

# **NHS London Service Specification**

# Home Oxygen Service Assessment and Review Service -HOSAR (Babies, Children & Young People)

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	Children Home Care Teams
	Hospital at Home Teams
	Community Neonatal Teams
	Specialist Respiratory Nurses
	Consultant Paediatricians in DGH & Acute Care Providers
	London Clinical Oxygen Network members

### Version control

Version	Reviewed by	Changes made		Date	Author/s
				changed	
1.2	Jane Manners	1.	Removed all forms and made them	27/11/2021	Tendai
	Clinical Senior		hyperlinks		Nzirawa
	Project Manager	2.	Removed the whole introduction		
	London Respiratory		section		
	Clinical Network	3.	Summarised the BTS indications		
		4.	Amended key objectives		



Paediatric Pan Lon	don Oxygen Group		
		<ol> <li>Equity section amended</li> <li>Interdependencies amended</li> <li>RSV &amp; oxygen section summarised</li> <li>Ordering Home Oxygen moved to become appendix 1</li> <li>Appendix 2 removed – storage and administration</li> </ol>	
1.3	Tamsyn Hernandez Paediatric Respiratory Long Term Ventilation Clinical Nurse Specialist Evelina London Children's Hospital	10 Flow chart for Service delivery requirements for HOS-AR pathway - In the box where it says "competency document to be completed by ward staff" too prescriptive as some areas the Clinical Nurse Specialist teams do this for respiratory patients  11 Where it says escalation care plan, could CNS be added to that part	Tendai Nzirawa
1.3	Moni Abiola-Peller Senior Lead for Medicines Management & Optimisation Operational Lead - London Home Oxygen Service	regarding completion of them  12. Highlighted to mention the safety impact of home oxygen by linking to the serious incident data (SIRI) for BCYP with oxygen – key data shared	Tendai Nzirawa
1.4	Dr Seema Sukhani Consultant Paediatrician with Respiratory interest	13. Audience – include Consultant Paediatricians in DGH & Acute Care Providers ACCEPTED and added as above  14. Define PEP - ADDED definition (Patient Escalation Process) whereby the patient doesn't allow us access to the property after x3 separate attempts to service the equipment and carry out risk assessment  15. Removed: Key objectives of a Paediatric Home Oxygen Assessment and review Service  16. Under Miscellaneous situations ACCEPTED: added greater than or equal to 90%  17. Comment only on page 9: Currently there is a risk assessment form which is completed with parents. NO physical checks occur currently (to my knowledge) Response: This guidance advises for all BCYP teams (community/hospital) to do a home assessment and complete a Paediatric Risk Assessment in conjunction with the Initial Home Oxygen Risk Mitigation (IHORM) form when planning home discharge.  18. Page 13: Not sure what this statement means? Do you mean the teachers are	Tendai Nzirawa



Paediatric Pan Lond	on Oxygen Group				
		19.	prepared or the patient is prepared about what will happen in the classroom? Corrected Page 13: Can you specify what training is needed and where this can be accessed, or perhaps reference / link to another document. ADDED in brackets		
		20.	(training is offered by the oxygen supplier by contacting the Regional Respiratory Nurse Advisor).  Page 16, with regards to home O2		
			weaning from 0.1L/min, week 1-5, access to the process and calendar is required, ideally via a link. LINK inserted		
		21.	Page 19 section I RSV: ACCEPTED corrections		
	Dr Colin Wallis Paediatric Respiratory Lead Great Ormond Street Hospital		There is need to put in the glossary what they mean by "sleep study" which they use throughout – recommendation to add Sleep study means a prolonged downloadable recording of oxygen saturations done by the community team in the home. ACCEPTED and added in the glossary and page 17	04/02/2022	Tendai Nzirawa
		23.	Comment: It needs to be clear that these children do not need to be referred to a sleep unit for a sleep study and that the overnight oximetry studies referred to here are organised downloaded and interpreted by the community team. ACCEPTED and added in the glossary		



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# A: Purpose of the Home Oxygen Assessment and Review Service

### **USER NOTE**

This specification has been designed to assist London Integrated Care Systems (ICS) in the delivery of services for Babies, Children and Young People with clinical conditions requiring treatment with home oxygen.

The specification is not mandatory, and the commissioner should review the whole of the specification to ensure that it meets local needs and, once agreed with the Provider, it should form part of a re-negotiated contract or form the relevant section of the NHS Standard Contract.

Given the increased demand on all health and care services due to the RSV surge, partners within each ICS (full form) will need to work together to ensure their local community neonatal and children's teams have the capacity required to support new care models (e.g., BCYP HOS-ARs) as they develop.

# Home Oxygen Service -Assessment and Review (HOS-AR)

In 2011, Primary Care Commissioners produced a good practice guide for clinical assessment and efficient supply of home oxygen therapy in England. Central to this guide was Home Oxygen Therapy Assessment and Review (HOS-AR) services unfortunately this only focuses on adult home oxygen patients.

A review conducted in 2019 by the Paediatric Pan London Oxygen Group (PPLOG), London Home Oxygen Service Contract Management Team and Air Liquide UK indicated that approximately 870 children or young persons (BCYP) living in London have Home Oxygen (HO) therapy prescriptions. This includes 471 BCYP with a Home Oxygen Order Form (HOOF) over 1 year old, 108 with HOOF variance, 143 in PEP (Patient Escalation Process) and 677 with ambulatory equipment.

