

GW Cancer Institute

THE GEORGE WASHINGTON UNIVERSITY

**Breast Cancer Survivorship in Washington, DC:
A Gap Analysis and Recommendations for Action**

**George Washington University Cancer Institute
Citywide Survivorship Initiative**

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Executive Summary

When breast cancer survivors end treatment, they are at increased risk for physical, emotional, social and practical challenges that may impact quality of life. Many cancer survivors will experience disparities in this phase of their cancer experience as well, which may impact their ability to access necessary post-treatment care. In Washington, DC, the disparities for breast cancer survivors are particularly significant. In fall 2014, the GW Cancer Institute conducted a gap analysis to support strategies identified in the DC Cancer Control Plan for increasing access to post-treatment care for DC cancer survivors. This report reviews the current state of survivorship care in DC, proposes a DC standard of care based on national guidelines and recommendations, and provides a collaborative strategy for better meeting the needs of DC-area breast cancer survivors. The main findings include:

- Several Commission on Cancer (CoC)-accredited cancer programs exist in the DC area and are working to meet the new survivorship accreditation standard.
- Survivors face physical and psychosocial effects but may be unable to access care they need as the CoC-accredited institutions try to respond to the new standard.
- Many critical services, such as rehabilitation and fertility services, exist but may be underutilized.
- Access to psychosocial support after treatment may be particularly challenging.
- Practical challenges continue for many DC-area survivors beyond treatment. Resources may be available but underutilized to deal with these challenges.
- Opportunities exist to better educate cancer survivors on what to expect in the post-treatment phase.
- DC has many community-based organizations that can help fill the gaps for cancer survivors.
- The standard of care for DC should be based on national guidelines and recommendations and should include: provision of survivorship care plans, provision of the **LIVESTRONG** Essential Elements, incorporation of evidence-based clinical guidelines, referral to community-based organizations, and continuing education on survivorship.
- Educational resources for cancer survivors exist but need greater dissemination.
- Educational resources need to be developed for families and caregivers.

Breast Cancer Survivorship in Washington, DC: A Gap Analysis and Recommendations for Action

Breast cancer survivors face long-term and late effects, including recurrence, second cancers, cardiovascular disease, and cognitive impairment, and have psychological, social, spiritual, financial, and employment needs.¹ Elderly women and minority survivors are more vulnerable to late effects.² African American breast cancer survivors report more symptoms, greater functional difficulties, greater perceived illness impact, and lower self-rated health after treatment.³ High rates of comorbidities in African American patients in treatment⁴ may lead to greater burden of the late effects.⁵ African American breast cancer survivors also report that financial difficulties during treatment persist into survivorship.⁶ Care coordination is important for quality survivorship care,⁷ yet African Americans and Hispanics report more problems with coordination of and access to care.⁸ Breast cancer survivors who visit a primary care provider and oncology specialist are more likely to get the requisite preventive care *and* survivorship care.⁹ Yet, survivorship care is not coordinated as African American breast cancer survivors experience disparities in receiving preventive services, such as colorectal cancer screening, influenza vaccination, lipid testing, bone densitometry,¹⁰ and mammography.¹¹

In Washington, DC these needs may be particularly pronounced due to significant health disparities. In DC Wards 7 and 8, breast cancer mortality rates are among the highest in the nation (32.9 and 30.7 per 100,000, respectively), with African American women and Latinas diagnosed at later stages and with more aggressive breast cancer despite screening rates comparable to white women.^{12, 13} Low income, lack of adequate insurance, and the need to travel far for treatment make survivors in Wards 7 and 8 more vulnerable than the general DC breast cancer population to going without survivorship care. Fragmentation compounds financial, logistical and cultural barriers to care, exacerbating disparities in health care access, quality of life, and survival.

In 2012 the George Washington University (GW) Cancer Institute was awarded a 3-year grant from Susan G. Komen® National Capital Area to implement the Citywide Survivorship Initiative (CSI). The CSI focused on increasing access to survivorship care through direct care provided at the GW Medical Faculty Associates, education of primary care and oncology providers, patient navigation and survivor education. In fall 2014, the GW Cancer Institute conducted a gap analysis to support continued focus on the needs of DC breast cancer survivors beyond the grant and to support strategies identified in the DC Cancer Control Plan.

The 2013-2018 DC Cancer Control Plan identifies 4 objectives to increase access to follow-up care, reduce recurrence, and improve the overall quality of life for the District's cancer survivors (see Appendix A). This report supports the plan's objectives by analyzing the current state of survivorship in DC and identifying gaps for DC breast cancer survivors; reviewing national standards to inform a DC standard of care; reviewing current educational offerings for cancer survivors; and proposing a strategic plan for improve survivorship care and services.

