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Why Bellberry Limited has a privacy policy

The *Privacy Act 1988* (the Privacy Act) requires 'entities' bound by the Australian Privacy Principles (the APPs) to have a privacy policy that outlines its information handling practices. Respect for privacy is a core ethical issue for our work. This privacy policy therefore reflects our commitment to provide a high quality service that respects the privacy of our staff and protects the highly confidential personal information we hold about Human Research Ethics Committee (HREC) members and researchers and their research projects.

It covers all the information we collect about our staff and the people who use our services. It also covers our website and the various webpages accessible at www.bellberry.com.au, eprotocol.bellberry.com.au, www.nationalpicf.com.au, www.nationalscientificcommittees.org.au and www.ctiq.com.au.

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

Content of the policy

This policy has three sections that set out information about:

- Bellberry – this section sets out information about Bellberry and its approach to privacy governance and accountability
- Our Personal Information Handling Practices – this section explains our general information handling practices across the company including how we collect, use, disclose and store personal information. It addresses the requirements of the APPs and will tell you about the sort of records we keep and why
- Our Website – this section explains our personal information handling practices when you visit our website.

About Bellberry

Bellberry Limited is a national, private, not for profit organisation providing streamlined scientific and ethical review of human research projects across Australia. The Company establishes and manages human research ethics committees (HRECS) that review human research projects and give an opinion on the safety of the research to researchers across Australia. Bellberry is governed by a Board of Directors who are listed on our website.

Bellberry Human Research Ethics Committees

Bellberry Limited has a number of HRECs. The HRECs are registered and certified under the National Approach to Single Ethical Review of Multi-Centre Research (National Approach)² with the National Health and Medical Research Council (NHMRC) and abide by the 'the National Statement on Ethical Conduct in Human Research 2007 incorporating any updates' (the National Statement). Bellberry HRECs also operate in accordance with the NHMRC guidelines issued under sections 95 and 95A and of the Privacy Act (section 95, and 95A guidelines).³

¹ See section 6 of the Privacy Act at www.austlii.edu.au/au/legis/cth/consol_act/pa1988108/s6.html

² <https://www.nhmrc.gov.au/health-ethics/national-approach-single-ethical-review-multi-centre-research>

³ The National Statement and the guidelines issued under sections 95 and 95A and of the Privacy Act are available at <https://www.nhmrc.gov.au/guidelines/search>

Our approach to Governance, Accountability and Compliance

The steps we take to protect privacy to a high and transparent standard include:

- only collecting personal information that is necessary to the services we provide and, in particular, taking steps to avoid collecting information about the participants in research projects
- appointing a privacy officer reporting to the Board of Directors
- basing our policies and practices on a sound understanding of privacy and security risks
- documenting policies including on security, records management and complaint handling
- providing privacy training to staff and to HREC members
- considering privacy, and building this into our contractual and other arrangements, where we use other organisations to help us deliver our services
- monitoring our activities to ensure compliance and to identify areas for improvement
- notifying individuals and the Australian Information Commissioner in the event of a data breach that is likely to result in serious harm to any of the information subjects.

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

Collection

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

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

We only collect personal information for purposes that are directly related to our 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 – We collect information about HREC members to allow us to recruit appropriately qualified people and to ensure we meet the National Statement requirements including about the composition of HRECs, ongoing education of HREC members and HREC operations. The information we collect includes:

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

We also collect and store invoices and bank details for payment processing.

Reviewing and monitoring research proposals – We 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 we take steps to avoid inadvertent collection, for example, as might otherwise occur in the context of adverse event reports.

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

We also keep agendas, minutes, background papers and other relevant documents for each HREC meeting. Records that we keep for HRECs 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.

Creating and maintaining mailing lists – Where people consent, including by subscribing to offers on our website, or becoming a registered user of Bellberry services, we collect email addresses so that we can:

- send our 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.

Responding to complaints – if people complain to us about the conduct of research approved by a Bellberry HREC or about Bellberry's handling of personal information about them we may need to collect personal information to investigate and resolve the matter. The information we collect includes:

- name and contact details of the complainant and, if we 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 we suspect that unlawful activity or serious misconduct is involved in the incident
- results of enquires or investigations

Employing staff – We collect personal information about applicants and employees to allow us to recruit appropriate staff and to manage the employment relationship. The information we collect 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 – We collect information about our 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 – We collect information to administer the company. These records will contain limited personal information relating to our contractors, suppliers and other administrative activities including medical indemnity insurance.

Use and disclosure

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

- 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 we use personal information are set out in the section on Collection above. We generally only disclose personal information in limited circumstances as follows.

HREC establishment and management files – We 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 our committee activities. Some information may be disclosed to our 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, the Code or the section 95 and 95A guidelines. Bodies assisting us 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 we store in Australia. We impose strict conditions on this access.

Staff files – We may need to disclose information about our 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. Our external auditors may also review files.

Complaint files – We 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, we 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 – We disclose information about our 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 our auditors, insurers, and accountant and to regulatory bodies.

Overseas disclosures

We disclose limited information about members when registering our 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

We take steps to ensure that the personal information we collect is accurate, up to date and complete. These steps include maintaining and updating personal information when we are advised by the people 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.

Data security

We take steps to protect the personal information we hold against loss, unauthorised access, use, modification or disclosure and against other misuse. Our policies are developed following careful assessment of risks and are regularly reviewed.

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

We generally keep our records for 15 years after the closure of the study in accordance with the National Statement. We keep records of studies concerning children permanently. We store archived documents off site with a secure document management service.

When no longer required, personal information is destroyed in a secure manner under our 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.

Access and correction

If a person asks for access to the personal information we hold about them, or asks that we change that personal information, we will allow access or make the changes unless we consider 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 we do not agree to provide access to personal information to the individual, we will tell the individual why in writing. The individual may ask us to review the decision and if not satisfied may make a complaint to the Australian Information Commissioner.

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

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

Our Website

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

The secure area of the website also allows:

- submissions to be made on line
- 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 subscriptions to our newsletter:

- Name
- Email address
- Organisation
- Address

Our website also uses database software and Google Analytics to gather information to evaluate the effectiveness of our website and the level of interest in particular pages. Our 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 us in the future.

Campaign Monitor allows us to gather information about how our 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.

Changes to Privacy Policy

We will change this policy from time to time. We will let you know of any changes, for example, when we next contact you. However we recommend that you re-visit our website regularly to learn of new privacy practices or changes to our policy.

Your right to make a privacy complaint

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

How to contact us

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

email us at bellberry@bellberry.com.au.

write to us at:

Bellberry Limited
123 Glen Osmond Road
EASTWOOD SOUTH AUSTRALIA 5063

telephone or fax us on:

Phone: 08 8361 3222

Fax: 08 8361 3322