Child Health and
Wellbeing Network
North East and North Cumbria

Epilepsy Project 2:

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

North East and North Cumbria

Child Health and Wellbeing Network

Findings and Recommendations Paper

October 2022

Follow us @EveryChildNENC

iCS
Integrated Care System
North East & North Cumbria

Foreword from the Child Health and Wellbeing Network

Dear Network Member

It gives us great delight to share this in-depth baselining report that has been developed by the Epilepsy Clinical Advisor in partnership with the Child Health and Wellbeing Network. We are proud that this work represents an example of close collaboration between primary, secondary and tertiary care and also the inclusion and involvement of wider stakeholders including education partners, Children and Young People and their families.

This provides us with a clear baseline about the availability of and access to psychology and mental health support services for CYP with epilepsy in the North East and North Cumbria ICS region. The report findings and recommendations enable us to identify areas of challenge and provisions to make service improvement.

It will be helpful to have this resource as a baseline to enable future review and an ability to monitor our progress and the impact of the ICS wide service improvement programme that will be the result of this evaluation and scoping work.

This report will be widely available to systemwide colleagues and partners and will be of particular interest to ICB commissioners and NHS Foundation Trust Chief Executive Officers and Specialist Clinical and Mental Health Leads as we seek to make necessary improvements.

The CHWN has developed its strategic relationship with the Paediatric Epilepsy Network North East and Cumbria (PENNEC) and will continue to work in partnership and support to operationalise and resource broader system improvement.

We hope that the incidence and prevalence modelling information contained within will help us to identify and target our limited resources to improve health outcomes for those CYP who are more likely to suffer challenge due to socioeconomic factors and other health inequalities.

The analysis of information is available at granular level and is rich and allows us to pinpoint areas of particular concern. Within the PENNEC/NENC ICS localities, acute Trusts in South Tees, Newcastle, South Tyneside and Sunderland and North Tees & Hartlepool are seeing CYP from the most deprived areas.

This report presents us with a golden opportunity to identify and share good practice and to provide clarity on how to make the biggest impact on the experiences, outcomes and ultimately the lives of CYP with epilepsy, and their families, in the NENC ICS region.

We hope this report is a helpful resource to highlight our areas for improvement and we look forward to working alongside you to achieve some longer-term Children and Young People Transformation Programme goals.

We must also acknowledge the multi-agency and systemwide team who formed to produce this report under the leadership of Dr Anita Devlin as the CHWN Epilepsy Clinical Advisor and

North East and Yorkshire Regional Advisor for Childhood Epilepsy. Please see the foreword from Dr Devlin that follows for these acknowledgements.

Best wishes

Dr Mike McKean

Heather Corlett

Clinical and Programme Leads of the NENC ICS's Child Health and Wellbeing Network (respectively) **Senior Responsible Officers** for the NENC CYP Transformation Programme

Preface

I am very pleased to present this report on behalf of the Child Health and Wellbeing Network (CHWN) for the North-East and North Cumbria (NENC) Integrated Care System (ICS). I have been a Consultant Paediatric Neurologist at the Great North Children's Hospital for over twenty years. Practitioners in the field of epilepsy in children and young people (CYP), have long recognised and attempted to address the additional mental health needs of this group and their parents/carers. However, there has been a lack of resource and expertise to do this adequately and in that sense, epilepsy services for CYP have fallen behind services for other long-term conditions such as diabetes.

It is due to the excellent work of researchers, paediatricians who have entered data into the Epilepsy12 audit, as well as the Epilepsy12 audit team themselves, that we now have data to support what we have long recognised. In addition, the NHS Long Term Plan prioritises epilepsy as one of the long-term conditions in CYP requiring service improvement, resulting in a nationally supported program of work to design and implement this.

The project leading to this report has only been possible due to the proactive resource commitment of the NENC ICS Child Health and Wellbeing Network (CHWN). Ahead of any national directives or initiatives, the network identified funds for scoping and gap analysis projects in epilepsy in preparation for the national implementation work which is now in progress.

This project is an example of close collaboration between primary, secondary and tertiary care, mental health services, education partners, and service users and their parents/carers. The report brings together information from these stakeholders, as well as data analysis from other sources, which form an integral part of the CHWN programme of work for CYP in the NENC. The benefits include the provision of a baseline for service improvements locally along with guidance about where to target resources. We hope that it also provides a starting blueprint for similar programmes of engagement and scoping exercises in other ICS areas and in other conditions.

I would like to acknowledge the excellent and significant contributions of my collaborators and co-authors who conducted the work for this project in addition to their usual roles:

Kate Swaddle, Education Advisor to the CHWN NENC and Deputy Head, St Stephens RC Primary School North Tyneside

Chloe Geagan, Clinical Psychologist, Health Psychology Department Great North Children's Hospital

Dr Vaishali Nanda, Primary Care Advisor to CHWN NENC, Clinical Director Central Middlesbrough PCN, Executive GP

Louise Dauncey CHWN NENC Network Delivery Manager CYPT and her administrative team

Phil Archman, Senior General Manager (Planning and Information) based at South Tees NHS FT

I hope that you will find the contents of this report enlightening and that you will join with us in our effort to improve mental health services for CYP with epilepsy.

Dr Anita Devlin MBBS MD MRCP MRCPCH MBA
Consultant Paediatric Neurologist, Great North Children's Hospital
Clinical Lead for Tertiary Paediatric Complex Epilepsy Service NENC
Clinical Lead for CYP Epilepsy NHSE North-East and Yorkshire
Clinical Advisor NHSE National Oversight group Epilepsy CYP and Workstream Co-chair

Acknowledgements

We have been able to benefit from learning from other system wide colleagues and professionals. Part of this work has been to collaborate with others to understand and describe a baseline for future service improvement work.

We thank the following individuals for their expertise and assistance throughout all aspects of our project and for their contribution to the drafting and finalisation of this findings and recommendations paper.

Phil Archman – Senior General Manager Planning and Information, South Tees Hospitals NHS FT, specifically for analysis, interpretation and presentation of the data to be included within this report and for the support in relation to the development of the narrative.

Helen Gilpin, Registered Nurse, Independent Nurse Prescriber, Epilepsy Specialist Nurse Advisor, South Tees Hospitals NHS Foundation Trust, specifically for the development of resources including the preparation of the ESN online survey.

Anne Jones - Senior Administration Support (Data and Digital) Child Health and Wellbeing Network, NHSE, specifically for support with the development of the MS forms

Dr Vaishali Nanda, Primary Care Advisor, Clinical Director - Central Middlesbrough PCN, Executive GP-Tees Valley CCG, GP Partner – Discovery Medical Centre Middlesbrough, specifically for the support in relation to primary care engagement, the development and review of the primary care online survey and also evaluation and assessment of results. In addition to the general intelligence about epilepsy care within primary care.

Emilia Soulsby -Network Development Manager, Child Health and Wellbeing Network, NHSE, specifically for support with the development of the MS forms

Kate Swaddle, Education Advisor, Deputy Head – St Stephens RC Primary School North Tyneside, specifically for the support in relation to how we engage with the education settings across the footprint, the development of the education settings online survey and for the general intelligence about epilepsy care in children within school settings.

*Special acknowledgements to Young Epilepsy and their Young Reps who took the time to contribute to stakeholder involvement. A further acknowledgement to N Wilson (Trainee Clinical Psychologist) for co-facilitating the parent focus group and qualitative analysis and G Crowther (Assistant Psychologist) for support in identifying services in the region.

We would also like to thank the ESN and medical workforce and the members of PENNEC, regional epilepsy network for the collation of information in relation to epilepsy services and their support, engagement and participation in the scoping exercise.

Table of Contents

Executive Summary

Background

As part of the NHS Long-Term Plan (1), NHSEI has prioritized epilepsy, diabetes and asthma as the long-term conditions in children and young people (CYP) for which service improvement is required. Established in 2009, the Epilepsy12 national audit (2) has produced 3 rounds of national data to assist epilepsy service providers and those who commission health services, to measure and improve care for CYP with epilepsy. The methodology and outcome indicators are aligned to NICE and SIGN epilepsy guidelines and recent Epilepsy12 results have highlighted 4 areas for epilepsy service improvement:

1) **Mental health screening and access to psychosocial Support**
2) **Access to tertiary services including surgery**
3) **Transition from paediatric to adult epilepsy services**
4) **Variations in epilepsy care (e.g. access to epilepsy specialist nurses)**

NHSEI has established a National CYP Epilepsy Oversight Group with 4 workstreams, aligned to the themes above, tasked with the development of service improvement outcome measures (deliverables), in a similar way to those recently developed for asthma.

When epilepsy was identified as one of the long-term conditions for service improvement, the Child Health and Wellbeing Network (CHWN) North-East and North Cumbria (NENC) ICS proactively commissioned two parallel projects aligned with the nationally identified themes. Both are scoping and gap analysis projects leading to recommendations for service improvement. Epilepsy project 1 focuses on themes 2, 3 and 4 based on the analysis of the Epilepsy 12 indicators mapped to the ICS footprint.

This project, Epilepsy project 2, focuses on mental health in CYP with epilepsy and engages with multiple stakeholder groups including education professionals, paediatrician epilepsy specialists, epilepsy specialist nurses, primary care, mental health services, services users and their parents and carers, and third sector organisations, in particular, Young Epilepsy. Engagement with different stakeholder groups allowed mapping of the types and availability of different mental health interventions, the contexts in which these were available along with access and pathways of referral to mental health services/support. Further analysis of the data collected has offered the opportunity to reach an interdisciplinary consensus concerning recommendations for service improvement and, to develop a common vision of mental health service provision for CYP with epilepsy.

Aims

Through engagement with practitioners from education, secondary care, primary care, mental health services as well as engagement with parents/carers and CYP the aims of the project included:

1. To identify the current availability, access and pathways of referral to mental health services and support for CYP with epilepsy
2. To suggest recommendations for service improvement through the analysis of gaps, inequalities and variation in provision
3. To agree a common vision for mental health service provision for CYP with epilepsy through consultation and feedback
4. To establish an interdisciplinary NENC epilepsy alliance group, crucial to further work on implementation

Detailed methodology is described in Appendix 1 and more specifically in each of the engagement chapters. The survey questions are also available for each of the stakeholder groups in the appendices which we hope will be helpful to other ICS groups when contemplating similar projects.

Recommendations

(After each recommendation below, a coloured symbol is shown to indicate which of the 4 themes the recommendation is aligned to as per the figure above).

Mental health in CYP with epilepsy in the education setting

1. Education mental health practitioner (EMHP) teams are a significant step forward in offering early, brief, evidence-based interventions to address mental health needs of CYP. However, in the context of a complex health condition such as epilepsy, it would be beneficial for additional assessment and support to be offered by hospital clinic-based teams. Liaison and partnership with school-based support services would then offer optimal support across the different contexts of the CYP's life. 🔴
2. Despite recognising that mental health problems are more common in CYP with epilepsy, only 27% of schools actively screen for mental health problems in CYP with epilepsy and the screening undertaken does not employ validated tools or approaches. Active screening of those at high risk of mental health difficulties should be undertaken, using agreed approaches and validated tools, across settings. One such tool is the Strength and Difficulties questionnaire (SDQ). 🔴🟢
3. In spite of 59% schools recognising that CYP with epilepsy are more likely to have cognitive problems, 85% do not have a specific screening algorithm or assessment protocol for these CYP. Cognitive screening should be carried out in an agreed and structured way for CYP at high risk of cognitive deficits. 🔴🟢

4. Care must be taken to avoid standardisation of methodology becoming a “one size fits all” approach which may not be suitable for complex situations. Conversely, an overly extensive and disparate number of interventions can also be unhelpful. An appropriate selection of evidence-based assessments and interventions should be agreed and provided. 🔴🟢

5. 76% of schools reported that further staff training is required with regard to the identification of and intervention for mental health and cognitive problems in CYP with epilepsy. Training for any agreed tools and approaches should be provided to nominated staff members. 🔴🟢

6. Clear pathways to seek additional supervision and referral are required where interventions based in education are either not accepted, appear ineffective or the complexity of the presentation is beyond the experience and expertise of the practitioner. 🔴🟢

7. For CYP with epilepsy and identified mental health problems who do not meet the Social, Emotional and Mental Health (SEMH) threshold on the SEND register, only 19% of schools sometimes record this and 29% of schools do not record this. Identified mental health issues should be consistently recorded even when the SEMH threshold for SEND registration is not reached and this should be updated annually. 🔴

8. 85% respondents from education felt that parents/carers are not an adequate source of all health information for CYP with epilepsy. This emphasises the need for continued, improved and structured multi-agency information sharing to optimise the care and support given to CYP with epilepsy. 🔴

9. These improvements across the ICS footprint can be facilitated by the NENC CHWN through:
    - Establishing a CYP epilepsy clinical lead role for the ICS. 🔴🟢🟣🔵
    - Establishing a children’s epilepsy working group with membership from the widest geographical area and with extensive multidisciplinary representation including health, education, social care, 3rd sector and CYP with epilepsy and their parents/carers. 🔴🟢🟣
    - Encourage further CHWN membership and participation from mainstream secondary schools who were under-represented in this survey. 🔴🟢
    - Through regular working group meetings and interdisciplinary working, develop a work programme to agree approaches and methodologies and then implement them with timelines and, outcome and audit metrics. Metrics should include service development and implementation in the context of indices of deprivation to prevent any inequalities of access and provision. 🔴🟢
    - Hosting a regular ‘Epilepsy Huddle’ with clinical updates and to show-case progress and impact for educational settings. 🔴🟢🟣🔵
    - Developing a series of resources for professionals, CYP and their families, available in an on-line digital format which explain (in an age-appropriate and child-

friendly way) the impact that epilepsy can have on some CYP physically and mentally – in line with the SEND Code of Conduct. The resources could include pre-recorded webinars/e-training modules which are focussed on the regional strategic and operational approaches to managing a CYP with epilepsy across the different contexts of their life. 🔴🟢

- Sign-posting links where available and creating material where not available in the form of digital videos and animations to help explain some of the mental health difficulties experienced by CYP with epilepsy and how these can be overcome. Working in partnership with third sector organisations such as Young Epilepsy would be beneficial to this aim. These could be made available on the *Healthier together* platform and shared with other CHWNs. 🔴🟢🟣
- Wherever possible CYP and their parents/carers should be represented in the creation of the work programme and resources. An example of this could be a video following three CYP of different ages with epilepsy in different educational settings to capture their voice and perceptions of how the condition affects them at school and the support they receive. 🔴🟢

Mental health in CYP with epilepsy in the secondary care setting

1. The number of epilepsy specialist nurses (ESNs) for CYP should be increased to achieve equity of access for all CYP with epilepsy and to allow ESN attendance at all epilepsy clinics for CYP. 🔴🟢🟣🔵
2. Separate clinics for young people >12 years are required with access to ESN and medical expertise. This should be available to young people at a time that is suitable for them (evenings included). Account should be taken of this in ESN staffing levels and in consultant job-planning. 🔴🟢🟣
3. There is no availability of mental health professional input to the epilepsy clinics for CYP with epilepsy across the footprint of the ICS when this is available for other conditions, for example diabetes. Embedding health psychologists within epilepsy clinics is the model that ESNs and Paediatrician epilepsy leads (CLs) think will best meet the mental health needs of CYP with epilepsy. It would also offer a source of recognition and risk assessment of emerging mental health problems in parents/carers. 🔴🟢🟣
4. The first level of mental health support to CYP with epilepsy and their families could be part of the ESN role. However, a significant increase in ESN resource would be required, along with appropriate training, supervision and agreed rapid onward referral pathways. 🔴🟢
5. A consistent and validated tool to screen for mental health difficulties in CYP with epilepsy should be employed in the clinic. 🔴🟢
6. Once mental health problems are identified:
    - More consistent information sharing amongst professional and carer groups should occur. 🔴🟢

- Onward referral pathways for further assessment and interventions for mental health and cognitive problems should be agreed and explicit both for those with normal cognition and for those with additional educational or neurodevelopmental needs. 🔴🟢

- Closer partnership working between education mental health practitioner (EMHP) teams, special educational needs co-ordinators (SENCOs) and the hospital-based clinical teams would reduce waiting times and provide an appropriate and needs-based approach to mental health and cognitive assessment and support. This is even more important for CYP with special educational needs who may not be able to communicate thoughts and feelings in typical ways. 🔴🟢

- Comprehensive and up-to-date contact details and information about relevant 3rd sector organisations both nationally and locally should be available to signpost to CYP and their parents/carers. 🔴🟢

- Support groups for CYP with epilepsy and separately for the families and carers should be provided and facilitated by one or more people with training in mental health support. This would also give CYP and their families a voice to feedback about services and to become actively involved in service development and improvement. 🔴🟢🟣

7. Further training is required and is being requested by both professional groups in this survey, covering the recognition, support and onward referral of CYP with mental health needs. Particular training should address these issues in CYP with special educational needs. 🔴🟢

8. This survey, with appropriate additions and modifications, should be repeated at intervals of not more than 2 years to ensure that progress is being made in these areas. 🔴🟢

Mental health in CYP with epilepsy in the primary care setting

1. As with adults with epilepsy, CYP with epilepsy should be easily identifiable on primary care information systems, with practices maintaining a register of patients who are invited for an annual review. It would be optimal if CYP with epilepsy could be included in the QOF commissioning framework and local incentive schemes for epilepsy. 🔴🟢🟣

   Whilst QOF is nationally agreed, the local primary care commissioners can influence the agenda to include quality improvement schemes for CYP <18 years. There is also an opportunity to feedback to PCNs regarding the IIF indicators and onward to commissioners to improve the focus on conditions affecting CYP <18 years.

   Local expectations could include:

   - requirement (or at least local expectation) that there is a paediatric epilepsy champion in each practice (or PCN) 🔴🟢🟣

  - requirement (or at least local expectation) that CYP with epilepsy – and their parents/carers are coded and recorded on a practice register 🔴🟢🟣

  - requirement (or at least local expectation) that CYP with epilepsy have an annual review with GP or practice nurse which includes lines of enquiry and a screening process around emotional wellbeing and mental health needs 🔴🟢🟣

  - requirement (or at least local expectation) that there is access to MH practitioner (for CYP) within each PCN 🔴🟢

  - develop evaluation criteria to measure the impact of the different types of intervention (if provided by practice/PCN MH practitioner) for CYP so that the offer can be responsive and adaptable to need 🔴🟢

2. An annual review template should be developed to be used in primary care which has a mental health screening tool embedded within it to make this a standardized and easy to use. 🔴🟢🟣

3. Mapping should be undertaken of available mental health support services and resources for CYP with epilepsy on a locality basis including those available within education, social care and third sector organisations. This should be widely shared with all stakeholders so that referrals can access the appropriate level of support with the minimum delay. This would also allow CYP to be referred onwards if needs escalated beyond the expertise of a lower-level intervention provider. 🔴🟢🟣

4. The referral criteria and pathways into CAMHS/CYPs services need to be clear, explicit and available to all referrers. An on-line referral mechanism with a checklist approach may be helpful which, also has links to other available mental health service providers in the locality. This will prevent these overloaded services from having to respond to inappropriate referrals and will facilitate the delivery of appropriate support without excessive delay. 🔴🟢

5. Primary care networks should be supported to have access to mental health assessment and support for CYP with epilepsy, delivered by a specifically trained CYP mental health practitioner, similar to that available to adults. Clinical supervision could be provided by Trust-based health psychology teams and once again, onward referral pathways should be clear. 🔴🟢

6. Training to be delivered to primary care practitioners regarding epilepsy in CYP and the effects of the condition on mental health. Training in the identification of mental health needs in CYP with epilepsy including the use of specific agreed tools is required. 🔴🟢

7. The additional mental health needs of the parents/carers of CYP with epilepsy need to be acknowledged and a register of carers would ensure that mental health problems are actively screened for during clinical encounters, when the parent/carer may attend alone. There should be a low threshold for offering referral to practice/PCN based mental health practitioners. 🔴🟢

8. Primary care has a crucial role to play in the transition of CYP from paediatric to adult services. This is an anxious time for CYP and their carers, even more so for CYP with

special needs. This would be a predictable process with time to anticipate a different care and prescribing model if annual reviews were being undertaken for CYP with epilepsy in primary care. The referral pathways to facilitate the transition process should be explicit. 🔴🟢🟣

Mental health in CYP with epilepsy in the mental health services setting

Several projects have been conducted already identifying gaps in service and making recommendations regarding integration of services, for example, Epilepsy 12 and the Rightcare Epilepsy toolkit. The Epilepsy 12 audit recommended that NHS England should support the ongoing establishment of a UK wide clinical network for epilepsy, as per the Long-Term Plan commitment. Part of this plan includes appropriate support and resources provided at regional and now at ICS and provider levels. The following recommendations are based on some of the issues highlighted by this survey of mental health professionals and also from other surveys within the project:

1. Clearer referral pathways to mental health services are needed for each locality. As discovered by the project team, it is difficult to establish what is currently on offer in the region and by whom this is provided. This creates a barrier for referrals from other professionals in education and health settings. 🔴🟢
2. Increased communication between mental health services, education and health services is needed. A list of current mental health services in the region which is kept up to date with an identified member of staff responsible for liaising with education and health professionals, is required. This may streamline the referral process and will ensure that CYP and their families are being referred to the most appropriate service. 🔴🟢
3. There is an apparent lack of group interventions being offered in the region, specifically lower-level intervention for CYP with epilepsy. One option which has been published is the Psychosocial group Intervention for young people with Epilepsy (PIE) group which, is a manual-based psychosocial group intervention delivered by clinicians aimed at improving epilepsy knowledge, self-management skills, and quality of life in young people with epilepsy (3). 🔴🟢🟣
4. Further training has been identified as an area of need for professionals within mental health settings. This is perhaps more the case for individuals in community mental health setting such as CAMHS/CYPS rather than hospital-based psychology teams. Furthermore, it appears that staff in the neurodevelopmental assessment pathway in CAMHS would particularly benefit from further training on some of the possible cognitive and behavioural consequences of having epilepsy. 🔴🟢
5. Many of the respondents in this survey reported that their service works with CYP with learning disabilities. However, the current survey did not explicitly look at professionals' views on CYP with epilepsy and a diagnosed learning disability. It would be beneficial to explore whether different recommendations would be needed for mental health professionals working directly with these young people and their families. 🔴🟢

6. Interventions for CYP with epilepsy should be staged and integrated so that, as far as possible, parents have access to one team who monitor the child's epilepsy and assess and support mental health including addressing cognitive concerns. This would be optimally achieved by having a psychologist embedded within the clinical team. 🔴🟢

7. Liaison and partnership with school mental health teams and SENCOs to inform and co-ordinate provision for any mental health or cognitive problems would ensure that CYP with epilepsy are supported in a holistic manner across all contexts in their lives. 🔴🟢

Mental health in CYP with epilepsy – engagement with parents/carers and CYP with epilepsy

1. Parents of children with epilepsy should have access to ongoing information and emotional support via dedicated epilepsy support specialists (e.g. epilepsy specialist nurses) and have access to reliable information forums. 🔴🟢

2. Screening for mental health difficulties should occur as a routine part of epilepsy clinics, not only for CYP with epilepsy, but also for parents for example, by using the Patient Health questionnaire 9 (PHQ-9) or Generalised Anxiety Disorder 7 (GAD-7) which act as quick screens for low mood or anxiety in parents and carers. 🔴🟢

3. Parents should have access to better information at diagnosis about how mental health and epilepsy may affect their child, but also for parents to have access to support for themselves as and when needed. 🔴🟢

4. It is important for individuals with epilepsy and their families, along with local teams and schools to have information about organisations, charities and specialist services that exist locally and nationally which offer mental health support. Clinical teams should have up-to-date local and national information and contact details for these organisations in order to sign-post CYP and families to them. 🔴🟢

5. Psychosocial groups for young people with epilepsy should be established as a way for them to meet other CYP going through a similar experience. Likewise, parents and other close family members would benefit from support group activities. 🔴🟢

6. Future work should also look at the needs and concerns of CYP with epilepsy and a learning disability to better identify support desired by CYP themselves and also their families. 🔴🟢

7. Increased involvement of children, young people and their families with their epilepsy care is essential for the continuous improvement and long-term impact of the care delivered by epilepsy services. It is important that the CHWN continues to engage with CYP with epilepsy and other health conditions as part of any future projects, including re-engagement following any service improvement work to ascertain if positive impacts from this work are tangible to service users. 🔴🟢

Introduction

Epilepsies in children and young people-complex conditions

Epilepsy is the most common significant long-term neurological condition of childhood, affecting about 1 in 220 children which approximates to 51,000 children and young people with epilepsy in England (0-16 years old)(4). Seizures and epilepsy account for about 5% of all childhood emergency admissions (5). Epilepsy in childhood is associated with a number of psychosocial co-morbidities including cognitive impairments, academic underachievement (6), difficulties with social skills and behavioural and psychiatric disorders (7). In particular, children with epilepsy are at significant risk of psychiatric disorders, which negatively impact the development of social skills, academic achievement, and quality of life(8). 37% of children with epilepsy have a co-existing mental health disorder, a higher prevalence than found in other long term childhood conditions such as diabetes (11%) (9). The most commonly reported psychiatric comorbidities in children and young people (CYP) with epilepsy are attention deficit hyperactivity disorder (ADHD), depression, and anxiety. Mental health difficulties impair educational attainment, are costly and have enduring effects into adulthood. 72% of children with epilepsy have 'low achievement at school' and 42% of children have 'underachievement' at school (10).

