

# YEAR THREE EVALUATION OF THE SOUTH DAKOTA SURVIVORSHIP PROGRAM

*CDC DP15-1501, Annual Report, Program Year 3*



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# Executive Summary:

## Final Outcomes of the South Dakota Survivorship Program

*CDC DP15-1501, Annual Report, Program Year 3*

Approximately 1.7 million individuals in the U.S. and 5,100 in South Dakota will be diagnosed with new cancer cases in 2018.<sup>1</sup>

Over the last three years (September 30, 2015 – September 29, 2018), the **South Dakota Survivorship Program** (SDSP) has collaborated with local cancer treatment centers and other partners. These collaborations have resulted in expansion of cancer survivorship surveillance systems, facilitation of community/clinical linkages, education for survivors and health care providers on cancer survivor best practices, and acceleration of the evidence related to survivorship practices.

Expanded survivorship services were, and continue to be needed in South Dakota (SD), where **11.8%** of the adult population are living with a history of cancer.<sup>2</sup> The percent of SD cancer survivors who report fair or poor health status is nearly triple that of South Dakotans without a cancer diagnosis (**30.3% vs. 11.4%**).<sup>3</sup> Following primary treatment, cancer survivors may continue to face long-term and late effects. Furthermore, cancer survivors have an increased risk for additional cancers compared with persons without a cancer history.<sup>4</sup>

The SDSP has provided mentorship and the funding needed to develop and/or expand cancer survivorship services throughout SD, partnering with local cancer treatment centers and registries over the last three years to promote statewide adoption of sustainable practice- and evidence-based survivorship activities. The following program highlights, key findings, and recommendations included in this report are reflective of program activities conducted between September 30, 2017 and September 29, 2018. Highlights of advancements across the three-year funding period are also provided.

# Program Highlights

- Four posters and two oral presentations featuring work of the SDSP were presented regionally and nationally during program year three.
- A SDSP developed manuscript, “Cancer survivorship care plans: Processes, effective strategies, and challenges in a Northern Plains rural state”, was published in *Public Health Nursing*.
- Recruitment occurred within both partnering health systems in SD for a study entitled Cancer Survivor’s Views of the Survivorship Care Plans. As a result, an aggregate report and two manuscripts (both under peer-review) were developed in program year three.
- Dedicated genitourinary oncology nurse navigator roles at both partnering health systems were developed in partnership with an auxiliary specialty center and supported by the SDSP. A white paper highlighting the unique collaborations with the specialty center was disseminated in May 2018.
- All program sites exceeded the CoC standard of providing SCPs to  $\geq 50\%$  of eligible patients by the close of 2017 and beyond. An overall increase of 35 percentage points was seen in eligible survivors receiving survivorship care plans from 2015-2017, from CoC reporting of 23% in 2015 to 58% in 2017.
- Nearly 85% of cancer survivors identified as tobacco users were referred to tobacco cessation resources in 2017, compared to 66% in 2016.
- Referrals for nutrition and/or physical activity services are expanding, with 232 eligible patients that completed treatment in 2016 receiving referrals and 353 eligible patients receiving referrals in 2017.
- Of cancer survivors identified as not up-to-date with one or more of the eligible screenings for colorectal cancer, 85% received a referral for colorectal cancer screening in 2017, compared to 65% in 2016.

## Background



Cancer incidence remains high in the United States (US), with estimates nearing **1.7 million** new cancer cases diagnosed in 2018.<sup>1</sup> Estimates for new cancer cases diagnosed in SD are at **5,100** cases for 2018.<sup>1</sup> Additionally, prevalence of cancer survivors in the US continues to increase, with more than **15.5 million** Americans with a history of cancer.<sup>1</sup> Some of these individuals were diagnosed recently and are still undergoing treatment, while most are many years past diagnosis with no current evidence of

cancer. Advancements in cancer care and an aging population are leading to a continued increase in survival rates. In SD, nearly **12%** of the population reports having cancer at one point in their lifetime.<sup>2</sup>

Through a three-year cooperative agreement with the Centers for Disease Control and Prevention, the SD Department of Health (SD DOH) established the South Dakota Survivorship Program (SDSP) in September 2015. Since then, the program has been diligently working to address the public health needs of cancer survivors in the state, to increase duration and quality of life for all survivors. The SD DOH contracted with the South Dakota State University Population Health Evaluation Center to evaluate the implementation and outcomes of the SDSP. Objectives and strategies outlined in the evaluation work plan quantified program progress in six assessment areas, including:

- 1) Patient Navigation**
- 2) Surveillance**
- 3) Survivorship Care Plans**
- 4) Health Status and Knowledge of Cancer Survivors**
- 5) Healthcare Provider Knowledge**
- 6) Dissemination of Evidence via Publications**

The information in this evaluation report celebrates the accomplishments of the SDSP and its partner cancer treatment center over the three-year funding period.

