**Data Protection Privacy Notice**

## Introduction

This page explains why information is collected about you and how your information may be used - this is called a Fair Processing Notice or Privacy Notice. This privacy notice applies to the information of patients consented to the **EQUAL study** and describes how the EQUAL study collects, uses and processes your personal information and how, in doing so, it complies with its legal obligations to patients. Your privacy is important, and the EQUAL study is committed to safeguarding your data privacy rights.

This document should be read in conjunction with the ethically-approved study documents found here

The General Data Protection Regulation (GDPR) became law on 25th May 2018. This is a single EU-wide regulation on the protection of confidential and sensitive information.

This notice will address the following areas:

* Key definitions
* Why we collect your information
* What personal information we collect
* How your information is used
* Who your information is shared with
* The lawful basis for collecting your information
* How the EQUAL study maintains the confidentiality of your records
* How long your information will be stored
* Your individual rights
* Objections and complaints
* How to contact the EQUAL study
* Changes to this notice

## Key definitions

**Data controller** – person or persons who determine the purposes and means of processing personal data, in this case, the unit/hospital where you receive treatment. For the purposes of this notice and how it affects your data the Data Controllers are the ERA-EDTA Registry, Amsterdam, and The Renal Association.

**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 EQUAL’s Data Protection Officer can be found at the end of this notice.

**What is the EQUAL Study?**

TheEQUALstudy **(**European QUALity Study on treatment in advanced chronic kidney disease) is an observationalstudy of people with chronic kidney disease who are 65 years and older with an estimated glomerular filtration rate (eGFR) below 20 ml/min/1.73m2. Each patient is followed up with questionnaires and using laboratory values.

The five major aims are as follows:

* To compare outcomes between starting dialysis with a higher versus lower renal function and to compare outcomes between starting dialysis with fewer signs and symptoms versus more signs and symptoms

# To provide insight in the development of uremic symptoms in late stage 4/ stage 5 CKD patients

# To determine the method of measuring renal function that provides the best information for deciding when to start dialysis

# To develop a decision tree (algorithm) that will aid medical decision making around the timing of initiation of dialysis

# To provide insight in the decision making process regarding the start of dialysis in patients of 65 years and older.

# Within the UK, the EQUAL study 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 here: <https://renal.org/>

## Why the EQUAL Study collects your information:

By allowing the research team to link your data with that gathered from other routine health and social care databases and clinical studies, researchers will be able to study the long-term outcome of your condition and treatments that you receive. This will help them to understand the consequences of advanced kidney disease amongst older people.

## How does the EQUAL study use your information?

If you agree (consent) to take part, information about your treatment and any medications you are on will be entered into the EQUAL study database by a member of your hospital’s research team. Personal data including your name, date of birth and NHS number will also be entered. These personal identifiers will be used to link the information your hospital submits with other databases such as the UK Renal Registry. Your data will then be analysed by researchers who are part of the EQUAL study. The results of these analyses will be collated by the EQUAL International Coordination Centre at the European Renal Association (ERA-EDTA – one of the data controllers for this study).

## Where your information will be collected from

Data can be collected from a number of sources including:

* **Your GP and hospital records**
* **The UK Renal Registry** **–** which collects data on patients with chronic kidney disease stage 3 and above and those who are on renal replacement treatments such as dialysis or transplant waiting lists
* **PatientView –** which, if you have signed up, collects information from your hospital records and makes it available to you via a website.
	+ **NHS Digital –** which collects, stores and analyses information from a variety of databases including:
	+ **Hospital Episode Statistics (HES) -** this includes information about all hospital admissions, including when, why and for how long they happen
	+ **Civil Registration –** this provides information on patients who have died, including the date and cause of death
* **Public Health England** – which collects data on long-term health conditions, infections and vaccination records. (Similar public health databases can be linked to in other countries of the UK.)
* Any other **UK-based ethically approved national research studies, registries or bio-banking schemes** that you have previously consented to and participated in, or will do so in the future

Both the UK Renal Registry and PatientView are managed and operated by the Renal Association.

Further information about where your data are collected from can be found in the EQUAL study documents here

## Who your information is shared with

Where the EQUAL study shares your data, we will make every reasonable effort to minimise the chance of you being able to be identified. Prior to sharing data, the EQUAL study will assign your data a unique number, which will be shared in place of your personal identifiable data (such as your name, date of birth and NHS number) so that you cannot be identified by researchers or other third parties. This process is called “pseudonymisation”.

By joining the EQUAL study, you give permission for UK-based researchers to use your pseudonymised past, present and future clinical data for ongoing and future ethically approved research into kidney disease and related conditions.

Your pseudonymised data may be shared with other researchers, including those from Universities and commercial organisations, who are investigating your condition. You will not be able to be identified or contacted by any of these researchers.

