



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH



UK Kidney Association

A new digital record to manage kidney care

A guide to switching from PatientView
to Patients Know Best

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Switching from Patient View to Patients Know Best

The UK Kidney Association (formerly known as The Renal Association) has signed an important deal with Patients Know Best to re-platform their national patient-facing system PatientView to the PKB personal health records platform. The 5-year agreement will improve the existing security and functionality of the current PatientView system, which was one of the first patient portals in the UK.

PKB is a social enterprise founded for patients. It is also the largest provider of digital personal health records to the NHS.

This new system offers patients and their professional teams, advanced features and functionality including increased security, care planning, team-based messaging and an ecosystem of integrated wearable and monitoring devices to support clinical transformation.

To support you through the transition of moving from PatientView to PKB, this guide provides an overview of where you can continue to find the information you need.



PatientView

Homepage

The screenshot shows the PatientView homepage with a teal header containing a user profile and navigation tabs (Home, News, My Details, My Conditions, Results, Medicines, Letters, Media, Research, Contact). The main content area includes:

- Featured Notices:** A list of five notices with dates and titles, such as "Invitation to Join the Haemodialysis Patient Participation Group" and "5th February 2021 - Update from Sussex Kidney Unit".
- Your Settings:** A section for user settings, including a "No Photo Uploaded" message and a "Change Your Settings/Password" button.
- Latest News:** A section for news updates, including "26th March Update" and "Do you have IgA Nephropathy or Henoch Schönlein Purpura?".
- User Profile:** A summary of user information including name, NHS number, last login, and membership details.
- Alerts:** A section for alerts, currently showing "Unread Messages 0".



Using Patients Know Best

Home

From your homepage you can navigate to other sections of the record and perform some common actions like send messages, view recent notifications, or access the main tiles that take you to the relevant part of the record.

The screenshot shows the Patients Know Best homepage with a teal header and a "Welcome" message. The main content area includes:

- Welcome:** A message welcoming the user to their Patients Know Best record and providing instructions on how to use it.
- Notifications:** A list of recent notifications, including "PROMS Generic Questionnaire" and "Fibre Assessment" messages.
- Main Tiles:** A grid of seven tiles for navigation: "Events & messages", "Health", "Treatments", "Diary", "Files", "Devices", and "Sharing".

PatientView



Letters & messages

Home | News | My Details | My Conditions | Results | Medicines | **Letters** | Media | Research | Contact

Help | Messages | FIRST NAME LAST NAME | Settings | Log Out

Letters Export

Letters are only shown when they have been sent by your unit's computer system.
 It is important to note that letters may be shown here before they have been finally approved and had mistakes corrected. This mainly applies if you are reading letters soon (e.g. within a week) after they have been typed.
 If you have any concerns you should discuss it at your next clinic appointment, or contact the author of the letter. You may delete letters if you don't want them, or if you find duplicates. This only removes the PatientView copy, but please be careful, it isn't easy to restore them. Deletions will be recorded.

Date	Type	Source	View	Delete
04-Feb-2021	LETTER	Leicester	View	Delete
24-Dec-2020	LETTER	Leicester	View	Delete
14-Oct-2020	LETTER	Leicester	View	Delete
17-Sep-2020	LETTER	Leicester	View	Delete
06-Aug-2020	LETTER	Leicester	View	Delete
05-Jun-2020	LETTER	Leicester	View	Delete
17-Apr-2020	LETTER	Leicester	View	Delete
24-Dec-2019	LETTER	Leicester	View	Delete
24-Dec-2019	LETTER	Leicester	View	Delete



Using Patients Know Best

Home > Events & messages

All messages between you and your professionals are displayed here. This includes any documents that have been sent by clinical teams e.g. appointment letters, clinic letters, referrals and discharge summaries.

Home > Events & messages

Events & messages

Send message

Start consultation

A record of events and communications between you and your teams. This includes events, messages, letters, online consultations and details of visits.

