Paediatric Pan London Oxygen Group

The PPLOG Journey 2021

Reducing variation in paediatric home oxygen

Website: *pplog.co.uk*
For more information please email: *contact@pplog.co.uk*

So what has been happening?

- PPLOG over 7 face to face study days (London, Essex, Southwest England)
- PPLOG virtual webinar August 2021
- PPLOG Discharge Bundle reviewed – November/December 2020
- Weaning / withdrawal of home oxygen therapy guidance
- Guidance on oxygen use in schools - Education and care plans
- Transition to Adult services for patients requiring home oxygen *(in association with LCON – London Clinical Oxygen Network)*
- Website and social media
- YouTube channel
- Newsletter

Governance - LCON

- **-** Meetings: Every 2 months, last Friday of the month
- Terms of Reference, minutes
- Registered as Non-profit organisation company number: 13597047
- In 2021, PPLOG secured funding to continue progressing work from Astra Zeneca

Paediatric Pan London Oxygen Group

COLLABORATION

Many other Collaborations

Weaning off oxygen: What is the research?

Dr Hazel Evans
Consultant Respiratory Paediatrician
Lead for Respiratory Sleep and Ventilation Services
Chair RCPCH Respiratory CSAC

Southampton Children's Hospital

The importance of home oxygen commissioning **Moni Abiola-Peller**
(Operational Lead – *London Home Oxygen Service &* Assistant Director – *Medicines Management)*

London HOS Contract Management Team

North Thames Paediatric Network
Connecting paediatric services

Bliss for babies born premature or sick | 40th

NEL NHS

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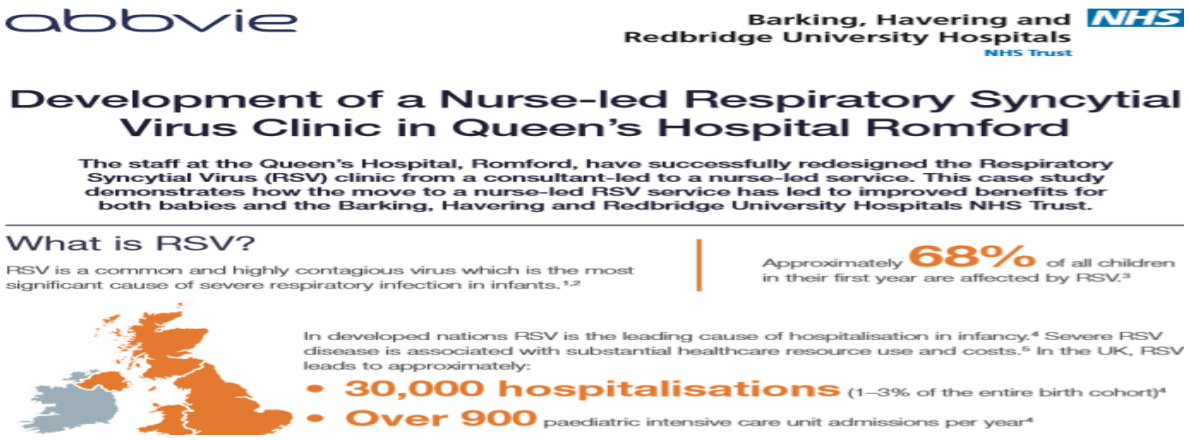
Case studies

- Respiratory Surge in Children - e-Learning for Healthcare (e-lfh.org.uk)
- Nzirawa t (2019) 4e of Green and Tones'Health Promotion: Planning and Strategies.

  https://study.sagepub.com/greentones4e.

