

## Introduction

This document explains why information is collected by the UK Kidney Association (UKKA) about its members, as well as attendees at UK Kidney Week and how their information may be used. This is called a Fair Processing Notice or Privacy Notice. It describes how the UKKA collects, uses and processes its members personal data and associated information and how, in doing so, it complies with its legal obligations to members. The privacy of its members is important and the UKKA is committed to safeguarding data privacy rights.

## What is the UK Kidney Association?

The UK Kidney Association (UKKA) is a trading name of the Renal Association (RA), a not-for-profit organisation registered with the Charity Commission (charity number 800733) as a membership organisation for healthcare professionals caring for people with kidney disease. Full details of the UKKA's work can be found here: <https://ukkidney.org/>

The UKKA collects information in order to:

- maintain records on individuals current and past standing as a member of the UKKA or user of UKKA services;
- provide individuals with membership of the UKKA;
- Run and facilitate attendance of UK Kidney Week;
- provide information about other products and services provided the UKKA such as events, and details of UKKA activities.

The UKKA is **data controller** for all uses of data described in this notice.

## Where does the UKKA collect your data from?

The UKKA collects information through the <https://ukkidney.org/> website or through the completion of a membership application. For UK Kidney Week, information will be collected directly from attendees or, where appropriate, provided by the attendees employer or associated organisation.

## What personal information does the UKKA collect?

### Membership

To become a member of the UKKA, individuals will be asked to fill out an application form collecting the following categories of information:

- Basic details – name, date of birth, gender, job title and affiliation
- Contact details – address, email address, telephone number(s)
- Special category data: Ethnicity

During the course of membership, the UKKA will also keep a record of its member's participation in UKKA Councils, special interest groups, sections, other UKKA groups, and attendance at UKKA events including UK Kidney Week.

## Newsletters

Where an individual signs up to one of the UKKA's newsletters, the UKKA will collect their name and email address only.

## UK Kidney Week

To attend UK Kidney Week, a national event hosted by the UKKA, individuals will need to provide the following categories of information:

- Basic details – name, date of birth, gender, job title and affiliation
- Contact details – address, email address, telephone number(s)
- Special category data: Ethnicity

Additional information such as dietary, and other requirements may also be collected. This information will usually be collected directly from the attendee, though may be collected through an affiliated group, if they are attending as part of a group booking.

## The "ukkidney.org" website

### Use of cookies by the UKKA

Cookies are small text files that are placed on an individual's computer by websites that they visit. They are widely used in order to make websites work, or work more efficiently, as well as to provide information to the owners of the site. Most web browsers allow visitors some control of most cookies through the browser settings or through free software such as Super-Antispyware or Cleaner. To find out more about cookies, including how to see what cookies have been set and how to manage and delete them, visit the All About Cookies website at <http://www.allaboutcookies.org>.

### Demographics

The UKKA's webserver records your visits to help the UKKA understand how visitors use the site, so it can improve the site and provide better services.

### Use of links

Throughout the UKKA's web pages, the organisation provides links to other sites which may contain information of interest to site visitors. The UKKA takes no responsibility for, and exercises no control over the organisations, their views, or accuracy of the information contained on other servers. Creating a text link from another website to the UKKA's website does not require permission.

## How does the UKKA use information?

### Membership

The UKKA uses the information provided via the membership application form to process the membership, collect membership fees, and to provide the benefits, services and information that come with membership.

During the period membership the UKKA will also maintain records of any involvement across its councils, special interest groups, sections, and attendance at its events, including UK Kidney Week, to ensure that members receive information and services suitable to their membership.

The UKKA will contact its members in line with their individual contact and marketing preferences. Members can change their preferences or opt-out of communications at any time. Instructions on how to do so can be found in the 'Data subjects rights' section below.

The UKKA collects data on the ethnicity and gender of its members as part of the UKKA's goal to have its membership reflect the make-up of the wider kidney community, ensure that its offerings and events are inclusive, and that opportunities are equally available to everyone.

### Newsletters

The information provided when subscribing to the UKKA's newsletters will be stored in a secured mailing list and used only to send subscribers a copy of the newsletter(s) that they have subscribed to.

Subscribers can opt-out of receiving the newsletter(s) at any time. Instructions on how to do so can be found in the 'Data subjects rights' section below. Subscribers will also be able to control what information they receive from the UKKA by following the "update your preferences" link at the bottom of each newsletter.

