National Respiratory Audit Programme (NRAP)

Pulmonary rehabilitation (PR) audit
Information for patients and caregivers

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

> What NRAP's national clinical audit of PR is

> How 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 care provided to patients, such as:

> 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 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.

Who is running the audit?
NRAP is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and it is run by the Royal College of Physicians (RCP).

What information will the audit collect?
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 they receive.

Use of confidential patient information without consent
This audit has gained special legal permission to collect confidential information without patient consent, unless a patient has set a national data opt-out preference. This applies from 1 April 2024.

Prior to this, PR services could only collect this information if patients explicitly agreed that it could be included in the audit.

Following Section 251 approval for England and Wales by the NHS Health Research Authority (CAG reference number: 23/CAG/0167), PR services can include patient identifiable information in the NRAP audit without the requirement to obtain explicit prior consent from patients. Section 251 support was recommended by the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG).

What confidential information is collected?

> NHS number (everybody in England and Wales has a different number that is on all their medical records)

> date of birth

> postcode

Once collected, this information will never be published in a way that can identify you.

How do we keep your information safe?
Strict NHS rules are in place to make sure information is confidential and secure. All organisations that handle information for NRAP must follow these.

We always ensure that those we agree to share information with have appropriate legal approvals in place and follow best practice in data protection and security.

Where does the confidential information go?
PR services taking part in this audit enter the information they collect about patients and their care into an online database called a 'web tool'. The information will be securely held there for the duration of the audit and then, for a further 5 years. NRAP's current contract runs until 31st May 2026, with potential to extend to 2028.

The information is held by an organisation called Crown Informatics who created the audit webtool. The PR service provider and staff at Crown Informatics will be the only people able to access confidential information (NHS number, date of birth and postcode). They must follow strict NHS rules on keeping your information safe and can only use your confidential information for very specific reasons (see below).

The staff at Crown Informatics remove any information that could be used to identify a patient. For example, they change the NHS number to an audit study ID number and the postcode to the first 4 digits (also known as 'Lower Super Output Area (LSOA)'. When all your identifiable information has been removed, Crown Informatics send it on to Imperial College London. Imperial College London analyses the information (to organise and look for patterns) and then returns the analysed service-level data to NRAP to generate reports. The Imperial College London or NRAP teams never receive or have access to confidential information.

Each month, Crown Informatics send information which includes some identifiable information to NHS England. Upon receipt, data processers in the NHS pseudonymise the information. This means personal information can no longer be attributed to a specific person without the use of additional information. Service level aggregate data will be released by NHS England in reports, presentations, and dashboards.

The data flow on our website shows this in more detail.

Why do you need confidential information?
This helps us find a patient's medical records if they 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 information safe?
Strict NHS rules are in place to make sure your information is confidential and secure. All organisations that handle information for NRAP must follow these rules.

We always ensure that those we agree to share your information with have appropriate legal approvals in place and follow best practice in data protection and security.

You can find out more about these rules by reading the PR fair processing document on our website, or get in touch with us using the details on page 5.

What does NRAP do with the information?
NRAP produces a range of reports highlighting if patient care in England and Wales follows national guidelines. These reports are then used by PR services to compare their data with the national/local average and other services. This enables services to see how good their care is and facilitate improvement.

All NRAP reports are publicly available on the audit website for you to understand the quality of care patients receive. You can see all our reports at: https://www.rcp.ac.uk/projects/reports

We may use the information collected to produce academic papers; however, we will never publish information that could be used to identify you.

Third party organisations may also request to use the data for research, audit and service evaluation purposes. The main use of the data will always be to improve care and services for people with respiratory conditions. This data will not contain any personal identifiers (such as NHS number). However, in the event that information is requested for statutory reasons, NRAP would be legally obliged to comply.

If third parties require more information than we collect in the audit to answer their questions, they may also request a 'linkage' to other sources of information. We will make sure the appropriate legal, ethical and security arrangements are in place to continue to keep personal information safe and secure. When appropriate, we will send identifiable information to the NHS organisations listed previously to facilitate this linkage.

We also use patient information to create real time service-level reports called run charts and benchmarking tables. These show how each PR service in England and Wales is performing in key areas of care. You can view live service-level performance at www.nrap.org.uk. Anyone can see these charts and because they only show PR service-level results, they will not show any of patient confidential information.

How long will you keep patient information for?
Patient 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).

What to do if you don't want your information to be used in the audit?
Saying 'no thank you,' in England, patients who have chosen to opt out of their confidential data being used for purposes other than their own care and treatment (national data opt-out programme) will not be included in this audit.

Wales does not operate a national opt-out programme, but patients are still able to opt out of individual audits such as this one.

Our PR audit works best when it collects information about as many people as possible. However, please speak to a member of the clinical team if you do not want information to be included. Saying this will not affect the care or treatment received in any way. They will ensure patient information is not included in the audit. If you think your information has been submitted to the audit and you would prefer to have it removed, please contact the service where you were treated, or the audit team.

What if I have a problem with the way the patient information has been used?
If you think that patient information is being used when you or some you care for 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.

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.

Commissioned by

HQIP
Healthcare Quality
Improvement Partnership