Current State of Survivorship Care in DC

Health care professionals across the country are struggling to better meet cancer survivors' needs. Current care practices do not adequately provide follow-up care consistently, and many community organizations focus on the screening and treatment phases of the cancer continuum. When looking at the state of cancer survivorship care in DC, it is important to keep in mind that the field of cancer survivorship is still relatively new and that many of the issues in DC can be seen across the country. This section of the report outlines the varying breast cancer survivor needs as well as services currently available in DC.

Breast Cancer Survivors' Needs

Research indicates that cancer survivors experience physical and psychosocial consequences, practical challenges, educational needs, and access to care issues.

Physical and Psychosocial Needs

Breast cancer survivors are at risk for numerous physical and psychosocial impacts that vary by person based on individual characteristics and treatment modalities.¹⁴ In a comprehensive review of studies on breast cancer survivors' health needs, Kenyon, Mayer, and Owens found that common late and long-term physical effects include:¹⁵

- Anthracycline-induced cardiotoxicity (chronic progressive dilated cardiomyopathy)
- Endocrine therapy-related cardiovascular disease, hypertension, hypercholesterolemia, and possibly ischemic heart disease
- Fatigue (disproportionate sense of physical, emotional, or cognitive exhaustion in relation to one's activity)
- Lymphedema
- Musculoskeletal symptoms, accelerated bone loss, and fractures
- Joint pain
- Chronic pain, including neuropathy
- Premature menopause, amenorrhea, and infertility
- Recurrence and new breast cancers
- Skin changes (due to radiation)
- Other cancers
- Sexual dysfunction

Kenyon, Mayer, and Owens also explored psychosocial issues and identified the following common effects for breast cancer survivors:¹⁶

- Anxiety
- Cognitive dysfunction
- Decreased satisfaction with life
- Depression
- Fear of recurrence
- Poor body image
- Post-traumatic stress disorder
- Sexual dysfunction

Limited data exists specific to DC-area breast cancer survivors. In 2010, **LIVESTRONG** conducted a national survey of cancer survivors. Thirty-seven respondents were from the Washington, DC area. Of these individuals, 78% reported at least one major physical concern and 74% reported one major emotional concern.¹⁷ The most common physical concerns were poor concentrating, low sexual functioning, lymphedema and low energy. Worry, grief, and concern over

appearance and identity were the most common emotional concerns. To address physical concerns, these survivors most often sought out governmental agencies or their primary care physicians. A common reason given by DC area survivors as to why they did not receive care for their physical, emotional or practical concerns was that they “learned to live with it.”

In 2013 the GW Cancer Institute conducted focus groups with 15 DC-area breast cancer survivors with an average age of 51 years. The majority self-identified as minorities, with 67% black or African American and 27% Hispanic/Latino. Physical issues, including lymphedema, neuropathy, and intimacy problems, were identified as the biggest challenge for participants with the majority of women reporting ongoing late effects from treatment. Other physical issues after treatment included hot flashes and joint pain concurrent with the use of hormonal therapies. Participants also reported wanting increased access to psychosocial resources to deal with issues such as body image, stress and anxiety, self-confidence, mental health, and spiritual support.

“I’m with my medical oncologist for five years and you know I [still] get anxiety as to whether the cancer will return.” – 2013 Focus Group Participant

Practical Challenges

The 2010 **LIVESTRONG** survey asked respondents about practical challenges and found that 75% had practical concerns, such as debt and challenges with health insurance.¹⁸ Of the 37 DC respondents, 57% reported at least one major practical concern, largely related to employment status and financial responsibilities. For common practical concerns such as unemployment, respondents often sought the help of social workers or family and friends.

When the **LIVESTRONG** survey was again conducted in 2012,¹⁹ all of the six DC breast cancer survivor respondents reported worry about their medical bills, and half reported that they or their families had to make financial sacrifices because of cancer. Two of the six breast cancer survivors reported experiencing a time when their health insurance would not cover a cancer-related medical visit to the doctor or facility of their choice, but all said that they were able to cover their share of costs for medical visits related to cancer. For coping with their financial concerns, DC respondents received help from family members, psychiatrists, support groups, and seeking out information themselves on the internet or in books. Additionally, DC-area focus group participants reported wanting more support navigating financial, insurance, and employment issues as a result of their treatment. For example, many stated having problems with not being able to return to work secondary to the late/side effects of treatment.

Informational Needs

In 2013, the GW Cancer Institute conducted a national survey, Best Practices for Cancer Survivor Education Programming Survey for Adult Survivors, that explored survivors’ needs and preferences for education related to post-treatment concerns. Respondents included 18 DC breast cancer survivors, the majority of whom were diagnosed within the last 3 to 5 years. Many survivors wanted more

“There’s a lot of issues after the five year survival thing and we need to know what to expect.”
– DC Focus Group Participant

knowledge on late effects of treatment, such as lymphedema, fatigue and adjusting to a new life after cancer. Sixty-one percent indicated that the medical and physical effects of cancer and nutritional health recommendations for survivors would be helpful topics to hear about after completing treatment. Sixty-one percent indicated that presenting this information within a hospital cancer center or community center would be effective. Forty-four percent indicated that they would use an online cancer survivor education program.

