NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM


# *Summarizing the First 12 Years of Partnerships and Progress Against Breast and Cervical Cancer*

**1991–2002 NATIONAL REPORT**

U.S. Department of Health and Human Services

CDC
Centers for Disease Control and Prevention

# National Breast and Cervical Cancer Early Detection Program

## 1991–2002 National Report

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# Foreword

**By Susan True, MEd, Director, NBCCEDP**

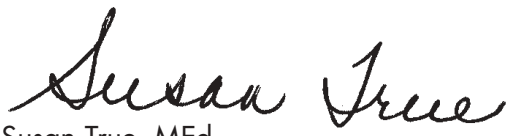
The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which was created in response to the Breast and Cervical Cancer Mortality Prevention Act passed by Congress in 1990, is both the first and thus far the only national cancer screening program in the United States. As a consequence, its successes and challenges are relevant not only to those who manage, implement, and are served by the program, but to policy makers, the health care system, the public health community, and the general public as well. CDC is pleased to offer this summary of the accomplishments of the NBCCEDP from 1991–2002. Through it the reader may gain insight into the complexity of this program designed to improve the quality of breast and cervical cancer screening and early detection services and assure access to them for women who, for a variety of reasons, would otherwise not receive these services.

Clients of the NBCCEDP have no health insurance that covers screening, and little or no discretionary income; they often have no "medical home." They represent minority populations and those who are geographically or culturally isolated from existing services. Most are over 40 but not yet 65—often working as well as caring for grandchildren or aging parents—with little social support or scheduling flexibility. Educating and motivating these women to want screening; ensuring that services are convenient, accessible, and provided in a respectful, culturally competent manner; and effectively communicating results, recalling, and assisting women who need additional services are among the responsibilities of every funded program. Grantees are held to high standards for reporting services provided, their appropriateness, timeliness, and outcomes. Quality assurance, including provider education and the development of data review processes to identify problems, is a critical component of this work.

This report summarizes the first 12 years of the NBCCEDP. During this period, the program grew from 8 to 68 grantees and from serving thousands to serving hundreds of thousands of women each year. Both CDC and Medicare policy changes influenced which women were served, and how they were served, during this period. The program has had a rich history, with many lessons assimilated into the way NBCCEDP is managed, implemented, and evaluated today.

Perhaps even more exciting, however, is the program's future. A strategic evaluation plan will guide our assessment of program components and outcomes for the next 5 years. We are exploring the impact of infrastructure choices on grantees' costs to deliver services and their success in eliminating disparities among women in the program. An evolving performance-based system for making awards is ensuring that federal dollars are well spent. By strengthening partnerships with our sister federal programs, private partners, and comprehensive cancer control programs, we are ensuring an environment in which the NBCCEDP can increasingly be a significant catalyst for reducing the illness and death associated with breast and cervical cancer in communities across the United States.

This report demonstrates our growing capacity to accomplish that goal. Future reports will update the data and show the impact of our performance improvement initiatives.



Susan True, MEd

# Executive Summary

The Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention is pleased to release the first programmatic summary report of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). The NBCCEDP helps low-income, uninsured, and underserved women gain access to potentially lifesaving screening programs for the early detection of breast and cervical cancer.

In 2004, an estimated 215,990 new cases of invasive breast cancer and 10,520 new cases of invasive cervical cancer will be diagnosed in the United States, and about 44,010 women will die of these diseases combined.[1] Many of these deaths could be avoided by increasing the cancer screening rates among women at risk. The U.S. Preventive Services Task Force (USPSTF) recommendations state that timely mammography screening among women aged 40 years or older could prevent a significant number of all deaths from breast cancer.[2] Papanicolaou (Pap) tests can detect cervical cancer at an early stage when it is most curable, and can prevent the disease altogether when precancerous lesions are found during the test and are treated in a timely manner.

Despite the availability of screening tests, deaths from breast and cervical cancer occur more frequently among women who are uninsured or under-insured. Mammography and Pap tests are underused by women who have less than a high school education, are older, live below the poverty level, or are members of certain racial and ethnic minority groups.[3] To help improve access to breast and cervical cancer screening among these at-risk populations in the United States, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which created the NBCCEDP. The program, funded at $30 million in fiscal year (FY) 1991, eventually grew to a nationwide program that received over $192 million in FY 2002. During this time, 1,175,759 women received 2,038,118 mammograms, and 1,329,523 women received 2,305,936 Pap tests through the NBCCEDP.

The intent of this report is to summarize the first 12 years of the NBCCEDP, from 1991 through 2002. Information on the program's framework and history are given in addition to data on breast and cervical cancer screening results and outcomes for women served through the program. This report provides a basis for researchers to develop research questions that can be answered with more specific and advanced analyses using both the national and program-specific data. Individual programs can use these data to help guide activities to improve program management, evaluation, data management, and outreach activities.

The NBCCEDP's comprehensive approach to breast and cervical cancer control ensures that not only medically underserved women benefit from this early detection effort, but that all women gain from the educational activities, public and private partnerships, and quality assurance standards implemented in our funded programs. At the state and community level, the development of early detection programs has resulted in a new organizational capacity and infrastructure for cancer control, increased staff resources and expertise, enabled multiple collaborative partnerships in the private and public sectors, built state and community coalitions, and promoted a greater understanding of the challenges in delivering preventive health services to women who are medically underserved. By presenting this report, the NBCCEDP hopes to demonstrate the continued momentum and commitment of federal and state governments to comprehensive screening programs that work to close the gap in health disparities, improve early detection rates, and reduce the illness and death from all cancers.

# Overview of the NBCCEDP

**"Early detection through screening is our best defense against morbidity and mortality from breast and cervical cancers and precancers."**

Julie Louise Gerberding, MD, MPH
Director, Centers for Disease Control and Prevention

The **National Breast and Cervical Cancer Early Detection Program (NBCCEDP**) is a nationwide, comprehensive public health program that helps uninsured and underserved women gain access to screening services for the early detection of breast and cervical cancer.

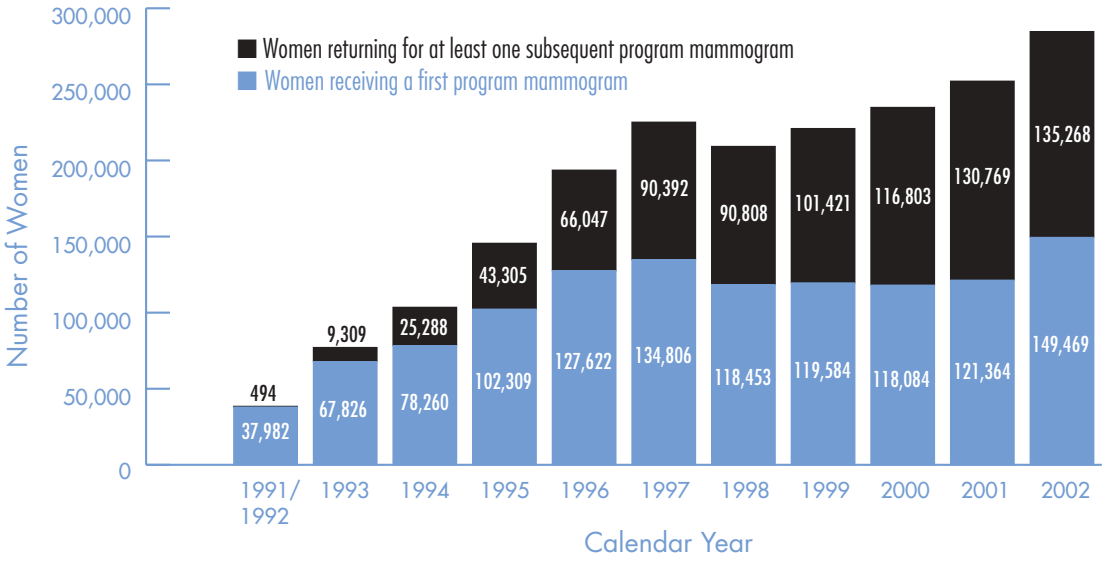
Breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer death among women in the United States.[1] Screening for and early detection of breast and cervical cancer reduces death rates and greatly improves cancer patients' survival.[2] However, there is a disproportionately low rate of screening among women of certain racial and ethnic minorities and among under- or uninsured women, which creates a wide gap in health outcomes between such women and other women in the United States.[3] To address this health disparity, Congress authorized the NBCCEDP in 1990, giving CDC the ability to implement a national strategic effort to increase access to mammography and Pap test screenings for women in need.

The NBCCEDP is implemented through cooperative agreements with state and territorial health departments, tribes, and tribal organizations (grantees). Sixty percent of federal funds received by a grantee must be expended on direct services for women. The other 40% of federal funds can be used to support program management, public and provider education, quality assurance, and surveillance and evaluation activities. The NBCCEDP is intended to be the payer of last resort for screening services; therefore, grant monies cannot be used to pay for services if other coverage is available through any state fund, private health insurance, or other government health benefits program such as Medicaid or Medicare. Grantees are also required to contribute $1 for every $3 of federal funds. Grantees contract with a broad range of provider agencies to deliver screening and other services, and each grantee has developed its own delivery system based on available resources.

The NBCCEDP is directed to low-income, uninsured women aged 18–64 from priority populations. The program provides clinical breast examinations, mammograms, and Pap tests for eligible women who participate in the program as well as diagnostic testing for women whose screening outcome is abnormal. Although treatment services are not directly paid for by the NBCCEDP, programs have always been required to identify resources for the treatment of breast and cervical cancer found through the program. To assist programs in identifying these resources, in 2000 Congress gave the states the option to provide medical assistance for treatment through Medicaid (PL 106-354). In addition to screening and diagnostic services, the legislation authorizing the NBCCEDP (PL 101-354) provided for public and professional education, quality assurance, and surveillance and evaluation systems to monitor program activities. Each grantee reports to CDC a subset of program data known as the minimum data elements (MDEs). The MDEs are a set of standardized data elements considered to be minimally necessary for grantees and CDC to monitor client demographics and clinical outcomes of women screened with NBCCEDP funds. The MDEs also are used to establish NBCCEDP policies and practices, assess the national program's screening outcomes, and respond to the information needs of CDC stakeholders and partners. A description of the MDEs can be found in ***Appendix I***.

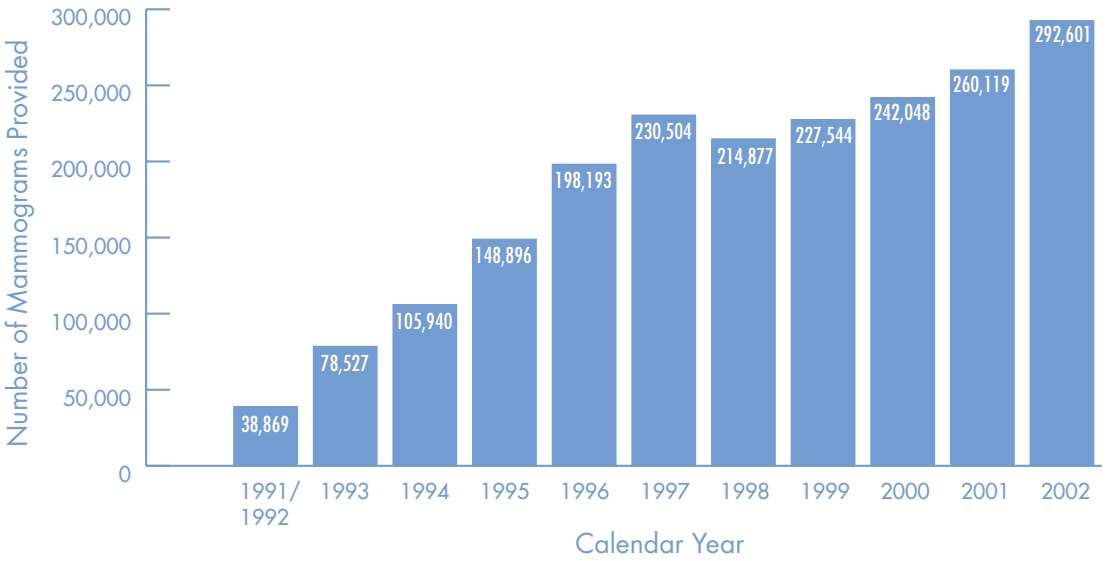
Since the NBCCEDP began in 1991, CDC has expanded the program to all 50 states, 4 U.S. territories, the District of Columbia, and 13 American Indian/Alaska Native tribes or organizations. Through the hard work of dedicated national partners, state health officials, community leaders, medical care providers, and others involved in the program, the NBCCEDP has provided more than 4 million breast and cervical cancer screening and diagnostic tests to almost 1.75 million low-income, uninsured women. From 1991 through 2002, 1,175,759 women have received 2,038,118 mammograms, and 1,329,523 women have received 2,305,936 Pap tests through the NBCCEDP (Figures 1–4). Because of these screenings, 9,956 cases of breast cancer, 12,187 cases of precancerous cervical lesions, and 832 cases of invasive cervical cancer were diagnosed.

*Figure 1. Number of Women Receiving Mammograms Through the NBCCEDP, 1991–2002**



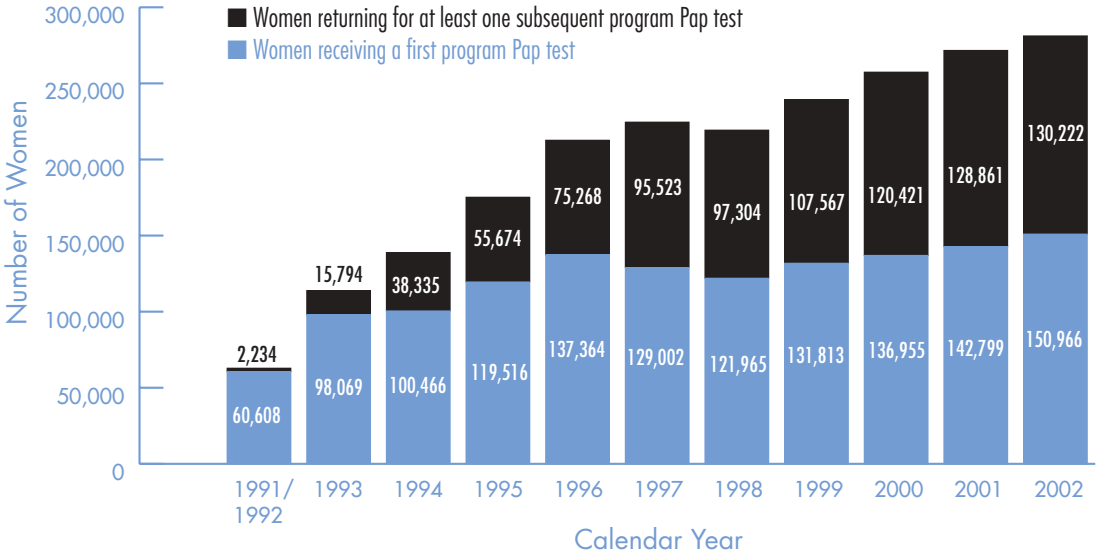

*During this period, 1,175,759 women received at least one paid mammogram through the NBCCEDP.

*Figure 2. Number of Mammography Screenings Provided Through the NBCCEDP, 1991–2002**



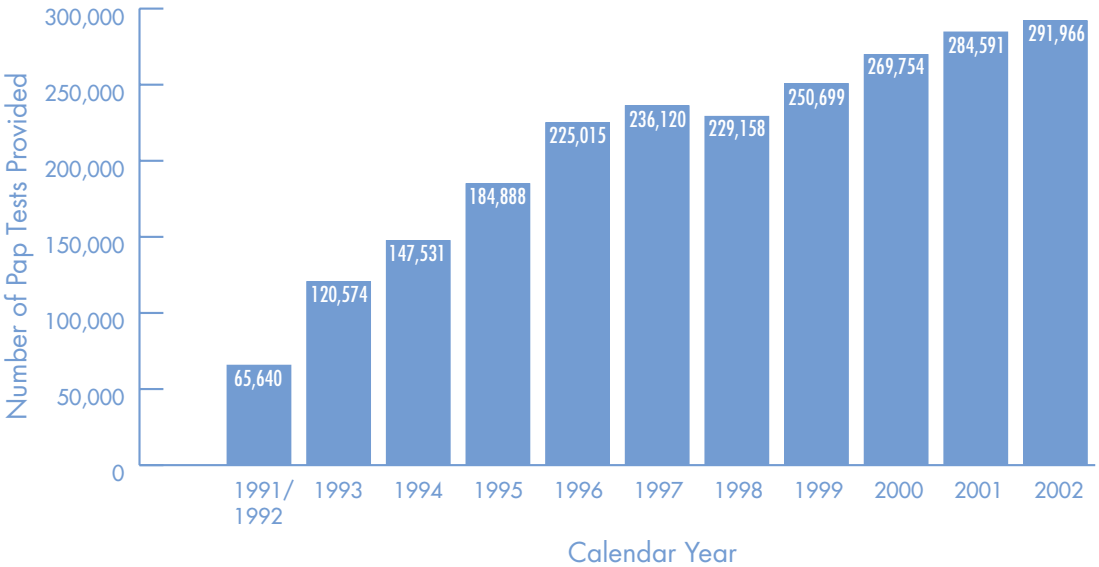

*During this period, 2,038,118 mammograms were paid for directly with program funds, and 309,229 unpaid mammograms were provided to women receiving at least one other NBCCEDP-funded service.

## *Figure 3. Number of Women Receiving Pap Tests Through the NBCCEDP, 1991–2002**




*During this period, 1,329,523 women received at least one paid Pap test through the NBCCEDP.

## *Figure 4. Number of Pap Test Screenings Provided Through the NBCCEDP, 1991–2002**




*During this period, 2,305,936 Pap tests were paid for directly with program funds, and 85,783 unpaid Pap tests were provided to women receiving at least one other NBCCEDP-funded service.

1991

Beginning of the NBCCEDP

1992

Implementation of the Capacity Building Program

1993

Amendment of the Breast and Cervical Mortality Prevention Act of 1990 (Public Law 103-183)

1996

Establishment of mammography age guidelines

1997

Nationwide expansion of the NBCCEDP

1998

Exclusion of Medicare-eligible women

Passage of Women's Health Research and Prevention Amendments of 1998 (Public Law 105-340)

1999

Passage of Balanced Budget Refinement Act of 1999 (Public Law 106-113)

2000

Implementation of Breast and Cervical Cancer Prevention and Treatment Act of 2000 (Public Law 106-354)

Cervical cancer screening policy change

2001

Passage of Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001 (Public Law 107-121)

# History of the NBCCEDP

Prior to 1990, CDC's Division of Cancer Prevention and Control laid the groundwork for building early detection programs by funding a few states to work on the design and implementation of breast and cervical cancer screening services for medically underserved women. In part through the advocacy of CDC's national partners, Congress recognized the importance of establishing a nationwide program and passed the Breast and Cervical Cancer Mortality Prevention Act of 1990. This landmark legislation authorized CDC to establish the **National Breast and Cervical Cancer Early Detection Program (NBCCEDP).** To begin the effort, Congress appropriated $30 million in fiscal year (FY) 1991 to fund efforts by the first eight states to establish early detection programs. Early lessons showing that individual programs needed more time for capacity building led to the development of a two-stage funding process. The Capacity Building Program offered grantees the opportunity to recruit personnel and design service delivery. After they developed their infrastructure, grantees were funded through a competitive application process to begin screening women primarily from low-income, under- or uninsured, and racial or ethnic minority groups. Since then, the NBCCEDP has experienced substantial growth and a number of legislative and policy changes.

- ***1991—Beginning of the NBCCEDP.*** CDC funded eight states in fiscal year (FY) 91 and added four more in FY 92.
- ***1992—Implementation of the Capacity Building Program.*** CDC funded an additional 18 states to develop the infrastructure necessary to deliver screening programs.
- ***1993—Amendment of the Breast and Cervical Mortality Prevention Act of 1990 (Public Law 103-183).*** This amendment authorized NBCCEDP funding for American Indian/Alaska Native tribes and tribal organizations and required CDC to give funding priority to those states with a high disease burden from breast or cervical cancer.
- ***1996—Establishment of mammography age guidelines.*** The NBCCEDP established a goal that 75% of federally funded mammograms be provided to women 50 years of age or older.
- ***1997—Nationwide expansion of the NBCCEDP.*** Funding was provided to 50 states, the District of Columbia, 5 territories, and 13 tribes or tribal organizations.
- ***1998—Exclusion of Medicare-eligible women.*** As a result of Medicare adding these cancer screening services under the Part B coverage option, women enrolled in Medicare–Part B were excluded from the NBCCEDP-eligible population.
- ***1998—Passage of Women's Health Research and Prevention Amendments of 1998 (Public Law 105-340).*** Congress allowed the NBCCEDP to add case management as a program component and

enabled program grantees to contract with for-profit entities.

- ***1999—Passage of Balanced Budget Refinement Act of 1999 (Public Law 106-113).*** Congress allowed the NBCCEDP to raise the reimbursement rate for Pap tests from $7.15 to $14.60 and to adjust the rate annually for inflation.
- ***2000—Implementation of Breast and Cervical Cancer Prevention and Treatment Act of 2000 (Public Law 106-354)***. Congress gave states the option to provide medical assistance through Medicaid to eligible women who were screened and found to need treatment for breast or cervical cancer or precancerous conditions.
- ***2000—Cervical cancer screening policy change.*** NBCCEDP grantees were encouraged to focus cervical cancer screening on women who had rarely or never been screened and to decrease over-screening of women enrolled in the program.
- ***2001—Passage of Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001 (Public Law 107-121).*** Congress amended Title XIX of the Social Security Act to clarify that Indian women with breast or cervical cancer who are eligible for health services provided under a medical care program of the Indian Health Service or of a tribal organization should be included in the optional Medicaid eligibility category of breast or cervical cancer patients added by the Breast and Cervical Cancer Prevention and Treatment Act of 2000.

As a result of the extensive system of data collection, analysis, and ongoing communication with grantees, the NBCCEDP has successfully enacted modifications to improve the program's structure and to more closely define those eligible for screening services. The changes that have had the most impact on the program were the issuance of mammography guidelines in 1996, which required that 75% of program-paid mammograms be provided to women 50 years of age and older, and the exclusion of Medicare-eligible women in 1998, which resulted in a temporary decrease in the number of women receiving screening services through the NBCCEDP (Figures 1–4). The program established other specific policies not listed above that have had the cumulative effect of focusing the delivery of services on women most likely to be rarely or never screened and those at or below 250% of the poverty level.[4] Through the hard work of those at state and territorial health departments, tribes, and tribal organizations, and with the assistance of national, voluntary, and private organizations, the NBCCEDP has grown significantly and is now filling a critical gap in the screening for and early detection of breast and cervical cancer in the United States.

# Components of the NBCCEDP

Breast cancer and cervical cancer are two very distinct diseases and require markedly different methods for their detection, diagnosis, and treatment. For breast cancer, a combination of clinical breast examination (CBE) and mammography can generally detect an abnormality at an early stage of the disease. For cervical cancer, Pap tests can detect precancerous lesions years before invasive cancer becomes apparent. While these screening services are key to early detection of breast and cervical cancer, their existence alone is not sufficient to achieve a reduction in the illness and death associated with these diseases. Other activities must also occur to support direct screening services. The NBCCEDP has eight major components.

