

Trustee and Committee Member records

Young Epilepsy Privacy Notice

This Privacy notice is intended to inform you how Young Epilepsy will use your personal data.



It also provides you with details on the Information Governance standards that Young Epilepsy complies with.

If you have any queries or concerns, further guidance may be accessed from the Chief Exec's Office or in the following ways:

- ☺ Susan Turner, Data Protection Officer (DPO) & IG Manager;
- ☎ Ext. 286;
- ✉ sturner@youngepilepsy.org.uk or dpo@youngepilepsy.org.uk;

Similarly, should you change your mind about the consent decisions you have made then please also contact the DPO, so we may record these changes on our systems:

Information Governance standards

Please find below details of the standards Young Epilepsy meets when using personal data

Data Protection

Young Epilepsy endeavours to meet the highest standards when collecting and using personal information. We are committed to upholding the standards and regulations embodied in the Data Protection Act 2018 (DPA 2018) and the UK General Data Protection Regulation (UK GDPR). Personal data will therefore at all times be:-

- ✓ Processed lawfully, fairly and in a transparent manner;
- ✓ Collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes;
- ✓ Adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;
- ✓ Accurate and, where necessary, kept up to date;
- ✓ Kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; and
- ✓ Processed in a manner that ensures appropriate security.

Young Epilepsy will furthermore:-

- ✓ Be responsible for and be able to demonstrate compliance with the DPA 2018 and the UK GDPR.

Individual Rights

Under the DPA 2018 and the UK GDPR you have the right to:

- Be informed (the purpose of this Privacy Notice);
- Access your information;
- Rectify inaccurate or incomplete data;
- Request the erasure of your information;
- Restrict how your data is processed;
- Data Portability;
- To object to the use of your information; and
- Rights in relation to automated decision making and profiling

Should you wish to exercise any of your Rights, please contact the DPO using the contact details provided.

Further information

Your information is held in a confidential manner with limited access, in accordance with the DPA 2018 and the UK GDPR. We are committed to ensuring that personal data is secure. In order to prevent unauthorised access or disclosure, your data will be held on secure servers and we have also put in place appropriate physical, electronic and managerial safeguards to further protect hard copy records.

Information will not ordinarily be processed overseas unless there is a specific request for us to do so, such as a need to send information to an individual or organisation in another country. If information is to be sent overseas then this will be done in accordance with the DPA 2018 and the UK GDPR and under the guidance of the DPO and the IT department.

Young Epilepsy is registered with the Information Commissioner's Office (ICO) under our legal name of the National Centre for Young People with Epilepsy. Our registration number is Z5611618.

Please note that should you be unhappy about the way we implement data protection you have the right to lodge a complaint with the ICO <https://ico.org.uk/>

Caldicott Principles statement

At Young Epilepsy we apply the Caldicott Principles to health and social care data, so that every flow of identifiable confidential information is regularly justified and routinely tested against the principles developed in the Caldicott Report.

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| Principle 1 | Justify the purpose(s) for using confidential information. |
| Principle 2 | Only use it when absolutely necessary. |
| Principle 3 | Use the minimum that is required. |
| Principle 4 | Access should be on a strict need-to-know basis. |
| Principle 5 | Everyone must understand his or her responsibilities. |

Principle 6	Understand and comply with the law.
Principle 7	The duty to share information can be as important as the duty to protect patient confidentiality.
Principle 8	Inform patients and service users about how their confidential information is used

Data Security & Protection Toolkit

As an NHS Business Partner, Young Epilepsy also completes the NHS' Data Security & Protection Toolkit, which enables organisations to measure and publish their performance against the National Data Guardian's ten Data Security Standards.

All organisations that have access to NHS patient data and systems must use this toolkit to provide assurance that they are practising good data security and that personal information is handled correctly.

Amendments

We may update this privacy notice from time-to-time by posting a new version on our website. You should occasionally check these pages to ensure you are aware of the changes. For more information about how the privacy notice is changed please contact the DPO using the details provided.

Trustee privacy notice

Please find below details on the ways in which your personal data will be processed

Information kept by Young Epilepsy.

Young Epilepsy maintains the following personal data¹ and special categories of personal data² related to Trustees and Committee Members.

