



North East and North Cumbria Child Health and Wellbeing Network

Report Appendices

Epilepsy Project 2:

Exploring Mental Health and Psychology
Support Approaches, Availability and Gaps
for CYP with Epilepsy

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Appendix 1 – Methodology

The project was undertaken between December 21 and May 22. Stages of the work plan were as follows

1. Establish interdisciplinary links to facilitate the mapping exercise.

The epilepsy workstream for NENC Child Health and Wellbeing Network had two distinct strands of work. Project Initiation Document (PID) and Logic Models were approved at Operational Oversight Group on 13th December 2021

Project 2 (this project) aims to improve mental health care and support for children and young people (CYP) with epilepsy by:

Ascertainment of the availability, access and pathways of referral to mental health services and support for CYP with epilepsy

Analysis of gaps in provision

Seeking consensus to develop recommendations for service improvement.

A Leadership Group for Project 2 was identified and set up with key roles (clinical leadership, psychology involvement and project management) and responsibilities by the end of December 2021. Key Delivery Tool finalised by end January 2022

Additional capacity to support with mapping, engagement and data analysis was engaged.

Phil Archman, Senior General Manager Planning and Information was appointed to support the programme with analytics for 0.2 wte for a 10-week period between January and March 2022, this role did not start to receive data for analysis until mid-February and as such has rolled over in to May 22.

Dr Chloe Geagan, Clinical Psychologist was appointed ½ PA for a 14-week period between December 21 and March 22, which has continued into April 22. This added skills, knowledge and capacity to lead the programme of Mental health service mapping and engagement as well as CYP and family stakeholder engagement.

Distribution lists were collated for education settings, primary care, paediatric epilepsy secondary care clinical leads and epilepsy specialist nurses and mental health leads by bringing together existing network lists together with additional and newly discovered contacts. In addition, the Epilepsy 2 Project Leadership Group developed a range of informative letters to support with the distribution and promotion of these surveys

2. Engagement with education services to establish how long-term conditions such as epilepsy are recorded, how mental health problems are recognised & addressed, identify training need

The education settings questionnaire was developed as an MS Form, led by Dr Anita Devlin with the support and input from Mrs Kate Swaddle, Education Advisor to the CHWN. This questionnaire was developed to capture detailed and broad ranging intelligence from across settings including primary and secondary school settings mainstream and special. Survey key lines of enquiry broadly follow the other surveys in the suite of documentation but include a few key aspects in addition:

- IMD score
- Numbers of CYP on roll with epilepsy
- Information management
- Existence of Individual Health Care Plans and Emergency Health Care Plans
- Involvement of ESN
- Training and availability of resources
- Epilepsy and SEND and additional needs in relation to the 4 areas of SEN
- MH interventions by education setting

We also distributed these questionnaires via colleagues and professionals who were identified as members of the Child Health and Wellbeing Network and who had indicated that they were Heads, Deputies, members of the Senior Leadership Teams, SEND/Inclusion or Pastoral Leads. In addition a list of 14 additional was created to ensure that we had appropriate coverage and representation in terms of geography and intake cohort (mainstream and special) 123 education settings received direct correspondence with a request to complete the survey and to cascade to colleagues who may be able to participate

This questionnaire was distributed on 25th January 2022, and was due to close on 13th February, this was followed up on 10th February. There were 28 responses from the 123 colleagues asked to complete it which is a return rate of c23%. The questionnaire took colleagues on average 34 minutes to complete.

3. Conduct mapping exercise with paediatrician epilepsy clinical leads and epilepsy specialist nurses at secondary level and with primary care to understand: the availability of mental health assessment and support services within the clinic/practice & pathways of referral to CYP mental health services

Detailed questionnaires/online surveys were developed for a range of different audiences and with relevant questions covering a similar range of themes, to enable and facilitate triangulation and detailed analysis of data. The lines of enquiry were as follows:

- Resource/Staffing
- Clinics
- Case load/service activity
- Adolescents/transition
- Mental Health- prevalence
- Screening
- Confidence/competence
- Referral pathways
- Training
- Mediation/prescribing
- Support groups
- Cognition and Learning
- Support to Parents and Carers
- Gaps and moving forwards

Questionnaires were distributed across the system, on a staggered basis with an expected response turnaround of approximately 2 weeks for each participant group. Participants received a prompt to complete the surveys mid-way through the response window to remind them of the importance of the work. In some cases, where timescales allowed, extensions were granted to enable as broader up take as possible across the system.

The **ESN questionnaire** was distributed on 1st February 2022, and was due to close on 13th February, this was followed up on 8th February, the survey closed initially on 14th February but was reopened with an extended closure date of the 18th February. There were 11 responses for a possible 13 which is a return rate of 85%. The questionnaire took an average of 24 minutes to complete. The **clinical leads questionnaire** was distributed on 17th February 2022, and was due to close on 4th March 2022, this was followed up on 28th February. There were 9 responses from the possible 14 which is a return rate of 64%. The questionnaire took an average of 39 minutes to complete. The **primary care questionnaire** was distributed on 14th February 2022, and was due to close on 27th February, this was followed up on 21st February and the closure date was extended on the 21st February to close on 6th March. There were 27 responses for a possible (approx.) 570 which is a return rate of c5%. The questionnaire took an average of 34 minutes to complete.

4. Engagement with CYP mental health services to establish patient data collected, case prioritisation, waiting times, education needs

The CYP mental health leads/services questionnaire was developed as an MS Form by Dr Chloe Geagan with the oversight of Dr Anita Devlin, the question framework and lines of enquiry aligned with the other surveys to enable detailed information to be gathered and for information to be triangulated.

In preparation for this phase of work Dr Chloe Geagan and another colleague (MSc Student Georgia Crowther) undertook a mapping exercise to scope mental health services across the NENC ICS footprint. This enabled 45 contacts to be identified. In addition, Louise Dauncey was able to identify a further 39 contacts through other forums and previous professional relationships

The survey was sent to these 84 individuals on 25th February 22 for return by 13th March 22 this was followed up on 3rd March 22. The survey was re-opened following the closure to enable a mental health colleague to respond. There were 12 responses from the 84 colleagues asked to complete it which is a return rate of c14%. The questionnaire took colleagues on average 25 minutes to complete.

5. Engagement with CYP with epilepsy and separately with parents/carers to establish: perception of mental health need & unmet needs in CYP

The epilepsy leadership group, led by Dr Chloe Geagan undertook development work in relation to a set of open-ended questions and tools for engagement to gather relevant information to be read in conjunction with the other sources of intelligence These resources and questionnaire/interview templates were developed with the input of Young Epilepsy (National charity) young reps,

As part of the development of the engagement plan and resources, advice and examples were sought from Young Person's Advisory Group North England (YPAGne) and further developed in line with research methodology to facilitate engagement and participation in stakeholder engagement.

CYP and families, who met a pre-defined criteria for selection were identified with the support of the ESNs within each of the Trust services and individual CYPs were given specially adapted information about the programme and invited to participate as part of a focus group or a one:one interview, whichever approach they felt most comfortable with. A selection of parents of CYP with epilepsy were also invited to participate in a focus group

A total of twelve families were identified across the NENC ICS region. Four parents opted to take part in the focus group. Out of the four families identified, only one young person

consented to taking part and this was in the form of a one-to-one semi structured interview. These stakeholder engagement sessions took place during March 2022

6. Collate findings, identify the gaps in provision & suggest recommendations for service improvement

Questionnaire data and other intelligence were analysed using descriptive statistics and content analytical techniques. Professionals worked collaboratively to interpret and understand the findings and to articulate a range of recommendations for improvement which have been aligned to the four national Children and Young Person Transformation Programme areas of focus:

- Mental health screening and access to psychosocial support
- Access to tertiary services including surgery
- Transition from paediatric to adult epilepsy services
- Variations in epilepsy care

7. Stakeholder consultation and feedback

Following the analysis and collation of the data and findings, colleagues who had been invited to support with the development and preparation of the report were asked to provide feedback for consideration in relation to the final iteration of this report. Contributors were engaged at the outset for their expertise and perspectives and were then provided with the various and relevant sections for review. The comments and feedback received have been reviewed and incorporated into the final version of this report.

Appendix 2 – Demography

The NENC region includes a population of children 0-18 years providing secondary epilepsy care across 8 Trusts working very closely with primary care and also with the tertiary unit for complex patients.

The population of CYP aged under 18 in North East North Cumbria ICS area is c600,000. The incidence of epilepsy in this population is 40/100,000 and the prevalence is approximately 5,000. Published rates of psychiatric disorder for those with epilepsy (37%) indicate that approximately 1,850 CYP with epilepsy in the NENC ICS footprint have mental health needs.

Work has been undertaken as part of this programme to consider the identification, diagnosis, prevalence, incidence and reporting rates across the ICS footprint in relation to each of the locality areas as well as in respect of regional and national data. This analysis has also taken into consideration comparator regions in relation to population demographic and geography.

The Paediatric Epilepsy Network for the North East and North Cumbria (PENNEC) helpfully operates across the same footprint as the NENC ICS boundary areas and as such oversees and influences the paediatric epilepsy services delivered by the following NHS Acute Provider Trusts. In this case, all Trusts and boundary locality services are affiliated to PENNEC and also participate in Epilepsy 12 Audit, to varying degrees depending on the available resources.

- South Tyneside and Sunderland NHS Foundation Trust
- North Cumbria integrated care NHS foundation Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- Northumbria Healthcare NHS Foundation Trust
- South Tees Hospitals NHS Foundation Trust
- North Tees and Hartlepool NHS Foundation Trust
- County Durham and Darlington NHS Foundation Trust

North East and Yorkshire has the highest rate of epilepsy diagnosis across all the Health Authorities as evidenced by Epilepsy 12 Audit data.

The age profile of the CYP assigned to Round 3 Cohort 2 (Epilepsy 12 2020 National Clinical Audit Results) within the PENNEC/NENC ICS region are consistent with the England and Wales national averages.

Further analysis of population demographics and modelled estimates of epilepsy incidence and prevalence rates in PENNEC/NENC ICS region and across other regions/networks (based on population size, age profile and deprivation levels) indicates that NENC ranks third highest nationally in terms of prevalence of CYP with epilepsy at 5.88 children per 1000 population (England average is 5.45).

PENNEC/NENC ICS region has the highest reported number of diagnosed epilepsy cases in the latest round of Epilepsy 12 data (Round3, Cohort2), and has the third highest conversion rate (37%) of referrals to diagnosed epilepsy cases across the Epilepsy regional networks. However, this may not be representative, as referral rates into the Epilepsy 12 study cohort relative to local population sizes of the participating Trusts and their associated networks varies significantly, ranging from 40 referrals per 1000 local CYP population up to 170 referrals per 1000 population. This variation is most likely a reflection of incomplete data submissions to Epilepsy 12. Also, there must be recognition that the participating Trusts in England represent around 72% of the overall CYP population in England and approximately 24% of acute Trusts (non-specialised) in England who are delivering epilepsy care to children and are not affiliated to an epilepsy network.

For the PENNEC/NENC ICS region, modelled estimations anticipated incidence levels for new cases per year (based on population size, age profile and deprivation levels) is 282 which looks to be consistent with the Epilepsy 12 diagnostics data from Epilepsy 12 2020 data (Round 3 Cohort 2) which identifies that 245 cases were diagnosed over the same timeframe. This number may also have increased as patients on 'watch and wait' may have been subsequently diagnosed with epilepsy. This indicates that the secondary services are identifying and diagnosing epilepsy in line with expected rates of incidence and this is a helpful indicator of success in relation to ensuring that families are able to receive accurate diagnosis giving greater chance of accessing services to meet their needs.

