

National Standards for Cancer Survivorship Care Toolkit

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Background

The Biden Cancer MoonshotSM, President Biden's whole-of-government response to accelerate progress against cancer and end cancer as we know it, established a goal to develop U.S. standards for survivorship care. The Department of Veterans Affairs (VA) and the National Cancer Institute (NCI) collaborated to define standards for (1) essential health system policy and process components of survivorship care programs, and (2) evaluation of the quality of survivorship care. This project was co-chaired by Dr. Michelle Mollica, deputy director of the NCI Office of Cancer Survivorship; Gina McWhirter, director of National TeleOncology at the VA; and Dr. Vida Passero, chief medical officer of National TeleOncology at the VA.

Process

A list of potential indicators was developed through a review of survivorship and cancer-specific guidelines, the Commission on Cancer (CoC) survivorship standard, existing survivorship quality frameworks, U.S. state cancer control plans, and relevant literature. NCI and VA held three virtual meetings with survivorship subject matter experts to prioritize the most important and feasible indicators and identify additional indicators; input was also solicited from meeting observers. The final set of indicators was then developed. The standards are available on the [NCI Office of Cancer Survivorship](#) website for health systems and organizations to assess survivorship care quality and to align current and future survivorship services. Please note that the use of the standards by health systems is voluntary, and components of care may or may not be covered by public or private insurance. For CoC-accredited institutions, these survivorship standards are not intended to replace CoC Survivorship Standard 4.8.

The purpose of this toolkit is to provide resources to support health systems as they use the survivorship standards to develop or enhance survivorship programs. Please note that the resources included were recommendations by survivorship subject matter experts. Inclusion of any resources should not be viewed as an endorsement of the content.

Key Concepts

Cancer Survivor

An individual from the time of a cancer diagnosis through the balance of life

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 deliver survivorship care through its embedded practices and procedures

Assessment/Evaluation

Measurement of the impacts of survivorship care within an organization

Standards of Care

Recommendations for organizations and health systems to apply to the patients they serve

Indicators

Standardized measures of care quality used to track policies, processes, and outcomes

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 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 health care 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



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



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 health care system (e.g., health care utilization, rate of referrals and completion, downstream revenue)

Organizational Assessment Tool

Health systems may use this tool to assess their existing survivorship programs as they align with the National Standards for Cancer Survivorship Care.

Health System Policy			
The organization has a policy that includes...	Indicate whether the organization has a policy that includes this indicator (Y/N)	Point of Contact	Comments (may include current status, data sources, priority level for each indicator)
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 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			

Health System Policy			
The organization has a policy that includes...	Indicate whether the organization has a policy that includes this indicator (Y/N)	Point of Contact	Comments (may include current status, data sources, priority level for each indicator)
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 health care 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			

Health System Processes			
Cancer survivors are...	Indicate whether the organization has a process related to each indicator (Y/N)	Point of Contact	Comments (may include current status, data sources, priority level for each indicator)
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			

Health System Processes			
Cancer survivors are...	Indicate whether the organization has a process related to each indicator (Y/N)	Point of Contact	Comments (may include current status, data sources, priority level for each indicator)
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			

Health System Evaluation/Assessment

The organization has a process to collect data on...	Indicate whether the organization has a process to collect data on this indicator (Y/N)	Point of Contact	Comments (include timing and measurement tool) (may also include current status, data sources, priority level for each indicator)
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			

Health System Evaluation/Assessment

The organization has a process to collect data on...	Indicate whether the organization has a process to collect data on this indicator (Y/N)	Point of Contact	Comments (include timing and measurement tool) (may also include current status, data sources, priority level for each indicator)
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 health care system (e.g., health care utilization, rate of referrals and completion, downstream revenue)			

Guidance for the Use of National Standards for Cancer Survivorship Care

- Health systems are not required to use the survivorship standards. Using the standards is voluntary; however, we encourage health systems and organizations that serve survivors to review the standards to see where their organizations could enhance the care they are providing.
- The order of indicators within each domain are not listed in the order of priority.
- The survivorship standards may be tailored to fit the needs of each health system and the cancer survivor population(s) they serve.
- The survivorship standards were developed using the NCI definition of “cancer survivor,” which is anyone from the time of diagnosis through the balance of life. As such, health systems should offer survivorship programs to people who are in treatment (including people living with advanced or metastatic cancers) or who have completed treatment. Subject matter experts emphasized, however, that health systems may only have the capacity to provide services to some subgroups of survivors.
- The survivorship standards also can be adapted for survivorship programs that are available for survivors of a specific cancer type.
- The delivery of services to cancer survivors should always be informed by evidence-based guidelines.
- While some of the indicators may be difficult to implement and/or are aspirational, they are included due to their importance to the overall delivery of quality care for survivors.
- The survivorship standards may be useful for identifying processes and other departments within systems that are doing this work. The standards may also be used to develop business cases for implementation in stand-alone or integrated survivorship clinics.
- The survivorship standards DO NOT replace the CoC Survivorship Standard 4.8 for CoC-accredited health systems. The National Standards for Cancer Survivorship Care are aligned with the CoC survivorship standard, however, and meeting the CoC standards is a first step toward meeting the National Standards for Cancer Survivorship Care.