Although smaller numbers than adults, in London there are no BCYP HOS-AR specific services and no standard as to who takes responsibility for these BCYP with regards to follow-up, review and oxygen equipment removal and transition. Instead, current practice is that they are varyingly followed up by specialist nurses, hospital @home services, children's home care teams, community neonatal teams or in a consultant led clinic. Due to this unwarranted variation the BCYP and their families experience differences in service delivery, nursing care and guidance around home oxygen therapy management.

### <u>London Home Oxygen OPENED BCYP Serious Cases – from 2017-2021</u>

CCG Name		SIRI Type	SIRI themes	Age range
NHS	24 SIRI cases	Smoking	<ul> <li>Smoking</li> </ul>	1 month – 19
NORTHEAST		Injury	<ul> <li>Patient refusal of</li> </ul>	years old
LONDON		Information	installation/access	
CCG			<ul> <li>Slips, trips, falls, handling</li> </ul>	
			<ul> <li>Violence or aggression</li> </ul>	
NHS	19 SIRI cases	Injury	<ul> <li>Smoking</li> </ul>	1 month - 13
SOUTHWEST		Information	<ul> <li>Unauthorised</li> </ul>	years
LONDON		Smoking	<ul> <li>equipment/installation</li> </ul>	
CCG			modification	



	oop		<ul> <li>Data protection         issues/security breach</li> <li>Failed/late delivery/ loss         of supply</li> <li>Slips, trips, falls, handling         &amp; use</li> <li>Patient over/under use</li> <li>Patient refusal of         installation/access</li> </ul>	
NHS NORTHWEST LONDON CCG	14 SIRI cases	Injury Smoking	<ul> <li>Smoking</li> <li>Welfare</li> <li>Fire</li> <li>Unauthorised equipment/installation modification</li> <li>Product quality</li> </ul>	5 months – 18 years old
NHS NORTH CENTRAL LONDON CCG	13 SIRI cases	Stat Injury Information	<ul> <li>External agency involvement (e.g., police, FRS)</li> <li>Patient over/under use</li> <li>Failed/late delivery/ loss of supply</li> <li>Product Quality</li> <li>Violence or aggression</li> <li>Not fitting in above categories</li> </ul>	1 year - 16 years old

Based on the table above (London Home Oxygen BCYP Serious Cases – from 2017-2021) there are 70 open SIRI cases that are either smoking, injury or information related. All SIRI themes raise great safety concerns and highlight the importance of risk assessments and reviews to be conducted by the health professionals to ensure the risk to the BCYP, public safety or risk to others is minimised as much as possible.

### Therefore, having a standardised regional HOS-AR specification will help to ensure:

- A reduction in unwarranted variation, address health inequalities and an increased value by creating equal access to high quality HOS-AR services to all service users across the London Region
- that the benefits of the HOS contract are realised by service users, clinicians, and commissioners

Home oxygen is an umbrella term for oxygen (medical gas) used in a variety of different situations.

The British Thoracic Society Guidelines for Home Oxygen in Children (Balfour-Lynn et al, 2009) state the following indications for long-term oxygen therapy (LTOT) in BCYP: -



Paediatric Pan London Oxygen Group  Medical condition	Indications for long-term oxygen therapy (LTOT)
Chronic neonatal lung disease/BPD	<ul> <li>Supplementary oxygen should be given to infants with chronic neonatal lung disease:</li> <li>to reduce or prevent pulmonary hypertension, reduce intermittent desaturations, reduce airway resistance, and promote growth.</li> <li>as it is likely to be beneficial for neurodevelopment in infants with CNLD/BPD.</li> <li>as it may reduce the associated risk of sudden unexplained death in infancy.</li> <li>as oxygen at home is preferable to a prolonged hospital stay for both quality of life and psychological impact for the infant, parents and family.</li> <li>as it saves days in hospital due to earlier discharge despite a significant readmission rate</li> </ul>
Other neonatal lung conditions	Home LTOT should be offered to infants with other oxygen-dependent neonatal lung conditions who are otherwise ready for hospital discharge.
Congenital heart disease	<ul> <li>Home oxygen should not be used for cyanotic congenital heart disease unless accompanied by other respiratory problems.</li> <li>In acyanotic heart disease there is no role for LTOT.</li> </ul>
Pulmonary hypertension	<ul> <li>In idiopathic pulmonary hypertension, supplementary oxygen is recommended for sleep-associated desaturations and for emergency use.</li> <li>In pulmonary hypertension associated with congenital cardiac defects, some children may gain symptomatic benefit and a small open study has suggested it may improve survival. However, there is a lack of good evidence that LTOT is of benefit and it is not recommended.</li> <li>LTOT is recommended for pulmonary hypertension secondary to pulmonary disease.</li> </ul>
Intrapulmonary shunting	<ul> <li>The benefits of LTOT in non-cardiac intrapulmonary shunting are unknown with no relevant publications; however, it should be considered if it leads to symptomatic improvement.</li> </ul>
Recurrent cyanotic-apnoeic episodes	<ul> <li>LTOT should be considered for infants and children who have recurrent cyanotic-apnoeic episodes severe enough to require cardiopulmonary resuscitation, assuming any anaemia has been corrected.</li> </ul>
Interstitial lung disease	<ul> <li>LTOT should be offered to hypoxic children with interstitial lung disease who are otherwise ready for hospital discharge.</li> </ul>
Obliterative bronchiolitis	LTOT should be offered to hypoxic children with obliterative bronchiolitis who are otherwise ready for hospital discharge.
Cystic fibrosis	<ul> <li>LTOT should be considered for hypoxic children with cystic fibrosis as a means to improve school attendance for those who obtain symptomatic relief.</li> <li>In cystic fibrosis, monitoring of CO2 levels should be carried out when oxygen therapy is initiated.</li> </ul>
Obstructive sleep apnoea	<ul> <li>In obstructive sleep apnoea, continuous positive airway pressure (CPAP) or occasionally non-invasive ventilation (NIV) is the therapy of choice if the upper airway obstruction cannot be relieved surgically. If this is not possible, LTOT should be used to improve the SpO2, but CO2 levels need to be monitored at initiation of treatment.</li> </ul>



