

Student records

Privacy Notice - Parental



This Privacy notice is intended to inform you how Young Epilepsy/St Piers (St Piers) will use student personal data.

If you have any queries or concerns, further guidance is available from, the DPO using the details provided below:

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

Information Governance standards



Please find below details of the standards St Piers meets when using personal data

St Piers 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.

St Piers 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 St Piers will not use student 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.

Overseas transfers

St Piers uses cloud-based software, such as Office 365. Depending on the service used, Microsoft may process and store data outside of the UK, such as in America or the European Economic Area. To safeguard this transfer of information overseas we rely on Microsoft's contractual commitments in its Data Protection Addendum, to process data only as instructed and to support UK specific safeguards.

Other than this, information will only be processed overseas if there is a specific request for us to do so. In such instances, 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.

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.

St Piers 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 St Piers we apply the Caldicott Principles, 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. |

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| 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, St Piers 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



This Privacy notice is intended to inform you how St Piers will use student personal data.

Information kept by St Piers.

St Piers maintains the following personal data¹ and special categories of personal data². This information may be held on computer, in our paper records or may take the form of video, photos or other electronic record, such as EEGs and telemetry.

Student information

St Piers may keep the following personal data and special categories of personal data relating to students:-

- ✓ Personal details;
- ✓ Educational information;
- ✓ Medical, therapy, psychology and health information;
- ✓ Safeguarding information;
- ✓ Social care information.

Family information

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

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. Although it is not standard practice in a very limited number of instances live feed CCTV may be used in a student's bedroom, if this is the case with your young person then you will be asked to consent to this.

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 students for research (subject to Research Ethics approval) or for audit purposes. It may also be used to provide training or for presentation outside of St Piers. 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.

The information we keep on our students 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 student has received. These records range from day journals which record a student's daily activities, to seizure charts and medication records. These allow us to monitor student progress and development. School and College also keep student work in order for students to obtain qualifications or other attainments.

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 student;
- 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 Application 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 St Piers.

Sharing information.

St Piers may share a student'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 St Piers.

St Piers 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;
- Your young person's Social Worker;
- Local service providers such as your young person's school, GP Surgery, Hospital, Other Health professionals involved with your young person's care including their GP, any local consultants and, if appropriate, the student's Child & Adolescent Mental Health Services team;
- Your local NHS body responsible for assessing and funding the student's Continuing Healthcare entitlements;
- 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.)

Inspections/Audits

St Piers is subject to a number of audit requirements and regulatory standards, such as the CQC, Ofsted, HMRC etc. and may therefore allow its records to be inspected as part of those processes, to ensure that St Piers is meeting the necessary standards.

Inspectors/auditors will be given access to records but only provided with copies in exceptional circumstances, for example, if a safeguarding concern is identified or it is necessary for audit completion.

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 St Piers. It does so under strict instruction from us and our contract ensures that the standards required by St Piers, 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 students cannot be identified from it.

An example of a data processor is the student Management Information System, the database on which most student information is recorded.

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.

Use of Artificial Intelligence (AI) technology

AI offers the opportunity for Young Epilepsy to enhance support and efficiency. This may include, but is not limited to, using AI, such as CoPilot, to transcribe meetings, summarise documents/notes and draft communications and documents. All AI generated work is reviewed and approved by staff who must ensure that it meets our own standards.

To minimise risks AI technology can only be used by staff if it: complies with UK GDPR and the DPA 2018; and has been assessed and approved using our AI Data Protection Impact Assessment. Personal data will not be shared with AI technology that uses data to train and learn, unless there is specific agreement to do so.

Virtual assistant technology devices

These devices, better known as Alexa, Echo, SIRI, Google Assistant etc., may be used on campus. Where they are in use, a privacy checklist and a Data Protection Impact Assessment will have been completed and the privacy settings will be set as high as is possible. These measures will include making students aware of where such a device may be in use, disabling the recording function and unplugging devices when a confidential discussion is being undertaken near its location.

Anonymisation

Some of the information we hold on our students 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

St Piers keeps records for different periods depending upon where the student has resided and the mental capacity of the student at time of leaving St Piers. The retention periods detailed below have been agreed by the organisation and accord with relevant legislation, guidance and legal opinion.

- Students who have resided on a children's home

For a student, who has resided on a children's home all of the student's records will be kept for 75 years from date of birth. This accords with the Children's Homes (England) Regulations 2015.

- Students who have not resided on a children's home, but lack capacity.

If a student lacks the capacity to understand the rights of action under the Limitations Act 1980 then all student records will be kept for 75 years from birth. This accords with legal opinion and the rights of action a student may have should capacity be attained at a later date.

- Students who have not resided on a children's home and have capacity

For a student who has capacity at the time of leaving St Piers all student records will be kept for 20 years from the date of leaving St Piers. This accords with the NHS Code of Practice for Health & Social Care records and the minimum retention period of the Information Management Toolkit for Schools.

A detailed copy of St Piers' retention schedule is available upon request.

CCTV.

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.

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 overleaf. Please note that the privacy notice covers the use of student data that is essential to the education, care and treatment we provide to our students.

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 St Piers.

It is in St Piers' legitimate interests to process some student 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 student data to measure the ethnic diversity of our student 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

St Piers is an important and specialist charity that dates back over 125 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

After reading the information provided on this form, please consider the following statements and only tick the appropriate box.

- ☐ Yes, I do consent to my young person's student records being processed as detailed above;
- ☐ No, I do not consent to my young person's student records being processed 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 whether these can be accommodated.

(Signature)

(Name)

(Date)

Name of student:- _____

Relationship to student