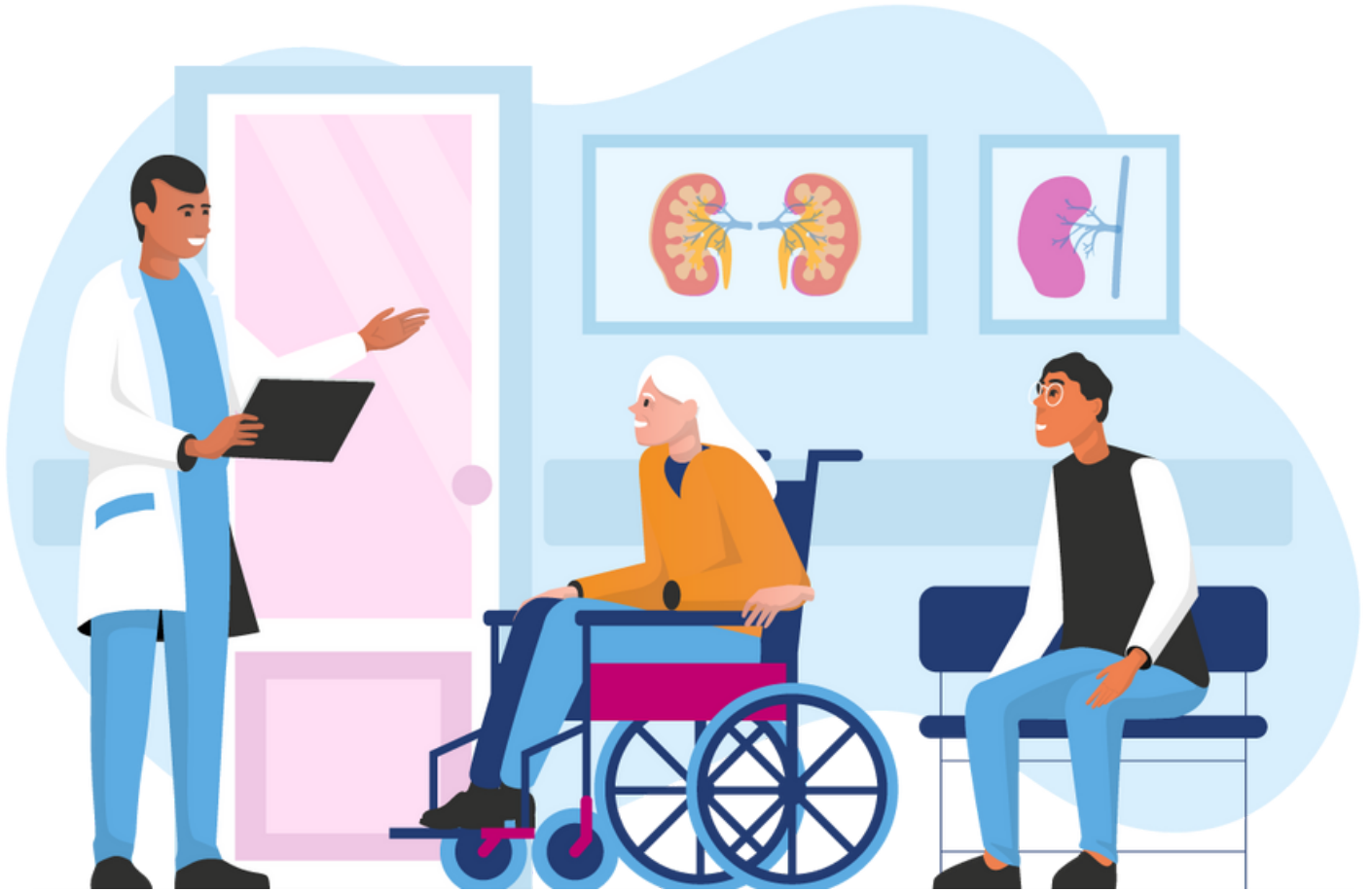




UK Kidney Association  
UK Renal Registry



# THE UK RENAL REGISTRY

*Helping to improve the care of people  
living with kidney disease in the UK*



[ukkidney.org](http://ukkidney.org)



[@ukkidney](https://twitter.com/ukkidney)



[ukka@ukkidney.org](mailto:ukka@ukkidney.org)

## WHAT IS THE UK RENAL REGISTRY?

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A clinical audit is a way to find out if care is being provided in line with standards, where services are doing well, and where improvements could be made. **The UK Renal Registry (UKRR) is a clinical audit of the quality of kidney care in the UK.** The UKRR is well established and has been bringing together information from hospitals and other NHS organisations for over 25 years!

To carry out its work, the UKRR collects information on every patient cared for by hospital kidney centres with chronic kidney disease, patients receiving dialysis, and patients with a kidney transplant. Information is provided by every kidney centre in England, Northern Ireland, Scotland, and Wales.

The UKRR is operated by the UK Kidney Association (UKKA), a not-for-profit organisation registered with the Charities Commission. The UKKA is a membership organisation made up of professionals from across the kidney community, including doctors, nurses, pharmacists, and technicians, all with the goal of improving the quality of care, safety, and outcomes for kidney patients.



