

National Kidney Patient Portal Switchover



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MANAGE YOUR HEALTH



UK Kidney Association

 @patientsco

 enquiries@patientsknowbest.com

 www.patientsknowbest.com



Retha Steenkamp, Head of Operations, The UK Kidney Association

“Working with PKB, we aim to provide a secure environment in which patients can access their data and take control of how their information is shared, and with whom. For patients and kidney teams, this means increased security, and advanced features and functionality, including team-based messaging and an ecosystem of integrated wearable and monitoring devices to support clinical transformation.”

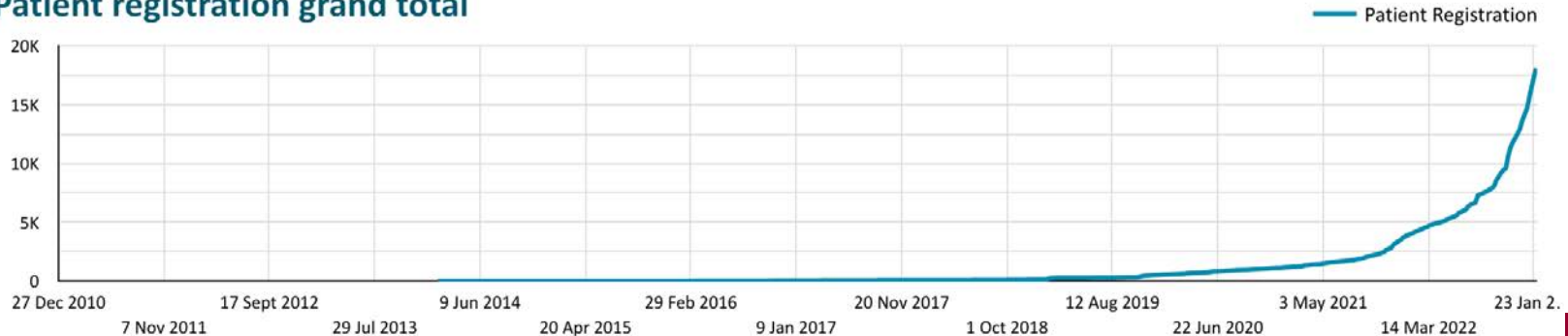
Benefits to patients and clinicians

- Access more data related to wider health not just in relation to renal condition
- Expands on the tools renal clinical teams can use with their patients to help manage their kidney conditions
- Increased security
- Care planning
- Wearables and monitoring devices can be used to support clinical transformation
- Fully integrated with NHS App (in England and soon Wales) enabling patients to see their renal data in it

Switchover statistics so far

- PKB switchover: 20,500 patients who have previously had a PatientView record (25%)
 - PV past: 30,000 previous PatientView accounts (78,000 records, 35%-40% actively being used by patients)
 - PKB target: 30,000 UKKA accounts in PKB (with some variance due to level of engagement from local kidney centres), with 100% of new patients registering on PKB going forward.
- Wales, Scotland and N Ireland not yet started registration, they will take us significantly closer to our target.
 - 56/58 Kidney Centres in England have historic patient data and are able to invite patients to register
 - Wales centres – end of February 2023
 - All Children’s Hospitals – end of February 2023
 - Scotland centres – end of March 2023
 - Northern Ireland centres– TBC

Patient registration grand total



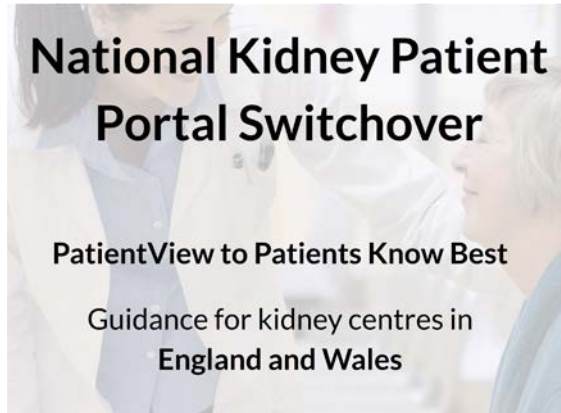
Phase One - Migrating 75,000 patients from PatientView to PKB

- PKB has attempted engagement with all existing PV kidney centres to explain and support deployment. Kick off meetings have been followed up with regular ongoing support and training from the PKB Success Team.
- Communicating to patients - lack of existing emails with many thousands of “dummy” emails created in the PV system ending in patientview.org
- Kidney Centres have supported where possible to communicate the switchover to patients and to collate accurate emails.
- Patient facing communications:
 - Information created by UKKA/PKB to enable kidney centres to direct patients to the information they need.
 - Dedicated webpage and explainer document, which highlights the differences between the systems, where data can be found, and explains the new functions available to patients.



Phase One - Migrating 75,000 patients from PatientView to PKB continued...

- Communications to support kidney centres:
 - “How to” guide sent by PKB team



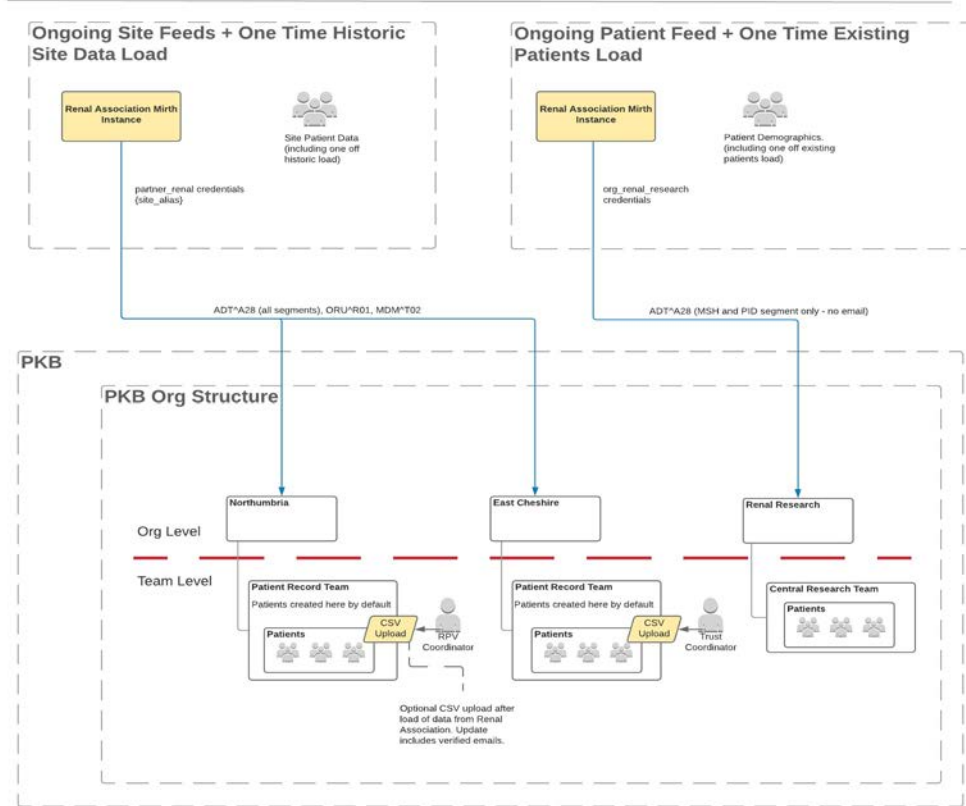
Contents

1. [Background to the switchover](#)
2. [How will this switchover work for existing PatientView patients?](#)
 - a. Timeline of PatientView to no longer receive new data from the UKKA in England and Wales.
 - b. What do kidney centres need to do?
 - c. What if a patient has not heard about the switchover and contacts the kidney centre in January to say that they are no longer receiving data in PV?
3. [Signing up new patients to PKB:](#)
 - a. Via the kidney centre.
 - b. What if a patient signs up directly or via NHS App prior to indicating to their kidney centre that they wish to register?
 - c. What if an existing PV patient does not wish to use PKB?
4. [What if a patient says they have not received data?](#)
5. [Accessing PKB and kidney data via the NHS App](#)

