Southern California CSU DNP Consortium

California State University, Fullerton
California State University, Long Beach
California State University, Los Angeles

SURVIVORSHIP PLANNING IN LATINAS
WITH CERVICAL CANCER

A DOCTORAL PROJECT
Submitted in Partial Fulfillment of the Requirements
For the degree of

DOCTOR OF NURSING PRACTICE

By

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ABSTRACT

A survivorship care plan (SCP) utilizing a survivorship planning tool (SPT) can improve the quality of care of cancer survivors as they move beyond their cancer treatment by helping restore a sense of power and control and promoting adherence with recommended treatment. Because SCPs are essential for cancer survivors’ wellbeing, the aim of this project was to develop a SPT specifically for Latinas with cervical cancer seen in a Gynecology-Oncology clinic setting.

This project involved four professionals who served on a content expert review panel (ERP) and 10 Latina participants who composed the Latina review panel (LRP). The panel members engaged in a collaborative and iterative review and feedback process in reviewing draft copies of a proposed SPT. An additional panel of five expert healthcare providers and five Latinas participated in a survey that evaluated the final SPT for understandability, readability, inclusiveness, practicality, and usability using a 5-point Likert scale system (5 being highest). The ERP mean scores for the SPT ranged from a high of 4.8 for inclusiveness to scores of 4.2 for both understandability and readability, 3.8 for practicality, and 3.6 for usability (easy to complete). The LRP understandability and readability mean scores were 4.8 each, 5.0 for inclusiveness, and 4.0 for both practicality and usability. Both groups expressed concerns about limited time available during clinical visits to complete the SPT as well as responsibility for its upkeep. Reassurance was provided regarding the joint and collaborative process that would be undertaken with both the healthcare providers’ team and survivors to complete the SPT.
In conclusion, healthcare providers play a pivotal role in improving health outcomes and quality of life for cancer survivors. Members of the healthcare team must be cognizant of the importance of cancer survivors having individualized SCPs and readily guide them in acquiring and maintaining a SPT.
TABLE OF CONTENTS

ABSTRACT ........................................................................................................................................ iii

LIST OF TABLES ............................................................................................................................... viii

LIST OF FIGURES ............................................................................................................................. viii

ACKNOWLEDGMENTS ....................................................................................................................... ix

BACKGROUND ................................................................................................................................... 1

Problem Statement ............................................................................................................................ 3
Purpose Statement ............................................................................................................................... 4
Supporting Framework ....................................................................................................................... 4
Step 1: Plan ........................................................................................................................................ 5
Step 2: Do .......................................................................................................................................... 5
Step 3: Study ...................................................................................................................................... 6
Step 4: Act .......................................................................................................................................... 6

REVIEW OF THE LITERATURE ........................................................................................................ 7

Overview .......................................................................................................................................... 7
Search Method .................................................................................................................................. 7
Pathophysiology of Cervical Cancer ................................................................................................. 8
Barriers and Facilitators to Cervical Cancer Screening and Survivorship .................................... 9
Survivorship Among Women with Cervical Cancer ....................................................................... 11
Survivorship Planning Care Approaches and Perceptions ............................................................ 13
Nursing Implications ....................................................................................................................... 16
Summary .......................................................................................................................................... 17

METHODS ......................................................................................................................................... 18

Design ............................................................................................................................................... 18
Ethical Consideration ....................................................................................................................... 18
Setting .............................................................................................................................................. 18
Participants ...................................................................................................................................... 19
PDSA (plan-do-study-act) Cycle .......................................................................................................... 20
Step 1: Plan ...................................................................................................................................... 21
Development of Survivorship Planning Tool .................................................................................... 21
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cervical Cancer by Race and Ethnicity Rates per 100,000 persons</td>
<td>2</td>
</tr>
<tr>
<td>2. Expert Review Panel Members’ Survivorship Planning Tool (SPT) Edits</td>
<td>31</td>
</tr>
<tr>
<td>3. Socio-demographic Variables (race, gender, and language preference)</td>
<td>32</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Plan-Do-Study-Act (PDSA) cycle</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>Delphi Technique/Process</td>
<td>25</td>
</tr>
<tr>
<td>3.</td>
<td>PDSA cycle for development of Survivorship Planning Tool</td>
<td>27</td>
</tr>
<tr>
<td>4.</td>
<td>Content Validity Survey Responses: Expert Members</td>
<td>34</td>
</tr>
<tr>
<td>5.</td>
<td>Content Validity Survey Responses: Latina Participants</td>
<td>36</td>
</tr>
</tbody>
</table>
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BACKGROUND

In 2015, 270,000 women worldwide died of cervical cancer with approximately 90% of these deaths occurring in lower to middle income countries (WHO, 2017). In 2016, an estimated 12,900 new cases of cervical cancer were diagnosed, and 4,120 women died in the United States (U.S.) (National Cancer Institute [NCI], 2016). In 2017, an additional 12,820 new cases of invasive cervical cancer were diagnosed, and nearly 4,210 women were projected to die last year from this disease (American Cancer Society [ACS], 2017). Of note, increased rates of detection, earlier diagnosis, and major advancements in treatment modalities have significantly improved the overall rate of cancer survivorship. Currently, in the U.S., 15.5 million individuals survived after being diagnosed with cancer (Miller et al., 2016). Although, cervical cancer is non-discriminatory, the incidence of cervical cancer in the Latina population is higher than in any other ethnicity at 9.4 per 100,000 women (see Table 1) (Center for Disease Control and Prevention (CDC, 2017).

In Los Angeles County (LAC) where Latinos make up the largest portion of the population (U.S. Census Bureau, 2015), the incidence of cervical cancer was once double that of the national rate. A 2017 study noted an incidence rate in LAC of 8.0 per 100,000 Latinas compared to 7.3 per 100,000 white non-Hispanic women (Los Angeles County Department of Public Health, Office of Women’s Health and Office of Health Assessment & Epidemiology, 2017). The current decrease in the incidence rate in LAC Latinas is partly due to the collaborative efforts and initiatives that targeted Latinas to increase their adherence with Pap smear testing.
Table 1

*Cervical Cancer by Race and Ethnicity, Rates per 100,000 persons: 2014 Centers for Disease Control and Prevention Data*

<table>
<thead>
<tr>
<th>Race and Ethnicity</th>
<th>Rate/100,000 population</th>
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<tbody>
<tr>
<td>Hispanic/Latina</td>
<td>9.4</td>
</tr>
<tr>
<td>Black</td>
<td>8.5</td>
</tr>
<tr>
<td>White</td>
<td>7.4</td>
</tr>
<tr>
<td>Asian/Pacific Islanders</td>
<td>5.8</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>5.6</td>
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Women diagnosed with cervical cancer have a 5- and 10-year survival rate of 68% and 64% respectively (Cancer.net, 2017). Detection at an early stage increases the 5-year survival rate; however, the 5-year survival rate drops to 57% when the tumor spreads to surrounding tissues or organs and or when it metastasizes to regional lymph nodes. Moreover, the 5-year survival rate decreases to 17% when the cancer spreads to a distant part of the body (Cancer.net, 2017). Ashing-Giwa et al. (2010) noted that Latinas have decreased survival and survivorship outcomes when compared to white non-Hispanic women. The ACS (2017) reported that from 2005-2011 Latinas had a 5-year survival rate of 75%. Of note, health care planning, as part of the survivorship trajectory, was shown to improve adherence to treatment plans, quality of life (QOL), and overall health outcomes (Tan, 2016). Thus, it is important to begin survivorship planning with the initial diagnosis of cervical cancer.

In 2005, the Institute of Medicine (IOM) issued a report - *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommending that all cancer patients receive an individualized survivorship care plan that includes guidelines for monitoring and
maintaining their health (IOM, 2005; National Academies of Sciences, 2017).

Survivorship planning has become an important aspect of cancer care, which recognizes the emotional, psychological, and physical distresses as well as the ongoing process of adjustment that the person may experience. Overall, receiving a diagnosis of cervical cancer can be overwhelming for a woman and her family members. Attempting to fully comprehend a variety of information presented about the disease and its treatment options can be challenging and often confusing. Consequently, it is important to help women navigate through the healthcare system and stay on track with their treatment plans as well as provide guidance about how best to incorporate lifestyle changes to improve their wellbeing.

**Problem Statement**

Casillas et al. (2011) and other researchers (de Moor et al., 2013; Keesing, McNamara, & Rosenwax, 2015; Vermeer et al., 2015) found most cancer survivors did not have survivorship planning as part of their care and lacked support to guide them during this challenging time. They identified the need to explore the range of available resources for survivorship planning and the practicalities of using a survivorship planning tool (SPT) to meet the needs of cancer survivors. Research supports survivorship planning as vital in restoring a sense of power and control that can aid in improving the quality of care for cancer survivors as they move beyond cancer treatment. The author conducted an extensive review of the literature but did not find a standardized SPT developed specifically for Latinas with cervical cancer to help guide their cancer survivor trajectory. In addition, the author viewed the lack of a resource guide for Latina survivors of cervical cancer in her practice setting as a barrier to providing quality patient
care. Therefore, developing a patient-centered SPT became the driving force for this project.

**Purpose Statement**

The use of SPTs has been shown to promote compliance with treatment, QOL, provide empowerment, and circumvent the potential recurrence of cancer (Keesing et al., 2015). Therefore, the purpose of this quality improvement (QI) project was to develop a SPT for Latinas diagnosed with cervical cancer.

**Supporting Framework**

The theoretical framework chosen for this QI project was the plan-do-study-act (PDSA) cycle. Figure 1 describes the activity for each step of the PDSA cycle. Known originally as the Shewhart learning and improvement cycle, the PDSA cycle was developed in 1924 and integrated both creative management thinking and statistical analysis (Oxford Reference, 2017). Shewhart used this framework while developing hardware for Bell Telephone at Western Electric Company to solve issues related to transmission systems reliability (Smith, 2011). Shewhart, dubbed the grandfather of total quality management, mentored Deming who further developed the framework surrounding the PDSA cycle (SkyMark, 2016). The PDSA cycle is an implementation and evaluation method commonly used for quality improvement programs and initiatives, one of which includes the U.S. Institute for Healthcare Improvement (IHI). The IHI recognizes the PDSA cycle as a principal model and framework that guides improvement (IHI, 2017). Consequently, the PDSA cycle was used to guide this survivorship planning QI project. The PDSA cycle’s four-step problem-solving, described in detail in the Method’s chapter, guided the development and evaluation of the SPT.
Figure 1. PDSA Cycle (Institute for Healthcare Improvement, 2017. Approval to use figure was obtained, see Appendix A).

**Step 1: Plan**

The PDSA cycle begins with the plan step, which involves identifying the aim, goal or purpose, formulating a theory, and defining success strategies (Provost, & Murray, 2011). Analyzing and understanding the problem is of utmost importance. Planning the details of the study implementation and making predictions about the outcomes of what to improve is key. Required resources for implementation and data collection methods are also identified. After the improvement objective is determined, an action plan to carry out the changes commences.

**Step 2: Do**

The activities in the plan section are followed by the do step, in which components of the plan are implemented and the products used. This step implements
the strategies for improvement. The study is conducted, and the data collected are analyzed. Information gathered in this step prepares for the study step.

**Step 3: Study**

The study step is where the outcomes are monitored to test the validity of the plan, check for signs of progress and success or problems and dilemma areas for improvement of the project. After establishment of the improvement initiative, the data are studied and analyzed to determine if the change resulted in the expected outcome.

**Step 4: Act**

The act step, the final step in the PDSA cycle, integrates the learning generated by the entire process. This step determines whether to terminate, modify/change or move forward with the solution which, in this case, is the use of the SPT. These four steps can be repeated multiple times as part of a never-ending cycle of continual improvement.
REVIEW OF LITERATURE

Overview

The purpose of this QI project was to develop a SPT for Latinas with cervical cancer. According to the National Comprehensive Cancer Network (NCCN), survivorship focuses on the health and life of a person from the time of diagnosis of cancer to the remainder of the individual’s life, which denotes a cancer survivor (NCCN, 2017). NCCN guidelines address the overall toll that both the diagnosis and treatment have on the survivor and how they affect the individual physically, mentally, socially, professionally, personally, sexually, and financially as well as their impact on the person’s overall health perspective (NCCN, 2017). An NCCN guideline for survivorship planning also considers the effects that the diagnosis of cancer has on family members, friends, and caregivers of the survivor.

Search Method

A comprehensive review of literature (ROL) was conducted, which focused on the topic of survivorship planning for Latinas with cervical cancer. The following electronic databases were searched for publications that were relevant to this topic: PubMed, Medline, CINAHL, ERIC, EBSCO host, Cochrane library, Google scholar, Agency for Healthcare Research and Quality (AHRQ), and Institute for Healthcare Improvement (IHI) websites. Key search terms used were: “Latinas” “Cervical Cancer,” “Survive,” “Survivor,” "Survivorship Planning," "Survivorship Planning Care," and “QOL”. Additionally, the Boolean term "AND" was used to link the preceding terms. In addition, the term “PDSA (plan-do-study-act)” was used to find supportive evidence on the chosen quality improvement method for this study. Inclusion for the search was
restricted to English language, peer reviewed scholarly journals/publications from the years 2000-2017. Qualitative research studies published from 2001-2017 were included as they were believed to add clinical value to the project topic. Exclusionary criteria were articles regarding non-operative or curative measures for cervical cancer.

Over 200 academic articles related to this topic were found which highlight the common use of the terms in medical and nursing literature. The search was further narrowed to include only those articles that were more specific to and focused on the topic of cervical cancer and survivorship. Abstracts were reviewed, and the articles were further reduced to include the most current and significant. The final total number of studies meeting the inclusion criteria were 14, which included two systematic reviews, one mixed methods, one quantitative, five qualitative, two retrospective reviews, and three descriptive exploratory design. These articles are included in the Table of Evidence (see Appendix B)

**Pathophysiology of Cervical Cancer**

Understanding the pathophysiology of cervical cancer is important in seeking ways to improve survivorship and decreasing rates of death from this disease. The lower part of the uterus, sometimes called the uterine cervix, the cervical opening, or the cervical os has an inner and outer portion. The endocervix is the inner portion of the cervix closest towards the body of the uterus. The ectocervix is the outer portion of the cervix pointing towards the vagina. The two main types of cells of the cervix are the squamous cells (found on the ectocervix side) and the glandular cells (found on the endocervix side), which are also known as columnar cells (Herfs et al., 2013). The area where the squamous cell (the ectocervix) meets the columnar cell (the endocervix) is
referred to as the squamo-columnar junction (SCJ). The SCJ is within the transformation zone (T-zone), which is the site of constant cell renewal known as squamous metaplasia (Herfs et al., 2013). Acquiring the human papillomavirus (HPV) infection allows the HPV deoxyribonucleic acid (DNA) in the T-zone to develop new cells with the abnormal DNA coding. Thus, the T-zone is the site where the abnormal changes and pattern commence and is where most cervical cancer begins (Herfs et al., 2013). Persistent cervical infection with high-risk classification HPV genotypes is necessary for the development of cervical cancer (ACS, 2017). HPV 16 and 18 are the most carcinogenic HPV genotypes.

