A Quality Improvement Project to enhance the identification and treatment of cCMV within the recommended 28 days of life in well babies with SNHL

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Objectives

Congenital CMV (cCMV) is the commonest congenital infection in developed countries and a leading cause of Sensorineural hearing loss (SNHL). There is an urgency to diagnose cCMV as current evidence suggests that starting antiviral treatment with oral valganciclovir may improve neurodevelopmental outcomes if started within the first 4 weeks of life.(1) Furthermore congenital infection must be diagnosed within 3 weeks of life.

Aims:

- To measure the time taken for completion of Newborn Hearing Screening Programme (NHSP) in well babies in Brighton and Hove against the NHSP standards of practice.(2)

- To assess the number of well babies meeting the local standards of practice for Audiology assessment within 21 days of life following a 'no clear response' result from their NHSP. (3)

- To identify any changes to the service that would enable initiation of treatment in well babies with cCMV within 28 days of life.

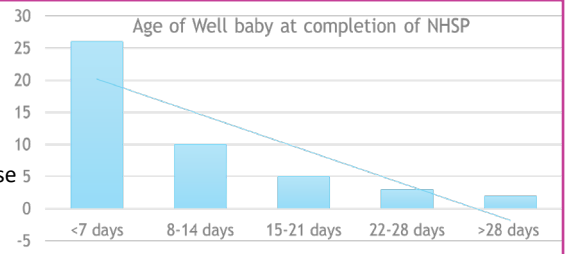
Methods

The data was gathered from the following searches on SMaRT4Hearing (S4H) in Brighton and Hove;
All 'Well babies' born during a randomly selected week '01/11/2023 - 08/11/2023'. This search identified 47 babies who were eligible for NHSP.

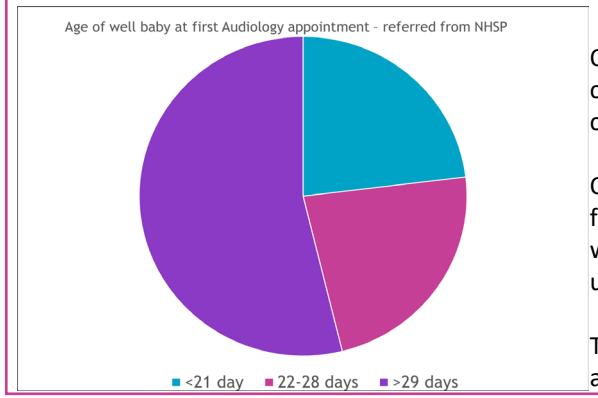
A second search was used to identify babies who failed their NHSP and required Audiology referral;
All 'well babies' born within '01/01/2023 – 01/01/2024' with 'audiology appointment' checked. This identified 17 babies who were all referred to audiology following completion of their NHSP in 2023.

Results

The results of the first search on S4H identified 47 babies. 1 baby did not complete screening. On average, well babies completed NHSP on day 8 of life
This is well within the National guidelines of NHSP completion by 28 days of life.(2)



The second search on S4H looked at well babies born from January 2023 to January 2024. In this year 17 babies were referred to Audiology following their NHSP. 3 of these babies were diagnosed with permanent congenital hearing loss, 2 of which had SNHL.



Of the 17 babies referred to Audiology the average age by which they completed their NHSP was on day 12 of life (AABR). Only 2 babies completed their NHSP > 21 days of life.

Of the 17 babies referred to Audiology on average they attended their first audiology appointment on day 32 of life (not including 4 babies with a 'clear response' on NHSP who were referred for targeted follow up).

The average time between the last NHSP appointment to the first audiology appointment was 16 days n=13.

Conclusions

These findings show that our NHSP team meet the national targets for well babies completing their hearing screening within 28 days and that they mostly complete screening within the first two weeks of life. However this QIP has identified a delay of approximately two weeks between a 'no clear response' on completing the NHSP and the baby attending their first audiology appointment. Unfortunately there is no place to document discussions with parents on S4H which may give more insight into factors that contribute towards this delay when the audiology appointment is booked.

