Children and young people’s asthma support

Suffolk and North East Essex

Published January 2024

healthwatch Essex
healthwatch Suffolk

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Acknowledgements

Healthwatch Suffolk and Healthwatch Essex would like to thank the parents, carers, guardians and children and young people who participated in this engagement project for their time given and the feedback received.

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement visits.

This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Suffolk and Healthwatch Essex during this time.

This independent analysis has been compiled by Healthwatch Suffolk CIC, and Healthwatch Essex.

The project was commissioned by the Suffolk and North East Essex Integrated Care Board to shape, influence and inform the future of asthma care and support for children, young people and families.

1. About this report

A brief introduction to this report, Healthwatch Suffolk and Healthwatch Essex. Find out how we worked together to capture people's experiences of local asthma support for children and families.

1.1 - About local Healthwatch

Healthwatch Suffolk CIC and Healthwatch Essex are local Healthwatch that gather and share people's experiences of health and social care to influence better standards of care and support. We influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving people's experiences of local support. We also provide an information service to help people access, understand, and navigate the health and social care system.

This project has been managed and coordinated jointly by Healthwatch Suffolk and Healthwatch Essex. For more information about our services, please visit the following links:

- For information about Healthwatch Suffolk CIC, please visit https://healthwatchsuffolk.co.uk. Details of professional services can also be found on https://healthwatchsuffolk.co.uk/theres-more-to-us/.

  ✉ **research@healthwatchsuffolk.co.uk** ☎ **0800 448 8234**

- For information about Healthwatch Essex, please visit https://healthwatchessex.org.uk. Details of professional services can also be found on https://healthwatchessex.org.uk/professionals/.

  ✉ **info@healthwatchessex.org.uk** ☎ **0300 500 1895**

1.2 - Our approach and methodology

Healthwatch Essex and Healthwatch Suffolk were commissioned by Suffolk and North East Essex Integrated Care Board (ICB) to explore people's experiences of support for children and young people with asthma (aged 5-18)

This report includes experiences shared by children, young people, parents, carers and guardians. Their responses will help to increase understanding about how support for children, young people and families could be improved, and how children and young people can be better supported to manage their asthma in communities. The results of this project will help NHS leaders within Suffolk and North East Essex, and across the east of England, to plan asthma care and support for children and young people in the future.

Co-production

The early development of this project was supported by a process of co-production with people who have lived experience of asthma support for children and young people. It was critical to making sure the research was focused on issues that were important to people accessing support for their child/family.

People attended workshops facilitated by both local Healthwatch (two in Suffolk and one in north east Essex) to share experiences, and also to inform the development of tools that would be used to capture people's experiences in the project. One of the workshops (hosted by Healthwatch Suffolk) was for professionals providing local care to young people and families.

How people's experiences were gathered

In total, 149 responses were gathered across several research methods outlined below.

The survey

Following the workshops, Healthwatch Essex led on the development of an anonymous online survey. It was finalised together with Healthwatch Suffolk and distributed across Suffolk and north east Essex (see examples of communication methods highlighted below). The survey was launched on 'SmartSurvey', which is a UK-based online survey platform.

The survey had tailored routing depending on who was answering the questions. For the parents, carers and guardians and young people aged 16+, the survey included qualitative and quantitative questions. Due to the age of respondents, the survey routing for children aged 11-15 consisted of solely quantitative questions.

In total, we recruited 130 participants. Of these, 111 were parents, carers or guardians, and 19 were children and young people (CYP) aged 11-18. We have further divided the CYP into children between the ages of 11-15, of which there were 5, and young people aged 16+ which there were 14.

Out of the 130 participants, 12 provided only partial responses. However, their responses have been included within the quantitative data.

If you are happy to help us, we will ask you some questions about things like...

This is a chance to tell us your ideas. Things like what would help you to look after yourself and stop your asthma from getting worse.

What will happen?

Your parent or carer, will be with you when we ask the questions.

We will record your answers to our questions so that we can listen to them later and write them down.

We will be speaking to lots of other people, and **we will write a report about what everyone has told us.**

A flyer was created to make sure children participating in interviews with their parents understood the purpose of the research, and how the things they said would be used.

This is an example of one of the pages featured in the document.

Interviews with parents, carers, guardians, children and young people

Using the co-production feedback and joint survey as a guide, Healthwatch Suffolk developed a process through which both young people and parents, carers and guardians could be interviewed together about their experiences.

After participating in the survey, people had the opportunity to click a link to sign-up for an informal semi-structured interview with the Healthwatch Suffolk team. The opportunity was open to all parents, carers and guardians and young people aged 16-18.

Children aged eight and above could be included in interviews with the informed assent of the child, and the informed consent of their parent. A specific consent form was developed for parents and carers, and this was supported by a flyer for children to obtain their assent at interview. The flyer was designed with age appropriate language and tested to make sure it could be understood by children aged eight and above.

Unfortunately, response rate to the opportunity to participate in interviews was low. However, two interviews were completed with three people. They were:

- A Mum and her child, aged 10. Diagnosis was given at the age of three, although they had experienced breathing difficulties prior to this. They have experienced two asthma attacks, one resulting in a hospital inpatient stay, the other was managed with her parent's support. Mum also has asthma, and has over 30 years of lived experience of managing her condition.

- A Mum, with over 15 years of experience of supporting her child with asthma. Her child, (currently aged 17) was diagnosed with asthma at the age of three but had several inpatient stays prior to this, with various breathing issues. Until the age of seven, their care was primarily overseen by the Consultant within the Hospital. Neither parent has personal experience of asthma themselves.

Both interviews were conducted online, as video meetings. All participants gave their consent/assent to have their interviews recorded and their experiences shared within this report. Feedback from these interviews is presented within each of the relevant sections throughout the report.

Engagement visits, and the Healthwatch Suffolk Feedback Centre

Healthwatch Suffolk led on several engagement visits to the West Suffolk NHS Foundation Trust and the East Suffolk North Essex Foundation Trust.

The visits meant Healthwatch staff had the opportunity to engage parents, carers and young people visiting children's wards and asthma clinics about their experiences. People were offered the chance to complete a survey (or to take a copy away after their visit), but they could also share feedback on the Healthwatch Suffolk Feedback Centre using a simple hard copy feedback form.

The Healthwatch Suffolk Feedback Centre (www.healthwatchsuffolk.co.uk/services). is a platform people can use to find, rate and review any health or social care service in Suffolk. There are more than 20,000 reviews currently listed against hundreds of local services. All feedback is moderated by the Healthwatch Suffolk team to make sure it is not abusive, that it is grounded in a genuine experience of using a service, and that it does not identify any person.

In total, 17 reviews, that referenced 'asthma support', were exported from the Feedback Centre and analysed to identify key themes and sentiment. All comments were recorded between June 2023 and Nov 2023. Please read more in our analysis from page 68.

Sharing the survey

The survey was distributed widely, using a range of communication sources. Some examples included:

- Social media activity by both local Healthwatch, including promoted posts on Facebook and Instagram that reached more than 58,000 accounts.

- Local Healthwatch websites and various newsletters.
- Information about the survey was sent to more than 400 schools and colleges within Suffolk and north east Essex to encourage them to share the survey link.
- Communication activity by the Suffolk and North East Essex (SNEE) ICB communication team and a local network of professionals providing asthma support.
- A feature in the **Suffolk 'Families' magazine**, supported by Suffolk County Council.
- Leaflets were distributed in communities, and shared with hospital leads for wards and distribution by professionals.
- Local GP practices received information about the survey and were encouraged to share it.
- Asthma and Lung UK agreed to share information about the survey with people connected to its networks in Suffolk or north east Essex.
- Local parish councils in north east Essex.

“They took ages to diagnose my child with asthma, stating that they were ‘attention seeking’.

“Eventually we were able to get peak flow tests done on a week schedule at home, putting the results on a chart. They could clearly see that there were issues. Just **could have done without the ‘fight’.”**

2. Who took part?

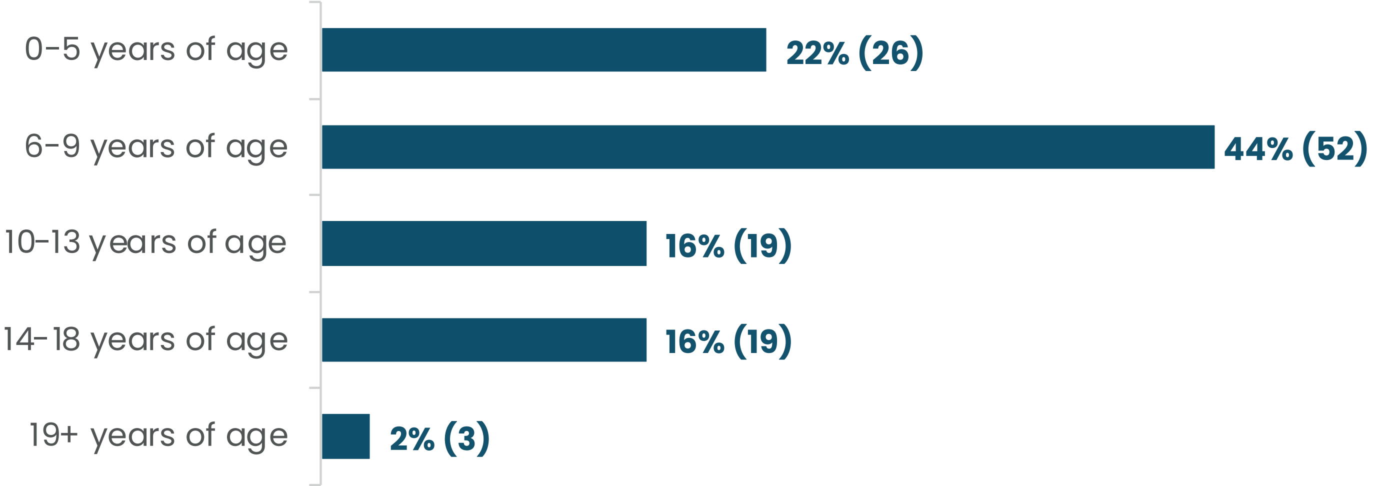
Read about our sample, including a breakdown of key demographics.

2.1 - Survey participants

Demographic details for each participant were collected via the survey if they chose to disclose it.

Age (Children and young people)

Parents, carers and guardians were asked about the age of their child(ren) with asthma. The graph below shows the results, combined with the age profile of young people (aged 11-18) completing the survey.



Location

Of those who provided a postcode location, 74 responses were from residents in Suffolk and 38 were from residents in Essex. The table below includes a full breakdown of postcode data.

Postcode	County	Count	Area
IP28	Suffolk	15	Mildenhall
CM7	Essex	15	Braintree
CO15	Essex	9	Clacton
CO10	Suffolk	8	Sudbury/Clare
IP14	Suffolk	6	Stowmarket
IP2	Suffolk	5	Chantry
IP1	Suffolk	4	Ipswich west and Whitton
IP32	Suffolk	4	Bury St Edmunds north
IP29	Suffolk	3	Ickworth
IP3	Suffolk	3	Gainsborough

IP4	Suffolk	3	Ipswich east
CB9	Suffolk	3	Haverhill
CO2	Essex	3	Colchester and Layer-de-la-Haye
CO3	Essex	2	Colchester West and Stanway
IP7	Suffolk	2	Hadleigh
CO8	Essex	2	Bures
CB8	Suffolk	2	Newmarket
IP6	Suffolk	2	Needham Market and Barham
IP8	Suffolk	2	Copdock
IP31	Suffolk	2	Ixworth
IP22	Suffolk	2	Diss
IP11	Suffolk	2	Felixstowe
CO4	Essex	1	Boxted/Langham
CO7	Essex	1	Dedham/Brightlingsea
IP17	Suffolk	1	Saxmundham
CO16	Essex	1	Thorpe-Le-Soken/Seawick
CO1	Essex	1	Colchester North
CO9	Essex	1	Halstead
IP5	Suffolk	1	Kesgrave
CO11	Essex	1	Mistley
CO5	Essex	1	Mersea and Tiptree
IP30	Suffolk	1	Elmswell
IP27	Suffolk	1	Brandon
IP9	Suffolk	1	Tattingstone, Shotley and Holbrook
IP12	Suffolk	1	Woodbridge

“My child is getting now to the age where they are getting frustrated about having to take regular medication. We have received no information about future plans with the asthma around medication.

“It is difficult to manage their questions when we do not have the answers to when they potentially might not have to have medication.”

3. Key findings

This section will share each of the questions asked and the responses that were received.

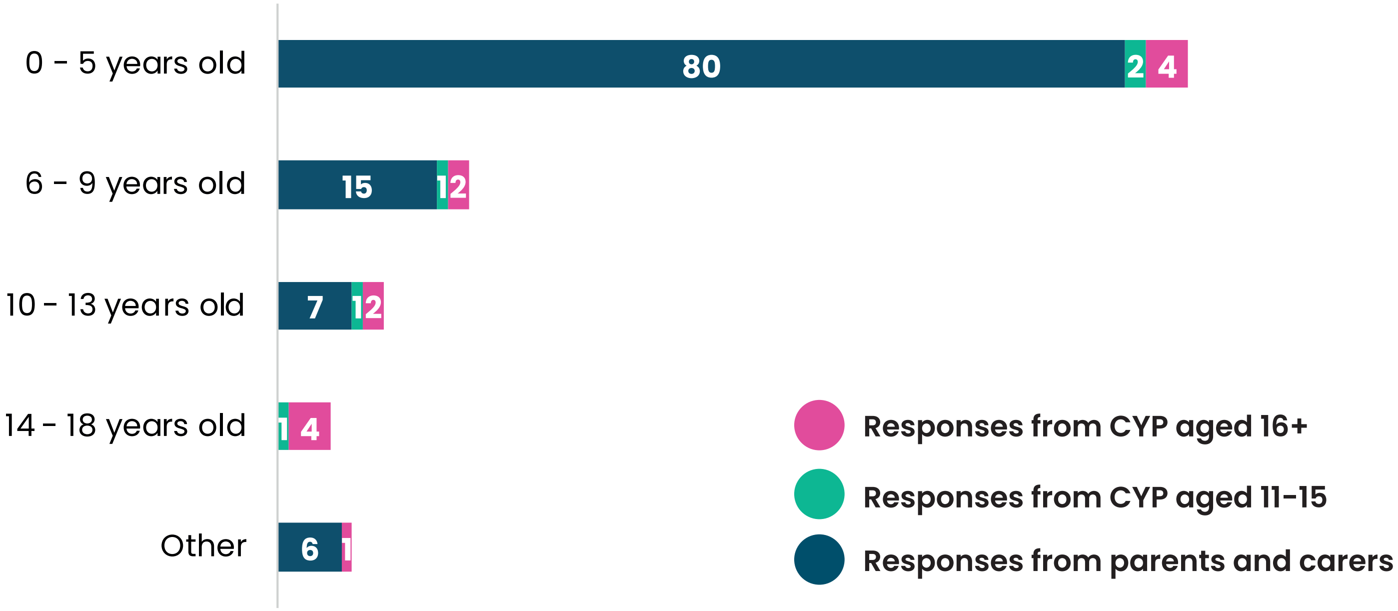
3.1 - Getting a diagnosis

Age of diagnosis

The first section of the survey aimed to explore how easy it was for children and young people (CYP) to get an asthma diagnosis.

Initially, participants were asked about their, or their child's, age when they received their asthma diagnosis. A total of 74% of parents and guardians, 40% of CYP aged 11-15, and 31% of CYP aged 16+ responded that the asthma diagnosis had taken place before the age of six.

The graph below shows the combined responses from parents, carers and guardians, and young people about the age of children and young people when they received a diagnosis.



Graph: The age that children and young people received a diagnosis of asthma based on responses from parents, carers and guardians and young people (based on 126 responses).

Seven parents, carers and guardians shared further information about the age of diagnosis (classified as 'other' in the graph). Their responses included:

> *"Son is 5, no official diagnosis yet but takes daily medication since 1 year."*
>
> *"Not yet"*
>
> *"Ongoing"*
>
> *"First prescribed an inhaler and advised of suspected asthma at approx 10 months, now aged 9 with a confirmed diagnosis but unsure of the exact aged at which this was formalised."*

Qualitative insight: 'How easy was it to get the asthma diagnosis?' (82 responses)

Both parents, carers and guardians and young people aged 16+ were asked this free text question. In total, 72 parents and carers and 10 young people answered the question.

Their responses were coded as "easy", "difficult", or "mixed". The charts below show how easy parents and children thought it was to get an asthma diagnosis.

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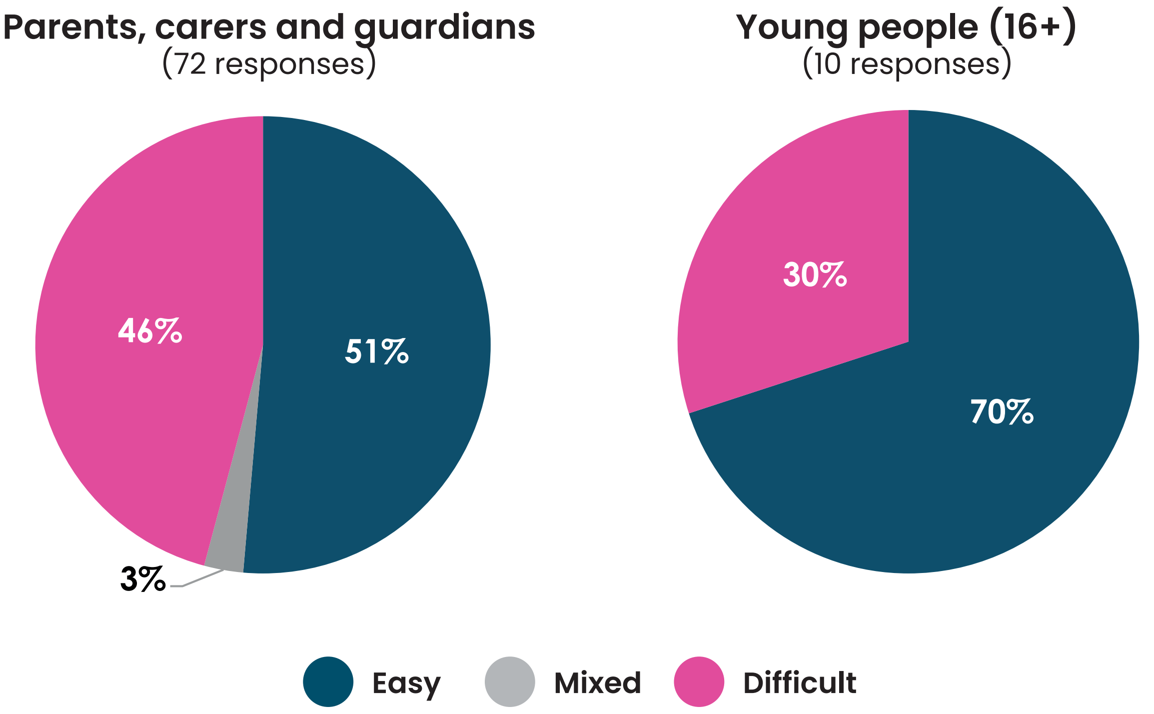

Children and young people aged 11-15 (quantitative responses)

Participants were asked 'Was it easy to get an asthma diagnosis?'. Five responded to the question, of which two selected 'yes', two were 'unsure' and one said 'no'.

