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.

Debbie Roots, cardiorespiratory nurse consultant, adult cardiorespiratory enhanced and responsive service, Homerton University Hospital, London, UK
Tamsyn Hernandez, paediatric long-term ventilation clinical nurse specialist, Evelina, London, UK
Billie Coverly, paediatric respiratory clinical nurse specialist, King's College Hospital, London, UK
Tendai Nzirawa, quality improvement manager, NHS England and NHS Improvement; Chair of the Paediatric Pan Oxygen London Group, London, UK
Caroline Lock, respiratory nurse advisor, Air Liquide, London, UK

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 Unpublished data from the London Home Oxygen Service and Medicines Management Team indicate that children and young people make up 12% of the London home oxygen population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).

All patients receiving home oxygen should be reviewed annually at minimum and their home oxygen order form updated.

Oxygen therapy for children and young people

The aim of oxygen therapy is to maintain oxygen saturation >92%. Adult patients with a resting stable oxygen saturation (SpO_2) ≤92% should be referred for a blood gas assessment in order to assess eligibility for long-term oxygen therapy (BTS, 2015). Children and young people 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 (Nzirawa, 2018; Devon Integrated Children's Services, 2018; Everitt et al, 2020; Garde et al, 2021).

Ordering oxygen

In children, almost all oxygen therapy is commenced and prescribed by hospital specialists (consultant paediatricians, neonatologists or specialist nurses). Depending on the child's age and diagnosis, ongoing instructions and monitoring are carried out by the community nursing team and hospital teams. For children who require continuous care, there is a reliance and expectation from discharging secondary care and tertiary centres that the child's ongoing oxygen needs will be co-ordinated locally. However, prescribing 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 (NHS England, 2020).

PPLOG study days have been delivered to over 500 health professionals and according to survey feedback, there is a lack of understanding around equipment available to best meet a child's needs. The PPLOG has been trying to address this gap by providing training and guidance, including the PPLOG (2018) discharge bundle, to improve knowledge of oxygen, its use and equipment available.

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 CO_2 monitoring. There is unwarranted variation in practice guidance for weaning infants on home oxygen therapy (Rahimi, 2019; Garde et al, 2021). The PPLOG (2021b) have launched a weaning guideline to address this, improve care and provide best practice.

Growth and neurodevelopment

Growth and neurodevelopment 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, vulnerable brain structures can become damaged. Magnetic resonance imagining scans have shown that hypoxia can target the hippocampus and cause damage (Great Ormond Street Hospital, 2020). The severity and persistence of neurocognitive deficits may be determined not only by the extent that hypoxia depletes the brain's energy reserve but also by the manner in which the brain responds to this challenge (Kirkham and Datta, 2006).

Prescribing home oxygen therapy for children and adults can improve life expectancy in many people with a lung condition and reduces the risk of complications, for example pulmonary hypertension, which occurs mostly in adults, and hypoxaemia and hypoxia in children (MacLean and Fitzgerald, 2006; World Health Organization, 2016).

Equipment

The flow rate requirements for younger children and young people are much lower than that of an adult. Specific low-flow equipment facilitates the provision of a suitable flow rate for children. As the child or young person grows, this will need to be reviewed. Almost all children receiving continuous oxygen therapy at home 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 large portions of the day. It is important to facilitate a discussion with the child or young person to choose the most suitable equipment to meet their individual lifestyle, and that this discussion is continued during face-to-face reviews and at the point of transition from paediatric to adult services.

Care and safety considerations

With the exception of some older children, almost all children require supervision from a parent/carer when using home oxygen services, as the administration of an inappropriate concentration of oxygen can have serious or even fatal consequences (British National Formulary, 2021). Children and young people and/or a carer will need clear information on how to use the equipment safely.

The Mental Capacity Act (NHS Health Research Authority, 2020) states that those over 16 years old have the capacity to make their own decisions. The Act is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. Decisions regarding oxygen therapy can be taken on behalf of a young person over the age of 16 years, either permanently or temporarily, if they lack the capacity to make the decision themselves. In this case, it is important that it has been clearly assessed that the young person does not understand the information relevant to the decision, is unable to retain that information or weigh it, and is unable to communicate a decision by any means. This ensures that measures are taken to protect an individual's human rights.

Preschool /school

Provision of oxygen may be necessary at nursery or school so that a child can play a full and active role in school life, remain healthy and achieve their academic potential (BTS, 2009; NHS England, 2020).

