Chapter 8:
Breast Cancer Control, Survivorship, and Outcomes: NCI's Investment and Recent Progress

To reduce the burden of breast cancer, we must sustain a vigorous and substantial commitment to basic and applied cancer control research conducted by scientists from diverse disciplines. Such an integrated research effort should address monitoring, prevention, surveillance, detection, treatment, and follow-up, including the provision of compassionate palliative care to those who die of the disease.... A fuller understanding is needed as to which groups of women are at risk for poor quality of life and psychosocial outcomes, and at what points along the disease or care continuum risks are elevated. *Charting the Course: Priorities for Breast Cancer Research*

The ultimate goal of cancer control research, as defined by the 1998 Breast Cancer PRG report, is to eliminate the burden of cancer. NCI has made much progress toward this goal, and recent research has shown that early detection and treatment of breast cancer have contributed to reduced mortality. NCI is supporting research to increase the numbers of women screened, enhance screening methodologies, ensure that all women receive needed treatment, and maximize quality of life for the growing numbers of breast cancer survivors. Several Centers of Excellence are developing communication strategies that will inform women about behaviors that can reduce their risk of developing breast cancer, recruit more women for breast cancer screening, enhance women's decision making about screening and treatment, and improve quality of life following breast cancer treatment. The seven research sites of the Breast Cancer Surveillance Consortium (BCSC) are assessing the accuracy, cost, quality, and intermediate outcomes of screening as it is practiced in the community. Data from the Consortium are critical to related NCI efforts (such as the Cancer Intervention and Surveillance Modeling Network [CISNET]) to estimate the impact of these practices on changes in breast cancer mortality. NCI-supported researchers are also addressing quality of life in breast cancer survivors and the impact of breast cancer on family members.

The PRG report identified 8 priorities that deal with important topics in breast cancer control research and 16 priorities that address critical issues in outcomes research. The cancer control priorities address the need to identify the mechanisms responsible for basic behavioral change, determine whether psychosocial factors influence traditional disease outcomes, facilitate better patient decision making, improve the delivery of breast cancer care to maximize desirable outcomes and minimize cost, identify the psychosocial benefits from unproven treatments, use advances in communications technology to study ways of delivering breast cancer information, determine the impact of breast cancer on the family, and identify communications strategies to reach diverse health providers. Outcomes priorities focus on the need to study the short- and long-term outcomes of multimodal treatment for breast cancer, investigate patient-focused outcomes across the continuum of age and for women with *in situ* breast cancer, integrate patient-focused data with biological prognostic information to make treatment decisions, improve patient outcomes, help meet survivors' needs, identify resources to study patient-focused outcomes, improve the management of symptoms and side effects, incorporate patient preferences into treatment decisions, collect patient outcome data in prevention trials, and advance the field of outcomes research.

The NCI has been responsive to the PRG priorities related to breast cancer control, survivorship, and outcomes. Recent research has demonstrated that certain recruitment strategies can increase the numbers of women who are screened for breast cancer at recommended intervals. Several factors have been identified that can improve the accuracy of mammography. As a result of research, treatment following an abnormal mammogram has improved in recent years, and disparities in the care received are being addressed. As more women survive with breast cancer, researchers are identifying the factors—such as social support and exercise—that maximize physical and emotional functioning.

Since the release of the PRG report, NCI has sponsored or cosponsored at least four major reports that are relevant to the Cancer Control, Survivorship, and Outcomes recommendations of the Breast Cancer PRG. In addition, the National Institutes

of Health *Consensus Development Conference Statement: Adjuvant Therapy for Breast Cancer, November 1-3, 2000*, addressed issues related to patient-focused outcomes when making decisions about adjuvant therapy (see Chapter 7 for details).

The first of these reports, *Evaluating Screening Performance in Practice*,[1] was developed by the Breast Cancer Surveillance Consortium. The BCSC is a consortium of seven research sites and one statistical coordinating center established by the NCI to address issues that can be adequately examined only in a very large sample drawn from diverse geographic and practice settings. This report describes the BCSC's current areas of research and its accomplishments to date, including more than 130 papers in peer-reviewed journals. One of the studies highlighted in the BCSC report found that screening mammography was less effective for detecting cancer in younger women than in older women, regardless of family history. This study shows the importance of further research to determine whether screening mammography is accurate enough to support screening recommendations for younger women with a family history of breast cancer. Another study found that mammography was equally accurate in black and white women but that black women with symptoms had larger and more aggressive tumors than white women. These results indicate that more research is needed to clarify the relationship between race/ethnicity, modifiable risk factors, and stage of disease at diagnosis.

The second report, *Exploring the Role of Cancer Centers for Integrating Aging and Cancer Research*,[2] summarizes the deliberations of a workshop organized by the NCI and the National Institute on Aging. The report notes the disproportionately high burden of cancer for older Americans, a particular concern in the context of the aging population in the United States. Workshop participants met in seven breakout sessions focused on such issues as treatment efficacy and tolerance; effects of comorbidity and cancer; and psychological, social, and medical issues. Each group developed three recommendations, including: incorporate the clinical expertise from NCI projects, particularly the NCI SEER projects, that is available in cancer centers to improve the quality of care of the medically underserved, aging population; develop clinical trials that are specifically designed for older cancer patients; develop models for decision making at the individual and clinical levels; and examine the cancer caregivers' functioning and quality of life and their impact on the older cancer patient's care and treatment trajectory. This report resulted in an NCI Program Announcement: Integrating Aging and Cancer Research.

The NCI's 2002 *Report of the Breast Screening Working Group*, prepared at the request of the NCI Director, was developed in response to debates in the professional literature and the news media about mammography's efficacy in certain age groups. This internal report was intended to help the Institute improve how it translates complex research evidence for the public and to examine the state of the science and what research and resources are needed to promote progress in breast cancer screening and diagnosis. The Working Group made several recommendations in its report, including increasing basic research on interval cancers, tumor microenvironment, and ductal carcinoma *in situ* (DCIS), and supporting translational research, technology development, and interdisciplinary collaboration. The Working Group also recommended that NCI communicate proactively and clearly about research on screening mammography to ensure that its key audiences are well informed.

The NCI cosponsored the Institute of Medicine's report *Meeting Psychosocial Needs of Women With Breast Cancer*.[3] This report was intended to examine the psychological consequences of the cancer experience, the availability and application of psychosocial services for women with cancer, and the training and education of cancer care providers. In a review of the literature, the report concludes that psychosocial interventions can be expected to reduce psychiatric symptoms and improve quality of life in routine breast cancer care. The report presents recommendations for providers and the delivery of care through: (1) promoting formal psycho-oncology education for oncology providers; (2) integrating standards of psychosocial care with cancer managemen; and (3) conducting collaborative studies to enhance the integrated coordination of care. The report also recommends to continue studies on psycho-oncology research and to encourage an NCI special study to ascertain the use of, and current need for, cancer-related supportive care services in the United States, including disparities by age, race/ethnicity, geography, and insurance coverage.

1 This report can be found on the BCSC Web site at http://breastscreening.cancer.gov/espp.pdf.

2 Available at http://www.nia.nih.gov/health/nianci/.

3 A brief review of this report can be found on the IOM Web site at http://www.iom.edu/report.asp?id=18136.

NCI's Investment and Response

From FY1998 to 2003, NCI's extramural investment in breast cancer control, survivorship, and outcomes research increased from $46.6 million to $82.8 million (Figure 8-1). This increase in funding corresponds to increases in the number of projects that are responsive to the 24 Breast Cancer PRG research priorities for cancer control, survivorship, and outcomes.

NCI's research support is summarized in Table 8-1 for the 8 Breast Cancer PRG research priorities pertaining to cancer control and in Table 8-2 for the 16 research priorities pertaining to outcomes.[4]

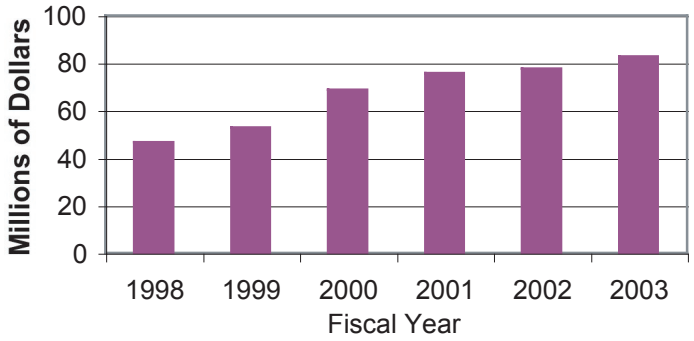
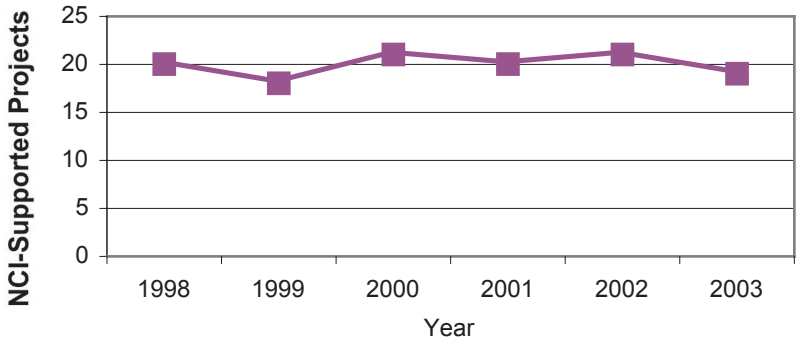


Figure 8-1. NCI's extramural investment in cancer control, survivorship, and outcomes research in breast cancer: 1998-2003 (in millions of dollars)

Table 8-1. NCI Efforts Responsive to PRG Priorities and Opportunities in Cancer Control Research[a]

PRG Priority:

What are the mechanisms responsible for basic behavioral change?



