# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

## Appendix I

# Materials for Clinical Application

**Version 5.0**
**October 2018**

CHILDREN'S ONCOLOGY GROUP

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# Contents

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# Reference Materials

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# Abbreviations

| Abbreviation | Definition |
|---|---|
| AAP | American Academy of Pediatrics |
| ABR | Auditory brainstem response |
| ACIP | Advisory Committee on Immunization Practices |
| ACS | American Cancer Society |
| AHA | American Heart Association |
| ALL | Acute lymphoblastic leukemia |
| ALT | Alanine aminotransferase |
| AMH | Anti-Mullerian hormone |
| AML | Acute myeloid leukemia |
| AST | Aspartate aminotransferase |
| ATG | Anti-thymocyte globulin |
| *ATM* | Ataxia telangiectasia cancer susceptibility gene (located on chromosome 11) |
| AVN | Avascular necrosis |
| BMD | Bone mineral density |
| BMI | Body mass index |
| *BRCA1* | Breast cancer susceptibility gene 1 (located on chromosome 17) |
| *BRCA2* | Breast cancer susceptibility gene 2 (located on chromosome 13) |
| BUN | Blood urea nitrogen |
| Ca | Calcium |
| CBC | Complete blood count |
| CCG | Children's Cancer Group |
| CDC | Centers for Disease Control |
| cGVHD | Chronic graft versus host disease |
| Cl | Chloride |
| CNS | Central nervous system |
| $CO_2$ | Carbon dioxide |
| COG | Children's Oncology Group |
| CT | Computed tomography |
| dB | Decibel |
| DES | Diethylstilbestrol |
| DLCO | Diffusion capacity of carbon monoxide |
| DTI | Diffusion-tensor imaging |
| DWI | Diffusion-weighted imaging |

| Abbreviation | Definition |
|---|---|
| DXA | Dual energy x-ray absorptiometry |
| ECHO | Echocardiogram |
| EKG | Electrocardiogram |
| EIA | Enzyme immunoassay |
| FAP | Familial adenomatous polyposis |
| FM | Frequency modulated |
| FNA | Fine needle aspirate |
| FNH | Focal nodular hyperplasia |
| FSH | Follicle stimulating hormone |
| G-CSF | Granulocyte colony stimulating factor |
| GH | Growth hormone |
| GI | Gastrointestinal |
| gm | Gram |
| GVHD | Graft versus host disease |
| Gy | Gray |
| HbA1c | Hemoglobin A1c |
| HBcAb | Hepatitis B core antibody |
| HBsAg | Hepatitis B surface antigen |
| HCT | Hematopoietic cell transplant |
| HCV | Hepatitis C virus |
| HDL | High-density lipoproteins |
| HIB | Haemophilus influenzae type B |
| HIV | Human immunodeficiency virus |
| HLA | Human leukocyte antigen |
| HNPCC | Hereditary nonpolyposis colorectal cancer |
| HPF | High power field |
| HPV | Human papillomavirus |
| ht | Height |
| Hz | Hertz |
| IBD | Inflammatory bowel disease |
| K | Potassium |
| I-131 | Iodine 131 radioisotope |
| IgA | Immunoglobulin A |
| IL-2 | Interleukin-2 |
| IM | Intramuscular |
| IO | Intra-Ommaya |

# Abbreviations (cont)

| Abbreviation | Definition |
|---|---|
| IQ | Intelligence quotient |
| IT | Intrathecal |
| IU | International unit |
| IV | Intravenous |
| IVIG | Intravenous immunoglobulin |
| kg | Kilogram |
| KUB | Kidneys, ureters, bladder radiograph |
| LH | Luteinizing hormone |
| LV | Left ventricular |
| $m^2$ | Square meter |
| MDS | Myelodysplastic syndrome |
| MIBG | Iodine-131-meta-iodobenzylguanidine |
| mg | Milligram |
| Mg | Magnesium |
| MOPP | Mechlorethamine, Oncovin, Procarbazine, Prednisone |
| MR | Magnetic resonance |
| MRI | Magnetic resonance imaging |
| Na | Sodium |
| *NF1* | Neurofibromin 1 (neurofibromatosis) cancer susceptibility gene (located on chromosome 17) |
| NHL | Non-Hodgkin lymphoma |
| NSAIDs | Non-steroidal anti-inflammatory drugs |
| *p53* | Cancer susceptibility gene associated with familial cancers (located on chromosome 17) |
| PAP | Papanicolaou |
| PCR | Polymerase chain reaction |
| PFTs | Pulmonary function tests |
| PNET | Primitive neuroectodermal tumor |
| PNS | Peripheral nervous system |
| PO | By mouth |
| $PO_4$ | Phosphate |
| PSA | Prostate specific antigen |
| QTc | Corrected QT interval |
| *RB1* | Retinoblastoma cancer susceptibility gene (located on chromosome 13) |
| RBC | Red blood cell |

| Abbreviation | Definition |
|---|---|
| RUQ | Right upper quadrant |
| SCUBA | Self-contained underwater breathing apparatus |
| SD | Standard deviation |
| SOS | Sinusoidal obstruction syndrome |
| T4 | Thyroxine |
| TBI | Total body irradiation |
| TPN | Total parenteral nutrition |
| TSH | Thyroid stimulating hormone |
| U | Units |
| USPSTF | United States Preventive Services Task Force |
| V-A | Ventriculoatrial |
| VOD | Veno-occlusive disease |
| V-P | Ventriculoperitoneal |
| V-V | Ventriculovenus |
| VZIG | Varicella zoster immunoglobulin |
| WAGR | Wilms' tumor, aniridia, genitourinary anomalies, range of developmental delays |
| wt | Weight |

# Chemotherapy Agents

| Generic Name | Additional Name(s) | Classification |
|---|---|---|
| Asparaginase | Elspar®<br>Erwinia asparaginase<br>Kidrolase®<br>L-asparaginase<br>Oncaspar®<br>PEG-asparaginase | Enzyme |
| Bleomycin | Blenoxane® | Anti-tumor antibiotic |
| Busulfan | Busulfex®<br>Busulphan<br>Myleran® | Alkylating agent |
| Carboplatin | CBDCA<br>Paraplatin® | Heavy metal |
| Carmustine | BCNU<br>BiCNU® | Alkylating agent |
| Chlorambucil | Leukeran® | Alkylating agent |
| Cisplatin | CDDP<br>Cisplatinum<br>Platinol® | Heavy metal |
| Cyclophosphamide | CPM<br>Cytoxan®<br>Neosar®<br>Procytox® | Alkylating agent |
| Cytarabine | Ara-C<br>Cytosar®<br>Cytosar-U®<br>Cytosine arabinoside | Antimetabolite |
| Dacarbazine | DTIC<br>DTIC-Dome® | Non-classical alkylator |
| Dactinomycin | Actinomycin-D<br>Cosmegen® | Anti-tumor antibiotic |
| Daunorubicin | Cerubidine®<br>Daunomycin<br>DaunoXome® | Anthracycline antibiotic |
| Dexamethasone | Decadron® | Corticosteroid |
| Doxorubicin | Adriamycin®<br>Doxil®<br>Rubex® | Anthracycline antibiotic |
| Epirubicin | Ellence®<br>Pharmorubicin PFS® | Anthracycline antibiotic |
| Etoposide | VePesid®<br>VP16 | Epipodophyllotoxin |
| Idarubicin | Idamycin® | Anthracycline antibiotic |
| Ifosfamide | Ifex® | Alkylating agent |
| Lomustine | CeeNU®<br>CCNU | Alkylating agent |
| Mechlorethamine | Mustargen®<br>Nitrogen Mustard | Alkylating agent |
| Melphalan | Alkeran® | Alkylating agent |
| Mercaptopurine | 6-Mercaptopurine<br>6MP<br>Purinethol® | Antimetabolite |
| Methotextrate | Amethopterin<br>Folex®<br>Mexate®<br>Trexall® | Antimetabolite |
| Mitoxantrone | Novantrone® | Anthracycline antibiotic |
| Prednisone | Deltasone®<br>Methylprednisolone<br>Prednisolone | Corticosteroid |
| Procarbazine | Matulane®<br>Natulan® | Alkylating agent |
| Temozolomide | Temodal®<br>Temodar® | Non-classical alkylator |
| Teniposide | VM26<br>Vumon® | Epipodophyllotoxin |
| Thioguanine | Lanvis®<br>Tabloid®<br>6-Thioguanine<br>6TG | Antimetabolite |
| Thiotepa | Thioplex® | Alkylating agent |
| Vinblastine | VBL<br>Velban®<br>Velbe® | Plant alkaloid |
| Vincristine | Oncovin®<br>VCR<br>Vincasar®<br>Vincrex® | Plant alkaloid |

# Radiation Fields Defined

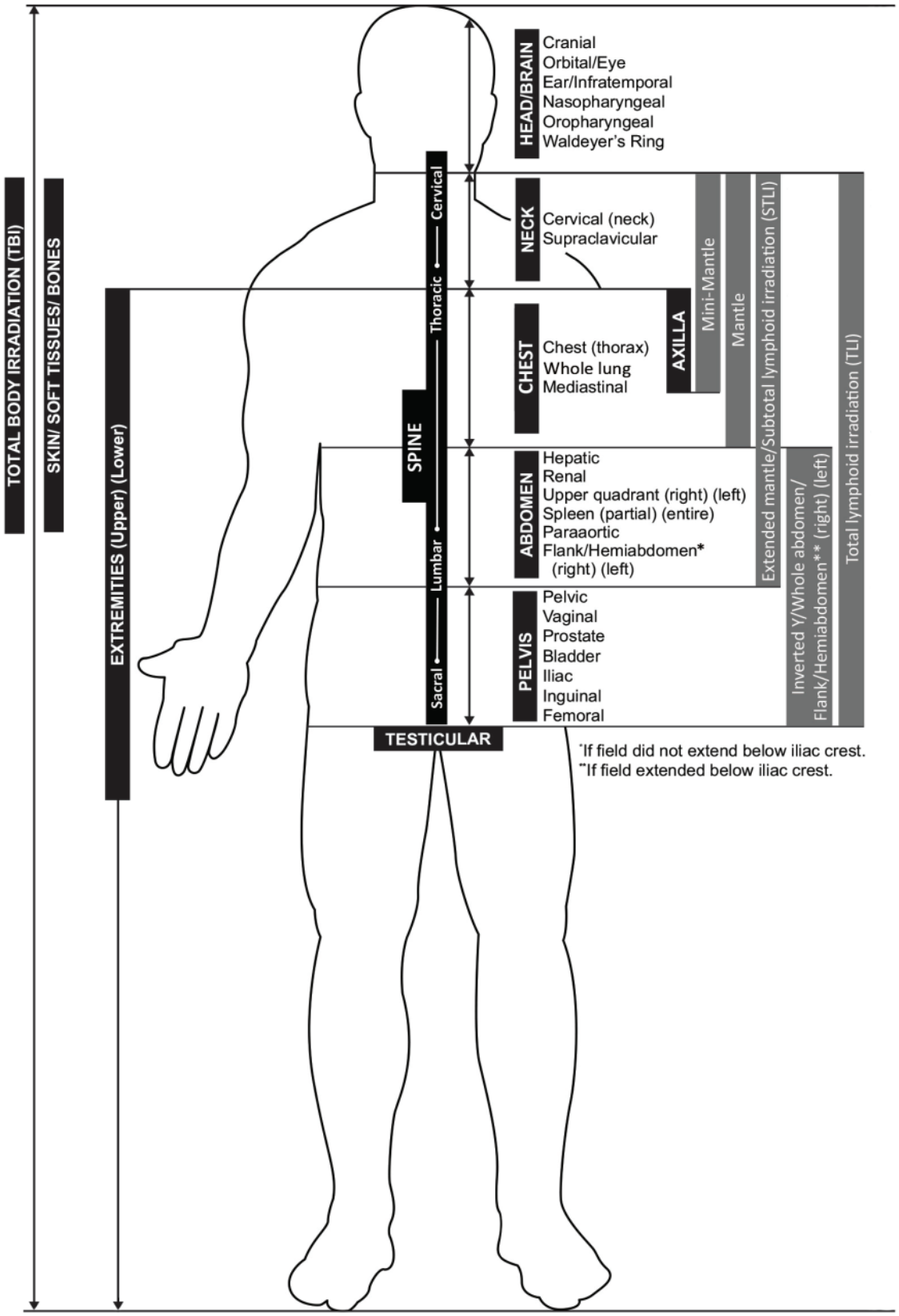
| Traditional Radiation Field | Definition | Corresponding Version 5.0 Fields |
|---|---|---|
| Total body irradiation (TBI) | Entire body; encompassing all radiation fields | TBI |
| Cranial | Any field involving the cranium, head, brain and/or face | Head/brain |
| Waldeyer's ring | Nasopharyngeal and oropharyngeal (tonsils and adenoids) | Head/brain |
| Spine-cervical | Including some or all of the cervical spine (C1–C7) | Spine (cervical) |
| Spine-thoracic | Including some or all of the thoracic spine (T1–T12) | Spine (thoracic) |
| Spine-lumbar | Including some or all of the lumbar spine (L1–L5) | Spine (lumbar) |
| Spine-sacral | Including some or all of the sacral spine (S1–S5) | Spine (sacral) |
| Spine-whole | Including the cervical, thoracic, lumbar and sacral spine | Spine (whole) |
| Mini-mantle | Bilateral cervical (neck), supraclavicular and axillary fields (excludes mediastinal and lung) | Neck<br>Axilla |
| Mantle | Bilateral cervical (neck), supraclavicular, mediastinal, hilar, and axillary fields | Neck<br>Axilla<br>Chest |
| Extended mantle | Mantle and paraaortic fields | Neck<br>Axilla<br>Chest<br>Abdomen |
| Subtotal lymphoid (STLI) | Mantle + paraaortic + splenic | Neck<br>Axilla<br>Chest<br>Abdomen |
| Inverted Y | Paraaortic + pelvic ± splenic | Abdomen<br>Pelvis |
| Total lymphoid (TLI) | Mantle + inverted Y (paraaortic/pelvic) + splenic | Neck<br>Axilla<br>Chest<br>Abdomen<br>Pelvis |
| Chest (thorax) | May include any of the following: Mediastinal, hilar, whole lung, chest wall | Chest |
| Mediastinal | Mediastinum and bilateral hilar fields | Chest |
| Abdomen<br>(also commonly referred to as "upper abdomen") | Top of diaphragm to iliac crests (bilaterally), including the following fields:<br>• Hepatic<br>• Upper quadrant (right, left)<br>• Renal/renal bed<br>• Paraaortic<br>• Spleen (partial, entire)<br>• Flank/hemiabdomen (right, left) | Abdomen |
| Paraaortic | Paraaortic lymph nodes (generally from T10 to L4 cephalad-caudad, and the transverse processes laterally) ± splenic | Abdomen |
| Renal | Renal bed | Abdomen |

