Division of Cancer Control and Population Sciences

2005 Overview and Highlights

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

Division of Cancer Control and Population Sciences

2005 Overview and Highlights

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Table of Contents

FOREWORD

ABOUT OUR DIVISION

SURVEILLANCE

MOLECULAR EPIDEMIOLOGY

QUALITY OF CARE

TOBACCO CONTROL

BEHAVIORAL RESEARCH

ENERGY BALANCE

SURVIVORSHIP

HEALTH DISPARITIES

DISSEMINATION AND DIFFUSION

Foreword

Robert T. Croyle, PhD

Director, Division of Cancer Control
and Population Sciences

Biosketch

Robert T. 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 of 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.

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, statistical methods, communication science, 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.

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

> *"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."*

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, geography, 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 non-governmental organizations. Second, careful priority setting, planning, and evaluation 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 inform 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.

DIVISION POINTS OF CONTACT

Back L-R:
Everett Carpenter, Information Technology
Mary Kashanchi, Administrative Resource Center
Stacey Vandor, Planning
Mark Alexander, Grants Management

Front L-R:
Arline Sanchez, Executive Assistant
Augustina Felix, Secretary
Cynthia Vinson, Dissemination

DCCPS
Dr. Robert T. Croyle
Director

DCCPS
Dr. Jon F. Kerner
Deputy Director for Research Dissemination & Diffusion

Office of Cancer Survivorship
Dr. Julia H. Rowland
Director

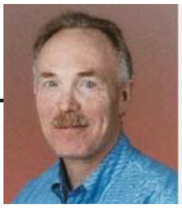
Epidemiology & Genetics Research Program
Dr. Edward Trapido
Associate Director

Analytic Epidemiology Research Branch
Dr. Mukesh Verma
Chief
(Acting)

Clinical & Genetic Epidemiology Research Branch
Dr. Deborah M. Winn
Chief

Behavioral Research Program
Dr. Linda Nebeling
Associate Director
(Acting)

Applied Cancer Screening Research Branch
Dr. Helen Meissner
Chief



Basic & Biobehavioral Research Branch
Dr. Michael Stefanek
Chief

Health Communication & Informatics Research Branch
Dr. Bradford Hesse
Chief
(Acting)

Health Promotion Research Branch
Dr. Louise Mâsse
Chief
(Acting)

Tobacco Control Research Branch
Dr. Cathy Backinger
Chief
(Acting)

About Our Division

LEADERSHIP AT A GLANCE

The DCCPS senior leadership team is often described as dedicated and innovative. We pride ourselves not only in our dedication to cancer control, but also in our willingness to utilize unconventional ideas and approaches to accelerate progress in cancer research.

To read DCCPS senior staff members' *Views from Leadership*, see pages 108-119.

Applied Research Program
Dr. Rachel Ballard-Barbash
Associate Director

Health Services & Economics Branch
Dr. Martin Brown
Chief

Outcomes Research Branch
Dr. Steven Clauser
Chief

Risk Factor Monitoring & Methods Branch
Dr. Susan Krebs-Smith
Chief

Surveillance Research Program
Dr. Brenda K. Edwards
Associate Director

Cancer Statistics Branch
Dr. Benjamin Hankey
Chief

Statistical Research Branch & Applications
Dr. Eric Feuer
Chief

Meet the DCCPS Staff

DCCPS was organized in 1997 to lead NCI's efforts in cancer control research. Since that time, the division has grown and evolved to become a stronghold of NCI's campaign to eliminate suffering and death from cancer. The division's achievements are made possible through the dedication and creativity of its talented and engaged professionals. By using knowledge gained from multiple disciplines and understanding how cancer impacts different populations in the United States, DCCPS strives to overcome cancer and improve quality of life for cancer survivors. This work is achieved through the support of dedicated staff as well as a diverse range of fellows, interns, and contractors.

OFFICE OF THE DIRECTOR

Alexander, Mark	MS
Blake, Kelly	MS, CHES
Carpenter, Everett	
Croyle, Robert	PhD
Cusano, Mary	BA
Cynkin, Laurie	MHS
Dold, Georgia	
Felix, Augustina	
Grauman, Dan	MS
Kerner, Jon	PhD
Kuan, Judy	MS
Leischow, Scott	PhD
Sanchez, Arline	
Uy, Annabelle	MS
Vandor, Stacey	MPA
Vinson, Cynthia	MPA

Office Of Cancer Survivorship

Aziz, Noreen	MD, PhD, MPH
Jeffery, Diana	PhD
Rowland, Julia	PhD
Sufian, Meryl	PhD

EPIDEMIOLOGY & GENETICS RESEARCH PROGRAM

Office of the Associate Director

Anderson, Linda	MPA
Choudhry, Jawahar	MS
Guest, Barbara	MSW, MPH
Lemrow, Shannon	PhD
Smith, Julian	
Trapido, Edward	ScD

Analytical Epidemiology Research Branch

Hartmuller, Virginia	PhD, RD
Iwamoto, Kumiko	MD, DrPH
Patel, Appasaheb	PhD
Starks, Vaurice	BS
Valle, Carmina	MPH
Verma, Mukesh	PhD

Clinical & Genetic Epidemiology Research Branch

Arena, Jose Fernando	MD, PhD
Kasten, Carol	MD
Mikhail, Isis	MD, MPH, DrPH
Seminara, Daniela	PhD, MPH
Winn, Deborah	PhD

BEHAVIORAL RESEARCH PROGRAM

Office of the Associate Director

Becker, Joan	BS
Moser, Richard	PhD
Nebeling, Linda	PhD, MPH, RD, FADA
Permuth-Levine, Rachel	MSPH
Vennell, Nicole	MSW

Tobacco Control Research Branch

Backinger, Cathy	PhD, MPH
Bloch, Michele	MD, PhD
Djordjevic, Mirjana	PhD
Fagan, Pebbles	PhD, MPH
Marcus, Stephen	PhD
Morgan, Glen	PhD
Parascandola, Mark	PhD, MPH
Stoddard, Jacqueline	PhD
Vollinger, Robert	MSPH

Applied Cancer Screening Research Branch

Breslau, Erica	PhD, MPH
Chollette, Veronica	MS, RN, BSN
Kobrin, Sarah	PhD, MPH
Meissner, Helen	PhD, ScM

Health Communications & Informatics Research Branch

Dresser, Connie	RDPH, LN
Harris, Linda	PhD
Hesse, Bradford	PhD
Solomon, Janice	BS
Woolley, Sabra	PhD

Health Promotion Research Branch

Agurs-Collins, Tanya	PhD, RD
Atienza, Audie	PhD
Grant, Yvonne	
Mâsse, Louise	PhD
Yaroch, Amy	PhD

Basic & Biobehavioral Research Branch

Heurtin-Roberts, Suzanne	PhD, MSW
McDonald, Paige	PhD, MPH
Nelson, Wendy	PhD
Stefanek, Michael	PhD

SURVEILLANCE RESEARCH PROGRAM

Office of the Associate Director

Edwards, Brenda	PhD
Flagg, Elizabeth (Betsy)	BA
Garson, Amy	BS
Harshman, Terri	
Meersman, Stephen	PhD
Reichman, Marsha	PhD, MA
Swan, Judith	MHS

Cancer Statistics Branch

Adamo, Margaret	RHIT, CTR
Clegg, Lin	PhD
Eisner, Milton	PhD
Fritz, April	BA, CTR, RHIT
Hankey, Benjamin	ScD
Hayat, Matthew	PhD
Johnson, Carol	BS, CTR
Kosary, Carol	MA
Lewis, Denise	PhD, MPH
Miller, Barry	DrPH
Peace, Steve	BS, CTR
Ries, Lynn	MS
Stinchcomb, David	MA-Geo/MSCS
Ware, Elliott	BS

Statistical Research & Applications Branch

Cronin, Kathleen	PhD
Das, Barnali	PhD
Davis, William	PhD
Dodd, Kevin	PhD
Feuer, Eric (Rocky)	PhD
Mariotto, Angela	PhD
Pickle, Linda	PhD
Tiwari, Ram	PhD

APPLIED RESEARCH PROGRAM

Office of the Associate Director

Ambs, Anita	MPH
Ballard-Barbash, Rachel	MD, MPH
Berrigan, David	PhD, MPH
McLaughlin, Wendy	MSW, MPA
Potischman, Nancy	PhD
Taplin, Stephen	MD, MPH
Willis, Gordon	PhD

Health Services & Economics Research Branch

Breen, Nancy	PhD
Brown, Martin	PhD
Harlan, Linda	PhD
Klabunde, Carrie	PhD
Potosky, Arnold	PhD
Shavers, Vickie	PhD
Warren, Joan	PhD
Yabroff, Robin	PhD, MBA

Risk Factor Monitoring & Methods Branch

Freedman, Andrew	PhD
Hartman, Anne	MS, MA
Krebs-Smith, Susan	PhD
Lawrence, Deirdre	PhD, MPH
Subar, Amy	PhD
Thompson, Frances	PhD, MPH
Troiano, Richard	PhD
Wideroff, Louise	PhD

Outcomes Research Branch

Arora, Neeraj	PhD
Clauser, Steven	PhD
Donaldson, Molla	DrPH, MS
Reeve, Bryce	PhD

ADMINISTRATIVE RESOURCE CENTER

Brown, Steve	
Curington, Tina	
Garvey, Anne	BS
Kashanchi, Mary	BA
Mesa, Mike	
Newball, Kim	BS
Schneider, Vicky	
Todd, Donna	
Turner, Rhonda	
Wolfe, Rosemary	BS

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 knowledge is translated into practice and policy 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.

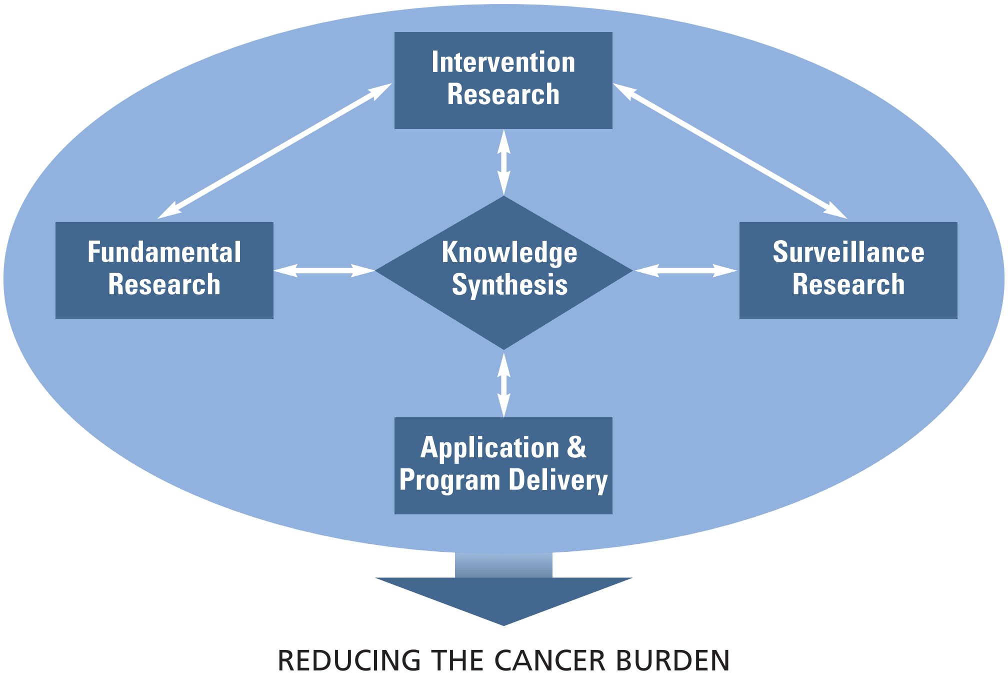
Definition

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).

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, epidemiological, 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.

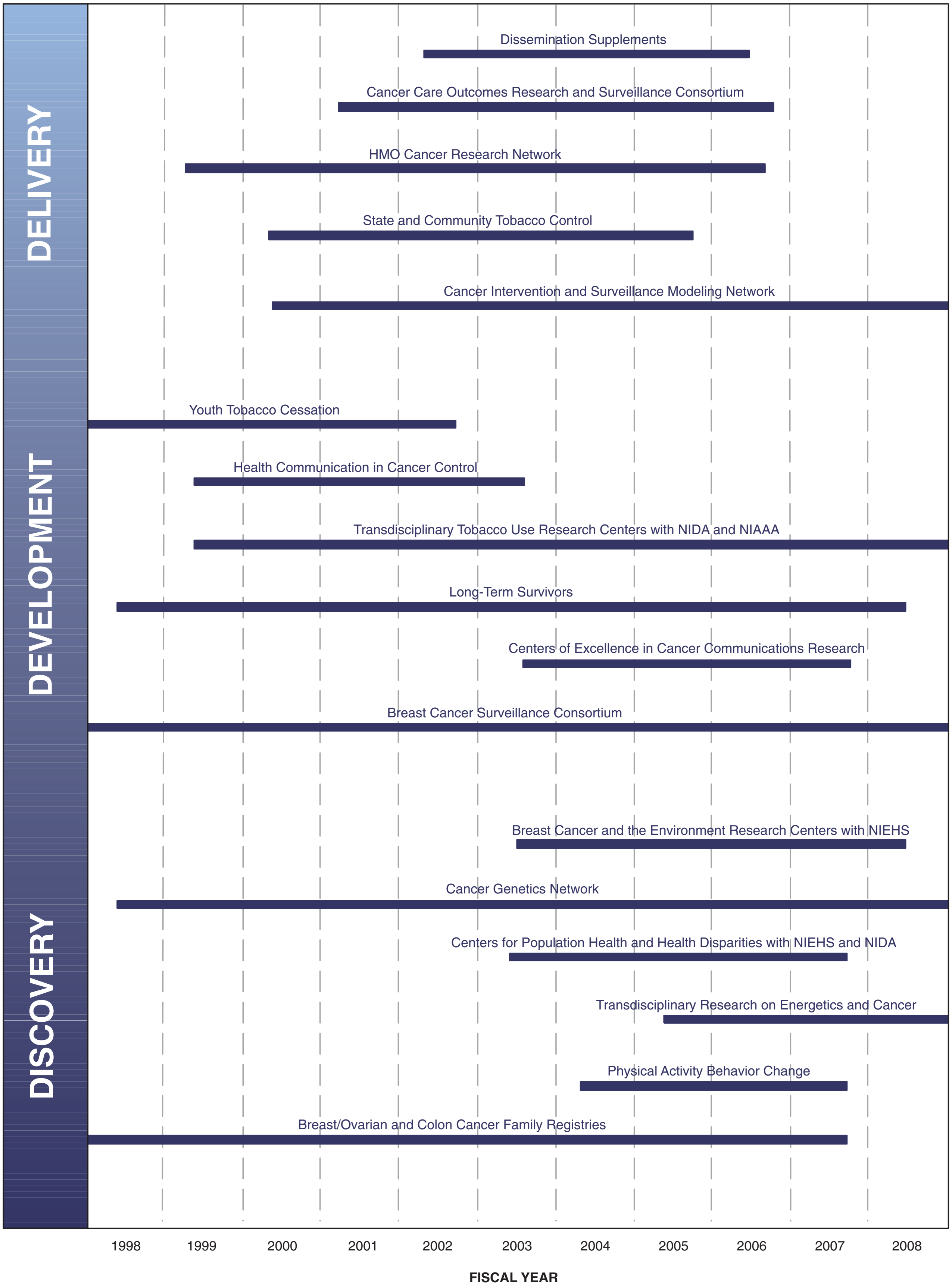
Cancer Control Research Activities



REDUCING THE CANCER BURDEN

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

Examples of Major Initiatives in DCCPS



HOW WE SUPPORT PRINCIPAL INVESTIGATORS

DCCPS Program Directors and Project Officers are recognized scientific experts who exercise oversight and monitor the scientific progress and programmatic aspects of grants, cooperative agreements, and research contracts. They participate in the decision-making process that identifies research goals and objectives, and recommend action for resource allocation. Program Directors and Project Officers collaborate and maintain effective liaisons with scientists in their program area and monitor technologic, scientific, and policy developments in order to consider future research priorities.

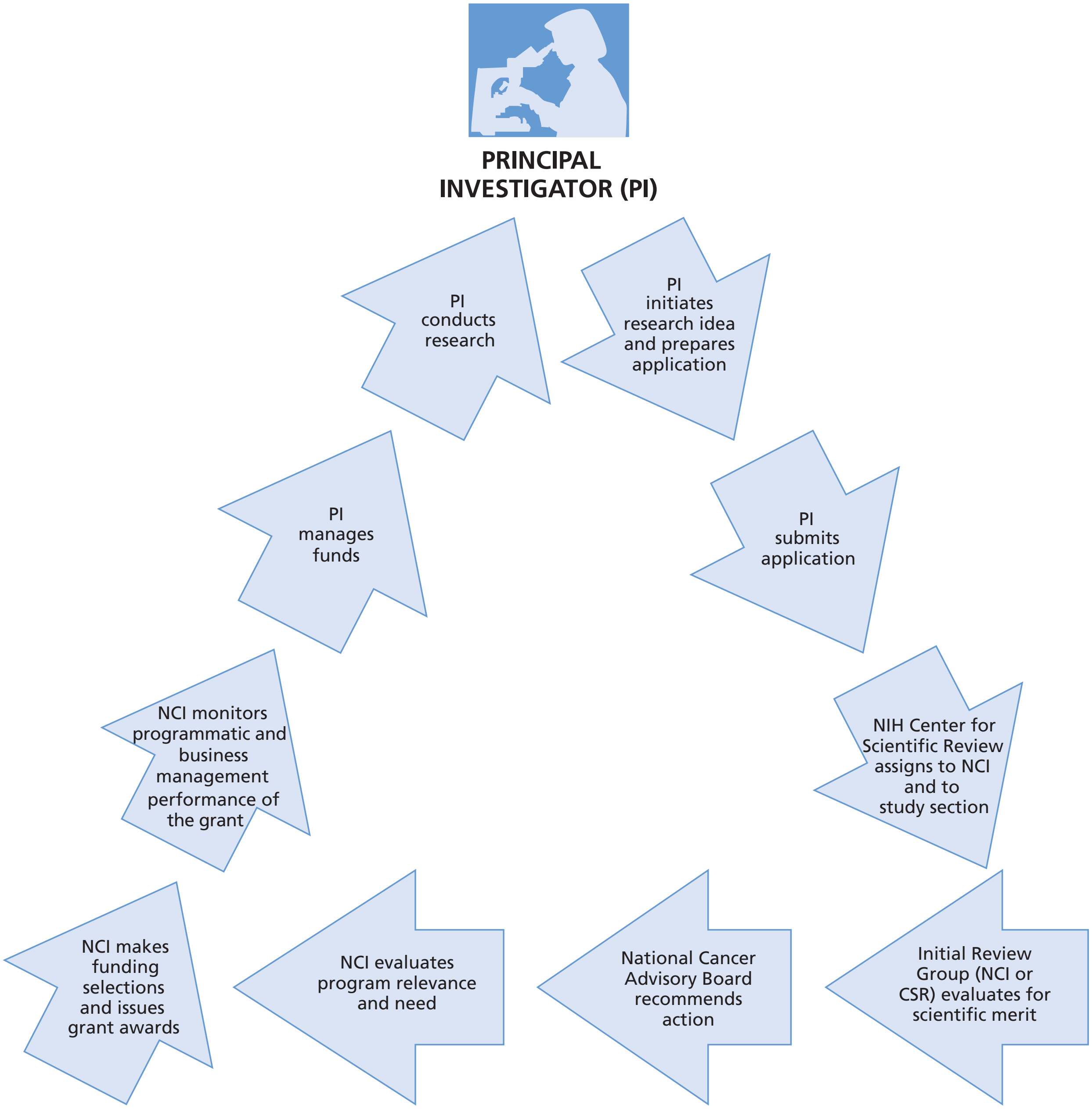
Program Directors and Project Officers are an important resource to grant applicants. They encourage the submission of quality applications that will be competitive for funding by helping applicants understand the available options for NIH support.

Program Directors and Project Officers are dedicated to ensuring that grants and contracts are fully implemented and evaluated. They review progress reports to determine whether sufficient progress is being made. They also encourage investigators to publish and disseminate research results, and to present relevant papers at national and international scientific meetings.

The Role of Program Directors and Project Officers

- Explain the NCI and NIH philosophy, grant and contract policies, and system of reviewing and awarding research applications
- Identify resources for locating funding opportunities and the best NIH institute or center for the potential funding of a project idea
- Describe grant and contract mechanisms that correlate with the goal and intent of the project and the experience of the investigator
- Refer applicants to Web sites for information on proposal preparation
- Clarify Request For Applications (RFA), Program Announcement (PA), and Request For Proposals (RFP) solicitations beyond what is printed in the announcements
- Provide information on the infrastructure of the application, including sources for acquiring forms
- Describe the review process from application submission to follow-up after peer review
- Provide advice on general research issues, such as clarification of the theoretical basis of the science involved, identification of ways an idea builds on the current state of science, pathways to justify NCI funding, and identification of how an idea or approach is unique when compared to existing research awards
- Respond to information requests concerning the grant and contracts portfolio
- Develop collaborations with other research funders
- Develop and propose to NCI leadership new concepts for RFAs and PAs
- Initiate and plan workshops and conferences to facilitate research planning, priority setting, and dissemination
- Serve as liaison to national and international associations

Grants Process Overview



Adapted from Everything You Wanted To Know About the NCI Grants Process, *published April 2002.*

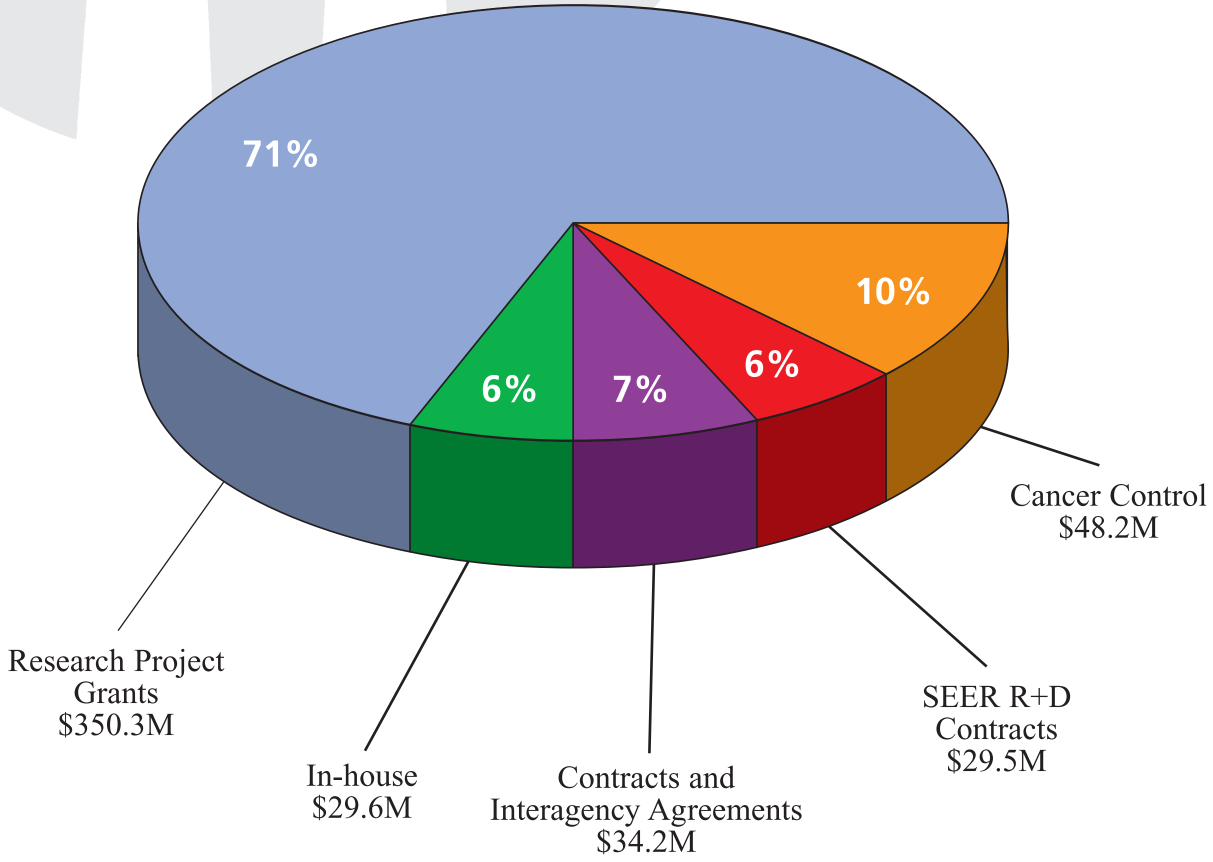
Research Grants & Contracts

THE RESEARCH ENTERPRISE OF CANCER CONTROL

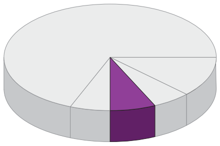
DCCPS is often considered a "hybrid" division, one that funds a large portfolio of grants and contracts, but also conducts original research to inform public health policy. In this section, we provide an overview of Fiscal Year 2004 research funding and support dollars valued at over $490 million. In addition to overview charts and graphs, see page 19 for the U.S. maps that show grant funding and SEER contract awards across the country.

Fiscal Year 2004 Research Funding and Support Dollars

Total Funding=$491.8M

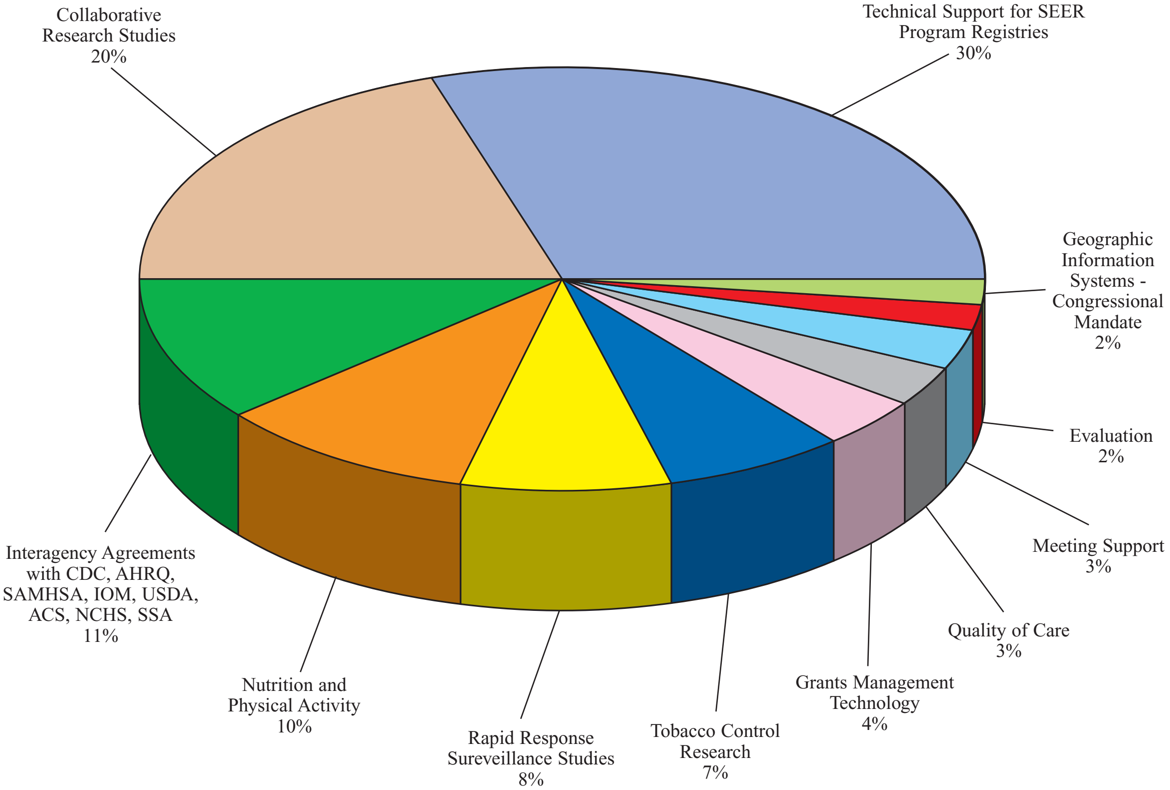


Approximately 23 percent ($34.2M) of the DCCPS operating budget in FY04 was spent on research and support contracts and interagency agreements. These are separate from the research and development contract expenditures that are devoted to the SEER program registries.

