NEUROENDOCRINE TUMOR RESEARCH FOUNDATION
RESOURCE SHARING POLICY

Resource sharing is a required outcome for all grants funded by the Neuroendocrine Tumor Research Foundation (NETRF). Sharing research outputs accelerates scientific advances, improves the quality and reproducibility of research, and reduces redundancy in the research process. The goal of the NETRF Resource Sharing Policy is to enable faster translation of research discoveries into improved treatments and outcomes for patients with neuroendocrine neoplasms (NENs), encompassing both neuroendocrine tumors and neuroendocrine carcinomas.

Resources to be shared encompass all unique research outputs developed, in whole or in part, with NETRF funding, including but not limited to: model organisms, cell lines, plasmids, antibodies, protocols, software, trained computational models, 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 the burden on individual researchers for long-term maintenance and distribution. **We strongly discourage sharing solely upon request.**

This policy defines the sharing expectations to guide applicants' Resource Sharing Plans submitted with new NETRF grant applications. The Resource Sharing Plan should address all categories of research output covered by this policy, including data management and sharing. Plans are reviewed as part of the peer-review process. Past sharing behavior and the planned sharing approach are evaluated. Grant recipients are asked to report on adherence to their sharing plans in semi-annual progress reports and final reports. Future NETRF grant funding is contingent upon faithfully adhering to the approved Resource Sharing Plan and the policies described herein.

Resource Sharing Costs

We recognize that comprehensive resource sharing has associated costs, including curation fees, data repository fees, open-access article processing charges, and shipping costs. Researchers are encouraged to include line items in their application budget that reflect a reasonable assessment of these costs. NETRF considers resource-sharing costs to be allowable direct expenses under the grant.

Default Sharing Timeline

Unless otherwise specified in this policy or approved by NETRF in writing, research outputs generated in whole or in part with NETRF funding must be shared as soon as practicable and no later than the time of associated publication or the end of the NETRF award period, whichever comes first. Any proposed delay, restriction, or alternative timeline must be justified in the Resource Sharing Plan and approved by NETRF.

Open Access Policy

NETRF is committed to ensuring research transparency and enabling unrestricted access to research results funded by the Foundation.

Preprints

Grant recipients must submit all original research publications (excluding review articles) that were funded in whole or in part by NETRF as a preprint to bioRxiv, medRxiv, or a comparable preprint server prior to or at the time of initial journal submission. Preprints must be posted under a CC BY 4.0 license. This allows the research community to immediately build on these results and accelerates the pace of scientific discovery relevant to neuroendocrine neoplasms.

Peer-Reviewed Publications

We require that peer-reviewed research papers supported in whole or in part by NETRF be made freely available to the public immediately upon publication, with no embargo. Authors must deposit the Author Accepted Manuscript in PubMed Central (or an equivalent open-access repository) no later than the official date of publication, consistent with the current federal zero-embargo standard. Publications should carry an open license that permits reuse (CC BY 4.0 preferred). It is the responsibility of the grantee to retain sufficient rights during the journal submission process to comply with this policy.

Acknowledgment

All publications and presentations arising from NETRF-funded research must include an acknowledgment in substantially the following form: “Supported by Grant ID # from the Neuroendocrine Tumor Research Foundation.”

Material Resources

We require that unique material resources generated with NETRF funding, including but not limited to cell lines, plasmids, and other nucleic acid-based vectors, antibodies, transgenic organisms, and other reagents, be shared openly with the research community consistent with the Default Sharing Timeline. We expect that, where available, resources will be deposited and archived in public, widely used repositories, such as Addgene for plasmids, DNA reagents, and viral vectors; The Jackson Laboratory for model organisms; and ATCC, DSMZ, or another appropriate authenticated cell repository for cell lines, rather than distributing materials upon request.

Distributing materials solely upon request should be avoided whenever possible. If distribution will occur upon request, applicants must specify in their Resource Sharing Plan: the expected response time for requests, how response time will be measured, who will be responsible for maintaining and sharing the resource, methods for authenticating the resource, and how sharing will continue after the grant ends.

