Survivorship Care after Childhood Cancer

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THE UNIVERSITY OF KANSAS
CANCER CENTER
Disclosure

I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity.

I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

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Care after Childhood Cancer

• Why do we need to talk about this?
• What are late effects and who is at risk for them?
• What resources are available to help when providing care for these patients?
Why Do We Need to Talk About This?

Prevalence....
Growing Numbers of Cancer Survivors


> 15 million cancer survivors in US today

The University of Kansas Cancer Center

NCI Designated Cancer Center

Bridging the Medical Gap in Long-Term Cancer Survivorship Care. ASCO JOP 2014;10:119-142
Growing Numbers of Childhood Cancer Survivors

National Cancer Institute - SEER Data
(Surveillance, Epidemiology, and End Results)

### Table 20.8

5-Year Relative Survival (Percent)

by Selected Primary Cancer Site and Year of Diagnosis

<table>
<thead>
<tr>
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<tbody>
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<td>All Races, Males and Females</td>
<td></td>
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<td></td>
<td></td>
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<td>68.1</td>
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<td>1998-99</td>
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<td>83.8</td>
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<td>2001-02</td>
<td>65.4</td>
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<td>81.9</td>
<td>83.8</td>
<td>85.5</td>
<td>86.2</td>
<td>86.1</td>
<td>86.4</td>
</tr>
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<td>2004-05</td>
<td>64.8</td>
<td>68.9</td>
<td>72.5</td>
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<td>85.5</td>
<td>86.2</td>
<td>86.1</td>
<td>86.4</td>
</tr>
</tbody>
</table>

**Note:**
- Neuroblastoma and Wilms' tumor are not mutually exclusive from the other tumors presented in table.
- Neuroblastoma is defined as histologies 9940-9099.
- Wilms' tumor is defined as histologies 9959-9969.
- The difference between 1975-77 and 2009-2015 is statistically significant (pc.05).
- The standard error is between 6 and 10 percentage points.
- The standard error is greater than 10 percentage points.
- Statistic could not be calculated due to fewer than 25 cases during the time period.

Source: SEER 9 areas (San Francisco, Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, and Atlanta).

Based on follow-up of patients into 2016. Expected survival rates are derived from the U.S. Annual Life Tables.

National Cancer Institute - SEER Data
(Surveillance, Epidemiology, and End Results)

1 in 530 young adults 20-39 years old is a childhood cancer survivor

CNS indicates central nervous system. Note: Lines represent joinpoint fitted trends. Benign and borderline brain tumors are not included. Malignant bone tumors include osteosarcoma and Ewing sarcoma. Average annual percent change for cancers with significant trends during 1975 through 2010: acute lymphocytic leukemia (0.7%), acute myeloid leukemia (1.1%), non-Hodgkin lymphoma (1.1%), testicular germ cell tumors (1.2%), and Hodgkin lymphoma (−0.7%). Source: Surveillance, Epidemiology, and End Results (SEER) program, 9 SEER Registries, National Cancer Institute.
Why Do We Need to Talk About This?

Provider Gaps....
ASCO Estimates National Oncologist Shortage

- ASCO analysis
  - number of practicing oncologists
  - number of training spots for new oncologists
  - oncology demand
- 2007, 2014
- Demand for oncologists predicted to grow 40%
- Supply of new oncologists predicted to grow 25%
- Shortage by 2025 (equivalent to 500,000 patient visits)
Survivorship Clinics for Childhood Cancer Survivors

Pediatric – Based CCS Programs
Adult - Based CCS Programs
TUKCC STC – Adult Based Program – Partnership with CMH

http://www.thenccs.org/long-term-clinics
National Children’s Cancer Society

Funding Source: MCA Partners Advisory Board, Tour de BBQ
Primary Care is Critical

- PCP’s play critical role in survivorship

- Oncology visits decline 5 years after treatment

- “Patients expected both their oncologists and primary care providers to be involved” in management of their survivorship care
Why Do We Need to Talk About This?

Knowledge Gap....
When presented with clinical vignette of female survivor of Hodgkin’s lymphoma...

- **34%** did not recommend appropriate surveillance for breast cancer
- **43%** did not recommend appropriate cardiac monitoring
- **24%** did not recommend yearly monitoring for thyroid function

Oncologists were...

- “...most comfortable” caring for survivors ≤ 21 years old
- “...less comfortable” with survivors between 21-30 years
- “...uncomfortable” with survivors ≥ 30 years
When presented with female survivor of Hodgkin’s Lymphoma and asked to select guideline recommended surveillance, providers collectively struggle...

- 34-91% incorrect breast
- 43-90% incorrect cardiac
- 24-25% incorrect thyroid

While these patients are being followed in these practices...providers describe discomfort with providing their care.

Common theme – prefer to work in collaboration with survivorship or late effects provider / clinic.
Survivorship Treatment Summary and Survivorship Care Plans

All patients should receive an individualized Treatment Summary

- Institute of Medicine
- American Cancer Society
- American College of Surgeons Commission on Cancer
- American Society of Clinical Oncology

Commission on Cancer Mandate - Survivorship Care Plans

- 25% all survivors by January 2016
- 100% all survivors by 2019
CUMULATIVE SUMMARY OF TREATMENT FOR:
Summary, Example

Provided by: Children's Mercy Hospitals and Clinics
Date Printed: March 02, 2015

Demographics
Name: Summary, Example
Med. Rec. #: 0000000
Sex: Female
Phone
Email
Date of Birth: 01-01-1992

Primary Diagnosis
Diagnosis: Central Nervous System Tumor
Diagnosis Date: 07-24-2003
Age Diagnosed: 11 Years 6 Months

Familial History

Past Medical History
Father with history of high blood pressure
Mother with history of diabetes