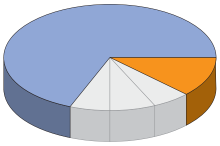


Fiscal Year 2004 Contracts and Interagency Agreements

Total Funding=$34.2M



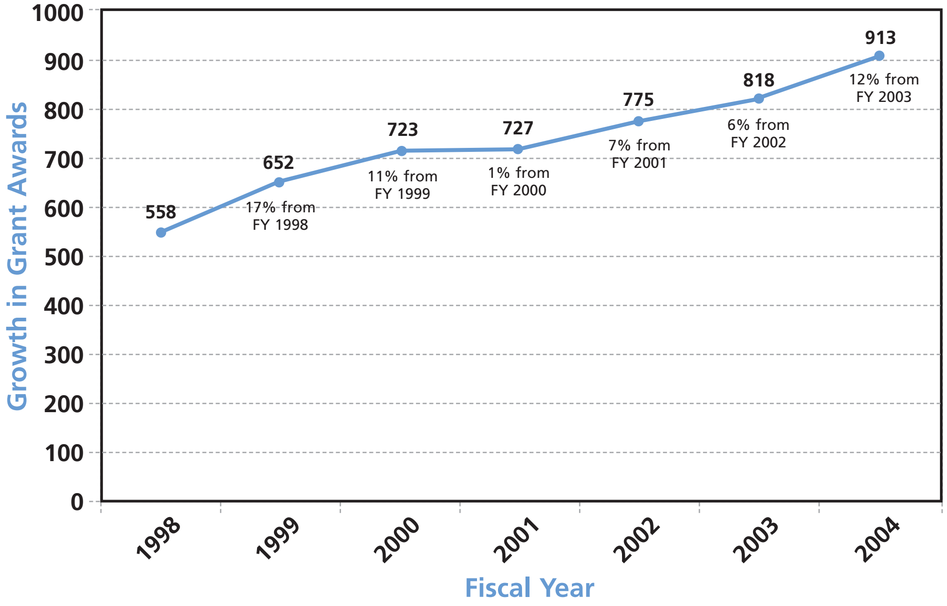
Research Grants & Contracts



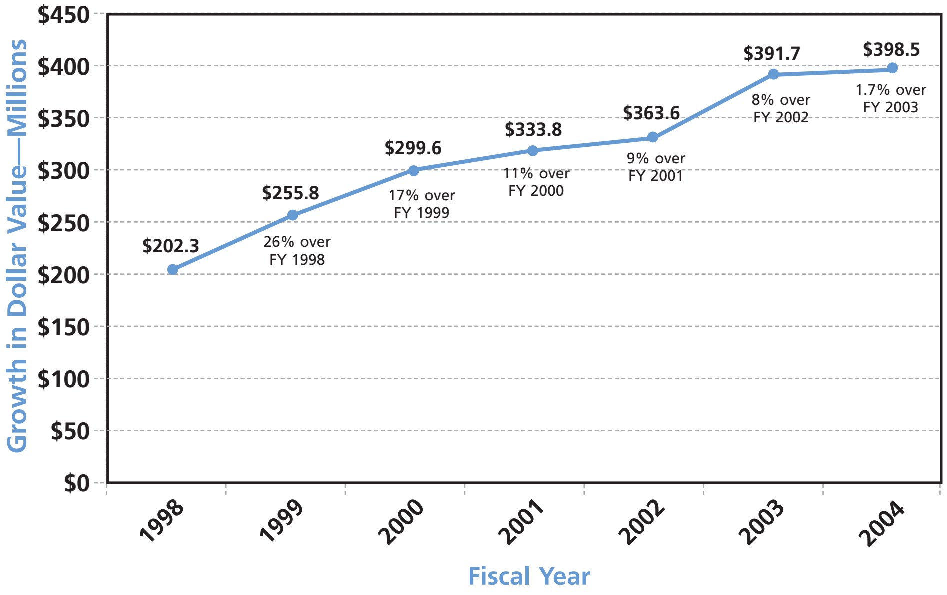
Summary of Fiscal Year 2004 Grant Funding by Mechanism

MECHANISM	# OF GRANTS AWARDED	TOTAL DOLLARS
R01 – Research Project Grant	513	$254,007,343
R03 – Small Research Grant	139	$10,250,167
R13 – Conference Grant	20	$402,950
R15 – Academic Research Enhancement Award (AREA)	2	$430,808
R21 – Exploratory/Development Grant	87	$13,196,532
R24 – Resource-Related Research Project	2	$524,487
R37 – Method to Extend Research in Time Award (MERIT)	1	$2,136,335
R42 – Small Business Technology Transfer (STTR) Grant - Phase II	1	$85,500
R43 – Small Business Innovation Research Grant (SBIR) - Phase I	20	$2,386,523
R44 – Small Business Innovation Research Grant (SBIR) - Phase II	24	$8,490,018
P01 – Research Program Project Grant	16	$28,849,787
U01 – Research Project—Cooperative Agreement	63	$46,235,969
U19 – Research Program—Cooperative Agreement	1	$5,078,607
U24 – Resource-Related Research Project—Cooperative Agreement	8	$4,502,373
P50 – Specialized Center Grant	16	$21,963,684
TOTAL	**913**	**$398,541,083**

Growth in the Number of DCCPS Research Grant Awards (Fiscal Year 1998–Fiscal Year 2004)

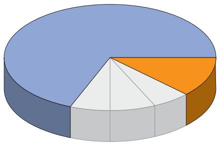


Growth in the Dollar Amount of DCCPS Research Grant Funding (Fiscal Year 1998–Fiscal Year 2004)

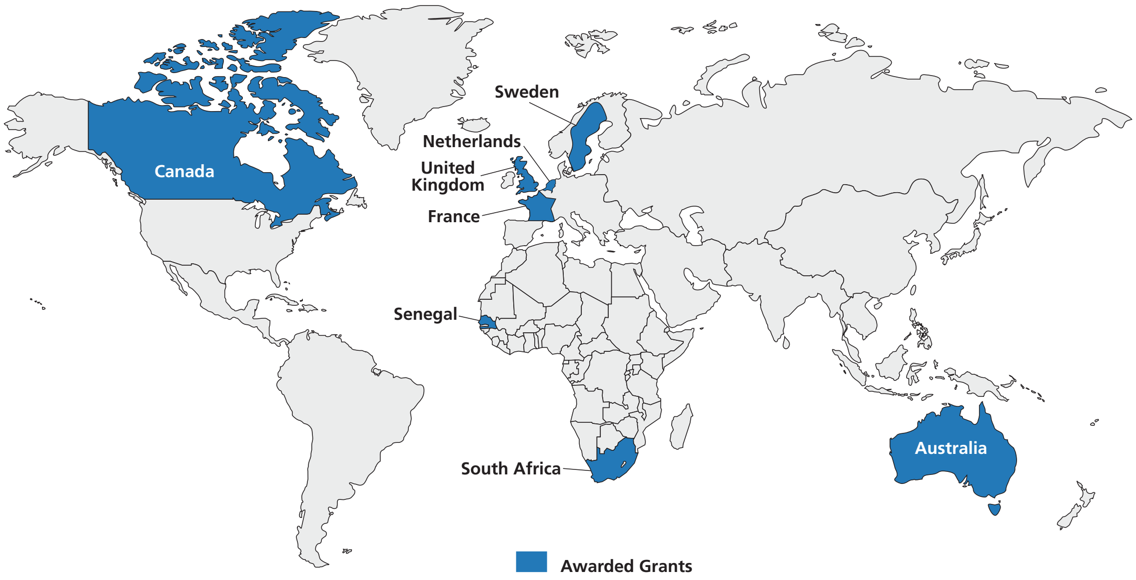


The overall increase in the dollar value of grants funded from FY 2003 to FY 2004 (1.7%) is relatively small compared to the increase in the number of grants awarded (12%) during the same period. This is due in part to an increase in the number of small grants that have strict budget caps (*e.g.*, R03s and R21s). Through DCCPS initiatives, NCI is funding more grant awards at a reduced cost.

Research Grants & Contracts



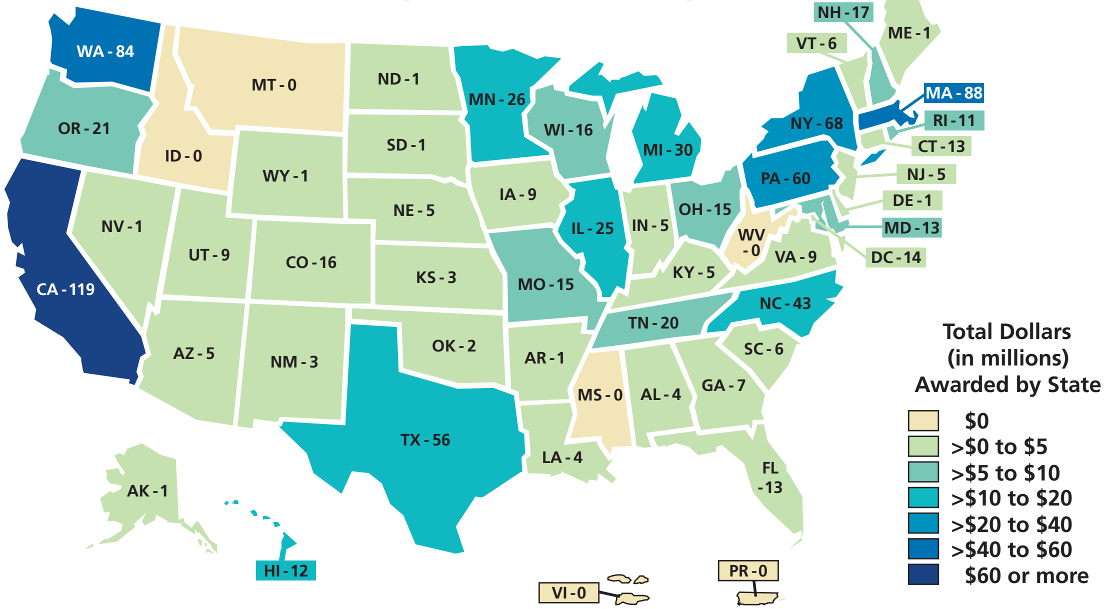
Foreign Countries with Direct Grant Awards (Fiscal Year 2004)



Grants reflected here are direct awards to foreign institutions. There are 23 grants valued at $8.5M awarded to countries highlighted in the map above and chart below. In addition, there are 85 domestic grants that have a foreign component in 41 countries. The domestic grants with a foreign component are included in the map showing DCCPS grants awarded by state on the next page.

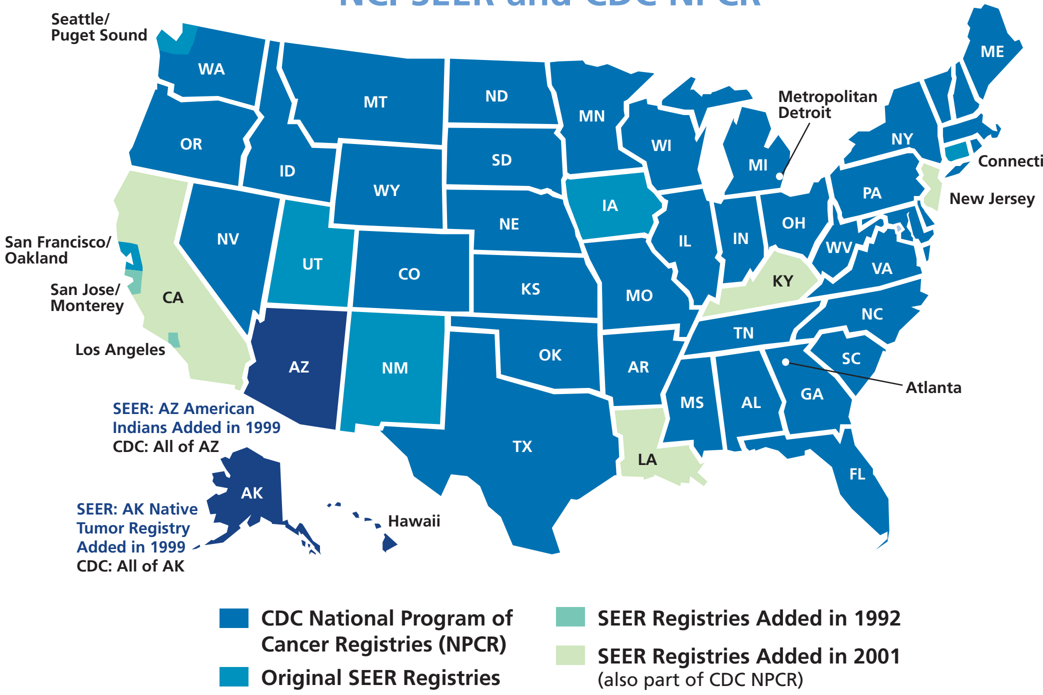
COUNTRY	# OF GRANTS AWARDED	TOTAL DCCPS DOLLARS
Sweden	3	$503,670
France	5	$1,697,088
Senegal	1	$27,000
United Kingdom	2	$442,650
Canada	4	$3,310,874
Australia	5	$2,375,298
Netherlands	2	$107,449
South Africa	1	$48,600
SUBTOTAL	**23**	**$8,512,629**
United States	890	$390,028,454
TOTAL	**913**	**$398,541,083**

DCCPS Grants by State (Fiscal Year 2004)



Grants awarded to foreign institutions are highlighted on previous page.

Cancer Registries: NCI SEER and CDC NPCR



Surveillance

The United States has a national cancer registration system that is structured and funded by interdependent programs operating within the federal, state, and private sectors. Federal programs at NCI and CDC provide almost $80 million annually to cancer registries in all 50 states, the District of Columbia, and several territories. Data are available and routinely published on all cancers. Cancer surveillance data provide quantitative measures of the burden of cancer and the impact of cancer control interventions in the general population. Efforts are currently underway to further integrate the use of cancer surveillance data more directly into federal, state, and local cancer control planning efforts, including resource allocation for the purpose of reducing the cancer burden. One of the key tools for improving the usability and utility of surveillance data is the Cancer Control PLANET Web portal, described on page 103.

MAJOR INITIATIVES

SEER Program

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

One of NCI's most important research infrastructures is the Surveillance, Epidemiology, and End Results (SEER) Program. SEER is an authoritative source of information on cancer incidence and survival in the United States, with more than 30 years of distinguished service to the research community. 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 suffering and death due to cancer. A brief history, including its recent expansion of coverage, is captured here.

- **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:** SEER 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 expanded SEER with awards to four 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 more than 15 years actively collaborating with other federal agencies and with professional and private organizations involved in cancer surveillance. Collaborators include the National Program of Cancer Registries, based at CDC; the North American Association of Central Cancer Registries, a professional organization devoted to standardized data collection procedures for cancer registries in North America; the Commission on Cancer of the American College of Surgeons; and the American Cancer Society.

Rapid Response Surveillance Studies

Contact Linda C. Harlan, PhD, 301-496-8500, lh50w@nih.gov or Limin (Lin) Clegg, PhD, 301-402-5830, cleggl@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 almost two decades, NCI has used this mechanism to conduct studies that provide additional information related to the quality of cancer registry data, develop techniques for more efficient registry operations, and develop applications systems that rely on current information technology. SEER also serves as a research resource for obtaining population-based comparisons for evaluation of biobehavioral and risk factors, screening patterns, and molecular and genetic surveillance to quantify the progress of cancer control at the population level. Such studies provide 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 exceptional productivity, with over 165 publications thus far.

Cancer Intervention and Surveillance Modeling Network (CISNET)

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

The Cancer Intervention and Surveillance Modeling Network (CISNET) cooperative agreements investigate 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. Funding for 15 awards totaling over $2 million annually was approved in fiscal year 2005.

- Cancer Intervention and Surveillance Modeling Network, Donald Berry, University of Texas MD 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, Memorial Sloan-Kettering Cancer Center

PARTNERSHIPS & COLLABORATIONS

Centers for Disease Control and Prevention (CDC)

- DCCPS and CDC's Division of Cancer Prevention and Control (DCPC) have a memorandum of understanding between NCI's Surveillance, Epidemiology, and End Results (SEER) Program and CDC's National Program of Cancer Registries to coordinate collecting and reporting cancer incidence and mortality data. 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. Staff from both agencies frequently co-author peer-reviewed publications on all aspects of cancer surveillance.

- DCCPS and CDC are collaborating to initiate a national consensus informatics model of cancer registry function. The model will be used as a reference for transmission, management, and analysis of cancer registry data.

Centers for Medicare & Medicaid Services (CMS)

- The 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 one 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.

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 as 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 initiated record linkage studies with state cancer registeries in Oregon, Idaho, and Washington. This will significantly improve the accuracy of data on the incidence and prevalence of diseases such as cancer among Northwest AI/AN.

- In 2003 and again in 2005, NCI funded SEER registries to link data to the IHS patient registration database. This effort is aimed at addressing racial misclassification in the cancer registries, and although not perfect, it is a logical step in the process of identifying additional cancer cases among American Indian populations. The process will become a continuing project for SEER. In related work, DCCPS is supporting the Northwest Portland Area Indian Health Board to conduct linkages with the IHS databases in Oregon, Idaho, and Washington.

- The Alaska Native Tumor Registry was initiated in 1974 in collaboration with CDC. It became a SEER member in 2000. The registry reports annually on cancer rates in Alaska Natives in cooperation with the Alaska Native Tribal Health Consortium, covering all eight IHS service units in the state.

American Cancer Society (ACS)

- The DCCPS SEER Program partners with ACS, the North American Association of Central Cancer Registries, NIA, and CDC—including the National Center for Health Statistics—to publish the *Annual Report to the Nation on the Status of Cancer.*

- DCCPS scientists have developed and validated a more accurate method for predicting cancer mortality rates, and this method was instituted by ACS for the 2004 edition of *Cancer Facts and Figures.*

C-Change

- 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 staff had a leadership role in the planning and implementation of the successful Cancer Surveillance Summit. The second summit is being planned with a focus on standardization of cancer surveillance data.

National Library of Medicine (NLM)

- DCCPS collaborated with the National Library of Medicine (NLM) to organize a workshop in June 2005 titled "The Crossroads of GIS and Health Information: Moving Ahead to Improve Cancer Control." The purpose of the meeting was to bring together GIS data providers and data users to discuss how to improve data availability and security, computer-based tools, and multi-partner collaborations to improve cancer control. NLM participated as the developer of TOXMAP, an online mapping system that displays the amount and location of toxic chemicals released into the environment, and as a provider of bibliographic resources to the medical community.

American College of Surgeons (ACoS) Commission on Cancer

- DCCPS has been working with the ACoS Commission on Cancer, along with the American Joint Committee on Cancer (AJCC) and other organizations to implement the Collaborative Staging System, which will standardize the guidelines for collecting cancer data in the United States. With this advancement, a computer algorithm unifies the various coding systems used by cancer registries.

American Society of Clinical Oncology (ASCO)

- Based on population-level data of ovarian cancer diagnosed in 1991, NCI identified that women with early-stage ovarian cancer were not receiving any nodal sampling to fully define their disease stage at diagnosis. To enhance understanding of the need for more complete nodal sampling, NCI developed an Ovarian Cancer Treatment Consensus Development Conference and further worked with ASCO, the Society of Gynecologic Oncologists, and the American College of Obstetricians and Gynecologists to provide education about appropriate treatment for ovarian cancer. Subsequent monitoring of quality of care through patterns and quality of care studies within the SEER Program indicate that rates of nodal sampling have improved, particularly in groups with the lowest rates in 1991.

TOOLS, PRODUCTS, & RESOURCES

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

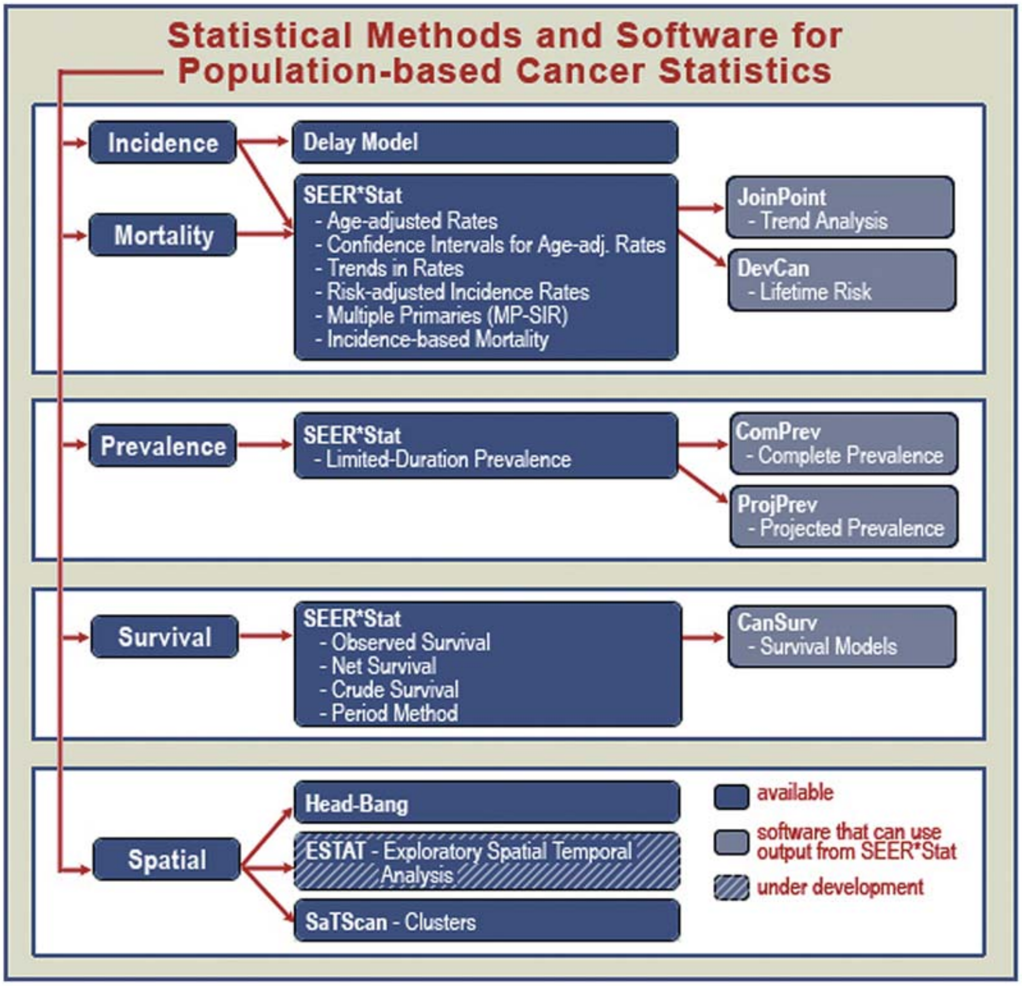
http://seer.cancer.gov

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 1975-2002 Cancer Statistics Review, complete with a search function. As a participant in the American Customer Satisfaction Index (ACSI), the SEER site will be evaluated pre- and post-implementation of a current redesign.

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 is used within NCI. 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 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 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. There is a choice of outputs, including vertical bar charts, line charts, tabular reports, or delimited data files. DCCPS is enhancing Fast*Stats to be responsive to the advocacy, research, and public health communities by including queries on survival and stage at diagnosis. The types of analyses are being expanded along with the usability of graphing functions.

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 from 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 from 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 trends have been calculated.

- *Prevalence* represents new and pre-existing conditions in individuals 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.

- *SEER*Rx — Interactive Antineoplastic Drugs Database*. A tool for cancer registries, SEER*Rx was developed as a one-step lookup for coding oncology drug and regimen treatment categories in cancer registries. Released in 2005, the program is provided free from NCI. The databases are scheduled to be updated every six months. SEER*Rx allows registrars to look up treatment categories for over 1,600 drugs and individual treatment categories for drugs in over 700 regimens. The screen provides information on generic name, brand name, NSC number, drug category and subcategory, cancer sites where the drug is used, and other details, including whether the drug should be coded as treatment. SEER*Rx is another informatics tool to facilitate consistent data collection across registries.

Collaborative Staging System

The Collaborative Staging System has been an effort to simplify and standardize the rules and guidelines for collecting cancer data in the United States. As the name implies, development of this system was a collaborative effort of the sponsor, the American Joint Committee on Cancer (AJCC), NCI’s SEER Program, CDC’s National Program of Cancer Registries, the North American Association of Central Cancer Registries, the National Cancer Registrars Association, and the Commission on Cancer. The new system builds on the strengths of NCI’s extent of disease coding system while accommodating the staging principles of the AJCC’s tumor-node-metastasis staging system and the legacy information from the NCI historic staging system. The Collaborative Staging System allows cancer registrars to collect the facts about a cancer case in a structured code. At the completion of data collection and coding with the new system, the registrar can now rely on a computer algorithm to take the codes and assign the T, N, M, Stage Group, and Summary Staging categories. In this manner, collaborative staging updates and unifies registry data collection rules and guidelines to meet the challenges of twenty-first century medical documentation.

The Collaborative Staging System has been approved and adopted by all of the collaborating organizations. All registry software programs—hospital and central—will use the same set of computer algorithms, which have been carefully developed to take the coded information and consistently assign the correct stage information based on the combinations of codes recorded. The computer-derived output is familiar to both the staging clinicians and researchers. Because so much of the work has been performed by federal agencies, the programs, computer algorithms, and associated materials are provided free of charge to software vendors, hospital registries, and central registries.

Collaborative Staging Task Force of the American Joint Committee on Cancer. (2004). *Collaborative Staging Manual and Coding Instructions, Version 1.0.* Jointly published by the American Joint Committee on Cancer (Chicago, IL) and U.S. Department of Health and Human Services (Bethesda, MD). NIH Publication Number 04-5496.

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 their knowledge, attitudes, and practices concerning cancer-related health behaviors and cancer screening modalities. A 2005 module is being planned.

NHIS/CCTM includes questions about cancer risk factors such as diet, tobacco use, and alcohol consumption. It also includes questions about cancer screening, and is used by DCCPS and others to monitor national levels, trends, and determinants for use of preventive services.

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. Fielded for the first time in 2000-2001, the survey provides information on a wide range of health indicators, including physical and mental health status, prevalence and management of chronic diseases, diet and exercise, health insurance coverage, and access to and utilization of preventive and other health services. The 2003 survey includes questions about screening for breast, colorectal, cervical, and prostate cancers, as well as sun avoidance.

The 2005 survey will include questions on cancer screening, family history of cancer, diet and nutrition, physical activity, and exercise.

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

Notes

Annual Report to the Nation

DCCPS has worked with the nation's other leading cancer organizations to report that Americans' risk of dying from cancer continues to decline and that the rate of new cancers is holding steady. The "Annual Report to the Nation on the Status of Cancer, 1975-2002," published in 2005 in the *Journal of the National Cancer Institute*, finds observed cancer death rates from all cancers combined dropped 1.1 percent per year from 1993 to 2002. Incidence rates were stable in men from 1995 to 2002 and increased 0.3 percent annually in women from 1987 to 1992. According to the report's authors, the data reflect progress in prevention, early detection, and treatment; however, not all segments of the U.S. population benefited equally from advances, a point outlined in a featured analysis of treatment trends.

First issued in 1998, the "Annual Report to the Nation" is a collaboration among NCI the American Cancer Society (ACS), the Centers for Disease Control and Prevention (CDC), and the North American Association of Central Cancer Registries (NAACCR). It provides updated information on cancer rates and trends in the United States.

Edwards, B.K., Brown, M.L., Wingo, P.A., Howe, H.L., Ward, E., Ries, L.A.G., Schrag, D., Jamison, P.M., Jemal, A., Wu, X.C., Friedman, C., Harlan, L., Warren, J., Anderson, R.N., Pickle, L.W. (2005). Annual Report to the Nation on the Status of Cancer, 1975-2002 Featuring Population-Based Trends in Cancer Treatment. *Journal of the National Cancer Institute* (in press).

