

Artificial Intelligence Procedure

This procedure implements the Information Governance Policy providing information on the use of Artificial Intelligence (AI) and outlining the processes needed to ensure Young Epilepsy/St Piers (Young Epilepsy) complies 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.

Young Epilepsy recognises that AI has many benefits to offer, including greater time efficiency and quality improvements and so does not want to prevent staff from utilising its advantages. However, it is only to be viewed as a supplement and cannot replace human judgment and intelligence.

BACKGROUND

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

- UK General Data Protection Regulation (UK GDPR);
- Data Protection Act 2018 (DPA 2018);
- Equality Act 2010
- Human Rights Act
- The Information Commissioner's Office (ICO) guidance.

Definitions

Artificial Intelligence

AI is a standard industry term for a range of technologies and has a variety of meanings, including:

- In the AI research community, it refers to various methods:
'for using a non-human system to learn from experience and imitate human intelligent behaviour'

BCS, The Chartered Institute for IT

- In the data protection context:
'the theory and development of computer systems able to perform tasks normally requiring human intelligence'.

International Working Group on Data Protection in Telecommunications

AI Data Protection Impact Assessment (DPIA)

This is the primary tool which enables Young Epilepsy to demonstrate that its use of AI to process personal data is lawful and within the terms of the UK GDPR and DPA 2018.

Machine learning is:-

the use of computational techniques to create (often complex) statistical models using (typically) large quantities of data. Those models can be used to make classifications or predictions about new data points.

While not all AI involves ML, most of the recent interest in AI is driven by ML in some way, whether in image recognition, speech-to-text, or classifying credit risk.

Personal data is:-

‘Any information relating to an identified or identifiable natural person (‘data subject’)

Processing is:-

‘Any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction’

Special Categories of Personal data is personal data revealing:-

- ‘Racial or ethnic origin;
- Political opinions;
- Religious or philosophical beliefs;
- Trade union membership;
- The processing of genetic data, biometric data for the purpose of uniquely identifying a natural person;
- Data concerning health;
- Data concerning a natural person’s sex life or sexual orientation’.

PROCEDURE format

- A. AI and the law
- B. Lawful basis for the use of AI
- C. Accountability & Governance Implications of using AI
- D. Accuracy and Statistical Accuracy when using AI
- E. Transparency requirements for the use of AI in decision making
- F. Use of AI in Young Epilepsy document generation

G. Further Guidance

A. AI and the law

There are a number of laws, which impact on the use of AI

1. UK GDPR & DPA 2018:

- a. The use of AI must be both fair and transparent (Principle One)
- b. Young Epilepsy must demonstrate accountability when using AI (Principle Seven)
- c. The use of AI must comply with the Individual Rights :
 - To be informed;
 - To access data;
 - To object to the processing;
 - Related to automated decision making, including profiling.

The above may mean that the following need to be completed/ reviewed:

- Data Protection Impact Assessment
- Privacy Notice

2. Equality Act 2010

The AI processing must not discriminate, harass or victimise a person based on the 'protected characteristics. These are:

Age	Disability
Gender reassignment	Marriage and civil partnership
Pregnancy/maternity; race	Religion/belief
Sex and sexual orientation.	

Staff need to ensure, and be able to demonstrate, that the AI result does not:

- Cause the decision recipient to be treated worse than someone else because of one of these protected characteristics; or
- Result in a worse impact on someone with a protected characteristic than someone without one.

Reasonable adjustments maybe needed.

3. Further legislation that may apply to includes, but is not limited to:

- e-Privacy legislation
- Law Enforcement Directive

- Consumer Rights legislation
- Financial Services legislation
- Competition law
- Human Rights Act
- Legislation about Health and Social Care
- Regulation around advertising and marketing
- Legislation about school admissions procedure

B. Lawful Basis for the use of AI

Where personal data is being processed, using AI, staff must have a lawful basis for that processing. If not, then Young Epilepsy is in breach of the UK GDPR and the DPA 2018.

The lawful basis should be specified in the AI DPIA and be monitored throughout the use of the AI system.

Lawful basis for using AI to process personal data

The following may be a lawful basis, in the circumstances outlined below:

1. Consent - where Young Epilepsy has a direct relationship with the person whose data is being processed.
2. Contract - where the AI processing is objectively necessary to deliver a contractual service to the relevant individual, or to take steps prior to entering into a contract at the individual's request
3. Legal obligation - where the AI processing of personal data is required to audit the AI systems to ensure they are compliant with various legislation
4. Public task - where AI is being used to exercise official authority or to perform a task in the public interest set out by law
5. Vital interests - in very limited cases where the processing of personal data by an AI system might be based on protecting the vital interests of the individual.
6. Legitimate interests - for both the development and ongoing use of AI.