Epilepsy12 National Audit

This national audit was established in 2009 and currently covers paediatric services within Health Boards and Trusts in England and Wales with the aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with epilepsies. The methodology is aligned to NICE and SIGN guidelines - 'The epilepsies: the diagnosis and management of the epilepsies in children and young people in primary and secondary care' (NICE, 2012) and 'Diagnosis and management of epilepsies in children and young people' (SIGN, 2005).

Round 3 of the audit began on 1 April 2017 as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and ran until 31 March 2022. The Royal College of Paediatrics and Child Health (RCPCH) have been awarded the contract to deliver the next round of Epilepsy12. Round 4 has been commissioned by HQIP to run from 1 April 2022 to 31 March 2025.

Round 3 cohort 3 data were published only very recently (11) which means that Epilepsy 12 data employed for analysis and comparison in this report and the appendices, are based on Round 3 cohort 2 (2). However, with regard to mental health findings Round 3 cohort 3 found:

- Very few of the CYP with epilepsy had an identified mental health condition (5%, 53/1124) compared to 37% known to be affected(9). This remains unchanged from Round 3 cohort 2.
- Only 19% (22/115) of Health Boards and Trusts have formal screening for mental health disorders. Similar proportions formally screen for autism spectrum disorder and/or ADHD.

- Only 18% (12/115) of Health Boards and Trusts had co-located mental health provision within their epilepsy service, compared to 15% (18/119) in 2020.
- Only 69% (79/115) of Health Boards and Trusts have agreed referral pathways for children with mental health conditions.

NHS Best Practice Criteria (2019) states that there should be some co-located mental health provision within epilepsy clinics and NICE Clinical Guideline 137 states that children and young people should have access to written and visual information, counselling services, information about voluntary organisations, epilepsy specialist nurses.

Epilepsy – part of the NHS Long Term Plan

The NHS Long Term Plan (1) includes proposals to improve the quality of care for children with Long Term Conditions (LTC). NHSEI has prioritised epilepsy, asthma and diabetes as the three long term conditions in CYP requiring service improvement and the outcomes of the Epilepsy 12 audit data have highlighted four areas for service improvement in CYP with epilepsy.

1) Mental health screening and access to psychosocial Support
2) Access to tertiary services including surgery
3) Transition from paediatric to adult epilepsy services
4) Variations in epilepsy care (e.g. access to epilepsy specialist nurses)

NHSEI have established a National Oversight Group for CYP with epilepsy with broad stakeholder representation including paediatric epilepsy specialists, epilepsy specialist nurses, commissioners, regional epilepsy leads, service users and third sector representatives. Work is currently underway to develop outcome measures and key deliverables in each of the four areas for which each ICS will be responsible, supported by the regional CYP transformation teams.

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 (12) emphasised the strong and persistent link between social inequalities and disparities in health outcomes and the importance of tackling the wider determinants of health to improve health outcomes and reduce health inequalities.

The North-East and North Cumbria (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 NENC ICS footprint have the highest proportion of CYP that are under review with epilepsy and live in the most deprived quintile. Recent 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. Furthermore, epilepsy in offspring results in a sustained increase in parental stress (13) also known to result in poorer mental health in children.

Work has been undertaken as part of this programme to consider the identification, diagnosis, prevalence, incidence and reporting rates across the NENC ICS in relation to each locality area and comparing this to available regional and national data. This analysis has also taken into consideration comparator regions in relation to population demographic and geography. A more detailed description of the demographic data and comparative analysis can be found in Appendix 2.

Child Health and Well-Being Board (CHWB) NENC ICS - Epilepsy programme CYP

When epilepsy was identified as one of the long-term conditions in CYP for service improvement, the CHWB NENC proactively commissioned two parallel projects aligned with the nationally identified themes. Both projects are scoping and gap analysis projects with Epilepsy Project 1 focusing on themes 2, 3 and 4 based on the analysis of the Epilepsy 12 indicators mapped to the ICS footprint.

Epilepsy project 2 focuses on mental health in CYP with epilepsy and engages with multiple stakeholder groups including education professionals, paediatrician epilepsy specialists, epilepsy specialist nurses, primary care, mental health services, services users and their parents and carers, and third sector organisations in particular Young Epilepsy. Engagement with these different stakeholder groups allowed us to ascertain the availability of different types of mental health intervention, the contexts in which these were available along with access and pathways of referral to mental health services and support. Further analysis of the data collected has offered the opportunity to reach an interdisciplinary consensus concerning recommendations for service improvement and, to develop a common vision of mental health service provision for CYP with epilepsy.

Mental health in CYP with epilepsy in the education setting

K Swaddle (Education Advisor to the CHWN NENC and Deputy Head of a primary school), AM Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor) C Geagan (Clinical Psychologist,) L Dauncey (Network Delivery Manager - CYPT), P Archman (Senior General Manager Planning and Information)

Introduction

The Epilepsy Project 2 team (mental health in CYP with epilepsy) devised a survey for education professionals on behalf of the NENC CHWB, to acquire qualitative and quantitative information about approaches to mental health in CYP with epilepsy in the education setting. Larger settings (e.g. secondary schools) are likely to have more children on-roll with epilepsy compared with smaller local community primary schools and it is well-documented that specialist school settings, additionally resourced provision units and pupil referral units have more children on-roll with a diagnosis of epilepsy than mainstream providers. The survey aimed to capture the views of staff working across these settings.

The survey was distributed to the following local authorities: Allerdale and Copeland, Carlisle, County Durham, Darlington, Eden, Gateshead, Hartlepool, Middlesbrough, Newcastle-Upon-Tyne, North Tyneside, Northumberland, Redcar and Cleveland, South Tyneside, Stockton-on-Tees and Sunderland.

Whilst the survey captured the views of staff as defined by local authority (LA) boundary, it also gave an insight into Clinical Commissioning Group/Integrated Care Partnership support. This is useful when attempting to define the next steps to achieve an integrated approach to improving and optimising service delivery for CYP with epilepsy. The survey requested information about current practice regarding mental health assessment and support available to students with epilepsy. Questions posed also asked responders about their awareness of third-sector support and the impact of epilepsy upon the four areas of the Special Educational Needs and Disability Code of Practice (SEND CoP, 2014, updated 2016).

Methods

The survey was devised by the Epilepsy Project 2 team (mental health in CYP with epilepsy) led by Dr Anita Devlin and Kate Swaddle (Education Advisor to the CHWN NENC and Deputy Head of a Primary School) using Microsoft forms. Education professionals were identified from the NENC CHWN register of members. In addition, a further 14 providers were identified from sites where no staff members had joined the network.

Survey responses were requested from senior leaders (e.g. headteachers, deputy/assistant headteachers and SENCOs) as they are more likely to have the knowledge required to complete the questionnaire. Some respondents forwarded the survey onto another member of staff to complete (this included senior mental health lead, emotional and wellbeing lead, or an administrator – 3 respondents). To avoid making completion of the survey too onerous respondents could make progress and complete the survey without responding to all of the questions. Therefore, the denominator changes depending on the number of respondents.

Outcomes of the survey

A full set of the questions posed by the survey to education professionals can be found in Appendix 3

Responder characteristics

There were 28 responses from 15 local authorities. At least 1 response was obtained from all local authorities within the network except Copeland (West Cumbria, based in Whitehaven).

Responses came from a mixture of school types including 5 SEN schools with the majority coming from nursery and primary schools (see below).

	Type of school	as a %
Mainstream nursery and primary schools	18	64%
Mainstream Middle / Secondary schools	3	11%
All through provision school	1	4%
Special educational needs schools	5	18%
Other	1	4%

The number of pupils at each school ranged from < 100 pupils to > 1000 pupils but 68% in this survey had between 100 to 399 pupils enrolled.

The independent sector was not represented and only 3 mainstream middle/secondary schools were represented. Mental health problems in CYP are more likely to present from puberty onwards and we recognise the under representation of mainstream education providers for this age-group in the survey.

Those who responded to the survey had the following roles:

Role of persons completing the questionniare		
Headteacher	8	
Deputy / Assistant Headteacher	7	5 with SENCO role
Senior leadership team member	2	both with SENCO role
SENCO	6	
High level teaching assistant	1	with SENCO role
Safeguarding lead and school health adviser	1	
Other	3	Emotional & well being lead; SEND administration manager; Administrator

The table shows that many deputy headteachers/assistant headteachers also fulfilled the SENCO role making them well-placed to respond to the survey's questions on the impact of epilepsy.

Indices of deprivation

The survey asked respondents if they knew the Index of Multiple Deprivation (IMD) for their school. 15/28 respondents reported scores which ranged from 1 (most deprived) -10 (least deprived) with a median of 4. Deprivation indices are relevant to epilepsy as there is an increased prevalence of epilepsy in those from deprived backgrounds with less favourable outcomes as they reach adulthood (Camfield, Camfield and Smith, 2016). IMD scores are perhaps less pertinent for special schools which, are more likely to receive pupils from a wider catchment area with a more diverse socio-demographic background.

Recording of epilepsy as a health condition by schools

21/28 schools (75%) reported that they had worked with children and young people with epilepsy in the last five years and in the case of special schools, 4/5 have cared for 16 or more. 96% schools confirmed that they recorded the presence of epilepsy on the school's central information management system which makes identifying this group of children and young people very straightforward.

SEND register and EHCP

The majority of mainstream schools (92%) have relatively few CYP with epilepsy on their SEND register whereas, as expected, special schools have the majority on the SEND register.

% of CYP with epilepsy currently on the SEND register	**0-19%**	**20-39%**	**40-59%**	**60-79%**	**80-100%**	**N/A**
Mainstream nursery and primary schools	11	0	0	0	1	6
Mainstream Middle / Secondary schools	3	0	0	0	0	0
All through provision school	0	0	1	0	0	0
Special educational needs schools	0	0	0	0	5	0
Other	0	0	0	0	1	0
	14	**0**	**1**	**0**	**7**	**6**
	64%	**0%**	**5%**	**0%**	**32%**	

Similarly, mainstream school respondents reported that a minority of students with epilepsy have an EHCP (education and healthcare plan), 2/16 (12.5%), whereas 4/5 special schools reported that all CYP with epilepsy had an EHCP

Identification and intervention for mental health problems

Respondents generally felt confident that staff are able to identify students at high risk of mental health problems (50% strongly agreed & 43% agreed) with only a slight reduction in confidence about offering intervention and support (29% strongly agreed, 54% agreed). This is encouraging, as is the finding that 75% of respondents recognised that mental health problems were significantly more frequent in CYP with epilepsy. However, only 11% knew that these problems are 4 times more frequent.

It is surprising that the majority of schools (85%) think that parents/carers are not an adequate source of all health information, for CYP with epilepsy. This included all 5 special schools. This emphasises the need for multi-agency information sharing to facilitate care and support given to children in the education setting.

Specific mental health issues and diagnoses

All respondents recognised that a range of mental health issues are more common in CYP with epilepsy. Anxiety (87% respondents) and depression (74% respondents) were identified as being the most frequent. Half of respondents identified ADHD/ADD and Autism Spectrum Disorder as being more common in CYP with epilepsy. However, a broad range of possible specific diagnoses were recognised as being more common both for those in mainstream and special education provision.

	Mainstream nursery and primary schools	Mainstream Middle / Secondary schools	All through provision school	Special educational needs schools	Other		No of responses	As a % of schools responding
Number of responses	14	3	1	4	1		23	
ADHD / ADD	6	1	1	4			12	52%
Anxiety Disorder	12	2	1	4	1		20	87%
Autism Spectrum Disorder	5	2	1	4			12	52%
Conduct Disorder	4	1	1	2			8	35%
Depression	11	2	1	2	1		17	74%
Obsessive-Compulsive Disorder	5		1	3			9	39%
Psychosis	4			2			6	26%
Other (Learning Difficulties)				1			1	4%

Given that there was a recognition of increased risk of mental health problems in CYP with epilepsy it might be anticipated that these would be routinely screened for. However, only 27% of schools surveyed reported actively screening for mental health problems in CYP with epilepsy. Where this occurs, it is conducted by staff with a variety of roles including SENCO, educational health support worker, school counsellor, designated 'active listeners', and RNLD (with CAMHS experience).

Recording of mental health difficulties

Only 11 out of 21 respondents, 52% of schools reported that they record the presence of identified mental health problems for CYP with epilepsy, who do not meet the SEMH threshold on the SEND register. 19% of schools did this sometimes and 29% of schools do not record any identified mental health issues for those CYP with epilepsy, who do not meet the SEMH threshold on the SEND register. When asked if the way in which education settings record and review mental health and cognitive problems for CYP with epilepsy requires improvement**,** 10 of 26 schools (38%) agreed that this requires improvement.

Suggestions on how to improve performance in this area included:

"More time dedicated to specific training as part of staff CPD. All staff understanding the impact and complications related to epilepsy beyond the medical management to support children long term."

"Direct support or a 'hotline' to a paediatrician. A school referral system into the healthcare system would be really beneficial - not just for epilepsy!"

"Closer relationship between school nurse and school."

"Funding - there is no resource available"

"Further specialist training."

Designated member of staff responsible for mental health and wellbeing

All schools identified at least 1 member of their teaching staff responsible for student mental health and well-being. This role was undertaken by individuals in a variety of different roles within their school (see below). In most schools a single individual was identified as having this role but in 50% of mainstream primary schools two or more people within the same school undertake this role.

who is the identified person or persons/team responsible for mental health support?	**Mainstream nursery and primary schools**	**Mainstream Middle / Secondary schools**	**All through provision school**	**Special educational needs schools**	**Other**
SENCO	10	1			
Pastoral lead/tutor	6			1	
Designated mental health first aider	5		1	2	
School counsellor	0				
Education Mental Health Practitioner (LA/NHS fund	4				
Safeguarding Lead	6	2		2	
Family Liaision Officer	4				
Other					
RNLD					1
Head of Year / Assistant Head / Deputy Head				2	
Support Staff member	1				

Two-thirds of schools recognised that the type of mental health support required by CYP with epilepsy can be similar to that offered to all CYP. However, some did suggest additional aspects that require attention for CYP with epilepsy with comments such as:

"I am sure that children and young people with additional health needs will require adapted support"

"School would have an increased awareness of the cognitive complications and additional support required as a result of an epilepsy diagnosis."

"Identifying triggers for the CYP as regards to their specific health needs."

"Co-morbidity can lead to more complexity."

"These pupils need to understand their condition and have access to an expert that can support their needs and understands 'epilepsy' holistically e.g. not just from a mental health point of view, but from a medical perspective i.e. understanding why/how epilepsy causes the difficulties it does. "

"Consideration of how their epilepsy effects them in school and wider life. "

"Pain related"

Interventions offered

Two-thirds of schools said they had not offered any mental health support required by CYP with epilepsy, in the last 18 months.

Mental Health Interventions offered to CYP with Epilepsy in the last 18 months

School counselling	7
Early Help Assessments	7
Educational Psychology input	7
Applications for Education Health Care Plans and/or alternative provision	6
Liaison with the wider multi-disciplinary team to seek additional guidance and support	6
Pastoral care sessions (either small group/one to one)	6
Sensory strategies e.g. Leaving lessons early to avoid over-crowding/therapeutic input for sensory overload	6
Nurture rooms/zones	6
Speech and Language Support	5
Pastoral interventions e.g. buddy systems	5
Social stories	4
Peer support systems e.g. Lego Therapy, Talkabout for Children, Turn taking	4
THRIVE Practitioner/Accredited Programmes	3
PACE approach – playfulness, acceptance, curiosity, empathy	3
Art therapy	2
Bespoke Education Mental Health Practitioner (EMHP) packages	2
Talkabout For Children	2
Journaling e.g. Happy Journal	2
Socially Speaking	2
Support for eating at lunchtimes	1
PATH approach – person centred planning	1
Academic interventions	1
Indirect bereavement support conducted in groups e.g. Rainbows group therapy	1
Five-point rating scales	1
Active listeners	1
Total	91

It is encouraging to see such a diverse range of interventions which are not mutually exclusive, and it demonstrates the increased attention given to the recognition and intervention for mental health problems in CYP in the education setting.

Staff training

85% schools have provided staff with additional training in the identification and intervention for mental health problems in students. Most of this has been in relation to the Senior Mental Health Lead role, mental health first aid and THRIVE practitioner training (see below).

Mental Health Training Provided		
Senior Mental Health Lead Training	10	(Place2Be; Anna Freud)
Mental Health First Aid	7	
THRIVE Practitioner	5	
Anna Freud national centre training courses	3	
Mental Health Lead Training	2	
Drawing and Talking	1	
Active listeners training	1	
Mental Health practitioner training	1	
CAMHS led training	1	
"We Eat Elephants" Training (Life skills)	1	
ELSA Training	1	
Bereavement Training	1	
Other - On line course on various mental health related topics eg. Eating disorders, ASD, ADHD, OCD	1	

However, 76% of schools reported that further staff training is required with regard to the identification and intervention for mental health and cognitive problems in CYP with epilepsy.

Onward referral for additional assessment and support

Epilepsy 12 (2020) found that *‘36% (43/119) of Health Boards and Trusts did not have agreed referral pathways for children with mental health conditions.’* Our survey revealed that there were a wide range of services that schools would refer on to if further assessment and support was required. Respondents identified CAMHS (70%), clinical / educational psychologist (58%) and counselling support (50%) as the services that they would very likely refer to. Interestingly two thirds of schools said they would likely refer to a public health school nurse and this therefore represents a valuable and available resource to consider in terms of future pathways for mental health assessment and support.

Approximately half of respondents would be likely to refer to the GP or to the paediatrician and only 41% would be likely to refer to a third sector provider.

Recognition of cognitive difficulties

85% of respondents reported that they and their staff felt confident or very confident about recognising specific cognitive problems in CYP with and without health problems. 16 out of 27 schools (59%) thought that CYP with epilepsy are more likely than other children, to have cognitive difficulties and the remaining 41% thought that CYP with epilepsy had the same likelihood of having cognitive difficulties as other CYP.

Those who reported an increased likelihood of cognitive problems suggested the following areas of increased need:

Cognitive Difficulty	No of responses
Specific problems with attention and	15
Specific problems with processing speed	13
Specific problems with executive function (independent planning, personal organisation, self-control, flexible thinking)	12
Specific problems with memory (working memory/long-term memory)	12
Specific visuo-spatial problems	11
Specific problems with verbal comprehension	10
Global cognitive impairment	9
Specific problems with reading	7
Specific problems with mathematical reasoning	6
Total responses	**95**

It is encouraging to see that the 4 most frequently anticipated problem areas are the most vulnerable areas for cognitive functioning in CYP with epilepsy and this represents a strong area of knowledge from these respondents.

Yet despite this awareness, the majority of schools (85%) did not have a specific screening algorithm or assessment protocol for those CYP who are at high risk of cognitive deficit. The remaining 15% reported using the following screening and assessment approaches:

- Educational Psychologist assessments
- Triangulation of ongoing teacher assessment, outcomes from educational psychology support and statistical cognitive testing and narrative dynamic assessment.
- The WRIT Assessment (Wide Range Intelligence Test) and Wide Range Achievement Test (WRAT)
- Assessment toolkits procured from GL Assessment

Interestingly, when asked if any of the following elements (table below) formed part of the school's cognitive screening algorithm, we obtained responses from 6 schools that reported not employing a cognitive screening algorithm in the preceding question. This could be because 'algorithm' is a word that is used less commonly by the teaching profession who more commonly use the phrase 'assessment procedures'.

Cognitive Screening Element	No of responses
SENCO keeps a watching brief	10
Referral to educational psychologist for observation/formal assessment of learning	10
Classroom observation	9
Assessment for learning	9
SEND register/Education Health Care Plan	8
Summative assessments	7
Parental requests for cognitive screening	6
Medical register information	5
Other (Multi agency approach)	1
Total Responses	**65**

Discussion

It is necessary to start the discussion about the outcomes of this survey by acknowledging identified areas of good practice with regard to the mental health support offered to CYP with epilepsy.

Identified areas of good practice

- All respondents recognised that mental health issues are more common in CYP with epilepsy with anxiety (87%), depression (74%) and ADHD/ADD being the most common.
- 52% of schools record the presence of identified mental health problems for CYP with epilepsy, who do not meet the SEMH threshold on the SEND register.
- All schools identified at least 1 member of their teaching staff responsible for student mental health and well-being.
- An extensive and diverse range of interventions providing mental health support are available. This demonstrates the increased attention given to the recognition and intervention for mental health problems in CYP in the education setting
- 85% of schools have provided staff with additional training in the identification and intervention for mental health problems in students.
- The 4 most frequently anticipated problem areas for cognitive functioning in CYP with epilepsy were correct representing a strong area of knowledge from a significant number of respondents.

