

Supporting Cancer Survivors through Comprehensive Cancer Control Programs



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CANCER CONTROL TAP
Tap into resources to control cancer

INTRODUCTION

Welcome to *Supporting Cancer Survivors through Comprehensive Cancer Control Programs*. The purpose of this survivorship report is to present a national snapshot of the current state of cancer survivorship in the U.S., including what we know about the health status, needs and disparities among survivors. The focus of this report will be on post-treatment survivorship issues. We will also highlight some systems-level approaches to addressing needs for post-treatment cancer survivors.

The intent of this report is to serve as a brief guide for comprehensive cancer control (CCC) program efforts to help CCC groups advance goals in their state, tribe or territory. Furthermore, this report will provide recommended benchmarks in the four domains as outlined in *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* report (Centers for Disease Control and Prevention [CDC] & **LIVESTRONG** Foundation, 2004):

- Surveillance and applied research
- Communication, education and training
- Programs, policies and infrastructure
- Access to quality care and services

Benchmarks can be used to help guide assessment of CCC survivorship efforts.

HOW TO USE THIS RESOURCE

Use this resource to:

1. Provide an introductory education for CCC staff and coalition members on cancer survivorship needs and opportunities for engagement
2. Revise your state cancer plan to include select survivorship benchmarks
3. Identify systems-level opportunities for supporting cancer survivorship in surveillance and applied research; communication, education and training; programs, policies and infrastructure; and access to quality care and services

If you need technical assistance or would like more information, please contact us at cancercontrol@gwu.edu.

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ABOUT THE INSTITUTE FOR PATIENT-CENTERED INITIATIVES AND HEALTH EQUITY AT THE GW CANCER CENTER

The mission of the Institute for Patient-Centered Initiatives and Health Equity at the GW Cancer Center is to foster healthy communities, prepared patients, responsive health care professionals and supportive health care systems through applied cancer research, education, advocacy and translation of evidence to practice. Our vision is a cancer-free world and health care that is patient-centered, accessible and equitable.

The GW Cancer Center is a collaboration between the GW Hospital, the GW Medical Faculty Associates, and the GW School of Medicine and Health Sciences to expand GW's efforts in the fight against cancer. The GW Cancer Center also partners with the Milken Institute School of Public Health at GW, and incorporates all existing cancer-related activities at GW, serving as a platform for future cancer services and research development.

ABOUT THE COMPREHENSIVE CANCER CONTROL PROJECT

In 2013, the Institute for Patient-Centered Initiatives and Health Equity (formerly the GW Cancer Institute) was awarded a 5-year cooperative agreement to work with the Centers for Disease Control and Prevention (CDC) to design and implement comprehensive, high-quality training and technical assistance to CCC programs and their partners to implement cancer control activities. To learn more, visit www.CancerControlTAP.org.

DISCLAIMER

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Supporting Cancer Survivors through Comprehensive Cancer Control Programs

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BACKGROUND

Current estimates suggest there are almost 15.5 million cancer survivors living in the United States (Siegel, Miller & Jemal, 2016). This number has grown immensely over the past few decades due partly to an aging population as well as increased early detection and improved treatment outcomes (Fairley, Pollack, Moore & Smith, 2009). The Centers for Disease Control and Prevention (CDC) defines a cancer survivor as "anyone who has been diagnosed with cancer, from the time of diagnosis through the balance of his or her life" (CDC & LIVESTRONG Foundation, 2004). The American Cancer Society (ACS) projects this number will increase to 20 million by the year 2026 (Siegel et al., 2016).

Cancer survivors are at an increased risk for a variety of issues due to cancer and its treatment including increased risk for a second primary cancer, long-term and late effects on both physical and mental well-being, impact on relationships and work life and financial hardship (Wood et al., 2012; Yarbroff, Lawrence, Clouser, Davis & Brown, 2004; Skolarus et al., 2014; El-Shami et al., 2015; Runowicz et al., 2015; Cohen et al., 2016; Weaver et al., 2012; Lewis, Sheng, Rhodes, Jackson & Schover, 2012; Whitney et al., 2016).

Because of the growing population and increasing recognition of the burden a cancer diagnosis can have on an individual's quality of life as well as those of their loved ones, over the past several decades there has been a growing movement to improve post-treatment survivorship care through the release of seminal reports, national plans, guidelines and standards for clinicians and health systems, public health objectives and increased surveillance (Institute of Medicine, 2006; Institute of Medicine, 2008; CDC & LIVESTRONG Foundation, 2004; Office of Disease Prevention and Health Promotion [ODPHP], 2000; ODPHP, 2010; American College of Surgeons, 2012; National Comprehensive Cancer Network [NCCN], n.d.; Rock et al., 2012; Andersen et al., 2014; Skolarus et al., 2014; El-Shami et al., 2015; Runowicz et al., 2015; Cohen et al., 2016).

According to the National Cancer Institute (NCI) (n.d.b):

"Survivorship focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases.

Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience."

(Dictionary of Cancer Terms)



THE ROLE OF COMPREHENSIVE CANCER CONTROL

In 2010, the CDC issued six priorities for CCC programs and coalitions, one of which is to address public health needs of cancer survivors (Seeff, 2010). In a recent evaluation of National Comprehensive Cancer Control Program (NCCCP) action plans assessing the inclusion of survivorship objectives in plans from 2010 to 2013, only 38% of NCCCP action plans included survivorship objectives for all three years (Underwood, Lakhani, Rohan, Moore & Stewart, 2015). However, a majority (94%) of action plans from 2010 to 2013 included cancer survivorship for at least one year, and more than half (64%) of the plans included objectives recommended in *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* report released by the CDC & **LIVESTRONG** Foundation in 2004.

Since 2013, the Comprehensive Cancer Control National Partnership (CCCP), a coalition of eighteen of the U.S.'s leading cancer organizations, selected tobacco cessation among cancer survivors as one of three priorities. In 2015, the CDC funded six NCCCP grantees under the mechanism, "Increasing the Implementation of Evidence-Based Cancer Survivorship Interventions to Increase Quality and Duration of Life among Cancer Patients" ([CDC-RFA-DP15-1501](#)) to implement a broad set of evidence-based survivorship strategies designed to increase surveillance and community/clinical linkages. CDC stated within the request for proposals: "Together, these strategies help to specifically identify and characterize the survivor population, and address survivor needs from diagnosis through treatment and post-treatment." (p. 5)

Cancer Survivorship Modules

Interested in reading questions asked in the cancer survivorship modules? Click on the links to view the 2009 BRFSS survey, 2010 NHIS survey and accompanying guide and estimates from the 1992 NHIS, which includes the questionnaire in the appendix.

It is clear CCC programs are committed to improving the health and quality of life of patients and survivors. However, even with the increased focus on post-treatment survivorship issues, there are gaps in both quantitative and qualitative data at national and state/territory levels, which creates a challenge for CCC programs when trying to benchmark progress on meeting the needs of cancer survivors in their state or territory.

In developing CCC survivorship efforts, it is important to use both national and community-level data to inform interventions, activities and next steps. However, it is also critical to engage cancer survivors and their loved ones to inform efforts. While this report highlights findings from the existing evidence-base, it also includes the personal experiences of cancer survivors and caregivers to illustrate the impact a cancer diagnosis has, even after treatment is over.

AVAILABLE DATA AND LIMITATIONS

There are some limitations with the data summarized from the existing evidence-base. For example, when the Behavioral Risk Factor Surveillance System (BRFSS) was administered in 2009, four core cancer survivorship questions were included by “all 50 states, the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands” (Underwood et al., 2012).



The first question of the four core questions asked: “Have you ever been told by a doctor, nurse, or other health professional that you had cancer?” If the respondent said yes, they were also asked about how many times they had been diagnosed with cancer, age at diagnosis and type of cancer. Since 2009, states have also had the option to offer the full cancer survivorship module, which includes a question about whether or not a person is currently receiving treatment. In 2010, the National Health Interview Survey (NHIS) conducted the full cancer survivorship module, which was previously conducted in 1992; however, excluding those years, people have only been asked the four core cancer survivorship questions in NHIS (Buchanan et al., 2013). Therefore, some analyses conducted by researchers on national data sets will not be exclusive to individuals who are post-treatment, which is the focus of this guide.

HEALTH STATUS AND NEEDS OF CANCER SURVIVORS

Cancer Screening, Surveillance and Follow-Up Care

Cancer survivors are at an increased risk for developing second primary cancers, which is why evidence-based follow-up care is critical, including screening for new primaries and coaching survivors to make healthful choices (Wood et al., 2012). There is variation in screening practices for second primary cancers among cancer survivors.

There is little literature regarding knowledge, attitudes and beliefs about screening among cancer survivors, while this area is more thoroughly explored among groups who are at risk for a primary cancer.

Some studies find survivors to be less adherent to screening or no different compared to non-survivors, while other studies find survivors are more adherent (Bishop et al., 2010; Wilkins & Woodgate, 2008; Bellizzi, Rowland, Jeffery & McNeel, 2005; Corkum et al., 2013; Homan, Kayani & Yun, 2016). This conflicting information suggests more research is needed on how best to optimize health behaviors in survivors by subpopulation.

Furthermore, factors/barriers identified in the literature tend to look at trends based on cancer type and socioeconomic information such as race, ethnicity, education, income and health insurance status. There is little literature regarding knowledge, attitudes and beliefs about screening among cancer survivors, while this area is more thoroughly explored among groups who are at risk for a primary cancer. Yet, it should be noted, some studies have highlighted the importance of provider recommendation, which did influence cancer survivors being screened for a second primary cancer (Hawkins et al., 2015).

