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

doi:10.1136/archdischild-2013-304107.001

[1]S Wilne, [1]J Liu, [2]L Clough, [2]J Dudley, [5]M Lakhanpaul, [6]C Kennedy, [1]S Lindsell, [4]M Baker, [2]J Trusler, [2]P Carbury, [2]R Grundy, [1]D Walker. *[1]Children's Brain Tumour Research Centre, University of Nottingham, Nottingham, UK; [2]The Brain Tumour Charity, Farnborough, UK; [3]RCPCH, London, UK; [4]RCGP, London, UK; [5]General and Adolescent Paediatrics, University College London, London, UK; [6]Faculty of Medicine, University of Southampton, Southampton, UK*

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

doi:10.1136/archdischild-2013-304107.002

[1]SN Khadr, [2]P Carmichael, [2]V Holt, [3]E Roche, [1]R Viner. *[1]General and Adolescent Paediatrics, UCL Institute of Child Health, London, UK; [2]Gender Identity Development Service, Tavistock and Portman NHS Foundation Trust, London, UK; [3]Department of Paediatrics, National Children's Hospital, Dublin, Ireland*

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

doi:10.1136/archdischild-2013-304107.003

[1,2,3]L Watson, [4]K Tullus, [5]C Pilkington, [6]C Chesters, [4]SD Marks, [6]P Newland, [3]C Jones, [1,7]MB Beresford. *[1]Dept of Womens and Childrens Health, University of Liverpool, Liverpool, UK; [2]Dept of Paediatric Nephrology, Royal Manchester Children's Hospital, Manchester, UK; [3]Dept of Paediatric Nephrology, Alder Hey Children's Hospital, Liverpool, UK; [4]Dept of Paediatric Nephrology, Great Ormond St Hospital, London, UK; [5]Dept of Paediatric Rheumatology, Great Ormond St Hospital, London, UK; [6]Dept of Biochemistry, Alder Hey Children's Hospital, Liverpool, UK; [7]Dept of Paediatric Rheumatology, Alder Hey Children's Hospital, Liverpool, UK*

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.

Aims and methods This prospective longitudinal study aimed to identify whether standard and/or novel biomarkers are useful for monitoring and predicting LN disease activity. Using patients recruited to the UK JSLE study, urine and blood samples were collected during routine clinical reviews. The study had full ethical approval.

Results The JSLE cohort (n = 64), seen at 3 (interquartile range IQR: 2–5) clinical reviews over 364 (182–532) days were aged 14.1 (11.8–15.8) years and 80% female. Active renal episodes (23% total; renal BILAG A/B) had significantly increased concentration of; monocyte chemoattractant protein 1 (MCP1), neutrophil gelatinase associated lipocalin (NGAL), erythrocyte sedimentation rate, anti-double stranded DNA, urine albumin:creatinine ratio (UACR), creatinine, and reduced complement 3 (C3), C4 and lymphocytes. Cross sectional multivariate analysis demonstrated MCP1 and C3 as independent variables ($p < 0.001$) for active renal disease. Longitudinally, MCP1 was an excellent predictor of improved renal disease (area under the curve AUC: 0.81; $p = 0.013$; concentration 343pg/ml, specificity 71%, sensitivity 70%); NGAL was a good predictor of worsened renal disease activity (AUC 0.76; $p = 0.04$; concentration 30ng/ml, specificity 60%, sensitivity 61%). Standard markers could not predict disease activity changes.

Conclusion Novel biomarkers (MCP1, NGAL) are able to predict changes in JSLE related renal disease activity. Biomarker-led monitoring may facilitate earlier intervention to prevent renal damage. The development of point of care biomarker testing is now in progress.

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P04 ADIPOSITY OF HEALTHY, FULL-TERM BREAST-FED AND FORMULA-FED INFANTS: A PROSPECTIVE COHORT STUDY

doi:10.1136/archdischild-2013-304107.004

[1]C Gale, [1]S Jeffries, [1]KM Logan, [1]JRC Parkinson, [1]S Uthaya, [2]G Durighel, [3]EL Thomas, [2]J Bell, [1]N Modi. *[1]Academic Neonatal Medicine, Imperial College London, London, UK; [2]Institute of Clinical Science, Imperial College London, London, UK; [3]MRC Sciences Centre, Imperial College London, London, UK*

Aims Although an association exists between method of feeding in infancy and increased risk of later overweight and obesity, it is unclear whether this represents a causal relationship. One plausible mechanism of action is through alteration in adiposity in infancy. We aimed to compare longitudinal changes in adiposity in healthy, full-term, breast-fed (BF) and formula-fed infants (FF).

