



INFORMING POLICY AND PROGRAMS

# 2022 UPDATE



**NATIONAL CANCER INSTITUTE**

Division of Cancer Control & Population Sciences

# TABLE OF CONTENTS

OVERVIEW .....	1
EVALUATING STRATEGIES FOR IMPROVING VALUE AND PATIENT OUTCOMES .....	2
TOBACCO CONTROL .....	8
A HEALTHIER GENERATION .....	10
CANCER AND THE ENVIRONMENT.....	14
PRACTICAL DATA AND EVIDENCE FOR POLICY MAKERS .....	16
INTERNATIONAL POLICY IMPACT.....	19
LOOKING AHEAD: THE POLICY HORIZON.....	22

## OVERVIEW

The Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI) supports science that helps inform policies and programs aimed at preventing, detecting, and treating cancer and improving outcomes for cancer survivors. The supported science includes work to understand and assist those living with a history of cancer, as well as their families. A key focus of this work is evaluating the effect of models of care, incentives, and identifying genetic and environmental factors that affect treatment outcomes and that can be addressed to improve care. Tobacco control research supported by DCCPS informs the Food and Drug Administration (FDA) in its authority to regulate the manufacture, marketing, and distribution of tobacco products in order to protect public health. Another critical focus is determining the environmental and genetic causes of cancer, supporting research on environmental exposures, climate change, neighborhood-level factors, and underlying genetic susceptibility to cancer and the effects of exposures. Research supported by DCCPS therefore provides policy makers with the practical evidence they need to make effective decisions.

The division's long-standing history of collaborating across the National Institutes of Health (NIH), US Department of Health and Human Services (HHS), and other agencies makes it uniquely suited to continue to play a role in the generation of evidence to shape and respond to national efforts to improve the health of the public and the value and effectiveness of cancer care. This brief provides examples of the division's research contributions related to public policy and illustrates its role in developing a comprehensive base of scientific evidence for policy makers and public health practitioners.



## EVALUATING STRATEGIES FOR IMPROVING VALUE AND PATIENT OUTCOMES

DCCPS conducts and supports ongoing research to inform public policy focused on improving access to health care services, improving patient outcomes, and reducing financial burden. Over recent decades, there have been dramatic paradigm shifts in cancer treatment, through the addition of targeted agents, immunotherapy, and an emphasis on oral regimens, which have had substantial impacts on cost of care and raised new issues around access; and on the other end of the spectrum, there has been more emphasis on reducing intensity of care and improving palliative care access. DCCPS is uniquely positioned to support research that will generate information needed to evaluate the impacts of these changes so that policy adjustments can be made as needed to achieve goals and avoid adverse consequences on care delivery and outcomes for all populations across the United States.

### Research Informing Coverage of Preventive Health Services

DCCPS plans, implements, and maintains a comprehensive research program to promote the appropriate use of effective cancer screening tests, as well as strategies for informed decision-making regarding cancer screening technologies, in both community and clinical practice.

Perhaps most notably, the [Cancer Intervention and Surveillance Modeling Network](#) (CISNET), funded by DCCPS, has provided key evidence

used by the United States Preventive Services Task Force (USPSTF), as the task force has created and/or updated screening guidelines for lung, breast, colorectal, prostate, and cervical cancers. Additionally, early in the era of the COVID-19 pandemic, CISNET conducted modeling in 2020 showing approximately 10,000 excess deaths in the following 10 years due to pandemic-related delays in screening and diagnosis for colorectal and breast cancers. The findings served as the basis for an editorial by NCI Director Ned Sharpless in *Science* titled “COVID-19 and Cancer.” In 2020, CISNET was recognized with the Society for Medical Decision-Making’s John Eisenberg Award for demonstrating sustained leadership in translating medical decision-making research into practice.

CISNET modeling studies are enabled by DCCPS-supported data resources such as the [Surveillance, Epidemiology, and End Results](#) (SEER) Program, an authoritative source for cancer statistics in the US, and the [Breast Cancer Surveillance Consortium](#) (BCSC), a well-established research resource for studies designed to assess the delivery and quality of breast cancer screening. BCSC data are used for Mammography Quality Standards Act (MQSA) compliance activities, as well as quality improvement activities, and the BCSC has worked with the American College of Radiology to develop common data collection forms. BCSC data have been included in several high-level reports by the Government Accountability Office (GAO) and Institute of Medicine (IOM), and they also have been used for USPSTF guideline development.

We recognize the importance of collaborating with other agencies to analyze data related to screening. For example, since 2001 DCCPS has collaborated with the Agency for Healthcare Research and Quality (AHRQ) to model how changes in screening, risk factors, and optimal use of chemotherapy would influence mortality rates from colorectal cancer. DCCPS worked

with AHRQ and the Centers for Medicare and Medicaid Services (CMS) to produce an economic analysis that CMS used to inform new coverage of a colorectal screening test, the immunochemical fecal occult blood test (FOBT). DCCPS research also informs the Centers for Disease Control and Prevention's (CDC's) National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides access to breast and cervical cancer screening services to underserved women.

Another critical DCCPS-supported initiative focused on screening services is the [Population-based Research to Optimize the Screening Process](#) (PROSPR) network, whose goal is to better understand how to improve the screening process (recruitment, screening, diagnosis, referral for treatment) for cancer. There have been two PROSPR funding cycles: PROSPR 1 (2011–2018) studied breast, cervical, and colorectal cancers, and PROSPR 2 (actively funded since 2018 at this writing) has been studying cervical, colorectal, and lung cancers, mapping out the complex process for these types of cancer screening. A particular focus of the second funding cycle of the PROSPR network has been to measure organizational factors associated with successful completion of the screening process. This will assist health care administrators and clinicians in identifying opportunities for improvement.

DCCPS experts also support CDC's Guide to Community Preventive Services. The guide is a free resource to help public health planners choose programs and policies to improve health and prevent disease in communities. DCCPS provides a crosswalk between the [Evidence-Based Cancer Control Programs \(EBCCP\)](#) website and the guide to assist with selection of evidence-based interventions that align with the guide recommendations. DCCPS experts participate in literature reviews, oversee the development of new research, and contribute to the development of the guide.

## HHS Development of a National Strategy to Improve Health Care Quality

DCCPS has supported comparative effectiveness research (CER) studies and developed the methods and data sets needed to conduct high-quality CER. Results from CER, also known as patient-centered outcomes research, provide the evidence patients and physicians need to choose between a wide variety of options for diagnosis, treatment, and monitoring. NCI-funded studies have provided a strong foundation for Patient-Centered Outcomes Research Institute (PCORI)-funded research to help patients and those who care for them make better-informed decisions about their options for preventing, diagnosing, treating, and surviving cancer. Other projects that DCCPS supports around CER include CISNET, BCSC, and physician surveys.

In response to the President's Cancer Panel's report, "Accelerating HPV Vaccination Uptake: Urgency for Action to Prevent Cancer," DCCPS has funded three rounds of grant supplements to NCI-Designated Cancer Centers to support development of expertise related to increasing HPV vaccine uptake. The first round, in 2014, supported collaborations with existing state and local coalitions and HPV immunization programs. The second round supported the same effort for an additional set of cancer centers. When the two groups gathered for meetings, they formed a coalition of cancer experts focused on increasing HPV vaccine uptake. This consortium has continued to meet approximately yearly, hosted by a cancer center that takes the opportunity to highlight local issues around HPV vaccination. A third group of cancer centers was supplemented in 2021 to increase that focus on local issues, this time specifically considering how local factors affect vaccine hesitancy. These supplements are part of a larger effort that NCI and CDC are undertaking to systematically bring together NCI-Designated Cancer Centers, CDC programs, and state and local health departments and their immunization programs.

Vaccine hesitancy is a new focus for funds from the Cancer Moonshot<sup>SM</sup>. DCCPS supports administrative supplements to NCI grants to build evidence on cervical cancer prevention and control by supporting research on local sources of vaccine hesitancy that affect uptake of the HPV vaccine, even when a strong provider recommendation is present. This focus is in addition to ongoing interests in feasibility and acceptability of HPV self-sampling; health decision analyses and cost-effectiveness modeling to guide screening decisions; and de-implementation of cervical screening approaches that are no longer supported by guidelines. The first round of supplements was awarded in fiscal year (FY) 2019, and additional supplements were funded in FY20, FY21, and FY22.

For the past several decades, NCI has funded the [Cancer Control Supplement \(CCS\) to the National Health Interview Survey \(NHIS\)](#) to collect data pertaining to knowledge, attitudes, and practices in cancer-related health behaviors, screening, and risk assessment. The NHIS CCS covers a variety of topics including diet, physical activity, cancer screening, sun protection, tobacco use, genetic testing, and cancer survivorship. In the second half of 2020 and in 2021, the survey also captured some information about how cancer screening and treatments were impacted by COVID-19. These data serve as an official monitoring tool for Healthy People cancer control objectives, which aim to improve the health of all Americans.

