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Feasibility Study for Evaluation of the Childhood Cancer Survivor Study (CCSS)

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March 2010

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Executive Summary

The Childhood Cancer Survivor Study (CCSS) is a retrospectively ascertained cohort of approximately 20,000 survivors and approximately 4,000 siblings of survivors of pediatric cancers diagnosed between 1970 and 1986 at 27 contributing clinical centers. A recently initiated expansion of the study aims to enroll an equally large cohort of survivors diagnosed between 1987 and 1999, and 1,160 had been enrolled as of the FY 2009 progress report. The CCSS has been supported through a cooperative agreement with the National Cancer Institute (NCI) since 1994. The study began with specific aims as a research project under a cooperative agreement, or U01 funding mechanism, but was converted to a resource-related research project (cooperative agreement), or U24 funding mechanism, in 1999. Investigators who wish to make use of CCSS data and resources to answer a particular question can apply for permission and support via one of nine CCSS Working Groups. Permission can also be sought to use the cohort as part of an ancillary study conducted with outside funding.

The purpose of this Feasibility Study was to explore whether evaluation of the CCSS is both warranted and feasible, and, if so, to make recommendations regarding the design of such an evaluation. Data collection methods included review of administrative data as well as a series of interviews with CCSS participants, NCI staff members, and extramural community members who do not participate in the CCSS.

Preliminary findings regarding CCSS outcomes include the following:

- The CCSS cohort itself is perhaps the most important product of the study. Interviewees noted that the CCSS was the first to assemble a cohort of pediatric cancer survivors of this scale, and it remains the largest cohort of its type in the world.
- Between 1998 and 2008, a total of 134 distinct studies were initiated by or otherwise associated with the CCSS Working Groups and approved by the CCSS Publications Committee. Of the Working Group studies for which analysis is complete, 64 (76%) have so far resulted in at least one peer-reviewed publication.
- Through June 2009, a total of 127 CCSS-associated peer-reviewed journal articles appeared in 41 different journals; more than one quarter of them (33 of 127 or 26%) appeared in the *Journal of Clinical Oncology*.

Through the end of 2008, at least 127 CCSS presentations were made at major conferences. The majority (75 of 127 or 59%) of them occurred at either the International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (the “Niagara” conferences, 39 presentations) or the American Society of Clinical Oncology (ASCO, 36 presentations).

Since 2005, the *Journal of Clinical Oncology* has published an annual list of the major advances in cancer treatment, prevention, and screening for the previous year. Between 2005 and 2008, five different CCSS publications or presentations were included in these lists.

More than one-quarter of the CCSS publications have been referenced in the Children's Oncology Group *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers.* The percentage of all publications referenced in the guidelines that are attributable to CCSS is small (3% and 4% of the publications in the in the 2006 and 2008 guidelines, respectively). CCSS publications were referenced frequently in guidelines related to psychosocial/behavioral outcomes, radiation therapy-related late effects, and screening guidelines. The nature of the Feasibility Study did not allow for the assessment of the reasons for the finding, but further investigation into the role the CCSS studies have played may be worthwhile.

The CCSS Steering Committee has approved 22 ancillary studies, the majority of which have been funded by NCI. Searches of the NIH RePORTER database identified 11 additional NIH awards that referred to the CCSS in their abstracts. Of these, 8 abstracts suggested direct use of CCSS data or resources, 2 referred to the CCSS but the relationship was not clear, and 1 was the Niagara conferences R13 award.

According to CCSS records, at least 30 investigators have participated in the CCSS as part of medical, graduate, or postdoctoral training. Of these, 22 participated as postdoctoral fellows, 5 participated as graduate students, 2 participated as medical students, and 1 was both a postdoctoral fellow and a medical student. Of the 25 who have completed their training experiences, 18 remain involved in academic medicine, 15 of them as faculty members. Of the 127 CCSS publications, 40 (31%) had a CCSS trainee as first author; one or more of the CCSS trainees has appeared as an author on 66 (52%) distinct publications.

The Feasibility Study team found that most CCSS outcomes are clearly defined and measurable. Further, no extraordinary barriers to additional data collection are anticipated and existing databases can be used as complementary data sources. An Outcome Evaluation of the CCSS would therefore be feasible. However, such an evaluation is not warranted. Because the CCSS is not a program but a single award, peer review is more appropriate than Outcome Evaluation as a mechanism for assessing the study's merit. It is also not clear that there are any similar resources to which the CCSS could meaningfully be compared. Perhaps most importantly, however, a retrospective Outcome Evaluation of the CCSS would not help NCI address the critical strategic issues it faces with respect to the future of its pediatric cancer survivorship research portfolio.

I. Introduction

The Childhood Cancer Survivor Study (CCSS) is a retrospectively ascertained cohort of approximately 20,000 survivors and approximately 4,000 siblings of survivors of pediatric cancers diagnosed between 1970 and 1986 at 27 contributing clinical centers. The CCSS has been supported through a cooperative agreement with the National Cancer Institute (NCI) since 1994.

To assess feasibility for evaluation of the CCSS, NCI contracted with the Science and Technology Policy Institute (STPI) to conduct a Feasibility Study to explore whether evaluation of the CCSS is both warranted and feasible, and, if so, to make recommendations regarding the design of future evaluation efforts. STPI engaged in the following data-collection and -analysis activities:

- **Interviews with CCSS participants**, including the principal investigator (PI), four senior collaborators, and three ancillary or Working Group study leaders.
- **Interviews with NCI staff members,** including the Director of the Office of Cancer Survivorship and current CCSS program staff members.
- **Interviews with extramural community members who do not participate in the CCSS**, including two U.S.-based survivorship researchers, a Dutch pediatric survivorship researcher, and an expert on cohort studies.
- **Review of available administrative data**, including internal NIH databases, applications, investigator progress reports, and records maintained by the CCSS coordinating center.

Section 2 of this report describes the history and structure of the CCSS. Section 3 describes CCSS outputs to date and assembles preliminary evidence for outcomes. Section 4 includes the major issues raised by stakeholders regarding the CCSS and, more broadly, its role as part of the NCI's pediatric cancer survivorship portfolio. Finally, Section 5 summarizes findings of the Feasibility Study and recommendations for future evaluation efforts.

2. CCSS Design and Implementation

CCSS History and Purpose

According to PI Dr. Leslie Robison, the idea for the CCSS originated in the late 1980s when he and a group of other investigators identified the need for a long-term follow-up study of survivors of childhood cancers. After initiating a pilot study at four institutions, the group submitted an application for funding via a U01 cooperative agreement mechanism. The study was funded in FY 1993 for $13.3 million (including supplements) between fiscal years 1993 and 1999. The CCSS is administered within the Cancer Therapy Evaluation Program (CTEP) of the Division of Cancer Treatment and Diagnosis (DCTD) within NCI.

The original CCSS application proposed to establish and follow a large-scale cohort of 5-year survivors of childhood cancer diagnosed between 1970 and 1986 at 27 participating clinical centers. A group of sibling controls were also to be recruited for comparison purposes. Clinical data on malignancy and treatment were to be abstracted from the medical records of participants. Self-reported data on risk factors such as family history and a wide variety of possible health and psychosocial outcomes were to be collected via a baseline questionnaire and a series of follow-up questionnaires as relevant. The original specific aims reflect the descriptive and epidemiologic character of the cohort as originally conceived (see Appendix A for complete specific aims). The first four aims referred specifically to describing the health trajectories of cancer survivors:

- Compare mortality in survivors with the general population;
- Better describe known treatment and disease-related factors associated with increased risk of subsequent cancers;
- Better describe long-term cardio-pulmonary toxicity and reproductive outcomes in survivors exposed to chemotherapy;
- Better describe long-term cardio-pulmonary toxicity and reproductive outcomes in survivors exposed to radiation;

The next two aims were somewhat broader, hinting at the future evolution of the CCSS:

- Better describe patterns of familial aggregation of cancer;
- Characterize health-related behaviors and patterns of medical care in survivors for use in developing prevention strategies and assessing follow-up needs.

The CCSS was renewed in 1999, at which point it transitioned to the U24 research resource mechanism. The renewal application included three specific aims. The first restated all six aims of the original application, with two major additions: (1) new areas of epidemiologic inquiry, including neuropsychological and quality of life data to be collected, and (2) emphasis on the importance of research focused on interventions. The second specific aim committed the CCSS to collecting biospecimen data, specifically mentioning tumor specimens, buccal cells, and peripheral blood. The third aim enshrined the concept of ancillary studies as a CCSS goal and identified two particular types of studies as priorities, (1) “fostering the future development of innovative intervention strategies that can be tested within the CCSS cohort” and (2) “the conduct of directed, hypothesis-testing molecular genetic studies that utilize the biologic materials to be collected and stored within the CCSS molecular genetic bank.”

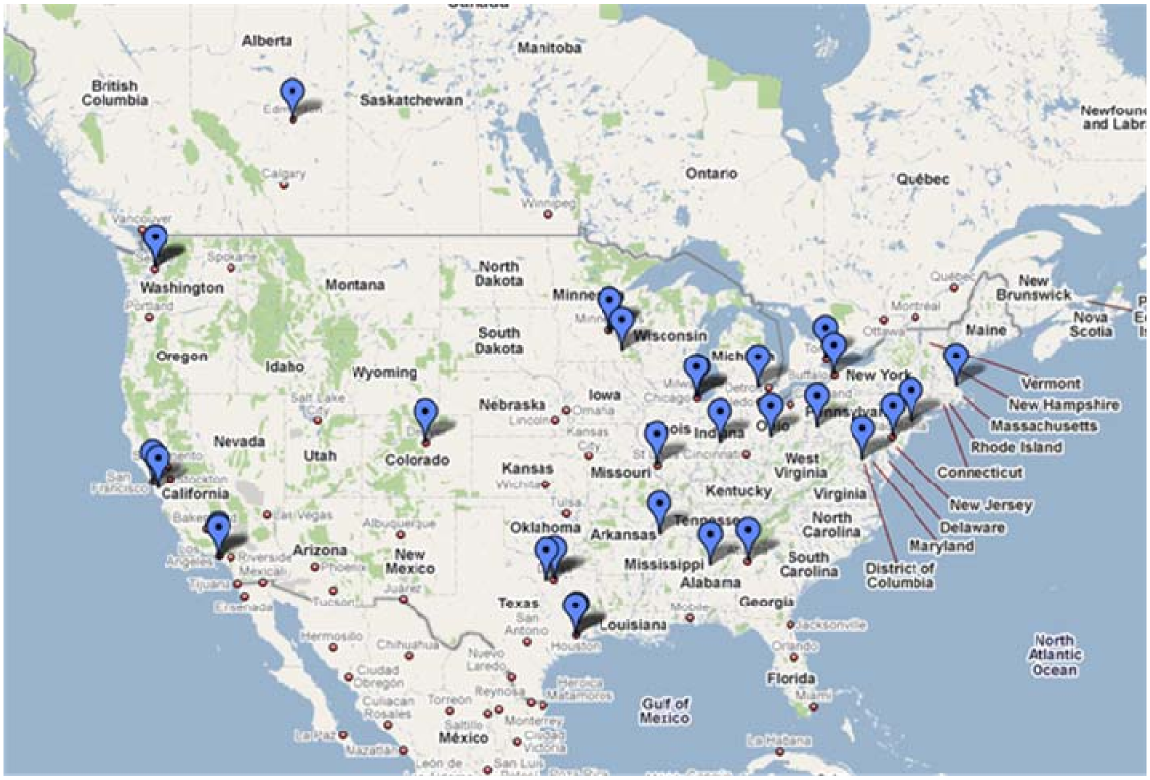
In 2004, the CCSS group submitted an application for competitive renewal of the U24. Again, three specific aims were delineated. The first subsumed specific aims 1 and 2 of the previous iteration, including continued monitoring for the original cohort and biospecimen collection. It also expanded somewhat on the emphasis on intervention from the previous iteration, including a sub-aim to “identify high-risk populations to aid in future cancer control activities including the design and testing of prevention, early detection and behavioral/therapeutic interventions intended to lower risk.” The CCSS here explicitly linked risk identification with intervention development. The second aim was a significant expansion of the study to include a new cohort of patients diagnosed between 1987 and 1999. Collection of biological samples and efforts to promote use of the resource were also to be expanded, including the development of a new public-use dataset. Specific Aim 3 added dissemination of CCSS findings as a new goal, including both increasing the number of publications and presentations and the creation of a public access dataset.

The current funding cycle runs through 2011, which will be the study’s seventeenth year. Total funding through FY 2010 for the resource has been $38.3 million in direct costs ($13.3 million as a U01 and $26.0 million as a U24).

CCSS Structure

Consortium Membership

The CCSS consortium originally consisted of 27 clinical pediatric centers contributing patients in the United States and Canada. According to the original application, these centers were selected based upon criteria that included: the size of the patient population, investigator expertise and interest in issues relating to childhood cancer survivorship, previous history of successful multi-institutional collaborative research, and geographic location. As of 2009 (CCSS Year 15), the CCSS included 31 participating pediatric cancer centers, as shown in Figure 1. A full list of participating institutions is included in Appendix B, Table B-1.



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Source: STPI analysis of Robison et al., 2009. The Childhood Cancer Survivor Study: A National Cancer Institute-Supported Resource for Outcome and Intervention Research. Journal of Clinical Oncology *27(14):2308-2318, Table 1.*

Figure 1. CCSS Institutions as of 2009

A coordinating center for the consortium was established at the University of Minnesota at the beginning of the study; the Coordinating Center moved with Principal Investigator Dr. Leslie Robison to St. Jude Children's Research Hospital in 2006. The primary role of the coordinating center is to obtain and coordinate information on subjects enrolled by the clinical centers.

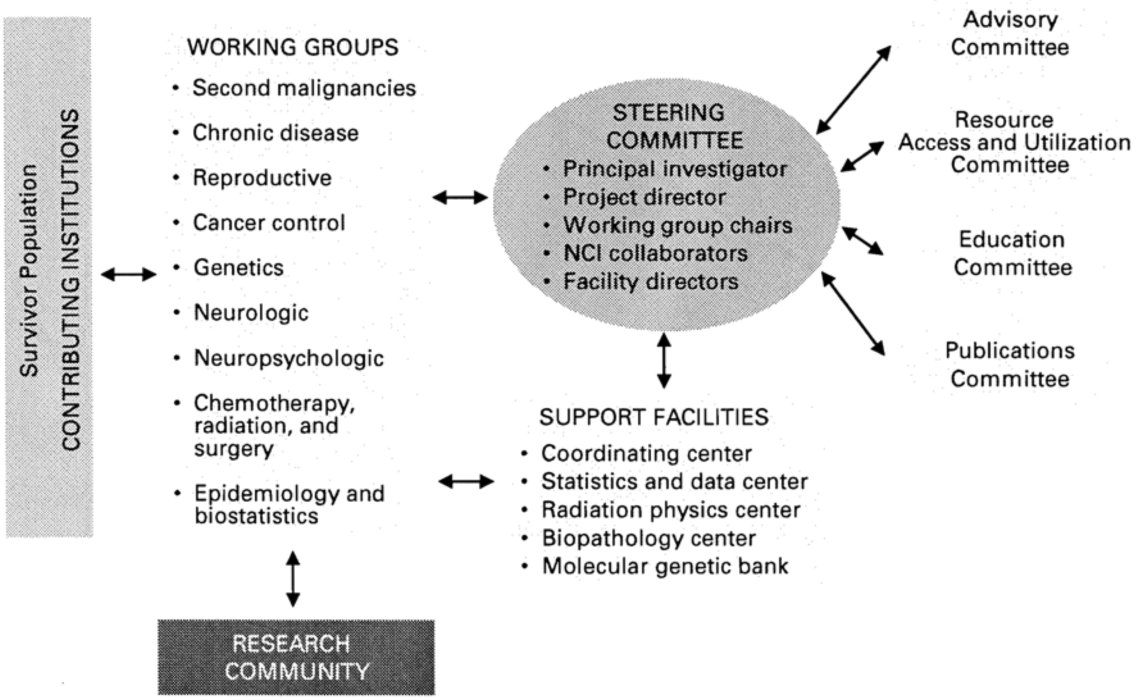
Four support facilities were established when the CCSS shifted to a U24 research resource during the 1999 renewal. A fifth support facility was established in the 2004 renewal. The facilities are as follows:

- *Data management and statistical support (Fred Hutchinson Cancer Research Center).* This facility is charged with maintaining and curating the CCSS databases as well as providing biostatistical support to CCSS studies as needed.
- *Radiation dosimetry (M.D. Anderson Cancer Center)*. Records of patients who received radiation therapy are sent to the radiation dosimetry core at M.D. Anderson, which estimates radiation dose received by organ or other anatomical site.
- *Pathology review (Nationwide Children's Hospital)*. This core validates all reported second neoplasms within the cohort.

- *Specimen repository (Cincinnati Children's Hospital)*. The CCSS specimen repository stores buccal cell samples (from which DNA is obtained) and peripheral blood samples taken from CCSS subjects with second neoplasms.
- *Follow-up center (University of Southern California)*. Added in 2004, the Follow-up Center's role is to trace potential CCSS participants who were not reached through initial recruitment efforts (via the distribution of the semi-annual CCSS newsletter). The Follow-up Center also traces subjects from the initial cohort who had been lost to locate and recruit them for participation.

Consortium Structure and Governance

Figure 2 illustrates the organizational structure of the CCSS. Overall leadership is provided by a Steering Committee that includes the Principal Investigator, a Project Director, four NCI staff members, directors of each of the five CCSS support facilities, and the chairs of the Working Groups (described in the next section). An External Advisory Committee provides input to the Steering Committee on various aspects of study design and management as needed.



Source: Robison et al., 2009. The Childhood Cancer Survivor Study: A National Cancer Institute-Supported Resource for Outcome and Intervention Research. Journal of Clinical Oncology *27(14):2308-2318, Figure 2.*

Note: The original excluded the Follow-up Center from the list of "Support Facilities"

Figure 2. CCSS Organizational Structure

Three additional committees have been established over time to provide additional input to the Steering Committee and to perform specific functions for the CCSS:

- *Education Committee.* The Education Committee is responsible for developing the CCSS newsletter, which is currently issued twice per year. The primary goal of the newsletter is to disseminate findings of the study to participating survivors, but it is also a useful mechanism for maintaining regular contact with participants to keep them engaged in the study. It typically contains summaries of research on topics of particular importance to survivors as well as a story featuring a particular survivor and the health issues he or she faces. Copies are distributed directly to study participants, and participating oncologists are encouraged to distribute extra copies more broadly.
- *Publications Committee.* The Publications Committee is responsible for reviewing proposals for Working Group studies (described below) and coordinating review of publications generated by those studies. Applications are considered once per month, and the data management and biostatistical support center is generally consulted to ensure that data analysis plans are sound and feasible. The Publications Committee assigns a score to each approved proposal that helps to determine the order in which resources are allocated to the project.
- *Resource Access and Utilization Committee.* Established at the most recent renewal in response to reviewer concerns, this committee has been charged with developing and implementing a strategic plan for promoting use of the CCSS resources by other investigators. The plan is to recommend approaches to advertising availability of the resources as well as establishing priorities for research initiatives that would best capitalize on the strengths of the CCSS.

Working Groups and Working Group Studies

The purpose of the Working Groups is to promote use of the CCSS resources to answer research questions in particular areas of interest. They are also responsible for endorsing – and in some cases soliciting – proposals for Working Group studies, which are one of two mechanisms by which investigators can apply to use CCSS data and resources. The second mechanism, the ancillary study, is described in the next section. Working Group studies are distinct from ancillary studies in that they are generally conducted entirely within the CCSS and do not rely on outside funding or resources (with the exception of the Principal Investigator's time).

The CCSS originally included eight Working Groups focused on the following topics: (1) second malignancies; (2) chronic disease; (3) reproductive systems; (4) cancer control; (5) genetics; (6) neuropsychologic; (7) chemotherapy, radiation, and surgery; and (8) epidemiology and biostatistics. A ninth Working Group focused on neurology was added later due to interest by a group of CCSS participants. The Working Groups are volunteer efforts, and membership is informal. In-person meetings are typically convened at least once per year at the CCSS annual meeting. Investigators from institutions that are not part of the consortium are welcome to participate in the Working Groups and propose Working Group studies; individuals interested in joining need only make themselves known to the chairs. Interviewees noted that some of the Working Groups have few or no active participants apart from the chairs.

The process for initiating a Working Group study begins when an investigator submits an application of intent to the Working Group. The application of intent outlines the aims of the study and includes a checklist to identify resources likely to be needed (e.g., biospecimens, biostatistical support, etc.). It is worth noting that some Working Groups were reported to be more proactive than others in terms of identifying priority research areas and working to generate interest. In those Working Groups, contact between the proposed PI and the Working Group is not uncommon prior to submission of the application of intent.