National Cancer Surveillance Moves Closer to Goal

In a major step toward coordination of cancer surveillance efforts in the United States, the organizations involved in national surveillance have developed a framework to enhance their systems to meet increased demands for data and to effectively address program planning, evaluation, and research on cancer prevention and control. Representatives from the American Cancer Society, American College of Surgeons, CDC, NCI, National Cancer Registrars Association, and North American Association of Central Cancer Registries have worked together on the National Coordinating Council for Cancer Surveillance to develop a national framework for cancer surveillance in the United States. The framework addresses a continuum of disease progression from a healthy state to the end of life and includes primary prevention (factors that increase or decrease cancer occurrence in healthy populations), secondary prevention (screening and diagnosis), and tertiary prevention (factors that affect treatment, survival, quality of life, and palliative care). The framework also addresses cross-cutting information needs, including better data to monitor disparities by measures of socioeconomic status, to assess economic costs and benefits of specific interventions for individuals and for society, and to study the relationship between disease and individual biologic factors, social policies, and the environment. Implementation of the framework will require long-term, extensive coordination and cooperation among these major cancer surveillance organizations.

Wingo, P.A., Howe, H.L., Thun, M.J., Ballard-Barbash, R., Ward, E., Brown, M.L., Sylvester, J., Friedell, G.H., Alley, L., Rowland, J.H., & Edwards, B.K. (2005). A national framework for cancer surveillance in the United States. *Cancer Causes and Control, 16,* 151-170.

Disparities in U.S. Incidence of Cervical Cancer, Mortality, Stage, and Survival, 1975-2000.

Cervical cancer incidence and mortality patterns over time and ethnic disparities in patient survival and stage at diagnosis in relation to socioeconomic deprivation measures have not been well studied in the United States. NCI investigators analyzed temporal area socioeconomic inequalities in U.S. cervical cancer incidence, mortality, stage, and survival using county and census tract poverty and education variables from the 1990 Census linked to U.S. mortality and Surveillance, Epidemiology, and End Results (SEER) cancer incidence data from 1975 to 2000. Substantial area socioeconomic gradients in both incidence and mortality were observed, with inequalities in cervical cancer persisting against a backdrop of declining rates. Cervical cancer incidence and mortality rates increased with increasing poverty and decreasing education levels for the total population as well as for non-Hispanic white, black, American Indian, Asian/Pacific Islander, and Hispanic women. Patients in lower socioeconomic census tracts had significantly higher rates of late-stage cancer diagnosis and lower rates of cancer survival. Even after controlling for stage, significant differences in survival remained. The five-year survival rate among women diagnosed with distant-stage cervical cancer was approximately 30 percent lower in low than in high socioeconomic census tracts. These results indicate that census-based socioeconomic measures such as area poverty and education levels could serve as important surveillance tools for monitoring temporal trends in cancer-related health inequalities and targeting interventions.

Singh, G.K., Miller, B.A., Hankey, B.F., & Edwards, B.K. (2004). Persistent area socioeconomic disparities in U.S. incidence of cervical cancer, mortality, stage, and survival, 1975-2000. *Cancer, 101(5)*,1051-7.

The Healthy People 2010 Smoking Prevalence Target Will not Be Reached: Results From the SimSmoke Tobacco Control Policy Simulation Model (United States).

Healthy People 2010 (HP2010) set a goal of reducing the adult smoking prevalence to 12 percent by 2010. Smoking prevalence rates do not appear to be declining at or near the rate targeted in the HP2010 goals. NCI's Cancer Intervention and Surveillance Modeling Network (CISNET) is a consortium of investigators interested in disease modeling. To provide information to the U.S. Department of Health and Human Services and others, CISNET investigators at the University of Baltimore examined the attainability of HP2010 smoking prevalence objectives through the stricter tobacco control policies suggested in HP2010. A tested dynamic simulation model of smoking trends, known as SimSmoke, was applied. Smoking prevalence evolves over time through initiation and cessation, behaviors which are in turn influenced by tobacco control policies. Investigators considered the effect of changes in taxes/prices, clean air laws, media campaigns, cessation programs, and youth access policies on projected smoking prevalence over the period 2003-2020, focusing on the levels in 2010. The SimSmoke model projected that the aging of older cohorts and the impact of policies in years prior to 2004 will yield a reduction in smoking rates to 18.4 percent by 2010, which is substantially above the 2010 target of 12 percent. When policies similar to the HP2010 tobacco control policy objectives are implemented, SimSmoke projects that smoking rates could be reduced to 16.1 percent. Further reductions might be realized by increasing the tax rate by $1.00. The SimSmoke model suggests that the HP2010 smoking prevalence objective is unlikely to be attained, but meeting the HP2010 policy objectives could bring the result much closer to the goal. Emphasis should be placed on meeting the tax, clean air, media and comprehensive campaigns, and cessation treatment objectives.

Levy, D.T., Nikolayev, L., Mumford, E., & Compton, C. (2005). The Healthy People 2010 smoking prevalence and tobacco control objectives: Results from the SimSmoke tobacco control policy simulation model (United States). *Cancer Causes and Control, 16,* 359-371.

Geographic Association Between Mammography Use and Mortality Reduction in the U.S.

Breast cancer mortality rates in women have been declining at the same time as breast cancer incidence rates, mammography rates, and use of effective adjuvant therapy have been increasing. Recent reports have called into question the results of randomized controlled trails, which examined the value of mammography screening in preventing breast cancer mortality. The objective of this study was to examine population data on breast cancer screening and breast cancer mortality to see if there is any geographic association between mammographic screening and breast cancer mortality reduction in the U.S., adjusting for therapy use. The analyses used data on mammography use from the Behavioral Risk Factor Surveillance System (BRFSS) at the state level, and estimates of adjuvant therapy use from the Surveillance, Epidemiology and End Results (SEER) Program. All the analyses showed a small but significant negative correlation between mammography usage and mortality reduction in breast cancer, both when unadjusted and adjusted for adjuvant therapy use. The results of the analyses seem to support the conclusions of randomized mammographic screening trials. While randomized controlled trials are certainly the gold standard in appraising the efficacy of new screening or treatment modalities, such trials are conducted under standardized conditions and do not always reflect the effect of these interventions at the population level. This paper attempts to examine population-level effects through ecologic analyses.

Das, B., Feuer, E.J., & Mariotto, A. (2005). Geographic association between mammography use and mortality reduction in the U.S. *Cancer Causes and Control, 16 (6).*

Modeling of Recovery Trajectories Following Radical Prostatectomy

As treatments improve and survival time lengthens, the course of recovery and long-term quality of life (QoL) is of great interest. The application of statistical models to longitudinal QoL data provides unique insights into recovery that are not otherwise evident. The Prostate Cancer Outcomes Study (PCOS), a large population-based observational study, provided the first opportunity to characterize individuals' recovery over time following prostate cancer surgery, and to determine factors associated with varying recovery experiences of patients. Four major patterns emerged that illustrate typical patterns of recovery following radical prostatectomy. Given a man's baseline data, this method produces estimates of the probability of belonging to each recovery class. The method is presented as a useful tool for identifying hypotheses associated with recovery and potential antecedents of importance.

Legler, J.M., Davis, W.W., Potosky, A.L., & Hoffman, R.M. (2004). Latent variable modeling of recovery trajectories: Sexual function following radical prostatectomy. *Statistics in Medicine, 23(18)*, 2875-93.

Notes

Molecular Epidemiology

Cancer is a complex disease that develops when errors occur in a person's genes. Some of these genetic errors are inherited. Others result from certain environmental exposures or individual behaviors, usually coupled with inherited susceptibility. Through the use of increasingly sophisticated molecular technologies and the tremendous resource generated by the mapping of the human genome, scientists now know that some inherited genetic errors nearly always give rise to cancer, regardless of a patient's environmental or lifestyle history. We are now in a position to greatly expand the knowledge base of epidemiologic risk factors and biologic mechanisms. The convergence of epidemiologic and molecular approaches has begun to yield important insights and opportunities that will lead to a fundamental understanding of cancer causation, including the role of environmental and genetic determinants and their interactions.

MAJOR INITIATIVES

Breast Cancer and the Environment Research Centers

Contact Kumiko Iwamoto, MD, DrPH,
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The National Institute of Environmental Health Sciences (NIEHS) 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 seven-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 are working collaboratively on two main fronts. Using animals, they are studying the development of mammary tissue and the effects of specific environmental agents. In the second collaborative project, they are enrolling different ethnic groups of young girls to 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 interact as a single program, though with some specialization at each center. All the centers work with advocacy groups to add the insight and experience of these groups 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 Council Working Group that oversees the projects.

Breast/Ovarian and Colon Cancer Family Registries

Contact Daniela Seminara, PhD, MPH,
301-594-7347, seminard@mail.nih.gov

The Breast/Ovarian and Colon Cancer Family Registries (CFR) studies support research to identify genetic changes that predispose individuals 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
- Australasian 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, Esther John, Northern California Cancer Center

Colon:

- Ontario Registry for Studies of Familial Colon Cancer, Steven Gallinger, Cancer Care Ontario
- Colorectal Cancer Family Registry, Robert Haile, University of Southern California
- Australasian Colorectal Cancer Family Registry, John Hopper, 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
- Seattle Familial Colorectal Cancer Registry, John Potter, Fred Hutchinson Cancer Research Center

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 in 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. 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 four-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 EMFs and an increased risk for breast cancer on Long Island.

Cancer Genetics Network

Contact Carol Kasten, 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. More than 20,000 individuals are enrolled, and enrollment now is focused on minority populations; individuals at high risk for breast, ovarian, and colon cancer; and families with multiple tumors.

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 at Chapel Hill
- 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 MD 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 Nadkarn

Cohort and Case-Control Consortia

Contact Mukesh Verma, PhD, 301-594-7344, vermam@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 are looking for inherited gene variants in biospecimens taken from patients with breast or prostate cancer, and are assessing 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 also is fostering development of case-control consortia. Investigators may come together informally at first to discuss shared interests, 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.

Trans-NCI Pancreatic Cancer Program Announcement

Contact Mukesh Verma, PhD, 301-594-7344, vermam@mail.nih.gov

DCCPS provided leadership on behalf of NCI to develop and publicize a program announcement to promote innovative research across multiple disciplines to better understand the etiology, early detection, progression, and prevention of pancreatic cancer. According to a recent estimate there will be 32,180 new cases of pancreatic cancer and 31,800 deaths from this disease in 2005. Pancreatic cancer is a highly lethal disease marked by pain, anorexia, sleep problems, and weight loss. Most pancreatic cancers are adenocarcinomas arising in the pancreatic ductal system, which have the worst prognosis of all the major malignancies. Due to its aggressiveness and our inability to detect pancreatic cancer at an early stage, the disease is often far advanced by the time the diagnosis is established. Despite efforts over the past century, conventional treatment approaches such as chemotherapy, radiation surgery, or combinations of these modalities have had little impact on the course of this disease. It is clear that a better understanding of the biology and biochemistry of pancreatic cancer is urgently needed to effectively diagnose, prevent, and treat this malignancy.

Pancreatic Cancer Cohort Consortia

Contact Mukesh Verma, PhD, 301-594-7344, vermam@mail.nih.gov

Rapidly developing technology in high-throughput genomic characterization and the creation of a large-scale population research infrastructure offer an extraordinary opportunity to uncover the etiology and identify the early markers for pancreatic cancer. Along with tobacco, family history of pancreatic cancer, and chronic pancreatitis, pre-existing diabetes, obesity, and high caloric intake are established contributors to the disease. Furthermore, geneticists have identified considerable genetic variation in the critical pathways, for instance, those that modulate insulin levels or metabolize tobacco. Systematic pursuit of the combined effects of genetic variants and environmental exposures holds great promise for revealing the underlying mechanisms of cancer development.

The goal of this effort is to create coordinated consortia based within existing population cohorts for which biological specimens have been collected before the cancers occurred. The consortia would also be based within hospitals that have the capability to identify cases as they occur, to obtain tumor tissue and detailed histories of suspected risk factors from medical records and interviews, and to record treatments and survival. With this coordinated approach, many extramural and intramural investigators can pursue research on basic fundamental etiology, conduct a broad spectrum search for early markers, and test promising leads for detection. Ultimately, investigators will be enabled to pursue prevention in a structured two-phase approach. Based on the experience of recently formed ad hoc case-control consortia, the proposed approach is expected to accelerate the discovery of molecular markers of pancreatic cancer progression and etiology, and rapidly eliminate the false leads that otherwise divert resources and slow progress.

The key to the success of this approach is that studying gene-environment interactions in the etiology of this complex, poorly understood tumor will require very large numbers of patients–more than can be accrued by any one study acting independently. A consortial approach for a less common tumor such as pancreatic cancer is especially advantageous, given the scarcity of cases and biologic specimens.

PARTNERSHIPS & COLLABORATIONS

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 is also a partner in projects to facilitate the development of consortia of cohort and case-control studies.

National Institute of Environmental Health Sciences (NIEHS)

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

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 is monitoring 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) is funding the initiative.
- DCCPS established the Interagency Cancer Epidemiology Research Funders Group (ICERF) 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.

National Institute of General Medical Sciences

- DCCPS is cosponsoring with the National Institute of General Medical Sciences (NIGMS) three research projects that are part of the Pharmacogenetics Research Network (PGRN), which is a nationwide collaboration of scientists studying the effects of genetic variation on individuals' responses to a wide variety of medicines. The funding supports translational use of biotechnology to understand the basis of human genetic variability in drug responses related to cancer risk or treatment.

American College of Epidemiology

- DCCPS cosponsors the annual meeting of the American College of Epidemiology (ACE) and helps set the program agenda and identify speakers. The conference is an important opportunity to disseminate information about DCCPS funding opportunities and NCI/DCCPS activities and resources to leading investigators in cancer epidemiology. It is also a major forum for the exchange of information on research developments.

Spotlight on Biorepositories

A report delivered from the National Biospecimens Network (NBN) to the NCAB last year revealed substantial heterogeneity in biorepository management practices across NCI. As a result, NCI formed a committee with representation from senior program managers from each division. This committee was tasked with harmonizing the biorepository management processes to maximize the utility of all NCI biorepositories. The committee divided the problem into two separate areas: the ethical, legal, and policy issues surrounding biorepositories and the collecting, processing, storing, and dissemination of biospecimens and their associated data.

Completion of the sequencing of the genome has dramatically increased the ability of researchers to identify genes predisposing the population to cancer. Continuing advances in technology have produced better measures of environmental exposures. Donated human specimens provide the vital link between the results of scientific observations and the causes of cancer in the population. No longer will we be constrained by studying either environmental exposures leading to cancer or single genetic predispositions to cancer. Biospecimens enable researchers to study the overlapping influence of genes and the environment on cancer development.

DCCPS oversees many cohort studies that have large biospecimen collections. Together, these studies have produced numerous findings that would not have been possible without biospecimens. The strength of DCCPS researchers' work comes from combining information obtained from the biospecimens with their associated data. For example, data gleaned from blood samples and their associated data from the participants in the Risk of Ovarian Cancer Algorithm (ROCA) study is producing a screening algorithm for early detection of ovarian cancer in high risk women. Moreover, circulating levels of estradiol and free estradiol have been analyzed from blood samples collected by the Nurses' Health Study. These analyses have demonstrated an association between the circulating level of hormones and the risk of developing breast cancer in postmenopausal women. Importantly, these findings are now being added to risk-prediction models for breast cancer. The potential ovarian cancer screening protocol and the additions to the breast cancer risk-prediction model are two of the contributions that population science has made through the coupling of biospecimens with their associated data.

As evinced by the two examples above, continuing longitudinal collection of biospecimens is crucial to the future work of population scientists. However, because of the magnitude of samples needed for a population-based study, the collection and maintenance of biospecimens is both time-consuming and costly. Therefore, population scientists not only design their experiments with these facts in mind—they also choose the biospecimen type based on the analysis of the analyte (DNA, RNA, protein, hormone, or metabolite) that will yield the most information toward their hypothesis.

Currently, there are a number of population scientists from different colleges and universities collaborating with one another. To facilitate this type of "Big Science," the researchers have drafted and used uniform collection, processing, storage, and dissemination procedures for biospecimens. One of the most well known efforts in this area is the Breast and Prostate Cancer Cohort Consortium. This type of team science is rapidly being used not only for large-scale cohort studies, but also for the study of rare cancers.

Lastly and most importantly, population scientists respect the privacy and intentions of the participants who have donated their biospecimens to research. Population scientists work tirelessly with institutional review boards and ethicists to determine that their biospecimen accrual protocols are the best for the research study and for the patient partner. When the biospecimen and questionnaire data have been collected, the principal investigators of these studies serve as stewards of the data and specimens. They protect the rights and privacy of the participants.

As we continue through this post-genome era, the collection of biospecimens is crucial to understanding relationships between environmental exposures and genetic composition. Stewardship of biospecimens and their associated data is paramount.

Geographic Information System for Breast Cancer Studies on Long Island

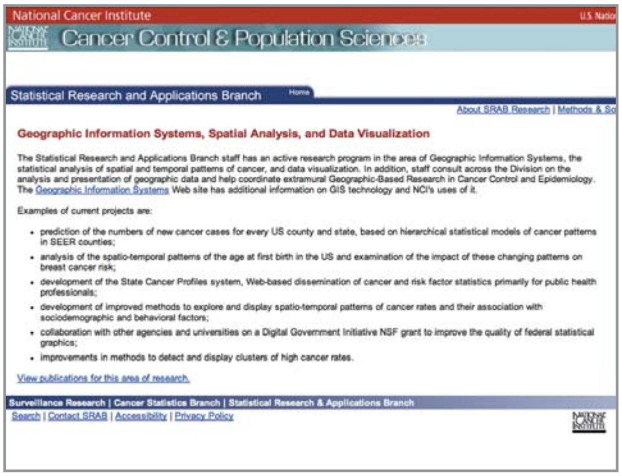
http://www.healthgis-li.com

The Epidemiology and Genetics Research Program has developed a Geographic Information System for Breast Cancer Studies on Long Island (LI GIS). 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 datasets covering 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 Systems, Spatial Analysis, and Data Visualization

The Statistical Research and Applications Branch staff has an active research program in the area of Geographic Information Systems, the statistical analysis of spatial and temporal patterns of cancer, and data visualization. In addition, staff consult across the Division on the analysis and presentation of geographic data and help coordinate extramural Geographic-Based Research in Cancer Control and Epidemiology. The Geographic Information Systems Web site has additional information on GIS technology and NCI's uses of it.

Examples of current projects are:

- prediction of the numbers of new cancer cases for every US county and state, based on hierarchical statistical models of cancer patterns in SEER counties;
- analysis of the spatio-temporal patterns of the age at first birth in the US and examination of the impact of these changing patterns on breast cancer risk;
- development of the State Cancer Profiles system, Web-based dissemination of cancer and risk factor statistics primarily for public health professionals;
- development of improved methods to explore and display spatio-temporal patterns of cancer rates and their association with sociodemographic and behavioral factors;
- collaboration with other agencies and universities on a Digital Government Initiative NSF grant to improve the quality of federal statistical graphics;
- improvements in methods to detect and display clusters of high cancer rates.

View publications for this area of research.

A Web site supported by the NCI for use by the public, cancer researchers, and the GIS Special Interest Group.

About GIS at NCI
- About this Site
- About the GIS Special Interest Group
- Contact Information

Overview of GIS at NCI
- Introduction to GIS at NCI
- Geographic-based Research & Applications at NCI
- GIS Database Development
- Spatial Data Analysis
- Geovisualization Tools Development
- Communication of Georeferenced Statistics

Examples of GIS Applications
- Federal Government
- State Health Departments
- General Use of GIS in Public Health

Data Sources
- Links to NCI & Other Government Data
- Miscellaneous Data

Key NCI Initiatives
- State Cancer Profiles
- Cancer Mortality Maps & Graphs
- Long Island Breast Cancer Study Project
- US Predicted Cancer Incidence, 1999: Spatial Projection Models

Tools & Resources
- Please read our Disclaimer
- General Resources
- Mapping
- Spatial Analysis
- Data Visualization
- Health Disparties
- Miscellaneous Tools
- Professional Services
- GIS Organizations
- Regulations (HIPAA, Confidentiality, Accessibility)

Funding
- How to Obtain Funding
- Currently Funded GIS Grants
- National Science Foundation Grants Program

What's New
- US Predicted Cancer Incidence, 1999: Spatial Projection Models

Helpful Links
- GIS Dictionary
- Upcoming GIS Events

Publications
- Best Practices
- Papers
- Journals
- Confidentiality Regulations in Research
- Newsletters, Listservs, URLs
- Search PubMed

Training
- Online Courses
- Reference

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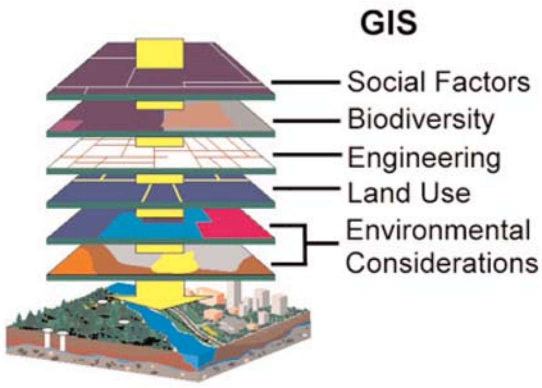
Geographic Information System Overview

Geographic Information Systems 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.



Notes

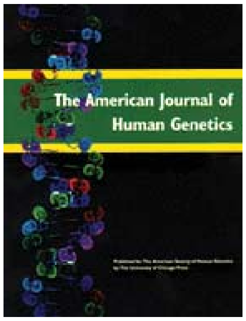
RECENT SCIENTIFIC ADVANCES

Prophylactic Mastectomy in BRCA1/2 Mutation Carriers Found Effective Preventive Measure

Bilateral prophylactic mastectomy decreases breast cancer risk in women with BRCA1/2 gene mutations by about 90 percent; the risk is reduced by about 95 percent in women who also have bilateral prophylactic oophorectomy, according to a study by Timothy Rebbeck, PhD, of the University of Pennsylvania, and colleagues. The findings are consistent with earlier studies, but go further by addressing some of their limitations and providing stronger data on the magnitude of risk reduction. Of 105 mutation carriers with bilateral prophylactic mastectomy in the cohort, two (1.9%) were diagnosed with breast cancer after bilateral prophylactic mastectomy compared with 184 (48.7%) of 378 controls. While the decision to have bilateral prophylactic mastectomy is complex, the scientists conclude, women who have done so have chosen an effective preventive strategy.

Rebbeck, T.R., Friebel, T., Lynch, H.T., Neuhausen, S.L., van 't Veer, L., Garber, J.E., Evans, G.R., Narod, S.A., Isaacs, C., Matloff, E., Daly, M.B., Olopade, O.I., & Weber, B.L. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: The PROSE Study Group. *Journal of Clinical Oncology, 22(6), 1055-62.*

Potential Familial Lung Cancer Gene Discovered



A research team led by Marshall Anderson, PhD, of the University of Cincinnati, has discovered a possible susceptibility gene for lung cancer. An interdisciplinary consortium of 12 research institutions and universities, including NCI and the National Human Genome Research Institute (NHGRI), identified a major lung cancer susceptibility region on a segment of chromosome 6.

The Genetic Epidemiology of Lung Cancer Consortium (GELCC) examined 52 families who had at least three first-degree family members affected by lung, throat, or laryngeal cancer. The team found strong evidence that a lung cancer susceptibility gene (or genes) is coinherited with a genetic marker on chromosome 6. Markers on chromosomes 12, 14, and 20 also indicated possible linkage to lung cancer susceptibility, although the results were not as strong.

Another discovery involved the effects of smoking on cancer lung cancer gene. In noncarriers, the more they smoked, the greater their risk of cancer. In carriers, on the other hand, any amount of smoking increased lung cancer risk. The findings suggest that smoking even a small amount can lead to cancer for individuals with inherited susceptibility.

Bailey-Wilson, J.E., Amos, C.I., Pinney, S.M., Petersen, G.M., De Andrade, M., Wiest, J.S., Fain, P., Schwartz, A.G., You, M., Franklin, W., Klein, C., Gazdar, A., Rothschild, H., Mandal, D., Coons, T., Slusser, J., Lee, J., Gaba, C., Kupert, E., Perez, A., Zhou, X., Zeng, D., Liu, Q., Zhang, Q., Seminara, D., Minna, J., & Anderson, M.W. (2004). A major lung cancer susceptibility locus maps to chromosome 6q23-25. *American Journal of Human Genetics, 75, 460-74.* (Epub ahead of print, Jul 21).

Aspirin May Decrease Risk of Hodgkin's Lymphoma

In the first study to examine the association between nonsteroidal anti-inflammatory drugs (NSAIDs) and Hodgkin's lymphoma, scientists found regular aspirin use to be associated with a 40 percent decreased risk of the cancer compared to nonregular aspirin use. The population-based case-control study by Ellen Chang, ScD, and Nancy Mueller, ScD, of the Harvard School of Public Health, and colleagues compared data on 565 patients with Hodgkin's lymphoma and 679 controls. A reduction in risk was not observed with regular use of other NSAIDs. However, regular acetaminophen use was associated with a 70 percent increased risk of Hodgkin's lymphoma. Regular analgesic use was defined as having taken at least two tablets per week on average over the preceding five years. Dose-response relationships also were seen. Aspirin inhibits the transcription factor κB (NF-κB), which is involved in immune and inflammatory responses and which, in laboratory studies, appears to be critical in the survival of Hodgkin's lymphoma cells. Perhaps aspirin guards against the cancer in this way.

Chang, E.T., Zheng, T., Weir, E.G., Borowitz, M., Mann, R.B., Spiegelman, D., & Mueller, N.E. (2004). Aspirin and the risk of Hodgkin's lymphoma in a population-based case-control study. *Journal of the National Cancer Institute, 96(4), 305-15.*

Anti-Inflammatory Drugs May Decrease Brain Cancer Risk

Use of aspirin and other nonsteroidal anti-inflammatory drugs (NSAIDs) has been associated with decreased risk of adult glioblastoma multiforme, which is the most common primary malignant brain tumor, in a study by Niccole Sivak-Sears, PhD, of the Ohio State University, and Margaret Wrensch, PhD, of the University of California at San Francisco, and colleagues. The population-based study included 236 adults with the cancer and 401 controls. Cases were less likely than controls to report use of at least 600 pills of all types of NSAIDs during the 10 years prior to diagnosis (odds ratio = 0.53). The findings were consistent for aspirin, ibuprofen, and naproxen and/or other NSAIDs. Cases also reported less use of acetaminophen than controls did.

Sivak-Sears, N.R., Schwartzbaum, J.A., Miike, R., Moghadassi, M., & Wrensch, M. (2004). Case-control study of use of nonsteroidal anti-inflammatory drugs and glioblastoma multiforme. *Epidemiology, 159(12), 1131-9.*

Aspirin May Decrease Risk of Hormone Receptor-Positive Breast Cancer

Women who regularly take aspirin seem to be at lower risk of hormone receptor-positive breast cancer than those who do not take aspirin, report Mary Beth Terry, PhD, and Alfred Neugut, MD, PhD, of Columbia University, and colleagues. Other studies have suggested that regular aspirin use may protect against breast cancer, but this study is the first to show that aspirin may be more effective at preventing certain types of the cancer. When the data were analyzed by hormone receptor status, the researchers found that the protective effect for all but estrogen receptor-negative/progesterone receptor-negative cancers. Regular aspirin use was associated with a 20 percent reduction in risk for breast cancer compared with nonuse. An even greater risk reduction (28%) was seen among women who took at least seven aspirin per week. Ibuprofen had a weaker preventive effect than aspirin, and acetaminophen had no protective effect. The study builds on preclinical models showing that drugs such as aspirin inhibit cyclooxygenase (COX), which is a key player in the synthesis of prostaglandins, which in turn stimulate the production of estrogen. The research is from data collected in a major case-control study of the Long Island Breast Cancer Study Project. The analyses were based on data from 1,442 breast cancer patients and 1,420 healthy women.

Terry, M.B., Gammon, M.D., Zhang, F.F., Tawfik, H., Teitelbaum, S.L., Britton, J.A., Subbaramaiah, K., Dannenberg, A.J., & Neugut, A.I. (2004). Association of frequency and duration of aspirin use and hormone receptor status with breast cancer risk. *Journal of the American Medical Association, 291(20), 2433*.

