reSOURCE Data Access Guidelines

Overview

The reSOURCE dataset, generated through Single Ventricle SOURCE, is designed to support research that advances understanding of single ventricle heart disease and related scientific questions.

Researchers from eligible academic, nonprofit, governmental, and commercial institutions may apply to access reSOURCE data. Applications are accepted on a rolling basis and reviewed by the SOURCE Data Access Committee (DAC). Access is granted for an approved research project and is subject to the requirements outlined in these guidelines and the SOURCE Data Use Certification Agreement (DUA). reSOURCE data are made available through Gencove, the cloud platform used to host and provide access to the dataset. Approved research organizations may analyze data using Gencove Explorer or, where permitted under the approved Data Access Request and DUA, export data to an approved external computing environment. There is no cost to access the reSOURCE dataset itself; however, cloud compute, storage, and data transfer charges may apply.

These guidelines provide a practical overview of the reSOURCE application and access process. The DUA contains the complete terms governing access and use of reSOURCE and controls in the event of any inconsistency.

reSOURCE Access Workflow at a Glance

1. **Submit Data Access Request**: Applicant completes all required ProposalCentral fields, identifies all Approved Users, completes required attestations, provides billing information, and uploads a completed and signed DUA.
2. **DAC Review**: The Data Access Committee reviews the complete application. Review is generally completed within 10 business days.
3. **Approval**: Additional Ventures sends the approval notification and Gencove onboarding instructions.
4. **Create Gencove Accounts**: The Primary Approved User and all Approved Users create or activate their individual Gencove accounts.
5. **Confirm Registration**: The Primary Approved User confirms account setup with Additional Ventures.
6. **Explorer Provisioning**: Gencove provisions Explorer. Provisioning generally requires approximately two business days.
7. **Access Confirmation**: Additional Ventures confirms that access is live and communicates the Effective Date.
8. **One-Year Access Period Begins**: Approved Users may begin working with reSOURCE under the approved project and DUA.

1. Applicant Eligibility.

Applicants must be currently affiliated with an eligible research institution or organization. Eligible organizations include:

- Nonprofit research organizations
- Public or private academic institutions and universities
- Governmental agencies with active biomedical research programs
- For-profit companies conducting biomedical research and/or commercial purposes, including the development of new treatments for patients

Both U.S. and international institutions are eligible to apply.

The individual responsible for the project must serve as the Primary Approved User and identify a Primary Institution. Applicants must have a ProposalCentral account. Use of an ORCID iD is encouraged.

2. Approved Users.

The Primary Approved User, typically the project PI or designated organizational lead, serves as the primary point of contact for Additional Ventures and is responsible for managing access for the project team.

Every individual who will access reSOURCE data must be listed in the DAR as an Approved User, including investigators, analysts, trainees, contractors, and other team members who require access. Projects may include collaborators from multiple institutions. Access is granted on a named-user basis; shared accounts or credentials are not permitted.

New users must be approved before receiving access. The Primary Approved User is responsible for removing users who no longer require access and notifying Additional Ventures of changes to the Approved User list.

3. Access Period.

Access is granted for one year from the Effective Date specified under the DUA. Before the end of the Access Period, the Primary Approved User must either request renewal or complete Project Close-out, including the required Progress Update. Renewal, close-out, data retention, and destruction requirements are governed by the DUA.

4. How to Apply.

Application Process:

1. Log in or create an account in ProposalCentral as an Applicant or Awardee.
2. Navigate to the reSOURCE Data Access Request under the Grant Opportunities tab.
3. Click “Apply Now” to begin a new request. To return to an existing DAR, use the Proposals tab.
4. Complete all required application sections and upload the completed and signed DUA.
5. Validate that all required information has been provided, then submit the application.

Applicants will be asked to provide:

- Project title and requested access period
- Primary Approved User and Primary Institution
- All individuals who will access the dataset
- A **Project Summary** (3,500 characters) describing the proposed research.
- The data types and participant subsets expected to be used
- Information about anticipated export or download of SOURCE data
- Security and responsible-use attestations
- Agreement to SOURCE data-sharing and publication requirements
- Institutional billing contact information
- A completed and signed **DUA**

Project Summary

Project Summaries will be made publicly available to support transparency and collaboration through the Additional Ventures Award Search Database. Applicants should not include confidential, proprietary, or sensitive information. Additional information about approved Projects may be made public as described in the DUA. Project Summaries should include:

- The scientific, clinical, or methodological question(s) being addressed
- The SOURCE cohort or participant subset(s) expected to be used
- The high-level study design and analytical approach
- The anticipated research outputs, such as variant discovery, phenotype association, risk stratification, method development, benchmarking, or other analyses

Applicants will also identify the data types and participant subsets they expect to use. These selections support governance review, researcher onboarding, audit and access review, and program reporting. Approved users may be provisioned access to the broader available reSOURCE release; however, all use of the Dataset must remain within the scope of the DAC-approved Project and DUA.

DUA

The DUA must be signed by an individual authorized to enter into data use agreements on behalf of the Primary Institution.

A Data Access Request is considered complete when:

- All required application fields have been completed
- All individuals who will access the dataset are listed as Approved Users in the DAR and DUA Appendix A
- All required attestations have been accepted
- A completed and signed DUA has been uploaded
- Final submission has been completed in ProposalCentral

The review period begins once a complete application has been submitted.

