

# National Standards for Cancer Survivorship Care: Opportunities to Advance Care and Research

*ASPO Survivorship SIG Webinar*

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# Overview

- ❖ *Background*
- ❖ *Development of Survivorship Standards*
- ❖ *Overview of Survivorship Standards*
- ❖ *Pilot Projects*
- ❖ *Next steps and opportunities for future research*

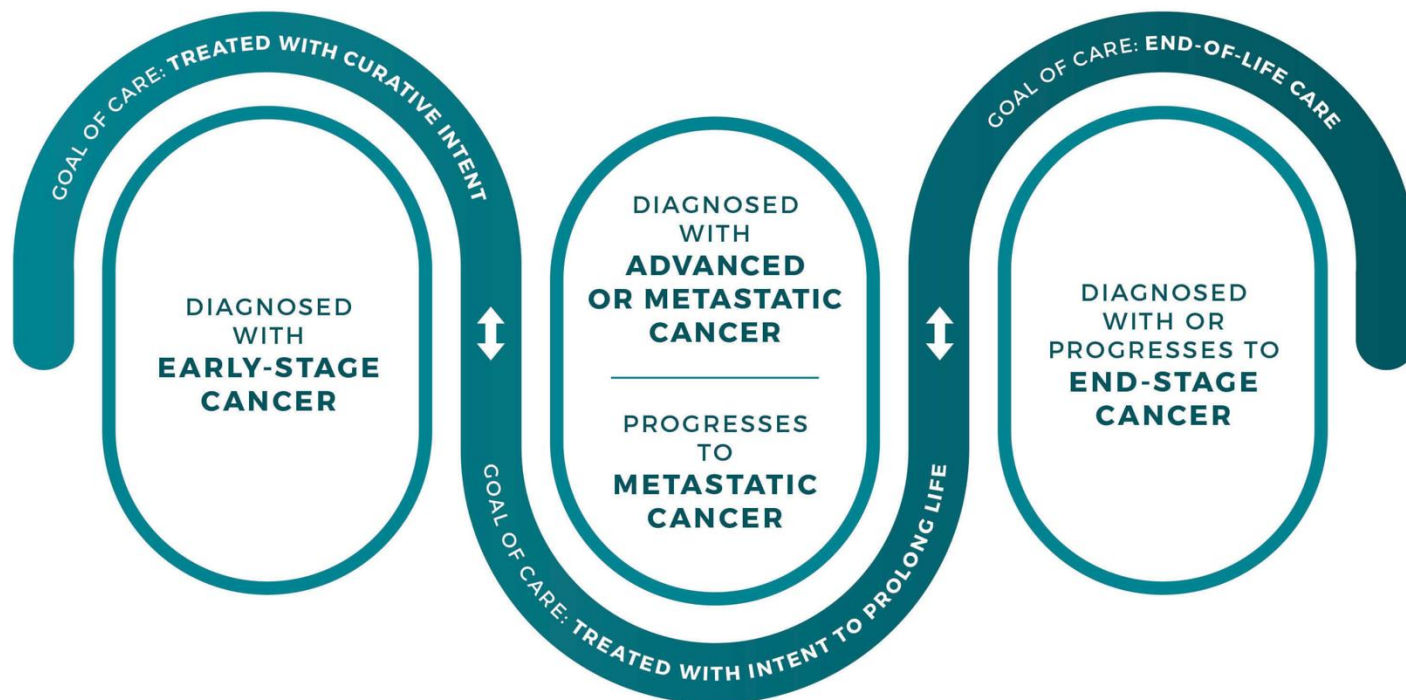
# ***Background***

# Exponential Growth in the Number of Cancer Survivors

An individual is considered a cancer survivor from the time of diagnosis, through the balance of life



# Phases of Survivorship



Mollica, M. A., Smith, A. W., Tonorezos, E., Castro, K., Filipski, K. K., Guida, J., Perna, F., Green, P., Jacobsen, P. B., Mariotto, A., Tesauro, G., & Gallicchio, L. (2022). Survivorship for individuals living with advanced and metastatic cancers: National Cancer Institute meeting report. *Journal of the National Cancer Institute*.

# CANCER SURVIVORSHIP

is a state of being, including the perspectives, needs, health, and the physical, psychological, social, and economic challenges experienced by people and caregivers after a cancer diagnosis.

