



# NBCCEDP Program Guidance Manual

Book 4  
Data Management  
Quality Assurance/Quality Improvement  
Evaluation

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# NBCCEDP Program Guidance Manual

## Data Management

Version 2

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# I. INTRODUCTION TO THE CHAPTER

## OVERVIEW OF THE CHAPTER

This chapter provides guidance and resources for collecting and analyzing data [Minimal Data Elements (MDEs)] to characterize screening, diagnostic follow-up, and treatment efforts; monitoring data collection and analysis efforts; reporting results to the Centers for Disease Control and Prevention (CDC); and using results for program improvement.

## CONCEPTUAL FRAMEWORK

The Data Management component is represented as a circle surrounding the Screening and Diagnostic Services component, indicating its focus on this component. Data, especially the results of screening and diagnostic services, should be used to inform and evaluate each of the other program components.

*(See the Introduction to the Manual, NBCCEDP Conceptual Framework.)*

## PURPOSE OF DATA MANAGEMENT

The purpose of data management is to ensure the availability of high-quality data for program planning, quality assurance, and evaluation.

## DEFINITION OF DATA MANAGEMENT

Data management is the ongoing, systematic collection, analysis, and interpretation of data for

- planning,
- implementation,
- quality assurance,
- evaluation of recruitment, screening efforts, results, diagnostic follow-up, and treatment.

## CDC PROGRAM POLICIES REGARDING DATA MANAGEMENT

The following aspects of this manual are relevant to data management:

- **Policies for the inclusion of data in the MDEs**—specifies scenarios in which screening and diagnostic MDEs are required and quality standards for those data
- **Policies on data sharing**—specifies CDC procedures for responding to MDE data requests for research purposes.

## ESSENTIAL ELEMENTS OF DATA MANAGEMENT

To meet the National Breast and Cervical Cancer Early Detection Program's (NBCCEDP) expectations in the area of data management, a grantee should do the following:

- Establish and maintain a data system to collect, edit, manage, and continuously improve the data needed to track a woman’s receipt of screening/rescreening, diagnostic, and treatment services
- Establish a system that provides routine and ad hoc reports for program management
- Establish mechanisms for reviewing and assessing the completeness, accuracy, and timeliness of data collected by the grantee
- Establish protocols to ensure the security and confidentiality of all data collected
- Utilize existing systems to collect and analyze population-based information on demographics, incidence, staging at diagnosis, and mortality from breast and cervical cancer

## **COMPETENCIES NEEDED TO IMPLEMENT DATA MANAGEMENT**

Staff members responsible for data management need the ability to

- collect data,
- enter and edit data,
- assess data quality,
- analyze and interpret data,
- prepare data reports, and
- evaluate quality of data systems.

Staff members responsible for data management need knowledge in

- CDC requirements for MDEs,
- data system hardware and software,
- database design and programming, particularly for those programs that do not use the Cancer Screening and Testing (CaST) system,
- cancer registries and other population-based data sources for surveillance.

## **II. ROLE OF DATA MANAGER**

Depending on a program’s size and staffing configuration, data management may be the responsibility of one individual—typically, the designated “data manager,” epidemiologist, or program director. Alternatively, several individuals may share this role. In either case, the basic expectations and activities are the same:

- To plan for data collection, analysis, and use of data for program planning, quality assurance, and evaluation
- To collect information and maintain a data system of clinical services provided through the program
- To develop and maintain procedures to protect the security and confidentiality of data

- To export clinical data into the standardized record format of the MDEs to report to CDC (The MDEs are a subset of the grantee’s data system and are considered to be minimally necessary for CDC to monitor program performance, patient tracking and follow-up, and clinical outcomes)
- To ensure completeness, accuracy, and timeliness of the MDEs
- To submit the MDEs to CDC twice a year on the required submission schedule
- To participate in MDE feedback calls with CDC and to respond to action items that are identified
- To respond to new or changed MDE reporting requirements
- To link MDE data with central cancer registries to validate, reconcile, and supplement data in both systems
- To link MDE data with cancer registries and other relevant population-based information to aid in determining cancer patterns and trends

To help support these data management functions, CDC maintains a contract for technical assistance services to both the NBCCEDP and its grantees. Details on the technical assistance and support provided through this contract are available on page 18.

## SETTING A COURSE

The primary reason for collecting data is to monitor the delivery of services and clinical outcomes of the program. For this activity, the main data set—the MDEs—is used. These data also help to

- provide a better understanding of who is being screened or diagnosed with program funds, as well as where services are being provided, by whom, and with what results;
- monitor and project clinical costs;
- track patients for clinical care and follow-up;
- meet the reporting requirements of CDC and other funding sources for the MDEs;
- link the MDEs with cancer registry and other surveillance data to compare women in the NBCCEDP with women throughout states, territories, tribes, and the nation regarding early diagnosis, care, and outcomes.

In addition to the MDEs, programs may choose to use other data for a variety of purposes. Some of these purposes are listed below, with the relevant program components noted in italics:

- To identify segments of the population at risk for disease, as well as populations at risk for not being screened (*Public Education and Targeted Outreach*)
- To monitor the number, distribution, and quality of breast and cervical cancer screening resources, including mammography facilities, cytology laboratories, and providers who offer diagnostic services (*Screening and Diagnostic Services; Quality Assurance/Quality Improvement*)

- To identify factors contributing to the disease burden, such as behavioral risk factors and limited or inequitable access to early detection and treatment services (*Partnerships; Professional Development; Public Education and Targeted Outreach*)
- To identify needed changes in program direction, operation, or management, including changes in recruitment, screening and diagnostic service delivery, partnerships, professional development, and quality assurance and improvement (*Program Management*)
- To measure the effectiveness of program activities in achieving short-term, intermediate, and long-term outcomes (*Evaluation*)
- To assess program efficiency and cost-effectiveness (*Evaluation*)
- To identify the need for additional resources and to prepare continuing or new applications for potential funding sources (*Program Management*)



### **Key Message**

***Knowing why the program is collecting the data helps to identify what data to collect. It ensures that only those data that will actually be used are collected—no more and no less.***

## ***Knowing the Environment***

One of the essential steps in planning for data collection and analysis is to know the environment in which data management will occur—and how that environment may impact data needs. Three aspects of the environment are particularly important: the data management infrastructure, relevant data systems, and partnering opportunities.

### **Data Management Infrastructure**

As with all program components, the infrastructure for data management may be highly centralized, highly decentralized, or a blend of the two. Typically, these models can be characterized as follows:

- **Centralized**—The grantee performs all data collection, entry, and analysis.
- **Decentralized**—One or more groups collect, enter, and analyze the data.
- **Blended**—Both the grantee and an individual or firm on contract share data management responsibilities, with each performing certain data management activities.

If a grantee is considering hiring a contractor to perform some or all of the data management functions, the grantee is encouraged to consult with CDC and the CDC data contractor early in the decision-making process and take advantage of collective expertise in this area. In addition, Federal grant requirements mandate that grantees obtain CDC approval prior to awarding any contracts, including those for data management.

*(See the Program Management chapter, Organizational Context, for more information on infrastructure.)*

## Relevant Data Systems

Many data collection efforts that relate to breast and cervical cancer, such as the Behavioral Risk Factor Surveillance System (BRFSS) and census data, are being pursued in each grantee's state, tribe, or territory. Knowing what these efforts are will help to identify linkages, reduce duplication, and allow grantees to learn from the experiences of others. Grantees should take time to become familiar with these systems and to understand

- why they were designed (their purpose),
- how long they have existed,
- who provides the data (the sources),
- who manages and staffs them,
- what links they have to other systems,
- how they are perceived, and
- how data are used.

Forming close working networks with other data managers and IT staff within the state, tribe, or territory will help programs avoid common mistakes and create positive synergy in the design of coordinated data collection systems.

## Partnering Opportunities

Another aspect of the data environment is the relationship of the NBCCEDP to other related programs within a State, tribe, or territory, including the CDC-funded cancer registry and comprehensive cancer control program in your community, other cancer programs (e.g., Comprehensive Cancer Control Program (CCCP) and Colorectal Cancer Control Program (CRCCP), risk factor programs (e.g., those related to nutrition and physical activity), and other chronic disease programs (such as CDC-funded WISEWOMAN programs in your community). Grantees should find out whether there are committees or workgroups that bring these program staff together, as well as, for example, the types of issues they discuss and their working relationships. This information will help grantees to identify opportunities to build partnerships and collaboration around data collection, analysis, and use.

(See Attachment A: Data Management Orientation Web Conferences.)

## MINIMUM DATA ELEMENTS

The MDEs are a set of standardized data elements, developed in collaboration with funded programs, to report demographic and clinical information on women served through NBCCEDP funds. The MDEs are the data items considered to be minimally necessary for grantees and CDC to monitor and evaluate the program. The MDEs are also used to inform NBCCEDP policies and practices, assess the national program's screening outcomes, and respond to the information needs of the CDC stakeholders and partners.

### Key Message



***Data are a reflection of clinical care. Using data, grantees can spot individual cases that need further attention as well as trends that need to be investigated.***

(See the Policies and Procedures chapter, PD.1: Inclusion of Data in the MDEs.)

The MDEs consist of information on women screened or diagnosed using program funds, including

- program enrollment location,
- patient demographic characteristics,
- patient-reported symptoms and patient screening history,
- screening services and results,
- diagnostic procedures and final diagnosis result,
- treatment initiation data,
- registry-acquired data on cancers detected, and
- indication of NBCCEDP as a funding source by screening procedure and diagnostic procedures.

This section highlights critical information for collecting, editing, reporting, analyzing, and using the MDEs. More detailed guidance can be found in two useful resources:

- The MDE Data User’s Manual, which contains the information needed to produce data for the NBCCEDP (e.g., definitions of data variables, reporting formats) and is updated regularly
- The NBCCEDP Resources Web site (<http://www.nbccedp.org>)\*, which provides up-to-date information on program resources and news, data submissions, submission feedback reports, and software upgrades

## Data Reporting

Clinical data are collected for each screening cycle, computerized, converted to a standardized MDE format, and transmitted to CDC via its data contractor. Grantees are expected to report data on the screening and diagnostic services received by eligible women and paid for solely by NBCCEDP funds (defined as “program funds”) or in part by NBCCEDP funds and any other funding sources, including state, private, or other Federal funds (defined as “blended funds”). In reporting these services, the program uses the payment fields on the MDE record to indicate whether program funds paid for these services.



### Key Message

*Although data submissions to CDC are only required twice a year, grantees are expected to examine the MDEs on a more frequent basis. If grantees are only looking at their data in preparation for a pending MDE deadline, they are missing opportunities to identify errors or missing information on a timely basis. More importantly, they may be overlooking ways to use the data to improve program efforts and outcomes. Grantees know that their MDE data are “working for them” when*

- *providers are aware of their individual performance,*
- *staff members are asking questions about the data set,*
- *staff and partners are eagerly awaiting the latest MDE runs.*



### Key Message

*Programs that have non-Federal funds to support clinical services have several options when distributing program funds and projecting costs, as reported in the Clinical Cost Worksheet. These programs should contact their program consultant or designated Program Services Branch staff member for assistance in thinking through the most accurate representation of their unique circumstances. This will ensure that they have sufficient Federal dollars to reimburse providers appropriately.*

(See the Policies and Procedures chapter, PDI: Inclusion of Data in the MDEs.)

## **What?**

Programs are required to provide CDC with MDE data files that contain information in these categories:

For each woman screened or diagnosed through program funds:

- Screening Location
- Patient and Record Identification
- Patient Demographic Information
- CBE Screening Information
- Pap Test Screening Information
- Initial Mammography Information

For abnormal cervical screening results or when diagnostic workup is planned or performed:

- Cervical Diagnostic Procedures
- Cervical Diagnosis Information

For cervical cancers/precancers diagnosed:

- Cervical Cancer Treatment Information
- Cervical Cancer Registry Data

For abnormal breast screening results or when diagnostic workup is planned or performed:

- Breast Imaging Procedures
- Breast Diagnostic Procedures
- Breast Final Diagnosis Information

For breast cancers diagnosed

- Breast Cancer Treatment Information
- Breast Cancer Registry Data

## **When?**

Data submissions are due twice each year. The submission cutoff dates provide grantees with a time lag to collect, clean, and report MDE data to CDC. A lag period of 3½ months is expected for reporting results of a screening procedure. An additional 6 months (a total of 9½



### **Key Message**

*The importance of a form's format should not be underestimated, as the goal of good forms design is ultimately to limit the number of completion errors. Grantees are encouraged to use the following suggestions when designing forms:*

- *Space text to make it easier to read. Crowded pages tend to be confusing and increase the chances of an item being overlooked.*
- *Use vertical lists whenever possible. Reading left to right and back and forth across a page can be confusing (e.g., hard to tell which response options correspond to which questions).*
- *Divide pages into sections with bold lines and clear headings, particularly on the screening form, where various types of information are usually collected.*
- *When offering response options, use a list of left-justified choices with check boxes.*
- *List results and diagnoses by placing those that occur most often (or with the greatest frequency) first.*
- *Use closed-ended questions as much as possible, since responses to open-ended questions are not conducive to data consistency and can be difficult to read.*
- *Look at examples from other programs.*

months) after the screening date is allowed to report results of diagnostic follow-up when it is needed.

(See Attachment B: MDE Submission and Feedback Cycle Calendar.)

## **How?**

To submit data, grantees must extract data from the program's data system and put those data in the MDE format. In order to aggregate the MDE data for national program reporting, each program must use the standard MDE format. Submissions must include all cumulative data from the beginning of the program. A unique patient ID number must be assigned to identify a woman, and a unique record ID must be assigned to identify a screening cycle for that woman. MDE files are submitted using the MDEs tab on the NBCCEDP Resources Web site (<http://www.nbccedp.org>).

(See Resources: Data User's Manual, Data Definition Table, and MDE Field Descriptions.)

## **Developing or Revising Data Forms**

Although they are extensive, the data elements in the MDEs are not intended to reflect a comprehensive picture of all screening services provided at the local, state/territory/tribe, or national level. Indeed, CDC fully expects and encourages grantees to design data systems that capture any additional information they might need to monitor, assess, and manage screening efforts. Such data may include personal identifiers, eligibility information, appointments, billing information, providers, contacts in provider sites, whether or not appointments are kept, types of care, case management done, contact types, referral sources, and how women learned about BCCEDP services.

If grantees design new forms or revise current forms, these forms should be reviewed by the medical advisory board for clinical concerns. They should also be reviewed by CDC and the data contractor; therefore grantees should allow adequate time for these reviews prior to printing and using any new or revised forms.

The following steps are suggested for developing or revising forms:

- The grantee drafts the forms, including all required MDEs. Extra information may be desirable for special interest studies or determining risk factors—but such information should be included only if it will be used (i.e., “if it's only nice to know, it's got to go”). Involving the medical advisory consultants will help to ensure that all necessary clinical information is collected and interpreted accurately.
- The grantee pilot-tests the forms when changes are substantial, soliciting feedback from all involved in the handling and use of forms.



### **Field Example**

*One program redesigned its forms to reflect only MDE items and a few fields necessary for program administration. Providers continue to collect the health histories and other information they need, as usual for patient encounters. This change has been widely accepted among providers because it has reduced data collection time and transcription errors, and it has facilitated a shift in emphasis from data entry to patient care.*

- The grantee revises the forms, on the basis of feedback, and submits the final draft to CDC and CDC data contractor prior to implementation.
- CDC and the data contractor review the forms and make recommendations.
- The CDC program consultant returns feedback to the grantee.
- The grantee develops any supplemental materials and training curriculum needed for the correct use of the new forms.

Basic forms components include the following:

- Informed consent
- Contact information
- Financial status and insurance information
- Relevant medical history
- Breast and cervical screening data
- Diagnostic and treatment data
- Confidentiality statement
- Form version number and date

## RELATED SOFTWARE

Various software packages are available to assist grantees with data collection and editing. The current data contractor, Information Management Services (IMS), has designed the stand-alone MDE Edit

Program specifically for evaluating the completeness and logic of the MDE data. The MDE Edit Program also reports results of critical quality indicators used by CDC to measure a program's success in meeting CDC standards, including timeliness and completeness of clinical follow-up. The MDE Edit Program (and a user's manual) may be downloaded from the NBCCEDP Resources Web site (<http://www.nbccedp.org>). A properly formatted MDE file is required for use with the MDE Edit Program.

(See Resources: *Data Definition Table and Data User's Manual*.)

The CDC contractor also supports CaST, a Windows-based data management system written and maintained for the NBCCEDP. CaST is a screening surveillance and reminder system that was developed to automate data collection and reporting from breast and cervical cancer screening programs. In addition to collecting data, it helps to track women screened for breast and cervical cancer, and it highlights the data items required for the MDEs. CaST has the potential to run as a stand-alone system. The database is "open" to allow linkage with other program databases.

CaST can be used to

- track women with normal examinations,
- generate reminders for the next appropriate screening time, and



### Key Message

*A major obstacle in data collection is the delay that occurs when a clinic does not submit the data collection form in a timely manner. Another common obstacle occurs when submitted data are incomplete or contradictory. Turnover in clinic and data entry staff may cause a disruption in data and forms submission. Simple forms and well-documented processes can help with a smooth transition. Grantees should encourage the training of a "backup" staff member who understands the importance of established routines and can provide support during absences of the primary staff members performing these functions.*

- track women who have abnormal breast or cervical screening examinations to help ensure appropriate diagnostic and treatment follow-up.

CaST has several key features and benefits.

- It performs the following edit checks:
  - Embedded edit checks within the data entry system
  - Edit checks for duplicate clients
- It generates a program mailing list to remind clients when they are due for rescreening.
- It meets all CDC data reporting requirements, including exporting of the MDE data file, and it is updated periodically (free of charge) to accommodate changes in CDC requirements.
- Data can be exported to an ASCII flat file and imported into other software products, such as SAS, Lotus, and Microsoft Excel.
- Data can be entered at local sites (e.g., local health departments) and later moved to a central or regional headquarters site or networked for distributed data entry.
- Data can be stored in either an Access or SQL Server database. If the application and SQL Server database are housed on a secure server, remote users can launch the application via the secure connection (i.e. Citrix server or Wide Area Network). This option also allows the remote sites to only view data from their site/region.
- It includes system reports and query capabilities.
- Although the software does not handle billing and generation of payments to providers, CaST data can be linked with other billing and payment systems.

Although CaST is a good system, CDC does not mandate its use. A grantee may develop a customized data system to meet its specific program needs as long as it has the ability to track women, manage the data, and report data in the required MDE file format. Grantees that develop a customized system need to budget appropriate resources to maintain and upgrade that system.

Grantees should continually assess their software data systems to ensure that they are meeting program needs efficiently and effectively. It is especially important that the software be robust enough to adapt to changes in NBCCEDP requirements and policies. The decision to seek new data management software must balance the unique needs of the program, the cost of developing and maintaining an in-house system, and the suitability of available off-the-shelf software. Data conversions from one system to another are complex, are likely to take 1 to 1½ years to complete, and can be expensive and labor intensive. Grantees are expected to keep CDC and the data contractor fully informed of any plans to develop a new data system and to maintain contact with CDC and the data contractor throughout the development and implementation process. It is essential that all data conversion efforts include a plan to test the MDE export function for accuracy and consistency prior to the next scheduled MDE submission. The data

contractor will process test submissions and provide review and feedback. The test process typically requires more than one iteration to address issues and should be scheduled accordingly.

