



PATIENTS KNOW BEST®  
MANAGE YOUR HEALTH

THE UK'S MOST INNOVATIVE HEALTH TECH COMPANY



# *Rolling out a patient portal at scale*

## WHITE PAPER

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Patients Know Best



# Introduction



**Dr Mohammad Al-Ubaydli**  
CEO and Founder,  
Patients Know Best

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*PKB has rolled out more patient portals to more patients than anyone else in the U.K. Along the way we have learned a few things, including mistakes you should avoid and best practises you should follow. This white paper by our solutions architect sums up the approach new organisations should take to making data available to patients: an exciting advance in the delivery of healthcare.*”

Access to health records through patient portal technology is a theme gaining considerable traction throughout advanced health economies. In the U.K., NHS Digital’s [roadmap](#) promotes adoption of patient portals; the [5-Year Forward View](#) focuses on

patient empowerment; and the [vision](#) of Secretary of State for Health and Social Care, Matt Hancock, is for a more tech-driven NHS. Patient portals have crept into the digital roadmaps of nearly all healthcare organisations.

[NHS Digital Roadmap](#)



As a powerful tool to radically boost patient engagement, patient portals are increasingly becoming a necessity. This online tool is centrally focused on giving patients a window into their own health by providing access to healthcare data anytime, from anywhere in the world. The data gives real-time information to patients that has previously been unseen including lab results, diagnoses, medications, care plans, physician notes, health histories, discharge summaries as well as the ability to directly communicate with healthcare teams.









At Patients Know Best (PKB) our experience of working with over 100 NHS organisations in the UK has put us at

the forefront of innovations in patient portals and personal health records (PHRs), and we have witnessed first-hand the impact they are having. From changing the dynamic between healthcare professionals and their patients by placing greater emphasis on self-management, to creating systemic change by improving efficiency, generating savings and streamlining care. What was once considered fragmentation in the system is being reformed to create patient pathways focused on the needs of individuals, rather than institutions. All this, and more, is now possible with a patient-owned and patient-controlled patient portal.



# Early considerations

Before embarking on this journey there are a number of early considerations to be made. This white paper brings together our knowledge and experience to outline the path towards not only successfully initiating a patient portal but also rolling it out at scale. This paper will provide a focus on the following key areas:

-  **1** *Objective statement*  
A CLEAR STATEMENT OF INTENTION
-  **2** *Information governance (IG)*  
GIVING DATA SUBJECTS ACCESS TO AND CONTROL OVER THE SHARING OF THEIR DATA
-  **3** *Architecture model*  
HOW THE DATA WILL INTEROPERATE
-  **4** *Integration*  
NAVIGATING INDUSTRY STANDARDS ON DATA AND INTEGRATING WITH LOCAL SYSTEMS
-  **5** *Patient control*  
CREATING TRANSPARENCY TO PROTECT INFORMATION AND PUT PATIENTS IN THE DRIVING SEAT
-  **6** *Marketing campaign*  
COMMUNICATING TO ENGAGE INTERESTED PARTIES
-  **7** *Accumulation and access to data*  
CURATING A RICH DATASET
-  **8** *Evaluation*  
MEASURING IMPACT AND RESPONDING TO THE STATISTICS





## Objective statement

### A CLEAR STATEMENT OF INTENTION

The first, and arguably the most important step, is to clearly state why you are undertaking a patient portal programme and what you expect to get out of it. For example, the objective statement should be as clear as:



*We are introducing a patient portal to empower our citizens to manage their health, improve patient outcomes and experience and realise cost savings for our organisation by releasing data to patients. We believe it is the right thing to do - giving ownership of data to patients will help us modernise our healthcare services and align our organisation to the future direction as set out in the NHS Five Year Forward View*



This removes any ambiguity around the purpose and scope of the project and informs all organisations participating about what is coming.



## Information Governance (IG)

### GIVING DATA SUBJECTS ACCESS TO AND CONTROL OVER THE SHARING OF THEIR DATA

Information Governance is a challenging discipline for every organisation. Applying a common approach is essential for productivity and efficiency in such a wide-ranging discipline. Organisations have tried and tested methods for giving professionals access to data, but giving patients routine access to and control over data is new, and the repercussions from any mistakes can be daunting. So organisations often proceed anxiously and slowly, sometimes incorrectly with assumptions from past practises.

