NPCR Program Manual

National Program of Cancer Registries

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Acronyms

ACoS	American College of Surgeons
ACS	American Cancer Society
AERRO	Advancing E-cancer Reporting and Registry Operations
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian and Alaskan Native
AJCC	American Joint Committee on Cancer
API	Application Program Interface
ASTCDP	Association of State and Territorial Chronic Disease Program Directors
ATSDR	Agency for Toxic Substances and Disease Registry
CAP	College of American Pathologists
CCRC	Central Cancer Registry Council
CDC	Centers for Disease Control and Prevention
CDMIS	Chronic Disease Management Information System
CER	Comparative Effectiveness Research
CiNA	Cancer Incidence in North America
CMS	Centers for Medicare and Medicaid Services
CoC	Commission on Cancer
CRC	Central Registry Council
CRCCP	Colorectal Cancer Control Program
CSv2	Collaborative Stage version 2
CSB	Cancer Surveillance Branch
CSS	Cancer Surveillance System
CSTE	Council of State and Territorial Epidemiologists
ODS	Oncology Data Specialist
DCO	Death Certificate Only
DCPC	Division of Cancer Prevention and Control
DCQA	Data Completeness and Quality Audit (now DQE)
DERs	Data Evaluation Reports
DQE	Data Quality Evaluation

DHHS	Department of Health and Human Services
eCC	CAP's electronic Cancer Checklists
HER	Electronic Health Record
EHR-MU	Electronic Health Record Meaningful Use
eMaRC	Electronic Mapping Reporting and Coding
EMR	Electronic Medical Record
EP	Eligible Provider
ePath	Electronic Pathology Reporting System
FERPA	Family Educational Rights and Privacy Act
FIPS	Federal Information Processing Standards
FOIA	Freedom of Information Act
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health
IACR	International Association of Cancer Registries
ICD-O-3	International Classification of Diseases for Oncology, Third Edition
IDSAT	Informatics, Data Science, and Applications Team
IDSE	Interstate Data Exchange
HIS	Indian Health Service
I&O	Industry & Occupation
MERP	Modeling Electronic Reporting Project (now AERRO)
MOA	Memorandum of Agreement
MOU	Memorandum of Understanding
MU	Meaningful Use
MP/H	Multiple Primary and Histology
N-IDEAS	National Interstate Data Exchange Application System
NAACCR	North American Association of Central Cancer Registries
NAPIIA	NAACCR Asian Pacific Islander Identification Algorithm
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCCCP	National Comprehensive Cancer Control Program
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
NCCCS	National Coordinating Council for Cancer Surveillance
NCHS	National Center for Health Statistics

NCI	National Cancer Institute
NCIC	National Cancer Institute of Canada
NCPCP	National Cancer Prevention and Control Program
NCRA	National Cancer Registrars Association
NETS	NPCR Education and Training Series
NHAPIIA	NAACCR Hispanic and Asian Pacific Islander Identification Algorithm
NHIA	NAACCR Hispanic Identification Algorithm
NIOSH	National Institute for Occupational Safety and Health
NOFO	Notice of Funding Opportunity
NPCR	National Program of Cancer Registries
OIRA	Office of Information and Regulatory Affairs
OMB	Office of Management and Budget
ONC	Office of the National Coordinator for Health IT
ORTAT	Operations Research and Technical Assistance Team
PEI	Program Evaluation Instrument
PHA	Public Health Advisor
PHIN	Public Health Information Network
PHIN MS	Public Health Information Networking Messaging System
RAF	Restricted Access File
RDC	Research Data Center
RPOH	Registry Plus Online Help
RRAF	Regional Restricted Access File
SDRG	Small Data Release Group
SEER	Surveillance, Epidemiology, and End Results
SERT	Surveillance, Evaluation, and Research Team
sFTP	secure File Transfer Protocol
SINQ	SEER Inquiry System
SRAF	State-level Restricted Access File
SWG	Science Workgroup
TNM	Tumor, Node, Metastasis
UICC	Union for International Cancer Control
USCS	U.S. Cancer Statistics

Introduction

In 2021 the latest year for which incidence data are available, 1,777,566 new cancer cases were reported, and 608,366 people died from the disease. For every 100,000 people, 439 new cancer cases were reported and 142 people died of cancer (CDC, 2024). Additionally, CDC reported that cancer remains the second leading cause of death in the United States spanning more than 75 years, exceeded only by heart disease. One of every five deaths in the United States is due to cancer.

Between 2015 and 2050, CDC expects new cancer diagnoses in the United States to stabilize in females and decrease in males. However, the CDC projects that colorectal, prostate, and female breast cancers will rise, and cancer diagnoses in older adults will continue to increase due to an aging population (Cancer Incidence Projections in the United States Between 2015 and 2050). This information is available to inform research and cancer policy recommendations because of central cancer registries and cancer surveillance staff who manage, and report complete and high-quality data. Availability of this critical data serves as the foundation that informs cancer prevention and control and health policy efforts at local, state, territorial, and national levels.

Since 1992, the Centers for Disease Control and Prevention (CDC) have administered the National Program of Cancer Registries (NPCR), a federally mandated program which supports populated-based cancer surveillance systems (CSS). Currently, NPCR supports central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Affiliated Pacific Islands, and the U.S. Virgin Islands to collect demographic and clinical information about cancer incidence.

The data collected for the NPCR–CSS aligns with the diagnosis, staging, and treatment of cancer by physicians in clinical settings. To ensure cancer data are of high quality, comparable and useful to clinical and public health practice, the NPCR-CSS is highly standardized. Multiple organizations are involved in classifying, defining, collecting, and submitting data standards.

Cancer surveillance standard setter organizations in the U.S. include CDC-NPCR; National Cancer Institute (NCI)-Surveillance, Epidemiology, and End Results (SEER); American College of Surgeons (ACoS); Commission on Cancer (CoC); and a convening umbrella organization, North American Association of Central Cancer Registries (NAACCR). These standard-setting agencies and organizations have developed collaborative relationships over the years to create consensus standards and best practices in cancer surveillance.

As cancer care becomes increasingly complex, the cancer surveillance community must continue to work together to refine existing standards and develop new ones that can be efficiently implemented to maintain the collection of high-quality data. Knowledgeable cancer registrars, along with adequately equipped central cancer registries, are fundamental to this endeavor.

Legislation Creates CDC's National Program of Cancer Registries

Citing the need for a national program to provide local, state, regional, and national cancer incidence data for health planning purposes, the U.S. Congress established the National Program of Cancer Registries (NPCR) in 1992 through the enactment of the Cancer Registries Amendment Act (42 U.S. Code 280e with amendments). The Cancer Registries Amendment Act authorizes the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to:

- Improve existing cancer registries
- Plan and implement registries where they did not exist
- Develop model legislation and regulations for states to enhance the viability of registry operations
- Set standards for data completeness, timeliness, and quality
- Provide training for registry personnel
- Help establish a computerized reporting and data processing system

Milestones in NPCR History

In 1994, through cooperative agreements, NPCR began providing financial support and technical assistance to state health departments for the operation of statewide, population- based cancer registries. In a cooperative agreement funding mechanism, there is substantial collaboration between CDC staff and the recipient to manage and guide program activities.

State health departments, or their authorized designees, were eligible for one of two funding categories. The first category of funding supported the enhanced operation of existing cancer registries. These "enhancement" programs were required to maintain their current (i.e., at the time of initial CDC funding) level of support, and to contribute (i.e., match) one state dollar for every three federal dollars of support received. Matching funds could be in the form of financial or direct (i.e., in kind) assistance. The second category of funding supported the planning and implementation of a new cancer registry where no cancer registry previously existed.

After the first program announcement in 1994 and the approval of a congressional appropriation of $16.8 million, 42 states and the District of Columbia were awarded funds (34 enhancement programs and nine planning programs). In 1997, three additional states and three territories were awarded funds (two enhancement programs and four planning programs).

In 2000, the NPCR-Cancer Surveillance System (CSS) was established to receive, evaluate, and disseminate data from NPCR-funded central cancer registries. NPCR-CSS is designed to provide cancer incidence data to meet CDC's public health surveillance responsibilities and to help monitor progress toward NPCR goals.

In response to the need for national population-based incidence data on all central

nervous system (CNS) tumors, Congress passed the Benign Brain Tumor Cancer Registries Amendment Act in 2002. This law changed NPCR's definition of reportable tumors to include benign and borderline CNS tumors. Both the NCI's SEER Program and the American College of Surgeons Commission on Cancer (ACoS CoC) agreed to require reporting of nonmalignant brain tumors, beginning with cases diagnosed on or after January 1, 2004.

CDC Organizational Structure (APPENDIX A)

The CDC includes 16 Centers, Institutes, and Offices which focus on a wide array of public health concerns ranging from environmental health to infectious diseases. Each center has divisions that focus on specific public health areas.

The Center of relevance to this manual, CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) has eight divisions and assists U.S. states, territories, tribes, and the District of Columbia, to promote health and well-being through the prevention and control of chronic disease.

The Division of Cancer Prevention and Control (DCPC) is a division under NCCDPHP and administers NPCR, which resides in the Cancer Surveillance Branch (CSB).

Cancer Surveillance Branch

The Cancer Surveillance Branch (CSB) is responsible for program management and capacity strengthening within the participating central cancer registries. CSB functions include data collection and enhancement, data receipt and evaluation, and data analysis and dissemination. The performance of these functions is distributed among three teams:

- Operations Research and Technical Assistance Team (ORTAT)
- Informatics, Data Science, and Applications Team (IDSAT)
- Surveillance Evaluation Research Team (SERT)

ORTAT priorities include:

- Leading NPCR program management and operations.
- Developing and monitoring NPCR program standards and performance. measures
- Performing quality assurance and improvement of data quality activities.
- Coordinating creation of educational products.
- Coordinating NPCR Program Directors meetings.
- Conducting program monitoring and evaluation activities.

For each NPCR recipient, ORTAT activities include:

- Monitoring the accuracy and completeness of data.
- Monitoring recipient work plans and progress.
- Monitoring recipient budgets.

- Providing technical assistance and guidance.

IDSAT functions include:

- Providing technical, statistical, and data analysis support to CSB and DCPC.
- Providing support in the collection, evaluation, and release of data.
- Developing and supporting cancer registry software products and web-based applications.
- Promoting electronic reporting of surveillance data to central registries.

SERT functions include:

- Managing the NPCR Cancer Surveillance System (CSS), including the annual data submission, data evaluation, and creation of data products (such as the internal analytic files, the U.S. Cancer Statistics Data Visualizations Tool, and the U.S. Cancer Statistics public use database).
- Evaluating the quality of data items for inclusion in data products.
- Describing cancer incidence and mortality at the county, state, regional, and national levels and for populations of focus.
- Promoting the use of surveillance data for cancer prevention and control by DCPC researchers and researchers external to CDC.
- Building capacity for NPCR registries to conduct advanced surveillance research and activities.
- Promoting use of NPCR data and ensuring data is made available to federal and state partners, and outside researchers through the National Center for Health Statistics (NCHS) Research Data Center.

Health and Programmatic Goals

The National Program of Cancer Registries (NPCR) contributes to the achievement of disease prevention and health promotion goals established through the national planning process spearheaded by the Department of Health and Human Services (DHHS). These goals are updated every ten years and are embodied in the "Healthy People 2030" document. As noted in NPCR's Notice of Funding Opportunity (NOFO) purpose statement, NPCR's programmatic goals are translated into standards for central cancer registries to provide measurable outcomes for the investment of public resources in cancer surveillance activities. NPCR and central cancer registry activities are centered in a national planning process, directed toward specific outcomes, and evaluated according to measurable achievements.

Measurable outcomes of the Cancer Prevention and Control Program for states, territories, and tribal organizations are in alignment with the following performance goals for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and Healthy People 2030:

- Reduce the age-adjusted annual rate of cancer mortality per 100,000 population (Healthy People C-01).
- Reduce the lung cancer death rate (Healthy People C-02).

- Increase the proportion of adults who get screened for lung cancer (Healthy People C-03).
- Reduce the female breast cancer death rate (Healthy People C-04)
- Increase the proportion of females who get screened for breast cancer (Healthy People C-05).
- Reduce the colorectal cancer death rate (Healthy People C-06)
- Increase the proportion of adults who get screened for colorectal cancer (Healthy People C-07).
- Reduce the prostate cancer death rate (Healthy People C-08)
- Increase the proportion of females who get screened for cervical cancer (Healthy People C-09).
- Increase the proportion of cancer survivors who are living 5 years or longer after diagnosis (Healthy People C-11).
- Increase quality of life for cancer survivors (Healthy People C-R01).

For more information, please see the CDC agency-wide goals and strategies, available from the CDC website.

DP22-2202 Notice of Funding Opportunity (NPCR Component)

Surveillance is the cornerstone of cancer prevention and control efforts and a strategic priority for the CDC. Vital information about cancer cases is necessary for monitoring trends, planning for, and evaluating the impact of cancer control programs, allocating health resources, responding to reports of suspected increases in occurrence, and developing research hypotheses. Expanding the application of cancer registries to prevention and screening can enhance NPCR's utility.

This Notice of Funding Opportunity (NOFO) supports the operations and enhancement of state, tribal, and territorial health departments/organizations population-based central cancer registries and promotes the use of registry data. NPCR-funded central cancer registries are encouraged to expand applied uses of cancer registry data to monitor preventable and screening-amenable cancer occurrence and outcomes in the United States; evaluate the impact of cancer prevention and early detection programs; and identify subpopulations where evidence-based interventions should be targeted to reduce the cancer burden.

CDC releases a NOFO every five years to identify and establish the long-term goals of the National Cancer Prevention and Control Program (NCPCP) through performance measures. A work plan is developed by each recipient to measure progress in meeting the requirements described in the NOFO.

The Notice of Funding Opportunity CDC-NOFO-DP22-2202, released in 2022, incorporated funding guidance for the following three Programs:

- Program 1: National Breast and Cervical Cancer Early Detection Program (NBCCEDP)
- Program 2: National Comprehensive Cancer Control Program (NCCCP)

- Program 3: National Program of Cancer Registries (NPCR)

NPCR goals are to:

- Collect and disseminate high quality data on all reportable incident cancer cases in a timely manner for the purpose of public health cancer prevention and control.
- Improve and enhance electronic reporting to central cancer registries.

Strategies and Activities: Program 3 NPCR

Recipients are expected to perform and implement the following strategies and activities:

Strategy 1: Enhance National Program of Cancer Registries data quality, completeness, use, and dissemination.

- Use data to monitor cancer risk factors, incidence, and mortality.
- Use cancer incidence and mortality data for program planning (e.g. to revise/update cancer control plans, select program priorities, set program baseline and targets).
- Share data to educate policymakers, partners, and the public about the people and places that are most impacted by cancer.

Strategy 2: Use surveillance systems and population-based surveys to assess cancer burden and inform programmatic efforts.

- Collaborate with internal and external partners to set and report on annual and five-year objectives.
- Conduct policy scans to identify facilitators and barriers to cancer prevention, screening, and survivorship.
- Use data to identify and collaborate with populations and geographic locations with the greatest burden.

Strategy 3: Support partnerships for cancer control and prevention.

- Convene and maintain a multisectoral cancer control coalition.
- Establish formal agreements with the cancer control coalition, partner organizations, and
- community members assuring their commitment to achieving NCCCP priorities/outcomes.
- Provide staffing and support for coalition engagement.

Strategy 5: Conduct program monitoring and evaluation.

- Create a performance measurement plan to report short, intermediate, and long-term outcomes.
- Develop and implement annual evaluation plans.
- Use program evaluation results for program improvement by sharing results with evaluation partners/collaborators, revising program work plans, and revising subsequent annual evaluation plans.
- Develop dissemination documents to share lessons learned.

- Participate in evaluation and dissemination implementation science-driven studies to contribute to viable models for sustainable comprehensive cancer control.
- DC Program Support to Recipients under the 22-2202 Collaborative Agreement.

CDC Program Support for Recipients

In a cooperative agreement, CDC staff is substantially involved in program activities, above and beyond routine grant monitoring.

CDC activities in this NOFO are as follows:

- Align programs with the division's strategic plan priorities, principles, and approaches; coordinate and facilitate consistent CDC recipient messaging, when needed; and support and facilitate cross-program coordination and collaboration to leverage opportunities and reduce duplication, where appropriate.
- Monitor recipient progress in implementing NOFO strategies and activities in CDC-approved workplans. Review recipient progress reports and program performance and evaluation data to assess progress and areas in need of improvement; provide technical assistance and corrective action plans, as needed.
- Provide ongoing guidance, consultation, and technical assistance to recipients and facilitate connection to subject-matter experts to support the planning, implementation, monitoring, and evaluation of NOFO strategies and activities.
- Facilitate and support training and capacity building activities including peer-to-peer sharing to optimize effective NOFO implementation.
- Provide guidance to recipients on program-applicable Public Laws.
- Provide guidance to recipients on relevant scientific evidence, research findings, and national/state/local data; current national and public health recommendations; current clinical guidelines and recommendations; documented best practices; and peer-to-peer success stories related to the NOFO.
- Provide data to help recipients identify specific populations for program focus to reduce cancer health disparities and achieve health equity. Provide eligible population estimates for available geographic areas to inform breast and cervical cancer screening targets and other interventions. For more information, see: Cancer Prevention and Control Programs for State, Territorial, and Tribal Organizations (CDC-RFA-DP22-2202).
- Manage and continually improve national program data systems (e.g., NBCCEDP clinical data; NPCR) and provide recipients with regular data monitoring feedback reports for their use in quality assurance, program improvement, and program monitoring and evaluation.
- Develop and implement national program evaluation plans (e.g., annual recipient surveys, cost-effectiveness studies) and support recipients'

development of their own high-quality evaluation plans. Conduct evaluation data analysis and report findings including publications in peer-reviewed journals.

- Develop and provide publicly available software programs for collecting, receiving, validating, processing, and analyzing data, and provide updated NPCR Program Standards and manuals to recipients.
- Aid in dissemination of information, including success stories.

Funding Restrictions

The Notice of Funding Opportunity (NOFO) restricts use of funds for several activities. Recipients may only expend funds for reasonable program purposes, including personnel, travel, supplies, and services, such as contractual. Additionally, the recipient must perform a substantial role in carrying out project objectives and not merely serve as a conduit for an award to another party or entity who is ineligible.

Research

Recipients are prohibited from using funds for research activities. CDC provides guidance on the definitions for public health research and public health non-research.

Data Collection

As a rule, NPCR dollars should not be used for data collection (abstracting) from reporting facilities. On a case-by-case basis, exceptions can be made, if the recipient submits a request with adequate justification. Unobligated funds can be used on a one-time basis to catch up on delinquent cases. Justification must be provided that summarizes why it is more efficient and cost effective for central cancer registry staff to perform data collection activities.

Lobbying

Section 503 of Division F, Title V, of the FY 12 Consolidated Appropriations Act (Public Law 112-74) reinforces and (in selected respects) expands long-standing provisions governing the use of appropriated funds by recipients for advocacy, lobbying, and related activities.

Revised CDC Grant Conditions: Additional Requirements 12 (AR-12)

Applicants should be aware that award recipients are prohibited from using CDC HHS funds to engage in any lobbying activity. Specifically, no part of the federal award shall be used to pay the salary or expenses of any recipient, sub-recipient, or agent acting for such recipient or sub- recipient, related to any activity designed to influence the enactment of legislation, appropriations, regulation, administrative action, or executive order proposed or pending before the Congress or any state government, state legislature or local legislature or legislative body. For more on additional requirements, see Additional Requirement 12: Lobbying Restrictions.

Restrictions on lobbying activities described above also specifically apply to lobbying related to any proposed, pending, or future federal, state, or local tax increase, or any

proposed, pending, or future requirement or restriction on any legal consumer product, including its sale or marketing, including but not limited to the advocacy or promotion of gun control.

This prohibition includes grass roots lobbying efforts by award recipients that are directed at inducing members of the public to contact their elected representatives to urge support of, or opposition to, proposed or pending legislation, appropriations, regulations, administrative actions, or executive orders (hereinafter referred to collectively as “legislation and other orders”). Further prohibited grass roots lobbying communications by award recipients using federal funds could also encompass any effort to influence legislation through an attempt to affect the opinions of the public or any segment of the population if the communications refer to specific legislation and/or other orders, directly express a view on such legislation or other orders and encourage the audience to act with respect to the matter.

In accordance with applicable law, direct lobbying communications by award recipients are also prohibited. Direct lobbying includes any attempt to influence legislative or other similar deliberations at all levels of government through communications that directly express a view on proposed or pending legislation and other orders and which are directed to members, staff, or other employees of a legislative body or to government officials or employees who participate in the formulation of legislation or other orders.

Lobbying prohibitions also extend to include CDC HHS grants and cooperative agreements that, in whole or in part, involve conferences. Federal funds cannot be used directly or indirectly to encourage participants in such conferences to impermissibly lobby.

However, these prohibitions are not intended to prohibit all interaction with the legislative or executive branches of governments, or to prohibit educational efforts pertaining to public health that are within the scope of the CDC award. For state, local, and other governmental recipients, certain activities falling within the normal and recognized executive-legislative relationships or participation by an agency or officer of a state, local, or tribal government in policymaking and administrative processes within the executive branch of that government are permissible. There are circumstances for such recipients, during such a normal and recognized executive- legislative relationship, when it is permissible to provide information to the legislative branch to foster implementation of prevention strategies to promote public health. However, such communications cannot directly urge the decision makers to act with respect to specific legislation or expressly solicit members of the public to contact the decision makers to urge such action.

To retain their tax-exempt status, many non-profit recipients have long operated under settled definitions of “lobbying” and “influencing legislation.” These definitions are a useful benchmark for all non-government recipients, regardless of tax status. Under these definitions, recipients are permitted to (1) prepare and disseminate certain nonpartisan analysis, study, or research reports; (2) engage in examinations and discussions of broad social, economic, and similar problems in reports and at

conferences; and (3) provide technical advice or assistance upon a written request by a legislative body or committee.

Award recipients should also note that using CDC HHS funds to develop and/or disseminate materials that exhibit all three of the following characteristics are prohibited: (1) refer to specific legislation or other order; (2) reflect a point of view on that legislation or other order; and (3) contain an overt call to action.

It remains permissible for CDC HHS recipients to use CDC funds to engage in activities to enhance prevention; collect and analyze data; publish and disseminate results of research and surveillance data; implement prevention strategies; conduct community outreach services; foster coalition building and consensus on public health initiatives; provide leadership and training and foster safe and healthy environments.

Also note that under the provisions of 31 U.S.C. Section 1352, recipients (and their sub-tier contractors and/or funded parties) are prohibited from using appropriated federal funds to lobby in connection with the award, extension, continuation, renewal, amendment, or modification of the funding mechanism under which monetary assistance was received. In accordance with applicable regulations and law, certain covered entities must give assurances that they will not engage in prohibited activities.

CDC cautions recipients of CDC funds to be careful not to give the appearance that CDC funds are being used to carry out activities in a manner that is prohibited under federal law. CDC-funded recipients should give close attention to isolating and separating the appropriate use of CDC funds from non-CDC funds.

Use of federal funds inconsistent with these lobbying restrictions could result in disallowance of the cost of the activity or action found not to comply and potentially other enforcement actions as outlined in applicable grants regulations.

Applicable Laws, Regulations and Guidance

As a program within a federal agency, NPCR is constrained by federal legislation, regulations and guidelines that may differ than those governing state central cancer registries. Those having a significant role are described in this section; others may be referenced in other sections of this manual.

HIPAA

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 was enacted to:

- Ensure health insurance coverage after leaving an employer.
- Provide standards for facilitating health care-related electronic transactions to improve the efficiency and effectiveness of the health care system.
- Mandate adoption of federal privacy protections for certain individually identifiable health information.

NPCR-funded central cancer registries must be aware of the implications of the

developing electronic data technologies for registry systems and operations, and the application of data privacy requirements to public health surveillance and research activities.

HIPAA provides for the study of issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information. NPCR promotes electronic data exchange among central registries and to the NPCR-CSS and incorporates new program standards relating to registries' use of electronic data as enabling technologies are realized.

The HIPAA Privacy Rule addresses the concerns for patient privacy and data confidentiality that arise with the collection and transmission of electronic health information. HIPAA recognizes the legitimate need for public health authorities to have access to personal health information for the purposes of health surveillance. It authorizes the disclosure of such information without patient authorization as required by state and local public health laws including reporting of cancer surveillance data to central cancer registries. The Privacy Rule, however, does require reporting sources to document disclosure of information to the central registries.

The Privacy Rule also distinguishes between public health practice (public health surveillance, disease control, or program evaluation) and activities which may develop into an ongoing research study and are, therefore, subject to research disclosure provisions.

A Morbidity and Mortality Weekly Report *(MMWR)* prepared by the CDC Epidemiology Program Office provides additional information about the HIPAA Privacy Rule and Public Health. This report is intended to help public health agencies and others understand and interpret their responsibilities under the Privacy Rule.

"Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule" addresses the impact of the Privacy Rule on health data research activities.

Fact sheets on "Institutional Review Boards and the HIPAA Privacy Rule" and "Research Repositories, Databases, and the HIPAA Privacy Rule" are available to review.

The full text of HIPAA along with comprehensive Department of Health and Human Services (DHHS) guidance is located on the HIPAA website.

FOIA

The Freedom of Information Act (FOIA), 5.U.S.C. § 552, enacted in 1966, establishes an effective legal right of access to government information. The 1996 amendments in Public Law 104-231 clarify that FOIA provisions apply to records maintained in electronic format and require agencies to provide reference materials or a guide for requesting records or information, including an index and description of all major information systems.

Data collected by central cancer registries and submitted to the NPCR become federal record and subject to federal laws and rules governing data release and records retention, including the FOIA. Data are protected under 308(d) Assurance of Confidentiality. The NPCR provides a Data Release Policy and recipient participation is written into the Notice of Award. Data re- release plans describe the content and format of data to be released as either non-identifiable public-use data or identifiable/potentially identifiable restricted-access data.

The CDC FOIA staff, Office of Public Affairs, is the focal point for all CDC FOIA requests; The Director, Office of Public Affairs (OPA), as the CDC Freedom of Information Act Officer, is the sole official with delegated authority to release or deny CDC records. For more information, see Freedom of Information Act (FOIA).