November | December | January | February | March | April

27-Jul-2020		PROMS Generic Questionnaire (example) - Online communication Started By: York Renal Professional [prof in Renal Team York Teaching Hospital NHS Foundation Trust] - Latest: York Renal Patient	General health	2
27-Jul-2020		Fibre Assessment - Online communication Started By: York Renal Professional [prof in Renal Team York Teaching Hospital NHS Foundation Trust] - Latest: York Renal Patient	General health	2
21-Jul-2020		Fibre Assessment - Online communication Started By: York Renal Patient	General health	1
21-Jul-2020		Appointment letter - Online communication Started By: York Renal Professional [prof in Renal Team York Teaching Hospital NHS Foundation Trust]	General health	1
21-Jul-2020		Sleep - Online communication Started By: York Renal Professional [prof in Renal Team York Teaching Hospital NHS Foundation Trust]	General health	1



Send a message

PatientView

Help Messages 1 FIRST NAME LAST NAME Settings Log Out

Home News My Details My Conditions Results Medicines Letters Media Research Contact

Messages [Create New](#)

Click on **View Messages** to see the full conversation or **Quick Reply** to reply to it. To send a new message, click on **Create New** above. When you send a message, the recipient will receive an email asking them to log in to read it, if they have an email address in the system.

Before sending your first message, check that we have the right email address for you in **Settings**

Showing Messages In **Inbox** Folder

Search Search All Folders [Clear](#) [Search](#)

New

Other comments to your local PatientView administrator

with: [Beverley](#) [Patient Support](#) [View Messages 2](#)

Most recent message from: [Beverley](#) [Quick Reply](#)

Hi XXXXXX, I have resent all your results to Patient View. Please let me know on Monday if you have received them all? Thank you, Beverley

17-Nov-2017 14:50 [Change Participants](#) [Print](#) [Archive](#)



Using Patients Know Best

Home > Events & messages > Send a message

To start sending messages, click on the top right hand corner of the previous Events & Messages page and click 'Send message', then complete the form. This button is also available from the homepage.

Home > Events & messages

Send a message

Do not use this for urgent problems as your message may not be read immediately.

To:
If the person you want to message is not listed you can invite them if you know their email address.

Subject:
Give a brief description of the reason for your message.

Message:
Write a short but complete message including all relevant details.

Attachment

PatientView



Diagnosis

Information provided by: Leicester

Condition Information	
Diagnosis	Diabetic Nephropathy Diabetes and the kidney (NKF) Diabetic kidney disease (EdREN) Chronic renal failure (EdREN)
Diagnosis Date	
Other Conditions	Ischaemic heart disease CABG Diabetic retinopathy Blind right eye Hyperparathyroidism Ischaemic/Neuropathic foot LV dysfunction HFpEF Type I diabetes Diabetic Nephropathy - Type I
Treatment	Kidney transplant Info on kidney transplants From the Kidney Patient Guide, with animations From EdREN Diet for people with kidney disease
Transplant Status	Kidney: No status uploaded (Explain This)



Using Patients Know Best

Home > Health > Diagnosis

All diagnoses added to the record can be found here. Current diagnoses are displayed first, then past diagnoses, if recorded. Click on a diagnosis to show who entered the information and when. We will also show coding information where available.

Diagnoses Allergies Symptoms Measurements Tests Imaging Audio Genetics

Current diagnoses Add diagnosis

> Autosomal dominant (AD) polycystic kidney disease General health

0 items selected Discuss selections

PatientView



Test results

Home News My Details My Conditions **Results** Medicines Letters Media Research Contact

Help Messages FIRST NAME LAST NAME Settings Log Out

Results **Table View** Export Diagnostics Enter Your Own Results

Showing Panel: Latest
Urea Creatinine eGFR Potassium Sodium

Latest 1 2 3 4 5 6

<p>Urea About test</p> <p>21.1 mmol/l</p> <p>Source: Leicester Showing Result: 17-Dec-2020 LATEST</p> <p>View Chart</p>	<p>Creatinine About test</p> <p>104 µmol/l</p> <p>Source: Leicester Showing Result: 17-Dec-2020 LATEST</p> <p>View Chart</p>	<p>eGFR About test</p> <p>62 ml/min/1.73m²</p> <p>Source: Leicester Showing Result: 17-Dec-2020 LATEST</p> <p>View Chart</p>	<p>Potassium About test</p> <p>4.6 mmol/l</p> <p>Source: Leicester Showing Result: 17-Dec-2020 LATEST</p> <p>View Chart</p>
<p>Sodium About test</p> <p>140 mmol/l</p> <p>Source: Leicester Showing Result: 17-Dec-2020 LATEST</p> <p>View Chart</p>			