Once the application of intent is endorsed, the Working Group collaborates with the proposing PI to flesh out the study design and develop a full proposal. Interviewees reported that it is common for the Working Group chairs to suggest appropriate collaborators for less experienced PIs. Full proposals are reviewed by the Publications Committee. Interviewees reported that about 90% of proposals are eventually approved, but the Publications Committee is also responsible for establishing which proposals are of highest priority for biostatistical support from the CCSS. Because only a handful of investigators outside of the data management and biostatistical support center have access and are sufficiently familiar with the dataset to conduct their own analyses, this is typically a rate-limiting step.

Finally, once analysis is complete, draft manuscripts for Working Group studies are submitted to the Publications Committee for review (waivers are occasionally granted, but this is rare). The Publications Committee sends each manuscript to two reviewers who provide feedback. Interviewees noted that comments from “friendly” reviewers can be useful and can help to anticipate comments from a journal’s reviewers when the manuscript is submitted for publication.

Ancillary Studies

Unlike Working Group studies, ancillary studies generally involve combining CCSS data with additional information collected using external funding. To initiate an ancillary study, an investigator typically contacts the CCSS staff for permission to include the resource in a grant application under development. One of the Working Groups is then assigned to work with the investigator to assess feasibility and develop a two- to three-page “concept document” similar to a letter of intent. The concept document is reviewed by the Steering Committee for scientific merit and also to ensure that the proposed activities will not overburden any group of cohort participants. If approved, the CCSS leadership works with the investigator to submit his or her grant application and provides a letter of support. Interviewees expressed the opinion that funders generally look favorably on incorporation of CCSS resources into research proposals, especially when doing so greatly reduces the effort that would otherwise be expended attempting to identify and recruit survivors for the study. If investigators are successful in competing for outside funding, the Coordinating Center handles initial contact with subjects.

Public Access to CCSS Data

Data tables stripped of personal identifiers and suitable for public access are a recent addition to the CCSS. The idea for these data tables arose from an ad hoc effort by a small group of CCSS-affiliated researchers who felt that the CCSS data on brain cancer had not been sufficiently analyzed. In an effort to promote development of papers in this area, they decided to assemble a "data book" of information on 118 brain cancer survivors in the cohort for distribution to interested researchers at the CCSS annual meeting. The effort succeeded in generating interest, and a series of four papers were eventually developed as a result.

This model was copied successfully by groups interested in other subsets of the cohort, including survivors of acute lymphocytic leukemia (ALL), acute myeloid leukemia (AML), neuroblastoma, and Hodgkin's disease. The most recent (2005) CCSS renewal application included the development of data tables suitable for public access for the entire cohort. A non-CCSS interviewee commented that the current version of the public access data tables would benefit from improved interactivity and better formatting.

CCSS Logic Model

Based on STPI review of CCSS documentation, and interviews with the CCSS PI and NCI program staff, STPI developed a logic model for the study in its current form (Appendix C). The logic model visually represents the inputs, activities, outputs, and expected outcomes of the program. Three categories of outcomes were identified:

- Scientific Outcomes: Value-Added Research and Improved Patient Care:
    - Identify high-risk cancer survivorship populations for latent effects and quantify the magnitude of risk they face;
    - Develop risk-based screening guidelines;
    - Conceptualize, develop, and test interventions to prevent or minimize latent effects.

- Expanded Cancer Survivorship Field Outcomes:
    - Epidemiologists and biologists (as well as oncologists) use resource;
    - Trained junior investigators become independent cancer survivorship investigators;
    - Field of cancer survivorship expands.

- Education Outcomes:
    - Study participants receiving newsletters use the information to influence their own health choices and care.

The logic model also identifies outputs (e.g., scientific, training, and educational results) of the CCSS:

- "Primary" Research:
    - Publications/presentations by CCSS investigators using observational data and
    - Guidelines making use of observational data.

- “Secondary” Research:
    - Publications/presentations, clinical protocols, or new lines of research by investigators using CCSS data to conduct ancillary studies.

- Resources for Research:
    - Quantity of high-quality biospecimens available for use;
    - New analytical tools;
    - Ancillary studies making use of resource;
    - Stored data tables available for download.

- Mentorship/Training:
    - Graduate students and fellows trained through CCSS.

- Public Communication:
    - Newsletter/educational outreach to study participants.

Section 3 (and Appendix B) present data collected during the Feasibility Study—both qualitative and quantitative—regarding the outputs and outcomes.

3. Preliminary Outputs and Outcomes

CCSS Cohort as a Resource

The CCSS cohort itself is perhaps the most important product of the study. The original cohort successfully enrolled 14,370 out of 20,879 eligible survivors diagnosed between 1970 and 1986 as well as 3,737 siblings of survivors. An equal number of survivors diagnosed between 1987 and 1999 have been targeted for the expansion, and 1,160 had been enrolled as of the FY 2009 (Year 15) progress report.

Interviewees noted that the CCSS was the first cohort of pediatric cancer survivors ever assembled at this scale, and it remains the largest cohort of its type in the world. While it does have certain limitations—particularly the reliance on self-reported outcome data and the exclusion of certain cancers (e.g., germ cell cancers and retinoblastoma)—interviewees described it as a unique resource, particularly because of the power derived from large numbers. Some also predicted that its value, like that of most long-term cohort studies, will continue to increase with time.

CCSS Working Group studies, publications, and ancillary studies (described in the next three subsections) constitute evidence that the cohort is in fact being used as a resource. Since the CCSS is funded through the U24 research resource mechanisms, however, it is expected that access to and use of the resource should be actively expanding. In the amended 2005 competitive renewal application, the CCSS investigators stated that they had been contacted by at least 82 investigators over the course of the study, and that, of these, 56 (68%) subsequently became involved in at least one of the following: development of a concept proposal; analysis of study data; submission of a grant application involving CCSS; and/or presentation or publication of CCSS data. Of the 82 new investigators, 33 (40%) were not associated with a CCSS contributing institution. The application materials did not indicate, however, what percentage of the 56 who subsequently became involved were not associated with a CCSS institution.

Working Group Studies

Between 1998 and 2008, a total of 134 distinct studies were initiated by or otherwise associated with the eight CCSS Working Groups. The Working Groups associated with the largest number of studies were chronic diseases, neurological/psychosocial, and cancer control and interventions (Table 1).

Of the 134 Working Group studies identified, publicly available information indicated current status for 115 (86%). Of these, the analysis phase was determined to be complete for 84 (73%) and still ongoing for 31 (27%). Of the studies for which analysis was complete, 64 (76%) have so far resulted in at least one publication, and one additional study has resulted in an ASCO abstract. The likelihood of a study to have published varies with time (Table 2). Nearly 70% of studies initiated between 1998 and 2000 had published one or more journal articles as of June 2009, with the percentage falling to 58% in the 2001–2003 cohort of studies, 42% in the 2004–2006 cohort, and 5% in the most recently initiated studies.

Table 1. Number of Working Group Studies, by Year of Study Initiation

Working Group	98	99	00	01	02	03	04	05	06	07	08	Total 98–08
Cancer Control/ Interventions	3	1	0	1	1	2	2	4	1	0	5	20
Chronic Diseases	3	0	3	0	8	2	5	10	2	4	1	38
Epidemiology and Biostatistics	4	1	1	0	3	1	1	1	2	0	0	14
Fertility and Reproduction	3	0	0	0	2	1	0	0	1	0	0	7
Genetics	0	1	1	0	0	1	0	0	0	0	1	4
Neurological/ Psychosocial	6	1	1	1	1	1	2	3	6	3	2	27
Second Malignancy	3	1	2	2	3	1	3	1	1	0	1	18
Multiple Groups: Genetics and Second Malignancy	0	0	0	0	0	1	0	0	0	0	0	1
Not specified	1	0	0	0	0	1	0	0	0	3	0	5
Total	23	5	8	4	18	11	13	19	13	10	10	134

Source: STPI analysis of CCSS Working Group studies, obtained from CCSS internet site, summer 2009 (http://ccss.stjude.org/your-resource/approved-concept-proposals).

Table 2. Status of Working Group Studies, by Year of Study Initiation

Study Status	Start In 1998–2000	Start In 2001–3	Start In 2004–6	Start In 2007–9	Total
Resulted in at Least One Peer-Reviewed Publication	25	19	19	1	64
Analysis Complete, No Journal Publications to Date	1	2	4	0	7
Analysis Underway	2	5	16	0	23
Analysis Not Yet Begun	0	0	2	6	8
Inactive/Ended Without Publication	7	4	2	0	13
Status Unclear from Web-site Listing	1	3	2	15	21
Total Working Group Studies	36	33	45	22	136
Percentage Published	69%	58%	42%	5%	47%

Source: STPI analysis of CCSS Working Group studies, obtained from CCSS internet site, summer 2009 (http://ccss.stjude.org/your-resource/approved-concept-proposals).

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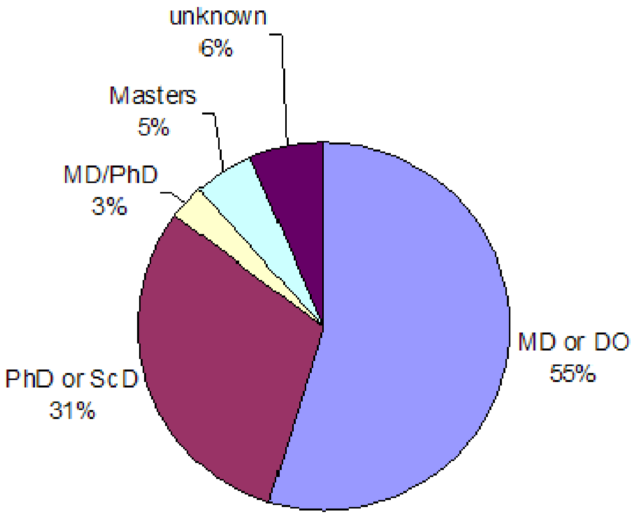
Working Group studies were led by 95 individuals, of whom more than half (55%) were physicians (Figure 3). An additional 31% had PhDs or ScDs as their highest degree, 3% had both an MD and a PhD, 5% had a Master's, and the highest degree of 6% could not be determined. Of the 55 Working Group study leaders with a medical degree (including MD/PhDs), most recent fellowship or residency information was available for 40. Of those 40, 30 were pediatric oncologists; the other 10 included specialists in adolescent medicine, cancer epidemiology, child psychiatry, family medicine, internal medicine, medical genetics, pediatric endocrinology, pediatric neurology, and pediatrics emergency medicine. Of the 32 Working Group study leaders with PhDs, the field of degree could be identified for 21. Of those, 9 had doctorates in epidemiology or public health; other fields included biochemistry, biostatistics, clinical psychology, environmental health sciences, nursing, physiology, psychology, social work and sociology, and statistics.



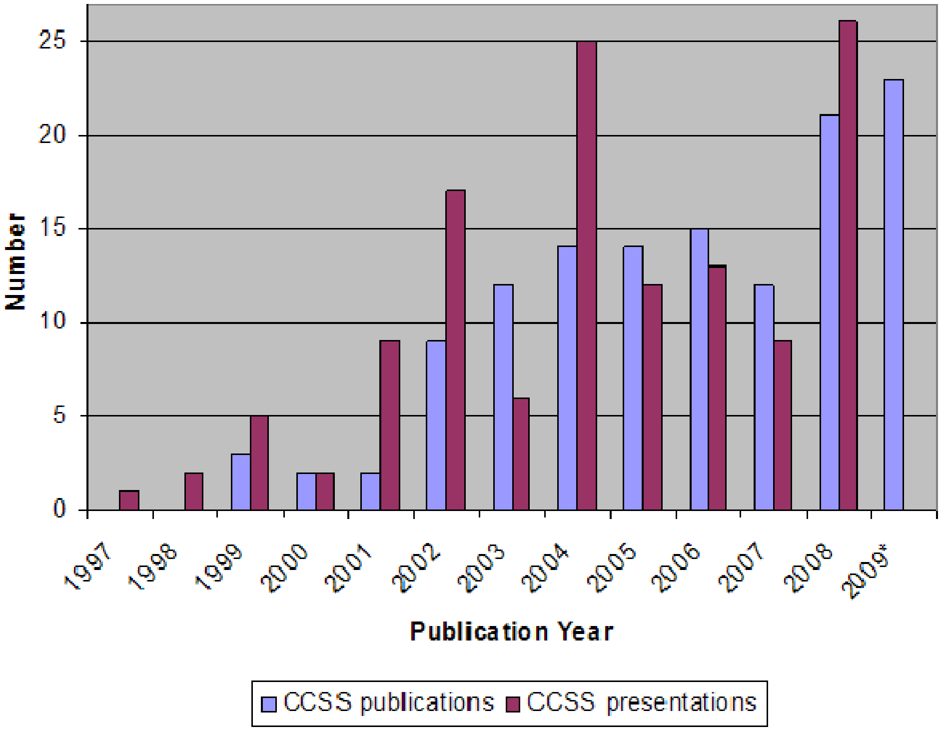
Source: STPI searches of the internet and of CCSS applications to identify highest degrees of individuals identified as Working Group study leaders from CCSS internet site, summer 2009 (http://ccss.stjude.org/your-resource/approved-concept-proposals).

Figure 3. Highest Degree of CCSS Working Group Study Leaders

Current and former Working Group study leaders are currently affiliated with at least 42 domestic institutions and 8 located outside of the United States, including 4 in Canada, and 1 each in the UK, the Netherlands, Israel, and Japan. One additional study leader, now deceased, finished her career at an Italian university. Institutions at which the largest number of CCSS Working Group study leaders are currently affiliated are the two home institutions—St. Jude Children's Research Hospital (11 investigators) and the University of Minnesota (6 investigators). Institutions home to three or more Working Group study leaders are Emory, Fred Hutchinson, UCLA, the University of Michigan, and NCI's Division of Cancer Epidemiology and Genetics.

Publications and Presentations

Using sources such as the CCSS Web site, the NIH SPIRES database, and MEDLINE searches (keywords "CCSS" and "Childhood Cancer Survivor Study"), STPI identified a total of 127 CCSS-associated peer-reviewed journal articles through June 2009 (Figure 4). A list of the 127 publications is included as Appendix B, Table B-2.



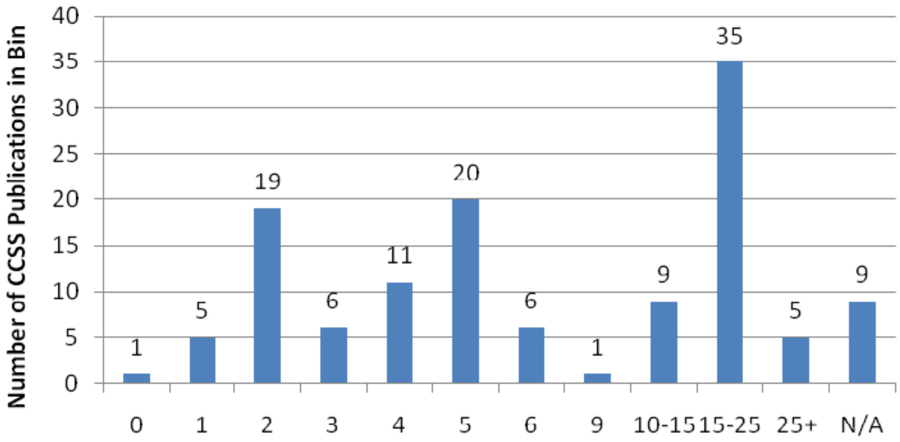
Source: STPI analysis of CCSS publications and presentations identified from CCSS internet site (http://ccss.stjude.org/published-research/publications and http://ccss.stjude.org/published-research/reviews for publications; http://ccss.stjude.org/published-research/abstracts for abstracts), CCSS application materials, and supplementary MEDLINE searches.

Note: Publications included were those published as of June 30, 2009, and presentations included were as of the end of calendar year 2008.

Figure 4. Numbers of CCSS Publications through June 30, 2009, and CCSS Presentations through 2008, by Year

Figure 4 shows that the numbers of CCSS publications per year has risen over time. The first CCSS publications came in 1999, more than 5 years after the resource's initial funding, and did not rise to more than 10 per year until 2003. More articles had been published through the end of June 2009 than in any previous calendar year.

CCSS publications have appeared in 41 different journals (Appendix B, Table B-3), but more than one quarter of them (33 of 127 or 26%) were published by the *Journal of Clinical Oncology*. The average 2008 Journal Impact Factor for a CCSS publication was 9.97, and the median was 5.24.[1] Figure 5 plots the Journal Impact Factors of CCSS publications. The plot shows a trimodal distribution—with the highest peak journals with Impact Factors between 15 and 25 (e.g., *Journal of Clinical Oncology, Annals of Internal Medicine*), a second peak corresponding to journals with Impact Factors between 5 and 6 (e.g., *Cancer, American Journal of Epidemiology, Epidemiology*), and a final peak corresponding to journals with Impact Factors between 2 and 3 (e.g., *Pediatric Blood & Cancer, Journal of Clinical Epidemiology*). While there is not a benchmark for NCI research in general or clinical oncology in particular, the concentration of CCSS publications in high-impact journals (40 of 127 or 31% in journals with an Impact Factor of 15 or higher; 49 of 127 or 38% in journals with an Impact Factor of 10 or higher) is notable.



Source: STPI identification of journal impact factor (using NIH library) for CCSS publications

Figure 5. Journal Impact Factors of CCSS Publications through 6/30/09 (*N*=127)

In a recent review article in the *Journal of Clinical Oncology,*[2] the CCSS authors attempted to characterize 98 of the CCSS publications by research area. Their findings are summarized in Figure 6. The characterization showed that the CCSS publications included fell into 25 distinct categories of research. The largest number of publications (11) was in the “second neoplasms” and “physical function/quality of life” categories, while two publications were characterized as “mortality” and

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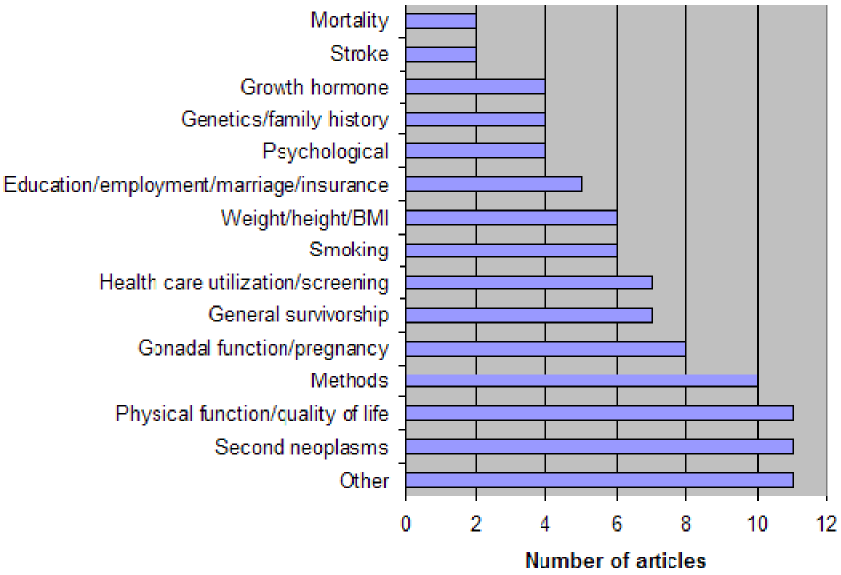
[1] As a comparison, *Proceedings of the National Academy of Sciences* has a journal impact factor of 9.6—below the average impact factor of the CCSS publications. The publication corresponding to the median impact factor is *Cancer*.

[2] L. L. Robison, G. T. Armstrong, J. D. Boice, E. J. Chow, S. M. Davies, S. S. Donaldson, D. M. Green, S. Hammond, A. T. Meadows, A. C. Mertens, J. J. Mulvihill, P. C. Nathan, J. P. Neglia, R. J. Packer, P. Rajaraman, C. A. Sklar, M. Stoval, L. C. Strong, Y. Yasui, and L. K. Zeltzer, “The Childhood Cancer Survivor Study: a National Cancer Institute-supported resource for outcome and intervention research.” *Journal of Clinical Oncology*, 2009 May 10; 27(14):2308–18.

"stroke." Eleven publications were placed in categories each including only a single paper. A similar attempt was made to characterize publication by disease area, but the majority (69 of 98 or 70%) was not disease-specific.



Source: STPI analysis of Robison et al. (2009).

Note: "Other" category encompasses the eleven publications that were placed in categories with one publication each.

Figure 6. CCSS Publications (*N*=98) by Research Area, as Categorized by Robison et al. (2009)

Although a total of 1,072 individuals are listed as authors on CCSS publications, a core group of CCSS investigators appear to have been heavily involved. Eleven investigators are listed as authors on 20% or more of CCSS publications, and the PI Dr. Leslie Robison and former coordinator Dr. Ann Mertens have each been involved with more than half of all CCSS publications (Table 3).

