

# **Program Guidelines**

**for**

## **Breast and Cervical Cancer Early Detection**

**1997**

# Acknowledgments

Many individuals worked together to prepare this document entitled *Program Guidelines for Breast and Cervical Cancer Early Detection*. These participants are gratefully acknowledged for their dedication to reducing avoidable mortality from breast and cervical cancer and for their commitment and persistence in developing the guidelines.

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Strategic Health Concepts—a private organization in Denver, Colorado—planned and facilitated the group process that led to the development of the guidelines presented in this document. The Centers for Disease Control and Prevention supported these efforts through Professional Services Contract #0009485736.

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# Introduction

**D**uring the 1990s, breast or cervical cancer will be diagnosed for about 2 million American women and half a million women will lose their lives to these diseases.<sup>1</sup> A disproportionate number of these deaths will occur among women of low income.

The scientific basis of early detection programs for breast and cervical cancer is well established. Because we do not know how to prevent breast cancer, detecting carcinoma of the breast at an early stage is important to more treatment options, improved survival, and decreased mortality.<sup>2</sup> Research has shown that the use of mammography can reduce mortality due to breast cancer among women aged 50–69 by 30%.<sup>3,4</sup> The primary goal of cervical cancer screening is to increase detection and treatment of cervical intraepithelial neoplasia (CIN) and thereby prevent the occurrence of invasive cervical cancer. Screening can also detect cervical cancer at an earlier stage and reduce morbidity and mortality from the disease. Although no clinical trials have studied the efficacy of the Papanicolaou (Pap) test in reducing cervical cancer mortality, experts agree that the technology is effective. Since the introduction of the Pap test in the 1940s, cervical cancer mortality rates have decreased by 75%.<sup>5</sup>

The program guidelines for breast and cervical cancer early detection presented here were developed to help public health professionals implement comprehensive programs to reduce and potentially eliminate morbidity and mortality associated with breast and cervical cancers. Sufficient experience in program development, implementation, and evaluation has been accumulated by the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to develop a set of guidelines that could be broadly agreed upon by the Centers for Disease Control and Prevention (CDC) and representatives from a wide range of states and program models.

These guidelines were developed jointly by CDC and representatives from state-based breast and cervical cancer programs funded through the NBCCEDP. In January 1995, a working group of representatives from 21 state programs, five facilitators from the private sector, and staff members from CDC's Division of Cancer Prevention and Control met in Denver, Colorado, to develop the guidelines. Over a 3-day period, the working group produced three drafts of the guidelines. Small-group meetings, conference calls, and written feedback were used to develop the final version of the guidelines following the workshop.

The primary audience for these guidelines is public health professionals of states, American Indian and Alaska Native tribes and tribal organizations, U.S.

territories, and organizations involved with breast and cervical cancer early detection programs. The guidelines can help public health professionals to develop, implement, and evaluate breast and cervical cancer early detection programs. Each guideline is considered a basic building block for a high-quality early detection program. However, these guidelines should not be construed as standards against which programs can be assessed and their effect determined. Unlike standards, the guidelines do not address how much a program should achieve to be effective or how a program should achieve its goals. The guidelines were developed to parallel the main program components found in the NBCCEDP.

These guidelines may be used to provide the following:

- Consistent direction and guidance for program efforts.
- A mechanism for identifying common gaps and needs in program services and ways to develop resources to address these issues.
- A resource for orientation and training.
- An operational framework for connecting the implementation of programs with the ultimate outcome of preventing avoidable deaths from breast and cervical cancers.
- Flexibility to develop a program that meets the individual needs of states, territories, and tribes and tribal organizations.
- A statement of program direction for partners and stakeholders.

# Background

In 1986, the National Cancer Institute issued the report, *Cancer Control Objectives for the Nation: 1985–2000*,<sup>6</sup> which summarized research on the efficacy of early detection programs for breast and cervical cancers, articulated national objectives, and estimated their effect on mortality. Subsequently, CDC described cancer screening behavior among women,<sup>7</sup> breast and cervical cancer mortality,<sup>8</sup> and breast cancer screening behavior among women aged 50 years and older.<sup>9</sup> In the first half of the 1990s, interest in and support for legislation to help reduce avoidable mortality from breast and cervical cancers surged. The most prominent example of this support was the passage in 1990 of the Breast and Cervical Cancer Mortality Prevention Act (Public Law 101-354, Title XV, Public Health Service Act). This act established the NBCCEDP to increase access to and use of breast and cervical cancer screening services among low-income women who are uninsured and underinsured. This CDC initiative has been implemented through cooperative agreements with state and U.S. territorial health agencies and American Indian and Alaska Native tribes and tribal organizations. Programs conduct activities in seven areas: public education; professional education; screening; quality assurance; surveillance, tracking, and follow-up; evaluation; and coalition and partnership development. Outreach efforts have been initiated to reach women in high-priority groups, including older women, women of racial or ethnic minority groups, lesbians, women with disabilities, and women who live in hard-to-reach areas. In addition to serving high-priority groups, this comprehensive approach ensures that all women can benefit from the Program's public and professional education activities; quality assurance standards; surveillance, tracking, and follow-up; and collaborative partnerships.

The NBCCEDP reimburses programs for providing clinical breast examinations, screening mammograms, pelvic examinations, Pap tests, and most diagnostic procedures. The law prohibits using federal money to pay for treatment; however, programs are required to identify and obtain financial resources to ensure that women for whom precancerous lesions or cancer is diagnosed receive timely and appropriate treatment. To ensure high-quality screening tests for program participants, all mammography facilities are required to meet quality assurance standards of the Food and Drug Administration. Laboratories that provide cytology services are required to comply with standards of the Clinical Laboratory Improvement Amendments of 1988 (Public Law 100-578).

In 1991, CDC and its state partners developed a set of standard data items for tracking NBCCEDP's screening, diagnostic, and treatment activities. Each time a woman receives a mammogram or Pap test through the program, information is collected about her demographic characteristics, history of prior mammogram or

Pap test screening results, diagnostic procedures and outcomes, and initiation of treatment. Programs use the data to track and follow women served by the program, monitor the quality of clinical services, and assess program practices and outcomes. The data are sent to CDC twice a year.

In fiscal year 1998, NBCCEDP began its eighth year. CDC now funds full-scale screening programs in 50 states, 4 U.S. territories, the District of Columbia, and 15 American Indian and Alaska Native tribes and tribal organizations. Puerto Rico currently receives funding for capacity building to prepare for the delivery of a screening program.



# Organization of This Document

**T**his document presents screening principles followed by a summary chart of the guidelines by program component. The guidelines are not numbered because they are not sequential and are considered part of integrated, comprehensive programs. Each component is then described by statements of the goals or ideals that a program should attempt to achieve. Each program component guideline (in *boldface italic* type in the text) is followed by a description of key issues and lessons learned that public health professionals may use in applying the recommended guidelines.

