


Collecting Cancer Data: Survivorship Care Plans
 2014-2015 NAACCR Webinar Series
 July 9, 2015




Q&A

- Please submit all questions concerning webinar content through the Q&A panel.

Reminder:

- If you have participants watching this webinar at your site, please collect their names and emails.
- We will be distributing a Q&A document in about one week. This document will fully answer questions asked during the webinar and will contain any corrections that we may discover after the webinar.



FABULOUS PRIZES









SPEAKERS

- A. Blythe Ryerson, PhD, MPH
 - Lead Epidemiologist at the Cancer Surveillance Branch, Division of Cancer Prevention & Control, Centers for Disease Control and Prevention
- Lisa Landvogt, BA, CTR
 - Accreditation Services Director Registry Partners Inc
- Cathy Bledsoe, MPH & Randi Rycroft, MSPH
 - Colorado Cancer Registry



**NAACCR Cancer Registry and Surveillance
Webinar Series**

Survivorship Care Plans

July 9, 2015

Introduction

Linking Cancer Registries and the Needs of Survivors and Clinicians

A. Blythe Ryerson, PhD, MPH
 Lead Epidemiologist
 Cancer Surveillance Branch, Division of Cancer Prevention & Control, Centers for Disease Control and Prevention


Presentation Outline

- **Survivorship IS public health**
- **National Program of Cancer Registries (NPCR)**
- **NPCR in survivorship practice & research**
 - Study recruitment
 - Patient-centered outcomes research
 - Treatment summaries and care plans
- **A vision for cancer registries: impacting quality care**
 - Quality assessment and improvement
 - Patient-reported outcomes

SURVIVORSHIP IS PUBLIC HEALTH

Cancer Survivorship

- **Cancer survivors in U.S. now exceed 13.4 million**
- **More people are living with cancer due to:**
 - An aging population
 - Earlier diagnosis
 - Better treatment



<http://www.cdc.gov/cancer/survivorship>

Issues Faced by Cancer Survivors

Medical	Recurrence, late effects
Physical	Pain, fatigue, infertility
Psychological	Anxiety, depression, resilience, awareness
Cognitive	Memory, learning, attention
Social	Relationships, communication, care giving
Practical	Access to care, understanding follow-up
Economic	Financial burden, lost income, insurance

Public Health Prevention

THE NATURAL HISTORY OF ANY DISEASE OF MAN				
Interrelations of Agent, Host, and Environmental Factors Production of STIMULUS		Early pathogenesis	Reaction of the HOST to the STIMULUS Discernible Early Lesions Advanced Disease Convalescence	
Prepathogenesis period		Period of Pathogenesis		
HEALTH PROMOTION	SPECIFIC PROTECTION	EARLY DIAGNOSIS and PROMPT TREATMENT	DISABILITY LIMITATION	REHABILITATION
Health education Good standard of nutrition adjusted to developmental phases of life Attention to personality development Provision of adequate housing, recreation and agreeable working conditions Marriage counseling and sex education Genetics Periodic selective examinations	Use of specific immunizations Attention to personal hygiene Use of environmental sanitation Protection against occupational hazards Protection from accidents Use of specific nutrients Protection from accidents Use of specific nutrients Protection from carcinogens Avoidance of allergens	Case finding measures, individual and mass Screening surveys Selective examinations <u>Objectives:</u> To cure and prevent disease processes To prevent the spread of communicable diseases To prevent complications and sequelae To shorten period of disability	Adequate treatment to arrest the disease process and to prevent further complications and sequelae Provision of facilities to limit disability and to prevent death	Provision of hospital and community facilities for retraining and education for maximum use of remaining capacities Education of the public and industry to utilize the rehabilitated As full employment as possible Selective placement Work therapy in hospitals Use of sheltered colony
Primary Prevention		Secondary Prevention		Tertiary Prevention

Baumann LC, Karel A. Prevention: Primary, Secondary, Tertiary. Encyclopedia of Behavioral Medicine. Springer Science+Business Media, New York 2013

