



DATA PROTECTION POLICY

Down Syndrome UK (DSUK) is dedicated to obtaining, handling, processing, transporting, and storing all such personal data, whether held on computer, or paper, lawfully and correctly, in accordance with the safeguards contained in the UK GDPR Act 2016 and the Data Protection Act 2018. This policy applies to anyone who has access to and/or is a user of DSUK's ICT systems, including staff, trustees, volunteers, parents / carers, contractors, and other community users.

DSUK undertakes to obtain and process personal data and data captured from the public domain fairly and lawfully. DSUK will do this by informing all personal data subjects of the reasons for data collection, the purposes for which data is held, the likely recipients of the data and the data subjects' right of access. Information about the use of personal data is printed on the appropriate collection form, or in our Privacy Notices. If details are given verbally, the person collecting the data will explain the issues before collecting the information. Subjects whose data has been captured from the public domain are given the opportunity to request their data be removed from DSUK database.

Terms used in the Policy:

- Processing, obtaining, recording, or holding the information or data or carrying out a set of operations on the information or data.
- data subject means an individual who is the subject of personal data or the person to whom the data relates.
- personal data means data which relates to a living individual who can be identified. Addresses and telephone numbers are examples.

DSUK has a responsibility to protect such personal data, especially sensitive personal data that it collects from data subjects. DSUK is committed to helping and supporting the Down syndrome community. To successfully achieve this, we need to collate and store data including personal information to create, analyse, and report on subjects. These can include a range of subjects including but not limited to information around maternity experience, ongoing health and education care and input, names and addresses of our members and their families. Submitting such data is entirely at the discretion and choice of each data subject.

We believe in establishing a clear, transparent, and accountable approach to our data protection to ensure that all those who support and engage with DSUK can do so safe in the knowledge that we will apply the same values to our data protection as we do to all our work and will handle their personal data in a secure, transparent, and responsible manner with full respect for their privacy, in line with all relevant legal obligations.

DSUK follows the principles of data protection as detailed in the UK GDPR Act 2016. Data must:

- be fairly and lawfully processed. This means that an organisation must be truthful about what personal data they wish to collect and what they want to use it for.
- be obtained for specified and lawful purposes. This means that an organisation cannot use personal data for any purpose other than that stated when they collected the data.



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- be adequate, relevant, and not excessive. This means that an organisation cannot ask for any data that is not immediately needed.
- be accurate and up to date. If data held about you is wrong or out of date, you have the right to have it corrected or deleted.
- not be kept for longer than is necessary. As soon as an organisation no longer needs your data, they must delete it.
- be processed in line with your rights. Your rights include the right to see any data held on you, and the right to correct inaccurate data.
- be held securely. This means safe from unauthorised access (e.g. with usernames and passwords), but also safe from accidental loss (by making backups).
- not be transferred to other countries outside the European Economic Area unless those countries have similar data protection laws.

DATA WE COLLECT

DSUK collects data that data subjects provide to us, which is information that can be used to identify someone as an individual. DSUK will only do this when the data subject has agreed to the request for personal data. Data may include the following:

- Name and address
- date of birth
- Health information
- Contact details
- your bank or credit card details where you provide these to make a payment (processed by third party)

HOW WE PROTECT PERSONAL DATA

DSUK follow applicable privacy and data security laws. DSUK may use third-party service providers (eg Salesforce, Survey Monkey and Stripe) to collect and maintain data. Appropriate and legal measures will be in place to protect the confidentiality and security of data.

DSUK will follow strict procedures and have many security features in place to protect data. However, as data transmission is not 100% secure, DSUK cannot guarantee the security of any information you transmit to us and therefore do so at your own risk.

Back ups of our data systems are held on an external hard drive which is securely stored to minimise the risk of accidental loss or theft.