# Screening Principles

Several underlying principles are critical to the development of high-quality breast and cervical cancer programs that transcend the individual guidelines.

- The consumer's perspective, along with the service provider's and other partners' perspectives, should be carefully considered in the overall program design and delivery of screening services.
- Screening services are not freestanding efforts and should be integrated into the community's service structure.
- Screening services should be integrated with other clinical services to ensure timely and appropriate diagnostic evaluation and treatment services.
- Client interventions should be individualized and consider cultural, language, and literacy issues.
- In order for programs to balance and integrate the various program components, ongoing, open communication should occur among the team of program implementers, and coordination with partners who provide clinical, educational, and support services is essential.
- Programs should be given the flexibility to allow for adaptation and growth in a health care system undergoing rapid and dramatic change.

**SUMMARY CHART OF PROGRAM GUIDELINES  
FOR BREAST AND CERVICAL CANCER EARLY DETECTION**

<b>Program Component</b>	<b>Guidelines</b>
Management	<p>The program should</p> <ul style="list-style-type: none"> <li>◆ develop and use a strategic plan, based on goals and objectives, that is responsive to the characteristics and needs of the priority populations. This plan should guide the development of an operational approach for managing day-to-day program activities.</li> <li>◆ have adequate human resources to support the implementation of the strategic and operational plans.</li> <li>◆ establish, nurture, and maintain a comprehensive network of partners to support the planning, implementation, monitoring, and evaluation of each program component.</li> <li>◆ identify and develop appropriate sources of data and use the information to inform decision making and enhance program management.</li> </ul>

Program Component	Guidelines
Public Education	<p>The program</p> <ul style="list-style-type: none"> <li>◆ and partners should develop a plan that defines the scope (content, priority populations, methods, strategies, outcomes, and resources) of the public education effort.</li> <li>◆ should build, enhance, and maintain the infrastructure necessary to sustain public education efforts for breast and cervical cancer early detection.</li> <li>◆ should use culturally appropriate public education strategies and methods that address barriers to, and incentives for, a woman's participation in breast and cervical cancer early detection.</li> </ul>

Program Component	Guidelines
Professional Education	<p>The program</p> <ul style="list-style-type: none"> <li>◆ and partners should develop a plan that defines the scope (content, provider populations, strategies, methods, outcomes, and resources) of professional education.</li> <li>◆ should prioritize professional groups to be trained and determine the content of the training.</li> <li>◆ should build, enhance, or maintain the infrastructure necessary to sustain professional education efforts for breast and cervical cancer early detection.</li> <li>◆ should provide feedback about data to health professionals in a form that may affect knowledge, attitudes, practices, and health service systems.</li> </ul>

Program Component	Guidelines
Service Delivery and Quality Assurance	<p>The program should</p> <ul style="list-style-type: none"> <li>◆ establish administrative, service delivery, and quality assurance mechanisms to provide breast and cervical cancer screening and diagnostic services for eligible women.</li> <li>◆ set minimum requirements and standards for quality service delivery.</li> <li>◆ establish and periodically review clinical practice guidelines for all phases of service delivery, including screening, diagnosis, and referral for treatment services.</li> <li>◆ develop services that are accessible (including location, cultural sensitivity, hours of operation, and types of providers) to women from priority populations.</li> <li>◆ ensure that women for whom screening results are normal return for rescreening at recommended intervals.</li> <li>◆ ensure that women with abnormal screening results, precancerous lesions, or cancer receive timely and appropriate diagnostic or treatment services.</li> <li>◆ develop policies to promote providers' ongoing participation in, and compliance with, screening, diagnostic, and treatment recommendations.</li> <li>◆ develop policies to promote women's ongoing participation in, and adherence to, screening, diagnostic, and treatment recommendations.</li> </ul>

Program Component	Guidelines
Surveillance, Tracking, and Follow-Up	<p>The program should</p> <ul style="list-style-type: none"> <li>◆ develop a system to collect, edit, manage, and continuously improve the quality of data.</li> <li>◆ ensure that adequate and appropriate data are collected to meet surveillance, tracking, and reporting requirements.</li> <li>◆ ensure that clinical data collected about enrolled women are used to provide diagnostic services to those with abnormal screening results and treatment for women with precancerous lesions or cancer.</li> <li>◆ develop an efficient reminder system to invite women with normal screening results to be rescreened at recommended intervals.</li> <li>◆ establish a mechanism to ensure the submission of timely, complete, and accurate data.</li> <li>◆ develop systems for ongoing data analysis and prompt response to requests for information.</li> </ul>

Program Component	Guidelines
Evaluation	<p>The program should</p> <ul style="list-style-type: none"> <li>◆ develop objectives that are specific, measurable, and defined by time for both the overall program and each program component.</li> <li>◆ develop an overall evaluation strategy to meet short- and long-term evaluation needs.</li> <li>◆ allocate sufficient resources to support evaluation activities to ensure quality results.</li> <li>◆ develop and maintain systems for data collection and ongoing evaluation.</li> <li>◆ use evaluation data to improve program management, practices, activities, and systems.</li> </ul>



# Management

**M**anagement guidelines are intended to help develop the infrastructure and operating environment necessary to the optimal use of program resources. Programs benefit by implementing strategic planning, broadly defined as the process for analyzing environmental challenges, issues, and opportunities that affect the organization. For breast and cervical cancer screening programs, this process should involve human resource and fiscal planning, identification of service gaps, and the use of data for decision making. Each program component should be addressed by a strategic and operational plan.

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*The program should develop and use a strategic plan, based on goals and objectives, that is responsive to the characteristics and needs of the priority populations. This plan should guide the development of an operational approach for managing day-to-day program activities.*

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## Key Issues

- ▶ Ensure that the strategic plan includes a mission statement, goals, measurable objectives, activities, and an evaluation plan.
- ▶ Ensure that goals, objectives, and activities are responsive to federal, state, territorial, tribal, and local regulations and requirements.
- ▶ Promote active participation of coalitions, priority populations, and key stakeholders (internal and external) in the development of the plan and its periodic review.
- ▶ Plan for fiscal, regulatory, billing, and provider reimbursement issues.
- ▶ Use a phased approach for implementing the strategic plan, and reassess and revise as circumstances change and new data are collected and analyzed.
- ▶ Integrate and coordinate the strategic plan with other plans for cancer control and with activities for other chronic diseases.

## Lessons Learned

- Ensure that the program is coordinated and integrated with broad state, tribal, or territorial cancer control plans.
- Expect gaps in program resources and plan to modify program activities and allocate resources accordingly.
- Continuously assess the characteristics, gaps, and resource needs of the program's service areas.
- Administrative constraints may restrict program flexibility and progress. These constraints should be communicated to program planners and partners so that they understand potential limitations and can help with problem solving.