## DATA QUALITY

Data files submitted to the data contractor are processed and used to create one aggregate file that contains data from all programs. The data contractor creates a set of feedback reports for each grantee program and for the national aggregate, and it compares an individual program's performance to that of all other programs combined. The reports are posted to the NBCCEDP Resources Web site (<http://www.nbccedp.org>) for viewing and retrieval by grantees. A conference call is then scheduled with staff members from each grantee (including the program director, data manager, and other program staff), the CDC program consultant, and the data contractor technical consultant to review the grantee's performance and identify action steps that the grantee must address.

The feedback reports assess the completeness and accuracy of the data, and they document the percentage of abnormal screening results that have complete diagnostic and treatment data, the timeliness of services, adherence to program policy indicators, correlation to expected ranges for clinical results, and selected demographic characteristics of clients. These reports include the following:

- **Frequency report**—a printout of values for selected variables in the raw MDE data submitted to CDC
- **MDE error report**—a summary of records with missing, invalid, and/or illogical data
- **Management report**—a comparison of program-specific data to the overall national program data in the 18 months prior to the screening cutoff date
- **Standard audit reports**—a list of records with follow-up data that are considered high priority
- **Graphs**—graphs of program-specific data with descriptive titles and footnotes
- **Data Quality Indicator Guide (DQIG)**—a summary of timeliness and adequacy of follow-up percentages in the 60 months prior to the screening cutoff date
- **DQIG frequencies**—frequency listings associated with the percentages in the DQIG
- **DQIG core program performance indicators**—table of program performance on priority indicators; histogram of distribution of performance across all grantee programs

(See *Resources: Data User's Manual and the NBCCEDP Resources Web site* [<http://www.nbccedp.org>].)

The DQIG is one of the most useful tools for monitoring the completeness of data collected and the timeliness and adequacy of the services delivered to women screened. The DQIG provides a comparison of program data with benchmarks determined by CDC, and it is set up to easily assess data in comparison with MDE benchmarks:

- Each row of the DQIG contains a specific MDE data element (variable).

- There are columns for three distinct time periods, and percentages for each variable or value are listed for each of the three time periods. The three consecutive time periods provide a total of 5 years of data.
- The far right column lists an expected range for each variable; these percentages are arrived at by consensus of CDC's MDE workgroup, which uses policy, published data, and national data averages to determine these benchmarks.
- Any data from the recorded time periods that fall outside the suggested range are printed in bold type.

The CDC DQIG has set goals for completeness for some variables. As with all data, when a sample size is small (i.e., fewer than 10 for any given reporting period) or when large portions of data are missing, programs *should be cautious about making interpretations*, much less generalizing these data, because of the instability of the estimate.

The DQIG provides, in an easy-to-use format, a way to look at a number of key performance elements over time and compare them to CDC-defined standards. As such, it is easy to see where problems lie. For fully understanding those problems, other reports (such as the DQIG Frequency Report) may also be useful.

## DATA SECURITY AND USE

### *Data Sharing*

Programs should feel free to proactively share data with providers as a way of building stronger partnerships, improving data quality, and enhancing service delivery. In addition, requests for data may come from multiple sources, including providers, the public, local health-related organizations, advocacy groups, elected officials, policymakers, the media, and other stakeholders. Each requestor may have a different understanding of what the NBCCEDP is and what it can provide. Being responsive to these requests is important, both from the standpoint of credibility as well as acceptance and program effectiveness. Programs

### Field Example



*For one program, provider submission of complete and timely data was an ongoing challenge. In 2002, the program implemented a policy that linked payment with submission of required data within 60 to 90 days of the first exam: **Incomplete forms are returned for correction; only correct forms result in payment.***

*This policy has improved timeliness significantly. In 2002, 59% of all forms were submitted and approved for payment within 60 days. In 2003, 62% met this standard, and 2004 data show 75% compliance. In addition, the need for staff members to contact providers for missing information has been greatly reduced.*

### Key Messages



- **Keep data collection forms and submission processes simple.**
- **Standardize training tools and methods.**
- **Highlight common errors regularly; if they persist, consider form or process changes.**
- **Test changes in forms with those who will complete them.**
- **Provide continuous feedback. Good data become their own incentive.**
- **Provide continuous training on data requirements, if needed because of staff turnover.**

should establish a procedure for responding promptly and accurately, with periodic review to ensure that the procedure is working as intended. However, confidentiality issues may conflict with freedom of information issues; thus, programs should establish internal policies for sharing data.

(See the *Policies and Procedures* chapter, PD.2: *Data Sharing*.)

## *Privacy and Confidentiality*

The patient identification (ID) number used in the MDEs must be unique and consistent throughout the entire screening system. It is important, for program purposes, to be able to track women over time. An ID number that is unique only to a provider is not sufficient because it cannot be used to track a patient between providers. Many programs do not have the capability of assigning the same unique identifier to a woman who changes providers. In these programs, matching is routinely done to identify the relatively small number of women who change providers. Date of birth, name, and Social Security number can be used for matching. Using a combination of any or all of these items ensures a greater number of matches.

## *Data Backup and Storage*

Program managers should work with their data managers to establish a reliable system for backing up and safely storing data. Typically, IT units or departments have procedures for such systems. If so, these procedures should be researched and followed. For example, data managers may be required to copy data weekly onto two separate CD-ROMs, putting one copy in an onsite fire-retardant safe box and storing the other copy in a secure offsite location. The issues of how long to keep paper copies of records and how to store them securely are also critical. Grantees should contact internal authorities to determine record retention requirements.

## *Data Use*

There is no point in collecting MDE data if they are not used. MDEs can be highly valuable for program monitoring, quality assurance, and evaluation as well as for communicating program efforts to the public, legislators, and advocates. Regular and thoughtful reviews of data reports can have a significant impact on program direction and effectiveness.

CDC uses the MDEs to routinely report national program results to the general public, through the Web-based NBCCEDP Screening Program Summaries on the CDC public Web site, and to Congress, using a standard set of measures routinely reported through Government Performance and Results Act Report.

(For more information about NBCCEDP Screening Program Summaries, see <http://www.cdc.gov/cancer/nbccedp/data/summaries/>.)



### **Key Message**

***Although a grantee will often be looking at its entire (aggregate) data set, aggregation can obscure problems—and solutions. Programs should develop a system to regularly look at data by provider or region. This will allow the grantee to find the provider who overuses ultrasound, for example, or the contractor doing a great job of recruiting never or rarely screened women.***

To best use its MDE data, a grantee should ask itself the following suggested questions when reviewing those data:

- Are there trends and differences in clinical care or outcomes among providers?
- How do program data compare to national data?
- What is the timeframe for women to complete screening? Is this longer than desired?
- Are projected screening targets being met?
- Are there sites where performance needs to be boosted?
- What are the demographics of women at different sites?
- How many women are lost to follow-up, and are these women (or providers who serve them) similar in some important way?
- What are the rescreening rates at different sites?
- Are benchmarks for the adequacy of follow-up being met?
- Are benchmarks for “lost to follow-up” below acceptable thresholds?
- To what extent does the program reach its eligible population?
- Based on cost projections, has the program reached or exceeded services that can be provided with available resources?

## **LINKING MDEs WITH OTHER CANCER DATA**

At the NBCCEDP’s inception, it was sufficient to concentrate only on MDE data for the women screened in the program. There were, and still are, sufficient data to keep staff busy for months. However, with the program’s evolution and the move toward comprehensive cancer control, MDE data are no longer enough. A higher set of expectations and standards is in order—one that requires grantees to scan additional data sets and to know the environments in which their efforts take place.

MDEs can illuminate who has been served, where screenings have taken place, the timeliness and adequacy of the services, and the outcomes experienced by the women. In addition, they can become an even more powerful tool when compared and combined with population-based information from other sources, such as cancer registries, the U.S. Census Bureau, and the BRFSS.

Linkages with and, in some cases, enhancements of existing cancer surveillance systems and other data sources can help to

- compare women in the NBCCEDP with women throughout states/tribes/territories and the nation regarding early diagnosis, care, and outcomes;
- identify segments of the population at higher risk for disease, as well as populations at risk for not being screened;
- determine where low-income eligible women live;
- analyze screening behaviors to identify groups of women most in need of improvement and to determine where those rarely and never screened women can be found;

- monitor the number, distribution, and quality of breast and cervical cancer screening resources, including mammography facilities, cytology laboratories, and providers who offer diagnostic services.

## *Cancer Registries*

Cancer registries contain information about the occurrence (incidence) of cancer, the types of cancers that occur and their locations within the body, and the extent of cancer at the time of diagnosis (disease stage). These data are reported to a central statewide registry from various medical facilities, including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories. Data collected by state cancer registries enable public health professionals to better understand and address the cancer burden.

State cancer registries are designed to

- monitor cancer trends over time;
- determine cancer patterns in various populations;
- identify cancer clusters;
- guide the planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference);
- help set priorities for allocating health resources;
- advance clinical, epidemiologic, and health services research;
- provide information for a national database of cancer incidence.

Two Federal programs exist to support population-based cancer registries in the United States: CDC's National Program of Cancer Registries (NPCR) and NCI's Surveillance, Epidemiology and End Results (SEER) Program.

NPCR was initiated in 1994, and it encompasses 45 states, the District of Columbia, and 3 U.S. territories, and collects data on cancer for 96% of the U.S. population. The program helps participating entities to

- improve their cancer registries;
- meet standards for data completeness, timeliness, and quality;
- use cancer data to support cancer prevention and control programs;
- train registry personnel;
- establish computerized reporting and data processing systems;
- develop laws and regulations that strengthen registry operations.

The SEER program gathers in-depth data on cancer cases diagnosed in specific state metropolitan areas and several rural/special population areas across the country, representing approximately 28% of the U.S. population. SEER registries submit data to NPCR's state registries. The NPCR and SEER registry programs are designed to be complementary and, together, they collect cancer data for the entire U.S. population.

A third national entity supporting cancer registries is the North American Association of Central Cancer Registries (NAACCR). Established in 1987, NAACCR is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. All central cancer registries in the United States and Canada are members.

Since 1999, CDC, NCI, and NAACCR have combined their data sources for cancer incidence (newly diagnosed cases) to produce a new set of official Federal statistics on cancer incidence from registries having high-quality data. This report—United States Cancer Statistics: 2002 Incidence and Mortality—can be found at <http://www.cdc.gov/cancer/npcr/uscs/>.

(For more information about cancer registries, see <http://www.cdc.gov/cancer/npcr/> and <http://seer.cancer.gov/>; for United States Cancer Statistics inclusion criteria, see <http://apps.nccd.cdc.gov/uscs/>; and for NAACCR certification, see <http://www.naacr.org/>)

### *NBCCEDP Requirements for data linkages with Central Cancer Registry*

In 2009, NBCCEDP and NPCR grantees were required to perform routine data linkages to share information on cancers diagnosed through the screening program, and collect a set of registry data elements to report in the MDEs. A primary objective for the NBCCEDP is to confirm the diagnostic outcomes reported and to acquire standardized data on stage at diagnosis. This linking is important for both evaluating data quality and for evaluating the overall program.

Linking registry and MDE data can help to evaluate data quality by

- identifying cases missing from the cancer registry,
- identifying interval cancers in NBCCEDP clients or cases that may have been missed at screening,
- verifying or correcting data elements related to cancers diagnosed through the program and reported in the MDEs,
- verifying or correcting information about clients in cancer registry records.

Linking registry and MDE data can help with program evaluation by

- comparing demographic characteristics of NBCCEDP and cancer registry cases,
- comparing treatment patterns,
- examining performance measures (e.g., sensitivity, predictive values, recall rates),
- monitoring timing and frequency patterns.

Some suggested steps in comparing MDE and registry data are for grantees to



#### **Key Message**

***The overall goal is to make the cancer registry—and the MDEs—as complete and robust as possible. Each grantee should take ownership of the quality of data, look for missing elements and discrepancies, and act boldly to fix them. Identifying and fixing data errors should be considered a strength—not a weakness.***

- develop a protocol for conducting linkages and reconciling records; document the plan in writing so that all individuals involved will know who is to do what and by when; and include in the plan steps for preventing the problem from arising in the future;
- develop a relationship with the cancer registry program;
- contact the appropriate provider as needed;
- agree on a joint course of action;
- follow up to be sure that the plan was carried out as intended and that the problem has been resolved.

### *CDC's Behavioral Risk Factor Surveillance System*

The BRFSS is the largest continuously conducted telephone health survey in the world. States use BRFSS data to identify emerging health problems, to establish health objectives and track their progress toward meeting them, and to develop and evaluate public health policies and programs. The BRFSS is the primary source of information for states and the nation on the health-related behaviors of adults. States use standard procedures to collect data through monthly telephone interviews with adults 18 years or older. BRFSS interviewers ask questions related to behaviors that are associated with preventable chronic diseases, injuries, and infectious diseases, such as having ever had a mammogram or a Pap test, or having had one recently. With appropriate funding, BRFSS programs can collect and report data in a number of ways (e.g., by county, by oversampling particular populations). Grantees should know who oversees the BRFSS in their area.

(For more information about the BRFSS, see <http://www.cdc.gov/brfss/about.htm>.)

### *U.S. Census Data*

The U.S. Census Bureau's Small Area Health Insurance Estimates (SAHIE) program produces estimates of health insurance coverage for states and all counties. As of 2008, SAHIE released annual estimates of health insurance coverage by age, sex, race, Hispanic origin, and income categories at the state-level and by age, sex, and income categories at the county-level. This program is partially funded by the CDC to provide these estimates within low-income categories defined at 200% and 250% of the federal poverty levels to assess the NBCCEDP eligible population. SAHIE now includes two new income-to-poverty-ratio categories (138%, 400%) reflective of the Health Care Reform initiative. The Affordable Care Act helps families gain access to health care by allowing Medicaid to cover families with incomes less than or equal to 138 percent of the federal poverty line. Families with incomes above the level needed to qualify for Medicaid, but less than or equal to 400 percent of the poverty line can receive tax credits that will help them pay for health coverage in the new health insurance exchanges.

(For more information about the SAHIE, <http://www.census.gov/did/www/sahie/index.html>.)

### *Geographic Information Systems*

With GIS software, users can map a variable or variables by geographic area. Maps can be overlaid to show bivariate distributions, helping to visualize areas of interest. For example, GIS can depict areas in a state

with high cancer mortality rates and then overlay those with locations of screening providers; using these maps, the program can more accurately determine where new providers should be located, or where recruitment and referral efforts to existing sites should be concentrated.

(For an example of interactive map use, see SAHIE website referenced above)

## State Cancer Profiles

State cancer profiles can be used to analyze the cancer burden for the nation, a state, or a county. Such profiles help to identify high-risk populations and prioritize cancer control efforts. The State Cancer Profiles Web site brings together data that are collected from public health surveillance systems to provide state-level and, where possible, county-level statistical data in a variety of formats. Using this Web site, program staff can manipulate tables, graphs, and maps to get needed data. Data are included from cancer sites for which there are prevention services and/or effective screening and treatment services. Since 2003, CDC has been collaborating with the U.S. Census Bureau to develop estimates and will share them with grantees when they are available.



### Key Messages

- **Programs should anticipate confidentiality issues when establishing record linkages with other databases.**
- **Delays in tumor registry reporting may pose challenges to linking MDEs with registry data.**

(For more information about state cancer profiles, see <http://cancercontrolplanet.cancer.gov>.)

## TECHNICAL ASSISTANCE AND TRAINING

CDC contractor provides data management technical assistance to the NBCCEDP and to deliver a high-quality national program data set. The contractor provides a wide range of technical assistance support to the NBCCEDP and grantees. Each grantee program is assigned a technical consultant to assist with MDE-related questions or concerns. Programs needing assistance or consultation may contact their consultant directly by telephone or e-mail. This service is available to programs at no additional cost.

### Role of CDC Contractor in Support of the NBCCEDP

- Manage the semiannual MDE submission and feedback process
  - Provide infrastructure to receive and protect data submissions through a secure Internet site
  - Process the MDE data, create an aggregate analysis data set, and provide standardized feedback reports to CDC and grantees
  - Perform data quality reviews, provide written feedback on each submission, and participate in conference calls with CDC and grantee staff to discuss the data
- Maintain, enhance, and distribute software and reference tools for collecting, reporting, and validating the MDEs
  - NBCCEDP Data User's Manual (MDE reporting specifications)
  - CaST data management system, with user's guide

- MDE Edit Program, with user's manual
- Provide grantee programs with training and technical assistance related to MDE data collection and reporting
  - Review and provide comments on data collection forms
  - Conduct MDE orientation training
  - Provide guidance on translating clinical data to an MDE screening cycle
  - Provide technical support and training for the CaST data management system and MDE Edit Program
  - Provide guidance for conducting data management system conversions
  - Perform MDE file comparisons for grantees transitioning to new data management systems
  - Respond to daily technical assistance requests
- Communicate routinely with CDC and grantee program staff
  - Participate in site visits to grantee programs
  - Participate in conferences and annual business meetings for program directors, data managers, and quality assurance coordinators
  - Participate in Web conferences
  - Manage a listserv for data managers
- Support the NBCCEDP Resources Web site (<http://www.nbccedp.org>), which is used by grantees to submit MDE data to CDC contractor/CDC and by CDC to distribute the following:
  - NBCCEDP resources focused on data management
  - Software and resource documents, including files from past meetings and Web conferences
  - Program-specific documents and MDE feedback reports
  - News and information related to data management

## COMMUNICATION FORUMS

Several opportunities have been created throughout the year to address data issues within the program or for data managers to convene, exchange information, develop skills, learn new techniques, and build networks.

- **Annual data managers meeting**—Data managers from all grantees are required to attend this annual business meeting, which provides them with an opportunity to network, share the results of data usage, and present program experiences and updates. This meeting may be held in conjunction with the annual program directors business meeting.
- **Web conferences**—CDC schedules Web conferences on an as-needed basis. These are announced in advance to program staff through blast e-mails that describe the presentation topic and intended audience. Conferences related to data management are attended by CDC, program, and data contractor data management staff and, optionally, grantee program directors and CDC program

consultants. These conferences offer an opportunity for CDC to provide training, share details of new requirements or program updates, and address comments from the audience. Data management Web conferences focus on topics such as MDE orientation, new MDE reporting requirements, and data contractor technical support updates. Most Web conferences are recorded and made available for replay at any time. Recorded conferences are available on the NBCCEDP Resources Web site (<http://www.nbccedp.org>).

*(See Attachment A: Data Management Orientation Web Conferences.)*

- **Correspondence through letters/e-mails on data issues**—Important issues, such as modifications to the MDE data definition or major program changes, are addressed to program directors.
- **MDE committee**—An internal committee was created early in the NBCCEDP’s existence, consisting of interdisciplinary representatives from across CDC’s Division of Cancer Prevention and Control, including medical advisors, epidemiologists, program consultants, certified tumor registrars, data contractor technical consultants, and individuals from other scientific and program disciplines. The original intent of the committee was to clarify the purpose and uses of the MDEs, identify data to be reported in the MDEs, and establish quality standards and measures. The committee has continued to meet regularly to discuss relevant and emerging topics, such as adding new data elements and reviewing requests for research and evaluation with MDEs.

