Data Protection Policy

Here at CDKL5 UK, we depend highly on the generosity of our supporters, donors and volunteers, as well as the goodwill and trust of the wider public. We are therefore committed to protecting any personal information you share with us, for example when you contact us for support, or when you make a donation, or any data which we obtain from you when you visit our website.

This Data Protection Policy sets out what personal information we collect from you and how we use it.

Introduction and Scope

This policy outlines CDKL5's commitment to data protection and compliance with the UK Data Protection Act. The purpose of this policy is to ensure that all personal data held by the charity is processed lawfully, fairly, and transparently, and that the rights of data subjects are protected. This policy applies to all individuals working on behalf of CDKL5 UK, including Trustees, members of staff, and volunteers.

Data Protection Lead

The CDKL5 UK Data Protection Lead is responsible for overseeing data protection and leading on any incident investigation and reporting. The Data Protection Lead also ensures that all members of staff and volunteers are provided with any induction, on the job or other training, and are made aware of their data protection responsibilities.

Data Protection

Data protection is the practice of safeguarding personal information by applying data protection principles and complying with the Data Protection Act. The Data Protection Act is a UK law that regulates the processing of personal data. The UK Information Commissioner's Office (ICO) provides guidelines on data protection that CDKL5 UK adheres to.

ICO Registration

CDKL5 UK is registered with the Information Commissioner's Office (ICO).

Last reviewed 13.03.25

You can check the register of fee payers here, by searching for 'CDKL5 UK' under 'Name': Information Commissioner's Office - Register of data protection fee payers

CDKL5 UK's Data Protection Officer is Carol-Anne Partridge, Co-Founder, Chair and Family Support Champion.

UK GDPR: The UK General Data Protection Regulation, which outlines the rules for processing personal data in the UK.

Data Processor: An individual or organisation that processes personal data on behalf of a data controller.

Data Controller: An individual or organisation that determines how and why personal data is processed.

Data Subject: An individual whose personal data is being processed.

Processing: Any operation performed on personal data, including collection, storage, use, and disclosure.

Personal Data: Any information that can identify a living individual, such as name, address, or email address.

Sensitive Personal Data: Personal data that requires extra protection, such as health information or ethnic origin.

Direct Marketing: Any communication aimed at promoting a product or service directly to an individual.

PECR: The Privacy and Electronic Communications Regulations, which govern electronic direct marketing.

Valid Consent: Consent given freely, specifically, and informed, and can be withdrawn at any time.

Legitimate Business Purpose: A lawful reason for processing personal data that is necessary for the legitimate interests of the data controller or a third party.

Data Protection Principles

Data is:

Processed lawfully, fairly and in a transparent manner

- There are several grounds on which data may be collected, including consent
- We are clear that our collection of data is legitimate and we have obtained consent to hold an individual's data, where appropriate

- We are open and honest about how and why we collect data and individuals have a right to access their data

Collected for specified, explicit and legitimate purposes, and not used for any other purpose

- We are clear on what data we will collect and the purpose for which it will be used
- And only collect data that we need
- When data is collected for a specific purpose, it may not be used for any other purpose, without the consent of the person whose data it is

Adequate, relevant and limited to what is necessary

- We collect all the data we need to get the job done
- And none that we don't need

Accurate and, where necessary, kept up to date

- We ensure that what we collect is accurate and have processes and/or checks to ensure that data which needs to be kept up-to-date is, such as beneficiary, staff or volunteer records
- We correct any mistakes promptly

Kept for no longer than is necessary.

We understand what data we need to retain, for how long and why

- We only hold data only for as long as we need to
- That includes both hard copy and electronic data
- Some data must be kept for specific periods of time (e.g. accounting, H&SW)
- We have an archive/review policy/process that ensures data which is no longer needed is destroyed

Processed to ensure

appropriate security, not only to protect against unlawful use, but also loss or damage

- Data is held securely, so that it can only be accessed by those who need to do so. For example, paper documents are locked away, access to online folders in shared drives is restricted to those who need it, IT systems are password protected, and/or sensitive documents that may be shared (e.g. payroll) are password protected
- Data is kept safe. Our IT systems have adequate antivirus and firewall protection which is up-to-date. Staff understand what they must and must not do to safeguard against cyber-attack, and that passwords must be strong and not written down or shared

- Data is recoverable. We have adequate data back-up and disaster recovery processes

Individual Rights

We recognise and respect that individuals' rights include the right to be informed, of access, to rectification, erasure, restrict processing, data portability and to object.

Use of Imagery/Video

All imagery is protected by copyright and cannot be used without the consent of the owner, usually the person who took the image. We also seek consent from the individuals in images (of individuals and small groups), which falls within the Data Protection Act. Where a person does not have the capacity to give consent, we obtain consent from that person's legal parent or guardian. Particular care is always taken when using images of children or other vulnerable people.

The questions we consider when using imagery are:

- For what purpose was the original image taken? If it was for one purpose, such as personal use, it cannot be used for another without the consent of the individuals concerned. If the individual does not have capacity to consent, have we obtained consent from the individual's legal parent or guardian?
- Is the image sensitive personal data? If it is, do we have the individual's consent?
- For small groups and individuals, has an image consent form been used?
- When using images of children, or people who may not have the capacity to consent, have we obtained consent from that individual's legal parent or guardian?
- When using images of children or other vulnerable people, are we confident that our use of the image will not place them at risk? Particularly, if it is to be used publicly, such as on social media or on our charity website?
- When photographing large groups, have the individuals been given a chance to opt out of the photograph? If individuals do not have capacity to give consent, has consent been obtained from the individual's legal parent or guardian?
- Has the person/people in the image been told how the image will be used?
- Are we using the image according to how the person/people were originally told it would be used when consent was obtained?

