

*‘Wales Knows Best’*

*The world’s first patient-controlled health record and a multi-award winning tool, nationally integrated in Wales.*

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CELEBRATING

*10 years*

EMPOWERING PATIENTS



PATIENTS KNOW BEST®  
MANAGE YOUR HEALTH

THE UK’S MOST INNOVATIVE HEALTH TECH COMPANY

## ***Higher quality care at a lower cost is possible with Patients Know Best.***

As we continue to hear well-rehearsed arguments for changing the way care is delivered, the reality is that the pace of change remains steady and that patients in most parts, still continue to receive suboptimal and disjointed care.

In our own experience of working across over 40 NHS organisations in the UK, we have ourselves witnessed the impact this is having. Patients routinely called in for appointments they don't need, patients who need appointments struggling to be seen within a reasonable timeframe for their care needs, unnecessary admissions to hospital, increasing length of stays and patients still repeating their story over and over again to the multiple healthcare professionals involved in their care - from primary to secondary, to community, social care and mental health, all because there is no such thing as the 'universal truth' when it comes to a patient's health record.

At Patients Know Best (PKB), we believe this fragmented system can only be reformed by creating patient pathways focussed on the needs of individuals, not institutions, whilst also acknowledging the real pressures faced in delivering those vital care and support services.

But don't just take our word for it. There is growing evidence that our approach is helping to maximise the number of patients who can self-manage through systematic transfer of knowledge and care planning. In turn, this can:

- reduce GP visits
- reduce hospital outpatient appointments
- help to prevent unnecessary hospital admissions
- reduce length of stay of necessary hospital admissions
- improve health status and self-efficacy
- enable patients to remain in their homes and communities for longer
- lead to reduced stress for patients and healthcare professionals

- increase choice for patients
- improve monitoring of care i.e. for conditions and medications
- helps patients to stay in control of their condition
- improve end of life care
- integrate all elements of care.

### **Empowering people in Wales**

PKB connects health and care information from multiple providers, creating a universal copy of the data in a single patient-held, health record. Patients log in to a secure, online portal to access their data and manage their health and wellbeing. They can also share their record with nominated healthcare professionals, family members and/ or carers using our patient- controlled access and consent model.

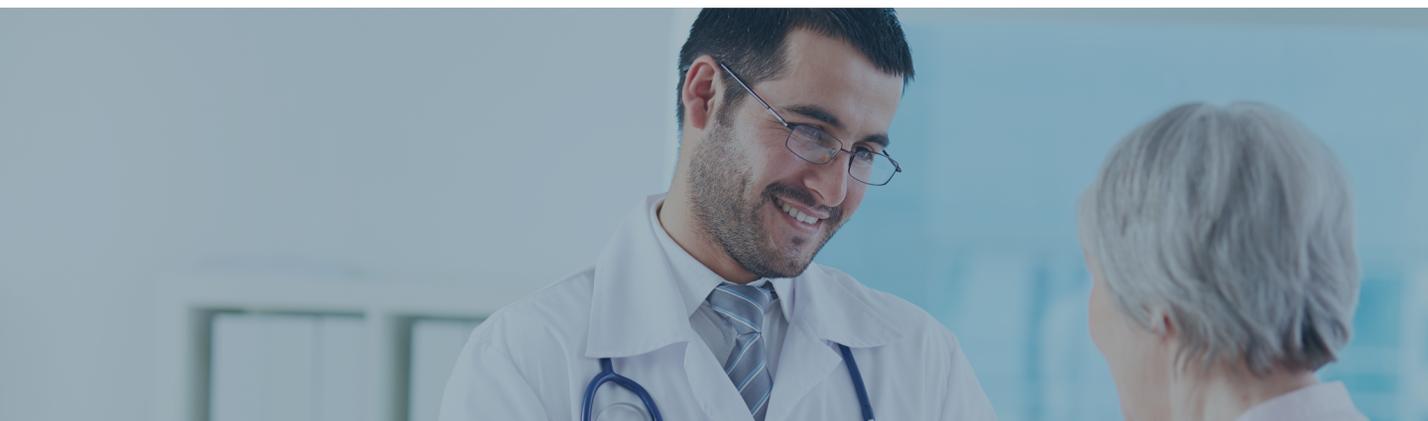
By handing over ownership of patient data to the rightful owners - patients, they are empowered to play a more active role in their health which also helps to relieve the pressure and capacity on healthcare professionals who already look after hundreds of patients at any one time. This also provides a greater focus on prevention, rather than just treatment.