## EVALUATING DATA MANAGEMENT

Programs must evaluate their data management systems in order to ensure that the data produced by those systems can be used to evaluate the quality of program services delivered. Assessment of the data management component encompasses three major areas:

- **Data quality**—Grantees are expected to establish and maintain a data system to collect, edit, manage, and continuously improve the data needed to track a woman’s receipt of screening/rescreening, diagnostic, and treatment services. They are also charged with establishing mechanisms to review and assess the completeness, accuracy, and timeliness of those data. Thus, program directors should evaluate the extent to which such systems and mechanisms exist and examine the quality of the data produced by them.
- **Data security**—Grantees are required to establish protocols to ensure the security and confidentiality of all data collected. Evaluation of the existence and effectiveness of these protocols helps to ensure that they are operating as intended.
- **Data use**—Grantees are responsible not only for producing valid data but also for ensuring that these data are shared and used by those who can affect service delivery. Data management evaluation should investigate the program’s effectiveness in providing meaningful data to relevant BCCEDP staff members, medical advisory consultants, service providers, and others and in supporting their interpretation and use of those data in improving program outcomes.

## *Measurable Objectives*

Data management evaluation should be guided by specific and measurable objectives that reflect a program's interests and priorities. Some suggested objectives are the following:

### Data Quality

- By [date], data systems to track services provided will be fully operational.
- From [date] to [date], the number of program data errors will be reduced from \_\_\_\_ to \_\_\_\_.

### Data Security

- By [date], protocols will be adopted by all providers to protect confidentiality of shared data.

### Data Use

- By [date], all providers will receive regular feedback on their performance.
- From [date] to [date], the number of requests for MDE data will be increased from \_\_\_\_ to \_\_\_\_.

## *Evaluation Questions*

Once a program establishes measurable objectives for data management, each of those objectives should be converted into a set of evaluation questions. Having identified these questions allows grantees to determine the best process for collecting the data needed to answer them. The following table shows examples of evaluation questions for data management and suggested methods for answering those questions.

In evaluating data management, a program should start with some evaluation questions related to the objectives and measures of success for data management described in its BCCEDP work plan. Then the program should consider other questions of interest that were not included in the work plan.

EVALUATION QUESTIONS	USES OF EVALUATION FINDINGS	PROCESSES	DATA COLLECTION STRATEGIES
Is data quality improving over time? Are data errors decreasing?	<ul style="list-style-type: none"> <li>Determine data errors that continue to occur</li> <li>Identify causes of data errors (e.g., specific data elements or providers)</li> <li>Suggest possible remedies to improve data quality</li> </ul>	<ul style="list-style-type: none"> <li>Review current data error reports</li> <li>Compare current data error reports with comparable reports from prior time periods</li> <li>Keep a log of major data errors and note changes over time</li> <li>Give feedback to providers on data quality and error issues</li> </ul>	<ul style="list-style-type: none"> <li>Use error reports generated as part of standard program requirements</li> </ul>
Are protocols in place to protect confidentiality when sharing data?	<ul style="list-style-type: none"> <li>Ensure that data are shared for research purposes according to CDC policy</li> </ul>	<ul style="list-style-type: none"> <li>Define protocols</li> <li>Share protocols with researchers</li> </ul>	<ul style="list-style-type: none"> <li>Survey researchers and program staff to determine the process used for sharing data</li> </ul>
Are data being requested and used?	<ul style="list-style-type: none"> <li>Identify major data users</li> <li>Determine ways of improving data utility</li> </ul>	<ul style="list-style-type: none"> <li>Keep a log of requests for data</li> <li>Analyze major types of requestors and requests</li> </ul>	<ul style="list-style-type: none"> <li>Survey potential groups of data users to elicit feedback on data usefulness</li> </ul>

Additional questions to consider include the following:

### Data Quality

- In what ways does the program ensure that data are accurate? What data quality assurance measures are in place?
- What staff members are responsible for monitoring the quality of these data?
- What protocols are in place to correct problems that arise with regard to data quality?
- Are there discrepancies between the data elements in the MDEs and those in the cancer registry (in terms of stage, tumor size, and/or date of treatment initiation)? How promptly are they addressed?
- Do providers receive feedback on their performance?
- Are errors in completing forms being identified and reduced?
- Are errors in data entry decreasing over time?
- Are errors in the computer programming system being identified and addressed promptly?

### Data Security

- Are systems in place to promptly identify and resolve breaches of confidentiality?
- How frequently are concerns about confidentiality raised?

### Data Use

- How frequently are requests for data received?
- Is the medical advisory board asking questions about and using the MDE data set?
- Are program staff members asking for the latest MDE runs?

- What is the ratio of staff time spent on data collection vs. use, and is this ratio appropriate?  
It is important to evaluate the process of data management in order to improve the completeness, quality, validity, and usefulness of the data for program decision-making.

### III. KEY RESOURCES

<b>NBCCEDP</b>
<a href="http://www.cdc.gov/cancer/nbccedp/index.htm">http://www.cdc.gov/cancer/nbccedp/index.htm</a>
<b>NBCCEDP 1991–2002 NATIONAL REPORT</b>
This report is the most comprehensive publication on the NBCCEDP. It summarizes the first 12 years of the program and provides information on the program’s framework, history, and future direction in addition to data on breast and cervical cancer screening outcomes for women served through the program.  <a href="http://www.cdc.gov/cancer/nbccedp/pdf/national_report.pdf">http://www.cdc.gov/cancer/nbccedp/pdf/national_report.pdf</a>
<b>NBCCEDP SCREENING PROGRAM SUMMARIES</b>
This report to the general public provides information on the most recent 5 years of grantee-specific and national aggregate data on clinical services provided through direct NBCCEDP Federal funding.  <a href="http://www.cdc.gov/cancer/nbccedp/data/summaries/">http://www.cdc.gov/cancer/nbccedp/data/summaries/</a>
<b>UNITED STATES CANCER STATISTICS: 2002 INCIDENCE AND MORTALITY</b>
<a href="http://www.cdc.gov/cancer/npcr/uscs/">http://www.cdc.gov/cancer/npcr/uscs/</a>

### IV. OTHER RESOURCES

- Data Definition Table (MDEs) (on NBCCEDP Resources Web site, <http://www.nbccedp.org>)
- Data User’s Manual (on NBCCEDP Resources Web site, <http://www.nbccedp.org>)
- MDE Edit Program Manual (on NBCCEDP Resources Web site, <http://www.nbccedp.org>)
- MDE Field Descriptions (on NBCCEDP Resources Web site, <http://www.nbccedp.org>)
- NBCCEDP Data Profile (on NBCCEDP Resources Web site, <http://www.nbccedp.org>)
- Data Management Orientation Web Conferences (Attachment A)
- MDE Submission and Feedback Cycle Calendar (Attachment B)

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\* Because of the evolving nature of the Internet, Web sites noted here may no longer exist. In such cases, a global Internet search or search from the noted entity’s homepage may be needed to locate specific documents and resources.

# ATTACHMENTS

# **ATTACHMENT A**

## **DATA MANAGEMENT ORIENTATION WEB CONFERENCES**

The following sessions related to data management are available through Web conference replay files, accessible at the NBCCEDP Resources Web site (<http://www.nbccedp.org>). New sessions will be added as they become available.

### **MDE ORIENTATION**

Three sessions present a comprehensive orientation to MDE data collection and reporting:

- MDE Orientation Session 1, Overview of the Web Conference Series, MDEs, and Screening Cycles
- MDE Orientation Session 2, Submission Requirements and Feedback Reports
- MDE Orientation Session 3, Maintaining a Screening, Tracking, and Follow-up Program

### **MDE ALGORITHMS**

Technical presentations describe the algorithms commonly used in MDE feedback and reporting:

- Standard terminology and algorithms used by CDC/CDC data contractor to quantify services funded through the program (e.g., women screened, women served, screening tests provided)
- Algorithms used to compute DQIG core indicator percentages
- Hypothesis test used in determining if the CDC performance standard was met on DQIG core indicators

# **ATTACHMENT B**

## MDE SUBMISSION AND FEEDBACK CYCLE CALENDAR

EVENT	TIMEFRAME
<p>Grantees submit MDEs to data contractor:</p> <ul style="list-style-type: none"> <li>■ Cumulative file of MDE records through designated cutoff dates*</li> <li>■ Submission narrative</li> </ul> <p>* Cutoff dates:</p> <ul style="list-style-type: none"> <li>■ April submission (screening data through December 31; diagnostic data through June 30)</li> <li>■ October submission (screening data through June 30; diagnostic data through December 31)</li> </ul>	Semiannually: April 15 and October 15
Data contractor performs preliminary data quality checks to ensure that the data meet minimum standards for inclusion in the national program analysis data set.	Immediately after submission
Data contractor prepares a SAS analysis data set and generates feedback reports.	After submission
<p>Data contractor provides submission feedback to programs and CDC:</p> <ul style="list-style-type: none"> <li>■ Feedback reports</li> <li>■ SAS analysis data set</li> </ul>	3 months after submission
<p>CDC, data contractor, and the grantee conduct the data review process:</p> <ul style="list-style-type: none"> <li>■ The program consultant schedules a data conference call with program staff and data contractor</li> <li>■ The data contractor technical consultant performs a data quality review and distributes data notes for review prior to the call.</li> <li>■ A conference call is held to discuss data issues, critical performance indicators, and data notes.**</li> <li>■ The program consultant sends a follow-up letter to summarize the discussion and a list of action items for the program to address and comment on in the subsequent submission narrative.</li> </ul> <p>** The data conference call is required only once a year, after the April submission. A call is also held after the October submission, if necessary because of new program or CDC staff members, data issues, or system changes or because it was requested by the program. Data notes and action items are prepared for all submissions.</p>	1 to 6 weeks after reports are available
The grantee follows up on action items and documents the response in the submission narrative that accompanies the next MDE submission.	Through end of cycle
The cycle starts over again.	



Centers for Disease Control and Prevention  
National Center for Chronic Disease  
Prevention and Health Promotion  
Division of Cancer Prevention and Control  
Program Services Branch  
770-488-4880



# NBCCEDP Program

# Guidance Manual

Quality Assurance/Quality Improvement

Version 2

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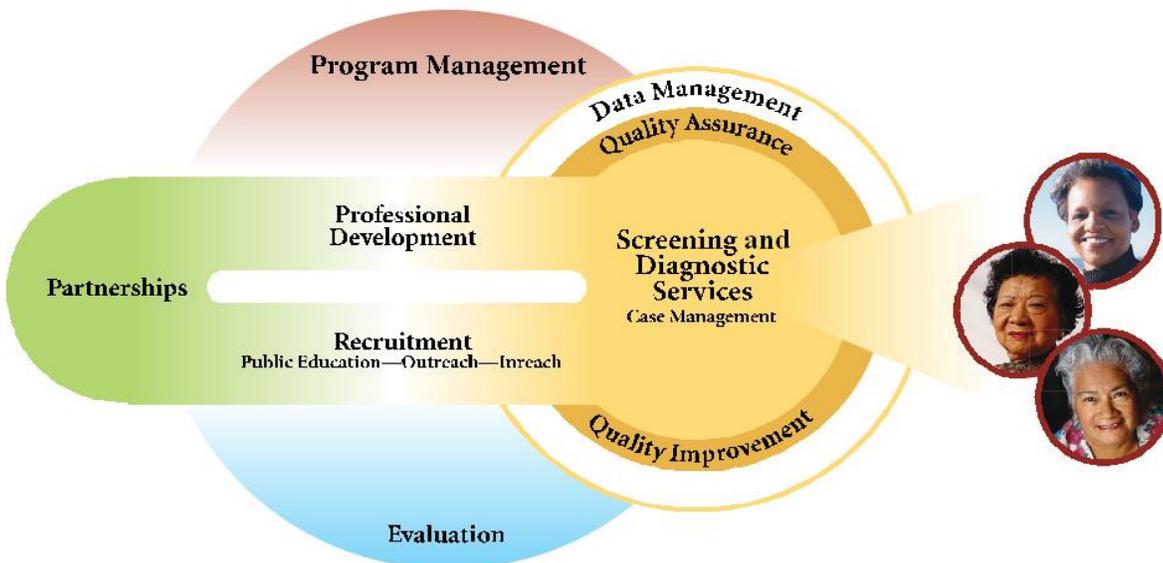
# I. INTRODUCTION

## OVERVIEW OF THE CHAPTER

This chapter provides guidance on how to monitor, assess, and improve the quality of the clinical services provided through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This will help to ensure that programs meet benchmarks outlined in the data quality indicator guide (DQIG) of the NBCCEDP minimum data elements (MDEs).

## CONCEPTUAL FRAMEWORK

The Quality Assurance (QA)/Quality Improvement (QI) component is represented as an inner circle within the NBCCEDP Conceptual Framework to show its direct connection to the Screening and Diagnostic Services component. It works in concert with the Data Management and Evaluation components to monitor, assess, and improve program outcomes. Quality Assurance is on the top, representing the program management responsibility of assuring quality care. Quality Improvement is on the bottom, showing its proximity to evaluation.



## PURPOSE OF QUALITY ASSURANCE AND QUALITY IMPROVEMENT

The purpose of quality assurance and improvement is to

- ensure the quality of services delivered through the NBCCEDP,
- monitor performance and identify opportunities for improvement, and
- plan effective strategies for improving services.

## **DEFINITION OF QUALITY ASSURANCE AND QUALITY IMPROVEMENT**

Quality assurance and quality improvement assures the quality of clinical services. QA is the process of monitoring the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. QI is the commitment and approach used to continuously improve every process in every part of an organization, with the intent of meeting and exceeding customer expectations and outcomes.

## **ESSENTIAL ELEMENTS OF QUALITY ASSURANCE AND QUALITY IMPROVEMENT**

To meet the NBCCEDP's expectations for QA/QI, a grantee should do the following:

- work with medical advisory board to oversee the quality of clinical services being delivered;
- ensure that program providers use established clinical practice guidelines and protocols that have been reviewed and endorsed by the medical advisory board;
- establish a system for monitoring program services to identify potential problems and/or best practices;
- regularly assess data for opportunities to improve outcomes for women served by the program; and
- initiate improvement strategies and ensure a continuous cycle of monitoring until outcomes demonstrate that improvement has been sustained.

## **COMPETENCIES NEEDED TO IMPLEMENT QUALITY ASSURANCE AND QUALITY IMPROVEMENT**

Staff members responsible for QA/QI need the ability to

- collaborate with the medical advisory board and other professional experts as necessary and
- provide feedback and reports designed to maintain or improve clinical outcomes.

Staff members responsible for QA/QI will need knowledge in

- how to use the NBCCEDP MDEs to identify problems and monitor outcomes of quality improvement interventions,
- data collection and analysis,
- breast and cervical cancer screening and diagnostic protocols,
- tools for monitoring, assessment, and improvement.

## **II. WHAT IS QUALITY ASSURANCE/QUALITY IMPROVEMENT?**

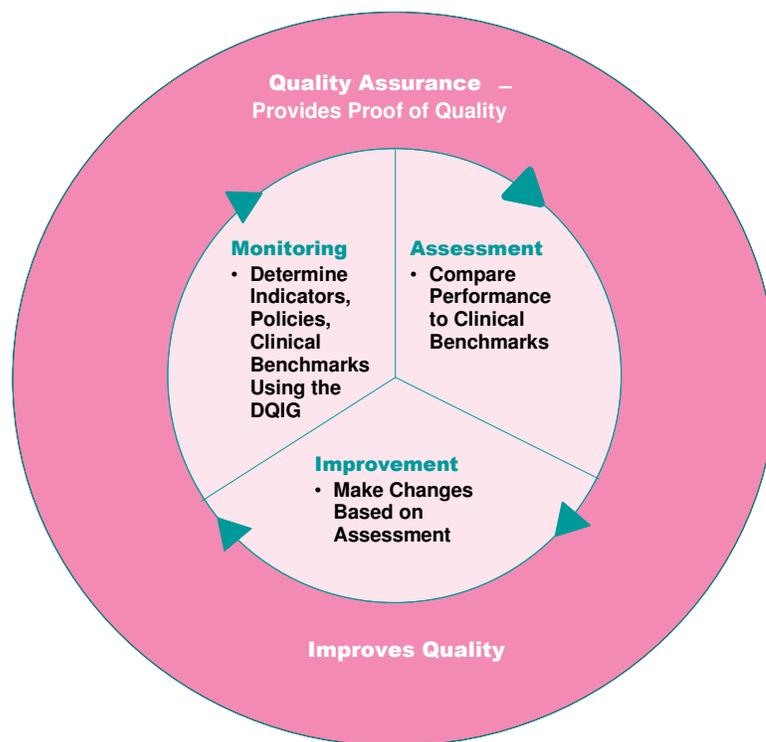
## THE NBCCEDP QUALITY ASSURANCE/QUALITY IMPROVEMENT MODEL

The NBCCEDP QA/QI model (Figure 1) blends QA and QI to ensure the delivery of quality services. Together, they aim to

- improve screening and diagnostic services;
- link structure and process and include standards, measurement, and actions;
- identify and remedy root causes of quality problems;
- meet customer needs;
- focus on high-volume, costly, high-risk, or problem-prone aspects of care as priorities.

These aims are achieved by assessing performance, making changes on the basis of assessment, and monitoring improvement. Activities that ensure quality services must maintain patient confidentiality.

**Figure 1. The NBCCEDP Quality Assurance/Quality Improvement Model**



**Quality monitoring**—This is the planned, systematic, and ongoing collection, compilation, and organization of data about the quality or appropriateness of an important aspect of care, as well as the

comparison of those data to a predetermined level of performance to determine the need for evaluation. The NBCCEDP DQIG is designed specifically for this purpose and represents aspects of care that CDC thinks are important to monitor.

**Quality assessment**—This is the measurement of the level of quality at some point in time. Assessing quality provides organizations with an opportunity to measure performance against standards (or benchmarks). Assessment creates a bridge between monitoring and improvement by establishing a common understanding of the quality of services provided and identifying opportunities for improvement. In setting priorities, assessment of clinical services is a key activity. Quality assessments above and beyond the DQIG parameters (e.g., client satisfaction, availability of provider appointments) also may be done on a periodic basis.

**Quality improvement**—This is the commitment and approach used to improve every process in every part of an organization continuously with the intent of meeting and exceeding customer expectations and outcomes. QI strives to find strategies that will institute a change and continuously improve quality.

## FOCUS ON QUALITY

CDC recommends that programs use a QI model to assess quality at a given time and plan strategies to improve outcomes. One useful model—FOCUS on Quality—has been used by many grantees. This model (Figure 2) uses five steps to address problems that have been identified in the quality assessment process.

**Figure 2. FOCUS on Quality**

<b>F</b>	<b>FIND A PROCESS TO IMPROVE</b>
<b>O</b>	<b>ORGANIZE A TEAM THAT KNOWS THE PROCESS</b>
<b>C</b>	<b>CLARIFY CURRENT KNOWLEDGE OF THE PROCESS</b>
<b>U</b>	<b>UNDERSTAND CAUSES OF VARIATION IN THE PROCESS</b>
<b>S</b>	<b>SELECT THE PROCESS IMPROVEMENT</b>

**Find a process to improve**—The first step involves identifying which processes to improve. Grantees should use MDE data to determine which service delivery activities or processes need improvement.

