

NATIONAL CANCER INSTITUTE Division of Cancer Control & Population Sciences

2018 Overview and Highlights



U.S. Department of Health & Human Services | National Institutes of Health

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Message from the Director



The Cancer MoonshotsM to accelerate cancer research aims to make more therapies available to more patients, while also improving our ability to prevent cancer and detect it at an early stage. In 2016, Congress passed the 21st Century Cures Act, authorizing funding for the Cancer Moonshot over 7 years. To ensure that the Cancer Moonshot's approaches are grounded in the best science, the Cancer Moonshot Task Force established a Blue Ribbon Panel of experts to make transformative research recommendations to accelerate progress against cancer.

The Division of Cancer Control and Population Sciences (DCCPS) has lead responsibility at NCI in a number of priority areas identified by the Blue Ribbon Panel, including engaging patients to contribute their tumor profile data; reducing cancer risk and cancer health disparities through approaches in development, testing, and broad adoption of proven prevention strategies; and collecting, sharing, and analyzing patient cancer data, to predict future patient outcomes.

In this issue of Overview and Highlights, we describe the division's role in advancing research initiatives that align with key recommendations of the Blue Ribbon Panel Report. Some of these initiatives are supported with existing funds, while others are supported using Cancer Moonshot funding authorized under the 21st Century Cures Act. Regardless of the funding source, these activities span the cancer control continuum and represent critical research opportunities poised for acceleration.

Since its creation, DCCPS has played a leadership role at NIH in the development of implementation science. The conceptual and methodological groundwork laid by the division was an essential prerequisite to the ambitious scientific efforts reflected in several Cancer Moonshot initiatives. The excitement and energy surrounding implementation science will only grow as a wave of DCCPS-funded projects produce a wealth of new evidence to inform cancer control.

As always, we proactively engage our extramural community, partners, and stakeholders in sharing their perspectives and identifying those areas where we can have the greatest and most rapid impact through our research investments.

We are grateful for the valuable insight and expertise we have received, and we will continue to solicit input into how we can most effectively champion opportunities for progress in cancer control for all Americans.

Robert T. Croyle, Ph.D. **Director, Division of Cancer Control and Population Sciences**

Leadership at a Glance



Office of the Director Dr. Robert Croyle, DIRECTOR

Office of the Director Dr. Deborah Winn, DEPUTY DIRECTOR



Office of the Director Dr. David Chambers, DEPUTY DIRECTOR FOR IMPLEMENTATION SCIENCE



Office of the Director Dr. Shobha Srinivasan, HEALTH DISPARITIES RESEARCH COORDINATOR

4 RESEARCH PROGRAMS



Epidemiology and Genomics Research Program Dr. Kathy Helzlsouer, ASSOCIATE DIRECTOR



Epidemiology and Genomics Research Program Dr. Emily Harris, DEPUTY ASSOCIATE DIRECTOR



Methods and Technologies Dr. Mukesh Verma, BRANCH CHIEF



Environmental Epidemiology Dr. Gary Ellison, BRANCH CHIEF



Genomic Epidemiology Dr. Elizabeth Gillanders, BRANCH CHIEF



Clinical and Translational Epidemiology Dr. Andrew Freedman, BRANCH CHIEF



Risk Factor Assessment Dr. Amy Subar, 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. Serban Negoita, BRANCH CHIEF



Surveillance Informatics Steve Friedman, ACTING BRANCH CHIEF

Dr. Angela Mariotto, BRANCH CHIEF





Statistical Research and Applications Dr. Eric Feuer, BRANCH CHIEF

Data Analytics



Behavioral Research Program Dr. William Klein, ASSOCIATE DIRECTOR



Behavioral Research Program Dr. Linda Nebeling, DEPUTY ASSOCIATE DIRECTOR



Basic Biobehavioral and Psychological Sciences Dr. Paige Green, BRANCH CHIEF



Health Behaviors Research Dr. Susan Czajkowski, BRANCH CHIEF



Health Communication and Informatics Research Dr. William Klein, ACTING BRANCH CHIEF



