



National Asthma and COPD Audit Programme (NACAP)

NACAP: Privacy notice

Version 5: March 2023

Introduction

This page is intended to provide information for patients, clinicians, parents/carers of service users whose information may be used for the National Asthma and COPD Audit Programme's (NACAP) work. It explains what type of information we collect, why we collect it and what we do with it.

This privacy policy was updated in May 2018 to meet the requirements of the General Data Protection Regulation (GDPR). We will update this privacy policy whenever we change the type of processing we carry out. Please regularly come back to this page and check this policy for any changes.

Our legal basis for collecting information

The legal bases for collecting and using personal data are:

Public Task

We collect only the information that is necessary to carry out our function and avoid collecting information that will not be used. This is received from healthcare providers, such as NHS Trusts and Health Boards. To see what information is held in your healthcare record please contact your local Trust or Board.

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.

Consent

Where people sign up to receive newsletters and updates, attend events or work with NACAP, consent is received for us to store and process personal data.

The Pulmonary Rehabilitation clinical audit collects patient data by obtaining consent from patients, as well as using Public Task and Special Categories of Data (ensuring high standards of healthcare). Information about the audit is provided to help clinicians obtain informed consent from patients.

Contract

For example, this is the basis we use when it is necessary for us to take specific steps before entering into a contract with you to supply you a service or vice versa.

Legal obligation

For example, this is the basis we use when it is necessary for us to comply with the law (not including contractual obligations) because we are required to keep documentation to produce in court proceedings.

Legitimate interests

This basis is used to allow us to hold information as evidence should we need it in the future, for example, if you ask us to unsubscribe you from our newsletter.

Common Law Duty of Confidentiality

We apply the Common Law Duty of Confidentiality to all data we hold.

Article 9 condition for processing special category data:

- 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.

When we collect your information

If you are a patient meeting the criteria of one of our clinical audits, we may collect your NHS number, date of birth and postcode as well as information about some aspects of your care.

If you are a clinician, we will ask for your name and email address, and possibly other information, when you:

- Complete a questionnaire
- Sign up for updates on the NACAP work programme
- Become a study contact or Advisory Group Member
- Attend an event organised by or involving NACAP.

Most of the personal information we collect has been received directly from you. You may give us your name and contact information or other personal data:

- When you fill out a form on our website
- When you communicate with us, for example if you make an enquiry
- When you attend an event, virtually or in person
- When you complete any surveys or feedback forms we send you
- When you fill in any forms
- When you apply for a job with us
- If you work for us or with us
- If you enter into a contract with us, for example if you are one of our suppliers, or if we are one of your suppliers
- If you buy one of our services or products, or if we buy from you
- Claim expenses from us

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The information we collect

Clinical audit data

We collect information about the care provided to a large sample of patients directly from hospitals for each clinical audit. This includes:

- NHS number and date of birth
- Date, time and department of arrival at hospital
- Demographic and health information, such as gender, postcode, ethnicity, smoking status
- Assessments, such as walking test, Chronic Respiratory Questionnaire
- Clinical measures, such as respiration rate, oxygen saturation, peak flow measurement
- Details about the admission to and discharge from hospital and referral
- Clinical care, including review by a specialist, provision of oxygen, use of non-invasive ventilation, spirometry, use of steroids and β 2 agonists, discharge bundle
- Outcomes, including death.

This information is entered into a secure online data collection tool which is created and managed by Crown Informatics on behalf of NACAP. The data is entered by staff at NHS hospitals who have registered with the clinical audit and on the secure data collection tool. No employee of NACAP has access to this information.

Shortly after the data collection deadline, Crown Informatics remove all of the identifiable information (such as NHS number, date of birth) and send the anonymised, patient-level data to Imperial College London. Imperial College London clean and analyse the data before sending it to NACAP to write reports.

Data 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 comes from civil registration data. NHS Digital and NWIS will receive patient identifiable information (NHS number, date of birth and postcode) from Crown Informatics to link the audit data to these sources.

England and Wales:

Once the data has been linked, it will be sent back to Crown Informatics for processing, including ensuring that all patient identifiable information is anonymised. Imperial College London will then be sent the anonymised patient-level records for the patients that participated in the audit from HES, PEDW and ONS. Imperial will then send analysed and aggregated data to the NACAP team so that we can write and publish information to support the national reports.

The aim of the data linkage is to get a picture of what happened to patients after they were treated for asthma or COPD, for example if they were readmitted to hospital. We only use and report overall numbers. No information will be released that could be used to identify individuals.

Patient-identifiable information is collected without obtaining consent from the patient under Section 251 of the NHS Act 2006 in England and Wales, given by the Health Research Authority, and under approval from the Public Benefit and Privacy Panel for Health and Social Care in Scotland*. This allows us to breach the Common

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Law Duty of Confidentiality by collecting personal data under specific circumstances and with strict data security procedures in place.