Heredity
None

Subsequent Malignant Neoplasm - None Indicated

Treatment Center - 1 center entered
1 Children's Mercy Hospital

Protocols - 1 protocol entered
Protocol Number: 000000

Surgery - 1 surgery entered
07-24-2003 Neurosurgery Brain

Chemotherapy - 3 chemotherapy entered

<table>
<thead>
<tr>
<th>Drug</th>
<th>Route</th>
<th>Dose</th>
<th>Date of Treatment</th>
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<tr>
<td>Vincristine</td>
<td>IV</td>
<td>27 mg/m2</td>
<td>07-24-2003</td>
</tr>
<tr>
<td>Cytosarone</td>
<td>IV</td>
<td>12 000 mg/m2</td>
<td>07-24-2003</td>
</tr>
<tr>
<td>Carccept</td>
<td>IV</td>
<td>875 mg/m2</td>
<td>07-24-2003</td>
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</table>

Radiation - 1 radiation entered

<table>
<thead>
<tr>
<th>Site/Field Type</th>
<th>Lateral</th>
<th>Date Start</th>
<th>Date Stop</th>
<th>Total Dose (Gray)</th>
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</thead>
<tbody>
<tr>
<td>Head/Brain/Cranial</td>
<td></td>
<td>START: 07-24-2003</td>
<td>STOP: 07-24-2003</td>
<td>18.00 Gy</td>
</tr>
<tr>
<td>Spine/Spine (whole)</td>
<td></td>
<td></td>
<td></td>
<td>38.00 Gy</td>
</tr>
</tbody>
</table>

Hematopoietic Cell Transplant - none indicated

Other Therapeutic Modalities - none indicated

Complications and Effects - 11 complications/ effects entered

<table>
<thead>
<tr>
<th>Problem</th>
<th>Active/Inactive</th>
</tr>
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<tbody>
<tr>
<td>1. Other fine motor coordination deficits</td>
<td></td>
</tr>
<tr>
<td>2. Auditory Hearing Loss - Requires hearing aids</td>
<td></td>
</tr>
<tr>
<td>3. Cardiovascular Dysfunction</td>
<td></td>
</tr>
<tr>
<td>4. Dermatologic Aplasia</td>
<td></td>
</tr>
<tr>
<td>5. Dermatologic Dystrophy</td>
<td></td>
</tr>
<tr>
<td>6. Endocrine Central hypogonadism (LH &amp; FSH deficiency)</td>
<td>Active</td>
</tr>
<tr>
<td>7. Endocrine Growth hormone deficiency</td>
<td>Active</td>
</tr>
</tbody>
</table>

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Treatment Summaries and Care Plans ... How are we doing?

• <10% oncologists always / almost always provide Survivorship Care Plans
• <5% oncologists provide written Survivorship Care Plans and have full discussions with patients

PCPs who receive a treatment summary and Survivorship Care Plans were over 9 times more likely to discuss survivorship care with patients

Blanch-Hartigan et al. Journal Clinical Oncology. 2014. Provision and Discussion of Survivorship Care Plans Among Cancer Survivors
Barton, Perspectives: Research in Context; A Cancer Journal for Clinicians. 2014. Oncologists and Primary Care Physicians Infrequently Provide Survivorship Care Plans
What is survivorship care? What are late effects?

- Health conditions related to prior cancer and cancer treatment
- May be physical or psychosocial
- May develop months to years after treatment
- May resolve or become chronic problems

3 out of every 4 childhood cancer survivors will develop at least 1 survivorship-related health problem

NCI at the NIH. [http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient/page1](http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient/page1)
How do we know?

Long Term Follow-Up Study

- University of Minnesota -> St Jude Children’s
- Internationally recognized
- 1 of largest and longest running studies of late effect outcomes in the world
- CCS in US and Canada
- Diagnosed before age 21 between 1970-1999
- 31 participating research sites
- Patients sign a release of treatment information and then complete baseline and follow-up questionnaires

For more than 23 years, the Long-Term Follow-Up (LTFU) Study has collected data on siblings to find out about the long-term effects of treatment for a serious illness. Researchers have been able to make recommendations to help survivors live healthy lives.

A unique and important study

The purpose of the LTFU Study is to learn about the health and social effects of treatment for childhood cancer. The information we collect from dedicated study participants guides the treatment and follow-up of children who are diagnosed with a serious illness.

The study’s findings also help alert current survivors and their health care providers to potential issues for adults, and identify ways to protect and promote their health.

The importance of the study is recognized internationally. It is one of the largest and longest running research projects of its kind in the world.

The Long-Term Follow-Up Study has been funded by the National Cancer Institute since 1994. The study originated at the University of Minnesota and is now led by researchers at St. Jude Children’s Research Hospital along with 30 additional partner hospitals in the US and Canada.
How do we know?

The Childhood Cancer Survivor Study, or CCSS, is a component of the Ltfu Study, which began in 1994 and is a collaborative, multi-institutional study supported by the National Cancer Institute (U24 CA55727) of the National Institutes of Health, USA. CCSS is designed to assess long-term outcomes in children who survived five or more years after diagnosis of a childhood cancer, diagnosed during childhood or adolescence.

The CCSS, which includes all participants in the Long Term Follow-up Study of childhood cancer, is a retrospectively ascertained cohort of 35,923 children diagnosed between 1970 and 1999. It also includes over 5,000 siblings as a comparison group for the study.

The CCSS cohort has been assembled through the efforts of the National Cancer Institute, USA, and the Children's Oncology Group. Other core facilities include the Statistical Center at the University of Minnesota, USA; the Biostatistics Center at the Fred Hutchinson Cancer Research Center (Seattle, WA); the Biopathology Center at Children's Hospital National Medical Center and the Biostatistics Center at M.D. Anderson Cancer Center (Houston, TX).