Table 1 Summary expected levels of epilepsy in CYP in PENNEC/NENC ICS region based on population size and demographics

Summary Expected Levels of Epilepsy in Children and Young People in PENNEC region based on Population Size and Demographics

Ranked in order of Prevalence (High to Low)		CYP Population (Mid 2020 ONS)	CYP living in most deprived households (Based on 2019 Income Deprivation Affecting Children Index (IDACI) rate)	Proportion of CYP population living in most deprived households	Expected Number of children with Epilepsy in area (Based on population size, age profile and deprivation levels)	Resulting Prevalence Rate per 1000 population	Anticipated Incidence levels for new cases per year (Based on population size, age profile and deprivation levels)	Resulting Incident rate (per 100,000 population)
1	South Tyneside	30255	8996	30%	189	6.25	15	49.6
2	Hartlepool	20108	6216	31%	125	6.22	10	49.7
3	Middlesbrough	33129	11693	35%	205	6.19	18	54.3
4	Sunderland	54965	14682	27%	340	6.19	27	49.1
5	County Durham	101979	24854	24%	614	6.02	49	48.0
6	Gateshead	39201	8849	23%	236	6.02	19	48.5
7	Redcar and Cleveland	27607	7833	28%	166	6.01	13	47.1
8	Newcastle upon Tyne	58922	15905	27%	346	5.87	29	49.2
9	Copeland	11301	2031	18%	65	5.75	5	44.2
10	Darlington	22633	5065	22%	130	5.74	10	44.2
11	Allerdale	18043	2982	17%	103	5.71	8	44.3
12	Stockton-on-Tees	44021	9968	23%	248	5.63	20	45.4
13	Northumberland	58801	11197	19%	330	5.61	26	44.2
14	Carlisle	21562	3462	16%	119	5.52	10	46.4
15	North Tyneside	42017	8130	19%	229	5.45	19	45.2
16	Eden	9135	886	10%	48	5.25	4	43.8
PENNEC OVERALL		593679	142749	24%	3493	5.88	282	47.5

CYP population estimates were taken from the ONS Mid 2020 population statistics and deprivation levels were taken from the English Indices of Deprivation 2019 (Index of Multiple Deprivation IMD 2019) and the Income Deprivation Affecting Children Index (IDACI) Score to assess the number of CYP living in the most deprived areas. Estimates of CYP epilepsy rates were then calculated based on childhood epilepsy incidence and prevalence rates (Aaberg et al, 2017) and deprivation levels also accounted for on the understanding that epilepsy prevalence and incidence are strongly associated with deprivation. A recent study (Pickrell et al, 2015) indicates that epilepsy incidence and prevalence rates are twice as likely in the most deprived deciles compared to the least deprived deciles and this was factored into the calculations.

Data sources:

Table SAPE23DT2: Mid-2020 Population Estimates for Lower Layer Super Output Areas in England and Wales by Single Year of Age and Sex,

www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/lowersuperoutputareamidyearpopulationestimates

Health inequalities

Social determinants, also known as wider determinants, are a diverse range of social, economic and environmental factors which impact on population health. These factors, influenced by local, national and international distribution of resources, shape the conditions of daily life and the extent to which individuals of all ages have the physical, social and personal resources to identify and achieve goals, meet their needs and respond to changes in their circumstances.

The Marmot review considered health inequality and health outcomes was published in 2010 it emphasised the strong and persistent link between social inequality and disparities in health outcomes and the importance of tackling the wider determinants of health to improve health outcomes and reduce health inequalities. Evidence suggests that these 'wider determinants of health' are more important than health care in ensuring a healthy population and reducing health inequality.

Table 2: Population Split by Ethnic Groups (based on 2011 census)

Ethnic Groups as a % of Population (Based on 2011 Census)

	White	Asian	Mixed Race	Black	Other
ENGLAND	85.4%	7.8%	2.3%	3.5%	1.0%
North East and North Cumbria	95.7%	2.6%	0.8%	0.5%	0.4%
County Durham	98.2%	0.9%	0.6%	0.1%	0.2%
Darlington	96.2%	2.1%	1.1%	0.3%	0.2%
Hartlepool	97.7%	1.4%	0.6%	0.2%	0.1%
Middlesbrough	88.2%	7.8%	1.7%	1.3%	1.1%
Northumberland	98.4%	0.8%	0.5%	0.1%	0.1%
Redcar and Cleveland	98.5%	0.6%	0.6%	0.1%	0.1%
Stockton-on-Tees	94.6%	3.5%	1.0%	0.6%	0.3%
Gateshead	96.3%	1.9%	0.8%	0.5%	0.5%
Newcastle upon Tyne	85.5%	9.7%	1.5%	1.8%	1.5%
North Tyneside	96.6%	1.9%	0.9%	0.4%	0.2%
South Tyneside	95.9%	2.2%	0.9%	0.3%	0.7%
Sunderland	95.9%	2.7%	0.6%	0.5%	0.3%
Allerdale	98.9%	0.5%	0.4%	0.1%	0.1%
Carlisle	98.1%	1.2%	0.5%	0.1%	0.1%
Copeland	98.4%	0.9%	0.5%	0.1%	0.1%
Eden	98.9%	0.6%	0.4%	0.0%	0.1%
NORTH WEST	90.2%	6.2%	1.6%	1.4%	0.6%
YORKSHIRE AND THE HUMBER	88.8%	7.3%	1.6%	1.5%	0.8%
EAST MIDLANDS	89.3%	6.5%	1.9%	1.8%	0.6%
WEST MIDLANDS	82.7%	10.8%	2.4%	3.3%	0.9%
EAST	90.8%	4.8%	1.9%	2.0%	0.5%
LONDON	59.8%	18.5%	5.0%	13.3%	3.4%
SOUTH EAST	90.7%	5.2%	1.9%	1.6%	0.6%
SOUTH WEST	95.4%	2.0%	1.4%	0.9%	0.3%

The NENC region as a whole has one of the highest proportions of CYP population (24%) living in the most deprived households in England (based on the Income Deprivation Affecting Children Index population estimates). The national average for England is 19%. This is also reflected in the Epilepsy 12 data (assigned to Round 3, Cohort 2) which shows that localities in the PENNEC/NENC ICS footprint have the highest proportion of CYP that are under review for Epilepsy and live in the most deprived quintile across all the localities within the regional networks.

Within the PENNEC/NENC ICS localities, acute Trusts in South Tees, Newcastle, South Tyneside / Sunderland and North Tees & Hartlepool are seeing CYP from the most deprived areas, and again, this is shown in both the Epilepsy 12 data and ONS population and Index of Multiple Deprivation IMD data. The highest level of deprivation is seen in the Middlesbrough area with 35% of the local CYP population living in the most deprived households; with Hartlepool (31%) and South Tyneside (30%) not too far behind. County Durham is the largest area in the NENC ICS footprint and has the largest CYP population to manage (c102,000), it also has the largest number of CYP population living in deprived households (c24,850).

Recent ONS and other population profiling data demonstrates that our region houses a large and expanding number of young people and families facing multiple disadvantages, including poverty, poor mental health and family breakdown.

Appendix 3- Education Questionnaire

Epilepsy Questionnaire for Education Settings

We are very grateful to you for taking the time to fill in this questionnaire which is an important part of the work on children's epilepsy being undertaken by the Child Health and Well Being Network for the North East and North Cumbria.

Epilepsy is the most common neurological condition in childhood and is characterized by recurrent seizures which usually need anti-seizure medication. Optimal management of epilepsy improves epilepsy related health outcomes and optimises learning, behaviour, mental health and quality of life.

A key part of this project is to engage across the system to capture views, experiences and expertise from the settings and services that serve CYP such as education. We would be very grateful for your help firstly, in describing what is currently available in your education setting and secondly, in identifying any areas that we could support you with that would improve the experience of CYP with epilepsy

* Required

1. Local Authority: *

- Allerdale
- Carlisle
- Copeland
- Eden
- Gateshead
- Newcastle-Upon-Tyne
- Northumberland
- North Tyneside
- County Durham
- South Tyneside
- Sunderland
- Darlington
- Hartlepool
- Middlesbrough
- Redcar and Cleveland
- Stockton-on-Tees

2. What type of education setting do you work in? *

- First school
- Infant school
- Middle school
- Junior school
- High school
- Primary school 4-11
- Primary school including nursery and/or pre-school provision

-
- Special school – primary
 - Special school – secondary
 - Special school - all through
 - Secondary school with ARP provision
 - All-through provision (e.g. 3-18)
 - Independent day school (3-11)
 - Independent 7-18
 - Independent boarding school 11-18
 - Independent all-through provision 3-18
 - Further education
 - Early Years (Private) setting
 - Early Years (Voluntary) setting
 - Early Years (Independent) setting
 - Early Years (Independent) setting
 - Portage
 - Playgroup
 - Childminder
 - Other

3. If you selected 'other' to question 2, please explain your setting?

4. Which best describes your role? (please select all that apply)

- Headteacher
- Deputy/Assistant Headteacher
- Head of Year

-
- Head of Department
 - Senior Leadership Team Member
 - SENCO
 - Pastoral Lead
 - Assistant/PA to the headteacher
 - Designated Safeguarding Lead
 - Education Inclusion Lead
 - Teacher
 - High Level Teaching Assistant
 - School Health Adviser
 - Other

5. If you selected 'other' to question 4, please explain your role?

6. How many pupils are on your roll?

- <100
- 100-399
- 400-799
- 800-999
- >1000

7. What is your school's Index of Multiple Deprivation decile score? (1 = most deprived and 10 = least deprived)

- 1
- 2
- 3

- 4
- 5
- 6
- 7
- 8
- 9
- 10
- Unsure

8. In the last five years, have you worked with children and young people with epilepsy?

- Yes
- No

9. Currently, how many children have epilepsy, within your setting?

- 0
- 1-6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16 or more

Don't know

10. Do you record the presence of epilepsy in your CYP on your school's central information management system?

Yes

No

Other

11. If 'other', where do you record this information?

12. For those children and young people with epilepsy, do parents/carers have to complete and sign a health declaration on behalf of their child (e.g. an **Individual Health Care Plan**)?

Yes

No

N/A - no CYP with epilepsy on roll

13. Is the **Individual Health Care Plan** updated, annually?

Yes

No

N/A - no CYP with epilepsy on roll

14. For those pupils with epilepsy, have you received support from your local epilepsy nurse?

Yes

No

Some

N/A - no CYP with epilepsy on roll

15. Does every child and young person, with epilepsy, have an **Individual emergency health care plan**, prescribed and issued by the hospital epilepsy team (e.g. detailing emergency medication/action to be taken in the event of a seizure, at school)?

- Yes - for all children with epilepsy
- Yes - for some children with epilepsy
- No
- N/A - no CYP with epilepsy on roll

16. If so, is the **hospital issued emergency health care plan** updated annually, with an epilepsy nurse colleague?

- Yes
- Some
- No
- N/A - no CYP with epilepsy on roll

17. In relation to training - approximately **what percentage of your staff have received specific epilepsy training**, outside of paediatric first aid, or general first aid accredited courses?

- 0-25%
- 26-50%
- 51-75%
- 76-100%

18. If epilepsy training has been delivered, who has provided it?

- Provided by epilepsy nurse
- Provided by an outside organisation
- Other

19. If 'other' has been selected, please specify the delivery organisation.

20. Are you aware of training resources, for epilepsy? (e.g. PET (Paediatric Epilepsy Training) Level Zero delivered by the British Paediatric Neurology Association/Epilepsy Action - Course for Teachers/Young Epilepsy (training for pupils and staff)?

- Yes
- No

21. Have you identified any further epilepsy training needs for your workforce?

- Yes
- No
- Don't know

Epilepsy and SEND

22. What % of CYP with epilepsy are on your SEND register (either SEN Support and EHCP)?

- 0-19%
- 20-39%
- 40-59%
- 60-79%
- 80-100%
- N/A- no CYP with epilepsy on roll

23. What % of CYP with epilepsy, in your setting, have an **education health, care plan (EHCP)**?

The value must be a number

24. For those children with epilepsy, how commonly do they display difficulties in the four areas of the SEND Code of Conduct?

	Very Infrequently	Infrequently	Occasionally	Frequently	Very Frequently
Cognition and Learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication and Language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory/Physical	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social, Emotional mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Mental Health Specific Questions

25. Part 1) How confident do you think that your staff are at identifying students at high risk of mental health problems?

Part 2) How confident do you think you and your staff feel about intervening and offering support to students with mental health problems?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Part 1) Identification of needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Part 2) Confidence in intervention and support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. Without looking up the answer, how does the frequency of mental health issues in CYP with epilepsy compare to CYP without any health issues?

