



UK Renal Registry



Patient Newsletter | 2025

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Welcome to the 2025 edition of the UK Renal Registry patient newsletter!

This annual newsletter has been created to enable us to share information, news and opportunities with you. In this first edition we will tell you about who we are, the data we collect and the work we do.



The UK Renal Registry (UKRR) was set up in 1995 to record and analyse health data about children and adults with kidney disease in the UK for **research, audit, and quality improvement** purposes. The registry is owned and managed the UK Kidney Association (UKKA).

The UKKA is the **oldest continuously active nephrology society in the world**, gaining its current name after the the British Renal Society and the Renal Association merged in 2021. As the leading professional body for the UK kidney community, the UKKA is **dedicated to improving lives** by supporting professionals in the delivery of kidney care and research. The UKKA has over 2,000 doctors, scientists and multi-professional team members.

The UKKA has an active and involved Patient Council. The Patient Council support the UKRR on topics relating to information governance (how data is managed and used) and how the data we hold can be used to improve the lives of patients living with kidney disease.

ukkidney.org/patients/patient-council

UKRR Research

By supporting and conducting research, the UKRR helps to improve the care of patients with kidney disease in the UK.



How do we collect data for research?

When you visit a hospital to receive kidney treatment, the staff who treat you will collect information about you, your general health, past care and medications. This clinical data is what allows the medical team to make decisions about **how to best treat and take care of you**.

To ensure that all kidney patients across the country are getting the highest quality of care possible, the NHS requires hospitals to submit the data collected by hospital staff to the UK Renal Registry (UKRR) where the data are analysed. The UKRR also collects data from hospital laboratories. We have approval from the NHS to collect this without asking each person individually to agree.

This means we can use all the information available to ensure we can answer research questions fully so that the right decisions are made about treatment and care.

Currently, the UKRR team manages **data collection, analysis and reporting** on three main areas:

1. Children and adults in the UK on dialysis or with a transplant (kidney replacement therapy) (approx. 70,000 people each year).
2. Acute kidney injury episodes reported in the UK (approx. 500,000 people each year)
3. Children and adults with advanced chronic kidney disease in England and Wales.

UKRR Research



What happens with the data?

We keep the data in a **secure database** and have a committee, called the Data Release Group, that reviews requests from researchers to use it. The research team working for the UKKA **conducts research** internally, but we also help other scientists and clinicians who want to conduct their own research. Any data that is shared is pseudonymised, that is, all the personal identifiable information is replaced with a unique number. This means that researchers cannot link any of the information with a specific person.

Key Definitions

ACUTE KIDNEY INJURY (AKI)

A sudden decline in kidney function that can be caused by reduced blood flow, infection, medicines, blockage or other problems.

KIDNEY REPLACEMENT THERAPY (KRT)


A medical treatment for kidney failure that replaces the normal kidney function.

CHRONIC KIDNEY DISEASE (CKD)

A long term condition where there is a long-term reduction in kidney function.

How are patients involved?

Four members of the Patient Council attend each Data Release Group meeting to represent the voice of patients. Applicants must satisfy our patient representatives for us to approve use of UKRR data.



Have a research idea?
An important question
you want answering?
Get in touch!

New opportunity to get involved in our research!

The **Consent for Approach to Research (C4AR) Database** is our new initiative coming later this year. It will be the home for kidney patients interested in research, led by patients, for patients.

The UKKA Patient Council members feel strongly about making sure that everyone living with kidney disease can use their own voice and is given the opportunity to take part in research that is of importance to them. The C4AR database aims to achieve this by creating a community of patients of all ages, happy to be contacted for research purposes. It is an exciting initiative and the **first of its kind for kidney patients on a UK-wide scale**.

