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

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

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