Public Health Prevention

THE NATURAL HISTORY OF ANY DISEASE OF MAN				
Interrelations of Agent, Host, and Environmental Factors Production of STIMULUS		Early pathogenesis	Reaction of the HOST to the STIMULUS Discernible Early Lesions Advanced Disease Convalescence	
Prepathogenesis period		Period of Pathogenesis		
HEALTH PROMOTION	SPECIFIC PROTECTION	EARLY DIAGNOSIS and PROMPT TREATMENT	DISABILITY LIMITATION	REHABILITATION
Health education Good standard of nutrition adjusted to developmental phases of life Attention to personality development Provision of adequate housing, recreation and agreeable working conditions Marriage counseling and sex education Genetics Periodic selective examinations	Use of specific immunizations Attention to personal hygiene Use of environmental sanitation Protection against occupational hazards Protection from accidents Use of specific nutrients Protection from accidents Use of specific nutrients Protection from carcinogens Avoidance of allergens	Case finding measures, individual and mass Screening surveys Selective examinations <u>Objectives:</u> To cure and prevent disease processes To prevent the spread of communicable diseases To prevent complications and sequelae To shorten period of disability	Adequate treatment to arrest the disease process and to prevent further complications and sequelae Provision of facilities to limit disability and to prevent death	Provision of hospital and community facilities for retraining and education for maximum use of remaining capacities Education of the public and industry to utilize the rehabilitated As full employment as possible Selective placement Work therapy in hospitals Use of sheltered colony
Primary Prevention		Secondary Prevention		Tertiary Prevention

Baumann LC, Karel A. Prevention: Primary, Secondary, Tertiary. Encyclopedia of Behavioral Medicine. Springer Science+Business Media, New York 2013

Cancer Survivorship

Public Health and Cancer Survivorship

- **A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies**
 - LIVESTRONG & CDC: April, 2004
<http://www.cdc.gov/cancer/survivorship/pdf/nap.pdf>
- **From Cancer Patient to Cancer Survivor: Lost in Transition**
 - IOM: November, 2005
<http://www.iom.edu/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx>
- **Cancer Care for the Whole Patient**
 - IOM: October, 2007
<http://www.iom.edu/Reports/2007/Cancer-Care-for-the-Whole-Patient-Meeting-Psychosocial-Health-Needs.aspx>
- **Living Well with Chronic Illness**
 - IOM: January, 2012
<http://www.iom.edu/Reports/2012/Living-Well-with-Chronic-Illness.aspx>



CDC and Cancer Survivorship



- Identify the needs of survivors
- Raise awareness of issues around survivorship
- Support research and programmatic efforts to meet the needs of survivors

NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR)

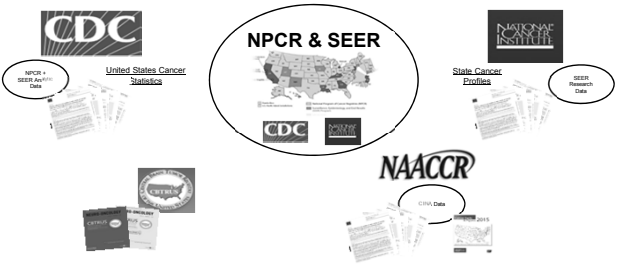
National Program of Cancer Registries

- CDC funds NPCR registries covering 96% of the U.S. population
- Established in 1992 through the Cancer Registries Amendment Act
- Develops and supports Registry Plus™



- Works collaboratively with many federal and non-federal partners: National Cancer Institute (SEER), NAACCR, ACS, etc.

Data Dissemination



NPCR IN SURVIVORSHIP PRACTICE & RESEARCH

Study Recruitment

- **Registries provide population-based lists of ALL patients diagnosed with cancer, regardless of**
 - Socio-economic states
 - Locality
 - Quality of clinical care
- **Can be used to evaluate effectiveness of interventions**
 - Treatments
 - Behavior change

Study Recruitment
Early Case Capture Project

- **Complexity of cancer reporting creates delays in collection, consolidation, dissemination, and use**
- **NPCR Early Case Capture for pediatric cases project**
 - Carolyn Pryce Walker Act (2008)
 - Seven NPCR programs collecting pediatric cases within 30 days of diagnosis
 - Faster data=high potential for clinical trial enrollment

