

Who we are and what we do

Bellberry Limited is a national, not for profit organisation providing streamlined scientific and ethical review of human research projects across Australia.

Purpose

If you are a researcher, research participant, employee, stakeholder, or have another reason to interact with Bellberry, we may collect information about you in order to provide our services. This policy aims to tell you more about the information we collect, and how and why we do so. It also aims to tell you about how to ask for access or make a complaint.

The purpose of this policy is to provide information about:

- What personal information we collect.
- How we handle personal information; and how you can access your personal information or make a complaint about our handling of your personal information.
- This policy meets the requirements for APP1. When we collect personal information from you, we will seek consent or provide a privacy collection notice as required by APP5.

Bellberry is subject to the *Privacy Act 1988* (Privacy Act) and the *Australian Privacy Principles* (APPs). The APPs set out the manner in which agencies and organisations may collect, store, use and disclose personal information and how a person can access and/or correct records containing their personal information.

Definitions

The **Privacy Act** is an Australian law that regulates how Australian Government agencies and some private sector organisations handle personal information.

Personal information means information or an opinion whether true or not, and whether recorded in a material form or not, about an identified or reasonably identifiable individual.¹ Put simply, **personal information** includes a broad range of information, or an opinion, that could identify you or someone else. It may include employee record information, photographs, an individual's name, opinions and survey responses or signature or phone number.

Policy

At Bellberry, we are committed to recognising and valuing the importance of privacy. Handling personal information appropriately supports us in building and maintaining the trust of our employees, researchers, partners and the wider community.

As part of our commitment, we:

- Are transparent about our information handling practices.
- Only collect personal information that is necessary for the services we provide and, in particular, take steps to avoid collecting information about the participants in research projects.
- Ensure personal information is handled in accordance with the law, which includes limiting use and disclosure to purposes related (or for sensitive and health information, directly related) to our functions and activities.
- Take reasonable steps to keep all personal information secure.
- Base policies and practices on a sound understanding of privacy and security risks.

¹ See section 6 of the Privacy Act

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- Document policies on information and environmental security, records management and complaint handling.
- Provide privacy training to our employees and to Human Research Ethics Committee (HREC) members.
- Build privacy considerations into our contractual and other arrangements, where other organisations/ personnel are used to help deliver services.
- Monitor activities to ensure compliance and identify areas for improvement.
- Notify affected individuals and the Australian Information Commissioner in the event of a data breach in accordance with our regulatory obligations.

Collection of personal information

We collect personal information from you to carry out our activities and functions. We may also collect sensitive information about you. **Sensitive information** includes information such as race, ethnicity, religious beliefs and criminal records. We will only collect sensitive information about you with your consent unless we are authorised or required by law to do so.

Where possible, we will provide you the option of not identifying yourself, or use a pseudonym, unless it would be impractical for us to carry out our functions.

How we collect your personal information, what we collect and why we collect it depends on your relationship and interaction with us.

How do we collect your personal information?

Generally, we collect personal information directly from you. We may collect your information from you in a variety of ways, including:

- When you complete forms – either in hard copy or electronically such as via eProtocol (a software and information management service provided by Key Solutions Inc).
- From relevant records in HREC meetings.
- In online interactions through our website.
- Through platforms (including office 365, payroll systems, browser-based platforms etc). These types of platforms often include built-in analytics, tracking functionalities, and other digital surveillance features that may collect data by default. This collection is not always by explicit design but is a consequence of the technologies we employ. This kind of data is often referred to as metadata.
- Through email or other forms of communication.

Sometimes, we will collect personal information about you from a third party. This can include where you have consented to your personal information being shared by the third party, in other circumstances we will either issue a privacy collection notice or seek further consent.

What types of personal information do we collect and why do we collect it?

Your relationship with us:	Types of personal information we collect including, but not limited to:	Why we collect the personal information:
HREC member	- Name and contact details. - Curriculum vitae. - Attendance at relevant courses and attendance and contributions to HREC meetings. - Invoices and bank details for payment processing. - Age, gender and date of birth. - Ethnic background and religious beliefs. - Conflicts of interest. - Affiliations. - Employment relationships. - Contract commencement and expiry. - Performance information.	Establishing and managing HRECs To allow appropriately qualified people to be recruited and to ensure Bellberry meets the <i>National Statement on Ethical Conduct in Human Research (2025)</i> requirements including about the composition of HRECs, ongoing education of HREC members and HREC operations. Reviewing and monitoring research proposals Bellberry keeps agendas, minutes, background papers and other relevant documents for each HREC meeting. The personal information Bellberry collects in HREC records includes: Opinions and comments made by HREC members relating to study review.
Researcher	- Name, address and contact details. - Curriculum vitae including work history, post graduate training, professional college affiliations, publications and research trial experience. - Research role/position. - Professional indemnity details. - Professional registrations. - Operation and progress of research trial and any trial issues.	Reviewing and monitoring research proposals To provide ethics review and approval and to monitor projects to ensure they are being conducted in accordance with the HREC approval, as well as for internal records purposes. We also keep agendas, minutes, background papers and other relevant documents for each HREC meeting. Certain personal information such as details of researchers may be collected as part of this. Providing HREC services does not generally require us to collect personal information about

