National Respiratory Audit Programme (NRAP)
Secondary care – chronic obstructive pulmonary disease (COPD) audit

Information for patients

What is the NRAP secondary care (hospital) COPD 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 (chronic obstructive pulmonary disease) get in hospital.

The information collected will be compared to a set of COPD guidelines.

What information is collected?

Since February 2017, the COPD audit has been collecting information from NHS hospitals in England and Wales that admit people with COPD. This information includes:

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

More information on what we collect is on our website: www.rcp.ac.uk/NRAP-copd

Why is this helpful?

The information collected will show which parts of COPD care 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 NHS number (everyone has a unique number that is used by the NHS), date of birth, ethnicity, and postcode. We will also collect your gender and ethnicity.

Why is it necessary to collect confidential information?

Confidential details are needed to link information collected by this audit with other sources.

We do this so we can track your care even if you are treated at different times or in different places. We also collect your gender and ethnicity to find out if this affects the treatment you receive.

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 NRAP must follow these.

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

Where does my confidential information go?

Hospitals taking part in this audit enter the information or data they collect about patients and their care into an online database called a 'web tool'. The data will be held there for the duration of the audit and then, for a further 5 years.

The data are held by an organisation called Crown Informatics who created the audit web tool.

Staff at Crown Informatics may see your personal details, such as NHS number, postcode, gender, and ethnicity as part of database administration.

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

Periodically, Crown Informatics will also send your data to a number of organisations in England and Wales to link to other sources. They send your NHS number, date of birth and postcode data to NHS England and DHCW (Data Health and Care Wales). NHS England has a record of all hospital admissions from the Hospital Episode Statistics (HES) dataset in England. DHCW holds this data from the Patient Episode Database for Wales (PEDW). HES and PEDW data will be linked to the audit data. NHS England 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.

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. The results are then shared with the NRAP team to produce outcomes reports.

A graphical representation of the 'data flow' can be found on our website.

How will my information be used?
NRAP produces a range of reports highlighting if patient care in England and Wales follows the national COPD guidelines. These reports are then used by hospitals to compare their data with the national/local average and other hospitals. This enables hospitals to see how good their care is.

All NRAP reports are publicly available on the audit website for you to understand the quality of care you receive. You can also view live hospital performance at performance at www.nrap.org.uk.

We may use the data 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 COPD. These data will not contain any personal identifiers (such as NHS number). However, in the rare case that personal identifiers are present, we may need to share these for statutory reasons.

We will make sure the appropriate legal, ethical and security arrangements are in place to keep your personal 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 to facilitate this linkage.

Why haven't hospital staff asked for permission to use my information?
This audit has special legal permission to collect confidential information without patient consent, the exception being where a national data opt-out is set. This is because it can be difficult to ask patients when they have an exacerbation of COPD. Some patients may find it hard to communicate and some won't have relatives with them who can communicate their preference on their behalf. An exacerbation of COPD is a very distressing time for patients and asking them about the audit at this time would not be the most important priority.

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.

National clinical audit works best when it includes information about as many patients as possible. However, please speak to a member of your clinical team if you do not want your information to be included. Saying this will not affect the care or treatment you receive in any way. They will ensure your 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 hospital where you were treated, or the audit team.

Who is running the audit?

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

If you have any questions, please ask the hospital staff who gave you this leaflet or contact the NRAP team via: copd@rcp.ac.uk | 020 3075 1526

You can find out more about the NRAP secondary care COPD audit at: www.rcp.ac.uk/NRAP-copd

Commissioned by

HQIP
Healthcare Quality
Improvement Partnership