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Survivorship objectives in comprehensive cancer control plans: a systematic review

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Abstract

Purpose—Over a decade ago, the National Academy of Medicine (NAM) recommended that states develop, implement, and evaluate plans that include consideration of survivorship care. The purpose of this study was to review comprehensive cancer control plans in the USA, specifically to identify the inclusion of cancer survivorship-focused goals and objectives and examine alignment of survivorship-focused objectives with the NAM recommendations.

Methods—Plans from 50 states, 7 territories, 5 tribal organizations, and the District of Columbia were reviewed to assess inclusion of survivorship goals and objectives. One territory plan was excluded because it did not include a survivorship-focused goal or objective (final $n = 62$). Objectives were assigned to domains based on NAM survivorship recommendations.

Results—Plans included between 1 and 19 survivorship-related objectives. Of the 345 survivorship objectives extracted and analyzed, the most prevalent domains addressed were *raising awareness, survivorship care plans, healthcare professional capacity*, and *models of coordinated care. Employment-related concerns, developing and implementing quality measures*, and *investments in research* were not frequently included in objectives.

Conclusions—Comprehensive cancer control plans represent an important strategy that may reduce the impact of cancer and its treatment. State, territorial, and tribal coalitions can use these

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results to systematically focus future survivorship efforts on areas relevant to their region and population.

Implications for cancer survivors—The growing number of survivors requires broad-ranging policy strategies. Future efforts are needed to assess the implementation and impact of plan strategies to improve the overall wellness of cancer survivors.

Keywords

Survivorship; Cancer control plans; National Academy of Medicine; Cancer

Introduction

Comprehensive cancer control plans, supported by the National Comprehensive Cancer Control Program (NCCCP) through the Centers for Disease Control and Prevention (CDC), provide a coalition-based, public health approach to decrease cancer burden [1]. Following the release of the 2004 National Action Plan for Cancer Survivorship [2], CDC has employed public health strategies to address the needs of cancer survivors [3, 4], and in 2010, CDC included cancer survivorship as one of four NCCCP priorities [5]. In addition, one of CDC's Division of Cancer Prevention and Control priorities is to improve the quality of life of cancer survivors [6]. The NCCCP provides support for all US states, the District of Columbia, and select tribal organizations and territories to develop and implement plans tailored to their population, including survivorship goals focused on improving the quality of life for cancer survivors [7, 8].

With an estimated 17 million cancer survivors in the USA, survivorship represents a critical phase along the cancer continuum [9]. While an individual is considered a survivor from the time of cancer diagnosis through the balance of their life [10], the National Academy of Medicine (NAM), formerly the Institute of Medicine, specifically called out the period as cancer patients complete active treatment [11]. The NAM landmark 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, detailed the complex needs of cancer survivors and provided ten actionable recommendations to improve the quality of cancer survivorship care (Table 1). One recommendation specifically called for comprehensive cancer control plans to address survivorship care from a public health perspective. Despite substantial progress over the last decade, survivorship care remains variable and often suboptimal [12, 13].

Previous reviews of comprehensive cancer control plans focused on cancer survivorship have examined activities and action plans across cancer control programs [7, 8, 14]. Results indicated that most coalitions implemented survivorship efforts and provided examples for incorporating cancer survivorship activities into their programs. While plans are not required to include the NAM recommendations, incorporation of these recommendations may serve as a mechanism to benchmark and systematically reflect on concrete actions that can be applied by coalitions and evaluate how such actions may impact and advance the quality of survivorship care among regions and communities.

The purpose of this study was to perform a systematic review of state, territory, and tribal organization comprehensive cancer control plans in the USA, specifically to (1) identify inclusion of cancer survivorship-focused goals and objectives and (2) assess alignment of survivorship-focused objectives with the ten NAM recommendations.

Methods

We identified each state, territory, or tribal organization's most current comprehensive cancer control plan using CDC's NCCCP website [15], along with web searches and direct outreach to state or jurisdiction program directors and CDC program consultants. We extracted survivorship goals and objectives from the most recent, currently available cancer control plans for all 50 states, six territories, five tribal organizations, and the District of Columbia (Supplemental Table 1) as of August 15, 2018. For the purposes of this analysis, we relied on cancer control plan use of the term "survivorship," which has been previously described as any individual from the time of a cancer diagnosis [16] to those who have completed active cancer treatment [11].