Methods Research Ethics Committee and NHS approvals were obtained. With informed maternal consent, healthy, term infants underwent whole body magnetic resonance imaging and hepatic spectroscopy to assess body composition and intrahepatocellular lipid (IHCL) content. Investigations were performed in natural sleep on two occasions, shortly after birth (T1), and between two and three months (T2) in accordance with our previously published protocols. Anthropometric measurements were obtained at both visits. Feeding was categorised according to World Health Organisation definitions. Comparison was made between exclusively or predominantly BF, and exclusively or predominantly FF infants. We used independent sample t-tests to compare body weights and multivariable regression to examine total and regional adipose tissue volumes at T2, with adjustment for baseline adiposity and body weight. Adipose tissue volumes (litres) and IHCL (ratio of lipid to water peak) are presented as mean (95% confidence interval).

Results Eighty-six infants were studied at T1, median [interquartile range] 13 [8–19] days, and 73 at T2, 63 [57–70] days. Of these, 38 infants were wholly or predominantly BF and 26 wholly or predominantly FF at both time points. At T2, while FF infants were heavier (mean, standard deviation: 5.399kg, 0.661kg; FF 5.435kg, 0.68kg); $p = 0.045$), total adiposity was not significantly different (BF 1.516 (1.433, 1.600); FF 1.633 (1.531, 1.735); $p = 0.08$). There were no statistically significant differences in regional adipose tissue volumes or IHCL (BF 2.398 (1.838, 2.958); FF 2.406 (1.708, 3.103); $p = 0.9$).

Conclusions While adiposity does not differ substantially between BF and FF infants by 9 weeks of age, further longitudinal evaluation is required to determine if the trend to greater total adiposity in FF infants is subsequently amplified.

P05 LEARNING FROM THE EXPERTS: UNDERSTANDING CHILDREN'S EXPERIENCES OF BEING NEWLY DIAGNOSED WITH CANCER

doi:10.1136/archdischild-2013-304107.005

[1]JE Mant, [2]A Burke, [2]A Kirby. *[1]Paediatrics, Luton and Dunstable Hospital, Luton, UK; [2]Paediatric Oncology, Addenbrookes Hospital, Cambridge, UK*

Aim Being given a diagnosis of cancer is a significant and highly distressing event for both children and their families. There has been a significant amount of research looking at parents' experiences and communication preferences at the time of diagnosis but little research has been done to explore and understand children's feelings. This qualitative study aims to understand from the child's perspective what it feels like to be told you have cancer with the hope that increased understanding can lead to improved communication and support for children newly diagnosed with cancer.

Methods The study was conducted using qualitative methodology. Children from a UK principle oncology centre were purposefully selected to participate. The children were enrolled within 4 weeks of being diagnosed with cancer and took part in semi-structured interviews conducted using the draw and write technique. The interviews aimed to explore children's experiences around the time of diagnosis. The results were analysed using interpretative phenomenological analysis.

Results Six children, aged 8 – 12 years, with a new diagnosis of cancer were interviewed. Five super-ordinate themes were identified: 1) Initially I felt shocked and scared. 2) Chemo is an awful thing. 3) Please talk to me: the more I know the better I feel. 4) I will accept treatment and quickly get used to it because I know I will get better. 5) My family are vital.

Children say that initially they feel shocked and scared. They continue to feel scared until they understand exactly what will be done to them. Then despite experiencing chemotherapy as an awful event, with information and help from family, they can learn relatively quickly to accept their diagnosis and treatment. However, this acceptance is in the unquestioning belief that the treatment will lead to cure.

Conclusions Children have unique needs at the time of being diagnosed with cancer. In order to minimise suffering clinicians must be prepared to talk to children directly. Children want to know, at the earliest opportunity, what will happen to them and that there is a potential for cure.

P06 BACTERIAL MENINGITIS IN BABIES 0–90 DAYS OF AGE: A UK AND REPUBLIC OF IRELAND PROSPECTIVE STUDY

doi:10.1136/archdischild-2013-304107.006

[1]I Okike, [2]K Henderson, [2]R Blackburn, [2]B Muller-Pebody, [3]M Anthony, [4]N Ninis, [2]A Johnson, [1]P Heath. *[1]Clinical Sciences and Vaccine Institute, St George's, University of London, London, UK; [2]HCAI &AMR, HPA Centre for Infections, London, UK; [3]Neonatalogy, John Radcliffe Hospital, Oxford, UK; [4]Paediatrics, St Mary's Hospital Paddington, London, UK*