Childhood Cancer Survivor Study (CCSS)
- Component of LTFU Study
- All patients from LTFU Study are included in CCSS
- Retrospectively ascertained cohort of CCS
- >35,000 CCS diagnosed 1970-1999
- Survived > 5 years after diagnosis
- Includes >5,000 siblings for comparison study group

St. Jude LIFE Study

Pediatric cancer treatments save lives, but can increase the risk of late effects. The St. Jude LIFE Cohort Study (SJLife) is an unprecedented research study that brings long-term cancer survivors back to St. Jude Children’s Research Hospital for periodic, comprehensive screenings throughout their adult lives.

To date, more than 4,300 participants and 580 controls have been recruited. We track a wide range of health outcomes, using measurement tools that assess cardiac, reproductive, neuromuscular, neurocognitive, and psychosocial function, among others.

The unique findings from St. Jude LIFE are helping our scientists, patients, and researchers with novel insights into the late effects of cancer therapy.

To date, the study has made significant advances in:

- Identifying new and unexpected late health effects
- Describing how cancer therapies impact organ function
- Developing innovative methods to monitor health risks

What causes late effects?

Location, Location, Location

Age
Gender
Genes

Type of cancer

Genetics

Treatment

Lifestyle
Health Behaviors

Surgery
Chemotherapy
Radiation

NCI at the NIH. http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient/page1
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
- Site
- Biology
- Response

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Treatment Events

Hudson et al, Cancer 2006
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
- Site
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- Response

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Cancer-Related Morbidity

Treatment Events

Hudson et al, Cancer 2006
Tumor type and site determines treatment

<table>
<thead>
<tr>
<th>Stage 1 Wilm’s tumor</th>
<th>Medulloblastoma</th>
</tr>
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<tbody>
<tr>
<td>• Nephrectomy</td>
<td>• Surgical resection</td>
</tr>
<tr>
<td>• Brief course of chemotherapy, usually with less toxic agents</td>
<td>• Cranial-spinal radiation</td>
</tr>
<tr>
<td></td>
<td>• Intense chemotherapy with more toxic agents</td>
</tr>
</tbody>
</table>
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
- Site
- Biology
- Response

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Events

Cancer-Related Morbidity

Hudson et al, Cancer 2006
Chemotherapy Agent Influences Risk

Glucocorticoids and Methotrexate: bone mineral density deficit

Anthracyclines (doxorubicin, daunorubicin): cardiomyopathy / subclinical LV dysfunction

Bleomycin and Busulfan: pulmonary fibrosis
Chemotherapy Dose Influences Risk

**Recommended Frequency of Echocardiogram**

<table>
<thead>
<tr>
<th>Anthracycline Dose*</th>
<th>Radiation Dose**</th>
<th>Recommended Frequency</th>
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<tbody>
<tr>
<td>None</td>
<td>&lt; 15 Gy or none</td>
<td>No screening</td>
</tr>
<tr>
<td>≥ 15 - &lt; 35 Gy</td>
<td>≥ 35 Gy</td>
<td>Every 5 years</td>
</tr>
<tr>
<td>≥ 35 Gy</td>
<td></td>
<td>Every 2 years</td>
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<tr>
<td>&lt; 250 mg/m²</td>
<td>&lt; 15 Gy or none</td>
<td>Every 5 years</td>
</tr>
<tr>
<td>≥ 15 Gy</td>
<td></td>
<td>Every 2 years</td>
</tr>
<tr>
<td>≥ 250 mg/m²</td>
<td>Any or none</td>
<td>Every 2 years</td>
</tr>
</tbody>
</table>

*Based on doxorubicin iso toxic equivalent dose. See dose conversion instructions in section 33.
**Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole, TBI]). See section 76.
Radiation Fields Influence Risk

Cranial radiation: neurocognitive, motor sensory deficits

Endocrine gland radiation: growth, metabolism, and reproduction
Radiation Dose Influences Risk
Threshold Dose & Hypothalamic-Pituitary Dysfunction

<table>
<thead>
<tr>
<th>HPA Disorder</th>
<th>Dose (Gy)</th>
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<tr>
<td>GH deficiency</td>
<td>&gt; 18</td>
</tr>
<tr>
<td>Precocious Puberty</td>
<td>&gt; 18</td>
</tr>
<tr>
<td>LH/FSH deficiency</td>
<td>&gt; 30</td>
</tr>
<tr>
<td>TSH deficiency</td>
<td>&gt; 30</td>
</tr>
<tr>
<td>ACTH deficiency</td>
<td>&gt; 30</td>
</tr>
<tr>
<td>Hyperprolactinemia</td>
<td>&gt; 50</td>
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Table 3. Risk Factors, Diagnostic Studies, and Treatment Options

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Highest Risk</th>
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<tbody>
<tr>
<td>GH deficiency</td>
<td>≥ 18 Gy CRT</td>
</tr>
<tr>
<td>Precocious puberty</td>
<td>18-24 Gy CRT</td>
</tr>
<tr>
<td>TSH deficiency</td>
<td>≥ 30 Gy CRT</td>
</tr>
<tr>
<td>ACTH deficiency</td>
<td>≥ 30 Gy CRT</td>
</tr>
<tr>
<td>Hyperprolactinemia</td>
<td>≥ 50 Gy CRT</td>
</tr>
</tbody>
</table>


45-60 Gy for therapy for Primary CNS Tumors
18 Gy for CNS therapy for ALL (acute lymphoblastic leukemia)
Combination therapy influences risk

**Chest radiation:**
Heart valve disorders
Coronary artery disease
Cardiomyopathy

**Anthracyclines:**
Cardiomyopathy
Subclinical LV systolic dysfunction
Combination therapy influences risk

Combined modality therapy including alkylating agents and gonadal radiation increases risk of gonadal dysfunction and infertility.
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
  - Site
- Biology
- Response

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Cancer-Related Morbidity

Treatment Events
Hudson et al, Cancer 2006
By age 45 years it is estimated that:

- 95.5% will have at least one chronic health condition
- 80.5% will have a serious chronic health condition

Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions
- Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
- Site
- Biology
- Response

