Paediatric Pan London Oxygen Group

Guidance Document

Home Oxygen- Paediatric to Adult Transition Approach

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Paediatric Pan London Oxygen Group

Table of contents:

Introduction.....4

The objectives of this document.....5

Appendix 1: Before Young Person turns 16.....6

Appendix 2: Before Young Person turns 18.....7

Differences in Adult and Paediatric Practice.....8

Complex needs.....11

Appendix 3: Transition checklist.....12

Appendix 4: Home oxygen transition patient questionnaire.....18

Appendix 5: London adult home oxygen services assessment review (HOS-AR) Directory.....24

References 27-28

Introduction

Transition in healthcare can be described as the process of preparing, planning and moving between services. For the purpose of this guidance, this document is focussing on the transition from paediatric to adult home oxygen services, which is a key phase in the patient journey for young people requiring long-term home oxygen therapy. Transition refers to assessment, initial planning, the transfer between services and support given throughout the process (NICE 2016). It is not a single event, but is a gradual process of supporting a young person and their family through their teenage years and into adulthood, building up their confidence and ability to manage the care and support their needs (Together for short lives, 2023). There are a number of different models and resources that can be used to support Transition in healthcare from paediatric to adult services, such as:

· Southampton Children's Hospital Ready Steady Go (Nagra et al 2015)

· The 8 Principles for Transition: Guidance from well child (2024)

· Together for Short Lives (2016) Moving to adult services: what to expect, a guide for young people with life-threatening conditions making the transition to adult services

· Royal College of Paediatrics and Child Health: Transition to adult services (2022)

The NICE (2016) guidance recommends that the transition process should start by 14 years of age. For young people entering the service close to the point of transfer, planning should start immediately. Across London there are approximately 669 children prescribed home oxygen (London Home Oxygen Service Team, SEL ICB, on behalf of the 5 London ICB - 23/09/2025). Of these, 121 are between 14-17 years old (London Home Oxygen Service Team, SEL ICB, on behalf of the 5 London ICB). Most Adult Home Oxygen Service Assessment review (HOSAR) services accept patient's from the age of 18 years.

The transition process can be daunting and at times stressful and confusing for young people and their families. The transition period can often be hard for those living it especially as the more complex the needs of the child or young person, the more complex the transfer of care can be NICE (2016). At a time when the young person is preparing for approaching adulthood, It is vital that the young person and their families are advised and supported in a developmentally appropriate way- to navigate between the paediatric and adult home oxygen services. This guidance document aims to support professionals to support these young people in their care to transition between paediatric and adult home oxygen services as smoothly as possible.