Policy on Releasing and Sharing Data

The NPCR is governed by federal rules and agency policies relating to the release and sharing of public health data collected in pursuit of its mission to understand and support programs addressing the cancer burden within the United States. The CDC policy states:

"The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) are the nation's principal disease prevention and health promotion agencies. To fulfill their missions, these agencies must collect, manage, and interpret scientific data.
CDC believes that public health and scientific advancement are best served when data are released to, or shared with, other public health agencies, academic researchers, and appropriate private researchers in an open, timely, and appropriate way. . .."

The goal is to have a policy on data release and sharing that balances the desire to disseminate data as broadly as possible with the need to maintain high standards and protect sensitive information. . .."

This policy references federal laws and directives with which it ensures compliance, including the Freedom of Information Act (FOIA), the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and the Office of Management and Budget (OMB) circulars on release of state- provided data and ensuring the quality and integrity of released data. Not all federal laws and directives referenced by this policy directly relate to NPCR. However, NPCR policies on releasing and sharing data may be compatible with the law and/or directives' intentions.

Attribution Guidelines

Acknowledgement of Federal Support

When issuing statements, press releases, requests for proposals, bid solicitations and other documents describing projects or programs funded in whole or in part with federal

money, all recipients receiving federal funds, shall clearly state (1) the percentage of the total costs of the program or project which will be financed with federal money, (2) the dollar amount of federal funds for the project or program, and (3) percentage and dollar amount of the total costs of the project or program that will be financed by non-governmental sources.

Publications

Publications, journal articles, presentations, and other end products produced under a CDC cooperative agreement must bear an acknowledgment and disclaimer, as appropriate, for example:
"This publication (Journal article, etc.) was supported by the Cooperative Agreement Number (###) from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention."

When data, that are collected and reported through support from CDC NPCR, are used for research and publication, acknowledgment of CDC NPCR in the text is expected. Text like the following sentence should be included:
"These data were collected by cancer registries participating in the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC)." (e.g., CDC NPCR should be described in the Technical Notes for Cancer in North America).

Conferences

Conferences funded by a cooperative agreement must include the following statement on conference materials, including promotional materials, agendas, and internet sites:

"Funding for this conference was made possible (in part) by the Centers for Disease Control and Prevention. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government."

Logos

Neither the HHS nor the CDC logo may be displayed if such display would cause confusion as to the conference source or give false appearance of Government endorsement. Neither the HHS nor the CDC logo can be used on conference materials without the expressed, written consent of either the Program Consultant or the Grants Management Officer. It is the responsibility of the recipient to request consent for use of the logo in sufficient detail to ensure a complete depiction and disclosure of all uses of the Government logos. In all cases for utilization of government logos, the recipient must ensure written consent is received from the Program Consultant and/or the Grants Management Specialist.

NPCR Program Standards Guidance

In the NPCR guidance section below, excerpts from the 2022-2027 NPCR Program Standards are enclosed in boxes followed by relevant and detailed operational instructions for recipients.

The NPCR Program Standards guidance section includes information about legislative authority, registry operations, data items, death clearance, and other pertinent registry topics. While abbreviated guidance from the Program Standards is referenced below, the full version of the current NPCR Program Standards is provided for reference in APPENDIX C.

Legislative Authority

NPCR registries must have a state/territory law authorizing a population-based central cancer registry:

"The state/territory has legislation or regulations in support of Public Health Service Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing the National Program of Cancer Registries."

National Cancer Registry Amendment Act

42 U.S. Code 280e with amendments provides the framework for needed legal support for operations of central cancer registries. Congress requires recipients, under state law, to provide for the authorization of the statewide cancer registry, including promulgation of eight categories of regulations to:

- Require reporting of newly diagnosed cancer cases by hospitals and other healthcare facilities.
- Require reporting of cancer cases by physicians and other healthcare practitioners.
- Guarantee access by the statewide cancer registry to all records of medical status of persons with cancer.
- Require the use of standardized reporting formats.
- Ensure confidentiality of cancer case data.
- Allow use of confidential case data by certain (approved) researchers.
- Authorize the conduct of studies using cancer registry data.
- Ensure protection of persons complying with the law from liability.

If state law/regulations do not specifically address each of the categories above, central cancer registries should work with appropriate staff/partners to assure each are included.

Many NPCR-funded programs provide access to their legislative statutes and regulations via their home website pages. NPCR maintains a list of contacts for all NPCR-funded Programs, including links to their individual websites, at Contact a Registry.

Administration and Operations

Operations Manual

Central cancer registries must maintain an operations (policies and procedures manual) manual describing registry operations, policies, and procedures. At a minimum, the manual must contain:

- Most current reporting laws/regulations.
- List of reportable diagnoses.
- List of required data items.
- Procedures for data processing operations.
- Procedures ensuring confidentiality and data security, including disaster planning.
- Procedures for data release, including access to and disclosure of information.
- Procedures for maintaining and updating the operations manual.

The Operations Manual provides the essential documentation for the management and operation of the central cancer registry and ensures consistency of internal registry operations over time. This manual also serves as a training guide for new staff and an informational resource for data users. It may include Standard Operating Procedures (SOPs) for staff cross-training, education and training, and major activities (data linkages, data exchange, deduplication, geocoding, etc.) conducted in preparation for annual data submission. It provides the documentation needed to support NPCR program applications and progress reports. The manual can be used to obtain funding support from state, federal, and private sources. NPCR recommends that registries consult the NAACCR Registry Operations Guidelines when creating or revising their Operations Manual.

For complete guidance on registry administration and operations, please see APPENDIX C: NPCR PROGRAM STANDARDS 2022–2027.

Management Reports

Management reports can range from simple counts to sophisticated statistical analyses; they can provide descriptive information about a system or compare and cross-tabulate values. Reports can be presented as data tables, charts, graphs, or as a statistical summary. Data visualizations may enhance understanding of report content. Management information can be used to trigger action or interventions to improve operations. The next section describes three management areas where reporting is critical.

Data Management

The central cancer registry software system should generate regular and ad hoc reports on the state of the registry database including, but not limited to, the following:

- Numbers of patient and cancer records entered or deleted from the database.
- Abstracts consolidated into single cancers.
- Abstracts flagged for review and abstracts reviewed.
- Sources and timeliness of reported records.
- Processing times as abstracts move through the system.
- Completeness of reporting based on expected numbers of cases.
- Receipt and processing of updated records.
- Edit failures/error rates, and corrections made to reported data.
- Staff workload assignments in relation to reported cases.
- User volume and response time.
- User access and permissions.
- Backup procedures and backup availability.
- Potential security breaches.

IT (Software) Management

Project management systems should be in place to track the progress of development activities from initiation to conclusion, such as design, writing, and implementation of new or enhanced software capability.

Personnel and Financial Management

Financial accounting systems should be in place to yield regular reports tracking employee time assignments and compare budgeted versus actual expenditures.

Abstracting and Coding Manual

Central cancer registries should produce an abstracting and coding manual for reporters. A standards manual is critical for promoting and preserving the reliability and consistency of cancer data collected and reported. Cancer data are assembled from many health record sources within single facilities, then consolidated from multiple facility abstracts, Health Level Seven (HL7) records, claims data, etc., by the central cancer registry. Therefore, different manuals should be created for the appropriate reporting source. Comparability and usefulness of the data at state, territorial, and national levels can only be achieved through the uniform application of standardized data definitions and codes. As coding rules change, central registry abstracting and coding manuals must also be updated.

Data Collection, Content, and Format

NPCR communicates requirements to NPCR-funded Programs for data collection through the Notice of Funding Opportunity (NOFO) and posted data submission requirements for the NPCR-CSS. These standards include reportability or case definition, data item definitions and coding structures, data edits, and data transmission format. For complete guidance on NPCR data collection requirements, please see Standard 1.3 in APPENDIX C: NPCR PROGRAM STANDARDS 2022–2027.

NPCR collaborates with other national organizations in creating, identifying, and publishing data standards. In particular, NPCR works through the procedures established by the North American Association of Central Cancer Registries (NAACCR) to define reportable cases, to request new data items, to identify NPCR-required data items in the , and to create and distribute data edits.

NPCR specifies the use of NAACCR-defined data layouts for the electronic transmission of cancer information between central cancer registries and from registries to NPCR. The NAACCR Data Dictionary specifies code structures and provides field descriptions for all data elements. Individual data items and reportability requirements for each standard setter, including the NPCR, are displayed in the "Required Status Table" in the NAACCR Data Standards and Data Dictionary.

Reportable Conditions

42 U.S. Code 280e and its amendments identify reportable conditions for the National Program of Cancer Registries. The primary resources for determining reportability are: International Classification of Diseases for Oncology, Third Edition (ICD- O-3), NCI SEER's Solid Tumor Rules, NCI SEER's Hematopoietic and Lymphoid Database and Manual, Cancer PathCHART, and the NAACCR Comparison of Reportable Cancers: CoC, SEER, NPCR, and CCCR, Reportable Diagnoses table. NPCR may periodically share updates to the Reportable Diagnoses table with NPCR recipients by email. NPCR encourages recipients to save these updates for their reference. Additionally, solid tumors of the brain and central nervous system are reportable, including the meninges and intracranial endocrine structures, listed in the ICD-O-3 with behavior codes of:

- "/0" benign disease
- "/1" disease of uncertain malignant potential
- "/2" in situ disease
- "/3" malignant disease

For more, see "Primary Site Codes for Non-Malignant Primary Intracranial and Central Nervous System Tumors."

Resources for Classifying Reportable Conditions

SEER electronically publishes an updated ICD-10-CM Casefinding List annually.

For cases diagnosed 01/01/2018 and later, ICD-O-3 is supplemented with the revisions published by the World Health Organization (WHO) and approved by NAACCR. These revisions consist of new codes, changes in behavior codes, and new terms associated with current codes. The changes reflect updates to the WHO Classifications for Tumors (Blue Books).

The International Agency for Research on Cancer (IARC) provides electronic versions of ICD-O-3. However, the IARC versions are not identical to versions used in the U.S.

In addition to ICD-O-3 (and its approved revisions), SEER's Hematopoietic and Lymphoid Neoplasm Database/Coding Manual should be used for classifying blood disorders and lymphoid neoplasms. Please visit the NAACCR and SEER websites for current ICD-O-3 revisions and for the Hematopoietic and Lymphoid Database.

Residency

A population-based cancer registry includes all tumors occurring in a population of interest, and rules must be in place for determining the members of that specific population. The goal of central registries is to include all cases of disease in state residents diagnosed and treated at facilities within state boundaries. Through data exchange agreements with other states, registries also collect data on state residents diagnosed and treated at facilities outside state boundaries.

NPCR requires registries to implement interstate data exchange agreements with, at a minimum, all bordering states to assure complete case ascertainment. See Data Exchange section for more information.

Central cancer registries use the same rules for patient address at diagnosis used by the Census Bureau in enumerating population. The 2010 Residence Rule and Residence Situations and the 2020 Residence Rule and Residence Situations guide cancer registries in making residence decisions for part-year residents, institutionalized and unhoused persons, military personnel, and students.

Required Data Items and Layout

The NAACCR Data Standards for Cancer Registries series, Data Standards & Data Dictionary (Formerly), lists all cancer items defined for data collection and reporting by the national standard setters: SEER, ACoS-CoC, and NPCR. Data items are defined with their coding structures or references to appropriate coding manuals.

Codes for Data Item Requirements	
.	No Recommendation
D	Derived
D*	Derived, when available
R	Required
R#	Required; central registries may code available data using either SEER or CoC data items and associated rules
R*	Required, when available
R^	Required, these text requirements may be met with one or several text block fields
RH	Historically collected and currently transmitted
RH*	Historically collected and currently transmitted when available
RS	Required, site specific
RS*	Required, site specific; when available

NPCR data item requirements are reviewed and updated each year. They are distributed to all programs via email, posted to the NPCR Program Directors SharePoint site, and

published in the NAACCR Data Standards and Data Dictionary.
Tables show the placement of data items in the NAACCR record layout (the format used for electronic transmission of registry information), and requirements for data collection and transmission established by SEER, CoC, and NPCR. Revised editions of the data dictionary and corresponding record layout are released on an annual basis. Historic and current versions of the dictionary and record layout are maintained in the NAACCR Data Standards and Data Dictionary.

NPCR requires registries to use NAACCR's standardized data exchange record layout for the electronic exchange of hospital and pathology cancer data. NAACCR has approved two record layout types for use: fixed length layout for cancer registry abstract data; and HL7 version 2.5.1 message standard for pathology report data. NPCR recommends that physician practices with Electronic Medical Records (EMRs)/EHRs use one of the two HL7 Clinical Document Architecture (CDA) standardized data exchange formats developed for Meaningful Use and supported by ONC certification standards. (See the Electronic Data Exchange section for more details).

For more information about NAACCR XML, please visit XML Data Exchange Standard.

Record Layout Format for Registry Data

The fixed length layout for registry abstract data is updated as needed changes are identified and released by NAACCR for implementation with cases diagnosed January 1st of the following year. NPCR-funded central cancer registries are expected to adhere to NAACCR's current format, which changes annually. NAACCR publishes detailed specifications and codes for each data item in the NAACCR Data Standards and Data Dictionary. NAACCR also publishes implementation guidelines and recommendations for cancer registries and software vendors.

Record Layout Format for Pathology Data

NPCR recommends use of NAACCR's Laboratory Electronic Pathology Reporting Guidelines, outlining specifications for electronically transmitting pathology reports based on Health Level 7 (HL7) Version 2.5.1.

Electronic Data Exchange

Electronic Reporting and Data Exchange Guidance

Electronic reporting and electronic data exchange refer to the format of the data being exchanged, and the method used by reporters for transmission to the central cancer registry. Electronic reporting is the transfer of data collected from source documents by hospitals, physician offices, clinics, or laboratories in a standardized, coded format that does not require manual data entry at the central cancer registry level to create an

abstracted record.

Electronic data exchange involves data transmission from the reporting source to the central cancer registry. Data must conform to the appropriate nationally adopted standardized formats for data exchange and mapping to the NAACCR record layout for inclusion in the central cancer registry database. There are several nationally adopted standards for reporting different types of data from non-hospital sources. Linkage with other data sources or databases, including claims data, to add or enhance cancer data is considered electronic data exchange.

Electronic reporting and electronic data exchange do not include faxing, mailing a portable storage device, or any similar methods of transferring data. The central cancer registry will use secure Internet-based software such as the Public Health Information Networking Messaging System (PHINMS), Web Plus, secure File Transfer Protocol (sFTP), or encrypted e-mail (such as HyperSend) to receive data from all reporting sources. The use of portable storage devices for data transmission is not recommended but may be used if internet access is not available.

For complete guidance on electronic data reporting and exchange, see Standard 1.4 in Appendix C: NPCR Program Standards.

Central cancer registries are required to adopt and use standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data. Registries will promote the use of the CDC-recommended formats by reporting sources that transmit data electronically to the registry. The CDC-recommended data exchange formats are identified in the following sections.

Hospital Reporting

The NAACCR Data Standards and Data Dictionary provides record layouts and specifications for several standard NAACCR record formats. The NAACCR record layout version used must match the corresponding diagnosis year. For example, Version 24 would be selected when processing cases diagnosed in 2024.

Physician/Other (Non-Hospital) Reporting

Electronic reporting includes not only proactive reporting, but also responses from physicians to central cancer registry inquiries such as death certificate-initiated cases. Reporting sources include radiation and medical oncology centers, ambulatory surgery centers, and any other reporting source that provides healthcare services to cancer patients outside of the hospital setting. Electronic reporting can be accomplished using CDC's Web Plus software. For more information regarding recommended standards for reporting, please see Standard 1.4: Electronic Data Exchange in Appendix C: NPCR Program Standards.

Laboratory Reporting

In-state and out-of-state laboratories should refer to NAACCR Laboratory Electronic Pathology Reporting Guidelines (version 4.0 or higher) for reporting to central cancer registries. This exchange format will be used for reporting pathology and prognostic factor (e.g., biomarker data) data for narrative reports and College of American Pathologists (CAP) Cancer Checklist reports.

Expanding Electronic Reporting

It is recognized that not all facilities will have the capability to electronically submit their cancer data. However, it is anticipated that as technology and/or resources become available, those facilities will embrace it. The goal is to increase the adoption and implementation of electronic reporting among data sources/reporters.

Some reporting facilities may not have trained staff for data collection, and the central cancer registry will need to abstract the data. These data should be abstracted into a secure cancer software program such as Web Plus, which can populate the appropriate fields at the central cancer registry.

When possible, all cancer data should be transmitted to the central cancer registry in an electronic format. Facilities that cannot submit cancer data electronically should use a flat ASCII text file.

Promoting Interoperability Programs

Centers for Medicare & Medicaid Services (CMS) establishes the criteria that Eligible Professionals (EPs) and hospitals as well as critical access hospitals must meet to qualify for Medicare and/or Medicaid EHR incentive payments as they adopt, implement, upgrade, or demonstrate meaningful use of certified EHR technology. The Office of the National Coordinator of Health Information Technology (ONC) establishes the standards, implementation specifications, and certification criteria for EHR technology that will support implementation of the criteria described by CMS. Cancer reporting from Eligible Professionals to central cancer registries was included as an optional objective for MU Stage 2, and in later stages under the broader public health reporting objective.

Through a collaborative effort with NAACCR, state central cancer registries, Integrating the Healthcare Enterprise, and other organizations, CDC developed the first version of the Implementation Guide for Healthcare Provider Reporting to Central Cancer Registries. Additional versions were developed to improve the content and structure and were cited as the standards to be used by EHRs in the 2014 and 2015 ONC Certification Rules, as detailed in the section above. These guides contain the necessary specifications for the implementation of standardized data transmissions from a health care provider EMR/EHR to the central cancer registry. A single method will allow efficient and accurate transmission of cancer information while reducing the burden on EMR/EHR system-specific or registry-specific implementations.

The Implementation Guides provide the business rules and specifications for EMR/EHR systems to:

- Identify reportable cancer cases.
- Identify the specific data elements to be retrieved and included in the cancer event report.
- Create a valid Health Level 7 CDA, Release 2 cancer event report.
- Transmit the cancer event report to a central cancer registry over a secure electronic transmission mechanism.

The CMS EHR Incentive Program (Stage 3) or MU/Promoting Interoperability Program Final Rule outlines Medicaid Eligible Provider (EP) objective, measure, and exclusions for public health registry reporting, which includes cancer registries. The CMS Quality Payment Program (QPP) Final Rule for certain Medicare Eligible Providers should also be reviewed.

The ONC 2015 Certification Final Rule cites the cancer registry reporting standard to be implemented by EHRs as the HL7 CDA Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, DSTU Release 1.1 – US Realm.

The CMS Stage 2 Meaningful Use Final Rule outlines EP objective, measure, and exclusions for reporting to a state cancer registry.

The ONC 2014 Edition Certification Final Rule cites the cancer registry reporting standard to be implemented by EHRs as the Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries, August 2012.

Data Completeness, Timeliness, and Quality

Data Completeness

NPCR Program Standards specify the requirements for data completeness, timeliness, and quality by which data submissions are evaluated. The data evaluation results are used as a component in NPCR's overall evaluation of central cancer registry program performance. Data evaluation results are also used to determine registry data eligibility for inclusion in national cancer data publications.

NPCR program requirements set standards for data completeness in the following data collection activities:

- Health care facilities and physician offices reporting
- Death clearance
- Data exchange among central cancer registries in bordering states
- Case finding audits of reporting sources
- Data linkages with other federally funded programs identifying cancers

For more information, see Standard 1.5 in Appendix C: NPCR Program Standards.

Death Clearance Activities

Death clearance is defined as the process of matching registered deaths in a population against reportable conditions in the central cancer registry database for two purposes:

- Ascertainment of vital status for persons in the central cancer registry (death clearance match)
- Identification of all deaths with a reportable condition mentioned as a cause of death which are not found in the central cancer registry (death clearance follow- back). A Death Certificate Only (DCO) case is a reportable case for which the death certificate is the only source of information. “Death Certificate Only” cases must represent 3% or fewer of total cases in the registry database.

More guidance for death clearance can be found in the Strategy 5 Section of the DP22-2202 NOFO. NPCR strongly encourages its funded programs to identify and reconcile non-matched cases, both at the patient and the tumor level with state death certificates. Patient level matches are required.

NPCR supports NAACCR’s revised Death Clearance Manual which includes:

- Redefinition of minimum requirements for conducting death clearance follow-back.
- Tools to promote automation of the death clearance process by providing enhanced tumor linkage guidelines and an appendix of Death Certificate Only (DCO) record default values.

Standardized Data Elements

NPCR references the Data Standards and Data Dictionary as the source of information for the prescribed data transmission layouts. The Data Dictionary specifies code structures and provides field descriptions for all data elements. Individual data items and reportability requirements for each standard setter, including the NPCR, are displayed in the “Required Status Table.”

Standardized Data Edits

The NOFO requires programs to use computerized standardized edits on all incoming abstracts and consolidated reports. Both edit sets are available in the current version of the NAACCR edits metafile. At a minimum, programs should run the NPCR-CSS Call for Data edits quarterly.

NPCR also recommends that programs create state-specific edit sets, based on the NAACCR edits metafile, that are appropriate for each reporting source (e.g., hospitals, physicians, pathology laboratories). These specific edit sets should be provided to the appropriate reporting-source and their use required for data submission to the central cancer registry. Programs should consider establishing a threshold for the percentage of records passing edits to accept data files from those reporting sources. Programs should also utilize an edit set specific to cases transmitted or received through interstate data exchange.

Record Consolidation & De-Duplication

NPCR-funded central cancer registries are required to perform consolidation of reported data following best practices or standards as they become available. The NPCR has adopted the definition of consolidation as stated in the NAACCR Standards for Completeness, Quality, Analysis, and Management of Data, Volume III: "The process of reconciling or compiling data obtained from more than one source on the same person or tumor." The consolidated record should contain the most reliable information from all available reports. Case consolidation is a major activity of central cancer registries, and the balance between computerized and manual practices varies widely. This variation in practice makes it extremely important for each central cancer registry to establish and follow consistent procedures. De-duplication of consolidated records should be on a monthly or quarterly basis.

Geocoding

Geocoding is the process of assigning geographic identifiers to patient address at diagnosis. Identifiers include geographic coordinates expressed as latitude and longitude, and census tract, which can be determined from the coordinates. All cases should be geocoded for each time-associated variable. NPCR requires reporting of census tract, and census tract certainty for each cancer diagnosis; latitude and longitude are required as available. Reviewing and updating address at diagnosis coding on individual records in preparation for geocoding improves information in existing data fields. Latitude and longitude information facilitates spatial analysis of cancer data in geographic information systems (GIS). Census tract identification facilitates analysis of cancer diagnosis and treatment using socioeconomic variables. The NPCR identifies GIS analysis and/or mapping as an advanced surveillance activity. Registries are encouraged to conduct GIS analysis, if they consistently meet or exceed the NPCR program standards. More information about GIS Resources is available on the NAACCR website.

Case Ascertainment and Timeliness

The NPCR has established standards to help ensure cancer data are available for use in a timely manner. Case ascertainment should be 90% complete within 12 months of end of diagnosis year and 95% complete within 24 months of end of diagnosis year.

There is no established standard for determining timeliness other than evaluating completeness of case ascertainment within a specified period, e.g., within 12- and 24-months of diagnosis. Completeness of case ascertainment is based on the calculation of observed to expected cases by NPCR. NPCR uses a modified version of the NAACCR method of estimating case completeness in that NPCR uses the NPCR incidence rate rather than the SEER incidence rate to create the Incidence to Mortality Rate Ratio. The NAACCR method is described in Standards for Completeness, Quality, Analysis, and Management of Data, Volume III.

Data Exchange

Implementation of the standard for data exchange among central cancer registries of bordering states may require enabling legislation or formal agreements between states to allow the release of patient-identifiable information from one state registry to another state registry. States may exchange information with cancer registries covered by the NPCR NDI application for the purpose of identifying potential duplicate case reporting.

NAACCR has developed a model National Interstate Data Exchange Agreement (ISDE) which allows states to exchange data on cases diagnosed or treated in other states. This single agreement will replace multiple interstate data exchange agreements.

Quarterly data exchange with geographically bordering central cancer registries is strongly encouraged. Working together with the central cancer registries you exchange data with to adopt a standard edit set is also strongly recommended to ensure data transmitted is edit free and of high quality. Note: cause of death data obtained from the National Death Index may not be exchanged.

NPCR Program Evaluation

NPCR evaluates registries to ensure that their cancer data meets NPCR completeness, quality, and timeliness standards. NPCR evaluates each program's overall success in operating a central cancer registry, which includes meeting the NPCR Program Standards and effectively disseminating and using cancer data to understand, quantify, and respond to the disease burden. The NPCR assesses each central cancer registry's operations to monitor progress made toward meeting long-term goals identified within DP22-2202 recipient work plans. NPCR-funded central cancer registries are responsible for creating a program evaluation plan to guide their program evaluation priorities and activities per DP22-2202 requirements.

In December 2021, NPCR shared program evaluation guidance with recipients to provide cancer registries with information on basic evaluation elements, suggested evaluation plan components, and share program requirements. NPCR recipients are required to submit evaluation summary, mid-term, and final reports. See NPCR Deadlines calendar for specific due dates. Reports should follow NPCR evaluation guidance and describe progress, successes, and any challenges experienced while implementing evaluation activities.

Final program evaluation results should be described in the final evaluation report due at DP22-2202 cooperative agreement closeout. For more information, see the NPCR Evaluation Plan Guide document in APPENDIX E and evaluation report guidance provided in AMP.

Data Management Plan (DMP)

Per 22-2202 Notice of Funding Opportunity (NOFO), each recipient is required to put a Data Management Plan (DMP) in place. These plans are required for cooperative

agreement awards where data collection or generation activities are necessary. As part of the continuation application (APR), each NPCR recipient is required to submit a DMP plan to CDC annually.

The DMP should provide a description of the data that will be produced using these NOFO funds; access to data; data standards ensuring released data have documentation describing methods of collection, what the data represent, data limitations; and archival and long- term data preservation plans.

Recipients must update their DMP and include the location of the deposited data during the 5-year funding cycle. Recipients can inform their program consultant or Paran Pordell, CDC NPCR ORTAT Team Lead, once the DMP update is made. The DMP is a living document that should be updated (as needed) throughout the life cycle of data and 5-year cooperative agreement cycle. For more information regarding Data Management Plans, please see the DMP Guidance Document in APPENDIX F.

