Royal College of Physicians | NACAP

National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP)

Pulmonary rehabilitation 2019 audit: Report for COPD patients and their families and carers

In association with:

British Thoracic Society

Imperial College London

PCRS UK Primary Care Respiratory Society UK

ARNS Association of Respiratory Nurse Specialists

RCPCH Royal College of Paediatrics and Child Health Leading the way in Children's Health

asthma UK

British Lung Foundation

THE ASTHMA UK AND BRITISH LUNG FOUNDATION PARTNERSHIP

RCGP Royal College of General Practitioners

Commissioned by:

HQIP Healthcare Quality Improvement Partnership

Contents

What is NACAP?

The National Asthma and COPD Audit Programme (NACAP) is a collection of projects, created with patients and designed to support improvements in the quality of care, services and outcomes for people with asthma and chronic obstructive pulmonary disease (COPD). Information is collected from general practices (local doctors) in Wales and hospitals and pulmonary rehabilitation (PR) services in England and Wales to find out about the care that people with asthma and COPD are receiving, and see if it can be improved.

The NACAP team works with patients and healthcare professionals to create improvement targets for services. We aim for these targets to focus on issues that patients think are most important.

The programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and run by the Royal College of Physicians (RCP).

We would like to thank the NACAP patient panel for working with us and providing guidance and expertise in writing this patient report.

What is the NACAP pulmonary rehabilitation audit?

Pulmonary rehabilitation (PR) is a treatment programme designed for people with lung conditions like COPD. PR programmes are specially designed to meet individual patients' needs, and include exercises and advice on managing their condition and symptoms. The goal of PR is to improve the patient's physical health and overall wellbeing.

NACAP has been running clinical and organisational audits of PR services in England, Scotland and Wales since March 2019.

Clinical audit

This collects information on patients who take part in PR programmes, including how much their health has improved, and how effective PR programmes are overall.

Organisational audit

This collects information on how different PR services work (eg how many staff work there).

The audit collects information on people with COPD who have been assessed for referral to PR. This is a **consent-based audit**, meaning that patients' information will only be sent to NACAP if they have agreed for this to happen (either verbally or in writing). The information collected includes:

1 Personal (confidential) information, such as NHS number, date of birth, gender and postcode. This information is used to identify patients throughout their PR journey, and to give information about which groups of people are more likely to access PR. All personal details are removed from the data before it is sent to NACAP.

2 Information about the treatment and care that people with COPD receive. For example, whether they:

- were referred for PR by their local doctor or hospital
- had to wait a long time for their PR programme to start
- had a walk test at their initial (first) and discharge (last) assessment
- had improvements to their health measured at their discharge assessment, for example whether they could walk further.

NACAP compares this information to national PR quality standards to see where people are receiving the recommended care and where there are areas for improvement. More information about the audit is available online: NACAP PR Resources.

Glossary

An audit is a project which compares care or service structure to **national guidelines and standards** (these provide information on what PR care should look like). Audits include finding out which parts of care or services could be better and helping services to improve – this is called **quality improvement (QI)**.

Walk tests are a way of measuring a person's level of fitness by measuring how far they can walk over a set period of time (eg a 6 minute walk test (6MWT)), or how long it takes them to walk a set distance (eg an incremental shuttle walk test (ISWT)). Walk tests should be done as part of a patient's initial assessment with a PR service and again at the end of the programme, to see whether their level of fitness has improved.

What does this patient report include?

This report sums up recommendations and key findings from the 2019 PR combined clinical and organisational audit report, which collected information on:

The care of

12,127

people with COPD assessed for PR between 1 June and 30 November 2019*.

How PR services worked between July and September 2019†.

This report includes information from

199 (87.7%)

of the PR services across England, Scotland and Wales.

This information shows how people with COPD are treated and what the PR services that treat them look like. A glossary is included at the bottom of each page to explain some of the words we have used in the report.

NACAP worked with the NACAP patient panel to make sure this report includes the most important information for patients. Anything the patient panel thought was especially important has been highlighted with the patient panel symbol.

*This was a continuous audit. Information was collected over a longer period to capture patients' experience throughout their PR journey.
†Information on services was recorded over a shorter period because it was less likely to vary over a long period of time.

Foreword

Sally Singh, pulmonary rehabilitation audit clinical lead

Pulmonary rehabilitation (PR) is an important treatment for people with chronic obstructive pulmonary disease (COPD). There is strong evidence that PR is very effective at improving people's breathlessness and ability to walk. It can also reduce levels of anxiety and depression and improve people's general health. Guidance recommends that PR should be offered to people with stable COPD (that has not resulted in an admission to hospital) who notice that they are having to walk slower than other people of the same age because they have trouble breathing. In addition, a course of PR should be offered to all people who have been admitted to hospital for a flare-up of their COPD.

