



Royal College
of Physicians

National respiratory audit
programme (NRAP)

National Respiratory Audit Programme (NRAP)

Secondary care - Children and young people asthma audit
Information for parents and carers

Version 6.0: June 2023





What is the NRAP 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 to a set of asthma guidelines.

What information will be collected about my child?

From June 2019 to at least May 2026, NHS hospitals in England and Wales that admit children and young people with asthma attacks will collect:

- personal (confidential) information: your child's NHS number, their date of birth, gender, ethnicity, mental health status and postcode
- information about the treatment and care your child receives.

More information on what we collect is on our website:

www.rcp.ac.uk/nrap

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, ethnicity, and mental health status to find out if this affects the treatment they get.

How do we keep your child's information safe?

We always ensure that 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 are held by an organisation called Crown Informatics which creates the audit web tool. Staff at Crown Informatics may see personal details, such as NHS number, postcode, gender, ethnicity, and mental health status as part of database administration.

Crown Informatics will remove information that would enable your child to be identified before sending it to Imperial College London, where the data will be analysed. The results will then be sent to the NRAP team at the Royal College of Physicians to produce reports. The NRAP team cannot 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 and Wales to link to other sources.

They send your child's 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 has 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 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 process, analyse and

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

A graphical representation of the 'data flow' can be found on our website at www.rcp.ac.uk/nrap

How will my child's information be used?

NRAP produces a range of reports highlighting if patient care in England and Wales follows national asthma 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 by clicking on the charts tab at nrap.org.uk. We may also 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 asthma. 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 not share any of your 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 to facilitate this linkage.

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 (unless where a national data opt-out is set).

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'

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.

Wales does not operate a national data 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 child's clinical team if you do not want their information to be included. Saying this will not affect the care or treatment they receive in any way. They will ensure your information is not included in the audit and will note this for the future on their patient database.

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 where your child was treated.

Who is running the audit?

NRAP is funded 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:
asthma@rcp.ac.uk | 020 3075 1526

You can find out more about the NRAP Children and young people asthma audit at: **www.rcp.ac.uk/nrap**

Commissioned by:



HQIP
Healthcare Quality
Improvement Partnership