Our current practice involves urine sample collection for CMV testing at the first audiology appointment if it has not already been collected. This means it is very difficult to achieve the recommended investigation of cCMV within the first 21 days of life, as per The European Consensus Statement of Diagnosis and Management(4), to enable diagnosis and initiation of treatment by 28 days of life.

I propose the following action plan to help us meet the recommended targets and align our practice with other units around the country(5). Firstly it is essential that if a term baby is referred to Audiology after failing the NHSP that the appointment is booked within 21 days of life. Secondly to consider if the NHSP team could send the baby's urine for CMV testing at the point of failed AABR prior to the audiology appointment. This may require further training to support the team in consenting parents for CMV testing. Thirdly we could pilot a salivary CMV PCR testing of babies that fail their NHSP. Finally we could develop an agreed urgent pathway for processing CMV PCR and informing the oncall Paediatric Infectious Diseases Consultant or Neonatal Consultant of a positive result to proceed with urgent initiation of treatment.

References

1. Shah, T., Luck, S., Sharland, M., Kadambari, S., Heath, P., & Lyall, H. (2016). Fifteen-minute consultation: diagnosis and management of congenital CMV. Archives of Disease in Childhood - Education & Practice Edition, 101(5), 232–235
2. https://www.gov.uk/guidance/newborn-hearing-screening-programme-overview
3. RL/NA/CM/LS issue date: April 2022 UHSussex Departmental Protocol: cCMV pathway Application: Define paediatric Patient pathway Journey for those diagnosed with congenital CMV
4. Luck SE, Wieringa JW, et al. cCMV - a European Consensus Statement of Diagnosis and Management European consensus guideline. In press.
5. F Walston, K McDevitt, S Walter, S Luck, T Holland Brown Issue date: 2017 East of England Neontal ODN Clinical Guideline: Diagnosis and Management of Congenital Cytomegalovirus

Acknowledgements: UHSussex Newborn Hearing Screening and Audiology teams.

The Assessment of Emotional and Mental Health Problems in Children with Cerebral Palsy: A Service Evaluation

Dr Sophie Sakmann, Dr Dannika Buckley, Dr Janetta Milea
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Objectives

Routine practice in our child development centre does not currently include formal screening for mental health problems in children with cerebral palsy (CP). NICE, however, advises using validated tools to assess for mental health problems in children with CP [1]. We conducted a service evaluation project to determine whether this is an unmet need for our patients. More specifically, we planned to:

- Determine the proportion of children with CP attending our school-age motor clinic who also experience mental health problems

- Determine whether the use of the Strengths and Difficulties Questionnaire (SDQ) is welcomed by our patients, their parents and our staff.

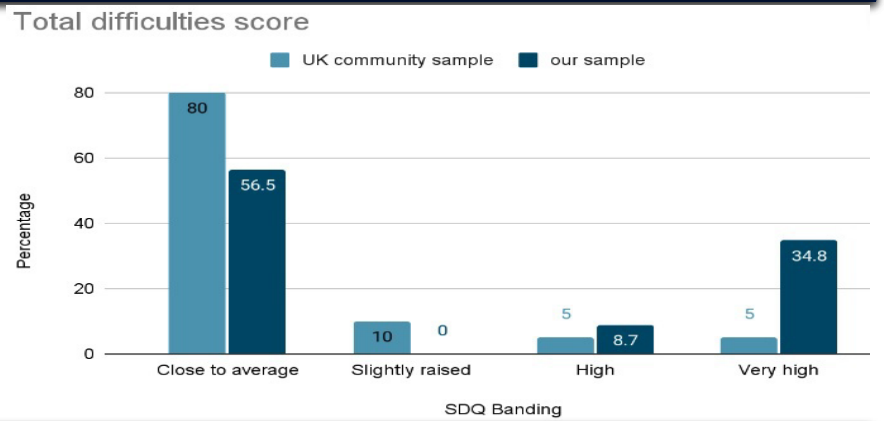
Methods

SDQs were provided to all families of patients with CP invited to an outpatient appointment in our school-age motor clinic over a one-year period. 25 questionnaires were completed; 24 were suitable for analysis. Of these, 52.2% related to 5 - 11 years old patients and 47.8% related to 12 - 17 years old patients. The male to female ratio was 14 to 10.

