

Beneficial Changes Network

Case study

Integrated Patient-Controlled Medical Record Patients Know Best

Summary

In 2020, Luton CCG began to pilot a patient-controlled medical record for children in Luton living with epilepsy: 'Patients Know Best' (PKB). This record empowers parents in their role as care coordinators for their children, and enables self-management and self-care by sharing educational materials such as care plans and verified links. It ensures the parent is equipped with all the information they need to support their child.

This is a joint project with the Luton & Dunstable Hospital and Cambridgeshire Community Services (provider of children's community health services in Luton). Work is in the pipeline to integrate with secondary care data to allow test results, appointments, and discharge letters to be shared directly with the patient or parent. The project is currently integrating with primary care data in terms of medicines (current and past), diagnoses and allergies. This will ultimately provide a single health and care record around the patient for them to share with every health care provider they encounter. The ability to upload seizure videos securely is appreciated by healthcare staff and families. As one parent put it: "Capturing a seizure video and being able to share it with those that need to see it, i.e. consultant, epilepsy nurse, carers, school etc will make it so much easier to see exactly what is happening and exactly what the seizure was like."

The pilot is running until 2023. The local experience shows that PKB is well liked and used regularly by clinicians. Many benefits are being experienced, including partnership working with parents to manage their child's condition, an increase in the safety of prescriptions and an ease of maintaining care plans. This case study summarises the feedback from stakeholders, captured during a focus group with the BCN team and includes information about key enablers, barriers and next steps.



Background

The NHS Long Term Plan includes proposals to create 'clinical networks' to improve the quality of care for children with epilepsy. It also mentions 'sharing best practice, supporting the integration of paediatric skills across services and bespoke quality improvement projects. Inequality also needs to be tackled. People with epilepsy living in poorer areas may be at a three times higher risk of death than people in wealthier areas. Many children with complex epilepsy also have a learning disability. Luton has a population of 214,000. It has a younger, more diverse population than the national average. It is a socially and economically deprived area and has been an outlier in the Public Health England map of outcomes for complex and long-term conditions (including epilepsy) for over a decade. The average list size per GP is 2,837 and Luton is a particular outlier at 3,336 patients per GP. There is also a need to improve access to services in the locality.

Epilepsy in Childhood

Epilepsy is the most common long-term neurological condition of childhood and it affects an estimated 112,000 children and young people in the UK. Not all emergency admissions to hospital for epilepsy or seizures are avoidable. However, there is evidence that education, support with epilepsy medications and emergency seizure management plans can reduce emergency admissions.

What does good look like?

- Investment in the epilepsy workforce: NICE recommends a comprehensive multidisciplinary approach to achieving the best outcomes for children and young people with epilepsies. However, Epilepsy12 found wide variation in standards of care for children and young people with epilepsy.
- Integrated services should be designed around paediatric epilepsy patients, so their physical and mental health needs are diagnosed and treated together in a holistic approach. The development of the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) will facilitate a network approach to care. The expectation is that this will accelerate adoption of best practice across all areas of the country, and harmonise existing referral pathways to establish shared care with tertiary paediatric neurology services, as well as ensure smooth transition for young people with epilepsies to a suitable adult service.
- Increased involvement of children, young people and their families with their epilepsy care is considered essential for the continuous improvement and long-term impact of the care delivered by epilepsy services in the UK. RCPCH&Us have developed advice and resources on how to utilise the UNCRC rights in clinical practice.

Source: [The Royal College of Paediatrics and Child Health](#)

Introduction of the medical record

The project aims to deliver an integrated, patient-controlled medical record for children in Luton who are living with epilepsy. With integration, it will consolidate information generated by the patient or parent/carer with information from Primary Care, Acute and Community Services. This helps to reduce the burden of care on these parents, carers and children, because communication with their health and care professionals becomes more effective, safer and more secure; all parties can see elements of the child's record that are currently digitally-unavailable to them and this creates improved access and decision-making. Many parents of children with epilepsy are the 'care coordinators' for their children: having all the necessary information they need on a digital patient-held record empowers children, parents, and their families to take charge of their own health.

