

## Purpose

This policy outlines the manner in which Bellberry holds and protects highly confidential personal information and outlines all the information Bellberry collects about staff and the people who use the Bellberry services, including the Bellberry website, as per the Privacy Act 1988.

## Definitions

**The Privacy Act 1988** is an Australian law dealing with privacy.

**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.<sup>1</sup>

## Policy

Bellberry is defined as a small business operator for the purposes of the Privacy Act. While this means Bellberry is not obliged to comply with the Act it has voluntarily 'opted in' to the Privacy Act regime.

The Privacy Act requires 'entities' bound by the Australian Privacy Principles (the APPs) to have a privacy policy that outlines its information handling practices. A core ethical issue for Bellberry is respect for privacy.

Bellberry will:

- Only collect personal information that is necessary to the services Bellberry provides and, in particular, take steps to avoid collecting information about the participants in research projects.
- Appoint a privacy officer reporting to the Board of Directors.
- Base policies and practices on a sound understanding of privacy and security risks.
- Document policies on information and environmental security, records management and complaint handling.
- Providing privacy training to staff and to HREC members.
- Build privacy into Bellberry's 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 individuals and the Australian Information Commissioner in the event of a data breach that is likely to result in serious harm to result in serious harm to any individual affected.

## Collection

It is usual practice to collect personal information directly from the individual. Sometimes Bellberry will collect personal information from a third party but only if the individual has consented to such collection, or, would reasonably expect Bellberry to collect their personal information in this way, or, there are very serious circumstances where the Privacy Act allows Bellberry to do so.

Most of the information Bellberry collects comes via the Bellberry website where researchers and others may gather information or submit forms through eProtocol, a software and information management service provided by Key Solutions Inc. Bellberry also collects information in reports and discussions with HREC applicants and members and researchers.

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<sup>1</sup> See section 6 of [the Privacy Act](#)

Bellberry will only collect personal information for purposes that are directly related to functions or activities and only when it is necessary for or directly related to such purposes. These purposes and the related information collections are as follows.

### **Establishing and Managing HRECs**

Bellberry will collect information about HREC members to allow appropriately qualified people to be recruited and to ensure Bellberry meets the *National Statement on Ethical Conduct in Human Research* requirements including about the composition of HRECs, ongoing education of HREC members and HREC operations. The information Bellberry collects includes:

- name and contact details
- curriculum vitae
- attendance at relevant courses and attendance and contributions to HREC meetings.

Bellberry will also collect and store invoices and bank details for payment processing.

### **Reviewing and monitoring research proposals**

Bellberry will collect information about researchers and research proposals in order to provide ethics review and approval and to monitor projects to ensure they are being conducted in accordance with the HREC approval. The information collected about researchers includes:

- name, address and contact details
- curriculum vitae including work history, post graduate training, professional college affiliations, publications and research trial experience
- medical indemnity
- medical registrations
- operation and progress of research trial and any trial issues.

Providing HREC services does not generally require Bellberry Limited to collect personal information about research participants and Bellberry take steps to avoid inadvertent collection, for example, as might otherwise occur in the context of adverse event reports.

Bellberry monitor research sites to ensure research is being conducted within the scope and requirements of the HREC approval. Bellberry may collect information about researchers, but not research participants, as a result of the monitoring process.

Bellberry also keep agendas, minutes, background papers and other relevant documents for each HREC meeting. HREC records that Bellberry keep include:

- details of research proposals and a copy of the proposal and all related correspondence;
- name of principal researcher or researchers;
- terms and conditions, if any, of approval of any proposal;
- duration of the approval;
- mechanisms to be used to monitor the conduct of the research; and
- relevance, if any, of the Commonwealth, State or Territory legislation or guidelines relating to privacy of personal or health information.

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**Creating and maintaining mailing lists**

Where people consent, including by subscribing to offers on the Bellberry website, or becoming a registered user of Bellberry services, Bellberry collect email addresses so that Bellberry can:

- send newsletter and other information about Bellberry's operation
- approach users to participate in research relevant to Bellberry's activities, including market research, for example, via focus groups or surveys
- tell users about additional services that Bellberry provides related to its activities such as training
- unsubscribe section.

Complaints must be managed in accordance with the Bellberry Complaints Policy (CG P9).

**Responding to complaints**

Bellberry may need to collect personal information to investigate and resolve complaints regarding the conduct of research approved by a Bellberry HREC or about Bellberry's handling of personal information.

The information Bellberry collects includes:

- name and contact details of the complainant and, if Bellberry pursue the matter, the respondent
- details of the problem or incident
- evidence supporting the complaint which may include health information about the complainant. In very limited circumstances it may also include medical information about other participants in the research. This would be where the participant has consented, or where it is not possible to gain consent, only when it is necessary to lessen or prevent a serious threat to life, health or safety or Bellberry suspect that unlawful activity or serious misconduct is involved in the incident
- results of enquires or investigations.

**Employing staff**

Bellberry collect personal information about applicants and employees to allow appropriate staff to be recruited and to manage the employment relationship. The information Bellberry collects includes:

- 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 and
- health information where relevant.