## Program Management

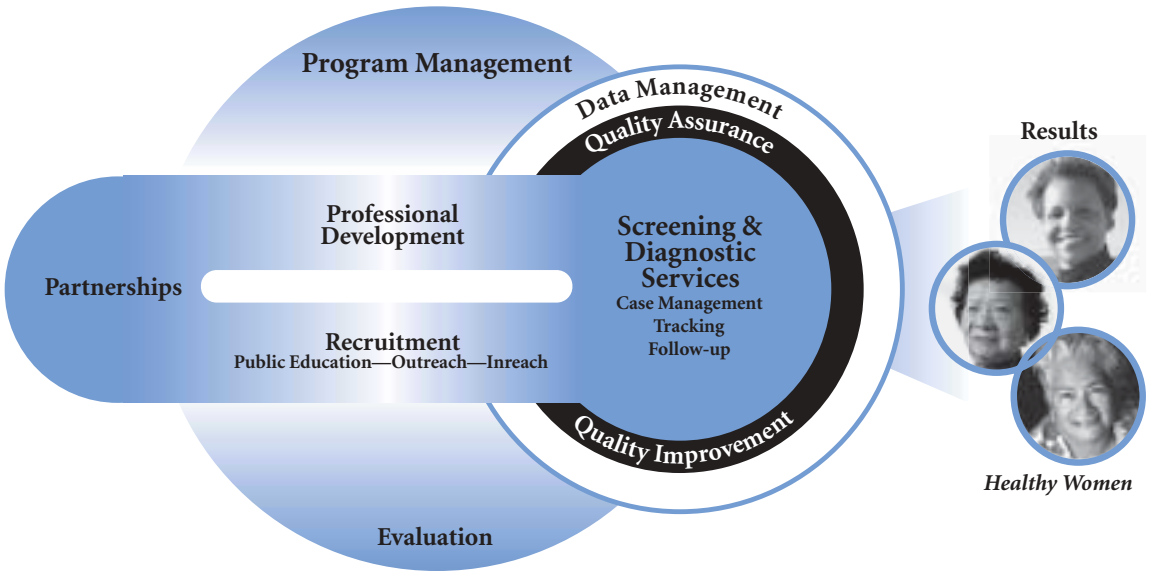
The overarching goal of program management is to implement all program components in accordance with established policies and procedures; to identify and leverage resources; and to provide leadership in planning, coordination, implementation, and evaluation. Program managers are required to

- Establish a sound fiscal system that tracks and monitors program expenditures.
- Develop an accurate budget request that corresponds with the program's work plan.
- Recruit and develop a qualified and technically diverse staff.
- Develop an annual work plan containing specific, measurable, time-phased, and realistic goals based on a thorough understanding of program components.

## Evaluation

The NBCCEDP defines evaluation as the systematic documentation of the operations and outcomes

*NBCCEDP Conceptual Framework*




of a program and the comparison of these results with a set of explicit standards or objectives. Evaluation activities must be carefully planned and implemented to ensure that program data are credible and useful. This information is critical to guiding operations and ensuring program success.

## Partnerships

Partnerships are critical to the NBCCEDP cancer control efforts. A successful national program to control breast and cervical cancer depends on the involvement of a variety of committed partners at the local, state, and national levels. Such partners help strengthen and maintain the NBCCEDP by contributing their expertise, connections, resources, and enthusiasm to the activities of the program.

## Professional Development

Professional development activities in the NBCCEDP are designed to improve the ability of health care providers to screen for and diagnose breast and cervical cancer so that women receive appropriate and high-quality screening and diagnostic services. Related activities include increasing the impact of the program on breast and cervical cancer mortality and improving providers' performance in following up on abnormal screening results.

## Recruitment

The purpose of recruitment is to increase the number of women in priority populations receiving clinical screening services by raising awareness, addressing barriers, and motivating women to use these screening services. Raising awareness through public education involves the systematic design and delivery of clear and consistent messages about breast and cervical cancer and the benefits of early detection using a variety of outreach and inreach strategies to promote the clinical services available for program-eligible women.

### PARTNERSHIP

The Iowa Tribe of Oklahoma, the Kaw Nation Breast and Cervical Cancer Early Detection Program (BCCEDP), and the Oklahoma Take Charge! Program of the Oklahoma BCCEDP are collaborating to serve the women living in and around the rural Payne County community of Perkins in north-central Oklahoma.

The Iowa Tribe operates a clinic in Perkins that serves tribal and other community members. The Tribal Health Director wanted to be sure that all women in the area had access to the BCCEDP. The collaboration of the three programs allows services to be provided for tribal members through the Kaw Nation BCCEDP, for other eligible women through the Take Charge! Program, and for insured women through the clinic's medical staff. Mammography services are provided by a mobile unit operated by the Oklahoma Breast Care Center in Oklahoma City.

Outreach strategies include displaying posters in community businesses and tribal offices, placing announcements in local and tribal papers, and setting up booths at tribal functions. The population of eligible women in the area is small and clinic utilization is limited; to date, the program has served 50 women. However, the partners remain committed to making the services available to all area women.

### PROFESSIONAL DEVELOPMENT

Alaska's Breast & Cervical Health Check (BCHC) program staff has begun using a multifaceted approach to improving mammography rates. BCHC awarded a $15 bonus fee to clinics for each woman aged 50–64 who had a mammogram within 60 days of her clinical breast examination (CBE). Program data were used to identify BCHC clinic sites with low mammography rates. These sites were notified of their rates and shown comparison rates from similar-sized sites where rates were higher. These data were accompanied by information about strategies for improving mammography rates, including the use of motivational communications based on the Stages of Change Theory. Clinics were supplied with specially designed "ticklers" that help simplify and make recall efforts reliable and timely. The ticklers are appropriate for use with any patient in the provider's practice, reducing his or her impulse to put time into implementing multiple tracking systems. *Tips for a Quality Mammogram* cards were distributed to patients at all BCHC clinics. Lay outreach staff received intensive training in motivational interviewing skills based on Stages of Change Theory. Clinicians were offered training in the vertical strip method of CBE and breast diagnostic algorithms.


Outreach relies on comprehensive, tailored, population-specific strategies designed to reach and bring women from NBCCEDP priority populations into clinical screening services. Inreach involves approaching program-eligible priority women who are using other health services (e.g., getting a flu shot, receiving care for diabetes) and recruiting them into NBCCEDP.

The essential elements of recruitment are

- Obtaining input from partners, including representatives from priority population groups, in assessing needs and developing comprehensive plans for public education, outreach, and inreach.
- Developing or revising, as needed, a public education and comprehensive outreach work plan that includes an appropriate mix of broad-based awareness-raising, community education, and one-on-one outreach strategies.
- Developing and using methods to evaluate the effectiveness of comprehensive outreach and inreach strategies, as well as public education messages, in recruiting women into screening.
- Placing priority for using program resources on implementing activities that are most effective in recruiting eligible women from priority populations for screening.

## Data Management

The collection, analysis, and use of quality data are essential for guiding program efforts. To meet CDC's data management expectations, a grantee is required to

- Establish and maintain a data system for collecting, editing, and managing the data needed to track a woman's receipt of screening, rescreening, diagnostic, and treatment services.
- Establish mechanisms for reviewing and assessing the completeness, accuracy, and timeliness of data collected.
- Establish protocols to ensure the security and confidentiality of all data collected.
- Collaborate with other existing systems to collect and analyze population-based information

### RECRUITMENT

Illinois Department of PUBLIC HEALTH

On April 1, 2003, the Illinois Breast and Cervical Cancer Program launched a statewide enrollment campaign targeting African American, rural, and Hispanic women between the ages of 50 and 64. Focus groups were used to obtain input on everything from appropriate take-home messages to which color scheme was most visually appealing. The result was a highly interactive campaign incorporating mass media and face-to-face communications encouraging women to "take charge" of their health. Tactics included direct mail, coalition building, "enrollment day" events, radio advertisements, faith-based outreach, and a "peer advocates" program. Direct mail and radio advertisements turned out to be the two most successful strategies in this campaign.

Direct mail pieces contained the toll-free Women's Health-Line number for women to call for referrals, as well as a postage-free reply card that could be torn off and mailed back. Paid radio advertisements ran in 60-second spots, promoting the program and the Women's Health-Line. Combined, these two strategies resulted in more than 2,200 referrals. Overall, the campaign motivated approximately 4,500 women to contact the program during a 9-month period. In terms of actual enrollments, 2,900 more women signed up for the program than enrolled during the same time period the previous year. This represented a 49% increase in enrollment overall and a 48% increase in enrollment by racial or ethnic minority women.

on breast and cervical cancer, including incidence and mortality rates, cancer stage at diagnosis, and the demographic profile of cancer patients.

## Quality Assurance

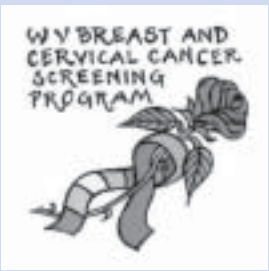
The NBCCEDP provides guidance on quality assurance and improvement methods that use data to identify training needs, improve services, and ultimately ensure women receive high-quality care. The overarching intent of quality assurance and improvement (QA/QI) activities is to

- Ensure the quality of services delivered through the NBCCEDP.
- Describe the role of QA/QI within the broader context of public health.
- Promote best-practice outcomes as benchmarks for improving clinical services for program women.

Health agencies that participate in the NBCCEDP use mammography facilities certified by the American College of Radiology and cytology laboratories that follow the Clinical Laboratory Improvement Amendments of 1988. CDC provides screening and diagnostic guidelines to all NBCCEDP grantees and helps them evaluate the appropriateness and quality of their clinical services. Under CDC's guidance, all grantees develop strategies to ensure that women receive the best care possible.

### QUALITY ASSURANCE

The foundation of any program for the early detection of breast and cervical cancer is quality data. Surveillance plays an important role in identifying data problems and establishing successful quality assurance activities to correct those problems. One of the challenges that the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP) faced was reaching a minimum of 20% in the "never or rarely screened" category (percentages ranged from 3.9% to 8.7%). Program staff knew this high-risk population of women existed in West Virginia, but the challenge was figuring out why they were not being captured in the data. During 2002, routine data surveillance identified an unusual increase in the number of women who answered "unknown" to the question about having had a prior Pap test. This increase prompted further investigation and resulted in a chart audit. Program researchers suspected that the key to solving the problem was related to the "unknown" prior Pap tests.




Indeed, the chart audit identified a misconception among WVBCCSP providers. Many thought that if a woman did not recall the exact date of her previous Pap test, they had to mark "unknown" on her Patient Data Form. Once the WVBCCSP staff recognized this misconception, they worked diligently to correct the problem by communicating with providers and reassuring them that partial or estimated dates were acceptable. To date, the WVBCCSP has performed three chart audits, and each has been essential in increasing the program's "never or rarely screened" percentages. Prior to the implementation of routine chart audits, the WVBCCSP's overall "never or rarely screened" percentage was 4.5%. That percentage increased to 24.9% following the completion of the first chart audit and has since remained above the mandated 20%. While chart audits proved to be a valid method of recapturing "never or rarely screened" populations for the WVBCCSP, they also—perhaps more importantly—emphasized the impact of provider education on data quality.

### SCREENING

The heart of the North Carolina Breast and Cervical Cancer Control Program (NC BCCCP) case management training is its Case Management Kit. The NC BCCCP compares the kit to a cookbook. Experienced cooks and new cooks use a cookbook differently. The Case Management Kit is designed to provide as much guidance as possible to new case managers but still allow experienced case managers to modify their approaches with creativity and confidence.

The Case Management Kit is a half-inch, indexed 3-ring binder that contains everything the NC BCCCP coordinator needs to follow the case management system. Contents include an overview of North Carolina's case management rationale and philosophy; PowerPoint notes; an algorithm used in training on the case management process; all forms needed to document case management, including a needs assessment form and six care plan templates; and the NC BCCCP case management policies.

## Screening

Screening and diagnostic services are the "heart" of the program. Screening encompasses five distinctly different program activities: screening, tracking, follow-up, case management, and rescreening. These activities work together to ensure that women in the program receive timely and appropriate follow-up. The NBCCEDP reimburses states and other grantees for clinical breast exams, screening mammograms, pelvic exams,

Pap tests, and some diagnostic procedures. State health agencies contract with a broad range of agencies to coordinate and deliver screening and diagnostic services.

# NBCCEDP Research and Evaluation

The data collected by the NBCCEDP facilitate the identification, analysis, and resolution of important issues in the provision of breast and cervical cancer screening to underserved women. Each grantee submits to CDC minimum data elements (MDEs) that are useful for planning and evaluation functions and as a basis for scientific studies. A selected list of scientific publications illustrating the breadth and importance of research using the MDEs is included in ***Appendix II***. As noted in this list of publications, researchers have examined such issues as how frequently Pap tests are needed once a series of tests are reported as negative,[5] differences in screening mammography between the United States and the United Kingdom,[6] and racial and ethnic differences in screening outcomes.[7] Additionally, analysis of NBCCEDP data has been valuable in determining that linkage of the MDEs with state cancer registries is important in consistently and accurately reporting cancer-stage data. This has led to greater cooperation between units in the health departments and from the community at large.

Of equal importance is the contribution of the MDE data set to public health practice. Designed to monitor the extent to which funded programs in the NBCCEDP achieve the objectives of the authorizing legislation, the MDEs provide demographic, service, and outcome data that have had a dramatic impact on policy and program development. For example,

- Descriptive reports of MDE data allow CDC to quickly identify programs struggling to meet clinical or service standards set for the national program and provide technical assistance before quality declines. These reports also guide the development of training for grantees and contribute to the identification of best practices for dissemination.

- Monitoring the MDEs may result in the identification of common deficiencies that suggest that system-wide changes are needed. New national policies or partnerships may result. An example is the relationship CDC has developed with the Migrant Clinicians' Network to enhance the cancer-related case management of migrant, homeless, and mobile people.

- Quality assurance (QA) is a major outcome of effective use of MDEs. Grantees can evaluate the work of individual providers against a standard and identify outliers for whom QA interventions may be needed. The MDE system provides essential information on the timeliness, adequacy, and appropriateness of follow-up of clinical care, ensuring that problems are addressed and changes made.

Outcomes of MDE reporting activities have resulted in significantly increased funding, allowing additional women to be screened nationwide for breast and cervical cancer. In addition, MDE data are useful in evaluating and influencing the development of updated national cancer screening recommendations and guidelines, tracking cancer rates among women who are never or rarely screened, testing the efficacy of screening technologies, and developing models to address other cancers. Data from the NBCCEDP support performance-based budgeting and the effective stewardship of taxpayers' dollars and public trust. Data about who is being served, with what services, within what time frame, and with what results allow CDC and its partners to assure the public that the NBCCEDP provides high-quality services to eligible women and contributes significantly to the reduction of the breast and cervical cancer burden in the country.

# Screening Results and Outcomes in the NBCCEDP

This report summarizes the data submitted by grantees from 1991 through 2002 on breast and cervical cancer screening participation, screening test results, diagnostic procedures performed, and final diagnoses. In addition to summary results, more detailed data are presented by time period (1991–1995, 1996–2000, and 2001–2002) in the ***Data Tables*** section. Most screening outcomes are reported by first and subsequent screening round because outcomes from the subsequent rounds in the NBCCEDP are more likely to reflect incidence of disease rather than prevalence. A woman's first program screening round is defined as her first NBCCEDP mammogram or Pap test. In reporting subsequent screening rounds, we excluded

results for women whose initial exam led to a final diagnosis of cancer. All screening result distributions, diagnostic follow-up rates, and cancer detection rates estimated for racial/ethnic groups were age-adjusted to the population of women receiving mammograms and Pap tests through the NBCCEDP in 2000 using the direct method.[8] A more detailed description of the methods used to obtain all breast and cervical cancer screening results and outcomes can be found in ***Appendix III.***

# Breast Cancer Screening

In the NBCCEDP, breast cancer screening includes both mammography and clinical breast examinations (CBEs). Mammography is currently the best available procedure for detecting breast cancer in its earliest, most treatable stage—an average of 1 to 3 years before the woman can feel the lump.[9] Additionally, CBEs are able to detect some of the few breast cancers that screening mammography may miss.[10] Thus, NBCCEDP breast cancer screening includes both types of examinations.

In the NBCCEDP, a breast cancer screening round can be initiated by either a mammogram or a CBE .[11] Mammography test results are categorized using the American College of Radiology (ACR) Breast Imaging Reporting and Data System (BI-RADS).[12] This system is a quality assurance tool designed to standardize mammographic reporting and facilitate outcome monitoring. Abnormal mammogram results that signal the need for additional diagnostic testing include suspicious abnormalities (BI-RADS category 4), those that are highly suggestive of a malignancy (BI-RADS category 5), and incomplete assessments (BI-RADS category 0). Diagnostic testing also is considered if the mammogram was done outside the program but the results are thought to have been abnormal. If a suspicious abnormality is found during a CBE, diagnostic work-up is required regardless of the initial mammogram findings. If diagnostic work-up is required or initiated in the NBCCEDP, documentation of diagnostic tests performed and the final diagnosis is expected. Additionally, for women diagnosed with breast cancer, documentation of the cancer's stage at diagnosis, the tumor size, the status of treatment, and the date of treatment initiation is required.

**Breast Imaging Reporting and Data System (BI-RADS)**
*Assessment Categories*

Category 0—Assessment incomplete–need additional imaging evaluation

Category 1—Negative

Category 2—Benign finding

Category 3—Probably benign–short interval follow-up suggested

Category 4—Suspicious abnormality–biopsy should be considered

Category 5—Highly suggestive of malignancy–appropriate action should be taken

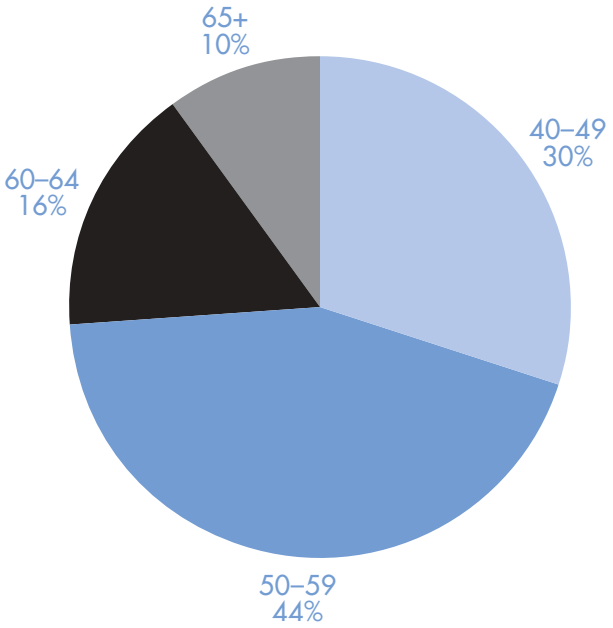
The Breast and Cervical Cancer Mortality Prevention Act of 1990 requires programs to take all appropriate measures to ensure that women with abnormal screening results receive the necessary follow-up services. CDC requires programs to establish and maintain a proactive surveillance system for the timely and appropriate referral and follow-up for women with abnormal or suspicious test results whose clinical services are paid for in whole or in part by the NBCCEDP funds. The NBCCEDP pays for select diagnostic services, including diagnostic mammography, repeat CBEs, breast ultrasounds, fine-needle aspirations, surgical consultations, and breast biopsies.

## Breast Cancer Screening Participation

When the NBCCEDP began in 1991, CDC followed recommendations for breast cancer screening that emphasized the value of screening mammography both for women aged 40–49 and for women aged 50 or older. All CDC-funded programs could screen women in both of these age groups. In 1996, however, the NBCCEDP established a more stringent age policy for funding breast cancer screening that would allow the best use of limited resources. The new NBCCEDP policy required that 75% of mammograms paid with NBCCEDP funds be provided to women 50 years of age or older. Consistent with the current age guidelines, most women screened in the program between 1991 and 2002 were 50–64 years of age at the time of their first screening (Figure 5).

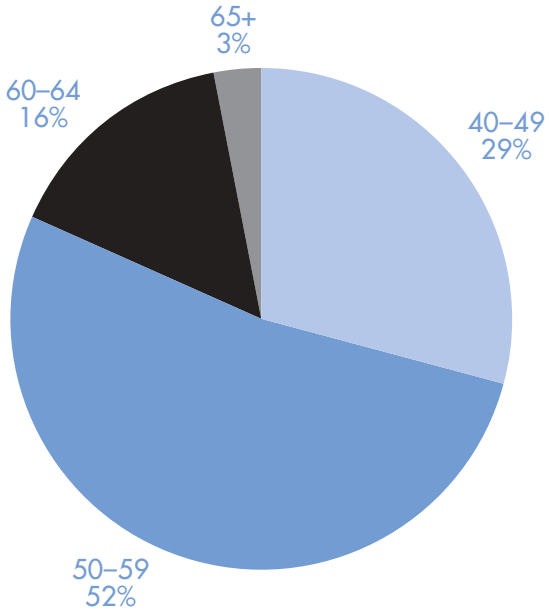
Figure 6 illustrates the age distribution of women screened in the program between 2001 and 2002. The recent shift in the age distribution of women receiving mammograms through the program is primarily due to a change in 1998 to exclude women 65 years

*Figure 5. Age* Distribution of Women Receiving Mammograms Through the NBCCEDP, 1991–2002*




*Age at time of first mammogram.

*Figure 6. Age* Distribution of Women Receiving Mammograms Through the NBCCEDP, 2001–2002*




*Age at time of first mammogram.

of age and older who are eligible for Medicare Part B coverage. The racial and ethnic distribution of women receiving mammography through the NBCCEDP is shown in Figures 7 and 8. Since the beginning of the program, approximately 88% of the women screened have been Hispanic/Latina, white, and black or African American (Figure 7). However, during 2001 and 2002 a slightly higher percentage of women screened were Hispanic/Latina and Asian/Native Hawaiian/Other Pacific Islander (Figure 8).

