



ALEX'S LEMONADE STAND FOUNDATION

RESOURCE SHARING POLICY

Resource sharing is an expected outcome for grants funded by Alex's Lemonade Stand Foundation (ALSF). Sharing research outputs accelerates scientific advances, improves the quality and reproducibility of the work, and reduces redundancies in the research process. The goal of the ALSF Resource Sharing Policy is to enable faster translation of research discoveries into cures for children with cancer. Resources to be shared encompass all unique research outputs developed, including but not limited to: model organisms, cell lines, plasmids, protocols, software, and data. We expect that, where available, resources will be deposited and archived in standard public repositories. Repositories ensure that resources are discoverable and archived, while reducing researcher burden for maintenance and distribution of a resource over time. We strongly discourage sharing upon request. Furthermore, we expect that sharing will be timely and unbiased, and outputs shared will be of the highest quality possible.

This policy defines sharing expectations which should guide applicants' [Resource Sharing Plans](#) that are submitted as part of new applications for ALSF grant funding. The Resource Sharing Plans are reviewed as part of the peer-review process as a scored criterion. Past sharing behavior plus the planned sharing approach are reviewed. Grant recipients are asked to report on adherence to their sharing plan in progress and final reports and are required to post unique research resources to the ALSF Childhood Cancer Research Resources Portal to make them discoverable and requestable. Future ALSF grant funding is contingent upon faithfully adhering to the approved Resource Sharing Plan and the resource sharing policies described herein.

RESOURCE SHARING COSTS

We recognize that comprehensive resource sharing has an associated cost (e.g. curation fees, data repository fees, shipping costs, etc.). Therefore, researchers are encouraged to and should provide a budget in their application that reflects a reasonable assessment of these costs.

ALSF CHILDHOOD CANCER RESEARCH RESOURCES PORTAL

The [ALSF Childhood Cancer Research Resources Portal](#) has an overarching goal to bring ultimate transparency to childhood cancer research resources available in the community, allowing users to post and request resources within the portal. All unique research outputs developed with ALSF grant funding within the grant period are required to be posted to the ALSF Childhood Cancer Research Resources Portal prior to or at the conclusion of ALSF grant funding. Resources developed with ALSF funding that are finalized after the grant end date are also required to be listed on the portal. To make posting resources straightforward, the portal allows researchers to import resources that are already listed with public repositories. Resources that are not stored in a repository can be listed manually to make the community aware that it exists and is available for request. Grant recipients are encouraged to continue using the portal, posting and requesting resources as desired, after the grant period ends.



OPEN ACCESS POLICY

ALSF is committed to sharing research information to ensure research transparency and enable unrestricted access to research results. Grant recipients must submit all publications, excluding non-research articles such as review articles, that were in part or fully funded by ALSF as a preprint to bioRxiv, medRxiv or a similar preprint sharing service prior to or at the time of initial journal submission. Preprints should have a CC BY or CC BY-NC license applied. This allows researchers to immediately begin building upon these results to accelerate the pace of scientific discovery.

We require electronic copies of any research papers, accepted for publication in a peer-reviewed journal and supported in whole or in part by ALSF, to be made freely available upon publication. Furthermore, publications should be shared under an open license that permits reuse (e.g., CC BY). Authors may comply with this policy by sharing a copy of their Author Accepted Manuscript via a trusted open repository (e.g. PubMed Central). It is the responsibility of the grantee to retain sufficient rights to post articles as required by this policy.

MATERIAL RESOURCES

We require that unique resources (e.g. cell lines, plasmids/clones, antibodies, transgenic organisms, and other reagents) generated with ALSF funding be shared openly with the research community no later than the date of publication or within 12 months after the end of grant funding, whichever comes first. We expect that, where available, resources will be deposited and archived in public, widely-used repositories, such as Addgene for plasmids/DNA reagents/viruses and Jackson Labs for model systems lines, rather than distributing materials “on request”.

Distributing materials “on request” should be avoided if possible. If distribution will occur upon request, applicants, in their Resource Sharing Plan, should specify the expected response time for requests for the resource, how the response time will be measured, who will be responsible for maintaining and sharing the resource, and how sharing will happen after the grant ends. If the lab will be maintaining the material or reagent, methods that will be used to authenticate the reagent should be specified, as well as when the authentication will occur and who is responsible (distributor, recipient).

DATA

Data generated through ALSF-funded research projects are to be made publicly available with as few restrictions as possible and easily accessible online through an appropriate license, such as CC0 or CC BY. We support FAIR data standards stating that data should be Findable, Accessible, Interoperable, and Reproducible. Data types include, but are not limited to: all “omics” data, imaging data, screening data, and any underlying data needed to accurately and independently reproduce experiments and findings. Data should not be made available “upon request”. Data must be shared to a public repository no later than the time of publication or within 12 months after the conclusion of ALSF grant funding, whichever comes first. Furthermore, a data accessibility statement that states where the data are available and how they can be accessed must be included in all publications referencing data collected through ALSF funding.



