



Royal College
of Physicians

NACAP

National Asthma and Chronic Obstructive
Pulmonary Disease Audit Programme (NACAP)

Children and young people asthma audit 2019/20

Report for children and young people
and their parents and carers

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Contents

What is the NACAP?	2
What should happen at hospital?	4
Foreword	5
Patient story	6
– Part 1: Diagnosis	6
– Part 2: Asthma triggers and being admitted to hospital for an asthma attack	7
– Part 3: Description of hospital experience – thoughts and/or treatments	8
Key findings	9
Asthma treatment – what to expect when you are admitted	10
Discharge planning	11
Transitional planning	13
Recommendations	14
Jargon buster	15
Useful web links	16

What is the NACAP?

The National Asthma and COPD (chronic obstructive pulmonary disease) Audit Programme (NACAP) is a collection of projects (we call these audits) that involves collecting information from hospitals across England, Scotland and Wales. The information shows which parts of asthma and COPD care are good and which parts could be improved for patients.

An important part of the NACAP's work with patients is selecting patient priorities. These are the areas of asthma and COPD care that are most important to patients. You can find out more about how NACAP patient priorities have been selected at: www.rcp.ac.uk/nacap.

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

In association with:



British
Thoracic
Society

Imperial College
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THE ASTHMA UK AND
BRITISH LUNG FOUNDATION
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Royal College of
Paediatrics and Child Health
Leading the way in Children's Health



Association of Respiratory
Nurse Specialists



Royal College of
General Practitioners

Commissioned by:



HQIP

Healthcare Quality
Improvement Partnership

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



The clinical audit collects information about how children and young people are treated when they go to hospital with an asthma attack. We have been running this audit since June 2019.

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



The organisational audit looks at what resources and services are available in hospitals for children and young people who are admitted with an asthma attack. It also looks at where improvements can be made.

What does this report include?

This report shows information about:

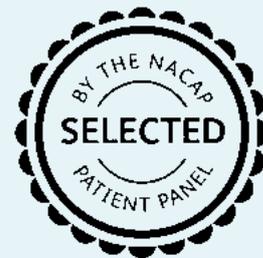
- > 8,506 children and young people admitted with asthma attacks from 1 June 2019 and discharged by 31 January 2020
- > the resources and services available in hospitals for children and young people with asthma between December 2019 and March 2020.

We have also included some stories we received from children and young people about their asthma care.

We would like to thank members of the NACAP children and young people panel and the Royal College of Paediatrics and Child Health (RCPCH) for working with us and helping us to create this booklet.

For further information on the NACAP and to read our annual reports visit www.rcp.ac.uk/nacap

Follow us on Twitter @NACAPaudit



What should happen at hospital?

Arrival at the hospital



You should be given medicine for your asthma within 1 hour



The doctor will ask you if you or anyone you live with smokes



The doctor will make sure you know how to use your inhaler. They will also review your personalised asthma action plan (PAAP) or give you one if you don't have one already



You should have a follow-up appointment in an asthma clinic within 4 weeks

For more information about the 2019/20 NACAP children and young people asthma audit, please visit www.rcp.ac.uk/CYP-asthma-2019-20

Foreword



Ian Sinha, children and young people asthma audit clinical lead

Welcome to our first patient report! We have conducted the largest ever review of how well children and young people with asthma are looked after when admitted to hospital with an asthma attack. We have done three things to get this information:

- 1** We measured how good the care was of children and young people who were admitted to hospital with asthma attacks compared with national standards. This is called an audit of care. Doctors and nurses looked through the notes of all children and young people who were admitted with an asthma attack between 1 June 2019 and discharged by 31 January 2020. They looked at various things that happened during the admission to see whether they were done correctly; for example, if a test was done or not, or a treatment given and how quickly it was given. We now have information on over 8,500 admissions – this makes our audit the largest ever of its kind, which is a great achievement by everyone who took part!
- 2** We asked doctors and nurses about how their asthma services work on a day-to-day basis. This included the number of staff they have to look after children and young people with asthma, how they link with other services and hospitals in the area, and whether they had a group of people whose job it was to try and improve things for children and young people with asthma.
- 3** We worked with children and young people who have asthma to help us make sense of the information. They also told us which things about hospital care were important to them.

All of this required lots of hard work from lots of people, and our team is very grateful for that. The reason we asked people to do all this work was to start the process of improving things for children and young people with asthma. The main findings from the audit were mixed – some were good, some were less good. If you read the report, it will help you to understand what good care for asthma should be

and that may help you to ask for that good care if you should be admitted to hospital in the future.

