Conclusions We have instituted a series of measures to increase awareness of infection and sepsis in Trisomy 21, and to reduce the risk of serious bacterial infection. This is in direct response to local data on the causes of mortality in Trisomy 21 in our centre. Whilst it is too early to assess the results of the implemented measures, our experience shows that a multifaceted, multi-departmental approach to reducing risk of mortality can be implemented.

G268

THE JAMES LIND ALLIANCE AND CYSTIC FIBROSIS: A JOURNEY TOWARDS CO-PRODUCTION OF RESEARCH

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Cystic Fibrosis (CF) is the commonest life limiting inherited condition in the UK, affecting 3895 children. Children with CF undertake burdensome, time-consuming treatment, much of which is not evidence-based. Questions for clinical research should reflect patient and clinician priorities because both the number of potential participants and funding are limited.

Aims We describe our work over a 4 year period to engage the CF community in prioritisation and co-production of clinical research.

Methods In 2016–17 we undertook a James Lind Alliance (JLA) Priority Setting Partnership (PSP) to find the top 10 priorities for clinical research in CF. Through a series of surveys and workshops these were agreed in conjunction with the global CF community. In 2018–2019 we undertook further global surveys to explore 4 of the top 10 questions in more depth (treatment burden, gastrointestinal symptoms, adherence and exercise in place of some airway clearance). To avoid cross-infection and increase global reach, we adapted JLA methodology to use video conferencing and social media.

Results During the past four years we have gathered opinions from 3729 respondents across six continents. Our youngest respondents were six years old and the median age of respondents with CF (answering directly or by proxy) was 15 years. On completion we disseminated the top 10 questions widely and worked to raise awareness with research funders such as the NIHR. This has resulted in two NIHR themed calls, featuring many of the JLA CF top 10 questions.

Conclusions Encouraging patient participation, including children, in all stages of evidence-based medicine is vital to ensure clinical research is of good quality and relevant to patient needs.

G269

CHAMPIONING THE EX-PRETERM CHILD AT SCHOOL

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Aims Children born prematurely are more likely to experience health, educational and social difficulties compared to matched

term peers. Educational professionals lack relevant knowledge and feel unprepared to support them.

This project evaluates local Special Educational Needs Co-ordinators (SENCOs) existing knowledge; develops and delivers a teaching package, and evaluates the effectiveness of this resource.

Method

- Initial survey developed and sent to all local primary school SENCOs.
- Teaching package developed.
- Teaching revised based on SENCOs and educational psychologist focus group feedback.
- Prematurity teaching package delivered to the regional Newly Qualified Teachers training.
- Post-teaching survey distributed and analysed.

Results

- 27% (22/77) of SENCOs completed the initial survey.
- 86% reported little/no previous training.
- 86% reported limited/no knowledge of the education and social effects.
- 67% reported school had no process for routinely identifying ex-preterms.
- Qualitative data, in response to ‘improving health and education working’:
- 12/33 responses requested ‘training about prematurity effects’ (95% felt face to face with/without written format would be optimal).
- The final teaching package was delivered to 37 teachers.
- Post-teaching survey showed an improvement in perceived: educational difficulties – 28/37 rated their knowledge after as good/excellent compared to 5/37 before social difficulties – 30/37 rating their knowledge after as good/excellent compared to 5/37 before 95% felt the teaching was ‘useful’/‘very useful’.
- 100% reported it would change their future approach. The most common thematic responses included ‘identifying’, ‘asking parents’ and ‘providing support’.
- 95% reported preference for face-to-face training over electronic. ‘Questions’, ‘explanations’ and ‘engaging’ were the most common qualitative themes.
- Feasibility to attend training was variable. 54% reported ‘easy’/‘very easy’, 38% ‘difficult’/‘very difficult’ and 8% left unanswered.

Conclusion The results of the SENCOs previous training and knowledge of prematurity survey are similar to national research and demonstrated a local training need.¹

The teaching package was positively received and produced a perceived improvement in knowledge with intended change to future practice to the benefit of local children born prematurely. Study limitations of small numbers and subjective assessment acknowledged and considered for future work.

