

# Cancer Survivorship Care Plan Utilization and Impact on Clinical Decision-Making at Point-of-Care Visits with Primary Care: Results from an Engineering, Primary Care, and Oncology Collaborative for Survivorship Health

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**Abstract** Every cancer survivor and his/her primary care provider should receive an individualized survivorship care plan (SCP) following curative treatment. Little is known regarding point-of-care utilization at primary care visits. We assessed SCP utilization in the clinical context of primary care visits. Primary care physicians and advanced practice providers (APPs) who had seen survivors following provision of an SCP were identified. Eligible primary care physicians and APPs were sent an online survey, evaluating SCP utilization and influence on decision-making at the point-of-care, accompanied by copies of the survivor's SCP and the clinic note. Eighty-eight primary care physicians and APPs were surveyed

November 2016, with 40 (45%) responding. Most respondents (60%) reported discussing cancer or related issues during the visit. Information needed included treatment (66%) and follow-up visits, and the cancer team was responsible for (58%) vs primary care (58%). Respondents acquired this information by asking the patient (79%), checking oncology notes (75%), the SCP (17%), or online resources (8%). Barriers to SCP use included being unaware of the SCP (73%), difficulty locating it (30%), and finding needed information faster via another mechanism (15%). Despite largely not using the SCP for the visit (90%), most respondents (61%) believed one would be quite or very helpful for future visits. Most primary care visits included discussion of cancer or cancer-related issues. SCPs may provide the information necessary to deliver optimal survivor care but efforts are needed to reduce barriers and design SCPs for primary care use.

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## Introduction

Survivorship care plans (SCPs) have been recommended as a tool for communication between oncologists and primary care providers [1–4]. The 2005 Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* ushered in the “care plan-era” and led to a cultural shift to implement and provide such SCPs to all cancer survivors as well as primary care [1]. Application of these recommendations has penetrated across multiple large consortiums including the American College of Surgeons’ Commission on

Cancer (CoC), which now mandates that accredited programs provide SCP documents and visits to > 75% of cancer survivors and their primary care providers by 2019 [5, 6]. While SCPs are increasingly implemented, their optimal format and use remain unclear. As institutions continue to generate and disseminate SCPs, more understanding is needed with regard to primary care utilization of SCPs. This will enable refinement of SCP content, layout, and provision to enhance use and, thus, ultimately improve survivorship care.

Studies regarding “real-world” utilization of SCPs are limited. They have generally focused on awareness of receipt and utility of SCPs as a communication tool between oncology subspecialists, primary care, and cancer survivors [4, 7]. In general, primary care providers regard SCPs as useful and feel that utilization of SCPs in the clinical context would not disrupt clinical workflow or take too much time [5, 7]. However, there is limited data regarding how primary care providers actually utilize SCPs and whether or not their clinical decision-making changes as a result of the information found within SCPs.

The University of Wisconsin (UW) Health Engineering, Primary care and Oncology Collaborative for survivorship health (EPOCh) formed to address ongoing survivorship health needs, such as improvements in SCP design and provision, at our institution. This Collaborative seeks to incorporate unique primary care and engineering perspectives to optimize the care of cancer survivors. Our first initiative was a primary care-directed education program on the topic of SCPs [8]. A follow-up initiative was designed with a view towards improving SCP delivery for primary care providers and inquired about real-world utilization of SCPs at primary care clinic visits. We conducted a cross-sectional survey of primary care physicians and advanced practice providers (APPs) with the objectives of (1) understanding the real-world utilization of SCPs within a primary care outpatient context and (2) assessing the impact that SCPs had on clinical decision-making within primary care clinic visits.

