# Division of Cancer Control and Population Sciences

## 2015 Overview and Highlights

**Advancing Cancer Control in the Next Decade**

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Message from the Director

In the Division of Cancer Control and Population Sciences (DCCPS) at NCI, we have a responsibility to ensure that we are doing all we can to effectively advance our mission. To that end, we need to be responsive to new demands, priorities, and contexts. Changes in science, policy, and cancer trends all must be considered and addressed. Implementation of health care reform, the growing number of cancer survivors, the development of new “omics” technologies, and the costs related to cancer care are only a few examples. By stimulating new ideas about bigger, longer-term opportunities and goals, we will be better able to answer key questions shaping our nation’s cancer control strategy for the future.

For this reason, I have initiated efforts to revitalize and reposition the division for the coming decade. From a science planning perspective, the time is ripe for these efforts, given that most of the large research initiatives that were launched during the first few years of the division (DCCPS was established in FY 1998) have ended or are nearing completion. The formation and early development of the division were guided by several formal reports, which not only called for expanded efforts in several scientific areas, but also influenced the changes we made to our organizational structure. Talented and committed staff and leadership, both past and present, as well as a large community of funded investigators and contractors produced remarkable progress in science, infrastructure, and application. Now is the time to build on those successes and engage our internal experts and those outside the division in identifying the most important scientific questions and cancer control objectives for the next generation of initiatives.

The goal of our FY 2015 effort is to maximize our ability to facilitate significant achievements in cancer control and population sciences. The focus will not be on ending those projects that continue to be valuable but rather on how best to target new and emerging priorities as well. We are also improving the structure of our division to incorporate these scientific priorities efficiently and effectively, most notably with the creation of a new Healthcare Delivery Research Program. In addition, we are working across all of our programs for greater integration and enhancement of cross-cutting scientific areas, including implementation science, cancer survivorship, and health disparities. We have initiated or are currently considering other enhancements throughout the division, all of which will be informed and guided by our scientific objectives.

I’m very excited by all of these changes and our new efforts to reposition DCCPS for the future. In addition to the remarkable range of talent within the division, we will reach out to our grantees and other stakeholders — many of whom have already contributed ideas and recommendations through various in-person and online forums. As fruitful as our first large wave of initiatives was several years ago, we now have greater capacity, infrastructure, tools, and personnel to launch an even more ambitious effort to accelerate progress in cancer control and population sciences.

Our current opportunities for scientific progress are without precedent. I invite you to join your colleagues in helping to generate new knowledge and shape the division’s strategic priorities as we work to advance cancer control for the next decade.
Leadership at a Glance

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

Office of the Director
Dr. Robert Croyle, DIRECTOR

Office of the Director
Dr. Deborah Winn, DEPUTY DIRECTOR

Implementation Science
Dr. David Chambers, DEPUTY DIRECTOR

4 RESEARCH PROGRAMS

Epidemiology and Genomics Research Program
Dr. Muin Khoury, ASSOCIATE DIRECTOR

Dr. Britt Reid, DEPUTY ASSOCIATE DIRECTOR

Methods and Technologies
Dr. Mukesh Verma, BRANCH CHIEF

Environmental Epidemiology
Dr. Gary Ellison, ACTING BRANCH CHIEF

Genomic Epidemiology
Dr. Elizabeth Gillanders, BRANCH CHIEF

Clinical and Translational Epidemiology
Dr. Andrew Freedman, BRANCH CHIEF

Risk Factor Assessment
Dr. Susan Krebs-Smith, ACTING BRANCH CHIEF

Surveillance Research Program
Dr. Lynne Penberthy, ASSOCIATE DIRECTOR

Surveillance Research Program
Dr. Kathleen Cronin, DEPUTY ASSOCIATE DIRECTOR

Data Quality, Analysis, and Interpretation
Dr. Zaria Tatalovich, ACTING BRANCH CHIEF

Surveillance Informatics
Dr. Angela Mariotto, ACTING BRANCH CHIEF

Statistical Research and Modeling
Dr. Eric Feuer, BRANCH CHIEF
Social media activity can provide a window into how people construe and act on health recommendations…
In the BRP, we continue to engage our research community as we move forward with emergent areas of scientific emphasis. Researchers, prospective grantees, and trainees are welcome to contact us to learn more about behavioral research at NCI: staffprofiles.cancer.gov.

The Epidemiology and Genomics Research Program

The division’s Epidemiology and Genomics Research Program (EGRP) is the world’s largest funder of cancer epidemiology research. EGRP provides funding opportunities for scientists to increase understanding of cancer occurrence and outcomes in human populations. The program promotes interdisciplinary collaborations and the development and use of resources and technologies to advance cancer epidemiology and its translation into clinical and public health practice.

Over the years, EGRP has funded large-scale epidemiologic studies that have been instrumental in assessing risk factors for almost all types of cancer, cancer precursors, and response to interventions, as well as survivorship and outcomes. EGRP also promotes inter- and multidisciplinary consortia that can answer unique questions in cancer occurrence and outcomes by pooling data from many institutions across the world and facilitating the translation of these findings to clinical and public health applications. Additionally, epidemiology cohorts funded by NCI and other funding agencies have joined together to examine risk factors for occurrence and outcomes of cancer and other common diseases, as well as the relationship between cancer and other health outcomes in diverse populations.