This health record enables care planning with all collaborators, accessing and updating a single document. This can include pre-emptive actions that a parent/carer needs to be aware of, in preparation for a patient's condition deteriorating. It is accessible by patients, carers, and family members on any internet-enabled device and means they don't always have to carry large ring-binder files of paper information with them.

About the project

This is a 3-year project which commenced in October 2020 and was initially funded by NHS England & Improvement. It is focussed on children under 18 years old with epilepsy, who are registered with a GP in Luton and who are seen by consultants at the Luton & Dunstable Hospital (the Luton site of the NHS Bedfordshire Hospital Foundation Trust). The project team consists of Paediatric epilepsy professionals working across hospital and community, supported by three members of staff from Luton CCG (Clinical Pharmacist and Project Lead, Pharmacy Technician and Project Support Manager) plus a Technical Support Manager from Patients Know Best. A map of wider stakeholders is illustrated in the figure 1 below.

Figure 1: Stakeholders



The team built the content of the digital platform by collaborating with young adults and parents/carers of children with different types of epilepsy. Functionalities within the platform were co-designed by engaging with parents/carers, children and clinicians through many Microsoft Teams meetings during COVID in an iterative process of development. The process is, and continues to be, iterative.

Key components of the platform

- Holds a **record of patient information** including clinical summary, current medication chart, emergency care plans, contact information of professionals and services.
- **Two-way communication portal** enables carers and young adults to message and receive information.
- Users can **attach videos and documents**.
- A **seizure diary maintained by carers** can be accessed live by professionals at any time.
- A **library of medical information about epilepsy**, safety, lifestyle, prognosis, and links to other epilepsy websites which hold authentic information.
- **24-hour secure access to this platform** on any web-based digital equipment such as smart phone, desktop or mobile tablets.
- **Further plan is to integrate PKB with hospital and GP records** for appointments, tests, and discharge letters.

Initially the project team gathered some patient stories and background on the kinds of issues patients were experiencing. The team then showed parents/carers and clinicians the digital platform and how it worked and asked about what would work well for them and what they would want it to feature. It was clear that the 'All About Me' leaflet was going to be a key component and this is not something the project team would have thought about. This leaflet is usually filled in during a hospital admission and feedback from parents had been that it was stressful to complete it upon admission. With the digital platform, they can complete it at home in their own time – in preparation for any future hospital admission - and it can be printed out by a clinician at the hospital. The inclusion of medical history was suggested by parents who have experience of having to repeat their stories. The questions in it were developed by clinicians and parents. Once filled in, the history doesn't change - and can be added to - creating a full picture.

The Impact

“When my child is really poorly and I arrive to the hospital, my mind is not thinking straight, and I can't remember what happened. I don't want to come across as rude to the doctors and nurses who are looking after my child, so I just show them the app and that's it, they know what's happening...I can just focus on comforting my child.”

Parent user of PKB

There are many stories of the impact PKB has had on patients, carers and families including:

- When a child with status epilepticus was admitted into St Mary's Hospital in London, the **clinicians had access to their medication regime and medical history** on PKB. At discharge, because St Mary's is integrated with PKB, the child's discharge letter, MRI scan and test results were all available in real time for clinicians at Luton to see.
- A teenage patient wanted to be able to **write her thoughts in the online journal** without her mum having access to it and this was enabled through the privacy settings. Having this facility has helped with her mental health.
- A mum has used the **messaging service** whilst on the family's first ever holiday after Lockdown, when her child was suffering from atypical seizures. She was given advice and reassurance which empowered mum to stay on the holiday and has given her the confidence to explore a holiday next year.
- **Time efficiency** for parents/carers who can simply leave a message and know they will be called back. It was noted that parents are very busy so this feature was appreciated. Previously, the parent would have phoned the Epilepsy service, an administrative staff member would have taken the call, and then they'd send the task onto the system for one of the clinicians to pick up; the clinician would then ring the parent back but the parent might have been out, or it might not have been at a time that was convenient for parents.