Chronic hypoventilation	<ul> <li>LTOT should be given in addition to ventilatory support if there is a hypoxaemia component of hypoventilation (assuming the child is optimally ventilated). On occasions when ventilatory support is not possible, supplemental oxygen may be the only alternative</li> </ul>
Sickle cell disease	<ul> <li>LTOT should be considered for children with sickle cell disease and persistent nocturnal hypoxia to reduce the risk of stroke and painful crises.</li> </ul>
Palliative care	<ul> <li>LTOT should be considered for hypoxaemic children undergoing palliative care who obtain symptomatic relief from supplemental oxygen.</li> </ul>

# Special situations

Medical Condition	Indications for long-term oxygen therapy (LTOT)
Intermittent LTOT	<ul> <li>In children with neuro-disability, oxygen may be given in the presence of hypoxia secondary to an acute lower respiratory tract infection. Children will usually be hospitalised but, where families opt for home treatment, facilities for home oxygen may be required if the infections are recurrent.</li> <li>The use of home oxygen in children with severe neuro-disability and low SpO2 should be driven by quality of life issues rather than oxygen saturation targets.</li> </ul>
Intermittent emergency oxygen therapy	<ul> <li>Although most children with asthma should receive bronchodilators via a spacer device, for those using a home nebuliser, unless there is a significant co-morbidity or the child has life-threatening acute exacerbations, it should be run off room air.</li> <li>Intermittent acute oxygen therapy at home should be considered for the few children with recurrent episodes of severe life-threatening asthma, as a temporary therapy prior to ambulance transfer to hospital.</li> <li>Intermittent acute oxygen therapy at home is not routinely recommended for seizures as there is no evidence that it reduces their duration, reduces harm from prolonged seizures or improves quality of life for the child or family.</li> </ul>

# Miscellaneous situations

Medical Condition	Indications for long-term oxygen therapy (LTOT)				
	<ul> <li>Infants with bronchiolitis requiring oxygen (SpO2 &lt; 92%)</li> </ul>				
Miscellaneous situations	should be admitted to hospital and can be considered for				
	discharge when their SpO2 is greater than or equal to 90% and they no				
	longer require oxygen (for at least 8–12 h).				



### The key objectives of the BCYP HOS-AR document:

The aim of the Babies, Children and Young People's Home Oxygen Assessment and Review Service (BCYP HOS-AR) is to ensure that home oxygen is appropriately prescribed to those BCYP who clinically require and benefit from it. It should ensure that people prescribed oxygen and prescribing clinicians alike are well informed about the nature, scope and capability of the home oxygen service, and that provision is evidence-based, clinically led, has robust governance, and continually strives to improve outcomes.

### High level Objectives:

- 1. To set standard guidance for integrated BCYP HOS-AR service delivery.
- 2. To provide recommendations to both systems and providers for BCYP on home oxygen to ensure seamless delivery
- 3. To provide educational guidance and signposting for staff managing BCYP on home oxygen therapy
- 4. To provide support to the carers with evidence-based information on how to care for their child on home oxygen therapy
- 5. To conduct evaluations of services/teams that deliver health care to BCYP on oxygen therapy within a home and school setting.
- 6. To provide leadership support to services and teams to reduce home oxygen waste, harm, and risk of adverse outcomes due to lack of timely assessments, annual reviews, and inappropriate prescribing.

### B: National and Local Context

Within The NHS Long Term Plan (2019) various stakeholders highlighted that the needs of children are diverse, complex and need a higher profile at a national level, with a plan required to oversee the delivery of Babies, Children and Young People's commitments in the NHS Long Term Plan. Positively, NHS England and NHS Improvement have created a BCYP Transformation Programme, however BCYP home oxygen therapy is not included in this.

A service development review presented by PPLOG at PCRS Respiratory Conference 2021, "Review of Home Oxygen Prescribing in School Age Children: Supporting the need for continues improvement of service users" demonstrated 68% (542) of these BCYP on home oxygen in London are of school age (4-17 years old) but only 14% (84) had a Home Oxygen account in an educational setting. A further 16.2% (92) BCYP had a HOOF with no activity, and 41% (233) of school aged BCYP had home oxygen prescriptions that had not been reviewed or updated in the last 5-10 years. The papers authors concluded this was due to lack of a defined pathway and guidance within schools in relation to home oxygen therapy.

Further challenges are encountered by professionals within education and health and commissioning when children transition into adult services. The NHS Long Term Plan (2019) states that the failure to achieve a safe transition can lead to disengagement, failure to take responsibility for their condition and ultimately poorer health outcomes.