# Radiation Fields Defined (cont)

| Traditional Radiation Field | Definition | Corresponding Version 5.0 Fields |
|---|---|---|
| Flank/hemiabdomen | Top of diaphragm to iliac crest (unilateral; medial border along contralateral vertebral bodies)<br>**Note**: *Most hemiabdominal fields do not extend beyond the iliac crest; however, in some cases, depending on tumor location, the hemiabdominal field may have extended into the pelvis. If the hemiabdominal field extended below the iliac crest, exposure to pelvic fields should be considered in assessing risk for late sequelae.* | Abdomen<br>± Pelvis |
| Whole abdomen | Includes all abdominal and pelvic fields | Abdomen<br>Pelvis |
| Pelvis | Iliac crest to 3 cm below ischium, including the following fields:<br>• Pelvic<br>• Iliac<br>• Vaginal<br>• Inguinal<br>• Prostate<br>• Femoral<br>• Bladder | Pelvis |
| Extremities | Including some or all of the arm(s), leg(s), feet or hand(s) | Extremities |

# Radiation Fields Defined (cont)

**Version 5.0 fields shown in black boxes**



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# Radiation Dose Calculations

**Instructions for Radiation Dose Calculation:**

Five sections of the COG Long-Term Follow-Up Guidelines (sections 59, 62, 65, 76, 77) include radiation dose specifications. These specifications indicate the minimum dose of radiation that is believed (based on available evidence and the recommendations of the expert panel) to place patients sufficiently at risk of the referenced late effect to recommend screening. For guideline sections that have a minimum specified dose, the following considerations apply in determining the applicability of the section for a patient based on his/her radiation exposure.

Sections with minimum dose specifications are applicable to a patient only if:

1. Patient received radiation to any field(s) relevant to the particular guideline section at ≥ the specified minimum dose†

**OR**

2. Patient received a combination of radiation to any relevant field(s)† **plus** relevant spinal radiation‡ **and/or** TBI, the sum of which is ≥ the specified minimum dose

†Total dose to each field should include boost dose, if given. If patient received radiation to more than one field relevant to a particular guideline section during a single planned course of radiation treatment (excluding spinal radiation and TBI), **the field that received the largest radiation dose should be used** in making the determination as to the applicability of the indicated guideline section(s). **Exception**: If patient received radiation to the same field at different times (e.g., at time of diagnosis AND at relapse), these doses should be added together when considering the applicability of the indicated guideline section.

‡Use the largest dose of radiation delivered to the spinal field(s) specified in the guideline section.

**Examples of Radiation Dose Calculations:**

Step 1: If radiation was given to more than one field relevant to the guideline (not including spine, TBI), select the largest dose received
Step 2: If patient received radiation to the same field at different times (e.g., at time of diagnosis AND at relapse), add these doses together
Step 3: If patient received relevant spinal field radiation, add the largest relevant spinal dose
Step 4: If patient received TBI, add TBI dose

**Example #1**

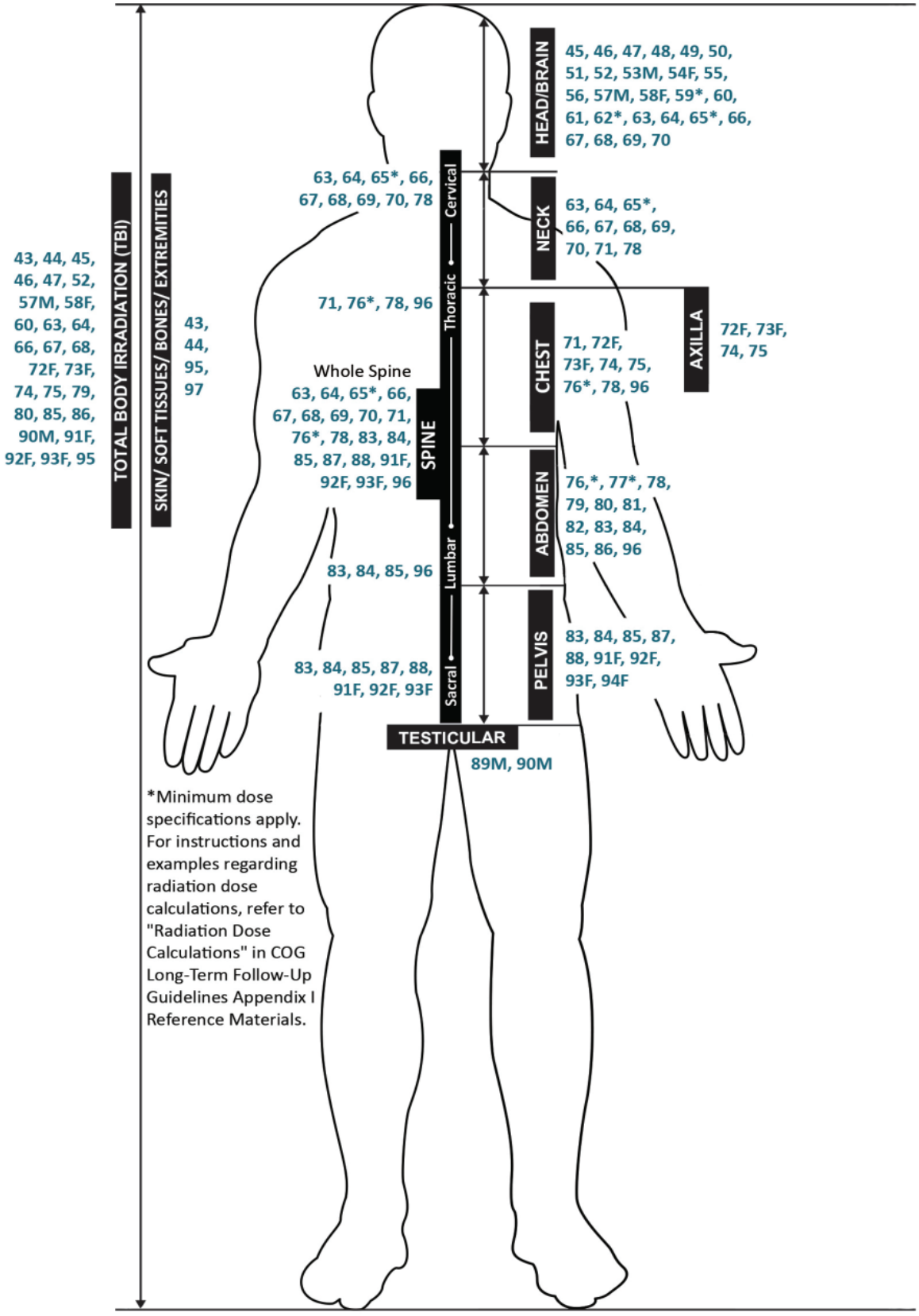
| Guideline Information | | | Patient Information | | | | | |
|---|---|---|---|---|---|---|---|---|
| Guideline section | Minimum dose specification for screening | Relevant radiation fields | Patient's relevant radiation fields | Step 1 | Step 2 | Step 3 | Step 4 | Conclusion |
| Section 65, osteoradionecrosis of the jaw | ≥40 Gy | Head/Brain<br>Neck<br>Spine (cervical)<br>Spine (whole)<br>TBI | Radiation at diagnosis:<br>• Head/brain: 24 Gy<br>• Neck: 18 Gy<br>Radiation at relapse:<br>• Head/brain: 12 Gy<br>• TBI: 12 Gy | 24 Gy | 24 Gy<br>+ 12 Gy<br>36 Gy | N/A | 36 Gy<br>+ 12 Gy<br>48 Gy | 48 Gy<br>Guideline 65 is applicable |

**Example #2**

| Guideline Information | | | Patient Information | | | | | |
|---|---|---|---|---|---|---|---|---|
| Guideline section | Minimum dose specification for screening | Relevant radiation fields | Patient's relevant radiation fields | Step 1 | Step 2 | Step 3 | Step 4 | Conclusion |
| Section 76, cardiac toxicity | ≥15 Gy | Chest<br>Abdomen<br>Spine (thoracic)<br>Spine (whole)<br>TBI | Radiation at diagnosis:<br>• Chest: 6 Gy<br>Radiation at relapse:<br>• Spine (whole): 12 Gy | 6 Gy | N/A | 6 Gy<br>+ 12 Gy<br>18 Gy | N/A | 18 Gy<br>Guideline 76 is applicable |

# Guideline Radiation Sections by Field

**Applicable guideline sections indicated in bold/dark blue; M=Male; F=Female**



# Guideline Radiation Sections by Potential Impact

**Applicable guideline sections indicated in bold/dark blue; M=Male; F=Female**

| Potential Impact | Fields | Dose | Section Numbers | Potential Late Effects |
|---|---|---|---|---|
| **All Fields** | Any radiation | Any | **43*** | Secondary benign or malignant neoplasm |
| | | | **44*** | Dermatologic toxicity |
| **Brain/Cranium** | Head/Brain | Any | **45*** | Brain tumor (benign or malignant) |
| | | | **46*** | Neurocognitive deficits |
| | | | **47*** | Clinical leukoencephalopathy |
| | | | **48** | Cerebrovascular complications |
| | | | **49** | Craniofacial abnormalities |
| | | | **50** | Chronic sinusitis |
| **Neuroendocrine Axis** | Head/Brain | Any | **51** | Overweight; Obesity |
| | | | **52*** | Growth hormone deficiency |
| | | | **53M** | Precocious puberty (male) |
| | | | **54F** | Precocious puberty (female) |
| | | | **55** | Hyperprolactinemia |
| | | | **56** | Central hypothyroidism |
| | | | **57M*** | Gonadotropin deficiency (male) |
| | | | **58F*** | Gonadotropin deficiency (female) |
| | | ≥30Gy** | **59** | Central adrenal insufficiency |
| **Eye** | Head/Brain | Any | **60*** | Cataracts |
| | | | **61** | Ocular toxicity |
| **Ear** | Head/Brain | ≥30Gy** | **62** | Ototoxicity |
| **Oral Cavity** | Head/Brain<br>Neck<br>Spine (cervical, whole) | Any | **63*** | Xerostomia; Salivary gland dysfunction |
| | | | **64*** | Dental abnormalities; Temporomandibular joint dysfunction |
| | | ≥40 Gy** | **65** | Osteoradionecrosis of the jaw |
| **Neck/Thyroid** | Head/Brain<br>Neck<br>Spine (cervical, whole) | Any | **66*** | Thyroid nodules |
| | | | **67*** | Thyroid cancer |
| | | | **68*** | Hypothyroidism |
| | | | **69** | Hyperthyroidism |
| | | | **70** | Carotid artery disease |
| | Neck<br>Chest<br>Spine (thoracic, whole) | Any | **71** | Subclavian artery disease |