*Figure 7. Racial/Ethnic Distribution of Women Receiving Mammograms Through the NBCCEDP, 1991–2002*

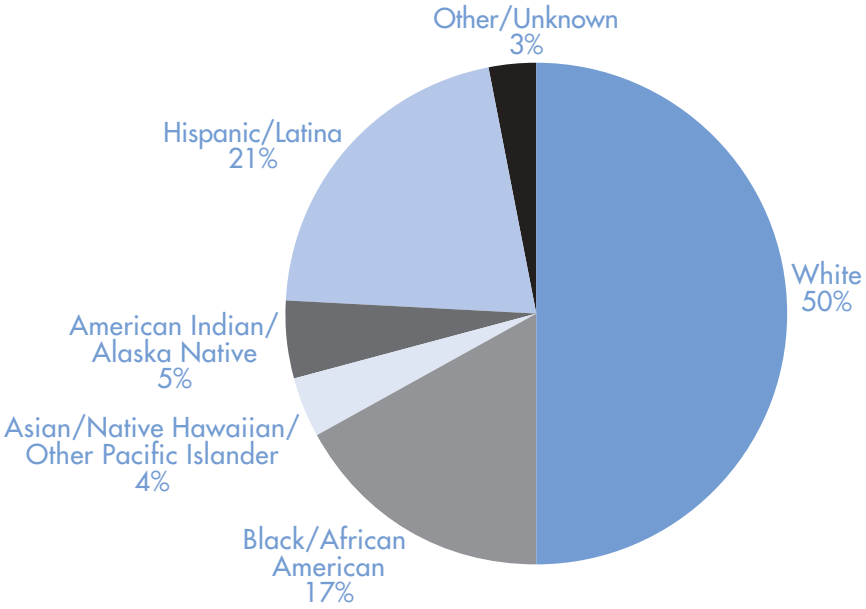
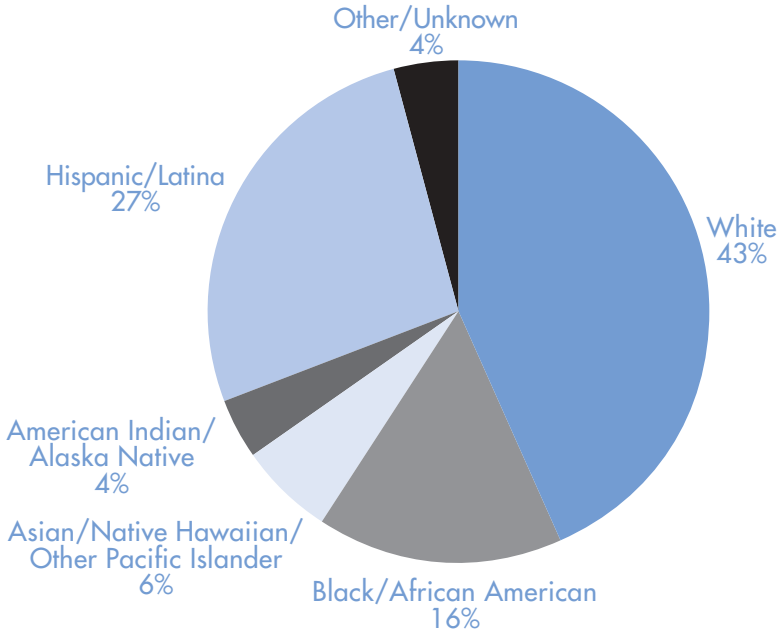


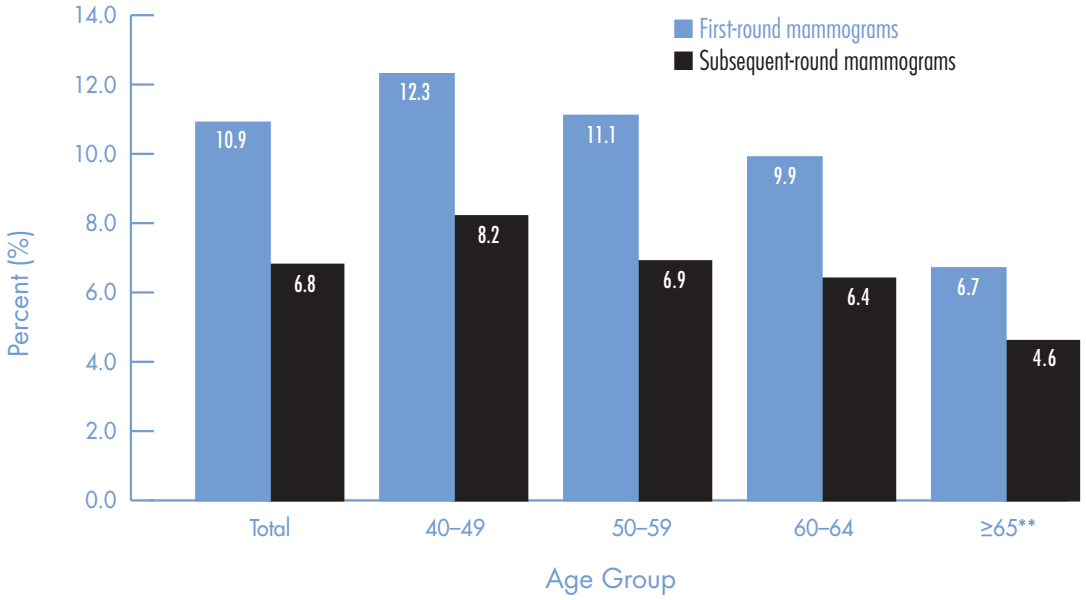

*Figure 8. Racial/Ethnic Distribution of Women Receiving Mammograms Through the NBCCEDP, 2001–2002*




## Breast Cancer Screening Results

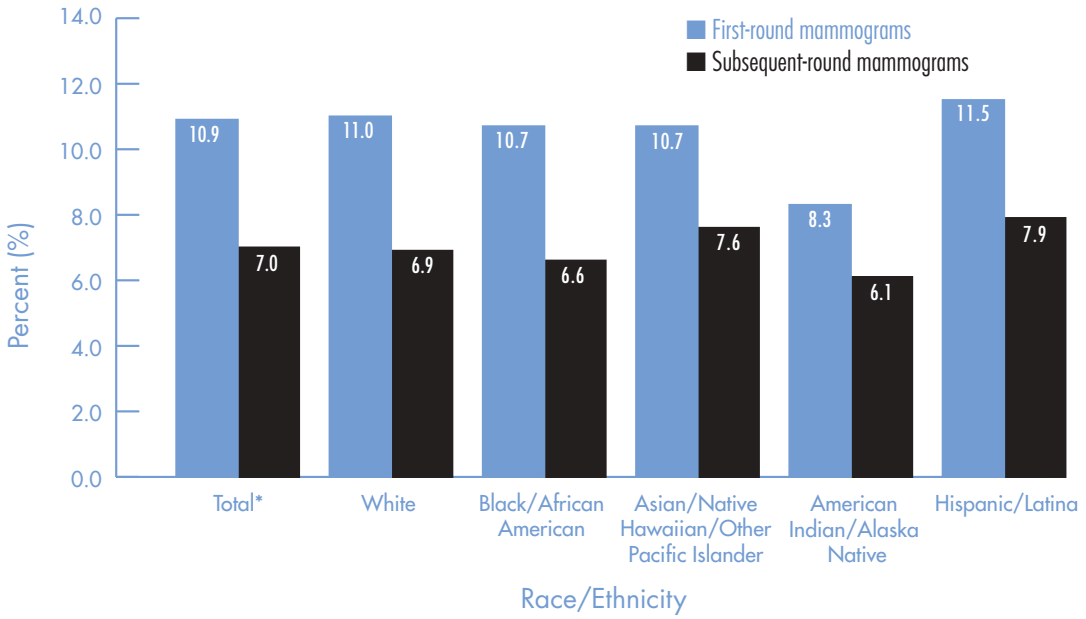
Figure 9 illustrates the age-specific percentage of screening mammograms that are abnormal during the first and subsequent screening rounds for women screened through the NBCCEDP between 1991 and 2002. Overall, the percentage of abnormal screening mammograms decreases with increasing age, and the percentage of women with abnormal mammography results is higher in the first screening round. An unknown number of women are referred to the program or seek out the NBCCEDP themselves after presenting with symptoms or after having an abnormal CBE or

*Figure 9. Percentage of Screening Mammograms That Are Abnormal* Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*




*Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."
**Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.

*Figure 10. Age-Adjusted* Percentage of Screening Mammograms That Are Abnormal** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*Age-adjusted to the 2000 NBCCEDP population.
**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

mammogram elsewhere. As a result, the percentage of women reporting symptoms was also greater in the first screening round (11.0%) than in subsequent rounds (6.7%).

Figure 10 displays the age-adjusted percentage of abnormal screening mammograms by racial and ethnic origin of the program participants. From 1991 through 2002 the age-adjusted percentage of abnormal screening mammograms for all women in the NBCCEDP was 10.9% and 7.0% for first and subsequent screening rounds, respectively. Hispanic/Latina women had the highest percentage of abnormal mammography screening results for both first and subsequent rounds.

Tables 1.1–1.3 and Tables 2.1–2.3 in the ***Data Tables*** section of this report show the distribution, by time period, of all breast cancer screening results for women screened through the NBCCEDP. In general, the percentage of abnormal mammograms increased over the 12-year time period covered in this report.

## Breast Cancer Screening Diagnostic Follow-Up

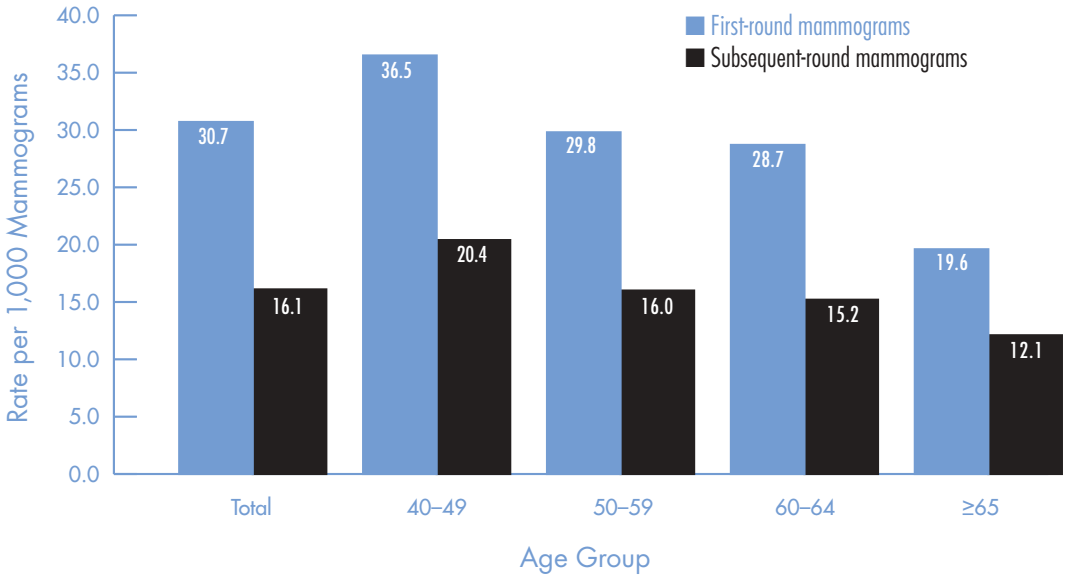
Diagnostic follow-up in the NBCCEDP can be initiated based on either an abnormal screening result or the level of concern of the patient or clinician. Diagnostic follow-up is defined as any surgical or imaging procedures other than the screening mammogram or CBE, including additional mammographic views, ultrasound, a repeat CBE or surgical consultation, a fine-needle or cyst aspiration, and biopsy or lumpectomy. The age-specific biopsy rates per 1,000 mammograms in the NBCCEDP are illustrated in Figure 11. Biopsy rates were inversely related to women's age. Figure 12 shows the age-adjusted biopsy rates by racial/ethnic group. Regardless of age, race, or ethnicity, the biopsy rates were substantially lower in subsequent rounds. This result is expected since many of the women screened for the first time in the NBCCEDP report having symptoms, have not been screened before, or are referred to the program by another clinician due to a suspicious finding.

Tables 3.1–3.3 and Tables 4.1–4.3 in the ***Data Tables*** section of this report show, by time period, the rates of all diagnostic follow-up in women screened through the NBCCEDP. During the 12-year time period covered in this report, the rate of diagnostic follow-up increased in all age groups.

## Breast Cancer Detection

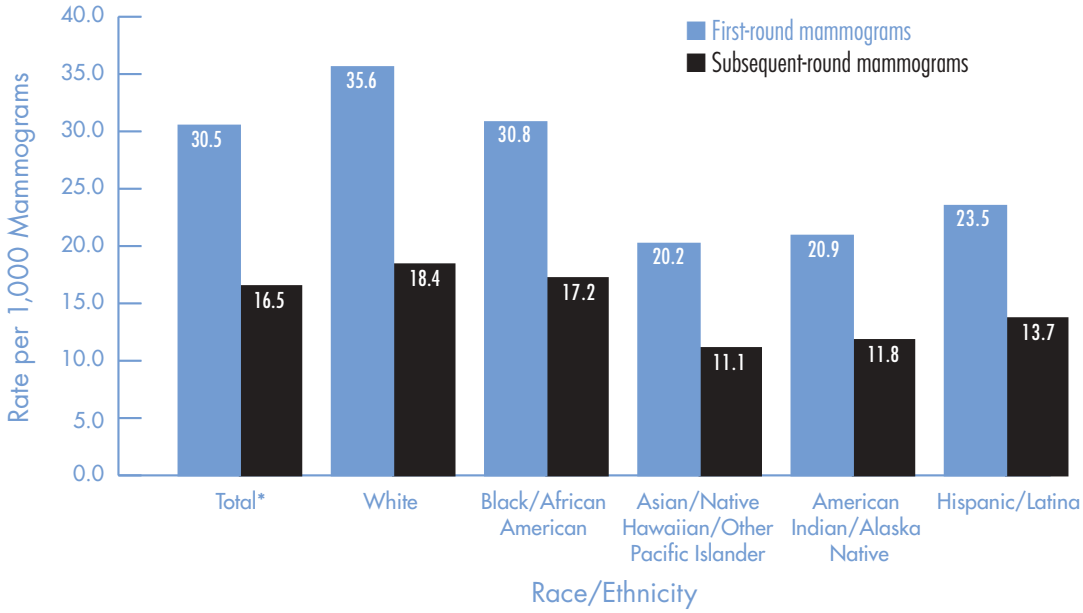
Figure 13 shows age-specific cancer detection rates (invasive and in situ combined) per 1,000 mammograms in the NBCCEDP. The cancer detection rates generally increase with age; however, there is a slight drop in rates for women 65 years of age or older. The age-

*Figure 11. Biopsy* Rates Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*



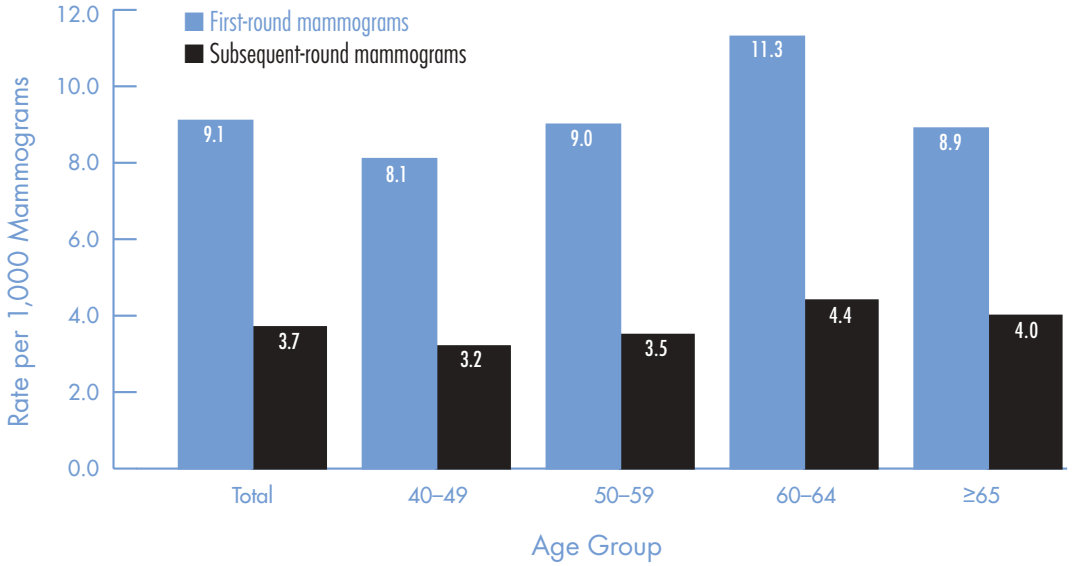

*Diagnostic follow-up may be initiated on the basis of an abnormal CBE, abnormal mammogram, or a high level of concern by the patient or clinician.

*Figure 12. Age-Adjusted* Biopsy** Rates Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*Age-adjusted to the 2000 NBCCEDP population.
**Diagnostic follow-up may be initiated on the basis of an abnormal CBE, abnormal mammogram, or a high level of concern by the patient or clinician.

*Figure 13. Rates of Breast Cancer* Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*

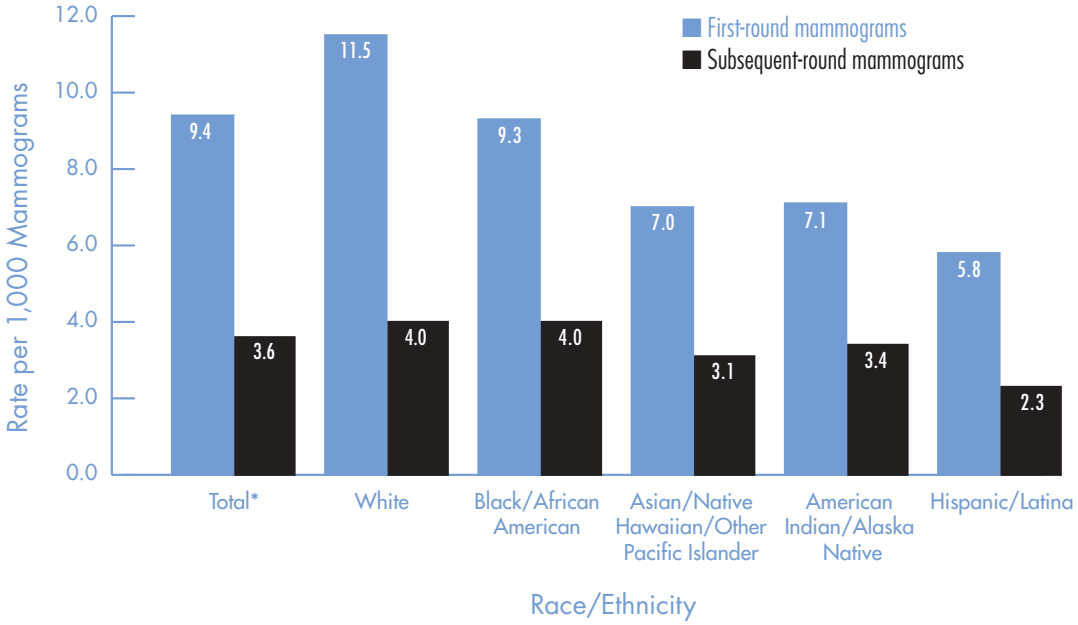



*Includes invasive breast cancer, Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

adjusted cancer detection rates are illustrated in Figure 14. Overall, and adjusted for age, there are 9.4 cases of invasive or in situ breast cancer diagnosed per 1,000 mammograms in the NBCCEDP. This rate is higher in white women, but lower in all other racial and ethnic groups. Regardless of age, race, or ethnicity, the detection rates for carcinoma in situ and invasive cancer were substantially lower in subsequent rounds, since many of the women screened during the first round were previously unscreened, symptomatic, or referred to the program by another clinician due to a suspicious finding.

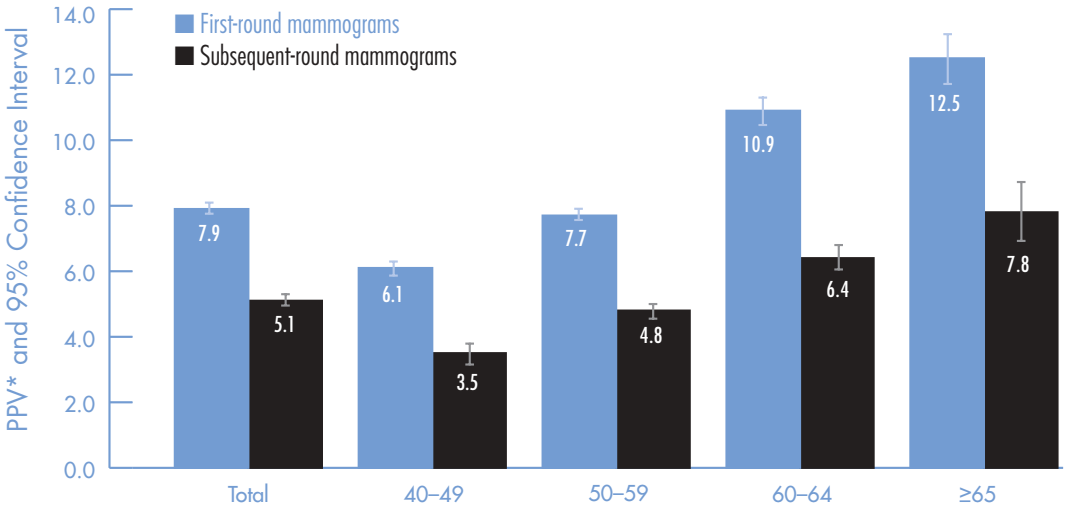
Tables 3.1–3.3 and Tables 4.1–4.3 in the ***Data Tables*** section of this report show, by time period, the invasive and in situ carcinoma detection rates in women screened

*Figure 14. Age-Adjusted* Rates of Breast Cancer** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*Age-adjusted to the 2000 NBCCEDP population.
**Includes invasive breast cancer, Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Figure 15. Positive Predictive Value (PPV)* of Abnormal Mammography Results** Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*




*The positive predictive value (PPV) was calculated by dividing the number of abnormal mammogram results leading to a final diagnosis of cancer by the total number of abnormal mammogram results.
**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

through the NBCCEDP. In general, cancer detection rates have increased since the beginning of the program.

## Positive Predictive Value of Abnormal Mammograms

The diagnostic value of a procedure is often defined by its positive predictive value, or the measure (%) of times a positive test result leads to diagnosis of disease. Here, the positive predictive value (PPV) of abnormal mammograms is defined as the proportion of abnormal mammograms that lead to a final diagnosis of breast cancer. Figure 15 illustrates age-specific PPVs of abnormal mammograms among women in the NBCCEDP. In general, first-round abnormal mammograms have a PPV of 7.9, whereas subsequent-round abnormal mammograms have a significantly lower PPV of 5.1. The PPVs are smaller for younger women but increase with increasing age. The variation by racial and ethnic group is shown in Figure 16. The PPV is significantly higher in black or African American women and white women when compared to the PPV in Asian/Native Hawaiian/Other Pacific Islander and Hispanic/Latina women.

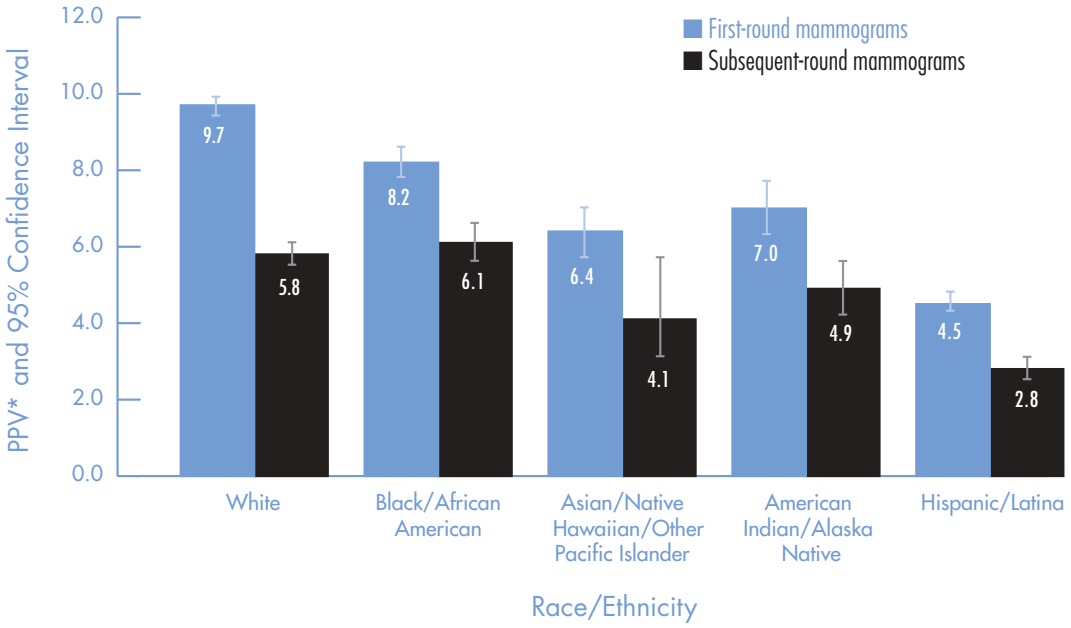
Tables 5.1–5.3 in the ***Data Tables*** section of this report show these results by time period.

