

Rhode Island Longitudinal Data System

Data Request & Release Policies

March 26, 2024

1. Purpose

Rhode Island Longitudinal Data System (“RILDS”) Data Request & Release Policies are articulated in the Rhode Island Longitudinal Data System Act (“RILDS Act”) as well as each of the data sharing agreements that have been established between the Rhode Island Longitudinal Data System Center (“Center”) and the Data Contributing Agencies. These agreements establish how data imported and linked through RILDS will be managed so that benefits to the State of Rhode Island (“State”) are maximized and risks are minimized. These policies detail how data requests and releases will be managed in practice.

The RILDS Center operates and maintains RILDS in accordance with federal and state laws and regulations particularly regarding education, health, and employment records, including, but not limited to the Family Educational Rights and Privacy Act (FERPA), the Individuals with Disabilities Education Act (IDEA), the Health Insurance Portability and Accountability Act (HIPAA). The following definitions pertinent to addressing data access issues are derived from these and other related documents.

2. Definitions

2.1. Data Contributing Agencies

Data Contributing Agencies are defined as any Rhode Island state agency, Rhode Island municipal government, research institution, non-profit organization, community foundation, or other entity that has executed the RILDS MOU.

2.2. Data Governance Committee

The RILDS Data Governance Committee established per R.I. Gen. Laws § 42-165-5(b)(6) with authority to approve Requests.

2.3. Executive Governing Committee

The RILDS Executive Governing Committee established per R.I. Gen. Laws § 42-165-5 with responsibility for governing RILDS.

2.4. Non-Data Contributing Agency

Any Rhode Island State agency, excluding Data Contributing Agencies, that serves on the Executive Governing Committee as named in the Rhode Island Longitudinal Data System Act, namely the Rhode Island Department of Administration, Rhode Island Division of the Information Technology, Rhode Island Executive Office of Health and Human Services, and Rhode Island Office of Management and Budget.

2.5. Personally Identifiable Information

Information that alone is linked or linkable to a specific individual and that would allow a reasonable person to identify the individual with reasonable certainty.

2.6. Public Output

Any presentation, publication, report and other product ready for public release containing aggregate-level RILDS data, such that individuals cannot be directly or indirectly identified. In other words, Public Outputs do not contain Personally Identifiable Information.

2.7. Request

Any Request for any use of RILDS Center services or RILDS data, including amendment of fully executed data use agreements.

2.8. RILDS

The data system formerly known as the Rhode Island DataHUB operated by DataSpark at the University of Rhode Island, is the State of Rhode Island's statewide longitudinal data system, established per R.I. Gen. Law § 42-165-2.

2.9. RILDS Center or Center

The entity formerly known as DataSpark at the University of Rhode Island, and whatever other resources are necessary to accomplish the powers and duties prescribed in R.I. Gen. Law § 42-165, manages and operates RILDS and conducts research and evaluates programs.

2.10. RILDS MOU

RILDS MOU refers to the memorandum of understanding or other agreement executed by and between the RILDS Center and any Rhode Island state agency, Rhode Island municipal government, research institution, non-profit organization, community foundation, or other entity for recurring participation in RILDS.

2.11. State and Federal Privacy Laws

All applicable state and federal laws and accompanying regulations, including but not limited to the federal Family Educational Rights and Privacy Act and its accompanying regulations (“FERPA”), Health Insurance Portability and Accountability Act (“HIPAA”), R.I. Gen. Laws § 28-42-38, 20 CFR 603.1 et seq., and any other privacy measures that apply to the personally identifiable information that is used by the RILDS Center and/or becomes part of the RILDS.

2.12. Third Party

Any entity, whether Rhode Island State agency, Rhode Island municipal government, research institution, non-profit organization, community foundation, or other individual or entity that is not a Data Contributing Agency, Non-Data Contributing Agency, or the RILDS Center.

2.13. Time-Sensitive Request

Any Request for the use of RILDS data or RILDS Center services, which must be processed quicker than the usual twenty (20) business days request, review, and release process.

2.14. User Fees

The fees charged by the RILDS Center, per R.I. Gen. Laws § 42-165-7, to compensate for excessive use of the data system, to recover costs that would otherwise typically be borne by the requesting data researcher, or both.

