

The Comprehensive Cancer Survivorship Act (CCSA)

*Rep. Debbie Wasserman Schultz, Sen. Amy Klobuchar, Sen. Ben Cardin,
Rep. Brian Fitzpatrick, and Rep. Mark DeSaulnier*

Section by Section

Section 1: Short Title

The Comprehensive Cancer Survivorship Act

Section 2: Findings

This section outlines key findings related to cancer survivors, including statistics, challenges, disproportionate impact, the impact to children and adolescents, the importance of clinical trials, the need and purpose of survivorship care, and the need for coordination of care.

Section 3: Definitions

This section defines several terms, including cancer survivor, caregiver, episode-of-care, patient experience data, psychosocial effects and care, survivorship, survivorship care plan, survivorship navigation, and treatment summary.

Section 4: Coverage of Cancer Care Planning and Coordination Services

This section provides for Medicare coverage and payment of cancer care planning and coordination services for individuals who are diagnosed with or treated for cancer, including the development of treatment plans, follow-up care, and any necessary revisions.

Section 5: Survivorship Transition Tools

This section directs the Office of the National Coordinator for Health Information Technology, in collaboration with the Director of AHRQ, to publish information resources for cancer patients and providers for consolidating treatment history and survivorship guidelines into a personalized survivorship care plan to guide follow-up care. This shall be accomplished by evaluating existing templates for care plans and existing tools used by national organizations, as well as collaboration with HHS to ensure privacy and security, especially with the use of technology.

Section 6: Alternative Payment Model

This section directs the Secretary of HHS to conduct a study and submit a report outlining an Alternative Payment Model for payment for items and services relating to survivorship care. The study shall include triggering events; length of participation and possible extensions; episodic models; inception of care plans and follow-up care; potential use of bundled payments; routine screenings needed; the importance of shared decision-making; services provided by different providers; strategies for coordination of care; strategies to address social determinants of care; a description of how such model will promote prevention, surveillance, and treatment as well as access to treatment and research; analysis of models based on varying episodes of care; and a plan to test the models, such as timing, impact, and potential barriers.

Section 7: Survivorship Navigation

This section requires the Secretary of HHS to complete a review of navigation programs and applicable standards of care to generate a report assessing how navigation programs can be best developed across the continuum of care. The study will review effectiveness, types of services, evolution of services, training needs, locations, federal financing, patient involvement, alternative payment, and existing community resources.

This section further requires the Secretary to carry out a demonstration program through grants to eligible entities, including community-based organizations, patient-centered education organizations, cancer centers, hospitals, and community health centers. These entities must use the grants to offer navigation services that emphasize the continuum of care, timely follow up, disparities, coordination, evidence-based guidelines, culturally appropriate services, and barriers such as food insecurity, housing, transportation, labor, access to broadband and telehealth, and childcare.

Section 8: Survivorship Care Demonstration Model

This section requires the Secretary of HHS to carry out a grant program aimed at improving the quality of cancer survivorship care through demonstration sites that ensure diversity in urban, suburban, rural, and tribal areas. The demonstration will focus on utilization of navigation, employment of risk-stratification, transitioning to primary care, utilization of care plans, potential use of at-home care, use of information technology for patient experience data, and expanding successful models. The Secretary shall then develop a plan to evaluate the demonstration and create a report.

Section 9: Cancer Survivor Workforce Assistance Grants

This section requires the Secretary of DOL, in consultation with HHS, to carry out a grant program for nonprofits to provide education and targeted assistance to survivors facing workforce challenges and their families and caregivers. The program will prioritize assistance and education pertaining to transportation, childcare, nutrition, and finances, such as accessing existing programs and financial benefits, and engaging in training assistance.

Section 10: Comprehensive Cancer Survivorship Program

This section directs the Secretary of HHS to establish three related programs: (i) a cancer survivorship resource center to provide evidence-based resources to cancer survivors, their families, and their caregivers; (ii) an educational campaign to provide health care professionals with resources to improve cancer survivorship care, and (iii) a program of supportive care services to improve the quality of life and long-term survivorship of cancer survivors.

Section 11: Cancer Survivorship Study

This section directs the Secretary of HHS to complete a feasibility analysis assessing the creation of an adult version of the Childhood Cancer Survivor Study and the financial costs of carrying out this duty, as well as identifying sources of data, gaps in data, and strategies to publish data in a manner accessible to survivors, providers, researchers, and the public.

Section 12: Survivorship Progress Report

This section requires the Secretary of HHS to coordinate with the GAO to conduct of study of the progress made in cancer survivorship over the last 50 years. GAO is required to investigate the nature and quality of survivorship care, transitions from active treatment, quality of life of survivors, outcomes of survivors, disparities, health systems offering care, contribution of community-based services, and payment of care. In carrying out the investigation, GAO shall hold public meetings with cross-sectional stakeholders.

Section 13: Promoting State Innovations to Ease Transitions to the Primary Care Setting for Children with Cancer

This section directs the Secretary of HHS to convene a stakeholder group of representatives of childhood cancer advocacy organizations, Medicaid beneficiaries, providers with childhood cancer expertise, the National Association of Medicaid Directors, and other relevant representatives to develop best practices for States to ease transition from active oncological care to primary care of child or adolescent with cancer. The Secretary will create a report and work with states on innovative strategies to help children and adolescents with cancer who transition from oncological care to primary care.

Section 14: Childhood Cancer Demonstration Model and Standard of Care

This section amends the CMS demonstration authority statute where there is a list of over 25 models that CMMI is encouraged to implement by including a new Medicaid pediatric survivorship care demonstration model. The model would promote a standard of care to manage the transition of children from active oncology care to primary care through the promotion and use of survivorship care plans.

Section 15: Medicaid Coverage of Fertility Preservation Services

This section amends the Social Security Act to ensure Medicaid coverage of fertility preservation services under Medicaid for individuals diagnosed with cancer undergoing treatment for such cancer that may lead to iatrogenic infertility.