

Policy

Privacy

1. 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.

2. What type of personal information do we collect?

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 as a medical research organisation.

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 to send tax deductible receipts, newsletters, invitations to events and other information related to NeuRA 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. 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, and from research collaborators who are working on these 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, ethically approved consent of the patient or research participant.

NeuRA may publish or participate in media 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 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.

Some NeuRA study-specific websites may track visitors' personal information across sessions for the purpose of securely syncing data to the server. Consent for tracking will be explicitly obtained from each participant enrolled in the study using the site.

In accordance with PCI DSS legislation, financial information is not retained and stored in electronic form on its network or on any computer.

d. Information about subscribers to newsfeeds or 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 lists by contacting the reception staff at NeuRA between 8.30am and 5.00pm Monday to Friday on (02) 9399 1000, or by opting out of any digital subscription.

3. 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.

4. 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 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.

5. Anonymity

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

6. 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.

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.

Accessing and correcting your personal information

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 ensure it obtained your written consent, for example as part of the Human Research Ethics Consent Form, prior to the disclosure or transfer of any personal information overseas.

8. Website Browsing and Email correspondence

Accessing pages on NeuRA websites will result in the following information being logged on the hosting servers:

- the time and date of access
- your internet protocol (IP) address
- the pages accessed and any items downloaded
- the type and version of the web browser you were using for access
- any search terms you used in local site-searches.

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

Accessing NeuRA websites may result in the storage of cookies on your web browser or mobile device. Any cookies not expired at the end of the browser session are only retained for the end user's convenience (e.g. login/screen name) and are not used for tracking purposes.

NeuRA does not permanently store any information and does not attempt to track users between visits. Where Google Analytics is used to track aggregated web usage behaviour, associated user and event data retention periods are either disabled or set to the minimum possible.

NeuRA does not use web beacons in order to identify or track website visitors or email behavior.

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

9. Complaints

If you have any complaints about the way we have handled your personal information, please send your complaint in writing to:

Privacy Officer
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.

If you are not satisfied with our response, or you consider that we may have breached the Australian Privacy Principles or the Privacy Act, you are entitled to make a complaint to the Office of the Australian Information Commissioner. The Office of the Australian Privacy Commissioner can be contacted on 1300 363 992 or full contact details can be found online at www.oaic.gov.au.

10. Access to this Policy

This Policy is available from NeuRA's website: <http://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.

11. Review

This policy will be reviewed according to Company standard guidelines of five years after approval, unless there are any changes to the relevant legislation.

Appendix A: Approval & Document History

Document No	Responsible Officer	Approved by	Review Date
COM3	CEO	Company Board	12/12/24

Version	Approved by	Approval Date	Sections modified
1.0	NeuRA Board	14/4/14	Policy created.
2.0	NeuRA Governing Council	4/4/19	Updated logo and format, Section 2 – clarify type of organisation Section 6 – simplified title
	Company Board	9/4/19	Section 8 – updated text and provided more information on web browsing Section 9 – updated text, new paragraph added on OAIC
2.1	Company Board	5/8/19	Co-badged Mindgardens. Review every 5 years.
2.2	Executive Committee	12/12/19	Section 2(c) – data collection updated