

National Cancer Institute

Division of
Cancer Control
and Population
Sciences



2006 Overview and Highlights

U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES

National Institutes
of Health

Division of Cancer Control
and Population Sciences

2006 Overview and Highlights

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Foreword

Robert T. Croyle, PhD

Director, Division of Cancer Control and Population Sciences



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 surprise that the disciplines of epidemiology and biostatistics are

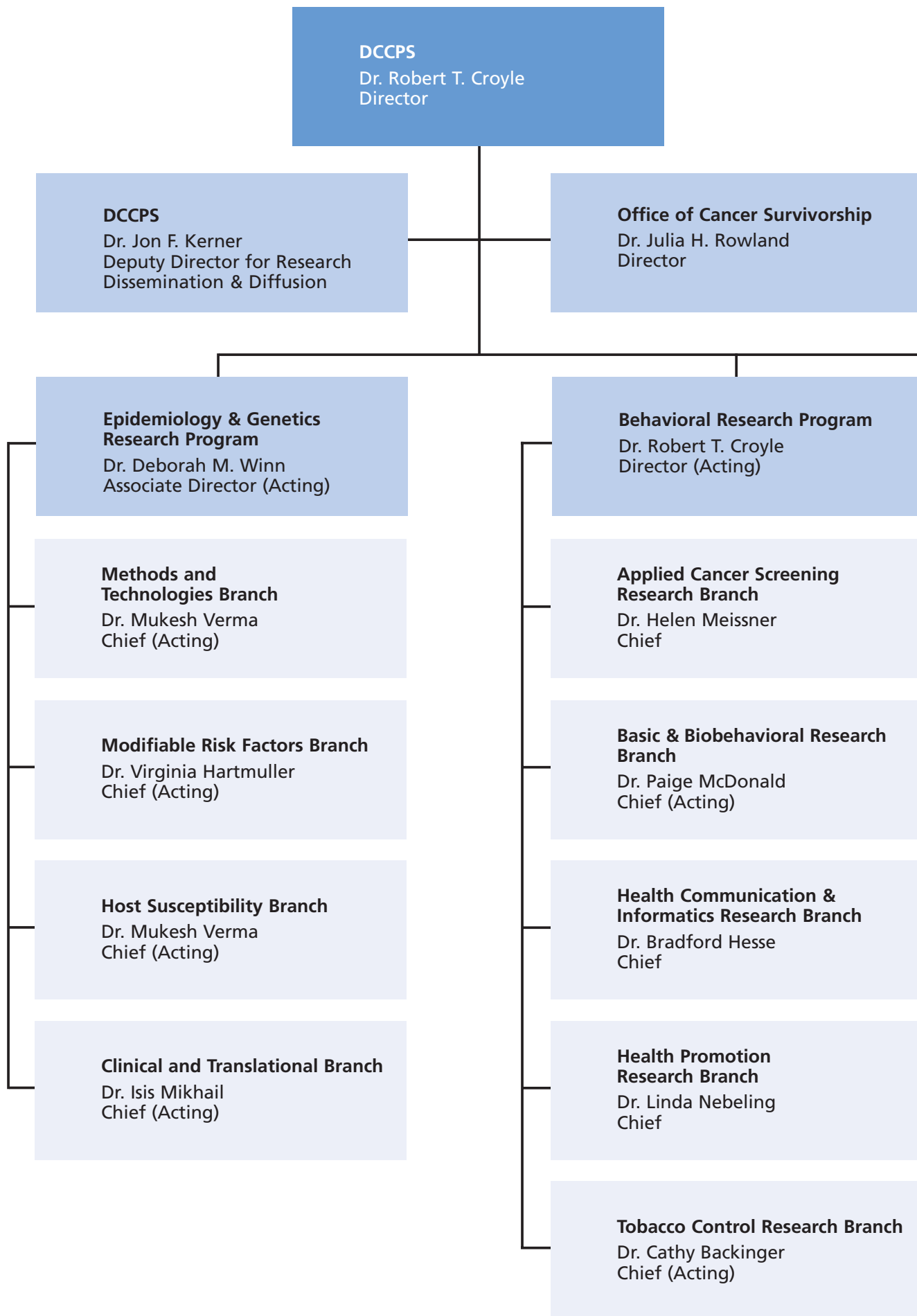
DCCPS is what many have referred to as a ‘hybrid’ division—one that funds a large portfolio of grants and contracts, but also conducts original research to inform public health policy.

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.

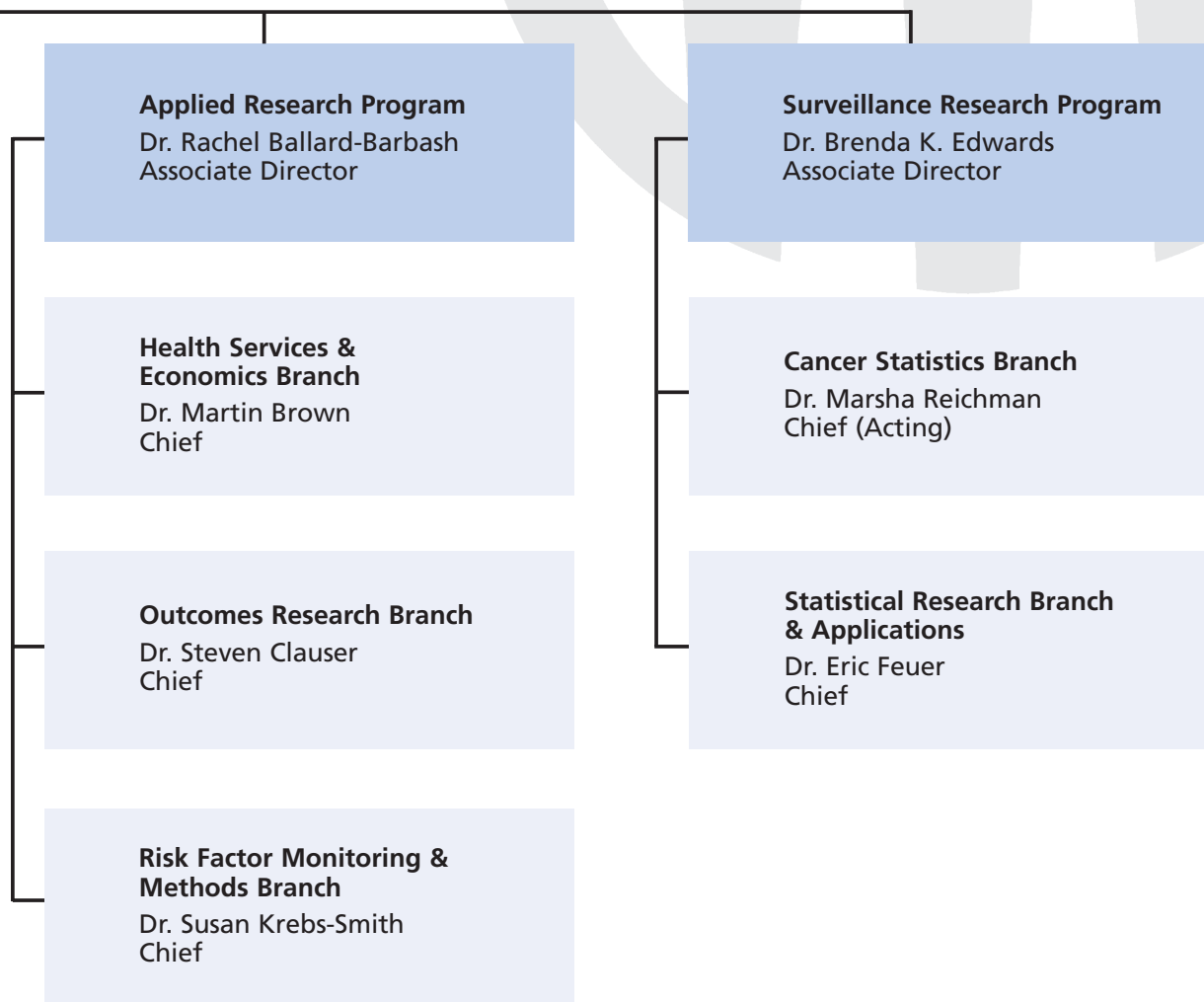


About Our Division

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 116-127.



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
Buckley, Denise	ELS
Carpenter, Everett	
Croyle, Robert	PhD
Cusano, Mary	
Cynkin, Laurie	MHS
Dold, Georgia	
Felix, Augustina	
Grauman, Dan	MS
Hall, Kara	PhD
Hartge, Trisha	MA, ScD
Kerner, Jon	PhD
Kuan, Judy	MS
McNeill, Kate	MA
Prabhu Das, Irene	PhD
Sanchez, Arline	
Srinivasan, Shobha	PhD
Trapido, Ed	ScD
Uy, Annabelle	MS
Vandor, Stacey	MPA
Vinson, Cynthia	MPA

Office Of Cancer Survivorship

Aziz, Noreen	MD, PhD, MPH
Bellizzi, Keith	PhD, MPH
Jeffery, Diana	PhD
Rowland, Julia	PhD
Sufian, Meryl	PhD
Valle, Carmina	MPH

EPIDEMIOLOGY & GENETICS RESEARCH PROGRAM

Office of the Associate Director

Choudhry, Jay	MA
Horn-Cruder, Diane	

Seminara, Daniela	PhD, MPH
Winn, Deborah	PhD

Methods and Technologies Branch

Fox, John	MPH
Verma, Mukesh	PhD

Modifiable Risk Factors Branch

Hartmuller, Virginia	PhD, RD
Harvey, Chinonye	MPH
Reid, Britt	DDS, PhD
Sansbury, Leah	PhD, MSPH
Starks, Vaurice	

Host Susceptibility Branch

Arena, Fernando	MD, PhD
Lemrow, Shannon	PhD
Rogers, Scott	MPH
Schully, Sheri	PhD
Verma, Mukesh	PhD

Clinical and Translational Branch

Kasten, Carol	MD
Lynch, Shannon	MPH
Mikhail, Isis	MD, MPH, Dr.PH

BEHAVIORAL RESEARCH PROGRAM

Office of the Associate Director

Batey, Pat	
Becker, Joan	BS
Croyle, Robert	PhD
Grant, Yvonne	
Moser, Richard	PhD
Permuth-Levine, Rachel	MSPH
Vennell, Nicole	MSW

Tobacco Control Research Branch

Augustson, Erik	PhD, MPH
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
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
Finney-Rutten, Lila	PhD, MPH
Hesse, Bradford	PhD
Woolley, Sabra	PhD

Health Promotion Research Branch

Agurs-Collins, Tanya	PhD, RD
Atienza, Audie	PhD
Nebeling, Linda	PhD, MPH, RD, FADA
Yaroch, Amy	PhD

Basic & Biobehavioral Research Branch

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

SURVEILLANCE RESEARCH PROGRAM

Office of the Associate Director

Edwards, Brenda	PhD
Flagg, Elizabeth (Betsy)	
Garson, Amy	
Harshman, Terri	
Meersman, Stephen	PhD
Swan, Judith	MHS

Cancer Statistics Branch

Adamo, Margaret	RHIT, CTR
Eisner, Milton	PhD
Horner, Marie-Josephe	MSPH
Johnson, Carol	CTR
Kosary, Carol	MA
Lewis, Denise	PhD, MPH
Miller, Barry	DrPH
Percy-Laurry, Antoinette	MSPH
Reichman, Marsha	PhD, MA
Ries, Lynn	MS
Ruhl, Jennifer	
Stinchcomb, David	MA-Geo/MSCS

Statistical Research & Applications Branch

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

APPLIED RESEARCH PROGRAM

Office of the Associate Director

Ambs, Anita	MPH
Ballard-Barbash, Rachel	MD, MPH
Berrigan, David	PhD, MPH
Dowling, Emily	MHS
McLaughlin, Wendy	MSW, MPA
Potischman, Nancy	PhD
Solomon, Janice	
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
Reedy, Jill	PhD, MPH, RD
Subar, Amy	PhD
Thompson, Frances	PhD, MPH
Troiano, Richard	PhD
Wideroff, Louise	PhD

Outcomes Research Branch

Arora, Neeraj	PhD
Clauser, Steven	PhD
Han, Paul	MD, MPH, MA
Reeve, Bryce	PhD
Smith, Ashley	PhD, MPH

ADMINISTRATIVE RESOURCE CENTER

Brown, Steve
Curington, Tina
Daly, Marilyn
Garvey, Anne
Kashanchi, Mary
Newball, Kim
Osborne, Joy
Schneider, Vicky
Turner, Rhonda
Wolfe, Rosemary

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.

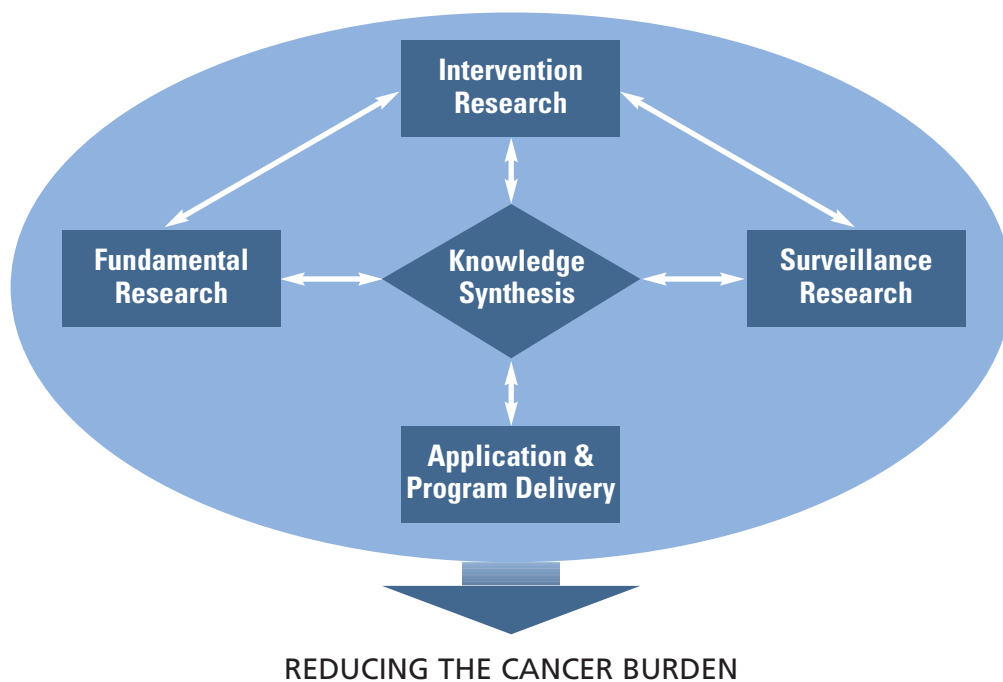
Definition

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



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

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

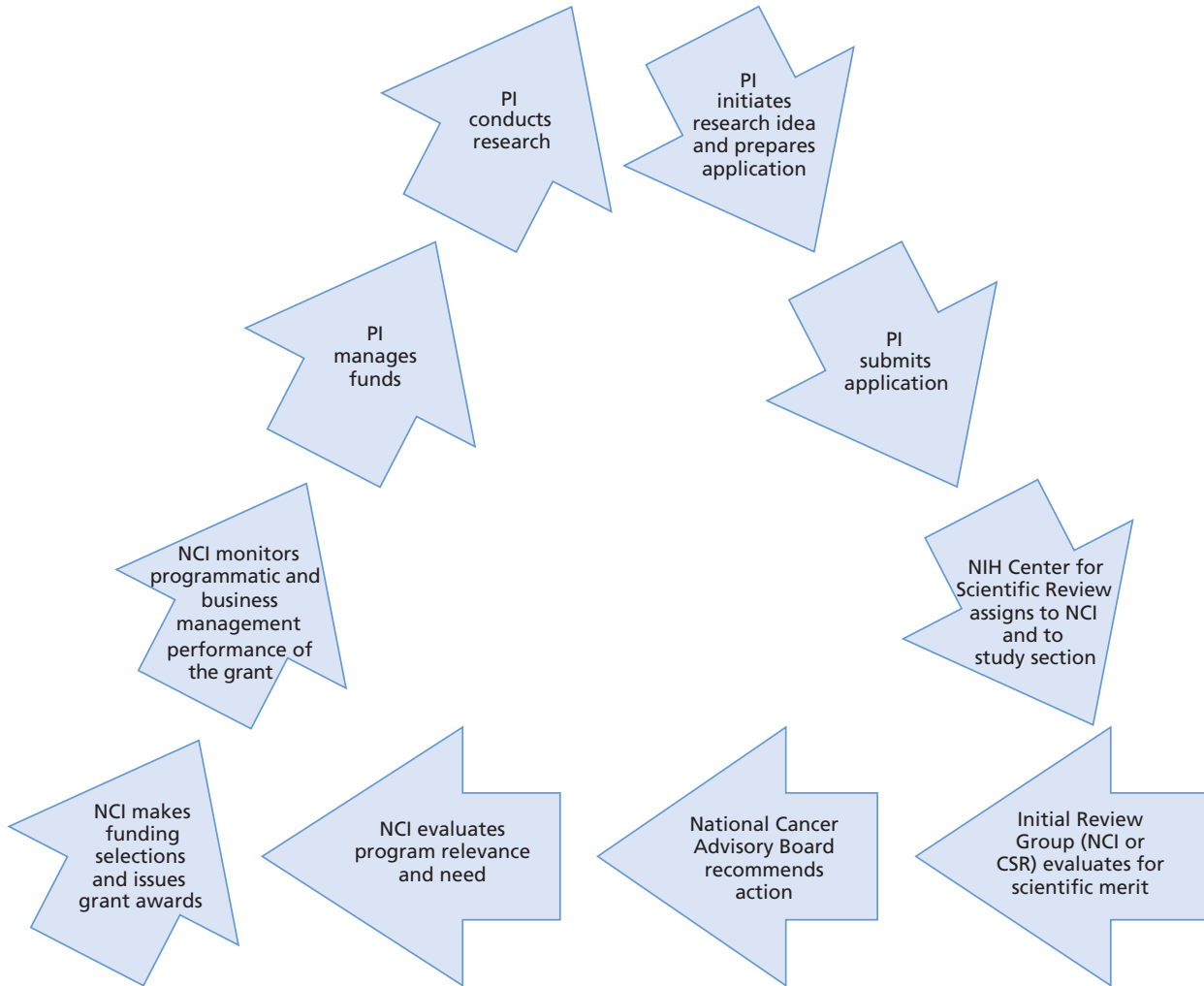
- Explain the NCI and NIH philosophy, grant and contract policies, and system of reviewing and awarding research applications
- Identify resources for locating funding opportunities and the best NIH institute or center for the potential funding of a project idea
- Describe grant and contract mechanisms 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
- Review progress reports to identify exciting and compelling scientific results



Grants Process Overview



PRINCIPAL INVESTIGATOR (PI)



Adapted from Everything You Wanted To Know About the NCI Grants Process, revised August 2005.