3. Request

3.1. Policy Statement

The Data Governance Committee must approve Requests before the Center proceeds with such use, release, or disclosure of RILDS data or RILDS Center services. All Requests are submitted through the online [Data Request Form](#) and at least fifteen (15) business days before the next Data Governance Committee meeting. The Center and the Data Governance Committee prioritize Requests from Data Contributing and Non-Data Contributing Agencies. Requests from Third Parties are processed in the order in which they are submitted. The Data Governance Committee approves Requests by a majority vote of all Data Contributing Agency members present, including Data Contributing Agencies whose Agency data *is not included* in the Request.

3.2. Scope

The above policy applies to all Requests that are not time sensitive, including but not limited to:

- Requests from Data Contributing Agencies for the Center to analyze RILDS data shared by their Agency alone;

- Requests from Data Contributing Agencies for the Center to analyze RILDS data shared by their Agency linked with RILDS data shared by another Data Contributing Agency;
- Requests from the Non-Data Contributing Agencies; and
- Request from Third Parties.

3.3. Reason for Policy

Standard policies and processes set expectations, rights and responsibilities of the Center, the Data Governance Committee, and the individual or entity submitting the Request.

RILDS is a shared resource, and the Data Contributing Agencies must collectively make decisions about the use of RILDS data and Center services. Similarly, the Data Governance Committee and the Executive Governing Committee have an interest in knowing about all interagency data use so that benefits to the State are maximized and the risks are minimized. Successful interagency data governance requires that each agency or entity sharing data through the integrated, longitudinal data system retains decision making authority over their data.

3.4. Processes

The individual or entity submitting the Request will complete the online [Data Request Form](#) at least fifteen (15) business days before the next Data Governance Committee meeting. The Data Governance Committee meeting dates are published on the RILDS website. Requests submitted less than fifteen (15) business days before the next Data Governance Committee meeting are held to a following meeting.

The Data Governance Committee must approve Requests before the Center proceeds with such use, release, or disclosure of RILDS data or use of RILDS Center services. The Center may respond to other inquiries without notifying the Data Governance Committee.

Five (5) business days before the next Data Governance Committee meeting, the Center will notify the Data Governance Committee of all Requests to be evaluated in the upcoming meeting. The Center's notice briefly describes:

- the individual or entity submitting the Request;
- the proposed research questions;
- the proposed study population and whether it is vulnerable;
- the RILDS data requested;
- whether the Request covers aggregate or individual-level data;
- how the results will benefit policies, programs, and citizens in Rhode Island and how the results will advance equity for Rhode Islanders;
- the estimated scope of Center services, in hours, required to process the Request; and
- the estimated cost to the individual or entity submitting the Request.

For individual-level Requests, the Center's notice also includes:

- a justification for individual-level data;
- whether the Request has Institutional Review Board approval;
- the proposed research design;
- the proposed statistical methodology;

- the name and CV of the principal investigator;
- the anticipated Public Outputs; and
- whether the Request is an amendment to the project scope or an extension of the project term.

The Center may limit the number of Requests evaluated in each meeting due to meeting time allowance. To the best of its ability, the Center tries to schedule Requests for the next meeting but makes no guarantees. The Center and the Data Governance Committee prioritize requests from Data Contributing Agencies and Non-Data Contributing Agencies. Requests from Third Parties are processed in the order they are submitted.

Since members of the Data Governance Committee are expected to attend the Data Governance Committee meetings and if they cannot attend, they are expected to send a delegate empowered with appropriate decision-making authority, requests are evaluated during Data Governance Committee meetings. The evaluation may proceed only if a majority of Data Contributing Agencies are present. The individual or the entity submitting the Request may participate in the Data Governance Committee meeting.

The Data Governance Committee evaluates Requests by a majority vote of all Data Contributing Agencies present, including Data Contributing Agencies whose data is not included in the Request. The Data Contributing Agencies may either approve, approve pending revisions, or deny Requests. In evaluating Requests, the Data Contributing Agencies consider:

- whether the Request complies with State and Federal Privacy Laws;
- the benefits and the risks to the State and Rhode Islanders of releasing the requested data; and
- whether the Request aligns with RILDS's priorities, including especially whether the Request advances equity for Rhode Islanders.

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency's data. Where a majority of Data Contributing Agencies approve the Request, the Center may proceed with the Request under the terms specified in relevant data sharing agreements and contracts between Data Contributing Agencies and the Center.

The Center publishes summaries of all Requests, as scoped, online. This summary includes the results of the Data Governance Committee's evaluation. For requests either scoped as 100 or more hours or requests involving vulnerable populations, the Center will provide quarterly updates the Data Governance Committee. Quarterly, the Data Governance Committee prepares a report on all Requests evaluated for the Executive Governing Committee's review.