Study Recruitment
Behavioral Interventions

- **Study recruitment through registries is a common practice for some registries, but not all**
- **CDC initiatives to understand barriers, and facilitators, including those at the federal level**
 - Improving cancer screening among breast and CRC survivors and their relatives
 - Promote proactive tobacco cessation among cancer survivors

Patient-Centered Outcomes Research

- **Comparing relative health outcomes, clinical effectiveness, and appropriateness of different medical treatment**
- **Cancer Registries = Population-based = "Real world"**
- **CDC initiatives to using NPCR data for this type of research:**
 - 2010: Establishment of NPCR Specialized Registries and baseline data collection on a 2011 PCOR cohort
 - 2013: measurement of intermediate outcomes for PCOR cohort

Patient-Centered Outcomes Research
NPCR Specialized Registries

- **NPCR received funds from the American Recovery and Reinvestment Act of 2009**
- **Collection of enhanced data for people diagnosed in 2011 with cancers of the**
 - Breast,
 - Colon,
 - Rectum,
 - Chronic myeloid leukemia
- **Enables examination of critical issues in cancer care**

Patient-Centered Outcomes Research
Collection of Intermediate Outcomes

- **In 2013, CDC received additional support through the Patient Centered Outcomes Research Trust Fund**
- **5 of the 10 NPCR Specialized Registries collecting intermediate outcomes on the 2011 cohort:**
 - Progression
 - Recurrence
 - Subsequent therapy
 - Vital Status

Treatment Summaries and Care Plans

- In 2010, CDC funded the Colorado Central Cancer Registry to develop a secure, web-based application for pre-populating and semi-automating care plans using registry data
- CDC continues working with Colorado to integrate the tool into Web Plus

A VISION FOR CANCER REGISTRIES: IMPACTING QUALITY CARE

Challenged, Yet Uniquely Capable

- **Barriers to overcome:**
 - Maintaining patient protects and confidentiality
 - Existing legal and regulatory requirements
 - Type of data routinely recorded in the health record
 - Resources
- **By overcoming these barriers (or despite them), cancer registries have tremendous potential to impact survivorship care and research**
 - Applying registry data for quality assessment and improvement
 - Linking registry data with patient-reported outcomes

Quality Assessment and Improvement

- Practice-specific measures, evaluation, and feedback
- Learning Healthcare System(s)
- Guide quality improvement initiatives

Patient-Reported Outcomes (PROs)

- Clinical data linked with the patient perspective are more powerful
- PROs are reports directly from the patient
 - Symptoms
 - Functioning
 - Treatment satisfaction
 - Health-related quality of life
 - Many others
- More fluid data exchange between cancer registries and patients, clinicians, and healthcare facilities would allow for better health communication and outcomes

Conclusion

- Cancer surveillance data remain the core of cancer epidemiology and outcomes in clinical cancer research
- Registries are the most sophisticated and standardized surveillance system in the U.S.
- Registries are uniquely poised to serve as a source of critical data for cancer survivors, clinicians, and researchers
- NPCR will continue to expand the usefulness of registry data to cancer survivors, providers, and researchers

Contact Information

Blythe Ryerson, MPH, PhD
 ARyerson@cdc.gov
 770-488-2426

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
 Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
 Visit: www.cdc.gov | Contact CDC at: 1-800-CDC-INFO or www.cdc.gov/info

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

National Center for Chronic Disease Prevention and Health Promotion
 Division of Cancer Prevention and Control





REGISTRY PARTNERS INCORPORATED
A National Provider of Oncology Quality & Research Services

Survivorship Care Plan:
 Standard 3.3


LISA LANDVOGT, BA, CTR
 ACCREDITATION SERVICES DIRECTOR, REGISTRY PARTNERS INCORPORATED

Survivorship Care Plan


- ▶ Let's start with the obvious...WHO is a cancer survivor?
 - ▶ From the Institute of Medicine (IOM) Report
 - ▶ "an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life, according to the National Coalition for Cancer Survivorship and the NCI Office of Cancer Survivorship."