## Methods

**Setting** UW Health is the integrated health system serving more than 600,000 patients each year in the Upper Midwest and beyond with 1400 physicians and 16,500 staff. This includes the Carbone Cancer Center, an NCI-designated comprehensive cancer center with accreditation from the American College of Surgeons’ Commission on Cancer (CoC), among others. All UW Health patients are assigned a primary care physician; however, these physicians work in collaborative primary care teams including APPs such as nurse practitioners and physician assistants. The UW Department of Family Medicine and Community Health (FM) has 20 clinics throughout the state, while the UW

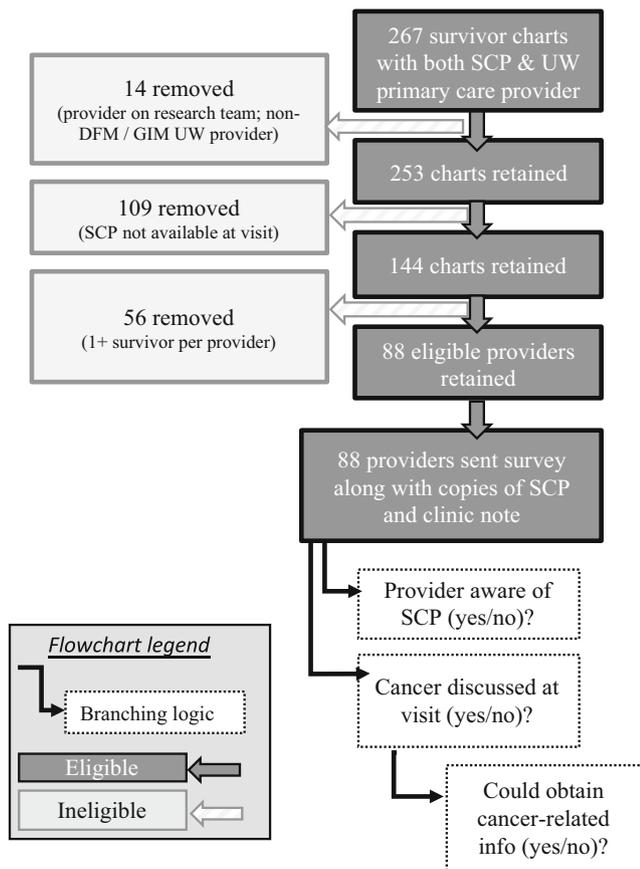
Division of General Internal Medicine (GIM) has nine clinics in Dane County and one regional clinic.

**EHR-Based SCPs** Since July 2015, UW Health has leveraged the electronic health record (EHR) in generating SCPs for curatively treated survivors, with additional groups of cancer survivors being added annually (e.g., breast cancer in 2015, colorectal cancer in 2016, gynecologic and prostate cancers in 2017) [9–11]. The SCP used at our facility is a survivor-facing document that addresses the Commission on Cancer guidelines [3], and contains IOM-recommended [4], American Society of Clinical Oncology (ASCO)-recommended [5], and National Comprehensive Cancer Network (NCCN)-recommended content [6]. As recommended, each survivor’s primary care physician receives a copy of this individualized SCP. In the case of UW Health, receipt occurs within the EHR’s internal communication and task management system as a specifically labeled document. Individualized SCPs are permanently associated with the cancer diagnosis in the survivor’s problem list and visible to members of the healthcare team with EHR access. The EHR interface and location of SCPs are the same for all providers, regardless of setting, degree, or departmental affiliation. Because the EHR generates the SCPs, it can identify survivors who have received SCPs along with the date(s) of receipt [12].

## Primary Care Physician/APP Identification and Eligibility

This EPOCh initiative was exempted from UW IRB review on the basis of being a quality improvement project. EHR analysts generated a database of breast cancer survivors who had (1) a primary care physician from the UW Health system and (2) an EHR-generated SCP in July 2015 or later. This database was generated using EHR data current as of October 2016. Data included the date of each survivor’s most recent point-of-care visit with a UW primary care physician or APP and the date of SCP provision to the survivor. The initial EHR-generated database included 267 unique survivor charts. Figure 1 contains the survey flowchart for identification and eligibility.

Eligible providers were defined as physicians (MD/DO) or advanced practice providers (NP/PA) within FM or GIM, actively seeing patients in a primary care context. We excluded the primary care physician who is a member of the Collaborative and those survivors who had a gynecologist or geriatrician listed as the primary care physician. The database was manually reviewed to (a) ensure primary care physician eligibility, (b) SCP provision was prior to the point-of-care visit with primary care, and (c) facilitate selection of most recent primary care clinic visit ( $n = 56$ ) for providers associated with more than one survivor (e.g., Dr. Jones listed as the primary care physician for two survivors, Ms. Doe and Ms. Smith, both have a SCP and both have seen Dr. Jones or an APP team member since SCP provision). The final primary



**Fig. 1** Survey flowchart

care database included 88 unique provider names (see Fig. 1) so that each primary care physician or APP would receive a single survey for the survivor most recently seen.