Table 3. Individuals Named as Authors on at Least 20% of CCSS Publications

Name	Number of Publications	Percentage of CCSS Publications (*N*=127)	Role
Robison, Leslie L.	98	77%	CCSS PI
Mertens, Ann C.	87	69%	CCSS Coordinator (former)
Yasui, Yutaka Y.	45	35%	CCSS Statistical Center leader (former)
Stovall, Marilyn A.	43	34%	CCSS Radiology Core leader
Whitton, John A.	36	28%	CCSS data manager
Sklar, Charles A.	34	27%	Working Group leader
Neglia, Joseph P.	31	24%	Working Group leader
Gurney, James G.	28	22%	Investigator
Hudson, Melissa M.	26	20%	Working Group leader
Oeffinger, Kevin C.	26	20%	Working Group leader
Ness, Kirsten K.	25	20%	Investigator

Source: STPI analysis of CCSS publications. Biographical information from internet searches and application materials.

Through the end of 2008, there were also 127 CCSS presentations at major conferences (for a full list of abstracts and numbers of presentations by conference, see Appendix B, Tables B-4 and B-5). The majority (75 of 127 or 59%) occurred at either the International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (the "Niagara" conferences, 39 presentations) or the American Society of Clinical Oncology (ASCO, 36 presentations). Three of these were identified as plenary session or media-recognized presentations.

Evidence for Impact of CCSS Research

Since 2005, the *Journal of Clinical Oncology* has published an annual list of the major advances in cancer treatment, prevention, and screening for the previous year. CCSS publications or presentations were included in these lists for 2005,[3] 2007,[4] and 2008.[5] When asked to identify

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[3] K. C. Oeffinger et al., "Prevalence and severity of chronic diseases in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study," Presented at the 41st Annual Meeting of the American Society of Clinical Oncology, May 2005, Orlando, FL.

[4] K. C. Oeffinger, A. C. Mertens, C. A. Sklar, et al., "Chronic health conditions in adult survivors of childhood cancers," *New England Journal of Medicine* 355:15:1572-1582, 2006; P. C. Nathan, M. L. Greenberg, K. K. Ness, et al., "Risk-based care in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS)," *Journal of Clinical Oncology* 25:18s, 2007; and D. C. Bowers, Y. Liu, W. Leisenring, et al. "Late-occurring stroke among long-term survivors of childhood leukemia and brain tumors: A report from the Childhood Cancer Survivor Study" *Journal of Clinical Oncology* 24: 5277-5282, 2006.

[5] D. Mulrooney, M. Yeazel, P. Mitby, et al., "Cardiovascular disease in adult survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS)," *Journal of Clinical Oncology* 26:504s, 2008.

the most significant findings of the CCSS, interviewees most commonly mentioned the study's findings on latent mortality from causes other than cancer, second neoplasms, and burden of chronic illness.

STPI also checked the Children's Oncology Group (COG) "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" (2006 and 2008 versions) for references to the CCSS publications (see Appendix B, Tables B-6 and B-7 for complete lists of CCSS papers referenced). Discussions with co-chairs of the Guidelines Core Committee identified the process by which new evidence is incorporated into the Guidelines, as described in the following paragraphs.

Task Forces are formed to review the literature on a 2-year cycle and are structured to be multidisciplinary (e.g., medical oncology, radiation oncology, primary care, patient advocate). Task Force chairs and co-chairs tend to be senior investigators. A few mid-career chairs have taken over only in the most recent cycle and after extensive mentoring by the former chair, with the former chair continuing to serve as a senior advisor. COG members volunteer to serve on the Task Forces, and there has not been difficulty in identifying interested participants.

The review identifies the current state of knowledge in that particular area of survivorship and using a structured process identifies the key references (usually limited to 10) for each section of the guidelines (the Task Force's unpublished material includes a detailed literature review, with annotations regarding the rationale for including each of the references that appear in the guidelines).

A panel of approximately 20 experts,[6] as well as the Core Committee, reviews the draft Task Force reports before the guidelines are finalized.

More than one-quarter of CCSS publications have been referenced in the guidelines, but the percentage of publications referenced that are attributable to CCSS is small (3% of the publications in the 2006 and 4% of the publications in the 2008 guidelines; see Table 4). The nature of the Feasibility Study did not allow for the assessment of the reasons for this finding. CCSS publications were referenced frequently in guidelines related to psychosocial/behavioral outcomes, radiation therapy-related late effects, and screening guidelines (see Tables 5 and 6).

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[6] Of the 17 members on the expert panel for the 2008 guidelines, 11 were CCSS-affiliated, including the CCSS PI (Leslie Robison), 7 CCSS Steering Committee members (Smita Bhatia, Daniel Green, Melissa Hudson, Meadows, Joseph Neglia, Kevin Oeffinger, Charles Sklar), and 3 investigators with CCSS affiliations (Debra CCSS investigator; Nina Kaddan-Lottick—a CCSS investigator and former CCSS trainee, Lillian Meacham—a CCSS institutional PI). Of the 4 Core Committee members, 2 (Smita Bhatia, Melissa Hudson) are affiliated with CCSS.

Table 4. References to CCSS Publications in 2006 and 2008 Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers

Measure	2006 Guidelines	2008 Guidelines
Number of unique publications referenced, all sources	601	738
Number of unique publications referenced, CCSS	15	27
Total number of references in guidelines	871	981
Number of references that are CCSS publications	25	39
Percentage of references from CCSS publications	3%	4%
Percentage of CCSS publications through the previous year cited in guidelines	27% (15 of 56 articles through 2005)	26% (27 of 103 articles through 2008)

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 (sections available from the National Guideline Clearinghouse internet site at www.guideline.gov); "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 3.0," October 2008 (available from http://www.survivorshipguidelines.org/pdf/LTFUGuidelines.pdf).

Table 5. References to CCSS Publications in 2008 Guidelines by Treatment Modality

Guidelines Related to:	CCSS-Related References	Total References	Percent CCSS
Psychosocial/behavioral	8	44	18%
Blood/serum-related late effects	0	17	0%
Chemotherapy-related late effects	2	209	1%
Radiation therapy-related late effects	24	400	6%
Hematopoietic cell transplant-related late effects	0	116	0%
Surgery-related late effects	3	134	2%
Other therapeutic modalities	0	10	0%
Screening guidelines	2	51	4%
Total	39	981	4%

Source: STPI analysis of Children's Oncology Group, "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 3.0," October 2008.

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

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.

Table 8. CCSS Ancillary Studies, by Funder

Funder	Number of Approved Ancillary Studies	Number of Studies that Mention CCSS in Proposal Abstract (But Not Approved)	Grand Total
American Cancer Society	1	0	1
ASCO Young Investigator Award and NCCF Fellowship Award	1	0	1
Genentech Foundation	1	0	1
Lance Armstrong Foundation	4	0	4
Robert Wood Johnson Foundation	1	0	1
Westlakes Research Institute	1	0	1
NIH-NCI	11	7	18
NIH-NHGRI		1	1
NIH-NINR		2	2
NIH-NIEHS	1	0	1
Grand Total	21	10	31

Source: CCSS application materials and list of ancillary studies provided by CCSS PI, summer 2009.

Training and Mentorship

Interviewees reported that one of the unanticipated outcomes of the CCSS is that it helped to bring a small number of new researchers into the field of childhood cancer survivorship by providing training opportunities they would not have had otherwise. According to records maintained by CCSS, at least 30 investigators participated in the CCSS[7] while undergoing medical, graduate, or postdoctoral training (for full list, see Appendix B, Table B-9). Of these, 22 participated as postdoctoral fellows, 5 participated as graduate students, 2 participated as medical students, and 1 was both a postdoctoral fellow and a medical student. Of the 25 who completed their training experiences, 18 remained involved in academic medicine (15 as faculty members); 3 were practicing clinicians; 2 were in government positions; and 2 were in industry.

In addition to simply providing opportunities to become involved in survivorship research, interviewees reported that the CCSS leadership has made a particular effort to mentor and encourage junior investigators. The CCSS PI has made a point of encouraging experienced researchers to partner with junior investigators with similar interest on concept proposals. Slots have also been reserved for junior investigators on the Steering Committee and Publications Committee in order to help them gain experience.

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[7] “Participation” was narrowly defined to include only those who have been, or shortly will be, first authors on CCSS-affiliated publications.

Analysis of CCSS publications shows the extent to which this group of trainees has participated actively. Of the 127 CCSS publications, 39 (31%) had a CCSS trainee as first author; one or more of the CCSS trainees appeared as an author on 67 (53%) distinct publications. Figure 7 shows authorship patterns of the 30 trainees. Twenty-four of the 30 trainees (83%) were first authors on studies published as of June 2009 (the others had articles submitted or otherwise in progress), and 26 (87%) had been authors. While most trainees were first author on a single publication, one former trainee was a first author on five CCSS publications and another, on four publications. Two trainees were authors on ten or more CCSS publications.

Source: STPI analysis of list of CCSS trainees provided by CCSS PI, summer 2009; list compared with list of CCSS publications assembled by STPI.

Figure 7. Trainee Authorships on CCSS Publications (*N*=30 Trainees)

Other Possible Outcomes and Impacts

In addition to the outcomes described above, interviewees hypothesized several other categories of outcomes and impacts that might be explored as part of any future evaluation of the CCSS. These include the following:

- The CCSS may have helped to raise the profile of survivorship issues more generally, drawing attention to survivorship in the media and in the scientific community.
- By coordinating a large-scale effort across multiple sites, the CCSS may have contributed to the development of a national and even an international network of researchers interested in childhood cancer survivorship.
- The CCSS may have helped to inspire and has almost certainly helped to shape the development of large cohort studies in other countries and regions, most notably in the UK, Scandinavia, the Netherlands, and Canada. As these cohorts mature, there may be opportunities to explore cross-national collaborations.

4. CCSS in the Context of Strategic Directions for Pediatric Cancer Survivorship Research at NCI

Arguments in Favor of Continued Support for the CCSS

As an expert on cohort studies interviewed as part of the Feasibility Study explained, large cohort studies have the following general advantages:

- They can assess risk from a wide range of exposures, intensities, doses, and durations.
- Because data are collected prospectively, recall bias is minimize.
- They typically produce more nuanced and better-grounded hypotheses for further testing than other types of epidemiologic studies.
- It is possible to look at multiple endpoints, which is particularly important when considering late effects of cancer treatment because possible endpoints are wide-ranging and difficult to predict.

As a historical example of the value of large cohort studies, the interviewee cited the Framingham heart study, which was the first of a series of cohorts that identified and refined cardiovascular health risks. Better knowledge of risk factors lead to clinical trials for drugs targeting reduction of low-density lipoprotein (LDL), high blood pressure, and the like. Similarly, the interviewee reasoned, cohort studies can be invaluable in identifying the intermediary factors involved in disease progression that may help to improve health outcomes for survivors.

There seemed to be general agreement among all interviewees that the CCSS is an example of a large cohort study that was initiated at the right time and has greatly advanced knowledge of late effects among survivors of pediatric cancer. In particular, interviewees agreed that the cohort has helped to quantify risks of second malignancies and other late effects in survivors of pediatric cancers. National and international leaders of the pediatric cancer survivorship research community acknowledged the CCSS as a pioneering effort and also as a model and inspiration for current efforts to build comparable cohorts in other countries.

Most interviewees favored continued support for the current cohort as well as the expansion begun in 2005. Arguments in favor of continued support for the current cohort included the fact that many enrollees are aging to the point where problems such as Type II diabetes, cardiovascular disease, and osteoporosis start to manifest in the general population. These interviewees expressed confidence that the cohort will break new ground in determining whether survivors are more susceptible to these conditions; interviewees also noted that there remains the possibility that as survivors age, new late effects may emerge. Interviewees also noted that cohort studies typically become more valuable as resources over time and that NCI should continue to reap the benefits of the substantial investment it has already made in the CCSS. Arguments in favor of the expansion included the need for the cohort to remain contemporary in terms of the treatment exposures and lifestyles of subjects.

Weaknesses of the CCSS Approach and Additional Needs for Research and Coordination

While most interviewees were enthusiastic about continued support for the CCSS resource, there were a few dissenters who suggested that the cohort had already been mined for the most important findings and that there might be more important priorities for future NCI investment in pediatric cancer survivorship research. Whether they favored continued support for the cohort or not, however, interviewees identified a number of areas where they felt that the CCSS approach was either inadequate or fell short of expectations. It is perhaps worth noting that it was often difficult to distinguish what might be characterized as "legitimate" criticism of the CCSS approach specifically from broader concerns about perceived gaps in the NCI pediatric cancer survivorship portfolio; in the minds of stakeholders, these issues appear to be linked. Issues and concerns raised in interviews included the following:

- *Failure to incorporate clinical follow-up data.* Interviewees agreed that clinical follow-up to verify outcomes for survivors would be preferable to the self-reported information currently collected by the CCSS through surveys. However, most acknowledged that clinical follow-up at the scale of the entire cohort would be logistically challenging and prohibitively expensive.
- *Reliance on telephone-based recruiting of participants.* Several interviewees observed that the new cohort of younger survivors has been more difficult to enroll using telephone-based methods. Some suggested that the CCSS should explore more diverse methods for contacting and enrolling the new cohort, including internet-based approaches.
- *Inadequate focus on intervention studies.* Interviewees agreed that using hypotheses generated by the CCSS as the basis for intervention studies to improve health outcomes for survivors is the next logical step. However, opinions were mixed regarding whether such studies should be ideally conducted under the auspices of the CCSS. COG was mentioned as an alternative organizational locus for interventional trials.
- *Inadequate focus on correlative studies and use of biological specimens.* Some interviewees identified correlative (e.g., genetic) studies as an area where the CCSS is not reaching its full potential. In particular, one interviewee expressed concern that the large quantity of biological tissues and samples collected by the CCSS are not currently being used to their full potential.
- *Lack of a coordinated research agenda.* Some interviewees commented that there does not appear to be a coordinated research agenda for either the CCSS or the pediatric cancer survivorship community more generally. Some expressed the opinion that coordinated strategic planning would be useful for both the study and the field in general.
- *Access to data and resources.* All of the interviewees who had participated in CCSS Working Group or ancillary studies described the process of obtaining access to the resources as reasonable. The only concerns raised among this group were the inconvenience of dealing with multiple Institutional Review Boards at the various clinical

centers and availability of biostatistical support as a potential bottleneck. However, at least one non-participant suggested that the CCSS should move toward a more decentralized mechanism for accessing the data from the cohort, adopting what the interviewee called a “public utility” model of serving the needs of the entire pediatric cancer survivorship community. The UK Biobank (http://www.ukbiobank.ac.uk/), which is still in the process of collecting samples and developing its procedures for access to data, was mentioned as a cohort still addressing issues of access but planning to be quite decentralized in terms of data access.

- *Continuity of follow-up and lack of integration with COG.* Some interviewees expressed the opinion that monitoring of “late effects” in survivors should occur in an integrated and continuous fashion from the point of treatment forward. These interviewees suggested that there should be a formal administrative relationship between the COG (where clinical trials occur and through whose institutions clinical care is provided and “early” late effects are traced) and the CCSS. While all CCSS institutions are part of COG, interviewees confirmed that data do not flow directly from COG to the CCSS. In addition to minimizing loss to follow-up, maintaining continuous contact with survivors would likely facilitate keeping them engaged and might make it easier to disseminate information and implement interventions to improve their health. Tighter administrative links between COG and CCSS could also simplify the process of obtaining treatment information for survivors.

CCSS in the Context of the NCI Pediatric Cancer Survivorship Portfolio

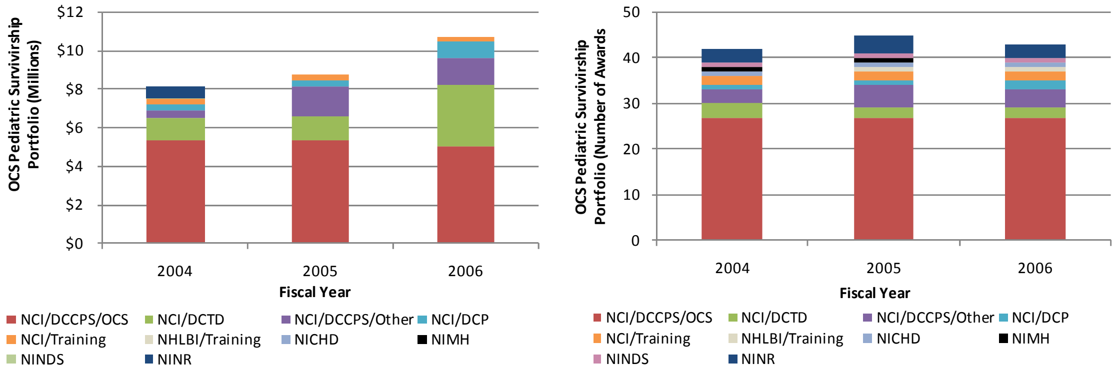
Finally, because questions facing NCI regarding the future of the CCSS will ultimately turn on the appropriate balance of investments, an attempt was made to assess the role of the CCSS and affiliated researchers in NCI’s portfolio of investment in pediatric cancer survivorship research. The NCI Office of Cancer Survivorship (OCS) has identified and attempted to characterize the NIH portfolio of active awards related to pediatric cancer survivorship for fiscal years 2004, 2005, and 2006. In each year during that time period, there were between 42 and 45 active awards, and total NIH investment in the portfolio over the 3 years was approximately $27.6 million (see Table 9). Approximately two-thirds of that funding went to descriptive studies (including the CCSS), one-third went to intervention studies; very little went to training.

Table 9. Number of NIH Awards and Total Dollars for Pediatric Cancer Survivorship, 2004–2006, by Office of Cancer Survivorship's Portfolio Category and Year

Portfolio Category	Number of Awards, 2004	Number of Awards, 2005	Number of Awards, 2006	Total Dollars, 2004–06 (Millions)	Percentage of Total Dollars
1.1 Descriptive Studies: Pediatric Biologic/Genetics	2	3	3	$2.1	8%
1.2 Descriptive Studies: Family and Caregiver Outcomes	3	4	3	$0.5	2%
1.3 Descriptive Studies: Health-related Behaviors	4	5	5	$2.6	9%
1.4 Descriptive Studies: Physiologic Sequelae/Long-Term Late Effects of Treatment	5	6	7	$5.2	19%
1.5 Descriptive Studies: Physiological and Psychosocial Sequelae and Late Effects of Treatment	5	4	4	$6.5	24%
1.6 Descriptive Studies: Psychosocial/ Health-Related Quality of Life	5	3	3	$1.3	5%
2.1 Intervention Research: Family Outcomes	5	5	5	$3.2	12%
2.2 Intervention Research: Health Behaviors	4	5	5	$4.7	17%
2.3 Intervention Research: Late Effects/Symptom Management	3	3	1	$0.5	2%
2.4 Pediatric Intervention Research: Psychosocial Outcomes	2	2	1	$0.0	0%
3.1 Pediatric Investigator Training and Conference Grants	4	5	2	$0.6	2%
3.2 Pediatric Training Awards	0	0	4	$0.2	1%
Total	42	45	43	$27.6	100%

Source: STPI analysis of NCI Office of Cancer Survivorship's pediatric cancer survivorship portfolios, FY 2004–2006, provided by NCI to STPI, summer 2009.

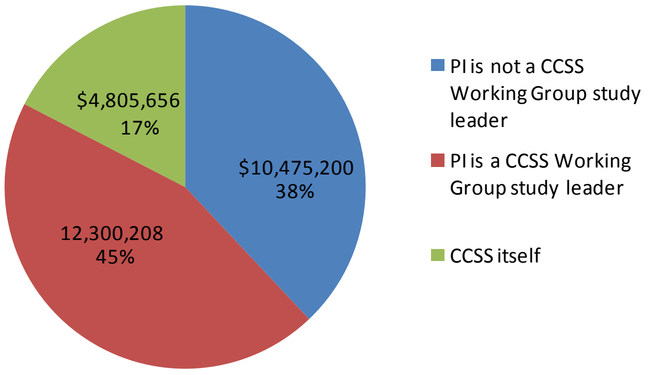
The majority of awards in the portfolio (more than 60% in each year) are administered by OCS. OCS also provides the majority of funds, although NCI/DCTD (which administers CCSS) also accounts for a substantial share of funding (Figure 8).



Source: STPI analysis of NCI Office of Cancer Survivorship's pediatric cancer survivorship portfolios, FY 2004–2006.