## Stage of Invasive Breast Cancer at Time of Diagnosis

The goal of screening for breast cancer is to detect the disease at its earliest and most treatable stage of development. Figure 17 illustrates the age-specific distribution of early- versus late-stage detection of invasive breast cancer in the NBCCEDP. From 1991 through 2002, 9,956 women had a diagnosis of invasive breast cancer, and 74.0% of these cancers were identified at an early stage.

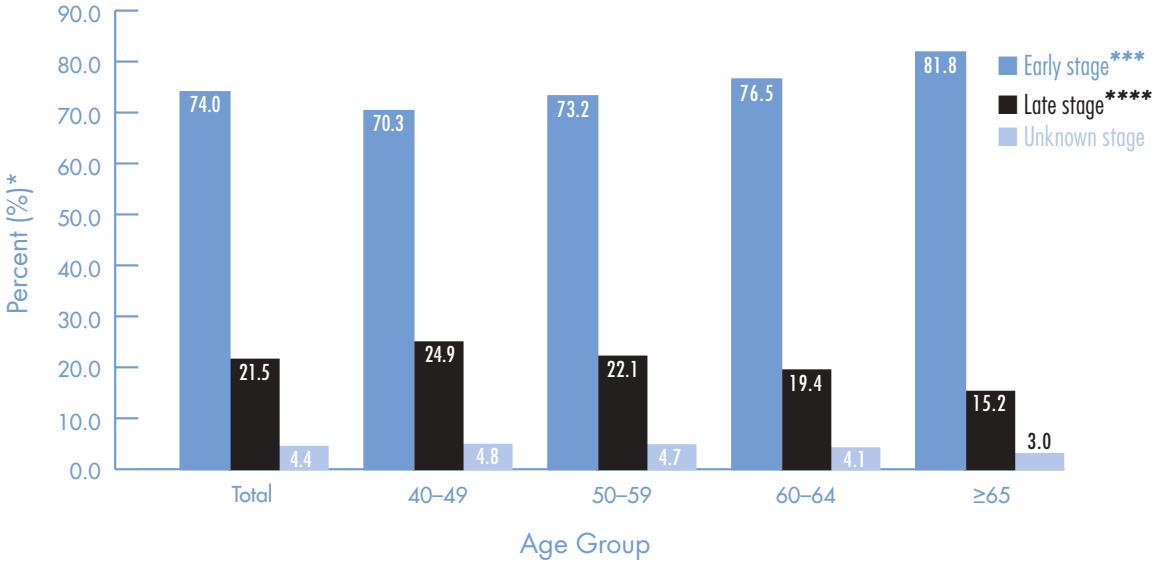
Tables 6.1–6.3 in the ***Data Tables*** section of this report show all breast cancer staging results by age and time period.

*Figure 16. Positive Predictive Value (PPV)* of Abnormal Mammography Results** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*The positive predictive value (PPV) was calculated by dividing the number of abnormal mammogram results leading to a final diagnosis of cancer by the total number of abnormal mammogram results.
**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Figure 17. Distribution (%)* of Early vs. Late Stage** Invasive Cancer at Time of Diagnosis in Women Screened Through the NBCCEDP, by Age Group, 1991–2002*




*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***Includes AJCC† Stage I and II, and SEER† summary local stage.
****Includes AJCC† Stage III and IV, and SEER† summary regional and distant stage.
†Abbreviations: AJCC=American Joint Committee on Cancer; SEER=Surveillance, Epidemiology, and End Results.

# Cervical Cancer Screening

Cervical cancer is largely preventable with appropriate screening. The standard screening method for early detection of cervical carcinoma is the Pap test. This screening test has helped reduce the cervical cancer morbidity and mortality rates and is the most cost-effective cancer screening method available.[13] The U.S. Preventive Services Task Force strongly recommends that women between the ages of 21 and 65 be screened regularly for cervical cancer.[2]

In the NBCCEDP, a cervical cancer screening round is initiated by a Pap test. The Pap test results are categorized using the Bethesda System.[14] This system is a quality assurance tool designed to standardize Pap test reporting and facilitate outcome monitoring. Abnormal Pap test results that signal the need for additional diagnostic testing include *low-grade squamous intraepithelial lesion* (LSIL), *high-grade squamous intraepithelial lesion* (HSIL), *squamous cell cancer* (SqCa), *atypical glandular cells* (AGC), and *atypical squamous*

**2001 Bethesda System Categories Used in the NBCCEDP**

- Negative for intraepithelial lesion or malignancy.
- Atypical squamous cells of undetermined significance (ASC–US).
- Low-grade squamous intraepithelial lesion (LSIL) encompassing: HPV, mild dysplasia/CIN I.
- Atypical squamous cells of undetermined significance–cannot exclude HSIL (ASC–H).
- High-grade squamous intraepithelial lesion (HSIL) encompassing: moderate and severe dysplasia, CIS/CIN II and III.
- Squamous cell carcinoma.
- Atypical glandular cells including atypical, endocervical adenocarcinoma in situ and adenocarcinoma.
- Other.

*cells–cannot exclude HSIL* (ASC-H), which was added to the reporting system in 2001. If diagnostic work-up is required or initiated in the NBCCEDP, documentation of diagnostic tests performed and the final diagnosis is expected. Additionally, for women diagnosed with cervical cancer, documentation of the cancer's stage at diagnosis, tumor size, status of treatment, and date of treatment initiation is required.

The Breast and Cervical Cancer Mortality Prevention Act of 1990 requires programs to take all appropriate measures to ensure that women with abnormal screening results are provided with necessary follow-up services. The NBCCEDP pays for diagnostic services, including colposcopy and colposcopy-directed biopsy.

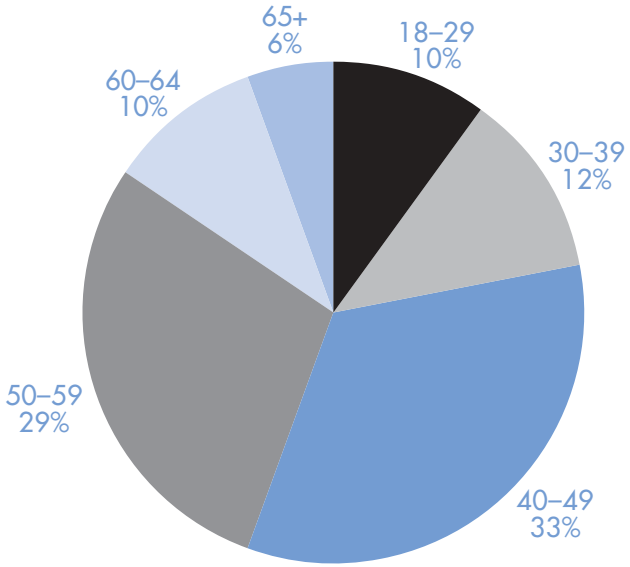
Although the overall rate of screening for cervical cancer in the United States has increased, many subpopulations are not being adequately screened. More than 60% of the women with a diagnosis of cervical carcinoma had never been screened or had not been screened within the previous 5 years of diagnosis.[15] In 1999, CDC and an external work group conducted a careful review of the scientific literature, the cervical cancer guidelines of professional organizations, and NBCCEDP data on Pap screening outcomes and collaborated on the development and implementation of a new cervical cancer screening policy. This policy encouraged all NBCCEDP grantees to focus cervical cancer screening on women who had rarely or never been screened and to decrease over-screening of women enrolled in the program.

At the same time, CDC changed the screening guidelines that recommended yearly Pap tests for all women. The new guidelines recommend a Pap test every 3 years after a woman has had three consecutive normal Pap test results within a 5-year period. For women who have not had three consecutive Pap tests with normal or benign findings within a 5-year period, annual screening is still recommended.

## Cervical Cancer Screening Participation

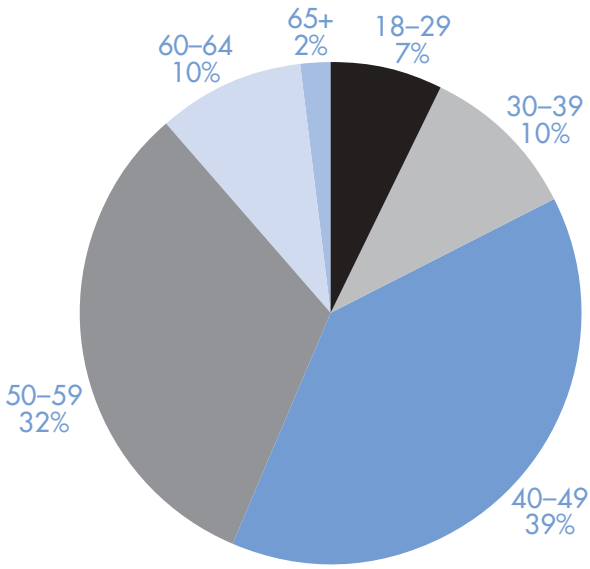
Figure 18 illustrates the age distribution of women receiving a Pap test in the NBCCEDP since the onset of the program, and Figure 19 shows the distribution for 2001 and 2002 only. More than half of the women screened in the program are 40–59 years of age. Only 22% of clients receiving cervical cancer screening during this entire period were under age 40. In the more recent time

*Figure 18. Age* Distribution of Women Receiving Pap Tests Through the NBCCEDP, 1991–2002*



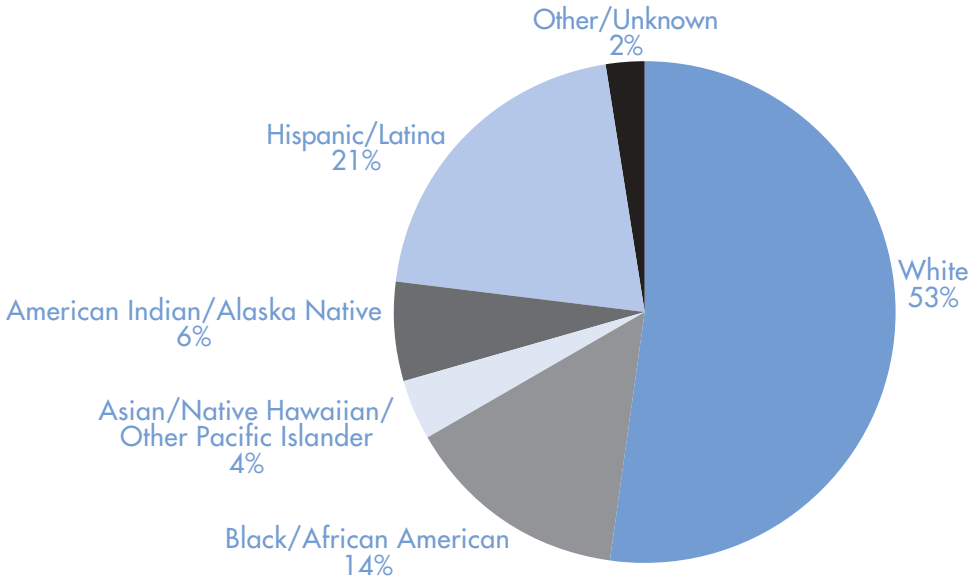

*Age at time of first Pap test.

*Figure 19. Age* Distribution of Women Receiving Pap Tests Through the NBCCEDP, 2001–2002*




*Age at time of first Pap test.

*Figure 20. Racial/Ethnic Distribution of Women Receiving Pap Tests Through the NBCCEDP, 1991–2002*




period, these younger age groups represent only 17% of the total population, which likely reflects the program's increasing emphasis on the recruitment of never or rarely screened women.

The racial/ethnic distribution of women receiving a Pap test through the NBCCEDP is shown in Figures 20 and 21. For all years combined, slightly less than half (47%) of the women were from racial/ethnic minority groups. For the most recent time period (2001–2002), the percentage from minority groups is slightly more than half (51%).

## Cervical Cancer Screening Results

Figure 22 illustrates the age-specific percentage of screening Pap tests with abnormal results during the first and subsequent screening rounds for women screened through the NBCCEDP between

*Figure 21. Racial/Ethnic Distribution of Women Receiving Pap Tests Through the NBCCEDP, 2001–2002*

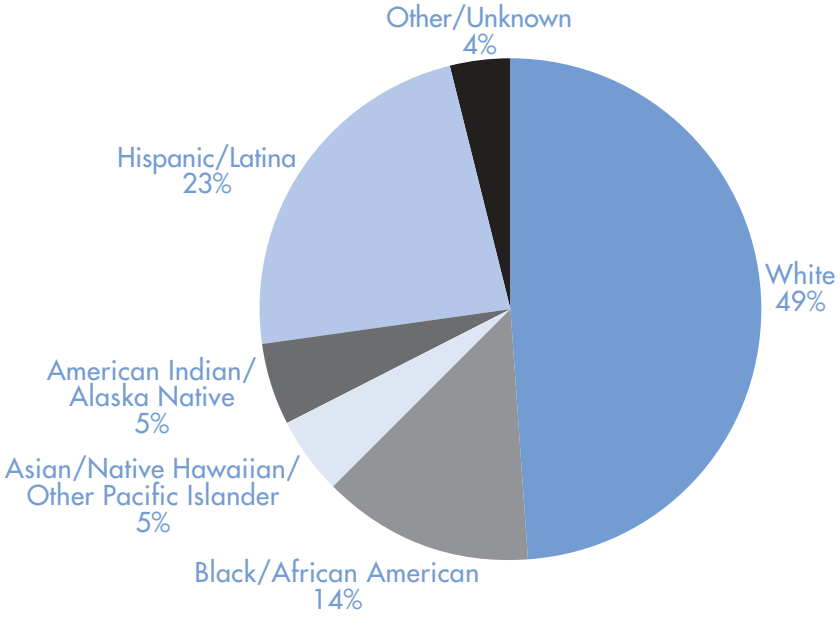
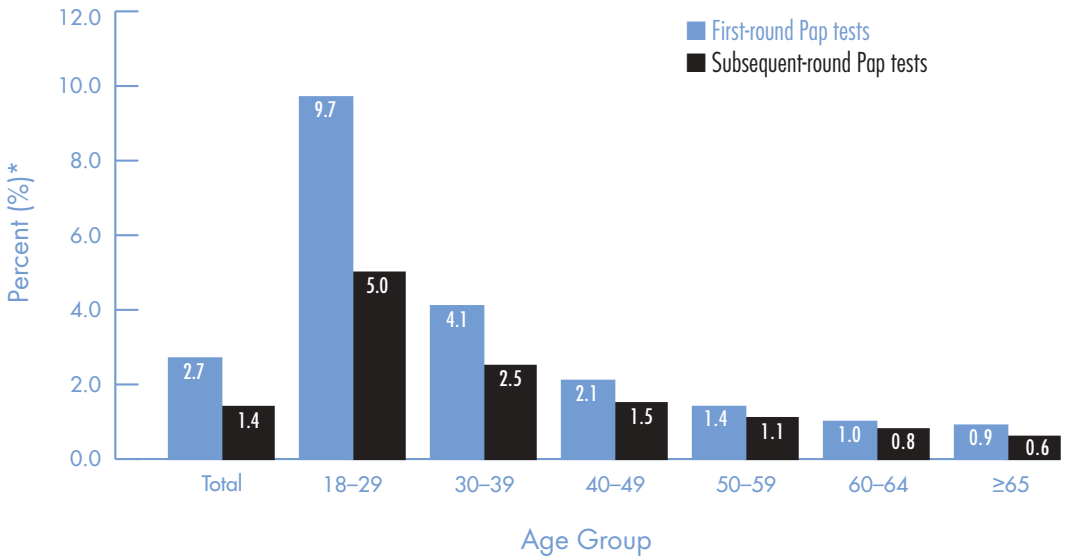



*Figure 22. Percentage of Screening Pap Tests That Are Abnormal* Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*




*Includes the following Pap test results: low-grade squamous intraepithelial lesions (LSIL), high-grade squamous intraepithelial lesions (HSIL), atypical squamous cells of undetermined significance—cannot exclude HSIL (ASC-H), atypical glandular cells (AGC), and squamous cell cancer.

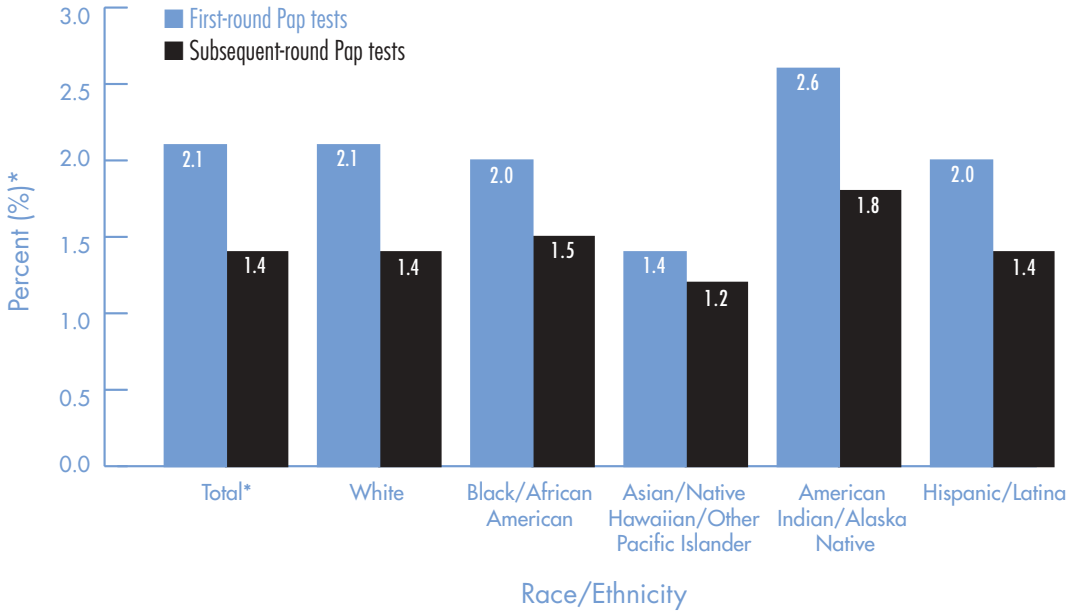
**Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.

1991 and 2002. For all women screened for the first time, the percentage of abnormal screening results was 2.7% from 1991 through 2002. Overall, the percentage of abnormal Pap test results decreases with increasing age, and the percentage of women with abnormal Pap test results is higher in the first screening round.

Figure 23 displays the age-adjusted percentage of abnormal Pap test results by racial and ethnic origin. For both first and subsequent screening rounds, American Indian/Alaska Native women had the highest percentage of abnormal Pap test results.

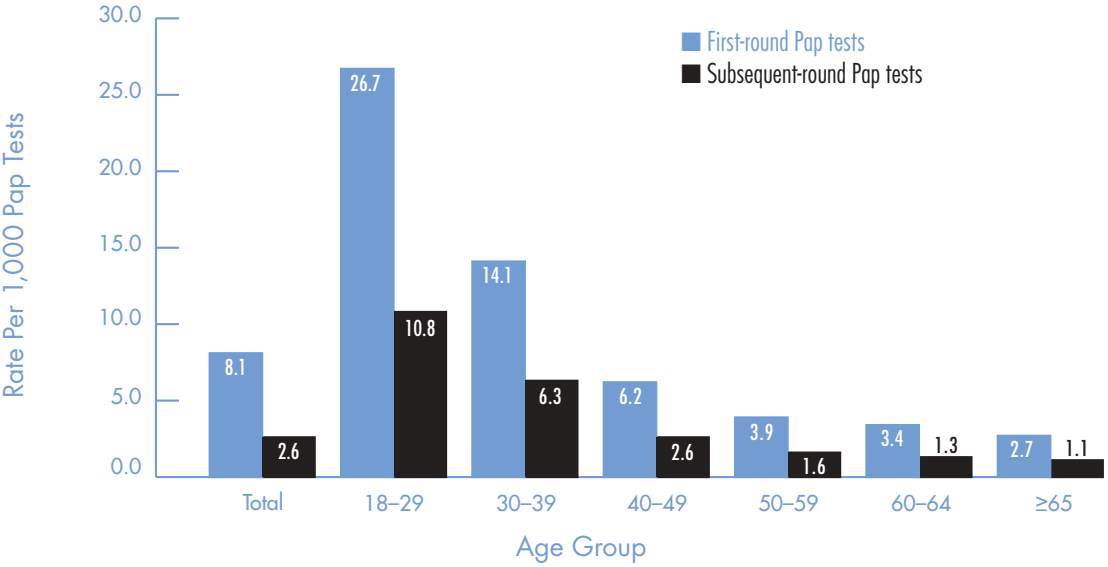
Tables 7.1–7.3 in the ***Data Tables*** section show the distribution of all cervical cancer screening results by age and time period. Tables 8.1–8.3 show the age-adjusted distribution by race/ethnicity for the

*Figure. 23 Age-Adjusted* Percentage of Screening Pap Tests That Are Abnormal** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*Age-adjusted to the 2000 NBCCEDP population.
**Includes the following Pap test results: low-grade squamous intraepithelial lesions (LSIL), high-grade squamous intraepithelial lesions (HSIL), atypical squamous cells of undetermined significance—cannot exclude HSIL (ASC-H), atypical glandular cells (AGC), and squamous cell cancer.

*Figure 24. Rates of Biopsy-Confirmed Cervical Intraepithelial Neoplasia (CIN) II or Worse* Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*



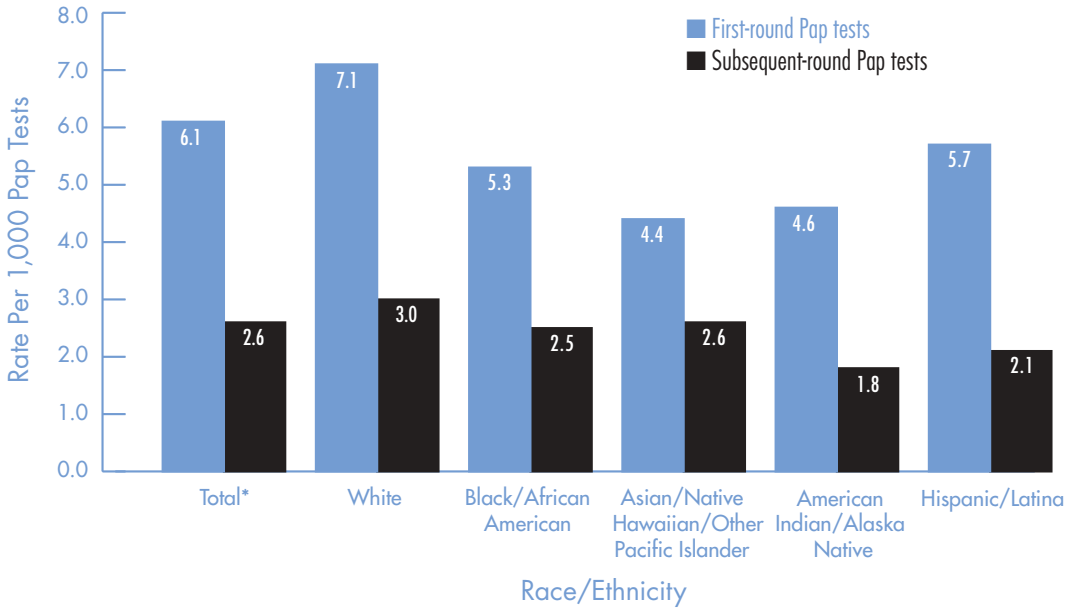

*CIN II or worse includes CIN II, CIN III, carcinoma in situ, and invasive cervical cancer.

three time periods. There were no substantial changes in the percentage of abnormal Pap tests during the 12-year time period covered in this report.

