



Royal College  
of Physicians

NACAP

# National Asthma and COPD Audit Programme (NACAP)

Secondary care – Children and  
young people asthma audit

Information for parents  
and carers





## What is the NACAP children and young people asthma audit?

You have been given this leaflet because your child has asthma. It tells you about the national clinical audit being carried out and how your information may be used.

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 children and young people with asthma get when they are admitted to hospital because of an asthma attack. The information collected will be compared with a set of asthma guidelines.

## What information will be collected about my child?

From June 2019 until at least February 2021, NHS hospitals in England, Scotland and Wales that admit children and young people with asthma attacks will collect:

- > personal (confidential) information: your child's NHS number (or CHI in Scotland), their date of birth, gender and postcode
- > information about the treatment and care your child receives.

More information on what we collect is on our website:

[www.rcplondon.ac.uk/nacap-CYP-asthma](http://www.rcplondon.ac.uk/nacap-CYP-asthma)

## Why is this helpful?

The information collected will show which parts of asthma care for children and young people 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.

Confidential details are needed so information collected by this audit can be linked with other sources. We do this so we can follow your child's care if they are treated at different times and in different places. We collect gender to find out if this affects the treatment they get.

## How do we keep your child's information safe?

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

## Where does my child's 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 in line with NHS guidelines.

The data is held by an organisation called Crown Informatics which creates the audit web tool. Staff at Crown Informatics may see personal details, such as NHS or CHI number, postcode, and gender as part of database administration.

Crown Informatics will remove information that would enable your child to be identified and send it to Imperial College London, where the data will be analysed. The results will then be sent to the NACAP team at the Royal College of Physicians to produce reports. The NACAP team do not see information on individual children or young people.

Periodically, Crown Informatics will also send your child's data to a number of organisations in England, Wales and Scotland to link to other sources.

They send NHS or 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 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. The 'linked' data will then have the confidential information removed by NHS Digital, NWIS and eDRIS. The 'linked' data are then sent to Imperial College London, to process, analyse and aggregate it. The results are then shared 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-CYP-asthma](http://www.rcplondon.ac.uk/nacap-CYP-asthma)

## How will my child's information be used?

Hospitals will receive their own reports about the care they provide to children and young people with asthma. The reports will compare hospitals with the national average. This helps hospitals to see how good their care is.

National and patient reports will also be made publicly available on the audit website. 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.

The main use of data will always be to improve care and services for children and young people with asthma. Normally this data will not contain any personal identifiers (such as your child's date of birth or NHS/CHI 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 and we will never publish information that could be used to

identify you. 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.

## Why haven't hospital staff asked for permission to use my child's information?

This audit has special legal permission to collect confidential information without parent/carer or patient consent.

This is because it can be difficult to ask patients or their parents/carers when they or their child is having an asthma attack. Some patients may find it hard to communicate and some may not have relatives with them who can communicate their wishes on their behalf. An asthma attack is a very distressing time for both patients and their parents/carers, and asking them about the audit at this time would not be the most important priority.

## Saying 'no thank you'

National clinical audit works best when it includes information from as many patients as possible. However, please speak to a member of your child's clinical team if you do not want their information to be included. Saying this will not affect their care or treatment in any way. They will ensure your child's information is not included in the audit.

If you think your child's information has been submitted to the audit and you would prefer to have it removed, please contact the hospital that treated your child or the NACAP team (see details below).

In England, young people over the age of 13, or parents/carers of children under 13, 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. Scotland and Wales do not operate a national opt-out programme but parents/carers or patients are still able to opt-out of individual audits, such as this one.

## 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 hospital staff who gave you this leaflet or contact the NACAP team via:

Email: [asthma@rcplondon.ac.uk](mailto:asthma@rcplondon.ac.uk)

Phone: **020 3075 1526**

You can find out more about the NACAP Children and young people asthma audit at: [www.rcplondon.ac.uk/nacap-CYP-asthma](http://www.rcplondon.ac.uk/nacap-CYP-asthma)

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Commissioned by:



**HQIP**

Healthcare Quality  
Improvement Partnership