In their own words - Parent Testimonial 1

The biggest impact has been on the patients and their parents as demonstrated below:

"I've found it a useful tool. My little girl's epilepsy is always quite unpredictable, she could be fine one minute or she has quite a few seizures and we go into hospital. So to have something that's on my phone that I can update all the time to show them when I speak to [health professionals]... to have everything in one place makes it so much easier to explain about [patient]. I can write how she's been in a day. I can just put in how many seizures she's had of this type or that type. I can message the [consultant] who can message me back and it saves a lot of time. I find it easy to use and I think now I've got into the swing of using long-term, I'd be lost without it.

It's quick to get on it, I use the journal quite a lot and I write every day how my little girl has been. When I go to a clinic to see a consultant, I can take my books, all the notes and I've got a pink folder with everything in it. But to have it all there, just a little sentence or a little picture of what she's done, it is so much more accessible for everybody that's involved in her life. Before PKB we had a thick pink folder and I'd have to make sure I knew where that was when she was in hospital. I'd worry about losing it and I kept a separate book of my own where I'd record how many seizures she was having on a daily basis, how her night was or if there was anything else going on. With PKB I can just put it all in there.

The project is being supported by the local Commissioning Support Unit which will provide data on the annual number of outpatient appointments, hospital admissions and A&E events and costs for each child. This is being collected monthly. Data will also be collected on time spent on phone calls vs time spent on messaging in PKB, and savings on postage due to all information now being available on the platform. Additional anonymised data is also being obtained from public health, hospital patient feedback services such as PALS and Friends & Family Tests, as well as usage trends from the PKB platform itself. Luton also took part in the Epilepsy UK Audit and this will also be used for evaluation of the project.

To date it is known that users have appreciated the accessibility of PKB on their phone, the sharing of records with professionals, the ability to keep a journal of events, the overview of medical history and the 'All About Me' leaflet – all of which are useful to aid a hospital admission if required.

Onboarding patients to the platform began in 2021, and as of February 2022, the project had 70 of a potential 160 registrations and the hope is to have all 160 registered (or as close as possible). Messaging has proved very popular with a total of 2,116 messages sent since June 2021. Data shows parents are logging in regularly and in terms of care plans the figure below provides an overview. A total of 556 care plans have been edited, 331 by patients and 225 by professionals.

Figure 2: Overview of Careplans



For the clinicians involved, PKB has meant that:

- The relationship has felt much more like **a partnership working with the parent/carer** and child at the centre of care.
- The **safety of prescriptions has improved**. Previously a prescription would be issued which might have quite lengthy regimes and weekly changing of medicines, or the parents would have to collect the prescription from the office which meant an added journey, or it would be sent by recorded delivery which is not the quickest way. Having the prescribing information available to parents/carers on the PKB platform is much more efficient.
- **Medication review is much easier** too; a parent can share the online platform with clinicians who can note down what is currently prescribed, so parents don't have to try and remember details such as exact dosage or have to refer to somewhere else. It saves a lot of time in consultations, making the journey much easier.
- **Care plans are easier to maintain** and add to. Previously a clinician might draft and send and then it could come back because they're not quite right. By putting them on PKB they can read it and if anything needs amending that can be done quickly.
- **Parents can be directed to the library** on the digital platform which is easier than getting directed to find a site on the internet themselves, clinicians searching for leaflets and books or printing something and sending by post.
- It is a local service **and videos are available which involve the parents to explain the different aspects of epilepsy care** and what it means to them. Children can also watch these and see the viewpoints of other parents.
- Having the information ready means that when it comes to **feeding into a National Audit for Epilepsy it is much easier** to, for example, be able to share the number of updated care plans.
- The seizure **video secure-upload function means clinicians can give a quick review and opinion** and do not have to worry about storage. The ability to go back to an earlier time to view a video and compare to now is really helpful in planning for the care of the children.
- For a general paediatrician who sees many children with complex illness the digital platform was described as 'inspirational'. The control the digital platform gives to **parents to be able to manage their child's condition** was applauded.
- The messaging function **allows clinicians to prioritise messages** to see which ones require communication first.
- The **availability of the seizure diary is helpful** for clinicians to be able to review in clinic. If there are several seizures per week, a month view can be taken which gives a good clue as to whether something is working or not.

