



Survivorship & Palliative Care

A Comprehensive Approach to a Survivorship Care Plan

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The National Cancer Institute (NCI) launched the Community Cancer Centers Program (NCCCP) in 2007 as a three-year pilot, forming a public-private partnership with 16 community hospitals to explore the best methods to enhance access to care, reduce cancer healthcare disparities, improve quality of care, and expand research within the community setting.¹ At the conclusion of the pilot period, the network sites collaborated to produce White Paper reports to document their experiences addressing program deliverables in specific focus areas. A series about the NCCCP White Papers was first introduced in the January/February 2011 edition of *Oncology Issues*.² This month's issue features the Survivorship and Palliative Care Subcommittee's White Paper. To learn more about the NCCCP and its expanded network of 30 hospitals, go to: <http://ncccp.cancer.gov>.

One of the NCCCP's goals is to enhance cancer survivorship and palliative care services. To meet this goal, the 16 pilot sites funded in 2007 were expected to:

- Develop and deliver cancer treatment summaries and follow-up care plans to cancer survivors completing therapy
- Expand existing, or create new, psychosocial and palliative care programs and services for patients and families.

At the start of the NCCCP program, a Survivorship and Palliative Care Subcommittee was formed with representatives from each of the original 16 NCCCP sites. This group worked collaboratively to help all NCCCP sites meet the expectations outlined above. The subcommittee's first project was two-fold: 1) to create a treatment summary template and 2) to explore approaches to deliver this treatment

summary. The subcommittee also identified barriers to the implementation of a treatment summary and shared strategies and successful models adopted by the community cancer centers within the network.

Developing the NCCCP Treatment Summary and Care Plan Templates

The Survivorship and Palliative Care Subcommittee's development of the treatment summary template spanned 12 months and involved intense collaboration among the NCCCP pilot sites. To start the process, all NCCCP sites completed an initial questionnaire to help establish the goals and agendas for the subcommittee's discussions.

Survey results and subsequent discussions indicated that only a few NCCCP pilot sites were providing treatment summaries, and therefore, the subcommittee selected as its initial project the development of a NCCCP treatment summary template. The subcommittee's approach was to outline the process, develop the template, and then determine the method for distribution. The plan involved the generation of a detailed medical treatment summary for sharing with patients and their primary care providers. Subsequent to this effort, the subcommittee worked to develop a long-term survivor care plan, tailored to a given patient's treatment experience and related long-term consequences, and incorporating recommendations to promote healthy lifestyle choices.

As the subcommittee began outlining the process, a few NCCCP pilot sites shared drafts of their existing treatment summary documents. In addition, the subcommittee carried out a brief environmental scan to identify other entities that might have model forms available for consideration for use (e.g., major cancer centers, Lance Armstrong Foundation, Children's Oncology Group, and American Society of Clinical Oncology). Rather than developing a *de novo* template, the sites decided to systematically and sequentially evaluate the American Society of Clinical Oncology (ASCO) treatment summary and survivorship plan templates and then discuss suggested revisions. To start, the group chose to focus on documents related to breast cancer survivors, as this choice would allow all NCCCP sites to have input into the template. Once the general treatment summary template was developed, each NCCCP site would be able to revise, customize, or update to meet the diverse needs—based on geography and patient populations served—of their own organizations.



A nurse practitioner-survivorship patient navigator from NCCCP site Hartford Hospital reviews a survivorship care plan with a patient.



As the subcommittee adapted the ASCO treatment summary template, it paid particular attention to recommendations in the 2005 Institute of Medicine (IOM) report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” in an effort to identify areas that might benefit from enhancements.³ For example, a key area missing from the ASCO template was information specific to psychosocial aspects of care: assessments completed, referrals made to support groups, symptom management, and other survivorship issues. Failure to address this aspect of patient care was itself the focus of a 2007 IOM report, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” (<http://www.iom.edu/Reports/2007/Cancer-Care-for-the-Whole-Patient-Meeting-Psychosocial-Health-Needs.aspx>).

Over the course of several months, NCCCP sites suggested additional information that might be incorporated into the treatment summary template. They also discussed several concerns, including:

- The importance of developing a template as a summary (rather than re-creating the entire medical record)
- The need for the template to be user-friendly for both patients and primary care providers
- How data would be collected, how the document would be collated, and who would prepare and deliver the treatment summary document.

As part of the template development process, the subcommittee explored the feasibility of developing an e-version of the NCCCP treatment summary. An online tool, which would pull data from the various primary sources, was determined to likely be a multi-year project. In the interim, it was suggested that NCCCP sites using the treatment summary template develop a spreadsheet to identify where the primary data needed to populate the template were located. For example, key data elements come from a variety of places, such as the tumor registry, physician office records, freestanding infusion center datasets, or an existing electronic health record (EHR). To avoid errors, the subcommittee stressed that primary source data are preferable whenever possible. Information compiled in the spreadsheets could then serve as a first step in assisting informatics staff at each NCCCP site in exploring e-versions with NCI Information Technology (IT) leads.