According to 2009 BRFSS data, for states that asked questions about cancer screening as part of the survivorship questions, authors found of those asked, 75.1% of cancer survivors had participated in colorectal cancer screening, with 77.9% of men and 73.1% of women screened for colorectal cancer (Underwood et al., 2012). Nearly eighty percent (79.4%) of female survivors had received a cervical cancer screening and 80.4% had received a mammogram.

It is also important for cancer survivors to participate in and receive regular coordinated surveillance and appropriate follow-up care. Cancer survivors can experience poorer health-related quality of life (HRQOL) compared to those who have never had a cancer diagnosis (Weaver et al., 2012). In an analysis of 2010 NHIS data, authors found “poor physical and mental HRQOL were reported by 24.5% and 10.1% of survivors, respectively, compared to 10.2% and 5.9% of adults without cancer (both p<0.0001). This represents a population of approximately 3.3 million and 1.4 million U.S. survivors” (Weaver et al., 2012). Compounding this, studies find variation in adherence by cancer type and socioeconomic factors. ***Survivors with lower socioeconomic status (SES) did not receive the same regular surveillance and follow-up care compared to survivors with higher SES*** (Advani et al., 2014; Earle & Neville, 2004; Palmer et al., 2015; Rolnick et al., 2005).



CAREGIVERS

The NCI states:

"Approximately 1.6 million new cases of cancer are expected to be diagnosed in the United States in 2016. Many patients diagnosed with cancer will eventually require support from a family caregiver. In fact, family caregivers form the foundation of the health care system in the United States, supporting advances in treatment such as multimodality treatment protocols given in outpatient and home settings." (Family Caregivers in Cancer Overview, 2016)

Yet, a review article from a recent two-day meeting co-sponsored by the NCI and the National Institute of Nursing Research reported that there is limited data about the experiences of cancer caregivers and particularly caregivers of post-treatment cancer survivors (Kent et al., 2016). For example, in 2009, an optional Caregiver module was developed for BRFSS. Data collection through this module does offer some insight into the needs of individuals who identify as a caregiver within the past 30 days; however, the needs of caregivers of post-treatment cancer survivors may not be fully captured.

In addition, available data is not fully representative of caregivers and much of the existing data tends to look at individuals who provide care to people with chronic illnesses, including cancer (Kent et al., 2016). However, we do know a cancer diagnosis can have a significant impact on caregivers (Kim & Given, 2008). ***In a study that specifically looked at the impact of a cancer diagnosis of post-treatment cancer survivors and their caregivers, caregivers reported lower quality of life, lower levels of social support and family hardness and a greater fear of cancer recurrence compared to survivors*** (Mellon, Northouse & Weiss, 2006).

Qualitative studies with caregivers at different points in the continuum reveal challenges with the practical and emotional aspects of care, a sense of helplessness and other emotional or psychosocial distress (Mosher et al., 2016; Trudeau-Hern & Daneshpour, 2012). From the Mosher et al. study, when discussing challenges one caregiver stated: "I'd say dealing with the sexual relations. That's hard because we were always really active before, so that is probably the biggest challenge." Another caregiver said:

"He...would say things like - 'I'm done'...And I just felt like he had no hope, had given up. And that, I mean, it just took everything. I would say that zapped my energy...That made me just really, really down. And yet I tried not to show it and I tried to be [positive]." (p. 2021).

Similar needs were identified in the Trudeau-Hern & Daneshpour study, with a male caregiver stating, "nobody cares for the caregiver." "There is lots of support for the patient, but nothing for the caregiver." Another stated, "no one should do this alone; one person may have cancer, but the spouse is also dealing with it" (2012).



Tobacco Use

Tobacco use continues for many people, even after a cancer diagnosis. Using NHIS data, the NCI estimates that between 2003-2012, 35.3% of cancer survivors between the ages of 18-44 were smokers and 22.6% of cancer survivors between the ages of 45-64 were current smokers, which is higher compared to the respective age groups in the general U.S. population during this timeframe (22.7% and 21.4%) (2015b). Yet, rates of smoking vary across survivors. Data from the 2010 BRFSS revealed that the percentage of breast cancer survivors that currently smoked (10.3%) was much lower compared to all other female cancer survivors (20.8%) (Homan et al., 2016) even after adjusting for sociodemographic characteristics.

The NCI estimates that between 2003-2012, 35.3% of cancer survivors between the ages of 18-44 were smokers, which is higher compared to their respective age groups in the general U.S. population during this timeframe (2015b).

Of particular note, in an analysis of 2009 BRFSS data, authors found cancer survivors who had health insurance were less likely to currently smoke compared to survivors who did not have health insurance (Burcu, Steinberger & Sorkin, 2016). For survivors who had health insurance, but currently smoked, barriers to care, such as cost to see a provider or no regular care provider, contributed to lower cessation rates.

However, providers also cite barriers to encouraging tobacco cessation among cancer survivors. In a 2012 online survey, which was open to all American Society for Clinical Oncology (ASCO) members (Warren et al., 2013), authors found that providers regularly ask their patients about tobacco use (90%) and advise quitting (84%), and most (87%) believe cessation should be part of the standard of care. However, 45.8% of providers felt they did not have adequate training in tobacco cessation interventions and 75.3% felt providers need more training in assessing tobacco use and implementing cessation interventions. Common barriers to tobacco cessation interventions cited by respondents were the patients' resistance to efforts and the inability to achieve cessation among patients. In 2015, the National Comprehensive Cancer Network [released smoking cessation guidelines](#) targeted to oncology providers.

Healthy Weight

The NCI estimates from 2003-2012, 29.2% of cancer survivors 18 and older were obese, which is similar to the general population (26.7%) during that time (NCI, 2015b). Trends from the 2009 BRFSS were similar with 27.5% of cancer survivors reporting being obese (Underwood et al., 2012). In the analysis of the 2010 BRFSS cancer survivorship modules, authors also found similar trends of obesity with 26.6% of breast cancer survivors reporting being obese and 29.1% of all other female cancer survivors reporting being obese (Homan et al., 2016).

Physical Activity

In the 2009 BRFSS, 31.5% of survivors reported no leisure-time physical activity within the past 30 days (Underwood et al., 2012) compared to 2012 NCI estimates that 38.8% of survivors, 18 years and older, report no physical activity during leisure time (2015b). Similarly, 2010 BRFSS data showed 34.1% of breast cancer survivors and 32.7% of all other female cancer survivors reported no physical activity in the last 30 days (Homan et al., 2016). Furthermore, breast cancer survivors were significantly less likely to engage in physical activity compared to women with no cancer history (AOR=0.73; 95% CI, 0.59-0.90). Finally, in a recent study, using NHIS Data (1997-2010), authors examined cancer survivors who met recommended physical activity levels in all 50 states and the District of Columbia (Tannenbaum et al., 2016). At a national level, the study found only "32% of cancer survivors [met] age adjusted [physical activity] recommendations." Similarly, at the state level, only one in three cancer survivors met recommended levels in 31 states.

FINDING SUPPORT THROUGH PHYSICAL ACTIVITY



LaWanda's Experience

LaWanda is a Stage II-A, Triple Negative breast cancer survivor

"The results came back that I was triple negative, and for those who are unfamiliar with that, triple negative is one of the more aggressive types of breast cancer and me being a black American it's more likely for me and also Hispanics to have triple negative breast cancer. I'm not one to do a lot of therapy or to go to a lot of sessions with a group who has gone through the same thing as me, I've never been that type of person - I needed something more to motivate me.

I had a couple of weeks left of radiation and I found out about a program called Healing with Basketball that was done where I work. It was a group of all breast cancer survivors - whether we had recently finished treatment or we were a few years out from treatment. We sat in a group, talked about how we felt, went through the goals of the day and then we started exercising. We did warm-ups, we learned the fundamentals of basketball, we had fun. We laughed and joked - no one cried-unless it was crying from laughing so much.

We might have come in the door feeling down and sad, dealing with the fact that we'll be cancer patients for the rest of our lives, even though we're survivors, we're still cancer patients. Once we do walk out the door and there is no more treatment, we need to know there is something else for us to do, someplace else to go, so we can continue with our after care."

Psychosocial Concerns

Cancer survivors report a number of psychosocial concerns during and after treatment, including, but not limited to: concerns about fertility, fear of cancer recurrence, employment, difficulties and financial challenges, changes in body image, communicating with family and friends, changes in relationships and how to make lifestyle changes (Deshpande, Braun & Meyer, 2015; Crist & Grunfeld, 2013; Whitney et al., 2016; Yarboff et al., 2016; Warner et al., 2016; Funk, Karnell & Christense, 2012; Rohan, Boehm, Allen & Poehlman, 2016; Lewis et al., 2012; Valdivieso, Kujawa, Jones & Baker, 2012). **Furthermore, cancer survivors typically report higher levels of depression and anxiety compared to the general population** (Mitchell, Ferguson, Gill, Paul & Symonds, 2013; Zhao et al., 2014). Long-term cancer survivors are also more likely to report higher use of mental health services and related expenditures compared to people with no history of cancer (Li, Li, Forsythe, Lerro & Soni, 2014).

VOICES OF SURVIVORS

Excerpt from Roberto Martinez's essay: Prostate Cancer Treatment Changed My Attitudes and Behaviors Concerning Sex (Pearlman, 2013)

"In the days after my prostatectomy, I went to a gay male prostate cancer support group to help sort out my thoughts, and most days discussions centered on disease and its cure. But after a relatively short period of time, I was most interested in focusing on the emotional dimensions of my sexual future; perhaps it was because, like many in this community, I had a close relative with the disease. That my sexuality was so important to me made me painfully aware of how my father's experience with prostate cancer must have been. In the months after my surgery, I met many men who had the same consequences with their prostate surgery as my father had. His operation in the late '80s predated today's nerve-sparing techniques and he suffered from total impotence for the last fifteen years of his life. In the group, men would speak of their own struggles with impotence; and in their anger and frustration, I heard my own father speaking to me from a world beyond." (p. 245)

To read Roberto's full essay and other essays from survivors about the impact of a prostate cancer diagnosis please read: *What Every Gay Man Needs to Know about Prostate Cancer: The Essential Guide to Diagnosis, Treatment & Recovery*.