	Less common	Same frequency	Twice as common	Three times as common	Four times as common
Frequency of mental health issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. What, if any, mental health issues/diagnoses may be more common in CYP with epilepsy? (please tick all that apply)

- ADHD/ ADD
- Anxiety Disorder
- Autism Spectrum Disorder
- Conduct Disorder
- Depression
- Obsessive-compulsive disorder
- Psychosis
- Other

28. If you have answered 'other' to the question above, please identify mental health need

29. Are mental health problems actively screened for, in CYP with epilepsy, at your school?

- Yes
- No
- N/A - no CYP with epilepsy on roll

30. If you answered yes to the above, who would conduct mental health screening?

- SENCO
- School counsellor
- Pastoral Care Team
- Other
- N/A** - no CYP with epilepsy on roll

31. If you answered 'other' to the above, who would conduct mental health screening?

32. Are identified mental health issues formally recorded/documented in CYP with epilepsy, who do not meet your SEMH threshold on the SEND register?

- Yes
- No
- Sometimes
- N/A - no CYP with epilepsy on roll

33. Is there a designated member of teaching staff responsible for student mental health and well-being in your school?

- Yes
- No

34. If so, who is the identified person/team responsible for mental health support (tick all that apply)?

- SENCO
- Pastoral lead/tutor
- Designated mental health first aider
- School counsellor
- Education Mental Health Practitioner (LA/NHS funded)
- Head of Year
- Safeguarding Lead
- Family Liaison Officer

-

Other

35. Do you think that the type of mental health support required by CYP with epilepsy differs from that needed by other CYP?

- Yes
- No

36. If you answered 'yes', in what way do you think it differs?

37. Have you offered any mental health interventions, for CYP with epilepsy, in your setting, within the last 18 months?

- Yes
- No
- N/A** - no CYP with epilepsy on roll

38. Which of the following interventions have you implemented for those CYP with epilepsy, within the last 18 months? (*Tick any that apply - N.B. this list is not exhaustive*)

- Applications for Education Health Care Plans and/or alternative provision
- Art therapy
- Indirect bereavement support conducted in groups e.g. Rainbows group therapy
- Early Help Assessment
- Bespoke Education Mental Health Practitioner (EMHP) packages
- Educational Psychology input
- Facilitating family therapy
- Five-point rating scales
- Journaling e.g. Happy Journal

- Liaison with the wider multi-disciplinary team to seek additional guidance and support
- Nurture rooms/zones
- Pastoral interventions e.g. buddy systems
- PACE approach - playfulness, acceptance, curiosity, empathy
- Pastoral care sessions (either small group/one to one)
- PATH approach - person centred planning
- Peer support systems e.g. Lego Therapy, Talkabout for Children, Turn taking
- School counselling
- Sensory strategies e.g. Leaving lessons early to avoid over-crowding/therapeutic input for sensory overload
- Speech and Language Support
- Social stories
- Socially Speaking
- Talkabout For Children
- THRIVE Practitioner/Accredited Programmes
- Words and picture therapy e.g. supporting family breakdowns
- N/A** - no children with epilepsy on roll
- Other

39. If you 'selected' other, please state the interventions you have implemented.

40. Have any of your staff undertaken additional training in the identification and intervention for mental health problems in students (e.g. Senior Mental Health Lead/Thrive Practitioner/Anna Freud)?

- Yes
- No
- We are due to undertake training

41. If you have answered 'yes' or 'we are due to undertake training', please describe the mental health training your member(s) of staff have undertaken or are due to undertake.

42. If a mental health need, in a CYP with epilepsy, is identified in school; following a discussion with parents, how likely would it be for the school to refer onwards to any of the following services/practitioners?

	Very Likely	Somewhat Likely	Neither Likely nor unlikely	Somewhat unlikely	Very unlikely
CAMHS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical/educational psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General Practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Paediatrician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public Health School Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Third Sector (e.g. Epilepsy Action)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

43. If you have answered 'other', who do you refer to?

Cognition

44. How confident do you think you and your staff feel about recognising specific cognitive problems in CYP with and without underlying health conditions?

	Very Confident	Confident	Neither Confident/Unconfident	Unconfident	Not confident at all
Recognising cognitive problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

45. Do you think that CYP with epilepsy are more or less likely than other children, to have cognitive difficulties?

- More likely than other CYPs
- Same as other CYPs
- Less likely than other CYPs

46. If you answered more likely, what kind of cognitive difficulties do you think that they are more likely to have? *(Tick any that apply)*

- Global cognitive impairment
- Specific problems with attention and concentration
- Specific problems with executive function (independent planning, personal organisation, self-control, flexible thinking)
- Specific problems with mathematical reasoning
- Specific problems with memory (working memory/long-term memory)
- Specific problems with processing speed
- Specific problems with reading
- Specific problems with verbal comprehension
- Specific visuo-spatial problems

47. Do you have a specific screening algorithm or assessment protocol for those CYP who are at high risk of cognitive deficit?

- Yes
- No

48. If you selected 'yes', please briefly summarise your algorithm/protocol.

49. Are any of the following element's part of your cognitive screening algorithm?

- Assessment for learning
- Classroom observation
- Medical register information
- Parental requests for cognitive screening

- Referral to educational psychologist for observation/formal assessment of learning
- SENCO keeps a watching brief
- SEND register/Education Health Care Plan pathways
- Summative assessments
- Other (e.g. assessment by external agency)

50. If you answered 'other' to the above, please specify.

Gaps in mental health and cognition: moving forward

51. Do you think the way in which education settings record and review mental health and cognitive problems, for CYP with epilepsy, requires improvement?

- Yes
- No
- Maybe

52. If you answered 'yes' to the above question, how do you think it could be improved?

53. Do you think that parents/carers are an adequate source of all health information, for CYP with epilepsy?

- Yes
 No

54. Do you think that further staff training is required with regard to the **identification of** and **intervention for** CYP with epilepsy?

	Yes- Further staff training is required	No
Identification of Mental Health	<input type="radio"/>	<input type="radio"/>
Identification of specific cognitive problems	<input type="radio"/>	<input type="radio"/>
Intervention for mental health	<input type="radio"/>	<input type="radio"/>
Intervention for specific cognitive problems	<input type="radio"/>	<input type="radio"/>

55. Thank you for taking your time to complete our questionnaire.

If you would like further information on the NENC CHWB Network's projects: Join the Network now to become part of our community.

<http://docs.google.com/forms/d/e/1FAIP-0LScvtwlc6t4NaF2e-SF8MZymNIh-3v P-dNUKT8A61 SSMGWWJJw/viewform>

[.\(http://docs.google.com/forms/d/e/1FAIP-0LScvtwlc6t4NaF2e-SF8MZymNIh-3v P-dNUKT8A61 SSMGWWJJw/viewform\).](http://docs.google.com/forms/d/e/1FAIP-0LScvtwlc6t4NaF2e-SF8MZymNIh-3v P-dNUKT8A61 SSMGWWJJw/viewform)

Find out more on our Child Health and Wellbeing Network | North East and North Cumbria ICS, and make sure to follow us on Twitter @NorthNetChild

Appendix 4- Clinical Leads (CL) Questionnaire

Mental Health Questions for Paediatrician Clinical Leads in Epilepsy

Dear Colleagues

As you may know the NHS Long-term Plan prioritizes epilepsy, asthma and diabetes as the three LTC in children and young people for service improvement.

This questionnaire forms part of a piece of work on epilepsy commissioned by the Child Health and Wellbeing Network for **NENC** (the new **NENC** ICS footprint). The purpose of this questionnaire is specifically to explore the availability and gaps in mental health assessment and provision for CYP with epilepsy.

You may have already had contact from my colleague Dr Kumar who is doing a different strand of the work on epilepsy. The initial questions may seem similar but this is just to give a context to the answers for the mental health questions.

It would be extremely helpful and very much appreciated if you could take the time to complete this questionnaire which is estimated to take approximately 30 minutes.

1. Are you the Clinical Lead or one of the clinical leads for epilepsy in CYP in your trust?

- Yes
- No

2. Which Hospital/Provider Trust/ Health board are you based in? Tick all that apply

- North Tees and Hartlepool NHS FT
- County Durham and Darlington NHS FT
- South Tees Hospitals NHS FT
- Newcastle Upon Tyne Hospitals NHS FT
- South Tyneside and Sunderland NHS FT
- Northumbria Healthcare NHS FT
- Gateshead Health NHS FT
- North Cumbria Integrated Care NHS FT
-

Other

3. Please specify Hospital(s) / Health board

4. How many WTE paediatricians are in your department?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- <12

5. Do you have a dedicated epilepsy clinic?

- Yes
- No

6. How many paediatricians in your trust have dedicated epilepsy clinics?

- 1
- 2
- 3
- 4
- 5

7. Approximately how many children with epilepsy do you have on your combined case load?

- 0-100
- 100-150
- 150-200
- 200-250
- 250-300
- 350-400

8. How many WTE paediatric ESNs are based at your Trust/Health Board

- 0
 - 0.5
 - 1
 - 1.5
 - 2
 - 2.5
 -
- Other

9. Does an ESN attend your epilepsy clinic?

- Always
- Sometimes
- Never

10. If an ESN attends your clinic does he/she conduct a consultation with the CYP with epilepsy which is separate to your consultation?

- Always
- Sometimes
- Never

11. Do you have separate epilepsy clinics for young people (e.g. >12 years)

- Yes
- No

12. Are the epilepsy clinics in your Trust attended by a mental health professional?

- Always
- Sometimes
- Never

13. If always or sometimes who is this professional

- Psychologist from Trust based Health Psychology
- Third sector representative
- CAMHS professional from CAMHS service
- LD professional
- Other

Mental Health

14. Do you think that you are the person who offers the 1st level of mental health support to CYP with epilepsy and their families?

- Yes
- No

15. Do you think that the ESN is the person who offers the 1st level of mental health support to CYP with epilepsy and their families?

- Yes
- No

16. Is this different if the CYP attends special needs educational provision?

- Yes
- No

17. If you answered yes, who would provide the 1st level of mental health support for CYP in special needs education?

18. Do you think that offering the 1st level of mental health support to CYP with epilepsy and their families is part of the ESN role?

- Yes
- No

19. If no, whose role do you think that this is?

20. Without looking up the answer, how does the frequency of mental health issues in CYP with epilepsy compare to CYP without any health issues?

- Less common
- Same frequency
- Twice as common
- Three times as common
- Four times as common

21. Are mental health problems routinely screened for as part of the child or young person's clinic visit:

	Always	Never	As Required
In the doctor's consultation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the consultation with the ESN?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. If yes, are any mental health screening tools used?

- Yes
- No

23. If yes which screening tools or questionnaires are used?

24. How confident do you feel in identifying mental health problems in CYP with epilepsy

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

25. How confident do you feel in identifying mental health problems in CYP with epilepsy who attend special educational provision (e.g. those with significant learning disability, autism etc)?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

26. If mental health problems have been identified who is this information shared with?
Please tick all that apply and assume that children are under 16 years

- Parents/carers
- Doctor in clinic
- GP
- School nurse
- School
- SENCO
- Other

27. Does your Trust have in-house Trust based child health psychology services?

- Yes
- No

28. If mental health or neurodevelopmental difficulties that require further assessment are identified in a CYP with normal learning ability is there a defined onward referral pathway for further assessment and intervention?

- Yes
- No

29. In the event of suspected ADHD please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

30. In the event of suspected anxiety disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school base

31. In the event of suspected autism spectrum disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

32. In the event of suspected depression please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

33. In the event of suspected obsessive-compulsive disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

34. In the event of suspected psychosis please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

35. In the event of suspected self-harming behaviour please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHs/CYPs

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school base

36. Are there any other services not mentioned above that you would refer CYP on to?

37. Which 3rd sector organizations do you recommend to CYP and their families? Tick all that apply

- Epilepsy Action
 - Young Epilepsy
 - Epilepsy Society
 - Mind
 -
-Other

38. In your experience what are the approximate current waiting times for further assessment by the various mental health services in your area? Please select the number of months

	<3	3-6	6-12	12-18	18-24	24+	Not Applicable
Local CAHMS/CYP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-house trust health psychology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based psychology in CCH	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 rd Sector	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School based services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

39. If mental health problems that require further assessment have been identified in a CYP who attends special educational provision, is the defined onward referral pathway for further assessment and intervention different?

- Yes
- No

40. Do you have learning disability psychology/psychiatry services in your area?

- Yes
- No

41. If you answered "no" to which service in your area, would you refer CYP with special needs and mental health problems?

