

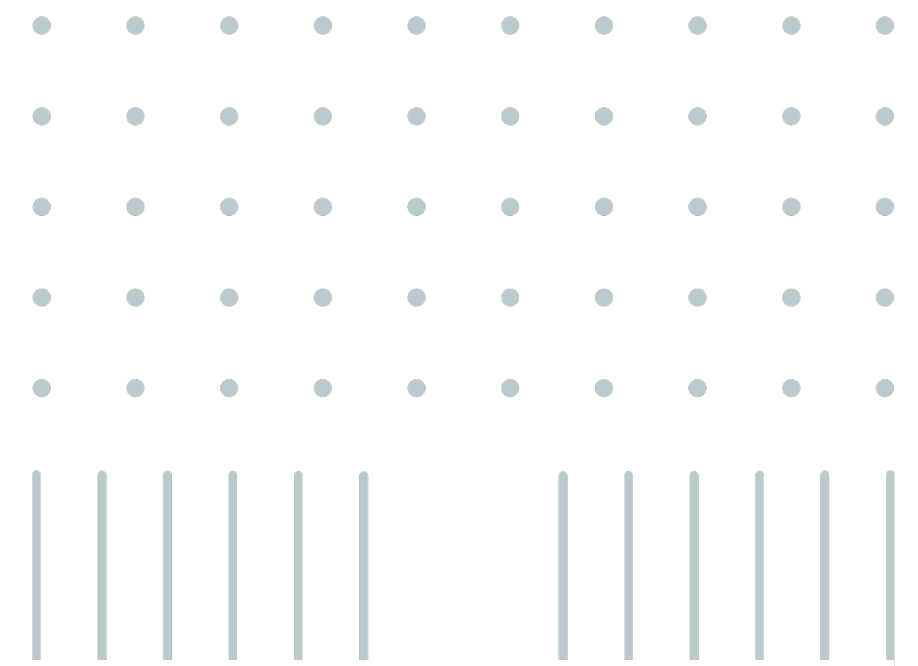
# National Standards for Cancer Survivorship Care

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**Michelle Mollica, PhD, MPH, RN, OCN**

Deputy Director  
Office of Cancer Survivorship  
National Cancer Institute

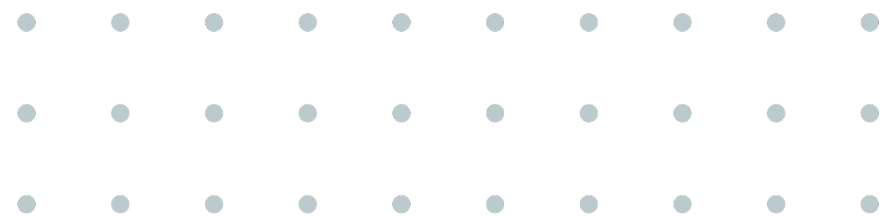
# Outline



- Background: previous efforts in survivorship care
- Development of National Standards for Cancer Survivorship Care
- Overview of Standards
- Next Steps

# BACKGROUND

Survivor: An individual is considered a cancer survivor from the time of diagnosis through the balance of life.