Statins May Reduce Risk of Colorectal Cancer

Use of statins for five or more years has been found to be associated with a significant reduction in risk of colorectal cancer in a study by Stephen Gruber, MD, PhD, of the University of Michigan Comprehensive Cancer Center, and colleagues. After controlling for potential confounding factors, such as use of aspirin or non-steroidal anti-inflammatory drugs, the risk associated with use of cholesterol-lowering statins was decreased by 47 percent. The population-based case-control study compared 1,953 colorectal cancer patients and 2,015 controls. The findings were specific to statins and not other types of cholesterol-lowering drugs. The scientists concluded that statins merit further investigation in chemoprevention and therapeutic trials

Poynter, J.N., Gruber, S.B., Higgins, P.D., Almog, R., Bonner, J.D., Rennert, H.S., Low, M., Greenson, J.K., & Rennert, G. (2005). Statins and the risk of colorectal cancer. *New England Journal of Medicine, 352(21)*, 2184-92.

Quality of Care

The quality of cancer care is a major national concern. Receiving the best possible medical treatment and care is the continuing hope for over 10 million cancer patients and survivors in the United States. The ultimate aim of the initiatives in quality of cancer care is to improve a range of outcomes important to patients, families, and other decision makers. These important outcomes include patient survival and health-related quality of life. NCI's efforts to improve quality of care across the discovery, development, and delivery continuum are accomplished through the sponsorship of research that provides insight into the issues, knowledge of evidence and research results, and leadership emphasizing substantive collaborations with DHHS agencies and non-governmental organizations.

MAJOR INITIATIVES

Quality of Cancer Care Committee

Contact Molla Donaldson, DrPH, MS,
301-435-1638, donaldsm@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, chaired by Dr. Mark Clanton, 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 (NCHS); 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.

- With NCI support from the QCCC, IHS has identified a substantial need for palliative care services (especially cancer pain and adverse symptom management) for American Indian and Alaska Natives in tribal, urban, and IHS-supported health programs. Current work with IHS focuses on implementing interventions to improve palliative care based on identified needs for services and evaluating those interventions for their effectiveness.

- AHRQ and NCI support work by investigators in AHRQ's Integrated Delivery System Research Networks to implement and evaluate innovative ideas for improving the quality of cancer care during the period from initial suspicion of cancer through the diagnostic process and plan of care.

- The QCCC is gathering information to form a foundation for ensuring that care provided to patients with cancer is safe, effective, patient-centered, timely, efficient, and equitable. The QCCC is sponsoring informational site visits to learn from the practice community about opportunities for and barriers to reliably and consistently delivering the best evidence-based research into practice.

- The Cancer Care Collaborative is one of the dissemination projects generated by the QCCC. It is a collaborative effort between NCI, CDC and

HRSA's Bureau of Primary Health Care (BPHC). This innovative project works with 25 BPHC-affiliated centers to drive organizational change that increases screening and reduces deaths from breast, colon, and cervical cancers. Avoidable deaths from these cancers persist, especially among disadvantaged ethnic and racial groups and those with lower socioeconomic status. The focus of this initiative is to teach methods for systematic assessment and improvements in cancer screening, and in follow-up of positive tests within community clinics affiliated with BPHC. This work includes moving cancer control research into primary care clinics to improve communication among providers and between providers and patients, as well as optimizing the process of care.

Developing Core Measures

Contact Steve Clauser, PhD, 301-451-4402, clausers@mail.nih.gov

- Standards for process measures of quality cancer care are being developed through a major 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 concise 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.

- NIH recently announced a $20 million, five-year extramural research project, the Patient-Reported Outcomes Measurement Information System (PROMIS), http://www.nihpromis.org/, as part of the NIH Roadmap for Medical Research. The PROMIS initiative will 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.

- 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.

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 five-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. With support from one statistical coordinating center, research teams from around the country are carrying out this DCCPS-coordinated effort.

- 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 at Chapel Hill

- 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

In 2004, NCI initiated the Caregivers Survey, a funded supplement to the CanCORS initiative. As more and more cancer patients are being treated in outpatient settings, many of these individuals will rely on the aid and assistance of family caregivers during much of their illness and afterward. To date, we have limited information about the role of family caregiving on quality of life, cost of care, and survival of individuals diagnosed with cancer. We know even less about the toll that being a caregiver may have on the health and functioning of the thousands who provide this support to a loved one. The recently-funded Caregiver Survey supplement leverages the larger CanCORS initiative to provide access to and support for a cross-sectional, descriptive study of linked cancer caregivers. The caregiver survey complements existing CanCORS data collection efforts to provide a more comprehensive assessment of the relationship between cancer-related care and patient and family outcomes. When completed, this study will be the largest national study of cancer caregiving.

HMO Cancer Research Network

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

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 and affiliated members have almost 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 also is 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.

Breast Cancer Surveillance Consortium

Contact Robin Yabroff, PhD, MBA, 301-594-7123, yabroffr@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 five 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.

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. 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

Contact Joan Warren, PhD, 301-496-5184, warrenj@mail.nih.gov

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. The process of updating the data link takes place on a routine three-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 150 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. The RAND Corporation is conducting this study, with joint oversight by DCCPS and the NCI Division of Cancer Treatment and Diagnosis.

SEER Rapid Response Surveillance Studies on Cancer Outcomes and Quality of Care

Contact Neeraj Arora, PhD, 301-594-6653, aroran@mail.nih.gov

SEER data are used in an ongoing program of special studies to address emerging cancer research questions. DCCPS has conducted special studies in the area of cancer outcomes and quality of care. For example, the Assessment of Patients' Experience of Cancer Care (APECC) study is designed to evaluate new and validate existing patient-reported measures of the healthcare experience of cancer survivors, including issues related to decision making and provider-patient communication. Analyses of data collected from over 750 leukemia, colorectal, and bladder cancer survivors will inform future efforts to develop standardized instruments to measure the experience of and satisfaction with care of patients across the cancer continuum.

The Experience of Care and Health Outcomes of Survivors of non-Hodgkin's Lymphoma (ECHOS) study is assessing the follow-up care patterns and health outcomes of over 400 survivors of aggressive non-Hodgkin's lymphoma. The relationships of several patient predisposing factors (*e.g.*, socioeconomic status, disease characteristics, personality) and enabling factors (*e.g.*, social support, interaction with the medical system) to cancer survivors' cognitive health appraisal, health behaviors, and health-related quality of life are being evaluated. The ECHOS study is one of the first population-based studies to conduct a detailed assessment of health outcomes of this largely understudied but growing population of cancer survivors.

PARTNERSHIPS & COLLABORATIONS

Agency for Healthcare Research and Quality (AHRQ)

- NCI supported the HMO Research Network annual meeting in April 2005. The HMO Research Network is an organization of HMO research programs whose mission is to use their collective scientific capabilities to integrate research and practice for the improvement of health and healthcare among diverse populations. Activities include the NCI-funded Cancer Research Network, a network of 12 HMO-affiliated research organizations, and the Centers for Education and Research in Therapeutics (CERT), an initiative funded by AHRQ to conduct research and provide education that optimizes the use of drugs, devices, and biological products.

- "Improving Colorectal Cancer Screening Delivery, Utilization, and Outcomes: The State of the Science," was held in April 2005 by NCI and AHRQ, and involved approximately 50 investigators and leaders in the field of colorectal cancer screening research. The objectives of the meeting were to describe and discuss innovative approaches to implementing colorectal cancer screening at the patient, provider, and healthcare system levels; discuss progress toward evaluating colorectal cancer screening practice and outcomes at the population level; and identify major areas of research progress and gaps.

American Cancer Society (ACS)

- NCI staff attended the annual meeting of the National Colorectal Cancer Round Table (NCCRT) on November 5, 2004. Staff reported on a variety of accomplishments in the health policy arena. They also reported on the recently approved, NCI-sponsored ACRIN trial on CT colonography and requested NCCRT endorsement of the pending NCI-CDC Health Plan Survey on Colorectal Cancer Screening.

American College of Radiology (ACR)

- The NCI-funded Breast Cancer Surveillance Consortium (BCSC), an effort to evaluate the performance of screening mammography in practice, provided standardized data forms and a dictionary to ACR to enhance the capacity to collect standardized data on mammography performance in software vending programs throughout the United States. In addition, data from the BCSC were central to the recent revision of the BIRADSTM Manual that is used by radiologists across the U.S.

American Medical Association (AMA)

- NCI has provided technical assistance to AMA's Physician Consortium on Performance Improvement (a group of 60 medical specialty societies) to develop performance measures for breast and colorectal cancer screening.

American Society of Clinical Oncology (ASCO)

- The National Initiative on Cancer Care Quality (NICCQ) was formed by the American Society of Clinical Oncology (ASCO) to develop a prototype for a national system that could monitor the quality of cancer care. Funded primarily by the Susan G. Komen Foundation, the study was initiated in 2000. The goals of NICCQ were to develop potential measures of the quality of cancer care for two common cancers (breast and colorectal cancer), to ascertain current practice for these two diseases, and to design and implement the first phase of a prototype quality monitoring system. Results were presented at the May 2005 ASCO annual meeting.

Centers for Disease Control and Prevention (CDC)

- NCI and CDC's Division of Cancer Prevention and Control are cosponsoring a national survey of health plan medical directors to examine colorectal cancer screening practices in managed care organizations. This is a follow-up of a similar survey fielded in 1999-2000 to examine changes in policies, procedures, and performance.

Centers for Medicare and Medicaid Services (CMS)

- NCI staff are collaborating with CMS to analyze data on recent trends in the utilization of FOBT, sigmoidoscopy, and colonoscopy by Medicare recipients. These rates are being compared to data from the National Health Interview Survey and the National Ambulatory Care Survey, conducted by the CDC National Center for Health Statistics, on the use of these tests by individuals over and under the age of 65.

- In 2003, NCI staff and grantees worked with AHRQ and CMS staff to produce a cost effectiveness analysis to inform a CMS coverage decision regarding the immunochemical fecal occult blood test for colorectal cancer screening—a type of test previously not covered by Medicare. As a result of this study, a decision was made to extend Medicare coverage to this type of test.

- NCI is working with the CMS Office of Clinical Standards and Quality to explore the development of a colorectal cancer screening initiative. NCI is working with CMS staff to develop a proposal for a series of pilot projects as part of the CMS Doctors Office Quality Information Technology Project to test the ability of enhanced office-based information technology to improve colorectal cancer screening rates and appropriate follow-up for abnormal results.

Health Research and Services Administration (HRSA)

- NCI, HRSA, and CDC, in partnership with the Institute for Healthcare Improvement, work with 21 community health clinics to implement strategies that improve screening, referral, and follow-up care for breast, cervical, and colorectal cancer diagnosis and treatment. The effort is now expanding in collaboration with leadership in the Bureau of Primary Health Care (BPHC) in order to develop a "train the trainer" model of dissemination. Together with BPHC and CDC, NCI is working with four health plans in the Northeast to train their staff in the collaborative approach to implementing planned cancer screening within their facilities. The goal is to develop an approach that can reach the 800 clinics of the BPHC and more than 16 million people they serve.

National Quality Forum

- In collaboration with AHRQ, CDC, and CMS, NCI has supported the creation of the Cancer Care Quality Measures Project (CanQual), conducted by the 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.

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. Currently in the field is a national survey of health plans that will assess plan coverage policy, patient education, and tracking and evaluation activities related to colorectal cancer screening. This survey will help to assess the impact of the recently implemented HEDIS measure on colorectal cancer screening. An update of the physician survey on screening is currently in the planning stages.

The 2000 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. Cancer screening items were also included on the National Health Interview Survey in 1987, 1992, 2000, 2003, and 2005. In recent surveys, the wording of the screening items was improved to characterize current screening modalities and to capture information on an individual's screening history rather than just their most recent screening test.

Outcomes Research

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:

- In January 2005, the Oxford University Press published a book entitled *Outcomes Assessment in Cancer: Measures, Methods, and Applications*, edited by Joseph Lipscomb, Carolyn Gotay, and Claire Snyder. The book provides a comprehensive assessment of the field, based on the perspectives of the Cancer Outcomes Measurement Working Group (COMWG). The COMWG comprises 35 experts drawn from academia, government, industry, and the cancer patient and survivorship communities. The book evaluates the state of the science in cancer outcomes assessment and offers perspectives on what is required to advance the field. The book is the most comprehensive assessment of patient-reported outcomes measurement and methods used in cancer research. Topics include alternative definitions and conceptual models for health related quality of life and the use of generic and general cancer HRQOL measures in cancer research, including the foundations, importance, and availability of preference-based measures currently available. Several chapters are devoted to measures and methods for assessing HRQOL during treatment of breast, lung, and colorectal cancer. Other chapters focus on assessing HRQOL across the cancer continuum, including recent work in cancer survivorship and end-of-life care. The book explores methodological considerations in outcomes measurement, including its application to clinical decision-making, adapting HRQOL instruments for use across different populations and cultures, and in the measurement of economic burden. The book also examines recent advances in modern psychometrics that inform the measurement, modeling and analysis of outcomes research. The book concludes with several contributions on outcomes data development and its application to policy decisions, including a review of currently available sources of data for conducting cancer outcomes research, including registries, medical records, administrative files, and surveys of patients, providers, and individuals at risk of cancer.

  Lipscomb, J., Gotay, C.C., & Snyder, C. (Eds.). (2005). *Outcomes Assessment in Cancer*. Cambridge University Press.

- Item Response Theory (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, DCCPS developed a tutorial—"An Introduction to Modern Measurement Theory,"—available at http://appliedresearch.cancer.gov/areas/cognitive/item.html.

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.

SEER-Medicare Linked Database

About the SEER-Medicare Database
- Brief Description of the Database
- How the SEER & Medicare Data are Linked
- Publications Using SEER-Medicare Data

The SEER-Medicare Data Files
- About the Data Files
- SEER Program & Data
- Medicare Enrollment & Claims Data
- Provider Files
- Determining File Sizes & Distribution Methods
- Number of Cases for Selected Cancers

Obtaining the SEER-Medicare Data
- Overview of the Process for Obtaining the Data
- Instructions & Data Use Agreements
- Proposal Requirements
- Proposal Review Process
- Requirements Following Receipt of Data
- Cost of Acquiring SEER-Medicare Data

Analytic Support for Researchers
- Measurement & Methods
- Identification of Diagnosis & Procedure Codes
- Cancer Testing Covered by Medicare
- Defining the Date of Diagnosis & Treatment
- Geographic Location of Care
- SEER-Medicare Data Limitations
- Resources for More Assistance

Privacy & Confidentiality Issues
- Encrypted & Restricted Variables
- HIPAA Regulations & SEER-Medicare Data
- IRB Approval

Contact SEER-Medicare

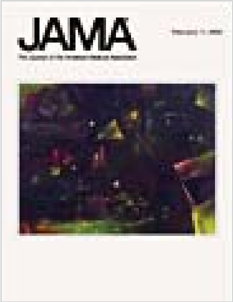
Programming Support
- SAS Inputs & Formats
- Using SEER*Stat to Analyze SEER-Medicare Data
- Calculation of Comorbidity Weights

What's New

Effective April 14, 2003, NCI has changed the data request process.

Investigators who have requested data in the past will note that system is streamlined.

Study Shows Link Between Antibiotic Use and Increased Risk of Breast Cancer



A study published in the *Journal of the American Medical Association (JAMA)* provides evidence that use of antibiotics is associated with an increased risk of breast cancer. The authors concluded that the more antibiotics the women in the study used, the higher their risk of breast cancer. Women who took antibiotics for more than 500 days, or had more than 25 prescriptions, over an average period of 17 years had more than twice the risk of breast cancer as women who had taken no antibiotics. The risk was smaller for women who took antibiotics for fewer days. However, even women who had between one and 25 prescriptions had an increased risk; they were about 1.5 times more likely to be diagnosed with breast cancer than women who didn't take any antibiotics. The authors found an increased risk across all classes of antibiotics that they studied.

The results of the study are consistent with an earlier Finnish study of almost 10,000 women. Further studies must be conducted, however, to understand why the researchers saw this increased risk with antibiotic use. Studies are also necessary to clarify whether specific indications for antibiotic use, such as respiratory or urinary tract infection, or times of use, such as adolescence or menopause, are associated with increased breast cancer risk. Additionally, breast cancer risks could differ between women who take low-dose antibiotics for a long period of time and women who take high-dose antibiotics only once in a while.

Velicer, C.M., Heckbert, S.R., Lampe, J.W., Potter, J.D., Robertson, C.A., & Taplin, S.H. (2004). Antibiotic use in relation to the risk of breast cancer. *Journal of the American Medical Association, 291(7), 827-35.*

Large Portion of Late-Stage Breast Cancers Associated With Absence of Screening

Increasing mammography screening rates and investing in research to improve breast cancer detection technologies should be top priorities, according to authors of a study published in a recent *Journal of the National Cancer Institute*. As many as 92 percent of late-stage breast cancer cases in the United States could be diagnosed and treated earlier, when there is greater likelihood of effective treatment. These outcomes would be possible if the healthcare system focused on recruiting women who have not been recently screened, and if early detection techniques could be improved to more accurately detect cancer. The study was conducted by researchers at NCI and the Cancer Research Network (CRN), a consortium of integrated health plans.

Study results indicated that not having had a screening mammogram for one to three years prior to diagnosis was associated with 52 percent of late-stage breast cancer cases. The authors state that to improve breast cancer outcomes, priority should be placed on reaching unscreened women and encouraging them to have mammograms—especially older, unmarried, less educated, and/or low income women, whom they found were less likely to have been screened.

The study was based on a review of all medical care received by 2,694 women during the three years prior to their breast cancer diagnosis. Researchers reviewed medical charts and records of women in seven integrated healthcare plans across the United States. The plans offer specialty and primary care within the same system, and serve 1.5 million women over age 50. All offer breast cancer screening mammograms at no or low cost. When the study began in 1999, 71 percent to 81 percent of these women had had mammograms. Women who had not been screened one to three years prior to diagnosis were more than twice as likely to have late-stage breast cancer. This illustrates an important reason for receiving regular mammograms: to increase the chance of catching breast cancer early. However, a second finding showed that better screening tests need to be developed. Almost 40 percent of women with late-stage breast cancer had a negative mammogram one to three years before their diagnosis.

Taplin, S.H., Ichikawa, L., Yood, M.U., Manos, M.M., Geiger, A.M., Weinmann, S., Gilbert, J., Mouchawar, J., Leyden, W.A., Altaras, R., Beverly, R.K., Casso, D., Westbrook, E.O., Bischoff, K., Zapka, J.G., & Barlow, W.E. (2004). Reason for late-stage breast cancer: Absence of screening or detection, or breakdown in follow-up? *Journal of the National Cancer Institute, 96(20), 1518-27.*

Cancer Outcomes Research: A New Frontier

The Journal of the National Cancer Institute this year published *Cancer Outcomes Research: The Arenas of Application*. The monograph describes and evaluates the peer-reviewed literature in cancer outcomes research, identifies key recent contributions, and highlights challenges in applying scientific evidence to cancer care decision making. The publication also includes an assessment of the state of the science by NCI staff scientists and a discussion of future directions in this field.

Cancer outcomes research seeks to describe, interpret, and predict the impact of interventions and other influences on outcomes important to decision makers, including patients, clinicians, and policymakers. The monograph focuses on such patient-reported outcomes as health-related quality of life, perceptions of and satisfaction with health care, and the economic burden of cancer and its interventions, rather than more traditional but extremely important outcomes such as survival and disease-free survival. The monograph details how outcomes research can enhance the knowledge base required for better cancer care decision making and focuses on three areas of outcomes measurement: the macro, meso, and micro levels. Macro-level studies explore trends in cancer-related outcomes and progress against cancer at the population level to inform policy and research. Meso-level studies include descriptive and analytical studies to better understand and improve cancer outcomes. Results of these studies influence decision making by patients, families, providers, payers, and organizations concerning the safety, efficacy, and cost-effectiveness of cancer care. Micro-level studies use patient-reported outcomes to improve patient-clinician communication and decision making and the overall quality of cancer care.

Lipscomb, J., & Donaldson, M.S. (Eds.). (2004). Cancer outcomes research: The arenas of application. *Journal of the National Cancer Institute Monographs,* 33.

Studies of Patient Centered Outcomes in Prostate Cancer

The Prostate Cancer Outcomes Study (PCOS) was designed to provide estimates of long-term complications in everyday clinical practice, using a large, diverse, population-based sample of more than 3,400 men diagnosed with prostate cancer in 1994-1995 and followed for more than five years. Several previous studies have reported results on the early experiences of men with clinically localized cancer who underwent Radical Prostatectomy (RP), External Beam Radiotherapy (EBRP), or androgen deprivation therapy. In 2004, several new findings were reported based on the five years of follow-up. Using new information collected in PCOS about the natural history of treatment complications can help guide and inform prostate cancer treatment decisions.

- Men initially treated with RP for localized prostate cancer continue to experience worse incontinence five years after diagnosis compared with men who had been initially treated with EBRT. However, mostly because of declines in erectile function among the EBRT patients, the two treatment groups became more similar with respect to overall sexual function.

- Among prostatectomy patients, African Americans had better recovery of urinary and sexual function five years after treatment; however, African Americans reported having more problems with sexual function than non-Hispanic whites at five years.

- Prostate cancer treatment led to significant five-year declines in urinary and sexual function that far exceed age-related changes in controls. Cancer patients had significantly worse function than controls for the disease-specific domains of health-related quality of life (HRQOL). Bowel function and general HRQOL were not associated with cancer status.

Potosky, A.L., Davis, W.W., et al. (2004). Comparison of 5-year health outcomes following surgery versus radiotherapy for localized prostate cancer. Update from the Prostate Cancer Outcomes Study. *Journal of the National Cancer Institute, 96(18), 1358-67.*

Johnson, T.K., Gilliland, F.D., Hoffman, R.M., Deapen, D., Penson, D.F., Stanford, J.L., Albertsen, P.C., & Hamilton, A.S. (2004). Racial/ethnic differences in functional outcomes in the 5 years after diagnosis of prostate cancer. *Journal of Clinical Oncology, 22(20), 4193-4201.*

Hoffman, R.M., Gilliland, F.D., Penson, D.F., Stone, S.N., Hunt, W.C., & Potosky, A.L. (2004). Cross-sectional and longitudinal comparisons of health-related quality of life between patients with prostate carcinoma and matched controls. *Cancer, 101, 2011-9.*

Prostate Cancer Treatment Trends

Since 1992, prostate cancer mortality in the U.S. has declined by more than 20 percent. The reason for this dramatic decline is unclear, since several changes in the diagnosis and management of the disease have occurred concurrently. The increased use of PSA screening has been well documented and may contribute to this decline in mortality. However, other researchers have indicated that the increasing use of early hormone therapy may also significantly contribute to the decline in prostate cancer mortality. Despite these observations, there are few studies documenting temporal treatment trends in prostate cancer or potential differences in treatment by race/ethnicity which might help explain dramatically higher mortality rates from prostate cancer among African American men.

Using a database of cancer registry linked with Medicare claims, Zeliadt and colleagues reported that the frequency of aggressive therapy has increased among Caucasian men over time, while aggressive therapy has recently declined among African American men. Furthermore, the use of androgen deprivation therapy (ADT) has increased substantially in both the primary and adjuvant settings. By 1999, 45.6 percent of Caucasian men and 35.8 percent of African American men who selected conservative management for early stage prostate cancer received primary ADT; among men treated with radiotherapy the proportion receiving adjuvant ADT was 53.7 percent for Caucasian men and 42.4 percent for African American men. This is the first report showing that among men with non-metastatic prostate cancer, there continue to be racial differences in the utilization of aggressive and conservative therapies.

In other studies using the same registry-claims linked database, Shavers and colleagues found that African American and Hispanic men were significantly more likely than non-Hispanic white men to receive watchful waiting for early stage prostate cancer after adjusting for multiple clinical and socio-demographic factors. Despite the fact that regular medical monitoring is considered a necessary standard of care for men receiving watchful waiting for early stage prostate cancer, these authors found that both African American and Hispanic men received less intensive medical monitoring for progression or recurrence of their prostate cancer than did non-Hispanic white patients.

Zeliadt, S.B., Potosky, A.L., Etzioni, R., Ramsey, S.D., & Penson, D.F. (2004). Racial disparity in primary and adjuvant treatment for nonmetastatic prostate cancer: SEER-Medicare trends 1991 to 1999. *Urology, 64(6), 1171-6.*

Shavers, V.L., Brown, M.L., Klabunde, CN., Potosky, A.L., Davis, W.W., Moul, J.W., & Fahey, A. (2004). Race/ethnicity and the intensity of medical monitoring under watchful waiting for prostate cancer. *Medical Care, 42(3), 239-50.*

Shavers, V.L., Brown, M.L., Potosky, A.L., Klabunde, C.N., Davis, W.W., Moul, J.W., & Fahey, A. (2004). Race/ethnicity and the receipt of watchful waiting for the initial management of prostate cancer. *Journal of General Internal Medicine, 19, 146-55.*

Studies of End of Life Care for Cancer Patients

Despite growing interest in cancer survivorship, until recently there has been little population-based research related to end of life care. The linked SEER-Medicare data can be used to assess care provided to elderly people at the end of life. As noted by the Institute of Medicine, the SEER-Medicare data are the only resource currently available for longitudinal tracking of care for cancer patients.

JOURNAL OF
Palliative Medicine

In 2003 and 2004, there were eight analyses that used the SEER-Medicare data to evaluate care of patients at the end of their lives. Most of these studies focused on hospice use, although two studies evaluated use of aggressive care toward the end of life. The findings from these studies are summarized below.

- Use of hospice services among Medicare beneficiaries has increased from 10 percent in 1988 to 30 percent in 1999.
- Hospice use by Medicare beneficiaries is higher among married persons and those residing in urban areas. Hospice use varies by demographic characteristics: Hispanics' use of hospice is comparable to that of non-Hispanics, while African Americans and Asian Americans have lower use of hospice than do whites.
- Among Medicare beneficiaries, persons with cancer who are enrolled in HMOs have significantly higher rates of hospice use and longer lengths of hospice service when compared to similar persons with fee-for-service coverage.
- Patients who are enrolled in hospice are to receive supportive care only. Yet 6 percent of Medicare beneficiaries in a hospice program with lung or colorectal cancer were hospitalized after entering hospice. One-third of these patients underwent an aggressive procedure during the hospitalization and 30 percent died in the hospital instead of at home.
- Among patients who died of cancer, 16 percent had received chemotherapy within two weeks of death.

Cintron, A., Hamel, M.B., Davis, R.B., Burns, R.B., Phillips, R.S., & McCarthy, E.P. (2003). Hospitalization of hospice patients with cancer. *Journal of Palliative Medicine, 6(5), 757-68.*

Earle, C.C., Neville, B.A., Landrum, M.B., Ayanian, J.Z., Block, S.D., & Weeks, J.C. (2004). Trends in the aggressiveness of cancer care near the end of life. *Journal of Clinical Oncology, 22(2), 315-21*.

Lackan, N.A., Ostir, G.V., Freeman, J.L., Kuo, Y.F., Zhang, D.D., & Goodwin, J.S. (2004). Hospice use by Hispanic and non-Hispanic white cancer decedents. *Health Services Research, 39(4 Pt 1), 969-83.*

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Tobacco Control

Tobacco use remains the leading preventable cause of death in the United States. More than 400,000 Americans die prematurely each year of tobacco-related disease. The best evidence indicates that effectively reducing tobacco use requires a balanced and comprehensive approach, which combines programmatic and policy initiatives to address the prevention and treatment of tobacco use. In addition, a comprehensive surveillance and evaluation program is needed to track the relative impact of those programs and policies so that adjustments can be made. A forward-thinking research program is also needed to ensure that the best scientific evidence drives future initiatives.

MAJOR INITIATIVES

Transdisciplinary Tobacco Use Research Centers

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

In 2004, NCI, the National Institute on Drug Abuse, and the National Institute on Alcohol Abuse and Alcoholism joined together to fund the reissuance of the Transdisciplinary Tobacco Use Research Centers (TTURC) initiative that began in 1999. 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.

The following grants were awarded under the reissuance:

- Tobacco Dependence: Treatment and Outcomes, Timothy Baker, University of Wisconsin, Madison
- Building the Evidence Base for Tobacco Control Policies, Michael Cummings, Roswell Park Cancer Institute
- Tobacco Exposure Reduction, Dorothy Hatsukami, University of Minnesota Twin Cities
- Genes, Environment and Tobacco Use Across Cultures, Anderson Johnson, University of Southern California
- Translating Basic Science to Improve Tobacco Dependence Treatment, Caryn Lerman, University of Pennsylvania
- Nicotine Dependence: Phenotype, Endophenotype, and Contexts, Raymond Niaura, Miriam Hospital
- Tobacco Dependence and Risk Factors for Treatment Failure, Stephanie O'Mally, Yale University

People who smoke are influenced by interconnected behavioral, social, environmental, psychological, genetic, and biologic factors. As evidenced by the diversity of collaborations and research outcomes since 1999, the TTURC initiative spans multiple perspectives and is leading to new strategies for addressing tobacco control. The Robert Wood Johnson Foundation has partnered with the original grantees to help disseminate research results.