Extraction of plan goals and objectives

The NCCCP defines goals as "a general statement of the underlying purpose of the plan," while objectives are defined as "specific, measurable statements of what is to be accomplished regarding the goals" [14, 17]. Some plans also include indicators or strategies for measuring and completing objectives. Because of the variability in plans, we were unable to systematically analyze indicators and strategies, and instead focused solely on goals and objectives. We manually extracted all goals and objectives that *explicitly* mentioned survivorship and coded them using NVivo coding software (version 10). Objectives that included palliative care, hospice, or end-of-life care were *only* included when they were described in the context of a survivorship goal or objective.

Identification of survivorship as a priority area

Fifty-four plans (86%) specifically identified "survivorship" as a priority area, as evidenced by inclusion of at least one survivorship-focused goal. The nine plans (six states and three territories) that did not identify survivorship with a unique or freestanding goal combined it into a goal related to *all* persons affected by cancer (which could include patients undergoing active treatment, post-treatment survivors, as well as those with advanced disease). Although these nine plans did not explicitly identify survivorship with its own goal, all but one plan included at least one survivorship-focused objective. Our final set of 62 plans included 50 states, six territories, five tribal organizations, and the District of Columbia.

Coding procedures

After data extraction, a subset of plans ($n = 6$) were initially reviewed, and members of the study team (MM, AF, LN) met to refine and finalize the data extraction criteria and codebook. The codebook included years covered by the current plan, survivorship identified as a priority area (identified as a goal of its own), number of goals related to survivorship, number of objectives related to survivorship, specific goals and objectives, and data sources. Each objective was then coded into domains based on the 10 NAM survivorship recommendations (for brevity, referred to as the following domains depicted in Table 1: (1) *Raising Awareness*; (2) *Survivorship Care Plan*; (3) *Utilizing Evidence-Based Guidelines*; (4) *Developing and Implementing Quality Measures*; (5) *Models of Coordinated Care*; (6) *Survivorship as a Public Health Concern*; (7) *Healthcare Professional Capacity*; (8) *Employment-Related Concerns*; (9) *Adequate and Affordable Health Insurance*; and (10) *Investments in Research* [11]. Throughout abstraction, each objective was examined and assigned to the single most appropriate domain. We then double coded a 10% sample of objectives to assess agreement and concordance of domain coding between readers. Percentage agreement between readers was high, ranging from 90 to 100% for objectives, with a Kappa coefficient of 0.92. Differences were discussed until three authors (MM, AF, LN) reached consensus.

Results

A total of 62 plans were included in the final analysis, with 2,278 objectives overall, of which 345 were coded as survivorship objectives (15%). Ten states, four territories, and two tribal organizations had plans (total $n = 16$) that did not include 2018 updated goals and objectives and were considered out-of-date, but were still included in the analysis as they included survivorship objectives. Each plan included between 12 and 109 total objectives, with 1–19 specifically related to survivorship. Each plan focused an average of 17% of its objectives on survivorship (#survivorship objectives vs. total objectives in plan).

Table 2 details the number of plans and objectives addressing specific NAM domains. Plans included an average of 2 NAM domains in their plans (range 0–6). Of the 62 plans, domains most prevalent in plans were *Raising Awareness* (34 plans; 55%), *Survivorship Care Plans* (33 plans; 53%), *Healthcare Professional Capacity* (29 plans; 47%), and *Models of Coordinated Care* (23 plans; 37%) (Fig. 1). Figure 2 shows the number of recommendation domains covered by plan objectives in each state, territory, and tribal organization. Table 2 also includes additional objectives included in plans that were not specifically recommended by NAM but relevant for cancer survivorship, including *Palliative Care* (72 objectives; 21%), *Health Promotion* (e.g., smoking cessation, diet, and physical activity) (26 objectives; 8%), *Physical Functioning* (18 objectives; 5%), *Psychosocial Functioning* (8 objectives; 2%), and *Mortality* (4 objectives; 1%).

An analysis of survivorship objectives indicated similar results. The most prevalent recommendation domains addressed by survivorship objectives included *Raising Awareness* (63 objectives; 18% of survivorship objectives), *Survivorship Care Plans* (34 objectives; 10% of survivorship objectives), *Healthcare Professional Capacity* (54 objectives; 16% of survivorship objectives), and *Models of Coordinated Care* (34 objectives; 10% of survivorship objectives). Objectives rarely addressed the following domains: *Employment-Related Concerns* (2 objectives; 1% of survivorship objectives), *Developing and Implementing Quality Measures* (3 objectives; 1% of survivorship objectives), and *Investments in Research* (3 objectives; 1% of survivorship objectives).

