

## Development of signposted information pack

### **Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust**

#### **RCPCH Epilepsy Quality Improvement Programme project team:**

Dr Vivek Desai, Consultant paediatrician special interest in epilepsy, Doncaster  
Dr Suhail Habib, Consultant paediatrician special interest in epilepsy, Doncaster  
Dr Bhupendra Singh, Consultant paediatrician special interest in epilepsy, Bassetlaw  
John Monaghan, Epilepsy specialist nurse, Doncaster  
Carys Amies, Epilepsy specialist nurse, Bassetlaw  
Jeanette Goodwin, Secretary Admin/Support for epilepsy  
Natasha Lloyd, Dietician, Doncaster  
Gemma Wilson, Physiotherapy, Doncaster  
Emma Cribb, Dietician Bassetlaw  
Kerry Jackson, Occupational Therapy, Doncaster

National Audit results included within this case study acts as a guide only to performance standards. The service improvements made during the EQIP cannot be entirely attributed to the reported results.

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## **Project aim**

To develop a signposted information pack about the children's epilepsy service, by involving the patients and parents in the whole process. 50% of patients will be signposted to the pack which would be available both electronically and in printed copies by May 2020.

## **Background:**

The onset of a seizure in children generates extreme anxiety in the whole family, which is augmented by the complex diagnostic path of epilepsy. Although seizures may be non-epileptic, the general population can have different beliefs about convulsions, and the enormous pool of information on the internet can increase their worries. A signposted information pack would address these concerns and create opportunities for staff to increase communication and working relationships with patients and their families. As a team working in geographically distant areas, there are limited opportunities to meet, but the team shares a desire to improve services across the board.

## **Area of focus**

Develop a signposted information pack in hard and digital copy about the children's epilepsy service by involving the patients and parents in the whole process..

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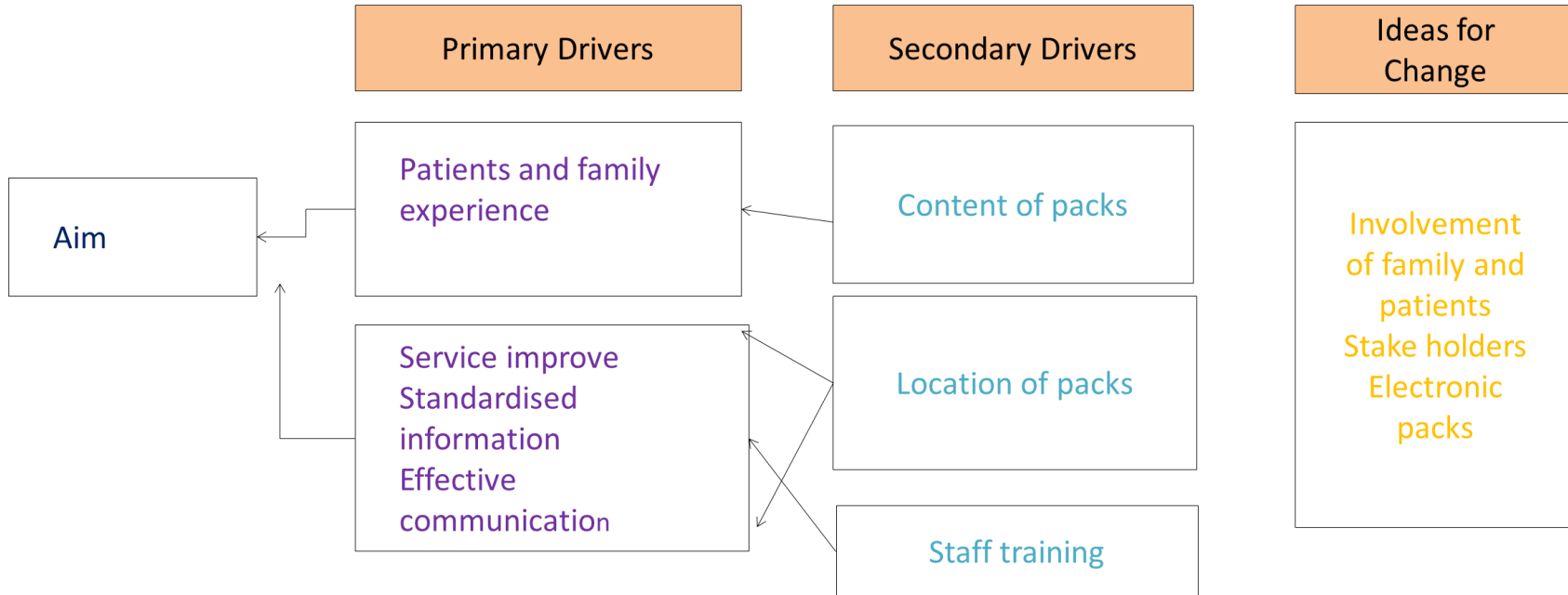
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## Changes