4. Aggregate-Level Release & RILDS Center Public Outputs

4.1. Policy Statement

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with the use, release, or disclosure of that Data Contributing Agency's data. Where a majority of the Data Contributing Agencies deny the Request, the Center will not proceed with the Request. Where a majority of Data Contributing Agencies approve the Request, the Center proceeds with the Request under the terms specified in the relevant data sharing agreements and contracts between Data Contributing Agencies and the Center.

The Center notifies the Data Governance Committee of all Public Outputs at least five (5) business days prior to their release. The Data Contributing Agencies, whose data is included in the Public Output, review the Public Output to ensure that data confidentiality is satisfactorily maintained. Only Data Contributing Agencies, whose data is included in the Public Output, may object to the Public Output's release, and only for concerns about non-compliance with State and Federal Privacy Laws and non-compliance with RILDS policies.

4.2. Scope

The above policy governs all data regularly integrated into RILDS and data integrated temporarily for project-specific use.

4.3. Reason for Policy

The above policy allows each Data Contributing Agency, whose data is included in the Request, to deny the use, release, or disclosure of their data. The above policy also requires a majority of Data Contributing Agencies to approve the Request. This structure balances two essential components of the interagency data governance – agency autonomy surrounding use of their data and collective decision-making around shared resources.

The Data Governance Committee follows policies established by the Executive Governing Committee regarding how data requests will be managed; the publishing of reports and other information to be made available to public stakeholders; and standards implemented by the RILDS Center for the security, privacy, access to, and confidentiality of data (R.I. Gen. Laws § 42-165-5). To ensure Public Outputs appropriately safeguard individual privacy, the Data Governance Committee must review these Public Outputs. Given the Center's expertise in analyzing interagency, longitudinal data and with State and Federal Privacy Law, the review period for Public Outputs produced by the Center is five (5) business days.

4.4. Processes

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency's data. Where a majority of the Data Contributing Agencies deny the Request, the Center will not proceed with the Request. Where a majority of Data Contributing Agencies approve the Request, the Center proceeds with the Request under the terms specified in the relevant data sharing agreements and contracts between Data Contributing Agencies and the Center.

While preparing the Request, the Center may coordinate with the individual or entity submitting the Request and the Data Contributing Agencies, whose data is included in the Request. This coordination ensures that the Public Output materially fulfills the Request, as possible with available data, under State and Federal Privacy Law, and under RILDS policies. It also ensures that data context is interpreted appropriately, improving RILDS data quality.

To the best of its ability, the Center notifies the Data Contributing Agencies, whose data is included in the Public Output, that the Center anticipates finalizing the Public Outputs in thirty (30) days. The notification prepares Data Contributing Agencies for the upcoming disclosure avoidance review, detailed below.

The Center notifies the Data Governance Committee of all Public Outputs produced using RILDS data at least five (5) business days prior to the Public Output's release. The Center shares the Public Output via email with all members of the Data Governance Committee and their delegates.

The Data Contributing Agencies, whose data is included in the Public Output, conduct disclosure avoidance review. They review the Public Output to ensure that data confidentiality is satisfactorily maintained. Only Data Contributing Agencies, whose data is included in the Public Output, may object to the Public Output's release, and only for concerns about:

- non-compliance with State and Federal Privacy Laws and/or
- non-compliance with RILDS policies.

The purpose of this review is not to alter, delay, or withhold findings. If a Data Contributing Agency, whose data is included in the Public Output, objects to the Public Output's release, the Center will revise and resubmit the Public Output for the Data Contributing Agencies' review. If after five (5) business days, no Data Contributing Agency, whose data is included in the Public Output, objects to the Public Output's release, the Center may proceed with such use, disclosure, or release, including publishing the Public Output to its website.

The Data Contributing Agencies, whose data is included in the Public Output, may notify the Center that it needs another five (5) business days to prepare for the Public Output's release. In these instances, the Center delays release for five (5) business days, and the Data Contributing Agency prepares as necessary. After the additional five (5) business days, the Center proceeds with release.

When releasing aggregate-level RILDS data, the Center follows applicable State and Federal Privacy Laws and employs appropriate disclosure avoidance techniques as defined by the National Center for Education Statistics in Technical Brief 3 "Statistical Methods for Protecting Personally Identifiable Information in Aggregate Reporting". At a minimum, the Center suppresses cell sizes smaller than ten (10) and makes a reasonable effort at complementary suppression.