While it was not the primary aim of this paper to review survivorship-related data sources within cancer plans, 58% of plans ($n = 36$) identified a data source to measure the indicators of interest for their objectives. Of these plans, the Behavioral Risk Factor Surveillance System (BRFSS), a survey that collects state-level data on health-related risk behaviors, chronic health conditions, and use of preventive services [18], was most often cited ($n = 26$ plans; 72% of plans identifying a data source) (data not shown).

Discussion/conclusions

The NAM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommended that collaborating stakeholders of states, territories, and tribal organizations include survivorship in comprehensive cancer control plans [11]. Assessing alignment of survivorship content in cancer plans with the NAM recommendations allows for targeting efforts to improve survivorship outcomes. It was promising to find that over 86%of plans specifically identified survivorship as a priority for cancer control, and that all but one plan included a survivorship-focused objective. The high prevalence of survivorship objectives in this review illustrates that the states, territories, and tribal organizations recognize the importance of this topic. In addition, the inclusion of quality of life in cancer survivors as a priority for CDC’s Division of Cancer Prevention and Control may have informed the decisions of some coalitions to make survivorship a focus of their plans. Our analysis of whether survivorship objectives were aligned with the NAM recommendations revealed variable results. It is important to note that cancer control coalitions do not require such alignment and may not have sufficient resources to address all ten recommendations. We propose that our results may allow coalitions to systematically evaluate their plans, decide what to include in their plans based on local context, priorities, and cancer burden, and take actionable steps to optimize the impact of cancer survivorship objectives (Table 3).

While there is growing recognition of the unique needs of survivors after treatment ends (NAM Recommendation 1), it is clear that increased awareness is still needed [19]. Survivors often experience late and long-term symptoms, and multiple chronic conditions, as well as financial hardship due to cancer and its treatments [11]. Coalitions can work with key stakeholders and decision makers to enhance education about these topics and the efficacy of evidence-based policy solutions. Increased efforts can focus on assessing region-level healthcare provider supports and education to ensure delivery of evidence-based survivorship care [20]. Shared-care models with coordinated communication across multiple providers directly align with NAM Recommendation 5 (Models of Coordinated Care), but research is needed to refine and assess the impact of these on patient, provider, and system-level outcomes [21–23].

While including objectives related to the domains of *Employment-Related Concerns*, *Developing and Implementing Quality Measures*, and *Investments in Research* may not be feasible for coalitions given resource constraints, awareness of these issues remains essential. Cancer survivors are at risk for financial hardship as a result of their cancer diagnosis and its treatment, including reduction in income, and medical debt, as well as an inability to work [24]. States, territories, and tribal organizations can support cancer survivors by working with local health care institutions and advocacy groups to address the financial impacts of cancer through supportive employment policies and protections. Regarding the development and implementation of quality measures of survivorship care

(NAM Recommendation 4), National Comprehensive Cancer Network (NCCN) guidelines and the American Society of Clinical Oncology's (ASCO) Quality Oncology Practice Initiative have aimed to advance cancer care quality mainly during the treatment phase, and guidelines from NCCN, ASCO, and the American Cancer Society have been released for survivorship [25–27]. Consistent quality measurement in survivorship care is still lacking; however, local jurisdictions can consider collaborating with academic institutions and patient groups with research and policy expertise to develop and implement systematic assessment of process and outcome measures that are relevant to stakeholders. Finally, the National Cancer Institute, the Centers for Disease Control and Prevention, and the American Cancer Society continue to support survivorship research (Recommendation 10) [3, 28]. State-, territory-, and tribal-level strategies may target the improvement of surveillance and applied research, as well as communication and training in cancer survivorship care.

It is notable that 53% of plans ($n = 33$) included an objective recommending the provision of a Survivorship Care Plan (SCP). At the time of our review, the American College of Surgeons Commission on Cancer (CoC), the largest accrediting body of cancer programs in the USA, required accredited programs to establish a process for developing and delivering SCPs to at least 50% patients completing cancer treatment. Implementation of SCPs has been challenging, however, due to unreimbursed clinical time and human and technological resources to support SCP development and delivery to patients and other providers [29, 30]. There is little evidence that the use of only a SCP improves health outcomes [29], which is not surprising given the variability of SCP content and the lack of alignment with guidelines to date. In fact, based on input from stakeholders, the CoC has revised its recommendation with a focus on the delivery of coordinated, evidence-based survivorship care, which includes rather than focuses on the SCP alone [31]. State, territory, and tribal coalitions seeking to promote the sustainability of quality survivorship care may support reimbursement of SCPs, survivorship care, and the goals of care planning with survivors by educating decision makers about the evidence base for these interventions.

