community patients were admitted to the acute inpatient setting. We therefore audited the standards relating to inpatient care which included the need to record the cause of neurodisability on admission, on daily ward rounds and at discharge, recording of a child's mobility, communication and if a child had a handheld patient record (or if one was recommended).

Methods We retrospectively audited 30 children admitted over a 1 year period, randomly selecting 10 elective admissions, 10 emergency admissions with short stay spells (<24 hours) and 10 longer term emergency admissions (>24 hours). Baseline data is shown in the table 1. Our short-term interventions following baseline data collection included delivering teaching to all ward doctors about the children with neurodisability & why these aspects of care were important to record and attaching a prompt sheet to notes trolleys. A re-audit of 10 patients over the next 2 months (limited numbers due to reduced summer admissions) showed improvement in all areas.

Results

Abstract G33 Table 1

	Baseline (30 patients)	After Intervention (10 patients)
Cause of neurodisability recorded:		
On Admission	87%	100%
Daily Summary	60%	90%
In discharge documentation	67%	100%
Mobility Recorded	3.3%	60%
Mode of Communication recorded	6.6%	50%
Patient Held Record (had or offered)	10%	60%

Conclusions Our short term intervention, which did not require any hospital committee approval or funding, showed significant improvement in our documentation towards the NCEPOD standards allowing us to better support these families. We have also designed a proforma for medical notes which is in the process of going through health records approval and will be re-audited once introduced.

G34 UK CHILDREN WITH PROGRESSIVE NEUROLOGICAL DISEASE: DIFFERENTIAL DIAGNOSES BY AGE

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Aims To review the cases referred to this UK-wide study of children with progressive intellectual and neurological deterioration (PIND) and analyse the differential diagnoses in these children by age at presentation.

Methods Children meeting the case definition for PIND were identified via the British Paediatric Surveillance Unit. Data were obtained by standard questionnaire, with additional information from hospital records and laboratory reports, allowing validation of diagnoses and estimation of the age of presentation to clinicians.

Results Between April 1997 and October 2019, 4612 children had been notified to the study. 2072 were found not to meet the PIND case definition. 2009 had an underlying diagnosis to explain their deterioration; of these the numbers presenting by age were: <1 year 805 (40%), 1–4 years: 825 (41%), 5–9

years 265 (13%), 10–15 years 114 (6%), with over 220 different disorders including 6 cases of variant Creutzfeldt-Jakob disease (vCJD) (the last identified in 2000). The children who presented aged 10–15 years included the 6 vCJD cases. Of the other disorders in this age group the commonest were: mitochondrial cytopathy (mito) 17, adrenoleukodystrophy (ALD) 9, Lafora body disease 8, Niemann-Pick type C 8, Huntington's disease 7, neuronal-ceroid lipofuscinoses (NCL) 7, SSPE 5, metachromatic leukodystrophy 4, Wilson's disease 4. The distribution of disorders varied with age e.g. the 3 commonest disorders in the other age groups were - 5–9 years: NCL, ALD, mito; 1–4 years: NCL, mucopolysaccharidosis III, mito; < 1 year: mito, GM2-gangliosidosis, Krabbe's disease.

Conclusion Since 1997 the PIND Study has provided unique epidemiological data about neurodegenerative diseases in UK children. It shows that children meeting the criteria for PIND tend to present early in life (over 80% before the age of 5 years) – not surprising because of the inherited basis for so many of these disorders. The study provides a differential diagnosis for PIND children by age and remains the only means of performing systematic surveillance of the neurodegenerative diseases that make up the differential diagnosis of vCJD.

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G35 NATIONAL SURVEILLANCE OF SEVERE MICROCEPHALY DIAGNOSED IN INFANTS IN THE UNITED KINGDOM AND IRELAND

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Background Severe microcephaly is defined by WHO as a head circumference (HC) more than 3 standard deviations below mean (<-3SD) for age and sex. Although UK congenital anomaly registrations suggest microcephaly is uncommon, there is uncertainty about the number of babies affected each year. To monitor emerging infections, such as Zika Virus, and understand the impact on health and neurodevelopment, it is essential to characterise the current burden of disease.

Aim To report the incidence, characteristics and causes of severe microcephaly diagnosed in children aged under one year in the UK and Ireland.

Methods Active surveillance through the British Paediatric Surveillance Unit for 13 months from October 2017 to ascertain all live born children aged under 1 year who were diagnosed during this period with microcephaly or noted to have a HC <-3SD or <0.4th percentile for age and sex, excluding babies with anencephaly. Clinicians who reported a child completed a clinical questionnaire.

The annual incidence of severe microcephaly was calculated for infants with HC <-3SD for age and sex. For all other analyses, children with HC <0.4th percentile were also included. All reported findings are based on confirmed cases to date.