Duska (2015) projected that the increase in HPV immunizations not only will account for lowered mortality rates, but also will be the cause for eradication of HPV associated cervical cancer in the future. Meanwhile, the combination of early detection and treatment is the main avenue toward significantly decreased mortality rates due to cervical cancer. Thus, recommendation for women 30-65 years of age with prior history of normal Pap test is to obtain both a Pap test and HPV typing known as co-testing every five years. Women 21 – 29 years of age can undergo a Pap test only, co-testing is not recommended (U.S. Preventive Services Task Force [USPSTF], 2016). In the latter age group, HPV typing is unnecessary because there is over a 90% regression rate of abnormal Pap tests. (Moscicki et al., 2010). This recommendation prevents the woman from undergoing unnecessary invasive procedures.

**Barriers and Facilitators to Cervical Cancer Screening and Survivorship**

Survivorship among Latinas with cervical cancer is influenced by their ability to adhere to screening and treatment recommendations. Barriers for Latinas’ adherence to
cervical cancer screening include, but are not limited to, transportation, spousal/partner support, fear, income, cost, childcare, education, immigration status, cultural belief, and language which are noted to influence compliance (Boyer, Williams, Clark Callister, & Marshall, 2001; Gregg, Centurion, Aguillon, Maldonado, & Celaya-Alston, 2011; Shelton, Jandorf, Thelemaque, King, & Erwin, 2012). Access to care and the inability to develop routine health-care habits were also noted. Gregg et al. (2011) indicated that Latinas feared the possibility of being diagnosed with cervical cancer as a deterrent for screening and correlated an abnormal pap with fear of spousal infidelity. Facilitators for Latinas’ adherence to screening recommendations were identified as partner involvement/support, access to care, economic status, language, culturally sensitive programs/promatoras, increased communication/awareness and knowledge of required follow-up/appointment dates (Boyer et al., 2001; Fernández-Esquer, & Cardenas-Turanzas, 2004; Hunt, De Voogd, Soucy, & Longworth, 2002).

Tisnado, Mendez-Luck, Metz, Peirce, & Montaño, (2017) in their study of Latinas in Los Angeles County with breast cancer noted that cancer survivors may experience gaps in care when transitioning from cancer treatment to cancer survivor, which include barriers to accessing care, lack of coordination of care, and poor communication between healthcare provider and cancer survivor. Tisnado et al. (2017) also indicated that there are deficiencies in survivorship planning, which cause confusion and anxiety regarding follow-up visits and post treatment expectations for ongoing care (Tisnado et al., 2017). Similarly, having limited information and lack of knowledge regarding their cancer and treatment type were cited as additional barriers. Thus, it is important to consider the
experiences patients have with the medical care system in long-term planning (Tsnado et al., 2017).

**Survivorship among Women with Cervical Cancer**

Early detection is key for successful treatment of cervical cancer. The larger the tumor size the higher the International Federation of Gynecology and Obstetrics (FIGO) stage of cervical cancer, leading to a greater chance for lymph node metastasis and a greater risk of recurrence and ultimately death. In seeking an efficacious survivorship trajectory, it is important to understand that the lower the stage the higher the survival rate. Chang, Chen, Chang, and Chiang (2016) state the overall five-year survival rate corresponding to staging is as follows: Stage 1A is almost at 100%; Stage 1B1 and smaller IIA tumors average around 70%- 85%; Stages IB2 and IIB average around 50%- 70%; Stage III averages 30%- 50%; and Stage IV averages 5%-15%.

According to Miller et al. (2016), as of January 1, 2016, there were 15.5 million people in the U.S. living with a history of cancer. Almost half of these cancer survivors were 70-years-old and above. Approximately 70% of these survivors completed cancer treatment within the past five years, 44% had survived 10 - 20 years, and 20% had survived more than 20 years (Miller at al., 2016). This gives credence to the fact that, now more than ever before in history, the population of cancer survivors is larger and steadily growing (de Moor et al., 2013). Subsequently, optimizing the positive outcomes for cancer survivors, such as women with cervical cancer, is of utmost importance.

Zeng, Li, and Loke (2011), Wenzel et al. (2015), Duska (2015), and Pfaendler et al. (2015) indicated that of all the gynecological cancers, women after surgery, chemotherapy, and or radiation therapy for the treatment of cervical cancer demonstrate
more complications with lingering gynecological, gastrointestinal, urinary, rectal, sexual, neurologic, medical, and psychological issues or needs. The survivorship trajectory in this population post-treatment is associated with long-term sequelae. Once declared cancer free, it is vital to have appropriate care available to these cancer survivors to offset the challenges they face that are associated with curing their disease.

Osann et al. (2014) noted Latinas with cervical cancer have a poorer QOL post chemotherapy and or radiation therapy and suffer higher levels of depression and anxiety above any other population of cancer survivors. Osann et al. (2014) further reported Latina cervical cancer survivors attribute their recovery and endurance in their survivorship trajectory to their faith in God. Livaudais et al. (2010) also shared that cancer survivors’ credit their faith in God and comfort with spirituality as a factor in positive survivorship outcomes. Conversely, their negative experiences included having inaccurate perceptions regarding cultural norms (e.g. undergoing an examination by a male healthcare provider), feeling embarrassed during examinations, lack of trust in healthcare providers, and feeling rushed during visits (Livaudais et al., 2010).

Consequently, it is recommended that survivorship planning incorporates culturally sensitive support groups and that healthcare providers be cognizant of cancer survivors’ experiences to allow them the opportunity to express their feelings and concerns (Iyer et al., 2016; Livaudais et al., 2010).

Survivorship planning is a useful, practical tool and has a great potential to support a positive trajectory for cervical cancer survivors (Keesing et al., 2015). Furthermore, Keesing et al. (2015) report that survivorship planning promotes empowerment, allows the cancer survivor to be knowledgeable regarding their care, and
provides vital information about their diagnosis, treatment, and required follow-up care, while enhancing communication between survivor and healthcare provider. Moreover, Keesing et al. (2015) recommended further studies focus on the variety of survivor care plans including their feasibility and practicality in meeting the cancer survivors’ needs. Ashing, Serrano, Weitzel, Lai, Paz, and Vargas (2014) developed and evaluated a Spanish survivorship care plan tool targeting the underserved, high-risk Latina population who were breast cancer survivors. These researchers also endorsed identifying approaches to improve surveillance and follow-up guideline adherence, which could lead to positive outcomes and QOL.

Survivorship Planning Care Approaches and Perceptions

The IOM’s 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition, admonishes that the cancer survivorship planning trajectory is deficient in advocating, educating, practicing, or researching to promote and provide quality cancer survivorship care (IOM, 2005). Once cervical cancer is diagnosed, it is paramount to initiate survivorship planning to ensure better QOL. Ashing et al. (2014) reported that cancer survivors are increasing in number in various parts around the world due to early diagnosis, increasing rates of detection, and improved innovations in treatment modalities. While a decrease in mortality rates is attributed to current treatment modalities, cervical cancer treatments leave a residual of numerous long-term sequelae more so in the Latina population as compared to others. Livaudais et al. (2010) found that after diagnosed with cancer, Latina cancer survivors feel secluded, cut-off, fearful, and have an overall sense of fatalism. According to Wenzel et al. (2016), Latinas and minorities experience disruptions in QOL that linger well after completion of treatment
and have unmet supportive care needs. These needs include, but are not limited to,
psychological, psychosocial, physical, spiritual, and educational concerns.

Nonetheless, Latinas who underwent psychosocial counseling and supportive care
had overall positive outcomes on cervical cancer specific concerns, less depression, and
less gynecological issues than a comparison group of Latina survivors who did not
receive these additional services (Wenzel et al., 2016). Survivorship planning buy-in
from both Latinas with cervical cancer as well as healthcare providers is crucial for
success in survivorship planning. Historically, the oncologist was accountable for the
primary care of cancer survivors. However, Nekhlyudov, O'Malley, and Hudson (2017)
specify that the growing number of cancer survivors, the greater span of survivorship life,
and fewer oncologists in the U.S. require a shift of survivorship planning care trajectory
to primary healthcare providers. In fact, these authors indicate that survivorship planning
for cancer survivors should be part of the training, education, and updates for all
healthcare providers (Nekhlyudov et al., 2017). Basic competencies like the knowledge
base that healthcare providers acquire for an array of medical diseases in managing those
without cancer need to be used when caring for cancer survivors. For example, having
knowledge of cancer survivors’ symptoms of distress or recurrent disease, physical,
psychological, and social issues, and baseline tumor markers to assess for recurrence is
essential (Nekhlyudov et al., 2017). Health and behavioral lifestyle modifications,
including psychosocial, psychological, and supportive counseling, must be emphasized to
improve QOL and overall health outcomes for cervical cancer survivors.

Casillas et al. (2011) in a study regarding confidence of cancer survivors
managing their care found that 55% of survivors lacked survivorship planning. This is a
worrisome indicator of a potential disservice and lack of appropriate care rendered. The knowledge gap for healthcare provider’s perception of their role when caring for cancer survivors must be circumvented to achieve effective survivorship planning. Likewise, the Latina cervical cancer survivor’s perception of the care that she may require long after treatment cessation is key to successful survivorship planning.

There are various online resources available to aide in effortlessly implementing survivorship care planning (SCP) both for cancer survivors and for healthcare providers. The American Society of Clinical Oncology (ASCO) has downloadable apps and an array of tools for cancer survivors to commence the survivorship planning trajectory. The ASCO (2017) has SCP available for the following cancers: breast, colorectal, prostate, and diffuse large B cell lymphoma. However, there is no SCP for cervical cancer.

Although the literature supports the use of SCPs in the care of patients with cancer, no studies have been found to validate the information that should be collected within them. Ashing et al. (2014) and ASCO (2017) developed specific SCPs for breast cancer that included information regarding demographics, provider type, diagnosis and staging, treatment, risk assessment, genetic testing, routine surveillance visits, symptom issues and health promotion. Likewise, other available SCP templates use similar information for planning care.
Nursing Implications

According to Casillas et al. (2011), it is vital to teach cancer survivors to advocate for their own survivorship planning. Likewise, it is of utmost importance that advanced practice registered nurses (APRNs) and nurses in general be vigilant in ascertaining patients’ history of cancer and inquiring about their survivorship planning status. Furthermore, it is imperative that nurses be familiar with available resources that can readily aide in generating survivorship planning templates, such as those listed on the ASCO’s website.

Nurses should be cognizant of the extreme physical, psychological, emotional, social, spiritual, sexual, financial, and the host of other post-treatment related side effects ailing this population and the need to render timely supportive care. Additionally, it is important to have an awareness of sexual challenges and be prepared to make appropriate professional referrals for survivors and their partners (Vermeer et al., 2015). Thus, educating cervical cancer survivors to express their feelings and quickly share any symptoms altering their daily living can help improve their QOL as well as their ability to manage the effects of treatment and monitor for recurrence. Zeng, Ching, and Loke (2011) indicate that nurses are key players in evaluating and promoting QOL for cancer survivors. As first-line healthcare promoters, nurses spend the most time with patients building rapport and establishing a relationship which is vital to allow openness and mutual respect. Providing a listening ear, being compassionate, supportive, and reassuring will encourage a positive survivorship planning trajectory in this population. Accordingly, with changing innovative treatment modalities it is essential to remain abreast of corresponding supportive measures. Maintaining current knowledge to swiftly
identify symptoms that require further work-up and appropriate referral requirements should be maintained.

**Summary**

Over the past thirty years, great strides have been made in decreasing the mortality rate from cervical cancer through regular screening, early treatment, and health behavior modification. Promoting education to improve adherence to timely screening and maintaining efforts to chip away barriers are essential factors associated with the progress made in cervical cancer survivorship. Encouraging better health care and improved QOL are equally important goals for cervical cancer survivors.

The call to become strategic in providing comprehensive survivorship planning began a national movement in the U.S. post the 2005 IOM report. The report urged collaborative involvement in survivorship planning between healthcare providers and cancer survivors. There is clear evidence that supports the benefits of survivorship planning and that it should commence immediately after a cervical cancer diagnosis is made (Ashing et al., 2014; Casillas et al., 2011; Keesing et al., 2015; Livaudais et al., 2010; Tisnado et al., 2017; Wenzel et al., 2015). A ROL supports the need for dedicated survivorship planning as a strategy for better health-care outcomes and attainment of improved QOL in this population (Vermeer et al., 2015; Zeng, Ching, & Loke, 2011; Zeng, Li, & Loke, 2011).
METHODS

Design

Polit and Beck (2017) describe QI projects as a form of research, which focuses on improving practice and processes within an organization, as well as for a specific population. Therefore, a QI research design was undertaken to develop a SPT to support Latinas with cervical cancer in their survivorship trajectory. The framework selected to guide this project was the Plan-Do-Study-Act (PDSA) cycle.

Ethical Consideration

A letter of support to develop the SPT at the Gynecology-Oncology (Gyn-Onc) clinic where the QI project was conducted was obtained from the division director. Institutional Review Board (IRB) approval was obtained from the Medical Center (see Appendix C). The letter of determination was submitted to California State University, Long Beach’s (CSULB’s) IRB and an expedited process yielded approval as well (see Appendix D). This QI project was judged to involve no risk to the healthcare providers involved in this project. The Latina participants were told that there may be minimal emotional risk as they might become somewhat uncomfortable with the topic of cancer survivorship. The only barrier identified was the time commitment required to participate in the educational in-service and review process. Participation was voluntary, and the participants were assured that they could withdraw from the QI project at any time without repercussion.

Setting

The setting for this QI project was a Gynecology-Oncology (Gyn-Onc) ambulatory care clinic within a 600-bed county facility and teaching institution in
Southern California. The hospital delivers a full spectrum of healthcare delivery services including emergency, inpatient, and outpatient facilities within the medical campus. This facility provides preventative as well as diagnostic and treatment services to many underserved and underinsured women within its catchment area. Women with a variety of gynecological cancers, such as uterine, ovarian, fallopian tube, cervical, vaginal, and vulvar, undergo various treatments at this Gyn-Onc clinic.