- Presented at the Nurse Clinics Conference 2018



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HOME OXYGEN RISK ASSESSMENT FORM PRIOR TO DISCHARGE

(completion by CCNT/CN and copy for the hospital and caregiver)

Property Access	
Property Type:	☐ House ☐ Bungalow ☐ Flat. Number of occupants_____ ☐ x 1 Lift Access ☐ x 2 Lift Access
Access:	☐ Building level ☐ *Steps- How many*_____ ☐ Hallway/exit route free from obstruction?
Doors:	☐ ? Width appropriate for buggy/wheelchair
Levels:	How many levels is the property situated over?_____
Home Insurance:	☐ Family are aware that they need to let their landlord and home insurance company know if they have oxygen in the home.
Physical Environment	
Space for equipment:	☐ Storage for 3 months-worth of consumables ☐ Storage For Oxygen Cylinders/Concentrator Comments:
CYP Bedroom:	☐ Wall Plug Socket available if having concentrator ☐ Appropriate space for equipment, away from heat sources and direct sunlight ☐ Is this the only address the child will sleep at?
Kitchen:	Open plan living space/kitchen area: ☐ Yes ☐ No Cooker: ☐ Electric ☐ Gas If Gas, aware of risk of open flames ☐
Electricity Payment:	☐ Billed ☐ Pay as You Go ☐ Direct Debit ☐ Family aware of electricity rebate scheme for 02 concentrator?
Smoke Alarms:	☐ How Many ____ Location: ☐ Working
Carbon Monoxide Alarms:	☐ How Many ____ Location: ☐ Working
Fire Brigade:	☐ Are family aware that they can contact the Fire Brigade on the non-emergency number to assess their property and formulate an escape plan for their family and home?
Heating:	☐ Yes ☐ No- is the heating functioning? ☐ Central Heating ☐ Electric Heaters ☐ Gas Fire ☐ Log Fire

PPLOG Risk Assessment : Condition of Property & Safety

Condition of Property	
Is the property in	☐ Good Condition ☐ Significant Disrepair
Is there mould in the property?	☐ Yes Location: _____ ☐ No
Any visible signs or smells of damp in the property?	☐ Yes Location: _____ ☐ No
Do you have any other concerns regarding the property in regards to the supply and installation of oxygen?	
Safety	
Telephone:	☐ **Ensure family have access to a telephone**
Car Insurance:	☐ **Family are aware that they need to let their Car insurance company know if they intend to travel with oxygen in the car?**
Fire Safety:	☐ **Discussed smoking (including e-cigarettes) around the child and oxygen.** ☐ **Discussed use of emollients and flammable skin care products.** ☐ **Discussed use of candles and incense.** ☐ **Discussed use and storage of any other flammable liquids/materials.**
General safety:	☐ **Oxygen tubing can pose a trip hazard. Discuss dangers for children and the elderly** ☐ **Pets- discuss hazard of pets chewing on oxygen tubing**

Pets & oxygen tubing

PCRS Respiratory Conference 2021
24th–25th September 2021
Virtual Conference

The Primary Care Respiratory Society

- Poster
- 3 mins video

Review of Home Oxygen prescribing school age children: Supporting the need for continuous improvement of service users

Authors: Lock C, Nzirawa T, Rawsthorne T

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AIR LIQUIDE Creative Oxygen

Introduction

Based on a review conducted by PPLOG and Air Liquide UK in 2019, around 870 children or young person (CYP) living in London currently have Home Oxygen (HO) therapy prescriptions.

The data identified that 68% (542) of these CYP are of school age (4-17 years old) but only 14% (84) CYP have a HO account in an educational setting.

The aim of this study is to have an deep dive review of the various HO therapy prescriptions recorded within London's educational settings. The review will enable the opportunity to identify any gaps in service provision, unwarranted variation and gives recommendations to support local CYP healthcare services to make relevant safety and quality improvements.

Method

Air Liquide (AL) is the provider of HO in London region. A review of Air Liquide database was undertaken by AL Respiratory Nurse Advisor in October 2019, then peer reviewed by the PPLOG chair as a way of ratification. The final results were shared with Paediatric Pan London Oxygen Group (PPLOG) and London Oxygen Network.