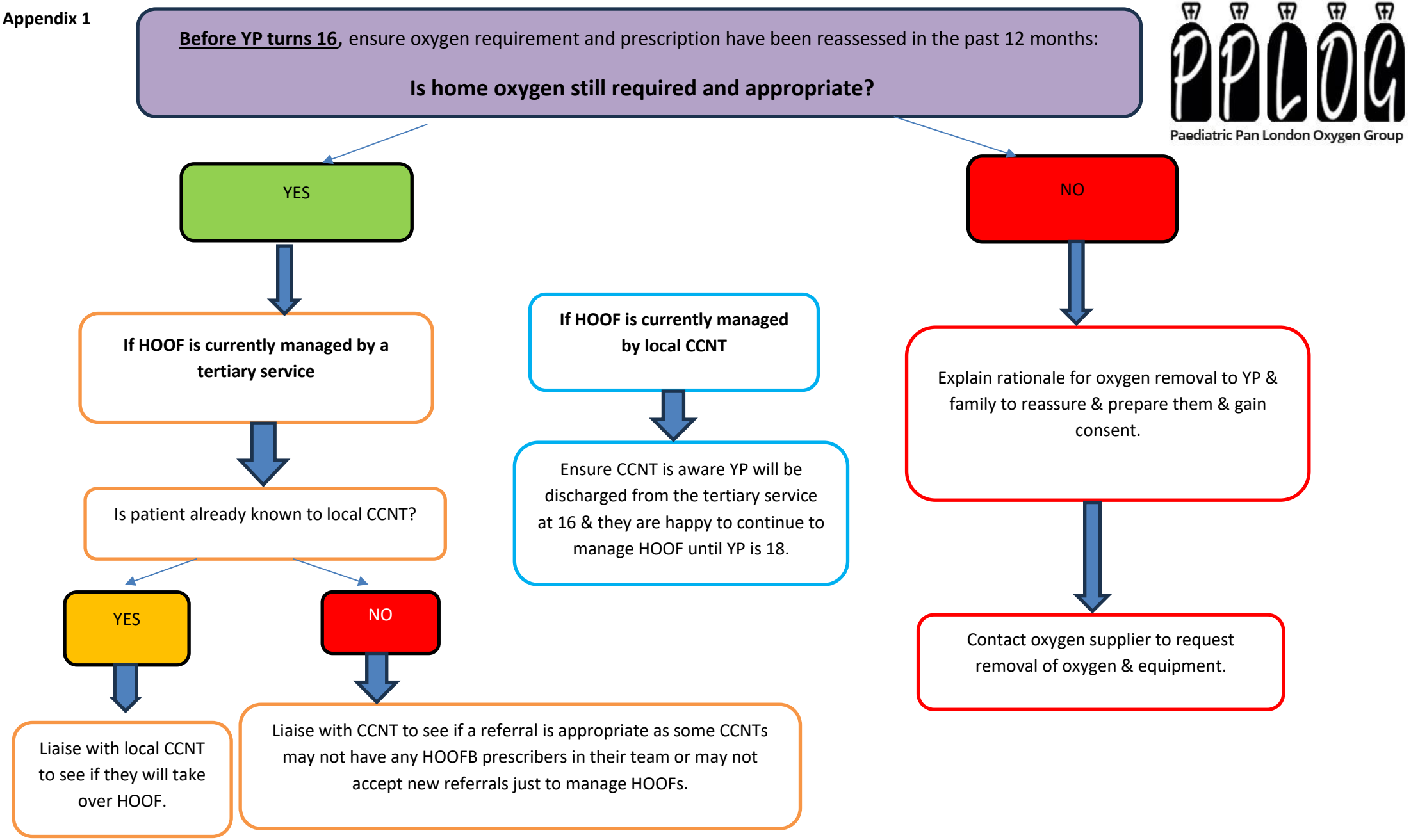
Much of the guidance for transition from paediatric to adult services recommends that a named individual, agreed with the young person, often called the key worker, co-ordinator or lead professional, works with the young person to co-ordinate their transition process (NICE, 2016, WellChild 2024, Scope 2025, Together for short lives 2016, NCPOD 2023). In Adolescent transition care: RCN guidance for nursing staff, the Royal College of Nursing (2013) noted that whilst in most hospitals the key worker is likely to be a children's clinical nurse specialist, or even an adolescent specialist nurse, this role could also be undertaken by another professional, such as a community nurse, social worker, general practitioner (GP) or occupational therapist (RCN, 2013). In the case of transition from paediatric to adult home oxygen services, the key worker is most likely the professional who has last completed or updated the home oxygen order form (HOOF) as the specialist overseeing the home oxygen care. This is most likely to be the children's community nurse (CCN) or clinical nurse specialist (CNS).

It is vital to identify the young person's home oxygen needs before transition of services. Whilst some patients are actively using home oxygen, there are some patient's where this is not the case. This is not only a clinical risk if oxygen is needed, but an inefficient use of resources and an unnecessary safety/fire risk if it is no longer required. This, however, should be determined during annual reviews. Where oxygen is no longer appropriate, the patient/carer will need education and support around the removal process. There is often a psychological reluctance to give the oxygen up as it causes anxiety to not have this readily available even if not clinically required. The recommendation would be to educate the child, young person (CYP) and parents when commencing home oxygen therapy, that when it is no longer needed it will be removed. This supported in the template annual review letter within the PPLOG Discharge Bundle (2025).

The objectives of this document:

- To understand the differences in paediatric and adult home oxygen service provision.
- To support paediatric & adult oxygen services in ensuring a smooth and co-ordinated transfer of care to adult services.
- To reduce stress on the young person/carer/parents by ensuring they have the information they need and know where to go locally for support.
- To reduce inappropriate use of oxygen provision.

