each source? ***Please check (✓) only one and, if yes, enterpercentage or number.***

Yes, standard percentage ➡ Enter percentage of cases reabstracted ____ %

Yes, standard number ➡ Enter number of cases reabstracted ____

No, neither a standard percentage nor a standard number of cases are reabstracted at each source.

29. Why are reabstracting audits done? ***Please check (✓) only one.***

Standard QA procedure

Response to specific problem

Other, specify: _____

USE OF REGISTRY DATA

30. For which years has an annual report been produced (either hardcopy or electronic) of cancer incidence for the State? ***Please check (✓) all that apply***

Available for 1997 data

Available for 1996 data

Available for 1995 data

Available for 1 or more years prior to 1995

None available

3 1. In which format(s) is the most recent annual report available? ***Please check (✓) all that apply.***

Hard copy

__ Electronic word-processed file

Web page/query system

___ Other, specify _____

32. To what population were the most recent incidence rates standardized? ***Please check (✓) all that apply.***

1970 U.S. standard population

1990 U.S. standard population

2000 U.S. standard population

___ Other, specify: _____

33. Have the CCR cancer data from the past five years been published or presented in NAACCR's *Cancer Incidence in North America?* ***Please check (✓) yes or no and, if yes, enter year.***

___ Yes ➡ Enter most recent year of published data: 19- -

No ➡ Skip to Q. 35

34. Were these data used in computing the U.S. combined incidence rates in the above-referenced publication? ***Please check (✓) yes or no.***

Yes

___ No

35. In which of the following ways have registry data been used in the past year (**1998**)? ***Please check (✓) all that apply.***

Incidence/mortality estimates

Health event investigations

Response to inquiries/data requests

Needs assessment/program planning

Program evaluation

___ Clinical studies

Quality-of-care studies

Epidemiologic studies

Linkage with breast and cervical cancer screening program to improve registry case finding

Linkage with breast and cervical cancer screening program to improve screening follow-up

Other, specify: _____

Not used

36. Does the CCR maintain a log of requests for registry data? ***Please check (✓) yes or no and, if yes, enter number requests received.***

___ Yes ➡ Enter number of requests received in past year (1998) _____

___ No

37. For which years is an analytic data file available for research? ***Please check (✓) all that apply.***

Available for 1997 data

Available for 1996 data

Available for 1995 data

Available for 1 or more years prior to 1995

None available

38. To whom are the analytic files available? *Please check (✓) all that apply.*

In-house staff

Outside researchers

Other, specify: _____

Not available

SELF ASSESSMENT

39. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for data **completeness.** ***Please use a "1" to indicate the most important factor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

40. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for **timeliness.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

41. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for data **quality.** ***Please use a "1" to indicate the most importantfactor, "2"for next most important, etc.***

Not enough staff

___ Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

42. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for **data use.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

PART A FEEDBACK: INFRASTRUCTURE AND PROCESSES

Please answer the questions below. You are also encouraged to mark comments or suggestions directly on the instrument itself. Feel free to use additional sheets of paper if needed.

- What topics, if any, do you think are missing from Part A? *Please explain.*

- Are any topics included in Part A that you do not think are important or useful for understanding the progress of central cancer registries towards meeting program objectives?
  ____ Yes ____ No

  Please explain _____

- Can you suggest improvements and/or additions to these questions to better reflect the infrastructure and operations of your central cancer registry?

- Are the questions worded clearly? *Please review the questions in Part A and list below any questions that you found confusing or unclear. Use the space provided below to explain what you found confusing and to offer suggestions for improving the question OR mark your comments and suggestions directly on the instrument.*

- Are the response categories clear and complete? *Please review the questions in Part A and list below any questions where you found the response categories to be unclear or incomplete. Use the space provided below to explain what you found confusing and to offer suggestions for improvement OR mark your comments and suggestions directly on the instrument.*

- Did you have difficulty locating the information needed to answer any of the questions in Part A?

  ____ Yes ____ No

  Please explain which questions were difficult and why _____

- What data source did you use to determine potential reporting sources (Question 15)?

- How accurate do you feel the information is that you used to answer questions 15 and 16 regarding reporting completeness?

	Very Accurate	Somewhat Accurate	Not At All Accurate
Q15		____	____
Q16	____		____

  Please explain _____

- Was it difficult to accurately answer any of the other questions in Part A?

  ____ Yes ____ No

  Please explain which questions were difficult to **accurately** answer, and why.

- Overall, how burdensome did you find it to complete the questions in Part A? Please check (J) one.

Not at all Burdensome	0	0	0	0	Very burdensome

- Approximately how many hours did it take you to complete the questions in Part A?

  _____

- Please provide additional comments on Part A below and/or directly on the instrument.

PART B:
OUTCOME MEASURES

In the future, we anticipate that the questions in this section will not be directed to State registry staff. Instead, they will be answered from the data that each central cancer registry will be asked to submit to CDC. Until that time, however, we ask that you please take the time to answer these questions based on your registry data. Your answers should reflect data for **diagnostic year 1996.**

DATA ITEMS/FORMAT

1. Were the following NPCR **required** data items collected or derived in **1996**? ***Please check (✓) yes or no for each data item*** Refer to most recent NAACCR standards, Vol II, for description of data items.

Item Name	Item #	Yes	No		Item Name	Item #	Yes	No
Name - Last	2230				Date of DX	390		
Name - First	2240				Type of Reporting Source	500		
Name - Middle	2250				Date Adm/First Contact	580		
Addr at DX - City	70				Primary Site	400		
Addr at DX - State	80				Laterality	410		
County at DX	90				Histologic Type	420		
Addr at DX - Postal Code	100				Behavior Code	430		
Census Tract†	110				Grade	440		
Census Tract Coding System †	120				Diagnostic confirmation	490		
Race 1	160				Hospital Sequence Number	560		
Span./Hisp. Origin	190				Summary Stage	760		
Sex	220				First course of treatment (SEER or CoC)* (selected items)	1200-1650		
Birth Date	240				Date of Last Contact (or Date of Death)†	1750		
Social Security #	2320				Vital Status	1760		
Text –Usual Occupation*	310				Cause of Death†	1910		
Text –Usual Industry*	320							

*When available

†Derived or added by central registry. Some items (e.g., date of death) could be coded by hospitals OR derived

2. Were the following NPCR **recommended** data items collected or derived in **1996**? ***Please check (✓) yes or no for each data item.*** *Refer to most recent NAACCR standards, Vol II, for description of data items.*

Item Name	Item #	Yes	No	Item Name	Item #	Yes	No
Patient ID Number	20			RX Date - BRM*	1240		
Registry ID	40			RX Date - Other*	1250		
NAACCR Record Version	50			RX Coding System - Current	1460		
Tumor Record Number	60			First Course Calc Method	1500		
Marital Status at DX	150			ICD Revision No†	1920		
Computed Ethnicity†	200			Place of Death†	1940		
Computed Ethnicity Source†	210			Over-rides (various)†	1990 - 2074		
Age at Diagnosis†	230			Date Case Report Exported	2110		
Birthplace	250			SEER Coding Sys - Current	2120		
Occupation Code - Census†	270			SEER Coding Sys - Original	2130		
Industry Code - Census†	280			COC Coding Sys - Current	2140		
Occupation Source†	290			COC Coding Sys - Original	2150		
Industry Source†	300			Date Case Report Received†	2111		
Occup/Ind Coding System†	330			Date Case Report Loaded†	2112		
Sequence Number - Central†	380			Date Tumor Record Availbl†	2113		
Reporting Hospital	540			Name - Alias	2280		
Accession Number - Hosp	550			Medical Record Number	2300		
Date of Inpatient Disch	600			Military Record No Suffix	2310		
Class of Case	610			Addr at DX - No & Street	2330		
Tumor Size	780			DC State File Number†	2380		
Regional Nodes Positive	820			Name - Maiden	2390		
Regional Nodes Examined	830			Text - Diagnosis (various)	2520 -2600		
RX Date - Ca Dir Surg*	1200			Text - Treatment (various)	2610 -2670		
RX Date - Radiation*	1210			Text - Remarks	2680		
RX Date - Chemo*	1220			Place of Diagnosis	2690		
RX Date -Hormone*	1230						

*When available.

†Derived or added by central registry. Some items (e.g., date of death) could be coded by hospitals OR derived

3. Does the CCR use the NAACCR data exchange record layout to import and export data? ***Please check (✓) yes or no and, if yes, indicate most recent version used.***

Import data? ___ Yes ➡ Latest layout version number: _____
No

Export data? Yes ➡ Latest layout version number: _____
No

Questions 4 through 6 refer to 12 months after close of diagnosis year

4. What was the percentage of expected 1996 cases reported to the CCR by **January 1, 1998**? ***Please provide numerator, denominator and percent in the spaces below.***

Numerator (# cases registered) _____
Denominator (#-expected cases) _____
Percent (use single decimal fraction) _____

5. What data were used to calculate the expected number of cases listed above? ***Please check (✓) only one.***

___ ACS estimates
SEER incidence rates
___ Historical state data
__ Other, specify: _____

6. How many 1996 cases passed the NAACCR EDITS metafile by **January 1, 1998**? ***Please provide numerator, denominator andpercent in the spaces below.***

Numerator (# cases passed) _____
Denominator (# cases edited) _____
Percent (use single decimal fraction) _____

Questions 7 through 14 refer to 24 months after close of diagnosis year

7. What was the percentage of expected 1996 cases reported to the CCR by **January 1, 1999**? ***Pleaseprovide numerator, denominator andpercent in the spaces below.***

Numerator (# cases registered) _____
Denominator (# expected cases) _____
Percent (use single decimal fraction) _____

8. What method was used to calculate the expected number of cases listed above?
Please check (✓) only one-

- NAACCR method (ratio of incidence to mortality)
__ ACS estimates
SEER incidence rates
___ Historical state data
___ Other, specify: _____

9. What was the percentage of 1996 cases reported by a death certificate only as of **January 1, 1999**? ***Please provide numerator, denominator and percent in the spaces below.***

Numerator (# cases death certificate only) _____
Denominator (# registered) _____
Percent (use single decimal fraction) _____

10. What was the number of 1996 duplicate cases per 1,000 as of **January 1, 1999**? ***Use NAACCR methodfor calculating duplicates and provide numerator, denominator and rate in the spaces below.***

Numerator (# duplicate cases) _____
Denominator (sample size checked) _____
Rate (per 1,000) _____

11. How many 1996 cases passed the NAACCR EDITS metafile by **January 1, 1999**?
Please provide numerator, denominator andpercent in the spaces below.

Numerator (# cases passed) _____
Denominator (# cases edited) _____
Percent (use single decimal fraction) _____

12. What percentage of 1996 cases had **missing** values for the following variables?
Values are missing if they are blank or have values defined as missing.

Age at diagnosis (item # 230) _____
Race 1 (item # 160) _____
Sex (item # 220) _____
Address at DX - State (item # 80) _____
County at DX (item # 90) _____
Primary Site (item # 400) _____
Date of DX (item # 390) _____
Diagnostic Confirmation (item # 490) _____
Summary Stage (item # 760) _____
Text - Usual Industry (item # 320) _____
Text - Usual Occupation (item # 3 10) _____

13. What percentage of unduplicated 1996 cases was microscopically confirmed? ***Please provide numerator, denominator andpercent in the spaces below.***

Numerator (# cases' confirmed) _____

Denominator (# cases registered) _____

Percent (use single decimal fraction) _____

14. What percentage of 1996 cases have a coded census tract (NAACCR Data Item #1 10) equal to each of the codes listed below? ***Please list percent in each of the spaces provided below.***

000 loo-949999 (census tract codes) _____

950100-998999 (census block codes) _____

000000 (area not census tracted) _____

999999 (area census tracted, but tract not available) _____

PART B FEEDBACK: OUTCOME MEASURES

Please answer the questions below. You are also encouraged to mark comments or suggestions directly on the instrument itself. Feel free to use additional sheets of paper if needed.

- Did you have difficulty locating the information to answer any of the questions in Part B?
  ____ Yes ____ No

  Please explain which questions were difficult and why_____

  _____

  _____

  _____

  _____

  _____

- Are the questions worded clearly? *For each question in Part B, please check (✓) one column to indicate whether or not that question was clear, somewhat confusing, or very confusing. Use the space provided at the bottom to explain what you found confusing and to offer suggestions for improving the question.*

	Clear	Somewhat Confusing	Very Confusing
Data items/format			
Q1			
Q2			
Q3			
12 month outcomes			
Q4			
Q5			
Q6			
24 month outcomes			
Q7			
Q8			
Q9			
Q10			
Q11			
Q12			
Q13			
Q14			

Please explain _____

_____

_____

_____

_____

- Are the response categories clear and complete? *For each question in Part B, please check (✓) one column to indicate whether or not the response categories for that question were clear, somewhat confusing, or very confusing. Use the space provided at the bottom to explain what you found confusing and to offer suggestions for improving the question.*

	Clear	Somewhat Confusing	Very Confusing
Data items/format			
Q1			
Q2			
Q3			
12 month outcomes			
Q4			
Q5			
Q6			
24 month outcomes			
Q7			
Q8			
Q9			
Q10			
Q11			
Q12			
Q13			
Q14			

Please explain _____

- Can you suggest improvements and/or additions to these questions to better reflect outcomes related to data completeness, timeliness and quality?

