

# Data Protection

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1) Guillain-Barré & Associated Inflammatory Neuropathies (**gain**) needs to collect and use certain types of information about members, patients and others who come into contact with **gain** in order to operate. This personal information must be dealt with properly however it is collected, recorded and used – whether on paper, in a computer, or recorded on other material – and there are safeguards to ensure this in the Data Protection Act 1998.

2) **gain** regards the lawful and correct treatment of personal information as very important to its operations, and to maintaining confidence between **gain** and those it deals with. **gain** ensures that personal information is treated lawfully and correctly. To this end **gain** fully endorses and adheres to the Principles of Data Protection, as detailed in the Data Protection Act 1998 and is registered with Information Commissioner.

3) Specifically, the Principles require that personal information:

- shall be processed fairly and lawfully and, in particular, shall not be processed unless specific conditions are met;
- shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes;
- shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed;
- shall be accurate and, where necessary, kept up to date;
- shall not be kept for longer than is necessary for that purpose or those purposes;
- shall be processed in accordance with the rights of data subjects under the Act;
- appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data;
- shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

4) **gain** will, through appropriate management, strict application of criteria and controls:

- observe fully conditions regarding the fair collection and use of information;
- meet its legal obligations to specify the purposes for which information is used;
- collect and process appropriate information, and only to the extent that it is needed to fulfil operational needs or to comply with any legal requirements;
- ensure the quality of information used;
- apply strict checks to determine the length of time information is held;
- ensure that the rights of people about whom information is held, can be fully exercised under the Act. (These include: the right to be informed that processing is being undertaken, the right of access to one's personal information, the right to prevent processing in certain circumstances and the right to correct, rectify, block or erase information which is regarded as wrong information);

- take appropriate technical and organisational security measures to safeguard personal information;
- ensure that personal information is not transferred abroad without suitable safeguards;
- treat people justly and fairly whatever their age, religion, disability, gender, sexual orientation or ethnicity when dealing with requests for information;
- set out clear procedures for responding to requests for information.

5) In addition, we will ensure that:

- there is someone with specific responsibility for Data Protection within GAIN;
- everyone managing and handling personal information understands that they are contractually responsible for following good data protection practice;
- everyone managing and handling personal information is appropriately trained to do so,
- everyone managing and handling personal information is appropriately supervised;
- anybody wanting to make enquiries about handling personal information knows what to do;
- queries about handling personal information are promptly and courteously dealt with;
- methods of handling personal information are clearly described;
- a regular review and audit is made of the way personal information is held, managed and used;
- methods of handling personal information are regularly assessed and evaluated;
- performance with handling personal information is regularly assessed and evaluated;
- a breach of the rules and procedures identified in this policy may lead to disciplinary action.

6) This policy will be updated as necessary to reflect best practice in data management, security and control and to ensure compliance with any changes or amendments made to the Data Protection Act 1998.

7) In case of any queries or questions in relation to this policy, please contact **gain**'s Data Protection representative.

8) **gain**'s Data Protection representative is the Director.