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Author manuscript

*Am J Prev Med.* Author manuscript; available in PMC 2021 February 19.

Published in final edited form as:

*Am J Prev Med.* 2015 December ; 49(6 Suppl 5): S536–S542. doi:10.1016/j.amepre.2015.08.011.

## Evidence-Based Cancer Survivorship Activities for Comprehensive Cancer Control

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### Abstract

**Introduction:** One of six priorities of CDC's National Comprehensive Cancer Control Program (NCCCP) is to address the needs of cancer survivors within the local population served by individually funded states, tribes, and territories. This report examines cancer survivorship activities implemented in five NCCCP grantees, which have initiated evidence-based activities outlined in *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* (NAP).

**Methods:** NCCCP action plans, submitted annually to CDC, from 2010 to 2014 were reviewed in February 2015 to assess implementation of cancer survivorship activities and recommended strategies consistent with the NAP. Four state-level and one tribal grantee with specific activities related to one of each of the four NAP strategies were chosen for inclusion. Brief case reports

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No financial disclosures were reported by the authors of this paper.

Appendix

Supplementary data

Supplementary data associated with this article can be found at, <http://dx.doi.org/10.1016/j.amepre.2015.08.011>.

describing the initiation and impact of implemented activities were developed in collaboration with each grantee program director.

**Results:** New Mexico, South Carolina, Vermont, Washington state, and Fond Du Lac Band of Lake Superior Chippewa programs each implemented activities in surveillance and applied research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services.

**Conclusions:** This report provides examples for incorporating cancer survivorship activities within Comprehensive Cancer Control programs of various sizes, demographic makeup, and resource capacity. New Mexico, South Carolina, Vermont, Washington state, and Fond Du Lac Band developed creative cancer survivorship activities that meet CDC recommendations. NCCCP grantees can follow these examples by implementing evidence-based survivorship interventions that meet the needs of their specific populations.

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## Introduction

A cancer survivor is defined as any person who has received a diagnosis of cancer, from the time of diagnosis throughout the person's life.<sup>1</sup> The growing population of cancer survivors in the U.S. faces a myriad challenges, including health-related, psychosocial, financial, and other barriers.<sup>1,2</sup> Cancer survivors often face adverse physical, psychosocial, and financial effects stemming from cancer diagnosis and treatment.<sup>3,4</sup>

CDC's National Comprehensive Cancer Control Program (NCCCP) identifies cancer survivorship as one of six program priorities, thus encouraging all programs to provide targeted, effective support for their local population of cancer survivors.<sup>5</sup> The NCCCP funds all 50 states, the District of Columbia, and select tribes and tribal organizations, U.S. territories, and associated Pacific Island jurisdictions to develop and implement evidence-based comprehensive cancer control plans tailored to their population that include survivorship goals, objectives, and implementation of recommended strategies.<sup>6</sup>

Recommended strategies for cancer survivors are identified in the 2004 *National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* (NAP), which provides nationally accepted, evidence-based cancer survivorship interventions.<sup>1</sup> The NAP, which was co-sponsored by CDC and Livestrong Foundation (formerly Lance Armstrong Foundation), was developed collaboratively with more than 45 organizations including the American Cancer Society, the National Cancer Institute, and several leading academic institutions and advocacy organizations. The NAP recommends strategies along four core public health areas:

1. surveillance and applied research;
2. communication, education, and training;
3. programs, policies, and infrastructure; and
4. access to quality care and services.

According to a recent CDC study, approximately 94% of all NCCCP grantees implemented cancer survivorship interventions; however, only 64% were consistent with NAP

recommendations.<sup>7</sup> In order to assist all NCCCP grantees in the implementation of appropriate, evidence-based recommendations, the current analysis highlights five diverse NCCCP grantees that have implemented NAP-recommended activities. The authors also describe the impact of those activities where available.

