

SPECIAL REPORT



THE NATIONAL AUDIT OF PULMONARY HYPERTENSION 2016 **KEY FINDINGS**

The specialist pulmonary hypertension centres in the UK are the envy of the world, and every year for the last seven years, the NHS has gathered data about PH services by asking them for information on what they do and what their outcomes are.

This data is then compiled into a report called The National Audit of Pulmonary Hypertension. This information is used by those in charge of funding and service developments in the NHS, to assess which parts of the PH service are working effectively and to agreed national standards - and where further investment may need to be made to maintain or see improvement in the quality of care and management of PH.

The following report shows some of the key findings from the audit, which looked at what happened at the UK's adult PH centres between 1st April 2015 and 31st March 2016.

There were 18 findings in total, and at PHA UK we asked 68 patients which ones they felt were most important to them. It is these we have chosen to include in this report, which is designed to help you understand, on a national scale, what happens within our specialist PH services.

Next year, we plan to produce a full interpretation of the 2016 National Audit of Pulmonary Hypertension, and we would be really interested to hear your thoughts about which areas you think would be most helpful, or what you would like to know more about. Would you like to see a breakdown for each centre, for example?

Let us know your thoughts by emailing us at office@phauk.org or giving us a call on 01709 761450.

Thank you to the PHA UK members who provided feedback on this year's findings, and we hope everyone finds this report useful.

Iain Armstrong
Chair of PHA UK



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In 2015/16, data for the national audit was submitted by the following specialist adult PH centres.

- Golden Jubilee National Hospital, Glasgow
- Hammersmith Hospital, London
- Papworth Hospital, Cambridge
- Royal Brompton Hospital, London
- Royal Free Hospital, London
- Royal Hallamshire Hospital, Sheffield
- Freeman Hospital, Newcastle

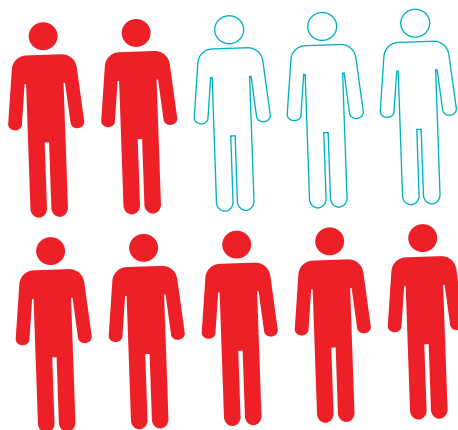
The following four findings were chosen by PH patients to be the most important to them. The percentages shown are an average across the seven adult PH centres who were audited.

How many patients, who have had at least one consultation in the last year, have had a quality of life questionnaire recorded during that time?

74%

PHA UK's view...

From research and survey work over the last ten years, we know that, consistently, improvement in quality of life is ranked number one above all other outcomes. Recording a quality of life questionnaire is important because it offers an insight into how effective the treatment pathway is that the individual is on. This is about helping PH patients manage the impact of the condition on their lives, rather than just treating the disease for them. The National Audit set a standard that 90 per cent of patients who have had at least one consultation in the last year should have had a quality of life questionnaire recorded during that time.

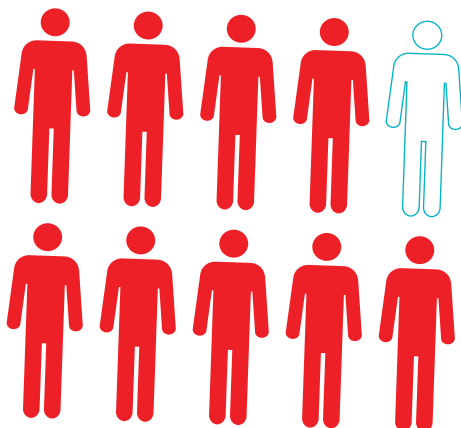


How many patients referred to a specialist centre were seen, assessed and diagnosed within six months?

92%

PHA UK's view...

We know that the journey to diagnosis is often a difficult one, with patients often telling us their symptoms have been ignored / misinterpreted. So once a patient has been referred to a specialist centre, it's imperative they are seen and assessed quickly. The National Audit set a standard that 95 per cent of patients whose referral letter was received over six months ago should have a diagnosis recorded. It's encouraging to see an average of 92 per cent being achieved.

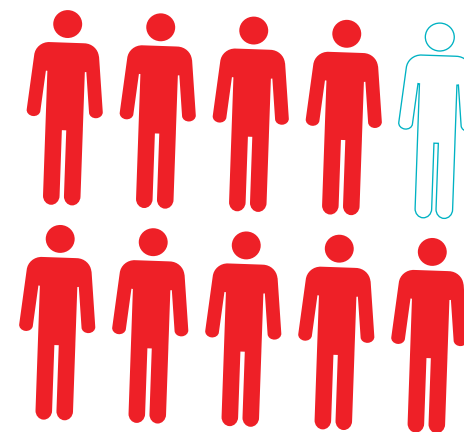


How many patients taking PH specific drugs have had at least one consultation at a specialist PH centre within the last 13 months?

92%

PHA UK's view...

It's important that when taking medication for PH, patients are assessed regularly to ensure they are responding correctly and safely to treatment. Some may need to come to clinic more often, but the NHS have set the audit standard as at least once in every 13 months, which the majority of centres are achieving.

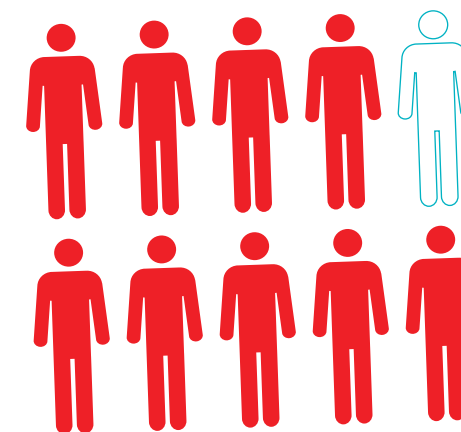


How many patients received a right heart catheterisation before being given drugs to treat PH?

88%

PHA UK's view...

Right heart catheterisation is considered as the 'gold standard' investigation/test in the diagnosis of PH. Without accurate diagnosis, the wrong patient may end up receiving the wrong drug at the wrong time. This has the potential of making the patient more ill, or may deny patients a more appropriate treatment. Just as importantly, using the wrong drug in the wrong patient is a complete waste of very expensive NHS resources. The National Audit set the standard that 95 per cent of patients receiving drug therapy for PH should have a cardiac catheterisation recorded before treatment begins.



See overleaf
for more key
findings from
the National
Audit of PH



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The National Audit also discovered that between 1st April 2015 – 31 March 2016:

PH centres
managed

7035
PATIENTS.



80%

of patients had a WHO
functional class and
six-minute walk or shuttle
exercise test recorded before
being given drugs to treat PH.



86%

of patients referred
to a specialist centre
attended a consultation
or were discharged
within 90 days and



45%

were seen or
discharged
within
30 days.

99%



of patients receiving drug
treatment for PH had an
official diagnosis recorded.



For **88%**

of patients, their first
line drug therapy was
a phosphodiesterase 5
inhibitor.



The full National Audit of Pulmonary
Hypertension, including all of the
findings, is available by visiting
www.content.digital.nhs.uk/ph

