RCPCH EQIP
Epilepsy quality improvement programme

Summary of changes in response to COVID-19 for paediatric epilepsy services

Over the past months participant EQIP teams have discussed the impact of COVID-19 on their paediatric epilepsy services and their response with challenges with team deployment and changes to work shift patterns. There has also been a significant drop of ED and GP referrals to paediatric epilepsy services. The use of technology has made a big impact with how teams now communicate with other members of staff and patients and their families. The social distance restrictions that will remain in place in-line with government guidance, has led to teams experiencing changes that will become permanent and introduced new ways of engaging previously hard to reach groups of patients and their families.

Listed below were the main topic areas discussed:

Staffing and team availability

Service staff described the changes experienced with teams having staff members being redeployed or working from home. This has led to reduction in staff within their paediatric epilepsy service and has led to seeking help from other peers within the Trust such as registrars and ED nurses where possible. Additionally, some teams have raised the challenges with shift patterns that make it difficult to conduct patient reviews.

Virtual clinics video/telephone

The implementation of Virtual/video clinics and telephone consultations have been one of the main changes experienced by paediatric epilepsy teams, in response to COVID-19. There have been little to no outpatient clinics where patients and their families are usually seen in person by the clinical staff.

Some teams have found the benefits of telephone consultations means that these appointments can be evenly shared between the team when contacting patients and their families. Teenage patients in particular seem to engage a lot more during telephone consultations. Some consultations via video clinics have been helpful in capturing a patients having a seizure during the consultation.

The challenges experienced using virtual/video clinics include having strong WI-FI or being unable to properly diagnose/refer a patient when not seen in person in clinic. Many of the teams agreed that virtual/video clinics will more than likely become a permanent change to services especially as social distance restrictions remain in place for the time being based on governance guidance.

The teams shared the names of virtual programmes such as 'Attend Anyway' and 'accuRx' that can be safely and securely used for consultations. Some teams agreed to share some of the processes used internally to structure video and telephone consultations. Some teams have already considered planning to evaluate and capture feedback from patients and their families regarding the use of both virtual and telephone clinics using surveys sent to them

after the appointment. Hopefully, with consent, the teams will be able to share the outcomes of this feedback using anonymous results.

Staff meeting technology

MS Teams has made an impact to the way members of staff communicate with those who may have redeployed within their team to other area clinical areas and those who are working from work. The benefits of using programmes such as MS Teams means that some staff members/colleagues have become more accessible and those at home do not feel isolated from their peers are at work.

Alternative communication methods

Teams discussed the increased usage of texting patients and their families via their NHS email address. The teams who have been using this method which has helped them to reduce the time spent sending important appointment reminder communications that need to be sent out to patients and families.

Processing of EEG referrals

One of the items of topics discussed were the challenges for paediatric epilepsy teams being unable to obtain a national steer on when investigations such as EEGs and MRI's will begin processing non-urgent referrals. Teams were keen to share their experience regarding only urgent referrals are being processed by these services.

Direct experiences shared from services:

"*We have been using 'Attend Anywhere' to undertake virtual calls for a few weeks, after a few teething issues it appears to be working well. There is also a function that we are able to get a text alert to advise that a caller is in the virtual waiting room. Whilst this cannot entirely replace face to face appointments I think this is going to change our practice for the better in the future. We have been able to offer face to face appointments for some of the new referrals once we have screened them which allows for a physical examination and by carefully scheduling the appointments we are ensuring that they don't come into contact with other service users. For patients who prefer to have a telephone conversation we have continued with joint clinics using speaker phone which is working well*".

Carolyn McAskill
Paediatric Epilepsy Specialist Nurse
East Suffolk and North Essex Foundation Trust (ESNEFT)

"*The current pandemic has affected our work as an epilepsy service in a number of ways, although within that has also demonstrated opportunities and ideas of how we can grow as a service. The direct effect of the current descaling of services from late March onwards has led to the following*

- *Cancellation of face to face OP clinic appointments*

- *Inability for members of the team to have regular communications (particularly face to face) as previous*
- *Restriction in supplementary investigations apart from in exceptional circumstances eg EEG, blood tests and MRI brain, reduction in genetic lab testing*
- *Restrictions to audits and QI projects already in place (including EQIP)*

It has forced us to make conscious changes to how we operate – the use of technology not previously relied on has become more prominent – the use of video consultation platforms has been a primary change.

This has been used for various purposes – patient contact, team meetings, neurology outreach clinics. Whilst not without technical difficulties at times we have found that it has been a positive experience in being able to reach out to patients and families. In being able to see patients and speak to them we are able to have better interactions than none or even telephone consultations, and even from an examination perspective there was some value in using the video interface. From a service provision perspective it opens up opportunities for expanding our service with the possibilities of ad hoc consults and evening clinics (eg teenagers with epilepsy) which we are now considering.

We have had to take a pragmatic approach given current restrictions when having to assess new patients and without access to investigations and/or direct patient contact, and in some cases make diagnostic and treatment decisions. We have endeavoured to highlight these in our consultations of patients and their families while discussing management plans and this generally has gone well. This could also have a lasting effect in terms of how we manage patients with epilepsy, immediate feedback is that the patient experience is maintained or enhanced with video consults although we will look to better capture this with more qualitative feedback to see how well we are doing and where things could be improved'.

Dr Ahmed Aldouri
Consultant Paediatrician
Royal Berkshire Hospital NHS Trust Foundation

Myself and the band 6 epilepsy nurse haven't been deployed to other areas which has enabled us to continue running the epilepsy service. Had we not continued to organise the epilepsy service there would have been a significant backlog of patients waiting to be seen/potentially attending children's ED.

We have mostly done telephone consultations instead of face to face for the follow up patients, the new patients/English second language and safeguarding we have tried to see face to face but some patients didn't initially want to come to the hospital. We have started to use NHS Attend Anywhere for a few of our families.

One difficulty has been obtaining the children's weight on calibrated scales.

Two main concerns were not being able to obtain GA MRI scans or non-very urgent EEGs. Swift action was taken which meant these concerns never became a reality. We have a one stop epilepsy morning once a week where all three epilepsy paediatricians see their clinic list of patients and the lead EEG technician is in the children's outpatient department so that if any urgent EEGs need doing she can complete these on the day. The EEG technician is very experienced so can often tell us if there is any obvious seizure activity on the EEG. If we are able we can then see the families again and prescribe medication.

Our paediatric management team (and the whole Trust actually) are outstanding, working round the clock to ensure safety and wellbeing for patients, families and staff.

Rachael Wheway
Children's Epilepsy Nurse
Derbyshire Children's Hospital