

EPILEPSY QUEENSLAND INC

Privacy Policy	
Authorised by: Chief Executive Officer	Date of Review: September 2009
Date of Development: September 2007	

Policy Statement:

Epilepsy Queensland supports the importance that the community places on the maintenance of confidentiality of individuals' personal and/or sensitive information. This extends to the collection and management of information held in Epilepsy Queensland's records regarding all individuals.

In order to pursue our mission and goals, Epilepsy Queensland must provide assurances to the community of its commitment to privacy of personal information.

The Privacy Amendment (Private Sector) Act 2000, effective 21 December 2001, sets out guidelines which regulate how organisations should treat personal and/or sensitive information they collect, use, handle or store.

What do the National Privacy Principles do?

The National Privacy Principles (NPP's) set minimum standards for:

- Collection, use and disclosure of personal information which could identify a person
- Quality, security and storage of that information
- Giving an individual access to their information
- Transferring information offshore, and
- Special categories of information such as "sensitive" information and "health" information.

What is personal information?

- Information or an opinion about an individual whose identity is apparent or can be ascertained from that information or opinion, and
- Includes names, addresses, telephone numbers, age and e-mail addresses.

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What is sensitive information?

This includes information about:

- Racial or ethnic origin
- Political opinion or association
- Trade union or professional association membership
- Religious beliefs or philosophical beliefs
- Sexual preferences
- Criminal record
- Financial details, and
- Health information.

What are the National Privacy Principles?

The National Privacy Principles establishes 10 principles to which an organisation must comply in regard to personal and sensitive information.

NPPI	Collecting information
NPP2	Using and disclosing information
NPP3	Data quality
NPP4	Data security
NPP5	Openness
NPP6	Access and correction
NPP7	Identifiers
NPP8	Anonymity
NPP9	Transborder Data Flow
NPP10	Sensitive information

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Collection of information

- Personal and sensitive information is only collected as is reasonably necessary for a function or activity to enable Epilepsy Queensland to maintain its activities and deliver services to the community and to maintain contact when relevant. This may include information from clients, service providers, service users, donors, supporters, staff, volunteers and other relevant stakeholders.
- Personal information about an individual should only be collected from that individual and with their consent.
- Collection will be undertaken by a method which is fair, lawful and non-intrusive.
- Individuals from whom personal information is collected are to be made aware of:
 - Epilepsy Queensland contact details
 - The primary purpose for which the information is collected

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- Any possible secondary purpose for which the information may be used, and
- The ability of individuals to access the information held on themselves.

Use and Disclosure of Information

- Information will only be used or disclosed for the primary purpose for which it was collected. In some instances, information provided by individuals may be used to keep them better informed about Epilepsy Queensland activities and services, such as by way of a newsletter. Individuals will have the right to opt out of receiving such additional mailings.
- Personal information about an individual will not be used or disclosed for a secondary purpose unless:
 - The purpose is closely related to the primary purpose and the individual would reasonably expect the information to be used in that way, or
 - The information is health information and its use is:
 - o To provide client services that have been requested
 - o For records or statistical analysis relevant to public health, or
 - o The information is necessary for funding requirements eg reports to Disability Services Queensland, or
 - The client has consented (recognising the competence to consent), or
 - Epilepsy Queensland has a legal obligation to disclose personal information which overrides the provisions of the primary legislation, or
 - Epilepsy Queensland is concerned that there is a serious risk to the client's life or that there is a danger to others.

Epilepsy Queensland will not sell or exchange or release personal information about an individual for commercial gain.

Quality of information

- Reasonable steps will be taken to ensure information collected and used is complete, accurate and up to date.

Security of Information

- Reasonable steps will be taken to ensure that personal information from misuse, loss, unauthorised use, modification or disclosure.
- Personal information will be destroyed or permanently de-identified when it is no longer needed for the purpose for which it was collected.

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- Epilepsy Queensland website will use secure technology for on-line transactions to protect personal details including credit card information.
- Epilepsy Queensland website will contain links to other websites. Epilepsy Queensland does not accept responsibility for the privacy practices or the content of linked websites.

Openness of Information

- This privacy policy setting out our management of personal information is available on request and will be posted on Epilepsy Queensland website.
- Reasonable steps will be taken to allow any person, on request to know generally what is the content of personal information held about them, for what purpose it is held, how it was collected, is stored and used.