Who is best placed to work with CYP with epilepsy and mental health problems in the education setting?

The establishment of LA/CCG education mental health practitioner (EMHP) teams in each local authority, may help to overcome the acute difficulties that CYP experience as a result of epilepsy. However, the EMHP teams' remit is to provide low-intensity work for a duration of 6-8 weeks to address problems associated with depression, anxiety or behavioural difficulties.

Trainees use a combination of approaches to '*provide early, brief evidence-based interventions to promptly address emerging mental health needs of children and young people, and support schools and colleges to improve mental wellbeing for students*' (NHS, 2022). Anecdotally, and from speaking to education colleagues across the region, it is evident that some EMHPs will offer bespoke packages to pupils in a one-to-one environment. However, other EMHP teams will offer small group interventions, which may not be appropriate for all those experiencing acute difficulties linked to an underlying medical condition.

While some schools may have access to an EMHP team, we know that this is not currently the case within every educational setting in the NENC region, due to the staggered and phased roll out of the newly formed teams. From experience, some EMHP teams also enquire about access to an NHS colleague who may help to support the CYP to understand their condition. There seems to be a lack of clarity and co-ordination about who is providing mental health support and there is an uncertainty around when/what is required.

What approaches and tools could be used to identify mental health difficulties in CYP with epilepsy in the education setting?

Over the last eighteen months, there has been a national drive to promote Mental Health Training within schools.

"*The Department for Education (DfE) is offering a £1,200 grant for a senior member of school or college staff to access quality assured training to implement an effective whole school or college approach to mental health and wellbeing in your setting. Grants of £1,200 are now available to eligible state schools and colleges in England who meet the conditions set out below and wish to commence training before 31 May 2022. This is part of the government's commitment to offer this training to all eligible schools and colleges by 2025.*"

All 28 survey respondents stated that they had a designated member of teaching staff responsible for student mental health and wellbeing in school. Many schools are developing social, emotional and mental health strategies. There are various provider organisations offering senior mental health first training, equipping members of the senior leadership team to be "*Senior Mental Health Lead qualified*." Whilst this is very welcome and a positive development, care must be taken that this does not become a "one size fits all" approach that may not serve more complex situations well. Clear onward referral pathways are required for more complex cases.

No consistent screening tools or methodologies to identify CYP with epilepsy and mental health difficulties, were identified by the respondents. There are free screening tools available to help schools identify difficulties with a children and young people's mental health and wellbeing. An excellent example of such a tool is the Strengths and Difficulties Questionnaire' (SDQ) which is a brief behavioural screening questionnaire validated for CYP aged 3–16 years. This tool is suitable for use across health and education settings and could represent a unified and co-ordinated approach for mental health screening across settings and across health conditions. It exists in several versions to meet the needs of researchers, clinicians, and educationalists. All versions of the SDQ ask about 25 psychological attributes, some positive and others negative, divided between 5 scales:

1) emotional symptoms (5 items)

2) conduct problems (5 items)

3) hyperactivity/inattention (5 items)

4) peer relationship problems (5 items)

5) prosocial behaviour (5 items)

1) to 4) added together to generate a total difficulties score (based on 20 items)

Similarly, the Spence Children's Anxiety Scale specifically screens for heightened anxiety in CYP and may also warrant consideration if anxiety is presenting as the major difficulty. Sub-scales are computed by summing the following items:

- Separation anxiety (items 5, 8, 12, 15, 16, 44)
- Social phobia (items 6, 7, 9, 10, 29, 35)
- Obsessive compulsive (items 14, 19, 27, 40, 41, 42)
- Panic/agoraphobia (items 13, 21, 28, 30, 32, 34, 36, 37, 39)
- Physical Injury (items 2, 18, 23, 25, 33)
- Generalised anxiety (items 1, 3, 4, 20, 22, 24)

https://novopsych.com.au/assessments/child/spence-childrens-anxiety-scale-child-scas-child/

Some schools do have access to screening tools to support the analysis of SEMH difficulties in CYP for example, the THRIVE framework (an integrated person-centred and needs led approach, to delivering mental health services for children and young people). However, some products, frameworks and screeners may have associated costs and for the purposes of this report, the authors want to focus on ways forward that are accessible to all for no additional cost.

What intervention, when and by whom?

Survey responses describe a wide range of support that is available for CYP with epilepsy and mental health difficulties, with 25% of respondents identifying that Early Help Assessments have been utilised to support those CYP with epilepsy. Other offered interventions include school counselling, nurture rooms, pastoral interventions, Lego Therapy, journaling and social interventions and whilst there are benefits to having a large number of possible approaches, currently there is no agreed, co-ordinated evidence-based strategy and interventions are reactive and focus on the most prominent presenting difficulty at the time. It would be beneficial to develop agreed intervention approaches for CYP with epilepsy, with clear pathways for seeking additional supervision and advice if interventions are either not accepted or appear ineffective.

An integrated approach

76% of respondents recognised that they would benefit from additional training to better equip them to identify mental health and specific cognitive difficulties in CYP with epilepsy. A further 85% also stated that they do not think that parents/carers are an adequate source of health information for CYP with epilepsy. Given these somewhat startling figures, it appears that an integrated approach to supporting CYP with epilepsy is vital and should include:

- Effective two-way communication between a named education professional and the hospital-based multidisciplinary epilepsy team.
- Regular and required information sharing between school, health, parents/carers and where appropriate social care to optimise the support offered to the CYP with epilepsy.

Recommendations

1. Education mental health practitioner (EMHP) teams are a significant step forward in offering early, brief, evidence-based interventions to address mental health needs of CYP. However, in the context of a complex health condition such as epilepsy, it would be beneficial for additional assessment and support to be offered by hospital clinic-based teams:
    - The name and contact details of the epilepsy specialist nurse should be documented and available in education settings to access care-planning, advice, support, training and to raise concerns.
    - Health psychology members of the epilepsy clinic team can offer more expert assessment and intervention when required.

    Liaison and partnership with school-based support services would then offer optimal support across the different contexts of the CYP's life.

2. Despite recognising that mental health problems are more common in CYP with epilepsy, only 27% of schools actively screen for mental health problems in CYP with epilepsy and the screening undertaken does not employ validated tools or approaches. Active screening of those at high risk of mental health difficulties should be undertaken using agreed approaches and validated tools across settings. One such tool that could be used in this way is the Strength and Difficulties questionnaire (SDQ).

3. Regardless of 59% schools recognising that CYP with epilepsy are more likely to have cognitive problems, 85% do not have a specific screening algorithm or assessment protocol for these CYP. Cognitive screening should be carried out in an agreed and structured way for CYP at high risk of cognitive deficits.

4. Care must be taken to avoid standardisation of methodology becoming a "one size fits all" approach which may not be suitable for complex situations. Conversely, an overly extensive and disparate number of interventions can also be unhelpful. An appropriate selection of evidence-based assessments and interventions should be agreed and provided.

5. 76% of schools reported that further staff training is required with regard to identification of and intervention for mental health and cognitive problems in CYP with epilepsy. Training for the agreed tools and approaches should be provided to nominated staff members.

6. Clear pathways to seek additional supervision and referral are required where interventions are not accepted, appear ineffective or the complexity of the presentation is beyond the experience and expertise of the practitioner.

7. For CYP with epilepsy and identified mental health problems who do not meet the SEMH threshold on the SEND register, only 19% of schools sometimes record this and 29% of schools do not record this. Identified mental health issues should be consistently recorded even when the SEMH threshold for SEND registration is not reached and this should be updated annually.

8. 85% schools felt that parents/carers are not an adequate source of all health information, for CYP with epilepsy. This emphasises the need for continued, improved and structured multi-agency information sharing to optimise the care and support given to CYP with epilepsy.

9. These improvements across the ICS footprint can be facilitated by the NENC CHWN through:
   - Establishing a CYP epilepsy clinical lead role for the ICS
   - Establishing a children's epilepsy working group with membership from the widest geographical area and with extensive multidisciplinary representation including health, education, social care, 3rd sector and CYP with epilepsy and their parents/carers
   - Encourage further CHWN membership and participation from mainstream secondary schools who were under-represented in this survey
   - Through regular working group meetings and interdisciplinary working, develop a work programme to agree approaches and methodologies and then implement them with timelines and, outcome and audit metrics. Metrics should include service development and implementation in the context of indices of deprivation to prevent any inequalities of access and provision
   - Hosting a regular 'Epilepsy Huddle' with clinical updates and to show-case progress and impact for educational settings
   - Developing a series of resources for professionals, CYP and their families, available in an on-line digital format which explain (in an age-appropriate and child-friendly way) the impact that epilepsy can have on some CYP physically and mentally – in line with the SEND Code of Practice. The resources could include pre-recorded webinars/e-training modules which are focussed on the regional strategic and operational approaches to managing a CYP with epilepsy across the different contexts of their life
   - Sign-posting links where available and creating material where not available in the form of digital videos and animations to help explain some of the mental health difficulties experienced by CYP with epilepsy and how these can be overcome. Working in partnership with third sector organisations such as Young Epilepsy would be beneficial to this aim. These could be made available on the *Healthier together* platform and shared with other CHWNs.
   - Wherever possible CYP and their parents/carers should be represented in the creation of the work programme and resources. An example of this could be a video following three CYP of different ages with epilepsy in different educational

settings to capture their voice and perceptions of how the condition affects them at school and the support they receive

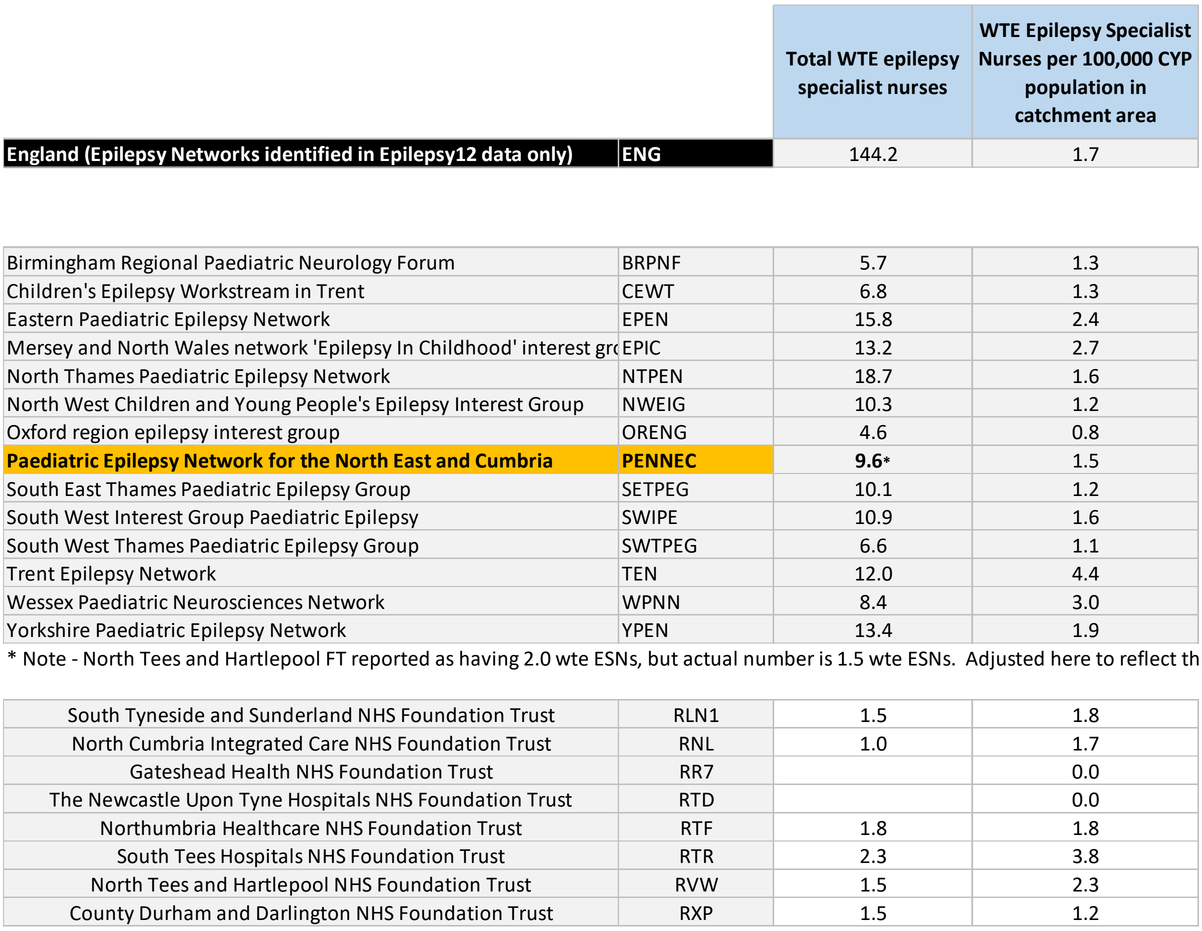
Mental health in CYP with epilepsy (Epilepsy Project 2) in the hospital-based secondary care setting

AM Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor), C Geagan (Clinical Psychologist), L Dauncey (Network Delivery Manager CYPT), P Archman (Senior General Manager Planning and Information)

Introduction

Detailed background information with national and ICS demographic data and national audit data form the Epilepsy12 audit can be found in Appendix 2 and provides a valuable context for this piece of work. Aspects of service provision and staffing including RCN recommendations are covered more comprehensively in the Epilepsy 1 project report. This introduction is focused on relevant contextual information as it pertains to paediatrician epilepsy clinical leads (CLs) and epilepsy specialist nurses (ESNs) as these are the two professional groups surveyed in secondary care.

The national average epilepsy specialist nurse (ESN) establishment is 1.7 WTEs per 100,000 CYP population (see table below). Across the epilepsy networks surveyed in the Epilepsy12 audit, this varies between 0.8 and 4.4 WTE ESNs per 100,000 CYP population. PENNEC/NENC ICS has 9.6 WTE ESNs and serves a CYP population of circa 600,000 which is equivalent to 1.5 WTE ESNs per 100,000, just below the national average. However, there is marked inequality and variation in provision ranging from Newcastle and Gateshead having no ESNs at the time of conducting this work, to South Tees having the equivalent of 3.8 WTE ESNs per 100,000 CYP population.



		Total WTE epilepsy specialist nurses	WTE Epilepsy Specialist Nurses per 100,000 CYP population in catchment area
England (Epilepsy Networks identified in Epilepsy12 data only)	**ENG**	144.2	1.7

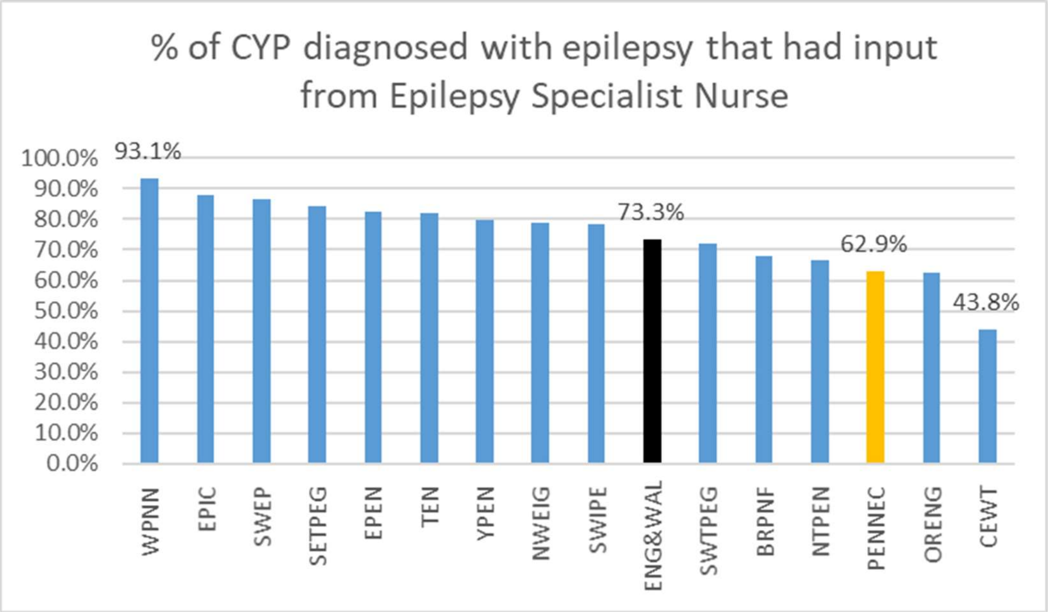
Birmingham Regional Paediatric Neurology Forum	BRPNF	5.7	1.3
Children's Epilepsy Workstream in Trent	CEWT	6.8	1.3
Eastern Paediatric Epilepsy Network	EPEN	15.8	2.4
Mersey and North Wales network 'Epilepsy In Childhood' interest gr	EPIC	13.2	2.7
North Thames Paediatric Epilepsy Network	NTPEN	18.7	1.6
North West Children and Young People's Epilepsy Interest Group	NWEIG	10.3	1.2
Oxford region epilepsy interest group	ORENG	4.6	0.8
Paediatric Epilepsy Network for the North East and Cumbria	**PENNEC**	**9.6***	1.5
South East Thames Paediatric Epilepsy Group	SETPEG	10.1	1.2
South West Interest Group Paediatric Epilepsy	SWIPE	10.9	1.6
South West Thames Paediatric Epilepsy Group	SWTPEG	6.6	1.1
Trent Epilepsy Network	TEN	12.0	4.4
Wessex Paediatric Neurosciences Network	WPNN	8.4	3.0
Yorkshire Paediatric Epilepsy Network	YPEN	13.4	1.9

* Note - North Tees and Hartlepool FT reported as having 2.0 wte ESNs, but actual number is 1.5 wte ESNs. Adjusted here to reflect th

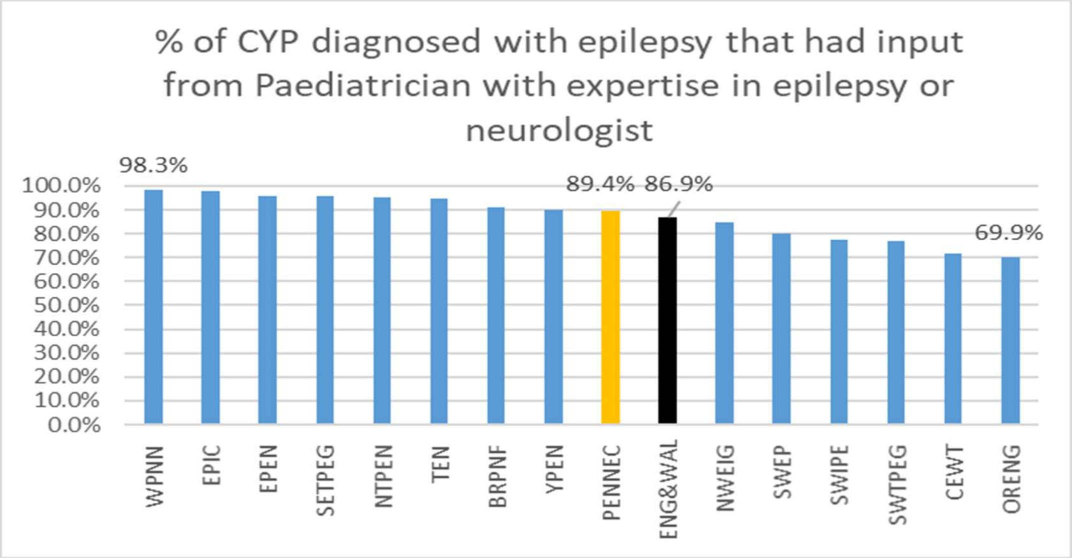
South Tyneside and Sunderland NHS Foundation Trust	RLN1	1.5	1.8
North Cumbria Integrated Care NHS Foundation Trust	RNL	1.0	1.7
Gateshead Health NHS Foundation Trust	RR7		0.0
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	RTD		0.0
Northumbria Healthcare NHS Foundation Trust	RTF	1.8	1.8
South Tees Hospitals NHS Foundation Trust	RTR	2.3	3.8
North Tees and Hartlepool NHS Foundation Trust	RVW	1.5	2.3
County Durham and Darlington NHS Foundation Trust	RXP	1.5	1.2

Table 1: Data from Epilepsy 12 audit (organizational) Round 3 Cohort 2 reported November 2020

The below average level and variation in provision of ESNs is reflected in the figure below from the Epilepsy12 national audit which shows the % CYP receiving ESN input in each of the regional epilepsy networks along with the figure for England and Wales. The NENC is shown in yellow.



Input from a paediatrician with expertise in epilepsy or neurologist in the PENNEC/NENC ICS (see below in yellow) has similar levels to the rest of the networks audited in the Epilepsy12 audit and is more or less average for England and Wales (87%).



The Epilepsy12 national audit data reveals that a significant proportion of children with a diagnosis of epilepsy also have some element of neurodisability. The numbers reported at regional level are too small to permit reasonable analysis, but national Epilepsy12 data reports 538 occasions where a neurodisability was identified from 2086 patients, although some individuals may have more than one type of neurodisability.

NEURODISABILITY

Epilepsy12 Round 3, Cohort	England	Paediatric Epilepsy Network for the North East and Cumbria
No. of CYP with epilepsy diagnosis_1st year That also have ………………	2086	245
Autistic spectrum disorder	142	15
Intellectual disability	131	16
Other learning difficulty	61	*
Cerebral palsy	59	6
Identified chromosomal disorder	46	9
Speech disorder	42	*
Attention deficit hyperactivity	36	*
Neurodegenerative disease	10	*
Dyslexia	6	0
Dyspraxia	5	*

MENTAL HEALTH PROBLEMS

Epilepsy12 Round 3, Cohort	England	Paediatric Epilepsy Network for the North East and Cumbria
Total No. of CYP with epilepsy diagnosis_1st year That also have …………	2086	245
Mood disorder	13	*
Anxiety disorder	25	0
Emotional problems	10	0
Self harm problems	7	*
Other mental health problems	33	*

No. of CYP with non-epileptic episodes only with Behavioral, Psychological And Psychiatric Disorders	1188	109

The number of CYP diagnosed with epilepsy that also have a mental health problem is reported as less than 5% in this national cohort. However, since research has demonstrated that 37% of CYP with epilepsy have a mental health diagnosis(9), this likely reflects the limitations of epilepsy services across the country to provide mental health assessment, diagnosis and support. It is noted that no CYP in PENNEC/NENC ICS were identified as having a mental health problem in the first year of diagnosis.