### **Access to PKB in Wales**

Accessing PKB is easier than you may think. This is because in 2017, PKB partnered with the NHS Wales Informatics Service (NWIS) to integrate our digital platform with national data systems in Wales. This was a real milestone in the history of the Welsh NHS and also great news for everyone in Wales. It signified the first time, patients and healthcare professionals can access health records anywhere, anytime - whether that's in the remote parts of Staylittle in Powys, or the west coast of Africa in Cederberg.

Email [enquiries@patientsknowbest.com](mailto:enquiries@patientsknowbest.com) to find out more.

Further examples showing how PKB is being used in different parts of the county, can be found in this pack.



# *A national integration unlocks patient empowerment in Wales*

## *Abertawe Bro Morgannwg University Health Board*

Abertawe Bro Morgannwg University (ABMU) Health Board had a bold vision to promote self efficacy and unlock patient empowerment across Wales. Armed with a team of passionate changemakers, they looked for a solution that would enable patients to be more involved in their care by securely providing access to their own health records. As a multi-award winning tool designed to more equally balance the patient vs professional dynamic, Patients Know Best was a good fit.

### **A significant partnership**

In 2017, AMBU, in partnership with the Welsh Government who part-funded an early demonstrator pilot through its Efficiency Through Technology Fund, joined forces with the NHS Wales Informatics Service (NWIS) to secure a Welsh national integration with PKB for data systems.

Following the successful pilot in three departments in Morriston, Singleton and Neath Port Talbot hospitals, a growing number of outpatients in the Princess of Wales Hospital in Bridgend are now able to access their personal health records.

As well as accessing their records anytime, anywhere, this means patients in Wales can choose who they want to share their information with, and work more closely and easily with clinicians to manage their care as a team. Care plans are created digitally with input from patients and clinicians, and videos and other media content that help patients to better understand their condition and manage their care are also available.

### **The evidence for patient empowerment**

Hamish Laing, Chair of the Project Board and former Medical Director at ABMU, said: "There is good evidence that giving patients greater access to their own health information and care plans, as well as other information about their health, helps them to take greater control of their health and offers us better ways to support them in doing so."

Cardiac outpatient Deborah started using PKB in July 2018 after suffering a heart attack in 2016.

Aged just 49, she was one of the first cardiology patients offered PKB when it was launched in August 2018. She said: "I'm able to think about the questions I want to ask ahead of speaking to my nurse. Before I'd go to an appointment and be told about my results and it might not have been afterwards that I'd have thought of something I'd like to have asked. Now I am much better prepared."

ABMU has rolled out the system across a number of departments at the Princess of Wales Hospital in Bridgend. By implementing a scalable approach through mass registration, there has been a sharp increase in registration from a number of clinical specialities including diabetes, audiology, cardiology, HIV, Inflammatory Bowel Disease and Ear, Nose and Throat (ENT). For patients being cared for by these specialities, PKB is enabling better integration and interaction with care pathways and transforming the way care is delivered.

All this has been possible because of the approach Wales has taken towards a national integration. Patients can now see their test results for the last 10 years along with real-time updates of new results.



**Deborah**

Cardiac outpatient  
The Princess of Wales Hospital, Bridgend

“

*I like the way that I am able to see my results online, so I'm better prepared ahead of an appointment.*”



# Reforming the audiology pathway to win a national award

## Cardiff and Vale University Health Board

The Cardiff and Vale Audiology team have transformed the audiology pathway from a consultant-led service to a self-managed pathway using Patients Know Best (PKB).

The team is using PKB to encourage self-efficacy by distributing information such as questionnaires, to patients prior to their appointment. This is helping to measure both initial handicap to inform treatment plans, and residual handicap prior to a final review. The team have found the latter often completely negates the need for a final review before patients are discharged to the open access clinics, releasing valuable clinical time.

The quality of information available is also vastly improved as patients complete questionnaires at home with support from family members or carers where required. Subsequently, this means there is more time during the appointments, enabling a more comprehensive assessment and rapport to be established.