Results

Within our sample, more patients were experiencing high to very high difficulties with their mental and emotional health than in the UK community sample upon which the SDQ is based. Comparing our sample with the UK community sample, 34.8% vs 5% scored “very high”; 8.7% vs 5% scored “high”, 0% vs 10% scored “slightly raised” and 56.5% vs 80% scored “close to average” (see graph). Overall, 43.5% of the patients in our sample experienced high or very high difficulties with mental and emotional health.

Parents expressed gratitude for having been asked about this aspect of their children’s lives and commented that this is an area which is frequently overlooked with the focus usually being their child’s physical skills. Staff explained they often do not have time to address all areas covered by the SDQ and felt it allowed them to screen for areas of concern whilst normalising discussions around mental and emotional health.



Conclusions

Almost 1 in 2 of the children with CP attending our school-age motor clinic experience difficulties with their mental and emotional health. This highlights a previously unidentified need. In response, we plan to screen every patient attending the clinic and to offer a resource package to those experiencing difficulties. We aim to use this service evaluation to advocate for access to on-site clinical psychology support, with an agreed referral pathway for the most severely affected patients.

References

[1] NG62. Cerebral palsy in under 25s: assessment and management. National Guideline Alliance (UK). London: National Institute for Health and Care Excellence (NICE); January 2017.

A Single Centre Review of the Management of Sleep Disturbance in Paediatric Patients with Neurodevelopmental Conditions

Dr Victoria Sadlers- ST7 Community Paediatrics
Dr Anne Noglik- Consultant Community Paediatrician

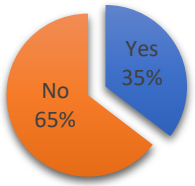
Wirral University Teaching Hospital
NHS Foundation Trust

- All patients reviewed in clinic in 1 month period identified.
- 548 patients with ASD and/or ADHD identified.

What's the problem?

- Sleep disturbance is a common complaint from our patients and parents.
- There is a significant impact on parents/ caregivers.
- No sleep service locally.

Prescribed Melatonin

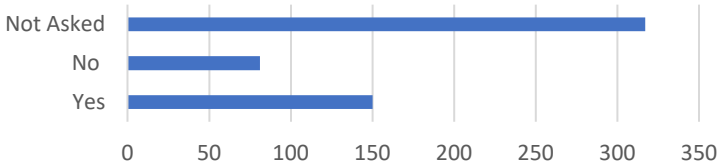


Yes No

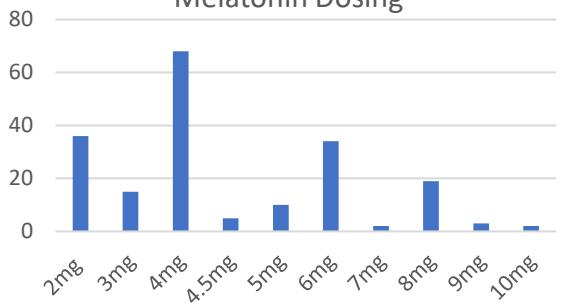
What did we find?

- 194 patients already taking melatonin (35%).
- 150 patients complained of sleep disturbance.
- Of these 150, 74 already on melatonin (49%).

