



Complete Summary

GUIDELINE TITLE

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 107-132: surgery.

BIBLIOGRAPHIC SOURCE(S)

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 107-132: surgery. In: Children's Oncology Group. Bethesda (MD): Children's Oncology Group; 2006 Mar. p. 26. [110 references]

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

** REGULATORY ALERT **

FDA WARNING/REGULATORY ALERT

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- [September 11, 2007, Rocephin \(ceftriaxone sodium\)](#): Roche informed healthcare professionals about revisions made to the prescribing information for Rocephin to clarify the potential risk associated with concomitant use of Rocephin with calcium or calcium-containing solutions or products.

COMPLETE SUMMARY CONTENT

** REGULATORY ALERT **

SCOPE

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IMPLEMENTATION OF THE GUIDELINE

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

SCOPE

DISEASE/CONDITION(S)

Late effects resulting from surgery to treat pediatric malignancies

Effects include complications from amputation, cystectomy, enucleation, hysterectomy, laparotomy, limb sparing procedure, nephrectomy, brain or spinal cord surgery, female or male reproductive surgery, splenectomy, thyroidectomy, pelvic or pulmonary surgery and use of a central venous catheter.

Note: These guidelines are intended for use beginning two or more years following the completion of cancer therapy, and provide a framework for ongoing late effects monitoring in childhood cancer survivors; however, these guidelines are not intended to provide guidance for follow-up of the pediatric cancer survivor's primary disease.

GUIDELINE CATEGORY

Evaluation
Management
Prevention
Screening

CLINICAL SPECIALTY

Cardiology
Colon and Rectal Surgery
Endocrinology
Family Practice
Gastroenterology
Internal Medicine
Nephrology
Neurological Surgery
Neurology
Obstetrics and Gynecology
Oncology
Ophthalmology
Orthopedic Surgery
Pediatrics
Physical Medicine and Rehabilitation
Plastic Surgery
Psychiatry
Psychology
Pulmonary Medicine
Surgery
Urology

INTENDED USERS

Advanced Practice Nurses
Nurses
Occupational Therapists
Physical Therapists
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

- To provide recommendations for screening and management of late effects in survivors of pediatric malignancies
- To increase quality of life and decrease complication-related healthcare costs for pediatric cancer survivors by providing standardized and enhanced follow-up care throughout the life-span that (a) promotes healthy lifestyles, (b) provides for ongoing monitoring of health status, (c) facilitates early identification of late effects, and (d) provides timely intervention for late effects

TARGET POPULATION

Asymptomatic survivors of childhood, adolescent, or young adult cancers who were treated surgically and who present for routine exposure-related medical follow-up

INTERVENTIONS AND PRACTICES CONSIDERED

Thorough history and physical examination, and targeted screening evaluations

MAJOR OUTCOMES CONSIDERED

Not stated

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Pertinent information from the published medical literature over the past 20 years (updated as of October 2005) was retrieved and reviewed during the development and updating of these guidelines. For each therapeutic exposure, a complete search was performed via MEDLINE (National Library of Medicine, Bethesda, MD).

Keywords included "childhood cancer therapy," "complications," and "late effects," combined with keywords for each therapeutic exposure. References from the bibliographies of selected articles were used to broaden the search.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)
Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

"High-level evidence" (recommendation category 1) was defined as evidence derived from high quality case control or cohort studies.

"Lower-level evidence" (recommendation categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series, and clinical experience.

METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

The guidelines were scored by the multidisciplinary panel of experts using a modified version of the National Criteria: Comprehensive Cancer Network "Categories of Consensus" system. Each score reflects the expert panel's assessment of the strength of data from the literature linking a specific late effect with a therapeutic exposure, coupled with an assessment of the appropriateness of the screening recommendation based on the expert panel's collective clinical experience. "High-level evidence" (category 1) was defined as evidence derived from high quality case control or cohort studies. "Lower-level evidence" (categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series and clinical experience. Rather than submitting recommendations representing major disagreements, items scored as "Category 3" were either deleted or revised by the panel of experts to provide at least a "Category 2B" score for all recommendations included in the guidelines.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

In 2002, the leadership of the Children's Oncology Group Late Effects Committee and Nursing Discipline appointed a 7-member task force, with representation from the Late Effects Committee, Nursing Discipline, and Patient Advocacy Committee. The task force was convened to review and summarize the medical literature and develop a draft of clinical practice guidelines to direct long-term follow-up care for pediatric cancer survivors. The task force followed a modified version of the guideline development process established by the National Comprehensive Cancer Network (NCCN), integrating available literature with expert opinion using reiterative feedback loops.

The original draft went through several iterations within the task force prior to initial review. Multidisciplinary experts in the field, including nurses, physicians (pediatric oncologists and other subspecialists), patient advocates, behavioral specialists, and other healthcare professionals, were then recruited by the task force to provide an extensive, targeted review of the draft, including focused review of selected guideline sections. Revisions were made based on these recommendations. The revised draft was then sent out to additional multidisciplinary experts for further review. A total of 62 individuals participated in the review process. The guidelines subsequently underwent comprehensive review and scoring by a panel of experts in the late effects of pediatric malignancies, comprised of multidisciplinary representatives from the COG Late Effects Committee.

Revisions

In order to keep the guidelines current and clinically meaningful, the COG Late Effects Committee organized 18 multi-disciplinary task forces in March 2004. These task forces were charged with the responsibility for monitoring the medical literature in regard to specific system-related clinical topics relevant to the guidelines (e.g., cardiovascular, neurocognitive, fertility/reproductive), providing periodic reports to the Late Effects Committee, and recommending revisions to the guidelines and their associated health education materials and references (including the addition of therapeutic exposures) as new information became available. Task force members were assigned according to their respective areas of expertise and clinical interest. A list of these task forces and their membership is included in the "Contributors" section of the original guideline document. The revisions incorporated into the current release of these guidelines (Version 2.0 – March 2006) reflect the contributions and recommendations of these task forces.

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score (see "Rating Scheme for the Strength of the Evidence"). Proposed revisions that were rejected by the expert panel were returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel. A total of 34 sections and 9 Health Links were added to Version 2.0 of these guidelines.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Each score relates to the strength of the association of the identified late effect with the specific therapeutic exposure based on current literature, and is coupled

with a recommendation for periodic health screening based on the collective clinical experience of the panel of experts. This is due to the fact that there are no randomized clinical trials (and none forthcoming in the foreseeable future) on which to base recommendations for periodic screening evaluations in this population; therefore, the guidelines should not be misconstrued as representing conventional "evidence-based clinical practice guidelines" or "standards of care".

Each item was scored based on the level of evidence currently available to support it. Scores were assigned according to a modified version of the National Comprehensive Cancer Network "Categories of Consensus," as follows:

1 There is uniform consensus of the panel that (1) there is high-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2A There is uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2B There is non-uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

3 There is major disagreement that the recommendation is appropriate.

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The initial version of the guidelines (Version 1.0 – Children's Oncology Group Late Effects Screening Guidelines) was released to the Children's Oncology Group (COG) membership in March 2003 for a six-month trial period. This allowed for initial feedback from the COG membership, resulting in additional review and revision of the guidelines by the Late Effects Committee prior to public release.

Revisions

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score (see "Rating Scheme for the Strength of the Evidence"). Proposed revisions that were rejected by the expert panel were

returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Grades of recommendations (1, 2A, 2B, 3) are defined at the end of the "Major Recommendations" field.

Note from the Children's Oncology Group and the National Guideline Clearinghouse (NGC): The *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* (COG LTFU) are organized according to therapeutic exposures; this guideline has been divided into individual summaries. In addition to the current summary, the following are available:

- [Sections 1-2: Any Cancer Experience](#)
- [Sections 3-5: Blood/Serum Products](#)
- [Sections 6-37: Chemotherapy](#)
- [Sections 38-91: Radiation](#)
- [Sections 92-106: Hematopoietic Cell Transplant](#)
- [Sections 133-136: Other Therapeutic Modalities](#)
- [Sections 137-146: Cancer and General Health Screening](#)

In order to accurately derive individualized screening recommendations for a specific childhood cancer survivor using this guideline, see "Using the COG LTFU Guidelines to Develop Individualized Screening Recommendations" in the [original guideline document](#). (Note: For ease of use, a Patient-Specific Guideline Identification Tool has been developed to streamline the process and is included in [Appendix I](#) of the original guideline document.)

Guideline Organization

The *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* are organized according to therapeutic exposures, arranged by column as follows:

System	Body system (e.g., auditory, musculoskeletal) most relevant to each guideline section.
Score	Score assigned by expert panel representing the strength of data from the literature linking a specific late effect with a therapeutic exposure coupled with an assessment of the appropriateness of the screening recommendation based on collective clinical experience.
Section Number	Unique identifier for each guideline section corresponding with listing in Index.

Therapeutic Agent	Therapeutic intervention for malignancy, including chemotherapy, radiation, surgery, blood/serum products, hematopoietic cell transplant, and other therapeutic modalities.
Risk Factors	Host factors (e.g., age, sex, race, genetic predisposition), treatment factors (e.g., cumulative dose of therapeutic agent, mode of administration, combinations of agents), medical conditions (e.g., pre-morbid or co-morbid conditions), and health behaviors (e.g., diet, smoking, alcohol use) that may increase risk of developing the complication.
Highest Risk Factors	Conditions (host factors, treatment factors, medical conditions and/or health behaviors) associated with the highest risk for developing the complication.
Periodic Evaluations	Recommended screening evaluations, including health history, physical examination, laboratory evaluation, imaging, and psychosocial assessment. Recommendation for minimum frequency of periodic evaluations is based on risk factors and magnitude of risk, as supported by the medical literature and/or the combined clinical experience of the reviewers and panel of experts.
Health Counseling/ Further Considerations	<p>Health Links: Health education materials developed specifically to accompany these guidelines. Title(s) of Health Link(s) relevant to each guideline section are referenced in this column. Health Link documents are included in Appendix II of the original guideline document.</p> <p>Counseling: Suggested patient counseling regarding measures to prevent/reduce risk or promote early detection of the potential treatment complication.</p> <p>Resources: See the original guideline document for lists of books and web sites that may provide the clinician with additional relevant information.</p> <p>Considerations for Further Testing and Intervention: Recommendations for further diagnostic evaluations beyond minimum screening for individuals with positive screening tests, recommendations for consultation and/or referral, and recommendations for management of exacerbating or predisposing conditions.</p>
References	References are listed immediately following each guideline section in the original guideline document. Included are medical citations that provide evidence for the association of the therapeutic intervention with the specific treatment complication and/or evaluation of predisposing risk factors. In addition, some general review articles have been included in the Reference section of the original guideline document for clinician convenience.

Note: See the end of the "Major Recommendations" field for explanations of [abbreviations](#) included in the summary.

**System = Musculoskeletal
Score = 1**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling/ Follow-up Considerations
107	Amputation	Amputation-related complications Impaired cosmesis Functional and activity limitations Residual limb integrity problems Phantom pain Neuropathic pain Musculoskeletal pain Increased energy expenditure Impaired quality of life and functional status Psychological maladjustment	Host Factors Skeletally immature/ growing children Treatment Factors Site of amputation: <ul style="list-style-type: none"> • Hemipelvectomy <ul style="list-style-type: none"> • Trans-femur amputation • Trans-tibia amputation Medical Conditions Obesity Diabetes Poor residual limb healing		History Phantom pain Functional and activity limitations (Yearly) Physical Residual limb integrity (Yearly) Screening Prosthetic evaluation (Every six months until skeletally mature, then yearly thereafter)	Health Counseling/ Follow-up Considerations See "Patient Resources" Amputation Counseling Counsel on skin care of poor fit, residual and prosthetic hygiene, fitness, and important to maintain healthy lifestyle. Considerations for Further Testing/ Intervention Physical consults needed periodically, changing status as weight gain, training prosthesis, non-pharmacologic pain management, Occupational therapy consults needed for with active daily living, Psychological

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						work con to assist emotion difficulti to body marriage pregnan parentin employ insuranc depressi Vocation counseli to identi vocation not produce, function limitatio

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Cardiovascular
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
108	Central venous catheter	Thrombosis Vascular insufficiency Infection of retained cuff or line tract			History Tenderness or swelling at previous catheter site (Yearly and as clinically indicated) Physical Venous	

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
					stasis Swelling Tenderness at previous catheter site (Yearly and as clinically indicated)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Urinary
Score = Chronic urinary tract infection: 1
Renal dysfunction: 1
Vesicoureteral reflux: 1
Hydronephrosis: 1
Spontaneous neobladder perforation: 1
Reservoir calculi: 2A
Vitamin B21/folate/carotene deficiency: 2B

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
109	Cystectomy Info Link: All potential late effects for pelvic surgery apply to Cystectomy (see also sections 126-129, below).	Cystectomy-related complications Chronic urinary tract infection Renal dysfunction Vesicoureteral reflux Hydronephrosis Reservoir calculi Spontaneous neobladder perforation Vitamin B12/folate/carotene			Screening Urology evaluation (Yearly)	Health Links See "Patient Resources" field Cystectomy Kidney Health

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
		deficiency Info Link: Reservoir calculi are stones in the neobladder (a reservoir for urine usually constructed of ileum/colon)				

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Ocular
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
110	Enucleation	Impaired cosmesis Poor prosthetic fit Orbital hypoplasia	Host Factors Younger age at enucleation Treatment Factors Combined with radiation		Screening Evaluation by ophthalmologist Evaluation by ophthalmologist (Yearly)	Health Links See "Patient Resources" field Eye Health Considerations for Further Testing and Intervention Psychological consultation in patients with emotional difficulties related to cosmetic and visual impairment. Vocational rehabilitation referral as

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						indicated.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Female reproductive
Score = 2A

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
111 (Female)	Hysterectomy Info Link: For patients who also underwent oophorectomy, see also: Section 123 (unilateral oophorectomy) or Section 124 (bilateral oophorectomy), below	Pelvic floor dysfunction Urinary incontinence Sexual dysfunction			History Psychosocial assessment Abdominal pain Urinary leakage Dyspareunia (Yearly)	Health Links See "Patient Resources" field Female Health Issues Counseling Counsel patients with ovaries regarding potential for biologic parenthood using gestational surrogate. Considerations for Further Testing and Intervention Reproductive endocrinology consultation for patients wishing to pursue pregnancy via gestational

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						surrogate.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = GI/Hepatic
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
112	Laparotomy	Adhesions Bowel obstruction	Treatment Factors Combined with radiation		History Abdominal pain Emesis Distention Vomiting Constipation (With clinical symptoms of obstruction) Physical Tenderness Abdominal guarding Distension (With clinical symptoms of obstruction)	Health Links See "Patient Resources" field Gastrointestinal Health Considerations for Further Testing and Intervention KUB as clinically indicated for suspected obstruction. Surgical consultation for patients unresponsive to medical management.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Musculoskeletal
Score = 1**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
113	<p>Limb sparing procedure</p>	<p>Complications related to limb sparing procedure</p> <p>Functional and activity limitations Contractures Chronic infection Chronic pain Limb length discrepancy Musculoskeletal pain Increased energy expenditure Fibrosis Prosthetic malfunction (loosening, non-union, fracture) requiring revision, replacement, or amputation Prosthetic revision required due to growth Impaired quality of life Complications with pregnancy/delivery (in female patients with internal hemipelvectomy)</p>	<p>Host Factors</p> <p>Younger age at surgery Rapid growth spurt</p> <p>Treatment Factors</p> <p>Tibial endoprosthesis</p> <p>Medical Conditions</p> <p>Endoprosthetic infection Obesity</p> <p>Health Behaviors</p> <p>High level of physical activity (associated with higher risk of loosening) Low level of physical activity (associated with higher risk of contractures or functional limitations)</p>	<p>Treatment Factors</p> <p>Radiation to extremity</p> <p>Medical Conditions</p> <p>Poor healing Infection of reconstruction</p>	<p>History</p> <p>Functional and activity limitations</p> <p>(Yearly and as clinically indicated)</p> <p>Physical</p> <p>Residual limb integrity</p> <p>(Yearly and as clinically indicated)</p> <p>Screening</p> <p>Radiograph</p> <p>(Yearly)</p> <p>Evaluation by orthopedic surgeon</p> <p>(Every six months until skeletally mature, then yearly)</p>	<p>Health Links</p> <p>See "Patient Resources" for</p> <p>Limb Sparing Procedures</p> <p>Counseling</p> <p>Counsel regarding need for antibiotic prophylaxis pre-dental and invasive procedures.</p> <p>Considerations for Further Testing and Intervention</p> <p>Antibiotic prophylaxis pre-dental and invasive procedures. Physical therapy consultation as needed per changes in functional status (such as post-lengthening, revisions, life changes such as pregnancy), and non-pharmacologic pain management. Consider psychological consultation as needed to assist with emotional difficulties related to</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						to body image, marriage, pregnancy, parenting, employment, insurance and depression. Vocational counseling/training to identify vocations that not produce/exacerbate functional limitations.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Urinary
Score = 1**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
114	Nephrectomy	Renal toxicity Proteinuria Hyperfiltration Renal insufficiency Hydrocele (males only)	Treatment Factors Combined with other nephrotoxic therapy, such as: <ul style="list-style-type: none"> • Cisplatin • Carboplatin • Ifosfamide • Aminoglycosides • Amphotericin • Immunosuppressants • Methotrexate • Radiation impacting the kidneys 		Physical Blood pressure (Yearly) Testicular exam to evaluate for hydrocele (Yearly for males) Screening BUN	See Res field Sing Hea See Kidn Cou Disc spo safe avo han inju

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	C
					Creatinine Na, K, Cl, CO₂ Ca, Mg, PO₄ (Baseline at entry into long-term followup. If abnormal, repeat as clinically indicated.) Urinalysis (Yearly)	prop sea wea arou wai to u with Cor for Test Int Nep con pati hyp prot prog ren insu

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation
115	Neurosurgery - Brain	Neurocognitive deficits Functional deficits in: <ul style="list-style-type: none"> Executive function (planning and organization) Sustained attention 	Host Factors Younger age at treatment Primary CNS tumor Treatment Factors Extent and location of resection Longer elapsed time since therapy	Host Factors Age <3 years at time of treatment Supratentorial tumor Predisposing family history of learning or attention problems	History Educational and vocational progress (Yearly) Screening Referral for for neuropsycholo

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation
		<ul style="list-style-type: none"> • Memory (particularly visual, sequencing, temporal memory) • Processing speed • Visual-motor integration <p>Learning deficits in math and reading (particularly reading comprehension) Diminished IQ Behavioral change</p> <p>Info Link: Neurocognitive deficits vary with extent of surgery and postoperative complications. In general, mild delays occur in most areas of neuropsychological function compared to healthy children. Extent of deficit depends on age at treatment, intensity of treatment, and time since treatment. New deficits may emerge over time. Neurosensory deficits (i.e., vision, hearing) due to tumor or its therapy may complicate neurocognitive outcomes.</p>	<p>In combination with:</p> <ul style="list-style-type: none"> • TBI • Cranial radiation • Methotrexate (IT, IO, high-dose IV) • Cytarabine (high-dose IV) 	<p>Treatment Factors Radiation dose ≥ 24 Gy to whole brain Radiation dose ≥ 40 Gy to local fields</p> <p>Medical Conditions Posterior fossa syndrome CNS infection</p>	<p>evaluation (Baseline at entry into long-term followup. Periodic as clinically indicated for patients with evidence of impaired educational or vocational progress)</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Con
116	Neurosurgery - Brain	Motor and/or sensory deficits Paralysis Movement disorders Ataxia Eye problems (ocular nerve palsy, gaze paresis, nystagmus, papilledema, optic atrophy)	Host Factors Primary CNS tumor Medical Conditions Hydrocephalus	Host Factors Optic pathway tumor Hypothalamic tumor Suprasellar tumor (eye problems)	Screening Evaluation by neurologist (Yearly, until 2 to 3 years after surgery or stable; continue to monitor if symptoms persist) Evaluation by physiatrist/rehabilitation medicine specialist (Yearly, or more frequently as clinically indicated in patients with motor dysfunction)	Con Con Test Inte Spee phys occu ther patie pers defic Cons cons with endo psyc obse com beha patie hyp pitui tumo Oph eval clini india

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
117	Neurosurgery - Brain	Seizures	Host Factors Primary CNS tumor Treatment Factors Methotrexate (IV, IT, IO)		Screening Evaluation by neurologist (Every six months for patients with seizure disorder)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
118	Neurosurgery - Brain	Hydrocephalus Shunt malfunction	Host Factors Primary CNS tumor		Screening Abdominal x-ray (After pubertal growth spurt for patients with shunts to assure distal shunt tubing in peritoneum) Evaluation by neurosurgeon (Yearly for	Counseling Educate patient/family regarding potential symptoms of shunt malfunction.

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
					patients with shunts)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
119	Neurosurgery - Spinal cord	<p>Neurogenic bladder</p> <p>Urinary incontinence</p>	<p>Host Factors</p> <p>Tumor adjacent to or compressing spinal cord or cauda equina</p> <p>Treatment Factors</p> <p>Radiation dose ≥ 45 Gy to lumbar and/or sacral spine and/or cauda equina</p>	<p>Host Factors</p> <p>Injury above the level of the sacrum</p> <p>Treatment Factors</p> <p>Radiation dose ≥ 50 Gy to lumbar and/or sacral spine and/or cauda equina</p>	<p>History</p> <p>Hematuria</p> <p>Urinary urgency/frequency</p> <p>Urinary incontinence/retention</p> <p>Dysuria</p> <p>Nocturia</p> <p>Abnormal urinary stream</p> <p>(Yearly)</p>	<p>Health Counseling</p> <p>See "Patient Resources" field</p> <p>Neurogenic Bladder</p> <p>Counseling</p> <p>Counsel regarding adequate intake, re voiding, s medical attention symptom voiding dysfunction urinary tr infection, compliance recomme bladder catheteriz regimen.</p> <p>Consideration for Further Testing</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						Intervention Urologic consultation for patients with urinary dysfunction or recurrent urinary tract infections

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
120	Neurosurgery - Spinal cord	Neurogenic bowel Fecal incontinence	Host Factors Tumor adjacent to or compressing spinal cord or cauda equina Treatment Factors Radiation dose ≥ 50 Gy to bladder, pelvis, or spine	Host Factors Injury above the level of the sacrum	History Chronic constipation Fecal soiling (Yearly) Physical Rectal exam (As clinically indicated)	Counseling Counsel regarding benefits of adherence to bowel regimen, including adequate hydration, fiber, laxatives/enemas as clinically indicated. Considerations for Further Testing and Intervention GI consultation to establish bowel regimen for patients with chronic

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						impaction or fecal soiling.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = CNS
Score = 2A

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
121 (Male)	Neurosurgery - Spinal cord	Sexual dysfunction (Male) Erectile dysfunction	Host Factors Tumor adjacent to or compressing spinal cord or cauda equina Treatment Factors Radiation to bladder, pelvis, or spine Medical Conditions Hypogonadism	Host Factors Injury above the level of the sacrum Treatment Factors Radiation dose ≥ 55 Gy to penile bulb in adult Radiation dose ≥ 45 Gy in prepubertal child	History Sexual function (erections, nocturnal emissions, libido) Medication use impacting sexual function (Yearly)	Health Links See "Patient Resources" field Male Health Issues Resources www.urologychannel.com Considerations Further Testing Intervention Urologic consultation for patients with positive history.
	Neurosurgery - Spinal cord	Sexual dysfunction (Female)	Host Factors Tumor adjacent to or compressing spinal cord or cauda equina Treatment Factors	Host Factors Injury above the level of the sacrum	History Dyspareunia Altered or diminished sensation, loss of sensation Medication	

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
			Radiation to bladder, pelvis, or spine Medical Conditions Hypogonadism Vaginal fibrosis/stenosis Chronic GVHD		use impacting sexual function (Yearly)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Female Reproductive
Score = 2A

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
122 (Female)	Oophoropexy Info Link: If shielding from radiation was incomplete: See also Section 84 (ovarian dysfunction related to radiation). (See related guideline summaries listed at the beginning of the "Major Recommendations" field.)	Oophoropexy-related complications Inability to conceive despite normal ovarian function Dyspareunia Symptomatic ovarian cysts Bowel obstruction Pelvic adhesions	Treatment Factors Ovarian radiation Tubo-ovarian dislocation, especially with lateral ovarian transposition		History Abdominal pain Pelvic pain Dyspareunia Inability to conceive despite normal ovarian function (Yearly)	Consideration for Further Testing and Intervention Gynecologic consultation for patients with positive history and/or physical findings.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Female reproductive
Score = 2A

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation
123 (Female)	Oophorectomy (unilateral)	Premature menopause Info Link: Evidence for premature menopause following unilateral oophorectomy is limited and has been extrapolated from the adult literature.	Health Behaviors Smoking	Treatment Factors Combined with: <ul style="list-style-type: none"> • Pelvic radiation • Alkylating agents • TBI 	History Pubertal (onset, tempo) Menstrual/pregnancy history Sexual function (vaginal dryness, libido) Medication use impacting sexual function (Yearly) Physical Tanner stage (Yearly until sexually mature) Screening FSH LH Estradiol (Baseline at age 13 and as clinically indicated in patients with delayed puberty, irregular menses, primary or secondary amenorrhea, and/or clinical signs and symptoms of estrogen deficiency)

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Female Reproductive
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counsel Further Consideration
124 (Female)	Oophorectomy (bilateral)	Hypogonadism Infertility			<p>Screening</p> <p>Gynecologic or endocrinologic consultation for initiation of HRT</p> <p>(At age 11)</p>	<p>Health Links</p> <p>See "Patient Resources" field</p> <p>Female Health Iss</p> <p>Resources</p> <p>American Society Reproductive Med (www.asrm.org)</p> <p>Fertile Hope (www.fertilehope.com)</p> <p>Counseling</p> <p>Counsel regarding benefits of HRT in promoting pubertal progression, bone cardiovascular health. Counsel women regarding pregnancy potential with donor eggs (if uterus is intact).</p> <p>Considerations for Further Testing Intervention</p> <p>Bone density evaluation for osteopenia/osteoporosis in hypogonadal patients. Reproductive endocrinology referral regarding assisted reproductive technologies.</p>

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Male Reproductive
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
125 (Male)	Orchiectomy	Hypogonadism Infertility	Treatment Factors Unilateral orchiectomy combined with pelvic or testicular radiation and/or alkylating agents	Treatment Factors Bilateral orchiectomy	History Pubertal (onset, tempo) Sexual function (erections, nocturnal emissions, libido) Medication use impacting sexual function (Yearly) Physical Tanner stage Testicular volume by Prader orchidometry (Yearly until sexually mature) Screening Semen analysis (As requested by patient for evaluation of infertility) FSH, LH, testosterone	Health Links See "Patient Resources" field Male Health Issues Counseling For patients with single testis - counsel to wear athletic supporter with protective cup during athletic activities. Considerations for Further Testing and Intervention Refer to endocrinologist for bilateral orchiectomy, delayed puberty, or persistently abnormal hormone levels. Consider surgical placement of testicular prosthesis.

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
					(For patient with bilateral orchiectomy, refer to endocrinology at about age 11. For patients with unilateral orchiectomy, obtain as clinically indicated for delayed puberty or signs and symptoms of testosterone deficiency.)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Urinary
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
126	Pelvic surgery Info Link: For patients with cystectomy: See also Section 109, above	Urinary incontinence Urinary tract obstruction Info Link: Urinary tract obstruction related to retroperitoneal fibrosis	Host Factors Tumor adjacent to or compressing spinal cord or cauda equina Treatment Factors Retroperitoneal node dissection Extensive		History Hematuria Urinary urgency/frequency Urinary incontinence/retention Dysuria Nocturia Abnormal urinary	Counseling Counsel regarding adequate fluid intake, regular voiding, seek medical attention for symptoms voiding dysfunction urinary tract infection, compliance

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
			pelvic dissection (e.g., bilateral ureteral re-implantation, retroperitoneal tumor resection): Radiation to the bladder, pelvis, and/or lumbar-sacral spine		stream (Yearly)	recommend bladder catheterization regimen. Considerations for Further Testing and Intervention Urologic consultation for patients with dysfunction voiding or recurrent urinary tract infections.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = GI/Hepatic
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
127	Pelvic surgery	Fecal incontinence	Host Factors Tumor adjacent to or compressing spinal cord or cauda equina Treatment Factors Radiation to the bladder,		History Chronic constipation, fecal soiling (Yearly) Physical Rectal exam (As clinically indicated)	Counseling Counsel regarding benefits of adherence to bowel regimen, including adequate hydration, fiber, laxatives/enemas as clinically indicated. Considerations for Further

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
			pelvis, or spine			Testing and Intervention GI consultation to establish bowel regimen for patients with chronic impaction or fecal soiling.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Male/Female Reproductive
Score = 2A**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counsel Further Consider
128 (Male)	Pelvic surgery	Sexual dysfunction (Male) Retrograde ejaculation Anejaculation Erectile dysfunction	Treatment Factors Retroperitoneal node dissection Retroperitoneal tumor resection Cystectomy Radical prostatectomy Tumor adjacent to spine Radiation to bladder, pelvis, or spine Medical Conditions Hypogonadism	Host Factors Extensive presacral tumor resection or dissection Radiation dose ≥ 55 Gy to penile bulb in adult and ≥ 45 Gy in prepubertal child	History Sexual function (erections, nocturnal emissions, libido) Medication use impacting sexual function Quality of ejaculate (frothy white urine with first void after intercourse suggests retrograde ejaculation)	Health Links See "Patient Resources" field Male Health Issues Resources www.urologychannel.com Considerations for Further Testing and Intervention Urologic consultation for patients with positive history and/or physical exam findings.

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counsel Further Consider
					(Yearly)	
	Pelvic surgery	Sexual dysfunction (Female)	Host Factors Chronic GVHD Hypogonadism Tumor adjacent to spine Medical Conditions Radiation to bladder, pelvis, or spine		History Dyspareunia Altered or diminished sensation, loss of sensation Medication use impacting sexual function (Yearly)	

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Urinary
Score = 1

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
129 (Male)	Pelvic surgery	Hydrocele	Treatment Factors Retroperitoneal node dissection		Physical Testicular exam to evaluate for hydrocele (Yearly)	Considerations for Further Testing and Intervention Urologic consultation for patients with hydrocele.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

System = Pulmonary
Score = 2A

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Con
130	<p>Pulmonary lobectomy</p> <p>Pulmonary metastasectomy</p> <p>Pulmonary wedge resection</p>	Pulmonary dysfunction	<p>Treatment Factors</p> <p>Combined with pulmonary toxic therapy</p> <ul style="list-style-type: none"> • Bleomycin • Busulfan • Carmustine (BCNU) • Lomustine (CCNU) <p>Medical Conditions</p> <p>Atopic history</p> <p>Health Behaviors</p> <p>Smoking</p>	<p>Treatment Factors</p> <p>Combined with:</p> <ul style="list-style-type: none"> • Chest radiation • TBI 	<p>History</p> <p>Cough</p> <p>SOB</p> <p>DOE</p> <p>Wheezing</p> <p>(Yearly)</p> <p>Physical</p> <p>Pulmonary exam</p> <p>(Yearly)</p> <p>Screening</p> <p>Chest x-ray</p> <p>PFTs (including DLCO and spirometry)</p> <p>(Baseline at entry into long-term follow-up. Repeat as clinically indicated in patients with abnormal results or progressive pulmonary dysfunction.)</p>	<p>Health</p> <p>See "Reso</p> <p>Pulmo</p> <p>Reso</p> <p>Extens</p> <p>inform</p> <p>regar</p> <p>cessat</p> <p>availa</p> <p>patien</p> <p>NCI's</p> <p>www.nccih.nih.gov</p> <p>Coun</p> <p>Couns</p> <p>tobac</p> <p>avoid</p> <p>cessat</p> <p>who d</p> <p>SCUB</p> <p>be adv</p> <p>medic</p> <p>from a</p> <p>medic</p> <p>Consi</p> <p>for Fu</p> <p>Testi</p> <p>Inter</p> <p>In pat</p> <p>abnor</p> <p>and/o</p> <p>consid</p> <p>evalua</p> <p>gener</p> <p>Pulmo</p> <p>consu</p> <p>patien</p> <p>sympt</p> <p>pulmo</p> <p>dysfun</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						Influenza pneumococcal vaccination

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Immune
Score = 1**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
131	Splenectomy	Asplenia At risk for life-threatening infection with encapsulated organisms (e.g., Haemophilus influenzae, streptococcus pneumoniae, meningococcus)			Physical Physical exam at time of febrile illness to evaluate degree of illness and potential source of infection (When febrile T ≥ 101 degrees F) Screening Blood culture (When febrile T ≥ 101 degrees F)	Health Links See "Patient Resources" field Splenic Precautions Counseling Medical alert bracelet/card noting asplenia. Counsel to avoid malaria and tick bites if living in or visiting endemic areas Considerations for Further Testing and Intervention In patients with T ≥ 101 degrees F (38.3 degrees C) or other signs of serious illness, administer a

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						<p>long-acting, broad-spectrum parenteral antibiotic (e.g., ceftriaxone), and continue close medical monitoring while awaiting blood culture results.</p> <p>Hospitalization and broadening of antimicrobial coverage (e.g., addition of vancomycin) may be necessary under certain circumstances, such as the presence of marked leukocytosis, neutropenia, or significant change from baseline CBC; toxic clinical appearance; fever ≥ 104 degrees F; meningitis, pneumonia, or other serious focus of infection; signs of septic shock; or previous history of serious infection.</p> <p>Immunize with Pneumococcal, Meningococcal, and HIB</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
						vaccines. Pneumovax booster in patients ≥ 10 years old at ≥ 5 years after previous dose.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Endocrine/Metabolic
Score = 1**

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
132	<p>Thyroidectomy</p> <p>Info Link: Total thyroidectomy is uncommon, but if done is associated with the risk of hypoparathyroidism. This complication generally occurs in the early postoperative period and may persist. Patients with a history of total thyroidectomy should be monitored for signs and symptoms of hypoparathyroidism (e.g., paresthesias, muscle cramping, altered mental status, hyperreflexia, tetany, hypocalcemia, and</p>	Hypothyroidism			<p>History</p> <p>Fatigue</p> <p>Weight gain</p> <p>Cold intolerance</p> <p>Constipation</p> <p>Dry skin</p> <p>Brittle hair</p> <p>Depressed mood</p> <p>(Yearly; Consider more frequent screening during periods of rapid growth)</p>	<p>Health Links</p> <p>See "Patient Resources" field</p> <p>Thyroid Problems</p> <p>Counseling</p> <p>Counsel at-risk females of childbearing potential to have their thyroid levels checked prior to attempting pregnancy and periodically throughout pregnancy.</p> <p>Considerations for Further Testing and</p>

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
	hyperphosphatemia)				Physical Height Weight Hair Skin Thyroid exam (Yearly; Consider more frequent screening during periods of rapid growth) Screening TSH Free T4 (Yearly; Consider more frequent screening during periods of rapid growth)	Intervention Endocrine consultation for medical management.

Note: See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

Abbreviations

- BUN, blood urea nitrogen
- Ca, calcium
- CBC, complete blood count
- Cl, chloride
- CNS, central nervous system

- CO₂, carbon dioxide
- CXR, chest x-ray
- DLCO, diffusion capacity of carbon monoxide
- DOE, dyspnea on exertion
- FSH, follicle stimulating hormone
- GI, gastrointestinal
- GVHD, graft versus host disease
- Gy, gray
- HIB, Haemophilus influenza b vaccine
- HRT, hormone replacement therapy
- IO, intraosseous
- IT, intrathecal
- IV, intravenous
- K, potassium
- KUB, kidneys, ureter, bladder radiograph
- LH, luteinizing hormone
- Mg, magnesium
- Na, sodium
- NCI, National Cancer Institute
- NSAIDs, non-steroidal anti-inflammatory drugs
- PFTs, pulmonary function tests
- PO₄, phosphate
- SOB, shortness of breath
- T, temperature
- T4, thyroxine
- TBI, total body irradiation
- TSH, thyroid stimulating hormone

Definitions:

Explanation of Scoring for the Long-Term Follow-Up Guidelines

1 There is uniform consensus of the panel that (1) there is high-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2A There is uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2B There is non-uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

3 There is major disagreement that the recommendation is appropriate.

Rating Scheme for the Strength of the Evidence

"High-level evidence" (recommendation category 1) was defined as evidence derived from high quality case control or cohort studies.

"Lower-level evidence" (recommendation categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series, and clinical experience.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

Although several well-conducted studies on large populations of childhood cancer survivors have demonstrated associations between specific exposures and late effects, the size of the survivor population and the rate of occurrence of late effects does not allow for clinical studies that would assess the impact of screening recommendations on the morbidity and mortality associated with the late effect. Therefore, scoring of each exposure reflects the expert panel's assessment of the level of literature support linking the therapeutic exposure with the late effect coupled with an assessment of the appropriateness of the recommended screening modality in identifying the potential late effect based on the panel's collective clinical experience.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Potential benefits of implementing these guidelines into clinical practice include earlier identification of and intervention for late onset therapy-related complications in this at-risk population, potentially reducing or ameliorating the impact of late complications on the health status of survivors. In addition, ongoing healthcare that promotes healthy lifestyle choices and provides ongoing monitoring of health status is important for all cancer survivors.

POTENTIAL HARMS

Potential harms of guideline implementation include increased patient anxiety related to enhanced awareness of possible complications, as well as the potential for false-positive screening evaluations, leading to unnecessary further workup. In addition, costs of long-term follow-up care may be prohibitive for some patients, particularly those lacking health insurance, or those with insurance that does not cover the recommended screening evaluations.

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- The information and contents of each document or series of documents made available by the Children's Oncology Group relating to late effects of cancer treatment and care or containing the title "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" or the title "Health Link," whether available in print or electronic format (including any digital format, e-mail transmission, or download from the website), shall be known hereinafter as "Informational Content." All Informational Content is for informational purpose only. The Informational Content is not intended to substitute for medical advice, medical care, diagnosis, or treatment obtained from a physician or healthcare provider.
- *To cancer patients (if children, their parents or legal guardians):* Please seek the advice of a physician or other qualified healthcare provider with any questions you may have regarding a medical condition and do not rely on the Informational Content. The Children's Oncology Group is a research organization and does not provide individualized medical care or treatment.
- *To physicians and other healthcare providers:* The Informational Content is not intended to replace your independent clinical judgment, medical advice, or to exclude other legitimate criteria for screening, health counseling, or intervention for specific complications of childhood cancer treatment. Neither is the Informational Content intended to exclude other reasonable alternative follow-up procedures. The Informational Content is provided as a courtesy, but not intended as a sole source of guidance in the evaluation of childhood cancer survivors. The Children's Oncology Group recognizes that specific patient care decisions are the prerogative of the patient, family, and healthcare provider.
- While the Children's Oncology Group has made every attempt to assure that the Informational Content is accurate and complete as of the date of publication, no warranty or representation, express or implied, is made as to the accuracy, reliability, completeness, relevance, or timeliness of such Informational Content.
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- Ultimately, as with all clinical guidelines, decisions regarding screening and clinical management for any specific patient should be individually tailored, taking into consideration the patient's treatment history, risk factors, co-morbidities, and lifestyle. These guidelines are therefore not intended to replace clinical judgment or to exclude other reasonable alternative follow-up procedures. The Children's Oncology Group recognizes that specific patient

care decisions are the prerogative of the patient, family, and healthcare provider.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Implementation of these guidelines is intended to standardize and enhance follow-up care provided to survivors of pediatric malignancies throughout the lifespan. Considerations in this regard include the practicality and efficiency of applying these broad guidelines in individual clinical situations. Studies to address guideline implementation and refinement are a top priority of the Children's Oncology Group (COG) Late Effects Committee, and proposals to study feasibility of guideline use in limited institutions are currently underway. Issues to be addressed include description of anticipated barriers to application of the recommendations in the guidelines and development of review criteria for measuring changes in care when the guidelines are implemented. Additional concerns surround the lack of current evidence establishing the efficacy of screening for late complications in pediatric cancer survivors. While most clinicians believe that ongoing surveillance for these late complications is important in order to allow for early detection and intervention for complications that may arise, development of studies addressing the efficacy of this approach is imperative in order to determine which screening modalities are optimal for asymptomatic survivors.

In addition, the clinical utility of this lengthy document has also been a top concern of the COG Late Effects Committee. While recognizing that the length and depth of these guidelines is important in order to provide clinically-relevant, evidence-based recommendations and supporting health education materials, clinician time limitations and the effort required to identify the specific recommendations relevant to individual patients have been identified as barriers to their clinical application. Therefore, the COG Late Effects Committee is currently partnering with the Baylor School of Medicine in order to develop a web-based interface, known as "Passport for Care," that will generate individualized exposure-based recommendations from these guidelines in a clinician-focused format for ease of patient-specific application of the guidelines in the clinical setting. As additional information regarding implementation of the Passport for Care web-based interface becomes available, updates will be posted at www.survivorshipguidelines.org.

IMPLEMENTATION TOOLS

Chart Documentation/Checklists/Forms
Patient Resources
Resources

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 107-132: surgery. In: Children's Oncology Group. Bethesda (MD): Children's Oncology Group; 2006 Mar. p. 26. [110 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2003 Sep (revised 2006 Mar)

GUIDELINE DEVELOPER(S)

Children's Oncology Group - Medical Specialty Society

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All Children's Oncology Group (COG) members have complied with the COG conflict of interest policy, which requires disclosure of any potential financial or other conflicting interests.

GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the [Children's Oncology Group Web site](#).

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Instructions for use. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 6 p.
- Introductory material. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 9 p.
- Summary of cancer treatment. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March.
- Patient-specific guideline identification tool. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March.

Electronic copies: Available in Portable Document Format (PDF) from the [Children's Oncology Group Web site](#).

PATIENT RESOURCES

In an effort led by the Nursing Clinical Practice Subcommittee, complementary patient education materials (*Health Links*) were developed and are available in Appendix II of the original guideline document. The following Health Links are relevant to this summary:

Section 107

- [Amputation](#)

Section 109

- [Cystectomy](#)

Sections 109, 114

- [Kidney Health](#)

Section 110

- [Eye Health](#)

Sections 111, 123, 124

- [Female Health Issues](#)

Section 112

- [Gastrointestinal Health](#)

Section 113

- [Limb Sparing Procedures](#)

Section 114

- [Single Kidney Health](#)

Section 115

- [Educational Issues](#)

Section 119

- [Neurogenic Bladder](#)

Section 121, 125, 128

- [Male Health Issues](#)

Section 130

- [Pulmonary Health](#)

Section 131

- [Splenic Precautions](#)

Section 132

- [Thyroid Problems](#)

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC STATUS

This NGC summary was completed by ECRI Institute on May 11, 2007. The information was verified by the guideline developer on June 11, 2007. This summary was updated by ECRI Institute on October 3, 2007 following the U.S. Food and Drug Administration (FDA) advisory on Rocephin (ceftriaxone sodium).

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