

clinicians were not aware of any specific guidance for CYP with EBNDIDs.

Due to significant restriction to direct face-to-face clinician contacts and redeployment of staff from Community Child Health (CCH) services, many core clinical activities became limited and most new referrals were kept on hold except for urgent services. CCH teams experienced significantly increased waiting lists. During the pandemic, many CCH services increased their telemedicine capacity exponentially. Telephone consultation was the commonest method of remote contact with patients (98%).

Preliminary report has confirmed that the Black, Asian and Minority Ethnic staff and patient communities have been disproportionately affected by morbidity and mortality from COVID-19 infection. Parents and carers were encouraged to make more effective use of online resources including contacting NHS 111 or the GP and only if necessary to going the nearest Emergency Unit.

A wide array of online resources designed for CYP with EBNDID and their families including webinars, online videos, sleep tips, post-diagnosis support etc have become more popular.

Conclusions The pandemic has significantly impacted on routine service provision for new referrals to CCH clinics and for the existing patients. Discontinuation of medical treatment necessitated by health service disruptions should be avoided during the future pandemic lockdowns to avoid serious detrimental effects of escalating challenging behaviour among CYP with EBNDID, stressful parent-child and intra-sibling relationships and exacerbation of family disruptions.

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IMPROVING PATIENT FEEDBACK IN THE CHILDREN'S EMERGENCY DEPARTMENT – PART 1: IMPROVING THE QUALITY AND QUANTITY OF FEEDBACK GIVEN

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Background Listening to and acting upon feedback from patients and their parents and carers are vital dimensions of the delivery and design of excellent emergency care for sick and injured children. However, a nationwide staff survey in 2019 found that just 58.2% of staff in acute hospitals reported that feedback from service users was used to make informed decisions in their department. This study is the first part of a wider programme of work to increase patient and parent engagement in the Children's Emergency Department (CED).

Objectives To understand how patients and their parents/carers want to give feedback on their experiences in the CED, to inform the future development of a dedicated CED patient feedback tool.

Methods A questionnaire was designed in digital and paper formats with input from the hospital patient experience team. The questionnaire consisted of multiple choice and free-text questions. The paper questionnaire was offered to patients attending the CED over a six day period, and a poster advertising a Quick Response code enabling patients and parents to give feedback via a digital questionnaire was placed on the waiting room wall for fourteen days.

Results 51 responses (40 paper responses and 11 electronic) were obtained. 15.7% (8/51) of responses were completed by

Abstract 266 Table 1 How would patients/parents like to give feedback on their experiences in the Children's Emergency Department?

On a phone/mobile device	32/51	62.7%
By email at home	18/51	35.3%
Writing on paper	9/51	17.6%
Via social media	4/51	7.8%
Drawing on paper	3/51	5.9%
Talking to someone	3/51	5.9%

patients themselves, and 84.3% (43/51) were completed an accompanying parent or guardian.

54.9% (28/51) of responses related to pre-school age patients, 21.6% (11/51) related to primary school age patients, and 23.5% (12/51) related to secondary school aged children.

More than half of patients/parents (26/51) reported never having given feedback on hospital services in the past, and 33.3% (17/51) reported that they had previously given feedback. 15.7% (8/51) patients/parents were not sure whether they had given feedback before.

35.2% (18/51) of respondents reported that they did not know how to give feedback on their experiences in CED.

When asked how they would like to feed back on their experiences in the Children's ED, a clear majority of respondents (62.7%, 32/51) stated that they would like to give feedback using a phone/mobile device, and more than a third (18/51) wanted to use email. See table 1 below.

Conclusions This study indicates that there is scope to increase the number of patients and parents who give feedback on their experiences in the Children's Emergency Department, and clearly demonstrates the importance of access to digital methods and raising awareness to enable this. Combining this with the staff survey results in the second part of our study, we have designed a new tool for obtaining patient feedback. This tool will be piloted, and further work will be undertaken to evaluate whether improvements in the quantity and quality of patient feedback are achieved.

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CHALLENGES IN THE DIAGNOSIS OF COMMON NEONATAL CONDITIONS IN RESOURCE-LIMITED SETTINGS

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Background Accurate and timely diagnosis and management of common neonatal conditions is crucial for reducing preventable neonatal deaths. In low- and middle-income countries, there is sparse information on how neonatal diagnoses are made including use of clinical guidelines and access to appropriate laboratory and radiology services. An improved understanding of the diagnostic pathways for neonates in low-resource settings will help to inform future interventions and the development of best practice guidelines.

Objectives To identify challenges in neonatal diagnosis in resource-limited settings by describing diagnostic pathways for common neonatal conditions.

Methods Between August 2018 and April 2019, standard forms developed by the Neonatal Nutrition Network (NeoNuNet)* collaborators were completed by clinicians for all infants

admitted to seven neonatal units in Nigeria and Kenya and diagnosed with birth asphyxia, respiratory disorders, abdominal conditions and suspected sepsis. Data was captured in REDCap** and the frequency of criteria used for each diagnosis in each NNU was analysed using SPSS.