In 2014, DCCPS created a novel resource for the scientific community by funding cancer care delivery research in the [NCI Community Oncology Research Program](#) (NCORP). NCORP is a network that brings cancer research to patients in approximately 1,000 community-based clinical settings across the United States. DCCPS funds and coordinates multidisciplinary research that seeks to improve clinical outcomes and patient well-being by intervening on patient, clinician,

and organizational factors that influence care delivery. The 22 cancer care delivery studies approved as of July 1, 2021, cover seven research gaps: case management, drug utilization, guideline adherence, health expenditures, health service accessibility, implementation science, and shared decision-making. Nearly 10,000 patients and 500 clinicians have been accrued to studies, with over 250 practices providing detailed information about their organizational context and processes. Many of the interventional studies take advantage of NCORP's unique structure to conduct trials randomized by practice. Base funding for this effort has been augmented by nine federal and three nonfederal grants or contracts to support specific studies. These successes have led to the emergence of NCORP as a premier venue for cancer care delivery research.

DCCPS played a leading role in the development, testing, and sustainability of a research resource to provide access to four state-of-the-science validated patient-centered outcomes measurement systems. These tools include PROMIS<sup>®</sup> (Patient Reported Outcomes Measurement Information System<sup>®</sup>), The NIH Toolbox<sup>®</sup> (The NIH Toolbox for Assessment of Neurological and Behavioral Function), Neuro-QoLTM (Quality of Life in Neurological Disorders), and ASCQ-Me<sup>®</sup> (Adult Sickle Cell Quality of Life Measurement Information System). These systems were designed to capture information about symptoms and functioning (e.g., pain, fatigue, cognitive and physical function) directly from patients using either fixed measures, computer adaptive testing, or performance measures. Each of these four systems were developed under separate NIH funding mechanisms with a goal of being brief, reliable, trans-disease, and available to patients across the lifespan. In 2014, these measures were brought together through a trans-NIH cooperative agreement led by NCI and DCCPS to form a publicly available resource known as HealthMeasures ([www.healthmeasures.net](http://www.healthmeasures.net)).

The [Improving the Management of symptoms during And following Cancer Treatment](#)

(IMPACT) Consortium is an initiative supported by funding provided through the Cancer Moonshot that was developed in response to a Blue Ribbon Panel (BRP) recommendation. The panel's Recommendation F was to "minimize cancer treatment's debilitating side effects." The goal of IMPACT is to support the implementation, evaluation, and scalability of integrated electronic systems that systematically collect and manage symptoms through guideline-concordant clinical interventions tested in stepped-wedge cluster randomized trials. All interventions are deployed via electronic health record (EHR) systems, and the pragmatic designs are developed and tested using implementation science-based approaches.

IMPACT consists of three individual research centers (RCs) that monitor and manage cancer symptoms in diverse practice settings, and a coordinating center that provides scientific expertise and logistical support to unite the consortium. The Symptom Management Implementation of Patient Reported Outcomes in Oncology (SIMPRO) RC is a multidisciplinary team from six health systems. SIMPRO's overarching goal is to develop, implement, and evaluate a multicomponent electronic patient-reported outcomes (PRO) management system to improve symptom control for patients recovering from cancer surgery or patients receiving palliative chemotherapy in small, rural, and community cancer centers. The Northwestern University IMPACT (NU IMPACT) RC builds upon an existing integrated cancer symptom monitoring and management system (NMPRO) to test the effectiveness of a system-wide symptom management intervention when implemented across Northwestern Memorial HealthCare Corporation outpatient oncology clinics. The Enhanced, Electronic Health Record-Facilitated Cancer Symptom Control (E2C2) RC's pragmatic clinical trial tests a bundled intervention that

leverages electronic health record interface and clinical decision support functionalities. This intervention operationalizes an approach that automatically triages symptomatic patients to automated self-management (low-touch) or nurse care management (high-touch), depending on patient-reported outcomes and other patient and clinical factors.

The consortium is uniquely positioned to examine symptom control among patients in underserved and under-resourced populations across the US. IMPACT will generate evidence about the symptom experience and challenges with accessing supportive care in multiple settings and in hard-to-reach cancer patients and survivors. Pooled consortium-wide data will allow for the evaluation of symptom control, treatment delivery, and health care utilization in patients across the cancer care continuum. Outcomes will inform the feasibility of regular PRO assessment in frontline health care delivery and the use of EHRs for real-world evidence generation.

[Accelerating Colorectal Cancer Screening and follow-up through Implementation Science](#)

(ACCSIS) was established in October 2017. ACCSIS is a consortium of research projects building the evidence base on multilevel interventions to increase rates of colorectal cancer screening, follow-up, and referral to care. Each research project implements a multilevel intervention and develops guidance for sustaining and scaling up these interventions to reduce the burden of colorectal cancer on the US population. This initiative targets the BRP scientific priority area Prevention and Screening: Implementation of Evidence-based Approaches. The ACCSIS Program supports UG3/UH3 phased award research projects and a U24 coordinating center.

The one-year UG3 phase is focused on the development and piloting of an intervention, to be tested in a clinical trial during the four-year UH3 phase. Progress from the first year to the



remaining four years is based on achievement of milestones described by the research projects and NCI scientific collaborators at the start of the first year of funding.

Program priorities specified in the ACCSIS research projects' Request for Application (RFA) include coverage of a sufficient geographic region (e.g., neighborhoods, cities, counties, states) such that the multilevel intervention would have a substantive impact on rates of colorectal cancer screening, follow-up, and referral to care. Additionally, multilevel intervention must be informed by relevant theories, frameworks, or models and guided by preliminary data on the local contextual barriers and facilitators.

## Economic Burden of Cancer and Rising Health Care Costs

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. DCCPS researchers have developed and reported to Congress estimates of both the overall cost of cancer care in the US and specific costs by tumor type and site, sex, age group, geographic location, and phase of care (i.e., initial, continuing, and last year of life). For example, researchers found that the costs of cancer care to Medicare are substantial and vary by tumor site, phase of care, stage at diagnosis, and survival, and that incurred debt among families of cancer patients remains an important concern.

These findings suggest that the cost of cancer care involves not only direct expenditures but also indirect costs borne by families, such as lost productivity, job loss, and time costs associated with treatment. DCCPS conducts and supports research to quantify these indirect costs. For example, DCCPS developed models using the human capital approach, which relies on earnings as a measure of productivity, to estimate the value of productivity lost as a result of cancer mortality. A DCCPS study was the first to estimate net patient time costs over the full course of cancer care for 11 of the most common cancer sites. In addition, DCCPS research found that time spent by informal caregivers was substantial. Incorporation of the value of informal caregiver time will be important when evaluating the costs and benefits of cancer control interventions.

In recent years, DCCPS co-funded the [Medical Expenditure Panel Survey \(MEPS\) Experiences with Cancer Survivorship Supplement](#), which, along with the main Medical Expenditure Panel Survey, has been used to improve national estimates of the burden of cancer, particularly medical expenditures for patients of all ages. MEPS is the only source of national data on the financial burden of cancer for survivors and has played an important role in describing financial toxicity, a topic that has become a priority for professional and patient advocacy organizations. Data from the MEPS supplement show that the cost of care among cancer survivors is considerable, even years after diagnosis.

## Cancer Survivorship

The [Optimizing the Management and Outcomes for Cancer Survivors Transitioning to Follow-up Care](#) initiative is an NCI-funded network of investigators with grants funded through RFA-CA-19-035. This funding opportunity announcement (FOA) solicited applications that develop and test models of care for adult survivors of cancer who are transitioning from active treatment to follow-up care. Through this



FOA, NCI supports multilevel interventions that enhance communication, collaboration, and coordination among oncology and non-oncology providers to improve survivor outcomes. The five grants funded through this initiative focus on multiple cancer types and aspects of survivorship, including surveillance for recurrence and new cancers, management of physical and psychosocial effects of cancer and its treatment, and health promotion. The effort represents an important step in survivorship research that has high potential to greatly impact health policy for cancer survivors.

### Efforts to Improve Outcomes for Pediatric, Adolescent, and Young Adult Cancer Survivors

Through RFA-CA-19-033, [Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors](#), NCI funded seven U01s to accelerate cancer research and stimulate the development, testing, and/or scaling of innovative, feasible, and effective interventions to address adverse physical and psychosocial late- and long-term effects in survivors of pediatric and/or adolescent/young adult cancers. Through RFA-CA-20-027 and RFA-CA-20-028, Research to Reduce Morbidity and Improve Care for Pediatric, and Adolescent and Young Adult (AYA) Cancer Survivors, NCI is supporting research designed to improve the care and/or quality of life for childhood and adolescent and young adult (AYA) cancer survivors by addressing one or more of the following domains related to survivor outcomes: (1) disparities in survivor outcomes; (2) barriers to follow-up care (e.g., access, adherence); (3) impact of familial, socioeconomic, and other environmental factors on survivor outcomes; (4) indicators for long-term follow-up needs related to risk for late effects, recurrence, and subsequent cancers; (5) risk factors and predictors of late/long-term effects of cancer treatment; and (6) development of targeted interventions to reduce the burden of cancer for pediatric/AYA cancer survivors.