The key findings we have highlighted are:

Children and young people get the right treatment, but it could be given quicker.

- 1** Doctors and nurses don't always ask about things that might trigger asthma attacks (like smoking), so you or your parent/carer should tell them these things even if they don't ask you, as this might help avoid future attacks.
- 2** When children and young people are admitted to hospital, doctors and nurses don't always check important things like whether they know how to use their inhalers, whether they have a personalised asthma action plan, or whether they have a clinic appointment made. You or your parent/carer should always ask for a nurse to check that you are using your inhaler correctly and to give you a written plan on how to look after your asthma. You should always leave hospital with an appointment to see the specialist in the hospital asthma clinic afterwards.
- 3** Not every hospital has an asthma nurse who is trained to look after children and young people. But we recommend that they all should.
- 4** All hospitals should have access to tests that can help make sure if a child or young person has asthma.

The teams who manage asthma around the country are excellent and very dedicated, and they will be using the results of the audit to look at where they can improve. We are sure they would want to hear your opinions, after you have read this report. Each hospital will continue to collect information on the standard of care that it provides and we should be able to see improvements in care quickly. By the time of the next report, we hope to see that things that were good stayed good, and things that could be better have improved. We have every confidence that the teams around the country can do this. We want everyone who has to go to hospital for treatment of their asthma to get the best possible treatment every time and in every hospital!

Patient story

We worked with our patient panel and asked them different questions. We wanted to know more about their experiences in hospital.

We hope their stories will help other children and young people to understand and ask for good care.

Part 1: Diagnosis

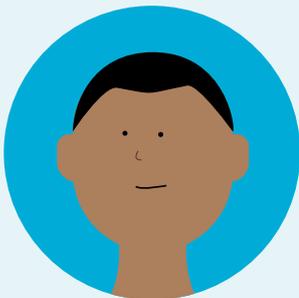
Finding out that you (or your child) has asthma and your thoughts about this



I was first diagnosed with asthma when I was 3 or 4. It was really scary as I couldn't breathe. **Child 1, aged 12**



When I was 5 I found out that I had asthma. I can't remember my first thoughts but it didn't affect me too much as it was mild. **Child 3, aged 12**



When I was about 8 years old, I was told I have asthma. We did get told that I had allergies and that made my eyes get swollen and red and it made my lips get swollen. Also my breathing got worse and then I got told that I have asthma too. My allergies are horse hair, dogs, rabbits, guinea pigs and weed pollen. If I do not take my tablets, nose spray and inhalers then my breathing gets wheezy and my chest gets tight. I sometimes find it hard having asthma because I love sports and gymnastics and if I forget my inhaler I panic. We have to always have a spare inhaler in the car and at my Nan and Grandad's just in case. **Child 2, aged 11**



It was in September 2013 that my son was first diagnosed with asthma after a visit to A&E. We had another trip to A&E in 2020. **Parent**

Part 2: Asthma triggers and being admitted to hospital for an asthma attack

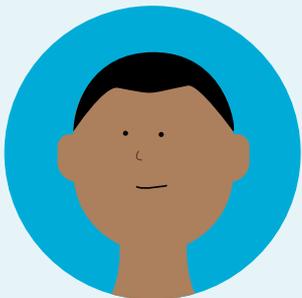
Did you ever go to hospital for your asthma? What happened before to make your asthma bad?



I was admitted into hospital several times when I was younger. It was always a cold that then turned into chest infections and asthma attacks.
Child 1, aged 12



Yes, I have when I was 5 and again exactly 7 years later when I was 12. I had a bad cold which caused a bad breathing attack on both occasions.’
Child 3, aged 12



My Mum told me I went to hospital when I was 4 but I don't really remember much. I do remember being allergic to horses and needing my inhaler though. I have been to hospital for my check-up meetings and they are always good. They tell me what I need and what will help. I now take medicine every day for my asthma, and it really helps.
Child 2, aged 11



My son had a very bad cold and it triggered an asthma attack. We waited for a telephone appointment from our local doctors' surgery for information and support but they never responded. I was so concerned that I took him to A&E to get him checked over.
Parent

Part 3: Description of hospital experience – thoughts and/or treatments

What was your experience when you were admitted to hospital?



I used to be rushed through A&E straight into ICU where I was wired up and put on a nebuliser which was very scary. I used to be in hospital for 10 days at a time and discharged once I got better. I think the long waits and appointment dates need improving.