42. How confident do you feel about recognizing when onward referral to mental health services is required for CYP with normal learning ability?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

43. How confident do you feel about recognizing when onward referral to mental health services is required for CYP who attend special needs educational provision?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

44. Have you participated in any additional training in the identification of mental health problems?

- Yes
- No

45. If yes please give detail of additional training

46. How confident do you feel about offering mental health support to CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

47. Do you ever feel that you are expected to offer mental health support to children and young people with epilepsy which is outside your experience and expertise?

- Yes
- No

48. If yes, who do you approach for support when this is the case?

49. How confident do you feel about prescribing anti-seizure medications to CYP on drug treatments for mental health problems?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

50. Do you prescribe any medication for mental health issues in children?

- Yes
- No

51. If yes which of the following medications are you willing to prescribe? Tick all that apply

- Methylphenidate
- Dexamphetamine
- SSRIs e.g. Fluoxetine
- Tricyclic anti-depressants
- Anti-psychotic medication e.g. risperidone
- Benzodiazepines
- Other

52. Does your department host any support groups for CYP with epilepsy and their families?

- Yes
- No

53. For CYP

- Yes
- No

54. For Parents and carers?

- Yes
- No

55. Are these combined or separate?

- Combined
- Separate

56. If support groups are offered how are they funded? (select all that apply)

- Trust
- Charity
- Industry
- Other

57. Are these support groups

- Face-to-face
- Combination Face to face and virtual
- Only virtual

58. If you have never held a support group virtually, is it something that you would consider for the future

- Yes
- No

59. If no why not?

60. Is there any attendance/participation in the support group by mental health professionals?

- Always
- Sometimes
- Never

61. Are mental health problems screened for as part of the transition process to adult services?

- Yes
- No

62. Which of the following models of service for providing mental health assessment and intervention do you think would best meet the needs of CYP with epilepsy? Please only tick one

- Local CAMHS/CYP
- Hospital based health psychology embedded within the clinic
- Community based psychology services
- School base services
- 3rd sector services

-

Other

Cognition

63. How confident do you feel about recognising specific cognitive problems in CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

64. When you suspect cognitive problems who would you refer to for further assessment?

	Yes	No	Not applicable
Trust based health psychology services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education psychology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SENCO at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

65. If other please state

Parents/Carers

66. In your experience do you think that there are increased mental health problems in the parents/carers of CYP with epilepsy compared to parents/carers of CYP with other long term conditions?

- Yes
- No

67. Is a significant amount of your time spent supporting parental/carer mental health?

- Yes
- No

68. Of the time you spend offering mental health/emotional support what% is spent supporting parents/carers?

- 10%
- 20%
- 30%
- 40%

- 50%
- 60%
- 70%
- 80%
- 90%
- 100%

69. How confident do you feel about recognizing mental health problems in parents/carers of CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

70. What kind of mental health support do you offer parents/carers (definite mental health need rather than usual emotional support) ?

71. How confident do you feel about recognizing when onward referral to mental health services is required for parents/carers of CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

72. Is there a defined onward referral pathway for parents/carers who are identified as having mental health/emotional needs? Please tick

- No
- GP with consent
- Mental health services with consent
- Third sector with consent
- Sign-posting to sources of support including GP
- Social Services
- Other

73. Do you ever feel that you are expected to offer mental health support to parents/carers of CYP with epilepsy which is outside your experience and expertise?

- Yes
- No

74. If yes, who do you approach for support when this is the case?

Gaps and moving forwards

75. Do you think that you would benefit from:

Additional training in the recognition of mental health problems in CYP?

- Yes
- No

76. Do you think you would benefit from:

	Yes	No
Additional training in the recognition of mental health problems in CYP?	<input type="radio"/>	<input type="radio"/>
Additional training in the recognition of mental health problems in CYP with special need?	<input type="radio"/>	<input type="radio"/>
Additional training with specific tools to identify mental health problems?	<input type="radio"/>	<input type="radio"/>
Additional training in offering initial support to CYP with epilepsy and mental health issues ?	<input type="radio"/>	<input type="radio"/>
Additional training about when to refer on to mental health services	<input type="radio"/>	<input type="radio"/>
Clearer referral pathways to CYP mental health services?	<input type="radio"/>	<input type="radio"/>
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy?	<input type="radio"/>	<input type="radio"/>

77. Do you think that you would benefit from:

	Yes	No
Additional training in the recognition of mental health problems in parents/carers of CYP with epilepsy?	<input type="radio"/>	<input type="radio"/>
Additional training with specific tools to identify mental health problems in parents/carers?	<input type="radio"/>	<input type="radio"/>
Additional training in offering initial support to parents/carers of CYP with epilepsy and mental health/emotional difficulties?	<input type="radio"/>	<input type="radio"/>
Additional training about when to seek consent for referral on to separate services (e.g.GP, mental health services, third sector)?	<input type="radio"/>	<input type="radio"/>
Clearer onward referral pathways?	<input type="radio"/>	<input type="radio"/>
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy?	<input type="radio"/>	<input type="radio"/>

78. Please use the space below to make any further comments about any of the issues above or any issues that have been left out of this survey but which are important to mental health and well-being in CYP with epilepsy and their families.

Appendix 5- Epilepsy Specialist Nurse (ESN) Questionnaire

Dear Colleagues

This questionnaire forms part of a piece of work commissioned by the Child Health and Wellbeing Board for NENC which is also the footprint of the new **NENC** ICS. The purpose of this questionnaire is specifically to explore the availability and gaps in mental health assessment and provision for CVP with epilepsy and it would be extremely helpful and very much appreciated if you could take the time to complete this. Questionnaire completion is estimated to take approximately 30 minutes

* Required

1. Are you a paediatric epilepsy nurse specialist? *

- Yes
- No

2. Is this your only role?

- Yes
- No

3. If no what other role do you have?

- Community nurse
- School nurse
- Health Visitor
- Hospital ward-based nurse
- Hospital out-patient based nurse
- GP practice nurse
- Nurse based in learning disability team

Other

4. Which Provider Trust/ Health board are you based in? Tick all that apply

- North Tyneside and Hartlepool FT (NTHFT)
- County Durham and Darlington FT (CDDFT)
- South Tyneside Hospitals FT (STHFT)
- South Tyneside and Sunderland FT (STSFT)
- Newcastle upon Tyne Hospital FT
- Northumbria Healthcare FT (NHCFT)
- North Cumbria Integrated Care FT (NCIC)
- Gateshead Health FT (GHFT) - QE Gateshead

5. How many WTE paediatric ESNs are based at your Trust/Health Board?

- 0
 - 0.5
 - 1
 - 1.5
 - 2
 - 2.5
 -
- Other

6. Approximately how many children and young people with epilepsy do you have on your combined case-loads?

- 0-100
- 100-150
- 150-200
- 200-250
- 250-300

- 350-400
- 400-450
- Not sure

7. Do you attend the children and young people's epilepsy clinics in your Trust?

- Always
- Sometimes
- Never

8. Do you conduct a consultation with the CYP, which is separate to the one with the doctor?

- Always
- Sometimes
- Never

9. Do you have separate epilepsy clinics for young people (e.g. > 12 years)

- Yes
- No

10. Are the epilepsy clinics in your Trust attended by a mental health professional?

- Always
- Sometimes
- Never

11. If always or sometimes - who is this professional ?

- Psychologist from Trust based Health Psychology
- Third sector representative
- CAMHS professional from CAMHS service
- LD professional

Other

Mental health

12. Do you think that you are the person who offers the 1st level of mental health support to CYP with epilepsy and their families?

Yes

No

13. Is this different if the CYP attends special needs educational provision?

Yes

No

14. If you answered yes, who would provide the 1st level of mental health support for CYP in special needs education?

15. Do you think that being the person who offers the 1st level of mental health support to CYP with epilepsy and their families is part of the ESN role?

Yes

No

16. If no, whose role do you think that this is?

17. Without looking up the answer, how does the frequency of mental health issues in CYP with epilepsy compare to CYP without any health issues?

Less common

Same frequency

Twice as common

Three times as common

Four times as common

18. Are mental health problems routinely screened for as part of the child or young person's clinic visit: In the doctor's consultation?

Always

Never

As required

19. Are mental health problems routinely screened for as part of the child or young person's clinic visit; in the consultation with the ESN? *

Always

Never

As required

20. If yes, are any mental health screening tools used?

Yes

No

21. If yes which screening tools or questionnaires?

22. How confident do you feel in identifying mental health problems in CYP with epilepsy

Very confident

Confident

Neutral

Not confident

Not at all confident

23. How confident do you feel in identifying mental health problems in CYP with epilepsy who attend special educational provision (e.g. those with significant learning disability, autism etc)?

- Very confident
- Confident
- Neutral
- Not confident
- Not at all confident

24. If mental health problems have been identified, who is this information shared with?
Please tick all that apply and assume that children are under 16 years

- Parents/carers
- Doctor in clinic
- GP
- School nurse
- School SENDCO
- Respite care providers
- Residential care providers

Other

25. Does your Trust have in-house Trust based child health psychology services?

- Yes
- No

26. If mental health or neurodevelopmental difficulties that require further assessment have been identified in a CYP with normal learning ability, is there a defined onward referral pathway for further assessment and intervention?

- Yes
- No

27. In the event of suspected ADHD please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

28. In the event of suspected ADHD please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

29. In the event of suspected Autism Spectrum Disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

30. In the event of suspected conduct disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

31. In the event of suspected depression please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

32. In the event of suspected obsessive-compulsive disorder please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

33. In the event of suspected pathological demand avoidance please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

34. In the event of suspected psychosis please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

35. In the event of suspected self-harming behaviour please rank (1-6) in order of priority the services to which you would refer the young person? (1 being the highest priority)

Local CAMHS/CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organizations

GP for onward referral

School nurse/school based

36. Are there any other services not mentioned above that you would refer CYP on to?

37. Which 3rd sector organisations do you recommend to CYP and their families? Tick **all** that apply

- Epilepsy Action
- Young Epilepsy
- Epilepsy Society
- Mind
- Other

38. In your experience what are the approximate current waiting times for further assessment by the various mental health services in your area? Please select the number of months

	<3	3-6	6-12	12-18	18-24	>24	NA
Local CAMHS/CYPS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-house trust health psychology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based psychology in CCH 3 rd sector	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School based services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

39. If mental health problems that require further assessment have been identified in a CYP who attends special educational provision, is the defined onward referral pathway for further assessment and intervention different?

- Yes
- No

40. . Do you have learning disability psychology/psychiatry services in your area?

Yes

No

41. . If you answered "no" to the question above, which service in your area would you refer CYP with special needs and mental health problems?

42. How confident do you feel about recognising when onward referral to mental health services is required for CYP with normal learning ability?

Very confident

Confident

Neutral

Not confident

Not at all confident

43. How confident to you feel about recognising when onward referral to mental health services is required for CYP who attend special needs educational provision?

Very confident

Confident

Neutral

Not confident

Not at all confident

44. Have you participated in any additional training in the identification of mental health problems and giving support?

Yes

No

45. If yes please state what the additional training was

46. Once mental health problems in the CYP have been identified do you personally offer any intervention/support?

- Yes
- No

47. If yes, what sort of intervention/support do you offer? Tick any that apply

- Linking with learning disability nurses
- Mental health first aid
- Social stories (e.g. preparation for hospital visits, EEG preparation)
- Signposting to third sector resources
- Signposting to LA resources for young people
- 1:1 counselling sessions
- Other

48. If you have answered 'other' please state

49. How confident do you feel about offering mental health support to CYP with epilepsy?

- Very confident
- Confident
- Neutral
- Not confident
- Not at all confident

50. Do you ever feel that you are expected to offer mental health support to children and young people with epilepsy which is outside your experience and expertise?

- Yes
- No

51. If yes, who do you approach for support when this is the case?

52. Does your department host any support groups for CYP with epilepsy and their families?

- For CYP without parents and carers
- For Parents and carers without CYP
- For both parents and CYP together

53. If support groups are offered how are they funded

- Trust
- Charity
- Industry sponsorship

Other

54. Are these support groups

Only face-to-face

Combination Face to face and virtual

Only virtual

55. If you have never held a support group virtually, is it something that you would consider for the future

Yes

No

56. If no why not?

57. Is there any attendance/participation in the support group by mental health professionals?

Always

Sometimes

Never

58. Are mental health problems screened for as part of the transition process to adult services?

Yes

No

59. Which of the following models of service for providing mental health assessment and intervention do you think would best meet the needs of CYP with epilepsy? Please only tick one

Local CAMHS/CYP

Hospital based health psychology embedded within the clinic

Community based psychology services

3rd sector services

School based services

Other

Parents and Carers

60. Do you think that the prevalence of mental health problems is increased in the parents/carers of children and VP with epilepsy?

