# 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: <a href="https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX">https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX</a>

Step 1	Link: https://rc.bcchr.ca/redcap/surveys/?s=MAL8WDFW7K39MJJX
Navigate to the Record- Level DAR screening form.	
Step 2 Select 'I need access to record-level data to conduct my own analysis or reporting'. Important Note: Currently, <i>all</i> research requests (aggregate-level and record-level) should be submitted as record- level request through this form. An improved process to separate record-level vs	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 Media Enquiries page. If you are seeking your own personal information or submitting a Freedom of Information request, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a Freedom of Information request, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a Freedom of Information request, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a Freedom of Information request, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a Freedom of Information request, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a Freedom of Information trequest, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information or submitting a freedom of Information trequest, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information the seeking your own personal information or submitting a freedom of Information trequest, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information trequest your own personal information or submitting a freedom of Information trequest, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information trequest, please do not use this form, but instead refer to our Endedmonthing the seeking your own personal information trequest place your own personal information trequest place your own personal information trequest place your own personal in
aggregate-level coming soon.	To begin, please choose from the following two options.
	I need access to aggregate data or an analysis/report to be done for me.
	I need access to record-level data to conduct my own analysis or reporting.

Step 3	Please choose your organizational affiliation. If you hold multiple affiliations, please choose the one most relevant to this particular request.
Choose your organizational affiliation	BC Provincial Health Services Authority ( <u>who is included</u> ?)
and carefully review the	BC Regional Health Authority or First Nations Health Authority
(note: the screenshot on	Academic or Other Organization
the right is truncated).	reset
	Please review the following use cases to determine the platform that may best suits your needs. If you are unsure, please contact <u>datagovernance@phsa.ca</u> for assistance.
	<b>I would like to access an <u>existing PANDA datamart</u> Completion of this form is not required. Please fill out a <u>PANDA User Request Form</u>.</b>
	I would like to perform analyses and create my own reports for:
	<ul> <li>operational, program evaluation, quality improvement, health surveillance, or other non-research uses related to PHSA's mandate,</li> <li>research that requires only PHSA datasets and is driven by PHSA's mandate, or</li> <li>research that requires PHSA and MOH datasets, is driven by PHSA's mandate and:         <ul> <li>the primary purpose is to directly inform the operations of a PHSA program or the provision of a treatment</li> <li>the primary purpose is to directly inform the operations of a PHSA program or the provision of a treatment</li> </ul> </li> </ul>
	<ul> <li>or intervention (a.k.a., applied research of hearning 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> </ul>
	<ul> <li>presentations and publications about the project will reflect PHSA as the research organization.</li> <li>PHSA's <u>Platform for Analytics and Data (PANDA</u>) may be the recommended platform for your project.</li> <li>However, please note that research activities in PANDA do not yet have dedicated funding, so approved</li> </ul>
Step 4	Please choose the platform required for your use case. *
After reviewing the data	PANDA
request information from	НДРВС
platform required for your	Other Platform
data request use case.	reset
Important Note: If you are looking for data from one of BCT's	Is your request for a research project? If you are unsure, go to the <u>PHSA Project Sorting Tool</u> . It is intended to help differentiate between research and non-research requests.
reportable registries (i.e.	Yes No
PROMIS, iTransplant, ODR),	reset
Platform'.	Submit
Select <b>'Yes'</b> to the research project question.	
Click <b>'Submit'.</b>	



#### 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'.

#### 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'.

#### 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.

**Burn Registry** 

Electronic Health Records for Adult Mental

Health and Substance Use Patients

**Organ Transplant Recipient Registry** 

**Perinatal Data Registry** 

Trauma Registry

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



## Organ Transplant Recipient Registry

Please specify the date range of d	ata requested
*From *To	Today Y-M-D
Explain in detail the population, er	counter, diagnosis, or other inclusion criteria that describe the subse
Explain in detail the population, er records that are needed for your p	ncounter, diagnosis, or other inclusion criteria that describe the subse roject.
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