**Point-of-Care Survey and Attachments** We defined clinical decision-making with regard to cancer survivorship as (1) monitoring (e.g., imaging; need for and timing of follow-up visits), as well as management of (2) ongoing treatment-related adverse events and (3) potential for future cancer or treatment-related adverse events. To assess impact at point-of-care, the Collaborative developed an electronic survey to determine (1) whether or not the primary care physician or APP utilized the SCP in the context of the recent visit, (2) whether or not the SCP influenced clinical decision-making at the visit, and (3) perceived barriers and/or facilitators to SCP use. The survey included 14 multiple-choice questions and up to 10 open-ended questions. The survey included branching logic on the basis of responses to minimize respondent burden:

- “Prior to this survey, did you know that this patient had a Survivorship Care Plan?”
- “At this visit, was cancer or a cancer-related issue discussed?”

- “For this visit, was there cancer-related information you needed but could not obtain?”

Based on branching logic, not all respondents would be asked the exact same questions, as the question “How much of this visit was spent discussing cancer or cancer-related issues?” would be irrelevant to a respondent who had already answered negatively to “At this visit, was cancer or a cancer-related issue discussed?”

We generated PDF copies of each survivor’s individualized SCP and the point-of-care clinic note associated with each survivor’s most recent primary care visit. The two PDFs and a hyperlink to the survey were sent to each primary care physician or APP via secure intradepartmental email. All surveys and responses were managed by the UW Carbone Cancer Center Cancer Prevention and Outcomes Data (C-POD) to maintain respondent anonymity. Electronic reminders were generated 7 and 14 days following the initial email. Supplemental Material 1 contains the survey and a sample individualized SCP.

**Statistical Analysis** Descriptive statistics were tabulated based on the survey responses.

## Results

Our survey was conducted in November 2016. We closed data collection after 3 weeks with a response rate of 45% ( $n = 40/88$ ). Respondents reported seeing a median of four breast cancer survivors per month (range 1–28).

Table 1 contains responses to key survey questions. Most respondents (60%,  $n = 24$ ) identified that at least some portion of the survivor’s primary care visit included reviewing cancer or cancer treatment-related issues, although we did not query as to the exact issue(s) discussed. Most respondents (73%,  $n = 29$ ) reported being unaware that the survivor had a SCP. From the minority of respondents (27%,  $n = 11/40$ ) who reported being aware that their survivor had a SCP, most (64%,  $n = 7/11$ ) had previously used it. Only four respondents (10%,  $n = 4/40$ ) reported using the SCP for the visit in question. Of these four respondents, all reported that the SCP was helpful. Respondents ( $n = 36$ ) who did not utilize the SCP for this visit were asked how helpful it would be for future visits with this survivor. The majority (61%,  $n = 22/36$ ) indicated the SCP would be “quite” or “very helpful” for future visits. Figure 2 indicates how these respondents ( $n = 36$ ) anticipated using SCPs in the future in response to the question: “If you use the Survivorship Care Plan in the future, what (information) would you be looking for?”

When asked how cancer-related information was obtained for this visit, 79% ( $n = 19/24$ ) reported asking the patient or family, 75% ( $n = 18/24$ ) reported checking oncologist notes in the EHR, while 17% ( $n = 4/24$ ) reported checking the SCP (providers could select all that applied). Only two respondents