## Methods

Action plans, submitted annually to CDC by all funded NCCCP grantees, were reviewed extensively in February 2015 for implemented survivorship activities, as previously published.<sup>7</sup> Briefly, annual action plans describing objectives and related programmatic activities from 2010 to 2014 were obtained from each of the 50 U.S. states, the District of Columbia, territories, tribes, and Pacific Island jurisdictions. The plans are maintained within CDC's Chronic Disease Management Information System. To assess the implementation of cancer survivorship objectives, the Chronic Disease Management Information System search engine was used to identify "survivorship" activities within each grantee plan during the study period. Cancer survivorship activities were then categorized by compatibility with nationally accepted, recommended strategies from the NAP report. Criteria included:

1. surveillance and applied research;
2. communication, education, and training;
3. programs, policies, and infrastructure; and
4. access to quality care and services.<sup>1</sup>

After compiling all Comprehensive Cancer Control program interventions that met evidence-based recommendations, CDC researchers selected a group of programs that implemented unique, innovative survivorship activities and represent geographic and demographic diverse populations. Four state programs were chosen for an in-depth analysis (New Mexico, South Carolina, Vermont, and Washington state). An additional tribal program that implemented activities in the surveillance and applied research area was also chosen in order to include information related to American Indian/Alaska Native cancer survivors (Fond Du Lac Band of Lake Superior Chippewa). Program directors (or designated staff) of each selected state or tribal program collaborated with CDC researchers to develop detailed case reports, which describe cancer survivorship activities, initiation, implementation, and impact of evidence-based interventions. Multiple conference calls were held to facilitate discussions with program directors to review and finalize content for case reports. CDC researchers and program directors worked together to compile findings and create this report.

## Results

Figure 1 shows the states and tribal programs selected for inclusion in this report. South Carolina implemented interventions related to surveillance and communication; New Mexico and Fond du Lac Band implemented activities along the communication, education, and training strategy; Vermont developed and implemented program, policy, and infrastructure interventions; and Washington state focused on access to quality care and

services. Each chosen state is in a different Census region or division of the U.S. (Northeast, Vermont; South, South Carolina; West Mountain, New Mexico; West Pacific, Washington). The Fond du Lac Band population resides in the U.S. State of Minnesota, which is in the Midwest Census region of the U.S. A summary of the initiatives, budget, and timeframe for interventions undertaken by the selected states and tribal program is included in Table 1.

### **South Carolina—Surveillance and Applied Research**

The South Carolina Comprehensive Cancer Control Program (SCCCCP) instituted survivor interventions following the realization there was a lack of information regarding cancer survivor services available within state healthcare facilities. To address this, the SCCCCP partnered with the South Carolina Cancer Alliance, the American College of Surgeons, and the Medical University of South Carolina's Hollings Cancer Center to survey cancer centers about survivorship resources provided to patients. The coalition formed to work on this project was awarded a grant to assess five service areas within each cancer center (patient navigation, psychosocial distress screening, survivor care plans, genetic screening, and services and palliative care) in the state. Surveys were delivered and completed via e-mail, with reminders sent at Weeks 2 and 4, and a personal phone call to non-respondent centers by Week 5. After 6 weeks, 16 of the 17 participating cancer centers completed the survey (94%). Surveys provided baseline data that identified gaps in services and systems. Findings from the survey were disseminated to SCCCCP partners via South Carolina Cancer Alliance meeting presentations and a written report. The survey helped identify gaps in care, and the findings allowed SCCCCP to recommend improvements in cancer survivorship support. As a result, patient navigation, psychosocial distress screening, and survivor care plans were each identified as areas of focus. Strategies (or systems changes) in these areas are currently being developed for implementation within cancer centers by October 2016. Ongoing research, surveillance, and evaluation of the project are currently in progress.

### **Fond Du Lac Band—Communication, Education, and Training**

Fond du Lac Band's "Circle of Life" Cancer Education Program is a culturally tailored program that provides community members with information about all aspects of cancer, including cancer survivorship. The Fond Du Lac Band first implemented an early version of Circle of Life in 2002. It was developed in response to feedback from community leaders and healthcare providers that indicated the need to raise cancer awareness and education across the population. In 2003, the Fond du Lac Band partnered with CDC to designate public health nursing staff to provide cancer education to community members. Later, tribal leaders partnered with the American Cancer Society to establish the current Circle of Life program. The current program utilizes outreach workers to provide individual and small group education sessions using modules on cancer type, cancer treatment, healthy habits, and caregivers that were designed by the American Cancer Society. The modules provide information for cancer survivors and include pre- and post-tests to assess knowledge uptake. An automatic, computer-based evaluation system records information uptake and generates reports. This program also connects cancer survivors and caregivers with available support services. The education program has successfully raised cancer awareness in the tribe and has reached more than 300 individuals. In addition to this, Fond du Lac Band holds an annual "Cancer Survivors Celebration" to bring together cancer survivors and caregivers to

