

About AAAMD

Thank you for visiting our website.

AAAMD ('us', 'we') is committed to protecting and respecting your privacy.

AAAMD is a 'data controller' for the purposes of the Data Protection Act 1998 and, after 25 May 2018, the General Data Protection Regulation (EU) 2016/679 and subsequently from 1 January 2021 'UK GDPR' (referred to in this privacy notice as the 'Data Protection Laws'). As a data controller, we are responsible for ensuring that your personal data is processed in accordance with the Data Protection Laws.

About this privacy notice

This privacy notice applies to our privacy practices for this website. It sets out the basis on which we process any personal data obtained from you via this website. Please read this notice carefully to understand how we process your personal data and your rights in relation to that processing.

The notice covers:

- What personal data we collect;
- What we do with that personal data;
- Whom your personal data may be shared with;
- Your rights in relation to your personal data.

Note that from time to time this website may contain links to and from the websites of third parties. These websites operate under their own privacy policies, and we do not accept any responsibility or liability for these websites or the privacy policies which apply to them.

Extra help

If you would like this notice in another format such as audio or braille, please contact us.

How you can contact us

Questions, comments and requests regarding this privacy notice are welcomed and should be addressed to benedict.kelly@actionagainstamd.org.

What personal data is collected about you

We collect and process the personal data that you give us, that is received from third parties, and that we obtain from this website. This personal data is not collected pursuant to any statutory or contractual requirement that applies to AAAMD. If you chose not to allow processing of your personal data, we will not be able to carry out any of the purposes described under **How do we use your personal data?** below.

- **You give us personal data** by filling in forms on this website or by corresponding with us by phone, e-mail or in person. The personal data you give us may include your name, address, e-mail address and phone number.
- **Personal data we receive from third parties.** We may receive personal data about you from third parties, including Google Analytics. We also work with third parties (including, for example, sub-contractors in technical and delivery services, search information providers or profiling agencies) and may receive personal data about you from them.
- **We use cookies to collect information about you** whenever you visit our website. Some of this data will be aggregated or statistical, which means that we will not be able to identify you individually, but some of it, particularly when combined with other data, could constitute personal data.

We collect and process your personal data on the basis of your consent. You give such consent when you contact us first. If we change our policy for processing your personal data, or change the scope of the personal data that we collect, we will contact you to ensure that we have your consent to these changes.

How do we use your personal data?

We will only use your personal data when the law allows us to. Most commonly, we will use your personal information in the following circumstances:

- you have given us consent,
- we need to perform a contract we are about to enter into, or have entered into, with you,
- where it is necessary for our or a third party's legitimate interests, and your interests and rights do not override those interests, or
- where we need to comply with a legal or regulatory obligation.

We **retain your personal data** for as long as is reasonably necessary for the purposes listed above. For further information about our approach to data retention please contact us at benedict.kelly@actionagainstamd.org, requesting a copy of our Data Protection Policy.

Purposes for which we use the information you give to us

We may use your personal information for a number of different purposes. For each purpose, we are required to confirm the 'legal basis' that allows us to use your information, as follows:

Purpose for which which we will use the information you provided us	The Legal Basis
To provide you with log in details to our online Information Portal.	Processing your details is necessary for the purpose of a contract (to provide you with services on our online information portal).

To provide you with services that we may offer in the future including (but not limited to): <ul style="list-style-type: none"> • Fund raising for core activities and medical research; • Facilitating research • Development of the Information Portal 	It will be necessary for the performance of the contract between you and us.
To respond to your enquiries made through our website.	We will only process your data as far as necessary for our legitimate interest to respond to your request for information.
To enable you to sign up to email updates about AAAMD.	You consent to providing us with your personal information for this purpose.
To notify you about changes to our website terms or this privacy policy	It will be necessary for our legitimate interests to ensure that you are aware of our current terms and conditions.
To administer our website and for internal operations including the use of cookies.	It will be necessary for our legitimate interests to ensure that you receive the best experience possible when accessing and using our website.
To invite you with information about events, such as seminars, workshops, conferences and dinners that you have requested	You have consented to us providing you with information for this purpose.

How we may disclose or share your personal data

We may share your personal data with such of our staff that need to know it to fulfil our obligations to you and their responsibilities to AAAMD.

We may also share your personal data with selected third parties including:

- our suppliers and sub-contractors (including IT support, pay roll, pension providers, legal advisers, storage and printing services) for the performance of any contract we enter into with you; and
- analytics and search engine providers that assist us in the improvement and optimisation of our site. Our outsourced IT services providers including, Dropbox, One Drive and other online cloud and data-room providers.
- Our Website hosts, Wix.com Inc,
- to a regulator where we are required to do so by law. For example, to HMRC or the Charity Commission.