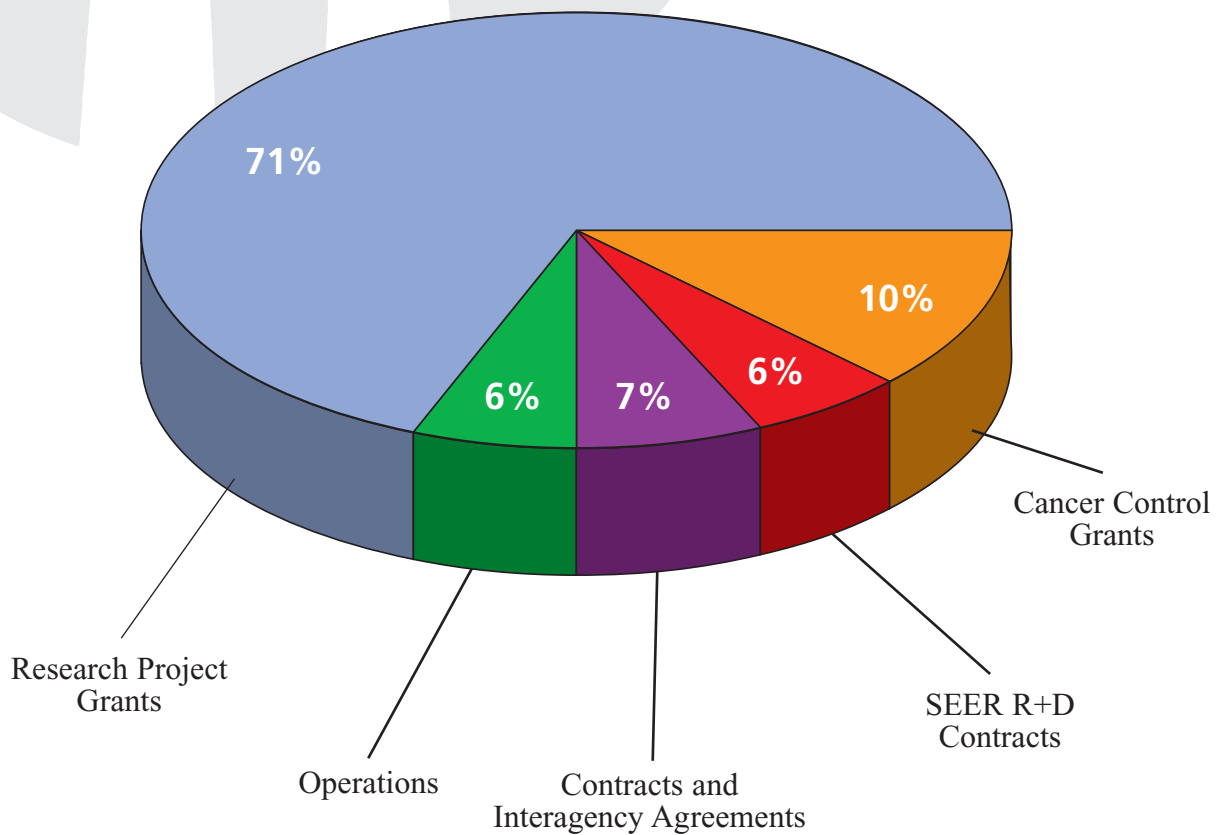


Research Grants & Contracts

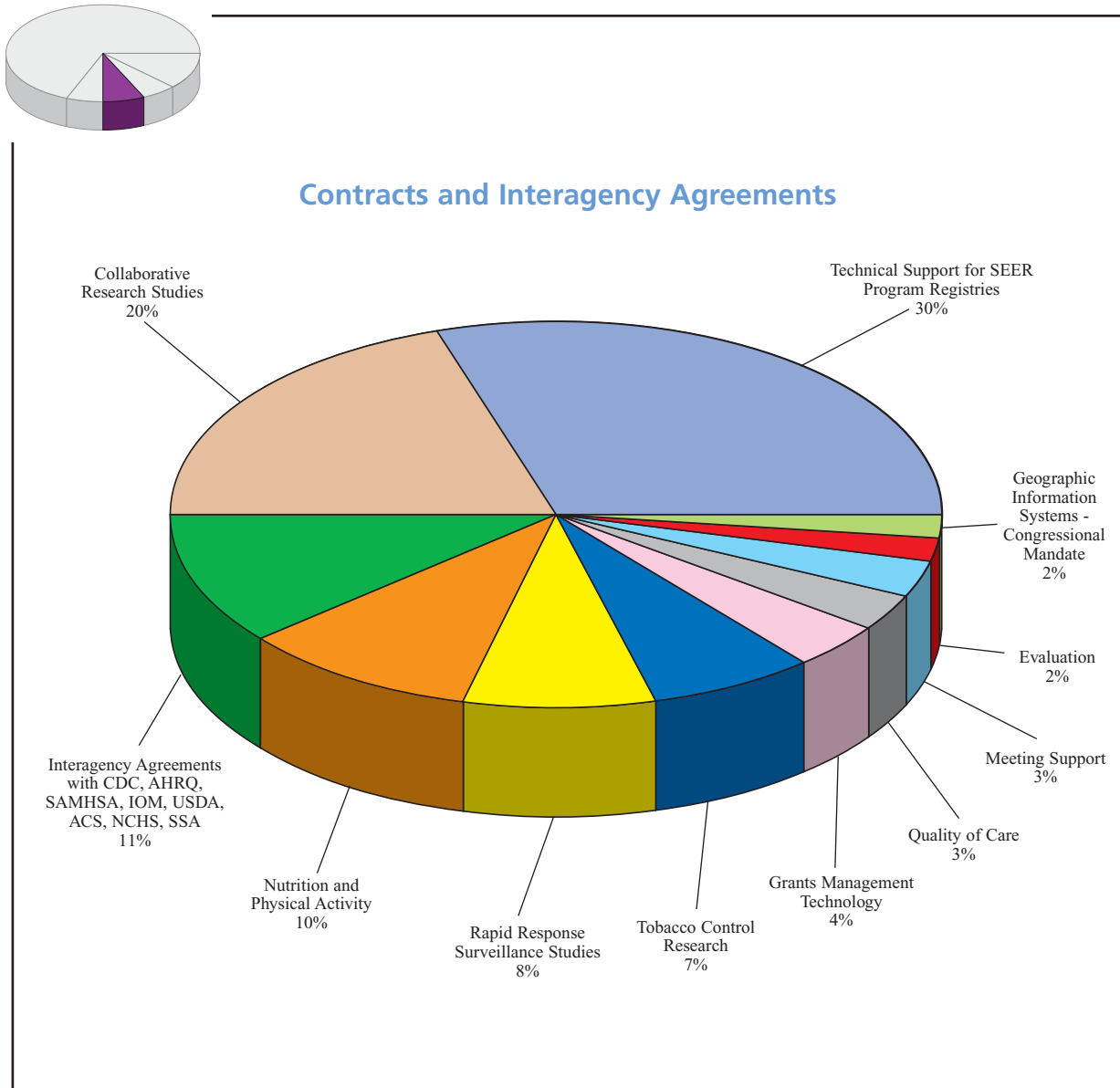
THE RESEARCH ENTERPRISE OF CANCER CONTROL

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 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.

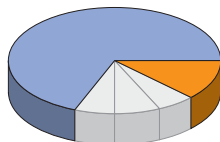
Research Funding and Support Dollars
Total Funding = \$490M



Approximately \$34M of DCCPS resources is 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.

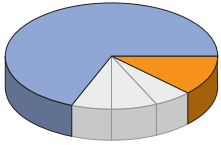


Research Grants & Contracts

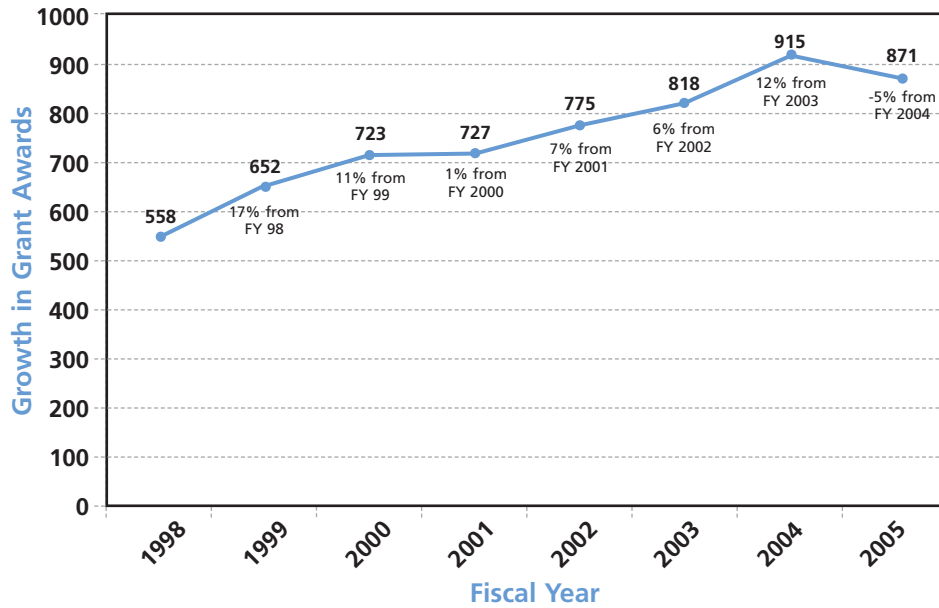


Grant Funding by Mechanism Fiscal Year 2005

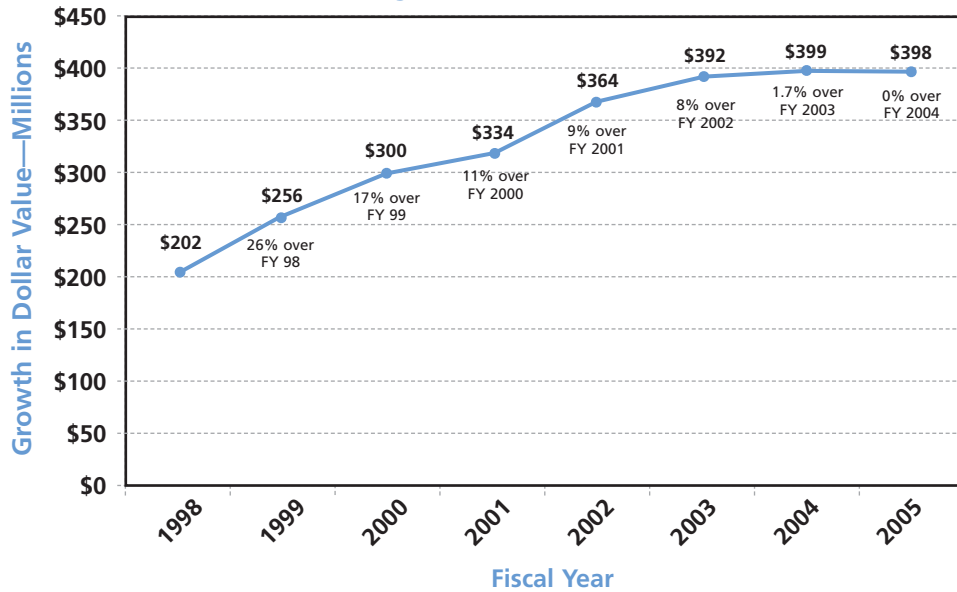
MECHANISM	# OF GRANTS AWARDED	TOTAL DOLLARS
R01-Research Project Grant	508	\$257,617,195
R03-Small Research Grant	131	\$9,771,767
R13-Conference Grant	14	\$628,670
R15- Academic Research Enhancement Award (AREA)	2	\$316,821
R21-Exploratory/Development Grant	84	\$12,420,475
R24-Resource-Related Research Project	2	\$540,587
R37-Method to Extend Research in Time Award (MERIT)	3	\$4,079,794
R42- Small Business Technology Transfer (STTR) Grant- Phase 1	1	\$752,738
R43-Small Business Innovative Research Grant (SBIR) Grant - Phase I	4	\$560,033
R44-Small Business Innovative Research Grant (SBIR) Grant - Phase II	16	\$5,986,663
P01-Research Program Project Grant	13	\$21,221,257
U01-Research Project - Cooperative Agreement	66	\$46,401,372
U19- Research Program - Cooperative Agreement	1	\$5,716,864
U54- Specialized Center – Cooperative Agreement	4	\$9,409,186
U24-Resource-Related Research Project - Cooperative Agreement	6	\$429,381
P50- Specialized Center Grant	16	\$22,489,844
TOTALS	871	\$398,342,647



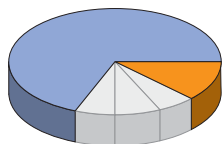
Growth in the Number of DCCPS Research Grant Awards (Fiscal Year 1998–Fiscal Year 2005)



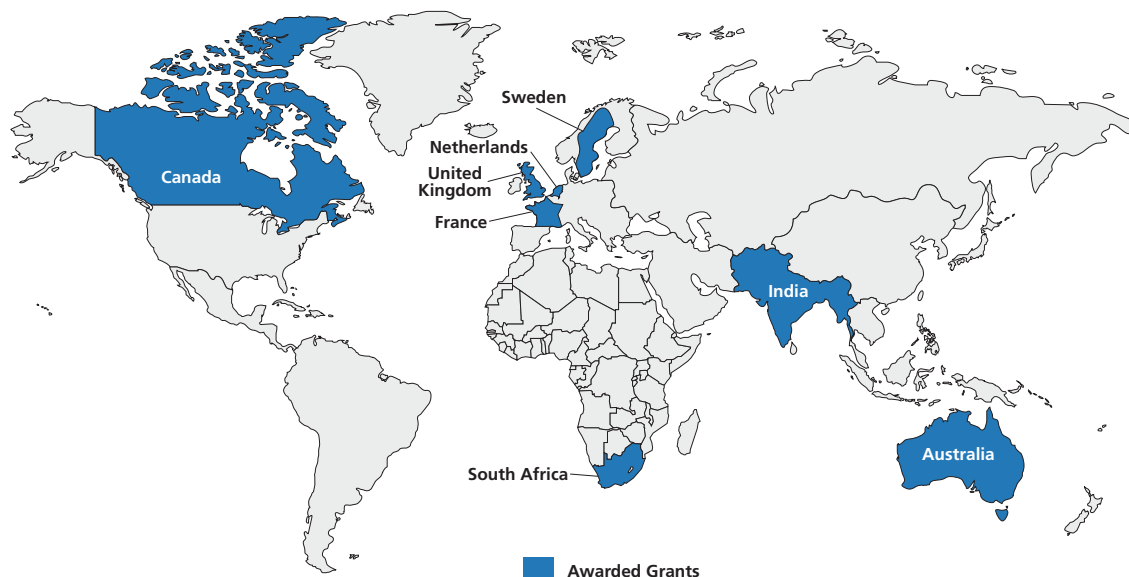
Growth in the Dollar Amount of DCCPS Research Grant Funding (Fiscal Year 1998–Fiscal Year 2005)



Research Grants & Contracts

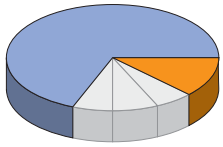


Foreign Countries with Direct Grant Awards (Fiscal Year 2005)

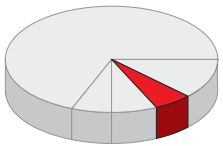
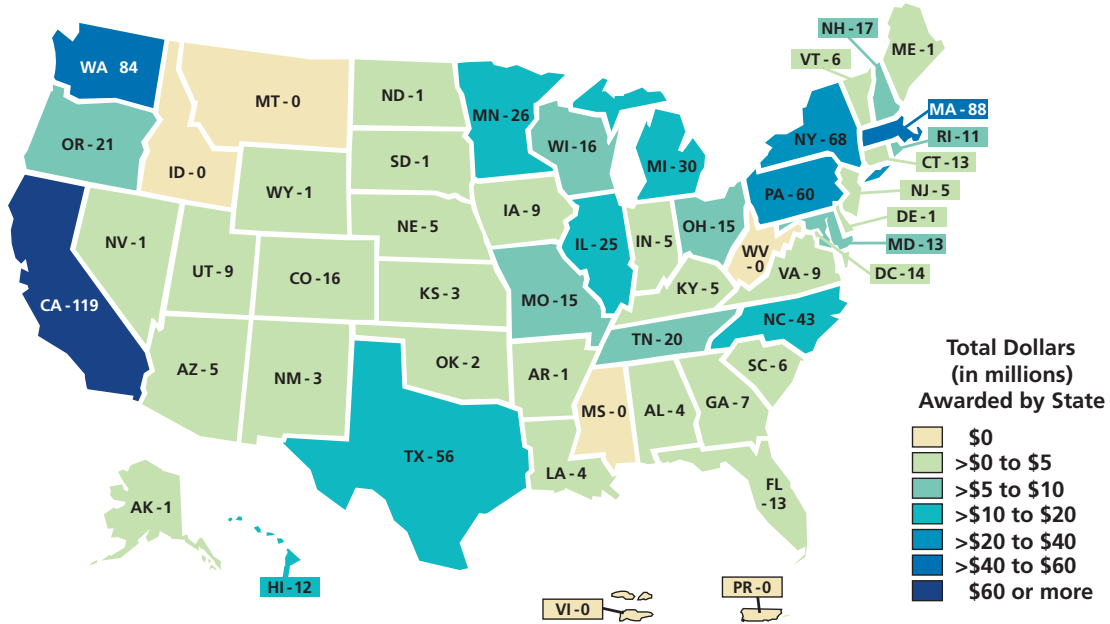


