



## Survivorship Care Implementation with Breast Cancer Survivors in Puerto Rico

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### Summary

This article presents the initial process of adapting and integrating the Survivorship Care Plan (SCP) in routine clinical oncology care in Puerto Rico, by the Plan-Do-Study-Act (PDSA) rapid-cycle improvement method.

cancer as chronic condition. The article created a global political movement. Policies began to emerge for adult and pediatric survivorship care by the National Coalition for Cancer Survivorship and other advocacy organizations.<sup>6</sup>

### Background

In 2019, there were approximately 16.9 million cancer survivors in the United States, amount that will surpass 22.1 million in 2030.<sup>1</sup> The number of survivors has increased due to advances in screening, early detection, and oncology treatment, particularly personalized medicine.<sup>2</sup> Cancer Survivorship outlines the stage in the cancer continuum in which patients end active treatment and need empowerment to address long-term health, the management of treatment side effects and comorbidities, and surveillance for cancer recurrences and new malignancies.<sup>3, 4</sup>

A committee established by the Institute of Medicine (IOM) examined the impact of cancer in adults.<sup>7</sup> The committee published a report with recommendations for survivorship care in this population. The second recommendation states: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.<sup>8</sup> Therefore, it was implicit that cancer survivors need education to understand their cancer history to be aware of steps to follow after treatment.

The concept of cancer survivorship was first mentioned in an article published at the New England Journal of Medicine by Dr. Fitzhugh Mullan.<sup>5</sup> As a cancer survivor, Fitzhugh Mullan realized there were challenges faced by patients in remission and those living with

In 2012, the Commission on Cancer (CoC) announced that Cancer Centers would have to demonstrate phase-in implementation of protocols to disseminate Survivorship Care Plans (SCPs). The CoC quality standard #3.3, now #4.8, took effect in 2015.<sup>9, 10</sup> Cancer Programs were required to have policies and

procedures to discuss and deliver written SCPs to survivors who end treatment.

The American Society of Clinical Oncology (ASCO) created SCP templates with guidelines on key information to compile in two sections: Diagnosis and Treatment Summary, and Follow-Up Care (Table 1). ASCO published statements emphasizing that sole delivery of SCPs would not be enough to address survivors' needs and concerns.<sup>11</sup>

**Table 1: Key Information Topics in a SCP**

Diagnosis & Treatment	Follow-Up Care Plan
<ul style="list-style-type: none"> <li>• Contact information of treating institutions and providers</li> <li>• Diagnosis</li> <li>• Stage of disease</li> <li>• Surgery (yes/no) If yes: procedure, location, date of surgery</li> <li>• Chemotherapy (yes/no) If yes: therapy agents, end date of treatment</li> <li>• Radiotherapy (yes/no) If yes: anatomic area treated, end date of treatment</li> <li>• Adverse effects of treatment</li> <li>• For selected cancers, genetic or hereditary risk factors or predisposing conditions, genetic testing results if performed</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing adjuvant/maintenance therapy including name, planned duration, expected adverse effects</li> <li>• Schedule of follow-up related clinical visits</li> <li>• Cancer surveillance tests for recurrence</li> <li>• Cancer screening for early detection of new malignancies</li> <li>• Other periodic testing</li> <li>• New, unusual, and/or Persistent symptoms to be brought to the attention of healthcare provider</li> <li>• List of late or long-term effects that may be experienced</li> <li>• List of issues that survivors may experience and should be discussed with oncologist and/or primary care provider</li> <li>• List of resources to obtain services</li> </ul>

Stenger M. ASCO Issues Clinical Expert Statement on Cancer Survivorship Care Planning. The ASCO Post. 2014 Dec 15. Available at <https://ascopost.com/issues/december-15-2014/asco-clinical-expert-statement-on-cancer-survivorship-care-planning/>

In 2011, HIMA•San Pablo Oncologic Hospital (HSPOH) started formal preparation for CoC accreditation. Thus, the purpose of this article is to present the process of adapting and integrating the SCP in routine clinical oncology care, by applying the quality improvement Plan-Do-Study-Act (PDSA) methodology.

### The PDSA applied to SCP implementation

The PDSA is a four-stage rapid-cycled quality improvement methodology for implementing and testing changes in clinical settings.<sup>12</sup> The PDSA involves four working phases: PLAN, developing a plan to implement change; DO, carrying out the plan and its strategies; STUDY, monitor the consequences of plan implementation; and ACT, identifying corrective actions to improve change adoption.