Figure 8. Number of Awards and Dollars Contributed to the NIH Pediatric Cancer Survivorship Portfolio, 2004–2006, by non-NCI NIH Institute or NCI Division

The CCSS itself accounted for about $4.8 million or 17% of portfolio funds in the 3 years studied (Figure 9). More than half of all other funds ($12.3M or 54%) went to PIs who were named as the leader of one or more CCSS Working Group studies. CCSS-affiliated investigators received 60% of (non-CCSS) portfolio funds for descriptive studies ($8.0 million/$13.8 million), 41% of portfolio funds for intervention studies ($3.5 million/$8.5 million), and 91% of portfolio funds for training ($760 thousand/$833 thousand).



Source: STPI analysis of NCI Office of Cancer Survivorship's pediatric cancer survivorship portfolios, FY 2004–2006 compared with list of CCSS participants.

Figure 9. Allocation of NIH Pediatric Cancer Survivorship Portfolio Funds, 2004–06, by PI Affiliation with CCSS

5. Findings

This Feasibility Study found that a CCSS Outcome Evaluation is feasible but is not warranted.

CCSS Outcome Evaluation Is Feasible

The study found that most CCSS outcomes are clearly defined and measurable. Looking at the right-hand side of the logic model (Appendix C), standard evaluation methods and measures exist for most CCSS outcomes (all but the CCSS educational outcomes). One potentially complex but vital outcome to measure would be the role of CCSS research in developing risk-based screening guidelines. The Children's Oncology Group issues guidelines related to late effects; the role of CCSS participants in the development of those guidelines can be readily mapped, and the list of references has been matched to CCSS publications to provide a starting point for detailed interviews with guideline developers to identify the relative roles of CCSS research and other sources.

Further, no extraordinary barriers to data collection are anticipated. The Feasibility Study assembled the set of CCSS's scientific outputs (journal articles and presentations), as well as information on Working Group and ancillary studies, trainees, and public access data table usage. The history of the CCSS is well described, and a recent special issue of the *Journal of Clinical Oncology* provides updated summary information across several CCSS research themes of interest. The CCSS leadership can be identified from the *Journal of Clinical Oncology* articles and application materials, while the list of CCSS investigators can be determined from publications/Working Group study information. A list of non-CCSS investigators working on issues of pediatric cancer survivorship is available from the OCS portfolio analysis of pediatric cancer survivorship research. One area where administrative data seem to be lacking is historical budget information; the switch in lead institution from the University of Minnesota to St. Jude Children's Research Hospital appears to have interrupted the continuity of CCSS spending and in-kind contribution information, which would need to be collected through a more intensive effort in an outcome evaluation. The Feasibility Study experience suggested that CCSS investigators and other members of the survivorship research community are generally responsive to and willing to cooperate with requests from an external evaluator.

In addition, existing databases can be used as complementary data sources. Extensive use can be made of NIH databases, particularly for program inputs and outputs. The two explored in depth as part of the Feasibility Study were the OCS 2004–2006 analyses of the pediatric cancer survivorship portfolio and MEDLINE.

CCSS Outcome Evaluation Is Not Warranted

Because the CCSS is not a program but a single award, peer review is more appropriate than Outcome Evaluation as a mechanism for assessing the study's merit. The NIH Guide to Program Evaluation specifies that evaluation activities are generally intended to assess programs or initiatives that encompass multiple awards. The peer review process is the standard and generally accepted mechanism for assessing the merit of particular extramural awards at NIH. The CCSS has been subjected to peer review three times already, and it will most likely undergo another round of review by a Special Emphasis Panel when the investigators apply for competitive renewal in 2010. Evaluation to assess scientific progress at this time would at best be duplicative and at worst serve to undermine the peer review process by second-guessing the expert judgment of the Special Emphasis Panels regarding the study's importance, productivity, and outcomes.

It is not clear that there are any similar resources to which the CCSS could meaningfully be compared. The Feasibility Study confirmed that the CCSS is by far the largest and most mature cohort of pediatric cancer survivors in the world. Options for comparison with other cohorts of pediatric cancer survivors are therefore limited to a handful of much smaller and more specialized cohorts in the United States or international efforts that are just getting off the ground. Furthermore, experts consulted during the Feasibility Study stated that they are not aware of comparable cohorts of survivors of chronic childhood diseases of any kind. While there are valid approaches to Outcome Evaluation design that do not include comparison strategies (e.g., cross-sectional and longitudinal designs), they are often viewed as producing evidence that is less convincing to stakeholders.

Most importantly, a retrospective Outcome Evaluation of the CCSS would not help NCI address the critical strategic issues it faces with respect to the future of its pediatric cancer survivorship research portfolio. Interviewees both inside and outside the CCSS identified a series of key strategic choices and issues that NCI faces regarding its pediatric cancer survivorship portfolio and the role that cohort studies (including the CCSS) play within it, including

- NCI's research priorities related to pediatric cancer survivorship;
- The relative distribution of NCI resources between observational/descriptive studies (such as the CCSS resource) and interventional studies within the OCS pediatric cancer survivorship portfolio;
- The definition of "survivorship" now that the majority of children with cancer are survivors, and whether all children with cancer should be followed in an integrated fashion from the point of diagnosis, through treatment, and then through life;
- The development of methods and approaches to identify the determinants of and early signs of late effects;
- Integration of the CCSS with other cohort studies (e.g., the National Children's Study, international pediatric childhood cancer survivorship cohorts);
- The utility of continuing to follow the original CCSS cohort now that cohort members are passing through middle age, especially since current cancer patients undergo very different treatment regimens; and
- The potential impact of pending legislation (e.g., HR 2109, Childhood Cancer Survivorship Research and Quality of Life Act of 2009, in the current Congress) that may change NCI's mandate and resources regarding survivorship.

None of these issues can be addressed through an Outcome Evaluation, and little additional information over and above what was collected during the Feasibility Study would provide insight into them.

Several process-related issues were identified during the Feasibility Study that may warrant future study or attention from the CCSS PI and NCI, including

- The degree to which the CCSS leadership proactively sets the research agenda for the resource and for individual Working Groups,
- The use of collected biospecimens,
- The extent to which researchers outside the CCSS are leveraging the resource through conduct of ancillary studies or use of the public access data tables, and
- Further inquiry into the integration of CCSS results into COG guidelines documents, focusing on the Task Forces' unpublished literature reviews.

Appendix A: CCSS Specific Aims from Applications

Original Application (1993)

1. Compare the mortality experience of survivors with the general population, particularly during the third and fourth decades of life.
2. Provide additional data on the known treatment- and disease-related factors associated with an increased risk of subsequent cancers, and: (a) documenting changes in the site and histologic distributions of second cancers as the interval from initial diagnosis/treatment increases; (b) identifying new associations between the risk of second cancers and initial cancer diagnosis, treatment factors (e.g., more intensive treatment programs), and family history; (c) proposing specific groups of survivors who, because of their increased risk, should be enrolled in programs for cancer prevention and early detection; and (d) providing data, for use in the design of future cancer treatment protocols, on specific treatment options which provide the lowest risk for second cancers.
3. Better describe the long-term cardio-pulmonary toxicity in survivors exposed to chemotherapy and radiation by: (a) supplying more detailed information on the incidence and risk factors for symptomatic cardiac or pulmonary disease; (b) quantifying the risk associated with interactions between radiation and specific chemotherapeutic agents; (c) examining the possibility that treatment-related factors may result in an earlier onset of “classical” adult cardiovascular disease (e.g., coronary artery disease); and (d) evaluating the influence of environmental exposures, such as tobacco smoke, on the occurrence of cardio-pulmonary disease.
4. Further investigate the consequences of various intensities of exposure to chemotherapy and/or radiation on reproduction, and: (a) quantifying the risk for adverse reproductive factors associated with treatment, age at exposure, type of cancer, and sex; (b) determining the overall, age-, sex-, diagnosis-, and therapy-specific fertility of survivors; (c) documenting the incidence of, and risk factors for, symptomatic gonadal failure and subsequent sequelae; and (d) establishing the risk for adverse pregnancy outcomes including recognized spontaneous abortion, low birth weight, and congenital anomalies, in order to develop a profile of high-risk pregnancies where specific recommendations can be made for preconception counseling, as well as pre- and peri-natal care.
5. Describe patterns of familial aggregation of cancer, including known (and variations of) cancer family syndromes, to: (a) provide additional information on the genetics of cancers; (b) establish estimates of risk to family members for use in genetic counseling and primary and secondary cancer prevention; and (c) identify family members in whom molecular genetic studies may yield valuable new information.
6. Characterize the health-related behaviors and patterns of medical care of survivors to use in the development of primary and secondary prevention strategies, as well as assessing the medical follow-up needs of this population.

Application Renewal (1999)

1. The CCSS cohort will continue to be followed to ascertain key outcomes including: (a) cause specific mortality, (b) subsequent malignant and benign neoplasms, (c) clinically significant cardiac events such as myocardial infarction and congestive heart failure, (d) reproductive outcomes such as the number and health status of offspring, (e) selected health behaviors such as smoking, alcohol, exercise, diet, and medical care, and (f) occurrence of serious illnesses requiring hospitalization and/or prescription of medications or other medical interventions. These follow-up data will be used to test specific hypotheses and to develop research on intervention strategies (see Section 1.4). In addition, expanded baseline information will be collected to characterize the population with regard to anthropometric, neuropsychological and psychosocial factors, and quality of life. Plans for maintaining a high level of participation by members of the study cohort are proposed to minimize both the number lost to follow-up and refusals.
2. To enhance the resource of the CCSS cohort, we will collect and store biologic specimens to study the molecular genetics of survivors and the sibling controls. Anticipated uses of this material include histopathologic characterization of second neoplasms, assessment of genetic polymorphisms as markers of susceptibility, and identification and characterization of induced or germline mutations. Specific biologic specimens include (a) tumor specimens from second and subsequent neoplasms, (b) buccal cells from all members of the cohort and the sibling control population as a source of genomic DNA, and (c) peripheral blood from a subset of the cohort and sibling controls to establish lymphoblastoid cell lines as a source of genomic DNA and RNA. Material will be received, processed and stored in designated resource laboratories. Guidelines for review and approval of proposals to utilize the material collected have been developed.
3. Within the framework of defined guidelines and procedures, the cohort will be available for investigator-initiated studies that address important questions relating to selected and well-defined subgroups of childhood cancer survivors. The strengths of the cohort allow the study of questions relating to risk factors and/or testing of interventions that could not be effectively investigated in other settings. The utility of the cohort is demonstrated by the three CCSS studies currently underway (i.e., Growth Hormone Study supported by a grant from the Genentech Foundation; Smoking Cessation Study funded by an R01 grant; and Premature Menopause Study funded by an R01 grant). An emphasis will be placed on (a) fostering the future development of innovative intervention strategies that can be tested within the CCSS cohort and (b) the conduct of directed, hypothesis-testing molecular genetic studies that utilize the biologic materials to be collected and stored within the CCSS molecular genetic bank. Recognizing the value of the cohort and the need to involve the cohort participants, rigorous criteria have been developed and will be applied when considering proposed uses of the cohort.

Active Application (2004)

1. Maintain the strong and productive resource of the CCSS through continued follow-up of the initial population, diagnosed between 1970–86. The current median age of active participants in the CCSS cohort is 32 years, with survivors ranging in age from 18 to 55. As the survivors in the CCSS population enter their fourth and fifth decades of life, we hypothesize that they will have significantly increased risk of developing adverse health-related outcomes (e.g., malignancy, cardiovascular, pulmonary, degenerative bone and joint disorders, endocrine dysfunction). Investigation of these outcomes will provide new insights into the relationships among genetic susceptibility, exposure to radiation and/or chemotherapy, and occurrence of adverse outcomes. To facilitate investigation of these outcomes we will:

    - systematically ascertain and characterize the occurrence of health-related outcomes and quality of life outcomes;
    - make available genomic DMA to allow the study of genetic susceptibility and gene-therapy exposure interaction;
    - continue to trace and recruit survivors who were previously considered to be lost-to-follow-up;
    - continue to validate all subsequent cancers, collect and store tumor specimens, and collect peripheral blood samples and establish lymphoblastoid cell lines for survivors with second neoplasms;
    - identify high-risk populations to aid in future cancer control activities including the design and testing of prevention, early detection and behavioral/ therapeutic interventions intended to lower risk.

2. **Enhance the resource by recruiting individuals diagnosed between 1987–99.** Over the past several decades there have been significant changes in therapy for children with cancer, including either intensification or reduction of therapy among subgroups defined by diagnosis and prognosis (refer to Table B.1). We hypothesize that the nature of and risk for developing late effects of therapy will be significantly altered among more recently treated survivors when compared to the earlier cohort. To investigate changes in therapy we will:

    - recruit and follow an additional 14,800 five-year survivors, selected in a manner that will over-sample those treated with regimens that differ from the initial population, and among ethnic/racial minorities;
    - collect selected baseline and follow-up outcome information comparable to the initial survivor population;
    - enroll 4000 siblings of survivors, selected from the pool of siblings within the expanded population;
    - extensively characterize survivors with respect to disease- and treatment-related factors;
    - collect and store buccal cell samples as a source of genomic DNA from survivors and sibling controls;

- ascertain and validate all subsequent cancers, collect and store tumor specimens, and collect peripheral blood and establish lymphoblastoid cell lines for survivors with second neoplasms.

3. **Promote and facilitate use of the CCSS resource.** Within the framework of defined guidelines and procedures, aggressive new initiatives will be undertaken to increase access/utilization of CCSS as a resource. These initiatives include (a) markedly increasing the visibility of CCSS through publications, presentations at national/international meetings, links with Web sites, direct marketing, and establishment of liaisons with professional societies; and (b) implementing an innovative strategy of establishing a comprehensive public-use data set.

Appendix B: Supplementary Information

Table B-1. CCSS Participating Institutions

Participating Institution	Location	1994 Application	1999 Renewal	2004 Renewal	2009 Paper
C.S. Mott Children’s Hospital/University of Michigan	Ann Arbor, MI	Yes	Yes	Yes	Yes
Children’s Hospital Los Angeles/USC	Los Angeles, CA	Yes	Yes	Yes	Yes
Children’s Hospital of Oklahoma	Oklahoma City, OK	No	No	Yes	No
Children’s Hospital of Philadelphia	Philadelphia, PA	Yes	Yes	Yes	Yes
Children’s Hospital Pittsburg	Pittsburgh, PA	Yes	Yes	Yes	Yes
Children’s Hospital Denver	Denver, CO	Yes	Yes	Yes	Yes
Children’s Medical Center Dallas/UT-Southwestern	Dallas, TX	Yes	Yes	Yes	Yes
Children’s Memorial/Northwestern	Chicago, IL	Yes	No	No	Yes
Children’s National Medical Center	Washington, DC	Yes	Yes	Yes	Yes
Cincinnati Children’s Hospital	Cincinnati, OH	No	No	Yes	No
Comer Children’s Hospital/University of Chicago	Chicago, IL	No	No	No	Yes
Cook Children’s Hospital	Fort Worth, TX	No	No	No	Yes
Dana-Farber	Boston, MA	Yes	Yes	Yes	Yes
Emory-Children’s Center	Atlanta, GA	Yes	No	No	Yes
Fred Hutchinson Cancer Research Center/University of Washington	Seattle, WA	No	No	No	Yes
Hospital for Sick Children	Toronto, ON	Yes	Yes	Yes	Yes
Lucille Packard Children’s Hospital/Stanford	Palo Alto, CA	Yes	Yes	Yes	Yes
Mayo Clinic	Rochester, MN	Yes	Yes	Yes	Yes
MD Anderson	Houston, TX	Yes	Yes	Yes	Yes
Memorial Sloan-Kettering Cancer Center	New York, NY	Yes	Yes	Yes	Yes
Minneapolis Children’s Hospital	Minneapolis, MN	Yes	Yes	Yes	Yes
Nationwide Children’s Hospital	Columbus, OH	Yes	Yes	Yes	Yes
Riley Children’s Hospital/University of Indiana	Indianapolis, IN	Yes	Yes	Yes	Yes
Roswell Park Memorial Institute	Buffalo, NY	Yes	Yes	Yes	Yes
Seattle Children’s Hospital	Seattle, WA	Yes	Yes	Yes	Yes
St. Jude Children’s Research Hospital	Memphis, TN	Yes	Yes	Yes	Yes
St. Louis Children’s Hospital	St. Louis, MO	Yes	Yes	Yes	Yes
Stollery Children’s/University of Alberta	Edmonton, AB	No	No	No	Yes
Texas Children’s/Baylor	Houston, TX	Yes	Yes	Yes	Yes
UCLA/Long Beach/Orange County/City of Hope	Los Angeles Metropolitan Area, CA	Yes	Yes	Yes	Yes
UCSF Children’s Hospital	San Francisco, CA	Yes	Yes	Yes	Yes
University of Alabama-Birmingham	Birmingham, AL	Yes	Yes	Yes	Yes
University of Minnesota	Minneapolis, MN	Yes	Yes	Yes	Yes

Source: STPI analysis of CCSS application materials, Robison et al. (2009) Table 1.

Table B-2. List of Published CCSS-Related Journal Articles

1: Armstrong GT, Liu Q, Yasui Y, Huang S, Ness KK, Leisenring W, Hudson MM, Donaldson SS, King AA, Stovall M, Krull KR, Robison LL, Packer RJ. Long-term outcomes among adult survivors of childhood central nervous system malignancies in the Childhood Cancer Survivor Study. J Natl Cancer Inst. 2009 Jul 1; 101(13):946-58. Epub 2009 Jun 17. PubMed PMID: 19535780; PubMed Central PMCID: PMC2704230.

2: Chow EJ, Friedman DL, Stovall M, Yasui Y, Whitton JA, Robison LL, Sklar CA. Risk of thyroid dysfunction and subsequent thyroid cancer among survivors of acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. Pediatr Blood Cancer. 2009 Sep; 53(3):432-7. PubMed PMID: 19459201; PubMed Central PMCID: PMC2713362.

3: Green DM, Kawashima T, Stovall M, Leisenring W, Sklar CA, Mertens AC, Donaldson SS, Byrne J, Robison LL. Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. J Clin Oncol. 2009 Jun 1; 27(16):2677-85. Epub 2009 Apr 13. PubMed PMID: 19364965; PubMed Central PMCID: PMC2690392.

4: Leisenring WM, Mertens AC, Armstrong GT, Stovall MA, Neglia JP, Lanctot JQ, Boice JD Jr, Whitton JA, Yasui Y. Pediatric cancer survivorship research: experience of the Childhood Cancer Survivor Study. J Clin Oncol. 2009 May 10; 27(14):2319-27. Epub 2009 Apr 13. Review. PubMed PMID: 19364957; PubMed Central PMCID: PMC2738644.

5: Green DM, Sklar CA, Boice JD Jr, Mulvihill JJ, Whitton JA, Stovall M, Yasui Y. Ovarian failure and reproductive outcomes after childhood cancer treatment: results from the Childhood Cancer Survivor Study. J Clin Oncol. 2009 May 10; 27(14):2374-81. Epub 2009 Apr 13. Review. PubMed PMID: 19364956; PubMed Central PMCID: PMC2677923.

6: Diller L, Chow EJ, Gurney JG, Hudson MM, Kadin-Lottick NS, Kawashima TI, Leisenring WM, Meacham LR, Mertens AC, Mulrooney DA, Oeffinger KC, Packer RJ, Robison LL, Sklar CA. Chronic disease in the Childhood Cancer Survivor Study cohort: a review of published findings. J Clin Oncol. 2009 May 10; 27(14):2339-55. Epub 2009 Apr 13. Review. PubMed PMID: 19364955; PubMed Central PMCID: PMC2677922.

7: Robison LL, Armstrong GT, Boice JD, Chow EJ, Davies SM, Donaldson SS, Green DM, Hammond S, Meadows AT, Mertens AC, Mulvihill JJ, Nathan PC, Neglia JP, Packer RJ, Rajaraman P, Sklar CA, Stovall M, Strong LC, Yasui Y, Zeltzer LK. The Childhood Cancer Survivor Study: a National Cancer Institute-supported resource for outcome and intervention research. J Clin Oncol. 2009 May 10; 27(14):2308-18. Epub 2009 Apr 13. Review. PubMed PMID: 19364948; PubMed Central PMCID: PMC2677920.

8: Armstrong GT, Liu Q, Yasui Y, Neglia JP, Leisenring W, Robison LL, Mertens AC. Late mortality among 5-year survivors of childhood cancer: a summary from the Childhood Cancer Survivor Study. J Clin Oncol. 2009 May 10; 27(14):2328-38. Epub 2009 Mar 30. Review. PubMed PMID: 19332714; PubMed Central PMCID: PMC2677921.

9: Ness KK, Hudson MM, Ginsberg JP, Nagarajan R, Kaste SC, Marina N, Whitton J, Robison LL, Gurney JG. Physical performance limitations in the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009 May 10; 27(14):2382-9. Epub 2009 Mar 30. Review. PubMed PMID: 19332713; PubMed Central PMCID: PMC2738647.