- Developed draft leaflets for internal information packs.
- Engaged with stakeholders and presented on the project at the Trust paediatric clinical governance meeting. Discussions included involving them in the decisions on the most suitable location to display the information packs that are accessible to patients and their families.
- Introduction of telephone clinic consultations and virtual clinics.
- Implementing the use of digital platforms meant that service teams could use systems such as 'Doctor-Doctor' software for the virtual consultations and MS Teams for team meetings because of the pandemic.

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## Project Driver diagram



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## Results

- December 2019: Each member of staff asked their patients and families two questions. Based on the first test, the patients were asked the following questions:
  - Have you received any written information about the service? Yes/No
  - What information would have helped you? Please list below.
- Completion and analysis of one patient and two questions were successful.
- During the project, the feedback results fell within eight different types/groups of information or advice, which would be included in the proposed information pack.
- In February 2020, the exciting and long-awaited pasta voting engagement method took place, and it was agreed to extend the collection of responses for staff working on acute admissions who directly provide care for patients with a suspected or confirmed diagnosis of epilepsy on a regular basis.
- Tests were conducted in three different clinics. An instructional leaflet was provided to the patients and families at the start of the consultation that showed them how to use the voting system with up to four pasta pieces on the chart in 4/8 sections.
- For the staff engagement, the chart was left in the staff coffee room using four different colour star stickers provided.
- March 2020: begun drafting an info pack based on evaluation results from both staff and patients and their families.

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## Results

- The results of both the patient and staff polls revealed they wanted to know the following:
  - 'What is epilepsy' in the majority and similarly 'safety measures', advice was asked by both groups.
  - 'Contact details of the team' didn't matter for patients.
  - There was a lack of interest in 'location of clinic' and 'website details'.
- Other questions included 'how can we get counselling support', 'how long will be the treatment', 'will the child be cured completely', and 'what are the prospects of other siblings getting epilepsy'.
- The results revealed what the team felt mattered to patients as a healthcare professional did not align with the feedback results of patients and families. Patients were more interested in their day-to-day management of their medical condition.
- Engagement feedback with patients and families using the pasta poll techniques fell within the following four topics:
  - What is Epilepsy?
  - First aid training
  - Details of support groups
  - How to inform schools

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The team created information leaflets on **'what to do if your child has a seizure'** and details on areas of support for patients and families when a child is first diagnosed with epilepsy which covers info on the following:

- Worries and anxieties,
- Disability Living Allowance (DLA),
- VAT relief,
- NHS low-income scheme (LIS),
- Free prescriptions,
- Support organisations,
- Blue badge,
- Contact details of the healthcare team.



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### Details of support for children and families



**CHILDREN'S EPILEPSY SERVICES**

- 1- Dr Vivek Desai Epilepsy Doncaster Secretary contact No
- 2- Dr Suhail Habib Doncaster Secretary contact No
- 3- Dr Dhupen Singh, Bassetlaw Secretary contact No
- 4- John Monaghan, Epilepsy nurse for Doncaster, Contact no
- 5- Carys Amies, Epilepsy nurse for Bassetlaw, contact no

When a child is first diagnosed with epilepsy, family members experience a range of feelings.

These emotions may include:

- Anger, "shock" or denial: Why my child? Why our family? This can't be true.
- Confusion: What is epilepsy? What is causing my child's epilepsy? Will my child have more seizures? What are medication side effects?
- Sadness: I want to be able to fix this or make it go away, and I can't.
- Guilt: What did we do wrong? Is there something I did to cause this? • Fear and worry: What does this mean for my child's life and future? Will my child outgrow the epilepsy? What will others think about my child? Will epilepsy affect my child's ability to learn? How will it affect our family?
- Anxiety and frustration: Parents may feel anxious and frustrated

All these concerns and emotions are very normal. Talking about them, learning to manage them and getting your questions answered all form an important part of adapting and learning to cope with a diagnosis of epilepsy. Your child's treatment team can give you support, as can "local" epilepsy organizations and support groups.