**Table 1** Breakdown of primary care provider responses

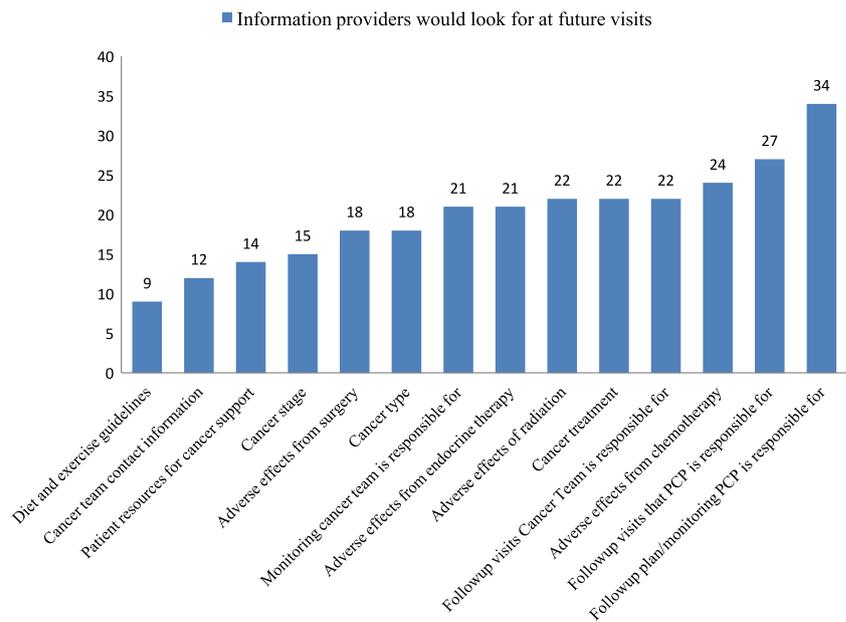
Survey question and response categories	Branch logic in place?	Responses**
Q2. “At <i>this</i> visit, was cancer or a cancer-related issue discussed?”	No	40
Yes*	Asked of all respondents	24 (60%)
No		16 (40%)
Q13. For <i>this</i> visit, was there cancer-related information you needed but could not obtain?	No	40
No	Asked of all respondents	37 (92.5%)
Yes		3 (7.5%)
Q4. “How much of <i>this</i> visit was spent discussing cancer or cancer-related issues?”	Yes	23
A little of the visit	Only asked if - Yes for Q2	10/23 (43%)
Some of the visit		8/23 (35%)
A lot of the visit		5/23 (22%)
Most of the visit		0 (0%)
Nearly all/all of the visit		0 (0%)
I do not recall		0 (0%)
Q7. “For <i>this</i> visit, did you need any of the following cancer-related information? Select ALL that apply.” <sup>‡</sup> &	Yes	24/40 (60%)
Cancer stage	Only asked if - Yes for Q2	6/24 (25%)
Cancer type (e.g., location, receptors)		6/24 (25%)
Cancer treatment		16/24 (66%)
Follow-up visits that Cancer Team is responsible for		14/24 (58%)
Monitoring that Cancer Team is responsible for		11/24 (46%)
Follow-up visits that PCP is responsible for		14/24 (58%)
Monitoring that PCP is responsible for		12/24 (50%)
Adverse effects of cancer medications		12/24 (50%)
Other		0 (0%)
I do not recall		2/24 (8%)
Q9. “To obtain the cancer-related information you needed for <i>this</i> visit, did you use any of the following resources? Select ALL that apply.” <sup>‡</sup> &	Yes	24/40 (60%)
Checking patient’s Survivorship Care Plan in [EHR]*	Only asked if - Yes for Q2	4/24 (17%)
Asking the patient/family member		19/24 (79%)
Checking oncology provider notes in [EHR]		18/24 (75%)
Checking an online resource (e.g. Up To Date)		2/24 (8%)
Checking outside records		1/24 (4%)
Other		0 (0%)
I don’t recall		0 (0%)
Q12. “For <i>this</i> visit, how helpful was your patient’s Survivorship Care Plan?”	Yes	4/40 (10%)
Not at all helpful	Only asked if - Yes for Q2 and checking care plan for Q9	0 (0%)
A little helpful		0 (0%)
Somewhat helpful		1/4 (25%)
Quite helpful		2/4 (50%)
Very helpful		1/4 (25%)
Q11 alternate. “For <i>this</i> visit, did you encounter any of these following barriers or difficulties in using your patient’s Survivorship Care Plan? Select ALL that apply.” <sup>‡</sup> &	Yes	20
I did not remember that the patient had a survivorship care plan	Only asked if - Yes for Q2 and did not select care plan for Q9	7/20 (35%)
I did not know that the patient had a survivorship care plan		10/20 (50%)
I did not have time to look for the survivorship care plan		2/20 (10%)
I could not find the survivorship care plan		6/20 (30%)
Using the survivorship care plan would disrupt my clinical workflow		2/20 (10%)
I thought it would be faster to find the information some other way		3/20 (15%)
I thought that the survivorship care plan wouldn’t contain the information I needed		1/20 (5%)
The survivorship care plan was outdated		0 (0%)
The survivorship care plan is too difficult to understand		0 (0%)
The survivorship care plan is too difficult to use		0(0%)
I already had enough information so I did not need to use it.		2/20 (10%)
Other		0 (0%)
I don’t recall		0 (0%)
Q13 alternate. “Having just reviewed your patient’s Survivorship Care Plan and your note (attached), how helpful will it be for <i>future</i> visits with this patient?”	Yes	36
Not at all helpful	Only asked if - Yes for Q2 and did not select care plan for Q9	0 (0%)
A little helpful		4/36 (11%)
Somewhat helpful		10/36 (28%)
Quite helpful		15/36 (42%)
Very helpful		7/36 (19%)

