



The Kennedy Trust for Rheumatology Research

Website Privacy Notice

Version control

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The Kennedy Trust for Rheumatology Research

Website Privacy Notice

About this privacy notice

The Kennedy Trust for Rheumatology Research (the “**Charity**”) is committed to protecting and respecting your privacy. For the purposes of the UK General Data Protection Regulation (the **UK GDPR**) and any subsequent UK legislation covering data protection, the Charity is the controller of your personal data (which means that we determine the purposes (the why) and the means (the how) of the processing of your data).

This privacy notice sets out why we collect personal data, how we collect and use it and who it is shared with. It also explains the legal basis for the use of your personal data and the legal rights you have over the way it is used.

Who we are

For the purposes of the UK GDPR and the Data Protection Act (**DPA**) 2018, the controller of your personal data is The Kennedy Trust for Rheumatology Research, a registered charity in England and Wales (registered charity number: 260059) and a registered company in England and Wales (company number: 963832). The Charity’s contact details are as follows:

- Address: One Lyric Square, London, W6 0NB
- Telephone number: 0208 049 8136
- Email: enquiries@kennedytrust.org

The Data Protection Lead for the Charity is the Trust’s Grants and Office Manager, who may be contacted via enquiries@kennedytrust.org.

How we obtain your personal data

We may collect your personal data in the following ways:

- **Information you give us directly:** for example, you may provide your details to us when you ask us for information, attend our events or contact us for any other reason.
- **Information shared by known third party organisations:** we may receive information about you from third party partners with whom you interact, for example your research institution. This may include information such as your name and contact information.
- **Information available publicly:** for example, we may include on our website some information obtained from social media or from articles/newsletters.

Types of personal data we process

The type and amount of personal data we collect depends on the purposes for which we will need to use it and will include:

- Information used to identify and keep in touch with you, such as your name and contact details (email address, phone number). We collect this data to communicate effectively with you.
- If you apply for a grant, the personal data you are asked to provide is set out in the application form and is limited to the information necessary for us to communicate with you and to consider your application (for example information relating to any eligibility criteria).
- Correspondence between us, for example if you email or write to us.
- Images, audio and video recordings, e.g. if you attend an event we are hosting.

Special category personal data

Certain categories of personal information are regarded by data protection law as more sensitive than others. Known as ‘special category personal data’, this relates to information about your health, racial or ethnic origin, details of sexual life, sexual orientation, religious beliefs, political opinions or any genetic or biometric data that is used to identify you. This information, and any information about criminal offences or convictions, warrants a higher level of protection under data protection law.

The Charity will only process special category personal data and criminal offence data where it has identified an appropriate lawful basis to do so, and where appropriate policy and safeguards are implemented in accordance with Article 9 and 10 UK GDPR and the DPA 2018. This could include incidents when:

- You have provided **explicit consent** (such consent may be withdrawn at any time by emailing enquiries@kennedytrust.org);
- The processing is **necessary in order to protect your or another person’s vital interests** where that person is physically or legally incapable of giving consent (for example, providing your details to a medical professional in a medical emergency);
- The processing relates to **personal data which is manifestly made public by the data subject** (for example, where you publish information about yourself in the public domain);
- The processing is **necessary for the establishment, exercise or defence of legal claims** or whenever courts are acting in their judicial capacity (for example, providing information to a court where a claim has been made);
- The processing is **necessary for reasons of substantial public interest**, in accordance with Part 2, Schedule 1 of the DPA 2018 (for example, where this is necessary for the purposes of protecting the physical, mental or emotional wellbeing of an individual).

Why we process your personal data

We will use your personal data for various purposes consistent with the legal basis we rely on to process your data. These purposes include:

- providing you with the information or services you have asked for;
- sending you communications with your consent that may be of interest, including information relating to new funding schemes or events hosted by the Charity;
- seeking your views on the services or activities we carry on so that we can make

- improvements;
- maintaining our organisational records and ensuring we know how you prefer to be contacted;

We do not use your personal data in automated decision-making, including profiling (i.e. we do not make decisions about you by way of automated means without human involvement).

Failure to provide personal data

When we collect personal data from you, we will make it clear whether you are required by law, or under a contract, to provide your personal data, and what will happen if you do not provide that data.

Our legal basis for processing your information

Data protection law requires us to have a lawful basis for processing your personal data. Depending on the purposes for which we use your data, we may rely on one or more of the following lawful bases:

- **Consent:** Where you have provided your consent for us to use your personal data. You may withdraw consent at any time by emailing us at enquiries@kennedytrust.org. This will not affect the lawfulness of processing of your information prior to your withdrawal of consent being received and actioned.
- **Performance of a contract:** It may be necessary for us to use your information to carry out our obligations under a contract entered into with you or to take steps you ask us to take prior to entering into a contract.
- **Vital interests:** It may be necessary for us to use your information to protect the vital interests of you or another individual. For example, providing your details to a medical professional in the case of a medical emergency.
- **Legal obligations:** It may be necessary for us to use your information to comply with our legal obligations. For example, if we are legally required to hold transaction details for accounting/tax purposes.
- **Legitimate interests:** It may be necessary for us to use your personal data for the purposes of “legitimate interests” pursued by the Charity or a third party (as long as those legitimate interests are not overridden by your rights and freedoms). For example:
 - Where we need to provide information or services to you, we may rely on the fact that it is necessary for our legitimate interests to provide the information or service requested, and given that you have made the request, we would presume that there is no prejudice to you.