As part of the proposed QI project, an educational information session was provided to both healthcare providers and Latina participants respectively. The educational in-service took place in the Gyn-Onc department’s conference room for the healthcare providers and in a private office within the Gyn-Onc clinic for the Latina participants.

Participants

This QI project required the expertise of the Gyn-Onc Attending Physicians and fellows (physicians), nurse practitioners (NPs), and clinic researchers. To be involved in this project, content expert reviewers had to be either Gyn-Onc physicians, NPs, or cancer clinic researchers with at least one year of clinical experience, specifically with cervical cancer cases. Their healthcare specialty training and experience of one year or longer in cervical cancer management qualified them as content experts. Individuals with less than one year of experience in Gyn-Onc or other ancillary staff within the department were excluded from participation. The participants who volunteered were referred to as members of the expert review panel (ERP). Additionally, five healthcare provider experts (HPE), who did not participate during the design phase, were invited to partake in a content validity survey.
Inclusion criteria for Latina participants were 18 years of age and older with a diagnosis of cervical cancer and at least one of their treatment modalities being radiation therapy. Exclusion criteria included being diagnosed with other types of gynecological cancer, cervical cancer without undergoing radiation therapy, or who received radiation therapy more than twenty years ago. These participants were referred to as the Latina review panel (LRP).

Ten Latinas with cervical cancer who met inclusion criteria were selected to provide feedback about the SPT. This purposive sample of Latinas partook in a collaborative and iterative process in conjunction with the providers who served as members on the ERP and assisted in the modification of the draft SPT. Once there were no further edits a final draft of the SPT was completed. This final draft was given to another set of five HPE members and five Latina participants who were asked to judge key factors related to the final SPT: understandability, readability, inclusiveness, practicality, and usability (see Appendix E).

**PDSA (plan-do-study-act) Cycle**

The PDSA (plan-do-study-act) cycle for this project began with acknowledging that a problem existed (i.e., no SPT for patients in the clinic), which impacted the process of quality care being rendered. The previously described sections (design, setting, and participants) were all part of the plan step. Each of the four steps that framed this project are described.
Step 1: Plan

Development of Survivorship Planning Tool

The author (principal investigator [PI]) developed a draft SPT based upon a ROL and available online templates. For the draft SPT, the author used the components previously included in the breast cancer SPT developed by both Ashing et al. (2014) and ASCO (2017). They included, but were not limited to, general information - name, telephone number, email address; healthcare providers - gynecology oncologist, radiation oncologist, primary care provider, surgeon, or other provider; diagnosis - diagnosis date, cancer type/location/histology subtype, stage (I, II, III, IV, not applicable); treatment summary - surgery date, surgical procedure, radiation start/end date, systemic therapy (chemotherapy, hormonal, other) start/end date; familial cancer risk assessment - genetic/hereditary risk factor(s) or predisposing conditions, genetic counseling/genetic testing results; treatment - name, plan for radiation, chemotherapy, or other therapies, and possible side effects; schedule of clinic visits - coordinating provider, when/how often; treatment completed - date declaring no evidence of disease (NED); routine surveillance visits - every three, four, or six months; list of issues that the cervical cancer patient may experience - fatigue, physical function, emotional and mental health, memory concentration loss, sexual functioning, need for financial advice or assistance, weight loss, weight gain, and or fertility issues; list of lifestyle modifications necessary for health promotion including alcohol consumption, weight management, diet, sunscreen use, physical activity, tobacco use/cessation (see Appendix F). The draft SPT was submitted to a bilingual expert who generated the Spanish version (see Appendix F).
Recruitment: Key Stakeholders

Recruitment of healthcare professional participants commenced when a verbal request was made to the division director of the Gyn-Onc clinic to allow the author to attend the department’s monthly meeting to provide an informational session regarding the QI project. A succinct PowerPoint presentation (PPT) was developed to guide the informational session for the key stakeholders. To recruit participants, a presentation was given at the monthly staff meeting. A laptop computer and screen were available in the Gyn-Onc department’s conference room for the presentation. All attendees were provided a hard-copy of the draft SPT. An in-depth description of the QI project including the collaborative and iterative feedback process was provided. Upon completion of the PPT, an invitation to participate was extended.

Furthermore, a follow up email was sent to all attendees listing the QI project purpose, goal, and description of the participant’s involvement in the process. The key stakeholders who volunteered formed the membership of the ERP. The members of the ERP reviewed, critiqued, and suggested any needed changes to the draft SPT.

Recruitment: Latina Participants

A flyer was developed to facilitate recruiting volunteers to serve on the LRP (see Appendix G). The flyer, written both in English and Spanish to recruit Latinas who spoke either or both languages, highlighted the QI project purpose and participant commitment required. The flyer contained information on the review process required by participants as well as meeting inclusion criteria of cervical cancer diagnosis and radiation therapy to treat their cancer. The author’s contact information was placed on the flyer for those who were eligible and interested in participating. During a five-week
period, the flyers were posted in the waiting room area where participants were processed prior to their visit with their clinician.

**Step 2: Do**

**Placing the Plan Step into Motion**

In the do step, the author provided an in-service to key stakeholders on the importance of developing a SPT for Latinas with cervical cancer and a copy of the initial draft SPT was issued. Additionally, the feedback process for the draft SPT was shared.

Similarly, the purposive sample of Latinas who responded to the recruitment flyer from November 1, 2017 through December 27, 2017, underwent an individual face-to-face informational session with the author. Upon contact by those interested in volunteering and those determined to meet inclusion criteria, the author provided information on the purpose and process as well as answered all questions. Afterwards, the author inquired about their willingness to participate. The ten Latinas who agreed to participate served as the LRP. The author reviewed verbatim the “Information Sheet” as a standard script for each potential Latina participant (see Appendix H). These sessions were provided individually in a private room. The “Information Sheet” and the draft SPT were given to the participants at the end of the session. Most participants requested to provide their feedback via a follow up telephone call appointment instead of returning to the clinic for individual face-to-face visits.

The members of the ERP and the LRP appraised, critiqued, and suggested any needed changes to the draft SPT. An iterative process amongst members of the ERP, the author, and the LRP ensued using the Delphi technique. The Delphi technique is a systematic consensus method, which involves structured interaction amongst experts on a
subject (Hasson, Keeney, & McKenna, 2000). Figure 2 demonstrates the Delphi
technique/process in the development of the SPT.

The iterative process involved a cycle of review, critique, and changes to the draft
SPT by the ERP. The author made the changes with resubmission to the ERP for
additional edits as needed. The author then presented the draft SPT to the LRP for
feedback and revisions. The ERP was privy to the critique, changes, and suggestions
made by the LRP. The author made requested changes as needed. Once each panel did
not have any further edits to the draft SPT the review process was finalized (see
Appendix I). The finalized SPT was then resubmitted to a bilingual expert (see Appendix
J).

Meanwhile, the author met with the Chair of both the Forms Committee and
Cancer Committee regarding submission of the SPT to seek approval for its general use
at the facility. The Chair shared her enthusiasm and excitement regarding this QI project
and informed the author that a process was currently in motion to create a standard
survivorship care plan (SCP) for all cancer survivors within the entire network. The
Chair expressed that the SPT would be instrumental in promoting their proposed project
and extended an invitation to the author to join her and the team, who in collaboration
with the IT/Cerner team, were developing a standardized SCP.

**Step 3: Study**

**Outcomes of Survivorship Planning Tool Redesign Monitored**

In the study step, outcomes were monitored, and validity of the plan was
evaluated to check for signs of progress and success. Thus, the SPT was evaluated for
Figure 2. Delphi Technique/Process.

- **Expert panel**
  - Review, critique, and suggest any needed changes
  - Submit to PI, new edits made.
  - Then PI gives to Latina participants

- **Author (PI)**
  - Reviews and makes changes accordingly
  - Resubmission to Latina participants
  - Resubmission to the professional review panel until all changes are finalized

- **Latina participants**
  - Review, critique, and suggest any needed changes
  - Reviews SPT for understandability, readability, and feasibility
content validity by five additional HPE who did not participate in the ERP during the design phase. These five HPE completed a survey designed to determine content validity. The survey tool, developed by the author, used a Likert scale design (see Appendix E).

Similarly, the author developed a survey tool in Spanish and submitted it to a bilingual expert for translation to allow Latinas to evaluate the SPT. The author selected five Latinas from the volunteer group who did not participate in the LRP during the design phase. These five Latinas completed a survey designed to determine content validity. Key factors related to the final SPT (i.e., readability, inclusiveness, understandability, and usability) were considered important in determining compliance.

**Step 4: Act**

**Evaluation of Survivorship Planning Tool**

The act step completed the PDSA cycle (see Figure 3). The author in a reflective manner reviewed the finalized SPT and took into consideration the results of the content validity survey given to both the five HPE and five Latinas with cervical cancer. The author with collaboration/feedback from key stakeholders and Latinas with cervical cancer designed a SPT. Implementation of the tool will take place in the clinic setting where the QI project was conducted within the next PDSA cycle.
Figure 3. PDSA cycle for development of Survivorship Planning Tool.
RESULTS

This interdisciplinary QI project was undertaken to develop a SPT specifically for Latinas with cervical cancer and was conducted during a three-month period, November 1, 2017 through February 28, 2018. Prior to recruiting the Latina participants, a pilot interview was conducted with one participant to obtain feedback regarding the scripted narrative and the commitment involved to participate, and to attain an estimation of the length of time required to perform the interview (Roush, 2015). The requirement for additional face-to-face visits to engage in the iterative feedback process was viewed as too arduous by the Latina who underwent the pilot interview. Therefore, appointments via telephone for all subsequent visits/interviews and edits to the “Informational Sheet” accordingly were applied after resubmission to IRB was approved.

Expert Members Panel

A total of nine healthcare providers participated in this project: four members who served on the content ERP, which included three board-certified gynecology-oncologist and an oncology nurse; and five HPE who did not participate as members of the ERP but were invited to partake in a survey designed to determine content validity. The HPE included a board-certified gynecology-oncologist, a primary care physician (PCP), a certified nurse midwife (CNM), a board-certified family nurse practitioner (FNP- BC) working as a Gyn-Onc clinician, and a board-certified women’s healthcare nurse practitioner (WHCNP-BC).

The four members of the ERP, who provided feedback regarding the draft SPT, had the following initial edits per section (see Table 2). The healthcare provider section had the following edits: generalizing the section to display Gyn-Onc clinic, primary care
clinic, radiation oncology clinic, and medical oncology clinic rather than listing provider for these subsections.

In the treatment summary section the following changes were made: deleted ER/PR (estrogen and progesterone) receptor sites because they are unrelated to cervical cancer; added a check box for stage IV disease as it was not initially included; changed hormonal treatment to immunotherapy in the systemic therapy row, which is the appropriate terminology; deleted chemotherapy agents Irinotecan, 5-FU, Taxotere, or Mitomycin, which are not used in this clinical setting; added Bevacizumab (Avastin), which is one of the agents frequently used at this clinical setting; added a start date for radiation therapy, which was omitted in the draft SPT; added brachytherapy, which is a treatment modality frequently used that was not originally included; added boxes for start/end dates for brachytherapy, which would be indicated if the participant underwent this treatment modality.

Additionally, in the treatment summary section a new row was added to include the phrase: Were you involved in any clinical trials? With a corresponding yes/no box, as it is important to know which agents have been previously used to treat the patient in further assisting survivors in the selection of alternative treatment options; added an additional phrase: “What was the name of the trial or the study agents?” with corresponding fill-in lines.

The follow-up care plan section underwent the following edits: deleted individual lines per visit timeframe to simplify and conserve space. Under the cancer surveillance segment, the bone density every five years starting age of 65 was added, which is standard protocol for this clinical setting; added a fill-in line space for starting age to
undergo annual mammograms, because some patients may need to start screening earlier than others pending their personal/familial history of breast and other cancers.

Furthermore, a new menopausal status section was added to reflect: age induced, surgery induced, radiation induced with corresponding yes/no box; hormonal therapy for menopausal symptoms with corresponding yes/no box; and type of hormone replacement with a fill-in line space for start/end dates. Each ERP member expressed 100% agreement once edits were incorporated.

**Latina Panel Members**

A total of fifteen Latinas with cervical cancer who met inclusion criteria were recruited to participate in this QI project and comprised the purposive sample asked to review the draft SPT. Ten of the participants were selected to participate during the iterative feedback phase for the draft SPT and were referred to as members of the LRP. The remaining five participants partook in the evaluation phase of the finalized SPT and were invited to participate in a content validity survey. The language preference for these participants was Spanish except for two who preferred English (see Table 3). The LRP member’s ages ranged from 25 to 68.

The concept of a SPT was a new and unheard-of concept for all participants. They were more intrigued by the notion of having this tool available rather than adding or deleting any of the information contained in the draft SPT. Ultimately, the main feedback obtained was in the ‘Follow-up Care Plan’ section to add additional boxes labeled “other” with fill-in lines/space to write in additional issues, concerns, symptoms, and or complaints (see Appendix I and J).
### Table 2

**Expert Review Panel Members’ Survivorship Planning Tool (SPT) Edits**

<table>
<thead>
<tr>
<th>SPT Section</th>
<th>Additions</th>
<th>Deletions</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Information</td>
<td>Gyn-Onc 4P21 clinic, Primary care clinic, radiation oncology clinic, medical oncology clinic rather than listing provider for these clinics.</td>
<td>Specifying a provider as patients can potentially be seen by different provider each visit.</td>
</tr>
<tr>
<td>Treatment Summary</td>
<td>Check box for Stage IV disease</td>
<td>ER/PR receptors site since unrelated to cervical cancer.</td>
</tr>
<tr>
<td></td>
<td>Start date for radiation therapy.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Brachytherapy.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Check boxes for Brachytherapy start/end dates.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Switched terminology in the systemic therapy row to immunotherapy rather than hormonal treatment.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Were you involved in any clinical trials with check boxes for yes/no.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Line to list the name(s) of the trial or study agents.</td>
<td></td>
</tr>
<tr>
<td>Follow-up Care Plan</td>
<td>Simplify schedule for clinic visits: every ____ months for ___ years, then every ____ months for ___ years, then yearly.</td>
<td>Simplify schedule for clinic visits by removing individual lines per visit timeframe.</td>
</tr>
<tr>
<td></td>
<td>Cancer Surveillance: Bone density- every 5 years starting at 65 yo. Mammogram- annually starting at age: _____.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Influenza Vaccine.</td>
<td></td>
</tr>
<tr>
<td>Follow-up Care Plan</td>
<td>Menopausal Status: Age induced, surgery induced, radiation induced with corresponding yes/no box; hormonal therapy for menopausal symptoms with corresponding yes/no box; type of hormone replacement with fill-in line and start/end date spaces.</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* ER/PR = estrogen and progesterone; Gyn-Onc = Gynecology Oncology; yo = year old.
The members of the LRP were informed of the edits submitted by the ERP and vice versa. Although ERP members were made aware of the LRP’s feedback, the ERP did not provide further comments and or edits. The LRP expressed 100% agreement without any additional feedback.