# SURVIVORSHIP CARE IS COMPLEX

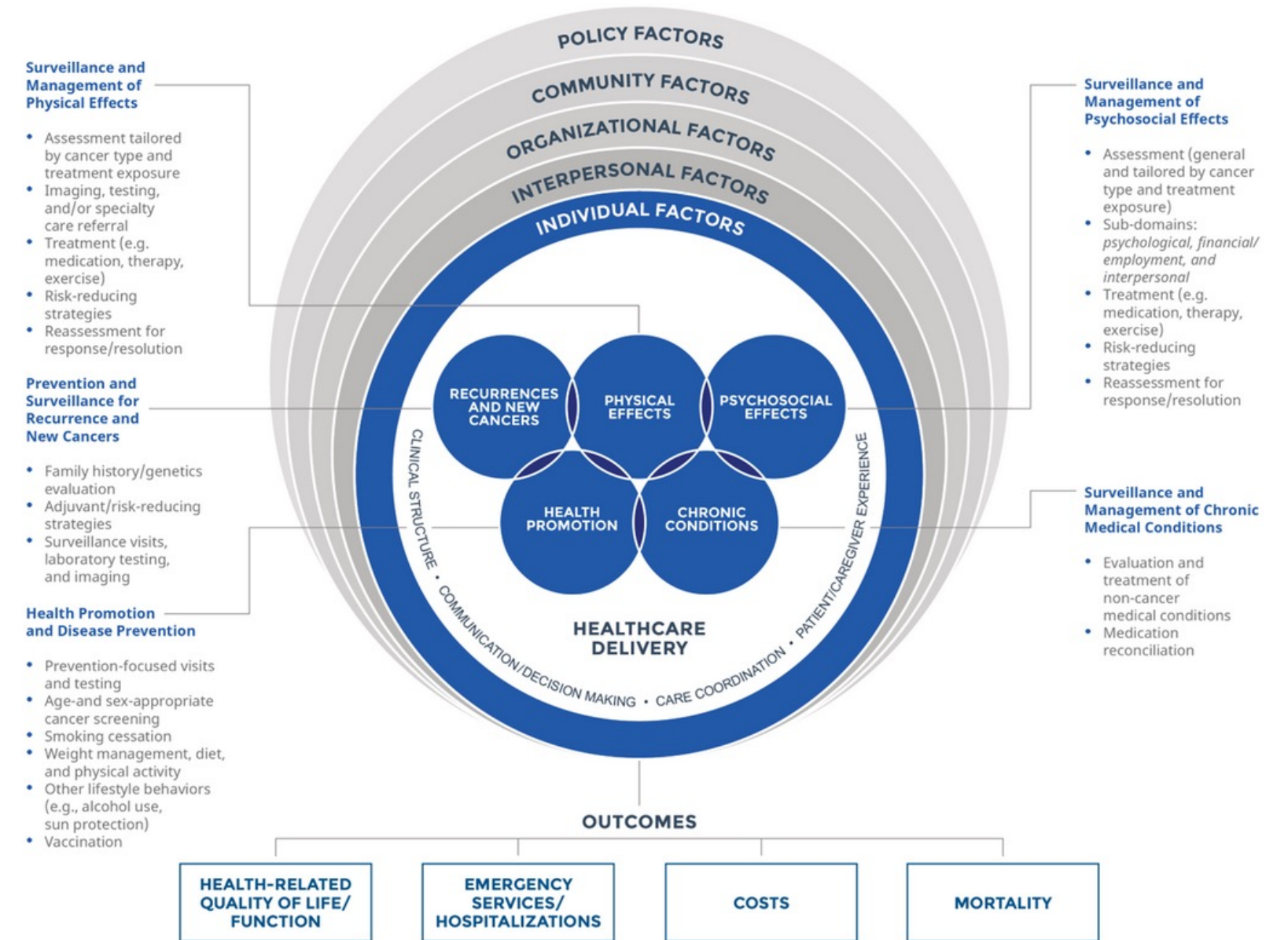


## Current Recommendations

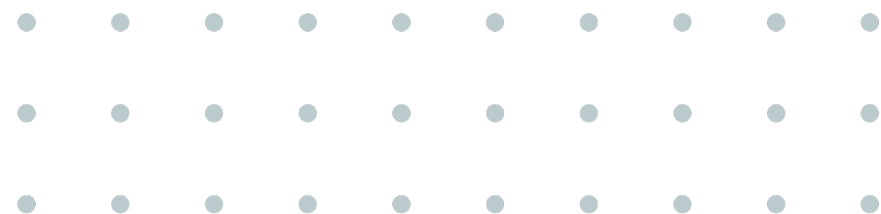
- Prevention and surveillance for recurrence
- Surveillance/ management of physical and psychosocial effects
- Promoting healthy lifestyle behaviors
- Identifying and managing comorbidities
- Screening for subsequent cancers
- Monitoring and improving mental well-being
- Coordinating care

# Previous Efforts informing Survivorship Care


- Survivorship guidelines
- LIVESTRONG Essential Elements of Survivorship Care
- Quality of Survivorship Care Framework
- Commission on Cancer Survivorship Standard 4.8



Nekhlyudov, L., Mollica, M.A., Jacobsen, P.B., Mayer, D., Shulman, L., Geiger, A. (2019). Developing a quality of cancer survivorship care framework: Implications for clinical care, research, and policy. JNCI.



