

RESEARCH INFORMATION SHARING AGREEMENT
Respecting
Provision of Information from British Columbia Transplant

THIS AGREEMENT dated for reference this _____ day of _____ 2019.

BETWEEN:

Provincial Health Services Authority (“PHSA”) on behalf of BC Transplant (“BCT”), a society registered under the Societies Act [SBC 2015] (“BCT”)

AND:

(“The Requestor”)

(referred to together as the “Parties”)

WHEREAS:

- A. BCT is a program of the PHSA, and is the provincial body responsible for providing the fiscal, organizational, clinical, academic and strategic direction for organ donation, solid organ and pancreatic islet transplant programs;
- B. The Requestor is a researcher who wishes to undertake the project outlined in Appendix A and requires personal information in the custody of BCT to carry out the research;
- C. The research application for information described in Appendix A has been considered and approved by BCT in accordance with applicable law; and
- D. The purpose of this agreement is to set out the limitations, terms and conditions under which the Requestor or those acting on the Requestor’s behalf may collect, use and disclose personal information controlled by BCT in connection with such research.

NOW THEREFORE in consideration of, the mutual covenants and agreements herein, the Parties agree as follows:

1.00 DEFINITIONS

- 1.01** In this Agreement, unless the context otherwise requires, the following definitions will apply:
- (a) “Act” means British Columbia’s *Freedom of Information and Protection of Privacy Act*, and regulations thereto, as the same may be amended from time to time;
 - (b) “Authorized Personnel” means any individual, including a student collaborator, funder or consultant, working for or with The Requestor to provide services related to the project described in Appendix A;
 - (c) “Authorized Site” means the Population Data BC (“PDBC”) secure data site, the location where the personal information is stored and accessed by the Requestor and its Authorized Personnel;
 - (d) “Personal Information” has the meaning set out in the Act;
 - (e) “Term” means the period set out in section 2.01;
 - (f) “Applicable Laws” means all statutes, ordinances, regulations, judgments and orders applicable to any person, property or event relating to this agreement, and, whether or not having the force of law, all official directives, rules, consents, approvals, standards, procedures or guidelines of any governmental authority having or purporting to have authority over a party to this agreement;
 - (g) “Loss” means costs, losses, damages, liabilities and expenses (including all reasonable legal costs, fees and disbursements).
 - (h) “Research Project” means the project described in Schedule A hereto; and
 - (i) “Requested Data” means the data fields specified in Schedule B hereto.

2.00 TERM

- 2.01** The term of this Agreement shall commence on the signing of the Agreement by both Parties and will continue until _____ or such other date as mutually agreed to by the Parties, unless otherwise terminated pursuant to sections 12.00 or 14.00 of this Agreement.

3.00 OBLIGATION OF BCT

- 3.01** The obligation of BCT to disclose Personal Information to The Requestor is subject to BCT being satisfied that:
- (a) disclosure of the Personal Information to the Requestor is authorized under the relevant legislation, including but not limited to the Act.
 - (b) the standards of the Requestor for the security and privacy protection of the Personal Information while in its possession and control are equivalent to, or greater than, those security standards established by BCT in section 9.00 of this agreement; and
 - (c) A detailed list of the data requested from BCT (see Annex A) and the purpose for which the Requestor requires Personal Information is as set out in Appendix A to this Agreement.

4.00 INFORMATION ACCURACY, LIABILITY AND INDEMNIFICATION

- 4.01** BCT provides the Requestor with no warranties as to the accuracy of any Personal Information provided under this Agreement, and BCT is not liable for any inaccuracies in Personal Information provided under this Agreement.
- 4.02** The Requestor agrees that it will not make any changes to the Personal Information provided pursuant to this Agreement. The Requestor will immediately notify BCT of any perceived inaccuracies in the Personal Information.
- 4.03** The Requestor will indemnify and hold harmless BCT harmless from all losses, expenses, costs (including legal costs) and damages resulting directly or indirectly from the actions of the Requestor or its Authorized Personnel in the collection, use or disclosure of the Personal Information provided under this Agreement. This indemnity shall survive the termination of this Agreement.
- 4.04** Without restricting the generality of the foregoing, the Requestor will indemnify and hold harmless BCT from all losses, expenses, costs (including legal costs) and damages resulting directly or indirectly from the actions of any party who obtains access to the Personal Information either on or off the Authorized Site as a result of the negligence of the Requestor or Authorized Personnel, or the failure of the Requestor or its Authorized Personnel to comply with any term of this Agreement. This indemnity shall survive the termination of this Agreement.

