Enhancing Quality of Life for Cancer Survivors in South Dakota

Outcomes from the South Dakota Cancer Survivorship Program

The South Dakota Survivorship Program was funded through cooperative agreement number DP006114 to the South Dakota Department of Health funded by the Centers for Disease Control and Prevention. The contents of this presentation are solely the responsibility of the presenters and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

PROGRAM OVERVIEW

Presenter: Lexi Pugsley, MS, RN

Background

- Cancer survivor refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life
- Cancer incidence remains high
  - 1.7 million new cancer cases diagnosed in the US in 2018
  - 5,100 new cancer cases diagnosed in SD in 2018
- Prevalence of cancer survivors in the US continues to increase
  - 15.5 million cancer survivors in the US
  - 39,330 cancer survivors in SD
- Advancements in cancer care and an aging population are leading to a continued increase in survival rates
- Nearly 12% of South Dakotans report having cancer at one point in their lifetime

Project Period: 9/30/15-9/29/18

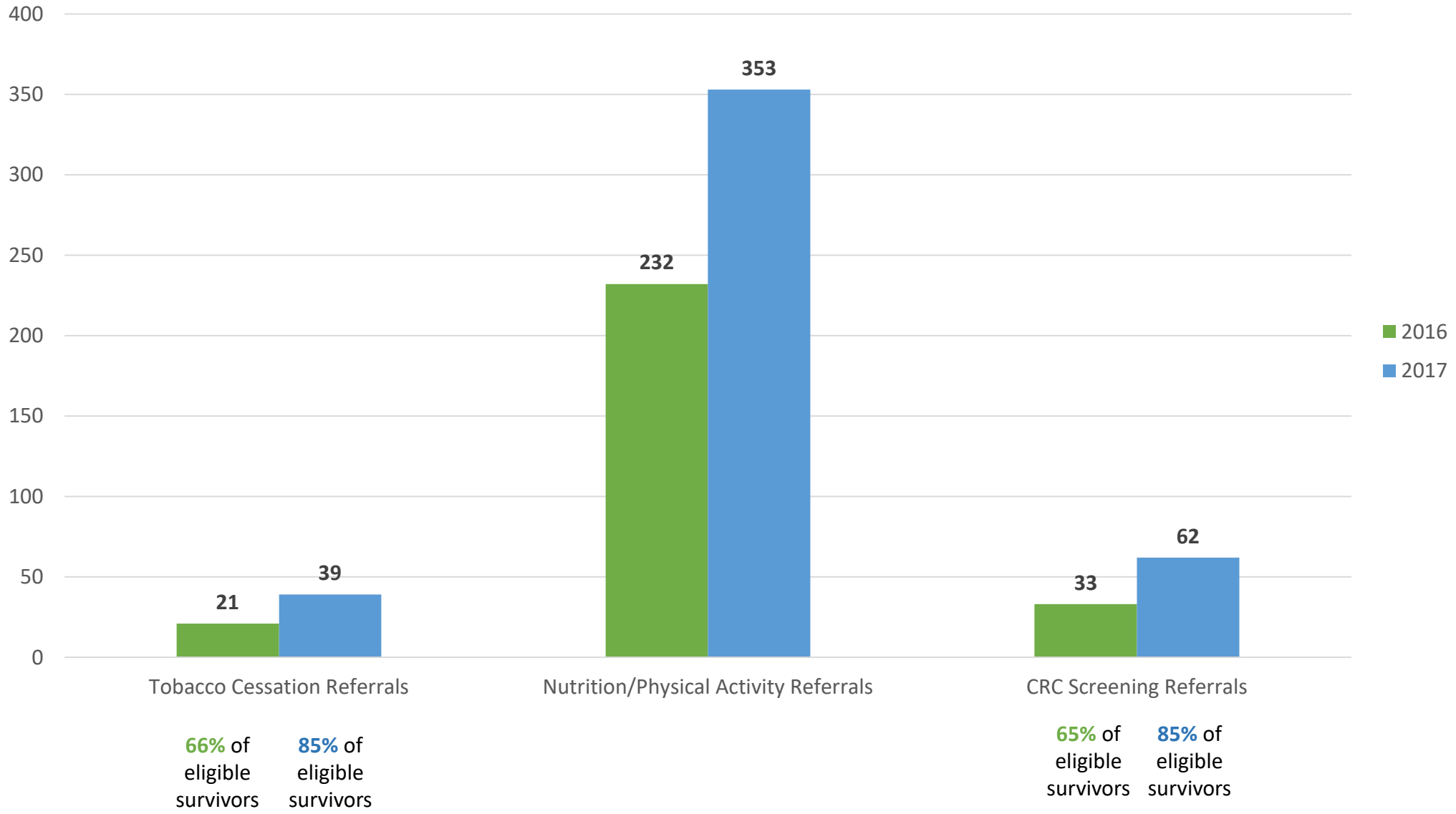
Clinical Partners:

- Avera Cancer Institutes: Aberdeen, Mitchell, Sioux Falls, and Yankton, Sanford Cancer Center, Urology Specialists

Focus Areas:

- Patient Navigation
- Surveillance
- Survivorship Care Plans
- Health Status and Knowledge of Cancer Survivors
- Healthcare Provider Knowledge
- Dissemination of Evidence via Publications

Patient Navigation



Surveillance

SOUTH DAKOTA BRFSS SURVEILLANCE BRIEF: CANCER SURVIVORSHIP

Background:
The American Cancer Society (ACS) estimates there are 39,330 cancer survivors residing in SD.[1] The National Cancer Institute identifies, "in cancer, a person is considered to be a survivor from the time of diagnosis until the end of life".[2] However, survivorship is often considered as the period after conclusion of active treatment for survivorship care plan delivery. Cancer survivors are at greater risk for developing secondary cancers and often have unique needs related to long-term treatment effects, follow-up care, and surveillance for reoccurrence. An Institute of Medicine Report identified failures in the U.S. healthcare system in providing coordinated and comprehensive follow-up care for cancer survivors. The report also identified a lack of guidelines and system failures for assisting cancer survivors with the care transition from oncology care and overcoming psychosocial or medical problems that they may face.[3] Survivorship Care Plans were identified as an opportunity to help improve communication and the quality of care for cancer survivors. Currently, two accreditation programs from the American College of Surgeons – the Commission on Cancer and National Accreditation Program for Breast Cancers – include standards on cancer survivorship care plans.[4]

Methods:
The South Dakota Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey of residents aged 18 and older and is conducted as a combined effort between the South Dakota Department of Health (DOH) and the Centers for Disease Control and Prevention. Further details on the SD BRFSS methodology can be found at https://doh.sd.gov/Statistics/2016BRFSS/Methodology.pdf.