Yes

No

61. Is a significant amount of your time spent supporting parental/carer mental health (definite mental health need rather than usual emotional support)

Yes

No

62. Of the time you spend offering mental health support what% is spent supporting parents/carers?

10%

20%

30%

40%

50%

60%

70%

80%

90%

100%

63. How confident do you feel about recognising mental health problems in parents/carers of CYP with epilepsy?

- Very Confident
- Confident
- Neutral
- Not Confident
- Not at all confident

64. How confident do you feel about recognizing when onward referral to mental health services is required for parents/carers of CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

65. Is there a defined onward referral pathway for parents/carers who are identified as having mental health needs?

- GP with consent
- Mental health services with consent
- No
- Sign-posting to sources of support including GP
- Social services
- Third sector with consent
- Other

66. Do you ever feel that you are expected to offer mental health support to parents/carers of CYP with epilepsy which is outside your experience and expertise?

- Yes
- No

67. If yes, who do you approach for support when this is the case?

Gaps and moving forwards

68. Do you think that you would benefit from (select all that apply):

- Additional training in the recognition of mental health problems in CYP with normal learning ability?
- Additional training in the recognition of mental health problems in CYP with special needs?
- Additional training with specific tools to identify mental health problems?
- Additional training in offering initial support to CYP with epilepsy and mental health problems?
- Additional training about when to refer on to mental health services?
- Clearer referral pathways to CYP mental health services?
- Additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy?

69. Do you think that you would benefit from (tick all that apply):

- Additional training in the recognition of mental health problems in parents/carers of CYP with epilepsy?
- Additional training with specific tools to identify these problems in parents/carers?
- Additional training in offering initial support to parents/carers of CYP with epilepsy and mental health/emotional difficulties?
- Additional training about when and how to seek consent for referral on to separate services (e.g. GP, mental health services, third sector)?
- Clearer onward referral pathways?
- Additional support/supervision from a qualified mental health professional in dealing with mental health issues in parents/carers of CYP with epilepsy?

-
- Clearer guidance on when mental health/emotional problems in a parent/carer who refuses to seek mental health support (e.g. from the GP) becomes a safeguarding issue?

70. Please use the space below to make any further comments about any of the issues above or any issues that have been left out of this survey but which are important to mental health and well-being in CYP with epilepsy and their families.

Appendix 6 -Primary Care Questionnaire

Epilepsy/Mental Health Online Survey for Primary Care

This questionnaire forms part of a piece of work commissioned by the **NENC** ICS Child Health and Wellbeing Network.

The purpose of this questionnaire is specifically to explore the availability and gaps in mental health assessment and provision for CYP with epilepsy and it would be extremely helpful and very much appreciated if you could take the time to complete this.

We are looking to understand the availability of services and pathways serving local populations in order to develop recommendations to improve these for CYP with epilepsy.

We have designed this questionnaire so that you do not have to spend time seeking out detailed information and have hopefully provided straightforward multiple-choice questions and answers to enable ease of completion.

Questionnaire completion is estimated to take no more than 10 minutes

1. Are you a:

- GP partner
- Salaried GP
- Practice Nurse
- Other

2. In which local authority is your practice based?

- Allerdale
- Carlisle
- Copeland
- Eden
- Gateshead
- Newcastle Upon Tyne

- Northumberland
- North Tyneside
- County Durham
- South Tyneside
- Sunderland
- Darlington
- Hartlepool
- Middlesbrough
- Redcar & Cleveland
- Stockton on Tees
- Other

3. What is the name of the PCN that your practice is part of?

4. How many practices are there in your PCN?

- Not known
- 2
- 3
- 4
- 5
- 6
- 7
- 8

- 9
- 10
- >10

5. Are there any GPs in your practice with a special interest in epilepsy?

- Yes
- No

6. Are there any practice nurses in your practice with a specialist interest in epilepsy?

- Yes
- No

7. How confident do you feel prescribing anti-seizure medication to adults with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

8. How confident do you feel prescribing anti-seizure medication to children with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

9. How confident do you feel prescribing medications to treat mental health conditions in adults with epilepsy who take anti-seizure medications?

- Extremely confident
- Somewhat confident

- Neutral
- Somewhat not confident
- Extremely not confident

10. How confident do you feel prescribing medications to treat mental health conditions in CYP with epilepsy, who take anti-seizure medications?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

11. Please provide any further relevant detail about prescription of medication to adults/children? (This question is optional)

12. Does your practice employ any mental health practitioners?

- Yes
- No

13. If no, does your practice have access to any mental health practitioners within your PCN?

- Yes
- No
- Not known

14. If yes how many mental health practitioners does your practice/PCN employ?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- Not known

15. What type of mental health practitioner is employed by your practice or available across the PCN?

- Nurse with additional training
- Mental health nurse
- Specialist Mental Health practitioner for Primary Care
- Psychological Wellbeing Practitioner (IAPT)
- Counsellor/Psychotherapist
- Psychologist (Counselling/Clinical)
- Not Known
- Other

16. If not do any mental health clinics occur in the practice?

- Yes
- No

17. If yes which organisation is the provider of these services?

18. How many mental health appointments are available per week in your practice or available to your practice in the PCN?

- Not known
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- >8

19. Are these for adult patients > 18 years only?

- Not known
- Yes
- No

20. If no from what age would CYP be offered mental health intervention at your practice?

- 0-5
- 5-10
- 10-12
- 12-14
- 14-16
- 16-18

21. What kind of interventions are offered?

- CBT
- Family therapy
- Psychotherapy
- Counselling
- Group sessions
-

Other

22. How are these interventions provided? (For example face to face or virtual sessions?)

23. Without doing a detailed search using various read codes do you know approximately how many CYP < 18 years with epilepsy you have registered at your practice?

- Yes
- No

24. If yes, please identify number of patients <18 years

- Not Known
- <6
- 7-10
- 11-15

- 16-20
- 21-25
- 26-30
- 31+

25. Does every CYP with epilepsy under the age of 18 years have an annual review with a GP or practice nurse?

- Yes
- No

26. When a CYP with epilepsy attends the practice for any reason is mental health screening conducted?

- Yes
- No

27. If yes how is this conducted?

28. How confident do you feel in identifying mental health problems in CYP with epilepsy

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

29. Without looking up the answer, how does the frequency of mental health issues in CYP with epilepsy compare to CYP without any health issues?

	Less Common	Same Frequency	Twice as common	Three times as common	Four time as common
Frequency of mental health issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. What, if any, mental health issues/diagnoses may be more common in CYP with epilepsy? (please tick all that apply)

- Not Known
- ADHD
- Anxiety Disorder
- Autism Spectrum Disorder
- Depression
- Obsessive-compulsive Disorder
- Psychosis
- Other

31. If you have answered 'other' to the question above, please identify mental health need(s)

32. In the event of suspected ADHD for a CYP with epilepsy please rank (1-6) in order of priority the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

- SEND local offer (if relevant)
33. In the event of suspected anxiety disorder for a CYP with epilepsy please rank in order of priority (1-6) the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

34. In the event of suspected Autism Spectrum Disorder for a CYP with epilepsy please rank in order of priority (1-6) the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

35. In the event of suspected depression for a CYP with epilepsy please rank in order of priority (1-6) the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

-
36. In the event of suspected obsessive-compulsive disorder for a CYP with epilepsy please rank in order of priority (1-6) the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

37. In the event of suspected psychosis for a CYP with epilepsy please rank in order of priority (1-6) the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

38. In the event of suspected self-harming behaviour for a CYP with epilepsy please rank (1-6) in order of priority the services to which you would refer the young person (1 being the highest priority)

Local CAMHS/ CYPS

Trust based health psychology

Community based psychology services linked to CCH

3rd sector organisations

School nurse/school based

SEND local offer (if relevant)

39. In your experience what are the approximate current waiting times for further assessment by the various mental health services in your area? Please select the number of months

	<3	3-6	6-12	12-18	18-24	>24	N/A
Local CAHMS/CYPS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-house trust health psychology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based psychology in CCH	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 rd Sector	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School based Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. When mental health concerns are identified who is this information shared with? Please tick all that apply and assume that children are under 16 years

- Parents/carers
- Hospital based medical team
- School nurse
- School SENDCO
- Respite care
- Residential care
- Other

41. Please provide any other relevant information in relation to sharing mental health concerns? (This question is optional)

42. In your experience, do you think that there are increased mental health problems in the parents/carers of children and VP with epilepsy?

Yes

No

43. Do you think that you spend more time supporting parental/carer mental health in parents/carers of CYP with epilepsy compared with CYP with other health conditions?

Yes

No

44. How confident do you feel about offering appropriate support to CYP with epilepsy?

Extremely confident

Somewhat confident

Neutral

Somewhat not confident

Extremely not confident

45. How confident do you feel about recognising when onward referral to mental health services is required?

Extremely confident

Somewhat confident

Neutral

Somewhat not confident

Extremely not confident

46. Do you ever feel that you are expected to offer support to children and young people with mental health issues which is outside your experience and expertise?

Yes

No

47. If yes, who do you approach for support when this is the case?

48. Could the mental health offer within your GP practice be improved with more training to identify mental health problems in CYP with epilepsy?

Yes

No

49. If you answered yes, which professional group/s would be the most effective to train?
Tick all that apply

GPs

Practice nurses

.....Other

50. Could the mental health offer within your GP practice be improved with more training in the use of specific tools to identify mental health problems?

Yes

No

51. If you answered yes, which professional group/s would be the most effective to train? Tick all that apply

GPs

Practice nurses

Other

52. Could the mental health offer within your GP practice be improved with more training to manage needs locally in practice?

Yes

No

53. If you answered yes, which professional group/s would be the most effective to train? Tick all that apply

- GPs
- Practice nurses
- Other

54. Could the mental health offer within your GP practice be improved with clearer referral pathways specifically for the mental health condition suspected?

- Yes
- No

55. Please use the space below to make any further comments about any of the issues above or any issues that have been left out of this survey but which are important to mental health and well-being in CYP with epilepsy and their families.

Appendix 7- Mental Health Services Mapping/Scoping

Mental Health Services Mapping and Scoping

Area	Service/department Name	Accessibility notes
North Tees and Hartlepool FT (NTHFT)	University Hospital North Tees & University Hospital Hartlepool:	Paediatric diabetes only. New service ASD under 5's
County Durham and Darlington FT (CDDFT)	Specialist Paediatric Health Psychology Service (via TEWV)	Not specific to epilepsy/neurology
County Durham and Darlington (community)	County Durham and Darlington Improving Access to Psychological Therapies (IAPT) service called Talking Changes	Long-term physical health conditions pathway-16y and over.
Tees, Esk and Wear Valleys NHS FT	Clinical Psychology based at Chester-Le-Street?? (Chester le street health centre?)	
TEWV CAMHS (North and South Durham teams, same referral route)	1)Middlesbrough CAMHS and learning disability CAMHS, 2)Redcar CAMHS and Learning disability CAMHS, 3) Hartlepool CAMHS and learning disability CAMHS 4) Stockton CAMHS and learning disability CAMHS	Single Point of access (separate referral for Neurodevelopmental team). 0-18 years old. Also accepts self-referrals
Tees Valley CCG	Hartlepool and Stockton's Need led Neurodevelopmental Pathway	Neurodevelopmental only
South Tees Hospitals FT (STHFT)	Clinical and Health Psychology team at James Cook: Clinical Psychology and Neuropsychology.	