Recognizing that a survivorship care plan includes both a treatment summary and a follow-up care plan, the subcommittee worked to modify ASCO’s existing templates. Once the treatment summary template (pages 34-35) and survivorship care plan template (pages 36-37) were finalized, the subcommittee co-chairs asked ASCO to review their work. Overall, ASCO was impressed with the additions and in some cases modified its forms to address NCCCP-identified gaps. ASCO only requested that its copyright

Multiple specialists, including surgeons, medical oncologists, radiation oncologists, nurses, and rehabilitation therapists, provide cancer care to patients. Because these specialists are typically located in separate sites and/or practices and often do not share a common patient health record,¹ various survivorship reports have made a strong case for creation of a treatment summary.²⁻⁴ Developed by the cancer treatment team, this document would facilitate communication between the cancer treatment team and the patient, as well as the cancer treatment team and the patient's other healthcare providers, including primary care physicians and staff.⁵

The patient's treatment summary guides the development of a survivorship care plan. A care plan is a written record of the patient's cancer history, contains recommendations for follow-up care, and includes guidelines for surveillance testing for the detection of possible disease recurrence. The survivorship care plan also provides healthy behavior recommendations that are important to the post-treatment needs of cancer survivors.

Applying a comprehensive approach to a survivorship care

plan, cancer care providers use the treatment summary to give patients detailed diagnostic and cancer-therapy-related information that previously had not been well or routinely provided. The treatment summary and follow-up care plan would also include:

- Information on short- and long-term effects of therapy
- Recommended monitoring for recurrence and adverse effects
- Referral information, as needed for persistent problems
- A review of and support for wellness strategies.

This approach has the potential to empower patients to resume control at a time when much control has been lost. In addition, the treatment summary communicates similar information to all allied providers, helping to ensure that each, including the patient's primary care provider, will be "on the same wavelength" in terms of plans for follow-up care. Having a clear summary treatment plan in place offers a number of other benefits, such as:

- Reducing the risk for inappropriate testing and duplication of services
- Promoting coordination of care by providing guidance on who is

doing what, when, and why

- Reducing the chance of providers failing to agree on needed follow-up care—a common situation that can lead to confusion, doubt, and concern on the part of the patient.

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- ⁵Boyajian R. Survivorship treatment summary and care plan: Tools to address patient safety issues. *Clin J Oncol Nurs*. 2009;13(5).

in the footer be removed and replaced with the following language: "Adopted from ASCO Breast Cancer Treatment Summary."

Next, NCCCP sites explored several models for successful implementation of the templates; some of these models included the development of survivorship programs and clinics to offer care and support to cancer survivors. Here is what they found.

Model 1—Treatment Summary Field Populated Through Cancer Registry

One NCCCP site populated the treatment summary field through its tumor registry. Initially, an Excel spreadsheet was created, and it was populated when registrars abstracted data for breast cancer patients. Manual completion of the treatment summary template took two to three hours per patient, so this NCCCP site looked at ways to complete the form electronically. After careful research and study by the site's Cancer Registry staff, a methodology was developed to automatically populate fields within the NCCCP Breast Treatment Summary by using the CNExT Registry software system.

Use of the follow-up letter function in the CNExT Registry system allowed available abstract fields to be electronically matched to corresponding NCCCP treatment summary fields. Unused abstract fields were reallocated and named to a new use to capture information not routinely abstracted by registrars. Cancer Registry staff did significant pre-implementation testing to ensure that all codes on the CNExT system assigned to the treatment summary form provided appropriate and meaningful numeric or text data. After testing was completed, Cancer Registry staff created and used abstract guidelines. These guidelines ensured that staff would follow a standardized abstracting process so that the treatment form would be consistently completed.

At this NCCCP site, the Principal Investigator (PI), a breast surgeon, and the NCCCP nurse practitioner (NP) piloted utilization of the treatment summary. One copy of the treatment summary was given to the patient; a second copy was filed in the patient's chart. The PI and NP reviewed the treatment summary with their respective patients during the patients' next scheduled visit after treatment completion.

This site successfully mentored other NCCCP sites to implement the treatment summary form in the most

One NCCCP pilot site was awarded a Lance Armstrong Foundation community grant to develop a survivorship program that would use a patient navigator to coordinate specific survivorship care.

efficient manner possible, particularly those sites with the CNEXT Registry system in place.

Model 2—Nurse Practitioner-Led Survivorship Program with Survivorship Software

One NCCCP pilot site was awarded a Lance Armstrong Foundation community grant to develop a survivorship program that would use a patient navigator to coordinate specific survivorship care. This program included the development of a treatment summary and care plan to be provided to and discussed with patients at a survivorship visit. After receiving the grant, the NCCCP site hired an NP to fill the survivorship patient navigator role. Using a nurse practitioner in this role provides patients with high-level, specialized survivorship care. In addition, the NP's services are billable, which creates a survivorship care model with the potential for self-sustainability and revenue generation.