Physician Reporting

Federal legislation establishing NPCR requires recipients to have 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." Individual state laws vary in how the physician reporting requirements are implemented. For more information, see Standard 1.5 in APPENDIX C.

Health Care Practitioners Required to Report Cancer Cases to Central Registries

All health care practitioners may be required to report according to state law. However, for the purposes of the NPCR Program Standards, the following health care specialties, at a minimum, should be targeted for reporting of cancer cases that are not otherwise reported from another source:

- Dermatology
- Urology
- Gastroenterology
- Hematology
- Medical Oncology
- Radiation Oncology

Types of Physician Reporting

Physician reporting can be active or passive. Active reporting is when a physician or facility proactively reports cancer cases without prior central cancer registry request. This may include the use of abstracting software, transmission from EMRs/EHRs, and/or the submission of paper reports. Passive reporting is when a physician or facility transmits

cancer cases in response to a central cancer registry request. Central cancer registries should strongly encourage increased active reporting, regardless of whether a case has been reported by another source. This effort helps to generate complete abstracts.

Methods to Monitor and Determine Compliance

At minimum, central cancer registry should annually monitor the total number of physician specialties reporting to determine compliance with NPCR Program Standards. Active and passive reporting are included in the analysis. Central cancer registries should consistently monitor the total number of physician specialties reporting from year-to-year. An increase or stability in totals should be observed for each subsequent year during the five-year project period. The goal is to observe an overall improvement in physician specialty reporting.

Determine Software and Develop Operational Procedures

When possible, registries should use NPCR software, such as Web Plus, for physician reporting. This program uses the internet for reporting, and all software and case information are maintained on a central cancer registry server providing data security.

If physicians/practices have EMRs/EHRs that can transmit cases directly, they may report using one of the HL7 CDA standard formats described above. They can transmit these reports using any appropriate secure transport mechanism such as Web Plus, Public Health Information Network Messaging System (PHIN MS), Direct, CONNECT, secure File Transfer Protocol (sFTP), etc.

Registries can also use NPCR's Abstract Plus software for physician reporting if the physician office does not have internet access. See the NPCR website for additional information on all CDC products.

Registries must develop procedure manuals to guide physician reporting. This resource should be made readily available to reporters through the registry's website. Further tips include:

- Place easy to find physician links on the central cancer registry webpage.
- Include cancer reporting laws and rules.
- Include reporting forms and manuals.
- Include physician reporting procedures.
- Include software manual for physician office staff.
- Include telephone and email contact information for the central cancer registry coordinator.

When establishing a physician or clinic database to monitor reporting, registries should:

- Determine if the primary database will be of physicians or practices. Decide whether it will be separate or part of a larger database that includes other reporters.
- Determine if any other health department division maintains a physician or

practice database that could be used, such as physician licensing or emergency medical service.

- Determine if central cancer registry software allows the generation and incorporation of a single doctor file which provides information on the central registry's reporting physicians.
- Develop a new database if necessary, using Microsoft Access, Microsoft Excel, or similar software products.
- Update the database on an ongoing basis and at least annually.
- Develop database elements to include:
  - Physician or practice identification number.
  - Contact information, including the entire address and the name of the person responsible for responses.
  - Reporting source, which can be an individual physician, clinic, or physician group; one physician can be listed with multiple clinics or practices.
  - Physician specialty.
  - Reporting status (proactive, responds to inquiries, does not respond).
  - Method of reporting (e.g., Web Plus, MU, electronic form, or other).
  - Date last updated.
  - Initials of person updating.
  - Sources of update.

Develop Strategic Plan to Increase Physician Reporting

Central cancer registries face similar challenges with compliance in physician reporting. The central cancer registry should develop strategies to increase physician reporting. Below are some ideas on how to improve physician reporting:

- Develop a physician reporting Advisory Group: Consider a sub-workgroup of the central cancer registry Advisory Committee. Include key partners such as the ACoS CoC state liaison physician, State Medical Society, and respected retired specialty physicians. Utilize physicians on the Advisory Committee for counsel on methods to achieve compliance and to advocate for physician reporting.
- Communicate with other central cancer registries about physician reporting to exchange tips and ideas for success.
- Target physician specialties with the highest number of missed cases identified through linkages with pathology reports, death certificates, or other databases.
- Evaluate rates for individual cancers compared to national rates to identify physician specialties where cases may be missing, such as urology (prostate/bladder) or dermatology (melanoma).
- Increase physician reporting gradually to make the process more manageable. Start with one specialty physician group and then move on to the second, and so on. At least one new category of specialty physicians should be targeted each year.
- Work with the NPCR to identify EMR/EHR systems capable of transmitting cancer reports and identify physicians/practices using these systems.

- Develop a Memorandum of Agreement (MOA) with state physician licensing agency that includes a mechanism to:
  - Receive regular updates of new licensees
  - Include central cancer registry information and/or cancer reporting requirements in license application
  - Institute a continual process to include renewals and exclude physicians who no longer practice in the state
  - Develop a process to make compliance with state reporting laws a requirement for physician licensure (i.e., licensing is contingent upon meeting all state reporting rules)
  - Send a list of noncompliant physicians to the state licensing board
- Look for other state programs/associations/societies which may already have physician directories that can be shared. Obtain lists of hospital staff physicians that may be updated annually
- Investigate the use of physician address services
- Use follow-back for pathology reports and death clearance certificates to identify new physician sources
- Recruit through hospitals, specialty group meetings and associations
- Arrange to have presentations made on the importance of physician reporting
  - Possible venues include State American Medical Association (AMA) meeting, state or local urology meeting, state or local dermatology meeting, state or local oncology association meeting.
  - Speakers include physician advisory board members and officers of the specialty associations.
  - Include examples of how data are used in presentation, listing the reports that are available because of reporting.
  - Focus on the impact of physician reporting on cancer surveillance and the importance of population-based cancer data for cancer control efforts.
- Follow-up with a personal contact with the physician or practice manager.
- Support physician and clinic office reporters
- Send new reporters a package which includes central cancer registry law that requires that physicians report all cases not reported by other facilities, HIPAA information (available on NAACCR website), procedures for how and when to report, a copy of the reportable list, and any state-specific documents.
- Introductory letter may be sent from state officials or central cancer registry administrator outlining reporting requirements.
- Address letters to Medical Director of practice or Office Manager.
- Set up a continual process to include newly practicing physicians and exclude physicians who no longer practice in the state.
- Provide training with targeted, clear, and concise educational materials and provide ongoing support.
- Provide demonstrations of available tools.
- Provide training for the physician office staff learning how to abstract reportable information.

- Send written reports such as annual monograph to physicians, so they can view positive outcome of participating in central cancer registry.

NPCR-CSS Data Evaluation Reports

Following each data submission, registries receive the NPCR-CSS Data Evaluation Report (DER), detailing completeness, accuracy, and timeliness of the five-year period under evaluation. DERs show the program's progress in meeting the following standards:

- Percent Completeness Adjusted for Duplicates: The percentage of observed to expected, unduplicated cases where the expected cases are estimated using methods developed by the North American Association of Central Cancer Registries (NAACCR). Annual case completeness evaluation is based on the current NAACCR method (as previously referred to in the Data Timeliness section).
- Unresolved Duplicate Rate: Because some cancer patients receive diagnostic or treatment services at more than one reporting facility, cancer registries perform a procedure to identify and resolve duplicate case reporting to ensure each cancer case is counted only once. Prior to the NPCR-CSS data submission, each registry performs a protocol developed by NAACCR for assessing duplicate cases. This information is reported to NPCR with the data submission.
- Percent Death Certificate Only Cases: Another measure of completeness of case ascertainment is the proportion of cases ascertained solely based on a death certificate, with no other information on the case available after the registry has completed a routine procedure known as "death clearance and follow back."
- Percent Missing Critical Data Elements (Age, Sex, Race and County): The proportion of cases missing information deemed critical for the reporting of population-based cancer incidence data.
- Percent Passing Edits: Edits test the validity and logic of data components. Edits are applied to single field variables, inter-field variables and to multiple records (each record denotes a case of cancer in a patient) in those instances where a patient has multiple cancer diagnoses. Inter-record (IR) edits are run on the entire data submission from the reference year through the most current 24-month data.

NPCR Program Evaluation Instrument (PEI)

The NPCR PEI assesses central cancer registry system attributes, including:

- Simplicity (the structure and ease of operation)
- Program flexibility
- Data quality activities
- Acceptability

- Activities affecting surveillance sensitivity
- Representativeness
- Timeliness
- Program stability

The PEI consists of a series of questions designed to provide a consistent approach to evaluating programs across NPCR. It is administered biannually through a secure web- based system. For both funded programs and NPCR, the PEI assesses whether the program's design and purpose are clear and defensible, documents which standards the programs are meeting, and whether valid long-term goals are met. The PEI includes sections on:

- Staffing
- Legislative Authority
- Administration
- Reporting Completeness
- Data Exchange
- Data Content and Format
- Data Quality Assurance
- Data Use
- Collaborative Relationships
- Advanced Activities
- Survey Feedback

Formalization of program evaluation using the PEI is intended to develop defensible and consistent progress toward funded programs meeting NPCR Program Standards and toward NPCR meeting program goals. The PEI provides NPCR the information needed to focus attention on:

- Strategic planning.
- Meaningful performance measures for funded programs and NPCR.
- Program results.
- Appropriate technical assistance that can improve data quality and program efficiency and usefulness.

When recipients complete the PEI, immediate access to a PDF of state or territorial information is provided. The information should be used for self-assessment of program goals and operations. Central registry and NPCR staff may review PEI results in preparation for upcoming site visits.

Linkages

Linkages conducted by the central cancer registry improve the quality of data within the registry database and are an efficient method to obtain information. This section includes examples of linkages conducted by central registries. For more guidance on linkages, see Standard 1.6 in APPENDIX C.

State Mortality Files

With the release of NAACCR's 2015 Death Clearance Manual, it was determined death linkage is still matched by person, but linking by tumor remains optional. Note: NPCR strongly recommends tumor linkage but does not require it. Tumor linkage is important for completeness, especially for multiple primaries and secondary cancers.

National Death Index and Social Security Index

Following the linkage with state death files, the registry should link with the National Death Index (NDI) every year. CDC has a funding agreement that allows the state central cancer registries to link with NDI. Various tools and guidelines are available on the NPCR-CSS Document Server to assist you with the NDI linkage process, including a user's guide, extraction utility, edits set, and SAS match reconciliation statements.

Prior to submitting data for National Death Index (NDI) linkage it is recommended that the registry conduct a Social Security Death Index (SSDI) data check or linkage. CDC makes the SSDI database available to central cancer registries through the NPCR-CSS Document Server and SSDI Query System. A login and password are required to access both sites. To request access to either or both sites, please contact your program consultant. The current SSDI database contains over 90 million names and vital information of deceased Americans and is updated monthly. It is an important source of data for linkage to verify vital status or other important demographic information such as date of birth, date of death, and to a lesser extent, state of residence and last known address.

Breast and Cervical and Colorectal Cancer Early Detection Programs

The NPCR requires central cancer registries to perform data linkage at least annually with state programs funded by CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Colorectal Cancer Control Program (CRCCP). These linkages may identify cancer cases missing in the registry database or discrepancies in diagnostic and treatment information between the databases. The NBCCEDP and CRCCP programs are required to collect and report a set of minimal data elements for all client participants. The linkage also assists the NBCCEDP and CRCCP in validating their information such as site and stage and is a quality control mechanism for all programs. NPCR recipients carry out the linkage with databases provided by the data managers of NBCCEDP and CRCCP. The guidance for this linkage, developed by NBCCEDP and NPCR, is on the CDC Partners SharePoint page, available through the System for Award Management (SAM) portal.

Indian Health Services

The NPCR-funded central cancer registries should perform data linkages between the Indian Health Service (IHS) patient registration database and the central cancer registry database to improve the identification and classification of American Indians and Alaska Natives. The IHS website provides further information on the cooperative agreements

with the CDC.

All NPCR-funded central cancer registries are required to participate in this linkage every five years. A subset of registries with one or more IHS Purchased/Referred Care Service Delivery Area (PRCDA) counties are required to perform IHS linkage every year. Instructions to carry out the required IHS linkage are included in the NPCR-CSS Call for Data Submission specifications document each year. An IHS extraction utility is available on the NPCR-CSS Document Server Utilities Page.

Other Linkages

The NPCR requires registries to process data using the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm (NHAPIIA) to improve the coding of ethnicity data.

NPCR encourages central cancer registries to perform other data linkages to enhance the completeness of central cancer registry data. Examples of partners for linkages include:

- A regional health care system
- A health statistics agency within the Health Department
- Local tribal registration lists

Data Quality Assurance and Education

Audit for Data Quality and Completeness

Discrepancies in the completeness and quality of cancer data among states have made analysis of cancer patterns by state and by geographic region difficult. Consequently, there is an ongoing need to assess the completeness and quality of cancer reporting, case finding, and data abstracting.

Data quality assurance requires a case finding and/or re-abstracting audit based on a sampling of source documents be conducted for each hospital-based reporting facility at least once every five years. These audits may include manual review of source documents and data linkages of electronic files from submitting facilities with the central cancer registry database. For more guidance on data quality assurance and education, see Standard 1.7 in APPENDIX C.

The audits require central cancer registry staff to have access to primary data sources, such as disease indexes, pathology reports, and treatment logs to assure all eligible cases are identified and reported.

Re-abstracting and recoding studies are audit procedures whose purposes are to:

- Standardize interpretation and abstracting of the medical record.
- Estimate rates of agreement.
- Identify problems in data collection and interpretation.

Central cancer registry options for conducting external audits of reporting sources include:

- Reliability studies developed by the CCR for reporting entities.
- Visual review of all reports from new abstractors with follow-back on data quality issues.
- Sampling of cases from facilities with visual review of coded data and text.
- Selection of certain site/histology combinations for annual review (i.e., all unknown primaries).
- Reconciliation of conflicting data between registries reporting the same case.

Central cancer registry options for conducting internal audits include:

- Periodic random review of coding of pathology reports sent directly to the central cancer registry.
- Systematic random review of case consolidation performed by central cancer registry staff.
- Quality checks of data collected and processed by central cancer registry staff.
- Participation in national quality assurance studies.
- Systematic random review of case information collected by central cancer registry staff.

Data completeness audits focus on the central cancer registry's activities to identify and collect all reportable cancers. Routine case finding may be organized as a collaborative activity between reporting agencies and the central cancer registry. For example, pathology laboratories may submit electronic data files of pathology reports, and the central cancer registry may identify the reportable cancer diagnoses from these electronic data streams.

Central cancer registries must have an appropriate mechanism for tracking reported versus non-reported cancers and cancers not eligible for inclusion in the registry. Mechanisms must also be in place to request new cancer reports for eligible cases which have not been submitted.

Data Quality

The NPCR program has established requirements to help ensure data quality. These requirements include:

- Electronic reporting format
- Standardized record layout
- Standardized data elements
- Standardized data edits
- Consolidation of multiple records into a single tumor record using best practices
- Geocoding to specify geographic locations of address at diagnosis
- Data linkages and algorithms to assign race and ethnicity
- Data audits

Data Quality Evaluation (DQE)

NPCR program requirements specify that NPCR-funded central cancer registries participate in an NPCR-sponsored independent Data Quality Evaluation (DQE), conducted by a CDC contractor. The continuous program of data assessment through the DQE process has the following characteristics:

- NPCR-funded central cancer registries participate in the DQE at least once every five years.
- Completeness and data accuracy of all designated sites are reviewed.
- Treatment data are evaluated.
- Focus is on summary information.
- Formal post-audit debriefing is provided to the central cancer registry.
- Final report is provided to the central cancer registry.

Special Audits

NPCR may conduct special audits to assess registry performance in response to significant changes in cancer data standards, or to investigate registry operations of special concern.

Education Program

Education and Training Coordinators (ETCs) are responsible for developing training plans and delivering training sessions or workshops to central cancer registry staff and to reporting facilities. ETCs must also attend NPCR Education and Training events, including the ETC Workshop at NCRA.

Training Plans

Training plans should be based on needs assessments such as review of registry data deficiencies and should anticipate the educational support needed to introduce new coding requirements to reporters. The training function must be goal-oriented, planned, carried out, and evaluated for contribution to the collection of quality cancer data.

Training plans may:

- Focus on updated coding systems.
- Include sessions on basic abstracting principles for new reporters and advanced abstracting for experienced registrars; such sessions are often presented in the context of comprehensive coding instruction on all registry data elements for specific primary sites of cancer.
- Focus on issues within cancer registry abstracting such as the application and resolution of edits, the review and revision of casefinding activities to promote more complete and timely collection of data, record consolidation, or the resolution of quality issues identified by central registry and NPCR audits or patterns of care studies.

NPCR emphasizes the critical importance of training for cancer registrars to support the collection of reliable, consistent, high-quality data needed for cancer prevention and control activities. NPCR develops and produces training materials using multiple communication technologies to reach the training audience. Education and Training Coordinators are encouraged to use web-based meeting technology when travel is not feasible.

NPCR embraces these education core values:

- Education is an essential element in achieving data quality. completeness, and timeliness.
- Content of education programs and products must respond to issues identified in quality assurance activities.
- Educational opportunities must be offered continuously in diverse formats and methods of access.

Education objectives include:

- Providing resources through sponsoring training opportunities. developing materials, and funding registries to participate in educational sessions.
- Strengthening the capacity of NPCR registries to provide education within their community of reporting facilities.
- Monitoring the educational infrastructure for gaps in access to education.
- Searching for methods and technology to improve access to education for the entire cancer surveillance community.

NPCR supports in-person meetings and training for participating states, including:

- Required trainer attendance at annual Train-the-Trainer meeting in Atlanta or wherever designated.
- Recommended attendance of at least one program registry representative at the annual NAACCR meeting.
- Recommended attendance of at least one program registry representative at the annual NCRA meeting.
- Recommended attendance at training sessions for application of new or revised coding and data collection rules.

Technology

NPCR supports web-conferencing and/or teleconferencing for trainer meetings and has adopted the use of webcasts for training sessions. CDC NPCR supports training webinars from various sources. NPCR's SharePoint site has an ETC (Education and Training Coordinator) section which supports all program educators with training materials, including presentations, time-sensitive resources and documents, and recordings of past webinars. Program Directors should contact NPCR for access to this ETC SharePoint section.

Currently, NPCR is providing a learning management system to all programs, "FLccSC". We encourage programs to onboard this Learning Management System and use this resource as another method for training and education. All resources found on SharePoint will be on FLccSC.

SEER*Educate

SEER*Educate is a comprehensive training platform tailored to improve technical skills of cancer registry professionals through applied testing on coding and concepts.

Cancer Registrar Educational Resources beyond NPCR

SEER offers educational materials for cancer registrars. There are five sections on this training site that include:

- Becoming a Cancer Registry Professional.
- SEER Training.
- SEER*Educate.
- SEER Self Instructional Manuals.
- SEER Advanced Topics for Registry Professionals.

In addition to these materials, the SEER Inquiry system (SINQ) is a collection of cancer registrar questions with the answers provided by SEER staff members.

The National Cancer Registrars Association (NCRA) has cancer registrar training materials available on their website.

NAACCR offers an educational webinar series as well as an ODS exam preparation and review webinar series.

Industry and Occupational Coding

Occupational risk factors for cancer have been extensively investigated with prospective cohort or case-control research methodology, and workplace exposures are now recognized as an important cancer risk factor. Occupational exposures are estimated to contribute to 40,000 new cancer cases and 20,000 deaths every year.

The Cancer Registries Amendment Act requires that the NPCR collect "information on the industrial or occupational history of the individuals with cancer, to the extent such information is available from the [medical] record" (see NAACCR Data Item 290 and 300).

NPCR worked with the National Institute for Occupational Safety and Health (NIOSH) to improve cancer registrars' data collection skills. In 2011, NIOSH collaborated with NAACCR to provide a webinar to improve the Industry and Occupation (I&O) collection skills of cancer registrars. Continuing education credits are available for registrars completing the module, along with other web-based learning modules to improve the completeness of I&O data collection.

To facilitate collection of I&O data, NIOSH developed the Industry & Occupation Computerized Coding System (NIOCCS), which is a web-based system that translates I&O text into standardized I&O codes. Registries can now use the NIOCCS system to assign I&O codes automatically and accurately. For more information about I&O coding, see "Collection of Industry and Occupation (I&O) Data For Cancer Registry Professionals." For further details regarding I&O text, see "A Cancer Registrar's Guide to Collecting Industry & Occupation."

Data Use and Data Monitoring

Data Use

A primary NPCR goal is to provide data to public health entities, researchers. and other collaborators monitoring the burden of disease and planning effective cancer prevention and control programs. Data collected by central cancer registries enable public health professionals to better understand and address the cancer burden. While registry data are critical for programs focused on risk- related behaviors or environmental risk factors, those programs may not be aware of the availability of such a rich data source.

NPCR-funded Programs are expected to be proactive in analyzing their data and using the findings to strengthen cancer control programs in collaboration with other programs and agencies. Such information is essential for identifying when and where cancer screening efforts should be enhanced, evaluating the effectiveness of such interventions and for monitoring the treatment provided to cancer patients. In addition, reliable registry data are fundamental to a variety of research efforts, including those aimed at evaluating the effectiveness of cancer prevention, control, or treatment programs. It is suggested that NPCR registries utilize U.S. Cancer Statistics (USCS) rates for comparison with the state data. For more guidance on data use and monitoring, see Standard 1.8 in APPENDIX C.

Success Stories

Success stories provide a record of innovative activities in which the central cancer registry has been engaged within the past year. Success stories may include ways in which central cancer registry data have been used, publications and journal citations, as well as other activities that may be of interest to other central cancer registries and to NPCR.

The Cancer Surveillance Branch (CSB) collects success stories annually from their CDC NPCR- funded programs to illustrate progress, a specific achievement, or identify impact of program strategies and activities performed under the cooperative agreements.

Success stories should: engage and inform the program partners and collaborators, increase program visibility, encourage peer-to-peer support, and share best practices. It

may be helpful to identify a key topic to focus your success story, such as:

- Registry operations
- Public health impact
- Stakeholder collaborations and alliances
- Specific cancer condition
- Data collection (MU, EHR etc.)

Examples of past success stories in central cancer registry operations include:

- Advances in electronic reporting.
- GIS activities.
- Death clearance activities.
- Automated database activities that have improved data processing efficiencies.
- Activities that have improved data quality, completeness, or timeliness.
- Advances in data security.
- Implementation of cancer inquiry response systems.
- Successful interstate collaborations and partnerships.

Benefits of creating and distributing success stories for NPCR-funded programs include:

- Capturing program progress over time and highlighting major accomplishments.
- Illustrating a problem or challenge being addressed and/or solved.
- Showcasing a specific achievement.
- Identifying the impact(s) of specific activities and strategies.
- Facilitating peer-to-peer support and development of new technical assistance resources.
- Engaging stakeholders, partners and public, and demonstrating responsible use of resources.
- Educating decision makers about the impact of the program.
- Broadening understanding in the cancer surveillance field of the value of central cancer registries.
- Garnering funding and additional support.
- Increasing awareness and visibility.
- Attracting new partners for collaboration.

Each year, CSB provides a success story outline template to NPCR-funded programs to use in developing their narratives, along with guidelines to enrich the storytelling. Every template includes the following components:

- Title: descriptive headline to grab readers' attention
- Summary
- Challenge: a concern that adversely affected a specific vulnerable population
- Solution: the action performed that prompted change
- Results/ Accomplishment/ Impact: describes goals achieved and outcomes
- Lessons Learned/Sustaining Success:
    - Inform peers to adopt or adapt practices
    - Maintain and continue efforts

    - Include “call(s) to action” when applicable
- Direct Quote: positive remarks and emotional insight from a patient, provider, or partner (optional)
- Contact Information/Author
- Point of contact and email address
- Graphics, Tables, Charts, etc. (optional)
- Photographs (optional)

Once the central cancer registry’s success story is submitted to the CDC, it is edited, and a final version is posted on CDC CSB internal and external SharePoint sites. Success stories are also printed in poster format where they are displayed at national cancer registry and cancer surveillance-related conferences. Finally, success stories are often shared via congressional inquiries, with other cancer prevention and control programs, and colleagues interested in learning more about specific central cancer registry operations, cancer conditions and/or other topics covered by success stories.

The National Program of Cancer Registries-Cancer Surveillance System (NPCR-CSS) began collecting data from central cancer registries in 2001. The goal of NPCR-CSS is to allow the analysis of aggregated data from NPCR-funded central cancer registries on a regional or national level, as a statistical basis for the planning and implementation of cancer prevention and control initiatives. Analysis of aggregated data provides more accurate and stable estimates of cancer incidence for population groups including racial and ethnic minorities, groups who may have limited access to health care services, and other subpopulations. Analysis of aggregated data also reveals geographic variability in cancer treatment practices, use of state-of-the-art cancer treatment, and deviations from standards of cancer care. The public use data files from the CSS provide greater access to cancer data for the public, scientists, and policy makers.

Data Submission

Submission Packet

The Data Submission requirements, Data Release Policy, and Utilities to aid in the preparation of data submission are available on the Utilities page of the NPCR-CSS website. The NPCR-CSS Submission Packet includes submission specifications, data items, data edits, all submission forms, confidentiality, data security, and frequently asked questions. For more guidance on Data Submission, see Standard 1.9 in APPENDIX C.

NPCR-CSS Data Release Policy

Starting with DP22-2202, participation in all CDC-created and hosted analytic datasets and web- based data query systems, as outlined in the NPCR-CSS Data Release Policy, is a required strategy. The NPCR-CSS Data Release Policy describes the planned release of data submitted to CDC as part of the annual NPCR-CSS data submission. This policy, which originally took effect October 2003, is updated annually, and can be found on the NPCR-CSS website.

Utilities

As a service to participating central cancer registries, NPCR offers the following utilities specific to the submission year.

- **NHIA V2 SAS Program**: All NPCR-funded central cancer registries are required to use Version 2 of the NAACCR Hispanic Identification Algorithm (NHIA) SAS program or equivalent and record the NHIA variable in the NPCR-CSS data submission. NAACCR has combined the NHIA program with the NAACCR Asian Pacific Islander Identification Algorithm (NAPIIA), into a single NAACCR Hispanic and Asian Pacific Islander Identification Algorithm (NHAPIIA). A copy of the SAS program and the associated files required to run the program are available from the NAACCR website. A SAS license is required to run the SAS program.

