Paediatric Pan London Oxygen Group

Guidance Document

Home oxygen Paediatric to Adult Transitional approach

PPLOG Home Oxygen Paediatric to Adult Transitional Authors:

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Introduction

Across London there are approximately 870 children prescribed home oxygen. Of these, 128 are between 14-17 years old (Air Liquide concordance data November 2020). Ideally, the process of transitioning begins around the age of 14 years of age before potentially moving across to adult services (NICE, 2016). For groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest. For young people entering the service close to the point of transfer, planning should start immediately (NICE, 2016).

This process may be confusing and sometimes frightening for Children Young People (CYP) and their families preparing for approaching adulthood, and will require support and advice to navigate between the services.

Whilst some of these patients are actively using the oxygen, there are many where this is not the case. This is a clinical risk if oxygen is needed, but a waste of resources and an unnecessary fire risk if it is no longer required. 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. Ideally parents should be informed before initiation that at some point it may no longer be needed and therefore removed.

Although home oxygen therapy is commonly required in the care of children, there is a striking lack of empirical evidence regarding implementation, monitoring, and discontinuation of supplemental oxygen therapy (ATS 2018). The recommendation would be to educate the child & parent at the start of home oxygen therapy that when it is no longer needed it will be removed. However historically this has not been the case, hopefully going forward and with this and other PPLOG guidance we will see improvement. The lack of care pathways and support can result in the family becoming the ‘expert carers’ with the danger of the family being over confident in management of the oxygen therapy.

Transition is the process of moving between services for example from neonatal to paediatrics or paediatrics to adult services. For the purpose of this guidance, this document is focussing on CYP to adult services. It refers to assessment, initial planning, actual transfer between services and support given throughout the process (NICE 2016)

Young people who have been diagnosed with a long term health condition during childhood should be supported by dedicated children’s services, working with their parent(s) or guardian(s). However, some children are discharged by the community team due to not requiring ongoing care from the community team and that these are the young people that are at risk of being ‘lost to follow- up’. (QNI 2018).

Once people reach young adulthood, they need to transition to adult health services. This process can be stressful and confusing for young people and their families, if for example there are gaps in communication or lack of joined-up working (QNI 2018).

According to the document," From the pond into the sea" (CCG 2014) there is inconsistent and often poor information and preparation from children's services for young people and their parents about the changes they can expect as they move into adult services. This leads to a lack of understanding of the process of transition.

This guideline aims to reduce this stress and confusion and to enable continuity of care for these patients.

The objectives of this document

- To support paediatric & adult oxygen services in ensuring a smooth and co-ordinated transfer of care to adult services.
- To reduce stress on the child/young person/carer/parents by ensuring they have the information they need and know where to go locally for support.
- To reduce wastage in oxygen provision that is not required or appropriate.

Guidance from the Department of Health (DH, 2008) recommends that a named individual, often called the key worker, co-ordinator or lead professional, works with the young person to co-ordinate their transition process. The health or care professional who undertakes this role should be agreed with the young person and should either be a transition key worker, a professional from the children's services, or a professional from the adult services.

In Adolescent transition care: RCN guidance for nursing staff, the Royal College of Nursing (RCN) noted that whilst in most hospitals the key worker is likely to be a children's nurse specialist, or even an adolescent specialist nurse, this role could also be undertaken by another professional, such as a community nurse, social worker, GP or occupational therapist (RCN, 2013a).

Whilst tertiary and specialist centres may have access to transitioning or adolescent specialists, these will not be available to those seen in the community or local hospitals. There is a directory of adult services at

Within paediatric services there needs to be an identified lead for transitioning (NICE 2016). Currently, this is not happening and many patients are not effectively transferred to adult services, which causes frustration and stress to both patients and clinicians.

Those in children's and adult services will need to develop their skills and knowledge of communicating with young people. It is difficult both for staff trained to support younger children as well as for those used to working with older people. (Together for short lives .2015). There is training available on the mefirst website, Great Ormond street hospital to support staff to develop. https://www.mefirst.org.uk/training/

"*When I was a child I was a human. When I turned 16 I became a number*". (QNI 2017)

Transitioning to Adult oxygen services

- Before transitioning, has the CYP been reassessed and the oxygen been reviewed?