Tobacco Control Research Dr. Michele Bloch, BRANCH CHIEF



Office of Cancer Survivorship Dr. Deborah Mayer, NTERIM DIRECTOR





Healthcare Delivery Research Program Dr. Ann Geiger, DEPUTY ASSOCIATE DIRECTOR



Healthcare Assessment Research Dr. Paul Doria-Rose, BRANCH CHIEF



Health Systems and Interventions Research Dr. Sarah Kobrin, BRANCH CHIEF



Outcomes Research Dr. Ashley Wilder Smith, BRANCH CHIEF

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DCCPS Response and Contribution to the Cancer Moonshot

This issue of Overview and *Highlights* features examples of the DCCPS response to the Blue Ribbon Panel's recommendations, including the following opportunities and initiatives made possible through Cancer Moonshot funding authorized under the 21st Century Cures Act. In addition to these priorities, the division continues to invest in research across the cancer control continuum. Most of the grants DCCPS funds are investigator initiated, not in response to a specific funding opportunity announcement. Potential grant applicants are encouraged to contact one of our program directors, whose contact information can be found on our website (https://cancercontrol. cancer.gov).

For each Cancer Moonshot priority, we include examples of DCCPSled funding announcements and activities that illustrate some ways in which the division is addressing each area.

Network for Direct Patient Engagement

Patient Engagement for Priority Cancer Sequencing—The Blue Ribbon Panel notes the importance of directly engaging with patients to facilitate participation in research and to ensure patients are respected and have access to the research enterprise. The goal of this initiative is to demonstrate the potential utility of direct patient engagement to complement existing infrastructures and traditional approaches to engaging patients in research. Through this Request for Applications (RFA), NCI will fund targeted direct patient engagement projects, with a focus on underrepresented populations, to generate a comprehensive genomic landscape of cancers that are poorly characterized, to address research gaps and NCI priority areas.

Portal to Support Patient Engagement Projects—The goal of this contract is to develop a master patient gateway portal that will provide a single point of entry for the existing Cancer Moonshot engagement efforts, as well as any future engagement projects funded by NCI. By providing a single point of entry, the patient gateway will amplify communication across NCI engagement efforts. The initial modular infrastructure to support study-specific portals will be driven by the requirements of the Moonshot Biobank and Rare Tumor Patient Engagement Network (RTPEN), but will be extendable and customizable to meet the needs of future communities. This project is a collaboration between the Data Ecosystem and Network for Direct Patient Engagement teams, and DCCPS played a critical role in developing and refining this concept.

PATIENT GATEWAY

DEMONSTRATION PROJECTS

FUNDAMENTAL RESEARCH

As part of a much larger undertaking, DCCPS is just one contributor of many working to realize the goals of the Cancer Moonshot. Under the leadership of Drs. Doug Lowy and Dinah Singer, NCI rapidly established a systematic process for implementing the Moonshot Blue Ribbon Panel (BRP) Report's recommendations. NCI staff led the effort to operationalize those recommendations, forming working groups and using a variety of mechanisms to develop funding opportunities aligned with each recommendation.

To promote and enhance data-sharing, all reports resulting from Cancer Moonshot activities are required to adhere to an open-access policy of immediate data release upon publication. NCI has also developed new partnerships with other government agencies, the private sector, and the international research community to further the goals of the Cancer Moonshot in general and the BRP recommendations in particular.

A National **Cancer Data Ecosystem for Sharing and** Analysis

Establishing Data Linkages: Unique Encrypted Patient Identifiers from Claims and *EMRs*—NCI's Surveillance Research Program (SRP) is undertaking steps to enhance Surveillance, Epidemiology, and End Results (SEER) Program data as a research resource. In September 2017, SRP utilized Cancer Moonshot funds

to sponsor a workshop with insurance companies to inform the direction of linkages between claims data and SEER data. The goals of this effort are to create a data science infrastructure that connects, collects, and shares a broad array of large data sets to enable patients, clinicians, and researchers to contribute and analyze data-facilitating discovery that will improve patient care and outcomes. To accomplish this goal, the SEER Program is expanding population-based linkage of claims from multiple insurers, focusing on efficiency (a standardized format from all health care providers, ANSI 837), accuracy, and collection of



data that are historically beneficial (SEER Medicare 65+).