Unequivocally, each participant asked who would be responsible for completing the SPT and expressed apprehension about the responsibility for upkeep. Reassurance was provided regarding the joint and collaborative process that would be undertaken with both the healthcare providers’ team and survivors to complete the SPT. Final modifications to the draft SPT were made based on the data collected from both members of the ERP and LRP respectively.

**Content Validity Survey**

The content validity survey questions involved a 5-point Likert scale giving each response a numerical value to measure each respondent’s attitude or belief. The range was as follows: 1 = strongly disagree, 2 = disagree, 3 = undecided, 4 = agree, and 5 = strongly agree. Higher mean scores above 2.5 are reflective of positive attitude, belief, or agreement (Roush, 2015). Whereas scores lower than 2.5 are more reflective

---

**Table 3**  
**Socio-demographic Variables (Race, Gender, and Language Preference)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Latina</td>
<td>15</td>
<td>100.00</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>100.00</td>
</tr>
<tr>
<td>Language Preference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish</td>
<td>13</td>
<td>86.67</td>
</tr>
<tr>
<td>English</td>
<td>2</td>
<td>13.33</td>
</tr>
</tbody>
</table>
with less favorable attitude, belief, or agreement (Roush, 2015). There were five questions specific to the finalized SPT that each member of the HPE panel answered (see Figure 4).

Overall, the mean score for the five questions ranged from 3.6 to 4.8. The APRNs (NPs and the CNM) found the tool to be understandable and easy to read with mean scores of 4.3 each. The APRNs agreed that the SPT was related to cervical cancer with a mean score of 5. Similarly, the physicians agreed that the SPT was understandable, readable, inclusive/related to cervical cancer with mean scores of 4, 4, and 4.5 respectively. However, the physicians scored the tool lower in the areas of practicality with a mean score of 3; usability/easy to complete received a mean score of 2.5. Two members of the HPE expressed concerns regarding the timeframe to complete the SPT during specified clinic visits. Reassurance was provided that the logistics for SPT review time would be addressed during the implementation phase (and second PDSA cycle). The author also shared the plan currently in motion with the cancer committee and IT team for developing a SPT on the electronic medical record to decrease human error and address time constraints.
Figure 4. Content and Validity Survey responses: Expert members.

Note. 1 = strongly disagree; 2 = disagree; 3 = undecided; 4 = agree; 5 = strongly agree. CNM = certified nurse midwife; Gyn-Onc = Gynecology-Oncology; MD = medical doctorate; NP = nurse practitioner; PCP = primary care physician.
The same key factors considered important in determining compliance with the final SPT that were evaluated by the HPE were also appraised by the members of the Latina panel using the Spanish survey tool: understandability, readability, inclusiveness, practicality, and usability. The survey tool used the same 5-point Likert scale system and scoring as described above.

The mean score for the five questions answered by the members of the Latina panel ranged from 4.0 to 4.8. The Latina panel found the tool to be understandable and readable with mean scores of 4.2 each; inclusiveness/related to cervical cancer obtained a mean score of 4.8; whereas practicality and simplicity both received mean scores of 4.0 (see Figure 5). Each participant expressed reservation regarding their lack of knowledge with the names of the chemotherapy agents listed on the SPT. Once again, reassurance was provided that most of the treatment summary section (as well as the other sections) including the chemotherapy agents would be completed by the healthcare provider and with collaboration of the Latina survivors who could shed insight on their individual treatment history. The members of the Latina panel quickly responded that if that were the case, then maintaining the SPT would be practical and simple.
Figure 5. Content Validity Survey responses: Latina participants.

Note. 1 = strongly disagree; 2 = disagree; 3 = undecided; 4 = agree; 5 = strongly agree
DISCUSSION

A survivorship planning tool (SPT) has been shown to improve the quality of care of survivors as they move beyond their cancer treatment including but not limited to offering the following benefits: provides a communication tool between healthcare provider and survivor to maximize health; is a useful and practical resource aimed in supporting continuum of care; informs the survivor about their diagnosis and treatment; empowers the survivor over their disease process and their care; leads to improved clinical cancer outcomes; incorporates a tool for monitoring follow-up care promoting compliance with treatment and care; and helps survivors store all information together (which can be used to communicate previous and current treatments should the survivor move or change healthcare provider). Considering these benefits, it is without question that all cancer survivors should have and use a SPT.

Healthcare providers including APRNs and nurses in general play a pivotal role in improving health outcomes and QOL for cervical cancer survivors. As such, it is imperative that members of the healthcare team be cognizant of the importance of an individualized survivorship care plan (SCP) for cancer survivors. Furthermore, all cancer survivors should have a SPT once a history of cancer has been ascertained. Primary care providers are encouraged to actively engage in evaluating whether an individual with a history of cancer survivorship has an individualized SCP (Nekhlyudov et al., 2017). Because there are fewer oncologists available to supervise follow-up care, an increase in cancer survivors, and more patients who comply with healthcare visits, the burden of ensuring that cancer survivors have a SCP should be shared jointly amongst the healthcare team and not just be deferred to the oncologist (Nekhlyudov et al., 2017).
Equally, nurses must be knowledgeable and vigilant when taking or reviewing a patient’s history and readily guide those identified as cancer survivors in attaining a SCP.

A SPT for Latina cervical cancer survivors was successfully developed to help them in their survivorship trajectory. The Gyn-Onc clinic SPT aligns with the recommendation from the IOM report of 2005: *From Cancer Patient to Cancer Survivor: Lost in Transition*, which indicated that every cancer survivor should have an individualized SCP. This QI project was viewed by an interdisciplinary team as a positive change in practice that would improve quality healthcare outcomes for these cancer survivors. Latina participants expressed support for the use of a SPT as a resource for this population.

**Limitations**

This QI project was conducted in a single setting, which may not be generalizable to other Latina groups or ethnic populations. Additionally, the SPT was only specific to cervical cancer which may limit its generalizability to other types of cancer.

**Conclusion**

The provision of a SPT is necessary and beneficial for cancer survivors. The survey responses from members of both the HPE panel and Latina panel gave credence to the importance of developing a SPT to provide an individualized SCP for cancer survivors to help their survivorship trajectory, provide a sense of control over their diagnosis and treatment, and improve their QOL. Each participant expressed gratitude, excitement, acceptance, and their perceived usefulness of the SPT. Therefore, it is important for nurses and other healthcare providers to be attentive in assessing
individuals with a history of cancer and or cancer survivorship to readily guide them in acquiring and maintaining a SPT.
REFERENCES


https://www.cdc.gov/cancer/dcp/research/articles/survivorship-supplement.htm


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## APPENDIX B
### TABLES OF EVIDENCE

**Barriers and Facilitators to Cervical Cancer Screening and Survivorship**

<table>
<thead>
<tr>
<th>Purpose, Design &amp; Key Variables</th>
<th>Sample &amp; Setting</th>
<th>Measurements, Operational Definitions of Variables</th>
<th>Results or Findings</th>
<th>Authors’ Conclusions; Study Limitations &amp; Your Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examined perceived factors affecting cervical cancer screening behaviors</td>
<td>Qualitative, descriptive research</td>
<td>Purposive sample of N = 20 Hispanic women 18 to 65 years of age</td>
<td>Author created questionnaire/interview guide &amp; demographic forms.</td>
<td>Emerging themes categorized as barriers &amp; motivators. Barriers: (a) Personal &amp; cultural factor: Lack of health promotion/disease prevention perspective, lack of knowledge about Pap, &amp; some specific cultural values. (b) Provider &amp; systems: Lack of access to female Spanish-speaking providers, failure of healthcare providers to recommend Pap smears, financial, &amp; inadequate access to health care. Motivators: experiences with women having CxCa, potential symptoms of CxCa, fear of spousal infidelity asso expo to STD, perceived importance maintaining health via pap, desire to be healthy to care for family.</td>
</tr>
</tbody>
</table>

(Boyer, Williams, Clark Calker, & Marshall, 2001) Interviews conducted in participants' homes.
<table>
<thead>
<tr>
<th>Purpose, (Author(s), year)</th>
<th>Design &amp; Key Variables</th>
<th>Sample &amp; Setting</th>
<th>Measurements, Operational Definitions of Variables</th>
<th>Results or Findings</th>
<th>Authors’ Conclusions; Study Limitations &amp; Your Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explored factors that influence repeated Pap smear screening among recently immigrated Latinas working in bars (cantinas). (Fernández-Esquer, &amp; Cardenas-Turanzas, 2004).</td>
<td>Cross-sectional design, a hierarchical regression model was adopted to account for variation in repeated Pap smear screening. (Face-to-face anonymous interview administered during the study’s formative phase). IDV= Recently immigrated Latinas working in bars. DV= Repeated pap smear screening</td>
<td>N = 360 immigrated Latinas working in cantinas. Four bars in Latino neighborhoods within a large metropolitan area in Tx were selected (two large residential areas with a history of Mexican Latinos)</td>
<td>Hierarchical linear regression measures 10-item scale evaluative attitudes Cronbach’s α = 0.69.</td>
<td>Demographic characteristics = 5% of the variance (R2 = 0.05), CxCa screening barriers = (R2 = 0.01), facilitators = (R2 = 0.14), psychosocial measures = (R2 = 0.12). Factors asso with repeated Pap smear screening may be different from those asso with initial screening. Ca screening facilitators explained a significant proportion of the variance in repeated screening, regardless of other variables in the equation.</td>
<td>Access to a clinic and to routine health care have a critical influence on ca screening habits of these women. Given the lack of universally accepted guidelines for women at high risk for CxCa, rec that all recently immigrated Latinas (particularly whose behaviors may put them at higher risk for CxCa) be advised to get yearly Pap smears. Limited to only Latinas (mostly Mexicans) working in cantinas in Tx. ROL demonstrates the importance of Pap smear adherence to ↓ CxCa in the Latina population.</td>
</tr>
<tr>
<td>Purpose, (Author(s), year)</td>
<td>Design &amp; Key Variables</td>
<td>Sample &amp; Setting</td>
<td>Measurements, Operational Definitions of Variables</td>
<td>Results or Findings</td>
<td>Authors’ Conclusions; Study Limitations &amp; Your Notes</td>
</tr>
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<td>-----------------------------------------------</td>
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<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Explore what Mexican immigrants believe about the Pap smear &amp; reasons they seek or avoid the exam. Investigate social &amp; cultural barriers to cervical cancer prevention among Latina immigrants.</td>
<td>Qualitative research interviews/ community based participatory Research (CBPR).</td>
<td>N = 28 Mexican immigrant women &amp; N = 23 Mexican immigrant men recruited through snowball sampling, 18-63 years of age located at Multnomah County, Oregon</td>
<td>In-Depth Interviews were conducted at a site of the interviewee’s choosing. Each person interviewed was offered incentive pay of $20.</td>
<td>Participants learned about the Pap smear from a wide variety of sources. Pap understood as an exam for STI, related CxCa to high-risk sexual behaviors. Men have greater power/behavioral freedom than women do in relationships thus considering men to have a significant role as cause for disease &amp; as barriers to screening. Quantitative &amp; qualitative methods, necessary to further clarify both generalizability links between beliefs about CxCa &amp; prevention</td>
<td>Interventions to improve CxCa prevention among Mexican immigrants may be more effective if they include both men &amp; women; recognize &amp; address concerns about STI spread &amp; prevention; recognize that even when women know how to prevent disease, they may feel disempowered with regard to making behavioral changes that will ↓ their risk for STIs or CxCa. Practical interventions to ↑ female empowerment. Relating pap smear to STI may hinder compliance due to not wanting infidelity label (both male &amp; females). Bias &amp; potential conflict of interest due to paid for interview.</td>
</tr>
<tr>
<td>Explore factors affecting incomplete follow-up among staff &amp; a group of Hispanic women with low incomes.</td>
<td>Qualitative, descriptive research</td>
<td>N = 11 Hispanic pt at a publicly funded clinic in a major city in south Texas. Average age 52 years old.</td>
<td>Author created questionnaire/ semi-structured, open-ended interview/face-to-face in-depth.</td>
<td>Contradictions between the staff &amp; pt accounts for missed appts: Four main staff-pt discrepancies: Follow up received elsewhere, poor communication, clinic errors, &amp; inordinate follow up requirements.</td>
<td>Authors set out to identify factors that could contribute to loss f/u. Unable to generalize findings to a broader population. Potential bias toward the experiences of contacted women that is quite</td>
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<td>Purpose, (Author(s), year)</td>
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<td>(Hunt, De Voogd, Soucy, &amp; Longworth, 2002).</td>
<td>All staff members at the clinic also interviewed.</td>
<td>Provided detailed table contrasting clinic &amp; pt account of the f/u process.</td>
<td>Several pts was unaware of missed appts that apparently had been scheduled for them without their knowledge</td>
<td>distinct from those who were unable to be located. Improved communication &amp; what is perceived by staff &amp; pt is imp in maintaining pap f/u.</td>
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*Note. Acc = Acculturation; Ack = Acknowledging; Asso = Associated; Cb = Cultural beliefs; CxCa = Cervical cancer; DV = Dependent variable; Edu = Education; Expo = Exposure; ESN = Existing social networks; FCV = Family-centered values Is = Immigrant status; IDV = Independent variable; Pt= patient; Rec = recommends; ROL = Review of the literature; STD = Sexually transmitted diseases; Tx = Texas; ↑ = Increase; ↓ = Decrease; & = and.*
**Survivorship in Cervical Cancer Patients**