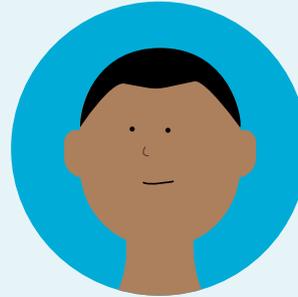
At hospital, I was

- > given steroids quite quickly
- > always given an action plan on discharge
- > always had follow-up appointments
- > always seen by a nurse specialist before seeing a consultant.

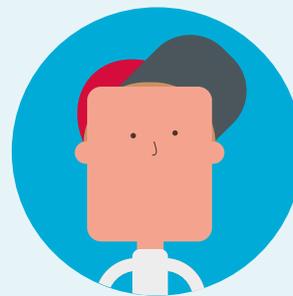
We also always go through the following:

- > medication checks
- > inhaler techniques
- > follow-up appointments
- > review of medications.

Child 1, aged 12



I haven't been to hospital for an asthma attack since I have been old enough to remember it properly because I was 4 years old when I last went in for my breathing. When I do feel wheezy though and struggle to breathe, it is scary and I panic and worry until I have my inhaler and it helps me to feel better. **Child 2, aged 11**



I was a bit stuffy and frightened. I didn't want to stay in. **Child 3, aged 12**



My son was

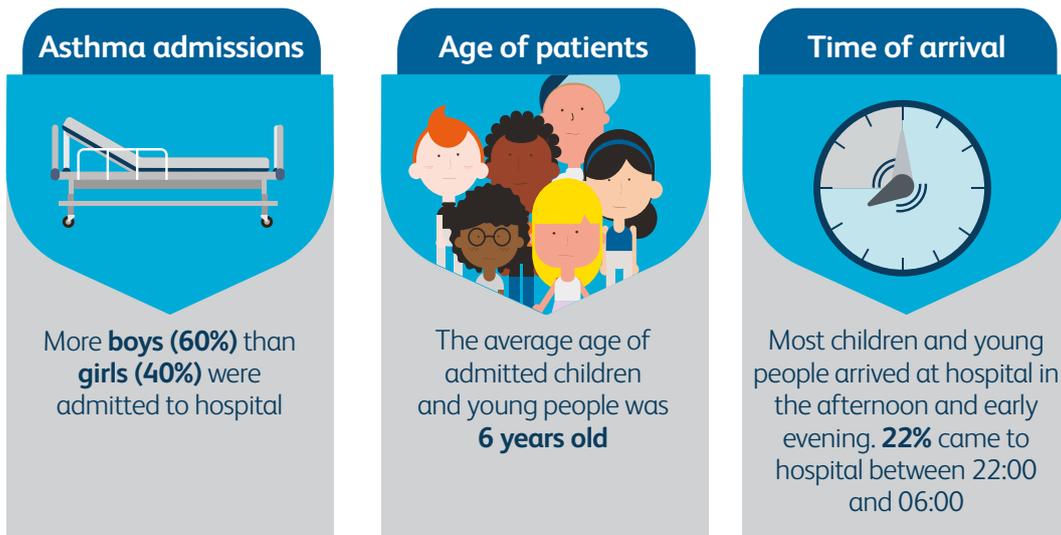
- > repeatedly seen by nurses, junior doctors and more senior staff
- > closely monitored (approx every 60 minutes) with oxygen checks, heart rate checks and checking his inhaler use
- > issued with an personalised asthma action plan on leaving hospital.

Parent

Key findings

Describing the children and young people admitted into hospital with an asthma attack

As well as collecting information on the care that patients receive when they are in hospital, the audit also collects some more general information about each patient, such as their age and gender. This allows us to understand things like which patient groups are more likely to be admitted to hospital, or stay there for a long time.



Smoking and exposure to second-hand smoke

- > Smoking is one of the biggest risk factors for asthma. A risk factor is something that increases the chance of a person developing a disease.
- > Breathing in cigarette smoke can trigger asthma attacks. Recording a child or young person's smoking status and exposure to second-hand smoke is therefore very important. Second-hand smoke is smoke released from burning tobacco. Whenever a cigarette, cigar or pipe is lit, second-hand smoke is produced. This is the smoke breathed out as well as the smoke created by the lit end. People who breathe in second-hand smoke are at risk of the same diseases as smokers. Children are especially vulnerable to the effects of second-hand smoke, which has been linked to an increase in conditions such as asthma.

42% of children and young people did not have their exposure to cigarette smoke recorded in their medical notes.



How sick were the children and young people when they came to hospital?