## Cervical Precancer and Cancer Detection

Figure 24 shows age-specific rates of biopsy-confirmed *cervical intraepithelial neoplasia* (CIN) II or worse (includes CIN II, CIN III, CIS, and invasive cancer) by screening round per 1,000 Pap tests in the NBCCEDP. The rates of CIN II or worse decrease with participants' increasing age in both first and subsequent screening rounds. The age-adjusted rates by

*Figure 25. Age-Adjusted* Rates of Biopsy-Confirmed Cervical Intraepithelial Neoplasia (CIN) II or Worse** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*Age-adjusted to the 2000 NBCCEDP population.
**CIN II or worse includes CIN II, CIN III, carcinoma in situ, and invasive cervical cancer.

race and ethnicity are illustrated in Figure 25. Overall, and adjusted for age, there were 6.1 cases of CIN II or worse per 1,000 Pap tests. In the first round of screening, white women had the highest age-adjusted rate (7.1 per 1,000 Pap tests), followed by Hispanic/Latina women (5.7 per 1,000 Pap tests). Regardless of age, race, or ethnicity, the detection rates were lower in subsequent rounds.

Tables 9.1–9.3 and Tables 10.1–10.3 show the rates of biopsy-confirmed CIN and invasive cervical cancer among women in the NBCCEDP. There were no substantial changes in the precancerous and cancer detection rates between 1991 and 2002.

## Positive Predictive Value of Abnormal Pap Tests

The diagnostic value of a procedure is often defined by its positive predictive value, or the measure (%) of times a positive test result leads to diagnosis of disease. Here, the positive predictive value (PPV) of an abnormal Pap test is defined as the proportion of Pap test results of LSIL, ASC-H, HSIL, AGC, or SqCa combined that result in a final diagnosis of CIN II or worse. Figure 26 illustrates the age-specific PPVs of abnormal Pap tests by screening round. Overall, in the first round the PPV is 25.4%, whereas subsequent rounds have a lower PPV of 14.1%. The PPVs are highest for women in their 30s. The variation by racial and ethnic group is shown in Figure 27. The PPV is highest in white women in the first round (29.0%) and in Asian/Native Hawaiian/Other Pacific Islanders in the subsequent rounds (16.3%).

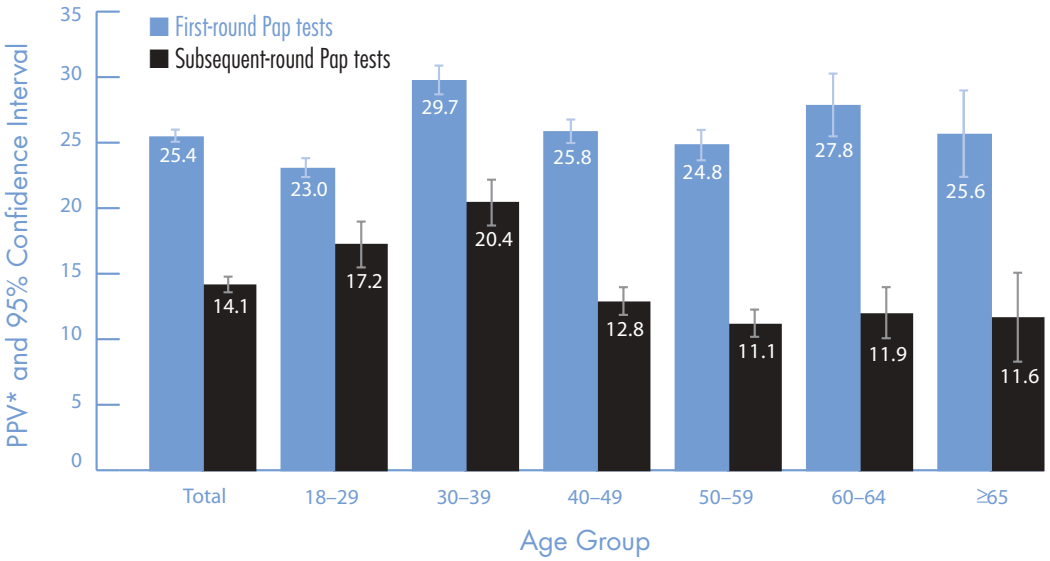
Tables 11.1–11.3 in the ***Data Tables*** section of this report show these results by time period.

## Stage of Invasive Cervical Cancer at Time of Diagnosis

Screening for cervical cancer allows for early detection when the disease is at its earliest and most treatable stage. Figure 28 illustrates the detection of invasive cervical cancer for women less than 50 years of age or 50 years and older in the NBCCEDP. A total of 832 women were diagnosed with invasive cervical cancer from 1991 through 2002 and 52.8% of these cases were identified as local disease. Regardless of age, most cases were detected in an early stage. However, women under 50 years of age were more likely than women over 50 to be diagnosed with local disease.

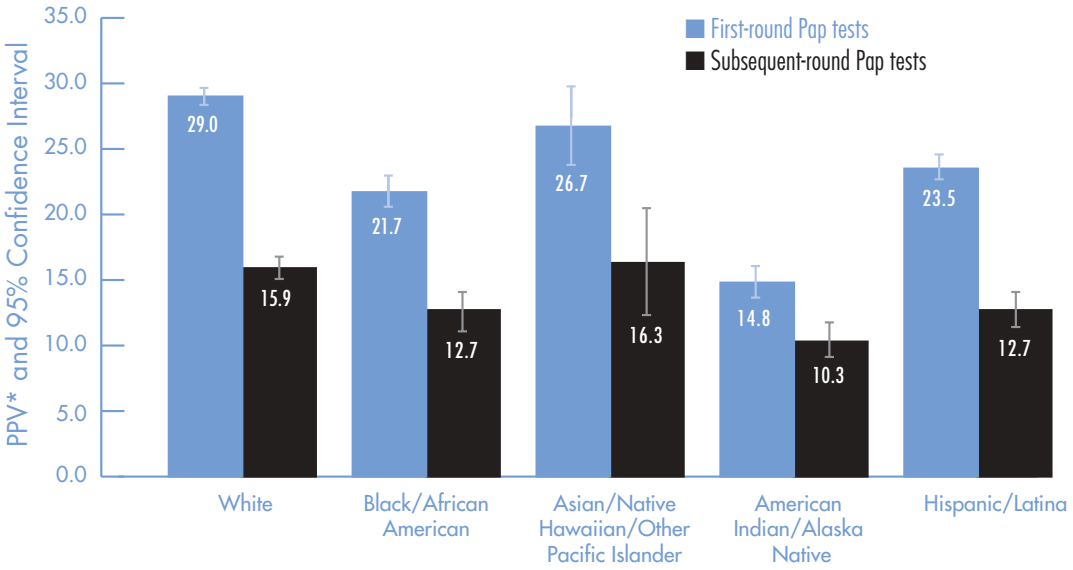
Tables 12.1–12.3 in the ***Data Tables*** section of this report show all cervical cancer staging results by age and time period.

*Figure 26. Positive Predictive Value (PPV)* of Abnormal Pap Test Results** Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–2002*



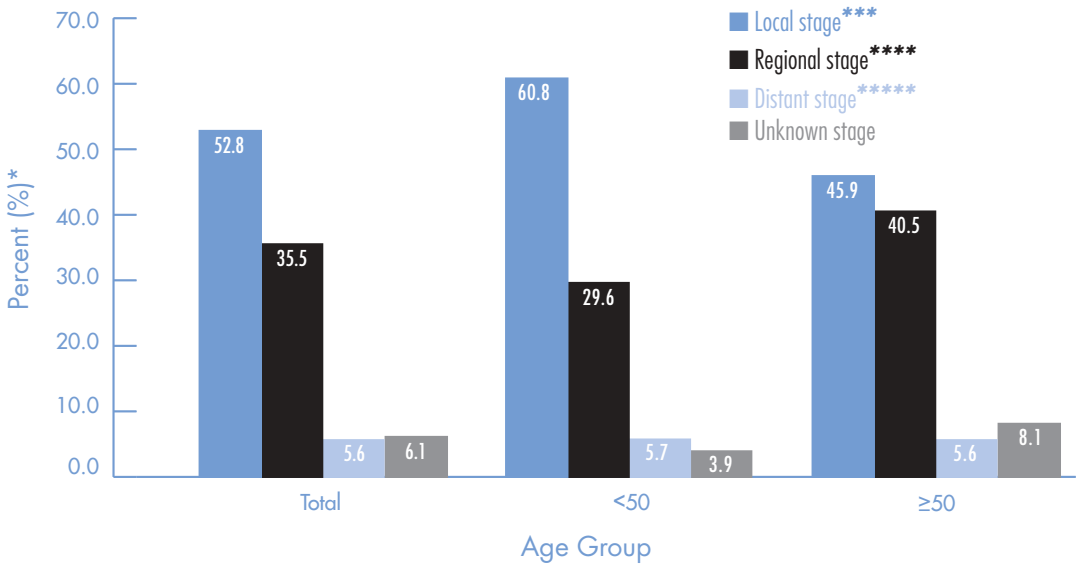

*The PPV was calculated by dividing the number of abnormal Pap test results** leading to a biopsy-confirmed high-grade lesion (CIN† II or worse) by the total number of abnormal Pap test results.
**Includes the following Pap test results†: LSIL, ASC-H, HSIL, AGC, and squamous cell cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells; ASC-H=atypical squamous cells of undetermined significance—cannot exclude HSIL.

*Figure 27. Positive Predictive Value (PPV)* of Abnormal Pap Test Results** Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–2002*




*The PPV was calculated by dividing the number of abnormal Pap test results** leading to a biopsy-confirmed high-grade lesion (CIN† II or worse) by the total number of abnormal Pap test results.
**Includes the following Pap test results†: LSIL, ASC-H, HSIL, AGC, and squamous cell cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells; ASC-H=atypical squamous cells of undetermined significance—cannot exclude HSIL.

*Figure 28. Distribution (%)* of Cancer Stage** at Time Invasive Cervical Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 1991–2002*




*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***Includes the International Federation of Gynecology and Obstetrics (FIGO) Stage I and the Surveillance, Epidemiology, and End Results (SEER) local summary stage.
****Includes FIGO/American Joint Committee on Cancer (AJCC) Stage II and III and SEER regional summary stage.
*****Includes FIGO/AJCC Stage IV and SEER distant summary stage.

# Future Directions

In cooperation with many local and national partners, the NBCCEDP continues efforts to expand screening services and improve program efficiency and effectiveness. Currently, there are several special projects administered by CDC's Division of Cancer Prevention and Control (DCPC) that are designed to improve our understanding of effective infrastructure choices, costs, and best practices. With cooperation from our funded programs, the results of these special studies and analyses will enhance the success of our program. The following section highlights some of the important projects underway.

## Sharing NBCCEDP Performance Data with the General Public

In response to a congressional initiative to share NBCCEDP performance data with the general public, CDC is developing a Web-based report accessible through the CDC public Web site that will provide a current summary of national and program-specific screening and diagnostic services and outcomes.

## The MDE Validation Project

CDC regularly reviews the MDE data for program monitoring purposes and also conducts analyses of the national data for publication in appropriate reports and professional journals. A list of previous publications is provided in ***Appendix II.*** To better assess the quality of these data, CDC has initiated a national evaluation of the MDE data. To evaluate the quality of the national database, breast and cervical cancer screening, diagnostic, and final diagnosis MDE data from a sample of NBCCEDP grantees will be compared with data in the patients' medical records.

## Estimates of the Percentage of the Eligible U.S. Population Screened Through the NBCCEDP

Efforts are under way to estimate the total number of women in the United States who are eligible for the NBCCEDP as well as the percentage of age-appropriate women currently being screened through the program. The estimates will be based on the MDEs and the Annual Social and Economic

Supplement of the U.S. Census Bureau's Current Population Survey. This information will be used to inform the program's estimates of resources needed to expand services, and may also be useful in identifying programs with more effective outreach strategies.

## Case Management Evaluation Project for the NBCCEDP

In an effort to learn more about the impact of the Women's Health Research and Prevention Amendments of 1998 (Public Law 105-340) and CDC's subsequent case management policy on NBCCEDP operations and clients, DCPC and the University of Michigan's School of Public Health are coordinating a multi-phased evaluation of case management services. The primary objective of the first year (Phase I) is to provide a descriptive understanding of how NBCCEDP grantees have implemented case management. Phase II, which is currently in progress, will describe the variety of approaches to staffing and reimbursement of case management services and investigate whether or not the case management policy has had an observable impact on two important indicators in the MDE data: the timeliness and completeness of care for women with abnormal screening results.

## Breast Cancer Screening Linkage Study

Linkage of the MDEs with outside data sources allows the NBCCEDP data to be supplemented with additional information and can serve as a useful data validation tool. A study is currently underway to link NBCCEDP data to breast cancer data from registries in six states. This study will examine performance measures such as sensitivity; assess data agreement; compare treatment patterns, demographic variables, and cancer variables among the NBCCEDP and registry cases; and develop recommendations for similar linkages in the future.

## Comprehensive Cost Analyses of the NBCCEDP

Currently in progress is the first attempt to estimate the overall cost of the NBCCEDP and to evaluate the cost effectiveness of individual program characteristics. The calculated cost effectiveness of screening for breast and cervical cancer and the cost effectiveness of the early detection of each cancer can then be compared to other large public health intervention programs. Evaluating the cost efficiency of individual program characteristics will help explain disparate funding needs among programs and also lead to more efficient use of federal funding.

## Evaluation of the Breast and Cervical Cancer Prevention and Treatment Act of 2000

Two studies have been undertaken to evaluate the effect of the Treatment Act on eligible women and the state BCCEDP and Medicaid programs. These studies include a 16-state study of the implementation of the Act and a 7-state study of the impact of the Act. The MDEs are used to further inform these primarily qualitative studies. Results from the implementation evaluation were disseminated in 2004, and results from the impact evaluation are expected in 2005.

Currently, the NBCCEDP is in the third year of a 5-year funding cycle (program announcement number 2060). At the end of this funding cycle, CDC will again publish this report, which will present the next 5 years of data (2003 through 2007) and discuss the results of some of the key projects described above.

The CDC's NBCCEDP is one of the largest efforts in chronic disease prevention and control ever undertaken by an agency of the federal government. The success of the program has contributed to the growing focus of state health agencies on chronic disease prevention and control. One of the greatest challenges for the future is to sustain the momentum and commitment of federal and state governments to expand screening coverage in currently funded programs. The CDC will continue working—through research, partnerships, and grantee organizations—to increase women's access to breast and cervical cancer early detection and treatment services, to develop strategies for improving rescreening rates among women enrolled in the program, and to implement public education and outreach strategies capable of reaching women who have rarely or never been screened.

# Data Tables

# Data Tables

## Breast Cancer Screening Results



## Diagnostic Follow-Up and Breast Cancer Diagnosis

## Positive Predictive Value of Abnormal Breast Cancer Screening Results



## Breast Cancer Stage at Time of Diagnosis



## Cervical Cancer Screening Results

## Cervical Cancer Diagnosis



## Positive Predictive Value of Abnormal Pap Test Results



## Cervical Cancer Stage at Time of Diagnosis

*Table 1.1. Distribution (%)* of Breast Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 2001–2002*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | **Total** | **40–49** | **50–59** | **60–64** | **≥65***** |
| **First-Round Mammograms (n)**** | **261,785** | **75,566** | **136,308** | **41,691** | **8,220** |
| Negative | 54.1 | 55.1 | 54.0 | 52.2 | 56.5 |
| Benign | 26.1 | 22.2 | 27.1 | 30.0 | 25.8 |
| Probably benign | 4.9 | 5.5 | 4.7 | 4.4 | 5.4 |
| Suspicious abnormality | 1.7 | 2.4 | 1.4 | 1.3 | 1.0 |
| Highly suggestive of malignancy | 0.6 | 0.6 | 0.5 | 0.6 | 0.6 |
| Assessment incomplete | 12.6 | 14.2 | 12.3 | 11.4 | 10.6 |
| Total abnormal mammograms**** | 14.8 | 17.1 | 14.2 | 13.3 | 12.2 |
| Mammograms with a CBE **(n)** | **231,088** | **64,951** | **122,145** | **36,804** | **7,188** |
| Normal/Benign | 93.0 | 87.5 | 95.0 | 95.5 | 96.5 |
| Abnormal | 7.0 | 12.5 | 5.0 | 4.5 | 3.5 |
| | | | | | |
| **Subsequent-Round Mammograms (n)**** | **267,253** | **32,948** | **155,283** | **70,370** | **8,652** |
| Negative | 54.1 | 55.7 | 54.2 | 52.4 | 58.4 |
| Benign | 34.8 | 30.9 | 34.7 | 37.2 | 32.1 |
| Probably benign | 2.9 | 3.3 | 2.9 | 2.8 | 2.8 |
| Suspicious abnormality | 0.7 | 0.8 | 0.7 | 0.7 | 0.6 |
| Highly suggestive of malignancy | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 |
| Assessment incomplete | 7.4 | 9.1 | 7.4 | 6.6 | 6.1 |
| Total abnormal mammograms**** | 8.2 | 10.1 | 8.2 | 7.5 | 6.7 |
| Mammograms with a CBE **(n)** | **232,476** | **27,298** | **136,552** | **61,591** | **7,035** |
| Normal/Benign | 96.7 | 93.5 | 96.9 | 97.3 | 97.7 |
| Abnormal | 3.3 | 6.5 | 3.1 | 2.7 | 2.3 |

*Totals may not add to 100% due to rounding.
**Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 1.2. Distribution (%)* of Breast Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 1996–2000*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | **Total** | **40–49** | **50–59** | **60–64** | **≥65***** |
| **First-Round Mammograms (n)**** | **596,117** | **160,447** | **278,523** | **99,095** | **58,052** |
| Negative | 61.6 | 61.9 | 60.8 | 60.8 | 66.0 |
| Benign | 21.1 | 18.1 | 21.8 | 23.3 | 22.1 |
| Probably benign | 6.5 | 7.0 | 6.5 | 6.2 | 5.0 |
| Suspicious abnormality | 1.9 | 2.4 | 1.8 | 1.7 | 1.4 |
| Highly suggestive of malignancy | 0.4 | 0.4 | 0.4 | 0.6 | 0.4 |
| Assessment incomplete | 8.5 | 10.1 | 8.7 | 7.5 | 5.1 |
| Total abnormal mammograms**** | 10.9 | 13.0 | 10.9 | 9.7 | 6.9 |
| Mammograms with a CBE **(n)** | **517,958** | **138,266** | **245,571** | **86,264** | **47,857** |
| Normal/Benign | 94.0 | 89.2 | 95.4 | 95.9 | 97.0 |
| Abnormal | 6.0 | 10.8 | 4.6 | 4.1 | 3.0 |
| | | | | | |
| **Subsequent-Round Mammograms (n)**** | **466,685** | **66,651** | **241,539** | **110,834** | **47,661** |
| Negative | 60.7 | 61.1 | 60.7 | 59.4 | 63.4 |
| Benign | 29.0 | 26.2 | 28.9 | 30.9 | 28.7 |
| Probably benign | 3.9 | 4.7 | 3.9 | 3.7 | 3.4 |
| Suspicious abnormality | 1.1 | 1.6 | 1.1 | 1.0 | 1.0 |
| Highly suggestive of malignancy | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 |
| Assessment incomplete | 5.1 | 6.3 | 5.3 | 4.9 | 3.3 |
| Total abnormal mammograms**** | 6.4 | 8.0 | 6.5 | 6.0 | 4.5 |
| Mammograms with a CBE **(n)** | **406,653** | **56,079** | **213,265** | **97,642** | **39,670** |
| Normal/Benign | 96.8 | 94.2 | 97.0 | 97.5 | 97.9 |
| Abnormal | 3.2 | 5.8 | 3.0 | 2.5 | 2.1 |

*Totals may not add to 100% due to rounding.
**Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 1.3. Distribution (%)* of Breast Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–1995*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | **Total** | **40–49** | **50–59** | **60–64** | **≥65***** |
| **First-Round Mammograms (n)**** | **273,337** | **102,706** | **90,928** | **38,182** | **41,521** |
| Negative | 68.3 | 68.7 | 67.8 | 68.3 | 68.1 |
| Benign | 16.6 | 14.6 | 16.8 | 17.4 | 20.6 |
| Probably benign | 7.9 | 8.9 | 8.0 | 7.4 | 5.9 |
| Suspicious abnormality | 2.2 | 2.4 | 2.2 | 2.1 | 1.7 |
| Highly suggestive of malignancy | 0.4 | 0.3 | 0.4 | 0.5 | 0.4 |
| Assessment incomplete | 4.6 | 5.0 | 4.7 | 4.3 | 3.3 |
| Total abnormal mammograms**** | 7.1 | 7.7 | 7.4 | 6.8 | 5.4 |
| | | | | | |
| **Subsequent-Round Mammograms (n)**** | **78,089** | **17,886** | **32,627** | **14,494** | **13,082** |
| Negative | 66.2 | 64.1 | 67.5 | 67.6 | 64.5 |
| Benign | 23.6 | 23.1 | 22.6 | 23.4 | 27.1 |
| Probably benign | 5.7 | 7.2 | 5.5 | 5.1 | 4.6 |
| Suspicious abnormality | 1.7 | 2.3 | 1.7 | 1.4 | 1.5 |
| Highly suggestive of malignancy | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 |
| Assessment incomplete | 2.5 | 3.1 | 2.5 | 2.3 | 2.1 |
| Total abnormal mammograms**** | 4.4 | 5.4 | 4.4 | 3.8 | 3.7 |

