

Short guide 1:

The Pulmonary Hypertension Clinical Reference Group

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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 how the NHS in England develops and provides care and services for people with pulmonary hypertension (PH).

This guide will explain how different NHS organisations come together to ensure that the services available meet the needs of PH patients. Importantly, it will highlight the opportunities for patients and clinicians to input into and have a voice in the way that services for people with PH are designed and 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 accompanying animation.

How does the NHS ‘buy’ services that treat patients in the UK*?

NHS England sits at the heart of the new NHS. NHS England is a body whose main aim is to improve health outcomes for people in England.

At a national level: NHS England directly commissions (or buys) key services at a national level. These include primary care services (contracts with GPs and doctors’ surgeries); specialised services (such as Pulmonary Hypertension); healthcare in prisons and services for the armed forces.

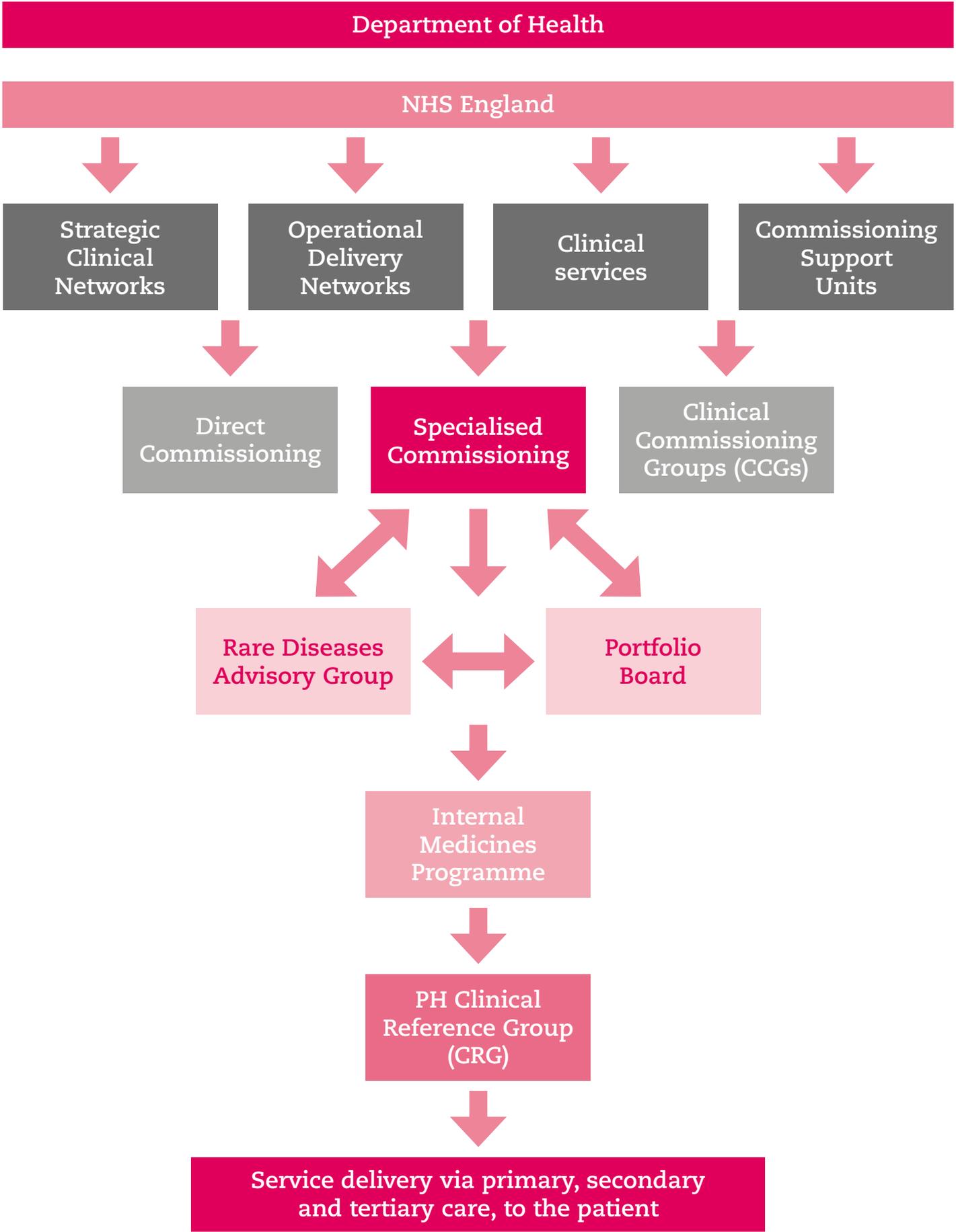
At a local level: Clinical Commissioning Groups (CCGs) decide which healthcare services to purchase and provide to patients at a local level.

CCGs are groups of general practices (including GPs and other healthcare professionals such as nurses) that join up in each area of England to commission (or buy) services for the local population.