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*The program should have adequate human resources to support the implementation of the strategic and operational plans.*

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## Key Issues

- Design and implement a human resources plan to meet the staffing needs of each program component. This plan should include job descriptions, workplans, and a process for performance reviews.
- Recruit and hire staff who have a broad range of expertise and reflect the diversity of the priority populations to be served by the program.
- Develop an orientation program for employees that provides an introduction to, and overview of, each program component.
- Dedicate significant time to training staff, especially when staff turnover occurs in the program and at provider sites.
- Define clearly the scope of work, reporting requirements, and timelines when executing contracts.
- Develop contracts that have performance-based goals and measures for ensuring contractors' accountability for deliverables and expected outcomes.
- Develop an action plan to address performance issues with contractors.

- Use several approaches to implement program strategies, such as subcontracting with community organizations, hiring lay health workers, and recruiting volunteers to help support program components where additional human resources are needed.
- Develop a working relationship with organizations, volunteers, and lay health educators who offer a broad range of experience and also reflect the diversity of priority populations to be served by the program.

## **Lessons Learned**

- Understand the capacity and limitations of your personnel system to plan for your human resource needs.
- Full-time equivalent positions may not be available, and contracts may be needed to support human resource needs.
- Plan for restrictions and delays in the recruitment and hiring process. The flexibility to replace staff or resources to hire new staff may fluctuate.
- Salaries may not be competitive with the private sector, and maintaining morale and retaining staff may be difficult. Be proactive and creative in identifying career and training opportunities.
- Recruiting and hiring staff who have multidisciplinary skills and are culturally sensitive may be difficult.
- Using contractors to implement program activities can be complicated by grant policies and requirements and the challenges of working with outside agencies.

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*The program should establish, nurture, and maintain a comprehensive network of partners to support the planning, implementation, monitoring, and evaluation of each program component.*

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## **Key Issues**

- ▶ Plan how to develop support for coalitions, which may require reimbursement for travel and meetings.
- ▶ Conduct an inventory of resources for program planning and implementation that will be broad in scope and includes staff needs, provider networks, and potential partners.
- ▶ Be creative in identifying relevant partners. Consider using community networks, community agencies, resource directories, and other state, tribal, and territorial organizations to identify potential new partners.
- ▶ Promote strong communication between program staff and partners by using committee meetings, newsletters, formal and informal meetings, conference calls, and ad hoc working groups.
- ▶ Develop ways to hold partners accountable for deliverables or outcomes of activities to which they have committed.

## **Lessons Learned**

- Ensure that roles of partners are well defined and that they benefit from participation in the program.
- The process of identifying partners and enlisting and sustaining their support is an ongoing and dynamic process.
- Be prepared to mediate, negotiate, and serve as a catalyst to encourage productive collaboration among partners.
- Duplication of effort among partners is likely and is usually acceptable, because most activities cannot be accomplished by only one entity.
- Partners can strengthen or compromise statewide coalition efforts. It may be possible to use existing coalitions to help accomplish the program's goals

and priorities. Some members may have extensive coalition experience; others may have limited experience.

- Some agencies or groups that have been active in the cancer control field may not accept your program.

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*The program should identify and develop appropriate sources of data and use the information to inform decision making and enhance program management.*

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## **Key Issues**

- ▶ Anticipate all possible requests for information and develop a plan for addressing them.
- ▶ Develop a plan and a schedule for refining data and disseminating program results.
- ▶ Institute a system for providing feedback about screening outcomes to staff responsible for other program components.
- ▶ Use a variety of resources and expertise to manage, analyze, and interpret program data and results.

## **Lessons Learned**

- Be prepared to handle freedom of information requests that may pose legal, ethical, liability, and confidentiality questions. Recognize that personal identifiers and screening, diagnostic, and treatment data are confidential information.
- Recognize that data quality may vary, and use caution in drawing conclusions about program results and making recommendations about future efforts.
- Understand how to use process and outcome data and the types of program decisions that can be made by using these data.

# Public Education

**P**ublic education can be a powerful frontline force in the early detection of breast and cervical cancers. Using different modes of communication and considering consumers' perspectives, public educators interact with women from priority populations in ways that are sensitive to their needs and interests. Public education motivates women and supports their efforts to adopt behaviors such as having a clinical breast examination and a pelvic examination, obtaining Pap tests and mammograms, and conducting routine breast self-examination. Education informs women of their risk for breast and cervical cancers and the importance of early detection, reduces or eliminates barriers that prevent participation in screening, and creates social and environmental support systems that encourage ongoing participation in screening.

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*The program and partners should develop a plan that defines the scope (content, priority populations, methods, strategies, outcomes, and resources) of the public education effort.*

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## Key Issues

- ▶ Establish measurable objectives for public education activities and determine how to measure results.
- ▶ Identify and describe the priority populations, including older women, women of racial and ethnic minority groups, lesbians, women with disabilities, and women who live in hard-to-reach areas.
- ▶ Apply and use health promotion theory in developing public education methods and strategies.
- ▶ Avoid duplication by assessing current public education efforts in your area and adapting proven strategies from them.
- ▶ Consider using technological advances such as e-mail, the Internet, teleconferencing, and computer health information databases to communicate education information.
- ▶ Define a common screening message that expresses a purpose and action and is adaptable to the cultural context of priority populations.

- ▶ Identify and use communication channels accessed by women from priority populations.
- ▶ Increase message effectiveness by tailoring messages and the methods of delivery to specific populations.
- ▶ Involve women from priority populations in program planning and implementation.
- ▶ Share ownership of your program by developing a broad and inclusive implementation plan. Collaborate with organizations and groups that have access and provide services to women from priority populations.
- ▶ Coordinate and cultivate relationships with partners who can support or assist clients with services that go beyond the scope of the program.

## **Lessons Learned**

- Unexpected events, changes in policy, or limited resources may influence the implementation of your plan.
- Partners already active in breast and cervical cancer control may prefer not to collaborate.
- A perceived lack of history or experience with a priority population may exist. Additional time may be necessary to establish trust in, and acceptance of, your program.
- Subgroups in a community may feel left out or overtargeted regarding participation in screening services. Be sure to establish balanced relationships with priority populations.
- Available information about priority populations may be inadequate; be prepared to find alternative ways to collect necessary information.
- Some public education strategies are more difficult to measure than others. Develop a process to assess whether public education efforts affect the number of women screened or rescreened. Consider using short-term and intermediate outcomes to measure the effectiveness of strategies.
- Education about breast and cervical cancers is only one part of cancer prevention and control and of overall health care.

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*The program should build, enhance, and maintain the infrastructure necessary to sustain public education efforts for breast and cervical cancer early detection.*

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## **Key Issues**

- ▶ Conduct an inventory of state and community capacity and resources, such as communication technology, educational materials, partnerships, and training centers, that can be used for public education.
- ▶ Develop partnerships and coalitions to increase the likelihood of community ownership and institutionalization of early detection activities.
- ▶ Recruit key community leaders to serve as advocates of public education initiatives.
- ▶ Use private sector organizations (e.g., insurance companies, managed care organizations, foundations, and corporations) that can help support and enhance community involvement in public education activities by contributing financial and in-kind resources.

