

## BC Transplant Data Access Request Form Instructions: Research Requests

This user guide is for **ALL RESEARCH (aggregate-level & record-level)** data requests. For any non-research data request, please navigate to the appropriate link and user guide in the [BC Transplant website](#).

**Link to form:** <https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX>

<p><b>Step 1</b></p> <p>Navigate to the Record-Level DAR screening form.</p>	<p>Link: <a href="https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX">https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX</a></p>
<p><b>Step 2</b></p> <p>Select ‘I need access to record-level data to conduct my own analysis or reporting’.</p> <p><b>Important Note:</b> Currently, <b>all research requests (aggregate-level and record-level) should be submitted as record-level request</b> through this form. An improved process to separate record-level vs aggregate-level coming soon.</p>	 <p>Welcome to the PHSA data request tool. Use this tool to request data for research or analysis purposes. If you are a member of the media, please do not use this form, but instead refer to our <a href="#">Media Enquiries page</a>. If you are seeking your own <a href="#">personal information</a> or submitting a Freedom of Information request, please do not use this form, but instead refer to our <a href="#">Freedom of Information Requests page</a>.</p> <p>To begin, please choose from the following two options.</p> <p>*</p> <p><input type="radio"/> I need access to aggregate data or an analysis/report to be done for me.</p> <p><input checked="" type="radio"/> I need access to record-level data to conduct my own analysis or reporting.</p> <p><a href="#">reset</a></p>

<p style="text-align: center;"><b>Step 3</b></p> <p>Choose your <b>organizational affiliation</b> and carefully review the information that pops up (<i>note: the screenshot on the right is truncated</i>).</p>	<p>Please choose your organizational affiliation. If you hold multiple affiliations, please choose the one most relevant to this particular request.</p> <p>*</p> <div style="border: 1px solid #ccc; padding: 5px; margin-bottom: 5px; background-color: #f0f8ff;"> <p style="text-align: center;">BC Provincial Health Services Authority (who is included?)</p> </div> <div style="border: 1px solid #ccc; padding: 5px; margin-bottom: 5px;"> <p style="text-align: center;">BC Regional Health Authority or First Nations Health Authority</p> </div> <div style="border: 1px solid #ccc; padding: 5px;"> <p style="text-align: center;">Academic or Other Organization</p> </div> <p style="text-align: right; font-size: small;">reset</p> <p>Please review the following use cases to determine the platform that may best suits your needs. If you are unsure, please contact <a href="mailto:datagovernance@phsa.ca">datagovernance@phsa.ca</a> for assistance.</p> <p><b>I would like to access an existing PANDA datamart...</b> Completion of this form is not required. Please fill out a <a href="#">PANDA User Request Form</a>.</p> <p><b>I would like to perform analyses and create my own reports for:</b></p> <ul style="list-style-type: none"> <li>• operational, program evaluation, quality improvement, health surveillance, or other non-research uses related to PHSA's mandate,</li> <li>• <b>research</b> that requires <b>only PHSA datasets</b> and is driven by PHSA's mandate, or</li> <li>• <b>research</b> that requires <b>PHSA and MoH datasets</b>, is driven by PHSA's mandate and:             <ul style="list-style-type: none"> <li>◦ the primary purpose is to directly inform the operations of a PHSA program or the provision of a treatment or intervention (a.k.a., "applied research" or "learning health system research") rather than to create generalizable knowledge or be academic in nature,</li> <li>◦ the approved REB application clearly reflects PHSA as the research organization and reflects the primary purpose above,</li> <li>◦ PHSA clinical or operational data is necessary,</li> <li>◦ MoH data is limited to data that is already in PANDA for operational purposes, and</li> <li>◦ presentations and publications about the project will reflect PHSA as the research organization.</li> </ul> </li> </ul> <p><b>PHSA's Platform for Analytics and Data (PANDA) may be the recommended platform for your project. However, please note that research activities in PANDA do not yet have dedicated funding, so approved</b></p>
<p style="text-align: center;"><b>Step 4</b></p> <p>After reviewing the data request information from Step 3, choose <b>the platform required</b> for your data request use case.</p> <p><b>Important Note:</b> If you are looking for data from one of BCT's reportable registries (i.e. PROMIS, iTransplant, ODR), then select <b>'Other Platform'</b>.</p> <p>Select <b>'Yes'</b> to the research project question.</p> <p>Click <b>'Submit'</b>.</p>	<p>Please choose the platform required for your use case.</p> <p>*</p> <div style="border: 1px solid #ccc; padding: 5px; margin-bottom: 5px;"> <p style="text-align: center;">PANDA</p> </div> <div style="border: 1px solid #ccc; padding: 5px; margin-bottom: 5px;"> <p style="text-align: center;">HDPBC</p> </div> <div style="border: 1px solid #ccc; padding: 5px; background-color: #2c5e8a; color: white; text-align: center;"> <p style="text-align: center;">Other Platform</p> </div> <p style="text-align: right; font-size: small;">reset</p> <p>Is your request for a research project? If you are unsure, go to the <a href="#">PHSA Project Sorting Tool</a>. It is intended to help differentiate between research and non-research requests.</p> <p>*</p> <div style="display: flex; justify-content: space-around; margin-bottom: 10px;"> <div style="border: 1px solid #ccc; padding: 5px; background-color: #2c5e8a; color: white; text-align: center; width: 150px;"> <p style="text-align: center;">Yes</p> </div> <div style="border: 1px solid #ccc; padding: 5px; width: 150px;"> <p style="text-align: center;">No</p> </div> </div> <p style="text-align: right; font-size: small;">reset</p> <p style="text-align: center; margin-top: 20px;"> <input type="button" value="Submit"/> </p>

