Division of Cancer Control
and Population Sciences

OVERVIEW & HIGHLIGHTS

National Cancer Institute
March 2004

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FOREWORD

As NCI's bridge to public health research, practice, and policy, the Division of Cancer Control and Population Sciences (DCCPS) plays a unique role in reducing the burden of cancer in America. DCCPS, an extramural division, has the lead responsibility at NCI for supporting research in surveillance, epidemiology, health services, behavioral science, and cancer survivorship. The division also plays a central role within the federal government as a source of expertise and evidence on issues such as the quality of cancer care, the economic burden of cancer, geographic information systems, tobacco control, and the translation of research into practice. As a result, DCCPS is what many have referred to as a "hybrid" division—one that funds a large portfolio of grants and contracts, but also conducts original research to inform public health policy.

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The diverse science funded and conducted by DCCPS is characterized by the varied and complex expertise and backgrounds of the division's scientific staff. Given the focus on cancer control, it comes as no surprise that the disciplines of epidemiology and biostatistics are well-represented. In addition, DCCPS has made a special effort to recruit experts in disciplines such as communication, anthropology, outcomes research, psychometrics, medical genetics, health psychology, economics, social work, policy analysis, and family medicine—all disciplines that have been historically underrepresented at NCI. This reflects an overarching philosophy of science that guides the division's planning and priority setting: the belief that scientific progress in the 21st century will depend on the transdisciplinary integration of research methods, models, and levels of analysis.

As you read this report about the activities and accomplishments of DCCPS, it is our hope that three themes will emerge. First, almost all of the division's efforts are accomplished through substantive collaborations with other NIH institutes, DHHS agencies, and nongovernmental organizations. Second, careful planning and priority setting ensure that our efforts complement and capitalize on the efforts of other research funding organizations. Third, our research portfolio reflects the clear pathways between discovery, development, and delivery so that etiology and surveillance research informs cancer control interventions that—when effectively tested, synthesized, and disseminated—reduce the suffering and death due to cancer.

Although this report is intended to provide our colleagues within DHHS with a timely overview of the major activities of the division, we hope that others might also find it a useful resource for identifying potential areas of interest and collaboration.

Robert T. Croyle, PhD

Director, Division of Cancer Control and Population Sciences

Robert Croyle, PhD, was appointed director of DCCPS in July 2003. He previously served as the division's associate director for the Behavioral Research Program, leading its development and expansion. Before coming to NCI in 1998, he was professor of psychology and a member of the Huntsman Cancer Institute at the University of Utah in Salt Lake City. Prior to that, he was a visiting investigator at the Fred Hutchinson Cancer Research Center in Seattle, visiting assistant professor of psychology at the University of Washington, and assistant professor of psychology at Williams College in Massachusetts.

Dr. Croyle received his PhD in social psychology from Princeton University in 1985, and graduated Phi Beta Kappa with a BA in psychology from the University of Washington in 1978. His recent research has examined how individuals process, evaluate, and respond to cancer risk information, including tests for inherited mutations in BRCA1 and BRCA2. His research has been published widely in professional journals in behavioral science, public health, and cancer, and he has edited two volumes: Mental Representation in Health and Illness (1991) and Psychosocial Effects of Screening for Disease Prevention and Detection (1995).

Dr. Croyle is a member of the Academy of Behavioral Medicine Research, a Fellow of the Society of Behavioral Medicine, and a recipient of several awards for his research and professional service. His efforts on journal editorial boards include being associate editor for *Cancer Epidemiology, Biomarkers and Prevention*, and consulting editor for *Health Psychology* and the *British Journal of Health Psychology*. Dr. Croyle received the NIH Merit Award in 1999 and 2002, and the NIH Director's Award in 2000.

Division Points of Contact

L-R Back:
Everett Carpenter, Information Technology
Stacey Vandor, Planning
Mark Alexander, Grants

L-R Front:
Ellen Moul, Administrative Resource Center
Arline Sanchez, Executive Assistant
Kelly Blake, Communications

WHO WE ARE

PEOPLE AT A GLANCE

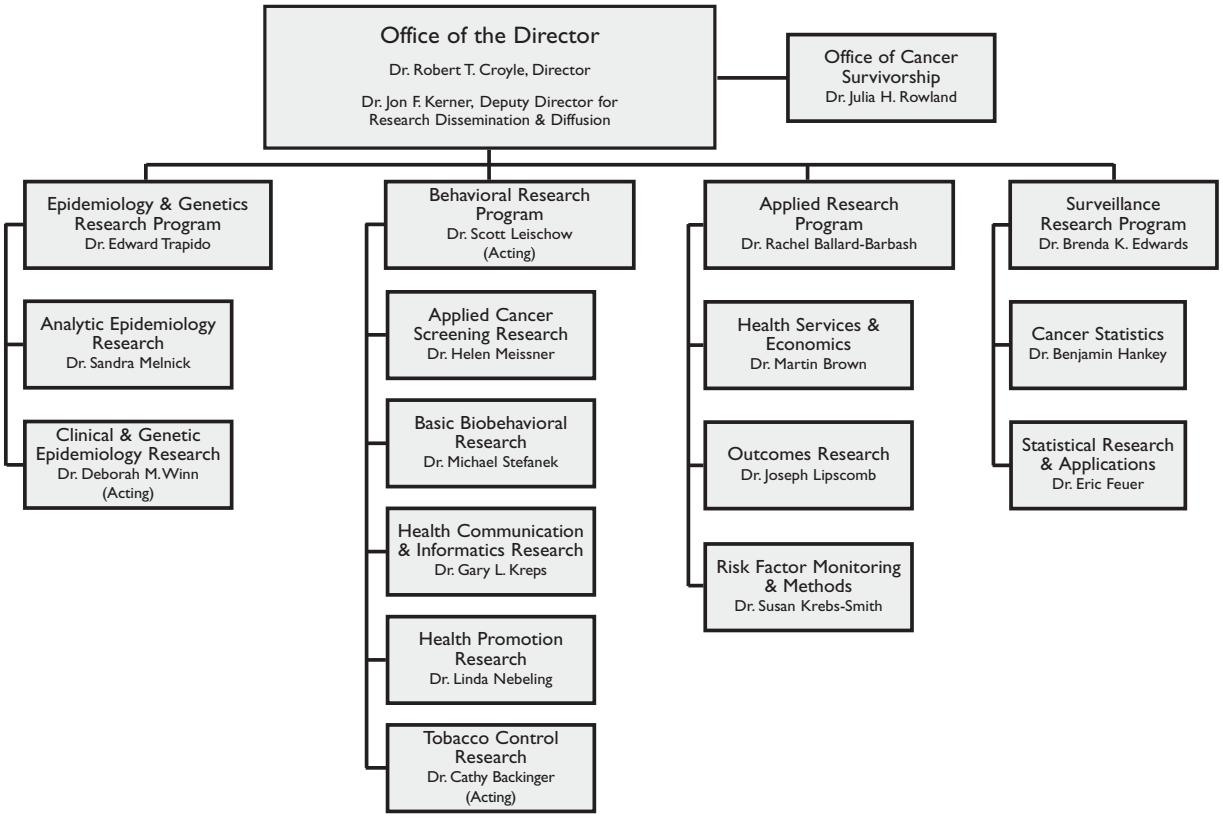
People have described the DCCPS senior leadership team as dedicated and innovative. What follows are photographs of the committed people that lead the division's programs and offices. They include:

- Dr. Rachel Ballard-Barbash, Associate Director for Applied Research
- Dr. Brenda Edwards, Associate Director for Surveillance Research
- Dr. Jon Kerner, Deputy Director for Research Dissemination and Diffusion
- Dr. Scott Leischow, Associate Director for Behavioral Research (Acting)
- Dr. Julia Rowland, Director, Office of Cancer Survivorship
- Dr. Edward Trapido, Associate Director for Epidemiology and Genetics Research

Read more about our people and priorities in the *Views from Leadership* section on page 86.

A brief introduction to the division's 12 branch chiefs also is provided here. And of course, although they are not featured in this guide, we have many other outstanding staff members across the division who contribute to the success and forward motion of NCI's cancer control research activities.

Division of Cancer Control and Population Sciences Organization & Leadership



SENIOR LEADERSHIP

Rachel Ballard-Barbash, MD, MPH
Associate Director
Applied Research

Brenda K. Edwards, PhD
Associate Director
Surveillance Research

Jon F. Kerner, PhD
Deputy Director
Research Dissemination & Diffusion

Scott Leischow, PhD
Associate Director (Acting)
Behavioral Research

Julia H. Rowland, PhD
Director
Office of Cancer Survivorship

Edward Trapido, ScD
Associate Director
Epidemiology & Genetics Research

See *Views from Leadership* on page 86.

The organizational units that make up DCCPS represent dedicated scientists, professionals, and support staff who work as a team to bring cancer control research activities to the forefront. Pictured below are the leaders of DCCPS' 12 branches.

BRANCH CHIEFS

Cathy Backinger, PhD (Acting)
Tobacco Control Research Branch,
Behavioral Research Program

Martin L. Brown, PhD
Health Services & Economics Branch,
Applied Research Program

Eric J. "Rocky" Feuer, PhD
Statistical Research &
Applications Branch,
Surveillance Research Program

Benjamin F. Hankey, ScD
Cancer Statistics Branch,
Surveillance Research Program

Susan M. Krebs-Smith, PhD
Risk Factor Monitoring
& Methods Branch,
Applied Research Program

Gary L. Kreps, PhD
Health Communication &
Informatics Research Branch,
Behavioral Research Program

BRANCH CHIEFS

Joseph Lipscomb, PhD
Outcomes Research Branch,
Applied Research Program

Helen I. Meissner, PhD
Applied Cancer Screening
Research Branch,
Behavioral Research Program

Sandra L. Melnick, DrPH, MPH
Analytic Epidemiology Research Branch,
Epidemiology & Genetics
Research Program

Linda Nebeling, PhD, MPH, RD, FADA
Health Promotion Research Branch,
Behavioral Research Program

Michael Stefanek, PhD
Basic Biobehavioral Research Branch,
Behavioral Research Program

Deborah M. Winn, PhD (Acting)
Clinical and Genetic Epidemiology
Research Branch, Epidemiology &
Genetics Research Program

PARTNERSHIPS & COLLABORATIONS

Summary of Key Collaborations in Cancer Control

	NIH Institutes and Offices	Agencies within HHS	Other Federal Depts	National Voluntary Orgs	National Philanthropic Orgs	Policy Orgs
DELIVERY		CDC/CMS/ACS - Smoking Cessation SAMHSA/CDC/AHRQ/ACS - PLANET AHRQ/HRSA - Quality of Cancer Care HRSA/CDC - Follow-up Care and Colorectal Cancer Screening	USDA - 5 A Day Program VA - Colorectal Cancer Practice	ACS - Body and Soul Program ACS/CDC - Cancer Control Leadership Institute	Produce for Better Health Foundation - 5 A Day Program American Legacy Foundation - Menthol Conference, Telephone-based Smoking Quitlines Lance Armstrong Foundation/ Cancer Care/ Intercultural Cancer Council/ Living Beyond Breast Cancer/ National Coalition for Cancer Survivorship - Survivorship Teleconference Series	President's Cancer Panel - Focus on Cancer Survivorship National Quality Forum - Focus on Quality of Care
DEVELOPMENT	FIC - Intn'l Tobacco Capacity Building NICHD - Obesity Prevention NIDA/NIAAA - Tobacco Research OBSSR - Health Disparities, Mind/Body, Energy Balance	FDA - New Tobacco Products CDC - Guide to Community Preventive Services, Prevention Research Center CDC/IHS - Cancer Surveillance AHRQ - Test Dissemination Approaches AHRQ/CMS - Colorectal Cancer Screening	USDA/FDA - Dietary Guidance USDA/CDC/ACS - Breast and Cervical Cancer Screening Program USDA/CDC- Dietary Surveillance	ACS/ACOS/ASCO/ ACR/ONS/NCCS/ NQF/Others - Quality of Cancer Care Core Measures ACS/CDC/ NAACR - Annual Report to Nation on Cancer Trends ACS - Biennial Cancer Survivorship Conference, Intn'l Meeting Smokeless Tobacco	Lance Armstrong Foundation - Survivor Researcher Mentor Program Robert Wood Johnson Foundation - Policy and Communications for Tobacco Centers	RAND Corporation - Cancer Intervention and Surveillance Modeling Network, Cancer Care Outcomes Research and Surveillance Consortium C-Change (formerly National Dialogue on Cancer) - Quality of Cancer Care, State Cancer Plans, Surveillance, Obesity, Primary Prevention
DISCOVERY	NIA/NIEHS/ OBSSR - Centers for Health Disparities NIEHS - Cancer and Environment	CMS - SEER-Medicare Links CDC - Family History Tool, World Trade Center				

PARTNER ORGANIZATION

The collaborations summarized here are described throughout this section.

MAKING CONNECTIONS

Inter- and transdisciplinarity are the cornerstones of many of the division's achievements. Our staff members build relationships with a number of agencies and organizations and together make important strides toward improving the cancer picture in the United States. Look to this section for:

- A summary table of collaborations across the discovery-development-delivery continuum
- Brief descriptions of selected activities the division engages in across NCI; with other NIH institutes and offices; agencies within HHS; other federal departments; national voluntary, philanthropic, and policy organizations; and professional societies.

Key Collaborations

Cancer control discovery, development, and delivery are inherently collaborative activities. The goals of DCCPS cannot be achieved without collaboration and partnerships. The many and varied agency and organizational collaborations in which DCCPS is involved are far too numerous to describe in full here. Following are brief descriptions of selected DCCPS partnerships across the research discovery-development-delivery continuum.

NCI Divisions and Offices

NATIONAL® CANCER INSTITUTE

Office of Communications, Cancer Information Service (CIS)

- DCCPS supports communication activities for low-literacy and cancer patient populations, as well as smoking cessation, diet, and cancer screening interventions for the general public and targeted populations.
- Six CIS regions are testing an improved 5 A Day program intervention from the CIS Research Consortium, funded by the new Dissemination and Diffusion Supplement Grant Program.
- DCCPS collaborates with the CIS to offer a toll-free number for smoking cessation services (1-877-44U-QUIT) and an instant messaging service for smoking cessation (Live Help).

Center to Reduce Cancer Health Disparities (CRCHD)

- Over 130 participants from 36 states with high cervical cancer mortality counties participated in Cervical Cancer Disparities Roundtable and think tank meetings. These were initiated and delivered by DCCPS staff in collaboration with NCI's Division of Cancer Epidemiology and Genetics, Division of Cancer Prevention, Division of Cancer Treatment and Diagnosis, and the CRCHD.
- DCCPS staff members have contributed their expertise to the patient navigator concept and to the community networks RFA.
- DCCPS staff members serve as reviewers of Special Populations Networks pilot projects.

Division of Cancer Epidemiology and Genetics (DCEG)

- DCCPS collaborates with DCEG on several high-priority areas, including the implementation of NCI's Special Studies Institutional Review Board, and leadership of NCI's strategic priorities in the areas of molecular epidemiology and genes and the environment. DCEG also is a partner in projects to facilitate the development of consortia of cohort and case-control studies.

Division of Cancer Prevention (DCP)

- DCCPS and DCP have many partnerships, including co-sponsorship of research initiatives in palliative care and cancer survivorship, as well as shared leadership responsibility for NCI's strategic priorities in the areas of energy balance; and prevention, early detection, and prediction. In addition, DCCPS staff members mentor and train fellows in the Cancer Prevention Fellowship Program.

Division of Cancer Treatment and Diagnosis (DCTD)

- DCCPS is working with DCTD to provide support for restructuring the way randomized treatment clinical trials are proposed, reviewed, and implemented. As part of this effort, DCCPS staff members are evaluating the efficiency and effectiveness of new ways to promote and manage NCI-sponsored treatment trials, including the contribution of a Web site to facilitate dissemination.

NIH Institutes and Offices

National Institute on Drug Abuse (NIDA)
National Institute on Alcohol Abuse and Alcoholism (NIAAA)

- DCCPS, NIDA, NIAAA, and the Robert Wood Johnson Foundation jointly fund the Transdisciplinary Tobacco Use Research Centers (TTURC). These novel centers are designed to bridge disciplinary barriers, establish new conceptual frameworks and methods to understand and treat tobacco use, speed the transfer of innovative approaches to communities nationwide, and create a core of new tobacco control researchers.

National Institute of Environmental Health Sciences (NIEHS)

- DCCPS and NIEHS cosponsor four Breast Cancer and the Environment Research Centers. The centers will study—through both laboratory and epidemiologic research—the prenatal-to-adult environmental exposures that may predispose a woman to breast cancer.

- DCCPS and NIEHS cofund research to develop tools and methods for assessing environmental exposures, and to investigate reasons for regional variations in breast cancer rates in the United States.

Office of Behavioral and Social Sciences Research (OBSSR)

- The NIH Behavioral Change Consortium studies, cofunded by DCCPS, provide a setting for researchers to validate DCCPS-developed short screening questionnaires to assess changes in intake of fats, fruits, and vegetables; and assess smoking dependence.

- DCCPS provides support for several OBSSR initiatives, including research on cognition, emotion, stress, and pathways to health outcomes; linking pathways to education and health; social and cultural determinants of health; and mind-body interactions and health.

National Institute of Child Health and Human Development (NICHD)

- DCCPS is cosponsoring several program announcements with NICHD. Research areas include understanding mechanisms in health risk behavior change, partnerships for improving functional outcomes in individuals with chronic disease, and school-based obesity prevention strategies for children.

- DCCPS participates with a working group that provides guidance to the advisory committee of NICHD's National Children's Study. In addition, DCCPS and DCEG participate on a workshop planning committee to revisit the evaluation of childhood cancers in the National Children's Study.

National Institute on Aging (NIA)

- The Centers for Population Health and Health Disparities are a collaborative effort cofunded by NIA, NIEHS, OBSSR, and DCCPS. Eight centers are conducting transdisciplinary research to examine how the social and physical environment, behavioral factors, and biologic pathways interact to determine health and disease in populations.

Fogarty International Center

- DCCPS cofunds research grants submitted in response to a Fogarty RFA on international tobacco and health research and capacity building.

- DCCPS and the Fogarty International Center contribute to a multiagency collaboration, including five NIH institutes and the World Health Organization's Tobacco Free Initiative, that funds research on tobacco use and related illness in developing countries.

- DCCPS, in partnership with NIEHS and Fogarty, cosponsored and conducted a weeklong science writing workshop for journalists from Latin American countries and Spanish-language news outlets in the United States.

Agencies within HHS

Agency for Healthcare Research and Quality (AHRQ)

- DCCPS and AHRQ are partners on a program announcement to study colorectal cancer screening in primary care practice. Research topics are relevant to assessing the delivery, utilization, and short-term outcomes of colorectal cancer screening in primary care practice. DCCPS and AHRQ also partner on a program announcement to test new dissemination research approaches to translating research into practice within primary care settings.

- DCCPS, AHRQ, and numerous other federal agencies are collaborating on a quality of cancer care initiative. This project coordinates cancer research activities with health care delivery activities to ensure that decisions on medical cancer treatment services and costs covered by the federal government are consistent with the best available scientific evidence on quality outcomes.

- Meta-analyses of nutrition behavioral interventions, decision aids, and dissemination and diffusion interventions are conducted for research synthesis and dissemination through a DCCPS contract with AHRQ's Evidence-based Practice Centers.

Health Resources and Services Administration (HRSA)

- DCCPS established the Quality of Cancer Care Committee in 2000 to improve the quality of federal-level decision making. Its membership includes the federal agencies, such as HRSA, that are involved in cancer care delivery, coverage, regulation, standards setting, and quality of care research.

- DCCPS, HRSA, and CDC—in partnership with the Institute for Healthcare Improvement—work with a number of community health clinics to develop strategies to improve screening, referral, and follow-up care for breast, cervical, and colorectal cancer diagnosis and treatment.

Centers for Disease Control and Prevention (CDC)

- DCCPS is collaborating with the CDC Office of Genomics and Prevention on its Family History in Preventive Medicine and Public Health initiative to support extramural studies to assess the analytic and clinical validity of a family history tool. The tool is intended for use in primary care and public health settings, and includes assessment of colon, breast, ovarian, and possibly other cancers.

- DCCPS is participating with the steering committee for the World Trade Center Responder Consortium, which will investigate the health status of workers and volunteers involved in the response to the attack on the World Trade Center. CDC's National Institute for Occupational Safety and Health (NIOSH) will fund the consortium.

- DCCPS established the Interagency Cancer Epidemiology Research Funders Group (I-CERF) to provide a forum for federal agencies that fund cancer epidemiology to share and exchange information and ideas. DCCPS and CDC are working together to expand participation from other agencies.

- DCCPS and CDC's Division of Cancer Prevention and Control (DCPC) have a memorandum of understanding to coordinate collecting and reporting cancer incidence and mortality data between NCI's Surveillance, Epidemiology, and End Results (SEER) Program and CDC's National Program of Cancer Registries. The memorandum provides a model framework for collaboration, and promotes new efforts to communicate up-to-date, high-quality, and comprehensive cancer data to the many cancer constituencies served by CDC and NCI.

- DCCPS and CDC's DCPC have developed, reviewed, and are working jointly to disseminate the cancer chapter of the Guide to Community Preventive Services.

- Through an interagency agreement, DCCPS cofunds with CDC's DCPC the cancer prevention research network within CDC's Prevention Research Center program.

- DCCPS and the CDC Office on Smoking and Health have a 5-year memorandum of agreement outlining specific future collaborations to facilitate prevention research and applications of research findings to address tobacco-related activities in the behavioral, social, and population sciences.

- Smokefree.gov is a state-of-the-art Web site developed by DCCPS in collaboration with CDC and ACS. It offers science-based tools and support to help smokers quit.

- DCCPS and CDC's DCPC work collaboratively to develop and analyze data from the National Health Interview Survey and the California Health Interview Survey, and DCCPS provides funding for the National Health and Nutrition Examination Survey conducted by CDC's National Center for Health Statistics.

Centers for Medicare and Medicaid Services (CMS)

- The Surveillance, Epidemiology, and End Results (SEER)-Medicare data include individuals' clinical and vital status information, collected by the SEER registries, that is linked to their Medicare claims across the health care system. These data are used by researchers to conduct surveillance and health services research examining the economics of cancer care, use of screening procedures, patterns of care during initial treatment, variation in care among diverse groups, and differences in initial treatment between health maintenance organization and fee-for-service patients. Of people aged 65 and older in the SEER data, 93 percent have been linked to Medicare's master enrollment file. SEER-Medicare data currently include over 1 million cases. NCI and CMS are working to link SEER to the Medicare Health Outcomes Survey to improve the surveillance of health-related quality of life.

- CMS and DCCPS are jointly funding a study of colorectal cancer screening practices in North Carolina and South Carolina. This is a two-year special study, conducted by the North Carolina Quality Improvement Organization, examining the feasibility of quality improvement in colorectal cancer screening rates.

- The CMS Healthy Aging demonstration project on smoking cessation benefits tested three different smoking cessation benefit packages for Medicare recipients. DCCPS provided technical assistance in the protocol design and provided two updated evidence-based smoking cessation guides (one for older Americans and one for Spanish-speaking Americans).

- In the coming year, CMS will fund nine demonstration programs to reduce cancer-related health disparities among racial and ethnic minorities and geographically underserved (e.g., rural White, Pacific Islander) populations. DCCPS is providing technical support to CMS to review the evidence for effective intervention models, collaborating to draft the RFP, planning to disseminate the RFP to cancer control partners, offering to help with the peer review of proposals, and will assist with the evaluation.

- AHRQ, DCCPS staff, and NCI-funded grantees partnered to develop a report on the cost-effectiveness of immunochemical fecal occult blood testing for colorectal cancer screening.

Indian Health Service (IHS)

- Over the last ten years, health care for Northwest American Indians and Alaska Natives (AI/AN) has evolved from a centralized system maintained by the IHS to a diverse and complex delivery environment. The Northwest Tribal Registry Project was developed in January 1999 by the Northwest Tribal Epidemiology Center, a tribally operated program located at the Northwest Portland Area Indian Health Board in Oregon. Through an interagency agreement with IHS, the existing disease registry has begun to do record linkage studies with state vital statistics data. This will significantly improve the accuracy of data on the incidence and prevalence of diseases such as cancer among Northwest AI/AN.

- DCCPS is funding patterns of care studies to profile contemporary cancer care among Native American populations. Data have been combined from several sources, including SEER and IHS, and augmented by abstracting data from medical records in a sample of cancer patients. The first project focused on the linkage of SEER and IHS data files to evaluate the completeness and quality of data elements.

- The Alaska Native Tumor Registry was initiated by NCI in 1974 in collaboration with CDC. Two recent reports—*Cancer in Alaska Natives 1969-1998, 30 Year Report* and *Alaska Native Cancer Update, 1987-1999*—have been distributed statewide to medical providers, tribal health board members, and key tribal personnel.

Substance Abuse and Mental Health Services Administration (SAMHSA)

- As part of a public/private effort, DCCPS collaborates with SAMHSA, CDC, AHRQ, and ACS on a new Web-based tool for comprehensive cancer control planning, implementation, and evaluation. The Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools) Web portal serves as a doorway to new evidence-based tools that can aid communities in better understanding and addressing their cancer burden.

Food and Drug Administration (FDA)

- DCCPS staff worked with colleagues from FDA to develop a dietary guidance statement to be used on food labels. The goal of the statement, "Diets rich in fruits and vegetables may reduce the risk of cancer and other types of chronic diseases," is to encourage good nutrition among consumers.

- DCCPS, NIDA, NIAAA, and FDA are working together to initiate a meeting to identify priority methods to be used, and biomarkers

to be collected, when conducting studies on products marketed to reduce harm from smoking. This seminal meeting—anticipated to be one of many to come—is in response to congressional requests for partnerships to provide guidance on this complicated issue. This important collaboration between NIH and FDA can help to elucidate key science issues that have regulatory significance.

Other Federal Departments

Department of Veterans Affairs (VA)

- A collaborative initiative with VA will improve the use of evidence about best practices for ongoing improvements in colorectal cancer screening, surveillance, treatment, and end-of-life care in the VA health care system.

U.S. Department of Agriculture (USDA)

- DCCPS dietary surveillance efforts include collaborative analyses of nationally representative data collected by USDA and the CDC's National Center for Health Statistics. Food and nutrient intakes are monitored in the general population and among selected populations defined by gender, age, race, and ethnicity.

- A collaboration between the DHHS and USDA, led by DCCPS, will build 5 A Day for Better Health Program partnerships to further the 5 A Day message in American schools, and target underserved populations with segmented communication campaigns.

- A DCCPS collaboration with the USDA, CIS, CDC, and ACS has led to a pilot program that links CDC's Breast and Cervical Cancer Early Detection Program staff with USDA's Cooperative Extension agents, CIS partnership staff, and ACS division staff, to target counties with high breast cancer and cervical cancer mortality in eight states. The goal is to deliver evidence-based screening promotion programs to reduce health disparities.

- DCCPS staff serve as consultants to USDA in efforts to revise the Food Guide Pyramid.

National Voluntary Organizations

American Cancer Society (ACS)

- ACS, along with NCI and CDC, developed in every ACS division, a leadership training program called the Comprehensive Cancer Control Leadership Institute for the States. DCCPS also supported the use of a qualitative research methodology (concept mapping) to help participants. A new round of advanced leadership institutes will begin in 2004. This partnership has become a model for national cancer control collaborative efforts.

- DCCPS and ACS jointly support scientific conferences, such as the Biennial Cancer Survivorship Conference and the Third International Meeting on Smokeless Tobacco. Continued support is planned to extend these important meetings.

- DCCPS has collaborated with ACS to adapt two successful NCI-funded intervention studies to create Body & Soul: A Celebration of Healthy Living, a nutrition program to be delivered through African American churches. NCI and ACS also developed the *Body & Soul Program Guide*, which assists regional ACS offices in enrolling participants and conducting the program. The program is an example of effective research dissemination to communities, as well as successful research collaboration between NCI and ACS.

- ACS, DCCPS, the North American Association of Central Cancer Registries, NIA, and CDC—including the National Center for Health Statistics—collaborate to provide an annual update to the nation on cancer occurrence and trends in the United States.

- DCCPS and ACS partner to distribute the *Facing Forward: Life after Cancer Treatment* series materials for cancer survivors.

