## BCCA Logo

## BCCA Data Access Request (DAR)

Revised: 24 May 2016

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| **SECTION I: APPLICANT INFORMATION** |
| **PRINCIPAL INVESTIGATOR / APPLICANT** |
| **LAST NAME**      | **FIRST NAME**      | **POSITION**      |
| **DEPARTMENT**      |
| **EMPLOYER ORGANIZATION**      |
| **IF EMPLOYER ORGANIZATION IS NOT BCCA, SPECIFY FACILITY/ORGANIZATION AFFILIATION WITH BCCA, IF ANY**      |
| **PHONE**      | **EXT.**      | **EMAIL**      |
| If this project has a different PI/Applicant from the one that appears on ethics review or data linkage documentation, indicate the reason for the discrepancy.       |
| **Because the Principal Investigator/Applicant is not a BC Cancer Agency (BCCA) staff member, a BCCA staff member needs to be identified as co-investigator.***This BCCA co-investigator fulfils the requirement for the chain of accountability; first to ensure that the data is being used and interpreted appropriately and secondly to ensure that confidentiality provisions are followed. Please note that the BCCA staff member will be required under the terms of the ISA to oversee that the PI complies with the obligations set out in this document.*IF YOU NEED ASSISTANCE WITH ACQUIRING A BCCA CO-INVESTIGATOR Email: datareq@bccancer.bc.ca |
| **BCCA CO-INVESTIGATOR** |
| **LAST NAME**      | **FIRST NAME**      | **POSITION**      |
| **DEPARTMENT**      | **EMAIL**      | **PHONE**      |
| **PRIMARY CONTACT** (if different than the Principal Investigator) |
| **LAST NAME**      | **FIRST NAME**      | **POSITION**      |
| **DEPARTMENT**      |
| **EMPLOYER ORGANIZATION**      |
| **PHONE**      | **EXT.**      | **EMAIL**      |

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| **PERSONS WHO WILL HAVE ACCESS TO THE REQUESTED DATA** |
| Please list anyone (excluding the Applicant) on the team that will access the project data. A signed ‘BCCA DAR Confidentiality Undertaking’will be required for each identified individual before any data are released. If changes to study personnel occur after data are released, the Applicant is expected to submit additional undertakings for additional team members at that time.  |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **FIRST NAME LAST NAME**      | **INSTITUTION**      | **POSITION**      |
| **SECTION II: PROJECT DESCRIPTION** |
| 1. PROJECT TITLE

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| 1. TITLE DIFFERENCE

If this project has a different title from the one that appears on ethics review or data linkage approval documentation, indicate the reason for the discrepancy.      |
| 1. PUBLIC INTEREST VALUE/PUBLIC BENEFITS OF PROJECT

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| 1. PROJECT OBJECTIVES: RESEARCH QUESTIONS AND HYPOTHESES

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| 1. PROJECT DESCRIPTION

Provide a general description of the project to be undertaken (*include background, research and statistical methodology, all sources of data, details of any record linkages)*      |
| 1. STUDY POPULATION AND INCLUSION/EXCLUSION CRITERIA

Provide a description of the study population and inclusion/exclusion criteria needed to select the subjects/data. Describe the criteria that should be applied to select your subjects/data within all of the requested data sources. (A sample study population is provided below)      *NOTE: Applicants are advised that any changes to the study population after approval may require an amendment and further review and approval by the Data Steward(s).****EXAMPLE*** *of DAR study population description**All invasive cervical cancer cases (ICDO-3 code C53) diagnosed 1999-2000, age at diagnosis 30-60; BC residents at diagnosis. We would also like the date of the most recent pap smear from the cervical cancer screening database prior to diagnosis (if one exists) where the smear site = cervix*. |
| 1. USE OF ‘PERSONAL INFORMATION’

In accordance with privacy law only the minimal amount of ‘Personal Information’ necessary for the project can be disclosed by the BCCA. In this section explain in detail why the project cannot be accomplished without access to this information in individually or potentially identifiable format:      Research rationales describing why each identifying field is required must be supplied before they will be considered for release. Note these fields are all identified on the BCCA DAR Field Extraction List **with an ‘\*’:**Rationales as to why other information has been requested must be provided in the appropriate spaces on the BCCA DAR Field Extraction List form.  |
| 1. REQUEST TO CONTACT INDIVIDUALS/PHYSICIANS [ ]  Yes [ ]  No