“We have the privilege of trying to help on a very small number of encounters and now often remotely, we share information in an absolutely rubbish way... and this has been a huge example of how things should be. It’s very exciting.”

Consultant Paediatrician, Luton and Dunstable University Hospitals Foundation Trust.

In their own words - Parent Testimonial 2

“When you’re looking after a child who is so poorly some days you just don’t have the time to get your notebook, and sometimes you might forget what you should be writing down. With PKB I find it so useful because I can write down how many seizures my son had. If he had an emergency rescue medication, I could leave a message to the epilepsy nurse.

What I like is the tick box feature so I don’t have to think about writing full sentences for example if he’s moderately tired which we know is a trigger for his epilepsy I can tick tired or whether he’s unwell or didn’t sleep well and it saves precious time. Before we had this platform, we had to call the Epilepsy Department phone line, and sometimes must leave messages and they might not get the messages quickly. With this platform, they get the message almost instantly, somebody will email back or text with a little note to say they’ve seen it and they will get back to me.

I think it’s just incredible. It’s a really good way of communicating and giving all the information. It’s a good way for parents and professionals working together and it’s lovely, I’m really happy.”

Key Enablers

- A dedicated team to enable this to happen; the clinicians involved in the project were really keen to emphasise the role that the project lead and others (including the pharmacy technician) have had in making the project viable.
- Employment of a pharmacy technician who has worked very closely with the epilepsy team has been beneficial as she has a dual role – helping with medication queries and helping onboard parents
- The clinicians in Luton have exceptional relationships with the parents of children with complex epilepsy. Prior to COVID they held bi-monthly meetings with parents at two different sites in Luton. During COVID, they set up bi-monthly Teams meetings.

- Co-design has been key in ensuring individual user needs are met. The project team set up weekly co-design meetings via Teams with clinicians, parents and children. Here the team listened to what parents told them such as how having to repeat their stories was traumatising.

“Thanks for the parents, because they’re the ones that, in the middle of COVID and despite trying to home school children, still came to these meetings to give us their views.”

Epilepsy Nurse Specialist, Cambridgeshire Community Services

- The shared medical history was created together with a contact list for professionals looking after the care of the children and the ‘All About Me’ leaflet embedded into the platform.
- The seizure diary was co-designed with parents insisting results should be displayed in a bar chart.
- Engaging with the national body Young Epilepsy (YE) to help develop the seizure diary. YE had received funding to develop a new seizure diary and are now partnering with PKB to rebrand it and use it in their cohort of patients and have regular meetings with them.
- The partnering with Young Epilepsy also affords the opportunity to begin to think about how even further benefits can be achieved.
- Well Child have lent their support to the project by helping to raise awareness.
- Time, to engage with people and think about what works best.
- A single point of access through SystemOne has been a big enabler in the onboarding of other settings including schools and community nurses who can also access and add to PKB. Although with Trusts this has proved more challenging and there is further engagement work underway.

In their own words - Parent Testimonial 3

“When I joined PKB, on my kitchen table I had many A4 ring binders of notes and letters. I had my daughter’s seizure diaries and I put it all onto PKB. That was a whole table worth of paperwork now on my phone. Since then, we’ve had appointments where I’ve been asked for details and it’s all on PKB, I can just have a look. It’s nice to have everything in one place, to have videos which are sent to a safe email so they’re in a different place, but now they’re attached to the actual seizures on PKB. It’s great for sharing with school as well, I can share the videos and if the care plan has changed. Normally I would have to wait for that to be written, sign, wait for it to come through the post and then give school a copy. It’s made things a lot easier and more accurate, I no longer need to make sure I’ve got all my folders if we need to go into hospital, I just have to make sure I’ve got my phone which I always have with me.”