If you want to contact us about your marketing preferences please contact enquiries@kennedytrust.org.

How we keep your personal data safe

We understand the importance of security of your personal data and take appropriate steps to safeguard it.

Records are held in the Microsoft 365 infrastructure, more details of which can be found here: <https://www.microsoft.com/en-gb/trust-center/privacy>. Hard copy data is in locked cabinets in locked rooms solely used by the Charity.

We always ensure that only authorised persons have access to your personal data, which means only those members of our staff, Trustees and Committee members who need to access your data to fulfil their roles. Everyone who has access to personal data is appropriately trained and aware of their obligations to ensure confidentiality and security of your data.

Please note, we interact via the internet and email, and no external data transmission over the internet can be guaranteed to be 100% secure. So, while the Charity strives to safeguard your personal data, we cannot guarantee the security of any information you provide online and you do this at your own risk.

Who has access to your personal data?

Occasionally, we may have to share your personal data with third parties. We will only share your personal data with third parties where the law allows us to do so.

Where we share your personal data, we require third parties (under contractual arrangements where appropriate) to put measures in place to protect your personal data and to only process your personal data in compliance with the law.

We may need to share personal data with third-party service providers or other third parties (please see below) or/and may be required by law to share some of your personal data with certain competent authorities.

It may be necessary to share your personal data with companies who provide services for us, such as:

- Our legal advisors;
- Our appointed accountants;
- Our IT services provider; and
- Parties providing mailing and marketing services.

Transfers of your personal data to other countries

We will not transfer your information to countries or territories outside the UK, except for funding applications where we may share your application with selected international experts who have been asked to provide an opinion on the application (peer review).

We meet the UK GDPR requirements by ensuring that personal data is protected as if it were being held in the UK. This will usually be because the country to which we transfer data either benefits

from an adequacy determination or we have entered into a contract with the third party which contains EU standard contractual clauses recognised as a valid data transfer mechanism in the UK.

If you would like more information about how we protect your personal data if it is transferred outside the UK please contact enquiries@kennedytrust.org.

How long we keep your personal data for

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements and, where required for us to assert or defend against legal claims, until the end of the relevant retention period or until the claims in question have been settled.

If you would like further information about our retention periods, please contact enquiries@kennedytrust.org.

Your rights

Data protection law provides individuals with various legal rights, which may be exercised in certain circumstances. You have the following legal rights over your personal data:

- **The right of access** (commonly referred to as a “subject access request” or “SAR”): This right enables you to obtain a copy of the personal data we hold about you as well as other information about how we are processing your personal data.
- **The right to rectification:** This right enables you to require us to correct the personal data we hold about you if it is inaccurate or incomplete.
- **The right to erasure** (also known as the right to be forgotten): In certain circumstances, you have the right to request that personal information we hold about you is erased (such as where we no longer need your personal data for the purpose it was originally collected for).
- **The right to restrict processing of your personal data:** You may ask us to restrict the use of your personal data in certain circumstances (such as where you believe your personal data is incorrect and we need to verify the accurate of the personal data we hold).
- **The right to object:** You may object to our processing of your personal data in certain circumstances, such as where we are processing your personal data on the basis of “legitimate interests”. Please note, you always have the right to object to processing of your personal data for direct marketing purposes.
- **The right to data portability:** This right allows you to request that we transfer your personal data to you or another third party in a commonly used, machine-readable format. Please note, this right only applies to automated information that you initially provided consent for us to use or where we used the information to perform a contract with you.
- **The right to withdraw consent:** Where we are relying on your consent to process your personal data, you have the right to withdraw your consent at any time, and may do so by contacting us via enquiries@kennedytrust.org. If you decide to withdraw your consent, that does not mean that our use of your personal data before you withdrew your consent is against the law.

Please note, some of your legal rights are subject to safeguards, limitations or exemptions.

If you wish to exercise your rights, please contact us via enquiries@kennedytrust.org and we will respond within the time limits set out in data protection law.

Complaints

If at any time you are not happy with how we are processing your personal information then you may raise the issue with the Data Protection Lead in the first instance.

If you are not satisfied with the handling of your issue, you may raise a complaint with the Information Commissioner's Office, which regulates and enforces data protection law in the UK.

Details of how to do this can be found at <https://ico.org.uk/make-a-complaint/>.

Keeping your information up to date

We really appreciate it if you could let us know if your contact details change. You can do so by contacting us at enquiries@kennedytrust.org.

Changes to this Privacy Notice

This privacy notice was published on 22 March 2022. This privacy notice may be changed from time to time. We will advertise any changes on our website or, if the changes are significant, we will contact you directly with the information.