

The Renal Association



The UK Renal Registry

Data Protection Privacy Notice

Introduction

This document explains why information is collected about you by the UK Renal Registry (UKRR) and how your information may be used. This is called a Fair Processing Notice or Privacy Notice. It describes how the UKRR collects, uses and processes your personal data and associated information and how, in doing so, it complies with its legal obligations to patients. Your privacy is important and the UKRR is committed to safeguarding your data privacy rights.

Information for patients on the work of the UKRR can be found at www.renalreg.org/patient-info/.

This notice will address the following areas:

- Key definitions
- What is the UKRR?
- Why the UKRR collects your information
- What personal information does the UKRR collect?
- Where does the UKRR collect your information from?
- How does the UKRR use your information?
- Who your information is shared with
- The UKRR's lawful basis for collecting your information
- How the UKRR maintains the confidentiality of your information
- The UKRR and partner organisations
- How long your information will be stored
- Your individual rights
- Objections and complaints
- How to contact the UKRR
- Changes to this notice

Key definitions

Data controller – the organisation, person or persons who determine the purposes and means of processing personal data. For the purpose of this notice and how it affects your data the data controllers are the Renal Association (the owner and operator of the UKRR).

Data processor – in relation to your personal data, means any person (other than an employee of the data controller) who processes the data on behalf of the data controller.

Data protection officer – an existing employee or externally appointed person in place to assist in monitoring internal compliance, informing and advising on data protection obligations, providing advice regarding Data Protection Impact Assessments (DPIAs) and acting as a contact point for data subjects and the supervisory authority. The contact details for the data protection officer can be found at the end of this notice.

What is the UK Renal Registry?

The main aim of the UKRR is to report on the healthcare of people with kidney disease and to help improve their healthcare in the future. This is primarily achieved through national audit by collecting, analysing and reporting on the data of people with kidney disease in the UK. The data are also used for research purposes, but only with careful controls over how the data will be used, as described below.

The UKRR is operated and governed by The Renal Association, a not for profit organisation registered with the Charity Commission as a membership organisation for healthcare professionals caring for people with kidney disease. Full details of their work can be found at <https://renal.org/>.

The UKRR originally only collected data on people with end-stage kidney disease on renal replacement treatments (dialysis therapies and kidney transplant recipients). The remit has since been extended to include cases of acute kidney injury and chronic kidney disease for patients not receiving dialysis.

Clinical information about people with kidney disease collected by hospitals across the UK is electronically transferred in a secure form to the UKRR and stored in its secure databases. The UKRR uses this information to provide grouped anonymised reports for the benefit of patients, clinicians, commissioners, researchers and regulators.

Why the UKRR collects your information

The UKRR collects patient information to improve the healthcare and outcomes of people with kidney disease. This is achieved through using the data received to:

- Audit – this is where the standards of healthcare given to people with kidney disease treated in renal units/hospitals are compared against each other and against national guidelines
- Identify trends in the nature and frequency of kidney diseases and their outcomes within the population and subgroups of the population
- Provide information to patients to make better informed choices and have better understanding of diseases and treatments
- Provide commissioners and policy makers with information to improve the delivery of renal services
- Assess the impact of quality improvement initiatives
- Facilitate research - this is where the data are used to improve understanding of diseases, treatments and interventions
- Support clinical trials that will provide the evidence to change clinical practice

What personal information does the UKRR collect?

As well as information about your treatment, the UKRR also collects personal information to allow it to identify you. These identifiers are your name, date of birth and NHS number. These identifiers are used to link your clinical data to other NHS databases so that we do not have to ask hospitals for data that is already available in other ways.

The UKRR may also collect information about your symptoms and your treatment in relation to how they affect your life via the 'Your Health Survey' (for further information see <https://www.renalreg.org/>). Again, this will include some identifying information such as your name, postcode and NHS number to link your survey results to other NHS databases.

Where does the UKRR collect your information from?

The UKRR receives data from the renal unit/hospital where you are being treated. This data is then linked to other relevant national health-related systems such as the NHS Blood & Transplant database, disease registries, the Hospital Episode Statistics database, or similar.

How does the UKRR use your information?