Our review has certain limitations. First, this analysis captured currently available comprehensive cancer control plans: as programs are constantly updating plans, our review may have missed some plans under revision. In addition, we included 15 out-of-date along with current plans despite their temporal differences. Second, we assessed plans, which are documents meant to serve as a blueprint for action—but we did not measure actual efforts and activities within each jurisdiction. This review also did not focus on program action plans, which would reflect program activities and the bandwidth of the coalitions. As such, stated efforts to address survivorship may not reflect activities. However, based on findings from a previous study assessing survivorship activities in the NCCCP, most awardees have implemented at least one survivorship activity [7, 14]. Lastly, we did not formally assess the effect of the plans on the cancer survivorship-related outcomes of care based on jurisdiction. We did, however, compare our mapped outcomes (Fig. 2) to published figures of cancer incidence rates, cancer death rates, and number of oncology providers across the USA [32, 33]. Our informal analysis revealed that states and territories with higher incidence and mortality, as well as regions with fewer numbers of oncology providers, had comparable focus on survivorship-related objectives as other regions. It is possible that this may suggest that cancer plans are identifying survivorship objectives, but that action plans and implementation efforts do not reflect these objectives. This observation serves as an important area for future research efforts.

In summary, our review is an important step in identifying the current state of survivorship as a priority among state, territory, and tribal organization cancer coalitions. Coalitions can use these results to systematically identify strategy options, measure impact, and promote implementation and dissemination of proven interventions. The NAM report was released over a decade ago, and challenges experienced by cancer survivors persist. It is clear that the growing number of survivors in the USA may increase the need for coordinated strategies to advance survivors' longitudinal health. Future work should assess implementation of plan strategies focused on survivorship and the impact of these strategies on the overall wellness of the almost 17 million cancer survivors in the USA.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Disclosures

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Institutes of Health (NIH) or the Centers for Disease Control and Prevention (CDC).

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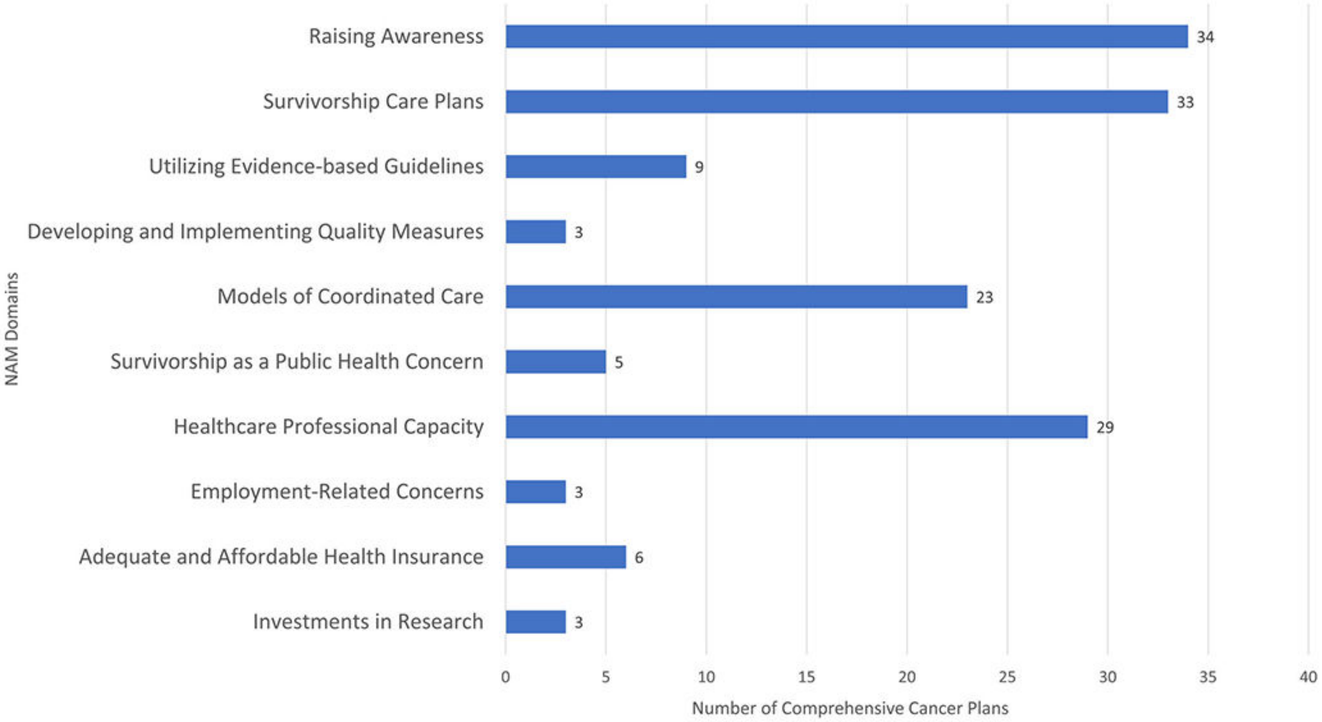