- Please provide additional comments on Part B below and/or directly

PART C:
ADVANCED ACTIVITIES

As the capacity of central cancer registries 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 these "advanced activities" that your CCR may currently engage in. Please answer the questions below and then in the space provided at the end, please describe other activities your CCR has engaged in that have not been addressed in these questions.

1. Does your CCR have the ability to do automated case finding using electronic linkage with any of the following sources? ***Please check (✓) all that apply-***

   Yes, via pathology reports

   Yes, via master disease index

   Yes, via some other source, specify: _____

   No, not able to do electronic case finding

2. Is your CCR able to receive encrypted data via Internet from reporting sources? ***Please check (✓) only one.***

   ___ ***Yes***

   Currently being developed and/or implemented

   Planning stages only

   No, not able to receive encrypted data via Internet from reporting sources

3. Does your CCR geocode cancer cases by latitude/longitude to enable mapping or reporting of cancer cases? ***Please check (✓) yes or no.***

   ___ ***Yes***

   No, the CCR does not geocode cancer cases

4. How often is your CCR linking to the National Death Index? ***Please check (✓) only one·***

   Annually

   Other frequency, specify: _____

   Does not link to the National Death Index ➡ Skip to Q. 7

5. How often is your CCR resolving possible matches with the National Death Index? ***Please check (✓) only one·***

   Annually

   Other frequency, specify: _____

   Not resolving possible matches with the National Death Index

6. After the National Death Index linkage has been performed, what is the percentage of cases for 1996 with known cause of death? ***Please use as your denominator those with a vital status equal to 'dead. "***

Numerator (# cases known cause) _____

Denominator (# cases vital status "dead") _____

Percent (use single decimal fraction) _____

7. Does your CCR conduct survival analysis? ***Please check (✓) yes or no***

Yes ➡ Briefly describe the method used: _____

_____

_____

_____

No

8. With which databases has your CCR linked its records in the past year (1998)? ***Please check (✓) ail that apply-***

State vital statistics

National Death Index

Department of Motor Vehicles

Department of Voter Registration

Medicare (Health Care Financing Administration)

Medicaid

Managed care organizations

Other, specify: _____

None

9. Briefly describe the research studies your CCR has conducted (can be ongoing) in the past year (1998) using registry data. ***Please include in your description the affiliations of the individuals who conducted the studies/projects (i.e., registry staff; other state staff (specify), university researchers (specify), other researchers (specify)) as well as a brief description of the research objectives.*** *If any published products have resulted from these studies, make sure they are included in the supplemental materials list at the beginning of this instrument.*

10. What other advanced activities has your CCR engaged in this past year (1998) that were not addressed in the questions above? ***Please describe in the space provided below.***

PART C FEEDBACK: ADVANCED ACTIVITIES

Please answer the questions below. You are also encouraged to mark comments or suggestions directly on the instrument itself. Feel free to use additional sheets of paper if needed.

- Are the questions worded clearly? *For each question in Fart C, please check (✓) one column to indicate whether or not that question was clear, somewhat confusing, or very confusing. Use the space provided at the bottom to explain what you found confusing and to offer suggestions for improving the question.*

	Clear	Somewhat Confusing	Very Confusing
Q1			
Q2			
Q3			
Q4			
Q5			
Q6			
Q7			
Q8			
Q9			
Q10			

Please explain _____

_____

_____

_____

- Are the response categories clear and complete? *For each question in Part C, please check (✓) one column to indicate whether or not the response categories for that question were clear, somewhat confusing, or very confusing. Use the space provided at the bottom to explain what you found confusing or incomplete and to offer suggestions for-improving the question.*

	Clear	Somewhat Confusing	Very Confusing
Q1			
Q2			
Q3			
Q4			
Q5			
Q6			
Q7			
Q8			
Q9			
Q10			

Please explain _____

_____

_____

- What additional questions can you suggest to help CDC understand the advanced activities that your state is engaged in?

- What additional questions can you suggest to help CDC understand the challenges that you face as you continue to develop your registry capabilities beyond the minimum requirements?

- Overall, how burdensome did you find it to complete the questions in Part C? *Please check (✓) one.*

Not at all Burdensome	0	0	0	0	Very burdensome

- Approximately how many hours did it take you to complete the questions in Part C?

- Please provide additional comments on Part C below and/or directly on the instrument.

OVERALL

- Overall, I found that the level of effort for completing this instrument was *(check one)*

Not at all Burdensome				Very burdensome
0	0	0	0	

. The topics and questions that I think are most important or useful to include are:

_____

_____

_____

_____

_____

_____

_____

_____

- The topics and questions that I think are least important or useful to include are:

_____

_____

_____

_____

_____

_____

_____

_____

. The changes that I'd most like to see made to this instrument are:

_____

_____

_____

_____

_____

_____

_____

_____

Please provide additional comments below.

Appendix B Pilot Test Results

Pilot test participants and methods

Six states were asked to participate in a pilot t

instrument. The states were selected to represent a range of experie

with respect to registry operations.

plan a registry (none had previously existed) in 1994 and had recentl

data (planning states); the other four received funding to enhance exi

operations and had been collecting data for several years.

basis will be substantially reduced with electronic implementation (s

able to update previous responses rather than repeating information p

year). Nevertheless, participants were also asked to provide comme

difficulty and to estimate the level of burden to complete the pilot tes

Pilot test results

The results of the pilot test are organized as fol

instrument; (2) organization of the instrument; (3) clarity of the ques

categories; (4) difficulty answering each question; (5) level of burden

and timeliness (Qs 39 and 40) even though this had not been listed as

categories. NPCR may want to consider whether it already has a sa

understanding of what these difficulties are or if it should undertake s

better understand these issues, either using this instrument or in some

The number of reporting sources reporting elec

the instrument, but not the percent of source records.

would add much to

NPC

warranted.

Finally, one participant suggested turning one o

more sense. No comments were received on the division of the instrument into three parts.

Clarity of questions/response categories

Part A, Staffing. Some confusion arose over how to determine which staff should be included as registry staff. Staff members may perform registry functions yet not be considered registry staff if they do not report to the registry director. This can lead a registry to list more individuals in the table in Q3 than are listed in staff totals in Q1. To address this problem, NPCR will need to clarify if it is interested in knowing about (1) all staff performing registry functions or (2) only those staff that are considered by the CCR to be registry staff.

If a decision is made to include all staff performing registry functions, Q1 could be reworded to be more inclusive (i.e., FTEs who "work in the CCR" or who "perform CCR functions" rather than FTES that were "funded at the CCR" as currently worded). If a decision is made to limit responses to only those staff that are considered by the CCR to be registry staff, this should be clarified in Q1, and instructions to Qs 2 and 3 should ask respondents to include only those staff that were included in Q 1. Regardless of which decision is made, a change in question order was suggested (Q1 followed by Q3 and then Q2) to help clarify that the same individuals should be included in all. questions.

A second source of confusion arose over who to include among those counted as federally-funded staff. Should these be restricted to those funded by NPCR? Or should the list include all federally-funded staff, such as staff paid with block grant monies?

There was also some confusion about the breakdown of activities included in Q3. Participants were uncertain about how to handle such activities as training, out-of-state case handling, non-hospital source reporting, record consolidation, quality control (visual review), registry/productivity statistics, and pathology laboratories. It was suggested that an instruction supplement be prepared to ensure consistency in definitions across registries. One participant suggested modeling the activity categories after a recent staffing survey conducted by NAACCR. Positive feedback was received from one

participant about allowing respondents to list position titles as they actually exist rather than trying to conform to preexisting staffing categories as in previous instruments.

Part A, Legislation: The questions and response categories in this section were viewed as clear and straightforward. Participants were somewhat confused about Q6 asking about a letter from the highest ranking State Legal Officer. This is a new requirement that states have not yet been made aware of. Once this requirement has been made clear to funded states, no difficulties are anticipated in their ability to answer this question.

Part A, Policies and Procedures. Participants were unsure how to handle the situation in which they have a case sharing agreement with a state and receive a letter from that state indicating that no cases were identified that year. If the column "received cases" is left blank, it may appear that despite having an agreement in place, the state did not search for relevant cases to share.

In Q9, participants stated that the question would be clearer if an example were provided of an organization or facility with which a CCR might case share.

Part A, Computer Infrastructure. Most of the questions in this section were clear to participants. For the most part, the response categories were also clear and straightforward. The only questions that arose concerned Qs 12 and 13. One participant was not familiar with the CDC EDITS program referenced in Q12. Another was confused about how to list "local edits" that are added to GENEDITS. Would this be handled by marking "In-house edits" under Q 13? Another participant did not understand the distinction between Q 12 and Q 13.

Part A, Reporting Completeness. The questions in this section were clear although it was hard to accurately answer them. There was some confusion over the first two response categories in Q15. According to participants, the Joint Commission approves hospitals, and the ACOS Committee on Cancer (COS) approves cancer programs. Therefore, one can distinguish between non-federal hospitals with cancer programs (registries) and non-federal hospitals without cancer programs. Hospitals with cancer programs/registries may or may not have their programs approved by ACOS. It appears that many CCRs distinguish in their data between hospitals with and without registries, but not necessarily whether they are ACOS approved. Thus, it is important to

clarify whether NPCR is solely (or primarily) interested in ACOS approval or the presence of a cancer program/registry.

For Q16, adding a response category "None of the above listed physician specialties reported cancer cases to the CCR in the past year" would make it clear that no "checks" means none reported, not that the question was skipped or overlooked.

Part A, Data Coding. The questions and response categories in this section were clear and straightforward. One participant asked for clarification on whether in Q23 maintenance of text information refers to computer or hardcopy maintenance or both. Only one participant used a write in response category, writing "NAACCR" in response to 417.

Part A, Audits. In this section, participants indicated that for both Qs 25 and 29, it may often be appropriate to check more than one response category. In other words, part of a CCR's standard QA procedure might be to conduct audits *either every* few years *or* when fewer than expected cases are reported. Three of the participants marked both response categories for these questions.

Answers to Q26 do not appear to be very informative. The problems that participants listed referred to missed cases – not a surprising or enlightening finding to report. To resolve these problems, participants discussed such things as making "facility reports," "recommending improvements in case finding procedures," and "providing training." This question should probably be dropped or reworded to obtain more useful information.

Part A, Use of Registry Data. Most of the questions in this section were clear and straightforward. The confusing questions for participants were Qs 37 and 38. Participants asked for clarification about what constitutes an analytic file. In particular, does an analytic file mean a public use file? Does it have personal identifiers? They also indicated that a file might only be available for some years for particular uses and not for others because of concerns about the completeness or quality of the data for some uses. In Q38, participants were quick to point out that requests are required from outside researchers and requests are granted only if the proposed use is viewed as appropriate to the data and if IRB processes have been complied with.

If the answer to Q30 is "None available," the respondent should be directed to skip to 435.

Part A, Self Assessment. Participants found the questions in this section somewhat confusing because they were unsure what program objectives were being referred to. These questions would be clear if participants were provided with a copy of the objectives.

The response categories for Qs 39 and 40 were inadequate. Five of the six participants listed "other" in response to both of these questions. Problems with reporting sources dominated the list of written response categories to both of these questions. Other responses included employee turnover, regulations (Q39), and lack of national data exchange agreements (Q40).

Part B. Participants were confused by several of the questions in this section. Those questions that at least one participant marked as either "somewhat confusing" or "very confusing" were Qs 3, 6, 11, 12, and 14. The confusion in Q3 was whether the question was asking about the NAACCR data exchange record layout version in place at the time of completing the instrument or at some previous point in time.

Question 6 was the most confusing question to participants -- none of the participants were able to provide a response to this question. The same confusion applies to Q11 which asks for the same outcome at a different point in time. One participant wondered if this was equivalent to the NAACCR's call for data edits. Another commented that they do not keep track of cases that pass or fail when facility reports are first received and edited. Another was confused about how this question relates to the response categories provided in Part A, Q 13. It may be that these questions could be easily answered by CDC or a third-party contractor using an appropriately dated data base, but they clearly do not work as questions to direct at state registry staff.