Further, through an agreement established between NCI and AHRQ, three reviews are being conducted to assist in identifying research gaps and setting future research priorities related to pediatric, adolescent, and young adult survivorship care. Reports from these reviews will address the following topics:

- Transitions of care from pediatric to adult services for children with special health care needs
- Cancer survivorship care models that include primary care for pediatric cancer survivors
- Disparities and barriers for pediatric cancer survivorship care

Efforts to support the development of interventions to address adverse biomedical and psychosocial effects in pediatric and AYA survivors also align with the goals of the Cancer Moonshot and BRP's recommendation to "minimize cancer treatment's debilitating side effects" (Recommendation F).

### Addressing Needs of Survivors Living with Advanced and Metastatic Cancers

DCCPS has had a long-standing commitment to advancing research for cancer survivors. Recently, the division has assessed the state of the science and the NIH grant portfolio focused on a unique population of survivors—those that are living with advanced and metastatic cancers. These populations represent a diverse set of individuals who may have significant unmet needs as compared to those who are diagnosed at earlier stages and treated with curative intent. DCCPS recently led a public meeting to gather researchers, clinicians, advocates, patients, and survivors to further identify key gap areas and opportunities to advance research focused on these populations. Next steps will include advancing the science in health care delivery, psychosocial research, epidemiology and surveillance, symptom management, and health behavior research, with the potential to drive policy change in the future.



## TOBACCO CONTROL

The Tobacco Control Research Branch (TCRB) of DCCPS leads and collaborates on research and disseminates evidence-based findings to prevent, treat, and control tobacco use. Through its large and diverse grant portfolio, TCRB supports research that informs tobacco prevention and control policies in order to create a world free of tobacco use and related cancer and suffering.

### Smoking Cessation within the Context of Lung Cancer Screening

In 2021, the US Preventive Services Task Force (USPSTF) updated its recommendations to promote annual screening for adults ages 50 to 80 who have a 20 pack-year smoking history and currently smoke or have quit smoking within the last 15 years for lung cancer. Low-dose computed tomography screening (LDCT) for these high-risk individuals is covered by Medicare and by private insurance under the Affordable Care Act. The [Smoking Cessation at Lung Examination \(SCALE\) Collaboration](#) is an initiative sponsored by DCCPS to conduct research on lung cancer screening and smoking cessation treatment with a specific group: long-term smokers who are screened for lung cancer using LDCT. The pairing of smoking cessation treatment and LDCT screening has the potential to generate a large pool of data on screening and cessation outcomes. Five of SCALE's projects were funded by NCI grants awarded in 2016.

### Family Smoking Prevention and Tobacco Control Act

The landmark Family Smoking Prevention and Tobacco Control Act of 2009 granted FDA

authority to regulate the manufacturing, marketing, and distribution of tobacco products. Evidence generated by DCCPS-funded research has contributed to FDA's ability to make informed decisions as it determines how to implement its regulatory authorities. To inform regulatory policy, in 2013 NIH and FDA announced the creation of 14 [Tobacco Centers of Regulatory Science \(TCORS\)](#), comprising scientists from diverse backgrounds to increase the knowledge across the full spectrum of basic and applied research on tobacco and addiction. In 2018, nine centers received funding. NCI programmatically manages four of the nine TCORS 2.0 sites. TCORS 3.0 information will be available in 2022. A [Notice of Intent to publish an RFA](#) soliciting another round of TCORS grant applications was released November 3, 2021, with an expected publication date in February 2022.

### Secondhand Smoke

DCCPS-funded research has shown that smokefree laws benefit nonsmokers by eliminating exposure to tobacco smoke and benefit smokers by providing an environment that encourages and facilitates quitting. As of October 2021, 28 states, Washington, DC, Puerto Rico, and the US Virgin Islands had enacted comprehensive smokefree laws. NCI has its own [tobacco-free policy](#), which prohibits the use of all tobacco products (cigarettes, cigars, pipes, smokeless tobacco, e-cigarettes, etc.) while on any of its workspaces.

Smokefree laws are essential to changing social norms regarding tobacco use and to reducing secondhand smoke exposure. In 2021, the Navajo Nation enacted the first [comprehensive ban on commercial tobacco products on American Indian tribal lands](#). [NCI-funded research](#) played a role in this important accomplishment through the Networks among Tribal Organizations for Clean Air Policies (NATO CAP) project, first funded in 2011. American Indian and Alaska Native

populations have higher tobacco use rates than other population groups within the US, and passage of this law is expected to improve the overall health of American Indian and Alaska Native persons as well as serve as a model for other Native nations.

Comprehensive smokefree policies can have a large public health impact when implemented in multi-unit housing settings. DCCPS scientists participate on a federal interagency workgroup (comprising the US Department of Housing and Urban Development [HUD], CDC, NCI, and the Environmental Protection Agency [EPA]), which has convened regularly since 2013 to share current research, disseminate the evidence base, discuss local-level implementation, and encourage the use of NCI smoking cessation resources as part of any implementation efforts. Since HUD adopted a policy to prohibit smoking in public housing in 2016, this workgroup has continued to identify opportunities for collaboration between HHS, HUD, and other federal agencies to promote effective implementation of the rule in public housing. At this writing, NCI has two actively funded grants ([5R01CA226074-03](#) and [3R01CA220591-05S3](#)) to understand the impact of the HUD rule.

## Tracking Tobacco Use, Cessation Practices, and Tobacco Control Policies

The [Tobacco Use Supplement to the Current Population Survey](#) (TUS-CPS), sponsored by NCI and FDA, is a public use survey of tobacco use and policy information that has been administered triennially as part of the US Census Bureau's CPS since 1992. Because of its large, nationally representative sample, the TUS-CPS is a key source of national- and state-level data on smoking, other tobacco use, policy, and intervention information in US households. A unique feature is the ability to link other social and economic Census Bureau and Bureau of Labor Statistics data and other sponsor-supported supplement data to the TUS-CPS

data. Many of these data can also be linked to cancer and other cause-specific mortality data through the National Longitudinal Mortality Study. NCI, FDA, and CDC staff, as well as the general extramural community, have [conducted](#) and continue to conduct research using this data resource.

## Addressing Electronic Nicotine Delivery Systems (ENDS) Use

ENDS represent a rapidly changing class of tobacco products known by many different names, including e-cigarettes, e-cigs, vapes, mods, and tank systems. NCI funds a broad spectrum of [research](#) projects about ENDS. The focus of these projects includes understanding ENDS use behaviors, particularly among adolescents and young adults; the impact of ENDS on other tobacco use behaviors; toxicity and health effects of ENDS; perceptions of ENDS' risks and harms; effects of industry marketing and promotion; effects of user-driven ENDS content on social media; communicating harms of ENDS use; and effects of tobacco- and ENDS-focused policies on ENDS use. NCI's grant portfolio also includes randomized trials focusing on whether ENDS can serve as a complete substitute for conventional cigarettes among adult smokers who are unmotivated to quit smoking.

Recognizing the ongoing epidemic of ENDS use by youth and the need to help youth to quit, NCI and FDA partnered to create online content that provides information and support to teens on how to quit vaping and deal with nicotine addiction and cravings. Featured on NCI's [SmokefreeTeen](#) website, an interactive quit plan builder tool was added to the content collection in 2020 to guide teens through a series of steps to create a personalized plan for quitting vaping. All content is developed in support of FDA's "The Real Cost" e-cigarette prevention campaign.



## A HEALTHIER GENERATION

In recent decades, a renewed emphasis on improving health behaviors was spearheaded by the Let's Move Initiative, The President's Challenge, the HHS Small Step Initiative, and most recently, the Surgeon General's Call to Action on Walking and Walkability, which DCCPS staff helped to draft and promote. In addition to such initiatives, DCCPS supports and provides a wide range of research to help inform ongoing public health efforts across the US and the world.

### Setting National Objectives for Promoting Health and Preventing Disease

The Healthy People 2030 initiative provides science-based, 10-year national objectives for promoting health and preventing disease. DCCPS staff serve on the Healthy People Cancer Chapter Workgroup. Since 1979, Healthy People has set and monitored national health objectives to meet a broad range of health needs, encourage collaborations across sectors, guide individuals toward making informed health decisions, and measure the impact of our prevention activity. With oversight from the NIH Office of Disease Prevention and Health Promotion, the Cancer Workgroup has representation from NCI and other lead agencies—CDC, AHRQ, the Veterans Health Administration (VHA), and the National Center for Health Statistics (NCHS)—and works toward setting new objectives and targets for the next decade while measuring progress from the past decade. DCCPS staff have also

worked to develop and evaluate objectives related to nutrition, obesity, alcohol, sleep, sun safety, and physical activity.

### Making Healthier Dietary Choices

The Dietary Guidelines for Americans (DGAs) are jointly issued and updated every five years by the Department of Agriculture (USDA) and HHS. They form the basis for federal nutrition policy and provide authoritative dietary advice to promote health and reduce risk for major chronic diseases. To be effective, these guidelines require an extensive evidence base to ensure the most accurate and up-to-date information is included. DCCPS-supported researchers developed methodologies for estimating usual dietary intake distributions and identifying sources of key dietary constituents, including added sugars, and the resulting data have proven to be critical for the recent and upcoming versions of the guidelines.

