

Abstract 26 Table 1 A/R Reviews and Investigations

Mandatory/core reviews & investigations	Additional reviews & investigations (as indicated)
Overnight sleep study	Pulmonary function testing
Medical review	Chest x-ray
Respiratory Physiotherapist review <i>includes peak cough flow with provision of device for home testing during future reviews</i>	Nutrition & dietetic review - <i>planned, not currently part of the pilot</i>
Respiratory Clinical Nurse Specialist review	Speech & Language therapy review - <i>planned, not currently part of the pilot</i>
Cough swab/ secretions MC+S	Respiratory physiologist review (those using non-invasive respiratory support) - <i>review of ventilator, settings, servicing, mask fit, skin lesions/midfacial hypoplasia</i>
Vit D/Ferritin	ECG and Echocardiogram - <i>plus cardiac review if needed</i>
Daytime Capillary blood gas or O ₂ /CO ₂	

Abstract 26 Table 2 Patient demographics

Diagnosis	No of patients
Neuromuscular	
SMA	15
Congenital myasthenia	1
Congenital myotonic dystrophy	10
Myotubular myopathy	3
Nemaline myopathy	1
Kleefstra syndrome	1
Duchenne Muscular Dystrophy	1
Friedreich's ataxia	1
Muscle eye brain disease	2
Complex neurodisability	
Undiagnosed hypotonia	1
Cerebral Palsy undefined	2
CTLC gene mutation	1
Hypoxic ischaemic encephalopathy	2
Other	5
Total	46

The A/R team met regularly to review admissions. Continuous improvement methodology was used to assess issues and implement process changes.

Key review findings were documented and shared with other teams involved. Patients and families were invited to provide feedback prior to discharge.

Results 47 AR's were performed for 46 patients. Mean age was 10.5 years (median of 11.9 years, range 1.3-17.6). 43% of patients were female.

33% (15/46 pts) had Spinal Muscular Atrophy (See table 2 for patient demographics)

54% of patients used nocturnal NIV, 11% using NIV for respiratory illnesses and 13% on oxygen. 19% had no respiratory support.

A/R led to management changes in 59% of patients. These included microbacterial growths on sputum and commencement of treatment, airway clearance plan alterations, NIV requirement/establishment, identification of cardiomyopathy, vitamin D and Iron supplementation.

Patients and families scored A/R's as 9.5/10 median (8-10).

Discussion This new model of individualised respiratory multi-disciplinary review ensured a range of issues were identified, and treatment adjusted to optimise respiratory management for this cohort. Patients and families appeared receptive to the process.

Further analysis is needed to determine whether A/R's reduce the burden of travel by facilitating virtual reviews at other times.

The A/R model is being expanded for children ventilated via tracheostomy and congenital central hypoventilation syndrome.

27 ON-LINE NATIONAL SURVEY TO EXPLORE THE CHANGES IN PRACTICE OF PAEDIATRIC LONG-TERM VENTILATION

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Background Long term ventilation (LTV) refers to mechanical support for breathing either at home or in hospital, for all or part of the day, for at least 3 months. Two national surveys carried out in 1998 and 2008, highlighted the increasing numbers of ventilator dependent children throughout the UK. Our objective was to collect current information about children receiving LTV in the UK, 10 years after the last national survey.

Methods All LTV centres in the UK completed a single time point census survey on 30th September 2019 using an electronic questionnaire. Data included the child's location, underlying diagnosis, interface and type of respiratory support, and whether disease-modifying drugs affected the decision to initiate LTV in specific groups within this target population.

Results Data was collected from 25 LTV centres. The total study population was 2383 children and young people. The median age of the overall sample was x (range x-x). 40.3% female; 57.2% of those recorded were male. Diagnoses were 417 (17.5%) central nervous system, 692 (29%) musculoskeletal and 1274 (53.5%) a respiratory, of which 31.8% of the total had upper airway obstruction. Notable changes since 1998 were the decline in the use of 24-hour ventilation, negative pressure ventilation and tracheostomy as an interface, and the increase in the proportion of patients treated at home. 115 children had received a disease-modifying drug. The use of Ataluren and Myozme did not influence the decision to treat with LTV, but in 35% of the children treated with Nusinersin the clinician stated that the use of this drug had or may have influenced their decision to initiate LTV.

Conclusion The number of children being treated with LTV has increased by 250% in the last 10 years with notable changes in practice over the last 20 years.

