

BREASTSCREEN AUSTRALIA: AT A GLANCE

OVERVIEW OF DATA AND RESEARCH

<p>State and Territory BreastScreen Registries and Client Information Systems</p>	<ul style="list-style-type: none"> Data is collected at the service and/or state coordination unit level for each jurisdiction. All State and Territory Registers/client information systems and use of data must comply with applicable state legislation and standards. Note: Not all data collected by jurisdictions are provided to the national databases. Data collected by the two national databases are outlined below. 	
National Data Bases	BSA Accreditation Database (JUNO)	BSA Database Performance Monitoring
Responsibility for maintaining register	National Quality Management Committee (NQMC): BSA NQMC Secretariat. Collection and use of data complies with national standards.	Australian Institute of Health and Welfare (AIHW). Collection and use of data complies with national standards.
Purpose	Data collected support accreditation decision-making of BreastScreen Services and State Coordination Units (SCU), as well as national quality improvement of services within the BSA Program. Reports are not publically available.	Data collected are used for national performance monitoring. Reports are publically available.
Data source	State and Territory BreastScreen Registries. Performance data reports are submitted in line with the requirements of the <i>BreastScreen Australia Data Dictionary</i> and <i>BreastScreen Australia National Accreditation Standards</i> .	State and Territory BreastScreen Registries. Data are collected in line with the <i>BreastScreen Australia Data Dictionary</i> .
Data custodians	States and Territories.	States and Territories.
Frequency of data collection	Annually.	Annually.
Types of Data collected	Data to support decisions regarding accreditation. Data are in accordance with the quantitative National Accreditation Standards (NAS) Measures.	Line data to allow the calculation of data for: participation, recall to assessment, invasive breast cancer detection, and ductal carcinoma in situ detection. Aggregate data for rescreening and sensitivity.

<p>National Data Bases</p>	<p>BSA Accreditation Database (JUNO)</p>	<p>BSA Database Performance Monitoring</p>
<p>Primary data use</p>	<p>Strategic purposes, accreditation decision making, quality improvement, program monitoring and evaluation, benchmarking quality improvement of services.</p>	<p>Strategic purposes, program monitoring and evaluation.</p>
<p>Secondary data use</p>	<p>RESEARCH i.e. any project which involves the use of breast screening data.</p>	
<p>BreastScreen Australia Priority Research Themes</p>	<ul style="list-style-type: none"> • Breast screening Service System including models of service delivery, infrastructure, program eligibility, access and equity and treatment modalities, including emerging and new technologies. • Clinical elements of screening, diagnosis and management. • Behavioural/social influences on participation in BreastScreen. <p>Note: See Attachment A for a further breakdown of these priority themes.</p>	
<p>Data assets available for research purposes</p>	<p>Data held by AIHW – BSA Database and other AIHW cancer data e.g. Australian Cancer Database; accreditation data; data held by Services/SCUs (images, bio-specimens); and other relevant data sets (e.g. clients such as research participants). Note:</p> <ul style="list-style-type: none"> • Research must have a public benefit relating to breast screening. • Data requested for research purposes may be identified or identifiable data; re-identified data; and or de-identified data. • Not all data assets will be available from each state or territory. It is advisable to contact the data custodian in each state or territory to discuss your requirements prior to applying to access data assets. • No BSA data will be released by any State or Territory without the written approval of: <ul style="list-style-type: none"> ○ a human research ethics committee constituted in accordance with NHMRC requirements (where required) ○ the NQMC and relevant states and territories where it relates to the accreditation data set. • Access to, and release of BSA data will be assessed against the Five Safes Principles: Safe project; Safe data; Safe people; Safe setting and Safe output. 	
<p>For prospective researchers – who to contact in the first instance (refer to Attachment B for contact details)</p>	<p>For data being sought from single state or territory contact the BSA service in that jurisdiction.</p> <p>For data being sought from multiple jurisdictions, in the first instance, contact the Commonwealth Program Manager, Department of Health, who can assist in coordinating your request.</p> <p>Commonwealth, state and territory contact details are at Attachment B.</p> <p>Researchers should be aware that states and territories may apply a fee for the processing of the application and/or the identification of release of data. This fee is set by each state and territory and may vary.</p>	

BSA RESEARCH FRAMEWORK – RESEARCH PRIORITIES

SERVICE SYSTEM RESEARCH PRIORITIES

- Epidemiology of breast cancer
- Technical and allocative efficiency and cost effectiveness of screening
- Program eligibility rules
- Access to modalities of treatment
- Factors including access and equity
- Impact of service delivery models on outcomes
- Service system capacity and planning (including workforce)
- Use and outcomes of non-BSA screening

CLINICAL RESEARCH PRIORITIES

- Risks and benefits of screening and early interventions
- Morbidity associated with screening and recall
- Risks and benefits of biopsy and imaging techniques
- Effectiveness of screening
- Optimal management of 'borderline' lesions
- Management of lesions detected by screening
- Use and impact of new technologies

BEHAVIOURAL / SOCIAL RESEARCH PRIORITIES

- Factors that influence participation
- Participation of special groups
- Women's experience of screening and management
- Awareness-raising
- Consent, choice and health literacy
- Optimal methods of recall

BREASTSCREEN AUSTRALIA: CONTACTS

Commonwealth	Cancer Screening Section breastscreen@health.gov.au
New South Wales	BreastScreen NSW CINSW-BSNSW_SCU@health.nsw.gov.au
Victoria	BreastScreen VIC info@breastscreen.org.au
Queensland	BreastScreen QLD cssb@health.qld.gov.au
South Australia	BreastScreen SA HealthBSSAEnquiries@sa.gov.au
Western Australia	BreastScreen WA breastscreenwa@health.wa.gov.au
Tasmania	BreastScreen TAS cscs.administration@ths.tas.gov.au
Northern Territory	BreastScreenNT BreastScreenNT.THS@nt.gov.au
Australian Capital Territory	BreastScreen ACT breastscreen@act.gov.au