## Program Context

At the onset of the SDSP, six cancer treatment centers from three of the largest health systems in SD agreed to partner with the program.

Collectively, the cancer treatment centers served most cancer patients residing in SD, making for an innovative partnership. Unfortunately, midway through the first program year, one of the three health systems elected to end their partnership with the SDSP. The SDSP moved forward with the five remaining partner cancer treatment centers and continued to serve a diverse geographic area with two of the largest health systems in SD. In program year two, the SDSP fostered a collaborative partnership between an auxiliary specialty center and the two health systems to enhance reach to survivors and maximize the SDSP impact.

In the final year of funding, the SDSP prioritized efforts to increase sustainability of the long-term program outcomes beyond the funding period. Evaluation activities over the last three years have monitored progress towards the short-, mid- and long-term outcomes, with successful achievement of the short-term outcomes in program years one and two. The identified mid- and long-term outcomes monitored over the final year included:

### Mid-term Outcomes

- 1) Increased knowledge of National Comprehensive Cancer Control Programs for the implementation of survivorship initiatives
- 2) Enhanced partnerships to facilitate and broaden program reach
- 3) Identified the capacity needed to sustain broad-based survivorship activities
- 4) Increased capacity to sustain survivorship interventions
- 5) Increased access to survivorship support resources

### Long-term Outcomes

- 6) Increased use of preventative services and engagement in health behaviors among cancer survivors
- 7) Reduced poor physical and mental health status among survivors
- 8) Increased quality and duration of life among cancer survivors

## Patient Navigation



Patient navigation programs aim to identify and resolve patient barriers to care, link patients and families to primary care services, specialist care, and community-based health and social services, all in an effort to provide more holistic, patient-centered care. Patient navigation programs have continued to expand in program year three.

A large focus for both health systems in year three was to develop, support and build upon the dedicated genitourinary oncology nurse navigator (GU Navigator) role in partnership with an auxiliary specialty center. The unique collaboration each health system developed with the specialty center has enhanced care collaborations between facilities, as well as enriched the overall patient experience for survivors of urogenital cancers. A white paper outlining the survivorship and patient navigation collaborations was developed for the SDSF in May 2018.<sup>5</sup> Further details are also provided under Dissemination of the Evidence via Publications.

The SDSF worked with both partnering health systems in the areas of tobacco use assessment and referral, nutrition and physical activity assessment and referral, and assessment and referral for preventative cancer screening with an emphasis on screening for colorectal cancer. Each health system has integrated an assessment and referral process to identify cancer survivors who are eligible for colorectal cancer screening, nutrition and physical activity services for cancer survivors (including community clinical resources and programs), and tobacco cessation assistance (including community clinical resources and programs for evidence-based cessation services such as the SD QuitLine).

Due to the retrospective look back required for data verification, calendar year data for 2017 is the most current aggregate data available and is estimated based off of grant year reporting. During the outlined timeframe, the partnering health systems identified 46 survivorship care plan (SCP) eligible cancer survivors as current tobacco users eligible for referral to tobacco cessation assistance, of which 39 (85%) were referred. Nutrition and physical activity assessment and referral also proved successful, with 353 SCP eligible cancer survivors referred for nutrition

and/or physical activity services in the outlined timeframe. Assessment of patients' colorectal cancer screening status during the same timeframe identified 73 cancer survivors that were not up-to-date with one or more of the eligible screenings for colorectal cancer. Of the 73 identified as not up-to-date, 62 (85%) received a referral. The chart below (Figure 1) shows referral metrics for 2016 and 2017.

**Figure 1. Referral metrics, 2016 & 2017**

	<b>2016</b>	<b>2017</b>
<b>Tobacco Cessation Referrals</b>	<b>21 survivors</b> <i>66% of eligible population</i>	<b>39 survivors</b> <i>85% of eligible population</i>
<b>Nutrition/Physical Activity Referrals</b>	<b>232 survivors</b>	<b>353 survivors</b>
<b>CRC Screening Referrals</b>	<b>33 survivors</b> <i>65% of eligible population</i>	<b>62 survivors</b> <i>85% of eligible population</i>

Celebrated patient navigation accomplishments among the partnering cancer treatment centers over the last three years include the development of a free-standing patient navigation center, housed within one of the SDSP partner cancer treatment centers, which offers 24/7 patient navigation services through a call center or walk-in model.<sup>6</sup> Outbound survivorship calls, piloted in August 2016, have also been initiated as a way to provide support in a pivotal time for cancer survivors. The addition of specialized GU Navigators at both health systems was key in developing survivorship and patient navigation partnerships with a specialty center to enhance coordination of care for a hard-to-reach patient population. Finally, the addition of nutrition navigation services and an evidence-based nutritional screening tool and best practice alert in 2018 within one of the SDSP partner cancer treatment centers further expanded nutrition assessment and referral opportunities for cancer survivors.