Grant recipients must notify NETRF when resources are deposited or made available, including repository names, accession numbers, DOIs, RRIDs, catalog numbers, or other persistent links

where applicable. NETRF may use this information to track compliance and, when appropriate, share resource availability with the NEN research community.

Data

Data generated through NETRF-funded research projects must be made publicly available with as few restrictions as possible and easily accessible online through an appropriate open license, such as CC0 or CC BY 4.0. NETRF endorses the FAIR data principles: data should be Findable, Accessible, Interoperable, and Reusable. Data types include, but are not limited to: all "omics" data (genomic, transcriptomic, proteomic, metabolomic, epigenomic), imaging data, screening data, clinical and phenotypic data (where permitted), and any underlying data needed to accurately and independently reproduce experiments and findings.

Data must not be made available solely "upon request." Data must be deposited in an appropriate repository consistent with the Default Sharing Timeline. A data availability statement that indicates where the data are deposited and how they can be accessed must be included in all publications that reference data collected with NETRF funding.

Data Management

The data management component of the Resource Sharing Plan should describe: the types of scientific data to be generated, the standards and metadata that will be used, the repository or repositories where data will be deposited, the timeline for data sharing, any access restrictions and their justification, and how data will be preserved after the grant period, if no repository is used. The data management component is reviewed as part of the peer-review process alongside all other elements of the Resource Sharing Plan.

Controlled-Access and Restricted Data

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 at all: when sharing would violate human subjects' privacy regulations, supersede regulations (laws or institutional policies), or infringe on intellectual property protections, or when sharing would cause an undue financial burden. Any limits to data sharing must be explained and justified in the Resource Sharing Plan at the time of application.

Considerations for Data Access Levels

Publicly Available: De-identified information should be shared publicly, including: clinical information that cannot be used to identify the patient (consistent with HIPAA Privacy Rule standards, where applicable,), output-oriented omic profiling data for tumors (such as gene expression data, somatic mutations, tumor-specific copy number and structural alterations, epigenetic and proteomic profiling data), specific molecular diagnoses, tissue pathology data, and small molecule screening and profiling data.

Controlled Access: Data that pose a significant risk of re-identifying the patient should be shared through controlled-access mechanisms, including: patient or tumor information combined with unverified or raw molecular data (such as certain array-based and sequencing files), specific patient demographic and phenotypic information (particularly in rare diseases such as NENs), and germline variants.

Not Shared: Any data that could be identifiable for which a patient has not provided consent for sharing must not be shared.

Metadata

For data to be maximally useful and meet the FAIR principles, they must be accompanied by metadata that describe the data, including the data collection methodology, variable definitions, units of measurement, and provenance. We recommend using standard, community-accepted ontologies and terminology to describe and structure data.

Data Repository Requirement

We expect that data will be deposited in a public, accessible data repository that assigns a persistent identifier such as an accession number or DOI. Best practice is to use repositories already established in a research field (e.g., GEO or ArrayExpress for gene expression data, SRA for sequencing data, TCIA for imaging data, Metabolomics Workbench for metabolomics data). When there is no public, widely used repository available, a general-purpose archival repository such as Figshare, Dryad, or Zenodo should be used.

Persistent Identifiers

NETRF expects the use of persistent identifiers throughout the research lifecycle. Datasets and code deposits should be assigned DOIs. Principal Investigators and co-investigators should maintain current ORCID profiles and link NETRF-funded outputs to those profiles. Where available, institutional identifiers (such as ROR IDs) should be used in metadata.

Patient Consent and Data Transfer Agreements

Patient consent information must be provided with the application, and any limitations regarding data use or sharing as stipulated by the consent must be highlighted in the Resource Sharing Plan. Any consent forms used as part of a funded study must include language permitting future research use and data sharing with qualified researchers at other institutions.

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 using language that is minimally restrictive, so that any limitations on data sharing are narrowly tailored to actual privacy risks or re-identification.

