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
Introduction

*Linking Cancer Registries and the Needs of Survivors and Clinicians*

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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 burdens, lost income, insurance

Public Health Prevention

THE NATURAL HISTORY OF ANY DISEASE OF MAN
Interrelations of Agent, Host, and Environmental Factors
Reactions of the Host to the Stimulus
Production of Stimulus

Early Pathogenesis
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
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 carcinogens
Avoidance of allergens

Case-finding measures, individual and mass
Screening surveys
Selective examinations

Objectives:
- 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

Public Health and Cancer Survivorship

- A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies
  - LIVESTRONG & CDC: April, 2004

- From Cancer Patient to Cancer Survivor: Lost in Transition
  - IOM: November, 2005

- Cancer Care for the Whole Patient
  - IOM: October, 2007

- 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 status
  - 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
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."
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.

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

- 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"

- 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

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

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 diagnostic 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

<table>
<thead>
<tr>
<th>Objective</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop and adopt a common definition of survivorship, patient navigation, community health worker roles, palliative care.</td>
<td>Number of partners adopting the definition of survivorship.</td>
</tr>
<tr>
<td>Complete or include needs assessment or re-assessment for survivorship.</td>
<td>Completed assessment or re-assessment.</td>
</tr>
<tr>
<td>Educate community health workers on the most important cancer information.</td>
<td>Number of community health workers trained.</td>
</tr>
<tr>
<td>Develop a strong survivorship resources network.</td>
<td>Development and promotion of online clearing houses of survivorship information.</td>
</tr>
<tr>
<td>Develop and increase use of treatment summaries and care plans.</td>
<td>Measure counts/percent of medical providers.</td>
</tr>
</tbody>
</table>

- Increase use of follow up care, patient self reporting, reduce 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.

- **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.

- **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

Questions?
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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

|--------------------------------------------|----------------------|---------------------|-------|----------------|

Notes on technology integration:

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American Society of Clinical Oncology (ASCO)

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

Common Criteria for Survivorship Care Plans

<table>
<thead>
<tr>
<th>Meets CoC standards?</th>
<th>SCP only</th>
<th>Patient-friendly report?</th>
<th>Notes on technology integration:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Maybe</td>
<td>Web-based, no PHI, no saving</td>
<td>Yes</td>
</tr>
<tr>
<td>SCP only</td>
<td>Unknown</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCP only</td>
<td>Unknown</td>
<td></td>
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Journey Forward
Journey Forward

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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>Yes</td>
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</tbody>
</table>

Notes on technology integration:
Working with several cancer registry software systems, EMRs, and mobile apps (*"My Care Plan"")

On Q Health

Common Criteria for Survivorship Care Plans

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<tbody>
<tr>
<td>Yes</td>
<td>EMR, registry</td>
<td>Yes, differs by size of system</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Secure cloud server</td>
<td>Planned for future</td>
</tr>
</tbody>
</table>

Notes on technology integration:
Working with METRIQ, piloting with Epic and CERNER, among others
Passport for Care (Pediatric)

Common Criteria for Survivorship Care Plans

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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>Free for COG members &amp; clinics</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>PHI encrypted at clinic level</td>
<td>Some, more in progress</td>
</tr>
</tbody>
</table>

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

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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Free for NPCR-funded states</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Web based, secure server</td>
<td>Yes</td>
</tr>
</tbody>
</table>

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

- Texas Children's Cancer and Hematology Centers. PASSPORT for Care Application. Retrieved from.

Questions?

Contact:

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(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