A recent paper by Roots et al (2021) provides key steps services need to consider, including a Home Oxygen Transition checklist and patient questionnaire, to ensure the transition of a BCYP to adult HOS-ARS is seamless and places the BCYP at the centre of the process.

### Addressing health inequalities

Currently the demographics of the BCYP population receiving oxygen in London are not known, however it is acknowledged that multi-morbidity is more prevalent in deprived areas and that Black, Asian and Ethnic minority populations are at higher risk of poor health outcomes. This BCYP HOSAR specification will help address these health inequalities and help achieve the following ICS Implementation Guidance (2021) aims: -

- improve outcomes in population health and healthcare
- tackle inequalities in outcomes, experience, and access
- enhance productivity and value for money
- help the NHS support broader social and economic development.

# C: Scope of service provision

The expectation of this guidance is to support the development and management of BCYP HOS-AR services in each ICS. The service or role should give professional expertise and leadership support to those professionals involved in BCYP home oxygen therapy based on the indications highlighted by BTS guidelines. The BCYP HOS-AR services will report to their ICS and the London Clinical Oxygen Network. They will not hold any patient caseloads, but will ensure that in each ICS there is a strategic and operational overview of BCYP HOS-AR services by:

- Giving support to providers and community teams
- Ensuring pathways and guidelines are followed
- Prompting services/teams to undertake annual reviews of home oxygen prescriptions
- Leading on ICS Quality Improvement projects and sharing best practice
- Evaluating and reporting on BCYP HOS-AR services
- Supporting and managing all complaints in relation to BCYP Home oxygen therapy with the support of Adult HOS-AR, London Clinical Oxygen Network and ICS
- Supporting the investigation and shared learning of reported serious incidents
- Supporting the implementation of changes associated with serious incidents
- Reviewing monthly oxygen concordance reports
- Reviewing monthly invoice data
- Engaging with the London Clinical Oxygen Network and other key networks
- Attending quarterly regional HOS-AR meetings

### Exclusion criteria for this Service

BCYP in whom the underlying clinical condition causing a need for home oxygen is not optimised

### Interdependencies with other services

- BCYP HOS-AR must be part of an MDT to ensure there is a central point of contact and support for all BCYP health care services to gain expert support.
- Acute & Community MDT to provide clinical input and oversight of the named BCYP
- London Fire & Rescue Service the fire service should conduct an on-site home safety check/risk assessment when liquid or cylinder oxygen is provided. Households where people



smoke have a higher risk of domestic fire which potentially dangerous when liquid or cylinder oxygen is involved.

- Home Oxygen Service Provider
- BCYP Networks & Forums
- Home Oxygen Service Regional Lead
- London Clinical Oxygen Network (LCON)

### **BCYP HOS-AR service expectations**

Local BCYP services/teams (Hospital@Home; Specialist Allied Health Professionals; Community Neonatal Nurses; Community Children's Nurses & Respiratory Nurses) will be expected to work closely with the Acute & Community MDT to ensure BCYP who require home and/or school oxygen are appropriately clinically assessed.

• To ensure home risk assessments for oxygen suitability and patient safety is appropriately conducted using the Paediatric Risk Assessment in conjunction with the Initial Home Oxygen Risk Mitigation (IHORM) form.

This will include consideration and mitigation of:

- a. tobacco dependence (with exhaled CO monitoring) and electronic cigarette use
- b. substance misuse disorder
- c. gas fires / gas cookers
- d. candles
- e. hoarding hazards
- f. trip hazards
- g. mobility levels
- h. frailty
- i. presence of working smoke detectors
- j. any identifiable social concerns within the BCYP's home environment
- Provide ongoing timely reviews of BCYP' home oxygen therapy following peer reviewed guidance
- Adhere to the requirements of safeguarding policies and procedures
- Provide advice and information to BCYP and their carers
- Provide very brief advice (VBA) and onward referral for smoking cessation treatment and support
- Provide a confidential and safe service
- Adhere to evidence-based recommendations and guidelines
- Adhere to local policies
- Manage all complaints
- Support the investigation and shared learning of reported serious incidents
- Support the implementation of changes associated with serious incidents
- Engage with the London Clinical Oxygen Network
- Join quarterly local ICS BCYP oxygen meetings
- Act as an educational resource to generalist and other non-specialist colleagues to support evidence-based care and safe effective clinical pathways



# Service delivery requirements for HOS-AR pathway



# Home Oxygen Service Assessment

### Based on the PPLOG competency document Link

Awareness of why home oxygen is required and understanding of medical condition

Awareness of deterioration and appropriate actions to follow

Awareness of health and safety in the home environment

Can safely use and maintain equipment at home

Awareness of equipment necessary to administer oxygen

Able to give oxygen via nasal prongs/cannula/mask/ ventilator/ tracheostomy

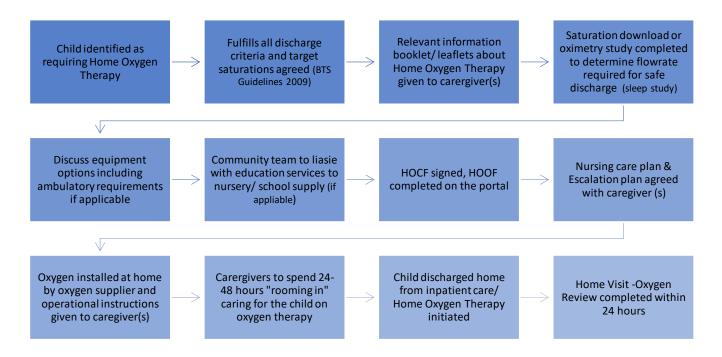
Aware of Basic Life Support

Aware of the ordering process

Initial Home Oxygen Risk Mitigation Form (IHORM) and Home Oxygen Consent Form (HOCF) for new patients only – please see the form on page 10 <u>Link</u>