Survivorship Care Plan





Commission on Cancer





Survivorship Care Plan

- ▶ The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes


Survivorship Care Plan

- ▶ Let's break this paragraph down:
 - ▶ Cancer committee develops a process to disseminate the following
 - ▶ Comprehensive care summary
 - ▶ Follow-up plan to patients with cancer who are completing cancer treatment



Survivorship Care Plan

- ▶ Let's break this paragraph down (continued):
 - ▶ The process is monitored annually and documented in the minutes
 - ▶ The process is evaluated annually and documented in the minutes
 - ▶ The process is presented annually and documented in the minutes




Survivorship Care Plan

- ▶ Missing a step in the written requirement can create an unnecessary deficiency even if the process is in place and functioning
- ▶ "if it's not in the minutes...it never happened"



Survivorship Care Plan

- ▶ Is **NOT** the responsibility of the Cancer Registrar
 - ▶ Repeat after me...Survivorship Care Plans are **NOT** the responsibility of the Cancer Registrar
 - ▶ The Cancer Registrar **DOES NOT** create a process for Survivorship Care Plans
 - ▶ The Cancer Registrar **DOES NOT** monitor or evaluate the process of Survivorship Care Plans




Survivorship Care Plan

- ▶ If not YOU, then WHO?
 - ▶ Medical Oncologist
 - ▶ Radiation Oncologist
 - ▶ Oncology Nurse
 - ▶ Nurse Practitioner
 - ▶ Oncology Social Worker
 - ▶ All of the above


Survivorship Care Plan

- ▶ The "Journey Forward" for Survivorship Care Plans
 - ▶ 1940's - 1950's
 - ▶ CancerCare established in 1944 (national nonprofit organization providing free professional support services to anyone affected by cancer)
 - ▶ American Cancer Society (ACS) established in 1946, the oldest voluntary health agency dedicated to conquering cancer through research, education, advocacy, and service




Survivorship Care Plan

- ▶ The "Journey Forward" for Survivorship Care Plan
 - ▶ 1980's - 1990's
 - ▶ The Wellness Community established in 1982
 - ▶ National Coalition for Cancer Survivorship established 1986
 - ▶ ACS, first Survivor Bill of Rights, 1988
 - ▶ National Breast Cancer Coalition established in 1990
 - ▶ Cancer Leadership Council established in 1993
 - ▶ Office of Cancer Survivorship established in 1996
 - ▶ Lance Armstrong Foundation (LAF) established 1997
 - ▶ National Cancer Policy Board begins operation under the Institute of Medicine (IOM), 1997





Survivorship Care Plan

- ▶ The "Journey Forward" for Survivorship Care Plan
 - ▶ 2000 – Present
 - ▶ LAF Livestrong Survivorship Centers of Excellence Network, 2000
 - ▶ President's Council Panel annual report Living Beyond Cancer: Finding a New Balance, 2003/2004
 - ▶ ASCO Survivorship Task Force Formed, 2004
 - ▶ NCI, Cancer Survivorship: Improving Treatment Outcomes and Quality of Life, 2004
 - ▶ IOM report to improve survivorship care, From Cancer Patient to Cancer Survivor: Lost in Transition, 2006
 - ▶ Commission on Cancer, Patient Care Standards, 3.3 Requirement of Survivorship Care Plans for accredited cancer programs, 2012





Survivorship Care Plan

- ▶ What was in the Institute of Medicine (IOM) Report?
 - ▶ Establish survivorship as a distinct phase of care
 - ▶ Implement survivorship care plans
 - ▶ Build bridges between oncology and primary care
 - ▶ Develop and test models of care
 - ▶ Develop and evaluate clinical practice guidelines
 - ▶ Institute quality of survivorship measures
 - ▶ Strengthen professional education
 - ▶ Expand use of psychosocial and community support services
 - ▶ Invest in survivorship research

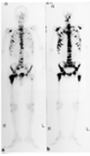

Survivorship Care Plan

- ▶ Who is Standard 3.3 intended to include?
 - ▶ Focused on a subset of survivors who are treated with curative intent
 - ▶ Have completed active therapy (other than long term hormonal therapy)
 - ▶ Includes patients from all disease sites