## Surveillance



The burden of cancer was assessed among cancer survivors using data from the Behavioral Risk Factor Surveillance System (BRFSS). The SD BRFSS is a telephone survey of residents aged 18 and older and is conducted as a combined effort between the SD DOH and the Centers for Disease Control and Prevention. South Dakota was fortunate to have included a subset of the BRFSS Cancer Survivorship Module questions into the 2015 survey, followed by the full thirteen question CDC Cancer Survivorship Module into the 2016, 2017, and 2018 surveys. The

optional module evaluates receipt of a survivorship care plan, clinical trial participation, and other relevant indicators for cancer survivorship. Two dissemination reports were developed utilizing combined 2015 and 2016 BRFSS data and were publicly disseminated in program year three.<sup>3, 7</sup>

*IN 2017, 58% OF ELIGIBLE SURVIVORS RECEIVED A SURVIVORSHIP CARE PLAN, COMPARED TO 23% IN 2015.*

*[PROGRAM RECORDS: COC ANNUAL REPORTING]*

## Survivorship Care Plans

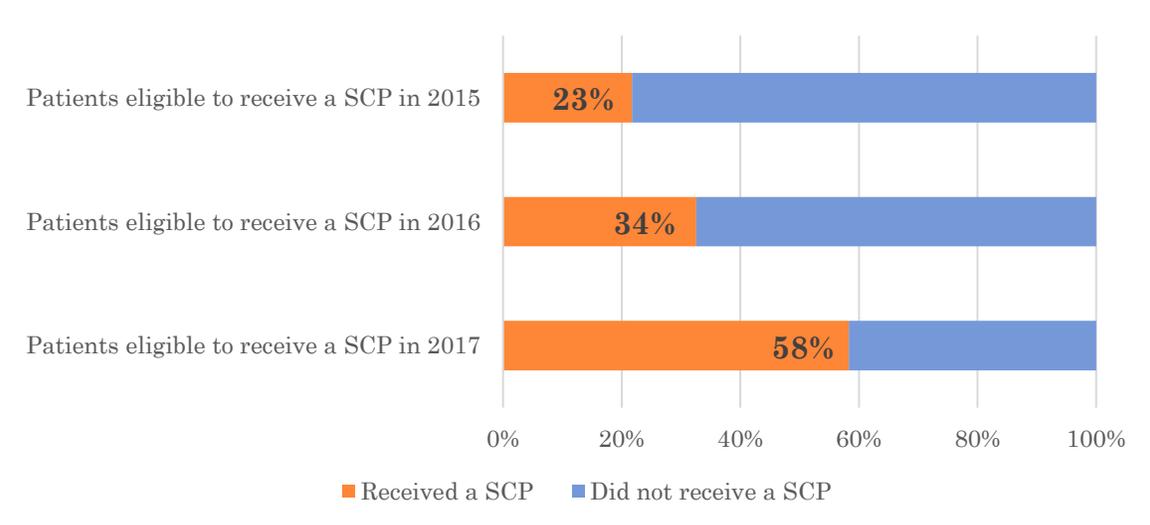


The Commission on Cancer (CoC) has played an integral role in setting the stage for SCP delivery. In 2015, the CoC implemented Standard 3.3 to facilitate implementation of SCPs in cancer treatment centers. Standard 3.3 requires cancer survivors be provided with a comprehensive treatment summary and SCP, and further outlines the timelines, guidelines and standards regarding SCP delivery. To maintain accreditation, programs must provide SCPs to  $\geq 10\%$  of

eligible patients by the close of 2015,  $\geq 25\%$  of eligible patients by the close of 2016, and  $\geq 50\%$  of eligible patients by the close of 2017 and beyond.<sup>8</sup> The SDSP worked with the partner cancer treatment centers to develop processes

to identify survivors eligible to receive a SCP. Many process enhancements have been made over the three-year program period to identify survivors eligible to receive a SCP through use of the partner cancer treatment centers' electronic health record systems. Eligibility is later verified and assessed for completeness using a data pull from local cancer registry data. At the close of 2017, partner cancer treatment centers had reached an aggregate 58% of eligible survivors receiving a SCP, an increase of 35 percentage points from 2015 distribution rates [Program Records: CoC Annual Reporting]. SDSP partnering cancer treatment centers have met and exceeded the CoC standards for SCP distribution in all three years of the program funding (Figure 2).