Sustainability of Survivorship Programs

Subject matter experts noted the importance of addressing the need for ongoing sustainability of survivorship care within a health system. Clinical sustainability capacity has been defined as “the ability of an organization to maintain structured clinical care practices over time and to evolve and adapt these practices in response to new information” (Washington University in St. Louis, 2018). Key tenets of sustainability include leadership, empowered professionals, exemplary practice, and strong outcomes to show impact.

There are existing frameworks focused on key components of sustainability; implementation of the National Standards for Cancer Survivorship Care should also address these components. The American Cancer Society National Navigation Roundtable (Dwyer et al., 2019) Patient Navigation Sustainability Assessment Tool includes the following components, which are highly relevant for the sustainability of quality survivorship care programs.

- **Engaged Staff and Leadership**
Champions at all levels, including staff, executive, and administrative positions, who understand the importance of ongoing, comprehensive survivorship care
- **Organizational Context and Capacity**
Internal support and infrastructure to identify the specific needs of survivors and triage them to appropriate levels of survivorship care
- **Funding Stability**
Consistent funding structure with plans for appropriate reimbursement of care components
- **Engaged Community**
Integration of survivor and caregiver perspectives throughout the development, implementation, and evaluation of survivorship care programs
- **Communication, Planning, and Implementation**
Using the National Standards to guide the development of policies and processes for implementing survivorship care
- **Workflow Integration**
Designing survivorship care programs to fit into existing workflows
- **Monitoring and Evaluation**
Continuous evaluation and tracking of implementation to inform future improvements
- **Outcomes and Effectiveness**
Collecting, analyzing, and disseminating data that focus on key metrics as specified in the National Standards

Subject matter experts specifically emphasized the importance of including a policy with a business plan and defined funding, as well as an evaluation of relevant business metrics, to show the return on investment of survivorship care to the health care system (e.g., health care utilization, rate of referrals and completion, downstream revenue).

Based on the domains listed above, health systems may want to consider their minimum viable product to inform a stepwise approach in building a survivorship program. A minimum viable product is a first step in setting up a new program and is based on the needs and resources of the setting. One example might involve the development of a cancer surveillance follow-up plan where a health system first focuses on ensuring surveillance follow-up for recurrence and new cancers.

Reference

Dwyer, A., Weltzien, E., and Harty, N. (2019). Patient Navigation Sustainability Assessment Tool for Preventive Cancer Screening. Colorado School of Public Health and University of Colorado Cancer Center, Aurora, CO.

Resources

Guidelines

American Society of Clinical Oncology – Patient and Survivor Care: <https://society.asco.org/practice-patients/guidelines/patient-and-survivor-care>

American Cancer Society Guidelines for Cancer Survivors: <https://www.cancer.org/cancer/survivorship.html>

Children’s Oncology Group Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers: <https://childrensoncologygroup.org/survivorshipguidelines>

National Comprehensive Cancer Network Survivorship Guidelines: <https://www.nccn.org/guidelines/guidelines-detail?category=3&id=1466>

Health System Evaluation and Assessment

When possible, validated measures should be utilized to assess for each of the indicators in this domain. Examples are below:

- **Patient-Reported Outcomes Measurement Information System (PROMIS):** Set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. <https://www.healthmeasures.net>
- **NIH Toolbox:** Includes more than 100 validated tests to assess cognitive, sensory, motor, and emotional function. <https://nihtoolbox.org/>
- **PhenX Toolkit:** Standard measurement resources for cancer outcomes and survivorship research <https://www.phenxtoolkit.org/>
 - **Publication:** Nekhlyudov et al (2023). The PhenX Toolkit: Standard measurement resources for cancer outcomes and survivorship research. *Journal of the National Cancer Institute*, 115(4), 473–476. <https://doi.org/10.1093/jnci/djad010>

More Information

Please note that the inclusion of resources should not be viewed as an endorsement of the content.