CDKL5 UK
Empowering Families
Embracing Hope

Personal data that we process

Purpose	Data (key elements)	Basis
Enquiring about our organisation and its work	Name, email, message	Legitimate interests - it is necessary for us to read and store your message so that we can respond in the way that you would expect
Subscribing to email updates about our work	Name, email	Consent - you have given your active, written consent (via the tick box statement on the form when you signed up)
Making a donation	Name, email, address, payment information	Contract - this information is necessary for us to fulfil your intention of donating money and your expectation of receiving a confirmation message
Website functionality	Website activity collected through cookies	Legitimate interests - it is necessary for us to store a small amount of information, usually through cookies, to deliver functionality that you would expect, such as remembering the contents of your order before you have fully completed the process

CDKL5 UK
Empowering Families
Embracing Hope

How we use your data

We will only use your data in a manner that is appropriate considering the basis on which that data was collected, as set out in the table above.

For example, we may use your personal information to:

- Reply to enquiries you send to us
- Handle donations or other transactions that you initiate
- Where you have specifically agreed to this, we will send you marketing communications by email relating to our work which we think may be of interest to you
- For internal record keeping
- For 'service administration purposes' which means that we may contact you for reasons related to your donations, such as your tax status with regard to Gift Aid, or content that you have signed up for
- To analyse and improve the activities and contact offered by our website to provide you with the most user-friendly navigation experience

Sharing your information

We will not under any circumstances, share your data with anyone for marketing purposes, and you will not receive offers from other companies or organisations as a result of sharing your information with us.

We may need to share limited information with our service providers who help us to prepare and send you our communications and process your donations and other responses. However, we will not allow these organisations to use your data for their own purposes and will take care to ensure they keep your data secure.

Other than this, we will not share your data with any third parties.

Data Breach

A breach is more than only losing personal data. It is a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data.

We will investigate the circumstances of any loss or breach, to identify if any action needs to be taken. Action might include changes in procedures, where they will help to prevent a recurrence or disciplinary or other action, in the event of negligence.

We will notify the ICO within 72 hours of a breach of data, if it is likely to result in a risk to the rights and freedoms of individuals. If unaddressed, such a breach is likely to have a significant detrimental effect on individuals.

For example, it may:

- Result in discrimination.
- Damage reputation.
- Cause financial loss.
- Cause a loss of confidentiality or any other significant economic or social disadvantage.

Other Considerations

Children

Young people under 16 years of age are not legally able to give consent. At CDKL5 UK, we ensure that privacy notices, or other information we distribute, are written and presented in a way that is understandable and fair to people of all ages.

People Without Capacity to Consent

Some people are unable to give consent, and so informed consent must be obtained from the person who is able to make decisions on their behalf, such as a Lasting Power of Attorney / Legal Parent or Guardian. Any decisions made on this person's behalf, must always be in the best interests of that person.

Vulnerable Groups

At CDKL5 UK, we are committed to ensuring that everyone is treated fairly and respectfully. This means that when we work with vulnerable people, every effort is made to ensure that they have the time and opportunity to access support in their decision-making, for example supporting them to discuss their potential choice with a trusted adult or relative. Every effort is made to develop methods of seeking consent using expert advice, support and training where appropriate.

Special Category Data

Special category (sensitive) data is more sensitive, and so needs more protection. For example, information about an individual's race, ethnic origin, politics, religion, trade union membership, genetics, biometrics (where used for ID purposes), health, sex life or sexual orientation.

CDKL5 UK
Empowering Families
Embracing Hope

Fundraising

We will ensure that our fundraising complies with the Data Protection Act and ICO guidelines and also the Fundraising Regulator guidelines including, if applicable, direct marketing and PECR. We will respect the privacy and contact preferences of our donors.

Fundraising Preference Service

We will respect the privacy and contact preferences of our donors. We will respond promptly to requests to cease contacts or complaints and act to address their causes.

Artificial Intelligence

We have adopted and comply with the Charity AI Ethics & Governance Framework and ICO AI guidance.

Data Retention

Our data will only be kept for as long as there is an administrative need to do so in order to enable our charity to carry out its business or support functions, or for as long as it is required to demonstrate compliance for audit purposes or to meet legislative requirements.

In general, records are kept for 6 years after the end of the accounting year to which they relate but we do not keep personal records any longer than necessary and certain records may be required to be retained for longer. Factors affecting retention periods include legal requirements, storage costs, historical value, industry standards, and archival needs.

Help And Support

The regulator, the Information Commissioner's Office (ICO) has produced guidance for charities here, or to contact the ICO by phone, e-mail or live chat, click here. You can find a self-assessment tool and other resources for micro, small and medium sized organisations here.

How to get in touch with us if you have any questions

Your privacy and safety are hugely important to us here at CDKL5 UK.

If you have any questions about how we keep and/ or use your information, or if you wish to change when and how we communicate with you, or update the information we hold, please get in touch with us at admin@curecdkl5.org.

Last reviewed 13.03.25

Cookies and usage tracking

A cookie is a small file of letters and numbers that is downloaded onto your computer when you visit a website.

Cookies are used by many websites and can do a number of things, e.g. remembering your preferences, and counting the number of people looking at a website.

Version Control - Approval and Review

Version No	Approved By	Approval Date	Main Changes	Review Period
1.0	C-AP	13/03/25	Document created	12 months