HOW WE USE DATA



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By providing personal data the charity may use your data to:

- Improve our services
- Campaign for better support and services
- Provide newsletters and updates
- Notify you of new events, training, fundraising campaigns or services we provide
- Ask for feedback
- Respond to your requests
- Keep in touch with our members / users
- Provide you with services, products or information requested

DSUK WILL:

- only collect personal data to serve a specific purpose and only gather the minimum amount needed
- will use only fair and lawful means to obtain the personal data.
- will be transparent with data subjects whose personal data we collect
- will obtain a data subject's consent to process personal data
- will not use personal data for a different purpose without getting the data subject's consent
- will update personal data where it is incorrect.
- ensure only authorised staff, trustees, and volunteers of DSUK will process personal data
- will not hold any payment data

SHARING PERSONAL DATA

DSUK will only share personal data in compliance with applicable law. Special cases include:

- to identify, contact or bring legal action against someone
- any request in connection with a criminal investigation by law enforcement authorities

DSUK will not sell or license your personal data to other third parties.

International Data Transfers

DSUK will not transfer personal data outside the UK unless:

- The country has been deemed to provide an adequate level of protection by the UK Government.
- Appropriate safeguards are in place, such as Standard Contractual Clauses (SCCs).
- The data subject has explicitly consented to the transfer after being informed of the risks.

PHOTOGRAPHY AND FILM

DSUK wishes to use photography, images, and film with your consent. The images can potentially be used across all media (such as newspapers, magazines, websites), or broadcast outlets, on social media, in publications, on our website, in printed or online fundraising materials, in fundraising, training resources and awareness resources or by



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our partners who help fund raise and/or raise awareness to support DSUK. You can ask us to stop using this any time.

CASE STUDIES Photography, images and film created for case studies are collected and used with your consent. We will discuss with you how your, and/or your child's, image and information is going to be used and ensure you are happy for it to be used in this way. You can ask us to stop using this any time.

EVENT PHOTOGRAPHY Where an event is organised by DSUK, we will notify you in advance that photographs will be taken, and you will be given the opportunity to advise if you do not wish to be photographed.

If you do not want your photograph taken, please either tell the photographer at the time, if it is convenient to do so, or contact DSUK before the event. You can change your mind at any time.

Where the event is organised by a third party, we will use photography from the event under our legitimate interests. We will be clear in our terms and conditions of entry if this is the case. If you do not want your photograph taken, please either tell the photographer at the time, if it is convenient to do so, or contact DSUK after the event.

At some events there may be photographers present who represent the media or the event organiser and for whom DSUK is not responsible. Please review the terms and conditions issued by the event organiser for more information and inform the event organiser of your preferences and wishes in respect of photography taken.

EQUALITY AND DIVERSITY MONITORING We are committed to ensuring that we value our differences and benefit from diversity of thought, background, and experience by reflecting the diversity of those that we work with and for.

For some case studies or surveys, we will ask you to provide equality, diversity, and inclusion data, called diversity monitoring data. Diversity monitoring data is provided to us directly by you and only where you choose to provide it. We will never require you to submit this information.

Diversity monitoring data is special category data under the UK GDPR and includes information regarding:

- ethnicity
- health data, including information about disability
- sexuality and gender identification, including reassignment
- religious beliefs.

We collect and process diversity monitoring data for reasons of substantial public interest to ensure compliance with the Equality Act 2010, and to monitor and promote equal opportunities and treatment to all.



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Your data is used in an anonymised format for equal opportunities monitoring and to compare representation of our community. It may be published as anonymised statistics or reported in an anonymised format to comply with legal and regulatory responsibilities, including those under the Equality Act 2010.

It is not used or published in a way that could identify.

MARKETING AND COMMUNICATIONS We use marketing communications to keep you up to date with what we are doing, how you can get involved, and news and features about DSUK which we feel will be of interest to you. This may include but is not limited to newsletters, surveys, financial appeals, raffle appeals, fundraising opportunities, or updates about DSUK.