Grants reflected here are direct awards to foreign institutions. There are 23 grants valued at \$8.5M awarded to countries highlighted in the map above and chart below. In addition, there are 85 domestic grants that have a foreign component in 41 countries. The domestic grants with a foreign component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

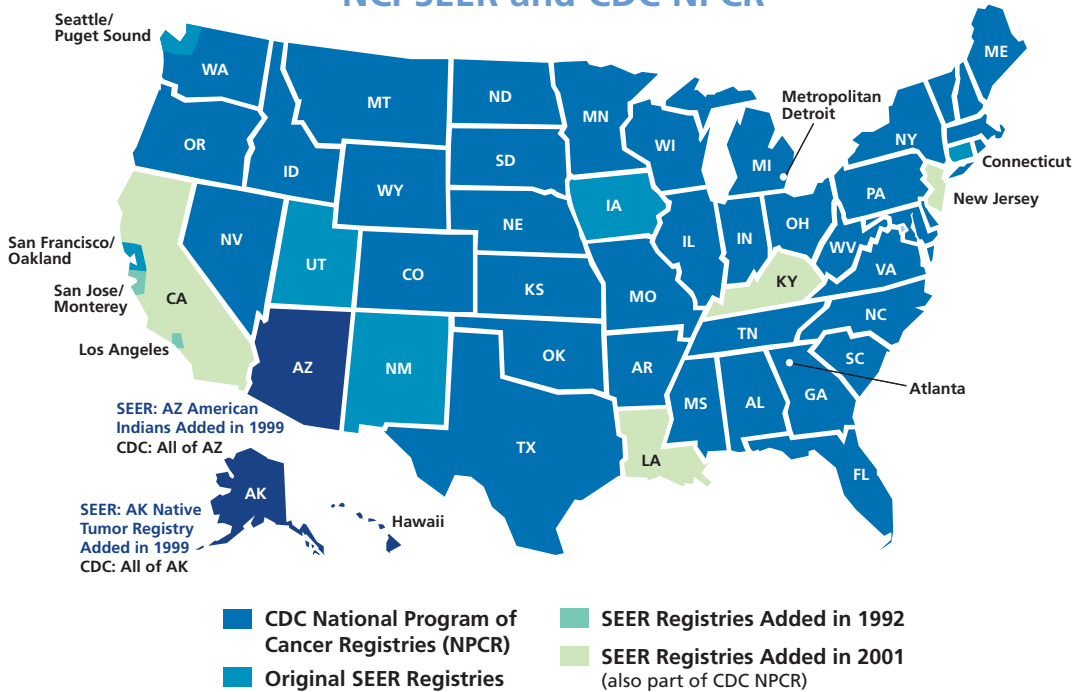
COUNTRY	# OF GRANTS AWARDED	TOTAL DCCPS DOLLARS
Sweden	5	\$1,621,862
France	5	\$1,333,349
United Kingdom	2	\$162,000
Canada	5	\$5,448,085
Australia	5	\$3,060,643
Netherlands	1	\$182,507
South Africa	1	\$48,600
India	1	\$200,813
Israel	1	\$54,000
TOTAL	26	\$12,111,859



DCCPS Grants by State



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.

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

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.

- 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
- CISNET: The “Spectrum” of Breast Cancer Disparities, 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 Zaubler, Memorial Sloan-Kettering Cancer Center
- Coordinating Center for Colorectal Microsimulation, Ann Zaubler, Sloan-Kettering Institute for Cancer Research
- A Trial-Based MISCAN Model for Prostate Cancer, Harry J. De Koning, Erasmus Medical 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 registries 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 developed and validated a more accurate method for predicting cancer mortality counts. This method was instituted by ACS beginning with the 2004 edition of *Cancer Facts and Figures* and continuing with the 2005 and 2006 editions.

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>

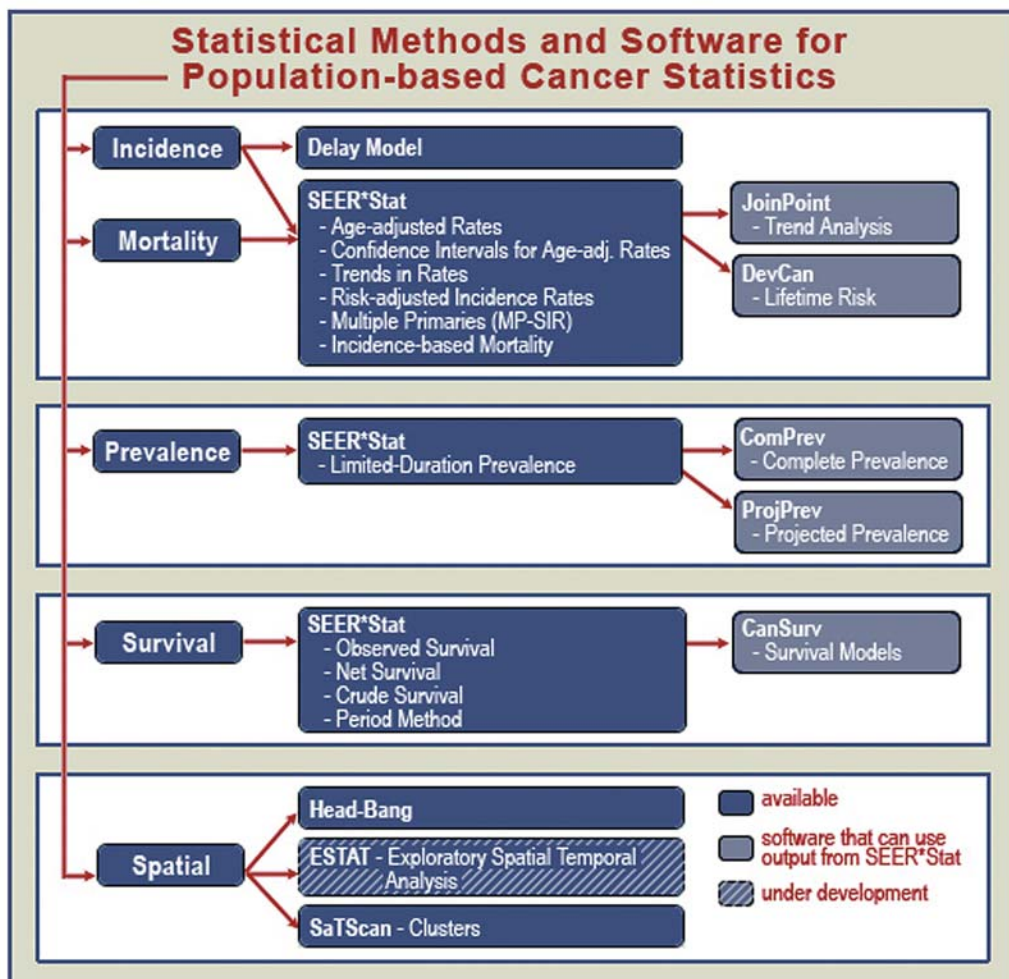
SEER Web site

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 **DE**veloping **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 more than 55,000 households selected from all 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 included questions about screening for breast, colorectal, cervical, and prostate cancers, as well as sun avoidance. The 2005 survey included 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. CHIS is unique in that it provides sufficient data on certain populations, such as Asians and Pacific Islanders, to permit improved analyses. CHIS responses are geocoded and can be linked to real data such as the Census or Area Resource File so that contextual analyses can be performed.

NCI has funded cancer control content and provided scientific expertise to CHIS since its inception. The survey is housed at the UCLA Center for Health Policy Research and conducted in collaboration with the California Department of Health Services and the Public Health Institute.

RECENT SCIENTIFIC ADVANCES

Annual Report to the Nation

DCCPS has worked with the nation's other leading cancer organizations to report that the long-term decline in overall cancer death rates continued through 2003 for all races and both sexes combined, and the rate of new cancers is holding steady. The "Annual Report to the Nation on the Status of Cancer, 1975-2003, Featuring Cancer among U.S. Hispanic/Latino Populations," published in the October 15, 2006, issue of *Cancer*, finds that the declines were greater among men (1.6 percent per year from 1993 through 2003) than women (0.8 percent per year from 1992 through 2003). Death rates decreased for 11 of the 15 most common cancers in men and for 10 of the 15 most common cancers in women. The authors attribute the decrease in death rates, in part, to successful efforts to reduce exposure to tobacco, earlier detection through screening, and more effective treatment, saying that continued success will depend on maintaining and enhancing these efforts.

The report includes a special section on cancer among U.S. Latino/Hispanic populations. It is the most comprehensive coverage of cancer information for this large and rapidly growing ethnic group and is based on

90 percent of the U.S. Latino population. The report finds that for 1999 to 2003, Latinos had lower incidence rates than non-Hispanic whites (NHW) for most cancers, but were less likely than the NHW population to be diagnosed with localized stage disease for cancers of the lung, colon and rectum, prostate, female breast, and cervix. However, Latino children have higher incidence rates of leukemia, retinoblastoma, osteosarcoma, and germ cell tumors than do non-Latino white children.

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

Howe, H.L., Wu, X., Ries, L.A., Cokkinides, V., Ahmed, F., Jemal, A., Miller, B., Williams, M., Ward, E., Wingo, P.A., Ramirez, A., Edwards, B.K. (2006). Annual Report to the Nation on the Status of Cancer, 1975-2003, Featuring Cancer among U.S. Hispanic/Latino Populations. *Cancer*. October 15, Vol. 107, Issue 7.

National Cancer Surveillance Moves Closer to Goal

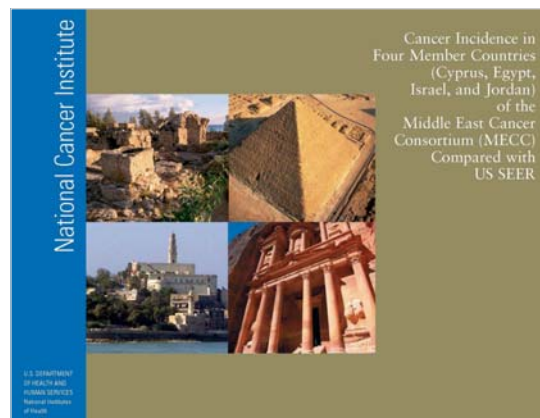
In a major step toward coordination of cancer surveillance efforts in the United States, the organizations involved in national surveillance have developed a framework to enhance their systems to meet increased demands for data and to effectively address program planning, evaluation, and research on 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.

Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER

In 1996, the Ministers of Health of Egypt, Israel, Jordan, Cyprus, and the Palestinian Authority (PA) signed an agreement to establish the Middle East Cancer Consortium (MECC). Turkey joined the Consortium in 2004. This is the first comprehensive publication of the MECC Cancer Registration Project. The monograph presents information about cancer incidence for populations in Cyprus, Egypt (Gharbiah Region), Israel (Jews and Arabs), and Jordan for the period 1996-2001. The MECC findings are compared with those from the U.S. Surveillance, Epidemiology, and End Results (SEER) Program.



Freedman, L.S., Edwards, B.K., Ries, L.A.G., Young, J.L. (eds). (2006). *Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel, and Jordan) of the Middle East Cancer Consortium (MECC) Compared with US SEER*. National Cancer Institute. NIH Pub. No. 06-5873. Bethesda, MD.

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.

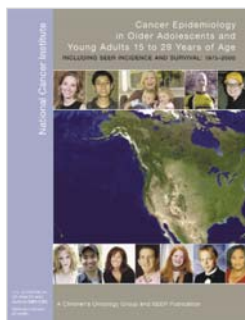
Breast cancer mortality rates in women have been declining at the same time as breast cancer incidence rates, mammography rates, and use of effective adjuvant therapy have been increasing. Recent reports have called into question the results of randomized controlled trials, which examined the value of 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).

Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, including SEER Incidence and Survival: 1975-2000

This monograph is the first to collect detailed information about cancer incidence and outcomes in adolescents and young adults (AYA). It was developed to gather population-based incidence, mortality, and survival data specific to cancers that occur in the AYA population, along with epidemiological data and risk factors for the development of age-specific cancers. The monograph is intended to help educate medical providers and the public about cancer incidence and survival in this age group, and provide the impetus for further research to improve the survival and the quality of life of these young people.



with special assistance from the Adolescent and Young Adult (AYA) and Epidemiology Committees, volunteer editors and authors from NCI, NCI-sponsored adult cancer cooperative groups (Southwest Oncology Group, Eastern Cooperative Oncology Group, Cancer and Leukemia Group B, National Surgical Adjuvant Breast and Bowel Program, American College of Surgeons Oncology Group), and NCI-Designated Comprehensive Cancer Centers.

Bleyer, A., O'Leary, M., Barr, R., Ries, L.A.G. (eds). (2006). *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD.

The publication was prepared by the NCI's SEER Program and the Children's Oncology Group (COG),

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 have evidence that genes as well as environmental and behavioral factors jointly contribute to cancer risk. 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 Deborah Winn, PhD
301-594-9499, winnde@mail.nih.gov

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 how their life exposures to a wide variety of environmental, nutritional, and social factors 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 and Colon Cancer Family Registries

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

The Breast and Colon Cancer Family Registries (CFR) studies support research to identify genetic changes that predispose individuals to breast 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 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:

- Ontario Cancer Genetics Network, Irene Andrulis, Cancer Care Ontario
- Utah Cooperative Breast Cancer Registry at Huntsman Cancer Institute, Sandra Buys, University of Utah

- Family Risk Assessment Program at Fox Chase Cancer Center, Mary Daly, Fox Chase Cancer Center
- Australian Breast Cancer Family Registry, John Hopper, University of Melbourne
- Metropolitan New York Registry, Mary Beth Terry, Columbia University
- Northern California Cooperative Family Registry for Breast Cancer, Esther John, Northern California Cancer Center

Colon:

- Ontario Familial Colorectal Cancer Registry, Steven Gallinger, Cancer Care Ontario
- USC Consortium, Robert Haile, University of Southern California
- Australasian Colorectal Cancer Family Study, John Hopper, University of Melbourne
- Hawaii Family Registry of Colon Cancer, Loic Le Marchand, University of Hawaii at Manoa
- Mayo Colorectal Cancer Family Registry, Noralane Lindor, Mayo Clinic
- Seattle Familial Colorectal Cancer Registry, John Potter, Fred Hutchinson Cancer Research Center

The Informatics Support Center for the two registries operates under a contract to Research Triangle Institute, David Hall, PhD, Project Director.

Long Island Breast Cancer Study Project

Contact Deborah Winn, PhD,
301-594-9499,
winnde@mail.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 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 another grant from NCI in 2001. Analysis of these data are underway.

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.

To meet the Public Law requirement for a “geographic system,” NCI developed the Geographic Information System for Breast Cancer Studies on Long Island (LIGIS). 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 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.

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 has provided

the supporting infrastructure. In fiscal year 2007, the CGN transitions to operating under a contract.

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 26,000 individuals (16,000 families) are enrolled.

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, Deborah Bowen, 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, Susan Domcheck, 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

The ITG consists of the University of California Irvine, Hoda Anton-Culver; Massachusetts General Hospital, Dianne Finkelstein; and Yale University, Prakash Nadkarni.

Cohort, Case-Control, and Familial Consortia

Contact Daniela Seminara, PhD, 301-594-7344, seminard@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, Imperial College, London

- 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, formal structures often 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 33,730 new cases of pancreatic cancer and 32,800 deaths from this disease in 2006. 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. 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. The grants funded under this program announcement will provide support for pilot projects, testing of new techniques, and/or development of innovative projects that could provide a basis for more extended research.

Pancreatic Cancer Cohort Consortia

Contact Patricia Hartge, ScD, 310-435-3914; hartgep@mail.nih.gov

Pancreatic cancer, very often diagnosed at an advanced stage, ranks fourth among the causes of death from cancer and

carries a poor 5-year survival rate (4%). Genetic variation likely plays a key role, partly through pathways that involve the effects of smoking, obesity, diabetes, and familial history of cancer, the established risk factors. Rapidly developing technology in high-throughput genomic characterization and the creation of a large-scale population research infrastructure offered an extraordinary opportunity to uncover the causes and early markers for pancreatic cancer. With no effective screening test and poorly understood etiology, a genome-wide scan was urgently needed to characterize the genetic profiles of people who subsequently develop pancreatic cancer. Because of the enormous amount of information encoded in the genome, and the millions of possible combinations, a large number of cases and controls must be studied. Because of the high fatality rate, patients enrolled in a cohort study well before their diagnosis are ideal for study. No single study could meet the requirements for such research.

With NCI support and participation, investigators leading 12 prospective cohorts and one clinic-based case-control study formed a consortium to combine the information on more than 2000 pancreatic cancer patients and an equal number of controls (PanScan). Using the DNA collected before diagnosis and stored in study biobanks, the NCI Core Genotyping Facility will analyze a dense set of the most common genetic variants in the human genome, single nucleotide polymorphisms (SNPs) determined by the International HapMap Project. The panel of markers includes an estimated 550,000 SNPs and serves as markers for about 90 percent of all common SNPs in Caucasians. After completion of PanScan, similar studies can be conducted in other populations.

SNPs that are highly likely to be markers for genetic variants related to pancreatic cancer risk are expected to emerge from this study and lead to further studies of gene-gene, gene-environment, and gene-lifestyle interactions. In addition, PanScan may provide a foundation for subsequent research on understanding familial pancreatic cancer. This understanding also may lead to future investigations of fine mapping, resequence, and functional characterization of plausible causal variants. Systematic pursuit of the combined effects of genetic variants and behavioral and environmental exposures holds great promise for revealing the underlying mechanisms of cancer development.

PanScan, an initiative of the Cohort Consortium, was funded by the Epidemiology and Genetics Research Program in DCCPS in the fall of 2006.

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.