Appendix 1


Before YP turns 16, ensure oxygen requirement and prescription have been reassessed in the past 12 months:
Is home oxygen still required and appropriate?
YES
NO
If HOOF is currently managed by a tertiary service
Is patient already known to local CCNT?
YES
NO
Liaise with local CCNT to see if they will take over HOOF.
Liaise with CCNT to see if a referral is appropriate as some CCNTs may not have any HOOFB prescribers in their team or may not accept new referrals just to manage HOOFs.
If HOOF is currently managed by local CCNT
Ensure CCNT is aware YP will be discharged from the tertiary service at 16 & they are happy to continue to manage HOOF until YP is 18.
Explain rationale for oxygen removal to YP & family to reassure & prepare them & gain consent.
Contact oxygen supplier to request removal of oxygen & equipment.

Appendix 2

<u>Before YP turns 18</u>, ensure oxygen requirement and prescription have been reassessed in the past 12 months:

Is home oxygen still required and appropriate?

If the local CCNT are unable to manage the HOOF, a discussion will need to take place between all relevant teams to determine how to proceed.

(As GPs are not normally HOOFB prescribers, it would not be appropriate to transition 16 or 17-year-olds to them).

YES

Find out if an adult respiratory or other specialist service been identified to take over the care.

Contact the **Adult HOSAR** (Home Oxygen Service: Assessment & Review) team to refer/handover the young person (inc. current oxygen prescription; diagnosis; rationale for home oxygen and any previous attempts at weaning or removal).

HOSAR is based on location of YP's GP.

NO

Explain rationale for oxygen removal to YP & family to reassure & prepare them & gain consent.

Contact oxygen supplier to request removal of oxygen & equipment.

If the HOOF is managed by CCNT, a joint home visit with the HOSAR team should be arranged to enable a smooth transition.

Guidelines:

There are more guidelines available for adult home oxygen than paediatric home oxygen. Refer to the British Thoracic Society (BTS) (2015)

Medical teams:

In children, almost all oxygen therapy is commenced and prescribed by hospital specialists (consultant paediatricians/neonatologists or specialist nurses). Depending on the age and diagnosis, the ongoing monitoring and prescribing is normally carried out by the hospital teams and/ or Children Community Nursing Team (CCNT). Please note this can vary depending on the hospital, borough and CCNT as not all community nurses will have the training or experience to oversee home oxygen prescriptions.

In adult services, most boroughs have a Home Oxygen Service Assessment and Review (HOSAR) team who undertake the management of patients' home oxygen. However, some boroughs are only managed by their home oxygen service and review team (HOSR), but they do not assess or prescribe the oxygen. Some services are also only commissioned to care for certain conditions, for example chronic obstructive pulmonary disease (COPD) or cluster headaches. Refer to Appendix 5 for details for each borough.

In adult services, the allocated HOSAR/ HOSR is determined by the borough the GP is in, whilst the CCNT is determined by the borough of the home address, as CCNT do not conduct home visits outside their borough. However, the HOOF will be managed by the CCNT where the GP is located. If a patient's GP is located in a different borough to the home address, it is strongly recommended that patient registers with a local GP.

Diagnosis:

The range of conditions seen in children is quite distinct from adults. There is a tendency for children's diseases to improve with time, or the conditions are life limiting, whereas in adults, they tend to deteriorate over time. It is very rare for adults to come off long-term oxygen therapy once prescribed as deterioration is the expected trajectory. Whereas the primary reasons for home oxygen in paediatric patients are Chronic Lung Disease (CLD), Chronic

Neonatal Lung Disease (CNLD) and neurodisability, in adults the main reasons for home oxygen use are COPD, Interstitial Lung Disease (ILD) and cluster headaches. **(BTS, 2015)**

Paediatric Pan London Oxygen Group

Indications:

Practice which appears relatively common in paediatric medicine is prescribing home oxygen for when the child is unwell or agreeing to allow patients who previously had a home oxygen requirement, to keep oxygen equipment in the home just in case it is needed in the future. This may be due to the relative lack of robust evidence in paediatrics, meaning rationalisation of prescriptions is more often left to the medical team. The focus in paediatrics is more on safeguarding, growth, development, and quality of life, rather than following strict saturation thresholds, hypercapnia considerations/risks and arterial blood gases (ABG) /capillary blood gas (CBG) results. Family-centred care, school liaison, and multidisciplinary working are also a much bigger part of paediatric care compared to adult services.

The practice of prescribing home oxygen for when unwell is not supported in adult patients so adult HOSARs/HOSRs will quickly work to have this oxygen removed. Adult clinicians taking on paediatric patients will likely struggle to review certain inherited prescriptions when the rationale in paediatrics services has often been less standardised and more individualised. Adult home oxygen guidelines are very formulaic and generally prescriptions follow strict clinic guidelines with few exceptions. It is important to inform families of this change in practice and even to liaise with the hospital team and families to attempt to have the oxygen removed before the young person turns 16 and 18.