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Events

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Cancer-Related Morbidity

Hudson et al, Cancer 2006
Health habits influence risk

Pulmonary toxicity:
- Bleomycin
- Busulfan
- Chest radiation

Smoking increases this risk of lung injury.
Health habits influence risk

Skin cancer risk
- Radiation therapy
- Sun exposure

Risk for developing skin cancer is 6.3 times higher in patients who received radiation therapy than the general population.
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions
- BRCA, ATM, p53 polymorphisms

Genetic
- Genetic factors

Tumor Factors
- Histology
- Site
- Biology
- Response

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Treatment Events
- Surgery
- Chemotherapy
- Radiation
- Transplant

Cancer-Related Morbidity

Hudson et al, Cancer 2006
Age at diagnosis influences risk

Younger patients are more vulnerable to neurocognitive dysfunction after cranial irradiation
Risk-based survivor care

Host Factors
- Age
- Gender
- Race

Premorbid conditions

Genetic
- BRCA, ATM, p53 polymorphisms

Tumor Factors
- Histology
- Site
- Biology
- Response

Treatment Factors
- Surgery
- Chemotherapy
- Radiation
- Transplant

Health Behaviors
- Tobacco
- Diet
- Alcohol
- Exercise
- Sun

Aging

Cancer-Related Late Effect Risk Profile

Treatment Events

Hudson et al, Cancer 2006
What are Some of the Most Common Things – Late Effects or Late Effect Concerns

Psychosocial
Fertility / Reproduction
Endocrine Dysfunction
Cardiac
Secondary Malignancies
Some of the Most Common – Late Effects or Late Effect Concerns

**Psychosocial**
Anxiety, Depression, Social Withdrawal, Education/Employment, Relationships

Risk Factors:
• Any Cancer Experience

Interventions:
• Awareness / Screening – GAD7, PHQ9
• Counseling / Social Services
• Medications
Some of the Most Common – Late Effects or Late Effect Concerns

Fertility / Reproduction

Risk Factors:
• Radiation - Cranial / Gonadal / TBI
• Chemo
  - Alkylating Agents (Cyclophosphamide, Ifosfamide)
  - Heavy Metals (Carboplatin, Cisplatin)

Interventions:
• Early fertility referral / counseling
• Cryopreservation
Some of the Most Common – Late Effects or Late Effect Concerns

Endocrine Dysfunction

Risk Factors:
• Radiation - Cranial / End Organ

Interventions:
• Awareness / ROS / exam
• HPA labs, DEXA screening, TSH monitoring
Some of the Most Common – Late Effects or Late Effect Concerns

Cardiac

Risk Factors:
• Radiation – Chest / TBI
• Chemo
  - Anthracyclines (doxorubicin, daunorubicin, Idarubicin)

Interventions:
• EKGs, guideline-based echo screening
• Education on symptoms
Some of the Most Common –
Late Effects or Late Effect Concerns

Secondary Malignancies (SMN)

Risk Factors:
• Younger age (at diagnosis), Female
• Radiation
• Chemo
  Alkylating Agents (Cyclophosphamide, Ifosfamide)
  Anthracyclines (doxorubicin, daunorubicin, Idarubicin)
  Etoposide, teniposide

Interventions:
• Regular exams, Guideline based screenings

CCSS – 30 year data >14,000 CCS
-9.3% Secondary Malignancy (SMN)
-6.9% Non-melanoma skin cancer

Breast cancer

Physical
- Clinical breast exam: Yearly, beginning at puberty until age 25, then every 6 months
- Breast MRI: Yearly, as an adjunct to mammography beginning 8 years after radiation or at age 25, whichever occurs last
- Mammogram: Yearly, beginning 8 years after radiation or at age 25, whichever occurs last

Colorectal cancer

Screening
- Regular screening selected from the options below based on informed decision-making between patient and provider
- Beginning 5 years after radiation or at age 30 years (whichever occurs last)

<table>
<thead>
<tr>
<th>Screening Options</th>
<th>Test</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Multitarget stool DNA test*</td>
<td>Every 3 years</td>
</tr>
<tr>
<td></td>
<td>Colonoscopy</td>
<td>Every 5 years</td>
</tr>
</tbody>
</table>

*Positive result should be followed up with timely colonoscopy.

Note: Colonoscopy is considered the gold standard for colorectal cancer screening in high-risk populations; however, recognizing that not all survivors are willing or able to undergo colonoscopy, the Multitarget stool DNA test is deemed a reasonable alternative. Alternative stool-based testing (e.g., annual fecal immunochemical testing [FIT] or high-sensitivity guaiac-based fecal occult blood testing) or alternative structural examination (e.g., every 5 year CT colonography or flexible sigmoidoscopy) may also be considered if colorectal cancer or multigene stool DNA testing are not feasible or acceptable to the survivor. All positive results from these alternative testing methods should be followed up with timely colonoscopy.

The University of Kansas Cancer Center
So... What now?
How to best help the patients in your practice

- Things we tell every survivorship patient
- Obtaining a treatment summary
- Obtaining a survivorship care plan
- Locating the guidelines
- Getting support from survivorship team
Things we tell every survivorship patient

- Exercise is medicine
- Healthy diet is critical
- Obesity increases cancer risk
- HPV vaccines help prevent GU and head / neck cancers
- Sunscreen
- Skin cancer exams (radiation therapy)
Obesity is...

- Clearly linked to an overall increased cancer risk and an increased risk of many individual types of cancer
- Most types of cancer associated with overweight / obese states have increased from 2005-2014

https://www.cdc.gov/vitalsigns/obesity-cancer/index.html
What Would Help?