Centers for Disease Control and Prevention (CDC)



- DCCPS is participating in a global network of genetic and molecular epidemiology consortia, the Network of Investigator Networks (NoN). The network aims to bring interdisciplinary large-scale science to bear on advancing human genome epidemiology. It is a resource to share information, provide methodological support, develop inclusive overviews of specific fields, and facilitate rapid confirmation of findings. The network was launched by the Human Genome Epidemiology Network (HuGENet), an initiative led by the CDC's National Office of Public Health Genomics.
- 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

NCI is leading a national initiative to systematically address and resolve the pressing problem of limited availability of carefully collected and controlled, high-quality human biospecimens annotated with essential data and properly consented for broad investigational use. The NCI-Wide Biorepository Coordinating Committee, with representation from each division, presented *First-Generation Guidelines for NCI-Supported Biorepositories* to the National Cancer Advisory Board in the fall of 2005. The board approved the guidelines, and they were published in the *Federal Registry* in the spring of 2006 to seek public comment. NCI's Office of Biorepositories and Biospecimen Research (OBBR), with assistance from the committee, is reviewing the comments and will distribute the guidelines widely when finalized (biospecimens.cancer.gov).

DCCPS and its grantees have extensive experience in overseeing biorepositories, maximizing their scientific value, and had major input in development of the guidelines. One critical issue raised by them is the need to identify the appropriate level of access for investigators to biorepositories associated with population science studies. To address this issue, division scientists are part of a working group that is identifying the key issues involved in an access policy and collecting many examples of such policies from the scientific community.

Biorepositories are crucial to progress in cancer research. 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, research by Dr. Paul Brennan, a DCCPS grantee with the International Agency for Research on Cancer (IARC), is a tangible example of the value of combining questionnaire and biological data to further our knowledge of chemoprevention. Recent chemical analyses have identified isothiocyanates as one chemopreventative component of cruciferous vegetables. However, only about 30% of people who consume the recommended number of servings of

cruciferous vegetables reap their chemopreventative rewards. Using blood donated by study participants who also answered questions about their cruciferous vegetable intake, Dr. Brennan and his colleagues identified two genes whose activity correlates with chemoprevention. When active, these genes rapidly metabolize isothiocyanates and reduce their chemopreventative effects, but when the genes are inactive (in about 30% of the population), they are unable to metabolize isothiocyanates and the individual benefits from their protective effects.

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. The NCI-supported Consortium of Cohorts has fostered harmonization of biospecimen handling and analysis in its ongoing Breast and Prostate Cancer Cohort Consortium (BPC3 Study) and in emerging projects on pancreatic cancer and multiple myeloma. For cutting-edge genomic studies, a single prospective cohort would not have enough cases of a particular cancer. By pooling their data and biospecimens, however, a consortium can have a sufficient study population to identify gene-environment interactions that would otherwise go undetected. The fundamental strength of these consortia is the intelligent use of their data coupled with the biological analyses of the collected biospecimens.

Most importantly, population scientists respect the privacy and intentions of the participants who have donated their biospecimens to research. Principal investigators of these studies serve as stewards of the data and specimens. They protect the rights and privacy of the participants.

The collection of biospecimens is crucial to understanding relationships between environmental exposures and genetic composition. Stewardship of biospecimens and their associated data is paramount.

TOOLS, PRODUCTS & RESOURCES

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 geographic, 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.

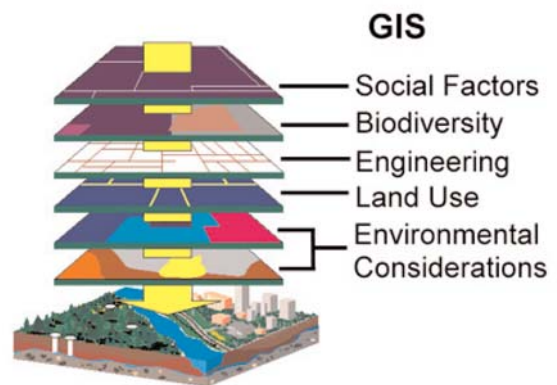
The LI GIS is of potential interest to many researchers. It can be used to study relationships between environmental exposures and breast cancer and other diseases, as well as to develop new or improved research methods, such as statistical techniques or exposure assessment methods.

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. Fourteen awards are currently funded in the division.



Geographic Information System Overview

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



Geographical Information Systems (GIS) and Cancer Research Brochure

The DCCPS brochure *Geographical Information Systems (GIS) and Cancer Research* provides an introduction to GIS for cancer researchers who do not currently use the technology in their work. The brochure includes information on how to use GIS in cancer research, applications for specific areas of research, resources available, research and funding opportunities, and examples of landmark studies. It explains how NCI can help researchers use GIS by providing tools to analyze spatial patterns and trends, and to evaluate the impact of cancer control interventions, as well as geographic, social, behavioral, genetic, and health care delivery factors on the cancer burden.



RECENT SCIENTIFIC ADVANCES

Striking Ethnic Discrepancies Seen in Smoking-Related Lung Cancer Risk

Lung cancer is more likely to develop in cigarette smokers who are African American or Native Hawaiian than in smokers who are white, Japanese American, or Latino, according to research by Christopher Haiman, ScD, of the University of Southern California, and colleagues. The findings are especially noteworthy because of the study's large size and its far broader ethnic and racial representation than other studies. The research team analyzed lung cancer incidence among 183,813 African American, Japanese American, Latino, Native Hawaiian, and white men and women from the Multiethnic Cohort Study (MEC) of more than 215,000 individuals in California and Hawaii. In the analysis, 1,979 lung cancer cases were identified between baseline (1993-96) and 2001.

Among those who smoked fewer than 30 cigarettes per day, risks for African Americans and Native Hawaiians were significantly greater than for the other groups. The difference between groups was particularly evident among those who smoked 10 or fewer cigarettes per day. Among those who smoked 10 cigarettes or fewer a day, whites had a 55 percent lower risk of lung cancer than African Americans, and among those who smoked 11 to

20 cigarettes a day, a 43 percent lower risk. For Latinos and Japanese Americans, the percentages were lower still. However, once smoking rates reached 30 cigarettes a day—the equivalent of a pack and a half—or more, the risk difference was minimal. The differences in risk were observed for both sexes and all histologic types of lung cancer. Environmental measures looked at—occupation, diet, and education (as a proxy for socioeconomic status)—could not explain what the researchers called “the striking racial and ethnic differences in the risk of lung cancer associated with cigarette smoking.”

The findings do not change the public health message on the hazards of smoking. Individuals are far more likely to get lung cancer if they smoke, and they can reduce their risks by quitting.

Haiman, C.A., Stram, D.O., Wilkens, L.R., Pike, M.C., Kolonel, L.N., Henderson, B.E., Le Marchand, L. (2006). Ethnic and racial differences in the smoking-related risk of lung cancer. *New England Journal of Medicine*, 354(4):333-42.

Consortium Hunts Low-Penetrance Breast and Prostate Cancer Gene

The research team testing the principle that pooling data and biospecimens across large-scale studies through consortial arrangements is an effective approach to research on genes and the environment describes its approach to searching for low-penetrance breast and prostate cancer genes of the hormone-regulated pathway in *Nature Reviews Cancer*.

The Breast and Prostate Cancer Cohort Consortium, also known as the BPC3 Study, is characterizing variations in approximately 50 genes that mediate two pathways associated with these cancers—the steroid-hormone metabolism pathway and the insulin-like growth factor signaling pathway—and are associating these variations with cancer risk. The BPC3 Study combines the resources of 10 large prospective cohorts; three genomic facilities; and epidemiologists, population geneticists, and biostatisticians from multiple

institutions. Data and biospecimens are being pooled on more than 8,000 cases of prostate cancer and 5,000 cases of breast cancer.

The BPC3 Study is the first research project initiated by the Consortium of Cohorts, a group formed by NCI to address the need for large-scale collaborations in the genetic and molecular epidemiology of cancer.

Hunter, D.J., Riboli, E., Haiman, C.A., Albanes, D., Altshuler, D., Chanock, S.J., Haynes, R.B., Henderson, B.E., Kaaks, R., Stram, D.O., Thomas, G., Thun, M.J., Blanche, H., Buring, J.E., Burt, N.P., Calle, E.E., Cann, H., Canzian, F., Chen, Y.C., Colditz, G.A., Cox, D.G., Dunning, A.M., Feigelson, H.S., Freedman, M.L., Gaziano, J.M., Giovannucci, E., Hankinson, S.E., Hirschhorn, J.N., Hoover, R.N., Key, T., Kolonel, L.N., Kraft, P., Le Marchand, L., Liu, S., Ma, J., Melnick, S., Pharaoh, P., Pike, M.C., Rodriguez, C., Setiawan, V.W., Stampfer, M.J., Trapido, E., Travis, R., Virtamo, J., Wacholder, S., Willett, W.C.; National Cancer Institute Breast and Prostate Cancer Cohort Consortium. (2005). A candidate gene approach to searching for low-penetrance breast and prostate cancer genes. *Nature Reviews. Cancer*, 5(12):977-85.

InterLymph Consortium Investigates Alcohol Consumption and Non-Hodgkin Lymphoma

InterLymph, short for the International Consortium of Investigators Working on Non-Hodgkin Lymphoma Epidemiologic Studies, is an open scientific forum for epidemiologic research in non-Hodgkin lymphoma (NHL) comprised of international researchers who have completed or are conducting ongoing case-control studies. The investigators discuss and undertake research projects that pool data across studies or otherwise undertake collaborative research.

For a recent pooled analysis, InterLymph researchers obtained original data from nine case-control studies totaling 15,175 individuals (6,492 cases and 8,683 controls) from the United States, United Kingdom, Sweden, and Italy to study the association between alcohol consumption and risk for NHL. They found that individuals who drank alcohol had a lower risk of NHL than nondrinkers. Risk estimates were lower for current

drinkers than former drinkers compared with nondrinkers. Risk did not decrease with increasing alcohol consumption, nor did the protective effect vary by type of alcohol consumed, although it did change by subtype of NHL. The lowest risk estimates were for Burkitt's lymphoma. Other studies on alcohol consumption and risk for NHL have yielded inconsistent results, as have studies that have investigated type of alcoholic beverage or subtype of NHL. Further study is warranted to confirm their findings and to determine the biological mechanism for the association, suggest the researchers.

Morton, L.M., Zheng, T., Holford, T.R., Holly, E.A., Chiu, B.C., Costantini, A.S., Stagnaro, E., Willett, E.V., Dal Maso, L., Serraino, D., Chang, E.T., Cozen, W., Davis, S., Severson, R.K., Bernstein, L., Mayne, S.T., Dee, F.R., Cerhan, J.R., Hartge, P.; InterLymph Consortium. (2005). Alcohol consumption and risk of non-Hodgkin lymphoma: a pooled analysis. *The Lancet Oncology*, 6(7):469-76.

Molecular Features of Adult Glioma Detailed

Malignant gliomas in adults represent a highly heterogeneous group of tumors with unknown etiology. Mutations in the *TP53* gene, most likely arising from DNA alkylation, are common in these brain cancers and are associated with various demographic risk factors, including age and ethnicity. Inactivation of the DNA repair protein O6-methylguanine-DNA-methyltransferase (MGMT), which repairs alkylation damage, is associated with *TP53* mutations in human cancers, and several heritable polymorphisms in MGMT have been defined. John Wiencke, PhD, of the University of California at San Francisco (UCSF), and colleagues conducted molecular analyses of 556 glioma tumors (astrocytic) and collected information on *TP53* status, epidermal growth factor receptor (*EGFR*) gene and murine double minute-2 (*MDM2*) gene amplification, and MGMT germline genotype data.

Patients with tumors bearing *TP53* mutations tended to be younger than those whose tumors did not have this mutation, and they were more likely to be nonwhite

(African American and Asian) than Latino and non-Latino white. In addition, *EGFR* gene amplification was associated with an older age of onset (68 years vs. 48 years); carriers of the *MGMT* variant 84Phe allele were less likely to have tumors with *TP53* overexpression; and *EGFR* gene amplification and protein overexpression were inversely associated with the variant *MGMT* allele. An inverse relationship between *TP53* mutation and *MDM2* or *EGFR* amplification was observed. The findings indicate that age, race/ethnicity, and inherited genetic factors are linked to molecular features of glioma, and it seems likely, say the researchers, "that applying these markers in molecular epidemiology studies holds promise in searching out the underlying causes of these cancers."

Wiencke, J.K., Aldape, K., McMillan, A., Wiemels, J., Moghadassi, M., Miike, R., Kelsey, K.T., Patoka, J., Long, J., Wrensch, M. (2005). Molecular features of adult glioma associated with patient race/ethnicity, age, and a polymorphism in O6-methylguanine-DNA-methyltransferase. *Cancer Epidemiology, Biomarkers & Prevention*, 14(7):1774-83.

Oophorectomy Confirmed as Protecting against Breast Cancer in Carriers of *BRCA1* Mutations

Findings from a large study by Andrea Eisen, MD, of Toronto Sunnybrook Regional Cancer Centre, and colleagues demonstrate that bilateral oophorectomy is an effective means of reducing risk for breast cancer in carriers of the *BRCA1* gene mutation, and may be effective for carriers of the *BRCA2* mutation as well. Oophorectomy was found to be associated with a 56 percent reduction in breast cancer in *BRCA1* carriers. A similar but nonsignificant reduction in breast cancer risk was found for *BRCA2* carriers (odds ratio [OR]: 0.57). The strongest effects were observed with oophorectomies performed in *BRCA1* carriers before 40 years of age (OR: 0.36) and for breast cancers that were diagnosed before 40 years of age (OR: 0.53). The protective effect for carriers of both the *BRCA1* and *BRCA2* mutations may be limited to a period of 15 years

following surgery (OR: 0.39). Data were analyzed on 1,439 patients with breast cancer and 1,866 controls from a registry of *BRCA1* and *BRCA2* carriers. These results confirm previously reported findings from smaller studies of women with hereditary susceptibility to breast and ovarian cancer, but go further. Earlier studies were not sufficiently large to estimate the magnitude of risk reduction by age of oophorectomy or by *BRCA1/BRCA2* mutation status, or to measure the duration of the effect.

Eisen, A., Lubinski, J., Klijn, J., Moller, P., Lynch, H.T., Offit, K., Weber, B., Rebbeck, T., Neuhausen, S.L., Ghadirian, P., Foulkes, W.D., Gershoni-Baruch, R., Friedman, E., Rennert, G., Wagner, T., Isaacs, C., Kim-Sing, C., Ainsworth, P., Sun, P., Narod, S.A. (2005). Breast cancer risk following bilateral oophorectomy in *BRCA1* and *BRCA2* mutation carriers: an international case-control study. *Journal of Clinical Oncology*, 23(30):7491-6.

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.

Notes

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 10.5 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 Paul Han, MD, MPH, MA,
301-594-6642, hanp@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. Paul Han, 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.
- In 2004, NIH 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, funded again in fiscal year 2003 for a second cycle, and will be reissued in 2007. 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 Stephen Taplin, MD, 301-402-1483, taplins@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, Diana Miglioretti, 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 Nancy Breen, PhD,
301-496-4675, breenn@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 May 2006. 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 15 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.
- The fourth in a series on translating or increasing the flow of research knowledge into health care practice and policy, the Translating Research into Practice and Policy (TRIPP) 2006 Conference was held in July 2006 by NCI and AHRQ. The conference highlighted strategies and tools for designing interventions to reach and influence different audiences and to promote change in different settings where evidence-based practices might be implemented.
- In collaboration with AHRQ, NCI funded the Health Care Systems as Research Summit in September 2005. The focus of the summit was development and maintenance of delivery-related resources in order to foster collaborations among cancer research and health care delivery organizations. The ultimate goal is to ensure that research is relevant to care, integrated into delivery, and disseminated, to accelerate progress in reducing the burden of cancer.

American Cancer Society (ACS)



- NCI staff participated in the annual meeting of the National Colorectal Cancer Round Table (NCCRT) on November 4, 2005, where they reported NCI's current data on colorectal cancer screening utilization. They also provided updates on current NCI-sponsored colorectal cancer

screening studies, including the Health Plan Survey, CISNET, and the National CT Colonography Trial conducted by American College of Radiology Imaging Network (ACRIN).

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 (NICCCQ) 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 NICCCQ 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.

TOOLS, PRODUCTS & RESOURCES

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. Analysis is under way of 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. Two new national surveys of primary care physicians are currently in the field. One focuses on breast, cervical, colorectal, and lung cancer screening and the second on physicians' characteristics, knowledge, attitudes, and practices related to services for diet, physical activity, and weight control.

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. It 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. 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 practical, cutting-edge applications for developing precise, valid, and efficient measurements of cancer-related outcomes such as pain, depression, and fatigue. Further, IRT methods are used to build "item banks," which serve as the foundation of computerized-adaptive testing (i.e., individually tailored assessment). To introduce IRT and its important applications to clinical researchers, DCCPS developed a tutorial, "An Introduction to Modern Measurement Theory," available at <http://appliedresearch.cancer.gov/areas/cognitive/item.html>. Presentations from a conference focused on IRT applications in health outcomes research can be viewed at <http://outcomes.cancer.gov/conference/irt/>.

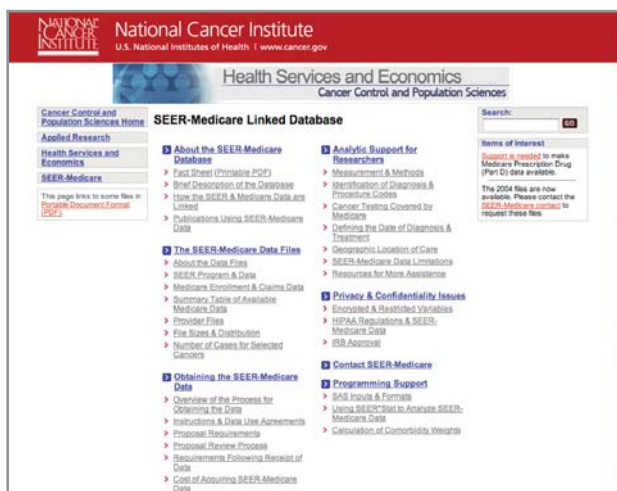
SEER-Medicare Datasets

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

The SEER-Medicare data are a unique resource that can be used for research related to the health care provided to persons with cancer. The database results from the linkage of two large population-based data sources: the Surveillance, Epidemiology, and End Results (SEER) cancer registries data and the Medicare enrollment and claims files. The SEER program collects information about cancer site, stage, and histology for persons newly diagnosed with cancer who reside in one of the SEER geographic areas. Medicare's master enrollment file is used to identify which persons in the SEER data are Medicare beneficiaries. For people who are Medicare eligible, the SEER-Medicare data include claims for covered health care services, including hospital, physician, outpatient, home health, and hospice bills. The SEER-Medicare data include over 2.4 million persons with cancer—its linkage being a collaborative effort of NCI, the SEER registries, and the Centers for Medicare and Medicaid Services (CMS).