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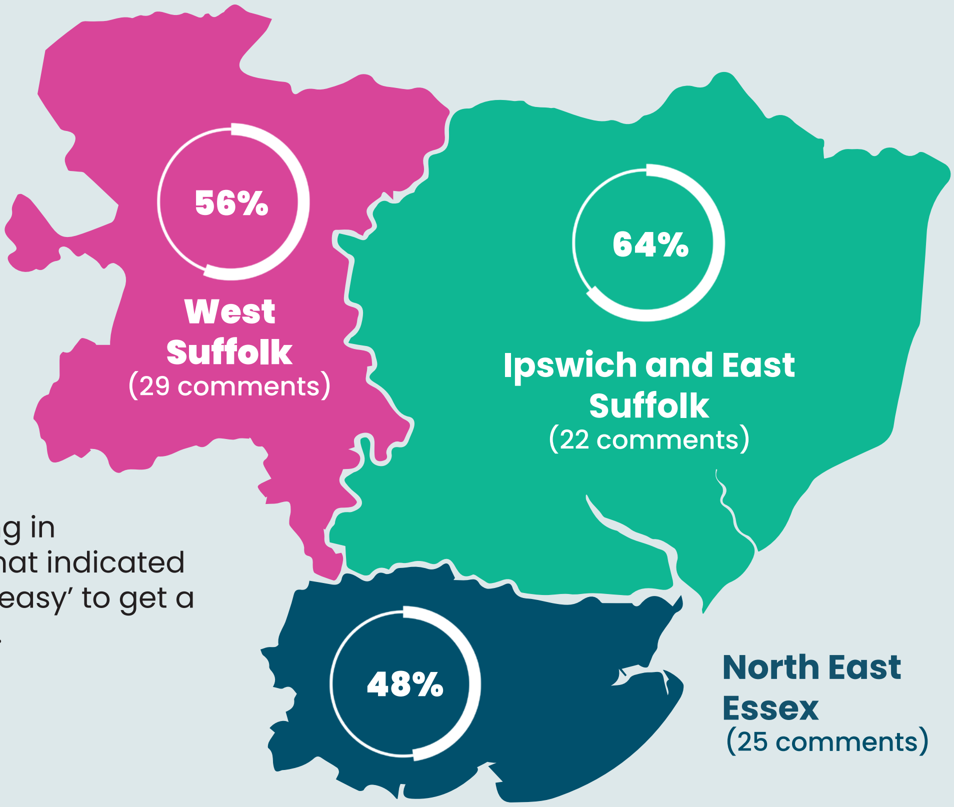
Who found getting a diagnosis 'easy'?
Alliance area breakdown

Out of 80 responses, 76 parents, carers, guardians, and young people offered a comment about how easy it had been to get a diagnosis, and gave their postcode.

This graphic shows the percentage of comments made by people living in each alliance area that indicated people had found it 'easy' to get a diagnosis of asthma.



Comments were also analysed by theme. The top themes are shown in the table below:

Theme	No area	IES	WS	NEE	Total
Difficult - Delays in diagnosis, or not diagnosed	0	1	4	4	9
Difficult – Getting a diagnosis at a young age	0	1	3	4	8
Easy – Diagnosis from GP or asthma nurse	0	2	1	4	7
Easy - Diagnosed during treatment at hospital	0	2	3	2	7
Easy - Clear symptoms of asthma	0	3	2	2	7
Difficult – Required hospital treatment	1	1	0	3	5
Difficult - Not listened to or believed	2	1	0	2	5

Themes - Ease of getting a diagnosis

Difficult - Delays in diagnosis, or not diagnosed

Nine parents, carers or guardians experienced significant delays in their child or young person getting a diagnosis, or said that their child had not yet been diagnosed.

> *"Very hard. My son has [had] issues with his chest since he was one and it has taken until six to be diagnosed." (Parent/ Guardian)*
>
> *"Not easy, had asthma symptoms and hospitalised when daughter was two, not diagnosed for a couple of years afterwards." (Parent/ Guardian)*
>
> *"Very difficult, we were in and out of hospital several times before it was diagnosed." (Parent/ Guardian)*

Difficult - Getting a diagnosis at a young age

Eight parents, carers or guardians reflected an awareness that it was difficult for children to receive a diagnosis at a young age.

> *"It was a bit difficult at first because she was so young but once they began to look into it, it was relatively easy." (Parent/ Guardian)*
>
> *"Difficult due to age and the NICE guideline recommendations of not diagnosing until five." (Parent/ Guardian)*
>
> *"Really difficult at such a young age but he was really struggling, wheezy, had a medical history of lung problems at birth and had eczema." (Parent/ Guardian)*

Easy - Diagnosis from GP or asthma nurse

Seven parents, carers or guardians were positive about the ease of getting a diagnosis from the GP or an asthma nurse.

> *"The GP suspected asthma following repeated visits (approx. three) to the surgery for a recurrent cough. I would say this was recognised fairly quickly." (Parent/ Guardian)*
>
> *"Fairly easy, saw the GP and asthma nurse." (Parent/ Guardian)*
>
> *"Easy as taken our child to the doctors and they immediately diagnosed it as asthma, however very difficult to actually get a plan in place to support our child." (Parent/ Guardian)*

Easy - Diagnosed during treatment at hospital

Seven parents, carers or guardians said their child had received an asthma diagnosis whilst in hospital. They reflected that it had been easy to get a diagnosis in these circumstances.

> "Easy as taken our child to the doctors and they immediately diagnosed it as asthma, however **very difficult to actually get a plan in place to support our child."**

> *"Went into hospital trouble breathing and was diagnosed whilst staying in. So pretty easy I'd say." (Parent/ Guardian)*

> *"Very - he was frequently wheezy and had several hospital admissions. They didn't diagnose officially asthma at first but did talk about it that it was likely." (Parent/ Guardian)*

> *"I took my child to A&E with severe cough and they [did] the test and said that my child had got asthma." (Parent/ Guardian)*

Easy - Clear symptoms of asthma

Six parents and one child or young person said they had clear symptoms of asthma, which made it easy to diagnose.

> *"Very [easy] as I was turning blue and having asthma attacks every week so I got the diagnosis quite quickly." (Child or young person)*

> *"Very easy - my daughter has always suffered with a terrible cough and as soon as I spoke to the nurse about it she knew it was asthma - an inhaler, after using it around a week stopped the continuous cough!" (Parent/ Guardian)*

> *"Quite easy as both his parents have it and he had the symptoms of asthma." (Parent/ Guardian)*

Difficult – Required hospital treatment

Five parents said getting an asthma diagnosis was difficult, and required one or more hospital admissions or appointments.

> *"It was hard. It took an emergency appointment where he couldn't breathe to be diagnosed." (Parent/ Guardian)*

> *"Very hard. Took multiple admittances to hospital and lots of back and forth to get stronger inhalers approved." (Parent/ Guardian)*

> *"Not straight forward. Several visits, first to emergency department and inpatient ward before diagnosis." (Parent/ Guardian)*

Difficult - Not listened to or believed

Four parents and one child or young person said they were not listened to or believed about their symptoms by health and care professionals.

> *"Very hard, my mum has asthma and so recognised the symptoms, but the doctors kept saying it was other things at the beginning." (Child or young person)*
>
> *"It was extremely difficult and I found the health professionals didn't want to listen to me. Apart from one doctor, who not only took the time to listen to my concerns he also checked my child over..., which in turn resulted in the diagnosis." (Parent/ Guardian)*
>
> *"It was so difficult. My child was born with a weird sounding cough... We took her to the doctors so many times, I remember going one week 4 times. We were constantly told she had a cold or a common cough. As a parent I knew this wasn't the case, I know my child... Fast forward a month we had an appointment at the hospital to which my child was diagnosed with asthma."* (Parent/ Guardian)

What our interview participants said about diagnosis

The experiences of getting a diagnosis, shared by our interview participants, reflected many of the issues already raised within survey responses. For example, the difficulty of diagnosing very young children, parents feeling their opinions are not 'listened to' or 'taken seriously' by health professionals, and the length of time to get a diagnosis. What perhaps came through more strongly in the interview responses was the lack of proactive support offered to families at the point of, or immediately after, diagnosis.

> *"Initially we saw a nurse practitioner and she said, 'well, we're not going to diagnose asthma because if we do, she won't be able to get into the army.' And so she sent me off with a Ventolin inhaler and said, 'see if that helps'. And so we went back a few weeks later and it had helped, and there was an improvement. And so I said, 'I'm absolutely convinced that she got asthma. I know what it sounds like. I know what it looks like, you know, and I know that the inhaler's working', because 10 minutes after using it, she would cough and the wheezing would clear, and that's what Ventolin does. And so she reluctantly did diagnose her, and then gave us a couple of inhalers and sent us packing... Everything [my child] knows about asthma has come from me. I feel lucky to be in the position I can teach her this stuff because no one else has offered to do that."*
>
> *"[We got the diagnosis] through the paediatrician at the hospital. We were under their care for quite a long time because it was quite hard to get [my child] stabilized and the more we kind of kept popping up with these things the more they sort of think you might have asthma. So it was just, it felt like, I don't know from the age of two to even seven or eight, it was a bit of a juggle and a bit of a wing and a prayer. But we got there eventually."*
>
> *"[Interviewer] And what kind of support did you receive at the time?*
> *We rotated through different consultants and that was annoying because each of them used to say a different thing. But we ended up with this really nice doctor who gave us consistent advice and gave us confidence and consistent messages. I also had a colleague who is a quite advanced Asthma nurse in a practice. I used to tap her up for help, just saying, 'does this feel right?' And then at one stage, I found the asthma UK website and I've been signed up to that ever since."*

> “Everything [my child] knows about asthma has come from me. I feel lucky to be in the position I can teach her this stuff because no one else has offered to do that.”

3.2 - Asthma medication and care

Suffolk and North East Essex ICB wanted to know if respondents had been provided with vital information on the asthma medication they were prescribed including what the medication was for, and how the young person was meant to use it.

The survey responses showed that a large proportion of parents, carers and guardians and young people felt a professional had explained to them or their child what asthma medicines they had, what they do and when to use them.

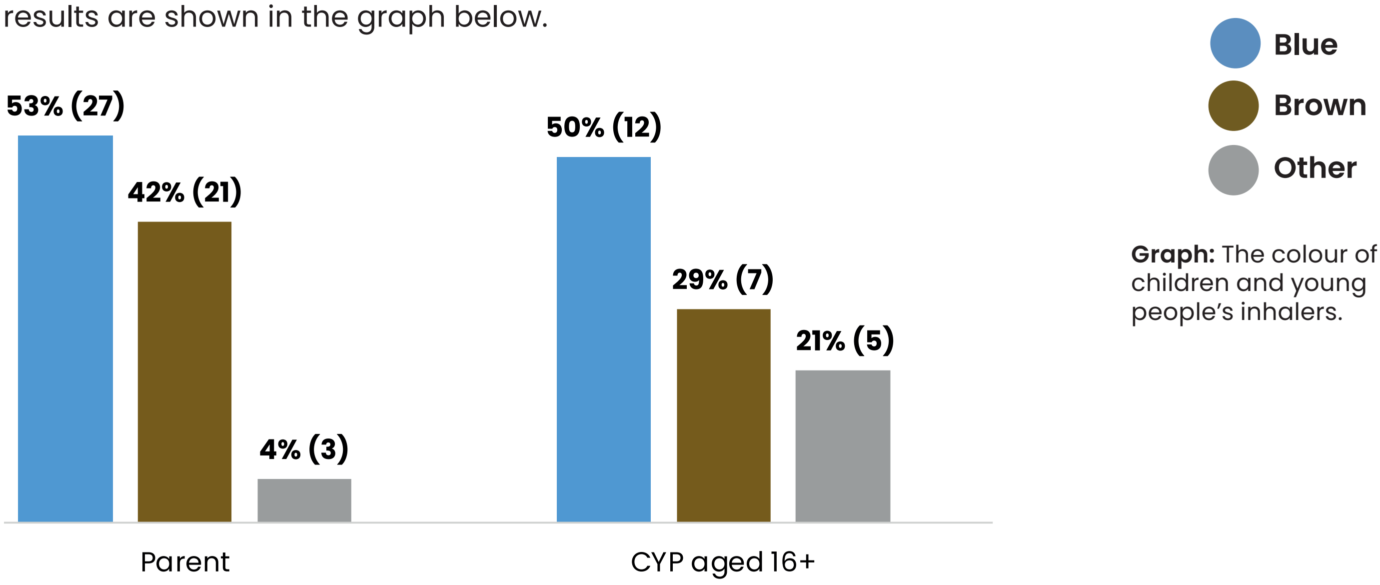
A total of 23% of children and young people said that a professional had not explained to them what asthma medicines they have and how to use them. However, only 4% of parents and guardians said that this hadn't happened for them.

Inhaler type

Parents, carers, guardians and young people (16+) were also asked about the inhaler(s) their child used, and young people (aged 16+) were asked about the colour of their inhaler. The results are shown in the graph below.

Has a professional explained to you and your child what asthma medicines they have, what they do and how/when to use them?

Parents and carers were most likely to answer 'Yes'. In total, just four parents and carers and three children and young people said 'No'. Four respondents were 'Unsure' across both groups.



Graph: The colour of children and young people's inhalers.

107 parents, carers and guardians responded to the question. Of which:

- 62 (58%) stated the clinical name of their child's medication.
- 39 (36%) gave an inhaler colour.
- 4 (4%) gave a medication name and an inhaler colour.

Other inhaler colours mentioned included:

- Orange (two parents and one young person)
- Purple (one parent and one young person)
- Red and white (two young people)
- Pink (one young person)

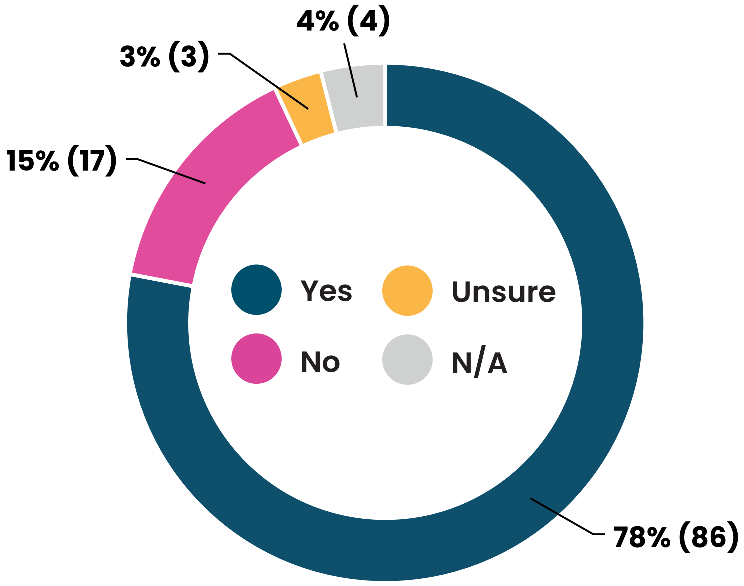
The table below lists a count of responses about the clinical name of medication listed by parents, carers and guardians.

Medication	Count / Frequency
Salbutamol	44
Clenil	28
Seretide	14
Ventolin	14
Salamol	10
Montekulast	7
Flixotide	3
Symbicort	3
Atrovent	1
Beclometesone	1
Becotide	1
Cetirizine	1
Flutiform	1
Serevent	1
Steroid	1

Two participants responded "Chenille" which is understood to be a misspelling of Clenil. These have not been included in the table above.

Using a spacer

Parents and guardians were also asked if their child had been prescribed a spacer, if they had been shown how to use it and if they were able to use the spacer on their own. In total, 75% of parents, carers and guardians (82) said their child could use a spacer on their own, 20% (22) said their child could not use a spacer on their own, and 5% (6) were unsure.



Graph: Responses from parents, carers and guardians to the question 'Has a professional shown your child how to use a spacer?'. Based on 110 responses.

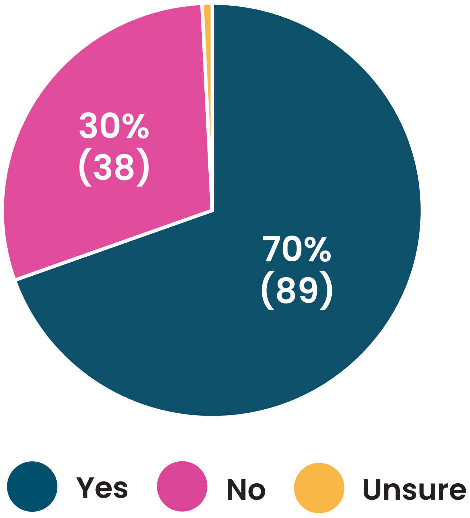
78% of parents, carers and guardians said their child had been shown how to use a spacer.

Using an inhaler

To continue exploring how much knowledge was provided to children and young people accessing asthma care, all participants were asked if they were shown how to use their inhaler.

In total, 68% of parents, carers and guardians, 100% of children aged 11-15, and 76% of young people aged 16+ indicated they had been shown how to use an inhaler.

The combined responses from parents, carers, guardians, and all young people are shown in the pie chart (see right).



Graph: Responses from all participants about whether children and young people had been shown how to use their inhaler by a GP or professional.