As a result of the nature of oxygen and its associated risks, it is imperative that an oxygen risk assessment should be undertaken in the educational setting before the child's attendance. This will identify any associated fire risks so that appropriate actions can be taken to mitigate them. The PPLOG (2021c) has produced guidance for schools. When transitioning, it is important to remember that oxygen may need to be removed from the children and young people'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.

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 (British National Formulary for Children, 2020).

When does the transition take place?

Ideally, the process of transitioning, which starts with identifying key professionals and initiating discussion with the child or young person, begins around the age of 14 years old, before they potentially move across to adult services (National Institute for Health and Care Excellence (NICE), 2016). For groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from school year 9 (age 13 or 14 years) at the latest. For young people entering the service close to the point of transfer, planning should start immediately (NICE, 2016). The NHS (2019) Long Term Plan section 3.47 states that selectively moving to a '0–25 years' service will improve children's experience of care, outcomes and continuity of care.

Currently, children can 'transition' to adult services from as young as 12 years old. However, failure to achieve a safe transition can lead to disengagement, failure to take responsibility for their condition and ultimately poorer health outcomes (NHS, 2019). Therefore, the plan states that by 2028, the system will have moved towards service models for young people that offer person-centred and age-appropriate care for mental and physical health needs (NHS, 2019).

BOX 1. 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

Addressing the challenges of the transition process

Understandably, this transition process can be confusing and sometimes frightening for children and young people and their families when preparing to approach adulthood. Therefore, it is important to provide as much support as possible, including advice to make it easier for them to navigate between the services (Nzirawa et al, 2017). The NHS (2019) Long Term Plan states its plans to expand children and young people mental health services in the next 5 years, and new approaches to young adult mental health services for people aged 18–25 years in order to support the transition to adulthood. The PPLOG hopes that by using the guidance outlined in this article as part of holistic and tailored healthcare delivery, clinical commissioning groups and integrated care systems might make financial savings and use the guidance as a preventative mechanism for children and young people to minimise unnecessary anxiety and confusion.

While some children and young people with home oxygen therapy are actively using oxygen, many are not. 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, children and young people or their 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 carer(s) 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 (American Thoracic Society, 2018). It is recommended that the child/young person and their parent or carer(s) are informed at the start of home oxygen therapy that when it is no longer needed it will be removed (Nzirawa, 2015; 2018; Nzirawa et al, 2017; Wilson et al, 2019). However, historically, this has not been the case (Nzirawa, 2018; Hayes et al, 2018; Rahimi, 2019). Going forward, with this and other guidance from the PPLOG, the authors hope that improvement will be seen.

The lack of care pathways and support can result in a family becoming 'expert carers'; this can be dangerous if a family becomes overconfident in their abilities to manage oxygen therapy without proper training or competencies. It is important to ensure that families are seen as partners in care and that there is collaboration between a family and healthcare professionals (Nursing and Midwifery Council, 2015; Nzirawa, 2015; Department for Education, 2020).

The transition

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, the focus is on the transition for children and young people from paediatric to adult home oxygen 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). *Box 1* shows a list of long-term conditions that may require home oxygen. However, some children are discharged by the community team because they do not require ongoing care from the community team. These young people are at risk of being 'lost to follow-up' (Queen's Nursing Institute (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 a lack of joined-up working (QNI, 2018).

The Care Quality Commission (2014) has reported that there is inconsistent and often poor information and preparation from children's services for young people and their carer(s) about the changes they can expect as they move into adult services. This leads to a lack of understanding of the process of transition.

Table 1. Paediatric Pan London Oxygen Group transition and transfer checklist

Name:	
Date of birth:	
Hospital number:	
NHS number:	
Address:	
Phone number and email address:	
Current flow rate:	
Current hours usage:	
Current equipment:	
Date of last home oxygen order form:	
Reason for receiving oxygen (diagnosis):	
Is the oxygen still required?	Yes ☐ No ☐ If no, remove oxygen from home
Is home oxygen order form up to date?	Yes ☐ No ☐ If no, then update
Is oxygen equipment still appropriate?	Yes ☐ No ☐ If no, then amend oxygen supply
Are 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 ☐
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 ☐
Young person knows the risk associated with smoking and oxygen:	
Ensure home oxygen order form B prescriber is changed on the portal	

A completed copy of this document is to be shared via a secure email address with the relevant home oxygen service assessment and review

This guidance aims to reduce this stress and confusion and to enable continuity of care for these patients, through the use of a transition and transfer checklist (*Table 1*) and a patient questionnaire (*Table 2*).