<table>
<thead>
<tr>
<th>Purpose, (Author(s), year)</th>
<th>Design &amp; Key Variables</th>
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<tr>
<td>Development of a template targeted for Latino breast cancer patients (LCA), for treatment summary and Survivorship Care Plan in Spanish (TSSCP-S)</td>
<td>Mixed Methods</td>
<td>N =12 Latina survivors/volunteers to recruit/promote participation; N=10 expert panel of diverse stakeholder specified as the review group to evaluate the TSSCP-S review via email</td>
<td>Two-component in development and evaluation of the tool using 12- Latina survivors/volunteers 10-expert panel of diverse stakeholder review group to evaluate the TSSCP-S</td>
<td>The implementation of the TSSCP targeted an underserved, high-risk population of Latinas with breast cancer. Identifying methods to improve surveillance and follow-up guideline adherence may lead to improved clinical cancer outcomes and quality of life.</td>
<td>Attest that this is one of the first studies regarding cultural and linguistic content modification for SCP to ↑ responsiveness and for Latina. Stakeholders involved both providers and survivors. Limitations noted by the author were small number of Latina survivors and stakeholders’ evaluators that participated in the development phase. Material was preferred because not everyone has access to online material. Gives a clear blueprint for the components of survivorship care plan culturally and linguist sensitive for Latina’s</td>
</tr>
<tr>
<td>Cancer survivors’ confidence in managing survivorship care</td>
<td>National survey study N = 376 LIVESTRONG™ Survivorship Center of Excellence Network sites</td>
<td>Self-reported survey assessing receipt of survivorship care planning, expectations of their providers, and confidence in managing their survivorship care. Multivariate logistic regression identified</td>
<td>41% low confidence in managing survivorship care for non-white lack of survivorship care plan Survivorship care planning 33% without Treatment Summary 48% without Survivorship Care Plan 55% without</td>
<td>Acknowledges growing population of young adult cancer survivors without long-term follow-up care and the need for both medical and psychosocial care to deal with late effects of cancer treatment. Only 26% of those surveyed reported having all required survivorship care planning documents. There are a high</td>
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<td>(Casillas, Syrjala, Ganz, Hammond, Marcus, Moss, &amp; Friedman, 2011).</td>
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<tbody>
<tr>
<td>Low confidence in managing survivorship care.</td>
<td>“Shared-Care Model” 90% without</td>
<td>percentage of cancer survivors without survivorship planning. Lack of survivorship planning associated with higher low self-confidence in managing care. Non-whites have higher lower confidence. The study limitations were uncertain of generalizability of findings due to convenience sample attained from NCI-designated CCC across the U.S. Significant percentage of cancer survivors had higher socioeconomic resources. Demonstration of importance of survivorship planning in confidence levels of cancer survivorship patients.</td>
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<tr>
<td>Overall survival and progression-free survival in cervical cancer, time-varying effect correlated to tumor size</td>
<td>Retrospective medical record review</td>
<td>N = 797 Kaohsiung Veterans General Hospital</td>
<td>Tumor size was measured FIGO scores obtained. Preoperative tumor markers CA125, CEA, CA199</td>
<td>Univariate and multivariate analysis conducted identified tumor size, stage, and lymph nodal metastasis as independent significant risk factors for both recurrence and death (P &lt; 0.05)</td>
<td>Tumor size, FIGO stage, and lymph node status are risk factors for recurrence and death in CxCa and have time-varying effect on recurrence and lessens with PFS. Limitations per author were retrospective design and limited number of pts from single institution, which hinder generalization of conclusions.</td>
</tr>
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<tr>
<td>Examined experiences of cancer survivors to provide their perspective on how survivorship care plans are used in practice (Keesing, S., McNamara, B., &amp; Rosenwax, L., 2015).</td>
<td>Systematic review of qualitative literature</td>
<td>N = 11 qualitative studies</td>
<td>Databases reviewed included CINAHL, AMED, Embase, MEDLINE, Informit, ProQuest, PsycINFO, ScienceDirect, Wiley Online Library, Scopus and Web of Science from 2000 to 2014 articles were appraised for methodological quality and content</td>
<td>SCP tool is useful and practical, aimed at supporting the survivorship care trajectory. However, further research is needed to explore the variety of SCPs available, their practicalities and usability.</td>
<td>Future studies should aim at obtaining larger sample sizes from multiple institutions and prospective studies. Tumor size is important to take into consideration in the survivorship planning care trajectory. The larger the size the more caution and alert one must be for potential recurrence. Acknowledges IOM promotion to use SCPs can empower and inform survivors about their overall care, diagnosis, treatment, monitoring required, and follow-up care needed. Additionally, it is a tool which can help communication between healthcare provider and survivor. Limitations: quantitative studies not included. Only perspective of the survivor and not the healthcare provider. This article supports the importance of SCP.</td>
</tr>
<tr>
<td>Explored cancer survivorship experiences among Hispanic men and women</td>
<td>Qualitative</td>
<td>Women (n = 31) Men (n = 10)</td>
<td>Five focus groups were conducted from February 2006–October 2007</td>
<td>Cancer diagnosis made survivor feel disconnected/isolated, fearful, believe was God's will, sense of fatalism. Conversely, faith</td>
<td>Culturally sensitive support groups are needed. Providers should be aware of the knowledge barriers that survivors in general have.</td>
</tr>
<tr>
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<td>Livaudais, Thompson, Godina, Islas, Ibarra &amp; Coronado, 2010)</td>
<td>Two rural Washington communities in the Lower Yakima Valley</td>
<td></td>
<td>in God and comfort and one spirituality report as helping with survivorship. Emerging themes: Experience with cancer- various seeking cancer diagnosis included inaccurate perception/cultural norms against male physician undergoing mammogram and Pap felt embarrassment, denial and fear. Experience with physicians- sense of trust, majority had negative experiences, felt in the glutted, felt rushed.</td>
<td>Encourage physicians to connect with their patients to help address/describe feeling in results section. Information and resources considered helpful for other cancer survivors. Providing resources in combination of having survivors/volunteer network. No limitations were provided. As healthcare providers, we must be cognizant of cancer survivor’s experiences and allow them to express their feelings and concerns.</td>
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<tr>
<td>Understanding breast cancer survivorship care in underserved and underinsured Latinas (Tisnado, Mendez-Luck, Metz, Peirce, &amp; Montaño, 2017).</td>
<td>Qualitative research N = 74 Los Angeles County</td>
<td>Six English- and six Spanish-language semi-structured focused groups</td>
<td>Promoting implementation of survivorship care plans Improving and increasing peer and professional support services for patients, family, and caregivers. Adds to the body of literature on the importance of survivorship care and experiences with the medical care system for Latinas in Los Angeles County.</td>
<td>Demonstrated the need for future research and methods of responding to the unmet needs of the Latina breast cancer survivor. Limitations in that although published in 2017, data was collected from 2009-2010, which may not represent current needs; women residing in Los Angeles County only; barriers in reaching those that were too ill to participate or with no access to facility were conducted.</td>
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<td>Helping cervical cancer survivors’ women seek help for sexual issues (Vermeer, Bakker, Kenter, Kroon, Stiggelbout, &amp; Kuile, 2015).</td>
<td>Multicenter cross-sectional questionnaire/cohort study</td>
<td>women (n = 343) and their partners (n = 154) Leiden University Medical Centre (LUMC) in partnership with the Centre for Gynecological Oncology Amsterdam</td>
<td>Women’s Prof healthcare needs were asked with 5 point Likert item (1 = never to 5 = very often)</td>
<td>51% women reported a need for info and/or prof help, 35% women had initiated a conversation with a prof about sexuality. Positive beliefs about the quality of professional psychosexual support yielded higher help-seeking intentions. Women embarrassed to discuss sexual issues with a prof were less likely to seek help. Most participants appreciate receiving info about sexuality and CxCa</td>
<td>Healthcare professionals’ awareness women need information and/or prof care for their sexual concerns. Participants thought that they were not adequately info about the consequences of the treatment on their sexual functioning. Low TPB variables related to help-seeking intentions, low internal consistency can compromise the validity and reliability of these measurements CxCa survivors have psychosexual healthcare needs. Women and their partners should be assessed for sexual healthcare services.</td>
</tr>
<tr>
<td>Psychosocial telephone counseling for survivors of cervical cancer</td>
<td>Randomized clinical trial IDV: CxCa survivor</td>
<td>N = 204 California cancer registries (Orange, Los Angeles, Imperial, UC (n = 115))</td>
<td>40% Hispanic 51% Non-Hispanic PTC (n = 115) UC (n = 89)</td>
<td>Significant difference in gynecologic and cancer-specific concerns (P&lt;.05) Greater improvement in QOL</td>
<td>Acknowledges mood, QOL, cancer-specific, and gynecologic concerns of</td>
</tr>
<tr>
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<td>cancer: results of a randomized bio-behavioral trial (Wenzel, Osann, Hsieh, Trucker, Monk, Nelson, 2015).</td>
<td>psychosocial telephone counseling DV: QOL domains and associations with biomarkers</td>
<td>and San Diego counties</td>
<td>PROs and biospecimens collected at 4 and 9 months assessment</td>
<td>underserved Hispanics were benefitted with PTC. Demonstrates the great value of psychosocial counseling for CxCa survivors</td>
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<td>QOL after CxCa among Chinese women (Zeng, Li, &amp; Loke, 2011).</td>
<td>Qualitative Narrative Research</td>
<td>N = 35, Mainland China</td>
<td>QOL includes physical, psychological, social, and spiritual wellbeing. Emerging themes were impacts on: psychological well-being, social well-being, spiritual well-being, and disruption to sexual life. Changes in roles and responsibility being a burden to the family. Coping methods and sources of support.</td>
<td>Exploration of what QOL means to CxCa survivors which indicated that being healthy and free of cancer is what survivors identify as QOL. Limitations were noted: only one tumor research setting which decreases transferability and no face-to-face interviews only written response. Cervical cancer survivors associate being cancer free with healthy and having QOL.</td>
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<tr>
<td>A systematic review of the literature for QOL in CxCa and direction for research (Zeng, Ching, &amp; Loke, 2011).</td>
<td>Systematic Review</td>
<td>N = 31 articles: 26 quantitative and N = 5 qualitative studies</td>
<td>Major QOL issues among CxCa survivors were categorized at the individual and systemic level. All findings categorized on table per the 31 articles found under this systematic review. Need to explore and optimize positive outcomes for CxCa survivors. Need interventions to reduce unhealthy lifestyles and behaviors. Exploratory studies to determine impact of survivorship on families.</td>
<td>This systematic review of the literature demonstrates a growing trend of QOL for CxCa survivors. Importance of focusing on positive aspect, unhealthy lifestyles, and behaviors contributing to poor QOL among CxCa survivors. Versus plan important role in assessing a promoting QOL.</td>
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Thus, it is important to assess QOL among survivors which could facilitate communication between nurses and other healthcare providers. Limitation showed that the three main types of instruments used to measure cervical cancer survivors did not adequately assess systemic level of QOL.

It is important for nurses to be alert, when pt disclose history of cervical cancer to readily inquire regarding QOL and other related issues.

Note. ASCO = American Society of Clinical Oncology; DV = Dependent Variable; CCC = Comprehensive Cancer Centers; Con = Conversation; CxCa = Cervical Cancer; IDV = Independent Variable; Info = Information; IOM = Institution of Medicine; NCI = National Cancer Institute; PCP = Primary Care Provider; PRO = Patient Reported Outcome; Prof = Professional; Pt = Patient; PTC = Psychosocial Telephone Counseling; QOL = Quality of Life; ROL = review of literature SCPs = Survivorship Care Plan; TPB- Theory of planned behavior; TSSCP-S = Treatment; summary and Survivorship Care Plan in Spanish; UC = Usual Care; U.S. = United States of America; ↑ = Increase
APPENDIX C

MEDICAL CENTER IRB APPROVAL

University of Southern California Health Sciences Campus
Institutional Review Board
LAC+USC Medical Center, General Hospital Suite 4700
1200 North State Street, Los Angeles, CA 90033
(323) 223-2340 phone
(323) 224-8389 fax
irb@usc.edu

Date: Oct 30, 2017, 08:03am
To: Ileana Meza, DNP Student, MSN, WHCNP-BC
Nurse Practitioner
GYNECOLOGIC ONCOLOGY

From: Health Sciences Institutional Review Board
General Hospital, Suite 4700
1200 North State Street
Los Angeles, CA 90033
(323) 223-2340

TITLE OF PROPOSAL:
Survivorship Care Planning Tool for Latinas diagnosed with cervical cancer. (Survivorship Planning Tool)

Action Date: 10/29/2017
Action Taken: Approve

Committee: Institutional Review Board Chairman

Note: Your iStar application and attachments were reviewed by the expedited mechanism by Dr. Deirdre Anglin on October 29, 2017.

The project was APPROVED.

The materials submitted and considered for review of this project included:
1. iStar application, dated 09/02/2017
2. Gynecology-Oncology Treatment Summary and Survivorship Care Plan for Cervical Cancer, undated (uploaded 09/25/2017)
3. Content and Validity Survey Tool for Survivorship planning tool for Content Expert, undated (uploaded 09/25/2017)
5. Recruitment Flyer, undated (uploaded 09/25/2017)
6. Recruitment Email, dated 09/23/2017
7. Recruitment PowerPoint, undated (uploaded 09/25/2017)
8. Information AACTSheet, dated 10/15/2017
Approval of your study will expire at the end of the day (midnight) on October 28, 2018.

Based on the information submitted for review, this study qualifies for expedited review according to §46.110(b) (7).

In approving this research, the IRB determined that all of the following requirements (45CFR 46.111) were satisfied: (1) Risks to subjects are minimized: (i) by using procedures which are consistent with sound research design and which do not unnecessarily expose subjects to risk, and (ii) whenever appropriate, by using procedures already being performed on the subjects for diagnostic or treatment purposes. (2) Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result. In evaluating risks and benefits, only those risks and benefits that may result from the research are considered (as distinguished from risks and benefits of therapies subjects would receive even if not participating in the research). (3) Selection of subjects is equitable (the purposes of the research and the setting in which the research will be conducted were taken into account). (4) Informed consent will be sought from each prospective subject or the subject's legally authorized representative, in accordance with, and to the extent required by 45CFR 46.116. (5) Informed consent will be appropriately documented, in accordance with, and to the extent required by 45CFR 46.117. (6) When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of subjects. (7) When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.

