required hospitalisation. Almost half of the parents self-funded certain services although this may have been influenced by the international pandemic with restricted access to healthcare. These data will help inform healthcare service development and service provision for children with DS. Monitoring these issues over time will enhance our understanding of any underlying problems and improve the care we provide for children with Down syndrome and their families.

British Paediatric Respiratory Society

1370

IS THE LIVERPOOL RESPIRATORY SYMPTOM QUESTIONNAIRE (LRSQ) AN ACCEPTABLE TOOL TO USE IN LONGITUDINAL COHORT STUDIES?

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Background The Liverpool Respiratory Symptom Questionnaire (LRSQ) is a validated tool for evaluating the prevalence of common paediatric respiratory symptoms amongst preschool children. The questionnaire also evaluates the quality of life for children, and their parents. The LRSQ was designed as an outcome measure for epidemiological and trial purposes, and can also be used to differentiate between children with and without active respiratory disease. To date, the LRSQ has not been validated for use in longitudinal cohort studies. The Liverpool Respiratory Birth Cohort Study (LRBCS) has used the LRSQ longitudinally, in order to identify the main determinants of poor respiratory health in preschool children over time. The content validity of the LRSQ was approved by respiratory paediatricians, as part of the questionnaire's original validation. Now, data from the LRBCS (about the questionnaire's internal consistency) may be able to support the use of the LRSQ in future longitudinal cohort studies.

Objectives To validate the LRSQ as a tool, which is suitable for use in longitudinal studies of preschool children.

Methods 689 infants were enrolled onto the LRBCS between 2013 and 2014. From 4-months-old to 58-months-old, the infants' parents completed the LRSQ via an online platform. This provided data about each child's respiratory health, in eight separate domains, at up to ten six-monthly 'timepoints'. The internal consistency of each of the questionnaire's eight domains was measured with Cronbach's alpha analysis – using all relevant responses from the entire dataset.

Results Of the LRSQ's eight domains, four showed excellent internal consistency – as indicated by an alpha score of ≥ 0.9 . The other four domains displayed good internal consistency – as indicated by an alpha score of ≥ 0.8 . By excluding one outlying survey 'timepoint', six domains have excellent internal consistency and two have good internal consistency.

Conclusions Based upon data from ten 'timepoints' over the first five years of childhood, the LRSQ displays a good to excellent level of internal consistency. This property proves that the LRSQ can detect changes in respiratory symptoms

over time, in this particular cohort of preschool children. Further external validation is required, using independent cohorts of preschool children.

Paediatric Critical Care Society

1371

USING A PATIENT REPORTED EXPERIENCE MEASURE (PREM) TO ASSESS THE EXPERIENCE OF CARERS IN PAEDIATRIC INTENSIVE CARE DURING THE COVID-19 PANDEMIC

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Background In April 2020, in response to the emerging COVID-19 pandemic, NHS England recommended limiting visiting to hospital inpatients, with resultant changes to our hospital policy of open visiting limiting visits to a single carer. In addition, changes to the way healthcare professionals interacted with carers had to be implemented, such as remote meetings, use of personal and protective equipment and social distancing.

Objectives Our objective was to understand the impact of these changes on carers of children requiring intensive care during the Pandemic.

Methods A patient reported experience measure (PREM) focusing on experiences of attending the hospital and the impact of the necessary changes was developed by clinicians, family liaison nurses and the PREM team at our institution. The PREM was distributed to carers whose child was either a planned or emergency admission to the Paediatric, Neonatal or Cardiac intensive care units between December 2020 and March 2021. Quantitative and thematic analysis of responses was undertaken.

Results To date, 80 PREMs have been given to carers and 67 completed questionnaires have been received (76% response rate). Overall levels of satisfaction were very high, with 94% reporting that they were very or mostly satisfied with the intensive care team and the service they provided. Nearly two-thirds of the carers were concerned about catching COVID whilst on the intensive care unit but this decreased to 43% for other public areas of the hospital, such as the cafeteria.

All carers understood the need for them to wear a mask but only 65% agreed that staff were able to interpret and respond appropriately to their emotions when they were wearing one. One third of respondents reported that they did not get the emotional support they needed from family or friends. Some carers found the restricted visiting policy challenging, with 24% reporting that it was not acceptable that the sole carer permitted at the bedside could not change as needed. This was supported by the qualitative comments, which indicated that whilst parents understood the rationale for the one carer policy, it caused additional distress.

Loneliness and lack of physical contact were identified by parents as particularly stressful, together with the need to cope alone with complex information. Carers described being 'fully alone' without their partners, which affected the mental

health of both parents and resulted in feelings of despair and confusion.

