

External Health Services Privacy Notice



This Privacy notice is intended to inform you how Young Epilepsy's External Medical Services will use Patient personal data.

This notice covers the:

- Assessment & Rehabilitation Service; and
- Diagnostic Suite.

If you have any queries or concerns, further guidance is available from the Assessment & Rehabilitation Service Manager, the Diagnostic Suite Manager or the Data Protection Officer using the details provided.

Information Governance standards



Please find below details of the standards Young Epilepsy meets when processing Patient 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 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; and
- To object to the use of your information.

There are two additional rights with regard to automated decision making and data portability. With regard to these Young Epilepsy will not use Patient information for automated decision making or profiling and will not undertake data portability.

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, data will be held on secure servers/cloud storage 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.

If you have any queries about how Young Epilepsy uses personal data, please contact the Data Protection Officer:

T. 01342 832243 ext. 286

E. sturner@youngepilepsy.org.uk or dpo@youngepilepsy.org.uk

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 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.

Privacy Notice



Information kept by Young Epilepsy.

Young Epilepsy may keep the following personal data and special categories of personal data relating to Patients:-

- ✓ Personal details;
- ✓ Educational information;
- ✓ Medical, therapy, psychology and health information;
- ✓ In-house Video-EEG, Video-Telemetry and MEG recordings, external imaging data, data analysis and reports and any data or reports shared with us from a referring hospital;
- ✓ Safeguarding information;
- ✓ Social care information.

Family information

Where it is pertinent to the treatment and care we provide to your young person we will also keep some information on you and on other members of your family. For example, the family's medical history may be kept, where it relates to your young person's health. This is extremely helpful to us, but if you do not want this information kept, please inform of us this immediately.

CCTV.

We have a small number of CCTV cameras on campus, for security purposes, such as by Facilities area where our minibuses are kept and, a live feed in our Assessment, & Rehabilitation Unit as an unobtrusive way to monitor Patients being assessed. Where CCTV may be used in a Patient's bedroom, we will seek consent for this usage.

All CCTV usage is approved by the Exec Lead, in accordance with the ICO's Code of Practice. Where there is CCTV there will be signage indicating its use. CCTV recordings are kept for seven days, unless an incident has been highlighted, in which case the CCTV will be kept until the incident is resolved.

Anonymised information.

We may also use anonymised information about the education/ care/treatment of our Patients for research (subject to Research Ethics approval) or for audit purposes. It may also be used to provide training or for presentation outside of Young Epilepsy. Please be assured though that in these situations the information is fully anonymised so that it is not possible to personally identify your young person.

What this information is used for.

In order for Young Epilepsy to assess your young person, information on his/her educational, medical, social and personal history is needed. This information will be used by our staff in order to make an assessment of your young person.

The information we keep on our Patients allows us to provide the most effective and efficient care and treatment for your young person. By reviewing any previous treatment or strategies used we are able to determine what care and treatment may work best for your young person.

It is also important that we keep a record of the care and treatment the Patient has received. These records range from day journals which record a Patient's daily activities, to seizure charts and medication records. These allow us to monitor Patient progress and development. School and College also keep Patient work in order for Patients to obtain qualifications or other attainments.

In our Diagnostic Suite EEG/MEG recordings including video footage, analysis and reports are used in order to undertake a diagnostic assessment.

Source of the personal data

In order to provide the most effective and efficient care and treatment for your young person it is essential that we have all pertinent information. This may involve obtaining information from the following sources:-

- The young person;
- Parents, family and friends of the young person;
- The funding authority/authorities;
- The referring authority;
- Former placement providers, such as previous residential placements or schools attended;
- Local service providers, such as your young person's school, therapists and CAMHS team;
- Health providers including both primary and secondary care; and
- The individuals or organisations whose contact details you have provided us with, on our Contact form.

This will have been obtained from relevant individuals and organisations either as part of the admissions process or during your young person's time at Young Epilepsy.

Sharing information.

Young Epilepsy may share a Patient's data as outlined below, for all other disclosures of information consent will be sought on an individual basis.

Routine sharing

Sharing information is beneficial for your young person as it helps provide a comprehensive understanding of his/her needs and development and also allows for all those involved in their care and treatment to be aware of the young person's development whilst at Young Epilepsy.

Young Epilepsy will therefore routinely disclose correspondence, reports and information with the following people/ organisations:-

- All professionals involved in funding the placement, which may include Local Authorities, Social Care and Health Commissioners;
- The referring authority, for example Maidstone and Tunbridge Wells Hospital or Great Ormond Street Hospital;
- The individuals or organisations whose contact details you have provided us with, on our Contact form;
- Your young person's Social Worker;
- Local service providers such as your young person's school, GP Surgery, Hospital, therapists and CAMHS team; and
- Other Health professionals involved with your young person's care including their GP, any local consultants and, if appropriate, the Patient's Child & Adolescent Mental Health Services team;
- Individuals who have parental authority, such as parents, guardians or carers. (Both parents will be given information unless we have been informed that parental responsibility rests solely with one.)

This sharing is for the benefit of your young person as it helps provide a comprehensive understanding of his/her needs and development and also allows for all those involved in their care and treatment to be aware of the young person's development and assessment whilst using the Assessment Service.