* Patients who received TBI are at risk for this late effect. For a full list of TBI related sections, refer to "Total Body Irradiation Related Potential Late Effects" in COG Long-Term Follow-Up Guidelines Appendix I Reference Materials.
**TBI should be included for dose calculation purposes only

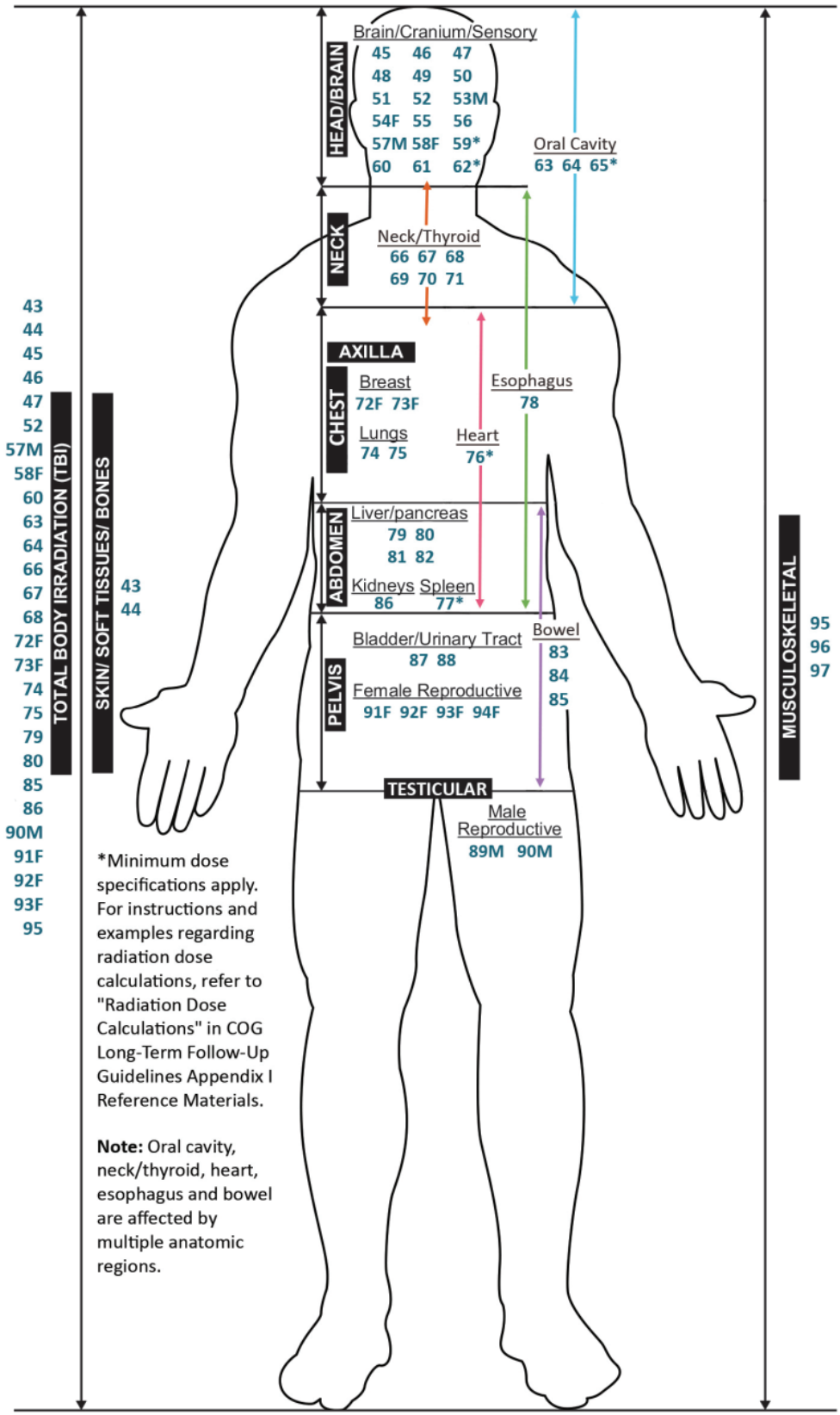
# Guideline Radiation Sections by Potential Impact (cont)

| Potential Impact | Fields | Dose | Section Numbers | Potential Late Effects |
|---|---|---|---|---|
| **Breast** | Chext<br>Axilla | Any | **72F*** | Breast cancer |
| | | | **73F*** | Breast tissue hypoplasia |
| **Lungs** | Chest<br>Axilla | Any | **74*** | Pulmonary toxicity |
| | | | **75*** | Lung cancer |
| **Heart** | Chest<br>Abdomen<br>Spine (thoracic, whole) | ≥15 Gy** | **76** | Cardiac toxicity |
| **Spleen** | Abdomen | ≥40 Gy** | **77** | Functional asplenia |
| **GI/Hepatic System** | Neck<br>Chest<br>Abdomen<br>Spine (cervical, thoracic, whole) | Any | **78** | Esophageal stricture |
| | Abdomen | Any | **79*** | Impaired glucose metabolism/diabetes mellitus |
| | | | **80*** | Dyslipidemia |
| | | | **81** | Hepatic toxicity |
| | | | **82** | Cholelithiasis |
| | Abdomen<br>Pelvis<br>Spine (lumbar, sacral, whole) | Any | **83** | Bowel obstruction |
| | | | **84** | Chronic enterocolitis; Fistula; Strictures |
| | | | **85*** | Colorectal cancer |
| **Urinary Tract** | Abdomen | Any | **86*** | Renal toxicity |
| | Pelvis<br>Spine (sacral, whole) | Any | **87** | Urinary tract toxicity |
| | | | **88** | Bladder malignancy |
| **Male Reproductive System** | Testes | Any | **89M** | Testicular hormonal dysfunction |
| | | | **90M*** | Impaired spermatogenesis |
| **Female Reproductive System** | Pelvis<br>Spine (sacral, whole) | Any | **91F*** | Ovarian hormone deficiencies |
| | | | **92F*** | Reduced ovarian follicular pool |
| | | | **93F*** | Uterine vascular insufficiency |
| | Pelvis | Any | **94F** | Vaginal fibrosis/stenosis |
| **Musculoskeletal System** | Any radiation | Any | **95*** | Musculoskeletal growth problems |
| | Chest<br>Abdomen<br>Spine (thoracic, lumbar, whole) | Any | **96** | Scoliosis/Kyphosis |
| | Any radiation | Any | **97** | Radiation-induced fracture |

* Patients who received TBI are at risk for this late effect. For a full list of TBI related sections, refer to "Total Body Irradiation Related Potential Late Effects" in COG Long-Term Follow-Up Guidelines Appendix I Reference Materials.
**TBI should be included for dose calculation purposes only

# Guideline Radiation Sections by Potential Impact (cont)

**Applicable guideline sections indicated in bold/dark blue; M=Male; F=Female**



# Total Body Irradiation (TBI) Related Potential Late Effects

The complete list of potential late effects and associated Guideline section numbers are included here for clinician convenience when evaluating patients who received TBI. For details regarding each potential late effect and indicated screening, please refer to the relevant section within the Guidelines.

| Section Number | Sex | Potential Late Effect |
|---|---|---|
| 43 | Both | Secondary benign or malignant neoplasm occurring in or near radiation field |
| 44 | Both | Dermatologic toxicity |
| 45 | Both | Brain tumor (benign or malignant) |
| 46 | Both | Neurocognitive deficits |
| 47 | Both | Clinical leukoencephalopathy |
| 52 | Both | Growth hormone deficiency |
| 57 | Male | Gonadotropin deficiency |
| 58 | Female | Gonadotropin deficiency |
| 60 | Both | Cataracts |
| 63 | Both | Xerostomia; Salivary gland dysfunction |
| 64 | Both | Dental abnormalities; Temporomandibular joint dysfunction |
| 66 | Both | Thyroid nodules |
| 67 | Both | Thyroid cancer |
| 68 | Both | Hypothyroidism |
| 72 | Female | Breast cancer |
| 73 | Female | Breast tissue hypoplasia |
| 74 | Both | Pulmonary toxicity |
| 75 | Both | Lung cancer |
| 79 | Both | Impaired glucose metabolism/diabetes mellitus |
| 80 | Both | Dyslipidemia |
| 85 | Both | Colorectal cancer |
| 86 | Both | Renal toxicity |
| 90 | Male | Impaired spermatogenesis |
| 91 | Female | Ovarian hormone deficiencies |
| 92 | Female | Reduced ovarian follicular pool |
| 93 | Female | Uterine vascular insufficiency |
| 95 | Both | Musculoskeletal growth problems |

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# Appeal Letter Following Denial of Insurance Claims

**Version 5.0**
**October 2018**

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## Instructions:

## Appeal Letter Following Denial of Insurance Claims for Survivorship Care

Not all insurance companies recognize the need for ongoing long-term follow-up care for survivors of childhood, adolescent, and young adult cancers. As with any medical care, it is prudent for the survivor to determine coverage for anticipated screening tests that may be recommended as part of their long-term follow-up care, and to work with the survivorship provider to obtain any pre-authorizations that may be necessary.

Nevertheless, we recognize that some essential services may be denied from time to time. The letters on the following pages are designed for use as templates to appeal denial letters from insurance companies, should the need arise. One letter is designed to be completed and submitted to the insurance company by the patient (or his/her parent). The other letter is designed to be completed and submitted to the insurance company by the patient's survivorship care provider. Although neither letter can guarantee insurance coverage, we are hopeful that these letters may be helpful in securing the indicated coverage for tests recommended as part of routine long-term follow-up care after the completion of cancer-directed therapy.

These templates were developed by Kristy Sharif and Alison Olig, COG Patient Advocacy Committee, 2018.

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# Appeal Letter Following Denial of Insurance Claims for Survivorship Care: Template for Letter from Patient, Parent or Guardian

**(Date)**

**(Name)**
**(Insurance Company Name)**
**(Address)**
**(City, State ZIP)**

Re: **(Patient's Name)**
**(Type of Coverage)**
**(Group number/Policy number)**

Dear **(name of contact person at insurance company)**,

Please accept this letter as **(patient's name)**'s appeal to **(insurance company name)**'s decision to deny coverage for **(name of test)**. It is my understanding based on your letter of denial dated **(date)** that **(name of test)** has been denied because:

**(Quote the specific reason for the denial stated in denial letter)**

It is possible that you did not have all the necessary information at the time of your initial review. **(Patient's name)** was diagnosed with **(disease)** on **(date)**. Currently **(name of long-term follow-up clinician)** from **(name of treating facility)**, a specialist in long-term follow-up after therapy for cancer during childhood, adolescence, and young adulthood, has indicated that **(patient's name)** requires **(name of test)** in order to monitor for long-term complications related to (patient's name) cancer treatment. Please see the enclosed letter from (**name of long-term follow-up clinician)** that discusses **(patient's name)**'s medical history and provides justification for this testing in more detail. Also included are medical records and support documentation explaining the evidence-based recommendations for this required monitoring.

Based on this information, **(patient's name)** is asking that you reconsider your previous decision and allow coverage for the procedure Dr. (name) outlines in the enclosed letter. **(Name of test)** is recommended to be completed by **(date)**. Should you require additional information, please do not hesitate to contact me at **(phone number)**. I look forward to hearing from you in the near future.

Sincerely,

**(Patient, parent or guardian name)**

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# Appeal Letter Following Denial of Insurance Claims for Survivorship Care: Template for Letter from Long-Term Follow-Up Clinician

**(Date)**

**(Name)**
**(Insurance Company Name)**
**(Address)**
**(City, State ZIP)**

Re: **(Patient's Name)**
**(Type of Coverage)**
**(Group number/Policy number)**

Dear **(name of contact person at insurance company),**

This letter is written in support of **(patient's name)**'s appeal to **(insurance company name)**'s decision to deny coverage for **(name of test)**. I am the clinician who is currently providing long-term follow-up care for this patient. Based on your letter of denial dated **(date)**, it is my understanding that **(name of test)** has been denied because:

**(Quote the specific reason for the denial stated in denial letter)**

**(Patient's name)** is a **(age)** year old **(male/female)** who was diagnosed with **(disease)** on **(date)** and began treatment on **(date)**. Treatment was completed on **(date)**.

The treatments that **(patient's name)** received for **(disease)** were lifesaving, however, this treatment has the potential to cause significant long-term complications (late effects) that can negatively impact **(patient's name)**'s health. Ongoing monitoring is required so that any long-term complications of cancer therapy can be identified and treated in a timely fashion in order to optimize **(patient's name**)'s health and prevent a decline in health status.

