

A11/S/b

**2013/14 NHS STANDARD CONTRACT
FOR PULMONARY HYPERTENSION: SHARED CARE (ADULT)**

PARTICULARS, SCHEDULE 2- THE SERVICES, A- SERVICE SPECIFICATIONS

Service Specification No.	A11/S/b
Service	Pulmonary Hypertension: Shared Care (Adult)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Pulmonary hypertension (PH) is a rare disorder of the blood vessels in the lung defined as an increase in mean pulmonary artery pressure (PAP) of 25mmHg or greater at rest as assessed by right heart catheterisation. It can be found in a diverse range of clinical conditions, including connective tissue disease, congenital heart diseases, chronic pulmonary thromboembolism, sickle cell disease, human immunodeficiency virus (HIV) infection, use of an appetite suppressant, and liver disease. Prevalence is estimated at 15-50 cases per million population.

The second national audit for pulmonary hypertension reports 6,196 patients seen by designated UK pulmonary hypertension services in 2010/11. During the year of the audit, there were 2,089 new patients referred to a designated centre with a wide variation in referral rates across the country. Around a third of new referrals did not have pulmonary hypertension. In a minority of patients diagnosed with pulmonary hypertension, the condition was secondary to other diseases, particularly left heart disease or lung disease, which require specialist assessment but are not treated within the pulmonary hypertension service and do not require follow-up by the service.

Pulmonary arterial hypertension is characterised by raised pressure in the pulmonary artery in the absence of other causes of pre-capillary PH such as lung disease, chronic thromboembolism, or other rare causes. If the cause is unknown

then it is referred to as idiopathic pulmonary arterial hypertension (IPAH). IPAH can occur sporadically or may be familial. Symptoms include breathlessness, fatigue, weakness, angina, syncope, and abdominal distension. Since many of these are shared with other common diseases and the signs of pulmonary hypertension are difficult to elicit, the delay between onset of symptoms and definitive diagnosis can be as long as two years.

The severity of symptoms is used to provide a functional classification for each patient (see table 1). In untreated patients, historical data suggests a median survival of 6 months in patients with the most severe disease (World Health Organisation-Functional Class (WHO-FC) IV), 2.5 years for those in WHO-FC III, and 6 years for WHO-FC I and II.

Table 1: Functional classification of PH

Class I	Patients with pulmonary hypertension but without resulting limitation of physical activity. Ordinary physical activity does not cause undue dyspnoea or fatigue, chest pain, or near syncope.
Class II	Patients with pulmonary hypertension resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity causes undue dyspnoea or fatigue, chest pain, or near syncope.
Class III	Patients with pulmonary hypertension resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes undue dyspnoea, fatigue, and chest pain or near syncope.
Class IV	Patients with pulmonary hypertension with inability to carry out any physical activity without symptoms. These patients manifest signs of right heart failure. Dyspnoea and/or fatigue may be present even at rest. Discomfort is increased by any physical activity.

Six centres in England are designated to provide pulmonary hypertension services for adults (see section 5). The centres offer investigation, diagnostic services and treatment of patients with idiopathic pulmonary hypertension, pulmonary hypertension complicating other diseases and assessment of response to treatment. The centres and staff also provide support for patients and their families.

Treatment is provided in accordance with the ***National commissioning policy for targeted therapies for the treatment of pulmonary hypertension in adults.***

This specification, developed by the Specialised Commissioning Groups in England, aims to support consistent access to high cost, disease-targeted therapies across England. Other key references for pulmonary hypertension services are:

- The Task Force for the Diagnosis and Treatment of Pulmonary Hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS).
- Second annual report: Key findings from the National Audit of Pulmonary

2. Scope

2.1 Aims and objectives of service

To support the specialist management of patients with pulmonary hypertension by providing investigations and ongoing routine care closer to patient's home within structured protocols and individual patient management plans agreed with designated PH centres. Improving access to specialist PH services in this way aims to ensure that all patients have access to services intended to improve their quality of life, functional capacity and life expectancy.

