

Applied Research Program

Breast Cancer Surveillance Consortium

<http://breastscreening.cancer.gov>

Overview

The Breast Cancer Surveillance Consortium (BCSC) is a resource for researchers who wish to examine the delivery and quality of breast cancer screening in the United States, including related patient outcomes. The BCSC is a collaborative network of seven mammography registries that link to pathology and/or tumor registries, and is supported by a central Statistical Coordinating Center (SCC). The Consortium is led by a multidisciplinary team that includes radiologists, primary care clinicians, pathologists, epidemiologists, health services researchers, and biostatisticians. Non-BCSC researchers are encouraged to propose collaborative efforts with the BCSC team.

The BCSC database contains information on 2.3 million women and 9.5 million mammograms, 7 million of which were screening mammograms. The database includes over 180,000 biopsies and 113,000 breast cancer cases, including nearly 19,000 diagnoses of ductal carcinoma in situ.

The history and early work of the BCSC is documented in *Breast Cancer Surveillance Consortium: Evaluating Screening Performance in Practice*, which can be accessed at <http://breastscreening.cancer.gov/espp.pdf>

Use of the BCSC Research Resource

The well-established BCSC data infrastructure, strong research foundation, history of multidisciplinary collaboration, and large, population-based sample make the resource ideal for research in breast cancer control. The BCSC has been a resource for more than 70 investigator-initiated studies funded by the National Cancer Institute (NCI), other federal and state agencies, and foundations.

Research Findings from the BCSC

More than 400 publications have resulted from the BCSC effort. Research areas include:

- Mammography performance
- Performance of new breast imaging technologies (e.g., breast MRI)
- Effectiveness of breast imaging by patient and provider factors
- Statistical methods
- Biologic measures of risk
- Health disparities
- Access and utilization
- Ductal carcinoma *in situ*

Visit

<http://breastscreening.cancer.gov/publications/> to search for BCSC publications.

Working With the BCSC: Guidance for Investigators

For the latest information regarding collaboration, visit the BCSC website, <http://breastscreening.cancer.gov>, and click on "Working with the BCSC".

Available individual-level data include demographic and risk factor information, clinical history, mammographic interpretation, mammographic breast density, breast biopsy findings, breast cancer diagnosis, and death. Maintaining patient and provider confidentiality is a primary concern of the BCSC; therefore, the pooled BCSC data are managed by the SCC. All personal identifiers for patient and medical care providers have been removed.

Investigators can request custom data sets to evaluate project feasibility, develop grant proposals and conduct research studies. Statistical analysis support and expert information on data use and interpretation are available from the SCC.

Investigators are required to submit a proposal and obtain approval before receiving data. The SCC will perform analyses if patient or provider confidentiality is a concern.

Steps for Submitting a Proposal and Using BCSC Data

- 1) Develop research questions
- 2) Contact the SCC to assess feasibility
- 3) Submit proposal to the SCC for review by the BCSC Steering Committee
- 4) Sign collaborative agreement
- 5) Plan analyses with the SCC, when applicable
- 6) Submit progress report to the SCC
- 7) Present findings to BCSC on webinar
- 8) Submit project results to the SCC
- 9) Send analytic datasets to the 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).

Current and Future Research

The BCSC has received NCI funding for additional data collection. The goal of this new research is to identify the most effective risk-based breast cancer screening strategies while taking into consideration their potential for harm. The project is designed to evaluate performance characteristics of standard and advanced breast imaging technologies by breast cancer risk and specific subgroups (e.g., age, race/ethnicity, breast density) as these technologies disseminate into community practice. The BCSC will use existing and new data collected from the six current BCSC breast imaging registries. Collaborations using these data will be possible in the future.

Current BCSC Site Registries

- **Carolina Mammography Registry**
(PI: Louise Henderson, PhD; University of North Carolina at Chapel Hill)
- **Group Health Cooperative**
(PI: Diana Buist, PhD; Group Health Research Institute)
- **New Hampshire Mammography Network**
(PI: Tracy Onega, PhD; Dartmouth Medical School)
- **San Francisco Mammography Registry**
(PI: Karla Kerlikowske, MD; University of California, San Francisco)
- **Vermont Breast Cancer Surveillance System**
(PI: Berta Geller, EdD; University of Vermont)
- **Metro Chicago Breast Cancer Registry**
(PI: Garth Rauscher, PhD; University of Illinois at Chicago)
- **Statistical Coordinating Center**
(Diana Miglioretti, PhD; Group Health Research Institute)

Previous Affiliated Sites

(Contributed data in the past to the BCSC)

- **New Mexico Mammography Project**
(Deirdre Hill, MPH, PhD; University of New Mexico)
- **Colorado Mammography Project**,
(Gary Cutter, PhD and Mark Dignan, PhD; The Cooper Institute)

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Working together to advance
breast cancer research

CONTACT INFORMATION

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