# THE PROBLEM: SURVIVORSHIP CARE IN THE US IS VARIABLE AND OFTEN SUBOPTIMAL



Survivorship guidelines exist but are not systematically implemented

Delivery of survivorship care varies based on healthcare setting, geographical area, resources, provider preferences

Lack of consistent survivorship care leads to survivors with unmet needs, symptoms, and issues accessing quality care

# GOAL OF PROJECT



Develop national standards for survivorship care, including:

- essential health system process and policy components; and
- assessment of the quality of survivorship care

**Standards:** recommendations for health systems that apply to the patients they serve



# HEALTH SYSTEM POLICY

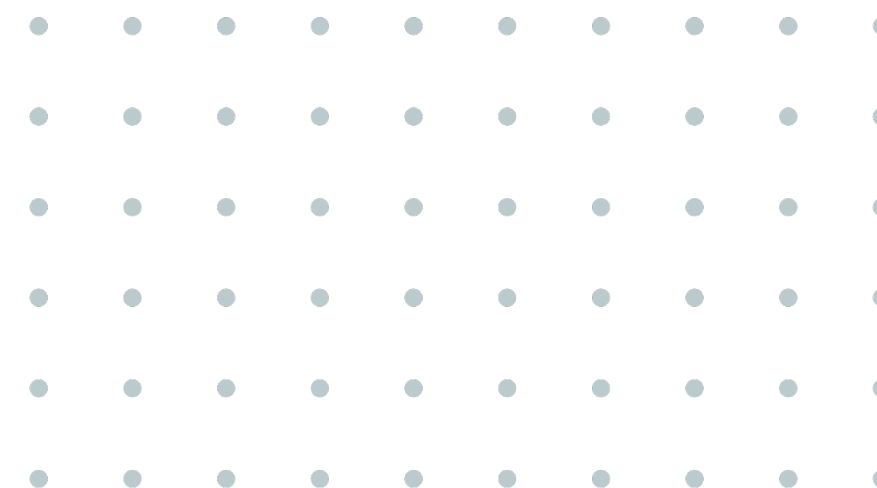
Principles and procedures  
guiding an organization's  
capacity and structure to  
provide survivorship care

# HEALTH SYSTEM PROCESS

An organization's capacity  
to delivery survivorship care  
through its embedded  
practices and procedures