Epidemiologic research increasingly integrates tools of molecular biology, genomics, and other “omic” fields—along with refined social, behavioral, and environmental measurements at the individual, community, and health system levels—in addition to assessing gene-gene and gene-environment interactions. These advances require significant core infrastructure and bioinformatics support.

In 2012, EGRP initiated an ongoing strategic planning effort to develop scientific priorities for cancer epidemiology research in the next decade, during a period of great scientific advances and resource constraints. EGRP is engaging the research community and other stakeholders to help shape new foci for research, especially in the applications of new methods and technologies that can be integrated into cancer epidemiology. These foci include developing, maintaining, and optimizing cohorts needed to study cancer and related outcomes; using epidemiology to inform and complement treatment and prevention trials; and developing epidemiologic approaches to integrating knowledge emerging from basic, clinical, and population sciences.
EGRP, along with grantees, collaborators, and stakeholders, developed eight broad recommendations for funding agencies, professional societies, and the research community to shape the future of cancer epidemiology following the Trends in 21st Century Epidemiology Workshop held in 2012. Those goals, in brief, are to

- Extend the reach of epidemiology beyond initial discoveries and a focus on etiology;
- Change the practice of epidemiology by providing greater access to data, metadata, and specimens to foster collaboration;
- Expand cohort studies across the life span and include multiple health outcomes;
- Develop and evaluate novel technologies for use in population studies;
- Develop systematic approaches to managing, analyzing, displaying, and interpreting large, complex datasets;
- Expand knowledge integration;
- Transform epidemiology training; and
- Develop and design rational, cost-effective resources to optimize funding for epidemiology studies, accelerate translation, and maximize health impacts.

EGRP plans to continue its progress toward implementing and expanding upon these recommendations in 2015 and looks forward to collaborating with the research community to accomplish these goals.

Health Disparities and Equity Research

The broad area of health equity and disparities has benefited significantly from transdisciplinary research teams in delineating the factors that contribute and exacerbate these inequities. These factors, referred to as the social determinants of health (SDOH), are shaped by the distribution of money, power, and resources at global, national, and local levels, which are themselves influenced by policy choices. Because these factors are avoidable, they can be addressed through a complement of scientific activities that will reduce the burden of these factors and improve overall health.

Social determinants of health (SDOH) can be understood as conditions in which people are born, grow, live, work, and age, including the health system. Research in the area of SDOH largely focuses on delineating differences among racial/ethnic groups and understanding the barriers in care for specific underserved populations and the subsequent development of behavioral interventions for these groups. These interventions, for the large part, have been partially successful but have not consistently sought to change the conditions in which people live, work, and play. Despite the growing evidence of the effects of SDOH on both short- and long-term health outcomes, there is little emphasis on developing theory and evidence-based multilevel and population (community) interventions that target both structural and individual factors. For these interventions to be effective, it necessitates the development of new measures on inequity, social environment, the adaptation of existing measures of SDOH, and a comprehensive understanding of the pathways by which the social context affects health.

In developing multilevel interventions, we must consider important questions. What are the key factors influencing cancer prevention strategies? How can we design and implement culturally appropriate interventions among indigent and medically underserved populations (including cancer survivors) to improve the health and quality of life of these populations? To what extent are clinical and community-based intervention programs designed to address cancer disparities informed by evidence from science, practice, and policy, and are they sustainable in real-life context?

Some general areas of focus would be the development of models and tools for measuring the effects of social context (i.e., place, built environment) on health among diverse populations; models to compare the effects of social context on health patterns and trends within various settings—including community and clinical settings; and common measures for greater interoperability. Another key area of focus would be real-time data and changing...
technology. For example, how can these be garnered to have greater impact on health promotion and disease prevention in low-income and ‘hard-to-reach’ populations?

While focusing on improving the health of the population, it is imperative that we also ensure that every sector of society benefits equally from the developments in health. In this regard, we encourage conducting research in small populations that are largely excluded from clinical trials and interventions due to their limited size (such as refugees, Asian Americans, Native Hawaiians and other Pacific Islanders, American Indians, Alaskan Natives, lesbian/gay/bisexual/transgender, and African American subpopulations). Focusing on research in these small populations and subpopulations requires improved methodologies and selection of an appropriate sample size that will allow for generalizations to the subpopulations across the United States. Some areas of further exploration are required on adapting or developing designs and statistical tools to conduct research on small populations, as well as on determining how evidence-based interventions from other large populations can be adapted to smaller diverse populations. What are the design and statistical factors that need to be considered when testing and implementing multilevel interventions? How can the concept of place be incorporated in these studies? Can these differences in communities be explained by social, environmental, or ecological factors?

As we plan for the coming decade, these are just a few of the questions that will need to be considered and integrated into research conducted across the cancer control continuum.