Inspections

Young Epilepsy is subject to a number of regulatory standards, such as the CQC, Ofsted, 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 obligations

We are also legally obliged to share certain information and, in such cases, will not seek your consent to do so. For example, all safeguarding concerns must be disclosed to the relevant organisations and individuals, such as the Local Authority, your young person's Social Worker and possibly the police. Similarly, we will also share certain information with new placement providers, such as a summary chronology of all safeguarding incidents and if your young person is a Looked After Child (LAC) then his/her Care Plan, Personal Education Plan and the minutes of LAC meetings.

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.

Some data processors use anonymised personal data for their specific reasons, such as statistical, quality control, security, research or other purposes. Where this occurs, we can confirm the data is always anonymised and Patients cannot be identified from it.

An example of a data processor is Earwig, a software that allows our Education staff to more effectively produce teaching evidence, assessments and reports and to track individual Patient progress. In order to utilise this software, we have to upload and record Patient information.

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 the DPO using the details provided.

Complaints/Reviews

Records may also be accessed by independent reviewers, such as when a complaint or other issue is independently investigated.

Anonymisation

Some of the information we hold on our Patients may be anonymised, so that we can share the results more widely. Your young person will not be identifiable in these records.

Retention of records

Young Epilepsy keeps records for different periods depending upon the nature of the record and its value. The retention periods detailed below have been agreed by the organisation and accord with relevant legislation, guidance and legal opinion.

- Interdisciplinary and Diagnostic assessments

Records generated by Young Epilepsy staff will be retained for 20 years after the date the assessment is completed and/or any issues resolved. This is in accordance with the NHS Code of Practice for Health & Social Care records relating to records of a long term illness or an illness that may reoccur. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

- Rehabilitation records

Records generated by Young Epilepsy staff will be retained for 20 years after the date the rehabilitation is completed and/or any issues resolved. This is in accordance with the NHS Code of Practice for Health & Social Care records relating to records of a long term illness or an illness that may reoccur. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

- Preview assessments/visits

Records generated by Young Epilepsy staff will be retained for six years after the date the assessment is completed. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after one year.

- Potential referrals for assessment

If we have received records on a young person, who does not end up attending a Preview visit or being assessed, then the records generated by Young Epilepsy staff will be retained for two years after a decision is made not to refer a young person or after contact ceases.

- [Video-EEG, MEG and Video-Telemetry records](#)

Records generated by Young Epilepsy staff will be retained for 20 years after the date of the Video-EEG/MEG/Video-Telemetry is completed and/or any issues resolved. This is in accordance with the NHS Code of Practice for Health & Social Care records relating to records of a long term illness or an illness that may reoccur. Other records, such as standard/general correspondence and records obtained from others involved with the young person, such as professionals or family members, will be securely destroyed after six years.

A full copy of the External Medical Service's retention schedule is available upon request.

[CCTV.](#)

In the unusual occurrence of a CCTV recording being made (usually only live feed is used), the recordings will be kept for a minimum length of time. For example, where the recording needs to be reviewed by a medical professional as part of the assessment process it will be kept until that review has been completed and any issues, such as seeking other professional advice, are resolved.

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 primary basis we seek to rely on is consent, however, there are other additional lawful bases, which are detailed below.

[Explicit consent](#)

Having outlined how we will use, keep and otherwise process your young person's data we would ask you to consent to this using the form below. Please note that the privacy notice covers the use of Patient data that is essential to the education, care, treatment and service we provide to our Patients.

[Legal claims and obligations](#)

Where the processing is necessary to establish, defend or exercise legal claims or where ordered by a court or tribunal.

[Legal and regulatory requirements](#)

Young Epilepsy complies with other regulatory and legislative requirements, which may also provide a lawful basis for us using and retaining your data, such as the requirement to keep financial records for seven years and to comply with the Statute of Limitation.

[The legitimate interests of Young Epilepsy.](#)

It is in Young Epilepsy' legitimate interests to process some Patient data for administrative and management purposes. This may include allowing staff access to your young person's data, such as our admin teams and using Patient data to measure the ethnic diversity of our Patient group

[Medical purposes.](#)

For example, for preventive medicine, for a working capacity assessment, for medical diagnosis or the provision of health or social care. For example, we may share personal data about your young person's medical history when making a referral to another medical professional.

[Public Interest](#)

Where the processing meets one of the 23 conditions set out in Schedule One, paragraphs 6-28 of the DPA 2018

Public health

Where the processing is necessary for public health monitoring and statistics; or responding to new threats to public health, such as epidemics/pandemics.

Historic value

Young Epilepsy is an important and specialist charity that dates back over 100 years, so some records, are permanently preserved for their historic value. For example, if your young person has their photo on one of our publications, then that document may be permanently retained.



Parental consent

Please consider the following statement about your young person and tick the box if you agree with it.

- Yes, I consent patient records containing information about my young person being kept, used and shared as detailed above.
- No, I do not consent patient records containing information about my young person being kept, used and shared as detailed above.

If this is the case, then please detail below your concerns or any restrictions or modifications that you would like put in place. Our staff team will then contact you to discuss these.

(Signature)

(Name)

(Date)

Name of patient:- _____

Relationship to patient