The service will deliver these aims for adults with pulmonary hypertension by:

- working with designated PH centres to deliver specialist care within agreed protocols and individualised management plans,
- providing patient centred care with appropriate support for patients and their families,
- ensuring effective communication with patients, their families and carers, as well as with designated PH centres, referring clinicians, commissioners and other services,
- providing continued prescribing and efficient management of homecare supplies in line with national policy for patients where shared care prescribing is appropriate,
- ensuring smooth and managed transition between services,
- contributing to data collection for quality monitoring and input to the national clinical database.

2.2 Service description/care pathway

The care pathway for patient with pulmonary hypertension is described in detail in the service specification for adults with pulmonary hypertension (designated centres) (A11/S/a).

Designated PH centres will work with shared care centres to deliver specialist care closer to the patient's home where appropriate

Shared care centres are designated following agreement with specialised commissioners and designated centres to provide elements of care as either level 1 or level 2 services (appendix 1).

- **Level 1** is a minimum level of service; less than this would not maintain skills and competencies.
- **Level 2** services are provided in addition to those provided by a Level 1 centre.

Since the clinical relationship between PH centres and shared care centres will vary, the responsibilities and governance arrangements will be determined locally in collaboration with commissioners.

There will be a clearly documented agreement between the designated centres and the designated shared care units setting out the key areas of responsibility and the parts of the patient pathway to be provided by each service. PH centres and their shared care partners will provide commissioners with evidence of service-level agreements, protocols and governance arrangements to confirm that safe and effective arrangements are in place. However, over time the specialist centres will be working to standardise best practice between the centres and the shared care providers.

There will be clear funding arrangements identified for the shared care units.

The PH centres will work with commissioners to identify and review appropriate shared care centres and arrangements.

2.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner, and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

Specifically, this service is for adults with pulmonary hypertension where there is agreement with the designated PH centre for the patient to be managed by a shared care centre in accordance with agreed protocols and management plans.

2.4 Any acceptance and exclusion criteria

Acceptance criteria

The service will accept patients following agreement of protocols and individualised patient plans with a designated PH centre

Exclusions

The following groups of patients are outside the scope of this service:

- patients who have not had a diagnosis of pulmonary hypertension made in

- conjunction with an multi-disciplinary team based at a designated PH centre,
- children,
 - asymptomatic patients,
 - patients where PH is not suspected as a cause of symptoms,
 - patients with cor pulmonale (NB further work is needed to identify those patients with heart/lung disease and 'out of proportion PH' who could benefit from a specialised PH service).

2.5 Interdependencies with other services

Relationships with other services will depend on the level of service provided but could include the following:

Co-located services

- Designated PH centres will have facilities for diagnostic investigations including echocardiography, computerised tomography (CT) scanning, nuclear imaging, magnetic resonance imaging (MRI), selective pulmonary angiography, right heart catheterisation, ultrasound, exercise testing and lung function testing.
- Other services will include an intensive therapy unit with relevant experience, pharmacy with access to the full range of drug therapies licensed for pulmonary hypertension and access to an experienced coronary care unit and /or high dependency unit.

Interdependent services

- There will be established links (e.g. referral criteria, patient pathway and clinical management protocols) to other services which may not necessarily be on the same site. These will include maternity services, genetic services, connective tissue disease service, family planning service, pulmonary endarterectomy service, lung transplantation services, HIV and liver diseases.

Related services

- There will be links to other services that may be relevant to a preceding or future part of the patient's journey including palliative care services, lung transplantation services, and grown-up and paediatric congenital heart disease services.

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

There are no technology appraisals or guidelines published by NICE that are relevant to pulmonary hypertension services.

Treatment will be provided in accordance with the national commissioning policy for targeted therapies in pulmonary hypertension in adults.