With the communication feature, patients can easily contact their clinician without the need to visit the site in person, or spend numerous

amounts of time waiting on busy telephone lines. Patients can also self-manage their care more effectively using a range of information and learning tools such as videos with instructions on the care and use of their hearing device, information on assistive listening devices and links to other available support services offered by the voluntary sector in the area.

The team hope to roll out PKB to many other areas in Audiology including Transition Services, Cochlear Implants, Bone Anchored Hearing aids, Tinnitus and Vestibular Services, to further streamline the care pathway and avoid the need for unnecessary appointments. The team is thrilled with the outcomes they have seen and said: "In Audiology we believe, patients really do know best!"



Audiology Team  
Cardiff and Vale  
University Health Board

“*In Audiology, we believe, patients really do know best!*”

*The Audiology team won the National Planned Care Programme Sustainability Award in November 2018.*

*During the event, Dr Andrew Goodall, NHS Wales Director General of Health and Social Services and Chief Executive, said: “The Planned Care Sustainability Award is a great way to celebrate best practice in improving patient care across Wales. It’s also a great opportunity to learn from each other and I hope it will stimulate some lively debate and fresh ideas that you will take back to your organisations.”*



# The largest shared patient portal in the UK

## Imperial Health Charity, North West London

In 2015, NHS healthcare providers in North West London rolled out the 'Care Information Exchange' (CIE) - a single patient portal hosting the records of up to 2.3 million people in North West London.

### Worldwide access to health records

Powered by Patients Know Best and funded by £3 million investment from Imperial Health Charity, CIE collects data from hospitals and GP practices in the area, and 15 other hospitals outside of North West London including Birmingham, Bristol, Liverpool, Manchester, Scotland and Wales. By using an Application Programming Interface (API) to display data in local medical systems, it enables hospital clinicians to see data about their patients who may also have been treated elsewhere in the country.

Driving productivity and better outcomes for patients

For patients like Paul who was diagnosed with HIV, CIE is helping him to stay informed and take control of his care. He said: "I'm treated for my HIV in Chelsea and Westminster, other conditions across London, and my GP in Wandsworth. So, really, I am the central repository of all the global information about me. I once took my iPad to Guy's Hospital for a consultation there. I was just about to be sent off for a whole raft of blood tests so I said: "Well, actually, you can see my results on here." The clinician took my iPad and I think

the only words she then said to me in the next 10 minutes was, "this is fantastic!"

### Access at scale

With the introduction of mass registration, people can now sign up to access their health record at scale and with speed in a number of ways; either by speaking to a member of staff; by using the kiosk check-in screen commonly found in waiting rooms during their outpatient appointment; or by letter of invitation to their home.

This approach is proving to be a great success at Imperial College Healthcare NHS Trust where kiosk registration signed up over 3,000 patients in the first month alone with more than 70 people completing registration every day. As the process is automated, it means no staff time is taken up to verify the identity of patients.

A system that allows data to move with patients Kevin Jarrold, Chief Information Officer at Imperial College Healthcare NHS Trust and Chelsea & Westminster NHS Foundation Trust, added: "We designed CIE so the data follows the patient wherever they are in the world. Our clinicians look after NHS patients from all over the UK in their national centres of excellence and with patients from London changing residence much more than the rest of the UK, it was important for us to choose a patient portal that allows patients to share data with any provider, and with open read-write APIs to integrate with their systems."

Andy Kinnear, Chief Information Officer from Connecting Care - a similar program developed in Bristol, is particularly supportive of this model as it allows patients who travel between Bristol and North West London for tertiary care to easily share their data. He said: "It's great that all data is truly available to the NHS via open APIs. But more than that, there is a consent layer that allows patients to express their preference on being contacted, taking part in research and sharing with friends and family that actually care for them. We have already had professionals in Bristol access data from London, and vice-versa."

Sanjay Gautama, Chair of North West London Information Governance Steering Group, added: "Patient-controlled data sharing is the right way to join up health and social care, and to consent, patients to contribute data for research."

Paul  
Patient, Imperial College  
Healthcare NHS Trust



“I can pretty much see what's happening within a couple of hours of having my bloods done...”