Figure 2. Aggregate Provision of SCPs, 2015-2017



## Health Status and Knowledge of Cancer Survivors

Despite extensive national support and anecdotal evidence supporting delivery of survivorship care plans, research on survivors' knowledge of their cancer treatment history and follow-up care, including primary prevention and self-management are limited in the health-related literature. Beginning in program year two, recruitment occurred within both partnering health systems in SD for an assessment project entitled *Cancer Survivor's Views of the Survivorship Care Plan*.<sup>9</sup> The purpose of the project was to examine the following among cancer survivors who have finished active curative treatment: 1) survivorship knowledge before and after receiving an individualized SCP, 2) cancer worry and general anxiety before and after receiving a SCP, 3) intent to modify behaviors that impact health in cancer survivors, 4) satisfaction with the SCP provision for ongoing health care needs, and 5) availability of specific resources related to cancer. Recruitment for the project closed in January 2018.

Two surveys were designed for this project. A pre-survey gathered information prior to the survivor's receipt of a SCP, and consisted of questions assessing participant demographics and clinical characteristics, perceived knowledge, cancer worry and general anxiety. A post-survey, completed three months later, addressed the same questions on perceived knowledge, cancer worry and general anxiety as outlined in the pre-survey. Also included in the post-survey were questions on survivor's use and satisfaction with the SCP, as well as how the SCP was shared between the oncology care team and the survivor. Survivors were also asked at the post-survey time point to indicate the changes in lifestyle behaviors they have already made or plan to make in the next six months, including eat healthier, be more physically active, maintain a healthy weight, get regular checkups, schedule preventative cancer screenings, stop smoking or using smokeless tobacco, and stop or limit alcohol use. As a final component, survivors were asked to indicate the availability of, or need for, specific resources related to cancers, including caregiver resources, dealing with emotional or physical

side effects, family history and genomics, financial concerns, going back to work, healthy eating, physical activity, quitting tobacco, cancer survivor support programs and services, moving from active treatment to follow-up care, and space to suggest additional resource needs. Two manuscripts were developed in program year three utilizing the gathered data.

The partnering health systems distributed nearly 700 survey packets to eligible patient survivors. Of the invited survivors a total of 335 survivors chose to participate in the study, 247 of which provided eligible pre-survey responses and 190 that provided eligible post-survey responses.

When comparing pre-SCP cohort responses to post-SCP cohort responses, a significant improvement in overall perceived knowledge was evidenced after receipt of a SCP. At the post-survey, respondents indicated high perceived knowledge of knowing which provider should monitor them for recurrence of cancer, as well as high perceived knowledge of knowing which provider is responsible for managing health problems not related to cancer, such as high blood pressure, and which provider is responsible for ordering screening tests, such as mammograms and colonoscopies.

From pre-survey to post-survey, respondents indicating “agree” or “strongly agree” to the question *I understand my treatment history* increased almost nine percentage points, from 90.2% to 98.9%. Additionally, the question *I know what my follow-up care should be* incurred over an eleven percentage point increase in agreement, from 87.3% to 98.4%.

Receipt of a SCP also improved survivors’ level of cancer-related anxiety. At the pre-survey time point, 34.3% of cohort respondents indicated “not at all anxious”, while at the post-survey time point 46.8% of cohort respondents indicated the same.

### Following receipt of a survivorship care plan:

\*study respondents who reported understanding their cancer treatment history increased almost 9 percentage points<sup>9</sup>

\*study respondents who reported knowing what their follow-up care should be increased over 11 percentage points<sup>9</sup>

Of the post-survey respondent cohort, 90.3% still had their survivorship care plan, 88.9% indicated that a member of their cancer care team reviewed the SCP with them to address their questions and concerns, and 84.0% determined the visit to review the SCP was a ‘good use of time’. The majority of respondents (97.2%) would recommend that other patients receive a similar care plan after cancer treatment. Finally, 86.6% of respondents indicated that the SCP has helped them feel more in control of future medical care.

Lifestyle behavior change is high among survivors that received a SCP. At the follow-up time point, 94.2% had already made at least one lifestyle behavior change, with 96.3% indicating they plan to make a lifestyle behavior change in the next six months.

Survivorship care plans intend to enhance quality of life and health outcomes by improving patient provider communication and coordination of care. Results from this assessment are promising, supporting the value of delivery of SCPs as a way to improve patients’ knowledge of their cancer and treatment history and their follow-up care needs.