We understand that some data cannot be shared publicly and must instead be shared in a controlled access manner. There are also limited circumstances in which data cannot be shared, when it would violate human subjects privacy regulations, superseding regulations (laws or institutional policies), intellectual property grounds or financial grounds, if sharing would cause undue financial burden. Any limits to data sharing must be explained in the Resource Sharing Plan upon grant application.

METADATA

For data to be maximally useful, there must be metadata that describe the data (i.e. the methodology for collecting the data, definitions of variables, units of measurement, etc). We recommend using standard terminology to describe and structure data.

DATA REPOSITORY REQUIREMENT

We expect that raw data will be deposited in a public, accessible data repository that assigns a permanent study identifier such as an accession number or DOI (digital object identifier). A best practice is to use public repositories already established in a research field (e.g., GEO or ArrayExpress for gene expression data, SRA for RNA-Seq data, etc.). When there is no public, widely-used repository available, a general purpose archival repository such as Figshare, Dryad or Zenodo should be used. See [here](#) for NIH's guide for the selection of data repositories.

PATIENT CONSENT AND DATA TRANSFER AGREEMENT CRITERIA

Patient consent information must be provided with the application and any limitations with regards to data use/sharing as per the consent should be highlighted in the ALSF Resource Sharing Plan. Any consent forms that will be used as part of a funded study must include provisions regarding data sharing with "promoting research initiatives at other institutions" as one of the stated intended uses of the data referenced in the Consent form. With regard to Data Transfer Agreements, it is critical that data sharing is not unnecessarily hindered by the language of the Agreement. To further data sharing, researchers must commit to suggesting language that is minimally restrictive, such that any limitations on data sharing are narrowly tailored to actual risk to privacy or re-identification.

CONSIDERATIONS FOR MAKING DATA PUBLICLY AVAILABLE:

Take into consideration the following to determine if data should be public or controlled access.

- 1) Publicly Available: the key here is to allow public access to all information that is de-identified, for example:
 - a. clinical information that cannot be used to identify the patient, maximum amount of data allowable under HIPAA guidelines (e.g. while date of birth is not allowable, age in month and year is permissible unless this information is somehow uniquely identifiable)
 - b. Omic profiling data for tumors, such as gene expression data, somatic mutations, tumor specific copy number and structural alterations, comparative genomic hybridization data, epigenetic and proteomic profiling data and related types of genomic data that are output oriented, and de-identified
 - c. Specific molecular diagnosis, tissue pathology data, small molecule screenings and profiling
- 2) Controlled Access: the key here is data that poses a significant risk of re-identifying the patient
 - a. patient/tumor information and unverified or raw molecular data (e.g. certain array-based and sequencing files) that pose a significant risk of patient re-identification



- b. some specific patient information such as demographic and phenotypic information (depending on disease rarity)
 - c. Germline variants
- 3) Not at all:
- a. Any data that could be identifiable, for which a patient has not provided consent

SOURCE CODE

Source code developed with ALSF funding must be stored in a version control system and made available through a version control service (e.g. GitHub, Bitbucket, or similar). A permissive license for the source code (such as MIT, BSD 2-Clause Plus Patent License, or Apache v2.0) must be specified because otherwise copyright is retained by the researcher and thus no one else is able to reproduce, distribute, or create derivatives from the work. All pre-existing and derivative code should be licensed under the most permissive license possible, given the licensing terms of the pre-existing code. Source code must be archived to an archival service (e.g. Zenodo) at the time of submission of manuscripts that rely on the source code and the conclusion of the grant.

PROTOCOLS

Experimental protocols generated by ALSF-funded work should be publicly shared through a protocol sharing service, such as protocols.io, prior to or by the date of publication or within 12 months after the end of grant funding, whichever comes first. These services allow protocols to become living records of the core experiments underlying research results and make reproducing experiments easier and more transparent for the labs that develop the methods as well as for others looking to build upon the work.

CLINICAL TRIAL REPORTING

ALSF-funded clinical trials, funded in part or in full, must be registered with ClinicalTrials.gov prior to the initiation of the study and must publicly report summary results there no later than 12 months after trial completion. Furthermore, in addition to positive trial results, negative and inconclusive results must be published in a timely fashion.

Clinical trial data should be made available at the time of publication or no later than 12 months after the completion of the trial, defined as submission of the final trial report to regulatory authorities. Any restrictions to this must be outlined in the Resource Sharing Plan at application submission.