The 2020–2025 DGAs include the first-ever recommendations for Americans from birth through 24 months old, and DCCPS staff provided additional data analyses and methodological context for the committee for this population. In addition, DCCPS works with researchers at USDA to develop and update the [Healthy Eating Index](#) (HEI), a measure of dietary quality, which assesses conformance to the DGAs and has been used in hundreds of studies, including the evaluation of USDA's multi-billion-dollar food assistance programs.

Drawing on extensive input from the broader external research community and the public, the NIH Nutrition Research Task Force (NRTF) developed the [2020–2030 Strategic Plan for NIH Nutrition Research](#). With a focus on precision nutrition—developing targeted and effective diet interventions in a diverse population—the plan emphasizes

cross-cutting, innovative opportunities to advance nutrition research across a wide range of areas, from basic science to experimental design to research training. These opportunities complement and enhance ongoing research efforts across NIH to improve health and to prevent or combat diseases and conditions affected by nutrition. DCCPS staff work with the NIH Office of Nutrition Research and serve on the Implementation Working Groups to expand collaboration across NIH institutes and centers to further research to develop targeted and effective recommendations about what, when, why, and how to eat to optimize health.

Achieving the goal of precision nutrition hinges on changing the way we think about diet, toward a holistic view that considers and analyzes dietary patterns, not individual nutrients. DCCPS staff are helping to lead the [NIH Common Fund's Nutrition for Precision Health](#) (NPH), powered by the *All of Us* Research Program. The goal of the NPH is to develop algorithms that predict individual responses to food and dietary patterns.

Research in this area continues to grow, and the ability to synthesize and compare the literature of dietary patterns is enhanced by efforts like the DCCPS-led [Dietary Patterns Methods Project](#) that found that more optimal dietary patterns were associated with an 11% to 28% lower risk of all-cause, cancer, and cardiovascular disease mortality. These analyses included several large NIH and DCCPS-funded cohorts, including the Multiethnic Cohort, with over 215,000 participants from five ethnic groups (Caucasians, Japanese Americans, Native Hawaiians, African Americans, and Latinos).

The DCCPS research portfolio includes studies aimed at understanding behaviors and barriers, along with effective interventions to increase the availability

of healthy food in the home, at schools, in childcare settings, in neighborhoods, and in communities. In addition, DCCPS has supported research on new policies that tax sugar-sweetened beverages, and also on school nutrition policy, including changes in food laws across states and in elementary schools, and the impact these changes have on behaviors and reducing obesity.

The [Family Life, Activity, Sun, Health, and Eating \(FLASHE\)](#) study, sponsored by DCCPS, collected survey data on psychosocial, generational (parent-adolescent), and environmental correlates of cancer-preventive behaviors. The purpose of the study is to help researchers understand lifestyle behaviors that relate to cancer risk. The majority of the survey questions focus on diet and physical activity, with additional survey items about sleep, sun safety, and tobacco use.

## Reversing the Childhood Obesity Trend

Obesity is a well-established risk factor for chronic diseases, including heart disease, diabetes, and cancer. Between 1980 and 2018, the prevalence of obesity has become epidemic among children, and today [nearly one in five of all children in the US are overweight or obese](#). Recognizing the need to reverse this alarming trend, HHS and the Surgeon General have implemented coordinated obesity prevention efforts.

Aiding in this national effort, DCCPS participates in the [National Collaborative on Childhood Obesity Research](#) (NCCOR), a partnership of CDC, NIH, USDA, and the Robert Wood Johnson Foundation. NCI is a member of the Executive Steering Committee in NCCOR, which seeks to improve the efficiency, effectiveness, and application of childhood obesity research by developing common measures and methods, evaluating and identifying



effective interventions, and assessing policy and environmental changes related to childhood obesity. DCCPS researchers lead the efforts to support the development of common measures and methods, and the considerations for adapting, developing, and validating measures for children and families in high-risk communities. Notable tools developed through this partnership include the [Measures Registry Resource Suite](#), which includes four [user guides](#) and a [decision tree](#) for choosing whether to apply, develop, or adapt a measure; the [Catalogue of Surveillance Systems](#); and the [Youth Compendium](#) of Physical Activities in English and Spanish.

## Increasing Physical Activity and Supporting Weight Loss and Maintenance

The [HHS Physical Activity Guidelines](#) (2008) were the first-ever such guidelines released for Americans. In 2018, the *Physical Activity Guidelines for Americans*, 2nd edition, was released. These documents describe the types and amounts of physical activity that offer substantial health benefits. DCCPS-funded investigators served on the advisory committees, and a DCCPS staff member co-led the process for HHS. DCCPS staff members were also on the subcommittee of the President's Council on Sports, Fitness, and Nutrition that developed the National Youth Sports Strategy. DCCPS stimulated novel research in the evaluation of physical activity through the Improving Diet and Physical Activity Assessment program announcements. DCCPS also funds a number of research initiatives that focus on enhancing the research base for physical activity and its effects on cancer, including mechanisms of physical activity behavior change, physical activity in women with infants, the protective effects of physical activity on adolescent smoking prevention, and active video games and sustainable

physical activity. In addition, through its funding mechanisms and initiatives, DCCPS is leading efforts to support epidemiological research examining the association of physical activity with cancer occurrence, recurrence, and survival outcomes and the role of exercise intervention in modulating biomarkers of cancer outcomes. DCCPS supports the Breast Cancer WEight Loss (BWEL) Study, a clinical trial to test the hypothesis that weight loss will increase invasive disease-free survival (IDFS) in overweight and obese women diagnosed with stage II and III breast cancer, and additional clinical trials testing the efficacy of exercise and nutrition to improve cancer treatment-related outcomes.

DCCPS-supported [transdisciplinary research](#) on obesity and cancer aims to strengthen our understanding of behavioral and biological mechanisms in obesity and cancer, enhance application of research on biomarkers, genetics/genomics, and interoception to advance individualized treatment, expand a translational research focus especially in cancer survivors and understudied populations, strengthen use and integration of theoretical constructs, and promote transdisciplinary training.

In addition, DCCPS supports trans-NIH initiatives to better understand variability in weight loss and maintenance in order to develop precision medicine approaches to improve treatment response to behavioral weight loss interventions:

[Accumulating Data to Optimally Predict obesity Treatment \(ADOPT\)](#) aims to identify key biological, psychological, behavioral, and environmental variables related to weight loss to determine potential predictors of successful weight loss and maintenance. DCCPS has funded three administrative supplements to DCCPS-supported weight-loss trials to add ADOPT measures to their



studies, and supported the identification of a set of environmental measures, including measures of neighborhood walkability, food outlet accessibility, and socioeconomic deprivation, that can be used to assess the role of the [environment in weight loss and maintenance](#).

The [Trans-NIH Consortium on Randomized Controlled Trials of Lifestyle Weight Loss Interventions for Genome-Wide Association Studies](#) aims to build on existing resources and advance research that examines the contribution of germline genetic variation to intentional weight loss and weight maintenance.

In addition, DCCPS has supported a range of research and tool development on school physical education policy, including the Physical Education-related Policy Classification System (PERSPCS). The PERSPCS provides a platform for the evaluation of physical education laws across states and the associations between state physical education staffing and curriculum standards with reported school practices. The PERSPCS and the School Nutrition Policy Classification System form the [Classification of Laws Associated with School Students](#) (CLASS). Consisting of two databases, CLASS is a resource for researchers, policy makers, and school officials interested in improving school nutrition and physical education as a means to address childhood obesity. The CLASS data have been used in numerous publications, and CLASS is a listed resource in the 2013 IOM report “Evaluating Obesity Prevention Efforts: A Plan for Measuring Progress” (2013).



## CANCER AND THE ENVIRONMENT

The US public has long been concerned about whether chemical and physical exposures increase the risk of cancers. This concern has led to proactive research initiatives led by NCI and the National Institute of Environmental Health Sciences (NIEHS) and several public laws that directed NCI and NIEHS research on this topic, particularly in the area of breast cancer.

### Breast Cancer and Environmental Research Act of 2008

In 2008, Congress passed Public Law (PL) 110-354, the Breast Cancer and Environmental Research Act. PL 110-354 required the Secretary of HHS to establish an [Interagency Breast Cancer and Environmental Research Coordinating Committee](#) (IBCERCC). It also authorized funding for research activities aimed at determining the genomic and environmental etiology of breast cancer. NCI shared responsibility with lead agency NIEHS in implementing the act by managing the IBCERCC. This committee's primary objectives were to review federal research activities on environmental factors that may be related to the etiology of breast cancer, summarize advances in understanding the environmental etiology of breast cancer, and make recommendations to the HHS Secretary regarding research gaps and needs. Published in February 2013, the [IBCERCC report](#) contained seven recommendations: (1) prioritize prevention, (2) transform how research is conducted, (3) intensify the study of chemical and physical factors, (4) plan strategically across federal agencies, (5) engage public stakeholders, (6) train transdisciplinary researchers, and (7) translate and communicate science to society.