SEER-Medicare Health Outcomes Survey Database (SEER-MHOS)

The SEER-MHOS is a research resource designed to improve our understanding of the quality of life of cancer patients and survivors enrolled in Medicare health plans. SEER-MHOS is sponsored by NCI and CMS. The SEER-MHOS linkage has data from 11 SEER registries. The database contains clinical, quality of life, socioeconomic, demographic, co-morbidity and other information from approximately 28,000 SEER-MHOS linked cancer patients and survivors. These both cross-sectional and longitudinal data will enable investigators to systematically investigate health-related quality-of-life (HRQOL) issues in this Medicare population.



RECENT SCIENTIFIC ADVANCES

Performance Benchmarks for Diagnostic Mammography

It is generally accepted that auditing of clinical outcomes for screening and diagnostic mammograms is a useful quality assurance procedure that provides performance parameter feedback both to mammography facilities and to individual interpreting radiologists. However, there is a need for more robust data on the clinical outcomes of diagnostic mammography examinations, in particular.

In a study published in *Radiology*, Edward Sickles and colleagues present a very extensive set of data on diagnostic mammography outcomes and performance benchmarks, among a patient population judged to be representative of the population examined in general radiology practice in the United States, with data designed to be used by mammography facilities and individual radiologists to evaluate their own performance for diagnostic mammography as determined by periodic comprehensive audits.

The investigators used data from the NCI-funded Breast Cancer Surveillance Consortium (BCSC) to evaluate a range of performance parameters for auditing of diagnostic mammography examinations, and to thereby

derive performance benchmarks. The BCSC data reported involve by far the most extensive published experience with diagnostic mammography and are likely to be representative of results in general practice throughout the United States rather than results achieved by highly skilled specialists. The study involved 332,926 diagnostic mammography examinations, 151 mammography facilities, and 646 interpreting radiologists. The overall BCSC outcomes data confirmed the previously reported UCSF observation that diagnostic mammography outcomes vary substantially by indication for examination.

The availability of these clinically relevant comparison data allows practicing radiologists to place into perspective the clinical outcomes observed from their own facility-wide and individual audits, for the purpose of continuing quality improvement through comprehensive audits.

Sickles, E.A., Miglioretti, D.L., Ballard-Barbash, R., Geller, B.M., Leung, J.W., Rosenberg, R.D., Smith-Bindman, R., Yankaskas, B.C. (2005) Performance benchmarks for diagnostic mammography. *Radiology*. 235(3):775-90.

Assessments of Cancer Outcomes

It is critical for oncologists and cancer researchers to understand the human and economic consequences of cancer and to quantify them in meaningful ways. Two recent publications report on assessments of cancer prevention, early detection, treatment, long-term care, and surveillance.

NCI's Cancer Research Network (CRN) fosters research to address important questions best answered by the collaborative involvement of multiple health systems and research centers. The new monograph, *Health Care Systems as Research Platforms: The Cancer Research Network*, released in November 2005, describes the management structure and processes and the data resources used by the network to carry out three core research projects and a variety of other cancer control studies. Three papers in the monograph describe the CRN's efforts to establish a productive consortium, develop its data infrastructure, and evaluate its progress. The remaining papers in the monograph describe findings from the three core projects and some affiliated

research projects. The monograph addresses substantive and methodologic issues on screening, disparities, translation of research into practice, cancer care, risk reduction, and health services, as well as the expanding infrastructure that makes it possible to examine key research questions across multiple healthcare systems. Perhaps most importantly, the monograph highlights and encourages use of the amazing resources present in integrated care systems for researchers.

In the book *Outcomes Assessment in Cancer: Measures, Methods, and Applications*, the Cancer Outcomes Measurement Working Group (COMWG), established by NCI in 2001, focuses on three outcomes (health-related quality of life, patient assessment of and satisfaction with care, and economic burden) and four cancer types (breast, prostate, lung, and colorectal). The working group looks at the full cancer continuum, from prevention and screening to end of life, and pays particular attention to the role of cancer outcomes data in decision making. The 28-chapter book presents the

findings and recommendations of the COMWG members and includes four invited papers covering relevant topics not specifically addressed by the working group. The book also outlines a much needed agenda to improve the scientific quality and usefulness of cancer outcomes measures.

Lipscomb, J., Gotay, C.C., Snyder, C., eds. (2005). *Outcomes Assessment in Cancer: Measures, Methods and Applications*. Cambridge, United Kingdom: Cambridge University Press.

Vogt, T. M., Wagner, E.H., eds. *Health Care Systems as Research Platforms: The Cancer Research Network*. (2005). *Journal of the National Cancer Institute*. Monographs Series, no. 35. Bethesda, MD: Oxford University Press.

Effect of Timing of Screening Mammography on Performance Measures

Little is known as to whether differences in the time since previous mammography affects performance parameters, and very few investigators include sensitivity in their comparisons of measures of screening performance. Bonnie Yankaskas and colleagues used data from the Breast Cancer Surveillance Consortium (BCSC) to evaluate whether there is an association between the number of months since previous mammography and performance measures (sensitivity, specificity, recall rate, cancer detection rate, and positive predictive value) in women who had U.S. community-based screening mammography. The investigators considered more than 1 million routine screening mammographies performed in women 40–89 years old for the years 1996; steps were taken to ensure that

diagnostic mammography was not included. Performance measures increased as months since previous mammography increased, except for specificity, which decreased, and these effects were stronger in older women for all measures except sensitivity. The study results indicate that time between mammograms is an important factor to consider when audits are reviewed or screening performance measures are compared.

Yankaskas, B.C., Taplin, S.H., Ichikawa, L., Geller, B.M., Rosenberg, R.D., Carney, P.A., Kerlikowske, K., Ballard-Barbash, R., Cutter, G.R., Barlow, W.E. (2005) Association between mammography timing and measures of screening performance in the United States. *Radiology* 234(2):363-73.

Employment Outcomes of Men Treated for Prostate Cancer

Cancer screening and early detection results in more men being diagnosed and treated for prostate cancer during their working years. Although early detection and treatment may have positive effects on survival, morbidity related to treatment may interfere with patients' ability to work, at least in the months immediately after treatment. Using the Metropolitan Detroit Cancer Surveillance System, a participant in NCI's SEER program, Cathy Bradley and colleagues studied employment outcomes 6 and 12 months after the diagnosis of prostate cancer in a prospective, population-based, longitudinal cohort of men 30–65 years of age who had been diagnosed with prostate cancer. The investigators compared the likelihood of employment to that of men in two population-based control groups without prostate cancer. The investigators found that patients with prostate cancer were less likely to be working 6 months after their diagnosis than men without prostate cancer. However, at 12 months after diagnosis, the likelihood of employment for prostate cancer patients and control subjects was not statistically significantly different. Some patients reported that cancer and its treatment

interfered with their ability to perform physical and cognitive tasks at work 12 months after diagnosis.

Armed with this information, patients can more effectively plan for extended periods of nonemployment with the optimism that they are likely to be able to return to work 1 year after diagnosis. However, patients employed in physically demanding jobs may experience difficulty performing their usual job tasks. The authors recommend that the impact of cancer and its treatment on employment be considered alongside clinical and quality-of life assessments when patients and physicians make prostate cancer treatment decisions. Data regarding possible periods of nonemployment and reasonable expectations for recovery can be integrated into patient and physician discussions so that a therapeutic regimen that is optimal for both treating the disease and meeting the work-related needs of the patient is selected.

Bradley, C.J., Neumark, D., Luo, Z., Bednarek, H., Schenk, M. (2005). Employment outcomes of men treated for prostate cancer. *Journal of the National Cancer Institute* 97(13):958-65.

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, C.N., 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.

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.

Lackan, N.A., Ostir, G.V., Freeman, J.L., Mahnken, J.D., & Goodwin, J.S. (2004). Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer. *Medical Care*, 42(2), 116-22.

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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, or Pebbles Fagan, PhD, MPH, 301-496-0277, faganp@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 Network on Disparities (TReND)

Contact *Pebbles Fagan, PhD, MPH, 301-496-0277, faganp@mail.nih.gov*

NCI has partnered with the American Legacy Foundation to develop and implement the Tobacco Research Network on Disparities (TReND). The mission of the Network is to understand and address tobacco-related health disparities by advancing the science, translating scientific knowledge into practice, and informing public policy. TReND is designed to stimulate new studies, challenge existing paradigms, and address significant gaps in research on understudied and underserved populations. This is a unique national research network on tobacco and health disparities that offers a forum for stimulating scientific inquiry, promoting scientific collaborations, and evaluating the scientific evidence of research. TReND includes diverse disciplines of researchers who seek to achieve the following goals:

- 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.

Tobacco Research Initiative for State and Community Interventions (TRISCI)

Contact Bob Vollinger, MSPH, 301-496-0275, vollingb@mail.nih.gov

The Tobacco Research Initiative for State and Community Interventions (TRISCI) stimulates research on new or existing tobacco control interventions relevant to state and community tobacco control programs. The initiative supports research on innovative tobacco prevention and control interventions at the community, state, or multi-state level, particularly policy or media-based interventions. TRISCI emphasizes collaboration among tobacco control researchers, state-based comprehensive tobacco control programs, and community-based coalitions.

Funded TRISCI projects relate to state and community tobacco control programs or innovative tobacco prevention and control interventions and include topics such as teen smoking restriction and movie exposure, smoking trajectories and state programs with limited budgets, community-based intervention models, and health care tobacco cessation programs.

Program Announcement on New Tobacco Product Research

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

The U.S. market includes over 1,200 brands of cigarettes that deliver a wide range of nicotine, tar, carbon monoxide, and other toxic agents in tobacco smoke. Recently, there has been proliferation of potential reduced-exposure products (PREPs) that are marketed and promoted by industry claims of implied reduced exposure or harm. However, little is known about the composition of these new products, how they are used, or the impact on users' exposure to harmful tobacco and smoke constituents. In 2004, NCI published a program announcement (PA) entitled "Testing Tobacco Products Promoted to Reduce harm," aimed at fostering investigator-initiated research in this area. The purpose of the PA is to stimulate multidisciplinary research on the chemical composition of tobacco and tobacco smoke, product design characteristics, behavior of use, exposure to toxic agents, addictive properties and differential toxicity, and individual and public health impact of new potential reduced-exposure tobacco products. This funding initiative calls for R01 and R21 application.

There is much to be learned about the potential public health impact of tobacco products new to the market,

both for individual users 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 the composition, use, and effects of PREPs.

Laboratory Research on Tobacco Product Use and Exposure

Contact Mark Parascandola, PhD, MPH, 301-451-5045, paramark@mail.nih.gov; or Mirjana Djordjevic, PhD, 301-496-8584, djordjev@mail.nih.gov

In recent years, the need for research on new tobacco products has been identified by scientific experts, public health organizations, and policy makers. In June 2003, two Congressional hearings cited the need for scientific information from NCI on different types of tobacco products. NCI advisory groups and planning documents have also specifically identified the need for research on the development of new methods related to tobacco products promoted to reduce harm.

In response, NCI awarded a 5-year, \$17 million research and development contract on September 15, 2006, to Georgetown University, "Laboratory Assessment of Tobacco Use Behavior and Exposure to Toxins among Users of New Tobacco Products Promoted to Reduce Harm."

The purpose of this contract is to advance scientific knowledge about the toxic and addictive properties of tobacco products marketed by the tobacco industry with claims that imply reduced harm. In particular, this contract will support research to study the chemical and physical properties of different tobacco products, characterize the ways in which people's behavior affects their exposure to tobacco toxins, and develop methods and biomarkers to measure exposure and risk for tobacco-related diseases. The methods and findings developed under this contract will be made available to a wide range of stakeholders, including the scientific and public health communities, government, policy makers, and the general public.

The scientific methods and resources developed under this contract with Georgetown University will provide essential research infrastructure and leadership to enable scientific advancement worldwide around tobacco products. This contract will support collaborative multidisciplinary research, drawing on expertise from many areas, from chemistry and toxicology to behavioral sciences and epidemiology.

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.

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.

- Since 2004, NCI has been collaborating with WHO’s Tobacco Laboratory Network (TobLabNet) to address research issues related to the establishment of global capacity for tobacco product testing and research. TobLabNet 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.
- In 2006, NCI will be participating in the collaborative project between WHO-TFI and the International Agency for Research on Cancer (IARC) to establish upper limits of toxin emissions in cigarette smoke. To achieve the project goal, TobReg Working Group I has been convened and charged to develop criteria for selection of constituents based on availability of toxicity data, and variability of constituent levels by brand, and developing science-based recommendations for advancing knowledge on tobacco products and their regulation.

Office of Medical Applications of Research (OMAR)

On June 12-14, 2006, NCI co-sponsored the NIH State-of-the-Science Conference “Tobacco Use: Prevention, Cessation and Control” in collaboration with the Office of Medical Applications of Research (OMAR). The goal of the conference was to gain a better understanding of how effective tobacco use prevention and treatment strategies can be developed and implemented across diverse segments of the population.

Noted experts presented research findings on the various aspects of tobacco control, discussing such issues as the role of culture in prevention and cessation programs, policy perspectives and interventions, consumer demand, strategies for specific populations, and health systems changes. In addition, several presenters discussed the need to create innovative prevention and cessation strategies that target specific populations, such as cultural groups (especially black and Latino populations), blue-collar workers, and individuals with low income.

A panel, composed of experts—none involved in tobacco research—from various fields was charged with developing an unbiased state-of-the-science statement that described the evidence currently available as well as the research needed. In developing its statement, the panel considered not only the scientific evidence presented by invited experts in tobacco-control research, a systematic literature review of some of the key aspects of the conference, and written comments submitted in advance of the conference, but also numerous comments and issues raised by members of the audience. More than 600 professionals in health care and health care policy attended the conference and were encouraged to provide public comment.

The panel concluded that tobacco use remains a very serious public health problem. Coordinated national strategies for tobacco prevention, cessation, and control are essential if the United States is to achieve the *Healthy People 2010* goals. Most adult smokers want to quit, and effective interventions exist. However, only a small proportion of tobacco users try treatment. This gap represents a major national quality-of-care problem. Many cities and states have implemented effective policies to reduce tobacco use; public health and government leaders should learn from these experiences.

Because smokeless tobacco use may increase in the United States, it will be increasingly important to understand net population harms related to use of smokeless tobacco. Prevention, especially among youth, and cessation are the cornerstones of strategies to reduce tobacco use. Tobacco use is a critical and chronic problem that requires close attention from health care providers, health care organizations, and research support organizations.

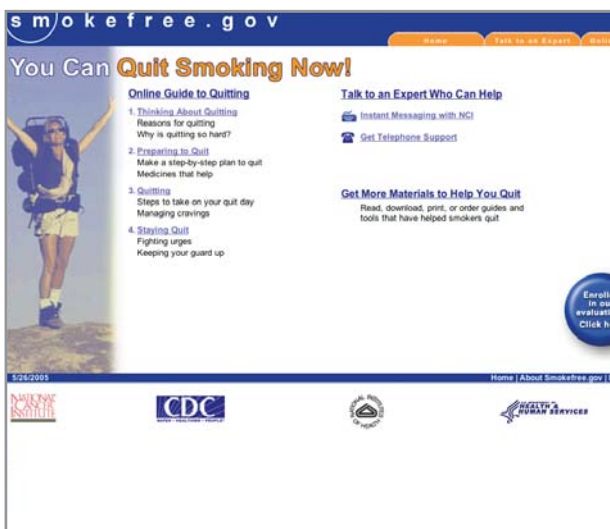
The State-of-the Science Statement, as well as videocasts of each day of the conference, the program, and the abstract book, are all available on the NIH Consensus Development Program website at <http://consensus.nih.gov/>.

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



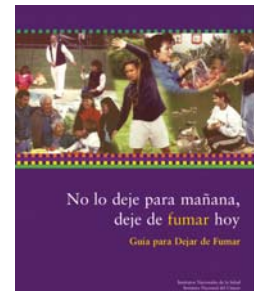
Clearing the Air



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

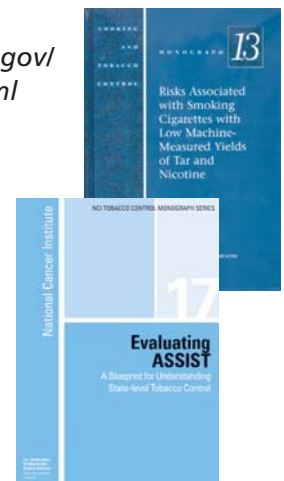
<http://riskfactor.cancer.gov/studies/tus-cps/>

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/tcrblmonographs/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.

NCI Smoke-Free Meeting Policy

smokefreemeetings.cancer.gov

In July 2006, NCI announced a new smoke-free meeting policy requiring that all meetings and conferences organized or primarily sponsored by NCI be held in a state, county, city, or town that has adopted a comprehensive smoke-free policy. The smoke-free meetings policy is effective on January 1, 2007.

Secondhand smoke, also known as environmental tobacco smoke (ETS), passive smoke, and involuntary tobacco smoke, is an important preventable cause of illness and death. Secondhand smoke causes lung cancer and heart disease in adult nonsmokers; serious illnesses such as bronchitis and pneumonia in infants and young children; and reduced birth weight and sudden infant death syndrome (SIDS) in infants of nonsmoking women. While the nation has made tremendous progress in reducing secondhand smoke exposure, many adults and children remain at risk. Smoke-free laws benefit nonsmokers by eliminating exposure to tobacco smoke, and smokers by providing an environment that encourages and facilitates quitting.