<p style="text-align: center;"><b>Step 5</b></p> <p>Review the information guide on how to successfully complete the <b>DAR Form</b> (note: the screenshot on the right is truncated).</p>	 <p><b>PHSA uses the internationally recognized 5 Safes model, a framework developed by the UK's Office of National Statistics, to assess the risk of data requests.</b></p> <p><b>This model has gained international recognition and has been implemented by various organizations, including the BC Health Data Platform and the BC Data Innovation Program.</b></p> <p><b>The evaluation of requests encompasses five key dimensions: People, Project, Data, Setting, and Output.</b></p> <p><b>Navigating the Data Access Request (DAR) application: Helpful guide for a smooth submission</b></p> <p><b>Before you start...</b></p> <ul style="list-style-type: none"> <li>• Make sure you have all of the approvals required by your organization.</li> <li>• Gather all of the information you will need to complete the form, such as:             <ul style="list-style-type: none"> <li>◦ The names, affiliations, and roles of the people who will be involved in the project.</li> <li>◦ The purpose, objectives, and methodology of your project.</li> <li>◦ The type of data you will be using, the source of the data, and how you will be using the data.</li> <li>◦ How the data will be stored and secured, and who will have access to the data.</li> </ul> </li> </ul> <p><b>Completing the form...</b></p> <ul style="list-style-type: none"> <li>• <b>People:</b> provide information about the people who will be involved in the project, including their names, affiliations, and roles.</li> <li>• <b>Project:</b> provide information about the project itself, including its purpose, objectives and methodology.</li> <li>• <b>Data:</b> provide information about the data that will be used in the project, including the type of data, the source of data, and how you will be using the data.</li> </ul>
<p style="text-align: center;"><b>Step 6</b></p> <p>Complete all required fields, ensuring all details are as specific and as accurate as possible to minimize request review and processing time.</p> <p>A valid, in-date <b>REB approval certificate</b> and <b>REB application document</b> is required for all research requests. If you do not have either of these documents at the time of submission, select either <b>'In process'</b> or <b>'No'</b> and provide an explanation in the text box that pops up</p>	<p><b>Has your proposed project been REB approved from a recognized ethics board?</b></p> <p>*</p> <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid #ccc; padding: 5px; background-color: #0070c0; color: white; border-radius: 5px;">Yes</div> <div style="border: 1px solid #ccc; padding: 5px; background-color: #e6e6e6; border-radius: 5px;">In Process</div> </div> <p style="text-align: right; margin-right: 20px;"><a href="#">reset</a></p> <div style="border: 1px solid #ccc; padding: 5px; background-color: #e6e6e6; border-radius: 5px; width: 100%;">No</div> <p><b>Please provide a copy of the Research Ethics Board application</b></p> <p>*</p> <p style="text-align: right;"><a href="#">Upload file</a></p> <hr/> <p><b>Please provide a copy of the Research Ethics Board approval certificate</b></p> <p>*</p> <p style="text-align: right;"><a href="#">Upload file</a></p>