NCI Efforts:

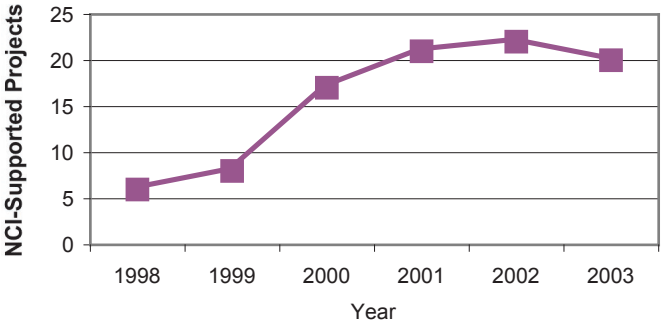
- In FY2003, examples of active areas of investigation included compliance with mammography screening guidelines, with an emphasis on older women, African Americans, and Hispanics; the relationship between trust and breast cancer prevention practices and behaviors in African Americans; the long-term physiological, psychological, social, and religious/spiritual effects of surviving cancer on older adults; and the impact of concerns about mortality on behavioral risk factors for cancer.
- On October 14-16, 1998, NCI sponsored the *5 A Day International Symposium* to address the health benefits of increased fruit and vegetable intake and behavior change interventions in community settings.
- NCI initiatives addressing this priority included the Small Grants Program for Behavioral Research in Cancer Control and Social and Cultural Dimensions of Health.

a. Some of the original PRG priorities are addressed jointly in Table 8-1 because these priorities address partially overlapping issues and they are relevant to many of the same research projects and initiatives.

4 A project may map to more than one PRG priority and, therefore, be represented in more than one figure. Projects active in 2003 are listed in Appendix B (Tables B-40 to B-58) by Principal Investigator's name for each PRG priority.

PRG Priority:

Do psychosocial factors including, but not limited to, interventions influence traditional disease outcomes (e.g., overall survival, disease-free survival, and disease response)?



NCI Efforts:

- In FY2003, examples of active areas of investigation included the motivations to obtain follow-up care of women who had experienced a false-negative mammogram; the relationships between breast cancer treatments and disease-specific and health-related quality of life outcomes; and the impact of environmental toxins, diet, physical activity, and weight gain on breast cancer risk.
- NCI initiatives addressing this priority included the Breast Cancer Specialized Programs of Research Excellence (SPOREs); Economic Studies in Cancer Prevention, Screening and Care; and Integrating Aging and Cancer Research.

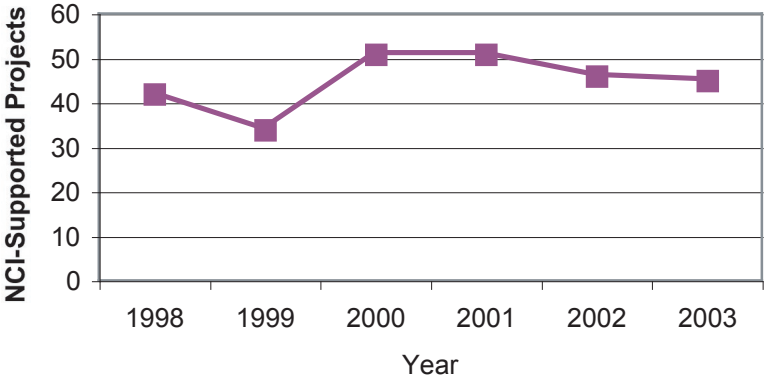
PRG Priorities:

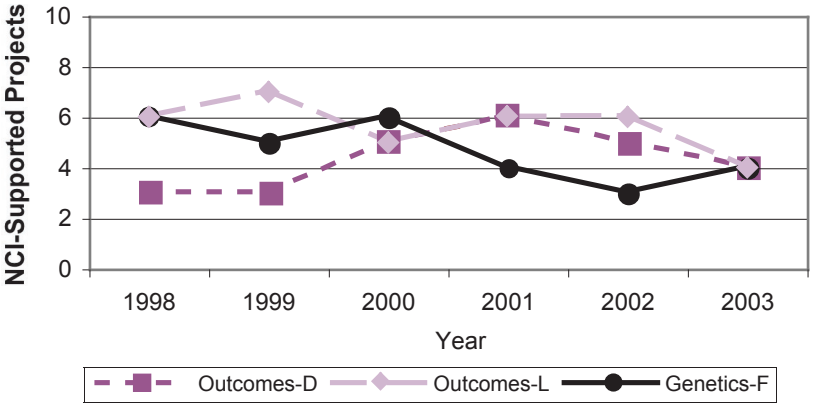
How can we facilitate better patient decision making, especially that based on risks and benefits? (Control-C)

How can patient-focused data be integrated with biological prognostic information to make the best treatment decisions? (Outcomes-D)

How can patient preferences be incorporated into treatment decisions? (Outcomes-L)

Discussion and resolution of social and legal issues of informed consent and privacy of medical information in the context of genetic testing and genetic predisposition.[b] (Genetics-F)





NCI Efforts:

- In FY2003, examples of active areas of investigation relevant to the following priorities included:
  - Control-C: comparative cancer epidemiology, prevention, and control in older minority populations; barriers to the use of symptom-management strategies by patients; the impact of culture, ethnicity, and income on screening behaviors; and the effects of education and counseling on the emotional, physical, and social adjustment of breast cancer patients

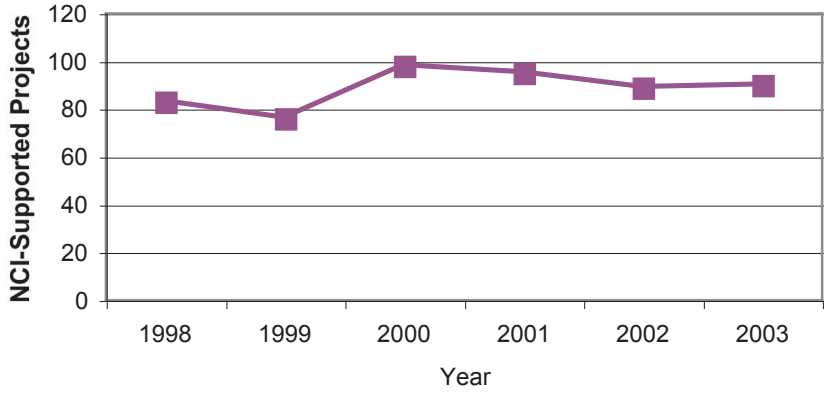
b. This priority was part of the Genetics section in the original Breast Cancer PRG report.

- Outcomes-D: a new functional evaluation tool for assessing cancer care, psychological and immune parameters associated with fatigue in breast cancer survivors, and performance status for decisions about therapies and eligibility for clinical trials
- Outcomes-L: breast cancer patients' preferences for local and systemic therapy
- Genetics-F: decisions about chemoprevention by families with hereditary breast and ovarian cancer and genetic counseling for these families

- Examples of clinical trials addressing these priorities included the following:
  - Randomized Genetics Study of Educational Methods for Patients With Breast or Ovarian Cancer Enrolling in a Breast Cancer Genetics Program (NCI-99-C-0081)
  - Chemotherapy Decisions and Outcomes in Older Women With Newly Diagnosed Breast Cancer (CALGB-369901)
  - Companion Study to Evaluate Quality of Life in Women With Axillary Node-Negative, Estrogen Receptor-Negative, Primary Invasive Breast Cancer Enrolled on Protocol NSABP-B-23 (NSABP-B-23-QOL)
- NCI initiatives addressing these priorities included the Cancer Centers Program, Insight Awards to Stamp Out Breast Cancer, and Special Populations Networks.

PRG Priority:

Can the delivery of breast cancer care from diagnosis and screening through treatment, follow-up, and end of life be improved in ways that maximize desirable outcomes and minimize cost?

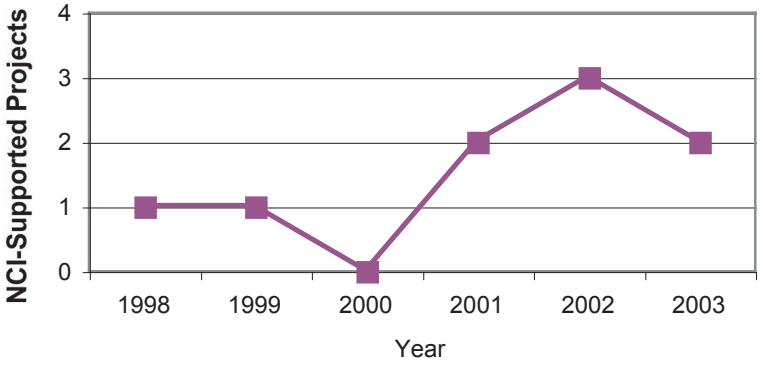


NCI Efforts:

- In FY2003, examples of active areas of investigation included culturally sensitive educational materials to improve screening use in minority populations; the impact of changes in behaviors, clinical practice patterns of health care providers, and interventions on incidence and mortality; effects and costs of a prevention case manager to improve cancer early detection; and a comparison of cancer diagnoses, interventions, and clinical and cost outcomes between persons with and without disabilities.
- Examples of clinical trials addressing this priority included the following:
  - Correlation of Menstrual Cycle Phase at the Time of Surgery With Disease-Free Survival in Premenopausal Women With Stage I or II Breast Cancer (NCCTG-N9431)
  - Randomized Study of Brief Physician-Initiated Smoking Cessation Strategies Versus Usual Care in Patients With Early-Stage Cancer Who Are Undergoing Treatment in Clinical Oncology Settings (NCI-P93-0042)
- NCI initiatives addressing this priority included Aging Women and Breast Cancer, Minority Institution/Cancer Center Partnership (MI/CCP), and Small Grants Program for Behavioral Research in Cancer Control.

