

## **Cancer Treatment Summaries and Long-Term Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study**

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**Introduction:** A cancer treatment summary is an essential component of a survivorship care plan and necessary for making screening recommendations.

**Method:** Childhood Cancer Survivor Study (CCSS) participants were asked in 2003-2004 about attendance at a long-term follow-up (LTFU) clinic and whether they and/or their physician had a cancer treatment summary or copies of their medical records. Eligibility for participation in the CCSS included: diagnosis and treatment of cancer before age 21 at one of the 26 collaborating centers between 1970-1986. Generalized linear regression models were used to assess multivariable associations between demographic and treatment characteristics with receipt of a treatment summary.

**Results:** Among 8309 survivors (median age, 42 years, range 27-65; 51% male; median age at diagnosis, 6 years, range 0-20; 7.7% had been seen in an LTFU clinic in the previous two years), 25% (95% CI: 24.1-25.9%) reported having a treatment summary and 36.9% (95% CI: 35.9%-38.0%) reported that their primary care doctor had a copy. Of survivors seen in an LTFU clinic, 41.5% reported that they had a treatment summary. Notably, 10% of survivors had a copy of their treatment summary but did not share it with their primary physician. Conversely, 21% of survivors did not have a treatment summary despite their primary physician having one. Overall, only 15% (95% CI: 14%-16%) of survivors reported that they and their doctor had a copy of their treatment summary. Factors associated with both the survivors and their physicians having a treatment summary in the multivariable analysis included younger current age, diagnosis, those treated with anthracyclines, alkylating agents or radiotherapy, and survivors followed in an LTFU clinic (Table).

**Conclusions:** A substantial proportion of survivors treated in the 1970s and 1980s, and their primary care physicians do not have a cancer treatment summary, potentially limiting survivors' ability to receive appropriate risk-based care. Further education about the importance of treatment summaries are needed for both survivors and their primary providers.

**Table. Multivariable Odds Ratios (with 95% CI) for associations of survivor characteristics with both survivors and the primary physician having a cancer treatment summary**

<b>Factor</b>	<b>OR (95%CI)</b>	<b>p-value</b>
Current age at study*	0.61 (0.54-0.70)	<0.01
Treatment era (1980-1986 vs 1970-1979)	1.03 (0.86-1.21)	0.77
Primary cancer diagnosis		<0.01
Leukemia	1.21 (0.88-1.65)	
Brain tumor	1.65 (1.16-2.36)	
Hodgkin lymphoma	1.51 (1.07-2.13)	
Non-Hodgkin lymphoma	0.99 (0.68-1.44)	
Wilms tumor	0.90 (0.61-1.32)	
Neuroblastoma	1.04 (0.70-1.55)	
Soft tissue sarcoma	1.21 (0.85-1.74)	
Bone cancer	1.00	
Treatment exposure		
Anthracycline chemotherapy (Yes vs.No)	1.15 (0.98-1.35)	0.07
Alkylating agent chemotherapy (Yes vs.No)	1.20 (1.03-1.39)	0.02
Any radiotherapy (Yes vs No)	1.37 (1.18-1.60)	<0.01
Bone marrow transplant (Yes vs.No)	1.10 (0.82-1.44)	0.53
Seen in LTFU clinic (Yes/No)	2.23 (1.84-2.71)	<0.01

Note: \* OR for every 10 years increased age