National Philanthropic Organizations

Lance Armstrong Foundation

- The Office of Cancer Survivorship, in collaboration with colleagues in the Office of Education and Special Initiatives, participated in 2003 in a groundbreaking, three-part teleconference series entitled, "Cancer Survivorship: Living with, through, and beyond cancer." DCCPS was an active partner with Cancer Care, the Intercultural Cancer Council, Living Beyond Breast Cancer, the National Coalition for Cancer Survivorship, and the Lance Armstrong Foundation. The program, which will be sponsored again, is made possible by an educational grant from the Lance Armstrong Foundation and matching funds from NCI.

- New to the NCI and ACS Biennial Cancer Survivorship Research Conference in 2004 will be a Survivor-Researcher Mentor Program. This exciting program has been designed to help develop emerging leaders in the cancer advocacy community. The Lance Armstrong Foundation will provide scholarships for selected applicants.

American Legacy Foundation

- In March 2002, the first conference on menthol cigarettes was held to identify what is and is not known about these products and the people who smoke them, and to develop a research agenda to eliminate knowledge gaps. Public and private partners supporting the conference included DCCPS, CDC, the American Legacy Foundation, Battelle, the Onyx Group, the Robert Wood Johnson Foundation (RWJF), the National Association of African Americans for Positive Imagery, California's Tobacco-Related Disease Research Program, and the Centers for Public Health Research and Evaluation.

- DCCPS, CDC, the American Legacy Foundation, RWJF, and the Arizona Tobacco Education and Prevention Program sponsored a conference to discuss best practices and lessons learned among state cessation telephone quitlines. The goal was to share information and resources to make quitlines as effective as possible nationwide.

- The North American Smoking Cessation consortium (comprised of the American Legacy Foundation, ACS, CDC, and other partners) aims to maximize collaboration among various telephone-based cessation efforts across the nation.

Produce for Better Health Foundation

- The National 5 A Day Program, established in 1991 as a public-private partnership between NCI and the Produce for Better Health Foundation, promotes increased consumption of fruit and vegetables as part of a healthy lifestyle. Other partners include CDC, USDA, ACS, and the American Dietetic Association.

Robert Wood Johnson Foundation (RWJF)

- One of NCI's largest public-private research partnerships, the Transdisciplinary Tobacco Use Research Centers, is led by DCCPS, NIDA, NIAAA, and RWJF. These centers foster unique research collaborations of scientists across many tobacco-related subject areas. RWJF has committed $14 million over five years to complement the NIH effort, and supports policy and communications work linked to innovative scientific findings emerging from the centers' research projects.

- RWJF, DCCPS, and CDC are co-funding the evaluation project, "Helping Young Smokers Quit" to identify, survey, and evaluate existing youth cessation programs. The results of this initiative will help fill a gap in knowledge about the types and elements of youth cessation that are currently being offered, whether they are effective or ineffective, and guide future research and programming. The University of Illinois at Chicago is conducting this research.

Policy Organizations

C-Change (formerly the National Dialogue on Cancer)

For the past several years, DCCPS has collaborated with C-Change on several issues, including quality of cancer care, cancer surveillance, state cancer planning, economics and cancer, and obesity prevention.

- DCCPS staff who chair and participate on NCI's Quality of Cancer Care Committee serve as liaisons to the C-Change team on access to quality of cancer care. The two groups focus on ways to foster translation of evidence into practice.
- DCCPS, along with CDC and ACS, work with C-Change to advance the Comprehensive Cancer Control Leadership Institutes, with a focus on training, implementation, and evaluation.
- DCCPS, CDC, and ACS are providing consultation to the C-Change State Cancer Plans Team. Part of this effort is to facilitate an advocacy role for C-Change to motivate states to take action, and to provide states with technical assistance to implement their state cancer plans.
- DCCPS senior leaders participate in C-Change efforts to identify barriers and opportunities related to the enhancement of cancer control surveillance systems in the United States.
- DCCPS is a contributor to the C-Change Leadership Summit on Obesity and Cancer to identify actions for science, public health, policy, and best clinical practices.
- DCCPS staff had a leadership role in the planning and implementation of the Summit on the Primary Prevention and Early Detection of Cancer, and the Cancer Surveillance Summit. Senior leaders served on the planning committee, cochaired the dissemination workgroup, and participated on several other workshops and workgroups.

National Quality Forum

- In collaboration with AHRQ, CDC, and CMS, DCCPS has supported the creation of the Cancer Care Quality Measures Project (CanQual), conducted by National Quality Forum, to identify a core set of quality of care measures for cancer. The appointed steering committee for CanQual includes individuals closely associated with a range of public and private organizations, including ACS, the American College of Surgeons, the American Society of Clinical Oncology, the American College of Radiology, the Oncology Nursing Society, the National Coalition for Cancer Survivorship, the National Cancer Policy Board of the Institute of Medicine, the Joint Commission on the Accreditation of Healthcare Organizations, and the National Committee for Quality Assurance.

President's Cancer Panel

- The President's Cancer Panel has made cancer survivorship its major area of focus and has partnered with the DCCPS Office of Cancer Survivorship to set priorities and inform practice. Meetings in the U.S. and Europe concentrate on issues including living beyond cancer, survivorship issues among pediatric cancer survivors, challenges for adolescent and young adult cancer survivors, and meeting the challenges of adult survivors. Intended outcomes of the partnership and activities include identifying both key issues and concerns for cancer survivors and research and service gaps to inform the activities of the national cancer program.

RAND Corporation

- NIA, NIEHS, OBSSR, and DCCPS cofund the Centers for Population Health and Health Disparities. The center that is administered by RAND will assess the impact of Los Angeles park improvements on the physical activity and health of local residents. The study is a partnership with the Department of Parks

and Recreation and Neighborhood Oversight Committees, the Wilmington Coordinating Council, and the Multi-Cultural Area Health Education Center, a community-based organization whose mission is to reduce health disparities among Latinos.

- The RAND Corporation holds one of the Cancer Intervention and Surveillance Modeling Network grants to develop a model for the comprehensive surveillance of population trends in lung cancer.

- In collaboration with UCLA, RAND also has a grant award from the Cancer Care Outcomes Research and Surveillance Consortium to study the role of variations in structure of care in understanding variations in processes and outcomes of care for lung and colorectal cancer patients.

Professional Societies

American Academy of Family Physicians
American College of Epidemiology
American College of Surgeons
American Public Health Association
American Society of Clinical Oncology
American Society of Preventive Oncology
Society for Behavioral Medicine

- DCCPS actively collaborates with many professional societies on initiatives related to identifying new scientific opportunities and moving research discovery into program delivery. These include training programs, conference support, workshops, Web sites, and many other activities. One example of a collaboration that ultimately will lead to an initiative is in the area of psychoneuroimmunology, which is described below.

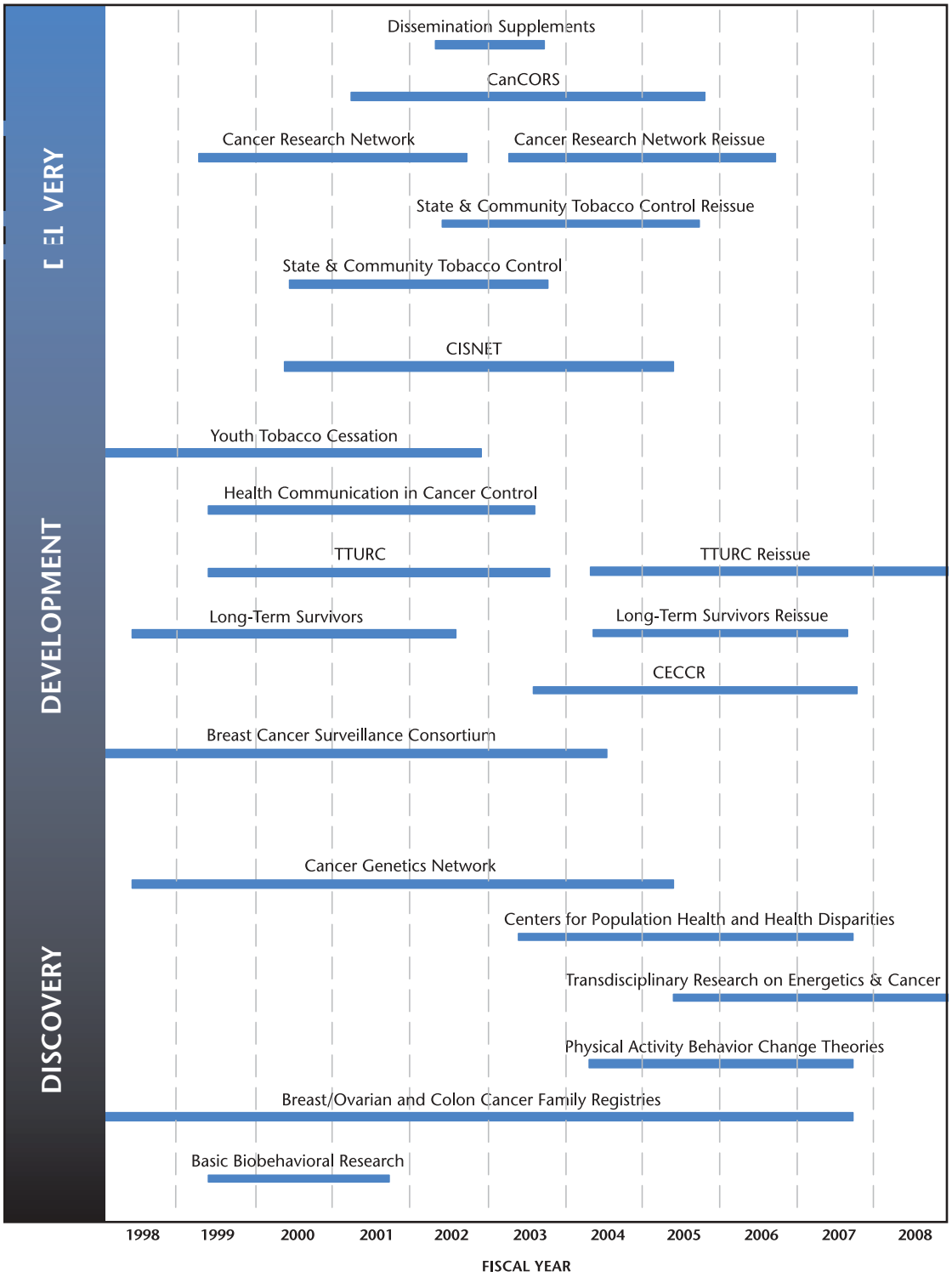
Psychoneuroimmunology Research Society (PNIRS)

- Since 2002, DCCPS has worked with PNIRS to facilitate science in the area of psychoneuroimmunology related to cancer control, including sponsorship of scientific symposiums and roundtable discussions at PNIRS annual meetings. This society has been an instrumental stakeholder in the Biological Mechanisms of Psychosocial Effects on Disease (BiMPED) initiative. Also, PNIRS played a key role in the development of a comprehensive Web-based bibliography on psychoneuroimmunology, currently hosted on the DCCPS Web site.

- PNIRS published a supplemental issue of its official journal, *Brain, Behavior, and Immunity*, dedicated to the science of the BiMPED initiative (Volume 17, February 2003, Supplement 1). DCCPS will continue to strive to advance the science of psychoneuroimmunology, and related disciplines, as applicable to cancer control.

MAJOR INITIATIVES

Ongoing & Planned Initiatives in DCCPS



Note on Exclusions: Cohort PAS-cost savings.

SUPPORTING RESEARCH AND ACTIVITIES TO REDUCE THE CANCER BURDEN

Since its establishment in 1997, DCCPS has initiated a number of vanguard initiatives and research priorities that are paving the way to a future when cancer is an uncommon and easily treated disease. This section first outlines our leadership of NCI scientific and strategic priorities, then describes the status and progress of major initiatives.

Section Overview

Leadership of NCI Priorities

Emerging Trends

- SEER Program
- Rapid Response Surveillance Studies
- Cancer Intervention and Surveillance Modeling Network

Genes and the Environment

- Breast Cancer and the Environment Research Centers
- Breast/Ovarian and Colon Cancer Family Registries
- Long Island Breast Cancer Study Project
- Cohort and Case-Control Consortia
- Cancer Genetics Network
- Epidemiology of Understudied Cancers of High Lethality

Improving the Quality of Cancer Care

- Quality of Cancer Care Initiatives
- Quality of Cancer Care Committee
- Developing Core Measures
- Cancer Care Outcomes Research and Surveillance Consortium
- HMO Cancer Research Network
- Breast Cancer Surveillance Consortium
- Prostate Cancer Outcomes Study
- SEER Patterns of Care/Quality of Care Studies
- SEER-Medicare Databases
- Studies on the Economics of Cancer

Tobacco and Tobacco-Related Cancers

- Transdisciplinary Tobacco Use Research Centers
- Youth Tobacco Prevention and Cessation
- State and Community Tobacco Control Interventions
- Tobacco Intervention Research Clinic
- Research on New Tobacco Products

New Directions in Behavioral Research

- Centers of Excellence in Cancer Communications Research
- Basic Biobehavioral Research on Cancer-Related Behaviors
- Biological Mechanisms of Psychosocial Effects on Disease
- Decision Making Related to Cancer Control

Energy Balance

- Physical Activity Behavior Change Theories
- Observing Protein and Energy Nutrition Study
- Centers for Transdisciplinary Research on Energetics and Cancer

Health Disparities

- Centers for Population Health and Health Disparities
- Native C.I.R.C.L.E.

Cancer Survivorship

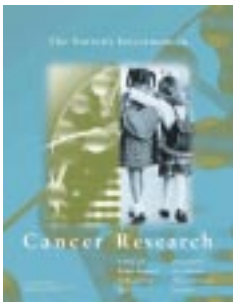
- Long-Term Cancer Survivors Research Initiative
- Innovative Cancer Control in Cancer Centers
- Research on the Impact of Cancer on the Family
- Research on Minority and Underserved Cancer Survivors

Dissemination and Diffusion

- 5 to 9 A Day for Better Health Program
- Cancer Control PLANET and Partnerships
- Dissemination and Diffusion Supplements
- Dissemination and Diffusion Research Program Announcement

Leadership of NCI Scientific and Strategic Priorities

The Nation's Investment in Cancer Research 2005



Improving Quality of Cancer Care, led by Drs. Joe Lipscomb, Martin Brown, and Jeff Abrams. Accomplishments include the Breast Cancer Surveillance Consortium, Cancer Care Outcomes Research and Surveillance Consortium, Colorectal Cancer Screening program announcement, Cancer Research Network, Quality of Cancer Care Committee, Cancer Care Quality Measures Project, Cancer Outcomes Measurement Working Group, and collaborations with the Agency for Healthcare Research and Quality, Health Resources and Services Administration, and Department of Veterans Affairs.

Reducing Cancer-Related Health Disparities, led by Drs. Jon Kerner, Harold Freeman, and Linda Brown. Highlights include efforts to decrease cervical cancer mortality, the newly approved concept for the Special Populations Networks reissuance, and the recently funded Centers for Population Health and Health Disparities, which is a trans-NIH collaborative research effort.

Genes and the Environment, led by Drs. Edward Trapido, Robert Hoover, and Steve Chanock. Selected accomplishments include the launch of the first initiative of the Consortium of Cohorts, establishment of the Breast Cancer and the Environment Centers with the National Institute of Environmental Health Sciences, Breast/Ovarian and Colon Cancer Family Registries, and Geographic Information Systems.

Research on Tobacco and Tobacco-Related Cancers, led by Drs. Scott Leischow and Neil Caporaso. Key initiatives include the Transdisciplinary Tobacco Use Research Centers trans-NIH collaborative effort, youth tobacco research, state and community tobacco control interventions, and future research investments to explore tobacco products that claim to reduce harm.

Cancer Communications, led by Drs. Ed Maibach and Bob Croyle, and Lenora Johnson and Nelvis Castro. Highlights are the Health Information National Trends Survey and the Centers of Excellence in Cancer Communications Research. Delivery efforts include the 9 A Day campaign for African American men, supplements to disseminate promising interventions, and the Cancer Control PLANET Web portal.

Cancer Survivorship, led by Drs. Julia Rowland, Norm Coleman, and Lee Helman. Selected accomplishments include the reissuance of the Long-Term Cancer Survivors Research RFA, supplements to stimulate research among family members of survivors and diverse survivor groups, the biennial cancer survivorship conference, international workshops on long-term follow-up care programs for survivors of pediatric cancer, and a state-of-the-science meeting on symptom management in cancer.

Energy Balance, led by Drs. Rachel Ballard-Barbash, John Milner, Arthur Schatzkin, and Michele Forman. As the newest addition to NCI's scientific priorities, the goal is to understand the causes of adverse patterns of weight, physical activity, and diet; define their contributions to cancer; and apply this knowledge to cancer prevention and control. A key research effort is the development of Centers for Transdisciplinary Research on Energetics and Cancer.

Early Detection, Prevention, and Prediction, led by Drs. Robert Croyle and Peter Greenwald. Transdisciplinary research units will address obesity, fitness, and cancer risk. Clinical trials will be aimed at the prevention of breast, colorectal, and prostate cancers, as well as lung cancer in former smokers. Through work with the FDA, NCI will evaluate surrogate biomarker endpoints on a case-by-case basis, leading to consideration of how best to use biomarkers to add efficiency to clinical trial design.

Emerging Trends

SEER Program

Contact Brenda K. Edwards, PhD, 301-496-8506, edwardsb@mail.nih.gov

NCI's Surveillance, Epidemiology, and End Results (SEER) Program is an authoritative source of information on cancer incidence and survival in the United States. The recent SEER 30th anniversary is a cause for celebration. NCI and its partners rely on the SEER Program to help track and understand the impact of advancements in cancer prevention, detection, and treatment, and to chart progress toward the goal of eliminating the suffering and death due to cancer. A brief history, including its recent expansion of coverage, is captured below.

- 1973: Case ascertainment for SEER began in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii, and the metropolitan areas of Detroit and San Francisco-Oakland.
- 1974-1975: The metropolitan area of Atlanta, and the 13-county Seattle-Puget Sound area were added.
- 1978: Ten predominantly African American rural counties in Georgia were added.
- 1980: American Indians residing in Arizona were added.
- Prior to 1990, three additional geographic areas participated in the SEER Program: New Orleans, Louisiana (1974-1977); four counties in New Jersey (1979-1989); and Puerto Rico (1973-1989). NCI also began funding a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska.
- 1992: The SEER Program increased coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco.
- 2001: NCI announced SEER's expansion, with awards to four additional states: Louisiana, Kentucky, New Jersey, and the remainder of California. This expansion increased SEER coverage to 23 percent of African Americans, 40 percent of Hispanics (32 percent of non-Mexican Hispanics), 42 percent of American Indians and Alaska Natives, 53 percent of Asians, and 70 percent of Native Hawaiians and Pacific Islanders. Overall, SEER coverage increased from 14 percent to 26 percent of the U.S. population (from about 39 million to nearly 74 million people).

The SEER Program has spent recent years in full-time collaboration with other federal agencies and with professional and private organizations involved in cancer surveillance. Collaborators have included the National Program of Cancer Registries, based at CDC, and the North American Association of Central Cancer Registries, a professional organization devoted to standardized data collection procedures for cancer registries in North America.

Rapid Response Surveillance Studies

Contact Rachel Ballard-Barbash, MD, MPH, 301-402-4366, barbashr@mail.nih.gov; or Brenda Edwards, PhD, 301-496-8506, edwardsb@mail.nih.gov

The SEER Program contracts provide a mechanism to augment data collection beyond the current reporting requirements and established standard data items. For more than a decade, NCI has used this mechanism to conduct studies that provide more information related to the quality of cancer registry data; develop techniques for more efficient registry operations; develop applications systems that rely on current information technology; and serve as a research resource for obtaining population-based comparisons for evaluation of biobehavioral and risk factors, screening patterns, and molecular and genetics surveillance, to quantify the progress of cancer control at the population

level. Such studies facilitate rapid responses to scientific inquiries of high priority to NCI, Congress, and advocacy groups, as well as for methodological development and feasibility studies upon which larger initiatives can be built. This transdivisional collaborative effort led by DCCPS has resulted in exceptional productivity, with over 150 publications thus far.

Cancer Intervention and Surveillance Modeling Network

Contact Rocky Feuer, PhD, 301-496-5029, feuerr@mail.nih.gov

The Cancer Intervention and Surveillance Modeling Network (CISNET) cooperative agreement awards explain the impact of interventions (screening, treatment, primary prevention) on population-based cancer trends in the United States. In Fiscal Year 2000, nine grants were funded under the initial issuance. In Fiscal Year 2002, eight additional awards were made as part of a planned expansion of CISNET. The reissuance of this initiative is anticipated for Fiscal Year 2005.

- Cancer Intervention and Surveillance Modeling Network, Donald Berry, University of Texas M.D. Anderson Cancer Center.
- PSA Screening and U.S. Prostate Cancer Trends, Ruth Etzioni, Fred Hutchinson Cancer Research Center.
- Simulating Breast Cancer in Wisconsin, Dennis Fryback, University of Wisconsin, Madison.
- Surveillance of Breast Cancer Trends by MISCAN, J. Dik Habbema, Department of Public Health, University of Rotterdam.
- A Population-Based Policy Model for Colorectal Cancer, Karen Kuntz, Department of Health Policy and Management, Harvard School of Public Health.
- Outcomes Across the Spectrum of Breast Cancer Care, Jeanne Mandelblatt, Georgetown University Medical Center.
- Breast Cancer Trend Analysis Using Stochastic Simulation, Sylvia Plevritis, Stanford University.
- Mechanistic Modeling of Breast Cancer Surveillance, Andrei Yakovlev, Huntsman Cancer Institute, University of Utah.
- Breast Cancer: Role of Early Detection, Treatment, and Prevention, Marvin Zelen, Dana-Farber Cancer Institute.
- Cancer Intervention and Surveillance Modeling Network, Rob Boer, RAND Corporation.
- Modeling Interventions for Lung Cancer Mortality, Theodore Holford, Yale University.
- Modeling Lung Cancer: Risks, Progression, and Screening, Marek Kimmel, Rice University.
- A Simulation of Tobacco Policy, Smoking, and Lung Cancer, David Levy, Pacific Institute for Research and Evaluation.
- Lung Cancer in the U.S.: Pathogenesis, Trends, Progression, Suresh Moolgavkar, Fred Hutchinson Cancer Research Center.
- Colorectal Cancer Screening: Evaluating Trends and Outcomes, Carolyn Rutter, Center for Health Studies.
- Survival Effects of Prostate Cancer Surveillance, Alexander Tsodikov, University of Utah.
- Colorectal Cancer Surveillance with MISCAN Modeling, Ann Zauber, Sloan-Kettering Institute for Cancer Research.

Genes and the Environment

Breast Cancer and the Environment Research Centers

Contact Kumiko Iwamoto, MD, DrPH, 301-435-4911, iwamotok@mail.nih.gov

The National Institute of Environmental Health Sciences and NCI are jointly funding Breast Cancer and the Environment Research Centers to study the prenatal-to-adult environmental exposures that may predispose a woman to breast cancer. The centers are funded through cooperative agreements totaling $35 million over a 7-year period.

The awards were made to the following investigators:

- Jose Russo, Fox Chase Cancer Center, Philadelphia.
- Sandra Haslam, Michigan State University, East Lansing.
- Robert Hiatt, University of California at San Francisco.
- Sue Heffelfinger, University of Cincinnati.

The centers will work collaboratively on two main fronts. Using animals, they will study the development of mammary tissue and the effects of specific environmental agents. In the second collaborative project, they will enroll different ethnic groups of young girls and study their life exposures to a wide variety of environmental, nutritional, and social factors that impact puberty. Early-onset puberty has been shown to increase breast cancer risk later in life. The four centers will interact as a single program, though with some specialization at each center. All the centers will work with advocacy groups to add their insight and experience to the research effort. Breast cancer survivors and members of advocacy groups are an integral part of each center's study team, and also are represented on the advisory board that oversees the projects.

Breast/Ovarian and Colon Cancer Family Registries

Contact Daniela Seminara, PhD, MPH, 301-496-9600, seminard@mail.nih.gov

The Breast/Ovarian and Colon Cancer Family Registries (CFR) studies support research to identify genetic changes that predispose to breast, ovarian, and colon cancers, and to explore gene-gene and gene-environment interactions that may contribute to the development of cancer among families with these cancers. These registries provide the tools and resources needed to clarify gene-environment interactions in cancer risk. They have identified thousands of families at high risk for breast, ovarian, and colorectal cancers who have agreed to be part of this research. Of particular interest are potential collaborations aimed at identification and characterization of cancer susceptibility genes; definition of gene-gene and gene-environment interaction in cancer etiology; and cooperative research on the translational, preventive, and behavioral aspects of such findings. The outcome will be a clearer understanding of the genes that affect the development of cancer, and how environmental factors may modify these genes.

Breast/Ovarian:

- Ontario Registry for Studies of Familial Breast Cancer, Irene Andrulis, Cancer Care Ontario.
- Cooperative Breast Cancer Registry, Saundra Buys, University of Utah.
- Comprehensive Familial Breast Cancer Registry, Mary Daly, Fox Chase Cancer Center.
- Australian Breast Cancer Family Study, John Hopper, University of Melbourne.
- Metropolitan New York Registry of Breast Cancer Families, Ruby Senie, Columbia University.
- Northern California Cooperative Family Registry, Dee West, Northern California Cancer Center.

- Informatics Center, Hoda Anton-Culver, University of California, Irvine.

Important findings are highlighted below:

- CFR investigators discovered that in studies of families with multiple members with cancer, comparing cases to sibling controls provides the most statistically efficient design.

- Variations by ethnicity in the risk of having a mother with breast cancer are higher in Hispanic breast cancer probands and somewhat lower in non-Hispanic White probands. No elevation of breast cancer risk was observed among mothers of Asian probands.

- Mutations in BRCA1 and BRCA2, which cause a dominantly inherited high risk of female breast cancer, seem to explain only a small proportion of the aggregation of the disease. A study of additional genetic components suggests that—after other possible unmeasured familial factors are adjusted for and the known BRCA1 and BRCA2 mutation carriers are excluded—there appears to be a residual dominantly inherited risk of female breast cancer, in addition to that derived from mutations in BRCA1 and BRCA2. This finding may have important implications for attempts to identify new breast cancer susceptibility genes.

- A study regarding ethical issues relating to informed consent and recruitment of participants revealed the following: Participants expressed a preference that the study be endorsed by a trusted and familiar source; the benefit of the research should be clear and personal, as well as benefit the participants' family members; risks of participation should be explicit (e.g., insurance discrimination); and education about the disease and its familial nature would maintain participants' commitment to the study. Findings from this study will aid future familial studies in developing a protocol that both adequately informs potential participants about the nature of familial research and maximizes participation.

Colon:

- Ontario Registry for Studies of Familial Colon Cancer, Steven Gallinger, Cancer Care Ontario.

- Colorectal Cancer Family Registry, Robert Haile, University of Southern California.

- Australian Colorectal Cancer Family Registry, Jeremy Jass, University of Queensland.

- Hawaii Family Registry of Colon Cancer, Loic Le Marchand, University of Hawaii at Manoa.

- Familial Colorectal Neoplasia Collaborative Group, Noralane Lindor, Mayo Clinic Rochester.

- Seattle Familial Colorectal Cancer Registry, John Potter, Fred Hutchinson Cancer Research Center.

Important findings are highlighted below:

- Using CFR colon cancer cases, investigators found that methylation of O-6-methlyguanine DNA methyltransferase characterizes a subset of colon cancers with low-level microsatellite instability. They suggest that silencing of this transferase, through methylation, may predispose to oncogenic mutation of the K-ras oncogene by overwhelming the DNA mismatch repair system.

- A study systematically evaluated, by immunohistochemistry (IHC), the correlation between age at diagnosis and loss of expression of hMLH1 protein in patients with colorectal cancer. The study was performed on tissue samples of 867 patients enrolled through the Colon CFR participating sites. Loss of hMLH1 expression in patients with colorectal cancer was associated with increasing age. This trend was most pronounced in female patients and in patients with tumors on the right side of the colon.