#### PLAN Phase

During the SCP planning phase in 2011, HSPOH started formal preparation for CoC accreditation. For instance, a Public Health Educator drafted an initial version of the Survivorship Care Plan Policy and Procedures for the institution. She conducted a literature review to search SCP templates and developed written educational materials for patients who ended treatment.

#### DO Phase

The hospital started SCP protocol implementation in 2013, with a SCP custom-made Spanish template based on CoC recommended topics. A Physician Assistant and the Public Health Educator worked together delivering SCPs to comply with minimum percentage of patients to receive the plan annually. However, the custom-made template required excessive paperwork and was time consuming. Further literature review helped identify a CoC-SCP English template for Breast Cancer; therefore, it was translated into Spanish, substituting the custom-made version.

To enhance the quality of care, a health education intervention (HEI) was developed to discuss the SCP. The intervention was conceptualized based on the primary author's experience providing health education in the oncology setting. The intervention integrates Motivational Interviewing strategies. It follows a patient-centered conversation methodology to trigger motivation to be adherent to follow up care, while acknowledging patients' capabilities for informed decision making.<sup>13</sup>

### **STUDY Phase**

Anecdotic data showed that breast cancer survivors responded positively to the HEI. The intervention was qualified by survivors as much needed and, exceeding conversations they had with their oncology team. Considering these observations, as part of the study phase, a quality improvement study was conducted to assess HEI impact on adherence to follow-up care.<sup>14</sup> A survey was administered to breast cancer survivors who were given the SCP plus the educational intervention.

Interviews were performed to a randomly selected convenience sample of 100 adult female breast cancer survivors, with diagnosis in Stage 0 to III who ended treatment at HSPOH in 2016. Participants were divided in Group 1 who received the SCP plus the HEI (n=50), and Group 2 who did not receive the intervention nor the SCP (n=50).

Participants were surveyed by phone using a structured custom-made questionnaire with 31 questions based in NCCN Clinical Practice Guidelines Version 2.2017 – Invasive Breast Cancer: Surveillance Follow-Up Care.

Results in Table 2 showed that survivors in both groups had adequate compliance with follow-up visits to the oncologist (100% vs. 92%), and with mammogram examinations (84% vs. 92%). Nevertheless, both groups were deficient in adherence to gynecological (61% vs. 65%), colorectal (52% vs. 54%), and bone health routine care (55% vs. 62%). The HEI did not show additional benefit on behavioral outcomes compared to receiving written SCP without the HEI. Results brought attention to the possibility that both the SCP and the HEI needed modifications.

Since survivors responded positively to the HEI, a research proposal was submitted and approved by the IRB of the Ponce Research Institute to continue analyzing both the HEI and the SCP implementation. The project's goals were: 1) to review and refine the SCP and HEI, and 2) to further evaluate impact of re-implementation on breast cancer survivors' sense of self-efficacy to comply with follow-up care.

As the first step, the team explored breast cancer survivors' opinion regarding content, use, and format of a written SCP. Nine (9)

**Table 2: Adherence to Follow-Up Care**

Group Number	Visited Oncologist		Had Mammo		Visited Ob-Gyn		Had Occult Blood Test		Had DEXA	
1 (n=50)	31	100%	26	84%	19	61%	16	52%	17	55%
2 (n=50)	24	92%	24	92%	17	65%	14	54%	16	62%

Ramírez-Solá M. Impact of a Health Education Survivorship Care Plan Delivery Intervention on Female Breast Cancer Survivors' Adherence to Follow-Up Care: Preliminary Data from a Quality Study. Poster presentation in FLASCO Puerto Rico Oncology Summit, San Juan (PR), Feb 2019.

survivors complied with inclusion criteria and agreed to participate in a focus group. Due to the COVID-19 pandemic restrictions, study activities were delayed. Amendments to the protocol were approved by the IRB to perform an audio-video recorded online focus group in which 4 out of the 9 survivors participated, all between 38 and 76 years of age, with Invasive Ductal Carcinoma in Stage I or II of disease.

The online focus group was performed in Spanish on December 11, 2020, lasting 1:10:07 hours. Members of the research team led the discussion as group facilitators. The focus group interview questions were developed by the authors as presented in Table 3.

Consent forms were sent out via e-mail to all participants to be reviewed in advance. At the beginning of the online session, consent forms were read aloud and participants verbally confirmed their voluntary participation.<sup>15</sup> Since one participant experienced internet connection problems, she was contacted for a phone interview

that lasted 47:50 minutes on December 21, 2020.