When ready to launch, we will reach out to patients by advertising in kidney units, through kidney patient charities and kidney patient associations, as well as via social media. If you would like us to let you know directly you are very welcome to **register your interest by emailing ukrr-research@ukkidney.org**

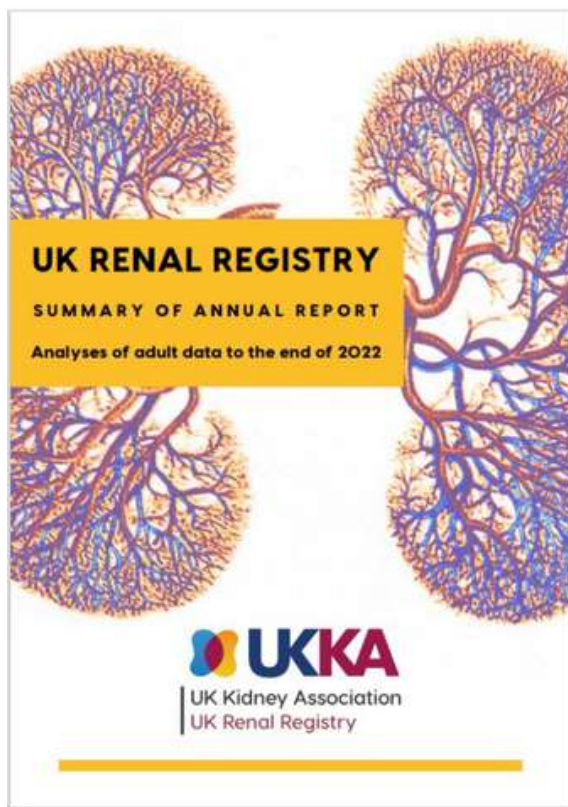
The UKKA is committed to learning about our patients' lived experiences and ensuring as many people as possible can contribute to improving kidney care throughout the UK. The research programme will focus on topics known to be important to kidney patients including health related quality of life measures. We know pain, fatigue, frailty, physical activity and mobility, poor sleep, depression and cognition are all areas patients want us to understand better. Participants will be able to share their experiences with us via electronic questionnaires and we will use the results to help improve understanding and improve patient care.



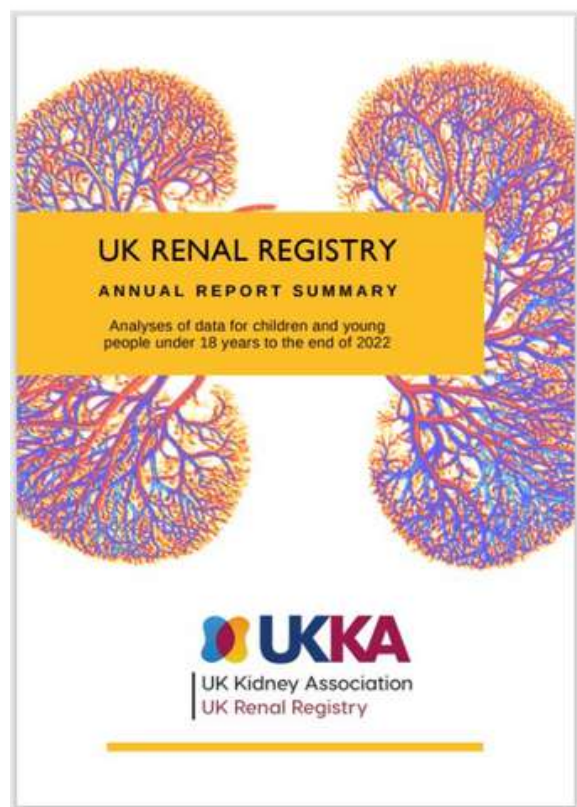
UKRR Audit

In addition to research, we conduct an annual audit. An audit is a carefully planned investigation that aims to improve services against a standard. It focuses on directly evaluating and improving current practices. Using the data collected by the UKRR, each year we can show how each kidney centre or hospital has performed in treating patients with kidney disease compared to the standards that have been set by the NHS. We check all the data very carefully and so each report takes more than a year to produce.

Adult data
(click the image)



Paediatric data
(click the image)



The latest patient summaries of data collected and analysed for 2022

UKRR Quality Improvement

The UKRR supports quality improvement projects and is a key partner of the UKKA KQIP (Kidney Quality Improvement Partnership). KQIP is a dynamic network of kidney health professionals, patients and carers who are committed to developing, supporting and sharing improvement in kidney services, to enhance outcomes and quality of life for people with kidney disease.