# Assessment for home oxygen flow chart



# D: STAGE 2 -Assessment for School oxygen

It is the role of both clinical and non-clinical staff to safely meet the health care needs of a BCYP within an education setting and discussions should be had in conjunction with the BCYP and their parents/guardians as they are equal partners in the care. The parents/guardians are often the most knowledgeable about the variations in their BCYP's healthcare needs so should be actively involved in care planning (PPLOG School Oxygen Bundle).

### Success criteria

- BCYP in an educational environment is receiving oxygen correctly and safely
- A Health Care Plan (HCP) is in place detailing the oxygen prescription
- The educational setting will have an oxygen account with oxygen supplier
- Training is provided for all staff who are identified through the HCP
- Educational setting follows the safety guidelines
- All staff are confident in their abilities to care for the BCYP and feel supported by clinical staff
- The BCYP is escorted to educational setting safely (if appropriate) and systems in place for transportation with oxygen
- The fire rescue service (FRS) is alerted when oxygen is stored at the educational setting and are able to provide additional support
- The educational setting notifies their building insurance that oxygen is stored on the premises
- The HCP is reviewed annually or sooner if appropriate



• The teachers in the class are prepared about what will happen in the classroom when there is a BCYP with oxygen

When a BCYP requires oxygen to be administered in an education setting, a health care plan and consent to administer oxygen should be completed and shared with appropriate professionals (Appendix 1 and 2). A risk assessment for the educational setting should be completed (Appendix 6) and training completed for appropriate staff members using teaching competencies (Appendix 3). Before a BCYP can be administered oxygen in the education setting, the responsible healthcare team must ensure that relevant staff have completed training in the safe use of oxygen using Appendix 3. Non-clinical staff must not give prescription medicines or undertake health care procedures without adequate training. This training is typically performed by the Children's Community Nursing Team, School Nurse or Oxygen Supplier.

### Risk Assessment

According to the PPLOG School Oxygen Bundle (2021) due to the nature of oxygen and its associated risks, it is essential that an oxygen risk assessment should be undertaken in the educational setting prior to the BCYP's attendance. This will identify any associated fire risks as well as other potential hazards so that appropriate actions can be taken to mitigate them (Appendix 6). The risk assessments should be completed by school staff e.g., special educational needs co-ordinator (SENCO), business manager, caretaker and any other key link professionals whilst working in partnership with clinical staff. It is advisable that educational settings develop and keep their own risk assessment

### Oxygen account at an Educational Setting

The Home Oxygen Order Form (HOOF) is completed online by an authorised Part B prescriber following a paediatric oxygen assessment. The online prescribing portal is password protected and can be accessed via: https://www.airliquidehomehealth.co.uk/hcp/ The Initial Home Oxygen Risk Mitigation Form (IHORM) in conjunction with the Home Oxygen Consent Form (HOCF) must be completed prior to ordering oxygen to identify and mitigate risk and to share patient identifiable data. Only Healthcare professionals who have undergone training can be a Part B prescriber (training is offered by the oxygen supplier by contacting the Regional Respiratory Nurse Advisor).

The oxygen supplier will require a separate HOOF from a Part B prescribing clinician to create an account. This will ensure that:

- The BCYP's own home supply is not depleted
- The educational setting has control over the safety, storage, and usage of the oxygen equipment
- The supplier will carry out six monthly maintenance and risk assessment
- The educational setting can manage replenishments and record keeping
- The FRS (Fire and Rescue Service) are automatically alerted of the presence of oxygen on the premises by the supplier
- The FRS can support the educational setting with risk management

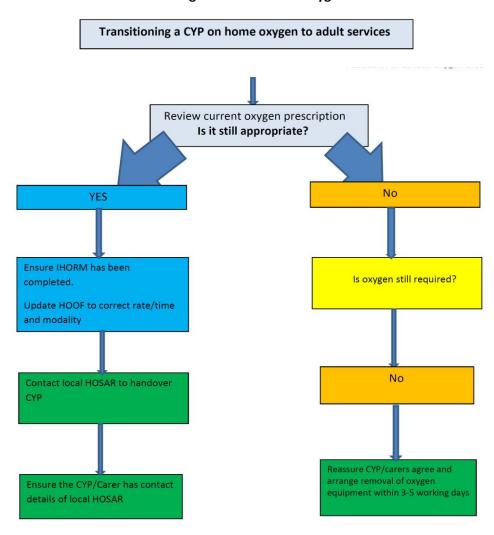
Educational Setting Risk Assessment - Link



### E: Assessment for Transition: Paediatric to Adult HOS-AR

PPLOG transition checklist full detailed guidance can be found Link

Flow chart – Transitioning a BCYP on home oxygen to adult services



# F: Assessment for Palliative Oxygen Therapy

Please see section A: Purpose of the Home Oxygen Assessment and Review Service to follow the BTS guidelines about the Indications for oxygen therapy in BCYP.