67% of children and young people were very sick when they came to hospital. Their asthma attack would be described as either 'severe' or 'life-threatening'.



Asthma treatment – what to expect when you are admitted

Review by a member of the multidisciplinary team (MDT) trained in asthma care

The children and young people asthma MDT consists of a group of specialists including an asthma nurse specialist, a pharmacist and a paediatric asthma consultant. You are more likely to receive good asthma care if you are seen by a member of this team.

What should happen?

- > Before you are discharged from hospital, you should be reviewed by a member of the MDT.

They will discuss all of the available treatment options with you, to make sure that you get the most suitable option for you.



81% of children and young people admitted were reviewed by a member of the MDT.



Medication

What should happen?

- > An important part of managing an asthma attack is by giving children and young people medication (steroids) by tablet, liquid or injection.

- > Giving children and young people this medication as soon as possible is good – it is best to give it to them within 1 hour of arriving at hospital.



88% The clinical audit showed that most children and young people **were given injected or tablet medication.** However, this was often not given quickly enough.



39% of children and young people who should have had this medication got it **within 1 hour.**



Discharge planning

What should happen?

Before children and young people go home after their asthma attack, it is important to make sure doctors and nurses do things to try and stop them from coming back with another attack. This is called discharge planning (discharge means going home from hospital).

When a child or young person is admitted to hospital for an asthma attack, the hospital team should try and do everything they can to help them to keep their asthma under control and prevent future asthma attacks and admissions to hospital.

The discharge process is a very important element in the treatment of children and young people with asthma, and this is why we have asked hospitals to ensure that:

95%



of children and young people should be provided with the following as part of their discharge bundle:



1 review or issue of a personalised asthma action plan (PAAP)



2 check of their inhaler technique



3 request of a follow-up appointment in a paediatric asthma clinic within 4 weeks

52% of children and young people received some form of **discharge bundle** before leaving hospital. Discharge bundles can be different in different hospitals.



We have listed below what children and young people should receive before they are discharged from hospital and the audit results for each:



of children and young people had their **inhaler technique checked**



of children and young people had a **personal asthma action plan (PAAP)** given or reviewed



Patient priority
A care plan that supports consistency with current dosage



of children and young people were discharged with **inhaled medication**



of children and young people had a **review of their regular (maintenance) medication**



of children and young people had a discussion about **asthma attack triggers**



of children and young people who were smokers had their **tobacco dependency addressed**



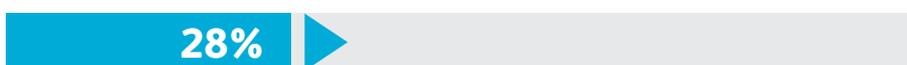
of **parents/carers** who smoked had their **tobacco dependency addressed***



of children and young people had a **community follow-up** requested to take place within 48 hours of discharge



of children and young people were either already in a **hospital clinic** or were referred to one



of children and young people had **hospital follow-up** requested to take place within 4 weeks

* 72% of hospitals included in the audit have a service to help people quit smoking, to which they can signpost parents, carers or children and young people with asthma as required. 52% of hospitals included in the audit have a service to help people quit smoking, to which they can refer children and young people with asthma.

Transitional planning

Moving from children and young people to adult asthma services

What should happen?

- > Transition from children and young people services should begin early, be planned and should involve you. It should also be appropriate for your age and your development. You should be given the opportunity to be seen without your parents or carers; however, transition services must consider the needs of your parents and carers.
- > Coordination of transitional care is very important, so a member of the hospital team should support you until you are settled within the adult system.
- > You should be encouraged to take part in transition or support programmes and/or be put in contact with other appropriate youth support groups.*

52% of hospitals have formal transitioning processes in place for young people moving from children and young people to adult services.



* www.brit-thoracic.org.uk/quality-improvement/guidelines/asthma/

Recommendations

For children and young people living with asthma, their parents and carers

1 If you are admitted to hospital with an asthma attack, there are some important things that you should know – you may want to talk about these with the team looking after you:



> You should have a high dose of injected or tablet medication within 1 hour of arriving at hospital (unless you had them before you came).



> Someone should check that you know how to use your inhaler before you go home.



> You should go home with an up-to-date personalised asthma action plan (PAAP). This might be a new plan, or someone checking your old plan to make sure it is right.



> If you are admitted to hospital with an asthma attack, you should be seen in a hospital asthma clinic within a few weeks. There should be an expert involved in your care in this clinic, such as a specialist nurse.