In an analysis of 2010 BRFSS data from six states that used both the Anxiety and Depression Module and Cancer Survivorship Module, authors were able to compare the prevalence of depression among cancer survivors compared to non-survivors and identified potential factors that put survivors at risk for depression (Zhao et al., 2014). Cancer survivors were more likely to experience depression compared to non-survivors (PR=1.66, 95% CI=1.42-1.94). There was variation by cancer diagnosis, for example, women with reproductive cancers and adults with melanoma and gastrointestinal cancers were more likely to report experiencing depression compared to other survivors. Other factors that contributed to a survivor being more at risk for depression included "cancer diagnosis within a year, being in

'other' racial/ethnic group, divorced, separated, widowed, or never married, current or former smoker, or having histories of diabetes, disability, or depression" (Zhao et al., 2014).

What is Palliative Care?

The Commission on Cancer (CoC) defines palliative care as:

"Not simply hospice care. Palliative care refers to patient- and family-centered care that optimizes quality of life and end-of-life care. The availability of palliative care services is an essential component of cancer care, beginning at the time of diagnosis and being 'continuously available' throughout treatment, surveillance, and when applicable, during bereavement. A multidisciplinary team of physicians, nurses, mental health professionals, social workers, and spiritual counselors provide palliative care services." (p. 53)

Examples of palliative care include: "Pain and non-pain symptom management; continuity of care across a range of clinical settings and services; attention to spiritual comfort; psychosocial support for patients and families" (American College of Surgeons, 2015). The 2016 CoC Cancer Program Standard 2.4 requires "palliative care services [be] available to patients either on-site or by referral" for cancer program accreditation.

Financial Impact

A cancer diagnosis can lead to both short- and long-term financial impacts on the individual and family (Guy et al., 2013; Hoffman, McCarthy, Recklitis & Ng, 2009; Kent et al., 2013; Whitney et al., 2016; Yarboff, et al., 2016, Lee & Salloum, 2016). In an analysis of 2010 NHIS data, authors examined the financial impact of a cancer diagnosis and its treatment (Kent et al., 2013). Respondents included in the analysis had not received treatment for cancer within the last 12 months. Respondents who identified as a racial or ethnic minority survivor were more likely to report financial problems related to cancer compared to non-Hispanic white survivors. Furthermore, survivors who were less than 40 or between the ages of 40-64 at diagnosis were more likely to report financial hardship compared to survivors who were more than 65 years old. Survivors who underwent chemotherapy, radiation or had a recurrence of more than one primary cancer were also more likely to report a financial impact because of cancer.

A cancer diagnosis can lead to both short- and long-term financial impacts on the individual and family.

When authors compared all survivors who reported financial problems to survivors who did not, and controlled for other variables such as race/ethnicity, SES and education, they found ***survivors who reported financial problems were significantly more likely to delay medical care*** (18.3% vs. 7.4%; p<0.0001). Furthermore, some of these individuals were more likely to forgo medical care altogether. Table 1 illustrates the percentage of survivors who forwent

care because of cost, comparing survivors who reported financial hardship and those who did not.

Table 1: Cancer Survivors Forgoing Care due to Financial Hardship (n=1556) (Kent et al., 2013)

Area of Care Forgone	Survivors Reporting Financial Hardship	Survivors Not Reporting Financial Hardship	P-Value
Dental	20.0%	8.3%	p < .0001
Overall Medical	13.5%	5.1%	p < .0001
Eyeglasses	13.7%	5.9%	p < .0001
Prescription Medications	13.8%	7.7%	p=0.001
Mental Health	9.4%	7.1%	p=0.03

In addition to delaying or forgoing medical care, adult cancer survivors, particularly those who are between the ages of 18-64 years old, are more likely to not work full time, miss work more frequently due to health impact or not be employed (Guy et al., 2013; Moran, Short & Hollenbeck, 2011; Whitney et al., 2016; Zheng et al., 2016).

Furthermore, in a recent analysis of the 2011 Medical Expenditure Survey and the 2010 NHIS survivorship supplement, authors found 17.2% of post-treatment survivors reported experiencing some sort of financial difficulty, such as, not able to pay medical bills, debt or bankruptcy and 24.8% had financial worry (Whitney et al., 2016). Also, when comparing survivors, both in treatment and not, who were less than 65 years old to those who were 65 or older, younger survivors had statistically significant differences ($p<0.05$) in the percent that reported any financial difficulty (27.3% vs. 10.0%) and any financial worry (39.3% vs. 19.1%). In predicting which survivors are more likely to experience financial difficulties, Whitney et al., state:

"We identified substantial disparities in financial difficulties, with survivors who were of race/ethnicity other than white, non-Hispanic, had incomes <400% of [Federal Poverty Level] FPL, who lived in non-metropolitan areas, or who reported good/fair/poor health at increased risk among those in active treatment, as well as survivors with good/fair/poor health status and between 12 and 16 years of education among those less than 65 years at age of interview. The disparities we identified persisted despite controlling for insurance, suggesting that survivors in these subgroups experience financial problems even when insured. ***The disparities we identified for financial difficulties are congruent with previous studies, which have consistently identified predictors of both financial hardship and productivity losses as younger age, minority race/ethnicity, lower income, and active treatment status/recent diagnosis***". (p. 246-247)

SYSTEMS LEVEL APPROACHES TO ADDRESS NEEDS FOR POST-TREATMENT CANCER SURVIVORS

Survivorship Care Plans

Cancer is a disease that has existed for thousands of years, yet the impact of the disease and its treatment has not always been known, talked about or acknowledged publicly. As poignantly illustrated in Dr. Mukherjee's book, *The Emperor of All Maladies*:

"In the early 1950s, Franny Rosenow, a breast cancer survivor and cancer advocate called the *New York Times* to post an advertisement for a support group for women with breast cancer. Rosenow was put through, puzzlingly, to the society editor of the newspaper. When she asked about placing her announcement, a long pause followed. 'I'm sorry, Ms. Rosenow, but the *Times* cannot publish the word *breast* or the word *cancer* in its pages. 'Perhaps,' the editor continued, 'you could say there will be a meeting about diseases of the chest wall.' Rosenow hung up, disgusted." (p.26-27)

If a person did survive cancer treatment, which focused on treating only the disease, there was an expectation that the patient would just "move on" after treatment. Yet, for many people impacted by cancer that was not enough. Cancer advocates, advocacy groups, caregivers, health care providers and many others have worked and continue to work to improve patients' experience across the cancer care continuum, including post-treatment. ***Part of the movement in improving post-treatment care was the development of the survivorship care plan prepared by the oncology care team, which includes both a treatment-summary and follow-up care instructions addressing physical effects and psychosocial concerns.*** This tool can then be used by the patient in the management of their own care as well as the patient's primary care provider to help guide the coordination of care moving forward.

A number of organizations have developed survivorship care plan templates and have made recommendations about what should be included in a survivorship care plan. The American Society of Clinical Oncology (ASCO) is one of these organizations and has defined minimum data elements that must be included in a survivorship care plan (Mayer et al., 2014). To move survivorship care plans into practice the Commission on Cancer (CoC) requires



that accredited programs provide a survivorship care plan that includes at least the data elements as defined by ASCO to patients who have completed cancer treatment with curative intent (American College of Surgeons, 2015). Data elements include providing a list of national and local resources to survivors to address psychosocial needs. Also, "a general statement emphasizing the importance of healthy diet, exercise, smoking cessation, and alcohol use reduction may be included; statements may be tailored if particularly pertinent to the individual" (Mayer et al. 2014).

For the implementation of survivorship care plans, the CoC is taking a stepwise approach: Accredited sites must provide survivorship care plans to at least 25% of their eligible patients by the end of 2016 and to 75% of their eligible patients by the end of 2018 to maintain accreditation (American College of Surgeons, 2015). A 2013 cross-sectional survey of survivorship care plan use among cancer programs across the U.S. showed wide variation among practices (Birken, Deal, Mayer & Weiner, 2014), of particular note, there was a statistically significant relationship between the use of survivorship care plans and geographic region. Cancer programs in the northeast delivered survivorship care plans to at least 75% of their survivors 40% of the time, while programs in the West and Midwest reported meeting the threshold of 75% none of the time and programs in the South reported meeting the threshold 20% of the time.

THE LONG-TERM EFFECTS OF TREATMENT

Kristin's Experience

Kristin is a Stage III colorectal cancer survivor



"My treatment was supposed to be 12 rounds for six months, but it did go longer due to the toll that it took on my body. The side effects that I experienced and continue to experience are chemo-brain, neuropathy in my feet and then just general fatigue. My life and activities after completing treatment have changed a lot also. Physically, I get tired, even after working a day at the office.

It's hard to walk on uneven ground such as grass, gravel or sand. And mentally is probably the hardest. There's been bouts of depression and of course the anxiety of the return of cancer. I just wanted my life to be normal after cancer, but definitely having to live with a new normal."