raise awareness of the cancer burden in their community. The event combines information sharing presentations with cultural festivities to create a supportive environment for cancer survivors and caregivers. The celebration is intended to raise awareness within the community, and the impact is evaluated with a survey that is distributed during the event. Results from the event surveys guide future decision making and event planning. The Circle of Life Cancer Education Program and Cancer Survivors Celebration have become key components of Fond du Lac Band's cancer control activities.

### **New Mexico—Communication, Education, and Training**

New Mexico has included cancer care summaries and follow-up plan activities in their cancer control efforts since 2006. They developed this area of work in response to an IOM recommendation,<sup>2</sup> with the program's Survivorship Work Group acknowledging the importance of cancer care summaries, follow-up treatment plans, and educating cancer survivors to maintain key patient information in the event a care plan was not provided. During implementation, program partners held information sessions to discuss post-treatment care with healthcare consumers at existing cancer survivorship workshops and conferences. Post-treatment care discussion topics included cancer care and treatment needs, care plans and follow-up information, screening recommendations, and other preventive medical needs. Information sessions continue to be held regularly at cancer survivorship events. These events include the annual "Long-Term Effects of Cancer Survivorship" conference hosted by Cancer Support Now, the semi-annual "Family Cancer Retreat" hosted by Cancer Services of New Mexico, and workshops in smaller communities across the state. New Mexico's messages for cancer survivors include specific types of medical information that all cancer survivors should keep, descriptions of the treatment summaries and follow-up care plans, and resources for additional information. It is estimated that information from these efforts has reached approximately 2,300 New Mexico cancer survivors.

### **Vermont—Programs, Policies, and Infrastructure**

The Vermont Department of Health's Comprehensive Cancer Control Program partnered with cancer survivors and advocates to establish the Vermont Cancer Survivor Network (VCSN). VCSN, a non-profit 501c3 organization, works to identify and implement strategies to meet the Vermont's survivorship goals. Soon after establishment, a focus group study of cancer survivors from around the state was commissioned to determine the needs of Vermont's cancer survivors. The focus group study design and main findings are listed in Table 2 and Table 3, respectively. A central theme from the focus group study was the critical need for interpersonal support for cancer survivors, preferentially from people who have also been diagnosed with cancer. Many survivors noted that support was lacking. To address this need, VCSN developed its own peer-to-peer support program, "Kindred Connections." This program holds at least 15 meetings across the state each year to train peer mentors (cancer survivors) in coping strategies to improve other survivors' quality of life. The trained peer mentors are then matched with cancer survivors in their regions to offer personal support as well as transportation, food preparation, and other activities to improve survivor physical and emotional health. The Vermont Department of Health continues to work with the VCSN to implement the Kindred Connections program and examine additional ways to build upon the success of the program. By the end of 2013, the

program had six active groups with more than 120 cancer survivors trained as peer mentors, who connect with thousands of cancer survivors across Vermont each year.

### **Washington—Access to Quality Care and Services**

The Washington Comprehensive Cancer Control Program developed and provided patient and provider educational material specifically containing information on the importance of survivorship care plans in 2011. An example of these materials is provided in the Appendix (available online). Following material dissemination across the state, the Washington Comprehensive Cancer Control Program held structured interviews with ten American College of Surgeons–affiliated hospitals across the state to assess awareness and use of survivorship care plans. The interviews yielded important findings and led to the establishment of the state’s Cancer Survivorship Clinic. This clinic was developed in partnership with the Providence Health and Services system, which is headquartered in Washington and has 42 clinic locations across the northwest region of the U.S. The Cancer Survivorship Clinic is dedicated to providing evidence-based cancer care accessible for all diagnosed with cancer, particularly those in poor and vulnerable populations. The clinic provides ongoing educational sessions for healthcare professionals on survivor care plans and other survivorship issues within the Providence healthcare system.

