

# **Coleman Supportive Oncology Initiative**

## Survivorship Training Module

### Topic: **What is Survivorship?**

Presenters: Stephanie Merce Boecher RN, OCN, MSN, BSN, BA and  
Frank J. Penedo, PhD

# Learning Objectives

**By the end of this module you should be able to:**

- 1. Define who is a cancer survivor**
- 2. Describe what survivorship care is**
- 3. Discuss trends of the survivorship population**

## Cancer Survivor Defined

- **National Comprehensive Cancer Network (NCCN)**

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also affected by cancer.”

*This definition was adapted with permission from the National Coalition for Cancer Survivorship as shown in the National Cancer Institute’s Office of Cancer Survivorship Definition. Available at: <http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>*

- **National Cancer Institute (NCI)**

A survivor is: “One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.”

*National Cancer Institute at the National Institutes of Health, NCI Dictionary of Cancer Terms. Available at: <http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=450125>*

- **American Society of Clinical Oncology (ASCO)**

“One common definition is a person having no disease after finishing treatment. Another common definition is the process of living with, through, and beyond cancer. According to this definition, cancer survivorship begins at diagnosis and includes people who continue to receive treatment to either reduce the risk of the cancer coming back or to manage chronic disease.”

*American Society of Clinical Oncology (ASCO), ASCOanswers, Cancer Survivorship 2014. Available at: [http://www.cancer.net/sites/cancer.net/files/cancer\\_survivorship.pdf](http://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf)*

# Understanding Survivorship

## What is survivorship?

“Cancer survivorship involves the vast and persistent impact that both the diagnosis and treatment of cancer have on the patient, family and caregiver. This includes the potential impact on health, physical and mental states, health behaviors, professional and personal identity, sexuality, social and family relations, and financial standing.”

Adapted from Hewitt M, Greenfield S, Stovall E. *Cancer Patient to Cancer Survivor: Lost in Translation*. Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council 2006. Available at: <http://www.nap.edu/catalog/11468.html>.

## What is survivorship care?

According to the 2005 Institute of Medicine (IOM) report, the essential components of survivorship care are:

1. Prevention of new and recurrent cancers and other late effects
2. Surveillance for cancer spread, recurrence, or second cancers
3. Assessment of late psychological and physical effects
4. Intervention for consequences of cancer and treatment (e.g., medical problems, symptoms, psychological distress, financial & social concerns)
5. Coordination of care between primary care providers and specialists to ensure all of the survivor’s health needs are met
6. Survivorship care planning (detailed on next slide)

# Standards for Survivorship Care

## What is a survivorship care plan?

The IOM 2005 Report recommends that patients who are completing the first course of treatment be "provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained". The purpose of this standard (American College of Surgeons/Commission on Cancer [CoC] Standard 3.3, Survivorship Care Plan) is to have cancer programs develop and implement a process to monitor the dissemination of a survivorship care plan as part of the cancer patient's standard of care.

### Process Requirements:

- a. A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input from the patient's other care providers.
- b. The survivorship care plan is given to the patient upon completion of treatment.
- c. The written or electronic survivorship care plan contains a record of care received, important disease characteristics and a follow-up care plan incorporating available and recognized evidence-based standards of care.

*CoC Accreditation Committee Clarifications for Standard 3.3 Survivorship Care Plan*, American College of Surgeons, Online September 9, 2014. Available at: <https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>

### Develop a survivorship plan that includes:

- Summary of treatment received
- Information regarding follow-up care and surveillance recommendations
- Information on post-treatment needs, including information regarding treatment-related effects and health risks when possible
- Delineation regarding roles of oncologists and primary care physician and timing of transfer of care if appropriate
- Healthy behavior recommendations

## Treatment Summary

**The core set of data elements for the treatment summary (comprehensive care plan), as recommended by American Society of Clinical Oncology (ASCO), are:**

- Contact information of the treating institutions and providers
- Specific diagnosis (e.g. breast cancer), including histologic subtype (e.g. non-small cell lung cancer) when relevant
- Stage of disease at diagnosis (e.g. I-III)
- Surgery (yes/no). If yes:
  - Surgical procedure with location on the body
  - Date(s) of surgery (year required, month optional, day not required)
- Chemotherapy (yes/no). If yes:
  - Names of systemic therapy agents administered (listing individual names rather than regimens)
  - End date(s) of chemotherapy treatment (year required, month optional, day not required)
- Radiation (yes/no). If yes:
  - Anatomical area treated by radiation
  - End date(s) of radiation treatment (year required, month optional, day not required)
- Ongoing toxicity or side effects of all treatments received (including those from surgery, systemic therapy and/or radiation) at the completion of treatment and any information concerning the likely course of recovery from these toxicities
- For selected cancers, genetic/hereditary risk factor(s) or predisposing conditions and genetic testing results, if testing is performed

## Follow-Up Care Plan

### The core set of data elements for the follow-up care plan, as recommended by ASCO, are:

- Oncology team member contacts with location of the treatment facility [repeat if separate document]
- Need for ongoing adjuvant therapy for cancer:
  - Adjuvant therapy name
  - Planned duration
  - Expected side effects
- Schedule of follow-up related clinical visits (to be presented in table format to include who will provide the follow-up visit, how often, and where this will take place)
- Cancer surveillance tests for recurrence (to be presented in table format to include who is responsible for ordering/carrying out the test, the frequency of testing and where this will take place)
- Cancer screening for early detection of new primaries – to be included only if different from the general population (presented in table format who is responsible for carrying out, the frequency of testing and where this will take place)
- Other periodic testing and examinations (rather than outlining specific testing, ASCO suggested an inclusion of a general statement to "continue all standard non-cancer related health care with your primary care provider, with the following exceptions: [if there are any]" )