**Organize a team that knows the process**—The grantee’s QI team should be composed of key individuals who perform different job functions and are closely involved in the process. For example, if the process that needs improvement is related to accuracy of data, data management staff need to be involved on the team.

**Clarify current knowledge of the process**—It is common for people to feel confident that they know how clinical services are delivered; however, the actual process may have changed over time and no longer match established procedures. Documenting the current process ensures a common understanding among all members of the QI team and enables a comparison between the actual process of care and the ideal process. A flowchart is a useful tool for clarifying steps in an existing process.

**Understand causes of variation in the process**—This may require gathering additional structure, process, and outcome data to understand the causes in variation. Flowcharts, cause-and-effect diagrams, and data drawn from representative samples are all common methods for understanding variation. Less common, but equally useful, methods include telephone interviews, site visits, and chart audits.

**Select the process improvement**—The results of steps F, O, C, and U should be used to draw conclusions about the root cause(s) of variation. From these identified causes, the QI team should select one cause that actually can be changed and then design a plan of action to make the change. The team would then implement and test the change to see if it achieves the desired results.

### *Plan-Do-Study-Act Cycle (PDSA)*

The PDSA cycle (Figure 4) is a “trial-and-learning” method for testing changes quickly to see how they work. The PDSA cycle is a scientific method for testing and implementing changes in real work settings. It guides the test of a change to determine whether the change is an improvement by planning it, trying it, observing the results, and acting on what is learned. Test cycles are repeated until they produce the desired results. This method differs slightly from the FOCUS method, but it is as effective.

**Form the team**—Including the right people on a process improvement team is critical to a successful improvement effort. Although teams vary in size and composition, QI literature suggests that teams be composed of those closest to the problem. Different problems require different teams. For example, the team formed to improve the problem of time delays between finding an abnormal Pap test result and appropriate follow-up could include a general practitioner, the office secretary, the laboratory staff member who reads and reports Pap test results, and the case manager. Yet a slightly different team would be needed if the problem were a higher than expected number of women refusing breast cancer treatment after being diagnosed.

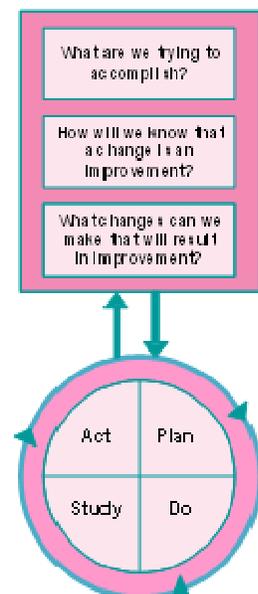
The PDSA model suggests asking three questions to guide the improvement process:

**What are we trying to accomplish?** The grantee should review objectives, background information, numeric goals, and scope of effort and timeframe (e.g., “reduce the time it takes from abnormal test results to final diagnosis by 50%, from 40 to 20 days, within 1 year”).

**How will we know that a change is an improvement?** The grantee should identify what will be inspected before and after the change intervention and focus on indicators that are important to the program and its clients. Grantees also should keep measures few in number and look for immediate results.

**What changes can we make that will result in improvement?** The grantee should brainstorm for ideas to improve the process. Program staff members should consult with others about their processes, especially

**Figure 4.**  
**PDSA Model**



leaders (benchmarks) in the field. Many changes include simplifying procedures, minimizing the unnecessary delegation of key tasks, and standardizing protocols.

## *Plan and Test*

After answering these three questions, programs should implement proposed solutions in an incremental fashion, being sure to test the interventions before institutionalizing the change.

### Step 1: Plan

The program should plan the test or observation, then do the following:

- State the objective of the test
- Make predictions about what will happen and why
- Develop a plan to test the change (Who? What? When? Where? What data need to be collected?)

### Step 2: Do

The program should try out the test on a small scale. The program then should do the following:

- Carry out the test
- Document problems and unexpected observations
- Begin analysis of the data

### Step 3: Study

The program should set aside time to analyze the data and study the results before doing the following:

- Complete the analysis of the data
- Compare the data to predictions
- Summarize and reflect on what was learned

### Step 4: Act

The program should refine the change on the basis of what was learned from the test, then do the following:

- Determine what modifications should be made
- Prepare a plan for the next test

## *Implement Changes*

After testing a change on a small scale, learning from each test, and refining the change through several PDSA cycles, the program is ready to implement the change on a broader scale—perhaps for a pilot population (e.g., women over 40 with abnormal Pap tests) or an entire unit (e.g., all women with abnormal Pap tests). At this point, implementation represents a permanent change in the way work is done, and as such, it involves building the change into the organization. It may affect documentation, written policies,

hiring, training, compensation, and aspects of the organization's infrastructure that were not relevant in the testing phase. Implementation also requires the use of the PDSA cycle.

### *Spread Changes*

After successfully implementing a change for a pilot population or an entire unit, the program should consider expanding the change to other parts of the organization or in other organizations (e.g., spreading a tracking tool to all providers after a pilot with a select group of providers). For example, a program can facilitate a smooth expansion effort by building on the lessons learned from implementation; these lessons may involve key infrastructure issues, optimal sequencing of tasks, and how to work with people to help them adopt and adapt to a change.

### *Common Quality Assurance and Quality Improvement Tools*

Programs should consider using the following QA/QI tools, as identified in the FOCUS on Quality:

**Benchmarking**—Setting benchmarks is a way of establishing a goal and measuring progress toward that goal. Core indicators in the MDEs are examples of benchmarks.

**Brainstorming**—This is a technique for eliciting a list of ideas or questions from a group without engaging in debate, discussion, or value judgments (e.g., brainstorming the causes of variation in a process). This technique can be very useful in generating possible courses of action to address identified problems.

**Cause-and-effect diagram**—This tool provides a visual display (often referred to as a fishbone diagram) for helping to identify and illustrate relationships between a problem and perceptions about the causes or factors that may be contributing to it. It is useful in making sense of information gathered during brainstorming sessions or focus groups.

**Checklist**—This is a form designed with checkboxes to make data collection or recording easier and more standardized (e.g., a chart review tool).

**Flowchart**—This is a diagram that is used to visually portray sequential steps in a process leading to various outcomes, depending on the path taken (e.g., the screening process shown).

**Focus group**—This is an information-gathering technique using small group discussion to identify the participants' range of views about a specific topic. The facilitator of the focus group needs to be neutral on the topic and solicit everyone's opinion in a nonjudgmental manner.

**Log**—This is a simple chronological record that tracks a sequence of events, problems, or procedures (e.g., attempts to contact women who need follow-up appointments).

(For more explanation on common quality control tools, see <http://asq.org/learn-about-quality/seven-basic-quality-tools/overview/overview.html>.)\*

## **BENEFITS AND COSTS**

### *Benefits of QI*

Key benefits of QI include the following:

- Ensures consistent and optimum health care
- Makes the screening and diagnostic process a more positive experience for the clients
- Makes women feel important, and reinforces the importance of clients taking care of themselves

- Expands the number of clients
- Makes clients more apt to come back

## *Cost of QA/QI*

The benefits of QA/QI come with a price. Costs include the staff time and resources necessary to conduct QA/QI activities. Quality costs include the following:

**Prevention costs**—These costs are related to activities conducted to prevent errors. These activities may include planning, data systems monitoring, professional development, assessment of client and provider needs, and work performed by quality management staff.

**Monitoring costs**—These costs are generated by monitoring and inspecting activities that determine the extent to which a service meets program requirements. Monitoring costs in the NBCCEDP include data management, clinical service QI, and systems that transmit clinical outcomes data from the provider to program staff for tracking, follow-up, case management, and rescreening.

**Internal failure costs**—These costs are associated with the correction of defective services and may include correcting incomplete or inaccurate data.

**External failure costs**—These costs are incurred when the client receives a defective service and may include incorrect diagnosis, inappropriate follow-up, or follow-up of client complaints.

It has been estimated that close to 30% of health care expenditures could be saved and shifted to patient care services. For example, the expense associated with training providers to complete data forms accurately can be more cost-effective than the expense of staff time needed for conducting a retrospective “data cleanup” to identify incomplete data.

## *QI Stakeholders*

Understanding the perspectives of stakeholders will help guide the development of the program’s QI process. An important concept of QI models is to identify the stakeholders for the quality of services rendered by the program. These stakeholders include

- **Congress**, which determines the annual resource allocation to the NBCCEDP;
- **Centers for Disease Control and Prevention (CDC)**, which administers the program;
- **grantees**, which conduct and facilitate program activities;
- **providers**, who serve the women;
- **clients**, who receive the services; and
- **partners**, which support the program.

Stakeholders may have distinctly different views of quality. From the program perspective, quality includes the degree to which screening and diagnostic services are effective in detecting cancer at an early stage. From the provider perspective, quality includes the degree to which screening and diagnostic services meet best practice standards that result in optimal outcomes. From the consumer perspective, quality includes

the degree to which symptoms (physical and emotional) are relieved, questions are answered, and the client is treated with sensitivity and respect.

### III. STRUCTURE FOR QUALITY ASSURANCE AND QUALITY IMPROVEMENT

#### QA/QI WORKPLANS

Some grantees choose to maintain all of their QA/QI activities at the state, tribal, or territorial level, administered by program staff. Other grantees decentralize some of their QA/QI activities and have contractors manage them at a regional level.

Regardless of the structure of activities, the specific work plan for QA/QI should be delineated in the annual NBCCEDP work plans. DQIG monitoring and assessment may reveal a number of quality problems from which the program can choose for work plan objectives. Programs should prioritize their QA/QI activities on the basis of resources and other factors, such as the environment of the provider network (e.g., another entity may be working on the problem). A useful way for programs to determine priorities is to identify which problems are high volume (justifying resource investment), prone to problems (justifying analysis of system deficiencies), high risk (justifying investments in risk management), and/or high cost (justifying streamlining of the process for cost savings).

#### MEDICAL ADVISORY BOARD

CDC expects grantees to actively solicit and incorporate medical advice from a group of medical advisors in the area of breast and cervical cancer. This group also can assist grantees by approving practice guidelines and providing oversight for the quality of the services delivered.

Grantees should consult with providers who have appropriate experience and expertise with the processes of screening, diagnosis, and initiation of treatment. Since many providers work together to offer a complete referral network for screening and diagnostic services, it is optimal for grantees to convene a multidisciplinary team composed of members who can each bring insight, evidence, and experience from his or her unique perspectives and involvement with clients.



#### Field Example

*One NBCCEDP grantee partnered with a peer-review organization to conduct annual evaluations of clinical data in both the medical records and their database, assess adherence to QI indicators for timeliness and appropriateness, provide QI training, and assist coordinators in identifying opportunities for improvement.*



#### Field Example

*One NBCCEDP grantee obtained medical consultation from a Cervical Advisory Committee and a Breast Advisory Committee. The Cervical Advisory Committee worked with the grantee on the updates to the Pap Test Form following the Bethesda reporting changes and on the use of ThinPrep® Pap tests. The Breast Advisory Committee worked with the grantee on its policies regarding abnormal CBEs.*

The potential functions of the medical advisors will vary, depending on program priorities and resources, but they may include the following:

**Approve practice guidelines for screening and diagnostic services**—This function, mandated by CDC, ensures that regional peers and colleagues familiar with the provider networks establish practice guidelines that are consistent with CDC’s requirements, yet adapted to regional standards and resources. Protocols should be reviewed periodically to ensure that they remain current with evidence-based, as well as meet CDC requirements.

**Provide clinical consultation**—Although programs have established general clinical guidelines, appropriate exceptions to the guidelines should be considered. A program should rely on its medical advisory board to provide clinical consultation and advice in problematic or unforeseen circumstances.

**Provide professional development recommendations**—Medical advisory boards are in a key position to identify professional development strategies that address concerns related to quality, and they also have insights about the professional development design and method that most suit their colleagues.

## CONFIDENTIALITY

Confidentiality must be maintained in the QA/QI process to ensure that identifying information related to clients and providers is protected. Reports released to the public should use aggregate (summary) data. Programs should release client and provider data only after a careful consideration of confidentiality issues and then only after identities have been removed. Deleting client names is mandatory. To protect confidentiality, programs should do the following:



**Key Message**

*A program must follow HIPAA guidelines and its agency (e.g., health department) regulations for confidentiality.*

- Develop and use a confidentiality protocol that guides staff members who collect, transmit, or report confidential data
- Use aggregate (summary) data in reports instead of “singling out” providers or clients
- Use codes or delete client and provider names when referring to specific examples
- Stamp or label all confidential documents accordingly
- Ensure that staff members and volunteers have appropriate HIPAA training

## IV. QA/QI METHODS

### *Categories of Data*

In QA/QI, data are used for monitoring problems, assessing the nature of any concerns, and evaluating whether a change has resulted in an improvement in quality. There are three categories of data for monitoring quality: structure, process, and outcome. In any model of assessment, inclusion of data from these three categories facilitates interpretation of the findings. Sometimes this interpretation will lead to a

reassessment of what and how data are collected and to a questioning of the accuracy of the data if findings do not seem to make sense.

**Structure data**—This category describes attributes of the setting in which care occurs, including human and material resources. In structure data, the presence or absence of a structure conducive to effective care can be assessed, but the quality of care cannot. Examples of structure data include the time allocated for the appointment, the existence of health history forms (including language and literacy level for priority populations), systems to track and follow patients, and adequate staffing to provide patient education on the importance of rescreening and follow-up as indicated.

**Process data**—This category details what is actually done in giving or receiving care, including patients' care-seeking behaviors and providers' communication skills. Knowledge about the relationship between the interpersonal process and the outcome of care is based on behavioral science research. Process data collection may include chart reviews, as well as close collaboration with case managers.

**Outcome data**—This category summarizes the effects of care on the health of patients or of populations. Direct assessment of the structure and process is needed to help identify root causes of poor-quality outcomes. Outcome data sources include MDEs (e.g., time between screening and diagnosis, percent lost to follow-up) and client or provider satisfaction surveys.



### Field Example

*One program originally was divided into six regions to provide case management services to women with abnormal results or a diagnosis of cancer (STRUCTURE data). The regional case managers served both providers and women to ensure timely and appropriate care and availability of resources. Looking at the caseload of the regional case managers, the program determined that two or more rural regions could be consolidated into one (PROCESS data) while maintaining quality services and efficient contact with women and providers. One year of experience with this new arrangement proved the decision to be fiscally responsible and to have maintained quality case management services (OUTCOME data).*

## MINIMUM DATA ELEMENTS

MDEs are a set of standardized data elements developed to ensure that programs collect consistent and complete information about women who are screened, including screening location, patient demographic characteristics, screening results, diagnostic procedures, and referral to treatment if indicated. (See the *Data Management* chapter for more information on data quality.)

There are two major ways in which MDE data can be used to ensure quality services: (1) prospective use and (2) retrospective use. The combination of these processes allows programs to identify and prioritize areas for improvement.



### Key Message

*MDEs are a program's single most important source of data for monitoring program activities and quality.*

Prospective use of MDE data is to “look forward” for monitoring program performance on two levels:

**Program level**—This level tracks the current screening status of an individual client. Examples of the prospective use of data include routine reminders to women to promote regular rescreening and inquiries to providers about results still pending.

**Case management level**—This level enables case managers to conduct client assessments and write plans for women with abnormal results or diagnoses of cancer. This real-time use of data allows case managers to intervene in support of quality services.

Retrospective use of MDE data reviews what has occurred in the past. This review is important in identifying overall program trends. The bi-annual submission of data and discussions between the grantee and CDC about the program’s MDE data are examples of the retrospective use of data to monitor the timeliness and adequacy of screening and follow-up services.

QA staff members must have a clear understanding of the MDEs and be competent in reading and interpreting MDE reports, specifically the DQIG. The DQIG is a tool for monitoring completeness of the data collected as well as the timeliness and adequacy of the services delivered to women screened. It provides a comparison of program data with the MDE standards determined by CDC.

The DQIG has set goals for completeness for some variables. As with all data, when a sample size is small (i.e., fewer than 25 for any given reporting period) or when large portions of data are missing, programs should be cautious about making interpretations and generalizations from the data.

Grantees submit MDE data bi-annually to CDC. Individual grantees, however, are encouraged to monitor data on a more frequent basis, particularly if there is a high-risk problem or a need to measure data before and after QI activities. When programs submit an MDE data file to CDC, they submit information in three major sections:

**All patients**—This section provides data on screening location, patient demographics, and screening results for Pap tests, mammograms, and clinical breast exams (CBE). It is completed for each screening procedure that is performed for all program-funded women.

**Abnormal Pap tests**—This section comprises diagnostic procedures, a final diagnosis, and treatment data for cervical cancer and CIN. It is completed only for abnormal Pap test results or when diagnostic workup is planned by the clinician (e.g., when there are multiple consecutive LSIL Pap test results).

**Abnormal CBE/mammograms**—This section includes diagnostic procedures, final diagnosis, and treatment referral data for breast cancer. It is completed only for abnormal CBE or mammogram results or when diagnostic workup is planned by the clinician.

CDC provides grantees with feedback on their MDEs through written reports (twice yearly following each submission) and follow-up conference calls with program staff (at least once per year).

Clinical quality reports include data that reflect the quality of clinical care:

- **DQIG** provides a detailed report of the patient and clinical data reported for each MDE cycle.
- **Critical program performance indicators** include the indicators that CDC considers critical for program performance evaluations.
- **MDE histograms** are visual comparisons of program data.

Data quality reports include the actual quality of the data collected in the MDEs:

- **MDE edit/summary reports** point out data that seem highly questionable and need investigation.
- **Management reports** contain frequency reports with raw data submitted to CDC, as well as standard audit reports that list important data missing from the submission.

(See the *Data Management* chapter for more information on the MDEs.)



### Field Example

**QA staff members in one program monitor clinical data (DQIGs) for clinics with case managers. At least two times a year, QA staff members share these data with case managers and highlight areas needing improvement. They also review individual data before and after case management services are provided. If areas needing improvement are identified, specific cases and the clinical systems used are reviewed to see whether specific changes can be implemented to achieve better outcomes.**

## Other Sources of Data

Although the MDEs are necessary for CDC to monitor the NBCCEDP, grantees can collect additional data for local program management purposes. A number of other sources of data can be useful to programs when monitoring and assessing the quality of services for program clients. These include the following:

- Case manager input on the established system for screening and diagnostic services, which can be insightful and critical toward identifying gaps in the provider network, provider noncompliance with the program and/or clinical standards, resources necessary to reduce client barriers, provider issues identified by the client, program issues identified by the provider.
- Data collected in provider site reviews, including data from chart reviews
- Focus group data from providers and/or priority populations
- Case review data from medical or QI teams



### Key Message

**The Physician Insurers Association of America (<http://www.halohc.com/pdfs/PIAASudy.pdf>) Breast Cancer Study, 2002, gives important information on the reasons for a delay of diagnosis of breast cancer.**

- Data shared by other partners (e.g., cancer registries, malpractice companies, insurance commissions)

## *Contracts for Services*

Contracts document agreements with providers to perform a specified set of services for NBCCEDP clients. A contract sets the foundation for performance expectations and standards of practice consistent with program goals and objectives. Policies, procedures, and protocols placed in a contract or agreement detail in writing a clear record of the requirements of the agreement. Clear communication of contract terms and conditions precedes monitoring contract compliance—an excellent source of data for assessing quality.

