NPCR PROGRAM STANDARDS
FAQ'S

GENERAL

Approved Standards are usually in place for a minimum of 5 years. Program Objectives or NPCR goals are developed around these standards. An example of a previous Objective is "By the year 2005, 100% of funded states will have authorizing legislation & all 8 reporting regulations that meet criteria specified in Public Law 102-515 (PL 102-515)." We expect the same type of Objectives will be developed for these new standards. The standards are included as an attachment in the Program Announcement.

Standards are set with the goal of obtaining a high percentage of compliance in the next 5 years. You may also want to view these standards similar to the Healthy People 2010 goals, as something towards which you strive to achieve.

These standards are still a draft and may be modified further before they are included in the next program announcement and considered final.

FAQ #1: If my central registry is not able to reach these standards, how will this affect funding?

ANSWER: DHHS and CDC are moving towards implementation of performance based funding. Performance in the NPCR program has historically been measured by a registry's ability to demonstrate progress towards meeting the program standards and not solely based on achievement of the standard.

FAQ # 2: How does NPCR expect us to do additional activities when financial resources are diminishing?

ANSWER: The first 10 years of the NPCR program focused on infrastructure building and getting ALL programs to meet MINIMUM standards. It is now time to start moving toward improving efficiencies and finding better ways to get things done with fewer financial resources.

II. ADMINISTRATION

FAQ # 3: The central cancer registry has an operational manual (or manuals---there are several of these that cover these varying issues, since it is part of a larger organization that covers these issues as well). Will this meet the standard for the central registry operations manual?

ANSWER: The Registry Operations Manual should be specific to the needs of the central cancer registry. However, we strongly recommend that this manual be in electronic format in a single location on a shared drive. This makes the materials more readily available and easy to update. If documentation only exists in paper format, these can be scanned and/or placed in the file as a PDF. A good reference for procedure manuals can be found in the NAACCR *Procedure Guidelines for Cancer Registries; Series III: Preparing a Policy and Procedure Manual.* This can be found on the NAACCR website under Registry Standards/Registry Operations Guidelines.

FAQ # 4: What will meet the criteria for management reports?

ANSWER: A good reference is NAACCR's *Cancer Registry Managements Reports: Design & Implementation*. NAACCR website: http://www.naaccr.org Training Modules Online
Examples include:

1. Monitoring completeness and timeliness of reporting
2. Monitoring the sources, types, and quality of cancer data received
3. Monitoring internal processing procedures

III. ELECTRONIC DATA EXCHANGE

GENERAL

Standards for electronic data exchange should be distinguished from standards for data exchange format.
Electronic reporting standards address the method of transmitting data to the CCR.
Data exchange format standards address the type of file used to transmit data, such as the NAACCR file format or HL7.

FAQ # 5: What is meant by electronic data exchange?

ANSWER: Electronic data exchange is a broad term used to describe methods of transferring data that do not require manual data entry to create an abstracted record.
Examples:

1. Encrypted NAACCR formatted cancer data is submitted on a diskette or CD Rom would be considered a method of electronic data exchange.
2. Data is submitted (preferably to a secure fax machine) from a physician's office on a data form that can be scanned and uses forms recognition software to create an electronic data file would be considered a method of electronic data exchange.
3. When CCR staff abstract data from a source document (either at the facility or from mailed copies of records) on to a laptop or directly into a CCR database it is considered a method of electronic data exchange. In this case the CCR has "an agreement with the facility to do their reporting" similar to other abstracting arrangements. NPCR has issued guidance on when CCRs can use NPCR funds to support this type of arrangement on a limited basis. See attached Guidance on Direct Data Collection.

   These methods of electronic data exchange would NOT meet the standard that the CCR uses a secure Internet-based, FTP, or encrypted email mechanism to receive data from all reporting sources.