## Follow-Up Care Plan (*continued*)

**The core set of data elements for the follow-up care plan, as recommended by ASCO, are:**

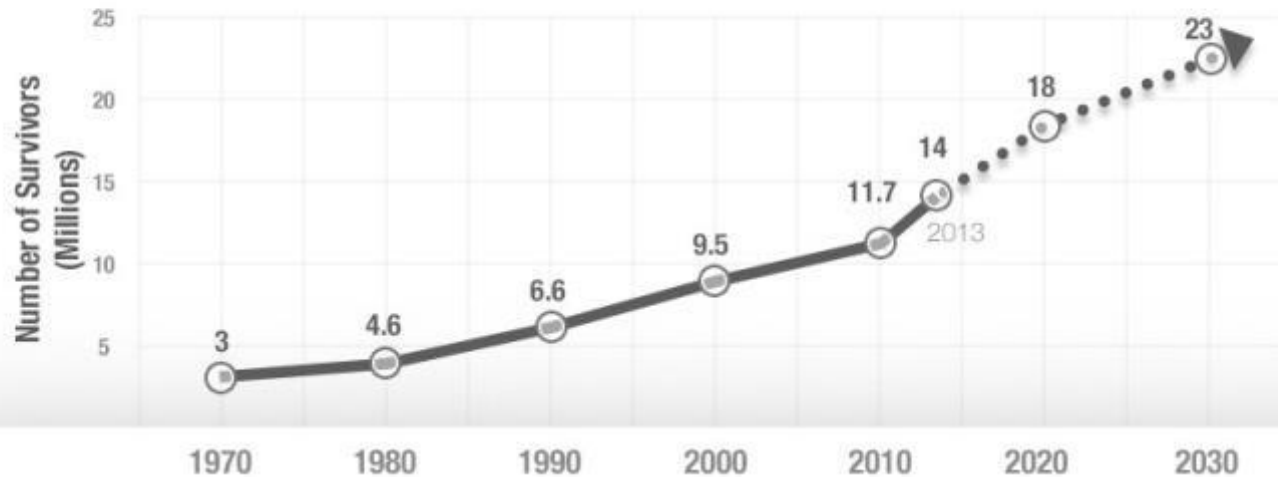
- Possible symptoms of cancer recurrence - ASCO suggests inclusion of a general statement, "Any new, unusual and/or persistent symptoms should be brought to the attention of your provider."
- A list of likely or rare but clinically significant late and/or long-term effects that a survivor may experience based on his or her individual diagnosis and treatment if known (including symptoms that may indicate the presence of such conditions)
- A list of items (e.g. emotional or mental health, parenting, work/employment, financial issues, and insurance) in standard language stating that survivors have experienced issues in these areas and that the patient should speak with his or her oncologist and/or PCP if having related concerns. ASCO recommends including a list of local and national resources to assist the patient in obtaining proper services.
- A general statement emphasizing the importance of healthy diet, exercise, smoking cessation and alcohol use reduction, tailored to the individual when pertinent.



## Trends of the Survivorship Population

- About 14 million cancer survivors in the US: globally over 20 million
- 3 out of 4 families will have at least 1 family member diagnosed with cancer
- 66% of adults diagnosed can expect to be alive in 5 years
- 61% of survivors are 65 years of age or older

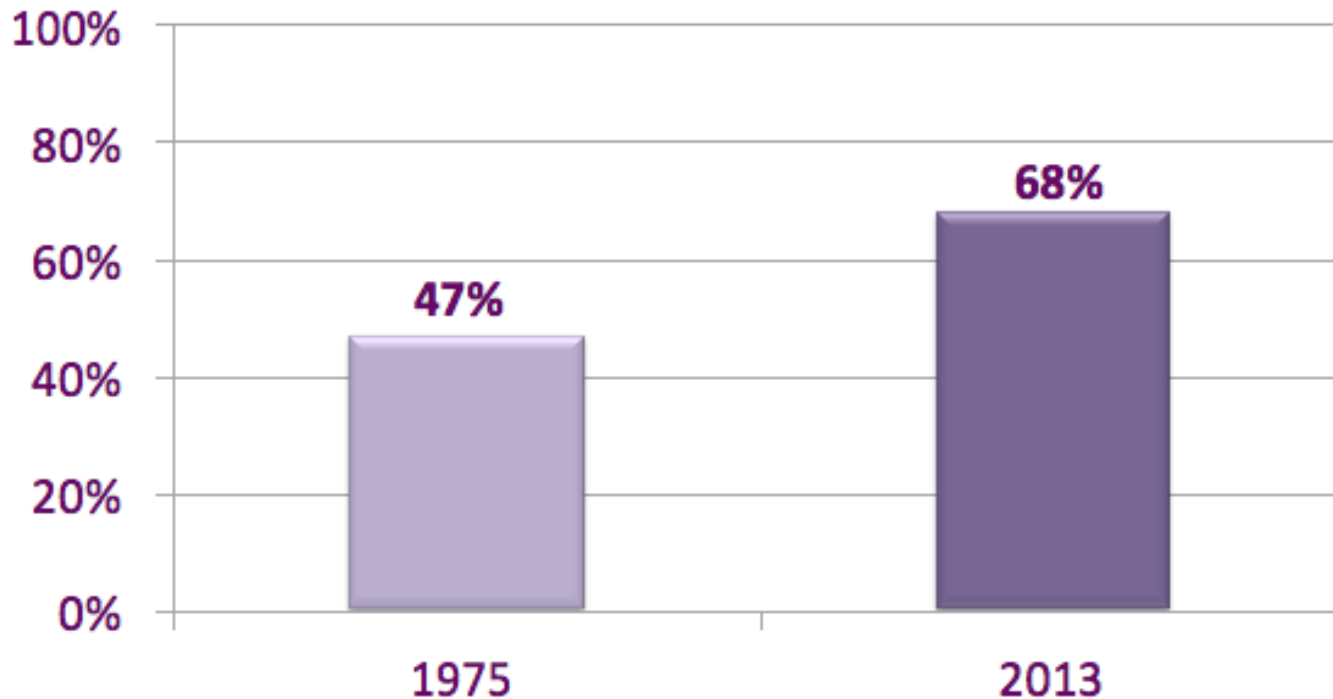
### Cancer Survivorship Will Continue To Surge