PRG Priority:

What psychosocial benefits do patients obtain from unproven treatments that cause them to seek out such treatments?

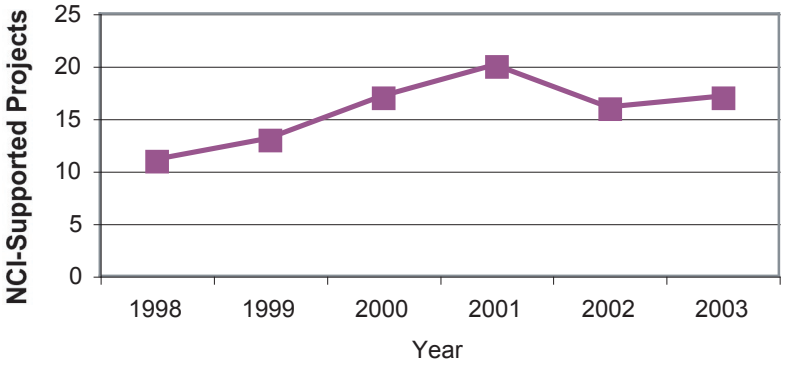


NCI Efforts:

- In FY2003, examples of active areas of investigation included spiritually based health education in African-American women and treating chemotherapy-induced nausea with acupressure.
- Examples of clinical trials addressing this priority included the following:
  - Phase III Randomized Study of Acupressure for Chemotherapy-Induced Nausea in Women With Breast Cancer Receiving One of Three Combination Therapy Regimens (MDA-NUR01-396)
  - Phase III Randomized Study of Black Cohosh for the Management of Hot Flashes in Women With Breast Cancer or Who Have Concerns About Developing Breast Cancer (NCCTG-N01CC)
  - Randomized Study of Acupuncture for Mucositis-Related Pain Secondary to High-Dose Chemotherapy in Patients Undergoing Hematopoietic Stem Cell Transplantation (NCI-03-C-0125)
  - Phase I/II Randomized Study of Adjuvant Doxorubicin and Cyclophosphamide With or Without Chinese Herbal Therapy for Symptom Management in Women With Stage I, II, or Early Stage III Breast Cancer (UCSF-CRO-97755)
  - Study of the Use of Complementary and Alternative Medicine Practices by Women at Increased Risk for Breast Cancer (NCI-00-C-0039)
- On June 9-11, 2000; October 19-21, 2001; and April 9-13, 2003, NCI sponsored *Comprehensive Cancer Care: Integrating Complementary and Alternative Therapies* to provide information on complementary and alternative therapies (CAM) for cancer to oncologists, other practitioners, and people with cancer.
- NCI initiatives addressing this priority included Basic and Preclinical Research on Complementary and Alternative Medicine (CAM) and Centers for Complementary and Alternative Medicine Research.

PRG Priority:

How can advances in communication technologies best be used for research in health communications and behavior change and for delivering breast cancer information?



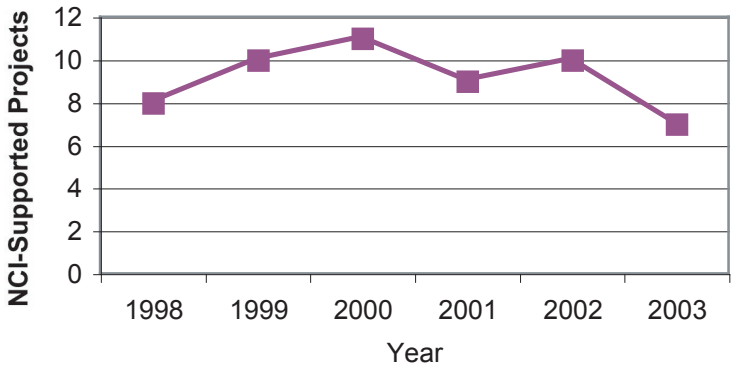
NCI Efforts:

- In FY2003, examples of active areas of investigation included: methods to improve recruitment of patients, especially from minority and low-income populations, into community-based clinical oncology trials; tailored and culturally appropriate communications interventions to increase mammography use; cancer communication among minority populations, including African Americans; and education about risk factors and methods for risk reduction.

- On October 25-28, 2000, NCI sponsored the *11th Annual Conference of the Cancer Patient Education Network (CPEN): Caring, Discovery, Excellence* to exchange information among patient educators from each of the NCI-designated Comprehensive and Clinical Cancer Centers.
- NCI initiatives addressing this priority included the Cancer Centers Program, Centers of Excellence in Cancer Communication Research, and Health Communications in Cancer Control.

PRG Priority:

What is the impact of breast cancer on the family? Specifically, what is its impact on other family members and the family unit, and what is the impact of the family unit on breast cancer outcomes?

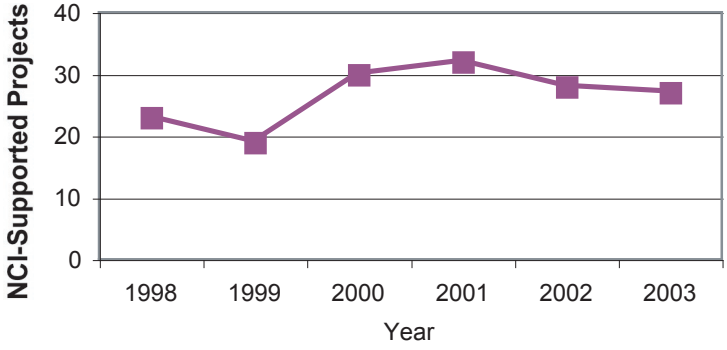


NCI Efforts:

- In FY2003, examples of active areas of investigation included the impact of psychosocial factors on cancer screening behaviors among unmarried women, the effect of education and counseling on patients with breast cancer and their partners, and helping mothers with breast cancer support their children.
- NCI initiatives addressing this priority included the Cancer Outcomes Measurement Working Group (COMWG), Research on the Impact of Cancer on the Family, and Small Grants Program for Behavioral Research in Cancer Control.

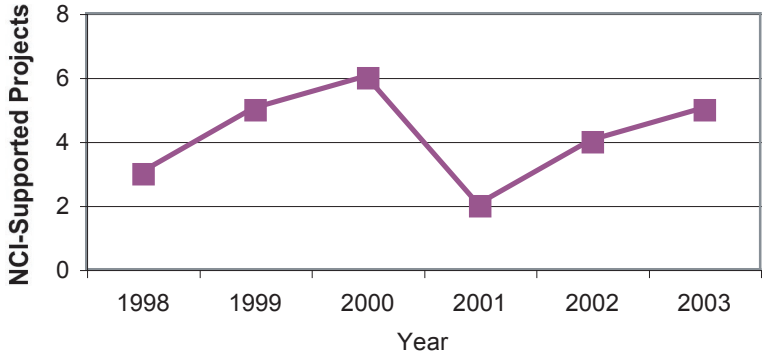
PRG Priority:

What kind of communication strategies are needed to reach the diversity of health care providers in the area of breast cancer?



NCI Efforts:

- In FY2003, examples of active areas of investigation included patterns and outcomes of screening mammography practice in North Carolina and increasing the participation of minority scientists in behavioral and translational cancer research.
- NCI initiatives addressing this priority included Cancer Research Training, Career Development, and Education Opportunities; the MI/CCP; and Special Populations Networks (SPNs).



Additional Breast Cancer Control Projects

NCI Efforts:

- Active research projects in FY2003 related to reducing breast cancer health disparities included: studies of risk-related behaviors and changes in diet and lifestyle in Hispanic breast

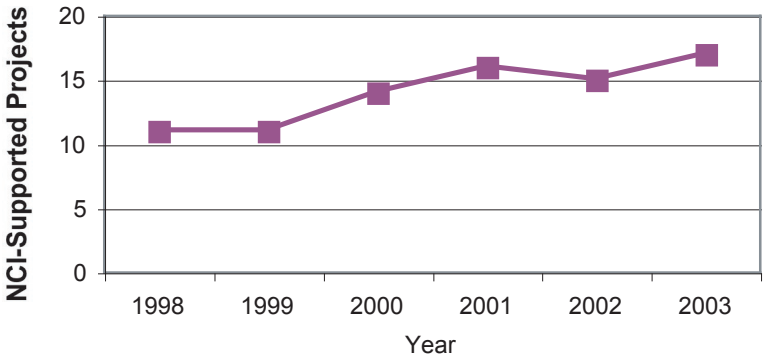
cancer survivors; use of mammograms and/or clinical breast exams and trust in health care providers among black women by level of education, age, income, and Hispanic ethnicity; physician and patient predictors of tamoxifen prescription and treatment adherence in older women; and impact of culture on cancer screening in Chinese women.