Implementation Science

The Implementation Science Team of DCCPS seeks to achieve the rapid integration of scientific evidence, practice, and policy, into real-world public health and clinical service systems. The ultimate goal is to improve the effect of research on cancer outcomes and promote health across individual, organizational, and community levels. NCI-funded implementation science research is conducted through research institutions in the United States and internationally with funding through trans-NIH opportunities with other divisions and centers and also with other programs in DCCPS.

The DCCPS Implementation Team has spent several years building and sustaining the field of dissemination and implementation science to enhance the integration of evidence-based guidelines, programs, and policies across the cancer control continuum, from primary prevention to end-of-life care. Over the years, the division has developed a multitude of initiatives, tools, trainings, and funding opportunities to improve the connection of research to practice, policy, and the community. The team engages with researchers, practitioners, and public health decision makers to determine the best connection between cancer interventions and practice. Notable examples include the Research to Reality (R2R) online community of practice; the Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based Tools) web portal that links public health professionals to evidence-based cancer control resources; the newly redesigned State Cancer Profiles website, providing dynamic views of cancer statistics; the Cancer Trends Progress Report, with timely cancer-related data and trends throughout the cancer control continuum; and the searchable database Research-tested Intervention Programs, also known as RTIPs, where program planners and public health practitioners can access over 150 interventions. To support new investigators, the team supports a series of training and education opportunities and resources, including webinars, conferences, and the annual Training Institute for Dissemination and Implementation Research in Health. In the funding arena, the Trans-NIH Funding Announcements for Dissemination and Implementation Research in Health encourage investigators to submit innovative research grant applications.

Collectively with our funded research community and partners, we have made tremendous progress in developing research capacity in the field, robust and rigorous.
conceptual models, empirically supported implementation strategies to embed effective practices in a range of health care settings, and a promising new cohort of talented investigators to catapult the field forward. We are now at a critical point to reap the benefits of the years of field development and to make a profound impact on the cancer community, and by extension, the broader biomedical enterprise as we plan for the next generation of initiatives in research, practice, training, and policy.

We are seeing exciting new research directions pursued—studies of local adaptation and sustainability of evidence-based practices, implementation science in the global context, investigations of rational de-implementation of suboptimal practices, and evolution of interventions to promote ongoing improvement—work that builds upon what we have collectively developed in the implementation science field, and the promise of greater impact of the research community on significantly narrowing the gap between what is possible in cancer care and what is standard practice. While so much progress has been made in better understanding etiology, epidemiology, and personalized treatments for cancer, we still recognize that the overwhelming majority of care takes place outside of the academic medical center, and much more can be done to improve surveillance, screening, reach of treatment, and ongoing monitoring. In this era of new data tools and resources, we see a broad range of activities that can expand current platforms for conducting implementation science, leverage technologies to improve the matching and delivery of effective interventions as needed by populations across the cancer continuum, and support the sustainability and ongoing evolution of cancer clinical and community practice.

The Healthcare Delivery Research Program
NCI leads the nation in championing research on the health and functioning of individuals with cancer, from screening and diagnosis, through treatment and beyond. Cancer care spans many years, making the quality of that care, as well as the quality of life of individuals living with a history of cancer and those caring for them, major national concerns. The goal of initiatives related to health services research at NCI is to improve survival and enhance the patient experience across the cancer control continuum (from risk assessment and preventive care, to screening, diagnosis, and treatment, through follow-up care and end-of-life care), and to reduce the financial burden related to care (both direct and indirect costs such as lost productivity, job loss, and time costs associated with treatment).

Ongoing health care reforms, the growing number of cancer survivors, and the costs and varied quality of cancer care are just a few examples of changes in science, policy, and cancer trends that need to be considered and addressed in the coming decade. As we plan for the future, we are building on successful activities we have in place, while also addressing the new challenges and opportunities for cancer control research in the context of health care systems.

Significant changes have been underway with the creation of the new Healthcare Delivery Research Program (HDRP) and efforts to expand health services research. DCCPS formed this new program from three existing branches (the Health Services and Economics Research Branch, the Outcomes Research Branch, and the Process of Care Research Branch), to serve as the foundation around which health services work throughout DCCPS will be organized. Over the next year, the HDRP will be engaging internal and external experts to identify the most important scientific questions and objectives for the next decade. The group will be asked to focus on NCI’s unique role within the broader landscape of research funders, given that this context has changed substantially over the past few years. What do we need to know 10 years from now to inform our nation’s cancer control strategy within the context of health care systems?

We have exceptional and broad expertise to draw upon within the division. We also have a long history of working alongside many of our grantees and other stakeholders,
who participate in workshops, focus groups, and online forums to contribute ideas and feedback for scientific areas across the division. Based in large part upon the expert input we receive, we will be creating new funding announcements and additional initiatives to energize and support the cancer control community and grow the health services research portfolio. As we develop initiatives, we will strive to communicate our priorities and goals broadly, as well as continually assess and evaluate our progress. All changes are—and will continue to be—informed and guided by our scientific objectives.

