

# Improving the Paediatric Epilepsy Pathway One Seizure at a Time

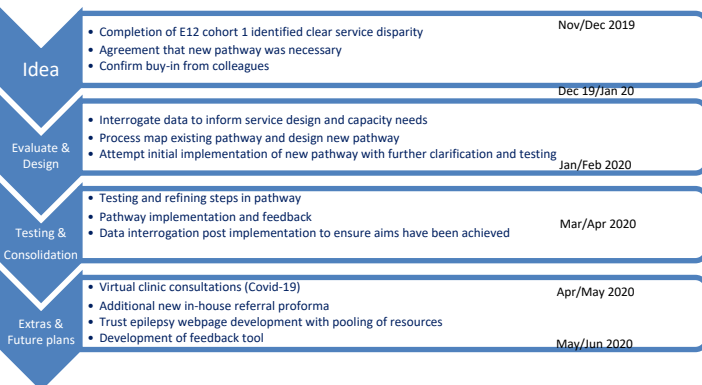


## Aim/purpose:

To develop and implement the first afebrile seizure pathway to provide a high standard, uniform service to all

## Background:

The nature of epilepsy means it can be difficult to diagnose accurately. Currently there are almost 300 paediatric patients with a diagnosis of epilepsy managed by the RUH. Of these, almost 25% are *not* managed via epilepsy clinic. The route into the epilepsy service is complex leading to disparity in the quality of care provided. Through evaluation of service demand together with implementation of a pathway for first afebrile seizures, we hope to change the service to introduce consistent, high quality care.

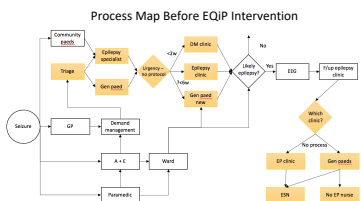


## Our new webpage

- First afebrile seizure in children - referral proforma**
- Resources to support Challenging Behaviour**
- Resources for Mental Health and Wellbeing**
- Safety and Lifestyle advice for young people living with epilepsy**

## How did you diagnose the issue

- Used RCPCH standard for epilepsy care and assessed E12 cohort 1 against these
- Informal conversation with colleagues identified need to win "buy-in"
- Evaluation of available data to guide anticipated service demand
- Review of existing pathway for patients through service (see process map on right)
- Regular small tests of change to tweak new pathway and produce new process map (below)
- Re-evaluated data to inform future service development/sustainability



## Qualitative Feedback from Families/Colleagues

There is some excellent work taking place in the epilepsy team at the moment

The website looks fab!

Thank you for phoning ahead of our clinic appointment, it really put my mind at rest

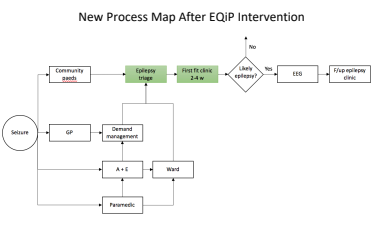
Can you keep these new video consultations after Covid - they are so much easier and we don't have to find somewhere to park!

Its great to have the same team looking after us from the start

Built in feedback to our new webpage

## Tests of change

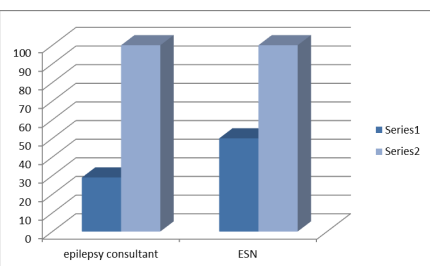
- Will the use of a "patient story" win "buy-in" for proposed changes
- Data capture complex! Estimation 8-12 clinic slots/month required for new epilepsy service
- Development of new process map
  - Proforma design to aid in-house referrals
  - Epilepsy email creation to facilitate triage by specialist
  - Improved data capture
- ESN contact with family bridging gap between referral and clinic
  - Agenda for first ESN call to family evaluated and optimized
- Peer review of referrals and SOP for First Fit Pathway developed to build in consistency
- Virtual clinics up and running



## Challenges

- Data Capture** – no process in place to capture data through coding so we had to be inventive!
- Time** – tricky to carve out time especially in winter and during Covid – virtual meetings have revolutionised this so a great learning point.
- Capacity** – both in terms of time capacity for individuals to expand role (ESN clinics for example), and room capacity – OPD space at a premium
- Geography** – hospital catchment large with system of "patch consultants" to enable patients to be seen closer to home
- Extracting data from **Epilepsy 12** – complex and time consuming unfortunately
- Complexity** of the referral routes for patients – luckily small tests of change helped us streamline a new pathway that hopefully works

## Outcome Data



- Before – E12 Cohort 1**
- 24 patients
  - 4 seen from the start by epilepsy specialist, 7 seen subsequently
  - 12 has been referred to ENS
  - 4 had delay of >4 months from referral to clinic review
  - 2 had delay of 2-4 months from referral to clinic review
  - Longest wait for clinic following GTC 4 months
- After EQIP Pathway Implementation**
- 53 patients
  - All seen by epilepsy specialist, all had ESN input
  - Majority seen within 6 weeks of referral
  - 11 seen within 2 weeks of referral
  - Longest wait for clinic following GTC 3 weeks with ESN contact within 2 weeks
- Work still to be done**
- 269 patients with diagnosis of epilepsy
  - 209 seen in epilepsy service
  - 60 seen by non-epilepsy specialist

## Team personal learning/next steps

- Future Plans**
- Review of pathway for internal referrals
  - Colleague feedback on new process and new webpage
  - Formal patient/family feedback via telephone on new webpage to inform future development
  - Integrate feedback tool into service to allow feedback and further improve
  - ESN & Virtual Clinic Development
  - Use E12 to interrogate data to ensure positive impact of EQIP is maintained long term
  - Showcase EQIP achievement to local network (when Covid allows)
- Personal Learning**
- Useful to have links with other EQIP teams to borrow ideas and resources
  - EQIP programme acted as a catalyst for change bringing the team together. The monthly calls created a deadline and prompted project to move along
  - EQIP provided and opportunity for joint working and building relationships
  - Opportunity to look at the small details of a service and critically assess and subsequently improve the process. The EQIP tools such as process mapping etc were of real benefit
  - An opportunity to recognise good practice as well as obtain peer review from other teams