Results The annual incidence of severe microcephaly (HC <-3SD) between November 2017 and October 2018 was 5.6

cases per 100,000 children aged under 1 year. Sixty-one children met the study case definition (51% girls; 41% born <37 weeks gestation; 56% white, 26% Asian, 18% other/unknown ethnicity). Neurodevelopmental abnormalities were reported for 46 (75%) children, including seizures, vision, hearing, and motor abnormalities. The most common identified causes of microcephaly were genetic conditions (n=5) and congenital infections (CMV, toxoplasmosis, and herpes; n=8), however the cause was unknown for 69% infants. No cases of Congenital Zika Syndrome were identified.

Conclusions The number of children with confirmed severe microcephaly was fewer than estimates based on European congenital anomaly registers. Infants of Asian ethnicity and those born preterm were over-represented. Most children were still under investigation for the cause of the microcephaly. Over three-quarters of children already demonstrated neurological abnormalities; further follow-up will capture later neurodevelopmental outcomes.

G37 PARENTAL NEEDS FOR PSYCHOLOGICAL SUPPORT FOLLOWING A DIAGNOSIS OF PERINATAL STROKE

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Background Parents of infants with conditions such as perinatal stroke (PS) often experience feelings of guilt and blame and are at risk of experiencing negative outcomes in terms of psychological wellbeing. This has the potential to adversely affect parent-infant interaction, impacting on the infant. Providing psychological support from an early stage is critically important.

Aims To identify key areas of parental expressed need for support (both met and unmet) following a diagnosis of PS.

Methods Data for the current study was obtained from primary research considering the feasibility of an early parent-delivered therapy intervention (Basu et al. 2018). Eligible participants were recruited from 8 hospitals acting as identification centres. Parents/carers of potential infant participants were identified by clinical staff and their details forwarded to the research team. Secondary analysis of 11 in-depth interviews, exploring parental experiences of delivering the therapy intervention, was carried out using thematic analysis, modelled on the inductive approach by Braun & Clark (2006).

Results Four overarching themes were identified: 'Lack of information' (due to uncertainty about the future and lack of understanding of clinical terms) was a stressor. 'Need for reassurance' related to wanting information, support, and a sense of purpose. 'Emotional processing' reflects changes in the nature and extent of difficulties experienced in processing the initial stage, coming to terms with the diagnosis and long term adjustment. 'Emotional sensitivity' relates to additional factors related to caring for the infant including social stigma, worrying about developmental discrepancies and the marital relationship, which can act as triggers further distress.

Conclusion The diagnosis of PS led to psychological distress in parents which could be characterised in specific themes. Uncertainty following diagnosis was responsible for significant emotional difficulties. Psychological adjustment to diagnosis

was affected by cognitive strategies – but this is a long term and emotionally sensitive process. Findings are discussed in relation to the literature. Recommendations for practice include timely provision of information and resources, restoring self-efficacy, promoting coping strategies to facilitate adjustment, and the compassionate support of healthcare professionals at a time of high vulnerability.

G38(P) KNOWLEDGE, ATTITUDES AND PRACTICE TOWARDS EPILEPSY AMONG PRIMARY SCHOOLS' TEACHERS IN KHARTOUM LOCALITY, SUDAN 2016

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Objective This study aims to assess primary schools teachers' knowledge, attitude and practice towards epilepsy.

Methods and Materials This is a cross sectional study that was conducted using structured questionnaire; self administered to 202 teachers selected through multistage-clustered sampling technique, in Khartoum locality, Khartoum state, Sudan.

Knowledge scoring was done by adding (causes variables + treatment options risk of transmission + symptoms and signs) =15 [less than 5 out of 15 >>poor knowledge. 5–10 out of 15 >>average knowledge. more than 10 out of 15 >>good knowledge]. Attitude score answering correctly to 5 different items and scoring was done [less than 2 out of 5 negative attitudes. 2–3 out of 5 neutral attitudes, more than 3 out of 5 positive attitudes]. Practice scoring was done using 7 items [>3 out of 7 =poor practice, 3–4 out of 7 average practice <4 out of 7 good practice].

Result A total of 202 teachers participate in this study. All respondent have heard about epilepsy, (83.2%) from their nearby community. About (27.7%) considered evil spirit as a cause for epilepsy and (20.3%) answered traditional remedy by herbs and sheikhs as best treatment option. (85.6%) considered epilepsy as non-contagious disease and (67.8%) considered epilepsy presentation as convulsion only. About (73.7%) of the participant have an average knowledge regarding initial procedure for seizures management and report removing sharp and maintain patient safety as a major practice.

Total of (71.8%) of teachers have an average knowledge about epilepsy, (59.5%) have average practice toward epileptic and a percentage of (66.3%) have a positive attitude toward epilepsy.

Conclusion and Recommendation Teachers had a relatively average knowledge about epilepsy, positive attitudes toward students with epilepsy and their practice toward student during seizure was generally average. Education campaigns of the general public on epilepsy should be encouraged. The need for a well-structured educational and evidence-based intervention for teachers about epilepsy is essential.

G39(P) FEATURES OF PHYSICAL DEVELOPMENT OF CHILDREN WITH CEREBRAL PALSY

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