There are also a significant number of CYP referred with a suspected diagnosis of epilepsy who are subsequently found not to have epilepsy but, have some form of behavioural, psychological or psychiatric problem. From the data provided through Epilepsy12 this could constitute approximately 20% CYP referrals. In addition, 13% (269/2106) CYP diagnosed with epilepsy, experienced episodes where there was uncertainty whether these seizures were epileptic or not and 1**%** (16/2106) of CYP with epilepsy had non-epileptic seizures identified.

Methods

The Epilepsy Project 2 team (mental health in CYP with epilepsy) devised a survey for paediatrician epilepsy clinical leads (CLs) and epilepsy specialist nurses (ESNs) in secondary care on behalf of the NENC CHWB, to acquire qualitative and quantitative information about approaches and provision for mental health needs in CYP with epilepsy in the ICS footprint.

The survey was distributed to CLs and ESNs in secondary care in 8 provider Trusts as follows:

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

The survey was developed through collaborative team working and was led by Dr Anita Devlin, Consultant Paediatric Neurologist and Project 2 Lead. The questionnaires distributed to the two professional groups, clinical leads and ESNs, were similar which allowed comparison of responses and views between the two groups. The full set of distributed questions for both groups can be found in Appendix 4 and Appendix 5.

Outcomes of the survey

Respondent characteristics

There were 11 ESN respondents and in all, this was their only employed role. More than 1 response was obtained from Durham and Darlington and South Tees who have more than 1 ESN. Responses were obtained from 7/8 provider Trusts with respect to ESNs as Gateshead does not employ an ESN currently. The response from Newcastle was from a neurology nurse specialist who is a member of the regional tertiary neurology team and not based in secondary care. At the time the survey was conducted Newcastle did not employ an ESN in secondary care although we understand that this post has subsequently been approved and appointed to.

There were 9 CL responses from 7 provider Trusts – in Durham and Darlington and North Cumbria Integrated Care Trust there is more than 1 CL response. Responses were obtained from only 7/8 provider Trusts as we did not receive a reply from Northumbria. All Trusts from which there was a response, offer dedicated epilepsy clinics for CYP by 1-6 paediatricians depending on the size of the Trust and the number of locations where secondary care is provided.

The variation in the location of the CL respondents compared with the ESN respondents means that the responses are not directly comparable, but some inferences can still be made when responses are compared (see table below).

Clinic provision

ESN attendance at the epilepsy clinic

Approximately half of the ESN respondents reported that they always attend the CYP epilepsy clinics in their Trust with most of the remainder attending sometimes. 3/7 Clinical Leads reported that ESNs always attend the CYP epilepsy clinics in their Trust with a further 4 reporting that ESNs sometimes attend the CYP epilepsy clinics. At the time of this survey, Newcastle and Gateshead did not have ESNs and responded “Never” to this question. However, it is clear that routine ESN attendance at clinic is in the region of 50%. Clinic represents an important contact opportunity between ESNs and CYP and, ESN input in our ICS region is significantly below that offered in other networks (see introduction).

Separate consultation between ESN and CYP with epilepsy at the clinic

The majority of ESNs (8/11) reported that when they do attend the epilepsy clinic, they always hold separate consultations with the CYP during the clinics. The remaining 3 ESNs sometimes have separate consultations. 3/7 clinical leads reported that ESNs always hold separate consultations with a further 4 reporting that this occurs sometimes. These responses may, in part, reflect ESN attendance at the clinics. However, a separate consultation offers a valuable face-to-face opportunity separate to the medical consultation and, where appropriate, separate to the parent/carer for the CYP to disclose and discuss any concerns.

Epilepsy Specialist Nurses - Mental Health in Epilepsy Survey

Q7. Do you attend the children and young people's epilepsy clinics in your Trust?	
Always	6
Sometimes	4
Never	1

Q8. Do you conduct a consultation with the CYP, which is separate to the one with the doctor?	
Always	8
Sometimes	3
Never	0

Q9. Do you have separate epilepsy clinics for young people (e.g. >12 years)	
Yes	4
No	7

Q10. Are the epilepsy clinics in your Trust attended by a mental health professional?	
Always	0
Sometimes	2
Never	9

Epilepsy Clinical Leads- Mental Health in Epilepsy Survey

Q9. Does an ESN attend your epilepsy clinic?	
Always	3
Sometimes	4
Never	2

Q10. If an ESN attends your clinic does he/she conduct a consultation with the CYP with epilepsy which is separate to your consultation?	
Always	3
Sometimes	4
Never	0

Q11. Do you have separate epilepsy clinics for young people (e.g. >12 years)	
Yes	0
No	9

Q12. Are the epilepsy clinics in your Trust attended by a mental health professional?	
Always	0
Sometimes	0
Never	9

Separate clinics for young people (>12 years)

4/11 ESNs indicated that they hold separate clinics for young people with epilepsy but the majority of ESNs do not. Furthermore, all CLs indicated that they do not have separate epilepsy clinics for young people. It has long been appreciated that young people >12 years benefit from having a clinic environment separate to younger children with access to more age-appropriate resources that assist with the transition process. The clinics can also be held at times that are more suitable for young people, for example, evening clinics that do not conflict with education commitments at a time when preparation for educational qualifications typically occurs.

Clinic attendance by mental health professional

The majority of ESNs (9/11) reported that the epilepsy clinics are not attended by a mental health professional. Two respondents indicated this happens sometimes, and in both cases, this is a psychologist from Trust-based Health Psychology services. All clinical leads indicated that the epilepsy clinics are not attended by a mental health professional. This shows that there is currently no clinic access to assessment and intervention by a mental health professional in the epilepsy clinic setting throughout the ICS footprint.

Identifying mental health problems in CYP with epilepsy in the clinic

Both professional groups are aware that mental health problems are more frequent in CYP with epilepsy compared to CYP without any health issues and in both groups three times as common was the most frequent answer (4/11 ESN & 4/9 CLs). However, a further 3 respondents from each group knew the reported frequency established by research – four times as common.

When asked about mental health screening in the clinic the following responses were obtained:

Epilepsy Specialist Nurses

Epilepsy Clinical Leads

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

Always	2
Never	1
As required	8

Always	0
Never	1
As required	8

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	4
Never	1
As required	6

Always	0
Never	1
As required	6

8/11 ESNs and 8/9 CLs reported that screening for mental health problems is undertaken as required in the doctor's consultation with 1/11 and 1/9 respectively reporting that this never occurs. 6/11 ESNs and 6/7 clinical leads reported that screening occurs as required in the ESN consultation with 1/11 and 1/7 respectively answering that this never occurs.

However, only 1 respondent from both groups combined (1/20) reported that a screening tool was used indicating that an informal approach is employed. However, only 4/11 ESNs and 3/9 CLs feel confident about identifying a mental health need using their own approaches. This indicates that there is a need for a more structured and validated approach to screening for mental health issues in this group who are known to be at higher risk for these problems than other groups of CYP(9).

Once mental health problems are identified both professional groups share this information with parents/carers and the GP in almost all cases. The school nurse and the SENCO are commonly informed by the ESNs and by some of the CLs whilst other groups such as respite/residential care providers and CAMHS are less commonly informed.

With regard to the recognition of cognitive problems, less than half of the CLs (4/9) are confident about recognising specific cognitive problems in CYP with epilepsy. When asked which service they would refer to for further assessment there were a variety of responses:

	YES	NO	N/A
Trust based health psychology services	3	1	2
Educational psychology	6	1	1
SENCO at school	7		
Other	4		

Other services included:

Neuropsychology assessment	**2**
Clinical Psychologist in CYPS	**1**
LD CAMHS	**1**

The most common referral is to the SENCO at school and the educational psychologist. However, two CLs indicated that educational psychology services no longer take direct referrals from Trust clinical teams in their area, and that this service can only be accessed by schools.

Current provision of mental health support by the clinical team

Epilepsy Specialist Nurses - Mental Health in Epilepsy Survey

Q12. 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	11
	No	0

Q13. Is this different if the CYP attends special needs educational provision?	Yes	4
	No	7

Q15. 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	7
	No	4

Epilepsy Clinical Leads- Mental Health in Epilepsy Survey

Q14. 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	7
	No	2

Q15. 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	7
	No	2

Q16. Is this different if the CYP attends special needs educational provision?	Yes	1
	No	8

Q18. 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	6
	No	3

All of the ESNs felt that they are the person who offers the 1st level of mental health support to CYP with epilepsy and their families. The majority of clinical leads (7/9) also reported that they are the person who offers the 1st level of mental health support to CYP with epilepsy and their families, with the majority (7/9) also acknowledging that the ESN is the person who offers the 1st level of mental health support. It is clear that both professional groups recognise this need in the CYP epilepsy clinic and are trying to meet it which demonstrates that the existing clinic setting provides a good opportunity both to identify and support mental health problems.

Approximately a third of ESN respondents reported that this is different when the CYP attends special needs educational provision, as the 1st level of mental health support in these cases is provided by school staff. The majority of CLs (8/9) felt that there is no difference if the CYP attends special needs educational provision. On CL indicated that the learning disability team get involved but they have to have severe LD; another indicated it depends on the school e.g. the special school for autism only has support through public health nursing who have no training in LD and autism; other special schools have some nursing input.

One-third of the ESNs reported that they did not think that providing the 1st level of mental health support to CYP with epilepsy and their families should be part of the ESN role. They indicated that it should be offered by a trained mental health professional referred to variably as mental health practitioner-psychiatry, specialist psychologist, mental health worker health professional and clinical psychologist specifically qualified in this area of practice. 6/9 CLs agreed that offering the 1st level of mental health support to CYP with epilepsy and their families is part of the ESN role. The remaining 3 CLs felt that this should not be part of the ESN role, indicating that it should be performed by trained MH professions/CAMHS.

Although there are mixed views between the 2 groups, 2/3 of respondents from each professional group agreed that it could be part of the ESN role. This offers an opportunity to develop this role as long as it is supported by an appropriate increase in ESN resource, training and supervision.

Mental health interventions

The survey asked about the degree of confidence of both groups to offer mental health support to CYP with epilepsy.

Epilepsy Specialist Nurses

Epilepsy Clinical Leads

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

Very Confident	0
Confident	1
Neutral	6
Not confident	3
Not at all confident	0

Very Confident	0
Confident	2
Neutral	4
Not confident	2
Not at all confident	1

Do you ever feel that you are expected to offer mental health support to CYP with epilepsy which is outside your experience and expertise?

Yes	6
No	4

Yes	6
No	3

Only 1 ESN reported being confident about offering mental health support to CYP with epilepsy. The majority of ESNs (6/10) are neither confident or not confident (neutral) in offering mental health support to CYP with epilepsy, and 3 are not confident. Only 2/9 CLs are confident about offering mental health support to CYP with epilepsy. 4/9 CLs are neutral and 3 are not confident.

Over half of the ESNs (6/10) feel that they are expected to offer mental health support to CYP with epilepsy which is outside their experience and expertise. In these circumstances advice and support is sought from colleagues including other ESNs, paediatric consultants, CAMHS, and in-house neuropsychologist (where available). Similarly, two-thirds of CLs (6/9) felt they are expected to offer mental health support to CYP with epilepsy which is outside their experience and expertise and seek advice from health psychology colleagues (albeit capacity is limited) and CAMHS/CYPS. However, they also reported that referrals to these services are often rejected and have long waiting times.

No support groups for CYP with epilepsy are currently hosted by secondary care across the ICS footprint. This would offer a further opportunity not only for professional support but for peer-to-peer support which is known to be so important to YP.

Recognition of the need for onward referral to mental health services

When both groups were asked about their confidence in recognising when onward referral to mental health services was required, mixed responses were obtained. 6/10 of the ESNs feel confident and 7/9 CLs feel confident in CYP with normal cognition. However, this falls to 0/10 ESNs and 4/9 CLs for CYP who attend special educational needs provision. This suggests that even closer partnership working is required with learning disability teams and special education providers to improve the recognition of mental health problems and to make the most effective onward referral. As can be seen from the table below, the minority of services screen for mental health problems as part of the transition process.

Epilepsy Specialist Nurses

Epilepsy Clinical Leads

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

Very Confident	0
Confident	6
Neutral	2
Not confident	2
Not at all confident	0

Very Confident	1
Confident	6
Neutral	1
Not confident	1
Not at all confident	0

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	0
Confident	0
Neutral	4
Not confident	6
Not at all confident	0

Very Confident	1
Confident	3
Neutral	3
Not confident	2
Not at all confident	0

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

Yes	2
No	5

Yes	2
No	6

Referral pathways

8/10 ESNs and 4/9 CLs reported that their Trust have in-house Trust-based child health psychology services (approx. 50%) and 4/10 ESNs and 6/9 CLs reported that there is a defined onward referral pathway when mental health or neurodevelopmental difficulties are identified in a CYP with epilepsy and normal learning ability. Approximately a third of both professional groups reported that for CYP who attend special educational provision, the defined onward referral pathway for further assessment and intervention is different.

When asked if learning disability psychology/psychiatry services are available in their area there is a difference in responses from the two professional groups with 5/9 ESNs reporting that these are available compared to 8/9 CLs.

Both professional groups were asked to rank in order of priority the services to which they would refer in a number of suspected mental health conditions and a summary of the answers obtained are shown in the table below.

A referral to CAMHS is the most common choice of both professional groups for all mental health conditions. Referral to Trust-based health psychology services is the 2nd choice for CLs for all conditions except suspected autism spectrum disorder. It is interesting that health psychology is 2nd choice to CAMHS even when it is available in approximately 50% of Trusts. This may be because Trust-based health psychologists usually work with CYP if mental health concerns are specifically linked to a health-condition for example, anxiety about having a seizure. Referrals where mental health problems appear to be due to other factors may be declined but this requires further exploration. The most common 3rd choice for CLs is referral back to the GP for onward referral, whereas the 2nd and 3rd most common choices for ESNs are a combination of Trust-based health psychology and community-based psychology services linked to community child health (CCH).

Table: Ranking in order of priority the services to which referrals would be made in various suspected conditions

Epilepsy Specialist Nurses - Mental Health in Epilepsy Survey

Epilepsy Clinical Leads- Mental Health in Epilepsy Survey

ESNs	1st Choice	2nd Choice	3rd Choice
ADHD	Local CAMHS/CYPS	Community based psychology services linked to CCH	School nurse/school based
Anxiety	Local CAMHS/CYPS	Trust based health psychology	School nurse/school based
Autistic Spectrum Disorder	Local CAMHS/CYPS	GP for onward referral	Community based psychology services linked to CCH / Trust based health psychology
Depression	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Obsessive-compulsive disorder	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH
Psychosis	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH
Self-harming behaviour	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH

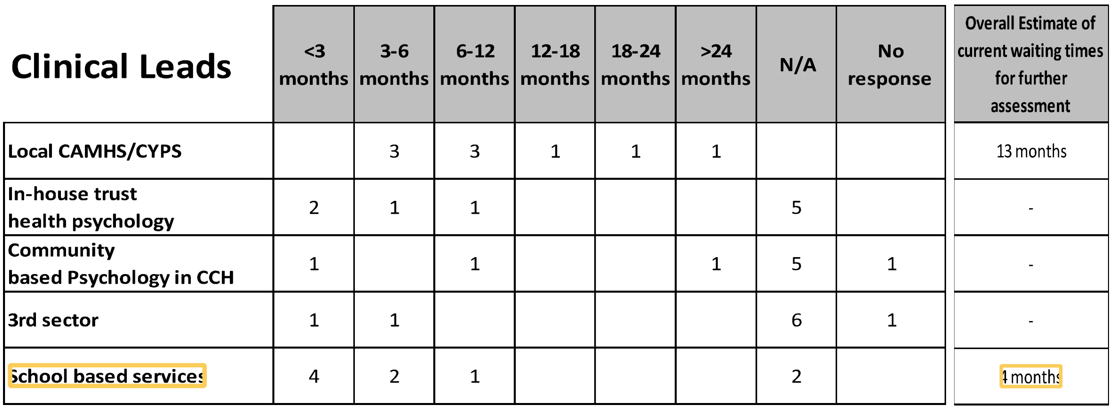
Clinical Leads	1st Choice	2nd Choice	3rd Choice
ADHD	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH
Anxiety	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH
Autistic Spectrum Disorder	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology / GP for onward referral
Depression	Local CAMHS/CYPS	Trust based health psychology	GP for onward referral
Obsessive-compulsive disorder	Local CAMHS/CYPS	Trust based health psychology	GP for onward referral
Psychosis	Local CAMHS/CYPS	Trust based health psychology	GP for onward referral
Self-harming behaviour	Local CAMHS/CYPS	Trust based health psychology	GP for onward referral

Table: Waiting times as reported by ESNs for various services

ESNs	<3 months	3-6 months	6-12 months	12-18 months	18-24 months	>24 months	N/A	No response	Overall Estimate of current waiting times for further assessment
Local CAMHS/CYPS		3	4	2				2	9 months
In-house trust health psychology	3	1	4				2	1	6 months
Community based Psychology in CCH	1	2	2	1			3	2	8 months
3rd sector	4	3	1					3	4 months
School based services	6	2	1					2	3 months

The longest waiting time identified for both groups is for CAMHS with a range of 3-24 months and an average between 9-13 months. The next longest wait is for community-based psychology in CCH with an average of 8 months. The shortest waiting time identified by both groups was for school-based services.

Table: Waiting times as reported by CLs for various services



Clinical Leads	<3 months	3-6 months	6-12 months	12-18 months	18-24 months	>24 months	N/A	No response	Overall Estimate of current waiting times for further assessment
Local CAMHS/CYPS		3	3	1	1	1			13 months
In-house trust health psychology	2	1	1				5		-
Community based Psychology in CCH	1		1			1	5	1	-
3rd sector	1	1					6	1	-
School based services	4	2	1				2		4 months

Epilepsy Action and Young Epilepsy are the two 3rd sector organisations most commonly recommended by both professional groups to provide support for CYP's mental health followed by the Epilepsy Society and Mind. However, other 3rd sector organisations were also mentioned including Epilepsy Sucks, Kooth, SUDEP action, Young Minds, Step by Step, and Talking Changes. Some 3rd sector and other partnership organisations may be localised and it is important that clinical teams have up-to-date information about support organisations locally as well as nationally. Most ESNs (8/10) indicated that they personally offer support to CYP with mental health problems by signposting to 3rd sector/ LA resources. No 1:1 intervention is currently offered by either professional group.

Prescribing for mental health problems

As expected, most CLs (7/9) indicated that they are confident in prescribing anti-seizure medications to CYP on drug treatments for mental health problems. However, only 2/9 prescribe for mental health problems in these CYP and in 1/9 the only drug the respondent would prescribe was risperidone. In the remaining single respondent drugs included methylphenidate, dexamphetamine (ADHD), benzodiazepines, and clonidine for tic disorders.

Preferred NHS service model for mental health assessment and intervention

When asked which service model for mental health assessment and intervention would best meet the needs of CYP with epilepsy, 7/8 ESNs and 6/8 CLs reported that hospital-based health psychology embedded within the epilepsy clinic would be the best model. This gives a very clear message from NHS epilepsy clinical teams about how the mental health needs of CYP with epilepsy would be best served.

Parent and carer mental health

All 11 ESNs and all 9 CLs reported that the prevalence of mental health problems is increased in the parents/carers of CYP with epilepsy compared with other long-term conditions. In addition, 8/9 CLs and 6/11 ESNs report spending a significant amount of time supporting parental/carer mental health. Both groups estimated that of the time they spend offering mental health support 20-30% of it is spent supporting parents/carers.

Despite this reported prevalence and time taken in this area, only 3/11 ESNs feel confident in recognising mental health problems in parents/carers of CYP with epilepsy and once recognised only 5/11 are confident about recognising the need for onward referral. Only 3/9 CLs reported feeling confident in recognising mental health problems in parents/carers of CYP with epilepsy and only 1/9 are confident about recognising the need for onward referral.

8/11 ESNs and 5/9 CLs said there is a defined onward referral pathway for parents/carers who are identified as having mental health needs, the most common responses being sign-posting to sources of support including GP and GP referral with consent.

Over half of the ESNs (6/10) feel that they are expected to offer mental health support to parents/carers of CYP with epilepsy which is outside their experience and expertise. In these instances, advice and support is sought from colleagues or other services involved with CYP, including other ESNs, paediatric consultants, psychology, and 3rd sector services.

4/9 CLs feel that they are expected to offer mental health support to parents/carers of CYP with epilepsy which is outside their experience and expertise. In these instances, most CLs indicated that they provide the usual emotional support and they either refer (with consent) or advise the parents /carers to see their GP, and possibly refer for social services support e.g. Early Help Services.

Mental health training for epilepsy clinical teams

Both groups of professionals were asked about the requirement for additional mental health training. The responses were remarkably similar (see tables below) identifying wide-ranging training needs for epilepsy clinical team members.

Epilepsy Specialist Nurses (n=11)

In relation to CYP with Epilepsy:

	YES Responses
Additional training in the recognition of mental health problems in CYP with normal learning ability	10
Additional training in the recognition of mental health problems in CYP with special needs	11
Additional training with specific tools to identify mental health problems	11
Additional training in offering initial support to CYP with epilepsy and mental health problems	9
Additional training about when to refer on to mental health services	10
Clearer referral pathways to CYP mental health services	11
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy	10

In relation to parents / carers of CYP with Epilepsy:

	YES Responses
Additional training in the recognition of mental health problems in parents/carers of CYP with epilepsy	10
Additional training with specific tools to identify these problems in parents/carers	11
Additional training in offering initial support to parents/carers of CYP with epilepsy and mental health/emotional difficulties	9
Additional training about when and how to seek consent for referral on to separate services (e.g. GP, mental health services, third sector)	9
Clearer onward referral pathways	11
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in parents/carers of CYP with epilepsy	9
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	10

All ESNs reported that they would benefit from additional training in at least 3 or more aspects of mental health both for CYP with epilepsy and their parents/carers, particularly around the recognition of mental health needs and the use of specific tools to identify them. All ESNs identified that they need clearer referral pathways. 10/11 ESNs also want additional support/supervision from a qualified mental health professional.

Epilepsy Clinical Leads (n=9)

In relation to CYP with Epilepsy:

	YES Responses
Additional training in the recognition of mental health problems in CYP with normal learning ability	7
Additional training in the recognition of mental health problems in CYP with special needs	7
Additional training with specific tools to identify mental health problems	8
Additional training in offering initial support to CYP with epilepsy and mental health problems	8
Additional training about when to refer on to mental health services	6
Clearer referral pathways to CYP mental health services	8
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy	8

In relation to parents / carers of CYP with Epilepsy:

	YES Responses
Additional training in the recognition of mental health problems in parents/carers of CYP with epilepsy	8
Additional training with specific tools to identify these problems in parents/carers	8
Additional training in offering initial support to parents/carers of CYP with epilepsy and mental health/emotional difficulties	7
Additional training about when and how to seek consent for referral on to separate services (e.g. GP, mental health services, third sector)	7
Clearer onward referral pathways	8
Additional support/supervision from a qualified mental health professional in dealing with mental health issues in parents/carers of CYP with epilepsy	9
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	8

8/9 CLs think that they would benefit from additional training in at least 6 aspects of mental health for CYP with epilepsy and their parents/carers as well as clearer referral pathways. The majority (8/9) also think that they would benefit from additional support/supervision from a qualified mental health professional in dealing with mental health issues in CYP with epilepsy and their parents.

