National Respiratory Audit Programme (NRAP)

What is the NRAP Pulmonary rehabilitation (PR) audit?
Information for patients

You have been given this leaflet because you have a respiratory condition and the person treating you thinks pulmonary rehabilitation (PR) might help you. The leaflet will tell you:

> What NRAP'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 NRAP pulmonary rehabilitation 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 NRAP PR audit looks at the way PR services in England and Wales are caring for people with respiratory conditions assessed for PR 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.
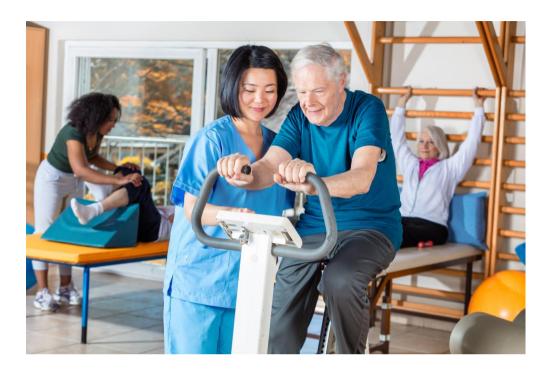
What information will the audit collect about me?

All PR services that are part of the NHS and care for people with respiratory conditions in England and Wales collect personal (confidential) information, and information about the care you receive. 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 you are happy with your information being included 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, ethnicity and mental health status.

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 staff members 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, Crown Informatics send it all on to Imperial College London. Imperial College London analyses the data (to organise and look for patterns) and then sends the data to NRAP to create reports. The Imperial College London or NRAP teams never see your confidential information.

Crown Informatics might also send your data to NHS organisations in England and Wales to 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 a flare-up of your condition). The 'linked' data will then have the confidential information removed by NHS England and DHCW. The 'linked' data are then sent to Imperial College London, to be processed, analysed and aggregated. These linked data are then sent back to NRAP so we can create outcome reports on what

happens to people after they are treated for their respiratory condition.

This data flow shows this in more detail.

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. NRAP and anyone else who sees your data must agree to these rules by law. Find out more about these rules or get in touch with us using the details on page 4.

What does NRAP 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 services' results to the national average, so they can see how well they are doing.

You can see all our reports at: www.nrap.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 respiratory conditions. 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 (NRAP is due to end in 2026) – 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 until when your information will be kept 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 your information can be included.

It's fine 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 receive.

If you say that your information can be used, but then change your mind later, that's fine 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 NRAP, it may still be used in a report, but there 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.

Commissioned by:

Who is running the audit?

HQIP is in charge of NRAP, and it is run by the Royal College of Physicians (RCP).

Where can I find out more?

If you have any questions about the audit, please contact the NRAP team (for audit queries only) via: praudit@rcp.ac.uk / 020 3075 1526. We cannot help with medical issues or appointments.

If you have any queries concerning the PR programme, please contact your PR service. If you need medical help or advice, please call 111 and for emergencies call 999.

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