KQIP aims to improve the lives of adults and children affected by kidney disease by supporting healthcare professionals, kidney units, kidney networks and commissioners across the UK to achieve the highest quality of care for patients. It helps kidney services embed quality improvement into daily practice so that it's part of the day job for everyone working to provide kidney services.



ukkidney.org/kqip/about-kqip

Getting involved in quality improvement

Involving people with lived experience of kidney disease is important for the success of the Kidney Quality Improvement Partnership. Improvement requires the knowledge and insight of those who experience kidney care.

There are many ways you can get involved in our projects and national programme.

The UKRR supports an annual **Kidney PREM (patient reported experience measure)** initiative. This is a national annual survey for people living with CKD. Patients share information that helps clinical teams to understand how they feel about their experience of care. The data helps the UKRR to show where improvement can be made and whether experiences differ nationally.

2024 was the eighth year with 13,347 people taking part!

[Click to read the PREM report](#)



www.ukkidney.org/kidney-patient-reported-experience-measure

✉ Contact kqip@ukkidney.org if you have any questions or would like to speak to our team about getting involved.



UKRR project results

Does hot weather affect the number of acute kidney injury episodes recorded?

As global temperatures continue to rise, the effects of heat on acute kidney injury (AKI) are of growing concern. Researchers looked at AKI episode data collected by the UKRR between 2017 and 2021 (more than 1.3 million episodes!) and the maximum daily temperature for each patient's postcode area at that time. We also looked at the effects during heatwaves*.

Researchers found that there were increased odds of an AKI episode at high temperatures, the odds rising a little with every degree increase above 17 degrees. A 7-day heatwave in July 2021 was associated with a 28.6% increase in AKI counts. **Heat-related AKI is a growing public health challenge.** The research concluded that as even small changes in kidney function can affect patient outcomes, susceptible individuals should be advised to take preventive measures whenever hot weather is forecast.

(*Heatwave defined as a period of extreme heat that significantly exceeds the usual temperature range for a region).

Is patient activation associated with symptoms and quality of life?

The knowledge, skills, and confidence to manage one's own health is termed patient activation and this can be assessed using a Patient Activation Measure (PAM). We looked at activation measures and outcomes of importance to people with chronic kidney disease (CKD) to try and understand the relationship between them.

Lower activation levels are associated with a higher symptom burden and reduced quality of life for CKD patients. Therefore, **targeted and holistic self-management support focussing on improving activation may have the potential to improve the quality of life of people living with kidney disease.**

UKRR project results

Are there differences in access to the kidney transplant waiting list in the UK?

WHO DID WE INCLUDE?



We looked at adults aged 18-75 who needed **dialysis or transplant** between 2017 and 2020

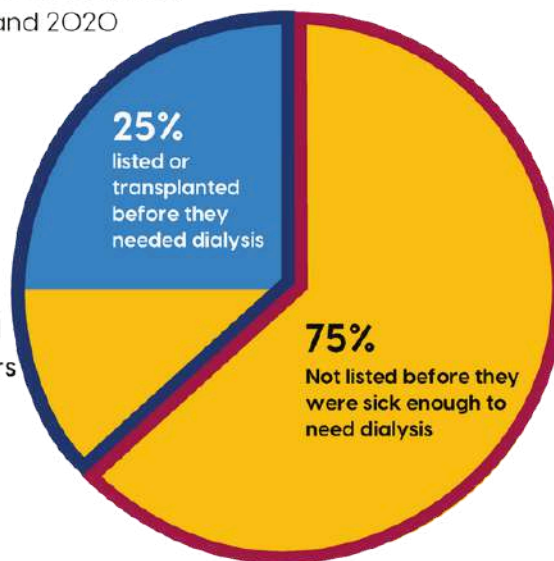
WHAT HAPPENED TO THEM IN 2 YEARS?