## **Lessons Learned**

- Plan for the possibility that public education may increase demand for screening services beyond the capacity of providers.
- Establishing trustful relationships with community organizations, priority populations, and providers may be difficult if there is a previous history of public education efforts being begun and eliminated.



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*The program should use culturally appropriate public education strategies and methods that address barriers to, and incentives for, a woman's participation in breast and cervical cancer early detection.*

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## **Key Issues**

- ▶ Review the literature and existing programs to identify interventions that can be adapted.
- ▶ Involve priority populations in planning outreach, developing messages, and improving service delivery. Their involvement will help identify the barriers that discourage women from seeking screening and the strategies that can address these issues.
- ▶ Hire culturally diverse staff who have experience working with priority populations and who can develop strategies to encourage women to participate in routine screening.

## **Lessons Learned**

- Differences in the screening guidelines recommended by various national and professional organizations may cause confusion among both women and providers. Providers' practices may also differ.
- Identifying and overcoming women's barriers to screening takes time, effort, and resources.
- If poor relationships exist with underserved communities, program staff will need to identify effective approaches for changing perceptions and establishing positive partnerships.

# Professional Education

The professional education guidelines describe a broad range of educational and training opportunities that have the ultimate goal of improving the quality of care for women. Professional education efforts can be focused in several key areas. Educational opportunities for health care professionals who provide breast and cervical cancer screening services can be influenced by the training curricula for new professionals enrolled at training institutions or through continuing education efforts for current professionals. By establishing educational opportunities through professional societies or training institutions, an ongoing educational initiative can be developed to influence and maintain future training. Professional education can also help develop clinical systems of practice that promote women's participation in screening. Quality-of-care issues should be addressed by improving client care systems that can help providers identify and track clients and remind them when they are due for rescreening. The opportunities are vast and challenging, but through establishing and cultivating partnerships with key professional groups, the program can create and support leaders for professional education who will influence practices for breast and cervical cancer early detection.

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*The program and partners should develop a plan that defines the scope (content, provider populations, strategies, methods, outcomes, and resources) of professional education.*

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## Key Issues

- ▶ Identify existing health care systems and determine how your program can work with and be integrated into such systems. View professional education from two perspectives: systems within which care is provided; and improvement of the knowledge and skills of professionals.
- ▶ Identify all types of professionals, including primary care physicians, surgeons, obstetrician-gynecologists, radiologists, radiologic technologists, nurse practitioners, registered nurses, licensed practical nurses, physician assistants, cytotechnologists, cytopathologists, pathologists, health educators, community health workers, and office staff, who may be involved in breast and cervical cancer screening in your program.
- ▶ Collaborate with groups that accredit, certify, or provide continuing education for health professionals in planning professional education. These

groups may include universities or hospitals, university schools of nursing, hospital nursing staff development offices, professional medical and nursing groups, state cytology societies, and radiologic technologist societies. Be knowledgeable of requirements for certification and continuing education for each profession, as these may vary from state to state.

- ▶ Identify and collaborate with coalitions, medical advisory groups, lay health advisors, and alternative providers such as traditional healers.
- ▶ Look for opportunities to integrate the program's educational activities with other training sponsored by professional organizations and health care agencies. This strategy is essential to the success and sustainability of professional education.

## **Lessons Learned**

- The scope of professional education goes beyond clinical practice to include provider-client communication, cultural sensitivity, and the environment in which health care is delivered.
- Professional education is a long-term, continuous process.
- State health agencies may not be viewed by health professionals as credible sources of professional education.
- Use of public resources to train health professionals may be viewed negatively in the community.
- Resources, including funds, qualified personnel, in-kind support, and training opportunities, may be scarce. The program may not be able to respond to the needs of all interested groups.
- Individuals and professional groups who are asked or even required to participate in professional education activities may prefer not to collaborate with the program.

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*The program should prioritize professional groups to be trained and determine the content of the training.*

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## Key Issues

- ▶ Ensure that providers delivering clinical services for breast and cervical cancer screening programs receive high priority for professional education and training.
- ▶ Set priorities for training among professional groups. For example, focus on groups that have gaps in knowledge and services needs; need to maintain professional accreditation; are affected by changes in clinical guidelines; or provide new opportunities to expand knowledge and skill of professionals.
- ▶ Design or influence training techniques that combine practice, application, and lecture.
- ▶ Use training methods appropriate to content. For example, clinical breast examination (CBE) should be taught using a skills-based approach, not a lecture method.
- ▶ Use medical schools and training systems that offer continuing medical education (CME), continuing nurse education units (CNEUs), and continuing education contact hours (CECHs) for certified health education specialists (CHESs) as vehicles for training programs.
- ▶ Evaluating skills is more difficult than evaluating knowledge. Consider issues such as time, resources, and audience acceptability in evaluating health professionals' knowledge and skills. An evaluation can occur immediately after the training has been completed or after staff members have returned to their agencies.
- ▶ Identify incentives for, and remove barriers to, attending training, such as CME/CNEUs/CECHs, location, resources, and timing.
- ▶ Know and use accepted guidelines for clinical care in professional education, such as the following examples:
  - *Cervical Cytology: Evaluation and Management of Abnormalities* (American College of Obstetricians and Gynecologists Technical Bulletin Number 183, August 1993)

- *Papanicolaou Technique: Approved Guideline* (The National Committee for Clinical Laboratory Standards document GP 15-A, July 1994)
  - *Breast Cancer in North Carolina: A Handbook for Health Care Providers* (North Carolina Comprehensive Breast and Cervical Cancer Control Coalition)
  - *Evaluation of Common Breast Problems: A Primer for Primary Care Providers* (prepared by the Society of Surgical Oncology and the Commission on Cancer of the American College of Surgeons for the Centers for Disease Control and Prevention)
- Design or recommend marketing strategies to promote participation in training programs.

## Lessons Learned

- Much of the information needed to prioritize professional education activities, as well as conduct and evaluate training, already exists. Review the literature and databases, such as the Cancer Prevention and Control Subfile in the Combined Health Information Database (CHID), contact key collaborators and professional education personnel in other states, and review program data.
- Balance program priorities (e.g., proper CBE techniques) with health professionals' requests for training (e.g., risk management).
- State laws and policies affecting clinical practice and state requirements for licensure may influence participation in training.
- Inequalities in training opportunities may exist among different professional groups or by geographic regions.
- A lack of knowledge or skill among health professionals may be due to a lack of available training or to reluctance toward training. Conduct a needs assessment to help with the development and implementation of a training plan.

