



Formerly known as the
Australia & New Zealand Breast Cancer Trials Group

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December 2019

PRIVACY POLICY

1. Policy statement

In Australia, the ANZ Breast Cancer Trials Group Limited (**BCT**) is bound by the *Privacy Act 1988* (Cth) and other privacy laws which govern the way in which organisations such as BCT hold, use and disclose personal information (including sensitive information). To the extent BCT conducts trials in New Zealand, it is bound by the *Privacy Act 1993* (NZ). In this privacy policy, applicable privacy legislation is referred to collectively as **Privacy Laws**.

We recognise our obligations under the Privacy Laws, and aim to carry them out properly and responsibly.

This policy is intended to provide a general overview of our approach to handling your personal information. Other policies may apply instead of or in addition to this policy in certain circumstances.

By using our website at www.breastcancertrials.org.au (**Website**) and/or providing your personal information to us, you consent to us handling your personal information in accordance with this policy.

We may amend, modify or replace this policy at any time. You should review our privacy policy each time you visit our Website or provide us with personal information.

2. Definitions

In this policy, the following terms have the meanings given to them under the Privacy Laws, which can be summarised as follows:

- **personal information** – information or an opinion about an identified individual, or an individual who is reasonably identifiable; and
- **sensitive information** – including information or an opinion about an individual's racial or ethnic origin, politics, beliefs, membership of a professional or trade association or union, sexual orientation or practices, criminal record, or health information.

3. Types of information collected

3.1 From clinicians, principal investigators, other medical research staff, participating institutions, BCT's members and other persons

BCT collects information from you which is necessary to properly manage our business or provide our services to you. The type of information that BCT may collect includes but is not limited to:

- contact details;
- position;
- affiliation details;
- where required, a full or abbreviated CV;
- where required, relevant information for to meet regulatory and program specific requirements, for example relevant financial information;
- payment details for clinical trial reimbursement payments to participating institutions;
- reasons for joining various programs that we may offer such as the Improving Participation and Advocacy for Clinical Trials (**IMPACT**) program, which may include disclosure of Health Information; and
- annual general meeting registration details – including method of payment (cheque and bank details, credit card number).

3.2 From participants in BCT's clinical trials and research programs

BCT collects information from you which is necessary to enable you to participate in clinical trials and research programs.

The type of information which BCT may collect from trial participants includes:

- relevant health and disease information as required by the particular clinical trial protocol which may include your health history, family history, past and current treatments, lifestyle factors etc.;
- biological samples and related information as required by the particular clinical trial protocol; and
- contact and address details and any other information which is necessary for the conduct of the trial.

3.3 From supporters

Where you have consented, BCT generally collects information from you for the purposes of receiving and managing supporter donations, providing information about breast cancer research and fundraising activities and to seek support for the BCT research program. The type of personal information collected from individuals includes:

- name;
- address;
- telephone / mobile;
- email address;
- donation details – including: cheque and/or bank account details, credit card number, receipt number, etc.; and
- other personal information such as reason for giving, age, acquisition channel, prior participation in appeals, responses to information provided by BCT, etc.

3.4 From job applicants

BCT generally collects information from you which is necessary to assess and engage applicants. This includes collecting personal information such as your name, address, professional experience, qualifications, references and past employers, and any other information which is necessary to assess your suitability for employment.

4. How we collect and purpose of collection:

4.1 Purpose of collection

BCT generally only collects personal information (including sensitive information and health information) that is necessary for the purposes of achieving one or more of its functions or activities, such as conducting breast cancer clinical trial programs.

4.2 How we collect your personal information

We will generally collect your personal information directly from you, including through:

- research, such as clinical trials, membership applications and phone calls;
- fundraising, such as media campaigns, direct mail solicitation, social media activities and corporate sponsorship opportunities; and
- as otherwise required and/or permitted under the Privacy Laws.

However, sometimes it might be impracticable or unreasonable to collect information directly from you. Accordingly, your personal information may be collected from third parties such as:

- clinicians, principal investigators, and other medical research staff involved in the conduct of BCT clinical trials program;
- members of BCT's IMPACT – Improving Participation and Advocacy for Clinical Trials program;
- members of BCT;
- attendees at BCT's Annual Scientific Meeting; and participants in BCT's clinical trials.

When collecting personal information BCT will take reasonable steps to inform you (such as by including it in this policy) of:

- the fact that the information is being collected;
- the purpose for which the information is being collected;
- the intended recipients of the information;
- the identity of BCT;
- whether the supply of information is voluntary or mandatory (and if mandatory, the law under which the information is required);
- the consequences of any failure to provide the information requested; and
- how the information is likely to be used.

When collecting personal and sensitive information from participants in clinical trials conducted by BCT, BCT generally follows the following procedure:

- informed written consent is obtained from each participant to the collection of the information; and
- the participants are informed of the purposes for which their information may be collected, used and disclosed.