- **GenEDITS Plus with the NPCR Edits Metafile**: GenEDITS Plus is a Windows-based stand- alone program packaged with the EDITS metafiles to run the NPCR single field and inter- field edits on a NAACCR record layout file. The program produces summary and detailed reports of edit errors. The README.TXT file contains installation and usage information.

- **NPCR-CSS Edits Metafiles**: The runtime EDITS metafiles for the NPCR single field and inter-field edits are provided for use by registries which have implemented the EDITS engine outside of the GenEDITS Plus program.

- **NPCR-CSS Call for Data Edits Dictionary**: The Edits Data Dictionary is a list created from EditWriter that includes all Call for Data Edits. This document includes the fields included in the edit, the error message(s), a description of the edit, and administrative notes. This PDF file contains information that may be useful to registries when preparing their NPCR-CSS submission. Please consult your NPCR consultant for a copy of the most current Data Edits Dictionary.

- **Inter-Record Edits Standalone Program**: The Inter-Record Edits Standalone Program validates the consistency of data between multiple records for a patient. The program produces summary and detailed reports of inter-record errors. After program installation, a help file is available describing its use. The Inter-Records Edits program should be run after the NPCR edits have been run and errors have been corrected. The program can also be configured and used during preparations for the NAACCR submission.
- Northcon Record Converter is a free-standing program for Microsoft® Windows® that converts files of cancer registry records from older NAACCR record layout versions to newer NAACCR record layout versions (i.e., NAACCR 15 to NAACCR 16). Converted output files will contain records in the newest record layout version.

Collaborative Relationships

To ensure program success, NPCR-funded central cancer registries are expected to collaborate across all CDC-funded cancer programs (CRCCP, NBCCEDP, and NCCCP) and other CDC-funded programs, as appropriate. For more guidance on Collaborative Relationships, see Strategy 3, Standards 3.1-3.2 in APPENDIX C.

Cancer program collaboration is essential to reducing the burden of disease in states and territories. NBCCEDP, NCCCP, and CRCCP collaborate with NPCR by sharing or requesting data, creating presentations and reports, and serving on chronic disease prevention and control committees including comprehensive cancer control coalitions.

Vital information about cancer cases is necessary for monitoring trends, planning for, and evaluating the impact of cancer control programs, allocating health resources, responding to reports of suspected increases in occurrence, and developing research hypotheses.

Expanding the application of cancer registries to prevention and screening can enhance the utility of the NPCR. NPCR-funded central cancer registries are expected to proactively collaborate in the state Comprehensive Cancer Control Program's planning and evaluation.

Collaboration to educate the public, partners, and collaborators about the cancer burden through data utilization, publication, and dissemination is a key task for NPCR

recipients.

Collaboration with Chronic Disease and Other Public Health Programs

The NPCR-funded central cancer registries are expected to actively collaborate with other appropriate chronic disease programs for increased efficiency and effectiveness. Typical partnerships include sharing data with programs such as WISEWOMAN, Coordinated Chronic Disease, Community Transformation Grants, Tobacco Prevention and Control, Diabetes, Tobacco Quit Lines, Lead Removal, Environmental Health, Nutrition, Physical Activity, and Obesity, Immunization, and government organizations like Centers for Medicaid & Medicare Services (CMS), State Medicaid and Medicare Programs, etc. Opportunities should be sought to plan internal and external strategic communications to foster collaboration with or inform and/or educate other health department staff, the public, cancer coalition members, partners, and decision makers about cancer burden, prevention, and control.

Central Cancer Registry Advisory Board

The NPCR-funded central cancer registries are required to establish and maintain an active Advisory Board. The Advisory Board serves as a resource for the central cancer registry in gaining community and legislative support for its programs. The Board also assists in developing long- term priorities and monitoring progress toward attainment of goals. Through collaboration with committee members, the central cancer registry gains access to a diversity of perspectives reflecting community needs, develops advocates, and widens opportunities for promoting data use. Key assistance that should be provided by the Advisory Board includes:

- Assist in setting goals and monitoring progress toward attainment of goals.
- Evaluate the efficiency and effectiveness of the central cancer registry.
- Advocate for necessary legislative changes.
- Serve as a data request review committee.
- Recommend policies on data use.
- Address problem-reporting issues and recommend solutions to identified problems.
- Provide spokespersons for the central cancer registry to make presentations at state medical association, cancer coalition, registrars association, and other professional meetings.

The Advisory Board should be composed of community members, medical professionals, and registry professionals. The structure of the Board may influence the membership; however, selection of appropriate members for the Advisory Board is key to its success. The Board should include representatives from different geographic areas and varied groups like cancer survivors, sex and ethnic minorities, advocacy organizations, and academic institutions. Advisory Board members may include:

- Personnel of the state's cancer prevention and control programs.
- Personnel of the state's chronic disease programs, such as the Tobacco Control Program.

- Cancer surveillance partners.
- Hospital cancer registrars.
- American Cancer Society.
- Clinical and laboratory personnel.
- Pathologists and clinicians.
- American College of Surgeons state Cancer Liaison Physician.
- Epidemiologists.
- Academic/Medical School Partners.
- Prevention Research Center leaders.
- Hospital Association.
- Cancer Centers.
- Legislators.
- Legal counsel (from central cancer registry agency).
- Other members as required by state legislation or regulations.
- Public relations and marketing experts.
- Community leaders.

The central cancer registry may face many new and changing rules and regulations; therefore, it is appropriate to evaluate the Advisory Board membership, procedures, and performance to modify or enhance the Board's effectiveness. Compliance with this program standard is monitored through performance measures, the annual progress report, and self-assessment on the NPCR Program Evaluation Instrument (PEI) survey.

State Registry Contacts

Each central cancer registry may use its website to present its own information, activities, and publications featuring data quality, data use, and other studies. NPCR provides links to each central cancer registry website.

NPCR Collaboration

NPCR works with national organizations, central cancer registries, and other key groups to develop, implement, and promote effective cancer surveillance practices and activities.

NPCR collaborative activities include:

- Providing funding and technical support for studies performed by collaborating agencies,
- Recruiting state programs for collaborative studies,
- Requiring the collection of data items or data linkages to support other agency goals,
- Providing technical advice on surveillance issues,
- Working with many agencies to effect a major change in surveillance models, coding systems, or rules,
- Sponsoring and participating in national organizations,
- Publishing data collaboratively with other organizations,

- Co-sponsoring conferences to define directions for cancer surveillance policies and activities,

Collaborations among the national cancer surveillance partnerships were previously organized by the National Coordinator Council for Cancer Surveillance (NCCCS). It was a group that met a few times per year to discuss cross-cutting issues. NCCCS dissolved in 2016. In response to the October 2016 release of AJCC Cancer Staging Manual Eighth Edition and the 2018 guidelines and resources released by NCI-SEER, NAACCR, and ACoS-CoC, NAACCR convened an Implementations Guidelines Task Force. This implementation task force and several specialized work groups formed by NAACCR, serve as the replacement for NCCCS.

NAACCR partners with all cancer registry surveillance groups, including CDC NPCR, to ensure harmonization. NPCR participates in several NAACCR surveillance work groups. CSB staff with ODS-C expertise actively participate on:

- Central Registry Operations Standards (CROS) Task Force
- Edits Work Group
- ICD-O-3 Work Group
- Implementation Guidelines Work Group
- Professional Development Subcommittee
- Recruitment & Retention Work Group
- Site Specific Data Items (SSDI) Work Group
- Solid Tumor Manual Ambiguous Terminology Work Group
- Uniform Data Standards (UDS) Work Group

Electronic Data Release Activities

Currently, NPCR has four products for electronic data release. These products are updated annually to include the most recent year of data. All data represented in these products must meet NPCR quality standards and their use must be authorized in writing by participating states.

Creation of Datasets

Prior to inclusion in a public data set, data files submitted by each participating registry are checked for data format, record layout, data consistency (reasonableness), and confidentiality in a pre-edit verification. If any records in a file contain discrepant or confidential data, the whole file is rejected, and the state or territory is notified.

Records in the retained data files are next checked for reportability criteria. Records are flagged for non-reportability if they show:

- State of diagnosis differing from submission state.
- Diagnosis year earlier than state reference year.
- Benign or borderline histology, except for CNS tumors diagnosed in 2004 and

later or borderline ovarian histology diagnosed from 1992 through 2000 (coded using ICD- O-2 criteria).
- Basal and squamous cell carcinomas of skin.
- Carcinoma in situ of cervix, AIN III, CIN III, VIN III, VAIN III.
- PIN III diagnosed 2001 and later.

Reportable records are processed through the EDITS program and edit set results are flagged for each record.

The analytic file is created using the cases flagged as reportable. For this file, in situ bladder cancers are recoded to malignant cancers. Pilocytic astrocytoma (coded as 9421/1 in ICD-O-3) are re-coded during abstraction and reported by central cancer registries as malignant (9421/3). Based on EDITS results, records are flagged within the file, and excluded from calculations for completeness of case ascertainment, for:
- Invalid, missing, or unknown age.
- Coding errors in single fields: primary site, race, and sex.
- Inter-field edit errors.
- Age/birth date/diagnosis date.
- Age/site/morphology.
- Birth date/diagnosis date.
- Sex/primary site.
- Cases submitted less than 24 months from date of diagnosis.

Databases for internal DCPC researchers

The following databases are available to internal researchers through SEER*Stat software:
- Internal Quality Control (QC) incidence analytic database (includes 12-month data)
- Internal U.S. Cancer Statistics incidence analytic database
- Internal U.S. Cancer Statistics incidence analytic database – linked with county attributes
- Survival database (NPCR-data only)
- Prevalence database (NPCR-data only)
- Delay-adjusted database (available only to CSB researchers)

Databases for NPCR Partners
- **American Cancer Society (ACS):** CDC provides data to trusted partners in accordance with the NPCR Data Release Policy through a Memorandum of Understanding (MOU). CDC provides ACS researchers with access to databases including the QC incidence analytic (selected variables), Survival, Prevalence, and Delay-adjusted database.
- **Central Brain Tumor Registry of the United States (CBTRUS):** CDC provides individual, record-level data to CBTRUS for their annual statistical report, Primary Brain Tumors in the United States Statistical Report

Supplement. CBTRUS annually publishes the print and web versions of this statistical report. The report includes age-adjusted rates and corresponding 95-percent confidence intervals on brain and other central nervous system tumors and is presented by State, histology, major histology grouping, primary site, behavior, sex, race, ethnicity, and age at diagnosis.

- **Environmental Public Health Tracking Network (EPHTN):** The National Environmental Public Health Tracking Network brings health data and environmental data together from national, state, and city sources and provides supporting information to make the data easier to understand. The Tracking Network has data and information on environments and hazards, health effects, and population health.

Databases for the Public

- **U.S. Cancer Statistics Public Use Database:** The U.S. Cancer Statistics Public Use Database was first made available to the public in August 2017. It is updated annually to include the latest submission data.
- **U.S. Cancer Statistics Restricted Access Database (RAD):** The restricted-access database is hosted at the National Center for Health Statistics Research Data Center (NCHS RDC). It includes variables that are not available in the public use database (for example, county at diagnosis and therapy variables such as merged radiation and RX Summ—Surgery Primary Site). The database is in a SAS-format. DCPC uses the NCHS RDC as a mechanism for researchers outside of the Division of Cancer Prevention and Control (DCPC) to request and gain access to NPCR data for research purposes. The restricted-access dataset is released to researchers through the NCHS RDC after CDC authenticates the requestor's identity and research intent through an extensive proposal review process and after the researcher completes the NCHS RDC confidentiality and security requirements. The requestor must also comply with the confidentiality procedures and data sharing agreements with the NCHS RDC.

United States Cancer Statistics (USCS)

U.S. Cancer Statistics are the official federal cancer statistics. These statistics include cancer registry data from CDC's NPCR and from the NCI's SEER Program and mortality data from CDC's National Center for Health Statistics. USCS provides information on newly diagnosed cancer cases and cancer deaths for all 50 states, the District of Columbia, and Puerto Rico. This national coverage enables the public, including researchers, clinicians, policy makers, and public health professionals to:

- Monitor populations most affected by cancer.
- Evaluate the success of programs designed to prevent cancer and diagnose cancer at early stages.
- Identify additional needs for cancer prevention and control efforts at national, state, and local levels.

Since 2002, CDC and NCI have combined their data sources to produce U.S. Cancer Statistics. Historically, the U.S. Cancer Statistics incidence and mortality data were published in the U.S. Cancer Statistics Report, initially as a hard-copy publication and

then as a web-based report starting in 2005. The web-based report was replaced with the Data Visualizations Tool in 2018.

A number of data products are generated using U.S. Cancer Statistics data, including the Data Visualizations Tool, the Public Use Database, and CDC WONDER. Other tools and background resources are available at the U.S. Cancer Statistics website.

The **U.S. Cancer Statistics Data Visualizations Tool** is an easy way to explore and use the latest Cancer Statistics data. This data product includes interactive graphics and data interpretations, which provide plain explanations of what the data mean. New cancer case rates, cancer deaths, survival and prevalence data are available in this tool. You can create trend graphs, maps, and tables by state, county, and demographic characteristics.

The **Public Use Database** allows researchers to access and analyze high-quality population- based cancer incidence data on the entire United States population.

CDC WONDER allows users to generate and export tables containing age-adjusted rates, crude rates, and case counts, requested by state, large metropolitan statistical areas, year of diagnosis, sex, race, and age for adult and childhood classifications of cancer.

State Cancer Profiles: The State Cancer Profiles website is managed by NCI SEER and is designed to be used by cancer control planning professionals. The focus is on cancer sites for which there are evidence-based control interventions. The cancer burden data are presented in a standardized manner to motivate action, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities. Interactive graphics and maps provide visual support, which may help users decide where to focus cancer control efforts.

Publications

Annual Report to the Nation on the Status of Cancer

Collaborations among the major national cancer organizations (CDC, NCI, ACS, NAACCR) led to the publication of the Annual Report to the Nation on the Status of Cancer, first published in 1998. The most recent Report, along with all archived volumes, can be found here.

National Healthcare Quality Report

Since 2003, the Agency for Healthcare Research and Quality (AHRQ) has published the National Healthcare Quality Report with the National Healthcare Disparities Report. In 2016, these two reports became the National Healthcare Quality and Disparities Report. This report is published on behalf of the U.S. Department of Health and Human Services (DHHS) in collaboration with an HHS-wide Interagency Workgroup.

This AHRQ consolidated resource examines and tracks the quality of health care in the United States, using the most scientifically credible measures and data sources available. It is a comprehensive national overview of disparities in access to and quality of healthcare among racial, ethnic, and socioeconomic groups; as well as among subpopulations including children and the elderly. The NPCR is a contributing source of data for these reports.

Cancer Incidence in Five Continents

Cancer Incidence in Five Continents presents comprehensive data, published every five years, on cancer incidence for over 200 populations worldwide. The five-year interval volumes contain three basic elements:

- Five-year tabulations from individual registries presenting case counts and incidence rates according to sex, age group, and cancer site.
- Summary tables permitting comparisons between registries.
- Tables presenting indices of the validity and completeness of the different contributions.

NPCR-funded central cancer registries that meet the following criteria may have their data represented in this report:

- IACR member
- Data meets United States Cancer Statistics (USCS) publication criteria
- Permission is granted for publication

CONCORD

CONCORD studies are a program of world-wide surveillance of cancer survival, led by the London School of Hygiene & Tropical Medicine; supported by the Union for International Cancer Control (UICC). CONCORD monitors progress towards the overarching goal of the UICC World Cancer Declaration 2013: “major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival.”

CONCORD studies examine world-wide cancer survival trends for certain cancer sites (i.e., stomach, colon, rectum, liver, lung, breast, cervix, ovary, prostate, esophagus, pancreas, and melanoma of the skin in adults; as well as leukemia’s, lymphomas, and brain tumors in both adults and children [age 0-14 years]).

NPCR submits data to CONCORD from central cancer registries meeting U. S. Cancer Statistics (USCS) publication criteria for survival analyses, and USCS data quality criteria. Additionally, data submitted to CONCORD comes from registries that have conducted active patient follow-up or linked records with the National Death Index (NDI).

Cancer Incidence in North America (CiNA)

NPCR-funded central cancer registries that submit data to NAACCR and meet the criteria for silver or gold certification are eligible to have their data included in the annual publication, Cancer Incidence in North America (CiNA). CiNA is comprised of a series of

products and tools known as CiNA Data Products, which were developed for easier access and to ultimately ease the cancer burden. The information can be used by national, state, provincial, and local health professionals for policy development, hypothesis generation, and as a resource
for the cancer registry or the public.

American Cancer Society (ACS)

Through a Memorandum of Understanding (MOU), the NPCR provides U.S. Cancer Statistics to the American Cancer Society (ACS) for the ACS publication, *Cancer Facts and Statistics*. Cancer Facts and Figures present data on cancer incidence, mortality, survival, cancer risk factors, and annual estimates of expected new cases and cancer deaths. Findings for the U.S. population, along with detailed state-by-state data on cancer cases and deaths are included.

Multi-Agency Projects

NPCR collaborates with other national and international organizations on several projects to develop standards/rules and adopt policies and procedures that will ensure consistent collection of high-quality data.

Indian Health Service (IHS)

Indian Health Service (IHS) is an agency within the U.S. Department of Health and Human Services (HHS) and is responsible for providing health services to American Indians and Alaska Natives (AI/AN). The IHS Division of Epidemiology and Disease Prevention aims to reduce the burden of cancer through improved surveillance, screening, provider training, and public health research. Nationally, AI/AN communities have lower rates of cancer. However, in certain regions such as Alaska and the Northern Plains states, AI/AN cancer incidence and mortality rates exceed those of the U.S. general population. As a response to these disparities, the CDC supports numerous cancer surveillance, prevention, and control projects in Indian Country through an interagency agreement between IHS and the CDC's Division of Cancer Prevention and Control (DCPC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

National Cancer Institute (NCI)

In 2000, CDC and the National Cancer Institute (NCI) entered a Memorandum of Understanding (MOU) to coordinate cancer surveillance activities around a shared vision for a comprehensive, federally integrated, national cancer surveillance system. This system builds upon and strengthens the existing infrastructure, improves the availability of high-quality data for measuring the nation's cancer burden, and advances the capacity for surveillance research. The scope of this coordinated cancer surveillance system includes coverage of the entire U.S. population with high-quality data to measure cancer risk, health behaviors, incidence, treatment, morbidity, mortality, and other health outcomes.

NCI and CDC have a joint responsibility for the dissemination of national cancer surveillance statistics through multiple mechanisms. NCI's emphasis is on a surveillance research program that characterizes the nation's cancer burden over time by integrating traditional cancer statistics, the widest possible collection of cancer-related data, and in-depth methodological studies in population subgroups. CDC's emphasis is on its responsibilities for public health surveillance, characterizing the cancer burden nationwide and in states, and meeting the needs of state health departments and the nation in developing, implementing, and evaluating effective cancer prevention and control efforts. The MOU was the genesis for the annual United States Cancer Statistics (USCS) report, a joint publication of CDC and NCI, in collaboration with NAACCR. The first report was published in 2002 and featured 1999 incidence data from NPCR and SEER cancer registries that met standards for high quality data.

Starting in 2005, rather than produce hard-copy reports, a web-based report was published. This web-based report was replaced with U.S. Cancer Statistics Data Visualizations – an interactive online tool, in June 2018.

North American Association of Central Cancer Registries (NAACCR)

North American Association of Central Cancer Registries (NAACCR) is a professional organization that develops and promotes uniform data standards for cancer registration. It provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care.

NPCR currently funds NAACCR under CDC's National Partnerships to Promote Cancer Surveillance Standards and Support Data Quality and Operations of National Program of Cancer Registries cooperative agreement (DP23-0008) to provide resources for standard-setting activities related to the operation of population-based cancer registries. The stated purposes of the cooperative agreement are to:

- Ensure uniform cancer data surveillance standards and interoperability to support NPCR operations, including efficiency of cancer data collection and exchange.
- Enhance capacity and flexibility to meet new data needs.

NPCR contributes to the definition of data standards maintained and published by NAACCR, and in turn uses protocols and methodologies published by NAACCR for the evaluation of data submitted to the NPCR-CSS. NPCR staff members, including Certified Oncology Data Specialists (ODS-C), actively participate on NAACCR committees and workgroups to develop consensus standards for the cancer registry community.

National Cancer Registrars Association (NCRA)

The National Cancer Registrars Association (NCRA) is a non-profit organization representing cancer registry professionals. NCRA's primary focus is education and

Oncology Data Specialist (ODS) certification. NCRA works to ensure all cancer registry professionals have the required knowledge to be successful in the cancer registry field.

CDC funds education and training efforts under Promoting Cancer Workforce, Education, and Data Use cooperative agreement DP21-2104. Under this cooperative agreement, CDC supports the NCRA annual conference, which advances professional development of cancer registrars by providing an education and training opportunity for registrars in hospitals, outpatient and free-standing facilities, and central cancer registries.

International Association of Cancer Registries (IACR)

The International Association of Cancer Registries (IACR) is a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It is primarily for population-based registries that collect information on the occurrence and outcome of cancer in defined population groups. To ensure that cases are properly recorded, and that the statistical data gathered are complete and can be used to make valid comparisons, cancer registries must conform to accepted working practices and standards. IACR fosters the exchange of information between cancer registries internationally, improving data quality and comparability between registries. The IACR conference advances professional development by providing an educational opportunity for cancer registrars from international cancer registries to increase their knowledge and expand their professional expertise. The IACR is headquartered in Lyon, France.

The Union for International Cancer Control (UICC)

The Union for International Cancer Control (UICC) is a non-governmental organization that unites and supports the cancer community to reduce the global cancer burden and to promote greater equity. With 48 partners, UICC has united 170 countries. The UICC is headquartered in Geneva, Switzerland.

NPCR Resources

Technical Assistance

NPCR program consultants are available to consult directly with central cancer registry management staff to resolve issues which may be affecting the registry's ability to attain or adhere to program standards. NPCR monitors performance of funded registries through performance measures, routine reports, and in-person, virtual, or reverse site visits.

NPCR also hosts conferences addressing public health surveillance issues, participates in research, publishes materials focused on registry operations and procedures, and develops software programs to support registry activities.

Software Programs for Cancer Registry Data

NPCR supports the development of software to aid central cancer registries in the collection and processing of cancer data. The software is distributed free to the public health community.

Registry Plus Software

Registry Plus is a suite of publicly available, free-of-charge, MS Windows-based software programs used for collecting, processing, maintaining, and using cancer registry data. Registry Plus currently includes 12 applications (see Table below), plus various utility programs. All programs are compliant with national standards and can be used separately or together for routine and special data collection. Additionally, the applications are fully customizable for user/registry-specific needs. For more information regarding Registry Plus software, please see the Registry Plus Fact Sheet in APPENDIX H.

Abstract Plus	• Cancer data collection tool to abstract and code cancer cases following basic cancer reporting standards suitable for reporting to central cancer registries from non-registry hospitals, clinics, and other sources for cancer incident reports. • Customized by central registries for distribution to and use by hospitals and other reporting sources to abstract reports of cancer, as well as for abstraction at the central registry. • Abstracts are validated by customizable edits, allowing for interactive error correction while abstracting. • Used for special projects and start-up registries.
Web Plus	• Used to abstract, code, and collect cancer data securely over the Internet. • Web Plus supports three main functions: online abstracting, secure file upload and download, and follow-back efforts. • Customized by central registries for abstracting and reporting cancer by physician's offices, low-volume facilities. • The follow-back features enable central registries to upload partially filled abstracts and to notify users to login and update the abstracts. • Supports upload and editing of files of abstracts in NAACCR format, or upload of files in any file format. • Eliminates need to distribute and maintain software at reporting facilities.

eMaRC Plus	• Builds pathology laboratory and physician databases and stores various HL7 data elements as discrete field values in tables in the database. • Creates NAACCR-formatted abstract records from pathology and physician reports during import. • Uses a search terms table to identify potential reports of cancer and uses the negation terms finder (NegEx) to enhance its text mining capabilities. • Shows pathology text report and a generated abstract side by side, allowing user to complete any missing information in the abstract. • Maps and auto populates the abstract with data received in pathology and physician reports. • Uses text mining functionality to identify histology, primary site, behavior, laterality, and grade. • Allows users to override any automated decisions about reportability and coding for pathology reports. • Flags multiple pathology reports as either duplicate or linked reports for the same patient and tumor from the same facility. • Merges multiple physician reports for the same patient and tumor from the same facility.
eMaRC Plus Lite	• Developed to assist laboratories and central cancer registries (CCR) with identifying reportable cancer pathology reports. • Utilizes the eMaRC Plus rule-based natural language processing (NLP) functionality to provide a simplified user interface with a base CDC-NPCR model, that can either be used as is or constrained further to meet specific CCR, hospital, and laboratory reporting requirements. • eMaRC Plus Lite has capabilities to: o Process batch HL7 files, a functionality useful for when multiple HL7 files must be processed. o Update NLP models, a functionality that enables the user to create a customized model by making changes to a copy of the CDC-NPCR base model that comes with the tool.
Exchange Plus	• Assists users who are not XML experts in producing valid NAACCR XML dictionaries. • Converts data exchange files from the flat-buffer format to NAACCR XML format, from NAACCR XML format to flat-buffer format and from NAACCR XML format to delimited. • Allows users to Import NAACCR files, view the data in a grid, update individual records in grid cells or apply batch updates for file manipulation, export updated files with or without application of filter criteria, anonymize confidential data, combine multiple NAACCR files into one data source and to split files by number of records or field value. • Runs schema validation to verify the xml file is a valid NAACCR xml document and that the file does not contain any data items that are not defined in the base or user-defined dictionary. • Maps data items with different code and format structure to NAACCR standard codes to assist registries with data linkages and preparing data to write to the database in the NAACCR standard format.