Source Code

Source code developed with NETRF funding must be stored in a version control system and made publicly available through a version control hosting service (e.g., GitHub, GitLab, Bitbucket, or similar). A permissive open-source license (such as MIT, BSD 2-Clause Plus Patent License, or Apache v2.0) must be applied, because without an explicit license copyright is retained by the developer and others cannot reproduce, distribute, or create derivative works. All pre-existing and derivative code should be licensed under the most permissive license possible given the licensing terms of any pre-existing code.

Source code must be made available and archived to a persistent archival service (e.g., Zenodo, Software Heritage) consistent with the Default Sharing Timeline, ensuring the code is assigned a DOI and remains accessible independent of any single hosting platform.

Computational and AI/ML Models

When NETRF-funded research produces trained computational or machine learning models (including but not limited to classifiers, neural networks, and predictive algorithms), the following should be shared to the extent permitted by data privacy and licensing constraints: trained model weights or parameters, model architecture specifications, training and evaluation code, training data or a description of training data provenance if the data themselves cannot be shared, and documentation of model performance metrics and any known limitations or biases.

Models should be deposited in an appropriate public repository (e.g., Hugging Face, Zenodo, or a domain-specific platform) under an open license consistent with the Default Sharing Timeline. Where patient data privacy constraints prevent sharing of model weights, a detailed model card describing the model's architecture, training procedure, intended use, and limitations must still be made publicly available.

Protocols

Experimental protocols generated through NETRF-funded work must be publicly shared through a protocol-sharing service, such as protocols.io, consistent with the Default Sharing Timeline. These services allow protocols to serve as living records of the core experiments underlying research results, making it easier and more transparent to reproduce experiments, both for the labs that develop the methods and for others looking to build upon the work.

Clinical Trial Reporting

NETRF-funded clinical trials must be registered with ClinicalTrials.gov, or a comparable international registry acceptable to NETRF, before enrollment of the first participant. For applicable clinical trials subject to FDAAA or other legal requirements, summary results must be submitted within the legally required timeframe, generally no later than 12 months after the Primary Completion Date. For NETRF-funded trials not legally subject to FDAAA, NETRF expects summary results to be posted on the registry or otherwise made publicly available within 12 months after primary outcome data collection is complete, unless NETRF approves a justified alternative timeline. 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 completion of primary outcome data collection, subject to participant consent, privacy protections, regulatory obligations, contractual restrictions, and an approved data-sharing plan. Any restrictions to this timeline must be outlined in the Resource Sharing Plan at application submission.

Resource Sharing Notification

Grant recipients must notify NETRF when NETRF-funded resources are deposited, published, registered, archived, or otherwise made available. Notifications should include sufficient information for NETRF to identify and track the resource, including persistent identifiers, repository links, accession numbers, RRIDs, catalog numbers, or other relevant access information. If a resource cannot be shared, the recipient must document the reason and any applicable consent, regulatory, contractual, intellectual property, or financial limitations.

Access Concerns. Researchers or other users who experience difficulty accessing a NETRF-funded resource that should be publicly available under this policy or an approved Resource Sharing Plan may contact the NETRF Research Team at grants@netrf.org. NETRF may follow up with the grant recipient, as appropriate, to facilitate access and assess compliance with applicable resource-sharing requirements.

Compliance and Reporting

Grant recipients are required to report on adherence to their Resource Sharing Plan in semi-annual progress reports and the final report, as specified in the NETRF Research Grant Agreement. Reports should include a description of any materials, protocols, software, data, or other resources resulting from the award that have been shared, including repository identifiers and persistent links.

Future NETRF grant funding is contingent upon faithfully adhering to the approved Resource Sharing Plan and the policies described herein. NETRF recognizes that circumstances may change during the course of a grant. Modifications to approved sharing plans require prior written approval from NETRF and should be requested as early as possible.

Version History

[July 9, 2026] – Initial adoption

[August 27, 2026] – Added access concern escalation pathway