NACAP looked at data from patients who take part in PR courses in two different ways. First, we looked at the 'process', for example how long people have to wait to start PR. Secondly, we looked at how much the programmes had improved patients' health, for example by looking at changes to how far they were able to walk. We also looked at how PR services work and compared their performance to national quality standards – these explain what the best possible PR care should look like. The report describes areas where services are performing well and key areas that could be better. For these areas, RCP has a quality improvement programme, which helps services by giving them advice on how they can improve.

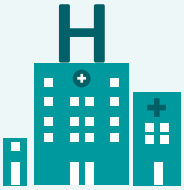
This report would not have been possible without the dedication and support of the PR staff and the team at the RCP; we owe a huge thanks to the teams up and down the country. The patient panel at NACAP have had a very important role in the programme and have made sure that access to PR is a key priority. We hope to continue working on improving access to PR so that everyone who needs it has equal access to a high-quality service.

What should I expect from my PR journey?

This map explains what you should expect when you are referred for PR and enrolled on a PR programme, based on NACAP's recommendations to PR services. See page 15 for all recommendations for people living with COPD, PR services and local doctors and nurses.

Stop 1: Referral and waiting times

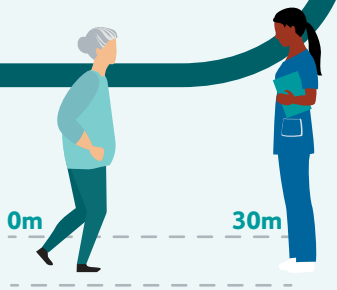
People with stable COPD who are more breathless when walking with people of the same age* should be **referred for PR** and **85%** should start it within **90 days** of the PR service receiving the referral.



People who have been **admitted to hospital** with a flare-up of their COPD should be **referred for PR** and start it **within 30 days** of the PR service receiving the referral.

Stop 2: Initial assessment

All people with COPD assessed for PR should complete a **walk test**, with a practice walk test before the actual test. If PR services are using a **6-minute walk test** (6MWT), they should be conducting it along a **30-metre course**.



Stop 3: Discharge assessment, improvement and maintenance

PR services should:

- make sure that at least **70%†** **of people with COPD** complete their PR programme and have a **discharge assessment**

- **assess the improvements** of **all people** with COPD following their PR programme
- provide **all people** with COPD with an **individualised discharge plan** – this supports people to carry on exercising at home to maintain improvements to their health.

Stop 4: Organisation of PR services

All PR services should:

- have a **Standard Operating Procedure** (SOP)
- **involve patients, their families and carers** in service planning and development.

*For more information on official breathlessness scoring, go to **www.pcrs-uk.org/mrc-dyspnoea-scale**.
†The targets on this page (eg 70%) are based on the targets set by national quality standards on the minimum number of patients they feel should receive these areas of care.

Audit results

These sections of the report present key results from the 2019 clinical and organisational audits.

Section 1: General information

The audit collects data on the care that people with COPD receive when they attend a PR programme. General information about each patient, such as their age and gender, is also recorded. This allows us to understand things like which groups of people are more likely to be assessed to see if PR could help them, and which patients are likely to attend and complete their PR programmes.

Age of patients

The **average age** at referral was **71 years**.

Gender

More **men (52.8%)**, than **women (47.1%)** were assessed for PR.

Socio-economic status

A **high proportion** of people with COPD assessed for PR came from **more deprived areas**.

Comorbidities

35.7% of patients had a history of **cardiovascular disease, 35.6%** had a history of lower limb or lower back **musculoskeletal disorders**, and **19.9%** had a history of **a mental health condition**.

Smoking

68.8% of COPD patients assessed for PR **used to smoke**. **21.7% currently smoked** at the time they were assessed.
All PR services surveyed offered PR to current smokers.

'I'm shocked that the average age of referrals are for the over 70s, a huge proportion of people with COPD are a lot, lot younger.'

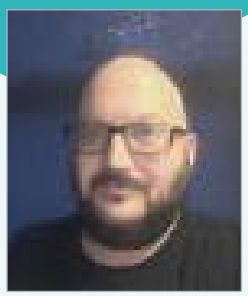
– Patient quote on age of patients

Glossary

Comorbidities are other health conditions that might affect people with COPD. Common comorbidities for COPD include **cardiovascular disease** (heart problems, eg heart attacks, strokes), **mental health conditions** like depression or anxiety, and **musculoskeletal disorders** (conditions that affect the joints, bones or muscles.)