They are responsible for commissioning most of the healthcare services that their patients need, including:

- **Planned hospital care**
- **Rehabilitation care**
- **Urgent and emergency care**
- **Most community health services**
- **Mental health and learning disability services**

*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 exactly is commissioning?

Commissioning is the process of planning, negotiating, purchasing and monitoring healthcare services. Commissioning is a complex process that involves negotiations across a whole range of services, ranging from GP surgeries and hospitals to dentists, opticians and care homes. Good commissioning delivers consistent, high quality care, while responding to local community needs and variations.

Pulmonary Hypertension is a ‘specialised service’... so how is this managed?

Healthcare and services for rare diseases like pulmonary hypertension are commissioned (or bought) centrally for the whole of the country, rather than through local CCGs. This is because GPs don't see many patients with rare diseases and may not fully understand what care and services these patients need.

Rare diseases like PH are commissioned as a ‘specialist service’ and they take advice and guidance on what healthcare to provide from a group of experts called the **Pulmonary Hypertension Clinical Reference Group (PH-CRG)**.

The **PH-Clinical Reference Group** is made up of clinicians, commissioners, public health experts as well as patients and carers.

The PH-CRG is not a decision-making body. Instead it acts as the main source of advice on the development of the PH specialised service. It works to ensure that healthcare services are developed and provided to PH patients that specifically meet their needs.

What responsibilities does the PH-CRG have?

The PH-CRG has seven key areas of responsibility:

- 1. Developing service specifications** – a document which sets out the standards of care that people with PH can expect. This ensures that services are consistently available throughout the country. The service specifications for PH are available here [insert address]
- 2. Developing commissioning policies** – these detail out the treatments and services that the NHS will commission (or buy) for patients
- 3. Developing CQUIN (Commissioning for Quality and Innovation) schemes** – CQUINs are financial incentives which aim to improve the quality of patient care
- 4. Developing QIPP (Quality, Innovation, Productivity and Prevention) plans** – as their name suggests, QIPP plans aim to redesign NHS services to bring improvements and efficiencies
- 5. Identifying potential innovations** within each service area
- 6. Consistent measures of quality** for each service area. For PH this could include time from referral to treatment, contact with social workers and impact on quality of life
- 7. Identifying organisations and stakeholders** with an interest in the work of the CRG and developing plans for communicating with them.

What is the Pulmonary Hypertension service specification?

A service specification for PH in adults was produced in 2013. It is a document that outlines the healthcare services that PH patients should expect to receive and how this care can be delivered to the highest possible standards, no matter where patients live.

A guide to the PH service specification is available from the PHA-UK [Insert link].

The full PH service specifications can be found on the NHS England website here [Insert link].

Who is involved in the PH-CRG?

The PH-Clinical Reference Group is made up of clinicians, commissioners, public health experts as well as patients and carers, as outlined below;

- **A Chair** – a clinical leader in the field of pulmonary hypertension
- **National Clinical Directors (specialist clinicians working with PH patients)** – who will co-chair the PH CRG
- **A Public Health Lead and Pharmacist**
- **Patient and carer members** – up to four patient and carers (usually represented via a patient association, like the PHA-UK)
- **Professional organisations** – up to four representatives involved in training and professional leadership for example, The British Thoracic Society and the British Cardiovascular Society
- **Commissioners** – accountable for the PH CRG (plus any additional commissioning representatives where appropriate)

Who else can get involved?

The new NHS structure aims to engage and involve a number of stakeholders, including patients and carers, as well as the wider public so that their experience and feedback can be used to improve the quality of NHS services.

What is a stakeholder?

A stakeholder is any individual or organisation that has an interest in a specific area of activity, (i.e. the management of pulmonary hypertension).

Potential stakeholders include:

- **Individual patients or carers or family members**
- **Patient or carer organisations**
- **Health and social care providers or commissioners**
- **Suppliers or commercial organisations involved in providing products or services relating to this area**

How can you get involved?

Registered stakeholders can get involved in a range of ways. The PHA-UK is registered as a [xxx] stakeholder, which means that they are invited to take part in.

From time to time, the PHA-UK may contact you, as a patient or carer, for your input and thoughts on the work they are doing, to ensure that they have incorporated the patient perspective and are addressing patient and carer needs through the work they are involved in with the CRG.

How often will I be involved?

As and when PHA-UK require patient and carer input they will contact you directly (if you have registered an interest to be contacted by them) to seek your input and feedback on services and materials they are developing with the CRG.

You can also voice your opinions, thoughts and feedback on service provision and your experience of care via PHA-UK, who will then endeavour to represent your views and share your feedback with the wider CRG, in their capacity as an [xxx] stakeholder.

Contact the PHA-UK at office@phassociation.uk.com.

So, now you know a bit more about the management of PH in adults in the UK, but what does this all mean for people with PH?

The Pulmonary Hypertension 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.

The new NHS system also provides more opportunities for patients and carers to provide feedback on their own experiences and contribute to the way future care for people with PH is shaped.

Please visit the PHA-UK website to learn more about the management of PH in adults in England.

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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