Post-Treatment Care and Access

According to the 2010 Komen National Capital Area Community Profile Report, fewer breast cancer services in general are available in Arlington and Alexandria counties, Prince William county, upper Prince George's county, and Wards 7 and 8 in Washington, DC.²⁰ These areas have limited resources, high morbidity and mortality rate, as well as a high proportion of minority populations, which likely impact survivors' ability to access post-treatment care.

In the 2013 Best Practices for Cancer Survivor Education Programming Survey for Adult Survivors, 92% of DC breast cancer survivor respondents indicated that an oncologist is currently managing their follow-up care, and 42% said they did not feel ready to transition back to primary care at the end of their cancer treatment. The respondents accessed a number of nonclinical resources after treatment. Fifty-six percent have engaged in a physical activity programs and thirty-nine percent sought the help of a physical therapist.

“Other places need to do the same thing literally get a program of transition so that they can have a place and go like a class or something so that we can get the coping skills and know what we need to know and if there's something we need to know we know how to ask questions.”

– DC Focus Group Participant

The 2013 focus group with DC-area breast cancer survivors explored whether survivors received a survivorship care plan, which includes a treatment summary and follow-up plan of care. Of the 15 breast cancer survivor participants, five (33%) had not received a follow-up care plan or treatment summary, one survivor (7%) received a follow-up care plan but not a treatment summary, four (28%) received just a treatment summary but no follow-up care plan, and only three (21%) received both a treatment summary and a follow-up care plan. The 2012 **LIVESTRONG** survey also asked about survivorship care plans.²¹ Of the six breast cancer survivor respondents to the 2012 survey who resided in DC, none remembered receiving a survivorship care plan; they reported that they did not receive a plan or were unsure if they received a plan.

When asked about preferences and improvements for survivorship care, DC breast cancer focus group participants identified the need for more positive interactions with clinicians, specifically more sensitivity from their health care providers, as key. Additionally, participants often felt clinicians communicated poorly with them, especially once treatment had ended. One survivor stated, “I

“I would like somebody to give me like a ten year, a five year of whatever some kind of guide or something, you know, what I need to think about or watch for. When I was diagnosed, I didn't have a lump, I was diagnosed with a mammogram.”

- DC Focus Group Participant

want for [doctors] to get together sometimes with you. Both of the doctors together talking to you and letting you know I am still going to be there for you but we're transitioning you over there. For both of the doctors to get together with you, talk to you like you're an adult and you're not afraid of what's coming down the pipe."

Services for Cancer Survivors in DC

Although limited, some services exist for cancer survivors in the DC area. Organizations and resources are listed in an Asset Map in Appendix B.

Survivorship Care Plans

To comply with newly revised standard 3.3, Commission on Cancer-accredited (CoC) programs are required to provide survivorship care plans to 10% of their nonmetastatic cancer patients treated with curative intent starting in 2015. All eligible survivors will need to receive a care plan starting in 2019.²² There are 8 CoC-accredited programs in DC, 8 in northern Virginia, and 6 in the areas of Maryland that are adjacent to DC (see Appendix C). Several cancer programs have developed processes to meet the new standard, although it is unknown how many cancer survivors in these programs are currently receiving survivorship care plans, and institutions are not required to provide them to the majority of patients for several more years.

Psychosocial Support

Treating institutions provide support groups, and community organizations are also sources of support, although the extent to which these services are tailored to cancer survivors is unclear. For some survivors, accessing these groups and resources that may only be offered Monday through Friday during the day during working hours can be a challenge. Location of services may also be a challenge for survivors who live far from institutions offering these services and who do not have reliable transportation. For survivors who require care from mental health providers, access to care and the cost of care can be prohibitive. Reimbursement for mental health services is limited, so providers often do not accept insurance, requiring patients to pay out of pocket for much-needed services.

Rehabilitation Services

Survivors have specific rehabilitation needs which may require trained physical therapists, occupational therapist, physiatrists, and lymphedema specialists to address. Rehabilitation during survivorship includes physical therapy, rebuilding strength, and examining sleep and eating patterns. Currently, Virginia Hospital Center and Reston Hospital Center are certified as Survivorship Training and Rehab (STAR) programs. The George Washington University Hospital is in the process of obtaining STAR certification. MedStar Washington Hospital has a STAR certified clinician on staff and offers rehabilitation services geared to cancer survivors. Treatment for lymphedema is typically a part of rehabilitation services offered during survivorship. In DC, lymphedema services are available at a number of area hospitals. Local lymphedema specialists are also available at physical therapy clinics and community centers.