Cancer Survivorship Guidelines for Providers

In recent years, guidelines have been developed to help guide providers in the care of post-treatment cancer survivors (NCCN, n.d., Rock et al., 2012; Andersen et al., 2014; Skolarus et al., 2014; El-Shami et al., 2015; Runowicz et al., 2015; Cohen et al., 2016). Guidelines address recommendations for screening, surveillance, health behaviors and psychosocial care. To put guidelines into practice, the CoC is requiring that accredited facilities screen for distress at least once at a pivotal visit, which could include a post-treatment follow-up visit (American

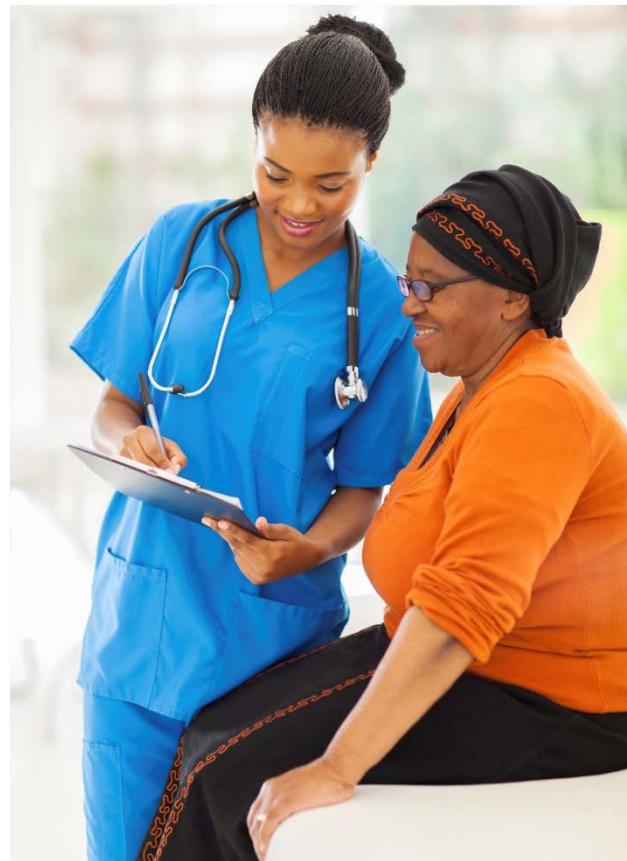
College of Surgeons, 2015). When a patient/survivor is screened for distress, accompanying resources to help meet needs identified must be made onsite or via referral. Furthermore, guidelines released by the American Cancer Society for primary care clinicians recommend screening cancer survivors for distress. In an analysis of 2005 and 2010 NHIS data, authors found individuals with cancer continue to experience psychological distress, even with increased attention to providing psychosocial care (Whitney, Bell, Bold & Joseph, 2015). In addition, individuals who had cancer along with another chronic disease reported having more needs met; however, for individuals with cancer and no additional chronic disease, unmet mental health needs remained the same (Whitney et al., 2015).

DISPARITIES IN POST-TREATMENT CANCER SURVORSHIP

As across the cancer care continuum, disparities in post-treatment survivorship care also exist (Blinder & Griggs, 2013). The information presented in this section, like the rest of this guide, only provides a snapshot of the current state of post-treatment cancer survivorship among medically underserved/vulnerable populations, with particular focus on racial/ethnic minorities, people who identify as lesbian, gay, bisexual, transgender or queer (LGBTQ), rural populations and adolescents/young adults. While this guide is taking a population-level view, it is important to remember a survivor's individual identity may intersect within these and other populations not described here. Use these snapshots to help guide additional areas of inquiry among your coalition as you think about meeting the needs of all post-treatment cancer survivors.

Racial and Ethnic Minorities

Racial and ethnic minority survivors are more likely to experience barriers to follow-up care and surveillance, indicate poorer patient provider communication, indicate not being prepared for side effects after treatment, report more unmet needs, not have access to culturally and linguistically appropriate resources and report lower quality of life (Palmer et al., 2015; Salz, Woo, Starr, Jandorf & DuHamel, 2012; Alanee et al., 2016; Palmer et al., 2014; Torres, Dixon & Richman, 2016; Haynes-Maslow, Allicock & Johnson, 2016; Le et al., 2015; McNutly, Kim, Thurston, Kim & Larkey, 2016; Wen, Fang & Ma, 2014; Yanez, Thompson & Stanton, 2011, Pinherio et al., 2016).



In order to better understand current research and identify gaps in research in the area of coping with breast cancer among women of color in the U.S., Yoo, Levine & Pasick (2014) conducted a systematic review of the literature, including quantitative and qualitative studies, spanning from 1980-2012. Of the 120 studies identified, 33 met inclusion criteria. Most studies focused on African American women, yet some studies did include Latinas and Asian American women, with Asian American women being the least represented group. Furthermore, most research focused on point of diagnosis through treatment, with less focus on post-treatment survivorship. Yet, commonalities did emerge across studies included in the review.

Yoo et al. (2014) found:

... positive forms of coping such as self-distraction, venting, and positive reappraisal were more common among women of color than white women. More negative forms of coping such as emotional suppression, wishful thinking, and behavioral disengagement were also more common among women of color than among whites. Negative forms of coping...were more likely to be associated with worse outcomes for women across race and ethnicity. Women who used these negative forms of coping experienced increased levels of distress and poorer survival. (p.820)

Furthermore, based on the evidence, Yoo et al. (2014) concluded:

...women of color tend to cope with breast cancer differently than white women. Moreover, the finding that coping was often dependent on how well significant others responded to the situation suggests that coping is a relational process centered on the ways that a woman's illness impacts those closest to her. (p.820)

Across studies, authors also identified the importance of spirituality as an important coping strategy among women of color, Yoo et al. (2014) state:

Positive spiritual and religious coping reduces distress and improves quality of life and physiological functioning. These studies contribute to a growing recognition of the importance of spirituality... and suggest coping strategies that could be enhanced and disseminated among women of different backgrounds. (p.820)

The importance of spirituality also emerged as one theme in a recent systematic review of cancer survivorship services for indigenous peoples. Studies were also limited with an initial 292 citations identified and of these only 17 articles met inclusion criteria. All articles were from the United States and only seven focused on the needs of survivors, the remainder focused on presenting findings from interventions (Cavanagh, Wakefield, McLoone, Garvey & Cohn, 2016). American Indians, Alaska Natives and Native Hawaiians participated in some studies and some studies included both survivors and caregivers; however, throughout most studies the term survivor was not clearly defined. Regardless, important common themes emerged from the studies, including "...the importance of family support, the negative effect of community stigmatization, possible fatalistic attitudes towards cancer, and the importance

of spirituality in both coping with, and understanding, their experience." In the interventions reviewed, by Cavanagh et al. (2016), survivors were involved in the development of them and indicated:

...a strong need for family to be present and involved in follow-up care and support groups. The inclusion of spiritual activities in survivorship programs was another need reported by survivors [and] the need for programs to inform others in the community about cancer to minimize the stigma associated with cancer. (p. 338)

People Who Identify as Lesbian, Gay, Bisexual, Transgender or Queer

People who identify as lesbian, gay, bisexual, transgender or queer (LGBTQ) face a host of health disparities, including cancer. This population is sometimes also referred to as sexual and gender minorities. At a national, population level the NCI's Surveillance Epidemiology and End Results (SEER) database has not historically collected data on sexual orientation or gender identity (SOGI), which makes it "impossible for researchers to use this database to estimate the incidence and prevalence of cancer among sexual and gender minorities" (Institute of Medicine, 2011).

Some states have included SOGI questions in their BRFSS (Centers for Disease Control and Prevention, 2016) or in other state or county surveys (Institute of Medicine, 2011). Yet, only a few researchers have primarily led the way in gathering of data about the cancer burden among LGBTQ people and identifying the disparities that exist.

While a dearth of data exists about cancer incidence and prevalence among LGBTQ people there is even less about the needs of LGBTQ post-treatment cancer survivors (Quinn et al., 2015). In an overview of literature available on "seven cancer sites that may disproportionately affect...LGBTQ populations," authors were unable to identify any studies that focused specifically on survivorship through the lens of sexual orientation/gender identity in anal, cervical, endometrial, colorectal or lung cancer and only limited studies in breast and prostate cancer (Quinn et al., 2015). In an analysis of 2009 BRFSS data among five states that included SOGI questions and asked the four core cancer survivorship questions, authors compared men who identified as heterosexual cancer survivors and men who identified as gay cancer survivors (Kamen et al., 2014). Authors found gay male cancer survivors were more likely to experience more frequent psychological distress, drank higher than the recommended amount of alcohol consumption for men and drank more frequently and participated less in moderate exercise (Kamen et al., 2014).

Rural Populations

Cancer survivors who live in rural areas face unique challenges such as availability of providers to address physical and psychosocial needs, transportation and lack of access to insurance options (Charlton, Schlichting, Chioreso, Ward & Vikas, 2015). Rural cancer survivors are also more likely to smoke, be less physically active, have health-related unemployment and report poorer physical and mental health and may be less likely to receive follow-up care recommendations from their provider and forgo medical care and retire early compared to urban cancer survivors (Weaver, Palmer, Lu, Case & Geiger, 2013; Schootman, Homan, Weaver, Jeffe & Yun, 2013; Palmer, Geiger, Lu, Case & Weaver, 2013; Burris & Andrykowski, 2010; Andrykowski, Steffens, Bush & Tucker, 2014; Sowden, Vacek & Geller, 2014). As with other populations highlighted here, there is a limited evidence base. For example, in a systematic review of quantitative and qualitative studies examining the psychosocial needs of cancer patients/survivors, of the 2,121 articles originally identified only 37 were able to be included in final review and of these 15 were studies conducted in the U.S., with less than half of these focused on post-treatment needs (Butow et al, 2012). However, based on the available evidence authors concluded "*...that in the area of supportive care, especially daily living needs, physical function and information and emotional support, patients may not currently be receiving such service. Such results were consistent across countries, suggesting this is a universal issue.*"

Adolescents/Young Adults

Adolescents/Young Adults (AYAs) are people who fall within the age range of 15-39. The NCI estimates that each year approximately 70,000 AYAs are diagnosed with cancer, which was roughly "six times the number of cases diagnosed in children ages 0-14" (2015a). Yet, research is limited among AYA survivors. *AYA survivors often have many unique and overlooked needs, such as issues with infertility, increased risk of developing a second primary cancer compared to those who receive a first cancer diagnosis at 40 years or older, damage to their heart, chronic medical conditions, engaging in risky behavior, lack of insurance and higher economic burden* (Soliman & Agresta, 2008; Patterson, McDonald, Zebrack & Medlow, 2015; Thai et al., 2012; Kirchoff, Lyles, Fluchel, Wright & Lesienring, 2012; Warner et al., 2016; Guy et al., 2014).