- Colorectal cancers from 1,144 patients were assessed for DNA mismatch repair deficiency by two methods: MSI testing and IHC detection of hMLH1 and hMSH2 gene products. IHC in colorectal tumors for protein products hMLH1 and hMSH2 provides a rapid, cost-effective, sensitive (92.3 percent), and extremely specific (100 percent) method for screening for DNA mismatch repair defects. Thus, IHC appears to offer a faster and less expensive alternative to MSI testing for classifying colorectal cancers by mismatch repair competency, with essentially 100 percent specificity and greater than 92 percent sensitivity.

Long Island Breast Cancer Study Project

Contact Deborah Winn, PhD, 301-594-9499, deborah.winn@nih.gov

The Long Island Breast Cancer Study Project (LIBCSP) is a multistudy effort to investigate whether environmental factors are responsible for breast cancer in Suffolk, Nassau, and Schoharie counties, New York, and in Tolland County, Connecticut. The investigation began in 1993 under Public Law 103-43, and is funded and coordinated by NCI, in collaboration with NIEHS.

The LIBCSP consists of epidemiologic studies, the establishment of a family breast and ovarian cancer registry, and laboratory research on mechanisms of action and susceptibility in the development of breast cancer. Researchers at major medical research institutions in the Northeast conducted most of the studies, and most of the findings have been reported.

The registry continues to enroll eligible families with breast and/or ovarian cancer, and to provide researchers a resource for their investigations. Additional analyses are being conducted of data collected for the centerpiece case-control study of breast cancer in Nassau and Suffolk counties (Long Island), chiefly as non-LIBCSP studies funded through separate sources. However, researchers continue to follow the women with breast cancer who participated in the centerpiece study to determine whether organochlorine compounds; polycyclic aromatic hydrocarbons (PAH), which are pollutants caused by incomplete combustion of various chemicals such as diesel fuel and cigarette smoke; and lifestyle factors influence survival of Long Island women diagnosed with the disease. For this research, Marilie Gammon, University of North Carolina at Chapel Hill, received a 4-year grant from NCI in 2001.

To meet the Public Law requirement for a "geographic system," NCI developed the Geographic Information System (LI GIS) for Breast Cancer Studies on Long Island. The LI GIS is available for use by researchers in investigating relationships between breast cancer and the environment, and in estimating exposures to environmental contamination. Geographic information systems are powerful computer systems that permit layers of information to be superimposed and analyzed. The LI GIS includes over 80 datasets, including geographic, demographic, health, and environmental data. The tool potentially can be used for research on other types of cancer, and other diseases and conditions.

Findings have been reported on the primary hypotheses investigating suspect chemical agents and electromagnetic fields (EMF), with the exception of the follow up to the centerpiece study. These completed investigations did not find an association between organochlorine compounds (pesticides), PAH, or polychlorinated biphenyls (PCB) and an increased risk for breast cancer on Long Island. The research also did not find an association between EMF and an increased risk for breast cancer on Long Island.

Cohort and Case-Control Consortia

Contact Sandra Melnick, DrPH, 301-435-49144, melnicks@mail.nih.gov

Among NCI's top priorities is to understand how genes that make individuals susceptible to cancer are influenced by environmental factors such as chemicals, diet, and pharmacologic agents. DCCPS and the Division of Cancer Epidemiology and Genetics (DCEG) are collaborating to facilitate the

development of consortia of cohort and case-control studies in order to accelerate research on gene-gene and gene-environment interactions in the etiology of cancer. The creation of such consortia is part of the revolutionary shift to big science, where studies of the future will be conducted on a much larger scale by multidisciplinary teams of scientists who pool their resources.

In 2003, NCI launched a new initiative to pool data and biospecimens from 10 large cohorts to conduct research on gene-environment interactions in cancer etiology. The investigative teams are collaborating on studies of hormone-related gene variants and environmental factors involved in the development of breast and prostate cancers. Data are being drawn from 8,850 patients with prostate cancer and 6,160 patients with breast cancer.

The investigators of these 10 cohorts will look for inherited gene variants in biospecimens taken from patients with breast or prostate cancer, and assess the variants' association with the development of the cancers. Then they will assess whether the identified gene variants are associated with levels of steroid hormones and growth factors that influence the risk for these cancers. The investigators also will evaluate whether the identified gene variants interact with lifestyle and anthropometric (body measurement) factors that have been associated with risk for the cancers.

Funded cohorts are listed below:

- Physicians' Health Study I and II; Nurses' Health Study; Health Professionals Follow-up Study; and Women's Health Study, David Hunter, Channing Laboratory, Harvard School of Public Health.
- American Cancer Society's Cancer Prevention Study–II (ACS CPS-II), Michael Thun, American Cancer Society.
- European Prospective Investigation into Cancer and Nutrition (EPIC), Elio Riboli, International Agency for Research on Cancer.
- Multiethnic Cohort, Brian Henderson, University of Southern California/Norris Comprehensive Cancer Center.
- Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial, Richard Hayes, DCEG.
- Alpha-Tocopherol, Beta-Carotene Cancer Prevention (ATBC) Study, Demetrius Albanes, DCEG.

NCI is also fostering development of case-control consortia. Investigators may come together informally at first to discuss shared interests, for example, as has already occurred for brain tumors. In time, a formal structure may evolve, as with the International Consortium of Investigators Working on Non-Hodgkin's Lymphoma Epidemiologic Studies (InterLymph Consortium). Another advantage of consortia arrangements is the potential for advancing study of less common cancers and highly lethal cancers, for which it is difficult, if not impossible, for individual investigators to recruit sufficient study participants.

Cancer Genetics Network

Contact Carol Kasten-Sportes, MD, 301-402-8212, kastenca@mail.nih.gov

The Cancer Genetics Network (CGN) is a national network of centers specializing in the study of inherited predisposition to cancer. The CGN consists of eight centers (most with additional partners) and an Informatics and Information Technology Group (ITG) that provides the supporting infrastructure. The CGN supports collaborative investigations on the genetic basis of cancer susceptibility, mechanisms to integrate new knowledge into medical practice, and means of addressing the associated psychosocial, ethical, legal, and public health issues. It seeks individuals who have a personal or family history of cancer and who may want to participate in studies about inherited susceptibility to cancer.

The growing database has information on 20,100 individuals (15,760 families) with cancer and/or a

history of cancer. Enrollment continues for minority populations; individuals at high risk for ovarian, colon, pancreatic, or renal cell cancers; and families with multiple tumors. Starting in 2005, the CGN core registry will be continued as a research resource throughout the nation.

Following are the participating institutions:

- Carolina-Georgia Cancer Genetics Network Center, Joellen Schildkraut, Duke University Medical Center, in collaboration with Emory University and the University of North Carolina.
- Georgetown University Medical Center's Cancer Genetics Network Center, Claudine Isaacs, Georgetown University Lombardi Cancer Center.
- Mid-Atlantic Cancer Genetics Network Center, Constance Griffin, Johns Hopkins University, in collaboration with the Greater Baltimore Medical Center.
- Northwest Cancer Genetics Network, John Potter, Fred Hutchinson Cancer Research Center, in collaboration with the University of Washington School of Medicine.
- Rocky Mountain Cancer Genetics Coalition, Geraldine Mineau, University of Utah, in collaboration with the University of New Mexico and the University of Colorado.
- Texas Cancer Genetics Consortium, Louise Strong, University of Texas M.D. Anderson Cancer Center, in collaboration with the University of Texas Health Science Center at San Antonio, University of Texas Southwestern Medical Center at Dallas, and Baylor College of Medicine.
- University of Pennsylvania Cancer Genetics Network, Barbara Weber, University of Pennsylvania.
- UCI-UCSD Cancer Genetics Network Center, Hoda Anton-Culver, University of California, Irvine, in collaboration with the University of California San Diego.

Informatics and Information Technology Group (ITG):

- University of California Irvine, Hoda Anton-Culver.
- Massachusetts General Hospital, Dianne Finkelstein.
- Yale University, Prakash M. Nadkarni.

Some important accomplishments are highlighted below:

- ITG developed the software program TrialDB which supports rapid electronic protocol development by nonprogrammer investigators. Protocol development is speeded by a data library that stores elements across different studies, such as lab parameters, case report forms, Adverse Event Report forms, and standardized questionnaire instruments. TrialDB is now an open-source code software that is widely available to researchers as a Web-accessible clinical data management system.
- Over 2,000 women are enrolled in the study to screen high-risk women for ovarian cancer using CA125 measurements. This large study group enables examination of the effects of demographics and other factors on baseline CA125 levels. Preliminary findings point to several factors that may significantly affect baseline CA125 values: race, cigarette smoking, menopausal status, and presence or absence of ovaries. New normative baseline values indicate that premenopausal African American women have lower CA125 levels compared to premenopausal non-African American women. Cigarette smoking appears to decrease baseline CA125. The absence of ovaries in postmenopausal women appears to substantially reduce baseline CA125. These

preliminary findings may prove important to improving ovarian cancer screening in high-risk women.

- Extended families with three or more members affected with pancreatic cancer, and at least two of whom were first-degree relatives, were studied for mutations in four candidate genes. BRCA2 gene sequencing revealed five mutations that are believed to be deleterious, and one point mutation not previously reported. These findings confirm the increased risk of pancreatic cancer in individuals with BRCA2 gene mutations, and identify germline BRCA2 gene mutations as the most common inherited genetic alteration yet identified in familial pancreatic cancer.

- In an evaluation of the accuracy of cancer family histories reported by CGN enrollees, researchers found that enrollees' reporting was highly reliable when reporting about most types of cancers among first-degree relatives. Overreporting of cancer was rare. Race or ethnicity and gender did not influence the accuracy of the reporting. Enrollees' accuracy was less reliable with second- and third-degree relatives for all cancer types combined, and for female breast, lung, prostate, and colorectal cancers.

Epidemiology of Understudied Cancers of High Lethality (future initiative)

Contact Ed Trapido, ScD, 301-435-4912, trapidoe@mail.nih.gov

A critical step toward the elimination of death from cancer by 2015 is to focus research resources on malignancies that are highly fatal. When certain cancers—such as pancreatic, esophageal, and liver cancers—are diagnosed, there is relatively little prospect for prolonging life or for quality of life. Understanding gene-environment interactions in these lethal diseases is important in learning who is at elevated risk and how that risk is regulated. Discoveries will be needed in these areas if we are to develop more accurate and cost-effective public health interventions aimed at eliminating mortality. The purpose of this future initiative is to stimulate epidemiologic etiologic research on three understudied, highly fatal cancers: pancreatic, esophageal, and liver cancers. It is important to note that some of these cancers disproportionately affect minority populations. For example, squamous cell esophageal cancer is three times more common among African Americans than Whites. Liver cancer rates are elevated in Whites. Also, Hispanics and African American men experience incidence and mortality rates for pancreatic cancer that are 50 percent higher than those for U.S. Whites.

Improving the Quality of Cancer Care

Quality of Cancer Care Initiatives

Contact Joe Lipscomb, PhD, 301-402-3590, lipscomj@mail.nih.gov; or Martin Brown, PhD, 301-496-5716, mbrown@mail.nih.gov

The quality of cancer care is a major national concern. Reports from the Institute of Medicine, the President's Cancer Panel, and the scientific literature suggest disturbingly large variations in the use of available prevention, screening, and treatment interventions. In many cases, there is substantial disagreement about what constitutes optimal care, especially from the patient's perspective, and about the best approaches for achieving improvement. Even where consensus appears to exist, there are often substantial differences in practice patterns across population groups or regions of the country. Consequently, it is critically important to advance understanding of how to measure, monitor, and improve the quality of cancer care.

In response, NCI has made improving the quality of cancer care one of its highest scientific priority areas. The major initiatives organized and supported within DCCPS that contribute this effort are briefly described below.

Quality of Cancer Care Committee

Contact Joe Lipscomb, PhD, 301-402-3590, lipscomj@mail.nih.gov

NCI established the Quality of Cancer Care Committee (QCCC) in 2000 to improve the scientific quality of federal-level decision making about cancer care. Its membership includes federal agencies involved in cancer care delivery, coverage, regulation, and standards setting—or research on those topics. The committee consists of senior representatives from NCI; the Agency for Health Care Research and Quality (AHRQ); Centers for Disease Control and Prevention (CDC), including the National Center for Health Statistics; Centers for Medicare & Medicaid Services (CMS); Health Resources and Services Administration (HRSA); Indian Health Service (IHS); Food and Drug Administration (FDA); Department of Veterans Affairs (VA); Department of Defense (DoD); and the Office of the Director of NIH. There is also a representative from the NCI Director's Consumer Liaison Group.

Through the QCCC, NCI supports the three interagency projects highlighted below:

- With NCI support, the VA established a Quality Enhancement Research Initiative (QUERI) to improve its screening, follow-up, treatment, and end-of-life care for colorectal cancer. The colorectal cancer QUERI has launched projects to enhance data collection on screening and referrals, improve the performance of non-cancer specialists in identifying and rendering appropriate care to cancer patients and others at elevated risk, and investigate the quality of diagnostic and therapeutic care received by approximately 1,000 colorectal cancer patients at 10 representative VA medical centers across the country.

- CMS and NCI work together to increase awareness and improve the delivery of Medicare-covered colorectal cancer screening services. Based in North Carolina and South Carolina, the project has developed and successfully tested alternative educational interventions to improve both Medicare beneficiary and health care provider knowledge regarding the risks of colorectal cancer, the availability and effectiveness of alternative screening approaches, and current Medicare coverage policies.

- The HRSA/CDC/NCI Cancer Care Collaborative is one of the dissemination projects generated by the QCCC. Organized and managed by the Institute for Healthcare Improvement, under contract to HRSA's Bureau of Primary Health Care (BPHC), this innovative project works through 20 BPHC centers to drive organizational change within health center practices. Avoidable deaths from breast, colon, and cervical cancers persist, especially among disadvantaged ethnic and racial groups, and those with lower socioeconomic status. The focus of this initiative is to improve the quality of breast, colon, and cervical cancer care by first improving cancer screening and follow-up of positive tests. This includes moving cancer control research into primary care clinics to improve communication among providers and between providers and patients, and optimizing processes of care. During Fiscal Year 2004, the Cancer Care Collaborative will build on results from pilot work, with the long-term goal of translating cancer control research into practice to reduce morbidity and mortality due to breast, colon, and cervical cancers.

Developing Core Measures

Contact Joe Lipscomb, PhD, 301-402-3590, lipscomj@mail.nih.gov

- In 2001, NCI convened the Cancer Outcomes Measurement Working Group (COMWG) to evaluate existing endpoint measures and instrumentation and formulate alternative strategies for valid, reliable, sensitive, and feasible measures. Composed of 35 internationally recognized experts in measurement, oncology, and the social sciences, the COMWG focuses on improving the measurement of such

patient-centered outcomes as health-related quality of life, patient perceptions of and satisfaction with cancer care, and economic burden. Variability in the scientific quality of these measures, and a corresponding lack of standardization in approaches, pose significant barriers to comparing findings across quality-of-care research studies.

- NIH recently announced a $20 million, five-year extramural research project to support applications of item response theory—a major focus of the COMWG's analyses—to develop item banks and carry out computer-based assessment of patient-centered outcomes for chronic diseases, including cancer.

- Standards for process measures of quality cancer care are being developed through a major new NCI collaboration with federal agencies and major cancer organizations in the private sector. The Cancer Care Quality Measures Project (CanQual), coordinated by the non-profit National Quality Forum, will identify a parsimonious set of evidence-based measures for evaluating the quality of cancer care. Topics identified by the project's 18-member public-private steering committee include diagnosis and treatment for breast, colorectal, and prostate cancers; access to care; communication and coordination of care; and symptom management across the cancer continuum, including end of life.

Cancer Care Outcomes Research and Surveillance Consortium

Contact Arnie Potosky, PhD, 301-496-5662, potoskya@mail.nih.gov

The Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) was launched in Fiscal Year 2001 to improve the methods and empirical base for quality of care assessment. The 5-year cooperative agreement awardees are studying the impact of targeted interventions on patient-centered outcomes, investigating dissemination of state-of-the-art therapies in the community, examining modifiable risk factors, and analyzing disparities in quality of care. CanCORS supports large, prospective cohort studies of newly identified lung and colorectal cancer patients, with a target enrollment of 5,000 patients for each cancer type. Research teams from around the country are carrying out this DCCPS-coordinated effort, with support from a statistical coordinating center:

- Lung and Colorectal Cancer Treatment in Los Angeles County, including African American and Hispanic Populations, Katherine Kahn, RAND-UCLA.

- Cancer Care Outcomes for Lung and Colorectal Cancer in Nine Counties of the Northern California Bay Area and Sacramento Region, including African American, Hispanic, and Asian American and Pacific Islander Populations, John Ayanian, Harvard University Medical School.

- Lung and Colorectal Cancer Treatment in Alabama and Atlanta, including Rural and Urban African American Populations, Mona Fouad, University of Alabama Birmingham.

- Lung and Colon Cancer Outcomes in the Cancer Research Network, Health Maintenance Organizations in Seattle, Portland, Hawaii, Detroit, and Massachusetts, including African American, Asian American, and Pacific Islander Populations, Jane Weeks, Dana-Farber Cancer Institute, Harvard University.

- North Carolina Colorectal Cancer Care Outcomes Research Study, Robert Sandler, University of North Carolina.

- Lung Cancer Care Outcomes in Iowa, including Rural Poor and Elderly Populations, Robert Wallace, University of Iowa.

- CanCORS Statistical Coordinating Center, David Harrington, Dana-Farber Cancer Institute, Harvard University.

HMO Cancer Research Network

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The HMO Cancer Research Network (CRN) consists of the research programs, enrolled populations, and data systems of 11 health maintenance organizations nationwide. The CRN was initiated in Fiscal Year 1999 and funded again in Fiscal Year 2003 for a second cycle. The overall goal of the CRN is to use a consortium of delivery systems to conduct research on cancer prevention, early detection, treatment, long-term care, and surveillance.

Together, the 11 participating health plans have nearly nine million enrollees, or three percent of the U.S. population. This facilitates large studies of common tumors, as well as research on rare cancers. The current portfolio of CRN research studies encompasses cancer control topics ranging from modification of behavioral risk factors, such as diet and smoking, to end-of-life care for patients with prostate or ovarian cancer.

Through this expansive research program, the CRN seeks to improve the effectiveness of preventive, curative, and supportive interventions for major cancers—such as breast, colon, and lung cancers—as well as rare tumors. The CRN is also uniquely positioned to study the quality of cancer care in community-based settings. As a reflection of the network's commitment to improving quality of care, the Agency for Healthcare Research and Quality is cooperatively supporting the CRN with NCI.

The CRN research centers are composed of scientists with expertise in epidemiology, health services, behavioral medicine, and biostatistics, as well as primary and specialty care clinicians. This environment facilitates a multidisciplinary approach to studying ways to improve cancer care. Group Health Cooperative is the lead site for the CRN. Ed Wagner, MD, MPH, has served as the CRN Principal Investigator since its inception. The participating health plans, along with their associated research centers, locations, and site principal investigators are listed here.

- Group Health Cooperative, Center for Health Studies, Seattle, Edward Wagner.
- Fallon Healthcare System, Meyers Primary Care Institute, Worcester, Massachusetts, Terry Field.
- Harvard Pilgrim Health Care, Department of Ambulatory Care and Prevention, Boston, Suzanne Fletcher.
- HealthPartners, HealthPartners Research Foundation, Minneapolis, Cheri Rolnick.
- Health Alliance Plan, Henry Ford Health System, Detroit, Christine Cole Johnson.
- Kaiser Permanente Colorado, Center for Clinical Research, Denver, Judy Mouchawar.
- Kaiser Permanente Georgia, Department of Research, Atlanta, Dennis Tolsma.
- Kaiser Permanente Hawaii, Center for Health Research, Honolulu, Thomas Vogt.
- Kaiser Permanente Northern California, Division of Research, Oakland, Lisa Herrinton.
- Kaiser Permanente Northwest, Center for Health Research, Portland, Mark Hornbrook.
- Kaiser Permanente Southern California, Department of Research and Evaluation, Pasadena, Ann Geiger.

A Scientific and Data Resources Core (SDRC) is developing data resources and methods to support epidemiologic and health services research across the CRN. The overall goal of the SDRC is to increase the quality and efficiency of CRN research projects through the identification, usage, and dissemination of optimal methods for data collection, data management, data transfer, and cost analysis. The complete portfolio of the CRN includes 22 projects. Following are the Core projects funded under the competing renewal:

- Clinical and Pathologic Predictors of Ductal

Carcinoma in Situ

- Making Effective Nutritional Choices for Cancer Prevention
- Using Electronic Medical Records to Measure and Improve Adherence to Tobacco Treatment Guidelines in Primary Care

Breast Cancer Surveillance Consortium

Contact Rachel Ballard-Barbash, MD, MPH, 301-402-4366, barbashr@mail.nih.gov

The Breast Cancer Surveillance Consortium (BCSC) is a cooperative agreement initiated in 1994 between NCI and investigators at medical research centers across the country. The BCSC is evaluating the performance of screening mammography in community practice in the United States. This research collaboration links data from mammography registries with data on cancer outcomes from pathology laboratories or cancer registries. The consortium's database contains information for more than 1.7 million women with over 5 million screening mammographic examinations. Within this group, about 38,000 breast cancers have been detected. Collaborative research among BCSC participants examines issues such as the effect of age, breast density, hormone replacement therapy (HRT), and family history on the accuracy of screening mammography, the relationship of mammographic assessment to final recommendation for diagnostic evaluation, biologic characteristics of screen-detected vs. interval cancers, and rates of detection of ductal carcinoma in situ among screened women. The consortium has produced over 150 peer-reviewed publications, contributed information to a number of federal reports on mammography screening, and served as a research resource for junior and senior investigators.

The BCSC also is working cooperatively with national and local partners to evaluate and disseminate information about screening performance. For example, the BCSC has been working with the Breast Imaging Reporting and Data System Committee of the American College of Radiology to streamline the data collection process.

Research findings from this effort include the following:

- A prospective cohort study on close to 330,000 women examined the combined and individual effects of age, breast density, and HRT on the accuracy of detection of cancer from screening. This study demonstrated that screening mammography is most accurate in older women with fatty breasts, and least accurate in younger women with dense breasts who use HRT.
- Cancer detection rates for women who had a first-degree relative with a history of breast cancer were similar to those in women 10 years older without such a history. The sensitivity of screening mammography increased significantly with age but did not differ significantly between women with and those without a family history.
- A comparison of recall rates, biopsy rates, and cancer detection rates between the United States and the United Kingdom revealed that recall rates were twice as high in the United States as in the United Kingdom. Rates of open surgical biopsies were also higher in the United States. However, the cancer detection rates between the two countries were strikingly similar. This comparison suggests areas for improvement in screening mammography practice in the United States.
- Recall rates are often used as a surrogate measure for accuracy indexes to determine the performance of screening mammography. A study of the effect on sensitivity and positive predictive value (PPV) of increasing recall rates determined that practices with recall rates between 4.9 percent and 5.5 percent achieve the best trade-off of sensitivity and PPV.
- An observational cohort study of 5,212 naturally postmenopausal women, aged 40 to

96 years, indicates that breast density changes associated with HRT are dynamic, and that they increase after therapy is initiated and decrease after therapy ends.

- The sensitivity of breast cancer screening is substantially decreased in women with higher breast density who use estrogen replacement therapy. Increased breast density and estrogen replacement therapy do not appear to have a negative effect on cancer stage at diagnosis, rate of lymph node involvement, or percentage of early cancers.

- The density of breast tissue changes during the menstrual cycle. Because density is less during the early, follicular phase, than during the later, luteal phase, scheduling a mammogram during the early part of the cycle may result in greater screening accuracy.

- Studies examining the effect of technical parameters on performance are also yielding new information. For example, a study on the effect of breast positioning found that sensitivity was highest among women with proper breast position, and fell significantly with incorrect positioning.

- A long-term study in Colorado has tracked changes in technical parameters—including radiation dose and film and processor performance—and provides the only data in the United States on these measures over time. These data indicate that mammography equipment performance has improved significantly over the past decade but that wide variations in some measures remain—especially for women with thicker breasts.

BCSC grant awards have been made to:

- Carolina Mammography Registry, Bonnie C. Yankaskas, University of North Carolina at Chapel Hill.

- Colorado Mammography Project, Gary Cutter, AMC Cancer Research Center.

- Breast Cancer Surveillance in a Defined Population, Diana Buist, Center for Health Studies, Seattle.

- New Hampshire Mammography Network, Patricia Carney, Dartmouth-Hitchcock Medical Center.

- New Mexico Mammography Project, Robert Rosenberg, University of New Mexico.

- San Francisco Mammography Registry, Karla Kerlikowske, VAMC.

- Vermont Breast Cancer Surveillance System, Berta Geller, University of Vermont.

- Statistical Coordinating Center, William Barlow, Washington Group Health Cooperative.

Prostate Cancer Outcomes Study

Contact Arnie Potosky, PhD, 301-496-5662, potoskya@mail.nih.gov

The Prostate Cancer Outcomes Study (PCOS) began in 1994 to examine the impact of treatments for primary prostate cancer on the quality of life of men living with prostate cancer. PCOS is collaborating with six cancer registries that are part of NCI's SEER Program. It is the first population-based evaluation, conducted on a multiregional scale, of health-related quality of life issues for prostate cancer patients. Better knowledge of the effects of treatment will help men, their families, and clinicians make more informed choices about treatment alternatives.

Study findings include the following:

- There are important differences in urinary, bowel, and sexual functions more than two years after different treatments for clinically localized prostate cancer.

- African American men have the greatest risk of developing advanced prostate cancer.

- In addition to prognostic factors (such as age and PSA value), baseline disease-related function, nonclinical variables, and marital status are important determinants of treatment of clinically localized prostate cancer.

SEER Patterns of Care/Quality of Care Studies

Contact Linda Harlan, PhD, 301-496-8500, harlanl@mail.nih.gov

The Surveillance, Epidemiology, and End Results (SEER) Patterns of Care/Quality of Care initiative (POC/QOC) evaluates the dissemination of state-of-the-art therapy into community practice, disseminates findings in scientific journals and at professional meetings, and works with professional organizations to develop relevant educational or training opportunities. Over the past 10 years, the SEER registries have performed POC studies on specific cancer sites as advances in treatment have highlighted the need to examine therapies in community practice. Beginning in 2001, a mechanism was established whereby the registries will perform a series of SEER POC/QOC studies, to be repeated every three to five years, with major cancer sites. Studies will be conducted in the alternate years for cancer sites with emerging new treatments or concerns regarding provision of state-of-the-art therapy.

SEER-Medicare Database

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The SEER-Medicare linked database is a significant national research resource, supporting studies on cancer patterns of care, quality of cancer care, and costs of cancer care. In the last few years, SEER-Medicare has grown from an informal inhouse research activity to a major program supporting both inhouse activities and extramural research. The process of updating the data link takes place on a routine 3-year cycle. Technical support is carried out through an extensive and detailed SEER-Medicare Web page; periodic conferences, workshops, and presentations; and publications in the professional literature, including a special supplement to the journal Medical Care. Extramural funding is facilitated through the program announcement, Cancer Surveillance Using Health Claims-based Data System. Over 100 peer-reviewed publications in the health services research literature are directly related to the SEER-Medicare database.

Studies on the Economics of Cancer

Contact Martin Brown, PhD, 301-496-5716, mbrown@mail.nih.gov

DCCPS has conducted a variety of studies on the economic burden of cancer, the cost of cancer screening and treatment, and the cost-effectiveness of cancer control interventions. The data resources of SEER-Medicare and Cancer Research Network (CRN)-affiliated health maintenance organizations have been enhanced to provide more accurate, detailed, and specific estimates of cancer costs. These estimates have been widely cited and used by governmental agencies and other decision makers and in cost-effectiveness research. DCCPS developed and sponsored several studies on the cost of cancer care for patients enrolled in clinical trials compared to patients receiving care in standard community settings. These early studies led to the development of a major national study on costs associated with clinical trials vs. community settings. This study is being conducted by the RAND Corporation, with joint oversight by DCCPS and the Division of Cancer Treatment and Diagnosis.

