

Privacy Policy

Our privacy commitment

Protecting your privacy is important to us. We comply with the *Privacy Act 1988* (Cth) (**Privacy Act**) and the Australian Privacy Principles set out in the Privacy Act when handling Personal Information.

This Privacy Policy explains:

- how The Kids Research Institute Australia (the **Institute**) treats the Personal Information provided to us by or on behalf of you;
- the types of Personal Information that we collect and use for the purposes of 1) improving the health of individuals and populations and 2) providing clinical and health services;
- details about your privacy rights (including how you may contact us if you have any concerns, complaints or questions about the handling of your Personal Information); and
- your general rights and obligations.

Key terms used in this Privacy Policy

In this Privacy Policy the expressions "**we**", "**us**" and "**our**" refer to the Institute. The expressions "**you**" and "**your**" refer to each individual whose Personal Information we may handle from time to time where we are required to comply with the Privacy Act in respect of such Personal Information. "**Privacy Policy**" means this document as amended from time to time.

What is Personal Information?

Personal Information means any information or an opinion about an identified individual, or an individual who is reasonably identifiable:

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

Some Personal Information may include Sensitive Information.

Sensitive Information has the meaning as set out in the Privacy Act, and includes health information.

What Personal Information do we collect?

The type of Personal Information we collect includes, but is not limited to, the following kinds of information:

- (a) name;

- (b) date of birth;
- (c) contact details (such as email, address, phone numbers);
- (d) sex and gender identity;
- (e) next of kin details;
- (f) payment information;
- (g) health or medical information, such as:
 - information about medical conditions or blood or other samples you have provided in connection with our medical trials or research;
 - other information as necessary for any research projects you have agreed to participate in; or
 - if we are providing you with a clinical or health service, information related to and needed for the provision of those clinical or health services, such as medical and family history, other health information, funding or billing details and other records as relevant; and
- (h) other Sensitive Information such as ethnicity.

Whose Personal Information do we collect?

We collect Personal Information from people who are connected to our operations and activities – including clients or participants attending our clinical and health services, potential employees, research participants, donors, students and volunteers.

How do we collect your Personal Information?

We collect Personal Information when you contact us, participate in any of our research projects, make a donation or apply for an employment opportunity with us.

If we provide you with a clinical or health service, we also collect Personal Information about you when you make an enquiry, book an appointment, complete forms and questionnaires, and during our interactions with you as part of the delivery of the clinical and health service.

Our preference is to collect Personal Information about you directly from you unless it is unreasonable or impracticable for us to do so. If we do collect Personal Information about you from third parties, such as your relatives or a third party healthcare provider, for example your GP, your insurers or Medicare, we will take reasonable steps to ensure you are made aware of the information collected and the reason and purpose of collection.

What happens if you don't provide all this information?

The Personal Information you provide to us is provided on a voluntary basis. If you do not provide some or all of the Personal Information requested, we may not be able to offer you all of our services (for example providing you with a health assessment or service, or a receipt for a donation or information about our causes, events, programs and projects). If you choose not to

provide us with full contact details, then you may not be contacted with updates on your research study, and we may not be able to provide you with clinical services.

Why do we collect your Personal Information?

Generally, to the extent permitted by applicable law, we only use and disclose your Personal Information for: (i) the primary purpose for which we collect the information; (ii) a secondary purpose reasonably (or directly if the Personal Information is Sensitive Information) related to the primary purpose for which you would reasonably expect us to use the collected information; or (iii) as otherwise permitted by the Privacy Act or applicable privacy laws.

The purposes for which we will use your Personal Information include (without limitation):

- research: conducting and/or funding child health research, for example participating in an online survey;
- donation purposes: sending you tax deductible receipts, newsletters, invitations and other Institute information;
- volunteering and other support: enabling you to assist us with volunteering, community fundraising, advocacy and other activities where we seek the community's assistance;
- service provision: account keeping, eligibility checks, billing and claiming, appointment management and therapy options, managing, training and clinically supervising personnel, auditing requirements, reports, referrals and correspondence and quality assurance, practice accreditation and complaint handling;
- recruitment: assisting us with engaging with you when you apply for a position with us;
- marketing: communicating with you about our operations and objectives and providing information to you about our activities, campaigns and events which we think you may be interested in (unless you have told us you do not want to receive such communications);
- verifying your identity; and
- complying with relevant laws.