- The PRG did not address screening in the context of cancer control, but several areas of investigation on this topic were active in FY2003, including the impact of community factors (such as availability of medical providers) on screening for breast cancer; how low-income African-American women interpret and act on health education messages regarding mammography; effects of soy on estrogen levels and mammographic densities; and the effects of driving distance on mammography use.
- In FY2003, other examples of active areas of investigation included the association between the incidence of breast cancer and body size at different ages, diabetes, and dietary patterns related to insulin resistance and post-treatment behavioral risk factors for recurrence of secondary breast tumors or new primaries.
- Examples of clinical trials addressing screening in the context of cancer control included the following:
  - Screening and Diagnostic Study of Magnetic Resonance Imaging in Women With Suspected Breast Cancer (UPCC-ACR-6884)
  - Randomized Screening and Diagnostic Study of Digital Mammography Versus Screen-Film Mammography in the Detection of Breast Cancer in Women (ACRIN-6652)

Table 8-2. NCI Efforts Responsive to PRG Priorities and Opportunities in Outcomes Research[a]

PRG Priority:

How can patient-focused outcomes be studied across the continuum of age? The impact of breast cancer treatments may be different among different age groups.



NCI Efforts:

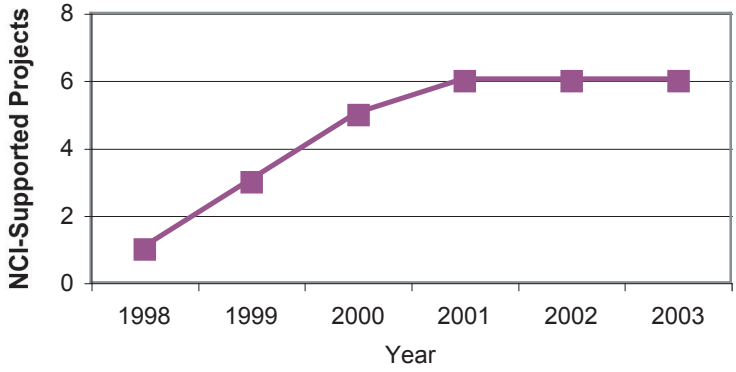
- In FY2003, examples of active areas of investigation included reproductive cancer education resources for women with breast cancer, educating older women about managing uncertainty after breast cancer treatment, helping the mother with breast cancer support her child, and facilitating positive adaptation to a breast cancer diagnosis.
- Examples of clinical trials addressing this priority included the following:
  - Phase II Randomized Study of Soy Protein in Postmenopausal Women With Breast Disease Taking Tamoxifen and Experiencing Hot Flashes (CALGB-79805)
  - Phase III Study of the Effect of Menstrual Cycle Timing With Breast Surgery on Prognosis in Premenopausal Women With Stage I, II, or III Breast Cancer (UCLA-9810046)
  - Phase III Randomized Study of Risedronate for Prevention of Bone Loss in Premenopausal Women Undergoing Chemotherapy for Primary Breast Cancer (NCCTG-N02C1)

a. Some of the original PRG priorities are addressed jointly in Table 8-2 because these priorities address partially overlapping issues and they are relevant to many of the same research projects and initiatives.

- On October 19-20, 2000, NCI sponsored *Cancer Survivorship Throughout the Lifespan: Challenges for the 21st Century* to address the complex medical, psychological, and social needs of cancer survivors.
- NCI initiatives addressing this priority included Integrating Aging and Cancer Research, SEER-Medicare Linked Database, and Small Grants Program for Cancer Epidemiology.

PRG Priority:

What are the patient-focused outcomes for women with *in situ* breast cancer?



NCI Efforts:

- In FY2003, examples of active areas of investigation included assessing quality of life for women with DCIS and studying the effects of various treatment regimens on quality of life for DCIS patients.
- Examples of clinical trials addressing this priority included the following:
  - Screening Study Following Local Excision in Selected Patients With Ductal Carcinoma *In Situ* (DCIS) of the Breast (E-5194)
  - Phase III Randomized Study of Hormone Replacement Therapy for Hot Flashes and/or Vaginal Symptoms in Postmenopausal Women With a History of Node-Negative Invasive Carcinoma or Ductal Carcinoma *In Situ* of the Breast Who Are Receiving Adjuvant Tamoxifen (E-2193)

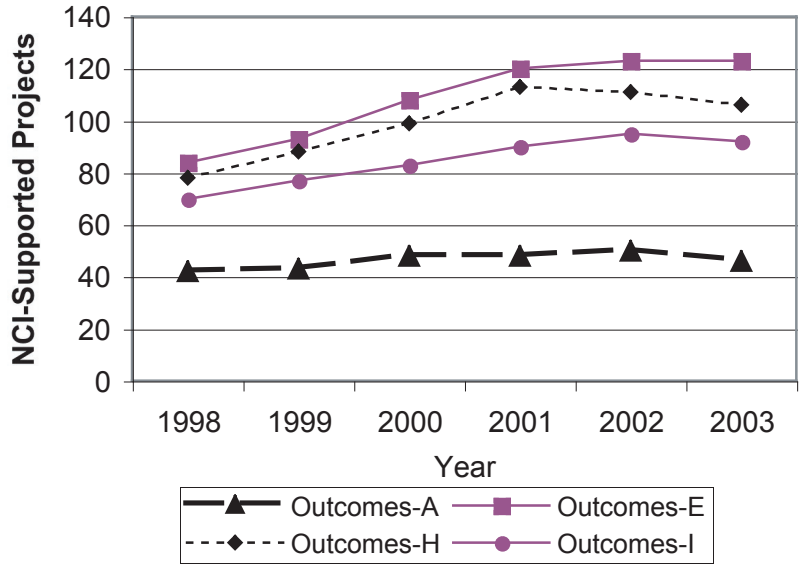
PRG Priorities:

What are the short- and long-term effects of multimodal treatment for breast cancer? (Outcomes-A)

How can we improve patient outcomes, including the physical, emotional, and social dimensions of health-related quality of life? (Outcomes-E)

How can the management of disease symptoms and treatment side effects be improved? (Outcomes-H)

How can the long-term medical and psychosocial outcomes for breast cancer survivors be improved? (Outcomes-I)



NCI Efforts:

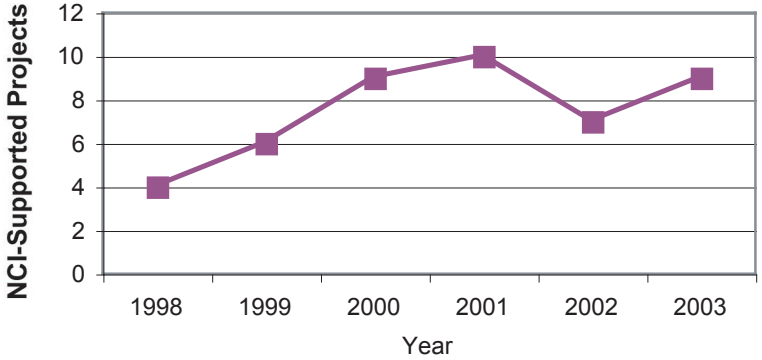
- In FY2003, examples of active areas of investigation relevant to the following priorities included:
  - Outcomes-A: investigating the cognitive deficits experienced by breast cancer patients undergoing systemic chemotherapy versus surgery plus radiotherapy, assessing the impact of breast cancer recurrence on Vietnamese women following various multimodal treatment regimens, and testing the effect of a breast tumor vaccine plus chemotherapy on tumor-specific immunity.

- Outcomes-E: assessing quality of life among minority cancer survivors, interactive cancer communication systems to improve the quality of life of patients and families facing cancer across the disease spectrum, insomnia intervention strategies for breast cancer patients, and using exercise to fight fatigue in breast cancer patients.
- Outcomes-H: the influence of sleep/wake rhythms on patients' tolerance of treatment and quality of life, changes in brain structure and function associated with chemotherapy, healthy weight management strategies for breast cancer survivors, and information for breast cancer survivors on issues that present or persist post treatment.
- Outcomes-I: assessing cognitive effects of chemotherapy treatment in women with breast cancer, the relationship between low-fat diet and breast cancer recurrence, a follow-up study to measure breast cancer survivor's health-related quality of life, and determining the physiologic, psychologic, and social long-term effects of surviving cancer on older adults.

- Examples of clinical trials addressing these priorities included the following:
  - Randomized Study of Health Promotion in Patients Who Are Prostate or Breast Cancer Survivors (DUMC-1547-02-8R4ER)
  - Phase III Randomized Study of Palliative Radiation Therapy for Bone Metastases From Breast or Prostate Cancer (RTOG-9714)
  - Oral Analgesia Regimen for Improved Pain Control in Cancer Patients (E-4Z93)
  - Phase II Study of High-Dose Chemotherapy, Total Body Irradiation, and Autologous Peripheral Blood or Bone Marrow Transplantation in Patients With Hematologic Malignancies or Selected Chemosensitive Solid Tumors (RPCI-DS-9115)
  - On October 19-20, 2000, NCI sponsored *Cancer Survivorship Throughout the Lifespan: Challenges for the 21st Century* to address the complex medical, psychological, and social needs of cancer survivors. A second conference, on June 2-4, 2002, addressed *Cancer Survivorship: Resilience Across the Lifespan*.
  - A report entitled *Meeting the Psychosocial Needs of Women With Breast Cancer*, cosponsored by the NCI, Centers for Disease Control and Prevention, and National Academy of Sciences, was released by the Institute of Medicine in January 2004
- NCI initiatives addressing this priority included Cancer Intervention and Surveillance Modeling Network (CISNET), Cancer Outcomes Measurement Working Group (COMWG), Minority and Underserved Cancer Survivors, Small Grants Program for Behavioral Research in Cancer Control, and Social and Cultural Dimensions of Health.