# Savings to be made in the care of inflammatory bowel disease

## Surrey and Sussex Healthcare NHS Trust

Inflammatory Bowel Disease (IBD) affects more than 300,000 people in the UK, causing inflammation of the gut where symptoms can flare up at any time.

### The importance of monitoring

Regular monitoring and the ability to receive prompt treatment at the time of the flare-up is vital for patients – something which the conventional diary-based outpatient model can not always accommodate.

However, Surrey and Sussex Healthcare NHS Trust (SASH) have introduced PKB to help IBD patients to self-manage their condition and remotely communicate with their clinical team, if and when needed. This allows the clinical team to monitor their care and provide timely access to treatment before symptoms progress.

PKB has been rolled out to approximately 4,000 IBD patients across Surrey and Sussex Healthcare NHS Trust (SASH). Dr Azhar Ansari, Project Lead and Consultant Gastroenterologist at SASH said: “Patients often experience distressing flare-ups of the disease which can require urgent hospitalisation. However, through using PKB, the patient can self-manage their condition far more effectively and warn us before problems occur. In many cases we can avoid A&E visits and that’s good news for the patient – and for our hospital”

### Reducing medication costs

Traditionally, IBD patients would be offered azathioprine - an immunosuppressive medication, the side effects of which can cause up to 50% of patients having to swap to an expensive monoclonal therapy.

However, since the introduction of PKB, patients are given a lower dose of azathioprine combined with allopurinol. The effective, low-cost treatment is better tolerated by the majority of patients, compared to azathioprine on its own.

Prior to treatment, a simple and readily available blood test that checks for an enzyme level encoded by the TPMT gene can show how an individual will more accurately process azathioprine. The dose can then be lowered to a level that the patient can tolerate but still, derive clinical benefit from.

PKB has allowed Dr Ansari and his team to undertake mandatory monitoring of azathioprine at scale without the need for face-to-face appointments. Patients can quickly flag up side effects via PKB, enabling early intervention for those that need it.

As Dr Ansari explains: “The cost implication is huge, as the next line of treatment for those taking azathioprine only is a monoclonal therapy, which can cost £10-15,000 a year. The combined low-dose azathioprine allopurinol treatment costs £200 a year and is delivered as a daily tablet, rather than an injection or hospital-based infusion. The economic cost to the patient is therefore greatly reduced, as they don’t need to take time off work for their treatment.”

The approach is paying dividends for patients and the hospital. With around 4,000 IBD patients, the national IBD standards published by the British Society of Gastroenterologists recommend a clinic that size would need four full-time IBD consultants and three IBD clinical nurse specialists.

Dr Ansari’s team is half that size and has been able to provide excellent care thanks to the fact that patients with the most severe form of IBD are able to benefit from the combined therapy and



Dr Azhar Ansari  
Consultant Gastroenterologist  
East Surrey Hospital

“ *In many cases we can avoid A&E visits and that’s good news for the patient – and for our hospital.* ”





Patients can be switched from  
**£10,000/yr to £200/yr**  
medication



PKB. In order to become a resilient service as more patients enrol onto PKB, further clinical nurse specialists and administration staff are required but without the increase in consultant staff. Through consultant supervision, clinical nurse specialists and administrators upskill in IBD enabling the service to develop its out-of-hospital experience.

Dr Ansari explained that as well as representing a shift in the model of care provided, this approach also needs a new strategy when it comes to funding. He said: "What we're doing at ESH strips out the 12 month follow up system, which is an obsolete way of running a service. But what this means is that rather than funding the service based on activity, Clinical Commissioning Groups need to look at a value-based or outcome-based model of funding.

"Our outpatient clinics will always be at capacity, but this is an opportunity to free up space for patients that need to be seen immediately, and provide an alternative for those with less severe symptoms not needing face-to-face appointments."

## A lifeline for a bright student

Liam is 22 years old and from East Surrey. Like many people his age, Liam was looking forward to starting a new chapter in his life, moving 70 miles away from home to study economics at the University of Portsmouth. However in April 2018 Liam's health started to deteriorate and, following a number of stays in hospital, he was eventually diagnosed with Ulcerative Colitis.