### UK Kidney Week

The UKKA uses the information attendees provide when signing up to UK Kidney Week to enable them to attend the conference and engage in the sessions and other offerings. Where applicable, details of membership may be cross-checked by the UKKA Membership Officer and Secretariat Team to ensure that the correct tickets have been purchased (ie Membership discounts) and that information provided is up-to-date. Other work for UKKW is primarily carried out by the UKKA's events team although in certain cases will require attendees' information to be passed onto third parties. Details of which organisations the UKKA shares data with can be found below.

The cross-checking between UKKW registrants and UKKA membership data will include the checking of ethnicity and gender data to ensure up-to-date and accurate records. Doing this will also ensure that UKKA can continue to improve the services it provides for UKKW and its other offerings.

## Who your information is shared with

### Membership

The UKKA shares membership information with a limited number of third parties in order to provide members with the benefits and services of membership. These include:

- The UKKA's bank & payment processing services – to process membership fees
- A marketing and communication platform – to manage mailing lists and send out communications
- Kidney Care UK (clinical directors only) to allow for the distribution of material promoting kidney health and related information for patients
- Venues – to organise and run UKKA events

From time to time, the UKKA may work with other organisations and interest groups which we think will be of benefit to our members. On such occasions, the UKKA will ask for each individual member to provide their consent before any membership or personal information is passed on.

## European Renal Association

For UKKA members who take up their complimentary membership of the European Renal Association, and agree for the sharing of data, the UKKA will share the following information with the ERA to process the membership:

- Basic details – name, date of birth, gender, job title and affiliation
- Contact details – address, email address, telephone number(s)

During membership, the ERA may also collect other information about its members. For more information about what information the ERA may collect and why, please refer to the ERA's privacy notice, available here: <https://www.era-online.org/privacy-policy/>

The ERA will be considered a data processor of the UKKA for these purposes and act within the terms of an agreement signed by both parties and in accordance with the requirements of UK and EU data protection legislation (the Data Protection Act 2018 and GDPR respectively).

## Newsletters

The information provided to the UKKA when subscribing to its newsletters will not be shared be any third parties.

## UK Kidney Week

In order to run UK Kidney Week the UKKA engages a number of third-party organisation to manage the preparation and running of the conference. Each organisation is a data processor for the purposes of UK Kidney Week. The third parties engaged for UK Kidney Week 2024 are as follows:

Third party	Purpose	Data provided
International Convention Centre Wales	Hosting and catering of the conference	Name
Voco Edinburgh – Haymarket	Accommodation services	Name, email address, phone number
Moxy Fountainbridge	Accommodation services	Name, email address, phone number
Doubletree by Hilton Edinburgh	Accommodation services	Name, email address, phone number
Hampton by Hilton West End	Accommodation services	Name, email address, phone number
Brightelm	Badges and event support	Name, organisation

Corporate sponsors	Compliance with industry regulations (Data provided cannot be used for market purposes unless individuals provide additional consent)	Name, organisation
Oxford Extracts	Registration and content administration (abstracts and presentation etc)	Name, Organisation, email address

## The UKKA’s lawful basis for collecting your information

All of the legal bases listed in this section are subject to safeguards required by the General Data Protection Regulation (GDPR) and with due consideration to your rights as an individual.

### Membership

The UKKA has a *legitimate interest* in continuing its charitable purposes by enabling it to provide its members benefits or services as appropriate to their membership (Article 6(1)(f) of the UK GDPR, Data Protection Act (2018)).

### European Renal Association membership

Membership of the ERA by UKKA members is opt-in and the UKKA will only share data with the ERA where the individual member consents to do so.

The ERA processes data in line with their own privacy notice found here: <https://www.era-online.org/privacy-policy/>

### Newsletters

The UKKA relies on consent to send subscribers its newsletter(s). If a subscriber wishes to withdraw their consent, they can do so by following the instructions in the ‘Data subject rights’ section below.

### UK Kidney Week

The UKKA has a *legitimate interest* in providing a national conference which further benefits the kidney community by the sharing of knowledge and networking.

## How the UKKA maintains the confidentiality of your information

The UKKA is very careful with the information provide to us. The UKKA has strict rules about how data are used and who can use it. The UKKA is committed to protecting individual privacy and will only use information collected lawfully in accordance with the:

- Data Protection Act (2018)
- General Data Protection Regulation (GDPR – EU) (2016/679)
- Human Rights Act (1998)

- Common Law in England and Wales, Scots Law in Scotland, and Northern Ireland Law in Northern Ireland

The UKKA keep information secure in accordance with its legal responsibilities; including taking reasonable steps to safeguard against information being accessed unlawfully or maliciously by a third party, accidentally lost, destroyed or damaged.

The UKKA will not disclose personal information to third parties outside of what has been described within this privacy notice unless there are exceptional circumstances such as situations when the health and safety of others is at risk, where the law permits information to be passed on, or where individual consent has been provided.