PRG Priority:

How are the health care needs of breast cancer survivors being met within the current health care system?



NCI Efforts:

- In FY2003, examples of active areas of investigation included telephone therapies that help women cope with breast cancer, assesment of the quality of care provided to Medicare patients with breast cancer, and evaluation of the determinants of quality of care for older breast cancer survivors.
- Examples of clinical trials addressing this priority included the following:

- Randomized Study of Health Promotion in Patients Who Are Prostate or Breast Cancer Survivors (DUMC-1547-02-8R4ER)
- Randomized Study of the Effect of Telephone Counseling by Breast Cancer Survivors on Well-Being of Women With Recurrent Breast Cancer (SWOG-S9832)

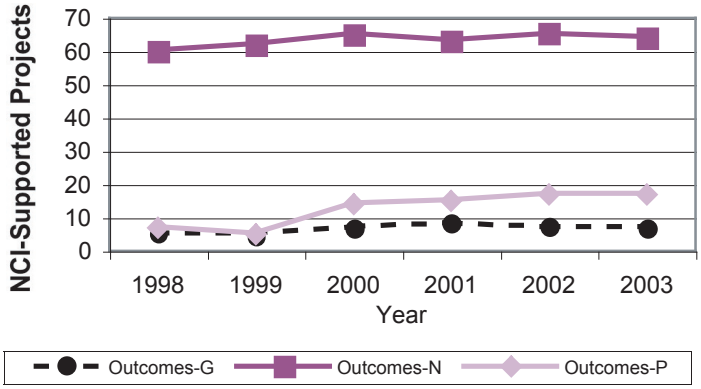
- On October 19-20, 2000, NCI sponsored *Cancer Survivorship Throughout the Lifespan: Challenges for the 21st Century* to address the complex medical, psychological, and social needs of cancer survivors. A second conference, on June 2-4, 2002, addressed *Cancer Survivorship: Resilience Across the Lifespan*.
- NCI initiatives addressing this priority included Minority and Underserved Cancer Survivors, SEER Patterns of Care/ Quality of Care (POC/QOC) Initiative, and Social and Cultural Dimensions of Health.

PRG Priorities:

What treatment research resources exist to foster research on patient-focused outcomes? (Outcomes-G)

What kinds of prevention research resources exist to facilitate patient-focused outcomes research? (Outcomes-N)

What cancer control and survivorship research resources are available to advance the field of outcomes research? (Outcomes-P)

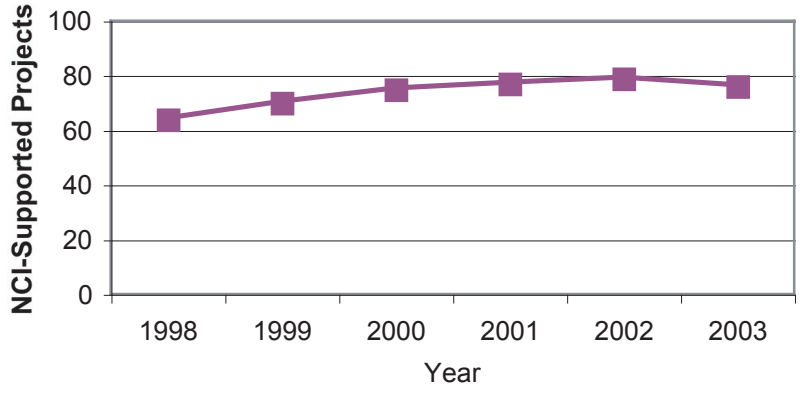


NCI Efforts:

- In FY2003, examples of active areas of investigation relevant to the following priorities included:
  - Outcomes-G: a new functional evaluation tool for cancer care, a cancer chemotherapy program project, and studies to test the effect of adjuvant therapy on long-term survival
  - Outcomes-N: a computerized decision-support tool that educates women about their breast cancer risk factors and risk reduction strategies and numerous Community Clinical Oncology Programs that participate in the Breast Cancer Prevention Trial
  - Outcomes-P: use of HMO data to characterize patterns of care and analyze the relationship between treatment and outcomes for breast cancers, as well as partnerships between NCI-designated Cancer Centers and minority institutions to assess breast cancer outcomes in underserved communities
- NCI initiatives addressing this priority included the CISNET, COMWG, Cancer Surveillance Using Health Claims-Based Data System, Community Clinical Oncology Program (CCOP), and Minority-Based CCOP (MBCCOP).

PRG Priority:

What secondary prevention and health promotion efforts are effective and appropriate for breast cancer patients/ survivors?

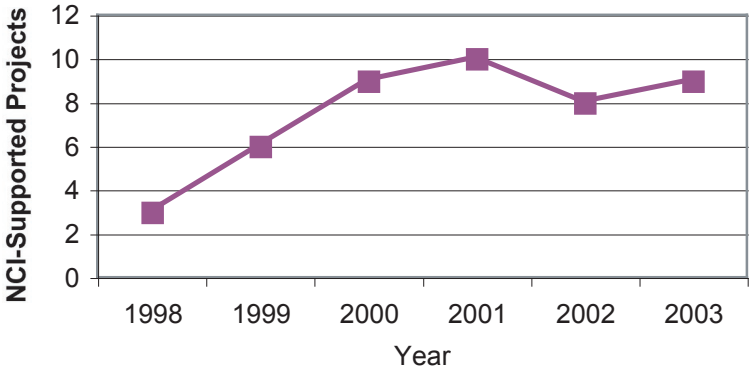


NCI Efforts:

- In FY2003, examples of active areas of investigation included assessing the impact of several dietary factors—including isothiocyanates and d-limonene, vegetables and vegetable juice, and limited fat—on risk of breast cancer recurrence, design of effective interventions for preventing osteoporosis in breast cancer survivors, and the effects of exercise and healthy weight management on quality of life and morbidity in survivors of breast cancer.
- Examples of clinical trials addressing this priority included the following:
  - Phase I Study of Perillyl Alcohol in Women at Risk for Recurrent Breast Cancer (CCF-IRB-3574)
  - Phase II Study of Pentostatin in Patients With Refractory Chronic Graft-Versus-Host Disease (CALGB-100101)
  - Randomized Study of Raloxifene With or Without Exercise Versus Exercise Alone in Women Previously Treated for Breast Cancer (OHSU-6312)
  - Randomized Study of Health Promotion in Patients Who Are Prostate or Breast Cancer Survivors (DUMC-1547-02-8R4ER)
- On October 19-20, 2000, NCI sponsored *Cancer Survivorship Throughout the Lifespan: Challenges for the 21st Century* to address the complex medical, psychological, and social needs of cancer survivors. A second conference, on June 2-4, 2002, addressed *Cancer Survivorship: Resilience Across the Lifespan*.
- NCI initiatives addressing this priority included the Small Grants Program for Behavioral Research in Cancer Control and Minority and Underserved Cancer Survivors.

PRG Priority:

What are the economic and health care outcomes for patients/survivors with breast cancer?

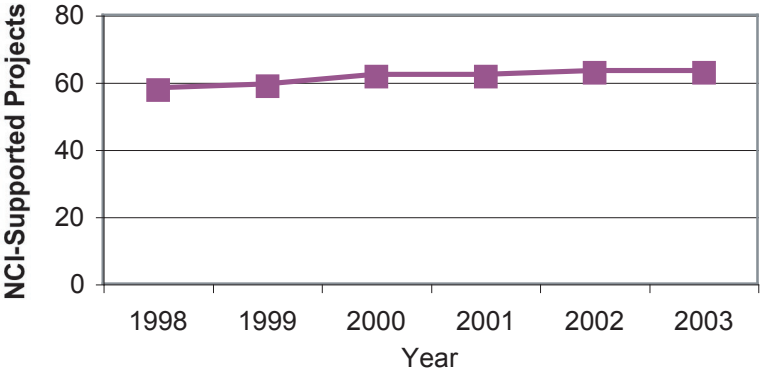


NCI Efforts:

- In FY2003, examples of active areas of investigation included assessing the effectiveness and cost-effectiveness of alendronate on bone mineral density and bone turnover in premenopausal women treated with adjuvant chemotherapy for breast cancer; determining the effects of various treatment strategies on DCIS recurrence rates, survival, costs, and quality of life; and labor market outcomes of long-term breast cancer survivors.
- NCI initiatives addressing this priority included COMWG; Cancer Research Network (CRN); Cancer Surveillance Using Health Claims-Based Data System; and Economic Studies in Cancer Prevention, Screening, and Care.

PRG Priority:

What patient outcomes data are being collected in prevention trials?



NCI Efforts:

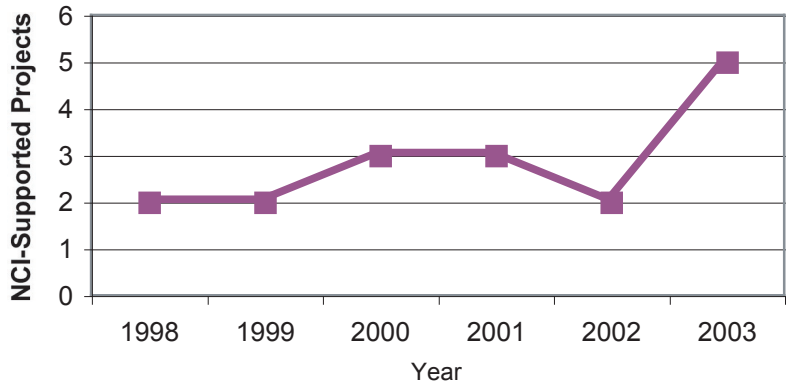
- In FY2003, examples of active areas of investigation included clinical research in cancer treatment and cancer control/prevention through

participation in NCI-supported trials and increasing the availability of protocol-based cancer prevention and control research trials to urban and rural minorities.

