



National Asthma and COPD Audit Programme (NACAP)

What is the NACAP Pulmonary rehabilitation (PR) audit?

Please note that this information leaflet is being redesigned and will be replaced with a new version in August 2022. The information will remain the same.

Information for people who might need PR

You have been given this leaflet because you have a lung condition called chronic obstructive pulmonary disease (COPD) and the person treating you thinks pulmonary rehabilitation (PR) might help you. The leaflet will tell you:

- > what NACAP's national clinical audit of PR is
- > how your information might be used in the audit
- > what to do if you don't want your information to be used in the audit.

What is the NACAP PR audit?

Clinical audits ask questions about the way that services care for people, like:

- > What should we be doing?
- > What are we doing?
- > How can we do better?

The NACAP PR audit looks at the way PR services in England and Wales are caring for people with COPD and compares it to **guidelines** which explain what care these people should be getting. This is to make sure that people are getting the right care, and if not, to see what needs to change.

What information will the audit collect about me?

All PR services that are part of the NHS and care for people with COPD in England and Wales collect personal (confidential) information and information about the care you get. They will only collect this information if you agree that it can be included in the audit. At the start of your treatment, your PR service will ask you if it is ok to include your information in the audit (this is called giving consent).

Some of your confidential information will be used in the audit:

- > your NHS number (everybody in England and Wales has a different number that is on all their medical records)
- > your date of birth
- > your postcode (this is to see which part of England or Wales you live in)
- > your gender and ethnicity.

Why do you need my confidential information?

This helps us find your medical records if you have been treated at different times and in different places by the NHS. It also helps us to see if everybody is getting the same care, no matter who they are or where they are from.



How do you keep my information safe?

The NHS has strict rules to make sure that your information is kept safe and private. NACAP and anyone else who sees your data must agree to these rules by law. You can find out more about these rules [here](#) or by getting in touch with us using the details on page 3.

Where does my information go?

If you agree, your service will enter your data onto a special database run by a company called Crown Informatics. A few small number of staff at Crown Informatics will be able to see your confidential information (NHS number, postcode, gender and ethnicity) but they follow the NHS rules on keeping data safe too and only use your confidential information for very specific reasons. The staff at Crown Informatics remove any information that could be used to find out who you are. For example, they change your NHS number to an audit ID and your postcode to the part of the country you are from. When all your identifiable information has been removed from the data, Crown Informatics send it to Imperial College London. Imperial College London analyses the data (organises it and looks for patterns) and then sends it to NACAP, who use it to create reports. The Imperial College London or NACAP teams never see your confidential information. Crown Informatics might also send your data to NHS organisations in England and Wales so it can be linked to other medical data. For example, information on what happens to you after you have completed your PR programme (if you are admitted to hospital for another COPD flare-up). This linked data is sent back to NACAP so we can create outcomes reports on what happens to people after they are treated for a COPD. This [data flow](#) shows this in more detail.

What does NACAP do with my information?

We use the information we get to write reports on the PR care that people are getting. Some of these reports compare PR service's results to the national average, so they can see how well they are doing. You can see all our reports at: www.nacap.org.uk We also use your information to create real time reports called run charts. These show how each PR service in England and Wales is doing in key areas of care. Anyone can see these charts and because they only show PR service results, they will not show any of your confidential information. Sometimes, other organisations ask to use our information. This is usually for research or projects to improve care for people with COPD. It is very unlikely that they will see any confidential information like your date of birth or NHS number. If we ever need to share this information, we will make sure everyone follows NHS rules to keep it safe and private, and applies national opt out preferences for people who have set them. We will never publish information that could be used to find out who you are.

How long will you keep my information for?

Your information will be kept safely for at least 5 years after the end of the audit (NACAP is due to end in 2023) – this is a rule for all clinical audits by the **Information Governance Alliance's (IGA) Records Management Code of Practice for Health and Social Care 2016**. The exact date your information will be kept to is decided by the group that are in charge of the audit, the [Healthcare Quality Improvement Partnership \(HQIP\)](#).



Saying no thank you

Our PR audit works best when it collects information about as many people as possible. Before you start PR, someone at your PR service will talk to you about the audit and ask if it is ok to include your information. It's ok if you say no – you just have to tell the PR service that you don't want them to use your information. This won't change the care that you get! If you said that your information could be used, but changed your mind later, that's ok too. You can tell your PR service at any time, and they will remove your information from the database. If you decide this after your information has been sent off to NACAP, it may still be used in a report, but it will never be any information that can be used to find out who you are, and it will not be included in any reports after that.

What if I have a problem with the way my information has been used?

If you think that your information is being used when you didn't want it to, or used the wrong way, you have the right to complain to the Information Commissioner's Office. Visit www.ico.org.uk.

Who is running the audit?

The Healthcare Quality Improvement Partnership (HQIP) is in charge of NACAP, and it is run by the Royal College of Physicians (RCP).

Where can I find out more?

If you have any questions about PR, please talk to the staff at your PR service. If you have any questions about the audit please contact the NACAP team via: pulmrehab@rcp.ac.uk / 020 307 1526.