This guidance was developed after PPLOG study days feedback from health professionals and commissioners highlighted a gap in service delivery and guidance in this group of patients. Data from the Medicines Management and Optimisation London Home Oxygen Service and Air Liquide London indicated there was a correlation with the feedback, although these data are unpublished.

Objectives of this guidance

This guidance aims to:

- Support paediatric and adult oxygen services in ensuring a smooth and co-ordinated transfer of care from paediatric to adult services
- Reduce stress for a child, young person and carer(s) by ensuring they have the information they need and know where to go locally for support
- Reduce wastage in oxygen provision that is not required or appropriate.

Guidance from the Royal College of Nursing (2013) recommends that a named

Table 2. Home oxygen transition patient questionnaire

Where the answer is 'yes', please rate your confidence using the following scale: 0 = not at all, 1–3 = a little bit, 3–7 = quite a lot, 8–10 = confident.

Where the answer is 'no' an automatic confidence score of 0 will be generated. Please indicate where you need some help.

Item	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			
Consultation/hospital visits			
I understand what the doctors and nurses say to me			
I can ask the doctor/nurse/therapists questions			
My carer(s) 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 carer(s) always sort out my home oxygen orders (score 1–3)			
I can arrange for a refill or service of my home oxygen equipment			
I can attend to any alarms on my home oxygen equipment (score 8–10) or my carer(s) 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			

Table 2. Home oxygen transition patient questionnaire (continued)

Item	Yes	No	I need some help
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 use of my oxygen with a future employer (where my 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 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 help from my carer(s)			

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 children's services, or a professional from adult services. In adolescent transition care, the Royal College of Nursing (2013) guidance for nursing staff noted that while 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.

Tertiary and specialist centres may have access to transitioning or adolescent specialists; however, these will not be available to those seen in the community or local hospitals. There is a directory of adult services that can be accessed via local clinical commissioning groups or integrated care systems. Each area has its own website and contacts for each clinical commissioning group and region. Within paediatric services, there needs to be an identified lead for transitioning (NICE, 2016). Currently, this does not take place, and many patients are not effectively transferred to adult services, which causes frustration and stress for both patients and clinicians (Department of Health, 2000).

Those working in children's and adult services will need to develop skills and knowledge for communicating with young