Lawful basis for using AI to process special category personal data

When special category data is being processed one of those necessary lawful bases will also be needed:

- Explicit consent;
- Vital interests;
- Legitimate activities of a not-for-profit body;
- Public interest in UK law;

- Manifestly made public by the data subject;
- Public interest in public health;
- Legal purposes;
- Medical purposes;
- Obligations under employment, social security or social protection law, or a collective agreement;
- Public interest archiving purposes, scientific or historical research purposes or statistical purposes

Inferences and affinity groups

When determining a lawful basis, the inferences that result from the use of AI must be considered, not just the data that is being processed.

An AI system makes an inference, about an individual or group, where it is asked to:

- Guess or predict details about someone, using information from various sources
- Analyse and find correlations between datasets, and use these to categorise, profile or make predictions.

An inference may result in special category data being processed.

Affinity Groups are created based on inferred interests rather than the personal traits of the individuals. Whether group inferences can be considered personal data will depend on the circumstances., such as how easy it is to identify an individual through group membership. Where an affinity group, is linked to a specific individual, then a lawful basis is needed

Risks, harms and mitigations must be considered throughout the lifetime of the AI system/tool.

C. Accountability & Governance Implications of using AI

AI must operate within the terms of the UK GDPR and DPA 2018, in particular Principle Seven, which requires Young Epilepsy to demonstrate Data Protection accountability and governance.

The primary way in which Young Epilepsy meets its accountability & governance requirements is by use of the AI DPIA.

Setting a meaningful risk level

The AI DPIA allows staff to:

- Identify and assess the risks that the AI poses to the individual;
- Manage and mitigate these risks; and
- Establish the impact this has on the use of AI.

The AI DPIA :

- Collates the information necessary to make decisions about the use of AI.
- Is a legal requirement under UK GDPR.
- Must be completed by staff for any new uses of AI to process personal data.

Data controller/processor roles

Often, several different organisations will be involved in developing and deploying AI systems, which process personal data. It is important to identify who is a controller, a joint controller or a processor so that their Data Protection obligations are clear.

Managing competing interests when assessing AI-related risks

The AI DPIA can help when there are several different values and interests to consider, often pulling in different directions. These are known as ‘trade-offs’. The right balance depends on the specific sectoral/social context, and the impact the processing may have on individuals. This is often a matter of judgement, but there are methods to assess and mitigate trade-offs:

- Decisions proportionate to the risks - this is often a matter of judgement, specific to the use and the context in which an AI system is to be used.
- Outsourcing and third-party AI systems - when Young Epilepsy either buys an AI solution from a third party, or outsources it altogether, an independent evaluation of any trade-offs as part of the due diligence process must be conducted.
- Culture, diversity and engagement with stakeholders – Young Epilepsy’s culture is fundamental in making judgement calls and determining the appropriate trade-offs. Staff should work collaboratively between different teams and with external stakeholders
- Mathematical approaches to minimise trade-offs- in some cases, it is possible to precisely quantify elements of the trade-offs, through the use of a number of mathematical and computer science techniques known as ‘constrained optimisation’.

D. Accuracy and Statistical Accuracy when using AI

It is essential that the statistical accuracy of an AI system used to make predictions, inferences or to assist with decision making is established. Statistical accuracy can change, and it must therefore be reviewed, monitored and reported on throughout the AI system’s lifecycle.

Data Protection Accuracy

Data must be accurate and up to date. Young Epilepsy (YE) must take all reasonable steps to ensure that the data its processes is not incorrect or misleading and where necessary correct data without undue delay

Statistical accuracy

This refers to the accuracy of an AI system itself. It is about how closely an AI system's predictions match the correct labels as defined in the test data. This can impact on four Data Protection requirements: fairness and lawfulness; adequate and relevant; accurate and up to date; and statistical accuracy requirements

Statistical accuracy - errors

- False positive or 'type I' error - when the AI system incorrectly labels a negative as a positive. E.g. emails are classified as spam, when they are in fact genuine
- False negative or 'type II' error - when the AI system incorrectly labels a positive as negative. E.g. emails are classified as genuine, when they are in fact spam.

There are more useful measures which reflect these two types of errors, including:

- Precision - the percentage of cases identified as positive that are in fact positive.
- Recall (or sensitivity) - the percentage of all cases that are in fact positive and are identified as such.

Generally, statistical accuracy depends on how possible it is to compare the AI's outputs to some 'ground truth'. I.e. by checking the results of the AI system against the real world.