4. A pathology laboratory that sends in paper copies of pathology reports would be considered reporting via paper.
5. A physician's office that sends in a standard paper form with patient information that must be manually keyed into a cancer registry program would be considered reporting via paper.

FAQ # 6: How did CDC determine the percents for the standards for electronic reporting?

ANSWER: We looked at the percentage of programs that are currently meeting the standard and determined what we thought would be an obtainable increase within the next five years.

FAQ # 7: How is the 95% of all hospitals; 85% of radiation therapy and ambulatory surgery center, and pathology laboratories; and 75 % of all physicians' offices calculated?

ANSWER: This will be calculated from the information that you enter into the APEI. We list the type of facility and we have added some definitions to this section so that everyone counts the same way. Then we ask you for the number of reporting sources required to report, the number reporting, and the number reporting electronically and on paper.

Examples of how to count facilities:

1. A hospital corporation owns several hospitals and one facility abstracts and reports cases from all facilities, but the individual hospitals each "own their medical records". Count each facility.
2. A hospital is part of a network that shares access to medical records and registry reporting is the responsibility of a centralized cancer registry. Again, each facility still "owns" their medical records. Count each facility.
3. A hospital has several satellite offices and the main hospital cancer registry abstracts and reports all cases from the satellite facilities. The medial records of the satellite facilities are owned by the main facility. Count as one facility.
4. A hospital "owns" several radiation therapy, or other treatment facilities. The main hospital facility is responsible for abstracting and reporting for these facilities. These should be counted as one facility (not counted individually as radiation therapy centers, etc.)

FAQ # 8: Is the percentage based on the number of facilities or number of cases expected from each?

ANSWER: It will be based on the number of facilities. We thought that this would be easier for the states to determine and provide a more stable denominator.

FAQ # 9: The pathologist(s) at some of the reporting hospitals maintain a privately owned pathology practice in addition to providing pathologic services for the hospital. The patient records and billing for the privately owned portion are not accessible to the hospital registrar. How do these fit in with the electronic reporting standards?

ANSWER: We have defined reporting requirements as those cases owned by the reporter. Since this is a private practice for the pathologist, he would own those records and be responsible for reporting them to the CCR just as any other pathology laboratory would be and this would be counted on the APEI as a pathology laboratory (not as part of the hospital). If the pathologist wants to make arrangements with the cancer registry at his hospital to do this reporting for him, it is his responsibility to make those arrangements, but he would still be counted as a pathology laboratory on the APEI.

FAQ # 10: The standard of 75% of physicians reporting electronically is unrealistic because the physician offices have no means to report electronically. How could this standard be met?

ANSWER: Please refer to the definition of "electronic reporting". Also, Abstract Plus and Web Plus are available free of charge and would enable physician offices to report electronically.

FAQ #11: Do these standards imply that all information from pathology labs is expected to be transmitted electronically or simply that any electronically-transmitted path information must be in the NPCR-recommended data exchange layout? If this standard is requiring central cancer registries to replace paper/manual path report processing with electronic HL-7 messaging, conversion to ASCII, and consolidation into our databases, then *significant additional resources would be required* to implement the standard.

ANSWER:

1. STANDARD: The central cancer registry uses and requires a standardized, NPCR-recommended data exchange record layout for the electronic exchange of cancer data. NPCR-recommended data exchange layouts include:

*a.*For abstract reports: The NAACCR record layout version specified *in Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*.

*b.***For pathology reports**: *NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting*.

This standard stipulates that the electronic exchange or transmission of all pathology reports **should** be in the NPCR recommended data exchange layout, NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting.

2. STANDARD: At a minimum, 85% of non-hospital reporting sources report to the central cancer registry in an electronic format (e.g. radiation therapy centers, ambulatory surgery centers, and in-state and out-of-state pathology laboratories where medical records are owned by the reporting source).

This second standard stipulates that **85%** of these non-hospital reporting sources that include pathology laboratories along with other non-hospital sources should report data in an electronic format *(as defined above)*.