Results 2852 neonates were included. Mean gestational age was 36 weeks (SD 4.27) and birthweight 2.42 kg (SD 0.94). 473 (16.6%) newborns died during admission and mortality was highest amongst very-low birth weight (<1500 g) infants (46.1%) and very preterm (<32 weeks' gestation) infants (41.3%). 1230 (43.1%) newborns were diagnosed with suspected sepsis, 874 (30.6%) with respiratory conditions, 587 (20.6%) with birth asphyxia and 71 (2.5%) with abdominal conditions. For all diagnoses, the most frequently used diagnostic criteria were clinical, whilst laboratory and radiological criteria were rarely used. In addition, there was marked variation between the NNUs, including within each country, in the use of many of the criteria for each diagnosis. Using suspected neonatal sepsis as an example, temperature instability was the most used clinical criteria (1036/1230 (84.2%) infants; varied from 72% to 93% in each NNU) whereas hypotension was rarely used (1.8% infants; 0% to 9%). For laboratory criteria, abnormal white cell count was the most commonly used (22.7% infants; 8% to 37%) but all were used infrequently: raised C-reactive (9.4% infants; 0% to 27%) and presence of a pathogen in blood (16.3% infants; 1% to 74%) and cerebrospinal fluid (1.9% infants; 0% to 13%).

Conclusions Clinicians adopted a syndromic approach when making diagnoses but with marked variation in use of clinical criteria between NNUs. Laboratory and radiology technologies were mostly either unavailable or unaffordable. As neonatal conditions often have non-specific and overlapping clinical features, this has implications for management such as overuse of broad-spectrum antibiotics for suspected sepsis. There is an urgent need to facilitate standardisation of diagnostic pathways based on World Health Organisation and national diagnostic guidelines to optimise clinical care. In addition, investment in affordable, sustainable diagnostics suitable for low-resource settings, including point-of-care tests, is a priority. Standardisation of diagnostic pathways would also facilitate comparing disease burdens and outcomes between NNUs as a basis for research to improve neonatal outcomes.

* <https://www.project-redcap.org/>

** <https://www.lstmed.ac.uk/nnu>

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UNUSUAL CAUSE OF NEONATAL INTUSSUSCEPTION: THE CLUE WAS POPPING OUT OF THE EARS!

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Background Infantile myofibromatosis (IM) is a rare benign tumour of infancy. Most cases of infantile myofibromatosis are believed to occur spontaneously and without a known family history of the disorder.

Objectives The objective of this case report is to highlight this rare disorder and its unusual presentation in neonatal period.

Methods A female term baby was born through an uneventful delivery with birth weight of 3.6 kg and did not need any neonatal resuscitation. Antenatal history was unremarkable except for high maternal BMI. There was no history of consanguinity. There was history of sarcoidosis in Dad.

Baby was noted to have bilious vomiting at 12 hours of life. On examination the observations were stable. There was no dysmorphism, but a fleshy pink peanut sized mass was noted arising from the left auditory canal completely occluding the external auditory meatus and a small soft mass on the pinna. Her abdomen was soft with no obvious distension; bowel sounds were hyperactive. The anal opening was patent. There was fresh blood in the nappy. There was minimal clear nasogastric aspirate and there were flecks of green meconium in the aspirate on gastric washout with saline. The abdominal x ray showed prominent gaseous bowel loops with paucity of gas in the rectum. Rest of the general and systemic examination was unremarkable. She was kept nil by mouth with nasogastric tube on free drainage and was commenced on intravenous antibiotics after screening for sepsis. The baby was transferred to the tertiary center for urgent surgical evaluation and management in view of the bilious vomiting.

Results At the tertiary center, contrast studies confirmed Malrotation. Laparotomy showed malrotation with ileocolic intussusception. Multiple nodules found in gut lining and masses noted adjacent to the ovaries bilaterally. Further imaging – whole body MRI/CT chest and abdomen/pelvis/Echocardiogram showed multiple lesions involving various organs. Histopathology and immunohistochemistry confirmed myofibromatosis. Currently this child is being treated with chemotherapy.

Conclusions Our case presented with unusual findings which had a common link. Infantile myofibromas can present with solitary or multiple nodules (firm flesh coloured to pink) and are often present at birth. At first the isolated mass in the ear canal and the bilious vomiting were thought to be separate problems. However as this case was subsequently investigated we learnt that the visceral myofibromas were responsible for the intussusception.

This form of infantile myofibromatosis can cause severe, life-threatening complications depending upon the location of the lesion and the specific organs involved. MRI and ultrasounds are useful adjuncts to gain more information about the extent of these tumours however, histopathology remains the gold standard for the diagnosis of this condition. In the majority of cases, which lack visceral involvement, prognosis is excellent and spontaneous regression is often observed. On the other hand, the presence of visceral lesions is associated with a significantly poor outcomes in the absence of therapy.

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THE DEVELOPMENT OF A PAEDIATRIC EARLY WARNING SCORE SYSTEM (PEWS) FOR MYANMAR; THE IMPACT ON CLINICAL OBSERVATIONS AND ESCALATION OF CARE

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Background The identification of the most unwell children in hospital, and the escalation of their care, is globally challenging, especially in resource-limited settings.

Objectives A Myanmar/UK working group (WG) has developed Paediatric/Neonatal Early Warning Scores and an escalation policy designed for children of all ages in Myanmar hospitals. We present here early data on the impact of a pilot project, to be followed in March 2021 by a full 4-month dataset following implementation in different settings.

Methods Review and design phase