

Patient manual

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Contents

Who are these instructions for?	2
Summary of the steps	2
Help	2
Explanation of the parties involved	2
Steps to take part into the CURIE project	3
1. Find your NHS number	3
2. Scan the QR code or go on the webpage	3
3. Start receiving questionnaires	3
How to use the Patients Know Best platform	4
1. Logging in and out	4
2. Logging in for the first time	5
3. Resetting your password	6
4. Events & messages	7
5. Consultations	8
Project management group	9
Copyrights statements	9

Who are these instructions for?

This manual is for all the patients treated at Imperial College Healthcare NHS Trust (Charing Cross Hospital) who need to access the Patients Know Best platform.



Summary of the steps

1. Have your NHS number nearby.
2. Scan the QR code or go on <https://my.patientsknowbest.com/registerPatientStart.action?icode=curie>
3. Register with your email address.
4. Wait to receive the first questionnaire directly in your personal emails.
5. Start completing questionnaires online when you are prompted by email.

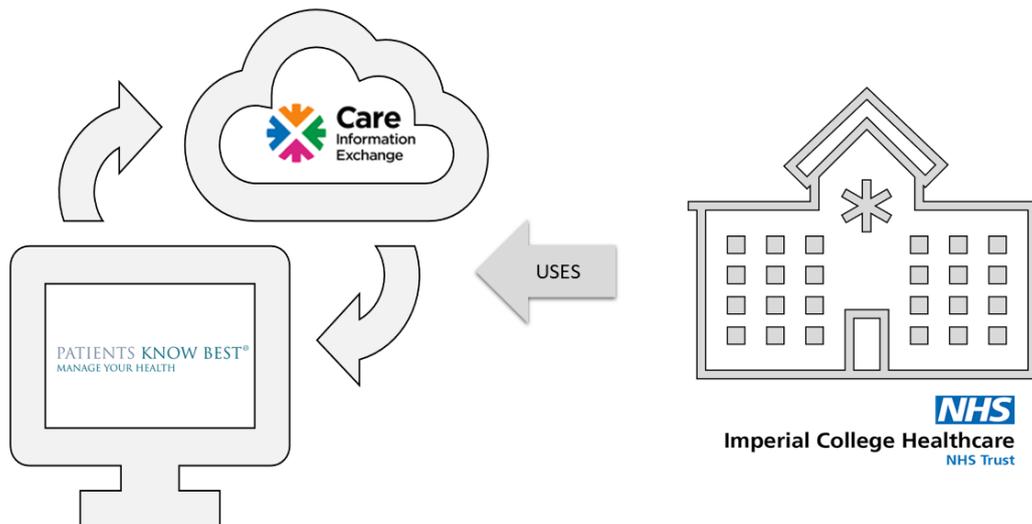
Help

You can browse the Patients Know Best manual (<https://manual.patientsknowbest.com/home>), if you have any difficulties navigating the platform.

Feel free to contact us on imperial.curie.project@nhs.net if you have any questions or concerns.

Explanation of the parties involved

In this document, you will read about Care Information Exchange (CIE), Patients Know Best (PKB) and Imperial College Healthcare NHS Trust. We want you to understand how they all fit together.



Care Information Exchange (CIE) is the **secure personal health record system** for patients and service users in North-West London.

Patients Know Best (PKB) is the system used by CIE.

Imperial College Healthcare NHS Trust is your treating hospital in North-West London. The clinical team use CIE and hence, PKB.

Steps to take part into the CURIE project

1. Find your NHS number

Your NHS number is printed on the medical card given to you when you register with a GP practice. You can find your NHS number on letters sent by your GP surgery and your clinical team. Each NHS number is made up of ten digits, as shown in this example: 450 557 7104.

2. Scan the QR code or go on the webpage

Scan this QR code with your cell phone or enter in your browser the link below:

<https://my.patientsknowbest.com/registerPatientStart.action?icode=curie>

You can now register by following the instructions on your screen. Do not forget to provide your preferred email address to receive reminders to complete your questionnaires.