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*The program should build, enhance, or maintain the infrastructure necessary to sustain professional education efforts for breast and cervical cancer early detection.*

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## **Key Issues**

- ▶ Advocate for the incorporation of breast and cervical cancer education in appropriate curricula for health professionals to have a long-term effect.
- ▶ Recruit health professionals who are knowledgeable about professional education and who can effect curricula changes in training institutions and through continuing education opportunities to serve on the program's medical advisory committee or coalition.
- ▶ Make use of training opportunities at teaching institutions and through continuing education opportunities to reach health professionals. Goals and outcomes for educating new professionals differ from those for educating current practitioners. For example, training new professionals (pre-service education) may have a long-term effect on screening practice. Changing the screening behaviors of current practitioners may take more time and effort.
- ▶ Establish relationships with partners from professional, national, and voluntary organizations and identify new ways of working together.
- ▶ Promote use of state-of-the-art technology and resources among providers, such as Physicians Data Query (PDQ), Cancer FAX, and Internet access.
- ▶ Develop consensus among providers who are using different professional guidelines for breast and cervical cancer screening.

## **Lessons Learned**

- Clinicians' behaviors may be driven by changes in clinical practices or the setting in which they work rather than by traditional continuing education.
- Understand that behavior change among health professionals may occur through changes in the licensing and recertification process rather than through continuing education.
- Identify curricula for new professionals in training as well as for current professionals.

- Be prepared to develop or revise curricula when guidelines for clinical care change.
- Negotiate evaluation expectations, criteria, and outcomes with collaborators early on in partnerships.
- Expect that some organizations actively involved in training in the cancer control field may prefer not to participate in the program's professional education efforts.
- Expanded professional responsibilities may result in new training needs and priorities.

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*The program should provide feedback about data to health professionals in a form that may affect knowledge, attitudes, practices, and health service systems.*

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## **Key Issues**

- ▶ Provide contractors with timely, constructive, and relevant feedback that is easy to understand.
- ▶ Use screening outcome data and other data sources to identify training needs and provide feedback to trainers. Data sources include data from the program, Behavioral Risk Factor Surveillance System, cancer registries, state and local survey results, Health Plan Employer Data and Information Set (HEDIS), and Health Care Financing Administration databases.
- ▶ Provide feedback to health professionals as part of an ongoing evaluation of education efforts.

## **Lessons Learned**

- Ensure that the data being used to identify professional education and training needs are accurate and current.
- Ensure that precautions are taken to protect providers' confidentiality in the data feedback process.

# Service Delivery and Quality Assurance

Service delivery concerns women's encounters with the clinical setting and their experiences with screening, diagnostic, and treatment services. The quality of care is determined by the degree to which breast and cervical cancer services for women increase the likelihood of desired health outcomes and are consistent with professional knowledge and practice. All components of the NBCCEDP contribute to the quality of clinical service. Service practices should adhere to accepted guidelines for clinical care and be client-centered. Women should receive a continuum of care that includes risk identification, screening and rescreening, and if needed, diagnostic and treatment services. Programs should ensure that women for whom a precancerous lesion or cancer has been diagnosed have access to timely and appropriate treatment.

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*The program should establish administrative, service delivery, and quality assurance mechanisms to provide breast and cervical cancer screening and diagnostic services for eligible women.*

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## Key Issues

- ▶ Include traditional and nontraditional partners (e.g., professional societies, hospitals, community agencies, voluntary organizations, and cancer support groups) in planning, developing, and evaluating all aspects of service delivery.
- ▶ Establish a medical advisory committee to provide guidance and consultation on professional education, quality assurance, and clinical issues.
- ▶ Enlist multidisciplinary teams of professionals to provide a full continuum of clinical, educational, and support services. These teams may vary within geographic regions, differ by population, and change over time.
- ▶ Use educational opportunities to provide training on risk management issues to help providers deliver clinical services that minimize their liability.
- ▶ Identify and enlist the cooperation and support of varied agencies and groups providing similar or related breast and cervical cancer early detection services.



- ▶ Promote the program's comprehensive delivery model to a broad audience of service providers.
- ▶ Develop forms for the release of clients' information, and have the forms reviewed by medical and legal advisors.

## **Lessons Learned**

- Providers' practices may differ from clinical guidelines. Professional education efforts and implementation plans should describe and provide training on recognized guidelines for clinical care.
- Adjustments to the program may be needed to address changes in priorities and funding levels.
- The program's reimbursement rates for clinical services may be lower than the community rates for that area and may influence provider participation.
- Conflicts among partners may arise that negatively affect the delivery of clinical services. A process for negotiation and conflict resolution may be required.
- Concern about liability related to screening, diagnosis, and treatment may influence provider participation. Be knowledgeable about liability issues that affect the program and providers.

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*The program should set minimum requirements and standards for quality service delivery.*

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## **Key Issues**

- ▶ Use a multidisciplinary team of professionals in developing program requirements and standards.
- ▶ Establish program standards that can be measured and are based on scientific evidence and accepted clinical practices.
- ▶ Identify a baseline from which to measure progress in meeting standards.
- ▶ Establish mechanisms to ensure that program requirements and standards are met (e.g., self-assessment, use of data reporting systems, and site visits).
- ▶ Ensure that all laboratories and mammography facilities meet quality assurance standards and report data in accepted formats.
- ▶ Collaborate with professional organizations, licensing bodies, and state agencies in updating and training providers to meet standards and improve the quality of service delivery.
- ▶ Identify new opportunities to influence health service delivery. For example, work with managed care organizations to develop surveillance, tracking, and follow-up systems for women with abnormal screening results.

## **Lessons Learned**

- Quality service delivery is a dynamic process that requires continuous review and revision. Collecting meaningful data for measuring compliance with standards may be difficult.
- Developing and revising standards is often difficult and time-consuming. Conflicting standards may exist, such as differences in reporting systems for Pap tests.
- Providers may resist changing their current practices to meet program requirements and standards. Data collected from multiple providers may be inconsistent and incomplete.

- Be prepared to provide ongoing orientation about program requirements and standards, as well as training, to address staff and provider turnover.
- Policy changes, resource limitations, and other factors may negatively influence the program's ability to offer incentives for encouraging providers to meet program requirements and standards.

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*The program should establish and periodically review clinical practice guidelines for all phases of service delivery, including screening, diagnosis, and referral for treatment services.*

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## **Key Issues**

- ▶ Use recognized guidelines for clinical care, established or endorsed by state or area medical agencies, while being sensitive to local variations in clinical practice.
- ▶ Use the program's medical advisory committee or convene an advisory panel of clinical experts to endorse existing guidelines or develop or revise guidelines.
- ▶ Obtain input and consensus on the guidelines from providers who follow the accepted clinical practices for a particular region or state.
- ▶ Collaborate and coordinate with professional organizations in reviewing and disseminating clinical practice guidelines.
- ▶ Ensure that participating providers use accepted diagnostic and treatment guidelines. Physician surveys may indicate whether guidelines are being followed.

## **Lessons Learned**

- Significant amounts of time may be needed to develop, periodically review, and revise clinical practice guidelines.
- Some providers may be reluctant to participate in the program if they are required to follow specific guidelines for clinical care.
- Different professional organizations support different guidelines for breast cancer screening. Conflicting guidelines regarding the appropriate age and

recommended interval for breast cancer screening will affect women's participation in screening.