Data from this patient assessment was utilized to develop Manuscript #2 and Manuscript #3 for the SDSP. Manuscript #2, “[Patient Knowledge of Cancer Treatment History and Follow-Up Care after Receipt of a Survivorship Care Plan](#)”, is currently under review with the publisher.<sup>10</sup> Manuscript #3, “[Making the Case for Optimal Use of Survivorship Care Plans](#)”, has also been submitted for review to a publisher (see Dissemination of Evidence via Publications).<sup>11</sup>

Following receipt of a survivorship care plan, **97.2%** of study respondents would recommend that other patients receive a similar care plan after cancer treatment.<sup>9</sup>

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## Healthcare Provider Knowledge



A navigator network was created in program year one to foster collaboration among cancer partners and to provide education and training opportunities for cancer professionals statewide. In program year three, the SDSP promoted the following training opportunities to the navigator network, which were attended by program partners:

### **GW Cancer Survivorship E-learning Series and Patient Navigation Training**

To enhance healthcare provider knowledge regarding treatment guidelines for cancer survivors, the SD DOH partnered with the American Cancer Society (ACS) and the George Washington (GW) Cancer Institute to offer the National Cancer Survivorship Resource Center's E-learning series to staff of the partner cancer treatment centers and members of the Navigator Network. The multi-part series provides no cost continuing education credits and offers modules for clinicians to learn about late effects of cancer treatment, coordinated care, and the importance of ongoing preventive care needs for cancer survivors. The ten modules include:

**Module 1:** The Current State of Survivorship Care and the Role of Primary Care Providers

**Module 2:** Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers

**Module 3:** Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors

**Module 4:** The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well

**Module 5:** A Team Approach: Survivorship Care Coordination

**Module 6:** Cancer Recovery and Rehabilitation

**Module 7:** Spotlight on Prostate Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

**Module 8:** Spotlight on Colorectal Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

**Module 9:** Spotlight on Breast Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

**Module 10:** Spotlight on Head and Neck Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

In program year three, five of the ten training modules were accessed with five total module completions, including Modules 1, 3, 4, 5, and 6.

### **Establishing Effective Patient Navigation Programs in Oncology: A Workshop**

The National Cancer Policy Forum Hosted a public workshop on November 13-14, 2017 to examine the optimal conditions and components of successful patient navigation (PN) programs in oncology. The workshop featured presentations and panel discussion on topics including access and utilization patterns of PN programs, models of delivery and design features of PN programs throughout the entire cancer care continuum, and potential opportunities to improve the implementation and effectiveness of PN programs. The live webcast was promoted to individuals involved in the SDSP.

### **Academy of Oncology Nurse & Patient Navigators (AONN+) Navigation & Survivorship Conference**

The AONN+ Eighth Annual Navigation & Survivorship Conference was held in Orlando on November 16-19, 2017. The conference focused on oncology navigation and survivorship topics. The event was attended by one individual involved in the SDSP.

### **Incorporating Cancer Survivorship into Primary Care (Webinar)**

The American Cancer Society, in collaboration with the SD Department of Health and the SD Cancer Coalition, hosted a webinar discussion on integrating cancer survivorship care into primary practice. The January 9<sup>th</sup>, 2018 webinar, presented by guest speakers Richard C. Wender, MD and Larissa Nekhlyudov, MD, MPH, centered around learning the goals for enhancing cancer survivorship, understanding the basics of cancer survivorship care, and accessing

available resources to support cancer survivors in their healthcare journeys. Sixty-three individuals registered for the online event.

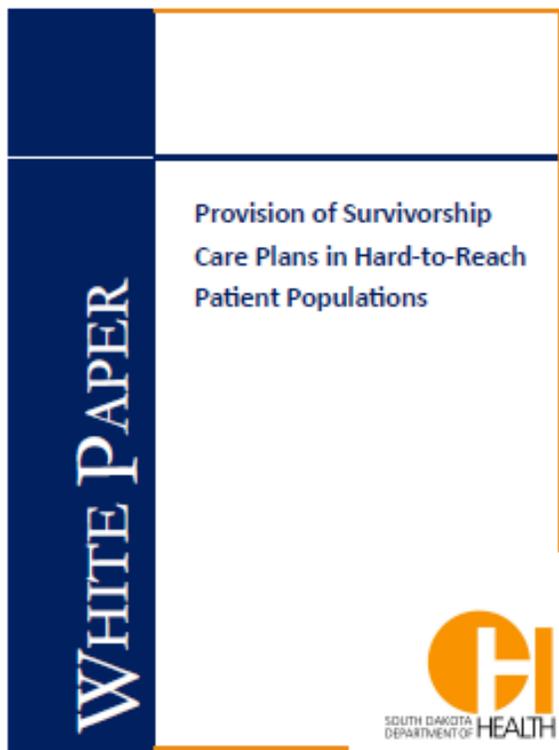
### **Motivational Interviewing Training**

