

SCHEDULE 1 – CCSS

Childhood Cancer Survivor Study (CCSS) Data Set Publications Policy

The CCSS is a multi-institutional, multi-disciplinary, NCI-funded collaborative resource (U24 CA55727; PI: Gregory Armstrong) established to evaluate long-term outcomes among survivors of childhood cancer. It is a retrospective cohort consisting of >38,000 five-year survivors of childhood cancer who were diagnosed between 1970-1999 at one of 31 participating centers in the U.S. and Canada. Self-reported outcomes across a spectrum of chronic health conditions, psychosocial and cognitive function and physical function outcomes have informed over 330 publications to date enumerating risk for this aging population.

In 2019 St. Jude Children's Research Hospital completed whole genome and whole exome sequencing on just under 3,000 survivors diagnosed 1987-1999, now available on the St. Cloud. The primary purpose of this sequencing of CCSS participants is to identify all inherited genome sequence and structural variants influencing the development of childhood cancer and occurrence of long-term adverse outcomes associated with cancer and cancer-related therapy. Additional objectives include, but are not limited to, the acquisition and analysis of additional genomic data, including epigenetic and gene expression data, data integration, and the development and validation of informatic and analytical solutions appropriate to the scale and nature of the project, as well as use of the data generated to answer important methodological and biological questions as specifically related to childhood malignancies.

CCSS investigators anticipate that data generated from the project will be used by other researchers (scientists who are employed by, or a student enrolled at or legitimately affiliated with, an academic, nonprofit, or government institution, or a commercial company) to develop new analytical methods, validate results, and identify additional genetic variations and alterations in the data. Authors who use data from the project must acknowledge the CCSS using the following wording "*This study makes use of data of the Childhood Cancer Survivor Study (CCSS) and shared through the St. Jude Survivorship Portal (<https://survivorship.stjude.cloud>)*" and cite

Matt GY, Sioson E, Shelton K, Wang J, Lu C, Zaldivar Peraza A, Gangwani K, Paul R, Reilly C, Acic A, Liu Q, Sandor SR, McLeod C, Patel J, Wang F, Im C, Wang Z, Sapkota Y, Wilson CL, Bhakta N, Ness KK, Armstrong GT, Hudson MM, Robison LL, Zhang J, Yasui Y, Zhou X. St. Jude Survivorship Portal: sharing and analyzing large clinical and genomic datasets from pediatric cancer survivors. *Cancer Discov.* 2024 Apr 9. doi: 10.1158/2159-8290.CD-23-1441. PMID: 38593228.

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and the relevant primary CCSS publication(s) if one has been published. Details of these publications are at: <https://ccss.stjude.org/published-research/publications.html>

Users should note that St. Jude and the CCSS investigators bear no responsibility for the further analysis or interpretation of these data, over and above that published by the CCSS study team.