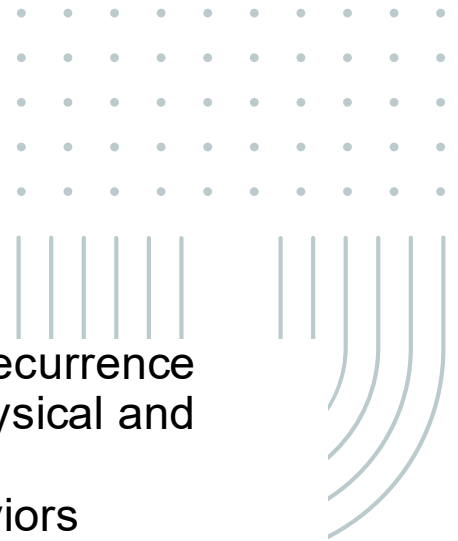


# Survivorship Care is Complex




## 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



# The Problem: Survivorship Care in the US is Variable and Suboptimal



Survivorship guidelines exist but are not systematically implemented

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

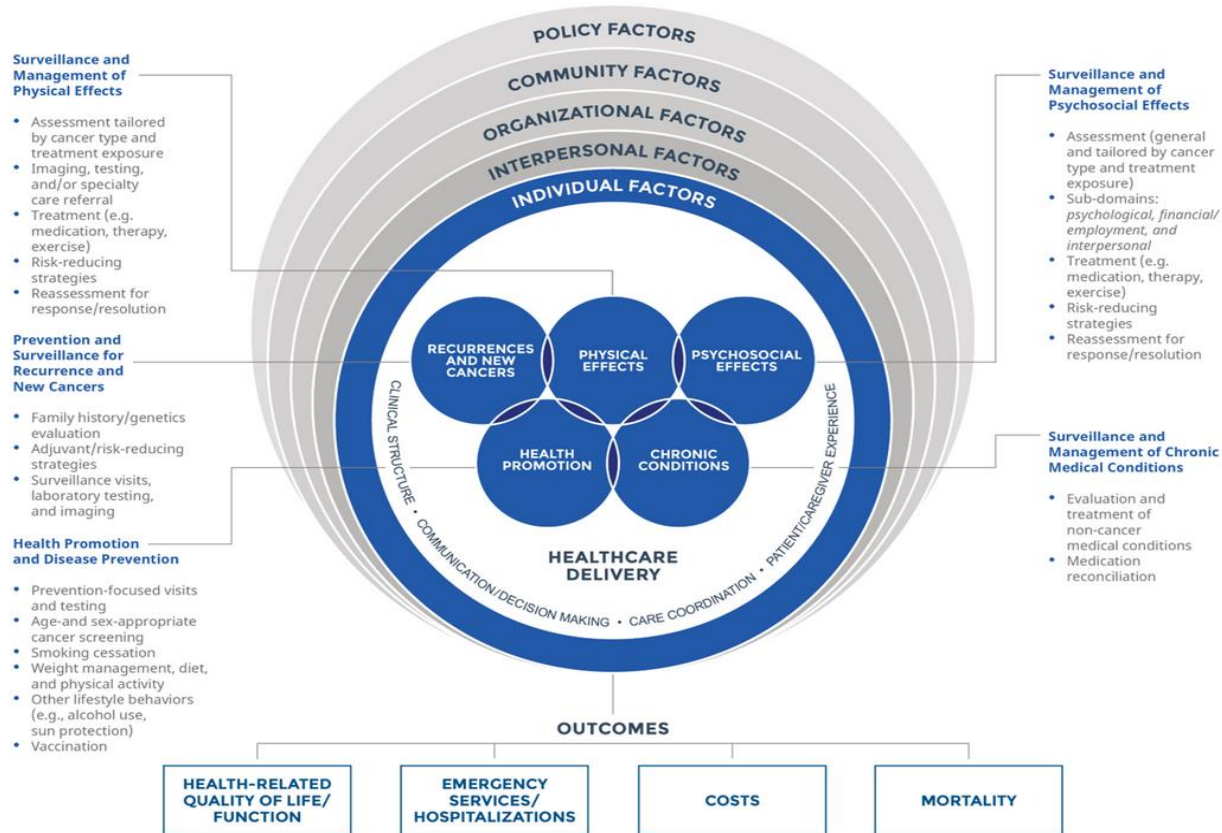
Lack of consistent survivorship care leads to survivors with unmet needs, symptoms, and issues accessing quality care



