

Turning Six research project Privacy Notice



This Privacy notice is intended to inform you how Young Epilepsy will use your personal data, provided to us by NHS England. It applies to patients who took part in The Epilepsy in infancy: relating phenotype to genotype (EPIPEG) study, who will be invited to participate in the subsequent follow up study, Turning Six.

If you have any queries or concerns, further guidance is available from the Research Coordinator 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 either the:

- Research Coordinator
T 01342 832243 ext.274
E. Research@youngepilepsy.org.uk
- 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.

- 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



Please find below details of the information we keep and how we use it.

Information kept by Young Epilepsy.

Young Epilepsy have been provided the following information about you:

- Mortality data (Date of Death, NHS Number & Date of Birth from the Civil Registrations of Deaths, held by NHS England)
- Contact Details (Address, NHS Number & Date of Birth from demographic information held by NHS England)

What this information is used for

Young Epilepsy have been provided the mortality data, outlined above, as this information will allow us to determine the children still living from the EpiPEG cohort. Identifiable patient information is required in order to make this identification and ensure that the parents of any child who has sadly passed away are not contacted by the study team with an invitation to participate in the Turning6 project.

Young Epilepsy have also been provided the up-to-date contact details for EpiPEG participants to allow us to contact them to invite them to participate in Turning6. To do so, we require the full address of the patient and their NHS number and DOB to ensure that the correct address is assigned to the correct patient.

Source of the personal data

The data that Young Epilepsy hold, which has been outlined above, has been provided to us by NHS England.

Sharing information.

Young Epilepsy will not share this information with third parties, except as outlined below:

Inspections

Young Epilepsy is subject to a number of regulatory standards, such as the CQC, ICO, 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.

Retention of records

Mortality data will be reviewed within two months of receiving the information, upon which point it will be deleted. Up to date contact details will be retained for a year, to allow a reasonable time frame to contact participants to invite them to be a part of the new research project. If participants decline to participate their contact details will be deleted, if participants agree to participate, explicit consent will supersede legitimate interest as the basis for processing.

Lawful basis

The DPA 2018 and the UK GDPR require us to have a lawful basis for processing your data and this is outlined below. The basis for processing the data outlined in this notice is:

Legitimate interests

Our legitimate interest in processing this data is to remove the potential of causing emotional harm by inadvertently contacting a parent, who has sadly lost their child. We have determined that this processing is necessary to achieve that and have made every effort to balance it against the individual's interests, rights and freedoms, so there is minimal impact on privacy. We have applied additional measures regarding data minimisation and storage, so that we are only processing essential data, mortality data will only be kept for two months and other data only for a year. Should you feel that this processing is contrary to your rights, interests and freedoms, please contact us to discuss this further.

Research exemption

The Data Protection laws allow for the processing of personal data for research purposes to be exempt from some of the usual Data Protection requirements. Please note that we are applying data minimisation measures to ensure we only process essential data and storage limitation measures so data will only be retained for one year.

Confidentiality

With regards to the duty of confidentiality, this processing falls within the following provision:

- National Health Service Act 2006 - s251 - 'Control of patient information'.

Section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002 allows the Secretary of State for Health to make regulations to set aside the common law duty of confidence for defined medical purposes. In practice, this means the person responsible for the information can disclose confidential patient information without consent to an applicant without being in breach of the common law duty of confidence, if the requirements of the regulations are met.