Final comments from both groups

Epilepsy Specialist Nurses - Mental Health in Epilepsy Survey	Epilepsy Clinical Leads- Mental Health in Epilepsy Survey

“I feel that schools are often asking for help with mental health issues and the first point of call is the ESN.”

“In our area we do have child psychologists working within other chronic health conditions such as CF & Diabetes but nothing around epilepsy.”

“The Term mental health is a very wide term and I feel that issues are sometimes missed and not treated.”

“With regard to mental health training, it would be appropriate to be able to identify those in need and have very clear referral pathways. However, qualified Mental Health workers are far more appropriate to be giving the support.”

“Mental health of our children with a diagnosis of epilepsy is such a big part of their care, and unfortunately not given the recognition or funding it requires. I certainly would really appreciate further training and support in this area as at times I feel we do all we can but we are letting our families down.”

“CYP and their families need support asap, access in a timely manner is poor with long waiting lists to be seen.”

“Need for Clinical psychologist is very much supported by our team, thank you for doing this piece of work which will hopefully give this the required impetus.”

“We need adequate provision to deliver appropriate support in a timely manner and we do not have this. I would much prefer in house health psychology who can develop some expertise around epilepsy.“

“CYPS provision is disorganised and it’s a lottery for families in terms of quality after a long wait.”

“The referral criteria for CAMHS can be subjective.”

“I feel that I have to “coach” parents as to what to say so as to make sure their child is not triaged to wrong/inadequate service.”

“Would welcome suspected seizure referrals direct from CYPS (not sent back to GP without any documentation to seek referral) so that all CYP, including those with MH problems benefit from expert, accurate, timely (2WW) assessment.”

Discussion

It is necessary to start the discussion about the outcomes of this survey by acknowledging areas of good knowledge and practice regarding the mental health assessment and support offered to CYP with epilepsy.

Identified areas of good practice

- With regard to % CYP with epilepsy who have input from a paediatrician with expertise or neurologist, the NENC performs at an average level for England and Wales.
- Both professional groups are cognisant of the increased rate of mental health problems in CYP with epilepsy compared to other CYP with and without long-term health conditions and recognise this as an area of need in this group.
- Both professional groups attempt to identify CYP with mental health problems in the clinic setting and to offer the first level of support. However, they also acknowledge their own limitations in confidence and competence in this area and are appropriately asking for more training and support.
- Some ESNs in particular, show a willingness to become more involved with the mental health assessment and intervention pathway for CYP with epilepsy. However, they require more ESN resource, training and supervision to participate in this aspect of care.
- Both groups attempt to support parents and carers and spend a significant amount of time giving this support. Whilst it is recognised that information sharing and supporting parents and carers is a fundamental component of paediatric care, the levels of mental health support needed for this parent/carer group is increased. Both groups recognise this and acknowledge that they require more training and support in this area.

Epilepsy Specialist Nurse provision and role

The summary data in the introduction highlights problems in two areas with regard to ESN provision. The first is that overall, there is below average provision in the ICS footprint. The second is that there is significant variation and inequality of access to ESNs across the ICS region. Currently, there are providers with no ESN provision and others with twice the national per capita provision. This inequality and variation in provision has a significant effect on the quantity and quality of care that can be offered to CYP and their families including mental health support. The recent NICE Guidance April 2022 states:

“Ensure that all children, young people and adults with epilepsy have access to an epilepsy specialist nurse who:

- has a central role in providing information, education and support
- supports epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite and social care settings
- is a point of contact for, and facilitates access to, other community and multi-agency services”

Clinic attendance by ESN in our ICS footprint (50%) is ESN input is significantly below most other epilepsy networks and below average for England and Wales. The majority of ESNs (8/11) reported that when they do attend epilepsy clinics for CYP, they always hold separate consultations with the CYP during the clinics. The inference therefore, is that this is required and valuable but unfortunately, half of the time it is unavailable to CYP. In addition, there are no separate clinics for CYP>12 years with access both to medical and nursing care which, is the recommended model across paediatrics in recognition of the different needs of this group, and as part of the transition process. Clinics represent a valuable face-to-face contact opportunity with CYP and this is arguably most relevant to those >12 years when mental health needs increase. The number of ESN posts needs to be increased including taking into account indices of multiple deprivation (IMD), to allow ESN attendance at all of the epilepsy clinics for CYP (including separate ones for CYP>12 years) with a separate room available for ESN consultations.

How should mental health assessment and support be provided for CYP with epilepsy and their families and by whom?

The data reveals that mental health assessment and support is required by CYP and, in the absence of a mental health professional, the ESNs and CLs are attempting to provide this at the 1st level. Two thirds of respondents from each professional group agreed that this could be part of the ESN role. This offers an opportunity to develop this role as long as it is supported by an appropriate increase in ESN resource and training. There would need to be adequate specialist supervision (potentially from health psychology) with clear onward referral pathways and, sufficient ESN resource to allow working in partnership with school-based mental health services, to offer a proportionate and staged approach.

Currently, only 1 ESN reported being confident about offering mental health support to CYP with epilepsy and over half of the ESNs (6/10) feel that they are expected to offer mental health support which is outside their experience and expertise. Similarly, only 2/9 CLs said they were confident about offering mental health support to CYP with epilepsy and two-thirds (6/9) feel they are expected to offer mental health support which is outside their experience and expertise. It is not acceptable to have an expectation of those who are neither confident or trained in mental health intervention to offer this, or to carry/manage the risk of the mental health need whilst the CYP waits on a long waiting list for further assessment and access to intervention. 7/8 ESNs and 6/8 CLs reported that access to hospital-based health psychology that is embedded within the epilepsy clinic would be the best model to assess and intervene for mental health problems in this group.

A trained psychologist is able to assess the nature of the mental health need as well as the level of intervention required and optimal mode of delivery. This includes recognising when onward referral to CAMHS is required. Only 6/10 of the ESNs and 7/9 CLs feel confident about recognising when onward referral is necessary and this falls to 0/10 ESNs and 4/9 CLs for CYP who attend special educational needs provision. A trained psychologist would be able to help in both of these circumstances and make a referral which will be of high quality, with a diagnostic formulation and grading of urgency, which is likely to be very helpful to colleagues in CAMHS and LD services.

The chapter of this report related to the Education setting highlighted the gradual introduction of LA/CCG school-based mental health initiatives such as education mental health practitioner (EMHP) teams in each Local Authority through which mental health problems in CYP with epilepsy could be assessed and supported. The EMHP teams' remit is to provide low-intensity work for a duration of 6-8 weeks to address problems associated with depression, anxiety or behavioural difficulties. This presents a valuable opportunity for school-based mental health services to work in partnership with hospital-based clinical teams including Trust-based health psychology to offer a proportionate and staged approach. Short, low-intensity school-based intervention may be appropriate for some CYP with epilepsy but, as previously highlighted, clear pathways for additional supervision and rapid referral are required where interventions are not accepted, appear ineffective or the complexity of the presentation is beyond the experience and expertise of the school-based practitioner.

Currently, a screening tool to identify mental health needs is used in only one clinic and in the other clinics mental health screening is informal and on an "as required" basis which is likely to significantly under-identify problems. In addition, only the minority of both professional groups feel confident in identifying mental health problems using their own informal methods. Therefore, a structured and validated approach to the identification of mental health needs is required. The Strength and Difficulties Questionnaire (SDQ) offers one such approach and this was mentioned in the education chapter of this report, as it can be used across all contexts of the CYP's life. Effective use of this questionnaire in the epilepsy clinic has been reported and published(14) and other on-going studies are using the SDQ as a screening tool(15). The transition process for CYP ought to include screening for mental health problems so that these can be identified and continue to be addressed by adult health services. In order to produce consistent epidemiological data which can be compared between providers and ICBs and can be linked to other factors such as age, ethnicity, IMD, it would be helpful if there was agreement about which screening tools to use across the footprint.

CYP with learning disability (LD) and neurodevelopmental disorders (ND)

It is more complex to identify mental health problems in those with learning disability and neurodevelopmental disorders and this is reflected in the responses. Approximately a third of ESN respondents reported that when a CYP attends special educational needs provision, the 1st level of mental health support is provided by school staff. Special education staff know their students well and can recognise changes in affect and behaviours, that would not be evident to someone during a brief encounter in a clinical environment. Any structured tool or approach in the clinic would have to be appropriately adapted so that CYP with LD and/or neurodevelopmental problems could provide meaningful responses.

Approximately a third of both professional groups reported that for CYP who attend special educational provision, the defined onward referral pathway for further assessment and intervention for mental health problems is different. When asked if learning disability psychology/psychiatry services were available in their area there was a difference in responses from the two professional groups with 5/9 ESNs reporting that these were available compared to 8/9 CLs. Clear and explicit onward referral pathways are required for CYP with epilepsy and co-existing LD or ND conditions with regard to mental health. It is important that mental health problems are not overlooked by being labelled as part of the underlying condition when that may not be the case, and it is important that this group do not suffer negative discrimination regarding the availability and provision of mental health services.

Prescribing for mental health problems in CYP with epilepsy

Unsurprisingly the survey revealed that CLs are confident in prescribing anti-seizure medication but not medication for mental health conditions. Managing mental health conditions is not just about prescribing but includes detailed and skilled assessment and follow-up by a mental health team which cannot be expected of the epilepsy team. If needed, medication for mental health problems ought to be available to CYP with epilepsy in a reasonable timescale, however, this is currently only available through CAMHS or community-based psychiatry teams which have significant waiting lists. There needs to be agreed and effective referral pathways for CYP with epilepsy, once more complex mental health issues have been recognised, so that they can benefit from timely access to more detailed assessment and intervention including medication.

Parental and carer mental health

Ill health in off-spring understandably causes anxiety, stress and grief in parents and carers. However, the clinical teams in this survey, who also care for or have cared for CYP with other conditions, report that they have observed higher levels of mental health problems in parents/carers of CYP with epilepsy than in other conditions. This is also reported by primary care respondents. ESNs and CLs report that that of the time they spend offering mental health support, 20-30% of it is spent supporting parents/carers. However, the majority of both professional groups reported that they do not feel confident in recognising mental health problems in this group or when onward referral is required. They also feel that they are expected to offer mental health support to parents/carers which is outside their field of expertise. Despite this, in the stakeholder chapter of this report, parents/carers describe how much they value support from ESNs particularly in the early stages post-diagnosis. A trained psychologist embedded in the epilepsy clinic will be able to identify problems, recognise when onward referral is required and will be able to support parents/carers through this process.

Training needs

Both professional groups reported the need for further training in all dimensions of mental health – recognition, screening, initial intervention, referral pathways, both for CYP and their parents/carers. Both groups acknowledge the requirement for support from a trained mental health professional which could be provided by a psychologist embedded in the epilepsy service.

Recommendations

1. The number of ESNs for CYP should be increased to achieve equity of access for all CYP with epilepsy and to allow for attendance at all epilepsy clinics for CYP.

2. Separate clinics for young people >12 years are required with access to ESN and medical expertise. This should be available to young people at a time that is suitable for them (evenings included). Account should be taken of this in ESN staffing levels and in consultant job-planning.

3. There is no availability of mental health professional input in the epilepsy clinics for CYP with epilepsy across the footprint of the ICS when this is available for other conditions e.g. diabetes. Embedding health psychologists within epilepsy clinics is the model that ESNs and CLs think will best meet the mental health needs of CYP with epilepsy. It would also offer a source of recognition and risk assessment of emerging mental health problems in parents/carers.

4. The 1st level of mental health support to CYP with epilepsy and their families could be part of the ESN role. However, a significant increase in ESN resource would be required, along with appropriate training, supervision and agreed rapid onward referral pathways.

5. A consistent and validated tool to screen for mental health difficulties in CYP with epilepsy should be employed in the clinic.

6. Once mental health problems are identified:
    - More consistent information sharing amongst professional and carer groups should occur
    - Onward referral pathways for further assessment and interventions for mental health and cognitive problems should be agreed and explicit both for those with normal cognition and those with additional educational or neurodevelopmental needs
    - Closer partnership working between education mental health practitioner (EMHP) teams, SENCOs and the hospital-based clinical teams would reduce waiting times and provide an appropriate and needs-based approach to mental health and cognitive assessment and support. This is even more important for CYP with special educational needs who may not be able to communicate thoughts and feelings in typical ways.
    - Comprehensive and up-to-date contact details and information about relevant 3rd sector organisations both nationally and locally should be available to signpost CYP and their parents/carers.
    - Once identified the appropriate level of further assessment and intervention should be provided in a timely manner by those with appropriate training, experience and supervision
    - Support groups for CYP with epilepsy and separately for the families and carers should be provided and facilitated by one or more people with training in mental health support. This would also give CYP and their families a voice to feedback about services and to become actively involved in service development and improvement

7. Further training is required and being requested by both professional groups in this survey, in the recognition, support and onward referral of mental health problems. Particular training should address these issues in CYP with special educational needs.
8. This survey, with appropriate additions and modifications, should be repeated at intervals of not more than 2 years to ensure that progress is being made in this area

Mental Health Support for CYP with Epilepsy in the Primary Care Setting

Preface by Dr Vaishali Nanda, Primary Care Advisor to the NENC CHWN

“Start with Why” says Simon Sinek (16) a mantra which never fails me.

In my role as Primary Care Advisor I have the formidable task of giving the primary care perspective as we explore various pathways to improve patient care. Many times, we become embroiled in what to do and how to do, that we forget the fundamental question of why?

When I was asked to become involved in the “Mental health in CYP with epilepsy” project my initial response was “Yet another questionnaire!” At a time of immense pressure in primary care this was my instinctive reaction. I was still not convinced that the questionnaire was needed when we could easily find service provision and gaps by talking to commissioners. As I went through the questions myself during the initial review of questions I understood “Why” this process was necessary!

It was challenging my ignorance and prompting me to look for answers. A very powerful question asks that without doing a detailed search, if the responder can identify the number of CYP < 18 years with epilepsy registered with the practice. I didn’t know the answer and the survey confirms the resounding ignorance.

For my part, I went looking for the Epilepsy Register on the QOF register (Quality Outcomes Framework) and realised that the only requirement was to hold a register of patients with epilepsy above the age of 18 years. QOF is a system introduced in 2004 to measure and reward quality in primary care. I realised how the framework is very focussed on improving quality in adult care I looked at the LIS (Local Improvement Scheme) commissioned locally by the CCG but that too is very adult centric. The Impact and Investment Fund (IIF) is an incentive scheme at Primary Care Network (PCN) level. It focusses on supporting primary care to deliver high quality care and that too is targeted at the >18 years age group in the main.

If primary care is not required to and does not maintain a register of CYP < 18 years with epilepsy, then how does one even understand the services and support required for this group and their carers? There is an absolute desire and willingness from the staff who responded from primary care to learn more about pathways to improve patient care. We have to value primary care for its generalist focus and try not to make clinicians into specialists. After all, epilepsy is just one of the many conditions primary care clinicians deal with.

The survey reflects the lack of confidence but also the desire to improve care. This has to be interpreted with caution and should not translate into generalists becoming specialists. It should be more about increasing awareness of referral pathways and moving support from secondary care into the community. It is obvious that the response rate is not significant despite using various routes to engage with primary care. I feel the survey mirrors my initial responses and due consideration should be given to the results despite the low response rate. Whilst QOF is nationally agreed the local system has the ability to influence the agenda to focus quality improvement schemes on conditions affecting CYP < 18 years. This survey should be used to triangulate the information from the commissioners.

Vaishali Nanda

Dr Vaishali Nanda

Primary Care Advisor to the NENC Child Health and Wellbeing Network

GP Partner Discovery Practice

Clinical Director Central Middlesbrough PCN Place based GP NENC Integrated Care Board

Mental Health Support for CYP with Epilepsy in the Primary Care Setting

AM Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor), V Nanda (Primary Care Advisor, GP), L Dauncey (Network Delivery Manager CYPT), C Geagan (Clinical Psychologist), P Archman (Senior General Manager Planning and Information)

Introduction

Primary care practitioners play a crucial role in the health care of children and young people (CYP) and their families throughout life. General practitioners (GP) are the first port of call for, all health concerns including the first presentation of epilepsy in a CYP, the ongoing prescription of antiseizure and other medication and, are likely to be the first point of contact for CYP with epilepsy experiencing mental health problems. As such, they are an important stakeholder group in all aspects of health management for CYP and we wished to involve them in this project.

The Epilepsy Project 2 team (Mental Health in CYP with epilepsy) developed detailed questionnaires/online surveys for primary care to gather qualitative and quantitative data about approaches to mental health in CYP with epilepsy across the North East and North Cumbria (NENC) Integrated Care System (ICS) footprint. The questionnaires included relevant questions covering a similar range of themes as those presented to other stakeholder groups, to permit meaningful comparison of responses from different groups. The lines of enquiry were as follows and a copy of the circulated questionnaire is available in Appendix 6:

- Resource/Staffing
- Case load/service activity
- Adolescents/transition
- Mental Health
    - screening
    - confidence/competence
    - referral pathways
    - training
    - mediation/prescribing
    - support groups
- Cognition and Learning
- Support to Parents and Carers
- Gaps and moving forwards

Whilst the survey captured the views of primary care providers as defined by CCG boundary it also gave an overview and insights into of the interagency relationships between primary and secondary care providers and other organisations and agencies working across wider geographic boundaries.

Methods

The primary care questionnaire was developed as an MS Form by Dr Anita Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor) with the support and input of Dr Vaishali Nanda, Primary Care Advisor to the CHWN, Louise Dauncey (CHWN Network Delivery Manager CYPT) and Dr Chloe Geagan (Clinical Psychologist). In order to gauge the complexity and length of the survey, the questionnaire was piloted with two network primary care colleagues who confirmed that the questions were sufficiently structured to allow ease of completion in a reasonable time.

We were unable to access a clear list of GP practices for the whole of the NENC ICS footprint so the project team refined a 20/21 list that was included within a national report dashboard which identified 570+ practices provided by 516 Primary Care Providers. This list was refreshed by confirming and consolidating the contact email addresses with those provided within secondary care contacts lists and also with information that was publicly available online on the GP Practice Websites (Only 65 practices readily publish and make available a contact email address). This was a time-consuming exercise. Other vehicles for distribution included the CCG Primary Care Commissioning Leads in each of the ICP areas, the GP Federations in place across the NENC ICS footprint and also HEENE were asked to support the work by undertaking onward distribution. In addition, personal and professional contacts were made in the meantime.

This 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 to 6th March. There were 27 responses from a possible (approx.) 570 which is a return rate of c5%. The questionnaire took colleagues 34 minutes on average, to complete.

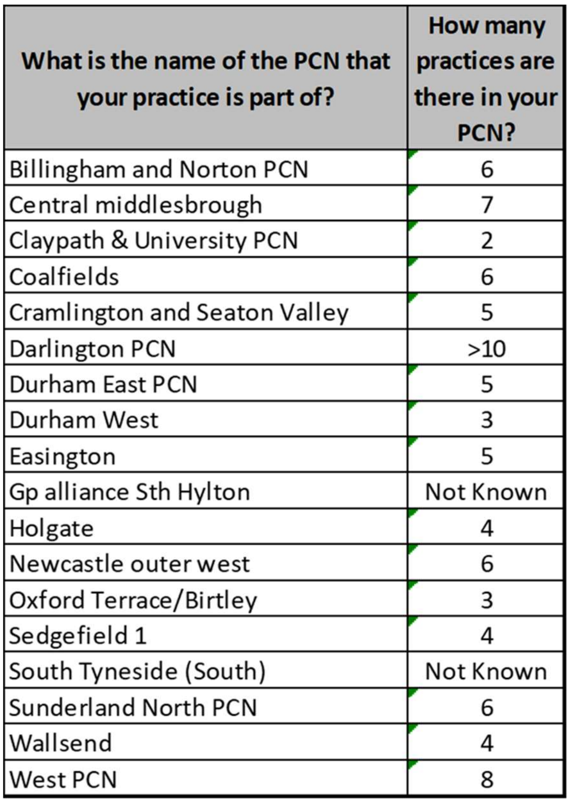
Outcomes from the survey

Responder characteristics

There were 27 responses from a possible (approx.) 570 which is a return rate of c5%. These responses originated from 10 Local Authority boundary areas. There were 4 Local Authority boundary areas that were not represented, 2 of these were from the South ICS footprint and the remaining area not represented was North Cumbria.

The 27 responses originated from a minimum of 18 Primary Care Networks (PCN) which when taken together have a combined total of over 123 practices across 10 Local Authority areas. There is an average of 5 GP practices within each PCN.

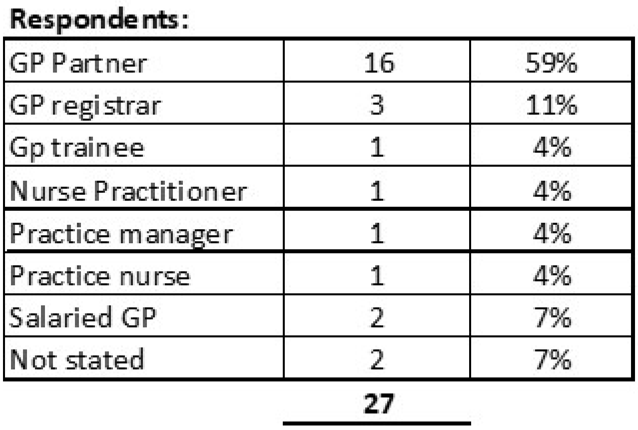
The following table shows the PCNs that were represented within the response and the number of practices within each PCN



What is the name of the PCN that your practice is part of?	How many practices are there in your PCN?
Billingham and Norton PCN	6
Central middlesbrough	7
Claypath & University PCN	2
Coalfields	6
Cramlington and Seaton Valley	5
Darlington PCN	>10
Durham East PCN	5
Durham West	3
Easington	5
Gp alliance Sth Hylton	Not Known
Holgate	4
Newcastle outer west	6
Oxford Terrace/Birtley	3
Sedgefield 1	4
South Tyneside (South)	Not Known
Sunderland North PCN	6
Wallsend	4
West PCN	8

The respondents had a range of roles including practice nurse/nurse practitioner, practice manager, trainee GP, GP Partner, GP registrars and salaried GP. By far the largest proportion (59%) of respondents were GP partners. The range of roles demonstrates the variability in approach within primary care.

Table: Breakdown of respondents to the survey



Respondents:

GP Partner	16	59%
GP registrar	3	11%
Gp trainee	1	4%
Nurse Practitioner	1	4%
Practice manager	1	4%
Practice nurse	1	4%
Salaried GP	2	7%
Not stated	2	7%
	27	

None of the respondents identified any staff (GPs or Nurses) in their respective practices with a special interest in epilepsy.