3 Most Highly Rates Themes

• #1 - Guideline Awareness / Access

• #2 - Patient-specific letter summary and recommendations

• #3 –Specialist access for collaboration / support

84% requested “collaboration with a cancer center-based physician or long term follow-up clinic”
## Table 3. Perceived Usefulness of Various Methods for Assisting General Internists’ Ability to Care for CCSs Independently

<table>
<thead>
<tr>
<th>Type</th>
<th>Mean Utility Rating/Percentage With Rating of 4*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to long-term follow-up guidelines for CCSs</td>
<td>3.8/85.5</td>
</tr>
<tr>
<td>Medical education seminars and courses about cancer follow-up care</td>
<td>3.2/44.0</td>
</tr>
<tr>
<td>Web site with information and opportunity for questions and answers</td>
<td>3.4/69.0</td>
</tr>
<tr>
<td>Patient-specific standardized letter from specialist with follow-up recommendations for the primary care physician sent directly to you</td>
<td>3.7/79.9</td>
</tr>
<tr>
<td>Patient-specific standardized letter from specialist with follow-up recommendations given to the patient</td>
<td>3.4/54.2</td>
</tr>
<tr>
<td>Ability to telephone or e-mail specialist for advice</td>
<td>3.4/55.1</td>
</tr>
<tr>
<td>Expedited routes of re-referral to cancer specialists</td>
<td>3.4/54.7</td>
</tr>
<tr>
<td>Pamphlets on follow-up cancer care</td>
<td>2.9/30.6</td>
</tr>
<tr>
<td>Expedited access to investigations (e.g. computed tomography scan, magnetic resonance imaging, and positron emission tomography scan) for suspected recurrence</td>
<td>3.1/44.2</td>
</tr>
<tr>
<td>Expedited access to support services (e.g. social work, psychology)</td>
<td>3.0/36.6</td>
</tr>
<tr>
<td>More medical or support staff in primary care office</td>
<td>2.7/26.8</td>
</tr>
</tbody>
</table>

CCS = childhood cancer survivor.

* On a scale of 1 (not at all useful) to 4 (very useful).

---

#1 - Guideline Awareness / Access

- [http://survivorshipguidelines.org/](http://survivorshipguidelines.org/)
- [https://www.nccn.org/professionals/physician](https://www.nccn.org/professionals/physician)
Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers

**NEW** - Version 5.0

The Children’s Oncology Group (COG) Long-Term Follow-Up Guidelines are resources for healthcare professionals who provide ongoing care to survivors of pediatric malignancies. These guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancers. The guidelines are evidence-based and recommend routine, early detection, and follow-up evaluations for survivors. The guidelines are not intended to replace the judgment of the treating healthcare professional. More extensive evaluations are recommended for patients who present with signs or symptoms suggesting illness or organ dysfunction. A basic knowledge of ongoing issues related to the long-term health of this patient population is assumed. Healthcare professionals who do not regularly care for survivors of pediatric malignancies are encouraged to consult with a pediatric oncology long-term follow-up center if any questions or concerns arise when reviewing or referring survivor patients.

Although the information within the guidelines will certainly prove valuable to the survivors themselves, the guidelines are primarily targeted to healthcare professionals. Therefore, survivors who choose to review these guidelines are strongly encouraged to seek the assistance of a healthcare professional knowledgeable about long-term follow-up care for survivors of childhood, adolescent, and young adult cancers.

Click below to download the COG LTU Guidelines and Appendices, Version 5.0:

COG Long-Term Follow-Up Guidelines
Appendix I (Materials for Clinically Appropriate Use)
Appendix II (Entire Set of Health Links)

Click below to download the following clinical tools:
Summary of Cancer Treatment (Abbreviated)
Summary of Cancer Treatment (Comprehensive)

Click below to download individual Health Links:

General and Psychosocial:
- Diet and Physical Activity (English) (Spanish)
- Educational Issues (English) (Spanish)
- Emotional Issues (English) (Spanish)
- Finding and Paying for Healthcare (English) (Spanish)
- Introduction to Long-Term Follow-up (English) (Spanish)

Dental:
- Dental Health (English) (Spanish) (French)
- Osteoradionecrosis (English) (Spanish)

Cardiac System:

Also Available:

COG Long-Term Follow-Up Resource Guide

This comprehensive guide is designed to assist healthcare professionals in identifying and enhancing programs for childhood cancer survivors collaboratively by the Children’s Oncology Group’s Late Effects Committee. It provides a broad perspective from a variety of disciplines within the Children’s Oncology Group’s Survivorship Program.
### CHEMOTHERAPY

<table>
<thead>
<tr>
<th>Sec #</th>
<th>Therapeutic Exposure</th>
<th>Potential Late Effects</th>
<th>Periodic Evaluation</th>
<th>Health Counseling/ Further Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>33</td>
<td>Anthracycline Antibiotics</td>
<td>Daunorubicin</td>
<td>Cardiac toxicity</td>
<td>HISTORY</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Doxorubicin</td>
<td>Cardiomyopathy</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Epirubicin</td>
<td>Subclinical left ventricular dysfunction</td>
<td>Dyspnea on exertion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Idarubicin</td>
<td>Congestive heart failure</td>
<td>Orthoepnea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mitoxantrone</td>
<td>Arrhythmias</td>
<td>Chest pain</td>
</tr>
<tr>
<td></td>
<td><strong>Dose Conversion</strong></td>
<td></td>
<td></td>
<td>Palpitations</td>
</tr>
<tr>
<td></td>
<td>To gauge the frequency of screening, use the following formula to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracyline dose. Clinical judgment should ultimately be used to determine indicated screening for individual patients.</td>
<td></td>
<td>If under 25 yrs: abdominal symptoms (nausea, vomiting)</td>
<td>Yearly</td>
</tr>
<tr>
<td></td>
<td>Doxorubicin: Multiply total dose x 1</td>
<td></td>
<td></td>
<td>PHYSICAL</td>
</tr>
<tr>
<td></td>
<td>Daunorubicin: Multiply total dose x 0.5</td>
<td></td>
<td></td>
<td>Blood pressure</td>
</tr>
<tr>
<td></td>
<td>Epirubicin: Multiply total dose x 0.67</td>
<td></td>
<td></td>
<td>Cardiac exam</td>
</tr>
<tr>
<td></td>
<td>Idarubicin: Multiply total dose x 5</td>
<td></td>
<td></td>
<td>Yearly</td>
</tr>
<tr>
<td></td>
<td>Mitoxantrone: Multiply total dose x 4</td>
<td></td>
<td>SCREENING</td>
<td>ECHO (or comparable imaging to evaluate</td>
</tr>
</tbody>
</table>