We may disclose your personal data to third parties in the event that we sell or buy any business or assets, in which case we may disclose your personal data to the prospective seller or buyer of such business or assets. If AAAMDAAAMDor substantially all of its assets is/are acquired by a third party, the personal data held by us about you will be one of the transferred assets.

Note that we are under a duty to disclose or share your personal data in order to comply with any legal obligation, or in order to enforce any contract with you or to protect the rights, property, or safety of us, our customers, or others. This sharing of personal data includes exchanging information with other companies and organisations for the purposes of fraud protection and credit risk reduction.

Where we store your personal data

Some of the data that we collect from you may be transferred to third parties (for example, to Dropbox and other cloud providers) who will store the data at a destination outside the United Kingdom.

If we share your data with third parties as set out above, your personal data may be transferred to, and stored at or processed by staff operating outside the European Economic Area (EEA). In this instance, we will ensure that your privacy rights are protected by a contract containing materially the same obligations as we have to you and protecting your Personal Data.

How we keep your personal data secure

We use technical and organisational measures to safeguard your personal data - for example we use secure connections on our website to ensure that your website is encrypted. This means that we convert your data into a computer code, which will make it harder for hackers to access your data on our website.

While we will use all reasonable efforts to safeguard your personal data, you acknowledge that the use of the internet is not entirely secure and for this reason we cannot guarantee the security or integrity of any personal data that are transferred from you or to you via the internet.

If you want further information about how we are keeping your data secure, or have any particular concerns about your information, please contact us at benedict.kelly@actionagainstamd.org.

Working with us to keep personal data secure

Where we have given you (or where you have chosen) a password which enables you to access certain parts of our website, you are responsible for keeping this password confidential. We ask you not to share a password with anyone.

How long we will store your personal information

To determine the appropriate retention period for personal information, we consider the amount, nature and sensitive of the personal information, the potential risk of harm from unauthorised use or disclosure of your personal information, the purposes for which we process your personal information and whether we can achieve those purposes through other means, and the applicable legal requirements.

The length of time that we will store your data will depend on the 'legal basis' for why we are using that data, as follows:

Legal Basis	Length of Time
Where we use/store your data because it is necessary for our legitimate business interests	We will use/store your data for as long as it is necessary for our legitimate business interests, or such earlier time as you ask us to stop. However, if we can demonstrate the reason why we are using/storing your data is more important than your interests, rights and freedoms, then we will be allowed to continue to use/store your data for as long as it is necessary for our legitimate business interests.
Where we use/store your data because you have given us your specific, informed and unambiguous consent.	We will use/store your data until you ask us to stop.
Where we use/store your data because it is necessary for the performance of the contract between you and us.	We will use/store your data for as long as it is necessary for the performance of the contract between you and us.
Where we use/store your data because it is necessary for us to comply with a legal obligation to which we are subject.	We will use/store your data for as long as it is necessary for us to comply with our legal obligations.

Third party links

Our website 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 and are not responsible for their privacy statements. When you leave our website, we encourage you to read the privacy notice of every website you visit.

About our cookies

Our website uses cookies to distinguish you from other users of our site. This website used two types of cookie:

- **Session (Transient) cookies:** these cookies are erased when you close your browser, and do not collect information from your computer. They typically store information in the form of a session identification that does not personally identify the user.

- **Persistent (Permanent/Stored) cookies:** these cookies are stored on your hard drive until they expire (i.e. based on a set expiration date) or until you delete them. These cookies are used to collect identifying information about you, such as Web surfing behaviour (see below) and your preferences when using this website.]

The data that we collect using cookies includes:

- technical information, such as the internet protocol (IP) address used to connect your device to the internet, your login information, browser type and version, time zone setting, browser plug-in types and versions, operating system and platform); and
- information about your visit, such as the full uniform resource locators (URL) clickstream to, through and from our site (including date and time), information you viewed or searched for; page response times, download errors, length of visits to certain pages, page interaction information (such as scrolling, clicks, and mouse-overs), and methods used to browse away from the page and any phone number used to call us.

For more detail about the cookies that we use, see our Cookie Policy.

Your rights

As a data subject (i.e. a living person about whom personal data is held), you have the following rights under the Data Protection Laws:

- the right of access to personal data relating to you;
- the right to correct any mistakes in your information;
- the right to ask us to stop contacting you with direct marketing;
- the right to erasure;
- the right to withdraw consent;
- rights in relation to automated decision taking;
- the right to restrict or prevent your personal data being processed;
- the right to have your personal data ported to another data controller;
- the right to complain about how we are processing your personal data.

