



NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

THE NCI OFFICE OF CANCER SURVIVORSHIP TWENTY-FIVE YEARS OF PROGRESS

A photograph of a rural landscape at sunset. A dirt road curves through a green field towards a line of trees. The sun is low on the horizon, creating a bright glow and long shadows. The sky is filled with soft, grey clouds.

1996-2021

CONTENTS

Foreword	2
Shared Words from Retiring DCCPS Director Dr. Robert Croyle and New DCCPS Director Dr. Katrina Goddard	3
Message from OCS Director Dr. Emily Tonorezos	4
Milestones in Cancer Survivorship	6
Thoughts on the 25th Anniversary of the NCI Office of Cancer Survivorship	12
Growth in the Cancer Survivorship Portfolio, and in Our Understanding	14
Data Resources and Tools	20
Survivor Cohort Studies	24
Partnerships and Collaborations	28
Biennial Cancer Survivorship Research Conference	29
Cancer Survivorship Telephone Workshop Series	29
Small Business Innovation Research	29
National Academies of Sciences, Engineering, and Medicine	30
Comprehensive Cancer Control National Partnership	30
Advocacy Community	31
Future Priorities	32
By the Numbers	36



SECTION 1
FOREWORD

SHARED WORDS FROM RETIRING DCCPS DIRECTOR DR. ROBERT CROYLE AND NEW DCCPS DIRECTOR DR. KATRINA GODDARD

The 25th anniversary of the creation of the National Cancer Institute (NCI) Office of Cancer Survivorship (OCS) commemorates a key moment in the national effort against cancer, which was cemented 50 years ago with the National Cancer Act. During a ceremony in the White House Rose Garden, President Clinton announced the creation of OCS, promoting recognition of the growing population of cancer survivors. It also gave the institute a new mission—one clearly focused on serving a growing, diverse community of cancer survivors through research on their unique needs.

Not long after the formation of the office in 1996, OCS became part of NCI's Division of Cancer Control and Population Sciences (DCCPS). OCS and its director serve an important role in maintaining the visibility of cancer survivorship, as well as in leading survivorship collaborations, not only within DCCPS and the research community, but also with other parts of NCI, other institutes at the National Institutes of Health (NIH), and agencies outside NIH, like the Centers for Disease Control and Prevention.

Initially, cancer survivor research was heavily focused on psychosocial oncology, a vital area we continue to support. But in recent years, there has been growth within cancer survivorship research, with an increasing breadth of disciplines and expertise, including epidemiology, surveillance research, numerous aspects of behavioral research, as well as health services and outcomes research.

Research in cancer survivorship is designed not only to address survivors' questions, but also to address those of their medical providers. In particular, providers need to be able to give optimal support and clinical care. Therefore, in addition to creating and offering resources for cancer survivors, we seek to also support both specialists and primary care providers, many of whom face challenges in providing care for their cancer survivor patients. We must also tackle care coordination, including communication among specialists, primary care providers, and their cancer survivor patients.

As cancer research evolves and new therapies are discovered, many survivors are living longer. At the same time, researchers are uncovering and learning more about new concerns and needs related to treatment and long-term survivorship. This is informing evidence-based interventions to optimize care and outcomes for survivors. It is critical, however, to address disparities in care for survivors. We must make sure that we're meeting the diverse sets of needs for all survivors.

This anniversary celebration is not just about the creation of the office. It's an opportunity for NCI to renew its commitment to the needs of the cancer survivor community. Even as Dr. Croyle retires from his position as director of DCCPS and we welcome Dr. Goddard as the new division director, we are committed to continuing to focus on cancer survivorship research for many years to come.

MESSAGE FROM OCS DIRECTOR DR. EMILY TONOREZOS



By the time the creation of the Office of Cancer Survivorship (OCS) was announced by President Clinton in a 1996 Rose Garden ceremony, the National Coalition for Cancer Survivorship was celebrating its 10th anniversary. One of its founding members, [Dr. Fitzhugh Mullan, put the call for survivorship research in these words](#): “Despite ... success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problem of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and sputter on their own in the belief that we have done all we can.”

It was in response to these words and those like them that the OCS was created. [At the time, establishing the OCS was described](#) as “a move signaling that NCI will not only continue to seek a cure for cancer, but will also research ways to improve the long-term care of cancer survivors.”

Since its inception, the position of OCS Director has been held by just four women, including myself. Each has put her own mark on the office, from establishing a vision and strategic plan, to transforming our influence, to revising our foundational definition. Our backgrounds—from pediatric oncology, psycho-oncology, oncology nursing, and general internal medicine—have been as varied as the field itself. Yet, our purpose has always been to support and encourage survivorship science through research, resources, and funding opportunities. Each component of survivorship care (surveillance for recurrence and subsequent malignancies; preventing, detecting, or ameliorating toxicities; healthcare delivery and care coordination) is included in these efforts.

The challenges of survivorship have always been delineated by cancer risk, diagnosis, and treatment. Research has increasingly shown the role that social determinants of health play in impacting risk for cancer and related health outcomes, as well as in delays in diagnosis and treatment. Most recently, the field has been transformed by new paradigms of cancer risk and emerging therapeutics, and corresponding shifts in survivorship science have occurred. These changes, reflected in people living longer and better after a cancer diagnosis, will continue to inspire and energize both the OCS and the science we support.

NORMAN E. “NED” SHARPLESS, MD

CURRENT NCI DIRECTOR



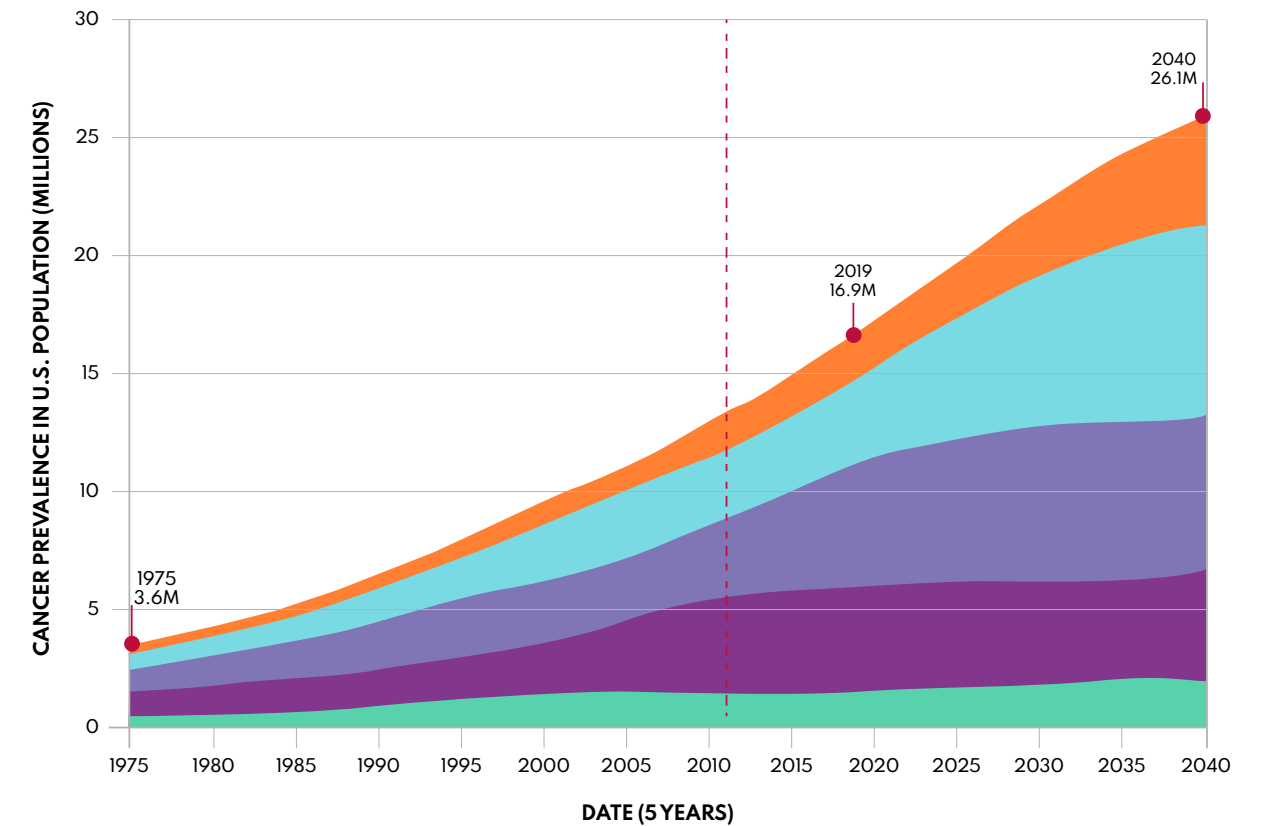
“With nearly 17 million cancer survivors living in this country today and many more expected in the coming years, the work of NCI’s Office of Cancer Survivorship has never been more important. Ending cancer as we know it today depends on understanding and meeting the distinct and diverse needs of this growing population, embracing a diverse constituency of survivors, investigators, patient and public health advocates, and caregivers. Nothing will stop us.”