- Who is responsible for doing this in your area?
- Is there a documented plan for adult services to take over care.
- Has there been a communication with the adult team.See appendix 3 for template

If not, how do you overcome the lack of services and identify resources available?

Is oxygen still needed and appropriate?

- If no longer appropriate, then prepare the young person's family for removal. Families must be supported during this transition.
- Explain rationale; reassure parents and remove (it is never easy especially if it has been in a long time. Some input and work will be required to win over trust from parents and reassure them).

If oxygen is to continue: -

- Do you know who the adult Home Oxygen Service – Assessment and Review (HOSAR) are and how to contact them? (Appendix ….)
- Liaise with the adult service to ensure continuity of care
- Oxygen use in Adults is different to paediatric use. The equipment used is often different with concentrators being used, however in children many are still using static cylinders
- Ensure carers/patients are given contact numbers for adult services in their area. (See appendix…)
- Ensure the CYP has been taught how to use their oxygen and how to order it. It will start to become their responsibility.
- Consider if they are moving away to University? Do they need further instructions and support to ensure they have a supply? This may also affect any accommodation.
- Do they need a secondary supply?
- Do they need to transfer to a team out of the area?

What differences are there between adult and paediatric practice?

Diagnosis

The range of conditions seen in children where continual oxygen is required is quite distinct from adults. There is a tendency for children's diseases to improve with time or the conditions are life limiting, whereas with adults, they tend to deteriorate over time.
There are more guidelines available for adult home oxygen, short burst oxygen is not recommended and for long term oxygen there needs to be 16 hours a day minimum of use. The BTS guideline for home oxygen in adults is the guidance followed by Adults services for Home Oxygen therapy and this will impact on their prescription. It is vital to communicate this change to prescribing from what they have been used to. (BTS 2015).

All patients receiving Home oxygen should be reviewed annually at the minimum and their HOOF updated.

Oxygen therapy CYP

The aim of oxygen therapy is to maintain oxygen saturation of above 92%. Adult patients with resting stable oxygen saturation (SpO2) of ≤92% should be referred for a blood gas assessment in order to assess eligibility for LTOT (BTS 2015). CYP may require supplemental oxygen, either for 24-hours a day or during periods of sleep; many children are eventually weaned off oxygen therapy as their condition improves.

Ordering oxygen

In children, almost all oxygen therapy is commenced and prescribed by hospital specialists (consultant paediatricians/neonatologist or specialist nurses). Depending on the age and the diagnosis, the ongoing instructions and monitoring is carried out by the community nursing team and hospital teams. For children who require continuing care, there is a reliance and expectation from discharging secondary care and tertiary centres, that the child's ongoing oxygen needs will be coordinated locally. However, the prescribing of oxygen is seen as a specialist skill and community teams may not have the necessary skills and knowledge or support to be able to oversee this.

There is a lack of understanding around equipment available to best meet the child's needs. PPLOG has been trying to address this gap by providing training and guidance, including the PPLOG discharge bundle to improve knowledge of oxygen, its use and equipment available. https://www.networks.nhs.uk/nhs-networks/london-lungs/documents/management-of-child-on-home-oxygen-documents-final-discharge-bundle

Assessment

In children, almost all oxygen assessments are done by pulse oximetry and not arterial blood sampling. Infants with chronic neonatal lung disease and older children may undergo sleep studies with transcutaneous C02 monitoring. There is a huge unwarranted variation in practice guidance for weaning infants on home oxygen therapy. PPLOG expect to launch their weaning guideline in early 2021 to address this and improve care and provide best practice. .

Growth and neurodevelopment

These are important considerations in children. The brain uses a tremendous amount of oxygen to facilitate growth and development in order to function. When the amount of oxygen that is available to the brain is temporarily reduced, we know that vulnerable brain structures can become damaged. MRI (magnetic resonance imagining) scans tell us that hypoxia can target a part of the brain called the hippocampus and cause damage (GOSH)**.** The severity and persistence of neurocognitive deficit may be determined not only by the extent hypoxia depletes the brain's energy reserve but, also by the manner in which the brain responds to this challenge (Kirkham et al 2006).