Statistical accuracy changes - known as 'concept/model drift'. It can be detected by:

- Measuring the distance between classification errors over time
- Regularly assessing drift and retraining the AI model on new data where necessary.
- Determining a threshold for when the AI needs to be retrained

Rules for the use of AI related to Accuracy

If AI is to be used staff must ensure that

- All functions and individuals involved with the AI are adequately trained to understand the associated statistical accuracy requirements and measures;
- Data is clearly labelled as inferences/ predictions, and not claimed to be factual;

- Trade-offs and reasonable expectations are managed;
- A common terminology is adopted that staff can use to discuss statistical accuracy performance measures, including their limitations and any adverse impact on individuals.

E. Transparency requirements for the use of AI in decision making

Young Epilepsy has a transparency obligation to inform individuals how their personal data will be processed in an AI system. This should be considered when the AI system is first being designed and throughout the AI system's life cycle. Information about the AI's purpose, how long the data will be retained for and who it will be shared with, should be included either in the AI system's or Young Epilepsy's privacy notice.

AI output or an AI-assisted decisions

AI decision - can be based on a prediction, a recommendation or a classification. It can also refer to a solely automated process without any human input or one in which a human is involved, where the human considers the output of the AI model, as well as other information available to them, and then acts (makes a decision) based on this. This is often referred to as having a 'human in the loop'.

Explanations

There are at least six different types of explanations that can be provided to individuals:

1. Rationale explanation - an accessible and non-technical outline of the reasons that led to an AI assisted decision.
2. Responsibility explanation - who is involved in the development, management and implementation of an AI system, and who to contact for a human review of a decision.
3. Data explanation - what data has been used in a particular decision and how
4. Fairness explanation - steps taken across the design and implementation of an AI system to ensure that the decisions it supports are generally unbiased and fair, and whether or not an individual has been treated equitably.
5. Safety and performance explanation - steps taken across the design and implementation of an AI system to maximise the accuracy, reliability, security and robustness of its decisions and behaviours.
6. Impact explanation - steps taken across the design and implementation of an AI system to consider and monitor the impacts that the use of an AI system and its decisions has or may have on an individual, and on wider society.

Contextual factors

There are an additional five contextual factors, which may affect the purpose an individual wishes to use an explanation for, and on how that explanation should be delivered:

- Domain in which the AI will work
- Data used
- Audience it is being presented to.
- Impact on the individual
- Urgency of the decision

Principles to ensure the AI decisions are explainable

These are underpinned by four principles to ensure that the decisions made by the AI system are explainable:

1. Be transparent
2. Be accountable
3. Consider the context being operated in
4. Reflect on the impact of the AI system on the individuals affected, and on wider society.

F. Use of AI in Young Epilepsy document generation

AI is only to be viewed as a supplement and cannot replace human judgment and intelligence.

AI must not be used for documents when:

- There has been no human review or input into the produced document.
- To generate the content, the AI tool requires personal data, confidential or sensitive organisational information and does not meet Young Epilepsy's security and Information Governance standards.

If staff wish to use personal data in this way, then the 'AI Data Protection Impact Assessment' must be completed

- Its use would be a breach of Young Epilepsy's policies, procedures and guides

AI may be used for documents when:

- The document writer has reviewed the document & determined that it:
 - i. Is accurate in terms of the facts, data, terminology etc. used in it.
 - ii. Meets Young Epilepsy's organisational standards on tone, format and style.
 - iii. Is relevant to the content being sought and references all relevant laws, regulations and standards.

iv. Does not

- ~ Plagiarise in its use of content.
 - ~ Include false information, such as attributions/quotes or data.
 - ~ Include discriminatory, offensive or harmful content.
 - ~ Breach Information Governance rules, such as Data Protection and Confidentiality.
 - ~ Breach copyright or intellectual property rights
- The use of AI is acknowledged by the writer in the document.

Special consideration must be given to the suitability of using AI where the intent is to create a:

- Legal document
- Person specific document – student, employee etc.

Please note that if AI is to be used for assessment purposes a Data Protection Impact Assessment or other IG compliance document must be completed.

In such cases either Head of Department or Exec Lead approval should be obtained.

Only AI tools approved by the Head of IT may be used.

At present a pilot scheme is being undertaken using a paid-for AI Tool. Once the pilot study has been completed a list of approved AI tools will be released

G. Further guidance

N.B. This is a fast-developing area, so please make sure that you always look on the IG SharePoint page to ensure that you have the most up-to-date Guides and documents

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

[Information Governance - Artificial Intelligence](#)

AI DPIA This document should be completed whenever AI is used to process personal data.

[Information Governance - IG Forms](#)

Other Guides As there is some overlap between many of the information-related procedures, additional information may also be found in the Confidentiality, 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

Date of next review: 30th June 2026

Title: Senior Information Risk Owner.

Director of HR, H&S & Health

Deputy CEO