**KPIN Privacy Policy**

The Kidney Patient Involvement Network (KPIN) understands that your privacy is important to you and that you care about how your personal data is used. We respect and value the privacy of all of our donors, beneficiaries, supporters, volunteers, staff and other stakeholders. We will only collect and use personal data in ways that are described here, and in a way that is consistent with our obligations and your rights under the law.

The privacy and security of your personal information is extremely important to us. We want everyone who joins KPIN to feel confident and comfortable that any personal information they share with us will be looked after.

This privacy policy explains how and why we use your personal data, to make sure you stay informed and can be confident about giving us your information.

**1. Who we are**

The Kidney Patient Involvement Network (KPIN) is a network of individuals, kidney (renal) organisations and charities committed to quality patient and public involvement and engagement (PPI/E) who are willing to work collaboratively on initiatives to improve standards and develop patient leaders of the future.

For more information about our work please visit: <https://kpin.org.uk/about-us/>

Whilst we are an independent network, our data management is overseen by Kidney Care UK, the UK’s leading kidney patient support charity, a registered charity (charity number 270288 in England and Wales, SC048198 in Scotland) and a company limited by guarantee (company number 1228114).

KPIN needs to keep certain information on its members in order to carry out its day to day operations, to meet its objectives and to comply with legal obligations.

We are committed to protecting individuals’ personal information and privacy and ensuring any personal data is dealt with in line with the General Data Protection Regulation (2018). To comply with the law, personal information will be collected and used fairly, stored safely and not disclosed to any other person unlawfully.

We will never sell your personal data and will only share it with trusted third party organisations we work with when it’s necessary to deliver our work, and the privacy and security of your data is assured. We work with Kidney Care UK to ensure that your data is stored securely and only accessible to those who have the right to see it.

**2. What personal data do we collect?**

We collect your personal information when you join KPIN as a patient, carer or professional member. This includes any information which identifies you, or which can be identified as relating to you personally, for example, name, address, phone number, email address etc.

We will only collect, use and otherwise handle your personal data:

* Where you have consented to this for specific, explicit and legitimate purposes, or for which we feel you would have a legitimate interest
* Where this is necessary to fulfil legal obligations that apply to us
* Where it is necessary for our legitimate interests relating to running our daily operations, as long as, in each case, these interests are in line with applicable law and your legal rights and freedoms

Membership of KPIN is aimed at those over the age of 18.

**Sensitive Personal Data**

As well as identifiable data, we also collect more sensitive personal data such as your health condition and treatment experiences. This information is only collected in order for us to deliver the best possible service to you, is always stored securely and is not shared more widely within the network. We will not pass on your details to anyone else without your express permission except in exceptional circumstances, such as anyone reporting serious self-harm or posing a threat to others, or children contacting us about serious issues such as physical abuse or exploitation.

Where you have given us your express consent that you are happy for us to share a vlog or blog story, then we may publish it on our website and publicise it through our email newsletter, Facebook group or Twitter, we will check that you are still happy for us to use your story prior to publication.

**Online Community and Social Media**

We provide and manage an online community for patient members within the network to talk to each other about their involvement in different activities, share experiences and offer peer support. The Facebook Group is closed but your identity on the group will be seen by other members. We ask all group members to abide by our community rules, which can be found in the group description.

We may obtain your personal data through your use of social media such as Facebook, Twitter and other social channels, depending on your settings or the privacy policies of these social media and messaging services. To change your settings on these services, please refer to their privacy notices, which will tell you how to do this.

**E-newsletter**

We use a third-party provider, MailChimp, to deliver our monthly e-newsletters and regular communications. We collect statistics around email opening and clicks using industry standard technologies. For more information, please see MailChimp’s privacy notice. (<https://mailchimp.com/legal/privacy/>)

**Website and Cookies**

A cookie is a small file which asks permission to be placed on your computer's hard drive. Once you agree, the file is added and the cookie helps analyse web traffic or identify you when you visit a particular site. Cookies allow web applications to respond to you as an individual. The web application can tailor its operations to your needs, likes and dislikes by gathering and remembering information about your preferences.

Overall, cookies help us provide you with a better website by enabling us to monitor which pages you find useful and which you do not. A cookie in no way gives us access to your computer or any information about you, other than the data you choose to share with us.

The KPIN website generates session cookies which monitor site usage anonymously using Google analytics. You can choose to accept or decline cookies. Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer.

**3. How we use your personal data**

We use the personal information collected to help us achieve our objectives:

* Create a network of members who want to be involved in different opportunities across the kidney community
* Gather involvement opportunities from our collaborating organisations and use the network to share these opportunities with members according to their agreed preference
* Share good practice and resources with members interested in accessing training to increase confidence and involvement experience
* Offer peer support to members involved in, for example, projects, advisory groups and committees, to allow them a platform to share experiences

Data is also collected in order to meet our administrative, legal, statutory or regulatory obligations, including:

* providing you with services, products or information you requested, or which may be of interest to you;
* providing further information about our work, services, activities or products;
* notifying you of any changes to our services;
* inviting voluntary participation in our work or surveys;
* analysing and improving our work, services, activities, products or information (including our website) or for our internal records;
* using IP addresses and monitoring website use to identify locations, block disruptive use, record website traffic or personalise the way information is presented to you;
* fraud prevention or otherwise as required by law or regulation.

We are committed to protecting individuals’ personal information and privacy and ensuring any personal data is dealt with in line with the Data Protection Act 2018 and the General Data Protection Regulations (2016). To comply with the law, personal information will be collected and used fairly, stored safely and not disclosed to any other person unlawfully.

We will only keep your information for as long as is reasonable and necessary for the relevant activity, which may be to fulfil statutory obligations.

**4. Keeping your information safe**

Your privacy is important to us, so we’ll always keep your details secure. In order to prevent unauthorised access or disclosure, we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect. As our Data Manager Kidney Care UK’s cyber security policy will be reviewed annually.

We will never sell or share your personal information with third party organisations so that they can contact you for any marketing activity. We will only share your information with trusted partners who work with us or on our behalf to deliver services to you, such as KCUK who help manage and store the data for KPIN. Any processing of your information is carried out under our instruction, after a non-disclosure agreement has been signed and we have made sure they store the information securely, delete it when they no longer need it and never use it for any other purposes.

**5. Updating your data and marketing preferences**

We'd love to stay in touch, but we don't want to out-stay our welcome - we want you to remain in control of your personal data.

You have the right to:

* request a copy of the information we hold about you;
* update or amend the information we hold about you if it is wrong;
* change your communication preferences at any time;
* ask us to remove your personal information from our records;
* object to the processing of your information for marketing purposes; or
* raise a concern or complaint about the way in which your information is being used.

If you have any questions about this privacy policy or how we use the personal data you share with us, please contact us in one of the following ways:

By email – [info@KPIN.org.uk](mailto:info@KPIN.org.uk)

Via the website at <https://kpin.org.uk/contact-us>

**6. Updates to this Privacy Policy**

We will review this policy at least once a year to make sure it is up to date and accurate. As a result, we may need to make changes to the policy, which will be posted on our website or by contacting you directly.