



1 Aims

Hereditary Spastic Paraplegia Support Group (HSPSG) needs to keep certain information on its trustees, volunteers, members, supporters and other individuals to carry out its day-to-day operations, to meet its objectives and to comply with legal obligations.

HSPSG is committed to ensuring any personal data is dealt with in line with the General Data Protection Regulation (GDPR). To comply with the law, personal information will be collected and used fairly, stored safely and not disclosed to any other person unlawfully.

The aim of this policy is to ensure that everyone handling personal data is fully aware of the requirements and acts in accordance with data protection procedures. This document also highlights key data protection procedures within HSPSG.

This policy covers trustees and individuals representing or undertaking work for HSPSG.

In line with the GDPR principles, HSPSG ensures that personal data will:

- Be obtained fairly, transparently and lawfully
- Be obtained for specific legitimate purposes
- Be adequate, relevant and limited to the purposes
- Be accurate and kept up to date
- Not be held longer than necessary
- Be subject to appropriate security measures

The GDPR applies to personal data, that is information about an individual which will be held in a system. This includes some paper based personal data as well as that kept on computer systems. The GDPR covers the 'processing' of personal data, which includes: obtaining, using, holding, amending, disclosing, destroying and deleting personal data.

2 Types of Information Processed

HSPSG processes personal information on members of the group and people with a connection to the group. All personal information is kept in the HSPSG membership database.

HSPSG has a privacy statement which sets out how data will be used, and is available as a separate document: HSP Support Group Privacy Statement.

HSPSG has a framework which describes those covered by the policy and sets out how information is processed, which is available as a separate document: HSP Support Group Data Processing Framework.

3 Responsibilities

The overall responsibility for personal data in a not-for-profit organisation rests with the governing body. In the case of HSPSG, this is the trustees.

The trustees are responsible for:

- understanding and communicating obligations under the GDPR
- identifying potential problem areas or risks
- producing clear and effective procedures

All of those who process personal information must ensure they understand and act in line with this policy and the data protection principles.

All trustees, members, volunteers and supporters must sign a confidentiality agreement as appropriate when working for or on behalf of HSPSG. The agreement is available as a separate document: HSP Support Group Confidentiality Agreement.

Breach of this policy may result in people being personally liable for any penalties arising from the breach.

4 Policy Implementation

To meet our responsibilities HSPSG will:

- Ensure any personal data is collected in a fair and lawful way;
- Explain why it is needed at the start;
- Ensure that only the minimum amount of information needed is collected and used;
- Ensure the information used is up to date and accurate;
- Review the length of time information is held;
- Ensure it is kept safely;
- Ensure the rights people have in relation to their personal data can be exercised

We will ensure that:

- Everyone managing and handling personal information is trained to do so.
- Any disclosure of personal data will be in line with our procedures.
- Queries about handling personal information will be dealt with swiftly and politely.

5 Key Risks

HSPSG has identified the following key data risks:

- Breach of confidentiality (information being given out inappropriately), which is managed through the provision of training.
- Breach of security of the membership database, which is managed by restricting access to the database.
- Personal data being entered inaccurately or becoming out of date, which is managed by regular contact with/review by those whose information is processed.

6 Subject Access Requests

Anyone whose personal information HSPSG processes has the right to know:

- What information we hold and process on them
- How to gain access to this information
- How to keep it up to date
- What we are doing to comply with the GDPR.

Anyone whose personal information HSPSG processes has the right to:

- Prevent processing of their personal data in some circumstances
- Correct, rectify, block or erase information regarded as wrong
- Access certain personal data being kept about them on computer and certain files

Details on how to gain access to your data are given in the separate document: HSP Support Group Privacy Statement.

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