



If you do not want your information to be included, please let them know. Saying no will not affect the care or treatment you receive in any way. The clinical team will ensure your information is not included in the audit.

If you have given permission for your information to be included in this audit but you later change your mind, please let your pulmonary rehabilitation service know. Your data will be removed from the web tool. However, if data has already been extracted for reporting, your data will be included in the report in an aggregated and anonymous format.

### Your right to complain to a supervisory body

If you think that your information is being used inappropriately, you have the right to complain to the Information Commissioner's Office.

Visit [www.ico.org.uk](http://www.ico.org.uk).



Commissioned by:



NACAP

## National Asthma and COPD Audit Programme (NACAP)

### Pulmonary rehabilitation audit Information for patients



### Data retention

At the point of audit end, the funders of the audit will decide how data will be retained and destroyed. The decision will be in line with the **Information Governance Alliance's (IGA) Records Management Code of Practice for Health and Social Care 2016**, which specifies that clinical audit records must be kept securely for a minimum of 5 years after the audit has been completed.

### Saying 'no thank you'

National clinical audit works best when it includes information about as many patients as possible. Once you have read and understood this information, a member of the pulmonary rehabilitation team will ask for your signed permission to include your information in this audit.

### Who is running the audit?

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

### Further information

If you have any questions please ask the pulmonary rehabilitation staff who gave you this leaflet, or contact the NACAP team via:

Email: [pulmrehab@rcplondon.ac.uk](mailto:pulmrehab@rcplondon.ac.uk) | Telephone: 020 3075 1526

You can find out more about the NACAP pulmonary rehabilitation audit at: [www.rcplondon.ac.uk/nacap-pr](http://www.rcplondon.ac.uk/nacap-pr).

You have been given this leaflet because you have chronic obstructive pulmonary disease (COPD) and have been referred for pulmonary rehabilitation.

This information leaflet aims to inform you about the national clinical audit being carried out at this service and, if you consent to being part of this audit, how your information may be used.

### What is the NACAP 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 improve?

This audit looks at the care people with COPD get in pulmonary rehabilitation services.

The information collected will be compared with a set of pulmonary rehabilitation guidelines.

### What information is collected?

From March 2019 all pulmonary rehabilitation services providing NHS care for people with COPD in England, Scotland and Wales will collect:

- > personal (confidential) information
- > information about the treatment and care you get.

You will be asked to give your permission for your information to be used in the audit.

More information on what we collect is on our website: [www.rcplondon.ac.uk/nacap-pr](http://www.rcplondon.ac.uk/nacap-pr).

## Why is this helpful?

The information collected will show which parts of pulmonary rehabilitation care for people with COPD are good, and which parts need improving. The audit will also help to make sure that information on the quality of care is available to the public.

## What confidential information is collected?

Your unique NHS number (or CHI number in Scotland), your date of birth and postcode. We will also collect your gender and ethnicity.

## Why is it necessary to collect confidential information?

Confidential details are needed so information collected by this audit can be linked to information held by national NHS organisations.

We do this so we can follow your care if you are treated at different times and in different places. We collect gender and ethnicity to find out if this affects the treatment people get.

## How do we keep your information safe?

Strict NHS rules are in place to make sure your information is confidential and secure. All organisations that handle data for NACAP must follow these rules. We always ensure those we agree to share data with meet NHS legal requirements, and follow best practice in data protection and security.

## Where does my information go?

Pulmonary rehabilitation services taking part in this audit enter the data they collect about patients and their care into an online database called a 'web tool'. The data (including confidential information) will be held there for the duration of the audit.

The data is held by an organisation called Crown Informatics who create the audit web tool. Crown Informatics meets all NHS legal requirements, and follows best practice in data protection and security. Staff at Crown Informatics may see personal details, such as NHS/CHI number, postcode, gender and ethnicity as part of database administration.

Crown Informatics will take the data that is inputted by services, remove information that would enable you to be identified and send it to Imperial College London, who analyse the data. Imperial College then send results of the analysis to the NACAP team to produce reports. The NACAP team do not see information on individual patients.

Periodically, Crown Informatics will also send your data to a number of NHS organisations in England, Wales and Scotland to link to their records. For example, they send NHS/CHI number, date of birth and postcode data to NHS Digital, NWIS (NHS Wales Informatics Service) and eDRIS (electronic Data Research and Innovation Service).

NHS Digital has a record of all hospital admissions from the Hospital Episode Statistics (HES) dataset in England. NWIS and eDRIS have this data from the Patient Episode Database for Wales (PEDW) and the Information Services Division (ISD) in Scotland respectively. HES, PEDW and ISD data will be linked to the audit data. NHS Digital will also provide date and cause of death data from the civil registration records on behalf of the Office for National Statistics (ONS) for England and Wales. eDRIS will provide this on behalf of the National Records of Scotland.

Once Crown Informatics receive this 'linked' data back, they will remove identifiers and send it to Imperial College London, to analyse and aggregate, who then share the results with the NACAP team to produce outcome reports. A graphical representation of the 'data flow' can be found on our website at [www.rcplondon.ac.uk/nacap-pr-resources](http://www.rcplondon.ac.uk/nacap-pr-resources).

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

## How will my information be used?

Pulmonary rehabilitation services will receive their own reports about the care they provide to adults with COPD. The reports will compare service results with the national average. This helps services to see how good their care is. We will also produce reports about the quality of care at regional and national levels.



These reports will be made available on the audit website at [www.nacap.org.uk](http://www.nacap.org.uk).

We may use the data collected to produce academic papers. Third party organisations may also request to use the data for research, audit and service evaluation purposes.

Normally this data will not contain any personal identifiers (such as your date of birth or NHS number). However, in very rare cases we may need to share these for statutory reasons. We will not share any data unless the appropriate legal, ethical and security arrangements are in place to keep your details safe and secure. If third parties need more data than we collect in the audit to answer their questions, they may also require a 'linkage' to other sources of information. In these cases, we will send identifiable data to the NHS organisations listed previously.

They will link the audit data to the other datasets, so that the third party can understand more about your care.

The main use of data will always be to improve care and services for people with COPD.