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*The program should develop services that are accessible (including location, cultural sensitivity, hours of operation, and types of providers) to women from priority populations.*

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## **Key Issues**

- ▶ Identify and secure screening, diagnostic, and treatment services that are accessible to women from priority populations.
- ▶ Assess the potential role of partners, lay health educators, and alternative providers, such as traditional healers, in the screening process.
- ▶ Maximize opportunities to promote screening among women already in the health care system, particularly if they have not sought screening services.
- ▶ Create systems that will reduce or eliminate barriers to services (e.g., provide transportation, simplify the intake process, escort women to appointments, address language and low-literacy needs, and provide counseling services).
- ▶ Develop mechanisms, such as telephone surveys, mailed surveys, or in-person interviews, to assess and promote client satisfaction.

## **Lessons Learned**

- Women are not likely to participate in services that do not meet their needs. Include consumers in the planning and development of the program.
- Establishing and maintaining relationships with screening, diagnostic, and treatment providers that are accessible to women from priority populations will be a challenge.
- Barriers to screening, diagnostic, treatment, and support services may limit women's participation in the program.

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*The program should ensure that women for whom screening results are normal return for rescreening at recommended intervals.*

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## **Key Issues**

- ▶ Ensure that program personnel and providers understand the purpose and importance of rescreening.
- ▶ Develop a policy that defines adequate procedures for rescreening.
- ▶ Define the roles of program staff and providers to clearly delineate responsibilities for rescreening.
- ▶ Help providers develop or adapt reminder systems for rescreening.
- ▶ Promote the importance of rescreening and compliance with recommended screening intervals through public and professional education efforts.

## **Lessons Learned**

- Acceptance of, and willingness to use, reminder systems will vary among providers. Different types of systems may be needed for different types of providers and different client populations.
- Types of client records and reminder systems may vary among providers, making coordination and tracking difficult. Site visits and record checks can be used to assess this problem.

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*The program should ensure that women with abnormal screening results, precancerous lesions, or cancer receive timely and appropriate diagnostic or treatment services.*

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## **Key Issues**

- ▶ Document and clearly communicate the policy and procedures for the referral, tracking, and follow-up process for women with abnormal screening results, precancerous lesions, or cancer. Ensure that providers establish appropriate referral, tracking, and follow-up systems.

- ▶ Ensure that dedicated staff are available to track and follow women with abnormal screening results, precancerous lesions, or cancer.
- ▶ Ensure that providers receive appropriate information about requirements for diagnostic and treatment services.
- ▶ Identify and secure timely and appropriate diagnostic services for women with abnormal screening results.
- ▶ Identify and secure timely and appropriate treatment services for women with precancerous lesions or cancer. Ensure that all women for whom CIN has been diagnosed receive treatment to prevent the occurrence of invasive cervical cancer.

## **Lessons Learned**

- Obtaining diagnostic and treatment services from providers may be challenging. Formal mechanisms should be in place with screening providers to ensure the provision of timely and appropriate diagnostic and treatment services.
- Diagnostic and treatment services may be unavailable in some geographic areas. Establish relationships with community partners that can assist women with transportation, lodging, and child-care costs.
- Diagnostic and treatment information may be difficult to obtain from providers. Formal mechanisms should be in place to ensure such information is provided to referring providers.
- Cultural beliefs and practices, as well as financial and logistical barriers, may impede women from following diagnostic and treatment recommendations.
- Innovative strategies are needed to reach women who do not adhere to diagnostic and treatment recommendations. Case management and outreach activities are time-consuming and labor-intensive. Systems should be developed to guide and document the activities of case managers and outreach workers.

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*The program should develop policies to promote providers' ongoing participation in, and compliance with, screening, diagnostic, and treatment recommendations.*

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## **Key Issues**

- ▶ Develop a policy that defines requirements for screening, tracking, and follow-up systems. Clearly distinguish between the program's role and providers' responsibilities related to these requirements.
- ▶ Increasing providers' participation may require accommodating providers' needs. For example, contract arrangements, training needs, and billing systems are some of the special issues that may need to be addressed.
- ▶ Establish a standard data report that is easy to complete. Avoid collecting data not essential to program operation and provider decision making.
- ▶ Establish mechanisms for determining providers' training needs related to changes in program requirements and recommended clinical practices.
- ▶ Develop plans for providing training and technical assistance in response to providers' needs.
- ▶ Provide information that may reinforce and strengthen relationships with providers. This information includes feedback about program data, outcomes, and accomplishments.

## Lessons Learned

- Competing priorities, resource considerations, and changing reimbursement systems may influence a provider's willingness to participate in the program.
- Misunderstandings about reimbursement practices, fee-setting policies, and payment responsibility among women, providers, and the program may interfere with service delivery.
- Identifying and securing in-kind support or financial sources for some diagnostic and all treatment services will be a challenge. Many creative avenues should be explored with providers, hospitals, health centers, government agencies, foundations, and corporations.

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*The program should develop policies to promote women's ongoing participation in, and adherence to, screening, diagnostic, and treatment recommendations.*

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## Key Issues

- Use multiple strategies to increase women's participation in, and adherence to, screening, diagnostic, and treatment recommendations.
- Ensure that providers are culturally sensitive, adaptable, and open to serving women from priority populations.
- Ensure that incentives are appropriate and culturally sensitive and consider the language and literacy needs of women from priority populations.

## Lessons Learned

- Women may have competing priorities (e.g., housing, food, and employment), that may affect participation in, and adherence to, screening, diagnostic, and treatment recommendations.
- Outreach and recruitment costs may vary according to the challenges encountered in recruiting women from priority populations. Community partners and coalition members may be critical in assisting with these activities.



# Surveillance, Tracking, and Follow-up

The surveillance, tracking, and follow-up system is an essential component of a breast and cervical cancer screening program. Women with normal screening results should be tracked for rescreening at recommended intervals. The program should have the capacity to track each woman with an abnormal screening result, a precancerous lesion, or cancer for proper referral, diagnosis, and treatment. Data collected through the system can be used to monitor clinical services, determine program policies and practices, and assess the effect of the program's screening services. Programs should design a system that meets program needs, allows for ongoing assessment of screening efforts, and provides data for responding to the information needs of program stakeholders and partners.

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*The program should develop a system to collect, edit, manage, and continuously improve the quality of data.*

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## Key Issues

- ▶ Identify the sources for, and the scope of, the data system and the personnel who will answer questions and manage the complexities of processing data from multiple sources.
- ▶ Investigate existing data systems to determine if they meet program needs. Work with other organizational units of your agency to identify systems that could be adapted for the program.
- ▶ Determine how data will be delivered to the system (e.g., diskette, e-mail attachment, or data collection forms).
- ▶ Develop methods of data collection that are appropriate to the resources and capabilities of personnel who collect the data. Simplify the process so that data can be submitted in a timely manner to the main collection point. Resource considerations include availability of appropriate equipment and supplies to meet data collection requirements.