SEER Partnership with the US Department of Energy—A key area of the enhancement of SEER is focused on electronic medical record (EMR) data integration. The SEER Program is partnering with Department of Energy (DOE) scientists, using Cancer Moonshot funding, to develop tools that will allow SEER to collect the data elements it has traditionally captured (e.g., cancer type and grade), as well as new data elements (e.g., biomarkers, recurrences) from patient data, including pathology

reports. Compared with the manual collection that is often used now, automated data collection would be far more reliable and rapid, even if some cases still require manual coding.

Symptom Management Research

Improving Management of symPtoms Across Cancer Treatments (IMPACT)—Currently, there are major barriers to effective symptom control among cancer patients, and a lack of systematic efforts to translate research into practice. The Blue Ribbon Panel therefore emphasizes the need to gather and monitor patient-reported symptoms and to provide decision support and care using evidencebased symptom management guidelines. This RFA encouraged the development of scalable, transferrable, and sustainable models for monitoring and addressing symptoms in routine practice, with multiple research centers expanding the breadth of models tested. The RFA supported the development of a research consortium, with the goal to produce findings and materials for wider implementation. Three research centers and one coordinating center have been awarded. The research centers are responsible for the deployment and evaluation of the symptom assessment and management system using implementation science approaches, while the coordinating center provides oversight and management of collaborative activities within the consortium.

Prevention and Early Detection: Implementation of Evidencebased **Approaches**

Accelerating Colorectal Cancer Screening and follow-up through Implementation Science (ACCSIS)—There is suboptimal uptake of evidence-based cancer prevention and screening programs, particularly among underserved populations. The purpose of this funding opportunity announcement is to promote research in colorectal cancer screening, follow-up, and referral-to-care among target populations for whom screening rates are below national standards. The goal of the ACCSIS program is to provide a robust evidence base for multilevel interventions that increase rates of colorectal cancer screening, follow-up, and referral-to-care, and best practices for how multilevel interventions can be scaled-up to reduce the burden of colorectal cancer on the United States population. Currently, three research grants and one coordinating center have been awarded, and the RFA has been reissued, with another round of funding planned for fiscal year (FY) 2019.

Accelerated Control of Cervical Cancer-Control of human papillomavirus (HPV)-related cancers and cancer health disparities were specifically identified as high-priority areas in the recommendations of the Blue Ribbon Panel. This proposal is

focused on accelerating research in cervical cancer screening, with implications for the United States - where cervical cancer is a health disparity for African-American, American Indian, and Hispanic women, and poor women generally - and globally. The goal is to control cervical cancer by combining new screening tools and simplified vaccination strategies across settings with varying resource levels. Therefore, the initiative promotes extramural research focused on both underserved, low-resource settings in the United States, as well as improving implementation of new risk-based screening and prevention strategies in high-resource settings.

Implementation Science for Cancer Control-For many years, health researchers may have assumed that tools and interventions deemed efficacious within clinical or community-based trials would be readily adopted and implemented; however, compelling evidence suggests that this has not been the case. This funding opportunity announcement encourages investigators to submit research grant applications that will identify, develop, test, evaluate and/or refine strategies to disseminate and implement evidence-based practices (e.g., behavioral interventions; prevention, early detection, diagnostic, treatment, and disease management interventions; quality improvement programs) into public health, clinical practice, and community settings. In addition, studies to advance dissemination and implementation research methods and measures are encouraged. Funding is planned for FY19.

Cancer **Prevention and** Early Detection: **Inherited Cancer Svndromes**

Approaches to Identify and Care for Individuals with Inherited Cancer Syndromes-Despite the availability of genetic testing and counseling, a substantial number of those at risk for cancer are not identified and thus may not benefit from available prevention and early-detection approaches. The purpose of this funding opportunity announcement is to increase case ascertainment and appropriate follow-up care, optimizing the delivery of evidence-based health care for individuals at high risk of

cancer due to an inherited genetic susceptibility. One grant was funded in FY18, and the RFA has been reissued for FY19 funding.

Communication and Decision Making in the Context of Risk and Uncertainty for Individuals with Inherited Cancer Syndromes —One of the most challenging tasks confronting an individual with an inherited cancer syndrome is understanding his or her risk of disease and applying this understanding to decisions involving disease risk management and disclosure of genetic test results to family members. The purpose of this funding opportunity announcement is to develop, test, and evaluate interventions and implementation approaches, or adapt existing approaches, to

Number of New Cases per 100,000 Persons by **Race/Ethnicity: Prostate Cancer**



U.S. 2011-2015, Age-Adjusted Source: https://seer.cancer.gov/statfacts/html/prost.html

improve patient/provider/family risk communication and decision making for individuals and families with an inherited susceptibility to cancer. This initiative will be funded in FY19.

