Student Data Access Request Guidelines

All requests for access to health data for research are reviewed and approved by the Ministry of Health (MOH) and, if data from a Health Information Bank is requested, the Data Stewardship Committee (DSC). This process is supported by MOH Service Providers including PopData BC and in collaboration with health authorities and partners such as the Canadian Institute for Health Information (CIHI).

A Student Data Access Request (DAR) may originate from academic or health research institutions, with the research topic chosen by the student, their supervisor, one of the student's committee members, or another research partner. Although the student's supervisor or committee member must act as primary investigator (PI) and submit the Student DAR, a student request may either be an independent project, or it may fall within the scope of a project which has already been approved. Student requests vary greatly from one another, but all requests are evaluated against a common set of criteria to ensure a fair process. The purpose of this guideline is to provide examples of common questions about the MOH and the DSC approval process.

The key requirements for completing a DAR are outlined in the MOH Access to Health Data for Research Policy and the DSC Policies Respecting the Disclosure of Information. It is highly recommended that Applicants review these policies before they submit a new request, and before submitting an amendment for an approved request. MOH Service Providers, other Data Stewards, and external partners may also have additional policies and guidelines in place related to student DARs that applicants may be advised to familiarize themselves with.

Student Data Access Requests

How do I submit a Student DAR?

Most typically, you will submit your request for student access to health data through PopData BC, who offer support for anyone applying for research access to MOH administrative data. If you are in a student research placement within a health authority, requests for access to MOH administrative data may be made through BC Health Authorities. Student requests for access to some national data sources which include BC data may also be made through the Canadian Institute for Health Information (CIHI).

Who qualifies as a student for the purpose of submitting a Student DAR?

A student is anyone who can demonstrate enrolment in one of these designated schools including medical residents training in a program affiliated with a Canadian college or university. Data can be provided for undergraduate and graduate student projects.

What if I don't have funding to pay for data access?

PopData BC offers fee waivers for students using their services, who may apply for up to a maximum of $7,500 in service charges and $5,000 for access to the Secure Research Environment. More information [can be found here](#).

Are there different kinds of Data Access Requests for Students?

There are two types of DARs for students available through PopData BC.

1) Access to data can be requested for the sole purpose of a student research project using the standard DAR process but with the student's supervisor as the principal investigator and the submission of a letter of support from the student's supervisor.

2) Access to data can be requested for a 'nested' student research project that can be completed within the scope of an existing approved DAR (e.g. one belonging to the student's supervisor or a supervisory committee member) using the standard DAR Amendment, submitted by the principal investigator for the existing DAR with a letter of support from the student's supervisor if they are not the principal investigator.

Note: A Student DAR or Student DAR Amendment covers access to data for the student's research project and research questions only. All new uses of the data, concurrently or in the future, require a new DAR or a new Amendment, including by the student (and after they graduate), their student supervisor or supervisory committee members, or research co-investigators.

How long will it take for my request to be reviewed and adjudicated?

Once your application package is finalized and considered submitted (all documents and any clarifying questions the DSC has about the submission have been answered by the applicant) the formal DAR application review is initiated. The MOH target days to approve a new data access request for research is 30 [clear days](#). This approval initiates but does not include the time necessary to complete all data provisioning processes. Typical timelines can be viewed on the MOH [Academic Researchers webpage](#).

If PharmaNet data (or access to data from another Health Information Bank) is part of the request, the application must be reviewed and adjudicated by the [Data Stewardship Committee](#) (DSC). The DSC meet monthly to adjudicate applications for data access, except in August and December, when only exceptional meetings may be held as and when necessary.

What supporting documents would I submit with my Student DAR?

To be considered complete for review and approval, your student DAR must include:

- **A plain-language summary of the data access request**, including the project title and names of the research supervisor and student, along with a description of the project objectives,

methodology, how the data requested will fulfill the requirements of the research, the study population/cohort, Health data requested, external data involved, and any intended linkage strategies;

DARs submitted through PopData will have this request summary by default. Other examples of documents you might wish to include are short-form funding proposals, one-page summaries, or abstracts.

- **Evidence of current, up-to-date ethics approval, including <u>both</u> the application which was submitted to gain approval, <u>and</u> the ethics certificate** from a recognized, independent Research Ethics Board;

    If a student project falls under their supervisor's overarching research project, the student would need to be added to the ethics approval for the supervisor's project. Ethics certificates must be in-date.