The instructions for Q12 were confusing. It would be clearer to state "values are missing if either missing or unknown." In the response categories, one participant noted that Date of DX (item # 390) leaves unclear if it should be considered missing if either the month or year is missing, or only if both are missing.

One participant stated that Q14 was confusing. However, upon further discussion it appears that the confusion disappears after looking at the NAACCR volume that describes the coding system.

Part C. Participants found most of the questions to be clear and straightforward. The two questions that were somewhat vague and confusing were Qs 9 and 10. Feedback provided regarding Q9 indicate that participants were unsure whether to only list studies that CCR staff were engaged in, or all studies that used CCR data. Participants also reported that this could be time-consuming to complete, and suggested just asking for a publication list, or using the information provided in the quarterly reports.

Question 10 was too vague for all participants. One participant suggested a 'longer explanation to the question, more like what is provided at the beginning of Part C. Another participant objected to the use of the term "advanced activities" as too pejorative.

In Q8, one participant asked for clarification as to whether the purpose of the linking was to do follow up.

The response categories in Qs 1 and 3 were reported to be too limiting. One participant advocated adding categories that allow registries to note whether they are in the process of developing these categories. One option would be to model the response categories after those provided in Q2. One participant asked for further clarification about what is meant by electronic linkage.

Degree of difficulty

Part A. The difficult questions in Part A are generally the same ones that took the longest to complete and were described as burdensome: staffing, case sharing, and reporting completeness.

Staffing (Qs l-3) was difficult to accurately describe because it was hard to define who to include, especially in large registries where staff from multiple programs (i.e., registry and surveillance) perform registry functions. Staff can also be fluid, changing functions and source of pay from month to month. It would be comparatively easy to list NPCR-funded staff only and to list their primary activities (see further discussion of this issue under clarity of questions above).

One participant described the question about case sharing (QS) as difficult to answer because the necessary information had not been compiled in one location. Other participants did not mention this question as particularly difficult to answer.

Reporting completeness (Q15) was a difficult question to answer for many participants. One participant said that the number of hospitals keeps changing so it is hard to define the number at any one time. That person suggested that using a range of facilities (i.e., 0-50, 5 l-l 00, etc.) might be easier. Another participant mentioned that getting information from IHS facilities has been difficult and often unreliable. Another difficulty encountered was determining the number of pathology laboratories to include as potential reporting sources. For example, should Planned Parenthood facilities be included? Coming up with the potential number of out-of-state pathology laboratories was reported as impossible by two of the participants.

In the feedback questions, participants were asked to describe the data source they used to determine the number of potential reporting sources and to estimate how accurate they feel the information was (very, somewhat or not at all). Three of the participants indicated that their information was very accurate. These participants used lists maintained by their respective registries or Departments of Health, supplemented in one case by the RMCDS database, and the American College of Surgeons. One of the participants indicating that the information was only somewhat accurate used similar lists, supplemented by surveys of physician offices. The remaining two participants indicated they did not use a data source or did not list their data source. Both indicated that the information was somewhat accurate.

Part B. Participants had a great deal of trouble completing questions in Part B. Registries do not "freeze" their databases in time. As new data are received databases are continually updated. Thus registry staff are not able (or find it difficult) to recreate numbers or percentages at a specific date in the past (Qs 4-14). In order to make these requests feasible for state registries, the dates specified in these questions would need to match the dates of data requests. Then registries could use existing printouts rather than trying to reconstruct databases which would be difficult at best, and may in fact not be possible for some states. Similarly, in order for CDC to be able to accurately answer these questions, data requests from the states would need to be made on those dates. It is

The number of hours to complete Part A was highly variable – ranging from 1 to 6 hours. The questions that were the most time consuming were those related to staffing, case sharing, and reporting' completeness. On a scale of 1 to 4, participants ranked the burden of completing Part A "3," with a range of from 2 to 4. From comments provided and follow-up discussions, it appears that participants would view the data collection process as less burdensome in future years if they were able to electronically view and update previous information. They noted that many of the answers in Part A would change very little if at all from year to year.

The length of time it took participants to complete Part C ranged from 15 minutes to 2 hours. This section was shorter to complete and was viewed as less burdensome than Part A, with participants ranking the level of burden as either "1" or "2." The difficult and time-consuming questions were the last two. One participant commented that information for Q9 (research studies) was available from quarterly reports. Participants all left blank responses to Q 10 and indicated in their comments that the question was confusing.

Participants were also asked to rank the level of burden for the whole instrument, using the same 1 to 4 scale they used for Parts A and C. Participants tended to assign the same level of burden overall as they did to whichever part they found most burdensome. Overall, participants ranked the level of burden to complete the entire instrument as "3," with a range of 2 to 4. From estimates and comments provided, it was clear that Parts A and B were the burdensome sections of the instrument, Part C was not as burdensome. Part B appears to be viewed as especially burdensome and difficult and likely was a major influence on the overall burden estimates provided. One participant commented that Part B was by far the most burdensome section. With a few significant exceptions, it was the sheer volume of information requested that participants found burdensome, rather than lack of clarity in the instrument.

Suggestions for improvement

Overall, the dominant suggestions for improving the instrument were to

- shorten the instrument by eliminating any questions that NPCR does not really need to know or does not have plans to use, and
- increase the level of coordination with other ongoing data collection activities (NAACCR, progress reports) to reduce the level of burden.

Other suggestions included providing an instruction supplement to ensure that questions are interpreted and answered as similarly as possible, and providing more space for writing in comments. Participants agreed that data collection will be easier when the instrument is electronically implemented.

Appendix C Revised Evaluation Instrument

Revised Evaluation Instrument

CDC's National Program of Cancer Registries (NPCR)

November 1999

Prepared for:

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NPCR REVISED EVALUATION INSTRUMENT

PREPARED 1 1/15/99

ADMINISTRATIVE DATA

To be completed by project officer

NPCR reference year _____

State _____

State program director _____

Cooperative Agreement # U75/CCU_ _ _ _ _ _ _ _

CDC project officer _____

Date first funded in NPCR

Please check (✓) only one

___ September 1994

___ May 1995

September 1997

Other, specify: _____

Type of current funding from NPCR

Please check (✓) only one

___ Enhancement

Planning

To be completed by State registry staff completing instrument

Your name _____

Title _____

Phone number (____) _____

Date completed (mm/yyyy) /____

PART A:
INFRASTRUCTURE AND PROCESSES

Part A contains core questions about the infrastructure and operations of your central cancer registry. These questions should be answered by appropriate registry staff.

STAFFING

INSTRUCTIONS:

The first three questions use the concept of a "Full-time Equivalent" also known as an "FTE." In each question you will be asked to report the number of FTEs. 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 .O FTE):

0.25 FTE = 10 hr/week
0.50 FTE = 20 hr/week
0.75 FTE = 30 hr/week
1 .OO FTE = 40 hrs/week.

Then add each converted position for the total number of FTEs. For example, if you have 1 epidemiologist working 35 hours and one working 20 hours, together they are 1.5 FTEs).

1. **On January 1, 1999,** how many full-time equivalent (FTEs) staff positions were funded at the CCR? Enter the number of filled and vacant **NPCR-funded** FTEs in the first row, and the number of filled and vacant **non-federally funded** FTEs in the second row. (***Please include contractors in your totals but do not include positions outside the registry even if those people sometimes engage in registry activities.)***

	filled	**vacant**
Number of **NPCR-funded** FTE positions:	_____._____	_____._____
Number of **non-federally funded** FTE positions:	_____._____	_____._____

2. We would like to know more about the filled staff positions you included in Question 1 (both federal and non-federally funded). ***In the first column, please list the filled staff positions in your CCR, including contractors. Then, for each position, list the number of full time equivalents (FTEs) and place a check (✓) under the primary activities (up to 4) persons in that position are responsible for-*** *(The total number of FTEs listed below should match the number of filled positions listed in Question 1.)*

		Primary Activities											
Position Title	Total Number of FTEs	Registry Management/ Leadership	Data Management	Data Analysis/ Research	Computer Support (hardware, software)	Public Inquiries/ Requests	Quality Control – Edits, Visual Review	Quality Control- Audits	Clerical Support	Death Certificate Clearance	Case Abstraction	Other, specify____	Other, specify____
Example 1 Director	*1.0*	✓											
Example 2 Epidemiologist	*1.25*			✓		✓							

3. How many of the FTEs counted in Question 1 had the following qualifications? ***(Please include contractors in your totals.)***

Number of filled FTE Certified Tumor Registrars (CTR) _____

Number of filled FTE Epidemiologists (Ph.D. or Dr. PH) _____

Number of filled FTE Epidemiologists (M.P.H.) _____

Number of filled FTE Medical Doctors (M.D.) _____

LEGISLATION

4. Does your State have a law authorizing formation of a statewide registry? ***Please check (✓) yes or no and, if yes, enter date-***

- Yes ➡ Enter date enacted (mm/dd/yyyy) _ / _ / _

No

5. Does your State have legislation or regulations to support the following 8 criteria specified in Public Law 102-515? ***Please check (✓) yes or no for each criterion.***

	Criteria	Yes	No
1	a means to assure **complete reporting** of cancer cases to the statewide cancer registry **by hospitals** and **other** facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;		
2	a means to assure the **complete reporting** of cancer cases to the statewide cancer registry **by physicians, surgeons, and all other health care practitioners** diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;		
3	a means for the statewide cancer registry to **access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities,** individuals or **agencies** providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;		
4	for the **reporting** of cancer case data to the statewide cancer registry in such a **format, with such data elements,** and in accordance with such standards of **quality, timeliness and completeness,** as may be established by the Secretary;		
5	for the protection of **the confidentiality** of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers;		
6	for a means by which confidential case data may in accordance with State law be **disclosed to cancer researchers** for the purposes of cancer prevention, control and research;		
7	for the **authorization or the conduct,** by the statewide cancer registry or other persons and organizations, of **studies utilizing statewide cancer registry data,** including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and		
8	for protection for individuals complying with the law, including provisions specifying that no **person shall** be **held liable** in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.		

6. Has your State supplied your CDC project officer with a letter from the highest ranking State Legal Officer certifying the extent to which the State is in full compliance with all criteria specified in PL 102-515? ***Please check (✓) yes or no and, if yes, enter date.***

___Yes ➡ Enter date of most recent letter (mm/dd/yyyy) _ / _/ _

___No

POLICIES AND PROCEDURES

7. For which of the following activities does your CCR have **written** central cancer registry operational policies and procedures? ***Please check (✓) all activities for which there are written policies and procedures as of January 1, 1999.***

___ Reporting from facilities/providers
Data receipt and tracking
Public inquiries/data requests
Data release/confidentiality
Data security
Death certificate clearance and follow back
Quality assurance
___ Reabstracting audits
Casefinding audits
___ Case consolidation
___ Other, specify: _____

8. Case sharing with other states and territories is one way to improve the completeness of case reporting. ***For each state and territory listed below, place a check (✓) in the appropriate columns to indicate whether or not your CCR has a formal, written case-sharing agreement as of January 1, 1999; has provided cases in the past year (1998); or has received cases from that state or territory in the past year (1998).*** *Exclude vendor software exchange. If an agreement was in place and a letter was sent or received indicating no cases were found, please check yes in the appropriate column.*

State	Formal agreement	Provided cases	Received cases		State	Formal agreement	Provided cases	Received cases
Alabama					Nevada			
Alaska					New Hampshire			
Arizona					New Jersey			
Arkansas					New Mexico			
California					NewYork			
Colorado					North Carolina			
Connecticut					North Dakota			
Delaware					Ohio			
District of Columbia					Oklahoma			
Florida					Oregon			
Georgia					Pennsylvania			
Hawaii					Rhode Island			
Idaho					South Carolina			
Illinois					South Dakota			
Indiana					Tennessee			
Iowa					Texas			
Kansas					Utah			
Kentucky					Vermont			
Louisiana					Virginia			
Maine					Washington			
Maryland					West Virginia			
Massachusetts					Wisconsin			
Michigan					Wyoming			
Minnesota								
Mississippi					Guam			
Missouri					Puerto Rico			
Montana					Palau			
Nebraska					Virgin Islands			

9. Some central cancer registries engage in case sharing directly with particular facilities or organizations (such as out-of-state hospitals like the Mayo Clinic). ***Please list below any other entities that the CCR has a case-sharing agreement with as of January 1, 1999. Then place a check (✓) in the appropriate columns to indicate whether or not your CCR has a formal, written case sharing agreement as of January 1, 1999; has provided cases in the past year (1998); or has received cases in the past year (1998).*** *Exclude vendor software exchange.*

