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| Assigned Project #:       |

## BC_Cancer_Agency2colCMYK

**BCCA Data Access Request (DAR)**

**Data Linkages**

Revised: 15 April 2016

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| **Project Information** |

**Applicant:**

**Project Title:**

Identify all data sources that you propose to link to data from the BC Cancer Agency Data (BCCA). Please note that unless a suitable rationale is provided below, it is expected that any data linkages will occur at the BCCA.

**\*External Data Holdings refers to data not under the Stewardship of the BCCA**.

NOTE: Applicants must submit any consent forms, application forms and approvals related to External Data proposed to be linked to BCCA data.

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| 1. DATA SOURCE
2. Name(s) and brief description(s) of \*External or Researcher collected dataset(s) you are providing for linkage. Please ensure you describe the types of variables and patient identifiers captured in the dataset(s):

     1. Data Custodian/Steward name(s):
2. Number of records in the dataset:
3. Data format:       *(fixed width or excel spreadsheet is preferred)*

NOTE: Attach any applications and approval(s) for the proposed linkage of the External dataset(s) to BCCA data.  |
| 1. LINKAGE APPROACH
2. Please indicate the proposed manner that the External data will be linked to BCCA data:

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| [ ]  *Probabilistic* – a probabilistic linkage requires the use of specialized software to assign a likelihood a patient is a match between two datasets. This is generally done when there is no single common field to use to link the file (e.g. personal health number) and several variables such as name, date of birth and address must be used. Please note that a charge may be required for probabilistic linkages [ ]  *Direct* – linkage on one or more common fields contained in the dataset(s) (e.g. PHN) |

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| 1. Please indicate the patient identifiers that you propose using for dataset linkage:

 [ ]  Personal Health Number [ ]  Postal Code

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| --- | --- |
| [ ]  Name | [ ]  Full Address |
| [ ]  Full Birth Date | [ ]  Sex |
| [ ]  Full Death Date | [ ]  Other *(eg. Chart or patient id)*       |

It is understood that some personal identifiers requested within the DAR have been requested for data linkage purposes. If any personal identifiers are required for analysis purposes in addition to the data linkage, the Applicant must ensure this is detailed in Section 7 of the DAR form. Failure to provide a suitable research rationale as to why personal identifiers are required beyond data linkage will result in denial of the request to retain the patient identifiers. If any of the following potentially identifying data fields are being provided to the Applicant from another data provider and will be retained in the final dataset(s) after linkage, please provide a research rationale as to why these potentially identifying fields are required beyond data linkage: 1. If you have not detailed the proposed linkage strategy for the datasets within the DAR form, it must be clearly specified here. For example indicate which dataset will contain the basic cohort of participants to be linked to the other dataset(s), who will transfer the files between organizations, the manner in which dataset(s) will be sent (e.g. encrypted files sent by courier) and how the final files will be assembled and sent to the research team:

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| 1. REQUEST FOR LINKAGE TO OCCUR IN LOCATION OTHER THAN THE BC CANCER AGENCY

[ ]  Yes [ ]  NoIf yes, please provide a rationale as to why the linkage must take place outside of the BCCA and describe any steps that will be taken to minimize the privacy risks of the proposed linkage at all stages. In particular, ensure you include the timeline for proposed removal and destruction of data used only for linkage: |
| 1. INFORMED CONSENT FOR EXTERNAL DATA

Has written informed consent from the individuals to whom the data apply been obtained to use and link the External data for the specified research purpose(s)? [ ]  Yes [ ]  No**ATTACHMENT**If yes, attach a blank copy of the Informed Consent form and any attachments provided to participants, as approved by the Research Ethics Board.If no, explain why not. If other methods have been used to obtain consent or if a waiver of consent by a Research Ethics Boards have been obtained, please describe:       |

Please send completed form along with DAR to: datareq@bccancer.bc.ca