

National Chronic Obstructive Pulmonary Disease (COPD) Audit Programme

- National COPD Primary Care (General Practice) Audit 2015

Information for Patients

What is the National COPD Primary Care Audit?

This clinical audit project is part of the National COPD Audit Programme. It will collect information to measure the delivery and quality of care which COPD patients receive at their GP surgery. All general practices (GP surgeries) that provide care for COPD patients in Wales will be able to take part.

The National COPD Audit Programme provides a major opportunity to work to ensure that all people with COPD receive appropriate care. It is led by the Royal College of Physicians (RCP), working in partnership with organisations such as the Royal College of General Practitioners, the Primary Care Respiratory Society UK, and is supported by the patient organisation the British Lung Foundation and by the British Thoracic Society. The programme also includes audits of hospital care and pulmonary rehabilitation programmes.

Why is this general practice providing my information?

This general practice (GP surgery) has agreed to take part in the national COPD primary care audit.

The NHS aims to provide you with the best care possible and national clinical audits play an important part in this. Audits monitor the standard of care received by patients.

They look at the care provided—what should we be doing?, are we doing it? and how can we improve?

Taking part in this audit shows that this practice is committed to improving care for COPD patients.

What information is collected?

This general practice will provide information on the care that you are given if you have been diagnosed with COPD. For further details of what is being collected, please ask the person who gave you this leaflet, or visit the audit programme website

<https://www.rcplondon.ac.uk/projects/primary-care-workstream>.

Why is this helpful?

It is now known that the care provided for people with COPD varies widely in terms of the way the diagnosis is made, the information provided to patients about the disease and how to manage it, the treatment provided including medication and services such as pulmonary rehabilitation. The information collected in this audit from general practice (GP) electronic records will help to highlight areas where COPD care for patients is good, and where improvements still need to be made, so that changes can be made to improve standards of care. The audit will also help to make sure reliable information on the quality of care and outcomes is available for patients and the public.

What confidential information is collected?

Your NHS number (everyone in the country has a unique number that is used by the NHS), date of birth and postcode. Also your gender and ethnicity. Your name and address are not collected.

Why is it necessary to collect confidential information?

Confidential details that can identify you as an individual are needed so that information from different sources about the care and treatment you receive can be linked together. This is so that the audit can follow the patient's care even if they are treated at different times and in different places (please see the section below on 'Where does the confidential information about patients go?'). Information about gender and ethnicity is used to understand whether there are differences in the way people of different genders or ethnic groups are treated.

Where does my confidential information go?

There are very strict rules about what happens to your confidential information. Using a highly secure processes, this general practice will provide information about the care you receive, along with your confidential information, to the NHS Wales Informatics Service (NWIS) (<http://www.wales.nhs.uk/nwis/>). The information is then transferred securely to the Health and Social Care Information Centre (HSCIC) (<http://www.hscic.gov.uk>), the official national body for information, data and IT systems in health and social care in England. The HSCIC collects data for a number of national clinical audits and is collecting this data on behalf of the National COPD Audit Programme. The details are stored on the HSCIC's secure data collection and storage system.

The HSCIC will use your confidential information to link to further sources of data that contain details of other aspects of your treatment and care (for example, visits to hospital (whether for COPD or for other reasons), rehabilitation treatment, and information about deaths kept by the Office for National Statistics). HSCIC will then send an anonymised version of the linked data to the National COPD Audit team at the Royal College of Physicians (RCP), who will analyse the data and produce audit reports. No information that could identify individual patients will be sent to them, or used in reports or other publications.

Very occasionally, authorised staff at NWIS and HSCIC may need to access personal details to fix any problems with the data, for example if there is duplication of information.

NWIS will only hold your confidential data for as long as is necessary for it to be transferred to HSCIC, after which it will be destroyed. It will be held by HSCIC for as long as the audit remains open. If the audit closes, it will be held for 5 years after the date of closure.

How do we keep your information safe?

There are very strict regulations and standards in place to ensure the confidentiality and security of patient information. All the organisations involved in the handling of data for the National COPD Audit Programme are required to comply with these. Confidential data will be held by NWIS and the HSCIC but only non-identifiable data is provided to others for analysis. Identifiable data is never provided to third parties.

How will my information be used?

The information collected from your practice will be analysed by the RCP, along with information from other practices in Wales. The RCP will not be able to see your NHS number or any other information that can be used to identify you.

Each practice which takes part in the audit will receive a report about the standards of care they are providing to their COPD patients, and how these compare with other practices in Wales. This information helps practices to see where they need to improve the care they provide to people with COPD.

Local and national reports will be published on the audit programme website (www.rcplondon.ac.uk/COPD). None of our published reports will contain NHS numbers or any other information that can be used to identify you. Your GP or other staff practice may also use the information they have collected for the audit so they can look at the standard of care they provide in more detail.

At some stage in the future the data collected through this audit may be used to produce academic papers for publication but these would not include any information that can be used to identify individual patients. Any such use of the data will always be in line with the overall aims of improving care and services for COPD patients.

Why haven't the general practice staff asked for my permission to use my information?

The national COPD audit has been given special legal permission to collect confidential information without asking permission from individual patients.

This is because it would be very difficult to ask each individual patient for

their permission, due to the large number of patients (over 800,000) diagnosed with COPD in England and Wales..

However, we are doing all that we can to make sure that COPD patients know that this data collection is going to take place, so that they can let us know if they do not want their information included.

What if I do not want to have my confidential information included?

National clinical audit works best when it has information from as many patients as possible. However, if you do not want your information to be used please tell the staff at your general practice. They will make sure your information is not used in the audit. Not taking part will not affect your treatment in any way.

In the future, there will be other national COPD audits taking place in different places, and at different times, such as in hospitals and pulmonary rehabilitation programmes. Asking not to be included in this primary care (general practice) audit will not automatically remove you from these future audits too. When they take place they will be advertised and you will have the opportunity to ask for your details not to be included in them at that time, if you wish.

How can I find out more about the national COPD audit programme?

You can visit the website:

www.rcplondon.ac.uk/copd

or contact the national COPD audit team by

Email: copd@rcplondon.ac.uk or

Telephone: 020 3075 1502.

Working with:



Commissioned by:

