

Process for Requesting Individual-Level Data¹ from the Nova Scotia Atlee Perinatal Database

Data Request Process

Step 1

Complete the application form entitled '**Joint Data Access Committee & RCP Data Access Committee Application Form**'. See specific instructions provided with the form, referred to as the '**Instructions for Completing an Application for Access to Data from the RCP Nova Scotia Atlee Perinatal Database**'. Email the completed form to RCPDAC_JDAC@iwk.nshealth.ca.

Submit the signature page (page 9) to the office of Janet Slaunwhite at the IWK Health Centre. **Each investigator must sign a completed copy of page 9** and either hand deliver the page, scan the original and e-mail it to: janet.slaunwhite@iwk.nshealth.ca, or fax the form to Janet Slaunwhite at 902-470-7190. Note: A scanned or faxed version of the investigator's original signature is acceptable but an electronically generated signature will not be accepted.

Requests are reviewed monthly by one of two Data Access Committees:

- ✓ The Joint Data Access Committee reviews projects that require a link between the NSAPD and any other database or data set (including data from a chart review), and projects that require data to leave Nova Scotia ([schedule](#)).
- ✓ The RCP Data Access Committee reviews projects that require data from the NSAPD only ([schedule](#)).

Prior to submitting a data request, consultation with a staff member from RCP is recommended. Call 902-470-6798 or e-mail RCPDAC_JDAC@iwk.nshealth.ca to arrange an appointment. **Prior to submitting a linkage project, consultation with the JDAC Chair or designate is required.** Call 902-470-6464 or email janet.slaunwhite@iwk.nshealth.ca to arrange an appointment.

Step 2

Attend the Joint Data Access Committee meeting or the RCP Data Access Committee meeting to describe your project. This step is optional but advisable. The committee chair will contact you with the time and location of the meeting.

Step 3

Respond in writing to any recommendations made by the RCP Data Access Committee or the Joint Data Access Committee (send a letter or e-mail addressed to the committee chair). Data access will not be granted until this step has been completed.

¹ Individual-Level data is Person-Level, Person-Identifiable, Health-Provider-Identifiable, or Institution-Identifiable. To request aggregate (tabular), de-identified data, please use the '[Request for Aggregate Data from the Nova Scotia Atlee Perinatal Database](#)' form.

Step 4

Complete a Research Ethics Board (REB) application². Include with the REB application the approval received from the Joint Data Access Committee or the RCP Data Access Committee. Although application for data access and to an REB can be made simultaneously, the IWK REB will not complete the review until data access is approved. Once received, forward the REB approval and any recommendations to RCP.

Step 5

Prior to submission of the completed application form and appendices, read the Data Sharing Agreement (Attachment B) to ensure that the research team can comply with the requirements described. Once all of the approvals are in place, your request will be placed in the queue. Requests are filled according to submission date, unless there are extenuating circumstances. The average turn-around time from the date the request is fully approved to return of data is 2-6 weeks, depending on the complexity of the request and the level of approval required.

You will be asked to sign a Data Sharing Agreement and forward it to the RCP office when your analysis file is ready. Your file will be made available once the signed agreement has been received. A copy of the signed agreement should be shared with all investigators involved with the project.

Cost

Those receiving a grant for their projects are asked to build in a retrieval fee to their budget submission. An estimate of the retrieval fee can be obtained from RCP for budget planning purposes. In some situations there is no cost for data retrievals requested by groups or individuals from Nova Scotia.

Publication

Users of the data must acknowledge the source of the data as the Department of Health & Wellness/RCP and the Nova Scotia Atlee Perinatal Database in all publications or presentations. All publications, abstracts, web-based documents and other presentations must be submitted to the Chair of the Joint Data Access Committee **OR** to the Co-chairs of RCP Data Access Committee:

- a) Publications submitted at the time the manuscript is first submitted to a Journal Editorial Board
- b) Presentations and other documents at an appropriate time prior to presentation/posting

Investigators Outside Nova Scotia

Investigators from outside of Nova Scotia must work with a Nova Scotia collaborator. Individual level data, even de-identified data, cannot leave the province but remote access to the analysis file may be possible.

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² Any request that uses IWK data requires IWK Research Ethics Board approval. The majority of database projects receive expedited review. Requests for expedited review can be submitted to IWK Research Services any time. There is no need to adhere to the REB submission deadline.