Results In phase one, 61% of the eligible babies were included in the study; 86.2% of the babies included were born after 24+0 weeks GA, with a mean GA of 25+3 weeks and a mean birth weight of 805 grams; 79.3% babies were discharged home on oxygen. 22.3% babies showed moderate to severe developmental delay.

The analysis of the parents' interviews identified two key themes: 'Emotions' (subthemes: 'The emotions related to the preterm birth – a rollercoaster', 'The post-traumatic stress syndrome', 'The overprotective parent') and 'Here and now' (subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early', 'The value of the follow up').

The onset of preterm labour marked the beginning of a different experience. The quality of this experience impacted on the bonding and relationship between baby and parents, and the relationship between parents and HCPs. Follow up offered re-assurance.

The analysis of the health professional's interviews identified two key themes: 'Communication' (subthemes: 'The Journey', 'The multi-disciplinary team post discharge') and 'The Child Not Brought' (subthemes: 'The impact on the baby', 'The NHS point of view', 'Why do parents not attend?').

Health professionals described the birth and follow up of an extremely preterm baby as a journey. The continuity of care and the good communication contributed to improve this journey. Due to the complexity of the team involved in the follow up of the extremely preterm baby, communication may suffer at different levels.

Conclusions NICE recommends follow up of babies born preterm to school age, however there is no established referral pathway into the paediatric services. Parents value continuity of care, which may be lacking if there is no clear transition process between the neonatal and paediatric teams. Ensuring a smooth transition at every level by designing a clear pathway for the neonatal follow up of extremely preterm babies and the transition to the paediatric services may improve the follow up process, parents' engagement with the system and their babies' outcomes.

Paediatric Critical Care Society

1093 PIMS-TS REFERRALS TO PAEDIATRIC CRITICAL CARE TRANSPORT TEAM FOR WEST MIDLANDS REGION DURING JANUARY -FEBRUARY 2021

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Background Paediatric inflammatory, multisystem syndrome temporally associated with COVID-19 (PIMS-TS) is a novel condition that was first reported in April 2020. It has been shown to be associated with the community prevalence of COVID-19 infection. Kids Intensive care and Decision Support (KIDS) is a collaborative Paediatric Intensive Care Transport Service for the West Midlands region and received increased referrals for PIMS-TS patients from the beginning of January 2021.

Objectives Undertake a descriptive study of the clinical and demographic characteristics of PIMS-TS patients referred to KIDS transport team during January -February 2021.

Methods 21 patients diagnosed with PIMS-TS were referred to KIDS service during the period- 1st January to 28th February 2021. All the patients were discussed with the PIMS-TS MDT for confirmation of diagnosis. We performed a retrospective review of transfer records for these patients and collected various clinical and demographic characteristics. These included age, sex, comorbidities, symptoms, COVID-19 exposure history, electrocardiogram (ECG) and echocardiography findings, cardiovascular and respiratory support, and immunomodulatory treatment received.

Results The median age for referred patients was 10 years (minimum 39 months, maximum 14 years 10 months). The male to female ratio was 13:8. Two patients had associated comorbidities, rest of the 19 were fit and well. 14 (66%) patients had COVID-19 exposure, with either previous COVID-19 positive result (9/21) or a history of COVID contact (5/21). For the patients with COVID-19 exposure, the median duration for PIMS-TS symptoms from exposure was 4.5 weeks. Fever was the commonest symptom, followed by rash and abdominal pain. These are summarised in table 1. Echocardiography was performed at referring hospital in 13 patients, out of which 6 showed poor cardiac function. 16 patients had an ECG done, of which 6 were abnormal. 19 (90%) patients were hypotensive at referral, of which 14 (67%) needed inotropic support and transfer to Paediatric Intensive Care Unit (PICU). 5 patients required respiratory support, 1 needing ventilation, 1 needing non-invasive ventilation (BiPAP) and 3 needing face mask oxygen. 16 (76%) patients received immunomodulatory therapy, either immunoglobulins or methylprednisolone or both at referring hospital. 2 patients were re-referred with hypotension concerns after being discharged from PICU. None of them required PICU readmission.

Abstract 1093 Table 1

Symptoms	Number	Percentage
Fever	21	100
Rash	14	66
Abdominal pain	13	62
Mucocutaneous symptoms	9	43
Conjunctivitis	8	38
Headache	7	33
Sore throat	3	14
Lymphadenopathy	2	10
Loss of smell	1	5
Syncope	1	5
Confusion	1	5

Conclusions There was an increase in PIMS-TS referrals and transfers to PICU during January -February 2021. This increased activity follows the second peak of COVID-19 infection. The patients had a wide variety of symptoms, with fever, rash and abdominal pain being the commonest. There was male predominance, and most of the patients were in the 10–15 years age group. Most of the affected children were previously fit and well, with no comorbidities. Almost two-thirds of the patients had previous

COVID-19 exposure. Most patients were hypotensive at referral, and 67% needed transfer to PICU for inotropic support.