5. Sensitive information

BCT will generally not collect sensitive information about an individual unless an individual consents to the information being collected and the information is reasonably necessary for one or more of BCT's functions or activities or the collection is otherwise permitted by the Privacy Laws.

6. Information about third parties

If you provide us with personal information about a third party, in doing so you will be representing to us that you have that person's consent for us to collect and handle their personal information in accordance with this privacy policy – and we will be collecting the information on that basis.

7. Use and disclosure

BCT will generally only use or disclose an individual's personal information, sensitive information and/or health information for the primary purpose for which it was collected, or as otherwise permitted by Privacy Laws. In all other circumstances, BCT will generally seek the individual's consent prior to using or disclosing any personal, sensitive and/or health information for another purpose, unless BCT is required or permitted by law (including the Privacy Laws) to do so without seeking an individual's permission.

Information collected by BCT is not generally 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);
- to comply with law;
- to conduct our internal management, quality assurance, risk management, audit and other administrative purposes;
- where contractually engaged to provide fundraising activities and/or services on our behalf; and/or
- with the consent from the individual.

Personal information collected by BCT may be disclosed to overseas recipients if BCT first takes reasonable steps to ensure the overseas recipient does not breach Privacy Law unless:

- BCT believes that the recipient will be subject to the same or similar requirements as those that BCT is subject to under the Privacy Laws and the individual will have the ability to enforce the relevant law;
- the disclosure is necessary for the purposes of conducting a trial approved by BCT and you have consented to the disclosure;
- the disclosure is to facilitate third party service providers; and/or
- the disclosure is required or authorised under applicable law.

8. Website

Our Website does not attempt to identify you as an individual user and it will not generally collect personal information about you unless you specifically provide this to us.

However, our Website does collect cookies from visitors (including members who log in) to our Website. Cookies are small data files placed on your machine or device which lets BCT identify and interact more effectively with your computer. Cookies do not identify individual users, but they do identify your web requests, internet service provider, browser type, browser language and the date and time of your request. You have the ability to turn cookies off on your computer. This information is anonymous and is only used for statistical and website development purposes and to improve our communications.

We may collect your personal information if you choose to provide this to us via an online form or email. That personal information is used and disclosed by us in accordance with this policy.

Our Website may contain links to third party websites. We are not responsible for the content or privacy practices employed by websites that are linked to our Website. You should review the privacy policy and terms of use for those websites each time you visit them.

9. Data storage security of information

9.1 Data storage and security

BCT strives to ensure the security, integrity and privacy of personal information, and will take reasonable steps to protect your personal information from misuse, interference, loss, unauthorised access, modification or disclosure. BCT reviews and updates (where necessary) its security measures.

Some of the measures that BCT has implemented to ensure that your personal information is not lost, misused or subject to any unauthorised access, modification or disclosure, include:

(a) *Site*

The offices of BCT have a security system

(b) *Computer network*

BCT operates 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 BCT is stored on secure databases which are also password protected, and which have internal security measures regarding levels of access for certain users.

(c) *Transmission of information*

The BCT encrypts and/or password protects any personal information sent via email to off-site third party service providers. Any off-site locations have security processes in place to ensure the security of personal information.

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

(d) *Staff*

All of BCT's staff sign an employment contract which includes confidentiality at the start of their employment. All temporary staff are also required to sign confidentiality statement. BCT only employs temporary staff from staff employment agencies which fulfil the obligations of the Privacy Laws.

(e) *Visitors*

Where applicable, BCT's visitors are required to sign confidentiality deeds.

9.2 Transactions and donations

Our Website accepts online transactions using a secure payment gateway. When a donation is made your credit card number is not stored or retained by us.

10. Access, correction and removal

BCT will generally ensure that individuals are given access to their personal information that is held by BCT. BCT will generally only refuse to allow access if it is legally required or entitled to do so.

Under the Privacy Laws, individuals have the right to request correction of their personal information held about them. BCT will respond to a request for access to or correction of personal information subject to the *Privacy Act 1993* (NZ) as soon as reasonably practicable and, in any event, no later than 20 working days after BCT receives the request.

A request for:

- access to personal information;
- to be removed from any further communications;
- further information about how BCT manages personal information; and/or
- BCT to correct or personal information,

can be made by contacting BCT via:

- **phone:** + 61 2 4925 3022 (within business hours);
- **letter:**
Privacy Officer
Breast Cancer Trials
PO Box 283
The Junction NSW 2291
AUSTRALIA
- **email:** privacy@bctrials.org.au

11. Questions and complaints

Individuals who have a question or wish to complain about the management of their personal information, should also contact BCT via the above listed methods.

BCT will review your question/complaint and respond to you within a reasonable time after receiving it (and within any applicable statutory timeframe).

If you are not satisfied with how we deal with your question/complaint, including the outcome, you can lodge a complaint with either the Office of Australian Information Commissioner or the New Zealand Office of the Privacy Commissioner.

12. Destruction

Once personal information held by BCT is no longer required for any permitted purpose and is not legally required to be retained, BCT will remove, de-identify and/or securely destroy the personal information.