Table 1: Breakdown of CYP in Educational Setting on oxygen therapy

CYP 4 -17 years of age	
Primary/Secondary School	23
Primary/Secondary (Special Needs)	56
Nursery	5
Total	84

Table 2: School accounts Distribution across London

North Central London	13
North East London	22
North West London	13
South West London	18
South East London	18

Table 3: Clinical Code on Home Oxygen Order Form (HOOF)

Bronchiectasis	3
Chronic Neonatal Lung Disease	9
Interstitial Lung Disease	2
Neurodisability	20
Neuromuscular	7
Obstructive Sleep Apnoea Syndrome	2
Other Conditions	11
Other Primary Respiratory	10
Paediatric Interstitial Lung Disease	4
Paediatric Cardiac Disease	2
Palliative Care	8
Unknown	6

Table 4: Equipment Type

Equipment Type	Number of modalities prescribed	Litres per Minutes (LPM)	Hours per Day (HPD)
Static concentrator	26	0.5 - 5 LPM	1-24 HPD
Static Cylinder	20	0.2-15 LPM	1-20 HPD
2 Litre Cylinder	56	0.2-15 LPM	0.5-12 HPD
1 Litre Cylinder	19	0.2-15 LPM	1-8 HPD

Results

The data identified that 68% (542) of these CYP are of school age (4 -17 years old) however only 14% (84) of these CYP have a HO account in an educational setting.
Out of this overall total, 67% (56) of CYP are in a Special Educational Needs School with a higher proportion based in North East London. Evidently, 18% of CYP within this higher proportion lived in two CCG's under the North East London area. Therefore, about 1/5 of CYP in these two CCG are needing designated teams to review and reassess their HO prescriptions.
The review found that HO clinical codes are numerous as outlined in Table 3. Significantly, at least 1 in 5 CYP have been recorded under the clinical indication as Neurodisability.
The types of oxygen (O2) equipment prescribed are illustrated in Table 4. 25 (29.7%) CYPs have ambulatory equipment with a flow rate > 4HPD. This again highlights the importance of reviews, why these CYP did not move to concentrator or static cylinder. Finally, it was noted that one of the oxygen prescription's was from a Nursery setting dating back to 2011. Resulting in total costs of over £7800 based on today's cost.

Conclusions

Our study found that there is a significantly large number 542 of CYP of school age on Home Oxygen therapy. 16.2 %(92) CYP have a HOOF with no activity. Furthermore, around 41% (233) of school aged CYP have not had their prescription reviewed or updated in the last 5-10 years. The review found that there are broader issues within services especially relating to a lack of pathways and guidance.

Recommendations:

- Trust/ICS (newly formed Integrated Care Systems) to coordinate the removal of oxygen equipment when it is no longer required.
- Offer structured evidence based staff training and ongoing support
- ICS to fund further studies/service reviews in order to investigate the extent of the CYP oxygen therapy challenges faced by professionals in schools and commissioners to ensure that oxygen is used safely in all educational settings.
- ICS would need to fund for Paediatric Home Oxygen Service Assessment Review (HOSAR) to lead and develop pathways to ensure the safety and quality of CYP on oxygen is not comprised.

Background & Key findings:

542 of CYP of school age on Home Oxygen therapy

16.2 %(92) CYP have a HOOF with no activity

41% (233) of school aged CYP have not had their prescription reviewed or updated in the last 5-10 years.

Other broader issues within services related to a **lack of pathways and guidance**.

Home Oxygen Weaning Guidance

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Guidance for home oxygen weaning in the community (PPLOG)

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Paediatric lung disease
Paediatric interstitial lung disease
Respiratory measurement
Sleep study
Infant oxygen weaning
Home oxygen management
Chronic lung disease CLD
Bronchopulmonary dysplasia (BPD)

ABSTRACT

The aim of this home oxygen weaning guidance is to bring evidence-based knowledge and the experiences of Respiratory Clinical Nurse Specialists, Community Children's Nurses and Community Neonatal Nurses together, to address the unwarranted variation across community children & young people (CYP) services in relation to Long Term Oxygen Therapy (LTOT). This guidance has been created with an aim to ensure the management of CYP on home oxygen therapy is safe, effective, timely and standardised within London and other England regions especially when the oxygen process begins.