10: Armstrong GT, Whitton JA, Gajjar A, Kun LE, Chow EJ, Stovall M, Leisenring W, Robison LL, Sklar CA. Abnormal timing of menarche in survivors of central nervous system tumors: A report from the Childhood Cancer Survivor Study. Cancer. 2009 Jun 1; 115(11):2562-70. PubMed PMID: 19309737; PubMed Central PMCID: PMC2746632.

11: Hudson MM, Mulrooney DA, Bowers DC, Sklar CA, Green DM, Donaldson SS, Oeffinger KC, Neglia JP, Meadows AT, Robison LL. High-risk populations identified in Childhood Cancer Survivor Study investigations: implications for risk-based surveillance. J Clin Oncol. 2009 May 10; 27(14):2405-14. Epub 2009 Mar 16. Review. PubMed PMID: 19289611; PubMed Central PMCID: PMC2677926.

12: Cox CL, Hudson MM, Mertens A, Oeffinger K, Whitton J, Montgomery M, Robison LL. Medical screening participation in the childhood cancer survivor study. Arch Intern Med. 2009 Mar 9; 169(5):454-62. PubMed PMID: 19273775; PubMed Central PMCID: PMC2654585.

13: Zeltzer LK, Recklitis C, Buchbinder D, Zebrack B, Casillas J, Tsao JC, Lu Q, Krull K. Psychological status in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. J Clin Oncol. 2009 May 10; 27(14):2396-404. Epub 2009 Mar 2. Review. PubMed PMID: 19255309; PubMed Central PMCID: PMC2677925.

14: Nathan PC, Ford JS, Henderson TO, Hudson MM, Emmons KM, Casillas JN, Lown EA, Ness KK, Oeffinger KC. Health behaviors, medical care, and interventions to promote healthy living in the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009 May 10; 27(14):2363-73. Epub 2009 Mar 2. Review. PubMed PMID: 19255308; PubMed Central PMCID: PMC2738646.

15: Meadows AT, Friedman DL, Neglia JP, Mertens AC, Donaldson SS, Stovall M, Hammond S, Yasui Y, Inskip PD. Second neoplasms in survivors of childhood cancer: findings from the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009 May 10; 27(14):2356-62. Epub 2009 Mar 2. Review. PubMed PMID: 19255307; PubMed Central PMCID: PMC2738645.

16: Gurney JG, Krull KR, Kadan-Lottick N, Nicholson HS, Nathan PC, Zebrack B, Tersak JM, Ness KK. Social outcomes in the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009 May 10; 27(14):2390-5. Epub 2009 Feb 17. Review. PubMed PMID: 19224833; PubMed Central PMCID: PMC2677924.

17: Ness KK, Leisenring WM, Huang S, Hudson MM, Gurney JG, Whelan K, Hobbie WL, Armstrong GT, Robison LL, Oeffinger KC. Predictors of inactive lifestyle among adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Cancer. 2009 May 1; 115(9):1984-94. PubMed PMID: 19224548; PubMed Central PMCID: PMC2692052.

18: Oeffinger KC, Ford JS, Moskowitz CS, Diller LR, Hudson MM, Chou JF, Smith SM, Mertens AC, Henderson TO, Friedman DL, Leisenring WM, Robison LL. Breast cancer surveillance practices among women previously treated with chest radiation for a childhood cancer. JAMA. 2009 Jan 28; 301(4):404-14. PubMed PMID: 19176442; PubMed Central PMCID: PMC2676434.

19: Cox CL, Montgomery M, Oeffinger KC, Leisenring W, Zeltzer L, Whitton JA, Mertens AC, Hudson MM, Robison LL. Promoting physical activity in childhood cancer survivors: results from the Childhood Cancer Survivor Study. Cancer. 2009 Feb 1; 115(3):642-54. PubMed PMID: 19117349; PubMed Central PMCID: PMC2653221.

20: Robison LL. Treatment-associated subsequent neoplasms among long-term survivors of childhood cancer: the experience of the Childhood Cancer Survivor Study. Pediatr Radiol. 2009 Feb; 39 Suppl 1:S32-7. Epub 2008 Dec 16. Review. PubMed PMID: 19083220; PubMed Central PMCID: PMC2664260.

21: Emmons KM, Puleo E, Mertens A, Gritz ER, Diller L, Li FP. Long-term smoking cessation outcomes among childhood cancer survivors in the Partnership for Health Study. J Clin Oncol. 2009 Jan 1; 27(1):52-60. Epub 2008 Dec 1. PubMed PMID: 19047296; PubMed Central PMCID: PMC2645097.

22: Nagarajan R, Mogil R, Neglia JP, Robison LL, Ness KK. Self-reported global function among adult survivors of childhood lower-extremity bone tumors: a report from the Childhood Cancer Survivor Study (CCSS). J Cancer Surviv. 2009 Mar; 3(1):59-65. Epub 2008 Nov 22. PubMed PMID: 19030995; PubMed Central PMCID: PMC2657188.

23: Ness KK, Leisenring W, Goodman P, Kawashima T, Mertens AC, Oeffinger KC, Armstrong GT, Robison LL. Assessment of selection bias in clinic-based populations of childhood cancer survivors: a report from the childhood cancer survivor study. Pediatr Blood Cancer. 2009 Mar; 52(3):379-86. PubMed PMID: 18989878; PubMed Central PMCID: PMC2628420.

24: Robien K, Ness KK, Klesges LM, Baker KS, Gurney JG. Poor adherence to dietary guidelines among adult survivors of childhood acute lymphoblastic leukemia. J Pediatr Hematol Oncol. 2008 Nov; 30(11):815-22. PubMed PMID: 18989158; PubMed Central PMCID: PMC2633871.

25: Thomas IH, Donohue JE, Ness KK, Dengel DR, Baker KS, Gurney JG. Bone mineral density in young adult survivors of acute lymphoblastic leukemia. Cancer. 2008 Dec 1; 113(11):3248-56. PubMed PMID: 18932250; PubMed Central PMCID: PMC2597561.

26: Garmey EG, Liu Q, Sklar CA, Meacham LR, Mertens AC, Stovall MA, Yasui Y, Robison LL, Oeffinger KC. Longitudinal changes in obesity and body mass index among adult survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. J Clin Oncol. 2008 Oct 1; 26(28):4639-45. PubMed PMID: 18824710; PubMed Central PMCID: PMC2653124.

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Table B-3. Numbers of CCSS-Related Articles by Journal through June 30, 2009

Journal Title	Number of Articles	2008 Journal Impact Factor
Journal of Clinical Oncology	33	17.157
Cancer	18	5.238
Pediatric Blood and Cancer	14	2.394
Journal of the National Cancer Institute	7	14.933
Journal of Clinical Endocrinology And Metabolism	6	6.325
Cancer Epidemiology, Biomarkers and Prevention	3	4.77
JAMA : The Journal of the American Medical Association	3	31.718
Annals of Internal Medicine	2	17.457
Blood	2	10.432
Journal of Cancer Survivorship: Research and Practice	2	N/A
Journal of Clinical Epidemiology	2	2.896
Journal of Pediatric Hematology/Oncology	2	1.176
Journal of Pediatric Oncology Nursing	2	N/A
Journal of Pediatrics	2	4.122
Medical and Pediatric Oncology	2	N/A
Psycho-Oncology	2	3.15
Addiction (Abingdon, England)	1	4.244
American Journal of Epidemiology	1	5.454
American Journal of Obstetrics and Gynecology	1	3.453
Annals of Epidemiology	1	2.621
Annals of Family Medicine	1	3.541
Archives of Internal Medicine	1	9.11
Archives of Physical Medicine and Rehabilitation	1	2.159
British Journal of Cancer	1	4.846
British Journal of Haematology	1	4.478
Epidemiology (Cambridge, Mass.)	1	5.406
Health Physics	1	0.869
International Journal of Radiation Oncology, Biology, Physics	1	4.639
Journal of Public Health Dentistry	1	1.046
Journal of the National Cancer Institute. Monographs	1	N/A
Lancet	1	28.409
Laryngoscope	1	1.877
Minnesota Medicine	1	N/A
New England Journal of Medicine	1	50.017
Pediatric Radiology	1	1.186
Pediatrics	1	4.789
Preventive Medicine	1	2.757
Psychological Assessment	1	N/A
Radiation Research	1	3.043
Sleep	1	4.475
Strahlentherapie und Onkologie	1	3.005

Table B-4. List of Abstracts of CCSS-Related Presentations

1. Hammond S, Qualman S, Neglia J, Meadows A, Robison L. Assessment and validation of second neoplasms in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology 1997. CCSS Abstract Number: A9701
2. Hammond S, Qualman S, Neglia J, Meadows A, Robison L. Mucoepidermoid carcinoma (MEC) of the salivary gland occurring as a second malignant neoplasm (SMN) in the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Pathology 1998. CCSS Abstract Number: A9801
3. Sklar C, Whitton J, Mertens A, Stovall M, Green D, Marina N, Greffe B, Wolden S, Robison L. Thyroid Dysfunction in Survivors of Hodgkin's Disease (HD): Data from the Childhood Cancer Survivor Study (CCSS). American Pediatric Society and Society for Pediatric Research 1998. CCSS Abstract Number: A9901
4. Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison L. Mortality Rates and Causes of Death in 5-Year Survivors of Childhood and Adolescent Cancer. American Society of Clinical Oncology 1999. CCSS Abstract Number: A9902
5. Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison L. Risk of Second Primary Neoplasms (SPNs) in Survivors of Childhood Cancer--Initial Analysis of the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 1999. CCSS Abstract Number: A9903
6. Neglia J, Mertens A, Yasui Y, Hammond S, Friedman D, Donaldson S, Meadows A, Robison L. Risk Factors For Second Primary Neoplasms (SPNs) in Long-Term Survivors of Childhood Cancer--Initial Analysis of the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting 1999. CCSS Abstract Number: A9904
7. Mertens A, Neglia J, Yasui Y, Potter J, Nesbit M, Ruccione K, Smithson A, Robison L. Mortality in Five-Year Survivors of Childhood and Adolescent Cancer — Preliminary Analysis of the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting 1999. CCSS Abstract Number: A9905
8. Green DM, Whitton J, Stovall M, Mertens A, Ruymann F, Pendergrass T, Robison L. Pregnancy Outcome After Treatment for Cancer During Childhood or Adolescence: A Report from the Childhood Cancer Survivor Study (CCSS). International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting 1999. CCSS Abstract Number: A9906
9. Packer RJ, Gurney J, Zeltzer L, Mertens A, Robison L. Long-Term Neurologic and Neurocognitive Status of Childhood Brain Tumors: A Childhood Cancer Survivor Study (CCSS) Report. Society for Neuro-Oncology 2000. CCSS Abstract Number: A0001
10. Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison L. Second Primary Neoplasms (SPNs) of the Central Nervous System (CNS) in Five Year Survivors of Childhood Cancer--A Report from the Childhood Cancer Survivor Study (CCSS). International Pediatric Neuro-Oncology Symposium 2000. CCSS Abstract Number: A0002
11. Sklar C, Mertens A, Mitby P, Qin J, Heller G, Yasui Y, Robison L. Risk of Disease Recurrence and Second Neoplasms (SN) in Survivors of Childhood Cancer Treated With Growth Hormone (GH): Data from the Childhood Cancer Survivor Study (CCSS). Pediatric Endocrine Society 2001. CCSS Abstract Number: A0101
12. Green D, Whitton J, Stovall M, Mertens A, Donaldson S, Ruymann F, Pendergrass T, Robison L. Pregnancy Outcome of Partners of Male Survivors of Childhood Cancer. A Report from the Childhood Cancer Survivor Study (CCSS). American Association for Cancer Research 2001. CCSS Abstract Number: A0102
13. Kadan N, Friedman D, Mertens A, Yasui Y, Whitton J, Robison L, Strong L. Clarification of Self-Reported Family History Data by Telephone Interview: A Report from the Childhood Cancer Survivor Study (CCSS). American Association for Cancer Research 2001. CCSS Abstract Number: A0103
14. Friedman D, Kadan-Lottick N, Liu Y, Mertens A, Robison L, Strong L. History of Cancer Among First-Degree Relatives of Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2001. CCSS Abstract Number: A0104
15. Neglia J, Yasui Y, Mertens A, Friedman D, Hammond S, Donaldson S, Stovall M, Meadows A, Robison L. Second Primary Neoplasms (SPNs) of the Central Nervous System (CNS) in Five Year Survivors of Childhood Cancer — A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2001. CCSS Abstract Number: A0105
16. Gurney JG, Packer R, Punyko J, Sklar C, Kadan-Lottick N, Neglia J, Nicholson S, Wolden S, McNeil E, Mertens A, Robison L. Non-neurological Late Effects Among Childhood Brain Tumor Survivors: A Preliminary Analysis from the Childhood Cancer Survivor Study. Society for Neuro-Oncology 2001. CCSS Abstract Number: A0106
17. The Investigators of the Childhood Cancer Survivor Study (CCSS). Long-Term Outcomes Among Survivors of Cancer During Childhood and Adolescence. Society for Epidemiologic Research 2001. CCSS Abstract Number: A0107
18. Mulvihill JJ, Strong LC, Robison LL. Genetic Disease in Offspring of Survivors of Childhood and Adolescent Cancer. American Society of Human Genetics 2001. CCSS Abstract Number: A0108

19. Hammond S, Neglia J, Qualman S, Mertens A, Yasui Y, Meadows A, Robison L. Tissue archive of second malignant neoplasms (SMN) in the Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies 2001. CCSS Abstract Number: A0109
20. The Investigators of the Childhood Cancer Survivor Study (CCSS). Long-Term Outcomes Among 5-Year Survivors of Childhood and Adolescent Cancers. American Society of Pediatric Hematology/Oncology 2002. CCSS Abstract Number: A0201
21. Nagarajan R, Clohisy D, Greenberg M, Neglia JP, Sklar C, Yasui Y, Zeltzer L, Robison LL. Limb Function and Quality of Life (QOL) of Survivors of Pediatric Lower Limb Bone Tumors: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2002. CCSS Abstract Number: A0202
22. Mitby PA, Robison LL, Whitton JA, Zevon MA, Gibbs IC, Tersak JM, Meadows AT, Stovall M, Zeltzer LK, Mertens AC. Utilization of Special Education (SE) Services and Educational Attainment (EA) Among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2002. CCSS Abstract Number: A0203
23. Hudson MM, Oeffinger K, Mertens A, Hobbie W, Chen H, Gurney J, Yeazel M, Robison L. General Health Status of Long-Term Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2002. CCSS Abstract Number: A0204
24. Kadan-Lottick N, Robison L, Gurney J, Neglia J, Yasui Y, Hayashi R, Hudson M, Greenberg M, Mertens A. What Do Childhood Cancer Survivors Know About Their Past Diagnosis and Treatment? A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2002. CCSS Abstract Number: A0205
25. Oeffinger KC, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Robison L. Obesity in Adult Survivors of Childhood Acute Leukemia: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2002. CCSS Abstract Number: A0206
26. Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison L. Pulmonary Complications in Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2002. CCSS Abstract Number: A0207
27. Nagarajan R, Clohisy DR, Greenberg M, Neglia JP, Sklar C, Zeltzer L, Yasui Y, Robison LL. Limb Function and Quality of Life (QOL) of Survivors of Pediatric Lower Extremity Bone Tumors: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0208
28. Kenney LB, Diller L, Friedman D, Neglia J, Yasui Y, Mertens A, Inskip P, Meadows A, Robison L. Risk Factors for Breast Cancer (BC) in Women from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0209
29. Oeffinger K, Mertens A, Hudson M, Castillo J, Gurney J, Yeazel M, Chen H, Robison L. Health Care Utilization of Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0210
30. Oeffinger K, Mertens A, Sklar C, Yasui Y, Fears T, Stovall M, Vik T, Robison L. Acute Lymphoblastic Leukemia and Obesity: A Report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0211
31. Pang JWY, Friedman DL, Whitton J, Weiss NS, Mertens A, Robison L. Employment Status of Adult Survivors of Pediatric Cancers: A Report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0212
32. Mertens A, Yasui Y, Liu Y, Stovall M, Hutchinson R, Sklar C, Robison L. Pulmonary Complications in Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0213
33. Yasui Y, Liu Y, Neglia J, Friedman D, Bhatia S, Meadows A, Mertens A, Whitton J, Robison L. A Cautionary Note on the Methodology for the Analysis of Second Malignant Neoplasm (SMN) Risk in Childhood Cancer Survivors: Breast SMN After Hodgkin Disease as an Example. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0214
34. Mitby P, Robison L, Whitton J, Zevon M, Gibbs I, Tersak J, Meadows A, Stovall M, Zeltzer L, Mertens A. Utilization of special education services and educational attainment among long-term survivors of childhood cancer. A report from the Childhood Cancer Survivor Study (CCSS). 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0215

35. Gurney JG, Punyko J, Neglia J, Packer R, Sklar C, Kadan-Lottick N, Nicholson HS, Wolden S, McNeil DE, Mertens A., Robison L. Non-neurological late effects among childhood brain tumor survivors. an analysis from the childhood cancer survivors study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0216

36. Kadan-Lottick N, Robison L, Gurney J, Neglia J, Yasui Y, Hayashi R, Hudson M, Greenberg M, Mertens A. What do childhood cancer survivors know about their past diagnosis and treatment?. A report from the Childhood Cancer Survivor Study. 7th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2002. CCSS Abstract Number: A0217

37. Neglia J, Inskip P, Liu Y, Yasui Y, Hammond S, Stovall M, Packer R, Meadows A, Mertens A, Robison L. Subsequent neoplasms (SNs) of the central nervous system (CNS) in survivors of childhood cancer. A case/control study from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2003. CCSS Abstract Number: A0301

38. Brownstein C, Mertens A, Mitby P, Stovall M, Qin J, Heller G, Robison L, Sklar C. Factors that affect final height and change in height SDS in survivors of childhood cancer treated with growth hormone (GH). A report from the Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies 2003. CCSS Abstract Number: A0302

39. Yeazel M, Oeffinger K, Gurney J, Mertens A, Hudson M, Emmons K, Chen H, Robison L. The cancer screening practices of long-term childhood cancer survivors. American Association for Cancer Research 2003. CCSS Abstract Number: A0303

40. Perkins J, Yasui Y, Liu Y, Hammond S, Stovall M, Neglia J, Meadows A, Robison L, Mertens A. Nonmelanoma skin cancer (NMSC) in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2003. CCSS Abstract Number: A0304

41. Mertens A, Mitby P, Radloss G, Perentesis J, Kiffmeyer W, Neglia J, Meadows A, Jones I, Potter J, Friedman D, Yasui Y, Robison L, Davies S. XRCC1 and glutathione s-transferase polymorphism and susceptibility to therapy-related cancer in Hodgkin's Disease survivors: A report from the Childhood Cancer Survivor Study. American Association for Cancer Research 2003. CCSS Abstract Number: A0305

42. Mulrooney D, Mertens A, Neglia J, Green D, Zeltzer L, Robison L. Fatigue and sleep disturbance in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2003. CCSS Abstract Number: A0306

43. Sigurdson A, Ronckers C, Mertens A, Sklar C, Stovall M, Smith S, Liu Y, Hammond S, Berkow R, Neglia J, Meadows A, Robison L, Inskip P. Second primary thyroid cancer after a first childhood malignancy: A report from the Childhood Cancer Survivor Study. American Association for Cancer Research 2004. CCSS Abstract Number: A0401

44. Lu Q, Myers CD, Owen J, Zebrack BJ, Zevon MA, Mertens A, Robison LL, and Zeltzer LK. Pain prevalence among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Pain Society 2004. CCSS Abstract Number: A0402

45. Recklitis CJ, Hudson MM, Zebrack BJ, Mertens AC, Mitby PA, Nagarajan R, Robison LL, Zeltzer L. Psychosocial functioning in a large-scale cohort of childhood cancer survivors: A report from the Childhood Cancer Survivor Study. American Psychosocial Oncology Society 2004. CCSS Abstract Number: A0403

46. Bassal M, Kadan-Lottick NS, Neglia J, Taylor L, Yasui Y, Friedman DL, Mertens AC, Robison LL, Meadows AT. Risk of rare adult-type carcinomas as a subsequent neoplasm in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0404

47. Bassal M, Kadan-Lottick NS, Neglia J, Taylor L, Yasui Y, Friedman DL, Mertens AC, Robison LL, Meadows AT. Risk of rare adult-type carcinomas as a subsequent neoplasm in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2004. CCSS Abstract Number: A0404