The Office of Cancer Survivorship
Created in 1996, the goal of the Office of Cancer Survivorship is to improve the length and quality of life of those diagnosed with and treated for cancer. The office pursues this mission through the promotion of research that identifies and seeks to address the many challenges faced by individuals living long-term after cancer, the training of scientists and practitioners in survivorship issues, and the communication of research findings to the scientific community, as well as to the public and survivors themselves. In the past two decades, understanding of the long-term and late-occurring effects of surviving a cancer diagnosis has expanded rapidly. Cancer survivorship is now broadly recognized as a unique place on the cancer control continuum. Furthermore, the number of researchers and clinicians working in the cancer survivorship space is increasing.

As the population of long-term survivors continues to expand, new questions and challenges are emerging, along with opportunities to address them. Is the pattern of treatment toxicities changing as treatments evolve, and, if so, how? Are there lifestyle behaviors or surveillance practices in which survivors should engage that will lead to reduced morbidity or mortality after cancer? These are just a few of many questions that survivor cohorts may enable us to examine—and more survivor cohorts are expected in response to revisions to the cohort infrastructure program announcement (PAR). Another open PAR seeks a better understanding of the specific mechanisms by which energy balance interventions may affect recurrence and survival. In addition, two active Survivorship Care Planning program announcements invite researchers to explore how individuals who have survived their illness should be followed and cared for—and by whom—after treatment ends. Can we design and systematically deliver multilevel interventions with the potential to reduce the adverse consequences of living beyond cancer? As survivorship science has matured, we are seeing a corresponding—and necessary—shift in funded projects away from descriptive studies to those that seek to prevent or ameliorate the problems identified. What is the role of family caregivers in improving survivors’ physical and psychosocial outcomes? This is a topic we will be exploring at scientific meetings in 2015.

Other, broader trends also serve to influence the focus of research. With the aging of the baby boomer population, it is clear that we need more information on the health and functioning of older cancer survivors, in particular. In addition, the shift to use of more oral medications is bringing attention to efforts to maximize adherence to long-term treatment regimens. As survivorship science evolves, there is pressure to identify metrics that will permit us to better understand the impact this research is having on survivors’ lives. For example, Healthy People 2020 has called for us to show that we are improving the psychosocial well-being of cancer survivors, and yet we have no ready database to track these outcomes.

The new vision in survivorship is one in which we strive to extend the health span of all cancer survivors and their loved ones. It is a future in which survivors are full partners in this effort at all levels of activity. With survivorship science now fully integrated across DCCPS, we can better leverage the more than 50 resident experts to direct and champion the broad range of topics involved in promoting sophisticated survivorship science into the future.
The Surveillance Research Program

The Surveillance Research Program (SRP) provides national leadership in the science of cancer surveillance through its analytical tools and methodological expertise in collecting, analyzing, interpreting, and disseminating reliable population-based cancer statistics. This surveillance infrastructure benefits the public, policymakers, and scientists by improving understanding of changes in cancer incidence and outcomes in all segments of the US population over time. SRP manages the Surveillance, Epidemiology, and End Results (SEER) Program, which is an integrated, comprehensive, multiple population-based reporting system. The SEER Program has been supporting research on the diagnosis, treatment, and outcomes of cancer since 1973. The group of SEER Registries has expanded over time to best represent epidemiologically significant population subgroups, and it now covers 28% of the US population. Data from the SEER Registries are a core component of the SEER Cancer Statistics Review (CSR), which is an annual report of the most recent cancer incidence, mortality, survival, prevalence, and lifetime risk statistics.

SRP seeks to promote and enhance the science of cancer surveillance as the gold standard for generating timely, complete, and accurate cancer surveillance data. SRP leadership, in developing statistical methodologies and tools, as well as in providing a surveillance infrastructure, will support cancer research in changing health care, technology, and scientific environments.

Health care systems have become more complex with the increasing sophistication of diagnosis, treatment, coordination of care, and follow-up plans. The evolution of technology in medicine has required improved data collection methods. We are currently piloting systems for capturing data from electronic medical records using natural language processing. The SEER Program’s new data capture initiatives include increasing the efficiency of data collection through linkages with existing electronic data sources, including claims and direct laboratory feeds. Automating data collection from these other sources will provide more timely, accurate, and complete data, which will support cancer research in a more relevant manner.

Developments in science, such as genome sequencing, have unlocked new sources of information in oncology. To fully realize its purpose, the cancer surveillance field must constantly improve data collection methods to incorporate and analyze the new information. A central focus of SRP’s vision is for the SEER Registries to progress toward supporting a broader scope of cancer research, generating data that are uniquely available via these population-based systems. These research initiatives will include understanding precision medicine in populations (through capture of predictive and prognostic biomarkers) and supporting exploratory basic and clinical research through tools such as the Virtual SEER-Linked Biorepository. SEER will also support the addition of critical data points along the cancer continuum, including the capture of outcomes other than survival (e.g., disease progression or recurrence). We will also collect more detailed information on treatment, especially oral antineoplastics.

As we plan for the next decade, we have several important goals:

1. Maintain our level of high-quality data standards despite increases in the amount and complexity of information;
2. Consolidate information from multiple sources that, over long periods of time, may provide conflicting data; and
3. Ensure data completeness.