In June 2018, the SD DOH offered a one-day motivational interviewing training for healthcare professionals in Rapid City, Pierre and Sioux Falls. The training featured trainers from the Patient Navigation Training Collaborative in Colorado. The trainings provided an opportunity to expand motivational interviewing skills related to the strategic use of questions and reflections to build upon and deepen client change talk as well as ways to work skillfully with resistance. Collectively, 100 professionals were trained. Evaluation of the training indicated high satisfaction with the training opportunity as well as a high percentage of respondents that plan to make changes in their practice as a result of the training.

In program year three, patient navigators within the navigator network also completed 18 certifications or professional memberships during the reporting period. These certifications and memberships include: Academy of Oncology Nurse & Patient Navigators (AONN+) Memberships, Oncology Nursing Society Memberships, Association of Oncology Social Work Membership, Oncology Nursing Society/Oncology Nursing Certification Corporation Chemo Certifications, Academy of Oncology Nurse & Patient Navigators, and Oncology Nursing Society Fundamentals of Administration Courses.

The SDSP continues to utilize and promote a local online learning platform that educates healthcare professionals on the SD QuitLine and tobacco cessation. The SDSP also continues to promote other local and national training opportunities to patient navigators through the Navigator Network. A quarterly newsletter is distributed to the Navigator Network containing links to registration and recordings of relevant webinars and trainings, journal articles of interest, and additional updates and highlights related to patient navigation and survivorship.

## Dissemination of Evidence via Publications



### **White Paper #3** Provision of Survivorship Care Plans in Hard-to-Reach Patient Populations<sup>5</sup>

In May 2018, the third program white paper was released. The purpose of the white paper was to highlight the unique collaboration of two individual health system cancer treatment centers with one auxiliary specialty center as they addressed provision of SCPs in a hard-to-reach patient population of urological cancer survivors, including surgery-only prostate patients, receiving care outside of a cancer treatment center model.

Across the country, cancer programs are diligently working to achieve and maintain Commission on Cancer (CoC) Standard 3.3 by incorporating SCPs as a standard of care. However, for some CoC accredited cancer programs, implementation in hard-to-reach populations remains a struggle.

Complications in identifying cancer survivors for SCP provision can arise when surgery privileges are granted to private providers outside of a health system. A cancer patient may have surgical oncology care performed by a private provider with surgical privileges at a health system, but receive the remainder of their treatment and follow-up care outside of that health system's cancer treatment center. As the surgery took place at the health system, these patients are subsequently included in the eligible analytic case load. The patient is then included in the denominator of eligible survivors for SCP receipt with the health system, despite not being a patient of the health system. As such, many of these patients are hard-to-reach for SCP provision

and discussion, as the remainder of their care occurs outside of the cancer treatment center model.

The white paper details how survivorship collaborations with specialty providers can enhance care collaborations, as well as enhance the overall patient experience. The two health system collaborations outlined in the white paper offer unique models of partnership for survivorship care provision with a specialty provider to access a hard-to-reach population of surgery-only patients. Each health system developed a model of collaboration that fit with the unique needs and resources of their health system.

Although the collaboration models varied in delivery methods, both models received positive patient feedback, indicating that the service provides value regardless of the method of delivery, and is a good investment for the patients' well-being. The collaborations help support care coordination among facilities and provide a team approach to patient care.

**Manuscript #1** Cancer survivorship care plans: Processes, effective strategies, and challenges in a Northern Plains rural state<sup>12</sup>

Despite the continued health threats that cancer survivors face after active treatment, research suggests that up to 60% of cancer survivors in the United States do not receive a written summary of their cancer treatment, and 65% do not receive written instructions for follow-up care.<sup>13</sup> Health systems face resource and time barriers to developing and implementing cancer survivorship care plans (SCPs) when active cancer treatment is completed. As part of the SDSP, interviews were conducted with partnering health systems to describe and compare the models of SCP development and implementation.

The health systems used similar processes for early designation of program personnel, developing SCP templates, provider/staff input, and identifying/tracking eligible patients. However, they developed differing processes for SCP completion and delivery. The health systems also identified effective strategies and challenges in SCP development and implementation.