Because **(patient's name)** received **(name of relevant therapeutic exposures/doses)** as part of **(his/her)** cancer therapy, **(he/she)** is at risk for **(relevant late effect(s))**. The Children's Oncology Group (COG) Long-Term Follow-Up Guidelines, which set the standard of care for the ongoing follow-up of survivors of childhood, adolescent, and young adult cancers, provide specific follow-up recommendations related to **(patient's name)**'s treatment, including **(name of test denied)**. These evidence-based guidelines are based on the known long-term risks associated with cancer therapy delivered during childhood, adolescence, and young adulthood. The recommendations within the COG Long-Term Follow-Up Guidelines represent the consensus of experts in the late effects of pediatric cancer treatment.

I have attached documentation that supports the recommended testing in more detail **[attach relevant sections from COG LTFU Guidelines and any additional supportive materials such as journal articles]**, along with **(patient's name)**'s relevant medical records. Additional information is available from the Children's Oncology Group at *www.survivorshipguidelines.org*.

Based on this information, as the clinician providing **(patient's name)**'s long-term follow-up care, I am asking that you reconsider your previous decision and allow coverage for **(name of test)**. **(Name of test)** is recommended to be completed by **(date)**. Should you require additional information, please do not hesitate to contact me at **(phone number**). I look forward to hearing from you

Sincerely,

**(Name of long-term follow-up clinician)**

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# Summary of Cancer Treatment

**Version 5.0**
**October 2018**

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# Instructions: Summary of Cancer Treatment

**Importance of a Comprehensive Cancer Treatment Summary**

The *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* are based on therapeutic exposures received during cancer treatment. Availability of a comprehensive treatment summary, including all therapeutic agents received by the survivor, is presumed. Patients who do not have a comprehensive treatment summary should be instructed to obtain one from the institution(s) where they received their treatment.

The following table outlines:

1. The **minimum** information necessary to generate patient-specific guidelines (i.e., an **abbreviated** treatment summary).
2. The ideal information included in the **comprehensive** treatment summary. We ***strongly*** advise that a ***comprehensive*** treatment summary be prepared for each childhood cancer survivor when feasible.

| At Minimum | Additional Information- *Strongly* Advised if Feasible |
|---|---|
| **Demographics** | **Demographics** |
| • Name<br>• Sex<br>• Date of birth | • Race/ethnicity<br>• Social security number, if available<br>• COG registration number, if available<br>• Contact information |
| **Cancer Diagnosis** | **Cancer Diagnosis** |
| • Diagnosis<br>• Date of diagnosis<br>• Date cancer therapy was completed | • Diagnosis, including date, site/stage, laterality, and relapse(s) if any<br>• Pertinent hereditary conditions, past medical history and subsequent neoplasms<br>• Treating institution and team |
| **Cancer Treatment: Protocols** | **Cancer Treatment: Protocols** |
| N/A | • Treatment protocol information, if applicable |
| **Cancer Treatment: Chemotherapy** | **Cancer Treatment: Chemotherapy** |
| • Names of all chemotherapy agents received<br>– For a list of chemotherapy agents addressed by these guidelines (Sections 10-42), see the "Chemotherapy" portion of the Patient-Specific Guideline Identification Tool in Appendix I.<br>– For generic and brand names of chemotherapy agents, see Chemotherapy Agents in Appendix I.<br>• Cumulative dose of all anthracycline chemotherapy received (i.e., doxorubicin, daunorubicin, idarubicin, mitoxantrone and epirubicin)<br>– See Section 33 of Guidelines for anthracycline isotoxic dose-equivalent conversion.<br>– For doses in mg/kg, multiply by 30 to obtain equivalent dosing in $mg/m^2$ (example: 2 mg/kg = 60 $mg/m^2$).<br>• For carboplatin, whether any dose was myeloablative (i.e., given as conditioning for HCT)<br>• For cytarabine and methotrexate:<br>– Route of administration (i.e., IV, IM, SQ, PO, IT, IO)<br>– If IV, designation of "high dose" (any single dose ≥ 1000 $mg/m^2$) versus "standard dose" (all single doses < 1000 $mg/m^2$) | • Cumulative doses for all other agents should be provided if available, particularly for alkylators and bleomycin.<br>– For doses in mg/kg, multiply by 30 to obtain equivalent dosing in $mg/m^2$ (example: 2 mg/kg = 60 $mg/m^2$).<br>• Route of administration for all other agents |

# Instructions: Summary of Cancer Treatment (cont)

| At Minimum | Additional Information- *Strongly* Advised if Feasible |
|---|---|
| **Cancer Treatment: Radiation** | **Cancer Treatment: Radiation** |
| • Names of all radiation field(s) treated<br>– For list of radiation fields addressed by these guidelines (Sections 43-97), see "Radiation" portion of the Patient-Specific Guideline Identification Tool in Appendix I<br>– For definition of radiation fields, see "Radiation Fields Defined" in Appendix I<br>• For head/brain, neck, chest, abdomen, spine (whole, cervical, thoracic) radiation and TBI, total dose (in Gy):<br>– Total radiation dose to each field (should include boost dose, if given)<br>– To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy) | • Laterality (if applicable), start/stop dates, radiation type, number of fractions, dose per fraction, boost dose/location (if applicable)<br>• Total dose (in Gy) for all other fields<br>– Should include boost dose if given<br>– To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)<br>• Treating institution and radiation oncologist |
| **Cancer Treatment: Hematopoietic Cell Transplant(s)** | **Cancer Treatment: Hematopoietic Cell Transplant(s)** |
| • Whether or not the survivor underwent a hematopoietic cell transplant (HCT), and if so:<br>– Transplant type (autologous vs allogeneic)<br>– Chronic graft-versus-host disease (cGVHD) status (no history of chronic GVHD, history of chronic GVHD, currently active chronic GVHD) | • Type(s), source(s), date(s), conditioning regimen(s), GVHD prophylaxis and/or treatment<br>• Treating institution and transplant physician |
| **Cancer Treatment: Surgery** | **Cancer Treatment: Surgery** |
| • Names of all surgical procedures.<br>– For list of surgical procedures addressed by these guidelines (Sections 114–149), see "Surgery" portion of the Patient-Specific Guideline Identification Tool in Appendix I | • Dates, site (if applicable), laterality (if applicable)<br>• Treating institution and surgeon |
| **Cancer Treatment: Other Therapeutic Modalities** | **Cancer Treatment: Other Therapeutic Modalities** |
| • Whether or not the survivor received radioiodine therapy (I-131 thyroid ablation) or systemic MIBG (in therapeutic doses) | • Names, routes and cumulative doses of all other therapeutic modalities received |
| **Additional Clinical Information** | **Additional Clinical Information** |
| N/A | • Significant complications/late effects with dates of onset/resolution<br>• Adverse drug reactions/allergies<br>• Additional information/comments |

**Templates for Summary of Cancer Treatment**

Two templates for summarizing cancer treatment are included in Appendix I (and also available in electronic format at *www.survivorshipguidelines.org*). These templates were originally developed by the COG Nursing Clinical Practice Subcommittee under the leadership of Lisa Bashore, MS, RN, CPNP, CPON® and Lori Boucher, RN, CRA. The templates were subsequently pilot tested and revised, then further refined based on feedback from the Late Effects Committee and a working group from the National Cancer Institute.

The abbreviated form contains all data elements currently necessary for generation of patient-specific recommendations from the COG LTFU Guidelines, and meets the minimum data requirements for initial use of the "Passport for Care" web-based guideline interface. However, the COG Long-Term Follow-Up Guidelines Core Committee recognizes that as new evidence becomes available and these guidelines are updated, additional details regarding the childhood cancer survivor's therapeutic exposures may be required in order to generate comprehensive recommendations. Therefore, we ***strongly*** advise that a ***comprehensive*** treatment summary be prepared for each childhood cancer survivor when feasible, including a record of ***all*** therapeutic exposures with applicable dates, details of administration, and cumulative doses of all agents, including those not currently addressed by these guidelines.

In addition to the treatment summary templates, a "key" for completing the comprehensive version of the treatment summary is also included in Appendix I.

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# Summary of Cancer Treatment (Abbreviated)

| Demographics | | |
|---|---|---|
| Name | Sex ☐ M ☐ F | Date of Birth |

| Cancer Diagnosis | | |
|---|---|---|
| Diagnosis | Date of Diagnosis | Date Therapy Completed |

**Chemotherapy** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| Drug Name | Additional Information† |
|---|---|
| | |
| | |
| | |
| | |
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| | |
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| | |

†**Anthracyclines**: Include cumulative dose in mg/m$^2$ (see section 33 of Guidelines for isotoxic dose conversion);
**Carboplatin**: Indicate if dose was myeloablative
**Methotrexate and Cytarabine**: Indicate route of administration (i.e., IV, IM, SQ, PO, IT, IO);
**IV Methotrexate and Cytarabine**: Indicate if "high dose" (any single dose ≥ 1000 mg/m$^2$) or "standard dose" (all single doses < 1000 mg/m$^2$)
**Note**: Cumulative doses, if known, should be recorded for all agents, particularly for alkylators and bleomycin.

**Radiation** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| Site/Field | Total Dose* (including boost) (Gy)** |
|---|---|
| | |
| | |

*For head/brain, neck, chest, abdomen, spine (whole, cervical, thoracic) radiation and TBI, include total doses (including boost dose, if given)
**To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)

**Hematopoietic Cell Transplant** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| | | |
|---|---|---|
| Transplant Type | Autologous ☐ Yes ☐ No | Allogeneic ☐ Yes ☐ No |
| Chronic Graft-Versus-Host Disease (cGVHD) | Ever diagnosed? ☐ Yes ☐ No | Currently active? ☐ Yes ☐ No |

**Surgery** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| Procedure | Site (if applicable) | Laterality (if applicable) |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**Other Therapeutic Modalities** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| |
|---|
| Did the patient receive radioiodine therapy (I-131 thyroid ablation)? ☐ Yes ☐ No |
| Did the patient receive systemic MIBG (in therapeutic doses)? ☐ Yes ☐ No |

| **Summary prepared by:** | **Date prepared:** |
|---|---|

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# Summary of Cancer Treatment (Comprehensive)

Superscript numbers correspond with lists in "Key for Completing Summary of Cancer Treatment Form"

| **Demographics** | | | | |
|---|---|---|---|---|
| Name | | | | |
| Sex ☐ M ☐ F | Date of Birth | Race/Ethnicity[1] | SS# | COG Reg # |
| Address | | | | Phone |
| Alternate contact | | Relationship | | Phone |

| **Cancer Diagnosis** | | |
|---|---|---|
| Diagnosis[2] | | |
| Date of diagnosis | Age at diagnosis | Date therapy completed |
| Sites involved/stage/diagnostic details | | Laterality ☐ Right ☐ Left ☐ NA |
| Hereditary/congenital history[3] | | |
| Pertinent past medical history | | |
| Institution | MD/APN | Medical record # |
| **Relapse(s)** ☐ **Yes** ☐ **No** ***If yes, provide information below*** | | |
| Date of diagnosis | Age at diagnosis | Date therapy completed |
| Sites involved/stage/diagnostic details | | Laterality ☐ Right ☐ Left ☐ NA |
| **Subsequent malignant neoplasm(s)** ☐ **Yes** ☐ **No** ***If yes, provide information below*** | | |
| Type[4] | | |
| Date of diagnosis | Age at diagnosis | Date therapy completed |
| Sites involved/stage/diagnostic details | | Laterality ☐ Right ☐ Left ☐ NA |

**Cancer Treatment Summary**

**Protocol(s)** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| Acronym/Number | Title/Description | Initiated | Completed | On-Study |
|---|---|---|---|---|
| | | | | |
| | | | | |

**Chemotherapy** ☐ **Yes** ☐ **No** ***If yes, provide information below***

| Drug Name[5] | Route[6] | Additional Information[†,7] |
|---|---|---|
| | | |
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| | | |

[†]**Anthracyclines**: Include cumulative dose in mg/m$^2$ and age at first dose (see section 33 of Guidelines for isotoxic dose conversion);
**Carboplatin**: Indicate if dose was myeloablative
**IV Methotrexate and Cytarabine**: Indicate if "high dose" (any single dose ≥ 1000 mg/m$^2$) or "standard dose" (all single doses < 1000 mg/m$^2$);
**Note**: Cumulative doses, if known, should be recorded for all agents, particularly for alkylators and bleomycin.