Completion of integration work

- Ensuring patients receive all existing data such as demographics, lab results, documents, measurements
- Creation of patient records in a national PKB team and then adding patients to the correct local unit PKB team
- Upload of historic data into patient accounts by UKKA using UKRR codes. New data will also then flow in when live.
- For Trusts with multiple kidney centres - PKB lists the ZTM for each of those centres and UKKA/PKB confirm the partner alias to be used in MSH-4
- Patients will see data from all the kidney centres/PV feeds they have received data from

RENAL ASSOCIATION DEPLOYMENT



Patient Registration

- In England and Wales, patients can be directed to the PKB/UKKA NHS Login page. From here they can verify themselves and register for PKB. They can also be invited en masse via csv upload. At this point they will be able to see their previous and any new data in PKB.
- If a patient struggles with NHS Login the local kidney centre can manually add them. If they are engaged they will have been trained in how to do this.
- In Scotland and Northern Ireland, the teams are collecting verified emails from patients and are able to invite en masse via csv upload and/or add as individuals.
- Adding patient emails via csv or individual upload to their record triggers the invite email. They can then follow the registration link to claim their record.



How to register

IF YOU ARE NOT REGISTERED WITH PKB

For patients in England and Wales : Click register below.

REGISTER

And continue by clicking the 'Register using NHS login' Button. Please find a support guide [here](#), and follow this from step 2.

IF YOU ARE REGISTERED WITH PKB


For patients in England and Wales : Connect yourself to the UKKA team by clicking register below.

REGISTER

And continue by clicking 'Share'.

For patients in Scotland and Northern Ireland

wanting to register - provide your team at your kidney centre with your email address and when ready they will send you an invite to register.



If you need any guidance during the sign up process, you can contact PKB [here](#) for additional support. For any other queries regarding your kidney data, contact the UKKA [here](#).



Early problems



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Registration is hard

NHS login security high

Local units are not
supporting alternatives



Already have an account?

Log in →

Log into your existing account

Share →

Share your record with Renal Services and Research at The UK Kidney Association

Are you a new user?

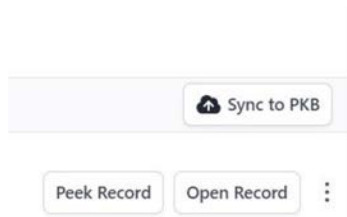
 Register using NHS login

Results missing



Renal unit has not sent data to UKKA

UKKA has not sent data to PKB



UKKA are about to release a new dashboard for kidney centres to sync the data themselves

Results missing reference range

UKKA will work on
showing reference
ranges like hospitals
already do in PKB



Test Results

Add result



For more information about a test result please contact the healthcare professional who requested the test.

Search for tests

All

Day

Week

Month

Year

FBC (full blood count)

Haemoglobin (g/L) >

g/L



Out of range Range Comment

Vitamins

Vitamin B12 or cobalamin >

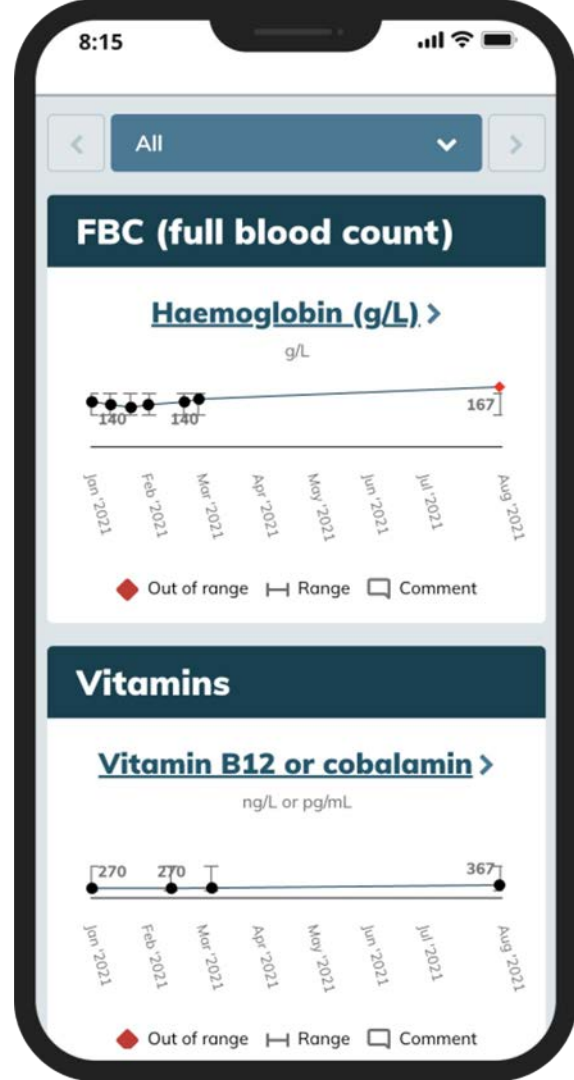
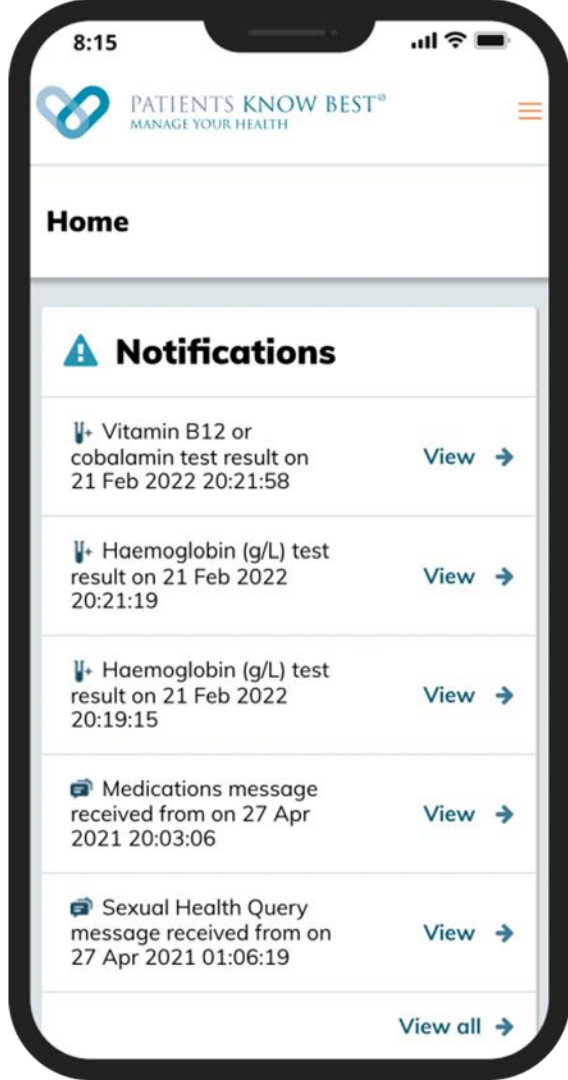
ng/L or pg/mL



