Plenary

P01 A SERVICE EVALUATION OF IMPLEMENTATION OF RCPCH BRAIN PATHWAYS CLINICAL GUIDELINE LINKED TO HEADSMART – BE BRAIN TUMOUR AWARE (HEADSMART). A HEALTH FOUNDATION, CLOSING THE GAP PROJECT

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Aims To evaluate the impact of the HeadSmart Campaign upon symptom interval (SI) for newly diagnosed childhood brain tumours at UK Children's Cancer and Leukaemia Group (CCLG) treatment centres.

Introduction HeadSmart's national awareness campaign (www.headsmart.org.uk) aims to disseminate the RCPCH endorsed Brain Pathways Guideline for referral and imaging of patients with symptoms suggestive of brain tumour.

Methods The SI experienced by children newly diagnosed with brain tumours was determined from January 2011 to December 2012 by HeadSmart Clinical Champions at 18 CCLG treatment centres reporting to an online database as part of a service evaluation under Caldicott guardian permission.

Results Data from 353 children (median 6.7 yr, range 0.02–17.71) is available. The median SI is 7.57 weeks (mean 21.8, range 0 to 435 weeks). The median symptom onset to consultation with a healthcare professional interval is 2.3 weeks (mean 12.9, range 0 to 433 weeks), and the median consultation to diagnosis interval is 2.7 weeks (mean 9.0, range 0 to 156 weeks). Imaging that identified the tumour took place as an outpatient in 28.3%, an inpatient in 43.3% and from the emergency department in 19.5%. 3.1% of children were referred via a "two week wait" cancer referral.

The most frequent symptoms and signs at symptom onset were headache (46%), vomiting (41%), abnormal coordination (12%), abnormal gait (12%), lethargy (12%); and at diagnosis were vomiting (53%), headache (48%), abnormal coordination (26%), abnormal gait (23%), lethargy (21%), and papilloedema (21%).

The medium SI prior to campaign launch was 9.3 weeks, and after launch 6.9 weeks ($p = 0.043$); mean SI during the same period was 22.9 and 21.0 weeks. The median consultation to diagnosis interval was 3 weeks prior to launch; post launch it was 2.3 weeks during the first 6 months, and reduced to 1.0 week between the 7th – 18th month of the campaign ($p = 0.026$). Changes in mean during the same period did not show a reduction trend; mean SI 15.2, 10.3, 13.3 weeks, respectively.

Conclusions Analysis of the SI experienced by UK children before and after the HeadSmart launch suggests that the SI and the consultation to diagnosis interval have reduced. Further data is required to determine whether this reduction is sustained.

P02 SURVEILLANCE STUDY OF GENDER IDENTITY DISORDER IN CHILDREN AND ADOLESCENTS

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Aims The incidence of childhood/adolescent Gender Identity Disorder (GID) is unknown. GID is an important condition where gender identity differs from biological sex. It is associated with significant distress, particularly with puberty, with much controversy internationally over the optimal timing of hormonal treatment. We examine the incidence and clinical presentation in UK and Irish children and adolescents.

Methods STUDY POPULATION: Children and adolescents aged 4–15.9 years in the UK and Republic of Ireland. DESIGN: Joint British Paediatric Surveillance Unit (BPSU) and Child and Adolescent Psychiatry Surveillance System (CAPSS) study. New cases of GID reported by clinicians over a 19-month reporting period (01-Nov-2011 to 01-June-2013) are validated against the authoritative DSM-IV-TR (2000). Exclusions include disorders of sexual differentiation and major psychosis. PRIMARY OUTCOME: Incidence of childhood/adolescent GID, calculated by dividing the number of validated cases by the base population of children/adolescents aged 4–15.9 years. Sources of denominator data: UK Office of National Statistics and the Central Statistics Office in Ireland. STATISTICAL ANALYSIS: Descriptive statistics and comparisons using two-sample t-tests/Mann-Whitney U tests for continuous data and Chi-squared/Fisher's exact tests for categorical data.

Results Preliminary descriptive data from the first nine months' surveillance (n = 80 cases, 42 males) indicate that similar numbers of males and females are affected by this condition. There is a lag of several years between median [range] onset of symptoms (6y [1–14y]) and presentation to Paediatricians or Psychiatrists (13y [4–14y]), with high levels of psychiatric co-morbidity at presentation, particularly depression (n = 15, 19%), Asperger Syndrome/autistic spectrum disorder (ASD) (n = 16, 20%) and previous self-harm (n = 24, 30%).

There appears to be a relationship between pattern of presentation and co-morbidities observed at diagnosis: nearly half of BPSU cases (5/11) have a co-diagnosis of Asperger Syndrome/ASD at diagnosis compared with 16% of CAPSS cases (11/69). Depression and anxiety have only been reported among CAPSS cases. It is unclear whether these discrepancies reflect referral pathways or different diagnostic approaches.

Conclusions We present the first ever population-level data on the clinical features and presentation of childhood/adolescent GID. These data will inform clinical management, including the highly controversial debate around early pubertal suppression in this group.

P03 NOVEL URINE BIOMARKERS FOR MONITORING DISEASE ACTIVITY IN JUVENILE LUPUS NEPHRITIS: A PROSPECTIVE LONGITUDINAL VALIDATION STUDY

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Background Systemic Lupus Erythematosus (JSLE) is a severe autoimmune condition with lupus nephritis (LN) seen more frequently in juvenile disease where up to 80% have renal involvement [1]. The renal biopsy is crucial for diagnosis and classification but has a limited role in monitoring. Current methods of monitoring renal disease activity over time rely on a variety of standard laboratory markers and the use of disease activity tools such as the British Isles Lupus Assessment Group index score (BILAG). Improving methods of monitoring and predicting disease activity may improve the long-term renal outcome.