As the Principal Investigator you are required to ensure that this research and the actions of all project personnel involved in conducting the study will conform with the research project and its modifications approved by the IRB; HHS regulations (45CFR46); FDA regulations (21CFR50,56); International Conference on Harmonization Good Clinical Practice Consolidated Guideline; IRB Policies and Procedures and applicable state laws. Failure to comply may result in suspension or termination of your research project, notification of appropriate governmental agencies by the IRB, and/or suspension of your freedom to present or publish results. Any proposed changes in the research project must be submitted, reviewed and approved by the IRB before the change can be implemented. The only exception is a change necessary to eliminate apparent immediate hazards to the research subjects. In such a case, the IRB should be promptly informed of the change following its implementation for IRB review. You must inform the IRB immediately if you become aware of any violations of HHS regulations (45CFR46), FDA regulations (21CFR50,56), applicable state laws or IRB Policies and Procedures for the protection of human subjects. You are required to notify the IRB office in the event of any action by the sponsor, funding agency or FDA, including warnings, suspension or termination of your participation in this trial. You must maintain all required research records and recognize the IRB is authorized to inspect these records.

IRB approval is valid for a maximum period of one year with continuing review by the IRB required at least annually in order to maintain approval status. You
may not enter subjects on the study before IRB approval or if IRB approval expires. In the latter case, you must immediately contact the IRB to obtain permission to continue subjects on the trial. You must submit a Continuing Review Form sufficiently (one to two months) prior to your study expiration date to permit IRB review before the expiration date.

You must inform the IRB of any unanticipated adverse event or injury no later than ten (10) business days following the time it becomes known that a subject suffered an adverse event/injury. To report external or internal adverse events to the IRB, you must complete and submit the Reportable Event forms in iStar. Furthermore, you must inform the IRB immediately of any significant negative change in the risk/benefit relationship of the research as originally presented in the protocol and approved by the IRB.

**INFORMED CONSENT**

The request for a WAIVER OF WRITTEN INFORMED CONSENT consistent with 45 CFR 46.117(c) has been approved as iStar #24.4 adequately documents that the research presents no more than minimal risk of harm to the subjects and involves no procedures for which written consent is normally required outside of the research context.

You must use the information sheet dated 10/15/2017 approved by the IRB for obtaining informed consent. A copy of the sheet must be given to the study subject.

The IRB-approved information sheet is located under the “Documents” tab in the iStar study. This is the APPROVED document. You must use a copy of the approved information sheet when consenting study participants.

Informed consent must be obtained by the investigator or person authorized to obtain informed consent from all research subjects or their legally authorized representatives. You must ensure that all project personnel involved in the process of consent/assent are trained properly and are fully aware of their responsibilities relative to the obtainment of informed consent/assent according to the IRB guidelines and applicable federal regulations.

Informed consent is obtained in the research participant's language. If the participant speaks Spanish and the informed consent document has been translated into Spanish, you must use the Spanish information sheets.

**HIPAA AUTHORIZATION**

The HIPAA Privacy Rule will not apply to this research. The investigator certifies that he/she is not accessing, using or obtaining protected (i.e., identifiable) health information held by: a) a healthcare provider (e.g., physician or other healthcare practitioner, hospital, clinic, nursing home); b) health plan (e.g., group health plan, insurance company, HMO); or c) health care clearinghouse (e.g., billing service) that is governed by the HIPAA privacy federal regulations.
Attachments:

DHS Level of Support: (3) Research performed at DHS sites with potential benefit to DHS patients in the future. DHS will allow access to resources, but the study must cover the cost of these resources.
APPENDIX D

CSULB IRB APPROVAL

Please note that California State University, Long Beach Institutional Review Board has taken the following action on IRBNet:

Project Title: [1059540-1] Survivorship Care Planning Tool for Latinas Diagnosed with Cervical Cancer
Principal Investigator: ileana meza, DNP(s)

Submission Type: New Project
Date Submitted: November 5, 2017

Action: EXEMPT
Effective Date: November 7, 2017
Review Type: Administrative Review

Should you have any questions you may contact Tiffany Rose at tiffany.rose@csulb.edu.

Thank you,
The IRBNet Support Team

www.irbnet.org
APPENDIX E

CONTENT VALIDITY SURVEY FOR EPERT AND LATINA PANEL

1. This survivorship planning tool is understandable?
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
   - Strongly Disagree

2. This survivorship planning tool is easy to read?
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
   - Strongly Disagree

3. This survivorship planning tool relates to cervical cancer?
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
   - Strongly Disagree

4. This survivorship planning tool is feasible and will be practical to use in the clinical setting?
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
   - Strongly Disagree

5. This survivorship planning tool is a simple tool that a provider can easily complete?
   - Strongly Agree
   - Agree
   - Undecided
   - Disagree
   - Strongly Disagree
1. ¿Este instrumento de planificación de la sobrevivencia es fácil de entender?
   - Totalmente de acuerdo
   - De acuerdo
   - Indeciso
   - Disacuerdo
   - Muy en desacuerdo

2. ¿Este instrumento de planificación de la sobrevivencia es fácil de leer?
   - Totalmente de acuerdo
   - De acuerdo
   - Indeciso
   - Disacuerdo
   - Muy en desacuerdo

3. ¿Este instrumento de planificación de la sobrevivencia se relaciona con el cáncer del cuello uterino?
   - Totalmente de acuerdo
   - De acuerdo
   - Indeciso
   - Disacuerdo
   - Muy en desacuerdo

4. ¿Este instrumento de planificación de la sobrevivencia es práctico para el uso de sobrevivientes de cáncer del cuello uterino?
   - Totalmente de acuerdo
   - De acuerdo
   - Indeciso
   - Disacuerdo
   - Muy en desacuerdo

1. ¿Este instrumento de planificación de la sobrevivencia es una herramienta simple que usaría?
   - Totalmente de acuerdo
   - De acuerdo
   - Indeciso
   - Disacuerdo
   - Muy en desacuerdo
# APPENDIX F

## DRAFT SURVIVORSHIP PLANNING TOOL ENGLISH AND SPANISH

<table>
<thead>
<tr>
<th>General Information</th>
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<tbody>
<tr>
<td>Patient Name:</td>
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<td>Patient DOB:</td>
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<td>Patient phone:</td>
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<td>Email:</td>
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**Health Care Providers** (Including Names, Institution)

- Gynecology Oncology Provider:
- Primary Care Provider:
- Radiation Oncologist:
- Medical Oncologist:
- Other Providers:

## Treatment Summary

### Diagnosis

- **Cancer Type:** Cervical Cancer
- **Histology Subtype:**
- **Receptors:**
  - ☐ Estrogen positive
  - ☐ Progesterone Positive
  - ☐ Enter positive
- **Stage:**
  - ☐ I
  - ☐ II
  - ☐ III
  - ☐ Fill In Stage________
  - ☐ Not applicable

### Treatment Completed

- **Surgery:**
  - ☐ Yes
  - ☐ No

#### Surgical procedure/findings:

- Lymph node removal:
  - ☐ Enter site (s)____________________
  - ☐ positive
  - ☐ negative

- **Radiation:**
  - ☐ Yes
  - ☐ No

#### Body area treated:

- End Date (year):

- **Systemic Therapy (chemotherapy, hormonal therapy, other):**
  - ☐ Yes
  - ☐ No

- **Before surgery** ☐ After surgery ☐ Type:

<table>
<thead>
<tr>
<th>Names of Agents Used</th>
<th>Dose</th>
<th>Start Date</th>
<th>End Date</th>
<th>Retreatment Date</th>
</tr>
</thead>
</table>
- Fluorouracil
- Cisplatin
- Carboplatin
- Docetaxel (Taxotere®)
- Gemcitabine (Genzar®)
- Ifosfamide (Ifex®)
- Irinotecan (Camptosar®)
- Methotrexate
- Mitomycin
- Paclitaxel (Taxol®)
- Topotecan
- Other

<table>
<thead>
<tr>
<th>Treatment Ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional treatment name</td>
</tr>
<tr>
<td>□</td>
</tr>
<tr>
<td>Other:</td>
</tr>
</tbody>
</table>

Persistent symptoms or side effects at completion of treatment:
- Fatigue: □ No □ Yes
- Menopausal symptoms: □ No □ Yes
- Pain: □ No □ Yes
- Degree of disability: ____________
- Numbness: □ No □ Yes
- Tingling: □ No □ Yes
- Other (enter type(s)): □
- Psychosocial/Depression: □ No □ Yes
- □ Comments:

**Familial Cancer Risk Assessment**

- Breast and or ovarian cancer in 1st or 2nd degree relatives: □ Yes ____________ □ No
- Received Genetic counseling: □ No □ Yes
- Genetic testing: □ No □ Yes

Genetic testing results:
Follow-up Care Plan

Your follow-up care plan is designed to inform you and your primary care providers regarding the recommended and required follow-up, cancer screening and routine health maintenance that is needed to maintain optimal health.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:
Fatigue, numbness, tingling, swelling of legs, bones become weak and at risk for fracture (osteoporosis). If these or any other new problems or complaints occur bring these to the attention of your healthcare provider.

These symptoms should be brought to the attention of your provider:

2. A problem or complaint
3. A persistent problem
   3. Anything you are worried about that might be related to the cancer coming back.

Please continue to see your primary care provider for all general health care recommended for a woman your age such as routine immunizations, and routine non-breast cancer screening like colonoscopy or bone density exams. Consult with your healthcare provider about prevention and screening for bone loss using bone density tests.

<table>
<thead>
<tr>
<th>Fill in problem (s):</th>
<th>Date Began</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

Schedule for Clinical Visits

<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>Routine Visits</th>
<th>Timeframe in Years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐ every 3 months x 2 year:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ every 6 months x 2 year:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ then yearly:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ every 6 months x 2 year:</td>
<td></td>
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<tr>
<td></td>
<td>☐ then yearly:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ other visit plan:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ other visit plan:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ then yearly:</td>
<td></td>
</tr>
</tbody>
</table>

Comments: Cancer Surveillance or Other Recommended Tests
<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>TEST</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breast Exam</td>
<td>Annually</td>
</tr>
<tr>
<td></td>
<td>Bone Density</td>
<td>As indicated by your provider</td>
</tr>
<tr>
<td></td>
<td>Colonoscopy</td>
<td>As indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>Age____and or as indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Pap</td>
<td>Annually or as indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Pelvic exam</td>
<td>Every exam visit</td>
</tr>
</tbody>
</table>

Cervical cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- Anxiety or depression
- Bladder functioning
- Emotional and mental health
- Fatigue
- Weight changes
- Fertility
- Sexual Functioning

☐ Anxiety or depression    ☐ Mental health    ☐ School
☐ Bladder functioning    ☐ Memory or concentration loss    ☐ Work
☐ Emotional and mental health    ☐ Parenting    ☐ Insurance
☐ Fatigue    ☐ Physical functioning    ☐ Stopping smoking
☐ Weight changes    ☐ Rectal/bowel movement functioning    ☐ Insurance
☐ Fertility    ☐ Financial advice    ☐ Other
☐ Sexual Functioning    ☐ Financial assistance    ☐ Other assistance

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

- Alcohol use
- Diet
- Management of my medications
- Management of my other illnesses

☐ Alcohol use    ☐ Physical activity    ☐ Other
☐ Diet    ☐ Sun screen use
☐ Management of my medications    ☐ Tobacco use/cessation
☐ Management of my other illnesses    ☐ Weight management (loss/gain)

Resources you may be interested in:

- [www.cancer.net](http://www.cancer.net)
- Other:

Other comments:
**Información General**

<table>
<thead>
<tr>
<th>Nombre de Paciente:</th>
<th>FDN de Paciente:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Número de teléfono de Paciente:</td>
<td>Correo Electrónico:</td>
</tr>
</tbody>
</table>

**Proveedores de Atención Médica** (Incluyendo Nombres, Institución)

- Proveedor de Ginecología Oncología:  
  Cirujano:  
- Proveedor de Atención Médica Primario:  
- Oncólogo de Radiación:  
- Oncólogo Médico:  
- Otros Proveedores:  

**Sumario de Tratamiento**

**Diagnosis**

- **Tipo de Cáncer:** Cáncer Cervical  
  **Histología Subtipo:**  
- **Receptores:**  
  Estrógeno positivo; Progesterona Positiva; Entra positiva:  
- **Fecha de la Diagnosis (año):**  
- **Etapas:** I, II, III  
  **Completar Etapa________**  
  **No es aplicable**

**Tratamiento Terminado**

- **Cirugía:**  
  **Fecha de Cirugía (s) (año):**  
- **Procedimiento Quirúrgico/resultados:**  
- **Extirpación de ganglio linfáticos:**  
  **Lugar (es):**  
  **positivo**  
  **negativo**  
- **Radiación:**  
  **Fecha Final (año):**  
  **Área del cuerpo tratado:**  
- **Terapia Sistémica (quimioterapia, terapia hormonal, otro):**  
  **Fecha Final (año):**  
  **Antes de cirugía**  
  **Después de cirugía**  
  **Tipo:**  

<table>
<thead>
<tr>
<th>Nombres de Agentes Utilizados</th>
<th>Dosis</th>
<th>Fecha Inicial Retratamiento</th>
<th>Fecha Final</th>
<th>Fecha de</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 5-Fluorouracil</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Cisplatin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nombre de Tratamiento</td>
<td>Duración Planificada</td>
<td>Posibles Efectos Secundarios</td>
<td></td>
<td></td>
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<tr>
<td>-----------------------</td>
<td>----------------------</td>
<td>-----------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Carboplatin</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Docetaxel</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Docetaxel (Taxotere®)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>☐ Gemcitabine</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>☐ Gemcitabine (Gemzar®)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>☐ Ifosfamide (Ifex®)</td>
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<td>☐ Irinotecan</td>
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<td>☐ Irinotecan (Camptosar®)</td>
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<td>☐ Methotrexate</td>
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<tr>
<td>☐ Mitomycin</td>
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<tr>
<td>☐ Paclitaxel (Taxol®)</td>
<td></td>
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<tr>
<td>☐ Topotecan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Otro</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Tratamiento En Curso**

<table>
<thead>
<tr>
<th>Nombre de Tratamiento adicional</th>
<th>Duración Planificada</th>
<th>Posibles Efectos Secundarios</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td></td>
<td>Complete los efectos secundarios:</td>
</tr>
</tbody>
</table>

Otros:

Síntomas Persistentes o efectos secundarios al terminar el tratamiento:
Fatiga: ☐ No ☐ Sí  Síntomas Menopáusicas: ☐ No ☐ Sí  Dolor: ☐ No ☐ Sí Grado de Discapacidad _
Entumecimiento: ☐ No ☐ Sí  Hormigueo: ☐ No ☐ Sí  ☐ Otro (entre tipo(s)):
Psicosocial/Depresión: ☐ No ☐ Sí  ☐ Comentarios: _

**Asesoramiento de Riesgo del Cáncer Familiar**

Cáncer de mama y u ovárico en parientes de 1 o 2 grado: ☐ Sí _ ☐ No
Recibió consejería Genética: ☐ Sí ☐ No  Pruebas Genéticas: ☐ Sí ☐ No
Resultado de pruebas genéticas:

<table>
<thead>
<tr>
<th>Tratamiento de Seguimiento</th>
</tr>
</thead>
<tbody>
<tr>
<td>Su tratamiento de seguimiento es diseñado para informarle a usted y sus proveedores de atención médica respecto al seguimiento recomendado y requerido, detección del cáncer y mantenimiento rutinario de la salud necesarios para mantener una salud óptima.</td>
</tr>
</tbody>
</table>

**Posibles efectos tardíos y largo plazo que alguien con este tipo de cáncer y tratamiento puede pasar:**

Fatiga, entumecimiento, hormigueo, hinchazón de piernas, huesos se debilitan y está a riesgo de fracturas (osteoporosis). Si estos problemas o cualquier otro problema nuevo ocurren comuníquelo a su proveedor de atención médica.