DEBORAH K. MAYER, PHD, RN, AOCN, FAAN

OCS INTERIM DIRECTOR, 2018–2020



“The Office of Cancer Survivorship has helped focus on the unmet needs of our growing number of survivors. This focus importantly is not only on quantity but quality of life and keeps attention on the impact of the cancer and its treatment on individuals and populations of survivors. We have made much progress but have much more to do.”



KEY

Signifies the year at which the first baby boomers (those born 1946–1964) turned 65 years old.

Age

- <50
- 50–64
- 65–74
- 75–84
- 85+

Projections based on data from Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the “Silver Tsunami”: Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev.* 2016;25:1029-1036.

SECTION 2

MILESTONES IN CANCER SURVIVORSHIP

1975

[Pediatric Cancer in Perspective: Cure Is Not Enough](#) (D'Angio, Giulio "Dan") is published in *Cancer*.

1975

The [Cancer Information Service \(CIS\)](#) is established, following the mandate of the [National Cancer Act](#) of 1971, giving NCI new responsibilities for educating the public, patients, and health professionals. Today, the CIS continues to provide accurate, up-to-date, and reliable information that is easy to understand and free of charge.

1985

[Seasons of Survival: Reflections of a Physician with Cancer](#) (Mullan, Fitzhugh) is published in the *New England Journal of Medicine*.

1988

The first National Cancer Survivors Day is held on June 5.

1996

[The National Cancer Institute's Office of Cancer Survivorship](#) is established in recognition of the large number of individuals surviving cancer for long periods of time and their unique and poorly understood needs. Dr. Anna Meadows is appointed acting director of the office.



1997

Competitive supplements are awarded to 20 existing grants, contracts, and cooperative agreements to explore the impact of cancer and its treatment among long-term survivors of cancer.

1997

[Long-Term Cancer Survivors Research Request for Application \(RFA\)](#) is released to support research that would examine and describe the health consequences of cancer and its treatment among long-term survivors, which was defined as those surviving five years beyond initial diagnosis.

1998

OCS holds its first major research conference, Research Issues in Cancer Survivorship, a [brief summary](#) of which appears in the *Journal of the National Cancer Institute*.

1999

Dr. Julia H. Rowland becomes the first full-time director of the office.

MILESTONES IN CANCER SURVIVORSHIP

2001

Over 100 total grants funded by OCS since 1998, the first full year of funding as part of the Division of Cancer Control and Population Sciences, in which OCS is housed.

2002

OCS hosts a research meeting on **Physical Activity and Cancer Survivorship** to review the state of the science and identify resources needed to promote research on survivors' health. Commissioned papers prepared for the sessions are published as a set in [Cancer Investigation](#) (2004, volume 22, number 1).

2002

The first three volumes in the [NCI Facing Forward series of publications](#) are released, addressing post-treatment survivorship issues: *Facing Forward: Life After Cancer Treatment*, *Siga adelante: La vida después del tratamiento del cáncer*, and *Facing Forward: Ways You Can Make a Difference After Cancer*. Today, all three continue to be updated periodically, and *Facing Forward: Life After Cancer Treatment* remains one of NCI's most popular patient education publications.

2002

The first Biennial Cancer Survivorship Research Conference, *Cancer Survivorship: Resilience across the Lifespan*, is held in collaboration with the American Cancer Society. [Proceedings](#) from this meeting were published in *Cancer*.

2003

The annual three-part spring teleconference series "**Cancer Survivorship: Living With, Through and Beyond Cancer**" is launched, coordinated by *CancerCare*, and conducted in partnership with the Lance Armstrong Foundation, Intercultural Cancer Council, Living Beyond Breast Cancer, and the National Coalition for Cancer Survivorship.

2003

The American Cancer Society releases health behavior guidelines for cancer patients and survivors, [Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices](#).

2003

The Institute of Medicine (IOM) releases report, [Childhood Cancer Survivorship: Improving Care and Quality of Life](#), for which OCS staff provided data and testimony.

2004

The Lance Armstrong Foundation and the Centers for Disease Control and Prevention (CDC) release report, [A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies](#).

2004

The Children's Oncology Group releases [guidelines](#) for follow-up care for survivors of childhood cancer.

2004

The President's Cancer Panel selects cancer survivorship as a topic of focus for fiscal years 2003 and 2004 and releases report, [Living Beyond Cancer: Finding a New Balance](#).

2004

Cancer Survivorship is identified as an Area of Public Health Emphasis in the NCI bypass budget [The Nation's Investment in Cancer Research: A Plan and Budget Proposal for Fiscal Year 2004](#).

2004

Over \$100 million in cumulative funding by OCS since 1998.

2005

[Facing Forward: When Someone You Love Has Completed Cancer Treatment](#) is created as a companion piece to [Facing Forward: Life After Cancer Treatment](#) to address the needs of cancer caregivers who are adjusting to life in the recovery and post-treatment phase.

2006

Cancer Survivorship is identified as one of eight key objectives (Improve the Quality of Life for Cancer Patients, Survivors, and Their Families) in [The Nation's Investment in Cancer Research: A Plan and Budget Proposal for Fiscal Year 2008](#).

2006

IOM releases report on adult cancer survivorship, [From Cancer Patient to Cancer Survivor: Lost in Transition](#), for which the OCS provided data and testimony.

2007

The first issue of the *Journal of Cancer Survivorship* is published.

2008

IOM releases consensus study report on the psychosocial problems created or exacerbated by cancer, [Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs](#).

2013

[Receipt of Psychosocial Care among Cancer Survivors in the United States](#) (Forsythe, Laura P et al) is published in the *Journal of Clinical Oncology*.

MILESTONES IN CANCER SURVIVORSHIP

2013

[Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care](#) (de Moor, Janet S et al) is published in *Cancer Epidemiology, Biomarkers & Prevention*.

2016

[Anticipating the “Silver Tsunami”: Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States](#) (Bluethmann, Shirley M; Mariotto, Angela B; Rowland, Julia H) is published in *Cancer Epidemiology, Biomarkers & Prevention*.

2016

Congress passes the 21st Century Cures Act, which provides funding to NCI for the Beau Biden Cancer MoonshotSM (Cancer Moonshot). Funding for the initiative begins in 2017.

2017

[Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship](#) (Nekhlyudov, Larissa et al) is published in the *Journal of Clinical Oncology*, a look back at the 2006 IOM report.

2018

Congress passes the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, developed in collaboration with many childhood cancer organizations to advance pediatric and adolescent and young adult (AYA) cancer research and treatments, improve cancer surveillance, and enhance resources for survivors and their families. The STAR Act authorizes an expansion of existing NCI-supported biospecimen collection and associated infrastructure, enhancements to CDC registry infrastructure, and a continuation of NCI-supported research to improve the care and quality of life for cancer survivors—including children and AYAs.

2018

[Models of Care for Survivors of Childhood Cancer from across the Globe: Advancing Survivorship Care in the Next Decade](#) (Tonorezos, Emily S et al) is published in the *Journal of Clinical Oncology*.

2018

Dr. Deborah Mayer becomes interim director of OCS.

2019

[Survivorship Science at the NIH: Lessons Learned from Grants Funded in Fiscal Year 2016](#) (Rowland, Julia H et al) is published in the *Journal of the National Cancer Institute*.