- ▶ Develop data collection forms that are clear and easy to complete by those who will use them. These forms should be field-tested before they are used.
- ▶ Assign a unique identifier to each woman listed in the database to properly identify her and a specific record.
- ▶ Design and implement data protection mechanisms, such as back-up files, virus protection services, and log-in security procedures.
- ▶ Develop methods for efficiently storing and archiving records.
- ▶ Develop a user manual that addresses all aspects of the system—from data collection to user feedback. Field-test the manual before it is published and disseminated.
- ▶ Field-test the system before it is fully implemented to ensure that all areas function as anticipated.
- ▶ Require documentation of all computer programs used to manage the data. Computer documentation simplifies the process of maintaining programs and serves as a useful training tool for new staff.
- ▶ Develop policies and procedures concerning ownership of, and access to, data when developing the data system.
- ▶ Establish a data system that ensures confidentiality.
- ▶ Establish the capacity to link with other data systems. For example, establish a relationship with the cancer registry for obtaining stage of cancer at diagnosis, treatment information, and other outcome data.
- ▶ Hire and train personnel dedicated to managing, analyzing, and interpreting data.

## **Lessons Learned**

- Developing a system that meets the information needs of management and staff can help to improve program practices and decision making.
- Developing a data system is a time-consuming and labor-intensive activity.

- Providers may not have the infrastructure, capability, and resources to meet data collection and reporting requirements, and may be reluctant to participate in the program.
- Developing unique client identifiers may be difficult because some populations served by the program are mobile.
- Anticipate confidentiality issues related to the linkage of records with other databases.
- Plan for data management and systems problems that may consume staff time and compromise the availability of data.
- Be prepared to revise and upgrade the data system.

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*The program should ensure that adequate and appropriate data are collected to meet surveillance, tracking, and reporting requirements.*

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## **Key Issues**

- Clearly define the data needs and requirements of the program.
- Review reports and data collection forms from other programs to assist in developing reporting methods.
- Train providers to properly collect and submit data to the program.
- Prepare providers for changes in reporting requirements by providing flexibility and offering training.

## **Lessons Learned**

- Changes in data needs and requirements over the course of the program are inevitable.
- Developing definitions of screening cycles may be problematic; some definitions may be inconsistent with clinical practice.
- Providers may not understand or may resist data reporting requirements.

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*The program should ensure that clinical data collected about enrolled women are used to provide diagnostic services to those with abnormal screening results and treatment for women with precancerous lesions or cancer.*

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## **Key Issues**

- ▶ Require providers to report in a timely manner information about women with abnormal screening results, precancerous lesions, or cancer.
- ▶ Establish a formal system for exchange of information and records between the primary referral source and providers of diagnostic and treatment services.

## **Lessons Learned**

- Clients' confidentiality needs must be protected when diagnostic and treatment information is shared.
- Cancer therapies are often provided by multiple providers, and the retrieval of treatment information can therefore be labor-intensive and time-consuming.
- Anticipate problems in obtaining clinical information from providers with whom the program has no financial relationship or direct oversight.
- Data reports submitted by providers may contain incomplete or incorrect information.

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*The program should develop an efficient reminder system to invite women with normal screening results to be rescreened at recommended intervals.*

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## **Key Issues**

- ▶ Require providers to implement a reminder system for rescreening women with normal screening results.
- ▶ Ensure that staff are dedicated to tracking and contacting women for rescreening.
- ▶ Establish a formal system for exchange of information between the program and providers to assess rescreening activities.
- ▶ Establish systems for tracking women who are mobile. Develop communication networks with community agencies and nonparticipating health clinics, and establish data exchange systems with public health agencies across geographic regions.

## **Lessons Learned**

- Many service delivery settings do not have tracking and reminder systems. Manual systems may need to be introduced and training provided toward the ultimate goal of making the transition to an automated system.
- Evaluation of rescreening rates may be difficult due to the change in the income and insurance status of women participating in the program.

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*The program should establish a mechanism to ensure the submission of timely, complete, and accurate data.*

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## **Key Issues**

- ▶ Dedicate time to providing training and technical assistance to providers concerning data collection and reporting requirements.
- ▶ Review data forms before data entry. Manual review of key data items and problematic data items will alert staff to site-specific problems that can be corrected early in the data entry process. Problems with the design of the data collection form may also be identified during this process.
- ▶ Use programs that edit data and check for input errors. Check for valid values being entered in each data field. Also institute a check system between related items on the same record and between related records. Identification and correction of problems during the data entry phase will substantially improve the overall quality of the database.
- ▶ Develop and implement a plan for monitoring the quality of data on an ongoing basis.
- ▶ Institute a system to inform providers of screening outcomes and problems with reported data.
- ▶ Linking reimbursement for services to the submission of timely, complete, and accurate data may encourage providers to comply with reporting requirements.
- ▶ Linking program data with cancer registry data at least once a year may identify women in the program for whom cancer was diagnosed but for whom information is missing from the program's database.

## **Lessons Learned**

- Definitions of timeliness, completeness, and accuracy are program-specific and may be affected by decision-making needs of management, local practice patterns, and providers' capacity.
- Trained staff dedicated to developing and maintaining the data system are necessary at the program and provider levels.

- Despite training efforts, adhering to data requirements is an ongoing challenge for providers.
- Continuous training on data requirements may be necessary to address provider staff turnover.
- Providing meaningful incentives to providers to collect and report data that are timely, complete, and accurate will be a continuous challenge.
- Ensuring the submission of timely, complete, and accurate data is a labor-intensive and time-consuming activity.
- Delays in cancer registry reporting may limit your ability to link program data with registry data.

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*The program should develop systems for ongoing data analysis and prompt response to requests for information.*

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## **Key Issues**

- Prioritize requests and develop user-friendly reports.
- Develop and implement a system for routine review and analysis of your data.
- Keep current with other relevant databases and analytic tools (e.g., software and hardware).
- Develop a plan for routine dissemination of reports that address the data needs of stakeholders and partners.

## **Lessons Learned**

- Requests for information may come from multiple sources, and each source may have different information needs and a different understanding about the capacity of the surveillance, tracking, and follow-up system.
- Technical expertise and resources are needed for ongoing data analysis and responsiveness to requests for information.

- Confidentiality issues may conflict with freedom of information issues.
- Definitions of key reporting items may change, and those changes should be addressed with program stakeholders and partners.



# Evaluation

**F**or public health programs, evaluation methods are used to systematically assess four general areas: Was the intervention delivered as intended? Were the desired effects or outcomes achieved? Can the outcomes be attributed to the interventions? What is the relative public health payoff for the resources required to bring about the effect? These four questions can serve as the basis for developing the program's evaluation framework and plan.