By learning more about your child's condition, you can also help your child understand and cope. Your child may have many questions, or they may not want to think or talk about the diagnosis. They may be anxious, confused or angry.

[Useful contact numbers and websites](#)

- Doncaster Children's Epilepsy Nurse John Monahan contact No.
- Bassetlaw Children's Epilepsy Nurse Carys Amies Contact No
- Epilepsy Society - [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)
- Epilepsy Action - [www.epilepsy.org.uk](http://www.epilepsy.org.uk)
- Young Epilepsy Helpline  
Call: 01342 831342 (Monday – Friday, 9am–1pm)  
Email: [helpline@youngepilepsy.org.uk](mailto:helpline@youngepilepsy.org.uk)  
Text: 07860 023789

Contact your Epilepsy specialist nurse for local support groups in your area

**Benefits and support**

Epilepsy in children and young people are of many different types. A good proportion of children and young people with epilepsy will be able to enjoy normal day to day activities without any significant restrictions. However, some children and young people with Epilepsy, either due to a very difficult to treat type of epilepsy (drug resistant epilepsy) or due to additional

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Page two and three of **'what to do if your child has a seizure leaflet.'**

medical conditions (co-morbidities), will have significant additional needs in day to day life.

Having a child with a disability can put pressure on you financially. There are benefit schemes and support networks are in place to help ease that pressure and ensure your child has all of the things that they need.

#### Disability Living Allowance (DLA)

DLA for children can help with the extra costs of looking after a child who has difficulties with mobility or who requires more looking after than a child of the same age who does not have a disability.

There are two components to DLA – a care component and a mobility component and the amount that you get for each will depend on your child's physical ability and their day-to-day needs. It may be that your child needs an assessment to check their eligibility, in the event of this you will receive a letter explaining where you must go and what paperwork that you are required to bring with you (e.g. birth certificates or passports as proof of identity). It is worth noting that your child will need to have an epilepsy diagnosis for at least 3 months before you

can apply for DLA. You can apply by completing a form online at the GOV.UK website or by calling 0345 712 3456 and ordering a printed form in the post.

#### VAT Relief

If your child is disabled or has a long-term illness then you will not need to pay VAT on a range of goods, including seizure alarm systems and equipment that has been designed solely for disabled people. You can learn more about VAT exemption for disabled people by going to the GOV.UK website or by calling HM Revenue and Customs on 0300 123 1073.

#### NHS Low Income Scheme (LIS)

If you are on a low income or benefits, you may be able to claim back any travel expenses you incur whilst attending hospital appointments. For more information you can call the

Low Income Scheme helpline on 0300 330 1343.

#### Free Prescriptions

If you live in the UK all children are eligible for free prescriptions, including antiepileptic medication.

#### Information, Advice & Support Services Network (IAS)

Formerly known as the National Parent Partnership Network (NPPN) IAS provides information, advice and support to disabled children and their parents. IAS is funded by the Department for

Education and there should be an IAS service within each local authority. You can find out more about IAS and the closest service to you by visiting their website:

[www.iasnetwork.org.uk](http://www.iasnetwork.org.uk)

#### Blue Badge


The Blue Badge scheme is designed to help people with mobility issues to park closer to the places that they need to go. Your child may qualify for a Blue Badge if they receive the higher rate of the mobility component of the Disability Living Allowance.

If your child has severe epilepsy and is under the age of 3 then they may also be eligible.


For more information about the scheme and to find out if your child qualifies for a Blue Badge, go to the website GOV.UK and search for 'Blue Badge'.




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**Schools Information Leaflet for Epilepsy**



**CHILDREN'S EPILEPSY TEAM**

- 1- Dr Vivek Desai Epilepsy Doncaster Secretary contact No
- 2- Dr Suhail Habib Doncaster Secretary contact No
- 3- Dr Bhupen Singh, Bassetlaw Secretary contact No
- 4- John Monaghan, Epilepsy nurse for Doncaster, Contact no
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**Schools information Leaflet for Epilepsy**

This guide is for people who work in schools or other educational settings. It provides information on supporting children with epilepsy to ensure they are safe and included in all aspects of school life.

Epilepsy is a very individual condition, so how it affects a child's education can vary.

Good communication between the school, parents and the child or young person plays a key role in ensuring the right support is in place. All staff working with a pupil with epilepsy should also be trained to understand their condition and its impact on their life at school.