Deprived areas are places that are seen as disadvantaged in specific ways, eg lower than average wages, less access to education and healthcare. This is worked out using a deprivation score that divides England, Scotland and Wales into five parts, from the most deprived (1 and 2) to the least deprived (5).

Socio-economic status is a way of measuring a person or family's quality of life and what opportunities they have. It can be worked out by taking a person's postcode and then finding out what the average income is, what kind of jobs people have and what access to healthcare and education is like in that area.



Patient story

Simon Pearce, 44

My diagnosis of chronic obstructive pulmonary disease and how it affects me

I was diagnosed with chronic obstructive pulmonary disease (COPD) in November 2013. This was after a bout of chronic bronchitis and a number of asthma flare-ups between August 2012 – April 2013. A series of lung function tests which took place throughout the following year then confirmed the COPD diagnosis.

My COPD affects me on a daily basis. I had to give up my job at a call centre because I was unable to talk on the phone for long periods of time. I can't walk more than 50 metres without getting short of breath, and I struggle with household chores such as vacuuming and dusting for the same reason.

This puts me in a catch-22 as I was also diagnosed with bronchiectasis and cat, dog and dust mite allergies in June 2014. So, household cleaning is difficult but I know I need to do it because of the allergies!

My experience of pulmonary rehabilitation (PR)

My experience of PR was great. It unfortunately took me 3 years to get a referral, but once I was referred it all went pretty quickly and smoothly.

The PR programme was run by the respiratory team in my area and consisted of 12 sessions over a period of 6 weeks. At my initial assessment the practice walk was done first, and the tests and questionnaires done last so I could rest between the practice walk and the actual walk test.

Once I was enrolled, each session was 2 hours long, with an hour of exercise followed by an hour of education on related subjects, eg diet.

During the exercise time we were asked to do around 10 exercises which were a mixture of cardio and strength exercises and could include: push ups off the wall, squats, stand up sit down, walking lengths, treadmill, exercise bike, cross trainer, bicep curls with weights, and sitting and lifting legs with weights on the ankles. Each exercise lasted 5 minutes.

The respiratory physiotherapists were great and supported everyone in the class.

One thing that did stand out for me was the fact that I was one of only two people on the programme in the 25–45 age bracket. Everyone else was in their late 60s to late 70s, which says to me there is a whole age range being missed.

How PR has helped me

I definitely felt improvement after the programme. PR has, in conjunction with my medication, certainly helped with the breathlessness. I still get short of breath but not as fast as before and I'm just able to do things slightly easier or better than previously, like walking home from town for example. PR has also provided me with some ideas and exercises I can do at home to help too.

Section 2: Access to pulmonary rehabilitation

When patients should be referred to PR and what should happen next

PR is is a treatment programme including exercise and advice, designed to help people with lung conditions like COPD manage their condition and improve their health.

NACAP recommends that:

- **all people** with COPD who find they are more breathless and walking slower than others of the same age **(MRC score 3+)** should be referred **for PR** and **85%** should then start it **within 90 days of referral**
- **all people admitted to hospital** with a flare-up of their COPD should be referred for PR and start it **within 30 days of referral**.

Key findings

Referral to PR

90.2% of people referred for PR had stable COPD.

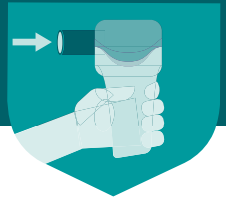
8.4% of people were referred after an admission to hospital for their COPD.

Waiting times

53.9% of people with stable COPD started PR within **90 days** of referral.

12.8% of people with COPD referred after a COPD-related hospital admission started PR within 30 days of referral.

Medical Research Council (MRC) score



Of people with COPD assessed for PR:
- most had an MRC score of either **3 (35.7%)** or **4 (31.1%)**

PR improvement priority
Referral to pulmonary rehabilitation upon COPD diagnosis

Not all services in England offered PR for MRC grades 3–5. In particular, MRC grade 5 was not offered PR in 12.9% of services in England.

Glossary

Medical Research Council (MRC) grade or score is a number between 1 and 5 that shows how breathless people with COPD become during day-to-day activities.

Section 3: Quality of pulmonary rehabilitation

What PR care should look like

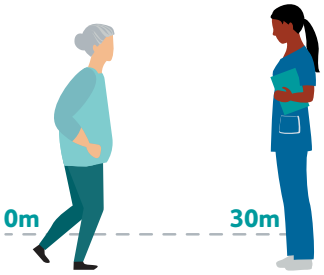
People with COPD who are referred to PR should have an initial assessment with a PR service. This is to find out if PR will benefit them and confirm if they should start a PR programme. Assessments should include two walk tests (first a practice walk test, then a formal walk test). This is to make sure patients understand the test and what they need to do. Both walk tests should meet national technical standards.