In some instances, you may not be able to ask for this yourself. If this is the case, we recommend that your parent/carer does this for you.



2 Children and young people with asthma and their parents and carers should help to make sure that hospitals are meeting quality care standards for asthma patients nationally.



3 Children and young people with asthma and their parents and carers should consider joining and taking part in groups that support improvements in asthma care for children and young people.

For hospital teams*

- > Record the smoking status and exposure to second-hand smoke in children and young people.
- > Give children and young people (aged 6 years old or over) injected or tablet medication (steroids) within 1 hour of arrival at hospital. (Unless this was given as part of their pre-hospital care.)
- > Provide children and young people with the following as part of their discharge bundle:
 - Review or issue of a personalised asthma action plan (PAAP)
 - A check of their inhaler technique
 - A follow-up appointment in a hospital asthma clinic requested to take place within 4 weeks
- > Ensure that you have a respiratory nurse specialist trained in the care of children and young people with asthma.

* We also make recommendations for healthcare commissioners (funders) and general practice (GP) teams. These can be found in the main national report: www.rcp.ac.uk/CYP-asthma-2019-20

Jargon buster

Admission	NACAP describes an admission as a patient being treated at a hospital for at least 4 hours.
Audit	An audit (project) collects information on how organisations, including hospitals, work. The aim of an audit is to use this information to see what is happening and see where improvements can be made.
Discharge bundle	A discharge bundle is a package of care given when a person with asthma is being discharged from hospital (preparing to leave the hospital) to maximise their future health and reduce the risk of them needing to come back to hospital as an emergency.
Maintenance medication	Maintenance medication is medication that is taken regularly to stabilise an illness or symptoms of illness.
Multidisciplinary team (MDT)	A multidisciplinary team involves a range of health professionals, from one or more organisations, working together to provide good patient care. A paediatric asthma MDT consists of a team of specialists including an asthma nurse specialist, a pharmacist and a paediatric asthma consultant.
Personal asthma action plan (PAAP)	<p>This is a small leaflet that tells you, and anyone with you:</p> <ul style="list-style-type: none">> which medicines you take every day to prevent symptoms and reduce your risk of an asthma attack> what to do if your asthma symptoms are getting worse> the emergency action to take if you're having an asthma attack and when to call 999. <p>You fill it in with your GP or asthma nurse, so it's personal to you and your asthma. You should take it along with you to all your asthma appointments, including any out-of-hours appointments or A&E, so your doctor or asthma nurse can help you keep it up to date.</p>
Second-hand smoke	Second-hand smoke is smoke released from burning tobacco. Whenever a cigarette, cigar or pipe is lit, second-hand smoke is produced. This is the smoke exhaled as well as the smoke created by the lit end. People who breathe in second-hand smoke are at risk of the same diseases as smokers. Children are especially vulnerable to the effects of second-hand smoke exposure, which has been linked to an increase in conditions such as asthma.
Specialist	A respiratory specialist is a healthcare professional who has expert knowledge in the care of people living with lung conditions such as asthma. They could be a doctor, nurse, pharmacist or physiotherapist.
Steroids	Steroids, also known as corticosteroids, are medicines that are given orally (in your mouth) or by injection and the medicine moves around the body in your blood.
Triggers	An asthma trigger is anything that brings on coughing, wheezing, trouble breathing, and other symptoms in a person with asthma. Some common triggers include colds, smoke, cold air, exercise, and certain things that cause allergic reactions, such as dust mites or pollen. Triggers can vary from person to person and from season to season. They also can change as a person grows older.

Useful web links

To find out more about asthma and how to stay well, we recommend the following online resources:

NACAP adult asthma audit patient report

This report provides information on adults aged 16+, admitted to hospital adult services with an asthma attack.

www.rcp.ac.uk/nacap-adult-asthma

Asthma UK and British Lung Foundation (AUK-BLF)

AUK-BLF is the UK's leading lung charity. They work to ensure that people can breathe clean air with healthy lungs. You can find information that they provide about managing asthma on the following web pages:

www.asthma.org.uk/advice/child/

www.blf.org.uk/support-for-you/asthma-in-children

The National Health Service (NHS)

The NHS provides information on managing your asthma at the following web page:

www.nhs.uk/conditions/asthma/living-with

For more detail on the results of this audit

including links to guidelines for care for children and young people with asthma formulated by the National Institute of Health and Care Excellence (NICE) and the British Thoracic Society, see the full 2019/20 adult asthma clinical report available at:

www.rcp.ac.uk/CYP-asthma-2019-20

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