## Trends of the Survivorship Population

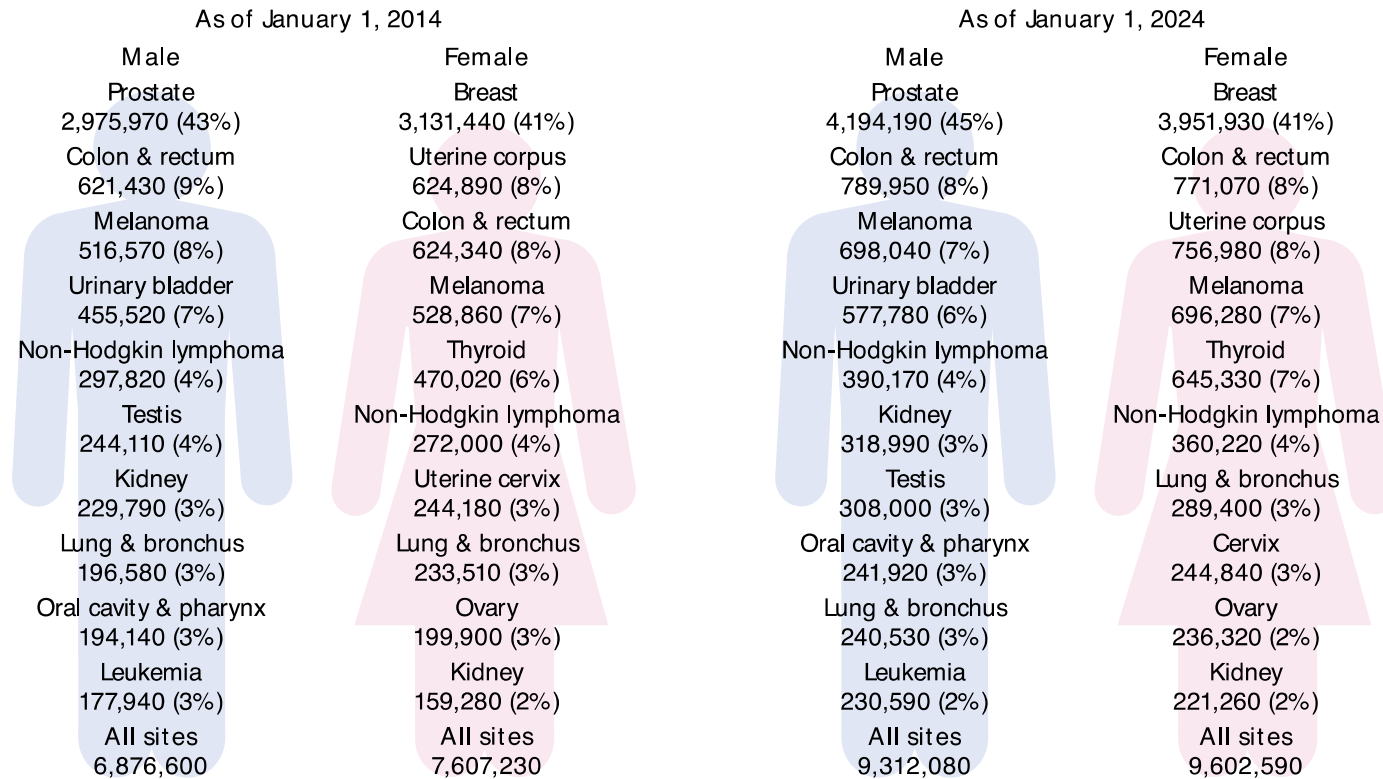
The increases in cancer survival rate can be attributed to significant advances in screening, early detection and treatment.

Increases in Cancer Survival Rate  
5 years Post-Diagnosis



# Trends of the Survivorship Population

Figure 1. Estimated Numbers of US Cancer Survivors by Site



Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society, Surveillance and Health Services Research, 2014

American Cancer Society. Cancer Treatment & Survivorship Cancer Facts and Figures 2014- 2015. Atlanta: American Cancer Society, Inc.

# Trends of the Survivorship Population

## How many cancer survivors are expected to be alive in the US in 2024?

By January 1, 2024, it is estimated that the population of cancer survivors will increase to almost 19 million: 9.3 million males and 9.6 million females.

**Table 1. Estimated Numbers of US Cancer Survivors as of January 1, 2014, by Sex and Time Since Diagnosis**

| Years since diagnosis | Male and Female |         |                    | Male      |         |                    | Female    |         |                    |
|-----------------------|-----------------|---------|--------------------|-----------|---------|--------------------|-----------|---------|--------------------|
|                       | Number          | Percent | Cumulative Percent | Number    | Percent | Cumulative Percent | Number    | Percent | Cumulative Percent |
| 0 to <5 years         | 5,149,350       | 36%     | 36%                | 2,731,710 | 40%     | 40%                | 2,417,640 | 32%     | 32%                |
| 5 to <10 years        | 3,407,910       | 24%     | 59%                | 1,739,950 | 25%     | 65%                | 1,667,960 | 22%     | 54%                |
| 10 to <15 years       | 2,263,770       | 16%     | 75%                | 1,070,460 | 16%     | 81%                | 1,193,310 | 16%     | 69%                |
| 15 to <20 years       | 1,455,280       | 10%     | 85%                | 617,230   | 9%      | 90%                | 838,050   | 11%     | 80%                |
| 20 to <25 years       | 912,890         | 6%      | 91%                | 338,530   | 5%      | 94%                | 574,360   | 8%      | 88%                |
| 25 to <30 years       | 547,240         | 4%      | 95%                | 175,620   | 3%      | 97%                | 371,620   | 5%      | 93%                |
| 30+ years             | 747,400         | 5%      | 100%               | 203,100   | 3%      | 100%               | 544,300   | 7%      | 100%               |

Note: Percentages do not sum to 100% due to rounding.

Source: Data Modeling Branch, Division of Cancer Control and Population Sciences, National Cancer Institute.

American Cancer Society. Cancer Treatment & Survivorship Cancer Facts and Figures 2014- 2015. Atlanta: American Cancer Society, Inc.

## Summary of Points Covered

### In this training module we addressed:

- **The most commonly accepted definitions for cancer survivor**
- **What survivorship and survivorship care are as well as the elements and expectations for survivorship treatment summaries and follow-up plans**
- **Current and projected trends in the survivorship population**

## Next Steps

For more detailed training on this topic, you can go to the following resources:

### National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)  
[http://www.nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)

### The George Washington University Cancer Institute

- [Guide for Delivering Quality Survivorship Care](https://cancersurvivorshipcentereducation.org/uploads/Guide_for_Delivering_Quality_Survivorship_Care_FINAL.pdf)  
[https://cancersurvivorshipcentereducation.org/uploads/Guide\\_for\\_Delivering\\_Quality\\_Survivorship\\_Care\\_FINAL.pdf](https://cancersurvivorshipcentereducation.org/uploads/Guide_for_Delivering_Quality_Survivorship_Care_FINAL.pdf)

### The Advisory Board Company

- [The CoC clarifies the survivorship care plan standard: What you need to know](https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2014/09/the-coc-clarifies-the-survivorship-care-plan-standard-what-you-need-to-know)  
<https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2014/09/the-coc-clarifies-the-survivorship-care-plan-standard-what-you-need-to-know>
- [ASCO weighs in on key survivorship care plan components](https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2014/06/asco-weighs-in-on-key-survivorship-care-plan-components)  
<https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2014/06/asco-weighs-in-on-key-survivorship-care-plan-components>

### American College of Surgeons

- [Standard 3.1, Chapter 3: Continuum of Care Services \(Video\)](https://www.facs.org/quality-programs/cancer/coc/standards/video/chapter3)  
<https://www.facs.org/quality-programs/cancer/coc/standards/video/chapter3>

### Commission on Cancer

- [Standard 3.3 Survivorship Care Plan \(Video\)](https://www.youtube.com/watch?v=tBCMrxO9P2E)  
<https://www.youtube.com/watch?v=tBCMrxO9P2E>