Tobacco and Tobacco-Related Cancers

Transdisciplinary Tobacco Use Research Centers

Contact Glen Morgan, PhD, 301-496-8585, morgang@mail.nih.gov

Seven Transdisciplinary Tobacco Use Research Centers (TTURCs) were established in 1999 with 5 years of funding by NCI, the National Institute on Drug Abuse (NIDA), and the Robert Wood Johnson Foundation. NCI, NIDA, and the National Institute on Alcohol Abuse and Alcoholism have joined

together to fund the reissuance of the TTURCs in Fiscal Year 2004. These novel centers are designed to bridge disciplinary barriers, establish new conceptual frameworks and methods to understand and treat tobacco use, speed the transfer of innovative approaches to communities nationwide, and create a core of new tobacco control researchers. The centers establish critical links across diverse scientific disciplines. They are not only unique for their transdisciplinary science; they have established multiple cross-center collaborations that are unusual in either public or private research ventures. The centers are creating innovative research techniques and technologies that are providing new perspectives on tobacco use and addiction, and are pioneering interventions to decrease tobacco use. Highlights of progress are briefly described below.

Research conducted at the University of California at Irvine (UCI) TTURC reveals links between specific personality traits and early initiation of cigarette smoking.

- Hostility and depression predicts smoking in White youth.
- A collaboration between UCI and the University of Southern California found that social interactions, but not hostility and depression, predict smoking in Asian youth.

Scientists at the University of Pennsylvania/ Georgetown University TTURC are studying the role of genetic and environmental factors in smoking initiation and addiction.

- Researchers generated the first empirical evidence that the CYP2B6 polymorphism predicts the efficacy of bupropion among female smokers.

The University of Minnesota TTURC examines tobacco exposure reduction approaches for treating individuals who are unwilling or unable to quit smoking.

- Investigators discovered that when subjects reduced cigarette consumption by 75 percent, the reduction in tobacco toxin exposure (total NNAL) did not exceed 30 percent.

The University of Southern California (USC) TTURC aims to prevent tobacco use across cultures including youth of Chinese, Vietnamese, Korean, Filipino, Mexican, South and Central American, and Middle Eastern descent.

- The curriculum of Project FLAVOR, a multicultural smoking prevention program tailored primarily for Hispanic and Latino youth, produced a reduction in smoking initiation among Hispanic/Latino youth but not among other racial/ethnic youth groups.
- The cultural values “respect for adults” and “interpersonal harmony” were protective against adolescent smoking among California youth.

The University of Wisconsin TTURC is developing a computer-based support system as a tool for preventing relapse among people who are trying to quit smoking.

- The new dependence assessment tool created by TTURC researchers is called the Wisconsin Smoking Dependence Motives questionnaire. This instrument surpasses extant metrics in that it predicts withdrawal severity and relapse likelihood. Beyond the development of this questionnaire, an important product of this research is greater knowledge of the nature of dependence.
- Wisconsin researchers have also found that women and those with a prior history of depression are more likely than others to show significant elevations in withdrawal symptoms.

The Brown University TTURC identifies familial, early childhood, and lifetime psychiatric factors that determine development of smoking and response to cessation treatment. In one study, investigators are exploring the potential impact of social network factors as predictors of adolescent smoking.

- Researchers found that major depression had a greater association than nicotine withdrawal symptoms on making the transition from regular smoking to nicotine dependence.

- In a study looking at whether nicotine dependence is elevated among adults who were exposed to nicotine while in utero, investigators found that those adults whose mothers smoked a pack or more a day are at increased risk for developing nicotine dependence.

The Yale University TTURC is making considerable progress investigating the links between depression, gender, and smoking. Results from its studies suggest that:

- Among men and women, negative emotion was strongly associated with smoking behavior, specifically the total number of cigarettes smoked, duration of puffs, and total volume of smoke consumed over the course of the study.

- In a trial of 40 cigarette smokers, selegiline was found to be superior to placebo for smoking cessation.

Youth Tobacco Prevention and Cessation

Contact Cathy Backinger, PhD, 301-435-8638, backingc@mail.nih.gov

Research funded by DCCPS has found that the pattern of nicotine dependence among youth does not parallel the model developed for adults. Contrary to past assumptions, adolescents who are not daily smokers still may encounter significant difficulty in quitting smoking. In order to assess adolescent tobacco cessation programs and inform future activities and research, NCI has formed collaborative partnerships with other NIH institutes and centers, the Centers for Disease Control and Prevention, the Robert Wood Johnson Foundation, and the American Cancer Society.

- Among the many new important findings from this initiative is evidence that exposure to smoking in popular movies increases the risk of smoking in teenage viewers.

Currently, NCI funds research grants in the areas of youth and tobacco research, including prevention; experimentation; onset of regular tobacco use, dependence, and withdrawal; and cessation and treatment of tobacco by adolescents. Selected findings are highlighted below:

- Researchers at Dartmouth Medical School reported a close link between tobacco promotional activities and adolescent smoking. Over time, the likelihood of smoking initiation is increased when an adolescent acquires a cigarette promotional item. Results suggest that elimination of cigarette promotional campaigns could reduce adolescent smoking.

- Researchers at the Fred Hutchinson Cancer Research Center found that the strongest predictive variables for smoking were rebelliousness and risk taking. The results suggest that smoking prevention programs should include the needs and expectations of rebellious and risk-taking youth, and should begin no later than fifth grade.

State and Community Tobacco Control Interventions

Contact Bob Vollinger, MSPH, 301-496-8584, bob.vollinger@nih.gov

The State and Community Tobacco Control Interventions initiative supports research on new or existing tobacco control interventions, particularly policy and media-based interventions, relevant to state and community tobacco control programs. The research results assist the nation's tobacco control programs in efforts to increase program effectiveness and reduce the prevalence of tobacco use. The initiative is noteworthy for its specific emphasis on fostering collaborations between tobacco control researchers, state-based comprehensive tobacco control programs, and community-based coalitions.

Under the first issuance of the RFA, NCI funded 12 grants. The RFA was reissued with three awards made in Fiscal Year 2001, and four additional awards made in Fiscal Year 2002.

The following grants were awarded under the first issuance:

- Studying Tobacco Control Policy in Massachusetts, Michael Begay, University of Massachusetts, Amherst.
- Denormalizing Smoking via Policy and Media Interventions, Lois Biener, University of Massachusetts, Boston.
- Tobacco Control Activities and Adolescent Tobacco Use, Anthony Biglan, Oregon Research Institute.
- Web-Based Support—Community Tobacco Control Coalitions, David Buller, AMC Cancer Research Center.
- Business Practices and Minors' Access to Tobacco, Pamela Clark, Battelle-Centers, Public Health Research Evaluation.
- The Alabama Tobacco-Free Families Program, Myra Crawford, University of Alabama at Birmingham.
- Follow-up of the COMMIT Cohort Participants 13 Years Later, Michael Cummings, Roswell Park Cancer Institute Corporation.
- Effects of Minnesota State and Local Programs on Youth Tobacco Use, Jean Forster, University of Minnesota, Twin Cities.
- Efficacy and Cost of State Quitline Policies, Jack Hollis, Kaiser Foundation Research Institute.
- Texas Multicultural Regional Community Tobacco Studies, Alfred McAlister, University of Texas Health Science Center, Houston.
- Policy to Support Tobacco Treatment in Health Care, Judith Ockene, University of Massachusetts Medical School.
- Youth Smoking and the Media, Melanie Wakefield, University of Illinois at Chicago.

Grants funded under the second issuance include the following:

- Community Surveillance and Novel Tobacco Products, Pamela Clark, Battelle-Centers, Public Health Research Evaluation.
- Preventing Teen Smoking by Restricting Movie Exposure, James Sargent, Dartmouth College.
- Randomized Study to Decrease Smoking in College Students, Beti Thompson, Fred Hutchinson Cancer Research Center.
- Effect of Smoking Cessation Interventions in a Chinese Population, Marianne Fahs, New School University.
- Community-Based Training Models for Tobacco Cessation, Myra Muramoto, University of Arizona.
- Parenting to Prevent Problem Behaviors, John Pierce, University of California San Diego.
- Healthcare Team Approach to Tobacco Cessation, Alexander Prokhorov, University of Texas M.D. Anderson Cancer Center.

Tobacco Intervention Research Clinic

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DCCPS has established a state-of-the-science tobacco intervention research clinic for NCI scientists and collaborators across NCI intramural and extramural divisions, as well as for other NIH institutes. The clinic is a resource for scientists conducting a range of genetic, epidemiological, and basic science and behavioral research studies. It also enables individuals from NIH and the local community to receive research-based tobacco

cessation services. Importantly, the clinic increases the opportunities to target research that focuses on the tailoring of interventions for special high-risk populations. The first study is exploring the potential of developing a potent smoking cessation intervention for cancer survivors by enhancing currently available treatments with contingency management, a promising behavioral technique that rewards patients for not smoking.

Research on New Tobacco Products

Contact Mirjana Djordjevic, PhD, 301-496-8584, djordjev@mail.nih.gov

The U.S. market includes more than 1,000 brands of cigarettes that deliver a wide range of nicotine, tar, carbon monoxide, and other smoke constituents. In recent years, there has been a proliferation of a new generation of tobacco products that are marketed and advertised with claims that imply safety. These products are relatively new, and information on their purported harm-reducing properties comes from the tobacco industry. The purpose of this NCI initiative is to fund multidisciplinary research on the interplay of behavior, chemistry, toxicology, and biology to determine the cancer risk potential of reduced-exposure tobacco products. There is much to be learned about tobacco products that purport to reduce harm and/or help smokers quit. NCI will continue to collaborate with partners to develop and implement a framework for the independent and objective scientific research, review, and interpretation of data on these tobacco products and their use.

New Directions in Behavioral Research

Centers of Excellence in Cancer Communications Research

Contact Gary Kreps, PhD, 301-496-7984, krepsg@mail.nih.gov

In Fiscal Year 2003, NCI awarded four Centers of Excellence in Cancer Communications Research to speed advances in cancer communications knowledge. Interdisciplinary teams of researchers develop, implement, and evaluate strategies to improve access to cancer information and the effectiveness and dissemination of efficacious interventions. The centers provide essential infrastructure to facilitate rapid advances in knowledge about cancer communications, develop effective interventions, translate theory and programs into practice, and train health communication scientists. The novelty and scope of this initiative reflect the enormous potential of cancer communications to improve health, and NCI's recognition that effective communications can and should be used to narrow the gap between discovery and application and to reduce health disparities among our citizens.

Center grants awarded and their themes include the following:

- Develop an efficient, theory-driven model for generating tailored health behavior interventions that is generalizable across health behaviors and sociodemographic populations, Victor Strecher, University of Michigan.
- Examine how people make sense of the complex public information environment and how that affects the behavioral choices they make relevant to cancer, Robert Hornik, University of Pennsylvania.
- Enhance the effectiveness of cancer communication among African Americans, Matthew Kreuter, Saint Louis University.
- Advance interactive cancer communication systems to improve the quality of life of patients and families facing cancer across the disease spectrum—with special emphasis on underserved populations, David Gustafson, University of Wisconsin, Madison.

Basic Biobehavioral Research on Cancer-Related Behaviors

Contact Mike Stefanek, PhD, 301-496-8776, ms496r@nih.gov

The Basic Biobehavioral Research in Cancer-Related Behaviors initiative funds research on the links between biology, behavior, and environment as they pertain to cancer-related risk behaviors. NCI funded eight grants under the first issuance and six additional grants under the reissuance in Fiscal Year 2000.

- Two projects, Psychobiological Mechanisms of Smoking Relapse, Mustafa Al'Abasi, University of Minnesota (Twin Cities), and Behavioral Vulnerability to Early Smoking Relapse, Richard Brown, Butler Hospital (Providence, RI), examine the biobehavioral (biological, physiological, emotional, and behavioral) mechanisms related to early smoking relapse. Results should hold considerable clinical and public health significance for early lapsers, a recalcitrant group of smokers at risk for continued nicotine dependence.

- Determinants of Delay Discounting in Smokers, Leonard Epstein, State University of New York at Buffalo, evaluates factors that may lead smokers to discount future positive benefits of not smoking. Results will likely contribute to the delineation of factors associated with maintaining abstinence.

- Presurgery Stress—Biological Impact in Breast Cancer, Dana Bovbjerg, Mount Sinai School of Medicine of New York University, examines the impact of presurgery stress on presurgery levels of natural killer cell activity, and surgery-related dissemination of tumor cells in the blood stream. These factors have been identified as potential predictors of metastatic disease development based on animal model research.

- Psychological Influences on Immune Responses to HPV, Carolyn Fang, Fox Chase Cancer Center, studies psychoneuroimmunologic pathways in women with mild dysplastic lesions of the cervix due to infection with highly oncogenic subtypes of human papillomavirus. Information can be used to guide the development of psychological and behavioral interventions to reduce distress and result in improved behavioral, immunologic, and health outcomes.

- Biobehavioral Immune Interactions in Ovarian Cancer, Susan Lutgendorf, University of Iowa, examines the relationship of stress, depression, social support, and coping in women presenting for surgical diagnosis of ovarian cancer. This work may provide evidence of an inflammatory pathway by which biobehavioral factors may contribute to ovarian cancer.

Biological Mechanisms of Psychosocial Effects on Disease

*Contact Paige McDonald, PhD, 301-435-5037, mcdonalp@*mail.nih.gov

The overarching goal of the Biological Mechanisms of Psychosocial Effects on Disease initiative is to elucidate the dynamic bidirectional relationships between cancer and human host environments. The intent is to encourage new research that explores how psychosocial characteristics and behaviors of the host influence cancer initiation, progression, and resilience through biological mechanisms (e.g., angiogenesis, DNA damage and repair, apoptosis). New transdisciplinary research—that bridges the divide between basic cancer biology and applied cancer biobehavioral sciences—is needed to fully explore the dynamic interrelationships among cancer cells, surrounding cells, the tumor, and host environments.

Decision Making Related to Cancer Control (future initiative)

Contact Wendy Nelson, PhD, 301-435-4590, nelsonw@mail.nih.gov

DCCPS is planning an initiative on decision making related to cancer control. The purpose of this effort is to better understand human decision-making

processes so that individuals can make more informed choices regarding their health care. To accomplish this, it is necessary to draw upon research in both the basic and applied arenas which have historically functioned as separate research domains. This initiative is focused at the level of the individual patient or health care provider, which may involve the patient-provider dyad, the patient-caregiver dyad, the patient-partner dyad, or the patient-family system. In 2003, DCCPS co-sponsored with the Federation of Behavioral, Psychological, and Cognitive Sciences, a one-day meeting devoted to decision research. The meeting brought together leading researchers in basic decision science and applied cancer decision making. A second meeting is planned for 2004. Proceedings will be published in a journal special issue and will be available on the Web.

Energy Balance

Physical Activity Behavior Change Theories

Contact Louise Masse, PhD, 301-435-3961, massel@mail.nih.gov

Given the importance of physical activity in the etiology, treatment, and prevention of many chronic diseases (such as cardiovascular disease, some cancers, and diabetes), it is important to understand how physical activity behavior can be increased. The purpose of this request for applications on Physical Activity Behavior Change Theories is to increase the knowledge base necessary to develop effective physical activity interventions in children, adolescents, adults, and older adults. Specifically, this RFA seeks to elucidate the psychosocial, environmental, and physiological factors involved in the mechanisms of physical activity behavior change to better understand the factors involved in the causal pathways that lead to physical activity behavior change. NCI's contributing partners include the National Institute of Diabetes and Digestive and Kidney Diseases, the Office of Behavioral and Social Sciences, NIH Office of Disease Prevention, and NIH Office of Research on Women's Health. Funding is planned for Fiscal Year 2004.

Observing Protein and Energy Nutrition

Contact Amy Subar, PhD, 301-594-0831, subara@mail.nih.gov

NCI and its partners are improving needed diet and physical activity measures, including both self-reported and objective measures. The Observing Protein and Energy Nutrition (OPEN) study, the largest of its kind, used biomarkers of dietary intake to assess the accuracy of dietary assessment methods commonly used in epidemiology, intervention, and surveillance research. The investigators found that self-reported intake measures used in many studies are not sufficiently accurate. Further research will examine whether these findings are true for diverse populations, for other dietary-report or physical activity instruments, and across varying nutrients and food groups, as well as how the measurement inaccuracies may affect ongoing prospective cohort studies.

Centers for Transdisciplinary Research on Energetics and Cancer

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The Centers for Transdisciplinary Research in Energetics and Cancer (TREC) will involve scientists from multiple disciplines and encompass projects spanning the biology and genetics of energy balance to behavioral, sociocultural, and environmental influences on nutrition, physical activity, weight, energy balance, and energetics. The TREC centers will foster collaboration among transdisciplinary teams of scientists with the goal of accelerating progress toward reducing cancer incidence, morbidity, and mortality associated with obesity, low levels of physical activity, and poor diet. They also will provide training opportunities for new and established scientists who can carry out integrative research on energetics, energy balance, and its consequences. The anticipated launch of this initiative is Fiscal Year 2005.

Health Disparities

Centers for Population Health and Health Disparities

Contact Suzanne Heurtin-Roberts, PhD, 301-594-6655, sheurtin@mail.nih.gov

The National Institute of Environmental Health Sciences, National Institute on Aging, NCI, and Office of Behavioral and Social Sciences Research recently awarded eight Centers for Population Health and Health Disparities. The centers support transdisciplinary, multilevel, integrated research to elucidate the complex interactions of the social and physical environment, mediating behavioral factors, and biologic pathways that determine health and disease in populations, leading to an understanding and reduction of health disparities. This leading-edge initiative responds to the recommendations of several recent reports from the National Academy of Sciences and employs NIH's most advanced and innovative population science to address the problem of health disparities. Using a community-based participatory research approach, these centers will engage and include community stakeholders in the planning and implementation of health research. Communities include the elderly, African Americans, poor Whites, and Hispanics. Studies will focus on obesity, cardiovascular disease, breast cancer, prostate cancer, cervical cancer, mental health, gene-environment interactions, allostatic load, oxidative stress, psychosocial stress, neighborhood environments, and built environments. Center awards were made to the following:

- Sarah Gehlert, The University of Chicago and University of Ibadan (Nigeria).
- John Flack, Wayne State University.
- Nicole Lurie, RAND Corporation.
- Katherine Tucker, Tufts University and Northeastern University.
- James Goodwin, The University of Texas Medical Branch Galveston.
- Timothy Rebbeck, University of Pennsylvania.
- Richard B. Warnecke, University of Illinois at Chicago.
- Electra Paskett, Ohio State University and University of Michigan.

Native C.I.R.C.L.E.

Contact Judith Swan, MHS, 301-496-8506, swanj@mail.nih.gov

Native C.I.R.C.L.E. (Native Cancer Information Resource Center and Learning Exchange) has been in operation since September 1998 as a national clearinghouse for population-tested cancer education materials (for lay and professional use) specific to American Indian and Alaska Native communities. It is a collaborative effort with the Mayo Comprehensive Cancer Center and an NCI-supported network of American Indian and Alaska Native cancer researchers. The center has evolved to become the educational arm for the American Indian/Alaska Native Special Population Network, "Spirit of Eagles," funded by NCI. Information requested from the resource center led to the distribution of over 20,000 pieces of literature and videos in 2003 alone. The center has provided materials to over 75 conferences in the past year, and serves as a coordinating center for the Native American cancer control research and Special Populations Networks supported by NCI. In addition, Native C.I.R.C.L.E. provides researchers working in Native communities with the most timely and comprehensive bibliography on cancer affecting American Indians and Alaska Natives.

Survivorship

Long-Term Cancer Survivors Research Initiative

Contact Noreen Aziz, MD, PhD, 301-496-0598, azizn@mail.nih.gov

The population of long-term cancer survivors continues to grow: 63 percent of adult and 78 percent of pediatric cancer survivors survive beyond

five years. Cancer can be, for most people, a chronic disease. The Long-Term Cancer Survivors Initiative, first funded in 1998, focused on questions related to the physiological and psychosocial experiences of cancer survivors five or more years post diagnosis, and interventions to promote positive outcomes. An additional round of funding is planned for Fiscal Year 2004. Over 125 applications were received. This request for applications is one of the cornerstone initiatives of the scientific priority in Cancer Survivorship. It directly responds to the recent Institute of Medicine reports on cancer survivorship, as well as the priorities of the President's Cancer Panel. Highlights from the first issuance are summarized below:

- There are long latencies for potentially life-threatening late effects (e.g., heart failure secondary to the cardiotoxic effects of cancer treatment), emphasizing the need for extended follow-up.
- Many disease- and treatment-related effects (e.g., fatigue, sexual dysfunction, cognitive impairment, neuropathies) can be persistent, and worsen over time.
- The adverse sequelae of cancer and its treatment contribute to the ongoing burden of illness, costs, and decreased length and quality of survival.
- Early identification of, and interventions for, those survivors at increased risk for disease- and treatment-related problems hold the promise of reducing adverse treatment outcomes.

Innovative Cancer Control in Cancer Centers

Contact Noreen Aziz, MD, PhD, 301-496-0598, azizn@mail.nih.gov

Innovative Cancer Control in Cancer Centers provides NCI-designated cancer centers with supplemental funds for innovative pilot research projects in cancer control and population sciences. NCI has awarded 36 pilot projects in areas including survivorship, cancer control intervention/pre-intervention, epidemiology, descriptive research, cancer screening, communications, health economics, and basic science research. Investigators have been successful, with four receiving NIH grants based on the data from completed pilot studies, and one who was awarded a non-NIH grant. Additionally, six scientific papers have been published to date, with more anticipated.

Research on the Impact of Cancer on the Family

Contact Gina Tesauro, MSW, 301-402-2747, tesaurog@mail.nih.gov

A review of NCI's FY 1999 research portfolio indicated that only 18 studies focused on the impact of cancer on the family. To stimulate research on family members of cancer survivors, DCCPS provided 1-year supplement awards to NCI-funded clinical and comprehensive cancer centers. Funded studies at 10 institutions 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. Final products were produced from six of the grants, including:

- Brochures to promote prostate cancer screening.
- A workbook for terminally ill patients and their caregivers.
- Three training manuals for health care professionals for delivering unique family-focused interventions.
- Two tools for the investigator community: a standardized method for observing and coding behavioral interactions between family members, and an instrument to help assess couples' intimacy.

In Fiscal Year 2002, one of the investigators was successfully awarded a small grant to expand upon preliminary findings derived from this supplemental funding. The grant employs a longitudinal design to assess the psychological and relationship functioning of lung cancer patients and spouses. This spin-off award exemplifies the importance of the

supplement mechanism to generate pilot data that can serve as a model for more expansive studies. The remaining nine grantees continue to be funded by NIH. There is a continuing need to develop future initiatives to understand the impact of cancer on the family and to further test interventions to alleviate the burden of cancer on family health and on psychosocial and economic well-being.

Research on Minority and Underserved Cancer Survivors

Contact Diana Jeffery, PhD, 301-435-4540, jefferyd@mail.nih.gov

Funded in Fiscal Year 2001, the purpose of this supplement to cancer centers was to promote research in cancer survivorship among minority and underserved patients who had completed initial treatment, as well as among the families of such patients. Awardees identified community linkages for research participation and plan to disseminate research findings to the targeted community and cancer centers. The following six awards were made:

- Experiences of Rural and Urban Elderly Cancer Survivors, Stephen Prescott and Susan Beck, University of Utah, Huntsman Cancer Institute.
- Partner-Assisted Coping Skills Training for Prostate Cancer Survivors, Mike Colvin and Francis Keefe, Duke University Cancer Center.
- Breast Cancer Survivors and Community Support, John Crissman and Diane Brown, Wayne State University, Karmanos Cancer Institute.
- Follow-up Care in Breast Cancer Survivors, Ronald Herberman and Jan Jernigan, University of Pittsburgh Cancer Center.
- Reproductive Health in African American Breast Cancer Survivors, John Mendelsohn and Leslie Schover, University of Texas, M.D. Anderson Cancer Center.
- Program for Depression Among Minority Cancer Survivors, Martin Abeloff and James Zabora, Johns Hopkins Oncology Center.

Dissemination and Diffusion

5 to 9 A Day for Better Health Program

Contact Lorelei DiSogra, EdD, RD, 301-496-8520, disogral@mail.nih.gov

NCI encourages all Americans to eat 5 to 9 servings of fruits and vegetables a day for better health. This advice is more critical for African American men, who suffer a disproportionately high incidence of, and mortality from, many chronic diseases related to diet, including cancer. In 2003, NCI launched a 9 A Day campaign for African American men. The campaign includes national radio programming on more than 230 affiliate urban stations and television programming outlets through a faith-based initiative and partnership opportunities with national African American organizations. In a related campaign, a National Basketball Association sports celebrity helped NCI spread the message to all men to "Shoot for 9" through public service announcements and media interviews that aired during the 2003 playoffs.

Cancer Control PLANET and Partnerships

Contact Jon Kerner, PhD, 301-594-6776, jon.kerner@nih.gov

As part of a public-private effort, in 2003 NCI and CDC launched a new Web portal for comprehensive cancer control planning, implementation, and evaluation. The tools available through Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools), were developed in collaboration with ACS, AHRQ, CDC, and the Substance Abuse and Mental Health Services Administration. PLANET helps take the guesswork out of state and community program planning and implementation by providing easy access to a set of evidence-based tools. The goal is to speed the translation of science into practice, and close the research discovery and delivery gap.

Dissemination and Diffusion Supplements

Contact Jon Kerner, PhD, 301-594-6776, jon.kerner@nih.gov

Knowing that an intervention is effective is not enough to improve public health. Effective interventions must be adopted and/or implemented to reach the target population. The purpose of the dissemination and diffusion supplements is to improve the control of disease and enhance health by disseminating promising interventions and products that have been developed and tested by NCI-funded grantees. The supplements facilitate the transfer of evidence-based interventions into practice and advance our understanding of effective strategies to encourage dissemination of evidence-based cancer control interventions.

Dissemination and Diffusion Research Program Announcement (future initiative)

Contact Jon Kerner, PhD, 301-594-6776, jon.kerner@nih.gov

Closing the gap between research discovery and program delivery is both a complex challenge and a necessity in order to ensure that all populations benefit from the nation's investments in new scientific discoveries. NCI is planning a PA that will build on the success of the supplements initiative. The purpose will be to support innovative approaches to understanding and overcoming the barriers to the adoption of health promotion, disease prevention, and treatment interventions that previous intervention research has shown to be effective. The initiative will expand the understanding of cost-effective dissemination approaches that will increase the adoption of promising intervention programs and products by public and private health and human service systems.

Notes

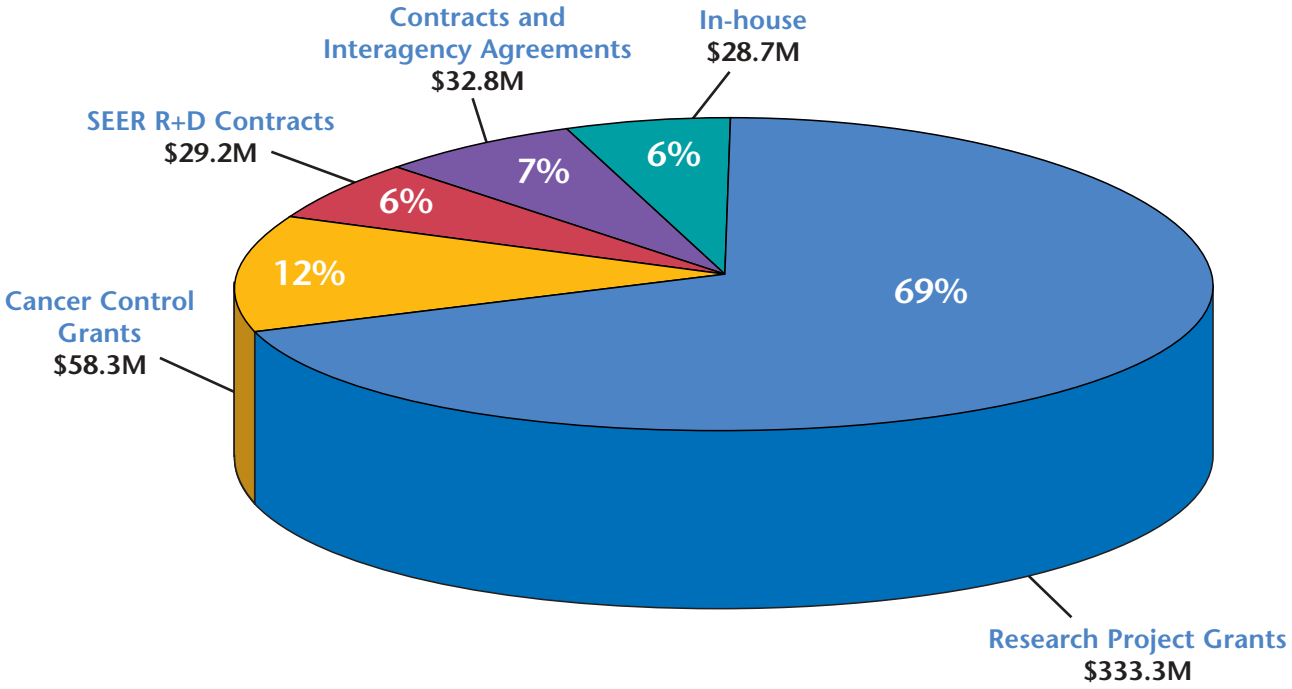
RESEARCH GRANTS & CONTRACTS

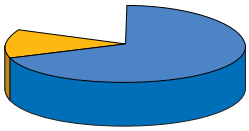
THE RESEARCH ENTERPRISE OF CANCER CONTROL

DCCPS is often considered a "hybrid" division, one that funds a large portfolio of grants and contracts, but also conducts original research to inform public health policy. In this section, we provide an overview of Fiscal Year 2003 research funding and support dollars valued at over $480 million. In addition to overview charts and graphs, look for the U.S. maps that show grant funding and SEER contract awards across the country.