# Previous Efforts Informing Survivorship Care

- Survivorship guidelines-NCCN, ASCO, ACS
- LIVESTRONG Essential Elements of Survivorship Care (2011)
- Commission on Cancer Survivorship Standard 4.8
  - Survivorship coordinator
  - Survivorship program documenting a minimum of 3 services offered each year to support patients
  - Focus on enhancing existing and developing new services

# Quality of Survivorship Care Framework



# ***National Standards for Cancer Survivorship 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

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# Survivorship Working Group Members

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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.

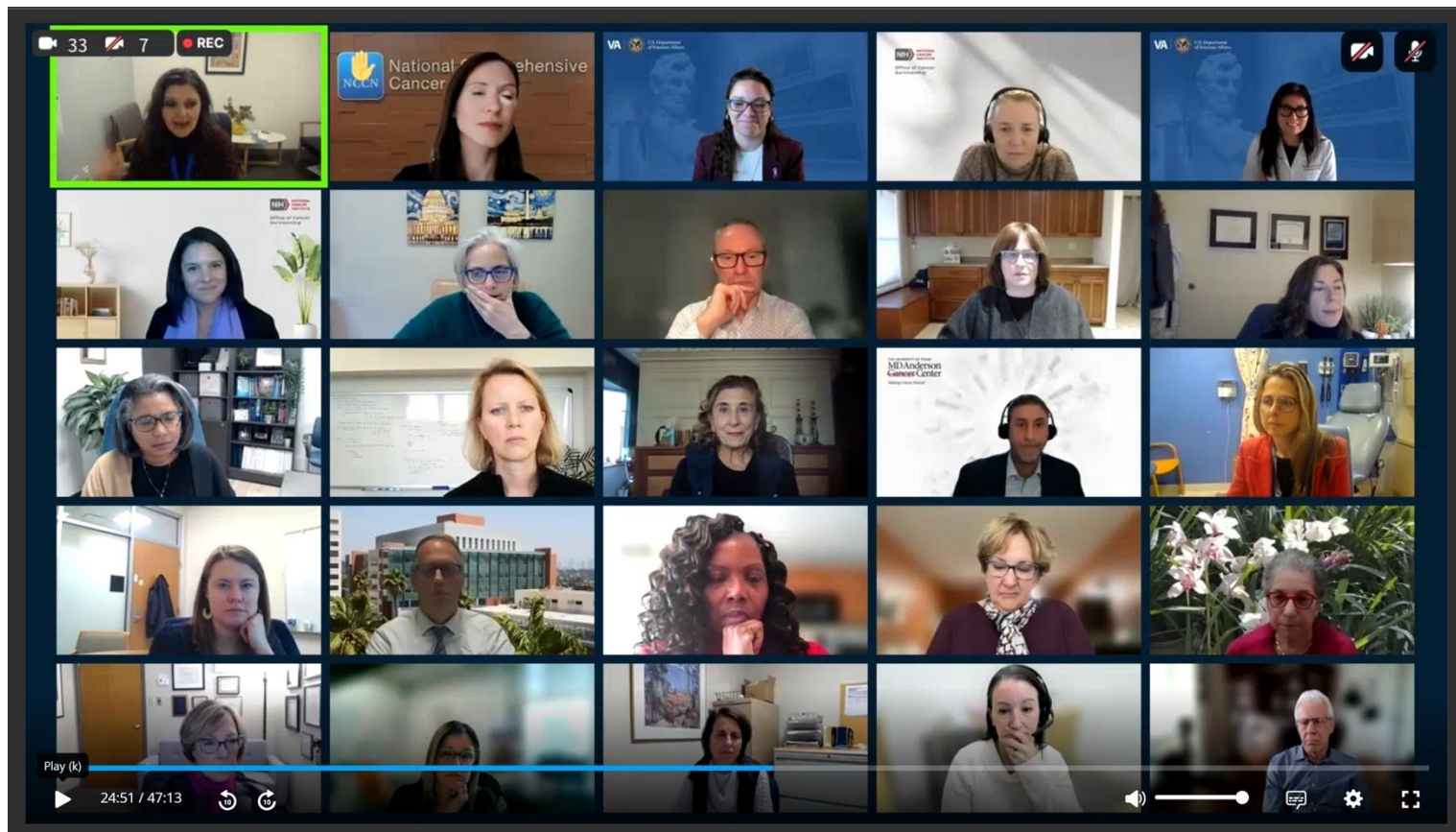
**FUTURE DISSEMINATION AND EVALUATION**



Mollica et al. (2024). Developing national cancer survivorship standards to inform quality of care in the United States using a consensus approach. *Journal of Cancer Survivorship*.



# Subject Matter Expert Consensus Meetings



# 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)

# Developing Resources

- **Resources:** Survivorship Standards Toolkit; FAQ videos
- **Health Policy Template:** developed by the Cancer Survivorship and Supportive care Professionals Network (CSPN)

## CSPN Survivorship Standard of Practice Template

Developed by The Cancer Survivorship Provider Network Working Group  
August 2024

### **I. POLICY DESIGNATION**

This document details the policies and procedures for Cancer Survivorship at the [enter name of organization].

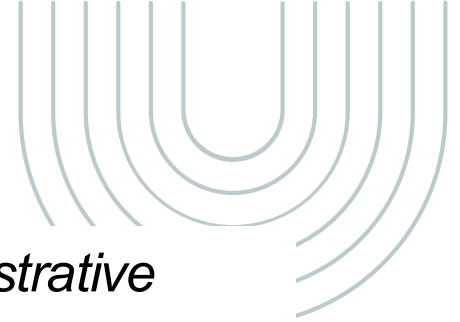
### **II. PURPOSE**

To specify organizational programmatic structure, development and delivery of cancer survivorship care and supportive services to patients within [name of organization].



Toolkit and FAQ videos: <https://cancercontrol.cancer.gov/ocs/special-focus-areas/national-standards-cancer-survivorship-care>  
Standards Template: <https://thecspn.circle.so/c/professional-8c962b/cspn-survivorship-standard-of-practice-template>