Entity or organization	Formal agreement	Provided cases	Received cases

COMPUTER INFRASTRUCTURE

10. Listed below are commonly used software systems for central cancer registries. What is the PRIMARY software system used to process and manage cancer data in your CCR? ***Please check (✓) only one.***

RMCDS (Rocky Mountain Cancer Data System)

___ C/NET

RegistryPlus

In-house software (developed specifically for your state), specify: _____

Other, specify: _____

None

11. Listed below are commonly used registry software systems. Thinking about your reporting sources, what software systems are used by most of your reporting sources as the PRIMARY software for managing cancer data? *Please **check (✓) the primary systems used.***

___ RMCDS (Rocky Mountain Cancer Data System)
C/NET
ELM (Premier) (IMPAC Medical Systems, Inc.)
CansurFacs (IMPAC Medical Systems, Inc.)
IMPAC (IMPAC Medical Systems, Inc.)
MRS (Medical Registry Services, Inc.)
OncoLog (Onco, Inc.)
ERS (Electronic Registry Systems, Inc.)
Abstract Plus
In-house software (developed specifically for your state), specify: _____
Other, specify: _____
None

12. What type of edit program is used by your CCR to check cases? *Please **check (✓) all that apply.***

CDC EDITS (batch)
CDC EDITS (interactive)
Other in-house, specify: _____
___ Other vendor, specify: _____
None

13. What automated edit checks are used by your CCR? ***Please check (✓) all that** apply.*

Unmodified NAACCR
Modified NAACCR
In-house edits
Vendor-supplied edits
SEER Metafile edits
American College of Surgeons (ACOS) edits
Other, specify: _____

14. How are edits applied at your CCR? ***Please check (✓) only one.***

Source records
Consolidated records
Both source and consolidated records

REPORTING COMPLETENESS

15. What types of facilities and health care providers report to your CCR? ***Please list the number of sources in the state that should be reporting, the total number that actually reported in the past year (1998), and indicate how many report electronically and how many report by paper.***

Type of Facility	Number of Reporting Sources Required to Report	Number of Sources Actually Reporting		
		Total Reporting	Reporting Electronically	Reporting By Paper
Non-federal Hospitals with a cancer registry				
Non-federal Hospitals'with no cancer registry				
Pathology Laboratories (in-state)				
Pathology Laboratories (out-of-state)				
Radiation Centers				
VA Hospitals				
Military Hospitals				
IHS Hospitals				
IHS Health Centers				
Tribally Owned Hospitals				
Tribally Owned Health Centers				
Surgery Centers				
Other, specify:_____				

16. Of the following physician specialties, which actually reported cancer cases to the CCR in the Past Year (1998)? ***Please, check (✓) all that apply.***

___ Derrnatologist
__ Urologist
Medical Oncologist
Radiation Oncologist
___ Other specialty, specify: _____
None of the above physician specialties reported cases in the past year

DATA CODING

17. What rules are used by your CCR for determining multiple primaries? ***Please check (✓) only one.***

___ SEER
___ International Agency for Research on Cancer (IARC)
__ Other, specify: _____
___ Don't know/ Not sure

18. Which coding system is used by your CCR for topography of incident cases? ***Please check (✓) all that apply.***

ICD-O-2
___ ICD-O-3
___ SNOMED
Other, specify: _____
Don't know/ Not sure

19. What coding system is used by your CCR for morphology of incident cases? ***Please check (✓) all that apply.***

___ ICD-O-2/SNOMED
__ ICD-O-3
___ Other, specify: _____
Don't know/ Not sure

20. From which sources are occupation/industry text data obtained by your CCR? ***Please check (✓) all that apply-***

Reporting facility records throughout the state
Reporting facility records in only certain geographic areas
___ Death certificates
___ Other source(s), specify: _____
No sources (not collected)

21. Are data on occupation and/or industry being coded by your CCR? ***Please check (✓) only one-***

Yes

No

Not applicable, no data are collected

22. Is text information (beyond simple labeling) to support coded data submitted to your CCR by reporting sources? ***Please check (✓) only one.***

Yes, by all sources

Yes, by most sources ➡ Specify type(s) of facility:_____

_____

No

23. Does your CCR maintain all information, including supporting text, from source records (either electronically or in hardcopy)? ***Please check (✓) only one.***

__ Yes

No

Not applicable, no text is received by CCR

AUDITS

24. Has your CCR performed case finding audits at reporting sources within the past year (1998)? ***Please check (✓) yes or no and, if yes, enter number audited.***

Yes ➡ Enter number reporting sources audited _____

___ No ➡ Skip to Q. 27

25. Why are case finding audits done? ***Please check (✓) all that apply.***

Standard QA procedure

When fewer than expected cases are reported

Other, specify: _____

26. What steps did you take at the CCR to reduce missing cases in the future? ***Please describe below.***

_____

_____

_____

_____

_____

27. Has your CCR performed reabstracting audits at reporting sources within the past year (1998)? ***Please check (✓) yes or no and, if yes, enter number audited.***

___ Yes ➡ Enter number reporting sources audited ____

___ No ➡ Skip to Q. 30

28. Is a standard percentage or number of cases reabstracted at each source? ***Please check (✓) only one and, if yes, enterpercentage or number.***

Yes, standard percentage ➡ Enter percentage of cases reabstracted ____%

Yes, standard number ➡ Enter number of cases reabstracted ____

No, neither a standard percentage nor a standard number of cases are reabstracted at each source.

29. Why are reabstracting audits done? ***Please check (✓) all that apply.***

__ Standard QA procedure

___ Response to specific problem

___ Other, specify: _____

USE OF REGISTRY DATA

30. For which years has an annual report been produced (either hardcopy or electronic) of cancer incidence for the State? ***Please check (✓) all that apply***

Available for 1997 data

Available for 1996 data

Available for 1995 data

Available for 1 or more years prior to 1995

None available ➡ Skip to Q. 35

3 1. In which format(s) is the most recent annual report available? ***Please check (✓) all that apply***

___ Hard copy

Electronic word-processed file

Web page/query system

___ Other, specify _____

32. To what population were the most recent incidence rates standardized? ***Please check (✓) all that apply·***

1970 U.S. standard population

1990 U.S. standard population

2000 U.S. standard population

___ Other, specify: _____

33. Have the CCR cancer data from the past five years been published or presented in NAACCR's *Cancer Incidence in North America?* ***Please check (✓) yes or no and, if yes, enter year-***

___ Yes ➡ Enter most recent year of published data: 19- -

-No ➡ Skip to Q. 35

34. Were these data used in computing the U.S. combined incidence rates in the above-referenced publication? ***Please check (✓) yes or no·***

Yes

N o

35. In which of the following ways have registry data been used in the past year (**1998**)? ***Please check (✓) all that apply·***

Incidence/mortality estimates

Health event investigations

Response to inquiries/data requests

Needs assessment/program planning

Program evaluation

Clinical studies

___ Quality-of-care studies

Epidemiologic studies

Linkage with breast and cervical cancer screening program to improve registry case finding

Linkage with breast and cervical cancer screening program to improve screening follow-up

Other, specify: _____

Not used

36. Does the CCR maintain a log of requests for registry data? ***Please check (✓) yes or no and, if yes, enter number requests received.***

__ Yes ➡ Enter number of requests received in past year (1998) _____

___ No

37. For which years is an analytic data file available for approved research? ***Please check (✓) all that apply-***

- Available for 1997 data

Available for 1996 data

Available for 1995 data

Available for 1 or more years prior to 1995

___ None available

38. To whom are the analytic files available? ***Please check (✓) all that apply.***

In-house staff

Outside researchers (approved studies)

Other, specify: _____

Not available

SELF ASSESSMENT

39. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for data **completeness.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

State data exchange not happening

Reporting facilities lack adequate staff

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

40. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for **timeliness.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Reporting facilities lack adequate staff

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

41. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for data **quality.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

Not enough staff

Not enough staff with the necessary qualifications

Software inadequate

Hardware inadequate

Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

42. Which of the following is primarily responsible for any difficulties your CCR experiences meeting NPCR program objectives for **data use.** ***Please use a "1" to indicate the most importantfactor, "2" for next most important, etc.***

___ Not enough staff

Not enough staff with the necessary qualifications

___ Software inadequate

___ Hardware inadequate

___ Other, specify: _____

None of the above, our CCR does not have difficulty meeting this objective.

2. Were the following NPCR **recommended** data items collected or derived in **1996**? ***Please check (✓) yes or no for each data item.*** *Refer to most recent NAACCR standards, Vol II, for description of data items.*

Item Name	Item #	Yes	No	Item Name	Item #	Yes	No
Patient ID Number	20			RX Date - BRM*	1240		
Registry ID	40			RX Date - Other*	1250		
NAACCR Record Version	50			RX Coding System - Current	1460		
Tumor Record Number	60			First Course Calc Method	1500		
Marital Status at DX	150			ICD Revision No†	1920		
Computed Ethnicity†	200			Place of Death†	1940		
Computed Ethnicity Source†	210			Over-rides (various)†	1990 - 2074		
Age at Diagnosis†	230			Date Case Report Exported	2110		
Birthplace	250			SEER Coding Sys - Current	2120		
Occupation Code - Census†	270			SEER Coding Sys - Original	2130		
Industry Code - Census†	280			COC Coding Sys - Current	2140		
Occupation Source†	290			COC Coding Sys - Original	2150		
Industry Source†	300			Date Case Report Received†	2111		
Occup/Ind Coding System†	330			Date Case Report Loaded†	2112		
Sequence Number - Central†	380			Date Tumor Record Availbl†	2113		
Reporting Hospital	540			Name - Alias	2280		
Accession Number - Hosp	550			Medical Record Number	2300		
Date of Inpatient Disch	600			Military Record No Suffix	2310		
Class of Case	610			Addr at DX - No & Street	2330		
Tumor Size	780			DC State File Number†	2380		
Regional Nodes Positive	820			Name - Maiden	2390		
Regional Nodes Examined	830			Text - Diagnosis (various)	2520 -2600		
RX Date - Ca Dir Surg*	1200			Text - Treatment (various)	2610 -2670		
RX Date - Radiation*	1210			Text - Remarks	2680		
RX Date - Chemo*	1220			Place of Diagnosis	2690		
RX Date -Hormone*	1230						

* When available

†Derived or added by central registry. Some items (e.g., date of death) could be coded by hospitals OR derived

3. Does the CCR use the NAACCR data exchange record layout to import and export data? ***Please check (✓) yes or no and, if yes, indicate version currently used-***

Import data? ___ Yes ➡ Latest layout version number: _____
No

Export data? ___ Yes ➡ Latest layout version number: _____
No

Questions 4 through 6 refer to 12 months after close of diagnosis year

4. What was the percentage of expected 1996 cases reported to the CCR by **January 1, 1998**? ***Please provide numerator, denominator and percent in the spaces below·***

Numerator (# cases registered) _____
Denominator (#-expected cases) _____
Percent (use single decimal) _____

5. What data were used to calculate the expected number of cases listed above? ***Please check (✓) only one·***

ACS estimates
SEER incidence rates
Historical state data
Other, specify: _____

Questions 6 through 11 refer to 24 months after close of diagnosis year

6. what was the percentage of expected 1996 cases reported to the CCR by **January 1, 1999**? ***Please provide numerator, denominator andpercent in the spaces below.***

Numerator (# cases registered) _____
Denominator (# expected cases) _____
Percent (use single decimal) _____

7. What method was used to calculate the expected number of cases listed above? ***Please check (✓) only one-***

- NAACCR method (ratio of incidence to mortality)

ACS estimates
SEER incidence rates
Historical state data
Other, specify: _____

8. What was the percentage of **1996** cases reported by a death certificate only as of **January 1, 1999**? ***Please provide numerator, denominator and percent in the spaces below.***

Numerator (# cases death certificate only) _____

Denominator (# registered) _____

Percent (use single decimal) _____

9. What percentage of **1996** cases had **missing** or unknown values for the following variables? ***Values are missing if any part is missing (i.e., month or year for dates).***

Age at diagnosis (item # 230) _____

Race 1 (item # 160) _____

Sex (item # 220) _____

Address at DX - State (item # 80) _____

County at DX (item # 90) _____

Primary Site (item # 400) _____

Date of DX (item # 390) _____

Diagnostic Confirmation (item # 490) _____

Summary Stage (item # 760) _____

Text - Usual Industry (item # 320) _____

Text - Usual Occupation (item # 3 10) _____

10. What percentage of unduplicated **1996** cases was microscopically confirmed? ***Please provide numerator, denominator andpercent in the spaces below.***

Numerator (# cases confirmed) _____

Denominator (# cases registered) _____

Percent (use single decimal) _____

11. What percentage of **1996** cases have a coded census tract (NAACCR Data Item #1 10) equal to each of the codes listed below? ***Please list percent in each of the spaces provided below.***

000 loo-949999 (census tract codes) _____

950100-998999 (census block codes) _____

000000 (area not census tracted) _____

999999 (area census tracted, but tract not available) _____

PART C:
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 these "advanced activities" that your CCR may currently engage in. Please answer the questions below and then in the space provided at the end, please describe other activities your CCR has engaged in that have not been addressed in these questions.