The initiatives briefly described earlier summarize the approach that SRP is taking to position SEER Registries to meet 21st century research needs. We have already begun expanding our activities to address the constantly evolving fields of technology and medicine. With each new scientific advancement, SRP will continue to assess and plan the application or development of necessary methods in cancer surveillance.
Enabling the Cancer Control Research Community

The sources of our greatest advances in cancer control are difficult to predict and typically emerge from the talented investigators in our funded research community. Often, their rich experimental ideas can only be realized with NCI funding support and free and open access to the robust, high-quality data and sophisticated research tools that DCCPS provides. By gathering, synthesizing, and making massive amounts of scientific information readily available, using the latest technology, DCCPS affords opportunities to our research community they otherwise would not have.

Here we list a few examples of some of the large-scale, sophisticated efforts led by DCCPS that ensure that researchers, public health practitioners, and policy makers have the resources they need to make large leaps in the complex and national effort to control cancer.

Team Science Toolkit
Cancer researchers are asking highly sophisticated questions and proposing multifaceted scientific initiatives that require a team approach that incorporates expertise of many individuals from different scientific backgrounds. The Team Science Toolkit, developed by DCCPS experts, includes nearly 1,000 resources to help users engage in, manage, facilitate, support, or evaluate team-based collaboration in science. The Toolkit is an interactive website that consolidates knowledge in the Science of Team Science (SciTS) field and facilitates resource sharing and information exchange among the broad community of stakeholders interested in team science.

NCI GeoViewer
In 2014, DCCPS launched NCI GeoViewer, the latest addition to the publicly available geospatial tools on GIS.cancer.gov for cancer surveillance and population-based cancer research. Geovisualization helps identify areas for greater epidemiologic investigation and as targets for interventions. With NCI GeoViewer, users can create maps of cancer statistics, demographics, and risk factors, with access to five sets of high-quality statistics: demographics, cancer incidence, cancer mortality, cancer prevalence, and screening and risk factors. Users are able to select the type of statistic and by-variables shown on the map, change the colors and groups of mapped statistics by choosing from a variety of map options, and extract the map by printing or saving an image or downloading the statistics in a delimited format for further analyses in other software.

Often, [the research community’s] rich experimental ideas can only be realized with NCI funding support and free and open access to the robust, high-quality data and sophisticated research tools that DCCPS provides.
Health Disparities Calculator (HD*Calc)
HD*Calc is designed to generate multiple summary measures to evaluate and monitor health disparities. The HD*Calc statistical software can be used either as an extension of SEER*Stat — allowing users to import SEER data — or with other population-based health data. HD*Calc was originally developed to expand the range of measures for evaluating health disparities related to cancer. However, because it can be used with any dataset, HD*Calc can be used in any research arena. Cross-sectional and trend data (e.g., cancer rates, survival, stage at diagnosis) categorized by disparity groups (e.g., area-socioeconomic status, race/ethnicity, geographic areas) can be imported into HD*Calc to generate four absolute and seven relative summary measures of disparity. The results are displayed as tables and charts, which may be exported for use in other applications. The latest version of HD*Calc was released in FY 2014.

State Cancer Profiles
A part of Cancer Control P.L.A.N.E.T., State Cancer Profiles is a comprehensive system of interactive maps and graphs enabling the investigation of cancer trends at national, state, and county levels. The goal of the site is to provide a system to characterize the cancer burden in a standardized manner in order to motivate action, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities. It is a collaboration between NCI and the Centers for Disease Control and Prevention (CDC). In FY 2014, State Cancer Profiles was redesigned to better serve cancer control planners, public health officials, researchers, and the general public interested in profiling cancer in order to meet the common goal of reducing the cancer burden. The newly redesigned website features a Cancer Control Continuum Dashboard as a point of access to cancer-related statistics that range from prevention to survival. Another important new access point on the home page is a clickable US map that provides a quick reference to the same cancer-related statistics across the geospatial continuum. In addition, the site offers more user-friendly interactive mapping capabilities, charts, and graphs that, all together, contribute to better understanding of cancer-related data over space and time. This release includes NCI SEER and CDC National Program of Cancer Registries incidence data through 2011, screening and risk factor data, and demographic data.
**Cancer Trends Progress Report**

One of NCI’s important responsibilities is communicating our nation’s progress against cancer to the public. The *Cancer Trends Progress Report* is a significant part of that dissemination process. First issued by DCCPS in 2001, the report summarizes our nation’s progress against cancer in relation to *Healthy People* targets set forth by the Department of Health and Human Services (HHS). The report draws on data from numerous federal departments and agencies, including the Environmental Protection Agency, the Department of Agriculture, and several offices and agencies within HHS, including the CDC, the Office of Disease Prevention and Health Promotion, the Substance Abuse and Mental Health Administration, and the National Institute on Alcohol Abuse and Alcoholism. The content, design, and production of the report are the results of a collaboration among federal and state agency partners, consumer advocates, the American Cancer Society, and others. Available only online, the report can be printed in part or in its entirety. Portions of the report are updated annually, while other sections are updated as new data become available. The latest release of the full report was updated in 2014 and will be released in early 2015.