NCI resources

- **Cancer Information Service:** Offers free, credible, and comprehensive information about cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, clinical trials, and news and links to other NCI websites. <https://www.cancer.gov/contact>
- **Office of Cancer Survivorship special focus area on primary care and cancer survivorship:** <https://cancercontrol.cancer.gov/ocs/special-focus-areas/primary-care-and-cancer-survivorship>
- **Radiation oncology resources:** Radiation Therapy and You: Support for People with Cancer. <https://www.cancer.gov/publications/patient-education/radiation-therapy-and-you>
- **Smokefree.gov:** Helpful resources to quit smoking. <https://smokefree.gov>
- **Evidence-Based Cancer Control Programs (EBCCP):** A searchable database of evidence-based cancer control programs. <https://ebccp.cancercontrol.cancer.gov/>

Centers for Disease Control and Prevention resources

- **Cancer Data and Statistics:** <https://www.cdc.gov/cancer/data/>
- **Resources for Cancer Survivors:** <https://www.cdc.gov/cancer-survivors/index.html>
- **Patient Navigation:** <https://www.cdc.gov/cancer/php/interventions/patient-navigation.html>

Community-based resources offering support to cancer survivors

- **Findhelp:** <https://www.findhelp.org>
- **Nancy's List:** <https://nancyslist.org>

The Cancer Survivorship Provider Network (CSPN): A peer-to-peer online community dedicated to supporting health care professionals in clinical and research practice through education, advocacy, peer networking, and collaborations. <https://thecspn.org/>

National Coalition for Cancer Survivorship (NCCS): A cancer survivor-led non-profit organization with the mission to advocate for quality cancer care for all people impacted by cancer. <https://canceradvocacy.org/>

American Society of Clinical Oncology Survivorship Compendium: <https://society.asco.org/news-initiatives/current-initiatives/cancer-care-initiatives/survivorship-compendium>

Example Health System Policies

Health systems may develop one comprehensive policy to include the necessary components in alignment with the standards. Links to example policy templates can be found below:

Policy template that aligns with US National Standards for Cancer Survivorship Care, developed by the Cancer Survivorship Provider Network

Background

CSPN has developed the Survivorship Standard of Practice Template which incorporates the National Standards for Cancer Survivorship Care, as well as other relevant standards and guidelines.

In addition to the template, a companion tool has been created for organizational documentation, including the tracking of survivorship models for each cancer-specific team, roles and responsibilities for team members, patient eligibility based on cancer type, educational tools offered to survivors and caregivers, documentation of survivorship programs and services, outcome measures, and a template for a business plan.

These resources can be accessed through the Cancer Survivorship Provider Network website at <https://thecspn.org/resources/>. Please contact the CSPN administrator at admin@thecspn.org with any questions.

Policy template that aligns with the Victorian (Australia) Quality Cancer Survivorship Care Framework and Policy Template: <https://www.petermac.org/patients-and-carers/support-and-wellbeing/life-after-treatment/survivorship/victorian-quality-cancer-survivorship-care-framework>

Relevant Publications

- **Halpern, M., et al. Myths and Presumptions About Cancer Survivorship.** Journal of Clinical Oncology, 42(2), 134-139 (2024). DOI:[10.1200/JCO.23.00631](https://doi.org/10.1200/JCO.23.00631)
- **Lisy, K., et al. How Do We Define and Measure Optimal Care for Cancer Survivors? An Online Modified Reactive Delphi Study.** Cancers, 13(10) (2021). DOI:[10.3390/cancers13102299](https://doi.org/10.3390/cancers13102299)
- **Mollica, M. A., et al. Developing National Cancer Survivorship Standards to Inform Quality of Care in the United States Using a Consensus Approach.** Journal of Cancer Survivorship, 18, 1190-1199 (2024). DOI:[10.1007/s11764-024-01602-6](https://doi.org/10.1007/s11764-024-01602-6)
- **Nekhlyudov, L., et al. Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy.** Journal of the National Cancer Institute, 111(11), 1120-1130 (2019). DOI:[10.1093/jnci/djz089](https://doi.org/10.1093/jnci/djz089)
- **Stout, N. L., et al. Implementing a Clinical Pathway for Needs Assessment and Supportive Care Interventions.** JCO Oncology Practice, 20(9) (2024). DOI:[10.1200/OP.23.00482](https://doi.org/10.1200/OP.23.00482)
- **Special Section: The History of Cancer Survivorship Programs in the US: Progress, Challenges and Opportunities.** Journal of Cancer Survivorship, 18(1), 1-58 (2024). <https://link.springer.com/journal/11764/volumes-and-issues/18-1>

Subject Matter Experts

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Janette Merrill , MS	American Society of Clinical Oncology (ASCO)
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