1. Does your CCR have the ability to do automated case finding using electronic linkage ***with*** any of the following sources? ***Please check (✓) all that apply.***

   Yes, via pathology reports
   Yes, via master disease index
   Yes, via some other source, specify: _____
   No, not able to do electronic case finding

2. Is your CCR able to receive encrypted data via Internet from reporting sources? ***Please check (✓) only one.***

   Yes
   Currently being developed and/or implemented
   No, not able to receive encrypted data via Internet from reporting sources

3. Does your CCR geocode cancer cases by latitude/longitude to enable mapping or reporting of cancer cases? ***Please check (✓) yes or no.***

   Yes
   ___ Currently being developed and/or implemented
   No, the CCR does not geocode cancer cases

4. How often is your CCR linking to the National Death Index? ***Please check (✓) only one.***

   Annually
   ___ Other frequency, specify: _____
   Does not link to the National Death Index ➡ Skip to Q. 7

5. How often is your CCR resolving possible matches with the National Death Index? ***Please check (✓) only one.***

   Annually
   Other frequency, specify: _____
   Not resolving possible matches with the National Death Index

6. After the National Death Index linkage has been performed, what is the percentage of cases for 1996 with known cause of death? ***Please use as your denominator those with a vital status equal to "dead."***

Numerator (# cases known cause) _____

Denominator (# cases vital status "dead") _____

Percent (use single decimal) _____

7. Does your CCR conduct survival analysis? ***Please check (✓) yes or no***

Yes ➡ Briefly describe the method used: _____

_____

_____

_____

___ No

8. With which databases has your CCR linked its records in the past year (1998) for follow up or some other purpose? ***Please check (✓) all that apply.***

State vital statistics

National Death Index

Department of Motor Vehicles

Department of Voter Registration

Medicare (Health Care Financing Administration)

Medicaid

Managed care organizations

Other, specify: _____

None

9. Briefly describe the research studies conducted (can be ongoing) in the past year (1998) using registry data. ***Please include in your description the affiliations of the individuals who conducted the studies/projects (i.e., registry staff, other state staff (speczyy), university researchers (speczyy), other researchers (speczyy)) as well as a brief description of the research objectives.*** *If any publishedproducts have resulted from these studies, make sure they are included in the supplemental materials list at the end of this instrument, If the list is long, you may restrict your response to the five studies you consider to be the most significant.*

10. 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 asked about some of these "advanced activities" that your CCR may currently engage in. What other advanced activities (i.e., advanced data security, implementation of cancer inquiry response system, etc.) has your CCR engaged in this past year (1998) that were not addressed in the questions above? ***Please describe in the space provided below.***

Supplementary materials requested by CDC project officer

The materials listed below will help your CDC project officer serve you better. It is important that you keep your project officer informed about new developments or changes in operations so that he or she can provide you with sound and appropriate technical assistance.

The tables below are designed to help you make sure that your project officer has the most recent versions of each of these important materials and is kept abreast of the latest publications resulting from your registry. Please use the first table to indicate when each document was last updated, whether you have already provided your project officer with this version, whether you are sending it now under separate cover, or whether you are unable to provide it at this time. If unable to provide a given document, please explain why and indicate when it can be made available.

Materials *@lease send most recent versions only*)	**Date** of most recent version	**Previously provided** (✓)	**Sending now** (✓)	**Unable to provide** (please explain)
Letter from State attorney general (see question A6)				
State legislation and regulations (see questions A4 and A5)				
Written policies and procedures (see question A7 for list)				
Annual report (hardcopy and/or electronic) (see question A3 0)				

New publications

Please use this table to list new (in the past year) publications and conference presentations by registry staff OR check (J) here _____ if a list will be sent under separate cover with the above materials.

Author(s)	**Title**	**Publication forum (journal name, conference, etc.)**	**Date of publication/ presentation**

Appendix D Implementation Recommendations

Implementation of an Evaluation for CDC's National Program of Cancer Registries (NPCR): Options and Recommendations for Data Collection

June 1999

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Implementation' of an Evaluation for CDC's National Program of Cancer Registries (NPCR): Options and Recommendations for Data Collection

Contract No. 200-96-0599
Task Order No. 16

Submitted to:

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1.0 Introduction

The CDC National Program of Cancer Registries (NPCR) has been providing funding since 1994 to establish or enhance state central cancer registries to reduce cancer mortality as part of a national disease prevention strategy. A cancer registry is a fundamental tool for cancer surveillance. Data collected through statewide cancer registries can be used to identify trends over time, to discover cancer patterns among various populations, and to show whether screening and other prevention measures are making a difference. This information is essential to states in directing effective cancer prevention and control efforts.

As NPCR looks ahead to its second five years of funding, the Cancer Surveillance Branch (CSB) in CDC's Division of Cancer Prevention and Control -the agency charged with implementing this national program — is in the process of reviewing the evaluation tools used to assess progress towards program goals and objectives. The Cancer Surveillance Branch contracted with Battelle Centers for Public Health Research and Evaluation to help with this review. Battelle is working with members of the Branch Evaluation Working Group to revisit program goals and objectives, evaluation criteria, and the evaluation instrument. In addition to helping CSB refine its evaluation instrument, Battelle has also been asked to identify the most effective and efficient method of data collection for administering it. This report surveys administration options and assesses the fit between these various options and the characteristic features of the instrument.

Every data collection method has its advantages and disadvantages. The best method of data collection for a given program evaluation depends upon the program being evaluated and the attributes of the evaluation tools designed to evaluate that program. Selecting the best method involves assessing the strengths and weaknesses of the method against the particular needs of the evaluation to find the best match between data collection method and the attributes of the evaluation tool.

The primary attributes of the revised evaluation instrument for the NPCR are listed below:

- *Basic administration requirements.* The evaluation instrument will be implemented annually in all states and territories receiving funding under NPCR, which means that the respondents are highly motivated and can be expected to cooperate. All funded programs (49 registries were funded in fiscal year 1997) will be required to complete the instrument (a 100% response rate is required).

- *Modular structure.* The instrument is comprised of three modules. The questions in the first module (Part A) will remain fixed over time. Answers to these questions, which relate to infrastructure to support registry activities, may change little from year to year for some states. Therefore, respondents need to be able to see and modify their previous year's

answers. Part B will be completed by all funded registries only until CDC has a system in place to receive data sets from the states. This will allow CDC to directly answer these questions rather than to rely on self reported information. The questions in the third module (Part C) may vary in content from year to year. This module is designed as a way for **NPCR** staff to gain understanding about the activities that funded registries are engaged in that are not required by the program but that enhance the ability of the states to effectively engage in cancer prevention and control activities.

- *Complexity of instrument design.* The questions are primarily closed-ended and responses can be easily precoded. There is no complicated skip logic.

- *Complexity of instrument content.* Many of the questions are complex and are potentially subject to variations in interpretation. Respondents will need access to instructions and definitions. This includes clarification of questions, instructions for how to perform calculations, and detailed descriptions of response categories. Respondents will also need to locate and collect information and perform calculations to be able to complete the instrument.

- *Centralized dataprocessing and analysis.* CDC will need to compile all responses from all central cancer registries into a single database for analysis. To monitor responses and respond to inquiries, CDC will want to have ready access to evaluation data. Trends over time will be of interest, so the database should be cumulative. In addition to responses to the evaluation instrument, CDC will also request **registry data set submissions** from each respondent. Datasets received from states will be managed and analyzed by CDC or a third-party contractor and used to answer questions in one of the modules (Part B). This information will need to be integrated with the responses received from states to questions in Parts A and C.

In the remainder of this report, we present a description of data collection methods available for this program evaluation and a discussion of the requirements for and the advantages and disadvantages of each option. We conclude by recommending the data collection method we believe to be the most effective and efficient for this evaluation. The data collection methods reviewed in this report include:

- Mail survey
- Telephone survey
- Electronic-mail survey
- Free-standing application
- World Wide Web-based system

2.0 Data Collection Options

In Section 2.0 we present several data collection options for CDC's annual evaluation of the National Program of Cancer Registries. For each option we describe generally how data collection is conducted, the basic requirements for implementation, and the advantages and disadvantages of the option, especially in relation to the primary attributes of the revised NPCR evaluation instrument. At the end of Section 2.0 is a table that provides a summary of this information for each option. The options discussed in this chapter are as follows:

- Mail survey (Section 2.1)
- Telephone survey (Section 2.2)
- Electronic-mail survey (Section 2.3)
- Free-standing application (Section 2.4)
- World Wide Web-based system (Section 2.5)

2.1 Mail Survey

The self-administered, paper-based, mail survey is a common form of data collection. The data collection and management process for a paper-based mail survey involves eight steps:

1. The questionnaire form is printed and then distributed to respondents through the mail or a package delivery service.

2. Respondents receive the questionnaire, mark their responses directly on the paper form, and return the questionnaire through the mail or package delivery service.

3. Telephone and/or mail follow-up are conducted to encourage timely and full responses in order to obtain. 100 percent response rate.

4. The returned questionnaires are reviewed by a data entry/editor specialist to make sure there are no immediately recognizable problems that might disrupt or compromise data entry and quality. Open-ended questions are coded. All editing and coding decisions are recorded in a log.

5. First round of data entry is conducted.

6. Second round of data entry is conducted.

7. The two rounds of data entry are compared to identify discrepancies. Discrepancies are resolved and both databases are corrected. Discrepancy reports are rerun until all differences are corrected.

8. Electronic data checks are performed to finish the data cleaning process and a codebook is prepared to accompany the data.

Once the eight steps are completed, the database is ready and reports and analyses can be generated or performed.

Requirements for Development, Operation, and Maintenance

Though a paper-based mail survey is relatively simple to produce and conduct, time and money are required to format the survey for self-administration, program data entry forms that match the instrument, conduct data entry, implement quality control procedures to produce a clean, accurate, complete database, program various reports or analyses, and conduct ongoing database maintenance. Time and costs associated with printing, distributing, redistributing, and tracking and receiving the questionnaires must also be considered. Staff must also be available to answer questions by telephone.

Producing copies for distribution to respondents is a simple matter of printing a copy of the formatted file and reproducing the desired number of photocopies. However, if different respondents are required to respond to different sets of modules, multiple versions of the questionnaire need to be created based on the required combinations of modules for the different groups of respondents. Care must be taken to ensure that each respondent receives the correct combination of modules. Distribution and return of the questionnaires by mail, although relatively low cost, takes considerable time. Distribution by package delivery service (e.g., UPS or FedEx) also takes considerable time and is relatively more expensive. While these costs may be relatively low during a single data collection period, for an annual survey they must be borne every cycle.

The data collected must be stored in an electronic database to facilitate analysis and reports. Computer programming is required to create and maintain this database. Data must be entered into the database, so a programmer must create data entry screens, and a trained staff is needed to enter the data. Additional programming, data entry, and editorial supervision are required to verify data entry, conduct quality control procedures, and ensure that the final database is free of errors. A tracking system must also be created.

Advantages

This option has several advantages when compared to the electronic or computerized data collection options. One of the main advantages is that the questionnaire is relatively inexpensive and easy to design and produce. Although survey design expertise is required, the questionnaire form can be created using any word processing or questionnaire development software package. Once a respondent has received the questionnaire, work on completing the form can proceed at the respondent's discretion, i.e., at any time or location that is convenient.

The up-front costs are low for the paper-based system compared to the other options because the questionnaire form can be produced easily with relatively cheap, readily available technology. The other options (e.g., computer-assisted telephone, Web-based, free-standing application) require an up-front investment to develop integrated electronic data collection and storage systems. However, even a good paper-based system will eventually require an electronic data storage system, so unless the questionnaire is an extremely simple one involving very limited data, an investment in development and maintenance of the system will have to be made at some point.

Disadvantages

This option has'several disadvantages when compared to the electronic or computerized data collection options. Since the NPCR evaluation is implemented annually, the process of conducting the paper-based questionnaire survey must be repeated, and thus expenses for mailing and tracking are incurred yearly. Savings could be realized from year to year with the electronically-based options since the development work conducted in the initial year to set up those systems would still be in place for subsequent years and would not need to be repeated.