### American Society of Clinical Oncology (ASCO)

- [ASCOanswers, Cancer Survivorship](http://www.cancer.net/survivorship)  
<http://www.cancer.net/survivorship>

## **Faculty Bio for Stephanie Merce Boecher, RN OCN MSN BSN BA**

**Stephanie Boecher has been a nurse for the past 17 years. She currently resides as the Director of Advocate Sherman Comprehensive Cancer Care Center and Inpatient Oncology Unit (Oncology Service Line), which includes medical oncology, radiation therapy, nurse navigation, research, cancer data registry, and a 24 bed inpatient oncology unit. She has been part of the multidisciplinary team responsible for NAPBC accreditation since 2011 as well Commission on Cancer. Stephanie has served as the nurse executive for the Advocate System Nurse Navigation/Survivorship standardization project for the past 18 months implementing improvements in NCCN distress thermometer processes, navigation documentation/EMR, quality metrics, education, community needs assessment, and navigation job descriptions. She previously worked at Presence St. Joseph Hospital's Cancer Care Center for 7 years as a clinical nurse and educator.**

**Stephanie holds a BA in History/English from the University of Wisconsin-Madison, BSN from Rush University and an MSN from the University of Phoenix. She has been an Oncology Certified Nurse (OCN) since 2007. She is a member of the Sigma Theta Tau International Honor Society of Nursing as well as a member of the Oncology Nursing Society both locally and nationally. Stephanie served as the Chemotherapy/biotherapy instructor from 2007-2013, Board member for Chicago Western Suburbs chapter as Social Media Chair 2013-present as well as a member of the Program Development team 2010-2012.**

## Faculty Bio for Frank J. Penedo, PhD

**Dr. Frank J. Penedo is the Roswell Park Professor of Medical Social Sciences, Psychology and Psychiatry and Behavioral Sciences. He is also the Program Leader of the Cancer Control and Survivorship Program in the Lurie Cancer Center and the Director of the Cancer Survivorship Institute at Northwestern Medicine. He is trained in clinical psychology and behavioral medicine and his research has focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life (HRQOL) and health outcomes in chronic disease populations with a major emphasis on diverse cancer survivors in regard to race, ethnicity and socio-economic status. Dr. Penedo has served as PI, co-PI or project leader on multiple NIH-funded studies addressing psychosocial and biobehavioral correlates of adjustment and the efficacy of psychosocial interventions in improving HRQOL, symptom burden and health outcomes in chronic disease populations. He has significant expertise in community based, cohort and intervention studies that target cancer survivors and involve collection and analyses of psychosocial and biological data. He has over 110 peer-reviewed publications, has served as associate editor of two major journals in his field, and some of his translational work has been disseminated as clinical intervention tools. Dr. Penedo currently serves as a standing member of the NIH BMIO study section and on the editorial board of several major journals in his field. He is the president elect of the International Society of Behavioral Medicine, a fellow of the Society of Behavioral Medicine and a member of the Academy of Behavioral Medicine Research. He has received numerous awards and also served on the advisory boards of community organizations such as the Wellness Community, the Intercultural Cancer Council and Salud America.**

**For additional information:**

<http://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=24719>



## References

American Cancer Society, ACS. Life After Cancer: Survivorship By the Numbers. Available at: <http://www.cancer.org/research/infographicgallery/survivorship-life-after-cancer>

American Cancer Society, ACS, 2014-2015. Cancer Treatment & Survivorship, Facts & Figures. Available at: <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-042801.pdf>

American College of Surgeons. Accreditation Committee Clarifications for Standard 3.3 Survivorship Care Plan. 2014. Available at: <https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>

Facing Forward: Life After Cancer Treatment  
<http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=450125>  
Increases in Survival Rate, 5-years Post-Diagnosis from NCI, 2012.

Institute of Medicine and National Research Council, *From Cancer Patient to Cancer Survivor: Lost in Transition*, Washington, D.C: The National Academies Press, 2006.  
Increases in Survival Rate, 5-years Post-Diagnosis from Institute of Medicine, 2005.

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National Comprehensive Cancer Network. NCCN Guidelines® for Survivorship (Version 2.2017). Available at: [http://www.nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf). Accessed July 28, 2017.

# **Coleman Supportive Oncology Initiative**

## **Survivorship Training Module**

# **How to Conduct a Screening of Patient Concerns and Distress at a Survivorship Appointment**

Presenters: Patricia Robinson, MD and Christine B. Weldon, MBA

Version: 08042017

## Learning Objectives

**By the end of this module you should be able to:**

- 1. Explain which guidelines and instruments form the basis for the various sections of the Survivorship Appointment Tool**
- 2. Describe the appropriate timing for the administration of the Survivorship Appointment Tool**
- 3. Discuss examples of how the tool is being used and its impact on the survivorship appointment visit**

## Sections of the Supportive Oncology Screening Tool

**The purpose of supportive oncology screening is to identify a patient's potential supportive oncology needs. The components consist of:**

- **Distress / Anxiety**
- **Practical Concerns**
- **Family / Caregiver Concerns**
- **Spiritual / Faith / Religious Concerns**
- **Nutrition**
- **Treatment or Care Concerns**
- **Physical Concerns**
- **Lifestyle Factors**

# “Questions for your Survivorship Appointment Tool”

Adapted from the NCCN Distress Thermometer and Problem List, with inclusion of the PHQ-4, NCCN Guidelines for Survivorship and ASCO Survivorship Guidelines

For a copy of the tool please contact:  
[christine.weldon@northwestern.edu](mailto:christine.weldon@northwestern.edu)

## Questions for your Survivorship Appointment

All patients are asked to complete this questionnaire as part of their standard of care. Please take a few minutes to answer the following questions to help us better address your needs.