Equipment

The flow rate requirements for younger CYPs are much lower than that of an adult. Specific low flow equipment enables this to be facilitated. As the CYP grows this will need to be

reviewed. Almost all children receiving continuous oxygen therapy at home and also require portable oxygen therapy as they are rarely housebound. Many older children have continuous oxygen for more than 15 hours a day and meeting these needs can be challenging if they are out and about for an inordinate amount of time during the day. It is important to facilitate a discussion with the CYP to choose the most suitable equipment to meet their individual lifestyle.
Equipment available from Air Liquide can be found here;
https://www.airliquidehealthcare.co.uk/home-oxygen-service-healthcare-professionals/home-oxygen-equipment

Care and safety considerations

With the exception of some older children, almost all children require supervision from a parent/carer. However, the mental capacity act states that those over 16years old have capacity to make their own decisions The Mental Capacity Act 2005(MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. The CYP and/or carer will need to have clear information on how to use the equipment safely.

Preschool/school.

Provision of oxygen may be necessary at nursery or school so that the child can play a full and active role in school life, remain healthy and achieve their academic potential (BTS 2009; Gov.uk)
Due to the nature of oxygen and its associated risks, it is imperative that an oxygen risk assessment should be undertaken in the educational setting prior to the child's attendance. This will identify any associated fire risks so that appropriate actions can be taken to mitigate them. PPLOG has produced guidance for schools which will be published in 2021. When transitioning, it is important to remember that oxygen may need to be removed from the CYP's current place of education and they may require support managing the process of installation in a new location, such as a university or place of work.

Glossary of conditions that may need home oxygen

- Bronchopulmonary dysplasia (chronic neonatal lung disease);
- Congenital heart disease with pulmonary hypertension;
- Pulmonary hypertension secondary to pulmonary disease;
- Idiopathic pulmonary hypertension;
- Sickle-cell disease with persistent nocturnal hypoxia;
- Interstitial lung disease and obliterative bronchiolitis;
- Cystic fibrosis;
- Obstructive sleep apnoea syndrome;
- Neuromuscular or skeletal disease requiring non-invasive ventilation;
- Pulmonary malignancy or other terminal disease with disabling dyspnoea.
  Increased respiratory depression is seldom a problem in children with stable respiratory failure treated with low concentrations of oxygen although it may occur during exacerbations; children and their carers should be warned to call for medical help if drowsiness or confusion occurs.(BNF for Children)

References

Adolescent transition care: RCN guidance for nursing staff, the Royal College of Nursing (RCN)Royal College of Nursing (2013) *Adolescent Transition Care: RCN Guidance for Nursing Staff*.

ATS-Home Oxygen Therapy for Children-An Official American Thoracic Society Clinical Practice Guideline. Hayes et al-2018.
https://www.atsjournals.org/doi/pdf/10.1164/rccm.201812-2276ST

British Thoracic Society for home oxygen in adults (2015)
https://thorax.bmj.com/content/thoraxjnl/70/Suppl_1/i1.full.pdf

BNF for Children https://bnfc.nice.org.uk/treatment-summary/oxygen.html

BTS guideline for home oxygen in children 2009 Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England. December 2015
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803956/supporting-pupils-at-school-with-medical-conditions.pdf

BTS guideline for home oxygen in adults -2015
https://thorax.bmj.com/content/thoraxjnl/70/Suppl_1/i1.full.pdf

CQC From the pond into the sea: Children's transition to adult health services 2014
https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

Hypoxic adaptation during development: relation to pattern of neurological presentation and cognitive disability Kirkham, Fenella J.; Datta, Avijit K.
Developmental Science , Volume 9 (4) – Jul 1, 2006
https://www.deepdyve.com/lp/wiley/hypoxic-adaptation-during-development-relation-to-pattern-of-oqCG2Ze30D

Hypoxia and memory impairment in children
https://www.gosh.nhs.uk/medical-information/clinical-specialties/neuro.