Accessibility of Information

Information held on an individual is accessible on request (except where frivolous and vexatious) and will generally be available free of charge. Reasonable steps will be taken to ensure the information provided is accurate and up to date.

Identifiers

- Identifiers used will be unique to Epilepsy Queensland.

Anonymity

- Individuals have the option of not identifying themselves when dealing with Epilepsy Queensland.

Transborder Data Flow

- Epilepsy Queensland will not sell, exchange or release personal information.

Sensitive Information

- Sensitive information about an individual will not be collected without that individual's consent, or
- The information is collected in the course of Epilepsy Queensland activities where the individual is in regular contact in relation to those activities and the individual understands that the information will not be disclosed without consent, or
- The information is necessary for funding requirements eg Disability Services Queensland, research relevant to public health, compilation

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or analysis of public health statistics, the management or monitoring of a health service and that purpose cannot be served by collection of non-identified information and it is impracticable to seek the individual's consent.

Confidentiality

- Personal and/or sensitive information will be collected and maintained on confidential databases maintained by Epilepsy Queensland in support of its activities and service provision.
- Staff who may have access to personal and/or sensitive information in the course of their duties, will respect its confidentiality and not disclose the information to any third party.
- Breaches of confidentiality will be dealt with in accordance with the conditions of appointment to the staff of Epilepsy Queensland.

Standards: 4.1, 4.2, 4.3, 4.4, 4.5, 4.6

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APPENDIX ONE – ACCESS TO ‘PERSONAL INFORMATION’ PROCEDURE

1. Procedure for requests by an individual for Access to Personal Information about the individual held by Epilepsy Queensland

- Individuals are entitled to access their Personal Information¹ held about them by us on request except where we can lawfully deny or limit access as prescribed by the Privacy Act 1988.
- An individual who is accessing personal information about themselves does not need to provide a reason for requesting access.
- The request will be assessed by the Chief Executive Officer.
- If access is to be given the Chief Executive Officer will as soon as possible and in any event no more than 7 days after the request, contact the Individual and indicate the range of choices of how access will be available depending on the individual’s particular needs. This may include:
 - Providing the individual with the information requested
 - Providing copies of the information, and/or
 - Providing a suitable person to assist the individual access the information
- If the individual believes that the Personal Information held about them is inaccurate, incomplete, or not up to date, the individual may request amendment of the information held.
- If the individual is able to establish that the information is not accurate, complete and/or up-to-date, we will take reasonable steps to correct the information.
- If we do not agree, we will note the individual’s request to amend on a conspicuous place with the information challenged.
- When processing the request for access, the Chief Executive Officer answers any of the following questions in the affirmative, further direction should be sought to determine whether access is to be allowed:
 - would providing access pose a serious threat to the life or health of any individual?
 - would providing access unreasonably affect the privacy of other individuals?

¹ For the definition of Personal Information see our Privacy Policy

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- is the request for access frivolous or vexatious? For example, is the request made simply to cause inconvenience; has the requesting individual repeatedly and unreasonably requested the same information?
 - are there legal proceedings between the individual requesting the information and Epilepsy Queensland? If so, advice should be sought as to whether the information is legally privileged or whether access should be denied to the individual in the proceedings.
 - Are there negotiations between the individual and Epilepsy Queensland? If so advice should be sought as to whether providing access would prejudice those negotiations;
 - would providing access be unlawful?
 - Is Epilepsy Queensland required or authorised by law to deny access?
 - are there any investigations of unlawful or improper activity being conducted at Epilepsy Queensland? Advice should be sought as to whether providing access would be likely to prejudice that investigation or the conduct of proceedings before court or the enforcement of law.
 - is the information commercially sensitive? Advice should be sought as to whether instead of providing access the individual is given an explanation for the commercially sensitive decision.
 - if Epilepsy Queensland are not required to provide the individual with access to the information because of any of the above, consider if Epilepsy Queensland could provide a person to act as an intermediary, allowing sufficient access to meet the needs of the individual and Epilepsy Queensland.
- Epilepsy Queensland will provide reasons for denial or limitation of access or a refusal to correct personal information.