Your clinical information

- Local hospital IT systems collect and store identifiable information, treatment information and laboratory results for routine use by clinical teams delivering healthcare to people with kidney disease
- A list of these data items has been agreed to be necessary to monitor the quality of healthcare provided by the NHS to people with kidney disease. Only these items are shared with the UKRR
- The hospital sends the UKRR a data file via secure email
- This is stored securely by the UKRR with access strictly controlled to only those people with permission to see and use the data
- If the UKRR needs to ask the hospitals to clarify the information that they have sent, the UKRR sends your relevant personal data back to them with a query attached
- If the permissions to keep data expire or the data are no longer required, it is deleted in a secure permanent way

Your 'Your Health Survey' Questionnaires

- Your renal team will securely send your questionnaire to the UKRR
- The UKRR analyses the results of the questionnaires and provides feedback and guidance to the hospital/renal unit about how they can best support you in managing your symptoms and treatment
- The UKRR also links the results to the clinical data collected from your renal unit/hospital to help in its audit and research functions

Who your information is shared with

The UKRR shares your information with third parties to fulfil some of its duties and functions. Your data are only shared under strictly controlled circumstances.

Grouped, **anonymised** data are shared with other parties in the form of summaries and reports produced by the UKRR. In addition, applications can be made by external parties to the UKRR for grouped data where a detailed justification for having the data is given and safeguards are in place for how the data will be stored, used and deleted once their work is completed. You cannot be identified as this data contains no personal identifiable information.

External research groups are able to apply to the UKRR for individual level patient data through a formal application process. This data always has information which could identify you removed and safeguards are in place to prevent the re-identification of patients. The application process places paramount importance on data security and confidentiality which is formalised in a signed data sharing agreement. Once the project is completed, an agreed timeframe for the secure deletion of the data is then followed.

The UKRR links data with other databases to improve understanding of kidney disease in the context of wider health conditions and services. Such data linkages are permitted under the various legal bases for audit and research work and where appropriate governed by a signed data sharing agreement between the data controllers of each respective database. Examples include:

- NHS Blood and Transplant to get additional information about kidney transplants
- Public Health England to identify bloodstream infections in dialysis patients
- Hospital Episode Statistics (HES) data to identify differences in the other health conditions of patients to allow for better comparison of patient survival between renal units/hospitals
- The Civil Registrations Service (CRS) and Patient Demographics Service (PDS) for mortality tracking data to monitor how long people live and the cause of death on different treatments

Personal identifiable data is used to link patient data between the databases but is then removed once the linkage has been made.

The UKRR will also share information as required by law, for example, to comply with a court order.

The UKRR'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.

The UKRR processes information under a number of lawful bases:

1. Specialist renal services in England are required to submit your data to the UKRR via an agreement with NHS England (a public authority) – specifically the renal unit service specification of the NHS Standard Contract 2018
2. Hospitals in England are required to submit your data relating to Acute Kidney Injury (AKI) via Patient Safety Alert *Standardizing the early identification of Acute Kidney Injury* (9th June 2014)
3. The UKRR has a 'legitimate interest' in processing your data to provide you with a service which benefits you and others who use NHS services (Article 6(1)(f) of the GDPR)
4. The information collected via your 'Your Health Survey' questionnaire is collected and processed with your consent. Your consent can be withdrawn at any time without it impacting on your healthcare in any way. If you want to withdraw your consent, please contact the UKRR via the details found at the end of this notice.
5. The audit and research work of the UKRR has approval from the Secretary of State for Health and Social Care under section 251 of the NHS Act 2006 and via the Health Research Authority which sets aside the common law duty of confidentiality. This means the UKRR can use patient identifiable data for audit and research without individual patient consent in circumstances when it is not possible to use anonymised information and when seeking individual consent is not practical.

The medical information that the UKRR collects is also afforded extra protection under the GDPR, alongside other special categories of data such as health records and ethnicity. A full list of special category data types can be found [here](#). To process these types of data, the UKRR relies on the following legal bases:

1. For the purposes of preventative or occupational medicine and providing health and treatment management systems and services (Article 9(2)(h) of the GDPR)
2. To ensure high standards of quality and safety of health care (Article 9(2)(i) of the GDPR)
3. For the purposes of archiving in the public interest, and using data for scientific research purposes, and statistical analysis (Article 9(2)(j) of the GDPR)

The UKRR collects information that is part of the essential activity of the NHS and the data are used in important medical audits and research:

- Audit is a way of finding out whether clinical teams are doing what they should be doing by asking if they are following guidelines and applying best practice
- Research is designed to provide new knowledge which can be generalised to benefit other patients

How the UKRR maintains the confidentiality of your information

The UKRR is very careful with the information hospitals provide about patients and their healthcare. The UKRR has strict rules about how the data are used and who can use it. The

UKRR is committed to protecting your 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)
- NHS Act (2006)
- Health and Social Care Acts (2001) & (2012)
- Access to Health Records Act (1990)
- Common Law in England and Wales, Scots law in Scotland, and Northern Ireland law in Northern Ireland
- NHS Codes of Confidentiality, Information Security and Records Management.