Fiscal Year 2003 Research Funding and Support Dollars

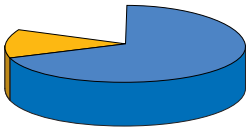
Total Funding = $482.7M



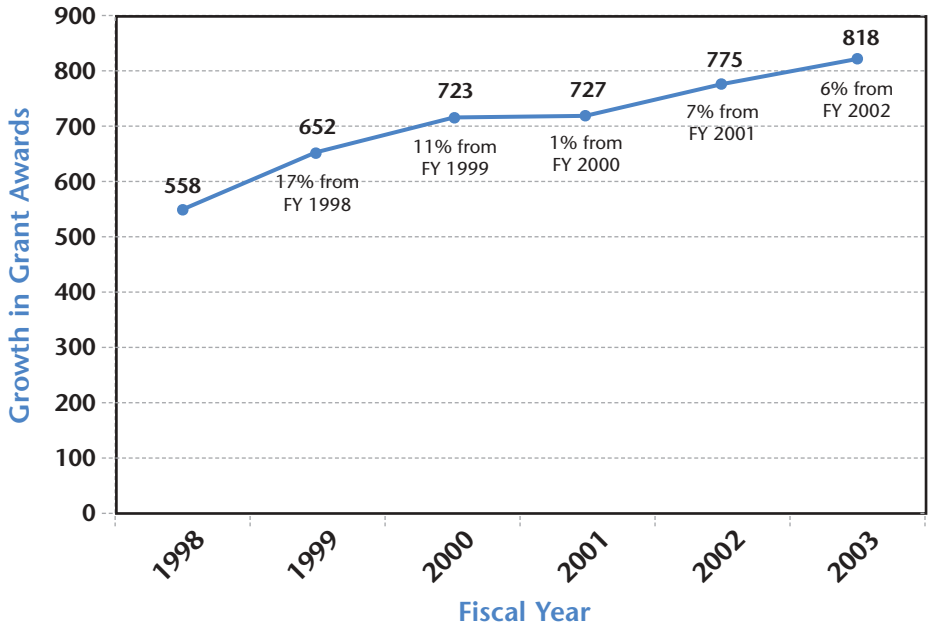


Summary of Fiscal Year 2003 Grant Funding by Mechanism

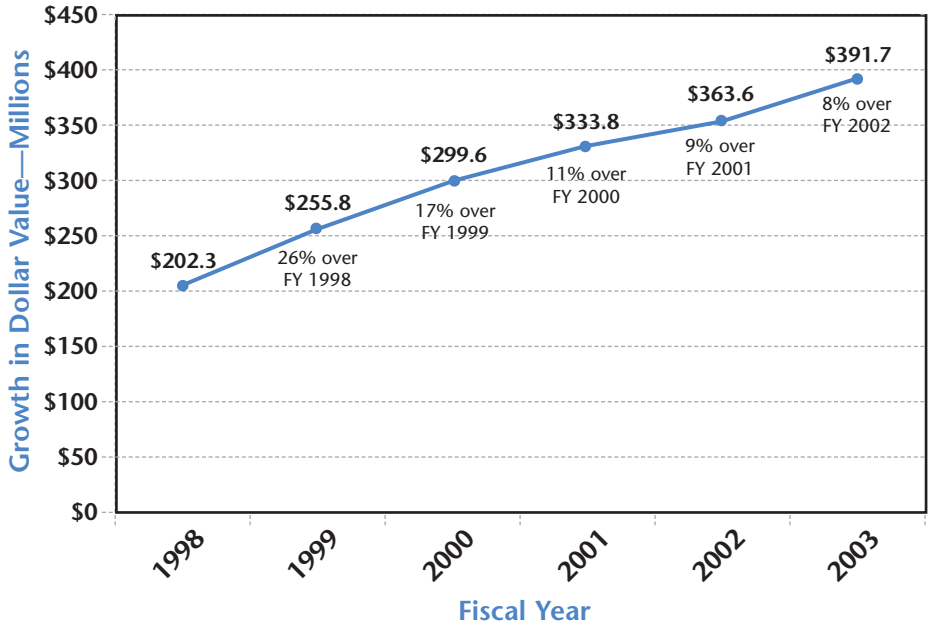
MECHANISM	# OF GRANTS AWARDED	TOTAL DOLLARS
R01 – Research Project	476	$241,701,029
R03 – Small Research Grant	126	$9,296,304
R13 – Conference Grant	13	$640,426
R21 – Exploratory/Development Grant	55	$9,008,474
R24 – Resource-Related Research Project	2	$510,201
R29 – First Independent Research Support & Transition Award (FIRST)	1	$106,161
R37 – Method to Extend Research in Time Award (MERIT)	1	$2,083,190
R43 – Small Business Innovation Research Grant (SBIR) - Phase I	13	$1,462,363
R44 – Small Business Innovation Research Grant (SBIR) - Phase II	23	$9,045,544
P01 – Research Program Project Grant	16	$30,651,652
U01 – Research Project—Cooperative Agreement	65	$50,850,789
U19 – Research Program—Cooperative Agreement	2	$5,304,739
U24 – Resource-Related Research Project—Cooperative Agreement	8	$6,518,284
P41 – Biotechnology Resource Grant Program	1	$100,000
P50 – Specialized Center Grant	16	$24,508,107
TOTAL	**818**	**$391,787,263**



Growth in the Number of DCCPS Research Grant Awards (Fiscal Year 1998–Fiscal Year 2003)



Growth in Dollar Amount of DCCPS Research Grant Funding (Fiscal Year 1998–Fiscal Year 2003)



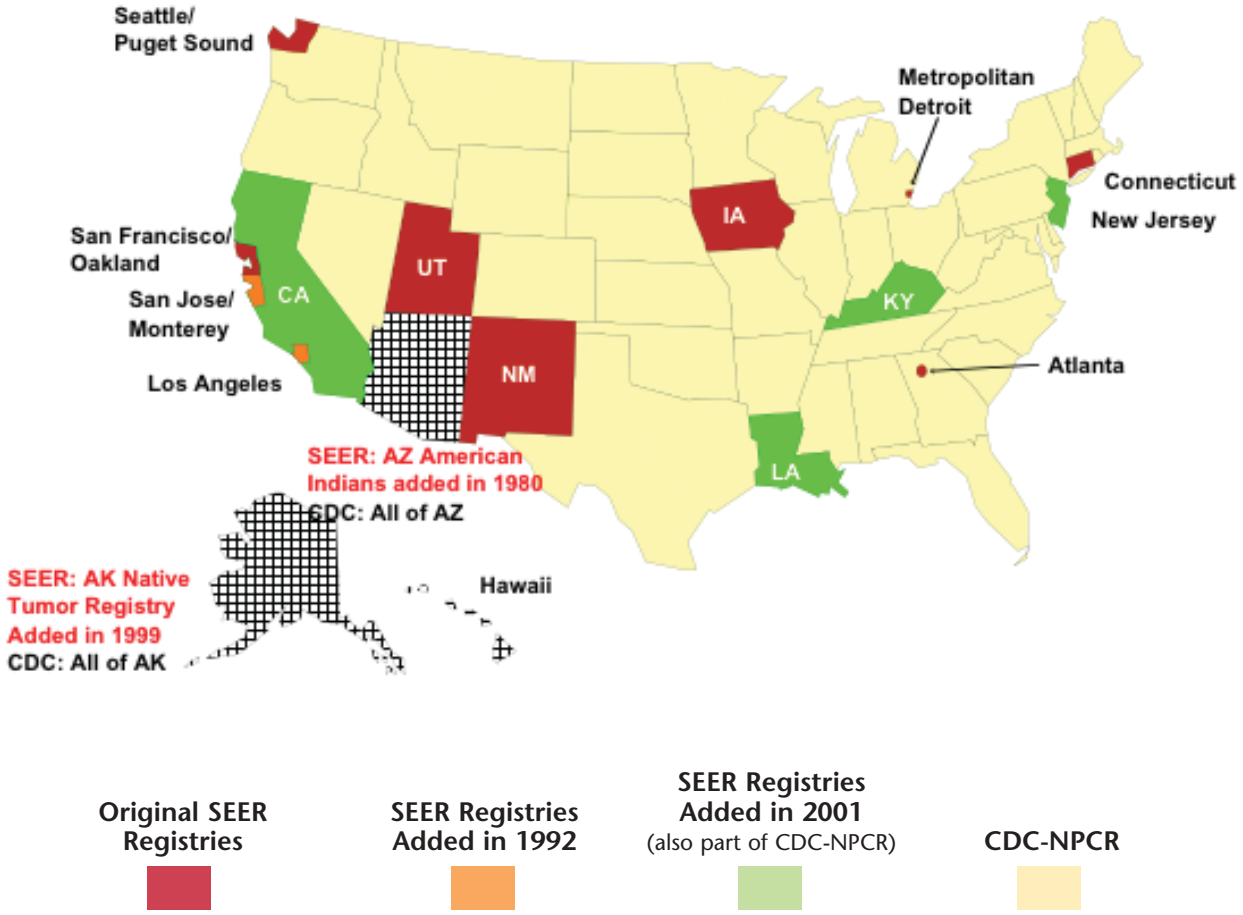
Map of DCCPS Grants by State (Fiscal Year 2003)

Grants Awarded to Institutions in Foreign Countries

COUNTRY	# OF GRANTS AWARDED	TOTAL DCCPS DOLLARS
Sweden	2	$478,437
France	6	$1,958,441
Senegal	1	$54,000
United Kingdom	1	$435,348
Canada	5	$3,400,062
Australia	4	$2,371,105
Netherlands	2	$158,177
SUBTOTAL	**21**	**$8,855,570**

Map and Table = 818 Grants

Map of Cancer Registries: SEER and NPCR



Notes

TOOLS, PRODUCTS & RESOURCES

ENABLING SUCCESS IN CANCER CONTROL

From the division's public Web sites and data resources to its internal planning and management tools, DCCPS staff members are innovators in creating resources for the public, researchers, and extramural investigators. This section highlights some of our most creative and functional products.

- Statistical Analyses
- Geographic Information Systems
- Quality of Care and Outcomes Research
- Cancer Communications
- Survivorship
- Survey Data
- Dietary Risk Factor Monitoring
- Dissemination and Diffusion
- Grants Management and Evaluation
- Public Web Site

Statistical Analyses

Finding Cancer Statistics

http://surveillance.cancer.gov/statistics/

Recently developed to facilitate the use of cancer data, *Finding Cancer Statistics* is a plain-language Web site that provides access to recent reports, datasets, and statistical tools for professionals and the general public. It includes definitions of commonly used statistics, descriptions of datasets and tools, and guides to their use.

Surveillance, Epidemiology, and End Results Program

http://seer.cancer.gov

SEER Web site

The SEER Web site is the preferred mechanism for distributing most of SEER's products. The power and redundancy built into the system years ago are paying dividends. Recent additions to the site include the SEER 1973-2000 Cancer Statistics.

SEER*Stat

SEER*Stat is a statistical system for the analysis of SEER and other population-based cancer databases. The system provides an easy-to-use Microsoft Windows desktop package for viewing individual cancer records and for producing statistics to assess the impact of cancer on populations. The newest version allows users to take advantage of the client-server system that has been used within NCI for two years. This version brings multiple primary selection capabilities to the frequency/rate and case listing sessions. The survival session has been expanded from two to five statistics, including cause-specific survival. Limited-Duration Prevalence can now be calculated using the SEER*Stat (http://seer.cancer.gov/seerstat) analysis software.

SEER*Prep

The SEER*Prep system allows users to prepare and format their own cancer incidence, mortality, population, and expected survival rate data for use with SEER*Stat.

Fast Stats

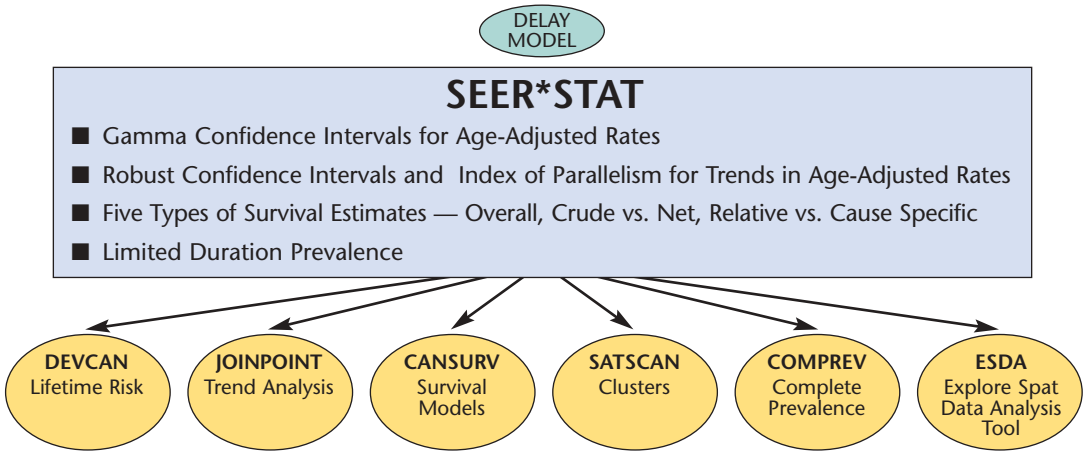
Fast Stats is a new feature of the SEER Web site. Fast Stats uses the Cancer Query System 2.0, CanQues, as an interactive system with Java interface to allow users access to millions of precalculated cancer statistics. Users have a choice of outputs, including vertical bar charts, line charts, tabular reports, or delimited data files. CanQues contains statistics that were created using SEER*Stat for the SEER Cancer Statistics Review, and is updated annually.

Other Statistical Methods and Software

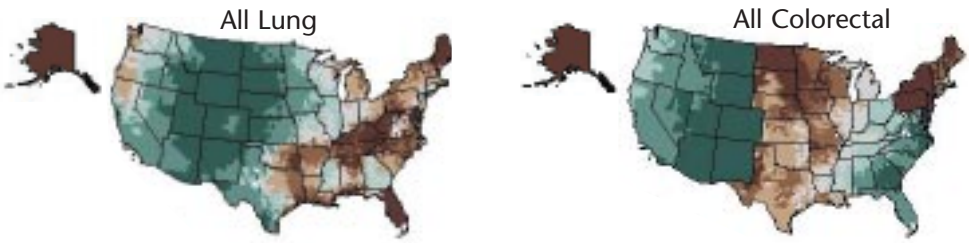
The Surveillance Research Program has developed new statistical methods and associated software tools for the analysis and reporting of cancer statistics. Methods associated with reporting basic cancer statistics are added directly to SEER*Stat, while methods that involve complex modeling are developed as separate applications that can be used with SEER*Stat.

- *DevCan* uses life table methods to compute the lifetime and age-conditioned probability of **DEV**eloping **CAN**cer and dying of cancer in the general population. Input data for the computations include cancer incidence and mortality rates, as well as "all cause" mortality rates. Datasets are supplied to estimate risks of developing and dying of cancer for over 20 cancer sites by race and sex.
- *Joinpoint* is a Windows-based statistical software tool that analyzes data trends in cancer rates. The tool uses a model with line segments connected at the "joinpoints," which indicate where significant changes in trend have been calculated.
- Prevalence represents new and pre-existing conditions alive on a certain date, in contrast to incidence, which reflects only new cases of a condition diagnosed during a specified period of time. Prevalence is important to public health in general and the survivorship community in particular because it identifies the level of burden of disease.

Statistical Methods Development for the Analysis and Reporting of Cancer Statistics



SEER State and County Level Maps, 2 Major Cancer Mortality Sites



Rate categorization = 7 equal percentiles (14.3%), browns are high, greens are low

Genes and the Environment

Geographic Information Systems for Cancer Research

http://epi.grants.cancer.gov/GIS.html

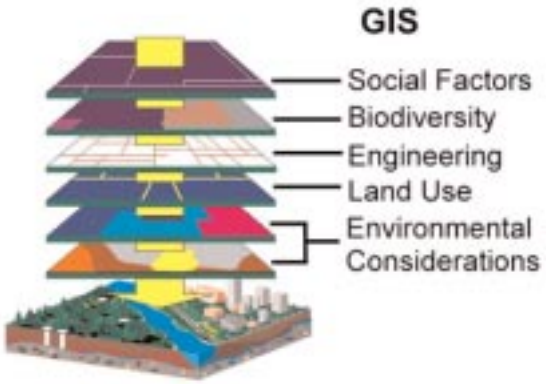
The Epidemiology and Genetics Research Program has developed a Geographic Information System for Breast Cancer Studies on Long Island (LI GIS), New York. The LI GIS provides researchers a unique tool with which to investigate potential relationships between environmental exposures and risk for breast cancer.

The system contains 80 databases, including demographic, environmental, and health data. Researchers are invited to apply to use the system. Only researchers with approved protocols may access the system because of privacy and confidentiality issues. A public mapping facility is being developed to provide interested individuals a glimpse of what is in the system and how it works.

The LI GIS is of potential interest to many researchers. It can be used to study relationships between environmental exposures and breast cancer and other diseases, as well as to develop new or improved research methods, such as statistical techniques or exposure assessment methods. In addition, DCCPS encouraged the submission of investigator-initiated research projects to use GIS to investigate determinants of geographic patterns of cancer uncovered in NCI's *Atlas of Cancer Mortality in the United States, 1950-1994*, and to refine GIS and related methodologies. Twelve awards were made in Fiscal Years 2001 and 2002.

Geographic Information System Overview

GIS' are powerful computer systems that can store, manipulate, analyze, and display the spatial (geographic location) relationships between dissimilar data types. A GIS produces a series of "stacked maps" or data layers of georeferenced data linked to descriptive attribute information. By processing multidimensional data at different geographic levels and maintaining the spatial relationships among them, a GIS provides a powerful tool for the analysis and presentation of spatial data. In addition, a GIS is capable of integrating both spatial and temporal data. This is important when studying diseases such as cancer for which the relevant time period of exposure may have occurred many years prior to diagnosis.



Quality of Care

Outcomes Research Products

Outcomes research, a growing area of cancer control, seeks to understand and predict the impact of interventions on end results that matter to decision makers. Such end results include not only better survival rates but also reduced suffering due to cancer, as captured by such patient-centered measures as health-related quality of life. DCCPS develops and releases many significant resources for outcomes research, including the following:

- *Outcomes Assessment in Cancer* reports the findings and recommendations of NCI's Cancer Outcomes Measurement Working Group, plus supplementary chapters by other experts in the field. Scheduled for publication by Cambridge University Press in mid-2004, the book surveys the state of the science in cancer outcomes measurement, with particular emphasis on patient-centered endpoints such as health-related quality of life, patient evaluation of care, and economic burden. The book is intended for a wide and growing audience of scholars, practitioners, and policymakers; pharmaceutical and medical device companies currently developing or planning oncology products; health services researchers and measurement experts in both the academic and private consulting communities; health law firms, management consulting firms, and contract research organizations, which are frequently employed by industry and large medical care organizations for strategic advice on product development, trial design, care delivery, and risk management; NCI-sponsored cancer centers, clinical trial cooperative groups, community clinical oncology programs, and their international counterparts; federal and state officials and policy analysts involved in cancer care delivery, coverage, or regulation; and medical and health sciences libraries throughout the world.

- Important statistical approaches to analyzing and interpreting data on health-related quality of life, discussed and advocated by psychometrics experts on the Cancer Outcomes Measurement Working Group, are based on item response theory (IRT). Long used in educational testing but comparatively new to health outcomes research, IRT offers the theoretical basis for such practical, cutting-edge applications as the development of survey "item banks" and their use in computerized adaptive testing. To introduce IRT and its important applications to clinical policy researchers, a tutorial—"An Introduction to Modern Measurement Theory"—was produced and is available at http://appliedresearch.cancer.gov/areas/cognitive/item.html.

- *Cancer Outcomes Research: the Arenas of Application* will be published in spring 2004 as a *Journal of the National Cancer Institute Monograph*. It will include a set of papers by leading cancer outcomes researchers that review and evaluate this burgeoning field and lay the groundwork for a 21st century research agenda. The monograph assesses contributions of outcomes research, particularly over the last decade, within the following arenas of application: population surveillance; studies (both controlled and observational) to evaluate the efficacy, effectiveness, and cost-effectiveness of treatment and screening interventions for five major cancer types (breast, colorectal, lung, prostate, and childhood leukemia); and efforts to enhance patient-provider communication and decisionmaking. Additional papers discuss ways to improve the quality of economic evaluations, and the need for an overarching outcomes measurement framework across many arenas to promote comparability of study findings and consistency in decisionmaking. The monograph concludes with observations from NCI staff—in their role as outcomes researchers—on the scientific challenges that lie ahead, and possible approaches to meeting them.

SEER-Medicare Datasets

http://healthservices.cancer.gov/seermedicare/

The SEER-Medicare datasets consist of linkages to the clinical data collected by the SEER registries about claims for health services collected by Medicare for its beneficiaries. These combined datasets can be used for an array of studies, including:

- Assessing patterns of care for persons with cancer.
- Use of tests and procedures during the period prior to and following, a cancer diagnosis.
- Determining costs of cancer treatment.

This linkage of the SEER data with Medicare claims is an important part of cancer health services and outcomes research.

Cancer Communications

Risk Communication Bibliography

http://cancercontrol.cancer.gov/DECC/riskcommbib

Because the public's perception of health risks is a key component of cancer control, investigators should be aware of risk communication research in their respective fields. DCCPS lead the creation of a risk communication bibliography which contains more than 650 references to published documents that address the communication of public health hazards. Users can search by health hazard, risk content, audience, communication channel, communication setting, and outcomes. Many of the documents contain information about illnesses, environmental conditions, and accidents. The citations and summaries in the Risk Communication Bibliography are an essential starting point for effectively understanding how risks are communicated to and understood by the public.

Users may search by keyword to obtain relevant citations regarding a risk communication topic. The article titles link to PubMed, which provides additional information and access to the articles.

Online Guide to Health Message Tailoring

http://cancercontrol.cancer.gov/messagetailoring/

Tailored communications allow practitioners to generate highly customized messages on a large scale through the use of computers. Empirical research shows that tailored print materials are more effective than nontailored ones in helping people change health behaviors such as smoking and physical activity. The health message tailoring Web site includes general information about, and instructions for, message tailoring and specific information about relevant research.

Translation of the Tobacco Use Supplement, Current Population Survey

According to the results of local and regional surveys conducted in the native language of the respondents, surveys conducted only in English can seriously underestimate the smoking prevalence of some U.S. subpopulation groups. In an effort to better capture the tobacco-related patterns and behaviors of U.S. communities with limited English proficiency, NCI has translated the national Tobacco Use Supplement to the Current Population Survey (TUS-CPS) (http://riskfactor.cancer.gov/studies/tus-cps/) into Spanish, Chinese, Vietnamese, and Korean. The Spanish version was cognitively tested, and pretested, before being fielded with the English version in 2003. The Chinese, Korean, and Vietnamese versions are currently being evaluated in cognitive interviews and are scheduled for cultural equivalency testing. The various translations of the TUS-CPS, which will be posted on the DCCPS Web site as they are finalized, will provide a valuable resource for a wide range of investigators.

Survivorship

Cancer Survivor Prevalence Data

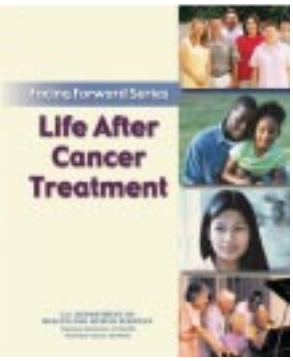
http://survivorship.cancer.gov/prevalence

How many cancer survivors are there? Who are they? These are examples of common questions that researchers, clinicians, and the public ask the Office of Cancer Survivorship (OCS). To better understand the demographics of the U.S. population of cancer survivors, OCS and the Surveillance Research Program worked together to develop survivorship prevalence estimates based on the Surveillance, Epidemiology, and End Results (SEER) registry database, which represents five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah), and four standard metropolitan statistical areas (Detroit, Atlanta, San Francisco-Oakland, and Seattle-Puget Sound). Prevalence is a statistic of primary interest in public health because it identifies the level of burden of disease or health-related events in the population and on the health care system.

In an effort to make survivorship prevalence estimates accessible and easy to understand, OCS displays graphical representations of the data on a Web page dedicated to the topic. Population-based estimates for the composition of current cancer survivors are derived by gender, cancer site, age, race, and time since diagnosis.

Facing Forward Survivorship Series

OCS and the Office of Education and Special Initiatives are working together to revise and expand a series of educational booklets for cancer survivors, their families, and healthcare providers. The updated series addresses the issues cancer survivors may face after they complete active treatment for their cancer. The first booklet in the series, *Facing Forward: Life after Cancer Treatment*, educates cancer survivors and their families about the physiologic and psychosocial changes they may experience upon completing cancer treatment. To better serve the Latino population, the booklet was also translated into Spanish and retitled *Siga adelante: La vida después del tratamiento del cáncer.* The second booklet, *Facing Forward: Ways You Can Make a Difference in Cancer*, outlines the numerous opportunities for survivors to get involved in cancer-related activities—from volunteering at local organizations to participating in research studies and serving as members of review committees. Both documents were created in response to feedback received from cancer survivors and their families through e-mails and focus groups.



Survey Data

Health Information National Trends Survey

http://cancercontrol.cancer.gov/hcirb/hints.html

The Health Information National Trends Survey (HINTS) is a nationally representative, biennial telephone survey of 8,000 randomly selected adults. For the first time, NCI is analyzing data to gain insight into people's knowledge about cancer, the communication channels through which they obtain health information, and their cancer-related behaviors. The survey:

- Provides updates on changing patterns, needs, and information opportunities.
- Identifies changing communications trends and practices.
- Assesses cancer information access and usage.
- Provides information about how cancer risks are perceived.

Tobacco Use Supplement to the Current Population Survey

http://riskfactor.cancer.gov/studies/tus-cps/

An NCI-sponsored federal survey of tobacco use was administered as part of the Current Population Survey conducted by the U.S. Census Bureau. The Tobacco Use Supplement to the Current Population Survey (TUS-CPS) is a key source of national and state data on smoking and other tobacco use in the United States. The dataset can be used by researchers for tobacco-related research and tobacco program evaluation, as well as to monitor progress in tobacco control.

In an effort to better capture the tobacco-related patterns and behaviors of U.S. communities with limited English proficiency, NCI has translated the TUS-CPS into Spanish, Chinese, Vietnamese, and Korean. The Spanish version was cognitively tested, and pretested, before being fielded with the English version in 2003. The Chinese, Korean, and Vietnamese versions are currently being evaluated in cognitive interviews and are scheduled for cultural equivalency testing.