(See the *Program Management* chapter for more detailed information on contracting with providers.)



### **Field Example**

*The results of a medical record review identified a provider who was billing for CBEs that were never performed. Because this fraudulent billing violated the terms of the contract, the program terminated the contract and reported the fraud to the appropriate authorities for legal action against the provider. Patients seen by this provider were contacted and scheduled for repeat screenings by other providers to ensure that they received quality clinical care.*

## *Satisfaction Surveys*

The use of satisfaction surveys and other feedback methods can provide tremendous insights on quality concerns and improvement opportunities.

**Provider satisfaction**—This type of survey can identify training and technical assistance needs as well as necessary infrastructure improvements that will contribute to provider satisfaction. Because effective structures can lead to effective processes that result in improved outcomes, this approach to quality is particularly useful. Surveys are only one of many methods for gathering feedback from providers; they may be supplemented with provider site visits that permit the program to focus on individual provider concerns.

**Client satisfaction**—This type of survey can identify concerns with provider services as well as public and patient education needs, which could improve the screening experience for program-funded women. Focus group activities are also excellent methods of obtaining client satisfaction data.

Design and implementation of the survey tool can affect the usefulness and quality of the data. The following factors are important for gaining meaningful feedback from providers and clients and subsequently using the information to improve services:

For all surveys, programs should

- use a simple rating scale that has word descriptors;
- include only one issue in a question;

- keep the survey short and easy to read and complete;
- make questions specific enough so information is useful;
- include the purpose for the survey and how the results will be used;
- use both closed and open-ended questions;
- include clear directions on how to complete the survey;
- give respondents the option to include their names if they want someone to call to follow up on any concerns;
- assure the confidentiality of responses;
- test the questions with a sample from the target audience to make sure that the survey is easily understood; and
- have a plan for reviewing surveys and reporting results.

For provider surveys specifically, programs should

- avoid the use of acronyms, unless they are clearly defined;
- solicit feedback from all provider staff members, not just clinicians;
- be clear about the time period that they want the feedback to reflect (e.g., before or after the site visit, since program inception, over the past 1 to 2 years); and
- include questions regarding provider expectations of the program and whether or not they were met.

For client surveys specifically, programs should

- use commonly understood language rather than medical jargon or acronyms;
- clarify whether they want responses based on a client's experiences during the previous year or the previous appointment;
- include questions to assess patient expectations and whether or not they were met;
- recognize that surveys may contain cultural biases, even when translated into the language read by the client; and
- provide alternative formats to gather feedback from clients who have limited abilities to read and write in English.

### *Provider Site Visits*

Conducting provider site visits involves meeting providers at their clinical service site to assess and improve quality. Because provider site visits consume the time of both the provider and patients, they

should be limited to times when identified problems can best be clarified or when requested by the provider. These visits can help the program to

- assess the accessibility and quality of services;
- train providers on program policies, procedures, and protocols;
- conduct and provide results of chart reviews;
- provide technical assistance to help providers enhance systems to improve care (e.g., tracking systems for program clients); and
- negotiate action steps to meet program requirements.



### Key Messages

- *Sites appreciate regular site visits, updated information, hands-on help with challenging cases, promotion plan development, and feedback/help in areas of concern.*
- *Site visits help a program's provider network feel valued, appreciated, and engaged.*
- *Site visits boost the energy and visibility of the program, which in turn can lead to increased enrollment.*

## Problem-Oriented Site Visits

These visits should occur when data have identified problem areas. These visits are intended to clarify the scope of the problem and its primary causes, and to provide options for resolving the problem or improving results. If corrective action needs to be taken, it is important that the program solicits support from its medical advisory board and other agency departments that have the experience and authority to pursue this level of intervention.



### Field Example

*One program performs a statewide QA review biannually, using three types of site visits:*

- ***Problematic site visits** are scheduled with sites that do not meet the DQIG standards. The program reviews the site data and tries to identify contributing problems. The program then suggests corrections or improvements.*
- ***Routine site visits** occur every 12 to 18 months. Activities include review of enrollment numbers; review of diagnostic cases; discussion about unusual cases/problematic cases; discussion of administrative issues (e.g., policy, billing, QA); and discussion of promotion plan development for the coming year.*
- ***Non-routine site visits** also may be conducted (1) every 6 months to review management reports if enrollment suddenly drops, (2) when there is an increase in the number of follow-up or billing issues/concerns, (3) when changes in staff require training, and (4) on request.*

There are four phases to conducting site visits.

- 1. Preparation phase**—In this phase, the program should
  - create the plan for the site visit, including the use of chart reviews;
  - develop a checklist that includes the quality indicators (criteria used to assess quality) and share the checklist with the clinical practice prior to the site visit; and
  - make arrangements with the provider to coordinate adequate time and availability of key office and clinical staff to complete the assessment.
- 2. Performance phase**—In this phase, the program should
  - meet briefly with the provider or liaison and others as appropriate to begin the assessment phase;
  - provide technical assistance and/or professional development activities to help providers understand the program requirements and processes; and
  - conduct an exit interview prior to leaving the site as a respectful way of sharing preliminary findings and outlining next steps for feedback and any corrective action if necessary.

Program staff members conducting the site visit should be able to

- listen actively and convey that the provider's point of view has been heard,
  - deliver feedback with a style of sharing ideas and information rather than giving advice,
  - encourage and promote open discussion of alternatives to improve outcomes,
  - share experience and common values,
  - convey a positive attitude that suggests a belief that differences of opinion are helpful, and
  - maintain trust and respect for the other party as a resource.
- 3. Reporting phase**—In this phase, the program should share organized data and information/findings, including recommendations for actions based on those findings.
  - 4. Closure phase**—In this phase, the program should follow up until provider actions satisfy the recommendations, then formally acknowledge closure of the site review.

## Chart Reviews

The chart review method for QA/QI is generally performed by the program in conjunction with a site visit, as previously outlined. However, chart reviews may be conducted as a separate independent study. The phases of the chart review are the same, with or without a concurrent site visit.

The purpose of chart reviews is to verify actual care compared to outcomes reported on data forms. Chart reviews help grantees to determine whether an identified problem is related to the delivery of care or if it is related to data collection and reporting. Once this distinction is clarified, the grantee can pursue a plan of action to correct the problem.



### Field Example

*In one program, chart reviews are conducted to assess the adequacy of clinical services. The chart review process allows program staff to provide the participating clinic with valuable feedback on its delivery system, identify areas for improvement, develop a plan for making improvements, and offer an extended site visit. Many clinics are interested in the results of the chart review and are eager to improve clinical services delivery. The process includes pulling a sample of charts within the time interval of interest. Once a sample is pulled, a request is forwarded to the clinic to schedule the chart review and make sure that charts are available. A set number of indicators are assessed in the clinical record and then recorded and compared against the “ideal” indicator. At the completion of the chart review, a verbal report is provided with preliminary results, followed by a formal report to the medical director detailing areas that need improvement and areas in which performance was excellent. Often, a second chart review is conducted 6 to 9 months later to determine whether areas of concern have improved.*

Although all chart review processes require a standardized set of indicator data, the actual tool used to conduct the review may be as simple as a paper checklist or as sophisticated as an automated software program. Regardless of the data collection method, it is important that the chart review focus on the quality indicators that can be monitored and assessed.

## Using Data as Feedback

Programs are encouraged to generate and distribute quality data reports to their providers and other partners as a method for offering continuous feedback and QI. Assessments of and feedback provided to providers are grounded by the notion that providing information to providers about their cancer screening services will serve as motivation for providers to screen patients appropriately for breast and cervical cancer.

When writing data reports, programs should first consider the audience and then determine which data elements are applicable and appropriate to disseminate. Data need to be given back to the providers who generated the information. By receiving reports, providers can gain an appreciation for the importance of their submitted data in the overall monitoring of the program. Reports to providers should focus on the

overall performance of the program (at the state, tribal, or territorial level) as it compares to national standards, with some reporting of how each individual provider is doing. Most providers intend to do an excellent job in serving women, and they often do not get to see how their individual results add up to describe the overall performance. Reports that describe the performance of an individual provider are a powerful QI tool.

Medical advisory boards are another key audience for reports about clinical care. Programs should provide these advisors with an overview of program guidelines and practices, CDC standards and policies, and a summary of the variance of performance by providers. Sharing this information may encourage advisors to help in the overall program monitoring, as well as allow them to assist in identifying the most important areas for improvement. Other audiences may include CDC, coalitions, and academic institutions.

Programs should consider the following tips for report format and content:

- Start with the goal and purpose of the report
- Describe the target audience
- Identify the data to be included in the report
- Select which MDE benchmarks to use
- Ensure that data are technically credible and accurate
- Match the report contents with the needs of the target audience
- Present the data graphically
- Draw conclusions about the data
- Develop recommendations for improvement
- List the limitations of the data report
- Clarify what the audience is to do
- Include an executive summary

Although specific data reports for providers are very effective for providing feedback, some grantees integrate data summaries into existing formats, such as provider newsletters.

## V. EVALUATING QA/QI

Programs must evaluate their QA/QI efforts to ensure that they are effective in improving care and meeting the quality indicators. QA/QI evaluation should be guided by specific and measurable objectives that reflect a program’s interests and priorities.

Once the program has established measurable objectives for QA/QI, it should convert each of those objectives into a set of evaluation questions. Having identified these questions allows grantees to determine the best process for collecting the data needed to answer them. The following table provides examples of evaluation questions for QA/QI and suggested methods of answering those questions.

EVALUATION QUESTION	USES OF EVALUATION FINDINGS	PROCESSES	DATA COLLECTION STRATEGY
Are there updated clinical practice guidelines that can be shared with program providers?	Disseminate guidelines to program providers to clarify program expectations for screening and diagnostic services	Review current protocols regularly Use medical advisory consultants to adapt and endorse approved protocols	Compare existing protocols with current evidence and program policy Compare protocols with those developed by other grantees
Are clients satisfied with the services (both screening and diagnostic) rendered by the program and providers?	Identify opportunities for improvement	Design a client satisfaction survey Implement the study Evaluate the results	Gather data with the survey instrument Conduct focus groups with clients

\* Because of the evolving nature of the Internet, Web sites noted in this chapter may no longer exist. In such cases, a global Internet search or search from the noted entity’s homepage may be needed to locate specific documents and resources.

## VI. RESOURCES

Key Resources
CLINICAL LABORATORY IMPROVEMENT AMENDMENTS QUALITY INITIATIVES
DATA MANAGERS MANUAL, NBCCEDP.
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Centers for Disease Control and Prevention  
National Center for Chronic Disease  
Prevention and Health Promotion  
Division of Cancer Prevention and Control  
Program Services Branch  
770-488-4880



# NBCCEDP Program Guidance Manual

## Evaluation

Version 2

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## ATTACHMENTS

**Attachment A:** Logic Model Requirement for NBCCEDP Grantees

**Attachment B:** BCCEDP Evaluation Plan Worksheet

**Attachment C:** Evaluation Standards

# I. INTRODUCTION

## OVERVIEW OF THE CHAPTER

This chapter provides an overview of evaluation, rationale for conducting evaluation, and resources for successful evaluation practices.

## WHAT IS EVALUATION?

Program evaluation is “the systematic collection of information about program activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or make decisions about future program development.”

**Systematic**—implies that evaluation is carefully planned and implemented to ensure that results are credible and useful.

**Information**—represents all evaluation data that are collected about the program to help grantees make judgments or decisions about program activities.

**Activities, characteristics, and outcomes**—identify what the program does, the features of the program, and the important program components that an evaluation plan should encompass to determine whether those components’ activities are reaching desired outcomes.

Evaluation aims to better serve program staff members, consumers, and partners, by **making judgments** about the program or its components, **improving effectiveness**, and **informing others about program accomplishments**.

There are three main types of evaluation:

1. Process
2. Outcome
3. Impact

## PROCESS EVALUATION

A process evaluation focuses on how a program or intervention works to attain specific goals and objectives. The process evaluation answers the following question: Are we doing what we said we would do? Process evaluation data often provide insight into why outcomes are or are not reached.

Process evaluation questions can include the following:

- How many women were screened for breast cancer and for cervical cancer [in a given quarter or year]?



### Key Message

*Through evaluation, grantees can examine the effectiveness and efficiency of the program overall. Evaluation data emphasize areas of program strength and highlight areas that need improvement.*

- In comparison to the location of clinics, where was the location of professional development events sponsored by the program in the past year?
- How many women received written materials (e.g., special flyers, brochures) that were distributed at a booth, near pharmacies, or in grocery stores to promote breast and cervical cancer screening?
- How many women at clinic A were advised by a provider to be screened?

## OUTCOME EVALUATION

An outcome evaluation is implemented to determine what effects a program actually has on those directly and indirectly experiencing it (i.e., clients, providers, communities). The outcome evaluation provides information about whether the program has been able to meet its short-term and intermediate goals and objectives.

Outcome evaluation questions can include the following:

- To what extent has the program met its screening targets?
- To what extent has the program delivered appropriate and timely screening and diagnostic services?
- How have community partners contributed to increasing screening rates?
- Are providers following clinical guidelines for screening?



### Key Messages

- *Evaluation is not a one-time process; an initial evaluation study often reveals significant findings and insights.*
- *In reality, evaluation is ongoing and integrated with all aspects of a program, starting with planning.*
- *Evaluation often requires ongoing monitoring of program results through program staff meetings.*
- *As information is collected, it may show that there are particular areas needing more in-depth evaluation.*

## IMPACT EVALUATION

An impact evaluation is implemented to assess the effects of the program on its participants, health systems and community.

Impact evaluation questions can include the following:

- Have the numbers of mammograms and Pap smears provided increased over time?
- Has the program maintained enrollment of women from priority populations over time?
- Has the program detected breast and cervical cancers in early stages?

## II. PURPOSE OF EVALUATION FOR THE NBCCEDP

The purpose of program evaluation is to assess the quality, implementation, effectiveness and efficiency of program activities, including population based activities. Program evaluation includes on-going monitoring efforts such as the collection and reporting of the minimum data elements (MDEs),

### ESSENTIAL ELEMENTS OF EVALUATION

To meet the National Breast and Cervical Cancer Early Detection Program's (NBCCEDP) expectations in the area of evaluation, a grantee should do the following:

- Design evaluation activities with the explicit purpose of improving the quality, effectiveness, and efficiency of a program's operations.
- Integrate evaluation activities within each program component.
- Use evaluation findings as the foundation for overall program planning and improvement.

### COMPETENCIES NEEDED TO IMPLEMENT EVALUATION

Staff members responsible for evaluation need the ability to

- describe the program (e.g., logic model);
- develop a comprehensive evaluation plan collect data using various quantitative and qualitative methods;
- analyze evaluation data and results;
- present evaluation findings in written and oral forms;
- use evaluation results for program improvement and planning.

### NBCCEDP EVALUATION GUIDANCE

The NBCCEDP has established specific guidelines for program evaluation. Each grantee is expected to do the following:

- Develop a comprehensive evaluation plan that includes each component of the program and describes how evaluation results will improve the program.

- Develop an overarching program framework for your program that illustrates how program components work together to achieve program outcomes. (See Attachment A: Logic Model Requirement for NBCCEDP Grantees.)
- Design and conduct a needs assessment to identify programmatic gaps and increase capacity across all program components with an emphasis on populations based screening activities.
- Develop component specific logic models to support program planning and guide evaluation planning. (See Attachment A: Logic Model Requirement for NBCCEDP Grantees.)
- Collect and report minimum data elements (MDEs) for on-going program monitoring of screening services.
- Conduct evaluation activities consistent with the evaluation plan developed for your program.
- Disseminate materials, synthesized/translated research evidence, lessons learned, and other information resulting from evaluation efforts, not limited to grantee’s network of partners, providers and key stakeholders.
- Review your progress in meeting objectives and performance indicators with the Centers for Disease Control and Prevention (CDC) staff members during regular conference calls and/or site visits

The components summarized in the other chapters of this manual provide guidance on what each grantee should monitor to assess how well the program is meeting CDC expectations. In many cases, CDC has provided indicators with acceptable ranges. Programs may use these guidelines as a start for their evaluation activities, but additional evaluation questions should be carried out.

The table below offers some examples of program data indicators.

EVALUATION MEASURE	DEFINITION	WHERE TO FIND	EXAMPLE
Essential elements	Minimum core expectations for each component	Listed in the introduction to each chapter	<b>Screening</b> —Establish, enhance, and coordinate a system for the delivery of breast and cervical cancer early detection services to program-eligible women in accordance with CDC policies and guidance, as well as established clinical practice standards
Data Quality Indicator Guide (DQIG)	A set of standardized data elements used to ensure consistent and complete information on screening location, patient demographic characteristics, screening services and results, diagnostic procedures and results, and initiation of treatment	DQIG	<b>Timeliness of diagnosis</b> —Cervical cancer screening: Ensure that the median time from abnormal screening test result to diagnosis is 90 days or less <b>Data management</b> —Ensure that the error rate in MDE submissions is 5% or less

## WHAT ARE THE PURPOSES OF EVALUATION?

There are several purposes for conducting evaluation.

PURPOSES	APPLICATION TO BCCEDP
Gather useful information to aid in planning and decision making	<p><b>Provide information about the program</b>—This information should be discussed in program staff meetings.</p> <p><b>Provide insight for planning and decision making about each program component</b>—For example, an evaluation could explore delays in follow-up services.</p> <p><b>Help to focus efforts on areas of need</b>—Evaluation and monitoring will identify what program components or activities do not work. These activities may then need attention and adjusting over the short term.</p>
Assess the quality, implementation, effectiveness, and efficacy of program components	<p><b>Offer data that can be employed to enhance program activities</b>—For example, program recruitment may be bringing in some rarely or never screened women for screening, but the program may not be meeting the standard. By conducting an evaluation, the grantee may learn from the women who came in for screening how they heard about the program and then use those successful methods for future recruitment.</p> <p><b>Describe the component activities of the BCCEDP, the associated costs, and achievement of outcomes</b>—This information will ensure that only effective strategies and activities are maintained and that resources are not spent on strategies that are ineffective.</p> <p><b>Assess the effects of the program</b>—An ongoing evaluation will allow the grantee to measure the extent to which program objectives and self-defined measures of success are met. Information about the effects of a program can be used to refine its activities.</p> <p><b>Compare outcomes over time</b>—As the program matures, monitoring information will reveal its effects over time.</p> <p><b>Promote program efficiency</b>—Efficiency is the amount of product resulting from a given level of resource. Monitoring allocated component budget and outcome data will help grantees to direct more resources to effective activities and fewer resources to ineffective activities. It also will help demonstrate the extent to which the program has productively used its resources.</p>

## WHAT ARE THE BENEFITS OF EVALUATION?

Evaluation findings help a grantee monitor progress toward desired outcomes, improve program operations and outcomes, and demonstrate to stakeholders how the program maximizes the use of resources. Evaluation findings also inform program planning.