2. Procedure for requests by an individual for access to personal information held by Epilepsy Queensland about another individual

- As a general rule we are obliged by the Privacy Act 1988 (as amended) to not disclose personal information about an individual to anyone other than the individual unless the individual whose personal information in question has consented, or the disclosure is otherwise allowed by the Privacy Act 1988.
- Situations where the access will be allowed by the act include:

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- where the request has come from a person to whom an appropriate power of attorney has been given. In most cases this will mean that an Enduring Power of Attorney is necessary. To comply with the Privacy Act 1988 suitable identification must be given and the original or a certified copy of the Attorney Document must be sighted.
 - where the disclosure is required by law or an enforcement authority.
 - where the individual has consented to another person accessing that information. Access will be denied in circumstances where it would be against the individuals expressed wishes.
- Epilepsy Queensland is, at our discretion, entitled to disclose personal information without consent to a relevant person/organisation/authority in situations including:
- If there is a perceived or real risk to the individual or to others
 - Where the individual is
 - a) physically or legally incapable of giving consent to the disclosure;
 - b) physically cannot communicate consent to the disclosure; and
 - c) a carer providing the health service for the organisation is satisfied that either:
 - i. the disclosure is necessary to provide appropriate care or treatment of the individual; or
 - ii. the disclosure is made for compassionate reasons; and
 - iii. the disclosure is not contrary to any wish expressed by the individual before the individual became unable to give or communicate consent; and of which the carer is aware, or of which the carer could reasonably be expected to be aware; and
 - iv. the disclosure is limited to the extent reasonable and necessary due to the individual being physically unable to communicate consent.

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- A person is responsible for an individual if the person is:
 - a parent of the individual; or
 - a child or sibling of the individual and at least 18 years old; or
 - a spouse or de facto spouse of the individual; or
 - a relative of the individual, at least 18 years old and a member of the individual's household; or
 - a guardian of the individual; or
 - exercising an enduring power of attorney granted by the individual that is exercisable in relation to decisions about the individual's health; or
 - a person who has an intimate personal relationship with the individual; or
 - a person nominated by the individual to be contacted in case of emergency.

- Definitions:
 - A child of an individual includes an adopted child, a step-child and a foster-child, of the individual.
 - A parent of an individual includes a step-parent, adoptive parent and a foster-parent, of the individual
 - A relative of an individual means a grandparent, grandchild, uncle, aunt, nephew or niece, of the individual.
 - A sibling of an individual includes a half-brother, half-sister, adoptive brother, adoptive sister, step-brother, step-sister, foster-brother and foster-sister, of the individual.

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APPENDIX TWO - PRIVACY GRIEVANCE PROCEDURE

An individual may make a complaint alleging a breach of an individual's Privacy or a refusal by us to provide access to Personal Information

The Complaint may be made to Epilepsy Queensland or the Privacy Commissioner.

Complaints to the Privacy Commissioner will, in most circumstances, be referred to us to enable us to attempt to first resolve the complaint.

When we receive a complaint we will acknowledge receipt to the individual (and, if the complaint has been referred by the Commission, to the Privacy Commissioner) within 7 days of receipt

We will also ensure that we have sufficient detail to understand and investigate the complaint and if necessary we will ask the individual to provide further explanation or material.

Within 14 days of receiving material sufficient to understand and investigate the complaint we will inform the individual that we are investigating the complaint and will contact the individual again within 14 days.

During that time we will prepare an Investigation Report (the 'Report') which due the nature of the material will be kept confidential and accessed only in accordance with our Privacy Policy and the *Privacy Act 1988 (as amended)*.

Once the Report is prepared the individual will be invited to discuss the complaint with us with a view to resolution of the complaint.

The individual will have access to the contents of the Report in accordance with our Privacy policy and the *Privacy Act 1988 (as amended)*.

If we are able to resolve the matter, the terms of the resolution should be recorded in writing, signed as agreed by us and the individual. and, if required , provided to the Privacy Commissioner.

If:

We, or the individual, decline to participate in a meeting or resolution as a whole or in part is not achieved at the meeting either we or the individual may propose a mediation of the dispute conducted by a mediator agreed between the parties or, in the event that there is no agreement as nominated by the Privacy Commissioner.

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Or if:

We, or the individual, decline to participate in a mediation or Resolution as a whole or in part is not achieved at the mediation the matter can then be referred to the Privacy Commissioner for assistance.

To assist the Privacy Commissioner we will provide:

The Report provided we are satisfied that to do so will not breach our obligations under the Privacy Act 1988 (as amended) and details of matters which remain in dispute and a further report detailing the steps taken to resolve the complaint prior to Privacy Commissioner's involvement.