

PRIVACY POLICY

7th September 2012

The Australia and New Zealand Breast Cancer Trials Group (**ANZBCTG**) was established in 1978 and registered as a company limited by guarantee in 1991. The ANZBCTG is registered for GST (ABN 64 051 369 496), has authority to fundraise in all states and territories in Australia and holds Australian Taxation Office tax deductibility status (ATO N0939).

The ANZBCTG is Australia's national organisation dedicated solely to breast cancer clinical trials research. It conducts a national clinical trials research program for the treatment of all stages of breast cancer and for the prevention of breast cancer. The research program involves multi-centre clinical trials and collaboration with 78 institutions and 600 researchers throughout Australia and New Zealand. The ANZBCTG also collaborates with other International Clinical Trials Research Groups from a number of countries.

The ANZBCTG is governed by an elected Board of Directors, has a Scientific Advisory Committee which plans and oversees the research program, and a Consumer Advisory Panel to ensure consumer involvement in the research program.

The ANZBCTG established the Breast Cancer Institute of Australia (BCIA) in 1994 to raise awareness and funding for its national clinical trials research program. The BCIA is the ANZBCTG's fundraising and education department.

The ANZBCTG is bound by the *Privacy Act 1988* (Cth) and all relevant state legislation governing privacy (**Privacy Laws**).

This policy explains:

- what types of Personal Information the ANZBCTG and the BCIA might collect,
- how the ANZBCTG and BCIA aim to use Personal Information,
- when the ANZBCTG and BCIA will disclose Personal Information,
- how the ANZBCTG and BCIA manage and secure Personal Information, and
- how Personal Information held by the ANZBCTG and the BCIA can be accessed.

This policy does not apply to information that has been de-identified, being information where the individual's identity is not apparent or reasonably ascertainable.

Relevant Definitions in the Privacy Act 1988 (Cth):

Personal Information is information or an opinion whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.

Sensitive Information is Personal Information about an individual's racial or ethnic origin, political opinions, religious/philosophical beliefs, sexual preferences, trade union membership, criminal record or Health Information.

Health Information is any information or opinion about:

- the health or disability of an individual;
- an individual's expressed wishes about a health service to be provided, future health services to be provided;

- Personal Information collected to provide a health service;
- Personal Information collected in connection with the donation of an individual's body parts, organs or substances; and
- genetic information.

The ANZBCTG – Privacy Policy

1.0 Purpose of Collection:

- 1.1 The ANZBCTG will only collect Personal Information (including Health Information) that is necessary for one or more of its functions or activities. The ANZBCTG collects Health Information and Personal Information for the purpose of conducting a national breast cancer clinical trials research program and for its related activities.

Information is sought from the following:

- Clinicians, principal investigators, and other medical research staff involved in the conduct of the ANZBCTG clinical trials program,
- members of the ANZBCTG,
- Attendees at the ANZBCTG's Annual Scientific Meeting,
- Participants in the ANZBCTG's clinical trials,
- Members of the community.

When collecting information, the ANZBCTG will inform the individual of the purpose for which the information is being collected, the identity of the ANZBCTG and how the information is likely to be used.

2.0 How Personal Information is Collected:

Information from clinicians, principal investigators, and other medical research staff and the ANZBCTG members is collected in the following ways:

- According to clinical trial protocol requirements;
- Annual General Meeting registration forms;
- The ANZBCTG's membership applications;
- as required.

Information from patients is collected by institutions participating in the ANZBCTG clinical trials program via the clinic visit schedule and treatment directions required by a particular clinical trial protocol (or guideline). The information is recorded on Case Report Forms (**CRFs**) which are study specific and in addition to any general hospital medical records.

When necessary, relevant contact information for well women is also collected via a free call 1800 number for the purpose of recruitment to the ANZBCTG's clinical trials.

3.0 Type of Information Collected:

- 3.1 **Clinicians, principal investigators, other medical research staff, participating institutions, the ANZBCTG's members and other participants**

The type of information that the ANZBCTG will collect includes but is not limited to:

- contact details
- position
- affiliation details
- where required, a full or abbreviated CV
- where required, a FDA 1572 Financial Disclosure information
- payment details for clinical trial reimbursement payments to participating institutions
- annual general meeting registration details – including method of payment (cheque and bank details, credit card number).

3.2 Participants in the ANZBCTG's clinical trials research program

In collecting Personal Information from participants in clinical trials conducted by the ANZBCTG, the ANZBCTG follows the following procedure:

- informed consent will be obtained from each participant to the collection of Personal Information which will include information about the purposes for which the information may be used and disclosed;
- participants will be anonymous. Each trial participant is given a unique ID number dependent on the study;

The ANZBCTG may collect the following information from participants:

- relevant health and disease information as required by the particular clinical trial protocol;
- biological samples and related information as required by the particular clinical trial protocol;
- Contact and address details obtained via consent, to be used by the ANZBCTG to obtain personal health information directly from trial participants for specific trials.

Some of the information collected by the ANZBCTG will also be governed by state privacy laws. For example, in NSW the collection of Personal Information is governed by the *Health Records and Information Privacy Act 2002 (NSW)*.

All clinical trial protocols are approved by the ANZBCTG Board of Directors, the ANZBCTG Scientific Advisory Committee, and institutional and/or Multi-centre Ethics Committees, of centres participating in the ANZBCTG clinical trials program, prior to the clinical trial commencing.

All Personal Information collected by the ANZBCTG for the purposes of clinical trials is subject to this privacy policy.

4.0 Use and disclosure

The ANZBCTG will only use or disclose Personal Information for the purpose for which it was collected it, and for any related purposes which the ANZBCTG consider will be within the individual's reasonable expectations. Otherwise, the ANZBCTG will seek the individual's consent prior to using or disclosing any Personal Information for another purpose, unless the ANZBCTG are required or permitted by law to do so without seeking an individual's permission.