In a small, recent study examining use of follow-up care among post-treatment young adult cancer survivors in Philadelphia (Szalda et al., 2016), authors found 45% of young adults had not engaged in cancer related follow-up care in the past 12 months. Of the 55% that did participate in cancer related follow-up care, half of these individuals received care from a primary care provider. Regardless of participating in follow-up care, most (88.8%) young adults did see a primary care physician "for routine maintenance visits or acute illnesses unrelated to their cancer history or late effects in the past year" (Szalda et al., 2016). For those who saw a primary care provider for follow-up care, Szalda et al. (2016) found individuals reported:

some discussion about cancer diagnosis (36%), treatment (32%), risk for late effects (23%), and necessary screening tests to monitor for late effects (27%).² Those who were not engaging in cancer related follow-up care, but seeing a primary care provider for another reason, reported "discussing their prior diagnosis (26.7%), treatment (16.7%), risk for late effects (10%), and screening for late effects (23%) in the minority of encounters. (p.347)

INSURANCE AND CANCER CARE

According to a recent 2016 Gallup Poll, the uninsured rate for the nation is 11%, which is an all-time low. People who are low-income, racial/ethnic or sexual and gender minorities have seen gains in insurance coverage and overall there has been a large increase in adults between the ages of 18-64 covered under plans paid by themselves or a family member. Research is still emerging around the impact of the Patient Protection and Affordable Care Act (ACA). The ACA went into effect in 2010 with many of the provisions taking full effect in 2013.



Emerging research indicates the ACA has had an overall positive impact on breast cancer and colorectal cancer screening; however, colorectal cancer screening has seen less of an uptick, which could indicate the need to continue to address other existing barriers (Cooper, Kou, Schluchter, Dor & Koroukian, 2016; Richman, Asch, Bhattacharya & Owens, 2016).

In a recent analysis of insurance coverage among young adult cancer survivors, authors found an increase in survivors, ages 18 to 25, covered under the dependent provision; however, there was no change in insurance rates among survivors ages 26 to 29 years old (Parsons, Schmidt, Tenner, Bang & Keegan, 2016). Authors also state:

"...despite the high rates of insurance identified in the current study, prior research has identified decreasing rates of insurance as patients with cancer progress from active treatment to survivorship. This may result from a number of factors, including the loss of eligibility to enroll in public programs once treatment is complete, job changes, marriage, and aging off a parent's insurance policy. For public programs specifically, eligibility for the Medicaid Medically Needy Program or the Breast and Cervical Cancer Program, and therefore eligibility for Medicaid more broadly, will most likely end at the time of treatment completion and varies by state of residence. Future research will be needed to examine how the dependent insurance varies by state of residence. Future research will be needed to examine how the dependent insurance provisions can combine with public programs (i.e. Medicaid cancer provisions) or expanded insurance options under the ACA health care exchanges to ensure survivors remain consistently insured after diagnosis and have access to survivorship care services" (p. 1771)

POTENTIAL BENCHMARKS FOR COMPREHENSIVE CANCER CONTROL PROGRAMS

While we have seen great strides made across the cancer care continuum, including survivorship, it is clear based on the snapshot presented here that there is more to be done. The number of cancer survivors will rapidly increase in the next 10 years. There must be a concerted effort across systems and professions to work together to address needs of survivors and caregivers as identified in the snapshot.



Comprehensive Cancer Control (CCC) programs and coalitions are uniquely positioned to address these needs by bringing together health care administrators and providers, researchers, survivors, caregivers, advocates, community based organizations, public and private organizations and others to create change at an individual, community and systems level.

As previously described, the purpose of this report was first to present a snapshot of the current state of cancer survivorship, and then offer potential benchmarks to help guide CCC survivorship efforts to meet gaps. Benchmarks fall under the four domains outlined here:

- Surveillance and applied research
- Communication, education and training
- Programs, policies and infrastructure
- Access to quality care and services

SHARING LESSONS LEARNED

Comprehensive Cancer Control Programs and Coalitions frequently disseminate lessons learned and best practices. Two recent dissemination examples come from Michigan and Georgia, both of which involved collaborative efforts. The Michigan Cancer Consortium collaborated with several partners to develop a learning collaborative to address the implementation of survivorship care plans (GW Cancer Center Generation and Translation of Evidence (GATE), 2016). The project was successful with a resulting [survivorship care plan implementation guide](#). Findings have also been disseminated through the GW Cancer Center's [GATE repository](#) and other channels. The Georgia Cancer Control Consortium's Survivorship Working Group conducted a needs assessment in 2014 with cancer survivors to better meet the needs of survivors as set forth in the state cancer control plan. [Findings from the assessment](#) were presented at the 8th Biennial Cancer Survivorship Research Conference, June 16-18, 2016 (M. Khalaf, personal communication, September 12, 2016).

Surveillance and Applied Research

Benchmark	Potential Measure(s)
<p>Increase use of Cancer Survivorship, Sexual Orientation and Gender Identity (SOGI), Anxiety and Depression and Caregiver Modules in BRFSS concurrently</p> <p>Increase use of standardized SOGI fields collected at cancer center level so data can be pushed systematically to cancer registries</p>	<ul style="list-style-type: none"> Number of modules offered Number of years offered Number of post-treatment cancer survivors participating in modules Number of cancer caregivers participating in module Identification of cancer survivor and caregiver needs at state level Incidence, prevalence, cancer outcomes for LGBTQ patients at cancer center or state level Number of channels used to disseminate findings, such as professional conferences, white papers, publications and/or websites
Assess use of survivorship care plans	<ul style="list-style-type: none"> Percentage of oncology care providers providing a survivorship care plan to eligible patients as defined in the Commission on Cancer Standard 3.3 Percentage of post-treatment cancer survivors who have received a survivorship care plan Percentage of primary care providers who are aware of survivorship care plans Percentage of primary care providers who have used a survivorship care plan to inform follow-up care for post-treatment cancer patients in their practice Number of channels used to disseminate findings to increase evidence-base, such as professional conferences, white papers, publications and/or websites
<p>Assess current tobacco cessation efforts and potential barriers among health care practices that treat or care for cancer survivors</p> <p>Assess current tobacco status, knowledge, attitudes and beliefs about tobacco cessation and barriers to cessation among post-treatment cancer survivors</p> <p>Pilot-test and evaluate a tailored evidence-based tobacco cessation intervention based on findings or existing research</p>	<ul style="list-style-type: none"> Percentage of referrals to existing cessation services Needs assessment on how to assist health care practices to improve tobacco cessation efforts Number of channels used to disseminate findings to increase evidence-base, such as professional conferences, white papers, publications and/or websites Percentage of survivors who have attempted to quit Percentage of survivors who are aware of existing cessation services Percentage of survivors who cease tobacco use

	<ul style="list-style-type: none"> • Assessment of tobacco cessation needs of subpopulations with higher tobacco use • Ways interventions were tailored for specific subpopulations based on needs assessment • Number of channels used to disseminate findings to increase evidence-base, such as professional conferences, white papers, publications and/or websites
<p>Assess knowledge, attitudes and beliefs about cancer screening, surveillance, psychosocial needs and follow-up care among survivors</p> <p>Pilot-test and evaluate a tailored evidence-based intervention based on findings</p>	<ul style="list-style-type: none"> • Measures depend on assessment focus - recommend reviewing any academic literature and adapting a validated or previously implemented survey for your needs • Number of channels used to disseminate findings, such as professional conferences, white papers, publications and/or websites

COMPREHENSIVE CANCER CONTROL SPOTLIGHT

Examples of goals from Comprehensive Cancer Control Plans addressing survivorship

Ensure all Alaskan cancer survivors have equal access to information, and follow-up medical, rehabilitative and psychosocial services (Alaska Department of Health and Social Services, 2005)

Train and prepare health care professionals to work with cancer survivors, their families, and their caregivers (Cherokee Nation, 2010)

Provide and support education efforts for health care professionals in survivorship, palliative, and end-of-life care Delaware (Delaware Cancer Consortium, 2014)

Improve the quality of life of cancer survivors by minimizing related side effects during and following cancer treatment through rehabilitative interventions (Mississippi Partnership for Comprehensive Cancer Control Coalition, 2006)

Improve access to culturally and linguistically competent, appropriate and effective cancer prevention, education, screening, diagnosis, treatment, and survivor services (New Mexico Department of Health, 2012)

Improve cancer survivors' quality of life through services that address the physical, emotional, social and vocational challenges of survivorship (Oregon Partnership for Cancer Control, 2005)

All people living in Palau who are cancer survivors will participate in life-long follow-up care and services (Ministry of Health, 2007)