*Totals may not add to 100% due to rounding.
**Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 2.1. Age-Adjusted* Distribution (%)** of Breast Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 2001–2002*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | **Total*** | **White** | **Black/ African American** | **Asian/ Native Hawaiian/ Other Pacific Islander** | **American Indian/ Alaska Native** | **Hispanic/ Latina** |
| **First-Round Mammograms (n)*** ** | **261,785** | **114,940** | **41,145** | **14,411** | **10,576** | **70,415** |
| Negative | 53.9 | 50.2 | 50.3 | 63.1 | 65.6 | 57.3 |
| Benign | 26.8 | 29.2 | 29.4 | 20.6 | 21.4 | 24.0 |
| Probably benign | 4.8 | 5.0 | 5.3 | 3.8 | 2.9 | 4.7 |
| Suspicious abnormality | 1.6 | 1.7 | 1.6 | 1.4 | 1.4 | 1.3 |
| Highly suggestive of malignancy | 0.6 | 0.7 | 0.6 | 0.4 | 0.5 | 0.3 |
| Assessment incomplete | 12.3 | 13.1 | 12.7 | 10.5 | 7.9 | 12.2 |
| Total abnormal mammograms**** | 14.5 | 15.5 | 14.9 | 12.4 | 9.9 | 13.9 |
| Mammograms with a CBE **(n)** | **231,088** | **101,875** | **35,459** | **13,382** | **8,455** | **63,246** |
| Normal/Benign | 83.0 | 81.7 | 80.6 | 89.9 | 76.3 | 86.1 |
| Abnormal | 5.5 | 7.0 | 5.5 | 3.1 | 3.7 | 4.3 |
| **Subsequent-Round Mammograms (n)*** ** | **267,253** | **142,768** | **41,385** | **8,122** | **16,628** | **53,761** |
| Negative | 54.4 | 51.3 | 52.1 | 65.6 | 65.8 | 57.5 |
| Benign | 34.3 | 36.9 | 36.2 | 23.7 | 26.4 | 31.0 |
| Probably benign | 3.0 | 3.2 | 3.5 | 2.6 | 1.3 | 2.7 |
| Suspicious abnormality | 0.7 | 0.8 | 0.8 | 0.8 | 0.5 | 0.5 |
| Highly suggestive of malignancy | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 |
| Assessment incomplete | 7.5 | 7.7 | 7.4 | 7.2 | 5.8 | 8.1 |
| Total abnormal mammograms**** | 8.3 | 8.6 | 8.3 | 8.0 | 6.4 | 8.7 |
| Mammograms with a CBE **(n)** | **232,476** | **125,156** | **36,165** | **7,107** | **12,687** | **47,546** |
| Normal/Benign | 83.4 | 83.9 | 83.5 | 85.0 | 74.1 | 84.5 |
| Abnormal | 3.1 | 3.2 | 3.4 | 2.1 | 2.3 | 3.3 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 2.2. Age-Adjusted* Distribution (%)** of Breast Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1996–2000*

| | | Race/Ethnicity | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First-Round Mammograms (n)*** ** | **596,116** | **308,144** | **102,540** | **24,157** | **31,031** | **115,852** |
| Negative | 61.1 | 59.4 | 60.1 | 65.5 | 70.7 | 62.8 |
| Benign | 21.5 | 22.6 | 22.2 | 19.3 | 18.4 | 19.2 |
| Probably benign | 6.5 | 7.0 | 7.0 | 4.6 | 2.8 | 6.2 |
| Suspicious abnormality | 1.9 | 2.1 | 1.7 | 1.1 | 3.0 | 1.5 |
| Highly suggestive of malignancy | 0.4 | 0.5 | 0.4 | 0.4 | 0.3 | 0.2 |
| Assessment incomplete | 8.5 | 8.3 | 8.5 | 9.1 | 4.7 | 10.0 |
| Total abnormal mammograms**** | 10.9 | 10.9 | 10.6 | 10.5 | 8.1 | 11.7 |
| Mammograms with a CBE **(n)** | **517,958** | **270,319** | **85,626** | **22,400** | **21,137** | **106,514** |
| Normal/Benign | 82.5 | 82.6 | 79.6 | 89.7 | 65.9 | 87.3 |
| Abnormal | 4.9 | 5.5 | 4.6 | 3.2 | 2.1 | 4.8 |
| **Subsequent-Round Mammograms (n)*** ** | **466,679** | **258,061** | **74,262** | **12,250** | **32,227** | **83,737** |
| Negative | 60.6 | 58.3 | 59.9 | 65.6 | 68.2 | 64.1 |
| Benign | 28.7 | 30.8 | 30.1 | 24.2 | 23.9 | 24.4 |
| Probably benign | 4.0 | 4.6 | 3.8 | 2.7 | 1.9 | 3.6 |
| Suspicious abnormality | 1.1 | 1.2 | 1.0 | 0.6 | 2.1 | 1.0 |
| Highly suggestive of malignancy | 0.1 | 0.1 | 0.2 | 0.1 | 0.1 | 0.1 |
| Assessment incomplete | 5.4 | 5.1 | 5.1 | 6.7 | 3.7 | 6.7 |
| Total abnormal mammograms**** | 6.6 | 6.4 | 6.2 | 7.4 | 6.0 | 7.8 |
| Mammograms with a CBE **(n)** | **406,653** | **228,417** | **63,207** | **11,096** | **21,784** | **76,834** |
| Normal/Benign | 84.3 | 85.3 | 82.3 | 88.3 | 67.3 | 88.3 |
| Abnormal | 3.0 | 3.1 | 2.8 | 2.6 | 1.6 | 3.4 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 2.3. Age-Adjusted* Distribution (%)** of Breast Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–1995*

| | | Race/Ethnicity | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First-Round Mammograms (n)*** ** | **273,334** | **143,414** | **46,245** | **8,307** | **15,949** | **55,706** |
| Negative | 68.0 | 64.9 | 70.6 | 79.0 | 57.6 | 74.3 |
| Benign | 16.6 | 18.8 | 14.3 | 8.1 | 32.0 | 10.9 |
| Probably benign | 8.0 | 9.2 | 8.5 | 4.5 | 2.8 | 6.7 |
| Suspicious abnormality | 2.2 | 2.5 | 2.1 | 1.4 | 2.7 | 1.6 |
| Highly suggestive of malignancy | 0.4 | 0.5 | 0.4 | 0.4 | 0.3 | 0.2 |
| Assessment incomplete | 4.6 | 4.1 | 4.1 | 6.5 | 4.4 | 6.1 |
| Total abnormal mammograms**** | 7.3 | 7.1 | 6.6 | 8.3 | 7.4 | 7.9 |
| | | | | | | |
| **Subsequent-Round Mammograms (n)*** ** | **78,089** | **41,549** | **11,569** | **1,500** | **8,618** | **14,229** |
| Negative | 66.8 | 60.7 | 68.2 | 76.6 | 70.5 | 78.2 |
| Benign | 23.0 | 27.8 | 23.0 | 12.4 | 22.4 | 12.2 |
| Probably benign | 5.7 | 7.5 | 5.2 | 3.6 | 1.3 | 4.1 |
| Suspicious abnormality | 1.7 | 1.6 | 1.2 | 0.5 | 3.9 | 1.4 |
| Highly suggestive of malignancy | 0.1 | 0.2 | 0.1 | 0.2 | 0.1 | 0.1 |
| Assessment incomplete | 2.6 | 2.2 | 2.3 | 6.6 | 1.7 | 3.8 |
| Total abnormal mammograms**** | 4.4 | 4.0 | 3.6 | 7.3 | 5.7 | 5.2 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Mammography test results are categorized using the American College of Radiology Breast Imaging Reporting and Data System (BI-RADS).
****Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 3.1. Rates* of Diagnostic Follow-Up,** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 2001–2002*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | Total | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 189.9 | 248.0 | 171.3 | 157.4 | 127.5 |
| Biopsy | 39.5 | 51.3 | 35.0 | 35.7 | 24.8 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 8.6 | 8.7 | 8.0 | 11.0 | 7.1 |
| Carcinoma in Situ*** | 3.1 | 2.8 | 3.0 | 3.3 | 3.5 |
| Carcinoma in Situ/invasive | 11.7 | 11.5 | 11.0 | 14.3 | 10.6 |
| | | | | | |
| **Subsequent Rounds** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 114.1 | 157.6 | 112.2 | 101.7 | 84.1 |
| Biopsy | 17.8 | 23.3 | 17.4 | 16.9 | 12.0 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 2.7 | 2.2 | 2.6 | 3.3 | 1.3 |
| Carcinoma in Situ*** | 1.4 | 1.2 | 1.3 | 1.6 | 0.9 |
| Carcinoma in Situ/invasive | 4.1 | 3.4 | 3.9 | 4.9 | 2.2 |

*Rates calculated per 1,000 mammograms.
**Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
***Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 3.2. Rates* of Diagnostic Follow-Up,** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 1996–2000*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | Total | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 151.5 | 202.1 | 144.0 | 128.2 | 87.6 |
| Biopsy | 30.3 | 37.6 | 29.1 | 28.0 | 19.1 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 6.9 | 6.5 | 6.6 | 8.5 | 6.6 |
| Carcinoma in Situ*** | 2.0 | 1.9 | 1.9 | 2.7 | 1.9 |
| Carcinoma in Situ/invasive | 8.9 | 8.4 | 8.5 | 11.2 | 8.5 |
| | | | | | |
| **Subsequent Rounds** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 98.5 | 134.7 | 98.5 | 89.9 | 68.0 |
| Biopsy | 15.6 | 20.7 | 15.5 | 14.4 | 12.0 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 2.5 | 2.2 | 2.3 | 3.1 | 2.6 |
| Carcinoma in Situ*** | 1.1 | 1.1 | 1.1 | 1.1 | 1.3 |
| Carcinoma in Situ/invasive | 3.6 | 3.3 | 3.4 | 4.2 | 3.9 |

*Rates calculated per 1,000 mammograms.
**Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
***Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 3.3. Rates* of Diagnostic Follow-Up,** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–1995*

| | | Age Group (years) | | | |
|---|---|---|---|---|---|
| | Total | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 101.7 | 115.1 | 102.5 | 94.5 | 73.2 |
| Biopsy | 23.1 | 23.8 | 24.0 | 22.8 | 19.3 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 5.6 | 4.0 | 6.0 | 7.1 | 7.2 |
| Carcinoma in Situ*** | 1.3 | 0.9 | 1.4 | 1.6 | 1.7 |
| Carcinoma in Situ/invasive | 6.9 | 4.9 | 7.4 | 8.7 | 8.9 |
| | | | | | |
| **Subsequent Rounds** | | | | | |
| Diagnostic follow-up** | | | | | |
| Any diagnostic procedure | 71.3 | 90.7 | 70.6 | 62.0 | 56.6 |
| Biopsy | 13.2 | 13.5 | 13.4 | 12.8 | 12.5 |
| Final diagnosis | | | | | |
| Invasive breast cancer | 2.3 | 1.7 | 2.1 | 2.3 | 3.5 |
| Carcinoma in Situ*** | 0.9 | 0.6 | 0.7 | 1.2 | 1.5 |
| Carcinoma in Situ/invasive | 3.2 | 2.3 | 2.8 | 3.5 | 5.0 |

*Rates calculated per 1,000 mammograms.
**Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
***Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 4.1. Age-Adjusted* Rates** of Diagnostic Follow-Up,*** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 2001–2002*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 181.0 | 208.8 | 181.6 | 139.7 | 123.1 | 162.5 |
| Biopsy | 37.9 | 47.9 | 40.8 | 22.3 | 23.2 | 27.6 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 8.9 | 12.2 | 9.1 | 4.9 | 6.2 | 4.7 |
| Carcinoma in Situ**** | 3.1 | 3.9 | 3.4 | 2.2 | 3.9 | 2.0 |
| Carcinoma in Situ/invasive | 12.0 | 16.2 | 12.5 | 7.1 | 10.2 | 6.8 |
| | | | | | | |
| **Subsequent Rounds** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 118.1 | 126.9 | 117.0 | 92.8 | 90.2 | 117.3 |
| Biopsy | 18.2 | 20.9 | 19.3 | 11.0 | 11.8 | 14.6 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 2.6 | 3.0 | 2.6 | 1.5 | 2.3 | 1.7 |
| Carcinoma in Situ**** | 1.3 | 1.5 | 1.4 | 1.0 | 0.8 | 0.8 |
| Carcinoma in Situ/invasive | 3.9 | 4.5 | 4.1 | 2.5 | 3.1 | 2.5 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 mammograms.
***Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
****Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 4.2. Age-Adjusted* Rates** of Diagnostic Follow-Up,*** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1996–2000*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 149.4 | 159.6 | 143.2 | 118.6 | 97.7 | 150.3 |
| Biopsy | 30.2 | 34.8 | 30.1 | 21.4 | 19.6 | 23.4 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 7.0 | 8.6 | 6.8 | 5.1 | 4.7 | 4.2 |
| Carcinoma in Situ**** | 2.1 | 2.4 | 2.1 | 2.5 | 2.0 | 1.2 |
| Carcinoma in Situ/invasive | 9.1 | 11.1 | 8.9 | 7.6 | 6.7 | 5.4 |
| | | | | | | |
| **Subsequent Rounds** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 102.9 | 105.6 | 95.5 | 95.2 | 78.1 | 113.4 |
| Biopsy | 16.1 | 17.7 | 16.9 | 11.8 | 12.3 | 13.5 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 2.4 | 2.6 | 2.6 | 1.9 | 2.7 | 1.7 |
| Carcinoma in Situ**** | 1.1 | 1.1 | 1.4 | 1.7 | 0.9 | 0.5 |
| Carcinoma in Situ/invasive | 3.5 | 3.8 | 4.1 | 3.5 | 3.6 | 2.3 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 mammograms.
***Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
****Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 4.3. Age-Adjusted* Rates** of Diagnostic Follow-Up,*** Carcinoma in Situ, and Invasive Breast Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–1995*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 102.4 | 108.9 | 92.1 | 99.9 | 78.6 | 100.6 |
| Biopsy | 23.6 | 26.9 | 23.3 | 12.7 | 21.6 | 18.8 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 5.9 | 6.9 | 5.5 | 4.0 | 5.2 | 4.6 |
| Carcinoma in Situ**** | 1.4 | 1.6 | 1.7 | 1.2 | 0.8 | 0.9 |
| Carcinoma in Situ/invasive | 7.3 | 8.5 | 7.2 | 5.2 | 6.0 | 5.5 |
| | | | | | | |
| **Subsequent Rounds** | | | | | | |
| Diagnostic follow-up*** | | | | | | |
| Any diagnostic procedure | 72.3 | 75.9 | 63.5 | 90.8 | 58.3 | 73.5 |
| Biopsy | 13.3 | 15.1 | 12.1 | 7.8 | 9.6 | 11.7 |
| Final diagnosis | | | | | | |
| Invasive breast cancer | 2.1 | 2.5 | 2.6 | 1.4 | 2.3 | 1.1 |
| Carcinoma in Situ**** | 0.8 | 0.9 | 0.5 | 1.2 | 0.6 | 0.9 |
| Carcinoma in Situ/invasive | 2.9 | 3.4 | 3.0 | 2.6 | 2.9 | 2.0 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 mammograms.
***Diagnostic follow-up may be initiated on the basis of an abnormal CBE, an abnormal mammogram, or a high level of concern by the patient or clinician.
****Includes Lobular Carcinoma in Situ (LCIS), Ductal Carcinoma in Situ (DCIS), and all other Carcinoma in Situ.

*Table 5.1. Positive Predictive Value (PPV)* of Abnormal Mammography Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 2001–2002*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 7.5 (7.3–7.8) | 4.6 (4.4–4.9) |
| **Age Group (years)** | | |
| 40–49 | 6.3 (5.9–6.7) | 3.1 (2.5–3.7) |
| 50–59 | 7.5 (7.1–7.9) | 4.5 (4.1–4.8) |
| 60–64 | 10.3 (9.5–11.1) | 6.1 (5.5–6.8) |
| ≥65 | 8.5 (6.7–10.2) | 3.1 (1.7–4.5) |
| | | |
| **Race/Ethnicity** | | |
| White | 9.5 (9.1–9.9) | 5.4 (4.9–5.8) |
| Black/African American | 7.7 (7.0–8.3) | 5.0 (4.2–5.7) |
| Asian/Native Hawaiian/Other Pacific Islander | 5.5 (4.5–6.6) | 3.5 (2.0–4.9) |
| American Indian/Alaska Native | 7.9 (6.3–9.6) | 4.2 (3.0–5.4) |
| Hispanic/Latina | 4.4 (4.0–4.8) | 2.8 (2.4–3.3) |

*The PPV was calculated by dividing the number of abnormal mammogram results leading to a final diagnosis of cancer by the total number of abnormal mammogram results.

**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 5.2. Positive Predictive Value (PPV)* of Abnormal Mammography Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 1996–2000*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 7.8 (7.6–8.0) | 5.2 (5.0–5.5) |
| **Age Group (years)** | | |
| 40–49 | 6.0 (5.7–6.4) | 3.7 (3.2–4.2) |
| 50–59 | 7.5 (7.2–7.8) | 4.9 (4.5–5.2) |
| 60–64 | 10.9 (10.3–11.5) | 6.5 (5.9–7.1) |
| ≥65 | 11.6 (10.6–12.6) | 8.2 (7.0–9.3) |
| | | |
| **Race/Ethnicity** | | |
| White | 9.4 (9.1–9.7) | 5.9 (5.5–6.3) |
| Black/African American | 8.0 (7.5–8.5) | 6.8 (6.0–7.5) |
| Asian/Native Hawaiian/Other Pacific Islander | 6.9 (5.9–7.9) | 4.5 (3.1–5.9) |
| American Indian/Alaska Native | 6.6 (5.7–7.6) | 5.4 (4.4–6.5) |
| Hispanic/Latina | 4.2 (3.9–4.5) | 2.7 (2.3–3.1) |

*The PPV was calculated by dividing the number of abnormal mammogram results leading to a final diagnosis of cancer by the total number of abnormal mammogram results.

**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 5.3. Positive Predictive Value (PPV)* of Abnormal Mammography Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 1991–1995*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 9.0 (8.6–9.4) | 6.5 (5.7–7.4) |
| **Age Group (years)** | | |
| 40–49 | 5.8 (5.3–6.3) | 3.5 (2.3–4.7) |
| 50–59 | 9.5 (8.8–10.2) | 6.1 (4.9–7.4) |
| 60–64 | 12.0 (10.8–13.3) | 8.5 (6.1–10.8) |
| ≥65 | 15.8 (14.3–17.3) | 11.7 (8.8–14.5) |
| | | |
| **Race/Ethnicity** | | |
| White | 10.8 (10.2–11.4) | 8.3 (7.0–9.7) |
| Black/African American | 10.0 (8.9–11.0) | 8.2 (5.6–10.9) |
| Asian/Native Hawaiian/Other Pacific Islander | 6.5 (4.6–8.4) | 3.8 (0.2–7.5) |
| American Indian/Alaska Native | 6.8 (5.4–8.2) | 4.2 (2.4–6.0) |
| Hispanic/Latina | 5.7 (5.0–6.4) | 3.9 (2.5–5.2) |

*The PPV was calculated by dividing the number of abnormal mammogram results leading to a final diagnosis of cancer by the total number of abnormal mammogram results.

**Includes the following mammogram results: "suspicious abnormality," "highly suggestive of malignancy," and "assessment incomplete."

*Table 6.1. Distribution (%)* of Cancer Stage** at Time Invasive Breast Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 2001–2002*

| | Total | Age Group (years) | | | |
|---|---|---|---|---|---|
| | (n=2,985) | 40–49 (n=728) | 50–59 (n=1,498) | 60–64 (n=690) | ≥65 (n=69) |
| **AJCC*** Cancer Stage** | | | | | |
| I | 30.4 | 21.8 | 32.0 | 35.8 | 30.4 |
| II | 34.9 | 39.4 | 32.8 | 35.1 | 31.9 |
| III | 15.1 | 18.1 | 14.4 | 13.0 | 20.3 |
| IV | 4.8 | 4.3 | 5.3 | 4.2 | 5.8 |
| **SEER**** Summary Stage** | | | | | |
| Local | 2.5 | 2.3 | 2.9 | 1.6 | 1.5 |
| Regional | 1.8 | 2.6 | 1.7 | 1.2 | 0.0 |
| Distant | 0.3 | 0.3 | 0.5 | 0.0 | 0.0 |
| **Unknown Stage** | 10.3 | 11.1 | 10.4 | 9.1 | 10.1 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***American Joint Committee on Cancer.
****Surveillance, Epidemiology, and End Results summary stage.

*Table 6.2. Distribution (%)* of Cancer Stage** at Time Invasive Breast Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 1996–2000*

| | Total | Age Group (years) | | | |
|---|---|---|---|---|---|
| | (n=5,262) | 40–49 (n=1,197) | 50–59 (n=2,372) | 60–64 (n=1,182) | ≥65 (n=511) |
| **AJCC*** Cancer Stage** | | | | | |
| I | 35.1 | 28.0 | 34.5 | 38.2 | 47.4 |
| II | 37.6 | 41.0 | 37.8 | 36.6 | 30.9 |
| III | 14.2 | 17.5 | 14.7 | 12.5 | 7.8 |
| IV | 4.6 | 4.6 | 4.6 | 4.8 | 3.9 |
| **SEER**** Summary Stage** | | | | | |
| Local | 3.5 | 3.4 | 3.5 | 3.3 | 4.5 |
| Regional | 2.8 | 3.0 | 2.8 | 2.8 | 2.2 |
| Distant | 0.4 | 0.6 | 0.3 | 0.4 | 0.4 |
| **Unknown Stage** | 1.8 | 1.8 | 1.8 | 1.4 | 2.9 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***American Joint Committee on Cancer.
****Surveillance, Epidemiology, and End Results summary stage.

*Table 6.3. Distribution (%)* of Cancer Stage** at Time Invasive Breast Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 1991–1995*

| | Total | Age Group (years) | | | |
|---|---|---|---|---|---|
| | (n=1,709) | 40–49 (n=441) | 50–59 (n=618) | 60–64 (n=303) | ≥65 (n=347) |
| **AJCC*** Cancer Stage** | | | | | |
| I | 38.4 | 28.6 | 36.6 | 42.2 | 51.0 |
| II | 34.4 | 43.5 | 33.3 | 30.4 | 28.0 |
| III | 10.5 | 11.8 | 13.1 | 6.6 | 7.8 |
| IV | 4.5 | 4.3 | 5.0 | 5.3 | 2.9 |
| **SEER**** Summary Stage** | | | | | |
| Local | 5.4 | 3.6 | 6.2 | 7.3 | 4.9 |
| Regional | 4.4 | 5.7 | 3.4 | 5.3 | 3.8 |
| Distant | 0.1 | 0.0 | 0.3 | 0.0 | 0.0 |
| **Unknown Stage** | 2.3 | 2.5 | 2.1 | 3.0 | 1.7 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***American Joint Committee on Cancer.
****Surveillance, Epidemiology, and End Results summary stage.