Survivorship Care Plan

- ▶ Exceptions to Standard 3.3
 - ▶ Patients with metastatic disease, though survivors by some definitions, are not targeted for delivery of comprehensive care summaries and follow-up plans


Survivorship Care Plan

- ▶ Core Data Elements, as recommended by American Society of Clinical Oncology (ASCO)
 - ▶ Treatment Summary
 - ▶ Follow-up Care Plan


Survivorship Care Plan

- ▶ Treatment Summary
 - ▶ Contact information of treating institutions and providers
 - ▶ Specific diagnosis: cancer type, cell type, stage, date and patient age at diagnosis
 - ▶ Treatment details
 - ▶ Surgical procedure(s): body location and date(s)
 - ▶ Chemotherapy: agent(s) administered and date ended
 - ▶ Radiation: specific type, anatomical area treated, dosage and dates




Survivorship Care Plan

- ▶ Treatment Summary
 - ▶ Complications/Side effects
 - ▶ Ongoing toxicity
 - ▶ On/Off treatment
 - ▶ Long term complications
 - ▶ Genetics for select cancers
 - ▶ On/Off treatment
 - ▶ Long term complications



Survivorship Care Plans


- ▶ Follow-Up Care Plan
 - ▶ Need for ongoing adjuvant therapy for cancer
 - ▶ Schedule of follow up related clinical visits
 - ▶ Cancer surveillance tests for recurrence
 - ▶ Cancer screening for early detection of new primaries
 - ▶ Other periodic testing and examinations
 - ▶ Symptoms of recurrence
 - ▶ List of long term effects
 - ▶ List of emotional or mental health, financial, employment, family issues
 - ▶ Importance of healthy lifestyle



Survivorship Care Plan


- ▶ Five Step Plan Development

Objective	Indicator
1 Develop and utilize a common definition of survivorship, patient navigation, community health worker roles, palliative care	Number of partners adopting the definitions
2 Complete a community needs assessment or re-assessment for survivorship services	Completed assessment or re-assessment
3 Educate community health workers on the most important cancer information	Number of community health workers trained
4 Develop a strong survivorship resources network	Develop and promote online clearing houses of survivorship information and resources and address gaps in services
5 Develop and increase use of treatment summaries and care plans	Measure counts/percent of medical providers, increased use of follow up care, patient self-reporting, decrease the recidivism rates



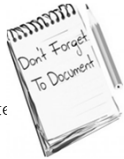

Survivorship Care Plan

- ▶ CoC Specific Requirements
 - ▶ A survivorship care plan is prepared by the principle providers who coordinate oncology treatment for the patient with input from the patient's other care providers
 - ▶ The survivorship care plan is given to the patient at the completion of treatment
 - ▶ The written or electronic survivorship care plan contains:
 - ▶ A record of care received
 - ▶ Important disease characteristics
 - ▶ Follow-up care plan incorporating available and recognized evidenced based standards of care, when available




Survivorship Care Plan

- ▶ CoC Specific Documentation
 - ▶ Complete the Survey Application Record (SAR)
 - ▶ During the on-site visit the surveyor will discuss with the cancer committee the methods implemented to create and disseminate a survivorship care plan



Survivorship Care Plan

- ▶ CoC Established Compliance Time Frame
 - ▶ By 1/1/15 – Pilot survivorship care plan process implemented involving **10%** of eligible patients
 - ▶ By 1/1/16 - Provide survivorship care plans to **25%** of eligible patients
 - ▶ By 1/1/17 – Provide survivorship care plans to **50%** of eligible patients
 - ▶ By 1/1/18 – Provide survivorship care plans to **75%** of eligible patients
 - ▶ By 1/1/19 – Provide survivorship care plans to **ALL** eligible patients





Survivorship Care Plan

- ▶ CoC Standard Rating Options
 - ▶ (1) Compliance
 - ▶ Cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment
 - ▶ Each year, the process is implemented, monitored, evaluated and presented to the cancer committee
 - ▶ (5) Noncompliance
 - ▶ The cancer committee does not fulfill one or both of the above mentioned compliance requirements