The full thirteen-question CDC cancer survivorship optional module was included on the 2016 SD BRFSS. This report utilizes data from this optional module to evaluate cancer survivorship care plan receipt, clinical trial participation, and other relevant indicators for cancer survivorship.

Results:
In 2016, 11.8% of South Dakota adults reported ever having cancer in their lifetime, including skin cancer. Among cancer survivors, 84.5% reported having one type of cancer, 13.9% reported having two types, and 1.6% reported having three or more. As outlined in Table 1, the cancer type most frequently reported was skin cancer, followed by breast, male reproductive, female reproductive and gastrointestinal. For respondents with two or more cancer types, their most recent type of cancer diagnosis was reported. The mean age at diagnosis was 53, and the age range at diagnosis was from 2 years to 89 years old. When asked to identify who provided the majority of their health care, 54.6% of cancer survivors reported family practitioner and 25.9% reported general practitioner. Most survivors (93.2%) reported having health insurance that covered all or part of their treatment. Clinical trial participation as part of cancer treatment was reported by 4.5% of cancer survivors. Only 4.9% of cancer survivors reported current physical pain due to cancer treatment. Due to a low number of events (LNE), pain control is not able to be reported.

Table 1. Cancer Types Reported

Cancer Type	% (95% CI)
Skin	48.7 (42.6-54.9)
Breast	11.8 (8.5-15.2)
Male Reproductive	11.1 (7.2-15.1)
Female Reproductive	10.1 (6.5-13.6)
Gastrointestinal	3.7 (1.7-5.6)
All Others[*]	Low Number of Events (LNE)

[*]all others include, but are not limited to, urinary, head/neck, leukemia, and thoracic

August 2018

SOUTH DAKOTA BRFSS SURVEILLANCE BRIEF: CANCER STATUS AND HEALTH INDICATORS

Background:
The American Cancer Society estimates over 15.5 million Americans alive today have a history of cancer.[1] Cancer typically occurs in older adults, with 87% of all cancers diagnosed among those aged 50 and older.[1] Practicing healthy behaviors such as maintaining a healthy weight, completing the HPV vaccine series, avoiding tobacco, limiting or eliminating alcohol intake, and practicing skin protection can reduce a person's risk of developing cancer. However, some risk factors such as getting older and genetics cannot be modified.[2]

Methods:
The South Dakota Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey of residents aged 18 and older and is conducted as a combined effort between the South Dakota Department of Health (DOH) and the Centers for Disease Control and Prevention. Further details on the BRFSS methodology can be found at https://doh.sd.gov/Statistics/2016BRFSS/Methodology.pdf.

Two questions related to lifetime cancer prevalence were included within the CDC core portion of the 2015 and 2016 SD BRFSS. The BRFSS does not allow differentiation between basal and squamous cell carcinomas of the skin and melanoma of the skin. Since basal and squamous cell carcinomas of the skin are not reportable by law to the SD Cancer Registry, this report compares respondents who indicated having been told by a doctor, nurse, or other health professional that they had any other type(s) of cancer, other than skin cancer, to those respondents who reported they had never been told they had cancer. In this report, these respondent groups are identified as cancer survivors and no cancer history; however, the no cancer history group may include respondents with a history of skin cancer. Results from the 2015 and 2016 BRFSS survey were combined to give more stable estimates. Data was age-adjusted using the 2000 Census population and the following age groups: 18-29, 30-39, 40-49, 50-64, 65-74, and 75+. Data analysis was conducted using SAS V9.3.

This report utilizes data from the 2015 and 2016 SD BRFSS to compare demographics, physician status, health behaviors, and quality of life indicators between cancer survivors and those with no cancer history. All questions were asked in both years, with the exception of questions on muscle strengthening guidelines and quality of life limitations due to physical, mental, or emotional problems. Those questions were only asked in 2015.

Table 1. Demographic comparison between cancer survivors and those with no cancer history, 2015 & 2016 SD BRFSS (N=12,988)

Demographics	% (95% CI)	95% CI
	Cancer Survivor	No Cancer History
	6.2 (5.6-6.8)	93.8 (93.1-94.4)
Age		
18-44	11.0 (7.5-14.6)	48.5 (46.9-50.1)
45-54	10.8 (7.1-14.5)	15.8 (14.7-16.8)
55-64	23.0 (18.98-27.1)	17.2 (16.1-18.2)
65-74	24.7 (21.2-28.3)	10.6 (9.8-11.4)
75+	30.5 (26.3-34.6)	8.0 (7.3-8.6)
Gender		
Male	35.6 (26.1-46.4)	50.9 (49.2-52.5)
Female	64.4 (53.6-73.9)	49.1 (47.5-50.8)
Race		
White	94.7 (89.3-97.4)	84.6 (83.0-86.0)
Other	LNE	LNE
American Indian	4.9 (2.3-10.1)	7.0 (6.2-8.0)
Education		
Less than high school	8.6 (4.7-15.4)	10.3 (9.1-11.7)
High school graduate	26.5 (19.7-34.6)	30.7 (29.1-32.3)
Some College	42.6 (32.5-53.3)	34.0 (32.5-35.6)
College graduate	22.3 (15.5-31.0)	25.0 (23.7-26.2)
Income		
<$20,000	25.3 (15.4-38.6)	13.8 (12.6-15.1)
$20,000-$34,999	16.1 (10.8-23.3)	18.6 (17.3-20.1)
$35,000-$49,999	21.0 (13.0-32.2)	17.4 (16.0-18.9)
$50,000-$74,999	19.4 (12.1-29.6)	18.9 (17.5-20.3)
$75,000+	18.2 (13.5-24.1)	31.3 (29.7-32.9)

Results:
In 2015 and 2016 combined, 7.1% of the South Dakota adult population stated that they had ever been told by a doctor or other health professional that they had cancer, other than skin cancer. When adjusted for age, the prevalence is 6.2%. Table 1 shows the age-adjusted prevalence rates for the demographics of the cancer survivorship population compared with those who have no history of cancer. Among cancer survivors, 64.4% were female while only 35.6% were male.