Fertility Services

Breast cancer survivors of childbearing age may experience infertility as a consequence of undergoing radiation, surgery, and/or chemotherapy treatment. Fertile Hope, a LIVESTRONG program, aims to address survivor's concerns with infertility. Fertile Hope is engaged in educational outreach about fertility options for survivors within the DC cancer community. They have partnered with local Washington, DC fertility clinics to provide fertility services to survivors looking to conceive.

Educational Services

Survivors have indicated a need for additional education to prepare them for the survivorship phase. The GW Medical Faculty Associates is currently offering a series of "lunch and learn" classes for survivors on nutrition, anxiety and depression, financial concerns, and return-to-work issues. Smith Center for Healing and the Arts also offers cancer survivorship education sessions. Through a grant from Susan G. Komen®, the GW Cancer Institute has partnered with Capital City Area Health Education Center, Smith Center for Healing and the Arts, and Nueva Vida to offer cancer survivorship education in the community over the last 3 years.

Practical Services

There are services in Washington, DC available to survivors outside of traditional cancer support programs. LIFT-DC is a local non-profit organization that aims to "lift" members of the community out of poverty. Their services are applicable to cancer survivors in that they aid their clients in securing employment and in reaching financial stability. The DC Office on Aging provides services to older adults, including housing, nutrition, and legal services. For survivors who may not qualify for financial and other services offered to those who are in treatment, community programs may be helpful resources. However, knowledge of these resources by those working with survivors in the cancer health care setting may be limited.

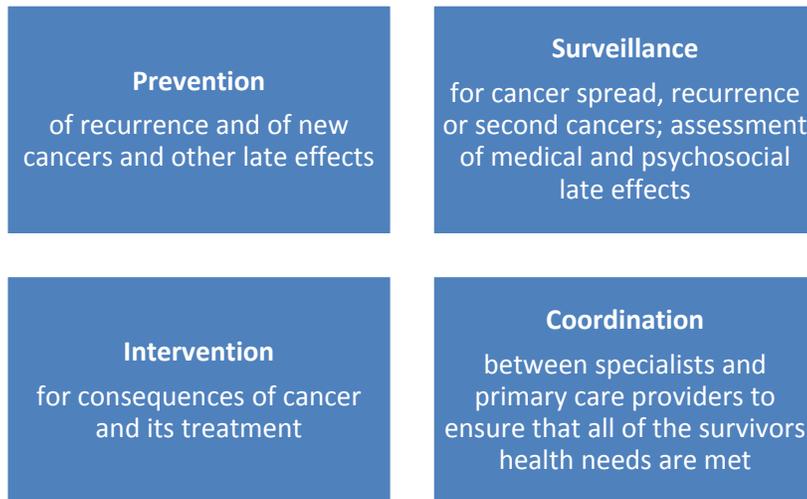
Conclusions Regarding Survivorship Services in DC

As is happening nationally, DC-area breast cancer survivors experience post-treatment needs that are currently being unmet. The gap analysis reveals that:

- Several Commission on Cancer-accredited cancer programs exist in the DC area and are working to meet the new survivorship accreditation standard.
- Survivors face physical and psychosocial effects but may be unable to access care they need as the CoC-accredited institutions try to respond to the new standard.
- Access to psychosocial support after treatment may be particularly challenging.
- Practical challenges continue for many DC-area survivors beyond treatment. Resources may be available but underutilized to deal with these challenges.
- Opportunities exist to better educate cancer survivors on what to expect in the post-treatment phase.
- DC has many community-based organizations that can help fill these gaps.

Setting the DC Standard for Survivorship Care

Given the significant challenges that cancer survivors face, several national efforts have identified main goals of care, care elements that should be provided, accreditation standards, and care guidelines. In 2004 the LIVESTRONG Foundation and the Centers for Disease Control and Prevention (CDC) released *A National Action Plan for Advancing Cancer Survivorship*,²³ which was the first national report to call for an increased focus on the post-treatment phase of the cancer continuum. In 2006, the Institute of Medicine (IOM) built on the *Action Plan* and outlined standards for survivorship care in the report, *From Cancer Patient to Cancer Survivor: Lost in Transition*.²⁴ The report emphasizes four key components of survivorship care:



In addition to the four key components of survivorship, the IOM report emphasized the use of survivorship care plans. These care plans are used to facilitate the process of patient follow-up once active treatment has ended. Survivorship care plans should include a summary of a patient's medical history, including the date they were diagnosed, a history of the treatments they received, and a list of preventive measures to maintain health.²⁵ The IOM also suggested that patient navigation should be incorporated into survivorship programs.²⁶ Patient navigators eliminate barriers patients face within the healthcare system by facilitating communication between patients and providers. Patient navigators can facilitate the transition of patients from primary to specialized care and back to primary care. Lastly, the IOM emphasized having a set of evidence-based, clinical guidelines to implementing survivorship care.²⁷

Essential Elements of Cancer Survivorship Care

LIVESTRONG expanded recommendations for survivorship in the 2011 report, *Essential Elements of Survivorship Care*.²⁸ This report separated which aspects of survivorship care all healthcare institutions must provide (Tier 1), should provide (Tier 2), and should aim to provide (Tier 3). Table 1 summarizes these elements.