48. Bowers DC, McNeil DE, Liu Y, Yasui Y, Stovall M, Gurney JG, Hudson MM, Robison LL, Oeffinger KC. Stroke following therapy for Hodgkin Disease (HD): A report from the Childhood Cancer Survivor Study. 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0405

49. Bowers DC, McNeil DE, Liu Y, Yasui Y, Stovall M, Gurney JG, Hudson MM, Robison LL, Oeffinger KC. Stroke following therapy for Hodgkin Disease (HD): A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2004. CCSS Abstract Number: A0405

50. Friedman DL, Whitton J, Yasui Y, Mertens AC, Hammond S, Stovall M, Donaldson SS, Meadows AT, Robison LL, Neglia JP. Risk of second malignant neoplasms (SMN) 20 years after childhood cancer: The updated experience of the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2004. CCSS Abstract Number: A0406

51. Friedman DL, Whitton J, Yasui Y, Mertens AC, Hammond S, Stovall M, Donaldson SS, Meadows AT, Robison LL, Neglia JP. Second malignant neoplasms in five-year survivors of childhood cancer: An update from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0407

52. Termuhlen A, Tersak J, Hudson M, Mertens A, Gimpel N, Bleyer W, Yasui Y, Robison L, Oeffinger K. Health status, medical care, preventive screening, and risk behaviors in adult survivors of cancer diagnosed during adolescence: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0408

53. Termuhlen A, Tersak J, Hudson M, Mertens A, Gimpel N, Bleyer W, Yasui Y, Robison L, Oeffinger K. Health status, medical care, preventive screening, and risk behaviors in adult survivors of cancer diagnosed during adolescence: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2004. CCSS Abstract Number: A0408

54. Meacham LR, Gurney JG, Mertens AC, Ness KK, Sklar CA, Robison LL, Oeffinger KC. Body mass index (BMI) and final height in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0409

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56. Meacham LR, Gimpel N, Overa R, Whitton JA, Sklar CA, Robison LL, Oeffinger KC. Diabetes mellitus in long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0410

57. Meacham LR, Gimpel N, Overa R, Whitton JA, Sklar CA, Robison LL, Oeffinger KC. Diabetes mellitus in long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). Society for Pediatric Research 2004. CCSS Abstract Number: A0410

58. Sklar C, Mertens A, Mitby P, Whitton J, Stovall M, Mulder J, Green D, Nicholson S, Yasui Y, Robison L. Premature menopause in survivors of childhood and adolescent cancer: Data from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0411

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60. Castellino SM, Hudson MM, Mertens AC, Yeazel M, Whitton J, Brooks S, et al. Comparison of long-term outcomes, health care utilization, and health behaviors in young adult African-American (AA) survivors of childhood cancer with white, non-Hispanic (WNH) survivors: A Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0412

61. Castellino SM, Hudson MM, Mertens AC, Yeazel M, Whitton J, Brooks S, et al. Comparison of long-term outcomes, health care utilization, and health behaviors in young adult African-American (AA) survivors of childhood cancer with white, non-Hispanic (WNH) survivors: A Childhood Cancer Survivor Study (CCSS). Pediatric Academic Societies 2004. CCSS Abstract Number: A0412

62. Perkins JL, Liu Y, Mitby PA, Neglia JP, Hammond S, Stovall M, Meadows AT, Hutchinson R, Dreyer Z, Robison LL, Mertens AC. Nonmelanoma skin cancer (NMSC) in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0413

63. Perkins JL, Liu Y, Mitby PA, Neglia JP, Hammond S, Stovall M, Meadows AT, Hutchinson R, Dreyer Z, Robison LL, Mertens AC. Nonmelanoma skin cancer (NMSC) in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2004. CCSS Abstract Number: A0413

64. Mulrooney DA, Mertens AC, Neglia JP, Green DM, Zeltzer L, Robison LL. Fatigue and sleep in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0414

65. Mulrooney DA, Mertens AC, Neglia JP, Green DM, Zeltzer L, Robison LL. Fatigue and sleep in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2004. CCSS Abstract Number: A0414

66. Owen JE, Myers CD, Lu Q, Zebrack B, Zevon M, Mertens AC, Robison LL, Zeltzer LK. Pain prevalence in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). 8th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer (Niagara-on-the-Lake) 2004. CCSS Abstract Number: A0415
67. Mertens A, Riley A, Patenaude A, Bursch B, Robison L, Zeltzer L. Health and Well-Being in Adolescent Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study. Cancer Survivorship: Pathways to Health After Treatment Symposium, Washington DC 2004. CCSS Abstract Number: A0416
68. Owen JE, Kawashima T, Myers CD, Lu Q, Zebrack B, Mertens A, Robison L, Zeltzer LK. Pain prevalence and retrospective incidence in childhood cancer survivors: A report from the Childhood Cancer Survivor Study. American Psychosocial Oncology Society 2005. CCSS Abstract Number: A0501
69. Nagarajan R, Clohisy DR, Neglia JP, Sklar C, Robison, LL. Amputation in pediatric lower extremity bone sarcoma survivors: Predictors of function and quality of life. American Society of Pediatric Hematology-Oncology meeting 2005. CCSS Abstract Number: A0502
70. Ness KK, Mertens AC, Hudson MM, Wall MM, Leisenring WM, Oeffinger KC, Sklar CA, Robison LL, Gurney JG. Physical performance limitations and participation restrictions among long-term childhood cancer survivors: The Childhood Cancer Survivor Study. American Society of Pediatric Hematology-Oncology meeting 2005. CCSS Abstract Number: A0503
71. Gurney JG, O'Leary M, Ness KK, Shalamar SD, Baker KS. Metabolic syndrome and growth hormone deficiency in adult survivors of childhood leukemia. American Society of Pediatric Hematology-Oncology meeting 2005. CCSS Abstract Number: A0504
72. Oeffinger K, Mertens A, Sklar C, Kawashima T, Hudson M, Meadows A, Marina N, Kadan-Lottick N, Leisenring L, Robison L. Prevalence and severity of chronic diseases in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2005. CCSS Abstract Number: A0505
73. Mertens A, Yasui Y, Liu Y, Neglia J, Robison L. Late cause-specific mortality in long-term survivors of childhood and adolescent cancer: An update from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2005. CCSS Abstract Number: A0506
74. Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison L, Cook F, Diller L. Sarcomas as a subsequent malignancy in survivors of pediatric malignancy: The Childhood Cancer Survivor Study. American Society of Clinical Oncology 2005. CCSS Abstract Number: A0507
75. Bowers DC, McNeil DE, Liu Y, Leisenring W, Gurney J, Stovall M, Donaldson SS, Packer RJ, Robison LL, Oeffinger KC. Risk of stroke among >5 year survivors of childhood leukemia and brain tumors: A report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2005. CCSS Abstract Number: A0508
76. Casillas J, Castellino DM, Hudson MM, Mertens AC, Whitton J, Brooks SL, Zeltzer LK, Ablin A, Robison LL, Oeffinger KC. The effect of insurance and ethnicity on healthcare access and health behaviors: The Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2005. CCSS Abstract Number: A0509
77. Mertens AC, Neglia JP, Hammond S, Perkins JL, Liu Y, Robison LL. Incidence rates of keratinocyte carcinoma (KC) in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). Society of Investigative Dermatology 2005. CCSS Abstract Number: A0510
78. Ergun-Longmire B, Mertens AC, Mitby P, Quin J, Heller G, Yasui Y, Robison LL, Sklar CA. Risk of second neoplasms in survivors of childhood cancer treated with growth hormone: An updated report from the Childhood Cancer Survivor Study. Endocrine Society 2005. CCSS Abstract Number: A0511
79. Chemaitilly W, Mertens AC, Mitby P, Whitton J, Stovall M, Yasui Y, Robison LL, Sklar CA. Acute ovarian failure in survivors of childhood and adolescent cancer: Data from the Childhood Cancer Survivor Study. Endocrine Society 2005. CCSS Abstract Number: A0512
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81. Casillas J, Brooks S, Mertens A, Hudson M, Robison L, Oeffinger K. Understanding the impact of Psychosocial Factors in Healthcare Access in Adult Minority Survivors of Childhood Cancer: A CCSS Study. Western Society for Pediatric Research 2006. CCSS Abstract Number: A0602
82. Henderson T, Whitton J, Hammond S, Stovall M, Meadows A, Mertens A, Neglia J, Robison L, Diller L. Sarcoma as a Subsequent Malignancy in Survivors of Childhood Malignancy: A Report from the CCSS. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer 2006. CCSS Abstract Number: A0603
83. Lansdale M, Marina N, Castellino S, Goodman P, Hudson MM, Mertens AC, Sklar CA, Leisenring W, Robison LL, Oeffinger KC. Screening for Hepatitis C Virus (HCV) Infection in Long-Term Pediatric Cancer Survivors: A Report from the Childhood Cancer Survivor Study (CCSS). Third biennial NCI Cancer Survivorship Conference 2006. CCSS Abstract Number: A0604

84. Lu Q, Tsao JCI, Leisenring W, Robison L, Zeltzer LK. Pain Prevalence among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). Third biennial NCI Cancer Survivorship Conference 2006. CCSS Abstract Number: A0606

85. Mertens AC, Schultz KA, Ness KK, Whitton J, Recklitis C, Zebrack B, Zeltzer L, Robison LL. Social Adjustment in Survivors of Childhood Cancer: A Report from the CCSS. American Psychosocial Oncology Society 2006. CCSS Abstract Number: A0607

86. Mertens AC, Steele JR, Goodman P, Oeffinger KC, Robison LL, Hudson MM. Follow-Up Care in Cancer Survivors: Newsletters Can't Do It Alone - A Report from the Childhood Cancer Survivor Study. American Psychosocial Oncology Society 2006. CCSS Abstract Number: A0608

87. Mitby PA, Mertens AC, Hudson MM, Eshelman DE, Jacox C, Jones JK, Kamani S, Allam RK, Oeffinger KC. Does a Cognitive-Based Intervention Increase the Likelihood of Screening for Serious Late Effects in Adult Survivors of Childhood Cancer? Project Vision: A Report from CCSS. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer 2006. CCSS Abstract Number: A0609

88. Mulrooney DA, Dover DC, Yasui Y, Ness K, Mertens AC, Neglia JP, Sklar CA, Robison LL, Davies SM. Twenty Years of Follow-Up Among Survivors of Childhood and Young Adult Acute Myeloid Leukemia (AML): A Report from the Childhood Cancer Survivor Study (CCSS). American Society of Hematology 2006. CCSS Abstract Number: A0610

89. Ness K, Mertens AC, Zeltzer L, Gurney J, Leisenring W, Robison LL. Physical performance and health related quality of life in adult survivors of childhood cancer. Psychosocial and Neurocognitive Consequences of Childhood Cancer 2006. CCSS Abstract Number: A0611

90. Schultz KAP, Ness KK, Whitton J, Recklitis C, Zebrack B, Robison L, Zeltzer L, Mertens AC. Social Adjustment of Adolescent Survivors in the Childhood Cancer Survivor Study. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer 2006. CCSS Abstract Number: A0612

91. Whelan KF, Kawashima T, Mitby P, Blatt J, Waterbor J, Castleberry R, Sande J, Packer R, Sklar C, Robison L, Mertens A. Auditory and Speech Complications on Childhood Cancer Survivors: A Report from CCSS. American Society of Clinical Oncology 2006. CCSS Abstract Number: A0613

92. Whelan K, Mertens A, Castleberry R, Mitby P, Kawashima T, Sklar C, Packer R, Waterbor J, Blatt J, Robison L. Visual complications in childhood cancer survivors: a Childhood Cancer Survivor Study report. 9th International Conference on Long Term Complications of Treatment of Children and Adolescent for Cancer 2006. CCSS Abstract Number: A0614

93. Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson SS, Sklar CA, Byrne J, Robison LL. Fecundity of males after treatment for childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2007. CCSS Abstract Number: A0701

94. Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson SS, Sklar CA, Byrne J, Robison LL. Fertility of males after treatment for childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). SIOP 2007. CCSS Abstract Number: A0702

95. Lown EA, Goldsby R, Mertens AC, Greenfield T, Bond J, Whitton J, Korcha R, Robison LL, Zeltzer LK. Alcohol Consumption Patterns and Risk Factors among Childhood Cancer Survivors Compared to Siblings and General Population Peers. American Psychosocial Oncology Society 2007. CCSS Abstract Number: A0703

96. Nathan PC, Greenberg ML, Ness KK, Mahoney MC, Gurney JG, Hudson MM, Donaldson SS, Leisenring WM, Robison LL, Oeffinger KC. Risk-based care in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2007. CCSS Abstract Number: A0704

97. Wasilewski-Masker K, Leisenring W, Meacham LR, Hammond S, Meadows AT, Robison LL, Mertens AC. Late recurrence in survivors of childhood and adolescent cancer: a report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2007. CCSS Abstract Number: A0705

98. Kaste SC, Baker S, Goodman P, Leisenring W, Stovall M, Hayashi R, Yeazel M, Hudson MM, Sklar C, Robison LL. Dental health of long-term survivors of childhood cancer: The childhood cancer survivor study (CCSS). American Society of Clinical Oncology 2007. CCSS Abstract Number: A0706

99. Garmey EG, Liu Q, Sklar CA, Meacham LR, Stovall M, Yasui Y, Robison LL, Oeffinger KC. Obesity in adult survivors of childhood acute lymphoblastic leukemia: A follow-up report from the childhood cancer survivor study. American Society of Clinical Oncology 2007. CCSS Abstract Number: A0707

100. Laverdiere C, Liu Q, Yasui Y, Nathan PC, Gurney J, Stovall M, Diller L, Cheung NK, Wolden S, Robison LL, Sklar CA. Long-term complications of neuroblastoma: A report from the childhood cancer survivor study. American Society of Clinical Oncology 2007. CCSS Abstract Number: A0708

101. Bluhm EC, Ronckers C, Hayashi RJ, Neglia JP, Mertens AC, Meadows AT, Mitby PA, Stovall M, Robison LL, Inskip PD. Cause-specific mortality and second cancer incidence after non-Hodgkin lymphoma: a report from the Childhood Cancer Survivor Study. ASH Annual Meeting 2007. CCSS Abstract Number: A0709

102. Mulrooney DA, Yeazel M, Mitby P, Kawashima T, Leisenring WM, Stovall M, Green DM, Sklar CA, Robison LL, Mertens AC. Cardiovascular Disease in Adult Survivors of Childhood and Adolescent Cancer: A Report from the CCSS. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0801

103. Armstrong GT, Ness KK, Whitton J, Leisenring W, Yasui Y, Zeltzer L, Donaldson SS, Hudson M, Robison LL, Packer R. Long-term Outcomes Among Survivors of Childhood Central Nervous System Tumors: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2008. CCSS Abstract Number: A0802

104. Armstrong GT, Ness KK, Whitton J, Leisenring W, Yasui Y, Zeltzer L, Donaldson SS, Hudson M, Robison LL, Packer R. Long-term Outcomes Among Survivors of Childhood Central Nervous System Tumors: A Report from the Childhood Cancer Survivor Study. International Symposium on Pediatric Neuro-Oncology 2008. CCSS Abstract Number: A0802

105. Armstrong GT, Whitton J, Chow E, Leisenring W, Gajjar A, Kun L, Robison LL, Sklar C. Abnormal Timing of Menarche In Survivors of Childhood Central Nervous System Tumors. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0803

106. Ellenberger L, Gioia G, Liu Q, Yasui Y, Packer R, Mertens A, Donaldson S, Kadan-Lottick N, Armstrong G, Robison LL, Zeltzer LK. Executive Functioning in Long-Term Survivors of Childhood Brain Tumors: A Report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0804

107. Liverier C, Liu Q, Yasui Y, Nathan P C, Gurney JG, Stovall M, Diller LR, Cheung NK, Wolden S, Robison LL, Sklar C A. Long-Term Outcomes in Survivors of Neuroblastoma: A Report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0805

108. Lown EA, Goldsby R, Mertens AC, Greenfield T, Bond J, Whitton J, Korcha R, Robison LL, Zeltzer LK. Alcohol Consumption Patterns and Risk Factors among Childhood Cancer Survivors Compared to Siblings and General Population Peers. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0806

109. Bluhm E, Oeffinger K, Sklar CA, Meadows A, Hayashi R, Mertens AC, Kawashima T, Donaldson S, Meacham L, Stovall M, Robison LL, Inskip P. Risk Factors for Common Health Conditions Occurring Five Years After NHL: A Report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0807

110. Ginsberg JP, Ness K, Goodman P, Leisenring W, Robison LL, Oeffinger KC. Long-Term Follow-Up Among Survivors of Childhood Ewing's Sarcoma: A Report of the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0808

111. Ness KK, Leisenring WM, Huang S, Hudson MM, Gurney JG, Whelan K, Hobbie WL, Lanctot JQ, Armstrong GT, Robison LL, Oeffinger KC. Physical Activity – Patterns and Predictors of Sedentary Lifestyle Among Adult Survivors of Childhood Cancer. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0809

112. Meacham LR, Chow EJ, Kadar KY, Ness KK, Chen Y, Yasui Y, Oeffinger KC, Sklar CA, Robison LL, Mertens AC. Cardiovascular Risk Factor Cluster in Adult Survivors of Pediatric Cancer: A Report of the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0810

113. Oeffinger KC, Ford JS, Moskowitz CS, Diller L, Hudson MM, Chou JF, Smith S, Mertens AC, Robison LL. Mammogram Practices of Women at Risk for Breast Cancer Following Chest Radiation for a Pediatric Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0811

114. Smith S, Ford JS, Rakowski W, Moskowitz CS, Robison LL, Oeffinger KC. Decisional Balance, Stages of Adoption, and Screening Mammography Among Women at Risk of Breast Cancer Following a Pediatric Malignancy: A Report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0812

115. Mertens A, Leisenring W, Mitby P, Hammond S, Perkins J, Robison LL, Hudson M, Meadows A. Sun Sensitivity, Sun Exposure and Risk of Skin Cancer in a Cohort of Adult Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0813

116. Bornstein MC, Haynes M, Hayashi R, Leisenring W, Armstrong G, Robison L, Zeltzer L. Mental Retardation and Learning Disability in Survivors of Childhood Cancer Diagnosed in Infancy: A Report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0814

117. Henderson T, Rajaraman P, Stovall M, Olive A, Smith S, Mertens A, Meadows A, Neglia J, Whitton J, Inskip P, Robison L, Diller L. New Primary Sarcomas in Survivors of Childhood Cancer: A Detailed Analysis of the Effects of Treatment: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2008. CCSS Abstract Number: A0815

118. Henderson T, Rajaraman P, Stovall M, Olive A, Smith S, Mertens A, Meadows A, Neglia J, Whitton J, Inskip P, Robison L, Diller L. New Primary Sarcomas in Survivors of Childhood Cancer: A Detailed Analysis of the Effects of Treatment: A Report from the Childhood Cancer Survivor Study. International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer 2008. CCSS Abstract Number: A0815

119. Lown EA, Goldsby R, Mertens AC, Korcha R, Greenfield T, Bond J, Whitton J, Robison LL, Zeltzer LK. Adult Siblings of Childhood Cancer Survivors Are Heavy Drinkers: Which Siblings Are at Risk? A Report from the Childhood Cancer Survivor Study. American Public Health Association 2008. CCSS Abstract Number: A0816

120. Ju Q, Tsao JCI, Leisenring W, Armstrong G, Robison L, Zeltzer LK. Posttraumatic Stress Symptoms, Pain, and Related Impairment Among Adult Survivors of Childhood Cancer: A Report From The Childhood Cancer Survivor Study (CCSS). 4th Biennial Cancer Survivorship Research Conference 2008. CCSS Abstract Number: A0817

121. Castellino SM, Tooze J, Geiger A, Leisenring W, Goodman P, Mertens A, Stovall M, Robison L, Hudson M. Risks of Mortality in 5 Year Survivors of Hodgkin's Lymphoma in the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2008. CCSS Abstract Number: A0818

122. Green DM, Kawashima T, Leisenring W, Stovall M, Donaldson S, Sklar CA, Byrne J, Robison LL. Fertility of Females After Treatment for Childhood Cancer: A Report from the Childhood Cancer Survivor Study. American Society of Clinical Oncology 2008. CCSS Abstract Number: A0819

123. Cox CL, Montgomery M, Oeffinger KC, Leisenring W, Zeltzer L, Whitton JA, Mertens AC, Hudson MM, Robison LL. Childhood Cancer Survivors: Treatment Sequelae, Survivor and Provider Influences on Physical Activity. 4th Biennial Cancer Survivorship Research Conference 2008. CCSS Abstract Number: A0820

124. Cox CL, Hudson MM, Oeffinger K, Whitton J, Montgomery M, Mertens A, Robison LL. Determinants of Participation in Recommended Medical Screening by At-Risk Adult Survivors of Childhood Cancer. American Public Health Association 2008. CCSS Abstract Number: A0821