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Available at: https://www.cancersd.com/evaluation-and-outcomes/

Survivorship Care Plan Content

- **Treatment Summary**
  - Contact information for providers and centers who administered the treatment
  - Basic diagnostic and staging information
  - Information on surgery, radiation therapy, systemic therapy (both chemotherapy and biologic therapies), and ongoing significant toxicities, including dates
- **Follow-Up Care Plan**
  - Surveillance plan to detect recurrence and late adverse effects
  - Interventions to manage ongoing problems resulting from the cancer and its treatment
  - Age- and sex-appropriate health care, including cancer screening
  - General health promotion

SCP Requirements: CoC Standard 3.3

- Must contain input from the principal physician and oncology care team who coordinated treatment, as well as input from the patient's other care providers
- The survivorship care plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record
- The timing of delivery of the SCP is within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy)
- Providing the SCP by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard

SCP Eligibility

- In general, cancer survivors meeting the following criteria are considered eligible for receipt of a SCP
  a) diagnosed and/or received first course of treatment, all or in part, at one of the participating locations
  b) cancer stage I, II, or III (plus ductal carcinoma in situ for centers accredited by the National Accreditation Program for Breast Centers)
  c) treated with curative intent for initial cancer occurrence
  d) completed active therapy

Barriers to SCP Implementation

- The substantial time required to complete an SCP
- Inadequate reimbursement for the time and resources required to complete the SCP
- Challenges in coordinating care among providers and between providers and survivors
- Incomplete penetration of EHR systems in the marketplace that can facilitate SCP completion

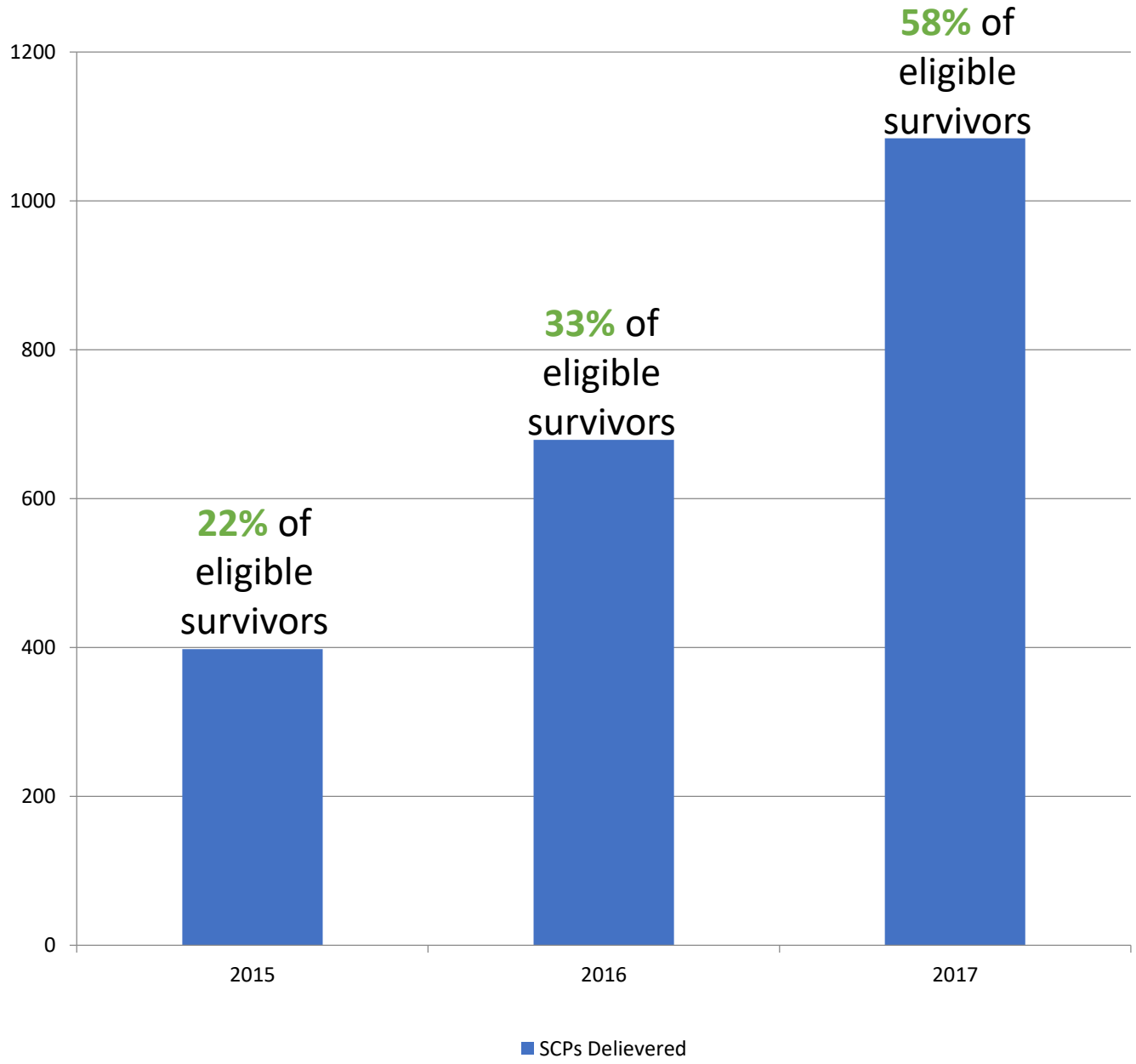
Project Implementation Efforts

- Adoption of SCP policies
- Patient navigation
- Professional education, certification, and competency adoption
- Workflow enhancements
- Implement EHR and reporting enhancements
- Focus on care coordination and PCP collaboration
- Test promising models and share best practices
- Focus on sustainable practices

Survivorship Care Plans

CoC Standards:

- End of 2015: ≥10% ✅
- End of 2016: ≥25% ✅
- End of 2017 and on: ≥50% ✅



Healthcare Provider Knowledge

In-Person

•Cancer Survivorship Training- May 2016

Motivational Interviewing- June 2018

Webinars

Patient Navigation in Oncology

ACS Survivorship Webinar Series

SD QuitLine and Tobacco Assessment and Referral

Incorporating Cancer Survivorship Into Primary Care

Online Training

Cancer Survivorship E-Learning Series for Primary Care Providers

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

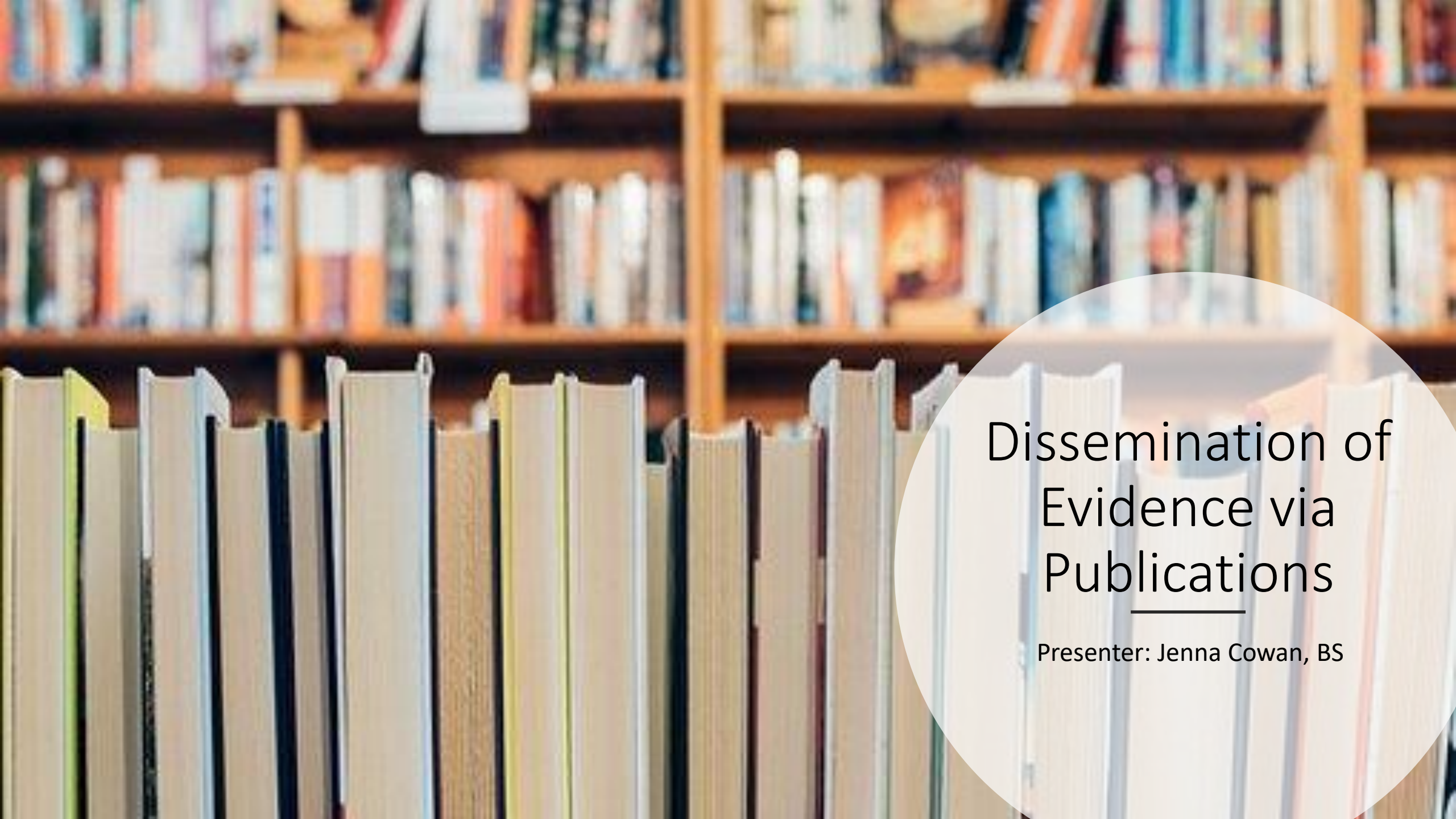
“Our greatest accomplishment has been the extension of survivorship care planning services to underrepresented and underserved populations.”

“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.”

Cancer Survivorship Efforts Moving Forward

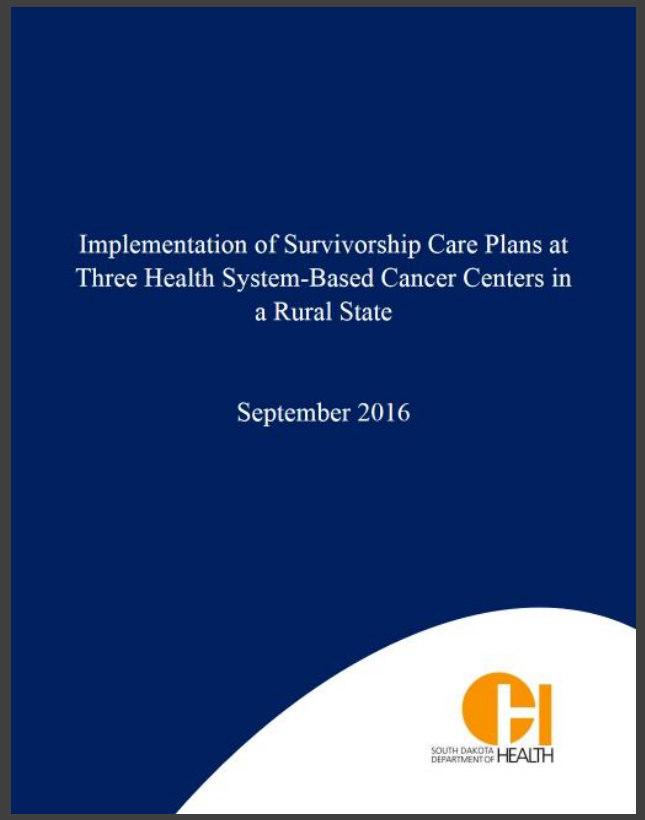
- SD Cancer Coalition - Cancer Survivorship Task Force

