

Short guide 2:

The Pulmonary Hypertension Service Specification (Adult)

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The Pulmonary Hypertension Clinical Reference Group

The Pulmonary Hypertension Association (PHA-UK) has produced this summary and an accompanying animation to provide a simple explanation of an important document called 'The Pulmonary Hypertension Service Specification'. This document informs the NHS in England how it should be providing healthcare and services, which meet the needs of adult patients with pulmonary hypertension (PH).

Importantly, this guide also highlights opportunities for patients and clinicians to have a voice and input into the way that services for people with PH are delivered.

If you would like further information on this subject, please contact us at office@phassociation.uk.com or go to [insert address] to view the animation.

A snapshot of PAH (pulmonary arterial hypertension) management in adults in the UK*

PAH is a rare disease and most doctors are not familiar with how it is diagnosed and treated. For this reason, adult patients with suspected or diagnosed PAH in the UK are referred to one of six specialist adult PH centres in England or to the Scottish Pulmonary Vascular Unit, based in Glasgow. This helps to ensure that they receive the specialist treatment and on-going care they need.

The six adult PH specialist centres in England are;

1. **Freeman Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust**
2. **Hammersmith Hospital, Imperial College Healthcare Trust, London**
3. **Papworth Hospital NHS Foundation Trust, Cambridgeshire**
4. **Royal Brompton Hospital, London**
5. **Royal Free, Hampstead NHS Trust, London**
6. **Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield**

In addition Great Ormond Street Hospital, London has a centre for the treatment of children with PH.

*patients in Scotland and Northern Ireland are treated in centres in their respective countries and/or England (depending on location). Patients in the Republic of Ireland are not covered by the UK healthcare system – please refer to <http://www.pulmonaryhypertension.ie/pha-ireland/> for more information on the management of PH in the Republic of Ireland.

What are the standards of care that these six centres should be delivering?

The PH Service Specification sets out the specific services and standards of care that patients with PH can expect to receive. Importantly, it defines how this care can be provided in a consistent way for all patients, no matter where they live.

The standards of care also reflect those recommended in the professional guidelines of the European Respiratory Society and European Society of Cardiology.

What is a service specification?

It is a service plan that informs NHS England how it can provide and deliver safe, effective and consistently high healthcare services that meet the needs of PH patients.

Service specifications form part of the contract between a commissioner (the organisation responsible for buying services e.g. NHS England) and a service provider (the organisation providing the service e.g. the hospital).

The PH service specification outlines the journey of care (often called the care pathway) for PH patients and sets out how care should be planned, delivered and monitored, including;

- **Referral**
- **Tests and investigations**
- **Diagnosis**
- **Treatment and treatment plans**
- **On-going care**

Below, we highlight the key points that are directly relevant to patients and what they can expect at each stage of their journey, according to the PH Service Specification.

Throughout this guide we also suggest ways in which patients and carers can become involved in the planning and delivery of their care. Action points are provided for patients throughout this guide.

1. Referral to a specialist Pulmonary Hypertension centre

For anyone with suspected PH there should be minimal delay between referral to a specialist PH centre and an outpatient consultation appointment for further tests and examination.

- **urgent referrals should be seen by a specialist within 1 month**
- **patients with severe symptoms should be seen within 2 weeks**
- **critically ill patients with unexplained PH should be offered a bed at the PH centre within 72 hours and those with known PH should be offered a bed within 5 days**

Action points

- **If you do not receive an appointment within the stated time, contact a member of your healthcare team to find out why there is a delay**
- **Once you have your appointment date, make sure you have directions to the PH centre and plan your travel arrangements in advance**
- **Allow plenty of time for your journey so you arrive on time and avoid unnecessary stress**
- **It can be helpful to take along some notes about the symptoms you have been experiencing and any questions you have for the healthcare team**

2. Investigations

If you have unexplained symptoms you should be offered a series of investigations (tests) to confirm whether you have PH and if so, what type of PH it is.

Tests include:

- **Right heart catheterisation** – a tube called a catheter is inserted through a vein in the groin or neck and fed through to the heart to measure the exact blood pressure in the heart and pulmonary artery
- **Computerised tomography (CT) and/or magnetic resonance imaging (MRI)** – tests to gain pictures of your heart and lungs
- **Perfusion scanning** – a scan to measure blood flow throughout the lung
- **Cardiopulmonary exercise testing** and **lung function tests** – tests to see how well your heart and lungs are working
- **Blood tests** – to see if any markers for PH show up in the blood stream

Further information about these investigations can be found on PHA-UK's website

All investigations should be completed and a treatment plan should be agreed within 12 weeks of your referral.

Action points

- **Make sure you understand which tests you will be having and what these will involve. For example if you have to do an exercise test you will need to take comfortable shoes and clothing. Also find out if you need to stay overnight in hospital**
- **If you are not offered the full range of tests, or you are experiencing delays in being invited for tests, contact your doctor or nurse**

3. Diagnosis

Once a diagnosis has been made, all members of the healthcare team should be involved in developing a treatment plan that is tailored to your needs.