British Association of General Paediatrics

1095

POPULATION BASED SCREENING METHODS IN BILIARY ATRESIA – A SYSTEMATIC REVIEW AND META-ANALYSIS

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Background Biliary Atresia (BA) is the leading cause of new-born cholestasis and the foremost reason for liver cirrhosis and liver transplantation in the paediatric population. The clinical course of BA can be improved with a Kasai portoenterostomy; however, this is time sensitive and delays in BA detection and treatment, with poor native liver survival, have been reported across paediatric hepatology centres worldwide.

The nature and clinical course of BA indicates a need for effective new-born screening. There is a clear definition of the illness, improved clinical outcomes from early recognition and potential cost savings. However, there is no consensus on the most effective method of population-based screening for the condition.

Objectives We aimed to systematically review and meta-analyse the methods of population-based screening for BA.

Methods We searched 11 databases between January 1 1975 and January 4 2021, identifying 5377 relevant titles. Studies exploring the use of a population screening tool to identify BA were included. Outcomes included sensitivity and specificity in screening for BA, age and time to Kasai, associated morbidity and mortality, and overall cost-effectiveness of screening. All studies underwent independent review by 2 trained reviewers, who extracted study data and assessed the risk of bias using the Newcastle Ottawa tool.

Results Twenty-four studies were identified, that included 2697 BA infants. Five methods of population-based screening for BA were present (number of papers): stool colour charts (SCC) (12), conjugated bilirubin measurements (4), assessments of stool light saturation (2), measurements of urinary sulphated bile acids (2) and assessment of bile acids in blood spots (4).

In a meta-analysis, conjugated bilirubin measurements were the most sensitive and specific in detecting BA, with an average sensitivity and specificity of 100.0% and 99.2% respectively. This was followed by urinary sulphated bile acid measurements (100.0%, 99.5%), SCC (88.7%, 99.9%), stool colour saturations (100.0%, 90.1%) and bile acid blood spot measurements (80.3%, 83.7%). Across 5 studies, the use of SCC was observed to reduce the age of subsequent Kasai to approximately 60 days, compared to 36 days for conjugated bilirubin measurements. The use of SCC and conjugated bilirubin was associated with improved overall and transplant free survival. Finally, the use of SCC was considerably more cost-effective than conjugated bilirubin measurements.

Conclusions Both SCC and conjugated bilirubin measurements are the most researched methods of population-based BA

screening. Conjugated bilirubin measurements have improved sensitivity and specificity in detecting BA. However, its use is expensive and considered invasive. SCC appear to not provide acceptable improvements in the age of Kasai. Further research into the practicality of conjugated bilirubin measurements, as well as alternative methods of population-based screening for BA, are required.

British Academy of Childhood Disability

1096

MODERN ILLNESS OR A THING OF THE PAST? SURVEILLANCE STUDY OF CHILDHOOD/ADOLESCENT SYDENHAM'S CHOREA IN THE UK AND THE REPUBLIC OF IRELAND

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Background Sydenham's chorea (SC) is a neuropsychiatric condition largely affecting children and adolescents, associated with prior group A streptococcal infection. SC is characterised by purposeless, involuntary, non-stereotypical movements of the trunk or extremities (chorea), often associated with muscle weakness and emotional and behavioural symptoms. Symptoms may range from mild to severe and last for two years or more. Although SC is considered a 'rare disease', such paediatric conditions may in fact have greater impact on families, who may become more isolated, lack information and experience more diagnostic delays. To date there have been no prior UK prospective surveillance studies to capture current incidence or to study presentation, management or outcomes. Working with partners including the Sydenham's Chorea Association, we designed a surveillance study to be carried out through the British Paediatric Surveillance Unit (BPSU).

Objectives Our main objective was to conduct the first prospective surveillance study of SC in the UK and ROI, and describe the current paediatric service-related incidence, presentation and management of SC in children and young people aged 0–16.

Methods Using standard BPSU surveillance methodology, clinicians notified the BPSU when they saw a case meeting our inclusion criteria (new case of suspected or clinically confirmed SC in those aged 0–16). Clinicians were then contacted by the research team to complete a questionnaire on clinical presentation, investigation, management, and functional impairment. The case-reporting period lasted for 24 months from December 2018 to December 2020.

Results Over a 24 month period, 72 reports were made via BPSU, of which 40 were eligible cases of suspected or confirmed SC. The remainder were ineligible, duplicates, or did not have returned questionnaires from clinicians. The mean age of cases was 9 years, and 60% were female. The majority (65%) presented with 'moderate' severity of chorea. The most common neurological presenting features (apart from chorea) were loss of fine motor skills, gait disturbance, and dysarthria. Over 75% also presented with emotional and/or behavioural symptoms. Almost all cases had evidence of prior