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Your relationship with us:	Types of personal information we collect including, but not limited to:	Why we collect the personal information:
		research participants and we take steps to avoid inadvertent collection, for example, as might otherwise occur in the context of a safety event. We monitor research sites to ensure research is being conducted within the scope and requirements of the HREC approval.
Subscriber to mailing list	- Names. - Email addresses. - Organisation details and addresses.	Creating and maintaining mailing lists. To enable us to: - Approach users to participate in research relevant to our activities, including market research (e.g., via focus groups or surveys). - Send newsletters and other information about our operations and activities. - Tell users about additional services that we provide related to its activities (e.g., training).
Enquirer or complainant (including family members, carers and responsible persons)	- Name and contact details of the complainant and, if we pursue the matter, the name and contact details of respondent. - Details of the problem or incident. - Evidence supporting the complaint which may include health information about the complainant. In limited circumstances it may also include medical information about other participants in the research where the participant has consented, or we are authorised or required by law to do so.	Responding to enquiries/complaints To resolves inquires and investigate complaints regarding the conduct of research approved by us, HREC or about our handling of personal information.

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Your relationship with us:	Types of personal information we collect including, but not limited to:	Why we collect the personal information:
	The results of enquires or investigations.	
Job applicant/Bellberry employee	- Name and contact details. - Curriculum vitae including work history and qualifications. - Tax file numbers and bank account details and nominated superannuation provider. - Referee reports and performance information. - Health information where relevant.	Recruitment and employment processes Administration of the recruitment process and to manage employment relationships.
Service provider/contractor/supplier	- Name and contact details. - Professional indemnity insurance.	Administrative activities
Bellberry Director	- Name and contact details. - Date of birth. - Tax file numbers; and bank details.	Administrative and regulatory obligations To pay fees, provide administrative support and to meet obligations under the <i>Corporations Act 2001</i>.
Trial Participants/Patients	(With the exception of complaint processes), we do not collect patient level/participant level information arising from research that we have oversight of.	

Search engines

When you browse our website,², we do not intentionally collect any personal information about you unless you choose to provide that information to us, such as through filling out a form or registering for an account. Our servers automatically gather some de-identified data about all visitors, including IP addresses, browser types, and times of visit, which help us improve our website and service. We do not use this data to personally identify you and is used solely for analytical purposes to understand website usage patterns.

The Bellberry website uses database software and Google Analytics to gather certain information to evaluate the effectiveness of the website and the level of interest in particular pages. The website only uses session cookies to track users to retain session information (so that once you log in you stay logged in until you either log out or close your browser). When you close your browser the session cookie is destroyed, and no personal information is kept which might identify you in the future.

Campaign Monitor allows us to gather information about how the newsletter is received. For example, we can generate reports about whether the newsletter has been opened, or was deleted without reading, and which pages were viewed. If you subscribe to our newsletter, you may opt out of further contact from us by clicking the unsubscribe option in all emails sent to you.

Disclosure of personal information

We will only disclose your personal information for the purpose we collected it. We will not use or disclose it for another purpose (a secondary purpose) unless you give your consent, or we are authorised or required by law to do so.

Generally, we only disclose personal information in the circumstances described below:

HREC establishment and management files

We may disclose personal information from these records to the National Health and Medical Research Council (NHMRC) or to the Australian Health Ethics Committee (AHEC) to meet accountability and monitoring requirements or if there is a complaint or investigation about committee activities. Some of that information may also be disclosed to external auditors.

HREC files associated with reviewing and monitoring research proposals

We may disclose some summary information to the NHMRC or AHEC in reports required under the *National Statement on Ethical Conduct in Human Research (2025)*, the *Australian Code for the Responsible Conduct of Research, 2018 (Code)* or *section 95 and 95A Privacy Act guidelines*. This information may also be shared with service providers engaged to support us in providing services (only if it is necessary to carry out their service to us). This includes Key Solutions Inc which is a US based company that provides the eProtocol software and information management service for HREC applications which Bellberry stores in Australia. Bellberry imposes strict conditions on this access.

² This information will not ordinarily be personal information, because you will not be identified, or reasonably identifiable from it.