**Recommended Frequency of Echocardiogram**

<table>
<thead>
<tr>
<th>Anthracycline Dose*</th>
<th>Radiation Dose**</th>
<th>Recommended Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>&lt; 15 Gy or none</td>
<td>No screening</td>
</tr>
<tr>
<td></td>
<td>≥ 15 - &lt; 35 Gy</td>
<td>Every 5 years</td>
</tr>
<tr>
<td></td>
<td>≥ 35 Gy</td>
<td>Every 2 years</td>
</tr>
<tr>
<td>&lt; 250 mg/m²</td>
<td>&lt; 15 Gy or none</td>
<td>Every 5 years</td>
</tr>
<tr>
<td>≥ 15 Gy or none</td>
<td>Every 2 years</td>
<td></td>
</tr>
<tr>
<td>&gt; 250 mg/m²</td>
<td>Any or none</td>
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</tr>
</tbody>
</table>

*Based on doxorubicin isotoxic equivalent dose. See dose conversion instructions in section 33.

**Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], T8). See section 78.

---

**HEALTH LINKS**

- Heart Health
- Cardiovascular Risk Factors
- Diet and Physical Activity

**COUNSELING**

- Maintain appropriate weight, blood pressure and heart-healthy diet.
-Regarding exercise:
  - Regular exercise is generally safe and should be encouraged for patients who have normal LV systolic function.
  - Survivors with asymptomatic cardiomyopathy should consult cardiology to define limits and precautions for physical activity.
- Cardiology consultation may be necessary to define limits and precautions for physical activity for high risk survivors (i.e., those requiring an ECHO every 2 years) who plan to participate in intensive exercise.
- If QTc interval is prolonged: Caution regarding use of medications that may further prolong the QTc interval (e.g., tricyclic anti-depressants, antihypertensives, macrolide antibiotics, metronidazole).

---

**POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION**

- MRI as an adjunct imaging modality when echocardiographic images are suboptimal.
- Cardiology consultation in patients with subclinical abnormalities on screening evaluations, left ventricular dysfunction, dysrhythmia, or prolonged QTc interval.
- Be patient only: For patients who are pregnant or planning to become pregnant, annual cardiology evaluation is indicated in patients who received:
  - 60 mg/m² anthracyclines
  - 5 Gy chest radiation, or
  - Thrombolytic therapy (any dose) combined with chest radiation (≥15 Gy).

**SYSTEM = Cardiovascular**

**SCORE = 1**
NCCN Guidelines Version 2.2019
Survivorship

NCCN Survivorship Panel Members
NCCN Survivorship Sub-Committee Members
Summary of the Guidelines Updates

General Survivorship Principles
- Definition of Survivorship & Standards for Survivorship Care (SURV-1)
- General Principles of the Survivorship Guidelines (SURV-2)
- Screening for Subsequent New Primary Cancers (SURV-3)
- Assessment By Health Care Provider at Regular Intervals (SURV-A)
- Survivorship Assessment (SURV-A)
- Survivorship Resources For Health Care Professionals And Patients

Preventive Health
- Healthy Lifestyles (HL-1)
  - Physical Activity (SPA-1)
  - Nutrition and Weight Management (SNWM-1)
  - Supplement Use (SSUP-1)
  - Immunizations and Infections (SIMIN-1)
- Cognitive Function (SCF-1)
- Fatigue (SFAT-1)
- Lymphedema (SLYMPH-1)
- Hormone-Related Symptoms (SMP-1)
- Pain (SPAIN-1)
- Sexual Function (SSF-1)
  - Female Treatment Options (SSF-2)
  - Male Treatment Options (SSF-3)
  - Sleep Disorders (SSD-1)

Late Effects/Long-Term Psychosocial and Physical Problems
- Anthracycline-Induced Cardiac Toxicity (SCARDIO-1)
  - Anemia, Depression, Fatigue, and Distress (SANDE-1)

Clinical Trials: NCCN believes that the best management for any patient with cancer is in a clinical trial.

NCCN Guidelines Version 2.2019
Survivorship: Anthracycline-Induced Cardiac Toxicity

STAGES OF CARDIOMYOPATHY (HEART FAILURE)1

Stage A
- (No structural disorder of the heart, but at risk of developing heart failure)2
  - Patients may have any of the following:
    - History of potentially cardiotoxic chemotherapy (including anthracyclines)
    - History of chest irradiation (especially mantle and left-sided)
    - Hyperension, CAD, diabetes mellitus
    - History of alcohol abuse, personal history of rheumatic fever, family history of cardiomyopathy

STAGE A TREATMENT
- Address underlying risk factors (hypertension, lipids, tobacco use, obesity, metabolic syndrome, diabetes)2
- Consider referral to cardiologist for management

STAGE A SURVEILLANCE
- Reassess based on symptoms

Stage B
- (Structural heart disease but no signs or symptoms of heart failure)2
  - Patients may have any of the following:
    - LV hypertrophy
    - LV dilation or hypococontractility
    - Asymptomatic valvular heart disease
    - Previous myocardial infarction

STAGE B TREATMENT
- Measures under Stage A as appropriate

STAGE B SURVEILLANCE
- Referral to cardiologist for management

Stage C
- (Signs and symptoms of heart failure with underlying structural heart disease)3

STAGE C TREATMENT
- Address underlying structural heart disease

STAGE C SURVEILLANCE
- Referral to cardiologist for management

Stage D
- (Advanced structural heart disease and marked symptoms of heart failure at rest despite maximal medical therapy and requiring specialized interventions)3

STAGE D TREATMENT
- Consider referral to a cardiologist, especially if additional anthracycline therapy or other cardiotoxic treatment is needed

Notes:
1. Consider use of biomarkers in select patients at high risk for heart failure (Stage A). (See Discussion.)
2. Any patient who has received potentially cardiotoxic chemotherapy and/or chest radiation (and specifically anthracycline-based chemotherapy) should be considered Stage A cardiomyopathy.
Welcome to the Passport for Care! Even more importantly, Welcome to Survivorship!