2019

NCI brings together cancer survivorship researchers, representatives of professional organizations, cancer survivors, and advocates for a one-day, in-person meeting to identify evidence gaps and next steps to advance cancer survivorship. At this meeting, and in a subsequent webinar to solicit input from the broader survivorship community, participants identified cross-cutting recommendations.

2019

[Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy](#) (Nekhlyudov, Larissa et al) is published in the *Journal of the National Cancer Institute*.

2019

The federal government announces the investment of \$50 million, proposed to be extended in equal amounts per year for the next 10 years, in the Childhood Cancer Data Initiative. These funds allow NCI to enhance data sharing, collection, analysis, and access for ongoing and planned childhood and AYA cancer and survivorship research throughout the institute.

2020

[Follow-up Care for Breast and Colorectal Cancer Across the Globe: Survey Findings from 27 Countries](#) (Mollica, Michelle A et al) is published in the *Journal of Clinical Oncology Global Oncology*.

2020

[Dr. Emily S. Tonorezos](#) becomes director of OCS.

2020

[Childhood Cancer and Functional Impacts across the Care Continuum](#) is published by the National Academies of Sciences, Engineering, and Medicine, with contribution from OCS Director Dr. Emily Tonorezos.

2021

The Agency for Healthcare Research and Quality (AHRQ) releases [Disparities and Barriers to Pediatric Cancer Survivorship Care](#), a technical brief commissioned by NCI to support the development of a research agenda associated with the Childhood Cancer STAR Act. Two other STAR Act-funded AHRQ reports, on transitions and models of care, will follow.

2021

DCCPS hosts a [virtual meeting](#) to discuss gaps in knowledge and areas of unmet needs for individuals living with metastatic and advanced cancers.

2021

DCCPS releases a funding announcement for administrative supplements to NCI-Designated Cancer Centers to support research aimed at better understanding and addressing organizational factors that contribute to disparities in outcomes among childhood cancer survivors.

2021

[Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop](#) (Gallicchio, Lisa et al) is published in the *Journal of the National Cancer Institute*.

THOUGHTS ON THE 25TH ANNIVERSARY OF THE NCI OFFICE OF CANCER SURVIVORSHIP

SUSAN LEIGH, CANCER SURVIVOR, RETIRED ONCOLOGY NURSE, FOUNDING MEMBER OF NCCS

I came home from one war in 1971 to find myself in another war in 1972. The first war was Vietnam, where I was an Army nurse. The second war was Hodgkin lymphoma, where I suddenly became a reluctant patient. Neither war had many, if any, guidelines to help me navigate such traumatic circumstances. Yet, I was surrounded by external support in the military. The cancer diagnosis, though, was an entirely different story.

At the ripe old age of 24, I entered a world of uncertainty, where there were no road maps and few guides to help me visualize a life beyond cancer. I had a multitude of questions that had no answers, thus leading to a life of trial-and-error survival. Once physically recovered from the cancer and its treatments, I entered the new field of oncology nursing, thinking that I might offer patients a bit of support and security—just what I was looking for! What became crystal clear to me was that the trauma of living through a cancer experience did not necessarily dissipate once treatments were over. Yet, we were often told to be grateful that we survived; to stop worrying and get on with our lives; to only think positive thoughts; that we were so lucky to have gotten a “good cancer” or effective treatment. Many of us were made to feel ungrateful if we expressed anything but joy and gratitude. But help was on the horizon.

In 1986 I attended a small meeting in Albuquerque, NM, where patients, family members, and professionals—all involved with cancer in one way or another—gathered to identify and discuss issues related to surviving cancer. It became obvious that there were numerous issues needing attention for countless numbers of cancer survivors and their loved ones. The issue of quality of life could no longer be ignored and needed as much attention, if not more, than quantity of life. Thus, the National Coalition for Cancer Survivorship (NCCS) was born, and raising awareness about the plethora of survivorship issues became a major part of our mission.

One of the most important projects during our first decade was publishing *Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability*. Our charismatic CEO at the time, Ellen Stovall, made sure that a copy of this publication got into the hands of Dr. Richard Klausner, then the director of the National Cancer Institute. Dr. Klausner immediately reacted to the contents of this report, wondered why something had not



been done about this before, and within the year authorized the establishment of the Office of Cancer Survivorship. To say that we were thrilled by this development can barely scratch the surface of our excitement. Finally, cancer survivorship was given a platform with real credibility, professionalism, and funding.

It could no longer be ignored or relegated to second-class status, and eventually became an integral part of the cancer care continuum. While disagreements surrounding the semantics of cancer survivor and survivorship remain, the general area of survivorship is here to stay. We now see guidelines, support mechanisms, and psychosocial research. We see attention paid to long-term survival and its late effects. We see increased awareness about the needs of family and loved ones. And we applaud the work of advocates in every area that is impacted by cancer. All of this we see as progress toward enhancing life after a diagnosis of cancer, no matter what the length of life may be.

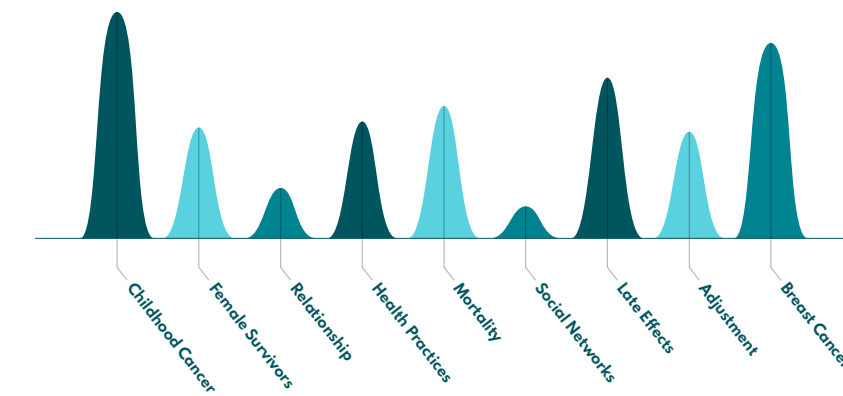
SECTION 3

GROWTH IN THE CANCER SURVIVORSHIP PORTFOLIO, AND IN OUR UNDERSTANDING

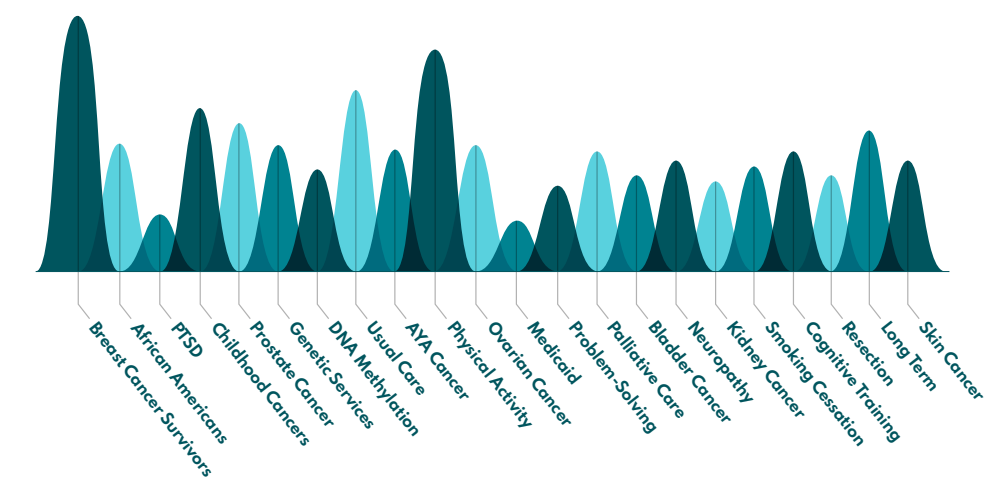
In 1975, Giulio “Dan” D’Angio, a pioneering radiation oncologist, wrote a seminal paper on the need for cancer survivorship research and clinical care, called “[Pediatric Cancer in Perspective: Cure Is Not Enough](#).” Advances in treatment had led to remarkable improvements in prognosis, particularly in his field of pediatric oncology. But Dr. D’Angio recognized the harmful effects of therapy, and he advocated for care that would minimize complications, also bearing in mind the heavy psychosocial and economic burdens of cancer and its treatment. Other early leaders, like Dr. Patricia Ganz, joined Dr. D’Angio in calling attention to the importance of understanding and addressing life after cancer. As the number of cancer survivors continued to grow, so, too, did the field of cancer survivorship.