Out of range Range Comment

Results do not highlight recent

Patients are right



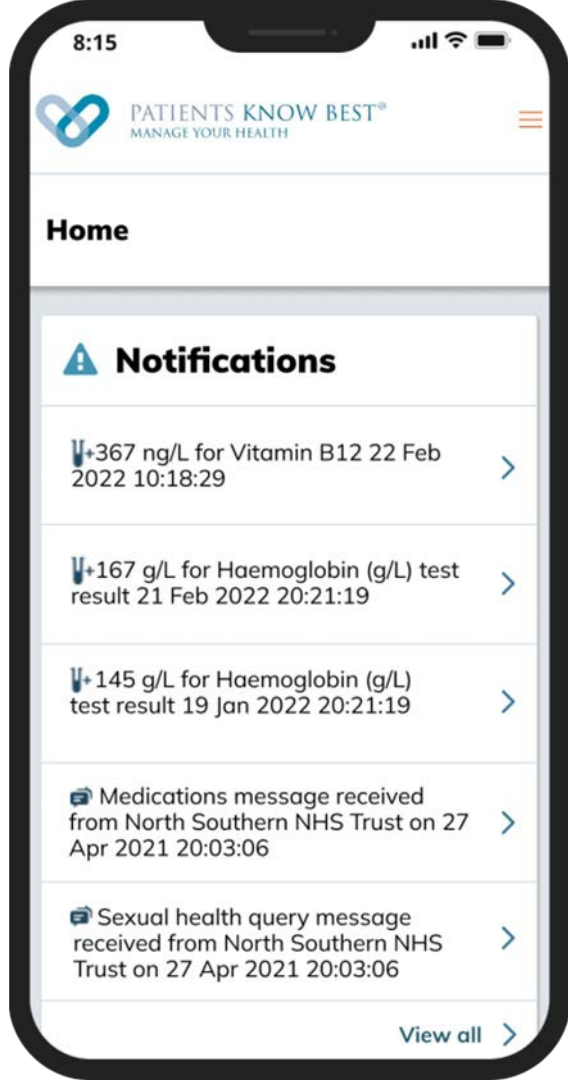
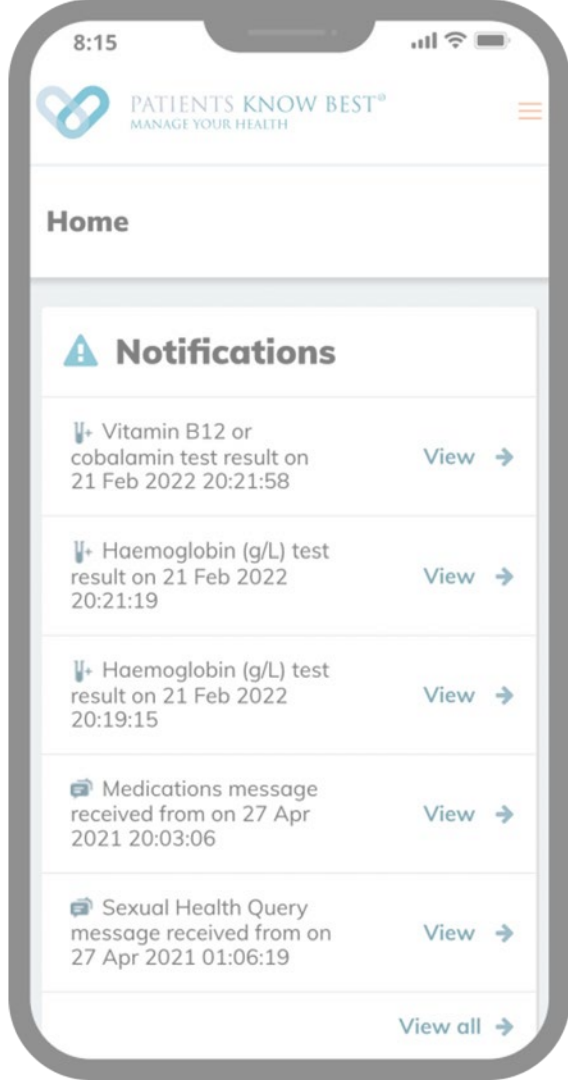
Results do not highlight recent

PKB Fixing this month (February)

Adding the value of each result to the notification panel

Log in, see your latest test results within the panel

Link to see further information and past results for that test



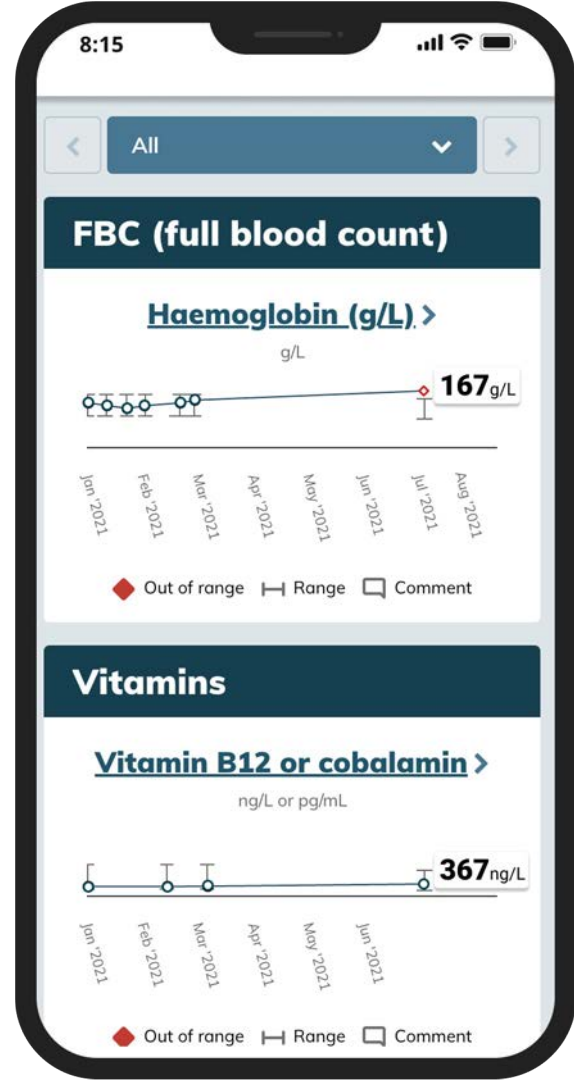
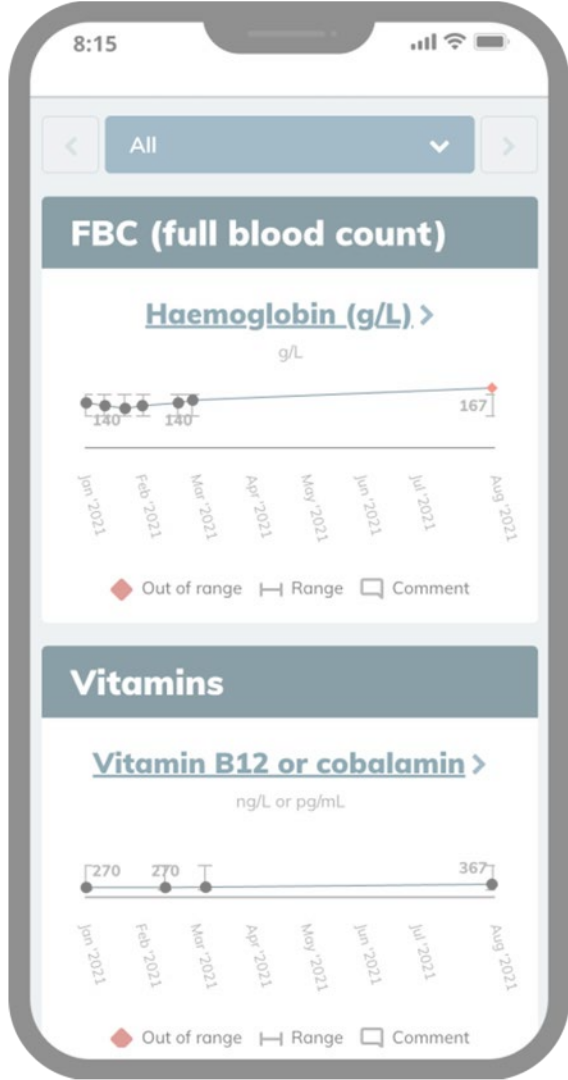
Results do not highlight recent