It is for this reason that PKB consults with Information Governance teams early in the relationship – aiding the development of new approaches and providing support for what, to many Information Governance teams, appears at first glance to be a challenging new frontier. There is a significant risk to the success of the project where IG teams are consulted late or as a mere formality, therefore they must be engaged from the start.

At PKB we have a team of seasoned experts that have rolled out more patient portal projects than any other organisation in the U.K. We recommend working closely with our team early on to benefit from their expertise and support. The main areas to be considered and agreed across all parties include:

#### **PARTNERS / ORGANISATIONS:**

A full list of all relevant parties participating in the project. This may include, but is not limited to, hospital trusts, GPs, mental health, social health, CCGs, STPs and emergency services.

#### **VENDORS:**

A full list of all relevant vendor solutions in use across the organisations identified above.

#### **INFORMATION PROCESSING AGREEMENTS (IPAs):**

Established General Data Protection Regulations (GDPR) compliant data processor IPAs, Data Protection Impact Assessments, Information Sharing Agreements and other documents must all be comprehensive and watertight. We are happy to share examples of these agreements, so please speak to us before you create new ones.



# Architecture model

## HOW THE DATA WILL INTEROPERATE

How is data going to be collected and disseminated to the patient portal? In the early stages, it's important to strike a balance between the ideal state and ease of implementation. To aid this, a number of decisions must be made including:

### BUILD VS. BUY:

Will you build your own solution or choose a vendor based on proven capabilities? We built PKB because we saw the challenges healthcare providers experienced when trying to develop their own software. As a healthcare organisation it's important to focus on your value-add, delivering the best healthcare possible, not necessarily building and maintaining software.

### SELF-HOSTED VS. MANAGED SERVICE:

Would you like to host the infrastructure locally or buy a service managed by a 3rd party? The market is clearly moving towards the latter, which releases capacity for the organisations to provide healthcare rather than manage hosting. PKB is a software-as-a-service (SaaS) company delivering a fully managed service, which aligns with the [Cloud First NHS](#) vision.

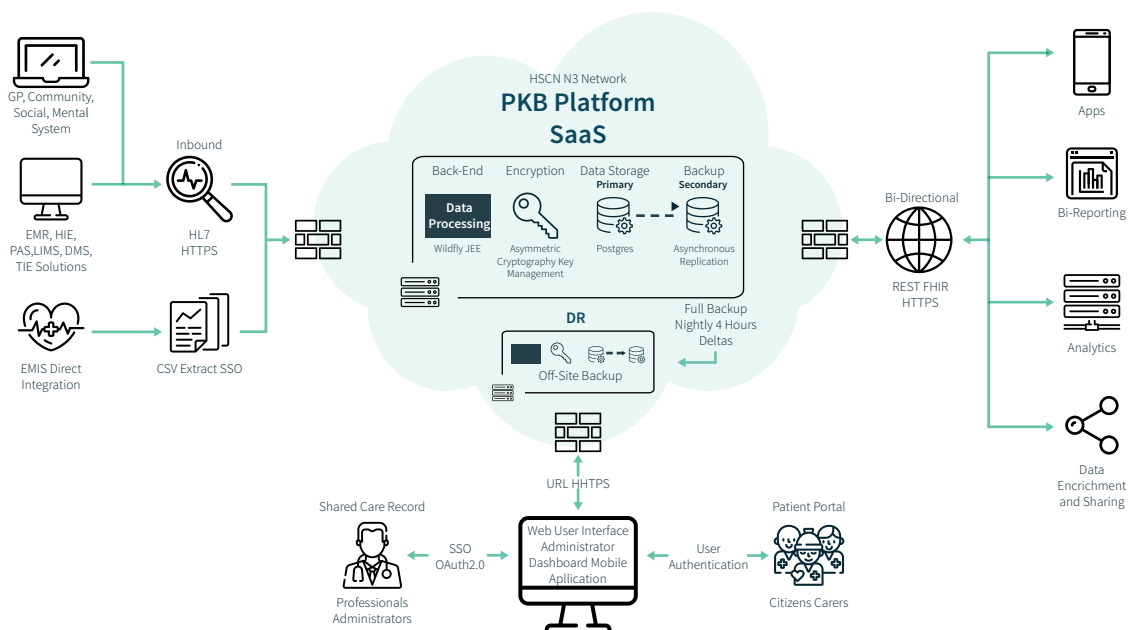
### FEDERATED VS. CENTRALIZED:

Will each participating organisation hold their data and respond to requests on demand or will a centralised data set be created to service the patient portal? Some organisations prefer federated as their approach to data controllership but there has never been a successful, functioning, federated patient portal in the UK.

### PUSH VS. PULL:

Showing data at the time of access is right for professionals but wrong for patients. For a professional, logging in at the point of care to see a snapshot is useful and therefore engaging, whereas receiving large volumes of alerts about new data for all patients can be overwhelming and therefore disengaging. By contrast, for a patient the arrival of new data drives engagement, whereas an experience of logging in to find no new data may well end their engagement. Patients need real-time updates to drive action in between appointments.

PKB architecture model





## Integration

### NAVIGATING INDUSTRY STANDARDS ON DATA AND INTEGRATING WITH LOCAL SYSTEMS

It is essential to establish some paradigms around industry standards from the outset to ensure fast and reliable information exchange. These include:

#### OPEN MESSAGING STANDARDS:

What language will your solutions speak to each other in? **FHIR** and **HL7 V2** are the two most widely accepted standards in the industry. For ease of implementation, conforming to these standards will give you the most bang for your buck and provide the highest likelihood that your integration will be successful. Avoid complex standards that haven't gained widespread adoption such as HL7 V3, CDA, XDS, etc. It is also important to avoid proprietary standards that are not open or public.

#### TRANSMISSION PROTOCOLS:

Likewise the method by which the data is transmitted should fall in line with industry-adopted standards. The most widely used are TCP/IP, REST and SOAP. These standards are highly scalable, simple and easy to modify and extend.



**Dave Boerner**  
Solutions Architect,  
Patients Know Best



*It's more important to pick a widely adopted open industry standard than the perfect paradigm. Use what has the most traction and will be the easiest to implement which is why FHIR and HL7 V2 are the standards I recommend.*



## Patient control

### CREATING A TRANSPARENT CONSENT LAYER TO PROTECT INFORMATION AND PUT PATIENTS IN THE DRIVING SEAT

What level of control will you give patients over the data? At PKB, we believe that each patient should own a copy of their own patient data, controlling who can access (and how) to provide the greatest level of transparency. However, no matter what you decide to do, at the very least the following considerations should be made:

#### CONSENT FOR ACCESS NOT STORAGE:

Consent is not needed for storage of medical data, only for access. Information Governance teams often mistakenly believe that consent is required based on existing practices for internal medical records systems, however patient portals separate storage from access.

#### GRANULARITY OF WHO CAN ACCESS:

Will consent be for the organisation or for teams within each organisation? Can the patient invite organisations other than yours? Can the patient invite individuals such as professionals? PKB gives patients the power to share with as many organisations and individuals as they want.

#### GRANULARITY OF WHAT THEY CAN ACCESS:

Will your portal allow for granular data sharing or will it be an "all or nothing" approach? PKB strives for a simple yet effective model, with each data point labelled as General, Mental, Sexual or Social Health. Patients can then decide which data points they want to share with individual organisations.





## Marketing campaign

### EFFECTIVELY COMMUNICATING TO ENGAGE INTERESTED PARTIES

Even the best patient portal in the world is worthless if there is no uptake. No matter how big or small the deployment is, you must communicate about it's availability and the benefits because the success of the entire programme depends on it. Once you have a good understanding of the communications and marketing requirements, it's essential to gain traction for the project. Some critical considerations include:

#### FAIR PROCESSING NOTICE (FPN):

Under the new [GDPR](#) regulations, organisations are required to be transparent about how personal information is used. Will a FPN be needed to inform patients and to give them adequate time for any questions and answers?