5.00 PURPOSE AND USE OF THE PERSONAL INFORMATION BY THE REQUESTOR

- 5.01** The Requestor acknowledges that the Personal Information is at all times the property of BCT for the purposes of the Act.
- 5.02** The Personal Information provided to the Requestor by BCT under this Agreement will be collected, retained, used and disclosed by the Requestor in a manner consistent with this Agreement, the provisions of the Act, any other relevant legislation, and any orders of the court. Where this Agreement imposes obligations in addition to those obligations imposed by the Act, or any other legislation, this Agreement will govern.
- 5.03** The description of the project for which the Requestor requires the Personal Information, and the intended use of the Personal Information, is as set out in Appendix A.
- 5.04** Unless the Requestor has obtained the prior written consent of BCT, access to and use of the Personal Information by the Requestor is strictly limited to that access and those uses set out in Appendix A.
- 5.05** No Personal Information linkage will occur other than as set out in Appendix A.
- 5.06** Except as expressly permitted in this Agreement, the Requestor shall not sell, distribute or copy the Personal Information, retransmit or combine the Personal Information with or into another database, or provide access to the Personal Information to any person by any means without the prior written consent of BCT.
- 5.07** The Requestor may not use the Personal Information for the purpose of contacting an individual for any reason, including to seek the participation of the individual in research.
- 5.08** Notwithstanding section 5.07, if the Requestor wishes to use the Personal Information for the purpose of contacting an individual for any reason, and BCT is prepared to consent to such a contact being made, the BCT and the Requestor will jointly make any necessary submission to the Office of the Information and Privacy Commissioner to seek approval for such contact to be made.
- 5.09** The Requestor agrees and understands that all access and storage of Personal Information will occur at the Authorized Site identified in this Agreement. The Requestor understands and agrees that no Personal Information may be accessed, stored, transmitted, or otherwise made available outside of Canada and no person outside of Canada shall have access in any manner except as expressly approved by BCT in writing. In accordance with this Agreement, the Requestor must notify the BCT in writing prior to changing the Authorized Site.

6.00 REMOVAL OF INDIVIDUAL IDENTIFIERS

- 6.01** The Requestor agrees to remove individual identifiers associated with the research information at the earliest time they can be removed without rendering the research purpose impossible.
- 6.02** The Requestor agrees to remove individual identifiers in a way that ensures remaining research information (including any found in research notes) cannot be used to identify the individuals to whom the research information relates.
- 6.03** The Requestor will remove all individual identifiers so as to preclude reconstruction or retrieval of personal information by others using the research information from which the identifiers have been removed.

7.00 TRANSMISSION OF PERSONAL INFORMATION

- 7.01** BCT will transmit the Personal Information to The Requestor or its Authorized Personnel in the manner, format and frequency specified in Appendix B. BCT in its sole discretion may change the manner, format or frequency of transmittal of the Personal Information upon written notice to The Requestor.
- 7.02** If transmission of the Personal Information is delayed or the Personal Information is unavailable for any reason, BCT will use all reasonable efforts to remedy the delay as quickly as possible. However, BCT shall not be liable to the Requestor, or any other person, for any delay or failure to transmit the Personal Information regardless of cause.

8.00 ACCESS TO PERSONAL INFORMATION BY THE REQUESTOR

- 8.01** All Personal Information will be kept by The Requestor or its Authorized Personnel in electronic form on a secure server which will be password protected. All paper charts must be secured in a locked cabinet.
- 8.02** Prior to obtaining a password or access to the secure server, Authorized Personnel will be required to sign a confidentiality undertaking in the form set out in Appendix C to this agreement (“Pledge of Confidentiality”). The Requestor will maintain and provide BCT with a copy of each such confidentiality undertaking upon request.
- 8.03** The Requestor may not provide Personal Information to any person except those Authorized Personnel who require the Personal Information in order to work on the project for which the Personal Information was obtained. Before any Personal Information is disclosed to such Authorized Personnel, the individual will be required to sign a confidentiality undertaking in the form set out in Appendix F to this agreement (“Pledge of Confidentiality”) or in another form acceptable to BCT. The Requestor will maintain and provide BCT with a copy of each such confidentiality undertaking upon request.