Application forms and interview notes

During the recruitment process, Young Epilepsy will process information about prospective Board or Committee Members as part of the normal recruitment and selection process. The information is used for management and administrative purposes. These records will include but are not limited to: application forms; shortlisting and interview documents; references; health, disability and ethnic monitoring forms; and any correspondence between you and Young Epilepsy.

Individual file

¹ Personal data is any information relating to an identified or identifiable natural person ('data subject')

² Special categories of personal data are personal data that reveal an individual's: racial or ethnic origin; political opinions; religious or philosophical beliefs; trade union membership; It is also: the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person; data concerning health; or data concerning a natural person's sex life or sexual orientation

All Trustees and Committee Members have their own individual file, which contains information about you. These records will include but are not limited to: the formal record of your appointment and any amendments to it; correspondence with or about you; contact and emergency contact details; training records; any assessment processes undertaken; requests to exercise any of the DPA 2018 and UK GDPR rights; vetting records, such as DBS checks and information about any criminal convictions you may have; any allegations of a child protection/safeguarding nature; and, where appropriate, disciplinary and grievance records.

Where necessary, we may also keep information relating to your health. This information will be used in order to comply with our Health and Safety and Occupational Health obligations.

[Trust Board and Committee records](#)

This includes minutes, agendas and papers considered by the Board and other Committees.

[Financial records](#)

If you have made any claim for expenses reimbursement or other financial payment then this will be recorded on our financial systems and in your personal file.

[Organisational survey results](#)

Many of Young Epilepsy's surveys are anonymous, but in some cases, a record may be kept of responders. If this is the case then the survey will make this clear.

[CCTV recordings](#)

We have a small number of CCTV cameras on campus. These may be for security purposes or for the monitoring of students. All CCTV usage is approved by the relevant Exec Lead and operates in accordance with the Code of Practice from the ICO. Where there is CCTV there will be signage indicating its use.

[Photographs and filming](#)

Whilst on campus or at Young Epilepsy events you may have your photograph taken or be filmed. These images may be used in corporate materials or for press/publicity purposes. They may be used in hard copy publications (such as newspapers/ magazines), be broadcast, recorded on DVDs for viewing by professionals and wider public audiences or be placed in the internet (on web pages or on social media, such as YouTube, Facebook etc.). The images may be used to promote Young Epilepsy or to promote another organisation involved in a particular activity, such as a sponsor or organisation running a specific event.

If you do not want your photograph or images to be used please make this clear to the photographer or person filming, who will either stop taking the photograph/image or ask you to remove yourself from the its' range. If you do not do this, then your presence in a photograph will be taken as implied consent, even if you have previously said you do not want your image used.

Please note that this is purely a personal decision for you. Whilst Young Epilepsy will always appreciate your help, you are under no obligation to appear in photos or other images.

What this information is used for

This information is primarily used for administrative and governance purposes. We will keep and use it to enable us to run the organisation and manage our relationship with you effectively, lawfully and appropriately whilst you are a Trustee or Committee Member and after you have ceased in this role.

It is also used to meet Young Epilepsy's legal obligations to maintain records relating to the organisation's functions, such as meeting minutes, and to ensure that appropriate procedures have been followed, such as vetting.

Source of the personal data

Primarily this data will have been provided by you, but it may also come from other people known to you, such as referees.

Sharing information

Young Epilepsy does not routinely share Trustee or Committee Member information with third parties, except as outlined below.

With other Trustees and Committee Members

In order to facilitate the work of the Board and other Committees, your contact details, such as an email address, phone number etc., will be shared with other Trustees and Committee Members.

Release of records you may have contributed to

You need to be aware that everything you write as a Trustee or Committee Member may and can be released, including emails. It is therefore essential that you everything you write is appropriate and professional at all times.

These records may be released as part of an Access Request or in response to a request from another professional working with the student or staff member, who is the subject of this information. We will endeavour to notify you of such a release of records, but reserve the right to release these records if we believe it is appropriate and right to do so.

Internal access

Appropriate staff will be able to access your records for administrative and governance purposes. For example, an employee who provides administrative support to a Committee, the member of the Exec team who leads on a Committee or staff in the CEO's Office.

Public disclosure

Some information, such as the names of Trustees are a matter of public record and may be noted, for example, on our website. At the time of your appointment, you should be informed whether this will apply to you.