Even though intermittent acute oxygen therapy at home is not routinely recommended for seizures in children, as there is no evidence that it reduces their duration or limits harm from prolonged seizures or improves quality of life for the child or family (BTS, 2009; National Library of Medicine 2021), healthcare professionals (HCPs) may still come across home oxygen prescriptions for seizure management. This is also not indicated in adult practice so HOSARs/HOSRs will work to cease this oxygen prescription.

Assessment:

In adult services, an arterial blood gas (ABG) or capillary blood gas (CBG) is essential to assess for long-term oxygen therapy, with pulse oximetry used mainly for ambulatory assessments. Adult thresholds are stricter than paediatrics and are guided by evidence around morbidity and mortality. By contrast, children are almost always assessed with pulse oximetry because it is less invasive and more tolerable. Paediatric services aim for higher saturations to protect growth and neurodevelopment. Sleep studies such as cardiorespiratory, oxygen titration and overnight oximetry's are also common in paediatrics,

since many children desaturate primarily at night. Sleep studies are seen more in adults with obstructive sleep apnoea, or with chronic hypercapnia/Type 2 Respiratory Failure (T2RF).

Equipment:

The flow rate requirements for children are often much lower (<1 L/min) than in adults, requiring precision flow meters and child-specific cannulae/masks. Ambulatory oxygen is crucial to allow normal play, school attendance, and development, so mobility is prioritised more. Parental training and safety education are also an essential part of the process.

Lightweight ambulatory cylinders are sometimes considered in paediatrics for children to carry around school with them.

Some adults on home oxygen are housebound therefore requiring less ambulatory equipment.

Many adults prescribed long term oxygen therapy, have ambulatory oxygen, but this is often for short exertional activity within the home rather than extensive outdoor use or an extension of their LTOT, since many are frail or less mobile.

Equipment decisions in adults balance mobility with frailty and comorbidities.

Schools:

Young people who require an oxygen supply in their educational setting, may need oxygen to be supplied in their college/university or workplace. Early liaison with any potential new settings would be beneficial.

Complex needs:

With modern advances in medicine and in healthcare, the population of children and young people with neurodisabilities are reaching adulthood in comparison to previous generations (Homer and Hughes, 2025). The WellChild (2023) guidance suggests that young people with neurodisabilities, complex health needs, and learning disabilities may benefit from the transition process starting sooner. These young people, will be known to several specialist teams and will have various additional needs aside from their home oxygen requirement; all of which will need to be implemented into the transition process. Adequate time is therefore required for planning the transition in order to ensure that it is a seamless process.

Additionally, the services available to this cohort of young people varies as the service provision differs depending on the geographical location the young person lives in, in the UK (WellChild, 2023). Those with neurodisabilities and who are on home oxygen therapy, are often followed up by a General Paediatrician or a Specialist Respiratory Consultant/clinical nurse specialist during their time in paediatric services. However, when it comes to adult services, many of these young people do not meet the criteria for a referral to a specialist adult respiratory team/ tertiary centre regardless of still needing supplemental home oxygen therapy and with their extensive co-morbidities. These young people are therefore discharged back to the GP for ongoing follow up. Hence, the GP plays a pivotal role in the transition process of these individuals (NICE guidelines, 2023) thus, it is imperative to check that the young person has a named GP and that the GP is included in all aspects throughout the transition process (NICE guidelines, 2025).

Though the process of transition should start early, when it comes to the children's community nursing and continuing care teams, you may find that the active transition of these young people to adult services is delayed until their 18th birthday. This is because they remain eligible to receive care from the NHS continuing healthcare service until they turn eighteen. This is according to the National Framework for Children and Young people's Continuing care (2016). For that reason, there may be a difference in the timeline of when a young person is transitioned between hospital teams and community teams.