When distributed to respondents through mail or package delivery, more tracking and quality control are required than with other methods. These steps are needed to ensure that the correct questionnaire was delivered to every respondent, the respondents comply with the data reporting requirements, and the questionnaire forms are filled out as completely as possible. It is easy for respondents to ignore or delay completing the questionnaire and to misplace or lose the form sent to them. Missing data are a regular occurrence with mail questionnaires, resulting in costs associated with follow-up to fill in the missing data. Time and expense are also involved in verifying that respondents have received the questionnaire, making follow-up calls when questionnaires are not returned in a timely fashion, and delivering additional questionnaires when those sent are lost or misplaced. Further, if mistakes are discovered on the questionnaire after distribution (e.g., inclusion of an incorrect set of modules), or initial responses have exposed some flaws in questionnaire design, it is expensive and time-consuming to retrieve the original questionnaire and correct, reprint, and redistribute the updated version.

Finally, respondents can save photocopies of questionnaires from previous years so they can refer back and then re-enter data that does not change from year to year. However, this is inefficient and more prone to errors when compared to electronically-based options that allow quick and easy review of previously entered data. Calculations necessary to provide certain types of numeric data, which could be programmed into a free-standing application or Web-based questionnaire, would need to be performed by individual respondents, increasing the possibility for error.

2.2 Telephone Survey

Telephone interviewing is a common and effective way to collect survey data. Interviewers make scheduled phone calls to respondents, asking them scripted questions and recording their responses on paper or into a computer (preferably directly into a database). Computer-assisted telephone interviewing (CATI) is the more sophisticated approach within this mode. CATI combines and supports sampling frame selection, scheduling, interviewing, and data entry. The interviewer uses the CAT1 system to select a respondent, make the call at a pre-scheduled time, and proceed through the questionnaire by asking the questions that appear on screen, entering the data directly into the computer where the data is stored in a project database. Alternatively, data could be collected without the use of CAT1 technology. For example, CDC staff could act as the interviewers, scheduling the calls, conducting the interviews, and recording responses either on paper or into a word processor. The data could be added to a central database at a later time.

Requirements for Development, Operation, and Maintenance

The telephone interview option, whether paper-based or CATI, requires interviewing staff and supervision of these staff. Paper-based telephone interviewing also requires data entry staff, plus all of the data preparation and management steps outlined for the mail survey. A CAT1 survey requires programming expertise and a technological infrastructure. It is likely that a CATI data collection effort would need to be performed by a third-party contractor with the necessary technology and expertise, Finally, for both options all respondents must have access to a telephone at the time of the scheduled interview and for the total duration of the interview. Given that most, if not all NPCR respondents will have this kind of access, this would not present a problem.

Advantages

Telephone interviewing has several advantages, especially ***with the use of*** *CATI.* First, for both CAT1 and non-CATI, there is flexible scheduling for administration of the questionnaire, including scheduling the initial interview appointment and completion/follow-up calls.

Second, the CAT1 system can be programmed in such a way that the correct combination of instrument modules for each respondent would appear on the interviewer's computer screen once the interview is initiated.

Third, for both CAT1 and non-CATI, it is relatively easy to modify the instrument mid cycle compared to the self-administered, paper-based option. If after the first few interviews a flaw in the instrument design is discovered, then changes can be made immediately, and interviewers can simply

implement the new version. Such a rapid response would be impossible with a mailed questionnaire. A CAT1 approach would facilitate the modification of the instrument modules from year to year via the ability to reprogram the CAT1 system.

Fourth, the interviewer has considerable control over administration and tracking of the questionnaire and can respond to problems immediately as they arise. If a respondent does not understand a question, the interviewer can provide a standardized explanation. If a respondent must quit the call before the interview is complete, the interviewer can immediately schedule a follow-up call. If using CATI, this function is automated. Also, if using a CAT1 system, data quality control is built in through pre-programmed data editing. In general, there is better quality control and tracking with the telephone interview as compared to the self-administered, paper-based option.

Lastly, there is no need for duplicate data entry if responses are recorded directly onto a computer by the interviewer (e.g., via data entry screens linked to a database such as with CATI). This saves time and money because additional data entry and data preparation staff are not required.

Disadvantages

One of the disadvantages of the telephone interviewing (both non-CAT1 and CATI) option is the up-front cost. Interviewers are needed to conduct the interviews, and they need at least a minimal amount of training in order to implement the instrument correctly and consistently. This means annual costs associated with the interviewing staff would be incurred. In addition, for the CATI option there would be programming costs associated with the development of the CAT1 system or some other type of supporting database with data entry screens for the interviewer. However, these programming costs. would diminish after the initial data collection period if the system did not require redevelopment but only limited modifications in subsequent years.

A second disadvantage is that there is less schedule flexibility for the respondent with the telephone interviewing option. Respondents must set aside a block of time to participate in the interview and cannot complete the questionnaire at their own pace. Furthermore, if a respondent does not have ready access to the requested information, then they may either provide inaccurate data or not be able to provide the data at the time of the interview. The latter would lead to an interrupted or incomplete interview, requiring additional follow-up interviews, and adding to the effort, cost, and time to collect the necessary data.

2.3 Electronic-mail Survey

A third option for collecting evaluation data is through electronic-mail systems. Special software allows the survey questionnaire to be imported from a word processor format (e.g., Microsoft Word or WordPerfect) and then converted to a self-extracting, executable file (e.g., a file with the ".exe" extension). The executable file is attached to an e-mail message, which is addressed to a list of respondents. When the respondents receive the e-mail message, they open the file, which then runs on their PCs as a "dummy-DOS" program. This means that the respondents can fill out the questionnaire on their computer screens without any special software, and the hardware and operating system requirements are minimal. To fill out the questionnaire, the respondents open the newly installed program and simply type the requested information directly into data entry fields. When the respondents have completed the questionnaire, they return the file with data by sending it back to the originator as an e-mail attachment. When the completed questionnaire is received, the file is imported into the special software which combines the new data with all other responses. The data can be verified, cleaned, and then used for analysis.

Requirements for Development, Operation, and Maintenance

This option requires special software for designing and creating the self-extracting, executable files such as, for example, GroupSystems for Windows'. A trained staff person or contractor is needed to design and create the executable files based on the revised evaluation instrument. As with the paper-based questionnaire, multiple versions of the questionnaire must be created based on the required combinations of modules, and care must be taken to ensure that each respondent receives the correct combination of modules. All respondents would need an e-mail account in order to receive the file. Once a questionnaire is returned, the data can be compiled automatically into a single database within the software. However, it may be necessary to export the compiled data into a statistical analysis software package (e.g., SAS or SPSS) if the data analysis capabilities of the particular software chosen to do the questionnaire do not meet CDC's needs. Data verification and cleaning must be done as well to ensure quality. Staff must also be available to do tracking and follow-up to ensure a 100% response rate and to provide technical assistance to respondents. With the growing prominence of e-mail, it is likely that the products available for creating and administering surveys via e-mail will continue to improve.

[1] Concepts Guide. Ventana Group Systems. Workgroup Edition 2.0. 1990-1998. Ventana Corporation, Tucson, Arizona. www.ventana.com.

Advantages

In many ways the e-mail questionnaire is similar to the paper-b

e-mail option uses an electronic medium and avoids the disadvantages associated with us

of the questionnaire. One of the main advanta

distribute and return the questionnaire. Also, there is no need to spend time printing cop

questionnaire, creating packages for each respondent, and distributing them by postal serv

delivery as is necessary with the paper-based questionnaire. There is no double entry of

each completed questionnaire, i.e., the executable file, can be imported into the software

into a single dataset. Furthermore, the costs of

interviewing staff is not needed.

with CDC or contractor staff persons to receive assistance. Because a 100% response rate is required and the questionnaires must be completely filled out with all of the required data, these efforts would have to be particularly intensive to achieve such outcomes. All of this can be time consuming and would require a significant investment of staff time.

The capabilities of the available software packages for e-mail questionnaires vary considerably and can be rather limited. In order to do advanced data cleaning, analyses, and management, the compiled data from each year may need to be transferred into another database or statistical software package (e.g., Paradox, SPSS, or SAS). There may also be limitations in the ability to create and manage different versions of the instrument based on different module combinations, and to recognize different groups of respondents.

Finally, access to the data from previous years could be limited, depending on the software used. For example, it may be possible for respondents to save copies of the executable files from previous years, which they could open and view on-screen when they need to reenter the same information in subsequent years. It may also be possible for respondents to print hardcopies of the questionnaire to file for future reference. However, such functions are not standardized and are dependent on the particular software product used to develop the e-mail questionnaire.

2.4 Free-standing Application

A free-standing application is a software program specifically designed to collect the desired information. The application is created and then installed on individual personal computers that are available to cancer registry program staff. This type of application is essentially a database designed to allow cancer registry staff to enter information through a series of data entry screens based on the sections of the evaluation instrument. Once all of the required data are entered and the database is complete, a copy would be delivered to CDC to be combined with a central database containing the same data items from all other registry programs.

An example of this option is the System for Technical Assistance Reporting (STAR), a Microsoft Windows-based application developed for the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). STAR is used to collect and report information on the management and infrastructure components of the NBCCEDP. STAR has three main components[2]:

1. *Data Entry* allows users to enter the requested data through a series of screens corresponding to the major categories of information. There are data entry fields for standardized or open-ended responses to each question. Users can navigate easily among all of the questions within the major categories.

[2] Guide to Using STAR: System for Technical Assistance Reporting. National Breast and Cervical Cancer Early Detection Program. February 1997.

2. *Reports* allow users to track their use of STAR. Users can determine which items have been completed and which have not or see what data they have entered for each question.

3. *Utilities* are functions that allow users to create data files from the data they have entered and to export the data so that their files can be combined in a central database.

Once all of the requested data are entered into STAR, the user creates a copy of the database file, compresses the file, and sends it to a third-party contractor as an electronic mail attachment or by mail on a floppy diskette. The contractor verifies the viability of the database file and then forwards a final copy of the file to CDC.

Requirements for Development, Operation, and Maintenance

The free-standing application requires a third-party contractor to develop and test the software. The software needs to be designed with hardware and operating system requirements designed to match existing PC technology. Ongoing technical support and maintenance are required from the contractor responsible for developing the software.

Advantages

The free-standing application has several advantages. The respondent has flexibility in providing the requested data. Like the paper-based, e-mail, and Web-based questionnaires, the respondent can enter data into the system at any time before the submission deadline, i.e., he or she is not restricted to an external schedule as with telephone interviewing. The respondent can locate all sources of information related to the instrument questions and respond thoroughly before submitting the completed questionnaire/data file. The application can be programmed to perform calculations when the respondent provides the basic numbers. And because the application is free-standing, it can run on a single PC for an unlimited amount of time without being dependent on connections to the Internet, as is necessary for a Web-based questionnaire. The application can easily be customized to install at each site only those modules that are appropriate.

Data quality control can be built into the application to prevent respondents from providing the wrong types of information for the question being asked. Assistance in filling out the questionnaire could be facilitated by context-specific, on-line help features. For example, "Help" buttons could be provided for specific questions or items in the instrument that, once clicked on by the user, would provide additional information such as in-depth explanations of questions or definitions of terms or concepts. Using such on-line help features could potentially reduce the amount of direct assistance requested of CDC or contractor staff and could increase data quality by reducing confusion over questionnaire items. Respondents have the ability to determine which items are complete and which are not, allowing them to

track their own work so that the final database file is as complete as possible. The application can also allow respondents to save database files for their own records so that they can refer back to these files when necessary. There is no need for interviewing or data entry staff other than the registry staff person working with the application. This approach also eliminates the need for second entry and discrepancy reconciliation.

Disadvantages

The free-standing application has the disadvantage of requiring a considerable up-front investment in order to develop the system. Because no pre-existing system is likely to meet the specific needs of the NPCR evaluation, a completely new application will have to be developed based on the current instrument.

Further, there are additional technical problems involved in installing and maintaining free-standing applications on PCs at multiple sites. In order for the system to work, it requires proper installation and compatibility with hardware or operating systems. There is also the cost of providing staff not only to answer the questions but also to deal with software bugs and other technical problems. Submission of data also requires effort and technical expertise on the part of the user, who must be able to download, zip, and transmit the file.

With the free-standing application there is little control over ensuring the quality of the data and completeness of the database files. Data quality is only verifiable once a "final" database file has been submitted. Completeness can only be determined after the database file has been created and submitted. If there are problems with the data or the database file is not complete, follow-up is required and a new database file may have to be submitted.

Finally, there is the problem of question modification. It is anticipated that one of the modules may change from year to year. The application would be designed based on a single version of the evaluation instrument. If the instrument were modified in any way, either within one data collection cycle or between cycles, a new version of the application would need to be developed. It would then be necessary to distribute the new version of the application and to make sure that it is properly installed and working correctly on the PCs for all cancer registries.