The establishment of OCS in 1996 created a scientific home within NCI for the support and direction of research to improve the length and quality of life of survivors. In 1998—the first full year of funding as part of DCCPS, in which OCS is housed—survivorship research in the division focused on approximately a dozen broad areas, with 13 grants funded at a total of \$3,150,482.

Survivorship Research Focus Areas – 1998

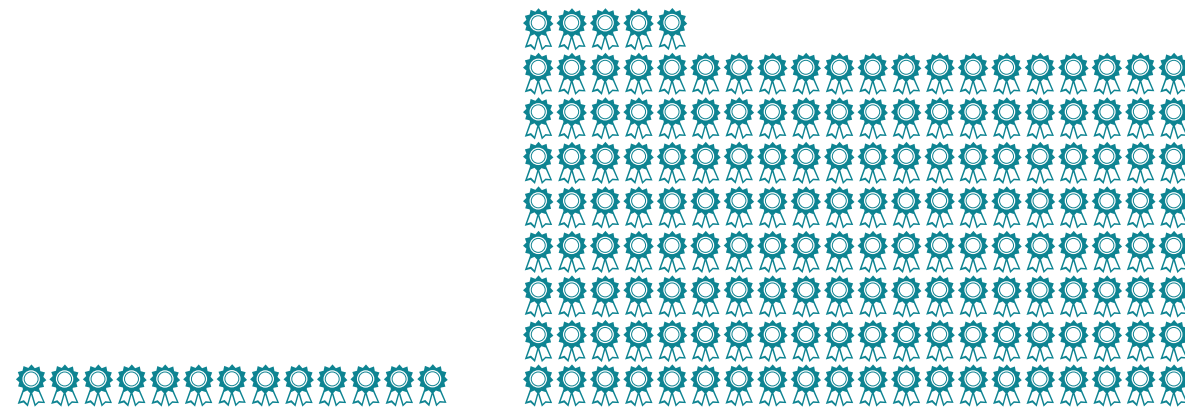


Survivorship Research Focus Areas – 2020



GROWTH IN THE CANCER SURVIVORSHIP PORTFOLIO, AND IN OUR UNDERSTANDING

Today, our research has grown to include numerous areas of investigation. In 2020, the division funded 165 grants, at a total of \$111,581,130, focused on cancer survivorship. These grant numbers represent funding through our annual appropriations, including resources for implementation of the STAR Act and additional resources provided through legislation such as the 21st Century Cures Act, which authorized funding for the Cancer Moonshot. Collectively, these allow us to further expand and enhance the portfolio.



1998: 13 AWARDS

2020: 165 AWARDS

The breadth of survivorship work extends beyond the division, such as funding opportunities in the Division of Cancer Prevention on side effects of cancer treatment, training programs in the Center to Reduce Cancer Health Disparities, and a trans-NCI forum on cancer and aging. NCI-funded research has played a vital role in identifying the unique medical, social, and psychological needs of both children and adults with a history of cancer. This includes NCI-funded studies documenting the large burden of late effects of cancer treatment—health problems that occur months or even years after diagnosis.

NCI also continues its commitment to fund research on the racial and ethnic disparities that exist, namely, the adverse effects on groups of people who have systematically experienced greater obstacles to health based on numerous characteristics historically linked to discrimination or exclusion. The harmful health differences are often closely linked with social, economic, and/or environmental disadvantage. The [Detroit Research on Cancer Survivors \(ROCS\)](#) study, for example, is a cohort of approximately 5,000 African American lung, prostate, colon, breast, and endometrial cancer survivors—the largest single cohort of African American cancer survivors—aimed at understanding the multiple causes of poorer outcomes in this population. Efforts like ROCS will help to reduce cancer disparities, so that advances in cancer prevention, diagnosis, treatment, and survivorship reach everyone.

The potential burden of the long-term effects of cancer and its treatment are particularly significant for survivors of pediatric cancers. Due to major advances in treatment, 80% of children (ages 14 and younger) and adolescents (ages 15–19) treated for cancer will now survive 5 years or more. Yet, as Dr. D’Angio highlighted years ago, many treatments that are effective against cancer increase the risk of conditions that can impair the quality and length of life. There is also emerging evidence that survivors of pediatric cancer experience the effects of accelerated aging (for example, frailty, comorbidities, or a decline in exercise capacity) and reduced life expectancy.

It is now well understood that cancer doesn’t affect just a body part, but rather the whole person—and often the person’s loved ones, as well. Here are examples of the many concerns that cancer survivors may face:

EXAMPLES OF CHALLENGES THAT CANCER SURVIVORS FACE

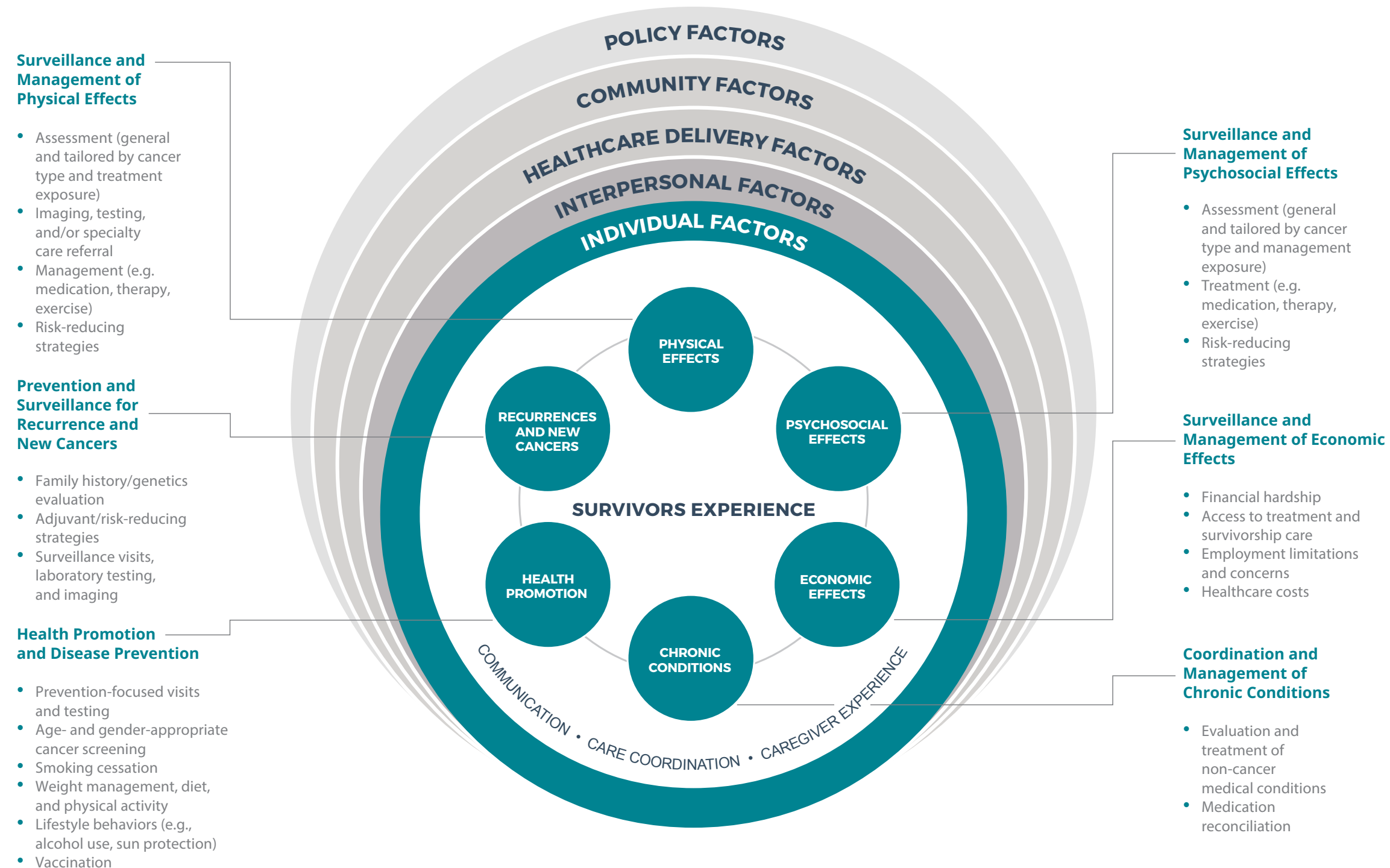
- ▶ Symptoms and conditions (cardiotoxicity, nausea, osteoporosis, fatigue, pain, sexual concerns, skin issues, sleep disturbances, cognitive challenges, hearing loss)
- ▶ Emotional distress (depression, anxiety/uncertainty, altered body image, survivor guilt)
- ▶ Change in lifestyle or quality of life
- ▶ Loss of fertility or diminished reproductive health
- ▶ Economic concerns (including difficulty maintaining or finding employment and problems related to the cost of treatment, which also includes childcare, supplies, transportation)
- ▶ Barriers to healthcare (high insurance and out-of-pocket costs for healthcare, lack of coordination of healthcare, limited access to specialty care)
- ▶ Risk of recurrence
- ▶ Increased risk of subsequent cancer