To facilitate straightforward smoke-free meeting planning, DCCPS has developed the Smoke-Free Venue Locator Tool. This interactive online resource assists NCI staff in finding smoke-free venues based on up-to-date smoking policy information for states and local jurisdictions within states.

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'-nitrosornicotine (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 is 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.

Exposure to Smoking in Movies Linked to Youth Smoking

It has long been acknowledged that social influences are the primary reason that children try smoking. Social influences include family and friends smoking, tobacco advertising, and images such as those contained in entertainment media. The relative contribution of entertainment media in promoting smoking has not been studied extensively.

A study by Dr. James Sargent and colleagues at Dartmouth Medical School found that young people who watched the most smoking in the movies were almost three times more likely to start smoking than their peers who watched the least amount of smoking in movies. This result was found throughout all regions of the country, regardless of race and ethnic group. The results of this NCI-funded study were published in the November 7, 2005 *Journal of Pediatrics*.

The researchers surveyed a total of 6,522 adolescents aged 10 to 14 from across the country using a random-digit telephone dial system. The participants were representative of the U.S. population of adolescents in terms of age, sex, household income, and census region. Using a telephone keypad, respondents indicated which movies they had seen

out of 50 that had been randomly selected from among the top 532 U.S. box office hits between 1998 and April of 2003 (74 percent of which included smoking).

The study showed that exposure to onscreen smoking was an independent, primary risk factor even after accounting for the impact of other known risk factors for smoking such as parental and sibling smoking, smoking by friends, and rebelliousness, among other factors. As a result, Dr. Sargent's research has spurred meetings between state attorneys general and movie industry groups to discuss ways to curb the amount of smoking in movies.

Sargent, J.D., Beach, M.L. Adachi-Mejia, A.M., Gibson, J.J., Titus-Ernstoff, L.T., Carusi, C.P., Swain, S.D., Heatherton, T.F., Dalton, M.A. (2005). Exposure to Movie Smoking: Its Relation to Smoking Initiation among U.S. Adolescents. *Pediatrics* 116 (5):1183-1191.

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.

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.

Basic and Applied Decision Making in Cancer Control

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

Decision making is fundamental to all aspects of cancer care and yet researchers and clinicians have limited knowledge of the ways in which patients and health care providers make critical health decisions. Individuals at risk, patients, and providers face a multitude of decisions across the cancer continuum that may profoundly affect outcomes in a number of domains: life expectancy, treatment outcomes, and overall quality of life. The goal of the Basic and Applied Decision Making in Cancer Control initiative is to enhance understanding of human decision-making processes so that individuals can make more informed and satisfying choices about their health. In order to achieve this aim, it is necessary to draw upon research in basic judgment and decision-making science, and applied behavioral science. For example, decision aids developed to assist patients make complex health decisions should be informed by sound basic science. In addition to evaluating the outcomes of decision aids, it is important to examine those processes that mediate the use of decision aids, such as risk perception, affect, motivation, and social influences. The following Funding Opportunity Announcements (FOA) seek to promote decision-making research that is informed by both basic judgment and decision-making science and applied behavioral science.

The FOA *Decision Making in Health: Behavior Maintenance* invites applications for research projects that will expand 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, and 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 FOA *Decision Making in Cancer: Single-Event Decisions* invites applications for research projects that will 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

Contact Sarah Kobrin, PhD, MPH,
301-435-1505, kobrins@mail.nih.gov

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 interdisciplinary 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.

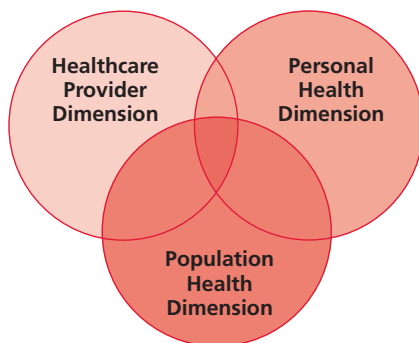
Benefits

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 Health Maintenance Consortium (HMC) studies, co-funded by DCCPS and the American Heart Association, are a continuation of the Behavior Change Consortium (BCC) initiative. The HMC brings together behavioral health experts to understand the long-term maintenance of behavior change as well as effective strategies for achieving sustainable health promotion and disease prevention activities. Twenty-one funded investigators are exploring aspects of dietary change, exercise, smoking cessation, cancer screening, HIV prevention, and substance abuse.
- 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 week long 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/DECCI/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.

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 2003 and 2005 data sets 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.



New to the Web site in 2006 are HINTS Briefs, which provide snapshots of noteworthy, data-driven research findings. The briefs introduce population-level estimates for specific questions in the survey and summarize significant research findings that are a result of analyzing how age, race, and gender influence specific outcomes. <http://cancercontrol.cancer.gov/hints/briefs.jsp>.

Lastly, a special supplement to the *Journal of Health Communication*, devoted to HINTS-related research, was published in May 2006 (*Journal of Health Communication*, 11, Suppl 1).

RECENT SCIENTIFIC ADVANCES

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. *Supportive 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 of 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.

Patient Decision-Making Preferences for Colorectal Cancer Screening

Currently, there are several effective screening options available for colorectal cancer (CRC), each with varying advantages/disadvantages in terms of sensitivity, specificity, cost, and safety. Because recommendation of one test over another is not currently supported, the U.S. Preventive Services Task Force recommendations for CRC screening include the consideration that clinicians involve patients in decisions about which screening examination is most appropriate for them. Few studies, however, have examined whether usual participation in decision making is consistent with patient preferences for involvement in decision making.

Catherine Messina and colleagues examined preferences for participation in CRC screening decision making among community adults age-eligible for screening who took part in the NCI-funded Early Detection Guidelines Education-2 (EDGE-2) project. The statistically significant results of this study suggest considerable agreement (77%) between participant preferences for decision making and how CRC screening decisions were usually made. Fifteen percent preferred to make screening decisions themselves, while 25% preferred to make decisions after considering their physician's opinion; nearly 50% preferred to share decision making, and 16% preferred that their physician make all screening

decisions. Lower educational attainment was associated with the likelihood of preferring that the physician make all CRC screening decisions. Black participants favored shared decision making with the physician. Not having recent CRC screening was associated with lower odds of preferring any physician involvement in screening decisions. Findings also suggest that patients who prefer to make their own CRC screening decisions may do so to avoid physician messages to be screened; in contrast, patients preferring physician involvement in screening decisions may benefit from interventions designed to encourage greater patient participation in CRC screening decision making, even if they may not initially prefer this.

The factors identified as significantly associated with preferences for decision making deserve further exploration for their application to clinical practice. Participation in decision making at the patient's desired level may increase the likelihood that screening decisions are consistent with patient preferences/values, positively impact satisfaction with screening decisions, and favorably influence screening.

Messina, C.R., Lane, D.S., Grimson, R. (2005). Colorectal cancer screening attitudes and practices preferences for decision making. *American Journal of Preventive Medicine* 28(5):439-46.

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.

Intervention Trial Tests Dissemination of a Skin Cancer Prevention Program on a National Scale

Skin cancer, the most common form of cancer in the United States, is increasing and childhood exposure to the sun's ultraviolet rays increases the risk for skin cancer later in life. Prevention programs for reducing sun exposure for children in outdoor aquatic settings may influence youth, their parents, and swimming pool environments, and can consequently achieve significant public health benefits if these programs are widely disseminated and successfully adopted, maintained, and continued.

The Pool Cool skin cancer prevention program is a multi-component educational and environmental intervention that was systematically developed, pilot tested, and evaluated in a randomized trial. In 2003, NCI provided funding for the Pool Cool Diffusion Trial, an ambitious, comprehensive effort to study the process of diffusion and to compare two approaches to promoting dissemination of a cancer prevention program on a national scale. The main outcome measures of this ongoing study are self-reported data from the pool managers and parents' reports of children's sun

protection habits and sunburns. The primary aims are to evaluate the effects of two strategies for diffusion of the Pool Cool skin cancer prevention program on program implementation, maintenance, and sustainability; improvements in organizational and environmental supports for sun protection at swimming pools; and sun protection habits and sunburns among children. In a report published in *Health Psychology*, Karen Glanz and colleagues summarize the first-year findings, discuss design and measurement considerations, and share lessons learned to date. The authors report that simple t tests and regression models showed that the cross-section of pools at follow-up had significantly higher scores on sun-safety Program and Policy scales than those responding at baseline, with a 52.3% increase in policies, environments, and programs for pool users.

Few health behavior diffusion studies to date have gone beyond measuring program implementation and maintenance to examine whether the ultimate audience improves their behaviors or health. The findings from this

large intervention trial will add to the science base about diffusion and cancer prevention, and will ultimately link research and practice to translate epidemiologic knowledge into effective action in communities.

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.

Glanz, K., Steffen, A., Elliott, T., O'Riordan, D. (2005). Diffusion of an effective skin cancer prevention program: design, theoretical foundations, and first-year implementation. *Health Psychology* 24(5):477-87.

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 Audie Atienza, PhD, 301-451-9350, atienzaa@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

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.

Energy Balance Provider's Survey

Contact Ashley Smith, PhD, MPH, 301-451-1843,
smithas@mail.nih.gov

NCI has begun a second physician survey to obtain current, nationally representative data on primary care physicians' characteristics, knowledge, attitudes, and

practices related to services for diet, physical activity, and weight control. The goal of this survey is to develop a national baseline on the use of energy balance risk assessment, counseling and referral services in physician practice, and to identify the characteristics of physicians who routinely incorporate these activities in patient care, in order to plan new initiatives to spread these practices more widely within the physician community. Data from the survey will be used to profile existing physician practice, understand barriers to counseling and referral, and to inform methods for improving the utilization of these services for adults and children. The survey will support and further the work of the NCI, NIH, and DHHS to monitor and evaluate providers' cancer control knowledge, attitudes, and practices and their impact on population health. Because of the importance of these services to the prevention and treatment of several chronic diseases, we are collaborating with six DHHS institutes/agencies to develop the survey: the Office of Behavioral and Social Sciences Research (OBSSR), the National Institute of Child Health and Development (NICHD), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Heart, Lung, and Blood Institute (NHLBI), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ). This trans-NIH work group has been meeting since August 2005 to discuss and identify key research domains and questions to be addressed and to develop survey instruments and is currently being co-funded by OBSSR and NICHD.

Automated Self-Administered 24-Hour Recall (ASA24)

<http://riskfactor.cancer.gov/tools/instruments/asa24.html>

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

The interviewer-administered 24-hour recall has long been regarded as the best methodology for recall of dietary intake because it provides the highest-quality and least biased dietary data for a single day. This method allows collection of detailed intake and portion sizes, and because the data collection occurs after the consumption, this methodology does not affect what an individual chooses to eat on a given day. The close proximity in time to the intake day minimizes memory and cognitive issues that afflict other methodologies. The development of a 24-hour recall that could be

unannounced, automated, and self-administered would make feasible the administration of multiple days of recalls in large-scale epidemiologic studies, surveillance studies, behavioral trials, or clinical research, thus enhancing investigators' ability to assess usual dietary intakes. Coding of food items and calculation of nutrient intake would be computed automatically. This instrument could either be sent to participants over the Internet or administered in a clinic/office setting at low cost. Therefore, an automated self-administered recall could potentially change the state of the art for data collection in large-scale population nutrition research.

NCI is leading the effort to develop the ASA24 software that will use state-of-the-art automated computer technology, including graphic enhancements, animated characters to guide participants, and audio language/cues to enhance use in low-literacy populations. The food list from which respondents select their intakes for the previous day will include all foods available from USDA's most current Food and Nutrient Database for Dietary Studies (FNDDS) database. In addition, the software will include pictures of foods in multiple portion sizes to aid portion size estimation by the respondent. The software will have the capacity to immediately compute nutrient and food group estimates for each recall day. In addition, ASA24 will be translated into Spanish and will have the capacity to be translated into other languages in the future. This work is being conducted collaboratively with other investigators at NCI and USDA and an external working group.

Advancing Diet and Physical Activity Monitoring through the NHANES

Contact Susan Krebs-Smith, PhD, 301-496-4766, krebsms@mail.nih.gov, or Richard Troiano, PhD, 301-435-6822, troianor@mail.nih.gov

NCI supported the use of physical activity monitors and food propensity questionnaires in the 2003-2006 National Health and Nutrition Examination Surveys (NHANES). The monitors, which record motion activity as people wear them over several days, circumvent the cognitive and cultural challenges inherent in collecting physical activity data by questionnaire. The monitors provided the first-ever objective assessment of physical activity on a national sample, and reveal substantially lower levels of physical activity in the population than previously estimated. The NHANES 2003-2004 data from the physical activity monitors are currently

available as public use data through the National Center for Health Statistics (NCHS) at http://www.cdc.gov/nchs/about/major/nhanes/nhanes2003-2004/exam03_04.htm.

The 2003-2004 data from the food propensity questionnaire are soon to be released, also as public use data through the NCHS Web site. These data can be used, in conjunction with the NHANES 24-hour dietary recall data, to estimate usual food intakes through statistical methods developed at NCI. This is a major advance in dietary assessment methodology and will greatly enhance our ability to monitor diets and to assess the effects of diet on health outcomes.

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.

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.

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 and DHQ* Web

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

The Diet History Questionnaire (DHQ) is a food frequency questionnaire (FFQ) for researchers that consists of 124 food items, and includes both portion size and dietary supplement questions. The DHQ was designed to be easy to use and has been shown to be as good as, or superior to, other FFQs for most nutrients. As an extension of the DHQ, NCI recently unveiled DHQ*Web, a Web-based questionnaire nearly identical in content to its predecessor. DHQ*Web is a free research resource that takes advantage of the key aspects of automated and electronic questionnaires—respondents follow automated skip patterns, must complete all questions before proceeding, can navigate within the instrument to modify responses, and can log in at any time. DHQ*Web provides more efficient data quality because respondents cannot complete the questionnaire with missing or inconsistent responses.

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

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.

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 American Journal of Preventive Medicine, demonstrate significant improvement in dietary fat and fiber consumption in this population.

Dr. Elizabeth Fries, of Virginia Commonwealth University, and her colleagues enrolled patients from three physician practices in rural Virginia and randomly assigned them to an intervention (tailored feedback on eating habits, brief counseling, and dietary self-help booklets) or control group. Intervention materials were written at or below a sixth-grade reading level and mailed along with letters from participants' physicians. Investigators conducted follow-up phone interviews 1, 6,

and 12 months after the intervention. Individuals in the intervention group significantly reduced their dietary fat intake, increased dietary fiber consumption, and expressed an intention to reduce dietary fat and eat more fiber, fruits, and vegetables.

Efforts to improve health in rural areas may be compromised because of reduced access to health care and lack of appropriate nutrition education. The authors note that rural primary care providers may be viewed by community members as the only legitimate source of health information; however, many are overburdened with a large patient load. This study shows 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.

Pregnancy Hormone Concentrations across Ethnic Groups and Implications for Cancer Risk

A variety of in utero factors have been associated with risk of adult cancers, particularly birth weight, toxemia, and gestational age. These factors are thought to reflect hormonal exposures during pregnancy. Nancy Potischman and colleagues hypothesized that the prenatal hormonal milieu may explain some of the variation seen in cancer rates across ethnic groups, for example, the higher incidence of breast cancer in Caucasian women compared with Hispanic women and the higher incidence of prostate and lower incidence of

testicular cancers among African-Americans compared with Caucasians. To test this hypothesis, the investigators measured hormones in early pregnancy blood samples from three ethnic groups in a health care plan in Boston, Massachusetts. The study sample was comprised of 420 women: 109 Hispanic, 56 African American, and 255 Caucasian. Mean levels of androstenedione, testosterone, estrone, and prolactin were significantly lower in Caucasian women compared with Hispanic women. Although not statistically

significant, estradiol levels were lower in Caucasian compared with Hispanic or African American women. Concentrations of androstenedione, testosterone, and progesterone were notably higher in African American compared with Caucasian or Hispanic women. These data are consistent with the hypothesis that in utero hormonal exposures may explain some of the ethnic group differences in cancer risk. Further research into the determinants of these differences will be important.

In addition, further research is warranted for evaluation of the relation of in utero and later cancer risk factors across the life span, particularly those that vary across racial groups.

Potischman, N., Troisi, R., Thadhani, R., Hoover, R.N., Dodd, K., Davis, W.W., Sluss, P.M., Hsieh, C.C., Ballard-Barbash, R. (2005). Pregnancy hormone concentrations across ethnic groups: implications for later cancer risk. *Cancer Epidemiology, Biomarkers & Prevention*, 14(6):1514-20.

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.

Evidence Continues to Accumulate that Physical Activity and Lower Weight Is Associated with Lower Breast Cancer Risk

A large Chinese epidemiological study provided strong evidence that being more physically active and leaner can significantly reduce the risk of getting breast cancer, particularly among postmenopausal women, according to a report in the June 2005 issue of *Cancer Epidemiology, Biomarkers & Prevention*. The Shanghai Breast Cancer Study compared data from interviews of 1,459 breast cancer cases and 1,556 controls in China. Researchers reported that women in the study with low levels of physical activity and higher body mass index (BMI) levels were at more than twice the risk of developing breast cancer than women who had lower BMIs and who exercised for the equivalent of about 45 minutes of brisk walking or 20 minutes of vigorous exercise daily.

The women's BMIs were calculated based on measurements, taken by the interviewers, of their weight, height, and circumference of waist and hips. This direct

approach enabled Dr. Alecia Malin and colleagues to overcome the primary problem affecting the accuracy of energy balance assessments based on self-reporting that leads to underreporting, particularly when overweight people account for their own energy intake.

Extrapolation of the results for Westerners should take into account the inherent differences in the relationship between BMI levels and disease risk that appear to exist between Western and Asian women. A BMI of 25 kg/m² among Western women is considered to be normal weight, while the same BMI level among Asian women is considered to be in the overweight category and was associated with an increased breast cancer risk in this study.

Malin, A., Matthews, C.E., Shu, X.O., Cai, H., Dai, Q., Jin, F., Gao, Y.T., Zheng, W. (2005). Energy balance and breast cancer risk. *Cancer Epidemiology Biomarkers & Prevention*, 14(6):1496-501.