Prep Plus	• Used to receive and apply data quality and completeness edits to batches of abstracts using NAACCR standard or registry customized edit sets. • Edit error reports are generated and can be shared with reporting sources to assist registries in identifying common errors and areas to target for education and training. • Stamps each record with the Date Case Report Received which can be used to track timeliness. • Customized by central registries for processing, visually reviewing, and editing reported abstracts.
CRS* Plus (including TLC* Plus)	• CRS Plus supports the linkage of incoming abstracts against the existing database, with software-assisted consolidation into patient, cancer, and facility tables. • Enhanced patient linkage is incorporated to assign higher prioritization to customized data items when limited demographic information is available. • Provides for automatic determination of multiple primary tumors and consolidation of data items from multiple case reports into incidence records. • Abstracts proceed through a defined data flow. At any point the program is unable to reach a definitive linkage or consolidation decision, the abstract is assigned a pending status code in CRS Plus for review. A suspense/transfer feature is incorporated for improved management of the pending queue. • A tracking system is updated with processing milestones for each abstract. • Produces extracts for NPCR and NAACCR call-for-data submissions. • Provides standard management reports.
NorthCon	• Freestanding utility program that converts files of cancer registry records from one NAACCR version to the next. • Input files conform to a NAACCR standard version and the output is the next NAACCR XML standard version meeting the conversion specifications provided in the NAACCR Implementation Guide for the specified version. • Data input files processed through NorthCon are expected to meet NAACCR standard data requirements and should be run through appropriate edit sets with errors corrected prior to conversion. • Previous versions of NorthCon meeting NAACCR standard conversion requirements are available on the NorthCon webpage.
Link Plus	• User Probabilistic methods to link records • Configured by central cancer registries for: o Detecting duplicates within the registry to reduce over-counting of cancers o Linking cancer registry files to external files for follow-back and research purposes
EditWriter	• Complete tool for creating and maintaining data edit checks. • Provides a means of maintaining standard definitions, defining data items and record layouts, specifying editing algorithms, logic, and documentation, and generating metafiles.
GenEDITS Plus	• Used to apply data quality edits to data files using metafiles and to generate error reports for error resolution.

Cancer Report Validator	• Validates structure and content of HL7 CDA documents from physician EMRs/EHRs. • Produces results in multiple report formats, including pdf, Excel, and XML. • For more information, visit CDA Guideline Validation (nist.gov)

***CRS: Central Registry System**

TLC: Tumor Linkage and Consolidation Registry Plus Training Manuals

User manuals are available for Abstract Plus, Web Plus, CRS Plus, eMaRC Plus, and Cancer Report Validator. Manuals for Prep Plus, RPOH, and Link Plus are under development. The user manuals are available on the NPCR SharePoint site and will be incorporated into each software application if they have not already been included.

Data Security

All Registry Plus modules not accessible outside the institution's firewall have completed the Level III review for software and networking products after addressing the issues of support, infrastructure impact, lifecycle maintenance and security requirements. These products must be demonstrated as compatible with CDC's IT strict infrastructure and IT Security standards. All Level III products must undergo and pass the Office of the Chief Information Security Officer (OCISO) Level III Security Risk Assessment process.

Obtaining Registry Plus Programs

More information about the various Registry Plus programs and installation files for Abstract Plus, Link Plus, Registry Plus Online Help, EDITS Tools, and Utility Programs can be downloaded from the Registry Plus section of the NPCR website.

Registries interested in obtaining other Registry Plus programs or have questions about any Registry Plus programs may contact NPCR at: cancerinformatics@cdc.gov

EDITS

EDITS software programs provide tools to improve data quality by standardizing the way data items are checked for validity. These tools can be built into interactive data collection systems to achieve real-time field-by-field editing during data entry. They can also be used in batch-editing processes for data already collected. EDITS provide software to support three types of data activities: defining standards for data quality, creating data collection processes, and analyzing data. The EDITS programs include EditWriter, the EDITS Application Program Interface, and GenEDITS Plus.

EditWriter is a versatile and complete development environment for defining, testing, documenting, and distributing data standards and maintaining standard data definitions. EditWriter produces metafiles (a compiled database which contains all the logic, tables, and values needed to check data fields for validity) that can be used on many operating systems and hardware platforms. Single-item, cross-field, and inter-record checks can be included in metafiles. Standard metafiles are distributed to the registry community through postings on the NAACCR website.

A new metafile containing all the edits approved by the standard setters is released

to accompany each new NAACCR layout, and to keep edits up to date with changing standards. State central cancer registries may also develop and distribute state-specific metafiles to support their individual state's data coding and collection requirements.

The EDITS Application Program Interface (API), a library of C language functions, can be incorporated into programs of many descriptions, including programs for interactive data entry, after-the-fact verification of data, recoding, reformatting, and vertical or horizontal sub setting. GenEDITS Plus, the generic EDITS driver program, is a batch application for editing any data file with an associated Metafile. Records gathered under different circumstances using different programs can be interpreted in a uniform way when validated with the same metafile.

Additional Information about EDITS programs and software downloads are available on the NPCR webpages. Originally written as MS-DOS programs, new windows-based versions of the programs have been released, which include all-new interfaces and are easier to use (more user friendly).

Registry Plus Online Help (RPOH) includes a description of all edit sets and edits included in the standard NAACCR edits metafile. Edit descriptions provide the standard rules for both individual and inter-field data edits and assist users in understanding edit errors and how to resolve them. In addition, edits Information for individual fields is cross-linked with information for the same field in the different coding manuals included in RPOH.

Confidentiality and Data Security

Each NPCR-funded registry must ensure the confidentiality and security of central cancer registry data through software and hardware security standards. This includes implemented and documented security policies and procedures; data release policies and procedures that include both access and disclosure of information; documented disaster data recovery plans; annual risk assessments and security audits for registry data; and ongoing security training for staff. Please refer to the NPCR Data Security webpage for more details.

NPCR-funded registries are subject to guidelines from policies and procedures for data security established by leading organizations in the central cancer registry and health care fields. These standards are outlined in the sections below.

NAACCR's Volume III: Standards for Completeness, Quality, Analysis, and Management of Data, provides central registry structural requirements, process standards, and outcome measures for access to source data and completeness of reporting, data quality, data analysis and reporting, and data management. NAACCR holds its member registries responsible for guarding data from unauthorized access and release. Each central cancer registry's Director has the ultimate responsibility for data security at the registry.

The U.S. Department of Health and Human Services (HHS) issued guidance on technologies and methods to protect personal electronic health care data to expand the use of electronic health records. The materials describe encryption and destruction as the means to protect personal health data by making the data "unusable, unreadable or indecipherable" to unauthorized individuals. The guidelines were developed through a joint effort by the HHS Office for Civil Rights, Office of the National Coordinator for Health Information Technology, and the Centers for Medicare and Medicaid Services.

Economic Analysis

NPCR conducted a multi-year economic analysis of program activities to compare operating costs for central cancer registries that have achieved standards for high-quality data with costs for registries that have not. The study examined:

- The cost of performing core surveillance activities.
- The cost of enhancing the infrastructure and operation of NPCR-funded registries.
- The cost of performing advanced surveillance activities.

Researchers determined factors and variables influencing costs and developed a resource- allocation model based on cost-effectiveness. The first report from this study, "The National Program of Cancer Registries: Explaining State Variations in Average Cost per Case Reported", is published in Preventing Chronic Disease, online serial, Vol. 2, No. 3, July 2005.

The second report from this study, "Economic Assessment of Central Cancer Registry Operations, Part I: Methods and Conceptual Framework" was published in the Journal of Registry Management, Fall 2007; Volume 34, Number 3.

NPCR-funded central cancer registries provided expenditure data along with details of staff, software, registry tasks, numbers of cases, etc. for analysis in the study. Reports have been provided to NPCR-funded central cancer registries comparing the individual registry cost with the regional and national analysis for their use.

CDC conducted projects with RTI and EARB to assess the cost of operations, electronic data exchange and best practices. Additionally, CDC collaborated with NACDD to better understand registry strengths, challenges, and best practices. CDC is currently collaborating with RTI and Implenomics to evaluate data modernization initiative (DMI) activities within registries. The project entails working with select registries to complete a costing tool, conducting case studies of APHL AIMS adoption/implementation in registries, and evaluation of CS-CBCP.

Central Registry Workload Management Study

In 2011, NPCR and NCRA funded a Workload and Time Management Study to assess the practices of the central cancer registries. The purpose of this study was to describe the work environment/work duties, assess work challenges, and understand staffing needs.

This study provided central cancer registries with benchmark data they can use for comparison with their own cancer registry data. These comparisons can help central cancer registries make decisions about staff size and configuration as well as advocate, plan, and budget for their registries.

The Value behind Cancer Registries and the Cancer Registrar Shortage

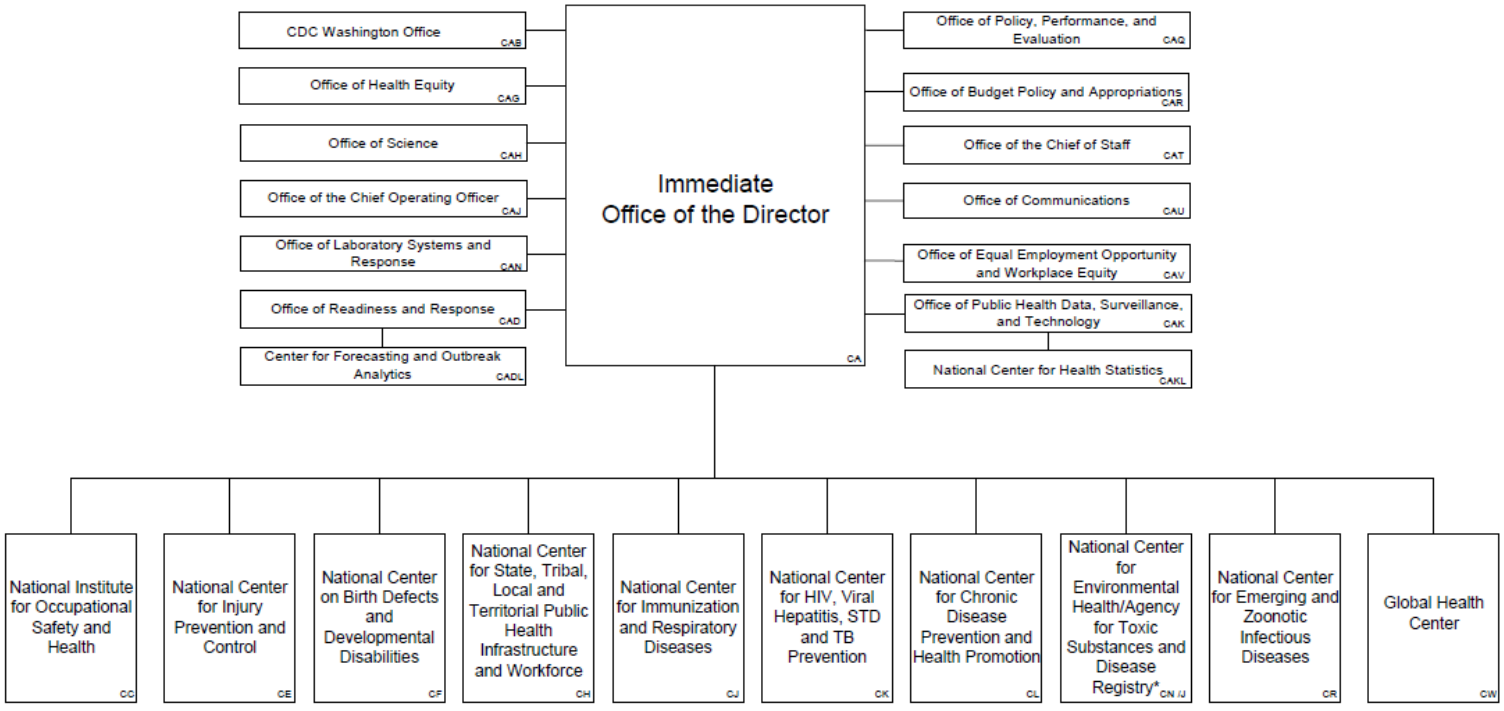
NPCR created an informational video on the impact of cancer and the importance of cancer registries. It is narrated by the CDC's Division of Cancer Prevention and Control Director and titled: "Cancer Registries: Measuring Progress. Targeting Action." To recruit new cancer registrars in a profession with mounting shortages, we invite you to share this video with Health Information Management (HIM) Education Programs and similar audiences.

APPENDIX A: Organizational Charts

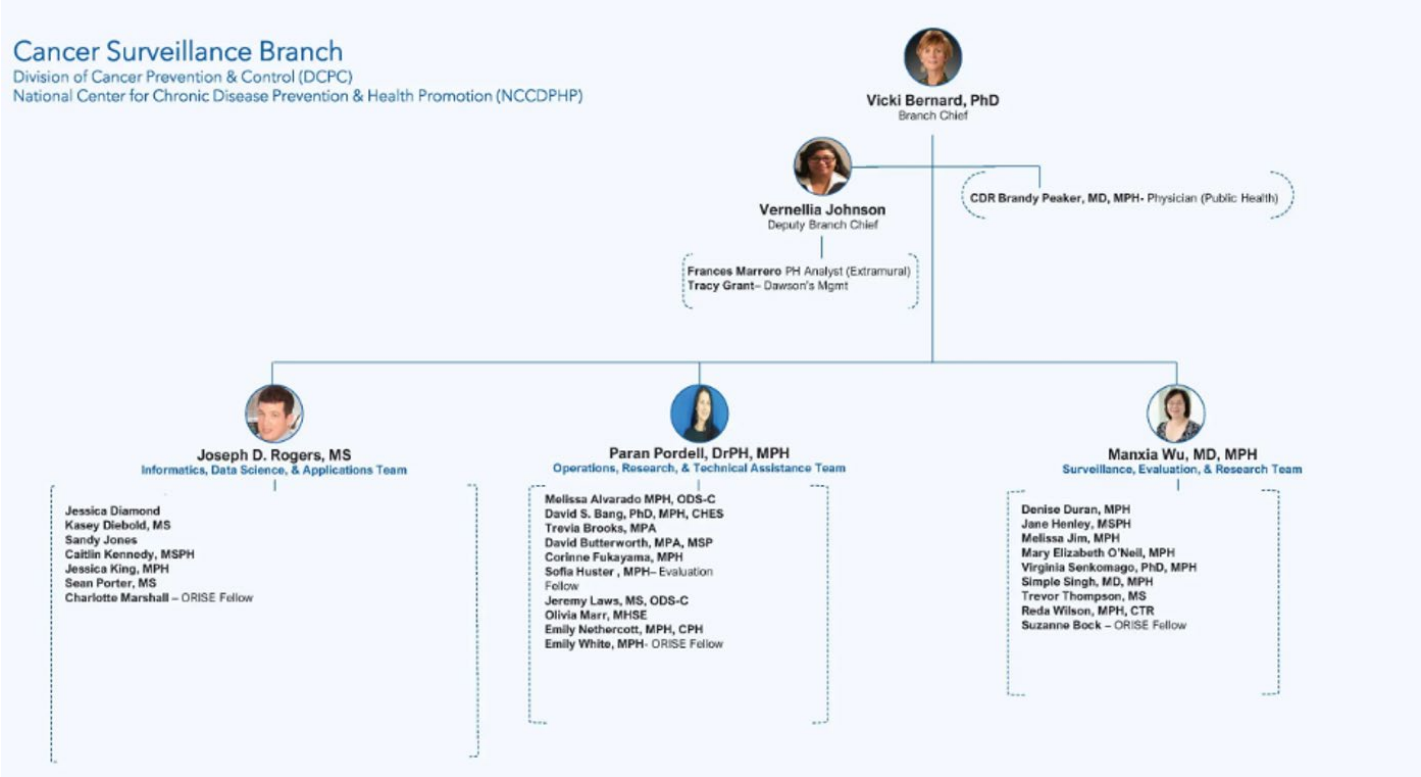
U.S. Department of Health and Human Services (DHHS)

Centers for Disease Control and Prevention (CDC)

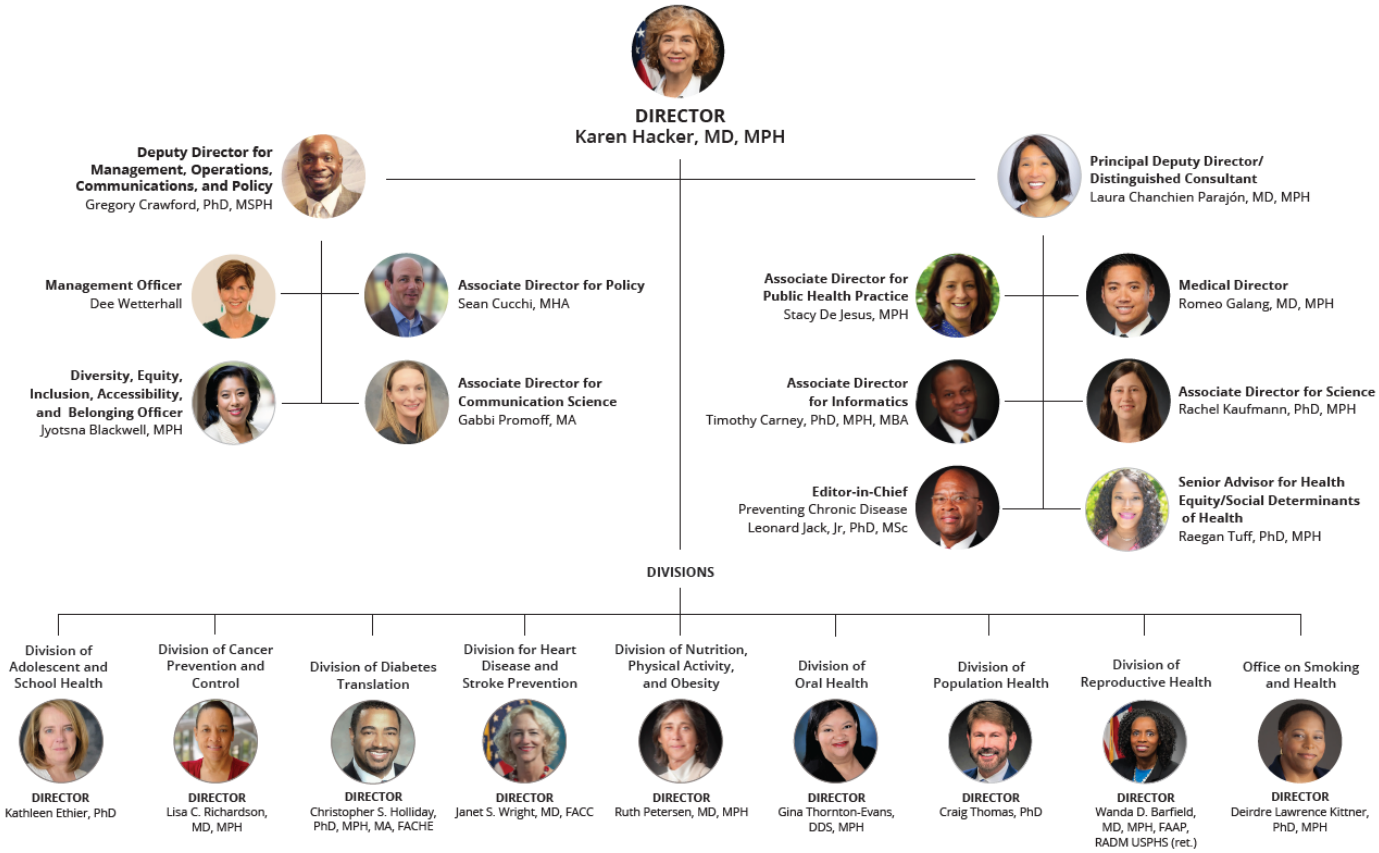
Organization Chart, Effective 9/13/2024



Division of Cancer Prevention and Control (DCPC)
Cancer Surveillance Branch (CSB)
Organization Chart, Effective 11/2024



National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
Organization Chart
Effective 9/2024



APPENDIX B: Reference Materials

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APPENDIX C: NPCR Program Standards

National Program of Cancer Registries (NPCR) Program Standards 2022–2027

Introduction

The goal of CDC's National Program of Cancer Registries (NPCR) is to collect, report, and disseminate high-quality data on all reportable incident cancer cases in a timely manner for the purpose of cancer prevention and control. The NPCR Program Standards are a set of interrelated expectations and requirements that provide a framework for effective cancer surveillance program implementation, evaluation, and continuous improvement. They build on one another to equip central cancer registries (CCRs) to assess the cancer burden through the collection, use, and dissemination of complete, timely, and high-quality cancer data. They are based on the 10 Essential Public Health Services that seek to protect and promote the health of all people in all communities and are aligned with the Healthy People 2030 cancer objectives.

The NPCR Program Standards also ensure that CCRs fulfill the overarching performance measures listed below, establish priorities, and perform activities that funded programs are expected to achieve, provide objective measures of program progress, and improve program processes that drive outcomes.

The 2022–2027 NPCR Program Standards build on progress achieved during the previous notice of funding opportunity (NOFO DP17-1701) to support and strengthen population-based CCRs and promote ongoing registry data use to inform evidence-based decision making.

At a minimum, an NPCR-funded CCR must be able to:

- Report cancer incidence trends by geographic area and provide cancer data to support cancer control programs.
- Collect and report incidence, burden, and stage data and use these data to create surveillance reports that can direct targeted interventions, guide research, and evaluate the success of cancer prevention and screening programs.
- Identify disparities by age, sex, race, ethnicity, and geographic areas in cancer incidence, stage at diagnosis, and mortality.
- Create and maintain registry and state or territorial policies that support use of cancer registry data for research.
- Strengthen its capacity to receive electronic reporting from facilities, labs, physician practices, and other data sources.

We organized CDC's 2022–2027 NPCR Program Standards by strategy, standards, corresponding activities, and performance measures. These standards are based on the legal authority provided to CDC under the Public Health Service Act (Title 42, Chapter 6A, Sub-Chapter II, Part M, § 280e) and subsequent amendments, and apply to all reportable cancers as defined in the Act and amendments. The relevant outcomes, as depicted in the NPCR logic model, and performance measures, which quantify progress toward performing activities and achieving outputs, are also included. Program standards may be revised during the 5-year cooperative agreement performance period.

Short-, Intermediate-, and Long-Term Outcomes

The following outcomes are the intended results of activities in the NOFO that recipients are expected to achieve by the end of the 5-year performance period.

Short-Term Outcomes

- Increased use of NPCR data by recipients, partners, collaborators, and researchers.
- Achievement of data quality standards by the CCR.
- Successful adoption of data modernization strategies.
- Improved timeliness, quality, completeness, and confidentiality of NPCR surveillance data.
- Increased collaboration among chronic disease and other public health programs.

- Increased access to cancer screening and preventive services among populations of focus.
- Increased knowledge about cancer prevention, screening, and survivorship among populations of focus.
- Increased reporting of high-quality program data to CDC.
- Increased use of evaluation findings for program improvement.
- Increased participation in special studies.

Intermediate-Term Outcomes

- Increased capacity, flexibility, and utility of CCR infrastructure to meet new data needs.
- Increased data use for cancer prevention and control.
- Improved health behaviors.
- More cancer primary prevention resources and screening available for populations of focus.
- Increased early detection of cancer among populations of focus.

Long-Term Outcomes

- Reduced cancer risk factors such as tobacco use, overexposure to ultraviolet rays, human papillomavirus (HPV) infections, and overweight and obesity.
- Better quality of life among cancer survivors.
- Decreased cancer incidence, morbidity, and mortality.
- Reduced cancer disparities.
- Increased health equity.

NPCR will monitor and assess the CCR's progress, results, and overall impact through:

- The annual National Program of Cancer Registries Cancer Surveillance System (NPCR-CSS) data submissions that monitor data timeliness, quality, and completeness.
- Regular assessments including recipient quarterly check-in responses, the Program Evaluation Instrument (PEI), and the Data Quality Evaluation (DQE).
- Annual Progress Reports (APRs).
- Regular communications with program consultants, such as conference calls and requests for technical assistance.

NPCR Logic Model Outputs

The NPCR logic model outputs correspond to multiple program standards. Since NPCR strategies and outcomes are interconnected, the NPCR Program Standards serve as building blocks that guide cancer registry program implementation and ongoing program improvement.

- Infrastructure in place for data collection.
- Reduced staff attrition: critical registry positions filled.
- Ongoing trainings and educational sessions for registry staff and facility registrars conducted.
- Cancer data processed and collected.
- Quality control procedures implemented.
- Completeness and data quality compliance reports completed.
- Data confidentiality and security maintained.
- Disaster plan that includes risk assessments, data breach plan, and security audits created and updated.
- CCR Operations Manual reviewed and updated.
- Required and additional data linkage performed.

- Effective and sustainable multi-sectoral collaborations developed and strengthened.
- Data modernization projects implemented.
- De-identified cancer data submitted.
- Cancer and related data shared with diverse partners and collaborators.

Strategy 1: Enhance NPCR data quality, completeness, use, and dissemination

Standard 1.1: Legislative Authority

Ensure that legislation supports cancer surveillance and has flexibility to meet innovations in the field.

Activities

1.1.1: Maintain existing law or regulations that provide legal authority for a CCR, as defined in Public Health Services Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e, authorizing NPCR.

1.1.2: Update existing law or regulations as needed to support criteria specified in Public Health Services Act Title 42, Chapter 6A, Sub-Chapter II, Part M, 280e specifically addressing and complying with electronic reporting, data exchange, data modernization and innovation, and data sharing and use requirements.

Performance Measure

PM 1: CCR reviews state or territorial cancer registry legislation **at least once per year**, works with state or territorial public health and policy entities to recommend revisions as needed, and provides an update in the Annual Progress Report (APR) narrative.

Standard 1.2: Administration and Operations

Maintain effective and efficient processes and high-quality staff to operate the registry.

Activities

1.2.1: Hire or retain staff sufficient in number and expertise to manage, implement, and evaluate the CCR, as well as use and disseminate the data. Core required staff must fill the following roles: program director, project director, or principal investigator (PD/PI) or operations or registry manager (OM), quality assurance or quality control (QA/QC) manager, information technology (IT) staff, and education and training coordinator (ETC). The QA/QC manager and ETC positions must be filled by qualified, experienced oncology data specialist (ODS).

- PD/PI or OM 1 full-time equivalent (FTE) 100%
- ETC 1 FTE 100%
- QA/QC manager 1 FTE 100%
- IT staff 0.25 FTE 25%

1.2.2: Ensure policy and procedure manuals are up-to-date and staff are cross-trained in key functional areas to maintain continuity of operations. At a minimum, the CCR Operations Manual contains:

1. The reporting laws and regulations.
2. A list of reportable diagnoses.
3. A list of required data items.
4. Procedures for data processing operations, including:
    - Monitoring timeliness of reporting.
    - Receipt of data.
    - Database management, including a description of the registry operating system software (this may be accomplished by citing a software vendor's website and documentation).
    - Conducting death certificate clearance.
    - Implementing and maintaining the quality assurance or quality control program, including procedures for:
        - Conducting follow-back to reporting facilities on quality issues, including rules for identifying when action or further investigation is needed.