PKB Fixing this month (February)

Highlight latest value on graphs of all test pages

See values for other results by hovering over to see a pop-up

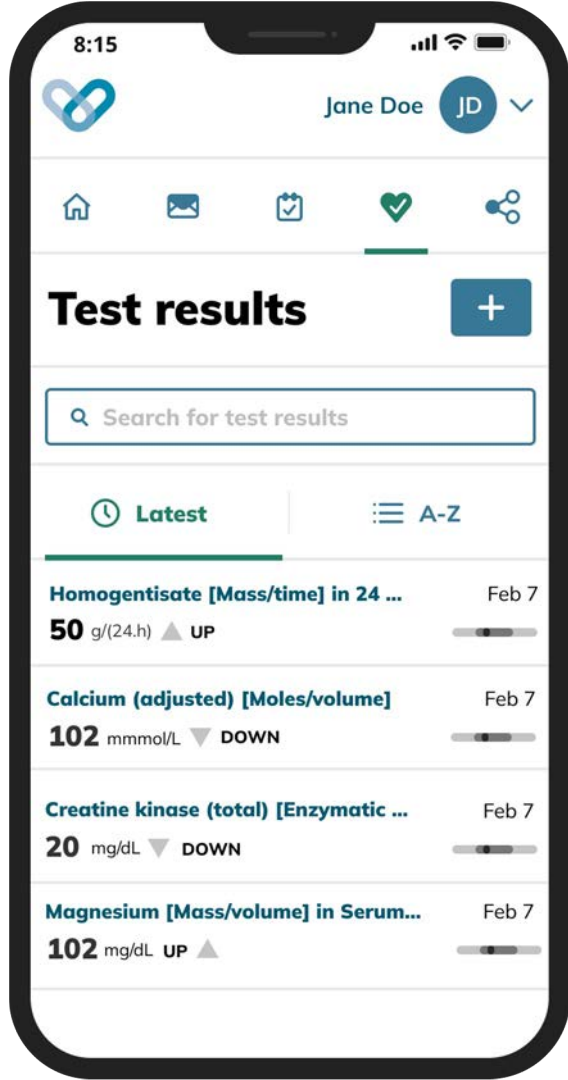
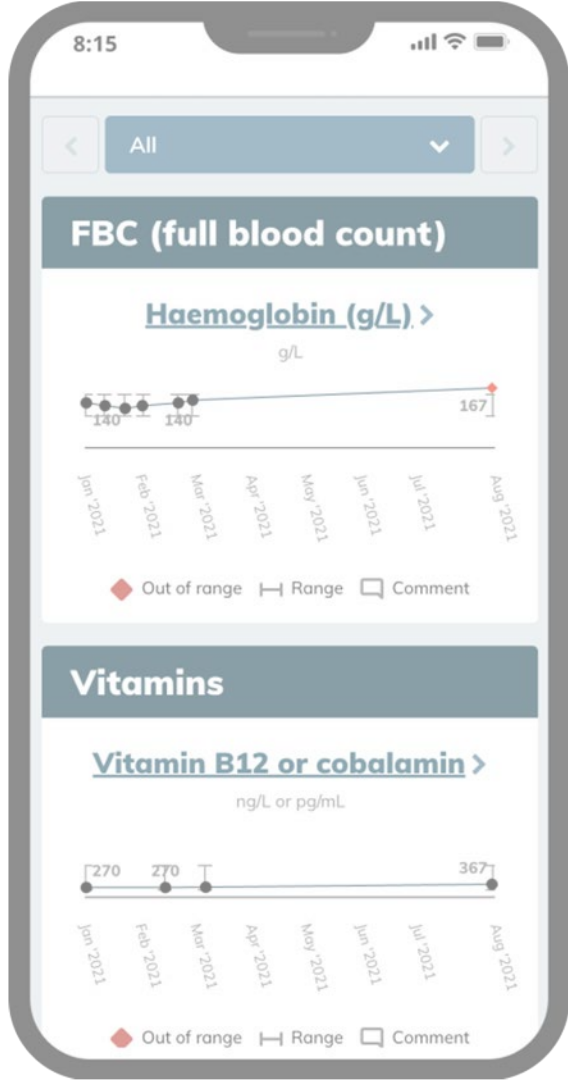
Pop-up menu reordered to show value first



