



## Data Protection Privacy Notice

### Introduction

This document explains why information is collected about you and how your information may be used. This is called a Fair Processing Notice or Privacy Notice. It applies to the information of patients using PatientView and describes how PatientView 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 PatientView is committed to safeguarding your data privacy rights.

If you are interested in understanding PatientView, full details of its work can be found at <https://www.patientview.org/>.

This notice will address the following areas:

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

**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 PatientView's data protection officer can be found at the end of this notice.

## **What is PatientView?**

PatientView is a web and mobile application via which patients can view and manage some aspects of their personal health records.

PatientView 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 PatientView collects your information**

PatientView collects your information to allow you to view your latest test results, letters from clinicians and medicines you are prescribed by clinicians treating you. You can also view information about your diagnosis and its treatment.

## **What personal information does PatientView collect?**

As well as information about your treatment, PatientView also collects personal information to allow it to identify you. The identifiers are your name, date of birth and NHS number. The identifiers are used to ensure that you can only see your own information and to link with your clinical data to give you an overview of your condition and treatment.

## **Where does PatientView collect your information from?**

PatientView receives data from the renal unit/hospital where you are being treated alongside any data that you choose to add to the application.

## **How does PatientView use your information?**

PatientView receives information consisting of your test results, letters, and medications and makes it available for you to view when you sign onto the PatientView website or application.

Your data are also used to create reports for NHS England and the participating hospitals. These reports provide counts of people registering for and using the PatientView system, but do not contain any information that might identify you as an individual.

The information that you can view in PatientView is also available to your General Practitioner in order to ensure that they have the most up to date information about your treatment. To access your information they must request their own login credentials to securely access your data via PatientView itself. If you choose to access PatientView on a smart phone or tablet via the PatientView app, then the data will be saved locally to your device so that you can read it when you are not connected to the internet.

You may also be asked by your hospital to complete and return a survey about your health. This information will also be entered into the PatientView system so that you can view it online.

## **Who your information is shared with**

PatientView shares information with you, the patient, and with your GP Practice to support your healthcare needs. We will also share information as required by law, for example, to comply with a court order.

PatientView also works in partnership with the Rare Disease Registry (RaDaR) to assist with its work in recording and researching treatments into rare diseases. Your information will only be shared with RaDaR if you have consented to do so. RaDaR is also owned and operated by the Renal Association.

## **The lawful basis for collecting your information**

PatientView processes information under a number of lawful bases:

1. PatientView has a 'legitimate interest' in processing your data in order to provide you with a service which benefits you
2. The registration form that you completed when you signed up to PatientView, agreeing to have your information sent to and displayed in PatientView is a legal basis under the common law duty of confidentiality
3. The renal unit service specification of the NHS Standard Contract 2018 (issued by NHS England, a public authority) states that specialist renal services in England are required to submit the specified data to PatientView for patients who have consented to PatientView
4. PatientView also relies on your consent to share your information with the Rare Disease Registry RaDaR. You will be asked to complete a RaDaR consent form if you choose to sign up to RaDaR

## **How PatientView maintains the confidentiality of your information**

PatientView 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.

PatientView 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.

Your personal information will not be disclosed 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 PatientView is also under a legal duty to keep it confidential.

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

## **PatientView and partner organisations**

PatientView was developed 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 here <https://renal.org/about-the-renal-association/>.

A steering group manages PatientView and reports to The Renal Association Operational Management Team. Solid State Group (<https://www.solidstategroup.com/>) is a data processor for PatientView and works on the development of the PatientView software. A limited number of employees of Solid State Group have access to your personal data, which is used to determine whether the system is working correctly. Solid State Group's processing is governed by a contract which includes strict instructions on confidentiality and security.

## **How long your information will be stored**

PatientView holds a record of a patient's test results, clinical letters and medications. Your information is retained in PatientView until you remove your consent or request your data be deleted, (see the section below about 'Your individual rights').

## **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 PatientView holds on you.

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

You have the right to see or have a copy of your personal information held within PatientView. To receive this information, you should make a written request to PatientView (see the section below on 'How to contact PatientView'). We will normally provide your information within one calendar 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 on PatientView corrected. The renal

unit/hospital treating you regularly sends your information to PatientView for display and information should be corrected on the renal unit/hospital records. A corrected file will then be sent to PatientView by your renal unit/hospital.

### **Right to have your information erased**

You can request in writing to have your information on PatientView erased.

PatientView will respond to your request within one month. You can contact your renal unit/hospital and PatientView directly when you want to have your information erased from PatientView (see the section 'How to contact PatientView' for contact details).

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

You have the right to request a secure transfer of your data from PatientView to another data controller. PatientView will transfer your data to your renal unit/hospital for them to transfer on to the new data controller. You should make the request in writing to PatientView (see the section 'How to contact PatientView' for contact details). No fee will be payable and the information will be transferred within one calendar month.

### **Right to object**

PatientView uses your information for the purpose you consented to. 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. PatientView will respond to your objection within a month (although we may be allowed to extend this period in certain cases).

### **Right to withdraw consent**

You consented at the renal unit/hospital treating you for them to send your information to PatientView. You have the right to withdraw your consent at any time by letting the renal unit/hospital treating you know and by contacting PatientView in writing (see the section 'How to contact PatientView' for contact details). If you withdraw your consent, your PatientView account and your information on PatientView will be securely deleted.

## **Objections and complaints**

Should you have any concerns about how your information is managed, please contact the data protection officer for PatientView (see section below 'How to contact PatientView'). 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 PatientView**

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

The data protection officer is Mr Tom Gray

He can be contacted by:

Post:

Tom Gray  
PatientView  
c/o The Renal Association  
Learning and Research Building  
Southmead Hospital  
Bristol  
BS10 5NB

Tel: 0117 4148 157

Email: [tom.gray@renalregistry.nhs.uk](mailto:tom.gray@renalregistry.nhs.uk)

Alternatively, you can contact:

The senior information risk owner – Dr Retha Steenkamp

Email: [retha.steenkamp@renalregistry.nhs.uk](mailto:retha.steenkamp@renalregistry.nhs.uk)

Or

The Caldicott Guardian – Dr James Medcalf

Email: [james.medcalf@nhs.net](mailto:james.medcalf@nhs.net)

## **Changes to this notice**

PatientView 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.