Health **Disparities**

Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics. Tumor Markers, and Social Stress (RESPOND)-African-American men are more likely to be diagnosed with prostate cancer than non-Hispanic white men, they are more likely to be diagnosed with aggressive disease, and they are more likely to die from prostate cancer than men

Number of Deaths per 100,000 Persons by **Race/Ethnicity: Prostate Cancer**

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in other racial and ethnic groups. In FY18, NCI provided support, using Cancer Moonshot funding, for RESPOND—the largest coordinated research effort to study biological and non-biological factors associated with aggressive prostate cancer in African-American men. The study is investigating social, environmental, and genetic factors related to aggressiveness of prostate cancer in African-American men to better understand why they disproportionally experience aggressive disease compared with men of other racial and ethnic groups. RESPOND is also supported by the National Institute on Minority Health and Health Disparities and the Prostate Cancer Foundation.

Improving Smoking Cessation in Socioeconomically Disadvantaged Populations via Scalable Interventions—Comprehensive tobacco control efforts have produced several decades of steady declines in smoking prevalence in the general US

population; however, this progress has not occurred equally across socioeconomic strata. This funding opportunity announcement is intended to stimulate research efforts aimed at the development of smoking cessation interventions that are targeted to socioeconomically disadvantaged populations and could be made scalable for broad population impact. Applicants may propose projects that develop and test novel cessation interventions with the potential to be scaled up, as well as projects that focus on enhancing the effectiveness, quality, accessibility, utilization, and costeffectiveness of currently scaled smoking cessation interventions.

Dissemination of a Colorectal Cancer Screening Program Across American Indian Communities in the Southern Plains and Southwest United States-Cancer screening programs are partly responsible for declining colorectal cancer incidence and mortality in the United States. Unfortunately,

American Indians have experienced either no change or an increase in colorectal cancer incidence and mortality, disproportionate diagnosis of late-stage disease, and poorer survival. Despite the effectiveness of colorectal cancer screening tests for average-risk adults, these tests are significantly underutilized by American Indians. This project supports research on system-level changes and culturally appropriate media that promote any USPSTFapproved colorectal screening test. In consultation with local tribes (such as Navajo, Southwest Pueblos, and Chickasaw), the research teams-made up of cancer centers in Arizona, New Mexico, and Oklahoma, local tribes, and epidemiology centers-will set up data sharing and ownership quidelines and agreements, with the ultimate goal of closing the gap in colorectal cancer outcomes between the American Indian population and the general US population.



Expanding Smoking Cessation Services at NCI-Designated Cancer Centers

Smoking rates have decreased substantially in the United States over the past several decades; however, too many smokers who are diagnosed with cancer don't guit smoking. Continued smoking after a cancer diagnosis can interfere with treatment and worsen a patient's prognosis, while quitting can help improve patients' symptoms and their ability to recover more quickly from treatment, in addition to improving their long-term outcomes.

To help address this issue and in response to the Cancer Moonshot Blue Ribbon Panel recommendation to better understand how to implement and sustain comprehensive tobacco control strategies among patients

using existing health-related infrastructure, NCI launched the Cancer Center Cessation Initiative.

Using Cancer Moonshot funds, the initiative provided resources in FY17 and FY18 to 42 NCI-Designated Cancer Centers to expand existing efforts intended to help their patients who are smokers to stop smoking. Centers will endeavor to identify and offer evidence-based cessation treatment to all cancer patients who smoke. They are also required to sustain these interventions for a minimum of 3 years after the funding ends.

Ultimately, the goal is to more fully integrate cessation interventions into routine patient care at cancer

centers, so that helping cancer patients who smoke to guit becomes the standard of care in cancer treatment. NCI's expectation is that centers that received these awards will substantially expand their delivery of cessation services and will sustain those services into the future. It is also hoped that these centers can share the lessons learned from their experience to provide guidance to cancer centers and to other hospitals to help more patients quit smoking.

Adapted from NCI's Cancer Currents Blog, November 22, 2017.