**Cancer Prevalence and Cost of Care Projections**

DCCPS conducts cutting-edge research on the economic burden of cancer and employs some of the nation’s top health economists. The division examines the determinants of the cost of cancer care and develops estimates of the overall economic burden of cancer. To prepare this information, DCCPS has worked to develop new methods and is using the most recent data to estimate the cost of cancer care and to provide projections of cost of care in the future based on population trends. This information has important policy implications for health care planning and resource allocation. On the DCCPS *Cancer Prevalence and Cost of Care Projections* website, visitors can see cost of care or prevalence by cancer site, sex, age, and year under various assumptions. Cancer prevalence is estimated and projected by tumor site through 2020 using incidence and survival data from the SEER Program and population projections from the US Census Bureau. Annualized net costs of care were estimated using Medicare claims linked to SEER data and adjusted to represent costs in 2010 US dollars. The site is based on a DCCPS study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available US population projections, cancer incidence, survival, and cost of care data.

**Cost of Cancer Care by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars**

<table>
<thead>
<tr>
<th>Phase of Care</th>
<th>2010</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial</td>
<td>50</td>
<td>70</td>
</tr>
<tr>
<td>Continuing</td>
<td>40</td>
<td>60</td>
</tr>
<tr>
<td>Last</td>
<td>30</td>
<td>50</td>
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![Cost of Cancer Care by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars](image)
Health Information National Trends Survey

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 the data to gain insight into people’s knowledge about cancer, the communication channels through which they obtain health information, and their cancer-related behaviors. Program planners are using the data to overcome barriers to health information usage across populations, and obtaining the data they need to create more effective communication strategies. Finally, social scientists are using the data to refine their theories of health communication in the information age and to offer new and better recommendations for reducing the burden of cancer throughout the population. As of FY 2014, 170 publications had used data from HINTS, which released new data in 2014 for free download.

Cancer Survivor Prevalence Data

To better understand the demographics of the US population of cancer survivors, the division’s Office of Cancer Survivorship and the Surveillance Research Program worked together to develop survivorship prevalence estimates based on the 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). Cancer survivor prevalence data published in FY 2014 by DCCPS and colleagues at the American Cancer Society indicates a current figure of 14.5 million survivors and projects the number of cancer survivors to increase by 31%, to almost 19 million, by 2024.

![Estimated Number of US Cancer Survivors by Sex and Years Since Diagnosis (as of January 1, 2014)](chart)
The Cancer Genomics and Epidemiology Navigator (CGEN)

CGEN is a searchable knowledge base, providing regularly updated linked information on NCI-funded cancer epidemiology and genomics research grants, peer-reviewed publications, and evidence-based cancer genomic tests. CGEN collates information derived from multiple sources into a centralized search engine to assess the impact of genomic, environmental, and clinical factors on cancer occurrence and outcomes. Ultimately, CGEN serves as a tool to accelerate cancer epidemiologic research. The EGRP in DCCPS recently launched this online resource in response to the concerns of researchers and grantees who reported having difficulty finding information about funded research and publications specific to cancer epidemiology and genomics. Filtering options (e.g., by cancer site, by risk factors, by authorship) allow users to fine-tune searches. For example, researchers can use the “Search CGEN” tool to find broad-based information on a particular risk factor (e.g., smoking); explore EGRP active grants to identify gaps in the EGRP-supported grant portfolio that could guide a research agenda; peruse publications to find peer-reviewed articles that have resulted from currently funded EGRP grants; identify potential collaborations with experts in a particular area, by filtering the list of principal investigators by their links to active or inactive grants and cancer sites; and find an NCI study section for a proposed application by searching for past and current grants with similar features.
OPPORTUNITIES FOR RESEARCHERS

In addition to encouraging the best scientific ideas for researchers through investigator-initiated applications and omnibus solicitations, DCCPS develops and participates in NIH funding opportunities aimed at stimulating new directions in specific research to examine, discover, and test methodologies to improve public health. The following are examples of recent Funding Opportunity Announcements to encourage research projects in emerging or priority areas:

- Core Infrastructure and Methodological Research for Cancer (PAR-14-160)
- Ethical Legal and Social Implications (ELSI) of Genomic Research Regular Research Program (PA-14-276)
- Bridging the Gap Between Cancer Mechanism and Population Science (PAR-13-081)
- Fundamental Mechanisms of Affective and Decisional Processes in Cancer Control (PAR-14-067)
- Exploratory Studies of Smoking Cessation Interventions for People with Schizophrenia (PAR-14-067)
- Research in Native American Populations (PAR-14-260)
- Dissemination and Implementation Research in Health (PAR-13-055, PAR-13-054, PAR-13-056)

More information about funding opportunities can be found at cancercontrol.cancer.gov/funding.html.

