

# DATA ACCESS REQUEST TYPES

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## Purpose

To outline the types of research projects that can be submitted to DataNB and explain the different types of Data Access Request (DAR).

## Access Pathways

Researchers can request access to administrative data, held in custody at DataNB, in two ways:

### Single-Site Requests (NB Only)

Submit directly to DataNB

- Complete a Feasibility Request.
- If feasible, submit a Data Access Request (DAR).
- Forms are available on the DataNB website

### Multi-Regional Requests (HDRN Canada)

Submit to HDRN Canada through DASH (Data Access Support Hub).

- Complete the DASH Intake Form.
- If feasible, submit a DASH DAR.
- Forms are available on the DASH portal

## Approval Overview

Regardless of how the project was received (single site or multi-regional), a multi-step DAR approval process is required to protect the data in custody at DataNB. These steps are also necessary for compliance with privacy legislation, signed UNB agreements with the province and data business partners, and the DataNB Data Access Approval policy.

## Approval Process

- Complete the DAR
- Governance Reviews (Institute Review, Data Research Committee Review, Preliminary Ethics Review Committee)
- Ethics Approval
- Completed Administrative Safeguards
- Data Access Agreement (DAA)

**Note:** If you are requesting to have external data imported, a Data Sharing Agreement (DSA) is required. Data must be in custody at DataNB before a DAA can be signed.

The DataNB Data Services Team will work with the Principal Investigator (PI) and

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the research team members to facilitate the approval steps and ensure that the appropriate processes are followed.

## DAR Types

There are four (4) types of DARs that require access to or involve linking with administrative data for secondary use.

### Quick Reference:

DAR Type	Purpose	Examples
Retrospective	Access existing data to study past events	Chronic disease trends (2010–2020)
Prospective	Studies that look forward and include data additions over time	Birth cohort followed over 10 years
Successive	Repeated study with 1 variable changing with each repetition.	6 diseases using the same dataset
Multi-Phase	Two-part studies: part 1, primary data collection, part 2, linking of primary data to administrative data held at DataNB	Survey data collected and then linked to line level health records

## Retrospective Research Projects

Research or program evaluation project requiring access to administrative data held on the DataNB platform. Project-specific data may be transferred to DataNB for use in such a project. This is the most common type of DAR received. Requires access to historical administrative data.

### Key Requirements:

- Feasibility Request form
  - Provide a copy of the informed consent form for review (if applicable)
  - Feasibility results will be provided within two weeks of receipt
- Data Access Request (following feasibility approval)
- Signed Data Access Agreement
  - DataNB will facilitate the signing of the Data Access Agreement (DAA) once the data access approval process is complete.

### Approval Process:

- A Feasibility Review will be conducted to determine if the project is feasible. Feasibility approval is valid for one year.
- Following the DAR submission, an Institute Review (IR), a Data Research Committee Review (DRC), and a review by the Preliminary Ethics Review Committee (PERC) will occur.
  - Additional review requirements<sup>1</sup> may be needed
  - Administrative Safeguard instructions are provided to all research team members; these must be completed before data access is granted.
  - A signed budget letter must be received before the Data Access agreement is sent to the Office of Research Services (ORS).
- After PERC, a copy of the UNB REB application will be sent to the UNB REB office; the PI will be cc'd. UNB REB approval must be obtained before the DAA can be signed.
- DAA is prepared by the Data Services Team.
  - DAA is first signed by the Vice President (Research) on behalf of DataNB.
  - DAA counter signatures are then obtained.
    - a. For a non-UNB affiliated PI: The DAA is sent by the Data Access Coordinator to the PI, who must obtain a signature from their host institution.
    - b. For a UNB affiliated PI: The DAA is sent by the Data Access Coordinator directly to the PI for their signature.
- Once the DAA is fully executed, the project folder and user accounts are created, and the research team can now begin analysis.

### **Project Considerations:**

- Vetting request
  - Once the analysis is complete, the research team submits a request for the vetting of research results.
  - Aggregate data is then released to the research team for preparation of their research results.
- Research Results Data Dissemination
  - The research team must submit the research results to DataNB for

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<sup>1</sup> At the request of certain Data Business Owners and as documented in certain data sharing agreements (e.g., IRCC, CANUE, CLSA, Atlantic Path, etc.).

review by the DRC prior to submission for publication, presentation, etc., in adherence with the *DataNB Dissemination of Research Findings Policy*.