# ASSESSMENT/ EVALUATION

How to measure the impact  
of survivorship care within  
an organization





# Survivorship Working Group Co-Chairs

**Michelle Mollica, PhD, MPH, RN, OCN**

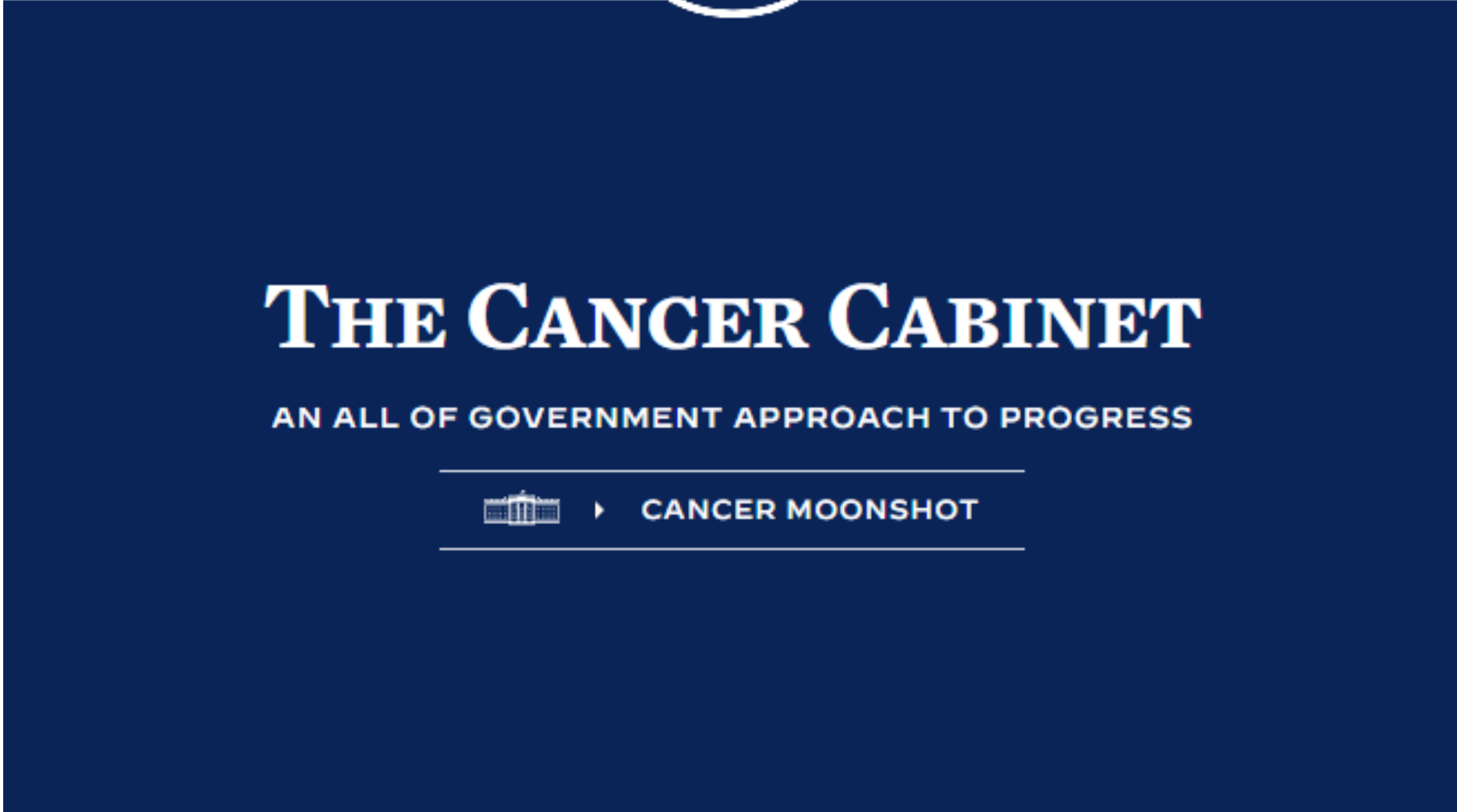
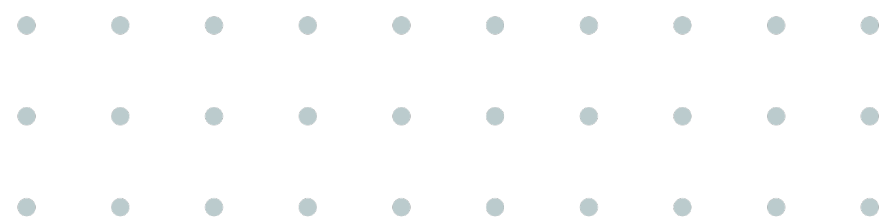
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# Survivorship Working Group Members

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## US Department of Agriculture

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Hillary Cavanagh, MS

## US Food and Drug Administration

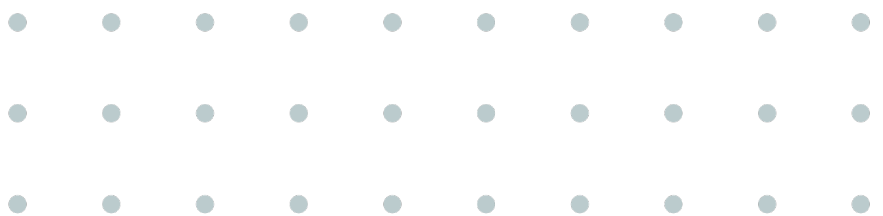
Martha Donoghue, MD

## Department of Defense

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Kimberly Lahm, LMFT, OASD(HA)  
LTC Christopher Luevano, DDS, OASD (HA)

## National Cancer Institute

Emily Tonorezos, MD, MPH





- 01. LANDSCAPE REVIEW**
  - 02. IDENTIFIED POSSIBLE INDICATORS**
  - 03. SUBJECT MATTER EXPERT CONSENSUS MEETINGS**
  - 04. DEVELOPMENT OF STANDARDS**
  - 05. PILOT TEST STANDARDS FOR FEASIBILITY**
  - 06. FUTURE DISSEMINATION AND EVALUATION**
- Below the list, there are three rows of small, light blue dots arranged in a grid pattern, with the first row starting under the '06.' and extending to the right.

