

Alpha-1 UK Data Protection/ Privacy policy

This policy describes how and why Alpha 1 UK uses your personal information, how we protect your privacy when doing so, and your rights and choices regarding this information. We promise to respect any of your personal information which is under our control and to keep it safe. We aim to be clear when we collect your information about what we will do with it.

The Alpha-1 UK is a not-for-profit organisation founded in 1997 by those diagnosed with the genetic condition Alpha-1 Antitrypsin Deficiency, dedicated to help, advise and support fellow sufferers, their families, carers and friends.

Our use of personal information allows us to make better decisions, fundraise more efficiently and, ultimately, helps us to reach our goal of supporting research and campaigning for better access to treatment for Alpha-1 patients.

This policy was last updated in January 2026

Who we are

In this Privacy Policy, **‘Alpha-1 UK’**, **“we”**, or **“our”** means

1. The Registered Charity in England and Wales (1146330) Scotland (SC043177)

How we collect information about you

Information you provide to us directly – via our sign up

We also use information from the following sources:

Social Media

Communication, engagement and actions taken through external social media platforms that we participate in are subject to the terms and conditions as well as the privacy policies held with each social media platform, respectively.

Depending on your settings or the privacy policies for social media and messaging services like Facebook, Instagram, LinkedIn or X (formally Twitter), you might give us permission to access information from those services, for example when you publicly tag us in an event photo.

You are advised to use social media platforms wisely and communicate / engage with them with due care and caution regarding your own privacy and personal details.

Information available publicly

We supplement information on our supporters with information from publicly available sources such as charity websites and annual reviews, corporate websites, public social media accounts, the electoral register and Companies House to create a fuller understanding of someone’s interests and support of Alpha-1 UK.

What personal information we collect

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

How we use your personal data

We use personal data for a wide range of purposes. We will use personal information to:

- provide you with the services, products or information you asked for;
- administer your donation or support your fundraising, including processing Gift Aid;
- keep a record of your relationship with us;
- respond to or fulfil any requests, complaints or queries you make to us;
- understand how we can improve our services, products or information by conducting analysis and market research;
- manage our events;
- check for updated contact details against third-party sources so that we can stay in touch if you move (see “Keeping your information up to date” below);
- to protect the health and safety of you, our staff, volunteers and other members of the public;
- further our charitable objectives;
- register, administer and personalise online accounts when you sign up to products we have developed;
- send you correspondence and communicate with you, using traditional channels and via social media platforms
- process applications for funding and for the administration of our role in the projects we fund;
- monitor the appropriate use of grant funds, including expenditure on individual salaries, and consider any virement requests
- ensure that participants involved in research are treated with dignity and respect
- administer our websites and to troubleshoot, perform data analysis, research, generate statistics and surveys related to our technical systems;
- test our technical systems to make sure they are working as expected;
- contact you if you enter your details onto one of our online forms, and you don't 'send' or 'submit' the form, to see if we can help with any problems you may be experiencing with the form or our websites;
- display content to you in a way appropriate to the device you are using (for example, if you are viewing content on a mobile device or a computer);
- generate reports on our work, services and events;
- safeguard our staff and volunteers;
- conduct due diligence and ethical screening;
- Identify potential supporters, donors, researchers or other partners;
- monitor website use to identify visitor location, guard against disruptive use, monitor website traffic, personalise information which is presented to you and/or to provide you with targeted advertisements;
- process your application for a job or a volunteering position;
- conduct training and quality control;
- audit and administer our accounts;
- meet our legal obligations, for instance, to perform contracts between you and us, or our obligations to regulators, government and/or law enforcement bodies;
- carry out fraud prevention and money laundering checks;
- undertake credit risk reduction activities; and/or

- establish, defend or enforce legal claims.

Our use of personal data for digital advertising and sharing content

Our website(s) may include links to third-party websites, plug-ins, and applications. Clicking on those links or enabling those connections may allow third parties to collect or share data about you. We do not control these third-party websites or how they use personal data. When you leave our website, we encourage you to read the privacy policy of every website you visit.

We use your data to tailor the marketing you see on websites, apps, social media and advanced TV, and to measure its effectiveness. This may be via Social Plugins (e.g. Like and Share buttons) or by providing the 3rd party platform with a list of email addresses or phone numbers, which they use to target individuals with, or exclude them from seeing, our advertisements. On occasion, we may also provide 3rd party platforms with prior donation information to create value-based Lookalike audiences (where we can target ads to audiences who are most like our high-value supporters). We will only include supporters in these lists if they have opted in to receiving our marketing.

The contract terms, under which they act as our processor for this purpose, do not permit them to make any further use of the details we provided. Data is deleted once it is no longer in use.

Managing your contact preferences

We make it easy for you to tell us how you want us to communicate, in a way that suits you. Our forms have clear marketing preference questions, and we include information on how to opt out or unsubscribe when we send you marketing. If you don't want to hear from us, that's fine, and you can change your preferences at any time. Just let us know when you provide your data, or contact us at info@alpha1.org.uk

Legal basis for processing

Data protection laws mean that each use we make of personal information must have a "legal basis". The relevant legal bases are set out in the General Data Protection Regulation (EU Regulation 2016/679) and in current UK data protection legislation.

Specific consent

Consent is where we ask you if we can use your information in a certain way, and you agree to this (for example, when we send you marketing material via post, phone, text or e-mail). Where we use your information for a purpose based on consent, you have the right to withdraw consent for any future use of your information for this purpose at any time.