Table 1: LIVESTRONG Essential Elements of Survivorship Care²⁹

| <u>Tier 1</u> |
|---|
| <p><i>All medical settings MUST provide direct access or referral to the following elements of care.</i></p> <ul style="list-style-type: none"> ▪ Survivorship care plan, psychosocial care plan, and treatment summary ▪ Screening for new cancers and surveillance for recurrence ▪ Care coordination strategy which addresses care coordination with primary care physicians and primary oncologists ▪ Health promotion education ▪ Symptom management and palliative care |
| <u>Tier 2</u> |
| <p><i>All medical settings SHOULD provide direct access or referral to these elements of care for high-need patients and to all patients when possible.</i></p> <ul style="list-style-type: none"> ▪ Late effects education ▪ Psychosocial assessment ▪ Comprehensive medical assessment ▪ Nutrition services, physical activity services, and weight management ▪ Transition visit and cancer-specific transition visit ▪ Psychosocial care ▪ Rehabilitation for late effects ▪ Family and caregiver support ▪ Patient navigation ▪ Educational information about survivorship and program offerings |
| <u>Tier 3</u> |
| <p><i>All medical settings should STRIVE to provide direct access or referral to these elements of care.</i></p> <ul style="list-style-type: none"> ▪ Self-advocacy skills training ▪ Counseling for practical issues ▪ Ongoing quality-improvement activities ▪ Referral to specialty care ▪ Continuing medical education |

Commission on Cancer Standard 3.3: Survivorship Care Plans

In 2012, the American College of Surgeons Commission on Cancer (CoC) issued new patient-centered care standards. Standard 3.3 calls for accredited institutions to develop and implement a process to disseminate survivorship care plans, including a comprehensive treatment summary and follow-up plan of care, to patients who are completing treatment.³⁰ There has been some communication from the CoC regarding flexibility on phasing in metrics for adherence to the standard; CoC-accredited institutions will be required to provide survivorship care plans to all eligible patients by 2019.³¹

Cancer Survivorship Clinical Practice Guidelines

Clinical care guidelines are also available for breast cancer survivors, including those from the National Comprehensive Cancer Network (NCCN), the American Society of Clinical Oncology (ASCO), and the American Cancer Society. Figure 1 summarizes the available guidelines.

Figure 1: Breast Cancer Survivorship Guidelines

| National Comprehensive Cancer Network | American Society of Clinical Oncology | American Cancer Society Survivorship Care Guidelines for Primary Care Providers |
|--|--|--|
| <ul style="list-style-type: none">•Breast cancer specific•By topic: anxiety and depression, cognitive function, exercise, fatigue, immunizations and infections, pain, sexual function (female/male), sleep disorders | <ul style="list-style-type: none">•Breast cancer specific•By topic: neuropathy, fatigue, anxiety and depression, fertility preservation | <ul style="list-style-type: none">•Releasing breast cancer specific guidelines in 2015 |

Recommendations

Because the field of cancer survivorship is still relatively new, the best strategies for survivorship care delivery have not yet been identified. Until research provides more guidance, we recommend that the DC standard of care follow national recommendations, including:

- All institutions that provide cancer treatment should pilot a cancer survivorship care planning process, reaching 10% of their cancer patients in 2015. This survivorship care plan should include information outlined by the IOM and the CoC and should be discussed with the patient and shared with the patient's primary care and other specialty providers. Programs should provide care plans to all eligible patients by 2019.
- Survivorship programs should include at minimum all Tier 1 Essential Elements as well as Tier 2 and Tier 3 elements when possible.
- Post-treatment care should be guided by evidence-based guidelines put out by NCCN, ASCO, and the American Cancer Society.
- Community-based organizations should be leveraged to provide additional support and resources.
- Oncology and primary care clinicians should seek continuing education related to survivorship care to ensure they have the most up-to-date information about care delivery strategies.

Survivor, Family and Caregiver Education

Over the past 3 years the number of educational programs for breast cancer survivors has increased. Some examples of programs include:

- Support groups at community organizations and at cancer programs
- Workshops through community organizations, such as Nueva Vida, Smith Center for Healing and the Arts, and the Capital City Area Health Education Center Pink Divas
- In-person informational sessions at cancer programs
- Online programs offered through the GW Cancer Institute, including the educational program, *Treatment's Over, Now What?*, and RISE, a wellness self-management program

To better prepare survivors for the post-treatment phase of cancer survivorship, greater dissemination of these programs is needed. Other formats and content should also be identified to ensure resources are available for the diverse breast cancer population. Resources should also be developed for families and caregivers as most of the available survivorship resources target survivors themselves.