# G: Follow up/Review home visit schedules

PPLOG Home Oxygen Review Form: Post Discharge from hospital (Home Visit Review completed within 24 hours) – full detailed guidance & checklist can be found <u>Link</u>

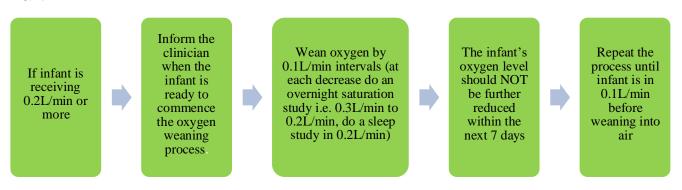
### H: Weaning home oxygen

This guidance has been created with an aim to ensure the management of BCYP on home oxygen therapy is safe, effective, timely and standardised within London and other England regions.

Hence a home oxygen weaning calendar was created. The calendar starts the weaning programme from a flow rate of 0.1L/min to air. Although very low flow meters exist, in theory the flow rate can be reduced further before weaning to air however there is limited evidence to support this practice. Garde et al (2020) points out that the size of the decrements used to wean oxygen flow rate, will result in infants being treated with LTOT for longer than expected. Furthermore, (Balfour-Lynn et al, 2005) argues that there is a concern that some carers may become confused with the decimal points therefore simpler and safer to start weaning off oxygen from 0.1L/min (Balfour-Lynn et al, 2005). Compared to Rhein et al (2020) and Broderick (2018), PPLOG home oxygen weaning guidance takes an average of 33 days for the BCYP to be completely off home oxygen therapy, accounting to around 28 days less. In conclusion, PPLOG's main ambitions are based on the WHO (2018) that every BCYP has coordinated, continuity and integration of care, that is equitable and within an appropriate specialist care pathway and delivered through a systematic approach.

### Pathway for infants receiving 0.2L/min or more nasal cannula oxygen

### Part A:



It is not necessary to perform a baseline study in the amount of oxygen the infant was discharged home in as this would have been done in the referring hospital. Obtaining a copy of the study would be useful as a comparison when you start weaning.

### Evidence suggests an infant is ready to start weaning when they have demonstrated:

- Clinically well no significant respiratory distress, no recurrent wheeze or infections
- Adequate growth and nutrition i.e. Following along their centile charts and meeting targeted weight
- Stable vital signs heart rate, respiratory rate, work of breathing and stable oxygen saturation
- Number of hospitalisations preferably none within the last month
- Parental agreement

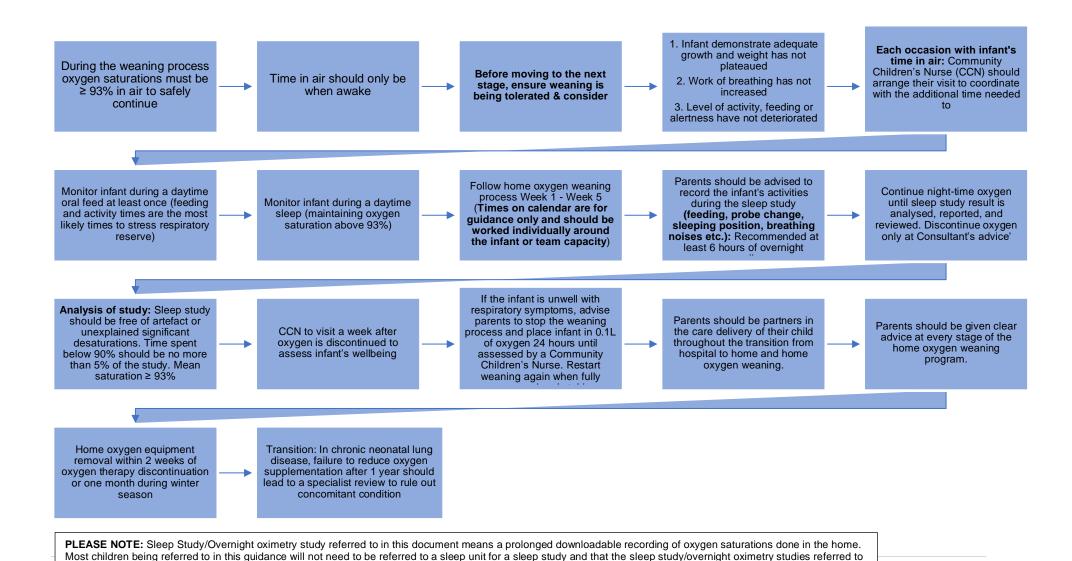


### Process if infant is receiving (0.1L)/min or less

here is organised, downloaded, and interpreted by the community team/ DGH Consultant Paediatricians.

Whereas a traditional cardiorespiratory sleep study looks at gas exchange and breathing during sleep and is a whole different test.

full detailed guidance & checklist can be found Link



17 | Page



# I: Managing home oxygen for RSV patients

In the UK, respiratory syncytial virus (RSV) is a seasonal winter virus causing lower respiratory tract infections (LRTIs) from October to March. Most RSV infections occur in a relatively short epidemic of about six weeks. LRTI, resulting from RSV, usually causes mild, self-limiting illness, but may cause severe illness in vulnerable infants at high risk of LRTI resulting in hospitalisation (COVID-19 rapid policy statement - Palivizumab passive immunisation against respiratory syncytial virus (RSV) in atrisk pre-term infants 2020/21).

Each year 3.4 million hospital admissions are associated with RSV infection (23 24 March 2015, WHO Consultation on respiratory syncytial virus (RSV) vaccine development).