*Table 7.1. Distribution (%)* of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 2001–2002*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | **Total** | **18–29** | **30–39** | **40–49** | **50–59** | **60–64** | **≥65***** |
| **First-Round Pap Tests (n)**** | **293,127** | **21,874** | **29,889** | **113,754** | **94,477** | **28,121** | **5,006** |
| Normal/Benign | 81.1 | 68.0 | 78.0 | 81.3 | 83.3 | 85.3 | 85.0 |
| Infection/Reaction | 11.2 | 13.1 | 12.3 | 11.5 | 10.7 | 9.6 | 9.7 |
| ASCUS† | 4.0 | 7.4 | 4.8 | 4.0 | 3.3 | 2.7 | 2.5 |
| LSIL† | 1.5 | 7.7 | 2.2 | 1.2 | 0.7 | 0.4 | 0.4 |
| ASC-H† | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| HSIL† | 0.8 | 2.6 | 1.2 | 0.6 | 0.5 | 0.4 | 0.7 |
| Squamous cell cancer | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 |
| AGC† | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.5 |
| Other | 0.4 | 0.2 | 0.3 | 0.4 | 0.5 | 0.5 | 0.3 |
| Unsatisfactory | 0.7 | 0.7 | 0.9 | 0.6 | 0.6 | 0.7 | 0.7 |
| Total abnormal Pap tests**** | 2.7 | 10.7 | 3.8 | 2.2 | 1.6 | 1.2 | 1.8 |
| | | | | | | | |
| **Subsequent-Round Pap Tests (n)**** | **268,914** | **6,417** | **17,813** | **85,425** | **112,460** | **42,373** | **4,426** |
| Normal/Benign | 82.8 | 74.4 | 79.0 | 81.7 | 83.7 | 85.5 | 85.7 |
| Infection/Reaction | 10.9 | 12.3 | 13.3 | 11.4 | 10.5 | 9.6 | 9.4 |
| ASCUS† | 3.9 | 7.5 | 4.5 | 4.4 | 3.7 | 2.9 | 2.5 |
| LSIL† | 0.9 | 3.9 | 1.4 | 1.1 | 0.7 | 0.6 | 0.4 |
| ASC-H† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| HSIL† | 0.2 | 0.7 | 0.4 | 0.2 | 0.2 | 0.1 | 0.2 |
| Squamous cell cancer | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| AGC† | 0.2 | 0.1 | 0.2 | 0.2 | 0.2 | 0.2 | 0.3 |
| Other | 0.4 | 0.1 | 0.1 | 0.3 | 0.4 | 0.4 | 0.5 |
| Unsatisfactory | 0.7 | 0.9 | 1.1 | 0.7 | 0.6 | 0.6 | 0.8 |
| Total abnormal Pap tests**** | 1.3 | 4.8 | 2.0 | 1.5 | 1.1 | 0.9 | 0.9 |

*Totals may not add to 100% due to rounding.
**Pap test results are categorized using the Bethesda System.
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following Pap test results: LSIL, ASC-H, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells; ASC-H=atypical squamous cells of undetermined significance–cannot exclude HSIL.

## *Table 7.2. Distribution (%)* of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 1996–2000*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | **Total** | **18–29** | **30–39** | **40–49** | **50–59** | **60–64** | **≥65*** ** |
| **First-Round Pap Tests (n)**** | **654,609** | **34,827** | **62,569** | **229,117** | **215,318** | **74,658** | **38,120** |
| Normal/Benign | 79.4 | 64.0 | 74.4 | 78.8 | 81.5 | 83.8 | 85.1 |
| Infection/Reaction | 13.0 | 14.4 | 15.1 | 13.6 | 12.5 | 11.1 | 10.4 |
| ASCUS† | 4.2 | 8.3 | 5.5 | 4.6 | 3.6 | 2.9 | 2.7 |
| LSIL† | 1.4 | 9.4 | 2.4 | 1.1 | 0.6 | 0.4 | 0.3 |
| HSIL† | 0.7 | 2.7 | 1.3 | 0.6 | 0.4 | 0.4 | 0.3 |
| Squamous cell cancer | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 |
| AGC† | 0.1 | 0.2 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 |
| Other | 0.5 | 0.3 | 0.2 | 0.5 | 0.7 | 0.7 | 0.5 |
| Unsatisfactory | 0.6 | 0.7 | 0.9 | 0.6 | 0.6 | 0.5 | 0.5 |
| Total abnormal Pap tests**** | 2.3 | 12.3 | 3.9 | 1.9 | 1.2 | 1.0 | 0.8 |
| **Subsequent-Round Pap Tests (n)**** | **519,745** | **16,342** | **44,843** | **152,098** | **190,620** | **78,178** | **37,664** |
| Normal/Benign | 80.6 | 72.7 | 75.8 | 78.8 | 81.6 | 83.9 | 85.3 |
| Infection/Reaction | 12.9 | 14.4 | 15.7 | 13.8 | 12.6 | 11.2 | 10.4 |
| ASCUS† | 4.4 | 7.7 | 5.5 | 5.0 | 4.0 | 3.3 | 3.1 |
| LSIL† | 0.9 | 3.5 | 1.6 | 1.1 | 0.6 | 0.5 | 0.4 |
| HSIL† | 0.2 | 0.9 | 0.5 | 0.3 | 0.2 | 0.2 | 0.1 |
| Squamous cell cancer | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 | 0.0 |
| AGC† | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.0 |
| Other | 0.3 | 0.1 | 0.1 | 0.3 | 0.4 | 0.4 | 0.3 |
| Unsatisfactory | 0.5 | 0.6 | 0.6 | 0.6 | 0.5 | 0.5 | 0.4 |
| Total abnormal Pap tests**** | 1.2 | 4.5 | 2.3 | 1.5 | 0.9 | 0.8 | 0.5 |

*Totals may not add to 100% due to rounding.
**Pap test results are categorized using the Bethesda System.
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following Pap test results: LSIL, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 7.3. Distribution (%)* of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–1995*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | Total | 18–29 | 30–39 | 40–49 | 50–59 | 60–64 | ≥65*** |
| **First-Round Pap Tests (n)**** | **370,335** | **75,385** | **67,687** | **97,335** | **71,122** | **29,029** | **29,777** |
| Normal/Benign | 81.6 | 75.1 | 78.7 | 82.4 | 84.9 | 87.0 | 88.3 |
| Infection/Reaction | 8.4 | 7.6 | 9.2 | 9.1 | 8.5 | 7.6 | 6.7 |
| ASCUS† | 5.3 | 7.8 | 6.2 | 5.0 | 3.8 | 3.1 | 3.0 |
| LSIL† | 2.6 | 6.7 | 3.2 | 1.6 | 1.0 | 0.7 | 0.6 |
| HSIL† | 0.8 | 1.5 | 1.2 | 0.6 | 0.5 | 0.3 | 0.3 |
| Squamous cell cancer | 0.1 | 0.0 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 |
| AGC† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Other | 0.3 | 0.2 | 0.3 | 0.4 | 0.4 | 0.3 | 0.3 |
| Unsatisfactory | 0.9 | 1.0 | 1.1 | 0.8 | 0.9 | 0.9 | 0.7 |
| Total abnormal Pap tests**** | 3.5 | 8.2 | 4.5 | 2.3 | 1.6 | 1.1 | 1.0 |
| **Subsequent-Round Pap Tests (n)**** | **118,049** | **13,866** | **20,745** | **32,940** | **27,312** | **11,277** | **11,909** |
| Normal/Benign | 82.7 | 76.6 | 79.6 | 82.1 | 84.7 | 86.2 | 89.1 |
| Infection/Reaction | 8.8 | 9.2 | 9.4 | 9.5 | 8.6 | 8.4 | 6.1 |
| ASCUS† | 5.2 | 7.4 | 6.4 | 5.5 | 4.2 | 3.6 | 3.2 |
| LSIL† | 1.9 | 4.8 | 2.7 | 1.6 | 1.1 | 0.7 | 0.5 |
| HSIL† | 0.4 | 0.9 | 0.6 | 0.2 | 0.2 | 0.2 | 0.2 |
| Squamous cell cancer | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| AGC† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Other | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.3 | 0.2 |
| Unsatisfactory | 0.8 | 0.8 | 0.8 | 0.8 | 0.8 | 0.6 | 0.5 |
| Total abnormal Pap tests**** | 2.3 | 5.7 | 3.3 | 1.8 | 1.3 | 0.9 | 0.7 |

*Totals may not add to 100% due to rounding.
**Pap test results are categorized using the Bethesda System.
***Most women 65 years of age or older were not served through the NBCCEDP because of eligibility for Medicare Part B coverage.
****Includes the following Pap test results: LSIL, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 8.1. Age-Adjusted* Distribution (%)** of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 2001–2002*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First-Round Pap Tests (n)*** ** | **293,127** | **143,565** | **40,156** | **14,684** | **15,252** | **68,438** |
| Normal/Benign | 82.0 | 82.1 | 78.7 | 83.3 | 84.7 | 82.3 |
| Infection/Reaction | 11.0 | 10.4 | 14.0 | 11.2 | 8.3 | 11.2 |
| ASCUS† | 3.7 | 4.0 | 4.2 | 2.8 | 3.7 | 3.3 |
| LSIL† | 1.2 | 1.4 | 1.1 | 0.7 | 0.8 | 1.0 |
| ASC-H† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| HSIL† | 0.6 | 0.8 | 0.6 | 0.5 | 0.5 | 0.5 |
| Squamous cell cancer | 0.1 | 0.1 | 0.1 | 0.0 | 0.0 | 0.1 |
| AGC† | 0.3 | 0.3 | 0.3 | 0.3 | 0.2 | 0.3 |
| Other | 0.4 | 0.3 | 0.4 | 0.4 | 1.0 | 0.5 |
| Unsatisfactory | 0.7 | 0.6 | 0.6 | 0.7 | 0.8 | 0.8 |
| Total abnormal Pap tests**** | 2.2 | 2.6 | 2.1 | 1.6 | 1.5 | 2.0 |
| | | | | | | |
| **Subsequent-Round Pap Tests (n)*** ** | **268,914** | **147,567** | **30,776** | **10,817** | **22,736** | **52,070** |
| Normal/Benign | 82.5 | 82.3 | 78.1 | 81.9 | 83.6 | 84.7 |
| Infection/Reaction | 10.9 | 11.1 | 14.5 | 12.2 | 9.4 | 9.3 |
| ASCUS† | 4.0 | 4.0 | 4.8 | 3.5 | 4.7 | 3.5 |
| LSIL† | 1.0 | 1.1 | 1.2 | 0.9 | 0.9 | 0.9 |
| ASC-H† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| HSIL† | 0.2 | 0.2 | 0.2 | 0.3 | 0.2 | 0.2 |
| Squamous cell cancer | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| AGC† | 0.2 | 0.2 | 0.2 | 0.3 | 0.2 | 0.2 |
| Other | 0.3 | 0.3 | 0.3 | 0.3 | 0.6 | 0.4 |
| Unsatisfactory | 0.7 | 0.8 | 0.7 | 0.6 | 0.6 | 0.6 |
| Total abnormal Pap tests**** | 1.5 | 1.6 | 1.6 | 1.6 | 1.2 | 1.4 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Pap test results are categorized using the Bethesda System.
****Includes the following Pap test results: LSIL, ASC-H, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells; ASC-H=atypical squamous cells of undetermined significance–cannot exclude HSIL.

*Table 8.2. Age-Adjusted* Distribution (%)** of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1996–2000*

| | | Race/Ethnicity | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First-Round Pap Tests (n)*** ** | **654,609** | **355,950** | **95,499** | **28,681** | **32,806** | **125,382** |
| Normal/Benign | 79.8 | 80.9 | 73.1 | 80.7 | 79.5 | 81.1 |
| Infection/Reaction | 12.9 | 11.8 | 19.1 | 13.4 | 13.9 | 11.4 |
| ASCUS† | 4.1 | 4.2 | 4.6 | 3.4 | 4.0 | 3.9 |
| LSIL† | 1.2 | 1.3 | 1.1 | 0.8 | 1.0 | 1.3 |
| HSIL† | 0.6 | 0.7 | 0.6 | 0.5 | 0.4 | 0.6 |
| Squamous cell cancer | 0.1 | 0.1 | 0.1 | 0.0 | 0.0 | 0.1 |
| AGC† | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 |
| Other | 0.5 | 0.5 | 0.7 | 0.3 | 0.3 | 0.6 |
| Unsatisfactory | 0.6 | 0.5 | 0.6 | 0.7 | 0.7 | 0.8 |
| Total abnormal Pap tests**** | 2.0 | 2.2 | 1.9 | 1.4 | 1.6 | 2.1 |
| **Subsequent-Round Pap Tests (n)*** ** | **519,745** | **296,342** | **67,050** | **16,426** | **40,041** | **92,659** |
| Normal/Benign | 80.2 | 81.1 | 73.0 | 82.1 | 78.6 | 83.3 |
| Infection/Reaction | 13.1 | 12.4 | 19.6 | 12.8 | 14.6 | 10.1 |
| ASCUS† | 4.5 | 4.4 | 5.2 | 3.2 | 4.7 | 4.1 |
| LSIL† | 1.0 | 1.0 | 1.0 | 0.6 | 1.0 | 1.0 |
| HSIL† | 0.2 | 0.3 | 0.3 | 0.3 | 0.2 | 0.3 |
| Squamous cell cancer | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| AGC† | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 | 0.1 |
| Other | 0.3 | 0.4 | 0.3 | 0.2 | 0.2 | 0.3 |
| Unsatisfactory | 0.5 | 0.4 | 0.4 | 0.6 | 0.5 | 0.8 |
| Total abnormal Pap tests**** | 1.3 | 1.3 | 1.4 | 1.0 | 1.4 | 1.3 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Pap test results are categorized using the Bethesda System.
****Includes the following Pap test results: LSIL, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 8.3. Age-Adjusted* Distribution (%)** of Cervical Cancer Screening Results Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–1995*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First-Round Pap Tests (n)*** ** | **370,335** | **191,562** | **54,112** | **8,879** | **35,000** | **76,305** |
| Normal/Benign | 83.6 | 85.9 | 76.3 | 87.5 | 74.6 | 85.8 |
| Infection/Reaction | 8.6 | 6.9 | 16.8 | 6.1 | 11.1 | 5.8 |
| ASCUS† | 4.4 | 4.2 | 3.6 | 3.4 | 7.7 | 4.5 |
| LSIL† | 1.5 | 1.3 | 1.6 | 0.8 | 3.5 | 1.4 |
| HSIL† | 0.6 | 0.6 | 0.6 | 0.5 | 0.7 | 0.7 |
| Squamous cell cancer | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 |
| AGC† | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.1 |
| Other | 0.3 | 0.4 | 0.1 | 0.3 | 0.4 | 0.3 |
| Unsatisfactory | 0.9 | 0.6 | 0.8 | 1.3 | 1.7 | 1.3 |
| Total abnormal Pap tests**** | 2.2 | 1.9 | 2.3 | 1.4 | 4.4 | 2.2 |
| **Subsequent-Round Pap Tests (n)*** ** | **118,049** | **65,558** | **14,422** | **2,050** | **13,619** | **21,585** |
| Normal/Benign | 83.4 | 86.4 | 75.9 | 85.6 | 74.2 | 84.1 |
| Infection/Reaction | 8.9 | 6.7 | 17.3 | 6.9 | 13.6 | 7.3 |
| ASCUS† | 4.9 | 4.7 | 4.0 | 4.4 | 6.5 | 5.2 |
| LSIL† | 1.5 | 1.1 | 1.4 | 0.8 | 4.1 | 1.3 |
| HSIL† | 0.3 | 0.2 | 0.2 | 0.1 | 0.3 | 0.3 |
| Squamous cell cancer | 0.0 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 |
| AGC† | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Other | 0.3 | 0.3 | 0.2 | 0.2 | 0.2 | 0.3 |
| Unsatisfactory | 0.8 | 0.4 | 0.9 | 1.4 | 1.0 | 1.4 |
| Total abnormal Pap tests**** | 1.7 | 1.4 | 1.7 | 1.0 | 4.5 | 1.7 |

*Age-adjusted to the 2000 NBCCEDP population.
**Totals may not add to 100% due to rounding.
***Pap test results are categorized using the Bethesda System.
****Includes the following Pap test results: LSIL, HSIL, AGC, and squamous cell cancer.
†Abbreviations: ASCUS=atypical squamous cells of undetermined significance; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 9.1. Rates* of Biopsy-Confirmed CIN** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 2001–2002*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | Total | 18–29 | 30–39 | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 6.2 | 31.2 | 9.9 | 4.7 | 2.7 | 1.7 | 1.2 |
| CIN II† | 3.1 | 17.1 | 5.2 | 2.2 | 1.1 | 0.6 | 0.8 |
| CIN III/CIS† | 4.2 | 14.8 | 7.7 | 3.5 | 2.2 | 2.0 | 3.2 |
| Invasive | 0.7 | 0.1 | 0.7 | 0.6 | 0.8 | 0.9 | 1.2 |
| CIN II or worse†** | 8.0 | 32.0 | 13.6 | 6.3 | 4.1 | 3.5 | 5.2 |
| **Subsequent Rounds** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 3.6 | 11.5 | 6.3 | 4.4 | 2.9 | 1.8 | 2.0 |
| CIN II† | 1.1 | 3.6 | 2.5 | 1.4 | 0.7 | 0.6 | 0.2 |
| CIN III/CIS† | 1.1 | 3.9 | 2.9 | 1.2 | 0.8 | 0.6 | 0.7 |
| Invasive | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 |
| CIN II or worse†** | 2.3 | 7.5 | 5.5 | 2.7 | 1.6 | 1.3 | 1.1 |

*Rates calculated per 1,000 Pap tests.
**CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 9.2. Rates* of Biopsy-Confirmed CIN** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 1996–2000*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | Total | 18–29 | 30–39 | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 6.7 | 48.9 | 11.9 | 5.0 | 2.7 | 2.0 | 1.0 |
| CIN II† | 2.6 | 19.0 | 5.5 | 1.8 | 0.9 | 0.6 | 0.5 |
| CIN III/CIS† | 4.0 | 16.6 | 8.8 | 3.7 | 2.1 | 2.1 | 1.5 |
| Invasive | 0.6 | 0.3 | 0.5 | 0.5 | 0.7 | 0.7 | 0.4 |
| CIN II or worse†** | 7.2 | 35.9 | 14.8 | 6.0 | 3.7 | 3.4 | 2.4 |
| **Subsequent Rounds** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 4.3 | 18.4 | 8.3 | 5.0 | 3.1 | 2.0 | 1.1 |
| CIN II† | 1.2 | 6.7 | 2.8 | 1.2 | 0.7 | 0.5 | 0.3 |
| CIN III/CIS† | 1.2 | 5.0 | 2.9 | 1.2 | 0.8 | 0.6 | 0.6 |
| Invasive | 0.9 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 | 0.2 |
| CIN II or worse†** | 3.3 | 11.7 | 5.8 | 2.5 | 1.6 | 1.2 | 1.1 |

*Rates calculated per 1,000 Pap tests.
**CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 9.3. Rates* of Biopsy-Confirmed CIN** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Age Group and Screening Round, 1991–1995*

| | | Age Group (years) | | | | | |
|---|---|---|---|---|---|---|---|
| | Total | 18–29 | 30–39 | 40–49 | 50–59 | 60–64 | ≥65 |
| **First Round** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 10.7 | 29.1 | 12.7 | 5.8 | 3.3 | 2.6 | 0.8 |
| CIN II† | 4.3 | 12.0 | 5.4 | 2.2 | 1.1 | 0.6 | 0.5 |
| CIN III/CIS† | 4.9 | 8.8 | 7.8 | 3.7 | 2.4 | 2.0 | 1.5 |
| Invasive | 0.5 | 0.1 | 0.4 | 0.6 | 0.5 | 0.7 | 0.6 |
| CIN II or worse†** | 9.7 | 20.9 | 13.6 | 6.5 | 4.0 | 3.3 | 2.6 |
| **Subsequent Rounds** | | | | | | | |
| Final diagnosis | | | | | | | |
| CIN I† | 7.5 | 20.2 | 12.2 | 5.8 | 4.2 | 2.7 | 1.3 |
| CIN II† | 2.4 | 7.6 | 4.1 | 1.5 | 0.8 | 0.9 | 0.6 |
| CIN III/CIS† | 1.8 | 3.5 | 3.7 | 1.3 | 0.8 | 0.9 | 0.6 |
| Invasive | 0.1 | 0.0 | 0.2 | 0.1 | 0.1 | 0.1 | 0.0 |
| CIN II or worse†** | 4.3 | 11.1 | 8.0 | 2.9 | 1.7 | 1.9 | 1.2 |

*Rates calculated per 1,000 Pap tests.
**CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 10.1. Age-Adjusted* Rates** of Biopsy-Confirmed CIN*** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 2001–2002*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 4.7 | 6.7 | 3.4 | 2.3 | 2.2 | 3.4 |
| CIN II† | 2.3 | 3.4 | 1.7 | 1.2 | 1.8 | 1.5 |
| CIN III/CIS† | 3.5 | 4.7 | 2.8 | 2.0 | 1.9 | 2.7 |
| Invasive | 0.7 | 0.8 | 0.7 | 0.9 | 0.5 | 0.6 |
| CIN II or worse†*** | 6.5 | 8.8 | 5.3 | 4.1 | 4.2 | 4.8 |
| **Subsequent Rounds** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 3.9 | 5.0 | 4.1 | 2.5 | 1.8 | 3.8 |
| CIN II† | 1.2 | 1.5 | 1.5 | 0.7 | 0.7 | 0.6 |
| CIN III/CIS† | 1.2 | 1.5 | 1.2 | 2.2 | 0.4 | 0.9 |
| Invasive | 0.1 | 0.1 | 0.1 | 0.0 | 0.0 | 0.1 |
| CIN II or worse†*** | 2.5 | 3.1 | 2.8 | 2.9 | 1.1 | 1.6 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 Pap tests.
***CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 10.2. Age-Adjusted* Rates** of Biopsy-Confirmed CIN*** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1996–2000*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 5.7 | 6.7 | 4.8 | 2.4 | 3.2 | 6.0 |
| CIN II† | 2.2 | 2.7 | 1.8 | 1.0 | 1.2 | 2.0 |
| CIN III/CIS† | 3.7 | 4.2 | 3.0 | 2.5 | 1.6 | 3.5 |
| Invasive | 0.6 | 0.6 | 0.5 | 0.8 | 0.3 | 0.6 |
| CIN II or worse†*** | 6.4 | 7.5 | 5.3 | 4.3 | 3.1 | 6.1 |
| **Subsequent Rounds** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 4.6 | 5.2 | 4.6 | 2.6 | 3.0 | 4.4 |
| CIN II† | 1.2 | 1.5 | 1.3 | 1.1 | 0.6 | 1.2 |
| CIN III/CIS† | 1.2 | 1.3 | 0.9 | 1.3 | 1.0 | 1.2 |
| Invasive | 0.1 | 0.1 | 0.2 | 0.0 | 0.0 | 0.1 |
| CIN II or worse†*** | 2.6 | 2.9 | 2.4 | 2.4 | 1.6 | 2.5 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 Pap tests.
***CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 10.3. Age-Adjusted* Rates** of Biopsy-Confirmed CIN*** and Invasive Cervical Cancer Among Women in the NBCCEDP, by Race/Ethnicity and Screening Round, 1991–1995*

| | Race/Ethnicity | | | | | |
|---|---|---|---|---|---|---|
| | Total* | White | Black/ African American | Asian/ Native Hawaiian/ Other Pacific Islander | American Indian/ Alaska Native | Hispanic/ Latina |
| **First Round** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 5.6 | 5.2 | 5.0 | 2.4 | 11.8 | 5.4 |
| CIN II† | 2.1 | 2.0 | 2.3 | 1.4 | 2.7 | 2.1 |
| CIN III/CIS† | 3.4 | 3.6 | 2.9 | 2.8 | 3.4 | 3.5 |
| Invasive | 0.6 | 0.5 | 0.6 | 1.1 | 0.7 | 0.6 |
| CIN II or worse†*** | 6.0 | 6.1 | 5.7 | 5.3 | 6.8 | 6.2 |
| **Subsequent Rounds** | | | | | | |
| Final diagnosis | | | | | | |
| CIN I† | 5.7 | 4.7 | 4.3 | 1.1 | 15.0 | 5.1 |
| CIN II† | 1.5 | 1.6 | 1.5 | 2.0 | 2.3 | 1.1 |
| CIN III/CIS† | 1.3 | 1.5 | 0.7 | 0.6 | 1.4 | 1.3 |
| Invasive | 0.1 | 0.2 | 0.0 | 0.0 | 0.1 | 0.0 |
| CIN II or worse†*** | 2.9 | 3.3 | 2.2 | 2.6 | 3.8 | 2.3 |

*Age-adjusted to the 2000 NBCCEDP population.
**Rates calculated per 1,000 Pap tests.
***CIN II or worse includes CIN II, CIN III, CIS, and invasive cervical cancer.
†Abbreviations: CIN=cervical intraepithelial neoplasia; CIS=Carcinoma in Situ.