When a child and their family receive a diagnosis of epilepsy, it is normal for them and their family to worry about how this will impact on their school life. Parents will need to be confident that their child is well supported and treated equally to their peers. Schools will also need regular updates from parents and professionals on changes in the child's condition which might affect them at school.

For some children, having epilepsy will not affect their ability to learn or achieve academically, but others may need extra time or support in class. For example, a child who has absence seizures may miss key points during lessons. Having a chance to catch up on what they have missed in class can be helpful if seizures happen frequently. Sometimes a child may need time to recover after a seizure and may need to sleep. Seizures at night can disrupt sleep patterns and affect memory for some time afterwards.

**Medication at school**

Some children with epilepsy take medication to prevent seizures or have 'rescue meds' should they have a seizure. If a child needs to take medication at school, they will have their own individual healthcare plan (IHP) which means that their medication can be managed and given effectively. This plan needs to be arranged by the school and agreed with the school's governing body and the child's family. Sample healthcare plans, and forms relating to giving medication at school, can be downloaded as part of the Department for Education (DfE) guidance on 'Supporting pupils with medical conditions at school'. School may need to access further training to administer some medication but further advice regarding should be sought from Epilepsy Specialist Nurses.

The individual healthcare plan (IHP)

The information about your child's medical condition and specific needs can be recorded in an IHP. Not all children with epilepsy will need an IHP. This would depend on the type of Epilepsy your child has and the support they require to deal with their condition in school.

The Children's Epilepsy nurses will formulate a care plan with parents/child/young person. Parents will have the copy of the care plan.

- Their type of epilepsy
- Their type of seizures
- Seizure description
- How long their seizures last
- Appropriate first aid
- What the school should do after your child has had a seizure
- How long child needs to rest following a seizure
- When the school should call an ambulance
- What the school should do in an emergency

Triggers for your child's seizures (if any)

- Any warnings your child has that they may be about to have a seizure (for example a headache or an aura)
- Any medicine they take, and when they need to take it
- Any medicine side-effects that the school needs to be aware of
- Any particular activities that you think may put your child at risk, and what can be done to reduce the risk
- Any other provisions the school needs to make, for example extra time in exams
- Any other medical conditions that your child has
- Who the healthcare professionals involved in your child's care are
- Any behaviour or emotional

An IHP should be easy to find for anyone who needs the information, but it should also make sure your child's details stay confidential.

The team also prepared a leaflet for schools. The guide is for people who work in schools or other educational settings. It provides information on supporting children with epilepsy to ensure they are safe and included in all aspects of school life.

The leaflet covers info on:

- Medication in school
- Individual Healthcare Plan (IHCP)
- Exam times in school
- How to make other pupils aware of epilepsy

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IHPs should be reviewed every year, or earlier if your child's epilepsy or needs change. They should be developed with your child's best interests in mind and ensure that the school assesses and manages risks to your child's education, health and social wellbeing.

#### Exam times at school

Whether a child's epilepsy affects their ability to do exams or tests depends on their individual epilepsy. If they are likely to have seizures in stressful situations, or at certain times of the day, this may affect how they perform in exams or tests. Tiredness and memory or concentration problems may also affect exams. Discussing concerns with the child and their parents may help to decide whether special arrangements are needed for exams.

#### How to make other pupils aware of Epilepsy

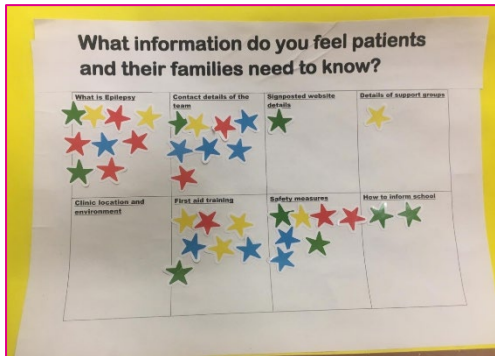
Generally, people feel more confident about epilepsy when they understand it and know what to do if someone has a seizure. Learning about epilepsy in the classroom can be a good way to introduce information about the condition, without any children with epilepsy feeling that they are singled out. This would need to be on an individual basis and appropriate for the age group of the children.