3.3 - Asthma plans

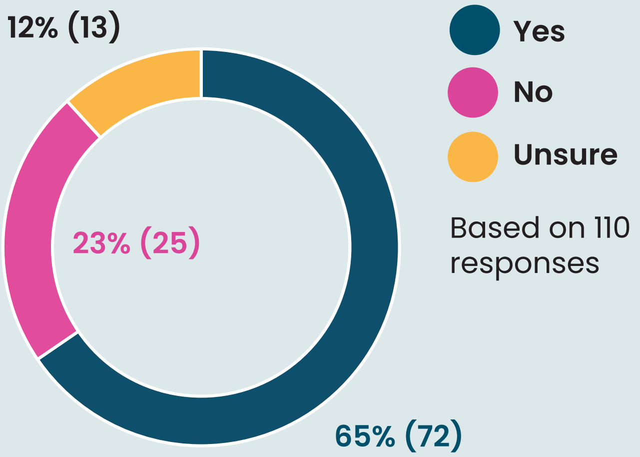
The next question asked participants about knowledge of asthma plans.

Everyone with asthma can benefit from using an asthma action plan. It includes details about the medicines people take to prevent symptoms and cut risk of an asthma attack, what to do if symptoms are getting worse, and emergency action to take in the event of a severe attack (including when to call 999).

Asthma plans are generally completed with a GP or asthma nurse, and should be discussed at asthma appointments (including in hospital).

Responses were mixed. In total, 65% of parents and guardians said their child had an asthma plan, whilst only 40% of children aged 11-15, and 31% of young people aged 16+ reported that they did.

Does your child have an asthma plan?



Most parents, carers and guardians felt their child had an asthma plan in place, but it is clear this was not the case for all respondents.

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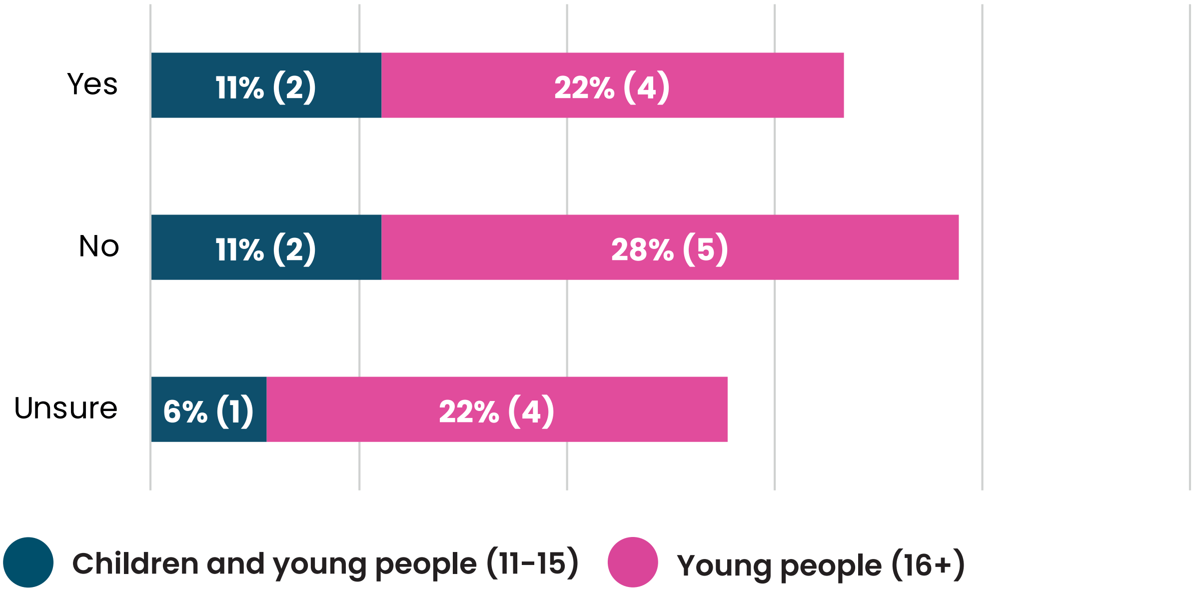
Do you have an asthma plan? - CYP responses



Graph: 'Do you have an asthma plan?' - Responses from all children and young people. Based on 18 responses.

Understanding information in asthma plans

Nearly 40% of parents and guardians responded that their child understood the information provided in their asthma plan. A total of 40% of children aged 11-15 also shared that they understood their asthma plan information. This compares to 23% of young people aged 16+.

More detail about responses across all groups is included in the graph below.

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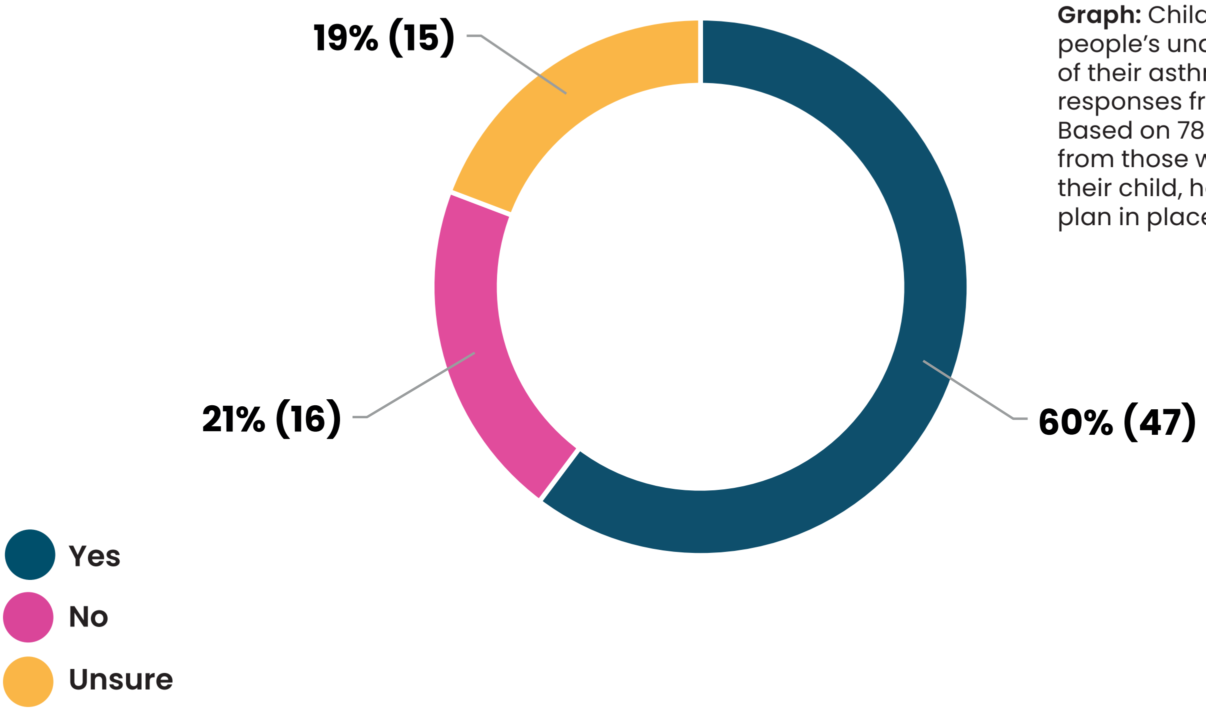
Understanding asthma plans - Parent/carer responses



Graph: Children and young people's understanding of their asthma plan - responses from all groups. Based on 78 responses from those who said they, or their child, had an asthma plan in place.

Overall, 72 parents and six children and young people said that they had an asthma plan. These respondents were asked a follow-up question about whether children and young people understood the information provided in their asthma plan.

Of all 78 responses from parents and children and young people, only 60% said 'Yes' they understood the information in their asthma plan. A further 21% said 'No' they did not understand the information, and 19% were 'Unsure'.

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What our interview participants said about asthma plans

The importance of having a clear and documented asthma plan was highlighted by one of our interview participants. Not only did it give them confidence about what they should do in certain situations, but it also helped them to understand their child's asthma better.

> "It was probably the one most helpful thing to us all, because it helped us understand what the severity of his asthma was, and what to do and when. I think before we had [the plan] we'd had contradictory advice. Like, do we just chuck loads of the blue inhaler at him? What do we do? Do we ring an ambulance? Do we go to A&E? Do we go to the GP, you know? I'm not a neurotic parent at all, I'm quite relaxed and laid back but I just think it wasn't really clear to us what the thresholds were for presenting yourself to a medical professional."

Getting the plan however had not been straightforward. It was not until their child was seven that the family received something resembling a plan. Even then, they had to take the initiative and engage with their GP practice to further develop the plan.

> *"It was a nurse in…. I don't, I can't even remember who, but it was somebody in the emergency department gave us this thing which looked, which was kind of their version of a….. this is what you need to do when and that we followed it religiously… And then we asked the GP practice to do one with us and so that's been done ever since, pretty much annually. So, we know what to do and when to do it. That's the most important thing. And from that point onwards, it's been absolutely fantastic."*

While the family clearly recognised the benefits of having an asthma plan in helping them to support their child with his asthma, they had not always received a positive response from health professionals, when following the instructions within the plan.

> *"There were a couple of times, I got quite upset when I did what I felt was the right thing and went to see the GP and he was quite rude to me and said in front of my son, 'you are aware, aren't you that children die from asthma and it's very serious and you have to bring them into the GP practice'. And I sat there, and I thought, 'I can't believe you just said that in front of my son. And secondly, I'm doing what my plan says to do and I'm here'. But that's happened twice and I just think that's awful. You're trying to do the right thing by your child, but you want to make sure that you're not wasting people's time at the same time."*

In contrast, the other family felt their asthma plan was lacking in essential detail that would help them manage in the event of an asthma attack, or their child experiencing breathing difficulties.

> *"You get a small yellow sheet of paper explaining to you to call 999 if they're not breathing well, but at what point do you call 999? I showed [the plan] to my husband and I said, would you know what to do if she had an asthma attack and, he said, 'reading this, no'."*

3.4 - Monitoring asthma

During the preliminary co-production workshops, it was revealed that some did not feel like their child's asthma was monitored enough. Following this feedback, we included questions in the survey that aimed to understand whether this was felt by people more widely.

Responses were reasonably even with 54% of parents and guardians, 40% of children aged 11-15 and 54% of young people aged 16+ answering that they felt their asthma was being monitored regularly enough.

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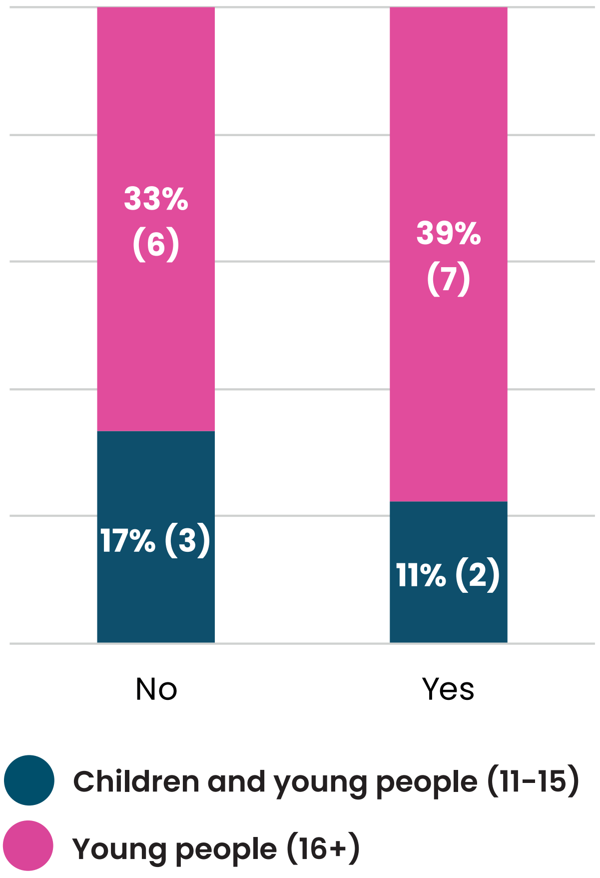
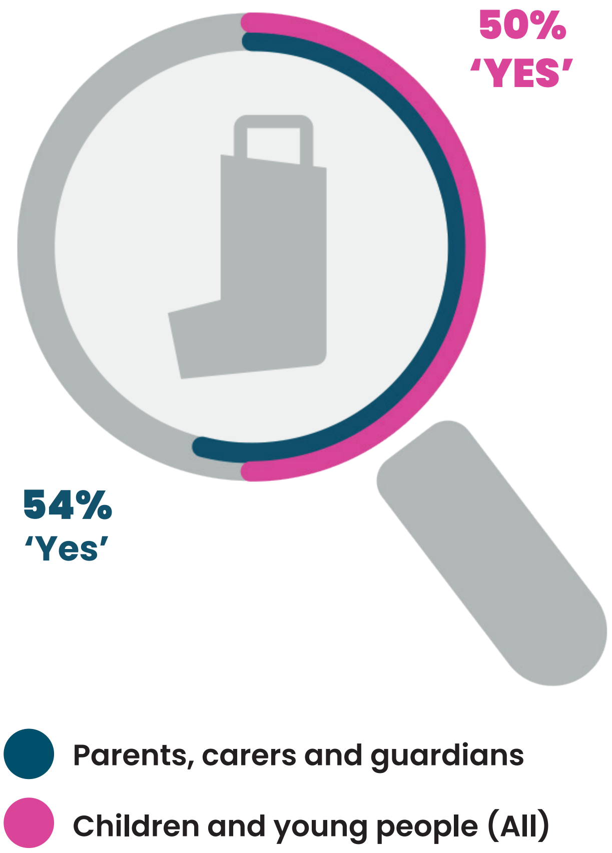
Children and young people's responses



Graph: 'Do you feel that your asthma is monitored regularly enough?' - Responses from all children and young people (11-15, and 16+). Based on 18 responses.

Do you feel like your asthma is being monitored regularly enough? (128 responses)



Around half of respondents felt their asthma was being monitored regularly enough, with responses fairly even across all groups.

In total, 47 parents, carers and guardians, and nine children and young people said 'No'. Four parents and carers were 'Unsure'.

“I have a good relationship with the asthma nurse at the GP surgery and I feel really listened to and engaged with.

“All asthma reviews take place over the phone which works well with school and work and I appreciate these more.”

What our interview participants said about monitoring asthma

The 'National Bundle of Care for Children and Young People with asthma' sets out a clear expectation that 'all CYP with asthma should undergo a structured review at least annually.'

While both families reported that reviews had taken place, the quality of these varied considerably creating some uncertainty, for one family particularly, about whether the child's asthma was truly being monitored.

> *"There's been times when they say they've done an annual review and they actually haven't, and I know they haven't, but generally, he's had an annual review and that's always been led by a nurse in the practice. They've been very helpful and they've been knowledgeable and if there's something I ask or they think about that, we don't know the answer to then they go to the GP for advice. So yeah, happy with that."*

> *"We have an annual asthma review. The last one was done on the phone and they told me to go and get the peak flow meter from Amazon and then when you've got your results, just phone them in and we'll put them on your record."*

Other issues raised in the interviews, about monitoring of asthma included:

- One parent felt she would like to have received more support and advice around reducing the levels of medication her son was being prescribed.

  > *"It felt like we got to a stage where they just chucked as many drugs at him as they could to get him under control, but now he's older and seems a bit more well controlled. I'm quite keen to try and get down to the lowest dose and does he need all of this?"*

- One family reflected how they had made the decision to stop using the blue inhaler with a spacer. This was a change they had made themselves, without the guidance of any health professionals, and was mainly in response to the lack of access to spare spacers.

  > *Child: " I normally take my blue inhaler without the spacer and my brown inhaler with the spacer....."*
  >
  > *Interviewer: "Was that a decision that you've made yourselves or is that something that you've discussed with a GP or a nurse?"*
  >
  > *Mum: "No, no.... When we went into hospital.... they were watching how she was [using the inhaler] and monitoring that and they were happy with the way she was doing it. No, nobody's ever said 'don't take it' or 'do take it' [with the spacer] but from my point of view, adults aren't expected to use spacers everywhere they go... Now she's older, we quite often just rely on the fact that she can use Ventolin on its own if she needs to, without the spacer."*

> *"But that's the reasoning, because the spacers are so expensive to buy, for something that's a plastic tube with a rubber mask on the end. So we just thought that it's, you know, she's able to do it, then at least if she gets caught out, she can use her inhaler."*

Qualitative insight: 'What could be improved about asthma care?' (78 responses)

Parents, carers and guardians were asked: 'Is there anything which could be changed or improved to help you support your child with their asthma care?'

Comments were analysed for themes. The top themes are shown in the table below.

Theme	No area	IES	WS	NEE	Total
Regular check-up or review	4	7	4	10	25
More information about condition or management	1	4	1	6	12
Better access to GP appointments	0	2	1	4	7
Information for schools or more support in school	1	2	2	1	6
Being listened to or believed about symptoms	0	1	1	2	4
Lack of asthma plan	0	2	0	1	3

Themes - Improving asthma support for children, young people and families

Regular check-up or review

Twenty one of 78 comments mentioned wanting more regular check-ups or reviews for their child or young person's asthma.

Some of these comments were simple, for example, "being reviewed", whilst others reflected that they had not received a check-up or review, or had very few, since being diagnosed with asthma. A few said they felt that they had to "chase" to get a check-up or review, and two said they would like face-to-face reviews.

Examples of these comments included:

> *"Regular check-ups that are initiated by the NHS, and not by us as parents chasing for an appointment." (Parent/ guardian)*

> *"My child has never had an asthma review in over two years, I explained everything to my child as I myself have asthma, he has never had a professional meet with him to explain or check his condition. We are very fortunate it is mild asthma and not more severe." (Parent/guardian)*

> *"Only been seen once since being diagnosed back in 2020. More appointments offered would help." (Parent/guardian)*

> *"Being seen for asthma check in person rather than over the phone with a parent." (Parent/guardian)*

More information about condition or management

The second biggest theme in the data was parents saying that they wanted more information about asthma, medication or how to manage their child's condition. These comments were further attributed to sub-themes of "Medication"; "Asthma Attacks" and "Continuity". Comments could refer to multiple sub-themes within "Information". These sub-themes are explored further below.

- **Medication -** Seven people wanted more information about medication or inhaler use. Some of these comments referenced concerns about the medication that their child used, or, wanting different types of medication. One mentioned wanting to be able to give their child more information about how long they might have to continue using an inhaler.
- **Continuity -** Five comments referenced a lack of continuity in the information people had received from different professionals. This could be between the hospital and primary care, or different professionals within primary care (e.g., GPs and asthma nurses).
- **Asthma attacks -** Three people mentioned wanting more information about how to manage asthma attacks.

Examples of comments about wanting more information included:

> *"To use evidence-based treatment rather salbutamol which is supposed to relieve asthma exacerbation. I believe if my child uses a preventer - inhaled corticosteroids, she'll not need a reliever. That has been clinically proven, but my GP just insists, only salbutamol, even though my child's asthma is not controlled, and she get exacerbations frequently." (Parent/guardian)*

> *"My child is getting now to the age where they are getting frustrated about having to take regular medication. We have received no information about future plans with the asthma*

"A professional to actually explain what is going on with his continued asthma attacks, such as what tests could be done to understand why he is getting them."