5. Data Access Review.

Complete applications are reviewed by the SOURCE Data Access Committee. The DAC evaluates applicant and institutional eligibility, consistency of the proposed Project with participant consent and permitted uses, and appropriate privacy and security protections. The DAC review is not a competitive assessment of scientific merit or novelty.

Complete applications are generally reviewed within 10 business days. Applications requiring clarification or additional review may take longer.

6. Data Available and Dataset Releases.

reSOURCE includes genomic, phenotypic, and supporting data, including raw sequencing, aligned sequence, variant, joint-called variant, QC, and phenotypic data. See reSOURCE Data and File Types for the files available in the current release.

The DUA applies to reSOURCE as the Dataset is updated over time. Approved users may access subsequent reSOURCE releases during an active Access Period without a new DAR or amendment, provided the new release is used within the scope of the approved Project.

Additional Ventures will maintain release documentation and notify active users of material corrections or updates that could affect analysis or interpretation. Researchers are responsible for documenting the reSOURCE dataset version used in their analyses and publications.

7. Accessing reSOURCE Through Gencove.

Following approval, all Approved Users must establish individual Gencove accounts before final access provisioning.

The access process is as follows:

1. **Approved Users create Gencove accounts.** The Primary Approved User and all other Approved Users create or activate individual accounts using their institutional email addresses. Approved Users who already have a Gencove account or are associated with another Gencove organization should contact Additional Ventures before creating another account or organization.
2. **The Primary Approved User confirms registration with Additional Ventures**. Once all Approved Users have activated their accounts, the Primary Approved User notifies Additional Ventures.
3. **Additional Ventures verifies users and shares the reSOURCE release**. Additional Ventures reconciles the registered Gencove users against the Approved User list and shares the applicable reSOURCE release with the approved research organization.
4. **Additional Ventures requests Explorer provisioning**. Provisioning generally requires approximately two business days after the request is submitted to Gencove.
5. **Additional Ventures confirms access**. Additional Ventures notifies the Primary Approved User when access is live.

Access is considered active once the organization can access the shared reSOURCE release and Approved Users can launch their provisioned Gencove Explorer environment.

The Primary Approved User is responsible for managing membership within the organization's Gencove account. If an Approved User leaves the project or no longer requires access, the Primary Approved User must promptly remove that individual and notify Additional Ventures. New users may not be provided access until an amendment to the Approved User list has been approved.

8. Responsible Use of SOURCE Data.

reSOURCE contains sensitive, de-identified genomic and clinical data. All use must remain within the DAC-approved Project and comply with participant consent and the DUA.

Approved Users may not attempt to identify or contact SOURCE participants, share data or credentials with unauthorized individuals, or use SOURCE data outside the approved Project. AI/ML uses, external data sharing, and other specialized uses are subject to the requirements of the DUA.

Applicants planning to use SOURCE data outside Gencove must describe the external environment in the DAR. If an external cloud service provider or third-party IT system will be used, the information provided must satisfy the Cloud Use Statement requirements in the DUA.

If SOURCE data are transferred outside Gencove:

- Data must be encrypted at rest and in transit
- Access must be restricted to Approved Users
- Appropriate access controls must be used
- Multi-factor authentication should be used where available
- Data must be stored in an institutional or otherwise managed computing environment
- SOURCE data may not be stored on personal devices or unmanaged systems
- A defined retention and destruction plan must be maintained

Additional security, incident-reporting, and external-compute requirements are governed by the DUA.

9. Gencove Explorer, Computing, and Costs.

reSOURCE can be analyzed within Gencove Explorer without downloading the full dataset. Each research organization has a default capacity limit of 800 concurrent vCPUs at any given time, shared across users in that organization’s Gencove environment; this is a compute capacity limit, not a spending limit.

Research organizations are responsible for compute, storage, data transfer, and other applicable cloud costs. Additional Ventures will invoice the Primary Institution based on finalized usage reported by Gencove. Invoices are generally expected to be issued monthly, although billing timing and processes may change. Invoices are due upon receipt and will be sent electronically by Additional Ventures’ billing partners, including AV-AP@armanino.com and/or Bill.com. Organizations can review their own usage and charges through the Gencove billing dashboard.

Analyses performed within Explorer do not incur egress charges. Data-transfer charges apply when SOURCE data are exported from the Gencove/AWS environment and may be substantial for large genomic datasets. Researchers planning large exports should review current pricing or contact Additional Ventures before initiating the transfer. The Primary Institution is responsible for all data export costs related to the project, regardless of the Approved User performing the export. Once an export is initiated, the institution is responsible for costs incurred.

10. Changes to an Approved Project.

Additional Ventures must approve new users before access is provided. Modifications to an approved Project may require an amendment to the existing DAR; new research uses outside the scope of the approved Project require a new DAR. Researchers should contact Additional Ventures before a change in Primary Approved User or institution, addition of another institution, or other change that could affect the approved use, DUA, or data-security requirements.

11. Publications and Public Dissemination.

Research outputs must comply with participant consent, the DUA, and applicable institutional and legal requirements. Publications and other public disclosures resulting from use of SOURCE data must include the following acknowledgment:

“The results analyzed and published here are based in whole or in part upon data generated by Single Ventricle SOURCE (www.svsource.org), accessed from the reSOURCE dataset [Dataset version], funded by Additional Ventures (www.additionalventures.org).”

Questions?

Questions about reSOURCE data access, Gencove onboarding, billing, or the Data Access Request process should be directed to the SOURCE team at contact@svsource.org.