Planning for evaluation should begin when the program is initiated. Evaluation can contribute to the overall program definition and design. As the program develops, evaluation activities can be used for monitoring progress, assessing program effectiveness, and providing information for decision making and program management.

Evaluation activities can range from informal assessments and routine data collection to formal assessments of specific program strategies. Programs should establish an overall evaluation plan that accounts for the types and levels of information needed. The plan must remain flexible, however, to accommodate changes that may occur as a program matures, to take advantage of unexpected "side effects" that emerge during program implementation, and to address unexpected needs. Successful evaluation depends on collaboration between the evaluators and the program staff, providers, partners, and members of priority populations.

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*The program should develop objectives that are specific, measurable, and defined by time for both the overall program and each program component.*

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## Key Issues

- ▶ Articulate the program's purpose and intended effects.
- ▶ Establish program priorities.
- ▶ Identify key stakeholders (e.g., management, program staff, priority populations, providers, and partners) and involve them in the process of developing objectives.

- ▶ Develop objectives that are meaningful and realistic for each program component.

## **Lessons Learned**

- Ensure that the program's purpose and priorities are clearly understood by all staff.
- Continue to ask why activities are undertaken and ensure that the relationship between program objectives and program activities remains clear.
- Program objectives may change as the program is fully implemented.
- Organizational and policy changes may result in shifting program priorities and affect the evaluation efforts of the program.
- Be aware that objectives based in behavioral science are generally more difficult to measure than are objectives based on clinical science.

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*The program should develop an overall evaluation strategy to meet short- and long-term evaluation needs.*

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## **Key Issues**

- ▶ Hire or obtain the services of an evaluation expert either in-house or through consultants.
- ▶ Enable staff to understand basic evaluation concepts and methods and apply them to their efforts.
- ▶ Identify key areas in which evaluation results are likely to improve program operations or management.
- ▶ Create a flexible evaluation plan to allow for change or expansion as the program matures.
- ▶ Coordinate evaluation efforts to address short- and long-term indicators of program progress and success.
- ▶ Design evaluation activities to measure the intended effect of program interventions developed for different population segments.

- ▶ Plan for the rigor and intensity of an evaluation study to generate the data needed to make sound decisions.

## **Lessons Learned**

- Start the evaluation process when the program is initiated. Evaluation can contribute to the overall program design by building in measures of progress and success.
- Anticipate changes in evaluation timelines and set reasonable expectations for completing evaluation activities.
- Staff may resist evaluation efforts if program expectations and program outcomes differ.
- Acknowledge partners' priorities and interests and coordinate evaluation efforts while maintaining program integrity.
- Recognize the value of subjective assessments when systematic data collection and analysis are not possible. Use anecdotal information and thoughtful estimates when appropriate.
- Longitudinal studies, annual review, and follow-up after an initial study are more revealing than a one-time evaluation.
- Build on previous evaluation work of your program and of others.

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*The program should allocate sufficient resources to support evaluation activities to ensure quality results.*

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## **Key Issues**

- ▶ Develop an evaluation budget at the outset of program planning, including the cost of staff, data collection and analysis, training, computer equipment and software, and other resources.
- ▶ Focus evaluation resources on questions of greatest importance and on information needed for decision making related to the program's objectives.

## Lessons Learned

- Ensure that decision makers are informed of costs and unexpected resources needed for evaluation.
- Consider the scope and cost of interventions when setting priorities for evaluation activities.
- Establish relationships with institutions of higher education through which use of faculty resources may be exchanged for access to data for analysis. Identify other avenues for collaboration with educational institutions to maximize program resources for evaluation.

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*The program should develop and maintain systems for data collection and ongoing evaluation.*

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## Key Issues

- ▶ Determine the level and type of data needed for continuous program monitoring and accountability.
- ▶ Identify existing databases or data collection systems and assess their adequacy for program needs.
- ▶ Review information about other evaluation efforts in cancer control to identify successful evaluation strategies and methods used by community organizations, national organizations, and academic institutions.
- ▶ Develop a standard approach to collect data for evaluation of program components where data are not available.
- ▶ Use standard definitions for data collection to facilitate sharing of information among various data sets.
- ▶ Integrate data collection needs into routine program activities (e.g., tracking systems and data reporting forms).
- ▶ Establish a network of partners for collecting and sharing data.
- ▶ Work with partners who may have useful baseline data for the program's priority populations.

- ▶ Use new evaluation methods and approaches that emerge as the science of evaluation develops.

## Lessons Learned

- Evaluation of some activities requires long-term data collection to meet short- and long-term information needs. For example, changes in mortality rates will not be seen for several years, but the identification of early-stage cancers *can* be an intermediate outcome.
- Meaningful baseline data are needed to measure change.
- Be realistic in establishing evaluation plans that can guarantee access to data as well as ensure data quality.
- The quality of existing data may be poor or may not include the program's priority populations. Time is needed to assess other data sources and available alternatives.
- Changes in program eligibility requirements, definitions of priority populations, and other aspects of the program may affect data collection and evaluation activities.

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*The program should use evaluation data to improve program management, practices, activities, and systems.*

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## Key Issues

- ▶ Ensure that feedback about program performance is consistent and objective. Establish standard systems and schedules for providing feedback.
- ▶ Identify program strengths and successes as well as problem areas for improvement when communicating evaluation results to contractors and other partners.
- ▶ Provide recommendations that are constructive and identify sources that may help correct program weaknesses and deficiencies.
- ▶ Negotiate in advance for the use of evaluation data from contractors.
- ▶ Involve partners in data analysis and interpretation of evaluation results.

- ▶ Use evaluation results to identify emerging program management and evaluation needs.

## **Lessons Learned**

- Evaluation results should be communicated to partners and stakeholders in a manner relevant to their interests and needs.
- Evaluation data may be misinterpreted or used in ways not intended by the program.
- Interpret evaluation results in light of other interventions or events that may affect the program's outcomes. Identify these factors and their effect on the program, providers, and clients.
- Communicate and disseminate evaluation results clearly to partners and stakeholders, taking into account their levels of knowledge concerning evaluation-related methods and issues.

# Conclusion

**R**outine screening can detect cancers of the breast and cervix at an early stage when treatment is most likely to be successful. The use of mammography and Pap tests is crucial to cancer prevention and control strategies, but these procedures are underused, particularly among women of low income. To achieve maximum effectiveness, breast and cervical cancer early detection programs should be carefully planned and systematically implemented. Research and experience have contributed to knowledge about how to plan and develop programs that can help reduce morbidity and mortality from these cancers. These guidelines provide an integrated, multidisciplinary view of the practical issues related to the development, implementation, and evaluation of an early detection program. In addition, the guidelines can help public health professionals envision those elements critical to building a high-quality early detection program. A challenge for the future is to sustain the commitment of federal, state, territorial, and tribal governments to support comprehensive, integrated screening programs that can continue progress toward achieving the national health objectives for breast and cervical cancer control.

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