SOCIAL MEDIA DSUK uses social media to communicate with you and share information about campaigns or events. Currently we use Facebook, Twitter, TikTok, LinkedIn and Instagram. We do this through advertising on our social media or through posting messages and information on our own social media pages which you may choose to “like”, “follow” or interact with.

We take your privacy and rights seriously but still deem your interest to us important. For this reason, we use our legitimate interest to use your information and communicate with you in this way. Therefore, we will not ask for your permission to market to you through social media, but you are always free to inform us that you do not want us to contact you in this way. You can also update your preferences within the social media site to stop receiving marketing.

COOKIES

DSUK uses cookies to enhance user experience. In compliance with UK GDPR and PECR. Cookies are small text files that are placed on your computer or mobile phone that distinguish you from other users of the website. By continuing to browse the website, you are agreeing to our use of cookies.

- Non-essential cookies (e.g. analytics, marketing) will only be set with the user’s explicit opt-in consent.
- A cookie banner will be displayed on first visit, allowing users to accept or reject non-essential cookies.

Our cookies help us:

- Make our website work as you’d expect.
- Remember your settings between visits.
- Improve the speed and security of the site.

We do not use cookies to:



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- Collect any personal information (without your express permission).
- Collect any sensitive information (without your express permission).
- Pass data to advertising networks.
- Pass personal information to third parties.
- Pay sales commissions.

Turning Cookies off

Users can change their cookie preferences at any time via the website. You can configure your web browser to refuse cookies, to delete cookies, or to be informed if a cookie is set. You can find out how to do this by clicking 'help' on your browser menu.

You should note that by deleting or blocking cookies, the website may not function correctly, and you may not be able to access certain areas.

It may be that your concerns around cookies relate to so called 'spyware'. Rather than switching off cookies in your browser you may find that anti-spyware software achieves the same objective by automatically deleting cookies considered to be invasive.

We use Google Analytics to help monitor and analyse use of our websites. To opt out of being tracked by Google Analytics across all websites, visit <http://tools.google.com/dlpage/gaoptout>.

Changes to Cookies

We may change this Cookie Statement at any time. If we make material changes to the way in which we use cookies, we will let you know either by posting the changes on the Website and/or in this Policy Statement. It is important that you review any of these changes. If you do not wish to agree to these changes, then we cannot continue to provide the website to you, and your only option is to stop accessing the website. For more information on cookies please visit www.aboutcookies.org

LINKS TO OTHER WEBSITES

The DSUK website may provide links to other websites. If you navigate to another site via the DSUK website, DSUK is not responsible for how these websites collect and use your personal data or the content of the websites. Please view the data protection policies for the website you are on before entering any data. This Policy does not apply to any other websites.

STAFF DATA

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This policy covers data protection in relation to all areas of DSUK's activities, including:

- legal compliance (UK General Data Protection Regulation – UK GDPR)
- recruitment, promotion, training, redeployment and/or career development
- administration and payment of wages
- calculation of certain benefits, including pension
- disciplinary purposes arising from an employee's conduct or inability to perform their duties
- performance review
- recording of communication with employees and their representatives
- compliance with policy and/or legislation regarding health and safety or other employment legislation and regulation
- provision of references to financial institutions, to facilitate entry onto educational courses and/or to assist future employers.

Recruitment and selection

When placing a recruitment advert, DSUK must identify itself properly – people should know who they are applying to. If using a recruitment agency, DSUK must ensure the agency identifies itself.

Information collected for recruitment or selection for an interview must be used for that purpose only and must be kept securely. Where sensitive personal data is collected, explicit written consent should be obtained from applicants at the point of data collection. The hiring Manager should ensure that equal opportunities data for applicants is anonymised before the applications are considered.

If verifying the information a person provides, DSUK must ensure the person knows how this will be done and what information will be checked.