These rights are explained in more detail below, but if you have any comments, concerns or complaints about our use of your personal data, please contact us at benedict.kelly@actionagainstamd.org. We will respond to any rights that you exercise within a month of receiving your request, unless the request is particularly complex, in which case we will respond within three months.

Right to access personal data relating to you

You may ask to see what personal data we hold about you and be provided with:

- a copy;
- details of the purpose for which it is being or is to be processed;
- details of the recipients or classes of recipients to whom it is or may be disclosed, including if they are overseas and what protections are used for those overseas transfers;
- the period for which it is held (or the criteria we use to determine how long it is held);
- any information available about the source of that data; and
- whether we carry out an automated decision-making or profiling, and, if we do, information about the logic involved and the envisaged outcome or consequences of that decision or profiling.

Please make your requests for details about the personal data that we process in writing to benedict.kelly@actionagainstamd.org; a copy of your request will be retained. To help us find the information easily, please give us as much information as possible about the type of information you would like to see.

Note that if, in order to comply with your request, we would have to disclose information relating to or identifying another person, we may need to obtain the consent of that person if possible. If we cannot obtain consent, we may need to withhold that information or edit the data to remove the identity of that person if possible.

There are certain types of data which we are not obliged to disclose to you, which include personal data which records our intentions in relation to any negotiations with you where disclosure would be likely to prejudice those negotiations.

Right to correct any mistakes in your information

You can require us to correct any mistakes in the personal data which we hold about you, free of charge. If you would like to do this, please contact us at benedict.kelly@actionagainstamd.org.

Right to ask us to stop contacting you with direct marketing

Should we use your personal data for direct marketing purposes, you can ask us to stop contacting you for direct marketing purposes. If you would like to do this, please contact us at benedict.kelly@actionagainstamd.org. We will implement this as soon as reasonably practicable.

Right to erasure

From 25 May 2018 and in accordance with the General Data Protection Regulations 2018, you can ask us to erase your personal data where one of the following applies:

- You do not believe that we need your personal data in order to process it for the purposes set out in this privacy notice.
- You have given us consent to process your data, and you want withdraw that consent and we cannot otherwise legally process your personal data;
- You object to our processing and we do not have any legitimate interests that mean we can continue to process your personal data.
- Your personal data has been processed unlawfully or has not been erased when it should have been.

Right to withdraw consent

Currently we process your personal data on the basis that we have your consent.

You have the right to withdraw your consent to the processing of your personal data at any point. You can exercise your right to prevent such processing by contacting us at benedict.kelly@actionagainstamd.org. We will deal with all opt out requests as soon as we reasonably can, but please note that you may receive communications that have already been sent by the time we received your request.

Rights in relation to automated decision taking/making

In the unlikely event that, at some future point, we use your personal data to carry out some type of evaluation, for example a credit check, you can request that no decisions about you are based solely on an automated process and that any decision is reviewed by a member of staff. This right does not apply in all circumstances, for example where the decision is authorised or required by law and steps have been taken to safeguard your interests.

Right to prevent processing of personal data

From 25 May 2018 and in accordance with the General Data Protection Regulations 2018, you may request that we stop processing your personal data temporarily if one of the following applies:

- You do not think that the personal data we hold about you is accurate. We will start processing again once we have checked whether or not it is accurate.
- The processing is unlawful but you do not want us to erase your data.
- We no longer need the personal data for our processing, but you need the data in order to establish, exercise or defend legal claims.
- You have objected to the processing of your personal data because you believe that your interests should override Action Against AMD's legitimate interests.

Right to data portability

From 25 May 2018, in accordance with the General Data Protection Regulations 2018, where relevant, you may ask for an electronic copy of the personal data which

we hold electronically about you and which we process when we have entered into a contract with you. You can also ask us to provide this directly to another party.

Right to complain

It is important that you ensure you have read this privacy notice, and if you do not think that we have processed your personal data in accordance with this notice, please let us know as soon as possible. Similarly, you may complain to the Information Commissioner's Office. Information about how to do this is available from www.ico.org.uk.

Changes to our privacy policy and this privacy notice

We may amend our privacy policy and this notice from time to time. Any changes we may make to our privacy policy in the future will be posted on this page and, where appropriate, notified to you by e-mail. Whenever you use our website, please check these this notice to ensure you understand the basis on which we process your personal data at that time. These notice provisions were most recently updated on 25th February 2021. Please check back frequently to see any updates or changes to our privacy policy.