3. Start receiving questionnaires

You will start receiving emails with direct links to the relevant questionnaires on the Patients Know Best platform to complete as you progress in your treatment. All the questionnaires will be saved on the platform and will be accessible online. You can then show your answers to your treating team at your next clinic appointment if you wish to discuss your answers in detail. The questionnaires were designed to be quick to complete (less than 10 minutes).

How to use the Patients Know Best platform

Whilst an extensive and complete manual can be found on the Patients Know Best website (<https://manual.patientsknowbest.com/patient>), we provide below the essential information you will need to take part in CURIE.

1. Logging in and out

How can I log into my Patients Know Best (PKB) account?

Go onto <https://my.patientsknowbest.com> website and enter your email address and password used to register on the Care Information Exchange (it can be your NHS login username and password if you registered with the NHS, or your email address and password used to register on CIE).

What if I have trouble logging in?

If you have trouble logging in, here are some things to check:

- Check you are using the email address you supplied when you registered for your record. If you cannot remember this, contact the team who treat you.
- If you cannot remember your password, you can reset this by clicking Forgot Password. There is no limit for how many password attempts you have when logging into PKB.

How do I log out?

Click the Log out button in the top right corner. It is best practice to log out before you leave your computer so that no one can else access your record, especially if others share your computer. The system will automatically log you out after 30 minutes of inactivity.

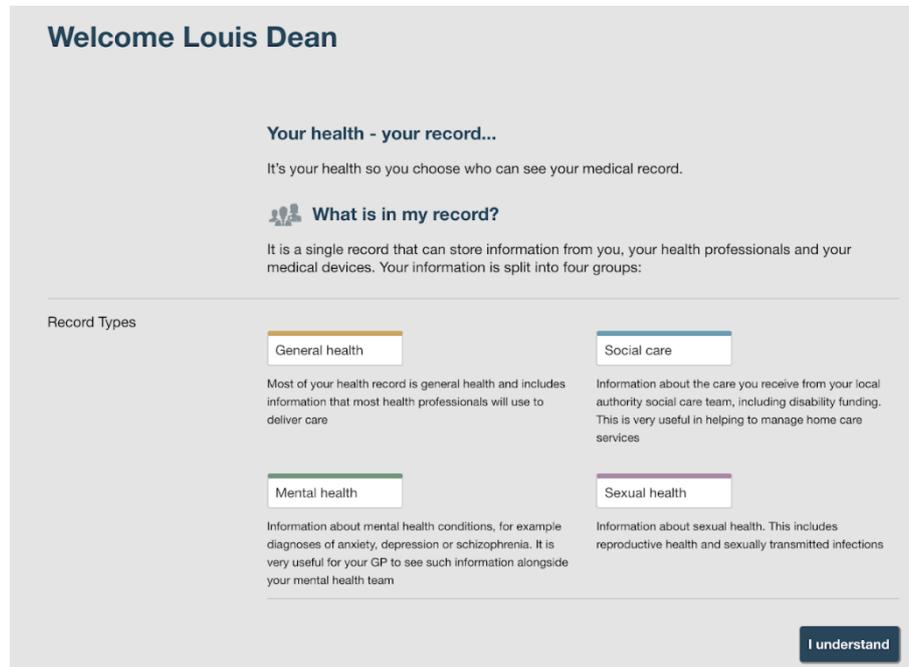


2. Logging in for the first time

What happens when I log in for the first time?

When you have completed registration and log into the system (<https://my.patientsknowbest.com> website) for the first time, you will be taken through our consent screens before we display your homepage.

The first page you will be shown is pictured below:



This page explains to you about the different record types. Each record type protects your personal information, as described below:

- General Health - this can be used for most of the health record and includes information that most health professionals will use to deliver care
- Mental Health - this can be used for anything relating to a mental health diagnosis such as depression or anxiety.
- Sexual Health - this can be used for anything relating to your sexual health.
- Social Care - this can be used for care from local authority social care team, including disability funding and home care services.

Once you have read all of the information, you can press the “I understand” button to be taken to the next page.

This next page, “Review sharing settings” allows you to decide what types of information you are happy to share with the CURIE team.

Some boxes may already be ticked by default. You can change this however - you can untick boxes if you don't want the CURIE team to have access to some information or you can tick more boxes if you want to share more with the team.