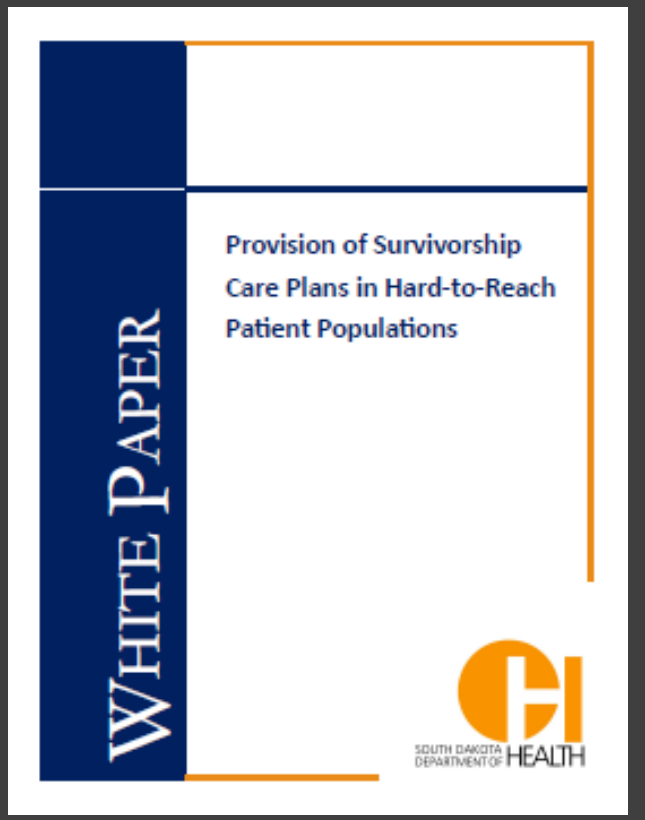
- Topics for consideration:
  - Survivorship Care Plan (SCP) Provision
  - Professional Development/Provider Referrals
    - Primary Care Providers and SCPs
    - Tobacco Cessation Referrals for Cancer Survivors
    - Physical Activity Referrals for Cancer Survivors
    - Community/Clinical Resource (Better Choices, Better Health, etc.) Referrals for Cancer Survivors
  - Caregivers
  - Coping



Dissemination of Evidence via Publications

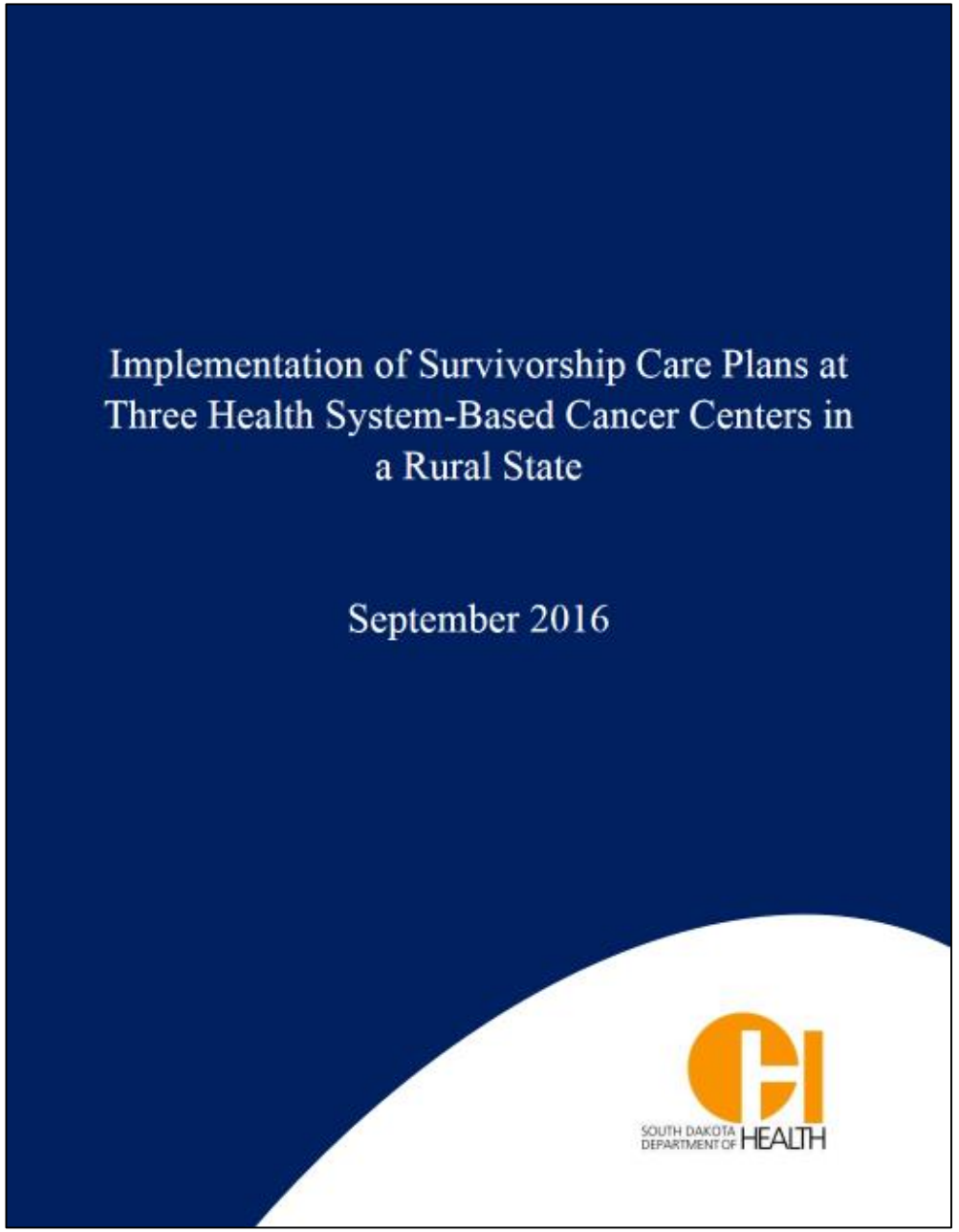
Presenter: Jenna Cowan, BS





White Papers

Available at: https://www.cancersd.com/evaluation-and-outcomes/



Conducted structured interviews with three health systems (representing six cancer treatment center sites)

Gained insights to how each health system elected to design and employ survivorship care plans

- SCP development
- SCP creation and delivery
- Successes and effective strategies
- Challenges and support needed

Framework for Implementation

- Build a foundation
- Gather resources
- Review the evidence
- Elicit input
- Implement in stages

Interview Questions:

How did you develop the templates for the survivorship care plan?

How has the process evolved since you initiated the survivorship care plan?

Describe how a patient is identified and then scheduled for the survivorship care plan appointment.

What is your current process for inputting information into the survivorship care plan template?