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 10.5 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: 66 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, Rush University Medical 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 Michigan
- 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, Sloan-Kettering Institute for Cancer Research
- Managing Uncertainty in Childhood Cancer Survivorship, Sheila Santacroce, Yale University
- Physical Activity and Lymphedema Project (PAL Trial), Kathryn Schmitz, University of Pennsylvania
- 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

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

- Program for Depression among Minority Survivors, Martin Abeloff and James Zabora, Johns Hopkins Oncology 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.

Cancer Survivorship: Embracing the Future

Third Biennial Cancer Survivorship Research Conference

<http://cancercontrol.cancer.gov>

Contact Carmina Valle, MPH, 301-402-2747, vallec@mail.nih.gov

This biennial conference provides an opportunity for researchers across many fields to share innovative research advances, interventions, methods, and more. Participants at the 2006 conference included researchers in biomedical and behavioral science, healthcare professionals, scientists, graduate students in health-related sciences, community-based advocates, state public health planners, and cancer survivors and their families.

Key objectives of *Cancer Survivorship: Embracing the Future* included the following:

- Identifying future directions of cancer survivorship research;
- Examining advances in e-health and communications;
- Identifying challenges to follow-up care for cancer survivors;
- Understanding and addressing the needs of cancer caregivers and families; and
- Reviewing research and strategies to address health disparities in cancer survivorship.

The conference was sponsored by NCI's Office of Cancer Survivorship, the American Cancer Society, and the Lance Armstrong Foundation.

PARTNERSHIPS & COLLABORATIONS

American Cancer Society (ACS)



- DCCPS and ACS jointly support scientific conferences, such as the Biennial Cancer Survivorship Research 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, designed for cancer survivors, their families, and their health care providers, was recently updated for re-release. 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.

CancerCare

- The Office of Cancer Survivorship (OCS), in collaboration with colleagues in the Office of Education and Special Initiatives and the Cancer Information Service at NCI, participates in a groundbreaking, three-part teleconference series launched in 2003 and entitled "Cancer Survivorship Series: Living With, Through, and Beyond Cancer." The OCS is an active partner with CancerCare, 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.

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.

Centers for Disease Control and Prevention (CDC)

- In partnership with the CDC, the OCS hosted a special dissemination meeting in conjunction with the 2004 Biennial Cancer Survivorship Research Conference to identify the best approaches to cancer survivorship research dissemination to help close the gap between research discovery and program delivery, and to foster transdisciplinary collaborations and partnerships that support and enhance cancer survivorship research diffusion and dissemination.
- CDC colleagues established a cancer survivorship interbranch working group in 2004 that includes regular conference calls with OCS staff to coordinate efforts to support research, publish data, and disseminate information materials.
- The OCS works with the CDC and ACS to develop and deliver a cancer survivorship module for inclusion in 2006 training of state planners as part of their Comprehensive Cancer Control Leadership Institute.

Lance Armstrong Foundation (LAF)

- In 2004, the NCI and ACS Biennial Cancer Survivorship Research Conference established a Survivor-Researcher Mentor Program. This exciting program was designed to help develop emerging leaders in the cancer advocacy community. The LAF provided travel scholarships for selected applicants to attend the 2004 conference and became a full partner in the 2006 biennial conference.

Notes

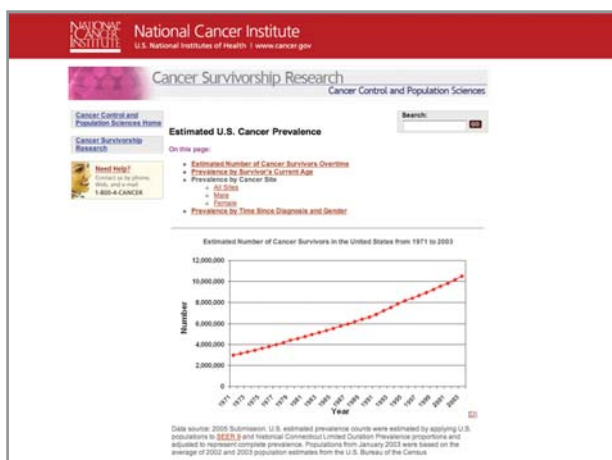
TOOLS, PRODUCTS & RESOURCES

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.

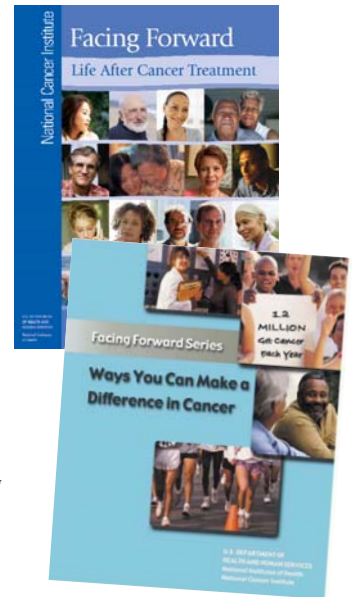
In an effort to make survivorship prevalence estimates accessible and easy to understand, OCS displays graphical representations of the data on a Web page dedicated to the topic. Population-based estimates for the composition of current cancer survivors are derived by gender, cancer site, age, race,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



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 Series: 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 Series: 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.

“Moving Beyond Breast Cancer” DVD/Video

NCI announces the availability of a new educational DVD/video, “Moving Beyond Breast Cancer,” to help women know what to expect as they finish breast cancer treatment. The 23-minute DVD/video features vignettes of women in different life stages who share their concerns and experiences regarding

- Body changes
- Emotions
- Relationships
- New perspectives

The video was funded by an NCI grant to the UCLA School of Public Health and the Jonsson Comprehensive Cancer Center; Patricia A. Ganz, MD, Antronette Yancey, MD, and Beth Leedham, PhD, served as executive producers, with videography by Eric Slade. It was a product that was developed as part of a multi-site, randomized, controlled trial of psychoeducational interventions for breast cancer patients.

<http://cancercontrol.cancer.gov>

RECENT SCIENTIFIC ADVANCES

Cardiac Changes Associated with Growth Hormone Therapy among Children Treated with Anthracyclines

The majority of children diagnosed with cancer are cured of their disease. But often the treatments leading to their cure may have associated risks. For example, anthracyclines are among the most widely used anticancer drugs and are often given to children as part of curative regimens. Yet cardiac damage is a major adverse effect of these drugs; childhood cancer survivors treated with anthracyclines frequently have reduced left ventricular wall thickness and contractility. Growth hormone therapy may produce improvements in left ventricular wall structure and function, however.

To determine the long-term effects of growth hormone therapy among anthracycline-treated children with left ventricle dysfunction, Steven Lipshultz and colleagues conducted a 10-year longitudinal study of cardiac structure and function before, during, and after growth hormone therapy. The investigators examined cardiac findings for 34 anthracycline-treated childhood cancer survivors with several years of growth hormone therapy with those for a comparison group (86 similar cancer survivors who did not receive growth hormone therapy).

During growth hormone therapy, the left ventricular (LV) wall thickness for the group treated with growth hormone was greater than that for the control group; however, by 4 years after therapy, there was no difference between the two groups. Further, the investigators found that LV contractility was decreased among growth hormone-treated patients before, during, and after growth hormone therapy.

Because growth hormone therapy does not result in long-term benefits in the reduction of progressive LV dysfunction among anthracycline-treated, long-term survivors of childhood cancer, continued research to identify strategies to prevent anthracycline cardiotoxicity during therapy is essential.

Lipshultz, S.E., Vlach, S.A., Lipsitz, S.R., Sallan, S.E., Schwartz, M.L., Colan, S.D. (2005). Cardiac changes associated with growth hormone therapy among children treated with anthracyclines. *Pediatrics*, 115(6):1613-22.

Posttraumatic Stress Symptoms during Treatment in Parents of Children with Cancer

As more children survive pediatric malignancies, the long-term well-being of the patient and family emerge as increasingly important. To offer optimal support to families of children with cancer, it's necessary to understand the nature of parental distress. Within pediatric cancer populations, posttraumatic stress symptoms (PTSS) are commonly experienced by parents of children who have survived treatment, and include intrusive thoughts, physiologic arousal, and avoidance of treatment-related events.

In the October 2005 issue of the *Journal of Clinical Oncology*, Anne Kazak and colleagues report on posttraumatic stress symptoms in mothers and fathers of children in current treatment for a pediatric malignancy. Data from a sample of mothers and fathers of patients from the same hospital 1 to 10 years from completion of their cancer treatment were used as a referent group to put the rates of the symptoms in the current sample into context. All but one parent reported symptoms consistent with at least mild PTSS. Approximately 68%

of mothers and 57% of fathers reported PTSS within the moderate-to-severe range. With respect to whether PTSS affects one or both parents (in two-parent families), 79% of the families in the sample in which two parents participated had at least one parent with moderate-to-severe PTSS. It was rare for both parents to report severe symptoms (6%) and untypical for both parents to report mild PTSS (14.5%).

Knowledge and attention to PTSS can lead to more appropriate multidisciplinary care of the patient and family. PTSS, while distressing, may be addressed systematically in routine clinical care and through the inclusion of evidence-based interventions for parents and families during treatment for childhood malignancies. By addressing the psychological needs of caregivers, the medical community may be best assuring that the psychological needs of the patients are also met.

Kazak, A.E., Boeving, C.A., Alderfer, M.A., Hwang, W.T., Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, 23(30):7405-10.

Quality of Life of Long-Term Survivors of Breast Cancer and Lymphoma

As the numbers of long-term survivors of cancer have increased, the need for research into psychosocial adaptation and quality of life (QOL) of these individuals has also increased. While analyses of QOL of cancer survivors has been generally encouraging, suggesting that some domains of QOL for cancer survivors are as good as or better than for healthy comparison groups, there are several gaps in knowledge. The majority of studies have evaluated survivors only 1 to 2 years after treatment and few studies have examined the impact of various therapies on long-term survivors' QOL and ability to function.

Using the Quality of Life—Cancer Survivors Tool, Tim Ahles and colleagues compared the quality of life of long-term survivors of breast cancer and lymphoma (mean, 10.0 ± 5.3 years after treatment) who had been treated with standard-dose systemic chemotherapy or local therapy only. Survivors who had been treated with systemic chemotherapy scored significantly lower on overall QOL compared with survivors treated with local therapy only. Analysis of covariance on the subscale

scores revealed that, compared with survivors who received local therapy, survivors treated with chemotherapy scored significantly lower on the Social subscale, but no differences emerged on the Psychological or Spiritual subscales. There was a statistically significant interaction between treatment and diagnosis, as measured by the Physical subscale, indicating that lymphoma survivors treated with chemotherapy scored worse than all other groups.

For many people with cancer, the survival advantage of chemotherapy far outweighs the potential long-term side effects. However, understanding the impact of chemotherapy on various domains of QOL is important so that cancer survivors understand the potential consequences of cancer treatment and interventions that improve coping with these consequences can be developed.

Ahles, T.A., Saykin, A.J., Furstenberg, C.T., Cole, B., Mott, L.A., Titus-Ernstoff, L., Skalla, K., Bakitas, M., Silberfarb, P.M. (2005). Quality of life of long-term survivors of breast cancer and lymphoma treated with standard-dose chemotherapy or local therapy. *Journal of Clinical Oncology*, 1;23(19):4399-405.

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.

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.

The Teachable Moment: Promoting Long-Term Health after a Cancer Diagnosis

Cancer survivors are at increased risk for several co-morbid conditions, and many make lifestyle changes to reduce dysfunction and improve long-term health.

To better understand the impact of cancer on adult survivors' health and health behaviors, Wendy Demark-Wahnefried and colleagues conducted a review of studies from 1996 and beyond to determine prevalent physical health conditions, persistent lifestyle changes, and outcomes of previous lifestyle interventions aimed at improving health within this population. The review, published in the *Journal of Clinical Oncology*, found that cancer survivors are at increased risk for progressive disease but also for second primaries, osteoporosis, obesity, cardiovascular disease, diabetes, and functional decline. The authors report that to improve overall health, survivors frequently initiate diet, exercise, and other lifestyle changes after diagnosis. However, those who are male, older, and less educated are less likely to adopt these changes. There also is selective uptake of messages, as evidenced by the findings that only 25% to 42% of survivors consume

adequate amounts of fruits and vegetables, and approximately 70% of breast and prostate cancer survivors are overweight or obese. Although there are several promising behavioral interventions for improving survivors' health-related outcomes, only 20% of oncologists provide guidance on these interventions.

The results of the review suggest that oncologists must expand their focus from acute care only to also managing the long-term health consequences of cancer. Although more research is needed, opportunities exist for oncologists to promote lifestyle changes that may improve the length, health, and quality of life of their patients. In particular, the authors discuss the importance of capitalizing on the "teachable moment" that a cancer diagnosis and the transition to survivorship provides.

Demark-Wahnefried, W., Aziz, N. M., Rowland, J. H., Pinto, B. M. (2005). Riding the crest of the teachable moment: Promoting long-term health after the diagnosis of cancer. *Journal of Clinical Oncology*, 23(24);5814-5830.

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.

Health Disparities

Some of our greatest opportunities for reducing the overall burden of cancer reside with our efforts to understand 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, researchers, and health professionals 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 *Shobha Srinivasan, PhD, 301-435-6614, sriniva2@mail.nih.gov*

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

National Institute on Aging (NIA)

National Institute on Aging
■ ♦ ★ * on Aging

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.

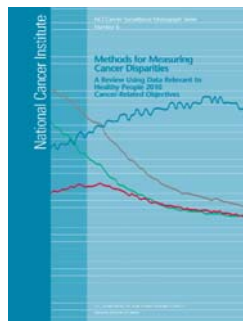
U.S. Census Bureau

- 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.

RECENT SCIENTIFIC ADVANCES

Methods for Measuring Cancer Disparities: A Review Using Data Relevant to Healthy People 2010 Cancer-Related Objectives

Healthy People 2010 has two overarching goals: to increase the span of healthy life and to eliminate health disparities across the categories of gender, race, ethnicity, education, income, disability, geographic location, and sexual orientation. This report raises some conceptual issues and provides an innovative methodological approach germane to measuring progress toward the goal of eliminating health disparities. It highlights major issues that may affect the choice of measurement techniques and systematically reviews methods used in health disparities research. The authors recommend a sequence of steps to measure and



monitor cancer-related disparity trends using a suite of indicators and measurement strategies explaining in detail the strengths and weaknesses of each.

The report was written under contract from the Surveillance Research Program and the Applied Research Program, with additional support provided by the Office of Disease Prevention in the Office of the Director of the National Institutes of Health.

Harper, S., Lynch, J. (2005). *Methods for Measuring Cancer Disparities: Using Data Relevant to Healthy People 2010 Cancer-Related Objectives*. NCI Cancer Surveillance Monograph Series, Number 6. Bethesda, MD: National Cancer Institute. NIH Publication No. 05-5777.

Broad-Based Tobacco Control Policies Do Not Have as Much Impact on Low-SES Women

Policies designed to protect the public from exposure to secondhand smoke may not have the same impact on women and girls of low socio-economic status (SES), who often do not have the resources at their disposal to avoid secondhand smoke exposure in the workplace or the home. This is the finding included in *Tobacco Control Policies: Do They Make a Difference for Low-SES Women and Girls?*, a special supplement to the September 2006 *Journal of Epidemiology and Community Health*. The research included in the supplement indicates that while broad-based tobacco control policies have helped large numbers of Americans avoid the dangers of secondhand smoke, low-SES women are less likely to benefit from these policies. Despite regulations, creating and enforcing a smoke-free environment might be more difficult for low-SES women and girls, as they are more likely to live in households with smokers or work at jobs where either smoking is permitted or not under their control to enforce. Although some tobacco control policies, such as cigarette pricing, have moderate effects on reducing

smoking among low-SES women and girls, others such as smoke-free workplace policies, do not always have the desired public health effect. The experts contributing to the supplement also suggest that prevention and cessation information currently available through public education campaigns and in medical settings might not be reaching these women and girls.

This special journal supplement is a product resulting from a meeting of the Tobacco Research Network on Disparities (TReND) held in September 2005, "Tobacco Control Policies: Do they make a difference for Low SES women and Girls?". The meeting was co-funded by DCCPS, NCI's Office of Women's Health, the Department of Health and Human Services' Office of Women's Health, and the American Legacy Foundation.

Tobacco control policy and low socioeconomic status women and girls. (2006). *Journal of Epidemiology and Community Health* September, Vol 60, Suppl 2.

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 P.L.A.N.E.T.

Contact Irene Prabhu-Das, PhD, 301-451-5803, prabhudasi@mail.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 P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based Tools) were developed in collaboration with ACS, AHRQ, CDC, Commission on Cancer (CoC), and the Substance Abuse and Mental Health Services Administration. P.L.A.N.E.T. 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 Surveillance Supplements

Contact Jon Kerner, PhD, 301-594-6776, kernerj@mail.nih.gov

Surveillance data on cancer incidence and mortality, behavioral risk factors, and health service utilization provide important opportunities for cancer control planning, implementation and evaluation. However, the collection and analyses of these data, while necessary, are not sufficient to ensure that efforts to control cancer

at national, state, and local levels are data driven. The purposes of the dissemination supplements for surveillance data are to test strategies for applying surveillance data to cancer-related program, practice, and policy decision-making; to test different communication approaches to “tell compelling stories” with surveillance research data that leads to informed action; and to improve strategies for the dissemination of surveillance research tools and data.

Dissemination and Diffusion Research Program Announcement

Contact Jon Kerner, PhD, 301-594-6776, kernerj@mail.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 P.L.A.N.E.T.

<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 P.L.A.N.E.T. is a portal that provides access to data and research-tested resources that can help planners, program staff, and researchers to design, implement, and evaluate evidence-based cancer control programs. If you would like to explore getting your country-specific cancer information up on Cancer Control P.L.A.N.E.T., please contact us at ccplanet@mail.nih.gov.