Challenges

- **Funding** is a particular challenge. Funding was originally given for a one-year project but the team quickly realised that due to the project's complexity, funding and timelines would need to be extended. Securing funding is time-intensive and time taken away from developing PKB. The project is due to end in September 2023, so avenues to further funding are currently being explored.
- Thinking and working through **Information Governance** issues takes time and should be not be underestimated.
- The team has a **dedicated person to help onboard parents** – the Pharmacy Technician - who holds that dual role of helping parents get set up and advising on the medication function. A big piece of learning is that onboarding parents involves much more than simply giving parents access to the digital platform.
- **A cultural shift takes time** and training is required for all users involved, both clinicians and parents.
- Support from clinicians at relevant **tertiary centres** has been welcomed, but **integration and interoperability between digital systems** takes time to achieve.
- The desired level of IT **integration with Bedfordshire Hospitals NHS Foundation Trust has also been a challenge due to circumstantial issues of stretched time and resources**. However, the team is exploring solutions to these challenges going forwards to enable the information flow of diagnostic test results, MRI scans and appointments onto the PKB platform. The Trust is also trying to provide clinicians with easy access to the child's record by providing a single point of access to PKB without having to go through the log-in process.

Next Steps

A paediatrician specialising in epilepsy from a neighbouring CCG was present at the interview for this case study and keen to share how they've started to implement PKB for their epilepsy service. They have watched Luton with interest and believe the success speaks for itself, as highlighted in this case study. Wearing a dual hat as Lead for the Epilepsy 12 National Audit, the paediatrician highlighted that nationally, they've been waiting for a digital solution for years. Previous attempts have not been able to sort out the interoperability and governance and were too confined to a locality. It was felt by many stakeholders that PKB is the first to have built in infrastructure to be scalable and interoperable and the potential to go beyond serving just epilepsy. There is also work being undertaken in Humberside and Essex using PKB for patients with Learning Disabilities.

“It’s great to see the altruistic benefits of everything that’s happened. The big thing here is integration and here you have a scalable solution. There are probably other integrators out there and it would be great if you can extend into other long-term conditions.”

Director of Apollo (tech company who have extracted data from Primary Care onto the PKB platform to enable integration with primary care and clinical systems)

The Director of Business Development for Young Epilepsy noted the team’s enthusiasm and approach to continuous improvement. The project provides a strong foundation and the technology could be developed even further to include data from wearable smart devices, for example. With such a versatile platform, there is great potential to expand as long as the basics are right for everyone involved along the way. The next practical step for the team will be to link with data from Trusts to be able to include discharge letters. This will be followed by onboarding of GPs who can change the medications in real time. Special Needs Nurses in schools are also starting to use it thus expanding into all aspects of the child’s care.

There has been much interest in this project with many interested parties looking to implement something similar. The Maternity Transformation Board has a drive to use digitalised personal handheld records for expectant mothers to help improve their care following on from the Ockenden Report. The respiratory team at what is now Bedfordshire, Luton and Milton Keynes CCG are interested in using PKB for Asthma Action Plans, uploading videos of children using their inhalers to assess technique and to build a resource library. The Birmingham Women’s and Children’s Trust is doing a similar project using an App to upload discharge letters. The Epilepsy project team has engaged Luton Borough Council because many of the children have educational care plans embedded into the platform and therefore there is a need to engage with the staff who work for the Council. On a national level the team has presented a poster, showcasing the project at The Organisation of Paediatric Epilepsy Networks (OPEN UK) and at the British Paediatric Association of Neurology (BPAN).

This case study has been produced by the Beneficial Changes Network with thanks to the team leading the PKB Epilepsy Pilot project at BLMK (formerly Luton CCG) and stakeholders. If you would like more information about this project please contact Usha Panchal, Project Lead, usha.panchal@nhs.net.

Please be aware that due to the short-term nature of the Beneficial Changes that have come from adapting to Covid-19, there is limited or emerging evidence in supporting these case studies. We will continually review and update these resources as further data becomes available for evaluation. Furthermore the publication of this case study is no way an endorsement of the described initiative by NHS England & Improvement.