Highlights of important scientific findings from the original TTURC grants are described below:

- Researchers at the University of Pennsylvania published the first study to identify specific genes that may influence adolescent smoking progression in conjunction with psychological factors.
- Investigators at the University of California, Irvine (UCI) found that hostile, anxious, and depressed teens are more likely to smoke.

A collaboration between the UCI and University of Southern California TTURC revealed, however, that such factors work differently in white and Asian youth. For example, hostility and depression are associated with smoking in white but not Asian youth; Asian youth are more likely to smoke in social situations.

- Results from Brown University show that offspring of mothers who smoked a pack or more of cigarettes per day during pregnancy had a higher risk for nicotine dependence compared to children whose mothers did not smoke during pregnancy.
- Research and collaboration at the Yale TTURC led to the development of a new radiotracer (a drug tagged with radioactivity that allows researchers to take pictures of where nicotine acts in the brain) that will not only examine the effects of tobacco smoking on the brain, but also will allow researchers to explore the role of the nicotinic system in Alzheimer's disease, alcoholism, major depression, and schizophrenia.

Youth Tobacco Prevention and Cessation

Contact Cathy Backinger, PhD, MPH, 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, the American Cancer Society, and the American Legacy Foundation. 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 in adolescents. Selected findings are highlighted.

- Researchers at Dartmouth 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 address the needs and expectations of rebellious and risk-taking youth, and should begin no later than fifth grade.

Tobacco Research Initiative for State and Community Interventions (TRISCI)

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

The Tobacco Research Initiative for State and Community Tobacco Control Interventions supports research on new and existing tobacco control interventions, particularly those based in policy and the media, that are 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.

This RFA was reissued and the following grants were funded in the second round:

- Community Surveillance and Novel Tobacco Products, Pamela Clark, Battelle Memorial Institute, Centers for Public Health Research and 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, Hunter College, City University of New York

- 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 MD Anderson Cancer Center

In addition, most of the 12 grants funded in the first round of the initiative are still active or have been awarded competing continuation grants.

Systems and Network Development Initiatives

Contact Scott Leischow, PhD, 301-435-3914, leischos@mail.nih.gov

Several projects have been funded to support the understanding of tobacco control systems (*i.e.,* improving the progression of discovery to development, and to delivery) and the development of collaborative networks of scientists in order to improve communication and collaboration on tobacco control research in priority areas. Collaborations ensure that funds are used as efficiently and effectively as possible. In addition, networks create the opportunity for increasing transdisciplinarity across existing research grants and initiatives. Networks for disparities and tobacco products purported to reduce harm have been created and are progressing, and networks for surveillance/evaluation and cessation are planned.

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 range of nicotine, tar, carbon monoxide, and other components of tobacco smoke. In recent years, there has been a proliferation of a new generation of tobacco products that are marketed and advertised with claims that imply reduced exposure or harm. The purpose of NCI's new tobacco products initiative, started in 2004, 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 the potential public health impact of these products, both for individual smokers and the population as a whole. 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.

The new Testing Tobacco Products Promoted to Reduce Harm initiative (PA-04-103) calls for R01 and R21 applications. The purpose of the PA is to stimulate multidisciplinary research on the chemical composition, behavior of use, exposure to toxic agents, addictive properties, differential toxicity, and individual and public health impact of potential reduced-exposure tobacco products.

Youth Tobacco Cessation Collaborative

The Youth Tobacco Cessation Collaborative (YTCC) was formed in 1998 to address the gap in knowledge about what cessation strategies are most effective in assisting youth to quit smoking. Collaborative members represent major organizations that fund research, program, and policy initiatives related to controlling youth tobacco use. Organizations include:

- American Cancer Society
- American Legacy Foundation
- American Lung Association
- Canadian Tobacco Control Research Initiative
- Centers for Disease Control and Prevention
- National Cancer Institute
- National Cancer Institute of Canada
- National Heart, Lung and Blood Institute
- National Institute on Drug Abuse
- Robert Wood Johnson Foundation

National Tobacco Cessation Collaborative

The National Tobacco Cessation Collaborative was created to improve the public's health by increasing successful cessation among tobacco users in the U.S. and Canada through collaborative efforts of committed organizations. Organizations include:

- American Academy of Family Physicians
- American Cancer Society
- American Heart Association
- American Legacy Foundation
- American Lung Association
- American Nurses Association
- American Society of Clinical Oncology
- Campaign for Tobacco Free Kids
- Centers for Disease Control and Prevention/OSH
- C-Change
- Latino Council on Alcohol and Tobacco Prevention
- National Cancer Institute/Tobacco Control Research Branch
- Partnership for Prevention
- Robert Wood Johnson Foundation

PARTNERSHIPS & COLLABORATIONS

Office of Communications, Cancer Information Service (CIS)

- DCCPS collaborates with the CIS and CDC to offer a toll-free number for smoking cessation services (1-800-QUIT-NOW) and an instant messaging service for smoking cessation (LiveHelp).

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.

Fogarty International Center

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

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

Agency for Health Care Research and Quality (AHRQ)

- DCCPS staff worked with AHRQ to update *Treating Tobacco Use and Dependence*, which reflects new, effective clinical treatments for tobacco dependence. The document, a Public Health Service-sponsored Clinical Practice Guideline, is the product of the Tobacco Use and Dependence Guideline Panel, consortium representatives, consultants, and staff. Thirty individuals were charged with the responsibility of identifying effective, experimentally validated tobacco dependence treatments and practices. http://www.surgeongeneral.gov/tobacco/smokesum.htm

Centers for Disease Control and Prevention (CDC)

- DCCPS and the CDC Office on Smoking and Health have a five-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 NCI in collaboration with CDC and ACS. It offers science-based tools and support to help smokers quit. Smokefree.gov complements the National Network of Smoking Cessation Quitlines that has established a new national telephone number (1-800-QUIT-NOW) so smokers in every state have access to information and proactive smoking cessation counseling.

- DCCPS staff collaborated with CDC, the Canadian Tobacco Control Research Initiative, and the American Legacy Foundation to develop the 2004 CDC publication, *Youth Tobacco Cessation: A Guide for Making Informed Decisions.*

Centers for Medicare and Medicaid Services (CMS)

- 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.

Food and Drug Administration (FDA)

- 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 scientific issues that have regulatory significance.

American Cancer Society

- DCCPS partnered with the American Cancer Society and several cancer organizations in Poland to cosponsor a meeting to involve Eastern European countries in tobacco control. Eastern European clinicians and policy makers were educated on the importance of tobacco control to cancer control.

American Legacy Foundation

- 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 Quitline 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.

Robert Wood Johnson Foundation (RWJF)

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

World Health Organization (WHO)

- The mission of the World Health Organization Tobacco Free Initiative Study Group for Tobacco Regulation (WHO-TFI) is to reduce the global burden of disease and death caused by tobacco, and to protect present and future generations from the harmful health consequences of tobacco consumption and tobacco smoke exposure. The Scientific Advisory Committee on Tobacco Product Regulation (SACTob) was established in 2000 to provide comprehensive scientific research, information, and recommendations to inform tobacco policies and regulation. In November 2003, SACTob was formalized from a scientific committee to a study group and renamed the Study Group for Tobacco Regulation (TobReg). TobReg provides a mechanism for reporting to WHO's governing bodies, and for drawing the attention of member states to WHO's efforts in this novel and complex area of tobacco control. NCI scientists have worked with SACTob/TobReg since November 2002 on the development of numerous recommendations aimed at improving public health and scientific research related to the effects of tobacco use.

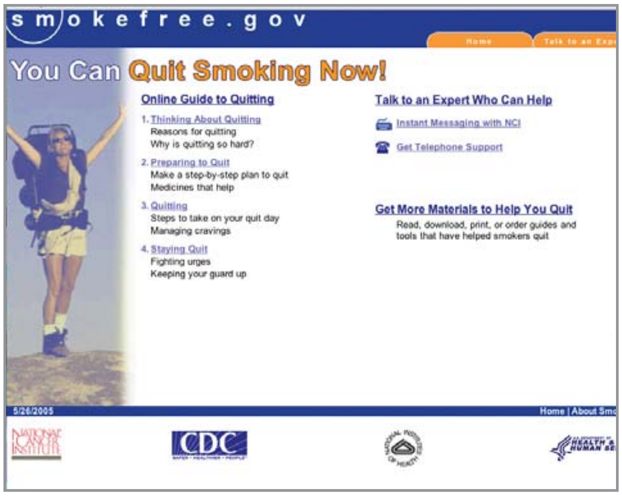
- In 2004, NCI collaborated with WHO-TFI on the development of the International Network for Tobacco Testing and Research for Regulation (INTTARR) to address research issues related to the establishment of global capacity for tobacco product testing and research. INTTARR collaborates with other networks such as the Tobacco Harm Reduction Network and the European Network of Government Laboratories on Tobacco and Tobacco Products, and with researchers across the world to advance research on tobacco product testing.

TOOLS, PRODUCTS, & RESOURCES

www.smokefree.gov

Smokefree.gov allows smokers to choose the help that best fits their needs as they become and remain nonsmokers. Immediate assistance is available in the form of:

- An online step-by-step cessation guide
- Local and state telephone quitlines
- NCI's national telephone quitline
- NCI's instant messaging service
- Publications, which may be downloaded, printed, or ordered



You Can Quit Smoking Now!

Online Guide to Quitting

1. Thinking About Quitting
   Reasons for quitting
   Why is quitting so hard?
2. Preparing to Quit
   Make a step-by-step plan to quit
   Medicines that help
3. Quitting
   Steps to take on your quit day
   Managing cravings
4. Staying Quit
   Fighting urges
   Keeping your guard up

Talk to an Expert Who Can Help

Instant Messaging with NCI

Get Telephone Support

Get More Materials to Help You Quit

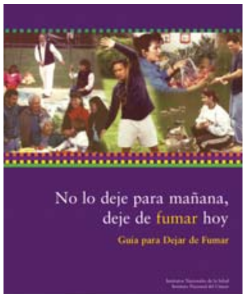
Read, download, print, or order guides and tools that have helped smokers quit

5/26/2005

Clearing the Air

Clearing the Air is designed to help smokers at any stage—whether they're still thinking about quitting, have made the decision to quit, or have already taken steps to quit and just need help maintaining a new lifestyle. Both ex-smokers and experts contributed to this guide.

Guía para Dejar de Fumar



The number of Spanish-speakers in the United States is growing rapidly. Hispanics are soon expected to become the second-largest ethnic group in the nation. Along with this trend comes a growing need for materials that will help them quit smoking and remain tobacco-free. Written for those who are thinking about quitting or have already decided to quit, this guide is filled with photographs, vibrant design elements, and content that draws upon Hispanic culture.

Tobacco Use Supplement to the Current Population Survey

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

NCI has supported federal surveys of tobacco use 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. Data from the most recent survey will be released in late 2005.

The Smoking and Tobacco Control Monographs

http://cancercontrol.cancer.gov/tcrb/monographs/index.html

NCI established the Smoking and Tobacco Control Monograph Series in 1991 to provide ongoing and timely information about emerging public health issues in smoking and tobacco use control. The series reduces the time between availability of information from research projects and the publication and wide dissemination of this information. It also enhances the rapidity with which NCI can use findings from research trials to reduce cancer morbidity and mortality.

Bibliography of Tobacco Use and Health Disparities

http://cancercontrol.cancer.gov/tcrb/bibliography_tobacco.html

This bibliography features literature on tobacco-related health disparities and focuses on special populations and themes such as Asian Americans and Pacific Islanders; Native Americans; African Americans; Latino/Hispanic Americans; Gay, Lesbian, Bisexual, and Transgender Americans; gender; religion; mental illness; disabilities; correctional facilities; occupation; and rural/urban areas.

Measures Guide for Youth Tobacco Research

http://cancercontrol.cancer.gov/tcrb/guide_measures.html

The Measures Guide for Youth Tobacco Research is intended as a resource for anyone conducting research on youth tobacco use or intervening with adolescent tobacco users. The guide assists researchers in achieving consistency of measurement across studies for describing smoking patterns, establishing inclusion and exclusion criteria for participation, measuring potentially important mediators and moderators of treatment outcomes, and measuring tobacco use outcomes. Each measure is briefly described and details are provided about the target population, administrative issues, scoring information, psychometrics, clinical utility of the instrument, research applicability, copyright/cost issues, references, authorship, and author's contact information.

Youth Tobacco Cessation: A Guide for Making Informed Decisions

http://www.cdc.gov/tobacco/educational_materials/cessation/youth_cess/index.htm

This CDC publication is filled with valuable information that helps public health practitioners understand how to approach implementing a tobacco cessation intervention for youth—including assessing community needs, developing a plan, choosing an intervention, and monitoring progress. The “better practices” model presented seeks to draw from both science and experience to identify approaches that are practical as well as effective.

RECENT SCIENTIFIC ADVANCES

Smokeless Tobacco Causes Oral and Pancreatic Cancer, Nitrosamines Classified as Human Carcinogens

An International Agency for Research on Cancer (IARC) monograph reports that smokeless tobacco, including snuff and chewing tobacco, causes oral and pancreatic cancer in humans. In addition, two tobacco-specific N-nitrosamines (TSNA), N'-nitrosonornicotine (NNN) and 4-(methylnitrosamino)-1-(3pyridyl)-1-butanone (NNK) were classified as human carcinogens. The chemicals occur in all smokeless tobacco products and are formed during the curing and processing of tobacco and during storage of manufactured smokeless tobacco products. Many studies in animals have shown that different routes of exposure to NNN and NNK cause benign and malignant tumors. Results of epidemiological studies of smokeless tobacco users and studies of the mechanisms of action of TSNA plausibly associate NNN and NNK with cancer in humans. The monograph's working group reaffirmed that the use of smokeless tobacco causes oral cancer in humans, and concluded that it causes pancreatic cancer as well. These findings reinforce that tobacco use in not safe in any form.

Cogliano,V., Streif, K., Bann, R., Grosse,Y., Secretan, B., & Ghissassi, F.E. (2004). Smokeless tobacco and related nitrosamines. *The Lancet Oncology, 5, 708.*

Parental Early Smoking Cessation Associated with Young Adult Children's Smoking Cessation

Little is known about how to help youth quit smoking. Bricker and colleagues examined the influence of parental quitting on youth quitting. Their prospective study found that parents who quit early can have a significant impact on their child's quitting. This study investigated the extent to which parental early and late smoking cessation predicts their young adult children's smoking cessation. Parental early smoking cessation status was assessed when children were in 3rd grade; parental late smoking cessation was assessed when children were in 11th grade; and young adult children's smoking cessation was assessed two years after high school. Forty Washington state school districts participated in the Hutchinson Smoking Prevention Project. Participants were the 1,553 families in which parents were ever regular smokers who had a young adult child smoking at least weekly at 12th grade who also reported their smoking status two years later. Questionnaire data were gathered on parents and their young adult children in a cohort with a 94 percent retention rate. Parents who quit early had children with 1.8 times higher odds of quitting smoking for at least one month in young adulthood compared to those whose parents did not quit early. In contrast, there was no association between parents quitting late and their young adult children's smoking cessation.

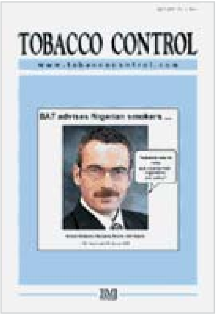
Bricker, J.B., Rajan, K.B., Andersen, M.R., & Peterson, A.V. (2005). Does parental smoking cessation encourage their young adult children to quit smoking? A prospective study. *Addiction, 100(3), 379-86.*

Parental Occupation, Education, and Smoking as Predictors of Offspring Tobacco Use in Adulthood

Occupational status (blue collar and service workers) has been linked with smoking among adults, but few studies have examined parental occupational influence on smoking among offspring. This study examined the interrelation of parental occupational status (blue- versus white-collar), parental education, parental smoking, parent-child relations, late adolescent tobacco use, and adult offspring smoking. A longitudinal data set was used, composed of 603 participants who were first studied in childhood and then followed to mean age of 27 years. Structural equation modeling showed that the distal factors of parental blue-collar status, low parental educational achievement, and parental smoking were related to adult offspring smoking. Specifically, parental blue-collar status and parental smoking were mediated by the latent construct of the parent-child relationship, which in turn was mediated by smoking in late adolescence with respect to adult offspring smoking. Parental educational level was partially mediated by the parent-adolescent relationship but also had a direct path to adult offspring smoking. The most powerful predictor of offspring smoking in adulthood was smoking in late adolescence. Findings imply areas that may be targeted by intervention programs to decrease offspring tobacco use.

Fagan, P., Brook, J.S., Rubenstone, E., & Zhang, C. (2005). Parental occupation, education, and smoking as predictors of offspring tobacco use in adulthood: A longitudinal study. *Addictive Behaviors, 30(3), 517-29.*

The Tobacco Industry in Asia: Revelations in Corporate Documents



The first collection of papers addressing Asian tobacco industry documents was published in the December 2004 supplement of *Tobacco Control*. The supplement represents the first coordinated attempt to collate information on Asia, home to half the world's smokers and a major growth area for the tobacco industry in the future. Topics range from smuggling and subversion of proposed legislation to tobacco industry youth campaigns, and encompass diverse countries such as China, Indonesia, Japan, Cambodia, the Philippines, Malaysia, Singapore, and Thailand.

In one article about Philip Morris' Asian Regional Tobacco Industry Scientist Team (ARTIST), researchers from the University of California, San Francisco, describe how the transnational tobacco industry has collaborated with local Asian tobacco companies to promote a scientific and regulatory agenda. In another article, researchers from the University of Sydney, Australia, illuminate through internal industry documents how RJ Reynolds exploited perceived cultural characteristics such as a preference for cleanliness, an eagerness to try new products, and social harmony to market the concept of cleaner, implicitly healthier cigarettes in Japan. Targeting women, RJ Reynolds successfully launched its new product, Salem Pianissimo, as a "clean" cigarette with less smell and smoke.

Tong, E.K., & Glantz, S.A. (2004). ARTIST: Philip Morris' attempt to exert a scientific and regulatory agenda on Asia. *Tobacco Control, 13(2), ii118-ii124.*

Assuntam, M., & Chapman, S. (2004). A "clean cigarette" for a clean nation: A case study of Salem Pianissimo in Japan. *Tobacco Control 13(2), ii58-ii62.*

Halting of Antitobacco Campaign Increases Youth Smoking Susceptibility

The discontinuation of an aggressive advertising campaign aimed at reducing tobacco use in teens increased the number of adolescents susceptible to cigarette smoking, according to a new study from University of Miami researchers. Six months after a comprehensive Minnesota state antitobacco campaign ceased in July 2003 due to massive cutbacks in funding for antismoking programs, the number of adolescents who said they would smoke sometime in the next year increased from 43.3 percent to 52.9 percent.

In the analysis, published in the April 16 *Morbidity and Mortality Weekly Report*, researchers looked at results from surveys of more than 1,000 teens aged 12 to 17 conducted during the three-year antitobacco campaign and after it ended. The survey was intended to gauge teens' awareness of the campaign. Teens were specifically asked about their awareness of the campaign's Target Market (TM) branding and whether they would smoke in the next year.

Studies have shown that comprehensive state antitobacco programs, especially those with strong advertising (i.e., paid media) campaigns, have contributed to the substantial decline in adolescent smoking since 1997. Findings suggest that state cutbacks in antitobacco campaigns might increase the susceptibility of youths to smoking, which is a key predictor of adolescent tobacco use.

Sly, D., Arheart, K., Dietz, N., Borgen, C., Trapido, E., Nelson, D.,McKenna, J. (2004) Effect of Ending an Antitobacco Youth Campaign on Adolescent Susceptibility to Cigarette Smoking-Minnesota, 2002-2003.Morbidity and Mortality Weekly Report, 53(14), 301-4.

Behavioral Research

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 behavior change: the steady reduction of tobacco use among adults. In addition to the traditionally supported areas of research such as smoking, fruit and vegetable consumption, and mammography utilization, we expanded our support of interdisciplinary sciences in areas such as risk communication, decision making, sociocultural research, consumer health informatics, policy analysis, neuroscience, and behavioral genetics.

MAJOR INITIATIVES

Centers of Excellence in Cancer Communications Research

Contact Brad Hesse, PhD, 301-594-9904, hesseb@mail.nih.gov

In fiscal year 2003, NCI funded 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 the 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. It is also reflective of NCI's recognition that effective communications can and should be used to both narrow the gap between discovery and application, and to reduce health disparities among our citizens.

Center grants 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

Small Grants Program for Behavioral Research in Cancer Control

Contact Veronica Chollette, MS, RN, BSN, 301-435-2837, cholletv@mail.nih.gov

The Small Grants Program for Behavioral Research in Cancer Control is designed to encourage investigators from a variety of academic, scientific, and public health disciplines to apply their skills to behavioral research investigations in cancer prevention and control. Small grants are short-term awards to provide support for pilot projects, development and testing of new methodologies, secondary data analyses, and innovative projects that provide a basis for more extended research.

Colorectal Cancer Screening in Primary Care Practice

Contact Erica Breslau, PhD, 301-435-2839, breslaue@mail.nih.gov or Carrie Klabunde, PhD, 301-402-3362, ck97b@nih.gov

NCI and AHRQ cofund the Colorectal Cancer Screening in Primary Care Practice grant program, which received 132 applications and has funded 28 grants through both R01 and R21 award mechanisms. The initiative encourages health services, social and behavioral, and outcomes researchers to develop innovative research projects that improve the delivery, utilization, outcomes, and evaluation of colorectal cancer screening in primary care practice. The division's Health Services and Economics Branch and Applied Cancer Screening Research Branch partner to manage grants in this important initiative.

Studies focus on several topics, including those highlighted here:

- Developing infrastructure and procedures necessary to create a population-based colonoscopy registry within a primary care colon cancer screening consortium
- Developing and testing the feasibility of using an interactive health communication tool to activate the colorectal cancer screening process within 10 rural primary care practice settings
- Using a randomized controlled trial to evaluate a multi-level intervention designed to activate the decision-making process between the provider, patient, and practice, and ensure follow through with screening decisions
- Assessing colorectal cancer screening, delivery, utilization, and related outcomes within county health center primary care practices
- Examining the feasibility of a model program for colorectal cancer screening by offering colonoscopy screening to 3,000 women at the time of mammography

Biological Mechanisms of Psychosocial Effects on Disease

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

Psychoneuroimmunology (PNI) is the study of interactions among behavior, neural, and endocrine function and immune system processes. PNI paradigms have been successfully used to study an array of diseases and health conditions (*e.g.*, HIV/AIDS, wound healing, autoimmune diseases, depression and other psychiatric disorders, upper respiratory infection). The Biological Mechanisms of Psychosocial Effects on Disease (BiMPED) initiative is designed to explore and evaluate the state-of-the-science of PNI and related fields, and the applicability of such paradigms to cancer control research. The overarching goal 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. NCI developed a Web site to host information about the initiative within the public domain. The Web site features profiles of active research related to the initiative, funding opportunities, initiative updates, relevant links and scientific resources, and a comprehensive, searchable bibliography on PNI and related fields.

The application of PNI paradigms to the study of cancer control is a relatively young empirical field. The field is at a critical juncture as it strives to advance our understanding of the biological mechanisms of cancer through a transdisciplinary microscope that filters in host behavior and psychosocial characteristics as important determinants. NCI will continue to support innovative, exploratory, high risk/high payoff scientific studies of interactions among behavior, neural and endocrine function, and immune system processes related to cancer control.

Decision Making Related to Cancer Control

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

Evidence from basic judgment and decision making research, as well as applied behavioral research, is necessary to move forward the science of decision making in cancer control. For example, studies that examine the effectiveness of decision aids in promoting positive health behaviors should be informed by sound basic science. In addition to evaluating outcomes, it is important to examine those processes underlying the use of decision aids, such as risk perception, affect, motivation, and social influence. This is precisely what NCI is promoting through two new program announcements. The overarching goal of these new initiatives is to better understand human decision-making processes so that individuals can make more informed choices regarding their health care.

The first new program announcement is “Decision Making in Health: Behavior Maintenance.” The announcement invites applications for research projects that will expand our knowledge of basic decision-making processes underlying initiation and long-term maintenance of healthy lifestyle behaviors that may reduce one’s risk of cancer and other chronic diseases, such as cardiovascular disease and diabetes. Specifically, NCI encourages research to elucidate the basic cognitive and affective processes involved in decisions that are made repeatedly over time, such as adhering to weight loss programs, exercise programs, smoking cessation programs, alcohol treatment programs, and adhering to medical treatment. Collaborations between basic judgment and decision making researchers as well as applied health behavior researchers are particularly encouraged.

The second new initiative, “Decision Making in Cancer: Single-Event Decisions,” invites applications for research projects that will enhance understanding of human decision-making processes so that individuals can make more informed and satisfying choices regarding their health. Specifically, NCI encourages research to elucidate single-event decision-making processes at the level of the individual patient or health care provider that are pertinent to cancer prevention, detection, treatment, survivorship, or end-of-life care. Decisions involving the individual patient, provider, patient-provider dyad, patient-caregiver dyad, patient-partner dyad, or the patient-family system are appropriate for study. For the purpose of this program announcement, a single-event decision is defined as a discrete decision made at a specific point in time. Examples of single-event decisions include selecting a particular cancer treatment, choosing to have mammography screening, or deciding to accept hospice care. Discrete, single-event decisions are distinct from decisions that must be made repeatedly, such as adhering to a weight loss program or abstaining from smoking.

Health Behavior Theories Project

The goal of the Theories Project is to identify and carry out activities that will help develop improved theories of health behavior. Its focus is on actions that individuals can take to prevent cancer and speed its early detection. The literature on health behavior is extensive, but progress in understanding health behaviors and in learning how to encourage healthy actions is not always apparent. Among the activities that may be considered are training in theory development and testing for health behavior researchers who lack such training; recruiting scientists with strong theory orientations to cancer behavior research; development of state-of-the-art summaries of theory-relevant topics where these are lacking; and better communication of opportunities for theory-focused research among current types of NCI grants. Current activities include:

- Workshop on Conceptualizing and Measuring Perceived Risk
- Constructs and Measures Web Resource
- Advanced Training Institute on Theory Development and Testing
- The Role of Perceived Risk in Health Behavior: A Comprehensive Review

Spotlight on Informatics Initiatives

The BioInformatics Context

In 1998, the National Committee on Vital and Health Statistics (NCVHS), a federal advisory committee composed of private sector experts, reported that the nation's information infrastructure could be an essential tool for promoting the nation's health. Since that time, a confluence of Health Information Technology (IT) initiatives has emerged. The DHHS Secretary established an Office of the National Coordinator for Health Information Technology with a mission of implementing the President's vision for widespread adoption of interoperable electronic health records within ten years. The NIH Roadmap for Medical Research, launched in 2003, represents a series of inter-disciplinary IT initiatives aimed at accelerating the pace of life science discovery from the bench into practice. At NCI, caBIG is enabling data sharing and tools, "creating a World Wide Web of cancer research," and the NCI-wide Informatics Implementation Team is developing an informatics research and applications plan to advise the NCI director.

DCCPS Informatics Strategic Plan

DCCPS has joined this suite of forward-thinking initiatives to ensure that population sciences and behavioral research continue to play a critical role in the advancement of health and health services research and the reliable and safe delivery of evidence-based care. A cross-division Health Informatics Steering Committee was established in 2004 to develop and implement a strategic plan that complements the National Health Information Infrastructure, the NIH Roadmap, and the NCI Center for Bioinformatics Infrastructure.

Strategic IT Goals

The DCCPS Informatics Strategic Plan involves the development of epidemiology-, behavior-, and surveillance-specific common data elements and vocabulary. These data elements and vocabulary will facilitate the development of standardized instrument modules, which, in turn, will lead to secure, interoperable database development and can underpin efforts to move toward electronic health records for cancer patients. This development process includes broad input from the DCCPS staff and the DCCPS extramural community, with the DCCPS Health Informatics Steering Committee acting as a bridge among DCCPS stakeholders.