Nice guideline 43 Transition from children's to adults' services for young people using health or social care services https://www.nice.org.uk/guidance/ng43

Queens nurse Institute. Transition of care programme 2018
https://www.qni.org.uk/nursing-in-the-community/from-child-to-adult/

Transition of Care Conference Summary
Transition through a patient's eyes - Hannah Phillips 10 November 2017
https://www.qni.org.uk/wp-content/uploads/2017/09/Transition-of-Care-Conference-Summary.pdf

Together for short lives 2015
https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/02/ProRes-Stepping-Up-Transition-Care-Pathway.pdf

Appendix 1: PPLOG transition checklist

Name	
DOB	
Hospital number	
Address	
Phone number	

Current flow rate	
Current hours usage	
Current equipment	
Date of last HOOF	
Reason for receiving oxygen *(diagnosis)*	

Is the oxygen still required?	Yes □ No □ If no, Remove oxygen from home
Is HOOF up to date?	Yes □ No □ If no, then update.
Is oxygen equipment still appropriate?	Yes □ No □ If no, then amend oxygen supply.
Risk assessments/ competency review required?	Does the young person know how to look after their own oxygen?

Has the discharge process been discussed with the family	Yes □ No □	
Identify accepting teams	Medical team	
	HOSAR service	
Young person knows who's who in the medical and nursing Team	Yes □ No □ Not applicable □	
Fill out referral letter template and send it via a secure email address		
Young person can describe their condition	Yes □ No □ Not applicable □	
Young person knows their flow rate	Yes □ No □ Not applicable □	
Young person knows how to operate their equipment	Yes □ No □ Not applicable □	
Young person knows how to order oxygen refills	Yes □ No □ Not applicable □	
Ensure HOOF B prescriber is changed on the portal		
Young person knows the risk associated with smoking & oxygen		

Appendix 2: Home Oxygen Transition Patient Questionnaire

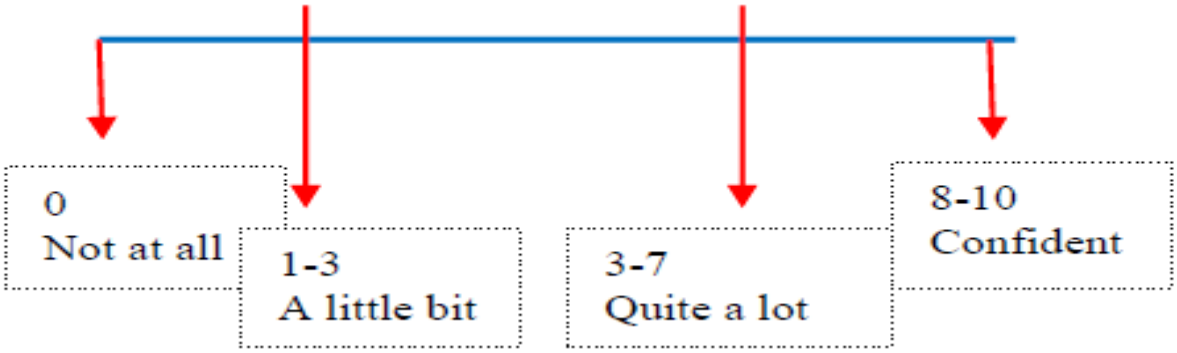
Home Oxygen Transition Patient Questionnaire to help you prepare for the transition of paediatric home oxygen services to adult home oxygen services

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** or **No** column to answer each of the statements below. Where you have answered **Yes**, then please rate your confidence using the confidence rating scale below. Where you have answered **No** this will automatically generate a confidence scoring of 0. Please indicate where you need some help.

Self – assessment confidence score:



	Yes	No	I need some help
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 usually remind 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 (score 8-10) or My parents always sort out my home oxygen orders (score 1-3)			
I can arrange for a re-fill or service of my home oxygen equipment			
I can attend to any alarms on my home oxygen equipment (score 8-10) or my parents always attend to any alarms on my home oxygen equipment (score 1-3)			
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			
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 and I know how this is ordered			
Work			
I have a career plan			
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 at home 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 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			

Appendix 3: London Home Oxygen Services Assessment Review (HOS-AR) Directory

London Regions
NHS North Central London
NHS North West London
NHS East London
NHS South West London
NHS South East London

NHS North Central London
Barnet Community Respiratory Tel: 0208 349 7539 Email: BarnetCOPD@nhs.net

Camden COPD and Home Oxygen Service Tel: 0203 317 5355 Email: cnw-tr.respiratoryandoxygen@nhs.net

