Tuberous Sclerosis Alliance Open Science Policy

The TS Alliance is a patient advocacy group dedicated to unlocking a cure for tuberous sclerosis complex and improving the lives of those affected.

As a nonprofit funded through contributions from the TSC community and the public at large, we are committed to being good stewards of these funds. We support projects that will rapidly advance our understanding of TSC and the development of therapies for the disease.

The TS Alliance seeks to inspire discovery and innovation by improving access to scientific data and outputs. Improved dissemination will lead to more opportunities for TSC investigators to collaborate and for build upon the latest developments in research.

In this regard, the TS Alliance has adopted an Open Science Policy to ensure transparency of and broad access to TS Alliance-funded research.

Scope of Policy

The Open Science Policy applies to the following projects, fully executed on or after July 1, 2019:

-   Scientific grants, including fellowships.
-   Distribution of data or biological materials from the TS Alliance, including but not limited to the TSC Natural History Database and the TSC Biosample Repository.
-   All scientific projects using TS Alliance research infrastructure, including but not limited to the TSC Preclinical Research Consortium and the TSC Clinical Research Consortium.
-   All scientific projects with a member of TS Alliance staff as a named author.

1. Open Access to Articles

All peer-reviewed journal articles resulting from projects that meet the above criteria must be made freely available on PubMed Central after an embargo period of no more than 12 months from the date of publication.

The TS Alliance has partnered with the Health Research Alliance to enable funded researchers to submit manuscripts directly to PubMed Central.

This requirement may also be fulfilled by publishing in an open access journal or choosing the paid open access option for a paywalled journal.

2. Monitoring and Compliance

Awardees and their institutions are responsible for meeting all award conditions, including the Open Science Policy. All progress reports for grants will include proof of compliance for manuscripts published. TS Alliance staff will additionally monitor compliance at their discretion.

The TS Alliance Board of Directors reserves the right to deny or delay the distribution of funds, data, or biological materials to investigators and institutions who do not comply with the Open Science Policy.

3. For Grant Applicants: Funding for Open Access Publication Fees

Open access publication fees may be included as a line item in the project budget.

4. For Grant Applicants: Open Access to Data and Code

If research results are published between the start date of the grant and 18 months after the expiration of the grant, all data, methods, code, and software needed for independent verification of those results must be curated and made available to the public immediately upon publication.

Awardees must make data, methods, code, and software for independent verification of all research results (regardless of publication status) available to the public no later than 18 months after the expiration of the grant. .

As part of the grant application process, applicants will submit a data management plan explaining how this mandate will be met. Exemptions to this policy may be granted if data sharing would violate human subject protections, intellectual property rights, institutional regulations, or government policies.

The TS Alliance has partnered with the Health Research Alliance to enable funded researchers to submit data to HRA Open, a branded version of the Figshare repository. Submission of data to other databases (such as dbGaP, NIMH Data Archive, etc.) may fulfill the requirement in many cases.

Applicants and grantees are encouraged to discuss appropriate repositories and data management techniques with the TS Alliance Chief Scientific Officer or other members of the TS Alliance staff at any time.

Approved by the Board of Directors March 7, 2019