The relatively low number of responses was disappointing but may be attributable to a number of factors including conflicting priorities, short timescales for completion and perceived length of the questionnaire. It was acknowledged by the Epilepsy Project 2 Team that capacity and resource within primary care is pressured and the questions were deliberately designed in a way to enable speed of completion with easy to navigate, intuitive and structured tick boxes.

Despite the relatively small number of responses, good geographic coverage was obtained which means where the responses obtained are the same or broadly similar, it is likely to reflect the situation and approaches in the wider ICS footprint.

Identification of CYP with epilepsy in primary care

The figure below shows that that majority of respondents (23 out of 27, 85%) did not know the approximate number of CYP with epilepsy at their practice. Those who did know (n=4), reported that the number of CYP with epilepsy within their respective practice varied from less than 6 (n=2) to more than 30 (n=1)

Approximately half of respondents (13/27, 48%) indicated that every CYP with epilepsy has an annual review with a GP or practice nurse. However, the survey revealed that there is no consistent way in which this group of patients are identified or flagged in primary care registers. Dr Nanda, the Primary Care Advisor to the CHWN informed us that epilepsy in adults is part of the Quality Outcomes Framework (QOF) framework and therefore patients >18 years of age are identifiable on primary care information systems. The Local Incentive Scheme (LIS) is another mechanism for improving quality in primary care but again, there are no requirements relating to paediatric epilepsy care or associated mental health conditions.

Medication and prescribing

Prescribers in primary care are doctors and in some cases nurse practitioners. Therefore, the number of prescribers responding to this question is taken to be 21. Only 5/21 (24%) respondents are somewhat confident in prescribing anti-seizure medication to **adults** with epilepsy. None of the respondents are confident in prescribing anti-seizure medication to **CYP** with epilepsy.

11/21 respondents (52%) are somewhat confident in prescribing medications to treat mental health conditions in **adults** with epilepsy, taking anti-seizure medications. Only 2 out of 21 respondents (10%) are somewhat confident in prescribing medications to treat mental health conditions in CYP with epilepsy, who take anti-seizure medications.

Respondents provided some additional information about their practice indicating that GPs generally only prescribe medication that has been commenced by epilepsy specialists and, that medication for mental health conditions is often prescribed by specialised secondary care colleagues. Additional comments are shown below:

"Our GP's would prescribe on notification from specialists who initiate, on formal diagnosis of epilepsy."

"In Children and YP under 18, I would not generally initiate medication for mental health problems without specialist advice, more so if epilepsy is a factor."

"I would let CAMHS take a lead on prescribing any medications to treat mental health in CYP and would only take over once the patient was stabilised with or without epilepsy"

"NICE suggest GPs should not initiate anti-depressant prescribing in CYP"

"In general practice we continue issuing the scripts from secondary"

"I guess most GPs are fine to prescribe medication if they were initiated in secondary care"

"GPs are not supposed to initiate medication for mental health in children and therefore always refer to secondary care"

"We initiate mental health medication for adults who have epilepsy all the time- this is normal practice. We normally don't initiate mental health medication for any child regardless of their epileptic status in children under the age of 17"

The results of the survey suggest that primary care colleagues are not confident to initiate prescriptions of anti-seizure medication in CYP but many are happy to continue the medication if initiated in secondary care. Responses also highlight that national guidance recommends that GPs should not prescribe medication for mental health needs in those under the age of 18 years.

Availability of mental health practitioners

Only 7/27 respondents (26%) reported that their practice employs a mental health practitioner.

Of the 20 practices that do not directly employ a mental health practitioner, the majority (16/20, 80%) have access to a mental health practitioner within their PCN, and a further 3 were unsure.

Of the 7 practices that employ mental health practitioners, the number of practitioners in post range between 1 and 3 with an average of 2 across the 7 practices.

Most practices have access to one type of mental health practitioner, either a specialist mental health practitioner for primary care (n=12) or a mental health nurse (n=6). Four practices have access to a mix of mental health practitioner types. Three practices were not sure about access to a mental health practitioner.

The table below provides this information summarised in tabular format

Specialist Mental Health practitioner for Primary Care;	15
Mental health nurse ;	8
Mental health wellbeing practioner;	1
Counsellor/Psychotherapist;	1
Psychologist	0
Not Known;	3

Only 1 of the 20 practices reported that they do not have access to a mental health practitioner.

We also learned that there is a scheme the ARRS (Additional Role Reimbursement Scheme) in which PCN (Primary Care Networks) are working with local mental health trusts to engage adult mental health practitioners to work in primary care. These practitioners are a bridge between primary care and secondary care for adults and support patients and primary care in managing those with mental health needs. However, there are no embedded mental health services for CYP in the PCNs surveyed.

Mental health intervention

Primary care respondents were asked to identify how many mental health appointments were available each week, responses varied between 2 per week (n=1) to more than 8 per week (n=7). Over half the respondents did not know how many appointments were available each week. The majority of respondents (21 out of 27) reported that the available mental health appointments are for adults only (>18 years). Of the 4 respondents who reported that the mental health appointments are not uniquely for adult patients >18 years, 2 indicated that they would see young adults between the ages of 16 and 18; the remaining 2 reported that they would see children from 12 years of age.

Counselling was cited as the most common intervention (n=11), with CBT (n=3) and psychotherapy (n=1) offered to a much lesser extent.

The table below provides a more detailed breakdown of the responses by those who answered this question

Counselling	11
CBT	3
Psychotherapy	1
Group sessions	0
Family therapy	0

18 respondents indicated that the majority of interventions consist of both face-to-face and telephone (n=14) appointments; 4 offer face-to-face appointments only; and 1 offers mainly virtual / telephone appointments only.

The findings of the survey suggest that there is a recognition of mental health need and an available resource to potentially support this, but that the service offered is almost exclusively for adults aged >18 years. There is no provision for CYP aged <12 years and it seems that CYP are largely referred to CAMHS/CYPS specialist services where there are long waiting times.

Identification of mental health needs

Primary care colleagues were asked to identify whether mental health screening is conducted when a CYP with epilepsy attends the practice (for any reason).69% of those who responded to this question stated that mental health screening is not routinely undertaken.

Of those who said that mental health screening is conducted (n=8), the majority indicated that they ask questions about mental health and wellbeing during the CYP consultation / visit. Two respondents indicated this is incorporated into a standard template used for consultations.

Of the 26 respondents, 38% (n=10) indicated that they are confident in identifying mental health problems in CYP with epilepsy.

When asked to share their understanding about the frequency of mental health needs for CYP with epilepsy the majority of respondents thought that mental health problems in CYP with epilepsy were 2 or 3 times more common than in CYP without health problems. Only 1 of the 24 respondents to this question identified that mental health issues for CYP with epilepsy are four times as common.

The consensus amongst respondents to this question was that CYP with epilepsy are more likely to suffer from a range of mental health issues compared to their peers, with anxiety disorder and depression being the most common mental health presentations, followed by Autism Spectrum Disorder and ADHD.

The table below identifies the mental health issues/diagnoses that are considered by those in primary care to be more common in CYP with epilepsy. Respondents were asked to identify all that were applicable)

	Overall responses
Anxiety Disorder	20
Depression	18
Autism Spectrum Disorder	16
ADHD	13
Obsessive-compulsive Disorder	11
Psychosis	5
Not known	5

When asked about information sharing when mental health concerns are identified in CYP aged under 16 years, all respondents (n=20) indicated that information would normally be shared with parents /carers in most situations. One respondent highlighted that a child under the age of 16 may come in confidence and that an assessment of their competence would need to be undertaken and would contribute to the decision to keep their mental health issues confidential. In addition, the hospital-based medical team and school nurse were also identified by over half of the respondents as key professionals with whom this information would be shared.

Other agencies that were identified for information sharing (as appropriate) were SENCO, respite care providers, residential care providers or other.

Referral pathways for mental health conditions

Primary care colleagues were asked to rank, in order of probability, the services that they would refer to for a range of suspected mental health conditions. The survey included six referral options for each condition to be ranked 1 to 6 (with 1 being the highest priority/1st choice and 6 being of least priority). The options were CAMHS/CYPS, Trust-based health psychology, community-based psychology, school nurse/school-based, SEND Local Offer and 3rd sector organisations. The top 3 referral choices for each condition are shown in the table below.

Overall, the local CAMHS / CYPS service was identified as the 1st choice for referral for all of the given health conditions. This was followed by either community-based psychology identified as 2nd choice in all cases except suspected psychosis, in which case the 2nd choice was referral to Trust-based health psychology. In all cases and all conditions, referral to the SEND Local Offer was identified as the last option.

The following table demonstrates the similarity in current practices for referrals for (suspected) mental health conditions

Primary care	1st Choice	2nd Choice	3rd Choice
ADHD	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Anxiety	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Autistic Spectrum Disorder	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Depression	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Obsessive-compulsive disorder	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology
Psychosis	Local CAMHS/CYPS	Trust based health psychology	Community based psychology services linked to CCH
Self-harming behaviour	Local CAMHS/CYPS	Community based psychology services linked to CCH	Trust based health psychology

Primary care colleagues indicated that local CAMHS / CYPS has the longest waiting time for further assessment, approximately 11 months. This is most likely due to the demand on the service as it has been identified as the 1st choice of onward referral and assessment for the majority of suspected mental health conditions. The shortest waiting time for further assessment was by school-based services, approximately 4 months.

Table: Approximate wait time, according to primary care respondents by service:

Primary Care	<3 months	3-6 months	6-12 months	12-18 months	18-24 months	>24 months	N/A	No response	Overall Estimate (average) of current waiting times for further assessment
Local CAMHS/CYPS	5	5	6	2	6	1	0	2	11 months
In-house trust health psychology	4	0	3	2	2		11	5	10 months
Community based Psychology in CCH	4	4	1	3	0	1	9	5	8 months
3rd sector	4	3	2	1	0	0	12	5	6 months
School based services	11	4	1	0	0	1	6	4	4 months

The findings from the survey and anecdotal feedback indicates that the focus should be on having clear pathways of referral, easy access to guidance and specialist support for patients, carers and primary care staff in the community. This was supported by some final closing comments from respondents for example "*Clear pathways would be helpful and perhaps outreach from the epilepsy services to support primary care*"

Primary care practitioners do not have access to the necessary skilled specialists within their own practice or PCN and are perhaps unaware of other mental health and emotional well-being services available within the wider education, health and social care context. This lack of awareness results in referrals automatically going to CAMHS/CYPS services which are over-subscribed.

Meeting the mental health needs of CYP with epilepsy

Only 7/25 (28%) respondents reported that they are confident about offering appropriate support to CYP with epilepsy, however, most primary care colleagues (19/25, 73%) reported that they are confident about recognising when onward referral to mental health services is required.

The majority of primary care colleagues, (21/25, 84%) felt that they are expected to offer mental health support to CYP with epilepsy which is outside their experience and expertise. This is a recurring theme and was reported by epilepsy specialist nurses and paediatrician epilepsy leads in secondary care.

In these instances, most respondents reported that they refer on to a specialist service, most indicating CAMHS or CYPS. A number of respondents (n=5) indicated they would seek advice from a more experienced colleague.

18/23 respondents (78%) reported that the mental health offer within their GP practice would be improved with more training to identify mental health problems in CYP with epilepsy.

Most suggested that further training of GPs and practice nurses would be the most effective approach. One respondent suggested school nurses and another suggested mental health workers with a specialist interest in children would improve access to mental health support. One respondent suggested it would be beneficial to extend training to all clinical staff who have contact with CYP.

Two-thirds of respondents (16/24) said the mental health offer within their GP practice would be improved with more training in the use of specific tools to identify mental health problems (16/24) and, this would allow them to manage these needs locally in practice (17/23)

The majority of primary care colleagues (22/25 respondents, 88%) reported that the mental health offer for CYP within their GP practice, could be improved with more appointments/support in the practice from specifically trained mental health professionals with expertise in CYP and 24/25 (96%) said the mental health offer could be improved with clearer referral pathways specifically for the mental health condition suspected.

Other comments that support the need for additional support and training for primary care practitioners and staff follow, however, some respondents indicate that specialist mental health support should be delivered by specialist services following referral from primary care.

"This is a very niche population, as a GP we have much bigger and wider populations to look after. I would refer all CYP with epilepsy and any mental health problem to CAMHS - they have a triage service and would then send that person to the most appropriate service"

"Mental health identification in CYP with epilepsy in GP is welcomed but provision should be the remit of specialist services/personnel - GP cannot be expected to deal with these patients and we simply cannot due to lack of capacity! "

"Training is always welcomed, but in primary care we do not have the time to manage these issues - yes, we should identify the need, but as for managing that need that should be done by the specialist services who have the skill and time"

Mental health needs in parents/carers

The majority of primary care colleagues (22/23 respondents) understood that the prevalence of mental health problems is increased in the parents/carers of CYP with epilepsy.

15/25 respondents (60%) indicated that they spend more time supporting parents/carers of CYP with epilepsy, with their own mental health issues, compared with parents/carers of CYP with other health conditions.

Chloe Jones and Colin Reilly of the Research Department at Young Epilepsy have undertaken a systematic review of PubMed studies that have focussed on symptoms of anxiety reported by parents and carers of children (0-18 years) with epilepsy (17)

Discussion

It is necessary to start the discussion about the outcomes of this survey by acknowledging identified areas of good practice regarding the primary care approach and facilitation of mental health support offered to CYP with epilepsy**.**

Identified areas of good practice

- 88% of respondents recognised that mental health problems were more frequent in CYP with epilepsy. This shows that primary care professionals recognise that CYP with epilepsy face challenges over and above their peers. However, less than 4% (n=1) of respondents were aware of the magnitude of the problem - mental health problems in CYP with epilepsy are 4 times more frequent than in the wider population.
- Nearly all respondents indicated that either a mental health practitioner is employed in their practice or that they have access to a mental health practitioner (either a specialist mental health practitioner or a mental health nurse) through their primary care network. However, the resource in terms of available appointments varied significantly. Furthermore, the majority of respondents identified that the mental health

appointments available are for adults only (people aged >18 years) with only 7% of responses indicating that children from the age of 12 would be seen.
- 73% of respondents reported that they are confident about recognising when onward referral of CYP with epilepsy to mental health services is required, however, the referral pathways and capacity of those services is a limiting factor.

Limitations to the survey

- Surprisingly, we were unable to access a clear list of GP practices for the whole of the NENC ICS footprint so were unable to target all practices reliably from the outset
- The survey received a return rate of c5%. There were 4 Local Authority boundary areas that were not represented.
- The relatively low number of responses could be attributable to a range of reasons, including conflicting priorities, short timescales for completion, perceived length of the questionnaire. It was acknowledged by the Epilepsy Leadership Group/Research Team that capacity and resource within primary care is pressured.

Identifying mental health needs in CYP with epilepsy

In contrast to adults, primary care does not currently identify CYP with epilepsy within the information systems which, means that a practice cannot recognise or monitor this group of vulnerable children. All of the commissioning and quality standards and measures relate only to people aged over 18. This represents inequality and variation in the health care and support offered to CYP. Change is required across the system to enable this group to be identified within primary care so that the needs of CYP with epilepsy can be anticipated, screened for, recognised and addressed. Consideration could be given to a similar annual review framework as exists for adults where mental health needs form part of the review. 78% of respondents think that the mental health offer from primary care can be improved by further training in the identification of mental health needs and 67% of respondents embraced the idea of a screening tool. This tool could be used during the annual review.

Despite only 39% of respondents feeling confident to identify mental health needs, answers to a follow-up question indicated that most feel skilled and able to identify mental health needs requiring onward referral. Some respondents indicated that providing mental health support falls out with their role and remit as a general practitioner.

What is currently on offer? What intervention, when and by whom?

The view from some clinicians within primary care is that responding to the emotional wellbeing and mental health needs of CYP with epilepsy falls out with their role and responsibility.

Paediatric epilepsy is in the first instance, overseen by paediatricians with expertise in epilepsy and epilepsy specialist nurses within secondary care settings. In most cases the contacts from

CYP with epilepsy and their parents/carers are with their hospital teams, whose role is to support the family with effective and safe management of the condition, associated needs in the community and onward referral to tertiary paediatric neurology services.

There appears to be a gap for CYP whose mental health needs are unrecognised within primary care and either unrecognised or unmet in secondary care. Not all CYP with emotional wellbeing needs require the input of specialised health services that have higher access/referral thresholds. The significant waiting times for CAMHS/CYPS services are recognised within primary care, within secondary care by ESNs and paediatrician clinical leads and by other stakeholders such as those in education. Often lower level and earlier intervention which can be provided by the wider health, education, social care and third sector is limited/non-existent or unrecognised in terms of availability.

In addition, 88% of respondents in primary care think that the mental health support offer for CYP within primary care can be improved through access to specifically trained mental health practitioners, as it is for adults. This represents a further area where there is inequality and variation in access to services between adults and children. If this is viewed as more specialised this could be provided on a primary care network basis rather than by individual practices. It is important for this support to be available to primary care as 84% respondents report that they are expected to offer mental health support to CYP with epilepsy that is out with their experience and expertise. This is a recurring theme and was also reported by ESN and secondary care paediatricians. This represents a risk both to the CYP and the practitioners themselves.

There is evidence throughout this report that agencies do not work effectively and seamlessly together to ensure that services are aware of each other, such that the right level of support is provided in a co-ordinated way, with a needs-based escalation through tiers of support as appropriate.

In many cases CAMHS/CYPs have specific referral criteria which are not clear to primary care practitioners. This means that they may waste time completing referrals which will not be accepted by a specialist service. There is a case for developing and mapping the local mental health support offer within education, social care and third sector organisations so that primary care practitioners are able to access these wider interventions that may meet the needs of CYP without referral into specialist services.

An integrated approach and training

As indicated above, a large proportion of the respondents highlighted that training provision within primary care would enhance and improve the mental health offer in primary care in relation to the identification of mental health needs, the appropriate use of screening tools and the offer of mental health support. However, it was also evident that referral options with clear referral criteria and pathways are also required so that time is not wasted and support for the CYP is not delayed.

The needs of parents and carers

It is well established that the impact of childhood epilepsy on the family can be significant (13, 18) for a host of reasons including increased potential for cognitive or behavioural difficulties that are often under treated (7), negative effect on Health Related Quality of Life (HRQoL) (8), difficulties in school (6) and most obviously parental wellbeing. Families of a **child** with epilepsy have been found to experience significantly more stress, anxiety, and restrictions in family life than other families(19).

Other key points from the systematic review (13) are as follows:

- Symptoms of anxiety appear to be common in parents of children with epilepsy but there is a lack of population-based data
- There has not been a consistent pattern regarding factors associated with parental anxiety
- Parental anxiety is associated with lower quality of life in children with epilepsy
- There is a need for future population-based studies focusing on a wide range of contributory factors to inform future interventions

Our survey reflects these findings with 60% respondents in primary care reporting that that they spend more time supporting parents/carers of CYP with epilepsy, with their own mental health issues, compared with parents/carers of CYP with other health conditions. It is important that the needs of this group of parents/carers are anticipated, recognised and supported by those working in primary care since they cannot be met in paediatric services.

Recommendations

These have been formulated from a combination of the survey responses and feedback from Dr Vaishali Nanda, Primary Care Advisor to the CHWN.

1. As with adults with epilepsy, CYP with epilepsy should be easily identifiable on primary care information systems, with practices maintaining a register of patients who are invited for an annual review. It would be optimal if CYP with epilepsy could be included in the QOF commissioning framework and Local Incentive Schemes for epilepsy.

   Whilst QOF is nationally agreed, the local primary care commissioners can influence the agenda to include quality improvement schemes for CYP <18 years. There is also an opportunity to feedback to PCNs regarding the IIF indicators and onward to commissioners to improve the focus on conditions affecting CYP <18 years.

   Local expectations could include:

   - requirement (or at least local expectation) that there is a paediatric epilepsy champion in each practice (or PCN)

- requirement (or at least local expectation) that CYP with epilepsy – and their parents/carers are coded and recorded on a practice register
- requirement (or at least local expectation) that CYP with epilepsy have an annual review with GP or practice nurse which includes lines of enquiry and a screening process around emotional wellbeing and mental health needs
- requirement (or at least local expectation) that there is access to MH practitioner (for CYP) within each PCN
- develop evaluation criteria to measure the impact of the different types of intervention (if provided by practice/PCN MH practitioner) for CYP so that the offer can be responsive and adaptable to need

2. An annual review template should be developed to be used in primary care which has a mental health screening tool embedded within it to make this a standardized and easy to use.

3. Mapping should be undertaken of available mental health support services and resources for CYP with epilepsy on a locality basis including those available within education, social care and third sector organisations. This should be widely shared with all stakeholders so that referrals can access the appropriate level of support with the minimum delay. This would also allow CYP to be referred onwards if needs escalated beyond the expertise of a lower-level intervention provider.

4. The referral criteria and pathways into CAMHS/CYPs services need to be clear, explicit and available to all referrers. An on-line referral mechanism with a checklist approach may be helpful which, also has links to other available mental health service providers in the locality. This will prevent these overloaded services from having to respond to inappropriate referrals and will facilitate the delivery of appropriate support without excessive delay.

5. Primary care networks should be supported to have access to mental health assessment and support for CYP with epilepsy, delivered by a specifically trained CYP mental health practitioner, similar to that available to adults. Clinical supervision could be provided by Trust-based health psychology teams and once again, onward referral pathways should be clear.

6. Training to be delivered to primary care practitioners regarding epilepsy in CYP and the effects of the condition on mental health. Training in the identification of mental health needs in CYP with epilepsy including the use of specific agreed tools is required.

7. The additional mental health needs of the parents/carers of CYP with epilepsy need to be acknowledged and a register of carers would ensure that mental health problems are actively screened for during clinical encounters, when the parent/carer may attend alone. There should be a low threshold for offering referral to practice/PCN based mental health practitioners.

8. Primary care has a crucial role to play in the transition of CYP from paediatric to adult services. This is an anxious time for CYP and their carers, even more so for CYP with special needs. This would be a predictable process with time to anticipate a different care

and prescribing model if annual reviews were being undertaken for CYP with epilepsy in primary care. The referral pathways to facilitate the transition process should be explicit

Mental health in CYP with epilepsy in mental health setting

C Geagan (Clinical Psychologist), AM Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor), L Dauncey (Network Delivery Manager CYPT), P Archman (Senior General Manager Planning and Information)

Acknowledgements to:
G Crowther (Assistant Psychologist) for support in identifying services in the region

Introduction

The impact that psychosocial factors and epilepsy treatments can have on the health -related quality of life (HRQOL) of individuals with epilepsy and their families has been well documented. CYP with epilepsy are particularly susceptible to developing social, emotional, behavioural, and learning difficulties, which, if not identified or addressed at an early stage, can negatively affect their HRQOL and long-term psychosocial outcomes. In recent years there has been an increasing clinical interest in psychological support to help CYP with epilepsy and their families to improve mental health and wellbeing, in addition to wider HRQOL (3, 14).