Survivorship Care Plan

- ▶ Survey Application Record (SAR)
- ▶ Program Activity Record (PAR)
 - ▶ Keep updated on at least an annual basis


Survivorship Care Plan

Questions?
 Lisa Landvogt, BA, CTR
 Accreditation Services Director
lilandvogt@registrypartners.com
 336-639-1703




Survivorship Care Plan


Quiz



Survivorship Care Planning

Using Technology to Help Provide Patient-Centered Care

Cathy Bledsoe, MPH & Randi Rycroft, MSPH



Agenda

- Background on Survivorship Care Plans (SCPs)
- SCP options available
- SCP Technology-enhanced solutions
- Example: WebPlus Survivorship Program
- Q&A/ Quiz

Learning Objectives

- Learn about the role that a treatment summary and survivorship care plan plays in cancer survivorship.
- Learn about the different options for TS/SCP templates.
- Learn about one strategy for meeting Standard 3.3 of the 2012 American College of Surgeons Program Standards which involves collaboration between cancer registries and oncology providers.

Background

Treatment Summary= A concise summary of diagnosis, treatment and related health factors.

Survivorship Care Plan= A guide for patients and PCPs to follow which summaries future care needs (follow-up, contact information, health and lifestyle recommendations, etc.)

Background

- Treatment Summaries and Survivorship Care Plans (TS/SCPs) are meant to help patients bridge the gap between oncology and primary care
- They are also meant to help empower patients to understand their diagnosis and future care needs and to help them locate resources.

Background

- This is not a new idea!
 - 1996- National Coalition for Cancer Survivors
 - 2004- President’s Cancer Panel, Action Plan on Survivorship (CDC and LAF)
 - 2005- Institute of Medicine report: *Lost in Transition*
- Despite the calls from nationally recognized organizations, implementation was slow.
- 2012 Commission on Cancer Program Standards

Templates: Things to Consider

- A good template should...
 - Be fast and easy to fill out
 - Provide the right amount of information to patients and their primary care providers
- Multiple Options available
- “Homegrown” templates/ mixtures of multiple resources

Templates: Things to Consider

- Registry data
- EHR data
- Patient reported outcomes
- Site-specific templates

Review of Templates

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Notes on technology integration:			

American Society of Clinical Oncology (ASCO)

Diffuse Large B-Cell Lymphoma Chemotherapy Treatment Plan and Summary

1

[Insert Practice Name/Info Here]

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

Practice site: _____ Patient name: _____ Patient DOB: (/ /)
 Patient phone: _____ Patient cell: _____ Patient email: _____
 Hem-onc provider name: _____ Hem-onc phone: _____
 Support contact name: _____ Support contact phone: _____

BACKGROUND INFORMATION

Age at diagnosis: (/ /) Diagnosis date: (/ /) Solid organ transplant: Yes No
 Symptoms/signs: Fever Night Sweats Weight Loss Other _____
 Family history/predisposing conditions: _____
 Major co-morbid conditions: _____

Biopsy site: _____ Histology: _____ Excisional/Incisional Core needle

Is this a new cancer diagnosis or recurrence? New Recurrence (date: / /)

HIV status: Positive Negative Unknown Hepatitis B status: Positive Negative Unknown

Immunodeficiency state: _____ Comments: _____

Study	Date	Findings/Details
Bone Marrow Biopsy		<input type="checkbox"/> Lymphoma <input type="checkbox"/> No lymphoma <input type="checkbox"/> Indeterminate
CT C/A/P		<input type="checkbox"/> Lymphoma <input type="checkbox"/> No lymphoma <input type="checkbox"/> Indeterminate
Lumbar Puncture		

American Society of Clinical Oncology (ASCO)

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Yes	In progress	Free	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
No	Maybe	Save files to local drive	No
Notes on technology integration:			
Working on HL7 integration, with a goal of pre-populating from EMRs			

Livestrong/ Oncolink

Page 5 of 7

Radiation Therapy

Hodgkin's Disease

Did you receive radiation therapy?