Employee files

We may disclose information about our employees to the following, including:

- Health service providers.
- Other employers in the course of conducting referee checks.
- The Australian Taxation Office.
- Workplace regulators including for occupational health and safety and workers compensation.
- Superannuation and insurance bodies.
- External auditors.

Complaint files

We do not disclose any information about complainants without their knowledge and consent unless we are authorised or required by law to do so. We may be required to disclose some information about complaints to researchers and others involved in the process, the NHMRC, AHEC, the Australian Information Commissioner or other regulators or law enforcement bodies.

Bellberry director's files

We disclose information about directors to the Australian Securities and Investment Commission as required by the *Corporations Act 2001 (Cth)*.

Administration files

We may disclose information from these files to auditors, insurers, and accountants and to regulatory bodies to meet our accountability, monitoring and regulatory obligations including responding to a complaint or investigation.

Overseas disclosures

We will only disclose information about members to organisations for the purposes of HREC accreditation, such as the US based Office for Human Research Protections (OHRP) and the Association for the Accreditation of Human Research Protection Programs (AAHRPP), or as otherwise authorised or required by law.

We will only disclose personal information to overseas recipients where reasonable steps have been taken to ensure the overseas recipient does not breach the APPs in relation to your personal information.

Data quality

We take steps to ensure that the personal information collected is accurate, up to date and complete. These steps include maintaining and updating personal information when we are advised by the individuals concerned that their personal information has changed, and at other times as necessary. For example, one of our key sources of information is the applications and other documents submitted by researchers themselves.

Keeping your personal information safe

Data storage

Many of our records are stored electronically in the eProtocol system on secure servers. We also hold electronic records in a variety of digital settings including: the Bellberry data lake, employee records on file shares, office suite (including office 365), and our accounting systems. These servers are held either behind firewalls by Bellberry, or on accredited Cloud providers.

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We also hold hard copy records containing, for example, employee files, historical activities and some sensitive commercial-in-confidence material. Hard copy records are kept in access-controlled office premises and in locked cabinets where appropriate.

Data retention

We generally keep records for 15 years after the closure of the study in accordance with the *National Statement on Ethical Conduct in Human Research (2025)*. We keep records of studies concerning children permanently. Bellberry stores archived documents off site with a secure document management service.

Data deletion

When no longer required, personal information is destroyed in a secure manner under contract with a confidential waste management system for hard copy files and all electronic copies are deleted. Electronic storage equipment is physically removed and destroyed.

Data security

The steps we take to protect the personal information we hold against loss, unauthorised access, use, modification or disclosure and against other misuse include:

- Encryption technologies to safeguard data in transit and at rest.
- Access controls to ensure only authorised personnel can access sensitive information.
- Regular security training for our staff to recognise and prevent potential threats.

To validate the effectiveness of our security practices, we conduct regular testing, including penetration testing and vulnerability assessments.

Access to and correction of personal information

If you would like to:

- Know what, if any, personal information we hold about you.
- Request access to personal information we hold about you.
- Correct any personal information we hold about you.

You can contact us using our contact details in the 'Contact us' section below.

If you request access to your personal information or to correct information we hold about you, we may need to verify your identity. We will provide you with access to your personal information or make the requested changes, subject to any applicable exceptions under the *Privacy Act*.

If we refuse to provide you with access to or correction of your personal information, we will notify you in writing of the reason. We will also provide you with options that may assist you where relevant (e.g., you can provide us with a statement about why you believe information is incorrect and request attachment of the statement to the relevant record). If you are not satisfied, you may ask us to review the decision. If you remain dissatisfied, you may make a complaint to the Australian Information Commissioner.

How to make a complaint

If you believe we have not collected or handled your personal information in accordance with the Privacy Act, please contact us so that we can assist you. You can make a complaint using the contact details below. To ensure that we fully understand the nature of your complaint and the outcome you are seeking, we prefer that you make your complaint in writing.

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If you are not satisfied with our response you may take your complaint to the Australian Information Commissioner.

Contact us

If you have any questions or comments about this Privacy Policy, or you would like to make a complaint about how we have handled your personal information, or you wish to request access or correction to your personal information, please contact us by:

- Postal/in person: Bellberry Limited, Level 1, 196 Greenhill Road, Eastwood, SA 5063
- Telephone 08 8361 3222.
- Email: bellberry@bellberry.com.au

All complaints are opened by the Bellberry Business Manager.

Changes to this Privacy Policy

We may update this Privacy Policy from time to time to take account of changes to our operation and practices. This Privacy Policy is effective as of 13/02/2024.

References

[Privacy Act 1988](#)

[Office of the Australian Information Commissioner](#)

[Corporations Act 2001](#)

[Australian Code for the Responsible Conduct of Research, 2018](#)

[National Statement on Ethical Conduct in Human Research \(2025\)](#)

HRO P3 Complaints