#### EMBEDDING THE PROCESS:

Think about the questions your communications team will ask you to successfully relay the message to your intended audience. By looking at these questions at the start of the process, project leads will be one step ahead – helping you and your communications team in the process. Although you may not have all the answers at this stage, it is important to consider:

- What is the overarching aim of the project?
- What is the purpose of communications?
- Which partners need to be involved? (i.e. who else needs to know/who do your communications team need to engage to get the message across?)
- Who is the target audience(s) for the message?
- What is the message you want to share? (think about the benefits)
- What is your strategy? (what communications channels will you use to get the message across, what are the timescales and how will you do this?)
- How will you measure success? (what targets need to be set and how will they be measured and evaluated?)





### INTEGRATE YOUR COMMUNICATIONS TEAM EARLY:

Once you have a better understanding of the communications requirements (as above), speak to your communications team early on. This will help them to communicate the value of the patient portal with the target audience identified in the most effective way. If you don't have a communications resource, you need to do something about it. Do you or anyone within your team have any experience of communications and public engagement? If the answer is no, then make a change to get the right skills in.

### CONTINUE TO DRIP-FEED INFORMATION:

As any communications professional will tell you, you can't always rely on the fact that your audience has seen or understood your message the first time. That's why it's imperative you continue to 'drip-feed' the message at different intervals over the coming months (and even years), using a range of approaches (e.g. case studies, flyers, posters, articles, FAQs etc.) and mechanisms or channels (e.g. social media, website, TV/radio advertising, press/media etc.) to reach your audience in the most effective way.

Sample PKB leaflet

## Welcome to Patients Know Best®

Patients Know Best is an online system that allows you to store your medical records. You may consult online with your doctors, nurses, and any other professionals you choose to share your Patients Know Best record with, through a secure messaging service.

You can use Patients Know Best on your computer, smartphone, tablet or any device that has an internet connection.



#### Is Patients Know Best secure?

Yes, Patients Know Best is covered by the Data Protection Act and operates within strict NHS security standards. Your record is encrypted so that only you and those you specify can see what's on it.

#### Who owns my medical information?

You do. Patients Know Best puts you in charge of your medical data because we believe it is your right as a patient to own your medical data. Putting you in control also makes it easier for you to involve everyone who looks after your health, wherever they may be, and bring them into one secure space online.

#### Where can I learn more?

Please visit our website for more information [www.patientsknowbest.com](http://www.patientsknowbest.com)

To learn more about how to use the system you can visit our help pages at <http://help.patientsknowbest.com>

#### How do I access my Patients Know Best account?

Your medical team will send you an email with a link to register for your Patients Know Best account (If you do not receive this email in your inbox, please check your junk folder). Click on the link, enter your details and choose a password. The password has to be difficult to guess to ensure the security of your account.

#### Who can access my account?

You, the patient, decides who gets to access your account. Log into your account and click on the "Team" page. You can invite a professional, such as your doctor, or a caregiver, such as a member of your family.

The people you give access to help you manage your account. For example, when you give your GP access to your account, they can invite other professionals on your behalf, for example your hospital specialist or your community nurse. When you give a family member access, they can consult with your doctors and nurses on your behalf.

If at any time you want to stop someone from accessing your account or amend the type of information they see, you can either log into your account and edit the sharing settings or you can ask one of the people with access to your account to do so for you. For example, you can ask your hospital nurse to stop your pharmacist from having access to your account.

#### How can I use Patients Know Best?

There are many areas in Patients Know Best that allow you to store different information about your health. Additionally your account lets you consult online with your medical team and you can manually enter information. Data may also arrive automatically in your account from your team, e.g. blood test results from your hospital. This process can take some time to set up so it may not be available immediately, but in the meantime you can take advantage of the other features of the system.