9.00 SECURITY AND PRIVACY PROTECTION

- 9.01** The Requestor will maintain the security and confidentiality of the Personal Information in its possession and control by making reasonable security arrangements and standards suitable to BCT against such risks as unauthorized access, collection, use, modification of use, disclosure or disposal.
- 9.02** Without limiting the generality of the foregoing, the following arrangements will be made by The Requestor to ensure the security of the Personal Information:
- (a) neither the Personal Information nor any notes taken from the Personal Information are to be removed from the Authorized Site without the written consent of BCT;
 - (b) the offices or rooms in which the Personal Information or notes taken from the Personal Information are kept must be securely locked, except when one or more Authorized Personnel identified as having authorized access to the Personal Information are present;
 - (c) all Personal Information and notes taken from the Personal Information must be stored in locked filing cabinets;
 - (d) all intermediate paper or electronic files made from the Personal Information are to be shredded or rendered unusable when the use for which they are required has ended;
 - (e) all Authorized Personnel who have been granted access to the Personal Information will maintain the Personal Information on a secure server or mainframe computer, with access to that computer being limited and protected by password;
 - (f) if any Authorized Personnel are required to maintain Personal Information on a personal computer or electronic storage device (i.e. PDA, memory stick, computer disk, CD/DVD, etc.), The Requestor will implement additional measures to be specified by BCT in order to maintain the security of the Personal Information held on the personal computer or electronic storage device. Unless otherwise agreed to in writing by the Parties, Authorized Personnel are prohibited from removing a personal computer or electronic storage device which contains Personal Information from the Authorized Site without written authorization from BCT;
 - (g) The Personal Information may not be transmitted by modem or by any other electronic device including, but not limited to, email and Internet.
 - (h) The Personal Information will not be transmitted by facsimile.

- 9.03** The Requestor will maintain appropriate records regarding access approvals it grants to Users (regarding access to the secure server) or Authorized Personnel (regarding access to Personal Information).
- 9.04** The Requestor will identify to BCT the individuals at the Authorized Site who are responsible for managing the obligations of the Requestor under this Agreement, including the individual responsible for approving access for each User and Authorized Personnel, and maintaining appropriate records of those approvals.
- 9.05** The Requestor must limit each individual Authorized Personnel's access to Personal Information to that necessary for work on the project for which the Personal Information was obtained.
- 9.06** The Requestor must protect the confidentiality of all passwords, encryption keys and user accounts assigned by the Requestor in accordance with applicable terms and conditions.

10.00 PUBLICATION AND DISTRIBUTION OF PERSONAL INFORMATION

- 10.01** Neither the Requestor nor its Authorized Personnel who have obtained Personal Information may disclose Personal Information or other information that in any way could be used to identify the individuals to whom it relates, in a form which may identify those individuals. All donor and transplant related information that is published and presented will fall within the BCT mission, vision and value statements, display the current BCT corporate logo and must be approved by the Provincial Executive Director of the BCT or his designate prior to circulation and communication.
- 10.02** The Requestor will provide BCT with copies of any written materials which result from an analysis or use of the Personal Information and which are intended to be published or distributed. BCT will be provided with the opportunity to comment on any use of the Personal Information in the written materials, and particularly to determine whether any individuals may be identified directly or indirectly through the use of the Personal Information prior to publication or submission. BCT will be deemed to have approved the proposed publication or distribution unless the Requestor is notified to the contrary within 45 days of the receipt of the materials by BCT.
- 10.03** The Personal Information may not be used for any purpose other than the purposes described in Appendix A to this Agreement unless BCT has provided written authority to do so.