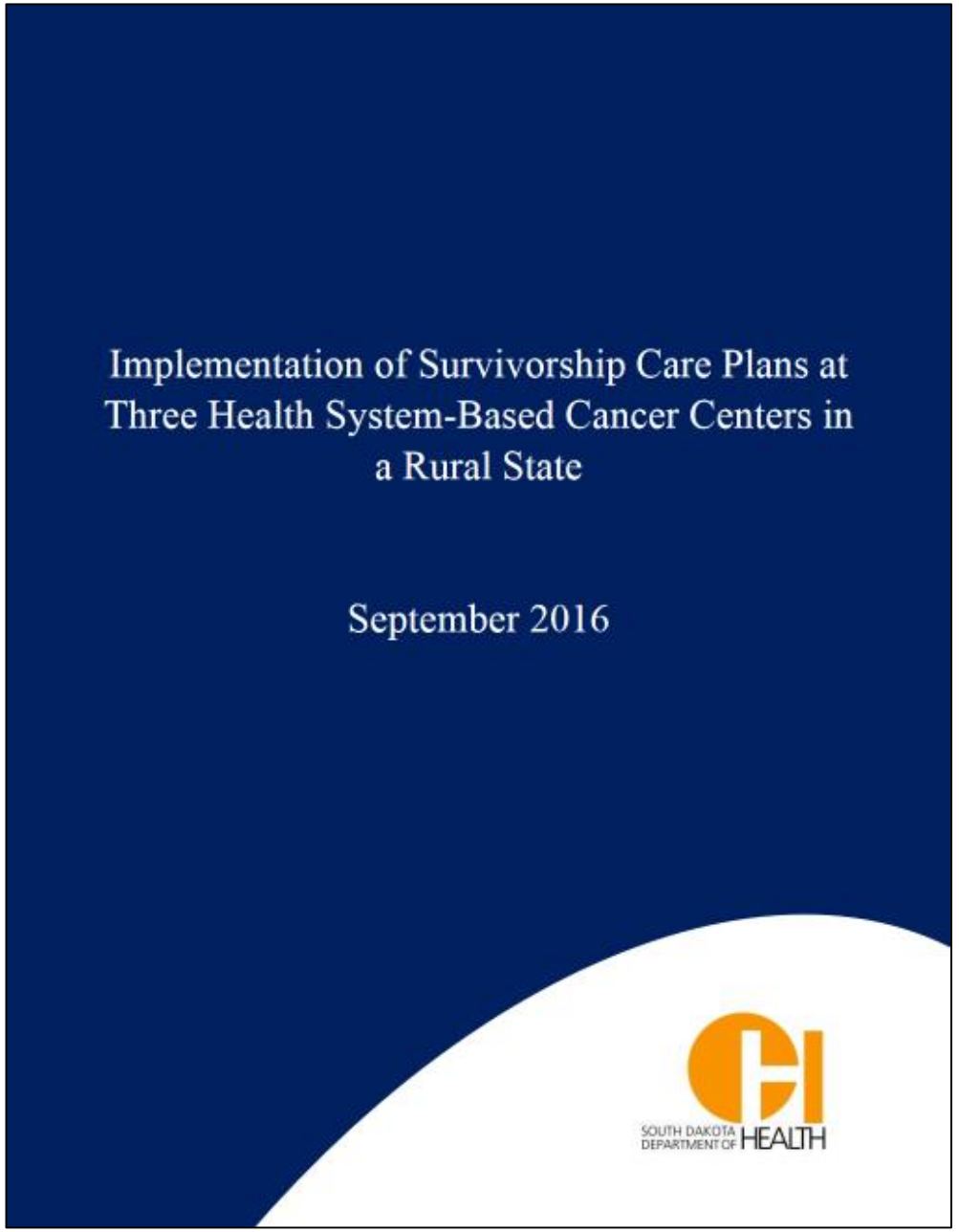
Describe how a patient receives the survivorship care plan.

How do you share the survivorship care plan with the patient's primary provider?

What have you found to be the most challenging aspects of the process of developing, populating, delivering, and then sharing the survivorship care plan?

Have you witnessed any evidence of how the survivorship care plan has resulted in better patient care or outcomes?

Is there anything else that you think would be helpful for us to know as we review your process for survivorship care plans?



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Avera Cancer Institute Navigation Center

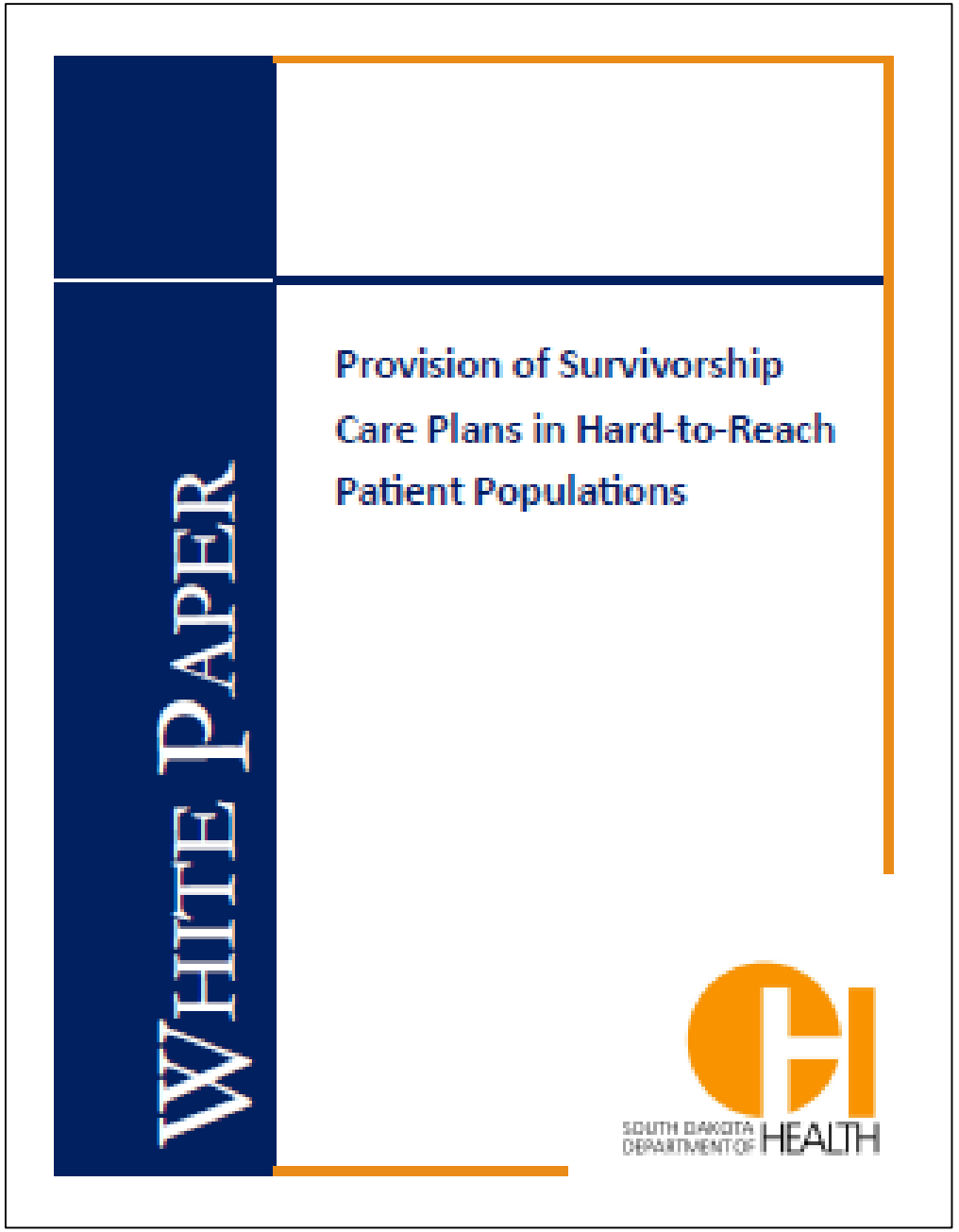
Expanding cancer care services from prevention through survivorship