Expected Products and Outcomes

Among the expected products and outcomes of the DCCPS IT Strategic Plan are population and behavioral science terminologies that are consistent with vocabularies such as SNOWMED CT, NAACCR; data standards for clinical trials and patient care, tissue banks, family histories, and genetics; interoperable middleware such as Application Programming Interfaces and Web services; data dictionaries; repositories for historical tracking of changes and for data sharing; dynamic forms and questionnaires; analytical and statistical tools; behavioral and population tracking; and quality measurement applications integrated into electronic medical records.

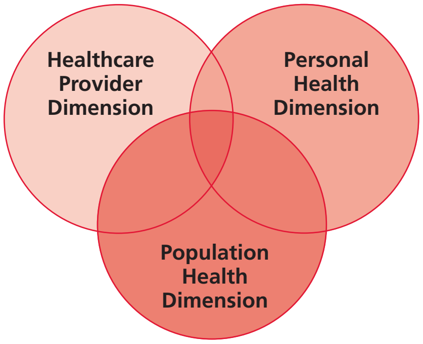
Benefits

DCCPS, through its intramural and extramural activities, continues to develop standardized terms, databases, and applications that will blend seamlessly and securely into the emerging health information infrastructures at NCI, NIH, DHHS, and throughout the private sector. These are the essential ingredients of seamless and secure health information infrastructures at all levels. They facilitate faster development and deployment, enhanced interdisciplinary communication, higher quality data, and expedited translation of science into practice.

NATIONAL HEALTH INFORMATION INFRASTRUCTURE

Examples of DCCPS Contributions

- Survey data
- Outcomes research instruments, longitudinal and cross-sectional data)
- Health services research (including research consortia)
- System support for clinical trials
- Economic analyses
- Quality of care analyses



Examples of DCCPS Contributions

- Public knowledge, behaviors (HINTS)
- Behavioral research data
- Tobacco control data
- Cancer survivorship data

Examples of DCCPS Contributions

- SEER patterns-of-care studies
- SEER-Medicare linkage information
- Cancer screening and detection surveillance
- Dissemination
- Other epidemiological and genetics research

PARTNERSHIPS & COLLABORATIONS

Agency for Healthcare Research and Quality (AHRQ)

- "Improving Colorectal Cancer Screening Delivery, Utilization, and Outcomes: The State of the Science," was held in April 2005 by NCI and AHRQ, and involved approximately 50 investigators and leaders in the field of colorectal cancer screening research. The objectives of the meeting were to describe and discuss innovative approaches to implementing colorectal cancer screening at the patient, provider, and healthcare system levels; discuss progress toward evaluating colorectal cancer screening practice and outcomes at the population level; and identify major areas of research progress and gaps.

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.

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 to 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.

American Cancer Society

U.S. Department of Agriculture (USDA)

Centers for Disease Control and Prevention (CDC)

- DCCPS partners with ACS, USDA, and CDC on Project Team-Up, an implementation and evaluation partnership to increase evidence-based cervical and breast cancer interventions among rarely or never screened women. The project seeks to:
    - Optimize the transfer of effective evidence-based interventions into practice in eight states with the lowest breast and cervical cancer screening rates
    - Foster state partnerships to enhance the dissemination of evidence-based screening interventions
    - Conduct regional coaching meetings using a Planning Assistance Team model to assist states in adopting and implementing evidence-based screening interventions
    - Evaluate the partnership using process, impact, and outcome evaluation methods

Fogarty International Center

- 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.

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 symposia 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 (February 2003, Volume 17, Supplement 1).

C-Change

- DCCPS staff had a leadership role in the planning and implementation of the Summit on the Primary Prevention and Early Detection of Cancer. Senior leaders served on the planning committee, cochaired the dissemination workgroup, and participated in several other workshops and workgroups.

National Library of Medicine

National Institute on Drug Abuse

National Institute of Mental Health

- More than 400 participants attended a Critical Issues in eHealth Research conference to discuss the latest behavioral research concerning the use and impact of the Internet and other new communication technologies. The conference, cosponsored by several agencies and private entities, convened government scientists, academic researchers from a variety of disciplines, survey research scientists and practitioners from the private and public sectors, and students to discuss the state of the science of eHealth research theory, design, methodology, ethics, and evaluation.

TOOLS, PRODUCTS, & RESOURCES

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 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 non-tailored 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.

Biological Mechanisms of Psychosocial Effects on Disease (BiMPED) Bibliography

The BiMPED bibliography contains over 2,800 references to published documents that address basic, applied, clinical, human, and animal research in psychoneuroimmunology (PNI), behavioral neuroimmunology, neuroendocrinology, psychophysiology, and related disciplines. The database includes research conducted in cancer, cardiovascular disease, pain, wound healing, infectious diseases, care giving, autoimmune diseases, psychiatric disorders, and other diseases frequently studied through PNI paradigms.

The searchable bibliography is intended for anyone with an interest in psychoneuroimmunology, mind-body interactions and health, and the interactions between behavior, biology, and health. The bibliography is useful to scientists in a variety of disciplines, including psychology, neurosciences, immunology, pharmacology, psychiatry, behavioral medicine, infectious diseases, endocrinology, rheumatology, and hematology/oncology.

Health Information National Trends Survey

http://hints.cancer.gov

The Health Information National Trends Survey (HINTS) is a nationally representative, biennial telephone survey of 8,000 randomly selected adults. NCI and extramural communication researchers are 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

The HINTS Web site expands access to HINTS data for multiple audiences, using tables, charts, population estimates, and technical history information on every question in the survey. The Web site reflects NCI's commitment to public data sharing by making the science of cancer communication easily accessible to multiple audiences. The new tools within the site were developed with extensive input from federal and private partners in cancer communication research and practice.

National Cancer Institute
U.S. National Institutes of Health | www.cancer.gov

How Americans find and use cancer information
Health Information National Trends Survey

View HINTS Findings
Search HINTS Questions
Survey questions & responses
Respondent characteristics
U.S. adult population estimates
Individual question responses displayed in charts
Question source

HINTS Briefs
Special reports
Factsheets
Brochures

Learn About HINTS
About HINTS
What HINTS does
How HINTS data are used
NCI presentations
Schedule of events

Conduct HINTS Research
Dataset
Downloadable SAS, SPSS formats
Registration required
Data version: May 2005

Survey Instrument
Sampling plan
Survey instruments
Screening & interview codebooks
Survey administration

Ongoing Research Using HINTS Data
Presentations & publications
Registered research abstracts
Submit a research abstract

Announcements
NCI Cancer Bulletin:
Health Information National Trends Survey Web Site Unveiled

HINTS Data Users Conference, Jan 20-21, 2005
Videocast
Presentations

HINTS 2 Update
HINTS 2 is currently underway, surveying approximately 7,000 people through September 2005.

Need Help?
Contact us by phone, Web, and e-mail
1-800-4-CANCER

A Service of the National Cancer Institute with support from the Health Communications and Informatics Research Branch of the Division of Cancer Control and Population Sciences

FIRSTGOV

Notes

Decreased Light Exposure is Correlated with Increased Fatigue in Breast Cancer Patients

Research published in the April 2005 *Supportive Care in Cancer* reveals a correlation between fatigue and light exposure among patients with breast cancer. The findings provide insight into the potential role that light therapy can play in alleviating radiation- and chemotherapy-related fatigue, and adds to scant literature on the topic.

Sixty-three women who were newly diagnosed with stage I–IIIA breast cancer and were scheduled to receive four cycles of adjuvant or neoadjuvant anthracycline-based chemotherapy were analyzed. Data were collected before and during weeks one, two, and three of cycle 1 and cycle 4. Fatigue was assessed using the Short Form of Multidimensional Fatigue Symptom Inventory. Light exposure was recorded with a wrist actigraph.

Increased fatigue was significantly correlated with decreased light exposure among patients with breast cancer. There were significant correlations between fatigue levels and light exposure within both cycle 1 and cycle 4, with higher levels of fatigue being associated with less light exposure. There were also significant correlations between changes in light exposure and changes in fatigue within the first two weeks of each cycle.

Although the cause and effect of exacerbated fatigue and decreased light exposure cannot be confirmed by the current study, and lower light exposure may be due in part to the fatigued patients spending less time outdoors in bright light, two hypotheses are proposed about the mechanisms by which light may alleviate the fatigue of patients with breast cancer. The first is that light may improve fatigue by activating circadian rhythms. The second hypothesis implies that light may alleviate breast cancer fatigue by improving mood. These results suggest the need for prospective intervention studies of light therapy for breast cancer-related fatigue.

Liu, L., Marler, M.R., Parker, B.A., Jones, V., Johnson, S., Cohen-Zion, M., Fiorentino, L., Sadler, G.R., & Ancoli-Israel, S. (2005). The relationship between fatigue and light exposure during chemotherapy. *Support Care Cancer* [Epub ahead of print].

Social Support Linked to Prognostic Marker for Ovarian Cancer

Social support and other behavioral factors are related to levels of a circulating protein, which at high levels is associated with a poor prognosis in advanced ovarian cancer. A study by Costanzo, Lutgendorf, and colleagues at the University of Iowa reports that factors that improved quality life, such as social support, were associated with low levels of a protein released by both immune cells and tumor cells, called interleukin 6 (IL-6). In contrast, negative quality of life factors were associated with higher IL-6 levels. The study is the first to find this association both in the peripheral blood and in the vicinity of the tumor.

IL-6 is an inflammatory cytokine that in healthy young people is almost undetectable. Levels of IL-6 increase with age, chronic psychological stress, and disease. Previous studies in humans and laboratory animals have shown IL-6 levels are also influenced by behavioral factors.

IL-6 has previously been shown to promote tumor growth, and IL-6 levels are also prognostic in ovarian cancer, with elevated levels associated with higher mortality and metastatic disease. Because depression and chronic stress are commonly associated with ovarian cancer, and IL-6 levels are responsive to psychosocial factors, researchers investigated whether IL-6 levels were linked to psychosocial factors in 61 women with advanced ovarian cancer.

While levels of IL-6 and the incidence of depression were elevated in these patients, those who reported strong social attachments had significantly lower levels of IL-6 in both the blood and in the ascites fluid surrounding the tumor. Women with weak social attachments had 1.7 times more IL-6 in the circulating bloodstream and 2.5 times more in the ascites fluid surrounding the tumor than women with strong social attachments. Higher levels in the bloodstream were also found among women who reported poor quality of life, such as fatigue and decreased physical function.

The investigators concluded that the finding that social attachment is strongly related to IL-6 not only in the periphery but also in the vicinity of the tumor suggests that psychosocial factors may be important clinically in the course of ovarian cancer.

Costanzo, E.S., Lutgendorf, S.K., Sood, A.K., Anderson, B., Sorosky, J., & Lubaroff, D.M. (2005). Psychosocial Factors and Interleukin-6 among Women with Advanced Ovarian Cancer. *Cancer*. Published Online: June 13, 2005; Print Issue Date: July 15, 2005.

Cognitive and Emotional Factors in Patients' Experiences of Post-surgery Side Effects

Pre-surgery cognitive and emotional factors play an important role in improving post-surgery recovery for women undergoing breast cancer surgery, according findings from an NCI-funded study published in the July 2004 issue of *Health Psychology*. The study sheds light on a topic that has not been well studied in surgical literature: the relationship between pre-surgery distress and post-surgery nausea.

Typically, half of women undergoing surgical treatment for breast cancer experience post-surgery nausea or vomiting. Pre-surgery distress is widely believed by clinicians to be a predisposing factor for post-surgery nausea. In this study, researchers analyzed 63 breast cancer surgery patients who were scheduled for either excisional breast biopsy (70 percent) or lumpectomy (30 percent). None of the women had been diagnosed with cancer before. They were not being treated for current psychiatric illness, nor had they been prescribed psychiatric medications as part of their surgical consultation. Patients completed Visual Analogue Scale measures of acute distress and expectations of post-surgery pain, nausea, fatigue, and discomfort.

Overall, the study data support the contribution of both pre-surgery distress and expectancies of specific post-surgery clinical outcomes. Pre-surgery expectancies were related to pain intensity, pain unpleasantness, and fatigue post-surgery, but not to nausea or discomfort. Pre-surgery distress contributed to post-surgery nausea, fatigue, and discomfort, but not to pain intensity or unpleasantness.

Patients who underwent lumpectomy experienced greater fatigue and nausea at discharge than those who had an excisional breast biopsy. Surgery type was unrelated to patients' pre-surgery distress or expectancies of post-surgery outcomes, and patients' pre-surgery expectancies were significant predictors of pain intensity, pain unpleasantness, and fatigue.

Montgomery, G.H., & Bovbjerg, D.H. (2004). Presurgery distress and specific response expectancies predict postsurgery outcomes in surgery patients confronting breast cancer. *Health Psychology, 23(4), 381-7.*

Provider Recommendations and Patient Information-Seeking Influence Men's Use of PSA

Analysis from NCI's Health Information National Trends Survey (HINTS) reveals that men aged 65 to 74 who have college degrees and who reported regularly seeking and paying attention to health information were more likely to report receiving a prostate-specific antigen (PSA) screening recommendation from their physicians. The study, published in the February issue of *Preventive Medicine*, also revealed that those with a usual source of healthcare and at least some college were more likely to have received a PSA test than those without health insurance or a regular source of care.

Data were examined to assess prevalence of self-reported PSA use and its association with patients' decision making. Investigators looked at survey responses from 927 males aged 50 or over with no history of prostate cancer, with consideration of respondents' attention to health information, cancer information-seeking behavior, and perceptions of healthcare providers' communication style. Men without a usual source of care and Hispanic men were less likely to report that providers involved them in healthcare decisions. Men who reported that providers involved them in decisions and recommended a PSA were more likely to have had the test.

Despite inconclusive evidence of its benefit in reducing mortality, PSA testing has increased rapidly in the U.S. Because it is not clear that the benefits of PSA testing outweigh the risks, NCI and professional organizations recommend that healthcare providers discuss the test with men over 50 and help them make informed decisions about screening, rather than recommending routine screening for age-eligible men.

Finney-Rutten, L.J., Meissner, H.I., Breen, N., Vernon, S.W., & Rimer, B.K. (2005). Factors associated with men's use of prostate-specific antigen screening: Evidence from Health Information National Trends Survey. *Preventive Medicine, 40(4), 461-8.*

Intervention for Rural Residents Improves Dietary Behavior

The first physician-endorsed, low-intensity dietary intervention to target a rural, low-income population made up of poorly educated, minority individuals demonstrated the feasibility of effectively changing dietary behavior in rural residents. Results of the NCI-funded Rural Physician Cancer Prevention Project, published in the February 2005 issue of the *American Journal of Preventive Medicine*, demonstrated significant improvement in dietary fat and fiber consumption in this population.

Fries and colleagues, of Virginia Commonwealth University, enrolled patients from three physician practices in rural Virginia and randomly assigned them to an intervention or control group. The dietary intervention consisted of tailored feedback on eating habits, brief counseling, and four dietary self-help booklets. Materials were written at or below a sixth-grade reading level, mailed over a five-week period, and accompanied by letters from participants' physicians. Investigators conducted follow-up telephone interviews at one, six, and 12 months after the intervention. A total of 516 participants completed the 12-month follow-up interview. Individuals in the intervention group significantly reduced their dietary fat intake, increased their dietary fiber consumption, and expressed their intention to reduce dietary fat and eat more fiber, fruits, and vegetables.

Efforts to improve health in rural areas may be compromised due to reduced access to health care and lack of appropriate nutrition education. Despite this, the authors note that physicians may be viewed by community members as the only legitimate source of health information. While rural primary care providers are in a unique position to influence dietary behavior change, many are overburdened with a large patient load. This study reveals that a low-intensity dietary intervention can net significant changes without increasing time constraints on physicians.

Fries, E., Edinboro, P., McClish, D., Manion, L., Bowen, D., Beresford, S.A., & Ripley, J. (2005). Randomized trial of a low-intensity dietary intervention in rural residents: The Rural Physician Cancer Prevention Project. *American Journal of Preventive Medicine, 28(2), 162-8.*

Reliability of Assessment and Circumstances of Performance of Thorough Skin Self Examination: The Check-It-Out Project

The vast majority of melanomas, including fatal melanomas, arise on the skin where they are plainly visible to the naked eye. Past studies have indicated that the practice of regular self-skin examination can reduce melanoma mortality as much as 63 percent. The Check-It-Out Project is a randomized trial designed to evaluate the efficacy of a primary care office-based intervention on performance of Thorough Skin Self-Examination (TSSE), defined to include partner-assisted skin self-examination and looking at the different areas of the skin deliberately and systematically. Researchers interviewed 2,126 patients before a scheduled routine visit with a primary care physician, inquiring about skin examination behavior and related issues. Among participants, the median age was 52 years; 23 percent were over 65 years of age; and 59 percent were women.

Estimates of TSSE performance varied substantially with the questions used to elicit this information. Using the researchers' definition of TSSE, 18 percent of participants performed this activity; however, when participants responded based on personal perception of TSSE, estimates widely varied from 12 percent to 38 percent. Partners, particularly spouses, appear to play a critical role in the conduct of TSSE, and wives appear more often and more effectively engaged in this process.

Appropriate circumstances, such as adequate vision and the availability of a wall mirror, are also important factors. These findings can be used to design interventions to increase TSSE performance with the ultimate aim of reducing melanoma mortality.

Weinstock, M.A., Risica, P.M., Martin, R.A., Rakowski, W., Smith, K.J., Berwick, M., Goldstein, M.G., Upegui, D., & Lasater, T. (2004). Reliability of assessment and circumstances of performance of thorough skin self-examination for the early detection of melanoma in the Check-It-Out Project. *Preventive Medicine, 38, 761-765.*

Promoting Cancer Screening: Lessons Learned and Future Directions for Research and Practice

A 2004 special issue of *Cancer* represents a collaborative effort from NCI, the American Cancer Society (ACS), and the Centers for Disease Control and Prevention (CDC) to identify lessons learned from more than twenty years of cancer screening research and promotion. The papers are forward-focused and intended to encourage and inform future intervention research and application efforts. Application of the lessons from this extensive knowledge base not only should accelerate the uptake of effective cancer screening tests currently available, but also can guide the next generation of research to promote cancer screening.

Cross-cutting themes emerged from the issue's nine articles:

- Multi-level approaches to screening offer the greatest potential for improving and sustaining screening rates and appropriate follow-up care.
- Future intervention studies should include cost-effectiveness analyses and plans for dissemination; the ability to sustain interventions in real-world settings is a challenge faced in all cancer screening efforts.
- It is not enough to promote the uptake of cancer screening tests. Practitioners must effectively communicate the benefits and risks of screening tests, as well as test options and limitations, so that people can make informed decisions about cancer screening.

Taplin, S. (2004). Foreword: Promoting cancer screening: Lessons learned and future directions for research and practice. *Cancer, 101(5), 1105-1106.*

Meissner, H.I., Smith, R.A., Rimer, B.K., et al. (2004). Promoting cancer screening: Learning from experience. *Cancer, 101(5), 1107-1117.*

Rakowski, W., & Breslau, E.S. (2004). Perspectives on behavioral and social science research on cancer screening. *Cancer, 101(5), 1118-1130.*

Vernon, S.W., Briss, P.A., Tiro, J.A., & Warnecke, R.B. (2004). Some methodologic lessons learned from cancer screening research. *Cancer, 101(5), 1131-1145.*

Pasick, R.J., Hiatt, R.A., & Paskett, E.D. (2004). Lessons learned from community-based cancer screening intervention research. *Cancer, 101(5), 1146-1164.*

Zapka, J.G., & Lemon, S.C. (2004). Interventions for patients, providers and health care organizations. *Cancer, 101(5), 1165-1187.*

Bastani, R., Yabroff, K.R., Myers, R.E., & Glenn, E. (2004). Interventions to improve follow-up of abnormal findings in cancer screening. *Cancer, 101(5), 1188-1200.*

Miles, A., Cockburn, J., Smith, R.A., & Wardle, J. (2004). A perspective from countries using organized screening programs. *Cancer, 101(5), 1201-1213.*

Rimer, B.K., Briss, P.A., Zeller, P.K., Chan, E., & Woolf, S.H. (2004). Informed decision making: What is its role in cancer screening? *Cancer, 101(5), 1214-1228.*

Andersen, M.R., Ramsey, S., Urban, N., & Briss, P.A. (2004). Examining the cost-effectiveness of screening promotion. *Cancer, 101(5), 1229-1238.*

Glasgow, R.E., Marcus, A.C., Bull, S.S., & Wilson, K. (2004). Disseminating effective cancer screening interventions. *Cancer, 101(5), 1239-1250.*

Meissner, H.I., Vernon, S.W., Rimer, B.K., et al. (2004). The future of research that promotes cancer screening. *Cancer, 101(5), 1251-1259.*

Energy Balance

The term “energy balance” refers to the integrated effects of diet, physical activity, and genetics on growth and body weight over an individual’s lifetime. Scientists are increasingly aware of the importance of understanding the effects of energy balance on the development and progression of cancer and on cancer patients’ quality of life after treatment. At a time when almost two-thirds of the U.S. population is considered overweight or obese, scientists have assembled compelling evidence that as weight and obesity increase, and physical activity decreases, the risk of developing many cancers rises. NCI is committed to providing leadership to advance energy balance research through targeted investments, as well as through collaborations with public and private partners.

MAJOR INITIATIVES

Centers for Transdisciplinary Research on Energetics and Cancer

Contact Linda Nebeling, PhD, MPH, RD, FADA, 301-435-6816, nebelinl@mail.nih.gov

The Centers for Transdisciplinary Research on Energetics and Cancer (TREC) 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 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 provide training opportunities for new and established scientists who can carry out integrative research on energetics, energy balance, and their consequences.

- Robert Jeffery, University of Minnesota
- Anne McTieran, Fred Hutchinson Cancer Research Center
- Michael Goran, University of Southern California
- Nate Berger, Case Western Reserve University
- Mark Thornquist, Fred Hutchinson Cancer Research Center (Coordination Center)

Physical Activity Behavior Change Theories

Contact Louise Mâsse, 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 behaviors can be increased. The purpose of the Physical Activity Behavior Change Theories initiative is to increase the knowledge base necessary to develop effective physical activity interventions in children, adolescents, adults, and older adults. Specifically, grantees funded under this RFA seek 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 Research, NIH Office of Disease Prevention, and NIH Office of Research on Women’s Health.

The following awards were made in fiscal year 2004.

- Psycho-physiological Influences on Physical Activity, Deborah Aaron, University of Pittsburgh
- Social Cognitive Theory and Physical Activity after Endometrial Cancer, Karen Basen-Engquist, University of Texas MD Anderson Cancer Center
- Involving Adolescents in Physical Activity Promotion, Amanda Birnbaum, Weill Medical College of Cornell University

- Mediators and Moderators of Exercise Behavior Change, Angela Bryan, University of Colorado at Boulder

- Individual and Environmental Mechanisms of Physical Activity Change, Paul Estabrooks, Kaiser Foundation Research Institute

- Understanding Change in Physical Activity Postpartum, Kelly Evenson, University of North Carolina at Chapel Hill

- Environmental Influences on Change in Elderly Walking, Yvonne Michael, Oregon Health and Science University

- Testing the Transtheoretical Model of Behavior Change, Claudio Nigg, University of Hawaii at Manoa

- On the Move: A Self Determination Exercise Intervention, Heather Patrick, Baylor College of Medicine

- Young Adult Environmental and Physical Activity Dynamics, Barry Popkin, University of North Carolina at Chapel Hill

Observing Protein and Energy Nutrition

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

NCI and its partners are improving measures of diet and physical activity, 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.

NIH Obesity Research Task Force

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

NCI is collaborating on a number of initiatives through the NIH Obesity Research Task Force, established by NIH Director Dr. Elias Zerhouni in April 2003 as a new effort to accelerate progress in obesity research across NIH. Staff members at NCI have taken the lead on trans-NIH initiatives in areas such as diet and physical activity assessment, the economics of diet and physical activity, and bioengineering approaches to energy balance and obesity. A new initiative on the evaluation of obesity policy is currently being planned.

PARTNERSHIPS & COLLABORATIONS

Agency for Healthcare Research and Quality (AHRQ)

- NCI initiated and funded a June 2004 evidence report conducted by AHRQ, *Effectiveness of Behavioral Interventions to Modify Physical Activity Behaviors in General Populations and Cancer Patients and Survivors*. The report provides comprehensive, science-based information to individual health plans, providers, consumers, and the health care system in hopes of improving health care quality.

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 intended to encourage good nutrition among consumers.

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.

- The Dietary Guidelines for Americans is a joint DHHS/USDA policy and public education effort to provide advice about dietary recommendations for the general population. Federally-funded research, including NCI-funded research, is essential in forming the scientific basis for recommendations. NCI scientists participate in the development and review of the final Dietary Guidelines summary.

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

American Cancer Society (ACS)

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

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.

Centers for Disease Control and Prevention (CDC)

- DCCPS has collaborated with CDC since October 2003 to develop a rating system that will evaluate state and local policies related to youth obesity. The purpose of the project is to develop the measurement tools (*e.g.*, a reliable rating system) that can be used to monitor policies that can have an impact on the school environment as it relates to nutrition and physical activity. The monitoring system can be used by researchers to evaluate the effect of these policies on children's nutritional and physical activity behaviors.

Notes

TOOLS, PRODUCTS, & RESOURCES

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 in Americans. 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. NCI and NHLBI are sponsoring a new NHANES module to be launched in 2005 to better understand weight loss history among children, adolescents, and adults.

Dietary Assessment Calibration/Validation Register

http://www-dacv.ims.nci.nih.gov/

The Dietary Assessment Calibration/Validation Register is a searchable tool that contains studies and publications comparing dietary intake estimates from two or more dietary assessment methods, including 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

http://riskfactor.cancer.gov/pyramid/

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

http://riskfactor.cancer.gov/DHQ/

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

http://riskfactor.cancer.gov/DHQ/dietcalc/

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

Percent Energy from Fat Screener

http://riskfactor.cancer.gov/diet/screeners/fat/

The Percent Energy from Fat Screener is a short assessment instrument used to estimate an individual's usual energy intake from dietary 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

http://riskfactor.cancer.gov/diet/screeners/fruitveg/

Two short assessment instruments estimate an individual's usual intake of fruits and vegetables. Both versions contain the same food item descriptions and portion size ranges; 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.

Glycemic Index Values Database

http://riskfactor.cancer.gov/tools/glycemic/

NCI has developed a listing of Glycemic Index (GI) values for individual foods. Food codes from the USDA Continuing Survey of Food Intakes of Individuals (CSFII) are used as a reference. The file provides GI values for those foods consumed by adults and queried on the Diet History Questionnaire (DHQ) or other Food Frequency Questionnaires used at NCI. Two files are provided on the Web site. The first is organized by CSFII food code. The second is organized by DHQ food groups consistent with line items on the questionnaire.

National Health Interview Survey

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

The 2000 and 2005 cancer control topical modules to the National Health Interview Survey contain a number of energy balance-related components. Major areas of emphasis include assessments of physical activity behavior such as walking and biking for transportation and leisure, occupational physical activity, and sedentary activity. The 2005 module added focused questions on walking for transportation and leisure, enhancing the ability to research the effect of the built environment on these behaviors.

California Health Interview Survey

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

In the 2001, 2003, and 2005 California Health Interview Surveys, NCI supported the fielding of questions about physical activity. In 2003 and 2005, there was an added emphasis on questions about walking for transportation and leisure.

RECENT SCIENTIFIC ADVANCES

Body Fat and Weight Can Increase After a Breast Cancer Diagnosis: Influence of Demographic, Prognostic, and Lifestyle Factors


JOURNAL OF CLINICAL ONCOLOGY

ASCO

Obese women and women who gain weight after a breast cancer diagnosis are at a greater risk for breast cancer recurrence and death compared with lean women and women who do not gain weight after diagnosis. In this population-based study, investigators assessed weight and body fat changes from the first year of diagnosis to the third year after diagnosis, and whether changes in weight and body fat varied by demographic, prognostic, and lifestyle factors in 514 women with incident Stage 0-IIIA breast cancer. Patients were participants in the Health, Eating, Activity, and Lifestyle (HEAL) study. Weight and body fat were measured (via dual-energy x-ray absorptiometry scans) during the baseline visit and two years later at a follow-up visit. Analysis of covariance methods were used to obtain mean weight and body fat changes adjusted for potential confounders. Findings from the study indicate that women increased their weight and percent body fat by 1.7 +/- 4.7 kg and 2.1 percent +/- 3.9 percent, respectively, from their first year of diagnosis to their third year after diagnosis. A total of 68 percent of patients gained weight, and 74 percent were found to have increased body fat. Greater increases in weight were observed among women diagnosed with a higher disease stage, younger age, being postmenopausal, and women who decreased their physical activity from diagnosis to three years after diagnosis.