As part of the Epilepsy Project 2 (Mental Health in CYP with epilepsy) a survey for mental health professionals was devised on behalf of the NENC CHWN by the lead author Dr Geagan and Dr Anita Devlin project lead, with collaboration and support from Louise Dauncey and her colleagues at the Network. The aim of the survey was to acquire qualitative and quantitative information about approaches to mental health assessment and support in CYP with epilepsy across the ICS footprint and to describe the availability and gaps in provision.

Methods

Online survey for mental health professionals

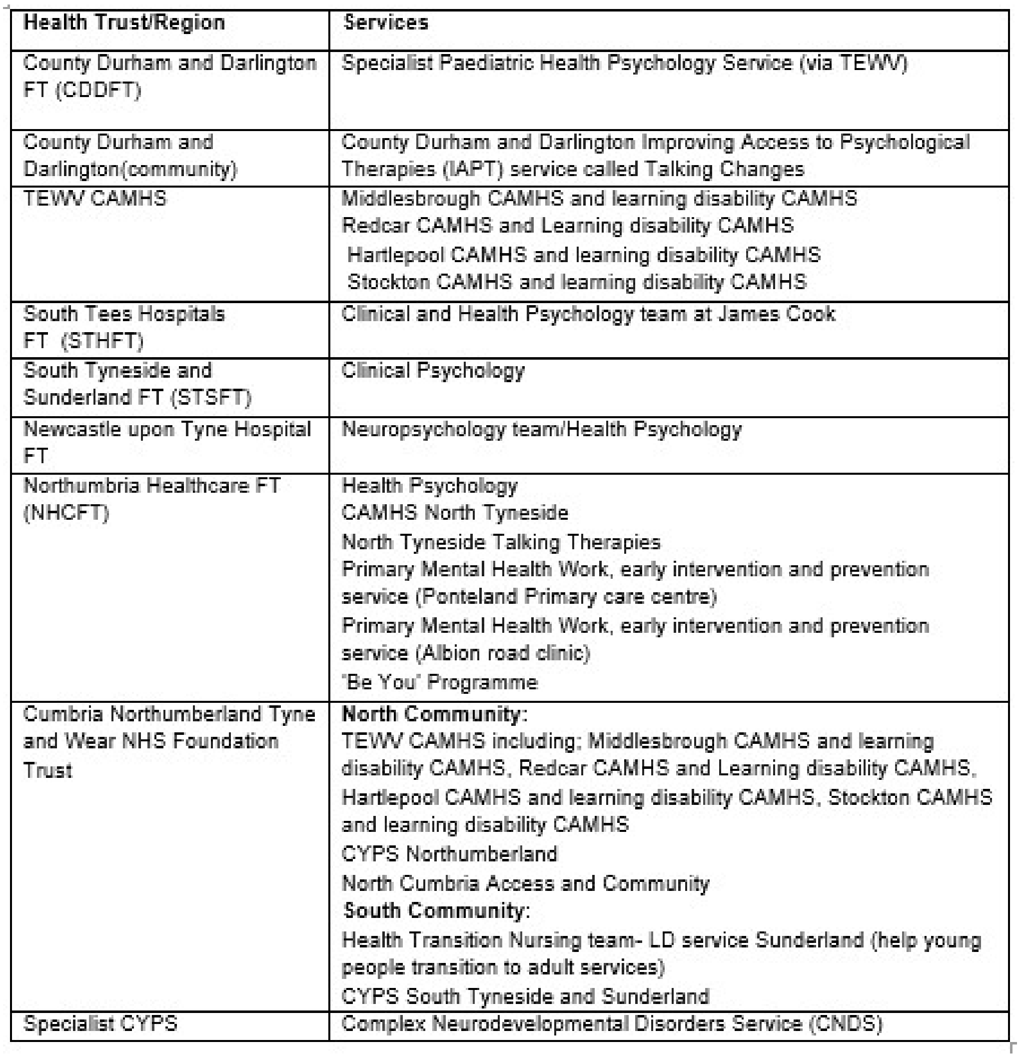
1.1 Mental Health Service mapping

The focus for this scoping exercise was specifically on mental health services for CYP offered by different NHS trusts across the North East of England and North Cumbria. It is noteworthy that there was no existing source of this information which was therefore not easily accessible to the project team. In order to identify relevant mental health leads with whom to share the survey, we first needed to identify relevant services and then the individuals within those services.

To facilitate collection of the data, three categories of services were identified: NHS/local authority provision, third sector organisations and digital support. Initial steps involved liaising with P Thompson (CYP Mental Health Network Delivery Manager, Northern England Clinical Networks, NHS England & NHS Improvement North East and Yorkshire) who provided information on commissioned mental health services in the region and a contact list of CYP Commissioners in North East and North Cumbria.

This information guided internet searches on services within the region which identified a total of 29 services under the headings of NHS/local authority service provision. Contact details for each service were then collected and an Assistant Psychologist contacted each service individually to acquire contact details for team leads and Psychology leads.

A summary table of the services identified and subsequently approached are summarised below. For a full list of services identified, including those who do not provide support for young people with Epilepsy, please see Appendix 7



Health Trust/Region	**Services**
County Durham and Darlington FT (CDDFT)	Specialist Paediatric Health Psychology Service (via TEWV)
County Durham and Darlington(community)	County Durham and Darlington Improving Access to Psychological Therapies (IAPT) service called Talking Changes
TEWV CAMHS	Middlesbrough CAMHS and learning disability CAMHS Redcar CAMHS and Learning disability CAMHS Hartlepool CAMHS and learning disability CAMHS Stockton CAMHS and learning disability CAMHS
South Tees Hospitals FT (STHFT)	Clinical and Health Psychology team at James Cook
South Tyneside and Sunderland FT (STSFT)	Clinical Psychology
Newcastle upon Tyne Hospital FT	Neuropsychology team/Health Psychology
Northumbria Healthcare FT (NHCFT)	Health Psychology CAMHS North Tyneside North Tyneside Talking Therapies Primary Mental Health Work, early intervention and prevention service (Ponteland Primary care centre) Primary Mental Health Work, early intervention and prevention service (Albion road clinic) 'Be You' Programme
Cumbria Northumberland Tyne and Wear NHS Foundation Trust	**North Community:** TEWV CAMHS including; Middlesbrough CAMHS and learning disability CAMHS, Redcar CAMHS and Learning disability CAMHS, Hartlepool CAMHS and learning disability CAMHS, Stockton CAMHS and learning disability CAMHS CYPS Northumberland North Cumbria Access and Community **South Community:** Health Transition Nursing team- LD service Sunderland (help young people transition to adult services) CYPS South Tyneside and Sunderland
Specialist CYPS	Complex Neurodevelopmental Disorders Service (CNDS)

1.2 Distribution of survey

As with other work streams within Project 2, questionnaires were distributed to team leaders, for example team managers, psychology leads, and psychiatry leads. Additional individuals known to the Project 2 team were also approached who might not have been identified by the search or included by their team leads. Survey distribution was followed by reminders to complete.

Outcomes of the survey

A full set of the questions posed by the survey to mental health professionals can be found in Appendix 8.

Responder characteristics

There were 11 responses from 88 generic team in-boxes and team leads contacted, a return rate of approximately 13%. This was disappointing given the effort required to map out the services but the mapping exercise has provided a significant contribution to a mental health service stakeholder directory which will be important to future network projects. A variety of mental health professionals responded (see below), with four different health settings represented (CAMHS/CYPS, Health Psychology, and Neuropsychology). Although not specifically approached in this survey, 1 respondent worked in the CAMHS Learning Disabilities team.

The majority of respondents said that they work with CYP from under 5yrs to 16+ years. 3/11 respondents did not see children under 5 yrs. 10 of the 11 respondents said their service see children with a learning disability. Respondents were based in a variety of geographical areas including Newcastle and Gateshead, Northumberland, Stockton-on-Tees, Middlesbrough, Redcar and Cleveland, Cumbria, and Durham. However, respondent numbers are low and therefore caution is required when considering how representative of the NENC the following responses are.

Role of persons completing questionnaire	
Psychologist (clinical, educational, counselling)	5
Nurse	3
Social Worker	1
Psychiatrist	1
Psychological therapist	1

Recording of the presence of epilepsy in CYP

Over half of the respondents reported that there was a clinician in their team interested in epilepsy. 9/11 respondents (82%) had worked with someone with epilepsy in the past 5 years. Around half of the respondents (45%) said that their service recorded the presence of epilepsy in CYP elsewhere in addition to the patient record. However, the majority of respondents (73%) did not know how many CYP <18 years old were currently on their team caseload. Those that were able to identify the number of CYP with epilepsy on their team's caseload reported that numbers were low, approximately 3 young people. One respondent commented that they would expect more CYP with epilepsy to be seen in their service given the number of CYP covered by the Trust.

Referral pathway

Clinicians were asked from where they were most likely to have received a referral for a CYP with epilepsy for difficulties with mental health. Hospital-based paediatric services, community based paediatric services and 'Other' (e.g. schools, self-referrals, CAMHS) were identified as the most frequent referrers and social services were the least likely to refer to mental health services.

It appears that CAMHS/CYPS are the service most frequently referred to for the majority of mental health or neurodevelopmental concerns. However, if there are concerns around adjustment to diagnosis, coping with epilepsy, or treatment, referrals are also made to Health Psychology or Epilepsy Action. Neuropsychology assessment of cognition and learning was directed to Paediatric Neuropsychology services.

Other services that CYP were referred to which were not included in the survey were: Paediatrician, Complex Neurodevelopmental Disorders Service (CNDS), Epilepsy Society, National Autistic Society, The Toby Henderson Trust, Kooth, Young Minds, Early Intervention Psychosis team.

Identification and intervention for mental health problems

Respondents generally felt confident that about identifying mental health difficulties in CYP with epilepsy without a comorbid learning disability (55% extremely confident and 36% somewhat confident) with a slight increase in confidence in identifying mental health difficulties in individuals with a learning disability (64% extremely confident). 91% of respondents recognised that mental health problems were more frequent in CYP with epilepsy. However, only 18% knew that these problems are 4 times more frequent, with the majority of respondents reporting that they were 2- 3 times more common.

Specific mental health issues and diagnoses

All respondents recognised that a range of mental health issues are more common in CYP with epilepsy.

When asked to report their experience about which of the conditions listed below are the most frequent reason for referral of a CYP with epilepsy to their service, the following responses were obtained:

	Very frequently	Somewhat frequently	Same as other CYP	Somewhat infrequently	Very infrequently	Responses
ADHD/ADD	2	4	3	0	1	10
Anxiety	4	2	2	1	1	10
Autism Spectrum Disorder	3	4	2	0	1	10
Depression	2	3	2	1	1	9
Obsessive-compulsive disor	2	1	3	1	2	9
Psychosis	0	1	3	1	3	8
Self-harming behaviours	2	2	4	1	1	10

The most frequent reasons for referral of a CYP with epilepsy to a mental health service are autism spectrum disorder (7/10 responses); anxiety (6/10 responses); ADHD/ADD (6/10 responses) and depression (5/9 responses).

Other reasons for referrals include concerns around challenging behaviour (very frequently), adjustment to diagnosis (including adhereing to treatment plan), non-epileptic seizures, cognitive difficulties, parental anxiety, bereavement and loss.

Most respondents (73%) acknowleged that the type of mental health support required by CYP with epilepsy differs from that needed by other CYP, although on this occasion it was not specifically asked what may be different about the support needed.

Waiting times for support

The majority of respondents (8/10) said that CYP have an initial assessment within 3 months of referral for a mental health need, although 1 respondent reported a wait of 12-18 months. A similar wait time was reported for CYP following a referral for assessment of a neurodevelopmental need, such as autism or ADHD.

Direct intervention in the form of therapy for mental health concerns or a full assessment for neurodevelopmental difficulties was reported by half of the respondents as being no more than 3 months. The other half of respondents reported a wait no longer than 3-6 months. This is somewhat in contrast to what has been reported in the ESNs and Epilepsy Clinical lead surveys where average waiting times for CAMHS/CYPS are reported to be between 9 and 13 months. It is worth noting that the sample size in the current survey is unlikely to be representative of all services in the region, which may explain the discrepancy between the stated waiting times by mental health professionals and epilepsy specialists.

Recognition of cognitive difficulties

The majority of respondents (10/11) said that CYP with epilepsy are more likely than other children to have cognitive difficulties. Most respondents said that their teams were extremely confident or somewhat confident in recognising specific cognitive difficulties in CYP with epilepsy.

Those who reported an increased likelihood of cognitive problems suggested the following areas of increased need:

Cognitive impairment	Number of Respondents (Total = 10) that identified the cognitive impairment is more likely in CYP with epilepsy compared to other CYP.
Global cognitive impairment	8
Specific problems with attention and concentration	10
Specific problems with executive function (independent planning, personal organisation, self-control, flexible thinking)	10
Specific problems with mathematical reasoning	9
Specific problems with memory (working memory/long-term memory)	9
Specific problems with processing speed	10
Specific problems with reading	9
Specific problems with verbal comprehension	9
Specific visuo-spatial problems	8

Respondents clearly have underlying knowledge of some of the difficulties which might be experienced as a result of epilepsy. We acknowledge that this survey might not be representative of the wider team. In light of this underlying knowledge, most respondents (9/11) said their teams were extremely or somewhat confident in recognising specific cognitive problems in CYP with epilepsy.

Cognitive assessments were provided for individuals with epilepsy in most of the services included in this survey (8/11). It was not specified whether this was a specialist neuropsychology assessment. If a service did not provide cognitive assessments, they reported that they would refer to the school or education psychology for input, or to the CYP's local paediatrician.

Medical prescribers

Only 1/11 respondents indicated that they were a medical prescriber. This individual reported that they were confident with prescribing stimulant medication, anti-depressants, anti-anxiety medication and anti-psychotics to CYP with epilepsy.

Onward referral pathways

When asked 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 the responses were as follows:

SUMMARY

Most likely place to refer or signpost to if mental health service is not suitable

	1st Choice	2nd Choice	3rd Choice
ADHD/ADD	CAMHS/CYPS	CAMHS Learning Disabilities	Health Psychology/ Neuropsychology
ANXIETY	CAMHS/CYPS	CAMHS Learning Disabilities	Health Psychology/ Neuropsychology
Autistic Spectrum Disorder	CAMHS/CYPS	CAMHS Learning Disabilities	Paediatrician
Depression	CAMHS/CYPS	CAMHS Learning Disabilities	Health Psychology/ Neuropsychology Talking Therapy (IAPT)
Obsessive-compulsive disorder	CAMHS/CYPS	CAMHS Learning Disabilities	Paediatrician
Psychosis	CAMHS/CYPS Early Intervention Psychosis team	CAMHS Learning Disabilities	Health Psychology/ Neuropsychology Paediatrician
Self-harming behaviours	CAMHS/CYPS	CAMHS Learning Disabilities	Paediatrician

CAMHS/CYPS is clearly 1st choice for onward referral if the respondent's mental health service or part of the service is not suitable, with CAMHS Learning Disability identified as the 2nd choice by respondents for all conditions. It is interesting that 8/11 of the respondents were based in CAMHS/CYPS or CAMHS LD so presumably this means referring to another professional within their own service or to a more specialised service.

Training

Most respondents stated that less than one-quarter of their team have received specific epilepsy training. If epilepsy training had been delivered, this was reported to be provided by an epilepsy nurse or an outside organisation. 55% of the respondents were aware of training resources for epilepsy, such as through the Epilepsy Society and Young Epilepsy.

Most respondents (9/11) said that further training is required to support them in identification and intervention of mental health and/or cognitive difficulties for CYP with epilepsy. Two respondents said that no further training was required.

Improvements in mental health support for CYP with epilepsy

Over half of the respondents (55%) said that improvement is required in the way mental health settings record and review mental health and cognitive difficulties for CYP with epilepsy. A further 4 respondents were uncertain, whereas 1 individual said no improvement is required.

Suggested areas for improvement included:

"By addressing a gap in knowledge around specific adaptations required for these individuals and co-occurring difficulties in CYP with epilepsy."

“Provision of a specialist health psychology service which can assess mental health and cognitive difficulties, provide a range of therapies (including family interventions) and advise on management of cognitive difficulties.”

“Expanding the existing Paediatric Psychology services. Requires investment to extend the team.”

“A process needs to be put in place to raise awareness or alerts between practitioners that a child is more susceptible to seizures due to mental health issues.”

Opinions on which was the best service model for providing mental health assessment and intervention to CYP with epilepsy was fairly evenly split between 3 options - local CAMHS/CYPs, hospital-based health psychology /psychiatry and school-based services which offers the opportunity for a stage approach depending on complexity and severity.

Final comments from respondents

“I think CAMHS/CYPS services need more training around epilepsy to increase the specialist skills and knowledge around working with children with epilepsy and mental health difficulties and feel ultimately children should be supported in children's mental health services for mental health issues.”

“Community NHS practitioners should be provided with more epilepsy specific training and information. This is definitely required for staff working into neurodevelopmental pathways. Epilepsy specific training and awareness was definitely encouraged for the nursing and support staff when I worked with autism inpatient services.”

"Epilepsy affects young people and their families in so many ways yet it is very misunderstood , the general public as a whole are lacking in insight and epilepsy and the link to mental health means that young people are often misunderstood and under supported due to ignorance and a lack of education . Many children with epilepsy grow into adults who don’t understand themselves and lives are lost due to this. The impact is massive. I do feel there is a need for more understanding and more public awareness of epilepsy and its impact on people. This would lead to better safeguarding outcomes and better mental health outcomes.”

“We have indicated further training for staff in other professions working with young people is required so there is a better provision for young people across all intensity provision from schools to specific mental health services. However, within our service we feel adequately trained to identify and respond to the needs of young people with epilepsy.”

“There is a commissioning gap in relation to specific learning difficulties across the board, not just for children with epilepsy. CAMHS can access cognitive testing if LD is strongly suspected but not to identify and diagnose specific learning difficulties. Schools are supposed to address it but struggle for access to educational psychology in a timely way.”

"I feel the two models that work best for paediatric health psychology are either to embed the psychologist into the team (as we do in CF & diabetes) or to take referrals from a range of professionals (as we do in cardiac)."

"To my mind psychology needs to be integrated into Children's epilepsy services in the same way we see in diabetes. I have always worked with really excellent epilepsy nurses and medics who make excellent and targeted use of psychology. There would need to be some access to neuro expertise in these services and referrals pathways set up in to CAMHS teams as and when needed with regular liaison."

Discussion

It is necessary to start the discussion about the outcomes of this survey by acknowledging identified areas of good practice regarding the mental health support offered to CYP with epilepsy.

Identified areas of good practice

- 91% of respondents recognised that mental health problems were more frequent in CYP with epilepsy. This shows the mental health professionals recognise that CYP with epilepsy might face challenges over and above their peers. However, only 18% of respondents knew that mental health difficulties in CYP with epilepsy are 4 times more frequent than in the wider population.
- The majority of respondents felt confident in recognising and providing intervention for both mental health and cognitive difficulties.

Limitations to the current survey

- A relatively small proportion of respondents took part in the survey, therefore it is likely that responses do not represent responses from the wider team and wider regional services. For example, only 1 medical prescriber responded to the survey, whereas the majority were clinical psychologists.
- Service identification in the region was a challenge and required a considerable amount of work. However, it is possible that relevant individuals or services may have been inadvertently missed. However, the current list of services collated as part of this project makes a significant contribution to a mental health service stakeholder directory which can be added to and updated for future CHWN projects.
- There is geographic variation in how services operate and what is provided which means that the current survey may not reflect what is offered in each locality.

What is currently offered?

Most respondents to the current survey work within CAMHS/CYPS or Health Psychology teams. As highlighted by survey responses from both education, ESNs and clinical leads, there are options for 'lower level' intervention or informal mental health support both within schools and through third sector organisations. As stated in the education chapter, the establishment of LA/CCG education mental health practitioner (EMHP) teams in each local authority, may help to overcome the acute difficulties that CYP experience as a result of epilepsy. However, it has already been identified that this might not be appropriate for individuals with an underlying health condition, unless further training is provided.

If concerns persist regarding a CYP's mental health, professionals are likely to refer to more specialist mental health services such as CAMHS/CYPS. The clinical leads survey reported that CAMHS referrals are often rejected, and long waiting times are common. It is likely that a proportion of those referred to CAMHS/CYPS services will not require specialist mental health support and will not be accepted by the service, however referral criteria are often not explicit. Following an initial assessment session, some CYP may require support of a different kind, such as social care, or may benefit from signposting to support provided elsewhere, for example voluntary sector organisations.

The mental health clinicians in this survey did not report similar concerns regarding length of waiting lists and accessibility for support as was mentioned by ESNs, clinical leads, and teaching staff. As noted previously, this is a relatively small sample size and therefore not representative of all services and professional views in the region.

What exactly is being offered in each mental health team was out with the scope of the current mapping exercise and it remains unclear whether services liaise with medical teams or educational professionals alongside offering individual, group or family therapy for CYP. In addition to this, there is also variation in the services available across different areas, for example although there is health psychology in Cumbria the service is currently only commissioned to see a select number of physical health conditions, excluding CYP with epilepsy.

Some professionals suggested that psychology should be integrated into epilepsy clinics in the same way seen in other health conditions such as diabetes. Adolescents with epilepsy have also been found to have poorer quality of life compared to those with chronic conditions such as diabetes (19), and asthma (20). Therefore, developing early interventions aimed at improving the psychosocial well-being of young people with would seem important. Ideally, integrated services would support a holistic approach to the physical and mental health of CYP with epilepsy. NHSE has prioritised epilepsy in CYP as a priority area for service improvement focussing on 4 main themes – mental health, transition, tertiary care and variation/inequalities. Key deliverables are under development by the national work streams in each of the 4 areas and it is anticipated that the implementation of these deliverables will improve services and reduce variation and inequalities.

Further specific training needs

Respondents to the current survey highlighted the need for more epilepsy specific training within their teams. A significant proportion of respondents stated that their team had no specific training relating to epilepsy and reported that further training is required to support them in identification and intervention for mental health and/or cognitive difficulties for CYP with epilepsy.

As 1 respondent highlighted this is particularly true in the neurodevelopmental pathways which are tasked with the assessment and diagnosis of Autism and/ or ADHD, both of which are common comorbidities with epilepsy:

"Community NHS practitioners should be provided with more epilepsy specific training and information. This is definitely required for staff working into neurodevelopmental pathways."