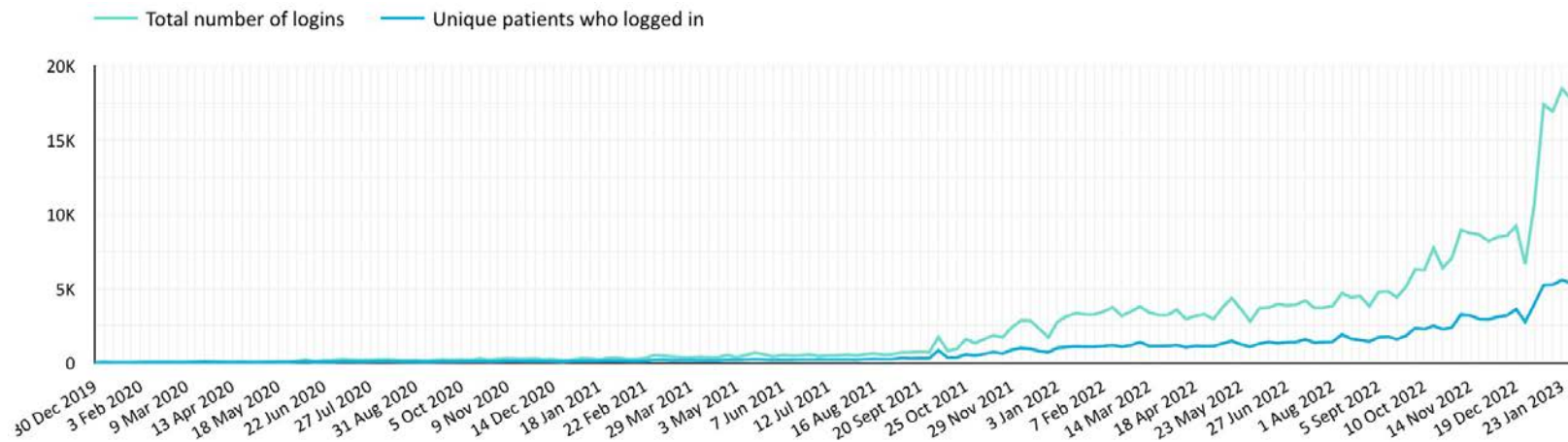
Results in chart not in list

PKB gathering user feedback on other designs

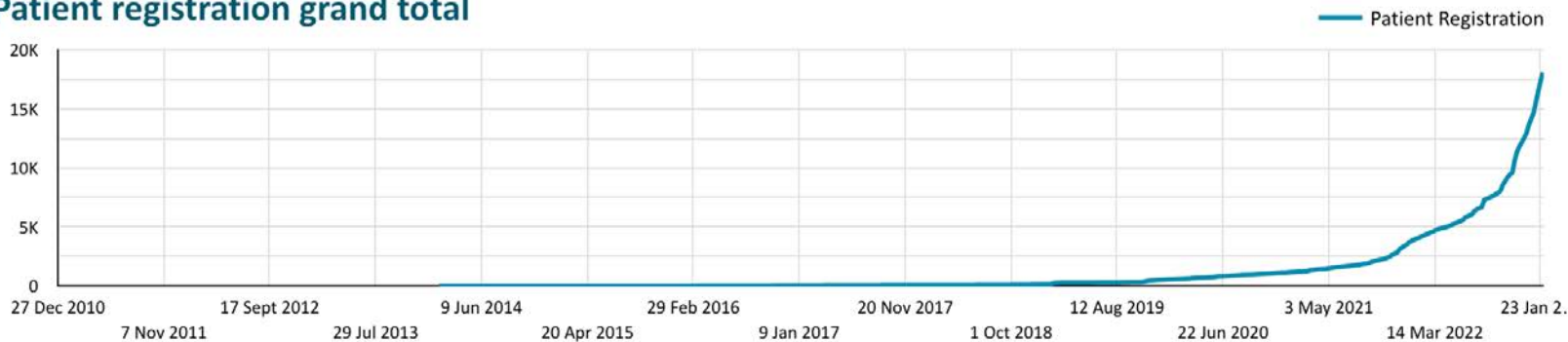
- list view of latest results
- condensed view
- results are up or down
- search for test results in list