The Passport for Care is a free online resource that can provide childhood cancer survivors access to a comprehensive treatment summary, potential late effects of therapy, educational pages on survivorship issues, and a tailored and comprehensive long-term follow up care plan based on the Children's Oncology Group recommendations, which you can be share with health care providers.

We also offer links to a variety of:

- Survivorship resources
- Transitioning to Survivorship
- Survivor Scholarships

Survivorship Resources

Life after childhood cancer treatment can be challenging. There is relief in knowing that your treatment is over, but there is also some fear that you won’t be seen as frequently or followed as closely – so it is important for survivors and parents of survivors to know what to look for and how to get help with issues that could arise after cancer treatment. Below are some resources that may be helpful. If you have specific questions, please ask your health care provider or email the PFC Survivorship Helpdesk.

- Children's Oncology Group Survivorship Guidelines of
- Children's Oncology Group Long Term Follow Up Care
- National Cancer Institute - Childhood Cancers
- National Cancer Institute – Late effects
#2 - Patient Specific Guidance

- Treatment Summary
- Survivorship Care Plan

---

**Table 3. Perceived Usefulness of Various Methods for Assisting General Internists’ Ability to Care for CCSs Independently**

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</tr>
<tr>
<td>Expedited access to support services (e.g., social work, psychology)</td>
<td>3.0/36.6</td>
</tr>
<tr>
<td>More medical or support staff in primary care office</td>
<td>2.7/26.8</td>
</tr>
</tbody>
</table>

CCS = childhood cancer survivor.
* On a scale of 1 (not at all useful) to 4 (very useful).
Request Treatment Summary

CUMULATIVE SUMMARY OF TREATMENT FOR:
Summary, Example

Provided by: Children’s Mercy Hospitals and Clinics
Date Printed: March 02, 2016

Demographics
Name: Summary, Example
Med. Rec. #: 00000000
Sex: Female
Date of Birth: 01-01-1900

Primary Diagnosis
Central Nervous System

Date Therapy Completed
Stage/Diagnostic Details

Treatment Center - 1 record enter

<table>
<thead>
<tr>
<th>Treatment Center</th>
<th>Treating Physician</th>
<th>Medical Record Number</th>
<th>MDMAPN Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dr. Maxine Hetherington</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Protocol</th>
<th>Start Date</th>
<th>End Date</th>
<th>Start Date (DD/MM/YY)</th>
<th>End Date (DD/MM/YY)</th>
<th>Total Days</th>
</tr>
</thead>
</table>

Chemotherapies - 3 medications entered

<table>
<thead>
<tr>
<th>Medication</th>
<th>Route</th>
<th>Dosage</th>
<th>Frequency</th>
<th>Days</th>
<th>Total Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>IV</td>
<td></td>
<td>27 mg/m2</td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td></td>
<td>12,000 mg2</td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td></td>
<td>875 mg2</td>
<td></td>
<td>5</td>
<td></td>
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</tbody>
</table>

Surgery - 1 surgery entered

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Start Date (DD/MM/YY)</th>
<th>End Date (DD/MM/YY)</th>
<th>Total Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurosurgery</td>
<td>06/15/2000</td>
<td>10/01/2000</td>
<td>14</td>
</tr>
</tbody>
</table>

Radiotherapy - 1 radiation entered

<table>
<thead>
<tr>
<th>Site/FIELD</th>
<th>Treatments</th>
<th>Dose per Treatment (Gy)</th>
<th>Total Dose (Gy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skull Brain</td>
<td>5 treatments</td>
<td>5.5 Gy</td>
<td>17.5 Gy</td>
</tr>
</tbody>
</table>

Hematopoietic Cell Transplant - 1 transplanted

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Start Date (DD/MM/YY)</th>
<th>End Date (DD/MM/YY)</th>
<th>Total Days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Complications/Late Effects - 1 complication noted entered

<table>
<thead>
<tr>
<th>Problem</th>
<th>Date Occurred</th>
<th>Active</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Fine motor coordination deficit</td>
<td>Active</td>
</tr>
<tr>
<td>2</td>
<td>Ocular dysfunction</td>
<td>Active</td>
</tr>
<tr>
<td>3</td>
<td>Gastrointestinal disturbance</td>
<td>Active</td>
</tr>
<tr>
<td>4</td>
<td>Dermatologic Aspects</td>
<td>Active</td>
</tr>
<tr>
<td>5</td>
<td>Dermatologic Dysplasia</td>
<td>Active</td>
</tr>
<tr>
<td>6</td>
<td>Endocrine: Central hypopituitarism (LH &amp; FSH deficiency)</td>
<td>Active</td>
</tr>
<tr>
<td>7</td>
<td>Endocrine: Growth hormone deficiency</td>
<td>Active</td>
</tr>
</tbody>
</table>
### Treatment Summary - Guidelines

**RADIATION**

<table>
<thead>
<tr>
<th>Section</th>
<th>Therapeutic Exposure</th>
<th>Potential Late Effects</th>
<th>Periodic Evaluation</th>
<th>Health Counseling/Further Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>53</td>
<td>Head, Brain</td>
<td>Precocious puberty</td>
<td>PHYSICAL</td>
<td>HEALTH LINKS: Precocious Puberty</td>
</tr>
</tbody>
</table>

**POTENTIAL IMPACT TO NEUROENDOCRINE AXIS (CONT)**

**PHYSICAL**
- Height
- Weight
- Tanner staging, Testicular volume by Prader orchidometer
  - Yearly until sexually mature

**HEALTH LINKS**
- PRECOCIOUS PUBERTY:
- www.magicfoundation.org

**RESOURCES**
- www.magicfoundation.org

**POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION**
- FSH, LH, testosterone as clinically indicated in patients with signs of accelerated pubertal progression and growth.
- X-ray for bone age in rapidly growing children.
- Endocrine consultation for accelerated puberty in boys <9 years old.