We followed them up for **two years** to see if they **received or were listed** for a transplant

43%

listed or transplanted within 2 years



57%

not listed or transplanted within 2 years

WHAT DIFFERENCES DID WE FIND BETWEEN THE PEOPLE WHO WERE LISTED AND THOSE WHO WERE NOT?



Males and females were **equally** likely to be listed



Patients with diabetes were **less likely** to be listed



Asian people were **more likely** to be listed



Black people were **less likely** to be listed



Patients who lived in more deprived areas were **less likely** to be listed



Patients treated in transplant centres were **more likely** to be listed than those in non-transplant centres



Which centre a patient was treated at appeared to affect how likely they were to be listed

WHAT NEXT?

We need to do more research to understand these differences.
We want to find out how to improve things so that everyone has equal access to the transplant waiting list.

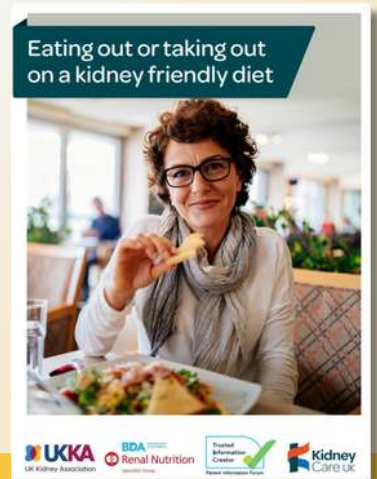
Information Spotlight

Eating out and taking out on a kidney friendly diet

Eating out or having a takeaway are both fun activities, and an important part of many social occasions. Having chronic kidney disease (CKD) does not mean you have to miss out. Whether you need to be careful with your food choices depends on how often you eat out, and your individual diet needs, which can be affected by your stage of CKD and your blood results.

Meals out and takeaways tend to have more salt, fat, sugar and larger portions than you would choose at home. If you eat out often, you might consider ways to make your choices healthier.

If you have been advised to limit salt, phosphate, potassium or fluid, you may find the patient leaflet useful. (Click the image)

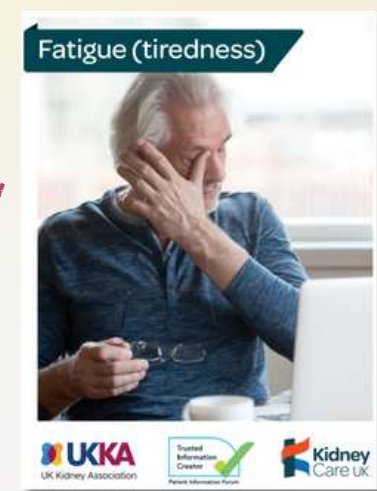


Fatigue

Everyone feels tired occasionally. Extreme, on-going tiredness, with a lack of energy, is often called fatigue. There are many reasons why you may experience fatigue including:

- If your kidneys are not working well, toxins build up in your blood and this can make you feel tired and weak. You may feel more tired as your CKD gets worse and your kidney function drops.
- CKD can lead to a shortage of red blood cells, causing you to be anaemic. If anaemia is not treated, it can result in you feeling more tired than usual.
- If you are receiving haemodialysis, you may find that you feel very tired afterwards. People describe this as feeling 'washed out' or 'drained'. This can last for a few hours after each session or sometimes longer.
- Poor sleep quality can also cause fatigue, particularly if you have problems falling or staying asleep.

You can find more information about the symptoms of fatigue, treatments and self-help advice in the full patient information leaflet. (Click the image)



These patient-focused leaflets are created in partnership with the UKKA Patient Information Committee and Kidney Care UK. Find out more at ukkidney.org/patients

For more
information
about this
newsletter or the
UK Renal Registry
please contact:



ukrr-research@ukkidney.org
ukkidney.org/uk-renal-registry

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**We welcome any feedback you might have so that
we can improve the content of future editions.**

We would love to hear from you!

[Click here](#) or follow the link below to share your views.

www.app.onlinesurveys.jisc.ac.uk/s/ukka/newsletter-feedback-ukrr

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