(Parent/ guardian)

> *around medication. It is difficult to manage their questions when we do not have the answers to when they potentially might not have to have medication." (Parent/ guardian)*

> *"When my son was first diagnosed, the advice we received tended to be different from each clinician (either between consultants, or GPs, or practice nurses) depending on what clinician you saw, which at times we found confusing and contradictory. I found advice from charities like Asthma UK really helpful." (Parent/ guardian)*

Better access to GP appointments

Access to GP appointments is a national issue in feedback about primary care. Seven comments said they found it difficult to access an appointment with their GP surgery for their child or young person's asthma. Examples of these comments included:

> *"I knew my daughter needed a steroid and was unable to get an appointment, 111 was hopeless and sent us to a pharmacy, who said we need to see a GP. Next time this happens we will go to A&E. Something has to change with getting GP appointments so that your child can be seen, we as parents know when our children are struggling after all." (Parent/ guardian)*

> *"[Make it] easier to get appointments especially when they are unwell." (Parent/ guardian)*
> *"Difficult as it is seasonal and frequency varies. It's difficult to see your GP full stop." (Parent/ guardian)*

Information for schools or more support in school

Six comments said support from schools for children and young people's asthma could be changed or improved. Most said schools needed more information, training, or awareness of asthma. A couple of parents said that their child had not been given access to an inhaler when they needed it by staff at school.

Examples of comments about support and information in schools included:

> *"I oversee medication in a large primary school. When a child first has an inhaler, please could there be some paperwork to explain/clarify this to schools. All asthmatic children with an inhaler need a second one so that one can be left in school [and] schools need a care plan." (Parent/ guardian)*

> *"Teachers being taught the need for inhalers. Last year we had a teacher refuse to give him his inhaler after PE." (Parent/ guardian)*

> *"I feel like my care within the NHS has been fine, the only issue I had was when I took her inhaler and spacer into school aged five. The teacher told me they weren't supposed to help them with it. At aged five they can't reach the inhaler and use enough force to press it down to give the medication let alone having to try and do it whilst short of breath and feeling uneasy. Thankfully the teacher did tell me she's willing to step in and help. Maybe smaller spacer and easier inhalers could be given to schools who aren't willing to help." (Parent/ guardian)*

> ***"I think schools should be taught what to do when a child is having an asthma attack.***
>
> *Our school decided he just needed a hug!!! At which point, after the hug, he went on to play again and had another [attack] alone on the field as he didn't want another hug."*
>
> *(Parent/ guardian)*

Being listened to or believed about symptoms

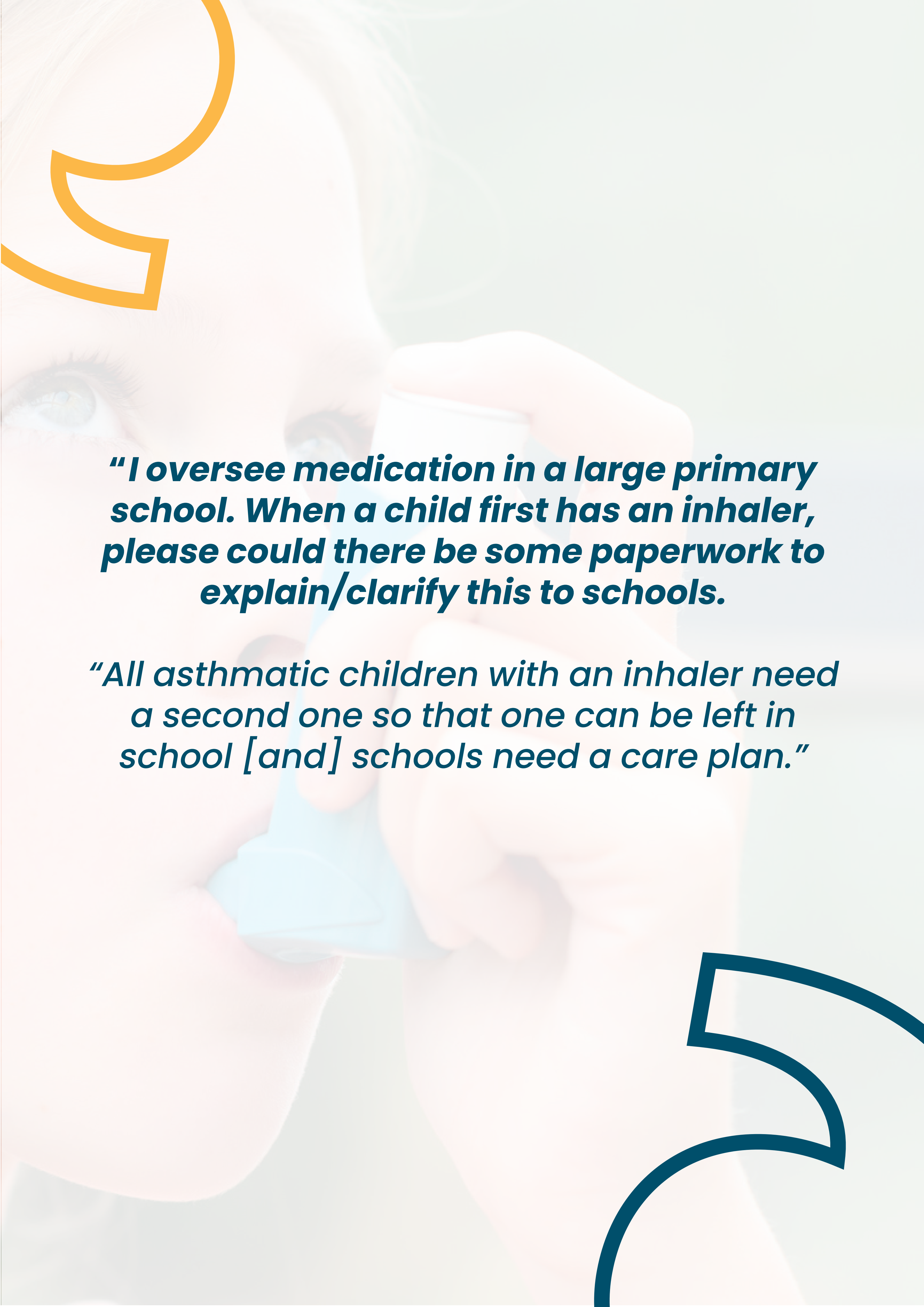
Four comments indicated that people did not always feel listened to or believed by health and care professionals about their children's asthma. Some felt this had impacted their access to diagnosis or timely care. Examples of these comments included:

> *"Listening to me [as] the mother. I have always known when my child has needed either antibiotics or steroids. I have shocked many health professionals with the knowledge I have and being able to pick up certain signs when my child needs something. I will always seek professional advice when I have a health concern regarding one of my children, and in the 17 years I have been a mother so far, I am yet to be proven wrong." (Parent/ guardian)*
>
> *"GP's / A&E doctors being aware that there is more than just a wheeze. Asthma has a cough variant and needs treatment, rather than constant blue inhaler. Stop turning mothers that know their children's symptoms away to battle on alone and without proper medical care." (Parent/ guardian)*
>
> *"Doctors surgeries understanding that if you as a parent tell them that your child needs to see a GP because they are wheezing and struggling, you can actually get an appointment to receive the medication they need." (Parent/ guardian)*

Lack of asthma plan

Finally, three comments reference not having an asthma plan. Examples of these comments included:

> *"To have a clear asthma plan." (Parent/ guardian)*
>
> *"More information for asthma plans, and provision and review of asthma plan." (Parent/ guardian)*



"I oversee medication in a large primary school. When a child first has an inhaler, please could there be some paperwork to explain/clarify this to schools.

"All asthmatic children with an inhaler need a second one so that one can be left in school [and] schools need a care plan."

3.5 - Managing asthma attacks

Controlling asthma

Participants were asked to rate how controlled they believed they/their child's asthma was, with 1 being not controlled at all and 10 being very well controlled.

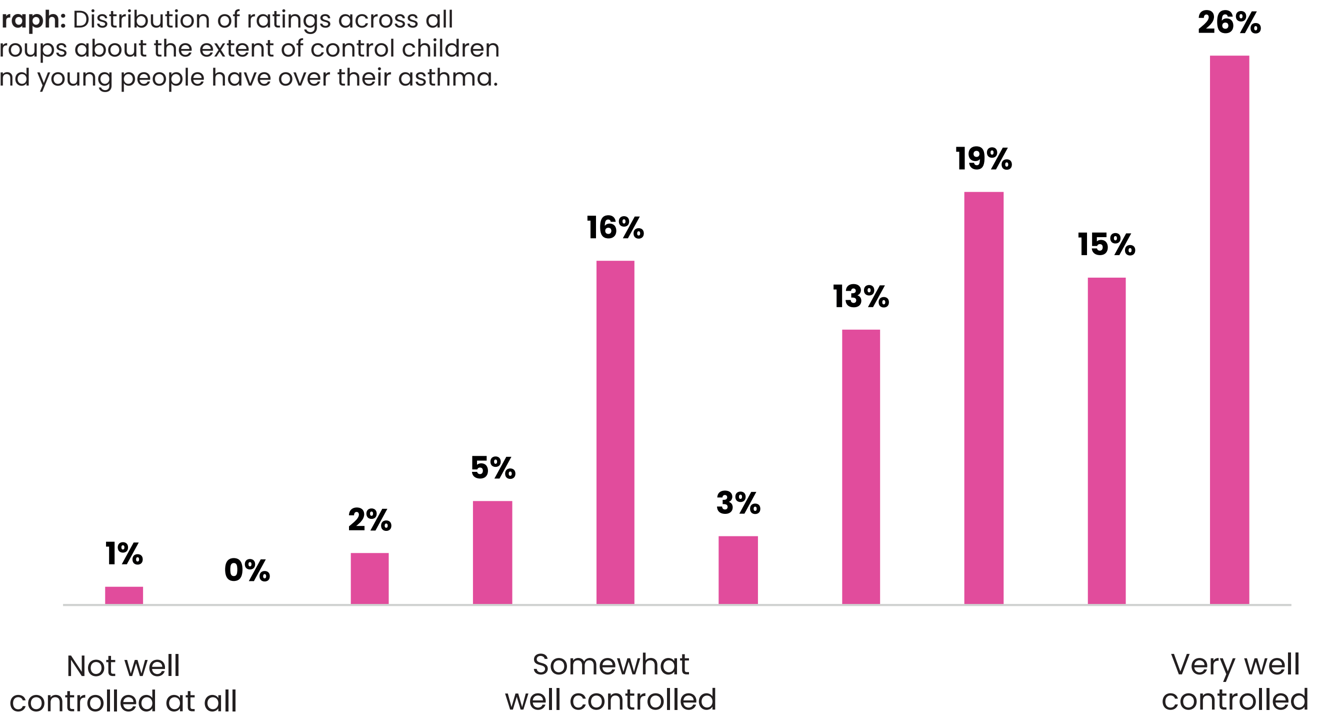
The most popular response was 10 ('very well controlled'), with this accounting for 29% of participant responses. For children aged 11-15, responses were mostly split between 5 and 8, with 40% of participants choosing each of these answers. For young people aged 16+, the most popular response was 7, which accounted for 31% of responses.

Based on 107 responses, the average score from parents, carers and guardians was 7.8, suggesting that people generally feel their child's asthma fluctuates between being 'somewhat well controlled' and 'very well controlled'. Just 8% of responses from this group fell in the zone between 'not well controlled at all' and 'somewhat well controlled'.

Based on 18 responses, children and young people aged 11 - 16+ were a little less likely to feel their asthma was well controlled, with an average score of 6.7 (just over one point lower than the ratings from parents and carers). However, a majority (16) selected a score within the range between 'somewhat well controlled' and 'very well controlled'.

The distribution of responses is shown in the graphs below.

Graph: Distribution of ratings across all groups about the extent of control children and young people have over their asthma.

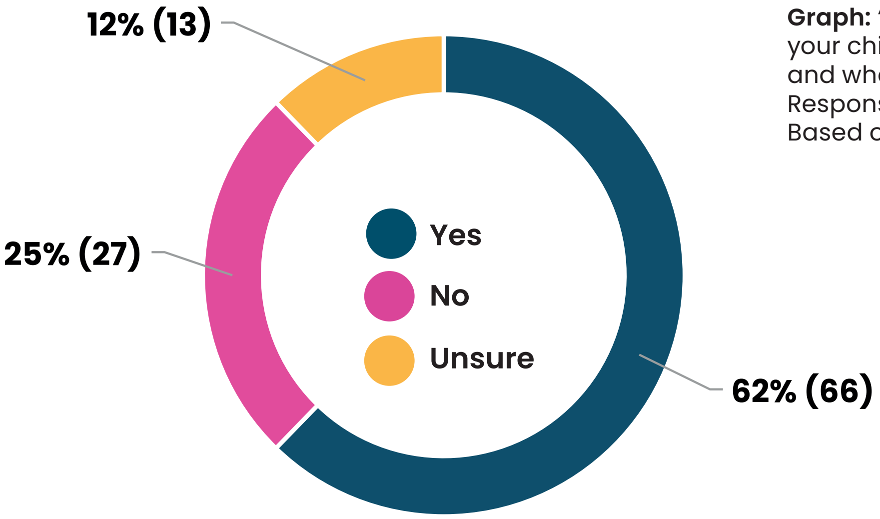


Triggers

All participants were asked if a GP had informed them or their child about their triggers and what to do if their asthma was triggered.

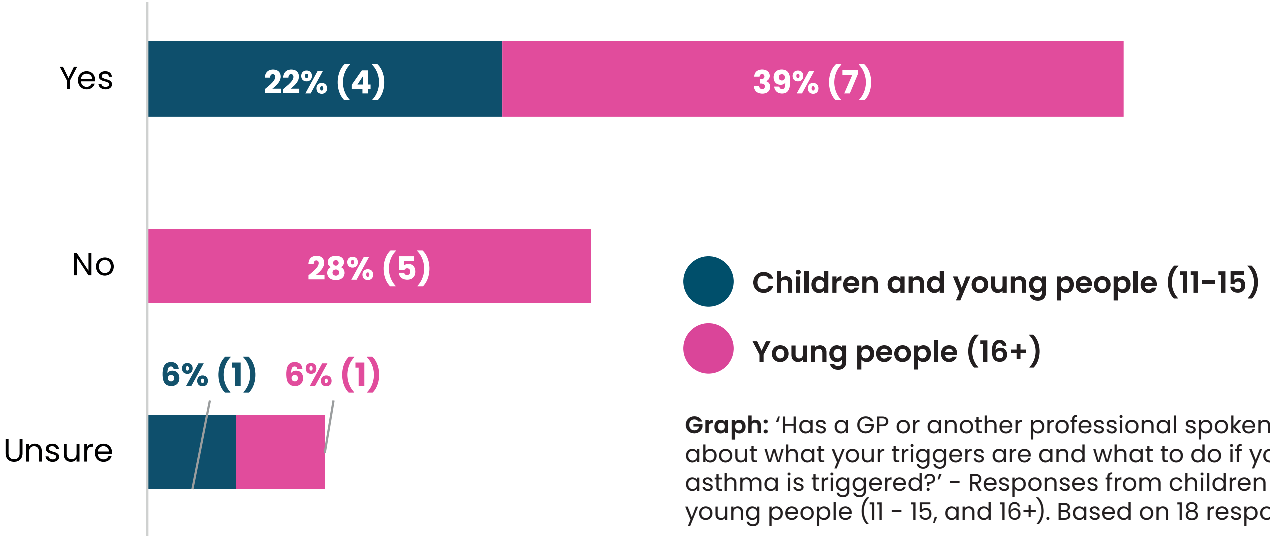
In total, 62% of parents and guardians, 80% of children aged 11-15 and 54% of young people aged 16+ shared that a GP had spoken with them, or their child, about their asthma triggers.

Information about triggers - Parent/carer responses



Graph: 'Have professionals spoken to you and your child about what your child's triggers are, and what to do if their asthma is triggered?' - Responses from parents, carers and guardians. Based on 106 responses.

Information about triggers - CYP responses



Graph: 'Has a GP or another professional spoken to you about what your triggers are and what to do if your asthma is triggered?' - Responses from children and young people (11 - 15, and 16+). Based on 18 responses.

What our interview participants said about triggers

Only one interview participant said they had received tests to identify any triggers for her child's asthma, while the other family expressed surprise that they had not been routinely offered these.

> *"They did some testing for him a lot as part of his journey, to work out what his triggers for asthma might be, other than just having a cold. He had some allergies so to supplement his treatment for asthma, he also had a drug which is sort of an anti allergen and he takes an antihistamine daily."*

> *"When I first got asthma, I had a skin test done to find out what my biggest triggers were. My daughter hasn't had that done and I would do wonder why she hasn't had it done."*

Confidence managing an attack

It was important to learn more about the young person's experiences of asthma attacks, and how confident they felt managing an asthma attack if they were to have one.

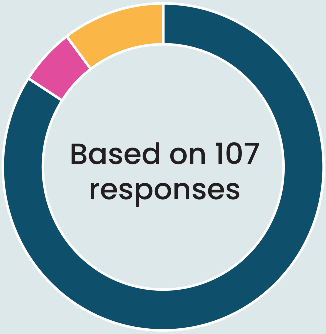
Parents, carers and guardians were asked 'How confident does your child feel managing an asthma attack?, and children and young people were asked 'How confident do you feel managing an asthma attack?'. Responses were noticeably varied.

For parents, carers and guardians, 25% felt 'somewhat confident' that their child would feel confident managing an asthma attack. For children aged 11-15, 80% of responses were between 5 ('somewhat confident') and 10 ('extremely confident'). For young people aged 16+, the most popular responses were at either end of the scale.

Average scores for both parents, carers and guardians (4.9), and children and young people (5.5) indicated that our respondents were generally 'somewhat confident' about managing asthma attacks, suggesting levels of confidence could be increased across all groups. The graph overleaf shows the distribution of scores across all groups.

In addition, parents, carers and guardians were asked a question about whether they would know what to do if their child was having an asthma attack. In total, 84% of participants shared that they would know what to do, 6% did not know what they would do, and 10% were unsure.