Registration and usage high and rising



Patient registration grand total





Phase 2 with PKB platform

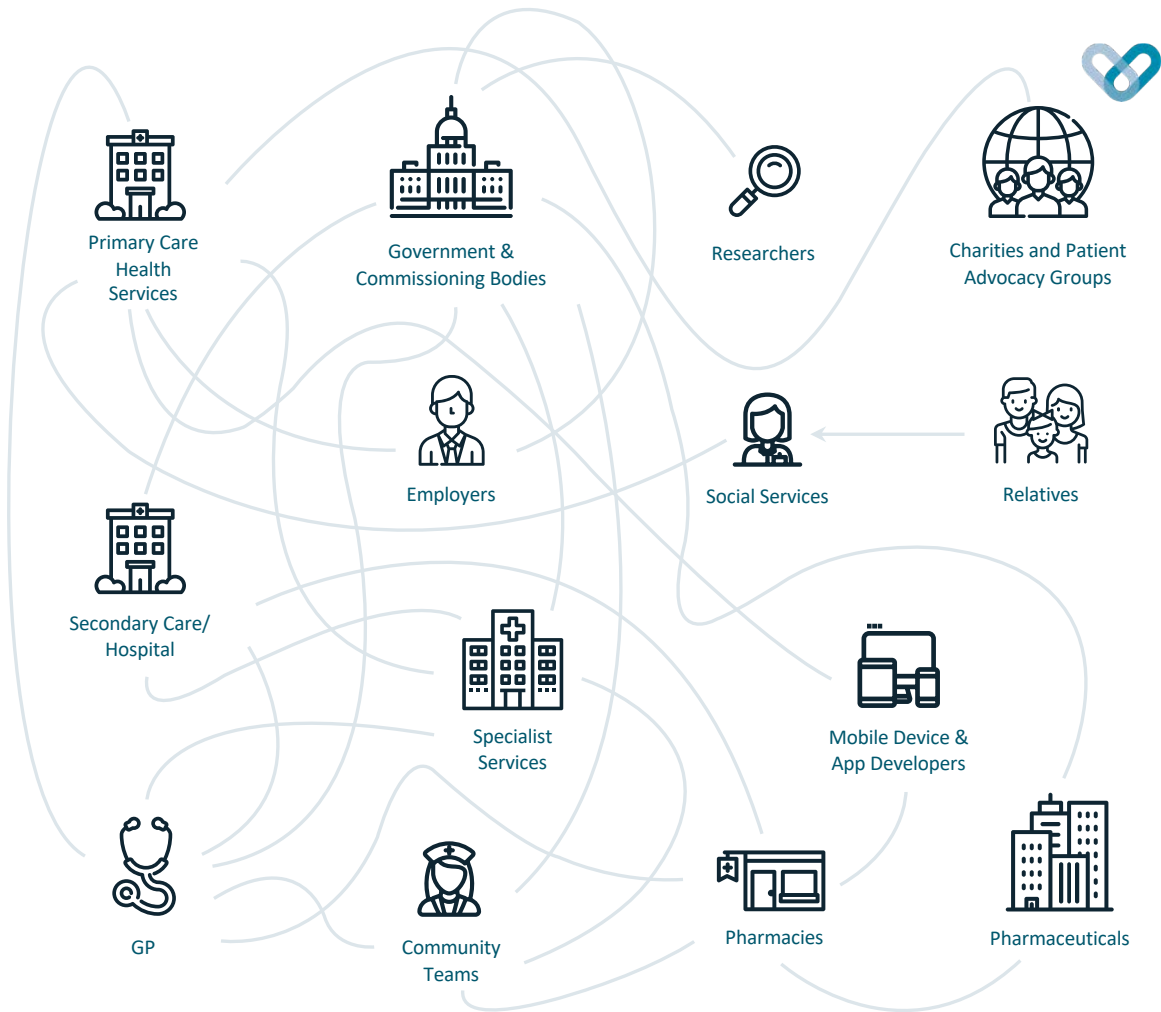


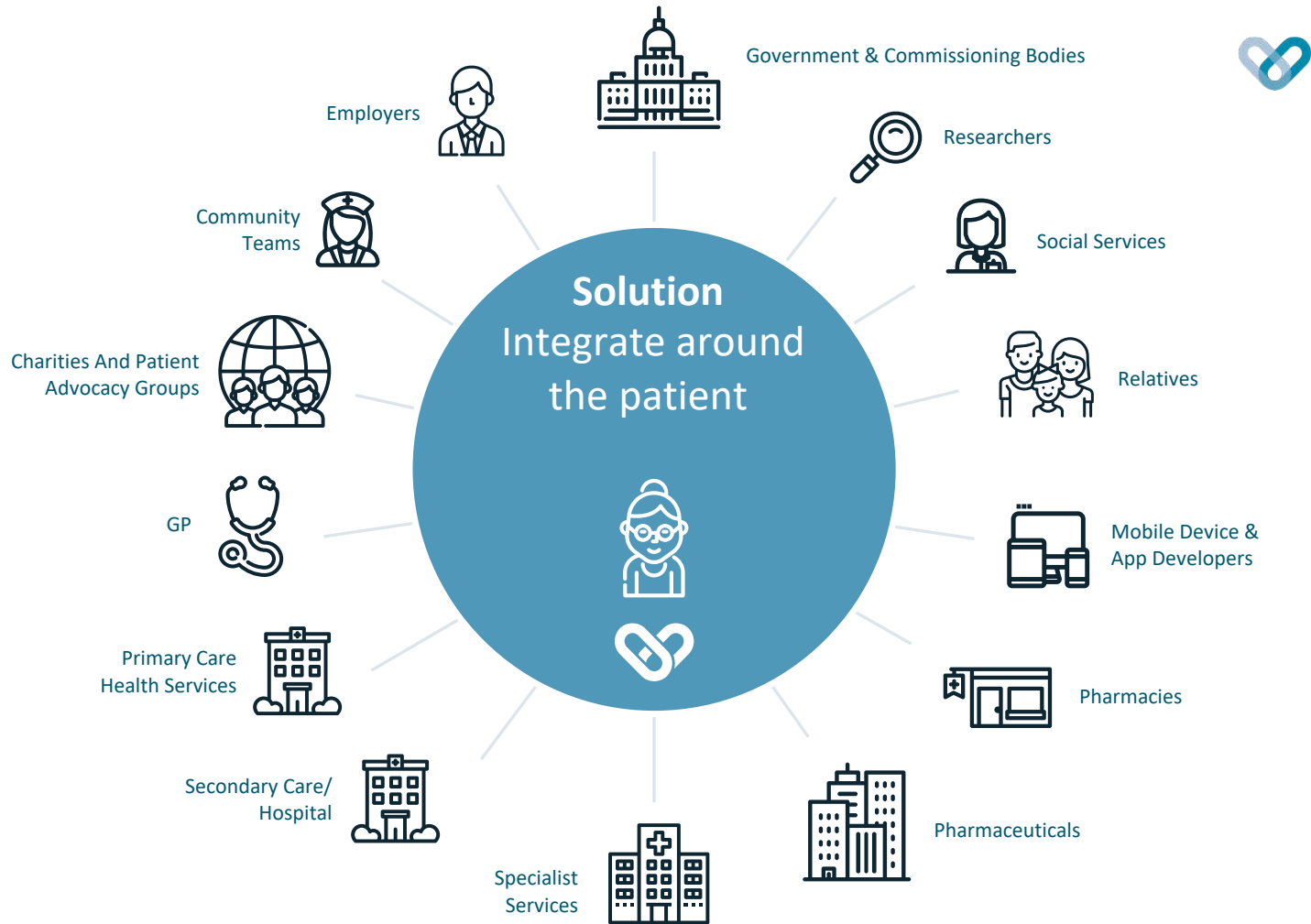
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The Problem

Fragmentation of Data in Healthcare

- Difficult to connect
- Technical problems
- Legal issues
- Patient excluded
- No one feels in control