“Cancer is so complex. You have so many providers involved with one patient. You have so many medications and so many treatment regimens. You have such a high volume of people traveling from very rural areas to the cancer treatment center. All of the traditional burdens and barriers that fall into healthcare tend to be exacerbated for oncology.”

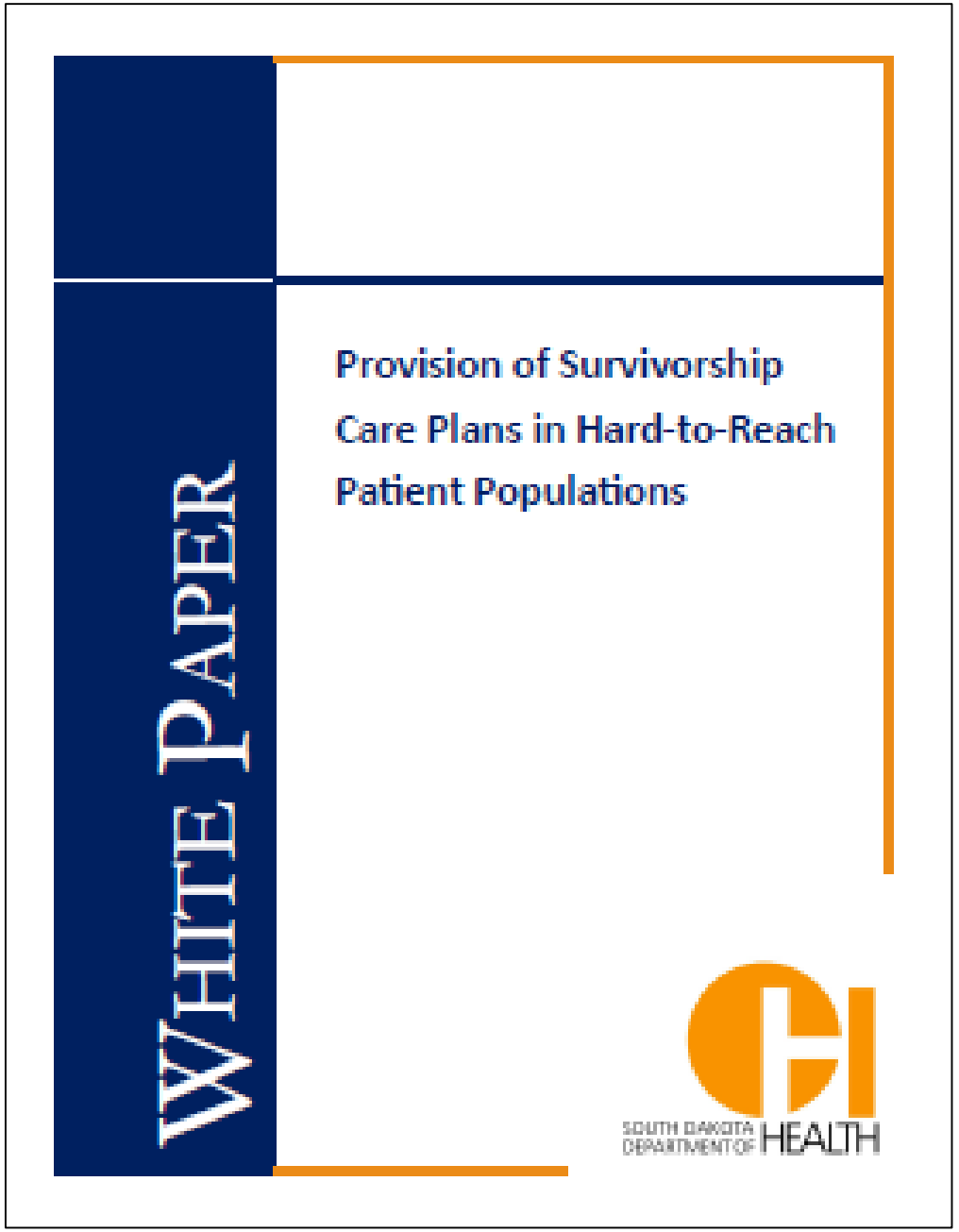

Avera
Cancer Institute
Navigation Center

Commission on Cancer Standard 3.3

To maintain CoC accreditation in 2018, cancer programs must provide survivorship care plans to ≥50 percent of eligible patients who have completed treatment



- With increases in the five-year survival rate, a focus on long-term survivorship care is of critical importance.
- Survivorship care plans are recommended by the Institute of Medicine to help survivors make a successful transition to post-treatment cancer survivorship.
- To maintain Commission on Cancer accreditation, cancer programs must provide survivorship care plans to ≥50 percent of eligible patients who have completed treatment.
- Complications in identifying cancer survivors for survivorship care plan provision can arise when surgery privileges are granted to private providers outside of a health system.
- This white paper highlights the unique collaboration of two individual health system cancer treatment centers with one auxiliary specialty center as they addressed provision of survivorship care plans in a hard to reach patient population of urological cancer survivors.