# Piloting Standards

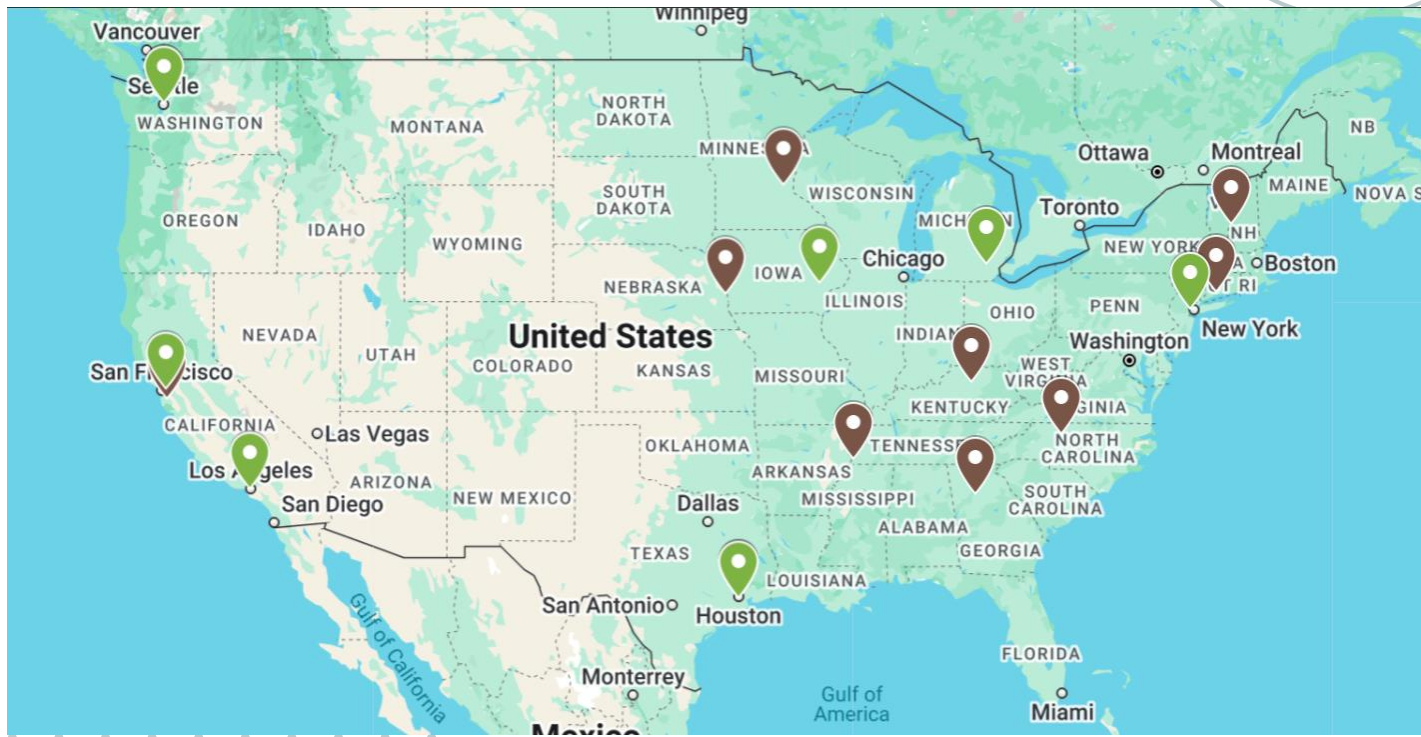


- NCI supplement awards: NOT-CA-24-41; *Administrative Supplements for Assessing and Enhancing Survivorship Care*
- VA Cancer Survivorship: utilizing standards in development of comprehensive survivorship program; part of National TeleOncology initiatives



# Survivorship Standards Grant Supplements

**Goal:** support research to define and improve survivorship care that is accessible by survivors within each cancer center or organization's catchment area using the survivorship standards as a framework



<https://cancercontrol.cancer.gov/research-emphasis/supplement/assessing-enhancing-survivorship-care>



# Example Supplement Topics

Assessing capacity to deliver survivorship care	Delphi process to prioritize survivorship indicators	Assessing institutional readiness
Evaluating of facilitators and barriers	Supporting rural cancer survivorship care	Developing implementation roadmaps and toolkits to guide care
Assessing reach of services within catchment area	Examining preferences for digital interventions	Mapping systems of pediatric cancer survivorship care
Developing survivorship strategic plans	Evaluating loss to follow up and no-show rates in survivorship	Pilot testing strategies to improve survivorship care delivery and evaluation

**Selected Populations:** Pediatric, AYA, older adult, rural, underserved geographic areas



# Next Steps

## Advance clinical care, research, and policy

- Disseminate findings from pilots
- Adapt standards to specific populations and settings
- Refine resources to guide readiness and implementation