As someone who had always previously been very healthy, the news of the diagnosis came as a shock to Liam and his family and also put in to question his future at university. Liam required regular close support from his healthcare team to monitor any flare-ups.

Shortly after the diagnosis, Liam was given access to his PKB account. He used this to educate himself about his new condition and also to monitor his blood tests, manage appointments and communicate directly with his specialist team, including Dr Ansari (Consultant Gastroenterologist, at East Surrey Hospital).

He said: "I use it as a quick way to contact the people I need to get in touch with at a much quicker timescale than it would take me if I were to use the other services. By early intervention, it allows me to prevent my condition from getting worse and then having to use the other emergency services.

Liam continued: "As an example, when I had to use my GP, it took over a month before I was referred and my condition severely worsened in that time space. With PKB, I am able to contact the necessary people in order to improve the outcome of my condition much quicker. I usually get a response the same working day which is excellent. Since I have been able to effectively use PKB, I have not been re-admitted to hospital as an early intervention approach has been taken and, for me, this has had a good impact on my personal wellbeing.

"Now that I have returned to university, it is important for me to use PKB to contact the necessary people for my care when needed like Dr Ansari. For example, last week my kidney test results came back high so I contacted Dr Ansari for advice as, unfortunately, I do not have access to the same quality of support for my IBD in Portsmouth as I do in Surrey."



# Generating savings for investment in patient care

## Western Sussex Hospitals NHS Foundation Trust

It's a common picture; hospitals sending out thousands of appointment letters every day via post and out of those some go missing and needless to say, it all comes at a huge cost.

For Western Sussex Hospitals NHS Foundation Trust (WSHFT), it's a similar story. Letters to patients are sent via royal mail but before that, they have to be generated, printed, folded, stuffed and franked, and eventually posted out along with the millions of other letters that are sent out in the UK every day.

Once a letter has been printed it cannot be traced which means there is a chance it could go missing. Patients could experience a delay receiving their letter or even worse, be unaware of a test result or not attend their appointment as a result - which also incurs a cost. This time-consuming process also involves a huge amount of resource, all which could be better used in other ways.

### Creating efficiencies

As part of the vision to go paperless, WSHFT developed a pilot for a 'hybrid mail system' for all outpatient appointment letters. The aim is to create appointments using the current process but instead, when letters are printed, they will be sent to a secure NHS accredited mail provider that will print, insert, stuff, frank and deliver to Royal Mail the same day, if printed before 5pm Monday to Friday. This will free up staff time to focus on direct patient care instead of back-end admin processes.

The hybrid mail solution also provides a direct interface into the Patients Know Best (PKB) patient portal which allows patients to receive letters electronically into a secure portal if they prefer. This helps the trust move towards its paper-free target, removing the need for paper correspondence and making it easier for patients to access their letters.

### Savings that are invested in patients

The patient portal also has the capability to go a step further. With an unlimited and unrestricted licence to use the patient portal by all registered patients and employed healthcare professionals of WSHFT, up to one million patients a year will benefit from savings made from the hybrid mail system.

Up to  
**1 million**  
patients a year  
will benefit



Although the initial rollout will allow patients to view their appointment letters, eventually they will also be able to do a lot more by using the dashboard to access test results, manage appointments and communicate directly with the clinical teams involved in their care to further improve outcomes and patient experience.

An audit trail means that patients can confidently give access to loved ones or carers, and other healthcare professionals involved in their care so that everyone has a holistic view of the care plan to improve integration with care pathways. As PKB's patient portal can be accessed from any internet enabled device, patients in Western Sussex will be able to see their health information anywhere at any time, empowering them to manage their care whilst bringing healthcare services in Western Sussex into the 21st century.



Up to  
**£650,000**  
per year to be saved



# Better communication leads to better care for HIV patients

## Derriford Hospital, Plymouth

Derriford Hospital in Plymouth became one of the first NHS hospital trusts in the UK to use Patients Know Best (PKB) to manage the care of its entire cohort of HIV patients .

### Advocating patient empowerment

Sexual Health and HIV Consultant, Dr Zoe Warwick, lead the initial rollout and today, the system is actively used by well over 300 HIV patients across Plymouth and the South West of England. As an advocate for patient-controlled health records for many years, she said: “PKB goes back to some basic principles of mine which is why I saw it had such potential. Medicine can be very paternalistic - we hold all the records, we write about patients, they don't own their records and have to apply to have access to their records – I've always felt that's wrong.”