Oxford Vaccine Group and Oxford University estimate 30,000 children under the age of five are hospitalised every year in the UK because of RSV. Public Health England modelling in 2021 showed a possible sharp rise in cases of respiratory syncytial virus (RSV), potentially 20 and 50 % more cases needing hospitalisation than normal

- Increased demand for paediatric intensive care beds
- Increase in other critical care resources for sick children forecast children 3 years & younger as many children have missed out on normal exposure to RSV due to COVID-19 lockdown

### RSV & home oxygen summary

The evidence of effectiveness of palivizumab in infants with co-morbidities is well recognised. The evidence reviews by Solutions for Public Health (SPH) suggested some benefit with palivizumab passive immunisation in preventing RSV hospital admissions in infants born pre-term with and without co-morbidities such as BPD. It important to acknowledge there will always be a group of children that might not qualify for the palivizumab and/or be discharged on short term oxygen during this RSV surge season (COVID-19 rapid policy statement - Palivizumab passive immunisation against respiratory syncytial virus (RSV) in at-risk pre-term infants 2020/21).

ICS will need to support their clinicians to ensure that

• There is prospective data being collected during the RSV season based on admissions and readmissions of RSV infection and bronchiolitis.



- There is a need to ensure the Multidisciplinary team is of diverse professionals and disciples in order to encourage an open safety culture.
- There is visible Transformational Leadership that can manage team dynamics
- The management of RSV service (clinics/pathways/processes) need to be a system approach that includes for example Neonatal, Paediatric & community, A&E, Commissioning, Primary Care Networks
- To address any possible health inequalities in the service delivery, we recommend that an
  Equality Impact Assessments should be conducted to ensure that any new service or change
  including pathways development aims to bring equity for the identified seldom heard
  population.

# J: Contingency plan for parents

A co-produced nursing care plan should be written by the named health professional with the parents/carers, and if necessary, an escalation care plan can also be included however this will be based on the multidisciplinary local discussions. Templates can be located within the Discharge Bundle link on the PPLOG website <a href="https://www.pplog.co.uk">www.pplog.co.uk</a>

# K: Removal of oxygen

Air Liquide Homecare Healthcare Provider, The Paediatric Pan London Oxygen Group (PPLOG) and London Clinical Oxygen Network (LCON), states that it is mandatory for the child's oxygen requirement and prescription to be reviewed weekly during the RSV season. If at the review the BCYP no longer requires/ fulfils criteria for the oxygen, then this should be explained to the parent/guardian and arrangements made for removal of the oxygen with the supplier.

When a BCYP is weaning from oxygen the appropriate healthcare professional will make amendments to the prescription and equipment via the Air Liquide Portal. Once completely weaned arrangements should be made for removal of the equipment within 7 days.

### L: Home Oxygen Therapy annual review letter

Full detailed guidance can be found on page 35 Link

# M: Escalation Care Plan: without saturation monitor at home

Full detailed guidance can be found Link

### N: Patient outcomes

There is evidence that through effective provision of Paediatric HOS-AR services to BCYP who require home oxygen therapy following outcomes can be achieved for them:

- Increased activity levels especially for BCYP who met the indications stated by the BTS guideline
- Increased BCYP/carer involvement in the pathway
- Improved BCYP/carer experience
- Annual renewal of HOOF as evidence of ongoing clinical care



- Provision of the right modalities based on oxygen needs and lifestyle
- Reduction in oxygen related patient re-admissions
- Reduction in oxygen related adverse events (including smoking related incidents)
- Increased BCYP and/or parent/carer knowledge of oxygen management
- Increased Health-Related and parental Quality of Life



# O: Performance indicators

When reporting progress against outcomes the Provider may wish to consider measures and calculations like those set out below. Data should be obtained from local audit, unless otherwise stated.

The Commissioner may wish to consider Remedial Action Plans to ensure compliance with the required threshold for certain measures if selected.

	Outcome	Expecte	Expected outcomes		Indicator description	Indicator	Measurement
		Year 1	Year 2	Year 3		threshold	
1	BCYP prescribed home oxygen have a follow up home visit within 24 hours	ТВА	ТВА	ТВА	The percentage of BCYP prescribed oxygen therapy who have a follow up home visit within 24 hours	90%	(x) The number of BCYP prescribed oxygen therapy who have a follow up home visit within 24 hours (y) The number of people prescribed oxygen therapy [x/y] x 100 = percentage of people who have a follow up home visit within 24 hours
2	BCYP on home oxygen therapy have a clinical review weekly and service review every 12 months (which includes stockholding & usage)	ТВА	ТВА	ТВА	The percentage of BCYP on oxygen therapy who have had a service review in the last	90%	The number of BCYP on home oxygen therapy who have had a review in the last
3	BCYP using the service and their carers are satisfied with the service	ТВА	ТВА	ТВА	The percentage of BCYP and carers surveyed who are satisfied with the service	90%	x) The number of surveys received with a satisfactory score



	don Oxygen Group						(y) The number of BCYP and carers surveyed [x/y] x 100 = percentage of BCYP and carers surveyed who are satisfied with the service
4	All BCYP HOSAR staff & other key professionals* delivering or supporting home oxygen who interact with BCYP and carers should be trained to give VBA (Very Brief Advice for Smoking cessation)	ТВА	ТВА	ТВА	Percentage of patient facing HOSAR staff trained to give VBA	90%	X) The number of VBA trained patient facing HOSAR staff (Y) The number of patients facing HOSAR staff [x/y] x 100= percentage of patient facing HOSAR staff who are trained in VBA
5	Adolescence & carers who are current smokers referred for home oxygen are offered very brief advice and treatment, and referral to local smoking cessation service	ТВА	TBA	ТВА	The percentage of Adolescence & carers using the HOS-AR service who are smokers who are offered stop smoking support and pharmacotherapy	90%	(x) The number of Adolescence & carers using the HOS-AR service who are smokers who are offered stop smoking support and pharmacotherapy to quit smoking (y) The number of Adolescence & carers using the HOS-AR service who are smokers [x/y] x 100 = percentage of people using the HOS-AR service who are smokers who are offered stop smoking support and pharmacotherapy