Fig. 1.

Number of plans including at least one objective in NAM domain (total *n* = 62)

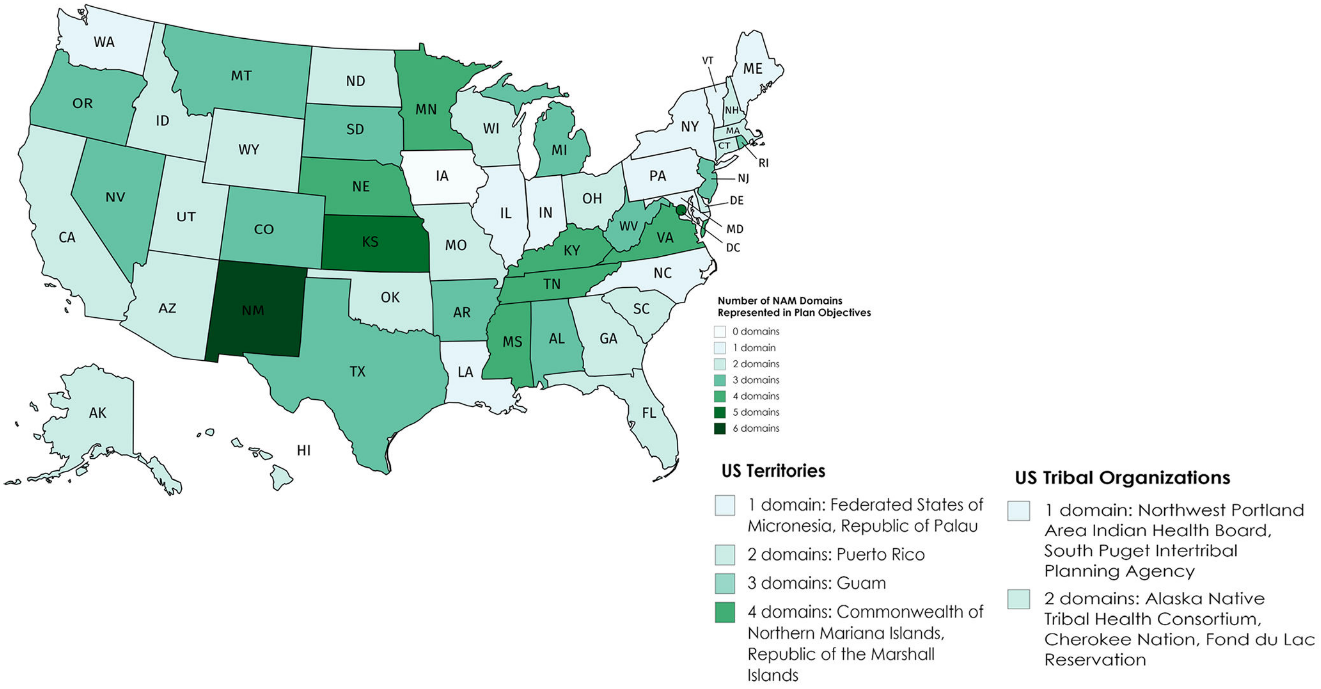

Fig. 2.