You may occasionally be contacted by a member of the central EQUAL study team or the UK EQUAL study coordinators. This may include invitations to patient information days, details of further research studies that you may be eligible to join or requests to re-consent to EQUAL if any changes are made in the future. To do this, these individuals will need access to your identifiable information. From time to time the EQUAL study may engage a 3rd party mailing house to produce and send out the above information to you.

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

## How your information is shared by the EQUAL Study

Any and all data sharing between the EQUAL Study and the types of third party named above are conducted under strict contractual terms, limiting the types and quantities of information shared and restricting the ways it can be used.

The sharing or linking of your information will only take place between organisations whose information security procedures and data protection measures have been approved by our data protection officer.

Your information is only transferred to approved organisations via secure means making full use of available technology and practices to ensure your information is safe.

## The lawful basis for processing your information

The EQUAL study processes information under a number of lawful bases:

1. We have a ‘legitimate interest’ in processing your data in order to provide you with a service which benefits you and others using NHS services (Article 6(1)(e & f) of the GDPR)
2. We process your ‘special category’ information for reasons of public interest in the area of public health (Article 9(2)(j) of the GDPR)
3. The consent form that you completed when you agreed to participate in the EQUAL study, is a legal basis under the common law duty of confidentiality

## The EQUAL consent documents can be found here

## How the EQUAL study maintains the confidentiality of your information

The EQUAL study is committed to protecting your privacy and will only use information collected lawfully in accordance with:

* Data Protection Act (2018)
* General Data Protection Regulation (2018)
* Human Rights Act (1998)
* Access to Health Records Act (1990)
* Common Law in England & Wales, Scots Law in Scotland, and Northern Ireland Law in Northern Ireland
* NHS Codes of Confidentiality, Information Security and Records Management.

Apart from the 3rd parties referred to above, the EQUAL study 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. Anyone who receives information from the EQUAL study is also under a legal duty to keep it confidential.

All employees working on the EQUAL study are asked to sign a confidentiality agreement as part of the employment contract. If a sub-contractor acts as a data processor for the EQUAL study an appropriate contract will be established for the processing of your information.

## How long your information will be stored

Your data will be stored on the EQUAL study indefinitely for research purposes. However, you are able to exercise your rights (as listed below) under Data Protection legislation at any time by contacting us via the details at the end of this notice.

## Your individual rights

This next 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 EQUAL study holds on you.

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

## You have the right to receive a copy of your personal information on the EQUAL study, without any charge, by making a written request to the address at the end of the document. We will normally provide your information within one month of receiving all the information we need 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 EQUAL Study directly via the address at the end of this document if you want information on the EQUAL Study corrected.

## Right to withdraw consent and have your information erased

You can withdraw from the EQUAL Study at any time without giving a reason. Please contact the EQUAL Study directly via the address at the end of this document if you want to do this. Your information will no longer be updated, and you would receive no further contact from the EQUAL Study. We will keep the information about you that we have already gathered, to ensure the reliability of any research that has already taken place. Withdrawing your consent will not impact on the standard of care you receive.

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

You have the right to request a secure transfer of your data from the EQUAL Study to another data controller. You should make the request in writing to the EQUAL study - see the section ‘How to contact the EQUAL Study’ for our contact details. No fee will be payable and the information will be transferred within one calendar month.

If you move to a different hospital your EQUAL Study record will be automatically updated.

## Right to object

The EQUAL Study uses your information for the purposes outlined in the information sheet and consent form you must sign to join the EQUAL Study, the additional participant information on the EQUAL Study website, and in this privacy notice. If you do not agree with any of these purposes 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 EQUAL Study will respond to your objection within a month (although we may be allowed to extend this period in certain cases).

## Right to complain to the regulator

Details on how you can do this are included in the section ‘Objections and complaints’ below.

## Objections and complaints

Should you have any concerns about how your information is managed, please contact the data protection officer for The EQUAL Study (see section below ‘How to contact The EQUAL Study’). 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

[www.informationcommissioner.gov.uk](http://www.informationcommissioner.gov.uk)

## How to contact the EQUAL Study

If you have any questions regarding this privacy notice, how your data are used, or wish to exercise your rights, you can contact the Renal Association (which manages and operates the EQUAL Study) on the details below.

The Renal Associations’ Data Protection Officer is: Mr Tom Gray

He can be contacted via:

Post:

Tom Gray
The Renal Association
Brandon House Building 20a
Southmead Road
Bristol
BS34 7RR

Tel: 0117 4148 157

Email: tom.gray@renalregistry.nhs.uk

Alternatively, you can contact:

The UKRR’s Senior Information Risk Owner – Dr Retha Steenkamp

Email: Retha.steenkamp@renalregistry.nhs.uk

Or

The UKRR’s Caldicott Guardian – Dr James Medcalf

Email: james.medcalf@nhs.net

## Changes to this notice

The EQUAL Study 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.