Inspections

Young Epilepsy is subject to a number of regulatory standards, such as the CQC, Ofsted, Fundraising Regulator etc. and may therefore allow its records to be inspected as part of that process, to ensure that Young Epilepsy is meeting the necessary standards.

Inspectors will be given access to records but only provided with copies in exceptional circumstances, for example, if a safeguarding concern is identified.

Legal obligation

We are legally obliged to share certain information and, in such cases, will not seek your consent to do so. For example, we must respond to HMRC requests for financial records or if safeguarding concerns were raised these must be disclosed to the relevant organisations and individuals.

If you wish Young Epilepsy to disclose your information in the form of a reference, you must complete the appropriate paperwork (available from HR).

Data Processors

We use data processors, this is an organisation responsible for processing personal data on behalf of Young Epilepsy. It does so under strict instruction from us and our contract ensures that the standards required by Young Epilepsy, the DPA 2018 and the UK GDPR are upheld at all times.

An example of a data processor is the company that provides the software that allows us to manage our relationships with donors and supporters and the company that manages our financial merchandise sales and donations. It also includes any company that runs a platform on which Young Epilepsy internet pages/sites may be located. Whilst these may be overseas our contract ensures UK standards are applied.

The growth in cloud technology means that it is likely that the use of data processors will become more common. If you wish to know who our current data processors are please contact us using the details provided to you.

Complaints

Sometimes if there has been a complaint or an issue raised, we may ask someone else to investigate. This person may look at your information.

Anonymisation

Some of the information we hold on you may be anonymised, so that we can share the results more widely. You will not be identifiable in these records.

Retention of records

Application forms and interview notes

If your application is unsuccessful, this information is held for a period of 6 months. If you are appointed as a Trustee or Committee Members then these records will be added to your individual file and held under the conditions detailed below.

Trustee and Committee Member individual file

The majority of these records are retained for seven years after your role ceases. A summary record will be kept either for seven years after your role ceases or until your 75th birthday, whichever is longer. This is in line with the good governance practices and is the same as the retention periods applied to staff records.

Trust Board and Committee records

Trust Board and Committee minutes are permanently preserved for their historic value. Where other records, such as reports and background papers, are needed to make sense of the minutes or are of historic significance these too may be permanently preserved. It should be noted that these may specifically record your opinions and input into these meetings.

Financial records

In accordance with HMRC Guidance these records will be kept for six years after the end of the financial year they relate to. Exceptional payment records may also be recorded in your individual file.

Survey results

After six months, any survey results that contain personal data will either be destroyed or anonymised.

CCTV recordings

Where a recording is being made it is usually kept for seven days, unless an incident has been highlighted, in which case the CCTV will be kept until the incident is resolved.

If you have any queries about CCTV usage or retention please contact the manager with responsibility for the area in which it is being used or the DPO.

Photographs and filming

Given the digital age once a photo has been taken and filming made these images will never really cease to exist and may exist online forever. Young Epilepsy may also permanently keep these for historic purposes.

For further information, detailed retention schedules are available on SharePoint or upon request

Lawful basis

The DPA 2018 and the UK GDPR require us to have a lawful basis for processing your data and these are outlined below.

The legitimate interests of Young Epilepsy.

For example, it is in the legitimate interests of Young Epilepsy to keep individual files on all Trustee and Committee Members, and to share contact details with others on the Board or Committee.

Consent

Consent is asked for in this privacy notice and may also be asked for at other times. For example, consent will be confirmed when surveys are conducted and when photographs/filming is undertaken. It may also be sought when the information is to be disclosed outside of the organisation.

Any information you provide to Young Epilepsy is processed on the basis that its provision indicates consent.

Legal obligation.

For example, HMRC requires Young Epilepsy to keep specific financial records, and other relevant regulations may specify what information has to be kept and for how long.

Historic value

Young Epilepsy is an important and specialist charity that dates back over 100 years, so some records, such as Trust Board minutes are permanently preserved for their historic value

Trustee consent/acknowledgement

Having read this form and the detail on how your personal data will be processed, please consider the following statement and tick the appropriate box:



Yes, I understand how my personal data is to be processed and, where relevant, consent to this;

No, I do not consent to my personal data being processed.

Please detail your concerns, or any restrictions or modifications that you would like put in place. The Chief Exec's Office will then contact you to discuss these.

(Signature)

(Name)

(Date)

Role (Trustee or committee you serve on).