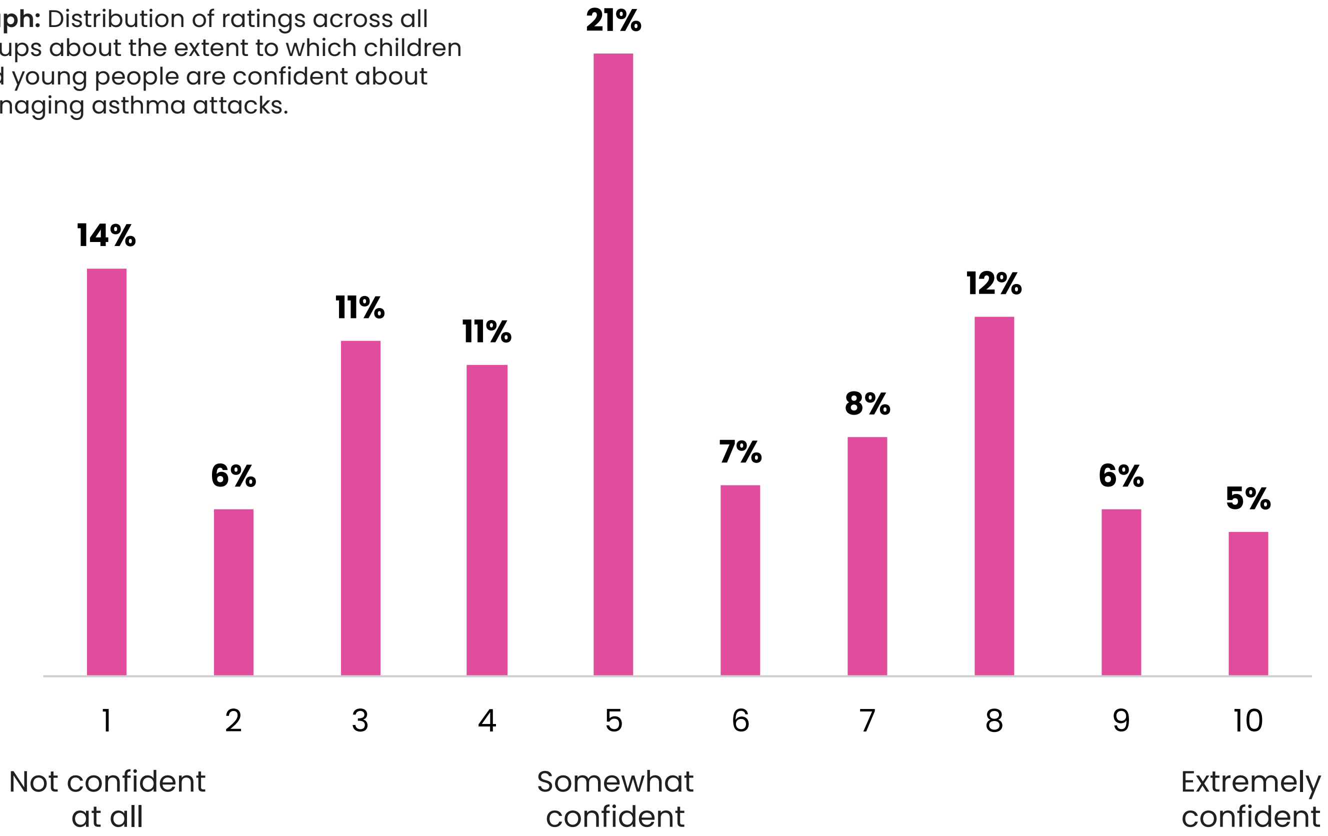
Would you know what to do if your child was having an asthma attack?



- ● **Yes - 84% (90)**
- ● **No - 6% (6)**
- ● **Unsure - 10% (11)**

84% of parents, carers and guardians indicated they would know what to do if their child(ren) had an asthma attack.

Graph: Distribution of ratings across all groups about the extent to which children and young people are confident about managing asthma attacks.



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Qualitative insight: 'What could increase both yours and your child's confidence in knowing how to manage an asthma attack? (82 responses)

74 parents/ guardians and eight young people gave a response. These comments were analysed for key themes, which are described below.

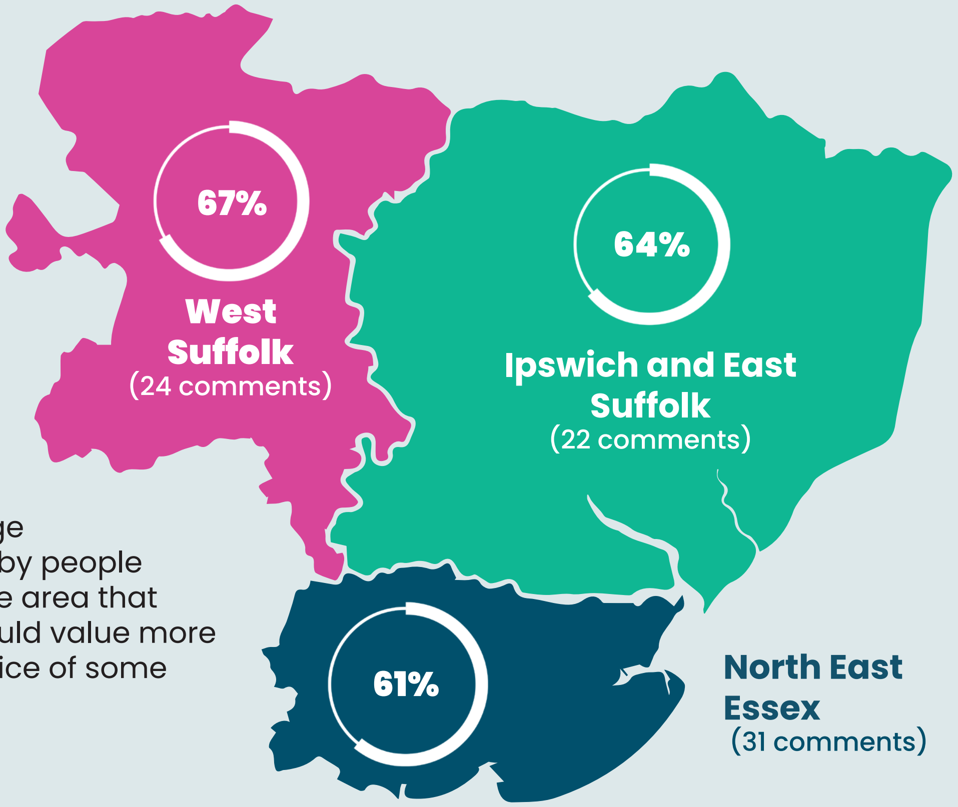
More information and advice

The vast majority of comments (54) from both parents, carers and guardians and young people said they wanted more information and advice of some kind. These responses are shown by alliance area below (note only 77 answered the question and gave a postcode).

Who wants more information about managing asthma attacks?
Alliance area breakdown

Out of 82 responses, 77 parents, carers, guardians offered a comment about things that could increase their confidence, and the confidence of their child(ren), to manage an asthma attack.

This graphic shows the percentage of comments made by people living in each alliance area that indicated people would value more information and advice of some kind.



There were a number of different sub-themes within the wider theme of wanting more information and advice. These are shown in the table overleaf. Comments could refer to multiple sub-themes.

Theme	No area	IES	WS	NEE	Total
Information or support from a professional	1	5	5	3	14
General information	1	3	2	5	11
Information directed to or suitable for children	0	5	2	4	11
A course, training or support group	0	2	2	4	8
Online resources	1	2	2	1	6
Information about potential signs or symptoms of an attack	0	0	3	1	4
Information about knowing when to seek help	0	0	3	1	4
Having an asthma plan or more detail in the asthma plan	0	1	1	1	3
Printed resources	1	0	1	0	2

Quotes reflecting these sub-themes are presented on pages 42 and 43.

- Eleven parents, and three children and young people, said they wanted more support, communication or information from a professional. Almost all these comments referred to an asthma nurse or GP, although some just said a 'professional'.
- Eleven parents made general comments about wanting more information about managing an asthma attack. Examples included:

  "More information." (Parent/guardian)

  "More instructions rather than just use the pump." (Parent/guardian)

  "More information on how to handle an asthma attack, as well as the information on how to control the asthma." (Parent/guardian)

- Eleven parents wanted more information that was suitable for their child. This was often linked to other themes, for example:
  - Explaining the asthma plan to the child.
  - Including the child in reviews.
  - Providing training workshops for parents and children together.
  - Helping children to feel more independent in managing an attack.

- Eight parents mentioned wanting a course, training or support group to help them feel more confident about managing asthma attacks. For example:

  > *"A course on what to do if the situation arises." (Parent/guardian)*
  >
  > *"Classes to teach both children and parents." (Parent/guardian)*
  >
  > *"Training on what to do, I think, is essential!" (Parent/guardian)*

- Six parents/carers mentioned wanting online resources to support their confidence to manage an asthma attack. These included YouTube videos and email signposting.
- Two mentioned printed resources, including cheat sheets/business cards for parents and visual aids for children.
- Four parents/carers mentioned wanting more information about the potential warning signs or symptoms of an attack.
- Three young people and one parent/carer said that they would like more information about when to seek help.
- Three parents said that they would like a plan of what to do if their child has an asthma attack.

Other things parents, carers, guardians and young people said could help them feel more confident about managing an asthma attack included:

- Six parents/carers and one young person said that quick access to the right medication would help them feel confident managing an asthma attack, and three parents wanted access to different medication at home. Examples of these comments included:

  > *"Having my inhaler always with me." (Child or young person)*
  >
  > *"Having a nebulizer at home." (Parent/guardian)*
  >
  > *"Having prednisolone at home for administration when needed before consulting GP." (Parent/guardian)*
  >
  > *"If the GP can kindly prescribe a preventer inhaler for my child, we wouldn't have to deal with so many scary attacks all year round." (Parent/guardian)*

Four parents noted that they needed to manage their child's and their own emotions or feelings of panic as part of their response to an asthma attack. Examples of these comments included:

> *"I think for my daughter it's the fear and despite trying to explain it will be OK it is very frightening." (Parent/guardian)*
>
> *"Nothing, I think any normal person would panic." (Parent/guardian)*

Examples of quotes about the information parents and young people would need to feel more confident managing an asthma attack included:

> *"Being seen more regularly and **being told what to do instead of having to Google it."***
>
> *(Child or young person)*

"Knowing when I need to contact doctors or go to A&E." (Child or young person)

"A professional explaining what is going on with our child's attacks, so we can understand why he is getting them to avoid future hospital scares." (Parent/ guardian)

"Advice from GP." (Child or young person)

"Maybe a session with asthma nurse to be shown visually what to do." (Parent/ guardian)

"I think parents should be taught how to manage an asthma attack, or have a care sheet or little business card so they can have it on them at all times." (Parent/ Guardian)

"Being explained what to do by a doctor." (Child or young person)

"Going through asthma plan and explaining it to a child so they can understand it." (Parent/ guardian)

What our interview participants said about managing asthma attacks

"When you see your child struggling to breathe and their chest... and you could see all their neck muscles you know, exploding almost and they look grey, it's horrible. No one wants to see their child struggling."

Having a clear, concise and documented plan of action was highlighted, by one of our interview participants, as being essential to giving families the confidence to manage an asthma attack.

> *"I think our confidence only grew when we knew what we needed to do and when we needed to do it and if that didn't work, we knew we needed to, I don't know ring the GP or ring 999 or whatever. So yeah. So that confidence only grew when we knew what we were supposed to do."*
>
> *"[The plan doesn't need to be] hugely detailed, but have enough detail, if that makes sense. As a parent you're panicking. You think, 'oh, what do I do?' You just need something simple and easy to look at, that is clear. If you do this and that and you wait this amount of time and that's not working, you then do this. You know, that's all you need, isn't it?"*

For our second family however, it was Mum's 'lived experience' of managing her own asthma condition that had been most critical when supporting her child through an asthma attack. Our youngest interview participant reflected how her Mum had helped her to calm down and focus on her breathing technique. Since the incident, she had further reflected on how changing the way she was breathing had helped to get more air into her lungs.

Whilst frightening at the time, she felt this experience had shown her not only what she needs to do to manage any future asthma attacks but also how she can support others who may find themselves in a similar situation.

> *"I was really in a panic when it was happening because I was like breathing really quickly and always through my mouth… I ended up, like, getting really upset, didn't I. And then you got some water. You told me how to slow my breathing down. You said you have to breathe in through your nose and out through your mouth. I know, like a lot of people say that, but it does actually help. But in that moment you don't think about that. All you're thinking about is not being able to breathe properly."*

> *"Also, I've realized since that happened that when I was breathing in my nose and out my mouth. I did breathing in my chest. And I started breathing down lower, and so that really helped… Now I guess I kind of know that if that were to ever happen again or if I were to get the slightest bit breathless, focus on how you're breathing, not that you're breathing badly."*

Crucially, however, these breathing techniques were not something that Mum had learnt from health professionals involved in either her own asthma treatment or that of her child, but had been suggested by a sports trainer. Mum had subsequently undertaken further online research about managing breathlessness. She strongly felt that these simple but potentially life-saving techniques should be routinely taught to parents to help them support a child through an asthma attack.

> *"I found out from sports training, not from professionals… So I get breathless obviously because I'm asthmatic and when we're doing a lot of cardio, I get out of breath. So one of the trainers said just sit, get your head down low and breathe in through your nose and out through your mouth to get more air in. After that I googled it and I started looking into it and you get more oxygen in if you do that and you get more circulation of air than panting in and out…. But no one is taught to calm their child down, you know, and help them to breathe in through… Parents aren't taught that stuff at all."*

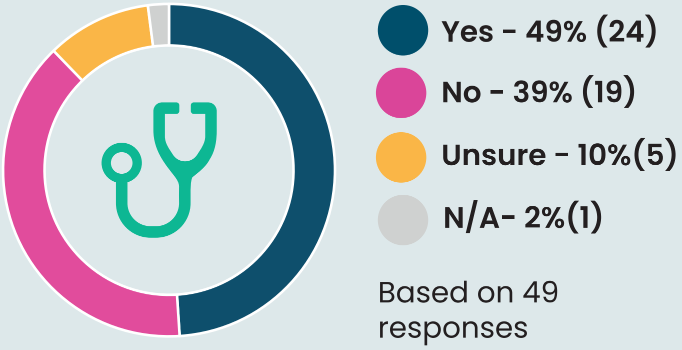
“[The plan doesn’t need to be] hugely detailed, but have enough detail, if that makes sense. As a parent you’re panicking. You think, ‘oh, what do I do?’ You just need something simple and easy to look at, that is clear. If you do this and that and you wait this amount of time and that’s not working, you then do this. You know, that’s all you need, isn’t it?”

3.6 - Hospital care

All participants were asked if they or their child had ever been admitted into hospital due to asthma:

- 46% of parents (49 of 106) said that their child had been admitted to hospital due to asthma. 34 parents and guardians said that their child had been admitted more than once.
- 31% of young people aged 16+ (four of thirteen) had been admitted to hospital due to asthma. Three young people said they had been admitted more than once.
- None of the children aged 11 – 15 who answered the survey had been admitted to hospital due to their asthma.

If your child has previously been admitted into hospital, did they have a follow-up review with their GP?



Based on 49 responses

Just over a third of parents, carers and guardians had not had a follow-up review of their child's asthma after being admitted to hospital. A further five respondents were 'unsure'.

Primary care follow-up

Participants who had experience of being admitted into hospital were also asked if they had a follow up review with their GP.

The National bundle of care for children and young people with asthma says all children and young people discharged from hospitals should undergo a review within 48 hours by an appropriately trained clinician in primary care. Yet, only 49% parents and guardians (24 of 49) and 25% (one of four) young people aged 16+ who had been admitted to hospital had a follow up review with their GP.

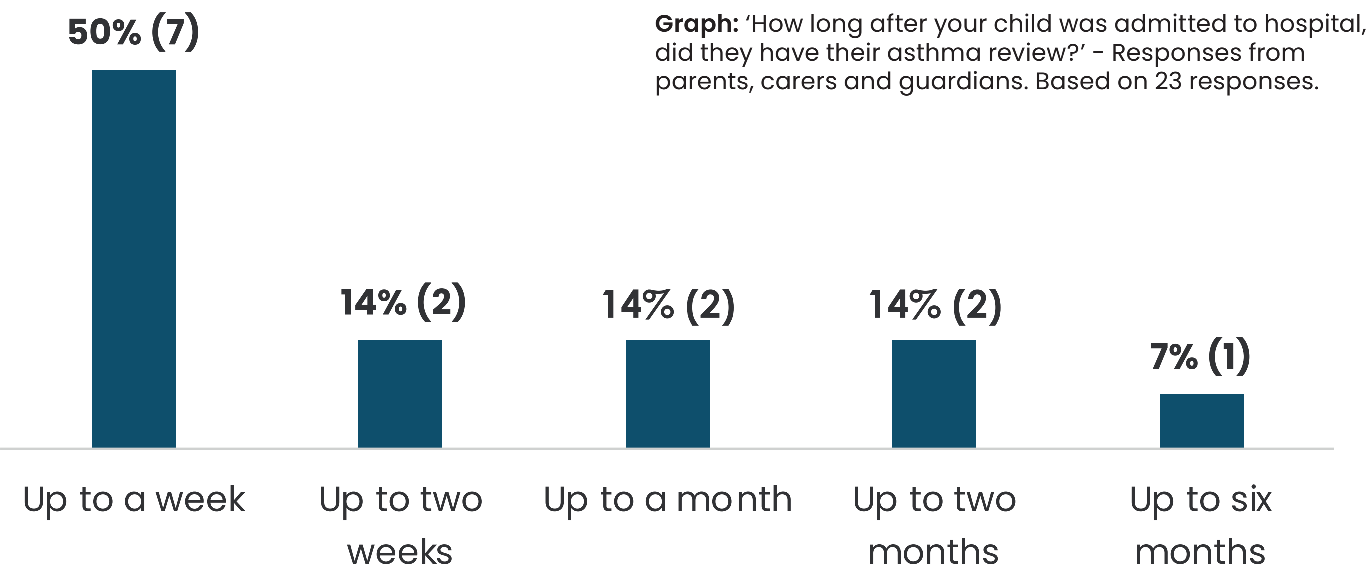
Of four young people aged 16 an above who answered the question, one said 'yes', they had a follow up with their GP. Two said 'no' they did not have a follow up with GP, and one was 'unsure'.

Length of time between admission and review in primary care

A total of 23 parents and guardians answered the follow up question about how much time had passed between their child being admitted to hospital, and any follow-up in primary care.