Breast Cancer Survivorship Stakeholder Meeting Findings

The GW Cancer Institute hosted a meeting on October 28, 2014 to discuss this gap analysis report with 14 DC-area stakeholders and create an action plan. Participants included representatives from the DC Department of Health (DOH), the medical oncology community, community and advocacy organizations and Susan G. Komen®. Several attendees were breast cancer survivors. The following were key findings from the meeting:

1. **Health care disparities.** While many cancer centers are striving to meet the new Commission on Cancer Standard 3.3 Survivorship Care Planning, differences in funding, infrastructure, leadership commitment to patient-centered care practices and other factors vary among institutions in the DC area and have led to disparities in the resources available to survivors. These differences in resources are complicated, since funding and expenses come from various sources including discounted drugs for 340B hospitals, health care delivery structures, overhead, patient volume and negotiated service rates. Stakeholders identified health insurance as a key determinant of services available to a survivor, as the type of health insurance and the services covered through that plan often dictate which institution a survivor will access for care.
2. **Patient navigation.** Stakeholders expressed that patient navigators play a critical role in ensuring quality care across the cancer continuum. Navigators can help fill information gaps as survivors prepare to transition off of active treatment. Currently, many survivors may have a feeling of being “let off the bus” without being told what to expect by their providers.
3. **Barriers beyond healthcare access.** Beyond access to healthcare, stakeholders identified practical barriers, such as transportation and financial hardships, as well as competing demands of daily life, as possible contributors to gaps in survivorship care.

To inform a collaborative strategy to improve access to patient-centered survivorship care for National Capital Region breast cancer survivors, stakeholders met in small groups to explore gaps in survivorship care related to what it means to be an informed and involved patient, support receptive and responsive health professionals, and create a supportive healthcare environment.

Informed and involved patient

Stakeholders cited rushed treatment visits, a cultural disconnect between providers and patients, and a need for support during transition as contributors to the physical, psychological, and practical unmet needs of patients. Stakeholders proposed building partnerships with cancer centers through a community coalition. The coalition would disseminate information to

“For women, once they finish their treatment, one thing that may be lacking is a concise plan that lists resources for survivors.”

“How do you know if the issue is truly access to care or are patients struggling just to pay their rent, get disability, or leave work for treatment?”

cancer centers to educate providers and patients on the varied community resources available to them to support survivors.

Receptive and responsive health professionals

Stakeholders indicated that providers may not feel that they have the time or resources to implement quality, collaborative care for cancer survivors. There are gaps in communication among various providers that collectively comprise the patient’s medical team and between providers and patients related to survivorship care. Stakeholders supported creating educational tools to inform providers about survivorship needs as well as giving them practical tools for implementing guidelines and incentivizing these trainings with continuing medical education credit.

Supportive Health Environment

A fragmented healthcare system and overburdened hospitals with an inability to bill for survivorship services were outlined as current barriers to implementing survivorship care within the healthcare system. Proposed solutions included compensating the implementation of new survivorship services through a bundled payment system that accounts for the time needed to compile a survivorship care plan as well as clinical education to explain the plan to the patient. Another suggestion included appointing a survivorship champion at each cancer center to ensure that each institution had an individual monitoring progress of their own institution in meeting the needs of cancer survivors, accreditation standards and payer requirements.

One Collaborative Strategy

Stakeholder participants supported leveraging an online education program created by the GW Cancer Institute called “Treatment’s Over: What’s Next?” to help support survivors’ transition off of treatment regardless of the treating institution. The group recommended a campaign titled “The Final Fifteen” which represents the final fifteen minutes of the cancer survivor’s last day with their treatment team. Survivors at all participating institutions would be invited to view the online module with their patient navigator during their final treatment visit or initial follow up visit. Stakeholders also proposed creating a presentation which could be used by any of the stakeholders to inform others at their institution about the importance of survivorship care and guidelines related to survivorship care planning. Physician champions will be identified at interested institutions to help advocate for the implementation of the module and survivorship care.

The following is a list of next steps for implementing the proposed strategy:

| Next Steps | Stakeholder | Proposed Timeframe |
|--|---------------------|--------------------|
| Finalize ‘What’s Next’ online module | GW Cancer Institute | December 2014 |
| Provide DC-specific resources to accompany module | GW Cancer Institute | December 2014 |

| | | |
|--|--|--|
| Develop slide deck promoting survivorship care in DC | GW Cancer Institute | December 2014 |
| Identify physician champions at area institutions | Dr. Jacquelyn Dunmore Griffith, Howard | Mid-Atlantic Breast Cancer Conference- March/April 2015 |
| Providing trainings, talking points, and coordination for physician champions | GW Cancer Institute , Amari Fields, DOH | April- June 2015 |
| Build promotion campaign for module | The Sisters Network | TBD |
| Distribute flyers/ promotion | Tina Cleland, Pamela Crum | TBD |
| Track unique visits to online module | GW Cancer Institute | TBD |
| Assess and monitor impact/ document in cancer registry | Amari Fields, DOH | TBD |
| Translating 'What's Next' module into Spanish | Fernando Ascencio, Nueva Vida | TBD |
| Press event/media campaign | Susan G. Komen | TBD |