Sleep disturbance



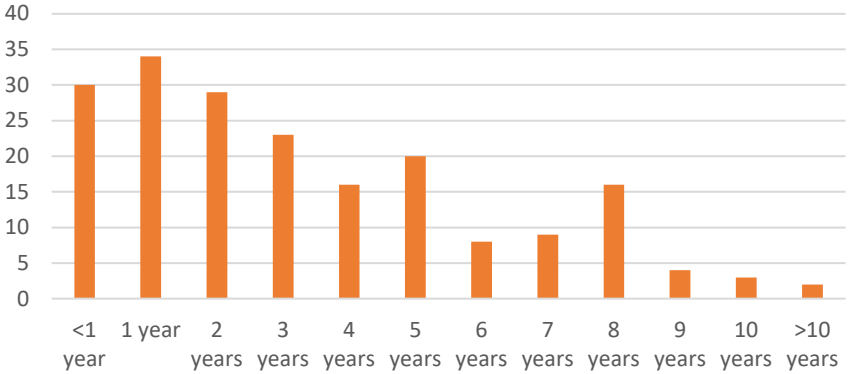
Melatonin Dosing



- Average Melatonin dose 4.5mg.
- Range 2-12mg.
- Significant inter professional variation in the doses used.

- Median duration 3.4 years (range 0-10+ years).
- 32% of patients had been on melatonin >5 years.
- 1% of patients had been on melatonin >10 years.
- No long term data for efficacy or safety available for paediatric population on Circadin.
- Significant cost burden (30 x 2mg Circadin tabs= £15.39).

Duration of Melatonin Therapy



What do we think?

- NICE guidelines suggest behavioural interventions are first line in any patient complaining of sleep disturbance.
- Majority of patients (63%) were not given sleep hygiene advice before initiation of melatonin.
- Our evidence suggests sleep disturbance is prevalent even among those already prescribed melatonin.
- Medical causes for sleep disturbance need to be considered, particularly in patients with risk factors (T21 etc).

What did we do?

- Introduced "Sleep Packs".
- Primary and secondary school aged sections.
- Contains leaflets, sleep diaries, websites, apps and self-help.
- Sent to patients complaining of sleep disturbance = first line

What's next?

- Repeat review.
- Present business case for funding of a sleep service!

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Raising the profile of community paediatrics – we are worth it!

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INTRODUCTION

- Introduction of Progress+ has changed training priorities
- Exposure to community paediatrics will be reduced so we offer an elective 'Community Paediatrics Module' within final year undergraduate training

AIMS

- Increase awareness & enjoyment of community paediatrics so future clinicians can make informed decisions when shaping their training
- To encourage evidence-based medicine within community paediatrics via a self-selected project and regional presentation
- To increase the understanding of child development amongst future doctors, whatever career they ultimately choose

METHODS

- 3 cohorts (15 undergraduate in total) are offered 8 face-to-face sessions & 1 self-led study day over a 2-month period
- Participation in small group tutorials on relevant topics such a cerebral palsy, autism spectrum condition & development
- Supervised development assessments of children
- Gain anonymous feedback at the end of the placement about their outlook on community paediatrics

RESULTS

- We analysed anonymous post-module feedback
- Some undergraduates fed back this should be within the curriculum, very positive outlook
- Prior to the module 25% did not know community paediatrics existed, following the module 100% would now consider a career in this area

CONCLUSIONS

- Trainees are no longer mandated to train within community
- We provide undergraduates exposure to our subspecialty and it was been well received: "I now have an insight into community paeds, and what a great career it could be!"
- The next consideration is incorporate this into undergraduate curriculum and replicate our module across the UK

"What now?": How our parent focus group showed us what really matters to parents of children diagnosed with Autism Spectrum Disorder.

Dr Pavneet Sandhu, Dr Deeksha Dhar, Dr Naomi Elson, Lee Foster, Dr Lara Staffurth, Dr Yui Sasaki

INTRODUCTION

We are one of many Child Development Centres (CDCs) experiencing increasing delays in the assessment and diagnosis of children with Autism Spectrum Disorder (ASD). We acknowledge this issue at initial assessment and signpost families to support. Is this enough to meet the families' needs? We conducted a parent-carer focus group to explore this further.