1. Background

In 2018, the Paediatric Pan London Oxygen Group (PPLOG) based in London launched the Home Oxygen Discharge Bundle. Based on feedback from numerous study days over the last three years, delegates highlighted the need for paediatric home oxygen weaning guidance. Consequently, PPLOG formed a sub-group to review current literature around weaning Children and Young People (CYP) on home oxygen therapy. Additionally, a survey was conducted to uncover how paediatric community teams across London wean CYPs off home oxygen therapy. The results of our survey are comparable to Garde et al. (2020), whereby a huge variation in practice and a significant number of Hospital Trusts did not have standarised weaning guidance for clinical staff and the CYP's carers to follow.

1.1. Literature synthesis and purpose for developing the guidance

Numerous CYP home oxygen therapy articles have been published which indicate the unwarranted variation in practice guidance when weaning off home oxygen therapy which is challenging. This variation is either due to services or organisations having no clear guidance or a lack of structured pathways (Maclean el al, 2006; Procaskey et al., 2018; Everitt et al., 2020; Garde et al., 2020, Broderick, 2018 and Nzirawa, 2018).

The lack of agreement about the indications for home oxygen prescribing among specialist health professionals is another contending issue faced by many CYP community services (Maclean et al., 2006; Garde et al., 2020; Everitt, 2020). Our survey findings identified some teams started the CYP weaning based on the named consultant direction after the CYP had been reviewed at their first outpatient appointment. Whereas in some geographical areas across London, home oxygen weaning was independently started by the named community nurse within the home dependent on various assessments. This method of home oxygen weaning was identified by Rhein et al. (2020) and Broderick (2018).

Rhein et al. (2020) randomised controlled trial was divided into two groups. One group was seen in clinic monthly whereas the second group complied all the recordings and sent the data for review and feedback within 48 hours from the home setting. Both of Rhein et al. groups were reviewed by a senior medical doctor. Whereas, Broderick (2018) study was performed within a home setting downloaded by the community nurses. Broderick's (2018) data was a shared ownership between the community nurse and the senior medical doctor.

Therefore, the main considerations for clinicians caring for CYP's in the community is:

- When is the right time to start the home oxygen weaning program?
- What is the best evidence-based process to wean the CYP off oxygen therapy?
- What are the criteria to follow and who is clinically responsible for this process?

Hayes et al. (2018) highlights the lack of uniform guidance with only 8 % of specialist paediatric pulmonologist have a standardised weaning guidance for infants and where weaning guidance exist, it can take an interminable amount of time to completely wean the CYP off oxygen.

Whereas, Yeh et al. (2016) implied that on average, it took 10 months to completely weaned off oxygen and at least 32 % of CYPs had non-medical supervision during the weaning process. The consequences of unsupervised safe oxygen weaning can lead to concomitant diagnosis

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This weaning guidance has been created with an aim to ensure the management of CYP on home oxygen therapy is:

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PPLOG Home oxygen weaning calendar

- Weaning commenced from 0.1L / min to Air
- Guidance takes an average of 33 days for the CYP to be completely off oxygen therapy *(accounting to 28 days less than Rhein et al, 2020 and Broderick,2018)*
- No evidence to support weaning using a low flow meter and often means the CYP requires oxygen for longer. *(Garde et al, 2020)*
- Decimal points can be confusing, therefore safer to start weaning off oxygen from 0.1L *(Balfour-Lynn et al, 2005)*

PPLOG VISION: *based on the WHO (2018) that every CYP has coordinated, continuity and integration of care, that is equitable and within an appropriate specialist care pathway and delivered through a systematic approach.*

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Transition a Paediatric patient with Home oxygen to Adult Services

Debbie Roots

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Home oxygen:

guidance for transitioning from paediatric to adult care

Transitioning from paediatric to adult care for home oxygen therapy can be confusing or even overwhelming for a child or young person. This guidance supports health professionals to make the transition as smooth and safe as possible, through the use of a checklist and questionnaire that aim to improve a child or young person's experience of care and outcomes.

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Across London, there are approximately 870 children prescribed home oxygen therapy (Paediatric Pan London Oxygen Group (PPLOG), 2021a). Unpublished data from the London Home Oxygen Service and Medicines Management Team indicate that children and young people make up 12% of the London home oxygen population and of these, 128 are between 14 and 17 years old.