- **Evidence of independent peer-review**;

    Examples include funding from the CIHR or another public funder who uses peer-review, a peer-reviewed publication evaluating the research proposed, or the Curriculum Vitae of the research supervisor.

- **Evidence of funding support**, including dates of commencement and expiry;

    This could be a funding letter, a scholarship notification, or a letter from an academic department outlining financial support for the project.

- **A completed Declaration of Research Independence** (DoRI) which has been signed by the student and one which has been signed by the supervisor;

    These documents will be supplied to the research team by PopData BC or a MOH reviewer. Depending on the nature of your project and project funding sources, MOH and the DSC may request that other research team members also sign a DoRI. If it was decided that this was required to support your request, this would be clearly communicated to you prior to approval, along with the reasons for this request.

- **Evidence of research supervisor support**;

    Your research supervisor should submit the request for student data access, and will be asked to confirm that they take ethical and legal responsibility for the DARs of their students.

- **A copy of any consent form(s)** which have or will be used in

    the research; PopData BC have consent form guidance

    available on their website.

and

- **Any research proposals** related to the application.

    For example, the proposal from an overarching project that includes the student's research strand would be important and helpful to provide context for the review and approval purposes.

What should I expect from the review process?

When your application appears complete and ready for review, and before it moves to the approvals phase MOH staff do a final check for internal consistency and the application can then proceed to the approvals phase. At this point, MOH and the DSC may request additional information from you if required to assist with adjudication of the request (e.g. proof of student status, updated ethics approvals).

How are review and approval outcomes handled?

The outcome of application reviews for student data access will be communicated promptly to you by MOH, the Secretariat for the Data Stewardship Committee, PopData BC, or (in the case of CIHI or requests through a Health Authority) another party. An application may be:

- Approved as requested;
- Conditionally approved; or
- Rejected.

If your application is approved, it proceeds to the Data Provisioning phase once the Research Agreement or Amendment is signed by MOH and the DSC Chair (if needed). Depending upon the data requested, Data Provisioning is coordinated by PopData BC or MOH in collaboration with other Data Stewards involved in the request.

If your application is rejected, reasons for that decision will be provided to you, and you may choose to re- apply with a new request.

What does a conditional approval of my application mean?

Conditional approvals are granted when most approval criteria are fulfilled but something is outstanding or raises questions for MOH or members of the DSC. Most frequently, they involve requests for clarification or requirements for further supporting documentation such as confirmation of student status or a contract governing funding or research relationships. More rarely, some data fields may be approved only at a certain level to protect privacy (e.g. date of birth to the month and year rather than exact day) or not approved for access. Any conditions which impact the data to be provisioned will be explained in the response from MOH or the DSC and you will be given opportunity to respond, clarify or provide missing information.

What happens if my request is rejected by the MOH and/or DSC?

You are encouraged to consider the feedback from review of your application and submit a new request. However, a new application must not replicate one which was rejected.

Can a Student DAR be changed later on?

Student applications require a signed Agreement with MOH or a formal Amendment to an existing DAR, and may be amended through the same process as other requests (to update a cohort, add new data fields, etc.). The standard conditions applying to other requests for research data access also apply to student applications, with the following exceptions:

- If a student application was submitted as an Amendment to the supervisor's request, student access to the data may be extended beyond the length of the supervisor's request to allow the student time to complete their research.
- A student application may not be converted to a different type of application. If the same data extract is required for research after graduation, a new DAR or Amendment request should be submitted.
- Any change to a student's supervisor requires a formal Amendment.

What if I change institutions or supervisors?

A change in student academic affiliation can be accommodated through an Amendment to the DAR. This Amendment should include an explanation regarding any other changes accompanying an institutional change, including changes to the funding, sponsorship, or supervision of the research. Any change to a student's supervisor requires an Amendment and submission of evidence of support from the new supervisor.

Further Information

I have a different question. Who can I contact?

For general questions about initiating applications for data access or using the PopData Secure Research Environment, please email dataaccess@popdata.bc.ca. For questions about MOH policy requirements, please email HealthDataCentral@gov.bc.ca. For questions about DSC policy requirements or the Committee adjudication process, email data.stewardship.commsupport@gov.bc.ca.