11.00 DESTRUCTION OF PERSONAL INFORMATION

11.01 The Requestor will destroy or return to BCT the Personal Information, and any copies of it, on:

- (a) the completion of the project for which the Personal Information was obtained as set out in Appendix A to this Agreement;
- (b) the expiration of the Term of this Agreement;
- (c) the earlier termination of this Agreement pursuant to section 12.04 or section 14.00; or
- (d) the demand of BCT;

whichever first occurs. The Personal Information contained in any of the Requestor's back-up tapes, discs, drives, or any other storage medium must also be destroyed

11.02 When the Personal Information or copies of it are destroyed by The Requestor, formal proof of the destruction must be provided to BCT upon request.

12.00 UNAUTHORIZED ACCESS, USE OR DISCLOSURE

12.01 Unauthorized access to, use, disclosure or modification of Personal Information, or modification of the permitted use of the Personal Information, is a fundamental breach of this Agreement and may result in termination of access at the sole option of BCT.

12.02 The Requestor will investigate all cases where it is alleged, suspected, or there is evidence that there may be unauthorized access to, use, disclosure or modification of Personal Information, or modification of the permitted use of the Personal Information.

12.03 If unauthorized access to, use, disclosure or modification of Personal Information, or modification of the permitted use of Personal Information is found, The Requestor will immediately advise BCT and will provide a detailed report of the circumstances and any remedial actions taken and will assist BCT with any investigations.

12.04 Upon notification by The Requestor of an instance of unauthorized access to, use, disclosure, or modification of Personal Information, or modification of the permitted use of the Personal Information, BCT may do any of the following:

- (a) review the steps the Requestor proposes to take to address, or prevent recurrence of the incident;

- (b) direct that the Requestor take steps specified by BCT to prevent a recurrence of such an incident in the future;
- (c) suspend the authority of the Requestor under this Agreement to deal with the Personal Information, including suspending the authority of The Requestor to collect, use or disclose that Personal Information, until BCT is satisfied that the Requestor has complied with the Agreement and any directions of BCT issued under paragraph (b).
- (d) Terminate the Agreement in accordance with Article 14.02.

12.05 Any harm suffered by BCT in the event of a breach or a threatened breach of this Agreement will not be compensable by monetary damages alone. In addition to other available legal or equitable remedies, BCT will be entitled to obtain an injunction against such breach or threatened breach.

13.00 AUDITING

13.01 NA

13.02 The Requestor will perform monthly security audits and report monthly on the results of those audits to BCT.

14.00 DEFAULT AND TERMINATION

14.01 Either Party may terminate this Agreement by providing written notice to the other Party sixty (60) days prior to the date on which the notifying party intends the Agreement to terminate.

14.02 In the event of breach by the Requestor of any terms, covenant or conditions in this Agreement, BCT may terminate the Agreement at any time in its sole discretion without notice to The Requestor, and BCT may also pursue other remedies at law or equity.

15.00 DISPUTE RESOLUTION CLAUSE

15.01 Any new issue, matter of general concern or dispute arising from this Agreement will be first directed to the designated representatives listed below for resolution, and if not then resolved within thirty (30) days it will be a matter of consultation and resolution between BCT and The Requestor in such manner as they see fit. The designated representatives are:

For BCT:

Provincial Operations Director: Ed Ferre

For The Requestor:

Name: _____

Telephone: _____

16.00 NOTICES

16.01 Any notice, document, statement, report or demand that either party may desire or be required to give or deliver under this Agreement will be in writing and may be given or delivered by personal delivery or by mailing in British Columbia with postage prepaid to the party to whom it is to be given, delivered or addressed:

If to BCT:

Manager, Communications
Telephone: 604-877-2184

If to the Requestor:

Name: _____

Telephone: _____

Any such notice, document, statement, report or demand so mailed will be deemed given to and received by the addressee on the third business day after the mailing of the same except in the event of disruption of postal services in British Columbia in which case any such notice, document, statement, report or demand will be deemed given to and received by the addressee when actually delivered to the particular address set out above.

16.02 Any notice, report, direction or document transmitted by facsimile transmission from either party will be conclusively deemed validly given to and received by the intended recipient when so transmitted to the facsimile numbers the Parties so advise.

17.00 LEGAL RELATIONSHIP

17.01 No partnership, joint venture or agency will be created or will be deemed to be created by this Agreement or any action of the Parties under this Agreement.