Collaboration Model #1

- Collaboration for survivorship began in 2013
- Follow-up care is provided by the specialty center for surgery only patients. However, since the surgery took place at the health system, the patient is included in the denominator population for SCP provision to meet Standard 3.3.
- Health system made a strategic decision to offer dedicated resources to provide care to this patient population that might not received any direct or additional services from the health system.
- Hired a genitourinary oncology nurse navigator to provide patient navigation services, SCP creation and delivery.
- Navigator has found success by having a physical presence at the specialty center, providing in-person delivery of the SCP.
- GU Navigator position benefits both facilities.

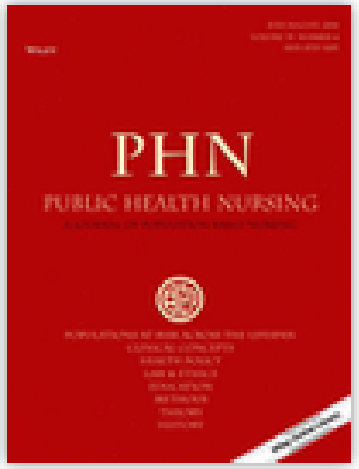
Collaboration Model #2

- Collaboration for survivorship initiated in May 2017
- Through the health system's involvement in the South Dakota Survivorship Program, funding was provided to support a GU oncology nurse navigator
- Gu Navigator role based at the Health System, SCP delivered by mail followed by a phone based visit
- Patients tend to be more open to discussing sensitive subjects over the phone rather than in person
- SCP provision supports both facilities mission and enhances the patient experience
- Exploring expansion of navigation services and SCP provision to patients of dermatology, thyroid, and other surgery-only patient populations.

Summary of Collaborations

- Survivorship collaborations with specialty providers can enhance care collaborations, as well as enhance the overall patient experience.
- Each health system developed a model of collaboration that fit with the unique needs and resources of their health system.
- Although the collaboration models vary in delivery methods, both models have received positive patient feedback, indicating that the service provides value regardless of the method of delivery, and is a good investment for the patient's well-being.
- A healthy working relationship and clear communication between facilities is a necessity.
- Collaborations help support care coordination among facilities and provide a team approach to patient care.
- Same model could be used in other population gaps, such as dermatology patients, head and neck cancers, and breast cancer patient receiving surgery only from an outside provider.

Manuscripts



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July/August 2018

Manuscript #1:

Cancer survivorship care plans: Processes, effective strategies, and challenges in a Northern Plains rural state

Mary J. Isaacson PhD, RN, CHPN, Polly A. Hulme PhD, CNP, RN, Jenna Cowan BS, Jennifer Kerkvliet MA, LPC, NCC

UNDER REVIEW FOR PUBLICATION

Manuscript #2:

Patient knowledge of cancer treatment history and follow-up care after receipt of a survivorship care plan

Manuscript #3:

Making the case for optimal use of survivorship care plans

Health Status and Knowledge of Cancer Survivors

Chamika Hawkins-Taylor, MHA, PhD

Patient Knowledge of Cancer Treatment History and Follow-Up Care after Receipt of a Survivorship Care Plan

Study Objective:

To assess survivor perceived knowledge about their treatment history and follow-up care before and after SCP receipt.

Methods:

- Across six study locations, eligible survivors received a pre-SCP and 3-month post-SCP survey assessing perceived knowledge about disease, treatment, and follow-up care.
- Non-parametric tests assessed total knowledge change from pre- to post-SCP.

Results:

- N = 152 survivors who completed both the pre and post surveys.
- The sample was 80% female (45% breast cancer) and mean age, 60.5 years (sd=11.1).

Table: Change in survivor care knowledge after SCP

		Knowledge Score (mean ± SD)			
Population[a]	N	Pre-SCP	Post-SCP	Post - Pre	P-Value[b]
Total	152	25.5 ± 7.2	27.2 ± 4.3	1.7 ± 6.7	0.002
Restricted	127	24.6 ± 4.4	26.8 ± 4.0	2.3 ± 4.7	<0.001

a) The total population had complete data at pre- and post-program and the restricted population had disagree or agree response at pre-program.
b) Wilcoxon Signed Rank test using post-SCP minus pre-SCP difference knowledge scores.

Conclusion:

- ✓ SCPs can improve knowledge, and may equip survivors with the knowledge and skills required for self-management of the physical, psychological, and social needs that they may experience post treatment.
- ✓ SCP provision enhances the patient experience, impacting higher perceived knowledge for more informed management of follow-up care leading to better quality of life for cancer survivors.

Making the Case for Optimal Use of Survivorship Care Plans

Results:

- N = 189 survivors who completed both the pre and post surveys.
- The sample was 82% female (49% breast cancer).
- 60% of patients in Stage I or Stage II.

	Number	Percent
Search Information Online		
No	149	78.8%
Yes	40	21.2%
Ask Physician or Nurse About Concerns		
No	105	55.6%
Yes	84	44.4%
Inform About Symptoms		
No	95	50.3%
Yes	94	49.7%
Find Referrals for Follow-Up Care		
No	153	81.0%
Yes	36	19.0%
Shared with PCP		
No	160	84.7%
Yes	29	15.3%
Shared with Spouse or Partner		
No	90	47.6%
Yes	99	52.4%
Shared with Family Members at Risk		
No	137	72.5%
Yes	52	27.5%

Study Aims:

1.) Examine the value of SCPs (survivorship plan use and health actions taken)

2.) Assess patient satisfaction with the SCP.

Methods:

Assessment of Outcome variables on pre and post survey related to:

1. Use of the SCP
2. Health Actions Taken
3. Satisfaction with follow-up information found on SCP.

Conclusion:

- Cancer survivors reporting SCP use were eleven times more likely to have taken a health action.
- Most frequently reported actions included getting regular checkups (53.9%), eating healthier (58.2%), being more physically active (52.9%) and scheduling preventive cancer screenings (51.9%).

QUESTIONS?