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, Commission on Cancer's state liaisons, and NCI's Cancer Information Service, as well as local researchers funded by ACS, AHRQ, CDC, and NCI



STEP 3

Research reviews of different intervention approaches

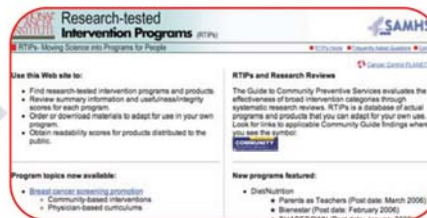
Learn about the most effective approaches for comprehensive cancer control and the research that examines various intervention strategies and approaches that have been shown to be effective or ineffective



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 your program

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 and Education, Cancer Information Service (CIS)

- DCCPS has collaborated with the Office of Communications and Education to develop and disseminate a train-the-trainer course on Using What Works that teaches users how to adapt research-tested intervention programs at the local community level.
- DCCPS and the Cancer Information Services (CIS) Partnership Program staff have been working with ACS regional planners, CDC National Breast and Cervical Cancer Early Detection Program staff, and USDA's Cooperative State Research, Education and Extension Service to build and sustain partnerships in six states through the Team-Up Cancer Screening Saves Lives project. This project encourages the adoption and implementation of evidence-based screening programs to reach those populations of women at greatest risk for cervical and breast cancer.

Agency for Healthcare Research and Quality (AHRQ)



- 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.
- DCCPS has partnered with AHRQ on a Web-based tool, Cancer Control PLANET, designed to help in the planning, implementation, and evaluation of evidence-based cancer control interventions. The Guide for Clinical Preventive Services is linked through STEP 3 on Cancer Control PLANET. Additionally, researchers from AHRQ are listed on STEP 2 of Cancer Control PLANET to enhance research-practice partnerships.

Centers for Disease Control and Prevention (CDC)



- DCCPS and CDC's Division of Cancer Prevention and Control (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 DCPC co-fund 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)



- Through an interagency agreement, DCCPS works with SAMHSA's National Registry of Effective Programs and Practices (NREPP) to review evidence-based programs posted on the Research-tested Intervention Programs (RTIPs) Web site. RTIPs serves as a doorway to new evidence-based programs that can aid communities in better delivering evidence-based interventions to reduce their cancer burden.

American Cancer Society (ACS)



- ACS, along with NCI and CDC, developed in every ACS division on a regional basis, leadership training programs called the Comprehensive Cancer Control Leadership Institutes for the States, tribes, and territories.
- 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.
- As part of a public/private effort, DCCPS collaborates with ACS, SAMHSA, CDC, AHRQ, on a Web-based tool, Cancer Control PLANET, for comprehensive cancer control planning, implementation, and evaluation.
- ACS, along with NCI, CDC, and C-Change, has been working to develop Comprehensive Cancer Control Leadership Forums, with a focus on cancer control planning and implementation in Latin America. The first forum was held in 2006 in Mexico City and brought together cancer control leaders from Brazil, Peru, Mexico, and Uruguay.

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.

Lance Armstrong Foundation (LAF) and the American Legacy Foundation

- DCCPS has partnered with LAF and Legacy to develop PRIME (Program Resources for Implementation, Management, and Evaluation). PRIME is a Web-based tool that will facilitate access to funding resources to assist with the implementation, management, and evaluation of evidence-based cancer control programs. PRIME will be included on STEP 5 of Cancer Control PLANET. LAF and Legacy are piloting the tool, which will launch in 2007. Other foundations that support cancer control service program funding will be identified with this tool. Links to regular funding opportunities and interactive templates of concept and grant applications will be provided.

TOOLS, PRODUCTS & RESOURCES

Translating Research into Improved Outcomes

The Translating Research into Improved Outcomes (TRIO) program is the centerpiece of the DCCPS commitment to move research discoveries through intervention development into evidence-based programs by 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.
- Collaborating 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.
- Working with national, regional, state, and local partner organizations to identify and overcome the infrastructure barriers to the adoption of evidence-based cancer control programs and practices.

Cancer Control P.L.A.N.E.T.

<http://cancercontrolplanet.cancer.gov>

The Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based Tools) was launched in April 2003. This public-private partnership led by NCI and co-sponsored by AHRQ, CoC, ACS, CDC, and SAMHSA, provides a lens to find tools and resources for comprehensive cancer control planning, implementation, and evaluation. DCCPS staff led the development of two Web sites within the P.L.A.N.E.T. portal: State Cancer Profiles and Research-tested Intervention Programs (RTIPs).

Cancer Control P.L.A.N.E.T.
Links to comprehensive cancer control resources for public health professionals

Follow 5 steps to develop a comprehensive cancer control plan or program

Step 1: Assess program priorities
State Cancer Profiles (CDC, NCI)
• Statistics for prioritizing cancer control efforts in the nation, states, and counties

Step 2: Identify potential partners
Find Program Partners in Cancer Control
Find Research Partners in Cancer Control
• Contact information for ACS, CDC, CoC and NCI program partners and research partners by state and region

Step 3: Research reviews of different intervention approaches
Guide to Community Preventive Services (Federally sponsored)
• Recommendations for population-based intervention approaches

Find information by cancer control topic

- Breast Cancer
- Cervical Cancer
- Colorectal Cancer
- Diet/Nutrition
- Informed Decision Making
- Physical Activity
- Sun Safety
- Tobacco Control

Help us improve this resource!
Complete the Cancer Control P.L.A.N.E.T. Evaluation.

State Cancer Profiles

<http://statecancerprofiles.cancer.gov/>

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.

State Cancer Profiles
Dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, states, and counties

Quick Profiles
Area: Choose a State
Cancer: Choose a Cancer Site
Generate Profile

Comparison Tables
Rate/Trend Comparisons
Death Rates
Incidence Rates

Interactive Graphs and Maps
5-Year Rate Changes
Historical Trends
Comparative Data (Microsum)
Interactive Maps
Support Data
Screening and Risk Factors
Demographic Data
Peer Counties

RTIPs Web site

<http://rtips.cancer.gov/rtips/index.do>

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 research projects or service programs across the country.

Research-tested Intervention Programs (RTIPs)
RTIPs - Moving Science into Programs for People

Use this Web site to:

- Find research-tested intervention programs and products.
- Review summary information and usefulness/integrity scores for each program.
- Order or download materials to adapt for use in your own program.
- Obtain readability scores for products distributed to the public.

Program topics now available:

- Breast cancer screening promotion
 - Community-based interventions
 - Physician-based curricula
- Cervical cancer screening promotion
 - Community outreach programs
 - Direct mail interventions
- Colorectal cancer screening promotion
 - Physician-based intervention programs
- Diet/Nutrition
 - Community-based social support interventions
 - Small group education interventions
 - Fruit and vegetable behavior change programs
- Informed Decision Making
 - Patient decision-making programs
- Physical activity

RTIPs and Research Reviews

The Guide to Community Preventive Services evaluates the effectiveness of broad intervention categories through systematic research reviews. RTIPs is a database of actual programs and products that you can adapt for your own use. Look for links to applicable Community Guide findings where you see the symbol.

New programs featured:

- Diet/Nutrition
 - Little by Little (Post date: December 2006)
- Breast Cancer Screening
 - The Witness Project (Post date: November 2006)
 - Increasing Mammography Among Long-Term Noncompliant Medicare Beneficiaries (Post date: October 2006)

New programs are released periodically. Please check for updates.

New Adaptation Tool Available:

- Using What Works: a train-the-trainer course that teaches users how to adapt a research-tested intervention program to the local community context.

Register your program now and be part of the RTIPs Community.

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 Trends Progress Report —2005 Update

<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. *Cancer Trends Progress Report – 2005 Update* (first published in 2001 and updated in 2003 as the *Cancer Progress Report*) is an online report that tracks the nation's progress against cancer across the cancer continuum.

This report includes up-to-date information on trends and key measures in the areas of prevention, screening, diagnosis, treatment, life after cancer, and the end of life. While presented in a manner that is accessible to the public, the *Cancer Trends Progress Report* is also designed to be useful to decision and policy makers in relation to the *Healthy People 2010* goals and objectives.

The screenshot shows the homepage of the National Cancer Institute's Cancer Trends Progress Report - 2005 Update. The page features a red header with the NCI logo and navigation links. The main content area is organized into several sections:

- Progress Report Tools:** Includes links for "Download this report", "Download this report", "Download this report", and "Download this report".
- Additional Contents:** Lists "Director's Message", "Introduction", and "Executive Summary".
- Related Resources:** Provides links for "About this Report", "Fact Sheets (PDF)", "FAQs", "Quick Links", and "Outlines".
- Feedback:** Encourages users to "submit your questions and comments about the Cancer Trends Progress Report".
- Report Highlights:** Summarizes the report's purpose and includes a "Major conclusions" section.
- Trends-at-a-Glance:** Offers "Trends and summary tables" for various cancer types.
- Prevention:** Focuses on "Tobacco, Physical activity, Diet, Sun prevention, more...".
- Treatment:** Covers "Breast cancer treatment" and "Colorectal cancer treatment".
- Early Detection:** Addresses "Breast, cervical, colorectal cancer screening".
- Life After Cancer:** Discusses "Survival (New data)" and "Costs of cancer care".
- Diagnosis:** Includes "Incidence (New data)" and "Stage at diagnosis (New data)".
- End of Life:** Covers "Mortality (New data)" and "Person-years of life lost (New data)".

At the bottom, there is a "Suggested Citation" and a note that the report is in the public domain. Logos for NCI, NCI/NIH, and FIRSTGov are visible at the very bottom.

Views from Leadership

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

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 200 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.

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.



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. The program was awarded funding under the Breast Cancer Stamp Act for a joint American Cancer Society/NCI project that examines approaches to improving interpretive performance of mammographers. 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.

Views from Leadership

Robert T. Croyle, PhD

Associate Director (Acting), Behavioral Research Program

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 to the mission of NCI and 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 increase the risks of other chronic diseases, such as cardiovascular disease. It is essential that we support both basic (fundamental mechanisms) and applied (cancer control-specific) behavioral science, in the same way we support both basic and applied biomedical science. We must continue to strengthen our successful collaborations with partners, within and outside NIH, to discover, develop, and deliver strategies to enhance health-promoting behaviors by individuals and the population.

With the establishment of BRP, we undertook a major effort to evaluate, strengthen, and expand the breadth of the research program and the expertise of the scientists who lead it. We support traditional areas of research and 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 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.

In 2006, the Behavioral Research Program provided leadership in several domains to accelerate progress in cancer control research. The BRP led the second NIH-wide conference on e-health research, which was co-sponsored by several federal and non-governmental partners. We also held an important workshop on "The Science of Team Science," which brought together scholars who have studied or evaluated transdisciplinary teams. In an ongoing effort to encourage the rigorous use and testing of theories in cancer control research, we supported for the third year a week-long summer course for junior investigators. In addition, a workshop concerning the use of theory in cancer screening research stimulated additional dialogue and identified next steps for this effort. A close partnership with the NIH Office of Behavioral and Social Sciences Research facilitated a number of efforts to further expand our collaborations in measurement technology, systems analysis, training for minority investigators, and health

It is essential that we support both basic (fundamental mechanisms) and applied (cancer control-specific) behavioral science, in the same way we support both basic and applied biomedical science.



disparities. Involvement in trans-NIH initiatives such as the Roadmap and the Genes and Environment Initiative were expanded. Finally, BRP organized and sponsored numerous pre-conferences, workshops and symposia in conjunction with the annual conferences of several professional associations.

Among the many organizations that represent important constituencies of the BRP are the American Public Health Association, the American Society of Preventive Oncology, the Society of Behavioral Medicine, the Society for Research on Nicotine and Tobacco, the International Society of Behavioral Nutrition and Physical Activity, the American Psychological Association, the Psychoneuroimmunology Research Society, the Society for Medical Decision Making, the International Communication Association, the Society for Social Work and Research, and the American Association for Cancer Research.

Over the past year, the BRP has made a special effort to work with these and other organizations to expand the breadth of expertise and disciplines involved in behavioral cancer control research. In the coming year, we expect to work with many of these organizations to further build shared research and training resources to strengthen links between the basic and applied social and behavioral sciences.

Views from Leadership

Brenda K. Edwards, PhD

Associate Director, Surveillance Research Program

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. By standardizing ways in which information is collected and processed, these projects have brought SRP closer to its informatics objectives.

Other important releases over the last year include the first monograph to collect detailed information about cancer incidence and outcomes in adolescents and young adults (AYA), 15 to 29 years of age. It was developed to gather population-based incidence, mortality, and survival data specific to cancers that occur in the AYA population, along with epidemiological data and risk factors for the development of age-specific cancers. We believe this monograph will help educate medical providers and the public about cancer incidence and survival in this age group, and provide the impetus for further research to improve the survival and the quality of life of these young people. Another monograph presents information about cancer incidence for populations in Cyprus, Egypt (Gharbiah Region), Israel (Jews and Arabs), and Jordan for the period 1996-2001. In 1996, the Ministers of Health for those countries and the Palestinian Authority (PA) signed an agreement to establish the Middle East Cancer Consortium (MECC). Turkey joined the Consortium in 2004. This is the first comprehensive publication of the MECC Cancer Registration Project.

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. 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. 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.

“Just as cancer trends will change, the cancer surveillance research program at NCI will continue to evolve in form and substance.”

Views from Leadership

Jon F. Kerner, PhD

Deputy Director, Research Dissemination and Diffusion

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 and have actually declined for the first time in more than 30 years. 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

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.

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 online *Cancer Trends Progress Report* provides users with a menu to select sections of the report they wish to print, and the ability to produce data tables and PowerPoint files from 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 the Lance Armstrong Foundation and the American Legacy Foundation to develop PRIME (Program Resources for Implementation, Management, and Evaluation). This Web tool will link the Cancer Control PLANET Web-based resources to individual philanthropic organization grant application forms to enhance the ability of community-based organizations to develop evidence-based cancer prevention and control service delivery funding requests.

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.

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Views from Leadership

Julia H. Rowland, PhD

Director, Office of 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, 66 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 10.5 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.

The year 2006 marks the tenth anniversary of the Office of Cancer Survivorship (OCS), which was established by NCI to formalize its commitment to better understand and address the unique needs of all cancer survivors. In the last decade, survivorship research has been growing in prominence in the cancer research agenda. 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 forward, 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.

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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.

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Views from Leadership

Deborah M. Winn, PhD

Associate Director (Acting), Epidemiology and Genetics Research Program

Epidemiology and Genetics Research

These are exciting times for those of us in the field of cancer epidemiology and a thrilling time to be at the National Cancer Institute. Major shifts are occurring in how epidemiologists work together and with the greater scientific community, the types of scientific questions they are asking, the technical approaches they are using to answer fundamental questions of cancer etiology, and the uses to which epidemiology is being put. These remarkable changes are likely to yield new insights into causes of cancer and potential applications to prevent and ameliorate the consequences of cancer.

The staff of the Epidemiology and Genetics Research Program (EGRP) are working directly with grant applicants and grantees to advance cancer epidemiology by advising them on funding mechanisms and on NCI's and EGRP's scientific priorities, as well as by monitoring scientific progress. Another important role of program staff in moving research forward is through development of funding initiatives and by developing scientific partnerships across NCI and NIH.

Epidemiologists have long recognized that cancer development is a multistep process. Both genetic and environmental factors influence cancer development, and there may be multiple genes involved, each with a potentially small effect. Studies with large numbers of participants are needed to unravel the distinct contributions of these multiple potential risk factors.

Epidemiologists are increasingly aware of the importance of achieving sample sizes that are often beyond the size of any given study and now are frequently creating scientific consortia to address scientific questions in cancer epidemiology. Consortia are groups of investigators who jointly pool data from their studies to enable analyses of data and biospecimens using larger numbers of study participants than would be possible by any single investigator's study. There are consortia that include investigators engaged in case-control studies of a particular tumor type, who are responsible for large population cohorts, and investigators who study families at high risk to understand genetic factors in cancer etiology. EGRP is taking a major role in developing and encouraging the formation of consortia in many different ways, including serving on steering committees that govern these collaborative teams, as well as providing advice on best practices, guidance on obtaining funding, and meeting support.

EGRP is also providing funding support to expand the type of scientific questions being asked in epidemiologic studies based on new discoveries in basic sciences. For example, EGRP has organized scientific conferences on both epigenetics and on mitochondrial DNA and the role that these biologic processes may play in cancer etiology. Epigenetic research focuses on reversible heritable changes in gene or cell function that occur without a change in DNA sequence. Mitochondrial DNA is the genetic

material of the mitochondria, the organelles that generate energy for the cell. EGRP has brought together epidemiologic experts and basic scientists to develop a research agenda to move the technologies into population settings to answer questions about the epidemiology of cancer. EGRP works extensively

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with epidemiologists and scientists in other disciplines in NCI's Division of Cancer Epidemiology and Genetics and elsewhere across NCI and NIH, and makes contributions to the institutes through service on key committees and working groups, such as a major NCI committee on biospecimen repositories. Building and sustaining these relationships promotes transdisciplinary approaches to synergize scientific discovery.

There has been a fundamental change in approaches to understanding the role of genetics in cancer etiology now that the costs are within reach to apply the technology for conducting genome-wide scans to large populations. Genome-wide association studies are defined as any study of genetic variation across the entire genome that is designed to identify genetic associations with cancer; these studies examine differences between people with cancer and control groups of people without cancer at hundreds of thousands of points across the genome. There are enormous challenges in the design, validation, and analysis of these studies and EGRP is helping to foster interchange among grantees to address these challenges, as well as contributing to NCI and NIH policies on these issues.

Epidemiologic studies help identify causes of cancer and increase our understanding of the biologic basis of cancer development, but also result in findings that provide tangible benefits to public health and clinical practice, as well as address questions of real concern to the

public. EGRP supports investigators who undertake studies to understand the basis of racial and ethnic disparities in cancer incidence, risks associated with positive family history of cancer, the role of energy balance in cancer development, risks from taking certain medications, and how viruses cause cancer, among others. Additionally, EGRP is partnering with the National Institute of Environmental Health Sciences to better understand environmental factors influencing puberty in girls as a way of understanding how this potential window of susceptibility for breast cancer may be involved in breast cancer etiology. The role of environmental factors in breast cancer development has long been an issue of public concern. Findings from grantees' studies also may lead to the development of interventions and approaches to prevent cancer, detect it earlier, and reduce morbidity and mortality among people with cancer. Epidemiologic findings often also provide the scientific basis for changes in public health and clinical practice.