South Tyneside and Sunderland FT (STSFT)	Clinical Psychology team	Adults only. Only covers: Bariatric Service (T3 and T4 assessment) Cardiology Services based at Sunderland Royal Hospital Chronic Fatigue Syndrome Diabetes Services based at Sunderland Royal Hospital Head & Neck Cancer Palliative Care Service Specialist Pain Management Service
Newcastle upon Tyne Hospital FT	Neuropsychology team/Health Psychology	
Northumbria Healthcare FT (NHCFT)	Health Psychology	
Northumbria Healthcare FT (NHCFT)	CAMHS North Tyneside	Up to 18 years old. North Tyneside.
Northumbria Healthcare FT (NHCFT)	North Tyneside Talking therapies	16 years +, Can provide specialist support for people with long term conditions such as COPD, heart disease and diabetes. North Tyneside residents/GP only
Northumbria Healthcare FT (NHCFT)	Primary Mental Health Work, early intervention and prevention service (Ponteland Primary care centre)	under 18's, moderate MH difficulties
Northumbria Healthcare FT (NHCFT)	Primary Mental Health Work, early intervention and prevention service (albion road clinic)	under 18's, moderate MH difficulties
Northumbria Healthcare FT (NHCFT)	'Be You' Programme	Trial in Hexham/Blyth. Part of PMHW
North Cumbria Integrated Care FT (NCIC)	Physical Health Psychology Cumbria	Only Diabetes, Cystic Fibrosis, Cardiac. Adults only for other physical health conditions. GP referral only

North Cumbria Integrated Care FT (NCIC)	Neuropsychology team	Adults only
Gateshead Health FT (GHFT) – QE Gateshead	Depends on address of YP- CNTW/CYPS for Gateshead residents; for out of area it's CYPS Monkwearmouth (South Tyneside/Sunderland) or Durham CAMHS	No access to clinical/health psychology at QEH for CYP- only through CYPS or perhaps tertiary neurology
CNTW		
Central community	EIP- Gateshead	Adult only
Central community	EIP-Newcastle	Adult only
Central community	CYPS Newcastle and Gateshead, Benton House	
North Community	CYPS Northumberland	Neuro and a mental health section.
North Community	Tees and Wear	see row 6
North Community	Stockton CAMHS (Tees, Esk and Wear)	
North Cumbria Access and Community	West Cumbria	CAMHS help children and young people who are finding it hard to cope with everyday life because of difficult feelings, thoughts, behaviour or relationships. 0-18 yrs. A comprehensive transition support package to those young people who are approaching their 18th birthday and may need continuing support as adults.
East Cumbria	East Cumbria CAMHS provided by CNTW	CAMHS help children and young people who are finding it hard to cope with everyday life because of difficult feelings, thoughts, behaviour or relationships. 0-18 yrs. A comprehensive transition support package to those young people who are approaching their 18th birthday and may need continuing support as adults.
South Community	Health Transition Nursing team- LD service Sunderland (help young people transition to adult services)	

South Community	CYPS South Tyneside and Sunderland	under 18's, Assessment, diagnosis and intervention on a range of mental health issues. Intensive response and home-based treatment for those children and young people whose mental health is causing significant concern. An intensive Eating Disorder Service to support children and young people on the eating disorder pathway who are at risk of an inpatient admission. A comprehensive transition support package to those young people who are approaching their 18th birthday and may need continuing support as adults. 24-hour access to support via a single point of access.
South Community	Sunderland Centre for Specialist Psychological Therapies – Sunderland Psychotherapy Service	Adults only.
Specialist CYPS	Complex Neurodevelopmental Disorders Service (CNDS)	ASD only. Not ongoing MH support- assessment only. We accept referrals from local Child and Adolescent mental health services and Child Health/Paediatric Services. Your child's case must be open to one of these services for the duration of their assessment/consultation with CNDS. Unfortunately we cannot accept referrals directly from parents or from GP/health visiting services.

Appendix 8- Mental Health Leads Questionnaire

Mental Health Professionals with regard to mental health in CVP with Epilepsy

This questionnaire forms part of a piece of work commissioned by the **NENC** ICS Child Health and Wellbeing Network.

The purpose of this questionnaire is specifically to explore the availability and gaps in mental health assessment and provision for CYP with epilepsy and it would be extremely helpful and very much appreciated if you could take the time to complete this. We are looking to understand the availability of services and pathways serving local populations in order to develop recommendations to improve these for CYP with epilepsy.

Questionnaire completion is estimated to take 30 minutes

1. Which best describes your role?

- Art therapist
- Primary Mental Health Worker
- Psychologist (Clinical, Counselling, Educational)
- Family therapist
- Nurse
- Psychiatrist
- Psychological therapist
- Social Worker
- Support Worker
-
- .Other

2. If other, please specify

3. In what region do you work? (please select all that apply)

- County Durham

-
- North Cumbria (East)
 - North Cumbria (West)
 - Darlington
 - Gateshead
 - Hartlepool
 - Middlesbrough
 - Newcastle-upon-Tyne
 - North Tyneside
 - Northumberland
 - Redcar & Cleveland
 - Sunderland
 - South Tyneside
 - Stockton-On-Tees
 -
- Other

4. If other locality, please specify

5. What type of mental health setting do you work in?

- CAMHS/CYPS
- CAMHS Learning Disabilities
- Health Psychology
- Neuropsychology
- Talking Therapy (IAPT)

Third Sector

Other

6. If other, please specify

7. Does your service see children with a Learning/Intellectual disability?

Yes

No

8. If you answered "no" to the question above, which service in your area, would you refer CYP with a Learning/Intellectual disability and mental health problems?

9. What is the age range of the children and young people accessing your service?
(Please mark all that apply)

Under 5

5-10

11-13

14-15

16+

10. Are there any clinicians in your team with an interest in Epilepsy?

Yes

No

Not sure

11. In the last five years, have you ever worked with a child or young person with Epilepsy?

- Yes
- No
- Not sure

12. Does your service record the presence of epilepsy in CYP anywhere other than in the patient record?

- Yes
- No

13. Without doing a detailed search, do you know approximately how many CYP < 18 years with epilepsy are currently on your team caseload?

- Yes
- No

14. If yes please state approx. number

15. If you receive a referral for a CYP with epilepsy who is suspected of having an underlying mental health condition where is the referral most likely to have come from?

	Very frequently	Somewhat Frequently	Same as other referrers	Somewhat infrequently	Very Infrequently
Hospital based paediatric services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based paediatric services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School based health services/school nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary care/GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other

16. If other please state referral source(s) and comment on frequency

17. How confident do you feel in identifying mental health problems in CYP with Epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

18. How confident do you feel in identifying mental health problems in CYP with Epilepsy who have a learning/intellectual disability?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

19. Without looking up the answer, how does the frequency of mental health issues in CYP with epilepsy compare to CYP without any health issues?

- Less common
- Same frequency
- Twice as common

- Three times as common
- Four times as common

20. In your experience what, if any, mental health issues/diagnoses may be more common in CYP with epilepsy? (please tick all that apply)

- ADHD/ADD
- Anxiety
- Autism Spectrum Disorder
- Depression
- Obsessive-compulsive disorder
- Psychosis
- Other

21. If other, please specify

22. In your experience which of the conditions listed below are the most frequent reason for referral of a CYP with epilepsy to your service

	Very Frequently	Somewhat Frequently	Same as other CYP	Somewhat Infrequently	Very Infrequently
ADHD/ADD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism Spectrum Disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obsessive- compulsive disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Psychosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-harming behaviours	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. If other please state condition(s)/need(s) and give approx. frequency

24. Which of the conditions listed below would your service assess and advise on management in a CYP with epilepsy- tick all that apply

- ADHD/ADD
- Anxiety
- Autism Spectrum Disorder
- Depression
- Obsessive-compulsive disorder
- Psychosis
- Self-harming behaviours
- other

25. If other, please specify

26. What would be the approximate waiting time from receipt of referral for a CYP for an initial assessment in your service?

Not Applicable	<3 month	3-6 month	6-12 month	12-18 month	18-24 month	>24 month
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	e	s	s	s	s	s	s
Mental health need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurodevelopmental need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. What would be the approximate waiting time from receipt of referral for a CYP to receive a therapeutic intervention?

	Not Applicable	<3 months	3-6 months	6-12 months	12-18 months	18-24 months	>24 months
Mental health need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurodevelopmental need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Do you think that the type of mental health support required by CYP with epilepsy differs from that needed by other CYP?

Yes

No

29. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

ADHD/ADD

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

30. Regarding 'other' and 'third sector' please state organisation/service

31. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

Anxiety

CAMHS/CYPS

CAMHS Learning Disabilities

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

32. Regarding 'other' and 'third sector' please state organisation/service

33. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

Autistic Spectrum Disorder

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public Health School Nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

34. Regarding 'other' and 'third sector' please state organisation/service

35. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

Depression

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

36. Regarding 'other' and 'third sector' please state organisation/service

37. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)
Obsessive-compulsive disorder

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

38. Regarding 'other' and 'third sector' please state organisation/service

39. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

Psychosis

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

40. Regarding 'other' and 'third sector' please state organisation/service

41. If a mental health need is identified in a CYP with epilepsy, and your service is not the most suited to support the CYP, who would you refer or signpost the family to? (please rank in order with 1 being the most likely to refer to and 8 being least likely)

Self-harming behaviours

CAMHS/CYPS

CAMHS Learning Disabilities

Paediatrician

Health Psychology/ Neuropsychology

Public health school nurse

Talking Therapy (IAPT)

Third Sector (e.g. Epilepsy Action)

Other

42. Regarding 'other' and 'third sector' please state organisation/service

43. If there are any conditions not discussed above in questions 24 to 36 inclusive, please state condition and where you would refer to?

44. Do you think that CYP with epilepsy are more or less likely than other children, to have cognitive difficulties?

- More likely than other CYPs
- Same as other CYPs

45. If you answered more likely, what kind of cognitive difficulties do you think that they are more likely to have? (Tick any that apply)

- Global cognitive impairment
- Specific problems with attention and concentration
- Specific problems with executive function (independent planning, personal organisation, self-control, flexible thinking)
- Specific problems with mathematical reasoning
- Specific problems with memory (working memory/long-term memory)
- Specific problems with processing speed
- Specific problems with reading
- Specific problems with verbal comprehension
- Specific visuo-spatial problems

46. How confident do you think you and your staff feel about recognising specific cognitive problems in CYP with Epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

47. Does your service provide cognitive assessment for CYP with Epilepsy?

- Yes
- No

48. If you have selected 'No' to the question above, and a cognitive need (such as memory difficulties) is identified in a CYP with epilepsy, who would you refer or signpost the family to? (select all that apply)

- General Practitioner
- Paediatrician
- Health Psychology
- Neuropsychology
- Public Health School Nurse
- Third Sector (e.g. Epilepsy Action)
- Other

49. If other, please specify

50. Are you a medical prescriber?

- Yes
- No

51. If yes, how confident do you feel prescribing stimulant medication to CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

52. How confident do you feel prescribing antidepressants to CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

53. How confident do you feel prescribing antianxiety medication to CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

54. How confident do you feel prescribing anti-psychotics to CYP with epilepsy?

- Extremely confident
- Somewhat confident
- Neutral
- Somewhat not confident
- Extremely not confident

55. Approximately what percentage of your team have received specific epilepsy training, outside of paediatric first aid, or general first aid accredited courses?

- 0-25%
- 26-50%
- 51-75%
- 76-100%

56. If epilepsy training has been delivered, who has provided it?

- Provided by epilepsy nurse
- Provided by an outside organisation

Other

57. If outside organisation or 'other' has been selected, please provide more detail and specify the delivery organisation.

58. Are you aware of training resources, for epilepsy? (e.g. through the Epilepsy Society, Young Epilepsy)

- Yes
- No

Gaps: moving forward

59. Do you think the way in which mental health settings record and review mental health and cognitive difficulties for CYP with epilepsy, requires improvement?

- Yes
- No
- Maybe

60. If you answered 'yes' to the above question, how do you think it could be improved?

61. Do you think that further staff training is required with regard to the identification and intervention of mental health and/or cognitive difficulties for CYP with epilepsy? (Tick all that apply)

	Yes – further staff training is required	No further training is required
Identification of mental health	<input type="radio"/>	<input type="radio"/>
Identification of specific cognitive problems	<input type="radio"/>	<input type="radio"/>
Intervention for mental health	<input type="radio"/>	<input type="radio"/>
Intervention for specific cognitive problems	<input type="radio"/>	<input type="radio"/>

62. Which of the following models of service for providing mental health assessment and intervention do you think best meets the needs of CYP with epilepsy?