- During the Research Results Data Dissemination review, a 25-business-day embargo period is in effect.
- Project closure:
  - The PI may initiate project closure following the completion of the Research Results Data Dissemination review. Alternatively, the Data Services team may initiate closure when the project term (i.e., UNB REB Approval) expires.
  - Access to the project folder is removed, and management of the project data follows the *DataNB Data Retention, Destruction, and Restoration Policy*.
- Amendment Requests:
  - Amendment requests are required if any edits are needed to the DAR after the DAA has been signed.
  - Projects that wish to extend beyond the typical UNB REB approval of 3 years must follow the amendment process for REB Approval Extension.

## Prospective Research Projects

A research project that requires access to data held on the DataNB platform for research, or program evaluation involving linked administrative data, that will require ongoing data analysis and the periodic addition of one or more defined data sets (s) for a specific cohort of study. This type of Data Access Request extends multiple years into the future, requiring amendments to the DAR as new data are added to the platform.

### Key Requirements:

- In addition to key requirements as found in the [DAR Retrospective](#), a submission of a DAR amendment is required to update the available date ranges of the previously approved data sets.

### Approval Process:

- All approval processes listed under [DAR Retrospective](#) apply to Prospective projects

### Project Considerations:

- All data Access considerations listed under [DAR Retrospective](#) apply to Prospective projects
- Amendments
  - The DAA can only be approved based on the data currently held at DataNB. Amendments will be required to include extended date ranges

## **Successive Research Project**

A research project that requires access to data on the DataNB platform for research or program evaluation, to conduct multiple research projects in sequence. The series of subprojects will follow the same scope, research question, and methodology as the original request, but each successive subproject will change one predetermined element (i.e., cohort, key variable of interest, or period of study) across each successive project.

Only one predetermined element can change (i.e., cohort, key variable of interest, or period of study); all other aspects of the DAR will remain the same. (e.g., A succession of projects examining a *different* disease using the same cohort, period of study, and research questions.)

### **Key Requirements:**

- In addition to key requirements as found in the [DAR Retrospective](#), a submission of a DAR amendment is required for each subproject in turn

### **Approval Process:**

- All approval processes listed under [DAR Retrospective](#) apply to Successive projects

### **Project Considerations:**

- All data Access considerations listed under [DAR Retrospective](#) apply to Successive projects
- Amendments
  - Each successive project requires a DAR Amendment
  - Must clearly define and limit what changes (e.g., 6 diseases using the same methodology)

## **Multi-Phase Research Project**

Research projects may require completion in multiple phases; for example, phase

1 may include the collection of primary data, followed by phase 2, where a request is made for the collected primary data to be linked to administrative data held on the DataNB platform for research or program evaluation. Multiphase research requires a separate REB approval for each phase.

### **Phase 1 - Data Collection**

The approval of the collection of primary data.

#### **Key Requirements:**

- Only a completed Feasibility Request form is required.
  - Provide a copy of informed consent for review (note consent letter of information must include details of future intention to link to administrative data held at DataNB)
  - Feasibility results will be provided within two weeks of receipt.
  - The DAR will not be completed or submitted until the primary data collection work is complete.
- UNB REB approval

#### **Approval Process:**

- A Feasibility Review will be conducted to determine if the project is feasible. Feasibility approval is valid for one year.
- UNB REB application, for approval specifically for the primary data collection phase, is required.

### **Phase 2 - Data Linkage (Data Access -Multi-phase)**

The collected primary data are linked with administrative data on the DataNB platform.

#### **Key Requirements:**

- All key requirements listed under [DAR Retrospective](#) apply to phase 2 of the multi-phase projects
  - If the previously approved feasibility has expired, a new feasibility request will need to be submitted.

#### **Approval Process:**

- All approval processes listed under [DAR Retrospective](#) apply to phase 2 of multi-phase projects
  - A second UNB REB approval is required to link the primary data

collected during phase 1 to the administrative data held in custody by DataNB.

**Project Considerations:**

- All data access considerations listed under [DAR Retrospective](#) apply to phase 2 of the multi-phase projects

**General Notes and Considerations**

- All feasibility approvals are valid for 1 year
  - If the previously approved feasibility has expired, a new feasibility request will need to be submitted.
- UNB REB approvals are typically valid for 3 years
- Amendments are required for:
  - UNB REB renewal
  - Adding variables, data sets or data years
  - Initiating new successive project phase
- DataNB reserves the right to:
  - assign DAR Type
  - re-evaluate resource needs for data access requests that extend beyond the initial approval period.
- Administrative safeguards and ethics compliance are mandatory for all team members

**Document Version, Review, and Approval History**

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1.0	A Lavigne and L Gilbert	Document refresh	July 5, 2023
2.0	A Lavigne	Reordered & finalized DAR Types	August 30, 2023
2.1	A Lavigne	Final look at Successive project	May 6, 2024
2.2	A Lavigne, C Hovey, and L Gilbert	Updates	June 17, 2024
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