**Bellberry directors**

Bellberry collects information about company directors to pay fees, provide administrative support and to meet obligations under the Corporations Act 2001. The information collected includes name, date of birth and contact information, tax file numbers and bank details.

**Administer the company**

Bellberry collects information to administer the company. These records will contain limited personal information relating to contractors, suppliers and other administrative activities including medical indemnity insurance.

Bellberry will only use or disclose personal information for the purposes for which it was given, or for purposes which are directly related to one of Bellberry's functions or activities. Bellberry do not give it to other government agencies, organisations or anyone else unless one of the following applies:

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- the individual has consented
- to have discussions with a regulator or a relevant professional body about a study or an investigator conducting a study
- the individual would reasonably expect, or has been told, that information of that kind is usually passed to those individuals, bodies or agencies
- it is required or authorised by law
- it will prevent or lessen a serious and imminent threat to somebody's life or health
- it is reasonably necessary for the enforcement of the criminal law or of a law imposing a pecuniary penalty, or for the protection of public revenue.

The purposes for which Bellberry use personal information are set out in the section on Collection above. Bellberry generally only disclose personal information in limited circumstances as follows.

**HREC establishment and management files**

Bellberry may disclose information from these records to the 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 information may be disclosed to external auditors.

**HREC files associated with reviewing and monitoring research proposals**

Bellberry may disclose some summary information to the NHMRC or AHEC in reports required under the *National Statement on Ethical Conduct in Human Research*, the Code or the section 95 and 95A guidelines. Bodies assisting Bellberry in providing services have access to the information 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.

**Staff files**

Bellberry may need to disclose information about staff to health service providers, other employers in the course of referee checks, the Australian Taxation Office, work place regulators including for occupational health and safety, and workers compensation and superannuation and insurance bodies. External auditors may also review files.

**Complaint files**

Bellberry do not disclose any information about complainants without their knowledge and consent unless authorised or required by law. With the knowledge and consent of the complainant, Bellberry may need 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**

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

**Administration files**

Bellberry may disclose information from these files to auditors, insurers, and accountant and to regulatory bodies.

### Overseas disclosures

Bellberry discloses limited information about members when registering HRECs with the US based Office for Human Research Protections (OHRP) to enable ethics approvals conducted by Bellberry HRECS to be taken into account in US ethics approval processes.

### Data quality

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

Bellberry's records are stored electronically in the eProtocol system on secure servers held behind firewalls by Bellberry. Bellberry also hold hard copy records, for example for staff 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.

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

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.

Bellberry takes steps to protect the personal information it holds against loss, unauthorised access, use, modification or disclosure and against other misuse. Policies are developed following careful assessment of risks and are regularly reviewed.

If a person asks for access to the personal information Bellberry holds about them, or asks that Bellberry change that personal information, Bellberry will allow access or make the changes unless Bellberry considers that there is a sound reason which is authorised under the Privacy Act or other relevant law to withhold the information or to not make the requested change.

If Bellberry do not agree to provide access to personal information to the individual, Bellberry will tell the individual why in writing. The individual may ask Bellberry to review the decision and if not satisfied may make a complaint to the Australian Information Commissioner.

If Bellberry do not agree to make requested changes to personal information Bellberry will tell the individual why in writing. The individual may make a statement about the requested changes and Bellberry will attach this to the record.

Individuals can obtain further information about how to ask for access or changes to the information Bellberry holds about them by contacting Bellberry (see details below).

When people only browse the Bellberry website, Bellberry do not collect their personal information. Sometimes, Bellberry collects personal information that people choose to give us via online forms or by email, for example when people ask to subscribe to the Bellberry newsletter.

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The secure area of the website also allows:

- Submissions to be made online
- Researchers to track the process of their application at all times
- Committee members to communicate with each other outside of meetings
- Management of committee minutes and correspondence

Bellberry collects the following information to manage newsletter subscriptions:

- Name
- Email address
- Organisation
- Address

The Bellberry website also uses database software and Google Analytics to gather 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 to Bellberry in the future.

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

Any changes to the privacy policy will be published on the services that Bellberry provide.

If you think that Bellberry have mishandled your personal information you may ask Bellberry to consider the matter and if you are not satisfied may make a complaint to the [Australian Information Commissioner](#).

### How to contact Bellberry

To exercise any of your rights or choices or for further information:

- Postal/in person: Bellberry Limited, 129 Glen Osmond Road Eastwood South Australia 5063
- Telephone 08 8361 3222
- Email: [bellberry@bellberry.com.au](mailto:bellberry@bellberry.com.au)

Bellberry Limited has adopted relevant National Standards for Information Security including: AS/ANZ ISO/IEC 27001:2006 Information Technology – Security techniques- Information security management systems – Requirements; and AS/NZS ISO/IEC 27002:2008 Information technology – Security techniques- Code of practice for information security management and AS ISO 15489.1 – 2002 Records Management.

### References

[Privacy Act 1988](#)

[Office of the Australian Information Commissioner](#)

CG P9 Complaints Policy