The research and expertise both within NCI and in our extramural community have helped us to better understand and find ways to address these and other concerns of cancer survivors. NCI-funded researchers are working to develop effective interventions that mitigate the short- and long-term adverse effects of cancer and its treatment, based on our growing understanding of the mechanisms that cause them.

Transitions have continued to be another challenge—the transition from pediatric to adult care settings, as well as the transition for survivors from specialty to primary care. As part of the [Cancer Moonshot](#) initiative, NCI is supporting research on interventions that enhance communication, collaboration, and coordination among oncologists and other healthcare providers to improve outcomes for cancer survivors and caregivers. NCI actively supports other research, as well, to understand how to improve the delivery of care to cancer survivors, especially in populations that continue to experience health disparities. We continue to work to eliminate these disparities and to achieve health equity.

Improving the quality of life of all survivors also requires continued research to better understand the role of health behaviors such as diet, physical activity, sleep, and the use of alcohol, tobacco, and other substances. Recent funding opportunities have focused on the effect of exercise and nutrition on patients’ outcomes, for example. The information gained from these studies should improve behavioral intervention protocols for cancer survivors and ultimately help translate research into clinical care.

Cancer Survivorship Research



Adapted from Nekhlyudov, L, Mollica, M, Jacobsen, P, Mayer, DK, Shulman, LN, Geiger, AM. (2019). Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research and Policy. JNCI, 111(11): djz089, first published online May 16, 2019.

Adapted from Nekhlyudov, L. et al. JNCI, 2019



SECTION 4

DATA RESOURCES AND TOOLS

Our ability to describe not only the number of cancer survivors, but also cancer survivors' health-related quality of life, their health behaviors, utilization and cost of care, as well as their care experiences, is dependent on the development and support of research infrastructure, data resources, and measurement tools. DCCPS has advanced the cancer control field, and specifically survivorship science, by prioritizing these areas. Some examples include the following:

- ▶ **The Cancer Patient Tobacco Use Questionnaire (C-TUQ)** – Studies have shown that cancer patients who smoke have increased morbidity and mortality compared to former or never smokers. The C-TUQ is a validated questionnaire exploring tobacco use in cancer patients and survivors that can be administered at study entry and follow-up. Data derived from the questionnaire can produce important research variables, while allowing for the collection of standardized information across multiple studies.
- ▶ **The Health Information National Trends Survey® (HINTS®)** – HINTS is a regularly administered survey that obtains nationally representative data on knowledge of, attitudes toward, and use of cancer- and health-related information by the US public. Every HINTS includes 500 to 600 cancer survivors, and the 2020 oversampling of survivors using three Surveillance, Epidemiology, and End Results (SEER) registries yielded responses from over 3,300 survivors. These data are used to monitor current health communication and information technology and assist in the creation of improved health communication strategies across different populations.
- ▶ **SEER Cancer Registry Data Linked to Data from the Centers for Medicare & Medicaid Services** – DCCPS offers four publicly accessible data sources that assist researchers interested in the care and quality of life of older cancer patients. The SEER Cancer Registry is linked to Medicare and Medicaid data from the Centers for Medicare & Medicaid Services (CMS). These resources include Medicare Claims Data (SEER-Medicare), Medicaid Claims Data (SEER-Medicaid), patient experience survey data (SEER-Consumer Assessment of Healthcare Providers and Systems [CAHPS]), and outcomes survey data (SEER-Medicare Health Outcomes Survey [MHOS]). SEER-Medicare contains data focused on patterns of care, comorbidities, healthcare providers and facilities, and treatment costs. SEER-Medicaid provides information about Medicaid beneficiaries diagnosed with cancer and can be used for epidemiological and health services research, such as assessing how enrollment in Medicaid impacts cancer presentation, surgical treatment, and survival. SEER-CAHPS includes information on timeliness, provider communication, access to care, and care coordination. Lastly, SEER-MHOS has beneficiary survey data on health-related quality of life, activities of daily living, and effectiveness of care.

- ▶ **Medical Expenditure Panel Survey (MEPS): Experiences with Cancer Survivorship Supplement** – MEPS is a national survey of families, medical providers, and employers that collects comprehensive information on healthcare utilization and expenditures. NCI, in collaboration with other US government and private organizations, provides funding for a MEPS supplement that includes a large sample of households with cancer survivors identified through the National Health Interview Survey. This publicly available data allows researchers to conduct a variety of studies to investigate the burden of cancer, including financial liability, access to care, employment and employment patterns, and prescription drug use.
- ▶ **NCI Community Oncology Research Program (NCORP)** – NCORP is a national network that brings cancer clinical trials and care delivery studies to people in their communities. The network designs and supports research in a variety of areas, including cancer prevention, screening, supportive care, surveillance, treatment, imaging, and health-related quality of life. NCORP is the primary source of accrual to NCI cancer control symptom management trials and health-related quality of life trials; the network also provides leadership for multi-center quality of life trials embedded within NCORP and NCI’s **National Clinical Trials Network (NCTN)**. In addition, NCORP incorporates research questions related to health disparities, with the purpose of reducing differences in clinical trial outcomes and cancer care delivery related to common cancers that disproportionately affect minority and underserved populations.

- ▶ **Group-Evaluated Measures (GEM)-Connect** – Originally developed as the **Grid-Enabled Measures Database** to promote use of standardized measures in behavioral research, the GEM-Connect platform will promote dissemination of vetted measures to enable more efficient research and collaboration. Researchers are encouraged to use the measures to increase comparability and reproducibility of research results. Look for these changes to GEM to be implemented in 2022.
- ▶ **National Health Interview Survey (NHIS) Cancer Control Supplement (CCS)** – The NHIS is a continuous national survey that serves as the main source of information on a variety of health topics in the United States. Each year, NCI provides a cancer control supplement to the NHIS to obtain data on knowledge of, attitudes toward, and practices of cancer-related health behaviors, screening, and risk assessment. CCS data, available on the National Center for Health Statistics website, are used for monitoring **Healthy People** cancer control objectives, and have also been used in the NCI **Cancer Trends Progress Report** and various peer-reviewed manuscripts.



ANNA T. MEADOWS, MD
OCS DIRECTOR, 1996-1999

“Setting up the office was exhilarating; I worked with incredibly accomplished scientists, administrators, and advocates, and with the support of NCI leadership. By creating funding opportunities for cancer centers, cooperative groups, and NGOs [non-governmental organizations], we encouraged researchers and clinicians to focus on survivors, even developing special programs for them. We hoped that our requests for proposals concerning long-term effects of therapy would begin to receive greater attention and trusted that applicants would ‘follow the money.’”