Currently, the NCCCP site is piloting a breast cancer survivorship program where patients are seen four to six weeks after the completion of their primary cancer treatment. During this initial survivorship visit, patients are given a breast cancer treatment summary and care plan that outline all of the cancer treatments they have received and note potential side effects and late effects of their treatment. In addition, at this visit, the NP gives patients individualized education and counseling about their care plan, and provides information on support services, appropriate screenings, wellness, and lifestyle modifications to improve their overall health and well-being as they transition to survivorship.

The NP is a point of contact for breast cancer survivors and assists in coordinating the care they receive from their other healthcare providers. This model improves continuity of care and may help eliminate unnecessary provider visits. After the survivorship visit, the NP sends the treatment summary to all of the patient's healthcare providers to be integrated into the patient's medical records.

This NCCCP site also used the CNEXT registry software to create its treatment summary. While this choice allowed the site to use existing resources to begin their survivorship program, the process is very time consuming and does not allow for a personalized approach to creating a care plan. Plans are under way to transition to an electronic, web-based survivorship package that will: 1) greatly decrease the time needed to create the treatment summary and 2) allow the NP to develop more personalized care plans for each patient using an extensive bank of published articles and educational information. Using this web-based survivorship tool, the goal is to expand the survivorship program more quickly to include additional cancer sites and patient populations.

This NCCCP site is using measures of patient qual-

ity of life and satisfaction with their survivorship care and experience to evaluate and improve the program and provide a database that would permit future research on the impact of survivorship care on patients' subsequent health-related outcomes. Surveys measuring quality of life (FACT-B), fear of recurrence (Assessment of Survivor Concerns), and survivorship program satisfaction are filled out at the initial survivorship visit and six months post-visit. This information will be used to guide program development as staff seeks to expand the survivorship program to other types of cancer.

Staff also hopes to publish and disseminate the findings of their survivorship program evaluation, to expand the available resources on cancer survivorship, and to participate in the development of best practice models and guidelines for developing and providing cancer survivorship care in community cancer centers. Using new technology, such as the Cogent survivorship software, and seeking feedback from survivors through the program evaluation will help continually improve and expand the program to best meet the needs of the site's cancer survivors.

Model 3—Using the Journey Forward Care Plan Builder

At one NCCCP site, oncology providers, administrators, and staff embraced the IOM's assertion that a survivor's transition from treatment to follow-up and surveillance should be individualized and understandable. This site also involved cancer survivors, their families, patient advocates, primary care physicians, and insurance providers as key stakeholders in the effort to implement survivorship plans.

In 2009, the site conducted two pilot evaluations to determine the best mechanism for delivering treatment summaries and survivorship care plans.

The first pilot study used a manually dictated treatment summary. In this study, patients received their survivorship care plans during a follow-up appointment with either a survivorship NP or with their oncologist.

The second pilot used the *Journey Forward Survivorship Care Plan Builder*, a treatment summary and survivorship care plan builder for breast, colon, and other cancer types. A joint project between the National Coalition for Cancer Survivorship, the University of California Los Angeles Cancer Survivorship Center, Wellpoint, Inc., and Genentech Inc., the *Survivorship Care Plan Builder 2.0* is available as a download from <http://journeyforward.org/> or via CD. In this pilot, patients received individual survivorship summaries from their providers in a support group setting.

While both studies indicated that the survivorship plans were well received by patients, the NCCCP site ultimately opted to implement the *Journey Forward Survivorship Care Plan Builder*, along with a copy of the patient's pathology report. The *Journey Forward Survivorship Care*

The survivorship patient navigator typically meets with the patient and, if possible, his or her caregiver(s), within the last two scheduled treatments to educate patients about their personal treatment summaries.

Plan Builder summary was deemed to be more patient friendly and easier to read.

The NCCCP site was under consideration by the collective developers of the *Journey Forward Survivorship Plan* as a possible 2010 beta site to incorporate this tool into the *Mosaic* EMR system. Although ultimately not chosen as a test site, this NCCCP site requested, and the Journey Forward organization agreed to, the following:

- Maintain and update the *Journey Forward Survivorship Care Plan Builder* during 2010-2012 to adhere to ASCO guidelines, and resolve any software maintenance issues that arose
- Release the *Journey Forward Survivorship Care Plan Builder 2.0* version in the first quarter of 2010, with the updated version including a “generic” survivorship care plan template and other enhancements, such as expanded capacity for users to use local resources for patients and providers
- Continue to offer the *Journey Forward Survivorship Care Plan Builder* free of charge.

In addition, this NCCCP site created a Survivorship Matrix Assessment Tool with several categories and scaled, objective criteria to measure program maturity and growth over time. Matrix categories included policies and procedures specific to survivorship care, treatment summary utilization, coordination of the survivorship visit, and communication to primary care providers. Overall, this NCCCP site found the Survivorship Matrix Assessment Tool useful as it worked to establish its program model.