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G270

DQ TYPING FOR DOWN SYNDROME SHOULD BE PART OF ROUTINE SURVEILLANCE

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Aims Down Syndrome (DS) is associated with increased prevalence of coeliac disease (CD). Recent meta-analysis estimates prevalence at 5.8%.¹ The DS Medical Interest Group (DSMIG), does not recommend routine screening, despite guidance from the European Society of Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN).² HLA-DQ haplotyping for CD has been offered for the last 3 years.³

Method Children with DS identified from Support Needs System (SNS). In 2016, families were invited for HLA DQ haplotyping for DQ2.2 2.5& 8 (and coeliac serology). Subsequently, families invited though discussions in clinic. Children with positive typing are offered coeliac serology every 3 years (or sooner if symptomatic).

Results 35 (17 female/18 male) DS children were identified. (1 child excluded as already diagnosed). 28 (76%) children have been tested. 12 (39%) had negative haplotypes, excluding them from life-long screening. 16 (57%), tested positive (table 1). Mean age at testing was 7 years.

Abstract G270 Table 1 Haplotypes subtypes

	Male	Female
DQ2.5 (all heterozygous)	5	3
DQ8	1	1
DQ2.2	2	4

5 (31%) had positive coeliac serology. Of these, 3 (60%) had CD, one from each haplotype. 2 had positive serology at initial screening with positive biopsies and 1 diagnosed when rescreened. All were clinically asymptomatic. The other 2 were both DQ2.5: 1 had negative biopsy for CD but had gastritis and 1 refused biopsy. Both are being clinically monitored.

Conclusions Prevalence of CD in DS in this area is currently 11% using HLA-DQ haplotyping and 3 yearly screening. All were asymptomatic at diagnosis and all successfully started on to gluten-free diet. DQ typing is effective in excluding DS children from ongoing screening.¹⁻³ Positive haplotyping is effective in educating parents about potential CD and risk stratification.⁴⁻⁵ Three yearly coeliac serology will be performed alongside annual thyroid function tests.

DQ typing can be performed at the earliest opportunity in any child prior to gluten exposure and should be a standard of care in the UK. It reduces the burden of testing for the child and the financial cost of repeated serology when symptomatic as CD is very unlikely.

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G272

INTENSIVE CARE ADMISSIONS IN CHILDREN WITH DOWN SYNDROME: TRENDS IN INCIDENCE AND OUTCOME

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Purpose In the first three years of life approximately 50% of children with Down Syndrome require hospitalisation. We aimed to investigate the epidemiology of admissions to Paediatric Intensive Care Units (PICU) in the UK for those with Down Syndrome, and to explore the impact of cardiac disease on admission.

Methods We obtained demographic and clinical data from PICA Net, the UK national audit database, on all children admitted to PICU who had a recorded diagnosis Down Syndrome. Patients were categorised as either cardiac or non-cardiac depending on their primary admission diagnosis. We used data from the Down National Down Syndrome Cytogenetic Register to calculate the proportion of children born with Down Syndrome who were admitted to PICU.

Results Our dataset included 2791 patients with 4561 admissions to PICU. Most patients had one admission to PICU, although there was an increasing trend for readmissions. Overall PICU mortality was 4.7% in this cohort. Over the study period mortality did not significantly change. A quarter of children born with Down Syndrome were admitted to a PICU by the age of 17 months (95% CI 13 – 24 months). Half of the admissions were due to cardiac disease.

Conclusions These data will inform future planning of PICU services and counselling of parents of new-borns with Down Syndrome. If current trends continue, there will be increasing numbers of repeat admissions of children with Down Syndrome presenting with both cardiac and non-cardiac disease.

G273

EFFICACY OF NUTRITIONAL REHABILITATION CENTRE INTERVENTIONS IN TREATMENT OF SEVERE ACUTE MALNUTRITION: A ONE YEAR LONGITUDINAL HOSPITAL BASED STUDY

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Aim Primary objective: Evaluate the effect of nutritional interventional measures of Nutritional rehabilitation centre(NRC) in promoting the nutritional status and growth of SAM children.

Secondary objectives:

- Follow-up of the study group after discharge to check for compliance of NRC interventions among beneficiaries.
- Factors responsible for compliance/noncompliance of interventions of NRC on follow up of admitted children.

Methods

Inclusion Criteria: Age: 6–60 months

Exclusion Criteria: Secondary malnutrition due to systemic illness or chronic infection

Management was based on 3 parameters

- Medical complications