“Sometimes in the NHS we know we can't really solve the big problems in the system – so we find workarounds. PKB wasn't like that. It could potentially solve a very big problem.”

“My patients can differ extremely. There are those who are very vocal and well informed – they want more control and PKB gives them that. But there's another group who are the opposite. They're very disempowered and disconnected from mainstream society. They might not instantly engage with PKB, but they have the potential to benefit from it hugely because they desperately need to have more control over their care.”

### Taking patients on the journey

Once PKB had been given the green light by hospital administrators, Dr Warwick began introducing the system to her patients – something that quickly confounded her expectations. She said: “I thought I knew who would and wouldn't want to use PKB – but boy was I wrong!” she said. “Some of the patients who I knew didn't even have a computer at home really wanted the system. So instead of picking off people to approach to use PKB I just offered it equally as enthusiastically to

everyone – and that's been my approach ever since.”

Central to Dr Warwick's success in engaging so many patients has been her enthusiasm for the system and her belief that it can offer real, tangible benefits. Something that comes across with every introduction she does to PKB.

“If you want patients to use any new system you need to be enthusiastic. You need to explain to patients why you believe they should use it, why you think using it will be good and what you believe the potential benefits are. That way they're going to be far more likely to adopt it”, she said.

Now the system is up and running, the team are seeing real benefits – both to patient care and to their own time management. The HIV team at Derriford are making particular use of the secure messaging functionality which means that patients can contact their doctors at a time that suits them.

Despite giving patients an additional channel of communication to use to reach the HIV team, they have found that reducing the barriers to access led to fewer messages being left and crucially, improvements to patient care.

“When patients feel they can't get hold of you, they panic and that leads to more messages being sent and left. When you lower the barriers to access then people become more relaxed about making contact because they know a channel is there if they need it. That means we get to hear about problems earlier than we would do otherwise and we can catch issues before situations become potentially dangerous.”

“For example, I have a patient who noticed a rash while on holiday and contacted me thinking they were having an adverse reaction to their meds. They were on the verge of stopping their meds altogether and flying home. I asked them to immediately send me a photo of the rash over PKB and was able to tell them it was nothing to do with their HIV medication. Some simple skin cream cleared things up the next day and we avoided the whole situation from escalating.



**Granular consent**  
gives patients control over who they  
share their information with.



# Using a personal health record to monitor the safety of ketamine in treatment-resistant depression

## An Oxford clinic tackles an international research challenge with PKB

The use of ketamine for treating clinical depression has been controversial since the late 1990's. Although a controlled licenced drug commonly used as an anaesthetic, ketamine also has a reputation as a divisive party drug, used recreationally in nightclubs.

However, following a number of clinical trials (including an open-label trial at Oxford Health NHS Foundation Trust between 2010-12) which proved that it was an effective drug for treatment-resistant depression, a cohort of patients are using ketamine with largely successful results.

The Ketamine Clinic at Oxford Health NHS Foundation Trust (OHNFT) provides treatment for people who have used routine care pathways and therapies for severe depression, without any previously successful results. This includes two types of antidepressants at a therapeutic dose and a form of talking therapy.

Patients come from all over the country (and sometimes abroad) and suffer from extreme types of depression, typically with entrenched and intractable thoughts and patterns of behaviour, leading to self-harm, attempted suicide, self-neglect and also anorexia or bulimia. For those patients and their families, the Ketamine Clinic can be the last hope when all other options have been exhausted.

### Data for monitoring

Due to the complexity of the patient's condition and the nature of the drug itself, safe treatment has only been possible with close monitoring by the clinical team using Patients Know Best (PKB) - a patient-controlled health record system.

Although ketamine is administered in a low therapeutic dose, the outcome for patients can be very black and white. PKB offers clinical teams the essential information needed to ensure patient safety. Dr Rupert McShane, a practising NHS Psychiatric Consultant at OHNFT who leads the clinic, said: "PKB was available quickly and is

relatively inexpensive for a small pilot, and I thought it was necessary to try and get something up and running. Perfection is a receding goal and in fact, it's better to just bite the bullet and get started. Even if we can't square the circle sufficiently, at least we have moved forward and learned something in the process."