2.5 World Wide Web-based System

A World Wide Web-based survey system is a data collection method which uses the Internet to collect the desired information. For this option the data collection instrument is converted to a series of

HTML[3] files to form a World Wide Web site. The respondents access the World Wide Web site through the Internet and provide the evaluation data through a series of interactive Web pages. The Web site would be hosted on a server and would be linked directly to a database that stores the provided data. Each page of the Web site would be based on sections of the instrument and could appear on screen the same way that the pages of the questionnaire would appear on paper. In this case a data entry field for providing information would correspond to each item on the instrument, and the user would be able to type the information directly into the data entry fields on-screen. After a section or page is completed, the respondent'can click an on-screen button that would then submit the data directly to the database on the host server. Once the section/page had been submitted, the next page/section would appear on screen and the respondent could continue. The site could be designed so that the respondent can view and interact with any section of the instrument at any time and can even print or review data previously submitted.

Requirements for Developuient, Operation, and Maintenance

Respondents would need to have good, consistent Internet access and a Web browser to use this system. In addition, the Web-based questionnaire would require a considerable amount of up-front programming, development, and testing to convert the existing instrument into an effective Web site and on-line database. A Web server would be required to host the Web site and the underlying database. CDC could dedicate one of its own servers to this task and hire programmers (or utilize current in-house staff with this expertise) to assist with development and maintenance. Alternatively, CDC could contract with a firm to provide the required programming expertise and a Web server to host the site. CDC would also need to be prepared to address technical inquiries and to provide support to respondents facing technical difficulties completing and sending the questionnaire.

Advantages

The Web-based questionnaire is excellent for periodic (in this case annual), multi-site data collection and has a number of advantages over the other options.

First, a respondent with any common Web browser application (e.g., Netscape Navigator or Microsoft Explorer) can access the system. There is no need to install a special application (such as STAR) on a computer at each site, and thus no need to be concerned about proper installation or other technical support issues associated with the application. In addition, there is no need to redesign, redistribute, and reinstall the software when new versions of the instrument are created, since accessing the Web site and providing data are not dependent on any single application. If changes to the instrument

[3] Hyper Text Mark-up Language, the standard format for all World Wide Web applications.

are made, the same changes can simply be made to the appropriate pages of the Web site. This reduces the costs of system development and maintenance that are associated with free-standing applications.

Second, a Web-based system would accommodate the modular instrument design. Access to the Web site would be limited to respondents with recognized user names and passwords. Access could be programmed in such a way that when respondents log in with user name and password, they only receive access to the appropriate modules. If respondents are expected to fill out different modules from one year to the next, their access would be altered to provide the correct set of modules each year.

Third, respondents are able to provide the data on their own schedule and over a series of sessions rather than at the more strictly scheduled sessions typical of telephone interviews. Respondents can also view previous years' responses, or the data provided for the current year but at an earlier session. As with the free-standing application, the system could be programmed so that calculations would be performed based on numbers provided by the respondents. The results of the calculation could then be viewed on screen as well as stored in the'central database.

Fourth, the Web-based system allows for automated tracking and follow-up of incomplete or late submissions. Modification of submitted entries is also greatly simplified. In some cases it is necessary to modify the data provided by a respondent, e.g., modify an existing record or finish an incomplete questionnaire. For a paper-based mail, e-mail, or free-standing application survey this would involve sending forms/files back for someone to fill in the missing or incorrect information or a telephone follow-up call. For the telephone-based survey it involves scheduling at least one call back. However, the Web-based questionnaire overcomes these limitations. For example, information can be provided on the Web site so the respondents can see which sections are complete and which ones are not. If the entire instrument has not been completed by a certain date, or a certain portion of all items is not filled out by a certain date, then e-mail messages could be automatically sent to the respondents who are falling behind, reminding'them of the deadline. Data editing and quality control can be programmed into the system so that anticipated errors and incorrect information would be identified at the time of submission and the respondent would be notified immediately.

Fifth, the Web-based questionnaire does not require interviewers or data entry staff, as do the paper-based mail and telephone interview options. The only data entry required is that done by respondents as they fill out the questionnaire on-line. Only a limited number of central staff would be required for programming and analysis, telephone follow-up of special cases, and limited respondent assistance. Providing assistance to respondents in filling out the questionnaire could be facilitated efficiently by context-specific, on-line help features. For example, hyperlinks could be provided for specific questions or items in the instrument that would download additional information such as in-depth explanations of questions or definitions of terms or concepts. Using such on-line help features could

potentially reduce the amount of direct assistance from CDC staff, and could increase data quality by reducing confusion over questionnaire items.

Furthermore, since all data submitted from all programs is automatically stored in the same database, there is no need to combine data sets from different cancer registries as would be necessary with the free-standing application. While the respondents can enter the data at any time up to a specified deadline, the central database always has the latest and most complete information. Either the database administrator or designated CDC staff have access to the data from the beginning, and ad hoc reports or analyses can be created and run on a daily basis. It would even be possible to allow state cancer registry staff access to reports, allowing them to compare their own progress with those of other registries. There is no need to wait for all the data to be collected, entered and/or combined to begin to learn from the information provided. The Web-based option could also be used to facilitate the submission of cancer registry data sets that will ultimately be requested by CDC to support Part B of the evaluation. The Web site designed to collect evaluation data can also include a page providing instructions for data preparation and the means to download an FTP application that would be used to make the actual data set submission.

Disadvantages

The Web-based questionnaire has limitations that may prevent its implementation in the short run. First, even though the Web-based questionnaire allows some control over instrument completion and data quality, it is still relatively limited compared to the telephone interview. In telephone interviews the interviewer is always present to talk the respondent through each item of the questionnaire and can assist the respondent with any questions or problems that arise. The on-line help features of the. Web-based questionnaire would not be as responsive or flexible as the interviewer. However, the completion rates and data quality may prove to be sufficient under this system, since NPCR respondents are required to respond as part of their program activities and are familiar with computerized applications.

Second, the respondent needs to have good, uninterrupted Internet access and a Web browser. Access to the Internet and Web browsers is becoming increasingly common, but we realize that not all organizations hosting a central cancer registry are at the same level of technological development. In some cases the organization may not support the technological infrastructure for the registry program staff to work with a Web-based questionnaire effectively, and these registries could have difficulty with the system. For other data collection options, the ability to participate only requires either a mailing address and a pencil, a telephone, an e-mail account, or a functional personal computer, most of which are taken for granted these days. As time goes on these limitations are likely to be overcome. Web access is growing and registries in the future are increasingly likely to use Internet platforms for case reporting,

data exchange, and data and report dissemination. Ongoing monitoring and evaluation via the Internet is likely to be the wave of the future.

Third, since the Web-based questionnaire may initially require that CDC contract with a third-party contractor for system development and maintenance, CDC would have to relinquish more of the data collection functions than may be necessary with the other options discussed in this report. The software and expertise needed to create this system are not widespread at this time, though many data collection and management firms do specialize in developing Web-based systems. However, reliance on a third-party is not unique to this data collection option and is far less than would be necessary with the development of a free-standing system.

Lastly, a concern that arises with a Web-based approach that does not apply to a free-standing system is that of data security. The security risks that need to be addressed before implementing a Web-based option include unauthorized access, data alteration, monitoring, and service denial. These are discussed in more detail in Section 3.

Table 1. Summary of Options for an Evaluation Data Collection System

Requirements	Advantages	Disadvantages
Mail Survey		
• Questionnaire formatted and printed to facilitate self-administration • Staff to prepare and mail questionnaires, track questionnaires and compliance, and conduct mail and/or telephone follow-up to attain required response rate • Programming to create database, tracking system, and data entry screens • Staff to conduct data entry, quality control and cleaning of data	• Low up-front costs to produce • Questionnaire is self-administered • Flexible scheduling for respondent, can enter data into application on own time and over a series of sessions • Easy to modify instrument between cycles • No development or maintenance of data collection system	• Costly to track distribution and completion • Follow-up to ensure response rate is time-consuming • Easy for respondents to ignore questionnaire, and to misplace or lose copy • Programming and data entry costs are high at the back end • Missing data are a regular occurrence, requiring follow back • Duplicate data entry required to ensure accuracy • Difficult and costly to change or modify questionnaire mid-cycle • Telephone help system needed • Calculations required must be performed by individual respondents and cannot be pre-programmed
Telephone Survey		
Non-CATI • Interview staff • Data entry software and staff • All respondents must have access to telephone for duration of interview	• Low up-front costs to produce • Interviewer has control over administration and tracking of questionnaire • Interviewer available to respondent during questionnaire completion to explain unclear terms or items (instant Help) • Modification or amplification of respondents answers is done while interview is in progress • Better tracking compared to self-administered option • Easy to modify instrument mid cycle • Easy to modify instrument between cycles	• Administration reauires trained interviewers • Interview mush happen at a pre-scheduled time • If respondent does not have ready access to information required, may result in inaccurate data, missing data, or an interrupted interview
CATI system (same as above except:) • CATI programming is required • Interviewers need computers with CATI system installed	(same as above except:) • Automated tracking of survey completion • No separate, duplicated data entry required; interviewers also serve as data entry staff • Good data quality control with built-in error traps as part of programming • Initial design and programming costs saved in subsequent cycles, although interviewing costs would remain	(same as above except:) • Cost and time for programming
Electronic-mail Survey		
• Special software that allows importation of the survey questionnaire from word processing software and conversion to a self-extracting, executable file • Respondents need e-mail account • Additional software may be required for statistical analysis (e.g., SAS, SPSS) • Staff for e-mail distribution, data verification and cleaning, tracking and follow-up, and technical assistance	• Low distribution costs • Questionnaire is self-administered • Flexible scheduling for respondent, can enter data into application on own time and over a series of sessions • Interviewing, double data entry, and data aggregation tasks are all avoided since respondent enters data that are compiled by software into a single data set • Easy to modify instrument mid cycle • Easy to modify instrument between cycles. Modifications are made\ to a master file with copies sent to respondents	• High uo-front work costs and technical expertise • Requires third-part contractor with the necessary software and expertise • Technical support required

Requirements	Advantages	Disadvantages
Free-standing Application		
• Up-front programming, development, and testing • Installation at multiple sites • Hardware, operating system compatibility • Technical support and maintenance staff	• Flexible scheduling for respondent, can enter data into application on own time and over a series of sessions • Allows respondent to track own progress in providing data • Allows respondent to keep and easily access records of previous years' responses • Calculations can be preprogrammed • Data quality control with built-in data editing as part of programming • No separate, duplicated data entry • Do not need interviewing and data entry staff (except data entry at registry program level) • Runs on individual PCs without Internet connection • Context-specific Help screens can be programmed into application	• High up-front costs to develop application • Tracking questionnaire administration and completion is more problematic, very little control • Difficult and costly to modify questionnaire • Technical problems: installation; hardware/OS compatibility; dealing with "bugs;" cost and administration of providing technical support to rectify problems • Aggregate database cannot be accessed until preparation is complete and then only by central compiler • Submission involves effort and technical expertise by user (downloading, zipping, and transmitting files)
World Wide Web-based System		
• Up-front programming, development, and testing of Web site and database • Dedicated Web server • User needs Internet access and Web browser • Small number of central staff to monitor and follow up responses, perform quality control, and provide some technical assistance	• Low distribution costs • Flexible scheduling for respondent, can enter data into application on own time and over a series of sessions • Easy to modify instrument, since Web site can be modified from central location by single programmer; central control over versions of questionnaire • Modification of already submitted surveys is not problematic • Good, automated tracking of questionnaire completion by all respondents; automated follow-up of partial, incomplete questionnaires • Questionnaire is self administered • Built-in data editing as part of programming • Respondent can easily access previous years' responses and update information • Aggregate database can be accessed at any time • Respondents can be given access to only those modules they need to complete • Context-specific Help screens can be programmed into application • Simple and direct electronic submission to central compiler (e.g., the push of a button) and automatic aggregation of data from multiple sites • Calculations can be pre-programmed	• High up-front costs to develop application • Less control over ensuring completion compared to telephone interview • Respondent/user needs Internet access and Web browser • Would likely require third-party contractor • Potential security issues • Technical support required

3.0 Recommendations

Each of the five options described here for implementing the NPCR evaluation instrument has its own set of requirements and its strengths and weaknesses in light of the features of the revised instrument. All are viable options but some are more ideally suited than others to the needs of NPCR. Based on our review of these options, we recommend that CDC seriously consider developing a **World Wide Web-based** survey **system.** Our recommendation is based on the many strengths and advantages this option provides over alternative options. We consider the Web-based option to be the best match between data collection mode and long-term program needs.