125. Sun Protection Behavior in a Cohort of Adult Survivors of Childhood and Adolescent Cancer: A Report from the Childhood Cancer Survivor Study (CCSS). 4th Biennial Cancer Survivorship Research Conference 2008. CCSS Abstract Number: A0822

126. Klesges L, Ness K, Lanctot J, Lown A, Whelan K, Huang S, Leisenring W, Oeffinger K, Robison L, Hudson M. Prevalence and Clustering of Multiple Unhealthy Behaviors in Adult Survivors of Childhood Cancer: Results from the Childhood Cancer Survivor Study. 4th Biennial Cancer Survivorship Research Conference 2008. CCSS Abstract Number: A0823

127. D. A. Mulrooney, M. Yeazel, P. Mitby, T. Kawashima, W. M. Leisenring, M. Stovall, D. M. Green, C. A. Sklar, L. L. Robison, A. C. Mertens. Cardiovascular disease in adult survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study (CCSS). American Society of Clinical Oncology 2008. CCSS Abstract Number: 9509

Table B-5. Numbers of CCSS-Related Presentations by Conference through 2008

Conference	Number of Presentations
International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer	39
American Society of Clinical Oncology	36
Cancer Survivorship Research Conference	6
American Association for Cancer Research	5
American Psychosocial Oncology Society	5
American Society of Pediatric Hematology/Oncology	4
Society for Pediatric Research	4
Pediatric Academic Societies	3
American Public Health Association	2
American Society of Hematology	2
Endocrine Society	2
International Society of Paediatric Oncology-American Society of Pediatric Hematology-Oncology meeting	2
Society for Neuro-Oncology	2
Society for Pediatric Pathology	2
Other meetings (13)	1 each
Grand Total	127

Table B-6. Specific References to CCSS Publications in 2008 Guidelines

Section of Guidelines	Total Refs	CCSS Refs	References
Section 1: Psychosocial disorders/Mental health disorders/Risky behaviors/Psychosocial disability due to pain/Fatigue	41	6	Emmons K, Li FP, Whitton J, et al. Predictors of smoking initiation and cessation among childhood cancer survivors: a report from the childhood cancer survivor study. J Clin Oncol. Mar 15 2002; 20(6):1608-1616. Lown EA et al. Alcohol consumption patterns and risk factors among childhood cancer survivors compared to siblings and general population peers. Addiction. 2008; 103(7):1139-48. Mitby PA, Robison LL, Whitton JA, et al. Utilization of special education services and educational attainment among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Cancer. Feb 15 2003; 97(4):1115-1126. Mulrooney DA et al. Fatigue and sleep disturbance in adult survivors of childhood cancer. Sleep. 2008; 31(2) 271-281. Schultz KA et al. Behavioral and social outcomes in adolescent survivors of childhood cancer. J Clin Oncol. 2007; 20; 25(24):3649-56. Zebrack BJ, Zeltzer LK, Whitton J, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. Pediatrics. Jul 2002; 110(1 Pt 1):42-52.
Section 2: Limitations in healthcare and insurance access	3	2	Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Ann Fam Med. Jan-Feb 2004; 2(1):61-70. Park ER et al. Health insurance coverage in survivors of childhood cancer: the Childhood Cancer Survivor Study. J Clin Oncol. 2005; 20; 23(36):9187-97
Section 7: Gonadal dysfunction in women (ovarian) due to alkylating agents	8	2	Chemaitilly W, Mertens AC, Mitby P, et al. Acute ovarian failure in the childhood cancer survivor study. J Clin Endocrinol Metab. May 2006; 91(5):1723-1728. Sklar CA, Mertens AC, Mitby P, et al. Premature menopause in survivors of childhood cancer: a report from the childhood cancer survivor study. J Natl Cancer Inst. Jul 5 2006; 98(13):890-896.
Section 38: Secondary benign or malignant neoplasm following radiation therapy (including TBI)	10	1	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629.

Section of Guidelines	Total Refs	CCSS Refs	References
Section 39: Dysplastic nevi; Skin cancer following radiation therapy (including TBI)	6	1	Perkins JL, Liu Y, Mitby PA, et al. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: a report from the childhood cancer survivor study. J Clin Oncol. Jun 1 2005; 23(16):3733-3741.
Section 42: Brain tumor (benign or malignant) following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring, TBI)	9	2	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629. Neglia JP, Robison LL, Stovall M, et al. New primary neoplasms of the central nervous system in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. J Natl Cancer Inst. Nov 1 2006; 98(21):1528-1537.
Section 45: Cerebrovascular complications (Stroke, Moyamoya, Occlusive cerebral vasculopathy) following radiation therapy (≥ 18 Gy to Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring, TBI)	6	1	Bowers DC, Liu Y, Leisenring W, et al. Late-occurring stroke among long-term survivors of childhood leukemia and brain tumors: a report from the Childhood Cancer Survivor Study. J Clin Oncol. Nov 20 2006; 24(33):5277-5282.
Section 48: Obesity/overweight following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring)	13	1	Oeffinger KC, Mertens AC, Sklar CA, et al. Obesity in adult survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. J Clin Oncol. Apr 1 2003; 21(7):1359-1365.
Section 50: Growth hormone deficiency following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring)	20	2	Brownstein CM, Mertens AC, Mitby PA, et al. Factors that affect final height and change in height standard deviation scores in survivors of childhood cancer treated with growth hormone: a report from the childhood cancer survivor study. J Clin Endocrinol Metab. Sep 2004; 89(9):4422-4427. Gurney JG, Ness KK, Sibley SD, et al. Metabolic syndrome and growth hormone deficiency in adult survivors of childhood acute lymphoblastic leukemia. Cancer. Sep 15 2006; 107(6):1303-1312.
Section 51: Precocious puberty following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring)	9	1	Chow EJ, Friedman DL, Yasui Y, et al. Timing of menarche among survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. Pediatr Blood Cancer. Apr 2008; 50(4):854-858.
Section 54: Gonadotropin deficiency following radiation therapy (≥ 40 Gy to Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, Waldeyer's Ring, TBI)	6	1	Chow EJ, Friedman DL, Yasui Y, et al. Timing of menarche among survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. Pediatr Blood Cancer. Apr 2008; 50(4):854-858.

Section of Guidelines	Total Refs	CCSS Refs	References
Section 62: Thyroid nodules following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Waldeyer's Ring, Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	8	2	Sigurdson AJ, Ronckers CM, Mertens AC, et al. Primary thyroid cancer after a first tumour in childhood (the Childhood Cancer Survivor Study): a nested case-control study. Lancet. Jun 28 2005; 365(9476):2014-2023. Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 63: Thyroid cancer following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Waldeyer's Ring, Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	13	2	Sigurdson AJ, Ronckers CM, Mertens AC, et al. Primary thyroid cancer after a first tumour in childhood (the Childhood Cancer Survivor Study): a nested case-control study. Lancet. Jun 28 2005; 365(9476):2014-2023. Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 64: Hypothyroidism following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Waldeyer's Ring, Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	9	1	Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 65: Hyperthyroidism following radiation therapy (≥ 40 Gy to: Cranial, Nasopharyngeal, Oropharyngeal, Waldeyer's Ring, Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	9	1	Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 66: Carotid artery disease following radiation therapy (≥ 40 Gy to: Cranial, Nasopharyngeal, Oropharyngeal, Waldeyer's Ring, Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	9	1	Bowers DC, McNeil DE, Liu Y, et al. Stroke as a late treatment effect of Hodgkin's Disease: a report from the Childhood Cancer Survivor Study. J Clin Oncol. Sep 20 2005; 23(27):6508-6515.
Section 67: Subclavian artery disease following radiation therapy (≥ 40 Gy to: Spine (cervical, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Mini-mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	2	1	Bowers DC, McNeil DE, Liu Y, et al. Stroke as a late treatment effect of Hodgkin's Disease: a report from the Childhood Cancer Survivor Study. J Clin Oncol. Sep 20 2005; 23(27):6508-6515.
Section 70: Pulmonary toxicity following radiation therapy (Chest (thorax), Whole lung, Mediastinal, Axilla, Mini-Mantle, Mantle, Extended Mantle, TLI, STLI, TBI)	15	1	Mertens AC, Yasui Y, Liu Y, et al. Pulmonary complications in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study. Cancer. Dec 1 2002; 95(11):2431-2441.
Section 83: Uterine vascular insufficiency following radiation therapy (Spine (lumbar, sacral, whole), Flank/Hemiabdomen(right, left), Whole abdomen, Inverted Y, Pelvic, Vaginal, Bladder, TLI, TBI)	11	1	Signorello LB, Cohen SS, Bosetti C, et al. Female survivors of childhood cancer: preterm birth and low birth weight among their children. J Natl Cancer Inst. Oct 18 2006; 98(20):1453-1461.

Section of Guidelines	Total Refs	CCSS Refs	References
Section 83: Gonadal dysfunction (ovarian) following radiation therapy (Spine (lumbar, sacral, whole), Flank/Hemiabdomen (right, left), Whole abdomen, Inverted Y, Pelvic, Vaginal, Bladder, Iliac, TLI, TBI)	17	2	Chemaitilly W, Mertens AC, Mitby P, et al. Acute ovarian failure in the childhood cancer survivor study. J Clin Endocrinol Metab. May 2006; 91(5):1723-1728. Sklar CA, Mertens AC, Mitby P, et al. Premature menopause in survivors of childhood cancer: a report from the childhood cancer survivor study. J Natl Cancer Inst. Jul 5 2006; 98(13):890-896.
Section 88: Musculoskeletal growth problems following radiation therapy (Spine (cervical, thoracic, lumbar, sacral, whole), Cervical (neck), Supraclavicular, Chest (thorax), Whole lung, Mediastinal, Axilla, Mini-Mantle, Mantle, Extended Mantle, Hepatic, Renal, Upper quadrant (right, left), Spleen (partial, entire), Paraaortic, Flank/Hemiabdomen (right, left), Whole abdomen, Inverted Y, Pelvic, Vaginal, Prostate, Bladder, Iliac, Inguinal, Femoral, Extremity (upper, lower), TLI, STLI, TBI)	9	1	Chow EJ, Friedman DL, Yasui Y, et al. Decreased adult height in survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. J Pediatr. Apr 2007; 150(4):370-375, 375 e371.
Section 107: Amputation-related complications following amputation	6	1	Nagarajan R, Neglia JP, Clohisy DR, et al. Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. Cancer. May 15 2003; 97(10):2554-2564.
Section 113: Complications following limb-sparing surgical procedures	11	2	Nagarajan R, Neglia JP, Clohisy DR, Robison LL. Limb salvage and amputation in survivors of pediatric lower-extremity bone tumors: what are the long-term implications?. J Clin Oncol. Nov 15 2002; 20(22):4493-4501. Nagarajan R, Neglia JP, Clohisy DR, et al. Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. Cancer. May 15 2003; 97(10):2554-2564.
Section 144: Skin cancer screening guidelines for cancer survivors	7	2	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629. Perkins JL, Liu Y, Mitby PA, et al. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: a report from the childhood cancer survivor study. J Clin Oncol. Jun 1 2005; 23(16):3733-3741.

Source: STPI analysis of Children's Oncology Group, "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 3.0," October 2008. Individual references are compared with the CCSS list of publications.

Table B-7. Specific References to CCSS Publications in 2006 Guidelines

Section of Guidelines	Total Refs	CCSS Refs	References
Section 1: Psychosocial disorders/Mental health disorders/Risky behaviors/Psychosocial disability due to pain/Fatigue	45	4	Emmons K, Li FP, Whitton J, et al. Predictors of smoking initiation and cessation among childhood cancer survivors: a report from the childhood cancer survivor study. J Clin Oncol. Mar 15 2002; 20(6):1608-1616. Mitby PA, Robison LL, Whitton JA, et al. Utilization of special education services and educational attainment among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Cancer. Feb 15 2003; 97(4):1115-1126. Rauck AM, Green DM, Yasui Y, Mertens A, Robison LL. Marriage in the survivors of childhood cancer: a preliminary description from the Childhood Cancer Survivor Study. Med Pediatr Oncol. Jul 1999; 33(1):60-63. Zebrack BJ, Zeltzer LK, Whitton J, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. Pediatrics. Jul 2002; 110(1 Pt 1):42-52.
Section 2: Limitations in healthcare and insurance access	5	1	Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Ann Fam Med. Jan-Feb 2004; 2(1):61-70.
Section 38: Secondary benign or malignant neoplasm following radiation therapy (including TBI)	10	1	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629.
Section 38 TBI: Secondary benign or malignant neoplasm following radiation therapy (all radiation fields, including TBI)	9	1	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629.
Section 39: Dysplastic nevi; Skin cancer following radiation therapy (including TBI)	6	1	Perkins JL, Liu Y, Mitby PA, et al. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: a report from the childhood cancer survivor study. J Clin Oncol. Jun 1 2005; 23(16):3733-3741.
Section 39 TBI: Dysplastic nevi; Skin cancer following radiation therapy (all radiation fields, including TBI)	6	1	Perkins JL, Liu Y, Mitby PA, et al. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: a report from the childhood cancer survivor study. J Clin Oncol. Jun 1 2005; 23(16):3733-3741.
Section 42: Brain tumor (benign or malignant) following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal, TBI)	3	1	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629.

Section of Guidelines	Total Refs	CCSS Refs	References
Section 48: Obesity/overweight following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal)	9	1	Oeffinger KC, Mertens AC, Sklar CA, et al. Obesity in adult survivors of childhood acute lymphoblastic leukemia: a report from the Childhood Cancer Survivor Study. J Clin Oncol. Apr 1 2003; 21(7):1359-1365.
Section 50: Growth hormone deficiency following radiation therapy (Cranial, Orbital/Eye, Ear/Infratemporal, Nasopharyngeal)	10	1	Brownstein CM, Mertens AC, Mitby PA, et al. Factors that affect final height and change in height standard deviation scores in survivors of childhood cancer treated with growth hormone: a report from the childhood cancer survivor study. J Clin Endocrinol Metab. Sep 2004; 89(9):4422-4427.
Section 62: Thyroid nodules following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Spine (cervical), Cervical (neck), Supraclavicular, Mini-mantle, Mantle, TBI)	6	2	Sigurdson AJ, Ronckers CM, Mertens AC, et al. Primary thyroid cancer after a first tumour in childhood (the Childhood Cancer Survivor Study): a nested case-control study. Lancet. Jun 28 2005; 365(9476):2014-2023. Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 63: Thyroid cancer following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Spine (cervical), Cervical (neck), Supraclavicular, Mini-mantle, Mantle, TBI)	10	2	Sigurdson AJ, Ronckers CM, Mertens AC, et al. Primary thyroid cancer after a first tumour in childhood (the Childhood Cancer Survivor Study): a nested case-control study. Lancet. Jun 28 2005; 365(9476):2014-2023. Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 64: Hypothyroidism following radiation therapy (Cranial, Nasopharyngeal, Oropharyngeal, Spine (cervical), Cervical (neck), Supraclavicular, Mini-mantle, Mantle, TBI)	6	1	Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 65: Hyperthyroidism following radiation therapy (≥ 40 Gy to: Cranial, Nasopharyngeal, Oropharyngeal, Spine (cervical), Cervical (neck), Supraclavicular, Mini-mantle, Mantle)	9	1	Sklar C, Whitton J, Mertens A, et al. Abnormalities of the thyroid in survivors of Hodgkin's disease: data from the Childhood Cancer Survivor Study. J Clin Endocrinol Metab. Sep 2000; 85(9):3227-3232.
Section 68: Breast cancer (≥ 20 Gy to: Mantle, Mini-mantle, Mediastinal, Chest (thorax), Axilla)	10	1	Kenney LB, Yasui Y, Inskip PD, et al. Breast cancer after childhood cancer: a report from the Childhood Cancer Survivor Study. Ann Intern Med. Oct 19 2004; 141(8):590-597.
Section 70: Pulmonary toxicity following radiation therapy (Mantle, Mediastinal, Chest(thorax), Whole lung, TBI)	6	1	Mertens AC, Yasui Y, Liu Y, et al. Pulmonary complications in survivors of childhood and adolescent cancer: A report from the Childhood Cancer Survivor Study. Cancer. Dec 1 2002; 95(11):2431-2441.

Section of Guidelines	Total Refs	CCSS Refs	References
Section 107: Amputation-related complications following amputation	6	1	Nagarajan R, Neglia JP, Clohisy DR, et al. Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. Cancer. May 15 2003; 97(10):2554-2564.
Section 113: Complications following limb-sparing surgical procedures	10	2	Nagarajan R, Neglia JP, Clohisy DR, Robison LL. Limb salvage and amputation in survivors of pediatric lower-extremity bone tumors: what are the long-term implications?. J Clin Oncol. Nov 15 2002; 20(22):4493-4501. Nagarajan R, Neglia JP, Clohisy DR, et al. Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. Cancer. May 15 2003; 97(10):2554-2564.
Section 144: Skin cancer screening guidelines for cancer survivors	7	2	Neglia JP, Friedman DL, Yasui Y, et al. Second malignant neoplasms in five-year survivors of childhood cancer: childhood cancer survivor study. J Natl Cancer Inst. Apr 18 2001; 93(8):618-629. Perkins JL, Liu Y, Mitby PA, et al. Nonmelanoma skin cancer in survivors of childhood and adolescent cancer: a report from the childhood cancer survivor study. J Clin Oncol. Jun 1 2005; 23(16):3733-3741.

Source: STPI analysis of Children's Oncology Group, "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers: Version 3.0," March 2006. Individual references are compared with the CCSS list of publications.

Table B-8. Ancillary Studies and Other Leveraged Funding

Place (at Time of Study)	Title	Principal Investigator	Funding Source	Grant Number (if NIH)	What Is It?
Baylor College of Medicine	Adult Neurobehavioral Late Effects of Pediatric Low Grade Brain Tumors	M. Douglas Ris	NIH-NCI	R01CA132899	Abstract mentions CCSS
Children's Hospital Medical Center (Cincinnati)	Empirical Likelihood Bayes Analysis of Quantile Regression Model	Mi-Ok Kim	NIH-NCI	R03CA133944	Abstract mentions CCSS
Children's Hospital Medical Center (Cincinnati)	Prediction Model for Radiation Sensitivity in Children With Cancer	Stella Margaret Davies	NIH-NCI	U01CA139275	Abstract mentions CCSS
Dana-Farber Cancer Institute	Genetics, Genomic Research, and Consent: Attitudes of Pediatric Cancer Survivors	Andrea F. Patenaude,	NIH-NHGRI	R03HG004301	Abstract mentions CCSS
Emory University	Men's Health Survey	Lillian Meacham	Lance Armstrong Foundation	Not applicable	Ancillary study
Harvard University	Smoking Cessation among Childhood Cancer Survivors	Karen Emmons	NIH-NCI	R01CA077780	Ancillary study (and abstract mentions CCSS)
International Epidemiology Institute	Preconception Radiation and Reproductive Outcomes among Survivors of Childhood Cancer	John Boice	Westlakes Research Institute	Not applicable	Ancillary study
Memorial Sloan Kettering Cancer Center	Encourage Mammography and Prevention Opportunities for Women Exposed to Radiation	Kevin Oeffinger	NIH-NCI	R01CA134722	Ancillary study (and abstract mentions CCSS0
Memorial Sloan Kettering Cancer Center	Premature Menopause in Survivors of Childhood Cancer	Charles Sklar	NIH-NCI	R01CA079024	Ancillary study (and abstract mentions CCSS)
Memorial Sloan Kettering Cancer Center	Safety/Efficacy of Growth Hormone Therapy in Survivors of Childhood Cancer	Charles Sklar	Genentech Foundation	Not applicable	Ancillary study
Northwestern University	Symptom Cluster Mixed Model in Adult Survivors of Childhood Cancer	Lorna Finnegan	NIH-NCI	R01CA136912	Ancillary study
Oregon Health Sciences Center	Quality of Life Following Successful Therapy of AML	H. Stacy Nicholson	NIH-NCI	R01CA078960	Ancillary study
St. Jude Children's Research Hospital	Efficacy of a Tobacco Quit Line for Childhood Cancer Survivors	Robert C. Klesges	NIH-NCI	R01CA127964	Ancillary study (and abstract mentions CCSS)