Irwin, M.L., McTiernan, A., Baumgartner, R.N., Baumgartner, K.B., Bernstein, L., Gilliland, F.D., & Ballard-Barbash, R. (2005). Changes in body fat and weight after a breast cancer diagnosis: Influence of demographic, prognostic, and lifestyle factors. *Journal of Clinical Oncology, 23(4), 774-82.*

Strategies for Increasing Fruit and Vegetable Intake in Grocery Stores and Communities: Policy, Pricing, and Environmental Change


AMERICAN JOURNAL OF PREVENTIVE MEDICINE

Grocery stores and community settings are important and promising venues for environmental, policy, and pricing initiatives to increase fruit and vegetable intake. This article examines supermarket-based and community environmental, policy, and pricing strategies for increasing intake of fruits and vegetables and identifies promising strategies, research needs, and innovative opportunities for the future. The strategies, examples, and research reported were identified through an extensive search of published journal articles, reports, and inquiries to leaders in the field. Recommendations were expanded with input from participants in the CDC/ACS-sponsored Fruit and Vegetable, Environment Policy and Pricing Workshop. Four key types of grocery store-based interventions include point-of-purchase (POP) information; reduced prices and coupons; increased availability, variety, and convenience; and promotion and advertising. There is strong support for the feasibility of these approaches and modest evidence of their efficacy in influencing eating behavior. Church-based programs, child care center policies, and multisectoral community approaches show promise.

Glanz, K., & Yaroch, A.L. (2004). Strategies for increasing fruit and vegetable intake in grocery stores and communities: Policy, pricing, and environmental change. *Preventive Medicine, 39(2), S75--80. Review.*

Dietary Intake Estimates in the National Health Interview Survey, 2000: Methodology, Results, and Interpretation

The objectives of this study were to describe the implementation of the Multifactor Screener in the 2000 National Health Interview Survey (NHIS); to provide intake estimates for fruits and vegetables, fiber, and percentage of energy from fat by various demographic and behavioral characteristics; and to discuss the strengths and weaknesses of the method. The 2000 NHIS was conducted in 38,632 households in a clustered sample representative of the 48 contiguous states in the U.S. The Cancer Control Module was administered to adults (18 years and older) and included 17 dietary intake questions. After excluding individuals with missing data or unlikely values on the diet questions, investigators computed individual intake of servings of fruits and vegetables, percentage of energy from fat, and grams of fiber. Findings suggest that, in general, intakes of these dietary factors were closer to recommendations among well-educated individuals, those engaged in other healthful behaviors, and underweight and normal weight individuals. Latinos had higher intakes of fruits and vegetables and fiber, and generally a lower percentage of energy intake from fat than did non-Latino whites and non-Latino blacks.

Thompson, F.E., Midthune, D., Subar, A.F., McNeel, T., Berrigan, D., & Kipnis, V. (2005). Dietary intake estimates in the National Health Interview Survey, 2000: Methodology, results, and interpretation. *Journal of the American Dietetic Association, 105(3), 352-63.*

NCI Observing Protein and Energy Nutrition Study

American Journal of

EPIDEMIOLOGY

The NCI Observing Protein and Energy Nutrition (OPEN) study this year released two landmark findings related to the implications of measurement error for both epidemiological and surveillance studies. The first of the OPEN studies compared the measurement error of a food frequency questionnaire (FFQ) with that of 24-hour dietary recalls for assessing diet-disease associations using unbiased biomarkers of intake: doubly labeled water for energy intake, and urinary nitrogen for protein intake. The study found that because of severe attenuation, the FFQ could not be recommended for evaluating relations between absolute intake of energy or protein and disease; for protein density, attenuations were lower. Attenuations for one or two 24-hour dietary recalls were also severe, but improved with four or more administrations. The findings indicate that neither an FFQ nor one or two 24-hour dietary recalls can be recommended as an instrument for evaluating relations between absolute intake of energy or protein and disease, but that multiple administrations of recalls might be of value. Since large nutrition cohorts and case-control studies have depended on FFQs, these results indicate that a reappraisal of future methodology for such studies is warranted.

The second OPEN study examined the traditional method of estimating usual dietary intake distributions and documented the degree to which such methods underestimate energy intake and overestimate within-person variance. These results have profound implications for determining the proportion of the population with intakes above or below a given reference cut point. The authors found that some of this error might be corrected for if biomarkers could be added to surveillance studies.

Kipnis, V., Subar, A.F., Midthune, D., Freedman, L.S., Ballard-Barbash, R., Troiano, R.P., Bingham, S., Schoeller, D.A., Schatzkin, A., & Carroll, R.J. (2003). The structure of dietary measurement error: Results of the OPEN biomarker study. *American Journal of Epidemiology, 158,14-21.*

Freedman, L.S., Midthune, D., Carroll, R.J., Krebs-Smith, S.M., Subar, A.F., Troiano, R.P., Dodd, K., Schatzkin, A., Ferrari, P., & Kipnis, V. (2004). Adjustments to improve the estimation of usual dietary intake distributions in the population. *The Journal of Nutrition, 134, 1835-43.*

Adult Weight Gain and Late-Onset Breast Cancer

NUTRITION AND CANCER

Adult weight gain has been associated with a twofold risk of postmenopausal breast cancer. Data are limited regarding whether weight gain during specific periods of demonstrated changes in estrogen- and insulin-related hormones have different risk associations. Investigators assessed the relationship of adult weight change overall and at specific, hormonally relevant times with diagnosis of a first breast cancer after age 55 (late onset). Framingham study data were used to assess premenopausal (25-44 years), perimenopausal (45-55 years), postmenopausal (more than 55 years), and adult lifetime (from 25 years) weight change in relation to late-onset breast cancer in 2,873 women. The women were followed for up to 48 years; 206 developed late-onset breast cancers. Results indicate that adult lifetime weight gain was associated with an increased risk of late-onset breast cancer. Weight gain during specific time periods was not associated with breast cancer. Data suggest a possible decreased risk of breast cancer with weight loss from ages 25 to 44 and 45 to 55 years. Authors note that these data confirm prior reports of an association between adult lifetime weight gain and increased risk of late-onset breast cancer and support current recommendations to avoid adult weight gain.

Radimer, K.L., Ballard-Barbash, R., Miller, J.S., Fay, M.P., Schatzkin, A., Troiano, R., Kreger, B.E., & Splansky, G.L. (2004). Weight change and the risk of late-onset breast cancer in the original Framingham cohort. *Nutrition and Cancer, 49(1), 7-13.*

Survivorship

Once almost uniformly fatal, cancer has become for most a chronic illness. For growing numbers of people, it has become a curable disease. The estimated number of cancer survivors in the U.S. is 10.1 million, and serves as a testament to our success. These successes include important progress in the delivery and use of cancer screening; enhancement of early detection technologies; discovery and use of more effective and often multimodal therapies; provision of a broadening array of supportive care and rehabilitative options; and, increasingly, wider adoption of active screening behaviors and healthier lifestyles by those at risk for cancer, as well as by those with a history of the disease. While the ultimate goal of eliminating cancer continues to be our long-term commitment, the capacity to dramatically reduce the suffering caused by cancer is within our immediate grasp. NCI leads the nation in championing research on the health and functioning of our growing population of cancer survivors.

MAJOR INITIATIVES

Long-Term Cancer Survivors Research Initiative

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

The population of long-term cancer survivors continues to grow: 64 percent of adult and 79 percent of pediatric cancer survivors live beyond five years. The Long-Term Cancer Survivors Initiative, first funded as an RFA 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.

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.

The RFA was reissued in 2004 to directly respond to the recent Institute of Medicine reports on cancer survivorship, as well as the priorities of the President's Cancer Panel. In fiscal year 2004, the following 17 grants were funded, with three in collaboration with NIA and CDC.

- Long-Term Health Outcomes in Breast Cancer Survivors, Bette Caan, Kaiser Foundation Research Institute
- Psychosocial Impact of Cancer-Related Female Infertility, Andrea Canada, University of Texas MD Anderson Cancer Center
- Research-out to Enhance Wellness in Older Survivors (RENEW), Wendy Demark-Wahnefried, Duke University
- Web-based Intervention for Cancer Survivors, Karen Emmons, Dana-Farber Cancer Institute
- Health Outcomes for Hodgkin's Disease Survivors, Debra Friedman, Children's Hospital and Regional Medical Center
- Long-Term Outcomes of Head and Neck Cancer Patients, Gerry Funk, University of Iowa

- Metabolic Syndrome in Adult Survivors of Childhood ALL, James Gurney, University of Minnesota Twin Cities
- Psychological Outcomes in Childhood Cancer Survivors, Anne Kazak, Children's Hospital of Philadelphia
- Health-related Quality of Life in Colorectal Cancer Survivors with Stomas, Robert Krouse, University of Arizona
- Preventive Health Care Use Among Elderly Survivors, Alexander McBean, University of Minnesota Twin Cities
- Fasting Glucose in Long-Term Breast Cancer Survival, Paola Muti, State University of New York at Buffalo
- Characterizing the Obesity of Long-Term Cancer Survivors, Susan Nunez, Children's Research Institute
- Mammography and High-Risk Survivors of Pediatric Cancer, Kevin Oeffinger, University of Texas South West Medical Center/Dallas
- Managing Uncertainty in Childhood Cancer Survivorship, Sheila Santacroce, Yale University
- Physical Activity and Lymphedema Project (PAL Trial), Kathryn Schmitz, University of Minnesota Twin Cities
- Impact of Breast Cancer on Older Survivors, Rebecca Silliman, Boston Medical Center
- Exercise and Fitness in Childhood Cancer Survivors, Stan Whitsett, Children's Hospital and Regional Medical Center

Innovative Cancer Control in Cancer Centers

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

The Innovative Cancer Control in Cancer Centers initiative provided NCI-designated cancer centers with supplemental funds for innovative pilot research projects in cancer control and population sciences. The initiative was created to jump-start the careers of junior investigators. NCI awarded 36 pilot projects in 1999 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; four have received NIH grants based on the data from completed pilot studies, and one was awarded a non-NIH grant.

Research on the Impact of Cancer on the Family

Contact Julia Rowland, PhD, 301-402-2964, rowlandj@mail.nih.gov

A review of NCI's fiscal year 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 one-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 awarded a small grant to expand upon preliminary findings derived from the supplemental funding. The grant employs a longitudinal design to assess the psychological and relationship functioning of lung cancer patients and spouses. This spinoff award exemplifies the importance of the supplement mechanism for generating pilot data that can serve as a model for more expansive studies. 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, 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, MD Anderson Cancer Center

The data generated from the Mendelsohn and Schover supplement was used to compete for an R01 grant in 2003. The awarded project is entitled SPIRIT: Reproductive Peer Counseling for Breast Cancer. It is a national study that partners with Sisters Network Inc., an advocacy group for African American breast cancer survivors.

Notes

PARTNERSHIPS & COLLABORATIONS

Indian Health Service (IHS)

- NCI, in collaboration with IHS, the Mayo Clinic, Spirit of Eagles, and the Native American Research Centers for Health (NIGMS/NIH), supports efforts to understand the need for and improve palliative care among American Indians and Alaska Natives.

American Cancer Society (ACS)

- DCCPS and ACS jointly support scientific conferences, such as the Biennial Cancer Survivorship Conference.

- NCI and ACS partner to distribute the Facing Forward: Life After Cancer Treatment series of materials for cancer survivors, their families, and health care providers. These documents were created in response to feedback received from cancer survivors and their families.

- NCI collaborated with ACS to establish a working group that met in March 2003 to revisit the first *Guide to Informed Choices for Cancer Survivors on Nutrition and Physical Activity*, published in 2001. The group consisted of 21 members and was developed in response to the burgeoning growth in research relevant to nutrition and physical activity among cancer survivors. The result was a document published in the September/October 2003 issue of *CA: A Cancer Journal for Clinicians*, called “Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices.” The report is for cancer survivors, their families, and their health care providers. It can be used as a guide for discussions between survivors and health care providers on issues such as diet, weight, physical activity, and nutritional complementary and alternative therapies.

Lance Armstrong Foundation

- The Office of Cancer Survivorship, in collaboration with colleagues in the NCI Office of Education and Special Initiatives, participates in a groundbreaking, three-part teleconference series launched in 2003 and entitled “Cancer Survivorship: Living with, through, and beyond cancer.” DCCPS is 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 is made possible by an educational grant from the Lance Armstrong Foundation and supporting funds from NCI.

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

President's Cancer Panel

- In 2003-2004, the President's Cancer Panel made cancer survivorship its major area of focus and coordinated with the Office of Cancer Survivorship to help set priorities and inform practice. Public hearings in the U.S. and Europe concentrated on issues including living beyond cancer, the survivorship of pediatric cancer survivors, challenges for adolescent and young adult cancer survivors, and meeting the needs of adult survivors. The Panel’s report identified both key issues and concerns for cancer survivors across the developmental spectrum and research and service gaps to inform the activities of the national cancer program.

Notes

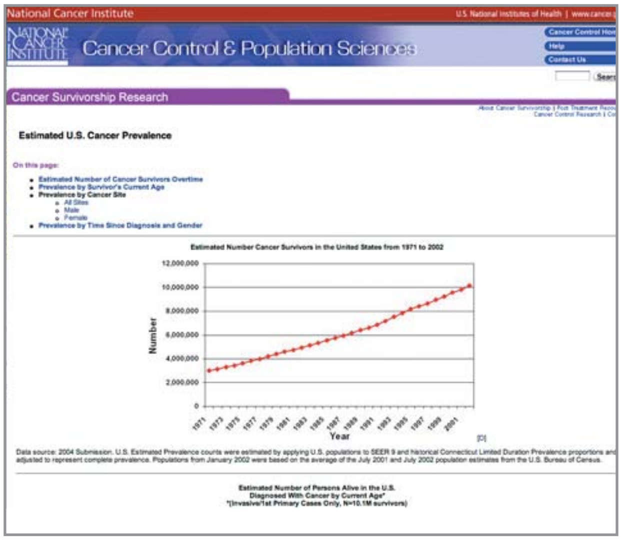
TOOLS, PRODUCTS, & RESOURCES

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. The data are updated annually.



Estimated U.S. Cancer Prevalence

On this page:

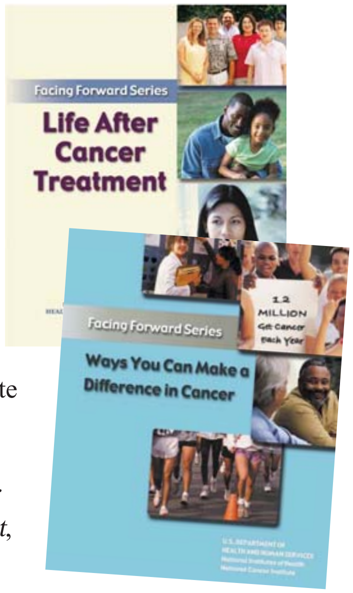
- Estimated Number of Cancer Survivors Overtime
- Prevalence by Survivor's Current Age
- Prevalence by Cancer Site
  - All Sites
  - Male
  - Female
- Prevalence by Time Since Diagnosis and Gender

Estimated Number Cancer Survivors in the United States from 1971 to 2002

Data source: 2004 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2002 were based on the average of the July 2001 and July 2002 population estimates from the U.S. Bureau of Census.

Estimated Number of Persons Alive in the U.S.
Diagnosed With Cancer by Current Age*
*(Invasive/1st Primary Cases Only, N=10.1M survivors)

Facing Forward Survivorship Series



OCS and the NCI 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.

Notes

Cardiovascular Abnormalities in Long-term Hodgkin's Disease Survivors


JOURNAL OF CLINICAL ONCOLOGY

ASCO

With the majority of pediatric cancer survivors expected to be cured of their disease, understanding and reducing risk for life-threatening events related to treatment is more important than ever. One of the more worrisome among these is late cardiac failure. Lipshultz and colleagues have found that a variety of unsuspected, clinically significant cardiovascular abnormalities are common in long-term survivors of Hodgkin's Disease who are treated at a young age with mediastinal irradiation. Even though every patient described their health as good or better in this study, and none had symptomatic heart disease at screening, all but one of the survivors had cardiac abnormalities when assessed. Similar risk for cardiac damage has been observed by these investigators in childhood cancer survivors exposed to doxorubicin as part of their curative therapy for leukemia. In an exciting pilot study, they found that dexrazoxane, a free-radical scavenger, prevents or reduces cardiac injury without compromising the antileukemic efficacy of doxorubicin. While longer follow-up will be necessary to determine the influence of dexrazoxane on echocardiographic findings at four years and on event-free survival, this work holds promise for reducing the human cost of cure in young survivors and potentially those treated with anthracyclines as adults.

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Lipshultz, S.E., Rifai, N., Dalton, V.M., Levy, D.E., Silverman, L.B., Lipsitz, S.R., Colan, S.D., Asselin, B.L., Barr, R.D., Clavell, L.A., Hurwitz, C.A., Moghrabi, A., Samson, Y., Schorin, M.A., Gelber, R.D., & Sallan, S.E. (2004). The effect of dexrazoxane on myocardial injury in doxorubicin-treated children with acute lymphoblastic leukemia. *New England Journal of Medicine, 351(2)*, 145-53.

Benefit Finding and Post-traumatic Growth: The "Silver Lining" in Survivorship

Historically, survivorship research has sought to identify the ways that cancer and its treatment result in damage, distress, disruption, and disorder. A newer approach to research suggests that cancer survivors experience positive as well as adverse consequences from diagnosis and treatment, and that capitalizing on these perceptions may improve survivors' health outcomes. Work by Carver and colleagues specifically examined longer term outcomes. A set of benefit-finding items along with measures of well-being were completed by 230 early-stage breast cancer patients in the first year after surgery. Four to seven years later, 96 of them again completed measures of well-being. Controlling for early distress and depression, initial benefit finding in this sample predicted lower distress and depression at follow-up. In subsequent research, this same research team found that a cognitive behavioral stress management (CBSM) intervention for women with early-stage breast cancer facilitated positive emotional responses to their breast cancer experience in parallel with later improvement in cellular immune function. Women in the CBSM intervention reported greater perceptions of benefit from having breast cancer compared to the women in the comparison group. At three-month follow-up, women in the CBSM group also had improved lymphocyte proliferation. Increases in benefit finding after the 10-week intervention predicted increases in lymphocyte proliferation at the three-month follow-up.

In a similar study examining post-traumatic growth after cancer, Manne and colleagues found that post-traumatic growth increased for both breast cancer survivors and their partners over time, and that the survivor's growth was associated with her partner's cognitive and emotional processing of breast cancer. All of these studies suggest that for many, the ability to identify positive aspects of the cancer experience may help in ultimate adjustment.

Carver, C.S., & Antoni, (2004). M.H. Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology, 23(6), 595-8.*

McGregor, B.A., Antoni, M.H., Boyers, A., Alferi, S.M., Blomberg, B.B., & Carver, C.S. (2004). Cognitive-behavioral stress management increases benefit finding and immune function among women with early-stage breast cancer. *Journal of Psychosomatic Research, 56(1), 1-8.*

Manne, S., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., & Grana, G. (2004). Posttraumatic growth following breast cancer: Patient, partner and couple perspectives. *Psychosomatic Medicine, 66, 442-452.*

Head and Neck Cancer Survivorship Outcomes

Because effects of head and neck cancer and its treatment can compromise speech, swallowing, self-image and self-esteem, survivors often face significant functional and quality of life challenges after treatment. Despite this, survivors of head and neck cancer have rarely been the focus of survivorship studies. Reversing this trend, Campbell and colleagues report a series of studies on outcomes for this neglected population. Among their findings is the surprising discovery that almost half of long-term nonlaryngectomy head and neck cancer survivors demonstrated at least some degree of aspiration. The presence of aspiration is associated with substantial weight loss, advanced initial tumor stage, diminished oropharyngeal swallowing efficiency, and lower scores on a variety of quality of life scales. Many long-term survivors of head and neck cancer treatment reported that poor speech intelligibility adversely affected quality of life, including distress about communication, eating, and recreation. In addition, pre-morbid pessimism was consistently the best predictor of quality of life measures. Of key importance in this research was the recognition that both psychosocial and physiologic effects together affect quality of life outcomes. These data have important implications for patient care.

Campbell, B.H., Spinelli, K., Marbella, A.M., Myers, K.B., Kuhn, J.C., & Layde, P.M. (2004). Aspiration, weight loss, and quality of life in head and neck cancer survivors. *Archives of Otolaryngology - Head & Neck Surgery, 130(9), 1100-3.*

Meyer, T.K., Kuhn, J.C., Campbell, B.H., Marbella, A.M., Myers, K.B., & Layde, P.M. (2004). Speech intelligibility and quality of life in head and neck cancer survivors. *Laryngoscope, 114(11), 1977-81.*

Holloway, R.L., Hellewell, J.L., Marbella, A.M., Layde, P.M., Myers, K.B., & Campbell, B.H. (2005). Psychosocial effects in long-term head and neck cancer survivors. *Head and Neck, 27(4), 281-288.*

The Economic Costs of Survivorship

Data suggest that among the most vulnerable population of survivors are those diagnosed as young adults—individuals who, by definition, are in their most productive years. While changes in treatment delivery enable many to receive care on an outpatient basis, cancer continues to exact an enormous toll on the employment status of those who survive. In a study by Short and colleagues of over one thousand survivors, employment from the time of diagnosis through the early years of survivorship was studied, self-reported effects of cancer survival on disability and employment were quantified, and risk factors associated with cancer-related disability and withdrawal from employment were identified. One in five survivors reported cancer-related disabilities at follow-up. Half of those with disabilities were working. A projected 13 percent of all survivors had quit working for cancer-related reasons within four years of diagnosis. More than half of survivors quit working after the first year, when three-quarters of those who stopped for treatment returned to work. Survivors of central nervous system, head and neck, and Stage IV blood and lymph malignancies had the highest adjusted risk of disability or quitting work. Similar findings have been reported by Bradley and colleagues, who found that African American breast cancer survivors may be at greater risk for leaving the work force after being diagnosed. Among all women in the study who continued to work, many worked fewer hours than their non-affected peers in the early period after diagnosis. These data highlight the need to address the work-related impact of cancer, with innovations in treatment and clinical and supportive services aimed at better management of symptoms, rehabilitation, and accommodation of disabilities.


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A Cancer Journal for Clinicians
Cancer Statistics, 2004

Short, P.F., Vasey, J.J., & Tunceli, K. (2005). Employment pathways in a large cohort of adult cancer survivors. *Cancer, 103(6),1292-301.*

Bradley, C.J., Neumark, E., Bedmarck, H.L., & Schenk, M. (2005). Short-term effects of breast cancer on labor market attachment: results from a longitudinal study. *Journal of Health Economics, 24, 137-160.*

Young Adult Cancer Survivors Could Be Developmentally Vulnerable

Although the majority of those diagnosed with cancer are over the age of 65, it is adult survivors younger than 65 years who may be most vulnerable to the adverse effects of the disease. Colditz and colleagues found that, compared with women age 40 or younger without breast cancer, breast cancer survivors of the same age experienced significant functional declines. Young women (age 40 or less) who developed breast cancer experienced the largest relative declines in health-related quality of life (HRQOL), compared with middle-aged and elderly women, in multiple domains including physical roles, bodily pain, social functioning, and mental health. Much of the decline in HRQOL among elderly women (age 65 or older) with breast cancer was age related. Work by Ganz and colleagues also shows that menopausal symptoms, which may contribute significantly to reported physical problems, are prevalent in survivors diagnosed before age 50. These are most persistent in women whose treatment caused them to transition abruptly into menopause. These findings emphasize the need to apply a life stage framework when evaluating the impact of cancer.

Kroenke, C.H., Rosner, B., Chen, W.Y., Kawachi, I., Colditz, G.A., & Holmes, M.D. (2004). Functional impact of breast cancer by age at diagnosis. *Journal of Clinical Oncology, 22(10), 1849-56.*

Crandall, C., Petersen, L., Ganz, P.A., & Greendale, G.A. (2004). Association of breast cancer and its therapy with menopause-related symptoms. *Menopause, 11(5), 519-530.*

Refining Knowledge About Quality of Life Outcomes for Prostate Cancer Survivors

Establishing strong prognostic indicators and developing treatment strategies to minimize potential side-effects are two areas that relate to the quality of life of men treated for prostate cancer. Sanda and his research team found that, in a sample of 1,414 men treated for prostate cancer, the amount of cancer in a biopsy core is a significant predictor of recurrence-free survival after prostatectomy, and complements baseline prostate specific antigen (PSA) and Gleason scores in predicting outcomes. One example of a treatment approach that may affect health status is the use of homologous blood transfusion during or after prostatectomy. Investigators studied how better to inform patients about the probability of transfusion, and found that surgical expertise predicted how patients were counseled. From this same study, the researchers also found that the administration of neoadjuvant hormonal therapy hindered sexual function outcomes among men with localized prostate cancer treated with radiation therapy. Collectively, these studies have implications regarding patient-physician communication about cancer prognosis and treatment decisions.

Nelson, C.P., Dunn, R.L., Wei, J.T., Rubin, M.A., Montie, J.E., & Sanda, M.G. (2003). Contemporary preoperative parameters predict cancer-free survival after radical prostatectomy: A tool to facilitate treatment decisions. *Urologic Oncology: Seminars and Original Investigations, 21, 213-218.*

Hollenbeck, B.K., Wei, J.T., Sanda, M.G., Dunn, R.L., & Sandler, H.M. (2004). Neoadjuvant hormonal therapy impairs sexual outcome among younger men who undergo external beam radiotherapy for localized prostate cancer. *Urology, 63, 946-950.*

Hollenbeck, B.K., Dunn, R.L., Wei, J.T., Sandler, H.M., & Sanda, M.G. (2004). Sexual health recovery after prostatectomy, external radiation, or brachytherapy for early stage prostate cancer. *Current Urology Report, 5, 212-9.*

Dash, A., Dunn, R.L., Resh, J., Wei, J.T., Montie, J.E., & Sanda, M.G. (2004). Patient, surgeon, and treatment characteristics associated with homologous blood transfusion requirement during radical retropubic prostatectomy: Multivariate nomogram to assist patient counseling. *Urology, 64, 117-122.*

Miller, D.C., Sanda, M.G., Dunn, R.L., Montie, J.E., Pimentel, H., Sandler, H.M., McLaughlin, W.P., & Wei, J.T. (2005). Long-term outcomes among localized prostate cancer survivors: Health-related quality-of-life changes after radical prostatectomy, external radiation, and brachytherapy. *Journal of Clinical Oncology, 23(12)*, 2772-80.

Hollenbeck, B.K., Dunn, R.L., Wei, J.T., Montie, J.E., & Sanda, M.G. (2003). Determinants of long-term sexual health outcome after radical prostatectomy measured by a validated instrument. *Journal of Urology, 169(4)*, 1453-7.

Notes

Health Disparities

Some of our greatest opportunities for reducing the overall burden of cancer reside with our efforts to overcome cancer health disparities. By providing universal access to the currently tested and available interventions for prevention, early detection, treatment, and follow-up, we could see both a dramatic reduction in cancer mortality in the short term and in cancer incidence in the long term. Collaborations and partnerships with federal, state, and local decision makers are needed to facilitate the development and adoption of policies to eliminate access barriers to healthcare and to promote quality health education and prevention strategies that lower the risk of cancer. Communities, caregivers, and researchers must form strong collaborations and explore creative solutions for developing culturally competent venues for service delivery. This cross-fertilization will create synergy and ensure stronger, more dynamic alliances for overcoming cancer health disparities. The measurement of health disparities is one of the challenges of research in this area, and DCCPS is working to add greater depth to the SEER database. Efforts include the linkage with the National Longitudinal Mortality Study to provide socioeconomic data at the individual level that cannot be obtained from the SEER database itself. In addition, the preparation of a new SEER monograph on cancer rates among racial/ethnic populations is underway.