Communication, Education and Training

Benchmark	Potential Measures
Promote cancer-specific trainings/certifications to community health workers (CHWs) and patient navigators through CCC efforts	<ul style="list-style-type: none"> Number of communications sent regarding opportunities Depending on promotion channel(s) could measure: Facebook click through rate, e-mail open rate and/or number of champions engaged Number of certified CHWs and/or cancer patient navigators
Promote education and training opportunities to health care providers, with a focus on primary care providers, to increase awareness of survivorship care guidelines and survivorship care	<ul style="list-style-type: none"> Number of communications sent regarding opportunities Depending on promotion channel(s) could measure: Facebook click through rate, e-mail open rate and/or number of champions engaged Number of learning opportunities offered Number of providers educated/trained Learning outcomes based on event objectives
Provide education and training opportunities to health care providers, with a focus on primary care providers, to increase awareness of survivorship care guidelines and survivorship care	<ul style="list-style-type: none"> Number of continuing education (CE) units awarded/providers trained
Promote existing evidence-based and nationally-recommended educational resources to cancer survivors and caregivers to help address follow-up care, lifestyle, psychosocial and financial concerns	<ul style="list-style-type: none"> Depending on promotion channel(s) could measure: number of materials distributed, number of web page hits and/or Facebook click through rate, e-mail open rate and/or number of champions engaged
Develop educational resources where there are gaps to meet needs of community and promote resources	<ul style="list-style-type: none"> Number of resources developed Depending on promotion channel(s) could measure: number of materials distributed, number of web page hits and/or Facebook click through rate, e-mail open rate and/or number of champions engaged
Provide educational opportunities for survivors and caregivers to increase awareness of resources to address lifestyle, psychosocial and financial concerns through multiple channels to reach diverse and hard to reach populations	<ul style="list-style-type: none"> Number of learning opportunities offered Topics addressed through education Number of survivors and caregivers engaged/educated Learning outcomes based on event objectives

Programs, Policies, and Infrastructure

Benchmark	Potential Measures
Assess current CCC survivorship activities	<ul style="list-style-type: none"> Number of survivorship objectives included in plan each year Development of survivorship workgroup, committee or task force Number of new CCC members recruited to survivorship work group or committees, including survivors and caregivers from diverse communities Assessment of needs of high-need populations of survivors (racial/ethnic, cultural, sexual and gender minority, rural, AYA)
Share lessons learned and best practices with other CCC coalitions and stakeholders	<ul style="list-style-type: none"> Number of shared successes Number and reach of channels for dissemination Number of clicks/downloads for success story
Develop CHW or Patient Navigator Network if one does not exist	<ul style="list-style-type: none"> Number of CHW/Patient Navigators who join network Number of in-person and/or virtual activities held in a year Assessment of added value of network
Assess current certification requirements for CHWs/Patient Navigators Advocate for inclusion of required CE units in cancer survivorship	<ul style="list-style-type: none"> Number of CE hours required for maintenance of certification in cancer survivorship
Assess current funding mechanisms for CHWs/Patient Navigators Advocate for sustainability approaches for CHWs/Patient Navigators	<ul style="list-style-type: none"> Current mechanisms in place Measures could include: Number of coalitions joined advocating for similar issue, number of letters of support sent, number of advocacy days conducted, number of bills introduced, number of co-sponsors, submission of Medicaid State Plan Amendment to support CHWs as reimbursed providers, use of data to inform health plan reimbursement algorithms (e.g. inclusion of CHW and patient navigation services in bundled payments)

Use evidence-based approaches to meet needs of medically underserved/vulnerable populations	<ul style="list-style-type: none"> ● Assessment of target population needs ● Number of programs implemented or supported by coalition ● Target populations served ● Outcomes evaluation varies by program
Use evidence-based approaches to increase physical activity and healthy eating habits among cancer survivors	<ul style="list-style-type: none"> ● Number of programs implemented or supported by coalition ● Outcomes evaluation varies by program
Use evidence-based approaches to increase psychosocial wellbeing among survivors	<ul style="list-style-type: none"> ● Number of programs implemented or supported by coalition ● Outcomes evaluation varies by program
<p>Assess current CE requirements for physicians, physician assistants, nurses and nurse practitioners</p> <p>Advocate for inclusion of required hours in cancer survivorship</p> <p>Advocate for inclusion of required hours in cultural and linguistic competency (CLC)</p>	<ul style="list-style-type: none"> ● Number of CE hours required for medical practice ● Number of CE hours required in cancer survivorship ● Number of CE hours required in CLC
<p>Assess system-level barriers to screening, surveillance, follow-up care, behavioral health, mental health, palliative care, psychosocial and rehabilitation services</p> <p>Advocate for solutions to address identified barriers</p>	<ul style="list-style-type: none"> ● Key barriers identified ● Number of channels used to disseminate findings to increase evidence-base, such as professional conferences, white papers, publications and/or websites
<p>Assess current fair employment laws/regulations for people diagnosed with cancer at state/territory and municipal levels</p> <p>Advocate for increased fair employment regulations, including employers who employ less than 15 people, for people diagnosed with cancer</p>	<ul style="list-style-type: none"> ● Number of laws/regulations in place ● Depending on outcome of assessment, could measure: Number of decision makers educated about impact of fair employment laws/regulations on cancer survivors, number of coalitions joined advocating for similar issue, number of letters of support sent, number of advocacy days conducted, number of bills introduced, number of co-sponsors ● New legislative protections passed

<p>Assess current state/territory regulations of private health insurance plans</p> <p>Advocate for increased coverage of behavioral health, mental health, psychosocial support, palliative care and rehabilitation services</p> <p>Advocate for increased coverage of uninsured or underinsured cancer survivors</p>	<ul style="list-style-type: none"> ● Percentage of coverage mandated by regulations ● Depending on outcome of assessment, could measure: Number of decision makers educated about impact of increased coverage, on cancer survivors, number of coalitions joined advocating for similar issue, number of letters of support sent, number of advocacy days conducted, number of bills introduced, number of co-sponsors ● New legislative protections passed
<p>Support local health departments in implementing survivorship activities into their programs</p>	<ul style="list-style-type: none"> ● Number of activities delivered focusing on post-treatment cancer survivors and caregivers ● Number of resources distributed ● Number of cancer survivors and caregivers reached
<p>Assess awareness and availability of support services for cancer survivors and their caregivers</p>	<ul style="list-style-type: none"> ● Number and type of local community support services available ● Percentage of cancer survivors and caregivers aware of available local and national resources ● Number of and frequency of channels used by CCC programs and coalitions to promote support services
<p>Assess current partnership with Commission on Cancer (CoC) site(s) to identify synergistic opportunities to advance coalition and cancer program goals</p>	<ul style="list-style-type: none"> ● Increase in screening and prevention programs offered by CoC site(s) every year through CCC activities ● Participation in the triannual Community Needs Assessment as part of the CoC Patient Navigation Process Standard ● Increase in number of resources available for referral integrated within electronic health record (EHR) such as tobacco cessation program or psychosocial support services
<p>Assess current partnerships with other oncology care and primary care providers, including but not limited to private practices, health systems and Federally Qualified Health Centers to identify synergistic opportunities to advance coalition and cancer program goals</p>	<ul style="list-style-type: none"> ● Increase in screening and prevention programs offered by site(s) every year through CCC activities ● Increase in number of resources available for referral integrated within EHR such as tobacco cessation program or psychosocial support services

Access to Quality Care and Services

Benchmark	Potential Measures
Support linkages to follow-up care for cancer survivors	<ul style="list-style-type: none"> Number of survivors reached through Patient Navigators/CHWs Number of survivors who engage in follow-up care services with support from Patient Navigators/CHWs
Support linkages to existing tobacco cessation services for cancer survivors	<ul style="list-style-type: none"> Number of survivors reached through Patient Navigators/CHWs Number of survivors who engage in tobacco cessation services with support from Patient Navigators/CHWs
Support linkages to psychosocial services	<ul style="list-style-type: none"> Number of survivors reached through Patient Navigators/CHWs Number of survivors who engage in psychosocial services with support from Patient Navigators/CHWs
Support linkages to cancer screening services for cancer survivors	<ul style="list-style-type: none"> Number of survivors reached through Patient Navigators/CHWs Number of survivors who engage in cancer screening services with support from Patient Navigators/CHWs
Support enrollment of eligible post-treatment cancer survivors into State/Federal Health Insurance Exchange	<ul style="list-style-type: none"> Number of survivors reached through Patient Navigators/CHWs Number of survivors who enroll in State/Federal Exchange with support from Patient Navigators/CHWs

RESOURCES TO HELP ACHIEVE BENCHMARKS

Below are some recommended resources to help you in setting goals and choosing benchmarks, organized by the *National Action Plan* domains.

Surveillance and applied research:	
Communication, education and training:	
Programs, policies and infrastructure:	
Access to quality care and services:	
Academy of Oncology Nurse & Patient Navigators Certification Offers a general oncology navigator certification examination, which is applicable for patient navigators and nurse navigators. It provides formalized education for this professional specialty and is meant to establish baseline competencies for navigators (Academy of Oncology Nurse & Patient Navigators, n.d.).	
Agency for Healthcare Research and Quality (AHRQ) Data Sources Offers online, searchable databases on topics such as the accessibility of care, the use of health care, health care disparities and health care quality, and these data are often available by state (Agency for Healthcare Research and Quality [AHRQ], 2015b).	
AHRQ Clinical-Community Linkages Features examples of successful clinical-community collaborations and includes more resources for linking clinical practices and community organizations, including publications on evidence-based strategies of partnerships and tools like roadmaps, toolkits and measure sets to aid researchers and providers to create and evaluate clinical-community relationships (AHRQ, 2015a).	
AHRQ Health Care Innovations Exchange Provides health professionals and researchers the opportunity to share and learn about evidence-based innovations and tools suitable for a range of health care settings and populations through a searchable database of innovation profiles, quality measurement tools and articles and resources (AHRQ, n.d.).	

