

Privacy Policy

Introduction

Neuroscience Research Australia (“NeuRA”) values and respects the privacy of all individuals and organisations seeking to donate time, personal information, money and resources to our organisation and to participate in research projects. NeuRA is committed to protecting the personal information that we hold and to managing it in an open and transparent manner.

This privacy policy (the “Policy”) sets out the type of personal information that we collect and use. It also provides some information about your privacy rights, along with our general obligations under applicable privacy laws including the *Privacy Act 1988* (Cth) and the Australian Privacy Principles (“Privacy Law”).

This Policy does not apply to NeuRA’s employee records.

1. What information NeuRA collects and holds?

The categories of personal information that NeuRA collects are set out below. NeuRA only collects personal information for the purpose of fulfilling its functions and activities.

(a) *Financial donors and supporters*

NeuRA may gather personal information (such as, name, address, phone number, bank account or credit card details and financial donation) from financial donors and supporters to enable NeuRA and the Neuroscience Research Australia Foundation (“NeuRA Foundation”) to send tax deductible receipts, newsletters, invitations to events and other information related to NeuRA and the NeuRA Foundation’s functions and activities. It is also used for fundraising purposes so that donors and supporters can be kept informed about news and events at NeuRA and the NeuRA Foundation, together with charitable and fundraising opportunities both inside and outside of NeuRA. At any time, a donor or supporter has the option to opt out of receiving such information from NeuRA by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000.

Only with a supporter or donor’s prior consent will we publish in our newsletters, bulletins and annual reports (which may appear on our website or in hardcopy form) the names and photographs of our donors and supporters. Where consent cannot be given, or where anonymity or pseudonymity is requested, donations will be published anonymously.

(b) *Research participants and patients, genetic and brain bank tissue and data*

NeuRA collects personal information (which may include name, sex, racial and educational background, date of birth, contact details, health information and photographic material) from research participants and patients for use in research projects and clinical trials. Where required, all research projects undertaken by researchers at NeuRA will have had prior approval from NSW ethics committee(s). Researchers undertaking those projects will first obtain the written consent of the individual to collect

any personal information that may be required for the research project. The personal information is securely stored, with only NeuRA's authorised personnel having access.

Personal information including biospecimens and the results of physical examinations and samples (where personal information has not been de-identified) will only ever be shared with third parties for research purposes and with the prior written consent of the patient or research participant.

Occasionally NeuRA may publish new stories in relation to patients and research participants. A patient or research participant's name and photographic material are only ever published with the written consent of the patient or participant.

NeuRA also collects de-identified personal information including genetic and brain bank tissue and data for research purposes.

(c) *Users of NeuRA products and services, including applications and tests*

NeuRA collects personal information including the name, contact, bank account details and application and test result data about the people who use or purchase NeuRA's products or services; for example users of downloaded applications and tests. This information is used by NeuRA for the purpose of supplying products and services; to track the categories of people who use NeuRA's products and services; and so that NeuRA can potentially provide future updates to users of its products and services. De-identified personal information, including data derived from a user or purchaser's test results, may also be used by NeuRA for research purposes and to enhance NeuRA's products and services.

(d) *Information about subscribers to newsfeeds/ mailing lists*

NeuRA collects the name and contact details about the subscribers to its newsfeeds and mailing lists for the purpose of distributing similar content to them. At any time a subscriber may remove themselves from NeuRA's mailing list by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000.

2. The quality and accuracy of personal information that NeuRA holds

NeuRA ensures, to the extent reasonably required, that all personal information it holds about an individual is kept accurate, up to date and complete.

3. How NeuRA stores and keeps personal information secure

NeuRA may store your personal information electronically or in hard copy form. All electronic data is stored on a secure network at NeuRA. All data is password protected and only accessible by authorised personnel. Hard copy paper records are stored in locked filing cabinets and/or secure rooms within NeuRA; with only authorised NeuRA personnel having access to those records.

Personal information is kept for no longer than is necessary for the purposes of the collection. NeuRA ensures that all personal information that it holds, which is no longer required is securely destroyed.

4. Anonymity

Wherever it is practicable, NeuRA allows individuals to deal with NeuRA anonymously or through use of a pseudonym in relation to a matter.

5. When and to whom NeuRA may disclose your personal information?

NeuRA will not disclose your health and genetic information or other sensitive information within the meaning of the Privacy Law, to a third party unless it is related to the primary purpose of the collection or unless NeuRA has obtained your prior written consent.

NeuRA may share non-sensitive personal information, such as your name, contact details and donation, with the NeuRA Foundation and third party charities to facilitate fundraising to you by those charities. If you would not like your personal information to be shared in this way please contact us and we will respect your wishes. At any time, you also have the option to opt out of NeuRA sharing personal information by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000.

The only other time that personal information may be disclosed to a third party is either where it has been de-identified or where the disclosure is required or authorised by law.

6. How you can access and correct personal information that NeuRA holds about you?

At any time, you may request access and/or correction of the personal information that NeuRA holds about you. The purpose of the information retention may also be queried.

There is no fee charged for requesting access to your information. If you find that the personal information we hold about you is inaccurate, incomplete or out of date, please contact us immediately and will take reasonable steps to either correct this information or, if necessary, discuss alternative action with you.

Please note that access to all or part of your personal information may be refused under Privacy Law.

You can request access or correction of your information by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000. NeuRA will provide you with a photocopy and/or printout of information held within 14 business days.

7. Disclosure of personal information outside Australia

From time to time some personal information may be disclosed outside Australia if directly related to the purpose of collection. For example, personal information may be disclosed to an overseas recipient for the purposes of collaborative research with an overseas not for profit entity or university. NeuRA will obtain your written consent prior to the disclosure or transfer of any personal information overseas.

8. Website Browsing

Accessing pages on NeuRA's website (www.NeuRA.edu.au) will result in the following information being logged:

- the time of access
- your internet protocol (IP) address
- the pages and any items downloaded from the www.NeuRA.edu.au webserver
- the type and version of the web browser you were using for access
- any search terms you used in a local site-search.

This information is held securely and cannot be used for identification purposes.

Any cookies created on your computer when accessing www.NeuRA.edu.au are removed at the end of your browser session. NeuRA does not permanently store any information and does not attempt to track users between visits.

The NeuRA website may contain links to external websites. NeuRA is not responsible for the content or privacy policies that govern these websites.

9. Complaints

Any complaints regarding the handling and management of personal information including an alleged breach of Privacy Law should be addressed to:

Administration and Compliance Manager
Neuroscience Research Australia
PO Box 1165
Randwick NSW 2031

Email: privacy@neura.edu.au

NeuRA takes complaints seriously and will respond to your complaint within 14 business days. If a breach is found, NeuRA will take steps to immediately rectify the breach.

10. Access to this Policy

This Policy is available from NeuRA's website: www.NeuRA.edu.au. You can also request a copy of it by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000. NeuRA will provide you with a copy free of charge.

This Policy is subject to regular review.