28 THE IMPACT OF THE COVID-19 PANDEMIC ON THE SLEEP AND MENTAL WELLBEING OF CHILDREN AND YOUNG PEOPLE WITH AND WITHOUT SPECIAL EDUCATIONAL NEEDS

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Background Children and young people (CYP) with special educational needs (SEN) are more likely to experience disturbed sleep and poorer mental wellbeing. This study explored

the differential impact of the COVID-19 pandemic on the sleep and mental wellbeing of CYP with and without SEN.

Methods NIHR Children and Young People MedTech Co-operative, Sheffield Children's NHS Foundation Trust, and The Sleep Charity carried out an online survey between 23 June 2020 and 17 August 2020. The 77-item survey was shared via social media platforms.

Results 559 participants were included in the analyses, 15.74% of whom reported having a CYP with SEN. While sleep changes due to the pandemic were largely similar for both groups, CYP with SEN (40.91%) were more likely to get or wake up during the night than CYP without SEN (40.91% vs 27.18%). CYP with SEN were significantly more likely than children without SEN to be demotivated (61.44% vs 31.57%), sad and tearful (36.15% vs 19.35%) or anxious and stressed (43.48% vs 14.82%) during the pandemic, as well as to report that increased anxiety was more likely to contribute to poorer sleep (43.48% vs 14.82%).

Conclusion While the majority of CYP in both groups reported sleep changes due to the pandemic, CYP with SEN experienced more sleep disturbance. The findings provide initial evidence to suggest that the pandemic may have had a greater impact on the sleep and mental wellbeing of CYP with SEN compared to CYP without SEN.

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THE COMFORT PROJECT: DEVELOPMENT OF CUSTOM-MADE MASKS FOR CHILDREN USING NON-INVASIVE VENTILATION

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Non-invasive ventilation (NIV) is assisted respiratory support delivered via facemask for people with chronic respiratory failure. Commercial NIV masks are available but masks that fit well are difficult to find for children who have small or asymmetrical facial features. Compromised ventilation can have significant health and quality of life impacts for patients and their families.

The overarching aim of the project was to improve comfort, fit and performance of NIV masks for children using 3D technology.

The needs of patients, parents/carers and healthcare professionals from 6 UK centres was ensured through events advising on mask design and research procedures. 3D scanning technologies were compared in vitro using workflows and deviation analysis and with 3 healthy and 19 patient volunteers. Early design concepts were tested and the final

Abstract 29 Table 1 COMFORT project: development of custom-made masks for children using non-invasive ventilation

Oxygen parameters	Usual mask	Bespoke mask
Median O ₂	95%	98%
Dip index	20.4	8.0
Time <90%	5.8%	1.1%
Min O ₂	71%	79%

prototype selected using a test mannequin and adult volunteers. Prototype masks were manufactured using biocompatible materials to IOS 13485 quality standards and evaluated with 19 patients. Feedback on fit, comfort and facial marking and oximetry data to demonstrate ventilator effectiveness were collected. The potential cost-effectiveness of the customised masks was assessed using an economic model.

A handheld structured light 3D scanner was selected due to superior resolution, ease of use, availability and cost. The final design was a semi-bespoke hybrid approach. 11/15 (73%) evaluation participants reported comfort and fit that was as good or better than their usual mask. 5/11 (45%) were unable to wear the mask due to poorly fitting headgear despite a well-fitting mask. All physiological ventilation parameters were improved (table 1). Preliminary health economics analysis demonstrated that to achieve a 5% improvement in fit and ventilation, a custom-made mask would be cost effective at a price below £500.

A series of in vitro, user-perspective, healthy volunteer and patient evaluations informed the development of custom-made masks for children using NIV.

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A COMPARISON OF MASIMO RAD97 AND SOMNOTOUCH OXIMETERS IN THE ASSESSMENT OF SLEEP DISORDERED BREATHING IN PAEDIATRIC PATIENTS

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Introduction Overnight oximetry is recommended as an initial screening tool to diagnose sleep disordered breathing (SDB) in children (Hang et al 2015). Oximetry is a key component of cardio-respiratory sleep studies (CRSS). Most CRSS equipment has integrated oximeters. This study aims to compare the oxygen saturation data obtained by the standalone Masimo Rad97 oximeter to the integrated Somnotouch oximeter.

Abstract 30 Table 1 A comparison of Masimo Rad97 and Somnotouch oximeters in the assessment of sleep disordered breathing in paediatric patients

	Somnotouch RESP	Masimo rad 97	p-value
Mean Oxygen Saturation	96 +/- 3.9	96.4 +/- 3.9	0.007
ODI3	11.5 +/- 16.3	18 +/- 27.1	0.0006
Number of desaturations	173.3 +/- 498.6	149.2 +/- 239.1	0.004
Time SpO ₂ = < 90%	5.3 +/- 19.4	5.3 +/- 18.9	0.85