Model 4—Survivorship Patient Navigator Populating Pencil and Paper Treatment Summary

In July 2009, one NCCCP site hired a BSN/OCN with extensive experience in oncology care to serve as a 0.7 FTE dedicated survivorship patient navigator. The navigator was instrumental in developing individual patient survivorship cancer treatment summaries and follow-up care plans. With feedback from the cancer center’s physicians, the NCCCP site adapted the ASCO Cancer Treatment Summary template to meet the perceived needs of its patients and primary care physicians. Alterations included simplifying the format and some of the information, with the goal of making the summary more reader friendly and applicable to any cancer diagnosis.

This site’s medical and GYN oncology clinics are currently in the process of converting to an EHR; some documentation resides in the paper chart and other documentation in the EHR. As a result, the survivorship patient navigator populates the treatment summaries by hand. Depending on the complexity of the case, this process can

take from as little as 10 minutes to one hour. Personal treatment summaries are provided to patients with a diagnosis of breast, prostate, head/neck, or lung cancer. In the near future, the site hopes to begin counseling patients who have completed treatment for GYN oncology diagnoses, colorectal cancer, and lymphoma.

Two methods are used to identify patients who are near completion of their planned therapies. For patients completing radiation therapy, the EHR designates them as a “finisher” in the daily master schedule. The survivorship patient navigator monitors the radiation therapy EHR master schedule almost daily to identify those patients who need personal treatment summaries developed. The second method of patient identification is through disease-specific patient navigators who help identify patients nearing the end of their chemotherapy treatments.

The survivorship patient navigator typically meets with the patient and, if possible, his or her caregiver(s), within the last two scheduled treatments to educate patients about their personal treatment summaries. Prior to the scheduled consultation, the survivorship navigator also works closely with the disease-specific navigators to obtain information about any specific needs that a patient may have so that these needs can be addressed during the consultation. If patients receive any treatment at an outside facility, the type of therapy and the provider’s contact information are noted on the patient’s personal treatment summary.

During the survivorship consultation, typically lasting 10-15 minutes, the survivorship patient navigator reviews the content of both the personal treatment summary and the survivorship care plan. A copy of the personal treatment summary and care plan is faxed or mailed to the patient’s primary care provider and any other significant healthcare provider. An electronic copy is always saved for future reference or revisions if the patient should receive future treatment.

During the consultation, the survivorship patient navigator will make any referrals that are requested or identified as needed. The survivorship patient navigator will also follow up with patients as necessary through phone calls or by attending the patient’s post-treatment appointments. Patients are encouraged to contact the survivorship patient navigator for any needs that may arise post-treatment. In this model, the survivorship patient navigator distributes treatment summaries and care plans to patients of specific diagnoses, though the navigator is also available to all patients of the cancer center through referrals or requests.

The Implementation Experience—Barriers, Strategies, and Resources

Many NCCCP sites struggled to implement a comprehensive survivorship care plan. Implementation barriers

Table 1. Barriers to Survivorship Treatment Summary and Care Plan Implementation

Barriers	Strategies to Overcome Barriers
<p>Time Constraints</p> <ul style="list-style-type: none"> ■ Time intensive to gather data and complete form ■ Time span between patient completing therapy and tumor registry abstracting data 	<ul style="list-style-type: none"> ■ Use tumor registry data to populate form ■ Purchase commercially available software product to electronically populate fields ■ Implement Rapid Quality Reporting System (RQRS) in tumor registry to provide more timely data abstraction
<p>Information Technology</p> <ul style="list-style-type: none"> ■ Manually populated forms versus documents automatically populated from EHR ■ Lack of shared EHR between cancer centers and private practice physician offices ■ Poor access to private practice medical records 	<ul style="list-style-type: none"> ■ Nurse navigators/nurse practitioners manually populate forms ■ Purchase software for shared EHR between cancer centers and private practice physician offices ■ Use existing processes for communicating and requesting information from private practice staff ■ Establish agreements for access to private practice medical records
<p>Processes and Responsibilities</p> <ul style="list-style-type: none"> ■ Who is appropriate to receive a treatment summary? ■ When additional treatment is received, how do updates get made to the summary? 	<ul style="list-style-type: none"> ■ Obtain feedback from multidisciplinary teams to identify survivor populations on which to focus for initial implementation ■ Establish survivorship clinics
<p>Care Plan Recommendations</p> <ul style="list-style-type: none"> ■ Lack of standards for adult cancer survivorship surveillance 	<ul style="list-style-type: none"> ■ Collaborate with multidisciplinary team members to establish follow-up surveillance recommendations based on ASCO, NCCN, and other professional guidelines

fell into one of four categories:

1. Time constraints
2. IT-related challenges
3. Processes and responsibilities
4. Care plan recommendations.

Table 1 (above) lists common barriers along with strategies that NCCCP sites used to overcome these barriers. General strategies suggested by the Survivorship and Palliative Care Subcommittee include providing education on best practices and establishing a workgroup to address barriers and identify successful strategies for implementation.