Seven said they did not know. Two gave non-specific answers, such as 'Few months', and 'A long time, but the hospital visit was during March of 2020 so this was likely due to the pandemic'.

A summary of the remaining 14 responses answers is shown in the chart overleaf.



Graph: 'How long after your child was admitted to hospital, did they have their asthma review?' - Responses from parents, carers and guardians. Based on 23 responses.

* * *

Thirteen responses gave both a time and a postcode by alliance area:

- All of three comments from West Suffolk had a follow up review within a week.
- Two of the five comments from Ipswich and East Suffolk had a review within a week. Two were seen within two months, and one waited up to six months.
- Two of the five comments from North East Essex were seen up to a week after discharge. One waited two weeks, and two waited up to a month.

No children and young people aged over 16 answered the follow up question about time that had passed between being admitted to hospital and any review by a GP.

Qualitative insight: Experiences in hospital (48 responses)

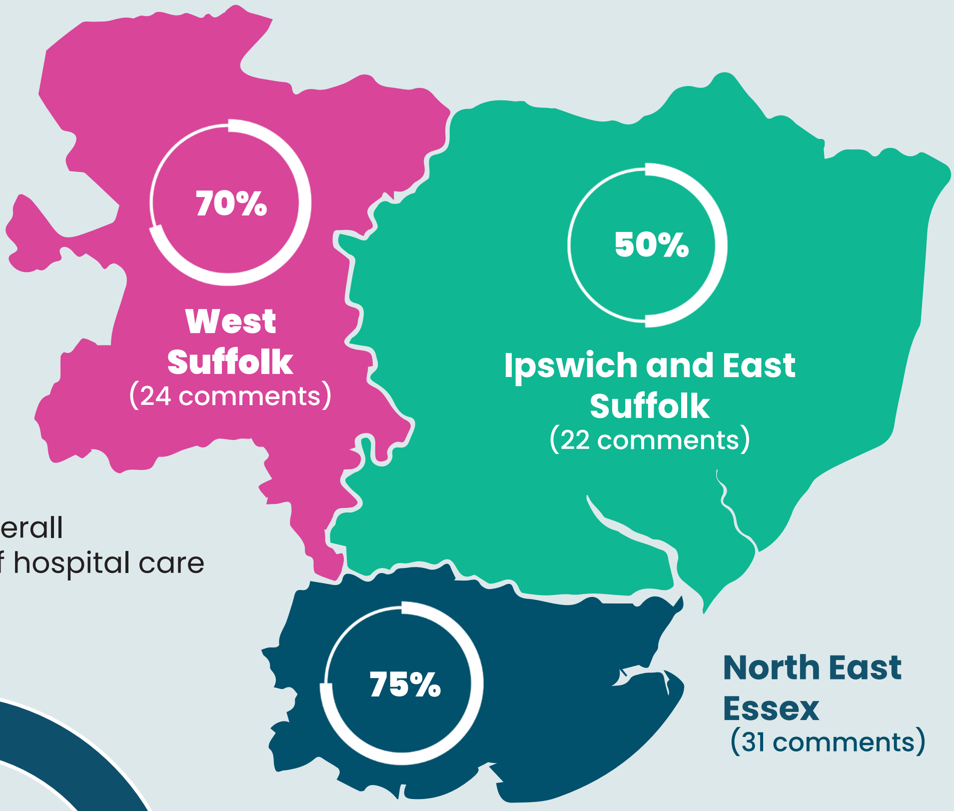
74 parents/ guardians and eight young people gave a response. These comments were analysed for key themes, which are described below.

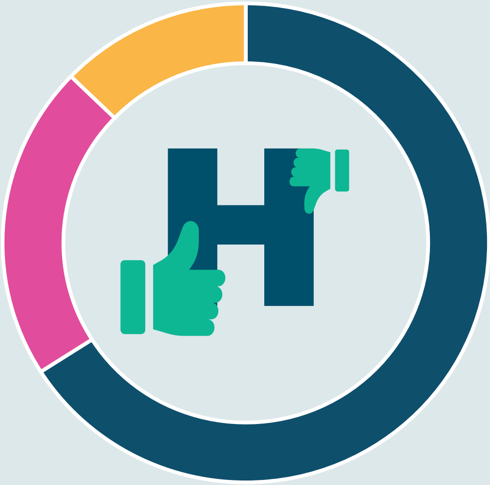
45 parents, carers and guardians and three young people gave a response. A sentiment was applied to each of them. Levels of overall positivity in each alliance area are shown below (note only 45 comments gave their postcode).

Positivity about hospital care
Alliance area breakdown

A total of 48 parents, carers, guardians and young people offered a comment about their experiences in hospital.

This graphic shows the percentage of comments made by people living in each alliance area that were positive overall about experiences of hospital care and support.





The chart left shows the overall sentiment for all of the comments about hospital care after child or young person's admission to hospital because of their asthma.

● **Positive - 66% (31)**
● **Negative - 13% (6)**
● **Mixed - 21% (10)**

Comments were also broken down by key theme. These are presented for each Alliance area (West Suffolk, Ipswich and East Suffolk, and North East Essex) below.

West Suffolk

Of the ten comments received from residents in the West Suffolk Alliance area, seven were positive, and three were mixed or neutral. All comments in West Suffolk came from parents or guardians. Within these:

- Five parents were generally positive about the care that they had received when their child was admitted to hospital. These contained broad comments such as 'excellent' and 'really helpful', as well as comments that described a positive outcome or experience of treatment. For example:

  > *"He was taken to hospital in an ambulance, and was given steroids which almost immediately eased symptoms." (Parent/ guardian)*
  >
  > *"It was good, in hospital she received treatment straight away." (Parent/ guardian)*

- Two parents said that they had received good follow up care or information following a hospital admission. Examples of these quotes included:

  > *"My son had an acute episode as a baby requiring nebulisers and oxygen. Gave us follow up care with the paediatric respiratory consultant as an outpatient." (Parent/ guardian)*
  >
  > *"It was good, learnt how to manage it better sleeping positions etc. and saw doctor straight away." (Parent/ guardian)*

- In contrast, one parent said that the care they received at the hospital was good, but that they required more information or support to better manage their child's asthma:

  > *"Excellent care to treat the acute attack, but less support or information following regarding how to manage day to day." (Parent/ guardian)*

- One parent said there had been a lack of focus on asthma in the treatment they received at the hospital:

  > *"Limited, the focus was on chest infection, not asthma. So, while child received care, the lack of knowledge on asthma prolonged recovery." (Parent/guardian)*

Ipswich and East Suffolk

Of the 18 comments from residents in the Ipswich and East Suffolk Alliance area, nine were positive, four were mixed or neutral and five were negative. Seventeen comments were from parents, carers and guardians, and one was from young person.

- Nine comments were generally positive about the care that they had received in hospital. Most of these comments were very general, for example: 'Good'; 'Fine', 'As expected', and 'Very good once admitted'.

- Two left more detailed comments.

  "OK. As a parent you are scared as your child is struggling to breathe. Our son was admitted three times, when he was under eight years old. The care he received was rapid, and had good levels of senior doctor oversight. It wasn't perfect, but he was treated, and we were happy to bring him home a few days later." (Parent/ guardian)

  "Fabulous, the care was brilliant. All staff couldn't have been more attentive." (Parent/ guardian)

- Two parents and one young person made negative comments about waiting a long time for treatment in hospital. Both parents implied that they had experienced long wait times for treatment or updates after they had been admitted. The young person said that they had waited a long time in A&E. Examples of comments about waits and delays in treatment included:

  "Many times, I was just sat in A&E not being able to breathe, and being told to go home as there is no space on a ward." (Child or young person)

  "Having to be admitted, wheezing plans of ten breaths of inhaler every hour, having to hold down a toddler whilst medication is given or a child that is passed out because they cannot breathe, no information given regularly, would regularly spend hours upon hours waiting for medication or ongoing support." (Parent/ guardian)

  "I wasn't impressed the second time as we were left in room on our own for a long time, no observations taken at beginning." (Parent/ guardian)

- Two parents said that they had received good care in hospital. However, they also felt that they required more information or follow up after the admission to be able to manage their child's asthma.

  "The care was good but there was still no training on what to do in the event of another attack." (Parent/ guardian)

  "The care was brilliant at hospital, however, it was difficult to get a diagnosis at first and took a long time to get stronger inhaler to help." (Parent/ guardian)

  - One parent reflected on a negative experience with staff at the hospital when administering medication.

  "Nursing staff pinned him down to administer inhaler. Took a long time then to build his trust with the inhalers." (Parent/ guardian)

North East Essex

There were 16 comments from residents of North East Essex. Of these, twelve were positive about their experience in hospital. One was negative, and three were mixed or neutral. Fifteen comments were from parents/ guardians, and one was from a child or young person.

- Twelve comments from people living within the North East Essex Alliance area were generally positive about the care they had received. Like the other areas, some of these comments were very general. For example, 'Very good' or 'Excellent'. Others gave more detail about their experience. A few of these reflected on fast or efficient treatment, and positive attitudes from staff.

> *"Really good, they were super quick with me." (Child or young person)*
>
> *"Brilliant. He was admitted as a toddler when his sats weren't improving despite inhalers and nebulisers. The nurses and doctors at Ipswich Hospital were amazing!" (Parent/ guardian)*
>
> *"All hospital admissions were before he started on the brown inhaler. They started him on nebuliser, but needed steroids so stayed in overnight… All the staff looked after both of us explained what was happening and why." (Parent/ guardian)*
>
> *"Brilliant, they made sure he was comfortable happy and distracted while he was on oxygen." (Parent/ guardian)*

- Two comments from parents in North East Essex said that the care they received was good, but that they required more support, information or follow up following an admission to hospital.

> *"Asthma attacks have always been linked / triggered by other illnesses. Hospital treat the other illness, not always the asthma. Have been promised multiple times a referral from hospital to an asthma specialist. Have never received a referral." (Parent/ guardian)*
>
> *"Neither a good or bad experience. Was given oxygen and monitored. No real support/ advice given." (Parent/ guardian)*

- Two parents in North East Essex left mixed comments about the support they had received in hospital.

> *"It was OK could be better." (Parent/ guardian)*
>
> *"When my child was age one, his care was diabolical. We were extremely lucky and thankful for the doctors that listened to me and explored my concerns, which ended with us leaving with asthma care plan and my child being discharged. The second time was due to allergy reaction which had also set off an asthma attack. This time was great… they eventually tried antihistamine and tests confirmed I was correct. My child has NOT been admitted into hospital since." (Parent/ guardian)*

What our interview participants said about hospitals and post-discharge support

Both families interviewed had experience of in-patient hospital stays related to their asthma. Both felt the care they had received in hospital had been good.

> *"I think he received quite good care each time he's been in. The consultants have been really lovely. So it's been fine. You know, the odd niggle here and there, but nothing to worry about, I would say so. We have had good care from the trusts."*

One family however questioned whether their child was really well enough to have been discharged, particularly as they were not offered any post-discharge review or check up.

> *"I mean, we walked from the hospital back to the car and we were walking at a snail's space because [my child] couldn't get her breath, you know? So she was definitely not recovered. And it took, as I said, it took a good couple of weeks to get fully back to normal.... I mean a parent leaving the hospital with their child in that state, you'd be questioning why they're leaving, you know. If they can't even walk a few paces without getting breathless, you would be questioning why they're being sent home. Me personally, I knew she would recover. It just would take time and rest for her to get to that."*
>
> *[Interviewer: did you get any follow up at all when you left hospital like with your GP?]*
>
> *"No, nothing. Nothing at all. Obviously a letter would have gone out for the GP because they always do. But yeah, there was nothing at all. There was no further check up..... The hospital did say come back if anything worsens, but that was it. It was just off you go and she's fine. She can go. Just give her lots of Ventolin."*

“Asthma attacks have always been linked / triggered by other illnesses. Hospital treat the other illness, not always the asthma. Have been promised multiple times a referral from hospital to an asthma specialist. Have never received a referral.”

3.7 - Accessing information about asthma care

The next set of questions asked participants about accessing information regarding their asthma care. All participants were asked if anything had ever prevented them or their child from being able to access an asthma appointment. This survey question had multiple choice answers where participants could choose more than one answer.

For parents and guardians, the most popular response was that their child had not been offered any asthma appointments. This was closely followed by appointments only being available during school or college hours. For children aged 11-15, all four participants also answered that appointment times during school or college hours prevented them from attending.

For young people aged 16+, there were more varied responses. However, they most frequently chose appointments during school or college hours, not having an asthma specialist at their surgery, and not being offered an asthma appointment as the most frequent barriers to attending appointments.

See the graphs below and overleaf for more detail about the responses across both groups.

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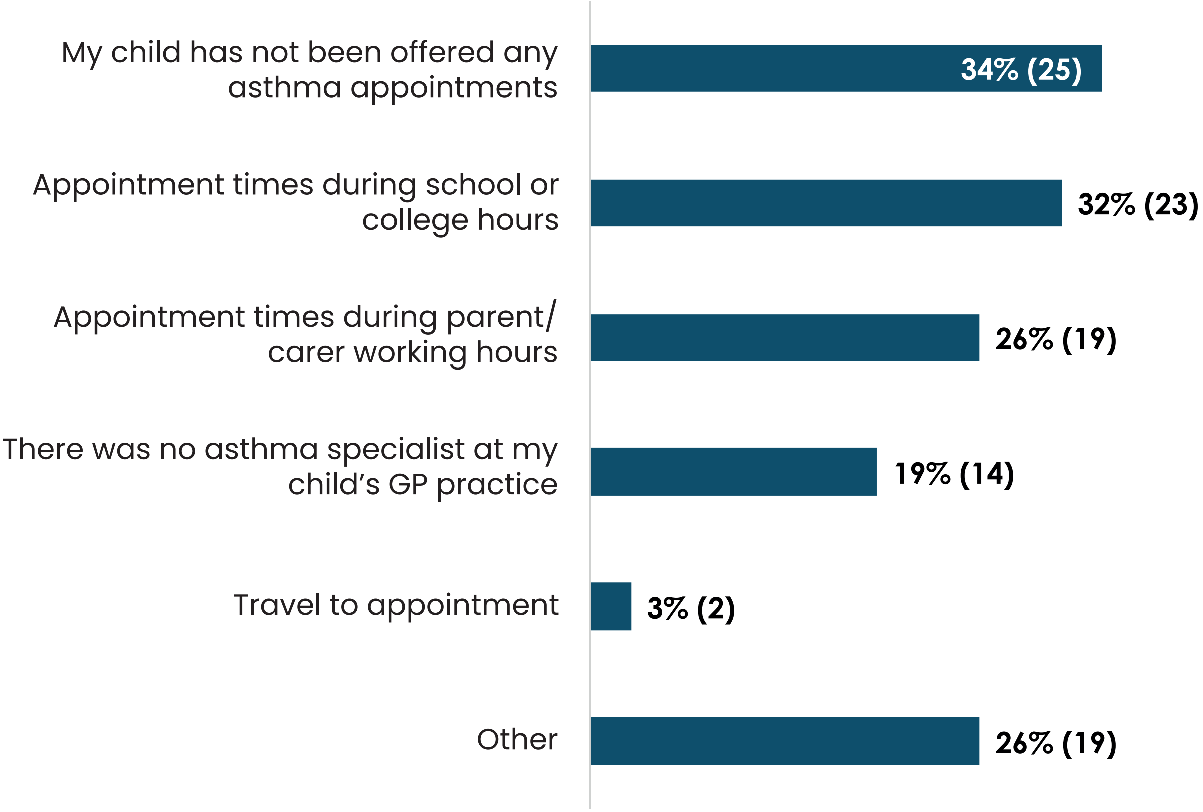
Barriers to support - Parents, carers and guardians



Graph: 'Has anything ever prevented your child from being able to access an appointment?' - Responses from parents, carers and guardians. Based on 73 responses.

There was an additional option choice of 'Other', which was selected by ten respondents. Of these, most had not had any issues being able to access an appointment. Their responses included:

> *"Child getting a letter in error saying she had to have blood test to get repeat prescription, so she refused to go as too scared and didn't get it."*
>
> *"GP… unhelpful."*
>
> *"They are happy to just prescribe over the phone."*
>
> *"Only had one phone call about Asthma. GP has never seen my child."*
>
> *"No nurse on the day to review a child's asthma and plan."*
>
> *"We have actually now been referred back to the GP care from the specialist which I'm really nervous about."*
>
> *"The surgery offered a telephone review on a specific date but did not specify a time. This was not convenient for me or my child so the practice agreed to arrange a face-to-face appointment, but I was told this was not the norm."*
>
> *"Fathers lack of acceptance of diagnosis means our child doesn't receive chronic treatment with him."*

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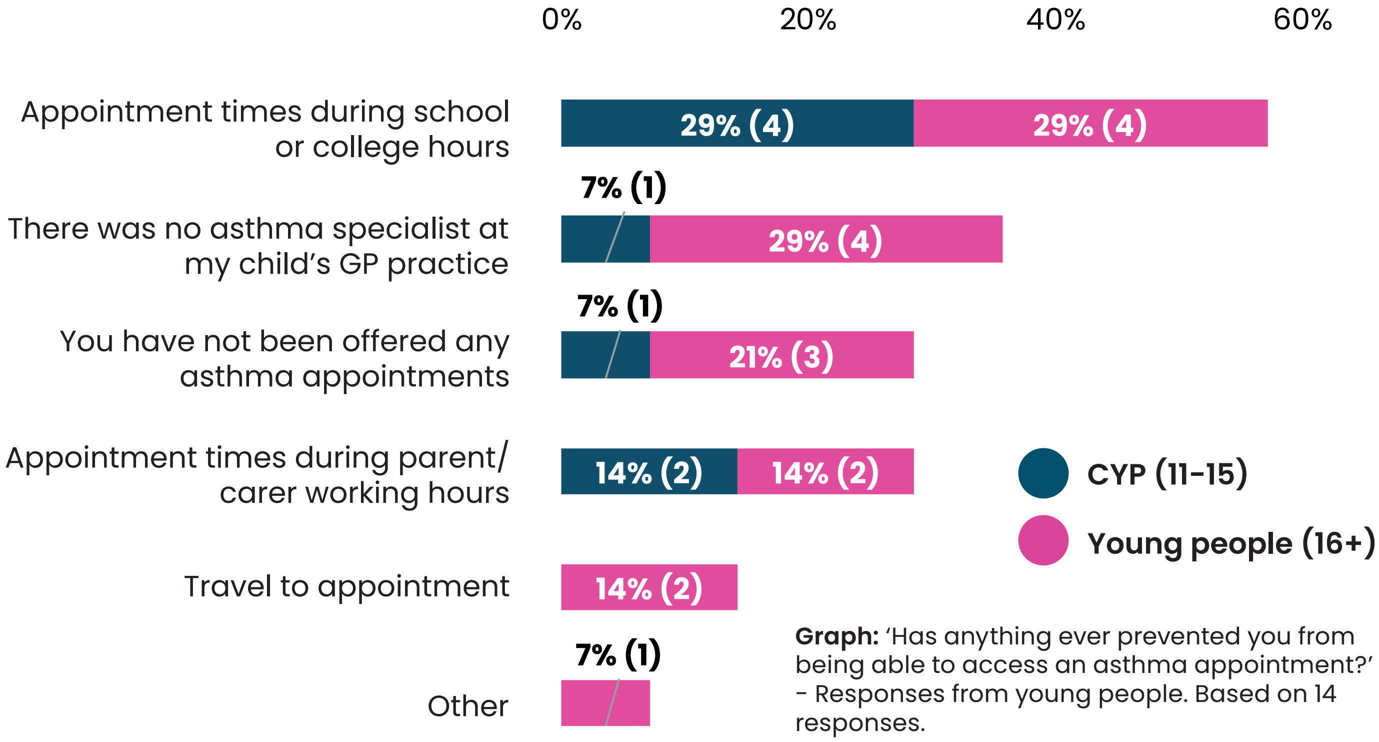
Barriers to support - Children and young people



Graph: 'Has anything ever prevented you from being able to access an asthma appointment?' - Responses from young people. Based on 14 responses.