[AHRQ Self-Management Support](#)

A variety of resources to help primary care clinicians and teams learn about and implement self-management support (AHRQ, 2015c). These resources assist clinicians in defining and sharing the roles and responsibilities of the practice care team, using tools and techniques to improve self-management support, learning skills that support patient self-management and selecting and using understandable, actionable educational materials.



[Alaska Cancer Survivorship Resource Plan 2013](#)

The Alaska Comprehensive Cancer Partnership developed this resource plan with a focus on the unique challenges and needs faced by Alaska cancer survivors (Alaska Department of Health and Social Services, 2013). This resource could be used as a model by other programs.



[American Cancer Society](#)

Provides a number of support services including online support and educational materials regarding staying active and healthy after cancer treatment, dealing with the possibility of cancer recurrence and improving quality of life.



[American Cancer Society care guidelines on colorectal, head and neck and prostate cancer survivorship; American Cancer Society/American Society of Clinical Oncology breast cancer survivorship care guidelines](#)

[care guidelines](#) to help primary care clinicians and other health care professionals provide comprehensive clinical follow-up care for adult post-treatment head and neck, breast, colorectal and prostate cancer survivors, including follow-up care recommendations for surveillance for cancer recurrence, screening for second primary cancers, assessment and management of physical and psychosocial long-term and late effects of the cancer and its treatment, health promotion and care coordination (ACS, n.d.a; ACS, n.d.b; ACS, n.d.c). ACS developed and published its breast cancer survivorship care guidelines in conjunction with the American Society of Clinical Oncology (ACS & American Society of Clinical Oncology [ASCO], n.d.).



[American Cancer Society's Nutrition and Physical Activity Guidelines for Cancer Survivors](#)

Guidelines on nutrition and physical activity during the cancer care continuum based on expert evaluation of scientific evidence and best clinical practices (ACS, n.d.d).



[American College of Surgeons Quit Smoking Before Surgery Program](#)

Provides resources to implement a smoking cessation program in surgical practices, including a Continuing Education e-learning program on how to implement and code for a smoking cessation program and accompanying patient education resources, relevant research and more (American College of Surgeons, n.d.b).



[American Indian Cancer Foundation](#)

Raises awareness of and provides resources to address the specific needs of American Indian cancer survivors and their caregivers, as these survivors face unique burdens accessing care, treatment and resources (American Indian Cancer Foundation, n.d.).



[American Society of Clinical Oncology \(ASCO\) Guidelines](#)

Develops and publishes a variety of clinical practice guidelines that address either specific clinical situations (i.e., diseases) or specific uses of approved medical products, procedures or tests (i.e., modalities). These guidelines address topics such as gastrointestinal and lung cancers, assays and predictive markers and patient and survivorship care (ASCO, n.d.a).



[ASCO Resources on Tobacco Cessation & Control](#)

Provides resources for oncology care providers and patients to aid in tobacco cessation, including guidelines for engaging in tobacco cessation efforts, from both the provider and patient perspectives, and related publications. (ASCO, n.d.b).



[Cancer and Careers](#)

Empowers people with cancer to thrive in their workplace through support and education to navigate the practical and legal challenges that follow a diagnosis for survivors as well as health care professionals (Cosmetic Executive Women Foundation/Cancer and Careers, n.d.).



[Cancer Control P.L.A.N.E.T.](#)

Provides evidence-based tools including state cancer profiles, existing research and research-tested program materials and guides for evaluation. It also hosts an interactive community for discussion, learning and enhanced collaboration (NCI, n.d.a).



[Cancer Legal Resource Center](#)

Offers "information and education about cancer-related legal issues to the public through its national telephone assistance line. The CLRC also conducts national education and outreach programs for community groups, employers and healthcare professionals and is actively involved in community activities to raise public awareness of cancer-related legal and public policy issues" (Disability Rights Legal Center, n.d.).



[Cancer Support Community](#)

A professionally-led nonprofit network of cancer support that offers social and emotional support for people impacted by cancer through a network of affiliates across the U.S., online and over the phone (Cancer Support Community, n.d.).



[Cancer Survivorship Care Plans: A Toolkit for Health Care Professionals](#)

Triage Cancer and the California Dialogue on Cancer (CDOC) have partnered to publish a toolkit for health care professionals to increase their awareness and understanding of survivorship care plans and increase the use of survivorship care plans. It includes sections on guidelines for, templates of and implementation challenges regarding survivorship care plans, among others (California Department of Public Health, Comprehensive Cancer Control Program, Survivorship Care Plan Advisory Group, & Triage Cancer, 2015).



[Cancer Survivorship E-Learning Series for Primary Care Providers](#)

The E-Learning Series is a collaboration between the American Cancer Society and the GW Cancer Center funded through a 5-year cooperative agreement with the Centers for Disease Control and Prevention. This program is intended for primary care providers, but is open to anyone who provides care to cancer survivors. The course covers late and long-term effects of treatment for a variety of cancer types. Continuing education credits offered at no cost.



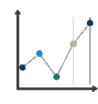
[CancerCare](#)

Offers "free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer." Its comprehensive services include counseling and support groups (both remotely and in-person), educational workshops, publications and financial assistance (CancerCare, n.d.).



[CDC's Behavioral Risk Factor Surveillance System \(BRFSS\)](#)

BRFSS collects data regarding health-related risk behaviors, chronic health conditions and use of preventive services for more than 400,000 U.S. adults each year. It includes core sections pertinent to cancer control such as breast, cervical, prostate and colorectal cancer screening, tobacco use, exercise and health care access, and optional modules like cancer survivorship and sexual orientation and gender identity (CDC, 2016a).



[CDC's Community Health Worker Toolkit](#)

A toolkit to support the effectiveness of CHWs in their communities, including helpful tools, resources and additional information (CDC, 2016b).



<p>CDC's Smoking & Tobacco Use State and Community Resources Offers a variety of resources, including best practices, for tobacco control programs (CDC, n.d.a).</p>	
<p>CDC's Community Guide Offers evidence-based strategies, which address a number of topics, including cancer screening, mental health and tobacco (CDC, n.d.b).</p>	
<p>CDC's Tobacco Cessation Fact Sheet for Physicians A fact sheet suggesting how providers can encourage tobacco cessation in their patients through sections summarizing methods to help patients quit smoking, compelling messages and key findings from the Surgeon General Report (CDC, n.d.c).</p>	
<p>City of Hope Online Continuing Medical Education Courses Offers accredited e-learning courses for Continuing Medical Education, including courses on various aspects of survivorship and patient-centered care. Furthermore, its <u>Center for Cancer Survivorship</u> offers a structured training program in Cancer Survivorship for clinicians (physicians, nurse practitioners and physician assistants) and researchers (physicians, nurses, epidemiologists and others) planning careers in the cancer survivorship field (City of Hope, n.d.).</p>	
<p>Colorado Patient Navigator Training These free online courses cover a variety of topics, including health care system and health issues, research, navigator skills and conduct and advanced techniques, and these trainings are offered at various levels (Colorado Patient Navigator Training Program, n.d.).</p>	
<p>Geographic Health Equity Alliance Provides information, tools and strategies to "reduce cancer and tobacco-related risk factors affecting geographically disadvantaged populations" (Geographic Health Equity Alliance, n.d.).</p>	
<p>GW Cancer Center's Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals This toolkit guides states in advancing patient navigation through training and technical assistance, system change and evaluation and policy.</p>	

[GW Cancer Center's Executive Training on Navigation and Survivorship](#)

This innovative program teaches the nuts and bolts of navigation and survivorship program development and implementation. The training walks participants through brief interactive presentations and customizable activities to create a program plan. Continuing education credits offered at no cost.



[GW Cancer Center's Generation and Translation of Evidence \(GATE\): A Cancer Community of Practice](#)

An online site that serves as an engagement and communication mechanism for cancer survivorship and cancer patient navigation, and in the future, other patient-centered care topics. The GATE fosters collaboration around patient-centered outcomes research dissemination and implementation.



[GW Cancer Center's National Cancer Survivors Day Social Media Toolkit](#)

Designed to help public health professionals establish a social media strategy built around National Cancer Survivors Day in June. Evidence-based messaging strategies for patients/survivors and health care professionals are provided in addition to pre-written social media posts.



[GW Cancer Center's Oncology Patient Navigator Training: The Fundamentals](#)

Through a collaborative process, the GW Cancer Center developed the first-ever, national consensus-based competencies for oncology patient navigators without a clinical license. This comprehensive, competency-based training uses evidence-based information and case studies to prepare patient navigators to effectively address barriers to care for cancer patients and survivors. Continuing education credits offered at no cost.



[GW Cancer Center's Patient Navigator Barriers and Outcomes Tool \(PN-BOT\)](#)

A free data entry, data management and reporting product designed for oncology patient navigation programs created by the GW Cancer Center. It can be used to document, track and generate reports on information such as patient volume, patient demographic profiles, cancer treatment profiles, timeliness of cancer care, barriers to care, navigator caseload and time, navigation services provided and patient outcomes.