- Support guidance to inform reimbursement of services
- Evaluate survivor and health system outcomes related to implementation of standards
- Align standards with CoC Survivorship Standard 4.8



# More Resources on the NCI Website

 **NATIONAL CANCER INSTITUTE**

DIVISION OF CANCER CONTROL  
AND POPULATION SCIENCES

OFFICE OF CANCER SURVIVORSHIP

## National Standards for Cancer Survivorship Care Toolkit

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## New lead for Survivorship Standards:

**Sallie Weaver, PhD, MHS**  
Senior Scientist and Program Director  
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Research Branch,  
Healthcare Delivery Research Program  
National Cancer Institute

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



# Expected Impact: Comprehensive Survivorship Care





**NATIONAL  
CANCER  
INSTITUTE**

**[cancer.gov](https://cancer.gov)**

**[cancer.gov/espanol](https://cancer.gov/espanol)**

# Survivorship Subject Matter Experts

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Anne Blaes, MD; University of Minnesota	Michael Jefford, MBBS, MPH, MHIthServMt, PhD, FRACP; Peter MacCallum Cancer Centre/ Australian Cancer Survivorship Centre (ACSC)
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
Shelley Fuld Nasso, MPP, National Coalition for Cancer Survivorship	Jessica MacIntyre, APRN; University of Miami/Sylvester Comprehensive Cancer Center
Patricia Ganz, MD; UCLA Jonsson Comprehensive Cancer Center	Molly Maher, MS; NCI Office of Cancer Centers; cancer caregiver



# Survivorship Subject Matter Experts

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