

Policy Title:	Requests for Access to Breast Screening Data for Research Purposes	
Section:	Access to Information	Reference No. SI 040
Effective:	January 2003	Revision: February 2018

## 1. SCOPE

All Breast Screening Program Staff
All Screening Program Data Requesters

#### 2. POLICY

Access to Screening Program data for scientific research is granted in accordance with Section 26(c) of the *Freedom of Information and Protection of Privacy Act* (FOIPPA), to ensure security and confidentiality. Scientific research is defined as the search/gaining for/of new knowledge for cancer control objectives using scientific principles. Impacts are population-based, not individually based.

Request to access identifying data must be presented with a completed BC Cancer Data Access Request (DAR) form, which outlines the expectations and limitations associated with the privilege of access, including:

- obligation of confidentiality,
- responsibility to notify/educate research staff about confidentiality expectations and practices,
- specification of the personal data to be accessed,
- intent of access,
- limits on the use of personal data,
- restrictions on release of data,
- storage and maintenance requirements, and
- obligation to remove or destroy identifiers at the earliest possible opportunity.

Non-BC Cancer investigators may have access to Screening Program data, including personal identifying data for research use, but for accountability to security and confidentiality requirements, and to ensure that the data is being used and interpreted appropriately there must be a BC Cancer or Breast Screening Program staff member named as a co-investigator.

## 3. PROCEDURE

1. Review the BC Cancer Why a DAR and TERMS AND CONDITIONS FOR ACCESS TO BC CANCER AGENCY PATIENT INFORMATION FOR RESEARCH PURPOSES (attached).



- 2. Develop your project objectives, describe your study population and inclusion criteria, identify funding and develop project timeline.
- 3. Follow the BC Cancer Data Access Request process and submit to datareg@bccancer.bc.ca
  - a. Download the DAR forms: <a href="http://www.bccancer.bc.ca/health-professionals/professional-resources/bc-cancer-registry/request-registry-data">http://www.bccancer.bc.ca/health-professionals/professional-resources/bc-cancer-registry/request-registry-data</a>
    - <u>Data Access Request (DAR)</u> (Internal investigators)
    - <u>Data Access Request (DAR)</u> (External investigators)
    - <u>Field Extraction Check List</u> (All investigators
  - b. Review the information on the forms. Data requests for a research purpose must include your research ethics board submission and approval before they can be processed.
  - c. Complete the forms
  - d. Submit the forms and supporting documentation datareq@bccancer.bc.ca
  - e. For studies requiring linkage of our data holdings to other source(s), an additional Data Linkages form must be completed and submitted.
  - f. Those interested in data linkage projects can also review the information about conducting linked-health data research studies at Population Data BC.
  - g. Data requests are placed in a queue based on date of receipt. Approval times and release of data will vary widely depending on the complexity of the request.
  - h. You will be contacted about your request if any clarifications are required. Requests should receive a confirmation email within 2-3 business days with information about next steps.
- 4. Any questions related to data requests and the data request process may be directed to the Cancer Surveillance & Outcomes Unit at <a href="mailto:datareq@bccancer.bc.ca">datareq@bccancer.bc.ca</a>.
- 5. At completion of the project Screening Program data will be returned or destroyed as outlined by the Screening Program.

#### Requests for aggregate data:

- The project proposal and data request will be forwarded to the Screening Program at screeningadmin@bccancer.bc.ca
- Within a reasonable time period, the Screening Program will respond to the principal investigator.
- All data requests will be processed as resources permit.



# 4. RELATED POLICIES

# 5. RESPONSIBLE PARTY

Screening Medical Director