

Applied Research Program

Breast Cancer Surveillance Consortium

<http://breastscreening.cancer.gov>

Overview

The Breast Cancer Surveillance Consortium (BCSC) is a research resource for studies designed to assess the delivery and quality of breast cancer screening and related patient outcomes in the United States. The BCSC is a collaborative network of five mammography registries and two affiliated sites with linkages to pathology and/or tumor registries. The network is supported by a central Statistical Coordinating Center.

As of May 2008, the Consortium's database contains information on 7,500,000 screening mammographic examinations, 86,700 breast cancer cases, and over 2,000,000 women.

A full description of the history and early work of the BCSC can be found in *Breast Cancer Surveillance Consortium: Evaluating Screening Performance in Practice* (http://breastscreening.cancer.gov/espp_report.html provides a PDF of the report).

Research Findings from the BCSC

BCSC investigators are multidisciplinary and include radiologists, primary care clinicians, pathologists, epidemiologists, health services researchers, and statisticians. More than 290 publications in journals across a range of disciplines have resulted from this effort (to search the BCSC publications database, please see <http://breastscreening.cancer.gov/publications/search.html>).

Areas of focus include:

- Mammography performance
- Patient characteristics and screening performance
- Provider characteristics and screening performance
- Statistical methods
- Biologic measures of risk
- Health disparities
- Ductal carcinoma in situ

Enhancing Use of BCSC Research Resources

The well-established BCSC data infrastructure, strong research foundation, history of multidisciplinary collaboration among BCSC investigators, and large, population-based sample make this an ideal resource for research in breast cancer control. To date, the BCSC has been a research resource for more than 65 investigator-initiated studies funded by the NCI, other federal and state agencies, and foundations.

Working With the BCSC: Guidance for Investigators

The Breast Cancer Surveillance Consortium is a research resource for studies designed to assess the delivery and quality of breast cancer screening as well as the biology of breast cancer. The development of new collaborations to achieve these ends is a key goal of the BCSC. The BCSC data are available to outside investigators for research purposes and this site provides detailed information regarding the specific variables and how collaborations may be developed.

The data include information at the individual level regarding demographics, breast symptoms, mammogram interpretations and cancer. Because the data is associated with individuals, maintaining patient and provider confidentiality is a primary concern of NCI. Therefore, the BCSC data are managed by the Statistical Coordinating Center of the BCSC. All personal identifiers for all patient and medical care providers have been removed from the data. Investigators are required to obtain approval of their idea and study site access in order to obtain the data. NCI will work with investigators requesting data files to balance their research needs with those of the individuals and institutions included in the data. The Statistical Coordinating Center (SCC) will do analyses if patient confidentiality is a concern.

Steps for Submitting a Proposal and Using BCSC Data

- 1) Develop research questions
- 2) Contact SCC
- 3) Develop proposal for review by BCSC Steering Committee
- 4) Refine proposal and submit to SCC for review by BCSC
- 5) Sign collaborative agreement
- 6) Plan analyses with the SCC
- 7) Prepare progress reports
- 8) Present findings to BCSC at twice-yearly meetings
- 9) Submit project results
- 10) Send programs, datasets, and files to SCC for archiving

These steps are described in full in the *BCSC Data Request Process Guide* (PDF available at http://breastscreening.cancer.gov/work/proposal_data.html).

BCSC Site Registries

- **Carolina Mammography Registry**
(Bonnie C. Yankaskas, PhD)
- **Group Health Cooperative**
(Diana Buist, PhD)
- **New Hampshire Mammography Network**
(Tracy Onega, PhD)
- **San Francisco Mammography Registry**
(Karla Kerlikowske, MD)
- **Vermont Breast Cancer Surveillance System**
(Berta Geller, EdD and Don Weaver, MD)
- **Statistical Coordinating Center**
(Diana Miglioretti, PhD)

Affiliated Sites

- (*contributed data in the past to the BCSC)
- **New Mexico Mammography Project**
(Robert Rosenberg, MD)
 - **Colorado Mammography Project**

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Working together to advance breast cancer research

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