The focus group and individual interviews were recorded and transcribed verbatim for analysis. Research staff completed transcript-based hand coding analysis independently to create coding categories.<sup>16, 17, 18</sup> Staff meetings were held afterwards to discuss and consolidate coding categories and to summarize findings through constant comparison analysis.<sup>19</sup>

Initial list of themes and codebook were coded by one of the investigators (MRS). Two additional members of the research team (EMCF and CBC) coded each transcript independently. Coders subsequently met to discuss codes and categories to further compare their analysis, discuss discrepancies and establish the inter-coder agreement. Disagreements were discussed until consensus was reached. Survivors' verbatim opinions are included in Appendix, and summarized under four major findings:

## Table 3: Interview Questions to Evaluate SCP

Research Project: Evaluation of a Health Education Intervention for the Discussion of the Cancer Survivorship and Follow-Up Care Plan  
Protocol #1910023461



### OPENING QUESTION

1. Tell me how important is for you a SCP?

Probing question

- a. Why?

### TRANSITION QUESTION

2. What kind of use does the SCP has?

Probing questions:

- a. How have you been using your SCP?
- b. What have you done with your SCP?
- c. Before today, how many time have you read your SCP?
- d. What sections have you read?
- e. Why and for what purpose you have read them?
- f. If you have not read your SCP, why?
- g. After receiving a SCP, with whom have you shared it and why?
- h. Where do you keep your SCP?

### KEY QUESTIONS

Questions about SCP Content

3. What use do you see for the *General Information* and the *Healthcare Providers* sections?

4. Let me hear your comments regarding *Section A – Summary of Diagnosis and Treatment*.

Probing questions:

- a. What kind of information does this section provides?
- b. What information does it help you to understand?
- c. Is there any confusing information? Which one?
- d. What are your suggestions to clarify it?
- e. What have you learned from the information you have in this section?

5. I would like to hear your comments on *Section B – Follow-Up Care Plan*.

Probing questions:

- a. Describe the information you find in this section.
- b. Please comment on your experience while using this information.
- c. How does this information have helped you, and in which areas?
- d. What recommendations have you followed?
- e. What recommendations have been difficult to follow, and why?
- f. What information is not included in this section but should have to?
- g. Why and for what purpose?

6. Which part of the SCP is more important for you and why?

Questions about SCP Template

7. What is your opinion on the SCP template?

Probing questions:

- a. How easy to read is the format?
- b. What do you think about the boxes?
- c. What do you think about the information and pages in the SCP?
- d. What do you think about the chronological order in which the information is presented?

8. From your point of view, does the SCP template is adequate or need changes?

Probing questions:

- a. Which changes do you recommend?
- b. How would you modify it?
- c. How does the information must be provided if a survivor does not read or tell us she has vision impairment?

Questions about SCP Language

9. What do you think about the language?

Probing questions:

- a. How does it is understood?
- b. What is not understood?
- c. How do we can clarify the language?
- d. How appropriate is the font letter?

### CLOSING QUESTIONS

10. In general terms, how much does the SCP helps?

11. How willing you are to recommend a SCP to other cancer survivors?

12. Based on your experience on receiving a SCP, what would you recommend to a person who receive a SCP for the first time?

Probing questions:

- a. Why?
- b. What other comments would you like to add on the topic?

1. A SCP was considered an important tool to remember and share information with primary physicians, to answer medical questions, to keep a summary of personal clinical information in one place, to remind follow-up tests, and be aware of healthy lifestyles that improve quality of life after treatment.
2. The SCP was described as a useful tool in conjunction with the educational intervention that precedes its delivery. Interestingly, survivors pointed out that the SCP could be updated and delivered before treatment completion, as it helps to understand treatment sequence and rationale. This seems to support ASCO Clinical Expert Statement regarding the need to explain the information to survivors in the SCP because the document by itself will not be sufficient to address survivors' concerns.
3. SCP Section A - Summary of Diagnosis and Treatment – was identified as the most important section of the plan because it helps survivors understand their diagnosis. Cancer staging was deemed the most difficult topic to understand.
4. The SCP template and format were considered adequate. If it were used with a blind patient or individuals with vision impairments, the document could be improved by adding color to each section, including larger letter size with bold font, and by delivering it with recorded information and a braille version.

### **ACT Phase**

With survivors' input, the team will refine the SCP template mostly because the document is the basis on which the HEI takes place. The review of the HEI in terms of information content and the application of motivational interviewing strategies is in progress while it is being delivered to breast cancer survivors. Then, a new cycle in the PDSA process will start. During re-implementation of the SCP and HEI reviewed versions, the team will evaluate their impact on breast cancer survivors' level of self-efficacy to comply with follow-up care. The PDSA methodology provides a cyclical process to elaborate action plans based on evidence.