- ▶ **Automated Self-Administered 24-Hour (ASA24®) Dietary Assessment Tool** – ASA24 is a free, web-based tool that enables multiple, automatically coded, self-administered 24-hour diet recalls and/or single or multi-day food records, also known as food diaries. Since ASA24 was released in 2009, researchers have collected more than 630,000 dietary recalls or food records, and more than 300 peer-reviewed scientific publications used the ASA24 to collect diet-related data. The ASA24 system can be used by anyone with access to a computer or mobile device with internet connection. Some of the most common uses include healthcare practitioners collecting 24-hour recalls or food records from patients, and researchers conducting epidemiologic, interventional, behavioral, or clinical studies.
- ▶ **Cancer Epidemiology Descriptive Cohort Database (CEDCD)** – The CEDCD contains descriptive information about cohort studies that follow groups of persons over time for cancer incidence, mortality, and other health outcomes. The CEDCD is a searchable database that contains general study information (such as eligibility criteria and size), the type of data collected at baseline, cancer sites, number of participants diagnosed with cancer, and biospecimen information. All data included in this database are combined for each cohort; there are no individual-level data. The goal of the CEDCD is to facilitate collaboration and to highlight the opportunities for research within existing cohort studies, including cohorts of cancer survivors.



SECTION 5

SURVIVOR COHORT STUDIES

As the number of cancer survivors in the United States continues to increase, disease recurrence and the possible late effects of cancer treatments are of increasing importance. While numerous epidemiologic studies have investigated factors that affect cancer risk, far fewer have addressed the extent to which demographic, lifestyle, genomic, clinical, and psychosocial factors influence recurrence and other cancer outcomes.

Cohort studies, in which groups of people with a set of characteristics or exposures are followed for the incidence of new cancers and cancer-related outcomes, are critical for epidemiologic research. Data from cohort studies have helped researchers to better understand the complex etiology of cancer, and have provided fundamental insights into key environmental, lifestyle, clinical, and genetic determinants of cancer and its outcomes.

NCI has made significant commitments to survivor cohort studies. The institute supports observational cohort studies that include broad cancer patient populations treated by a variety of practitioners and address critical research on early and late treatment effects, quality of life, and risks of new primary cancer and other health outcomes. This research collects important disease- and treatment-related data, studying physical, psychological, social, and financial outcomes of cancer, providing critical information to develop interventions to improve outcomes. A distinct advantage of population-based observational studies is to capture a broader survivor “real-world” experience, compared to the more selective nature of clinical trial populations.

There are expected shifts in the sociodemographic composition of cancer survivors, with the aging of the population and the rising numbers of racial and ethnic minorities in the United States. To date, there is a disparity in cancer survival among minority populations, as well as worse health outcomes among minorities, the uninsured/underinsured, immigrants, rural populations, and the poor. Longitudinal research of cancer survivors can identify the complex factors contributing to these poor outcomes and guide interventions and clinical guidelines to mitigate or prevent adverse health effects.

Currently funded cohorts in FY2021 are shown in the table below, focusing on different types of cancers and demographic groups.

270,000

The Epidemiology and Genomics Research Program funded 21 cohort studies of **more than 270,000 cancer survivors** between 1991 and 2021.

Cancer Survivor Cohorts - Active (as of July 2021)

Principal Investigator Name	Grant #	Cohort Name	Project Title	Organization Name
Anderson, Garnet	5U01CA173642-08	WHI Cancer Survivorship Cohort	Women's Health Initiative (WHI) Cancer Survivorship Cohort	Fred Hutchinson Cancer Research Center
Bhatia, Smita	5U01CA213140-03	BMTSS-2	Blood or Marrow Transplant Survivor Study-2 (BMTSS-2)	University of Alabama Birmingham
Cerhan, James	2U01CA195568-06A1	LEO Study	The Lymphoma Epidemiology of Outcomes (LEO) Cohort Study	Mayo Rochester
Christiani, David	5U01CA209414-05	BLCS	The Boston Lung Cancer Survival Cohort (BLCS)	Harvard School of Public Health
Doherty, Jennifer	5R01CA243188-02		Racial/Ethnic Disparities in Ovarian Cancer Treatment and Survival: An Integrative Approach	University of Utah
Haiman, Christopher	5U19CA214253-04	RESPOND	Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Immunity and Stress (RESPOND)	University of Southern California
Hudson, Melissa	2U01CA195547-07	SJLIFE	The St. Jude Lifetime Cohort (SJLIFE)	St. Jude Children's Research Hospital
Kushi, Lawrence	2U01CA195565-06	Pathways Study	Infrastructure for Pathways, a Prospective Study of Breast Cancer Survivorship	Kaiser Foundation Research Institute
Kwan, Marilyn	5R01CA172855-05		Diet and Lifestyle in a Prospective Study of Bladder Cancer Survivors	Kaiser Foundation Research Institute
Lin, Daniel	5U01CA224255-03	PASS	Prostate cancer Active Surveillance Study (PASS) Cohort: Infrastructure Support for Cancer Research	Fred Hutchinson Cancer Research Center
Milam, Joel	7R01CA237230-02		Project Milestones: Young Adult Cancer Survivorship	University of Southern California
Miller, Kimberly	1R01CA261888-01		Individual, cultural, and area-based factors associated with survivorship care among Asian/Asian American childhood cancer survivors	University of Southern California
Pal, Tuya	5R01CA204819-05	BRIGHT	Breast Cancer In Blacks: Impact of Genomics, Healthcare Use and Lifestyle on Outcomes (BRIGHT)	Vanderbilt University Medical Center
Penedo, Frank J	1UG3CA260317-01	Leading Pathways	Avanzando Caminos (Leading Pathways): The Hispanic/Latino Cancer Survivorship Cohort Study	University of Miami Coral Gables
Scheurer, Michael E	1UG3CA260607-01	SALUD	Survivorship and Access to care for Latinos to Understand and address Disparities (SALUD)	Baylor College of Medicine
Schildkraut, Joellen	5R01CA237318-02		Ovarian Cancer Survival in African-American Women	Emory University
Schwartz, Ann	5U01CA199240-05	Detroit ROCS	Detroit Research on Cancer Survivors (Detroit ROCS)	Wayne State University
Traube, Chani	5R01CA244500-02		Delirium in Children Undergoing Hematopoietic Stem Cell Transplants	Weill Medical College of Cornell University
Travis, Lois	2R01CA157823-07A1	Long-term Survivor Study	Genetic Susceptibility and Biomarkers of Platinum-related Toxicities	Indiana University/Purdue University, Indianapolis
Ulrich, Cornelia	2U01CA206110-06	ColoCare Study	Transdisciplinary Team Science in Colorectal Cancer Prognosis: the ColoCare Study	University of Utah
Yao, Song	1UG3CA260602-01	DiRECT	Disparities in REsults of Immune Checkpoint Inhibitor Treatment (DiRECT): A Prospective Cohort Study of Cancer Survivors Treated with anti-PD-1/anti-PD-L1 in a Community Oncology Setting	Roswell Park Cancer Institute Corporation
Zebrack, Bradley	1R01CA261752-01		Social genomic mechanisms of health disparities among Adolescent and Young Adult (AYA) cancer survivors	University of Michigan



SECTION 6

PARTNERSHIPS AND COLLABORATIONS

The office's many collaborations—with organizations ranging from other government agencies to nonprofit foundations—have been instrumental in helping to improve cancer survivorship. Our diverse partnerships illustrate our dual role: supporting research to advance cancer survivorship understanding and implementation, while also providing resources to improve the lives of cancer survivors and their loved ones through healthcare professionals, advocates, and directly to cancer survivors themselves. Included below are some examples of the office's partnerships and collaborations over the years.

BIENNIAL CANCER SURVIVORSHIP RESEARCH CONFERENCE

From 2002 to 2016, OCS partnered with the American Cancer Society, the **LIVESTRONG** Foundation, and the CDC* to hold the [Biennial Cancer Survivorship Research Conference](#). The conferences brought together researchers, clinicians, cancer survivors, advocates, policymakers, and public health experts every two years to share and learn about the most up-to-date cancer survivorship research. The biennial conference proved to be an important vehicle in building and advancing the field.

CANCER SURVIVORSHIP TELEPHONE WORKSHOP SERIES

OCS also co-led the [Cancer Survivorship Telephone Workshop Series](#) with CancerCare, **LIVESTRONG**, the American Cancer Society, the Intercultural Cancer Council, Living Beyond Breast Cancer, and the National Coalition for Cancer Survivorship.* A free series from 2003 until 2012, it offered cancer survivors, their families, friends, and healthcare professionals practical information to help them cope with concerns and issues that arise after treatment ends.