18.00 GENERAL

18.01 The headings in this Agreement are inserted for convenience only and do not form part of this Agreement.

18.02 BCT may assign its rights under this Agreement at its sole discretion.

18.03 This Agreement constitutes the entire agreement between the Parties with respect to the subject matter of this Agreement.

18.04 Any amendment to the terms and conditions of this Agreement must be agreed to by the Parties, in writing and duly executed by both Parties. If any provision of this Agreement is found to be invalid, illegal, void or unenforceable, it will be severable from this Agreement and all other remaining provisions or remaining part of such provisions, as the case may be, continue to have full force and effect, and will be valid, legal and enforceable.

18.05 All provisions of this Agreement for BCT and all rights and remedies of BCT either at law or in equity will survive the expiration or sooner termination of this Agreement.

18.06 The Appendices attached to this Agreement are an integral part of this Agreement as if set out at length in the body of this Agreement.

18.07 This Agreement may be executed by the Parties in separate counterparts, each of which when so executed and delivered shall be an original, and all such counterparts may be delivered by facsimile transmission and such transmission shall be considered an original.

18.08 This Agreement will be governed by and construed and interpreted in accordance with the laws of British Columbia.

IN WITNESS WHEREOF the Parties have executed this Agreement on the date first above written; the _____ of _____, _____.
(day) (month) (year)

SIGNED by the Provincial Health Services Authority on behalf of BC Transplant in the presence of:

_____)
_____)
_____) _____
(Witness)) Data Steward, BCT

SIGNED on behalf of The Requestor)
by a duly authorized representative)
in the presence of:)

_____)
_____) _____
(Witness)) Principal Researcher

APPENDIX A

Intended purpose and use of Personal Information

Study Summary: *(Objectives)*

Documents & Approvals:

Attach a copy of:

- Research Protocol
- Entire ethics research application
- Sample patient consent form
- Ethics certificate
- Other, please specify:

Principal Investigator:

Attach a Curriculum Vitae *(not required for PHSA staff: as defined by individuals who are on PHSA payroll and have signed a confidentiality agreement)* for the principal investigator involved in the project who will have responsibility for access to, security, and use of the Personal Information.

Significance, Methodology, Rationale:

- Provide a general description of the research project *(include research methodology: e.g. all information sources, record linkage and statistical methodology)*.

- Describe the benefits to result from the research project:

- Explain why the research project cannot reasonably be accomplished without access to Personal Information:

- Explain how the Personal Information will be used.

- Provide a timeline for PROMIS information retrieval (eg. One time, monthly, information updates, etc.) and any accrual total targets:

- Personal information selection criteria (Ex: date range required):

Please attach Annex A to define the data fields required

- Access to BCT Charts required for research (refer to “Appendix C-Request for BCT)

Yes No

- Output format required:

Excel PDF

- Explain how the project supports the operational mandate of the BCT.

- Please state your request's legal authority to possess information from BCT.

- The Researcher **will** only give access to Personal Information to the following persons:

- Please identify the location and address of the Authorized Site:

APPENDIX B

Transmission of Personal Information

**APPENDIX C
Pledge of Confidentiality**

Complete, save and print a copy of the “Pledge of Confidentiality” form for each individual listed in Appendix A to this agreement.

*I, _____ **solemnly declare that I will not disclose** any Personal Information released to The Requestor as governed by the FOIPPA and by the BCT except as expressly authorized in writing by a representative of BCT.*

I acknowledge that I have read and will abide by the terms and conditions included in this Agreement between The Requestor and the BCT dated ___ of _____, 20__ for the use and security of the Personal Information.

I make this declaration knowing it is of the same legal force and effect as if made under oath.

Primary Requestor

<p>Name:</p> <p>Position:</p> <p>Department:</p> <p>Facility/Organization/Affiliation:</p> <p>Date Signed:</p> <p>Signature: _____</p>
--

Authorized Personnel

<p>Name:</p> <p>Position:</p> <p>Department:</p> <p>Facility/Organization/Affiliation:</p> <p>Date Signed:</p> <p>Signature: _____</p>
--

Witness

<p>Name:</p> <p>Position:</p> <p>Department:</p> <p>Facility/Organization/Affiliation:</p> <p>Date Signed:</p> <p>Signature: _____</p>
--