### Breast Cancer and the Environment Research Program

To address how environmental exposures and personal susceptibility factors influence breast cancer risk, NIEHS and NCI co-funded the [Breast Cancer and the Environment Research Program](#) (BCERP) in 2003. BCERP was renewed for a third phase in October 2015, with similar overarching objectives as the previous two phases and a scientific agenda that is responsive to the IBCERCC recommendations. BCERP emphasized a transdisciplinary approach and timely dissemination of scientific findings facilitated by community partnerships for the prevention of breast cancer.

Specifically, BCERP aimed to study environmental exposures that may predispose a woman to breast cancer throughout her life, with a focus on specific periods of time, referred to as “windows of susceptibility,” when the developing breast may be more vulnerable to environmental exposures. Initially, BCERP addressed multiple factors that may influence pubertal onset and long-term risk of breast cancer, with laboratory studies aimed at understanding biological mechanisms in rodents and tissue culture models, and with population studies focused on pubertal development in young girls. The program evolved to include other critical breast developmental periods, from in utero to post-menopause as well as intermediary markers of breast cancer risk (e.g., breast density). A [2019 publication](#) by BCERP investigators highlights how the focus on environmental exposures during critical windows of susceptibility offers a framework for prevention research.

BCERP investigators discovered that girls were entering puberty at earlier ages than previously believed, and that certain chemicals, such as triclosan, 2,5-dichlorophenol, and low-molecular-weight phthalates may be contributors. Earlier pubertal maturation increases the risk of breast, ovarian, and endometrial cancers. Results from a pilot study in the Cincinnati BCERP cohort led to partnerships with the greater Cincinnati water treatment departments to reduce

exposure to per- and polyfluoroalkyl substances (PFAS) through water filtration. BCERP has also generated a number of scientific resources, including a rodent model with breast lesions that progress like human mammary tumors, and optical spectroscopy as an alternative to mammogram for measuring breast density. In addition to scientific discoveries, [BCERP produced materials](#) and toolkits for parents and caregivers, health care professionals, educators, and advocates that included culturally relevant brochures and public service announcements, and fact sheets discussing the risks of plastics, phthalates, and other chemicals, as well as teaching and training modules for advocates.

BCERP exemplifies a long-standing and ongoing collaboration between NIEHS and NCI to investigate the impact of environmental exposures to cancer risk. The Long Island Breast Cancer Study and the Northeast and Mid-Atlantic Breast Cancer Study preceded BCERP to showcase these programmatic collaborations between the institutes. BCERP projects are ongoing during a no-cost extension into 2022, thus the full impact of the initiative has yet to be realized and will continue to evolve.

### Analysis of Geospatial Information

Geographic variation in cancer incidence and mortality reflects the substantial role of the physical and social environment on an individual's health. Toxic exposures are known to vary spatially and temporally. In addition, characteristics of the built and social environments can have a strong influence on people's ability to adopt a healthy lifestyle and access high-quality health services. Understanding the spatial context of environmental exposures, lifestyle behaviors, and built and social environments throughout an individual's life is, therefore, important for cancer control and prevention efforts.

Advancements in geospatial approaches that include location-based technologies such as geographic information systems (GIS), global

positioning systems (GPS), mapping techniques, and applied spatial methodologies have propelled cancer control and prevention research forward in recent years. [NCI supports research](#) that integrates and analyzes geospatial data and/or spatial methodology to examine how place and location interact with exposures and behaviors relevant to diverse aspects of cancer control and prevention.

### Human Health Exposure Analysis Resource (HHEAR)

The Human Health Exposure Analysis Resource (HHEAR) is a research initiative led by NIEHS with support from NCI, NHLBI (National Heart, Lung, and Blood Institute), and the NIH ECHO (Environment influences on Child Health Outcomes) program. The goal of this initiative is to advance our understanding about how the environment impacts human health and disease through the life course by promoting the characterization of the totality of human environment exposures called the exposome.

The program provides infrastructure to enable NIH-funded researchers to measure environmental exposure and integrate their data with other data sets by providing access to laboratory, statistical, and data science analysis services. The HHEAR network consists of six laboratories that provide targeted and untargeted analyses and adhere to strict quality assurance/quality control procedures to ensure accurate and comparable analytic measurements for all studies. Researchers will harmonize data to gain a better understanding of complicated interactions between environmental factors as determinants of health. In addition, after a brief period, the data will be made freely available and placed in a public repository for the greater biomedical research community. With the paucity of a robust epidemiologic literature evaluating environmental factors and cancer risk, the efforts from the HHEAR initiative will go a long way toward providing a better understanding of the etiologic role the environment plays on cancer.



## PRACTICAL DATA AND EVIDENCE FOR POLICY MAKERS

DCCPS develops multiple tools to provide the evidence that policy makers and public health officials need to develop thoughtful and comprehensive public health programs. The data and evidence available cover a wide range of topics, including quality of cancer care, the economic burden of cancer, geographic information systems, statistical methods, communication science, tobacco control, and the translation of research into practice.

### Implementation Science Resources

Implementation science approaches to facilitate the uptake of evidence-based research into practice has increasingly been recognized as a critical area of study. The DCCPS Implementation Science (IS) Team supports the evidence-based implementation of policy and practice by advancing the science of implementation itself. In addition to supporting the generation and execution of dissemination and implementation research studies, the IS Team develops and maintains several resources to support evidence-based practice implementation, including web-based data and successfully tested research models through Cancer Control P.L.A.N.E.T. and [Evidence-Based Cancer Control Programs \(EBCCP\)](#). The team offers training programs to promote a scientific approach to implementation of research findings, guidelines, and policies. In addition, they provide consultation and assistance to other sections of DCCPS and to grant applicants.

In addition to the work advanced and supported by the IS Team, there are many

DCCPS initiatives embedded across the division with substantial implications for practice and policy. Several examples have been described previously, such as the IMPACT and ACCSIS Consortia.

### Health Information National Trends Survey

The [Health Information National Trends Survey \(HINTS\)](#) collects nationally representative data about the American public's need for, access to, and use of health- and cancer-related information. HINTS monitors trends in media and technology use, as well as behavioral risk factors for cancer, knowledge of cancer risks, and attitudes toward cancer communication-related public health policies. Some HINTS items are used by the Office of the National Coordinator for Health Information Technology to monitor EHR use and other important advances resultant of the Health Information Technology for Economic and Clinical Health (HITECH) Act. HINTS is also used by the HHS Office of Disease Prevention and Health Promotion as a benchmark for Healthy People goals.

### Surveillance, Epidemiology, and End Results Program

The National Cancer Act of 1971 mandated the collection, analysis, and dissemination of data useful in the prevention, diagnosis, and treatment of cancer, which led to the establishment of the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) in 1973. SEER is the authoritative source of information on cancer incidence and survival in the US, and currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 50 percent of the US population. It is also the key source for current estimates and future projections of cancer prevalence, the number of Americans who are currently—or will become—cancer survivors, information vital to state and federal planning and spending.

## Health Care Data Resources

DCCPS oversees the [SEER-Medicare](#) linked database, which reflects the linkage of SEER cancer registry data with longitudinal Medicare enrollment and claims for covered health care services from the time of a person's Medicare eligibility until death. The linkage of these data, which was first created in 1991 and is updated every other year, results in a unique population-based data resource that is made available to the research community for assessing an array of epidemiological and health services research questions. For example, investigators using this combined resource have conducted studies on patterns of care for persons with cancer before a cancer diagnosis, over the period of initial diagnosis and treatment, and during long-term follow-up. Investigators have also examined the use of cancer tests and procedures and the costs of cancer treatment. DCCPS also oversees other linkages between SEER data and data from the Centers for Medicare & Medicaid Services (CMS). The [SEER-CAHPS](#) data resource links SEER cancer registry data with the CMS Medicare Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience surveys and Medicare claims. These data provide a rich opportunity for analyses of Medicare beneficiaries' experiences with their care at various stages across the cancer care continuum. The [SEER-MHOS](#) data resource links SEER cancer registry data and the CMS Medicare Health Outcomes Survey (MHOS). These data provide information about the health-related quality of life of Medicare Advantage Organization enrollees. Additionally, the [SEER-Medicaid](#) data resource links SEER cancer registry data with longitudinal Medicaid enrollment data from all 50 states and the District of Columbia. First made available to the research community in 2020, the SEER-Medicaid database will provide insights into how enrollment in Medicaid relates to cancer presentation, treatment, and survival.

The [NCI Patterns of Care](#) (POC) studies are a congressionally mandated initiative

to evaluate dissemination of state-of-the-art cancer therapy and diagnostics into community oncology practice. POC studies began in 1987 in collaboration with SEER registries; since then, POC has included more than 20 cancer sites. Each year, POC collects detailed information for individuals diagnosed with two to four different cancer sites, including cancer therapies, biomarker testing, participation in clinical trials, risk factors, and characteristics of treating hospitals. POC data have enabled investigators to examine change over time in cancer diagnosis, treatment, and survival, as well as disparities in receipt of cancer care by age, race/ethnicity, insurance status, and urban vs. rural residence. They are also used to show trends in cancer treatment for sites with multi-year data for the NCI Cancer Trends Progress Report.