### **Discussion**

The five programs highlighted here have done unique and innovative work to address the needs of cancer survivors within their population. The activities presented in this report provide both examples of activities and methods for implementation that may be replicated by other NCCCP grantees. Some common themes are apparent in the highlighted survivorship activities. First, prior to implementation, several grantees had discussions with various stakeholders and sought out and established local partnerships to assist with implementation. These partners appear to be instrumental in the design and initiation of the activities. Additionally, several grantees saw a need to focus on activities related to survivorship care plans. This focus was based on both recommendations and demonstrated population needs.

Partnerships are a cornerstone of public health practice and have been used effectively to address many areas in cancer, including receipt of cancer screening<sup>8–10</sup> and treatment.<sup>11,12</sup> The NCCCP has a long history of partnering with governmental and non-governmental organizations to achieve common goals and initiatives. The Comprehensive Cancer Control National Partnership, a network established to assist the NCCCP, contains 15 partners that voluntarily develop strategies and resources to support implementation of cancer control plans across the nation.<sup>13</sup> This National Partnership includes the National Cancer Institute, the American College of Surgeons Commission on Cancer, the American Cancer Society, and Livestrong Foundation, among others.<sup>13</sup> Though the national partners offer much support, partnering locally with academic institutions, cancer centers, and other health networks as the grantees did in this study are also effective ways of moving activities forward. Local partners may have more-specific goals that align directly with those of the

grantee, and also may help with access to additional financial resources that may be necessary for NCCCP grantees to achieve success.

Survivorship care plans are an increasingly relevant area in survivorship, and it is therefore not surprising that several grantees have activities related to them. A seminal report released by IOM in 2005 recommended that survivorship care plans be developed and used as a tool to communicate and coordinate survivorship care.<sup>2</sup> In this report, the care plan was promoted in the report as a means to deliver patient-centered care by enhancing communication between the oncology team and the patient, as well as communication and coordination of care between the oncology team and the primary care provider. IOM provided a comprehensive list of components to be included in the survivor care plan, covering both the treatment summary and follow-up care plan.<sup>2</sup> However, to date, there has been limited success in implementing care plans in oncology practice, which may be related to the time-consuming process of completing a care plan, or the lack of a universally accepted care plan model.<sup>14,15</sup> A recent review noted that only 43% of National Cancer Institute–designated cancer centers present survivor care plans to their breast or colorectal cancer survivors and none of these address all components recommended by IOM.<sup>16</sup> In order to improve care plan development and use, the American Society of Clinical Oncology released an expert statement in 2014 to help clinicians recognize the importance of developing patient-centered care plans and delivering the information to both the patient and primary care providers.<sup>15</sup> Additional research to improve the practice and use of care plans is needed, however, and CDC and others are actively involved in care plan research. In the meantime, the efforts of New Mexico and Washington state presented here demonstrate that local partnerships can help with the development and dissemination of care plan information. The community and clinical partnerships outlined in this report have demonstrated effective and appropriate delivery of information to survivors.

Addressing cancer survivor needs remains a central goal of the NCCCP. In an effort to increase the number of grantees implementing evidence-based survivorship interventions and build upon the successes of the programs highlighted here, CDC recently provided additional funding to a subset of NCCCP grantees for survivorship activities related to surveillance, survivorship care plans, patient navigation, and provider education.<sup>17</sup> As the U.S. survivor population increases, the widespread adoption and sustainability of these efforts will become necessary. Projects that include the collection of information regarding the resources needed for sustainable survivorship efforts, including staffing, financial, and partner resources, will be necessary to ensure the continued survivorship efforts. Additional research in the economic impact of and best practices for survivorship activities will also be very valuable in ensuring that resources are maximized.