SEER-Medicare Health Outcomes Survey Linked Database

The SEER-Medicare Health Outcomes Survey (SEER-MHOS) linked database is a unique resource that can be used to improve understanding of the health-related quality of life of cancer patients and survivors enrolled in Medicare Advantage health plans. The database contains clinical, quality-of-life, socioeconomic, demographic, and other information, and is the result of the linkage of two large population-based data sources: SEER cancer registries data and Medicare enrollment and claims files. The database is sponsored by NCI and the Centers for Medicare & Medicaid Services and has been publicly available to external investigators since 2010. With recent additions, the SEER-MHOS database now contains MHOS surveys from more than one and a half million beneficiaries, with over 82,000 linked to the SEER cancer registry. As of FY 2014, approximately 1,000 publications have used SEER-Medicare data, with topics spanning the continuum of cancer control activities, including diagnosis/treatment, survivorship, second occurrence, and end of life. (A complete list of publications can be found at the SEER-Medicare website.)

Genetic Simulation Resources

Genetic simulations play an important role in genetic research, specifically for the development and testing of analytic methods and assisting with the interpretation of results. Numerous simulation programs have been written for a variety of applications; however, choosing the right tool for a particular study can prove challenging. To this end, the Genetic Simulation Resources (GSR) catalogue was created by DCCPS. The purpose of the GSR is to help investigators identify the genetic simulator most suitable for their research needs. The GSR website includes more than 90 existing software packages that were identified based on publications in relevant scientific journals. The site provides basic information about these applications, such as descriptions, release dates, and links to web pages for the simulation programs. In addition, the GSR characterizes applications by many different attributes, including simulation method, type of genetic variation, input/output formats, programming languages, and license information. Users are able to search and compare simulation software on the GSR website according to these attributes so that they can quickly identify the most appropriate software application for their study.

A centralized listing of scientific tools, reagents, services, and information developed by the NCI that are available to the research community free or at minimal cost are available at the NCI Research Resources webpage: resources.nci.nih.gov.
Investment in Cancer Control Research

Researchers funded by DCCPS have advanced the science to improve public health for nearly two decades, and we celebrate their scientific advances and research accomplishments in cancer control and population sciences. Major programmatic areas include epidemiology and genomics research, behavioral research, health services and outcomes research, surveillance research, and survivorship research.

In FY 2014, DCCPS funded 789 grants valued at more than $430 million, with work in the United States and internationally aimed to reduce risk, incidence, and deaths from cancer, and to enhance the quality of life for cancer survivors. While the majority of DCCPS funding is for investigator-initiated research project grants, the division also uses a variety of strategies to support and stimulate research such as multi-component specialized research centers and cancer epidemiology cohorts.

Learn more about the DCCPS grant portfolio and funding trends at maps.cancer.gov/overview.

DCCPS Research Portfolio by Fiscal Year

Total Grants

Total Dollars (in Millions)

Dollars (U.S. in Millions)
DCCPS Signature Initiatives

DCCPS funds a number of large, signature initiatives across the cancer control research continuum, including

- Integrated surveillance systems;
- Epidemiology consortia, registries, and large-scale genetic studies;
- Transdisciplinary science centers to address public health challenges;
- Networks and consortia to examine quality of care and outcomes; and
- Tobacco control research initiatives.

These initiatives are often carried out in collaboration with our partners at other agencies and research organizations, both within the United States and globally. Below, we highlight selected examples of currently funded initiatives to illustrate the capacity, variety, and breadth of these large initiatives.

Cohorts and Consortia
The NCI Cohort Consortium is an extramural-intramural partnership formed by DCCPS to address the need for large-scale collaborations to pool the large quantity of data and biospecimens necessary to conduct a wide range of cancer studies. The Consortium, through its collaborative network of investigators, provides a coordinated, interdisciplinary approach to tackling important scientific questions, economies of scale, and opportunities to quicken the pace of research. The NCI Cohort Consortium includes investigators responsible for more than 40 high-quality cohorts involving more than 4 million people. The cohorts are international in scope and cover large and diverse populations. Extensive risk factor data are available on each cohort, and biospecimens including germline DNA collected at baseline, are available on more than 2 million individuals. Investigators team up to use common protocols and methods and to conduct coordinated parallel and pooled analyses.

Cancer Intervention and Surveillance Modeling Network
The Cancer Intervention and Surveillance Modeling Network (CISNET) is a consortium of NCI-sponsored investigators who use statistical modeling to improve our understanding of cancer control interventions in prevention, screening, and treatment and their effects on population trends in incidence and mortality. These models can be used to guide public health research and priorities. For example, CISNET researchers are able to analyze the real-life benefits and risks of cancer screening, as well as examine the impact of health policies such as those in tobacco control, which CISNET modelers estimated to be associated with the avoidance of 8 million premature deaths since 1964.
Tobacco Centers of Regulatory Science

Despite decades of work to reduce tobacco use in the United States, it continues to be the leading cause of preventable death and disease. A new, first-of-its-kind regulatory science tobacco program, Tobacco Centers of Regulatory Science (TCORS), has been designed to generate research to inform the regulation of tobacco products to protect public health. Using designated funds from the US Food and Drug Administration, TCORS is coordinated by NIH’s Office of Disease Prevention, and administered by NCI (through the DCCPS Tobacco Control Research Branch), the National Institute on Drug Abuse, and the National Heart, Lung, and Blood Institute. This interagency partnership brings together investigators from across the country to aid in the development and evaluation of tobacco product regulations. Taken together, the 14 TCORS sites will increase knowledge across the full spectrum of basic and applied research on tobacco and addiction. The program also provides young investigators with training opportunities to ensure the development of the next generation of tobacco regulatory scientists.