## Annual Report to the Nation on the Status of Cancer

Produced in collaboration with the American Cancer Society, CDC, and the North American Association of Central Cancer Registries, and relying on data from NCI's SEER Program, the [Annual Report to the Nation on the Status of Cancer](#) provides an update on cancer occurrence and trends in the US. Each report includes a section providing an in-depth look at particular cancer trends. Past reports have featured topics such as survival by stage, race/ethnicity, and state for common cancers; rates for new cases and deaths, most common cancers, and prostate cancer trends; cancer in men and women aged 20–49 years; progress toward Healthy People objectives; and patient economic burden of cancer care, to name a few examples.

## Cancer Trends Progress Report

Providing a summary of our nation's progress against cancer, the [Cancer Trends Progress Report](#) includes key measures of progress along the cancer control continuum, from prevention to end of life, and uses national

trend data to illustrate where advances have been made. The content, design, and production of this report are the results of a collaboration of federal and state agency partners, consumer advocates, the American Cancer Society, and others.

### State Cancer Profiles Website

Produced in collaboration with CDC, [State Cancer Profiles](#) is a comprehensive system of interactive maps and graphs that enable 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, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities.

### Tobacco Control Monograph Series

Established in 1991, [the series](#) of nearly two dozen tobacco control monographs provides ongoing and timely information about emerging public health issues in smoking and tobacco use control. The series reduces the time between availability of information from research projects and the publication and wide dissemination of this information and enhances the rapidity with which NCI can use findings from research trials to reduce cancer morbidity and mortality.

### National Health and Nutrition Examination Survey

DCCPS funded the inclusion of accelerometers in the National Health and Nutrition Examination Survey (NHANES) 2003–2006 to obtain device-based measures of physical activity. The 2003–2006 data are the basis of more than 200 published articles, including at least nine directly related to cancer risk, cancer survivorship, and cancer mortality. For NHANES 2011–2014, DCCPS joined with other NIH institutes and offices and the Department of Defense to support the inclusion of wrist-worn

accelerometer devices and measures of muscle strength. The accelerometer data, which were released in late 2020, show increased compliance with the wrist-wear and provide metrics of sleep in addition to physical activity-related movement.

### Obesity Policy Research

The DCCPS research portfolio supports [evaluation research on time-sensitive policies or programs](#) that may affect diet, physical activity, or weight at the population level. This type of research is generally described as evaluation of natural experiments, which most often occurs at the state and local levels. This research is an important focus area for the NIH Obesity Research Task Force. Examples of relevant policies and programs include changes to front-of-pack nutrition labels, urban design changes to encourage walking and cycling, food and beverage taxes and subsidies, and Medicare coverage for obesity-related counseling.





## INTERNATIONAL POLICY IMPACT

DCCPS has long supported NCI's mission to improve cancer control worldwide. Below, we provide some examples, both past and present, of the division's contributions and engagement in global cancer control efforts.

### International Agency for Research on Cancer

The World Health Organization's (WHO) International Agency for Research on Cancer (IARC) convenes expert panels to evaluate the world's scientific research on environmental agents to determine whether exposure to those agents causes cancer. Experts from NCI and DCCPS are frequently called upon to serve on these panels. The resulting reports are highly authoritative and used extensively worldwide to provide the scientific basis for public health action and for regulatory purposes. Working with other organizations, DCCPS and IARC also support workshops on topics of joint interest, such as guidelines for assessing evidence for gene-environment interactions.

### Framework Convention on Tobacco Control

The WHO Framework Convention on Tobacco Control (WHO FCTC) is the first treaty negotiated under the auspices of WHO. The FCTC was developed in response to the globalization of the tobacco epidemic and is an evidence-based treaty that reaffirms the right of all people to the highest standard of health. DCCPS is funding a number of projects, including evaluating the effectiveness of tobacco control policies

in high- versus low-income countries, and, through the support of a special journal issue, is working to stimulate the field of global tobacco research to inform future practice and the implementation of the FCTC. A DCCPS scientist is a member of two WHO committees that inform the FCTC: the Study Group on Tobacco Regulation and the Tobacco Laboratory Network.

### WHO Workshop on Research Priorities to Advance the FCTC Workshop: Research-to-Policy in Low- and Middle-Income Countries (LMICs)

NCI, along with the Society for Research on Nicotine and Tobacco (SRNT) and the Mayo Clinic, sponsored a full-day preconference meeting, held March 17, 2015, at the 16th World Conference on Tobacco or Health. NCI and SRNT provided support for a special issue of *Nicotine and Tobacco Research* in 2013 to identify critical research priorities in support of the FCTC, with a focus on LMICs. The goal of this workshop, Research-to-Policy in Low- and Middle-Income Countries (LMICs), was to present findings from the special issue and to explore how to build research capacity and foster communication and collaboration between researchers and public health practitioners in LMICs.

Participants also took part in a process to identify a small number of research priorities that are both feasible and responsive to the needs of LMICs. NCI's priorities in global tobacco control research were presented with analyses of the DCCPS research portfolio and current grants and training programs.

### Smokeless Tobacco and Public Health: A Global Perspective

NCI and CDC issued [\*Smokeless Tobacco and Public Health: A Global Perspective\*](#), the first-ever report on the global use and impact of smokeless tobacco, which found that more than 300 million people

in at least 70 countries use these products. The report was released at the National Conference on Smoking or Health in Mumbai, India, on December 15, 2014 (now the National Conference on Tobacco or Health). Representatives from the government of India and WHO participated in the release and accompanying scientific symposium. Thirty-two leading experts from around the world contributed to the report. In addition to detailing the serious and well-documented health effects of smokeless tobacco products, the report also examines the distinct challenges and policy solutions in reducing the burden of smokeless tobacco use. For example, a wide range of smokeless tobacco products with different characteristics are in use around the world, yet limited data are available detailing the contents of these products, how they are used, and their prevalence within different population groups. The report identifies key research gaps and makes recommendations for capacity building in research and surveillance of smokeless tobacco use, with the aim of reducing the burden of smokeless tobacco use worldwide.

### World Health Organization Pregnancy Guideline

Tobacco use and second-hand smoke (SHS) exposure during pregnancy have adverse health effects on women and infants. Potential increases in tobacco use and SHS exposure among pregnant women threaten to undermine improvements in maternal and child health outcomes achieved in the past 50 years. Currently, most low- and middle-income countries lack up-to-date, evidence-based guidelines for identifying and managing tobacco use and exposure to SHS in pregnancy. Furthermore, many existing guidelines do not include all forms of tobacco use or measures to limit maternal SHS exposure. With support from NCI and CDC, the World Health Organization

developed [WHO Recommendations for the Prevention and Management of Tobacco Use and Second-hand Smoke Exposure in Pregnancy](#) to help fill these gaps. The primary objective of these guidelines is to reduce tobacco use and SHS exposure in pregnant women by providing evidence-based recommendations to health care providers and other related service providers. (These recommendations are part of a larger project of the WHO Noncommunicable Diseases and Mental Health cluster, which aims to make recommendations regarding the management of substance abuse in pregnancy, covering tobacco, alcohol, and other psychoactive substances.) NCI and CDC provided both financial and technical expertise in support of the guideline document, which was published in 2013.

### World Health Organization Physical Activity Guidelines

DCCPS staff served on the Guidelines Development Group for the [WHO Guidelines on Physical Activity and Sedentary Behaviour](#). The WHO guidelines provide a basis for governments and stakeholders in nations around the world to develop recommendations to support increased physical activity.

### World Cancer Research Fund/ American Institute for Cancer Research Cancer Prevention Recommendations

In 2018, the World Cancer Research Fund (WCRF) and American Institute for Cancer Research (AICR) published [Diet, Nutrition, Physical Activity, and Cancer: A Global Perspective](#), the WCRF/AICR Third Expert Report. This report underpinned the updated [ten cancer prevention recommendations](#) that serve as a benchmark for evidence-based guidance, including eating a healthy diet, maintaining a healthy body weight, and engaging in regular physical activity,

as well as specific recommendations for breastfeeding women and cancer survivors. The WCRF/AICR Continuous Update Project (CUP) Expert Panel, who authored the recommendations, highlighted that each recommendation was intended to be one part of a comprehensive package of modifiable lifestyle behaviors that, when taken together, promote a healthy pattern of diet and physical activity conducive to the prevention of cancer, other noncommunicable diseases, and obesity.

Many past studies used the 2007 WCRF/AICR Cancer Prevention Recommendations from the Second Expert Report to derive scores to investigate associations between adherence and cancer risk and health outcomes, but no standard scoring approach was ever developed, limiting direct comparisons of results. Thus, DCCPS staff formed a collaborative team to create a standardized scoring system that could be used globally by researchers to examine how adherence to the 2018 recommendations is associated with cancer risk and cancer-related outcomes. The collaborative team that developed the 2018 WCRF/AICR Score included researchers from AICR, WCRF International, and ISGlobal, in consultation with the WCRF/AICR CUP Expert Panel and additional international researchers.