Using Patients Know Best

Home > Health > Tests

Home > Health > Tests

Diagnoses Allergies Symptoms Measurements **Tests** Imaging Audio Genetics

Test Results Add result U+

Search for tests All Day Week Month Year

FBC (full blood count)

Red blood cell (RBC) count >
10¹²/L

Apr '20 May '20 Jun '20 Jul '20

White blood cell (WBC) count >
billion/L or 10⁹/L

Apr '20 May '20 Jun '20 Jul '20

All test results that have either been manually entered or automatically sent from other systems used by the hospital, can be found here. To see details of a test, click on the individual test to open its history page.

PatientView



Medicines

Medicines

Help Messages FIRST NAME LAST NAME
[Settings](#) [Log Out](#)

Home News My Details My Conditions Results Medicines Letters Media Research Contact

Medicines
Export

Medicine lists come from a hospital or your GP's computer system. Please read the cautions and explanation:

Important

The list of medicines may not be complete or accurate, because (1) Some hospitals do not yet keep full records of medicines for all patients, (2) Changes made in one place may not quickly get to every list. Please point out changes when you next attend an appointment, or send a note or message if it is important.

Two Kinds of List

Lists from your GP sometimes show some medicines twice; once as regular medicines and once as one-off prescriptions. For one-off you may see a number in brackets, the numbers of tablets prescribed, like (28). Or (RP) to show it's a repeat prescription.

This link to [Medline Plus](#) is good if you want more information on individual drugs, or on herbs and supplements.

Filter By Source

Start Date	Medicine Name	Dose	Source
03-Feb-2021	Losartan	50 mg x1/d	Leicester
11-Sep-2020	Metformin	1000 mg x2/d	Leicester
07-Aug-2019	Bumetanide	1 mg x1/d	Leicester
06-Dec-2017	Prednisolone	2 mg x1/d	Leicester
12-Jul-2017	Rivaroxaban	20 mg x1/d	Leicester
01-Jun-2016	Bisoprolol	5 mg x2/d	Leicester
05-Apr-2016	Mycophenolate	250 mg x2/d	Leicester
08-Oct-2015	Creon	10000 units x2/d	Leicester



Using Patients Know Best

Home > Treatments > Medicines

All medications added to the record can be found here. For current medications we show the ones **started** most recently first. For past medications we show the ones **stopped** most recently first. Click on a medication to see more details.

Medicines

Add medication

Current medicines

- [Cinacalcet](#) 30mg daily started 26 Apr 2021 General health [edit](#)
- [Diafer](#) 200mg monthly started 22 Feb 2021 General health [edit](#)
- [Fosrenol \(Lanthanum Carbonate\)](#) 1g tds started 09 Jan 2020 General health [edit](#)
- [One Alpha Calcidol](#) 0.25mcg daily started 31 Oct 2019 General health [edit](#)
- [Amitriptyline](#) 25mg on started 10 Oct 2019 General health [edit](#)
- [Lansoprazole](#) 15mg od started 10 Oct 2019 General health [edit](#)

New Pages and Features

The switch to Patients Know Best will offer you a range of new pages and features explained below.

Some of these allow your healthcare providers to share more information with you and interact with you digitally.

Many of these you can use independently to help manage your health.



Allergies



Using Patients Know Best

Home > Health > Allergies

All allergies added to the record can be found here. Most recently recorded allergies will appear first. Click on an allergy to show detailed information, such as the date it was recorded and associated severities and reactions.