It is important to remember that if the box is ticked the team will be able to see [that information](#). For example, if you tick “General health” and “Mental health” the team will be able to see any information in your record in that record type.

Review sharing settings



Choose what you want to share with the **Crisis team** team at **St. Augustine Mental Health Trust**. You can change your choices at any time in your sharing preferences.

Medical record: The default privacy access is determined by the team. If no privacy is selected, the professionals in that team will only be able to see data added by their team. They can still add to your record and send messages. **This team has access to data marked with the following privacy. You can change the access this team has by changing the privacy levels selected below.**

<input checked="" type="checkbox"/> General health <small>Most of your health record is general health and includes information that most health professionals will use to deliver care</small>	<input type="checkbox"/> Social care <small>Information about the care you receive from your local authority social care team, including disability funding. This is very useful in helping to manage home care services</small>
<input checked="" type="checkbox"/> Mental health <small>Information about mental health conditions, for example diagnoses of anxiety, depression or schizophrenia. It is very useful for your GP to see such information alongside your mental health team</small>	<input type="checkbox"/> Sexual health <small>Information about sexual health. This includes reproductive health and sexually transmitted infections</small>

If you untick all boxes, the team will not be able to see any data you add to your record, or any data added by other people (such as other clinicians who are contributing to your record, or any carers). They will, however, be able to see any data their team has added to the record.

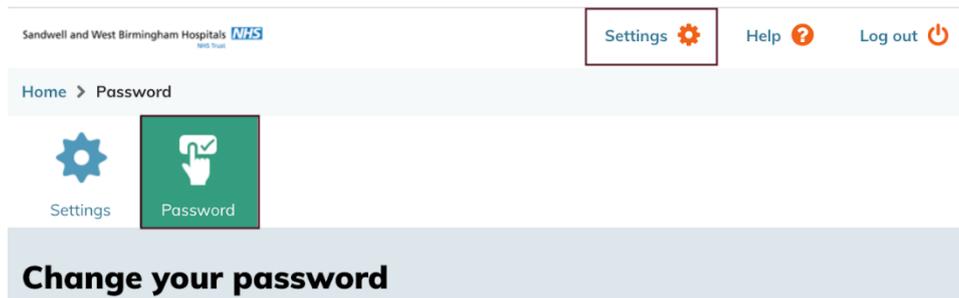
If you have been added to multiple projects, you will have to repeat this process for each project before you are taken to the homepage. We display the project name and the organisation at the top of the page, so you always know who you are granting access to during this process.

The settings you decide when you first log in can be changed at any point by you - you will always remain in control of who can see your record.

3. Resetting your password

How do I change my password?

Click "Password" on the Settings page and complete the form.



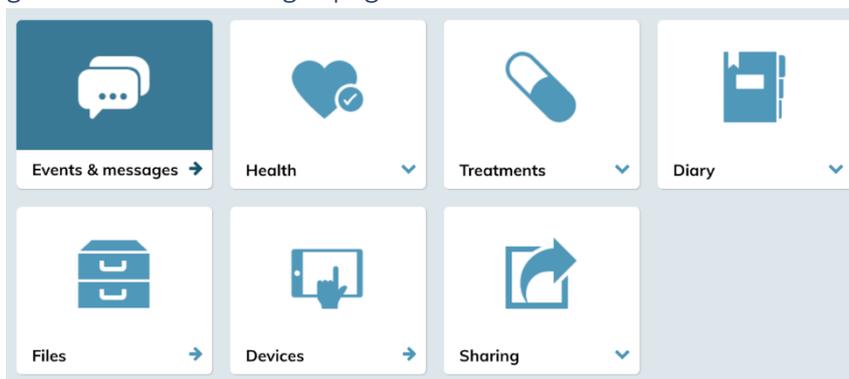
How do I reset my password if I have forgotten it?

Click the "Forgot password" link on the login page (<https://my.patientsknowbest.com/>) and follow the instructions.

If you are unable to reset your own password for any reason, you can ask the CURIE team on imperial.curie.project@nhs.net to trigger a password reset email for you. The password reset link will take you to a page to create a new password and security question.