## WHAT ARE THE DIFFERENCES BETWEEN EVALUATION AND RESEARCH?

Often, program evaluation is thought to be research applied to a particular program. Although research and evaluation do share some traits, there



### Key Message

*Evaluating BCCEDP components helps grantees to do the following:*

- *Monitor compliance with CDC guidance*
- *Identify what its program has done*
- *Learn about its program's strengths and successes*
- *Identify program needs and weaknesses*
- *Identify effective and ineffective activities*
- *Improve the quality, effectiveness, and efficiency of its program*
- *Improve program operations and outcomes*
- *Recognize gaps in the overall program*
- *Demonstrate program effectiveness to stakeholders*
- *Use findings for program planning, monitoring, and decision-making*

are key differences in both philosophy and practice between research and evaluation. Evaluation focuses on collecting data within the current program context and permits all stakeholders and those who have an interest in the program to collaborate in the process. Research, however, focuses on increasing knowledge and applies the scientific method.

The following table presents some key differences between evaluation and research.

	EVALUATION	RESEARCH
<b>Purpose/Intent</b>	Develops and improves program operations	Promotes an increase in knowledge
<b>Questions asked</b>	Centers on the program	Focuses on the generation of new knowledge
<b>Method</b>	Focuses specifically on the processes of identifying program needs, gathering evidence, and ensuring the use of results to improve the program	Applies the scientific method in more controlled situations

NBCCEDP funds cannot be used for research. However, programs can partner with universities and agencies to evaluate a particular intervention strategy. When data are collected for program development or to improve a public health practice, the effort is considered evaluation, not research. Grantees do not need to obtain permission from CDC’s Intuitional Review Board (IRB) for data collection activities associated with program evaluation; nevertheless, data collection methods should be scientifically rigorous and valid so that program recommendations will be based on quality data. For additional information on research and non-research activities, please see CDC policy document: [Distinguishing Public Health Research and Public Health Non-Research](http://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf) (<http://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf>).

## EVALUATION INFRASTRUCTURE

Evaluation requires that grantees invest time and resources, including personnel and funding, into the evaluation process. Staff members assist with and coordinate data collection, analysis, and reporting of information for, at a minimum, their particular component areas.

Structures and systems should be in place to help with evaluation of your program. These structures involve adequate staff and training on evaluation terminology and processes. Many of these structures are mandated by CDC (e.g., performance indicators, progress reports, work plans). An important question to ask is whether or not your program is spending most of its time and resources collecting and reporting this data for CDC, and little time using the information for program planning.

(See the *Data Management* chapter and the *Screening and Diagnostic Services* chapter.)

## PROGRAM STAFF MEMBER ROLES IN A COLLABORATIVE EVALUATION PROCESS

The program director is responsible for the coordination of the overall program evaluation process. It is the role of the program director to keep all program staff members and individuals working on relevant areas of the evaluation process, ensure that program monitoring data are collected and used, and keep

staff members informed about relevant evaluation findings. All program staff members should contribute to evaluation efforts as needed because they are knowledgeable about the program activities and instrumental to the daily operations of the program. Staff members can help monitor the progress of the program and identify areas for improvement. Other stakeholders of evaluation, in addition to the program staff, include the medical advisory board and community partners. Their involvement also will help highlight the benefits of evaluation efforts and how to think critically by asking more questions about the program and its effects.

Program staff members should be involved in the development of the evaluation plan. They should attend all general program meetings regularly and share information and data when component areas related to their responsibilities are discussed. Evaluation discussions can be built into these meetings when necessary. Many staff members should play a role in the collection of evaluation data for their related component area. For example, the recruitment coordinator could assist with data collection and a review of program records to answer evaluation questions related to the extent that the program is reaching never or rarely screened women for screening.

The staff members who are involved directly in the evaluation process should consist of both internal program staff members and external contractors or experts. For example, the data manager will be responsible for monitoring the program data (including indicators of performance) and reporting back to the staff about the progress of the program. The medical advisory board (i.e., medical experts) should review these reports and assist with interpretation and analysis. Individuals on the evaluation team need to plan and implement evaluation activities, perform data management and analysis, and disseminate and use the findings.

It may be effective for the grantee to create a collaborative evaluation committee or advisory panel that includes representatives from each of the stakeholder groups to make decisions and direct the evaluation process. Although the collaborative approach may at times be challenging, it can have a number of benefits: reduced suspicion and fear; increased awareness and commitment; increased possibility of achieving objectives; broadened knowledge base; greater opportunity to teach evaluation skills; strengthened partnerships; increased possibility that findings will be used; and broadened mix of differing perspectives.



### **Key Message**

***Evaluation should involve the entire program staff. The grantee should do the following:***

- ***Educate program staff members and partners on how evaluation helps to improve the program by identifying what is or is not working within individual program components.***
- ***Include evaluation discussions on program staff meeting agendas to help reinforce evaluation's importance.***
- ***Take other steps to ensure that evaluation is seen as a core function of the program.***



### **Key Message**

***When a grantee plans its evaluation budget and sets priorities for evaluation activities, it should consider the scope and cost of interventions.***

## BUDGETING FOR EVALUATION

Because evaluation is an essential part of the NBCCEDP, grantees should include a budget for evaluation in the 40% program management allotment. The evaluation budget could cover line-item expenses for the following:

- Staff or volunteer expenses
- Fees for a consultant or contractor, who may help with survey development, data collection, or data analysis
- Costs of duplicating data collection instruments or reports
- Communication costs, such as postage and phone calls
- Travel costs
- Incentive fees to encourage respondents to participate
- Printing of reports

### *Getting Help with Evaluation*

Program evaluation relies on a variety of complex theories and processes, and at some point, it may be helpful for a grantee to seek the expertise of evaluation experts. Evaluation experts may help in the following areas:

- Evaluation planning and design
- Data collection methods, including development of instruments (e.g., surveys)
- Data management
- Data analysis
- Report writing

National resources, such as those developed by the American Evaluation Association (<http://www.eval.org/>), provide advice about evaluation. However, grantees also must develop in-house evaluation expertise within the program.

Grantees also can obtain help with evaluation through the following options:

- **Identify a program partner**—Grantees may find a person with evaluation expertise within the local health department or health agency or through external partners (e.g., voluntary health



### **Key Messages**

- ***A grantee should think through the financial resources needed for evaluation.***
- ***Often, program resources are allocated primarily to program component activities other than evaluation. Grantees should be sure to allocate funding for evaluation in the program budget.***
- ***Grantees should seek help on certain aspects of evaluation from other program directors, program partners, or CDC program consultants.***
- ***Grantees can hire an outside contractor to conduct specific evaluation activities, if necessary.***



### **Key Message**

***Grantees should use educational institutions as an additional resource. For example, a grantee can identify avenues for collaboration with educational institutions to maximize program resources for evaluation.***

organizations, universities, other health agencies). Other BCCEDP programs may provide help with lessons learned from previous evaluation efforts, share surveys or forms as methods of data collection, or act as an external reviewer. Technical assistance from CDC also may be helpful.

- **Work with faculty and students from local universities as a free resource**—Students represent a low-cost (or free) method for conducting specific evaluation tasks or projects (e.g., data collection, data entry, report writing). They are often supervised by faculty members who have experience in public health programs and/or evaluation. Grantees should look for local colleges and universities with community health or public health programs that may offer course-related evaluation expertise.
- **Hire a contractor or consultant**—A contractor may be able to help with a specific part of the program evaluation. Although it is not necessary to recruit other professionals to aid in evaluation, contractors or consultants may specialize in a particular area of evaluation (e.g., design, methodology, data analysis, report writing). For example, when designing and implementing an evaluation, a grantee may benefit from the assistance of an evaluation design expert, such as a behavioral scientist. These professionals also can be helpful in developing survey instruments and identifying databases. Similarly, an epidemiologist can aid in the organization and analysis of data. Distributing certain tasks can reduce the burden on the principal evaluator and ensure that all essential evaluation activities occur.



### **Field Example**

*One grantee contracted with a breast cancer outreach program through a university's school of nursing to implement and evaluate intervention strategies with two other contractors. The goal of the strategies was to increase the screening and diagnosis of African American women aged 50–64 by 15%. The program evaluated the number of screenings performed, outcomes of outreach strategies, referrals, and follow-up activities.*

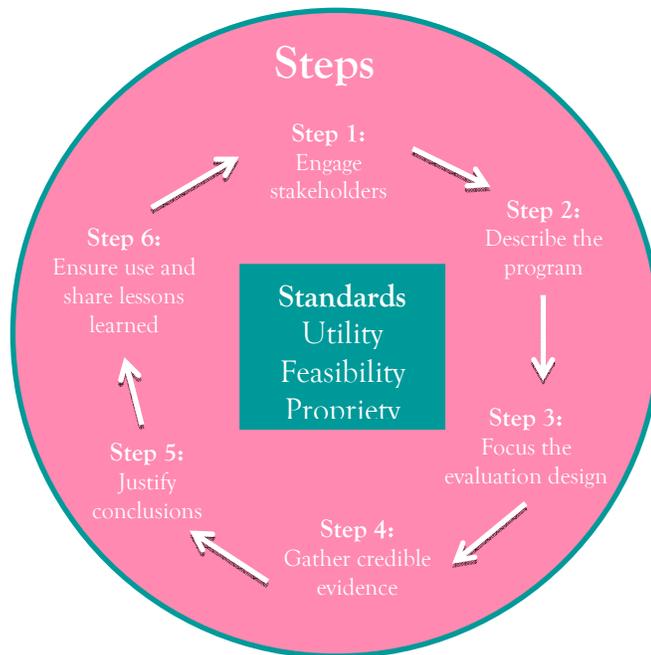
Many types of people may serve as evaluation contractors or subcontractors. When selecting a consultant, grantees should strive to hire one with the following characteristics and skills:

- Has experience in the type of evaluation needed
- Is comfortable with qualitative and quantitative data collection methods and analysis
- Is able to work with a wide variety of BCCEDP stakeholders, including representatives of priority populations
- Has an understanding of cancer screening programs
- Educates program personnel about designing and conducting evaluation
- Provides the full findings
- Has strong coordination, communication, and organization skills
- Respects all levels of personnel

Generally, grantees should consider the consultant's level of training, evaluation philosophy, experience, and ability to meet the evaluation needs. The consultant's background and approach should match the goals of the evaluation.

### III. CDC'S FRAMEWORK FOR PROGRAM EVALUATION

CDC's framework for program evaluation in public health is the recommended process for conducting evaluations. This framework outlines six steps for program evaluation (Figure 1):



**Figure 1: Framework for Program Evaluation**

The following section uses this framework as a guide to the evaluation process for NBCCEDP and describes the steps as they relate to NBCCEDP evaluation.

#### **STEP 1: ENGAGE STAKEHOLDERS**

The first step in the program evaluation process is to engage stakeholders. Stakeholders, in terms of evaluation, are those persons or organizations that have an investment, or stake, in what will be learned from an evaluation and what will be done with the knowledge. Grantees should involve stakeholders in the planning and implementation stages of evaluation to ensure



#### **Key Message**

*During evaluation, grantees should do the following:*

- **Address the fear of consequences by including stakeholders in the evaluation process**
- **Engage the stakeholders as an important part of the evaluation process**
- **Provide support for the evaluation and uses for its findings**
- **Inform stakeholders that an evaluation may reveal program successes or problems and that both types of information are important**
- **View the potential discovery of problems as an opportunity to learn and improve the program.**

that their perspectives are understood and that the evaluation reflects their areas of interest. Involving stakeholders increases awareness of different perspectives, integrates knowledge of diverse groups, increases the likelihood that findings will be used, and reduces suspicion and concerns related to evaluation.

In established programs, such as the NBCCEDP, various stakeholders are involved in different aspects of the program. Grantees should identify which of these stakeholders to involve in the evaluation process, then determine possible roles for each of them. Stakeholders' roles may include the following:

- Serve on an advisory committee for the evaluation
- Prioritize aspects of the program to evaluate
- Develop questions or surveys
- Serve as a resource (e.g., American Cancer Society (ACS), CDC)
- Offer data sources (e.g., National Cancer Institute (NCI), CDC)
- Analyze data
- Communicate evaluation results

Stakeholders may be decision makers, implementers, program partners, or participants, as outlined in the following table.

STAKEHOLDER TYPES	EXAMPLES OF STAKEHOLDERS
Decision makers	Program directors CDC staff members Evaluation coordinators Chronic disease directors
Implementers	Program staff members Clinical staff members Medical care providers Community-based organizations Medical societies Malpractice companies Licensing boards
Program partners	ACS NCI Susan G. Komen Foundation Professional associations Local health departments Local, State, and regional coalitions Advocacy groups Local universities and colleges Local businesses TV and radio stations Newspapers Medical care providers
Participants	Consumers Women eligible for program or enrolled in program

## STEP 2: DESCRIBE THE PROGRAM

The second step in the program evaluation process is to describe the program. An accurate program description and purpose make it easier for the grantee to focus the evaluation efforts and ensure that the results will be of wide use. The program description should include the following aspects: the need for the program, resources, component activities, and expected outcomes.

Grantees have already begun this step by developing program work plans, grant applications, progress reports, and other program administrative materials. In these documents, grantees should have discussed the need for the program, existing program resources, program activities, and expected outcomes or measures of successes. The grantee should think of the context of the program when designing and conducting the evaluation.

### *A Logic Model of NBCCEDP*

A logic model shows the larger context of a program, including the relationships between individual activities and the expected results, to describe how all of these program aspects work together to achieve the program's long-term outcomes. By contrast, the workplan concentrates on the selected activities, with less focus on their relationship and expected short- and long-term results.

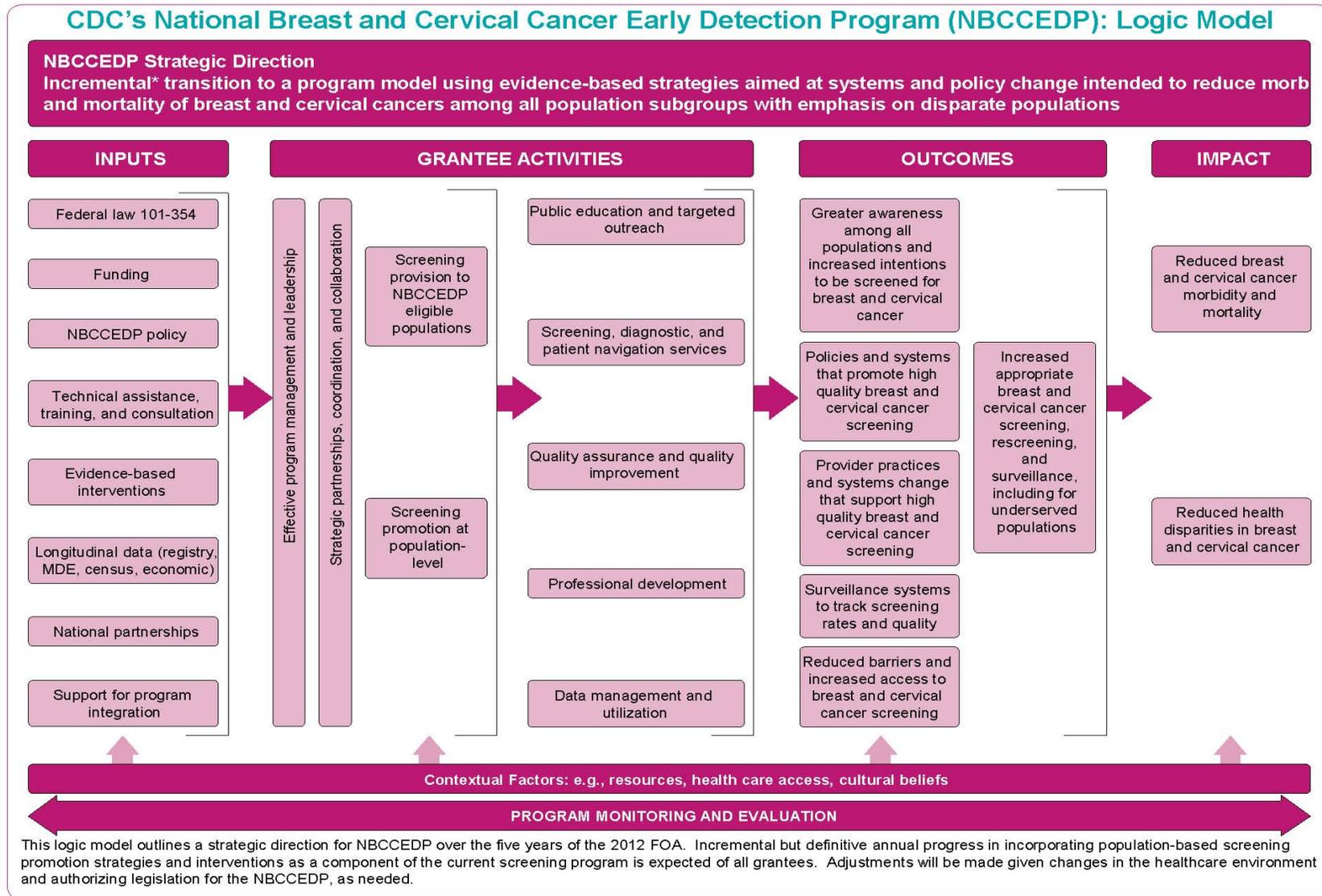
The components of a logic model are as follows:

- Inputs or program resources
- Component activities (conduct of the NBCCEDP's essential elements)
- Outputs or process indicators of the program activities'
- Short-term, intermediate, or long-term outcomes

Figure 2 shows the NBCCEDP logic model. This model suggests that the NBCCEDP core components and the core functions of management and evaluation will lead to short-term and intermediate outcomes that impact program screening and diagnostic services. Ultimately, the program outcomes will lead to the long-term goals of the program—to reduce morbidity and mortality, as well as disparities, related to breast and cervical cancer.

*(For additional information regarding Logic Models, their various components, and NBCCEDP requirements, see Attachment A: Logic Model Requirement for NBCCEDP Grantees.)*

**Figure 2: NBCCEDP Logic Model—Breast and Cervical Cancer Early Detection Program**



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### STEP 3: FOCUS THE EVALUATION DESIGN

Once the key players are involved and there is a clear understanding of the program, grantees should focus on the evaluation design and determine the evaluation's purpose, users, uses, questions, and plan. (See *Attachment B: BCCEDP Evaluation Plan Worksheet*.) The design should be sure to address the issues that are most important to the stakeholders. Focusing the evaluation design will increase the chances that the evaluation will succeed by identifying procedures that are practical, politically viable, and cost-effective. Grantees must think through the data collection plan to ensure that it will meet the needs of the evaluation; it is often difficult to change the process once it has begun.

It may be helpful to review program documents (e.g., the work plan, meeting minutes, site visit reports, MDE reports) to determine the areas on which evaluation efforts should be focused. Grantees should examine aspects of the program that demonstrate effective impacts or outcomes, as well as those that are not working well.

#### *Prioritizing What to Evaluate*

Because of the large size, complexity, and finances of the program, it is not possible to evaluate every aspect of the program. Grantees should first examine the DQIGs and program performance, and then focus evaluation efforts on the program areas that are not working optimally. It is, however, important for grantees to look at the program as a whole and think about how each aspect of the program should be evaluated. Once the program has been looked at as a whole (e.g., Are screening goals being met? Are standards of timeliness and appropriateness of services being met? What are the clinical costs?) and the overall program evaluation needs have been established, areas must be prioritized for further evaluation.