## Strengths and Limitations

This study has several strengths and limitations. One strength is the focus on work that was actually implemented and in practice, as opposed to planned or in theory, and the direct access of programmatic staff for information contained in this report. Another strength is the geographic and racial variation of the programs chosen for highlighting, which assist with the application of our findings. A limitation of the study is the use of written reports (action

plans) to select the programs for inclusion. Because these plans may not fully and accurately characterize the activities implemented, it is possible that the authors missed some key activities worth highlighting in this report.

## Conclusions

Nearly all NCCCP grantees have acknowledged the importance of addressing needs among cancer survivors, and are actively working to provide assistance to the growing survivor population. This report provides specific, implemented examples for incorporating cancer survivorship activities within programs of various sizes and resource capacity. New Mexico, South Carolina, Vermont, and Washington states and the Fond Du Lac Tribe all developed innovative, creative cancer survivorship activities that met CDC and other nationally recognized recommendations. These activities provide a roadmap for other NCCCP grantees and public health programs working in cancer survivorship to assist with meeting the needs of their specific survivor populations.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

Publication of this article was supported by the Centers for Disease Control and Prevention, Division of Cancer Prevention and Control.

The authors of this report would like to acknowledge Mary Puckett, PhD for assistance with graphics design for this report.

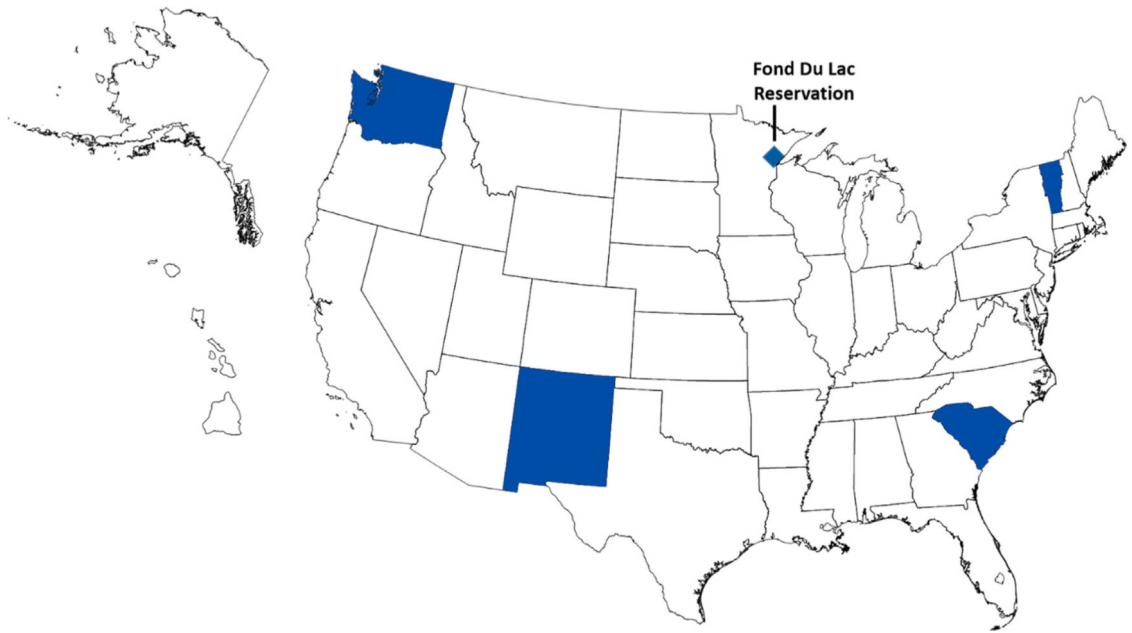
This work was supported by CDC's Division of Cancer Prevention and Control. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of CDC.