\*Root of branching logic

\*\*Calculated as a percentage of total respondents

‡ Responses will not sum to 100% as respondents could select multiple options

**Fig. 2** Number of responses to the question “If you use the Survivorship Care Plan in the future, what (information) would you be looking for?” for PCPs ( $n = 36$ ) who reported *not* using the survivorship care plan during the visit



noted needing information that they could not immediately obtain (described as duration of endocrine therapy and side effects of therapy). This information was subsequently obtained by scheduling patient follow-up with oncology and sending a message to the cancer team, respectively.

## Discussion

Breast cancer survivors often discussed cancer or cancer-related issues with providers at primary care clinic visits. This demonstrates the importance of ensuring that primary care providers are informed and comfortable providing survivorship care. However, despite routine provision of SCPs, most primary care physicians and APPs did not utilize SCPs during follow-up visits. Of the respondents ( $n = 20$ ) who reported discussing cancer or a cancer treatment-related issue at the point-of-care visit and answered questions about the barriers to SCP use, half (50%) selected not knowing the survivor had a SCP and 30% not knowing how to find SCPs as barriers. In our results, one-third of providers aware of the SCP reported using it ( $n = 4/11$ ), although this conclusion is limited by the small numbers. Our results suggest that a major barrier to SCP use within the clinical context remains awareness of their existence [12]. In previous work conducted by the Collaborative, we surveyed primary care providers and found that baseline knowledge of SCP existence was lacking, with 27% not knowing what they were and 91% unable to locate them within the EHR [8]. In response, a primary care-focused education program was created and facilitated by the EPOCh primary care physician specializing in survivorship [8]. Following that education program, 59% of primary care providers reported knowing where to find the SCP, a significant improvement in knowledge [8]. The current point-of-

care survey was undertaken 7 months after the primary care education program, yet this knowledge change following the education program did not translate into clinical practice. Nearly three-quarters of our primary care providers still reported not knowing whether their survivor had a SCP or how to find it. Instead, primary care providers identified obtaining necessary cancer-related information by asking the patient and/or family member (79%) and/or chart review of oncology notes (75%) more often than accessing SCPs (17%).

We uniquely focused on the utilization of SCPs by physicians or APPs within the clinical context of a primary care visit as well as the utility of such plans as a clinical decision-making tool. Previous literature emphasizes the SCP’s potential as a communication tool between oncologists, primary care, and cancer survivors [13, 14]. Barriers to primary care SCP utilization have been reported as insufficient penetration into practice, lack of time to find and/or review, and the need to promote primary care training and awareness [13, 15, 16]. Current recommendations assume that primary care providers have a baseline knowledge of both the existence and possible clinical uses for SCPs [17]. Trials conducted over the past several years have identified ongoing gaps in primary care awareness of SCP existence for cancer survivors [9, 18, 19]. Based on these data, there appears to be a persistent and significant barrier to SCP utilization at the point-of-care *despite* increasing SCP provision as well as primary care provider education [8, 12, 20]. UW Health SCPs have been housed within a standardized location (the EHR problem list) since inception. However, primary care utilization of SCPs has not substantially increased within our system: 17% in 2014 [12] vs 27% in 2016. [8] We speculate that perhaps we have not reached a “critical mass” of *routine* provision to *enough* survivors over a *sufficient* duration. However, additional

significant barriers to SCP utilization may very well lie within the realm of integration into primary practice.