If DSUK needs to verify criminal conviction information, it will only do this by getting a Disclosure and Barring Service (DBS) check. DSUK must ensure it is entitled to receive this information and must follow the DBS's procedures strictly. DSUK may only keep a record that a satisfactory/unsatisfactory check was made, but it may not store any detailed information. DBS checks will be repeated every 2 years.

Employment records

DSUK is permitted to collect, maintain, and use employment records. However, staff should know what information about them is kept and what it will be used for. DSUK will not keep information that it has no genuine business need or legal duty to keep.

Employment records must be kept in a secure, locked place, and computerised records must be password protected. Only authorised staff should have access to employment records (usually, the individual's line manager, relevant director, HR Manager and the Chief Executive).

DSUK will keep employment records of staff who have left for three years to allow for information to be supplied for references. After this time, records will be destroyed.



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Sickness records

DSUK will collect information about a staff member's health in accordance with DSUK's Sickness Policy and Procedure and record it on SharePoint HR site and if necessary for payment on QuickBooks. Access to the information is strictly limited to authorised staff.

Pension or insurance scheme records

DSUK will only use the information about a staff member for the administration of the scheme and will inform the staff member of what information the insurance company or scheme provider will pass back to DSUK.

Disclosure

DSUK will only disclose information on a staff member if, in all circumstances, it is satisfied that it is in line with GDPR and is reasonable to do so or as part of legal disclosure. Fairness to the staff members will always be DSUK's first consideration. DSUK will allow staff access to their own records to ensure the information is correct.

DSUK's staff rights

Staff have a legal right of access to the information DSUK holds on them and the right to challenge the information if it is thought to be inaccurate or misleading. If a staff member objects to DSUK holding or using information about them because it causes them distress or harm, DSUK will delete the information or stop using it in the way complained about unless DSUK has a compelling reason to continue holding and/or using that information.

SUBJECT ACCESS

The Data Protection Acts entitles all data subjects a right of access to their own personal data.

Anyone who has personal data held by the Charity has the right to make a subject access request. This could be to update, correct or remove your personal data at any time. DSUK will deal promptly with subject access requests.

DSUK complies with GDPR by providing the following rights for individuals:

- the right to be informed
- the right to access to a copy of their personal data
- the right of rectification of data
- the right of erasure (or right to be forgotten)
- the right to restrict processing
- the right to data portability (in relation to processing by automated means)
- the right to object to processing
- rights in relation to automated decision-making and profiling.



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The **right to be informed** encompasses DSUK's obligation to provide information on how personal data is collected and used ('fair processing information'), typically through the DSUK's privacy notice, which can be found [DSUK Privacy and GDPR Policy - Down Syndrome UK](#), and to be transparent in how personal data is used.

With regard to the **right of access**, DSUK will provide confirmation that the data is being processed and, if requested, grant access to personal data free of charge within 28 days of receiving the request (this can be extended by a further month if the request is complex or onerous).

Under the **right of rectification**, DSUK will correct any inaccurate or incomplete data within 28 days of notification. DSUK will also inform any third parties, if applicable, of these rectifications.

In compliance with the **right to erasure**, DSUK will delete data under the following specific circumstances:

- Personal data is no longer necessary in relation to the purpose for which it was originally collected/processed.
- An individual withdraws their consent.
- The individual objects to the processing and there is no overriding legitimate interest for continuing processing.
- The personal data was unlawfully processed.
- The personal data has to be erased to comply with a legal obligation.
- The personal data is processed in relation to online services to children.

DSUK will ensure that, in certain circumstances, the **right to restrict processing of personal data** is satisfied. This can include situations where data may be inaccurate or where the individual has objected to the processing, and DSUK is considering whether its legitimate grounds for processing data override the rights of the individual.

Under the **right to data portability**, an individual can ask for their data in a form that can easily and securely be transferred from one IT environment to another. DSUK would ensure that data held can be securely transferred if a request is made.