Where possible, a member of the team (such as a specialist nurse or counsellor) should be with you when your diagnosis is discussed.

Your GP should be told about the results of the tests and the diagnosis within 5 working days.

Action points

- It can be helpful to take a friend or family member with you to appointments with your PH team, particularly when you are first diagnosed or when you are being given test results. If you are on your own, it can be difficult to take in all the information you are given
- Before your appointment, jot down any questions you have for the healthcare team and take a pen and paper with you so you can make notes
- If there is anything you don't understand, ask a member of your PH team to give you an explanation – ask for written information if this would be more helpful
- Remember that PHA-UK can provide support and information on all aspects of PH

4. Treatment plan

Once you have been diagnosed with PH, your specialist team will draw up a treatment plan for you. This should be explained to you in detail and you should be given the opportunity to ask questions and discuss any concerns.

If you are prescribed disease-targeted therapy (such as calcium channel blockers, endothelin receptor antagonists, phosphodiesterase 5 inhibitors and prostaglandins), you will receive on-going treatment and monitoring at your nearest PH centre – disease-targeted therapy should only be prescribed by doctors working in designated PH centres.

New treatments or changes to medication should be reviewed after 3 months and then every 3-6 months.

Patients with chronic thromboembolic PH (CTEPH) should be referred to Papworth Hospital in Cambridge to see whether they would be suitable for pulmonary endarterectomy (PEA), a surgical procedure to remove old blood clots from the pulmonary arteries. If endarterectomy is recommended, surgery should be carried out within 18 weeks (less for patients with a deteriorating condition).

For patients who are eligible for lung transplantation, a letter of referral should be sent within 5 working days to the lung transplant centre.

Further information about the different treatments for PH can be found on PHA-UK's website.

Action points

- Make sure that you understand what treatment is being recommended and why this form of treatment has been suggested for you
- Ask for information about the results you can expect from your treatment and what type of side effects (if any) you may experience
- Ask for written confirmation of your treatment plan if this has not already been given to you
- Ensure that you have follow-up appointments when your medication has been changed

5. Ongoing care

Most patients who are treated with disease-targeted therapy will have lifelong follow-up at their PH centre. However, some patients may be offered the option to receive some of their treatment at a shared-care centre. There is a separate service specification to cover shared-care services in adults with PH.

All patients should have the opportunity to discuss and agree a long-term care plan. You should be given a specific point of contact within the PH team and should be given clear instructions what to do in the case of emergency. You should also be given contact details for PHA-UK.

Action points

- Between appointments, keep a note of any side effects, changes in your symptoms or points that you would like to discuss. If you have concerns in between your appointments get in touch with your PH specialist team
- If you are unhappy about any aspect of your treatment, speak to a member of your PH specialist team
- Ensure that you have been provided with a main point of contact on your PH specialist team and that you know who to contact in case of an emergency

How will performance of my PH specialist centre be measured?

As well as guidance on care, the Pulmonary Hypertension service specification also contains specific guidelines on how each PH specialist centre should be managed and monitored.

All centres participate in an annual audit to review and evaluate how well they are performing. In this audit, service performance is measured against 5 key outcomes:

1. **Preventing people from dying prematurely** – improving life expectancy
2. **Enhancing quality of life** – improving the functional performance of people with PH so they can live a fuller life, and reducing time spent in hospital
3. **Helping patients recover from episodes of ill health** – streamlining patient care and reducing waiting times so that patients can get on with their lives
4. **Ensuring that patients have a positive experience of care** – improving services and seeking patient feedback
5. **Treating and caring for people in a safe environment** – reducing the incidence of avoidable harm (e.g. infections associated with intravenous lines)

PH Centres are monitored on an on-going basis to ensure they meet the required standards under each area listed above.

As a patient receiving care, you may be asked by your centre or through PHA-UK to provide feedback on your experiences of care from your specialist PH centre.

Visit our website to find out more about providing feedback about PH healthcare services and getting involved in driving improvements PHA-UK's website

So, now we know a bit more about the PH service specification, but what does this mean for people with PH on a day-to-day basis?

The PH service specification aims to ensure that healthcare services for PH patients meet their specific needs, helps patients understand what care they can expect from the NHS and works to ensure care is provided at a consistently high level across the country.

Being better informed about healthcare services allows patients and their carers to get more involved in treatment plans, so they are more likely to receive a service that meets their needs.

The full service specification can be downloaded from the NHS England website at <http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-a/a11/>.

Please visit the PHA-UK website to learn more about the PH service specification and what support is available to you.

Don't forget to watch our short animation to learn more

A guide to the management of Pulmonary Hypertension in adults in the UK



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