Enfield Community Respiratory Services Tel: 0208 702 5860 / 0208 702 3259 Email: beh-tr.EnfieldCommunityRespiratoryService@nhs.net

Haringey COmmunity REspiratory Team (CORE) Tel: 0207 288 5474 Email: whh-tr.haringeyhos@nhs.net

Islington COmmunity REspiratory Team (CORE) Tel: 0207 288 5474 Email: whh-tr.islingtonhos@nhs.net

NHS North West London
Brent Cardio & Respiratory Medicine Centre Tel: 0208 453 2079 Email: lnwh-tr.brentrespcomm@nhs.net

Central London Community Cardiology and Respiratory Service Oxygen Mobile: 07554330644 Email: imperial.kcw-hosar@nhs.net

Ealing Respiratory Services Tel: 0208 453 2142 Email:

Hammersmith & Fulham Community Cardio-Respiratory Service Tel: 0203 311 716 Email: RespiratoryTeamHF@nhs.net

Harrow Community Respiratory Team Tel: 0208 931 4719 / 07824319056 Email: CLCLHT.HarrowRespiratory@nhs.net

Hillingdon (Harefield Hospital) Home Oxygen Service Tel: 01895 828851 Email: rbh-tr.oxygen@nhs.net

The Hounslow Service Tel: 0800 012 1858 / 0208 630 3979 Email: BOC.clinicalservices@nhs.net

West London Community Cardiology and Respiratory Service Oxygen Mobile: 07554330644 Email: imperial.kcw-hosar@nhs.net

NHS East London
Barking & Dagenham Community Respiratory Team (IRT) Tel: 0300 300 1761 Email: respiratory.bdchs@nhs.net

Havering Community Respiratory Team (IRT) Tel: 0300 300 1551 Email: Hav.respiratory@nhs.net

Redbridge Community Respiratory Team (IRT) Tel: 0300 300 1826 Email: hos.Redbridge@nhs.net

Waltham Forest Community Respiratory Service
Tel: 0300 300 1710 ext 66055 Email: nem-tr.hoswalthamforest@nhs.net

City & Hackney ACER Respiratory Team Tel: 0208 510 5107 Email: HomertonCOPD@nhs.net

Newham REDS Community Team Newham Hospital Respiratory Team: 0207 476 4000 Blp 4144 Community Chest Clinic: 0208 586 5014/5229 Email: bhnt.nuh_redsteam@nhs.net

Tower Hamlets Adult Respiratory Care and REhabilitation Team (ARCaRe) Oxygen Mobile: 07733179433 Email: Nelcsu.hos.towerhamlets@nhs.net

NHS South West London
Croydon Respiratory Team (CRT) Tel: 020 8401 3974 Option 2, Option 2 Email: ch-tr.hos.croydon@nhs.net

Kingston Hospital Respiratory Department Tel: 020 8934 3347 Email: nelcsu.hoskingston@nhs.net
Merton Cardio-Respiratory CommunityTeam Tel: 0333 241 4242 Email: CLCHT.MertonRespiratory@nhs.net

Richmond Community Respiratory Care Team Tel: 0208 487 1783 Email: richmond.rct@nhs.net

Sutton Community Respiratory Team Tel: 0208 296 4100 Email: esth.shc-respiratory@nhs.net

Wandsworth Community Respiratory Team Tel: 0333 300 2350 Email:

NHS South East London
Bexley Community Respiratory Team Tel: 0208 320 3345 Email: oxl-tr.bexleyrespiratoryteam@nhs.net

Bromley Oxleas Community COPD Team Tel: 0300 330 5777 Email: bromh.cccpod2@nhs.net