**Step 6 (cont'd)**

Ensure that you select **'Organ Transplant Recipient Registry'** as the dataset that you wish to access.

Failure to do so will result in your request not being properly assigned to BCT.

Complete the rest of the form, ensuring all details are as specific and as accurate as possible to minimize request review and processing time.

Click **'Submit'**.

DATA

The Data Safe is used to determine if we have the authority and ability to disclose the requested data, and that sensitive information (e.g., patient identifiers) is limited and protected. In this section, you will enter information about the data used by the project. Additional data sets can be requested to be added to your project in the future via submission of an amendment request.

Please select the dataset(s) that you wish to access.

\*

- Burn Registry
- Electronic Health Records for Adult Mental Health and Substance Use Patients
- Organ Transplant Recipient Registry
- Perinatal Data Registry
- Trauma Registry

**Step 7**

Complete the **Organ Transplant Recipient Registry Form**, ensuring all details are as specific and as accurate as possible to minimize request review and processing time (*note: the screenshot on the right is truncated*).

Please be aware that you may incur a fee depending on the number of hours required by the BCT team to fulfill your data request. The final cost will be communicated to you by email after reviewing the data request (please refer to the BCT Costing Model attachment).

Click **'Submit'**.



Organ Transplant Recipient Registry

Inclusion Criteria

Please specify the date range of data requested

\*From

Today Y-M-D

\*To

Explain in detail the population, encounter, diagnosis, or other inclusion criteria that describe the subset of records that are needed for your project.

\*

Expand

**Step 8**

Complete the **Attestation Form**, ensuring all details are accurate (*note: the screenshot on the right is truncated*).

Click **'Submit'**.



You are now completing the Attestation Form.

**Attestation**

This section requires formal acknowledgement of responsibilities for data access, compliance and declaration of conflict of interest, if applicable.

As a condition of access to the data requested in this form, my organization and I agree to comply with the [PHSA Data Access and Use Terms](#).

\*

[reset](#)

**Has the Principal Investigator completed the annual PHSA Research Conflict of Interest Declaration?**

*Please Note: The Principal Investigator, and any other person involved in research-related activities, regardless of title or position who is responsible for the design, conduct, or reporting of research must submit an annual PHSA Conflict of Interest Declaration at [coi.phsa.ca](http://coi.phsa.ca) (accessible from health authority or research institute network only).*

*Learn more about the Research Conflict of Interest Policy and Protocol [here](#). If you have any questions about the Research COI Policy, please contact [researchadministration@phsa.ca](mailto:researchadministration@phsa.ca)*

**Thank you for completing the DAR survey.**

Have a nice day!

**Survey Queue** [Get link to my survey queue](#)

Listed below is your survey queue, which lists any other surveys that you have not yet completed. To begin the next survey, click the 'Begin survey' button next to the title.

Status	Survey Title
✔ Completed	Request Type
✔ Completed	DAR Form
✔ Completed	BCT Checklist
✔ Completed	Attestation Form

**Step 9**

You have successfully submitted your research request!

The BCT team will review your request and will be in touch in due course.