The PPLOG and the London Home Oxygen Service conducted a scoping review (not yet published) that found three main challenges in relation to transitioning from paediatric to adult home oxygen services. First, there is a lack of multidisciplinary team care under specialist and local centres as well as a lack of joint working between teams to ensure communication and continuity of care. Second, there is a lack of consistent referral and continuity of care pathways across the region and there is variation in clinical practice. Third, there is a lack of commissioning of home oxygen assessment and review services that include paediatric service specifications. There is a lack of consistent assessment and review service provision and limited commissioner involvement with assessment and review performance management.

Based on the three challenges highlighted above, there are concerns that some children and young people may have old versions of the home oxygen order form. The home oxygen order form is recognised as a form of medication chart whereby a health professional requests a child or young person's home oxygen via the oxygen company portal. The form should include the flow rate, oxygen requirements and the type of oxygen needed (concentrator or cylinders) (Nzirawa, 2018). Some of the children and young people with older forms have not had recent assessments and clinical commissioning groups continue to spend on unused home oxygen equipment (British Thoracic Society (BTS), 2009; Nzirawa, 2018; Hayes et al, 2018; Rahimi, 2019). This is both a clinical and safety risk. The NHS (2019) Long Term Plan section 3.45 states that 'from 2019/20 clinical networks will be rolled out to ensure we improve the quality of care for children with long-term conditions such as asthma, epilepsy and diabetes' and that 'this will be achieved though sharing best clinical practice, supporting the integration of paediatric skills across services and bespoke quality improvement projects'. Currently, there is minimum information as to if this will be rolled out to home oxygen for children and young people as well.

Differences between adult and paediatric practice

Diagnosis

The range of conditions seen in children where continual oxygen is required is quite distinct from those in adults. There is a tendency for children's diseases to improve with time or the conditions are life-limiting, whereas in adults, the condition tends to deteriorate over time (Balfour-Lynn et al, 2005; BTS, 2009).

There are guidelines available for adult home oxygen from the BTS (2015). Short burst oxygen is not recommended and for long-term oxygen there needs to be minimum 16 hours a day of use. The BTS (2015) guideline for home oxygen in adults is followed by adult services for home oxygen therapy and this will impact on their prescription. It is vital to communicate any changes to prescribing from what the child or young person is used to (BTS, 2015).

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MENTAL HEALTH:

THE IMPACT OF PARENTAL & INFANT MENTAL HEALTH WHEN A CHILD IS ON HOME OXYGEN

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Perinatal Mental Health vs Home Oxygen

- Survey completed by 18/24 parents/carers (North London)
- 16.5% Felt alone regarding the needs of their baby & would appreciate more support
- 27.5% overwhelmed by their baby's needs & felt emotional strain
- 33% felt their family was greatly affected by the needs of their baby on home oxygen
- 39% felt support by the community neonatal nurse/children's home care team
- 22% reported difficulty with using portable oxygen outdoors

Nzirawa et al (2017) Primary care givers of infants on home oxygen therapy. Journal of Neonatal Nursing

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Perinatal Mental Health & PPLOG

1. Reduce parental anxiety – planning & communication
2. Support parents – emotional/psychological support
3. Awareness of parents challenges – Discharge planning
   - ***PPLOG Discharge planning checklist***
   - ***PPLOG Home oxygen escalation care plan***
   - ***PPLOG Community nursing team care plan***
4. Coping with Transition hospital to home – follow up from specialist nursing support
   - ***PPLOG risk assessment for prior to discharge***
   - ***PPLOG home visit review document***
5. Isolated – sign post to groups/peer support
6. Ability to handle home oxygen equipment – competencies
   - ***PPLOG Parent/Carer/Staff competencies***

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Next steps

- Paediatric HOS-AR document (in association with LCON) – for Integrated Care Systems (ICS) Named CYP oxygen lead
- Planning monthly drop in session September 2021 – March 2022
- Review all survey results – write articles to share learning & good practice
- Develop Smoking & Oxygen guidance
- Scoping Oxygen and Palliative Care, Sickle Cell and etc
- Develop eLearning module
- NICE guidance
- Create a database of PPLOG champions for each CYP service – support and facilitate safe and best practice
- Collaboration! Collaboration!