Recommendations

Several projects have been conducted already identifying gaps in service and making recommendations regarding integration of services, for example Epilepsy 12 and the Rightcare Epilepsy toolkit. The Epilepsy 12 audit recommended that NHS England should support the ongoing establishment of a UK wide clinical network for epilepsy, as per the Long-Term Plan commitment. Part of this plan includes appropriate support and resources provided at regional and now at ICS and provider levels. The following recommendations are based on some of the issues highlighted by this survey of mental health professionals and also from other surveys within the project:

1. Clearer referral pathways to mental health services are needed for each locality. As discovered by the project team, it is difficult to establish what is currently on offer in the region and by whom this is provided. This creates a barrier for referrals from other professionals in education and health settings.

2. Increased communication between mental health services, education and health services is needed. A list of current mental health services in the region which is kept up to date with an identified member of staff responsible for liaising with education and health professionals, is required. This may streamline the referral process and will ensure that CYP and their families are being referred to the most appropriate service.

3. There is an apparent lack of group interventions being offered in the region, specifically lower-level intervention for CYP with epilepsy. One option which has been published is the **P**sychosocial group **I**ntervention for young people with **E**pilepsy (PIE) group which, is a manual-based psychosocial group intervention delivered by clinicians aimed at improving epilepsy knowledge, self-management skills, and quality of life in young people with epilepsy (3).

4. Further training has been identified as an area of need for professionals within mental health settings. This is perhaps more the case for individuals in community mental health setting such as CAMHS/CYPS rather than hospital-based psychology teams. Furthermore, it appears that staff in the neurodevelopmental assessment pathway in CAMHS would particularly benefit from further training on some of the possible cognitive and behavioural consequences of having epilepsy.

5. Many of the respondents in this survey reported that their service works with CYP with Learning Disabilities. However, the current survey did not explicitly look at professionals' views on CYP with epilepsy and a diagnosed learning disability. It would be beneficial to explore whether different recommendations would be needed for mental health professionals working directly with these young people and their families.

6. Interventions for CYP with epilepsy should be staged and integrated so that, as far as possible, parents have access to one team who monitor the child's epilepsy and assess

and support mental health including addressing cognitive concerns. This would be achieved optimally by having a psychologist embedded with the clinical team.

7. Liaison and partnership with school mental health teams and SENCOs to inform and co-ordinate provision for any mental health or cognitive problems would ensure that CYP with epilepsy are supported in a holistic manner across all contexts in their lives.

Mental health in CYP with epilepsy - service user and parental and carer views

C Geagan (Clinical Psychologist), AM Devlin (Paediatric Neurologist and Epilepsy Clinical Advisor), P Archman (Senior General Manager Planning and Information), L Dauncey (Network Delivery Manager CYPT).

Acknowledgements to:
Young Epilepsy and their Young Reps who contributed to stakeholder involvement.
N Wilson (Trainee Clinical Psychologist) for co-facilitating the parent focus group and qualitative analysis

Introduction

NHS England and NHS Improvement promote the need for public and patient voices to be central in shaping healthcare service. (Patient and Public Voice Partners policy, NHS England). A primary aim of stakeholder involvement, in this case children and young people (CYP) with epilepsy and their parents/caregivers, is to get a better insight into people's own perspectives, understanding and views about mental health and epilepsy.

There is already a large body of evidence from stakeholders across England that more is needed in terms of mental health support for CYP with epilepsy and their families., However, it remains important to adopt the approach of 'nothing about us without us' (21). Initially the stakeholder engagement was with CYP with epilepsy, however, epilepsy does not only affect the diagnosed individual, but has significant effects on the wider family so we included parents/care givers as well.

Methods

Focus group

1.1 Development of survey questionnaires for parents and CP

Advice was sought from Young Person's Advisory Group North England (YPAGne) based at the Great North Children's Hospital about consent processes for engaging with CYP and documentation. These were further developed in line with research methodology to facilitate identification of participants and their engagement in the focus groups. These can be seen in full in Appendix 9 to 15 and are as follows:

- A concise description of the project and the purpose of the focus groups to distribute to epilepsy specialist nurses in the region who had agreed to help with identification of potential participants.

- Consent to contact form
- Parent consent form
- YP consent form if over 16, and young person assent if under 16 years.
- Information sheet for parents
- Information sheet for YP
- Group engagement form.

1.2 Linking in with 3rd sector and local organisations

In addition to the ESNs in the region inviting families to participate, the team also approached 'Young Epilepsy' (YE) (national charity) to discuss the possibility of their Young Reps becoming involved. Young reps are individuals with epilepsy who contribute to campaigns to improve daily life with epilepsy by sharing their own stories. An adapted version of the information previously shared with the ESNs regarding the project was sent to them by YE and we received responses from 2 young reps who helped to formulate the questionnaires for focus groups/interviews (see Appendix 16 for list of questions and prompts used).

1.3 Involvement of CYP with epilepsy and their families

The ESNs in the region were contacted by the project team and were asked to identify at least 2 families on their caseload who met the eligibility criteria for the project. CYP aged 12-17 years with epilepsy and no identified learning disability were eligible as were their parents/caregivers. CYP with an intellectual disability were not invited to take part on this occasion as there are likely to be differences between their experiences and those of CYP with no learning disability. The forum and presentation of questions and materials would also need to be appropriately adapted in order to obtain meaningful responses. This should form part of future work to ensure that their voices are heard.

CYP were invited to take part in a focus group, however if they did not want to participate in a focus group, they were offered a 1:1 interview with the Clinical Psychologist. Due to time constraints within the project, parents were only offered the option of a focus group.

ESNs were provided with a short description of the study by the project team which outlined the aim of the focus groups (see Appendix 9). Eligible families were then contacted over the phone and the project along with the aims of the focus groups were explained to them by their ESN. Nurses at each site were provided with information on the focus groups to share with families and young people (see above 1.1). Identified participants were then asked to complete a consent to contact form if they wished to be contacted by the Clinical Psychologist facilitating the group. Verbal consent was deemed sufficient and was documented. The names, telephone numbers and email addresses of consenting participants were then provided to the Clinical Psychologist.

After the Clinical Psychologist received consent, the families were contacted using their preferred method (phone or email) to arrange dates and answer any questions that they might have. Families were provided with both a parent and YP version of the information sheet to make an informed decision as to whether they would like to take part (see above 1.1) Families were then offered a couple of days to consider participation before being contacted again. This was to ensure that families understood the project and what would be asked of them. A consent form was completed whether the participant opted for the focus group or interview.

A total of 5 families were identified directly by the ESNs. Three of these opted in to taking part in the focus group. A further 7 families were identified across the region by the consultant neurologist leading on the project. One of these parents opted to take part in the focus group. Out of the 4 families identified by ESNs and the Neurologist, only 1 young person consented to taking part and this was in the form of a one-to-one semi structured interview.

1.4 Focus group

Based on feedback from the Young Reps at YE, the project team developed a semi-structured interview during which parents were asked a series of open-ended questions (see Appendix 16 for a full list of questions and prompts asked). A separate interview was conducted with the young person who agreed to take part. Interviews were audio-recorded and transcribed using thematic analysis. Two people read the interviews and agreed on the themes.

Outcomes from the focus group

A total of 4 parents attended on the day, including 2 parents of 1 young person, therefore representatives from 3 families. The ages of the CYP with epilepsy within the families were 12, 15 and 17 years. Individuals discussed the challenges of raising a CYP with epilepsy and all families were at different stages of diagnosis and treatment. One parent reflected on his/her child being diagnosed at a very early age offering a contrast to other parents whose child had been diagnosed more recently at an older age. The key findings from this focus group with parents are outlined in the following table:

Table 1. *Parent interview themes and subthemes.*

Themes	**Subthemes**	**Quotes**
How has epilepsy affected your child?		
Adjustment to diagnosis Impact on all aspects of life Epilepsy is a big life change that presents new challenges at different life stages.	Impact on friendships/socialising/relationships	*"it's another layer of complexity to the teenage… teenage years. It's just it's it's, it's hard enough being a teenager and then having to deal with that extra layer."* *"It was just completely out of the blue. One day, a huge thing to.. to get your head around"*
	Different challenges being faced as CYP gets older	
	Missing out or being held back by epilepsy	
	Loss of some levels of independence for CYP and family	

Impact on you as parents?		
Adjustment to diagnosis Uncertainty Having to explain to others	Taking time to sink in, feeling like they have taken a step back	*“Think we were almost in denial at first, we couldn't believe it… Oh well, it's a one off. It's not. It's not gonna happen again. And then when it did happen again and we said this is real now.”* *“I need… to kind of get that she is becoming an adult, and it’s her decision to share with anybody.”*
	Tolerating uncertainty	
	It’s the child’s choice to tell, but parents often need to tell someone- seizures take away that choice.	
Mental health- what does it mean to you?		
Mental health and physical are closely linked Adjustment to diagnosis, acceptance can improve mental health.	Difficulties with mental health can make everything harder	*“we shouldn't be separating mental health and health because it's.. it's all about us, whether it's up there* (points to head*) or somewhere else.”* *“I’ve always been a worrier. I’ve always been anxious. This is taking it to another level”.*
	It’s normal to have struggles, important to find ways to cope (applies to both parents and young people)	
Mental health as part of epilepsy care		
Lack of regular conversations about mental health in epilepsy care Support from Epilepsy Specialist Nurses valued Accessing support outside of clinics Being able to speak to someone who is not family	Conversations about mental health not routine	*“I think there's things that you would say in a meeting when it was a parent without your child there.”* *“she's* (epilepsy specialist nurse) *always just at the end of the phone…I kept on apologising for phoning in all the time and asking her questions. And she said, ‘don't be silly’. She says I find that this happens with families... I'll speak to them so, so much at the beginning.*
	Opportunity for parent to speak without CYP in room or vice versa	
	Counselling support in schools helpful	
	Signposting to mental health support and resources	

		And then she says, when I'm not hearing from you, that's when I know everything's OK.”
What support would you like?		
Talking to others with shared experience/ personal/ professional knowledge important. Feeling understood. Epilepsy as a journey Parents having lots of questions, need to be able to access support. Managing their own worries and emotions.	Lot of questions before clinic already around seizures and medication- would be helpful to have time to speak about mental health	*“it’s a life changing experience So from that point of view, I think whoever you're talking to professionally, they need to know a bit about what that means.”* *I always think something to read is helpful so you can, you can have a look through things and take things in at your own pace...”*
	Not having access to an epilepsy nurse increases parental worry	
	Important for individual support mental health to also have understanding of epilepsy	

Other topics which were discussed included worries around what might happen as their children get older and face new challenges regarding the impact on their daily lives, education, relationships, and work. Some time was also spent reflecting on transition to adult services, and how their children will have to develop more independence in their epilepsy care.

ESNs were identified by 2 families as playing a very important role during the early stages of diagnosis and in the months following. The other parent reflected on their experience of not having easy access to an ESN and reflected on how their experience as a family might have been different across the years, particularly as a source of advice and help with early worries and questions.

The daily impact of epilepsy was also discussed. Parents reflected on the impact of day -to-day tasks such as taking medication, living with the uncertainty or worry that your child might have a seizure and where this might happen. Frustration at certain aspects of care was also raised, for example, parents discussed the difficulties they sometimes experience when trying to acquire medication from their local GPs.

Outcome of Interview with a young person with epilepsy

For this project, the young person who volunteered to be interviewed was 12 years old and recently diagnosed (<1 year). The following is a summary of some of their views on mental health and epilepsy.

How has having epilepsy affected you?

The time around diagnosis was described as stressful and overwhelming at times. Although some of this anxiety has decreased over the past year, there are still times that they worry about having a seizure, particularly in school. Other worries include how other people might treat them differently once they find out about the epilepsy. For example, they feel like the way their teachers and even their parents speak to them might be different to before, and that they might be checking in with them more. They also reported that since the diagnosis there have been changes in what they are able to do without the support of others, for example they were at the stage where they would walk to school, but now have to get dropped off and picked up. This can lead to a mixture of feelings and changes in how they think, including:

"Like being wrapped in cotton wool."

"Closed in, that you're, like, trapped in, but at the same time, I know it's like coming from a good place and that it's for my benefit."

"More conscious around you, asking you are ok and all that… thankfully my friends are just, like, the same, joking on and all that…"

Despite being relatively early in their epilepsy journey, early levels of support from family and school have been described as very helpful in coming to terms with their diagnosis:

"Since I've been diagnosed, I found myself at the start thinking about it a lot (epilepsy), but I've…like… accepted it a bit more. It is still in the back of my mind, but it is fading away a lot."

What support would you find helpful?

Mental health support was offered quite early on for this young person in the form of counselling at school. They also report having good family support but valued the chance to speak to someone outside of the family. They appreciated having their parents there at the start, especially in medical appointments otherwise they explained that they would feel very nervous. As time has gone on, they now feel more comfortable speaking to nurse or doctor alone.

The young person stated that they would feel comfortable speaking to a doctor or nurse who knows about epilepsy and that they have already met with a few times. However, this would be harder if it were someone new that they had not met before. School was also identified as a possible avenue for support. They explained that it would help to know that support is available if needed and that it is easy to access. This support would ideally come from speaking to someone directly rather than reading a leaflet. Despite this, they felt that it might be helpful to have information resources to share with friends and family to help them explain epilepsy if needed.

Comments from Young Reps (Young Epilepsy)

As mentioned previously, questions for the focus group were co-produced by 2 Young Reps from Young Epilepsy. During the process, they offered some reflections on the questions and consented for these to be included below.

Link between mental health and epilepsy

As with the parent group, the link between epilepsy and mental health was highlighted.

"Epilepsy and mental health have a direct impact on one another, it's a vicious cycle, which without support, inevitably leads to the deterioration of one another. Even now, whenever I go to a hospital or GP appointment, they don't make that connection or simply show interest in mental health."

Accessing support

Young people are increasingly aware about mental health and wellbeing. Therefore, for many young people a lack of knowledge around mental health is not a concern, rather it is being able to get support when needed that appears to be one of the primary issues. The difficulty with access to support depending on where you live and resources in your locality was highlighted.

"Mental health is something that most young people know far too much about, if not from personal experiences, it's from the constant bombardment at school or college with leaflets/assemblies; all with the same basic & outdated information. But when you actually need the help, it's never accessible, or if it is there is a year's waiting list for places like CAMHS. I have seen little to no practical MH advice when it's comes to epilepsy even though it's something that has a direct impact on the condition itself. Unless you can afford private therapy, which can be very pricey, you're just left with all this irrelevant info that offers no real help or impact. So I don't think it's a question of people knowing where to get help but there actually being good resources available."

Discussion

It is necessary to start the discussion about the outcomes of this survey by acknowledging identified areas of good practice regarding the mental health support offered to CYP with epilepsy.

Identified areas of good practice

- ESNs were acknowledged for the support and role they play, especially in the early stages post diagnosis. One parent did reflect on how this had not been the case for them, and that they would have appreciated that level of support
- Schools appear to be offering mental health and wellbeing support in the region, however as noted previously, access to this might be dependent on funding to schools and capacity to see young people.
- Young people appear to have a good understanding of mental health, however, are faced with challenges in knowing who to go to for support. Additionally, it can be unclear what support is available and whether this will be in a timely manner.

Limitations to the current stakeholder involvement

- The current project was very limited in time and as a result, there were a relatively small number of participants, and it is likely that responses are not representative of CYP and families across the region. We know that everyone's experience of epilepsy is individual therefore it is important that a wider range of voices are heard in any future projects carried out by the CHWN.
- Voices of young people who have epilepsy and a co-morbid learning disability were not included in this current project. The needs and experiences of these young people and also their families may be different to those of CYP without a learning disability and any future network CYP engagement work should adapt approaches and materials to ensure that their voices are heard.

The discussion points from the current stakeholder involvement mirror some of the issues and concerns raised by CYP and families nationally. For example, the needs of CYP and their families can change and evolve during the epilepsy journey. What might be needed during the early stages of the diagnosis is likely to be very different to what is needed a few years later. Worries about the transition to adult services were not explicitly explored in this project due to the demographics of participants, although it is acknowledged that this can be a particularly stressful period for families.

Parents in the current focus group identified support that they would find beneficial, including informational and emotional support, not only relating to seizures, but also other difficulties which might arise from having epilepsy. The Sussex Early Epilepsy and Neurobehaviour study identified similar themes of parents wanting ongoing access to support both for epilepsy and the associated developmental and behavioural difficulties (17). This highlights the need for a supportive team to be around young people and their families to offer advice and guidance when needed. Additionally, parents, caregivers and other family members can also experience impacts on mental health. It is important to recognise that a diagnosis of epilepsy does not just affect one person. Supporting someone with epilepsy can lead to increased feelings of worry, especially in early stage of diagnosis, times of transition, or if seizures are not well controlled. Parents of CYP with epilepsy are more likely to experience depression, anxiety, general stress, sleep problems and fatigue (17). This is reflected in the secondary care chapter of this report where epilepsy specialist nurses and epilepsy clinical leads report spending a significant amount of time offering emotional and mental health support to parents and carers of CYP with epilepsy.

A more detailed survey carried out by Young Epilepsy in 2021 (22) exploring young people's experiences of epilepsy and mental wellbeing found that 99% of young people said living with epilepsy has had an impact on their mental wellbeing (77% significant impact, 22% small impact). This impact was described as anxiety/worry, depression, life-changing, impact on self-worth/identity, isolation, overwhelming, lack of control, fear, stress and feelings of suicide. The majority of respondents were aged 18 to 25. Unfortunately, only 1 CYP from NENC registered interest in taking part in the current project. However, reflecting on responses from the wider survey carried out by Young Epilepsy (22) several similar themes were identified. The importance of everyday activities such as hobbies and support networks such as family and friends can be invaluable. However, knowing that there is support available that is easily accessible is highlighted as very important. It is important to note that many CYP with epilepsy may not need direct one to one talking therapy, however knowing that there are different options available if they did need support is very important.

Recommendations

1. Parents of children with epilepsy should have access to ongoing information and emotional support via dedicated epilepsy support specialists (e.g. Epilepsy Specialist Nurses) and have access to reliable information forums.
2. Screening for mental health difficulties should occur as a routine part of epilepsy clinics, not only for CYP with epilepsy, but also for parents for example, by using the Patient Health questionnaire 9 (PHQ-9) or Generalised Anxiety Disorder 7 (GAD-7) which act as quick screens for low mood or anxiety in parents and carers.
3. Parents should have access to better information at diagnosis about how mental health and epilepsy may affect their child, but also for parents to have access to support for themselves as and when needed.
4. It is important for individuals with epilepsy and their families, along with local teams and schools to have information about organisations, charities and specialist services that exist locally and nationally which offer mental health support. Clinical teams should have up-to-date local and national information and contact details for these organisations in order to signpost CYP and families to them.,
5. Psychosocial groups for young people with epilepsy should be established as a way for them to meet other CYP going through a similar experiences. Likewise, parents and other close family members would benefit from support group activities.
6. Future work should also look at the needs and concerns of CYP with epilepsy and a learning disability to better identify support desired by CYP themselves and also their families.
7. Increased involvement of CYP and their families with their epilepsy care is essential for the continuous improvement and long-term impact of the care delivered by epilepsy services. It is important that the CHWN continues to engage with CYP with epilepsy and other health conditions as part of any future projects, including re-engagement following any service improvement work to ascertain if positive impacts from this work are tangible to service users.

References

1. NHS Long Term Plan https://wwwlongtermplannhsuk/online-version/. 2019.
2. Epilepsy12 summary report Round 3 Cohort 2. https://wwwrcpchacuk/sites/default/files/2021-07/Epilepsy12%20summary%20report%2033_0pdf. 2021.
3. Dorris L, Broome H, Wilson M, Grant C, Young D, Baker G, et al. A randomized controlled trial of a manual-based psychosocial group intervention for young people with epilepsy [PIE]. Epilepsy Behav. 2017;72:89-98.
4. Royal College of Paediatrics and Child Health. The case for investing in children and young people's epilepsy services. London: RCPCH. . 2018.
5. K Armon TS, V Gabriel, R MacFaul, P Eccleston, U Werneke, S Smith. Determining the common medical presenting problems to an accident and emergency department. Arch Dis Child 2001;84:390-2.
6. Fastenau PS, Jianzhao S, Dunn DW, Austin JK. Academic underachievement among children with epilepsy: proportion exceeding psychometric criteria for learning disability and associated risk factors. J Learn Disabil. 2008;41(3):195-207.
7. Ott D SP, Gurbani S, et al. Behavioral Disorders in Pediatric Epilepsy: Unmet Psychiatric Need. Epilepsia. 2003;44:591-7.
8. Baca CB, Vickrey BG, Caplan R, Vassar SD, Berg AT. Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. Pediatrics. 2011;128(6):e1532-43.
9. Davies S, Heyman I, Goodman R. A population survey of mental health problems in children with epilepsy. Dev Med Child Neurol. 2003;45(5):292-5.
10. Reilly C, Atkinson P, Das KB, Chin RF, Aylett SE, Burch V, et al. Academic achievement in school-aged children with active epilepsy: a population-based study. Epilepsia. 2014;55(12):1910-7.
11. Epilepsy12 2022 Combined organisational and clinical audits:
    Report for England and Wales
    Round 3, Cohort 3 (2019-21). https://wwwrcpchacuk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022. 2022.
12. M M. Health Equity in England: the Marmot review 10 years on. Institute of Health Equity. 2020.
13. Jones C, Reilly C. Parental anxiety in childhood epilepsy: A systematic review. Epilepsia. 2016;57(4):529-37.
14. George C, Felix SA, McLellan A, Shetty J, Middleton J, Chin RF, et al. Pilot project of psychological services integrated into a pediatric epilepsy clinic: Psychology Adding Value - Epilepsy Screening (PAVES). Epilepsy Behav. 2021;120:107968.
15. Bennett SD, Cross JH, Coughtrey AE, Heyman I, Ford T, Chorpita B, et al. M.I.C.E-Mental Health Intervention for Children with Epilepsy: a randomised controlled, multi-centre clinical trial evaluating the clinical and cost-effectiveness of MATCH-ADTC in addition to usual care compared to usual care alone for children and young people with common mental health disorders and epilepsy-study protocol. Trials. 2021;22(1):132.
16. Sinkek S. Start with Why: Penguin; 2011.
17. Jones C, Atkinson P, Memon A, Dabydeen L, Das KB, Cross JH, et al. Experiences and needs of parents of young children with active epilepsy: A population-based study. Epilepsy Behav. 2019;90:37-44.
18. Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, et al. Standards for epidemiologic studies and surveillance of epilepsy. Epilepsia. 2011;52 Suppl 7:2-26.
19. Hoare P KS. Psychosocial adjustment of children with chronic epilepsy and their families. Dev Med Child Neurol 1991;33:201-15.
20. Austin JK, Huster, G. A., Dunn, D. W., & Risinger, M. W. Adolescents with active or inactive epilepsy or asthma: a comparison of quality of life. Epilepsia. 1996;37:1228-38.
21. J C. Nothing About Us Without Us: University of California Press; 2000.
22. Epilepsy Y. Young people's experiences of epilepsy and mental wellbeing - Survey findings. Report. 2021.