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## Appendix

### Results in Verbatim

Ramírez-Solá M, Castro-Figueroa E & Burgos-Cardona C, Interviews to Breast Cancer Survivors Regarding SCP Content, Use and Format. HIMA•San Pablo Oncologic Hospital. Dec. 2020

### Use and Benefit of SCP

Breast cancer survivors consider SCP as an important tool to share information with primary physicians, to have clinical information in one place, to answer medical questions and remember follow-up tests.

#### Participant #1

*For me it is important and for the doctors to whom I delivered the document as well... for the information, as it is written... When I delivered this plan to my physician... he loved it. He said: everything is clear and well specified... And that's what I also found. Because there are times when I was asked a question and... it took me some time to answer it, and here I have everything very clear, to be able to brief others about my condition... It educates us and prepares us to be aware of our health condition.*

*Para mi es importante y para los médicos que le he llevado el documento... por la información, como está escrita... Cuando le entregué esta plan a mi médico de cabecera... le encantó. Me dijo: está bien claro y bien especificado todo... Y eso también... (es) lo que yo he encontrado. Porque hay veces que a mi me hacían una pregunta y... me tardaba en contestarla y aquí lo tengo todo muy claro para poder informar a otros mi condición... Nos educa y nos prepara para que tengamos conocimiento de nuestra condición de salud.*

#### Participant #2

*Well... I really liked it too because I have all the information about my condition... and it's easy to find everything and explain to ... other physicians, all the information about my condition. The follow-up plan will... help... they also guide you..., what's the next step after you finish treatment. And that also helps us, to eventually seek additional assistance... to be well. (It)... helps me to have all the information about my condition quite specific. So I can... give the right information to my physicians and to my family members as well...*

*Pues a mi también... me gustó mucho porque tengo toda la información de mi condición... y es bien fácil encontrar todito y explicarle a los... demás médicos pues, toda la información de mi condición. El plan de seguimiento me... ayuda ... ellos también te orientan ... de lo próximo, cuál es el próximo paso luego que termines el tratamiento. Y eso también nos ayuda, pues para eventualmente estar bien y buscar otras ayudas necesarias para... que nuestra salud esté bien.*

*... me ha ayudado a que tengo toda la información sobre mi condición y bien específica. Y así yo poder... darle la información correcta a los médicos y a mis familiares también...*

### Comments on Healthcare Providers Section

Participants viewed the healthcare providers section as helpful to contact physicians in case of emergency.

#### Participant #1

*...any need I have to communicate with one of them,... there I have... phone*

*numbers ... with extension numbers. I can refer to them in any emergency.*

*... cualquier necesidad que tenga que comunicarme con uno de ellos, pues ahí tengo.. números de teléfono bien claritos... con sus números de extensiones. Que puedo recurrir a ellos en cualquier emergencia.*

#### Participant #4

*Well, here are the physicians. The primary medical staff. ...the doctors who have seen me... For me it's very important. Because these are the ones who... take care of me.*

*Bueno, aquí están los médicos. Paquete médico primario. Este... todos los médicos que me han visto... Para mi es algo bien importante. Porque estos son los que... me cuidan.*

### Comments on Section A

#### (Summary of Diagnosis & Treatment)

Participants considered Section A as the most important part of the SCP. This section helped them to understand relevant information about their diagnosis (e.g. anatomic location of primary tumor, date of diagnosis, and what 'fuels' cancer cells).

#### Participant #1

*This area was the most interesting for me... Because it tells me what I had, the type of cancer, where it was located, in what area, and the dates of diagnosis, which is very important to me, because the doctors will be asking (me).*

*Esta área fue la más interesante para mi... Porque ahí me dice qué era lo que yo tenía, el tipo de cáncer, donde estaba localizado, en qué área y las fechas del diagnóstico, que es muy importante para mi, porque los médicos le van a estar preguntando a uno.*

#### Participant #2

*I think it(s) one of the most important (parts) because that's where it tells me exactly everything... very specific.... (it) says what feeds (the cancer)... the date of diagnosis, the type... because sometimes they ask one... and you don't have much knowledge, you don't remember, but here (the information) is well summarized.*

*Creo que (es) una de las (partes) más importantes porque ahí me dice exactamente todo... bien específico.... dice de qué se alimenta,... la fecha del diagnóstico, el tipo...pues a veces le preguntan a uno...y uno no tiene mucho conocimiento, no recuerda, pero aquí (la información) está bien resumida.*

One participant made reference to the benefit of using visual illustrations during the educational intervention for the discussion and delivery of the SCP.