Enhancements to NCI's SEER Program Creating New Research Opportunities

Since its launch 45 years ago, NCI's Surveillance, Epidemiology, and End Results (SEER) Program has been the nation's premier source for clinically relevant patient data at the population level-data that the research community, as well as patients, want and need to better understand cancer and its impact. One of NCI's most important partnerships with the Centers for Disease Control and Prevention, the SEER Program is the most comprehensive population-based cancer registry in the world and is an invaluable resource for conducting populationbased observational studies, as well as clinical and even basic research.

In FY18, after a lengthy and complex re-competition process, DCCPS awarded contracts to the SEER Program registries. The new Program includes 16 registries covering 34% of the population and 19 different geographic areas, and is valued at more than \$40 million per year. Also in recent years,

DCCPS and SEER leadership have been working with many groups and experts to better understand the cancer research community's needs and the opportunities that could be created through strategic, targeted enhancements to SEER.

In those discussions and forums, the main data needs that were identified included those that cover

- All treatments received by individual patients from diagnosis until their death;
- Outcomes other than incidence and mortality-in particular, recurrences; and
- The genomic composition of patients' tumors.

As might be expected, enabling SEER to collect such data, and ensuring that they are accurate, is an extremely complex undertaking. It's because of that great complexity that NCI is moving forward with these enhancements in a thoughtful

and systematic way—one that we believe will lay the foundation for successfully integrating them into the broader SEER Program.

Among the most important enhancements to the SEER Program is the expansion of the size and diversity of the population it covers. With the expansion in FY18, SEER is now collecting data on approximately 550,000 new individual cancer cases each year. This expansion was implemented with a strategic focus: adding US cancer registries that include more underserved and ethnic/racial minorities, in order to capture cancer data that more fully represent the US population.

Unfortunately, we can't immediately start collecting every type of data we'd like SEER-wide. Therefore, the Program has also launched a series of pilot studies that can help us better understand the barriers and challenges to collecting these new types of data.

For example, as mentioned previously, NCI is partnering with Department of Energy (DOE) scientists, using funding provided through the Cancer Moonshot, to develop tools that will allow SEER to collect the data elements it has traditionally captured (e.g., cancer type and grade), as well as new data elements (e.g., biomarkers, recurrences), from patient medical records. Compared with the manual collection that is often used now, automated data collection would be far more reliable and rapid, even if some cases still require manual coding. Another SEER pilot study is focusing on collecting data on the use of oral cancer drugs and adherence to prescribed regimens by linking registry data with pharmacy data. Similar pilot efforts are creating

linkages between SEER registries and health insurance claims data from some of the largest health insurance companies in the country. Other pilot linkage efforts under way involve collecting data on the results of genomic tests. As oncology continues on the road to precision medicine, the ability to systematically collect these data would go a long way toward informing this movement.

While these linkage pilots are noteworthy, another exciting enhancement to SEER under active evaluation is on the other end of the research spectrum: the development of a "virtual biorepository." The aim of this repository is to provide information on tumor samples stored at institutions across the country. This



will allow investigators to search for samples from patients with certain demographic or clinical characteristics or certain outcomes, and then request those samples (including all related clinical data on that patient) via an honest broker for use in their research.

Over the coming decade, stay tuned to hear more about a remarkable array of new scientific opportunities. As always, DCCPS welcomes ideas and feedback from the cancer community about ways to strengthen the utility and usability of SEER data for both cancer research and cancer control planning.

Adapted from NCI's Cancer Currents Blog, August 23, 2018.



Research to Improve Cancer Control in Rural Communities

In addition to higher poverty rates and lower educational attainment, rural communities face numerous challenges compared to urban areas. Rural communities have higher average death rates from cancer for all cancer sites combined, higher incidence and death rates for cancers associated with smoking (e.g., lung and laryngeal cancers), and higher rates of colorectal and cervical cancers—cancers that can be prevented by screening. And although death rates from cancer are decreasing in both rural and urban areas, they are decreasing much more slowly in rural areas, further compounding these cancer disparities.

Research has shown that some of these cancer disparities can be attributed to financial barriers and barriers to health services, such as no or insufficient insurance coverage, transportation issues, and lack of preventive and screening services. There are also rural-urban differences in behaviors that are associated with cancer, including higher rates of tobacco use, alcohol consumption, and obesity; and lower rates of physical activity, adoption of sun safety measures, and HPV vaccination rates in rural compared to urban areas.