## Accumulation and access to data

### CURATING A RICH DATASET

It's critical to have a deep and rich set of health data for the patient to interact with when they get access to their record. Patient activation will fall dramatically if that first interaction is an underwhelming experience involving little or no health data or history. There are a few ways to acquire this data at the start:

#### BULK HISTORIC LOAD:

The idea here is to upload in advance of go-live, from each data contributing upstream solution, a historic set of data to generate the longitudinal record.

#### INTEGRATION AHEAD OF GO-LIVE:

Another option would be to turn on the integration feeds ahead of patient registration. This gives your Clinical Document Repository (CDR) time to accumulate information to present to the patient upon the first interaction.

## Mass Registration

If you've made it this far, then congratulations, you're ahead of the curve! A fully fledged patient portal will need a mechanism to allow for validated citizens to claim their records. Without this mechanism, your patient portal will never achieve the scale that is necessary to claim success. To roll out at scale, we have a number of options:

#### FACE-TO-FACE REGISTRATION

(i.e. during routine outpatient appointments):

This can be cumbersome and slow and will limit the rate of sign-up to in-person episodes. Nevertheless, on the upside, it is a secure method to verify citizens and allow them to register on the spot.

#### SELF-REGISTRATION VIA A PORTAL:

This method requires a citizen identity solution, whereby the citizen is able to prove that they are who they say they are, in order to claim their personal health record.

#### TOKEN-BASED REGISTRATION:

This option allows secure tokens to be generated and distributed to patients in a number of ways, such as through post or via a kiosk during check-in at appointments. It's important to have at least a two-factor authentication mechanism in place such as a postal address and date of birth to verify the patient adequately.

#### AUTOMATIC SIGN-UP AT SCALE:

If your organisation already owns verified delivery options (email address, phone number, address) then it's possible to automatically send an invitation to patients for registration. This method would also require a two-factor authentication mechanism as described above.

#### Sample PKB invitation letter

NHS Foundation Trust

TEST PATIENT

Dear TEST PATIENT, Letter Date 05 Jun 2018


We are very pleased to offer you a new online service.

As a patient of Torbay and South Devon NHS Trust you can now see your appointment letters and laboratory test results from Torbay and South Devon NHS Trust, and send secure messages to your clinical team online. To enable this to happen your clinical team have set up your personal account. To use it, please register following these instructions:

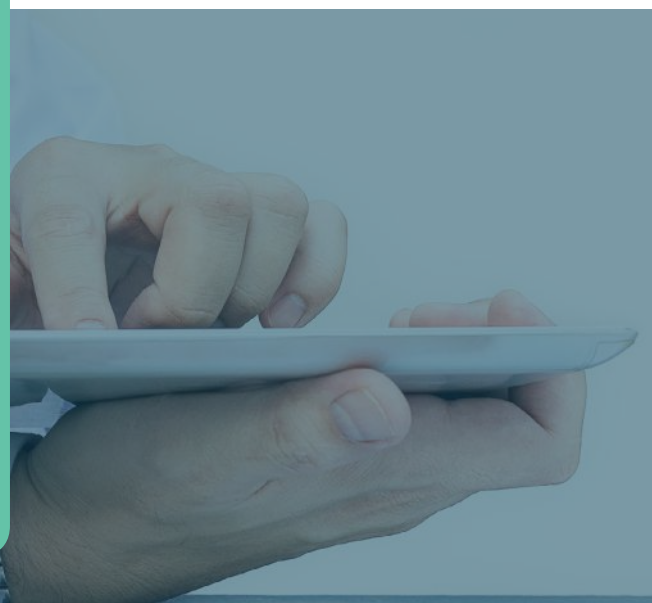
**To register**

1. Go to the website by typing the below address into your browser or scanning the QR code with your smartphone.

Joinpkb.com



2. Once you are there you will be asked for two codes, please enter these details - they are personal to you:





## Evaluation

### MEASURING IMPACT AND RESPONDING TO THE STATISTICS

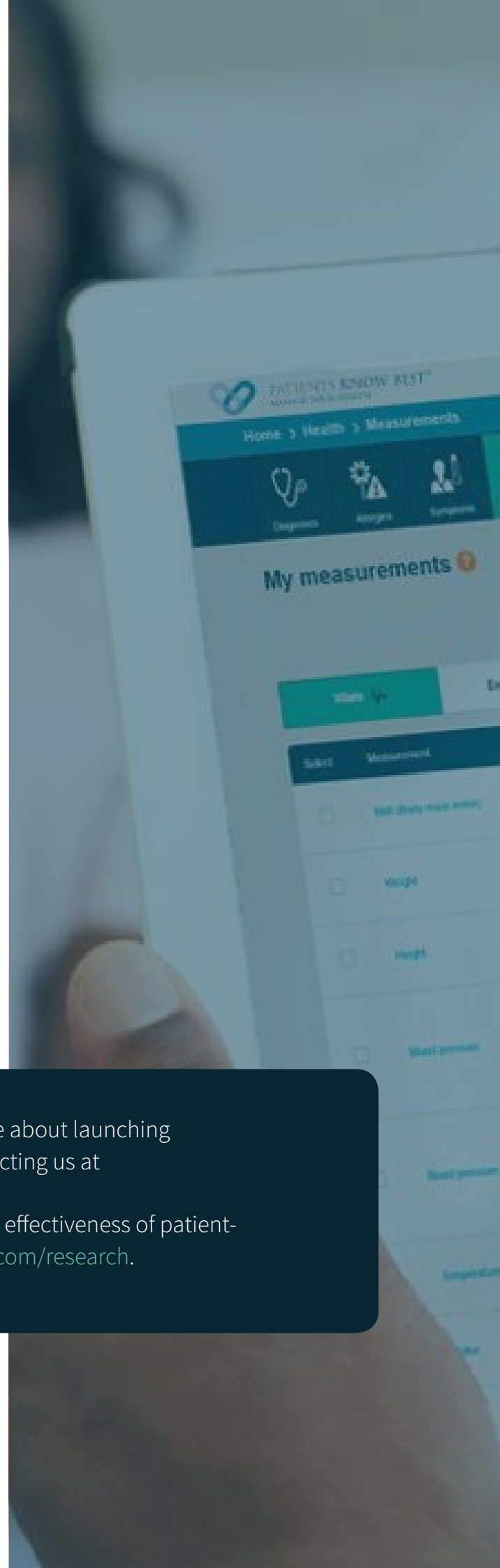
Finally, you can't improve what you can't measure. As such it's important to gather statistics to help evaluate progress along the way. The metrics can be selected at the outset which will allow for experimentation to help test which approaches work best. For example, one could test what the uptake rate is for face-to-face registration vs. a check-in kiosk implementation, or:

- The registration rate i.e. at what percentage are patients being invited, and at what percentage are they registering.
- The activation or engagement rate i.e. at what percentage are registered patients engaging with the solution.
- The financial metrics i.e. how is the project affecting the bottom-line? Have DNAs, A&E attendances or virtual consultation rates changed?

By taking a measured and pragmatic approach to address each of the areas identified above, you give your organisation the best chance of rolling out data access through PHRs at scale to your patient population.

Talk to us if you are interested in learning more about launching a patient portal initiative of your own by contacting us at [enquiries@patientsknowbest.com](mailto:enquiries@patientsknowbest.com).

You can also learn more about the impact and effectiveness of patient-controlled records at [www.patientsknowbest.com/research](http://www.patientsknowbest.com/research).





## ***Patients Know Best***

Patients Know Best (PKB) are the pioneers of the world's first patient-controlled digital health record, able to connect to all sources of healthcare data from primary, secondary, specialist, mental health and social care, as well as the patient's own apps and devices.

PKB provides patients with one consolidated record that they can share with whoever they trust, wherever they go, empowering them to self-manage their care whilst creating efficiencies for the wider NHS.

The record is a rich source of data with information about appointments, care plans, diagnoses, medications, test results, measurements and symptoms, and also allows remote communication between patients and healthcare teams.

Used in over 100 NHS organisations, PKB hosts the records of millions of patients across every county in the UK, from the Shetland Islands to the Scilly Isles. PKB is also available in 7 countries and in 19 languages.

Find out more at [www.patientsknowbest.com](http://www.patientsknowbest.com).