Priorities for evaluation might include the following:

- Any new initiative with resources allocated to it
- Any activity that consumes a high amount of resources
- Activities that are not successful at meeting their measures of success
- Program inconsistencies (to explore why they exist)
- Any unevaluated activity (e.g., recruitment strategies, screening) that is employed frequently by the program

In prioritizing the evaluation questions to address, the grantee first should review the program work plan and develop an evaluation plan. Second, once the plan has been created, the grantee should rate the evaluation questions and activities as being of high, medium, or low priority. The grantee can then start with the highest priority questions and continue down the list until resources are expended.

In addition, the grantee should examine documents that highlight program areas. The following documents can be reviewed to help determine the crucial components to evaluate, as well as their priority:

- Annual work plan
- Program meeting notes
- Updates or reports of program coordinators for recruitment, professional development, data management, and services
- Progress reports
- Conference calls with CDC program consultants
- Materials from CDC, such as site visit reports, application review feedback, and MDE feedback
- Annual reports

Looking at the overall work plan and program documents should help to address the big picture and ensure that evaluation resources are spent on the most important and constructive areas. *Work plans: A Program Management Tool* suggests a process that may streamline this step (available at <http://www.cdc.gov/cancer/nbccedp/training/workplans/index.htm>.)



### Key Message

**Grantees should consider program evaluation in the early stages of program planning:**

- **Make evaluation a part of program planning**
- **Think about what outcome an activity should produce and how to determine if it is successful**
- **The program evaluation plan should be developed at the same time as the overall program work plan.**



### Field Example

**One program's evaluation was conducted by an external consultant who was asked to review various aspects of the screening program. The consultant met with each staff member individually, including regional contractual staff members, providers, medical advisory board, and partners to discuss strengths, weaknesses, opportunities, and threats to the program. A client satisfaction form was developed, evaluated by the agency's IRB, and distributed by the program's public health nurse and nurse consultant.**

**The evaluation clearly revealed the program's strengths and weaknesses, and it provided recommendations for improvement. It also provided the opportunity for staff members, providers, and contractors to express their concerns in a nonthreatening and anonymous environment. The greatest benefit was to see the problems and solutions that exist and to understand the perceptions of stakeholders. The results indicated that the clients valued the screening resources, education, and attitude of the staff members but felt that the process, including paperwork and scheduling, was overly cumbersome. The consultant report provided concrete recommendations for reducing the burden on women and offering training to providers to minimize program documentation and change their practice schedule. Recommendations also suggested that the program should continue to conduct outreach and provide educational resources to women.**

## Evaluation Plan

An evaluation plan is a program management tool that provides direction and guidance for the overall evaluation and for each evaluation component. It is designed to be used for evaluation planning, implementation, and monitoring progress.

The evaluation plan may vary in how extensive or formal it is. For example, it could be a 3-year plan with annual activities, or it could be a segment of the CDC work plan. In either case, the plan will outline the tasks necessary to complete the evaluation. Grantees must remember to revise the evaluation plan when critical changes occur in programs, budgets, or procedure.

The plan starts with the evaluation questions. It then describes the users and uses of the evaluation findings, the data collection process, and data analysis. (An example of an evaluation plan can be found at the end of this chapter.) The following table outlines a simple evaluation plan.



### Key Message

**Grantees should clarify the purpose and priorities of the evaluation:**

- **Ensure that the program's purpose and priorities for evaluation are clearly understood by everyone involved**
- **Structure evaluation activities to address the program priorities**

EVALUATION QUESTION	USES OF EVALUATION FINDINGS	DATA COLLECTION PROCESSES	DATA ANALYSIS
<p>The evaluation questions ask about aspects of the program that are to be examined. Grantees can begin with evaluation questions related directly to the objectives and/or measures of success described in the workplan.</p> <p>Grantees also may want to consider other bigger picture questions of interest to the program, which go beyond the workplan.</p>	<p><b>Uses</b>—To be useful to the program, evaluation results must be applied. The results could, for example, identify an ineffective activity, suggest a way to adjust resources, document a positive outcome, or mobilize support for the program.</p> <p><b>Users</b>—A subset of stakeholders can clarify intended uses, help prioritize questions and methods, and prevent the evaluation from becoming misguided or irrelevant. The users are the consumers and will use the evaluation findings.</p>	<p>The data collection processes are events or things that will need to be in place to answer the evaluation question.</p>	<p>Data analysis includes reviewing data or comparing data to set targets or measures of success.</p>

Grantees may ask many different types of evaluation questions. Some questions may be based on objectives for particular components described in the work plan. Other questions may address larger issues to be answered about the program. Evaluation questions can be developed on the basis of the component outcomes listed in the Program Outcomes section below. Examples include the following:



### Field Example

**To evaluate whether it met the NBCCEDP standards for timeliness, a program examined its interval between cervical cancer screening and diagnosis. The program's mean number of days was 78; CDC's requirement was 60 days. Although not happy with this result, the program was able to focus on this problem and identify the variables contributing to the prolonged interval.**

- Did women’s knowledge of breast and cervical cancers and screening tests increase as a result of public education activities?
- How many women obtained mammograms and Pap tests as a result of the program?
- Has the number of collaborations or partnerships to address breast and cervical cancer in the community increased or been maintained?
- Are more providers counseling women about the benefits of breast and cervical cancer screening because of the program’s professional education activities?
- To what extent are clients receiving services in a timely manner?
- To what extent do women who have received abnormal results or a diagnosis of cancer obtain follow-up services in a timely manner? Are they receiving appropriate follow-up services?
- Have rescreening rates increased for women who are currently being served by the program?

#### STEP 4: GATHER CREDIBLE EVIDENCE

Grantees can improve an evaluation’s overall validity and value by (1) using multiple purposeful or systematic procedures for gathering, analyzing, and interpreting data and (2) encouraging participation by stakeholders.

The following table explores data issues to be considered when gathering evidence in an evaluation.

DATA ISSUE	DEFINITION	APPLICATION
Data quality	The accuracy, appropriateness, and integrity of information used in an evaluation. Data quality influences the believability of the recommendations and the use of the results and recommendations. Factors affecting quality include survey design, data collection procedures, training of data collectors, source selection, coding, data management, and routine error checking.	If a grantee develops a survey to measure program satisfaction among enrolled women, the following should occur: <ul style="list-style-type: none"> <li>• The survey should be reviewed by experts to check for readability, cultural appropriateness, and comprehensiveness of questions.</li> <li>• The survey should be pilot-tested with members of the audience to whom it will be administered.</li> <li>• Collectors should be trusted to administer the survey.</li> <li>• Collected data should be checked routinely for entry errors and/or other errors.</li> </ul>
Data quantity	The amount of information gathered in an evaluation. Data quantity, in part, determines whether the evaluation will have sufficient information to reliably represent the group.	Program partners should be asked for input on the benefits of the collaborative relationship between them and the program (rather than just one or two partners).
Data indicator	A specific, measurable characteristic that represents an achievement of the outcome.	Number of women rarely or never screened for cervical cancer received screening services in the program. Number of women diagnosed in the program in the early stages of breast and cervical cancer.

In gathering data, grantees should start with the evaluation questions listed in the evaluation plan. These questions should identify the indicator of interest. The data collection process should then identify the sources for collecting information on each indicator. The sources could include persons, documents, or observations (examples are given in the table below). If evaluation was included as part of the planning process, the program should already include data collection activities. If existing data systems cannot answer the evaluation questions, the grantee should consider developing its own system to monitor or track what it is interested in evaluating.

INDICATOR	SOURCE
Number of women who receive screening	Intake survey at program clinics
Clients with cancer diagnosis starting treatment within 60 days	Clinical charts and follow-up Written plans
Patient satisfaction with services	Patient satisfaction survey
Collaboration activities with program partners	Meeting minutes

### Qualitative Versus Quantitative

Not all data collection methods are quantitative. Qualitative methods can be used to increase understanding and to answer questions asking “how” and “why.” Common qualitative data collection methods include observations, interviews, document review, and focus groups. Often, a combination of quantitative and qualitative methods provides the most accurate representation of the program. For example, a grantee may find that interviews with providers in its provider network or site visits of clinics may give more information about service delivery than relying solely on surveys.



#### Key Message

*Grantees should recognize the value of qualitative data, collected through interviews or observations, when quantitative data collection and analysis are not possible. Anecdotal information and thoughtful estimates should be used when appropriate; however, meaningful baseline data are needed to measure change.*



#### Field Example

*A program conducted a quantitative and qualitative assessment of its case management activities. The assessment included a review of performance measures and intervals, as well as a cost comparison between categorical funding, fee for service, and no funding. Workgroups and interviews with contractors were conducted to assess and evaluate their case management activities. One of the findings indicated that the fee-for-service model was more cost-effective and best able to provide all contractors with the opportunity to be compensated for their labor-intensive case management efforts.*

The following table presents a list of data sources for BCCEDPs, separated into primary data (collected by the program) and secondary data (collected by another group).

<b>BCCEDP PROGRAM DATA SOURCES</b>	
<b>Primary Data</b>	<b>Secondary Data</b>
<b>Quantitative</b>	<b>Quantitative</b>
Enrollment, screening, and diagnosis service forms MDEs Staff surveys and interviews Site visit reports Tracking of media Provider surveys or interviews Surveys of intended audience Logs Progress reports Needs assessments	Cancer registries BRFSS Medical records Medical claims data Census data Vital statistics National Health Interview Survey data Vital records
<b>Qualitative</b>	<b>Qualitative</b>
Exit interviews of participants Focus groups Topic expert interviews Staff meeting minutes Observations of activities, staff members, and clients	Administrative reports Publications and journals

## STEP 5: JUSTIFY CONCLUSIONS

Evaluation conclusions are justified when they are linked to the data gathered and judged against agreed-upon values or standards. Stakeholders must agree that conclusions are justified before they will use the evaluation results with confidence. After reviewing preliminary evaluation findings, the grantee should interpret and discuss them with program staff members and stakeholders and then develop appropriate action steps. Conclusions can be justified and presented through the use of standards; analysis and synthesis; interpretation; judgment; and recommendations.

The following are major activities in justifying conclusions:

- Analyze the evaluation data
- Interpret the results to discover what the data say about the program
- Make judgments about the program data on the basis of previously set standards (e.g., national, CDC/NBCCEDP, program) or compare the data with those from previous years



### **Key Message**

*Grantees should examine the results and reflect on what led to them. For example, if results show that women in the neediest areas are not being served, the program should consider what region is being targeted by recruitment strategies or what barriers could have led to the low numbers.*

Specific questions to help justify evaluation conclusions include the following:

### WHAT ARE THE STANDARDS, AND HOW DID THE RESULTS COMPARE TO THE STANDARDS?

Use standards developed by the funder (e.g., CDC) or by the medical advisory board, indicators of performance, results of other similar programs, past program results, and national averages.

### WAS THERE A THOROUGH PROCESS FOR ANALYSIS AND SYNTHESIS OF THE INFORMATION?

Isolate important findings (analysis) or combine sources of information to reach an understanding (synthesis) that may help detect patterns of evidence. For example, look at recruitment efforts for different demographic groups in addition to the entire population to understand if the efforts are effective in none, some, or all of the demographic groups.

### HOW CAN THESE FINDINGS BE INTERPRETED IN THE OVERALL PROGRAM CONTEXT?

Determine the practical significance of the findings through discussions with program staff members and stakeholders. Interpreting findings includes comparing program data baselines or similar results with other programs and theories.

### ARE THE RESULTS CREDIBLE?

On the basis of the data collection process, consistency with other findings, and amount of data collected, determine the merit, worth, or significance of the results. Review results for any limitations. Consider whether the results are consistent with what was expected and if they can be explained; if not, additional investigation may be needed to confirm the findings.

### WHAT ARE THE RECOMMENDATIONS FOR THE PROGRAM, BASED ON THESE FINDINGS?

Develop a list of recommended actions based on the evaluation. Discuss the recommendations with the individuals involved in the particular area that will be affected, so that appropriate improvements can be made. For example, if the findings show a lack of follow-up in the larger clinics, as compared with that in the smaller clinics, look at what caused the difference and then develop a strategy to overcome this gap in service.

### WHAT ARE THE LIMITATIONS OF THE EVALUATION FINDINGS?

Think about the limitations of the evaluation findings. Make sure that different perspectives are involved to help interpret the findings. Consider the number of participants and whether the sample was large enough to generalize the findings. Think about any errors that could have occurred in data collection, entry, or analysis, which could affect the findings.



### Key Message

*The strengths, weaknesses, opportunities, and threats—or SWOT—method of evaluation worked very well to identify management, communication, outreach methodologies, and clinical issues, but it did not identify potential problems in funding (e.g., if the program was actually spending funds geographically where they needed to be spent). The planning process should provide the evaluator with detailed instructions and specific areas of concern to ensure adequate evaluation and recommendations.*

## STEP 6: ENSURE USE AND SHARE LESSONS LEARNED

Once the findings are established, the grantee must make a concerted effort to share the lessons learned with stakeholders in a timely manner. This step involves the preparation of tangible products from the evaluation, including an overall evaluation report and specific and targeted recommendations.

### *Use Findings*

Despite all of the time and energy expended on evaluation efforts, the evaluation findings and their recommendations are irrelevant unless they are used and shared. Grantees should use findings to improve the program on an ongoing basis. In addition, evaluation results should be reviewed by program staff members and stakeholders and be considered in program planning and work plan development for the following year. Evaluation findings also can aid in budget development, resource allocation, and decision making for the program in the future.

To effectively use evaluation findings, grantees must do more than just report them. For areas of weaknesses in the program, grantees should continue to ask questions and consider what led to those results. In this way, program aspects can be identified that need recommendations for improvements or changes.

An example of asking questions is offered below, showing the value of really *probing* into evaluation results.

Screening targets for a particular group of woman are not being met. An evaluation of the demographics of women screened presents information on where most of the women served are coming from. From that information, the grantee can ask the next question: Are women in the neediest areas being served? If not, the program can change recruitment and targeted outreach strategies to address that weakness.

### *Sharing With Stakeholders and Other Programs*

Early in the evaluation planning process, each grantee should develop a strategy for disseminating evaluation findings to users of the evaluation data. Sharing information with stakeholders will help maintain their buy-in with the program. Grantee also should disseminate findings to others in the field that may be able to learn from the evaluation efforts and results. Results can be shared formally or informally. Deliberate effort is needed to ensure that the evaluation processes and findings are used and disseminated appropriately. Methods of sharing information include the following:

- Writing a formal report to CDC, other funders, and stakeholders, modifying it for each audience
- Preparing a press release



#### **Field Example**

*A program's surveillance data presented in a progress report showed that the majority of women screened were Hispanic. A much smaller percentage was African American women, even though this population was the program's primary screening focus. The program shared these data with recruiting staff members, leading to an objective to encourage contractors to increase by 15% the screening and diagnosis of African American women aged 50–64.*



#### **Field Example**

*One program evaluation identified lack of partner and stakeholder input. This led the program to develop a Breast and Cervical Cancer Advisory Group (in addition to the Medical Advisory Board). This evaluation was shared with the advisory group for their comment and recommendations.*

- Making an oral report to staff members, funders, and local partners
- Making presentations to health care providers and provider networks to show them how they have contributed to the program results
- Using evaluation results to help document program data for new or continued grant funding
- Sharing the evaluation reports with colleagues in similar programs
- Sharing evaluation highlights through program newsletters and health channels in the community
- Publishing evaluation efforts and findings in a research or practice journal
- Developing a presentation of the project evaluation for a regional or national conference on breast and cervical cancer
- Giving presentations at women’s clubs or libraries
- Posting a message on the NBCCEDP Programs and Partners Web Forum
- Sharing results at NBCCEDP-related conferences or meetings
- Discussing the evaluation and sharing its findings during a program conference call

### *Writing an Evaluation Report*

Writing an evaluation report is a way of sharing results within the program and with program stakeholders. In many cases, different versions of reports should be developed for specific groups, with each report including only the information relevant to the specific group’s portion of the program. An evaluation report often includes the following sections:

- Executive summary
- Introduction
- Methods
- Results (may include tables, figures)
- Discussion
- Conclusion
- Recommendations/action plan
- Appendices



**Key Message**

*Grantees should share relevant evaluation information, communicating results to partners and stakeholders in a manner relevant to their interests and needs.*

The six steps of CDC’s framework for program evaluation are meant to guide an evaluation in which stakeholders are consulted; program goals and objectives are defined; evaluation questions are written; data are collected, analyzed, and interpreted; judgments and recommendations are made; and evaluation findings are shared. For help in ensuring that evaluation activities are well designed, evaluation standards can offer guidelines in designing and implementing program evaluation.

(See Attachment B: Evaluation Standards.)



### **Field Example**

*A program contracted with an external consultant to evaluate its screening efforts because screening targets were not being met. Data were collected from a staff retreat, staff meetings in an evening activity, and an annual conference for providers. The results revealed that extensive staff turnover had created an unstable climate regarding communication, policy changes, and effective outreach mechanisms. These results led to the development of standard procedures and clear, written documentation, which helped ease transition during periods of staff turnover and ultimately increased screening numbers.*

## **IV. CONCLUSION**

Program evaluation at its most basic level should help a program answer two very important questions:

Did the program do what it said it was going to do?

Did the program get the desired outcomes?

Grantees should make evaluation a continuous activity that will help the program meet the goals of the NBCCEDP, as well as its own objectives. When designing the plan, grantees should remember that each component chapter in this manual has an evaluation section. Those sections contain examples of evaluation questions specific to that component and a suggested plan for addressing them.

The table below shows a sample plan for an evaluation of the Evaluation component. However, the sample plan is only a starting point—a grantee should tailor its selected strategies to its specific program needs.

EVALUATION QUESTION	USES OF EVALUATION FINDINGS	PROCESSES	DATA ANALYSIS
Does the evaluation plan cover each component to some degree?	Ensure that the program meets Program Announcement 1205 evaluation criteria for having an evaluation plan	Write an annual program work plan to include measurable objectives and measures of success Develop an evaluation plan to address priority evaluation questions as determined by program staff members	Review the work plan to ensure the presence of objectives, measures of success, and an evaluation plan
To what extent are evaluation results used to shape program decision making?	Establish whether the program is using data to inform programmatic and financial planning	Conduct an evaluation of major priority evaluation questions for the program Analyze evaluation data from the evaluation questions	Review evaluation results and recommendations from each evaluation question and present data for use among program staff members and stakeholders

Evaluating and reporting on a program, as CDC requires, help to ensure that program resources are spent wisely. Evaluation should always lead to action. Program efforts and achievements should be presented to program staff members, CDC, and other stakeholders.

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\* Because of the evolving nature of the Internet, Web sites noted here may no longer exist. In such cases, a global Internet search or search from the noted entity's homepage may be needed to locate specific documents and resources.