This long-standing public health challenge calls for sustained support for research along the entire cancer control continuum, with interdisciplinary cross-sectional collaborations. This past year, DCCPS awarded 21 administrative supplements to P30 Cancer Center Support Grants to develop rural cancer control capacity. These supplements will provide resources to support the time and effort of teams at NCI-Designated Cancer Centers, in collaboration with rural communities and clinics, who will develop a comprehensive rural cancer control program that serves low-income and underserved populations. Seven of these

awarded supplements focus on Native American populations.

Initial analysis of broadband and cancer data has shown that rural "cancer hotspots" are areas that also face large gaps in broadband access and adoption, which put care solutions out of reach for many. Therefore, DCCPS joined forces with the Federal **Communications Commission** to increase broadband access and adoption in rural areas to improve the lives of rural cancer patients. The project-titled LAUNCH (Linking & Amplifying **User-Centered Networks** through Connected Health): A Demonstration of Broadband-Enabled Health for Rural Populations in Appalachia-will target areas that face the dual challenge of higher cancer mortality rates and lower levels of broadband access. The initial geographic focus is planned for rural Kentucky. The LAUNCH demonstration project links recommendations from the

President's Cancer Panel's 2016 report (Improving Cancer-Related Outcomes with Connected Health) with selected targets of opportunity from the Cancer Moonshot Blue Ribbon Panel 2016 Report.

DCCPS also spearheaded a meeting in May 2018 that brought together more than 250 researchers, clinicians, and

agency and community partners from a wide range of backgrounds and expertise to address rural health disparities. That meeting and its resulting discussions and partnerships—along with a new funding opportunity, Improving the Reach and Quality of Cancer Care in Rural Populations, which will be awarded in FY19 for approximately \$35M over 5 years—will spur more



research in this domain to improve the reach and quality of cancer care in rural populations. Focused research initiatives will provide the groundwork to develop and implement cancer control programs that are sustainable in these rural communities across the United States.

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Health Care Delivery Research

Health care delivery research at NCI incorporates the study of cancer care, factors influencing care, and outcomes of care. Cancer care refers to medical services offered across the cancer continuum, such as screening individuals not known to have cancer; treating cancer patients; following cancer survivors for recurrence; and providing psychosocial support at the end of life for patients and their caregivers. Ultimately, the outcome of most interest in health care delivery research is reducing the burden of cancer on individuals and society.

DCCPS' Healthcare Delivery Research Program leads the Cancer Care Delivery Research (CCDR) area of NCI's Community **Oncology Research Program** (NCORP). NCORP is a national network that brings cancer prevention clinical trials and cancer care delivery research to people in their communities. The CCDR portion specifically examines how

social factors, financing systems, organizational structures and processes, health technologies, and health care provider and individual behaviors affect cancer outcomes, access to and guality of care, cancer care costs, and the health and well-being of cancer patients and survivors. NCORP clinical trials and research studies are under way at sites throughout the country. The network's research bases are "hubs" for the network that design and spearhead the conduct of multicenter clinical trials.

Another network supported by DCCPS' Healthcare Delivery Research Program is the Population-based Research Optimizing Screening through Personalized Regimens (PROSPR) initiative, which focuses on the challenges and processes of cancer screening for breast, colon, and cervical cancers in community settings. For the second PROSPR funding cycle, which started in April 2018, NCI

funded one coordinating center and three research centers (one each focused on cervical, colorectal, and lung cancer). Each research center includes a minimum of three heterogeneous health care systems with diverse patient populations. The overall goal of PROSPR is to enhance understanding of the implementation and effects of screening as practiced in multiple health care environments in the United States. In addition to conducting multilevel observational research to evaluate factors that affect the quality of the screening process for the selected cancer type, the research centers will develop and pilot-test interventions aimed at improving the screening process for that cancer. PROSPR's publicly available data set can be used in research to understand the long-term consequences of screening and provide a basis for interventions.