## LOOKING AHEAD: THE POLICY HORIZON

### Health Equity

Achieving health equity is the goal of [Healthy People 2030](#) and has been a major thrust of all the programs within DCCPS since its inception. The division has a very broad-based perspective in funding and conducting research on adverse health conditions that exist among specific population groups to inform prevention and intervention programs. These population groups may be characterized by gender, age, race, ethnicity, education, income, social class, disability, geographic location, or sexual orientation. Looking to the future, we hope to increase our investment in developing interventions for underserved and disadvantaged populations who face the excess burden of those social determinants of health that are mostly responsible for health inequities. Given that these social factors are avoidable and can be eliminated, they can be addressed through a complement of scientific activities that will reduce the burden of these factors, inform policy, and improve overall health.

Nutrition plays an important role in promoting health and preventing disease throughout our lives. But where we live or how much money we earn can affect our ability to access or afford healthy food. Ensuring food security and access to nutritious food are key to preventing health disparities in diet-related diseases and conditions. DCCPS staff joined with others at NIH to plan a virtual nutrition [health disparities research and implementation](#)

[workshop in September 2021](#) to review the state of the science around food insecurity and the neighborhood food environment, identify research gaps, and explore innovative research strategies that could inform policies and practices.

Additionally, the COVID-19 pandemic has exacerbated health, economic, and well-being inequities, and marginalized populations. The division is supporting research that will improve understanding and documentation of food security, financial stability, and mental health from pre-pandemic to more than one year following the US outbreak by capitalizing on an ongoing, longitudinal study, the Pittsburgh Hill/Homewood Research on Neighborhood Change and Health (PHRESH). The PHRESH cohort is a natural experiment occurring in two low-income, predominantly African American neighborhoods in Pittsburgh, PA. It will study whether differential investments, and the differential social and economic contexts they wrought, have buffered pandemic effects in the neighborhood that received them (relative to the other neighborhood).

DCCPS has made very large investments in supporting large research consortia such as the NCI Cohort Consortium and other large collaborative networks focused on specific cancer outcomes such as rare cancers and rare environmental exposures in understudied populations, which can only be adequately powered through the pooling of data from multiple cohort studies. Findings from cancer epidemiology cohort studies focused on ethnic/minority populations, such as the Southern Community Cohort Study, the Multiethnic Cohort Study, and the Black Women's Health Study, have contributed to a greater understanding of the etiology of rare cancers and cancer subtypes, and modifiable risk factors for common cancers in these populations. Additionally, DCCPS, in collaboration with NIEHS, plans to support

approximately five new research-based prospective cohorts to address gaps between environmental exposures, genetics, and other molecular factors and cancer etiology to better understand racial, ethnic, and geographic disparities.

DCCPS also aims to improve the inclusion of diverse populations in sequencing studies, as racial and ethnic minorities remain underrepresented in these studies. This research gap has created deficits in scientific knowledge, which in turn limits conclusions that can be drawn from genomic research. Furthermore, the inadequate representation of racial and ethnic minority populations in genomic studies limits the translational impact of findings in these populations. There may be additional implications for genomic and cancer epidemiologic research, where understanding variation across populations is critical for accurate interpretation of findings. This underscores the urgency to ensure appropriate representation of minority populations to address this major translational gap in genomic medicine, and for future utilization of genetic information in the prevention and treatment of cancer.

## Environmental Health and Toxins

In 2010, the President's Cancer Panel reported findings and conclusions based on testimony from 45 experts from academia, government, industry, and the environmental and cancer advocacy communities, as well as from members of the public, related to environmental causes of cancer. The report called for information sharing and coordination across agencies. Among other findings, it determined that radiation exposure from medical sources is underappreciated. DCCPS maintains a steadfast commitment to support research on low-dose radiation and cancer as well as research focused on assessing and identifying risks that could affect an individual's chances

of getting cancer. Additionally, DCCPS added a new section on environmental chemical carcinogens to our Cancer Trends Progress Report, including biomarker data on exposure trends in the general population to four known carcinogens: arsenic, benzene, cadmium, and nitrate. To address knowledge gaps related to the impact of environmental exposures on carcinogenesis and cancer risk, DCCPS has released [funding opportunity announcements](#) to support new prospective cohorts. These etiology cohorts will focus on emerging classes of chemicals, contaminants from industrial and other sources, as well as mixtures and exposure to multiple environmental toxins in racially/ethnically and geographically diverse populations.

## Cannabis and Cancer

The US legal landscape of both recreational and medicinal cannabis use has changed dramatically over the past decade. Recent surveys suggest that more than a quarter of cancer patients use cannabis to manage common symptoms of their treatments, including anorexia, nausea, and pain, and there is some evidence of beneficial effects. However, there are a number of risks associated with cannabis use, including recent reporting that vaping tetrahydrocannabinol (THC) has been implicated in the cause of severe respiratory illness. Research examining the risks and benefits of cannabis use has significantly lagged behind changing state policies and increases in use by the general public and cancer patients.

To begin to address research gaps regarding cannabis and cancer, DCCPS funded administrative supplements to 12 NCI-Designated Cancer Centers to understand the patterns and extent of cannabis use and the perceived risks and benefits among a diverse group of cancer patients. Surveys of more than 12,000 recently diagnosed cancer patients, undergoing or having

recently completed active treatment, will be conducted. Results are expected in 2022 and will inform future research activities as well as clinical care.

In collaboration with other NCI divisions, DCCPS hosted the trans-NCI [Cannabis, Cannabinoids, and Cancer Research Symposium](#) in December 2020. The symposium highlighted research gaps concerning cannabis use, including potential drug-drug interactions, side effects, impact on comorbid conditions, beneficial effects, modes of use, and dosages. The symposium identified the most promising areas of future study, the current barriers to conducting the research, and strategies to overcome those barriers. In December 2021, a [special edition of JNCI Monographs](#) was published that provides a synopsis of the symposium.

## Geospatial Approaches to Cancer Control and Population Sciences

Cancer incidence and mortality display geographic patterns worldwide and in the United States. Environments where individuals live, work, and play are increasingly being recognized as important across the cancer control continuum, including the risk of cancer development, detection, diagnosis, treatment, mortality, and survivorship. This spatial variation in exposure, and other factors influencing cancer risk and outcomes requires research using geospatial approaches including the use of location-based technologies such as geographic information systems (GIS), global positioning systems (GPS), or improved mapping techniques and applied spatial methodology. Geospatial methods are an innovative way to shed light on the relationship between exposures and cancer outcomes. These approaches are also critical in advancing research into the impact of climate change on health generally and cancer specifically. Cancer-related disparities

also show strong geographic patterns, and spatial approaches provide powerful tools for documenting health disparities and exploring their causes. Research is needed to integrate and analyze geospatial data and/or spatial methodology across the cancer control continuum.

## Combining Cancer Epidemiology and Economics

Due to changes in cancer-related risk factors, improvements in diagnostic procedures and treatments, and the aging of the population in most developed countries, cancer accounts for a major and increasing proportion of national health care expenditures. At a 2010 international and interdisciplinary meeting in Rome, Italy, health economists, statisticians, and epidemiologists from multiple European countries, the US, and Canada (1) compared and discussed different methodologies developed in country-specific contexts, in terms of data availability, prevention and health care policies, and health care systems; and (2) improved the dialogue among fields of research, with the common aim to estimate present and future costs of cancer. Measuring the burden of disease will continue to be of great interest to public health researchers and policy makers.

## Benefits of Screening Evolves with Advances in Treatment and Screening Technology

The recent intense debate surrounding the updated USPSTF recommendations on breast cancer are a reflection of a broader discussion about the net benefits of broad-based population screening for cancers in general. These debates focus on the effect of screening on not only those who will develop cancer, but also those who will remain free of cancer. As technologies (such as Artificial Intelligence and Machine Learning software to detect very small early-stage tumors within minutes) and treatments improve, the potential benefits



and harms of screening for those who have cancer must be continually assessed against the harms to those who will never get it.

This comparison must be considered in the context of the modern era of targeted cancer therapies, which focus only on those with cancer and promise more specific effects on cancer with less-toxic effects on the patient. DCCPS will continue to conduct and support the research that examines the role of various screening modalities in preventive health care.

## Value

Value is an important factor in providing cancer care, as cost of care can be a major burden on patients and families. The American Society of Clinical Oncology (ASCO) defines value in cancer care by looking at clinical benefit (efficacy), toxicity (safety), and cost (efficiency). The director of the Congressional Budget Office (CBO) has stated that comparative clinical effectiveness research, combined with changes in payment incentives, “offers a promising mechanism for reducing health care costs to a significant degree over the long term while maintaining or improving the health of Americans.” America’s Health Insurance Plans, a trade association representing health insurance plans, has urged Congress to give CMS the authority to use comparative effectiveness and cost-effectiveness information in its coverage and reimbursement decisions.