SMALL BUSINESS INNOVATION RESEARCH

Advances in cancer survivorship, as in any field, require innovation. By definition, innovation is the introduction of something new, and small businesses are a national resource for new ideas. NCI's [Small Business Innovation Research \(SBIR\)](#) was created to stimulate technological innovation by increasing private-sector commercialization of federal research and development, increasing small business participation in federally funded research and development, and fostering participation by minority and disadvantaged companies in technological innovation. Several recent contracts funded through the SBIR program are especially relevant to cancer survivors. SBIR contracts have focused on digital healthcare platforms to reduce financial hardship in cancer patients and to connect cancer caregivers to care teams; on connected health technologies to address and improve health outcomes of long-term cancer survivors; on clinical decision support to improve cancer symptom management; and on informatics tools to measure cancer care coordination.

NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE

The [National Academies of Sciences, Engineering, and Medicine](#) (NASEM) bring together committees of experts to address critical national issues and to give advice to the federal government and the public. Support for the meetings and resulting publications has been from contracts with NCI/NIH and other government entities, such as the CDC, and with professional societies, nonprofits, and other private and public partners. The National Academy of Medicine, the “M” of NASEM, was called the Institute of Medicine (IOM) until 2015. NASEM/IOM has played an important role in the cancer survivorship field, particularly with its 2006 landmark report, [From Cancer Patient to Cancer Survivor: Lost in Transition](#). Based on a series of meetings—including a presentation by the OCS director at the time, Dr. Julia Rowland—the resulting report raised awareness of the medical, functional, and psychosocial consequences of cancer and its treatment and included recommendations to improve the quality of care that cancer survivors receive.

In 2017, NASEM held a workshop to examine progress in cancer survivorship care since that seminal report, with Dr. Rowland serving on the planning committee with other leaders in the field. The workshop and resulting proceedings, [Long-Term Survivorship Care After Cancer Treatment](#), published in 2018, highlighted potential opportunities to improve the planning, management, and delivery of cancer survivorship care.

In 2020, the National Policy Forum of NASEM again hosted a cancer survivorship-focused workshop, titled [Addressing the Adverse Consequences of Cancer Treatment](#), including a presentation by current OCS Director Dr. Emily Tonorezos. Other recent key cancer survivorship efforts by NASEM include [Childhood Cancer and Functional Impacts Across the Care Continuum](#) in 2021, also involving Dr. Tonorezos, as well as the recent [Diagnosing and Treating Adult Cancers and Associated Impairments](#), for which former OCS Interim Director Dr. Deborah Mayer served as a reviewer.

COMPREHENSIVE CANCER CONTROL NATIONAL PARTNERSHIP

The [Comprehensive Cancer Control National Partnership \(CCCNP\)](#), formed in 1998, is a group of over a dozen federal and national cancer organizations in the United States dedicated to building and strengthening comprehensive cancer control efforts across the nation. Through coordination and collaboration, the CCCNP helps comprehensive cancer control coalitions develop and sustain implementation of comprehensive cancer control plans at the state, tribe, territory, US Pacific Island Jurisdiction, and local levels.

With many cancer survivors continuing to use tobacco after diagnosis, contributing to treatment delays and complications, worsened prognosis, and diminished quality of life, tobacco cessation in cancer survivors was identified as one of CCCNP’s focus areas. The group [released a guide](#) in 2017, detailing the

importance of tobacco cessation for cancer survivors and providing recommendations on how local health departments can use existing resources to connect cancer survivors to cessation services.

The CCCNP has since broadened its survivorship focus beyond tobacco cessation, with the current [Healthy Behaviors for Cancer Survivors Work Group](#) now incorporating the previous work of the tobacco cessation group—and other partners working on related initiatives—to focus more broadly on addressing public health needs of cancer survivors, including physical activity, nutrition, mental health and emotional support services, and fertility preservation, in addition to tobacco cessation. The group also focuses on access to comprehensive follow-up care, evidence-based surveillance protocols, and secondary prevention measures, as well as promoting resources that support the development and delivery of survivorship care plans and patient navigation programs.

ADVOCACY COMMUNITY

The office’s work with the advocacy community is interwoven into the history of the office. In the spring of 1996, Ellen Stovall, then-president and CEO of the NCCS, acted on behalf of the broader cancer survivorship advocacy community to present then-NCI Director Dr. Richard Klausner with *Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability*, a report that highlighted recommendations to advance the science and care necessary to better understand and meet the needs of the growing number of individuals living long-term after a cancer diagnosis. It was in response to this report that OCS was established.

As the survivorship population has grown, the advocacy community has continued to play a vital role, both directly with OCS, as well as with the [NCI Office of Advocacy Relations](#). Over the past few years, for example, the advocacy community has worked with NCI to ensure that survivors with advanced or metastatic cancer are not excluded from the cancer survivorship conversation nor resources. Given that more and more survivors will continue to be treated for cancer throughout their life, a growing number of survivors would not utilize the many resources created for “life after cancer.” OCS, understanding the importance of acknowledging this growing population of cancer survivors, [updated its definition of “survivor” to formally recognize that there are many different types of survivors](#). The office also brought together stakeholders for a [meeting in May 2021 focused on survivors with advanced and metastatic cancers](#), to explore areas of high priority for research in that specific survivor population.

OCS is grateful for the many partners it has worked with in the past and continues to work with today. All of these collaborations will be no less valuable as the office looks toward the next steps in cancer survivorship.

*Note that not all listed partners co-sponsored all events.

SECTION 7

FUTURE PRIORITIES

In April 2019, OCS convened a meeting to bring together cancer survivorship researchers, representatives of professional organizations, cancer survivors, and advocates for a one-day, in-person meeting to identify evidence gaps and opportunities to advance cancer survivorship. At this meeting, and in a subsequent webinar to solicit input from the broader survivorship community, participants identified the following cross-cutting recommendations:



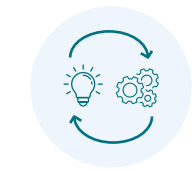
Understand and address disparities among cancer survivors



Conduct longitudinal studies as well as longer-term (more than 5 years post-diagnosis) follow-up studies



Leverage existing data



Incorporate implementation strategies to translate findings into practice

The 2019 meeting and webinar and the resulting identified gaps provided solid guideposts for the field. While there has been progress since that time, we are still asking questions.

For example, how can we best utilize technology to integrate survivorship into clinical care throughout the continuum? People often think of technology, such as electronic health records, as tools to enable care coordination between doctors. It can be just as vital, though, in the identification of patient-reported outcomes. NCI has funded research to identify new, information-technology-enabled delivery models that support systematic screening and treatment of depression in cancer patients, and to test the effectiveness and feasibility of implementing these new delivery models in a variety of oncology settings, especially for underserved populations. New funding opportunities focus on the innumerable potential roles of technology in survivorship care.

While we are starting to see signs that an increasing number of healthcare providers are addressing more than just a patient's cancer, we continue to ask how we can develop a system-based approach that consistently tackles survivorship holistically, taking into account the many interactions at multiple levels: survivors and their caregivers or loved ones; survivors and their clinicians; between clinicians of different specialties; and the influence of the organization, healthcare system, and community on delivery of care. Given workforce shortages and the projected growth in the survivor population over the coming years—due to the aging of the population, better detection strategies, more effective cancer treatments, and improved supportive care—the importance of establishing a healthcare delivery system that effectively addresses the needs of survivors has grown. Understanding the many factors that influence care, and how they act and interact, is an essential component of healthcare delivery research supported by NCI. The knowledge generated from this research can be used to design and test interventions that will promote patient-centered, evidence-based care.

OCS celebrates the successes of cancer diagnosis and treatment, while at the same time acknowledging the struggles and challenges of long-term and late effects. The most recent [Annual Report to the Nation on the Status of Cancer](#), for example, highlighted an accelerated drop in lung cancer and melanoma deaths, largely due to advances in targeted therapies and other treatments. These positive advances mean a growing number of these survivors, who will have their own unique concerns and needs.