Understanding and Addressing the Needs of Cancer Survivors

As of January 2019, it is estimated that there are 16.9 million cancer survivors in the United States, and this number is projected to grow to over 26 million survivors by 2040. These numbers underscore the growing importance of better understanding the needs of cancer survivors and how best to care for those survivors. Childhood cancer survivors, in particular, have unique needs, with two thirds of childhood cancer survivors suffering from at least one health problem caused from their treatment. Beyond physical health issues, childhood and adolescent and young adult (AYA) survivors have unique challenges in health care delivery (e.g., unmet needs for long-term follow-up, issues with continuity of care) and are at increased risk for a myriad of psychosocial and behavioral adverse effects. The number of childhood cancer survivors continues to grow, as well. In the latest published data at this time, there were approximately 429,000 survivors of childhood and

adolescent cancer in the United States. That number will continue to increase, given that the incidence of childhood cancer has been rising slightly in recent decades and that survival rates overall are improving.

In May 2018, Congress passed The Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act, developed in collaboration with many childhood cancer organizations as a comprehensive childhood cancer



bill to advance pediatric and AYA cancer research and treatments, improve cancer surveillance, and enhance resources for survivors and their families. The STAR Act authorizes improvements to biospecimen collection and associated infrastructure, registry infrastructure, and research to improve the care and quality of life for cancer survivors - including children and AYAs.

DCCPS has issued a funding opportunity announcement to efficiently implement major elements of the STAR Act by funding multiple intervention research project grants beginning in FY19. This Cancer Moonshot research funding announcement (RFA) focuses on stimulating the scientific development of effective, feasible, and scalable interventions to address biomedical, behavioral, and psychosocial adverse effects in survivors of pediatric/AYA cancers. This RFA requests applications from investigators to address the areas of research outlined in the STAR Act by proposing intervention

studies to improve health care delivery or to prevent or mitigate adverse effects in pediatric/AYA cancer survivors. The development of interventions to address health disparities and the needs and preferences of minority or other medically underserved populations will be of high priority in all research areas.

DCCPS has also proposed an RFA focused on survivors of adult-onset cancers. This RFA is designed to stimulate interventional research aimed at enhancing communication, engagement, and coordination between oncology

specialists and providers not involved in active cancer treatment, in order to optimize follow-up care for cancer survivors. It is expected that the ability to care for the growing number of survivors will be advanced by demonstrating how other types of care providers can be engaged in coordinated survivorship care, thereby conserving scarce specialized resources for those in need of more intense, cancer-focused care. Accordingly, this RFA has the potential to change the face of cancer survivorship care.



Investments in Cancer Control Research

Researchers funded by DCCPS have advanced the science to improve public health for more than 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 care delivery research, surveillance research, and survivorship research.

In FY18, DCCPS funded 647 grants valued at more than \$433 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. In addition, the division funded \$88.5 million in contracts, which includes the SEER Program. While the majority of DCCPS funding is for investigatorinitiated 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.



Total Dollars (in Millions)



Total Grants



Opportunities for Researchers

In addition to encouraging 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:

- Modular R01s in Cancer Control and Population Sciences (PAR-18-869)
- Secondary Analysis and Integration of Existing Data to Elucidate the Genetic Architecture of Cancer Risk and Related Outcomes (PA-17-239, PA-17-243)
- Core Infrastructure and Methodological Research for Cancer Epidemiology Cohorts (<u>PAR-17-233</u>)

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

- Using Information Technology to Support Systematic Screening and Treatment of Depression in Cancer (<u>PA-18-492</u>, <u>PA-18-493</u>)
- ► U.S. Tobacco Control Policies to Reduce Health Disparities (PAR-18-675, PAR-18-674)
- Tobacco Use and HIV in Low and Middle Income Countries (<u>PAR-18-023</u>, <u>PAR-18-022</u>)

DCCPS by the Numbers

As a window into the many ways DCCPS provides return on investment, we highlight here just a few snapshots of progress from the past year.

Smokefree.gov experienced a 69% increase in website visits from FY17 to FY18 (2.25 million to 3.8 million) due to programmatic improvements involving search engine optimization, site navigation, and adjusting content to better match how real smokers are seeking online information about smoking cessation.

69%

436

1,388

1,103

195

As of FY18, 436 peer-reviewed publications had used data from the Health Information National Trends Survey (HINTS), which monitors changes in the rapidly evolving fields of health communication and health information technology.

The searchable online Measures Registry of the National Collaborative on Childhood Obesity Research (NCCOR) contains 1,388 annotated validation studies of measures of diet, physical activity, and their environmental determinants. With NCCOR collaborators, DCCPS developed the Measures Registry and provides ongoing updates.