#### Participant #3

*This part... explains the condition. That's where they give you more emphasis... If you didn't understand... (the Health Educator)... showed me... some pictures. She explained (the information) again... that is when you realized... what you really have. (This section helped me to understand) the receptors... what had fed*

*(my condition). Because sometimes... people confuse you... all cases are different.*

*La parte donde... más te explica la condición. Ahí fue donde más énfasis te dan... Si no entendiste... (la Educadora en Salud)...me enseñó... unas láminas que tenía. Volvió y te explicó... ahí... es que como que uno cae más en tiempo... qué es realmente lo que uno tiene. (Esta sección me ayudó a entender) pues los receptores... de qué se alimentó lo que yo tenía. Porque a veces... la gente te confunde... todos los casos son diferentes.*

Participants were asked if any information about diagnosis and treatment in Section A was confusing. One participant referred to the cancer stage information as difficult to understand.

#### Participant #1

*In my case... the area where it says stage, has... a few terms that are a little bit... rares, but... the Health Educator explained me completely and then I understood it perfectly.*

*En mi caso... el área donde dice estadio, que te ponen como... unos términos ahí un poquito...extraños, pero...la Educadora en Salud me lo explicó completamente y luego lo entendí a la perfección.*

#### Comment on Section B (Follow-Up Care Plan)

The SCP was considered useful to increase awareness about adoption of healthy lifestyles and routine clinical care.

#### Participant #2

*At least those exams... after I finish treatment then... I'm going to work (on) them slowly (little by little) with different physicians. (I've followed some recommendations)... some (of) them... like the diet, avoiding fat... I've taken them into account and they already became a habit for me.*

*Por lo menos esos exámenes...después que yo termine el tratamiento pues...los voy a ir trabajando poco (a poco) con los diferentes médicos. (He seguido algunas recomendaciones)...algunas (de) ellas... como la dieta, evitar las grasas...las he tomado en cuenta y ya son un hábito para mi.*

#### Comments on SCP Format

SCP's format (graphic template, letter font size, chronologic order and amount of information), was considered adequate by all participants. In the event that participants would be able to make changes to the format for individuals with vision impairment, they would differentiate each section subtitle with colors, they would use a larger letter font size including bold fonts, and would provide a SCP braille version with recorded information.

#### Participant #1

*I see it clear and accurate. The letters are fine... the organization of the format, I find it excellent.*

*Yo lo veo claro y preciso. Las letras están bien...la organización, mejor dicho, el formato, yo lo encuentro excelente.*

Participant #4

*Well if you can't read, then a recording... that one put it on a CD... that one put it on once, twice, three times, and so one understands.*

*Bueno si es que no saber leer, pues a través de una grabación... que uno lo ponga en CD... que uno lo ponga una, dos, tres veces y así uno entiende.*

Participant #1

*Well, it can be... a larger font size... it can also be... in braille.*

*Pues puede ser...la letra más grande... también puede ser...en braille.*

Participant #3

*I think that the best thing in the subtitles, in other words... general information, completed treatment,... is... color or something like that so that people can... specifically see what that section is all about as such...*

*Creo que a lo mejor en los subtítulos, o sea... información general, tratamiento completado,... podría ser... a color o algo así para que la gente pueda... específicamente ver de qué se trata esa sección como tal...*

**Comment on Language**

All participants described the language at the SCP as understandable.

Participant #3

I understand that (the language) is quite clear.

*Yo entiendo que ... (el lenguaje) está bien claro.*

**Comment on Recommending SCP to Breast Cancer Survivors**

All survivors would recommend a SCP to other breast cancer survivors but together with the educational intervention.

Participant #1

*100%. At least along with the orientation I would recommend it 100%.*

*100%. Por lo menos junto con la orientación yo lo recomendaría al 100%.*

Participant #2

*For me the document is very valuable because sometimes... doctors ... they speak with many terms and many specifications, and in this document... they make it easy for you to understand, just as you can explain to your family and the other physicians that work together with you...*

*Para mi el documento es muy valioso porque a veces... los médicos ...hablan con muchos términos y con muchas especificaciones y en este documento...te aclaran todito, bien fácil, bien sencillo para que tú lo entiendas, al igual que tú le puedas explicar a tu familia y a los otros médicos en conjunto que trabajan contigo...*