<p>GW Cancer Center's Technical Assistance Portal (TAP)</p> <p>A centralized website that pulls together existing and new technical assistance for cancer control professionals. The TAP features a resource repository, monthly e-newsletters and e-learning sessions.</p>	
<p>LGBT HealthLink</p> <p>Formerly The Network for LGBT Health Equity, a community-driven network of experts, advocates and professionals working to enhance LGBT health by eliminating tobacco use and reducing disparities regarding cancer and other health issues within LBGT communities, primarily by education on best practices (LGBT HealthLink, n.d.).</p>	
<p>LIVESTRONG Foundation</p> <p>Provides direct services and develops community programs to support cancer survivors, caregivers and loved ones and address their concerns and challenges following diagnosis, as well as advocates for system change to transform the way the world fights cancer (LIVESTRONG, n.d.).</p>	
<p>Malecare</p> <p>A leading men's cancer survivor support and advocacy nonprofit organization providing free services and programs for patients and families, particularly underserved populations such as African-American, LGBT and Native American cancer survivors (Malecare, n.d.).</p>	
<p>National Academy for State Health Policy</p> <p>Provides a variety of resources for analysis and research of state policies and practices, including publications, charts, maps and toolkits. These resources include a robust section on quality and performance management, which includes cancer control benchmarks such as state-level data on cervical and breast cancer screenings (National Academy for State Health Policy, n.d.).</p>	
<p>National African American Tobacco Prevention Network (NAATPN)</p> <p>Provides tobacco cessation education resources and works to develop and implement "...comprehensive and community competent public health programs to benefit communities and people of African descent" (NAATPN, n.d.).</p>	

<p>National Alliance for Hispanic Health</p> <p>A community-driven organization working to improve the health and wellbeing of Hispanics. It provides general information and resources on cancer survivorship in English and Spanish, including through a health helpline, and its demonstration program, <i>Nuestras Voces</i>, aids community-based organizations to implement tobacco and cancer control programs (National Alliance for Hispanic Health, n.d.).</p>	
<p>National Association of County & City Health Officials webinar—Moving toward Integration of Tobacco Cessation in Cancer Survivorship Care Plans</p> <p>This webinar describes the guidelines that require incorporation of tobacco cessation into cancer survivorship care plans and provides an example of the efforts in one community (National Association of County & City Health Officials, 2016).</p>	
<p>National Behavioral Health Network for Tobacco & Cancer Control</p> <p>Offers resources for both health care professionals and individuals, which address tobacco use among people living with mental illnesses or addictions (National Behavioral Health Network, n.d.).</p>	
<p>National Cancer Institute's (NCI) Research-tested Intervention Programs (RTIPs)</p> <p>A searchable database of evidence-based cancer control interventions and program materials and is designed to provide program planners and public health practitioners easy and immediate access to research-tested materials. The database includes programs on the topic of survivorship and supportive care (NCI, n.d.c).</p>	
<p>NCI's Research to Reality</p> <p>An online community of practice designed to bring together cancer control practitioners and researchers to discuss moving evidence-based programs into practice (NCI, n.d.d).</p>	
<p>NCI's Smoking in Cancer Care (PDQ®)- Health Professional Version</p> <p>Provides a summary presenting smoking as a primary risk factor for cancer, focusing on the effect of smoking on: a diagnosis of a second primary cancer or recurrence; recommendations for smoking prevention for cancer patients; and patterns of quitting and continued smoking in cancer patients. The data and information helps health care professionals support and care for their patients during and after treatment (NCI, 2014).</p>	

[NCI's Surveillance, Epidemiology End Results \(SEER\) Program](#)

An authoritative source of information on cancer incidence and survival in the United States. SEER also supports special studies addressing topical issues in cancer prevention and control (NCI, n.d.e).



[National Cancer Survivorship Resource Center](#)

A collaboration between the GW Cancer Center and the American Cancer Society that provides evidence-based information, resources and support to cancer survivors, caregivers, friends and family; improves the survivorship knowledge and skills of health care professionals, community-based and government organizations; and recommends action to policy- and decision-makers to improve the quality of life of cancer survivors and caregivers and reduce death and disability due to cancer.



[National Cancer Survivorship Resource Center's Moving Beyond Patient Satisfaction: Tips to Measure Program Impact](#)

This guide, produced by ACS and the GW Cancer Center, details indicators and outcome measures that can be used to monitor the success of survivorship programs, specifically by illustrating quality of life domains and providing examples of program interventions, possible intended outcomes and suggestions for measurement (ACS, & GW Cancer Center, n.d.).



[National Cancer Survivorship Resource Center Toolkit: Implementing Clinical Practice Guidelines for Cancer Survivorship Care](#)

This toolkit provides resources to help with implementing ACS cancer survivorship care guidelines for colorectal, head and neck and prostate cancers and the ACS/ASCO cancer survivorship care guideline for breast cancer. In addition to the guidelines, information is included on training opportunities for primary care providers and patient materials to help activate cancer survivors to be full participants in their survivorship care.



[National Coalition for Cancer Survivorship](#)

Advocates for changes in quality cancer care research, regulation, payment and delivery and provides cancer survivors tools for self-advocacy (National Coalition for Cancer Survivorship, n.d.).



[National Community Health Worker Training Center](#)

Offers certified training for Community Health Workers and Community Health Worker instructors, including certification and Continuing Education online and in-person in both English and Spanish (Texas A&M Health Science Center, n.d.).



[National Comprehensive Cancer Network](#)

Offers guidelines for providers including survivorship; detection, prevention and risk reduction; age-related recommendation; and guidelines for patients. NCCN also offers continuing education courses on survivorship issues for physicians, nurses, pharmacists and other providers (National Comprehensive Cancer Network, n.d.).



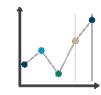
[National Conference of State Legislatures' Bill Information Services](#)

Provides access to pending and enacted state legislation through databases that include available bill text, status and information, as well as specialized legislative and statutory analyses (National Conference of State Legislatures, n.d.).



[National Health Interview Survey \(NHIS\)](#)

The leading source of information on a broad range of health topics for the civilian noninstitutionalized U.S. population. NHIS data is used to monitor trends in the amount, distribution and effects of illness and disability, as well as services provided (CDC, 2016c).



[National LGBT Cancer Network](#)

Offers online support groups and educational resources for survivors and also conducts cultural competence training for health providers to "offer more culturally-competent, safe and welcoming care" (National LGBT Cancer Network, n.d.).



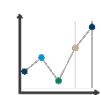
[National Native Network](#)

Offers resources for both health care professionals and individuals, which address tobacco use, prevention and screening for American Indians and Alaska Natives (National Native Network, 2015).



[North American Association of Central Cancer Registries' Data Analysis Tools](#)

Offers a variety of tools for data analysis that utilize variables such as race, ethnicity, geography and socioeconomic status to stratify registry data (North American Association of Central Cancer Registries, n.d.).



Patient Advocate Foundation

Provides professional case management services to resolve problems related to patients' ability to access care and financial obstacles, including insurance, job retention and/or debt crisis matters as they relate to diagnosis. (Patient Advocate Foundation, n.d.). Patient Advocate Foundation also operates the SelfMade Health Network which "...focuses on reducing and eliminating tobacco-related and cancer health disparities in documented populations containing those with low socioeconomic status" (SelfMade Health Network, 2015).



Prepared Patient® by the GW Cancer Center

Helps patients make informed decisions about their health and health care by gathering a collection of trusted resources, tips and stories from patients, caregivers and health care experts about finding good care and making the most of it, including those for post-treatment and survivorship to address the different types of challenges cancer survivors and their caregivers face.



RAISE Network (Reaching Asian Americans Pacific Islanders through Innovative Strategies to Achieve Equity in Tobacco Control and Cancer Prevention)

Offers resources for both health care professionals and individuals, which address tobacco use among Asian Americans, Native Hawaiian and Pacific Islander communities (RAISE Network, n.d.).



Redes En Acción: The National Latino Cancer Research Network

A national network of community leaders, researchers, governmental officials and advocates dedicated to fighting cancer among Latinos through research, training and education (Institute for Health Promotion Research, n.d.).



SAMHSA-HRSA Center for Integrated Health Solutions- Tobacco Cessation

A list of general resources as well as information on tobacco-related research and articles, webinars, behavioral interventions, nicotine replacement therapy/use of medications, policies and assessments for tobacco cessation (SAMHSA, & Health Resources and Services Administration, n.d.).



SAMHSA Behavioral Health Treatment Services Locator

A confidential and anonymous source of information for persons seeking treatment facilities in the United States or U.S. Territories for substance abuse/addiction and/or mental health problems. All information in the Locator is updated annually (SAMHSA, n.d.).



Sisters Network Inc.

A leading voice African American breast cancer survivorship organization committed to increasing attention to the devastating impact that breast cancer has in the African American community through educational resources, support and national and local events (Sisters Network, n.d.).



Susan G. Komen

Provides breast cancer survivorship resources on topics of medical care after treatment, other health concerns, complementary and integrative therapies, healthy lifestyles and stress, fear and concerns (Susan G. Komen, n.d.).



Triage Cancer

Supports survivors, caregivers, health care professionals and advocates through educational events, online tools and resources and a national Speakers Bureau (Triage Cancer, n.d.). Triage Cancer provides information on a variety of cancer survivorship issues, such as access to health care, treatment options, psychosocial care and survivorship care planning.



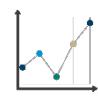
Ulman Cancer Fund for Young Adults

A community of support for young adult cancer survivors and their loved ones through various direct support programs and resources, including quarterly activities for young adult survivors to connect outside of traditional support group or clinical settings (Ulman Cancer Fund for Young Adults, n.d.).



United States Cancer Statistics (USCS)

Provides a comprehensive report on state/regional-level data for cancer incidence and cancer deaths. This data can be stratified by state/region, race/ethnicity, gender and cancer/tumor type, and it can provide further insight into incidence by state through rankings and comparisons with national incidence (U.S. Cancer Statistics Working Group, 2016).



Young Survival Coalition

Provides information, resources and support to young women diagnosed with breast cancer from diagnosis through long-term survivorship and to health care providers, researchers and legislators to educate them about the unique issues young women with breast cancer face (Young Survival Coalition, n.d.).



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