NACAP recommends that **all**:

- people with COPD referred for PR have a practice walk test at their initial assessment,
- 6-minute walk tests (6MWT) are carried out on a 30-metre course, and
- PR services have an SOP.

Key findings

Walk tests



84.3% of people with COPD referred for PR **completed an initial assessment**

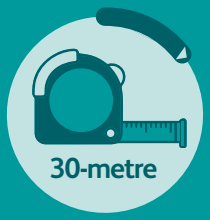
42% of these completed an incremental shuttle walk test (ISWT)

42.3% of these completed a 6-minute walk test (6MWT)

Practice walk tests

47% of patients performed two walk tests at their assessment (a practice walk test and a formal walk test).

Technical standards for 6MWT



Only **13%** of PR services surveyed were using a 30-metre course to conduct a 6MWT.

Standard operating procedures

84% of PR services had a standard operating procedure (SOP).

Glossary

Standard operating procedure (SOP) is a document which gives step-by-step information on how to provide PR care.

Walk tests are a way of measuring peoples' fitness level, and should be done at the start and end of a PR programme. See page 3 for more detail.

Technical standards explain how walk tests should be done. For example, 6-minute walk tests should be done on a 30-metre long track.

Section 4: Discharge assessment and improvement

What should happen when a patient completes a PR programme?

People with COPD who are enrolled onto a PR programme should have a discharge assessment at the end of their programme. This measures whether their exercise capacity and health have improved. These improvements are measured with walk tests and health status questionnaires.

At their discharge assessment, patients should be given an individualised discharge plan. This gives patients specialised advice to maintain improvements after they finish treatment.

NACAP recommends that:

- **70%** of people with COPD have a discharge assessment, and
- **all** people with COPD who have a discharge assessment are assessed to see if they feel better after finishing PR.

Key findings

Discharge assessments

66.7% completed their PR programme and had a discharge assessment.

People from more deprived areas or with a history of cardiovascular disease or depression were less likely to complete their discharge assessment

Outcomes for people with COPD

Of people with COPD who had a discharge assessment:

65% experienced an improvement in exercise capacity.

56% experienced an improvement in health status.

Individualised discharge plans

79.3% received an individualised discharge plan.

Glossary

Cardiovascular disease means a condition that affects the heart and/or blood vessels, like a heart attack or stroke. See page 8 for more detail.

Deprived areas are places that are seen as disadvantaged in specific ways. See page 8 for more detail.

Exercise capacity means how much excercise/activity a person is able to do comfortably.

Health status means the health (good or poor) of a person. For PR, improvements in health status are measured with health status questionnaires at initial and discharge assessments.

Outcomes describe what happens to a patient after they have finished their PR programme.

Recommendations

The targets in these recommendations (eg 70%) are based on the targets set by national quality standards on the minimum number of patients they feel should receive these areas of care.

For people living with COPD and their families and carers

- Ask for information on PR when you visit your healthcare professional and discuss whether a referral to your local PR service might help you.
- If you are admitted to hospital with a flare-up of your COPD, you should be referred to your local PR service. If you are not, ask your healthcare professional about this.
- If you have experience of COPD and PR, think about being a patient representative for a PR service. Patient representatives make sure other patients know why PR is important, and what they should expect from their PR programme.

What we are recommending for PR services

- Offer PR to **all people with COPD** who find that they are feeling more breathless when walking than other people their age.
- Hospitals to make sure **all people admitted to hospital** for COPD are offered PR. These people should **start PR within 30 days**.
- **Start PR within 90 days** of referral for **85%** of patients with **stable COPD**.
- Carry out **all walk tests** to national standards and make sure that **all people** with COPD do a **practice walk test** at their initial PR assessment.
- Ask **all people** with COPD attending PR **if they feel better** once their PR programme has finished.
- Complete PR programmes and **discharge assessments** for **70% of people** with COPD who start PR.
- Ensure **all PR services** have an agreed **standard operating procedure** (SOP).
- **Involve patients, their families and carers**, and patient/carer representatives in planning and improving PR services.

What we are recommending for local doctors (GPs) and hospitals

- **Assess all people with COPD** to see if PR may help them. Make sure that PR is offered to **all people who find they are walking slower** than others of the same age.
- Provide **information** on the benefits of PR to **all staff** who work with COPD patients.

Glossary

Patients with **stable COPD** are able to manage their condition at home and have not needed to be admitted to hospital recently. These patients might be referred to a PR programme by their local doctor or nurse.

Standard operating procedure (SOP) is a document which gives step-by-step information on how to provide PR care.

Walk tests are a way of measuring peoples' fitness level, and should be done at the start and end of a PR programme. See page 3 for more detail.

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