What now? What does our life look like? What does his life look like?

AIMS

- Understand parent-carer experience of referral, assessment and post-diagnostic support (the pathway).
- Identify the barriers and positive factors in this pathway.
- Work collaboratively with parent-carers to develop our service.

METHODS

We retrospectively identified 30 families whose children had been diagnosed with ASD within the previous 6 months. We invited parents to attend face-to-face focus groups or complete an anonymous emailed survey. We used a semi-structed interview format with 5 open questions. We identified themes via facilitator discussion.

I've managed it for so long. I don't know what a website will tell me.

CONCLUSION

This focus group highlighted the barriers and positive factors for families navigating ASD assessments in our CDC. Following this, we are developing a monthly, virtual 'drop in' psychoeducation service, to meet both social and clinical need. We have updated our written supportive information with input from parents as experts-by-experience.

RESULTS

5 families attended focus groups and 3 completed the online survey. Themes included:

- Lack of clarity around referral pathways
- Transparency around assessment timeframe
- Positive relationships with all CDC staff
- The need for and value of parent support groups
- Lack of post-diagnostic support, including inaccessible written resources
- A need to involve parents in care delivery

Is geographical variation in emergency epilepsy admissions related to variation in new epilepsy diagnoses among children and young people across England? An observational study using linked datasets

Dr. Rakhee Shah, Sandeepa Arora & Dr. Dougal Hargreaves

Introduction

- Epilepsy is estimated to affect over 112,000 children and young people (CYP, 0-24 years) in the UK.
- Quality and coordination of health care are important determinants of outcomes for CYP with epilepsy.
- Failure to provide consistently high-quality care for CYP with epilepsies has been linked to high rates of over- and under-diagnosis of epilepsy and wide geographical variation in epilepsy admission rates and deaths.
- Geographical variation in paediatric epilepsy admissions in England is significant even after adjusting for factors such as deprivation and ethnicity, and the causes for variation remain largely unknown.

Methods

Aim

To investigate the extent to which geographical variation in epilepsy admissions among children and young people (CYP) aged 0-18 years, in England, reflects variation in new epilepsy diagnoses.

Design and setting

A retrospective secondary analysis of Hospital Episode Statistics data for emergency admissions between April 2018 and March 2019, and Epilepsy12 audit data for new epilepsy diagnoses in England, between July and November 2018.

Outcome measures

- The ratios of observed to expected epilepsy admissions and new diagnoses were calculated for each hospital Trust, based on their catchment population and adjusted for age, sex, and deprivation.
- Standardised ratios of observed to expected epilepsy admissions were plotted against standardised ratios of observed to expected new diagnoses of epilepsy at Trust level and the Pearson correlation coefficient was calculated.

Results

- 9246 emergency admissions for CYP to 134 Trusts with a primary diagnosis of epilepsy in England during the study period.
- 60 Trusts (44.4%) had either significantly lower or higher than expected standardised admission ratios for a primary diagnosis of epilepsy.
- There were 960 new diagnoses of epilepsy between July and November 2018 for 74 Trusts.
- 14 Trusts (18.9%) had either lower or higher standardised diagnosis ratios for a new diagnosis of epilepsy.
- There was no correlation between standardised emergency epilepsy admissions ratios and standardised new epilepsy diagnoses ratios at Trust level (Pearson r -0.06, p 0.63) Figure 3.

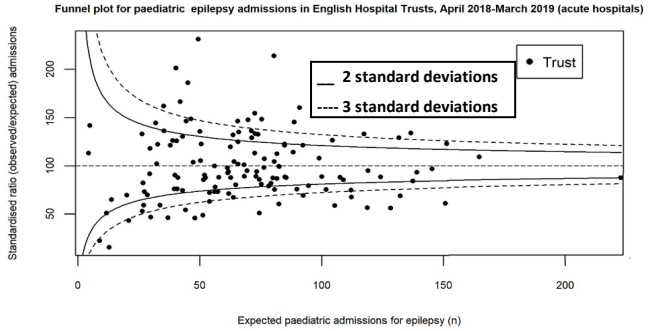


Figure 1 (Above): Funnel plot showing the standardised ratio (observed/ expected) for paediatric epilepsy admissions in English Hospital Trusts between April 2018 and March 2019.