Home > Health > Allergies

Diagnoses Allergies Symptoms Measurements Tests Imaging Audio Genetics

Allergies

Add allergy

> Pollen Mild allergy causing Itching eyes noted 12 Jun 2018 General health

0 items selected Discuss selections



Care plans

Care plans include instructions on what to do in common situations such as worsening of your condition. It can also contain helpful information or videos, as well as goals and targets to reach in between consultations.



Using Patients Know Best

Home > Treatments > Plans

The *Kidney Results and Measurements Tracker* has been designed to support patients in managing their kidney condition. It will provide some of the most important tests and measurements from the past, and will automatically pull through the results of new tests taken.

Plans Medicines Library

General health Edit

My Kidney Results and Measurements Tracker

Created by Dr P Sru 15-Jul-2021 Last edited by Dr P Sru 20-Jul-2021

Monitoring

Measurements

- Creatinine [Moles/volume] in Serum or Plasma**
413 umol/L
• Date: 04 Jun 2021 15:54
- BMI (Body mass index)**
• 38.9 kg/m²
- Haemoglobin (g/L)**
107 g/L
• Date: 02 Jun 2021 10:21
- Height**
• 168 cm
- Potassium [Moles/volume] in Serum or Plasma**
4.4 mmol/L
• Date: 04 Jun 2021 15:54



Care plans



Using Patients Know Best

Home > Treatments > Plans

The *My Conditions* care plan contains details of diagnoses, and provides links sent by the UK Kidney Association to support you in managing your condition.

Plans Medicines Library

General health Edit

MyConditions

Created by 09-Jul-2021 Last edited by Dr P Sru 15-Jul-2021 [See other versions >](#)

Action plan

- Treatment:Haemodialysis
 - From the Kidney Patient Guide, with animations
 - Info on haemodialysis from EdREN
 - Diet for people with kidney disease



Symptoms



Record and track your symptoms here.

Where a team has requested certain symptoms to be monitored, they will appear here. You can also record any symptom from the entire list to track progress over time.

Using Patients Know Best

Home > Health > Symptoms

Home > Health > Symptoms

Diagnoses Allergies **Symptoms** Measurements Tests Imaging Audio Genetics

Symptoms

Add symptoms +

Your professionals will not be routinely checking this information. So it is important that you contact them directly about anything concerning you.

1 Month 6 Months Today < >

None Mild Moderate Severe

	8 Mar 2021	15 Mar 2021	22 Mar 2021	29 Mar 2021	5 Apr 2021
Abdominal bloating frequency					
Abdominal discomfort frequency					
Abdominal pain					



Library



Useful information and links to resources can be stored in the Library.

Clinical teams can add and edit links and you can add your own links too. Simply click 'Add Link' and enter the URL of the website to add information.

Using Patients Know Best

Home > Treatments > Library

Home > Treatments > Library

Plans Medicines **Library**

Website

- Welcome to The Plymouth Nephrology Service
- JINARC® (tolvaptan) - Patient/carer education brochure
- Your renal transplant-your new medications.pdf
- Support Group Leaflet .pdf
- Welcome to the Plymouth Dialysis Unit.pdf
- Kidney Biopsy - A Patient's Guide.pdf
- Information from your CKD Team

Discuss



Appointments



Appointments can be found here.

You can add your own appointments and edit them too. Simply click on the ellipsis menu, followed by 'Edit'. A status can also be added for each appointment where required, for example, 'Cancelled'.

Using Patients Know Best

Home > Diary > Appointments

Home > Diary > Appointments

Journal Appointments

Appointments Add appointment

Appointments your teams have added to your record. You can also add appointments for your own reference.

Past

- Mr York Renal Patient
 - CBT Appointment - 1st
 - 31 July 2020 at 11:00
 - Location: Clinic
 - General health
- Mrs York Renal Professional
 - online consultation
 - 19 July 2020 at 10:00



Journal



You can add Journal entries to note how you are feeling on any given day. It is also possible to start a discussion about the entries in the Journal. Click 'Add Entry' to complete the form, or 'Edit' using the options (ellipsis) menu.

Using Patients Know Best

Home > Diary > Journal

Home > Diary > Journal

Journal Appointments

Journal Add entry

Record your own observations about your health here.