No
 Yes

If you received radiation, what type of radiation did you receive?

X-ray based Radiation
 Brachytherapy
 Stereotactic radiosurgery (Cyber knife or Gamma knife)
 Proton-based Radiation
 Cobalt-based radiation

LIVESTRONG CARE PLAN
From Medicine's StrongDial

Breast Cancer

Your Options

There are several treatment options for breast cancer. The best treatment option for you depends on the type and stage of your cancer, your overall health, and your preferences. Your doctor will help you understand your options and make a decision that is right for you.

What are your options?

Systemic Therapy:

- Chemotherapy
- Targeted Therapy
- Hormone Therapy
- Immunotherapy

Local Therapy:

- Surgery
- Radiation Therapy

Combining Your Care

Many breast cancer treatments are used in combination. For example, you may have surgery followed by chemotherapy and radiation therapy. Your doctor will help you understand the benefits and risks of each treatment option and how they can be combined to provide the best care for you.

Livestrong/ Oncolink

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
SCP only	Unknown	Free	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Maybe	Maybe	Web-based, no PHI, no saving	Yes
Notes on technology integration:			
Unknown			

Journey Forward

Cancer Survivorship Care Plan Builder

Lymphoma (Diffuse Large B-cell) Summary

Background Information

Diagnosis Date: 1/15/12
 Primary Site: Diffuse Large B-cell Lymphoma
 Stage at Diagnosis: IV
 Response to Chemotherapy: Partial Response
 Response to Radiation: None

Treatment Plan & Summary

Category	Plan Treatment	Post-Treatment
Chemotherapy	CHOP	CHOP
Radiation	None	None
Immunotherapy	None	None
Targeted Therapy	None	None
Hormone Therapy	None	None
Other	None	None

Journey Forward

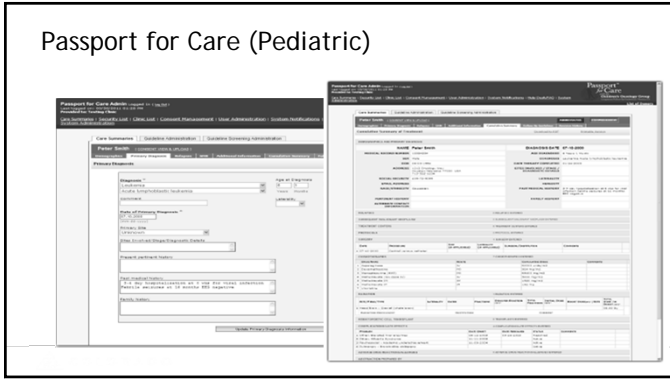
Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Yes	Yes	Free	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Yes	Yes	Local storage	No
Notes on technology integration:			
Working with several cancer registry software systems, EMRs, and mobile apps ("My Care Plan")			

On Q Health



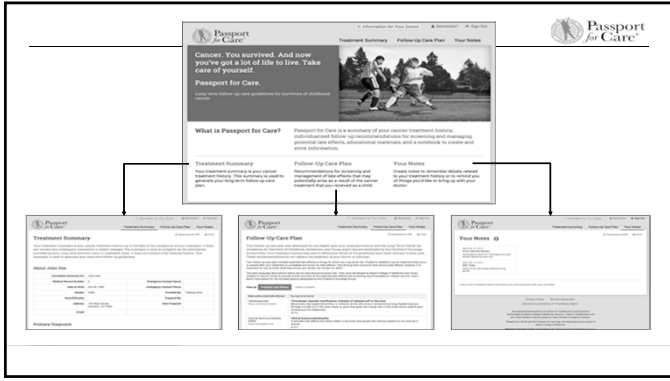
On Q Health

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Yes	EMR, registry	Yes, differs by size of system	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Yes	Yes	Secure cloud server	Planned for future
Notes on technology integration:			
Working with METRIQ, piloting with Epic and CERNER, among others			



Passport for Care (Pediatric)

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Yes	No	Free for COG members & clinics	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Yes	Yes	PHI encrypted at clinic level	Some, more in progress
Notes on technology integration:			
Survivor portal launches April 15!			