The evaluation suggests that partnerships between state health departments and local health systems could be key for meeting the nation-wide goal of universal SCP implementation. Particularly, other low-population rural states like SD can use the findings to help build their SCP programs.

Full results from this evaluation were published in *Public Health Nursing*.<sup>12</sup>

## **Manuscript #2** Patient knowledge of cancer treatment history and follow-up care after receipt of a survivorship care plan<sup>10</sup>

The objective of this study was to assess survivor perception of knowledge of their treatment history and follow-up care before and after receipt of a post-treatment SCP. Across six study locations, eligible survivors received a pre-SCP and three-month post-SCP survey including a 13-item scale assessing perceived knowledge about disease, treatment, and follow-up care. Results are based on 152 survivors who completed both the pre and post surveys.

For both the total knowledge score and all individual questions, there was a significant ( $p < 0.05$ ) increase in responses indicating an increase in perceived knowledge from pre-SCP to post-SCP. A multiple regression model showed no significant associations of the change in total knowledge score with any of the demographic and cancer characteristics measured (all  $p > 0.05$ ).

The use of the survivorship care plan in the population included with this study was associated with a significant increase in knowledge about post-cancer effects, access to information and resources for the survivors and their family members, and role of primary care and specialty providers in cancer and non-cancer related follow-up care.

The study identified several content areas where 10-17% of survivors still showed evidence of a knowledge gap. The respondents indicated a diminished knowledge in regard to resources concerning finances and knowing who to contact with emotional concerns. These findings suggest a need to further emphasize these topic areas within the SCP.

The results of the study are consistent with improvement in knowledge following SCP, and thus SCPs may equip survivors with the knowledge and skills required for self-management of the physical, psychological, and social needs post cancer treatment.

\*The manuscript is currently under review with publisher. For more details, see Health Status and Knowledge of Cancer Survivors.

## **Manuscript #3** Making the case for optimal use of survivorship care plans<sup>11</sup>

The objective of this study was to examine the value of SCPs with regard to use and health actions taken, as well as assess patient satisfaction with the SCP. Surveys gathered information prior to and three months after survivors

received the SCP. Of 189 respondents, the three most reported SCP uses were to share with their spouse/partner (52.4%), to inform themselves about symptoms (49.7%), and to ask their physician or nurse about concerns (44.4%). The least reported use of the SCP was to share with their primary care provider (15.3%).

Cancer survivors who reported any use of the SCP were 11.1 times more likely to have taken a health action. However, one in five survivors did not use the SCP in any way. Further use of the SCP was associated with high levels of satisfaction with the SCP as a care management tool.

\*The manuscript is currently under review with publisher. For more details, see Health Status and Knowledge of Cancer Survivors.

## **Presentations**

Content from the White Papers and Manuscripts was also disseminated through numerous presentations throughout program year three, including:

- Oral Presentation: 2017 Sanford Nursing Research and Evidence Based Practice Conference, Sioux Falls, SD, October 6, 2017
- Poster Presentation: Avera/SDSU Research Symposium, Brookings, SD, October 25, 2017
- Poster Presentation: SD Public Health Association, Sioux Falls, SD, June 19, 2018
- Poster Presentation: SD Cancer Coalition Fall Meeting, Mitchell, SD, September 26, 2018
- Oral Presentation: SD Chronic Disease Partner's Meeting, Mitchell, SD, October 16, 2018
- Poster Presentation: American Public Health Association, San Diego, CA, November, 2018

## Program Satisfaction



Staff involved in the SDSP from the partner cancer treatment centers were invited to participate in an evaluation survey, repeated from program years one and two, assessing their satisfaction with collaboration to achieve the goals of the program. The questions contained in the survey were designed to generate feedback about the strengths, weaknesses and the steps needed to enhance program efforts.

Overall program satisfaction remained high among all partners during the three-year program period, with a mean respondent rating of 8.25 (scale of 0 to 10). Satisfaction with program leadership was high, with many respondents rating the overall leadership of the SDSP as very good. The highest leadership rating was in coordinating communication among people and organizations.

Staff from partner cancer treatment centers rated the quality of the collaboration and partnership among all the participating cancer treatment centers. Overall, the five partnership measures received average scores, with the aggregate respondent mean for all partnership components ranging between good to very good. Partnership ratings dropped significantly from program year two to program year three, however, with the small respondent population this is largely due to a negative rating from one involved individual.

Availability of resources was also assessed in the program satisfaction survey. Partners were asked to think about the funding, support, and expected timeframes provided by the SDSP and indicate their level of satisfaction. The program resource assessment components received moderate scores, with a mean aggregated level of agreement from 3.83 to 4.5 (scale of 0 to 5). The highest resource rating was sufficient training or support to carry out the requested activities of the SDSP (4.5), and the lowest resource rating was for the amount of funding provided to carry out SDSP activities (3.83).