In addition, the Survivorship and Palliative Care Subcommittee identified the following key elements as necessary for successful implementation of treatment summaries and, ultimately, survivorship care planning or programs.

Administrative and Physician Support. Successful implementation of treatment summaries requires a physician and an administrative champion, as well as the general

support of private practice physicians early in the planning phase. Identifying these champions is crucial to developing and sustaining quality cancer survivorship care. One major challenge is the ability to access private practice physician medical records to garner information for the treatment summary. A possible solution may be to develop a confidentiality agreement with private practice physicians so that tumor registrars, data analysts, and patient navigators from the hospital or community cancer center have access to pertinent files.

Information Technology and Cancer Registry. Ideally, EHR integration between hospital systems, as well as with private practice physician offices, will streamline implementation of survivorship plans. However, given the current lack of EHR integration with private practitioners, NCCCP sites focused on cancer registry databases to populate patient treatment summaries. Survivorship programs need to create an environment that promotes continued follow-up and support for long-term care. Key measures

Given the challenges of collecting data as radiation oncology, dedicated staff information required to

such as quality of life and tracking of latent side effects and second cancers are among some of the meaningful data to be compiled and tracked. In the absence of system-wide, compatible EHR systems, community cancer centers should use reliable sources currently in place to populate treatment summary forms with minimal duplication of effort. To this end, community cancer centers may need to survey many data sources, including the cancer registry, radiation and medical oncology records, and hospital surgical and pathology reports.

Establishing a registry or data repository for tracking patients is necessary to provide an ongoing means of evaluating the survivorship program, as well as patient outcomes. The cancer registry and any existing EHR systems are reasonable places to begin identifying data fields that are aligned with the NCCCP/ASCO-recommended treatment summaries and care plans. The survivorship program development team should include a representative from the cancer registry, as well as the IT department. These team members are essential to an overall understanding of where data are housed and how data might be exported into treatment summaries.

Staffing Resources. In addition to physician support and IT solutions, adequate staffing is necessary for successful implementation of treatment summaries. Given the challenges of collecting data from private practice oncology offices, as well as radiation oncology, dedicated staff is needed to collect the patient medical record information required to complete the treatment summary. For many community cancer centers this process is manual.

One solution may be to employ a nurse navigator to complete treatment summaries and distribute them to supporting physicians. The treatment nurse navigator, who already has an established relationship with the patient, could provide the treatment summary. Alternatively, a dedicated survivorship navigator, a registered nurse with oncology experience, could take on this role. The treatment nurse navigator would transition the patient to the survivorship navigator upon completion of acute treatment. A survivorship navigator may offer a number of benefits, including:

- Supporting and “navigating” patients during their transition from active treatment through recovery and beyond
- Improving patient satisfaction and health outcomes
- Establishing relationships with primary care physicians and facilitating communication between the oncologists and the primary care physicians
- Educating patients about the treatment summary and survivorship plan
- Ensuring that the psychosocial, financial, physical, and spiritual needs of patients continue to be met.

Nurse practitioners can provide clinical survivorship assessment, planning, intervention, and follow-up care for patients entering the survivorship phase. Survivorship clinics allow for the provision of comprehensive care plans using evidence-based and best practice guidelines. Since survivorship plans are necessary elements to empower patients to effectively manage the long-term and late effects of cancer and cancer treatment, a survivorship clinic with dedicated support staff may facilitate successful implementation of these tools.

Delivery of Survivorship Plans. Integration of the survivorship plan into the continuum of care process requires a multidisciplinary approach. Time must be established to allow for discussion between the dedicated survivorship staff and the patient to review the patient’s survivorship plan and address any questions or concerns. In addition, patients should be encouraged to discuss aspects of the plan with other members of their medical team.

Patient Resources. Each step of the cancer care continuum requires education tailored to an individual patient’s journey, taking into account issues of health literacy, language, and culture. Healthcare providers may be challenged in terms of accessing adequate communication tools and appropriate patient education resources.

Ideally, survivorship care planning should begin at the time of diagnosis, as recommended by the IOM³, with the ultimate goal of empowering patients with knowledge and tools designed to increase their self-care behaviors and quality of life, to adhere to recommended care, and to decrease anxiety and symptom severity. One solution is to provide patients with a survivorship organizer with tabs and file pockets to keep important information related to their diagnosis and treatment.

The Lance Armstrong Foundation currently provides such a tool (<http://www.store-laf.org/guidebook.html>). Each tab covers topics pertinent to the complete continuum of care for cancer patients. These survivorship organizers can be provided to newly diagnosed cancer patients and individualized patient education materials can be added throughout the continuum of care.

Survivor and Provider Satisfaction. When survivorship plans are implemented, satisfaction surveys (for survivors and providers) should be developed to evaluate these services on an ongoing basis. Feedback should be obtained from survivors, primary care physicians, and oncologists to determine how best to help survivors transition to recovery and to meet patients’ post-treatment follow-up care needs.

