

Confidentiality Procedure v6

This Young Epilepsy/St Piers (Young Epilepsy) Procedure implements the Information Governance (IG) Policy providing information on Confidentiality and outlining the processes needed to ensure compliance with all legislative, regulatory and best practice requirements. It seeks to establish and promote a culture of good practice around the ethical, lawful, secure and confidential processing of information and use of information systems to support the provision of high-quality care to all our service users.

BACKGROUND

It is essential that records are kept and maintained by Young Epilepsy on its students, staff and other service users, but it is equally as important that the right to confidentiality with regards to these records is both acknowledged and respected.

Students, parents, staff and other service users entrust us with, or allow us to gather, confidential information, including personal and special category personal data, in order that we may work together. They do so in the legitimate expectation that staff will respect their privacy and act appropriately. In some circumstances students may lack the competence to extend this trust, or may be unconscious, but this does not diminish the duty of confidence.

In drafting this Procedure, the following legal and regulatory obligations and best practice guidance have been considered:

- NHS Confidentiality Code of Practice;
- Common law duty of confidentiality;
- UK General Data Protection Regulation (UK GDPR);
- Data Protection Act 2018 (DPA 2018);
- Human Rights Act 1998;
- Health & Social Care Act 2001: Section 60;
- Public Interest;
- Legal requirements to disclose;
- National Minimum Standards for Residential Special Schools;
- National Minimum Standards for Children's Homes;
- Care Quality Commission Standards.

Definitions

Anonymisation

Anonymised information is information that cannot be used to identify an individual either directly or indirectly. Once anonymised confidential information ceases to be confidential and is no longer personal data.

Disclosure

This is the divulging or provision of access to data.

Explicit or Express Consent

Consent is a clear and voluntary indication of preference or choice, which is freely given in circumstances where the available options and the consequences have been made clear.

Healthcare Purposes

These include all activities that directly contribute to the diagnosis, care and treatment of an individual and the audit/assurance of the quality of the healthcare provided. A Healthcare purpose can only be undertaken by a healthcare professional. They do not include research, teaching, financial audit and other management activities.

Medical purposes

Medical purposes include but are wider than healthcare purposes. They include preventative medicine, medical research, financial audit and management of healthcare services. The Health and Social Care Act 2001 explicitly broadened the definition to include social care.

Public Interest

Exceptional circumstances that justify overruling the right of an individual to confidentiality in order to serve a broader societal interest. Decisions about the public interest are complex and must take account of both the potential harm that disclosure may cause and the interest of society in the continued provision of confidential health services.

PROCEDURE format

- A. Confidentiality
- B. The five confidentiality rules
- C. Legal basis for disclosing confidential information
- D. Appropriate care
- E. The confidentiality Model
- F. Confidentiality breaches and incidents
- G. The Caldicott Principles
- H. Young Epilepsy employment contract requirements

I. Further guidance

A. Confidentiality

Definition

The key principle of confidentiality is that information confided should not be used or disclosed further, except as originally understood by the confider, unless consent is obtained to do so.

A common law duty of confidentiality arises when :

- Information is private information about a person (or their child who lacks capacity);
- Information is given to someone who owes a duty of confidence; and
- The person expects that information to be used in confidence.

All student/parent/service user information is considered to be confidential.

Staff information is considered confidential where it meets the above test.

A duty of confidence:

- Is a legal obligation that is derived from case law;
- Is a requirement established within professional codes of conduct;
- Forms part of the Young Epilepsy employment contracts and is linked to disciplinary procedures;
- Continues after the end of staff employment and after the individual the information is about has died;
- Ceases to apply if the confidential data is anonymised.

Personal confidential information (PCI)

PCI may include personal and special category data, so can include names and addresses as well as a person's health and care information. It applies to both hard copy and digital records.

B. The five confidentiality rules

1. Confidential information about students, parents, staff and service users should be treated confidentially and respectfully.
2. Members of a care team should share confidential information when it is needed for the safe and effective care of an individual.

3. Information that is shared for the benefit of the community should be anonymised.
4. We must respect an individual's right to object to the sharing of their confidential information.
5. Application of Young Epilepsy's Policies, Procedures, Guides and systems will ensure that the confidentiality rules are followed.

C. Legal basis for disclosing/using confidential information

Confidential information can only be disclosed or used if one of the following conditions is in place:

1. Explicit consent has been obtained;
2. It is being used for a healthcare purpose by a healthcare professional;
3. It is required by law or the courts;
4. It can be justified as sufficiently in the public interest to warrant a breach of confidentiality.
5. It is supported by section 60 of the Health and Social Care Act 2001.