Lastly, staff were asked to describe what they feel has been the greatest accomplishment of the SDSP at their facility in the last year and throughout the three-year program period. We proudly share the below comments as

examples of the impact the SDSP has made in the last year, as well as across the last three years of program implementation.

*“Our greatest accomplishment has been the standardization of survivorship care planning services across a geographically diverse health system.”*

*“Throughout our work with this grant, we identified multiple data tracking issues that we had in our processes. Having the support and the backing of the grant has allowed us the opportunity to identify and work through those issues. Without the reporting requirements of the grant, some of these may have been identified much later, so being able to implement change early on has been a huge help with our survivorship program.”*

*“Our greatest accomplishment has been the extension of survivorship care planning services to underrepresented and underserved populations.”*

*“Being able to implement a dedicated GU Navigator has been a huge accomplishment. This has allowed us to reach a population we were previously unable to connect with, and has increased collaboration with the urology group and oncology group as a whole.”*

A full report of program satisfaction results was provided to the SDSP in August 2018.<sup>14</sup>

## Summary of Program Year 3



### SUMMARY:

Over the last three years of the South Dakota Survivorship Program (September 30, 2015 – September 29, 2018), collaborations with local cancer treatment centers and other partners have resulted in numerous outcomes.

Cancer survivorship surveillance systems have been expanded through incorporation of the full BRFFS Survivorship Module in years 2016, 2017, and 2018. Data gathered through this module has contributed to two South Dakota specific surveillance briefs. Additionally, the SDSP worked with the partner cancer treatment centers over the three-year program period to develop and enhance processes to identify survivors eligible to receive a SCP through use of the cancer treatment centers' electronic health record systems. These enhancements have allowed the partnering cancer treatment centers to meet and exceed the CoC standards for SCP distribution in all three years of program funding.

Community/clinical linkages have been facilitated through patient navigation programs. The development of integrated assessment and referral processes to identify eligible cancer survivors for referral to tobacco cessation assistance, nutrition and physical activity assessment and referral, and assessment and referral for preventative cancer screenings with an emphasis on colorectal cancer screening has led to extensive growth in referral metrics among the partnering health systems.

The Navigator Network, developed in program year one, has fostered collaboration among cancer partners and offered a platform to share cancer

survivor best practices. Numerous training opportunities were provided to cancer professionals statewide.

Finally, the SDSP has accelerated the evidence related to survivorship practices through development of three peer-reviewed manuscripts and three program white papers. This literature has been shared with program partners and key stakeholders through the state cancer website, [www.cancersd.com](http://www.cancersd.com), and through journal publication.

As the funding for the South Dakota Survivorship Program comes to a close, the following recommendations are offered for sustainability of the achieved program outcomes:

### **RECOMMENDATIONS:**

- 1) **Invite program partners and key stakeholders to be involved in the SD Cancer Coalition.** A taskforce has been formed to address Priority 13 of the South Dakota Comprehensive Cancer Control State Plan: Promote Patient-Centered Care to Enhance Quality of Life for Cancer Survivors.<sup>15</sup> Insights from cancer treatment center partners would be a valued addition to the taskforce.
- 2) **Offer education to primary care providers regarding the transition of care for survivors.** Transition of care from a survivor's oncology team back to their primary care provider is an integral part of a survivor's journey. The South Dakota Cancer Coalition taskforce, Promote Patient-Centered Care to Enhance Quality of Life for Cancer Survivors, is ideally positioned to organize survivorship training focused specifically towards primary care providers.
- 3) **Promote resources for patient self-management.** *Better Choices, Better Health* offers a self-management program developed specifically for cancer survivors.<sup>16</sup> The program, entitled Cancer: Thriving and Surviving, is offered as a six-week online workshop, with new lessons posted each week. Course subjects include: 1) healthy eating, 2) creating a physical activity program, 3) managing stress, 4) working with health care providers, 5) better communication with family, friends, co-workers and providers, 6)

managing emotions and relationships, 7) managing fatigue, and 8) effects of treatment. Program outcomes indicate that people who took the program more than 2 years after cancer treatment, compared to those who did not, showed significant changes in insomnia, exercise, fatigue, visits to physicians, communication with physicians, and depression.<sup>16</sup> Referral to this online workshop in combination with receipt of a personalized SCP may equip survivors with the knowledge and skills required for self-management of the physical, psychological, and social needs post cancer treatment.

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