Information obtained by the ANZBCTG is not disclosed to any third parties except as required by the data flow requirements of a clinical trial protocol (informed consent for this will be sought at the outset), by law, audit, or if consent from the individual is obtained.

5.0 Access to Personal Information

The ANZBCTG will ensure that individuals are given access to the Personal Information that is held about them. The ANZBCTG is only able to refuse to allow access if it is legally required or entitled to do so.

The ANZBCTG will also ensure that if it becomes aware that information held about an individual is not accurate, complete and up to date, it will amend its records accordingly.

The ANZBCTG provides regular opportunity for an individual to be removed from the ANZBCTG member's database. Regular advice on how to be removed is contained in mail correspondence and in verbal discussion where appropriate.

Patients participating in the ANZBCTG's clinical trials can withdraw from participation in a trial at any time and withdraw their data. This option is explained during informed consent process.

Any individual or business can have access to their Personal Information at any time, and/or request further information about how the ANZBCTG manages this Personal Information.

Applications can be made by contacting the ANZBCTG on Ph: + 61 2 4925 5255 (within business hours), or by written application to:

Privacy Officer
Australia and New Zealand Breast Cancer Trials Group
PO Box 283
The Junction
NSW 2291
AUSTRALIA

6.0 Storage of information

The ANZBCTG has implemented the following security measures to ensure that Personal Information is not misused or subject to any unauthorised access.

6.1 Site:

The offices of the ANZBCTG have a security system and security patrols.

6.2 Computer:

The ANZBCTG Offices operate under a computer network system that is secured by user names and passwords. This system is protected from external access via a secure firewall. Each computer "locks" after a nonoperational period of 15 minutes to ensure security of information stored. User passwords must be changed regularly.

The Personal Information collected by the ANZBCTG is stored on secure databases which are also password protected, and which have internal security measures regarding levels of access for certain users.

6.3 Transmission of Information:

The ANZBCTG encrypts and/or password protects any Personal Information sent via email to off-site locations.

All other personal, confidential or secure information is transmitted verbally, by facsimile or by direct face-to-face communication.

6.4 Staff:

All of the ANZBCTG's staff sign Confidentiality Deeds at the start of their employment. All temporary staff are also required to sign Confidentiality Deeds. The ANZBCTG only employs temporary staff from staff employment agencies which fulfill the obligations of the Privacy Laws.

6.5 Visitors:

Where applicable, the ANZBCTG's visitors sign Confidentiality Deeds.

Breast Cancer Institute of Australia (BCIA) – Privacy Policy

1.0 Purpose of Collection:

1.1 The BCIA seeks to encourage support for the breast cancer research programs of the ANZBCTG.

The BCIA collects Personal Information from the BCIA's donors, supporters and other individuals and businesses for the purpose of:

- providing information about breast cancer research and fundraising activities, for example: newsletters, surveys, specific event brochures, etc.
- seeking support for the breast cancer research programs of the ANZBCTG.

1.2 How information is collected:

The BCIA collects information from individuals who respond to its acquisition programs. Acquisition of new donors is conducted via the media (television, radio and print media including magazines), the internet, direct mail solicitation (including unaddressed mail pieces and rental of mailing lists), special events and projects, and corporate sponsorship opportunities.

2.0 Type of Information Collected:

The type of Personal Information collected from the BCIA's donors, supporters and other individuals and businesses includes:

- name
- address
- telephone / mobile
- email address
- donation details – including: cheque and/or bank account details, credit card number, receipt number, etc.
- other Personal Information such as reason for giving, age, breast cancer survivor, etc.

3.0 Security Measures:

3.1 Site:

The offices of the BCIA have a security system.

3.2 Computer:

The BCIA office operates under a computer network system. This system is protected from external access via a secure firewall. Each computer work station is password protected and “locks” after a nonoperational period of 15 minutes to ensure security of information stored.

Personal Information collected by the BCIA is stored on a secure database which is also password protected, and has internal security measures regarding level of access for certain users.

3.3 Transmission of Information:

The BCIA encrypts and/or password protects any Personal Information sent via email to off-site locations.

All other confidential or secure information is transmitted verbally or by direct face-to-face communication.

3.4 Staff:

All of the BCIA's staff sign Confidentiality Deeds at the start of their employment. All temporary staff are also required to sign Confidentiality Deeds. The BCIA only employs temporary staff from a staff employment agency which fulfills its obligations under the Privacy Laws.

4.0 Disclosure:

Information obtained by the BCIA may be disclosed to third parties for the purpose of distributing information on behalf of the BCIA and for donor segmentation and analysis. All relationships with third parties are governed under Confidentiality Deeds which include the obligations required under the Act.

The BCIA will not disclose any Personal Information to third parties who have not entered into a Confidentiality Deed except as required by law, or if consent from the individual/business is obtained.

5.0 Access to Information:

The BCIA provides regular opportunity for an individual or business to be removed from the database. Regular advice on how to be removed is contained in all mail correspondence and in verbal discussion where appropriate.

Any individual or business can have access to their Personal Information at any time, and/or request further information about how the BCIA manages this Personal Information.

Applications can be made by contacting the BCIA on 1800 423 444 (within business hours), or by written application to:

Privacy Officer
Breast Cancer Institute of Australia
PO Box 283
THE JUNCTION NSW 2291

BCIA aims to keep all Personal Information it holds both accurate and up to date and encourages individuals to tell us of any changes to contact details.

Individuals can contact BCIA on Ph: (02) 4925 3022 or enquiries@bcia.org.au to update any Personal Information held by BCIA.