# ST. JUDE CLOUD
## ST. JUDE LIFETIME (SJLIFE)

St. Jude Lifetime (SJLIFE) is a follow-up study from St. Jude Children's Research Hospital that aims 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. Basic clinical data is available for relevant subjects. Data will be deposited in St. Jude Cloud and will be governed by the St. Jude Lifetime Data Access Committee (SJLIFE DAC).

**Data Access Committee Members**

- Dr. Melissa Hudson, Member, Oncology, St Jude Children's Research Hospital, Memphis, Tennessee
- Dr. Les Robinson, Chair, Epidemiology & Cancer Control, St Jude Children's Research Hospital, Memphis, Tennessee
- Dr. Zhaoming Wang, PhD, Computational Biology, St Jude Children's Research Hospital, Memphis, Tennessee
- Dr. Yutaka Yasui, Member, Epidemiology & Cancer Control, St Jude Children's Research Hospital, Memphis, Tennessee
- Dr. Jinghui Zhang, Chair, Computational Biology, St Jude Children's Research Hospital, Memphis, Tennessee

**Application Process**

All requests will come from St. Jude Cloud. The Data Access Agreement that the applicant submitted with their request is evaluated with the following criteria:

- The entirety of the form must be filled out
- A Contemplated Use explanation for the data has been provided
- It has been submitted by a qualified researcher who is embedded in a recognized research institution that can provide institutional responsibility for appropriate research governance

Once the above criteria have been met, the Data Access Request is sent to the Data Access Committee, along with the applicant's verified information, the nature of the request – cloud only or copy/download, and a statement provided on the application outlining the Contemplated Use. The Data Access Committee then evaluates the Data Access Request based on the following criteria:

- The project described constitutes 'biomedical research' in the context of the consent process, and is likely to be understood as such by the sample donors
- It does not breach any of the ethical permissions or restrictions in the consent forms for any component cohort or collection
- It does not have the potential to produce information that will enable identification of individual participants or other individually identifiable information

- Research Trainees (including PhD students and post-doctoral fellows) include details of their research supervisors, and that a laboratory head, principal investigator or departmental chair requests access to the data

In considering applications, the SJLIFE DAC has clarified policies in regard to specific data access requests and agrees that:

- The SJLIFE DAC does NOT attempt to peer review the scientific quality of proposals. However, it does ask for a brief summary of the research to be undertaken, to judge whether it falls within the scope of the consents. It also considers whether the research is grossly inadequate or ethically questionable, and reserves the right to require clarification for those requests that do not appear to attain even a minimal standard of competence
- The use of data by commercial companies for commercial purposes is prohibited; and use of de-identified and anonymized data in teaching is permissible; and to protect participant confidentiality the data may not be removed from the teaching laboratory.

**Policy for Approval of a Data Access Request**
The policy for Approval of a Data Access Request is dependent on the Data Access Committee.

- If the request fails to meet the basic criteria for an acceptable request, then it will be rejected immediately
- If at least 3 of the 5 committee members approve, the request will be approved
- If at least 3 of the 5 committee members reject, the request will be rejected
- The request will not be moved forward until one of the above criteria are met

**Data Available**
The available data and the accompanying clinical information is subject to change due to updates in records.

- Diagnosis
- Age at diagnosis
- Self-reported sex
- Self-reported ethnicity