National Health Interview Survey Cancer Control Topical Module

http://appliedresearch.cancer.gov/surveys/nhis/

The National Health Interview Survey (NHIS) is an annual nationwide survey of 36,000 households conducted by the National Center for Health Statistics and administered by the U.S. Census Bureau. In 1987, 1992, and 2000, Cancer Control Topical Modules (CCTM) were administered as part of the NHIS to adults aged 18 and older to determine knowledge, attitudes, and practices concerning cancer-related health behaviors and cancer screening modalities. NHIS/CCTM includes questions on cancer risk factors such as diet, tobacco use, and alcohol consumption. It also includes questions on cancer screening, and is used by DCCPS and others to monitor national levels, trends, and determinants for use of these preventive services. The NHIS is one of the best national sources of data about cancer-related health behaviors.

Physician and Health Plan Surveys

http://appliedresearch.cancer.gov/physician.html

DCCPS develops, conducts, and analyzes national surveys to answer specific questions about the status of cancer control at the national level. Examples include the 1992 National Survey of Mammography Facilities and the 2000 Survey of Colorectal Cancer Screening Practices in Health Care Organizations. These two studies provided national benchmark assessments of breast and colorectal cancer screening.

The Physician Survey on Cancer Susceptibility Testing surveyed 1,251 physicians in the United States to track the diffusion of cancer genetics services in health care delivery. It assessed physicians' use and knowledge of—and attitudes toward—genetic tests for inherited mutations associated with increased cancer risk. The survey will provide valuable baseline data on the use of genetic testing for cancer susceptibility.

California Health Interview Survey

http://appliedresearch.cancer.gov/surveys/chis/

The California Health Interview Survey (CHIS) provides population-based, standardized health-related data from 55,000 households selected from all 58 counties in California. The survey includes questions about screening for breast, colorectal, cervical, and prostate cancers, and sun avoidance.

Although similar to NHIS, the CHIS is modified for telephone implementation and is less detailed. The CHIS is unique in that it provides sufficient data on certain populations, such as Asians and Pacific Islanders, to permit improved analyses.

National Health and Nutrition Examination Survey

http://riskfactor.cancer.gov/studies/nhanes/

DCCPS provides funds to the National Center for Health Statistics to support modules in the National Health and Nutrition Examination Survey (NHANES). Support for these modules is necessary for risk factor monitoring. To date, no national surveys have provided estimates of usual dietary intake or objective assessments of physical activity. NHANES data allow DCCPS staff to estimate the number and percent of persons in the U.S. population, and designated subgroups, with selected cancer risk factors; monitor trends in risk behaviors and environmental exposures; study relationships between diet, physical activity, and health; and establish and maintain a national probability sample of baseline information on physical activity and dietary behaviors.

Monitoring Dietary Risk Factors

http://riskfactor.cancer.gov

In order to monitor and assess cancer risk factors in general populations, and in subpopulations of particular interest, researchers need a variety of tools, including questionnaires, survey instruments, and quick assessment instruments. They also need databases that permit accurate analysis of the data collected. DCCPS is especially proud of the dietary assessment resources described below.

Dietary Assessment Calibration/Validation Register

The Dietary Assessment Calibration/Validation Register is a searchable tool that contains studies and publications that compare dietary intake estimates from two or more dietary assessment methods. Dietary assessment methods include food records or diaries (including weighed intakes), dietary recalls, food frequency questionnaires, dietary histories, observed intakes, chemical analyses of duplicate collections of foods consumed, and biological assessments.

Pyramid Servings Database for NHANES III

The Pyramid Servings Database facilitates the examination of dietary data from the National Center for Health Statistics' Third National Health and Nutrition Examination Survey (NHANES III, 1988-1994) for servings from each of The Food Guide Pyramid's major and minor food groups.

Diet History Questionnaire

The Diet History Questionnaire (DHQ) is a food frequency questionnaire that covers 124 food items and includes portion size and dietary supplement questions. Cognitive research findings were used in the design of the instrument to make it easy to use. The questionnaire takes about one hour to complete.

Diet*Calc

NCI developed the Diet*Calc software to analyze DHQ data files. Diet*Calc interprets the DHQ data to provide nutrient and food group intake estimates.

Percent Energy from Fat Screener

The Percent Energy from Fat Screener is a short assessment instrument used to estimate an individual's usual intake of percent energy from fat. The foods selected for the instrument were considered the most important predictors of variability in percent energy from fat among adults in the U.S. Department of Agriculture's 1989-1991 Continuing Survey of Food Intakes of Individuals. The screener is machine scannable.

Fruit and Vegetable Screeners

Two short assessment instruments estimate an individual's usual intake of fruits and vegetables. Both versions contain the same food item description and portion size ranges, yet they differ in that one asks about usual intakes of all items (termed the All-Day version), and the other asks about usual intakes of fruits and vegetables by time of day (termed the By-Meal version). Both are machine scannable.

Research Dissemination and Diffusion

Translating Research into Improved Outcomes

The **T**ranslating **R**esearch into **I**mproved **O**utcomes (TRIO) program is the centerpiece of the DCCPS commitment to move research discoveries through program development into evidence-based service delivery. The TRIO program has three overarching goals:

- Close the discovery-delivery gap by disseminating cancer and behavioral surveillance data to identify needs, track progress, and motivate national, state, and local action.
- Collaborate with federal and state public health and clinical practice agencies and voluntary organizations to promote the adoption of evidence-based public health and clinical service programs to reduce the overall cancer burden and eliminate cancer health disparities.
- Work 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.

Knowledge transfer teams and Web site help to achieve these overall goals. These elements are listed and described below.

- Knowledge transfer teams within each of the DCCPS research programs, where scientific program directors work with NCI's communication and education specialists to identify the science that is ready for dissemination, set program priorities for dissemination, and initiate dissemination activities.
- The Designing for Dissemination Web site, which links to DCCPS-initiated research dissemination and diffusion activities.
- Cancer Control PLANET, a DCCPS-led public-private partnership Web portal that provides a one-stop source for surveillance data, partnership information, and evidence-based tools and other resources for comprehensive cancer control planning, implementation, and evaluation at state and local levels.
- Evidence-based product directories of programs and products developed and tested through NCI's Small Business Innovation Research (SBIR) program.

Designing for Dissemination

http://cancercontrol.cancer.gov/d4d

The Designing for Dissemination (D4D) Web site provides researchers and public health practitioners a single location for knowledge transfer in cancer control, including access to current research, funding opportunities, information and resources, and research findings. Links to systematic research evidence reviews and conference presentations are available, with both PDF reports and PowerPoint presentation files available for downloading.

Cancer Control PLANET

http://cancercontrolplanet.cancer.gov

The Cancer Control PLANET (**P**lan, **L**ink, **A**ct, **N**etwork with **E**vidence-based **T**ools) was launched in April 2003. This public-private partnership led by NCI and DCCPS—and cosponsored by the Agency for Healthcare Research and Quality, the American Cancer Society, the Centers for Disease Control and Prevention (CDC), and the Substance Abuse and Mental Health Services Administration (SAMHSA)—provides a gateway to tools and resources for comprehensive cancer control planning, implementation, and evaluation.

DCCPS staff led the development of two Web sites within the PLANET portal: State Cancer Profiles and Research-tested Intervention Programs (RTIPs). State Cancer Profiles (Step 1 of the PLANET), jointly sponsored by CDC, provides user-friendly access to cancer incidence, mortality, and behavioral risk factor data at state and county levels for comprehensive cancer control program planning and evaluation. The RTIPs Web site (Step 4 of the PLANET), jointly sponsored by NCI and SAMHSA, was developed with the help of cancer control researchers, with peer-reviewed funding, who have created and tested cancer prevention, early detection, diagnosis, treatment, and survivorship intervention research products, and published their intervention research findings in peer-reviewed journals. As the inventory of RTIPs programs grows, it provides NCI's communication and education staff, extramural researchers, and public health professionals with a "store of knowledge" in which to find evidence-based products that can easily be downloaded or ordered through the RTIPs Web site. These products can then be replicated or adapted for use in similar projects or programs across the country.

Evidence-Based Product Directories

http://cancercontrol.cancer.gov/hcirb/sbir

DCCPS involved its Small Business and Innovation Research (SBIR) grantees in the development of an SBIR products database. The database is organized by topics such as behaviors associated with cancer risk, diverse populations, innovative alternative teaching methods, systems for primary care professionals and oncologists, and systems for the public. The Web site allows users to search for health communication products and view product descriptions, including information on type (CD-ROM, Web, VHS, etc.), demographics, costs, settings, and awards. This is an important step toward closing the discovery-to-delivery gap in cancer control research.

Research Grants Tracking and Analysis

The Portfolio Management Application (PMA) is an integrated Web tool for managing extramural grants. It was developed by DCCPS information technology leaders and is enhanced regularly based on ongoing staff suggestions for new features and improvements. Currently, PMA has almost 400 users throughout several extramural divisions and offices across NCI.

The application has many features that provide staff with timely grant information for portfolio analyses. PMA enables users to search for data that can be viewed on screen, printed on reports, and exported to other applications such as Word, Excel, and Outlook.

Management and Evaluation of Large Initiatives

http://camp.nci.nih.gov/dccps/large_init/

In response to the Institute of Medicine's report on "big science," the congressional focus on the importance of quantifying the return on investment in research, and the doubling of the NIH/NCI budget, DCCPS has developed an evaluation infrastructure to measure progress in its large scientific initiatives. The Transdisciplinary Tobacco Use Research Centers (TTURC) initiative was used as a pilot to develop evaluation metrics for this new infrastructure, including concept mapping and goal setting, markers of goal attainment, surveys, bibliometric analyses, peer evaluation, content evaluation, and financial assessment. The results of the TTURC evaluation were used to inform the division's decision to pursue the TTURC request for applications reissuance and to shape the content of the reissuance concept.

Through the infrastructure development effort, DCCPS has created tools and resources that can be applied to other public health-related research evaluation efforts. A transdivisional team that evaluates large initiatives serves as a forum to do the following: develop new evaluation tools and methods; consult with program directors to provide evaluation assistance; and develop a training program, as well as best practices, that can be shared across NCI. Other large initiatives currently undergoing evaluation include the Cancer Care Outcomes Research and Surveillance Consortium, the Breast Cancer Surveillance Consortium, and the SEER program.

Public Web Site

http://cancercontrol.cancer.gov

The DCCPS public Web site provides researchers, staff members, and the public with information about division programs and branches, research funding opportunities, extramural policies, grant information, products, and much more. The policy information section succinctly displays current NIH grants policy information. The funding opportunities section hosts the most current information about requests for applications and program announcements. The current research section describes division-funded grants and scientific progress in detail. The site provides an array of resources such as links to evidence-based interventions, publications on health disparities and cancer statistics/trends, and Institute of Medicine reports.

Notes

SCIENTIFIC ADVANCES

RETURN ON INVESTMENTS IN CANCER CONTROL

Although it would be impossible to include every scientific contribution from each of NCI's investments in cancer control, this section provides timely highlights from many of our varied research endeavors. What follows is a brief selection of recent scientific advances that have stemmed from many of the initiatives described in this guide. See highlights from:

- Surveillance
- Epidemiology
- Health Services
- Tobacco Control
- Behavioral Research
- Survivorship

SURVEILLANCE

New Methodology for Calculating National Prevalence Estimates

Prevalence is an important estimate of the cancer burden and survivorship in a population. It refers to the number of new and pre-existing cancer cases in people living with cancer on a certain date. Over the past year, NCI scientists have developed a new method for calculating prevalence that is more representative of the nation than previous methods.

In the recent Cancer Statistics Review, prevalence was reported by race, age, and time since diagnosis for a comprehensive list of cancer sites. The total number of people alive as of January 1, 2000, in the United States who had been diagnosed with cancer is estimated to be 4.2 million men and 5.3 million women. Of these, 43.4 percent men and 34.7 percent women were diagnosed with cancer in the previous five years. Estimates of people diagnosed 25 or more years earlier are 261,159 men and 572,093 women representing, respectively, 6.2 percent and 10.1 percent of the prevalent population. Prostate cancer accounted for 38 percent (1.6 million) of male prevalent cases, followed by colorectal cancer (12 percent) and bladder cancer (8 percent). For women, breast cancer contributed to 41 percent of the prevalent cases, followed by corpus uteri cancer (12 percent) and colorectal cancer (10 percent). On average, 28 percent of men and 19 percent of women aged 75 years and older have had a prior diagnosis of cancer.

Since the development of the cancer prevalence methodology, the NCI Office of Cancer Survivorship has reported these figures to survivorship groups across the country. The methodology is being disseminated to researchers through the 2003 release of SEER*Stat, which includes the software to calculate limited duration prevalence estimates and its variance. The software is a powerful tool that will enable researchers to calculate prevalence in very flexible ways, such as for different cancer sites, stage, race, time prior to diagnosis, and different methods for the inclusion of people with multiple tumors.

A related development in methodology allows for calculation of the number of cancer patients undergoing treatment during a particular year ("care prevalence"). Using Medicare claims linked to SEER data, researchers estimated care prevalence for colorectal cancer care, i.e., the proportion of elderly people diagnosed with colorectal cancer who were receiving treatment for their cancer during a recent year. Among the U.S. population aged 65 years and older, 1.81 percent had a diagnosis of colorectal cancer in the previous 21 years, and 1.12 percent received at least one service related to their cancer. This translates to 380,783 people receiving colorectal cancer care in the United States. Care prevalence estimates can give public health officials and policy makers a better estimate of the impact of cancer on cancer resources.

Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Mariotto A, Fay MP, Feuer EJ, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2000, NCI. http://seer.cancer.gov/csr/1975_2000, 2003.

Clegg LX, Gail MH, Feue EJ. Estimating the variance of disease-prevalence estimates from population-based registries. *Biometrics.* 58, 684-688.

Mariotto A, Warren J, Knopf K, Feuer E. The prevalence of patients with colorectal carcinoma under care in the U.S. *Cancer.* 2003; 98(6):1253-61.

U.S. Predicted Cancer Incidence, 1999: Complete Maps by County and State from Spatial Projection Models

While NCI has published U.S. cancer mortality maps since 1974, the 2003 publication of the 1999 maps presents, for the first time, complete county-level maps and state-level maps and tables of estimated cancer incidence. The estimates are based on a statistical modeling of county-level demographic and lifestyle characteristics, in addition to data from the Surveillance, Epidemiology, and End Results (SEER) program. Data are included for total cancers, for the four most frequent cancer sites (lung and bronchus, colon and rectum, prostate, and breast), and for all other cancer sites combined.

The maps represent a qualitative advance in their use of state- and county-level sociodemographic and lifestyle data for estimation. These data fill gaps where state cancer registries have not yet reached the level of complete reporting required for inclusion in the United States Cancer Statistics (USCS). Although rapid progress is being made toward that goal, even after it is reached these data will prove valuable on both national and state levels.

From a national perspective, the maps illustrate the geographic distribution of cancer incidence across the country and of the magnitude of differences among states. They show higher predicted incidence rates for lung cancer in states in the Southeast, for colorectal cancer in Midwestern states, and for all cancers combined in Northeastern states. A greater range of predicted incidence rates among states is observed for lung and colorectal cancers than for other cancers. Smoothed maps of county-level incidence highlight the differences among geographic regions other than by state only. For example, the predicted high female lung cancer incidence rates for counties along the northern Pacific coast are clearly visible in smoothed county maps. Smoothed county-level maps of cancer incidence may also allow correlation with geologic data or environmental data, enabling those with community-level knowledge to see correlations between local conditions and cancer incidence patterns.

From the perspective of individual states, these data offer the ability to utilize county-level data for estimates of new cancer cases expected at the beginning of the data collection year. Cancer control specialists can target interventions to specific areas by using these data in conjunction with information from various state programs (e.g., screening and early detection) and with demographic characteristics including income, race/ ethnicity, medical insurance, etc. In addition, these data can be used for quality control by states in the process of improving their cancer registries, and by states where the variation in cancer incidence from the national levels requires emphasis.

Pickle LW, Feuer EJ, Edwards BK. U.S. predicted cancer incidence, 1999: complete maps by county and state from spatial projection models. NCI Cancer Surveillance Monograph Series, Number 5. 2003; NIH Publication No. 03-5435.

Pickle LW, Feuer EJ, Edwards BK. Predicting cancer incidence in non-SEER counties. Proceedings of the Biometrics Section of the 2000 Annual Meeting of the American Statistical Association. 2001; 45–52.

SURVEILLANCE (cont.)

Area Socioeconomic Variations in U.S. Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999

This monograph is the first of its kind in the United States to provide a comprehensive population-based analysis of the role of socioeconomic factors in U.S. cancer incidence, mortality, treatment, and survival for all cancers combined and for six major cancers: lung, colorectal, prostate, breast, and uterine/cervical cancers, and melanoma of the skin. It is aimed at public health researchers and policymakers interested in tracking the nation's progress toward reducing the cancer burden and health disparities among various segments of the U.S. population.

The effect of socioeconomic factors on such major chronic diseases as heart disease, stroke, diabetes, and respiratory diseases is well established, but their effect on cancer is less well studied. As shown in this report, the relationship between socioeconomic characteristics and cancer is a complex one and varies according to cancer type. Despite overall improvements in mortality and patient survival, substantial socioeconomic disparities in cancer persist, and may be changing or widening over time.

Documenting and monitoring socio-economic and racial/ethnic disparities in cancer incidence, mortality, disease stage, treatment, and survival remain central to cancer surveillance research, both in terms of identifying important cancer-related health disparities and for generating scientific evidence needed to develop comprehensive population-based strategies for cancer prevention and control.

Singh GK, Miller BA, Hankey BF, Edwards BK. Area socioeconomic variations in U.S. cancer incidence, mortality, stage, treatment, and survival, 1975-1999. NCI Cancer Surveillance Monograph Series, Number 4. 2003. NIH Publication No. 03-0000.

New Methodology for Predicting U.S. and State-Level Cancer Mortality Counts

Every January for more than 40 years, the American Cancer Society (ACS) has estimated the total number of cancer deaths that are expected to occur in the United States and individual states in the upcoming year. The estimates are presented in an annual ACS publication, Cancer Facts and Figures, with a distribution of more than 250,000 copies, and are probably the most widely cited cancer statistics in the U.S. In a collaborative effort to improve their accuracy, investigators from NCI and ACS have developed and tested a new prediction method, based on a state-space model (SSM).

Using historical data, the accuracy of the SSM was compared with the previous method at national and state levels. At the national level, while neither method was better for every cancer site, for most cancer sites the SSM performed better than the previous method. In particular, the SSM method was more sensitive to recent changes in cancer mortality rates (and associated counts) that occurred for several major cancer sites in the early and mid-1990s. The improved accuracy of the new method was particularly evident for prostate cancer, for which mortality rates changed dramatically in the late 1980s and early 1990s.

Tiwari RC, Ghosh K, Jemal A, Hachey M, Ward E, Thun MJ, Feuer, EJ. A new method of predicting U.S. and state-level cancer mortality counts for the current calendar year. *CA Cancer J Clin.* 2004; (in press).

Jemal A, Tiwari RC, Murray T, Gafoor A, Samuels A, Ward E, Feuer EJ, Thun M. Cancer statistics 2004. *CA Cancer J Clin.* 2004; (in press).

EPIDEMIOLOGY

Electromagnetic Fields Not Associated with Risk for Breast Cancer

Stony Brook University scientists studying rates of female breast cancer on Long Island, New York, found no association between residential exposure to electromagnetic fields (EMFs) and breast cancer. Levels of in-home spot, 24-hour, ground-current measurements, and wire codes did not differ between women who were diagnosed with breast cancer (cases) and women who did not have the disease (controls). Further, differences in risk were not observed between the two groups when the data were controlled for age, family history of breast cancer, personal history of benign (noncancerous) breast disease, number of children (parity), and education. These findings are similar to those reported last year by scientists at Fred Hutchinson Cancer Research Center. Both of these studies included a comprehensive set of in-home measurement of EMF exposure and wire codes. This new study led by Stony Brook University scientists included ground-current magnetic field measurements, which were not included in the earlier study. In addition, the study included only long-term residents, with the objective of assessing exposures over an extended period.

Schoenfeld ER, O'Leary ES, Henderson K, Grimson G, Kabat GC, Ahnn S, Kaune WT, Gammon MD, Leske MC. Electromagnetic fields and breast cancer on Long Island: a case-control study. *Am J Epidemiol.* 2003; 158(1):47-58.

New Clues on Genetic Susceptibility for Aggressive Prostate Cancer

A variety of genetic epidemiologic studies are investigating how better to identify men at risk for aggressive prostate cancer. Previous research has suggested that chromosome 19q harbors a gene for aggressiveness of prostate cancer. A new study confirms this finding and provides strong evidence for the association.

Scientists analyzed genome scan data from men in 161 families where there was a family history of prostate cancer. The study suggested that chromosome 4q may also be involved in tumor aggressiveness. In other research, the presence of a certain allele (a mutational form of a gene) was found to be strongly associated with younger age at diagnosis of prostate cancer. This "A" allele of the cell cycle-regulating gene cyclin D1 also has been associated with early onset colorectal cancer and poorer prognosis for lung cancer. Still other research indicates that certain polymorphisms (variants of genes) in the androgen receptor and in genes that influence androgen metabolism are associated with increased risk for being diagnosed with prostate cancer and with more aggressive disease. These studies have important implications for improving diagnosis and treatment, and for identifying ways to prevent the disease.

Powell IJ, Land SJ, Zhou J, Sun Y, Dey J, Patel NP, Sakr WA, Hughes MR, Everson RB. Influence of androgen receptor and androgen metabolism polymorphisms on prostate cancer prognosis after prostatectomy in an ethnically diverse population. American Association for Cancer Research Proceedings. 2003.

Slager SL, Schaid DJ, Cunningham JM, McDonnell SK, Marks AF, Peterson BJ, Hebbring SJ, Anderson S, French AJ, Thibodeau SN. Confirmation of linkage of prostate cancer aggressiveness with chromosome 19q. *Am J Hum Genet.* 2003; 72(3):759-62.

Sanchez-Ortiz RF, Yamamura Y, Frazier ML, Babalan RJ, Troncoso P, Pettaway CA, Strom S. Relationship between cyclin D1 polymorphism and age at diagnosis of prostate cancer. Abstract #1090. American Association for Cancer Research Proceedings. 2003.

EPIDEMIOLOGY (cont.)

Searching for Reasons for Elevated Rates of Colon Cancer among African Americans

African Americans have the highest incidence rate for colon cancer among U.S. racial ethnic groups, and the reasons are largely unknown. The North Carolina Colon Cancer Study, which is a large case-control study with similar numbers of African Americans and Whites, provides a unique opportunity to search for clues. Scientists found that total energy intake was consistently positively associated with increased risk for colon cancer for both Whites and African Americans. However, associations with individual macronutrients (fat, carbohydrate, protein) varied somewhat by race and by adjustment for energy intake. For African Americans, saturated fat was associated with increased risk for colon cancer when risk estimates were not adjusted for total energy intake, and dietary fiber was statistically significantly associated with reduced risk both with and without adjustment for total energy intake. These findings, coupled with those from an earlier study specific to African Americans, suggest that a high-fiber, low saturated-fat diet may decrease risk for colon cancer for this group. For Whites, when risk estimates were not adjusted for total energy, high intakes of total energy and most macronutrients were positively associated with increased risk for colon cancer, but the associations largely disappeared when total energy was taken into account. Alcohol intake was not associated with increased risk for colon cancer in either racial group.

In other analyses on this study population, vitamins E and C from food sources were associated with a reduction in risk for colon cancer among African Americans when comparing individuals with intake in the highest quartile to those in the lowest quartile. Beta-carotene, vitamin C, and calcium were associated with a reduction in risk for colon cancer among Whites when comparing individuals in the highest to the lowest quartile. This research suggests that micronutrients may be independently associated with 30 percent to 70 percent reductions in risk for colon cancer in the two groups.

Satia-Abouta J, Galanko JA, Potter JD, Ammerman A, Martin CF, Sandler R. Associations of total energy and macronutrients with colon cancer risk in African Americans and Whites: results from the North Carolina colon cancer study. *Am J Epidemiol.* 2003; 158(10):951-62.

Satia-Abouta J, Galanko JA, Martin CF, Potter JD, Ammerman A, Sandler RS. Associations of micronutrients with colon cancer risk in African Americans and Whites: results from the North Carolina colon cancer study. *Cancer Epidemiol Biomarkers Prev.* 2003; 12(8):747-54.

Some Breast Cancers May Be Due to Inherited Susceptibility to Hormones at Puberty

New research indicates that certain breast cancers may be linked to an unusual inherited sensitivity to the ovarian hormones that flood the body at puberty. Scientists found that among identical female twins who were both diagnosed with breast cancer, the twin who began menstruating earlier was more than five times more likely to develop breast cancer before the other twin. Females who started menstruating before age 12 were especially susceptible to getting breast cancer first within the pair. In contrast, only among pairs of identical and fraternal twins in which one twin had breast cancer were some of the well-known risk factors for breast cancer, such as late age at first pregnancy and at menopause, associated with increased risk for breast cancer. These findings suggest that there may be another pathway to development of breast cancer that is related to genetic susceptibility. In some genetically susceptible women, ovarian hormones that surge through the body at puberty might affect breast cells when they are still immature and vulnerable, and the damage manifests itself as cancer decades later.

Hamilton AS, Mack TM. Puberty and genetic susceptibility to breast cancer in a case-control study in twins. *N Engl J Med.* 2003; 348(23):2313-22.

Increase in Lobular Carcinoma Pursued

Past research suggests that combined estrogen and progestin hormone replacement therapy (CHRT) may be associated with increased risk for breast cancer, particularly invasive lobular breast carcinoma. The finding is noteworthy because lobular carcinoma is more difficult to detect by physical examination and mammography. Scientists report that incidence rates for lobular carcinoma increased steadily from 1987 to 1999 (the proportion increasing from 9.5 to 15.6 percent of all breast cancer cases), while rates for ductal carcinoma remained constant. The increase in rates for lobular carcinoma was most pronounced for women aged 50 and older. In further research focusing on postmenopausal women, scientists found that the risk for invasive lobular breast carcinoma and other histologic types of breast cancer increased among women who were currently taking CHRT. Unopposed estrogen therapy (ERT) was not associated with increased risk of any histologic type of breast cancer. Neither CHRT nor ERT substantially increased the risk of ductal breast carcinoma. Scientists also found that incidence rates for lobular carcinoma in situ have steadily increased over the past 25 years among postmenopausal women. (In situ breast cancer is early cancer that has not spread to neighboring tissue.) These findings suggest the need for further research to explore the reasons for these trends.

Li CI, Anderson BO, Daling JR, Moe RE. Trends in incidence rates of invasive lobular and ductal breast carcinoma. *JAMA*. 2003; 289(11):1421-4.

Daling JR, Malone KE, Doody DR, Voigt LF, Bernstein L, Coates RJ, Marchbanks PA, Norman SA, Weiss LK, Ursin G, Berlin JA, Burkman RT, Deapen D, Folger SG, McDonald JA, Simon MS, Strom BL, Wingo PA, Spirtas R. Relation of regimens of combined hormone replacement therapy to lobular, ductal, and other histologic types of breast carcinoma. *Cancer*. 2002; 95(12):2455-64.

Li CI, Anderson BO, Daling JR, Moe RE. Changing incidence of lobular carcinoma in situ of the breast. *Breast Cancer Res Treat.* 2002; 75(3):259-68.

Sunlight-Induced DNA Damage Associated with Increased Risk for Melanoma

This hospital-based case-control study is the first and largest epidemiologic study to show that reduced DNA repair capability may play a role in causation of sunlight-induced melanoma. The scientists found a dose-response relationship between the DNA damage and risk of melanoma. That is, the greater the loss of DNA repair capability, the greater the risk of melanoma.

Sunlight exposure, particularly intermittent bursts of exposure early in life, is known to be directly associated with risk for melanoma. However, only a relatively small proportion of individuals exposed to sunlight develop melanoma. This suggests that genetic susceptibility plays a role in causation of the cancer. This is an important area to investigate, as the incidence rate for melanoma has been increasing over the past several decades. In 2003, an estimated 54,200 individuals will be diagnosed with the cancer in the United States.

Wei Q, Lee JE, Gershenwald JE, Ross MI, Mansfield PF, Strom SS, Wang LE, Guo Z, Qiao Y, Amos CI, Spitz MR, Duvic M. Repair of UV light-induced DNA damage and risk of cutaneous malignant melanoma. *J Natl Cancer Inst.* 2003; 95(4):308-15.