**Estos síntomas deberían ser comunicados a su proveedor de atención médica:**

4. Un problema o una queja  
5. Un problema persistente  
3. Cualquier cosa que le preocupa a usted que pueda ser relacionado con el regreso del cáncer.

Por favor continúe viendo a su proveedor primario de atención médica para toda atención médica general recomendada para una mujer con su edad tal como las vacunas rutinarias, y exámenes rutinarios que no detectan cáncer de mama como la colonoscopía o examen de densidad de ósea. Consulte con su proveedor de atención médica sobre la prevención y examen de perdida de ósea utilizando pruebas de densidad de ósea.

Complete el problema(s):                                      Fecha de Inicio                                      Fecha de Terminación

<table>
<thead>
<tr>
<th>Proveedor Coordinador</th>
<th>Visitas Rutinarias</th>
<th>Plazo en Años</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐cada 3 meses x 2 año:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐cada 6 meses x 2 año:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐posterior anualmente:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Comentarios: Vigilancia de Cáncer u Otras Pruebas Recomendadas

<table>
<thead>
<tr>
<th>Proveedor Coordinador</th>
<th>Prueba</th>
<th>Frecuencia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examen de mama</td>
<td>Anualmente</td>
<td></td>
</tr>
<tr>
<td>Densidad de Ósea</td>
<td>Como sea indicado por su proveedor</td>
<td></td>
</tr>
<tr>
<td>Colonoscopia</td>
<td>Como sea indicado por su proveedor</td>
<td></td>
</tr>
<tr>
<td>Mamografía</td>
<td>Edad ___ y o como sea indicado por su proveedor</td>
<td></td>
</tr>
<tr>
<td>Papanicolaou</td>
<td>Anualmente o como sea indicado por su proveedor</td>
<td></td>
</tr>
<tr>
<td>Examen pélvico</td>
<td>Cada visita de examen</td>
<td></td>
</tr>
</tbody>
</table>

Sobrevivientes de cáncer cervical pueden pasar por problemas en las áreas enumeradas a continuación. Si usted tiene alguna inquietud en estas u otras áreas, por favor hable con sus doctores o enfermera para averiguar como usted puede recibir ayuda en ello.

- Ansiedad o depresión
- Funcionamiento de la vejiga
- Salud mental o emocional
- Fatiga
- Cambios de peso
- Fertilidad
- Funcionamiento sexual
- Salud mental
- Perdida de memoria o concentración
- Crianza de hijos
- Asesoramiento Financiero
- Ayuda Financiera
- Escuela
- Trabajo
- Seguro
- Dejar de Fumar
- Seguro
- Otro
- Otra ayuda
Series de comportamientos/estilos de vida pueden afectar su salud en curso, incluyendo el riesgo que vuelva el cáncer o desarrollar otro cáncer. Hable sobre estas recomendaciones con su doctor o enfermera:

- ☐ Uso de Alcohol
- ☐ Actividad física
- ☐ Otro
- ☐ Dieta
- ☐ Uso de protector solar
- ☐ Gestión de mis medicamentos
- ☐ Uso/cesación de Tabaco
- ☐ Gestión de mis otras enfermedades
- ☐ Gestión de peso (perdida/aumento)

Recursos que puedan interesarle:
- www.cancer.net
- Otro:

Otros comentarios:

Preparado por: Entregado en:
APPENDIX G

RECRUITMENT FLYER

Attention Gynecology-Oncology Clients:

If you were treated for cervical cancer and have undergone chemotherapy and or radiation therapy and may be interested in providing your valuable input in the development of a survivorship care planning tool, please contact Ileana Meza at 323-226-3511 or you can ask the XXXX receptionist for her availability to speak with you. Participation is voluntary and you can withdraw from the project at any time without repercussion.

VOLANTES DE RECLUTAMIENTO

Atención Clientes de Ginecologia-Oncologia:
Si usted recibió tratamiento para cáncer del cuello de la matriz y recibió quimioterapia o radiación es y está interesada en dándonos su opinión valiosa en el desarrollo de un plan para sobrevivientes de cáncer, por favor llámame al 323-226-3511 y pregunte por Ileana Meza o pregúntele a la recepcionista de XXXX por su disponibilidad. Su participación es voluntaria y se puede retirar sin repercusiones.
APPENDIX H
INFORMATION SHEET ENGLISH AND SPANISH

INFORMATION SHEET

A QUALITY IMPROVEMENT PROJECT: DEVELOPING A SURVIVORSHIP PLANNING TOOL FOR LATINAS WITH CERVICAL CANCER

You are invited to participate in a quality improvement project conducted by Ileana M. Meza, board certified Women’s Health Care Practitioner (WHCNP-BC) and principal investigator (PI), (Faculty advisor, Dr. Lynda Roman) at the Gynecology-Oncology clinic at Los Angeles County + University of Southern California (LAC+USC) Medical Center. This quality improvement project is conducted as part of a graduate project in a Doctorate of Nursing Practice (DNP) program. Your participation in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether to participate. Please take as much time as you need to read the information consent form. You may also decide to discuss participation with your family and friends. Whether or not you choose to participate in this quality improvement project you will be given a copy of this form.

PURPOSE OF THE STUDY
The purpose of this quality improvement project, is to develop a Survivorship planning tool pamphlet for the Latina woman diagnosed with cervical cancer to help them plan for their immediate and long-term follow-up care with their healthcare provider. Survivorship Planning, is vital to help restore a sense of power and control, and help improve the quality of care of survivors, like yourself, moving beyond their cancer treatment. It has been shown to promote compliance with treatment, improve quality of life, provide empowerment, and circumvent the potential recurrence of cancer.

PROCEDURES
If you volunteer to participate in this quality improvement project, you will be asked to review the draft Survivorship planning tool pamphlet and discuss with Ms. Meza your recommendations, additions, deletions, that would help you and other cervical cancer survivors use the Survivorship Planning Tool. She will take notes during this discussion, but they will not have your name or other identifying information on it. Your input will be incorporated into the Survivorship planning tool pamphlet. Then a panel of healthcare providers will review your suggestions and make their recommendations. You will be given an opportunity to see the panel of healthcare providers’ input as well. This process of reviewing and giving feedback will continue until you and panel of healthcare providers have no further input.

The initial visit will be face-to-face, one-to-one and held in an office in the Outpatient Department (ODP), room 4P21-S or assigned office space at Keck Hospital of USC and Norris. The initial visit may take 30 minutes to one (1) hour or less to explain your role and review your feedback. Subsequent appointments, either face-to-face or via telephone depending upon your preference, will be scheduled in two (2) to three (3) weeks to review...
the panel of healthcare providers’ input and provide any additional feedback that you may have. This cycle will continue until no further input are made by either you or the expert panel member.

Once the Survivorship planning tool pamphlet has been finalized, a brief survey will be given to specified participants to evaluate the usability and clarity of the Survivorship Planning Tool.

POTENTIAL RISKS AND DISCOMFORTS

You may experience some anxiety or emotional discomfort related to the topic of cancer survivorship. To alleviate those concerns you can withdraw from the project at any time without consequences. The only barrier identified is the time commitment required to participate in the review process of the Survivorship Planning Tool.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

There are no direct benefits that are expected for the participants of this quality improvement project, however:
1. You will take pride in knowing that your work with healthcare providers can improve the quality of cervical cancer survivors.
2. You will have a personalized Survivorship planning tool pamphlet that help you better manage your care and cancer survivorship.

Overall, having an individualized survivorship care plan (Survivorship Planning Tool) has been shown to promote compliance with treatment, improve quality of life, provide empowerment, and circumvent the potential recurrence of cancer.

CONFIDENTIALITY

Any information that is obtained relating to this quality improvement project and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by not using any data that can identify you. The Survivorship planning tool that needs revision will be kept in a locked file cabinet in a locked office that only the PI has access to.

PARTICIPATION AND WITHDRAWAL

You can choose whether or not to participate in this quality improvement project. Participation is voluntary and you can withdraw from the project at any time without consequences.

INVESTIGATOR’S CONTACT INFORMATION

If you have any questions or concerns about the research, please feel free to contact Ileana M. Meza at:
1200 N. State Street, Room 520
Los Angeles, CA 90033
imeza@dhs.lacounty.gov
323-226-3511
RIGHTS OF RESEARCH PARTICIPANT – IRB CONTACT INFORMATION
If you have questions, concerns, or complaints about your rights as a research participant or the research in general and are unable to contact the research team, or if you want to talk to someone independent of the research team, please contact the Health Sciences Institutional Review Board (HSIRB), 1200 North State St. Suite 4700, Los Angeles, CA 90033, (323) 223-2340 or irb@usc.edu.
HOJA DE INFORMACIÓN

UN PROYECTO PARA MEJORAR LA CALIDAD: DESARROLLO DE UN INSTRUMENTO DE PLANIFICACIÓN DE LA SUPERVIVENCIA PARA MUJERES LATINAS CON CÁNCER DE CUELLO UTERINO

Usted está invitada a participar en un proyecto de mejoramiento de la calidad dirigido por Ileana M. Meza, practicante certificada de atención médica femenina (WHCNP-BC) e investigadora principal (PI), (consejera docente, Dra. Lynda Roman) en la clínica de ginecología y oncología en el Centro Médico del Condado de Los Ángeles + Universidad del Sur de California (LAC + USC). Este proyecto de mejora de la calidad se lleva a cabo como parte de un proyecto de posgrado en un programa de Doctorado en Práctica de Enfermería (DNP). Su participación en este estudio es enteramente voluntaria. Por favor lea la siguiente información y pregunte sobre cualquier cosa que no entienda, antes de decidir si participa o no. Tome tanto tiempo como necesite para leer el formulario de consentimiento. También podrá consultarlo con sus familiares o amistades. Ya sea que elija o no participar en este proyecto para optimizar la calidad, se le entregará una copia de este formulario.

PROPÓSITO DE ESTE ESTUDIO
El objetivo de este proyecto de mejora de la calidad, es desarrollar un folleto de un sistema de planificación de supervivencia para la mujer latina diagnosticada con cáncer de cuello uterino, para ayudarla a planificar su atención de seguimiento inmediata y de largo plazo con su profesional de atención médica.

La planificación de la supervivencia es vital para ayudar a restaurar la sensación de poder y control, y para ayudar a mejorar la calidad de la atención de los sobrevivientes como usted, yendo más allá de su tratamiento contra el cáncer. Se ha demostrado que esto promueve el cumplimiento del tratamiento, mejora la calidad de vida, proporciona vitalidad y elude la posible recurrencia del cáncer.

PROCEDIMIENTOS
Si se ofrece como voluntaria para participar en este proyecto de mejora de la calidad, se le pedirá que revise el borrador del folleto del sistema de planificación de supervivencia, y hable con la Sra. Meza sus recomendaciones, adiciones y eliminaciones, que le ayudarán a usted y a otros sobrevivientes de cáncer cervical a utilizar el sistema de planificación de supervivencia. Ella tomará notas durante esta discusión, pero no tendrá su nombre ni otra información que lo identifique. Su aporte se incorporará en el folleto del sistema de planificación de la supervivencia. Luego, un panel de proveedores de atención médica revisará sus sugerencias y hará sus recomendaciones. Se le dará la oportunidad de ver también el panel de los profesionales de atención médica. Este proceso de revisión y comentarios continuará hasta que usted y el panel de proveedores de atención médica no tengan más información.

La visita inicial será en persona, uno a uno y tendrá lugar en una oficina en el Departamento de Pacientes Ambulatorios (ODP), en la habitación 4P21-S o en un espacio de oficina asignado en el Hospital Keck de la USC y de Norris. La visita inicial puede tardar de 30 minutos a una (1) hora o menos para explicarle su función y revisar sus comentarios. Las citas subsiguientes, ya sea en persona o por teléfono, según su preferencia, se programarán en dos (2) a tres (3) semanas, para revisar la opinión del panel de proveedores de servicios de salud y proporcionar cualquier retroalimentación adicional que pueda tener. Este ciclo continuará hasta que usted o el miembro experto del panel no realicen ninguna otra entrada. IRB # HS-17-00724 Fecha de la version: 14 de noviembre de 2017
Una vez que se haya finalizado el folleto de la Herramienta de planificación de la supervivencia, se realizará una breve encuesta a los participantes específicos para evaluar la utilidad y la claridad del sistema de planificación de la supervivencia.

**POSIBLES RIESGOS Y MOLESTIAS**
Puede experimentar cierta ansiedad o incomodidad emocional relacionada con el tema de la supervivencia al cáncer. Para aliviar esas preocupaciones, puede retirarse del proyecto en cualquier momento sin consecuencias. La única dificultad identificada es el tiempo requerido para participar en el proceso de revisión del sistema de planificación de la supervivencia.

**POSIBLES BENEFICILOS A LAS PARTICIPANTES O A LA SOCIEDAD**
Sin embargo, no se esperan beneficios directos para las participantes de este proyecto de mejora de la calidad:

1. Se sentirá orgullosa de saber que su trabajo con los proveedores de atención médica puede mejorar la calidad de las sobrevivientes de cáncer de cuello uterino.
2. Tendrá un folleto personalizado del sistema de planificación de supervivencia que le ayudará a administrar mejor su atención y la supervivencia del cáncer.

En general, se ha demostrado que contar con un plan individualizado de atención de sobrevivientes (Sistema de planificación de supervivencia) promueve el cumplimiento del tratamiento, mejora la calidad de vida, proporciona vitalidad y elude la posible recurrencia del cáncer.