MAJOR INITIATIVES

Centers for Population Health and Health Disparities

Contact Suzanne Heurtin-Roberts, PhD, MSW
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The National Institute of Environmental Health Sciences, National Institute on Aging, NCI, and NIH Office of Behavioral and Social Sciences Research recently funded 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—which will lead 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 engage and include community stakeholders in the planning and implementation of health research. Communities include the elderly, African Americans, poor whites, and Hispanics. Studies 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

Tobacco and Health Disparities Research Network

Contact Pebbles Fagan, PhD, MPH, 301-496-8584, faganp@mail.nih.gov

The Tobacco and Health Disparities Research Network is a unique endeavor whose mission is to understand and address tobacco-related health disparities by advancing the science, translating scientific knowledge into practice, and informing public health policy. The goals are to encourage collaborations among multiple research disciplines, serve as a forum for generating new ideas and research projects focusing on tobacco-related health disparities, establish a translation mechanism for communicating and interacting with other networks and community advocacy groups, promote the involvement and training of junior investigators and the participation of senior researchers in health disparities research, and provide scientific information and serve as a resource on tobacco and health disparities issues. The network will stimulate new studies, challenge existing paradigms, and address significant gaps in research for understudied and underserved populations. NCI partners include Pennsylvania State University and the American Legacy Foundation.

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 Populations Network, “Spirit of Eagles,” funded by NCI. Information requested from the resource center has led to the distribution of over 20,000 pieces of literature and videos each year. 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.

Native American Cancer Registries

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

Now a full member of the SEER Program, the Alaska Native Tumor Registry has been in operation since 1974 in collaboration with NCI and CDC. From the outset, the procedures and policies followed were those of the NCI SEER Program, and the registry received technical assistance from SEER over a number of years.

The problem of scarcity of quality data on cancer incidence, treatment, and survival trends for American Indians is prevalent in Oklahoma, where it is estimated that there is significant under-reporting of cancer mortality among Native Americans. In partnership with the Cherokee Nation of Oklahoma, NCI is funding a pilot cancer registry with the goal of building an infrastructure that will be able to meet the SEER standards in case finding, patient follow-up, data processing, data reporting, and quality assurance. The target population includes all Native Americans residing in the Cherokee Nation's 14-county tribal jurisdictional service area eligible for health care through tribal or Indian Health Service facilities.

The Northwest Tribal Registry Project was developed in January 1999 by the tribally operated Northwest Portland Area Indian Health Board (NPAIHB) in Portland, Oregon. With NCI funding, the registry has completed several record linkages with state cancer registries in Oregon, Washington, and Idaho. The goal is to allow ascertainment of the incidence and prevalence of cancer among Northwest American Indians and Alaska Natives with an accuracy not previously possible. A critical difference between the Northwest Tribal Registry Project and previous linkage studies is the longitudinal focus on building trend data.

Population Surveys

Contact Nancy Breen, PhD, 301-496-4675, breenn@mail.nih.gov

DCCPS funds a number of population surveys and data resources that can be used to research health disparities. The California Health Interview Survey, which has been culturally adapted for and translated into five languages, contains data on the health and health needs of the nation's most racially, ethnically, and linguistically diverse populations. Other surveys and studies that can be used in health disparities research include the NHIS and CPS-TUS surveys, the SEER-Medicare database, and the Healthy Eating and Active Lifestyle (HEAL) Study. NCI has also joined NHLBI to co-fund the Hispanic Community Health Study, a prospective cohort study among four distinct Hispanic communities, which will allow in-depth examination of risk factors unique to these populations and the role of acculturation and community and environmental exposures in the development of risk factors.

PARTNERSHIPS & COLLABORATIONS

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 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.

National Institute on Aging (NIA)

National Institute on Environmental Health Sciences (NIEHS)

- 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.

Centers for Medicare & Medicaid Services (CMS)

- 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. NCI provides technical support to CMS to review the evidence for effective intervention models, collaborated to draft the RFP, plans to disseminate the RFP to cancer control partners, and assists with the evaluation.

U.S. Department of Agriculture (USDA)

- 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.

U.S. Census Bureau

- In a collaboration begun in 1999 with the Census Bureau and other federal agencies, DCCPS is working to overcome the limited availability of sociodemographic information on death certificates and to obtain self-reported racial/ethnic data. This has involved the extension and expansion of the U.S. National Longitudinal Mortality Study (NLMS) and linkage to the National Death Index. Other sponsoring agencies are the National Heart, Lung, and Blood Institute; the National Institute on Aging; and the National Center for Health Statistics. Data are available for major racial/ethnic census groups. The data for a 20-year mortality follow-up from 1979 to 1998 were obtained in 2002, and Phase II expansion of the NLMS data will continue through 2008.

- Another project under development will link SEER to the NLMS to add socioeconomic data at the individual level that cannot be obtained from the SEER database itself. Researchers will use the combined database for estimation of differentials in cancer incidence, survival, and tumor characteristics according to self-reported race/ethnicity, marital status, education, income, occupation and industry, residence, nativity/immigrant status, smoking status, health status, and availability of health insurance.

Notes

Dissemination and Diffusion

The burden of illness imposed on society as a result of cancer represents a major issue in health care throughout the world. As a result, significant resources are directed toward cancer control research. This includes a broad spectrum of basic and applied research in the behavioral, social, and population sciences. Such research covers the continuum of cancer control from prevention to end-of-life care. However, the impact of these advances in cancer control research is limited by the failure to transfer new, evidence-based findings into the widespread delivery of both individual and population health care. Recognition of this problem has prompted research initiatives investigating methods to assist the dissemination of new knowledge to a larger target audience, and the implementation of evidence-based interventions for providers, policy makers, and the general public.

MAJOR INITIATIVES

Cancer Control PLANET

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

As part of a public-private effort, in 2003 NCI launched a 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 help close the research discovery and delivery gap.

Dissemination and Diffusion Supplements

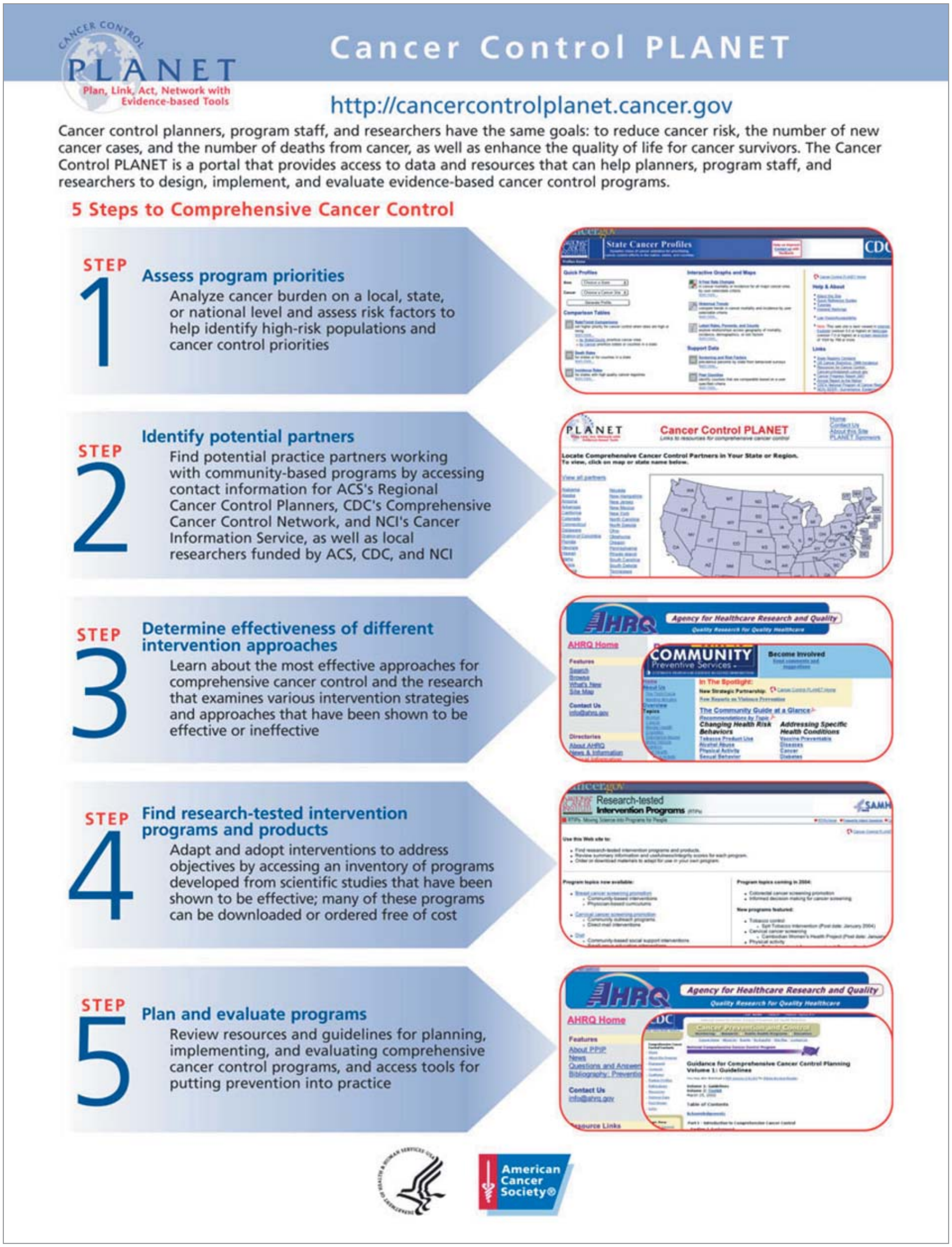
Contact Jon Kerner, PhD, 301-594-6776, jon.kerner@nih.gov

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. A future focus of the supplements program will be the dissemination of surveillance data.

Dissemination and Diffusion Research Program Announcement

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 working with other NIH institutes and offices to plan a program announcement that will build on the success of the supplements initiative. The purpose is 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 and implementation approaches that will increase the adoption of promising intervention programs and products by public and private health and human service systems.



Cancer Control PLANET

http://cancercontrolplanet.cancer.gov

Cancer control planners, program staff, and researchers have the same goals: to reduce cancer risk, the number of new cancer cases, and the number of deaths from cancer, as well as enhance the quality of life for cancer survivors. The Cancer Control PLANET is a portal that provides access to data and resources that can help planners, program staff, and researchers to design, implement, and evaluate evidence-based cancer control programs.

5 Steps to Comprehensive Cancer Control

STEP 1

Assess program priorities

Analyze cancer burden on a local, state, or national level and assess risk factors to help identify high-risk populations and cancer control priorities

STEP 2

Identify potential partners

Find potential practice partners working with community-based programs by accessing contact information for ACS's Regional Cancer Control Planners, CDC's Comprehensive Cancer Control Network, and NCI's Cancer Information Service, as well as local researchers funded by ACS, CDC, and NCI

STEP 3

Determine effectiveness of different intervention approaches

Learn about the most effective approaches for comprehensive cancer control and the research that examines various intervention strategies and approaches that have been shown to be effective or ineffective

STEP 4

Find research-tested intervention programs and products

Adapt and adopt interventions to address objectives by accessing an inventory of programs developed from scientific studies that have been shown to be effective; many of these programs can be downloaded or ordered free of cost

STEP 5

Plan and evaluate programs

Review resources and guidelines for planning, implementing, and evaluating comprehensive cancer control programs, and access tools for putting prevention into practice

PARTNERSHIPS & COLLABORATIONS

Office of Communications, Cancer Information Service (CIS)

- Six CIS regions are testing an improved 5 A Day Program intervention from the CIS Research Consortium, funded by the dissemination and diffusion supplement grant program.

Agency for Healthcare Research and Quality (AHRQ)

- 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.

- NCI has worked with AHRQ to develop a program announcement for Practice-Based Research Networks (PBRNs) and the Translation of Research Into Practice (TRIP). DCCPS currently co-funds research into methods of disseminating efficacious cancer control interventions. A second round of applications is now being solicited, and one successful test of screening dissemination was funded by AHRQ after a July 2004 review.

- In July 2004, NCI, AHRQ, and VA sponsored the second annual TRIP conference. Conference attendees examine current and national challenges to translating research into practice, share innovative tools and models for implementing research in clinical practice and health policy, and promote knowledge exchange and collaborative partnerships to move research into practice.

Centers for Disease Control and Prevention (CDC)

- 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, NCI and CDC's Division of Cancer Prevention and Control cofund the Cancer Prevention Research Network within CDC's Prevention Research Center program. The effort tests methods of disseminating research findings into practice, including tobacco cessation and screening for colorectal, cervical, and breast cancer.

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 Web-based tool for comprehensive cancer control planning, implementation, and evaluation. The Research Tested Intervention Programs (RTIPs) Web site serves as a doorway to new evidence-based tools that can aid communities in better delivering evidence-based interventions to reduce their cancer burden.

Department of Veterans Affairs (VA)

- NCI collaborates with the VA to promote the translation of research discoveries and innovations into patient care in order to reduce the incidence, late detection, suffering, and mortality from colorectal cancer.

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. This partnership has become a model for national cancer control collaborative efforts.

- 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.

C-Change

- 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.

TOOLS, PRODUCTS, & RESOURCES

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 aims to:

- 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.

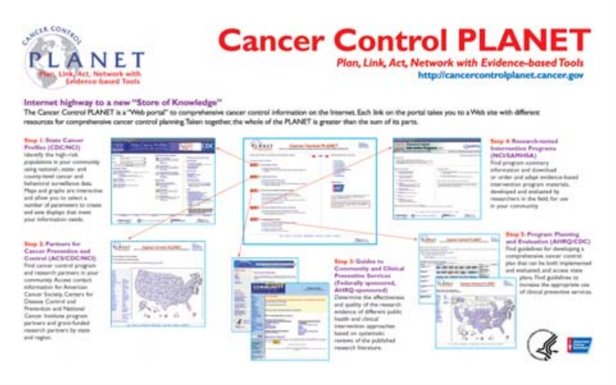
Cancer Control PLANET

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 cosponsored by AHRQ, ACS, CDC, and 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, 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, jointly sponsored by NCI and SAMHSA, was developed with the help of cancer control researchers with peer-reviewed funding. They 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.



Cancer Control PLANET

Plan, Link, Act, Network with Evidence-based Tools

http://cancercontrolplanet.cancer.gov

Internet highway to a new "Store of Knowledge"

The Cancer Control PLANET is a "Web portal" to comprehensive cancer control information on the Internet. Each link on the portal takes you to a Web site with different resources for comprehensive cancer control planning. Taken together, the whole of the PLANET is greater than the sum of its parts.

Step 1: State Cancer Profiles (CDC/NCI) Identify the high-risk populations in your community using national-, state- and county-level cancer and behavioral surveillance data. Maps and graphs are interactive and allow you to select a number of parameters to create and save displays that meet your information needs.

Step 2: Partners for Cancer Prevention and Control (ACS/CDC/NCI) Find cancer control program and research partners in your community. Access contact information for American Cancer Society, Centers for Disease Control and Prevention and National Cancer Institute program partners and grant-funded research partners by state and region.

Step 3: Guides to Community and Clinical Preventive Services (Federally sponsored, AHRQ-sponsored) Determine the effectiveness and quality of the research evidence of different public health and clinical intervention approaches based on systematic reviews of the published research literature.

Step 4: Research-tested Intervention Programs (NCI/SAMHSA) Find program summary information and download or order and adapt evidence-based intervention program materials, developed and evaluated by researchers in the field, for use in your community.

Step 5: Program Planning and Evaluation (AHRQ/CDC) Find guidelines for developing a comprehensive cancer control plan that can be both implemented and evaluated, and access state plans. Find guidelines to increase the appropriate use of clinical preventive services.

SBIR 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.

Research Outcomes: Directory of Developed Products

Diverse Populations

?Take Charge: For Men Newly Diagnosed With Prostate Cancer? and ?Prostate
Gerardine Wurzburg, BA, MA

Adaptive MammaCare?
Mark Kane Goldstein, PhD

Breast Health Over 60
Robin Y. Wood, EdD, RN

Interactive Multimedia Breast Cancer Education Kiosk
Armando Valdez, PhD

Kidz with Leukemia: A Space Adventure
Judith K. Jones, MD, PhD

Prostate Cancer: Your Decision Notebook
Susan G. Brink, MSHA, DrPH

Designing for Dissemination

http://cancercontrol.cancer.gov/d4d

The Designing for Dissemination 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 Progress Report

http://progressreport.cancer.gov

One important leadership function of NCI is to ensure that information on the nation's progress against cancer is widely disseminated to the public. The 2003 and forthcoming 2005 updates to the *Cancer Progress Report*, first published in 2001, are a critical part of that process. This single Web site provides up-to-date information on topics across the cancer continuum—from disease prevention to the impact of deaths from cancer—and tracks the successful application of cancer research into practice. This reference is unique in the data it reports, and in the comparisons it provides to the nation's Healthy People 2010 goals.

While presented in a manner that is accessible to the public, the *Cancer Progress Report* is also designed to be useful to decision and policy makers.

CANCER PROGRESS REPORT - *2003* Update

The *Cancer Progress Report* is about our nation's progress against cancer. The information presented on this site was gathered through a collaborative effort with other key agencies and groups, such as the Centers for Disease Control and Prevention and the American Cancer Society. The report was first issued in 2001, and will be updated again in late 2005. The 2003 update is available online only.

Suggested Citation

Report-at-a-Glance
- Overview of major conclusions
- Summary tables and trends for all measures
- Comparisons to Healthy People 2010 objectives

Prevention
- Tobacco & alcohol use
- Diet & nutrition, weight
- Sun protection
- Environment

Treatment
- Clinical trials
- Outcomes research

Early Detection
- Breast cancer screening
- Cervical cancer screening
- Colorectal cancer screening

Life After Cancer
- Survival
- Costs of cancer care

Diagnosis
- Incidence
- Stage at diagnosis

End of Life
- Mortality
- Person-years of life lost

Suggested Citation: *Cancer Progress Report - 2003 Update*, National Cancer Institute, NIH, DHHS, Bethesda, MD, February 2004, http://progressreport.cancer.gov/.

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Rachel Ballard-Barbash, MD, MPH

Associate Director, Applied Research Program

Biosketch

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. 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 90 peer-reviewed publications and five 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, is NCI's representative on the NIH Obesity Research Task Force, and is active in several NCI committees examining health services, quality of care and outcomes research.

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, four 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 from 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 as well as supporting research to identify measures relevant to cancer treatment.

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 timely 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

Biosketch

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

NCI's Surveillance Research Program (SRP) 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.

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.

Defining and Codifying Surveillance Research

Ten years ago, NCI's perspective on a comprehensive system that measured the cancer burden throughout the cancer control continuum was considered a desirable but unattainable goal. However, after a decade of planning and expert review performed in collaboration with many 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 combine 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-old program, SEER is a source of information on long-term national trends. It is the only source for population-based data on cancer survival and prevalence. Its coverage has grown from nine geographic areas in 1973 to 18 at present, representing 26 percent of the U.S. population. This coverage complements the National Program of Cancer Registries (NPCR) managed by the CDC. Collaborative reports from SEER and NPCR are issued annually, an accomplishment resulting 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.

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. SEER's most notable recent activities include publication of the *Collaborative Staging Manual* jointly with the American College of Surgeons Commission on Cancer and the NPCR. Collaborative Staging requires that a carefully selected set of data items be used by all central and hospital registries in the U.S. and Canada, making possible the largest compilation of cancer registry data ever achieved. In addition, deployment has begun of a new Data Management System within SEER to facilitate the collection and reporting of new cancers. SEER*Rx, an interactive database of antineoplastic drugs was released in July 2005. The application was developed as a one-step lookup for coding oncology drug and regimen treatment categories in cancer registries. The program is free and can be downloaded from the SEER Web site. The databases are scheduled to be updated every six months. By standardizing ways in which information is collected and processed, these projects have brought SRP closer to its informatics objectives.

To better monitor the differential cancer burden experienced by various population groups, SRP joined with the Applied Research Program in 2004 to commission "Methods for Measuring Cancer Disparities: A Review Using Data Relevant to Healthy People 2010 Cancer-Related Objectives," which delineates and documents potential ways to define and monitor cancer-related health disparities. The report will be published as an NCI Monograph. In addition, the targets for the HP 2010 cancer objectives are being evaluated by the Cancer Intervention and Surveillance Modeling Network (CISNET), a cooperative group of grantees funded to model cancer trends as a function of cancer control interventions and optimal cancer control planning.

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. These include a continuing interest in geospatial approaches to the analysis of cancer data, including new methods for data visualization. A workshop on geographic information systems was recently held in collaboration with the Library of Medicine, during which we solicited programmatic input from users of our geospatial products.

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, and they are easily accessible through a number of Web sites. SRP sponsored another innovative workshop to advise and instruct representatives from the cancer advocacy community in the use of cancer statistics. As part of the follow up to the workshop, we will collaborate with the Cancer Information Service to develop distance learning modules for use by cancer advocates and others seeking to use SEER data in their work.

Other transagency collaborations, for example the National Longitudinal Mortality Study, provide research databases for investigations into the social determinants of diseases such as cancer. We expect to expand the opportunities for analysis of these collaborations. Support for State Cancer Profiles will continue to provide a Web-based system of interactive graphs and maps that facilitates greater local use of cancer data.

With improvements in both the cancer surveillance databases and their accessibility, we expect many exciting developments over the coming years.

Jon F. Kerner, PhD

Deputy Director, Research Dissemination
and Diffusion

Biosketch

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 funded investigator and peer reviewer, Dr. Kerner also served as the first chair of the NIH Community Prevention and Control Study Section (now Community-Led Health Promotion Study Section) for NIH.

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 the *American Journal of Public Health*; *Cancer*; *Cancer Epidemiology, Biomarkers and Prevention*; and the *Journal of Women's Health*. Dr. Kerner is currently NCI's representative to the NIH Prevention Research Coordinating Committee, 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, and the Healthy People 2010 Progress Review Committee.

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.

Despite large increases to NIH and NCI budgets in the intervening years, this challenge remains—particularly as the NIH and NCI budgets have flattened out. If we are to increase the demand by patients and their families, practitioners, the public health practice community, and the public for additional investments in science and the use of evidence-based cancer control interventions, we must demystify cancer research. Three approaches to accomplishing this 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 and implementation.
- 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 creating science and evidence-based interventions that are compelling. NCI's Translating Research into Improved Outcomes (TRIO) program was initiated to:

1) Better communicate cancer surveillance data to motivate action and track progress. For example:

- State Cancer Profiles was launched in April 2003 on the Cancer Control PLANET Web portal to facilitate easy access by public health practitioners to state and county cancer incidence and mortality data and behavioral risk factor data. In April 2004, at the request of thousands of users, data from additional cancer sites were added to State Cancer Profiles, and in May 2005 a county mortality mapping feature was added to facilitate graphic communication of cancer burden within states.
- The 2005 on-line Cancer Progress Report will provide users with a menu to select sections of the report they wish to print, and the ability to print pocket size versions of any portion of the report for greater dissemination flexibility.

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. For example:

- DCCPS is working with AHRQ and HRSA as well as the other PLANET partners (ACS, CDC) to develop an innovative Web service that will link to primary care offices' electronic medical records, providing patient specific contact sheets and patient education materials at the point of clinical care. CLIPs (Clinicians Linking Information to Patients) will also provide local referral resources for cancer prevention and control services.

3) Identify special regional and local partnership opportunities for model programs to address significant infrastructure barriers to the adoption of evidence-based cancer control.

- DCCPS worked with ACS and CDC to develop a new Web site entitled CancerPlan.org. This Web site will provide states a forum for sharing their best practices and finding state and local resources for comprehensive cancer control. As such, it is designed to complement the research-tested information available on the Cancer Control PLANET Web portal, with the information based on field experiences at the state and local levels.

Integrating the lessons learned from science with the lessons learned from public health and clinical practice experience is the key to closing the gap between research discovery and program delivery. To ensure a continued public interest in discovery, NCI must continue to grow its investment in supporting partnerships with public health and clinical practice delivery systems that reach all people at risk of developing, suffering, and dying from cancer.

> ***"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."***

Linda Nebeling, PhD, MPH, RD, FADA

Associate Director (Acting), Behavioral Research Program

Biosketch

Linda Nebeling, PhD, MPH, RD, FADA has been the acting associate director of the Behavioral Research Program since August 2004. Before serving in this role, she was the chief of the Health Promotion Research Branch since 2000 and acting chief since 1998. Before coming to DCCPS, she was a nutritionist in the Cancer Control Research Branch/5 A Day Program from 1996-1998 and was an NCI Cancer Prevention Fellow from 1992-1996, both in the former Division of Cancer Prevention and Control. She has worked as a research assistant in the Department of Nutrition, Case Western Reserve University, and as a clinical dietitian at Memorial Sloan-Kettering Cancer Center in New York.

Dr. Nebeling received her PhD in nutrition from Case Western Reserve University in 1992. She received her MPH from the Johns Hopkins School of Public Health and Hygiene in 1993, and completed her dietetic internship at Memorial Sloan Kettering Cancer Center in 1984. Her research has focused on the relationship between fruit and vegetable consumption in different population groups, carotenoid intake, and cancer risk. In 2001, she was awarded the status of Fellow of the American Dietetic Association.

Dr. Nebeling has served on numerous committees on the executive board of the Oncology Nutrition Dietetic Practice Group, American Dietetic Association, and was Chair in 1999-2001. She is a past member of the editorial board of the *Journal of the American Dietetic Association* and is a reviewer for a number of professional journals.

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, lack of exercise, and under use of effective cancer screening tests account for a large proportion of the national cancer burden. 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. Expanding efforts to modify lifestyle behaviors that impact energy balance address certain risks for select cancers and other chronic diseases related to obesity.

NCI's Behavioral Research Program (BRP) is a global leader in transdisciplinary 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.

In 1998, when the Behavioral Research Program was founded, 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 national 5 A Day Program, as well as the American Stop Smoking Intervention Study (ASSIST) project, which provided the foundation for CDC's National Tobacco Control Program.

With the establishment of BRP, 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, anthropology, consumer health informatics, physical activity and energy balance, skin-cancer prevention, policy analysis, neuroscience, psychometrics, and behavioral genetics. Today, BRP is home to nationally and internationally recognized senior leaders in behavioral science. They 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 real-time data technologies that make the systems function most effectively.

From its inception, 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, USDA, the NIH Office of Behavioral and Social Sciences Research, other NIH institutes, non-governmental organizations such as ACS and RWJF, and corporate partners when appropriate. For example, trans-agency partnerships have been established to explore key issues in energy balance and cancer risk, evaluate efforts to lessen tobacco products' harmful effects, and to understand long-term maintenance of behavior change and effective strategies for achieving sustainable healthy behaviors. Indeed, achieving the HHS goal for HealthierUS 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 as we strive to create a future that is free from the burden of cancer.

> ***"NCI's Behavioral Research Program is a global leader in transdisciplinary behavioral science."***

Julia H. Rowland, PhD

Director, Office of Cancer Survivorship

Biosketch

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 and health 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 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 many a chronic illness and, for growing numbers of people, a curable disease. In the absence of other competing causes of death, current figures indicate that for adults diagnosed today, 64 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 to be 10.1 million in the United States, represents a clear challenge to NCI. These individuals and their family members 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 grant 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. Among these risks are 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 health care providers negotiate the treatment decision making process.

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 40 percent 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 nature and impact of different patterns of followup 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 needed to optimize outcomes, we must find ways to communicate this knowledge to those who need it most: diverse health care providers, and survivors themselves. 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.

- **Evaluation.** Identifying appropriate methods and metrics for tracking our success in improving outcomes for all cancer survivors will be critical if we are to monitor progress in eliminating suffering and death due to cancer.

NCI will continue to guide and champion significant advances in our capacity to understand and enhance cancer survivorship. Through strengthening partnerships with professional and service delivery organizations and advocacy communities, our capacity to translate research from discovery to delivery will accelerate. 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

Biosketch

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 the 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 national 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 Extramural Division Directors Committee, and the Trans-NIH Tobacco Research Group. Dr. Trapido has authored over 70 peer-reviewed publications.

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 affects cancer, and for elucidating how this susceptibility interacts with environmental factors 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. 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 mitigating 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.

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 both 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 for cancer.

A major 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 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, and many cancer sites now have developing consortia, including brain, lung, and non-Hodgkin's lymphoma.

EGRP also created, funds, and provides leadership for multi-institution registries of cancer patients and their families, and of 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 epidemiologic studies and issues. For example, it has supported research 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 the 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.

> ***"The maturing consortia that EGRP supports are truly moving science forward, and definitive findings on both the interaction between genes and the environment and the development of cancer are expected shortly."***

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