- Examples of clinical trials addressing this priority included the following:
  - Phase I Study of Indole-3-Carbinol for the Prevention of Breast Cancer in Nonsmoking Women at High Risk for Breast Cancer (KUMC-8508-01)
  - Phase II Trial of Dietary Fatty Acids: Roles in Hormonally Mediated Cancers in Normal Premenopausal Women (UMN-9509M10234)
  - Pilot Chemoprevention Study of Tamoxifen and Fenretinide in Subjects at High Risk for Developing Invasive Breast Cancer (NCI-94-C-0056L)
- NCI initiatives addressing this priority included the Clinical Trials Cooperative Groups Program and the CCOP.

PRG Priority:

How can patient-focused outcomes for women with advanced metastatic breast cancer be improved?



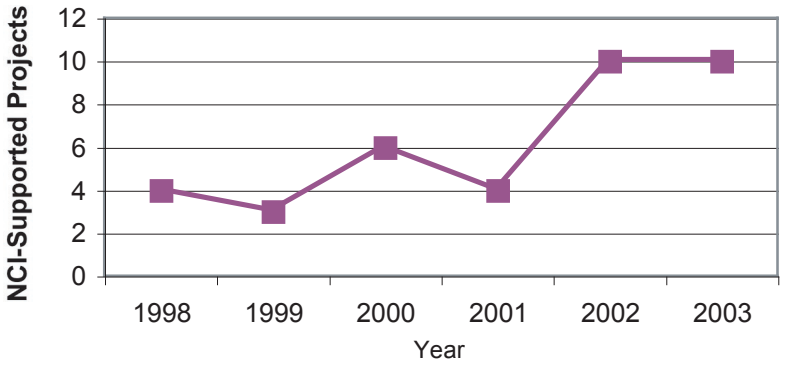
NCI Efforts:

- In FY2003, examples of active areas of investigation included improving pain management in women with breast cancer, assessing symptom occurrence and severity in low-income and racially disparate groups of patients with metastatic breast cancer, and improving palliative care for patients with breast cancer.
- Examples of clinical trials addressing this priority included the following:
  - Phase I Study of Recombinant Vaccinia DF3/MUC1 Vaccine in Patients With Metastatic Breast Cancer (DFCI-97050)
  - Phase II Pilot Study of High Dose Doxorubicin, Cyclophosphamide, Paclitaxel, and Amifostine Followed by Peripheral Stem Cell Rescue in Patients With High-Risk Stage II/III and Responsive Stage IV Advanced Breast Cancer (CHNMC-IRB-99002)
  - Phase II Study of High-Dose Chemotherapy With Autologous Peripheral Blood Progenitor Cell Rescue for Women With Metastatic Breast Cancer, Plus Evaluation of Outpatient Imipenem for Neutropenic Fever (MSKCC-94077)
  - Phase III Randomized Comparison of High Dose Chemotherapy Plus Filgrastim to Filgrastim for Mobilization of Peripheral Blood Stem Cells for Autologous Transplantation for Patients With Responsive Metastatic Breast Cancer or High-Risk Stage II and III Patients (MDA-DM-95047).
- NCI initiatives addressing this priority included the Breast SPOREs

Additional Breast Cancer Outcomes Projects

NCI Efforts:

- Active research projects in FY2003 related to reducing breast cancer health disparities included psychological adjustment among rural breast cancer survivors, quality of life in African-American and Hispanic survivors of breast cancer, and determinants of the quality of care of older breast cancer survivors.



- In FY2003, examples of other active areas of investigation included the relationship between postmenopausal hormone therapy and breast cancer mortality, the risk of developing endometrial cancer and breast cancer as a result of exposure to tamoxifen, enhancing the well-being of individuals recently diagnosed with breast cancer through increased verbal processing of traumatic events, and a computer-based imaging system to reduce anxiety and distress relating to alopecia in women being treated for breast cancer.

The initiatives relevant to research on breast cancer control, survivorship, and outcomes between FY1998 and 2003 include the following list of general initiatives that are described in Table 2-1[5] (Chapter 2) and the category-specific initiatives that are listed and described in Table 8-3.[6]

- Aging Women and Breast Cancer
- Basic and Preclinical Research on Complementary and Alternative Medicine
- Breast and Ovarian Cancer Family Registries (CFRs)
- Breast Cancer Surveillance Consortium (BCSC)
- Cancer Biomedical Informatics Grid (caBIG)
- Cancer Centers Program
- Cancer Genetics Services Directory
- Cancer Research Network
- Cancer Research Training, Career Development, and Education Opportunities
- Clinical Trials Cooperative Group Program
- Community Clinical Oncology Program (CCOP)
- Developmental/Pilot Projects in Cancer Complementary and Alternative Medicine (CAM)
- Exploratory Grants for Correlative Laboratory Studies and Clinical Trials
- Insight Awards to Stamp Out Breast Cancer
- Integrating Aging and Cancer Research
- International Breast Cancer Screening Network

5 Initiatives that impact multiple categories of breast cancer research.

6 Initiatives that are unique to the cancer control, survivorship, and outcomes research category.

- Minority-Based Community Clinical Oncology Program (MBCCOP)
- Minority Institution/Cancer Center Partnership (MI/CCP)
- NCI Center for Bioinformatics (NCICB)
- Small Grants Program for Cancer Epidemiology
- Southern Community Cohort Study (SCCS)
- Special Population Networks
- Specialized Programs of Research Excellence (SPOREs) in Breast Cancer

Table 8-3. NCI Initiatives Relevant to Breast Cancer Research: Cancer Control, Survivorship, and Outcomes[a]

Initiatives With Breast Cancer-Relevant Components

- Basic Biobehavioral Research on Cancer-Related Behaviors (RFA-CA-99-014)
  - Overview: Supports research on the links among biology, behavior, and the environment as they pertain to cancer-related risk behaviors.
  - Relevant Research Projects Resulting From This RFA: Between 1998 and 2003, one project relevant to breast cancer research was supported through this RFA. This project can be found in Appendix B, Table B55, by searching for the RFA number.
- Cancer Control PLANET (http://cancercontrolplanet.cancer.gov/)
  - Overview: A collaborative effort aimed at providing access to data and resources that can help cancer control planners, health educators, program staff, and researchers design, implement, and evaluate evidence-based cancer control programs. It is now being expanded to include tools for primary care clinicians that facilitate the implementation of proven cancer control techniques in practice. Cancer Control PLANET is jointly supported by NCI, the Centers for Disease Control and Prevention (CDC), the American Cancer Society (ACS), the Substance Abuse and Mental Health Services Administration, and the Agency for Healthcare Research and Quality.
  - Relevant Resource Resulting From This Initiative: The Web portal provides access to resources that can assist in:

    Assessing the cancer and/or risk factor burden within a given state

    Identifying potential partner organizations that may already be working with high-risk populations

    Understanding the current research findings and recommendations

    Accessing and downloading evidence-based programs and products

    Finding guidelines for planning and evaluation
- Cancer Intervention and Surveillance Modeling Network (CISNET) (http://cisnet.cancer.gov/about)
  - Overview: A consortium of NCI-sponsored researchers whose focus is to use modeling techniques to describe the impact of prevention, screening, and/or treatment interventions in population-based settings.

a Lists of the projects derived from each initiative can be located on the online Supplement to the Breast Cancer Progress Report: Initiative Database.

- Relevant Projects Resulting From This Initiative: There are currently seven funded projects within the consortium that focus on breast cancer:

  Breast Cancer Trend Analysis Using Stochastic Simulation

  Breast Cancer: Role of Early Detection, Treatment, and Prevention

  Cancer Intervention and Surveillance Modeling Network (CISNET)

  Mechanistic Modeling of Breast Cancer Surveillance

  Outcomes Across the Spectrum of Breast Cancer Care

  Simulating Breast Cancer in Wisconsin

  Surveillance of Breast Cancer Trends by MISCAN

  Specific projects can be found in Appendix B, Tables B7, B9, B31, B41, B43, B51, B52, and B58, by searching for the RFA number (CA99-013).

- Cancer Outcomes Measurement Working Group (COMWG) (http://outcomes.cancer.gov/methods/measures/comwg)
  - Overview: Members of COMWG evaluate existing endpoint measures, including health-related quality of life, economic burden, and patient satisfaction. They also work to formulate alternative strategies for identifying valid, reliable, sensitive, and feasible clinical and patient-centered endpoint measures for use in quality of cancer care studies. Thirty-five members of the working group were selected to provide expertise in outcomes measurement for four cancer sites, including breast cancer.
  - Relevant Resource Resulting From This Initiative: Findings of the Working Group have been reported to the NCI and will be published as the book *Outcomes Assessment in Cancer*.
- Cancer Surveillance Using Health Claims-Based Data System (http://dccps.nci.nih.gov/ARP/research/health.asp)
  - Overview: Support for research to investigate the utility of health claims information as a reporting source for assessing the national cancer burden.
  - Relevant Projects Resulting From This Initiative: Between 1998 and 2003, five projects relevant to breast cancer research were supported through this initiative. Specific projects can be found in Appendix B, Tables B49, B52, and B53, by searching for the PA number (PA-99-015).
- Cancer Survivorship Studies in Established Epidemiologic Cohorts (PA-98-027)
  - Overview: Fosters research on issues related to long-term cancer survivorship through the use of existing epidemiologic study populations, particularly in the areas of specific health or lifestyle outcomes and their modulation by common risk factors and other exposures.
  - Relevant Research Projects Resulting From This PA: Between 1998 and 2003, three projects relevant to breast cancer research were supported through this PA. Specific projects can be found in Appendix B, Tables B2, B29, and B30, by searching for the PA number.
- Centers for Complementary and Alternative Medicine Research (RFA-AT-00-001)
  - Overview: Research conducted at these centers will examine the potential efficacy, safety, and validity of complementary and alternative medicine practices, as well as the physiological or psychological mechanisms underlying or contributing to the effects of these practices.