Over the **last 14 days**, how often have you been bothered by the following problems?

|   | Not at all               | Several Days             | More than half the days  | Nearly every day         |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| <i>Please mark one box per row</i>                |                          |                          |                          |                          |
| Feeling nervous, anxious or on edge               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not being able to stop or control worrying        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Little interest or pleasure in doing things       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Feeling down, depressed, or hopeless              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fear of developing another cancer or a recurrence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please indicate if you developed any of the below concerns as a result of your cancer treatment by checking Yes or No for each.

| YES                      | NO                       | <u>Financial Concerns</u>  | YES  | NO                       | <u>Physical Concerns</u>                                    |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
|--------------------------|--------------------------|--|--|--------------------------|---|-----|----|---------------------------|--------------------------|--------------------------|--------------------|--------------------------|--------------------------|--------------------------------|--------------------------|--------------------------|---------------|--------------------------|--------------------------|--|--------------------------|--------------------------|----------------------|--------------------------|--------------------------|-----------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Paying for food and/or housing   | <input type="checkbox"/>   | <input type="checkbox"/> | Ability to have children                                    |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Paying for my medication or medical care                                 | <input type="checkbox"/>   | <input type="checkbox"/> | Appearance  |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance coverage or no health insurance                                | <input type="checkbox"/>   | <input type="checkbox"/> | Breathing   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> |  | <input type="checkbox"/>   | <input type="checkbox"/> | Constipation or Diarrhea                                    |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| YES                      | NO                       | <u>Social Concerns</u>   | <input type="checkbox"/>   | <input type="checkbox"/> | Hot flashes and/or vaginal dryness                          |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about my children   | <input type="checkbox"/>   | <input type="checkbox"/> | Nausea or Vomiting  |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about my partner  | <input type="checkbox"/>   | <input type="checkbox"/> | Difficulty with chewing or swallowing due to cancer therapy |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Issues with work or school   | <input type="checkbox"/>   | <input type="checkbox"/> | Pain  |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual / Faith / Religious Concerns</u>                            | <input type="checkbox"/>   | <input type="checkbox"/> | Sexual intimacy or function                                 |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| YES                      | NO                       | <u>Nutrition Concerns</u>  | <input type="checkbox"/>   | <input type="checkbox"/> | Dry skin  |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about body weight   | <input type="checkbox"/>   | <input type="checkbox"/> | Sleep   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about diet (food) and cancer risk/incidence                     | <input type="checkbox"/>   | <input type="checkbox"/> | Decreased range of motion or loss of strength               |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about alternative/herbal supplements                            | <input type="checkbox"/>   | <input type="checkbox"/> | Lower energy level  |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> |  | <input type="checkbox"/>   | <input type="checkbox"/> | Swollen arms/legs   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| YES                      | NO                       | <u>Treatment or Care Concerns</u>  | <input type="checkbox"/>   | <input type="checkbox"/> | Tingling in my hands/feet                                   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Lack understanding about my cancer diagnosis or stage                    | <input type="checkbox"/>   | <input type="checkbox"/> | Trouble remembering, concentrating                          |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Have questions about potential long term complications from my treatment | <p>Please indicate which factors may be relevant to your lifestyle by checking Yes or No for each.</p> <table border="1"> <thead> <tr> <th>YES</th> <th>NO</th> <th><u>Life Style Factors</u></th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I use tanning beds</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I am often outside, in the sun</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I use tobacco</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I use prescription pain medication for reasons other than pain control</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I exercise regularly</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I drink alcohol</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>I use recreational drugs</td> </tr> </tbody> </table> |                          |   | YES | NO | <u>Life Style Factors</u> | <input type="checkbox"/> | <input type="checkbox"/> | I use tanning beds | <input type="checkbox"/> | <input type="checkbox"/> | I am often outside, in the sun | <input type="checkbox"/> | <input type="checkbox"/> | I use tobacco | <input type="checkbox"/> | <input type="checkbox"/> | I use prescription pain medication for reasons other than pain control | <input type="checkbox"/> | <input type="checkbox"/> | I exercise regularly | <input type="checkbox"/> | <input type="checkbox"/> | I drink alcohol | <input type="checkbox"/> | <input type="checkbox"/> | I use recreational drugs |
| YES                      | NO                       | <u>Life Style Factors</u>  |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I use tanning beds   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I am often outside, in the sun   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I use tobacco  |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I use prescription pain medication for reasons other than pain control   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I exercise regularly   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I drink alcohol  |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | I use recreational drugs   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Developed other illnesses as a result of my cancer treatment             |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Issues with transportation to/from appointments                          |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Need help coordinating my care   |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Need cancer screening  |  |                          |   |     |    |                           |                          |                          |                    |                          |                          |                                |                          |                          |               |                          |                          |  |                          |                          |                      |                          |                          |                 |                          |                          |                          |

**Other problems or concerns:**  
 \_\_\_\_\_  
 \_\_\_\_\_

\*This tool is adapted from: (1) The National Comprehensive Cancer Network, NCCN Guidelines\*for Distress Management, Problem List, Version 3.2015; (2) the PHQ-4 developed by Kroenke K, Spitzer RL, Williams JB, Löwe B.; (3) American Society of Clinical Oncology, *Providing High Quality Survivorship Care in Practice: An ASCO Guide*, (2014)

# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

Over the **last 14 days**, how often have you been bothered by the following problems?

*Please mark one box per row*

|   | Not at all               | Several Days             | More than half the days  | Nearly every day         |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| Feeling nervous, anxious or on edge               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not being able to stop or control worrying        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Little interest or pleasure in doing things       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Feeling down, depressed, or hopeless              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fear of developing another cancer or a recurrence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Distress / Anxiety

- The PHQ-4 tool was selected based on the ASCO’s 2014 Distress Guidelines (Andersen BA, JCO 2014 ).
- The PHQ-4’s purpose is to allow for very brief and accurate measurement of depression and anxiety.
- PHQ-4 is a 4 item inventory rated on a scale. Its items are drawn from the Generalized Anxiety Disorder-7 Scale and the Patient Health Questionnaire-9, developed by Kurt Kroenke, Robert L. Spitzer, Janet B.W. Williams and Bernd Löwe.
- Last question, “Fear of developing another cancer or a recurrence” added to address fear of another cancer or recurrence

# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

| YES                      | NO                       | <u>Financial Concerns</u>                 |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Paying for food and/or housing            |
| <input type="checkbox"/> | <input type="checkbox"/> | Paying for my medication or medical care  |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance coverage or no health insurance |

## Financial Concerns

- Based on the NCCN Distress Thermometer and Problem List with an expansion of the financial concerns

| YES                      | NO                       | <u>Social Concerns</u>     |
|--------------------------|--------------------------|----------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about my children |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about my partner  |
| <input type="checkbox"/> | <input type="checkbox"/> | Issues with work or school |

## Social Concerns

- Based on the NCCN Distress Thermometer and Problem List with adaptation

# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

| YES                      | NO                       |   |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual / Faith / Religious Concerns</u> |

## Spiritual / Faith / Religious Concerns

- Based on the NCCN Distress Problem List

| YES                      | NO                       | <u>Nutrition Concerns</u>                            |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about body weight                           |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about diet (food) and cancer risk/incidence |
| <input type="checkbox"/> | <input type="checkbox"/> | Concerns about alternative/herbal supplements        |

## Nutrition Concerns

- Based on the NCCN Distress Thermometer and Problem List, with an expansion to incorporate concepts from the NCCN Guidelines for Survivorship



# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

| YES                      | NO                       | <u>Treatment or Care Concerns</u>  |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | Lack understanding about my cancer diagnosis or stage                    |
| <input type="checkbox"/> | <input type="checkbox"/> | Have questions about potential long term complications from my treatment |
| <input type="checkbox"/> | <input type="checkbox"/> | Developed other illnesses as a result of my cancer treatment             |
| <input type="checkbox"/> | <input type="checkbox"/> | Issues with transportation to/from appointments                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Need help coordinating my care   |
| <input type="checkbox"/> | <input type="checkbox"/> | Need cancer screening  |

## Treatment or Care Concerns

- Developed this new section, in accordance with the IOM 2013 report and NCCN Guidelines for Survivorship and ASCO Survivorship Care Guidelines

# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

| YES                      | NO                       | <u>Physical Concerns</u>                                    |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children                                    |
| <input type="checkbox"/> | <input type="checkbox"/> | Appearance  |
| <input type="checkbox"/> | <input type="checkbox"/> | Breathing   |
| <input type="checkbox"/> | <input type="checkbox"/> | Constipation or Diarrhea                                    |
| <input type="checkbox"/> | <input type="checkbox"/> | Hot flashes and/or vaginal dryness                          |
| <input type="checkbox"/> | <input type="checkbox"/> | Nausea or Vomiting  |
| <input type="checkbox"/> | <input type="checkbox"/> | Difficulty with chewing or swallowing due to cancer therapy |
| <input type="checkbox"/> | <input type="checkbox"/> | Pain  |
| <input type="checkbox"/> | <input type="checkbox"/> | Sexual intimacy or function                                 |
| <input type="checkbox"/> | <input type="checkbox"/> | Dry skin  |
| <input type="checkbox"/> | <input type="checkbox"/> | Sleep   |
| <input type="checkbox"/> | <input type="checkbox"/> | Decreased range of motion or loss of strength               |
| <input type="checkbox"/> | <input type="checkbox"/> | Lower energy level  |
| <input type="checkbox"/> | <input type="checkbox"/> | Swollen arms/legs   |
| <input type="checkbox"/> | <input type="checkbox"/> | Tingling in my hands/feet                                   |
| <input type="checkbox"/> | <input type="checkbox"/> | Trouble remembering or concentrating                        |

## Physical Concerns

- Based on the NCCN Distress Thermometer and Problem List, with expansion of additional side effects and symptoms that often impact patients’ quality of life during survivorship

# Instruments and Guidelines Incorporated into “Questions for Your Survivorship Appointment”

Please indicate which factors may be relevant to your lifestyle by checking Yes or No for each.

| YES                      | NO                       | <u>Life Style Factors</u>  |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | I use tanning beds   |
| <input type="checkbox"/> | <input type="checkbox"/> | I am often outside, in the sun   |
| <input type="checkbox"/> | <input type="checkbox"/> | I use tobacco  |
| <input type="checkbox"/> | <input type="checkbox"/> | I use prescription pain medication for reasons other than pain control |
| <input type="checkbox"/> | <input type="checkbox"/> | I exercise regularly   |
| <input type="checkbox"/> | <input type="checkbox"/> | I drink alcohol  |
| <input type="checkbox"/> | <input type="checkbox"/> | I use recreational drugs   |

## Lifestyle Factors

- Based on the NCCN Guidelines for Survivorship and ASCO Survivorship Guidelines that encourage a review of lifestyle factors as they relate to cancer risk, recurrence and prevention as part of patients’ transition to survivorship. This content is also a standard part of the survivorship care plan.

## Timing of Questions for your Survivorship Appointment

### The Commission on Cancer (Standard 3.3)

- A cancer survivorship care plan is prepared by the principal provider(s) who coordinated each patient's oncology care (with input from other relevant health care providers).
- The cancer survivorship care plan is given to the patient upon completion of active curative-intent treatment. This ranges by organization from 30 to 90 days after that point.

## **Example of How “Questions for Your Survivorship Appointment” is Used in Clinic**

- **Patient completes “Questions for Your Survivorship Appointment” tool in waiting room or infusion center. (This tool is also available in Spanish.)**
- **Staff (e.g., navigator, medical assistant, or nurse) reviews supportive oncology screening tool and pages appropriate identified staff (e.g., social worker) to be available to patient if PHQ-4 score is more than half the days and/or if the patient notes financial or social concerns.**
- **Survivorship clinician reviews form with patient focusing on items with a positive screen answered “Yes”. It serves as the foundation for the educational component of the consultation as it directly addresses the concerns of the patient.**

## Example of How “Questions for Your Survivorship Appointment” is Used in Clinic

### Impact of Using “Questions for Your Survivorship Appointment”

- Patients indicate that there are items on the questionnaire that they forgot about or would not have thought to bring up.
- It provides a good review of the cancer diagnosis (including stage and histology) therapy and treatment impact (including late and long-term complications of care).
- Patients indicate that there are items on the questionnaire which stimulate conversation that a regular clinic appointment does not.
- Patients also indicate that the questionnaire prompts/reminds them to discuss symptoms that may not have been acute at the time of their regular clinic appointment
- Patient’s answers on the questionnaire ensure that the patients' concerns are addressed just as much as the clinician's.
- These answers also serve as an educational tool that guides the discussion.

## Summary of Points Covered

**In this training module we addressed:**

- **Which guidelines and instruments inform various sections of the “Questions for a Survivorship Appointment” tool**
- **The appropriate timing of the “Questions for a Survivorship Appointment” tool**
- **Examples of how the “Questions for a Survivorship Appointment” tool has been used in a clinic setting**

## Next Steps

For more detailed training on this topic, you can go to the following resources:

### National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Distress Management](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)  
[http://www.nccn.org/professionals/physician\\_gls/pdf/distress.pdf](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)
- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)  
[http://www.nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)

### American Society of Clinical Oncology, ASCO®

- [Institute for Quality™, Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation](http://www.institutequality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society)  
<http://www.institutequality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society>
- [Cancer Survivorship](http://www.asco.org/practice-research/cancer-survivorship)  
<http://www.asco.org/practice-research/cancer-survivorship>
- [ASCO Cancer Survivorship Compendium](http://www.asco.org/practice-research/asco-cancer-survivorship-compendium)  
<http://www.asco.org/practice-research/asco-cancer-survivorship-compendium>

### George Washington Cancer Institute

- [Guide for Delivering Quality Survivorship Care](https://smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare)  
<https://smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare>

### MD Anderson Cancer Center

- [Cancer Survivorship Series](http://www.mdanderson.org/education-and-research/resources-for-professionals/professional-educational-resources/professional-oncology-education/survivorship/index.html)  
<http://www.mdanderson.org/education-and-research/resources-for-professionals/professional-educational-resources/professional-oncology-education/survivorship/index.html>