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# Summary of Cancer Treatment (Comprehensive) (cont)

## Cancer Treatment Summary (cont)

**Radiation** ☐ Yes ☐ No *If yes, provide information below*

| Site/Field[8] | Laterality | Start/Stop Dates | Type[9] | Fractions | Dose per Fraction (Gy)* | Initial Dose (Gy)* | Boost Site[10] | Boost Dose (Gy)* | Total Dose (including boost) (Gy)* |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| | | | | | | | | | |

| Institution | Radiation oncologist |
|---|---|
| | |

*__Note__: To convert cGy or rads to Gy, divide dose by 100 (example: 2400 cGy = 2400 rads = 24 Gy)

**Hematopoietic Cell Transplant** ☐ Yes ☐ No *If yes, provide information below*

| Type[11] | Tandem? | Source[12] | Date of Infusion | Conditioning Regimen[13] |
|---|---|---|---|---|
| | ☐ Yes ☐ No | | | |

| Institution | Transplant physician |
|---|---|
| | |

**Graft-Versus-Host Disease (GVHD) Prophylaxis/Treatment (for transplant patients only)** ☐ Yes ☐ No *If yes, provide information below*

| Type[14] | First Dose | Last Dose |
|---|---|---|
| | | |
| | | |

**Was** the patient ever diagnosed with chronic GVHD? ☐ Yes ☐ No Does the patient currently have active chronic GHVD? ☐ Yes ☐ No

**Surgery** ☐ Yes ☐ No *If yes, provide information below*

| Procedure[15] | Date | Site (if applicable) | Laterality (if applicable) | Institution/Surgeon |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

**Other Therapeutic Modalities** ☐ Yes ☐ No *If yes, provide information below*

| Therapy[16] | Route[6] | Cumulative Dose[7] (if known) |
|---|---|---|
| | | |
| | | |

## Additional Clinical Information

**Complications/Late Effects** ☐ Yes ☐ No *If yes, provide information below*

| Problem[17] | Date onset | Date resolved | Status |
|---|---|---|---|
| | | | ☐ Active ☐ Resolved |
| | | | ☐ Active ☐ Resolved |
| | | | ☐ Active ☐ Resolved |
| | | | ☐ Active ☐ Resolved |

**Adverse Drug Reactions/Allergies** ☐ Yes ☐ No *If yes, provide information below*

| Drug | Reaction | Date | Status |
|---|---|---|---|
| | | | ☐ Active ☐ Resolved |

**Additional Information/Comments** ☐ Yes ☐ No *If yes, provide information below*

| |
|---|
| |

| **Summary prepared by**: | **Date prepared**: |
|---|---|
| **Summary updated by**: | **Date updated**: |

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# Key for Completing Summary of Cancer Treatment (Comprehensive)

| #1: Race/Ethnicity |
|---|
| Asian |
| Black/African American |
| Caucasian (non-Hispanic/non-Latino) |
| Hispanic or Latino |
| Native American/Alaskan Native |
| Native Hawaiian/Pacific Islander |
| Multi-racial/multi-ethnic |
| Race/ethnicity, other, specify: |
| **#2: Cancer Diagnosis** |
| **Central Nervous System Tumor** |
| Astrocytoma |
| Cerebellar astrocytoma |
| Supratentorial astrocytoma |
| Brainstem glioma |
| Choroid plexus neoplasm |
| Craniopharyngioma |
| Ependymoma |
| Germ cell tumor, intracranial |
| Optic glioma |
| Pineal tumor |
| PNET |
| Cerebellar (medulloblastoma) |
| Supratentorial PNET |
| Spinal cord tumor, intramedullary |
| CNS tumor, other, specify: |
| **Endocrine tumor** |
| Adrenal tumor (non-neuroblastoma) |
| Thyroid tumor |
| Parathyroid tumor |
| Gastroenteropancreatic tumor |
| Multiple endocrine neoplasia syndrome |
| Endocrine tumor, other, specify: |
| **Germ cell tumor (extracranial)** |
| Seminoma |
| Germinoma |
| Dysgerminoma |
| Non-seminomas |
| Yolk sac tumor |
| Embryonal carcinoma |
| Choriocarcinoma |
| Teratoma |
| Mature |
| Immature |
| With malignant transformation |

| #2: Cancer Diagnosis (cont) |
|---|
| **Germ cell tumor (extracranial) (cont)** |
| Germ cell tumor, other, specify: |
| **Langerhans cell histiocytosis** |
| **Leukemia** |
| Acute lymphoblastic leukemia |
| Acute myeloid leukemia |
| Chronic myeloid leukemia |
| Myelodysplastic syndrome |
| Myeloproliferative disorder |
| Leukemia, other, specify: |
| **Liver tumor** |
| Hepatoblastoma |
| Hepatocellular carcinoma |
| Liver tumor, other, specify: |
| **Lymphoma** |
| Hodgkin lymphoma |
| Non-Hodgkin lymphoma |
| Lymphoblastic lymphoma |
| Burkitt's lymphoma |
| Large cell lymphoma |
| Anaplastic large cell lymphoma |
| Diffuse large B-cell lymphoma |
| Lymphoma, other, specify: |
| **Nasopharyngeal carcinoma** |
| **Neuroblastoma** |
| Ganglioneuroblastoma |
| **Renal tumor** |
| Wilms tumor |
| Clear cell sarcoma |
| Renal cell carcinoma |
| Renal tumor, other, specify: |
| **Retinoblastoma** |
| **Sarcoma** |
| Ewing's sarcoma/peripheral PNET |
| Osteogenic sarcoma |
| Rhabdomyosarcoma |
| Soft tissue sarcoma (nonrhabdomyosarcomatous) |
| Alveolar soft part sarcoma |
| Fibrosarcoma |
| Leiomyosarcoma |
| Liposarcoma |
| Malignant fibrous histiocytoma |
| Malignant peripheral nerve sheath tumor |
| Neurofibrosarcoma |

| #2: Cancer Diagnosis (cont) |
|---|
| **Sarcoma (cont)** |
| Soft tissue sarcoma (nonrhabdomyosarcomatous) (cont) |
| Synovial sarcoma |
| Undifferentiated sarcoma |
| Sarcoma, other, specify: |
| **Skin cancer** |
| Basal cell carcinoma |
| Malignant melanoma |
| Squamous cell carcinoma |
| Skin cancer, other, specify: |
| **Malignancy, other, specify:** |
| **Diagnosis, other, specify:** |
| **#3: Hereditary/Congenital History** |
| Congenital heart disease |
| Congenital disease, other, specify: |
| Hemihypertrophy |
| Neurofibromatosis<br>Specify: ☐ Type I ☐ Type II |
| Down syndrome |
| Syndrome, other, specify: |
| Hereditary condition, other, specify: |
| None |
| Unknown |
| **#4: Subsequent Malignancy Diagnosis** |
| **Bladder cancer** |
| **Breast cancer** |
| **Central nervous system tumor** |
| Malignant, specify type and location: |
| Meningioma, specify location: |
| CNS tumor, other, specify type: |
| **Cervical cancer** |
| **Gastrointestinal cancer** |
| Esophageal cancer |
| Stomach cancer |
| Colorectal cancer |
| Hepatocellular carcinoma |
| Pancreatic cancer |
| GI cancer, other, specify: |
| **Leukemia** |
| Acute lymphoblastic leukemia |
| Acute myeloid leukemia |
| Chronic myeloid leukemia |
| Myelodysplastic syndrome |
| Myeloproliferative disorder |

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# Key for Completing Summary of Cancer Treatment (Comprehensive) (cont)

| #4 Subsequent Malignancy Diagnosis (cont) |
|---|
| **Leukemia (cont)** |
| Leukemia, other, specify: |
| **Lung cancer** |
| **Lymphoma** |
| Hodgkin lymphoma |
| Non-Hodgkin lymphoma |
| Lymphoblastic lymphoma |
| Burkitt's lymphoma |
| Large cell lymphoma |
| Post-transplant lymphoproliferative disorder (PTLD) |
| Lymphoma, other, specify: |
| **Peripheral nerve sheath tumor/ Schwannoma/Acoustic neuroma** |
| **Renal cancer** |
| Renal cell carcinoma |
| Clear cell sarcoma |
| Renal cancer, other, specify: |
| **Sarcoma** |
| Ewing's sarcoma/peripheral PNET |
| Osteogenic sarcoma |
| Rhabdomyosarcoma |
| Soft tissue sarcoma (nonrhabdomyosarcomatous) |
| Undifferentiated sarcoma |
| Sarcoma, other, specify: |
| **Skin cancer** |
| Basal cell carcinoma |
| Malignant melanoma |
| Squamous cell carcinoma |
| **Thyroid cancer** |
| **Malignancy, other, specify:** |
| **None** |
| **Unknown** |

| #5: Chemotherapy |
|---|
| Asparaginase |
| Bleomycin |
| Busulfan |
| Carboplatin<br>Myeloablative dose? ☐ Yes ☐ No |
| Carmustine (BCNU) |
| Chlorambucil |
| Cisplatin |
| Cladribine |
| Clofarabine |

| #5: Chemotherapy (cont) |
|---|
| Cyclophosphamide |
| Cytarabine<br>If IV: Any single dose ≥ 1000 mg/m$^2$? ☐ Yes ☐ No |
| Dacarbazine (DTIC) |
| Dactinomycin |
| Daunorubicin |
| Dexamethasone |
| Docetaxel |
| Doxorubicin |
| Epirubicin |
| Etoposide (VP-16) |
| Fludarabine |
| Fluorouracil |
| Gemcitabine |
| Hydrocortisone |
| Hydroxyurea |
| Idarubicin |
| Ifosfamide |
| Imatinib Mesylate |
| Irinotecan |
| Lomustine (CCNU) |
| Mechlorethamine |
| Melphalan |
| Mercaptopurine |
| Methotrexate<br>If IV: Any single dose ≥ 1000 mg/m$^2$? ☐ Yes ☐ No |
| Mitoxantrone |
| Oxaliplatin |
| Paclitaxel |
| Prednisone |
| Procarbazine |
| Temozolomide |
| Teniposide (VM-26) |
| Thioguanine (6-TG) |
| Thiotepa |
| Topotecan |
| Trimetrexate |
| Vinorelbine |
| Vinblastine |
| Vincristine |
| Chemotherapy, other, specify: |
| None |
| Unknown |

| #6: Route |
|---|
| PO |
| IM |
| IV |
| SQ |
| IT |
| IO |
| Route, other, specify: |
| Unknown |
| **#7: Cumulative Dose**<br>**(** *Note: this is a required field for anthracyclines and optional but suggested for all others* **)** |
| mg/m$^2$ |
| units/m$^2$ |
| mg/kg<br>(**Note**: computer will multiply mg by 30 and display as mg/m$^2$) |
| Not available |
| Not applicable |
| Cumulative dose, other, specify: |
| Unknown |
| **#8: Radiation Site/Field** |
| **Head/brain** |
| Cranial |
| Orbital/eye<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Ear/infratemporal<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Nasopharyngeal |
| Oropharyngeal |
| Waldeyer's ring |
| Head/brain radiation, other, specify: |
| **Neck** |
| Cervical (neck)<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Supraclavicular<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| **Spine** |
| Spine – cervical |
| Spine – thoracic |
| Spine – lumbar |
| Spine – sacral |
| Spine – whole |
| **Axilla**<br>Specify: ☐ Right ☐ Left ☐ Bilateral |

# Key for Completing Summary of Cancer Treatment (Comprehensive) (cont)

| #8: Radiation Site/Field (cont) |
|---|
| **Chest** |
| Chest (thorax) |
| Whole lung<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Mediastinal |
| Chest, other, specify: |
| **Abdomen** |
| Hepatic |
| Renal<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Upper quadrant<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Spleen<br>Specify: ☐ Partial ☐ Entire |
| Paraaortic |
| Flank/hemiabdomen<br>Specify: ☐ Right ☐ Left<br>Specify: Extended below iliac crest: ☐ Yes ☐ No |
| **Pelvis** |
| Pelvic |
| Vaginal |
| Prostate |
| Bladder |
| Iliac |
| Inguinal |
| Femoral |
| **Testicular**<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| **Extremity** |
| Upper<br>Specify: ☐ Right ☐ Left ☐ Bilateral<br>Specify: ☐ Proximal ☐ Distal ☐ Entire |
| Lower<br>Specify: ☐ Right ☐ Left ☐ Bilateral<br>Specify: ☐ Proximal ☐ Distal ☐ Entire |
| **Total Body Irradiation (TBI)** |
| **Combination Fields:** |
| Mantle |
| Mini-mantle |
| Extended mantle |
| Inverted Y |
| Whole abdomen |
| Total lymphoid irradiation (TLI) |
| Subtotal lymphoid irradiation (STLI) |

| #8: Radiation Site/Field (cont) |
|---|
| **Radiation site/field, other, specify:** |
| **None** |
| **Unknown** |
| **Add comment:** |
| **#9: Radiation Type** |
| Brachytherapy |
| Conformal |
| External beam (conventional) |
| IMRT |
| Proton beam |
| Stereotactic |
| Radiation type, other, specify: |
| None |
| Unknown |
| **#10: Radiation Boost** |
| Tumor bed, specify location: |
| Radiation boost location, other, specify: |
| None |
| Unknown |
| Add comment: |
| **#11: Hematopoietic Cell Transplant – Type** |
| Autologous |
| Matched related |
| Mismatched related |
| Haploidentical related |
| Syngeneic |
| Matched unrelated |
| HCT type, other, specify: |
| Unknown |
| **#12: Hematopoietic Cell Transplant – Source** |
| Bone marrow |
| Peripheral blood stem cells |
| Cord blood |
| HCT source, other, specify: |
| Unknown |
| **#13: Hematopoietic Cell Transplant – Conditioning Regimen** |
| ATG |
| Busulfan |
| Carmustine (BCNU) |
| Cyclophosphamide |
| Etoposide |
| Fludarabine |

| #13: Hematopoietic Cell Transplant – Conditioning Regimen (cont) |
|---|
| Melphalan |
| Thiotepa |
| TBI |
| HCT conditioning regimen, other, specify: |
| Unknown |
| **#14: GVHD Prophylaxis/Treatment** |
| ATG |
| Cyclosporine |
| Methotrexate |
| MMF (mycophenolate mofetil) |
| Prednisone |
| PUVA |
| Sirolimus |
| Tacrolimus |
| GVHD prophylaxis/treatment, other, specify: |
| None |
| Unknown |
| **#15: Surgery** |
| Amputation, specify site:<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Central venous catheter |
| Cystectomy |
| Enucleation<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Hysterectomy |
| Laparotomy |
| Limb sparing procedure, specify site:<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Nephrectomy<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Neurosurgery – brain<br>Potential to affect hypothalamic-pituitary axis?<br>☐ Yes ☐ No |
| Neurosurgery – spinal cord |
| Oophoropexy |
| Oophorectomy<br>Specify: ☐ Right ☐ Left ☐ Bilateral |
| Orchiectomy<br>Specify: ☐ Partial ☐ Unilateral ☐ Bilateral<br>If partial or unilateral, specify: ☐ Right ☐ Left |
| Pelvic surgery |
| Thoracic surgery* |
| Splenectomy |

# Key for Completing Summary of Cancer Treatment (Comprehensive) (cont)

| #15: Surgery (cont) |
|---|
| Thyroidectomy |
| Surgery, other, specify: |
| None |
| Unknown |
| Add comment: |
| *Thoracic surgery includes: thoracotomy, chest wall surgery, rib resection, pulmonary lobectomy, pulmonary metastasectomy, and pulmonary wedge resection |
| **#16: Other Therapeutic Modalities** |
| **Systemic Radiation** |
| Radioiodine therapy (I-131 thyroid ablation) |
| Systemic MIBG (in therapeutic doses) |
| Systemic radiation, other, specify: |
| **Bioimmunotherapy** |
| Hematopoietic growth factors: |
| G-CSF |
| Erythropoietin |
| Thrombopoietin |
| Interferon: |
| Alpha interferon |
| Gamma interferon |
| Interleukin: |
| IL-2 |
| IL-11 |
| Other, specify: |
| Monoclonal antibody, specify type: |
| Retinoic acid, specify type: |
| Bioimmunotherapy, other, specify: |
| **Other therapeutic modality, specify:** |
| **None** |
| **Unknown** |
| **#17: Complications/Late Effects (by system)** |
| **Auditory** |
| Conductive hearing loss |
| Eustachian tube dysfunction |
| Otosclerosis |
| Sensorineural hearing loss |
| Tinnitus |
| Tympanosclerosis |
| Vertigo |
| Auditory complication, other, specify: |
| **Cardiovascular** |
| Arrhythmia |

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Cardiovascular (cont)** |
| Atherosclerotic heart disease |
| Cardiomyopathy |
| Carotid artery disease |
| Congestive heart failure |
| Infection of retained cuff or line tract |
| Myocardial infarction |
| Pericardial fibrosis |
| Pericarditis |
| Post-thrombotic syndrome |
| Subclavian artery disease |
| Subclinical left ventricular dysfunction |
| Thrombosis |
| Valvular disease |
| Vascular insufficiency |
| Cardiovascular complication, other, specify: |
| **Central Nervous System (CNS)** |
| Ataxia |
| Cavernomas |
| Chronic pain, central neuropathic |
| Clinical leukoencephalopathy |
| Dysarthria |
| Dysphagia |
| Hemiparesis |
| Hydrocephalus |
| Movement disorders |
| Moyamoya |
| Neurocognitive deficits |
| Academic fluency |
| Behavioral change |
| Diminished IQ |
| Executive function (planning and organization) |
| Fine motor dexterity |
| Language |
| Learning deficits in math and reading (particularly reading comprehension) |
| Memory (particularly visual, sequencing, temporal memory) |
| Processing speed |
| Sustained attention |
| Visual-motor integration |
| Neurogenic bladder |
| Neurogenic bowel |

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Central Nervous System (CNS) (cont)** |
| Occlusive cerebral vasculopathy |
| Paralysis |
| Seizures |
| Shunt malfunction |
| Spasticity |
| Stroke |
| CNS complication, other, specify: |
| **Dental** |
| Dental caries |
| Ectopic molar eruption |
| Enamel dysplasia |
| Malocclusion |
| Microdontia |
| Osteoradionecrosis of the jaw |
| Periodontal disease |
| Root thinning/shortening |
| Salivary gland dysfunction |
| Temporomandibular joint dysfunction |
| Tooth/root agenesis |
| Xerostomia |
| Dental complication, other, specify: |
| **Dermatologic** |
| Altered skin pigmentation |
| Nail dystrophy |
| Permanent alopecia |
| Sclerodermatous changes |
| Skin fibrosis |
| Telangiectasias |
| Vitiligo |
| Dermatologic complication, other, specify: |
| **Endocrine/Metabolic** |
| Central adrenal insufficiency |
| Diabetes insipidus |
| Dyslipidemia |
| Gonadotropin deficiency (LH/FSH deficiency) |
| Growth hormone deficiency |
| Hyperprolactinemia |
| Hyperthyroidism |
| Hypothyroidism, primary (thyroid gland failure) |
| Hypothyroidism, central/secondary (T4/TSH deficiency) |

# Key for Completing Summary of Cancer Treatment (Comprehensive) (cont)

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Endocrine/Metabolic (cont)** |
| Impaired glucose metabolism/diabetes mellitus |
| Overweight<br>Age 2–20 yrs: BMI for age ≥ 85 – <95%ile<br>Age > 20 yrs: BMI 25 to 29.9 |
| Obesity<br>Age 2–20 yrs: BMI for age ≥ 95%ile<br>Age > 20 yrs, BMI ≥ 30 |
| Precocious puberty |
| Thyroid nodule |
| Endocrine/metabolic complication, other, specify: |
| **Gastrointestinal/Hepatic** |
| Abdominal adhesions |
| Bowel obstruction |
| Cholelithiasis |
| Chronic enterocolitis |
| Cirrhosis |
| Esophageal stricture |
| Fecal incontinence |
| Fistula |
| Focal nodular hyperplasia |
| Hepatic dysfunction |
| Hepatic fibrosis |
| Iron overload |
| Sinusoidal obstruction syndrome (SOS) [previously known as veno-occlusive disease (VOD)] |
| Strictures |
| Vitamin B12/folate/carotene deficiency |
| Gastrointestinal/hepatic complication, other, specify: |
| **Immune** |
| Asplenia - functional |
| Asplenia - surgical |
| Chronic hepatitis B |
| Chronic hepatitis C |
| Chronic graft-versus-host disease (cGVHD) |
| Chronic infection |
| Chronic sinusitis |
| Decreased B cells |
| HIV infection |
| Hypogammaglobulinemia |
| Secretory IgA deficiency |
| T cell dysfunction |

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Immune (cont)** |
| Immune complication, other, specify: |
| **Musculoskeletal** |
| Chronic pain, musculoskeletal |
| Contractures |
| Fibrosis |
| Functional and activity limitations |
| Hypoplasia |
| Impaired cosmesis |
| Increased energy expenditure (related to amputation/limb salvage) |
| Kyphosis |
| Limb length discrepancy |
| Osteonecrosis (avascular necrosis) |
| Prosthetic malfunction (loosening, non-union, fracture) requiring revision, replacement or amputation |
| Radiation-induced fracture |
| Reduced bone mineral density (BMD) |
| Reduced or uneven growth |
| Residual limb integrity problems |
| Scoliosis |
| Shortened trunk height |
| Musculoskeletal complication, other, specify: |
| **Ocular** |
| Cataract |
| Chronic painful eye |
| Gaze paresis |
| Glaucoma |
| Keratitis |
| Lacrimal duct atrophy |
| Maculopathy |
| Nystagmus |
| Ocular nerve palsy |
| Optic atrophy |
| Optic chiasm neuropathy |
| Orbital hypoplasia |
| Papilledema |
| Papillopathy |
| Poor prosthetic fit (related to enucleation) |
| Retinopathy |
| Telangiectasias |

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Ocular (cont)** |
| Xerophthalmia (keratoconjunctivitis sicca) |
| Ocular complication, other, specify: |
| **Peripheral Nervous System (PNS)** |
| Areflexia |
| Chronic pain, peripheral neuropathic |
| Dysesthesias |
| Foot drop |
| Paresthesias |
| Vasospastic attacks (Raynaud's phenomenon) |
| Weakness |
| PNS complication, other, specify: |
| **Psychosocial** |
| Anxiety |
| Dependent living |
| Depression |
| Educational problems |
| Fatigue |
| Limitations in healthcare and insurance access |
| Impaired quality of life |
| Post-traumatic stress |
| Psychological maladjustment |
| Psychosocial disability due to pain |
| Relationship problems |
| Risky behavior (behaviors known to increase the likelihood of subsequent illness or injury ) |
| Sleep problems |
| Social withdrawal |
| Suicidal ideation |
| Under-employment/Unemployment |
| Psychosocial complication, other, specify: |
| **Pulmonary** |
| Acute respiratory distress syndrome |
| Bronchiectasis |
| Bronchiolitis obliterans |
| Chronic bronchitis |
| Interstitial pneumonitis |
| Obstructive lung disease |
| Pulmonary fibrosis |
| Restrictive lung disease |
| Pulmonary complication, other, specify: |

# Key for Completing Summary of Cancer Treatment (Comprehensive) (cont)

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Reproductive – Female** |
| Adverse pregnancy outcome |
| Delivery complications |
| Fetal malposition |
| Adverse pregnancy outcome (cont) |
| Low-birth weight infant |
| Neonatal death |
| Premature labor |
| Pregnancy complications |
| Spontaneous abortion |
| Breast tissue hypoplasia |
| Dyspareunia |
| Infertility |
| Pelvic adhesions |
| Pelvic floor dysfunction |
| Premature ovarian insufficiency/ premature menopause |
| Psychosexual/sexual dysfunction |
| Puberty - absence |
| Puberty - delayed/arrested |
| Reduced fertility |
| Symptomatic ovarian cysts |
| Uterine vascular insufficiency |
| Vaginal fibrosis/stenosis |
| Vulvar scarring |
| Reproductive – female complication, other, specify: |
| **Reproductive – Male** |
| Anejaculation |
| Azoospermia |
| Ejaculatory dysfunction |
| Erectile dysfunction |
| Infertility |
| Oligospermia |
| Puberty - absence |
| Puberty - delayed/arrested |
| Reduced fertility |
| Retrograde ejaculation |
| Testosterone deficiency/insufficiency |
| Reproductive – male complication, other, specify: |
| **Urinary** |
| Asymptomatic bacteriuria |
| Bladder fibrosis |

| #17: Complications/Late Effects (by system) (cont) |
|---|
| **Urinary (cont)** |
| Chronic urinary tract infection |
| Dysfunctional voiding |
| Fanconi syndrome |
| Glomerular injury |
| Hemorrhagic cystitis |
| Hydrocele |
| Hydronephrosis |
| Hyperfiltration |
| Hypertension |
| Hypophosphatemic rickets |
| Proteinuria |
| Renal dysfunction |
| Renal insufficiency |
| Renal tubular acidosis |
| Reservoir calculi |
| Spontaneous neobladder perforation |
| Urinary incontinence |
| Urinary tract obstruction |
| Vesicoureteral reflux |
| Urinary complication, other, specify: |
| **Other, specify:** |
| **No late effects identified** |
| **Unknown** |

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# Patient-Specific Guideline Identification Tool

**Version 5.0**
**October 2018**

CHILDREN'S ONCOLOGY GROUP

The world's childhood cancer experts

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# Instructions:
# Patient-Specific Guideline Identification Tool (Version 5.0)

To determine Long-Term Follow-Up Guideline sections relevant to an **individual** patient:

1. Place a checkmark in the "Mark if Patient Received" column for each chemotherapy agent, radiation field, transplant type, surgery, or other therapeutic modality that the patient received.
2. Compile a list of all section numbers generated during step 1. Include the following sections as applicable:
   - Sections 1 - 6 — Applicable to all patients
   - Section 7 — Patients diagnosed before 1972
   - Section 8 — Patients diagnosed before 1993
   - Section 9 — Patients diagnosed between 1977 and 1985
   - Section 10 — All patients who received chemotherapy
   - Sections 43, 44, 95 — All patients who received radiation
   - Sections 99 - 104 — All patients who underwent hematopoietic cell transplant
     - Section 99 is for males only
     - Section 100 is for females only
   - Sections 156 - 164 — Applicable to all patients
     - Sections 162, 164 are for males only
     - Sections 156, 157, 159 are for females only
   - Section 165 — Applicable to all patients
3. For patients who received radiation for which a minimum dose specification is indicated, follow the "Instructions for Radiation Dose Calculation" in Appendix I. Delete from your list those radiation section(s) for which the patient did not receive the minimum radiation exposure at which the section(s) become applicable.
4. You now have a finalized list of all guideline sections applicable to this patient.

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# Patient-Specific Guideline Identification Tool

**Applicable guideline sections indicated in bold/dark blue; M=Male; F=Female**

| **Name**: | **Sex**: ☐ M ☐ F | **Date of Birth**: |
|---|---|---|

| **Cancer Diagnosis**: _____ | **Date of Diagnosis**: _____ | **End Therapy Date**: _____ |
|---|---|---|
| ☐ **Sections 1–6 applicable to all patients** | Prior to 1972: ☐ **Section 7**<br>Prior to 1993: ☐ **Section 8**<br>1977–1985: ☐ **Section 9** | **LTFU guidelines are applicable to patients who are ≥ 2 years following completion of cancer therapy.** |

**CHEMOTHERAPY**: ☐ **Yes** ☐ **No**

If yes: ☐ **Section 10 *and*** applicable guidelines for specific chemotherapy agents below

| Mark If Patient Received | Chemotherapy Agent | Applicable Guideline Sections |
|---|---|---|
| | Asparaginase | **Section 39** |
| | Bleomycin | **Section 34** |
| | Busulfan | **Sections 11M, 12M, 13F, 14F, 15, 16, 17** |
| | Carboplatin: All doses | **Sections 11M, 12M, 13F, 14F, 15, 22, 23** |
| | Carboplatin: Myeloablative dose (conditioning for HCT) | **Section 21** |
| | Carmustine (BCNU) | **Sections 11M, 12M, 13F, 14F, 15, 16** |
| | Chlorambucil | **Sections 11M, 12M, 13F, 14F, 15** |
| | Cisplatin | **Sections 11M, 12M, 13F, 14F, 15, 21, 22, 23** |
| | Cyclophosphamide | **Sections 11M, 12M, 13F, 14F, 15, 18, 19** |
| | Cytarabine: Low dose IV (all single doses <1000 mg/m$^2$), IO, IT, SQ | **Section 25** |
| | Cytarabine: High dose IV (any single dose ≥1000 mg/m$^2$) | **Section 24** |
| | Dacarbazine (DTIC) | **Sections 11M, 12M, 13F, 14F, 15** |
| | Dactinomycin | **Section 35** |
| | Daunorubicin*<br>Cumulative dose = _____ mg/m$^2$<br>Doxorubicin isotoxic dose = _____ mg/m$^2$ = Cumulative dose x 0.5 | **Section 32, 33** |
| | Dexamethasone | **Sections 36, 37, 38** |
| | Doxorubicin*<br>Cumulative dose: _____ mg/m$^2$<br>Doxorubicin isotoxic dose = _____ mg/m$^2$ = Cumulative dose x 1 | **Section 32, 33** |
| | Epirubicin*<br>Cumulative dose: _____ mg/m$^2$<br>Doxorubicin isotoxic dose = _____ mg/m$^2$ = Cumulative dose x 0.67 | **Section 32, 33** |
| | Etoposide (VP16) | **Section 42** |
| | Idarubicin*<br>Cumulative dose: _____ mg/m$^2$<br>Doxorubicin isotoxic dose = _____ mg/m$^2$ = Cumulative dose x 5 | **Section 32, 33** |
| | Ifosfamide | **Sections 11M, 12M, 13F, 14F, 15, 18, 20** |
| | Lomustine (CCNU) | **Sections 11M, 12M, 13F, 14F, 15, 16** |
| | Mechlorethamine | **Sections 11M, 12M, 13F, 14F, 15** |
| | Melphalan | **Sections 11M, 12M, 13F, 14F, 15** |
| | Mercaptopurine (6MP) | **Section 26** |
| | Methotrexate: High dose IV, Low dose IV, IM, PO | **Sections 27, 28, 29** |
| | Methotrexate: High dose IV, IO, IT | **Sections 30, 31** |

# Patient-Specific Guideline Identification Tool (cont)

| Mark If Patient Received (cont) | Chemotherapy Agent (cont) | Applicable Guideline Sections (cont) |
|---|---|---|
| | Mitoxantrone*<br>Cumulative dose: _____ $mg/m^2$<br>Doxorubicin isotoxic dose = _____ $mg/m^2$ = Cumulative dose x 4 | Section 32, 33 |
| | Prednisone | Sections 36, 37, 38 |
| | Procarbazine | Sections 11M, 12M, 13F, 14F, 15 |
| | Temozolomide | Sections 11M, 12M, 13F, 14F, 15 |
| | Teniposide (VM26) | Section 42 |
| | Thioguanine (6TG) | Section 26 |
| | Thiotepa | Sections 11M, 12M, 13F, 14F, 15 |
| | Vinblastine | Sections 40, 41 |
| | Vincristine | Sections 40, 41 |

***Instructions for Anthracycline Dose Calculation:** Use formulas below to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose:

**Daunorubicin** – multiply total dose x 0.5 **Doxorubicin** – multiply total dose x 1 **Epirubicin** – multiply total dose x 0.67

**Idarubicin** – multiply total dose x 5 **Mitoxantrone** – multiply total dose x 4

**Note**: There is a paucity of literature to support isotoxic dose conversion; however, the above conversion factors may be used for convenience in order to gauge screening frequency. Clinical judgment should ultimately be used to determine indicated screening for individual patients.

**RADIATION**: ☐ **Yes** ☐ **No**

If yes: ☐ **Sections 43, 44, 95** ***and*** applicable guidelines for specific radiation fields below

| Mark If Patient Received | Radiation Field* | Dose | Applicable Guideline Sections |
|---|---|---|---|
| | Any Radiation (not including TBI) | Any | Section 97 |
| | Head/Brain | Any | Sections 45, 46, 47, 48, 49, 50, 51, 52, 53M, 54F, 55, 56, 57M, 58F, 60, 61, 63, 64, 66, 67, 68, 69, 70 |
| | Head/Brain | Minimum dose specifications apply** | Sections 59, 62, 65 |
| | Neck | Any | Sections 63, 64, 66, 67, 68, 69, 70, 71, 78 |
| | Neck | Minimum dose specifications apply** | Section 65 |
| | Axilla | Any | Sections 72F, 73F, 74, 75 |
| | Chest | Any | Sections 71, 72F, 73F, 74, 75, 78, 96 |
| | Chest | Minimum dose specifications apply** | Section 76 |
| | Abdomen | Any | Sections 78, 79, 80, 81, 82, 83, 84, 85, 86, 96 |
| | Abdomen | Minimum dose specifications apply** | Sections 76, 77 |
| | Pelvis | Any | Sections 83, 84, 85, 87, 88, 91F, 92F, 93F, 94F |
| | Testes | Any | Sections 89M, 90M |
| | Spine (whole) | Any | Sections 63, 64, 66, 67, 68, 69, 70, 71, 78, 83, 84, 85, 87, 88, 91F, 92F, 93F, 96 |
| | Spine (whole) | Minimum dose specifications apply** | Sections 65, 76 |
| | Spine (cervical) | Any | Sections 63, 64, 66, 67, 68, 69, 70, 78 |
| | Spine (cervical) | Minimum dose specifications apply** | Section 65 |
| | Spine (thoracic) | Any | Sections 71, 78, 96 |

# Patient-Specific Guideline Identification Tool (cont)

| Mark If Patient Received (cont) | Radiation Field* (cont) | Dose (cont) | Applicable Guideline Sections (cont) |
|---|---|---|---|
| | Spine (thoracic) | Minimum dose specifications apply** | **Section 76** |
| | Spine (lumbar) | Any | **Sections 83, 84, 85, 96** |
| | Spine (sacral) | Any | **Sections 83, 84, 85, 87, 88, 91F, 92F, 93F** |
| | TBI | Any | **Sections 43, 44, 45, 46, 47, 52, 57M, 58F, 60, 63, 64, 66, 67, 68, 72F, 73F, 74, 75, 79, 80, 85, 86, 90M, 91F, 92F, 93F, 95** |
| | TBI | For cumulative dose calculation purposes only; these sections are not applicable to patients who received TBI alone** | **Sections 59, 62, 65, 76, 77** |

***Instructions for Determining Radiation Field**
Refer to "Radiation Fields Defined" in COG Long-Term Follow-Up Guidelines Appendix I pages 8-10 to determine applicable radiation fields. Note, for patients who received radiation to the flank/hemiabdomen, include the pelvis only if the field extended below the iliac crest.

****Instructions for Radiation Dose Calculation:**
Five sections of the COG Long-Term Follow-Up Guidelines (sections 59, 62, 65, 76, 77) include radiation dose specifications. These specifications indicate the minimum dose of radiation that is believed (based on available evidence and the recommendations of the expert panel) to place patients sufficiently at risk of the referenced late effect to recommend screening. For guideline sections that have a minimum specified dose, the following considerations apply in determining the applicability of the section for a patient based on his/her radiation exposure.

Sections with minimum dose specifications are applicable to a patient only if:
1. Patient received radiation to any field(s) relevant to the particular guideline section at ≥ the specified minimum dose†
**OR**
2. Patient received a combination of radiation to any relevant field(s)† **plus** relevant spinal radiation‡ **and/or** TBI, the sum of which is ≥ the specified minimum dose

†Total dose to each field should include boost dose, if given. If patient received radiation to more than one field relevant to a particular guideline section during a single planned course of radiation treatment (excluding spinal radiation and TBI), **the field that received the largest radiation dose should be used** in making the determination as to the applicability of the indicated guideline section(s). **Exception:** If patient received radiation to the same field at different times (e.g., at time of diagnosis AND at relapse), these doses should be added together when considering the applicability of the indicated guideline section.
‡Use the largest dose of radiation delivered to the spinal field(s) specified in the guideline section.

For examples of radiation dose calculations, refer to "Radiation Dose Calculations" in COG Long-Term Follow-Up Guidelines Appendix I page 11.