- Relevant Resources Resulting From This Initiative: The National Center for Complementary and Alternative Medicine (NCCAM) Web site provides information on complementary and alternative medicine practices, advisories, treatment options, clinical trials, and funding information. Seven NCCAM clinical trials are applicable to breast cancer:

  Acupuncture for Shortness of Breath in Cancer Patients

  Distance Healing in Wound Healing after Breast Reconstruction Surgery

  Macrobiotic Diet and Flax Seed: Effects on Estrogens, Phytoestrogens, & Fibrinolytic Factors

  Massage Therapy for Breast Cancer Treatment-Related Swelling of the Arms and Legs

  Massage Therapy for Cancer-Related Fatigue

  Mistletoe Extract and Gemcitabine for the Treatment of Solid Tumor Cancers

  Pycnogenol for the Treatment of Lymphedema of the Arm in Breast Cancer Survivors

- Centers of Excellence in Cancer Communication Research (http://dccps.nci.nih.gov/eocc/ceccrs_index.html)
  - Overview: Supports research and outreach aimed at increasing knowledge of, access to, and use of cancer communication tools by the public, patients, survivors, and health professionals. These Centers provide essential infrastructure to facilitate rapid advances in knowledge about cancer communications, translate theory and programs into practice, and train health communication scientists.
  - Projects Resulting From This Initiative: Four academic institutions were established as Centers of Excellence in Cancer Communication Research in 2003. The following Centers are actively pursuing breast cancer-relevant projects:

    Saint Louis University: Capture on videotape the stories of 80 African-American breast cancer survivors, examine the effectiveness of these stories in promoting mammography in 900 African-American women, and test a new explanatory model of narrative cancer communication effects

    University of Michigan: A multiphased experimental process to explore methods of communicating risk regarding tamoxifen prophylaxis to women at high risk for breast cancer

    University of Wisconsin, Madison: Controlled trial will examine whether breast cancer patient outcomes change as different types of conceptually distinct CHESS (Comprehensive Health Enhancement Support System) services (information, social support, and skills training) are systematically added to a patient's treatment resources

- Digital Divide Pilot Projects (http://cancercontrol.cancer.gov/eocc/ddpp_awards.html)
  - Overview: Supports research and programs to understand and eventually breach the Digital Divide that exists among many minority populations in accessing and utilizing cancer information on the Internet.
  - Relevant Projects Resulting From This Initiative: In collaboration with NCI's North Central and Mid-West Regions Cancer Information Service (CIS), the University of Wisconsin and the Karmanos Cancer Center will expand the CHESS Program that puts personal computers and Web-based support resources into the homes of African-American breast cancer patients.
- Economic Studies in Cancer Prevention, Screening and Care (http://cancercontrol.cancer.gov/ARP/research/economic.asp)
  - Overview: Supports research directed toward increasing knowledge of the economic aspects of cancer prevention, screening, and care.

- Relevant Projects Resulting From This Initiative:

  Long-Term Cost and Outcomes of Breast Cancer Screening

  Tamoxifen & Breast Cancer—Acceptance/Cost Effectiveness

  Use of Cancer Screening in a Managed Care Environment

- Exploratory Grants for Behavioral Research in Cancer Control (PA-99-163)
  - Overview: Supports the development of novel or conceptually creative ideas that may produce innovative advances in the behavioral sciences, specifically in the areas of cancer prevention and control.
  - Relevant Research Projects Resulting From This PA: Between 1998 and 2003, 12 projects relevant to breast cancer research were supported through this PA. Specific projects can be found in Appendix B, Tables B45, B51, and B53-55, by searching for the PA number.
- Health Communications in Cancer Control (RFA-CA-98-014)
  - Overview: Supports research on the use of interactive digital media in cancer prevention and control and promotes the refinement of communications systems to improve dissemination of cancer control-related information.
  - Relevant Research Projects Resulting From This RFA: Between 1998 and 2003, three projects relevant to breast cancer research were supported through this RFA. Specific projects can be found in Appendix B, Table B51, by searching for the RFA number.
- Long-Term Cancer Survivors: Research Initiatives (RFA-CA-04-003)
  - Overview: Promotes and supports research that will lead to the decrease in physiologic and psychosocial morbidity and mortality associated with long-term (over 5 years) survival from cancer.
  - Relevant Research Projects Resulting From This RFA: Between 1998 and 2003, three projects relevant to breast cancer research were supported through this RFA. Specific projects can be found in Appendix B, Tables B40, B49, and B51, by searching for the RFA number and the previously issued number (RFA-CA-97-018).
- Minority and Underserved Cancer Survivors (http://cancercontrol.cancer.gov/ocs/underserved)
  - Overview: Supports supplements to NCI-designated Cancer Centers for research on cancer survivorship among minority and underserved cancer populations in community settings.
  - Relevant Projects Resulting From This Initiative:

    Breast Cancer Survivors & Community Support

    Follow-Up Care in Breast Cancer Survivors

    Reproductive Health in African-American Breast Cancer Survivors
- Research on the Impact of Cancer on the Family (http://dccps.nci.nih.gov/bb/research_family.html)
  - Overview: Supports supplemental awards to NCI-funded Clinical and Comprehensive Cancer Centers to expand the study of the impact of cancer on the family.
  - Relevant Projects Resulting From This Initiative: Studies at ten institutions were funded that spanned the life cycle, focusing on both child and adult caregivers, and addressed multiple cancer sites, including breast, colon, prostate, brain, head and neck, and pediatric cancers.

- Research Supplements for Underrepresented Minorities (http://cancercontrol.cancer.gov/ocs/underrepresented/)
  - Overview: Supplements research support to: (1) reach out to minority graduate and undergraduate students studying biomedical or behavioral sciences; and (2) provide an opportunity to develop research capabilities.
  - Relevant Projects Resulting From This Initiative: Five projects are supported through this program, most of which are generally applicable to behavioral, survivorship, and communication research. The following project is directly related to breast cancer research:

    Young Breast Cancer Survivors: A Population-Based Cohort
- SEER-Medicare Linked Database (http://healthservices.cancer.gov/seermedicare)
  - Overview: Supports a large database that incorporates two large population-based sources of data that provide detailed information about elderly persons with cancer. The data come from the Surveillance, Epidemiology, and End Results (SEER) program of cancer registries that collect clinical, demographic, and cause-of-death information for persons with cancer and the Medicare claims for covered health care services from the time of a person's Medicare eligibility until death.
  - Relevant Resource Resulting From This Initiative: The SEER-Medicare Linked Database Web site includes a section on analytic support to assist researchers who use the database.
- SEER Patterns of Care/Quality of Care (POC/QOC) Initiative (http://cancercontrol.cancer.gov/bb/seer_pattern.html)
  - Overview: Evaluates the dissemination of state-of-the-art therapy into community practice, disseminates findings in scientific journals and professional meetings, and works with professional organizations to develop relevant educational or training opportunities.
  - The SEER registries perform POC/QOC studies every 3 to 5 years for the major cancer sites (including breast). Cancer sites with emerging new treatments or concerns regarding provision of state-of-the-art therapy would be conducted in alternate years.
- Small Grants Program for Behavioral Research in Cancer Control (http://dccps.nci.nih.gov/smallgrants/index.html)
  - Overview: Designed to encourage investigators from a variety of academic, scientific, and public health disciplines to apply their skills to behavioral research investigations in cancer prevention and control.
  - Relevant Research Projects Resulting From This Initiative: Between 1998 and 2003, 30 projects relevant to breast cancer research were supported through this initiative. Specific projects can be found in Appendix B, Tables B9, B10, B12, B33, B41, B43, B47, and B51, by searching for the PA numbers (PAR-02-037 and PAR-99-006).
- Social and Cultural Dimensions of Health (PA-02-043)
  - Overview: Encourages further development of health-related social sciences.
  - Relevant Projects Resulting From This PA: Pending—this PA will remain open until December 21, 2004.
- Surveillance, Epidemiology and End Results (SEER) (http://seer.cancer.gov)
  - Overview: Database of information on cancer incidence and mortality. SEER currently collects and publishes data from 11 population-based cancer registries and 3 supplemental registries. Approximately 26% of the U.S. population is represented, including a substantial portion of racial/ethnic minorities and other medically underserved individuals.
  - Relevant Resource Resulting From This Initiative: SEER recently published the *Annual Report to the Nation on the Status of Cancer, 1975-2000*, which updates statistics on four main cancer types, including breast.

