

to the needs of children and their parents. Further research is required to explore the views of children and bereaved parents who have experienced deferred consent.

P08

BACKGROUND INCIDENCE TRENDS OF INTUSSUSCEPTION AMONG CHILDREN IN ENGLAND: RETROSPECTIVE ANALYSIS USING HOSPITAL EPISODE STATISTICS AND DATA LINKAGE TO COMPARE HES WITH THE BRITISH PAEDIATRIC SURVEILLANCE UNIT

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Aims To estimate background trends in intussusception admissions prior to the introduction of rotavirus vaccine in the UK. To compare the quality of Hospital Episode Statistics (HES) with intussusception data from the British Paediatric Surveillance Unit (BPSU).

Methods Retrospective analysis of the NHS inpatient HES was carried out to estimate background intussusception trends in the paediatric population in England from 1995 to 2009. Data linkage was performed between HES and previously obtained BPSU data on intussusception among infants from March 2008 to March 2009.

The ICD-10 intussusception codes (K56.1, K38.8) were used to identify cases in HES (1995–2009). Incidence trends were calculated using the Office for National Statistics live births and mid-year population estimates as denominator.

We performed probabilistic data linkage to match HES records with BPSU cases, followed by a manual review to confirm the status of matched (and possibly matched) pairs (2008–2009). Capture-recapture methods allowed assessing the accuracy of HES and completeness of both data sources for intussusception. Validated incidence rates in infants were obtained following data linkage.

Results Of 11,259 intussusception records identified in HES and after excluding 2538 (22.5%) duplicates, 8721 (77.5%) cases were retained for trends analysis. A significant decline in background trends was observed predominantly among infants from 86.0/100,000 in 1997 to 34.0/100,000 in 2009 (60% reduction, $p = 0.001$). Seasonal modelling showed a significant excess of intussusception cases in winter and spring during 1995–2009 ($p = 0.001$, $n = 4957$ infants).

Data linkage between 254 intussusception cases in HES and 190 cases previously obtained via the BPSU (2008–2009) resulted in 163 matched pairs. Completeness of reporting was 85.8% for HES (163/190 BPSU cases) compared to 81.5% for BPSU (163/200 HES cases). The positive predictive value of HES was 78.7% (200/254 confirmed cases). The Lincoln-Petersen estimate yielded a total of 233 intussusception cases (95% CI: 227.4 to 238.8). The estimated annual incidence of intussusception among infants in England increased from 24.2/100,000 (unvalidated) to 28.9/100,000 (validated) (2008–2009).

Conclusions Background intussusception trends have declined among infants in England. The high accuracy and completeness of HES for intussusception highlight the usefulness of routinely collected data in monitoring rotavirus vaccine safety in England.

P09

INITIAL DIAGNOSTIC OUTCOME OF SCREENING FOR CONGENITAL HYPOTHYROIDISM AFTER NEWBORN BLOODSPOT SCREENING: A UK SURVEILLANCE STUDY

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Introduction Primary congenital hypothyroidism (CHT) is due to reduced thyroid hormone production. Oral thyroxine therapy commenced soon after birth improves cognitive development and growth. Despite 30 years of newborn screening for CHT in the UK, its success in identifying babies who require lifelong therapy for CHT remains unclear.

Aim To determine, through UK-wide active surveillance, the number and characteristics of children aged ≤ 5 years diagnosed annually with CHT, detected by screening or after clinical manifestations, and to describe clinical management.

Results During 13 months of surveillance, 704 children with positive screening results were reported by screening laboratories. Local clinicians completed 643 questionnaires (response rate = 91%). An additional 20 children aged < 5 years were notified who were not identified through screening, including three diagnosed prior to screening (2 family history, 1 unwell) and 17 with negative screening tests (10 preterm, 5 unwell, 2 Down's syndrome); screening results were untraceable for 2 children. Of 643 screen positive children, 260 (40%) were boys, 130 (20%) were < 37 weeks gestation and most were of white or Asian ethnicity (379[59%] and 133[21%] respectively).

Investigations carried out soon after referral demonstrated serum TSH > 40 mU/l in 365; in an additional 43 children an abnormal thyroid scan result was associated with serum TSH ≤ 40 mU/l. Based on the reported initial investigations for 643 children, an expert panel assigned a diagnosis of CHT in 410, excluded CHT in 120 and considered 113 had probable/possible CHT requiring follow-up. The local clinicians commenced 485 children on oral thyroxine, 401 of whom were assigned as having definite CHT by the expert panel. During 12 months of follow up after diagnosis, eleven children died of causes unrelated to CHT.

Conclusion Our findings suggest that the predictive value of a positive screening test is at most 81% (523/643) assuming CHT is confirmed in those with possible CHT as an initial diagnosis. Our data suggest that permanent CHT cannot be confirmed at initial diagnostic investigation in a significant proportion of screen positive babies. Follow up of this cohort is continuing to determine outcome by two years of age.

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PLANNING AND IMPLEMENTING SERVICE CHANGE IN CHILDREN'S COMMUNITY NURSING

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