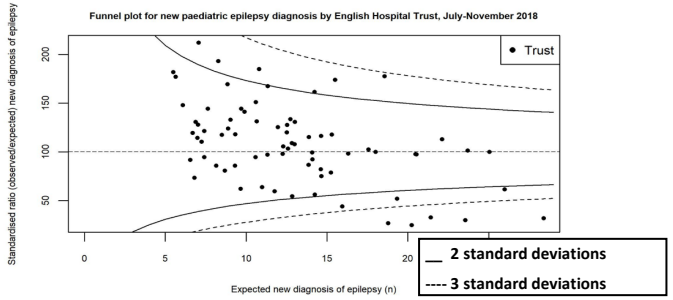
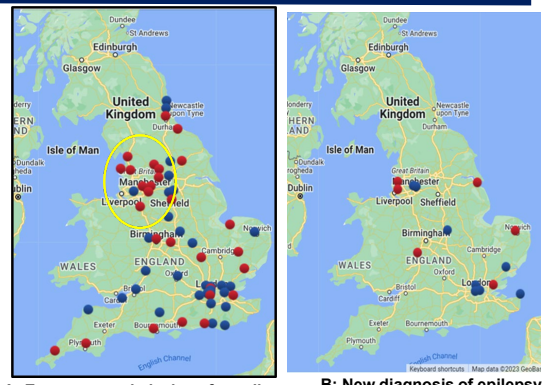


Figure 2: Funnel plot showing standardised ratios for observed versus expected new diagnoses of epilepsy by NHS Trust

Map showing geographical location of trusts that have higher or lower than expected emergency admission ratios (figure A) and new diagnosis ratios for a primary diagnosis of epilepsy (figure B)

Red dots – Trusts with significantly higher (≥ 2 standard deviations) observed admission or new diagnosis ratios for epilepsy than expected.

Blue dots – Trusts with significantly lower (≤ 2 standard deviations) observed admission or new diagnosis ratios for epilepsy than expected.



A: Emergency admissions for epilepsy **B: New diagnosis of epilepsy**

Relationship between emergency admission ratios of epilepsy and new diagnoses of epilepsy by Trust

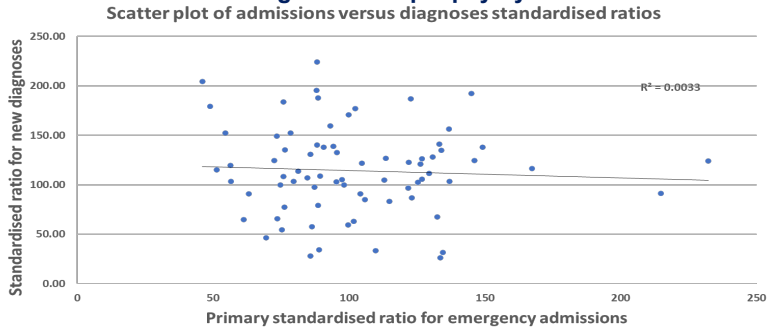


Figure 3: Scatter plot of the standardised ratio for emergency epilepsy admissions against the standardised ratio for new epilepsy diagnoses.

Conclusions

- Widespread unexplained variation in epilepsy admissions cannot be explained by variation in new epilepsy diagnosis.
- This raises concerns about the equity and accessibility of epilepsy services.
- Further work is needed to investigate the causes of this wide variation. The North-West of England could be a place to target for further work
- Further work on whether CYP with epilepsy managed in the community have access to epilepsy specialist nurses and tertiary neurologists which have been shown to have an impact on unplanned emergency hospital admissions is required.