Data collected not related to specific studies

- Your name
- Your contact details
- Your job role and your organisation
- If you apply for a job with us, we will collect information about your employment history, qualifications and references
- If you work for us, we will collect and use additional personal information, such as health details and financial details
- If you claim expenses from us, such as travel expenses for attending a meeting, we will hold your name and address for the purposes of accounting and auditing
- If you fill in any questionnaires, surveys or feedback forms we will collect your experiences, opinions and any health information you are happy to share with us
- If you interact with our website we may collect certain technical information, such as your browsing activity across our website and your IP address. An IP address provides the location of server you are contacting us from. We only use this information to ensure website security.

How and why we use the information

The primary purpose of NACAP's work is to investigate the quality of care provided to patients in order to improve the care of future patients. Direct or ongoing individual patient care will not be affected.

All patients who meet the criteria we are looking at, such as children and young people with asthma who have been in contact with hospital services during the audit period, will be entered into the online data collection tool. If a patient has chosen to opt-out of their data being used for any purposes other than their healthcare, they will be removed from the sample by the hospital submitting the data. Only date of birth and NHS number and postcode are collected along with non-identifiable information about their care.

Patient-identifiable information is collected without obtaining consent from the patient under Section 251 of the NHS Act 2006 in England and Wales, given by the Health Research Authority. This allows us to breach the Common Law Duty of Confidentiality by collecting personal data under specific circumstances and with strict data security procedures in place.

The anonymised and analysed data is kept for 5 years, in line with the Information Governance Alliance's Records Management Code of Practice for Health and Social Care 2016.

How we protect your information

We take the responsibility of holding people's personal data very seriously. We have internal policies which set out and guide our data security. All staff adhere to this approach and are regularly trained in data protection.

Electronic patient and organisational information (such as databases, online portals etc.) are kept on secure servers. Patient-identifiable information is only submitted to Crown Informatics and is anonymised before being analysed.

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Information Security and Information Governance requires clear and effective management and accountability structures, governance processes, documented policies and procedures, trained staff and adequate resources. As such we have created the following documentation to clearly detail the policies and procedures we have in place.

To view the Royal College of Physicians' privacy statement please [click here](#).

Who we share your personal data with

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 NHS number). However, in the rare cases it does, we will make sure the appropriate legal, ethical and security arrangements are in place to keep your personal details safe and secure.

Names of clinicians, clinical audit/governance professionals, Study Advisory Group members, Board members and other professionals that we work with will be shared within the team in the necessary running of the audits.

What are your rights over your personal data?

The right to erasure

You can request that we don't use personal information about you in our studies and we will ensure that any of your information we hold is destroyed. This will need to be done on a study-by-study basis otherwise the only way we could remove you from all studies would be to hold personal data about you to compare with the patient information that we receive.

You also have the right to restriction of processing and to object to processing. We treat these the same way as the right to erasure and remove all information about you.

If you decide that you would prefer that your information is not used, please let us know by contacting us in writing at the postal address or via this email: nacap@rcp.ac.uk.


The right of access

You have the right to see what information is held about you. Crown Informatics are the only organisation in the clinical audit programme that receives personal data, and this is anonymised as soon as possible. If you are a patient, we don't use names and addresses so you would have to know your NHS number. Once the data has been anonymised it would not be possible to identify if you were included in the audit sample. You have the *right to rectify* any data that is incorrect but rectifying it with us would not change the information in your health record and you may want to contact your healthcare provider directly.

The right to data portability

If we do have information held about you and you wish to see it, we will provide your data in a format that you will be able to use, such as Microsoft Word, Excel or CSV.

To see what information we hold about you, please contact nacap@rcp.ac.uk. There is no charge for this.

	<p>We do:</p> <ul style="list-style-type: none">• use personal data to help improve health care services• keep all personal data secure and confidential
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	<ul style="list-style-type: none"> • give you the right to opt out of any of our studies
x	<p>We do not:</p> <ul style="list-style-type: none"> • share your personal data with third parties • use personal or identifiable data in our reports

Data Protection Officer

The Data Protection Officer at Royal College of Physicians is Pamela Forde. Further information is available by emailing dataprotection@rcp.ac.uk or by contacting the NACAP office on 020 3075 1526.

Overview of current data collections

NACAP is currently holding information for the following work programmes:

- Adult asthma national clinical audit
- Children and Young People’s national clinical audit
- Chronic Obstructive Pulmonary Disease (COPD) national clinical audit
- Primary care national clinical audit
- Pulmonary rehabilitation national clinical audit
- Quality improvement workshops

Contact the Information Commissioner’s Office

If you are unhappy with the way we handle your data or have dealt with a request, you have the right to lodge a complaint with the Information Commissioner’s Office at <https://ico.org.uk/concerns/> or telephone 0303 123 1113.

Contact NACAP

If you have any questions or want to request that your data is not included in a study, please contact:

Teena Chowdhury
Operations Director, Audit and Accreditation
Care Quality Improvement Department
Royal College of Physicians
11 St Andrews Place | Regent’s Park | London NW1 4LE
Email: Teena.Chowdhury@rcp.ac.uk

More detailed information about the work of NACAP can be found at:

<https://www.rcp.ac.uk/projects/national-asthma-and-copd-audit-programme-nacap>

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