Cancer survivorship has become a topic of important discussion and recognition among national primary care-based consortiums [21, 22] with developing primary care-driven initiatives to integrate cancer survivorship care into mainstream primary care practice during preventative and other health visits. Primary care providers in our study were surveyed regarding survivorship care provided within point-of-care visits and were provided with a copy of a survivor-specific SCP. When asked, 61% identified that the information contained within SCPs would be “quite helpful” or “very helpful” in future visits with the survivor. Additionally, our primary care providers identified that if the SCP was used in the future, it would be utilized to identify follow-up responsibilities in addition to adverse side effects of treatment. This agrees with data from the Survey of Physician Attitudes Regarding the care of Cancer Survivors (SPARCCS) which found that primary care providers who reported always/almost always receiving SCPs were more likely to report never having uncertainty or difficulties related to care coordination for cancer survivors [7]. Primary care providers felt confident in their knowledge of cancer surveillance and late/long-term side effects of cancer treatment if they always/almost always received a SCP [7]. Thus, SCPs may improve primary care providers’ understanding of survivorship care, although exploring whether high levels of SCP receipt are a surrogate marker of other facilitators of communication and coordination will be important. We should address the assumption that primary care providers know where to locate SCPs and can readily integrate them into routine clinical practice. Future work needs to address primary care-centered design of SCP format and content, location in the EHR, and the ability to “push” relevant or needed survivorship information to primary care at the right time.

Our data have several key strengths and limitations. First, our good response rate (45%) for a clinician survey, attributed to priming from our primary care leadership regarding the survey. Second, we incorporated feedback from multiple primary care providers into survey questions and design. This facilitated insight into their perspectives of SCP utility and real-world usage, and resulted in a shorter survey with branch logic to lessen the number of questions and improve relevance. However, our study was limited to primary care providers within our healthcare system. Thus, our data reflects a large academic center utilizing a single EHR in the outpatient and inpatient setting. We did not survey external primary care providers with more limited access to our EHR. Such primary care providers might rely more on the SCP given less access to oncology records. However, EHR use is high within Wisconsin [23] and many external primary care providers can access UW oncology records via our vendor’s Health Information Exchange [24]. A second limitation is that we only assessed primary care providers receiving breast cancer SCPs. Our data may not be

generalizable to primary care providers encountering less common cancers in point-of-care visits (e.g., sarcoma, neuroendocrine cancers). Further research may be needed to determine the generalizability of our findings.

In summary, this study demonstrated that a majority of point-of-care visits taking place between a breast cancer survivor and primary care providers covered cancer or cancer-related issues, but primary care providers largely relied on patients or oncologist’s notes to obtain information rather than SCPs. Further research is warranted to evaluate methodology for improving primary care knowledge of SCP existence and location. However, we should also consider that the primary intent of SCPs is to disseminate relevant information regarding management and future or chronic risks faced by cancer survivors. The 2014 ASCO statement on Cancer Survivorship Care Planning assessing the role of technology described the EHR as “unrealized potential to facilitate the care plan process” [20]. Generation of a SCP could be used to capture and build clinically relevant information into an EHR-based cancer survivor registry as a population health management strategy. Such a strategy could be used to prompt primary care or oncology providers to consider appropriate cardiac risk management without relying on SCP document review. For example, the registry could flag a survivor as having received an anthracycline and can automatically notify a provider when combined with other predefined factors (e.g., family history of cardiac disease, blood pressure) at a preventative health visit. Thus, we should also explore strategies for leveraging the data collected within SCPs to further assist survivorship providers, whether primary care or oncology. Research is ongoing at our institution to assess how survivor-facing SCPs can be retooled to better address primary care information needs. Such strategies might help us realize the intent behind SCPs and move us past mere SCP document provision into proactive management of survivor health.

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#### Compliance with Ethical Standards

**Conflict of Interest** SMD: none

JEH: none

ZL: none

DAF: none

MM: none

ERT: none

SAK: none

JMS: none

LGW: ElucentMedical

MES: none

AJT: Epic Systems, Corp. (family member)

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