To determine the success of treatment summary implementation and survivorship programs, patient satisfaction surveys that evaluate navigation and clinical program services should be developed and disseminated. Results of

from private practice oncology offices, as well is needed to collect the patient medical record complete the treatment summary.

patient satisfaction surveys may lead to the development of quality improvement initiatives within the cancer center and, as a result, may improve patient outcomes.

Key Recommendations

NCCCP sites have learned several important lessons with regard to the development and implementation of comprehensive survivorship plans. One general recommendation is the significance of understanding survivorship issues from the perspectives of both survivors and their health-care providers; another is to become familiar with available resources, reports, articles, and literature from national agencies focused on cancer survivorship. Other key recommendations for cancer centers include:

- Know the capabilities of the cancer center's EHR software and use the best data available to construct summaries, recognizing that—as yet—there is no single place where all of the relevant data resides.
- Engage key stakeholders to move survivorship from a concept to a reality.
- Focus not only on the patient's physical needs but also on psychosocial needs in survivorship follow-up care.
- Tailor recommendations and referrals provided in the survivorship plans to the specific needs of each survivor.
- Ensure that treatment summaries have a multidisciplinary approach.
- Recognize that not all patients are transitioned back to primary care providers for their follow-up care.
- Personalize survivorship programs to meet institutional needs (i.e., EHRs, data availability, staff availability). There are many ways to get this done. Reshaping some existing data strings and sharing practices between hospitals and physician offices may help reduce apparent barriers.
- Personalize the treatment summary to meet the needs of the cancer center's patient population and program, as long as essential elements are included.
- Use existing databases and resources in the public domain to reduce cost and staff time.
- Ask existing programs for help and advice; they likely have gone through the learning curve and would be happy to share what works.

Development of the treatment summary and care plan tools was a labor-intensive but gratifying collaborative process that involved a great deal of dedication at each NCCCP site. The Survivorship and Palliative Care Subcommittee members actively champion the premise that a survivorship care plan is not only important to the patient but is also an instrumental tool that can be used by health-care providers—including primary care and other non-oncology specialty care providers—to positively affect the

health and well-being of survivors for years to come. While having the resources and systems in place to ensure the delivery of treatment summaries and care plans can be very challenging, the benefits and the rewards to the survivors and other care providers are enduring. 

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Breast Cancer Adjuvant Treatment Plan and Summary

The Treatment Plan and Summary provide a brief record of major aspects of breast cancer adjuvant treatment. This is not a complete patient history or comprehensive record of intended therapies.

Patient name: _____ Patient ID: _____ Race: _____
 Patient DOB: (___/___/___/) Age at diagnosis: _____ Patient phone: _____
 Support contact name: _____ Relationship: _____ Support contact phone: _____

BACKGROUND INFORMATION

Family history: None 2nd degree relative 1st degree relative Multiple relatives BRCA 1/2: Pos Neg
 Previous breast cancer: Yes (___/___/___/) Type: No Breast Atypia: Yes (___/___/___/) No
 Definitive breast surgery: Date: (___/___/___/) Type: Lumpectomy Mastectomy Mastectomy/immediate recon
 # lymph nodes removed: _____ # lymph nodes positive: _____ Biopsy date: (___/___/___/)
 Axillary dissection: Yes (___/___/___/) No Sentinel node biopsy: Yes (___/___/___/) No
 Notable surgical findings/comments: _____ Surgical margin clear: Yes No
 Tumor type: Infiltrating ductal Infiltrating lobular DCIS Other: _____ Tumor size: _____
 T stage: Tis T1 T2 T3 T4a T4b T4c T4d N stage: N0 N1 N2 N3 M Stage: M0 M1
 Pathologic stage: 0 I II III IV Oncotype DX recurrence score: _____ Breast: Right Left Bilateral
 ER status: Positive Negative PR status: Positive Negative HER2 status: Positive Negative
 Major comorbid conditions: _____ HRt use: Yes No oophorectomy Hysterectomy
 Echocardiogram or MUGA result prior to chemotherapy (if obtained): EF= % Onset of Menses: (___/___/___/)
 Onset of menopause: Yes (___/___/___/) No Smoking History: No Yes/Current Yes/Past Years: _____

ADJUVANT TREATMENT PLAN

ADJUVANT TREATMENT SUMMARY

White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy

Height: _____ in/cm Pre-treatment weight: _____ lb/kg Post-treatment weight: _____ lb/kg
 Pre-treatment BSA: _____ Date last menstrual period: (___/___/___/) Date last menstrual period: (___/___/___/)
 Name of regimen: _____
 Start date: (___/___/___/) End Date: (___/___/___/)

Chemotherapy Drug Name	Route	Dose	Schedule	Dose reduction needed	Number of cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	

Side effects experienced: _____ Anthracycline administered: Doxorubicin _____ mg/m2
 Hair loss Nausea/Vomiting Epirubicin _____ mg/m2
 Neuropathy Low blood count _____
 Fatigue Menopause symptoms _____
 Cardiac symptoms Cognitive _____
 Other: _____
 Allergic events: _____
 Serious toxicities during treatment (list all): _____
 Hospitalization for toxicity during treatment: Yes No
 Neurotoxicity that impairs activities of daily living: Yes No
 Reason for stopping adjuvant treatment: _____

Adopted from American Society of Clinical Oncology Breast Cancer Treatment Summary
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Breast Cancer Adjuvant Treatment Plan and Summary

The Treatment Plan and Summary provide a brief record of major aspects of breast cancer adjuvant treatment. This is not a complete patient history or comprehensive record of intended therapies.