Sources of information and advice

Additionally, participants were asked to share where they or their child would be most likely to turn to for advice and help with their asthma. Respondents were provided the opportunity to select more than one answer.

In total, 90% of parents and guardians, 100% of children and young people aged 11 - 15, and 85% of young people aged 16+ said they would go to their GP practice. Other popular responses included getting advice from a relative living with asthma, and going to see a pharmacist.

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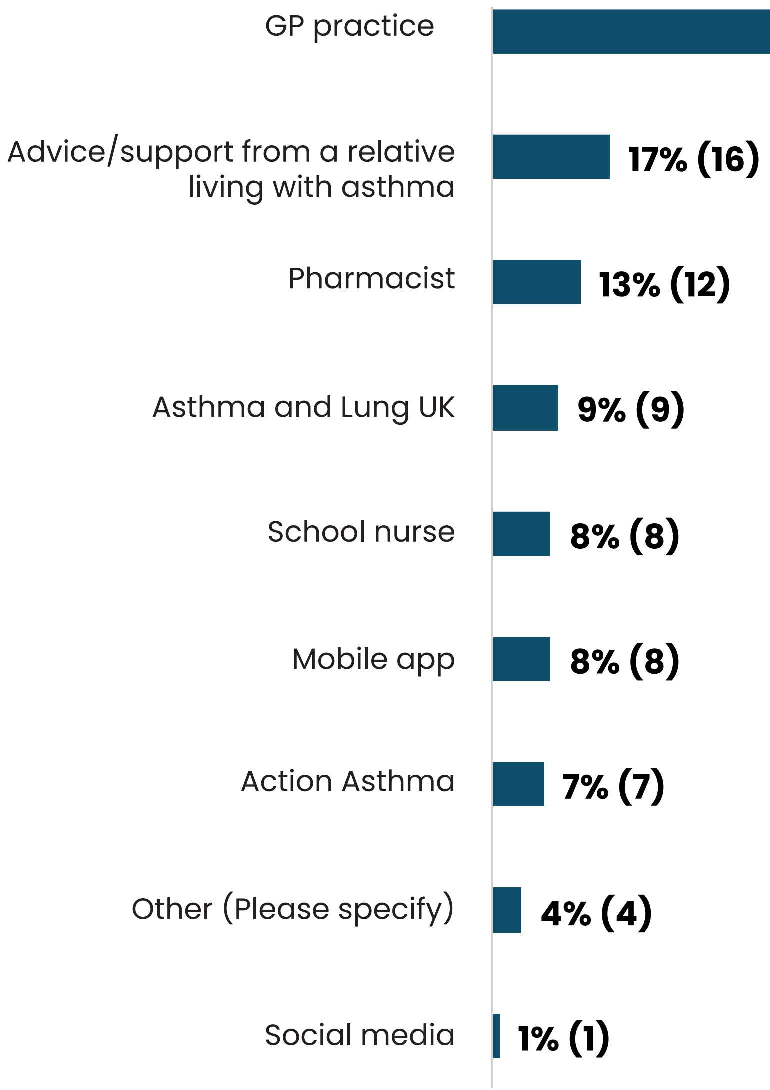
Preference for sources of advice - Parents, carers and guardians



Four parent, carer and guardian respondents selected 'Other' as one of their answers. Their responses included:

"Google."

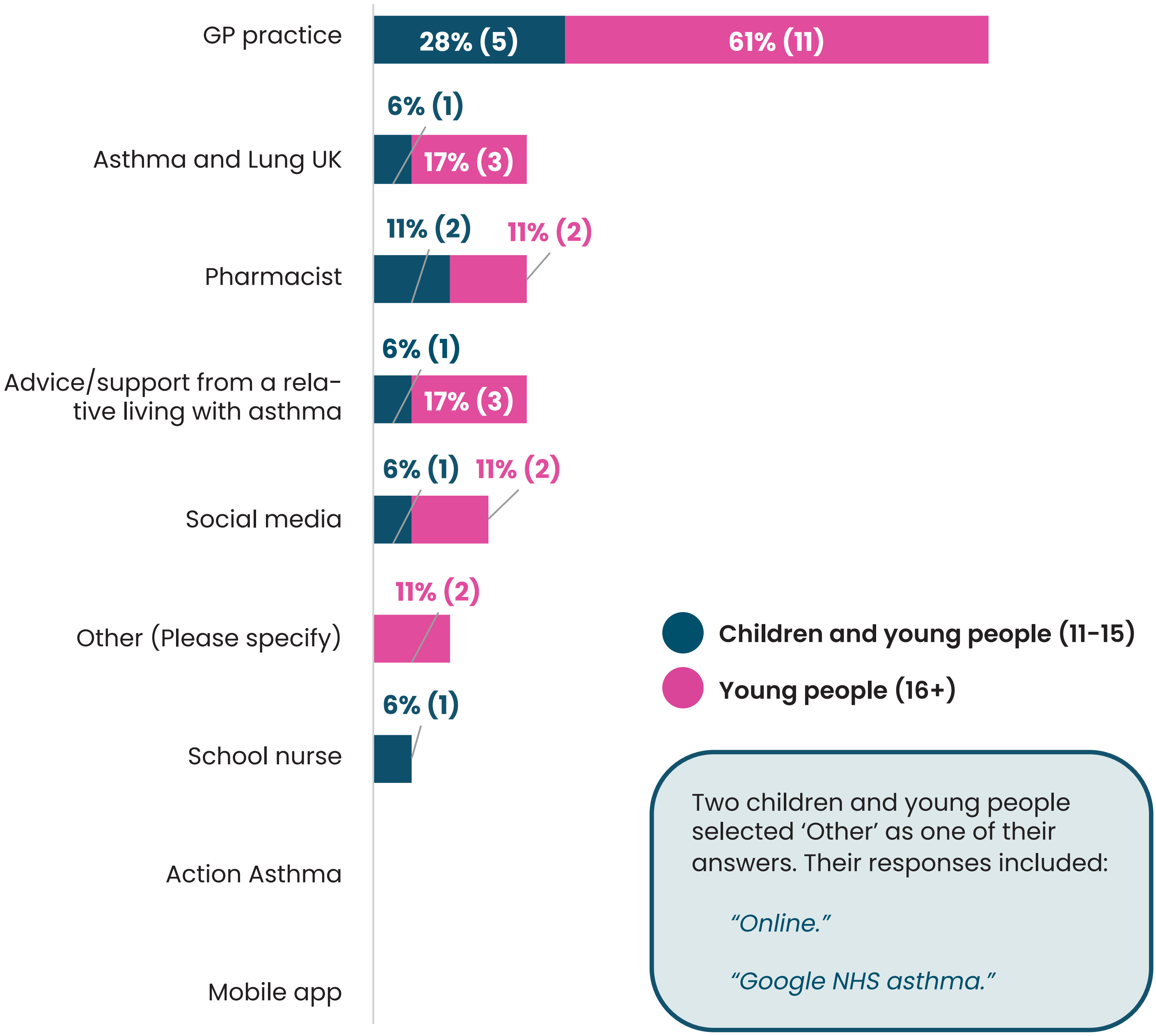
"Asked to be referred back to paediatrician."

"Respiratory specialist doctors."

"Respiratory nurse in London or local consultant."

Graph: 'Where would you and your child be most likely to turn to for advice and help with their asthma?' - Responses from parents, carers and guardians. Based on 96 responses.

Preference for sources of advice - Children and young people



Two children and young people selected 'Other' as one of their answers. Their responses included:

> *"Online."*
>
> *"Google NHS asthma."*

Graph: 'Where would you be most likely to turn to for advice and help with your asthma?' - Responses from children and young people. Based on 18 responses.

Receiving general information

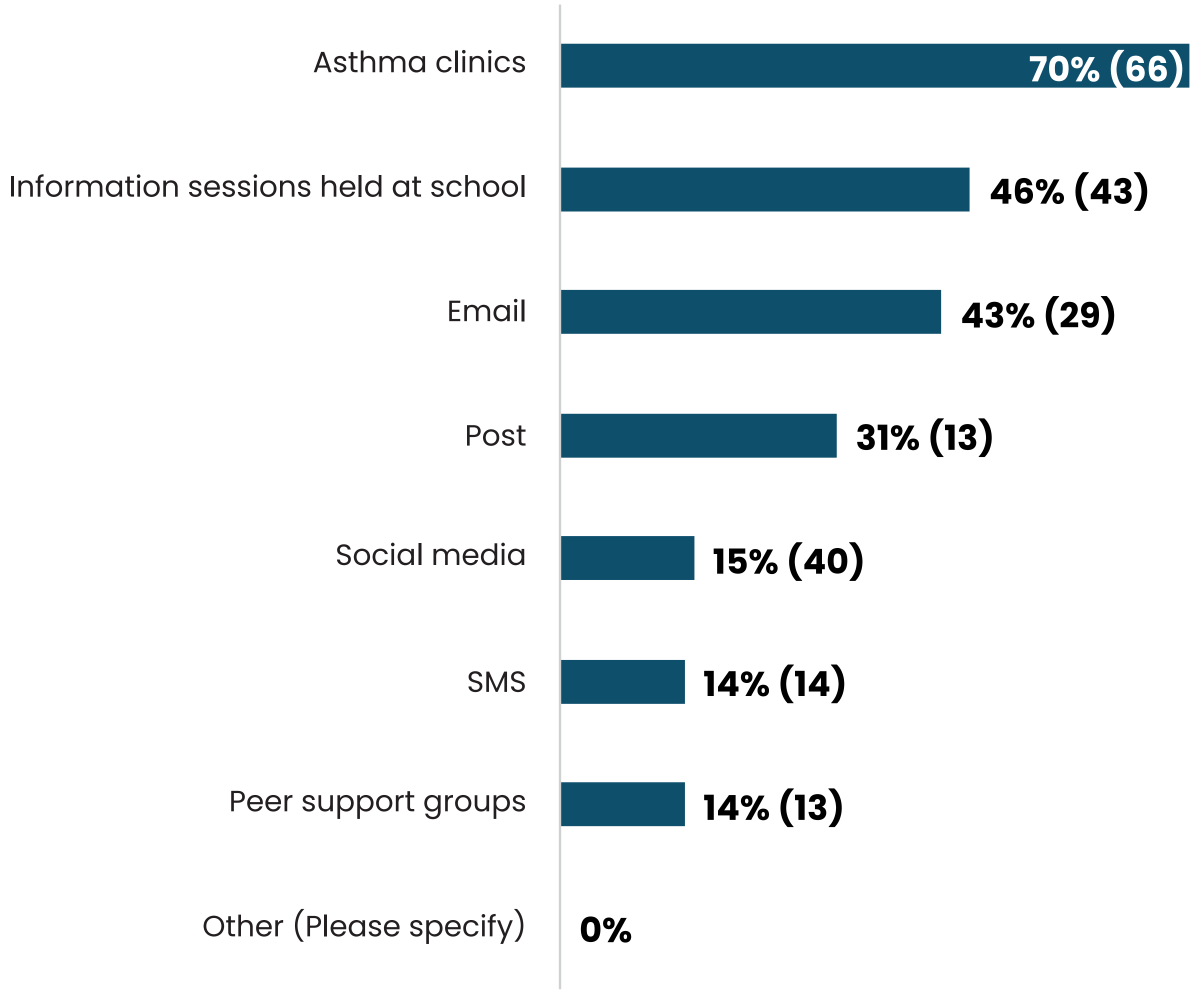
The survey then provided respondents with the opportunity to share how they would like to receive general information about asthma care. Participants were able to choose multiple options. For parents and guardians, asthma clinics was the most popular answer, followed by information sessions at schools and information via email.

Children aged 11-15 selected information from email and social media, followed by asthma clinics and information sessions at schools. For young people aged 16+, asthma clinics was the most popular response. This was closely followed by information via email.

More detail about the responses from all groups is shown in the graphs below and overleaf.

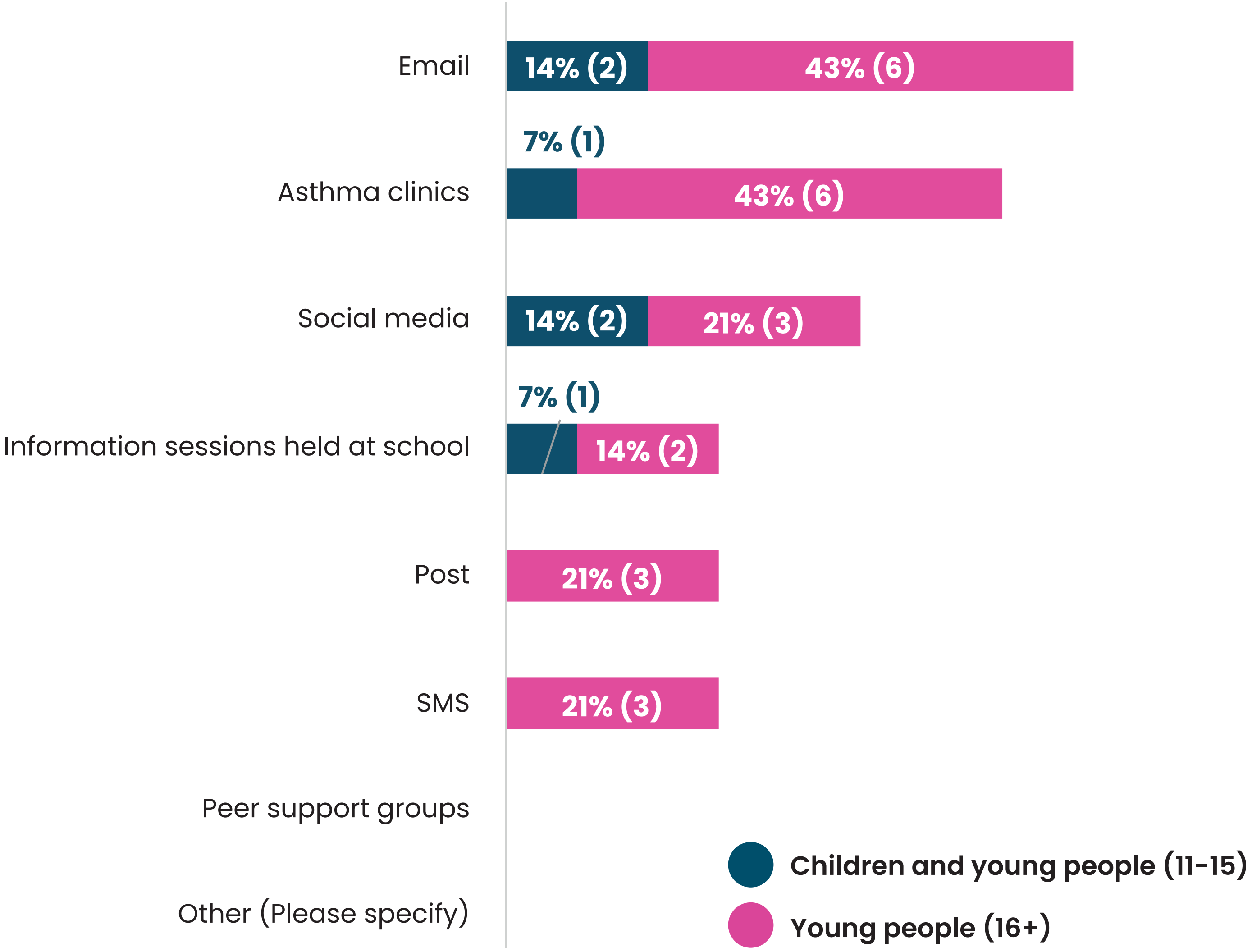
• • • • • • • • • • •

Preference for receiving general information - Parents, carers and guardians



Graph: 'How would you and your child like to receive general information about asthma care?' - Responses from parents, carers and guardians. Based on 94 responses.

Preference for receiving general information - Children and young people



Graph: 'How would you like to receive general information about asthma care?' - Responses from children and young people. Based on 16 responses.

What our interview participants said about accessing information about asthma

The survey responses show that most parents would turn to their GP practice for advice and information to help them manage their child's asthma. However, the reality for the two families interviewed was that the most useful help and advice had come either from informal networks (e.g., colleagues, family members with lived experience of asthma, fitness instructors), or from undertaking their own online research.

> *"I feel quite lucky really, because I understand asthma really well and because I've had so many ups and downs with mine over the years. I know how to deal with it, but other people don't get taught that. Mine's just lived experience."*
>
> *"I had a colleague who is a quite advanced asthma nurse in a practice. I used to tap her up for help. Just saying, 'does this feel right?'"*
>
> *"And then one stage, I found the Asthma UK website and I've been signed up to that ever since."*
>
> *"It was [my fitness instructor], who said about controlling my breathing initially, but then I started looking into it."*

Where parents had sought advice from health professionals they had sometimes found this to be contradictory or lacking in detail.