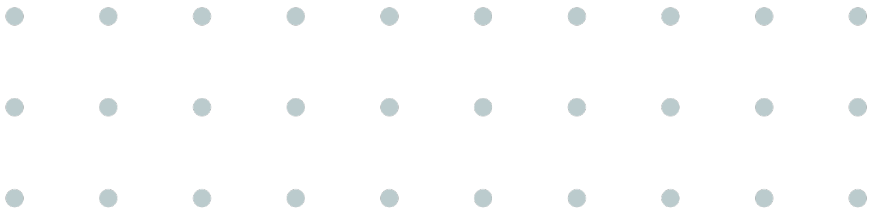
# Survivorship Subject Matter Experts

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Precilla Belin, PhD, MA, MCHES; NCI Office of Cancer Centers	Linda Jacobs, PhD, CRNP; Abramson Cancer Center, University of Pennsylvania
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Hillary Cavanagh, MS; Centers for Medicare & Medicaid Services	Nancy Keating, MD, MPH; Harvard Medical School
Lanie Francis, MD; University of Pittsburgh	Anne Kirchoff, PhD, MPH; Huntsman Cancer Institute, University of Utah
David Freyer, DO, MS; USC Norris Comprehensive Cancer Center and Children's Hospital LA	Michelle Kirschner, NP-C; OneVillage/ The Cancer Survivorship Provider Network (CSPN)
Danielle Friedman, MD; Memorial Sloan Kettering Cancer Center	Ron Kline, MD; Centers for Medicare & Medicaid Services
<b>Shelley Fuld Nasso, MPP, National Coalition for Cancer Survivorship</b>	Jessica MacIntyre, APRN; University of Miami/Sylvester Comprehensive Cancer Center
Patricia Ganz, MD; UCLA Jonsson Comprehensive Cancer Center	<b>Molly Maher, MS; NCI Office of Cancer Centers; cancer caregiver</b>



# Survivorship Subject Matter Experts

Janette Merrill, MS; American Society of Clinical Oncology (ASCO)	Alyssa Schatz, MSW; National Comprehensive Cancer Network (NCCN)
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Min He, PhD; NCI Office of Cancer Centers	Deborah Mayer, PhD, RN, AOCN, FAAN; UNC Chapel Hill



# National Standards for Cancer Survivorship Care



## Health System Policy

### The organization has a policy that includes...

establishment or existence of a survivorship program either on-site, through telehealth, or by referral

a framework for the provision of survivorship care informed by survivor stakeholders and relevant survivorship guidelines (e.g., American Cancer Society, American Society of Clinical Oncology, National Comprehensive Cancer Network, Children's Oncology Group)

a description of multidisciplinary care, including each team member's specific roles and responsibilities and workflow(s) for referrals to team members

an overview of how to stratify and refer survivors to appropriate models of care based on age, treatments, and risk factors

description of the approach and timing of transitions in survivorship care and shared care (e.g., pediatric to adult providers and settings, oncology team to survivorship team and/or primary care) and efforts to prevent/mitigate loss to follow-up care

an outline for the provision of information for support services (e.g., navigators, social work, interpreters) for survivors based on their needs (including but not limited to health, insurance, and financial literacy, disability status), including survivors from diverse and underserved backgrounds

identification of an executive-level survivorship care lead (with succession plan) whose role is to ensure compliance with standards, with reporting to an appropriate executive committee

collection of longitudinal data on survivors' experience of survivorship care and patient-reported outcomes

requirements and methods for training healthcare providers (either on-site or through an external training program) to deliver survivorship care within their scope of practice

a business case/plan, including budget, with funding allocated for survivorship care

# National Standards for Cancer Survivorship Care

## Health System Processes

### Cancer survivors are...

provided with access and referral to a survivorship program that addresses the needs of cancer survivors either on-site, through telehealth, or by referral

assessed at multiple points in their follow-up care for physical effects during and following cancer treatment, including monitoring for late effects and chronic conditions, and provided with treatment and/or referrals

provided with access to appropriate specialty care services to manage potential late effects (e.g., cardiovascular issues) either on-site, through telehealth, or by referral

assessed at multiple points in their follow-up care for emotional and psychological effects of cancer and its treatment and provided with treatment and/or referrals