- Conducting record consolidation.
- Maintaining detailed documentation of all quality assurance operations.
- Education and training.

- Conducting data exchange, including a list of states and territories with which case-sharing agreements are in place.
- Conducting data linkages.
- Ensuring confidentiality and data security, including disaster planning.
- Data release, including access to and disclosure of information.
- Maintaining and updating the operations manual.

5. Management reports that include processes and activities to monitor the registry operations and database.
6. An abstracting and coding manual that is used by reporting sources that abstract and report cancer cases.

1.2.3: Ensure that adequate hardware and software systems are in place to support the CCR activities, including data collection, database management, interstate data exchange, data linkages, quality assurance, data analysis, and management reporting. Provide the memorandum of understanding with the IT department if IT staff are not embedded in program.

1.2.4: Develop or use promising practices and tools to strengthen communication with data reporters to improve data quality, completeness, and timeliness.

1.2.5: Implement promising processes to improve real-time reporting and data quality.

1.2.6: Ensure the confidentiality and security of CCR data through software and hardware security standards. This includes:

1. Implementing and documenting security policies and procedures.
2. Documenting data release policies and procedures that include both access to and disclosure of information.
3. Developing a disaster plan that includes annual risk assessments, security audits for registry data, and a mechanism to track ongoing security training for staff and telework options. Details are included on the NPCR data security pages at www.cdc.gov/national-program-cancer-registries/php/data-security/.
4. Developing, submitting, and implementing a data management plan (DMP) that conforms with CDC requirements and guidelines.

Performance Measures

PM 2: CCR secures necessary registry management and operations staff per NPCR Manual and NOFO requirements (core required positions: PD/PI or OM, 1 FTE 100%; ETC, 1 FTE 100%; QA/QC manager, 1 FTE 100%; and IT staff, 0.25 FTE 25%).

- **Target**: At least 75% of required CCR staff positions are filled on an annual basis.

PM 3: CCR reviews Operations Manual **twice per year**, updates sections as needed, and provides an update in the APR narrative.

PM 4: CCR reviews data management plan (DMP) **once per year** and updates as needed.

PM 5: CCR maintains a list of reporting facilities that is verified and updated **once per year.**

Standard 1.3: Data Collection, Content, and Format
Ensure that the registry collects all reportable data in accordance with NPCR requirements.

Activities

1.3.1: Central cancer registries must collect and submit data for all reportable cancers and benign neoplasms including, at a minimum, primary site, histology, behavior, date of diagnosis, race, ethnicity, age at diagnosis, sex, stage at diagnosis, and first course of treatment, according to CDC specifications and other information required by CDC.

1.3.2: For all CDC-required reportable cases, the CCR collects or derives all required data items using standard codes prescribed by CDC.

1.3.3: Regardless of residency, the CCR collects data on patients who were diagnosed or received the first course of treatment in the registry's state or territory.

1.3.4: The CCR uses a standardized, CDC-recommended data exchange format to transmit data to other central cancer registries and CDC.

Performance Measures

PM 6: CCR conducts bi-weekly or monthly check-ins with reporting facilities to ensure timely reporting of cancer cases.

PM 7: CCR creates a remediation plan to address reporting challenges due to staff turnover, software issues, or other reasons for reporting delays within 60 days and shares its expectations with the reporting facility.

Standard 1.4: Electronic Data Exchange
Use and promote electronic reporting among facilities and data sources.

Activities

1.4.1: Develop and implement a plan to enhance timely reporting via the expansion of electronic reporting by one or more means such as data modernization activities, electronic health record (EHR) reporting, and ePath reporting, and through data exchanges including interstate data exchange.

- The CCR is required to adopt and use standardized, CDC-recommended data transmission formats for the electronic exchange of cancer data (see CDC NPCR Electronic Reporting and Data Exchange Guidance). Registries should promote the use of these formats by reporting sources that transmit data to the registry electronically. CDC-recommended data exchange formats include:

    1. Hospital reporting: The North American Association of Central Cancer Registries (NAACCR) record layout version specified in year-appropriate *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary.*

    2. Anatomic pathology laboratory reports: NAACCR's *Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting* version 5.0 (or newer standards such as HL7 FHIR).

    3. Non-hospital sources using electronic medical records: Office of the National Coordinator for Health Information Technology (ONC) Certification Criteria 2015 Edition: Health Level Seven (HL7) Clinical Document Architecture (CDA®) Release 2 Implementation Guide: Reporting to Public Heath Cancer Registries from Ambulatory Healthcare Providers, Release 1, Draft Standard for Trial Use (DSTU) Release 1.1- US Realm, or newer standards such as HL7 Fast Healthcare Interoperability Resources (FHIR).

- For hospitals reporting to the CCR, increase the percentage reporting electronically every year to meet the standard of all hospitals reporting electronically by the end of the 5-year performance period.

- For non-hospital facilities reporting to the CCR, increase the percentage reporting electronically every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the 5-year performance period.

- The CCR uses a secure Internet-based, file transfer protocol (FTP), https, or encrypted e-mail mechanism to receive electronic data from reporting sources.

Performance Measures

PM 8: Percentage of labs reporting data electronically using HL7 2.5.1 or other standard HL7 format (measure for e-path reporting).

- **Target:** Increase the percentage of labs reporting data electronically in the designated HL7 format by 3% each year.

PM 9: Percentage of hospitals reporting electronically to the CCR each year.

- **Target:** Increase the percentage every year to meet the standard of 100% of hospitals reporting electronically by the end of the 5-year performance period.

PM 10: Percentage of non-hospital facilities reporting electronically to the CCR each year.

- **Target:** Increase the percentage every year to meet the standard of at least 80% of these facilities reporting electronically by the end of the 5-year performance period.

Standard 1.5: Data Completeness, Timeliness, and Quality
Cancer data meet NPCR completeness, timeliness, and quality standards.

Activities

1.5.1: Implement procedures to ensure timeliness, quality, and completeness of data in accordance with CDC data quality standards.

1.5.2: Inform CDC in a timely manner if barriers to data collection processes or procedures may negatively affect compliance with CDC data quality standards or delay data submission. Work with CDC to resolve and prevent future occurrence.

1.5.3: Establish interstate data exchange agreements with other central cancer registries to obtain data on residents who have been diagnosed or treated outside of catchment area and perform data exchanges with them at least twice per year. Quarterly data exchange with geographically bordering central cancer registries is strongly encouraged.

1.5.4: CCR's annual data submission adheres to the National and Advanced National Data Quality Standards.

1.5.5: Perform linkages with external data sets to improve data completeness and quality.

1.5.6: Develop and promote good relationships with reporting facilities.

1.5.7: Develop and implement a plan to monitor status of case reporting and completeness.

1.5.8: Develop and implement procedures to handle ePath volume effectively.

1.5.9: Participate in testing of Registry Plus software, which includes:

1. Installing test versions of Registry Plus software on a desktop computer or test server.
2. Testing the application using protocols provided by the Registry Plus support team.
3. Reporting any issues related to bugs or standards.
4. Installing revised test versions and retesting until all issues have been resolved.

Performance Measures

PM 11: CCR creates and routinely uses management reports that monitor data reporting, completeness, and quality, attaches templates with the APR submission, and provides a brief explanation of these tools in the narrative.

PM 12: Interstate data exchange occurs **at least annually** between CCR and designated states or territories and **quarterly** (if feasible) between CCR and neighboring states.

PM 13: CCR's annual data submission adheres to the following data quality criteria for 12- and 24-month data, as measured via the data evaluation report (DER):

1. There are 3% or fewer death-certificate-only cases.

2. There is a 1 per 1,000 or fewer unresolved duplicate rate.

3. The maximum percentage missing for critical data elements are:
    - 2% age.
    - 2% sex.
    - 3% race.
    - 2% county.
4. 99% pass a CDC-prescribed set of standard edits for 12-month data, and 97% pass a CDC-prescribed set of standard edits for 24-month data.

PM 14: CCR increases case reporting by at least 2% each year for urologists, dermatologists, and gastroenterologists, as required by law, to demonstrate continuing progress and improvement by the end of the 5-year performance period.

PM 15: CCR increases case reporting by at least 2% each year for medical oncologists, radiation oncologists, and hematologists, as required by law, to demonstrate continuing progress and improvement by the end of the 5-year performance period.

Standard 1.6: Linkages
Perform linkages to improve data quality, completeness, and accessibility.

Activities

1.6.1: Create and employ data linkages as described in the NPCR Program Standards and additional linkages which are necessary for successful registry operations. Linkages include, but are not limited to:

1. State or territory vital statistics (at a minimum, death records) annually.
2. Indian Health Service administrative records (as appropriate).
3. Social Security Administration Death Master File annually.
4. National Death Index annually.
5. Veterans Administration (if feasible).

- The CCR links with state or territory death files at least once every year and incorporates results on vital status and cause of death into the registry database.
- The CCR links with the National Death Index at least once every year and incorporates results on vital status and cause of death into the registry database.
- The CCR links with the state or territory breast and cervical cancer early detection program at least once every year to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.
- The CCR links with the Indian Health Service (IHS) Administrative Database at least once every five years. However, central cancer registries within IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS at least once every year.

1.6.2: Perform linkages that assist in addressing other public health issues as they relate to cancer, including tobacco use, human papillomavirus (HPV) and hepatitis B vaccination, physical activity, and overweight and obesity. Linkages may include behavioral risk factor data such as from the Behavioral Risk Factor Surveillance System (BRFSS), socioeconomic status data, and social determinants of health data, including available data on intersectionality.

- The CCR uses linkages to address gaps identified in data quality and completeness or to improve the utility of the data. Potential sources of information include:
    1. Statewide electronic health files for casefinding and completeness of required data items.
    2. Claims data for casefinding and completeness of required data items.

3. Census data (or similar) for socio-demographic variables.
4. Birth records for demographic information.
5. Department of Motor Vehicle records for demographic information.
6. Voter registration files for demographic information.

- The CCR should strive to conduct at least one additional linkage per year, inclusive of developing needs such as COVID-19.

Performance Measures

PM 16: CCR performs linkage with state or territory death files at least **once every year** and incorporates results on vital status and cause of death into the registry database.

PM 17: CCR links with the National Death Index at least **once every year** and incorporates results on vital status and cause of death into the registry database.

PM 18: CCR links with the state or territory breast and cervical cancer early detection program at least **once every year** to identify potentially missed cases, reconcile differences between the two systems, and update appropriate data fields to capture post-linkage information.

PM 19: CCR links with the Indian Health Service (IHS) Administrative Database at least **once every five years**. However, CCRs within IHS Contract Health Service Delivery Area counties link their records with patient registration records from IHS at least **once every year**.

Standard 1.7: Data Quality Assurance and Education

Establish policies, procedures, and processes for data quality assurance that link with education and training to maintain high-quality data.

Activities

1.7.1: Develop, implement, and maintain an education and training plan for internal staff and reporting facilities with the goal of improving CCR data quality.

1.7.2: Conduct internal registry quality control and quality improvement activities by CCR staff.

1.7.3: Participate in NPCR-defined national data quality assurance activities including Data Quality Evaluation (DQE) projects, ad hoc data evaluation, audits, and other special data quality control and improvement activities. Complete and submit the Program Evaluation Instrument (PEI) by the due date.

1.7.4: Use available training and educational resources and program's ETC to educate staff and reporters.

1.7.5: Incorporate findings and results of NPCR Data Evaluation Reports (DER), PEI, and audits into educational and training plans.

1.7.6: Conduct routine data quality evaluations showing continuous data quality improvement, for example, lower the percentage of records with unknown values.

Performance Measures

PM 11: CCR creates and routinely uses management reports that monitor data reporting, completeness, and quality, attaches templates with the APR submission, and provides a brief explanation of these tools in the narrative.

PM 20: At least once every 5 years, CCR conducts casefinding and re-abstracting audits from a sample of source documents for each hospital-based reporting facility. This is in addition to the CDC-funded and sponsored Data Quality Evaluation (DQE).

PM 21: CCR provides at least four online trainings or continuing education opportunities and one in-person workshop (if possible) or training to CCR staff and reporting partners each year.

PM 22: CCR meets a percentage completeness each year based on observed-to-expected cases (see **PM 13**).

- **Target:** CCR-submitted 12-month data meets 90% completeness.
- **Target:** CCR-submitted 24-month data meets 95% completeness.

Standard 1.8: Data Use and Data Monitoring

Use cancer and related program data and disseminate to partners, collaborators, and researchers to expand use of registry data, promote a common understanding of the state or territorial cancer burden, and inform evidence-based decision making.

Activities

1.8.1: Within 12 months of the end of the diagnosis year with data that are 90% complete, the CCR produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year by Surveillance, Epidemiology, and End Results (SEER) site groups to monitor the top cancer sites within the state or territory.

1.8.2: Within 24 months of the end of the diagnosis year with data that are 95% complete, the CCR, in collaboration with local cancer control programs, produces the following electronic reports:

- Reports on age-adjusted incidence and age-adjusted mortality rates for the diagnosis year using SEER site groups and, where applicable, stratifying by age, sex, race, ethnicity, and geographic area.
- Biennial reports providing data on stage and incidence by geographic area, with an emphasis on screening-amenable cancers and cancers associated with modifiable risk factors such as tobacco use, overweight and obesity, and human papillomavirus (HPV) infection.

1.8.3: The CCR ensures annual use of cancer registry data for public health and surveillance research purposes in **at least five** of the following ways:

1. Comprehensive cancer control.
2. Detailed incidence and mortality by stage and geographic area.
3. Collaboration with cancer screening programs for breast, colorectal, or cervical cancer.
4. Health event investigations.
5. Needs assessment and program planning, such as Community Cancer Profiles.
6. Program evaluation.
7. Epidemiologic studies.
8. Survivorship programs.

Performance Measures

PM 23: CCR submits a success story to CDC **annually** detailing how registry data have been used to affect public health.

PM 24: Number of cancer surveillance publications, burden reports, presentations, and data briefs created and disseminated to NPCR and other entities **annually.**

- **Target:** CCR creates and disseminates at least one comprehensive cancer surveillance report that includes age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups stratified by age, sex, race, ethnicity, and/or geographic area.
- **Target:** CCR presents analysis findings to at least two state or territorial groups and one national group each year (NPCR counts as a national group).
- **Target:** CCR collaborates on at least one summary surveillance report outside of the cancer registry, such as environmental health, immunization, nutrition and physical activity, substance abuse (alcohol, marijuana, opioid use), HIV/AIDS, or sexually transmitted infections.
- **Target:** Creates five one-page cancer surveillance data briefs each year.

Standard 1.9: Data Submission
Submit cancer data to CDC each year in accordance with CDC's standards and requirements.

Activities

1.9.1: Submit electronic data files to the NPCR-CSS according to the timeframe and content established by CDC that meet the reporting requirements outlined in the NPCR-CSS Submission Specifications document. Submitted data should meet the criteria for publication in the United States Cancer Statistics (USCS), the National Data Quality Standard, and the Advanced National Data Quality Standard.

- In appropriate data submission years, when the CCR data file meets specified data completeness and quality standards, the CCR data are included in the *Cancer in Five Continents* publication.

1.9.2: Participate in all CDC-created and hosted analytic datasets and web-based data query systems as outlined in the annual NPCR-CSS Data Release Policy.

Performance Measures

PM 22: CCR meets a percent completeness each year based on observed-to-expected cases (see **PM 13**).

- **Target:** CCR-submitted 12-month data meets 90% completeness.
- **Target:** CCR-submitted 24-month data meets 95% completeness.

PM 25: Baseline and annual participation in all CDC-created analytic data sets outlined in the NPCR-CSS data release policy.

Standard 1.10: Innovation Projects
As applicable and available, participate in NPCR-funded innovation projects.

Activities

1.10.1: Plan, implement, and evaluate innovation projects. Engage cancer coalition leadership and task groups to identify potential project topics.

1.10.2: Share promising practices with partners, cancer coalition, collaborators, and cancer program recipients.

1.10.3: Participate in CDC sponsored special studies and pilot projects.

Performance Measure

PM 26: Present innovation project findings at one state, territorial, or national conference or meeting **annually** and submit at least one manuscript for publication within the 5-year performance period.

Strategy 2: Use surveillance systems and population-based surveys to assess cancer burden, examine health disparities, target program efforts, and inform efforts to address social determinants of health (SDOH)

Standard 2.1: Share cancer surveillance data with NCCCP, CRCCP, NBCCEDP, and other organizations and agencies to enable implementation of evidence-based interventions.

Standard 2.2: Promote and disseminate data to facilitate program planning and evaluation.

Activities

2.1: Promote use of surveillance data to assess risk factors and health behaviors among populations highly affected by chronic diseases.

2.2 Produce or participate in the creation of biennial reports of incidence measures appropriate for the cancer and population (rates, counts, proportions) at geographic levels appropriate for the local population (county, city, or statistical health area) for screening-amenable cancers (breast, cervical, colorectal, and lung) diagnosed at a late stage, and cancers associated with overweight and obesity, tobacco, and HPV infection.

2.3: Submit the final biennial cancer surveillance report to CDC and disseminate to the state or territory cancer coalition and other partners as appropriate.

Performance Measures

PM 27: CCR creates a target number of cancer surveillance publications, burden reports, presentations, and data briefs and disseminates them to NPCR and other entities **annually.**

- **Target:** CCR creates and disseminates at least one comprehensive cancer surveillance report that includes age-adjusted incidence rates, stage at diagnosis, and age-adjusted mortality rates for the diagnosis year using SEER site groups stratified by age, sex, race, ethnicity, and/or geographic area.
- **Target:** CCR presents analysis findings to at least two state or territorial groups and one national group each year (NPCR counts as a national group).
- **Target:** CCR collaborates on at least one summary surveillance report outside of cancer registry, such as environmental health, immunization, nutrition and physical activity, substance abuse (alcohol, marijuana, opioid use), HIV/AIDS, or sexually transmitted infections.
- **Target:** CCR creates five one-page cancer surveillance data briefs each year.

Strategy 3: Support program collaboration and external partnerships for cancer control and prevention

Standard 3.1: Support collaboration across NPCR, CDC's NBCCEDP, CDC's NCCCP and other chronic disease programs.

Standard 3.2: Convene, support, and sustain partnerships and networks necessary to support implementation of cancer program priorities and activities.

Activities

3.1: The CCR serves on the state, tribal, or territorial cancer coalition to develop and implement data-informed, equity-driven cancer control plans.

3.2: The CCR establishes a working relationship with other cancer control programs, including screening programs and tobacco control programs, to assess and implement cancer control activities.

3.3: The CCR establishes and regularly convenes an advisory committee to help build consensus, cooperation, and planning for the registry and to enhance chronic disease program coordination and collaboration. Representation should include key organizations and individuals within (such as representatives from all cancer prevention and control components and chronic disease programs) and outside the program (such as hospital cancer registrars, the American Cancer Society, the American College of Surgeons, clinical and laboratory personnel, pathologists, and clinicians). Advisory committees may be structured to meet the needs of the state or territory, such as the comprehensive cancer control program committee structure, an advocacy group, or a focus group.

3.4: Use the advisory committee to develop and refine quality improvement initiatives.

3.5: Establish and promote greater awareness and use of the cancer registry data.

3.6: Collaborate on program planning and identification of populations of focus, based on the jurisdictional cancer control plan.

3.7: Share cancer surveillance data with NCCCP, CRCCP, NBCCEDP, and other organizations and agencies identified by the advisory committee to enable implementation of evidence-based interventions for health systems change.

Performance Measures

PM 28: Registry advisory committee meets at least twice per year to discuss CCR data reporting, quality, analysis, use, staffing, special projects, and partnerships.

PM 29: Registry advisory committee or cancer coalition develops at least one data quality improvement initiative each year.

Strategy 5: Conduct program monitoring and evaluation to strengthen program processes and improve equitable outcomes

Please note: NPCR does not require recipients to implement strategy 4.

Standard 5.1: Participate in CDC-led program monitoring, evaluation and dissemination activities including periodic data quality audits, PEI surveys, quarterly program updates, and annual success story submissions.

Standard 5.2: Develop an evaluation plan according to CDC guidance. This plan should be implemented and reported on annually throughout the 5-year performance period.

Activities

5.1: Conduct process and outcome evaluation to assess all program activities and use findings to continuously improve registry operations, data quality, and completeness.

5.2: Provide an update on annual evaluation progress to CDC in the Annual Progress Report (APR). The update should summarize program monitoring and evaluation findings and describe how findings were used for registry program improvement.

5.3: Submit the NPCR Program Evaluation Instrument (PEI) as directed.

5.4: Participate in the NPCR Data Quality Evaluation (DQE) as requested.

Performance Measures

PM 30: The CRR adopts the number of quality assurance measures required to meet Advanced National and National Data Quality Standards annually.

- **Target:** CCR implements **at least three** quality assurance measures to meet Advanced National and National Data Quality Standards.

APPENDIX D:
Meaningful Use and Electronic Physician Reporting

Electronic Data Exchange Language in the Funding Opportunity Announcement (NOFO) Develop and implement a plan to enhance timely reporting via the expansion of electronic reporting by one or more means (e.g., Meaningful Use and ePath [electronic pathology] reporting), and through data exchanges (including interstate data exchange).

Pros and Cons of Physician Reporting from Electronic Health Record Systems (EHRs) and Meaningful Use (MU)

Benefits:

- Provides the potential to identify cancer cases and treatment that may have been missed through hospital and pathology reporting.
- Increases the completeness, timeliness, and accuracy of cancer surveillance data.
- Provides a more secure means of reporting private information.
- Enables ambulatory providers to meet public health jurisdictional and Meaningful Use reporting requirements through use of a single standardized specification.
- Facilitates the implementation of an automated electronic process for the identification and reporting of cancer cases, treatment, and outcomes using ambulatory healthcare provider EHR systems to create a cancer event report and submit it to public health central cancer registries.
- In the long term, reduces the resources required by ambulatory healthcare providers and public health central cancer registries to meet the objectives of cancer surveillance.

Barriers:

- Difficult and time consuming to implement.
- Many different EHR systems.
- Additional cancer case data needs to be processed.
- Limited skillset available within the registry.

How CDC addresses these barriers:

- NPCR IDSAT provides two software applications: Cancer Report Validator (CRV) to validate the MU reports and eMaRC Plus to process the reports and generate NAACCR abstracts.
- NPCR IDSAT works closely with central cancer registries to provide technical assistance for reviewing and validating MU documents.
- NPCR IDSAT works closely with central cancer registries and EHR vendors to address issues identified and make recommendations to vendors to fix them.
- CDC-NPCR meets with vendors and CCRs as needed to discuss needs and issues related to Meaningful Use and software issues. Contact cancerinformatics@cdc.gov to schedule a meeting or if you have issues with

Meaningful Use or Physician Reporting in eMaRC Plus.

How CCRs can implement with limited resources

Everything in Meaningful Use and Physician Reporting does not need to be implemented immediately. The NPCR Program Standards for 2022 through 2027 identify the goals for physician reporting that annually increase the reporting to the central cancer registry as required by state law to meet the standard of having all physicians reporting by the end of the five-year project period. In addition, to monitor compliance with these standards, funded NPCR registries should use consistent methods to count and report improvements in physician reporting.

Specific suggestions for limited implementation:

- Focus on onboarding high priority providers, such as dermatology, urology, gastroenterology, hematology, medical and radiation oncology, independent surgery, and other providers you know are not reporting through other means.
- Onboard one provider at a time, or whatever workload you can handle.
- Match physician reports with central registry database to identify which reports will provide new information (e.g., missed cases, missed treatment).
- Only export reports from eMaRC Plus that are likely to be: 1) cases that will not be otherwise reported at all, and 2) abstracts that can be consolidated with others in your central database to augment information, such as treatment. eMaRC Plus has export features to help with this, such as filtering which abstracts to export based on histology, primary site, provider, etc.
- Do not focus all your time and effort on forming complete and high-quality abstracts from these physician reports.

Software Tools to Support Physician Reporting

- NPCR's Web Plus software should be used for physician reporting when possible. Web Plus can create custom data collection displays specific to the physician specialty.
- If physicians or practices have EHRs and can report in the format specified for Meaningful Use in either the Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries August 2012, or the HL7 CDA® Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, DSTU Release 1.1—US Realm, they can transmit these reports using the secure transport mechanism selected by the CCR, such as Web Plus, Public Health Information Network Messaging System (PHIN MS), Direct, NwHIN Connect, or secure FTP (sFTP).
- Use NPCR's eMaRC Plus software for receiving and processing physician reports transmitted from physician EHRs in one of the HL7 Clinical Document Architecture (CDA) formats.
- Use NPCR's Cancer Report Validator (CRV) software for testing and validation of physician reports transmitted from physician EHRs in one of the CDA formats.
- Use NPCR's Abstract Plus software for physician reporting if the physician office does not have Internet access.
- Access the Registry Plus Knowledgebase for eMaRC Plus for the latest information regarding software updates and manuals.

See NPCR's Web site for information on all Registry Plus™ software products including Web Plus, Abstract Plus, eMaRC Plus, and physician training in Cyber Cancer Registry: www.cdc.gov/national-program-cancer-registries/registry-plus/.

For all assistance with Registry Plus software products, please contact the Help Desk at CancerInformatics@cdc.gov.

APPENDIX E: NPCR Evaluation Plan Guide

National Program of Cancer Registries (NPCR) Evaluation Plan Guide

Intended Audience: DP22-2202 NPCR Applicants

CDC Division of Cancer Prevention and Control
Cancer Surveillance Branch

1. Introduction

Purpose of the Guide

The information and resources in this document will guide you in developing your central cancer registry (CCR) evaluation plan. CDC-DP22-2202 requires applicants to submit an evaluation plan with their NPCR funding application. Any necessary revisions to the evaluation plan are due within six months of the award. This guidance is intended to help applicants develop an evaluation plan. The integrated cancer program logic model included in the notice of funding opportunity (NOFO) is provided later in this document. The NPCR logic model is provided in a separate document.

Central cancer registry data are used to:

- Monitor cancer trends over time.
- Show cancer incidence and mortality disparities in various populations and identify high-risk groups.
- Guide planning and evaluation of cancer control programs.
- Help set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.