"But the thing that I noticed first that made me think, "Wow, that's really helpful," is that we could configure a consultation that asks the patient about their psychiatric history and the medication they had previously taken. I can review the information in about five minutes at the consultation, where normally it would take me 40 minutes or more to get all that information from the patient. So I've already saved 35 minutes because the patient has filled it in before they come into clinic using PKB."



**Dr Rupert McShane**  
Consultant Psychiatrist  
Oxford Health NHS FT

*“I can review the information in about five minutes at the consultation, where normally it would take me 40 minutes or more...”*

Patients are routinely added to the system when they are given an appointment for their first assessment. They are asked to complete a pre-consultation questionnaire and care plan before they arrive at the clinic. iPads are also available in the clinic for patients to update their information before the appointment.



79%

Patients sign-up to the online service  
(46 patients out of 58 invited)

67%

Patients regularly use the system  
(Logging in at least once in past 4 weeks)

547

Symptoms tracked by patients

268

Online consultations completed

Patients attend the clinic every couple of months for an intravenous infusion and it's vital that the drug's effectiveness is regularly monitored in between treatment. Hayley Truman, Psychiatric Nurse at OHNFT, has played an instrumental part in setting up the clinic and said: "When our patients feel they're going downhill they come in, they have a treatment and they get back on the track. Often, it doesn't work how it does in the trials where people magically get better in 24 hours - we don't see that very much. It actually takes a few attempts to see a response."

### The Ketamine Registry

Similar to the challenges around access to mental health pathways in the NHS, access to psychiatric treatment can be equally difficult. This posed a potential problem for Dr McShane who was concerned that the lack of availability for this potent treatment would result in people going to the private sector. As he explains: "The problem with that is when people move between the private and the public sector, there's a risk of the left hand not knowing what the right hand is doing and in America, that's been one of the factors that has allowed an opiate epidemic to arise."

Following years of extensive research about ketamine's usage and effectiveness, Dr McShane set out to develop a registry which covers the treatment that patients receive both in the private sector and the NHS. Available to new clinics and private providers, it will act as an information system to track and monitor all patients using ketamine across the UK.

PKB's consent model means it is both the local clinical record for the patient and the national and international research registry. Data for (and from) the patient is immediately available for the clinicians looking after the patient. And, for patients who provide consent, data is also available to the researchers managing the registry. As the data in the registry is used for daily clinical care, it is available in real-time, complete and accurate - a unique advantage of PKB compared to traditionally siloed research registries.

Depression is an introspective disorder, and the team have found that patients as well as clinicians, are interested in monitoring what's going on with their own internal state. PKB provides a structure that allows patients to keep track of their condition, whilst also taking the data with them as they move from one provider to another. Dr McShane says: "I've heard from people who come from abroad, America for example, that it's been really helpful. They move between America and the UK to get treatment, which is not wildly common, but it's certainly not unusual."

The clinic operates with two funding streams; a commercial stream which allows patients from all over the world to come and pay for treatment; and a much smaller NHS stream, which is funded by the income generated. This allows the clinic to treat people from the local area, plus those patients who have been stuck in hospital with no other treatment options available to them.

There were **2,944** admissions for recurrent depressive disorders which lead to **3,862** finished consultant episodes and **161,729** bed days in 2016.



### Future challenges

Although ketamine is a licenced drug which can be prescribed by doctors, it is still not licensed for treatment-resistant depression. However, the NHS is looking at making available 'esketamine'. Also not yet licensed, esketamine is arguably more potent than ketamine and can be administered intra-nasally as a highly potent, low volume spray.

Although this is good news for patients, clinical safety may be compromised if usage is not managed from the outset. "The issue we have is that people are going to move between taking esketamine and ketamine. That's when the problem starts because if they are taking both at the same time from different doctors, then it's important to know about", says Dr McShane.

He adds: "I don't think we're going to be able to win that argument, simply because at the moment there isn't a problem. But if we have a registry that's sitting there and is operational, including using it voluntarily, if a problem arises then there is a mechanism that it could be made mandatory. And, my hunch is that is what's going to happen."



PATIENTS KNOW BEST®  
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