Whenever decisions are to be made about confidential health information, all staff should apply the "Medical confidentiality decisions in practice" Guide, taken from the NHS Code of Practice.

If disclosure of confidential information is likely to be of benefit to society and one the lawful basis listed above does not apply, then the information should be anonymised.

D. Appropriate Care

Staff must always treat confidential data with appropriate care

Disclosing with appropriate care

Before disclosing any confidential information, staff must:

- Follow any established information sharing protocols;
- Identify enquirers so information is only shared with the right people;
- Ensure appropriate standards are applied in respect of all methods of sharing information (emails, post, verbal etc.);
- Share the minimum necessary to provide safe care or satisfy other purposes;
- Apply the UK GDPR, DPA 2018, NHS Code of Practice and other best practice standards.

Recording information accurately and consistently

It is essential that all staff record information in an accurate and consistent manner.

Keeping information secure

Young Epilepsy staff must ensure that confidential data is securely held, by applying the required level of people, physical and electronic security measures

E. The confidentiality model

All staff must apply the confidentiality model, which has four key requirements.

1. Protect confidential information

Young Epilepsy staff must protect confidential information. This can be achieved by applying Young Epilepsy's related Policies, Procedures and Guides.

2. Inform

The Privacy Notice is the usual method for informing students, parents and service users about the use of their confidential data. However, if the intended use falls outside of that Notice, then staff must ensure that the student/ parent/service user is informed prior to the confidential data being used.

3. Provide choice

Young Epilepsy employees must recognise that students/parents/service users have different value and needs and make every effort to facilitate these.

4. Improve

Staff should continually seek to improve the confidentiality provided to service users through awareness, training and reporting.

F. Confidentiality breaches and incidents

Confidentiality falls within the process for IG incidents and breaches (see relevant Guides on this) and should therefore be immediately reported to the Data Protection Officer (DPO).

G. The Caldicott Principles

These principles assist with the maintenance of confidentiality and must be applied by staff whenever confidential health and social care data is used.

1. Justify the purpose (s) for using confidential information;

2. Only use it when absolutely necessary;
3. Use the minimum that is required;
4. Access should be on a strict need-to-know basis;
5. Everyone must understand his or her responsibilities;
6. Understand and comply with the law;
7. The duty to share information can be as important as the duty to protect confidentiality. (This Principle must not be applied without having consulted with the Data Protection Officer first.)
8. Inform patients and service users about how their confidential information is used

H. Young Epilepsy employment contract requirements

Breaches of confidentiality

A breach of confidentiality by staff may amount to gross misconduct and is subject to disciplinary procedures.

Responsibilities

An employee's obligation of strict confidentiality applies both during employment and after leaving Young Epilepsy, without limitation of time.

It is the responsibility of all staff to maintain the confidentiality of information and not directly or indirectly:

- Reveal it to any person unless this disclosure is required and authorised as part of an employee's duties; or
- Use it for any purpose other than for the proper performance of staff duties of employment

The duty of confidentiality will not apply where the relevant information:

- Has entered the public domain, other than by unauthorised disclosure whether by the individual employee or someone else; or
- Is 'protected' under the Public Interest Disclosure Act 1998 and the employee has followed the Whistleblowing Procedure.

Regulatory standards

Staff must apply all regulatory standards that Young Epilepsy is subject to. These include, but are not limited to, those of the Care Quality Commission, Ofsted and National Minimum Standards.

Professional standards

All staff must apply the standards of their profession.

I. Further guidance

Confidentiality guides This procedure is supported by a number of specific confidentiality Guides, which are available to all staff on the IG SharePoint page.

[Information Governance - Confidentiality Guides \(sharepoint.com\)](#)

Other Guides As there is some overlap between many of the information-related procedures, additional information may also be found in the Data Protection, Information Governance and Information Risk Management procedures and Guides available to all on SharePoint.

[Information Governance - IG Policies, Procedures and Guides \(sharepoint.com\)](#)

Guidance and advice If further detail, guidance, or advice is needed, please do not hesitate to use the following contact details

Person: Susan Turner, Data Protection Officer;

Telephone: Ext. 286;

Email sturner@youngepilepsy.org.uk

This procedure is agreed by the Director of HR and will be implemented by all departments.

Signed:

Date: .30th June 2025

Name: Sarah Stookes
Title: Senior Information Risk Owner.
Director of HR, H&S & Health
Deputy CEO

Date of next review: 30th June 2026