NPCR expects a transition to occur throughout the next five years from paper based pathology reports to the electronic submission of such reports. During this transition phase, the expectation is that some paper forms will still be submitted and processed. This transition will entail significant adjustments to existing systems, both in terms of software and staff. NPCR believes that such an adjustment is critically important to position ourselves to take advantage of the opportunities in electronic reporting and, in the process, to improve registry efficiency and timeliness of reporting.

FAQ # 12: Is the CDC going to be providing states the resources, either through funding or software development the tools necessary for states to meet these standards?

ANSWER: CDC-NPCR has produced (and is working on) a number of tools to assist NPCR registries in the transition to electronic reporting. In brief, the CDC central cancer registry software is evolving to handle electronic pathology reports as well as other electronic cancer reports. See the attachment at the bottom of these questions for a description of projects that are underway to support electronic reporting. In addition, NPCR expects both hospital and central cancer registry software to evolve to take advantage of the electronic health record. Many cancer registry software vendors/developers are making adjustments to accept transmission from electronic health records and to process that data within the cancer registry system.

VI. DATA QUALITY ASSURANCE

FAQ # 13: STANDARD: At least once every 5 years, case-finding and re-abstracting audits from source documents are conducted at each *hospital-based* reporting facility.

We are a large state and would have to do hundreds of audits a year to have all of our current reporting facilities audited once every 5 years.

ANSWER:
We realized that we did not write what we really intended for this standard and have modified it to indicate that it only refers to **hospital-based** facilities.

There are several ways to conduct audits that would meet this standard. An example is comparison of electronic disease indices from hospital-based facilities with the CCR database as a case-finding audit.

VII. DATA USE

FAQ # 14: Please provide the rationale for producing pre-calculated data in tables in an electronic data file or report for incidence rates, counts or proportions with data that are only 90% complete. When would data that is 90% complete be used?

ANSWER:
1. USCS and CINA both publish data that is, at minimum, 90% complete.
2. Data collected at 12 months could be disseminated as provisional data and can be used as a benchmark for the completeness and timeliness of registry data
3. Examples of when states might use 12 month data that is 90% complete include cancer control planning.

FAQ # 15: How does CDC plan to use the information?

ANSWER:

An ongoing goal for the USCS series is earlier data dissemination. However, CDC has no plans to publish or circulate the 12 month data at this time. CDC will continue to request that these data be submitted to us as part of the annual NPCR-CS submission. Data collected at 12 months serve as a pre-evaluation of the data at 24 months. For example, 12-month data provide a first look at the data prior to publication to see if there are any QC issues looming, such as completeness and timeliness for the primary sites of cancer.

FAQ # 16: Due to the dynamic nature of our data sets, central cancer registries already experience variability in data sets created 24 months after the close of a diagnosis year, with min. 95% completeness. Statistics produced 12 months after the close of a year, with min. 90% completeness would have even more variability. In small states, with small numbers of cancer cases relative to other states, the variability is amplified. Also, it would be confusing to users of the data to have 2 sets of tables - one for the 12 month standard and another for the 24 month standard

ANSWER: This issue is addressed in the USCS Technical notes since each year the website version of USCS data is updated with the most current version of each year's data. These continual updates by state and federal agencies illustrate the dynamic nature of cancer surveillance and the attention to detail that is

characteristic of cancer registries. Users are advised to be mindful of the data submission date for all data used in their comparisons.

FAQ # 17: The standard states: The central cancer registry, State health department, or its designee used registry data for planning and evaluation of cancer control objectives in at least three of the following ways in the past year. Would "or its designee" include ACS or statewide cancer consortium?

ANSWER: When we referred to "its designee" we mean the Department of Health's central cancer registry designee. In some states this may be a university or some other entity responsible for cancer registry operations. However, since the cancer registry provides the data to the ACS and/or statewide cancer consortium, it would be an acceptable use of data to meet this standard.