- Local CAMHS/CYPs
- Hospital based health psychology/psychiatry
- IAPT or other community-based therapy services
- School based services
- Other

Appendix 9- Epilepsy Specialist Nurse (ESN) Summary Narrative Introductory Overview for ESNs

Dear (insert name of nurse here),

As you are aware, the NENC Child Health and Wellbeing Network is carrying out two parallel but related scoping projects relating to paediatric epilepsy. The project we are contacting you about is the one relating to mental health and epilepsy in CYP. A crucial part of the project involves hearing from CYP themselves and their parents/carers to ensure that their views, perspectives and experiences are included. You kindly assisted us recently by completing the questionnaire for ESNs on this subject and we would be very grateful to you for some further assistance.

We would be grateful for your help in identifying and approaching 1-2 young people (aged between 12-17 years old) who you think would be willing to participate in a focus group regarding mental health and epilepsy. We plan to have a final group of between 4-8 young people from across the region who would be willing to share their views, service experiences and thoughts about service models regarding mental health and epilepsy. We have decided not to approach CYP with learning disability for this part of the project. The group meeting will take place virtually over Teams, and will last for around 90 minutes. However, if a young person is interested in sharing their views but does not wish to take part in a group event, we will offer a 1:1 interview.

We would also like to host an additional and separate focus group for the parents and carers of the young people to cover the same issues but from their perspective. We would therefore be very grateful if you would be willing to approach their parents/caregivers at the same time as approaching the young person to ask if they would be interested in participating in this.

As previously mentioned there are two parallel projects running simultaneously (Helen Gilpin may have already asked you to start identifying some families for the other part of the project). To avoid excessive demands on families we think that it would be beneficial to identify different families for the different strands of the project. Therefore, we hope that identifying one or two families on your caseload for this part of the project will feel manageable.

Your role would be to approach the young person and the parents/carer with the information above and if they are interested in participating, obtain their contact details and their consent for you to share these details with us. We will then contact them separately to provide further details about the planned focus group meeting including the consent process required to take part.

Appendix 10- Epilepsy Nurse Specialist (ESN) Consent to Contact Form



APPENDIX 10 CONSENT TO CONTACT FORM (VERSION 0.3)

Mental Health in Young people with Epilepsy

Please fill in the form, initialling the relevant box only if you agree.

Please initial box

- 1 I agree to the clinicians from the above project contacting my child and me to explain more about this group.

This is the phone number I wish to be contacted on:

This is my postal address so I can be sent further written information about the group:
.....

This is my email address so I can be sent further information about the group:
.....

My preferred method of contact is (tick):

Email	<input type="checkbox"/>
Telephone	<input type="checkbox"/>

Preferred time for parent group to take place (please cross out any that do not suit)

Weekday	Morning	Afternoon	Evening
Weekend	Morning	Afternoon	Evening

Preferred time for CYP group/interview to take place (details will be confirmed once all families have been contacted):

Weekday	Morning	Afternoon	Evening
Weekend	Morning	Afternoon	Evening

Please note any dates/times that do not work for family. Details will be confirmed once all families have been contacted):

Name (Block Letters)

Date

Signature

Appendix 11- Parental Consent Form



Appendix 11|

Verbal Consent

Participant ID:	Initials:
Date of Birth (CYP):	NHS/Hospital Number (CYP):
Name of person taking consent:	
Date of verbal consent call: _/_/___ (dd/mmm/yyyy)	
Time of verbal consent call: _/_ (00.00 hr)	
Format of verbal consent e.g. video, phone call:	

We would like to send you a copy of the consent form to keep for your information. Could you please confirm for me how you would like to receive this, via post or email (**highlight preferred option**)? Please confirm your contact details for me:

Address:.....

Email:

PARTICIPANT VERBAL CONSENT CONFIRMATION FORM (PARENT)

- | | | |
|--|---------------------------------|--------------------------------|
| 1. After explaining the one-off group/1:1 interview to the participant's parent/carer, I can confirm that the parent/carer understands and agrees to their child participating in the one-off group/ 1:1 interview (please cross out the one that does not apply). | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 2. After explaining the one-off group meeting to the parent/carer, I can confirm that the parent/carer understands and agrees to participate in the group. | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 3. The parent/carer understands and agrees that the group/ interview is voluntary, and that their child can withdraw at any time without their medical care or legal rights being affected. | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 4. The parent/carer understands and agrees that the group is voluntary, and that they can withdraw at any time without their medical care or legal rights being affected | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 5. The parent/carer understands and agrees to the storage, including electronic, of their child's personal information for the purposes of this project. They understand that any information that could identify their child will be kept strictly confidential and that no personal information will be included in study reports or other publications. | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 6. The parent/carer understands and agrees to the storage, including electronic, of their own personal information for the purposes of this project. They understand that any information that could identify them will be kept strictly confidential and that no personal information will be included in study reports or other publications. | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 7. The parent/carer agrees to their child's X session being audio-video recorded for the purposes of being transcribed for research | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 8. The parent/carer agrees to their group session being audio-video recorded for the purposes of being transcribed for research | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |

Participant's parent/carer

Full name (*block capitals*):

Date/time verbal consent provided by participant:

DD/MMM/YYYY Time (24 hr)

..... / /:.....

Person taking consent

I have explained the study to the above named participant's parent/carer and they have indicated their willingness for their child to participate.

Full name (*block capitals*):

Signature:

Date:

DD/MMM/YYYY

..... / /

Original to be retained and filed in the site file, one copy for the participant, and one copy to be filed in the participant's medical notes.

Appendix 12- YP (16/17) Consent form



Appendix 12

Verbal Consent

Participant ID:	Initials:
Date of Birth (CYP):	NHS/Hospital Number (CYP):
Name of person taking consent:	
Date of verbal consent call: _/_/____ (dd/mmm/yyyy)	
Time of verbal consent call: _/_ (00.00 hr)	
Format of verbal consent e.g. video, phone call:	

We would like to send you a copy of the consent form to keep for your information. Could you please confirm for me how you would like to receive this, via post or email (**highlight preferred option**)? Please confirm your contact details for me:

Address:.....

Email:

PARTICIPANT VERBAL CONSENT CONFIRMATION FORM (CYP 16+)

- | | | |
|--|---------------------------------|--------------------------------|
| 1. After explaining the one-off group/1:1 interview to the participant, I can confirm that they understand and agree to participating in the one-off group/ 1:1 interview (please cross out the one that does not apply). | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 2. The participant understands and agrees that the group is voluntary, and that they can withdraw at any time without their medical care or legal rights being affected | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 3. The participant understands and agrees to the storage, including electronic, of their own personal information for the purposes of this project. They understand that any information that could identify them will be kept strictly confidential and that no personal information will be included in study reports or other publications. | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 4. The parent/carer agrees to their group session being audio-video recorded for the purposes of being transcribed for research | Yes
<input type="checkbox"/> | No
<input type="checkbox"/> |

Participant

Full name (*block capitals*):

Date/time verbal consent provided by participant:

DD/MMM/YYYY Time (24 hr)

..... / /:.....

Person taking consent

I have explained the study to the above named participant and they have indicated their willingness to participate.

Full name (*block capitals*):

Signature:

Date:

DD/MMM/YYYY

..... / /

Original to be retained and filed in the site file, one copy for the participant, and one copy to be filed in the participant's medical notes.

Appendix 13- Parent Information Sheet

North East and North Cumbria: Child Health and Wellbeing Network

Epilepsy and Mental Health Project

Parent Information Sheet

Version 0.1, Dated 28-Feb-2022

Contact details

Dr Chloe Geagan, Clinical Psychologist

Old Children's Outpatients

Royal Victoria Infirmary

Queen Victoria Road

Newcastle Upon Tyne

NE1 4LP

Telephone: 0191 282 4081

1.What is the purpose of these groups?

Epilepsy is the most common neurological condition in childhood, affecting 112,000 children and young people (CYP) in the UK. Having epilepsy can have a big impact on quality of life for young people and their families. One of the key difficulties is learning to cope with long-term problems that might not go away. The best possible management of epilepsy improves epilepsy-related health outcomes, as well as supporting learning, behaviour, mental health and quality of life.

The issue of mental health support for CYP with epilepsy has been identified as an area of specific need. In order to do this, we are running two separate one-off groups (one for children and young people, and one for parents). The focus of these one-off groups is to gather views from CYP and their parents about how mental health support is included within their routine epilepsy care and whether there may be ways to improve this.

2.Who is running these one-off groups?

We are reaching out to you on behalf of the North East and North Cumbria Child Health and Wellbeing Network. Epilepsy Clinical Leads from hospitals in the region have been appointed to the Child Health and Wellbeing Network, to undertake a scoping and mapping exercise within the North East and North Cumbria. Psychology professionals based at the Great North Children's hospital in Newcastle Upon-Tyne will run both groups.

3.Why have we been asked to take part?

- a) Why have we been asked to take part?
 - Your child is being invited to take part because they have epilepsy and are between the age of 12-17
 - We would like to hear from you, the parent of a child or young person with epilepsy, about your experiences of mental health issues and services available to help your child with this.
- b) Do you have to take part in this group?
 - No. It is up to you and your child to decide whether to take part. If you decide to take part, you will be given this information sheet and children will be given their own version to read. You will be asked to sign or verbally complete a consent form to confirm that you understand what is involved when your child takes part in this group. If you and your child decide to take part, you are both free to leave the group at any time and without giving a reason.
 - If we do not get enough people interested in the CYP group, or if your child does not wish to take part in a group (but would still like to contribute), they will be

offered the opportunity for a 1:1 interview with one of the Psychology professionals.

- Unfortunately, due to time restrictions on this project, parents will only be offered the opportunity to take part in a group. 1:1 interviews will not be possible at this time.
- A decision to withdraw at any time, or a decision not to take part, will not affect the care your child receives.

4. What do we have to do ?

- a) What will happen to us if we agreed to take part in the one-off group meetings?
- One of our clinical psychologists will ask to speak with you and your child. If you are happy for them to speak to you, they will explain the groups in more detail and ask you and your child some questions. We will answer any questions you may have. We will ask for your verbal consent to allow your child to take part in the study. We will ask your child for their verbal agreement to take part after they have had the group explained to them and we have answered all their questions. The clinical psychologist will then try and find out what times would be best for you and your child to take part in the groups. These will be on different days in order to allow the group facilitator to run both.
 - Both the CYP group and parent group will take place with 4-8 people and will last no more than 90 minutes (1.5 hours). Most of the time will be spent answering questions about how you feel mental health is included in your child's epilepsy care and whether there are things that you would like to be different. We might ask if anyone feels able to talk about their own experiences of mental health problems and the support that was available to them. Similar questions will be asked in both groups.
 - The meeting will be over video call (Microsoft Teams), so that you can attend from home. With your permission, we will audio-video record the group meeting so that we do not miss anything important. Both group recordings will be destroyed once the project is finished. Any use of recordings for the project will only be from written transcripts with all names, places and dates removed so you or your child cannot be identified. The Psychology professionals who have facilitated the group and who will follow the confidentiality agreement in place will type transcripts.
 - We may use anonymous quotes from the group or interviews in reports or materials arising from the project.
 - Responses to the group/interview questions will be stored safely and anonymously.

- If you and your child decide you will take part in this study, you will be given a copy of this information sheet to keep and a copy of the signed consent form.
- Participation in this project does not affect your child's rights to consult your usual doctors or seek treatment from other healthcare providers. If you have any concerns about your child's symptoms you should continue to see your usual doctors and/or other healthcare providers.
- If your child chooses to complete a 1:1 interview instead of a group meeting, all of the above apply. However, they will be given the option to complete the interview over the phone or over video call.

5.What are the possible benefits?

- There will be no direct benefit for you or your child taking part in these groups or interviews. However, the experience and opinions you share could help improve services for you and other young people with epilepsy in the future.

6.What are the disadvantages?

- Group members will be able to contribute their views about any mental health problems that they have faced and what was available or offered to them if they wish. If group members have or have not faced any mental health issues, then they can still share their views on what they think would be helpful to young people with epilepsy who need mental health support. Most people do not mind these questions, but some people may find discussing these topics upsetting.

7.What will happen to my data?

a) Will my child's taking part in this study be kept confidential?