Under the **right to object**, DSUK will stop processing personal data where there is an objection unless there are compelling legitimate grounds to continue processing data, or if the processing is for the establishment, exercise or defense of legal claims. DSUK will stop processing personal data for direct marketing purposes as soon as an objection is received. The right to object is included in the DSUK's privacy notice.

DSUK will secure personal data in a way that is proportionate to the risk to the interests and rights of the individual and ensuring that it cannot be used to discriminate against the individual.

Should an individual wish to exercise any of the above rights, they can do so by contacting the Operations Manager at operationsmanager@downsyndromeuk.co.uk. On request from an individual, the Operations Manager will supply

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details of what information is held, why it is held and to whom it may be disclosed. A copy of the relevant record of data on the individual may be supplied.

DSUK will aim to comply with requests for access to personal data records within one month.

IMPORTANT: Breaches of procedure or loss of data

Any breach of confidentiality should be reported to the Operations Manager, who will then appoint an appropriate independent person (e.g. a member of the board of trustees or a senior member of staff) to investigate the matter. If, following a written summary of findings, the Operations Manager finds that a breach has occurred, they have the discretion to take appropriate action within 28 days. This may include consideration of pursuing disciplinary action or, in the case of a volunteer, asking the person to withdraw from DSUK's service.

GUIDANCE TO STAFF

DSUK's employees should bear in mind the following considerations:

- Sensitive and confidential information must be treated with particular attention.
- Personal data must not be emailed to staff members' personal email accounts, as there is no guarantee of security of these accounts.
- Any personal data stored in paper format must be held securely locked in filing cupboards and destroyed when no longer required.
- All DSUK personal computers must be password protected. All personal data should be kept in the appropriate IT system (i.e. customer details in Salesforce and staff details in the HR SharePoint file and QuickBooks). If electronic equipment is lost or stolen, access to the server and database from that piece of equipment will be severed.
- The database holding members' data must only be accessed using 2 step verification procedures and multiple electronic equipment access should be kept to a minimum. Data access should be set up depending on the role within the charity.
- If you download any files for ease of working, make sure you save them in the appropriate place on SharePoint, password protected, if necessary, as soon as you have finished working on them and delete any local files.
- Any changes to personal data (e.g. a change in home address) must be updated on Salesforce database within 28 days of receipt.
- Personal data must not be given out to any third party unless the individual has agreed to release this information.
- Any personal data kept in paper format that is no longer required must be destroyed.
- Any personal data kept electronically that is no longer required must be deleted. DSUK will diarise an annual data audit for all staff to carry out data minimization.

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- If data needs to be processed for profiling or for other statistical information, pseudonymise it. The procedures for this should be documented to ensure that the identification of the individuals is kept separate from the processed data.

CHANGES

DSUK will continually update this policy to ensure it follows all changes in applicable laws.

COMPLAINTS DSUK is always seeking to implement best practice and strives for the highest standards. DSUK operates an “open door” policy to discuss any concerns about the implementation of this policy or related issues – see Complaints Policy

There is a right to make a complaint to the Information Commissioner’s Office (ICO), but under most circumstances the ICO would encourage the complainant to raise the issues in the first instance with DSUK

The ICO is contactable at: Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Telephone: 0303 123 1113.

LEGISLATION AND GUIDANCE

This policy considers the following:

- The General Data Protection Regulation (GDPR) 2018
- The Data Protection Act (DPA) 2018.
- The Protection of Freedoms Act 2012
- Guidance published by the Information Commissioner’s Office

OUR CONTACT DETAILS If you have any questions or queries about this Privacy Notice, please contact us: info@downsyndromeuk.co.uk

We will regularly review and update this document.

Significant changes will be notified through an announcement on our website.

Policy Ratified on	September 2021
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Policy Reviewed Date	30 th October 2025
Policy Review Date	30 th October 2026
Trustee sign off	Casimir Knight