To whom do we disclose your Personal Information?

Subject to the paragraph below, we do not share your information with any third parties unless we have your specific consent to do so and we do not sell or share mailing lists.

To the extent permitted by the Privacy Act and other applicable privacy laws, we may provide your Personal Information to:

- our staff, including paid employees and volunteers, as well as with third parties (including our subcontractors) providing services to us in relation to our activities and operations;
- third parties on a confidential basis for the purposes verifying your identity or as may be required by law;
- any third party to whom we assign or novate any of our rights or obligations or to any person that may acquire our business;
- your organisation, where you are acting on behalf of an organisation; and/or
- if we are providing you with a health service, with Medicare, the National Disability Insurance Agency and private health insurers.

Using a pseudonym or engaging with us anonymously

Where practicable, you will be given the opportunity to engage with us on an anonymous basis, or using a pseudonym.

Website usage information and cookies

When you browse the Institute's web site, you do so anonymously. We typically log your IP address (the Internet address of your computer) to give us an idea of which parts of our web site you visit and how long you spend there. However, we do not link your IP address to anything personally identifiable. The only other information automatically provided to us is the type of computer and operating system you are using. Your browser supplies us with this information.

Like many other web sites, the Institute web site may use a standard technology called a 'cookie' to collect information about how you use the site. 'Cookies' cannot be used to personally identify you.

Communication from us - opting out of direct marketing communications

We do not use Sensitive Information for marketing purposes.

Where you have requested this, we may use and disclose your Personal Information (other than Sensitive Information) to provide you with information about our activities, campaigns and events.

Where we use your Personal Information to send you marketing and promotional information by post, email or telephone, we will provide you with an opportunity to opt-out of receiving such information. We will always ensure that our opt-out notices are clear, conspicuous and easy to take up.

If at any time you no longer wish to receive any direct marketing communications from us or do not want your information disclosed for direct marketing, please contact our Development Services Manager, PO Box 855, West Perth, WA, 6872 or call us on 08 6319 1222.

Please note that even if you have requested not to receive further direct marketing communications, we may nevertheless continue to provide you with information about changes to our terms and conditions relating to our research and donation programs, health and clinical services and other factual information as permitted under the Privacy Act and the *Spam Act 2003* (Cth).

Where is your Personal Information stored?

Both us and our third party service providers or international research partners or collaborators to whom we disclose your Personal Information may hold electronic records of your Personal Information using cloud technology or by other electronic means, or in paper form. These means of holding Personal Information may include transferring and storing the information outside of Australia.

These third parties may be located overseas including but not limited to the countries specified in the Appendix below. It is not practicable for us to specify in advance the location of every service provider with whom we deal.

While we take steps that are reasonable in the circumstances to ensure the overseas recipient complies with Australian privacy laws,, the overseas recipient may not be subject to any

principles similar to the Privacy Act (including the Australian Privacy Principles). We cannot always control how these overseas recipients handle your Personal Information that we disclose to them. We require all our service providers to implement appropriate measures to ensure any such transfers comply with applicable privacy laws.

Data security

We will take such steps as are reasonable in the circumstances to protect the Personal Information we hold from misuse or loss and from unauthorised access, modification or disclosure including ensuring electronic data is stored securely and password protected.

We will also take steps as are reasonable in the circumstances to destroy or de-identify Personal Information once we no longer need it for any purpose for which the information may be used, disclosed or retained under the Privacy Act.

However, when using our website you should be aware that no data transmission over the Internet can be guaranteed as totally secure. Although we strive to protect such information, we do not warrant the security of any information that you provide us over the Internet and you do so at your own risk.

Changes to our Privacy Policy

We may change or update parts of this Privacy Policy in order to maintain our compliance with applicable law and regulation or following an update to our internal practices. We will do this by updating this Privacy Policy on www.thekids.org.au. You may obtain a copy of our current Privacy Policy from our website or by contacting us via the details provided below.