Largest PHR platform in Europe



PKB users are highly engaged

76% read within 2 days
50% read within 2 hours

550,000+ users log in every month
250,000+ users log in every week

2.5+m
users



14 million
test results / month

30% of UK population

Data: hospital, GP, mental
health, patient, devices



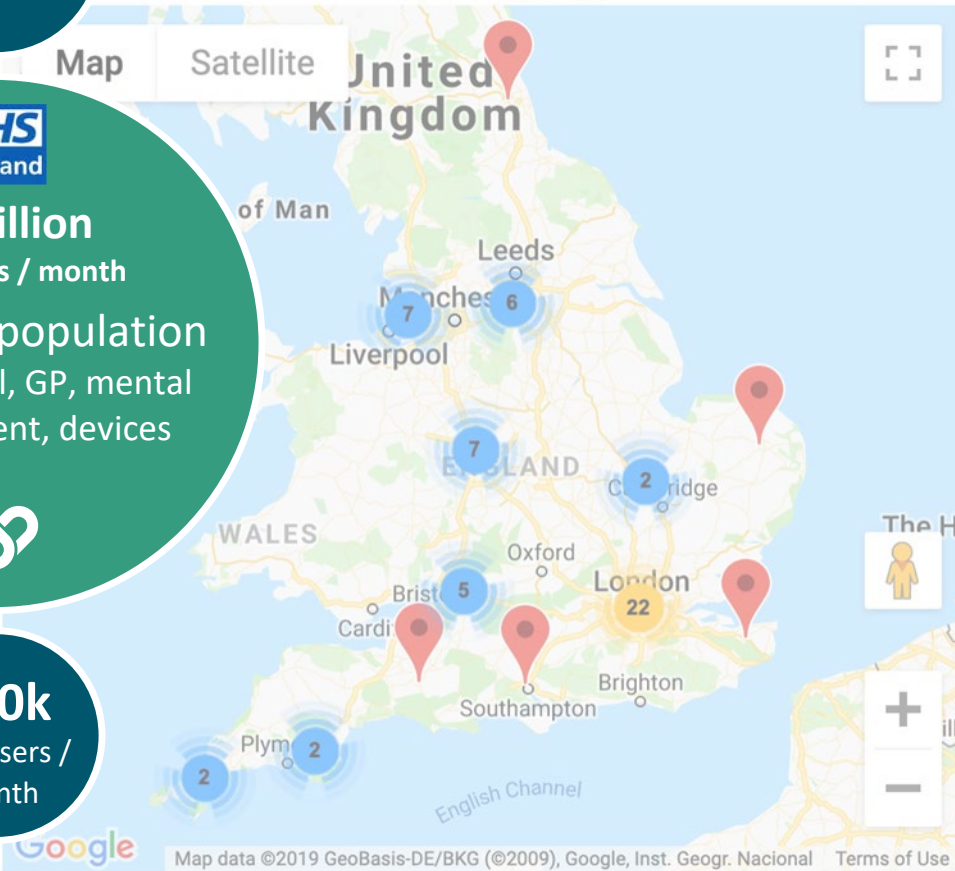
100k
new users /
month



NHS
Digital

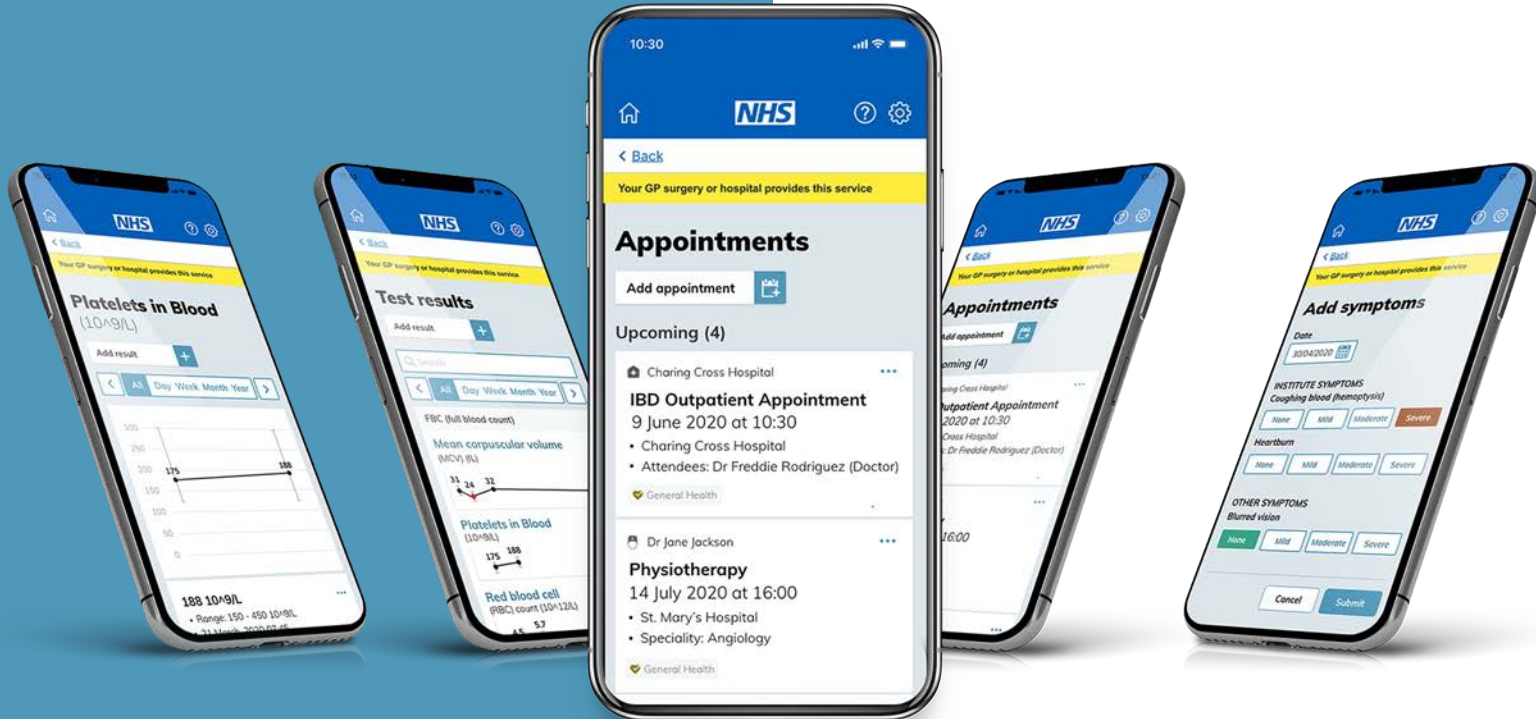
70
YEARS

Personal Health Record contacts map



NHS App

14 of 42 regions in England +3 coming
2 of 7 in Wales in NHS Wales App

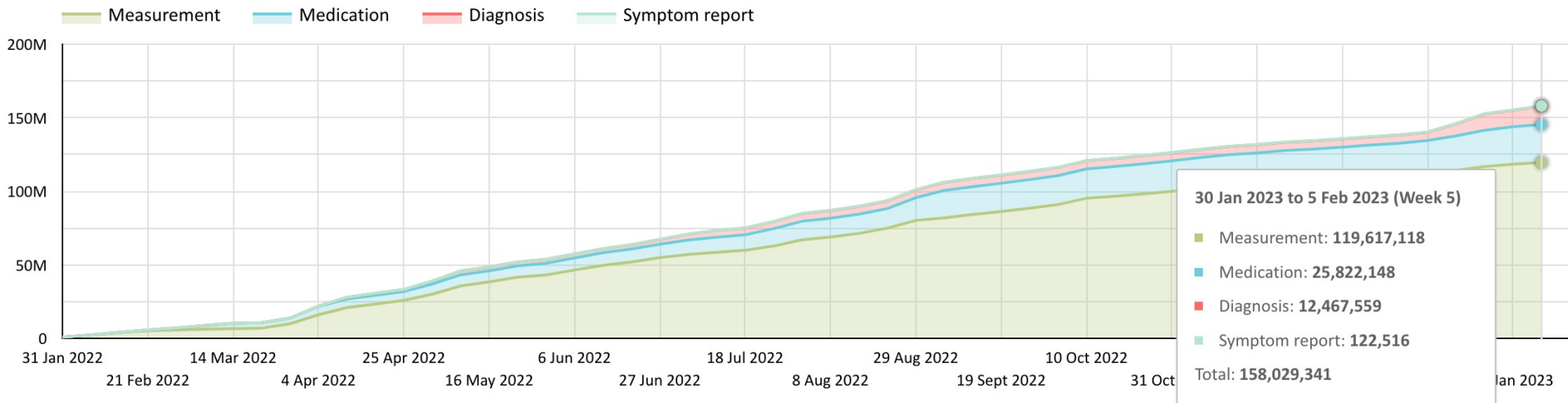


Non-hospital data already big

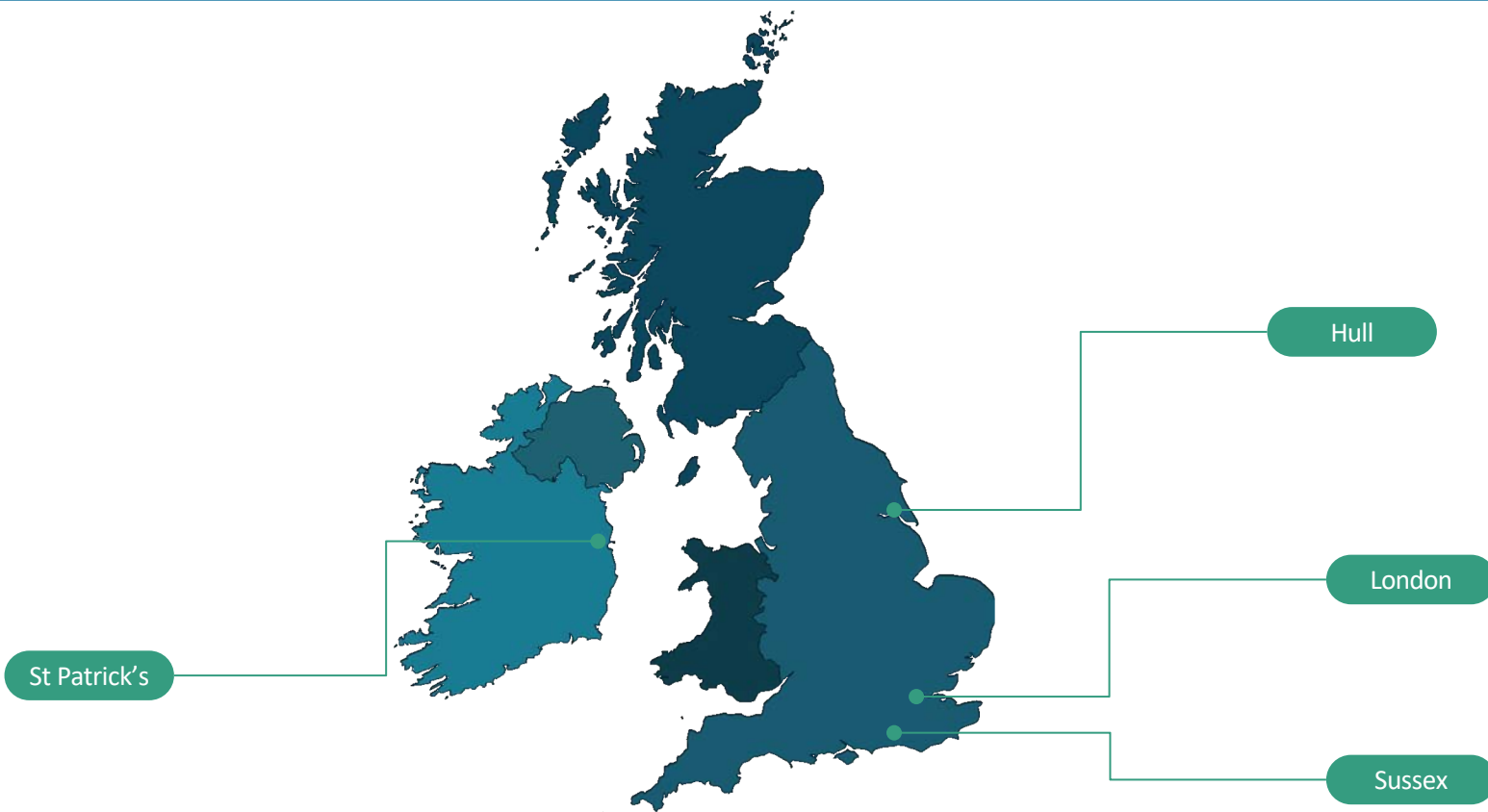


Getting bigger

5+ million GP records
coming from London



Questionnaires API live 2022/12



Questionnaires new functionality



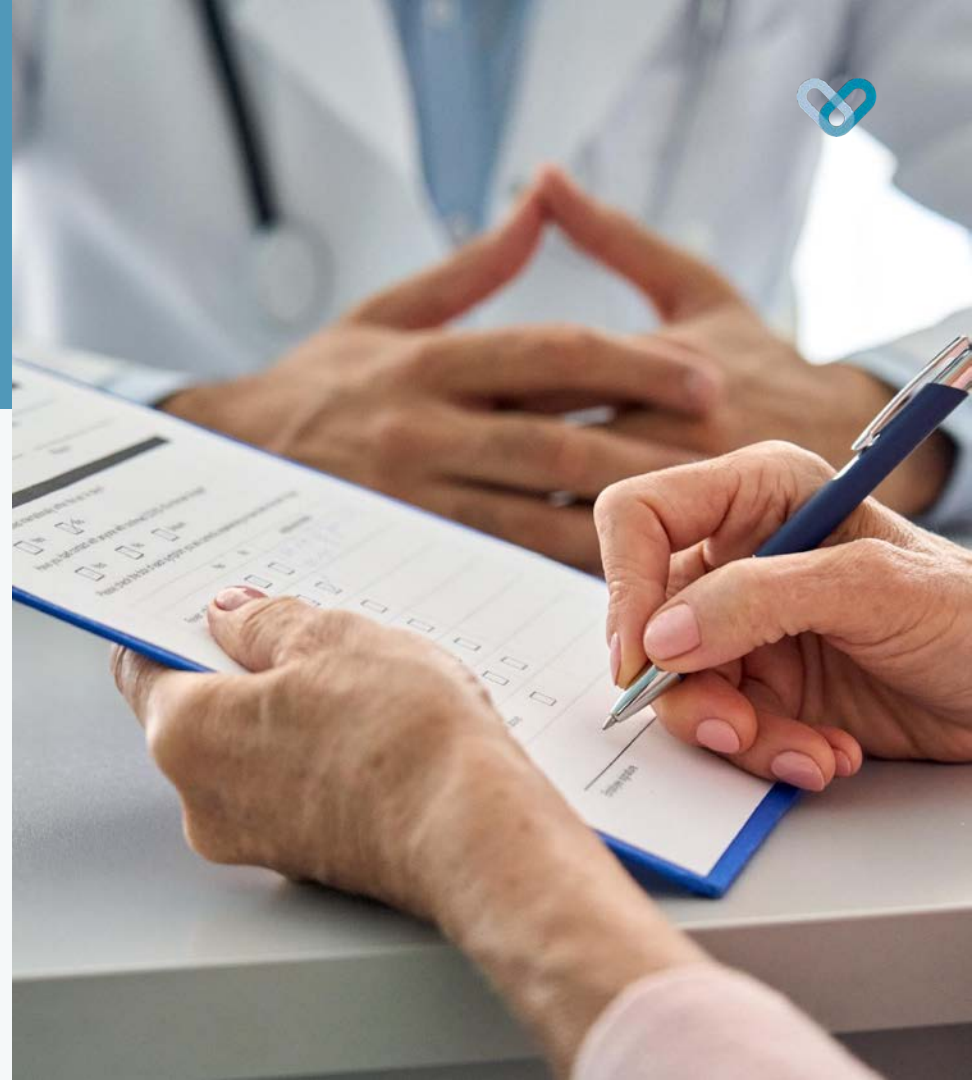
- Collect data from 100% of patients



- Questionnaires with scoring and coded data



- Register patients after they provide data



Partner apps easy to build



DrDoctor

OMRON



FreeStyle *Libre* 



Regions using PKB for all data and all patients



Regions happy with any app plugged into PKB



Professionals and researchers focus on workflow (not data integration and not patient registration)

RESEARCH SAVED MY LIFE

Register now



What is NWL Health Research Register?

NWL Health Research Register is a register of adults

What is health research?

Health research that you may be able to participate in, ranges from:

Why should I join?

By joining the register you will be told about research opportunities that are relevant to you, giving you

Welcome to Patients Know Best

A social enterprise working with North West London Health Research Register to help you manage your health.



Already have an account?

Log in



Log into your existing account

Share



Share your record with Care Information Exchange at North West London Health Research Register



Are you a new user?

 Register using NHS login

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About Patients Know Best

Patients Know Best (PKB) is a social enterprise working with North West London Health Research Register to help you manage your health.

The information in your records Patients Know Best is under your control as the patient. You can share it with as many professionals as you would like and can stop sharing at any time.



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KPUG

Kidney PKB User Group

**discuss with each other how using
come up with big ideas for future usage**



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