Unfortunately, the physical, emotional, and financial toll of cancer has been exacerbated by the COVID-19 pandemic. Many people with a history of cancer are at increased risk for complications from COVID-19. In addition, concerns about exposure to the virus and interruptions in healthcare services have delayed millions of cancer screenings and diagnoses, as well as treatment. Analyses thus far have suggested that these factors could lead to thousands of additional cancer-related deaths. At the same time, the COVID-19 pandemic has resulted in rapid expansion of telehealth services, which will lead to improved access to care for many cancer survivors.

NCI highlighted survivorship as an important area of focus in its [Annual Plan and Budget Proposal for Fiscal Year 2022](#), demonstrating the institute’s continued commitment to improving the lives of cancer survivors. Moving forward, OCS has set the following goals: support survivorship researchers, build infrastructure, leverage expertise, generate collaborations, and promote understudied research areas.

Specific initiatives further supporting these goals include the development of funding opportunities to address key gaps in survivorship science. For example, [RFA-CA-20-030, Utilizing Cohort Studies to Address Health Outcomes in Cancer Survivors](#), supports research in understudied cancer populations and rare cancer sites. The newly funded cohorts (funded in FY2021) focus on cancer survivors treated with immune checkpoint inhibitors, Hispanic/Latino adult and pediatric patients, and survivors of sarcoma. In addition, two recent initiatives, [RFA-CA-19-033, Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors](#) and [RFA-CA-20-027/028, Research to Reduce Morbidity and Improve Care for Pediatric, and Adolescent and Young Adult \(AYA\) Cancer Survivors](#), were developed with the goal of supporting both interventional and observational research focused on improving care and health-related quality of life for childhood and AYA cancer survivors. These RFAs were developed in direct response to the Childhood Cancer STAR Act, passed by Congress and signed into law in 2018.

Recognizing that each survivor’s journey is unique, NCI-supported researchers are also seeking to better understand how to tailor the level of survivorship care based on individual needs. For instance, certain patients may warrant more intensive follow-up care than others, based on, for example, risk of recurrence or physical and/or psychosocial effects of their cancer treatment. NCI is committed to supporting research to understand how these and other precision-oncology-focused topics translate to care for survivors.

As awareness and understanding of cancer survivorship has evolved, so, too, has our terminology. Survivors used to be called “victims,” and we spoke about our country—and people diagnosed with cancer—as fighting a “war” on cancer. Today we recognize survivorship as a “journey.” We also acknowledge that survivors may have their own preference for terms; for example, they may see themselves as “thrivers” rather than survivors.


In [Seasons of Survival: Reflections of a Physician with Cancer](#), years before the creation of OCS, Dr. Mullan wrote: “Survivorship should be studied as a phenomenon in itself rather than as a byproduct or afterthought of basic research on cancer treatment. Organizations such as the National Cancer Institute [...] need to collaborate with interested groups and individuals in developing such a program.” Now, 25 years after the creation of OCS, we face the future with immeasurable expertise and continued desire to collaborate, clear next steps and goals, and the hope that, armed with our growing knowledge and resources, both longevity and quality of life can be improved for all who have ever received a cancer diagnosis.



JULIA ROWLAND, PHD

OCS DIRECTOR, 1999-2017

“The most powerful—and visible—testament to the many successes achieved in the prevention and control of cancer since the passage of the National Cancer Act in 1971 is the burgeoning population of cancer survivors! The Office of Cancer Survivorship, created 25 years after Nixon signed the act, created a vibrant home at NCI for research addressing the poorly understood needs and care of those living with and beyond their cancer. Twenty-five years later, building on the work of the visionary leaders and advocates who came before us, those of us privileged to champion this effort are celebrating the recognition by the broader cancer community that cancer does not end when treatment ends. Today, it is clear that a focus on healthspan is as important as lifespan in designing and delivering cancer care. Looking to the future, continued robust funding of survivorship science and state-of-the-art care will be critical if we are to successfully reduce the global burden of cancer.”



SECTION 8 BY THE NUMBERS

The numbers below provide a snapshot of progress in the cancer survivorship field, just some examples of many. By supporting these and innumerable other initiatives, we hope to continue making strides to advance cancer survivorship.

26.1 million

As of January 2019, the latest data available, it is estimated that there are 16.9 million cancer survivors in the United States. Due to the growth and aging of the population, better early-detection strategies, more effective cancer treatments, and improved supportive care, that number is projected to grow to **26.1 million** by 2040, highlighting the importance of improving our understanding of—and our ability to address—the needs of cancer survivors.

52

NCI supported **52 cancer centers** as part of the Cancer Moonshot [Cancer Center Cessation Initiative](#) to help build and implement sustainable tobacco cessation treatment programs for cancer patients.

28

In FY2010–12, DCCPS awarded eight early-stage investigators (ESIs) for work in cancer survivorship. That number grew to **28 awarded ESIs** in FY2019–21, a 250% increase in 10 years.

5,000

Detroit Research on Cancer Survivors (ROCS) is a **cohort of approximately 5,000 African American lung, prostate, colon, breast, and endometrial cancer survivors**—the largest single cohort of African American cancer survivors—aimed at understanding the multiple causes of poorer outcomes in this population.

59%

Fifty-nine percent of the DCCPS FY2020 Cancer Survivorship Research Portfolio was coded as having a *health disparities* or *minority health* focus.

2,000

DCCPS hosted 11 webinars attended by **more than 2,000 participants** in the [Perspectives on Cancer and Aging: The Arti Hurria Memorial Webinar Series](#). Established in October 2019, this series honors the legacy of Dr. Arti Hurria, a pioneer in the fields of geriatrics and oncology. It serves as a platform to cultivate a community of researchers and broadly disseminate advances in cancer and aging research.

8

NCI supported **8 NCI-designated P30 Cancer Centers** as part of the [Cancer and Aging initiative](#) to expand research capacity and foster interdisciplinary research at the intersection of cancer and aging.

\$111,581,130

In 1998, DCCPS funded 13 grants to support cancer survivorship research, at a total of \$3,150,482. By 2020, those numbers grew to 165 grants at a **total of \$111,581,130**.

72

Since 1987, the [Patterns of Care \(POC\) initiative](#) has evaluated the dissemination of state-of-the-art cancer therapy and diagnostics into community oncology practice; identified patient-, provider-, and system-level factors that are associated with receipt and utilization of cancer care; and disseminated findings through scientific publications and presentations. To date, POC has collected information on 32 types of cancer, and **72 papers** have been published highlighting the results of this work.

34,005

Per [PubMed](#), from 1947 (the first year that citations are included in PubMed) to 1995, the number of publications with the words *cancer survivor* was only 2,340. Since the creation of OCS in 1996, as of December 2021 there have been **34,005 cancer survivor publications**, reflecting the expansion of cancer survivorship research championed by NCI.

270,000

The Epidemiology and Genomics Research Program funded 21 cohort studies of **more than 270,000 cancer survivors** between 1991 and 2021. The duration of these research projects ranges from 1 to 27 years, and they encompass at least 16 different types of cancer survivors, including those with bladder, breast, colorectal, endometrial, leukemia, lung, lymphoma, melanoma, ovarian, prostate, and testicular cancer, and including children, adolescents and young adults, Hispanic/Latino cancer survivors, cancer survivors treated with immune checkpoint inhibitors, and adult cancer survivors.

35

[Thirty-five language translations](#) have been validated—and 17 more are in development and testing as of July 2021—for the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE™), a patient-reported outcome measurement system developed by NCI to evaluate symptomatic adverse events in children, adolescents, and adults participating in cancer clinical trials. A pediatric module for reporting by children ages 7–17 or their parent caregiver has also been tested. The pediatric module is currently available in English, Italian, and simplified Chinese, and several other languages are currently being tested, including Spanish, German, Korean, Danish, and French.

10,000

The [Improving the Management of symptoms during And following Cancer Treatment \(IMPACT\)](#) consortium, an initiative funded by the Cancer Moonshot, supports three research centers and a coordinating center to evaluate the implementation of systematic symptom management in cancer care delivery. The research centers are deploying integrated systems via electronic health record platforms tested in pragmatic trials. They will examine the effects of routine symptom surveillance along with action by a clinician for severe symptoms on patient health, treatment delivery, healthcare utilization, and implementation outcomes. These multicomponent interventions are being tested in **more than 10,000 patients** in diverse cancer treatment settings.





NATIONAL CANCER INSTITUTE

Division of Cancer Control & Population Sciences