**CONFIDENCIALIDAD**
Cualquier información que se obtenga relacionada con este proyecto de mejora de la calidad y que se pueda identificar con usted será confidencial y se divulgará sólo con su permiso o según lo exija la ley. La confidencialidad se mantendrá al no usar ningún dato que pueda identificarla. El sistema de planificación de la supervivencia que necesite revisión, se mantendrá en un archivador bloqueado en una oficina bloqueada a la que solo el PI tiene acceso.

**PARTICIPACIÓN Y RETIRO**
Puede elegir participar o no en este proyecto de mejora de la calidad. La participación es voluntaria y puede retirarse del proyecto en cualquier momento sin consecuencias.

**INFORMACIÓN DE CONTACTO DEL INVESTIGADOR**
Si tiene alguna pregunta o inquietud sobre la investigación, no dude en ponerse en contacto con Ileana M. Meza:
1200 N. State Street, Oficina 520
Los Ángeles, CA 90033.
imeza@dhs.lacounty.gov
323-226-3511

**DERECHOS DE LA PARTICIPANTE EN LA INVESTIGACIÓN - INFORMACIÓN DE CONTACTO DEL IRB**
Si tiene preguntas, inquietudes o quejas sobre sus derechos como participante en la investigación o la investigación en general, y no puede comunicarse con el equipo de investigación, o si desea hablar con alguien independiente de éste, comuníquese con la Junta de Revisión (HSIRB, siglas en inglés) del Departamento de Ciencias de la Salud., 1200 North State St. Suite 4700, Los Ángeles, CA 90033, (323) 223-2340 o irb@usc.edu.
APPENDIX I

FINALIZED SURVIVORSHIP PLANNING TOOL

<table>
<thead>
<tr>
<th>General Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name:</td>
</tr>
<tr>
<td>Patient phone:</td>
</tr>
</tbody>
</table>

**Health Care Providers** (Including Names, Institution)

- Gynecology Oncology Clinic: Surgeon:
- Primary Care Clinic:               
- Radiation Oncology Clinic:        
- Medical Oncology Clinic:          
- Other Clinics:                     

<table>
<thead>
<tr>
<th>Treatment Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>Cancer Type: Cervical Cancer</td>
</tr>
<tr>
<td>Stage: □I □II □III □IV □Fill In Stage________ □Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery: □ Yes □No</td>
</tr>
<tr>
<td>Surgical procedure/findings:</td>
</tr>
<tr>
<td>Lymph node removal: □Enter site (s)______________________ □ positive □ negative</td>
</tr>
<tr>
<td>Radiation: □ Yes □No</td>
</tr>
<tr>
<td>Systemic Therapy (chemotherapy, immunotherapy, other): □ Yes □ No</td>
</tr>
<tr>
<td>Before surgery</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>☐</td>
</tr>
</tbody>
</table>

Names of Agents Used | Dose | Start Date Date | End Date | Retreatment |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Cisplatin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Carboplatin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Gemcitabine (Gemzar®)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Ifosfamide (Ifex®)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Irinotecan (Camptosar®)</td>
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<tr>
<td>☐ Methotrexate</td>
<td></td>
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</tr>
<tr>
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<td></td>
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</tr>
<tr>
<td>☐ Topotecan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Bevacizumab (Avastin)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Were you involved in any clinical trials?: ☐ Yes  ☐ No
If yes, what was the name of trial or the study agents? _______________________   ______________________

Treatment Ongoing

<table>
<thead>
<tr>
<th>Additional treatment name</th>
<th>Planned duration</th>
<th>Possible Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td></td>
<td>Fill in side effects:</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Persistent symptoms or side effects at completion of treatment:
Fatigue: □ No □ Yes  Menopausal symptoms: □ No □ Yes  Pain: □ No □ Yes Degree of disability_____________
Numbness: □ No □ Yes  Tingling: □ No □ Yes  □ Other (enter type(s)):
Psychosocial/Depression: □ No □ Yes  □ Comments:

Familial Cancer Risk Assessment
Breast and/or ovarian cancer in 1st or 2nd degree relatives: □ Yes_______________________ □ No
Received Genetic counseling: □ Yes □ No  Genetic testing: □ Yes □ No  Date:__________________
Genetic testing results:

Follow-up Care Plan
Your follow-up care plan is designed to inform you and your primary care providers regarding the recommended and required follow-up, cancer screening and routine health maintenance that is needed to maintain optimal health.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:
Fatigue, numbness, tingling, swelling of legs, bones become weak and at risk for fracture (osteoporosis). If these or any other new problems or complaints occur bring these to the attention of your healthcare provider.

These symptoms should be brought to the attention of your provider:

6. A problem or complaint
7. A persistent problem
   3. Anything you are worried about that might be related to the cancer coming back.

Please continue to see your primary care provider for all general health care recommended for a woman your age such as routine immunizations, and routine non-breast cancer screening like colonoscopy or bone density exams. Consult with your healthcare provider about prevention and screening for bone loss using bone density tests.

Fill in problem(s): Date Began Date Stopped
## Schedule for Clinical Visits

<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>Routine Visits</th>
<th>Timeframe in Years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐ every ___ months for ___ years, then</td>
<td>____________________</td>
</tr>
<tr>
<td></td>
<td>☐ every ___ months for ___ years, then</td>
<td>____________________</td>
</tr>
<tr>
<td></td>
<td>☐ yearly starting_________</td>
<td>_______</td>
</tr>
</tbody>
</table>

## Comments: Cancer Surveillance or Other Recommended Tests

<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>TEST</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pelvic exam</td>
<td>Every exam visit</td>
<td></td>
</tr>
<tr>
<td>Pap</td>
<td>Annually or as indicated by provider</td>
<td></td>
</tr>
<tr>
<td>Breast Exam</td>
<td>Annually or as indicated by provider</td>
<td></td>
</tr>
<tr>
<td>Bone Density</td>
<td>Every 5 years starting age 65 or as indicated by provider</td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>As indicated by your provider</td>
<td></td>
</tr>
<tr>
<td>Mammogram</td>
<td>Annually starting age_______</td>
<td></td>
</tr>
<tr>
<td>Influenza Vaccine</td>
<td>As indicated by your provider</td>
<td></td>
</tr>
</tbody>
</table>
Cervical cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- Anxiety or depression
- Mental health
- School
- Bladder functioning
- Memory or concentration loss
- Work
- Emotional and mental health
- Parenting
- Insurance
- Fatigue
- Physical functioning
- Stopping smoking
- Weight changes
- Rectal/bowel movement functioning
- Other______
- Fertility
- Financial advice
- Other______
- Sexual Functioning
- Financial assistance
- Other______
- Other______

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

- Alcohol use
- Physical activity
- Other
- Diet
- Sun screen use
- Management of my medications
- Tobacco use/cessation
- Management of my other illnesses
- Weight management (loss/gain)

Resources you may be interested in:
- www.cancer.net
- Other:

Other comments:

Prepared by:  
Delivered on:
**Información General**

<table>
<thead>
<tr>
<th>Nombre de Paciente:</th>
<th>FDN de Paciente:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Número de teléfono de Paciente:</td>
<td>Correo Electrónico:</td>
</tr>
</tbody>
</table>

**Proveedores de Atención Medica** (Incluyendo Nombres, Institución)

<table>
<thead>
<tr>
<th>Proveedor de Ginecología Oncología:</th>
<th>Cirujano:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proveedor de Atención Medica Primario:</td>
<td></td>
</tr>
<tr>
<td>Oncólogo de Radiación:</td>
<td></td>
</tr>
<tr>
<td>Oncólogo Medico:</td>
<td></td>
</tr>
<tr>
<td>Otros Proveedores:</td>
<td></td>
</tr>
</tbody>
</table>

**Sumario de Tratamiento**

**Diagnosis**

<table>
<thead>
<tr>
<th>Tipo de Cáncer: Cáncer Cervical</th>
<th>Histología Subtipo:</th>
<th>Fecha de la Diagnosis (año):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptores: ☐ Estrógeno positivo; ☐ Progesterona Positiva; ☐ Entra positiva:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Etapa: ☐ I ☐ II ☐ III ☐ IV ☐ Completar Etapa________</td>
<td>☐ No es aplicable</td>
<td></td>
</tr>
</tbody>
</table>

**Tratamiento Terminado**

<table>
<thead>
<tr>
<th>Cirugía: ☐ Si ☐ No</th>
<th>Fecha de Cirugía (s) (año):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedimiento Quirúrgico/resultados:</td>
<td></td>
</tr>
<tr>
<td>Extirpación de ganglio linfáticos: ☐ Lugar (es)______________________</td>
<td>☐ positivo ☐ negativo</td>
</tr>
<tr>
<td>Radiación: ☐ Si ☐ No</td>
<td>Área del cuerpo tratado:</td>
</tr>
<tr>
<td>Terapia Sistémica (quimioterapia, terapia hormonal, otro): ☐ Si ☐ No</td>
<td></td>
</tr>
<tr>
<td>Nombres de Agentes Utilizados</td>
<td>Dosis</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Cisplatin</td>
<td></td>
</tr>
<tr>
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<td>Bevacizumab (Avastin)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

**Tratamiento En Curso**

<table>
<thead>
<tr>
<th>Nombre de Tratamiento adicional</th>
<th>Duración Planificada</th>
<th>Posibles Efectos Secundarios</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Complete los efectos secundarios:</td>
</tr>
</tbody>
</table>

Otro:
Síntomas Persistentes o efectos secundarios al terminar el tratamiento:
Fatiga: □ No □ Si Síntomas Menopáusicas: □ No □ Si Dolor: □ No □ Si Grado de Discapacidad___________
Entumecimiento: □ No □ Si Hormigueo: □ No □ Si □ Otro (entre tipo(s)):
Psicosocial/Depresión: □ No □ Si □ Comentarios:

Asesoramiento de Riesgo del Cáncer Familiar
Cáncer de mama y u ovárico en parientes de 1 o 2 grado: □ Si________________________ □ No
Recibió consejería Genética: □ Si □ No Pruebas Genéticas: □ Si □ No
Resultado de pruebas genéticas:

Tratamiento de Seguimiento
Su tratamiento de seguimiento es diseñado para informarle a usted y sus proveedores de atención médica respecto al seguimiento recomendado y requerido, detección del cáncer y mantenimiento rutinario de la salud necesarios para mantener una salud óptima.

Posibles efectos tardíos y largo plazo que algunos con este tipo de cáncer y tratamiento puede pasar:
Fatiga, entumecimiento, hormigueo, hinchazón de piernas, huesos se debilitan y está a riesgo de fracturas (osteoporosis). Si estos problemas o cualquier otro problema nuevo ocurran comuníquelo a su proveedor de atención médica.

Estos síntomas deberían ser comunicados a su proveedor de atención médica:

8. Un problema o una queja
9. Un problema persistente
   3. Cualquier cosa que le preocupa a usted que pueda ser relacionado con el regreso del cáncer.
Por favor continúe viendo a su proveedor primario de atención médica para toda atención médica general recomendada para una mujer con su edad tal como las vacunas rutinarias, y exámenes rutinarios que no detectan cáncer de mama como la colonoscopía o examen de densidad de ósea. Consulte con su proveedor de atención médica sobre la prevención y examen de perdida de ósea utilizando pruebas de densidad de ósea.

Complete el problema (s): Fecha de Inicio Fecha de Terminación
# Horario para Visitas a la Clínica

<table>
<thead>
<tr>
<th>Proveedor Coordinador</th>
<th>Visitas Rutinarias</th>
<th>Plazo en Años</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ cada 3 meses x 2 año:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ cada 6 meses x 2 año:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ posterior anualmente:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ cada 6 meses x 2 año:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ posterior anualmente:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ otro plan de visita:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ otro plan de visita:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ posterior anualmente:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Comentarios: Vigilancia de Cáncer u Otras Pruebas Recomendadas

<table>
<thead>
<tr>
<th>Proveedor Coordinador</th>
<th>Prueba</th>
<th>Frecuencia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Examen de mama</td>
<td>Anualmente</td>
</tr>
<tr>
<td></td>
<td>Densidad de Ósea</td>
<td>Como sea indicado por su proveedor</td>
</tr>
<tr>
<td></td>
<td>Colonoscopia</td>
<td>Como sea indicado por su proveedor</td>
</tr>
<tr>
<td></td>
<td>Mamografía</td>
<td>Edad ___ y o como sea indicado por su proveedor</td>
</tr>
<tr>
<td></td>
<td>Papanicolaou</td>
<td>Anualmente o como sea indicado por su proveedor</td>
</tr>
<tr>
<td>Examen pélvico</td>
<td>Cada visita de examen</td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------</td>
<td></td>
</tr>
<tr>
<td>Sobrevivientes de cáncer cervical pueden pasar por problemas en las áreas enumeradas a continuación. Si usted tiene alguna inquietud en estas u otras áreas, por favor hable con sus doctores o enfermera para averiguar como usted puede recibir ayuda en ello.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Ansiedad o depresión</td>
<td>☐ Salud mental</td>
<td>☐ Escuela</td>
</tr>
<tr>
<td>☐ Funcionamiento de la vejiga</td>
<td>☐ Perdida de memoria o concentración</td>
<td>☐ Trabajo</td>
</tr>
<tr>
<td>☐ Salud mental o emocional</td>
<td>☐ Crianza de hijos</td>
<td>☐ Seguro</td>
</tr>
<tr>
<td>☐ Fatiga</td>
<td>☐ Funcionamiento Físico</td>
<td>☐ Dejar de Fumar</td>
</tr>
<tr>
<td>☐ Cambios de peso</td>
<td>☐ Funcionamiento de Intestino/Rectal</td>
<td>☐ Seguro</td>
</tr>
<tr>
<td>☐ Fertilidad</td>
<td>☐ Asesoramiento Financiero</td>
<td>☐ Otro</td>
</tr>
<tr>
<td>☐ Funcionamiento sexual</td>
<td>☐ Ayuda Financiera</td>
<td>☐ Otra ayuda</td>
</tr>
</tbody>
</table>

Series de comportamientos/estilos de vida pueden afectar su salud en curso, incluyendo el riesgo que vuelva el cáncer o desarrollar otro cáncer. Hable sobre estas recomendaciones con su doctor o enfermera:
| ☐ Uso de Alcohol | ☐ Actividad física | ☐ Otro |
| ☐ Dieta | ☐ Uso de protector solar |
| ☐ Gestión de mis medicamentos | ☐ Uso/cesación de Tabaco |
| ☐ Gestión de mis otras enfermedades | ☐ Gestión de peso (perdida/aumento) |

Recursos que puedan interesarle:
- [www.cancer.net](http://www.cancer.net)
- Otro:

Otros comentarios:
Preparado por: 

Entregado en: