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About this Publication

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Table 6. References to CCSS Publications in 2006 COG LTFU Guidelines by Treatment Modality

Guidelines related to:	CCSS-related References	Number of References	Percent CCSS
Psychosocial/behavioral	5	50	10%
Blood/serum-related late effects	0	17	0%
Chemotherapy-related late effects	0	191	0%
Radiation therapy-related late effects	15	365	4%
Hematopoietic cell transplant-related late effects	0	84	0%
Surgery-related late effects	3	110	3%
Other therapeutic modalities	0	10	0%
Screening guidelines	2	44	5%
Total	25	871	3%

Source: STPI analysis of Children's Oncology Group, "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 2.0," March 2006.

Note: Counts based upon references, not upon unique publications.

In evaluating the significance of these findings, it is important to note that the CCSS did not begin publishing until 1999. Less than half of the references in the 2006 version of the COG guidelines were to papers written in 2000 and afterward (420 of 871 or 48%), while just under 60% of the references in the 2008 version were to papers written in 2000 and beyond (578 of 981 or 58%). Including only those papers written in 2000 and afterward, CCSS publications account for 6% of the references in the 2006 guidelines (25 of 420) and 7% of the references in the 2008 guidelines (39 of 578).

Analysis of the guidelines' authors suggests that in addition to more than half of the 2008 guidelines Expert Panel being CCSS-affiliated, approximately one-quarter of the total membership of the guideline-drafting group was affiliated with the CCSS, and that for all of the task forces except for Auditory/Hearing, at least one member of each subgroup was CCSS-affiliated. More than half of the Task Force chairs and co-chairs (19 of 33 or 58%) were CCSS-affiliated, and at least one chair/co-chair was CCSS-affiliated for 15 of the 18 Task Forces (all but Auditory/Hearing, Fertility/Reproduction, and Urinary Tract).

Table 7. Affiliation of Members of the 2008 Guidelines Task Forces

Task Force (2008 Long-Term Follow-up Guidelines)	Members CCSS- Affiliated	Members not CCSS- Affiliated	Total	Percentage CCSS- Affiliated
Amputation/Limb Sparing	2	7	9	22%
Auditory/Hearing	0	7	7	0%
Cancer Screening	4	7	11	36%
Cardiovascular	1	8	9	11%
Endocrine/Metabolic	5	8	13	38%
Fertility/Reproduction	2	12	14	14%
Gastrointestinal/Hepatic	2	6	8	25%
Guideline Development	1	6	7	14%
Hematopoietic Cell Transplant	2	6	8	25%
Immune/Spleen	2	6	8	25%
Musculoskeletal Dental Dermatologic	1	9	10	10%
Neurocognitive/Behavioral	3	10	13	23%
Neurologic	2	5	7	29%
Ocular/Vision	1	6	7	14%
Psychosocial	2	8	10	20%
Pulmonary	2	7	9	22%
Skeletal: Osteonecrosis Osteopenia Osteoporosis	4	5	9	44%
Subsequent Malignant Neoplasms	4	4	8	50%
Urinary Tract	1	8	9	11%
Total	41	135	176	23%

Source: STPI analysis of authors of Children's Oncology Group, "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 3.0" compared with list of CCSS participants assembled from lists of Working Group studies and other CCSS documents.

Leveraged Funding

In addition to the Working Group studies described in the previous section, 21 ancillary studies had been approved by the CCSS Steering Committee, the majority of which have been funded by NCI (see Table 8). Searches of the NIH RePORTER database identified ten additional NIH awards that referred to the CCSS in their abstracts (also in Table 8). The full list of ancillary and other studies with known connections to the CCSS is included as Appendix B, Table B-8.