The Applicant should not contact any individual to whom ‘Personal Information’ relates, either directly or indirectly, unless they have been authorized to do so. Contacting individuals using information from BCCA data repositories may require permission of the *Office of the Information and Privacy Commissioner of BC*. The Applicant should be aware that, if authorized, contacting individuals or their physicians using information from the BC Cancer Agency is only permitted under a strict contact protocol. Applicants should contact datareq@bccancer.bc.ca for direction on studies that aim to contact individuals or physicians.If individuals or their physicians will be contacted, provide an explanation of the purpose for the planned contact and the proposed method that will be used. Please also include any proposed materials to be sent along to the individual or physician with your application.      |
| 1. DATA RETRIEVAL INTERVAL

Describe data retrieval interval *(e.g. one time, weekly, monthly, data updates, need accrue to max. # of patients/cases etc.).*      |
| 1. DATA FIELDS

Submit BCCA DAR Field Extraction Checklist for list of data fields required |
| 1. OUTPUT FORMAT

Indicate the desired data file output format *(e.g. Access, Excel, tab/comma-separated value/fixed width file etc.)*      |
| 1. PROJECT OUTPUT

What is the intended output from your project? (e.g. peer-reviewed publication, technical report, conference presentation)?       |
| 1. PROJECT TIMELINE

Specify any deadlines you have with respect to the receipt of your data?      |

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| **SECTION III: DATA LINKAGES** |
| If your project includes linking to data sources other than those noted on the BCCA DAR Field Extraction Checklist, complete and attach the BCCA DAR Data Linkages form. |
| **SECTION IV: FUNDING** |
| Do you have data retrieval and preparation funding available? [ ]  Yes [ ]  NoIf yes, who is funding your research project (Identify ALL funding, commissioning and contracting sources, including those requested but not yet confirmed plus Expiry Dates)      [ ]  My project has received no funding (please explain why):       |
| **SECTION V: DATA SECURITY AND TERMS OF USE** |
| 1. PHYSICAL LOCATION AND SECURITY OF DATA

All project records containing ‘Personal Information’ must be contained in a physically secure location. No records can be left visible and unattended.1. At what address will the records containing ‘Personal Information’ and any notes be stored:

     1. Indicate any physical security features in place at the above location to secure the ‘Personal Information’ against unauthorized access?

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| [ ]  Locked filing cabinet for paper records | [ ]  Building has security which patrols all areas# hours security patrol per day:       |
| [ ]  Paper records to be secured in a locked office | [ ]  Shredding bins available in work area for paper records |
| [ ]  Work area requires key/swipe card access | [ ]  Other: Please Specify:       |

*NOTE: All physical locations housing data must be locked, except when an individual authorized to access the data is present.* |
| 1. ORGANIZATIONAL SAFEGUARDS

The Applicant will provide organizational safeguards that will support the security and confidentiality of ‘Personal Information’ in this project.

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| [ ]  I am governed by the Tri-Council Guidelines for *Ethical Conduct for Research Involving Humans* | [ ]  I am bound by a code of conduct from a professional society (e.g. CMA code of ethics)       |
| [ ]  I have completed my employer organization’s privacy training | [ ]  My project is carried out under the oversight of an accredited Research Ethics Board |
| [ ]  Other: Please Specify:       |
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| 1. Technical Safeguards for Electronic Records

The Applicant understands and agrees that anyone allowed access to the data shall not remove or have remote access to any ‘Personal Information’ from any location outside of Canada. Please provide information on the technical safeguards that are in place to protect the electronic records:**a) For data storage within BCCA/PHSA environment please indicate:** i) network location: [ ]  BCCA/PHSA secure network[ ]  BC Cancer Research Centre secure networkii) folder protections:[ ]  Data will be stored in a network folder with access restricted to project team members. Do you need us to setup a network folder for your project in our secure file location? [ ]  Yes [ ]  No***If both i) and ii) have been checked above, please skip to #4 below.*** **b) For data stored outside of the BCCA/PHSA environment:**Please indicate any technical safeguards in place to protect the records:

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| [ ]  Data to be stored on a secure computer network | [ ]  Password changed every       days |
| [ ]  Firewall | [ ]  Data to be stored in a network folder with access restricted to project team members |
| [ ]  Password rules (minimum length, complexity) | [ ]  Access tracking of data storage location |
| [ ]  Screen locks requiring password for re-entry | [ ]  Monitors are not visible to non-project members |
| [ ]  Antivirus software on PC’s accessing data: Please Specify:       | [ ]  Other: Please Specify:       |