#### Local and National contacts & References

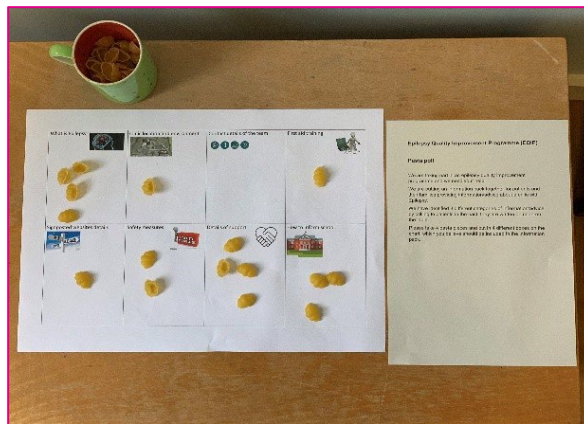
- Young Epilepsy – [www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)
- Epilepsy Society - [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)
- Epilepsy Action - [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Page two of leaflet for schools.

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Staff star voting results	
What is Epilepsy 9	Clinic location and environment 0
Contact details of the team 9	First aid training 7
Signposted website details 1	Safety measures 7
Details of support groups 1	How to inform school 2



Patients voting results	
What is Epilepsy 10	Clinic location and environment 4
Contact details of the team 0	First aid training 8
Signposted website details 3	Safety measures 6
Details of support groups 8	How to inform school 9

**A variety of interesting responses from patients included:**

- Don't know what epilepsy is
- Would like first aid training
- What will happen at the clinic and what questions will be asked
- Who will be seeing us in the clinic
- Is there any counselling service
- Who should we contact if the child's seizures are getting worse

# Audit results for cohort 3 - Comprehensive care planning content - Doncaster and Bassetlaw

**91% of children and young people diagnosed with epilepsy in Doncaster and Bassetlaw Teaching Hospitals Foundation Trust had documented evidence of communication regarding relevant core elements of care planning.**

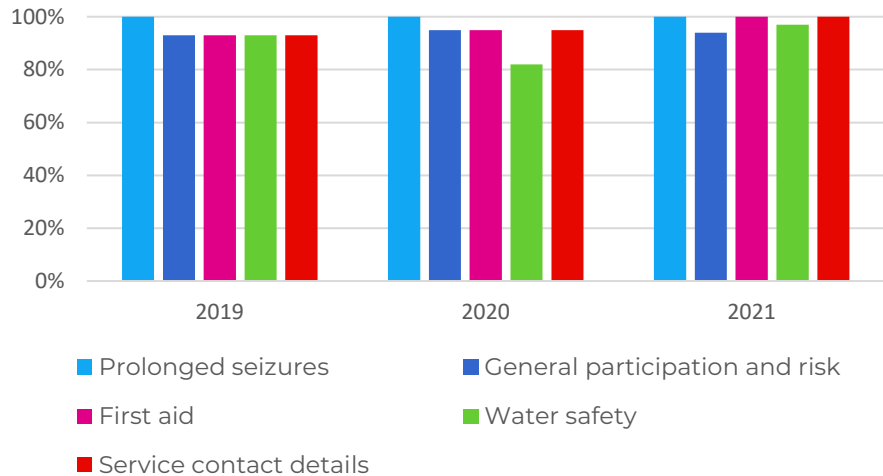
Performance Indicators	2019	2020	2021	2021 - TEN	2021- England & Wales
10. Comprehensive Care Planning agreement	60%	82%	76%	<b>79%</b>	<b>70%</b>
11. . Comprehensive Care Planning content	93%	82%	91%	<b>88%</b>	<b>75%</b>

Performance indicator 10: Comprehensive Care Planning agreement	2019	2020	2021	2021 - TEN	2021 – England & Wales
% of children and young people with epilepsy after 12 months where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers and primary and secondary care providers, and the care plan has been updated where necessary	60%	82%	76%	<b>79%</b>	<b>70%</b>
% of children and young people with epilepsy after 12 months that had an individualised epilepsy document with individualised epilepsy document or a copy clinic letter that includes care planning information	93%	100%	97%	<b>96%</b>	<b>91%</b>
% of children and young people with epilepsy after 12 months where there was evidence of agreement between the person, their family and/or carers as appropriate	80%	100%	94%	<b>88%</b>	<b>79%</b>
% of children and young people with epilepsy after 12 months where there is evidence that the care plan has been updated where necessary	60%	82%	76%	<b>82%</b>	<b>75%</b>