HEALTH SERVICES

National Survey of Colorectal Cancer Screening Practices

Colorectal cancer is the second leading cause of death from cancer in the United States, with an estimated 147,500 new cases and 57,000 deaths in 2003. In February 1997, the American Gastroenterological Association published clinical practice guidelines sponsored by AHCPR (now AHRQ) for colorectal cancer screening. Seven other clinical organizations endorsed the guidelines. Despite these and other recommendations and coverage decisions, screening for colorectal cancer remains at relatively low levels.

The National Survey of Colorectal Cancer Screening Practices was conducted in 2000 to collect information about the coverage of colorectal cancer screening procedures by national health plans. The survey also examined colorectal screening practice guidelines developed and carried out by health plans, and asked about health plan programs that are designed to promote the use of colorectal cancer screening and monitor its performance.

To date, seven studies have been published based on data from the survey. Following is a summary of the findings:

- Awareness of colorectal cancer screening among primary care physicians is high, but there are knowledge gaps regarding the appropriate timing and frequency of screening, and physicians self-report that only a minority of their patients receive screening at recommended levels.
- Colorectal cancer screening by double-contrast barium enema is viewed as very effective by radiologists but not by most primary care physicians. The procedure is performed at relatively low volume by radiologists.
- Nonphysician health care providers are underutilized in the delivery of colorectal cancer procedures. Sixty percent of gastroenterologists, 40 percent of primary care physicians, and 15 percent of general surgeons agreed that nonphysician health care providers could effectively perform flexible sigmoidoscopy procedures.
- Although adequate endoscopy capacity exists, in principle, substantial organizational challenges must be met if this capacity is to be used effectively and efficiently.

Klabunde CN, Frame PS, Meadow A, Jones E, Nadel M, Vernon SW. A national survey of primary care physicians' colorectal cancer screening recommendations and practices. *Prev Med.* 2003; 36:352-362.

Klabunde CN, Jones E, Brown ML, Davis WW. Colorectal cancer screening with double-contrast barium enema: a national survey of diagnostic radiologists. *Am J Roentgenol.* 2002; 179:1419-1417.

Sansbury LB, Klabunde CN, Mysliwiec P, Brown ML. Physicians' use of non-physician health care providers for colorectal cancer screening. *Am J Prev Med.* 2003; 25:179-186.

Brown ML, Klabunde CN, Mysliwiec P. Current capacity for endoscopic colorectal cancer screening in the United States: data from the National Cancer Institute survey of colorectal cancer screening practices. *Am J Med.* 2003; 115(2):129-33.

Individual and Combined Effects of Age, Breast Density, and Hormone Replacement Therapy Use on the Accuracy of Screening Mammography

A large prospective cohort study of the combined and individual effects of breast density, age, and hormone replacement therapy (HRT) on the accuracy of screening mammography showed that both breast density and age are important independent predictors of mammographic accuracy, and that HRT affects accuracy only through its effect on breast density.

Previous studies have demonstrated the importance of radiographic breast density as a risk factor in breast cancer occurrence. The risk of breast cancer is four to six times higher in women with dense breasts than in other women. Furthermore, breast density may decrease the sensitivity, and therefore the accuracy, of mammography. Breast density is affected by a number of factors, including age, use of HRT, menstrual cycle phase, number of births, body mass index, and genetics. Investigators have examined the individual effects of these factors, but the combined effects of breast density, age, and use of HRT have not been fully evaluated.

Investigators analyzed data on 329,495 women in the United States who collectively underwent 463,372 screening mammograms between 1996 and 1998. In this study population, 2,223 women received a diagnosis of breast cancer. Screening data were taken from seven registries participating in the Breast Cancer Surveillance Consortium; pathology data were collected from regional SEER programs, state cancer registries, or pathology laboratories. Results showed that both breast density and age were important independent predictors of the sensitivity and specificity of screening mammography. Adjusted sensitivity ranged from 62.9 percent in women with dense breasts to 87.0 percent in women with fatty breasts, and from 68.6 percent in women 40 to 44 years of age to 83.3 percent in women 80 to 89 years of age. After adjusting for breast density, HRT use was not significantly associated with sensitivity. Adjusted specificity increased from 89.1 percent in women with dense breasts to 96.9 percent in women with fatty breasts. In women who did not use HRT, adjusted specificity increased with age (91.4 percent in women aged 40-44 years to 94.4 percent in women aged 80-89). Age had no effect on specificity in HRT users.

The findings of this large study demonstrate that screening mammography is most accurate in older women with fatty breasts and least accurate in younger women with radiographically dense breasts who use HRT. Although HRT use is not an independent predictor of accuracy, it reduces mammography sensitivity by increasing breast density.

Carney PA, Miglioretti DL, Yankaskas BC, Kerlikowske K, Rosenberg R, Rutter CM, Geller BM, Abraham LA, Taplin SH, Dignan M, Cutter G, Ballard-Barbash R. Individual and combined effects of age, breast density, and hormone replacement therapy use on the accuracy of screening mammography. *Ann Intern Med.* 2003; 138:168-75.

TOBACCO CONTROL

Genes May Influence Smoking Cessation

Increased attention is being devoted to research on the genetic basis of smoking behavior in order to improve understanding of nicotine dependence and its treatment. Researchers found that smokers with a specific combination of two genetic variants may be more likely to remain abstinent and less prone to relapse when trying to quit smoking. Participants with particular variants of the SLC6A3 dopamine transporter gene and the DRD2 dopamine receptor gene reported significantly higher abstinence rates and a longer time before relapse than smokers carrying other variants of these genes. This study provides the first evidence that genes that alter dopamine function may influence smoking cessation and relapse during treatment. This research has important implications for the development of more effective treatment strategies that are tailored to individual smokers' needs.

Lerman C, Shields PG, et al. Effects of dopamine transporter and receptor polymorphisms on smoking cessation in a bupropion clinical trial. *Health Psychol.* 2003; 22(5): 541-8.

Smoking Expert System for Teens in Primary Medical Care

Teens seen in primary care settings, especially those who are regular smokers, are interested in and responsive to brief, individualized tobacco control efforts. Therefore, medical settings are an important supplement to schools for delivering tobacco interventions to teens.

Teen REACH was a randomized trial of brief clinician advice, the Pathways to Change interactive computer program, and brief motivational counseling to reduce smoking among 14- to 17-year-old smokers and nonsmokers seen at primary care visits. This population-based, individually tailored intervention capitalized on the teachable moment offered by medical visits and the attractiveness of computers to teens. Of 3,747 teens approached in waiting rooms, 2,526 (67 percent) completed a short questionnaire and received additional health information after the visit. Baseline 30-day smoking prevalence was 23 percent. Teens were randomly assigned to either tobacco intervention or brief dietary advice. Response rates at the one-year (93 percent) and two-year (88 percent) follow-ups were good.

Among both baseline smokers and nonsmokers, 77 percent of the tobacco intervention group versus 73 percent of the diet control group were smoke-free for at least 30 days after one year of follow-up (GEE OR=1.38, CI=1.11-1.70). After two years, the difference was reduced by one-third and was no longer significant. Among regular smokers at baseline, however, 23 percent of the tobacco group versus 13 percent of controls were smoke-free in the past 30 days (GEE OR =2.46, CI=1.47-4.12) at one year, and this difference was largely maintained after two years (19 percent vs. 10 percent, $p<0.03$, OR=2.43, CI=1.39-4.22). Five alternate methods of handling missing data had little effect on outcomes or conclusions.

This grant, the only one funded by NCI thus far showing a positive outcome for smoking cessation among adolescents, represents a starting point for effective youth tobacco control interventions.

Hollis JF, Polen MR, Lichtenstein E, Whitlock EP. Tobacco use patterns and attitudes among teens being seen for routine primary care. *Am J Health Promot.* 2003; 17(4):231-9.

Viewing Smoking in Movies Predicts if Adolescents Will Start Smoking

Viewing tobacco use in movies appears to be linked to initiation of smoking among adolescents, even after controlling for other known factors associated with adolescent smoking. Results from this study—the first of its kind (longitudinal rather than cross-sectional)—suggest that viewing smoking in movies strongly predicts whether adolescents initiate smoking, and that the effect increases significantly with greater exposure. In fact, adolescents who viewed the most smoking in movies were almost three times more likely to initiate smoking than those with the least amounts of exposure.

In 1999, the researchers surveyed children aged 10 to 14 about a variety of behaviors, including smoking and movie watching. From this survey, the researchers identified 3,500 adolescents who had never tried smoking. They re-contacted 2,600 of these adolescents one to two years later to determine if they had started smoking. In the follow-up interview, 10 percent of the students reported that they had tried smoking.

The statistical analyses of the follow-up survey data showed that the strongest predictor of first-time cigarette smoking was the amount of smoking seen in movies. Even after controlling for other factors that might influence smoking behavior—such as friend, sibling, or parent smoking—children who had seen the most smoking in movies were more than two and one-half times more likely to start smoking compared to children who had seen the least amount of smoking.

Data indicate that 52 percent of smoking initiation among adolescents in this study can be attributed to movie smoking exposure. This suggests that reducing adolescents' exposure to smoking in movies could significantly reduce the number of adolescents who initiate this behavior.

Dalton MA, Sargent JD, Beach ML, Titus-Ernstoff L, Gibson JJ, Ahrens MB, Tickle JJ, Heatherton TF. Effect of viewing smoking in movies on adolescent smoking initiation: a cohort study. *Lancet*. 2003; 362(9380):281-5.

BEHAVIORAL RESEARCH

Biobehavioral Immune Interactions in Ovarian Cancer

Substantial evidence suggests that psychosocial factors such as stress, depression, and social support are able to modulate many of the immunologic activities relevant to cancer. In addition, a number of studies support a relationship between psychosocial factors and cancer progression. However, to date there has been only weak evidence that cellular immune factors account for this relationship. Moreover, little is known about other mechanisms by which biobehavioral factors may influence growth and progression of cancer.

Angiogenesis, the formation of new blood vessels that enhance tumor growth, is a key process in the growth of most solid tumors and their metastatic spread. In a recent *Cancer* article, Dr. Lutgendorf and colleagues report that presurgical ovarian cancer patients with higher levels of social support had lower levels of vascular endothelial growth factor (VEGF), a key factor in tumor angiogenesis that has been related to survival in ovarian cancer. Patients with higher levels of distress had higher VEGF. This finding, which has since been supported by in vitro work, points to novel pathways by which stress hormones could potentially contribute to tumor progression, i.e., stimulation of angiogenic and tumor growth pathways. This type of finding has the potential to open a new area of inquiry for understanding relationships between psychosocial factors (or stress hormones) and tumor progression. Support of this research in larger-scale studies could point to the possibility of treating cancer with therapeutics (pharmacological or behavioral) that block the actions of stress hormones.

Lutgendorf SK, Johnsen EL, Cooper B, Anderson B, Sorosky JI, Buller RE, Sood AK. Vascular endothelial growth factor and social support in patients with ovarian carcinoma. *Cancer*. 2002; 95(4):808-15.

SURVIVORSHIP

Cancer as a Motivator for Healthy Behavior Change

Many have argued that the threat imposed by a cancer diagnosis can be life altering, particularly in the area of health behaviors. In one study examining this effect, researchers found that, since cancer diagnosis, 47 percent of survivors improved their dietary habits and 46 percent of survivors who were smokers quit smoking. However, 30.1 percent of survivors in the study exercised less. In light of the risk for physical inactivity following cancer and its corresponding adverse impact on weight and health, a number of researchers are using exercise interventions to improve survivors' emotional and functional well-being.

In other studies, results, limited thus far to breast cancer survivor groups, are compelling. Exercise programs or training benefits cardiopulmonary function and quality of life, reduces fatigue, and helps maintain functional ability. When combined with group psychotherapy, exercise may improve women's quality of life beyond the benefits received from group participation alone, particularly in relation to physical and functional outcomes. While it is not clear whether these types of interventions will alter the course of cancer (specifically, rate of, or time to, recurrence or death), they hold the promise of reducing cancer-related morbidity and promoting general health. Such interventions also appear to have enormous appeal to survivors eager to reduce the perceived stress in their lives and to "take control" of their bodies after cancer.

Blanchard CM, Denniston MM, Baker F, Ainsworth SR, Courneya KS, Hann DM, Gesme DH, Reding D, Flynn T, Kennedy JS. Do adults change their lifestyle behaviors after a cancer diagnosis? *Am J Health Behav.* 2003; 27(3):246-56.

Courneya KS, Friedenreich CM, Sela RA, Quinney HA, Rhodes RE, Handman M. The group psychotherapy and home-based physical exercise (group hope) trial in cancer survivors: physical fitness and quality of life outcomes. *Psychoonc*. 2003; 12(4):357-74.

Courneya KS, Mackey JR, Bell GJ, Jones LW, Field CJ, Fairey AS. Randomized controlled trial of exercise training in postmenopausal breast cancer survivors: cardiopulmonary and quality of life outcomes. *J Clin Onc.* 2003; 21(9):1660-8.

Kolden GG, Strauman TJ, Ward, A., et al. A pilot study of group exercise training (GET) for women with primary breast cancer: feasibility and health benefits. *Psychoonc*. 2002; 11: 447-456.

Pediatric Cancer Affects the Family, Not Just the Survivor

Agrowing body of research is beginning to show that it is not only the cancer patient who may be traumatized by disease, but also the family. NCI-supported scientists found that levels of post-traumatic stress (PTS) are elevated for siblings of childhood cancer survivors. Adolescent siblings of pediatric cancer survivors report more PTS symptoms than a reference group of nonaffected teens with similar levels of general anxiety. About half (49 percent) reported mild PTS, about one-third (32 percent) indicated moderate to severe levels, and one-fourth thought their brother/sister would die during treatment. These data remind us that cancer is often a family disease. As such, identifying members at risk and intervening early to reduce emotional distress may be critical for the subsequent health and well-being of both the individual and the family.

Alderfer MA, Labay LE, Kazak AE. Brief report: does post-traumatic stress apply to siblings of childhood cancer survivors? *J Pediatr Psychol.* 2003; 28(4):281-6.

Cancer Control Framework and Synthesis Rationale

In 1997, the Division of Cancer Control and Population Sciences was established to enhance NCI's ability to alleviate the burden of cancer through research in epidemiology, behavioral sciences, health services, surveillance, and cancer survivorship. Cancer control research aims to generate basic knowledge about how to monitor and change individual and collective behavior, and to ensure that this newfound knowledge is translated into practice rapidly, effectively, and efficiently.

Cancer Control Research Activities

The dynamic and interdisciplinary nature of the division's activities is illustrated in the cancer control framework. This framework illustrates three categories into which all cancer control activities can be assigned, and the central role of knowledge synthesis. All research areas act through application and program delivery to reduce the cancer burden, with a strong commitment to dissemination and diffusion, and collaborations that facilitate the application and program delivery of evidence-based approaches to cancer control.

Definition

Cancer control science is the conduct of basic and applied research in the behavioral, social, and population sciences to create or enhance interventions that, independently or in combination with biomedical approaches, reduce cancer risk, incidence, morbidity and mortality, and improve quality of life (Cancer Control Program Review Group, 1998—modified).

Adapted from the 1994 Advisory Committee on Cancer Control, National Cancer Institute of Canada

DCCPS Overview

Vision

The Division of Cancer Control and Population Sciences (DCCPS) generates new knowledge and seeks to ensure that the products of cancer control research are effectively applied in all segments of the population. Through innovative research initiatives, leadership, knowledge synthesis, and dissemination, we have built this program to be the nation's model for cancer control science.

Mission

DCCPS aims to reduce risk, incidence, and deaths from cancer as well as enhance the quality of life for cancer survivors. The division conducts and supports an integrated program of the highest quality genetic, epidemiologic, behavioral, social, applied, and surveillance cancer research. DCCPS-funded research aims to understand the causes and distribution of cancer in populations, support the development and delivery of effective interventions, and monitor and explain cancer trends in all segments of the population. Central to these activities is the process of synthesis and decision making that aids in evaluating what has been learned, identifying new priorities and strategies, and effectively applying research discoveries to reduce the cancer burden.

Program Review Group

The Cancer Control Program Review Group was convened in 1996 by NCI's director and the chair of the NCI Board of Scientific Advisors to assess the scope of NCI's cancer control research program and recommend changes aimed at accelerating reductions in the nation's cancer burden. The review group recommended several major changes and new directions for cancer control at NCI, including attention to basic biobehavioral research.

Realizing that the scope of cancer control reflects the concurrent needs of society and developments in scientific knowledge, the group identified several important trends to which NCI's research needed to be responsive. These trends included the increasing age and diversity of the population, new discoveries in genetics, the revolution in information technology, and the restructuring of the health care delivery system.

History

The Cancer Control Program Review Group endorsed plans to establish NCI's Division of Cancer Control and Population Sciences and ensure that it included a range of research, from fundamental and intervention research to surveillance research. The Cancer Surveillance Research Program joined the newly created DCCPS from the former Division of Cancer Prevention and Control (currently the Division of Cancer Prevention). The surveillance program has since been reorganized into two separate DCCPS programs: Surveillance Research and Applied Research.

Some parts of the DCCPS Behavioral Research Program (BRP) were created from components of the Division of Cancer Prevention and Control. Likewise, the Epidemiology and Genetics Research Program joined DCCPS from the Division of Cancer Epidemiology and Genetics.

Several branches within BRP, including Basic Biobehavioral Research and Health Communication and Informatics Research, are entirely new. The Office of Cancer Survivorship is new as well; it was created to expand research benefiting cancer survivors, who today number more than 9.6 million. DCCPS established the Research Diffusion and Dissemination arm of the Office of the Director to develop partnerships and initiatives in the delivery of evidence-based interventions and products.

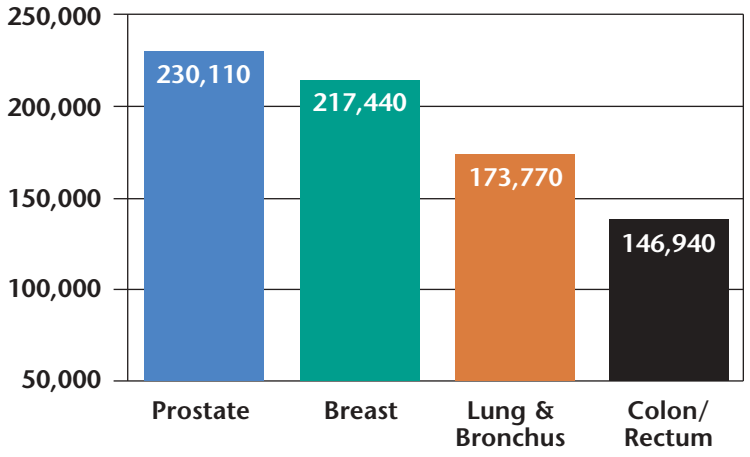
Milestones in the History of Cancer Control in Congress and at NCI

1937	Congress enacts legislation to establish the National Cancer Institute.
1971	Congress reaffirms its support by enacting The National Cancer Act and including specific language regarding cancer control.
1973	NCI creates the Division of Cancer Control and Rehabilitation, the first structural unit within the institute devoted to cancer control.
1983	NCI forms the Division of Cancer Prevention and Control to accelerate the science of cancer control, giving a new definition to the term and a framework that describes a linear series of phases, from hypothesis generation to demonstration projects.
1996	NCI's Director and Board of Scientific Advisors convene the Cancer Control Program Review Group to assess NCI's cancer control research program and make recommendations for the pursuit of research opportunities with the greatest potential to reduce the nation's cancer burden.
1997	NCI undergoes a major programmatic reorganization and establishes the Division of Cancer Control and Population Sciences.
1998-2004	Congress expresses interest and requests information on DCCPS scientific priorities, including cancer registries, environment and breast cancer, cancer in minorities, tobacco control and harm reduction, health communications, cancer screening technologies, 5 A Day and other nutrition programs, weight, physical activity, and cancer survivorship.

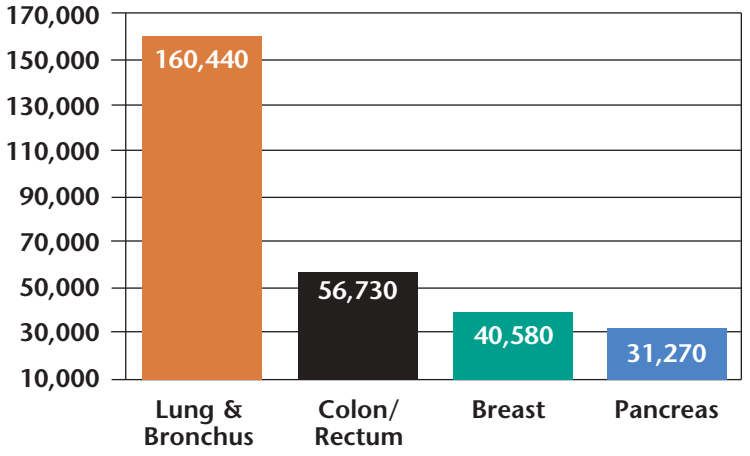
Cancer Burden Statistical Overview

In 2004, an estimated 1,368,000 people will be diagnosed with cancer in the United States, and 563,700 Americans are expected to die from their disease.

Estimated Incidence by Cancer Site—2004



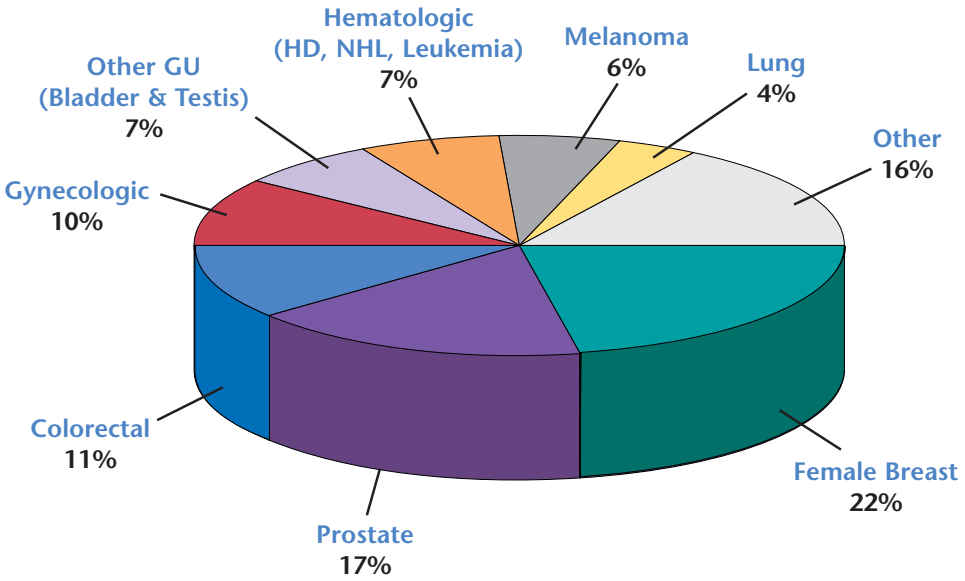
Estimated Mortality by Cancer Site—2004



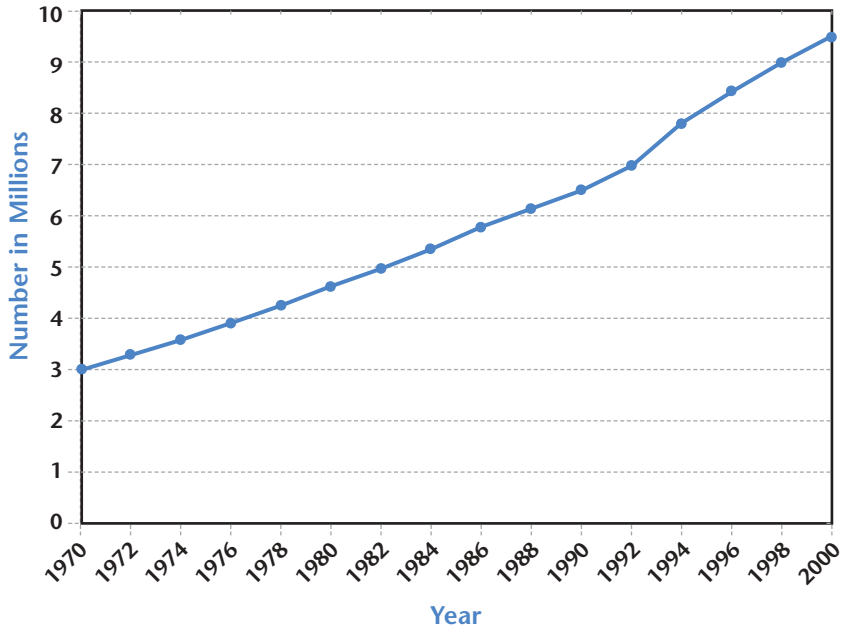
Facts & Figures 2004, American Cancer Society.
SEER Program, NCI, 2004.
National Center for Health Statistics, CDC, 2004.

Cancer Burden Statistical Overview (cont.)

Estimated Number of Persons Alive in the U.S. Diagnosed With Cancer by Site (n=9.6 million)



Estimated Number of Cancer Survivors in U.S.—1971 to 2000



Data source: November 2002 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 Limited Duration Prevalence proportions. Populations from January 2000 were based on the average of the July 1999 and July 2000 population estimates from the U.S. Bureau of Census.

Notes

VIEWS FROM LEADERSHIP

Rachel Ballard-Barbash, MD, MPH

Associate Director, Applied Research Program

Rachel Ballard-Barbash, MD, MPH, has been the associate director of NCI's Applied Research Program since October 1999. She has focused her research on defining the association of diet, weight, and physical activity with cancer risk and prognosis in order to identify targets for prevention and control of primary and recurrent disease through epidemiologic, clinical trials, and clinical metabolic research. She has also focused on improving methods and systems for tracking cancer preventive measures in national and local populations, and on examining the delivery of health care utilization and services in screening and treatment. Dr. Ballard-Barbash joined NCI in 1987 as a staff fellow. She served as the DHHS nutrition policy advisor in the Assistant Secretary's Office of Disease Prevention and Health Promotion in 1990 and 1991, and returned to NCI in November 1991.

Dr. Ballard-Barbash received her MD from the University of Michigan in 1981 and her MPH in Epidemiology from the University of Minnesota in 1985. She trained in internal medicine at Northwestern University, and in preventive medicine and clinical nutrition at the Mayo Clinic. In addition to her research career, she has also practiced in preventive medicine and clinical nutrition. She has authored over 80 peer-reviewed publications and four book chapters, and has participated in major national and international reviews, including the 2002 International Agency for Research on Cancer's 2002 Handbook of Cancer Prevention, *Weight Control, Physical Activity and Cancer*. She leads an NCI-wide effort to advance research efforts to improve our understanding of the role of energy balance on cancer, and is NCI's representative on the NIH Obesity Research Task Force.

Dr. Ballard-Barbash has been a member of several advisory boards, is the chair of NCI's editorial committee for the JNCI *Cancer Surveillance Series*, and serves as a reviewer for many journals. She has been recognized with a DHHS Secretary's Award for Distinguished Service, three NIH Merit awards, two NIH Director's awards, and an NIH Plain Language Award.

Program Accomplishments in Applied Research

Evaluating progress in individual, social, and system-level factors that influence cancer outcomes is critical to developing a well-targeted cancer control program. Because people do not act in isolation of society, systems, and their environment, we seek to improve data resources and methods for evaluating these factors—from food and tobacco supply to health care. While many health surveillance systems collect detailed information at the individual level, it has been a greater challenge to obtain information on social and system-level factors that may influence dissemination and adoption of cancer control practices. Advances from geographic information systems are being used to link individual with ecological data to explore how such contextual measures influence individuals. Results from research supported by the Applied Research Program (ARP) have improved our ability to identify factors underlying our measures of cancer burden, make critical scientific and public health policy decisions, develop and monitor prevention and control measures, and assess whether interventions at the local or national level are making a difference.

ARP has made tremendous progress in developing monitoring systems, advancing methods, expanding health services and outcomes research, disseminating research resources electronically, and advancing their utility for research. Collaborative and coordination efforts with many public and private partners have made these accomplishments possible.