## Faculty Bio for Patricia Robinson, MD

**Institution/title:** Cardinal Bernardin Cancer Center, Loyola University

**Roles:** Director, Cancer Survivorship Clinic; Associate Professor, Department of Hematology and Medical Oncology, Loyola University Medical Center

**Area of Expertise:** Breast oncology, Cancer survivorship, Cancer Disparities

**Practice type:** Academic Medical Center/ University

**Organization/Association Memberships:** Member, Health Disparities Committee 2014-2017

**Bio:** Dr. Robinson is an Associate Professor of Medicine at Loyola University. She specializes in breast oncology. She graduated from the University of Michigan with a B.S. and received her M.D. from Michigan State University. Dr. Robinson completed her residency at Loyola University and Fellowship in Hematology-Oncology at Fox Chase Cancer Center. Dr. Robinson serves as the Director of the Cancer Survivorship Clinic at the Cardinal Bernardin Cancer Center. She serves on the Cancer Survivorship Committee and Breast Committee of the Southwest Oncology Group. In addition to clinical research, Dr. Robinson has several roles in the medical school. She serves as the assistant director for the Internal Medicine clerkship.

**For additional information:**

<https://www.loyolamedicine.org/doctor/patricia-robinson>

## **Faculty Bio for Christine B. Weldon**

**Christine Weldon is director and co-founder of the Center for Business Models in Healthcare (CBM-HC), an independent health services research organization focused on personalized care and precision medicine in oncology. Ms. Weldon's work follows a unique framework which involves collaborations with academic institutions, including Northwestern University and University of California San Francisco, medical centers, health care payers, product development companies and patient advocacies.**

**Christine has over twenty years of experience in business advisory, research and consulting services. Her expertise includes business model design, business visioning and planning, strategic decision-making support, facilitation of complex initiatives, business process optimization, organizational design and information management.**

**Ms. Weldon is an Adjunct Faculty member of the Northwestern University Feinberg School of Medicine and possesses an MBA from the Kellogg School of Management, Northwestern University and a BSBA from Drake University.**

List of Ms. Weldon's publications available at:

<http://www.ncbi.nlm.nih.gov/sites/myncbi/1Bc7czwoYfu/bibliography/43309719/public/?sort=date&direction=ascending>

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National Comprehensive Cancer Network®, NCCN Guidelines® for Survivorship, Version 2.2017 Available at: [http://www.nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)

# **Coleman Supportive Oncology Initiative**

## Survivorship Training Module

### Topic: **Commission on Cancer Requirements for Survivorship Care Plan**

Presenters: Sofia F. Garcia, PhD and Sara M. Goetzman, BA

## Learning Objectives

**By the end of this module you should be able to:**

- 1. Identify the minimal data elements required by CoC Program Standard 3.3 to be included in cancer survivorship care plans**
- 2. Describe the process requirements of a survivorship care plan**
- 3. Summarize the timeline by which CoC-accredited institutions need to provide comprehensive care summaries and follow-up plans**

## American College of Surgeons, Commission on Cancer (CoC)



- **The CoC is “dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care.”**
- **CoC-accredited cancer care institutions must undergo evaluation and performance reviews, and be found to comply with established CoC standards.**
- **There are more than 1,500 CoC-accredited institutions, which provide care for approximately 70% of patients with newly diagnosed cancers in the United States.**

## CoC's Standard 3.3 Defined

**“The cancer committee develops and implements a process to disseminate a treatment summary and follow-up plan to patients who have completed cancer treatment. The process is monitored and evaluated annually by the cancer committee.”**

## CoC's Standard 3.3 Defined (con't.)

- **Standard based on IOM and National Research Council 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition***
  - Recommended that patients who are completing their first course of cancer treatment be “provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.”
  - Suggested that survivorship care plans would help prevent cancer patients from getting “lost” in the transition out of primary active treatment and into extended survivorship.
  
- **Standard’s purpose is for cancer programs to “develop and implement a process to monitor the dissemination of a survivorship care plan as a part of the standard care of patients with cancer.”**
  - The process is implemented, monitored, evaluated, and presented annually to the cancer committee.
  - The presentation is documented in minutes.



## CoC Standard 3.3 Minimal Data Elements

### Treatment Summary, as recommended by ASCO:

- Contact information of the treating institutions and providers
- Specific diagnosis (e.g., breast cancer), including histologic subtype (e.g., non-small cell lung cancer) when relevant
- Stage of disease at diagnosis (e.g., I-III)
- Surgery (yes/no). If yes,
  - a. Surgical procedure with location on the body
  - b. Date(s) of surgery (year required, month optional, day not required)
- Chemotherapy (yes/no). If yes,
  - a. Names of systemic therapy agents administered (listing individual names rather than regimens)
  - b. End date(s) of chemotherapy treatment (year required, month optional, day not required)
- Radiation (yes/no). If yes,
  - a. Anatomical area treated by radiation
  - b. End date(s) of radiation treatment (year required, month optional, day not required)
- Ongoing toxicity or side-effects of all treatments received (including those from surgery, systemic therapy and/or radiation) at the completion of treatment. Any information concerning the likely course of recovery from these toxicities should also be covered.
- For selected cancers, genetic/hereditary risk factor(s) or predisposing conditions and genetic testing results if performed

## CoC Standard 3.3 Minimal Data Elements

### Follow-Up Care Plan, as recommended by ASCO:

- Oncology team member contacts with location of the treatment facility [repeat if separate document]
- Need for ongoing adjuvant therapy for cancer: adjuvant therapy name, planned duration, expected side effects
- Schedule of follow-up related clinical visits\*
- Cancer surveillance tests for recurrence\*
- Cancer screening for early detection of new primaries – to be included only if different from the general population\*
- Other periodic testing and examinations (rather than outlining specific testing, the group suggested an inclusion of a general statement to "continue all standard non-cancer related health care with your primary care provider, with the following exceptions: [if there are any].")
- Possible symptoms of cancer recurrence (rather than including a list of possible symptoms, the group suggested inclusion of a general statement, "Any new, unusual and/or persistent symptoms should be brought to the attention of your provider.")

\*To be presented in table format who is responsible for ordering/carrying out the test, the frequency of testing, and where this will take place

## CoC Standard 3.3 Minimal Data Elements (con't)

### **Follow-Up Care Plan, as recommended by ASCO:**

- A list of likely or rare but clinically significant late and/or long-term effects that a survivor may experience based on his or her individual diagnosis and treatment if known (including symptoms that may indicate the presence of such conditions)
- A list of items (e.g. emotional or mental health, parenting, work/employment, financial issues, and insurance) with standard language stating that survivors have experienced issues in these areas and that the patient should speak with his or her oncologist and/or PCP if having related concerns. Here ASCO recommends including a list of local and national resources to assist the patient in obtaining proper services.
- A general statement emphasizing the importance of healthy diet, exercise, smoking cessation and alcohol use reduction tailored to the individual if pertinent.