assessed for practical and social effects of cancer and its treatment (e.g., social risks, health-related social needs, education and employment/return to work or school) and provided with resources and/or referrals

assessed for their risk of recurrence or new cancers, including family history and genetic testing, and provided with recommendations and referrals regarding surveillance for recurrence or new cancers

assessed for lifestyle behaviors and provided with recommended strategies for management and appropriate referrals or education as needed (e.g., smoking cessation, diet/nutrition counseling, promoting physical activity)

provided with access and referrals to appropriate supportive health services (e.g., nutrition, occupational and physical therapy, rehabilitation, sexual health, fertility services, dental and podiatry services)

assessed for financial hardship/toxicity and concerns regarding insurance coverage, and provided with resources and support as needed

engaged in the care planning process including discussion of shared goals of care, advanced care planning, and coordination of care with providers and services (e.g., primary care provider, other health professionals, and community-based services) as needed

# National Standards for Cancer Survivorship Care



## Health System Evaluation/Assessment

**The organization has a process to collect data on...**

survivors' patient-reported outcomes, including quality of life, and experiences of survivorship care

survivors' functional capacity

survivors' return to previous participation in paid and unpaid work/ school/ productive activities of living

survival rates (1, 5, and 10-yr) from the time of diagnosis

rate of recurrence

rate of subsequent cancers

number and relevant characteristics (demographics, clinical factors) of survivors lost to follow-up

caregivers' experiences and unmet needs

number of health professionals trained to provide survivorship care

relevant business metrics to show return on investment of survivorship care to the healthcare system (e.g., healthcare utilization, rate of referrals and completion, downstream revenue)



# Next Steps

01.

## Pilot test standards

VA Comprehensive Survivorship Program

Adapt to specific cancer survivor populations and health system needs

Available to healthcare organizations to assess for alignment or develop new programs

NCI Supplement Notice: *NOT-CA-24-041- Assessing and Enhancing Survivorship Care*

02.

## Develop toolkit

Resources and guidance

Checklist tool to assess alignment

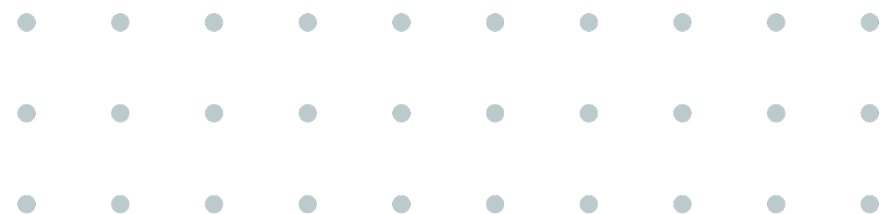
03.

## Advance research and policy

Evaluation of survivor and health system outcomes related to implementation of standards

Resources to guide reimbursement of services

Alignment of standards with CoC Survivorship Standard 4.8



# More Resources on the OCS Website

## National Standards for Cancer Survivorship Care

[Office of Cancer Survivorship](#) / [Special Focus Areas](#) / [National Standards for Cancer Survivorship Care](#)

The National Cancer Institute (NCI), in partnership with the Department of Veterans Affairs (VA) and other Health and Human Services Agencies, led a consensus-building process with subject matter experts to develop the National Standards for Cancer Survivorship Care. This collaboration defined standards for (1) essential health system policy and process components of survivorship care programs; and (2) evaluation of the quality of survivorship care. The effort was undertaken as part of the Biden Cancer Moonshot, President Biden's whole of government response to accelerate progress against cancer and end cancer as we know it, and the President's Cancer Cabinet.

<https://cancercontrol.cancer.gov/ocs/special-focus-areas/national-standards-cancer-survivorship-care>



# National Cancer Survivors Month Initiatives

- June 18 Director's Series Webinar featuring a panel of cancer survivors and advocates
- New cancer survivor stories
- New special focus area webpages covering topics including
  - National Standards for Cancer Survivorship Care
  - Health Equity and Health Disparities in Cancer Survivorship
  - Primary Care and Cancer Survivorship

OCS Home Statistics and Graphs Definitions Resources and Information Funding and Grants Special Focus Areas About OCS

## Health Equity and Health Disparities in Cancer Survivorship

Office of Cancer Survivorship / Special Focus Areas / Health Equity and Health Disparities in Cancer Survivorship

Advancing health equity in cancer survivorship is central to the Office of Cancer Survivorship (OCS) mission to enhance the quality and length of survival of all persons diagnosed with cancer.