Legal obligation

We have a basis to use your personal information where we need to do so to comply with one of our legal or regulatory obligations. For example, in some cases we may need to share your information with our various regulators, such as the Charity Commission, Fundraising Regulator, Information Commissioner or Gambling Commission, or to use information we collect about you for due diligence or ethical screening purposes.

Performance of a contract / take steps at your request to prepare for entry into a contract

We have a basis to use your personal information where we are entering into a contract with you or performing our obligations under that contract. Examples of this would be if you are buying something from us (for instance, some branded merchandise or an event place), applying to work/volunteer with us, or being funded to undertake research.

Vital interests

We have a basis to use your personal information where we must protect life or health. For instance, if there were to be an emergency impacting individuals at one of our events, or a safeguarding issue which required us to contact people unexpectedly or share their information with emergency services.

Legitimate interests

We have a basis to use your personal information if it is reasonably necessary for us (or others) to do so and in our/their "legitimate interests" (if what the information is used for is fair and does not unduly impact your rights).

We consider our legitimate interests to include all of the day-to-day activities Alpha-1 UK carries out with personal information. Some examples not mentioned under the other bases above, where we are relying on legitimate interests, are:

- analysis and profiling of our supporters or potential supporters;
- update your address using third-party sources if you have moved house (please see the "Keeping your information up to date" section below for more on this).
- use of personal information when we are monitoring the use of our website or apps for technical purposes;
- use of personal information to administer, review and keep an internal record of the people we work with, including supporters, and volunteers;

We only rely on legitimate interests where we consider that any potential impact on you (positive and negative), how intrusive it is from a privacy perspective and your rights under data protection laws do not override our (or others') interests in us using your information in this way.

When we use special category personal data (please see the "What personal information we collect" section above), we require an additional legal basis to do so under data protection laws, so will either do so based on your explicit consent or another route available to us at law for using this type of information (for example if you have made the information manifestly public, we need to process it for employment, social security or social protection law purposes, your vital interests, or, in some cases, if it is in the public interest for us to do so).

How we keep your information safe

We ensure that there are appropriate technical and organisational controls (including physical, electronic and managerial measures) in place to protect your personal details. For example, our online forms are always encrypted, and our network is protected and routinely monitored.

How long we keep information for

We consider various criteria when determining the appropriate retention period for personal data, including:

- the purposes for which we process your data and how long we need to keep the data to achieve these purposes;
- how long personal data is likely to remain accurate and up to date;
- for how long the personal data might be relevant to possible future legal claims;
- any applicable legal, accounting, reporting or regulatory requirements which specify how long certain records must be kept.

Your rights

Under UK data protection law, you have rights over personal information that we hold about you. We've summarised these below:

Right to access your personal information

You have a right to request access to the personal data that we hold about you. You also have the right to request a copy of the information we hold about you, and we will provide you with this unless legal exceptions apply.

Right to have your inaccurate personal information corrected

You have the right to have inaccurate or incomplete information we hold about you corrected. If you believe the information we hold about you is inaccurate or incomplete, please provide us with details and we will investigate and, where applicable, correct any inaccuracies.

Right to restrict the use of your personal information

You have a right to ask us to restrict the processing of some or all of your personal information in the following situations: if some information we hold on you isn't right; we're not lawfully allowed to use it; you need us to retain your information for you to establish, exercise or defend a legal claim; or you believe your privacy rights outweigh our legitimate interests to use your information for a particular purpose and you have objected to us doing so.

Right to erasure of your personal information

You may ask us to delete some or all your personal information, and in certain cases, subject to certain exceptions, you have the right for this to be done. If we are unable to delete your information, we will explain why this is the case.

Right for your personal information to be portable

If we are processing your personal information (1) based on your consent, or to enter into or carry out a contract with you, and (2) the processing is being done by automated means, you may ask us to provide it to you or another service provider in a machine-readable format.

Right to object to the use of your personal information

If we are processing your personal information based on our legitimate interests or for scientific/historical research or statistics, you have a right to object to our use of your information.

If we are processing your personal information for direct marketing purposes, and you wish to object, we will stop processing your information for these purposes as soon as reasonably possible.

If you want to exercise any of the above rights, please contact us at info@alpha1.org.uk. We may be required to ask for further information and/or evidence of identity. We will endeavour to respond fully to all requests within one month of receipt of your request; however, if we are unable to do so, we will contact you with reasons for the delay.

Please note that exceptions apply to a number of these rights, and not all rights will be applicable in all circumstances. For more details, we recommend you consult the guidance published by the [UK's Information Commissioner's Office \(ICO\(link is external\)\)](#).

Complaints

If you are unhappy with any aspect of how we are using your personal information, we'd like to hear about it. We appreciate the opportunity this feedback gives us to learn and improve. You can find out more and read our Complaints Policy on our website alpha1.org.uk

You also have the right to complain about any use of your information to the [Information Commissioners Office\(link is external\)](#), the UK data protection regulator.

For individuals based in the EEA, please refer to the EU Representative details in the 'Contact Us' section.

Contact us – info@alpha1.org.uk

Alpha-1 UK, 27 Old Gloucester Street, Holborn, London WC1N 3AX.

This Safeguarding Policy is approved by:

Maisy Sheldon
Data Protection Officer
1 February 2026