The Mental Capacity Act (2005) states that when a young person becomes 16 years of age, they are ultimately regarded as being able to make decisions for themselves unless they have been assessed to be lacking capacity. Please refer to the Mental Health Act (2005) for more information. Any individual lacking the mental capacity to make informed decisions regarding their health may not be able to give consent. This being a key element to consider when it comes both providing care and transitioning a young person with complex health needs, learning disabilities or neurodisabilities. Consent in healthcare refers to when an individual is able to provide permission prior to receiving any form of medical treatment and/or undergoing any investigation (NHS,

2022). Young people with complex health needs, learning disabilities and/or neurodisabilities, may not be able to give consent or may lack the mental capacity to make informed decisions about their healthcare (NHS, 2022). In this instance, either the medical professionals caring for the young person will make decisions in their best interest (ref), or the parent/ guardian of the young person may have applied via the court for 'lasting power of attorney' (LPA). If a parent/ guardian has been appointed as the LPA, they are legally permitted to make decisions for the health and welfare for that particular young person (NHS, 2024).

Transition Checklist:

Appendix 3:

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Patient name:	
DOB:	
NHS/ Hospital Number:	
Address:	
Secondary address (if applicable):	
Education setting (if HOOF present):	
Contact detail:	

Diagnosis: **Last sleep study:**	
Is oxygen therapy still required?	☐ YES ☐ NO
HOOF updated? **Date of last update?**	☐ YES ☐ NO
Is the current oxygen equipment still appropriate?	☐ YES ☐ NO If no, amend HOOF

Current HOOF:

Current flow rate:	
Current hours of usage:	
Current oxygen equipment:	Static: _____ Ambulatory: _____ Consumables:

Young person:

Has transition been discussed with the Young person and Family?	☐ YES ☐ NO
Identify accepting teams:	
Young person aware of role of different teams?	☐ YES ☐ NO ☐ N/A
Young person can describe their condition?	☐ YES ☐ NO ☐ N/A

Young person aware of their oxygen flow rate/ prescription?	☐ YES ☐ NO ☐ N/A
Young person trained in:	How to safely manage home oxygen therapy: ☐ YES ☐ NO ☐ N/A
	Knows how to use oxygen equipment: ☐ YES ☐ NO ☐ N/A
Date when training was completed:	
Young person knows how to order oxygen refills and how to troubleshoot with oxygen company?	☐ YES ☐ NO ☐ N/A

Paediatric Pan London Oxygen Group

Essential documents to handover:

Home oxygen assessment:	☐ YES ☐ NO
HOCF:	☐ YES ☐ NO
HOOF & IHORM:	☐ YES ☐ NO
Young person's oxygen competencies:	☐ YES ☐ NO ☐ N/A
Respiratory Escalation Care plan:	☐ YES ☐ NO

Paediatric Pan London Oxygen Group

Appendix 4

Home Oxygen Transition Patient Questionnaire to help you prepare for the transition of paediatric home oxygen services to adult home oxygen services

The medical and nursing team aim to help prepare you for transition from paediatric home oxygen services to adult home oxygen services. This questionnaire aims for you to assess yourself using the self – assessment confidence score to rate where you are so that the team can further support you to gain the confidence and skills to take charge of your home oxygen.

Using the Questionnaire:

Indicate in the **Yes**, **No, N/A or unsure** column to answer each of the statements below.

	Yes	No, I need some help	N/A	Unsure
Knowledge about my home oxygen				
I know why I am on home oxygen				
I know how much oxygen I am prescribed				
I know what equipment I have for my home oxygen				

I understand my home oxygen plan				
I understand that the oxygen equipment I currently use may change				
I understand that if I no longer require oxygen, the oxygen will need to be removed				
Consultations/Hospital visits				
I understand what the Doctors and Nurses say to me				
I can ask the doctor/nurse/therapists questions				
My parents/ guardian usually reminds me about my appointments				
I know when, where and with whom I have my next appointments				
I keep a record of my outpatient appointment e.g. diary/calendar/phone				
Personal responsibilities				
I am responsible for using my home oxygen				

I have completed the home oxygen competency with a nurse and I have a copy of my home oxygen competency				
I keep an eye on when my home oxygen equipment needs replacing or servicing without being reminded				
My parents/guardian always sort out my home oxygen orders				
I can arrange for a re-fill or service of my home oxygen equipment				
I know what to do if the alarm on my concentrator sounds				
I can attend to any alarms on my home oxygen equipment				
My parents/ guardian always attend to any alarms on my home oxygen equipment				
My general health and being independent				
I know what to do if I suddenly become unwell				

I know how to contact my GP				
I know where to get advice about different health issues.				
I do worry about my health				
I want to know more about how my home oxygen helps me				
I know about the risks of smoking/ e-cigarettes/vaping				
I know about the risks of misusing legal and illegal drugs				
I know about the effects of alcohol				
Education				
I feel confident that I can communicate my health needs to my college or school lecturers/teachers				