## HOW DOES THE UKRR HELP PATIENTS?

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By collecting information about the care that kidney patients receive and how well they do, we can:

- Help doctors, nurses, and other kidney professionals to decide on the **best treatments** and care
- Support projects in hospitals that aim to **improve the quality of care** and outcomes for patients
- Summarise the information for patients so that they can **learn more about kidney disease** and the treatment options

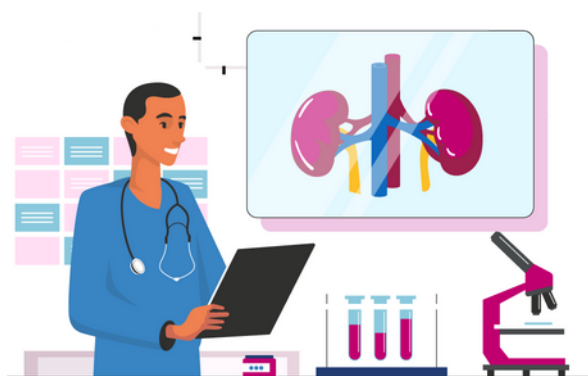
## WHAT INFORMATION IS COLLECTED?

Each time patients visit a kidney centre, the centre sends information to the UKRR on the treatments and care that patients receive. This information includes blood test results, any diagnoses, and the type of treatment that patients receive (Haemodialysis, Peritoneal Dialysis, and/or Transplant). In addition, the UKRR receives information such as the patient's name, date of birth, sex, ethnicity, contact details and NHS number.



We use some of these identifiable details to help us link with other information, held in different parts of the NHS. For example, the UKRR can find out about hospital visits relating to a patient's kidneys from NHS Digital, information about any infections they might have had from the UK Health Security Agency, and details about transplants from NHS Blood & Transplant.

The UKRR collects information about a patient's sex and ethnicity to see if there are any differences in the quality of care and outcomes. We use this information to help the NHS to identify and correct any inequalities.



**The UKRR has permission from the government to collect information without asking each individual patient for their consent. This means that we can include everyone and make sure the information we use to help patients is as complete and accurate as possible.**

## WHAT IF PATIENTS DON'T WANT TO BE INCLUDED?

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We understand that some patients may not wish to have their identifiable information collected and used by organisations such as the UKKA.

Although the National Data Opt-out programme allows NHS patients to decline the use of their data beyond their immediate care, some of the UKRR's audits of hospitals treating patients for their kidney condition have been allowed to be exempt by the Department of Health and Social Care. This means that patients being treated for their kidney condition, whether by dialysis or transplant, or patients that have had an acute kidney injury (AKI) will be included in the UKRR's data collection even if they have opted-out via the National Data Opt-out.

To opt-out of the UKRR data return, a patient will need to tell this to their kidney centre directly. The staff at the kidney centre will not ask for any specific reason and will simply record and action the patient's decision. Some medical information will continue to be sent to support the audit but it will be anonymous. This means that patient-identifiable information will not be shared, and the UKRR will not know who the data belongs to.

While the patients who opt-out will still be anonymously included in the UKRR's audit, their information cannot be linked to other organisations, such as NHS Digital and the UKHSA. This means that for patients who decide to opt-out, the UKRR is limited in how it can analyse the information to help achieve its goals.

Patients who wish to opt-out of having their identifiable information included in the UKRR's audits can do so by contacting the UKRR via: [dataprotection@ukkidney.org](mailto:dataprotection@ukkidney.org)

## HOW ELSE CAN PATIENTS GET INVOLVED?

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### Join the UKKA Patient Council

The UKKA Patient Council is a long-standing group that helps shape the work carried out by the UKRR and the UKKA. Meeting four times a year (usually virtually), they discuss issues around how patient data is used, raise concerns about aspects of kidney care across the country and give a voice to patients in the workings of the organisation.

In recent years they have helped with the production of the Patient Summary of the UKRR's annual report, which presents the key messages of the annual audit of kidney care in a patient-friendly way.

[Patients can find more information here.](#)

## Participate in research opportunities

If patients are interested in participating in research that improves the treatment and outcomes of kidney patients, they might like to think about joining the UKRR's database of patients that consent to be contacted for research purposes. This initiative is led by the UKKA Patient Council. Details about this and the National Registry of Rare Kidney Diseases can be found on [the UKKA website](#).

In addition to UKKA opportunities, we would also encourage you to seek out further information and support through organisations such as [Kidney Care UK](#) and the [National Kidney Federation](#), both charities with which the UKKA works closely to help improve the lives of kidney patients.



## WHERE CAN I GET MORE INFORMATION?

The [UKKA website](#) has more information on how the organisation works, what we do and how it helps patients.

[Privacy notice](#) – The UKKA patient privacy notice provides a detailed description of what data the UKKA collects, for what purposes and how we keep patient data secure.

[Follow the UKKA on Twitter](#) for regular updates on our activities!