- Translating Research into Improved Outcomes (TRIO) (http://cancercontrol.cancer.gov/bb/trio.html)
  - Overview: Supports efforts to move research discoveries through program development into evidence-based service delivery. Three overarching goals include: (1) closing the discovery-delivery gap by disseminating cancer and behavioral surveillance data to identify needs, track progress, and motivate national, state, and local action; (2) collaborating with public health, clinical practice, and voluntary organizations to reduce the overall cancer burden and eliminate cancer health disparities; and (3) working with national, regional, state, and local partner organizations to identify and overcome the infrastructure barriers to the adoption of evidence-based cancer control programs and practices.
  - Relevant Resource Resulting From This Initiative: TRIO supports communication efforts in breast cancer screening through the breast cancer screening section of the Cancer Control PLANET Web portal and the NCI/USDA/ACS/CDC collaboration in eight states promoting breast and cervical cancer screening among women never or rarely screened who live in high-mortality counties.

Ongoing NCI Research: Recent Progress in Breast Cancer Control, Survivorship, and Outcomes

The Importance of Mammography

Early detection of breast cancer through periodic examinations and mammography is considered the most effective method of breast cancer control. Although breast cancer screening methods have advanced substantially in the last few years, these are only of benefit to women who are actually screened. Recent research has shown that women are more likely to obtain a mammogram if they receive tailored communications. Specifically, women who receive targeted educational materials or telephone counseling are up to 20% more likely than women receiving standard care to obtain a mammogram within the recommended period (Champion et al., 2003; Clark and Wold, 2002; McCaul and Wold, et al., 2002). Although telephone and mailed reminders have both been tested, the most effective methods to encourage screening are combined interventions in which women receive written communications as well as motivational telephone interviews or in-person counseling with a letter from a physician (Champion et al., 2003; Valanis et al., 2003; Legler et al., 2002).

Advances in education have helped increase the use of mammography; in 1998, almost 70% of U.S. women age 40 or older reported receiving a mammogram within the last 2 years, compared with less than 30% of women in 1987 (Legler et al., 2002; Swan et al., 2003). As a result, mammography was the only type of cancer screening test for which the *Healthy People 2000*[7] goal was reached. Unfortunately, not all populations have experienced these dramatic improvements, as older individuals, those with less education, and those with lower incomes are still less likely to be screened than other women (Hiatt et al., 2002; Meissner et al., 2003). In addition, while differences in mammography rates have narrowed between Caucasian and African-American women in recent years, rates for Hispanic women remain lower than those of either group (Legler et al., 2002). This issue remains important for our nation because, among women with late-stage cancer, over 50% have not undergone screening (Taplin et al., 2004 in press). To approach the mortality reduction goals for the year 2010, we must screen women of all backgrounds and reach those who have not been screened.

Factors Affecting the Accuracy of Mammography

Although screening mammography is the best technique available for reducing mortality from breast cancer, mammography does not detect every breast cancer. Much has been learned in recent years about some of the factors that affect the ability of mammography to accurately detect cancer. We now know, for example, that in a population offered screening, 40% of late-stage cancers occur among women who have had negative screening tests within the previous 3 years (Taplin et al., 2004).

7 Healthy People 2000 is available at http://odphp.osophs.dhhs.gov/pubs/hp2000.

One key factor is breast density, which makes the interpretation of mammograms challenging because dense breast tissue can resemble cancerous tissue on mammographic film (Carney et al., 2003; Mandelson et al., 2000; Rosenberg et al., 1998). Breast density appears to be associated with several factors, including age, race, and hormone usage. Breast density decreases with age, so it is perhaps not surprising that the accuracy of mammography increases with age (Barlow et al., 2002; Carney et al., 2003; Rosenberg et al., 1998; Ziv et al., 2003). Asian and black women are more likely than white women to have dense breasts, although black and white women over 65 have similar breast density (El-Bastawissi et al., 2001). However, researchers found that screening mammography is as accurate in black women as in white women after controlling for age, breast density, and time since the previous mammogram (Gill and Yankaskas, 2004). Women who use hormone replacement therapy (HRT) are two to three times as likely as women who do not use HRT to have dense breasts, but these differences decrease when HRT use is stopped (Rosenberg et al., 1998; Rutter et al., 2001). The impact of HRT on mammography accuracy appears to be completely attributable to the fact that HRT use increases breast density (Carney et al., 2003).

Another factor that influences the quality of the screening process is breast positioning during the mammogram procedure. Specifically, mammograms are up to 20% more likely to detect cancers when the breast is positioned properly on the machine, and women with cancers found after a negative mammogram result are more than twice as likely to have been positioned improperly at the time of the screening examination (Taplin et al., 2002).

Quality of Care

Although a vast literature addresses the use of screening mammography for breast cancer, less attention has been devoted to follow-up of abnormal test results. Recent research has begun to address this gap, showing that over 25% of patients with an abnormal screening mammography result do not receive the recommended follow-up care. Thus, barriers to appropriate follow-up exist at the provider, patient, and health care system levels (Yabroff et al., 2003). Rates of inappropriate follow-up are even higher in some populations, as almost one-third of black women with an abnormal mammogram or clinical breast exam do not receive appropriate follow-up 6 months after being screened (Kerner et al., 2003).

Treatment provided to women with early-stage breast cancer appears to be consistent with the results of national consensus conferences and clinical trials addressing this topic (Guadagnoli et al., 1998; Harlan et al., 2002); however, some disparities remain in the care of women with breast cancer. For example, women of low socioeconomic status are more likely than others to be diagnosed with late-stage cancer, to experience a recurrence, and to die from breast cancer (Bradley, Given, et al., 2002; Gordon, 2003). In addition, elderly women enrolled in an HMO are less likely to have breast cancer diagnosed at a late stage and more likely to receive breast-conserving therapy than women enrolled in a fee-for-service setting (Riley et al., 1999). However, other disparities have decreased. Specifically, investigators have shown that African-American women tend to be diagnosed with breast cancer at the same stage, receive the same treatment, and have the same survival rates as white women after controlling for several patient characteristics, such as age, disease stage, socioeconomic status, and insurance coverage (Bradley, Given, et al., 2002; Gordon, 2003). Furthermore, disabled women have the same risk of dying from breast cancer as women who are not disabled (Roetzheim and Chirikos, 2002).

Survivors' Issues

Women with a history of breast cancer account for over 40% of all female cancer survivors. As the number of breast cancer survivors increases, it is becoming increasingly apparent that these women are much more resilient than previously assumed.

Breast cancer survivors report a broad range of physical symptoms after completing treatment (Michael et al., 2000). Some groups of women are at greater risk for adverse effects following breast cancer diagnosis and treatment; women who have had adjuvant chemotherapy and those who are younger appear to be more likely than other women to experience problems with general health, physical functioning, and social functioning (Ganz et al., 2002).

Behavioral research has demonstrated that social support mediates individuals' general well-being, and this may be particularly true after a cancer diagnosis. An analysis of data from the Nurses' Health Study found that level of social integration is an important predictor of subsequent health-related outcomes for breast cancer survivors—even more than treatment or tumor characteristics. On average, socially isolated women were more adversely affected by breast cancer than socially integrated

women in terms of their role function, vitality (feeling energetic and alert), and physical function. Rehabilitation programs should emphasize interventions that address the availability of adequate social support (Michael et al., 2002).

It now appears that the threat to life imposed by cancer can be life altering, especially with respect to health behaviors. In one study examining this effect, researchers found that after their cancer diagnosis, almost half of smokers quit smoking, and a similar proportion of study participants improved their dietary habits; however, one-third exercised less (Blanchard et al., 2003). Several researchers are studying the risk for physical inactivity following cancer and its corresponding adverse impact on weight and health; these researchers are using exercise interventions to improve survivors' emotional and functional well-being. The results for breast cancer survivors are compelling: exercise training programs have beneficial effects on cardiopulmonary function and quality of life (Courneya, Mackey, et al., 2003; Pinto et al., 2003), reduce fatigue, and help maintain functional ability (Kolden et al., 2002), and, when combined with group psychotherapy, may improve women's quality of life beyond the benefits of group therapy alone, especially with respect to physical and functional outcomes (Courneya, Friedenreich, et al., 2003). While it is not clear if these types of interventions will alter the course of cancer (i.e., rate of or time to recurrence or death), such programs hold promise for reducing cancer-related morbidity and promoting general health. They also appear to have enormous appeal to survivors eager to reduce the perceived stress in their lives and take control of their bodies after cancer.

As the number of long-term survivors increases, the indirect morbidity and disability costs of breast cancer may also be rising. Research indicates that breast cancer has an economic impact on long-term survivors. In one study, survivors who were working when they were originally diagnosed experienced much larger reductions in their annual earnings over 5 years than working control subjects (Chirikos et al., 2002). Breast cancer survivors are also 10% less likely to be working than women without breast cancer. However, women who survive breast cancer and continue to work report working approximately 3 more hours a week than women who do not have cancer. This suggests that the morbidity associated with certain types and stages of breast cancer and its treatment does not interfere with a woman's ability to work (Bradley, Bednarek, et al., 2002).

Continuing Needs and Evolution

In spite of recent progress, most women in the United States still do not obtain recommended annual mammograms. Advances are clearly needed in communications strategies to educate more women about the importance of mammography. More research is also needed on barriers to screening and ways to reduce them to ensure that all women are screened at recommended intervals. Furthermore, mechanisms need to be identified to reduce health disparities by increasing the rate at which underserved populations receive mammography screening. Disparities in treatment, including likelihood of receiving breast-conserving surgery and outcomes of various breast cancer treatments, also require further exploration. In addition, we need new screening techniques that are more sensitive and specific than mammography and that offer improved data storage, transmission of results, cost, and ease of use. Because the accuracy of individual radiologists in interpreting mammograms varies (depending on such factors as training, experience, and type of screening program), more research is needed on sources of variation and ways to increase radiologists' accuracy.

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