I have a secondary supply of oxygen at school or college and I know how this is ordered				
Work				
I am confident about discussing my use of oxygen with a future employer. (Where oxygen may be used in the workplace)				
I know that my use of oxygen and underlying condition may affect my ability to do certain jobs				
Leisure				
My friends understand that I use oxygen and are helpful				
I know that my use of home oxygen does not affect all activities that I might want to try				
I know what support is available in my local community and which organisations can help				

Health Transition to adult services				
I understand the meaning of transition to adult services				
I understand what confidentiality means				
I feel I am ready to be seen alone for part of my hospital visits				
I find it easy to talk to my Doctors and Nurses alone				
I feel I need some support to explain my needs during clinic visits				
I feel I am ready to start preparing for transition by developing a Health Plan				
I know the names and roles of the doctors, nurses, therapists and GP that I will be seeing in adult services and how to contact them				
I have agreed a transfer plan with dates with the members of the children's and adult healthcare team				
I feel confident that I can deal with Doctors and Nurses in A&E without my parents help				

Paediatric Pan London Oxygen Group

Appendix 5: London Adult Home Oxygen Services Assessment Review (HOS-AR) Directory

Please note different teams follow different referral pathways. Contact the relevant team (based on the location of the patient's GP) to obtain details of their referral process.

Some teams are HOSR only, so they do not assess or prescribe oxygen.

Some services are also only commissioned to care for certain conditions, for example COPD.

These differences highlight the importance of liaising with the adult service in your borough as early as possible.

London Regions

NHS North Central London

NHS Northwest London

NHS East London

NHS Southwest London

NHS Southeast London

NHS North Central London

Barnet: hos.barnet@nhs.net 07943 828371

Camden: cnwl.camdenhosar@nhs.net 0203 317 5355

Enfield: nclicb.hos.enfield@nhs.net 0204 553 5693

Haringey: whh-tr.hanigeyhos@nhs.net 0207 288 5474 (HOSR only)

Islington: whh-tr.islingtonhos@nhs.net (HOSR only)

NHS Northwest London

Brent: clcht.brentcomrespiratory@nhs.net 0208 102 3456 (Option 2 & 6)

Kensington, Chelsea & Westminster: imperial.kcw-hosar@nhs.net 07554 330644

Ealing: HOSAR-wlm.tr.hosar.casemanagement@nhs.net 0300 123 4544

Hammersmith & Fulham: imperial.hf-hosar@nhs.net 0203 311 7161 option 2

Harrow: clcht.harrowhos@nhs.net

Hillingdon: rbh-tr.hos.hillingdon@nhs.net 0330 128 5021

Hounslow: wlm-tr.hounslowrespiratory@nhs.net 07484 913795

NHS East London

Barking & Dagenham: respiratory.BD@nelft.nhs.uk 0300 300 1761

Havering: havoxygen@neflt.nhs.uk 0300 300 1551

Redbridge: hos.Redbridge@nelft.nhs.uk 0300 300 1826

Waltham Forest: hoswalthamforest@nelft.nhs.uk 0300 300 1710

City & Hackney: homertonCOPD@nhs.net 0208 510 5107

Newham: bartshealth.nuh.oxygenservice@nhs.net 0207 363 9026

Tower Hamlets: bartshealth.hostowerhamlets@nhs.net 0208 223 8509/07733 179433

NHS Southwest London

Croydon: ch-tr.crt@nhs.net 020 8401 3974 Option 2

Kingston: khft.kingstonhospitaloxygeb@nhs.net

Merton: CLCHT.MertonRespiratory@nhs.net 0333 241 4242

Richmond: Richmond.rct@nhs.net 0208 487 1783

Sutton: esth.shc-respiratory@nhs.net 0208 296 4111

Wandsworth: clcht.wandsworthoxygen@nhs.net

NHS Southeast London

Bexley: oxl-tr.hosbexley@nhs.net 0208 320 3345

Bromley: bromh.bromleyhosar@nhs.net 0300 330 5777

Greenwich: oxl-tr.COPD@nhs.net 0208 320 3340

Lambeth & Southwark: kch-tr.oxygen@nhs.net

Lewisham: lg.respiratorynursingteam@nhs.net 0208 333 3210/0203 192 6187

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