



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

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PRIVACY POLICY

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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.

BCT is committed to protecting the privacy of the personal information and sensitive information which it collects and holds. This privacy policy explains:

- (a) the kind of personal information BCT might collect and hold and how that information is collected and held;
- (b) the purposes for which the BCT collects, holds, used and discloses that personal information;
- (c) how BCT manages and secures personal information;
- (d) how Personal Information held by BCT can be accessed and corrected; and
- (e) how you may complain if BCT breaches its privacy obligations.

This policy does not apply to the extent that BCT uses de-identified information.

2. Definitions

In this policy, the following terms have the meanings given to them in the *Privacy Act 1988* (Cth) or the *Privacy Act 1993* (NZ), whichever is applicable.

2.1 Privacy Act 1988 (Cth) definitions

These definitions apply when considering information collected used, or disclosed in Australia:

personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- (a) whether the information or opinion is true or not; and
- (b) whether the information or opinion is recorded in a material form or not.

sensitive information means:

- (a) Personal Information or an opinion about an individual's:
 - i. racial or ethnic origin; or
 - ii. political opinions or membership of a political association; or
 - iii. philosophical beliefs or religious beliefs or affiliations; or
 - iv. membership of a professional or trade association or union; or
 - v. sexual orientation or practices; or
 - vi. criminal record; or
- (b) health information about an individual; or
- (c) genetic information about an individual that is not otherwise health information ; or

- (d) biometric information that is to be used for the purpose of automated biometric verification or biometric identification; or
- (e) biometric templates.

health information means:

- (a) personal information or an opinion about:
 - i. the health or disability (at any time) of an individual; or
 - ii. an individual's expressed wishes about the future provision of health services to him or her; or
 - iii. a health service provided, or to be provided, to an individual;
- (b) other personal information collected to provide, or in providing, a health service; or
- (c) other personal information about an individual collected in connection with the donation, or intended donation, by the individual of his or her body parts, organs or substances; and
- (d) genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual.

2.2 Privacy Act 1993 (NZ) definitions

These definitions apply when considering information collected used, or disclosed in New Zealand: **personal information** means information about an identifiable individual; and includes information relating to a death that is maintained by the Registrar-General pursuant to the Births, Deaths, Marriages, and Relationships Registration Act 1995, or any former Act (as defined by the Births, Deaths, Marriages, and Relationships Registration Act 1995).

health information means:

- (a) information about the health of that individual, including his or her medical history; or
- (b) information about any disabilities that individual has, or has had; or
- (c) information about any health services or disability services that are being provided, or have been provided, to that individual; or
- (d) information provided by that individual in connection with the donation, by that individual, of any body part or any bodily substance of that individual or derived from the testing or examination of any body part, or any bodily substance of that individual; or
- (e) information about that individual which is collected before or in the course of, and incidental to, the provision of any health service or disability service to that individual.

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 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 Job applicants

BCT 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 will only collect personal information (including sensitive information and health information) that is necessary for the purposes of achieving one or more of its functions or activities. BCT primarily collects personal information and sensitive information for the purpose of conducting a breast cancer clinical trials programs and for its other related activities.

Personal information may be collected by BCT in a number of ways, including:

(a) Research

- according to clinical trial protocol requirements;
- annual General Meeting registration forms;
- BCT's membership applications;
- BCT's IMPACT – Improving Participation and Advocacy for Clinical Trials program application form; and
- as otherwise required and/or permitted under the Privacy Laws.

(b) Fundraising

- media campaigns (television, radio and print media including magazines);

- online advertising and internet campaigns;
- direct mail solicitation (including unaddressed mail pieces and rental of mailing lists);
- social media activities;
- special events and projects;
- third party intermediaries; and
- corporate sponsorship opportunities.

4.2 How we collect your personal information

We will usually collect your personal information directly from you, however sometimes 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;
- participants in BCT's clinical trials; and

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.

In collecting personal and sensitive information from participants in clinical trials conducted by BCT, BCT 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.