Place (at Time of Study)	Title	Principal Investigator	Funding Source	Grant Number (if NIH)	What Is It?
St. Jude Children's Research Hospital	Health-Related Behaviors in Childhood Cancer Survivors	Cheryl Lorane Cox	NIH-NINR	R03NR009203	Abstract mentions CCSS
St. Jude Children's Research Hospital	Long-Term Complications of Children/Adolescents and Cancer	Daniel Michael Green	NIH-NCI	R13CA095124	Abstract mentions CCSS
University Of California Los Angeles	Psychosocial Outcomes In Childhood Cancer Survivors	Lonnie Zeltzer	NIH-NCI	F32CA089875	Ancillary study (and abstract mentions CCSS)
University Of Chicago	Health Beliefs and Behavior: Cohort Studies in Pediatric Cancer Survivorship	Tara Henderson	NIH-NCI	K07CA134935	Ancillary study (and abstract mentions CCSS)
University Of Chicago	Prognostic Genetic Biomarkers for Cancer	Kenan Onel	NIH-NCI	R21CA129045	Abstract mentions CCSS
University of Cincinnati	Adult Neurobehavioral Late Effects of Pediatric Low Grade Brain Tumors	Douglas Ris	NIH-NCI	R01CA132899	Ancillary study
University of Cincinnati	Environmental Exposure: Susceptibility Alleles in a DNA Damage Response Pathway	Peter Stambrook	NIH-NIEHS	R01ES016625	Ancillary study (and abstract mentions CCSS)
University of Illinois At Chicago	Symptom Cluster Subgroups in Adult Survivors of Childhood Cancers	Lorna Finnegan	NIH-NCI	R01CA136912	Abstract mentions CCSS
University of Minnesota	Function and Quality of Life of Survivors of Pediatric Lower Limb Tumors	Rajaram Nagarajan	ASCO (Young Investigator Award) and NCCF (Fellowship Award)	Not applicable	Ancillary study
University of Minnesota	Health Profiles in Adolescent Survivors of Childhood Cancer	Ann Mertens	American Cancer Society	Not applicable	Ancillary study
University of Minnesota	Metabolic Syndrome In Adult Survivors of Childhood ALL	James Gurney	NIH-NCI	R21CA106778	Ancillary study (and abstract mentions CCSS)
University of Minnesota	Radiation Dosimetry for Childhood Cancer Survivors	Ann Mertens	Lance Armstrong Foundation	Not applicable	Ancillary study
University of Minnesota Twin Cities	Late Effects In Survivors of Stem Cell Transplantation	Kevin S. Baker	NIH-NCI	K23CA085503	Abstract mentions CCSS

Place (at Time of Study)	Title	Principal Investigator	Funding Source	Grant Number (if NIH)	What Is It?
University of Texas, Southwestern	Feasibility Study for Project VISION: A Virtual Information Center for Survivors	Kevin Oeffinger	Lance Armstrong Foundation	Not applicable	Ancillary study
University of Texas, Southwestern	Mammography and High-Risk Survivors of Pediatric Cancer	Kevin Oeffinger	NIH-NCI	R21CA106972	Ancillary study (and abstract mentions CCSS0
University of Texas, Southwestern	Patient Perceived Barriers to Long-Term Follow-up for Adult Survivors of Childhood Cancer	Kevin Oeffinger	Robert Wood Johnson Foundation	Not applicable	Ancillary study
University of Washington	Health Outcomes for Hodgkin Disease Survivors	Debra Friedman	NIH-NCI	R01CA106750	Ancillary study (and abstract mentions CCSS)
Villanova University	Hope Intervention to Influence Quality of Life Among Female Survivors of Childhood Cancer	Mary Ann Cantrell	NIH-NINR	R15NR010788	Abstract mentions CCSS

Source: List of ancillary studies provided by CCSS PI to STPI, summer 2009. List of studies whose abstracts mention CCSS; STPI search of NIH RePORTER database (http://projectreporter.nih.gov/reporter.cfm), for studies with "CCSS" or "Childhood Cancer Survivor Study" in their abstracts.

Table B-9. CCSS Trainees

Trainee/Mentee	Training Experience	Location of Experience	Current Position	Number of authorships	Number of first authorships
Nina Kadan-Lottick, MD, MSPH	Postdoctoral Fellowship	University of Minnesota	Assistant Professor	10	4
Brad Zebrack, PhD	Postdoctoral Fellowship	UCLA	Assistant Professor	6	3
Pauline Mitby, MPH	Graduate Training	University of Minnesota	Clinical Research Associate	14	1
Rajaram Nagarajan, MD, MS	Postdoctoral Fellowship	University of Minnesota	Assistant Professor	7	5
Carrie M. Brownstein, MD	Postdoctoral Fellowship	MSKCC	Senior Clinical Scientist and Sr. Associate Clinical Director Roche Pharmaceuticals	1	1
Lisa Kenney, MD, MPH	Postdoctoral Fellowship	Dana-Farber	Instructor	1	1
Elyse Park, PhD	Graduate Training	Harvard Medical School	Assistant Professor	5	2
Sharon Castellino, MD, MS	Graduate	Duke	Associate Professor	1	1
Joanna Perkins, MD, MS	Postdoctoral Fellowship and Graduate Training	University of Minnesota	Hematology-Oncology	1	1
Judy Punyko, PhD	Graduate Training	University of Minnesota	State Maternal and Child Health Epidemiologist	6	3
Wassim Chemaitilly, MD	Postdoctoral Fellowship	MSKCC	Assistant Professor	1	1
Mylene Bassal, MD	Postdoctoral Fellowship	University of Colorado Health Sciences Center	Assistant Professor	1	1
Berrin Ergun-Longmire, MD	Postdoctoral Fellowship	Weill Medical College/Cornell	Assistant Professor	1	1
Cecile Ronckers, PhD	Postdoctoral Fellowship	NCI	Epidemiologist	4	1
Tara Henderson, MD, MPH	Postdoctoral Fellowship and Graduate Training	Dana-Farber	Assistant Professor	3	1
Eric Chow, MD, MPH	Postdoctoral Fellowship and Graduate Training	Fred Hutchinson/UW	Research Associate	6	3
Todd Florin, MD	Medical Student	University of Rochester	Pediatric Emergency Fellow	1	1

Trainee/Mentee	Training Experience	Location of Experience	Current Position	Number of authorships	Number of first authorships
Kris Ann Schultz, MD, MS	Postdoctoral Fellowship and Graduate Training	University of Minnesota	Hematology-Oncology	1	1
Jenny Pang, MD, MPH	Postdoctoral Fellowship and Graduate Training	Fred Hutchinson/UW	Clinical Assistant Professor	1	1
Irina Dinu, PhD	Postdoctoral Fellowship	University of Alberta	Assistant Professor	2	2
Daniel Mulrooney, MD, MS	Postdoctoral Fellowship and Graduate Training	University of Minnesota	Assistant Professor	5	2
Elizabeth Bluhm, MD, MPH	Postdoctoral Fellowship	NCI	Department of Internal Medicine	1	1
Anne Lown, DrPH	Postdoctoral Fellowship	Alcohol Research Group	Assistant Clinical Professor	1	1
Edward Garmey, MD	Postdoctoral Fellowship	MSKCC	Associate Director for Clinical Development	1	1
Natasha Buchanan, PhD	Postdoctoral Fellowship	Yale University	Behavioral Scientist	0	0
Meagan Lansdale, MD	Medical Student	Stanford	Anesthesiology Resident	0	0
Caroline Laverdiere, MD	Post-Fellowship Training	MSKCC	Department of Pediatrics	1	0
Christopher Jason, MD	Medical Student	Children's Hospital	Pediatric Resident	0	0
Karen Wasilewski-Masker, MD, M.Sc.	Postdoctoral Fellowship	Emory	Assistant Professor	2	0
Lisa Kahalley, PhD	Postdoctoral Fellowship	St. Jude's	Department of Behavioral Medicine	0	0

Source: STPI analysis of list of trainees provided by CCSS PI to STPI, summer 2009. Number of publications and number of first authorships derived from comparison of trainee names with STPI database of CCSS publications.

Appendix C: Logic Model for CCSS

The CCSS logic model in Figure C-1 describes program inputs, program activities, program outputs, and outcomes, as well as external factors impinging upon the resource.

Inputs include:

- Institutions
    - Clinical pediatric centers;
    - Programs within institutions that overlap with CCSS functions;
    - Institutional commitment and history of CCSS participation.

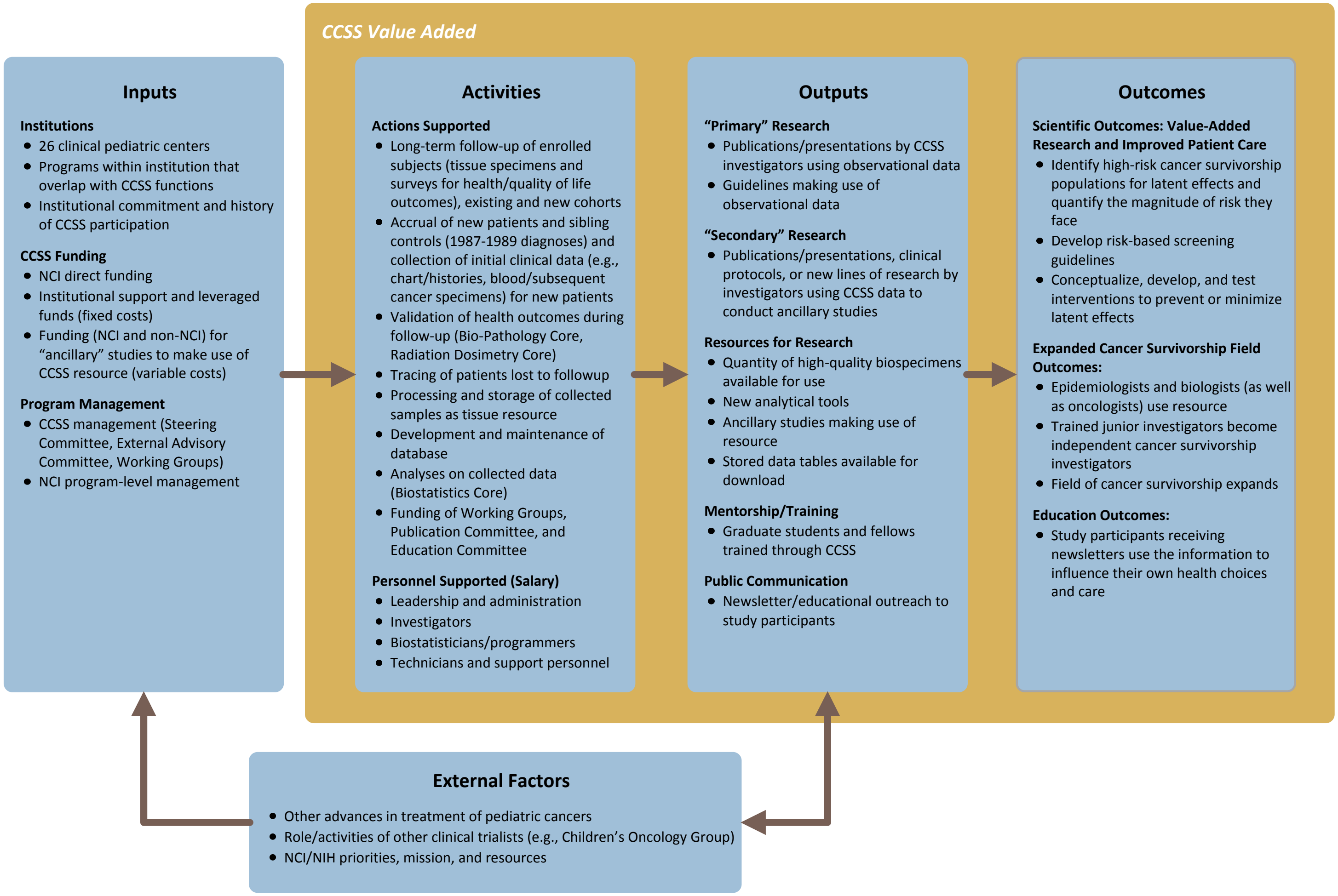
- Funding
    - NCI direct funding;
    - Institutional support and leveraged funds (fixed costs);
    - Funding (NCI and non-NCI) for “ancillary” studies to make use of CCSS resources (variable costs).

- Program Management
    - CCSS management (Steering Committee, External Advisory Committee, Working Groups);
    - NCI program-level management.

Activities include:

- Actions Supported
    - Long-term follow-up of enrolled subjects (tissue specimens and surveys for health/quality of life outcomes), existing and new cohorts;
    - Accrual of new patients and sibling controls (1987–1989 diagnoses) and collection of initial clinical data (e.g., chart/histories, blood/subsequent cancer specimens) for new patients;
    - Validation of health outcomes during follow-up (Bio-Pathology Core, Radiation Dosimetry Core);
    - Tracing of patients lost to follow-up;
    - Processing and storage of collected samples as tissue resource;
    - Development and maintenance of database;
    - Analyses on collected data (Biostatistics Core);
    - Funding of Working Groups, Publication Committee, Education Committee.

- Personnel Supported (Salary)
    - Leadership and administration;
    - Investigators;
    - Biostatisticians/programmers;
    - Technicians and support personnel.



CCSS Value Added

Inputs

Institutions

- 26 clinical pediatric centers
- Programs within institution that overlap with CCSS functions
- Institutional commitment and history of CCSS participation

CCSS Funding

- NCI direct funding
- Institutional support and leveraged funds (fixed costs)
- Funding (NCI and non-NCI) for "ancillary" studies to make use of CCSS resource (variable costs)

Program Management

- CCSS management (Steering Committee, External Advisory Committee, Working Groups)
- NCI program-level management

Activities

Actions Supported

- Long-term follow-up of enrolled subjects (tissue specimens and surveys for health/quality of life outcomes), existing and new cohorts
- Accrual of new patients and sibling controls (1987-1989 diagnoses) and collection of initial clinical data (e.g., chart/histories, blood/subsequent cancer specimens) for new patients
- Validation of health outcomes during follow-up (Bio-Pathology Core, Radiation Dosimetry Core)
- Tracing of patients lost to followup
- Processing and storage of collected samples as tissue resource
- Development and maintenance of database
- Analyses on collected data (Biostatistics Core)
- Funding of Working Groups, Publication Committee, and Education Committee

Personnel Supported (Salary)

- Leadership and administration
- Investigators
- Biostatisticians/programmers
- Technicians and support personnel

Outputs

"Primary" Research

- Publications/presentations by CCSS investigators using observational data
- Guidelines making use of observational data

"Secondary" Research

- Publications/presentations, clinical protocols, or new lines of research by investigators using CCSS data to conduct ancillary studies

Resources for Research

- Quantity of high-quality biospecimens available for use
- New analytical tools
- Ancillary studies making use of resource
- Stored data tables available for download

Mentorship/Training

- Graduate students and fellows trained through CCSS

Public Communication

- Newsletter/educational outreach to study participants

Outcomes

Scientific Outcomes: Value-Added Research and Improved Patient Care

- Identify high-risk cancer survivorship populations for latent effects and quantify the magnitude of risk they face
- Develop risk-based screening guidelines
- Conceptualize, develop, and test interventions to prevent or minimize latent effects

Expanded Cancer Survivorship Field Outcomes:

- Epidemiologists and biologists (as well as oncologists) use resource
- Trained junior investigators become independent cancer survivorship investigators
- Field of cancer survivorship expands

Education Outcomes:

- Study participants receiving newsletters use the information to influence their own health choices and care

External Factors

- Other advances in treatment of pediatric cancers
- Role/activities of other clinical trialists (e.g., Children's Oncology Group)
- NCI/NIH priorities, mission, and resources

Figure C-1. CCSS Logic Model

Outputs include:

- “Primary” Research
    - Publications/presentations by CCSS investigators using observational data;
    - Guidelines making use of observational data.

- “Secondary” Research
    - Publications/presentations, clinical protocols, or new lines of research by investigators using CCSS data to conduct ancillary studies.

- Resources for Research:
    - Quantity of high-quality biospecimens available for use;
    - New analytical tools;
    - Ancillary studies making use of resource;
    - Stored data tables available for download.

- Mentorship/Training:
    - Graduate students and fellows trained through CCSS.

- Public Communication:
    - Newsletter/educational outreach to study participants.

Outcomes are:

- Scientific Outcomes: Value-Added Research and Improved Patient Care
    - Identify high-risk cancer survivorship populations for latent effects and quantify the magnitude of risk they face;
    - Develop risk-based screening guidelines;
    - Conceptualize, develop, and test interventions to prevent or minimize latent effects.

- Expanded Cancer Survivorship Field Outcomes:
    - Epidemiologists and biologists (as well as oncologists) use resource;
    - Trained junior investigators become independent cancer survivorship investigators;
    - Field of cancer survivorship expands.

- Education Outcomes:
    - Study participants receiving newsletters use the information to influence their own health choices and care.

External factors include:

- Other advances in treatment of pediatric cancers;
- Role/activities of other clinical trialists (e.g., Children’s Oncology Group);
- NCI/NIH pediatric cancer survivorship priorities, mission, and resources.

Appendix D: Proposed Study Questions/Areas of Emphasis for Pediatric Cancer Survivorship Portfolio/CCSS Needs Assessment

As described in Section 5, the Feasibility Study identified a range of issues regarding the strategic challenges NCI faces in managing a portfolio of pediatric cancer survivorship activities. Table D-1 includes three columns. The left-hand column lists relevant issues identified by the Feasibility Study; the middle column lists data organized by the Feasibility Study itself; and the right-hand column identifies potential evaluative questions that the Needs Assessment would address.

Table D-1. Recommended Questions and Areas of Emphasis for CCSS Needs Assessment

Positive/Descriptive Question Where Data Already Collected for Feasibility Study	Data Source(s)	Evaluative Questions for Needs Assessment/Expert Panel to Address
I. Clinical Practice Needs and Considerations		
1. What is the state of knowledge regarding pediatric cancer survivorship, and what role has the CCSS played in advancing that knowledge?	Interviews (PI, NCI staff, external stakeholders); analysis of CCSS-acknowledging publications	A. What are the most pressing research needs regarding pediatric cancer survivorship? B. Where is more research necessary requiring characterization of risk to survivor populations? C. Where have risks been characterized, but successful interventions remain to be developed and disseminated?
II. The NCI Pediatric Cancer Survivorship Portfolio, and the Role of the CCSS within It		
2. What is the current NCI/NIH portfolio with respect to pediatric survivorship?	Analysis of OCS 2004–2006 portfolio; analysis of CCSS trainee data; Interviews (PI, NCI staff, external stakeholders)	D. What are NCI's research priorities with respect to its pediatric cancer survivorship portfolio? What should they be? E. What should the balance be between descriptive/observational studies and interventional studies? F. What are the most appropriate administrative structures/funding approaches for descriptive/observational studies? Interventional studies? G. What role should be played, if any, by a single cohort study/repository/registry of survivorship information such as the CCSS? H. How should the next generation of pediatric survivorship investigators be trained? Are current training mechanisms sufficient?

While the Needs Assessment’s goal would be to set priorities for the overall NCI pediatric cancer survivorship effort, given the role and size of the CCSS within the NCI pediatric cancer survivorship portfolio, the Needs Assessment likely would provide insights into the future design and implementation of the CCSS, including regarding questions such as:

- Is the overall design of the resource well suited for achieving proposed future stated goals and objectives? If not, how should the resource change?
- Should the CCSS include clinical data? If so, what changes to the CCSS budget would be required to collect and store those data?
- Should the CCSS be integrated with other cohort studies (e.g., international pediatric cancer survivorship cohorts)? How should this be done?
- Should NCI continue to support the original cohort of survivors enrolled or should the CCSS focus on the new cohort?
- Are there opportunities for further leveraging the CCSS dataset?
- Are there opportunities for enhanced communication of CCSS findings to patients, oncologists, or other stakeholders?

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13. SUPPLEMENTARY NOTES

14. ABSTRACT

The National Cancer Institute-supported Childhood Cancer Survivor Study (CCSS) is a cohort of approximately 20,000 survivors and approximately 4,000 siblings of survivors of pediatric cancers diagnosed between 1970 and 1986. A recently initiated expansion of the study aims to enroll an equally large cohort of survivors diagnosed between 1987 and 1999. Investigators can use CCSS funds to conduct analyses of the data collected through the cohort study, as well as to use outside funds for research making use of the cohort. NCI is considering conducting an evaluation of the CCSS, and tasked STPI to conduct a preliminary Feasibility Study. The purpose of this Feasibility Study was to explore whether evaluation of the CCSS is both warranted and feasible, and, if so, to make recommendations regarding the design of such an evaluation. The Feasibility Study team found that most CCSS outcomes are clearly defined and measurable. Further, no extraordinary barriers to additional data collection are anticipated and existing databases can be used as complementary data sources. An Outcome Evaluation of the CCSS would therefore be feasible. However, such an evaluation is not warranted, especially because such a study would not help the National Cancer Institute address the critical strategic issues it faces with respect to the future of its pediatric cancer survivorship research portfolio.

15. SUBJECT TERMS

National Cancer Institute; Feasibility Studies; Outcome Evaluation; Childhood Cancer Survivor Study; Portfolio Analysis

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