Population-based Research Optimizing Screening through Personalized Regimens

Evidence-based cancer screening can save lives, but only if people get screened. The Population-based Research Optimizing Screening through Personalized Regimens (PROSPR) Initiative, a major research effort funded by DCCPS, supports research to better understand how to improve the screening process (recruitment, screening, diagnosis, referral for treatment) for breast, colon, and cervical cancers. As of 2014, the initiative had assembled data for 3,311,749 patients, 14,489 providers, and 3,918 facilities from a diverse set of institutions that reflect the complexity of medical care in our country. The overall aim of PROSPR is to develop multisite, coordinated, transdisciplinary research to document the entire screening process to evaluate and improve it. To accomplish this aim, the centers study the comparative effectiveness of existing and emerging screening processes in community practice; examine the balance of benefits and harms across recognized cancer risk profiles; and conduct preliminary studies to inform future research to optimize screening. The PROSPR Initiative is uniquely positioned to contribute to efforts to identify individuals most likely to benefit from cancer screening and to create efficient processes to ensure that screened individuals receive high-quality and timely care.

This interagency partnership brings together investigators from across the country to aid in the development and evaluation of tobacco product regulations.
NCI Community Oncology Research Program

The NCI Community Oncology Research Program (NCORP) is a national network of investigators, cancer care providers, academic institutions, and other organizations serving as stakeholders in the conduct of cancer research. NCORP conducts multisite cancer clinical trials and studies in diverse populations in community health care settings across the United States. The overall goal of the program is to bring cancer clinical trials, as well as cancer care delivery research, to individuals in their own communities, generating evidence that contributes to improved patient outcomes and a reduction in cancer disparities. Enabling cancer patients to join research studies in their own communities allows them to stay close to family, friends, support systems, and their local physicians and health organizations, where high-quality clinical studies result in better care. In collaboration with the Division of Cancer Treatment and Diagnosis, the Center to Reduce Cancer Health Disparities, and the Division of Cancer Prevention (which leads NCORP), DCCPS provides leadership for the program’s Cancer Care Delivery Research activities.

Cancer Prevention and Control Research Network

A collaboration of DCCPS and the CDC’s National Center of Chronic Disease Prevention and Health Promotion, the Cancer Prevention and Control Research Network (CPCRN) is a national network of academic, public health, and community partners who work together to reduce the burden of cancer, especially among those disproportionately affected. Its members conduct community-based participatory cancer research across its 10 network centers, crossing academic affiliations and geographic boundaries, to accelerate the adoption of evidence-based cancer prevention and control in communities, through increased understanding of the dissemination and implementation process. The CPCRN is a thematic research network of the Prevention Research Centers, which are CDC’s flagship programs for preventing and controlling chronic diseases. Having a network with broad geographic reach and strong relationships among investigators allows the network to achieve more than any individual center could achieve on its own.
Collaborative Research on Addiction

Social networking sites and social media interactions present an important data source for understanding health behaviors and attitudes, including the use and abuse of alcohol, tobacco, and other drugs. However, current scientific evidence for social media’s utility in health promotion is limited and inconclusive. To address this emerging area, DCCPS and its partners (the National Institute on Alcohol Abuse and Alcoholism and the National Institute on Drug Abuse) in the trans-NIH initiative known as Collaborative Research on Addiction (CRAN) recently released a Funding Opportunity Announcement (“Using Social Media to Understand and Address Substance Use and Addiction”) to inspire and support research projects investigating the role of social media in risk behaviors associated with the use and abuse of alcohol, tobacco, and other drugs, and projects using social media to ameliorate such behaviors. The strong collaborative framework that CRAN provides enables this type of critical new research by integrating resources and expertise to advance substance use, abuse, and addiction research and public health outcomes.

Person-Centered Assessment Resource

The Person-Centered Assessment Resource (PCAR), funded in 2014, is a new trans-NIH initiative to support the development of a person-centered outcomes measurement information system, called Health Measures, which will be released in spring 2015. The initiative is led by NCI through DCCPS, with support from 12 NIH institutes, offices, and centers. The purpose of the PCAR is to support the creation of a single research resource to support, administer, and provide an integrated platform for automated use of four measurement information systems, originally developed as separate NIH programs: the Patient-Reported Outcomes Measurement Information System, Quality of Life Outcomes in Neurological Disorders, the NIH Toolbox for Assessment of Neurological and Behavioral Function, and the Adult Sickle Cell Quality of Life Measurement Information System. These four systems measure a complement of important health outcomes from an individual’s perspective or provide performance measures of function. In combination, these systems cover the spectrum of health and disease and can be used among healthy individuals, in the general population, in clinical research and trials, and in clinical settings.