- Mr York Renal Patient
 - Stomach pain
 - 08 Apr 2021 01:03
 - Mild and persistent stomach pain since last night.
 - General health
- Mr York Renal Patient
 - Trouble sleeping
 - 21 Jul 2020 10:48
 - I am struggling to sleep waking 4-5 times every night. Could it be something to do with my meds? Need to discuss on next appointment.
 - General health



Access log



The Access Log stores a record of anyone that has accessed the record.

Here you can see who accessed the record, when and what they viewed.

Using Patients Know Best

Home > Sharing > Access Log

Home > Sharing > Access log

Professionals Friends/Family Pending Past Access log

Access log for York Renal Patient

Who saw your record, when they saw it, and what permissions they have.

Hide my own access

Date	Accessed by	Access type	Accessed via	Permissions
24 Sep 2020 06:54:30	jean testings	Accessed invitation	PKB website	
27 Jul 2020 04:32:28	York Renal Professional in team Renal Team	Accessed messages and events	PKB website	
27 Jul 2020 04:32:20	York Renal Professional in team Renal Team	Accessed messages and events	PKB website	
27 Jul 2020 04:32:20	York Renal Professional in team Renal Team	Accessed messages and events	PKB website	
27 Jul 2020 04:31:40	York Renal Professional in team Renal Team	Accessed messages and events	PKB website	
27 Jul 2020 04:31:40	York Renal Professional in team Renal Team	Accessed messages and events	PKB website	



Add a professional



Where a healthcare team does not use PKB, you can give individual professionals access to help manage your care.

Click 'Add an individual' and their details. Then, choose which privacy labels should be applied.

Using Patients Know Best

Home > Sharing > Professionals

Home > Sharing >

Professionals Friends/Family Pending Past Access log

Professionals

Add an individual

Teams Edit all

These teams can see your records. Click edit to change what they can see.

Edit

Renal Team
York Teaching Hospital NHS Foundation Trust
• Access: General health · Sexual health · Mental health · Social care

Individuals
Invite individual health and care professionals to see your record.

DR my gp local Edit



Add a carer



You or a professional can add a carer to your record.

Simply click 'Add carer' and complete the form. An invitation will then be sent to the carer's email address where they can accept the invitation by completing a form.

Using Patients Know Best

Home > Sharing > Friends/Family

Home > Sharing > Friends/Family

Professionals Friends/Family Pending Past Access log

Caring Ask for access Add carer

People I look after

Click "Ask for access" to request permission to see the record of someone you look after.

Name	Date of birth

People looking after me

Click "Add carer" to invite a carer or relative to see your record.

Name	Date of birth	Sharing	
<input type="checkbox"/> mr jean testings	01 Jan 1980	General health Social care Mental health	Edit



Files



Keep hold of any important paper letters or medical information safely in one place, for example, any hospital letters.

Simply click 'Add File' to upload a digital copy here.

Using Patients Know Best

Home > Files

Files Add file

Upload documents such as letters, reports or photographs. Note, medical documents from your teams will appear in the relevant part of your record e.g. letters in the "Events & messages" section, imaging reports in the "Imaging" section.

Name	Uploaded by	Date	Notes	
<input type="checkbox"/> Power of Attorney Letter.pdf	Miss Barbara Basket	26 Apr 2021	Signed Power of Attorney document.	Social care Edit View
<input type="checkbox"/> Discharge Summary .jpg	Mr Simon Smith	19 Dec 2019	Discharge Summary from hospital when I crashed my car.	General health Edit View
<input type="checkbox"/> Scan of Letter.jpg	Mr Simon Smith	19 Dec 2019	Letter Scan from Lewisham Hospital Referral	General health Edit View

0 items selected Delete Discuss



For more information

- If you are an existing PatientView user and would like to register for PKB please click [here](#)
- If you have questions about PKB that may not have been answered in this document then have a look at the [Frequently Asked Questions](#)
- If you would like to find out more about how you can share your PKB record with a carer or professional then take a look [here](#)
- For more information about the UK Kidney Association (formerly known as The Renal Association) click [here](#)



The ‘future is bright’ for patients of the Kidney Dietetics Service

“The transformation for our service has been brilliant! We no longer have to rely on email to send patients their information and we can benefit from all the functions that PKB offers.”



