

Executive Summary

National Standards for Cancer Survivorship Care

The Biden Cancer Moonshot, President Biden's whole of government response to accelerate progress against cancer and end cancer as we know it, established a goal to develop US 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 National Cancer Institute 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 comprehensive landscape review of survivorship and cancer-specific guidelines, the Commission on Cancer survivorship standard, existing survivorship quality frameworks, U.S. state cancer control plans, and relevant literature. NCI and VA held three iterative, 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 align current and future survivorship services. Please note that use of the standards by health systems is voluntary, and components of care may or may not be covered by public or private insurance.

Key Definitions

Cancer survivor: any 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

National Standard for Cancer Survivorship Care

 Health System Policy	 Health System Processes	 Health System Evaluation/Assessment
<p>The organization has a policy that includes...</p> <p>establishment or existence of a survivorship program either on-site, through telehealth, or by referral</p> <p>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)</p> <p>a description of multidisciplinary care, including each team member's specific roles and responsibilities and workflow(s) for referrals to team members</p> <p>an overview of how to stratify and refer survivors to appropriate models of care based on age, treatments, and risk factors</p> <p>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</p> <p>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</p> <p>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</p> <p>collection of longitudinal data on survivors' experience of survivorship care and patient-reported outcomes</p> <p>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</p> <p>a business case/plan, including budget, with funding allocated for survivorship care</p>	<p>Cancer survivors are...</p> <p>provided with access and referral to a survivorship program that addresses the needs of cancer survivors either on-site, through telehealth, or by referral</p> <p>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</p> <p>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</p> <p>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</p> <p>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</p> <p>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</p> <p>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)</p> <p>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)</p> <p>assessed for financial hardship/toxicity and concerns regarding insurance coverage, and provided with resources and support as needed</p> <p>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</p>	<p>The organization has a process to collect data on...</p> <p>survivors' patient-reported outcomes, including quality of life, and experiences of survivorship care</p> <p>survivors' functional capacity</p> <p>survivors' return to previous participation in paid and unpaid work/ school/ productive activities of living</p> <p>survival rates (1, 5, and 10-yr) from the time of diagnosis</p> <p>rate of recurrence</p> <p>rate of subsequent cancers</p> <p>number and relevant characteristics (demographics, clinical factors) of survivors lost to follow-up</p> <p>caregivers' experiences and unmet needs</p> <p>number of health professionals trained to provide survivorship care</p> <p>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)</p>

Subject Matter Experts

Expert	Organization
Catherine Alfano, PhD	Northwell Health
Precilla Belin, PhD, MA, MCCHES	NCI Office of Cancer Centers
Anne Blaes, MD	University of Minnesota
Hillary Cavanagh, MS	Centers for Medicare & Medicaid Services
Lanie Francis, MD	University of Pittsburgh Medical Center Cancer Center
David Freyer, DO, MS	USC Norris Comprehensive Cancer Center and Children's Hospital Los Angeles
Danielle Friedman, MD	Memorial Sloan Kettering Cancer Center
Shelley Fuld Nasso, MPP	National Coalition for Cancer Survivorship
Patricia Ganz, MD	UCLA Jonsson Comprehensive Cancer Center
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Michael Jefford, MBBS, MPH, MHLthServMt, PhD, FRACP	Peter MacCallum Cancer Centre/ Australian Cancer Survivorship Centre (ACSC)
Nancy Keating, MD, MPH	Harvard Medical School
Anne Kirchoff, PhD, MPH	Huntsman Cancer Institute, University of Utah
Michelle Kirschner, NP-C	OneVillage and The Cancer Survivorship Provider Network (CSPN)
Ron Kline, MD	Centers for Medicare & Medicaid Services
Jessica MacIntyre, DNP, MBA, APRN, NP-C, AOCNP®	University of Miami/Sylvester Comprehensive Cancer Center
Molly Maher, MS	NCI Office of Cancer Centers; cancer caregiver
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Ethan Schilling, PhD	Cancer Survivor Advocate
Kathryn Schmitz, PhD, MPH	University of Pittsburgh/ Hillman Cancer Center
Lisa Schwartz, PhD	University of Pennsylvania
Emily Tonorezos, MD, MPH	National Cancer Institute Office of Cancer Survivorship