## References

1. National Center for Chronic Disease Prevention and Health Promotion (U.S.); Lance Armstrong Foundation. A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. Atlanta, GA: USDHHS, CDC; 2004.
2. Stovall E, Greenfield S, Hewitt M. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: National Academies Press, 2005.
3. [Editorial]. Cancer survivors: living longer, and now, better. *Lancet*. 2004;364(9452):2153–2154. 10.1016/S0140-6736(04)17601-0. [PubMed: 15610781]
4. Underwood JM, Townsend JS, Stewart SL, et al. Surveillance of demographic characteristics and health behaviors among adult cancer survivors: Behavioral Risk Factor Surveillance System, United States, 2009. *MMWR Surveill Summ*. 2012;61(SS01):1–23.
5. Stewart SL, Lakhani N, Brown PM, Larkin OA, Moore AR, Hayes NS. Gynecologic cancer prevention and control in the National Comprehensive Cancer Control Program: progress, current activities, and future directions. *J Women's Health*. 2013;22(8):651–657. 10.1089/jwh.2013.4465.
6. Major A, Stewart SL. Celebrating 10 years of the national comprehensive cancer control program, 1998 to 2008. *Prev Chronic Dis*. 2009;6(4):A133. [PubMed: 19755009]
7. Underwood JM, Lakhani N, Rohan E, Moore A, Stewart SL. An evaluation of cancer survivorship activities across national comprehensive cancer control programs. *J Cancer Surviv*. 2015;9(3):554–559. 10.1007/s11764-015-0432-4. [PubMed: 25732543]



8. Boehm JE, Rohan EA, Preissle J, DeGross A, Glover-Kudon R. Recruiting patients into the CDC's Colorectal Cancer Screening Demonstration Program: strategies and challenges across 5 sites. *Cancer*. 2013;119(S15):2914–2925. 10.1002/cncr.28161. [PubMed: 23868486]
9. Seeff LC, Major A, Townsend JS, et al. Comprehensive cancer control programs and coalitions: partnering to launch successful colorectal cancer screening initiatives. *Cancer Causes Control*. 2010;21(12):2023–2031. 10.1007/s10552-010-9664-9. [PubMed: 21086035]
10. Teal R, Moore AA, Long DG, Vines AI, Leeman J. A community-academic partnership to plan and implement an evidence-based lay health advisor program for promoting breast cancer screening. *J Health Care Poor Underserved*. 2012;23(2):109–120. 10.1353/hpu.2012.0076. [PubMed: 22643559]
11. Gage-Bouchard EA, Rodriguez EM, Saad-Harfouche FG, Miller A, Erwin DO. Factors influencing patient pathways for receipt of cancer care at an NCI-designated comprehensive cancer center. *PLoS One*. 2014;9(10):e110649. 10.1371/journal.pone.0110649. [PubMed: 25329653]
12. Goodman M, Almon L, Bayakly R, et al. Cancer outcomes research in a rural area: a multi-institution partnership model. *J Community Health*. 2009;34(1):23–32. 10.1007/s10900-008-9123-7. [PubMed: 18850070]
13. Hohman K, Rochester P, Kean T, Belle-Isle L. The CCC National Partnership: an example of organizations collaborating on comprehensive cancer control. *Cancer Causes Control*. 2010;21(12):1979–1985. 10.1007/s10552-010-9644-0. [PubMed: 20872239]
14. Halpern MT, Viswanathan M, Evans TS, Birken SA, Basch E, Mayer DK. Models of cancer survivorship care: overview and summary of current evidence. *J Oncol Pract*. 2014 JOP.2014.001403.
15. Mayer DK, Nekhlyudov L, Snyder CF, Merrill JK, Wollins DS, Shulman LN. American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. *J Oncol Pract*. 2014 JOP.2014.001321.
16. Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. Survivorship care plans in research and practice. *CA Cancer J Clin*. 2012;62(2):101–117. 10.3322/caac.20142. [PubMed: 22241452]
17. CDC. Increasing the implementation of evidence-based cancer survivorship interventions to increase quality and duration of life among cancer patients. [www.acf.hhs.gov/hhsgrantsforecast/index.cfm?switch=grant.view&gff\\_grants\\_forecastInfoID=100000356](http://www.acf.hhs.gov/hhsgrantsforecast/index.cfm?switch=grant.view&gff_grants_forecastInfoID=100000356) Published 2015 Accessed May 6, 2015.



**Figure 1.** National Comprehensive Cancer Control Program (NCCCCP) grantees selected for inclusion. *Note:* NCCCCP programs in Fond du Lac Band, New Mexico, South Carolina, Vermont, and Washington state participated in this analysis.