Katherine Durrans
Clinical Lead Renal Dietitian

AT A GLANCE

Features used

- Library
- Secure messaging
- Care plans
- Consultations

Outcomes

- Improved self-care
- Two-way interactions
- More responsive to real time patient needs
- Quicker response times for patients

Background

The Kidney Dietetics Service at Hull University Teaching Hospitals NHS Trust supports acute renal patients at Hull Royal Infirmary but the service also manages a more extensive cohort of outpatients through its renal satellite clinic. This clinic covers a wide geographical area - from Bridlington, Scunthorpe and Grimsby, with patients even spread out as far as Doncaster, Lincoln, Scarborough and York.

As the second Covid-19 lockdown went into force (July 2020), the team were no longer able to travel to see their patients and in order to stay in touch, required a new way of working to maintain communication and support. As well as introducing basic video and phone consultations, the service concluded that Patients Know Best (PKB) could offer a continuation in service delivery throughout the pandemic and also support their broader ambitions to go digital.

Digital engagement

Although the service had historically used Patient View - an online platform that formerly gave renal patients in the UK a view of their clinical data, many features were missing which could offer renal patients a more holistic experience.

The transition to Patient Know Best (PKB) came at the optimal time, helping to instantly bridge the gap that covid-19 had impeded on professionals and patients. Katherine Durrans, Clinical Lead Renal Dietitian, said: “The transformation for our service has been brilliant! We no longer have to rely on email to send patients their information and we can benefit from all the functions that PKB offers.”



Outcomes

The service has improved how patient care was delivered but it also meant:

- less overall travel time for both patients and staff to the satellite clinics - this is better for patients and the environment
- more timely access to health information for patients and professionals
- faster response times to queries through secure messaging
- better use of clinic time by enabling patients to complete questionnaires in advance.

Next steps

Despite starting with a small cohort of patients during the pilot phase, the service is inviting a further 420 dialysis patients to register. “PKB enables me to promote patient centered care by using it as an educational tool as well as a clinical tool”, said Katherine.

Patients are increasingly asked to update their care plans before their initial and follow up appointments, to enable more constructive dialogue with clear outcomes that are subsequently documented in their PKB health record. This allows patients, and anyone they choose to share their record with (i.e. family members, carers, GP, pharmacist etc.) to refer back to this information to maintain integrated care and support at any time.

Since the implementation of PKB, the Kidney Dietetics service is better placed to support patients in the self-management of their renal condition. Patients can add their own measurements and symptoms to keep an eye on and the ability to contact the department for advice if they are concerned. Allowing for much better self care and supporting Patient Initiated Follow Ups.

“The future is bright for us in Kidney Dietetics”, said Katherine. “It’s proving to be something that we can’t do without - I definitely think that’s the case!”

Features used

1. Library

The service identified a range of resources to support patients at all stages of their care. These resources were added to the ‘Library’ feature so patients could access this information anytime. To begin with, the service added:

- recipe books
- YouTube tutorials
- patient leaflets
- links to charities
- links to local health App libraries.

2. Secure messaging

The service began to use two-way messaging to enable patients and clinicians to continue communicating remotely.

This meant:

- patients no longer had to leave answerphone messages and wait a couple of days for a response.
- the service was more responsive to a patients’ ‘real-time’ care needs.

3. Care plans

By enabling an interactive two-way action plan of treatment, care plans were drawn up for:

- Bowel assessment
- Food diaries
- Nutritional screening.

4. Consultations

The service opted to send questionnaires for a patient to complete online and return securely through PKB. The first consultation created was for a ‘dietary recall’ which allows the Kidney Dietetics service to have a snapshot of a patient’s intake.

READ THE FULL CASE STUDY, WATCH THE INTERVIEW AND SEE RENAL CARE PLANS AT:

www.patientsknowbest.com/hull-kidney

For more detailed information about any of the Patients Know Best features, please refer to the user manual: manual.patientsknowbest.com



www.patientsknowbest.com