**Hematopoietic Cell Transplant: ☐ Yes ☐ No**

If yes: ☐ **Sections 99M, 100F, 101, 102, 103, 104** ***and*** applicable guidelines below

| Mark If Patient Received | Transplant Type | Chronic GVHD Status | Applicable Guideline Sections |
|---|---|---|---|
| | Autologous | N/A | **Section 98** |
| | Allogeneic | Without history of chronic GVHD | **No additional guideline sections** |
| | Allogeneic | With history of chronic GVHD | **Sections 105, 106, 107, 108, 109, 111, 112F, 113** |
| | Allogeneic | With currently active chronic GVHD | **Section 110** |

**Surgery: ☐ Yes ☐ No**

If yes, applicable guidelines for specific surgical procedures below

| Mark If Patient Received | Surgical Procedure | Applicable Guideline Sections |
|---|---|---|
| | Amputation | **Section 114** |

# Patient-Specific Guideline Identification Tool (cont)

| Mark If Patient Received (cont) | Surgical Procedure (cont) | Applicable Guideline Sections (cont) |
|---|---|---|
| | Central venous catheter | Section 115 |
| | Cystectomy | Sections 116, 141, 142, 143M, 144M, 145F |
| | Enucleation | Section 117 |
| | Hysterectomy | Section 118F |
| | Laparotomy | Section 119 |
| | Limb sparing procedure | Section 120 |
| | Nephrectomy | Sections 121M, 122F |
| | Neurosurgery – brain (all types) | Sections 123, 124, 125, 126 |
| | Neurosurgery – brain (applies only to neurosurgery with potential to affect the hypothalamic-pituitary axis) | Sections 127, 128 |
| | Neurosurgery – spinal cord | Sections 129, 130, 131M, 132F, 133 |
| | Oophoropexy | Section 134F |
| | Oophorectomy – unilateral | Section 135F, 136F |
| | Oophorectomy – bilateral | Section 137F |
| | Orchiectomy – unilateral/partial | Sections 138M, 139M |
| | Orchiectomy – bilateral | Section 140M |
| | Pelvic surgery | Sections 141, 142, 143M, 144M, 145F |
| | Splenectomy | Section 146 |
| | Thoracic surgery | Sections 147, 148 |
| | Thyroidectomy | Section 149 |

**Other Therapeutic Modalities**: ☐ **Yes** ☐ **No**

If yes, applicable guidelines for specific modalities below

| Mark If Patient Received | Other Therapeutic Modality | Applicable Guideline Sections |
|---|---|---|
| | Radioiodine therapy (I-131 thyroid ablation) | Sections 150, 151 |
| | Systemic MIBG | Sections 152, 153, 154 |
| | Bioimmunotherapy (e.g., G-CSF, IL-2, erythropoietin) | Section 155 |

**Cancer Screening Guidelines**

All patients: ☐ **Sections 158, 160, 161, 163**
Male patients: ☐ **Sections 162, 164**
Female patients: ☐ **Sections 156, 157, 159**

**General Health Screening**

All patients: ☐ **Section 165**

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# Section Number Comparison COG LTFU Guidelines Version 4.0 vs 5.0

**Version 5.0**
**October 2018**

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# Section Number Comparison
# COG LTFU Guidelines Version 4.0 vs 5.0

| Version 4.0 | Version 5.0 | Potential Late Effect |
|---|---|---|
| | | **Any Cancer Experience** |
| 1 | 1 | Adverse psychosocial/quality of life effects |
| 2 | 2 | Mental health disorders |
| 3 | 3 | Risky behavior |
| 4 | 4 | Psychosocial disability due to pain |
| 5 | 5 | Fatigue; Sleep problems |
| 6 | 6 | Limitations in healthcare and insurance access |
| | | **Blood/Serum Products** |
| 7 | 7 | Chronic hepatitis B |
| 8 | 8 | Chronic hepatitis C |
| 9 | 9 | HIV infection |
| | | **Chemotherapy** |
| 10 | 10 | Dental abnormalities |
| 11 | 12 | Impaired spermatogenesis |
| 12 | 11 | Testicular hormonal dysfunction |
| 13 | 13 | Separated into 2 sections in V5: Ovarian hormone deficiencies |
| | 14 | Separated into 2 sections in V5: Reduced ovarian follicular pool |
| 14 | 15 | Acute myeloid leukemia; Myelodysplasia |
| 15 | 16 | Pulmonary fibrosis |
| 16 | 17 | Cataracts |
| 17 | 18 | Urinary tract toxicity |
| 18 | 19 | Bladder malignancy |
| 19 | 20 | Renal toxicity |
| 20 | 21 | Ototoxicity |
| 21 | 22 | Peripheral sensory neuropathy |
| 22 | 23 | Renal toxicity |
| 23 | 24 | Neurocognitive deficits |
| 24 | N/A | Removed from V5: Clinical leukoencephalopathy related to cytarabine (high dose IV) |
| 25 | 25 | No known late effects related to cytarabine (low dose IV, IO, IT, SQ) |
| 26 | 26 | Hepatic dysfunction; Sinusoidal obstruction syndrome (SOS) |
| 27 | 27 | Reduced bone mineral density (BMD) |
| 28 | 28 | Update in V5: No known renal late effects related to methotrexate |
| 29 | 29 | Hepatic dysfunction |
| 30 | 30 | Neurocognitive deficits |
| 31 | 31 | Clinical leukoencephalopathy |
| 32 | 32 | Acute myeloid leukemia |
| 33 | 33 | Combined in V5: Cardiac toxicity |
| 34 | | |
| 35 | 34 | Pulmonary toxicity |
| 36 | 35 | No known late effects related to dactinomycin |
| 37 | 36 | Reduced bone mineral density (BMD) |
| 38 | 37 | Osteonecrosis (avascular necrosis) |
| 39 | 38 | Cataracts |
| 40 | 39 | No known late effects related to asparaginase |
| 41 | 40 | Peripheral sensory or motor neuropathy |
| 42 | 41 | Vasospastic attacks (Raynaud's phenomenon) |
| 43 | 42 | Acute myeloid leukemia |
| | | **Radiation** |
| 44 | 43 | Combined in V5: Secondary benign or malignant neoplasm occurring in or near radiation field |
| 45 | | |
| 47 | | |
| 46 | 44 | Dermatologic toxicity |
| 48 | 45 | Brain tumor (benign or malignant) |
| 49 | 46 | Neurocognitive deficits |
| 50 | 47 | Clinical leukoencephalopathy |
| 51 | 48 | Cerebrovascular complications |
| 52 | 49 | Craniofacial abnormalities |
| 53 | 50 | Chronic sinusitis |
| 54 | 51 | Overweight; Obesity |
| 55 | 52 | Growth hormone deficiency |
| 56 | 53 | Precocious puberty (male) |
| 57 | 54 | Precocious puberty (female) |
| 58 | 55 | Combined in V5: Hyperprolactinemia |
| 59 | | |

# Section Number Comparison
# COG LTFU Guidelines Version 4.0 vs 5.0 (cont)

| Version 4.0 | Version 5.0 | Potential Late Effect |
|---|---|---|
| 60 | 56 | Central hypothyroidism |
| 61 | 57 | Gonadotropin deficiency (male) |
| 62 | 58 | Gonadotropin deficiency (female) |
| 63 | 59 | Central adrenal insufficiency |
| 64 | 60 | Cataracts |
| 65 | 61 | Ocular toxicity |
| 66 | 62 | Combined in V5: Ototoxicity |
| 67 | | |
| 68 | 63 | Xerostomia; Salivary gland dysfunction |
| 69 | 64 | Dental abnormalities; Temporomandibular joint dysfunction |
| 70 | 65 | Osteoradionecrosis of the jaw |
| 71 | 66 | Thyroid nodules |
| 72 | 67 | Thyroid cancer |
| 73 | 68 | Hypothyroidism |
| 74 | 69 | Hyperthyroidism |
| 75 | 70 | Carotid artery disease |
| 76 | 71 | Subclavian artery disease |
| 77 | 72 | Breast cancer |
| 78 | 73 | Breast tissue hypoplasia |
| 79 | 74 | Pulmonary toxicity |
| N/A | 75 | New in V5: Lung cancer |
| 80 | 76 | Combined in V5: Cardiac toxicity |
| 81 | | |
| 82 | 77 | Functional asplenia |
| 83 | 78 | Esophageal stricture |
| 84 | 79 | Impaired glucose metabolism/diabetes mellitus |
| 85 | 80 | Dyslipidemia |
| 86 | 81 | Hepatic toxicity |
| 87 | 82 | Cholelithiasis |
| 88 | 83 | Bowel obstruction |
| 89 | 84 | Chronic enterocolitis; Fistula; Strictures |
| 90 | 85 | Colorectal cancer |
| 91 | 86 | Renal toxicity |

| Version 4.0 | Version 5.0 | Potential Late Effect |
|---|---|---|
| 92 | 87 | Combined in V5: Urinary tract toxicity |
| 93 | | |
| 94 | 88 | Bladder malignancy |
| 95 | 93 | Uterine vascular insufficiency |
| 96 | 91 | Separated into 2 sections in V5: Ovarian hormone deficiencies |
| | 92 | Separated into 2 sections in V5: Reduced ovarian follicular pool |
| 97 | 94 | Vaginal fibrosis/stenosis |
| 98 | 90 | Impaired spermatogenesis |
| 99 | 89 | Testicular hormonal dysfunction |
| 100 | 95 | Musculoskeletal growth problems |
| 101 | 96 | Scoliosis/Kyphosis |
| 102 | 97 | Radiation-induced fracture |
| **Hematopoietic Cell Transplant (HCT)** | | |
| 103 | 98 | Acute myeloid leukemia; Myelodysplasia |
| 104 | 99 | Solid tumors (male) |
| 105 | 100 | Solid tumors (female) |
| 106 | N/A | Removed from V5: Lymphoma related to HCT |
| 107 | 101 | Hepatic toxicity |
| 108 | 102 | Osteonecrosis (avascular necrosis) |
| 109 | 103 | Reduced bone mineral density (BMD) |
| 110 | 104 | Renal toxicity |
| 111 | 105 | Dermatologic toxicity |
| 112 | 106 | Xerophthalmia (keratoconjunctivitis sicca) |
| 113 | 107 | Oral toxicity |
| 114 | 108 | Pulmonary toxicity |
| 115 | 109 | Immunologic complications |
| 116 | 110 | Functional asplenia |
| 117 | 111 | Esophageal stricture |
| 118 | 112 | Vulvar scarring; Vaginal fibrosis/stenosis |
| 119 | 113 | Joint contractures |
| **Surgery** | | |
| 120 | 114 | Amputation-related complications |

# Section Number Comparison
# COG LTFU Guidelines Version 4.0 vs 5.0 (cont)

| Version 4.0 | Version 5.0 | Potential Late Effect |
|---|---|---|
| 121 | 115 | Thrombosis; Vascular insufficiency; Infection of retained cuff or line tract; Post-thrombotic syndrome |
| 122 | 116 | Cystectomy-related complications |
| 123 | 117 | Impaired cosmesis; Poor prosthetic fit; Orbital hypoplasia |
| 124 | 118 | Pelvic floor dysfunction; Urinary incontinence; Sexual dysfunction (female) |
| 125 | 119 | Adhesions; Bowel obstruction |
| 126 | 120 | Complications related to limb sparing procedure |
| 127 | 121 | Hydrocele; Renal toxicity (male) |
| 128 | 122 | Renal toxicity (female) |
| 129 | 123 | Neurocognitive deficits |
| 130 | 124 | Motor and/or sensory deficits |
| 131 | 125 | Seizures |
| 132 | 126 | Hydrocephalus; Shunt malfunction |
| 133 | 127 | Overweight; Obesity |
| 134 | 128 | Diabetes insipidus |
| 135 | 129 | Neurogenic bladder; Urinary incontinence |
| 136 | 130 | Neurogenic bowel; Fecal incontinence |
| 137 | 131 | Psychosexual dysfunction (male) |
| 138 | 132 | Psychosexual dysfunction (female) |
| 139 | 133 | Scoliosis/Kyphosis |
| 140 | 134 | Oophoropexy-related complication |
| 141 | 135 | Separated into 2 sections in V5: Ovarian hormone deficiencies |
| | 136 | Separated into 2 sections in V5: Reduced ovarian follicular pool |
| 142 | 137 | Ovarian hormone deficiencies; Loss of ovarian follicular pool |
| 143 | 138 | Separated into 2 sections in V5: Testicular hormonal dysfunction |
| | 139 | Separated into 2 sections in V5: Impaired spermatogenesis |
| 144 | 140 | Testosterone deficiency; Azoospermia |
| 145 | 141 | Urinary incontinence; Urinary tract obstruction |
| 146 | 142 | Fecal incontinence |
| 147 | 143 | Separated into 2 sections in V5: Psychosexual dysfunction (male) |
| | 144 | Separated into 2 sections in V5: Sexual dysfunction (anatomic); Infertility (male) |
| 148 | 145 | Sexual dysfunction (female) |
| 149 | 146 | Asplenia |
| 150 | 147 | Pulmonary dysfunction |
| 151 | 148 | Scoliosis/Kyphosis |
| 152 | 149 | Hypothyroidism |
| **Other Therapeutic Models** | | |
| 153 | 150 | Lacrimal duct atrophy |
| 154 | 151 | Hypothyroidism |
| 155 | 152 | Hypothyroidism |
| N/A | 153 | New to V5: Thyroid nodules |
| N/A | 154 | New to V5: Thyroid cancer |
| 156 | 155 | Insufficient information currently available regarding late effects of biological agents |
| **Cancer Screening Guidelines** | | |
| 157 | 156 | Breast cancer (female) |
| 158 | 157 | Cervical cancer (female) |
| 159 | 158 | Colorectal cancer |
| 160 | 159 | Endometrial cancer (female) |
| 161 | 160 | Lung cancer |
| 162 | 161 | Oral cancer |
| 163 | 162 | Prostate cancer (male) |
| 164 | 163 | Skin cancer |
| 165 | 164 | Testicular cancer (male) |
| **General Health Screening** | | |
| 166 | 165 | General health screening |