4. Key Service Outcomes

Domain 1: Preventing People from Dying Prematurely

Improving life expectancy: reviewing survival figures on an annual basis on a whole service basis with international comparisons and on an individual centre basis. The figures would be analysed by disease sub type e.g. connective tissue disorder.

Data available from National Audit for Pulmonary Hypertension.

Domain 2: Enhancing Quality of Life for People with Long Term Conditions

Improving functional performance in people with long term conditions: reviewing who function class data and scale of improvement achieved through treatment and care provided.

Data available from National Audit of Pulmonary Hypertension.

Time spent in hospital because of condition: reviewing the number of unplanned hospital admissions and lengths of stay.

Data available from Secondary Uses Service (SUS) and contract monitoring systems.

Domain 3: Helping People to Recover from Episodes of Ill Health or Following Injury

Reducing the time from referral to diagnosis and streamlining the patient pathway: reviewing waiting times for outpatient consultant appointment and inter hospital transfers; reviewing referral to treatment plan.

Data available from contract monitoring.

Domain 4: Ensuring that People have a Positive Experience of Care

Improving people's experience of outpatient care: development of a joint initiative with Pulmonary Hypertension Association to obtain patient feedback.

Domain 5: Treating and Caring for People in a Safe Environment and Protecting them from Avoidable Harm

Reducing the incidence of avoidable harm: reduction in the number of cases of bacteraemia associated with intravenous (IV) lines.

Data available from SUS

5. Location of Provider Premises

Designated PH Centre	Shared Care Link
Newcastle	Hull, Queen Victoria Hospital, Belfast
Sheffield	Manchester Royal Infirmary Queen Elizabeth Hospital, Birmingham Leeds General Infirmary
Royal Brompton & Harefield	Southampton Hospitals St Georges Hospital
Imperial (Hammersmith)	Heart Hospital (UCH) Bristol Royal Infirmary Queen Alexandra Hospital (Portsmouth) Maidstone Hospital
Royal Free	Royal United Hospitals, Bath St Thomas's Hospital Queen Alexandra Hospital (Portsmouth) Derriford Hospital, Plymouth Ulster Hospital, Dundonald Kings College Hospital, London
Papworth	Plymouth Norfolk & Norwich Hospitals

Appendix 1: Level 1 and 2 services

Level 1 services:

Follow up out patient care following initiation of treatment by designated centre including

- 6 minute walk test
- Lung function test
- Echocardiograms
- CT scans

Initial treatment/stabilisation of acute emergencies before transfer to a centre.
Regular discussion with the centre on a case by case basis.

Level 1 infrastructure requirements:

- Named physician (cardiology, respiratory or adult congenital heart disease for shared care centres who look after congenital heart disease))
- Named specialist PH nurse who has received training and has competency in PH
- Named pharmacist
- Echocardiography service
- Regular outpatient clinics
- Access to specific patient information and support
- Capacity to capture, and where necessary input, data for national database as agreed with the designated PH centre
- Protocols agreed with the designated PH centre for :
 - assessment of new patients
 - diagnosis – to be made as part of multi-disciplinary team discussion that involves clinician from shared-care centre
 - treatment (oral and IV)
 - prescribing arrangements/supply of medicines to be managed by the designated centre in accordance with national arrangements for home delivery and local clinical and financial governance procedures
 - follow up (at least annual review by specialist clinician from designated PH centre)
 - transfer criteria/arrangements
 - management of complications.

Level 2 services (in addition to those in Level 1)

- In-patient care
- Initiation of oral therapy following discussion with the designated PH centre
- Follow up monitoring

Level 2 infrastructure requirements (in addition to those in Level 1)

- Named physician in PH who spends at least one session a week in PH
- Named Specialist Registrar (SpR) in PH
- Cardiac MRI service with appropriately experienced general radiologist
- Available beds for admission
- Regular outpatient clinics at least once a month
- Right heart catheterisation and vasodilator testing by competent operator designated by the PH centre and involved in multi-disciplinary team meetings.

Interim for Adoption from 01/10/13