The self-administered, paper-based questionnaire and the telephone interview are the least suited to this evaluation, Although both have the advantage of low front-end costs to develop the instrument (this advantage would disappear with the telephone option if CATI technology were used), the back-end functions and costs — data entry and quality control -would be assumed by CDC. Nor do these options lend themselves well to the automated help and support functions that can be integrated into the other systems. Furthermore, the telephone option is poorly suited to an instrument that requires respondents to gather information or make calculations prior to responding to a question.

While the e-mail questionnaire may offer better help and support functions, depending on the software selected, the state-of-the-art technology limits the format in which responses can be received and aggregating the responses into a database suitable for analysis is not a trivial task.

The free-standing application option, modeled on the NBCCEDP's STAR system, has considerable advantages over the other three systems previously discussed. These include: quality control functions (editing/error trapping) and technical support (help screens) can be integrated into a free-standing system; respondents can access previous answers for easy updating; and no separate data entry at the receiving end is required. The major disadvantages of the system are technical difficulties associated with installation and maintenance of the free-standing system in multiple sites, and the costs and difficulties associated with implementing future modifications to the instrument.

The World Wide Web-based option, in contrast, provides many of the same advantages of the free-standing option without its limitations. That is, the Web-based evaluation instrument can be accessed via any common Web browser application, and changes to the instrument can be easily implemented from a centralized location. If desired, access to the various modules of an instrument can be controlled centrally such that respondents are allowed access only to those modules they are responsible for completing.

Web-based applications have gained popularity in recent years and are fast becoming an industry standard. All of the major software companies have developed packages to help individuals design and implement Web-based applications, including Microsoft (with InterDev), Oracle (with Enterprise Developer Suite), Inprise (formerly Borland, with IntraBuilder), and Sun (with NetDynamics), among others.[4]

In the introduction to this report, we listed the primary attributes of the revised evaluation instrument that will govern NPCR's choice regarding the best method of survey administration for an annual evaluation. At the end of Section 3.0 is a table that indicates the compatibility between each data collection option and the attributes of the evaluation instrument. As the table demonstrates, the Web-based option is a good fit in each of these areas. This fit between the evaluation instrument and the Web-based option is discussed in more detail below.

Annual Administration

The front-end costs involved in programming the instrument for either a Web-based system or a free-standing application would likely not be justified were the instrument intended for a single use. For a single administration survey, the simple approach of a paper-and-pencil instrument might well be the best choice. However, because the evaluation instrument will be administered every year into the foreseeable future, the front-end costs are justified. Once the system is developed and operating, costs associated with maintenance, modification, and enhancement will be greatly reduced in subsequent years, whereas costs for annual mailings or interviews will be incurred each cycle.

Modular Structure

The Web-based option is well suited to the modular structure of the evaluation instrument. Respondents will be able to electronically recall their answers from the previous year and simply update Part A to reflect any changes. Furthermore, differential access to the modules by subgroups of respondents can be easily managed. That is, if registries in the planning phase are not asked to complete Part C, they would simply not have those screens appear in their version of the instrument. Web-based technology also offers a relatively easy way to change the questions in a module from year to year. Unlike the free-standing application, which requires any modifications to be installed on each PC (in NPCR's case, some 50 sites throughout the country), the Web-based instrument requires changes only to

[4] Web sites for the companies and their products:
Oracle Developer, http://www.oracle.com/tools/wds/award.html
MS InterDev, http://msdn.microsoft.com/vinterdev/News/default.asp
Borland IntraBuilder, http://www.borland.com/jbuilder

the centrally maintained Web pages. This would greatly enhance NPCR's ability to modify the evaluation instrument in both the short- and long-term.

Simple Format and Sequence

The simple format and sequence of the questions in the revised NPCR instrument make it relatively easy and cost-effective to do the front-end programming required for a Web-based system. This attribute also makes it easier for respondents to complete the evaluation questionnaire, since they will not have to navigate among multiple Web pages to follow a complex skip pattern. This attribute of the NPCR evaluation instrument would also be advantageous for the other automated data collection modes, e-mail and free-standing.

Complex Information

While the format and sequencing of the revised NPCR questionnaire is straightforward, the information respondents are required to locate and compile is not. The Web-based option is well suited to the type of complex information that NPCR respondents will need to access in order to complete the evaluation instrument. Respondents can answers portions of the instrument, leave, and return to complete the remainder as their time dictates. Context-specific help and support functions can also be integrated into the Web-based option, just as they can with the free-standing option. The primary advantage of the Web-based approach over the free-standing approach is that definitions and instructions can be more easily modified in response to difficulties that registry staff encounter from one administration to the next. In other words, if CDC discovers that registries are not interpreting a question as it was intended, the help files can be modified in the central Web site so that instructions are clearer to respondents. Alternatively, CDC can post an alert on the Web with specific instructions on how respondents should interpret a given question.

Centralized Data Processing and Analysis

Finally, the Web-based option offers considerable advantages when it comes to centralized data processing. Both the free-standing and the Web-based options simplify the data entry and quality control functions associated with data collection. There is no need for data entry to be conducted by CDC or a third-party contractor, as respondents will enter data themselves as part of their program responsibilities. However, the primary advantage of the Web-based option over the free-standing application in this regard is the fact that the Web-based option allows immediate submissions of the evaluation data over the

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Sun NetDynamics, http://netdynamics.com

Internet to a central database. Under a free-standing application system, respondents must create and deliver a final evaluation data file to a third-party contractor who then compiles all submissions into a central database. Another advantage of the Web-based option over the free-standing option is the way the Web-based system can facilitate the submission of cancer registry data sets that will ultimately be requested by CDC to support Part B of the evaluation. The Web site designed to collect evaluation data can also include a page providing instructions for data preparation and the means to download an FTP application that would be used to make the actual data set submission.

Security Issues in the Implementation of a Web-based Questionnaire

One concern that arises with a Web-based approach that does not apply to a free-standing system is that of data security. The security risks that need to be addressed before implementing a Web-based option include:

- *Unauthorized access:* Someone accesses a computer system to steal sensitive information
- *Data alteration:* The content of the data is altered en route
- *Monitoring:* A hacker eavesdrops on confidential information
- *Service denial:* An attacker shuts down the site or denies access to visitors

Fortunately, steps can be taken to protect the security of data on the Web. These include:

- *Passwordprotection.* Usernames and passwords can limit access to the instrument and the data to selected personnel. Those without a usemame and password would not be able to review the data or instrument. Different access rights can be assigned to different individuals. For example, one person's password may only allow him or her to view, enter, and edit data; another might have a password that permits report generation as well; a third might also be allowed to make changes to the instrument template. While this system offers access protection, a savvy computer hacker might succeed in circumventing the password.

- *Digital certificates*. A digital certificate is an electronic "credit card" that establishes the user's identity when conducting transactions on the Web. The certificate contains the user's name, a serial number, expiration dates, a copy of the certificate holder's public key (used for encrypting and decrypting messages and digital signatures), and the digital signature of the certificate-issuing authority so that a recipient can verify that the certificate is real. Digital certificates authenticate that their holders — people, Web sites, etc. — are truly who and what they claim to be. They are tamper-proof and cannot be forged, thus offering a higher level of protection from computer hackers. This approach is commonly used for electronic-commerce.

- *Intranets.* Conceptually, an intranet is a Web inside the Web. Special software exists to build a "firewall" around a Web so that only authorized personnel can gain access. A firewall is a set of related programs, located at a network gateway server that protects the resources of a private network from users from other networks. There are several firewall screening methods. A simple one is to screen requests to make sure they come from acceptable (previously identified) domain names and IP addresses. For mobile users, tirewalls allow remote access in to the private network by the use of secure logon procedures and

authentication (digital) certificates. This provides the highest level of security but is also the most expensive approach.

Summary of the Advantages of a World Wide Web-based Questionnaire

To summarize, the following characteristics of the Web-based option lie at the heart of our recommendation in its favor:

- Data entry and data transfer are both accomplished automatically as each section of the instrument is completed.
- The system can be accessed with any common Web browser application.
- Changes to the instrument can be easily made from a central location. This advantage is important for providing flexibility in the instrument content over time.
- Respondents can easily review their responses from the previous year (or the previous day).
- Many data editing and quality control functions can be programmed into the system.
- Context-specific on-line help systems can be developed so that respondents can click on a question or response category for clarification or additional information.
- Providing reminders and feedback to respondents is easy and straightforward

We believe that a Web-based questionnaire is the best match between data collection mode and long-term program needs. The disadvantages and security concerns associated with this option are outweighed by the considerable advantages it has over other options. The primary disadvantage of a Web-based system is that it requires access to the Internet and to a Web browser. While this is not expected to be a problem at University-based registries nor at many health department-based registries, it may be a serious limitation for a few states and territories. We believe, however, that this disadvantage will rapidly disappear for most registries in the next few years and that a Web approach will prepare NPCR well for the future. We furthermore believe that the current state-of-the-technology is sufficiently advanced to adequately protect the security of the data. In short, we recommend this option as the most effective and efficient method of data collection for NPCR's annual evaluation instrument.

Table 2. Attributes of Evaluation Instrument and Data Collection Options

Feature of NEER Instrument/Respondents	Related Requirement for Data Collection System	Data Collection Option: Mail Survey	Telephone Survey	Telephone Survey Computer Assisted	Electronic Mail Survey	Free-standing Application	Web-based System
Basic Administration Requirements							
Annual administration	Low up-front costs	+	+	–	–	–	–
	Savings later in terms of ease of modifications, processing, and analysis			+	+ / -	+	+
Approximately 50 respondents	Cost of administration is low regardless of the number of respondents				+		+
Respondents are all trained professionals completing the instrument as part of their responsibility to their funder	Respondents can complete survey independently	+			+	+	+
Respondents are very busy	Respondents can complete questionnaire easily and at their own convenience	+		+ / -	+	+	+
A 100% response rate is required	Tracking and follow-up for non-response and incomplete response can be automated (i.e., made easy and low cost)			+	+		+
Modular Structure							
Not all respondents will complete all modules	Different combinations of modules can easily be given to different subgroups of respondents			+		+	+
Modifications to the survey instrument may be necessary, sometimes during an administration cycle	Modifications to survey instrument are easy and low-cost to make mid-cycle		+	+ / -	+		+
At least one module can be expected to vary considerably in content from year to year	Modifications to survey instrument are easy to make in subsequent cycles	+ / -	+	+ / -	+		+
Answers to questions in at least one of the modules may change little from year to year	Easy for respondent to review and update information provided during the previous administration cycle			+		+	+
Complexity of Instrument Design							
The questions are primarily closed-ended	Responses can be easily predoded and automatically entered as check boxes			+	+	+	+
There is no complicated skip logic	Self-administration is possible	+			+	+	+

Feature of NCCR Instrument/Respondent	Related Requirement for Data Collection System	Data Collection Option: Mail Survey	Telephone Survey	Telephone Survey Computer Assisted	Electronic Mail Survey	Fire-standing Application	Web-based System
Complexity of Instrument Content							
Many of the questions are of a complex nature and open to various interpretations	Context-specific assistance may be provided while respondent completes survey	–	+	+	–	+	+
	Context-specific assistance can be automated	–	–	–	–	+	+
Accuracy and appropriateness of responses is critical	Some but not all aspects of data quality control can be automated	–	–	+	–	+	+
Respondents will need to gather and compile information in order to complete the instrument,	Interruption of administration while respondent seeks further information is not a problem	+	–	–	+	+	+
Respondents may need to add or modify evaluation data after submission	Modifications to evaluation data once submitted to central processing is readily possible	–	–	+	+/–	+/–	+
Respondents will need to perform calculations to be able to complete the instrument	Calculations can be preprogrammed into data collection system	–	–	+	+	+	+
Centralized Data Processing and Analysis							
Data from multiple sites must be compiled into a single data set for reporting and analysis	Data from multiple sites can be automatically aggregated	–	–	+	+/–	–	+
CDC needs ready access to evaluation data at all times in order to respond to Congressional and other inquiries	The central processors do not need to wait for delivery of all data before having ready access to data submitted	–	–	–	+/–	–	+
	Access to the data base is easy and flexible	–	–	–	+	–	+
CDC staff or a third-party contractor will contact non-respondents to ensure timely responses and a 100% response rate	Procedures for following up with nonrespondents or partial respondents are not overly burdensome	–	–	–	+	–	+
CDC will request from respondents submission of evaluation data, supplemented by a registry data set	Submission of evaluation data can be readily automated	–	–	+	+	+/–	+
	Submission of additional data (i.e., registry data set) can be readily automated	–	–	–	–	+/–	+
CDC staff or a third-party contractor will provide maintenance and technical support	Low level of system maintenance and technical support required	+/–	+/–	+	–	–	+/–

Symbols indicate degree to which data collection option supports the state feature: + Strong support; +I- Moderate support; -Weak s

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