More than 1,100 peer-reviewed publications have resulted from the Transdisciplinary Research on Energetics and Cancer (TREC) Centers initiative. TREC fosters collaboration across multiple disciplines and projects, from the biology, genomics, and genetics of energy balance to behavioral, sociocultural, and environmental influences upon nutrition, physical activity, weight, energetics, and cancer risk. The initiative also has trained 135 early-career researchers through annual transdisciplinary training workshops on energy balance and cancer.

The Research-Tested Intervention Program (RTIPs) is a searchable database of more than 195 evidence-based cancer control interventions and program materials, spanning 13 topics of interest, for program planners and public health practitioners.

The NCI Cohort cohorts, and mor cancer risk facto

by researchers.

The Cancer Epidemiology Descriptive Cohort Database (CEDCD) contains descriptive information from more than 60 cohorts in 17 different countries. The CEDCD includes brief descriptions of the cohorts, contact information, questionnaires, types of data collected, enrollment numbers, number of cancer cases, and number of biospecimens collected. Its purpose is to foster collaborations and encourage cohort-based research.

In FY18, 1,064 studies were published using data from the Surveillance, Epidemiology, and End Results (SEER) Program, a premier source for cancer statistics in the US. In addition, 1,220 SEER custom data set requests were fulfilled for the research community, and 191,000 analyses were conducted using SEER*Stat software.

There were 40,650 total views for *all* videos in the *Did You Know?* Video series. Each of the more than two dozen videos in the series provides key statistical data on different types of cancer to a lay audience in understandable, clear, and concise language.



Health formational Trends

XNCCOR







The 2018 Training Institute in Dissemination and Implementation Research in Cancer (TIDIRC) provided 50 investigators with a thorough grounding in conducting dissemination and implementation (D&I) research with a specific focus on cancer across the cancer control continuum. The institute was delivered both online and in-person and was led by a faculty of leading experts in theory, methods, and evaluation approaches in implementation science.

50

million

6,660

60

The NCI Cohort Consortium has more than 7 million participants in 58 international cohorts, and more than 40 projects that have made scientific discoveries about cancer risk factors and technical advances in cohort methodologies.

The Automated Self-Administered 24-hour (ASA24®) Dietary Assessment Tool is a web-based tool that enables multiple, automatically coded, self-administered 24-hour recalls. Beginning with the 2016 release, ASA24 also permits data collection using single or multi-day food records. In 2018, on average 114 studies per month registered to use ASA24, and 6,660 recall/record days per month were collected

40,650

1,064



DCCPS staff members are innovators in creating resources for the research community, such as methods and tools for population-based cancer statistics. In FY18, there were 3,205 downloads of Joinpoint, a statistical software for the analysis of trends using joinpoint models; that is, models where several different lines are connected together at the "joinpoints."

3,205

As of the beginning of December 2018, DCCPS had hosted 53 webinars for the research community, with 5,628 participants in 2018. These webinars are one of the platforms DCCPS uses to share critical information with key audiences located across the country or in other parts of the world.

5,628

Nearly 3,300 participants have been accrued to Cancer Care Delivery Research (CCDR) studies of NCI's Community Oncology Research Program (NCORP). NCORP is a national network that brings cancer prevention clinical trials and cancer care delivery research to people in their communities.

3,300

There were more than 2,200 customizable forms downloaded in FY18 for the Patient-reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) to capture symptomatic adverse events in patients on cancer clinical trials.

2,200

There were over 200 new requests to use SEER-linked data in FY18, including SEER-Medicare, SEER-Medicare Health Outcomes Survey (SEER-MHOS), and SEER-Consumer Assessment of Healthcare Providers and Systems (SEER-CAHPS).

200

9

In 2018, NIH and FDA renewed their commitment to the Tobacco Centers of Regulatory Science (TCORS) Program and awarded a second cohort (TCORS 2.0) of centers to nine institutions. The TCORS are made up of scientists with a broad range of expertise, who generate critical research that informs the FDA's regulation of tobacco products. NCI holds four of the new TCORS center grants; all of these grants include key scientific aims related to e-cigarettes/Electronic Nicotine Delivery Devices (ENDS) products.

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