6	There is a named BCYP respiratory	ТВА	Having a named consultant for	TBA	There is a named
	consultant clinician linked to the		the service		consultant clinician for the
	HOS-AR for oversight (at least				team and the consultant
	monthly).				has time allocated for
					oversight (support any
					BCYP HOS-AR service
					specification based on
					clinical expertise)

<sup>\*</sup>Respiratory specialist nurses, medical doctors, school nurses & school /nursery staff

# P: Logic Model

A logic model is a representation of how an activity is intended to deliver results. The model shows the logical relationships between the resources that are invested, the activities that take place and the benefits or change that can result. The model is another way of showing indicators and can be used by commissioners when considering their approach to developing services locally. Below is a suggested logic model for HOS AR.

Suggested logic infoder for	<u> </u>
Impact	Reduction in respiratory mortality Reduction in inappropriate prescribing and costs Reduction in home oxygen related harm and waste Reduction in variation in prescribing
Outcome	Increase the number of patients concordant with LTOT Increase the number of patients concordant with ambulatory oxygen Increase number of patients with annual reviews Reduction in number of smokers (adolescent and/or carers) on home oxygen therapy Reduction in oxygen related adverse events Reduction in hospital re-admissions Reduction in payments for unused oxygen equipment
Output	% of people prescribed oxygen who had a follow-up home visit within 24 hours after hospital discharge % of patients requiring adjustment of oxygen therapy flow rate % of patients not hypoxaemic and/or deriving no benefit where withdrawal recommended % of patients on oxygen after withdrawal recommended % of patients and carers who are satisfied with the service % of patients accurately prescribed oxygen % of patients with zero concordance who have equipment in place % of patients from Black, Asian and Ethnic Minority Background prescribed oxygen % of patients from most deprived areas on oxygen therapy (focus on BCYP age, ethnicity and diagnosis)
Intervention	Full and comprehensive service [including home visits] delivered as per PLLOG Guidelines and in line with recommendations from various national guidance (NICE, RCN & British Thoracic Society) Conducted by suitably qualified and trained health professionals with appropriate premises and equipment.  HOS-AR service should be integrated within a comprehensive patient pathway.
Input	Patients that have a clinical condition requiring home oxygen therapy where there is a clear identified need for home oxygen

# P: List of PPLOG oxygen guidance

The Paediatric Pan London Oxygen Group has produced some best practice guidance including some publications to address unwarranted variation in service provision and encourage appropriate prescribing of home oxygen. Links are below.

Guidance Title	Link to guidance
Discharge Bundle updated 2021	www.pplog.co.uk
Educational Setting Oxygen Bundle	
Weaning from home oxygen therapy	
Transitioning a BCYP on home oxygen to adult	
services	

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Respiratory Surge in Children programme: <a href="https://www.e-lfh.org.uk/programmes/respiratory\_surge\_in\_children/">https://www.e-lfh.org.uk/programmes/respiratory\_surge\_in\_children/</a>

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# S: Glossary of Terms and Abbreviations

A&E Accident and Emergency Department also known as Emergency Department (ED) or

Emergency Room (ER)

BLS Basic Life Support

BTS British Thoracic Society

**CCNT** Children's Community Nursing Team

Child Throughout this document the term 'child' is used to refer to babies, Babies, Children and

Young People

CNS Clinical Nurse Specialist

**DLA** Disability Living Allowance (Under 16 years of age)

DPM Discharge Planning Meeting

EHC or EHCP Education Health and Care Plan

EHIC European Health Insurance Card

FRS Fire and Rescue Services

**GP** General Practitioner/ Family Doctor

HOCF Home Oxygen Consent Form
HOOF Home Oxygen Order Form

HR Heart Rate

Managing team, The team that made the decision that the child requires Home Oxygen Therapy and/ or will

be following up the management of the Home Oxygen Therapy

MDT Multi-Disciplinary Team

OPA Out-Patient Appointment

PIP Personal Independence Payment (16 years+)

PEP Patient Escalation Process

PPLOG Paediatric Pan London Oxygen Group

Rooming in Parent(s)/ Carer(s) stay by the child and care for all their care needs including any new

healthcare needs in order to ensure that they are confident at caring for the child

independently. This is usually for a minimum of a 24-hour period so that they are aware of

how to care for the child's needs both day and night if applicable

RR Respiratory Rate

RSV Respiratory Syncytial Virus (a common virus that causes coughs and colds in winter, the most

common cause of bronchiolitis in infants)

SEN Special Educational Needs

SpO<sub>2</sub> Peripheral capillary oxygen saturation

Sleep study A prolonged downloadable recording of oxygen saturations done by the community team in

the home