All employees of the UK Kidney Association are asked to sign a confidentiality agreement as part of their employment contract. If a sub-contractor acts as a data processor for the UKKA an appropriate contract will be established for the processing of information.

## **How long personal information will be stored by the UKKA**

### **Membership**

The UKKA will retain personal information for the duration of an individual's membership, and then for one further year after the end of their membership. At the end of that one year, the UKKA will delete the individual's information with the exception of any financial information relating to their membership (e.g. records of membership fee payments) which will be held for six years in accordance with legal audit requirements.

### **Newsletters**

The UKKA will only keep an individual's subscription information for as long as they continue to be subscribed to the newsletter(s). When they no longer wish to be subscribed, the UKKA will delete their information.

### **UK Kidney Week**

The information collected about UK Kidney Week attendees will be retained by the UKKA for a period of one year after the event. At the end of that one year, the UKKA will delete the information with the exception of any financial information relating to their attendance (e.g. records of conference payments) which will be held for six years in accordance with legal audit requirements.

## **Data Subjects rights**

This next section describes how individual data subjects can access, amend, erase and move their personal data, withdraw consent, object to or complain about the data that the UKKA holds about them.

### **Right to access data (data subject access requests)**

Individuals have the right to see or have a copy of their personal information held by the UKKA. If they want to receive a copy of their information, they should make a written request to the UKKA (see the section below on 'How to contact the UKKA'). The UKKA will normally provide

the requested information within one month of receiving all the information needed from the individual to respond to their request.

### **Right to rectification (right to amend)**

Individuals have the right to have their information amended. If an individual wants to amend their information held by the UKKA, they should make a written request to the UKKA (see the section below on 'How to contact the UKKA').

### **Right to withdraw consent for the UKKA to process your data**

Individuals have the right to withdraw your consent for the UKKA to process your information at any time. They should be aware however, that without providing consent for the UKKA to process their personal data, individuals will be unable to maintain membership of the UKKA, receive the information and services that come with membership, or attend events such as UK Kidney Week.

Should an individual wish to withdraw their consent they can do so by contacting the UKKA in writing using the details found in the 'How to contact the UKKA' section below.

Alternatively, if anyone wish to unsubscribe from the UKKA's newsletter(s) or other communications they can do so by clicking the 'Unsubscribe' link at the bottom of the communication and follow the instructions from there.

### **Right to have your information erased**

Individuals can request in writing to have their **identifiable** information erased at any time. This right does not extend to information that has been anonymised.

The UKKA will respond to requests within one month. Please see the section 'How to contact the UKKA for our contact details.

### **Right of data portability (right to move your data)**

Individuals have the right to request a secure transfer of their data from the UKKA to another data controller. The UKKA will transfer the relevant data to the individual or directly to a third party of their choosing in an accessible format. Individuals should make the request in writing to the UKKA (see the section below on 'How to contact the UKKA'). No fee will be payable and the information will be transferred within one month.

### **Right to object**

The UKKA uses personal information for the purposes described. If an individual does not agree with this they have the right to object. See the section below on 'Objections and complaints' that explains who to contact. The UKKA will respond to the objection within a month (although we may be allowed to extend this period in certain cases).

### **Objections and complaints**

Should any individual have any concerns about how their information is managed, they can be submitted in writing to the data protection officer for the UKKA (see the section below on 'How to contact the UKKA'). If there are still concerns following a review by the data protection officer, the individual has the right to lodge a complaint with the Information Commissioner:

Information Commissioner:  
Wycliffe house  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF  
Tel: 01625 545745

<https://ico.org.uk/>

## How to contact the UKKA

Any questions regarding this privacy notice, how data are used, or requests to exercise data subject rights, can be sent to the UKKA on the details below.

The UKKA's data protection officer is: Mr Tom Gray

He can be contacted by:

Post  
Tom Gray  
UK Kidney Association c/o the Renal Association  
Brandon House, Building 20a1  
Southmead Road  
Bristol  
BS34 7RR

Email: [tom.gray@ukkidney.org](mailto:tom.gray@ukkidney.org)

Alternatively, you can contact:

The senior information risk owner – Mr Ron Cullen

Email: [ron.cullen@ukkidney.org](mailto:ron.cullen@ukkidney.org)

Or

Events Manager – Ms Sarah Crimp

Email: [sarah.crimp@ukkidney.org](mailto:sarah.crimp@ukkidney.org)

## Changes to this notice

The UKKA may amend this privacy notice from time to time. If you are dissatisfied with any aspect of this privacy notice, please contact the data protection officer.