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Appendix A: DC Cancer Control Plan Survivorship Goal and Objectives

The 2013-2018 District of Columbia Cancer Control Plan was created to pinpoint collaborative goals and aims to decrease the burden of cancer in Washington, DC.³² The plan provided goals and objectives for delivering quality survivorship care within DC. The following are the goals and objectives for cancer survivorship included in the 2013 DC Cancer Control plan:

Overall Goal: Increase access to follow-up care, reduce recurrence, and improve the overall quality of life for the District's cancer survivors

Objective 1

Analyze and report on the current state of survivorship needs, including medical, psychosocial, financial, nutrition, transportation, and rehabilitation needs for District resident survivors.

- Gather information from previous national and DC assessments of survivorship
- Develop a needs assessment of the current medical, financial, transportation, and rehabilitation needs of survivors in the DC area
- Collect data on current survivorship services available in the DC area and compare the needs to the services available
- Develop a report on the current state of survivorship care in DC

Objective 2

Utilizing national standards, establish District-wide comprehensive standards of care for survivorship programs, and subsequently educate providers on these standards.

- Examine the survivorship care plan templates currently in place nationally and within the District; pick out key themes
- Compare plans with the national standards laid out by the IOM and LIVESTRONG and engage providers and community health educators to develop the DC standards of survivorship care

Objective 3

Educate survivors, families, and caregivers on survivorship issues and appropriate standards for follow-up care

- Create and disseminate educational tools on survivorship for survivors, families, and caregivers
- Disseminate these tools through focus groups and conferences and evaluate their impact on increasing knowledge on survivorship

Objective 4

Develop a strategic plan to address survivorship needs

- Address possible challenges and barriers that would prevent the completion of the previous objectives
 - Develop plan and present these findings to key stakeholders
-

Appendix B: Asset Map

| Breast Cancer Survivorship Asset Map | | |
|---|--|--|
| <u>Survivorship Care Plans, Psychosocial Support, Educational Programs</u> | <u>Services</u> | <u>Contact</u> |
| Inova Alexandria Hospital | <ul style="list-style-type: none"> • Partnership with Life with Cancer • Breast Cancer Support Groups | Laura Harty, (703)- 504-7921 laura.harty@inova.org |
| Inova Fairfax Hospital | <ul style="list-style-type: none"> • Partnership with Life with Cancer • Survivors Offering Support | Pamela Crum, (703) 698-2532 pamela.crum@inova.org |
| MedStar Washington Hospital Center | <ul style="list-style-type: none"> • Survivors Offering Support • Transition to Wellness - Jumpstart Your Entry Into Survivorship | Edla Coleman, (443) 777-2505 Edla.V.Coleman@medstar.net |
| George Washington University Medical Faculty Associates & GW Cancer Institute | <ul style="list-style-type: none"> • Thriving After Cancer Adult Survivorship Clinic • Post-treatment Breast Cancer Support Group • Dealing with Cancer: During and After Treatment | Elizabeth Hatcher, (202) 994-2215 eohatcher@gwu.edu Carrie Tilley, ctilley@mfa.gwu.edu |
| MedStar Georgetown Hospital | <ul style="list-style-type: none"> • Transition to Survivorship Breast Cancer Workshop | Denise O'Neill, (202) 444-5285 |
| Sibley Memorial Hospital | <ul style="list-style-type: none"> • Meditation and Yoga Classes • Cancer Education Programming | Pam Goetz, (202) 243-2320 pgoetz4@jhmi.edu |

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| Howard University Hospital | <ul style="list-style-type: none"> • S.E.E.D.S Cancer Support Group for cancer survivors and their caregivers | <p>Kimberly Higginbotham (202) 865-4655 Teletia R. Taylor, PhD (202) 806-4199</p> |
| Providence Hospital | <ul style="list-style-type: none"> • Breast Cancer Support Group | <p>(202) 269-7497 (202) 269-7543 http://www.provhosp.org/services/cancer-oncology-services/breast-cancer</p> |
| Washington Adventist Hospital | <ul style="list-style-type: none"> • Breast Cancer Support Group | <p>Cancer Care Call Line (240) 826-6297</p> |
| Doctors Community Hospital | <ul style="list-style-type: none"> • Breast Cancer Support Group | <p>Center for Comprehensive Breast Care (301) 552-8524 Terry Trimmer ttrimmer@dchweb.org Dr. Regina Hampton www.signaturebreastcare.com</p> |
| Facing Our Risk of Cancer Empowered (F.O.R.C.E) | <ul style="list-style-type: none"> • Information, advocacy, and support for women affected by breast cancer and their caregivers | <p>Susan Davis, susan.davis11@verizon.net</p> |
| Hope Connections | <ul style="list-style-type: none"> • Support groups for survivors and caregivers • Educational classes | <p>(301) 634-7500</p> |
| GoPink! DC | <ul style="list-style-type: none"> • Network that engages survivors in physical activity through dragon boating • Focus on physical activity, mobility, nutrition, fitness, and mental health | <p>Jane Crawford, crawford@gopinkdc.com</p> |