We will advise you if it is possible for you to be involved with us and for us to provide our services on anonymous basis or using a pseudonym. If you do not consent to the collection of your personal information or provide inaccurate information we may not be able to provide you our services. BCT will 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.

BCT will only collect personal information from third parties where you have consented to such collection or the collection is permitted by laws.

Personal information, including health information, from individuals is collected by institutions participating in BCT's 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 completed either manually or electronically and submitted to BCT. CRF's are study specific and in addition to any general hospital medical records. BCT does not usually collect personal information from patients participating in trials, but to the extent that it does, BCT

complies with the Privacy Laws and requires that institutions participating in the BCT clinical trials program comply with the Privacy Laws.

Health information may also be collected from BCT's IMPACT – Improving Participation and Advocacy for Clinical Trials program application form.

When necessary, relevant contact information is also collected via a free call 1800 number (or similar) for the purpose of recruitment to BCT's clinical trials, with consent.

5. Use and disclosure

BCT will 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 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 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;
- with the consent from the individual.

Personal information collected by BCT may be disclosed to overseas recipients only 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; or
- the disclosure is necessary for the purposes of conducting a trial approved by BCT and you have consented to the disclosure; or
- the disclosure is to facilitate third party service providers; and
- the disclosure is required or authorised under applicable law.

6. Direct communications

If we have done business with you, we may add your name and contact details to our publication or communications database list.

To keep you up to date with our services, publications, fundraising events and other resources, we may communicate with you, for example by contacting you via email. If you no longer wish to receive this information, you can just let us know and we will remove your details from the mailing list or alternatively, you can follow the opt out procedure included in all such correspondence by us.

7. Website

This section of the privacy policy explains how we handle your personal information which is collected from our website at www.breastcancertrials.org. This privacy policy applies to your use of our website and the use of any of the facilities on our website.

When you use our website, we do not attempt to identify you as an individual user and we will not collect personal information about you unless you specifically provide this to us.

However we do collect a cookie from visitors (including members who log in) to our website. A cookie is a small data file 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 privacy policy. We may create links from our website to third party websites. We are not responsible for the content or privacy practices employed by websites that are linked to our website.

8. Data Storage security of information

8.1 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 and security patrols.

(b) Computer

BCT 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 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 sign confidentiality deeds.

8.2 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.

9. Access, correction and removal

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

BCT takes reasonable steps to ensure that information held about an individual is accurate, complete and up to date. If it becomes aware that information held about an individual is not accurate, complete and up to date, it will amend its records accordingly.

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.

Individuals can request BCT not to disclose their personal information to other organisations and/or to be removed from all further marketing communications. Regular advice on how to be removed is contained in all mail correspondence and in verbal discussions where appropriate. If an individual elects not to receive further communications from BCT, BCT will retain certain personal information of that individual for the purpose of ensuring that they do not receive any further marketing communications from BCT.

A request for:

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

can be made by **contacting BCT** as follows:

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

10. Complaints

Individuals who have a question or wish to complain about the management of their personal information, should contact BCT, as set out below:

Privacy Officer
Breast Cancer Trials
PO Box 283
The Junction NSW 2291
AUSTRALIA

Ph: + 61 2 4925 3022 (within business hours)
Or email: privacy@bctrials.org.au

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

You can also lodge a complaint with the Office of Australian Information Commissioner.

If your complaint relates to an alleged breach by BCT of the *Privacy Act 1993* (NZ):

- BCT will acknowledge it in writing within five working days of receipt (unless it is resolved to your satisfaction within that period).
- Within ten working days of acknowledging receipt, we will decide whether we accept that the complaint is justified. If we need more time to investigate (and the additional time required is more than twenty working days), then we will inform you of that determination and the reasons for it.
- As soon as practicable after we determine whether a complaint is justified, we must inform you of the reasons for the decision, any actions we propose to take, any internal appeal procedure, and your right to complain to the Privacy Commissioner.

11. 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.