Costs are not always easy to define or measure. The total treatment costs may differ, sometimes dramatically, depending upon which perspective (e.g., patient, government payer, private insurer, society) is taken in the analysis and which costs are included. Much of the controversy surrounding whether costs should be included in comparative effectiveness research lies in the questions, “When, how, and by whom will the research results be used to make decisions?”

The issue is most controversial if results that include costs are used to make insurance reimbursement, pricing, or coverage decisions. The inclusion of costs in research tends to be less controversial when the results are not directly linked to medical and health policy decision-making. DCCPS will address these cost-of-care questions by continuing to fund comparative effectiveness research, research on how costs affect patients and their families, and through the division’s support of the Medical Expenditure Survey (MEPS), a set of large-scale surveys of families and individuals, their medical providers, and employers across the US. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage.

## Patient-Reported Care Experiences and Outcomes

Looking ahead, several DCCPS initiatives are well positioned to contribute to our understanding of cancer patients’ and survivors’ experiences when assessing quality of care, evaluating new drugs, and ensuring patients achieve the outcomes they value. The NCI [Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events](#) (PRO-CTCAE<sup>®</sup>) Measurement System was developed to evaluate symptomatic toxicities by self-report in children, adolescents, and adults participating in cancer clinical trials. It was designed to be used as a companion to the Common Terminology Criteria for Adverse Events (CTCAE), the standard lexicon for clinician adverse event reporting. The PRO-CTCAE Measurement System allows patient self-reporting of the frequency, severity, interference or presence/absence of symptomatic adverse events. A module for parent/caregiver reporting is available for use with younger children, who may have difficulty completing a self-report measure.

All components of the PRO-CTCAE Measurement System are developed and validated in accordance with well-established measurement principles. PRO-CTCAE has been translated and linguistically validated in more than 30 languages, thereby facilitating the participation of under-represented populations in cancer clinical trials. PRO-CTCAE is currently being used in more than 150 clinical research studies to enhance the precision and reproducibility of adverse event reporting. It provides information that complements clinician reporting using CTCAE, and represents the patient perspective of the experience of symptomatic adverse events.

The Patient Reported Outcomes Measurement Information System® (PROMIS®), described previously and provided as part of the HealthMeasures research resource, assesses patient-reported health status for physical, mental, and social well-being, and has the potential to be used for quality measurement and reimbursement by practices, as well as CMS and other payers. HealthMeasures, a sustainable resource, provides automated use of PROMIS and three other measurement systems, and promotes their uptake in the scientific and clinical communities. These measures are widely used across a range of clinical specialties and in clinical and pragmatic trials. They are also being utilized in submissions to support labeling claims for new drug development, in studies of health care quality, in government population health tracking reports, and significantly, in the course of routine care delivery, where they are being integrated into electronic medical records.

In addition to these measurement systems, DCCPS has provided leadership to several trans-NIH funding opportunities focused on measurement, interpretation, and application of patient-reported data. These have funded efforts to the development of new measures

or methodologic approaches (e.g., PAR-18-352; PAR-18-378; RFA-AG-16-013) as well as the interpretation of patient-reported data for use in clinical practice (NOT-OD-20-079).

## Digital Health

With modern advances in health information technology, approaches to gathering data relevant to cancer care and outcomes have evolved. The way in which evidence is gathered and applied has the potential to allow individuals and institutions to leverage electronic platforms and digital advances to more effectively gather and share information on the effectiveness and value of care. DCCPS is engaging the broader community of scientists and practitioners to develop innovative digital efforts to answer critical questions across the cancer care continuum. These efforts include the development and dissemination of web-based tools and other electronic methods, as well as funding opportunities that leverage cutting-edge technology to inform cancer prevention and control.

There are many examples, such as electronically based PRO tools (e.g., those available via HealthMeasures, such as PROMIS); Small Business Innovation Research initiatives that are developing software to assist patient navigation through the cancer care continuum; digital tools to improve health outcomes in pediatric cancer survivors; digital tools for clinical decision support to improve symptom management in cancer; digital platforms to reduce financial hardship in cancer patients; and software to address social determinants of health in cancer patients, and the IMPACT Consortium efforts to test pragmatic symptom management interventions that include clinical decision support (CDS) tools and supportive care that are implemented via EHR platforms.

A critical digital health opportunity has emerged in recent years. Due to the COVID-19 pandemic and the accumulating evidence suggesting that connected health approaches could lead to better patient-centered communication and improved health, there has been a dramatic increase in the use of telehealth to deliver care across the cancer control continuum. This uptick has been seen across care settings including primary care, oncology care, and other specialty care. A strong evidence base is needed to determine best practices and under what situations telehealth approaches can most effectively be used in cancer care. Further, there is a need to evaluate cancer-related telehealth impacts on access to care, care quality, patient-provider communication, and health outcomes.

In response to the COVID-19 public health crisis and the need to establish an evidence-base for telehealth-focused cancer care, DCCPS is leading NCI's efforts to establish a national research agenda on telehealth-centric research. One example is the Centers for Telehealth Research for Cancer-Related Care, which are focused on creating and disseminating patient-centered, equitable, and sustainable telehealth models of cancer care delivery in an evolving health care, technology, communication, and policy environment. This research will help inform policies and activities of federal agencies and payers and the health care delivery practices of the broader clinical care and cancer control communities.

The cancer community has also come to leverage advances in data science and artificial intelligence (including machine learning [ML] and deep learning) to abstract information from existing resources and link to additional data resources to provide a more complete picture of each patient's cancer journey. For example, through its collaboration with the Department of Energy, DCCPS has

developed ML algorithms to automatically abstract tumor characteristics from pathology reports, which will enable closer to real-time reporting on cancer surveillance data that ultimately informs health data. Linkages of cancer surveillance data to additional data sources, such as information from pharmacies on oral antineoplastic agents, further fills out the information we have available regarding longitudinal treatment of cancer patients. There are countless potential resources of information that could be leveraged to expand the breadth and depth of data to inform evidence on cancer screening, early detection, and treatment; the community is still working toward determining how to ensure information in these federated data sources is findable, accessible, interoperable, and reusable (FAIR). Expansion of these and similar efforts could make available the rich information in disparate data resources that would provide evidence to support decisions in cancer screening, early detection, and treatment.

## Cancer Survival Statistics

DCCPS supports research and participates in international meetings to improve the statistical methods used to determine survival rates. Current research is focused on developing more accurate models that consider a variety of factors that may influence survival, such as co-morbidities. The research will provide more reliable and efficient statistical methods that can facilitate scientists' understanding of cancer, as well as help inform public health research and priorities.

## Genomics and Health Policy

DCCPS increasingly funds research in public health genomics, a multidisciplinary field concerned with the effective and responsible use of genome-based technologies for the benefit of population health. This research helps inform policies and activities of

various government groups such as FDA, CMS, AHRQ, and CDC. It provides data for independent evidence review panels, such as the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) working group, an independent multidisciplinary committee sponsored by CDC, which makes recommendations on the use of genomic applications in medicine and public health. EGAPP has already addressed several topics related to cancer and, given that more than two-thirds of new genomic applications used in clinical practice are cancer related, the panel is likely to address more in the near future. In addition, a DCCPS senior scientist participates in the IOM Roundtable on Genomics-Based Research for Health.

The division's Genetic Associations and Mechanisms in Oncology (GAME-ON) initiative included approximately 200,000 samples from previously understudied populations and helped identify cancer risk variants across and unique to different populations. DCCPS continues to build rich genomic resources and promote the inclusion of diverse populations in genetic epidemiologic research. Current efforts at this writing include "Genome-wide Genotyping of Existing Samples from Minority Racial/Ethnic Populations and Sharing of Associated Epidemiologic Data" ([NOT-CA-21-049](#)), which will leverage existing biospecimens to diversify germline genome-wide genotyping data repositories and further enhance them with accompanying exposure, phenotype, and outcome data. These data resources will allow the study of genetic cancer susceptibility in diverse populations, to better understand its role in cancer health disparities.

In 2017, DCCPS fielded the National Survey of Precision Medicine in Cancer Treatment, the first nationally representative survey of oncologists about the current practice of precision medicine in cancer treatment. The findings provided data about the prevalence of genomic testing in practice as well as key barriers, drivers, and other factors that influence oncologists' use of genomic testing in clinical practice.

In light of DCCPS' work in genomics, the division is well suited to provide advice on the medical, ethical, legal, and social implications of genomic technologies.

# PARTNERS

Agency for Healthcare Research and Quality

American Cancer Society

Cancer Information Service, NCI

Centers for Disease Control and Prevention

Centers for Medicare and Medicaid Services

Department of Veterans Affairs

Food and Drug Administration

National Academy of Medicine (formerly, Institute of Medicine)

National Heart, Lung, and Blood Institute

National Institute for Environmental Health Sciences

National Institute on Aging

National Institute on Alcohol Abuse and Alcoholism

National Institute on Drug Abuse

NIH Office of Behavioral and Social Sciences Research

North American Association of Central Cancer Registries

Public Health Institute

Robert Wood Johnson Foundation

US Census Bureau

US Department of Agriculture

World Health Organization



NATIONAL CANCER INSTITUTE  
Division of Cancer Control & Population Sciences