ADJUVANT TREATMENT PLAN

ADJUVANT TREATMENT SUMMARY

ENDOCRINE THERAPY

None Tamoxifen Aromatase inhibitor Other

Medication:

Date endocrine therapy started (or to start) (___/___/___)

Duration:

TRASTUZUMAB (HERCEPTIN) THERAPY

Trastuzumab (Herceptin) planned: Yes No

Trastuzumab (Herceptin) prescribed: Yes No

Planned or completed dates of trastuzumab therapy:

Pre-trastuzumab ejection fraction: %(___/___/___)

Start date (___/___/___) End date (___/___/___)

Most recent ejection fraction: %(___/___/___)

Radiation Therapy Summary

Location	Beam Arrangement	Area	Mode	Tumor Dose Total	Dates of Rx From To	# of Visits	Elapsed Days
		<input type="checkbox"/> Local (breast)					
		<input type="checkbox"/> Regional (nodes)					
		Partial Brst RXT: <input type="checkbox"/> Yes <input type="checkbox"/> No					

Lymphedema: Yes No Date: (___/___/___)

Breast Reconstruction: Yes No Date: (___/___/___)

ONCOLOGY TEAM MEMBER CONTACTS

SURVIVORSHIP CARE PROVIDER CONTACTS

Provider:

Provider:

Name:

Name:

Contact Info:

Contact Info:

Supportive and Survivorship Services

Survivorship Clinic Appointment Made: Yes No Date: (___/___/___) Provider Name Phone Number

Nutrition Services			
Genetic Services	<input type="checkbox"/> Yes <input type="checkbox"/> No Date: (___/___/___)		
Social Work/Psychology	<input type="checkbox"/> Yes <input type="checkbox"/> No Date: (___/___/___)		
Rehabilitation Services	<input type="checkbox"/> Yes <input type="checkbox"/> No Date: (___/___/___)		
Other Support Service(s)	<input type="checkbox"/> Yes <input type="checkbox"/> No Date: (___/___/___)		
Living Will: <input type="checkbox"/> Yes <input type="checkbox"/> No	Advanced Directive: <input type="checkbox"/> Yes <input type="checkbox"/> No		

Complementary Services (e.g. Yoga, Tai Chi):

Survivorship Educational Materials Provided:

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NCI COMMUNITY CANCER CENTERS PROGRAM
Breast Cancer Survivorship Care Plan 08/08

Patient Name:		
FOLLOW-UP CARE TEST	RECOMMENDATION	PROVIDER TO CONTACT
Medical history and physical (H&P) examination (see below)	Visit your doctor every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter.	
Post-treatment mammography (see below)	Schedule a mammogram one year after your first mammogram that led to diagnosis, but no earlier than six months after radiation therapy. Obtain a mammogram every six to 12 months thereafter based on the guidance of your physician.	
Breast self-examination	Perform a breast self-examination every month. This procedure is not a substitute for a mammogram.	
Pelvic examination	Continue to visit a gynecologist regularly (at least annually). If you use tamoxifen, you have a greater risk for developing endometrial cancer (cancer of the lining of the uterus). Women taking tamoxifen should report any vaginal bleeding to their doctor.	
Coordination of care	About a year after diagnosis, you may continue to visit your oncologist or transfer your care to a primary care doctor. Women receiving hormone therapy should talk with their oncologist about how often to schedule follow-up visits for re-evaluation of their treatment.	
Genetic counseling referral	Tell your doctor if there is a history of cancer in your family. The following risk factors may indicate that breast cancer could run in the family: <ul style="list-style-type: none"> • Ashkenazi Jewish heritage • Personal or family history of ovarian cancer • Any first-degree relative (mother, sister, daughter) diagnosed with breast cancer before age 50 • Two or more first-degree or second-degree relatives (grandparent, aunt, uncle) diagnosed with breast cancer • Personal or family history of breast cancer in both breasts • History of breast cancer in a male relative 	

YEARLY BREAST CANCER FOLLOW UP & MANAGEMENT SCHEDULE

Visit Frequency for H&P	Years 1-3:	3 months	6 months	(circle one)
	Years 4-5:	6 months	12 months	(circle one)
Visit Frequency for Mammography:		6 months	12 months	(circle one)
VISIT FREQUENCY	HISTORY AND PHYSICAL	MAMMOGRAPHY		
3rd Month (if applicable)				
6th Month (if applicable)				
9th Month (if applicable)				
12th Month (if applicable)				
Notes:				
<ul style="list-style-type: none"> • Risk: You should continue to follow-up with your physician because the risk of breast cancer continues for more than 15 years after remission. 				
<ul style="list-style-type: none"> • Symptoms of Recurrence: Report these symptoms to your doctor: new lumps, bone pain, chest pain, shortness of breath or difficulty breathing, abdominal pain, or persistent headaches. 				
<ul style="list-style-type: none"> • Not Recommended: The following tests are not recommended for routine breast cancer follow-up: breast MRI, FDG-PET scans, complete blood cell counts, automated chemistry studies, chest x-rays, bone scans, liver ultrasound, and tumor markers (CA 15-3, A 27.29, CEA). Talk with your doctor about reliable testing options. 				

