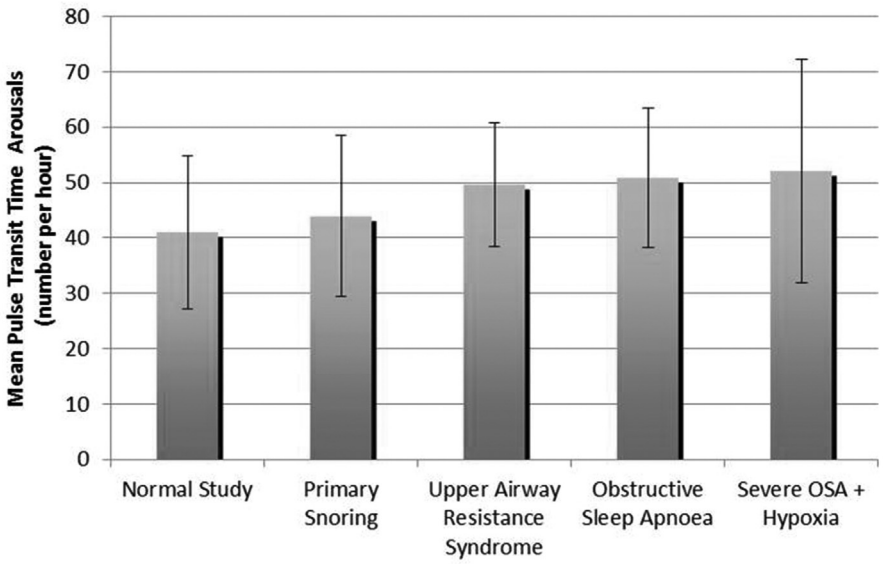

Abstract G399(P) Figure 3 Mean pulse transit time arousals for each outcome category of sleep study (error bars show standard deviation)

between normal/borderline and abnormal oximetry categories (p = < 0.005 for both) and between normal (including primary snoring) and abnormal sleep study categories (p = < 0.005 for both). However, the trends are not discriminatory enough to be used as stand-alone measurements of degree of OSA as there is significant overlap between the categories (p values = > 0.05).

Conclusion PTT is not sufficiently discriminatory if used in isolation for assessment of OSA in children, but is a useful addition when combined with pulse oximetry and other parameters.

REFERENCE

1 Katz ES, Lutz J, Black C, Marcus CL. Pulse transit time as a measure of arousal and respiratory effort in children with sleep-disordered breathing. *Pediatr Res*. 2003;**53**:580–588

G400(P) HOW USEFUL IS RECORDING PREFERRED PLACE OF END OF LIFE CARE AND PLACE OF DEATH AS OUTCOME MEASURE IN PAEDIATRIC PALLIATIVE CARE?

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Aims To evaluate the preferred place for end of life care and place of death as an outcome measure in paediatric palliative care

Methods Medical records of children dying under the care of the Paediatric Palliative Care team from January 2009 to December 2013 were audited.

Results 187 deaths were identified: mean 37.5 deaths per year. Deaths per year increased over the 5 year period (p > 0.05). 53% of deaths were in the 0–4 years age range and 5% were over 18 years. 58% of deaths were non oncology palliative care, 38% oncology palliative care and 5% oncology on active treatment. Oncology deaths on active treatment increased over the 5 year period (p > 0.05). Preferred place for end of life care was recorded in 77% children dying during palliative care. 57% oncology and 33% non oncology patients identified home as their preferred setting for end of life care. 25% non oncology and 12% oncology patients identified hospice as their preferred place of care. Increasing numbers of non oncology families chose home and oncology families chose hospice over the 5 year period. Overall 92% children died in their preferred setting for end of life care. The number of rapid discharges required to achieve preferred place for end of life care increased (p < 0.05). Ten children did not die in the preferred setting for end of life care. In 3 cases the palliative care team was not aware that the patients had been admitted to hospital until after the child had died, three rapid discharges were abandoned due to rapid deterioration. Four children died suddenly. When statistics were broken down by quarter the small numbers of deaths overall resulted in large but not statistically significant swings in the percentage of children achieving death in the preferred setting for end of life care.

Conclusions Recording of preferred setting for end of life care and death in the setting of choice for end of life care is achievable. Small numbers of patients, result in large but not statistically significant swings by quarter. This measure is not appropriate for me intervals of less than a year.

UK Children's Cancer and Leukaemia Group and British Paediatric Haematology Society

G401 LONGITUDINAL ASSESSMENT OF LUNG FUNCTION IN CHILDREN WITH SICKLE CELL DISEASE

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Aims To prospectively undertake longitudinal assessment of lung function in children with sickle cell disease (SCD) and similar aged and ethnic matched controls. Our aim was to test the hypotheses that lung function in SCD children, but not controls would deteriorate with increasing age and the rate of decline would be greater in younger children who are more likely to have suffered acute chest syndrome (ACS) episodes.