In prevention and screening, we have augmented data on risk and family history, and on health behaviors such as tobacco use, diet and physical activity, screening, sun avoidance, use of common medications related to cancer outcomes, and use of genetic testing. Expanded data collection in areas covered by high-quality cancer registration has improved the potential for interpretation of factors underlying the cancer burden. NCI contributed to tracking progress in achieving the *Healthy People 2010* cancer control objectives through research utilizing these resources. In addition to population-level health monitoring, we have examined the adoption of new advances in cancer risk assessment and screening through physician surveys. Through direct linkage of individual-level screening data to cancer outcomes, we are providing national measures of mammography performance, and we are exploring the potential to develop similar measures for colorectal cancer screening.

> "We have augmented our data collection on risk and family history, and health behaviors such as tobacco use, diet and physical activity, screening, sun avoidance, use of common medications related to cancer outcomes, and use of genetic testing."

NCI has made major advances in supporting research on the development of data systems and methods for tracking evidence-based measures of quality cancer care. The SEER-Medicare linked data, a national research resource for quality and cost-of-care research, has led to over 100 publications. Through the collection of detailed data on treatment within physicians' offices in areas covered by SEER registries, NCI supports research examining patterns and trends in care for major cancers. NCI also has supported research in cohorts of cancer patients (prostate, breast, colon, and lung cancers) that will provide much-needed information across the clinical course, from diagnosis through treatment and long-term survival.

In addition to improving data resources, ARP is supporting efforts to improve research methods to ensure that measures used for research, evaluation, and monitoring of progress are accurate and valid over time. To improve self-reported measures commonly collected, we have supported methodological research that incorporates objective biologic or physical measures of exposures to quantify measurement error from self-report of key health behaviors, such as diet and physical activity. The use of cognitive testing and psychometric methods are improving self-reported measures in other critical areas, such as quality of life and symptom management. Finally, we are exploring the potential for enhancing information systems for real-time data collection, integration of information across diverse elements, and feedback—critical elements to the development of rapid evaluation and feedback from population monitoring to public health and clinical practice.

Ensuring the rapid translation of evidence-based care into practice is a national priority. In addition to publication of ARP research findings and presentations at meetings, rapid distribution of information and resources through NCI's public Web pages has helped increase the timeliness of transfer of research into practice. ARP is also engaged in many collaborative translation efforts with partners involved in the delivery of care. For example, pilot projects with federal health care delivery organizations, such as the Cancer Collaborative with Community Health Centers, are increasing the delivery of evidence-based screening and follow-up diagnostic evaluation of major cancers. In a joint NCI Breast Cancer Surveillance Consortium and American College of Radiology project, we have developed streamlined and standardized data collection instruments and software systems for evaluating mammography across the United States. NCI also works with the National Quality Forum, a public-private partnership created to foster voluntary consensus standards on the quality of health care, including measures for cancer treatment, survivorship, and palliative care. These initiatives seek to improve the delivery of cancer control through ensuring the adoption of evidence-based interventions within public health and clinical practice.

Brenda K. Edwards, PhD

Associate Director, Surveillance Research Program

Brenda K. Edwards, PhD, has been associate director of the Surveillance Research Program and its predecessor organizational unit since 1989. She has been involved in cancer prevention and control since its formative days early in the 1980s. Dr. Edwards began her affiliation with NCI in 1978 as a researcher in cancer treatment clinical trials, and four years later joined the team conducting some of the first cancer prevention trials. Prior to coming to NCI, Dr. Edwards was on the faculty of a Midwestern medical school where she was involved in community-based and environmental/occupational studies.

Dr. Edwards received her PhD in biostatistics from the University of North Carolina at Chapel Hill. Her research has included the full spectrum of cancer surveillance, including risk factors, patterns of care, behavioral studies and survivorship, statistical methodology, and analytic activities. Under her leadership, NCI's Surveillance, Epidemiology, and End Results (SEER) Program has become an important resource for monitoring the nation's cancer burden and for measuring progress in cancer control. During the past few years, Dr. Edwards' focus has been directed toward enhancing coordination of cancer surveillance in the U.S., increasing coverage while maintaining the quality of the SEER Program, disseminating surveillance data, and improving the quantitative assessment of health disparities.

Dr. Edwards has received the Calum S. Muir Memorial Award and the NIH Director's Award for her work in cancer surveillance. She has coauthored over 80 peer-reviewed publications.

National Cancer Surveillance

It is important to take stock of major accomplishments and to highlight future directions within the context of the U.S. cancer surveillance system of the 21st century. Significant changes have taken place in the past decade, representing a stronger and more vital infrastructure, enhanced collaborative alliances among federal and private partners, expanded coverage, and improved cancer-specific health information for all Americans. These changes have included considerable growth in the development of statistical tools and applied technology to enhance the use of surveillance data in the control and reduction of cancer. NCI's Surveillance Research Program has played a vital role in defining and establishing the national cancer surveillance systems, not only as a catalytic force but also as the source for substantive technical expertise that constitutes the system's foundation.

Defining and Codifying Surveillance Research

Ten years ago, representatives of organizations and agencies involved in collecting and reporting information on cancer formed the National Coordinating Council for Cancer Surveillance. At the time, NCI's perspective on a comprehensive system that measures the cancer burden throughout the cancer control continuum (prevention→early detection→diagnosis→treatment→survival) was considered a desirable but unattainable goal. However, after a decade of planning and expert review performed in collaboration with these partners, a national framework for cancer surveillance is now in place, and accomplishing this goal is within sight. Today, population-based cancer registries—including NCI's SEER Program—are central components to surveillance research and cancer control. This comprehensive system has evolved to couple information on the cancer patient with other factors such as risk, clinical care, economics, survivorship, and societal influences.

Building on a Strong Foundation

As a mature 30-year program, SEER is the national source of information on long-term national trends

and the only source for population-based data on cancer survival and prevalence. It began by collecting information on cancer among residents of nine geographic areas, representing ten percent of the U.S. population in 1973. Coverage was extended early in the 1990s to 14 percent of the nation. SEER provided data on incidence patterns such as the dramatic increase of prostate cancer diagnoses and the subsequent decline and rise over that decade. In addition, SEER investigators initiated special studies on patterns of care among cancer patients, many of which now include ten years of follow-up. Most recently, SEER has extended its coverage to 26 percent of the U.S. population, complementing the National Program of Cancer Registries (NPCR), managed by CDC. Collaborative reports from SEER and NPCR are issued annually and have provided cancer incidence data based on 65 percent to 84 percent of the U.S. population. These accomplishments result from the work of many people and professional groups, including hospital-based registry programs that form the critical building blocks of population-based registry systems.

> "Today, population-based cancer registries and the NCI SEER Program are central components to surveillance research and cancer control."

In 1987, NCI was a founding sponsor of the North American Association of Central Cancer Registries (NAACCR), and served in the supportive roles of executive secretary and technical leadership. Today, NAACCR is an independent not-for-profit organization that receives federal funding from CDC and NCI to underwrite and augment its programs of data standards and use. As part of the process, SEER has been in the vanguard of setting standards throughout its existence, sharing its reservoir of technical expertise with others to make the national cancer registry programs a reality. Some of SEER's most notable recent activities include leadership of the Collaborative Stage project, implementation of ICD-O-3, initiation of the collection of benign brain tumors, and review of classification rules for reporting multiple tumors.

Poised to Meet the Challenges of the Next Decade

Just as cancer trends will change, the cancer surveillance research program at NCI will continue to evolve in form and substance. We will continue to maintain high-quality data systems and utilize advances in information technology. We will develop additional innovative methods and statistical models for interpreting measures of cancer control at the individual and societal levels. On the horizon are improvements in data quality and comparability, illustrated by the Collaborative Staging System for harmonizing information collected by hospitals and population registries. SEER is redesigning its data management systems and transitioning into greater capacity for electronic data capture and processing. Additional approaches for user-friendly communication of cancer data are being designed for the broadest possible dissemination.

The latest statistical techniques are readily available in our analytical tools and applications software, particularly spatial techniques. Improved data collection, coupled with technology such as Global Positioning Systems, research in Geographic Information Systems, and participation with partners such as the U.S. Geological Survey and the National Science Foundation and its Digital Government Initiative, will enhance our capacity to utilize data sources such as LandSat and to visualize data with new software such as SatScan and parallel coordinate plots.

Other transagency collaborations, for example the National Longitudinal Mortality Study, provide research databases for investigations into the social determinants of diseases such as cancer. The fruits of collaborations with CDC and the American Cancer Society will appear as Web-based systems of interactive graphs and maps that facilitate greater local use of cancer data. The tension between an individual's privacy and societal benefit will remain a significant problem as we address confidentiality and the protection of sensitive data, and is an ongoing subject of discussion among surveillance partners.

Jon F. Kerner, PhD

Deputy Director, Research Dissemination and Diffusion

Dr. Kerner joined the DCCPS Office of the Director in March 2000 with two primary areas of responsibility: research diffusion and dissemination, and co champion of NCI's Reducing Cancer Health Disparities Challenge. Prior to joining NCI, Dr. Kerner spent 13 years at Memorial Sloan-Kettering Cancer Center developing its cancer control research program, and then served seven years as the associate director for prevention and control in the Lombardi Cancer Center at Georgetown University Medical Center. In addition to his over 20 years as a peer-reviewed investigator and peer reviewer, Dr. Kerner also served as the first chair of the NIH Community Prevention and Control Study Section (now Community-Level Health Promotion Study Section).

Dr. Kerner completed his PhD in community psychology at New York University in 1980, and received postdoctoral training in cancer epidemiology, clinical trials design, and advanced multivariate statistical analyses at Johns Hopkins University School of Public Health in 1985. In his 20-year career as a cancer control investigator, Dr. Kerner developed more than 25 collaborative research projects and many knowledge transfer networks with schools and departments of public health, community hospitals, American Cancer Society (ACS) units and divisions, and community-based organizations. He has made more than 150 presentations nationally and internationally, and has more than 50 peer-reviewed publications.

Dr. Kerner served on the boards of the American Society for Preventive Oncology, the Association of Community Cancer Centers, and the ACS National Committee on Cancer in the Socioeconomically Disadvantaged. He is a peer reviewer for many journals, including *AJPH; Cancer; Cancer Epidemiology, Biomarkers and Prevention; and the Journal of Women's Health.* Dr. Kerner is currently NCI's representative to the Centers for Disease Control and Prevention's (CDC) Breast & Cervical Cancer Early Detection Program Federal Advisory Committee, the CDC Comprehensive Cancer Control Evaluation Committee, the Agency for Healthcare Research and Quality (AHRQ) Translating Research into Practice Conference Planning Committee, the Health Services and Resources Administration (HRSA) Sentinel Research Network, and the Healthy People 2010 Progress Review Committee. He also serves on the National ACS Health Disparities and Research Advisory Committees and the ACS Mid-Atlantic Division's Outcomes Review and Cancer Surveillance Committees.

Demystifying Cancer Research to Increase Demand for Evidence-based Cancer Control

In the mid-1980s, Dr. Louis Sullivan, then-Secretary of DHHS, gave the plenary at the dedication of Memorial Sloan-Kettering Cancer Center's new Basic Science Research Building. Dr. Sullivan noted how this new research infrastructure would greatly enhance the contributions made to and by basic science in our efforts to prevent and control cancer. Yet, he said, the new building's windows *"did not open."* He challenged the research community to *"throw open the windows and doors"* to our *"temples of science"* and help the American people understand how and why the investment of their tax dollars in biomedical research was such a good investment.

> "The challenge is to help the American people better understand how and why the investment of their tax dollars in biomedical research is such a good investment."

Despite large increases to NIH and NCI budgets, this challenge remains. If we are to increase the demand by patients and their families, practitioners, the public, and the public health practice community for additional investments in science and the use of evidence-based cancer control interventions, we must demystify cancer research. Three approaches are:

- Increase NCI support for community-based participatory research so that individuals, institutions, and communities that are the subjects of study are also partners in the study design, implementation, results review, and publication.
- Expand support for diffusion and dissemination research on interventions tested in NCI-funded efficacy trials, in collaboration with entities such as the American Cancer Society and the Centers for Disease Control and Prevention, which have many valuable community-based channels for dissemination.
- Expand NCI partnerships with federal and state service delivery agencies and organizations to increase adoption of evidence–based interventions and to understand how infrastructure and delivery resource barriers to cancer control can be overcome with cost-effective interventions.

Considerable progress has been made toward making science and evidence-based interventions more compelling. NCI's **T**ranslating **R**esearch into **I**mproved **O**utcomes (TRIO) program was initiated to (1) better communicate cancer surveillance data to motivate action and track progress, (2) expand partnerships with other federal agencies and national voluntary and philanthropic organizations to increase demand for and adoption of evidence-based cancer control intervention programs and products, and (3) identify special regional and local partnership opportunities for model programs to address significant infrastructure barriers to the adoption of evidence-based cancer control.

Scott J. Leischow, PhD

Associate Director (Acting), Behavioral Research Program

Dr. Leischow became acting associate director of the Behavioral Research Program in December 2003, after serving for over three years as chief of the Tobacco Control Research Branch. Dr. Leischow came to NCI in July 2000 from the University of Arizona, where he was associate professor of public health at the College of Public Health, director of the Arizona Program for Nicotine and Tobacco Research, and co-director of the Biobehavioral Research Program at the University of Arizona Cancer Center.

Dr. Leischow received his MA and PhD in health education from the University of Maryland at College Park. He then completed a postdoctoral fellowship in behavioral pharmacology at the Behavioral Pharmacology Research Unit, Johns Hopkins University Department of Psychiatry. His research interests focus on the areas of nicotine behavioral pharmacology, tobacco cessation, and the translation of clinical smoking cessation research into community practice. In addition to conducting seminal clinical research studies evaluating the safety and efficacy of potential smoking cessation medications, Dr. Leischow played a senior role in the development of several statewide tobacco treatment and evaluation programs in Arizona, including the creation of the Arizona Smokers Helpline. Since arriving at NCI, he has also worked to foster the development of systems thinking and network-centric approaches to tobacco control, with an eye toward how such approaches can apply to NCI's priority-setting processes beyond tobacco.

In 1998 Dr. Leischow was named Arizona Prevention Center Researcher of the Year, and in 2003 he received the NIH Director's Award. Dr. Leischow has published many articles in peer-reviewed journals such as *Nicotine and Tobacco Research, Archives of Internal Medicine, Archives of Family Medicine, Psychopharmacology,* and the *New England Journal of Medicine.*

Strengthening Behavioral Science within the National Cancer Institute

Behavioral science provides a critical foundation for effective cancer prevention and control. Behavioral risk factors such as smoking, poor diet, and lack of exercise account for a large proportion of the national cancer burden. Similarly, most of the recent progress in reducing cancer morbidity and mortality has been a direct result of a particular kind of behavior change: the steady reduction of tobacco use among adults.

> "NCI can and should be an international leader in behavioral science."

NCI can and should be an international leader in behavioral science. This is vital not only to the mission of NCI, but also to NIH's mission to accelerate the acquisition and application of knowledge about health behavior and adaptation to disease. Many of the behaviors that increase one's risk of cancer also increase the risks of other chronic diseases, such as cardiovascular disease. Therefore, it is important for us to support both basic (fundamental mechanisms) and applied (cancer control-specific) behavioral science, just as we support both basic and applied biomedical science. Furthermore, we should continue to expand our successful collaborations with other partners, both within and outside NIH, to discover, develop, and deliver strategies to enhance health-promoting behaviors by individuals and the population.

Five years ago, NCI had a small portfolio of behavioral research projects, largely focused on smoking, fruit and vegetable consumption, and mammography utilization. In addition, a large proportion of the budget was allocated to contracts with state health departments to support the American Stop Smoking Intervention Study (ASSIST) project, which provided the foundation for CDC's national tobacco control program. With the establishment of the Behavioral Research Program (BRP) in DCCPS, we undertook a major effort to evaluate, strengthen, and expand both the breadth of the research program and the expertise of the scientists who lead it. In addition to the traditionally supported areas of research, we expanded our support of interdisciplinary sciences in areas such as risk communication, decision making, sociocultural research, consumer health informatics, policy analysis, neuroscience, psychometrics, and behavioral genetics. Today, BRP is home to nationally and internationally recognized senior leaders in behavioral science who are guiding a wave of scientific progress that is built on the foundations of transdisciplinary science networks; systems approaches that emphasize the discovery, development, and effective delivery of science; and the growth of communication sciences and practices that make the networks and systems function most effectively.

From its inception, the BRP has emphasized and fostered scientific excellence, open communication, optimism, leadership, and the primacy of collaboration. Because of our mission, we make special efforts to coordinate our work with colleagues at CDC, FDA, the NIH Office of Behavioral and Social Sciences Research, other NIH institutes, non-governmental organizations, and corporate partners when appropriate. For example, scientists are working with NIDA, NIAAA, CDC, and FDA to explore optimal methods and measures for testing efforts to lessen tobacco products' harmful effects. Indeed, achieving NCI's 2015 goals is dependent on many partners working together in a strategic way to understand and improve health behaviors, such as tobacco use, diet, exercise, and treatment adherence. This reality serves as a daily reminder to the many leaders within BRP that solid behavioral science is essential to patients, providers, policy makers, and the public at large as we strive to create a future that is free from the burden of cancer.

Julia H. Rowland, PhD

Director, Office of Cancer Survivorship

Julia Rowland, PhD, was appointed director of NCI's Office of Cancer Survivorship in September 1999. Before coming to DCCPS, she was the founding director of the Psycho-Oncology Program at the Lombardi Cancer Center at Georgetown University (1990-1999). Prior to that, she trained and worked for 13 years in psycho-oncology at Memorial Sloan-Kettering Cancer Center (MSKCC). Dr. Rowland received her PhD in developmental psychology from Columbia University in 1984 and was one of the first two post-doctoral fellows at MSKCC to receive NIH-supported training in the then newly-emergent field of psychosocial oncology. While at MSKCC, where she held joint appointments in pediatrics and neurology, Dr. Rowland helped establish and was the first director of the Post-treatment Resource Program.

Her research has focused on both pediatric and adult cancer survivorship. She has published extensively on women's reactions to breast cancer, as well as on the roles of coping, social support, and developmental stage in a patient's adaptation to cancer. She co-edited the groundbreaking text, *Handbook of Psychooncology: Psychological Care of the Patient with Cancer* (1989), and is the author of more than 75 scientific articles, reviews, and book chapters. She is also a frequent speaker to both lay and professional audiences on issues related to quality of life after cancer.

Dr. Rowland is a member of several advisory boards, including that of the National Coalition for Cancer Survivorship and the American Psychosocial Oncology Society. Her service on journal editorial boards includes being editor of the recently-added survivorship department for *Cancer Investigation*, and contributing editor for *Breast Diseases: A Yearbook Quarterly*. Since coming to NCI, Dr. Rowland has been awarded an NIH Plain Language Award and was appointed co-champion of NCI's Extraordinary Opportunity in Cancer Survivorship.

Addressing the Burden of Suffering Due to Cancer

Once almost uniformly fatal, cancer has become for most a chronic illness, and for growing numbers, a curable disease. In the absence of other competing causes of death, current figures indicate that for adults diagnosed today, 63 percent can expect to be alive in five years. Almost 80 percent of childhood cancer survivors will be alive at five years, and 10-year survival is approaching 75 percent. As past and future advances in cancer detection, treatment, and care diffuse into clinical practice, and with the aging of the population, the number of survivors can be expected to increase.

The steadily increasing number of cancer survivors is a testament to the many successes achieved by NCI. At the same time, this population of survivors, currently estimated as numbering 9.6 million in the United States, represents a clear challenge to NCI. These individuals serve as a reminder that we have an obligation to look beyond the search for a cure and provide hope for a valued future to those living with and beyond a cancer diagnosis.

With the establishment of the Office of Cancer Survivorship (OCS) in 1996, NCI formalized its commitment to better understand and address the unique needs of all cancer survivors. Since the inception of this office, there has been an almost five-fold increase in NIH-funded grants in cancer survivorship—and most of these are housed within the OCS. The rapid growth of applications in this area reflects the awareness in the investigator community of the critical need for data on survivor outcomes. It also is a reflection of OCS's achievements in shepherding the science of survivorship.

Looking to the future, it is clear that research is needed in several important arenas. First, more descriptive and analytic epidemiologic research is needed on the chronic and long-term impact of cancer on survivors. Few of our current cancer treatments are benign; most carry the potential to cause adverse long-term and late effects. As children and adults with a history of cancer live longer, and data from research studies supported by NCI mature, more of these risks are being documented and reported, including the following: neurocognitive problems, premature menopause, cardiorespiratory dysfunction, sexual impairment, infertility, chronic fatigue and pain syndromes, and second malignancies. Research shows that many survivors also experience significant negative psychosocial outcomes: fear of recurrence, poor self-esteem, anxiety and depression, employment and insurance discrimination, and relationship difficulties. It is clear that for those who are post-treatment, being disease-free does not mean being free of their disease. Access to information about treatment-related risks is critical if we are to help patients and their providers negotiate the treatment decision making process.

> "The steadily increasing number of cancer survivors is a testament to the many successes achieved by NCI."

A second vital area is the development and application of interventions that will prevent or reduce the adverse sequelae of cancer and its treatment on survivors' physical, psychological, and social functioning. Awareness within the investigator community of the importance of this research is reflected in the fact that almost half of the currently funded grants in the survivorship area contain an intervention component.

In addition to these two large areas of research focus, we have identified additional areas where we need to grow the science.

- **A focus on underserved and poorly studied populations of survivors.** A number of recent reports highlight the unequal burden of cancer faced by those from low-income backgrounds, diverse ethnocultural minority groups, and rural communities. In addition, information about older survivors and those with some of the most common malignancies (e.g., colorectal cancer, gynecologic cancer, lymphoma) is also surprisingly limited.

- **Attention to economic outcomes, patterns of care, and service delivery.** Research is needed on the impact of cancer on work, economic status, and insurability, and on the impact of patterns of follow-up care on survivors' health status, morbidity, and mortality.

- **A focus on family.** We are beginning to appreciate the impact of cancer on the functioning and well-being of the millions of family members affected by this illness, many of whom may themselves be at increased risk for cancer due to shared cancer-causing genes, lifestyle, and/or toxic exposures.

- **Instrument development.** As survivors live longer, new instruments are needed that will enable us not only to describe more accurately the late effects of treatment, but also to compare the well-being of those with a history of cancer to that of their peers without such a history.

- **Education.** As we learn more about the cancer survivorship experience and the interventions or care needed to optimize outcomes, we must find ways to communicate this knowledge to those who most need it. At the same time, we need to mentor and train the next generation of clinicians and researchers to develop, study, and deliver state-of-the-art cancer care.

NCI is uniquely poised to champion significant advances in our capacity to understand and enhance cancer survivorship. Importantly, the survivor community is strong and articulate and prepared to share the cutting-edge information generated by our research community.

Edward Trapido, ScD

Associate Director, Epidemiology and Genetics Research Program

Edward Trapido, ScD, has been the associate director of NCI's Epidemiology and Genetics Research Program since fall 2002. Before joining NCI, he was professor and vice chair of the Department of Epidemiology and Public Health, University of Miami School of Medicine. He also was associate director for cancer prevention and control at the Sylvester Comprehensive Cancer Center, and directed the MPH and PhD Epidemiology Teaching Programs.

Dr. Trapido earned an MSPH in parasitology from the University of North Carolina at Chapel Hill in 1974, and holds ScM and ScD degrees in epidemiology from Harvard University School of Public Health. As a principal investigator at the University of Miami, Dr. Trapido directed several major cancer control research and education programs, including the Coastal NCI Cancer Information Service covering Florida, Puerto Rico, and the U.S. Virgin Islands; the Florida Cancer Data System; the Florida Comprehensive Cancer Control Initiative; and the Southeast Region of *Redes En Action*, which focuses on Hispanic cancer prevention and control activities. He also was director of the Tobacco Research and Evaluation Coordinating Center, and was a special consultant to the Florida Tobacco Pilot Program, which has received nationwide acclaim for reducing teenage smoking.

One of Dr. Trapido's major research interests has been the assessment of cancer incidence and mortality among Hispanics, and the development of intervention projects resulting from such investigations. He is a member of NCI's Health Disparities Research Committee and the Trans-NIH Tobacco Research Group. Dr. Trapido has authored over 70 peer-reviewed publications. He is a fellow in the American College of Epidemiology.

Epidemiology and Genetics Research

Epidemiology is the science that provides the tools for understanding the distribution of cancer in populations. It is at the interface of fundamental science and its application into effective clinical and public health interventions. In recent years, epidemiology has provided keys for unlocking the promise of discoveries in the human genome, for understanding how genetic susceptibility effects cancer, and for elucidating how this susceptibility interacts with environmental factors that are also known to lead to cancer or affect its outcome. But epidemiology has a broader playing field than genetics. It also helps us understand the etiologic role of lifestyle factors such as tobacco use, diet, physical exercise, and adherence to screening procedures. And its methods are applied in the field of health services research as we try to understand the roles of health systems and delivery on cancer incidence and outcomes. Epidemiologists find applications for their skills throughout cancer prevention and control. In DCCPS, the focus of our activities is in the Epidemiology and Genetics Research Program (EGRP).

EGRP supports population-based research aimed at better understanding cancer etiology and prevention for use in setting priorities for individual and community-based interventions and public health policy. In essence, this research provides a bridge between basic biological and behavioral research and prevention and intervention research. Etiologic studies estimate cancer risks from a broad range of possible causes and evaluate their contribution to the cancer burden. Knowledge of these risk factors provides targets for cancer control research directed at preventing cancer, identifying it at its earliest stage, and ameliorating its consequences. Our overarching vision is that EGRP-

supported research in cancer epidemiology and genetics will lead to interventions that reduce the impact of cancer among all populations.

EGRP's mission is to advance the understanding of cancer etiology and prevention through epidemiologic and genetic investigations by supporting and collaborating with national and international scientists. Its portfolio of over 400 grants (the largest in DCCPS) consists mainly of investigator-initiated research. The research involves every cancer site, appropriately emphasizing the most common ones. We've learned that possible etiologic factors include genetic susceptibility; biologic factors, such as endogenous hormones; tobacco use; dietary practices and alcohol consumption; physical activity; and exposure to pharmaceuticals, radiation, infectious agents, and environmental pollutants.

> "This research provides a bridge between basic biological and behavioral research and prevention and intervention research."

One of the more salient developments in cancer epidemiology is that studies are becoming very large and more interdisciplinary. They may sometimes include more than 100,000 study participants and involve the processing of very large numbers of biological specimens. Nowhere is this more evident than in genetic epidemiology—where definitive approaches to gene discovery, gene characterization, and gene-environment and gene-gene interactions are needed. EGRP provides the national leadership necessary to integrate new research findings and needs with the appropriate resources and to prioritize future research directions.

EGRP is heavily involved in addressing NCI's strategic priority to advance our understanding of cancer through molecular epidemiology. In particular, it is pursuing many ways to further research on genes and the environment. A key area is the development of consortia of research teams that conduct very large cohort and case-control studies with existing human biorepositories previously supported chiefly by NCI. The aim is to encourage and support parallel or combined analyses of genetic and environmental risk factors of cancer.

A new EGRP initiative is supporting the pooling of data and biospecimens from 10 large cohort studies to collaborate on studies of hormone-related gene variants and environmental factors involved in the development of breast and prostate cancer. An aim of this initiative is a "proof of the principle" that pooling data and biospecimens across large-scale studies through consortia arrangements is an effective approach to conducting research on genes and the environment. EGRP is similarly encouraging development of case-control consortia, with the central focus on the International Consortium of Investigators Working on Non-Hodgkin's Lymphoma Epidemiologic Studies (InterLymph Consortium).

EGRP also created, funds, and provides leadership for multi-institution registries of cancer patients and their families, or individuals at high risk of cancer.

Beyond the immense challenges of genetic epidemiology, EGRP has responsibility for the congressionally mandated Long Island Breast Cancer Study Project and other highly visible epidemiology studies and issues. For example, it has supported studies employing multiple approaches and study designs to investigate possible environmental contaminants, especially pesticides, associated with elevated breast cancer rates on Long Island, New York. A major methodologic contribution is development of the Geographic Information System for Breast Cancer Studies on Long Island (LI GIS), which was completed in 2001 and is now in operation. EGRP also cofunds four new Breast Cancer and the Environment Research Centers in collaboration with the National Institute of Environmental Health Sciences.

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