---

**ADDITIONAL INFORMATION**

- Consider patient and cancer/treatment factors, pre-morbid/co-morbid health status:
  - Patient factors: Younger age at treatment
  - Cancer/Treatment factors: Tumor near hypothalamus and/or optic pathway
  - Pre-morbid/Co-morbid medical conditions: History of hypopituitarism

**REFERENCES**

- Ogilvy-Stuart AL, Clayton PE, Shaltak SM. Chondral ossification and early puberty. J Clin Endocrinol Metab. 78:1282-4, 1994

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**SCREENING**

- TSH
- Free T4 Yearly, consider more frequent screening during periods of rapid growth
Request Survivorship Care Plan

In addition to annual cardiopulmonary history and exam:
- Fasting lipids
- A1C / glucose
- EKG
- Echo every 2yr
**Breast cancer**  
**Radiation:** TBI  
**Age:** 72

<table>
<thead>
<tr>
<th>Physical</th>
<th>Screening</th>
</tr>
</thead>
</table>
| **Clinical breast exam** | **Breast MRI**  
Yearly, beginning at puberty until age 25, then every 6 months  
**Mammogram**  
Yearly, as an adjunct to mammography beginning 8 years after radiation or at age 25, whichever occurs last  
Yearly, beginning 8 years after radiation or at age 25, whichever occurs last |

**Colon cancer**  
**Radiation:** TBI  
**Age:** 85

<table>
<thead>
<tr>
<th>Screening Options</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Regular screening</strong> selected from the options below based on informed decision-making between patient and provider</td>
<td><strong>Beginning 5 years after radiation or at age 30 years (whichever occurs last)</strong></td>
</tr>
</tbody>
</table>

*Colonoscopy is considered the gold standard for colorectal cancer screening in high-risk populations; however, recognizing that not all survivors are willing or able to undergo colonoscopy, targeted stool DNA testing is deemed a reasonable alternative. Alternative stool-based testing (e.g., annual fecal immunochemical testing (FIT) or high-sensitivity guaiac-based fecal occult blood testing) or alternative structural examination (i.e., every 5 years CT colonography or flexible sigmoidoscopy) may also be considered if colonoscopy or multigene stool DNA testing are not feasible or acceptable to the survivor. All positive results from these alternative testing methods should be followed up with timely colonoscopy.*

**THE UNIVERSITY OF KANSAS CANCER CENTER**
<table>
<thead>
<tr>
<th>Table 3. Perceived Usefulness of Various Methods for Assisting General Internists’ Ability to Care for CCSs Independently</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type</strong></td>
</tr>
<tr>
<td>Access to long-term follow-up guidelines for CCSs</td>
</tr>
<tr>
<td>Medical education seminars and courses about cancer follow-up care</td>
</tr>
<tr>
<td>Web site with information and opportunity for questions and answers</td>
</tr>
<tr>
<td>Patient-specific standardized letter from specialist with follow-up recommendations for the primary care physician sent directly to you</td>
</tr>
<tr>
<td>Patient-specific standardized letter from specialist with follow-up recommendations given to the patient</td>
</tr>
<tr>
<td>Ability to telephone or e-mail specialist for advice</td>
</tr>
<tr>
<td>Expedited routes of re-referral to cancer specialists</td>
</tr>
<tr>
<td>Pamphlets on follow-up cancer care</td>
</tr>
<tr>
<td>Expedited access to investigations (e.g. computed tomography scan, magnetic resonance imaging, and positron emission tomography scan) for suspected recurrence</td>
</tr>
<tr>
<td>Expedited access to support services (e.g. social work, psychology)</td>
</tr>
<tr>
<td>More medical or support staff in primary care office</td>
</tr>
</tbody>
</table>

CCS = childhood cancer survivor.
* On a scale of 1 (not at all useful) to 4 (very useful).
TUKCC Survivorship Transition Clinic

Patient Population

Location – 38 counties
- Kansas
- Missouri
- Illinois
- Tennessee
- Georgia
- New York

Ages
- 19-65 y/o
TUKCC Survivorship Transition Clinic

Patient Population

Diagnosis

- Leukemia: 15%
- Hodgkin's: 15%
- CNS Tumors: 14%
- Sarcoma: 9%
- Non-Hodgkin's: 18%
- Other: 29%

Gender

- Female: 40%
- Male: 60%

Type of Care

- PCP: 44%
- Consultative Care: 56%
What We Have Learned

• Most patients do not have treatment summaries or survivorship care plans
• Time intensive to create
• Critically important
• Supportive treatment summary software program linked to COG guidelines
TUKCC Survivorship Transition Clinic

- Collaborate with PCPs
- Annual survivorship visits
- Provide patient and PCP
  - Treatment Summary
  - Survivorship Care Plan
- Patient Education
- Guideline-based testing that is indicated
  - Order at KU
  - Provide list back to PCP to order locally
Educate and Empower Patients

Welcome to the Passport for Care Site.

Please enter your username and password to access the system.

Username:  
Password:  
Forgot your password? Read it here.

https://www.passportforcare.org/

- Provider inputs treatment information
- Program pulls recommended screening guidelines
- Mapped to COG Long-Term Follow-Up Guidelines
- Treatment Summary and Survivorship Care Plan
- Patient Portal - access anytime / anywhere
Midwest Cancer Alliance (MCA)

An outreach arm of KU Cancer Center

Network of hospitals, physician groups, cancer support and research organizations across Kansas and western Missouri
Thank You