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

The UKRR will not disclose your information to third parties without your consent unless there are exceptional circumstances such as situations when the health and safety of others is at risk, or where the law permits information to be passed on.

All employees of the Renal Association working for the UKRR sign a confidentiality agreement as part of their employment contract. If a sub-contractor acts as a data processor for the UKRR an appropriate contract will be established for the processing of your information.

UKRR and partner organisations

The UKRR was established through an initiative of The Renal Association. The Renal Association is the leading professional body for the UK kidney community, dedicated to improving services and outcomes for patients and families through education, research and training for the prevention and effective treatment of kidney disease. You can find out more about The Renal Association at <https://renal.org/about-the-renal-association/>.

The UKRR is governed by the RA Operational Management Team. The UKRR uses servers at Aimes Grid Services to store data; this is a secure data hosting organisation which houses sensitive data for a number of public sector organisations. The UKRR also uses network facilities at North Bristol NHS Trust where the UKRR office is physically located. Neither of these organisations can access your personal data and both are governed by contracts with strict instructions on data security and confidentiality.

How long will your information be stored?

The data are retained as long as is approved by the Health Research Authority. In most cases this would be for as long as the UKRR is in operation, plus an additional five years. However, you are able to exercise your rights (as listed below) under Data Protection legislation at any time by contacting the UKRR using the details at the end of this notice.

Your individual rights

This section describes how you can access, amend, erase and move your personal data, withdraw your consent and object to or complain about the data that the UKRR holds about you.

Right to access your data (data subject access request)

You have the right to see or have a copy of your personal information held by the UKRR. If you want to receive this information, you should make a written request to the UKRR (see the section below on 'How to contact the UKRR'). The UKRR will normally provide your information within one month of receiving all the information needed from you to respond to your request.

Right to rectification (right to amend your data)

You have the right to have your information amended. Please contact the renal unit/hospital treating you if you want information at the UKRR corrected. The renal unit/hospital treating you regularly sends your information to the UKRR and information should be corrected on the renal unit/hospital records. A corrected file will then be sent to the UKRR by your renal unit/hospital.

Right to opt out of the UKRR being sent my data

If you are happy for the UKRR to use your information you need do nothing further. You have the right to opt-out of the UKRR being sent information which identifies you. This will not affect the standard of healthcare or treatment you receive in any way. Anonymised clinical information as required for national audit will still be submitted and remain part of the audit database but the UKRR will not be able to identify you, link your records or use your records in any research.

If you wish to 'opt-out' please contact your renal unit/hospital to arrange this. Alternatively, you can contact the UKRR in writing (see the section below on 'How to contact the UKRR') and the UKRR will contact your renal unit/hospital to let them know.

Right to have your information erased

You can request in writing to have your identifiable data at the UKRR erased at any time. This right does not extend to information that has been anonymised.

The UKRR will respond to your request within one month. You can contact your renal unit/hospital or the UKRR directly when you want to have your identifiable data erased from the UKRR database (see the section 'How to contact the UKRR' for our contact details).

Right of data portability (right to move your data)

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

Right to object

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

Objections and complaints

Should you have any concerns about how your information is managed, please contact the data protection officer for the Renal Association (see the section below on 'How to contact the UKRR'). If you are still unhappy following a review by the data protection officer, you have a 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 UKRR

If you have any questions regarding this privacy notice, how your data are used, or wish to exercise your rights, please contact the UKRR using the details below.

The data protection officer is: Mr Tom Gray

He can be contacted by:

Post:
Tom Gray
UK Renal Registry
c/o The Renal Association
Learning and Research Building
Southmead Hospital
Bristol
BS10 5NB

Tel: 0117 4148 157
Email: tom.gray@renalregistry.nhs.uk

Alternatively, you can contact:
The senior information risk owner – Dr Retha Steenkamp
Email: retha.steenkamp@renalregistry.nhs.uk

Or
The Caldicott Guardian – Dr James Medcalf
Email: james.medcalf@nhs.net

Changes to this notice

The UKRR 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.