The Center releases Public Outputs produced using public data without notifying the Data Governance Committee.

5. Individual-Level Release & Third Party Public Outputs

5.1. Policy Statement

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency's data. Where a majority of the Data Contributing Agencies deny the Request, the Center will not proceed with the Request. Where a majority of Data Contributing Agencies approve the Request, the Center proceeds with the Request under the terms specified in relevant data sharing agreements and contracts between the Data Contributing Agencies and the Center.

The Center and any Third Party requesting individual-level RILDS data must execute a data use agreement specifying the State and Federal Privacy Law permitting release, the RILDS data to be released, the project or purpose for which the RILDS data may be used, and the terms and conditions of such use. Third Parties must provide all Public Outputs to the Center at least twenty (20) business days prior to release, and the Center, in turn, shares these Public Outputs with the Data Governance Committee at least fifteen (15) business days prior to their release.

5.2. Scope

The above policy governs all data regularly integrated into RILDS and data integrated temporarily for project-specific use.

5.3. Reason for Policy

The above policy allows each Data Contributing Agency whose data is included in the Request to deny the use, release, or disclosure of their data. The above policy also requires a majority of Data Contributing Agencies to approve the Request. This structure balances two essential components of the interagency data governance – agency autonomy surrounding use of their data and collective decision-making around shared resources. This structure balances two essential components of the interagency data governance – agency autonomy surrounding use of their data and collective decision-making around shared resources.

The Data Governance Committee follows policies established by the Executive Governing Committee regarding how data requests will be managed; the publishing of reports and other information to be made available to public stakeholders; and standards implemented by the RILDS Center for the security, privacy, access to, and confidentiality of data. To ensure Public Outputs appropriately safeguard individual privacy, the Data Governance Committee must review them.

5.4. Processes

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency's data. Where a majority of the Data Contributing Agencies deny the Request, the Center will not proceed with the Request. Where Data Contributing Agencies approve the Request, the Center proceeds with the Request under the terms specified in relevant agreements between Data Contributing Agencies and the Center.

The Center and the Third Party must execute a data use agreement specifying the State and Federal Privacy Law permitting release, the RILDS data to be released, the project or purpose for which the RILDS data may be used, and the terms and conditions of such use.

At their project's end, Third Parties must provide all Public Outputs to the Center at least twenty (20) business days before the Public Output's release. The Center, in turn, shares these Public Outputs with the Data Governance Committee at least fifteen (15) business days prior to their release. The Center shares Public Outputs via email with all members of the Data Governance Committee and their delegates.

The Data Contributing Agencies, whose data is included in the Public Output, review the Public Outputs to ensure that data context is interpreted correctly and that data confidentiality is satisfactorily maintained. Only Data Contributing Agencies, whose data is included in the Public Outputs, may object to the Public Outputs' release, and only for concerns about:

- non-compliance with State and Federal Privacy Laws;
- non-compliance with RILDS policies; and/or
- miscalculation or misinterpretation of data.

The purpose of this review is not to alter, delay, or withhold findings. If a Data Contributing Agency, whose data is included in the Public Output, objects to the Public Output's release, the Center will notify the Third Party. If after fifteen (15) business days, no Data Contributing Agency, whose data is included in the Public Output, objects to the Public Output's release, the Third Party may proceed with such use, disclosure, or release.

The Data Contributing Agencies, whose data is included in the Public Output, may notify the Center that it needs another five (5) business days to prepare for the Public Output's release. In these instances, the Center delays release for five (5) business days, and the Data Contributing Agency prepares as necessary. After the additional five (5) business days, the Center proceeds with release.

Any member of the Data Governance Committee, including members from Non-Contributing Agencies, may provide feedback regarding these Third Party Public Outputs. The Center, in turn, shares this feedback with the Third Party. The Third Party is not obligated to incorporate this feedback.

6. Time-Sensitive Requests

6.1. Policy Statement

The Data Contributing Agencies and the Non-Data Contributing Agencies can submit Time-Sensitive Requests, which must be processed quicker than the usual twenty (20) business day in section 3.4. The Center prioritizes Time-Sensitive Requests over all other approved Requests.

6.2. Scope

The above policy applies to all Time-Sensitive Request, including:

- Requests from Data Contributing Agencies for the Center to analyze RILDS data shared by their Agency alone;
- Requests from Data Contributing Agencies for the Center to analyze RILDS data shared by their Agency linked with RILDS data shared by another Data Contributing Agency; and
- Requests from the Non-Data Contributing Agencies.