Evaluation and performance measurement are essential to cancer registry program success and consistent attainment of NPCR data quality standards. Evaluation helps demonstrate the achievement of intended program outcomes and drives continuous quality assurance and improvement. CDC's evaluation strategy is grounded in the CDC Program Evaluation Framework (available at www.cdc.gov/evaluation/php/evaluation-framework/). CDC requires ongoing evaluation and performance measurement under this NOFO and expects recipients to maintain sufficient staff and analytic capacity to meet these requirements.

Ongoing Evaluation Creates Stronger Programs

Evaluation, or the systematic collection of information about how a program operates and its impact, is an important part of program management. A good evaluation enables you to monitor program implementation, demonstrate the success of programmatic activities in achieving outcomes, and identify areas for improvement.[1]

Evaluation involves thoughtful planning to decide what questions you want to answer[2] and how you will gather data to answer those questions.[3] An evaluation plan guides your efforts based on registry, partner, and collaborator priorities, time and resource constraints, and skills required to accomplish evaluation goals successfully.[4] Partners should be involved in writing evaluation plans to encourage transparency and create a shared understanding about the evaluation's purpose and how the results will be used.[5,6] Written evaluation plans have additional benefits, including fostering buy-in about evaluation methods, drawing connections between evaluation activities, strengthening evaluation capacity, and easing transitions during staff turnover.[4]

Whether conducted internally or externally, evaluations are significantly enhanced by a written plan that outlines essential details, including important programmatic context. While evaluation planning is a process, evaluation itself does not have to be expensive, time-consuming, or overly complicated. Well-focused evaluations can be completed with limited resources and by internal staff who are not professional evaluators.[1] Evaluation training and resources are widely available; see www.cdc.gov/evaluation/php/about/.

2a. Evaluation Plan Components

Include basic elements in the evaluation plan. While the format of written evaluation plans can vary, the following elements are recommended.[4] Suggested page limits for each section are provided (excluding appendices). Where applicable, listing items (partners) with bullet points is appropriate.

- **Title page** showing applicant and program name, program component to be evaluated, and dates or program years covered (1 page).
- **Plan overview** presenting a high-level summary of evaluation questions and a general approach to the evaluation (1/2 page).
- **Intended use and users of evaluation results**, specifying purposes of the evaluation such as program improvement or accountability and who has access to results for decision-making or other intended uses (1/2 page).
- **Program description**, including a logic model of the program components (CCR operations) to be evaluated and a brief narrative describing the activities and how beneficiaries are affected by programmatic activities (2 pages).
- **Evaluation focus** detailing evaluation questions and a brief description of how evaluation questions were determined and prioritized; for example, the questions were based on a logic model, registry priorities, partner interests, evaluation purpose, or feasibility (1/2 page).
- **Data collection plan**, including a summary of qualitative or quantitative methods that align with evaluation questions, and specifying relevant indicators, performance measures, data sources, and who has data collection responsibilities (1 page).
- **Analysis and interpretation plan** describing collaborator and partner involvement, the process for drawing conclusions, and who has data analysis responsibilities (1 page).
- **Plan for dissemination and use of findings** detailing communication strategies, audiences (such as a cancer coalition, health care professionals, or registrars), format (such as standardized feedback reports), who has dissemination responsibilities (such as regular monthly data reviews), and how audience feedback and action steps will be documented and monitored (2 pages).
- **Evaluation timeline** summarizing dates for data collection, analysis, and dissemination of findings (1 page).

2b. Tips for Successful Evaluation Planning

The following tips are offered as general guidance:

- **Connect the dots.** Evaluation plans connect program planning and evaluation by highlighting program goals, clarifying measurable objectives, and linking program activities with intended outcomes. Therefore, evaluation plans, work plans, and logic models work together. Work plans should reflect the inputs and activities included in the logic model. Evaluation questions and data collection plans should be linked to outputs and outcomes in your logic model. Ideally, evaluation planning and program planning occur at the same time. This helps ensure that evaluation efforts are well integrated from the start. Align the work plan and the evaluation plan so that evaluation information can be used for program monitoring and improvement.[4]

- **Consider strength of evidence.** CDC recognizes that recipients have limited evaluation resources and cannot always implement highly rigorous evaluation designs, such as matched designs. However, evaluation should provide the strongest evidence possible within programmatic constraints. Go beyond process evaluation to examine outcomes.

- **Treat your evaluation plan as a living document.** Like logic models, evaluation plans are meant to represent current thinking. As priorities and internal and external factors change, evaluation plans can be revised as appropriate.

- **Plan to assess process and outcomes.** The CCR evaluation plan should include evaluation questions that address how the activity or intervention is being implemented and at least one outcome depicted in the logic model (what changed because of implementing the activity).

- **Engage your program consultant.** Throughout the development process, talk with your program consultant (PC). PCs are a great resource for maximizing limited resources, ensuring you are going in the right direction, and sharing practice wisdom from other cancer programs and colleagues.

2c. Analysis

- What methods will you use to analyze your data, such as descriptive statistics, inferential statistics as part of overall quantitative analysis, or qualitative data analysis using content or thematic analysis?

- Provide example table shells, templates, or a qualitative codebook that specifies the output for each type of analysis you plan to conduct.

2d. Interpretation

- Who will you involve in drawing, interpreting, and justifying conclusions? Does this group include program participants or others affected by the program?

- What are your plans to involve them in this process, including evaluation capacity strengthening activities?

2e. Data Sources

Some of the following data sources can be used to conduct primary or secondary data analysis:

- Internal audits and quality checks of data collected and processed by central cancer registry staff.

- CDC-sponsored data quality audits or evaluations.

- Program Evaluation Instrument (PEI) submissions.
- NPCR data evaluation reports.
- Program documents such as advisory committee meeting minutes, cancer coalition documents, registry meeting minutes, memoranda of understanding, financial records, management reports, comprehensive cancer control plans, and other registry-specific data monitoring documents.
- Data collected by a cancer coalition, advisory committee, registry, partner, or collaborator.

2f. Potential Evaluation Methods

- Notes from discussions with program staff or other key personnel.
- Observation of partnership meetings or job performance during site visits.
- Quantitative surveys conducted online, by phone, or in person.
- Document analysis and review.

3. CDC's Evaluation Framework and Evaluation Standards of Practice

Figure 1 and Table 1 below depict CDC's Framework for Program Evaluation and Evaluation Standards of Practice, which guide all CDC evaluations. Engaging collaborators and partners typically represents the first step in evaluation planning, and the standards of practice are a step-by-step process. The framework is a cyclical process that takes time, resources, and dedicated staff, and may change as programmatic priorities, resources, and needs change. This information is intended to help applicants think through their evaluation plan components, purpose, priorities, and outcomes.

Beyond the 5-year budget period, a targeted NPCR evaluation plan supports strategies and activities that promote registry program sustainability. The NPCR evaluation and recipient work plans can work together to improve cancer registry data. Results can be used in many ways, including success stories or areas for improvement reported to CDC, partners, and collaborators.

Figure 1: CDC Program Evaluation Framework[3]

www.cdc.gov/evaluation/php/evaluation-framework/

Table 1 CDC's Evaluation Standards of Practice[3]

1. Engage stakeholders.
2. Clearly state evaluation questions, purpose, and objectives.
3. Use appropriate evaluation design, methods, and analytical techniques.
4. Address ethical considerations and assurances.
5. Identify resources and articulate a budget.
6. Develop data collection and management plans.
7. Ensure evaluators are qualified and independent.

8. Monitor evaluation planning and implementation.
9. Produce quality evaluation reports.
10. Disseminate the results.
11. Use the findings for program improvement.

Approach to CCR Evaluation Planning - DP22-2202

This list will help applicants organize evaluation steps and corresponding activities as well as inputs. It is recommended that applicants complete and submit this list with the CCR evaluation plan, since it helps applicants plan their evaluation activities using CDC's evaluation standards of practice. This list represents a broad example of information that could accompany the CCR evaluation plan. An applicant's list should align with the registry and NPCR logic models and may include more detail specific to the registry's activities and operations.

Develop CCR Evaluation Plan

- Engage collaborators and partners (year 1).
- Describe the program, including the NPCR recipient logic model (can use NPCR logic model) and the program narrative (year 1).
- Focus the evaluation design and identify key evaluation questions and the evaluation methodology (year 1).

Implement CCR Evaluation Plan

- Gather credible evidence using a variety of data sources (all years).
- Assess CCR data quality, timeliness, and completeness using data sources from prior years (year 1).
- Collect data to evaluate processes and other outcomes by checking data regularly (monthly, quarterly, biannually, or yearly) and conducting facility audits to assess data quality (year 1).
- Assess data timeliness, completeness, and quality (all years).
- Analyze evaluation data, summarize findings, and justify conclusions (all years).

Use Evaluation Findings and Share Lessons Learned

- Communicate evaluation results to collaborators and partners, including other cancer and chronic disease programs, advocacy groups, policymakers, and CDC (all years).
- Identify areas of program improvement based on evaluation findings (all years).

Revise CCR Evaluation Plan

Review the evaluation plan each year and revise as needed (years 2 through 5).

4. NPCR

Applicants must provide an Evaluation and Performance Measurement Plan that demonstrates how the recipient will fulfill the requirements described in the CDC Evaluation and Performance Measurement and Project Description sections of the NOFO (pages 31–34 of NOFO). NPCR outcomes are listed on page

10–11 and strategies and activities are listed on pages 20–24 of the NOFO. Please note that the updated NPCR Program Standards document included in the DP22-2202 NOFO appendices is a helpful resource that connects NPCR strategies to standards, activities, and performance measures. Applicants can use the performance measures to help inform CCR evaluation priorities, questions, potential data sources, and areas for improvement. At a minimum, the plan should include:

- How the applicant will collect the performance measures, respond to prioritized evaluation questions, and use evaluation results for continuous program improvement.
- Use of available data sources, including any new data sources, feasibility of collecting appropriate evaluation and performance data, and other relevant information.

In addition, the applicant is encouraged to provide an evaluation plan that describes clear monitoring and evaluation procedures which address:

a. Evaluation of timeliness, quality, and completeness of registry data.

b. Current status of and improvements to electronic case capture.

c. Collaborations with other cancer and chronic disease programs.

d. Planning and implementation of data modernization strategies.

e. Planning and implementation of innovative projects.

The NPCR logic model, provided in a separate document, should serve as the foundation for all CCR evaluation plans. The integrated cancer program logic model is shown below. Both logic models illustrate how required strategies relate to short-, intermediate-, and long-term outcomes.

CCR Evaluation Reporting Requirements

NPCR requires each recipient to submit:

12. A mid-term evaluation plan and progress report at the year 3 midpoint.

13. A final, comprehensive evaluation report in year 5.

14. An evaluation progress summary as part of each annual submission.

15. Performance measure reports by the due date.

Recipients are also expected to provide **quarterly updates on evaluation progress in the form of summary bullets** as part of ongoing communication with their program consultant.

DP22-2202 Integrated Cancer Program Logic Model

Strategy 1: Enhance NPCR data quality, completeness, use, and dissemination

Short-Term Outcome

- Improved timeliness, quality, completeness, and confidentiality of NPCR surveillance data.

Intermediate-Term Outcomes

- Increased capacity, flexibility, and utility of NPCR infrastructure.
- Improved health behaviors among groups that have been disproportionately affected by cancer.
- Increased early detection of cancer among populations at increased risk of late-stage cancer diagnosis.
- Increased number of eligible women served through CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP).
- Increased breast and cervical cancer screening rates in NBCCEDP partner clinics.
- Increased social and community support for cancer survivors, individuals who have a family history of cancer, and their caregivers.

Long-Term Outcomes

- Reduced cancer risk.
- Better quality of life among cancer survivors.
- Decreased cancer incidence, morbidity, and mortality.
- Reduced cancer disparities.
- Increased health equity.

Strategy 2: Use surveillance systems and population-based surveys to assess the cancer burden, examine health disparities, target program efforts, and inform efforts to address social determinants of health (SDOH)

Short-Term Outcome

- Increased rigorous use of surveillance and population data by recipients and other partners.

Strategy 3: Support partnerships for cancer control and prevention

Short-Term Outcomes

- Increased collaboration among chronic disease programs to identify, examine, and reduce cancer-related health disparities.
- Improved access to cancer screening and preventive services by population of focus.
- Improved implementation of jurisdiction-specific comprehensive cancer control plans.

Strategy 5: Conduct program monitoring and evaluation to strengthen program processes and improve equitable outcomes

Short-Term Outcomes

- Faster reporting of high-quality program data to CDC.
- Increased robust special study data related to program processes, SDOH, and health equity.

5a. Key Concepts: Types of Evaluation[10]

Evaluation types and related terms are defined below. We strongly recommend that recipients evaluate a process or outcome based on available central cancer registry, organizational, or health department expertise and resources.

Evaluation: The systematic collection and analysis of information about the characteristics and outcomes of programs and projects as a basis for judgments to improve effectiveness or inform decisions about current and future programming. Evaluation is distinct from assessment, which may be designed to examine country or sector context to inform project design, or an informal review of projects.

Formative evaluation: An assessment conducted to inform the development of a program; for example, conducting community needs and asset assessments and focus groups to identify appropriate cancer control strategies.

Process evaluation: A type of evaluation that focuses on program or intervention implementation; for example, access to services, whether services reach the intended population, how services are delivered, client satisfaction and perceptions about needs and services, and management practices. In addition, a process evaluation might provide an understanding of cultural, socio-political, legal, and economic contexts that affect implementation of the program or intervention. Example of question asked: Are activities delivered as intended, and are the right participants being reached?

Outcome evaluation: A type of evaluation that determines if, and by how much, intervention activities or services achieved their intended outcomes. It focuses on outputs and outcomes (including unintended effects) to judge program effectiveness but may also assess program processes to understand how outcomes are produced. Statistical techniques may be used when control or comparison groups are not available, such as for the evaluation of a national program. Example of question asked: To what extent are desired changes occurring due to the program, and who is benefiting?

Impact evaluations (IEs) measure the change in an outcome that is attributable to a defined intervention by comparing actual impact to what would have happened in the absence of the intervention (*the counterfactual scenario*). These evaluations are based on models of cause and effect and require a rigorously defined counterfactual scenario to control for factors other than the intervention that might account for the observed change. There are a range of accepted approaches to applying a counterfactual analysis, though IEs in which comparisons are made between beneficiaries that are randomly assigned to either an intervention or a control group provide the strongest evidence of a relationship between the intervention under study and the outcome measured to demonstrate impact.

5b. Glossary[10]

Monitoring: Monitoring provides an indication of progress against goals and indicators of performance, reveals whether desired results are occurring, and confirms whether implementation is on track. In general, the results measured are the direct and short-term consequences of program activities.

Outcome: A short- or intermediate-term effect of an intervention's outputs, such as a change in knowledge, attitudes, beliefs, or behaviors.

Outputs: The direct products or deliverables of program or intervention activities, such as the number of HPV vaccines provided per patient or site, the number of people served, or the number of cervical cancer screenings performed.

Program: An overarching response to a disease. A program generally includes a set of interventions to attain specific objectives and involves activities that may cut across sectors, themes, or geographic areas.

Project: An intervention designed to achieve specific objectives within specified resources and implementation schedules, often within the framework of a broader program.

6. Evaluation Resources

Recommended tools follow CDC's Framework for Program Evaluation, include program examples to illustrate concepts, and provide templates, worksheets, or checklists to facilitate the development process and completion of a written evaluation plan.

- American Evaluation Association. Guiding Principles for Evaluators. Available at: www.eval.org/About/Guiding-Principles.
- American Evaluation Association. An Evaluation Roadmap for a More Effective Government. Available at: www.eval.org/Policy-Advocacy/Effective-Government-Roadmap.
- Centers for Disease Control and Prevention. *CDC Program Evaluation Framework*. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Dept. of Health and Human Services; 2024. Available at: www.cdc.gov/evaluation/php/evaluation-framework/.
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[3]Centers for Disease Control and Prevention. CDC Program Evaluation Framework. Available at: www.cdc.gov/evaluation/php/evaluation-framework/.

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[5]Patton, MQ. *Utilization-Focused Evaluation: The New Century Text* (3rd ed). Thousand Oaks, CA: Sage Publications; 1997.

[6]Centers for Disease Control and Prevention, National Asthma Control Program. *Finding the Right People for Your Program Evaluation Team: Evaluator and Planning Team Job Descriptions.* Atlanta, GA: Centers for Disease Control and Prevention, U.S. Dept. of Health and Human Services; 2013.

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NPCR Evaluation Plan Guide

For DP22-2202 NPCR Recipients

Helpful Resources

CDC Evaluation Framework and Evaluation Standards of Practice

Figure 1 and Table 1 below depict the CDC Framework for Program Evaluation and Evaluation Standards of Practice, which are used to guide all CDC evaluations. While engaging stakeholders is usually the first step in evaluation planning and the standards of practice are a step-by-step process, the framework demonstrates a cyclical process that takes time, resources, dedicated staff, and is meant to be an organic process that may change with changing programmatic priorities, resources, and needs. This information is included as a helpful guide for NPCR recipients, as recipients think through their evaluation plan components, purpose, priorities, and outcomes. Since NPCR programs did not receive funding specifically for conducting robust program evaluations, Figure 1 and Table 1 are being shared for illustrative purposes to help guide evaluation brainstorming and planning. Please note that both reflect the 2024 CDC Evaluation Framework.

Conducting program evaluation and creating a cohesive and specific evaluation plan are requirements of DP22-2202 for NPCR and this information and resources provided at the end of this guide are meant to help walk recipients through the evaluation planning, implementation, analysis, and results dissemination process to improve program outcomes. Beyond the 5-year budget period, a targeted NPCR evaluation plan supports strategies and activities that promote registry program sustainability. The NPCR evaluation and recipient work plans are tools that can operate in synergy to help further enhance and advance cancer registry data. NPCR evaluation plan results can potentially serve as a key source for generating success stories reported to CDC and other stake- holders.

Please see Table 2: Approach to NPCR Evaluation Planning- DP22-2202 on page 6, which will help recipients organize evaluation steps and corresponding activities as well as inputs. It is recommended that recipients complete and submit Table 2 with the recipient NPCR evaluation plan since the tool has been included in the guide to help recipients plan their evaluation activities using some of the evaluation standards of practice steps in Table 1. NOTE: Table 2 represents a broad example of what could accompany the NPCR evaluation plan. A recipient-created table should align with recipient and NPCR logic models and can include more detail that is specific to the recipient's central cancer registry activities and operations.

Figure 1: Framework for Program Evaluation[3]

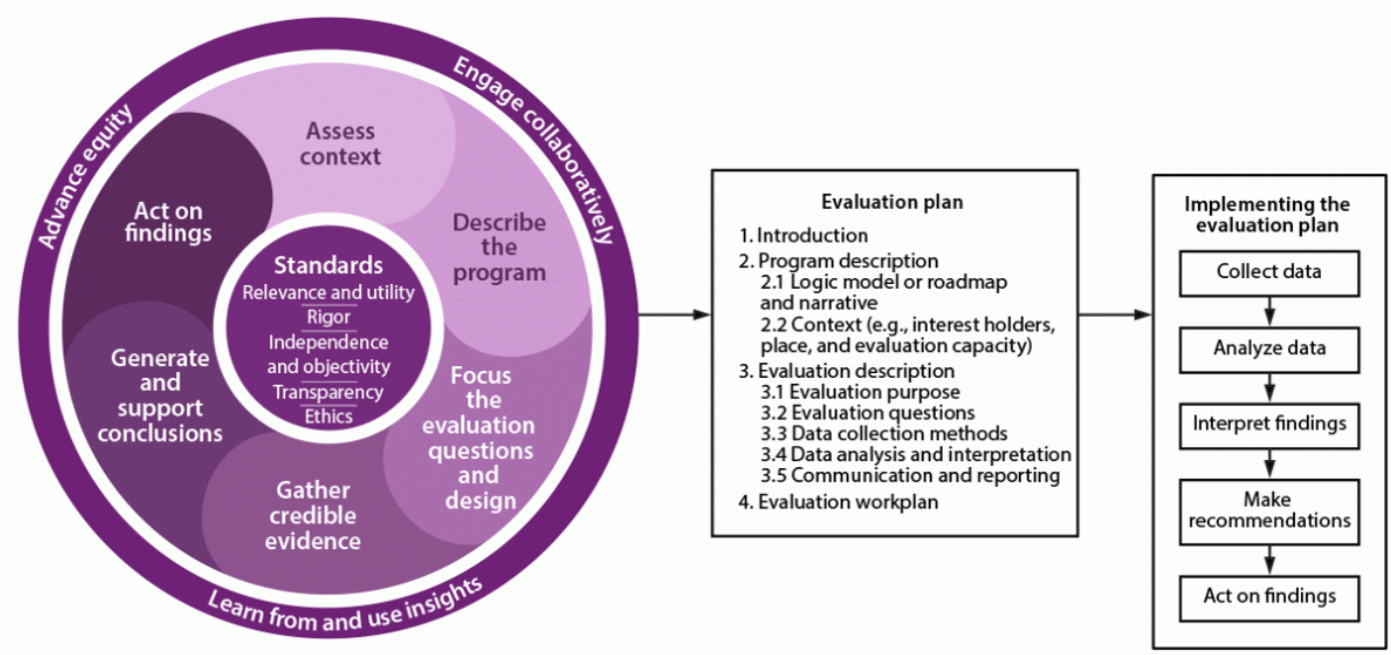


Table 2: Approach to DP22-2202 NPCR Evaluation Planning

Years marked in blue designate when to start step and/or continue step throughout evaluation plan implementation.

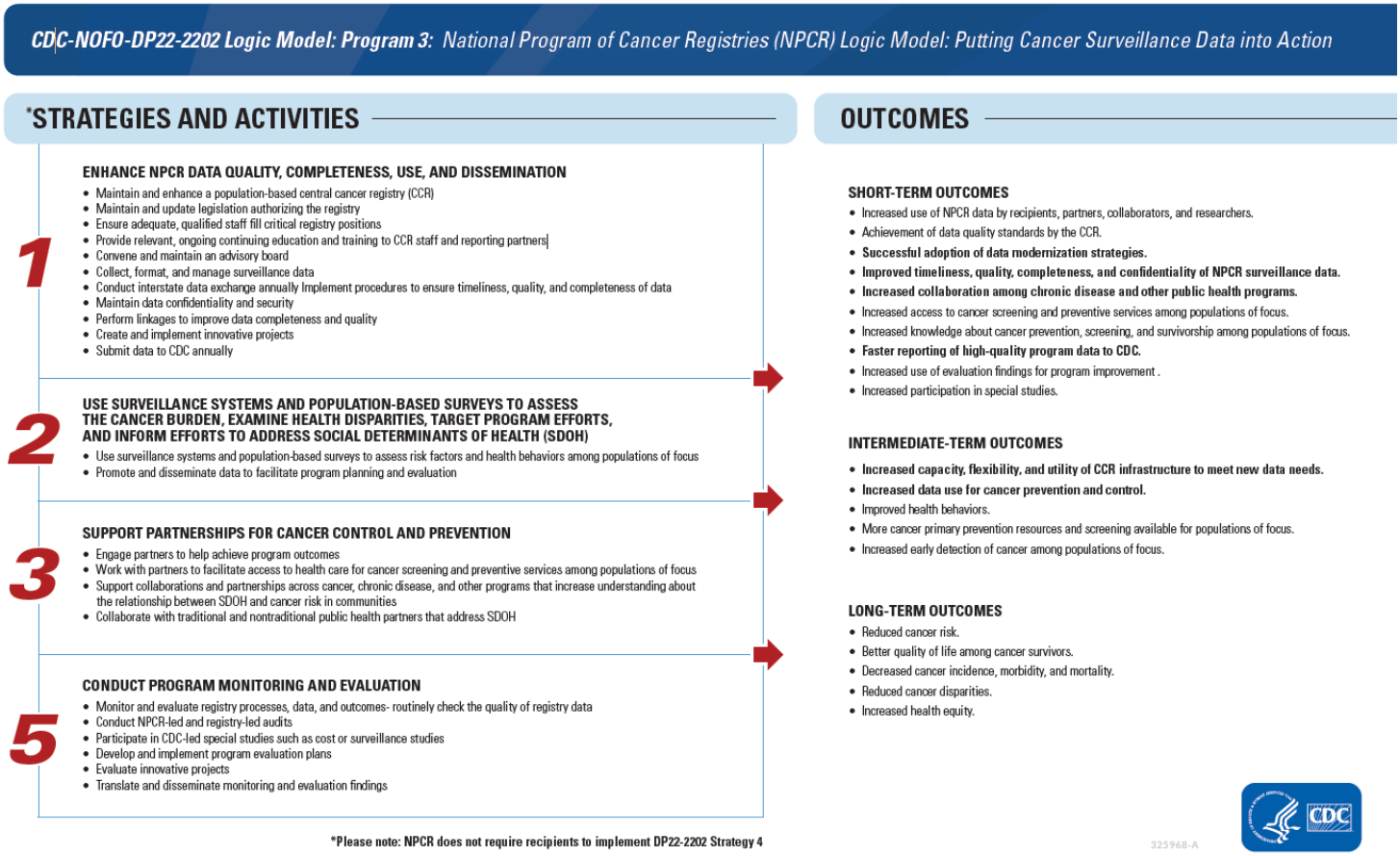
Evaluation Planning Steps		Year 1	Year 2	Year 3	Year 4	Year 5
Develop NPCR Evaluation Plan	Engage interest holders					
	Describe the program, including: NPCR recipient logic model program narrative					
	Focus the evaluation design and identify evaluation questions of interest and methodology					
Implement NPCR Evaluation Plan	Gather credible evidence using a variety of data sources					
	EXAMPLE: Assess NPCR data quality, timeliness, completeness using multiple data sources from prior years (from 12- 1205 as baseline, if possible)- Look at PEI 2015, DER, potentially DQE, other audits					

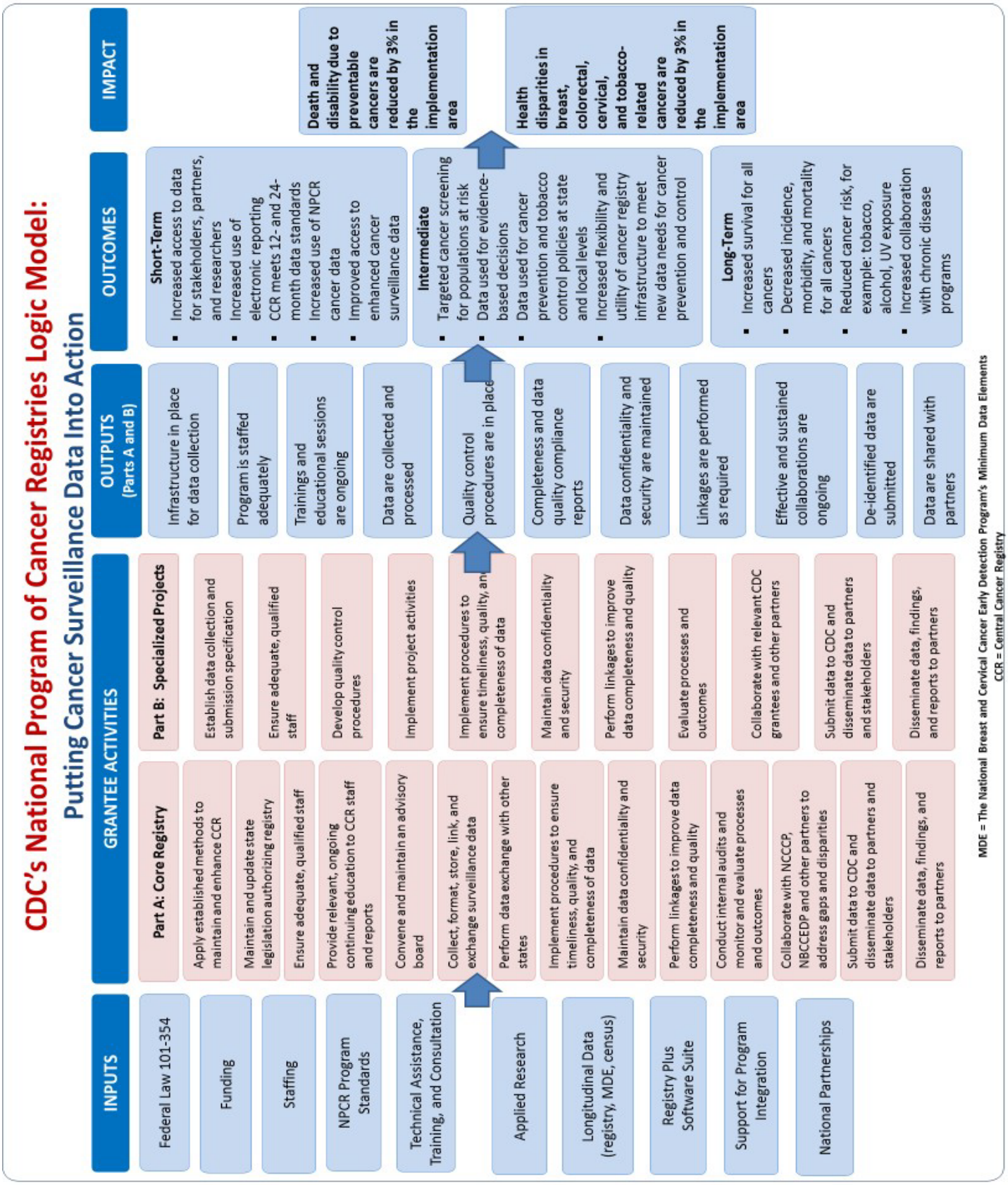
	EXAMPLE: Collect data to evaluate processes and other outcomes by performing routinized QC checks of CCR data (monthly, quarterly, biannually, or yearly), and facility audits to assess data quality					
	EXAMPLE: Assess data timeliness, completeness, and quality					
	Analyze evaluation data, summarize findings, and justify conclusions					
Ensure Use of Evaluation Findings and Share Lessons Learned	Communicate evaluation results to stakeholders, including other cancer and chronic disease programs, partners, and CDC					
	Identify areas of program improvement, based on evaluation findings					
Revise Evaluation Plan	Revisit evaluation plan and revise as needed					

For more information about the DP22-2202 Logic Model, please see pages 14-16 of the DP22-2202 NOFO.