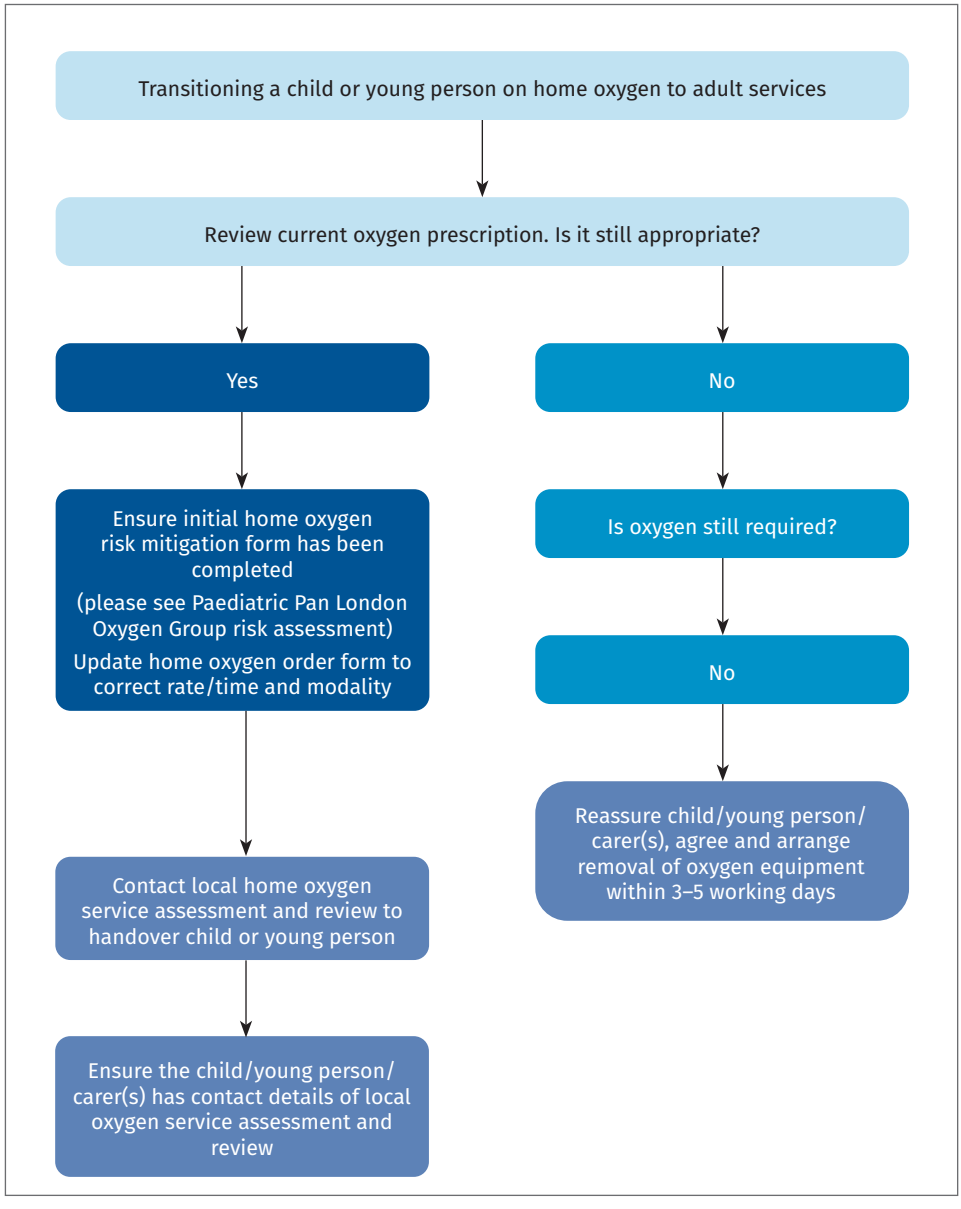

Figure 1. A flowchart illustrating how to transition a child or young person on home oxygen to adult services

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 Me first (2021) website, a resource produced by Great Ormond Street Hospital to support staff to develop communication skills.

According to the QNI (2017), as a child or young person transitions to adult home oxygen services, they begin being identified primarily by their NHS number.

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

It is important for services to improve the visibility of young people in healthcare and consider the difference it can make to be referred to by a name rather than a number, in order to ensure successful engagement and transition.

Transitioning to adult oxygen services

Before transitioning, there are questions that a child/young person and a health professional need to consider to ensure the process is holistic and focuses on all clinical aspects of care (Department for Education, 2015; QNI, 2017;) (*Table 2*). For a healthcare professional, these questions include:

- Has the child or young person been reassessed?
- Has 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 communication with the adult team? If not, how do you overcome the lack of services and identify resources available?
- Is oxygen still needed and appropriate?

If oxygen is no longer appropriate, then the young person's family should be prepared for its removal. Families must be supported during this transition (*Figure 1*).

It is important that a healthcare professional explains the rationale behind a decision to halt oxygen services to parents or carers and reassures them. If it has been provided for a long time, its removal may cause stress to the family. Some input and work will be required to establish trust with carer(s) and reassure them.

If oxygen is to continue:

- Do you know who the adult home oxygen service assessment and review team are and how to contact them?
- Can you liaise with the adult service to ensure continuity of care?

Oxygen use in adults is different to paediatric use. For example, in terms of equipment, concentrators are used in adult services but in paediatric services many still use static cylinders.

It is important to ensure carers/patients are given contact numbers for adult services in their area, and ensure that the child or young person has been taught how to use their oxygen and how to order it. It will start to become their responsibility as they transition to adult services.

You may need to consider if the child or young person is moving away to university. If this is the case, do they need further instructions and support to ensure they have a supply? This may also affect any accommodation, as well as considerations as to whether they need a secondary supply and whether they need to transfer to a team out of the area.

Conclusions

With over 12% of children and young people in London on home oxygen therapy, this guidance aims to make the transition process between paediatric and adult

services smoother and safer for children, young people and their carer(s). It is important to use this guidance alongside the included templates for the patient questionnaire and transfer checklist to ensure nothing is missed during the process (*Tables 1* and *2*).

The PPLOG recommends that each trust, clinical commissioning group or integrated care service should have a named professional leading and coordinating the transition from paediatric to adult services for home oxygen. This named professional will be able to support children and young people, family and other health professionals as a point of contact until the transition has been completed. **CHHE**

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