

Transformation of delivery of Paediatric epilepsy care at a district general hospital utilising “Patients Know Best (PKB)”, a patient held medical record on an interactive web-based digital platform

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Introduction:

- Luton is a socially and economically deprived area and is an outlier in the Public Health England map of outcomes for complex and long-term condition including epilepsy for over a decade
- Patients Know Best (PKB) is an already existing digital platform developed & tested in different hospitals in NHS across the country in adult medicine.
- In an attempt to improve accessibility, enhancing patient experience and care delivery, primary and secondary care epilepsy professionals at Luton worked together on PKB to develop a platform. The project received funds from NHS England. We would like to share our results at this piloting stage

Methodology

Period : June 2020 and Aug 2021

Project team: Paediatric epilepsy professionals working across community and hospital.

Process: We built the content of application improving utility by collaborating with young adults and parents of children with complex epilepsies.

Key Components of Platform:

- Holds 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 regarding clinical management. Portal allows secure attachment of videos and other digital files.
- Seizure diary maintained by carers can be accessed live by professionals at anytime.
- 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 phones, desk-top or mobile tablets.
- Further plan is to integrate PKB with hospital and GP records, appointment letters, letters from professionals and quick access to results of investigations.

Results:

Patient/Parents benefits perceived on feedback

- All information in one place & readily available
- Able to carry information securely on digital format
- Messaging with videos to professionals
- Diary of seizures and symptoms for review
- Care plans in-hand to share
- “All about me” and medical summary
- Library of information
- Medications list – up to date
- Ready flow of information when changes made
- Duplication reduced
- Feel empowered

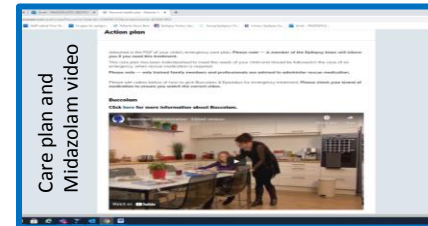
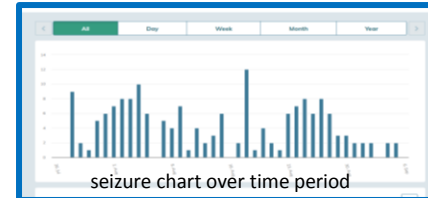
Professional Benefits

- Able to provide care with ease
- Seizure diaries helpful in clinics
- Instant communication on medication changes
- Care plans to view and upload when changed instantly
- Instant review of videos and reply
- Storage of videos in PKB record –until discharge
- Medications list with details shared between professionals (Primary and secondary care)
- Refer to library with links for educating parents (No printing hassle)
- Videos of education
- Communicate about local/ regional /national events - via news bulletin

Down side

- Professional time involved in entering data
- Parents to contribute to records
- Motivation expected from parents
- Parents/carers need to be IT educated
- Cultural shift in professionals is required
- Initial investment of time and money from NHS

Case Study Example -LR



Current medicines	
<input type="checkbox"/> >Clobazam 1ml Once a day started 09 Apr 2021 Taken at night, orally.	General Health
<input type="checkbox"/> >Epidolex 2 ml Twice a day started 09 Apr 2021 Taken orally.	General Health
<input type="checkbox"/> >Chloral hydrate 5ml Take as needed started 06 Jun 2019 Taken orally when required.	General Health
<input type="checkbox"/> >Phenobarbital 2.5ml Twice a day started 06 Jun 2019 Taken orally.	General Health
<input type="checkbox"/> >Keppro 4 ml Twice a day started 01 Jun 2016 Taken orally.	General Health
<input type="checkbox"/> >Melatonin 1 mg Take as needed started 01 Jun 2016 Taken orally when required.	General Health

Luton Dunstable University Hospital Serves	4 CCGs (Luton, South beds, Central Beds & Hertfordshire)
Total no. of Epileptic CYP	400+
Epileptic CYP in Luton CCG	200+
No of CYP entries in PKB	100+
No. parents CYP invited	50
Pilot Cases	10

Future plan and sustenance

- Integration with secondary and tertiary hospitals’ records
- Extending to entire epilepsy population in Luton CCG
- Funding application for extension to BLMK ICS
- PKB data flow seamless into Epilepsy 12 National Audit
- When successful locally – national roll out

Conclusions

- Paediatric epilepsy care needs ongoing support to parents and CYP which can be best achieved by modernisation
- Encouraging results were perceived from Pilot cases in PKB project at DGH
- PKB platform has potential to enhance quality of care and improve patient experience
- Future care in Paediatric epilepsy can be transformed