4. Events & messages

Understanding the Events & messages page



Here we display a list of all messages between you and the professionals caring for you. This includes any documents that have been sent to you by your clinical teams, e.g., appointment letters, clinic letters, referrals, discharge summaries. Clinical events you may have had, e.g., inpatient stays, outpatient visits, emergency visits, are also listed here.

How is the information displayed?

All events and messages display as a list, with each row in the list representing one documents, message thread or one event. The list displays in date order with the most recent event or message displayed at the top of the page. To read older messages, click on the “>” arrow at the bottom of the page, or “>>” to view the oldest ones.

Unread messages, documents or events are highlighted in green and white, so they are easy to find.

Each row will contain useful information such as the date of the latest message, the message subject and how many messages are in each thread. If there is a document or other attachment, then a paperclip icon will be visible to the right of the row.

A timeline will also display above the list of messages and events, so you can clearly see in which months you have had activity.



How do I open a message, document, or event?

Clicking anywhere on the row will open it up so you can see the contents of the message, document, or event.

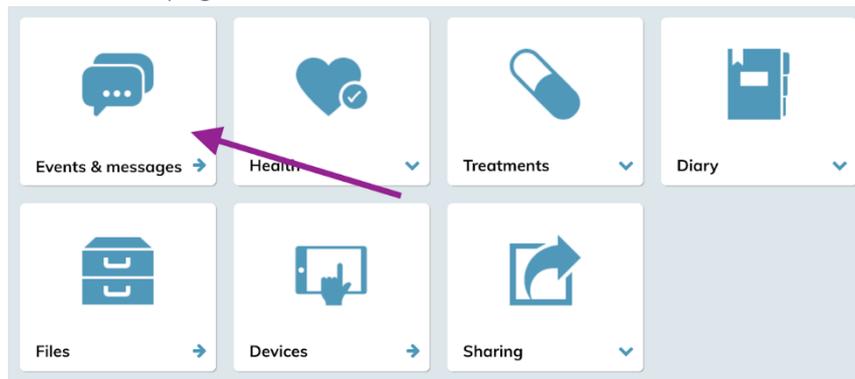
How is the information displayed within a message thread?

Once a message thread is open, all messages will be displayed in chronological order with the oldest first. At the top of the thread the title, participants and privacy label are visible. Beside each message in the thread the name of the sender is shown.

To reply to a message, enter the text in the “reply” box and click send. Files can be attached to messages by clicking “Add file”. PKB will automatically save the text you type as a draft if it is typed but not sent.

5. Consultations

Finding the consultations page



What are consultations?

Consultations are sets of questions that healthcare professionals can send out for completion by you, your carers or other professionals who treat you. They allow you to share information about your health with your treating team without having to attend a physical appointment. A follow-up questionnaire, similar to the example below, is one type of consultation that you might receive.

Home

Breast Clinic Follow Up Questionnaire

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

The Breast Care unit at Torbay hospital would appreciate it if you could fill out this survey before your follow up appointment. All your answers are confidential and will not affect your treatment/care.

1 Have you had any new breast problems since your last visit?

2 I am bothered by problems after my operation. Please score from 1 - 5

3 One or both of my arms are swollen or tender. Please score from 1 - 5

How do I complete a consultation?

If you are sent a consultation, you will receive an email notification to alert you of this. The message will include a link to the consultation that, you can ~~then~~ fill ~~this~~ in and your responses will be sent back to the sender.

Project management group

Lead Clinician: Dr Matthew Williams

Collaborators: Ms. Isabel Ho, Miss Radvile Mauricaite

PPI lead: Miss Lillie Pakzad-Shahabi

Patient Representatives: Jacqui Gath, Pete Wheatstone

Project Management: Miss Kerlann Le Calvez

RCR representative: Dr Hannah Tharmalingam

Copyrights statements

The section “Register for access to the Care Information Exchange” is extracted from the Imperial College Healthcare NHS Trust website (<https://www.imperial.nhs.uk/patients-and-visitors/patient-information/my-records>).

The text and screenshots from the section “How to use the Patients Know Best platform” were written by the Patients Know Best team (<https://manual.patientsknowbest.com/patient>).