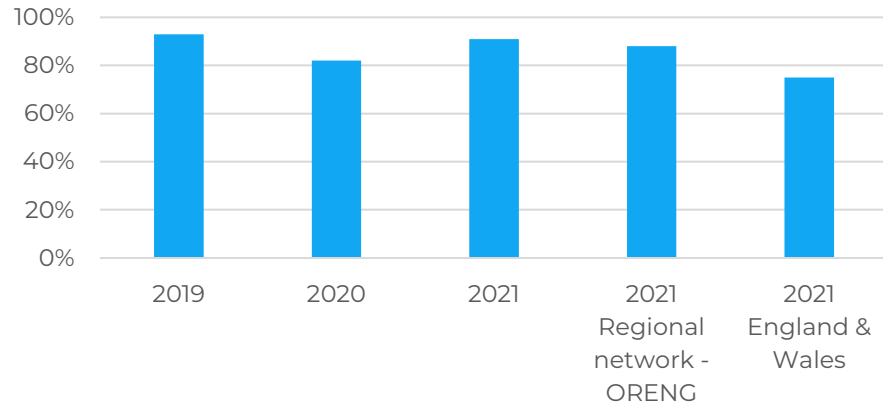
# Audit results for cohort 3 - Comprehensive care planning content - Doncaster and Bassetlaw

The percentage of CYP with documented evidence of communication regarding core elements of care planning has increased in 2021 and more specifically achieving 100% in Prolonged seizures, first aid, service contact. Additionally, the percentage of CYP with documented evidence of communication regarding core elements (91%) increased above national (75%) and regional (88%) averages in 2021.

Percentage of CYP with documented evidence of communication regarding core elements of care planning



Percentage of CYP with documented evidence of communication regarding core elements of care planning



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## Challenges

- Prior to the EQIP, there was no information pack available locally; the team normally relied on national information sources from Epilepsy Action and Epilepsy.org.uk for general information, including safety advice for parents and patients. The contact details of the team and signposting of the team would be communicated verbally or within the patient's EHCP. Therefore, it was crucial that the teams' contact details were included on each leaflet.
- There has been a considerable change in service provision with the progression of the pandemic.
- Collectively, the team noticed that there was lots of duplicate information in the leaflets.
- It became a challenge to decide whether to reduce the number of leaflets to two instead of four. Eventually, it was agreed that, per the results of the engagements, it is better to design four small leaflets because they would address the different concerns and provide information that can be used separately, if not together.

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## Outcomes

- Achieved their project aim to develop an information pack containing four leaflets covering the following information:
  - 'What is Epilepsy', 'Support available', 'How to inform School' and 'First Aid Training'.
- Increased engagement amongst fellow paediatric and emergency department colleagues who welcomed the newly created information leaflets.
- The team's confidence increased when engaging with children and young people and parent/carers.

## National audit results revealed

- 91% of children and young people diagnosed with epilepsy in Doncaster and Bassetlaw Teaching Hospitals Foundation Trust had documented evidence of communication regarding relevant core elements of care planning.
- The percentage of CYP with documented evidence of communication regarding core elements of care planning has increased in 2021 and more specifically achieving 100% in prolonged seizures, first aid and service contact. Additionally, the percentage of CYP with documented evidence of communication regarding core elements (91%) increased above national (75%) and regional (88%) averages in 2021.

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## Lessons learnt

- Engaging with patients and families helped to eliminate the teams' assumptions on what they thought were the concerns of their patients and discovered they wanted information on the diverse aspects of epilepsy care, including a greater understanding of 'what is epilepsy' or 'long-term effects of epilepsy on lifestyle and health'.
- Quality improvement is a continuous process that uncovers more areas for improvement along the way.
- Pasta voting was an interactive, entertaining, and informative method, offering the opportunity for participants to express their views and increase engagement in a more effective way.
- Although there are lots of opportunities for improvement, the team had to focus on achievable tasks.
- The team learned how to organise and reduce the number of diverse questions that can be addressed in a systematic process.
- Asking simple and easy questions provides speedier feedback to act on, providing confidence about the service provision.
- An essential part of the quality improvement experience was to improve the perception and experience of their patients and families.
- Although it has been a difficult and challenging time during the pandemic, the team felt they had provided the same level of care and learned new skills in the process, which will have an everlasting effect on the way the team practices and cares for their patients.



<https://eqip.rcpch.ac.uk>

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[eqip@rcpch.ac.uk](mailto:eqip@rcpch.ac.uk)

 [@RCPCHEQIP](https://twitter.com/RCPCHEQIP)