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**Table 1****Innovative Cancer Survivorship Activities Among National Comprehensive Cancer Control Grantees**

Fond Du Lac
Implementation date(s): 2012–Present
Budget: \$1,000/year
NAP recommendation: communication, education & training
Activity description: cancer survivors celebration to raise awareness of cancer burden
New Mexico
Implementation date(s): 2012–Present
Budget: \$2,500
NAP recommendation: communication, education, and training
Activity description: held workshops and distributed factsheets to discuss post-treatment care for survivors
South Carolina
Implementation date(s): 2010
Budget: \$45,000
NAP recommendation: surveillance and applied research
Activity description: survey cancer centers to assess support resources for cancer survivors
Vermont
Implementation date(s): 2008–present
Budget: \$15,000/year
NAP recommendation: programs, policies, and infrastructure for cancer survivors
Activity description: provide peer mentorship and support for cancer survivors
Washington
Implementation date(s): 2011–Present
Budget: \$10,000/year
NAP recommendation: improve access to quality care and services
Activity description: promote awareness, distribution, and use of cancer survivorship care plans

*Note:* National Comprehensive Cancer Control Program (NCCCP) program directors and staff provided all activity information. The date(s) provide complete time period for activities. Budget includes all funds used to implement activities, and may not be limited to NCCCP funding. NAP Recommendation is the outlined activity described in *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*.

**Table 2**

## Design and Characteristics of Vermont's Survivor Focus Group Study

Location	Men	Women	Total no. of participants	Level of service available in region
Bennington	0	13	13	Hospital-based community cancer center, including radiation services; previously—medical humanist
Colchester	1	6	7	Comprehensive cancer center/academic medical center; urban
Montpelier	1	7	8	2 medical oncologists; cancer coach; no designated oncology beds; no radiation
Newport	2	6	8	Part-time oncologist; nurse-coordinator; very rural; no radiation
Rutland	6	4	10	Hospital-based community cancer center, including radiation service
VT Cancer Survivor Network (statewide)	0	5	5	Varied (statewide representation)
Total	10	41	51	

Note: Study results were abstracted from Cancer Survivors Focus Group study, conducted by Vermont National Comprehensive Cancer Control Program, <http://healthvermont.gov/prevent/ccc/documents/CancerSurvivorFocusGroups.pdf>.

**Table 3.**

**Main Findings of Vermont’s Survivor Focus Group Study**

Support	The most predominant theme throughout the various threads of the focus group study is that support plays a critical role for cancer survivors. Support from other cancer survivors is especially important. Connecting with other survivors, both through support groups and one-to-one contact, provides opportunities to give and receive emotional support and to exchange information. Despite its importance, the need for peer support is being poorly met in the state.
Information	The majority of focus group participants described a profound and ongoing desire for information. Information needs change over time as individuals move through the stages of survivorship. Survivors want to have information offered to them rather than always having to search for it. Survivors have concerns about the reliability of the information they find on their own, particularly on the Internet. Information about diagnosis and treatment options is more readily available than information about “everything else,” and information and resources related to less common cancers can be hard to find.
Transitions and emotional well-being	Transitions frequently present emotional challenges for cancer survivors. The end of treatment was well-being experienced as a difficult and sometimes frightening transition, even when outcomes are positive. The end of an active relationship with an oncologist often leaves survivors feeling that they have been cast adrift, a situation that is compounded by a lack of discharge planning that could smooth the transition to post-care. Survivors are generally surprised by the depression and anxiety that occurs during these transitions because they are rarely advised that a period of emotional adjustment is common. Survivors report that their doctors rarely open the door to discussion of emotional issues, and survivors would like them to do so. Emotional support and counseling, like information, needs to be offered on an ongoing basis as individuals’ needs change. Practices such as meditation, yoga, and spiritual practices are found to be useful by many survivors.

*Note:* Study results were abstracted from Cancer Survivors Focus Group study, conducted by Vermont National Comprehensive Cancer Control Program, <http://healthvermont.gov/prevent/ccc/documents/CancerSurvivorFocusGroups.pdf>.