*Table 11.1. Positive Predictive Value (PPV)* of Abnormal Pap Test Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 2001–2002*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 25.4 (24.4–26.3) | 12.8 (11.7–13.9) |
| **Age Group (years)** | | |
| 18–29 | 25.0 (23.3–26.8) | 13.5 (9.7–17.4) |
| 30–39 | 30.6 (27.9–33.3) | 22.5 (18.2–26.7) |
| 40–49 | 24.9 (23.2–26.6) | 13.7 (11.8–15.6) |
| 50–59 | 22.7 (20.5–24.8) | 10.4 (8.7–12.1) |
| 60–64 | 25.7 (21.0–30.3) | 8.9 (6.2–11.7) |
| ≥65 | 27.0 (17.7–36.2) | 7.1 (0.6–14.9) |
| | | |
| **Race/Ethnicity** | | |
| White | 29.2 (27.8–30.5) | 14.6 (13.1–16.2) |
| Black/African American | 21.7 (19.0–24.4) | 11.6 (8.7–14.6) |
| Asian/Native Hawaiian/Other Pacific Islander | 24.9 (19.5–30.3) | 14.3 (8.9–19.7) |
| American Indian/Alaska Native | 19.5 (15.4–23.7) | 8.9 (5.9–11.9) |
| Hispanic/Latina | 19.1 (17.2–21.0) | 9.5 (7.3–11.7) |

*The PPV was calculated by dividing the number of abnormal Pap test results** leading to a biopsy-confirmed high-grade lesion (CIN† II or worse) by the total number of abnormal Pap test results.

**Includes the following Pap test results†: LSIL, ASC-H, HSIL, AGC, and squamous cell cancer.

†Abbreviations: CIN=cervical intraepithelial neoplasia; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells; ASC-H=atypical squamous cells of undetermined significance–cannot exclude HSIL.

*Table 11.2. Positive Predictive Value (PPV)* of Abnormal Pap Test Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 1996–2000*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 27.3 (26.6–28.0) | 14.2 (13.4–15.1) |
| **Age Group (years)** | | |
| 18–29 | 24.5 (23.2–25.8) | 19.3 (16.5–22.2) |
| 30–39 | 33.0 (31.1–34.8) | 19.8 (17.3–22.3) |
| 40–49 | 26.9 (25.6–28.2) | 12.6 (11.2–14.0) |
| 50–59 | 26.3 (24.6–28.0) | 12.1 (10.6–13.5) |
| 60–64 | 30.8 (27.4–34.2) | 12.7 (10.0–15.4) |
| ≥ 65 | 27.7 (22.7–32.6) | 11.6 (7.2–16.0) |
| | | |
| **Race/Ethnicity** | | |
| White | 29.7 (28.7–30.7) | 15.3 (14.2–16.5) |
| Black/African American | 24.1 (22.1–26.1) | 12.8 (10.5–15.2) |
| Asian/Native Hawaiian/Other Pacific Islander | 26.6 (22.3–30.9) | 18.1 (11.7–24.5) |
| American Indian/Alaska Native | 16.3 (13.6–19.0) | 11.0 (8.7–13.3) |
| Hispanic/Latina | 25.0 (23.5–26.5) | 13.6 (11.7–15.5) |

*The PPV was calculated by dividing the number of abnormal Pap test results** leading to a biopsy-confirmed high-grade lesion (CIN† II or worse) by the total number of abnormal Pap test results.

**Includes the following Pap test results†: LSIL, HSIL, AGC, and squamous cell cancer.

†Abbreviations: CIN=cervical intraepithelial neoplasia; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 11.3. Positive Predictive Value (PPV)* of Abnormal Pap Test Results** Among Women in the NBCCEDP, by Age Group, Race/Ethnicity, and Screening Round, 1991–1995*

| | PPV* (95% Confidence Interval) | |
|---|---|---|
| | First Screening Round | Subsequent Screening Round |
| **Total** | 23.4 (22.7–24.1) | 15.4 (14.1–16.8) |
| **Age Group (years)** | | |
| 18–29 | 21.2 (20.2–22.3) | 16.6 (14.0–19.1) |
| 30–39 | 26.8 (25.2–28.3) | 20.2 (17.2–23.1) |
| 40–49 | 24.5 (22.7–26.3) | 11.9 (9.3–14.4) |
| 50–59 | 23.9 (21.4–26.5) | 9.0 (6.1–12.0) |
| 60–64 | 23.8 (19.3–28.4) | 20.0 (12.2–27.8) |
| ≥65 | 22.9 (17.9–27.8) | 13.6 (6.5–20.8) |
| | | |
| **Race/Ethnicity** | | |
| White | 27.9 (26.7–29.0) | 20.0 (17.6–22.4) |
| Black/African American | 19.5 (17.7–21.3) | 14.2 (10.0–18.5) |
| Asian/Native Hawaiian/Other Pacific Islander | 29.7 (22.6–36.9) | 20.0 (2.5–37.5) |
| American Indian/Alaska Native | 13.6 (12.2–15.0) | 10.4 (8.3–12.4) |
| Hispanic/Latina | 24.4 (22.8–26.1) | 15.0 (11.7–18.4) |

*The PPV was calculated by dividing the number of abnormal Pap test results** leading to a biopsy-confirmed high-grade lesion (CIN† II or worse) by the total number of abnormal Pap test results.

**Includes the following Pap test results†: LSIL, HSIL, AGC, and squamous cell cancer.

†Abbreviations: CIN=cervical intraepithelial neoplasia; HSIL=high-grade squamous intraepithelial lesion; LSIL=low-grade squamous intraepithelial lesion; AGC=atypical glandular cells.

*Table 12.1. Distribution (%)* of Cancer Stage** at Time Invasive Cervical Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 2001–2002*

| | Total | Age Group (years) | |
|---|---|---|---|
| | (n=223) | <50 (n=100) | ≥50 (n=123) |
| **FIGO*** Cancer Stage** | | | |
| I | 39.9 | 45.0 | 35.8 |
| II | 23.8 | 23.0 | 24.4 |
| III | 13.0 | 12.0 | 13.8 |
| IV | 4.9 | 4.0 | 5.7 |
| **SEER**** Summary Stage** | | | |
| Local | 3.6 | 5.0 | 2.4 |
| Regional | 1.4 | 1.0 | 1.6 |
| Distant | 0.5 | 0.0 | 0.8 |
| **Unknown Stage** | 13.0 | 10.0 | 15.4 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***The International Federation of Gynecology and Obstetrics (FIGO) stage.
****Surveillance, Epidemiology, and End Results summary stage.

*Table 12.2. Distribution (%)* of Cancer Stage** at Time Invasive Cervical Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 1996–2000*

| | Total | Age Group (years) | |
|---|---|---|---|
| | (n=429) | <50 (n=188) | ≥ 50 (n=241) |
| **FIGO*** Cancer Stage** | | | |
| I | 51.8 | 61.7 | 44.0 |
| II | 22.4 | 15.4 | 27.8 |
| III | 11.7 | 8.5 | 14.1 |
| IV | 4.9 | 5.3 | 4.6 |
| **SEER**** Summary Stage** | | | |
| Local | 3.0 | 3.2 | 2.9 |
| Regional | 2.8 | 3.7 | 2.1 |
| Distant | 0.5 | 0.5 | 0.4 |
| **Unknown Stage** | 3.0 | 1.6 | 4.1 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***The International Federation of Gynecology and Obstetrics (FIGO) stage.
****Surveillance, Epidemiology, and End Results summary stage.

*Table 12.3. Distribution (%)* of Cancer Stage** at Time Invasive Cervical Cancer Was Diagnosed in Women Screened Through the NBCCEDP, by Age Group, 1991–1995*

| | Total | Age Group (years) | |
|---|---|---|---|
| | (n=180) | <50 (n=97) | ≥50 (n=83) |
| **FIGO*** Cancer Stage** | | | |
| I | 47.2 | 48.5 | 45.8 |
| II | 21.1 | 21.7 | 20.5 |
| III | 2.8 | 2.1 | 3.6 |
| IV | 6.1 | 6.2 | 6.0 |
| **SEER**** Summary Stage** | | | |
| Local | 12.2 | 15.5 | 8.4 |
| Regional | 5.0 | 3.1 | 7.2 |
| Distant | 0.6 | 1.0 | 0.0 |
| **Unknown Stage** | 5.0 | 2.1 | 8.4 |

*Totals may not add to 100% due to rounding.
**Staging information in the NBCCEDP data may not be consistent with that from cancer registries due to variation in type of information reported by individual programs.
***The International Federation of Gynecology and Obstetrics (FIGO) stage.
****Surveillance, Epidemiology, and End Results summary stage.

# Appendix I—The Minimum Data Elements

The minimum data elements (MDEs) are a set of standardized data variables developed to ensure that consistent and complete information on screening location, patient demographic characteristics, screening results, diagnostic procedures, final diagnosis, and treatment information is collected on women screened or diagnosed with NBCCEDP funds. The MDEs are collected for each woman, converted into a standardized format, and transmitted to CDC.

The MDEs are divided into three sections: the All Patients Section, the Abnormal Pap Test Section, and the Abnormal Mammogram/Clinical Breast Exam (CBE) Section. The All Patients Section is completed for each screening test performed for women with program funds. It includes the screening location, patient demographic information, and screening results for Pap tests, mammograms, and clinical breast exams. The Abnormal Pap Test Section and the Abnormal Mammogram/CBE Section are completed only for abnormal Pap test results and abnormal mammogram/CBE screening results. These sections provide data on diagnostic procedures, final diagnoses, and treatment for breast and cervical cancer.

# All Patients Section

| ITEM NAME | PURPOSE |
|---|---|
| State, Territorial, or Tribal Program of Screening | To specify the FIPS or Tribal Program code for the state, territory, or tribe where screening occurred. |
| County of Screening | To specify the FIPS code for the county of the primary B&C provider. |
| City of Screening | To specify city of the primary B&C provider. |
| Enrollment Site | To specify the point of enrollment into the program. |
| Pap Test Screening Site | To specify the site where the woman received her Pap test. |
| Mammogram Screening Site | To specify the site where the woman received her mammogram. |
| Patient ID Number | To specify patient's identification number. |
| Record Identifier | To uniquely identify one record among many for a woman. |
| Record Type | To specify a patient's record type. |
| County of Residence | To specify the FIPS code for the county of residence. |
| State or Territory of Residence | To specify the FIPS code for the state or territory of residence. |
| Zip Code of Residence | To specify zip code of residence. |
| Date of Birth | To specify date of birth. |
| Race 1 | To specify race. |
| Race 2–6 | To specify a second through sixth race for individuals who choose to identify themselves as multiracial. |
| Hispanic or Latina Origin | To specify Hispanic or Latina origin. |
| Breast Symptoms | To specify breast symptoms reported by the woman. |
| Clinical Breast Exam (CBE) | The provider's assessment of the clinical breast exam. |
| Date of Clinical Breast Exam (CBE) | To specify date of clinical breast exam. |
| Clinical Breast Exam Paid by NBCCEDP Funds | To determine if the CBE was paid for with NBCCEDP funds. |
| Previous Pap Test | To determine if a woman has had a previous Pap test. |
| Date of Previous Pap Test | To specify date of previous Pap test. |
| Bethesda System Used | To specify whether the Pap test results for a woman were reported using the 1991 Bethesda System Categories or the 2001 Bethesda System Categories. |
| Specimen Adequacy of Screening Pap Test | This field gives programs a way to report specimen adequacy as noted under the Bethesda System. |
| Results of Screening Pap Test (Bethesda 1991) | To report results of screening Pap test using the 1991 Bethesda System. |
| Specimen Type for Pap Test | To indicate how the Pap test specimen was collected. |
| Results of Screening Pap Test (Bethesda 2001) | To report results of screening Pap test using the 2001 Bethesda System. |
| Other Screening Pap Test Results | To specify other screening Pap test results. |
| Diagnostic Work-Up Planned for Cervical Dysplasia or Cancer | To indicate the clinical recommendation for immediate diagnostic work-up. |
| Date of Screening Pap Test | To specify date of screening Pap test. |
| Screening Pap Test Paid by NBCCEDP Funds | To determine if Pap test, laboratory services, or pelvic exam were paid by NBCCEDP funds. |
| Previous Mammogram | To determine if a woman has had a previous mammogram. |
| Date of Previous Mammogram | To specify date of previous mammogram. |
| Mammography Test Results | To report results of mammography using the American College of Radiology lexicon. |
| Diagnostic Work-Up Planned for Breast Cancer | To indicate the clinical recommendation for immediate diagnostic work-up. |
| Date of Mammogram | To specify date of mammography. |
| Mammogram Paid by NBCCEDP Funds | To determine if mammogram was paid for by NBCCEDP funds. |
| MDE Version Number | To indicate the version of the MDE that is being used for submitting data. |

## Abnormal Pap Test Section

| ITEM NAME | PURPOSE |
|---|---|
| Colposcopy without Biopsy | To specify if a colposcopy without biopsy was performed. |
| Colposcopy-Directed Biopsy | To specify if a colposcopy-directed biopsy was performed. |
| Other Procedures Performed | To specify if other diagnostic procedures were performed. |
| Description of Other Procedures Performed, Part 1 | To specify other diagnostic procedures performed. |
| Description of Other Procedures Performed, Part 2 | To specify additional diagnostic procedures performed. |
| Cervical Diagnostic Procedures Paid by NBCCEDP Funds | To indicate if one or more diagnostic procedures were paid for with NBCCEDP funds. |
| Final Diagnosis | To specify final diagnosis. |
| Stage at Diagnosis | To specify stage at diagnosis for women with invasive cervical cancer. |
| Final Diagnosis–Other | To specify a final diagnosis of "other." |
| Status of Final Diagnosis | To specify the status of final diagnosis. |
| Date of Final Diagnosis | To specify date of final diagnosis. |
| Status of Treatment | To specify the status of treatment for precancerous lesions and cervical cancer. |
| Date of Treatment Status | To specify date of treatment status. |

## Abnormal Mammogram/Clinical Breast Exam Section

| ITEM NAME | PURPOSE |
|---|---|
| Additional Mammographic Views | To specify if additional mammographic views were performed. |
| Repeat Breast Exam/Surgical Consultation | To specify if a repeat breast exam and/or surgical consultation was performed. |
| Ultrasound | To specify if an ultrasound was performed. |
| Biopsy/Lumpectomy | To specify if a biopsy or lumpectomy was performed. |
| Fine-Needle/Cyst Aspiration | To specify if a fine-needle or cyst aspiration was performed. |
| Other Procedures Performed | To specify if other diagnostic procedures were performed. |
| Description of Other Procedures Performed, Part 1 | To specify additional diagnostic procedures performed. |
| Description of Other Procedures Performed, Part 2 | To specify other procedures performed. |
| Breast Diagnostic Procedures Paid by NBCCEDP Funds | To indicate if one or more diagnostic procedures were paid for with NBCCEDP funds. |
| Final Diagnosis | To specify final diagnosis. |
| Stage at Diagnosis | To specify stage at diagnosis for women with invasive breast cancer. |
| Tumor Size | To specify tumor size for women with invasive breast cancer. |
| Status of Final Diagnosis | To specify the status of final diagnosis. |
| Date of Final Diagnosis | To specify date of final diagnosis. |
| Status of Treatment | To specify the status of treatment for breast cancer. |
| Date of Treatment Status | To specify date of treatment status. |

# Appendix II—NBCCEDP Publications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# Appendix III—Methods

## Breast Cancer Screening Analysis

We analyzed data for women 40 years of age or older who received a valid screening mammogram paid for by the NBCCEDP on or before December 31, 2002. The MDEs for women with mammography test results are reported using categories from the American College of Radiology's Breast Imaging and Data System (BI-RADS), which was designed to provide an organized approach to image interpretation and reporting.[12] In the NBCCEDP, a screening mammogram is defined as the first mammogram a woman receives in a single screening round, regardless of whether she reports symptoms or has had a positive clinical breast exam (CBE). We defined a valid screening mammogram as one with an associated BI-RADS code (0–6) or an unsatisfactory result.

Breast screening outcomes are reported by first and subsequent screening rounds. A woman's first program screening is defined as her first NBCCEDP mammogram. In reporting subsequent screening rounds, we excluded results for women whose initial exam led to a final diagnosis of breast cancer. Additionally, we excluded results of mammograms that occurred less than 9 months after the first program mammogram because these are considered short-interval follow-up or "surveillance" exams after a probably benign finding.

Prior to 1994, the categories used to define the results of a CBE were not sufficiently detailed to provide valid and useful information, and therefore results from 1994 and earlier are not reported here. In order to better collect such information, "model clinical categories" for the collection of CBE data at the clinical level were proposed. We have reported the results of CBEs directly associated with a screening mammogram conducted from January 1, 1996, through December 31, 2002. Although most CBEs associated with a mammogram are reported on the same data record in the MDEs, some CBEs are located on a separate record or on a record associated with a cervical cancer screening cycle. Therefore, we linked 25,784 CBEs that were reported separately from the associated mammogram if they occurred up to 60 days before the woman's screening mammogram.

Age was calculated on the basis of the date of birth reported by the woman at enrollment. Although we did report data on women 65 years of age or older, the number of women in this age group is small because many of the women 65 years of age or older were not eligible for the NBCCEDP because of Medicare coverage. Race/ethnicity is based on self-reports of participants and recorded separately on the MDEs. Women reporting Hispanic or Latina origin were classified as *Hispanic/Latina* regardless of their racial classification. All other women were classified as *white, black/African American, Asian/Native Hawaiian/Other Pacific Islander,* or *American Indian/Alaska Native*. Women not claiming any racial or ethnic classifications and those reporting more than one race were classified as *other/unknown*.

We calculated the distribution of all breast cancer screening results by program participants' age and race/ethnicity. An abnormal mammogram was defined as a screening mammogram with any of the following results: *suspicious abnormality* (BI-RADS category 4), *highly suggestive of malignancy* (BI-RADS category 5), or *assessment incomplete* (BI-RADS category 0). The NBCCEDP recommends diagnostic follow-up for all women with abnormal mammogram results. Additionally, diagnostic follow-up may be initiated on the basis of abnormal CBE results or concern of the patient or clinician regardless of the mammography results. We calculated diagnostic follow-up rates as the number of records with at least one diagnostic test recorded per 1,000 mammograms. Cancer detection rates were calculated per 1,000 mammograms for invasive breast cancers, in situ cancers, and both combined. All screening result distributions, diagnostic follow-up rates, and cancer detection rates estimated for racial/ethnic groups were age-adjusted to the population of women receiving mammograms through the NBCCEDP in 2000 using the direct method.[8]

We computed the positive predictive value (PPV) of abnormal mammography results by participants' age and race/ethnicity as the number of cancers diagnosed per 100 abnormal results. Finally, we calculated the

distribution of stage at diagnosis of invasive breast cancer by age group. Stage of diagnosis was reported through one of two systems: the system of the American Joint Committee on Cancer (AJCC) or the summary staging system used by the Surveillance, Epidemiology, and End Results (SEER) Program with local, regional, and distant categories.[16] However, the stage reported in the NBCCEDP varies by individual program, ranging from the stage reported in the state cancer registry to preliminary clinical staging information. Therefore, breast cancer staging information reported here may not be consistent with that from cancer registries.

## Cervical Cancer Screening Analysis

We analyzed data for women 18 years of age or older who received a valid Pap test paid for by the NBCCEDP on or before December 31, 2002. From 1991–2000, the programs reported Pap test results using the 1991 Bethesda System categories: *normal, infection/reaction, atypical squamous cells of undetermined significance* (ASCUS), *low-grade squamous intraepithelial lesion* (LSIL), *high-grade squamous intraepithelial lesion* (HSIL), *squamous cell cancer* (SqCa), *and atypical glandular cells* (AGC).[14] In 2001 the programs began using the 2001 Bethesda System, which subdivides ASCUS into *atypical squamous cells of undetermined significance* (ASCUS) and *atypical squamous cells–cannot exclude HSIL* (ASC–H). Data from 2001–2002 reflect this change, with a row included for ASC-H.

Pap test and biopsy results are reported separately for the initial screening and subsequent screening rounds. In reporting the results of subsequent screening tests, we excluded those women whose initial exam led to a diagnosis of cancer. We also excluded results of tests conducted less than 9 months after the first program screening test because these exams were most likely conducted as follow-up for an abnormal result.

We calculated participants' age from the date of birth they reported at enrollment and determined age groups after considering age-related influences on screening rates, such as Medicare benefits primarily for those aged 65 years or older. Race and ethnicity designations were based on participants' self-reports. Women reporting Hispanic or Latina origin were classified as *Hispanic/Latina* regardless of their racial classification. All other women were classified as *white, black/African American, Asian/Native Hawaiian/Other Pacific Islander,* or *American Indian/Alaska Native*. Women not claiming any racial or ethnic classifications and those reporting more than one race were classified as *other/unknown*.

We calculated the percentages of all Pap test results interpreted as abnormal by participant's age and race/ethnicity. Abnormal was defined as LSIL, HSIL, SqCa, ASC-H, or AGC. It should be noted that AGC was included in our *other* category until 1999 when a separate field, *atypical glandular cells*, was created. About 27% of the programs retroactively took the AGC results out of *other* and incorporated them into the AGC category. We computed detection rates for each grade of CIN and invasive cancer as the number of cases with a final histologic diagnosis of cervical intraepithelial neoplasia (CIN I, CIN II, CIN III/carcinoma in situ [CIS]) or invasive cancer per 1,000 Pap tests performed. To estimate the detection rate of high-grade lesions, we combined biopsy results of CIN II, CIN III/CIS, and invasive cancer (i.e., CIN II or worse). All screening result distributions and cancer detection rates estimated for racial/ethnic groups were age-adjusted to the population of women receiving Pap tests through the NBCCEDP in 2000 using the direct method.[8]

We computed the positive predictive value (PPV) of abnormal Pap test results by participants' age and race/ethnicity as the number of invasive cancers (CIN II or worse) diagnosed per 100 Pap tests read as LSIL, HSIL, ASC-H, AGS, or SqCa. Finally, we calculated the distribution of stage at diagnosis of invasive cervical cancer by age group. Cervical cancer stage is reported in the MDEs using two staging systems: the International Federation of Gynecology and Obstetrics (FIGO)[17] definitions or the Surveillance, Epidemiology, and End Results (SEER)[18] Summary Staging System. Local disease was defined as either stage I (FIGO) or local (SEER). However, the stage reported in the NBCCEDP varies by individual program, ranging from the stage reported in the state cancer registry to preliminary clinical staging information. Therefore, cervical cancer staging information reported here may not be consistent with that from cancer registries.

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