Attachment I: Description of NPCR projects to support electronic reporting

1. **National Program of Cancer Registries (NPCR)-Modeling Electronic Reporting Project (MERP):** NPCR-MERP is a collaborative project to develop a national cancer surveillance model for the standard transmission of data from the hospital's electronic health record (comprised of multiple electronic database systems) and other data sources (such as private pathology laboratories) to hospital registries and state central cancer registries. The NPCR-MERP models will be compliant with standards that have been adopted by the Public Health Information Network (PHIN) and the Department of Health and Human Services' (DHHS') Office of the National Coordinator for Health Information Technology (ONCHIT), as appropriate.

   For more information on NPCR-MERP, visit the following Web site: http://www.cdc.gov/cancer/npcr/merp.

2. **ePath Reporting Pilot Project:**
   The purpose of this pilot project is to test the implementation of electronic anatomical pathology reporting from a national laboratory to the state central cancer registries. NPCR-MERP will solicit states for participation in this project. This project will implement electronic pathology reporting using the recently approved standard in the NAACCR HL7 Implementation Guide for E-Path Reporting and the business rules defined in the draft NAACCR E-Path Reporting Process Guide. This project could potentially move the cancer registry community forward in utilizing consistent standards for electronic pathology reporting that will improve the completeness, timeliness, and quality of cancer registry data. The goal for this project is to 1) implement consistent electronic pathology reporting from a national laboratory to participating state central cancer registries and 2) provide guidance to state cancer registries and pathology laboratories for implementing electronic pathology reporting in their respective environments. Additionally, it will provide states with new and improved capabilities for utilizing pathology reports as a source of cancer information. The objectives of this project are as follows:

   - Test and document the implementation of electronic pathology reporting from a national laboratory to state central cancer registries.
   - Identify and/or develop software needed to successfully implement electronic pathology reporting.
   - Provide guidance to state central cancer registries and pathology laboratories on the requirements for implementing electronic pathology reporting.

3. **NPCR Reporting Pathology Protocols (RPP) Projects:** The purpose of NPCR RPP projects is to assess the feasibility of collecting and transmitting pathology information in a new way. Traditionally, pathology data have been reported in a "term paper format." The NPCR RPP projects are designed to assess the use of the College of American Pathologists synoptic checklist reporting to capture pathology data in a more computer friendly format by using standards from the PHIN--including Logical Observation Identifiers Names and Codes (LOINC) and Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) vocabularies, and HL7 messaging. In 2001, CDC funded demonstration projects in California and Ohio to apply the protocol for cancers of the colon and rectum. In 2004, CDC initiated a second project for melanoma and cancers of the breast and prostate, and funded California, Maine, and Pennsylvania.

4. **National Electronic Disease Surveillance System (NEDSS):** The NPCR representative to NEDSS from the Cancer Surveillance Branch is involved with a project to identify ways to integrate existing

cancer registry software with the NEDSS platform. This project will assess the applicability of NEDSS component systems that could be utilized by the cancer surveillance community. As a major component of PHIN, NEDSS is a CDC initiative for state health departments that promotes the use of data and information system standards. NEDSS is designed to develop and maintain integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the Internet. CDC/NPCR will assess the following PHIN/NEDSS tools for use in cancer surveillance: PHIN Messaging System (PHINMS); NEDSS Messaging Subsystem; and the NEDSS Reporting Database (RDB).

For more information on NEDSS, visit the following Web site: www.cdc.gov/nedss.

5. **NPCR Registry Plus Software/Tools:** The NPCR is committed to modifying the Cancer Registry software/tools to meet required standards for implementing the receipt and transmission of data electronically at the central registry level.

6. **State funding for development of software programs:** NPCR has provided funding to states for development of tools to assist in transitioning to many forms of electronic reporting. All programs developed with federal funds are in the public domain and available to all NOCR programs.