Conclusions Our intensive care is one of the largest paediatric units in the UK and during the pandemic we increased our capacity to accommodate intensive care patients from other paediatric units that reconfigured to treat adult patients. During the pandemic, our usual approach to carer support was challenged by visiting and communication restrictions, the impact of which may have long-term consequences. Despite these challenges, we were able to sensitively provide the high standards of care expected by patients and their families.

Quality Improvement and Patient Safety

1372 PAPERLITE: ELECTRONIC DOCUMENTATION FOR TRANSITIONAL CARE (NTC) IN A TERTIARY NEONATAL UNIT IN LONDON, UK

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Background Electronic documentation (Paperlite) was introduced at The Royal London Hospital's Neonatal Transitional Care Department in November 2020. All documentation pertaining to neonates under the care of paediatricians transitioned from handwritten patient notes to electronic entries used across Barts Health NHS Trust.

Objectives Prior to Paperlite, all documentation was handwritten which presented several problems. Primarily, only 70% of patient notes were available during perinatal clinic follow-up appointments which is a patient safety issue. Our aim was to ensure 100% patient record accessibility both during admission and post discharge.

Methods The availability of handwritten patient notes in follow-up perinatal clinics was audited. Subsequently, electronic templates were introduced and relevant staff (paediatricians, nurses and midwifery teams) were informed. The availability of patient notes in perinatal clinics was re-audited in February 2021 and paediatricians were surveyed.

Results 100% of patient documentation was available in perinatal clinics in February 2021.

Statement	Mean score
The Paperlite NTC templates are accessible	4.9
The Paperlite NTC templates provide a useful and relevant guide to what information should be documented	4.7
You prefer using Paperlite Documentation as compared to documenting on paper notes	4.9

We carried out a post-intervention survey amongst junior doctors, senior doctors and consultants and the results were overwhelmingly positive.

We asked participants of the survey to rate on a likert scale how much they agreed with the statements below (0=strongly disagree, 5= strongly agree)

Conclusions The introduction of Paperlite documentation helps clinicians have better access to patient information, saves

clinical time and accelerates patient discharge as well as provides guided and uniform templates for documentation.

It also allows many aspects of patient care to be audited and ensures medico-legal compliance. Moving forward, we hope to use this electronic system to also streamline documentation for common neonatal procedures (such as lumbar punctures) and to record referrals and patient observations electronically.

British Association of Perinatal Medicine and Neonatal Society

1373 RAPID EXOME SEQUENCING FOR ACUTELY UNWELL CHILDREN: EXPERIENCES FROM YORKSHIRE REGIONAL GENETICS SERVICE

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Background Rare monogenic disorders in children and babies are difficult to diagnose, however establishing the diagnosis plays an important role in informing patient management and influencing clinical decision-making. On 1st October 2019, the National Rapid Exome Sequencing Service for acutely unwell children with a likely monogenic disorder (R14) was introduced across NHS England, via the National Genomic Test Directory. All Neonatal Intensive Care Units (NICUs) in England have access to the national R14 service. Informed consent for this test is essential, as the results may give uncertain or unexpected information, including about a child's biological parents. Rapid trio Whole Exome Sequencing (WES) via R14 has enabled urgent diagnoses to be sought where this may affect the clinical management of the child.

Objectives We undertook an audit and service evaluation of the R14 service in our region by reviewing all referrals to Yorkshire Regional Genetics Service (YRGS) over a one-year period since the commencement of the R14 service.

Methods We reviewed all R14 referrals from YRGS to the nationally-commissioned Exeter Genomics Lab between 1st October 2019 and 30th September 2020. Our data collection tool enabled a standardised screening of patient notes, electronic patient records and genomic and other test results. Patient demographics, clinical and phenotypic information, and genomic outcome data were collected.

Results 46 cases were identified; 18 male (39%), 28 female (61%). The median age of the proband at time of review was 20 days. A heat map demonstrated that most patients who had accessed the service were concentrated in West Yorkshire. At the time of request, 65% (n=30) of patients were on NICU. In 50% (n=23), the neonatal unit requested the test. In 43% (n=20), Clinical Genetics requested the test. In 4% (n=2), the test was requested by neurology, and 2% (n=1) by a High Dependency Unit. Request forms were fully complete in 74% (n=34) of cases. In 46% (n=21) of cases, consent for testing (via a record of discussion form) was not documented. The mean turnaround time from receipt of samples by the Exeter Genomics Lab to issuing of final reports was 12.7 days