



## National Asthma and COPD Audit Programme (NACAP)

### Pulmonary Rehabilitation audit - Fair Processing Information/Privacy notice

Version 9.3: July 2022

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The Healthcare Quality Improvement Partnership (HQIP) are the data controllers for all data collected and reported on by the National Asthma and Chronic Obstructive Pulmonary Disease (COPD) Audit Programme (NACAP) pulmonary rehabilitation audit. You can contact HQIP by visiting <https://www.hqip.org.uk/contact-us/> and completing the contact form, or by writing to them at Healthcare Quality Improvement, Partnership Ltd, 27A Harley Place, London W1G 8LZ.

All data collected by the audit programme is processed to ensure patient confidentiality is maintained. Data processors include:

- **Crown Informatics** – who provide the audit web tool, data management and reporting services
- **Imperial College London** – who provide statistical data analysis services
- **Royal College of Physicians** – who run the audit and produce national and local reporting outputs
- **NHS Digital and DHCW (Data Health and Care Wales)**– who periodically link data from the audit to other databases to allow the programme to report on outcomes.

The organisations above may change in the future and up-to-date information will always be provided on our website.

#### Purpose of NACAP pulmonary rehabilitation (PR) audit

This audit looks at the quality of care people with COPD receive when they attend PR services. PR is a complex intervention that involves a combination of exercise, with education and behavioural interventions. The complex nature of PR means that there is variability in outcomes for patients and quality of service provision. The information collected in this audit will show which parts of PR care for people with COPD are good, and which parts need to be improved. The audit will also help to make sure that information on the quality of care is available to the public, and that services are supported to improve the quality of care being provided to patients with COPD.

#### Approvals and legal basis

##### *Common Law Duty of Confidentiality*

This audit operates on a patient consent model meaning eligible patients are required to provide consent prior to their data being included in the audit. PR services must confirm they have gained consent from patients on the online data collection tool (via tick-box) before being able to enter patient data. The PR audit collects the following patient identifiable items:

- NHS number,
- date of birth,
- and home postcode.

Further details about the audit data flows (also outlined below) and the full dataset is available via the [audit resources](#) page. Patient information sheets, posters and consent forms are also available via this link.

For more information about Common Law Duty of Confidentiality, how it applies to NACAP, and other organisations who request NACAP data, see this [short video](#) from the [Understanding Health Data Access](#) (UHDA) project.

#### *General Data Protection Regulations (GDPR)*

The PR audit's legal basis under GDPR is:

- **Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.** This is justified through commissioning arrangements which link back to NHS England, Welsh Government and other national bodies with statutory responsibilities to improve quality of health care services.
- **Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.** This is justified as the PR audit aims to drive improvements in the quality and safety of care and to improve outcomes for patients with a primary diagnosis of COPD accessing PR services.

#### **Main data flows**

From 1 March 2019, identifiable patient data (for patients that provide their written consent) will be entered into the audit web tool managed by Crown Informatics. This data will be entered by selected and authorised users at PR services in England and Wales\*. Raw, unadjusted data at site-level (non patient-identifiable) are presented on run charts in near to real time (one month after data submission). These are publicly available and support local quality improvement.

Periodically, these patient-level data will be sent to Imperial College London by Crown Informatics in a completely anonymised format for analysis. Imperial College London will then send analysed and aggregated data to the NACAP team at the Royal College of Physicians so that we can write and publish national and local reports. Only aggregate data will be presented, and no information will be released that could be used to identify individuals.

#### **PR audit – fair processing information | V9.3: July 2022**

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[pulmrehab@rcp.ac.uk](mailto:pulmrehab@rcp.ac.uk) | 020 3075 1526

[www.rcp.ac.uk/nacap](http://www.rcp.ac.uk/nacap)

**\*Scotland** - Scotland ceased to commission NACAP as of 1 March 2021. Information on Scottish COPD patients who were referred to and assessed for PR was therefore only collected by NACAP between 1 March 2019 – 10 April 2020 to ensure there was no risk of any patient data being unused. No data was collected past this point and all remaining patient data collected was included in the [2019 clinical audit report](#) published in December 2020. During this time NACAP held Public Benefit and Privacy Panel approval for Scotland (reference number: 1819-0229). All unpublished Scottish data were destroyed by NACAP, Crown Informatics and Imperial in December 2021.

## Linkage

### *England and Wales*

The audit information will be linked with data already held by NHS Digital and Data Health and Care Wales (DHCW): namely, the Hospital Episodes Statistics (HES) and Patient Episode Database for Wales (PEDW) datasets and the Office of National Statistics (ONS) mortality data. HES is a record of all hospital admissions in England, PEDW records all episodes of inpatient and day-case activity in NHS Wales hospitals, while ONS mortality data is sourced from civil registration data. NHS Digital and DHCW will receive patient identifiable information (NHS number, date of birth and postcode) from Crown Informatics to link the audit data to these sources.

### *All nations (England and Wales)*

Once the data has been linked, NHS Digital and NHS Wales will remove all patient identifiable information, leaving only the unique audit identifier. Imperial College London will then be sent the pseudonymised patient level record files for the patients that participated in the audit from HES, PEDW and ONS (cause of death, and date of death will be provided to Imperial College London from ONS mortality data). Imperial College London will then send analysed and aggregated data to the NACAP team at the Royal College of Physicians so that we can write and publish a supplement to the national clinical reports. Only aggregate data will be presented and no information will be released that could be used to identify individuals.

## Third party data requests

Third party organisations may also request to use data for research, audit and service evaluation purposes. The main use of data will always be to improve care and services for people with COPD. NACAP will not share any of this data unless the appropriate legal, ethical and security arrangements are in place to keep it safe and secure.

## Data retention

Data will be retained by NACAP over the period that the audit continues to operate. This will allow post-audit queries to be answered, outstanding longitudinal analyses to be completed and for third party data requests to be approved and completed. In addition, the [Information Governance Alliance \(IGA\)'s Records Management Code of Practice for Health and Social Care 2016](#) specifies that clinical audit records must be kept securely for a minimum period of 5 years after the audit has been completed and if the NACAP closes in the future, this requirement will be considered by NHS England and the Welsh Government and appropriate arrangements made as required.

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### **Saying 'no thank you'**

National clinical audit works best when it includes information about as many patients as possible. Once a patient has read and understood the patient information given to them by a member of staff from their PR service, they will be asked to give written or verbal permission for their information to be used in the PR audit. If they do not want their information to be included, they are advised to speak to a member of their clinical team. Saying this will not affect the care or treatment they receive in any way. The clinical team will ensure that the patient's information is not included in the audit.

If a patient has given permission for their information to be included in the audit but later change their minds, they are advised to contact their PR service. Their information will be removed from the audit web tool with the understanding that their data may have already been extracted from the web tool, aggregated and used in reports.

### **Right to complain to a supervisory body**

If a patient thinks that their information is being used inappropriately, they have the right to complain to the [Information Commissioners Office](#) (ICO).

If you have any queries regarding the processing of data as part of this audit, please contact the audit team at [pulmrehab@rcp.ac.uk](mailto:pulmrehab@rcp.ac.uk).