You may not be directly notified of such a change so please ensure that you regularly check this Privacy Policy so you are fully aware of any changes or updates.

Research project information

All research projects undertaken by the Institute involving Personal Information have been submitted to and approved by one or more Australian ethics committees. Research projects then obtain your consent to gather Personal Information such as your name and contact details as well as detailed health information.

How does the Institute use this research project information?

We use your Personal Information gathered as part of a research project to:

- process research project results looking for the causes or ways of preventing particular childhood conditions;
- process results of clinical trials related to treatments for particular childhood diseases;
- perform medical research and statistical analyses into the general health of populations to inform health providers and assist in government policy planning; and
- other purposes as outlined in the relevant research consent forms.

Access to your Personal Information

We will, upon your request, and subject to applicable privacy laws, provide you with access to your Personal Information that is held by us. However, we request that you identify, as clearly as possible, the type(s) of information requested. We will deal with your request to provide access to your Personal Information within 30 days. Your rights to access Personal Information are not absolute and privacy laws dictate that we are not required to grant access in certain circumstances.

If we refuse to grant you access to your Personal Information, we will provide you with reasons for that decision (within 30 days) and the avenues available for you to complain about the refusal.

Due to the potentially sensitive nature of some of the information we hold, we require photo identification of the applicant. Any applicant requesting information on behalf of a minor or other individuals for whom consent cannot be obtained must also provide proof of their relationship to this person.

Updating your Personal Information

We will take such steps as are reasonable in the circumstances to ensure that the Personal Information which we collect remains accurate, up to date and complete.

We will provide you with access to your Personal Information held by us unless we are permitted under the Privacy Act to refuse to provide you with such access. Please contact us at The Kids Research Institute Australia, PO Box 855, West Perth, WA, 6872 or call us on 08 6319 1000 or email privacy@thekids.org.au, if you:

- (a) wish to have access to the Personal Information which we hold about you;
- (b) consider that the Personal Information which we hold about you is not accurate, complete or up to date; or
- (c) require further information about our Personal Information handling practices.

There is no charge for requesting access to your Personal Information but we may require you to meet our reasonable costs in actually providing you with access.

Complaints

If you have a complaint or inquiry about the way in which we have handled any privacy issue, please contact us using the details below. We will use reasonable efforts to deal promptly with complaints and inquiries and, in any event, acknowledge your complaint within 30 days.

Privacy Officer, The Kids Research Institute Australia

PO Box 855, West Perth, WA, 6872

Telephone: (08) 6319 1000

Email: privacy@thekids.org.au

If you are not satisfied with how we manage your complaint, you may contact the Office of the Australian Information Commissioner.

Appendix: Locations of service providers/research partners

We hold and disclose Personal Information worldwide, including but not limited to the following countries:

- Chile;
- France;
- Germany;
- India;
- Sweden;
- United Kingdom; and
- United States of America.

| Version | Approved By | Approval Date | Review Date | Sections Modified | Owner | Implementation Officer | Author |
|----------------|-------------------------------|----------------------|--------------------|----------------------------------------------------------------------------------------------------------------|--------------------|-----------------------------------|-----------------------------------|
| 1.0 | | | | | | | |
| 2.0 | Risk and Compliance Committee | 11/04/14 | 11/04/17 | All: Revised following Privacy Amendment (enhancing privacy protection) Act 2012 which commenced in March 2014 | Executive Director | Head Risk and Compliance | Head Risk and Compliance |
| 3.0 | Risk and Compliance Committee | 06/12/19 | 06/12/22 | All | Executive Director | Legal Counsel | Corporate Governance |
| 3.1 | Executive Director | 13/09/2024 | 6/12/2022 | Update to align with new brand | Executive Director | Senior Lawyer, Legal & Governance | Senior Lawyer, Legal & Governance |
| 4.0 | Board | 8/05/2025 | 8/5/2028 | All: Update to reflect clinical services work | Executive Director | Senior Lawyer, Legal & Governance | Senior Lawyer, Legal & Governance |