Greenwich Community COPD Team Tel: 0208 320 3340 Email: oxl-tr.COPD@nhs.net

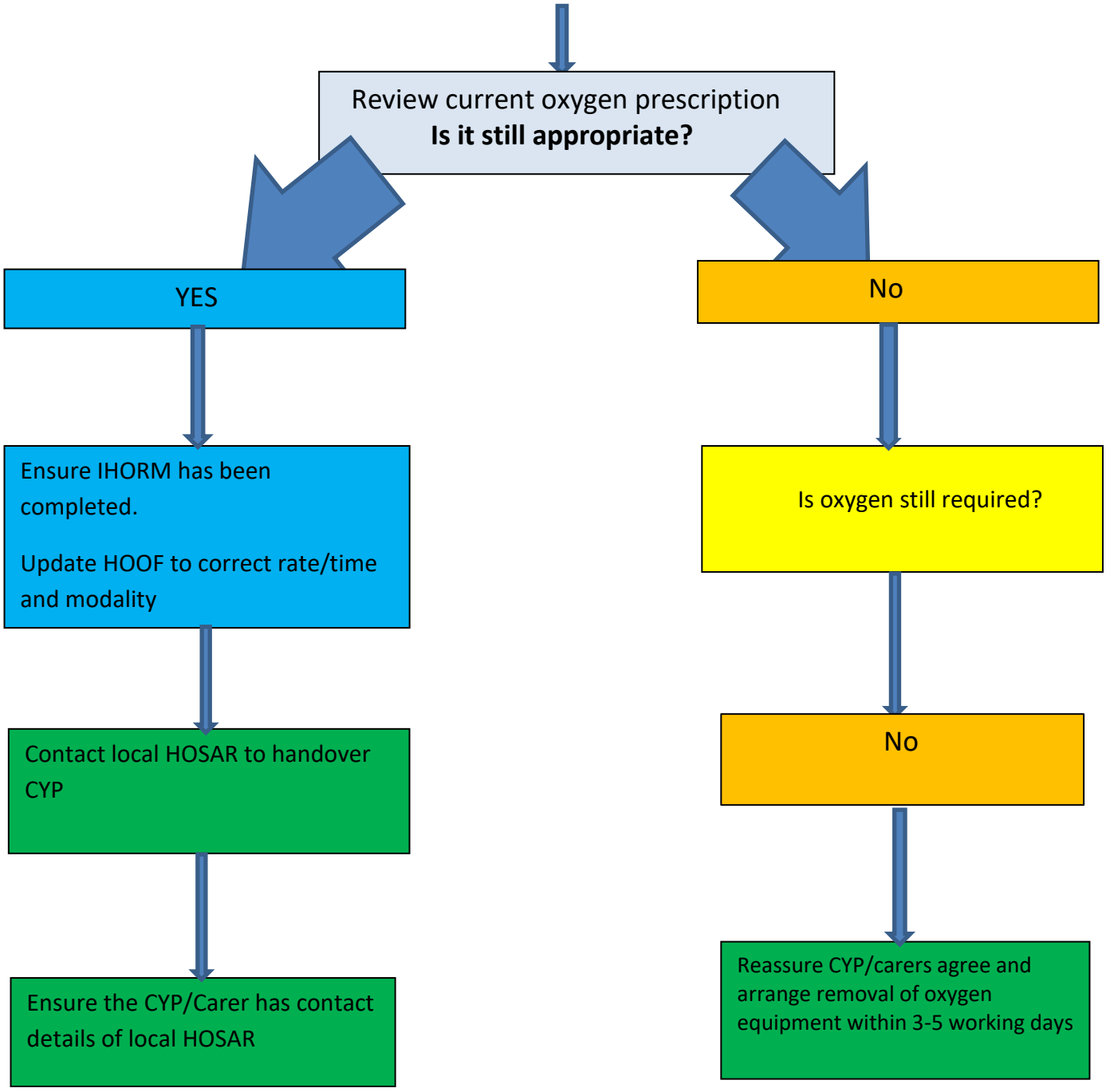
Lambeth Integrated Respiratory Team (IRT) Tel: 0203 299 4740 Email: kch-tr.oxygen@nhs.net

Lewisham Respiratory Team Tel: 0208 333 3210 / 0203 192 6178 Email: lg.respiratorynursingteam@nhs.net

Southwark Integrated Respiratory Team (IRT) Tel: 0207 188 8636
LTOT: gst-tr.ltotrefferalgstft@nhs.net;
AO: gst-tr.ambulatory-oxygen-referral-gstft@nhs.net

Appendix 4: Flow chart - Transitioning a CYP on home oxygen to adult services

Transitioning a CYP on home oxygen to adult services



CYP – Children & Young people
IHORM - Initial Home Oxygen Risk Mitigation Form
HOSAR - Home Oxygen Service Assessment and Review
HOOF - Home Oxygen Order Form