**The Web Plus Survivorship Tool:
A case study of technology in action**

**Web Plus Survivorship Tool:
Background**

- Received funding in 2010 from CDC/ National Program of Cancer Registries for "innovative uses of cancer registry data"
- **Purpose:** Develop a way to pre-populate SCPs with data from the registry and demonstrate that it is feasible in oncology practices

Web Plus Survivorship Tool

Website demonstration


Web Plus Survivorship Tool

Common Criteria for Survivorship Care Plans			
Meets CoC standards?	Able to import data?	Cost?	User friendly?
Yes	Yes- Any Cancer Registry	Free for NPCR-funded states	Yes
Patient-friendly report?	Provider friendly report?	Security?	Available in Spanish?
Yes	Yes	Web based, secure server	Yes
Notes on technology integration:			
Uses standard cancer registry file for integration, will work with any registry software			

Web Plus Survivorship Tool: Background

- Ran a small pilot in the summer of 2012
- Interviewed patients and providers on their experience with the tool and templates
- Also conducted before/ after document reviews

Web Plus Survivorship Tool: Pilot Results



Nurses:

- Ease of Use- 8.8/10
- Usefulness- 8.0/10
- Acceptability- 9.9/10

Most changes suggested for templates, not web app

Provider Profile idea

Web Plus Survivorship Tool: Pilot Results

Patients:

- Information not new, but helpful
- Timing and a written record important
- 100% would recommend



“It made it all so clear. It made it understandable. It’s easy to believe after reading through it all that the cancer is controllable.”

Next Steps for this project

- Module is currently being incorporated into the CDC’s Web Plus software product.
- Colorado and Idaho will be completing final testing, creating training videos for providers, and developing an implementation guide for states.
- The product should be available to states later this year.

Next Steps for the Field of Survivorship Care Planning

- Most products are moving toward Cancer Registry or EHR integration
- Some are also moving toward patient engagement through PROs and patient portals
- Research needed more than ever!

Learning Objectives

- Learn about the role that a treatment summary and survivorship care plan plays in cancer survivorship.
- Learn about the different options for TS/SCP templates.
- Learn about one strategy for meeting Standard 3.3 of the 2012 American College of Surgeons Program Standards which involves collaboration between cancer registries and oncology providers.

References

National Research Council. (2005). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press.

- [Video](#)

American College of Surgeons Commission on Cancer. (2011). *Cancer Program Standards 2012: Ensuring Patient-Centered Care* (version 1.2.1). Chicago, IL.

American Society of Clinical Oncology. *ASCO Cancer Treatment Summaries and Survivorship Care Plans*. Retrieved from <http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-summaries-and-survivorship-care-plans>

Colorado Department of Public Health and Environment. *Colorado Survivorship Care Planning Program*. Retrieved from <https://www.colorado.gov/pacific/cdph/survivorship>

Journey Forward. Survivorship Care Plan Builder. Retrieved from <http://www.journeyforward.org/professionals/survivorship-care-plan-builder>

LIVESTRONG. *Livestrong Care Plan*. Retrieved from <http://www.livestrongcareplan.org/>

On Q Health. *On Q Health Care Planning System (CPS)*. Retrieved from <http://onqhealth.com/onqhealth-care-planning-system/>

Texas Children's Cancer and Hematology Centers. *Passport for Care Application*. Retrieved from

Questions?

Contact:

Cathy.Bledsoe@state.co.us
 (303) 691-4047
 Randi.Rycroft@state.co.us

Quiz

- 1) How many cancer survivors will there be in the U.S. by 2020?
- 2) When should a treatment summary/ survivorship care plan be given?
- 3) How much of the TS/SCP can be pre-populated with cancer registry data?
- 4) What can and cannot be the role of the cancer registrar?

COMING UP...

- Collecting Cancer Data: Central Nervous System
 - 8/6/15
- Coding Pitfalls
 - 9/3/15

AND THE WINNERS ARE.....











CE CERTIFICATE QUIZ/SURVEY

- Phrase
- Link
 - <http://www.surveygizmo.com/s3/2224318/Survivorship>

NAACCR