All cancer survivors should have the opportunity to achieve their highest level of health possible, also known as *health equity*. Unfortunately, there are obstacles to health that can affect where cancer survivors live, grow, learn, work, play, worship, access care, and age. These barriers can create differences in healthcare utilization, quality of care, and health outcomes, also known as *health disparities*.

Some cancer survivors may experience obstacles to health based on their racial or ethnic group; religion; socioeconomic status; age; mental health; cognitive, sensory, or physical disability; sexual orientation; gender identity; geographic location (place/context); or other characteristics historically linked to discrimination or exclusion.

The causes of health disparities are therefore multiple, multilevel, complex, and intertwined. However, researchers, advocacy groups, community organizations, health systems, clinicians, cancer survivors, caregivers, and other collaborators can work together to advance health equity in survivorship by identifying and intervening upon the modifiable obstacles, pathways, and mechanisms that create and amplify health disparities.

Selected examples of health equity research in cancer survivorship include the following:

- addressing the available resources, opportunities, and built environment to help cancer survivors engage in and sustain healthy behaviors

**ON THIS PAGE**

- Areas of Research Emphasis
- Selected OCS Staff Publications
- Funding Opportunities
- Featured Webinars
- Additional Resources
- Contacts

**How is NCI Addressing Issues Related to Health Disparities?**

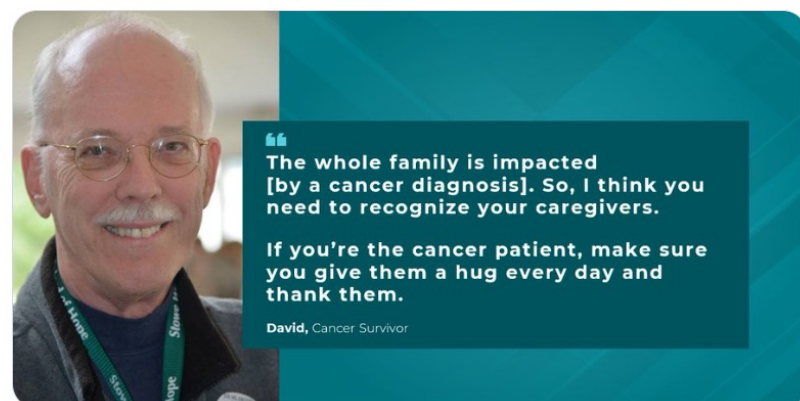
**Q&A Series**  
with the OCS Director

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**NCI Office of Cancer Survivorship @NCICancerSurv · Jun 5**

Following his Chronic Myeloid **#Leukemia** diagnosis in 1999, David set a goal to help at least one **#CancerSurvivor** a day. Since then, he's volunteered for cancer organizations, helped write his state's cancer plan, and more.

Read David's story: [cancercontrol.cancer.gov/ocs/resources/...](https://cancercontrol.cancer.gov/ocs/resources/...) **#CML**



**NIH** **NATIONAL CANCER INSTITUTE** **Division of Cancer Control & Population Sciences**

Office of Cancer Survivorship

OCS Home Statistics and Graphs Definitions Resources and Information Funding and Grants Special Focus Areas About OCS

## National Standards for Cancer Survivorship Care

Office of Cancer Survivorship / Special Focus Areas / National Standards for Cancer Survivorship Care

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This project was co-chaired by Michelle Mollica, PhD, MPH, RN, OCN, deputy director of the National Cancer Institute Office of Cancer Survivorship (OCS); Gina McWhirter, MBA, MSN, RN, director of National TeleOncology at the VA; and Vida Passero, MD, MBA, chief medical officer of National TeleOncology at the VA.

**Background**

Cancer survivors have unique needs. Many survivors experience physical and psychosocial symptoms during and long after their treatment has ended. In addition, they are at risk for recurrence of their cancer and subsequent cancers, and often need support to promote healthy behaviors (e.g., avoiding smoking and excessive alcohol use, and increasing physical activity). As a result, most survivors require long-term follow-up care to manage their diverse needs.