## V. RESOURCES

KEY RESOURCES*	
NBCCEDP Work plan	<a href="http://www.cdc.gov/cancer/nbccedp/training/workplans/htm">http://www.cdc.gov/cancer/nbccedp/training/workplans/htm</a> This online self-study packet is part of the NBCCEDP's Work plans: A Program Management Tool Education and Training Packet. It helps to develop a work plan for efficient and effective program management.
CDC Evaluation Working Group—Resources	<a href="http://www.cdc.gov/eval/resources/index.htm">http://www.cdc.gov/eval/resources/index.htm</a> This site provides numerous links to private organizations and individuals, nongovernmental organizations, other CDC sites, universities, evaluation groups, and other useful resources.
CDC Evaluation Working Group—Framework for Program Evaluation	<a href="http://www.cdc.gov/eval/framework/index.htm">http://www.cdc.gov/eval/framework/index.htm</a> This site provides a good basic introduction to CDC's program evaluation framework, steps, and standards.

OTHER EVALUATION RESOURCES	
Community Tool Box	<a href="http://ctb.ku.edu/en/default.aspx">http://ctb.ku.edu/en/default.aspx</a> This site provides guidance and skill building tips on program planning, management, and evaluation. It is a great resource for community-based agencies in conducting public health programs.
Demonstrating Your Program's Worth: A Primer on Evaluation for Programs to Prevent Unintentional Injury	<a href="http://www.cdc.gov/ncipc/pub-res/demonstr.htm">http://www.cdc.gov/ncipc/pub-res/demonstr.htm</a> This primer, written primarily for managers of injury prevention programs, details the importance of evaluation, as well as step-by-step instructions on conducting a simple evaluation.
Evaluation Guidance Handbook: Strategies for Implementing the Evaluation Guidance for CDC-Funded HIV Prevention Programs	<a href="http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/strat-handbook/pdf/guidance.pdf">http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/strat-handbook/pdf/guidance.pdf</a> This manual was developed specifically for evaluating HIV programs. It is a useful reference tool for finding examples such as data collection methods and development of objectives and outcomes.
Introduction to Program Evaluation for Comprehensive Tobacco Control Programs	<a href="http://www.cdc.gov/tobacco/tobacco_control_programs/surveillance_evaluation/evaluation_manual/pdfs/evaluation.pdf">http://www.cdc.gov/tobacco/tobacco_control_programs/surveillance_evaluation/evaluation_manual/pdfs/evaluation.pdf</a> This site is helpful in distinguishing evaluation from other public health activities, such as surveillance and research. It provides a basic overview of CDC's framework.
Physical Activity Evaluation Handbook	<a href="http://www.cdc.gov/nccdphp/dnpa/physical/handbook/pdf/handbook.pdf">http://www.cdc.gov/nccdphp/dnpa/physical/handbook/pdf/handbook.pdf</a>
Program Operations: Guidelines for STD Prevention—Program Evaluation	<a href="http://www.cdc.gov/std/program/ProgEvaluation.pdf">http://www.cdc.gov/std/program/ProgEvaluation.pdf</a> This guide was developed by CDC for use by STD programs in deciding the placement of priorities and resources.

## OTHER EVALUATION RESOURCES (CONTINUED)

Program Development and Evaluation: Evaluation Publications	<a href="http://www.uwex.edu/ces/pdande/evaluation/evaldocs.html">http://www.uwex.edu/ces/pdande/evaluation/evaldocs.html</a> This site offers links to a variety of PDF files, addressing questionnaire design, sampling, data collection and analysis, and reporting evaluation results. Because each topic is discussed in a separate file, relevant information can be accessed easily.
Taking Stock: A Practical Guide to Evaluating Your Own Programs	<a href="http://www.horizon-research.com/reports/1997/stock.pdf">http://www.horizon-research.com/reports/1997/stock.pdf</a> Taking Stock was written for program managers interested in conducting a basic evaluation. It describes the concepts and techniques important to evaluation, and it uses numerous examples throughout the text.
W.K. Kellogg Foundation Evaluation Handbook	<a href="http://www.wkkf.org/knowledge-center/resources/2010/W-K-Kellogg-Foundation-Evaluation-Handbook.aspx">http://www.wkkf.org/knowledge-center/resources/2010/W-K-Kellogg-Foundation-Evaluation-Handbook.aspx</a> Part Two of the handbook is a blueprint for programs to use when conducting evaluation. It details definitions and case studies in planning for an evaluation, then describes designing and conducting evaluation, and concludes with communication findings and results.
Understanding Evaluation: The Way to Better Prevention Programs	<a href="http://www2.ed.gov/PDFDocs/handbook.pdf">http://www2.ed.gov/PDFDocs/handbook.pdf</a>
User-Friendly Handbook for Mixed Method Evaluations	<a href="http://www.nsf.gov/pubs/1997/nsf97153/start.htm">http://www.nsf.gov/pubs/1997/nsf97153/start.htm</a>
American Evaluation Association Guiding Principles for Evaluators	<a href="http://www.eval.org/Publications/GuidingPrinciples.asp">http://www.eval.org/Publications/GuidingPrinciples.asp</a>

## HEALTH COMMUNICATIONS/CAMPAIGNS

CDCynergy	<a href="http://www.cdc.gov/healthcommunication/CDCynergy/index.html">http://www.cdc.gov/healthcommunication/CDCynergy/index.html</a> CDCynergy is a multimedia CD-ROM used for planning, managing, and evaluating public health communication programs. This innovative tool is used to help in designing health communication interventions.
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## LOGIC MODEL RESOURCES

W.K. Kellogg Foundation Logic Model Development Guide	<a href="http://www.wkkf.org/knowledge-center/resources/2006/02/WK-Kellogg-Foundation-Logic-Model-Development-Guide.aspx">http://www.wkkf.org/knowledge-center/resources/2006/02/WK-Kellogg-Foundation-Logic-Model-Development-Guide.aspx</a> This manual describes in detail how to develop logic models.
Program Development and Evaluation: Logic Model	<a href="http://www.uwex.edu/ces/pdande/evaluation/evallogicmodel.html">http://www.uwex.edu/ces/pdande/evaluation/evallogicmodel.html</a> This site provides an explanation of logic models in PDF and PowerPoint file formats.

## EVALUATION TEXTBOOKS

Dignan, M. D. (1989). <i>Measurement and evaluation of health education</i> (2nd ed.). Springfield, IL: Charles C. Thomas.
Fink, A., & Kosecoff, J. (1987). <i>An evaluation primer</i> . Beverly Hills, CA: Sage.
Fitz-Gibbon, C. T., & Morris, L. L. (1987). <i>How to design a program evaluation</i> . Newbury Park, CA: Sage.
Levin, H. M. (1983). <i>Cost-effectiveness: A primer</i> . Thousand Oaks, CA: Sage.
Patton, M. Q. (1987). <i>How to use qualitative methods in evaluation</i> . Thousand Oaks, CA: Sage.
Patton, M. Q. (2002). <i>Qualitative evaluation and research methods</i> (2nd ed.). Thousand Oaks, CA: Sage.
Rossi, P. H., & Freeman, H. E. (1993). <i>Evaluation: A systematic approach</i> (5th ed.). Thousand Oaks, CA: Sage.
Sarvela, P. D., & McDermott, R. J. (1993). <i>Health education evaluation and measurement: A practitioner's perspective</i> . Madison, WI: Brown & Benchmark.
Shaddish, W. R., Cook, T. D., & Leviton, L. C. (1991). <i>Foundations of program evaluation: Theories of practice</i> . Thousand Oaks, CA: Sage.

# ATTACHMENTS

# ATTACHMENT A

## LOGIC MODEL REQUIREMENT FOR NBCCEDP GRANTEES

### Component 3: Health Systems Change and Quality Clinical Preventive Services in the National Breast Cervical Cancer Early Detection Program

#### LOGIC MODEL REQUIREMENT

In DP12-1205 funding announcement, CDC requires the following for NBCCEDP grantees: “The development of an overarching program framework and component specific logic models within the first year of the project period.” The intent of this requirement is to promote improved program planning and evaluation on the part of NBCCEDP grantees.

#### WHY ARE LOGIC MODELS HELPFUL?

Logic models are tools that help planners, implementers, and evaluators graphically depict the relationship between program activities and its intended effects, that is, logic models reflect the program’s theory of change. In this way, logic models support a key step in the CDC evaluation framework to “describe the program.”

By developing a logic model, program planners and implementers can help ensure plausible relationships between the proposed activities and their intended short, intermediate, and long-term outcomes. In addition, logic models benefit program planning by (1) building understanding and clarity about your program among program staff and stakeholders, (2) identifying resources needed for your program, (3) identifying the sequencing of activities that should be implemented, and (4) serving as a basis for program evaluation. Logic models can also serve as a key partnership and communications tool. Your stakeholders’ involvement in constructing a logic model will promote their commitment to, and shared vision and ownership of the program plan, as well as their initial buy-in for evaluation. In-turn, involving stakeholders will help them to better understand the time it takes to achieve short, intermediate and long-term outcomes, as well as the importance of prioritizing the activities that need to be evaluated.

#### GRANTEE REQUIREMENTS

- 1. Overall NBCCEDP Framework.** Grantees are required to create and finalize an overarching program logic model or framework for the NBCCEDP within the first year of the project period. The overarching program framework should illustrate how program components work together to achieve program outcomes outlined in the FOA, as well as other outcomes that are important to the program. The overarching framework should reflect key program strategies and interventions (e.g. small media campaigns, professional training programs), including those activities that go beyond addressing women directly screened by the program (screening provision) to include strategies that implement evidence-based interventions on a population level (screening promotion). See figure 2 above, the NBCCEDP logic model for the national program as an example.

**2. Component Specific Logic Models.** Grantees are also required to create and finalize component-specific logic models. Outcomes in these models should link to the overarching NBCCEDP program framework. Grantees are encouraged to develop logic models for each program activities implementation. At a minimum, however, grantees should develop 2 component-specific logic models within the first year of the project period (June 30, 2013):

- Public Education and/or Targeted Outreach, and
- Quality Assurance and Quality Improvement

**3. Logic Model Elements.** Logic models developed by grantees should include the following elements:

- **Inputs** - Tangible or intangible resources, contributions, and investments brought to support the program. (e.g., What do we need to implement and evaluate the program?)
- **Activities** - Processes, activities, services, events, tools, technology, products, and actions that are an intentional part of the grantee's program implementation and are undertaken to bring about desired outcomes. (e.g., What are we doing as part of our program to bring about desired changes?)
- **Outputs** - Tangible products that measure and ensure the effective implementation of program activities. (e.g., What are the immediate results of our activities? Are we implementing the activities well?)
- **Outcomes** - The expected changes for individuals, groups, communities, organizations, or systems based on the program activities, typically cast as: short-term, intermediate, and long-term. (e.g., What are the desired changes for the program?)

# **ATTACHMENT B**

## BCCEDP EVALUATION PLAN WORKSHEET

Using the BCCEDP Evaluation Plan Worksheet, grantees can develop a roadmap for evaluating major questions about their programs.

After completing this worksheet, the grantee should have a fully developed evaluation plan, including activities that need to be completed to address all priority evaluation questions. Grantee staff members should keep in mind both the **evaluation standards** and the program's **evaluation capacity** (i.e., its resources) as they develop the evaluation plan.

As grantee staff members think through each aspect of the evaluation plan, they may need to revise other components of the plan. The process will likely be an ongoing cycle of revisions rather than a linear, step-by-step process.

To prioritize what to evaluate, grantee staff members should determine what objectives were not met last year. They then should develop a plan to evaluate why these objectives were not met. Also, any new or expensive initiatives should be identified and evaluated.

### INTRODUCTION OF THE EVALUATION PLAN COMPONENTS

1. **Evaluation questions**—Identify evaluation questions to be examined in the evaluation. Questions can be derived from the objective listed in the program workplan, or they can be about the program in general.
2. **Uses of evaluation findings**—Describe potential uses and users of the evaluation data. Grantee staff members should think about ways in which the information gathered from the evaluation will be applied, starting with something as simple as informing next year's plans. Relevant audiences should be identified, ranging from CDC (funder) to policymakers and other stakeholders.
3. **Processes**—Identify activities necessary to answer the evaluation question and provide a brief description of them. For example, the evaluation method for the previously mentioned evaluation questions may include a review of program forms, an observation of data entry to look for errors, or a review of the data system. Think through the design, method, data collection instrument, and source. Grantees should consider the quality (the appropriateness and integrity of information), quantity (the amount of evidence gathered), and logistics (methods, timing, and physical infrastructure for gathering and handling evidence).
4. **Data collection strategy and analysis**—Describe the data review processes to answer the evaluation questions. Grantees should indicate the data to be used in demonstrating whether or not the objective was met. They also should identify the actual data indicator or specific, measurable characteristic that represents an achievement of the outcome. In addition, the data source from within the program should be indicated. Data sources could be secondary data, existing information that has been collected already, or primary data that needs to be collected. They could be the same items that are listed in the data section of the workplan for a particular objective.

The numerical objectives for a data indicator, or measure of success, in the achievement of the outcome and the data analysis for the related evaluation question should be identified. The program can set targets for the indicator or expectations for the amount of change. Performance standards set by the program or CDC can be used to help set these expectations. Sometimes, the measure of success in the workplan is the same as the outcome performance standard.

*Examples:*

**Data indicator**—The number of women who have never or rarely been screened in the program.

**Data source**—Medical records.

**Performance standards/measures of success**—(1) Twenty percent of newly enrolled women have not been screened in 3 years for cervical cancer, and (2) at least three recruitment activities to reach priority populations for screening were conducted in the past year.

The following tables present a sample program evaluation plan developed from a sample work plan.

## EXAMPLE PROGRAM COMPONENT: SCREENING WORK PLAN

GOALS FOR THIS YEAR	MEASURES OF SUCCESS
Provide a BCCEDP in 20XX for uninsured and underinsured women aged 35–64 or below 250% of the poverty level, with emphasis on reaching underserved women who have never or rarely been screened	<ol style="list-style-type: none"> <li>1. At least 4,000 women aged 35–64 will receive mammograms and Pap tests.</li> <li>2. At least 75% of Program X women receiving mammograms will be aged 50–64.</li> <li>3. At least 20% of Program X women who received Pap tests will have never or rarely been screened for cervical cancer.</li> </ol>

	OBJECTIVES	ACTIVITIES PLANNED TO ACHIEVE EACH OBJECTIVE	DATA	TIMEFRAME FOR ASSESSING PROGRESS	TEAM MEMBERS RESPONSIBLE
1.	By June 30, 20XX, Program X will screen 4,000 women for mammograms and Pap tests.	Contract with health department and community clinics to recruit and schedule women for screening	Enrollment and screening data program records	12/1/20XX	Program director Service delivery coordinator
2.	By June 30, 20XX, 75% of women receiving mammograms through Program X will be aged 50–64.	Continue efforts to screen women aged 50–64 through local agencies Assess this percentage on a quarterly basis	Client data program records	Quarterly	Program director Service delivery coordinator
3.	By June 29, 20XX, 20% of Program X clients receiving Pap tests will have never or rarely been screened for cervical cancer.	Continue efforts to screen women who have never or rarely been screened Assess this percentage on a quarterly basis	Client data program records	Quarterly	Program director Service delivery coordinator

## EXAMPLE EVALUATION PLAN FOR SCREENING

EVALUATION QUESTION	USES OF EVALUATION FINDINGS	PROCESSES	DATA ANALYSIS
To what extent did Program X reach its goal for screening 4,000 women for mammograms and Pap tests?	<p>Determine if program reached screening targets</p> <p>Inform program staff members, program service providers, and CDC of how the program is progressing toward the screening goals</p> <p>Determine next year's budget request</p>	Review patient demographic data to determine the number of women screened	<p>Compare evaluation results with set program or CDC standards—4,000 or more women aged 35–64 will be offered mammograms and Pap tests</p> <p>Assess and discuss results monthly; present them in a progress report to CDC every 6 months</p>
To what extent did Program X reach its target of 75% of women aged 50–64 receiving mammograms?	<p>Determine if recruitment efforts are working as intended and allow staff members to change recruitment efforts if necessary</p> <p>Inform program staff members, program service providers, and CDC on whether progress toward the performance indicators is being made</p>	Review patient demographic and screening information data to determine the number of women screened aged 50–64	<p>Compare evaluation results with set program or CDC standards—75% or more of Program X's women will be aged 50–64</p> <p>Assess, report, and discuss this percentage on a quarterly basis</p>
To what extent did Program X reach its target of 20% of newly enrolled women receiving Pap tests having never or rarely been screened for cervical cancer?	<p>Determine if recruitment efforts are working as intended and allow staff members to make changes in recruitment efforts if necessary</p> <p>Inform program staff members, service providers, and CDC on whether progress toward the performance indicators is being made</p>	Review patient demographic and screening information data to determine the number of women screened who have never or rarely been screened for cervical cancer	<p>Compare evaluation results with set program or CDC standards—20% or more of newly enrolled Program X women who received Pap tests will have never or rarely been screened for cervical cancer</p> <p>Assess, report, and discuss this percentage on a quarterly basis</p>

## SELECTION OF AREAS TO IMPROVE FROM THE EVALUATION

A grantee can use its evaluation findings to help in making decisions. For example, if a program did not meet its target of screening 4,000 women but successfully met the other two objectives, the screening target would become the object of further focus.

Grantees should think about reasons why the program did not meet its objectives. For example, the following should be considered:

1. Is 4,000 a reasonable target?

*Answer:* Yes. This goal still reaches only 10% of the overall eligible population.

2. Of the eligible women, who is most likely and least likely to get screened?

*Answer:* Women in X county are most likely to get screened, and Hispanic women are the least likely.

3. Did the program have a complete marketing plan?

*Answer:* Yes. A marketing plan exists. In the review of the plan, the grantee found that the plan does not delineate any specific marketing to Hispanic women.

This process shows that the examination of program data can be useful in finding out what the program did. These data also may indicate that the program is doing well in certain areas and, thus, that its focus should shift so that areas of weakness can be improved. Grantees should then think about why the program is not meeting the set objectives and suggest potential solutions.

Therefore, using evaluation data can be a very iterative process that allows a grantee to identify and focus on keys areas for improvement.

# **ATTACHMENT C**

## EVALUATION STANDARDS

The Joint Committee on Standards for Educational Evaluation developed 30 program evaluation standards in four main categories to be used for assessing whether evaluative activities are well designed and working to their potential.\* These standards provide practical guidelines that grantees can follow when deciding among evaluation options. Grantees should consider these overarching standards throughout the evaluation process.

	CATEGORY	KEY QUESTIONS	RESULTING CONSIDERATIONS
1.	Utility	Will the evaluation activity lead to something useful?	Valuable resources (employee time and/or money) should not be wasted if there is no plan or process for using the evaluation results.
2.	Feasibility	Is the activity practical and politically viable?	Can the program get the information it needs?
3.	Propriety	Is the activity ethical? Does the activity harm anyone? Is the activity honest and responsible?	A provider evaluation that publicly details preliminary, unsubstantiated concerns over quality would not be ethical.
4.	Accuracy	Will the activity lead to accurate results and valid interpretation?	Data that are known to be extremely flawed should not be used.

\*Joint Committee on Standards for Educational Evaluation. (1994). *The program evaluation standards: How to assess evaluations of educational programs* (2nd ed.). Thousand Oaks, CA: Sage.

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