Methods Two cohorts of SCD children and age and ethnic matched controls were recruited. Cohort one (47 SCD children and 26 controls) had a median age of 8.8 years at recruitment and were followed for two years. Cohort two (45 SCD children and 26 controls) were recruited at an older age (median age 10.2 years) than cohort one (p = 0.007) and were followed for ten years. Forced expiratory volume in one second (FEV_1), vital capacity (VC), forced expiratory flow between twenty-five and seventy-five% of VC ($FEF_{25–75}$), total lung capacity (TLC) and residual volume (RV) were measured at recruitment and at the end of follow-up.

Results In both groups of SCD children, but in neither control group, lung function declined significantly. The rate of decline was greater in cohort one than cohort two for FEV_1 (p = 0.008), VC (p = 0.001), $FEF_{25–75}$ (p = 0.030), TLC (p = 0.004), and RV (p = 0.043). During follow-up, ACS episodes were more common in cohort one than cohort two (one episode per 1.93 patient/years versus one episode per 12.6 patient/years) p < 0.0001. ACS episodes were the only independent predictor of a greater decline in lung volumes.

Conclusions Lung function deteriorated in SCD children compared to similar aged and ethnic matched controls. The most rapid period of deterioration took place during early childhood when ACS episodes were more common. Our results suggest that treatment strategies to prevent ACS episodes need to be started in young SCD children if they are to be most effective in preventing the decline in lung function.

G402 THE IMPACT OF A STANDARDISED TRANSCRANIAL DOPPLER TRAINING PROGRAMME IN SCREENING CHILDREN WITH SICKLE CELL DISEASE: A EUROPEAN MULTI-CENTRE PERSPECTIVE

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Background Routine use of Transcranial Doppler (TCD) screening is standard management for the prevention of Stroke in children with Sickle Cell Disease (SCD). However, due to a number of factors including the lack of adequately trained TCD operators, less than 50% of children receive this service. The study objectives were to determine the effectiveness of modular TCD training, to improve the quality and standardisation of TCD assessment and thereby facilitate an increase in the number of children screened.

Methods The modular training programme comprised of a two-day course, covering theory and practical aspects of TCD and incorporating significant hands-on instruction. This was followed by local scanning with continuous monitoring and feedback from the training centre in the United Kingdom (UK). Competency evaluations were undertaken at the end of the instructional course and 6–12 months later when a log book of at least 50 scans was completed. Data were compared with that acquired from the same patients in the year prior to the training programme using imaging and/or non-imaging TCD. Statistical analysis was performed using Pearson Chi-Square controlling for possible treatment bias.

Results Data were obtained from 326 patients (male 168 (51.5%); female 158 (48.5%); mean age 7.6 ± 3.5, range 1–17) in the UK, Ireland and Italy. Genotypes were; HbSS 79%, HbSC 19%, HbSbetathalassemia° 1%, HbSbetathalassemia$^+$ 1%. 462 pre-training scans (imaging and/or non-imaging TCD); 134 from the UK, 193 from Ireland and 135 from Italy, and 377 post-training scans were available; 114 from the UK, 167 from Ireland and 43 from Italy. Statistical analysis revealed a significant difference in the STOP distribution between the three centres (C^2 = 53, p < 0.001) prior to training, with no treatment bias (no treatment C^2 = 47, p < 0.001; treatment n = 82, C^2 = 23, p < 0.001). Anomalous technique between centres pre-training included the erroneous use of Doppler angle correction, poor vessel/Doppler angle optimisation and inconsistent STOP velocity thresholds for imaging and non-imaging studies. After training the STOP distribution was similar in the three centres (C^2 = 7.1, p = 0.311; no treatment C^2 = 11, p = 0.074; treatment n = 81, C^2 = 7.8, p = 0.252). The consistent STOP distribution post-training, achieved using either imaging or non-imaging TCD,

Conclusion This is the first modular TCD training programme that has demonstrated efficacy when delivered in different European countries. TCD was either imaging or non-imaging techniques and should facilitate the more widespread.

G403 ASSESSING THE VALUE OF BONE MARROW ASPIRATE AND TREPHINE IN IDENTIFYING METASTATIC INVOLVEMENT IN CHILDREN WITH EWING'S SARCOMA: A RETROSPECTIVE SINGLE CENTRE EXPERIENCE

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Background Bilateral Bone marrow aspirates and trephines are part of the initial staging evaluation of patients with Ewing's sarcoma. However, the utility of performing this invasive investigation in addition to imaging with MRI and Technetium 99 bone scan has not been assessed.

Aim To assess the value of performing bone marrow aspirates and trephines in identifying metastases when compared to imaging, particularly Technitium 99 bone scan.

Methods Retrospective review of 48 children aged 16 and under with Ewing's sarcoma treated in our institution over a 14 year period (August 2000–September 2014).

Results The demographic details of our patients were as follows-we treated 25 males and 23 females (M:F = 1.08:1). 54% of patients were over 10 years old while 12.5% of patients were under 5 years old; the remaining 33.3% were aged between 5 and 10 years. Using imaging alone, 69% had localised disease while 31% had metastatic disease. 81% of patients (n = 39) had bone marrow aspirates and trephines performed, of which 3 were positive for disease; one of these patients had a pelvic primary and the marrow was positive on the left side which was the location of the primary site. 43 patients (90%) had a bone scan, of which 10 were positive for bony metastases. All three patients who had bone marrow positivity also had metastatic