Survivorship care is complex and multifaceted and includes prevention and detection of recurrence and new cancers, monitoring and amelioration of

**OCS** **Director's Series** **DIRECTOR'S SERIES**

Division of Cancer Control and Population Sciences

June 18, 2024 2-3:30 p.m. ET

## Survivor Voices: The Vital Role of Survivors in Advancing Cancer Survivorship Research

Moderated by OCS Director Emily S. Tonorezos, MD, MPH

**Phuong Gallagher**  
RATS Program Manager  
Fight Colorectal Cancer

**Colin Goodwin, PsyD**  
Psychosocial Service Coordinator  
Oncology Department  
Kaiser Permanente San Jose

**Ameish Govindarajan, MD**  
Hospice and Palliative Medicine Fellow  
Department of Medicine  
Memorial Sloan Kettering Cancer Center

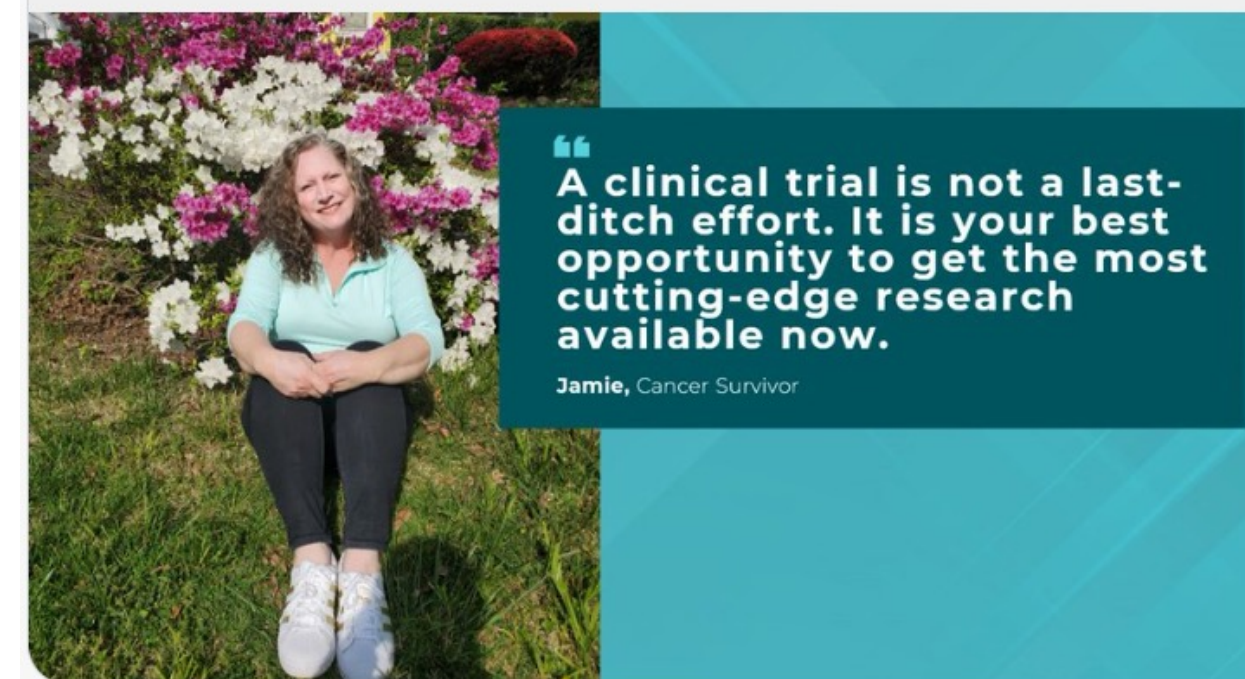
**Montessa Lee, MS**  
Advocate  
Lung Cancer Foundation  
of America

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**NCI Office of Cancer Survivorship @NCICancerSurv · Jun 2**

When Jamie was diagnosed w/ stage 4 **#melanoma**, treatment options weren't promising. She enrolled in a clinical trial. Now, more than 10 years later, she works to ensure that **#CancerSurvivors** know about **#ClinicalTrials** & how to access them. Read Jamie's story [cancercontrol.cancer.gov/ocs/resources/...](https://cancercontrol.cancer.gov/ocs/resources/...)



# *Thank you!*

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[michelle.mollica@nih.gov](mailto:michelle.mollica@nih.gov)

Sign up for the OCS  
listserv!