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Version 2.0

NCI COMMUNITY CANCER CENTERS PROGRAM
Breast Cancer Survivorship Care Plan 08/08

Late Effect	Population at Risk	Risk	Interventions
Cancer recurrence	All women with a history of breast cancer	Varies by stage and tumor characteristics	Mammography, physical examination
Second primary cancer	All women with a history of breast cancer	Varies by treatment, age, and genetic predisposition (women with BRCA ^a mutations are at higher risk)	Mammography, pelvic examination, general physical examination, patient education
Psychosocial distress and depression	All women with a history of breast cancer	Approximately 30 percent experience distress at some point; distress declines over time	<ul style="list-style-type: none"> • Assessment for distress/depression • Some psychosocial interventions are effective in reducing distress/depression
Arm lymphedema	Women who had axillary dissection and/or radiation therapy	Across treatments and time since treatment, approximately 12 to 25 percent of women develop lymphedema	Massage and exercise (manual lymphatic drainage), use of elastic compression garments, complex decongestive therapy
Premature menopause and related infertility and osteoporosis	<ul style="list-style-type: none"> • Women who received adjuvant chemotherapy (e.g., alkylating agents such as cyclophosphamide) • Women with BRCA mutations who elect oophorectomy 	Risk depends on the chemotherapy regimen, the cumulative dose, and patient age (see details below)	<ul style="list-style-type: none"> • New reproductive technologies for infertility • Diagnostic and preventive strategies for osteoporosis • Assessment of sexual function
Symptoms of estrogen deprivation (e.g., hot flashes, sweats, vaginal discharge)	Women taking endocrine therapy	More than half report symptoms, although mild in most cases	Promising non-hormone treatments include antidepressants, dietary changes, and exercise
Weight management	Women who had adjuvant chemotherapy and experience menopause	Roughly half report weight gain of 6 to 11 pounds; one-fifth report weight gain of 22 to 44 pounds	Diet/exercise interventions "Heart Healthy" lifestyle behaviors
Cardiovascular disease	<ul style="list-style-type: none"> • Women receiving specific therapies (e.g., anthracycline chemotherapy, trastuzumab [Herceptin]) • Premenopausal women with ovarian failure following chemotherapy 	<ul style="list-style-type: none"> • Congestive heart failure develops in 0.5 to 1 percent of women • Increased risk of atherosclerosis 	<ul style="list-style-type: none"> • Symptomatic women should have a symptom-directed cardiac work-up; routine screening of cardiac function is not recommended • Preventative strategies for heart disease
Fatigue	Women with breast cancer	Reported in one-third of survivors 1 to 5 years after diagnosis. Prevalence similar to that seen in women in the general population of same age. A subgroup of survivors has more severe and persistent fatigue.	Exercise programs appear promising
Cognitive changes	Women who received adjuvant chemotherapy	Estimates vary, but up to one-third of women report cognitive changes. New evidence suggests onset may precede chemotherapy treatment.	Evidence lacking
Risk to family members	All survivors	An estimated 5 to 10 percent of women with breast cancer have a hereditary form of the disease. Likelihood increases to 20 percent in women with multiple factors	Genetic counseling
Sexuality (decrease in libido and dryness)	Women who had adjuvant chemotherapy or HRT	Predicting the risk of infertility to each individual is often impossible. Risk is dependent on the drug(s) used, dosage received, duration of use, and the individual's age at the time of administration.	<ul style="list-style-type: none"> • Assessment of sexual function • Referrals to appropriate care providers
Spirituality	All women with a history of breast cancer	Some survivors have reported that the cancer experience has led them to re-examine their spiritual beliefs and contributed to changes in their life and relationships. Surviving cancer is more like a spiritual journey that teaches how to change your life and your relationships.	<ul style="list-style-type: none"> • Referrals to spiritual care advisors

^aBRCA genes (e.g., BRCA1 and BRCA2) are genes that normally help to suppress cell growth. A person who inherits an altered version of the BRCA genes has a higher risk of getting breast, ovarian, or prostate cancer.

^bPossible Late Effects Among Breast Cancer Survivors (IOM. 2006. From Cancer Patient to Cancer Survivor: Lost in Transition. Hewitt, M, Greenfield S, Stovall E, eds. Washington DC: National Academies Press pgs. 82-83)

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