- If you consent for your child and you to take part in this project, any information collected will remain strictly confidential at all times. Information such as consent forms will be held securely at your child's treating hospital under the provisions of the General Data Protection Regulation and the Data Protection Act. People who do not need to know who your child is will not be able to see their name or contact details. Your child's data will have a code number instead.
- The only time that confidentiality would change is if we felt we needed to share relevant information to protect your child's safety or the safety of others.

b) Use of your child's personal data in the project

- We will need to use some information from your child for this project. This information will include your child's name, date of birth, locality and contact details. This information will only be shared with us if you have agreed to speak to us after your child's epilepsy specialist nurse has initially contacted you.
- If you withdraw consent before the group/interview, your details and your child's details will be removed from the project.
- In line with Good Clinical Practice guidelines, at the end of the study, your data will be securely archived for a minimum of 5 years. After this period arrangements for confidential destruction will be made.
- Once we have finished the project, we will use the data to analyse the results. We will write our reports in a way that no-one can work out that you or your child took part in the project. You and your child can stop being part of the project at any time, without giving a reason, but we may keep information about them that we have already collected if they have completed the group. Information from 1:1 interviews will be deleted.
- If you agree for your child to take part in this project, they will have the option to be invited to take part in future work related to this project.

8.What will happen if my child or I do not want to carry on with the group?

- You and your child can decide to withdraw at any time without giving a reason. This would not affect any other healthcare they receive. Please tell you Epilepsy Specialist Nurse or the group facilitator (Chloe Geagan) if you do not wish to continue.

9.What happens when the study is finished?

- Your child's care will not change as a result of taking part in the project. So after the project you can continue to access your child's usual healthcare providers in the same way. If you are interested in finding out the results of the project, we can keep your contact details and inform you of results when the project is completed.

10. What if there is a problem?

- If you or your child has a concern about any aspect of the group or interview, ask to speak with the group facilitator (Chloe Geagan) who will do her best to answer your questions.
- If you remain unhappy and wish to complain formally, you can do this through the Child Health and Wellbeing Network.

11. Further Information

- You are encouraged to ask any questions you wish before, during or after you or your child participate in the group (or 1:1 interview if your child selects this option). If you have any questions about the group, please speak to a member of the project team using the contact details at the top of this information sheet. They will be able to provide you with up to date information about what the group/interview involves. If you require any further information or have any concerns while taking part in the study please contact the group facilitator (listed at the top of this document).
- If you decide you would like your child to take part then please read and complete the consent form. You will be given a copy of this information sheet and the consent form to keep. A copy of the consent form will be filed in your child's medical notes, and one will be filed with the project records.
- You can have more time to think this over if you are at all unsure. Please let us know by the 14th March 2022.

Appendix 14- Young Person Information Sheet

North East and North Cumbria: Child Health and Wellbeing Network

Epilepsy and Mental Health Project

Participant Information Sheet

Hello! You have been given this information sheet because your doctor or nurse thinks that you may be interested in taking part in a one-off group meeting of children and young people with epilepsy. .

Please read the information below to learn more about the group. If you find you have any questions after reading the information, please do not be afraid to ask.



Who do I contact if I have questions?

If you have any questions about this group meeting please contact your Epilepsy Specialist Nurse or:

Dr Chloe Geagan - Clinical Psychologist
Group facilitator
Tel: 0191 282 4081

What is this group about?

We would like to hear from children and young people with epilepsy about their experiences of mental health issues and services available to help with this.

Why do we need this information?

We want to learn from you how we can improve the support for young people with epilepsy who need mental health support.

Why have I been invited?

You have been invited because you have epilepsy and you are aged between 12 and 17 years old. Your Epilepsy Specialist Nurse thought you might be interested in taking part.

Do I have to take part in the group and can I change my mind?

You do not have to take part. You can say no if you want to. This will not change how you are treated by your doctors. If you agree to take part and change your mind, then that is okay you can stop taking part. You do not need to give us a reason.

What will happen to me if I take part in this group?

You will be invited to attend a one-off group meeting with other young people with epilepsy that will last no more than 90 minutes (1.5 hours). Most of the time will be spent answering some questions about how you all feel mental health is included as part of your epilepsy care and if there are things that you would like to be different. We might ask if anyone feels able to talk about their own experiences of mental health problems and the support that was available to them. You do not need to tell us anything if you are not comfortable doing so. Your parents or other family members will be invited to attend a different group so that we can get their views and opinions on mental health in epilepsy.

This meeting will be conducted over a video call (Microsoft Teams), so you can attend from home. With your permission, we will audio-video record the group meeting or so that we do not miss anything important. We will then type everything that was said and take out any names or places, so that there is no way in which those who participated can be identified.

What will happen to any information about me?

Your information will be used by the epilepsy project team of the Child Health and Well-being Network of the new Integrated Care System (ICS) to find out what you think about the mental health support available to you as part of your Epilepsy care. When your information is used, it will not have your name or anything that could identify you. All information collected as part of this group will be kept confidential and stored securely.

Any recordings from the group will be deleted by 30th September 2022

Will taking part in this group help me?

There will be no direct benefit for you taking part in this group. However, the experiences and opinions you share could help to improve services for you and other young people with epilepsy in future.

What are the disadvantages or risks of taking part?

Group members will be able to contribute their views about any mental health problems that they have faced and what was available or offered to them if they wish. If group members have or have not faced any mental health issues, then they can still share their views on what they think would be helpful to young people with epilepsy who need mental health support. Most people do not mind these questions, but some people may find discussing this upsetting.

Can I have more time to decide?

Yes, you do not need to decide right now. However, we do need to know **by 14th March 2022**. Please discuss participation in this group with anyone you think can help you to decide.

What if I want to stop participating?

You may stop at any stage, without saying why - just tell your nurse or the group facilitator (Chloe Geagan).

What do I do if I have concerns about the group?

If you have any concerns or questions before or after taking part in the group, you should contact the group facilitator (Chloe Geagan). She will be happy to answer any questions you might have.

Appendix 15- Engagement Group Agreement Form

North East and North Cumbria: Child Health and Wellbeing Network

Stakeholder Engagement Group Agreement

Epilepsy Discussion Session

The group will do lots of different things, including:

- Give feedback to service managers, leads and commissioners to help them improve their services
- Support researchers and colleagues communicate with and get real feedback from young people who receive health services
- Make sure that service improvement is based largely on the experiences and views of CYP who use the services
- Make sure members of the understand what the research is about and what is expected of them
- Develop links and support the potential for developed relationships between CYP in our local ICS area
- Tell other young people what researchers are finding out through written summaries also presenting the information (without identifying individuals) at events (e.g. conferences)

Group members should:

- Be willing to be part of the discussion group and be open-minded and supportive of others who are also attending and participating
- Respect the confidentiality of others in the group
- Work as a team with other group members
- Respect other people's views
- Try to come to the meeting if they have agreed to and let the group organisers know if they cannot attend a meeting or are going to arrive late
- Remember that it is OK to ask questions and say what you think about something

Group organisers will:

- Organise the meeting and send details out in good time
- Make sure that meetings are comfortable, safe, interesting and enjoyable.
- Make sure that any reports or information gathered does not identify individuals in any way
- Make sure that people who have contributed receive feedback about the work and how their views and input have contributed to service improvement

I confirm that I am happy to be a member of the discussion group and understand what this will involve.

Name (print)

Signature Date

Appendix 16 – Focus Group Interview Prompts

Focus Group Interview Prompts

Epilepsy.org.uk: [What information do children and young people with epilepsy need about mental health? | Epilepsy Action](#)

What will I have to do?

You will be asked to join one online focus group using Zoom (you don't have to have your camera on) or have an interview over the phone. You can also have someone with you during the focus group or telephone interview if you want. You can choose which would be best for you. Each focus group or interview will last about 90 minutes.

If you are a child or young person, you will be asked questions like: Do you think it would be helpful to know more about mood (e.g. happiness, worry, sadness) and epilepsy?

Parents/carers will be asked questions like: Do you think it would be useful for you and your child to receive information on mental health and epilepsy?

Epilepsy focus group (Parents)

Opening/Introduction: Thanks for participating in the study and for giving up this time.

Reminder of the focus of the study: We are interested in finding out about your views about mental health and epilepsy and your experiences about the how things have been for your child.

Introductions: facilitators and ppts. Give reminder regarding the confidentiality of the data and how results will be used. Double check that they have signed 'group agreement'.

1. **Can you tell me a little about your child's epilepsy and how their epilepsy affects you?**
 - a. *Physically, emotionally, socially, family life, etc*
 - b. *Do you feel like you need to make changes to your daily life because of your child's epilepsy*
 - c. *School, impact, learning*
 - d. *Participation, impact on self-esteem*
 - e. *Impact on home life? Social life? Self-view*

2. **Has your doctor (or other health professional) ever asked your child about their mental health or general well-being at any point during your epilepsy care?**
 - *What does mental health mean to you?*

- *What aspects of MH would you want to discuss in an appointment*
- *What kind of questions were asked, e.g. how are you feeling, worries, low mood*
- *Asked to complete a questionnaire? general conversation, chat*
- *What was that like?*
- *Did you feel like your child was able to talk about how they felt? Any barriers, e.g. setting/relationship with staff, parents being there*
- *Those who weren't asked a) would you mind being asked about it, b) should it become part of a routine in care*
- *How able do you feel to have conversations about mental health with your child?*
- *If you wanted to speak to someone about how your child was feeling- would you like to have someone in the clinic that you could speak to in the hospital, or would you prefer to keep it separate. Why? What would be the benefit? What would be the downsides.*

3. What kind of information or support would you like to receive about mental health and epilepsy?

- *Example: Knowing where to go if needed help, signs to look out for, general information, how others around you could support you (friends, family, school)*
- *Would this information be best given verbally, leaflets, websites*
- *If struggling with mental health, who would you approach*
- **Optional:** *if willing to share, anyone experienced difficulties with mental health as a result of looking after a child with Epilepsy (see if linked with Epilepsy- careful if not). What was this like, did you receive support, would you have liked anything to have been different.*
- *What services are you aware of for support, what have you been directed towards*
- *Was this support useful? How easy was it to access support (was it a charity, mental health team, e.g. CAMHS etc, apps)*

4. Are there any questions you wished we had asked you about this topic (leave time to discuss)

- *Is there anything else that we have not spoken about that was important about your experiences? Or anything else you would like to add?*

Session close: reiteration of confidentiality and how data will be used. Contact details for facilitator if they have questions.

Epilepsy focus group (CYP)

Opening/Introduction: Thanks for participating in the study and for giving up this time.

Reminder of the focus of the study: We are interested in finding out about your views about mental health and epilepsy and your experiences,

Introductions: facilitators and ppts. Give reminder regarding the confidentiality of the data and how results will be used. Double check that they have signed 'group agreement'.

5. **Can you tell me a little about when your epilepsy and how your epilepsy affects you?**
 - a. *Physically, emotionally, socially, family life, etc*
 - b. *Do you feel like you are treated differently by others such as your parents compared to other people your age, e.g. what you can and can't do (socialising, hobbies etc)*
 - c. *School, impact, learning*
 - d. *Participation, impact on self-esteem*
 - e. *Impact on home life? Social life? Self-view*

6. **Has your doctor (or other health professional) ever asked you about your mental health or general well-being at any point during your epilepsy care?**
 - *how are you feeling, worries, low mood*
 - *Asked to complete a questionnaire? general conversation, chat*
 - *What was that like?*
 - *Did you feel able to talk about how you felt? Any barriers, e.g. setting/relationship with staff, parents being there*
 - *Those who weren't asked a) would you mind being asked about it, b) should it become part of a routine in care*
 - *If you wanted to speak to someone how you are feeling- would you like to have someone in the clinic that you could speak to in the hospital, or would you prefer to keep it separate. Why? What would be the benefit? What would be the downsides?*

7. **What kind of information would you like to receive about mental health and epilepsy?**
 - *Example: Knowing where to go if needed help, signs to look out for, general information, how others around you could support you (friends, family, school)*
 - *Would this information be best given verbally, leaflets, websites*
 - *If struggling with mental health, who would you approach*
 - **Optional:** *if willing to share, anyone experienced difficulties with mental health (see if linked with Epilepsy- careful if not). What was this like, did you received support, would you have liked anything to have been different.*
 - *Was this support useful? How easy was it to access support (was it a charity, mental health team, e.g. CAMHS etc, apps)*

8. **Are there any questions you wished we had asked you about this topic (leave time to discuss)**
 - *Is there anything else that we have not spoken about that was important about your experiences? Or anything else you would like to add?*

Session close: reiteration of confidentiality and how data will be used. Contact details for facilitator if they have questions.