Alignment of Survivorship Content in Comprehensive Cancer Plans to NAM Recommendations

Table 1

National Academy of Medicine *Lost in Transition* Recommendations [11]

Recommendation #	Domain	National Academy of Medicine Recommendation
1	Raising Awareness	Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care
2	Survivorship Care Plan	Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This Survivorship Care Plan should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.
3	Utilizing Evidence-Based Guidelines	Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.
4	Developing and Implementing Quality Measures	Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.
5	Models of Coordinated Care	The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
6	Survivorship as a Public Health Concern	Congress should support Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.
7	Healthcare Professional Capacity	The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.
8	Employment-Related Concerns	Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.
9	Adequate and Affordable Health Insurance	Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
10	Investments in Research	The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, private voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Table 2

Inclusion of NAM Survivorship Recommendations and Additional Domains in Comprehensive Cancer Control Plan Survivorship Objectives

Recommendation domain	**Number of objectives in domain**	**Number of plans including at least one objective in domain**	**Proportion of aggregate survivorship objectives represented by domain (out of total *n* = 345 survivorship objectives)***	**Proportion of plans including at least one objective in domain (out of *n* = 62 plans)***	**Example objective****
Raising Awareness	63	34	18%	55%	Develop and promote the utilization of a common definition for cancer survivor, patient navigator, community health worker and palliative care.
Survivorship Care Plans	34	33	10%	53%	Increase the proportion of cancer survivors who have received treatment summaries and survivorship care plans.
Utilizing Evidence-Based Guidelines	9	9	3%	15%	Increase adherence to nationally recognized follow-up care guidelines for cancer survivors among oncologists and primary care providers.
Developing and Implementing Quality Measures	3	3	1%	5%	Identify and endorse evidence-based high-quality standards for the care of cancer survivors.
Models of Coordinated Care	34	23	10%	37%	To increase access to cancer patient case management, care coordination and navigators, across the continuum of cancer care: from outreach to end-of-life.
Survivorship as a Public Health Concern	5	5	1%	8%	Establish a collaborative relationship with at least two entities interested in partnering with the Nebraska Cancer Coalition to evaluate the highest priorities for cancer survivorship research.
Healthcare Professional Capacity	54	29	16%	47%	Increase health care providers' education regarding survivorship issues, including end of life, to improve comprehensive cancer care and management.
Employment-Related Concerns	2	3	1%	5%	Reduce financial and legal burdens on cancer patients.
Adequate and Affordable Health Insurance	6	6	2%	10%	Increase the proportion of cancer survivors who report having their insurance pay for all or part of their cancer treatment.
Investments in Research	3	3	1%	5%	Encourage and promote cancer survivorship research projects and grants.
Additional Domains					
Palliative Care for Survivors	72	37	21%	60%	Set a baseline and increase the proportion of all cancer survivors receiving palliative care services.
Health Promotion	26	15	8%	24%	Promote smoking cessation among cancer survivors who smoke.
Physical Function	18	15	5%	24%	Optimize each survivor's physical functioning through symptom control beginning at the time of diagnosis.
Psychosocial Function	8	8	2%	13%	Decrease the proportion of cancer survivors who report poor mental health.
Mortality	4	4	1%	6%	Increase the survival rate of ovarian cancer patients by ten percent.
Supportive Resources	2	2	1%	3%	Establish a cancer survivors group or network to provide support.

[*] Percentage rounded to nearest whole number

[**] Objectives taken from comprehensive cancer plans

Table 3

Options for comprehensive cancer control coalition actions to optimize the impact of cancer survivorship objectives

1. Expand state, territory, and tribal organization comprehensive cancer control plans to include survivorship goals aligned with NAM recommendations as appropriate.
2. Implement systematic assessment of patient-reported outcomes relevant to cancer survivors (e.g., quality of life, functional status, distress).
3. Prioritize survivorship objective implementation based on assessment of jurisdiction-level patient and provider needs.
4. Assess region-level healthcare provider supports needed to improve provision of evidence-based cancer survivorship care.
5. Educate healthcare providers on available cancer survivorship-focused clinical practice guidelines using evidence-based learning strategies.
6. Focus on sustainability of quality survivorship care through adequate reimbursement.
7. Partner with researchers to track, assess, and evaluate plan goals, objectives, and impact on stakeholders.
8. Publish action plans and jurisdiction-level outcomes at least annually through a public-facing report to enhance peer learning.
9. Use evaluation data for continuous quality improvement of prioritized comprehensive cancer control survivorship strategies.
10. Disseminate best practice approaches to other jurisdictions.