If data are to be stored on a personal computer, laptop or portable storage device, please justify why this is the case and why the data cannot be stored on an institutional computer network (note that this type of request would rarely be approved in the absence of a significant research rationale as to why this type of storage is required) :      Attach any relevant documentation that describes the secure environment if data are to be stored outside of the PHSA/BCCA environment. |
| 1. REMOVAL AND DESTRUCTION OF PERSONAL IDENTIFIERS

In accordance in FIPPA legislation, the Applicant **will** remove and destroy any individual identifiers in the information at the earliest reasonable time at which it can be accomplished consistent with the research purpose described in this application. Please describe how the data set will be de-identified (e.g. identifiers replaced with random study ID’s, dates replaced with time intervals, etc) and when the identifiers will be removed.       |

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| **Section VI:** **REQUIRED DOCUMENTATION CHECKLIST** |
| Ethics review may be pending, but all other documents must be included. Final ethics approval certificates must be provided before data will be released. Electronic copies of all documents must be provided.PLEASE SUBMIT A COPY OF ALL **APPLICABLE** DOCUMENTS NOTED BELOW |
| **Research Ethics Board (REB) Approval:** Please attach the following documentation and approvals: * Copy of REB approval certificate
* Copy of REB application
* The application and protocol submitted for review by the REB.
* Copies of ALL supporting documentation reviewed by the REB. For example, on UBC’s certificates, these are noted under “List of Documents Approved”.
* Copies of informed consent forms and any other documents provided to participants, as noted on REB approval certificate/application.
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| * Research Grant Competition
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| * Privacy Commissioner’s Approval - if approval has been obtained to use the requested identifiable information for study recruitment purposes.
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| * Funding Agreement
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| * BCCA DAR Field Extraction Checklist
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| * BCCA DAR Data Linkages
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| * Authorization to link external data to BCCA data holdings (e.g. agreement with or email/letter of support from Data Steward of external data source and any relevant documentation).
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| **All the above documents will become part of the DAR application** **and will be reviewed by the applicable Data Steward(s)****IF THE PROJECT HAS NOT BEEN APPROVED OR SUBMITTED FOR REVIEW BY AN ACCEPTABLE RESEARCH ETHICS BOARD, the Data Steward(s) may refuse to consider the application.** |
| **ONCE APPLICATION IS COMPLETE** |
| * save document
* submit the application form/attachments **electronically** to datareq@bccancer.bc.ca.
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| **WHY A DAR?** A DAR must be completed for all research projects and secondary-use requests for access to BCCA data. This is to ensure compliance with provincial privacy legislation around use and disclosure of ‘Personal Information’. The following types of data may be considered as ’‘Personal Information’’: 1. *Small Cell Aggregate:* aggregate data with small cell counts (e.g. cells < 5) may be treated as requests for identifying information.
2. *Potentially Identifiable:* Data elements which include information (ie. Medical history, diagnosis date, birth date, death date, postal code) that a person can use in combination with other information, to re-identify an individual; this includes line listed data that has been stripped of overt identifiers such as name, address, etc.
3. *Identifiable:* Data elements include names, addresses, personal health number or other similar identifying numbers.
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| **NOTICE TO APPLICANTS**1) Prior to completing this form, please review the *Requests for Access to Identifiable or Potentially Identifiable Data Extracts for Research and Other Secondary Uses* *Policy* designed to address privacy compliance for data applications and provide request evaluation criteria. Please note that the more information you provide upfront through this form, the faster we are able to process your request for review.2) Collection of the information which the applicant provides on this form is authorized by Section 26(c) of the *'Freedom of Information and Privacy Protection Act'*. It is required for the operations of a program of the BC Cancer Agency. Any questions about the ‘Personal Information’ required on this form may be directed to:Cindy Brice, PHSA Corporate Director Information Access & PrivacyPhone: 604-707-5834 ⦁ Email: cbrice@phsa.ca3) The BC Cancer Agency may publish a list of approved research projects and researchers that utilize BC Cancer Agency data.4) Should this application for data access be approved, the Applicant will be required to sign an Information Sharing Agreement (ISA) which sets out specific terms and conditions of use for any data provided as a result of this application. The ISA requires the signature of an authorized representative from the applicant’s institution. The Applicant should review a template ISA prior to submitting this application and verify that they:a) are in agreement with the provisions set out in the document b) are able to abide by the terms set out inthe document including the PHSA policies identified in the Schedules of the ISAc) can identify an individual who is able to sign on behalf of their institution and submit their name and contact information to the BC Cancer Agency to be included in the ISA. |