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| Sisters Network Washington, DC | <ul style="list-style-type: none"> • Social support through a social network of local survivors. • Financial assistance to breast cancer survivors through the Breast Cancer Assistance Program (BCAP) | Vonda Jones Shelley Barnes (202) 695.2228 washingtondc@sistersnetworkinc.org |
| Sisters Network Inc.-Prince George County | <ul style="list-style-type: none"> • Social support through a social network of local survivors. • Financial assistance to breast cancer survivors through the Breast Cancer Assistance Program (BCAP) | Madeline Long-Gill Mary Gabourel (301) 494-7315 snpgc@sistersnetworkinc.org |
| African Women's Cancer Awareness Assoc. | <ul style="list-style-type: none"> • Address disparities in awareness, prevention and access to quality healthcare services for African communities that face cancer | Ify Nwabuku, Founder and President (301) 565-0420 www.awcaa.org |
| Life with Cancer | <ul style="list-style-type: none"> • Support groups • Education programs | Sage Bolte, ABD, LCSW, OSW-C (703) 698-2520 sage.bolte@inova.org |
| Nueva Vida | <ul style="list-style-type: none"> • Mental health and emotional support services to Latina survivors • Survivor and family support group | Emily Gurdon, LPN Anna Quijada, Navigator (202) 223-9100 info@nueva-vida.org |
| Capital City Area Health Education Center | <ul style="list-style-type: none"> • DC Pink Divas: Education and | |

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| | empowerment to impact the health of the community | |
| Smith Center for Healing and the Arts | <ul style="list-style-type: none"> Holistic support services, including classes on emotional well-being, nutrition, acupuncture, and yoga | (202) 483-8600 |
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| <u>Rehabilitation Services</u> | <u>Services</u> | <u>Contact</u> |
| Reston Hospital Center | <ul style="list-style-type: none"> STAR Cancer Rehabilitation Program | Susan Foy, Oncology Services Director (703) 639-9425 |
| Sibley Memorial Hospital | <ul style="list-style-type: none"> Lymphedema Specialists | Pam Goetz, (202) 243-2320 pgoetz4@jhmi.edu |
| Virginia Hospital Center | <ul style="list-style-type: none"> STAR Cancer Rehabilitation Program | Cancer Resource Center (703) 558-5550 |
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| <u>Fertility Services</u> | <u>Services</u> | <u>Contact</u> |
| Shady Grove Fertility- Multiple locations | <ul style="list-style-type: none"> In vitro fertilization (IVF), cryopreservation of eggs, sperm, embryos | (888)761-1967 |
| Columbia Fertility- Multiple locations | <ul style="list-style-type: none"> IVF, cryopreservation of eggs, sperm, embryos | (202) 293-6567 |
| Virginia Center for Reproductive Medicine- Reston, VA | <ul style="list-style-type: none"> Egg freezing, IVF | (703) 437-7722 |
| Genetics and IVF Institute- Fairfax, VA | <ul style="list-style-type: none"> Fertility Center for Cancer Patients: IVF and cryopreservation of egg, sperm, testicular tissue, and embryos | (703) 698-7355 |
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| <u>Practical Services</u> | <u>Services</u> | <u>Contact</u> |

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| Food and Friends | <ul style="list-style-type: none"> • Delivery of prepared meals to those living with a life changing health condition • Nutritional counseling and education | (202) 269-2277 |
| LIFT- DC | <ul style="list-style-type: none"> • Resume building and aid for clients in their job search and homeownership | The Arc Office (202) 450-2787 |
| DC Office of Aging | <ul style="list-style-type: none"> • Educational and job training programs for seniors • Housing services | (202) 724-5622 dcoa@dc.gov |

Appendix C: Commission on Cancer-Accredited Programs in the DC Area

DC Programs

- George Washington University Hospital
- Howard University Hospital
- MedStar Georgetown University Hospital
- MedStar Washington Hospital Center
- Providence Hospital
- Sibley Memorial Hospital
- Walter Reed National Military Medical Center
- Washington DC VA Medical Center

Northern Virginia Programs

- Inova Alexandria Hospital
- Inova Fair Oaks Hospital
- Inova Fairfax Hospital
- Inova Loudoun Hospital Center
- Inova Mount Vernon Hospital
- Novant Health Prince William Medical Center
- Reston Hospital Center
- Virginia Hospital Center

Maryland Programs

- Anne Arundel Medical Center
- Holy Cross Hospital
- MedStar Montgomery Medical Center
- Shady Grove Adventist Hospital
- Suburban Hospital
- Washington Adventist Hospital

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