Figure 2 below illustrates the NPCR logic model, which should serve as the foundation for all evaluation plans. Figure 3 (on the next page) shows the integrated cancer program logic model, which is found on pages 10-11 of the DP22-2202 NOFO. It is included in this guide to help illustrate how required strategies relate to short, intermediate, and long-term outcomes. For overall logic model representing all cancer programs, please refer to the DP22-2202 NOFO.

Figure 2. NPCR Logic Model





Key Concepts: Types of Evaluation[10]

EVALUATION: Evaluation is the systematic collection and analysis of information about the characteristics and outcomes of programs and projects as a basis for judgments, to improve effectiveness, and/or inform decisions about current and future programming. Evaluation is distinct from assessment, which may be designed to examine country or sector context to inform project design, or an informal review of projects.

PROCESS EVALUATION: A type of evaluation that focuses on program or intervention implementation, including, but not limited to access to services, whether services reach the intended population, how services are delivered, client satisfaction and perceptions about needs and services, management practices. Additionally, a process evaluation might provide an understanding of cultural, sociopolitical, legal, and economic context that affect implementation of the program or intervention. Example of question asked: Are activities delivered as intended, and are the right participants being reached?

OUTCOME EVALUATION: A type of evaluation that determines if and by how much, intervention activities or services achieved their intended outcomes. It focuses on outputs and outcomes (including unintended effects) to judge program effectiveness but may also assess program process to understand how outcomes are produced. It is possible to use statistical techniques in some instances when control or comparison groups are not available (e.g., for the evaluation of a national program). Example of question asked: To what extent are desired changes occurring due to the program, and who is benefiting?

IMPACT EVALUATION (IE): Measures the change in an outcome that is attributable to a defined intervention by comparing actual im- pact to what would have happened in the absence of the intervention (*the counter-factual scenario*). These evaluations are based on models of cause and effect and require a rigorously defined counterfactual to control for factors other than the intervention that might account for the observed change. There are a range of accepted approaches to applying a counterfactual analysis, though IEs in which comparisons are made between beneficiaries that are randomly assigned to either an intervention or a control group provide the strongest evidence of a relationship between the intervention under study and the outcome measured to demonstrate impact.

Helpful Definitions/Terms[10]

MONITORING: Monitoring provides an indication of progress against goals and indicators of performance, reveals whether desired results are occurring, and confirms whether implementation is on track. In general, the results measured are the direct and near-term consequences of program activities.

OUTCOME: Short-term or medium-term effect of an intervention or program's outputs, such as a change in knowledge, attitudes, beliefs, behaviors.

OUTPUTS: The results of program/intervention activities; the direct products or deliverables of program/intervention activities, such as the number of HPV vaccines provided per patient or site, the number of people served, the number of cervical cancer screenings performed.

PROGRAM: An overarching national or subnational response to a disease. A program generally includes a set of interventions marshaled to attain specific global, regional, country, or subnational objectives; involves multiple activities that may cut across sec- tors, themes and/or geographic areas.

PROJECT: An intervention designed to achieve specific objectives within specified resources and implementation schedules, often within the framework of a broader program.

More Evaluation Resources

Recommended tools follow **CDC's Framework for Program Evaluation (1999, 2024)**, include program examples to illustrate concepts, and provide templates, worksheets, or checklists to facilitate the development process and completion of a written evaluation plan.

- American Evaluation Association (AEA), *Guiding Principles for Evaluators*.

- Krause, H., and Richburg-Hayes, L. The Data Equity Framework: a concrete and systematic equity-oriented approach to quantitative data projects; 2023. https://osf.io/preprints/socarxiv/sqt4u
- Centers for Disease Control and Prevention. CDC Program Evaluation Framework. Available at: www.cdc.gov/evaluation/php/evaluation-framework/
- *Comprehensive Cancer Control Branch program evaluation toolkit*. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control, Comprehensive Cancer Control Branch, 2010.
- *Developing an effective evaluation plan*. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; Division of Nutrition, Physical Activity, and Obesity, 2011.
- *Learning and growing through evaluation: State Asthma Program evaluation guide*. Centers for Disease Control and Prevention, National Center for Environmental Health, Division of Environmental Hazards and Health Effects, Air Pollution and Respiratory Health Branch, 2010. Available from: www.cdc.gov/national-asthma-control-program/php/program_eval/guide.html
- Kidder DP, Fierro LA, Luna E, et al. CDC Program Evaluation Framework, 2024. MMWR Recomm Rep 2024;73(No. RR-6):1-37.
- Yarbrough, D. B., Shulha, L. M., Hopson, R. K., and Caruthers, F. A. (2011). *The Program Evaluation Standards: A Guide for Evaluators and Evaluation Users* (3rd ed.). Thousand Oaks, CA: Sage.

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U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, released in June 2024.

[1]*Evaluation toolkit: How to evaluate activities intended to increase awareness and use of colorectal cancer screening*. Developed for the National Colorectal Cancer Roundtable by Wilder Research, 2012.

[2]Centers for Disease Control and Prevention. *Checklist for assessing your evaluation questions*. Atlanta, GA: CDC, National Asthma Control Program, 2013.

[3] Kidder DP, Fierro LA, Luna E, et al. CDC Program Evaluation Framework, 2024. MMWR Recomm Rep 2024;73(No. RR-6):1-37.

[4]*Developing an effective evaluation plan*. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; Division of Nutrition, Physical Activity, and Obesity, 2011.

[5]Patton, MQ. (1997). *Utilization-focused evaluation: The new century text* (3rd ed.). Thousand Oaks, CA: Sage Publications. [6]Centers for Disease Control and Prevention. *Finding the right people for your program evaluation team: Evaluator and planning team job descriptions*. Atlanta, GA: CDC, National Asthma Control Program, 2013.

[7]Torres, R. T., Preskill, H. S., & Piontek, M. E. (1996). *Evaluation strategies for communicating and reporting: Enhancing learning in organizations*. Thousand Oaks, CA: Sage.

[8]*Comprehensive Cancer Control Branch program evaluation toolkit*. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control, Comprehensive Cancer Control Branch, 2010.

[9]*Learning and growing through evaluation: State Asthma Program evaluation guide*. Centers for Disease Control and Prevention, National Center for Environmental Health, Division of Environmental Hazards and Health Effects, Air Pollution and Respiratory Health Branch, 2010.

[10] *US President's Emergency Plan for AIDS Relief (PEPFAR)*. Evaluation Standards of Practice, Version 2.0, 9/11/2015. US Department of State. Office of the US Global AIDS Coordinator and Health Diplomacy.

APPENDIX F: CDC DP22-2202 NPCR Data Management Plan (DMP)

Per 22-2202 Notice of Funding Opportunity (NOFO), each recipient should have a Data Management Plan (DMP) in place. These plans are required for cooperative agreement awards where data collection or generation activities are necessary. As part of the continuation application for year 4, NPCR recipients are required to include their DMP plans to CDC. **Please upload NPCR DMPs to GrantSolutions as part of the APR 2020 February submission.** All submitted DMPs will be reviewed and approved by CDC staff. If additional information or discussion is needed, CDC will follow up with recipients.

If NPCR recipients already have a data management plan in place for NPCR activities, they are encouraged to use that language and expand it to cover NPCR data collection, storage, access, security, confidentiality, etc.

Description of DMP from DP22-2202

The DMP should provide a description of the data that will be produced using these NOFO funds; access to data; data standards ensuring released data have documentation describing methods of collection, what the data represent, and data limitations; and archival and long-term data preservation plans.

For more regarding CDC's DMP policy, visit: https://www.cdc.gov/grants/additional-requirements/ar-25.html

Part 1: A DMP for each collection and/or generation of NPCR public health data funded by 22-2202 should include the following information:

- A description of the data to be collected or generated for NPCR
- Standards to be used for the collected or generated NPCR data
- Mechanisms for or limitations to providing access to and sharing of the data (include a description of provisions for the protection of privacy, confidentiality, security, intellectual property, or other rights). This section should address access to identifiable and de-identified data or justification for not making the data accessible (see below for additional information about access)- Designate the data as non-public or restricted in your DMP
- Statement of the use of NPCR data standards that ensure all released data have appropriate documentation that describes the method of collection, what the data represent, and potential limitations for use; and
- Plans for archiving and long-term preservation of the data or explaining why long-term preservation and access are not justified. This section should address archiving and preservation of identifiable and de-identified data (see below for additional information regarding archiving).

Human Subjects and HIPAA Issues

State and Federal laws mandate strict confidentiality of data about cancers and health care providers reported to central registries. Confidentiality is the highest priority in registry operations. There is no direct contact with human subjects and data collection is consistent with ongoing Registry operations. The Health Insurance Portability and Accountability Act (HIPAA) requires that health care providers obtain consent from all patients for the release of their medical records. Because the central cancer

registries (CCR) are required by law to obtain cancer information, and are considered public health authorities, the CCRs are exempt from the patient consent provisions of HIPAA. The scope of the work described in the 22-2202 Notice of Funding Opportunity is consistent with public health practice activities routinely carried out by CCR staff, researchers, and collaborators in fulfilling statutory mandates or
related special studies that further the Registry's mission.

Part 2: Access to and Archiving of the Data

For public use de-identified (removal of sensitive identifiable or potentially identifiable information) datasets, an accompanying data dictionary, codes, and other documentation relevant to use of the data set should be deposited in a sustainable repository to provide access to the data. Data that cannot be de-identified can be provided on request under a data use agreement. **If data shared through CDC's United States Cancer Statistics (USCS) is your only means of making data available to the public, you may indicate that in your document as your avenue for making data accessible.**

For data underlying scientific publication, recipients should make the data available coincident with publication of the paper, unless the data set is already available via a release or sharing mechanism. At a minimum, release of the data set should consist of a machine-readable version of the data tables shown in the paper.

Requirements set forth in this policy are not intended to conflict with or supersede applicable grants regulations related to agency access to recipient data and records.

The final version of a collected and/or generated data set intended for release or sharing should be made available within thirty (30) months after the end of the data collection or generation, except surveillance data that should be made accessible within a year of the end of a collection cycle. In addition, recipients should ensure the quality of the data they make accessible and seek to provide the data in a nonproprietary format. **If data cannot be made accessible, a justification for not doing so should be provided in the final DMP.**

Recipients will be required to inform their **NPCR Program Consultant**, in the award via an update to their DMP, of the location of the deposited data. The DMP is a living document that should be updated (as needed) throughout the life cycle of data and 5-year cooperative agreement cycle.

APPENDIX G: Data Modernization Initiatives (DMI)

The goal of CDC's Data Modernization Initiative (DMI) is to get better, faster, actionable insights for decision-making at all levels of public health. Our vision is to create one public health community that can engage robustly with healthcare, communicate meaningfully with the public, improve health equity, and have the means to protect and promote health.

For more information about Data Modernization Initiatives, please see:
Data Modernization Initiative | CDC
NPCR Data Modernization | CDC

Cancer FHIR:
The Cancer FHIR Pilot is a multi-phase initiative to test and implement an automated, standard approach to improve data collection and exchange between EHRs, data providers, and central cancer registries. In the initial phase various clinical sites, EHR vendors, and central cancer registries were recruited to implement the architecture and test the exchange using FHIR IGs and FHIR APIs. The architecture tested in the initial phase leverages the MedMorph IG which operates using the eCR Now app at its core. Enabling the data collection and exchange using the MedMorph IG is one approach to this exchange, but vendor developed solutions are also possible. Cancer registry reporting is one of several use cases modeled for Making Electronic Data More Available for Research and Public Health (MedMorph). MedMorph is a multi-partner effort to create a standard FHIR based, common framework and methodology for automated electronic reporting. MedMorph provides a standard resource, the Reference Architecture Implementation Guide (RA IG), addressing data exchange needs with a common, streamlined approach. The Cancer Use Case focuses on transmission of cancer information from EHRs to Central Cancer Registries (CCRs) using FHIR. The CDC/NPCR is currently piloting automated, electronic reporting from EHRs to central cancer registries by leveraging the MedMorph RA IG and the HL7 Balloted and published Cancer Registry Reporting Content Implementation Guide (https://hl7.org/fhir/us/central-cancer-registry-reporting/2022Jan/usecases.html). CDC/NPCR has been recruiting ambulatory clinical sites and central cancer registry for participation in the pilot and initial testing will focus on eCR Now app configuration. Next phases will focus on complete data evaluation and integration with eICR.

APPENDIX H: NPCR Registry Plus Fact Sheet

This section provides an overview of the products offered through the NPCR Registry Plus suite.

1) CDC/NPCR recipients that utilize the suite of Registry Plus will be prime candidates for our Data Modernization Initiatives and PCOR funding projects in the coming years. Our goals are to promote real-time/electronic reporting and reduce the burden on central registry staff. We will only pilot with Registry Plus users.
    a. Data Modernization Initiative | CDC
    b. NPCR Data Modernization | CDC
2) Registry Plus products are free to CDC/NPCR recipients and are fully supported by a contract that is written to promote a high degree of customer satisfaction.
    a. Registry Plus | CDC
    b. Data Flow Diagrams | Registry Plus | CDC
3) The CDC/NPCR NOFO stipulates that funding cannot be used for informatics/IT projects or applications that are already freely available to recipients by CDC/NPCR, i.e., Registry Plus.
4) CDC/NPCR is moving Registry Plus to the Cancer Surveillance Cloud-Based Computing Platform (CS-CBCP). This structure will provide a single platform for data reporters and a seamless approach to process cancer reporting. Recipients will have full control over their data in this cloud environment.
    a. Cancer Surveillance Cloud-based Computing Platform | CDC
5) Cancer Informatics Help Desk: Benefits, SOPs, and customer support
    a. Dedicated Registry Relationship Manager: liaises with the registries and helps with testing and other technical aspects. This position is dedicated to ensuring that registries have the support that they need to be successful.
    b. Web-based customer help management system that utilizes a ticketing approach and user sign-in password protection.
    c. Self-service portal with knowledge base and self-guided ticket submission.
    d. Graduated tiers of customer service support based on complexity of issue. Customer support responds to every help desk request within 24 hours of receiving the request.
6) CRS Plus is the main central registry database program.
    a. Supports the linkage of incoming abstracts against the existing database, with software-assisted consolidation into patient and tumor tables.
    b. Enhanced patient linkage to assign higher prioritization to other data items when SSN or other demographic data items are not available.
    c. Automated tumor linkage logic meeting national standards in Solid Tumor Rules with review for significant differences in important data items.
    d. Provides automated processing of duplicate and modification records.
    e. Allows side-by-side displays and automated comparisons of incoming and stored data.
    f. Updates the tracking system with processing milestones for each abstract.
    g. Provides management reports.
    h. Exports records in North American Association of Central Cancer Registries (NAACCR) format.
    i. Automates preparation of files for national calls for data. Program and database script files are distributed as specifications for these extracts are released.

j. Provides backend support for ad hoc requests (dashboards, epi studies, linkages, and so on).
k. Suspense/Transfer feature for improved management of Pending Queue.
l. SSDI Display customization options for customized displays.

7) Registry Plus Users Group (RPUG) includes all Registry Plus product users and is coordinated by the Registry Plus team to support users across many different avenues, including monthly calls, newsletters, and ad hoc workgroups.
    a. Monthly calls: The RPUG has virtual monthly meetings on the third Thursday of each month at 1 p.m., ET. The agenda for calls include:
        i. Review of product status related to new releases and updates.
        ii. Presentations/product demonstrations from the Registry Plus team when we roll out new features or products that may require a little more explanation.
        iii. Presentations from CCRs on innovative ways they are using the Registry Plus products or other topics of interest.
        iv. General discussion of other topics, issues, hurdles, etc., that CCRs would like to review.
        v. Other topics that the Registry Plus team wants to update the CCR community about, including data modernization plans and new opportunities.
        vi. Presentations summarizing NAACCR version changes including detailed information regarding implementation in Registry Plus products.
        vii. All monthly calls are recorded and posted to our NPCR Registry Plus SharePoint site within 48 hours of completing the call so that if any users miss a call or want to watch a presentation again, they can do so.
    b. Monthly Registry Plus Product Team Newsletter that we send on the first workday of each month to highlight topics that we think the product users may want to know more about (for example, the current newsletter highlights a new eMaRC Plus Lite product we are developing, a new feedback tool we are about to launch on our Help Desk, DMI updates, reminder of recent Call for Data notices, etc.)
    c. Depending on the activity that CCRs are interested in joining, there are multiple breakout workgroup calls, as well. For example, the Web Plus and eMaRC Plus cloud-based products have had specific workgroups that meet separately to discuss what they are doing, receive user feedback, and provide demonstrations of product status. When appropriate, these calls are often scheduled as monthly meetings. Beyond the calls, we may send information via email updates or other methods.
    d. Enhancement Requests: The Registry Plus support team regularly seeks user feedback from customers to understand ways that we can enhance products to make them more useful and improve their “real world” functionality.
    e. Annual NAACCR standards updates: Each of the Registry Plus products is updated annually to reflect the updated standard setter requirements. Part of this activity includes providing updates and information to the RPUG members as our team is aware of the changes and how they may impact our customers.

8) EDITS integration:
    a. CDC/NPCR provides EDITS tools to improve data quality by standardizing the way data items are checked for validity.
    b. The NPCR-EDITS software supports defining standards for data quality, checking data during the collection process, and preparing data for submission and analysis.

c. Our EDITS programs are updated annually to coincide with updates from the standard setters for data items collected, including new and revised data items. We also work closely with standard setters to ensure our EDITS programs are well aligned with what the customers will need to collect and prepare data for submission requirements.
d. The Registry Plus team has dedicated support to assist customers with installing and utilizing our edits programs and continually work on ways to make the products better.
e. For example, we have worked on improving the performance and versatility of our Edits software in the following ways:
    i. Decreased time for running large files in GenEditsPlus
    ii. Enabling simultaneous Edits calls in WebPlus
    iii. Capability of writing Edits rules in common accepted programming languages as .NET C#
    iv. Accessing Edits via Web API
    v. Improved metafile quality control via new EditWriter 6 edit logic checks
f. The Registry Plus edits support team also conducts regular training presentations on various abstractor community calls (including the NPCR RPUG calls, NAACCR training calls, NCRA meetings, etc.). As needed, our EDITS support team will also meet one-on-one with customers to help understand their specific user needs and environment.

9) Exchange Plus: This useful tool assists central cancer registries in several registry operation activities beyond working with the XML data exchange format. Provides the following support:
    a. Dictionary Maintenance
    b. Format conversion from NAACCR XML to flat-buffer and delimited formats.
    c. Import/View/Update/Export NAACCR Data – data quality tool to create, run, and save scripts to update data in batch mode; anonymize confidential data, combine multiple NAACCR files into one data source
    d. Linkage: CRS Plus users can connect to the CRS Plus database to run linkages to assist with case finding, completeness, and prioritization of work.
    e. XML Validation
    f. Data File Mapping: converts delimited files or fixed column position files to NAACCR XML and maps data items defined differently than the NAACCR standard format to assist registries with linkage and prepare data to write to the registry database.
10) ePath Reporting: The CDC/NPCR is developing real-time pathology reporting from laboratories to public health agencies through implementation with the APHL AIMS and the CS-CBCP.
11) eMaRC Plus: determine reportability of ePath laboratory reports, auto coding, and formatting to NAACCR XML output. Consolidate/process physician EHR submissions (CDAs) into NAACCR XML.
12) Natural Language Processing (NLP): eMaRC Plus Lite is a web API that references laboratories' hosts inside their firewall. Using Natural Language Processing, reporters can pass HL7 messages through the API to determine if it is reportable or not to the Central Cancer Registry. This will greatly assist case-finding efforts and reduce manual intervention from CTRs.
    Last Updated: 12/04/2023

APPENDIX I: NPCR Recommendations for Registrars in Training

Purpose: The purpose of this document is to provide guidance to CCRs on recommended roles and responsibilities for registrars in training vs. ODS-certified (ODS-C) staff. Please note that each CCR has unique needs and may have an ample or limited applicant pool of candidates to choose from to fill critical CCR roles. For this reason, some roles may be filled by a registrar in training staff member who plans to sit for the ODS exam within 2 years of start date.

Please note that the roles and duties described below may depend on where the registrar is employed-hospital or CCR.

Potential duties for non-certified CCR registrars include:

- Death clearance tasks
- Casefinding
- Reportability Screening
- Limited Data Quality Checks
- Case abstraction
- Case Consolidation
- Incorporation of other registry functions into a training plan, on a limited basis

Registrars in training need to be supervised by an ODS-C, as their case abstraction/consolidation tasks need to be reviewed by an ODS-C. They can perform most registrar functions.

For CCRs with staff performing case abstraction as part of training, it is recommended that CCRs create detailed guidelines for non-certified registrars, based on experience. For example, entry-level registrars should have direct supervision when abstracting, while intermediate-level registrars should be routinely audited.

Case Consolidation
It is recommended that new, non-ODS registrars begin case consolidation in a limited manner. For example, the registrar could learn one primary site, as dictated in their training plan, while under supervision. It is highly recommended that registrars first become familiar with cancer registry resources and manuals. Additionally, CCRs should take advantage of “test environments” within their software, if available. This way, registrars can learn consolidation without changing “live” data. It is recommended that a strict case review process is in place to assist the registrar in developing their skills while ensuring data quality. Otherwise, time and energy of QA/QC staff may be unnecessarily spent verifying case accuracy (e.g. determining multiple primaries).

Case Abstraction
Like consolidation, it is recommended that non-ODS staff begin abstracting cases in a limited and focused manner. These registrars must be familiar with all relevant resources, in some instances, when a CCR hires a non-ODS registrar, they are assigned to casefinding and reportability screening tasks. (This is. When the non-ODS registrar is ready to consolidate, they are assigned one primary site. They are expected to learn/master coding those cases before being approved to code additional primary sites. These tasks should be completed under the supervision of the ETC or a manager that is ODS certified.

Other Roles
The Education and Training Coordinator (ETC) must be an ODS-C. In some circumstances, due to

recruitment and retention challenges, an ETC could be a non-ODS who is preparing to take the ODS exam within 2 years. Similarly, it is strongly recommended that the CCR QA/QC Coordinator be an ODS or be preparing to take the ODS exam within two years. In some CCRs, hospital case auditing is performed by an ODS, or a collaboration of an ODS and the database manager. It is strongly recommended that only ODS staff audit and review cases completed by CoC facilities.

Applicable Law
In some jurisdictions, statute dictates which CCR tasks must be performed by an ODS-certified registrar. Any remaining tasks could be performed by non-ODS staff, depending on the needs of the registry.

Commission on Cancer-accredited (CoC) Hospital Registrars
For questions regarding registrars in a Commission on Cancer-accredited (CoC) facility, please consult the Optimal Resources for Cancer Care (2020 Standards). This document specifies activities that can only be performed by a certified ODS in CoC-accredited facilities.