6.3. Reason for Policy

In some instances, Data Contributing Agencies and Non-Contributing Agencies request information quickly. The Time-Sensitive Request policy and process balances the competing priorities of accuracy, quality, and timeliness.

The Data Governance Committee's quarterly monitoring of Time-Sensitive Requests ensures that Time-Sensitive Requests do not override established priorities and overwhelm the Center.

6.4. Processes

To qualify as Time-Sensitive Request, the Request must:

- be submitted by a Data Contributing Agency or Non-Contributing Agency;
- cover only aggregate-level RILDS data;
- require an estimated twenty (20) hours or less.

The Request proceeds according to the usual process in section 3.4, except:

- the Data Contributing Agency or Non-Contributing Agency submitting the Request must justify the need for need for processing this request within less than twenty (20) business days, and
- the Center may object to Time-Sensitive Requests for reasons of capacity and feasibility.

For the Center to fulfill Time-Sensitive Requests, all required data must be integrated and linked through RILDS. If the Center objects for reasons of capacity or feasibility, the Center provides the Data Contributing Agency or Non-Contributing Agency submitting the Request with the option to proceed with Request under the usual twenty (20) business day process.

The Data Governance Committee evaluation proceeds according to the usual process in section 3.4, except:

- the Center notifies all members of the Data Governance Committee and at least four other representatives from each Data Contributing Agency and Non-Contributing Agency via email with the subject line specifying “RILDS Time Sensitive Request,” and
- no response after two (2) business days is considered approval.

Where a Data Contributing Agency, whose data is included in the Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency’s data. Where a majority of Data Contributing Agencies approve the Time-Sensitive Request, the Center may proceed with the Request under the terms specified in relevant data sharing agreements and contracts between Data Contributing Agencies and the Center. The Center prioritizes Time-Sensitive Requests over all other approved Requests.

The review of Public Outputs is waived for Time-Sensitive Requests. The Center shares Public Outputs with the individual or entity submitting the Request and with all members of the Data Governance Committee as soon as possible.

The Data Governance Committee monitors Time-Sensitive Requests. On a quarterly basis, the Data Governance Committee reviews all Time-Sensitive Requests and may deny future Time-Sensitive Requests because of an Agency’s over-reliance on this process.

7. Amendment or Extension

7.1. Policy Statement

The Center and any Third Party receiving individual-level RILDS data execute a data use agreement specifying the State and Federal Privacy Law permitting release, the RILDS data to be released, the project or purpose for which the RILDS data may be used, and the terms and conditions of such use. Third Parties may request modification of this fully executed data use agreement.

7.2. Scope

The above policy governs all data use agreements fully executed by and between the Center and any Third Party receiving individual-level RILDS data.

7.3. Reason for Policy

The Data Governance Committee follows policies established by the Executive Governing Committee regarding how data requests will be managed; the publishing of reports and other information to be made available to public stakeholders; and standards implements by the RILDS Center for the security, privacy, access to, and confidentiality of data. To make appropriate, effective, and informed decisions regarding data use, members of the Data Governance Committee, especially members from Data Contributing Agencies, are expected to be familiar with State and Federal Privacy Law and RILDS policies.

The Data Governance Committee has an interest in knowing about all interagency data use so that benefits to the State are maximized and the risks are minimized.

7.4. Processes

The Center notifies the Data Governance Committee of all Requests to modify fully executed data use agreements.

Amendments to the project scope (i.e., research questions, data elements, substantial personnel change) require, first, approval by the Data Governance Committee and, second, amendment of the data use agreement. This amendment Request proceeds according to the usual process in section 3.4. The Third Party requesting amendment will complete the online [Data Request Form](#) at least fifteen (15) business days before the next Data Governance Committee meeting. Where a Data Contributing Agency, whose data is included in the amendment Request, denies the use, release, or disclosure of their data, the Center shall not proceed with use, release, or disclosure of that Data Contributing Agency's data. Where a majority of the Data Contributing Agencies approve the amendment Request, the Center may proceed with may proceed with amendment to the data use agreement under the terms specified in relevant data sharing agreements and contracts between Data Contributing Agencies and the Center.

Extensions of the project term do not require approval by the Data Governance Committee but do require amendment of the data use agreement. The extension Request proceeds according to the usual process in section 3.4., except the Third Party requesting extension will complete the online [Data Request Form](#) at least seventy-five (75) business days before the end date of the data use agreement. After notifying the Data Governance Committee, the Center may proceed with the extension of the data use agreement.