## CoC Standard 3.3 Process Requirements

- A cancer survivorship care plan is prepared by the principal provider(s) who coordinated each patient's oncology care (with input from the relevant other health care providers).
- The cancer survivorship care plan is given to the patient upon completion of active curative-intent treatment.
- A survivorship care plan must contain a record of cancer care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care.
- Survivorship care plans can be in paper or electronic formats.

## CoC Standard 3.3

# 2013 Readiness Survey of CoC Member Organizations

- Only 37% of responding cancer programs endorsed feeling "completely confident" that their program would be able to provide survivorship care plans to all post-treatment survivors by 2015.
- Only 40% of respondents were addressing the entire Standard.
- The 60% of respondents *not* addressing the entire Standard indicated that help was needed in these areas:
  - Information about how to evaluate survivorship care plans processes
  - Tools that could be used for comprehensive care plan and follow-up plans
  - Information about what is required to successfully implement the Standard
  - Recommendations for implementing the Standard
- Only 21% indicated that a survivorship care plan process had been developed.
- Of responding cancer programs, 63% believed that Standard 3.3 is the most difficult to implement, compared to Standard 3.1 (navigation) and 3.2 (distress screening).

## CoC Standard 3.3, 2014 Clarification

- **The American Society of Clinical Oncology (ASCO) gathered input from multiple stakeholders, including patients, to produce a set of fields that they concluded should serve as minimal data elements to be included in treatment summaries and survivorship care plans.**
- **The CoC Accreditation Committee determined that the ASCO data set would constitute the minimal elements to be included in treatment summaries and survivorship care plans as required by Standard 3.3. However, cancer care programs may choose to add extra data elements to their survivorship care plans.**
- **Treatment summaries and survivorship care plans must be provided to survivors who have completed active therapy with curative intent (other than long-term hormonal therapy). This includes patients with cancer from all disease sites. Patients with metastatic disease, although often considered “survivors,” are not targeted for delivery of treatment summaries and follow-up plans under Standard 3.3.**

## CoC Standard 3.3 Timeline

### The Accreditation Committee time frame and scope of implementation for Survivorship Care Plans(SCP):

- Jan 1, 2015 – Dec 31, 2015
Implement process to provide SCPs to  $\geq 10\%$  of eligible patients who have completed treatment
  
- End of 2016
Provide SCPs to  $\geq 25\%$  of eligible patients who have completed treatment
  
- End of 2017
Provide SCPs to  $\geq 50\%$  of eligible patients who have completed treatment
  
- End of 2018
Provide SCPs to  $\geq 75\%$  of eligible patients who have completed treatment

For updated standards:

<https://www.facs.org/quality%20programs/cancer/coc/standards>

## Summary of Points Covered

**In this training module we addressed:**

- **The minimal data elements required by Standard 3.3 to be included in cancer survivorship care plans**
- **The process requirements of a survivorship care plan**
- **Timeline by which CoC-accredited institutions need to provide survivorship care plans**



## Next Steps

For more detailed training on this topic, you can go to the following resources:

### National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)  
http://www.nccn.org/professionals/physician\_gls/pdf/survivorship.pdf

### American College of Surgeons

- [Cancer Program Standards \(2016 Edition\)](https://www.facs.org/quality-programs/cancer/coc/standards/)  
https://www.facs.org/quality-programs/cancer/coc/standards/
- [Cancer Program Standards 2012: Ensuring Patient-Centered Care](https://www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012.ashx)  
https://www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012.ashx
- [Accreditation Committee Clarifications for Standard 3.3 Survivorship Care Plan](https://www.facs.org/publications/newsletters/coc-source/special-source/standard33)  
https://www.facs.org/publications/newsletters/coc-source/special-source/standard33
- [Chapter 3: Continuum of Care Services](https://www.facs.org/quality-programs/cancer/coc/standards/video/chapter3)  
https://www.facs.org/quality-programs/cancer/coc/standards/video/chapter3

### American Society of Clinical Oncology

- [Cancer Survivorship](http://www.asco.org/practice-research/cancer-survivorship)  
http://www.asco.org/practice-research/cancer-survivorship

### GW School of Medicine & Health Sciences

- [Survivorship & Navigation Resources](https://smhs.gwu.edu/gwci/survivorship/casnp/initiatives)  
https://smhs.gwu.edu/gwci/survivorship/casnp/initiatives

### Nation Cancer Institute at the Nation Institutes of Health (NIH)

- [Facing Forward: Life After Cancer Treatment](http://www.cancer.gov/cancertopics/life-after-treatment)  
http://www.cancer.gov/cancertopics/life-after-treatment

## **Faculty Bio for Sofia F. Garcia, PhD**

**Sofia Garcia, Ph.D. is an Assistant Professor in the Departments of Medical Social Sciences, and Psychiatry and Behavioral Sciences, at Northwestern University, and a licensed clinical psychologist. She is Translational Research Director of the Cancer Survivorship Institute of the Robert H. Lurie Comprehensive Cancer Center (RHLCCC).**

**Dr. Garcia has over ten years of research experience in patient-reported outcome measure development and applications in oncology. Her research has focused on developing and validating patient reported outcome measures and evaluating patient-centered care initiatives, including those that incorporate health information technology and are tailored to vulnerable populations. She has served as principal investigator of six, and scientific project director of four, cancer control and survivorship studies. Dr. Garcia, has been scientific project director, mentored investigator and site principal investigator on three Patient Reported Outcomes Measurement Information System (PROMIS) supplement awards. She has also served as a co-investigator on numerous federally-funded studies. In her clinical role, Dr. Garcia provides psychological treatment and evaluation through the Supportive Oncology Program of the RHLCCC.**

**For additional information:**

**<http://www.mss.northwestern.edu/faculty/profile.html?xid=16269>**

## **Faculty Bio for Sara M. Goetzman, BA**

**Sara M. Goetzman is the Program Manager of the Biopsychosocial Mechanisms and Health Outcomes (BMHO) Research Program directed by Dr. Frank J. Penedo within the Department of Medical Social Sciences of Northwestern University, Feinberg School of Medicine.**

**As manager of the BMHO Research Program, Ms. Goetzman oversees all research activity for Dr. Penedo's NIH-funded studies, which are focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life and health outcomes in chronic disease populations with a major emphasis on ethnically diverse cancer survivors. She has also served as The Coleman Foundation Supportive Oncology Initiative (CSOI), Distress and Survivorship Project Coordinator since the inception of the initiative in December 2014.**

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