> *"Seeing someone different each time, and yes, they all kind of said something slightly different and GP's are exactly the same. They're very lovely. They can contradict themselves quite a lot too."*
>
> *"The asthma plan is very basic....It says 'we've agreed that you use your Ventolin as and when needed. We've agreed that you use your steroid inhaler twice a day, 2 puffs a day. We've agreed that if your breathing gets really bad, you go to hospital."*

One family had found the asthma UK website to be a particularly useful resource for more practical tips and advice and identifying little changes they could make which would help her child's condition, however there had been no proactive signposting to this resource.

> *"It's full of information. It's the only website I use and I've signed up to the newsletter and, you know, just little tips and things like that. I think as a parent you think 'what could I do? What else could I do?'. Like for instance, because pollen is a trigger for my child, asking 'have you had a wash?' You know, just make sure you just do basic hygiene factors to try and reduce your risk of having an exacerbation. Yeah, so that's what they're really great for. So yeah, I found that [website] is the only one I use, it's really helpful."*

One Mum reflected that, although she felt confident in managing her child's asthma, when it came to other conditions that her children had, she had found facebook groups to be particularly helpful because they offered practical tips and advice that you can only get from people who are living with and managing the condition. She felt that families where parents were not familiar with asthma may benefit from this type of peer-to-peer support.

> *"I have to say, actually, for other conditions which my children have got, I've found the most information I've found on any of them have been other parents on Facebook groups. Because it's knowledge it's just lived experience... We've had a good year [managing my child's condition] because of information from other people, not even from medical staff or dieticians or anything like that. This is from other people and their own experience. So you can gain a wealth of experience from other peoples lived experience."*

Feedback from the interviews also highlighted the need for wider education about asthma i.e. not just targeted at patients and parents. Grandparents, siblings, friends, schools, leaders of out of school activities, all need to be aware of the dangers of asthma and what they can do to support a young person with asthma.

> *"My blue inhaler, you have to bring it everywhere with you. Even you do, don't you? And you have to bring it everywhere with you, because you never know. And our nan, she used to not bring it, but you ended up telling her that she needs to bring it everywhere, no matter where we go. Yeah, and no matter what it is. And now she does."*

Neither family felt particularly confident that schools knew how to support their children with their asthma. One parent reflected that despite asking for information about her child's condition the school had not engaged the family in any discussion about how they could best support her child. When her child had experienced breathing problems at school, the default position seemed to always be to call the parent to sort the situation out.

> *"I think that's been pretty awful actually. As part of his admission into a school, they send you a questionnaire about your child's health, but not once did the schools contact me about the information I put on those forms and that sort of surprised me. I had expected there might just be a conversation but there wasn't any at any school. He's at college now, and they haven't asked either and it's fine because he knows what to do now and he's big enough. The schools have always had spare rescue inhalers, that's about it really. All of his schools, I think they haven't been great understanding what they need to do. They've always called us. We've been there and we've sorted it out."*

Our youngest interviewee experienced an asthma attack at school, albeit during an after school activity. Despite flagging the situation to her teacher, he was 'too busy' to respond to her request for her inhaler. Fortunately, her parents were on site and managed the situation.

"Not at all, because there's I think there was another time when I was like..... I think it might have been the same time actually.... I went to get my inhaler but because my teacher who was doing the football, he was the ref of the whole match, he wouldn't listen to me because we have to ask to go and get your inhaler from the first aid bag and he wasn't listening to me and he wasn't trying to be mean, but he was guiding the football game. So when I went to actually ask, he was like, 'hang on, hang on, hang on'. And I was like, 'I need it'.

"Mum: Luckily, we were there, weren't we? We showed you how to calm yourself down. Slow your breathing down."

3.8 - Final comments

Parents, carers and guardians were asked for any further comments they would like to make about asthma care for children and young people. Examples from the 14 responses are shown below.

> *"There is a lack of communication between my doctors and the hospital who diagnosed my son with asthma. They were unsure how many times a day/how many MG my son was supposed to have his asthma pump. It's taking a while to even get my prescription." (Parent/ guardian)*
>
> *"Funding for inhalers should be treated as the same as diabetic medication, asthma kills people! Quickly! £10 for an inhaler is expensive." (Parent/ guardian)*
>
> *"Prior to this year my daughters asthma has been controlled for three years. I really feel I need some support at the moment for advice but I have nowhere to turn." (Parent/ guardian)*
>
> *"The teachers at my sons school have no knowledge on asthma and are clearly have no intention of improving. I've said he needs his inhaler before lunchtime play and sport but he's never been given it at school- EVER!" (Parent/ guardian)*
>
> *"My son was diagnosed during the pandemic and although our GP has been amazing when I've needed to speak to them, it's always been over the phone and no check ups have been made." (Parent/ guardian)*
>
> *"A review of asthma within children needs to happen. It should have not have taken as long as it did for us to receive support that has massively made a difference to our lives, also the lack of ongoing support needs to change as well, especially when medication is working. We have no idea how long this will last and my child is becoming increasingly frustrated and I have no way to support them, without risking further attacks."*

“I think that’s been pretty awful actually. As part of his admission into a school, they send you a questionnaire about your child’s health, but not once did the schools contact me about the information I put on those forms and that sort of surprised me. I had expected there might just be a conversation but there wasn’t any at any school.

“All of his schools, I think they haven’t been great understanding what they need to do. They’ve always called us. We’ve been there and we’ve sorted it out.”

What our interview participants said could be improved about asthma care for children, young people and families

Our research participants made several suggestions for improvement that could be made to asthma care. Many of them reflected the ideas already given by the survey respondents, however they did raise some additional issues.

- Ensure families have an asthma plan, that provides enough information for parents to understand what they should do and when.

  > *"We'd have loved to have had that asthma action plan a little bit earlier in his life, because that's the important thing. I think as a parent and as a child to start to understand what does good look like and when you go away from good, what do you need to do and when."*

- Provide more training and information for parent and children about managing asthma attacks, as well as information on how to stay calm during an attack.

  > *"Training videos for parents and different ones for children that are child friendly to show them what to do if they have an asthma attack and if anyone else around them has an asthma attack. They don't necessarily need face to face, long winded conversations taking up staff's time, but videos would be amazing that you can send every newly diagnosed patient links to these videos. Tell them to watch them and say come back to us if you have any questions."*

  > *"People need to know what to expect when it does hit because your instant reaction when you can't breathe…. it's like trying to breathe through a straw, when you're out of breath, so you want to get lots of air in, but it only comes in through a straw. So I think people need to know to expect that. That it's going to be frightening, you know, it's not going to come on gradually. It's going to hit you like a brick wall and you will be scared, but you need to make sure you calm yourself down, but people aren't told what it's going to be like. They're just told that they're asthmatic."*

- Offer physiotherapy to help children strengthen their lungs and to teach them essential breathing techniques that can improve the supply of air to the lungs.

  > *"Courses but more physical. Like a physio therapy. Yeah, but for asthma and how to strengthen your lungs. Like holding your breath longer."*

- Carry out more general awareness raising about asthma, so people are aware of how serious the condition is and how they can support someone who is having an asthma attack.

  > *"I think there should be some people that could volunteer to help. People that actually understand Asthma and they work with the NHS and they go around*

> *like making ads, like the ones for autism, and more things on the Internet and things that explain how to deal with asthma."*

- Improve access to spare medication and equipment. Children and young people lead busy lives, spending time at school, grandparents, out of school clubs and activities etc. It is important that children with asthma have access to their medication (and the equipment to administer the medication) at all times. It is not always practical to carry bulky items (such as spacers) everywhere they go.

> *"With relievers, it's better to have a few of them dotted around the place. So we've drilled it into him that he carries one with him at all times, but that doesn't always happen. But then we have one in the car and then you're like, well, he wants to have probably one at college and one here. And you just think sometimes they said, 'oh, you've ordered a lot'. And I said, 'yeah, it's not because he's uncontrolled, it's because we need to give them to different people' and when I've said that, they've been absolutely fine. I think sometimes they look at the number of prescriptions that been issued for the relievers and think that equals an uncontrolled child when that's not necessarily the case. It could be that you just need to make sure that there's a reliever at granny's."*

> *"The spacers you know, I know the NHS are spending a fortune on prescriptions and they're haemorrhaging money, but we were allowed one spacer on prescription and [my child] spends time in several different locations and it's not practical to take the spacer to school every day and then go to the office at the end of every day, remember to pick it up to bring it home and then take it to her nan's and everywhere else she goes."*

- Improve the taste of the inhalers to make it more appealing for children, and help them get into the habit of taking their medicine regularly.

> *"I would say first of all, make inhalers user friendly. Both children's and adults. They're not the most pleasant experience. Make them taste nice."*

> *"GPs do try to get you off of Ventolin onto Salbutamol, which I believe is less costly. But the taste of Salbutamol was disgusting. They're doing the same job, and I've been told before that they shouldn't taste any different from each other, but they absolutely do taste different, and Salbutamol has got a really strong chemical taste to it. So I've asked the doctors to only give [my child] prescriptions for Ventolin, because it's horrible, and unless they've used it themselves, they don't know that it tastes different, but they don't use them. You know, it's only other asthmatics, understand."*

- Support teenagers to take responsibility for their health, by removing unnecessary barriers. Adolescence can be a difficult for some teenagers, as they start to become more independent and take more responsibilities for themselves. It is important that teenagers with asthma should be supported through this phase, without putting unnecessary obstacles in the way of them managing their health well.

> *"I was told, 'oh, when he hit 16, he has the right to order [his medication] himself, so we remove that right for a parent or carer. I said, 'well, that's really interesting because nobody had that conversation with us. How are we supposed to know that. And I said, oh, OK, well, what do we need to do?' And she said, 'if he gives you permission, you can carry on ordering them until he's 18. So you need to fill in this form, both of you and he needs to bring in some ID. It was a bit of a palaver. But I said, 'well, he's coming for his annual review. Can we bring all the documents in for his annual review? Because it's just getting more difficult to order his drugs. And actually, it should be even easier because with teenagers you shouldn't make things difficult.*
>
> *"We took all the documents in and we got told yes it'll be sorted and then I went to order his meds the other day and. Oh, guess what? It hadn't been sorted… I'm just thinking, if I wasn't such a switched on parent, I do wonder if there are kids that hit 16 that suddenly without them necessarily knowing is a bit of a barrier to them getting them. Medication and whether they would bother and be put off by the barriers that the NHS put in place and I just thought, do you know what it should be just as easy for a 16 year old and a 17 year old and 18 to get access to their medication. And if there is a change in process tell us about it and then we'll work with you. Don't do it unto us and then not tell us and then we have to work through the consequences."*
>
> *"We need to make life as easy as possible for teenagers, and that just felt all very convoluted and complicated, and a barrier to being able to kind of access your normal medicines that keep you well controlled."*

“We’d have loved to have had that asthma action plan a little bit earlier in his life, because that’s the important thing. I think as a parent and as a child to start to understand what does good look like and when you go away from good, what do you need to do and when.”

4. Feedback Centre

Analysis of public feedback gathered on the Healthwatch Suffolk website, including any comments recorded as a part of engagement visits to local hospitals completed by Healthwatch Suffolk.

4.1 - Feedback summary

In addition to the online surveys and the qualitative interviews, Healthwatch Suffolk has analysed comments people have shared about CYP asthma services on the Healthwatch Suffolk Feedback Centre (www.healthwatchsuffolk.co.uk/services). Many of the comments were gathered as a part of engagement visits (coordinated by Healthwatch Suffolk Community Development Officers) to hospitals linked to the project.

The Healthwatch Suffolk Feedback Centre is a platform people can use to find, rate and review any health or social care service in Suffolk. There are more than 20,000 reviews currently listed against hundreds of local services. All feedback is moderated by the Healthwatch Suffolk team to make sure it is not abusive, that it is grounded in a genuine experience of using a service, and that it does not identify any person.

In total, 17 reviews that referenced asthma support for children and young people were exported from the Feedback Centre and analysed to identify key themes and sentiment. All comments were recorded between June 2023 and November 2023.

- Seven comments were recorded as a result of engagement activity undertaken by Healthwatch Suffolk within West Suffolk Hospital Foundation Trust
- Nine people made specific reference to asthma care and treatment for children and young people in their overall feedback about their GP practice. Seven of these comments were about GP practices in west Suffolk and two were for GP practices in east Suffolk.
- One person provided feedback about their experience in hospital, however they did not specify which area this related to.

Analysis of sentiment

Each comment was assigned a sentiment, as follows:

- **Positive –** comments that were positive about the asthma care received.
- **Mixed/ Neutral –** comments that were either mixed in their feelings about the asthma care and treatment received, or comments that did not express a view.
- **Negative –** comments that were negative about the asthma care and treatment received.

Overall, six people left comments that were positive in sentiment. Five people complimented, and expressed gratitude for, the care and support received from their GP practice. Regular reviews, access to appointments and being seen quickly were highlighted within these comments as being particularly helpful.

One person reflected positively on their entire asthma 'journey', including having an asthma plan that they felt 'comfortable with', the speed and responsiveness of professionals to any issues they had, the treatment they had received (despite the lack of diagnosis) and the positive attitudes of staff within the hospital.

Seven people left negative comments about the asthma care and treatment they and their child had received. These comments reflected similar themes to those already heard from respondents and are outlined in more detail in the analysis of themes below.
Three of the comments left on the feedback centre were mixed in sentiment. In each instance the person providing the feedback had reflected on their broader 'asthma journey' rather than a specific incident or service. As a result, they reported that some aspects of the care and support they had received had been good whilst they felt improvements could have been made in other areas. These issues are explored in more detail in the analysis of themes below.

One person simply gave a factual account of the care and support they had received to date. They did not express any opinion about whether they felt this to have been good or not.

Analysis of themes

Comments on the Feedback Centre, generally reflect the same themes reported by those who responded to the survey.

Primary care

Nine people mentioned the care they had received from their GP. While five were generally satisfied, four reported difficulties in accessing GP or face to face appointments.

> *"Children are seen very quickly and their asthma is dealt with well by the doctors and if anything happens they are seen quickly and I've been very happy with the care."*
>
> *"We've had very good asthma care for our child, with regular reviews and great advice from the nurse we see. Very pleased with all the care received."*
>
> *"I really can't fault the care the surgery provide for my asthmatic children. We are here regularly and it works so well to get the appointments for them when they are needed."*
>
> *"Asthma care for our child has all been on the phone and since diagnosis we've not had a face to face appointment, even though we've had A&E visits."*
>
> *"We've had to wait three days to get children seen. We called on Friday but nothing was available, called again Monday, got through at 9am saw a pharmacist but was given nothing more than over the counter medication to help with our child's breathing. Also seen a nurse and been given a wrong diagnosis and I don't like that care navigators are deciding who you get to see."*

Getting a diagnosis

Four people commented on getting a diagnosis. Two had yet to be formally diagnosed, though they were both being treated for asthma/had been given an inhaler. The age of the child was given as the reason for a lack of diagnosis in one instance.

Of the two cases where a diagnosis had been given, one had received their diagnosis from the hospital, following multiple visits to A & E with breathing difficulties. The other felt that their

> *"We are quite sure that our 7 year old son has the beginning symptoms of asthma, his dad and his granddad both have it and his dad thinks he might have it starting.*
>
> ***"But we cannot seem to get past the care navigators yet to even see a GP about my concerns. We will keep trying I just want to have some peace of mind on this."***

GP had not listened to or taken their concerns seriously and had labelled their child as simply 'attention seeking'.

> *"We know that he can't get a formal asthma diagnosis until he is 6 years old, but we are nearly there and they seem as though they are treating him for asthma already."*
> *"No formal diagnosis given still, but we have an inhaler."*
>
> *"I didn't use the GP for a diagnosis, I actually had to take my son on 4 or 5 separate occasions to A & E at WSH with his symptoms. It was the WSH who gave a diagnosis of asthma eventually."*
>
> *"They took ages to diagnose my child with asthma stating that they were 'attention seeking.' Eventually we were able to get peak flow tests done on a week schedule at home putting the results on a chart and they could clearly see that there were issues. Just could have done without the 'fight'."*
>
> *"We know that he can't get a formal asthma diagnosis until he is 6 years old, but we are nearly there and they seem as through they are treating him for asthma already."*

Asthma plans

Of the six people who mentioned asthma plans within their feedback, four were generally satisfied, and one felt their existing plan needed reviewing and amending. The remaining respondent commented that the lack of a formal diagnosis had prevented a 'plan' being written.

> *"She has an 'asthma plan' in place and we are happy with it."*
>
> *"I know what to do to support my son as needed. He has an asthma plan and the guidance within it I am comfortable with."*
>
> *"We have an asthma plan and we are comfortable with it."*
>
> *"We have an asthma plan but we want a new one so hopefully I will be able to discuss that at my appointment today."*

> *"This has been going on for some months, and it is hard to know as a parent how to manage it and what to do when no formal diagnosis is made. When they have a cold/cough this is loosely when things get worse, but there is no 'plan' due to no diagnosis."*

Training

Two people felt there should be more training and information for parents, to enable them to support their child more effectively.

> *"I do feel that the education for parents aspect is missing, as I am not 100% sure when she needs the medication."*

> *"I do feel that it would be helpful if training was given to me and my husband on using the spacer, as my son is very young and does not like the spacer, he doesn't understand it is to help him. So, some face to face training to show us how we do this especially when he is screaming and wriggling, would be very useful because I am concerned ,that he is not actually taking all of the medication he needs. He is obviously getting some, as there is an improvement. Even a YouTube instructional video would have been helpful to us. Also the spacer requires a weekly thorough clean which was never pointed out to me."*

Access to medication

Four comments were made about access to medication and equipment (e.g., spacers). Two respondents felt limits placed on the number of inhalers and spacers were unhelpful or unsafe. The remaining two respondents would have liked access to, or changes made to, medication earlier.

> *"We are only given one spacer per year, but I think it would be good to be given two so that there is a spare back up one."*

> *"I don't feel that a family members asthma is being well monitored. They have chronic asthma but the number of inhalers is being limited and they are only allowed a certain number a year."*

> *"I would have preferred it if the hospital A & E had changed her medications rather than have to wait to see the GP for them to do it."*

> *"If I was going to suggest one improvement, I would have wished for my son to have been given a 'preventer' to use sooner, on one of the earlier A & E visits, as the 'preventer' has been very helpful to him."*

“We’ve had very good asthma care for our child, with regular reviews and great advice from the nurse we see. Very pleased with all the care received.”

5. Key learning

Areas of key learning regarding asthma care and support for children, young people and families in Suffolk and north east Essex.

5.1 - key learning for systems and services

After engaging with children, young people and their families in Suffolk and north east Essex, it is evident that having access to clear and transparent information about asthma care is vital. Please see each of our headings below for more detail about key learning from the experiences people have shared as a part of this project.

Getting a diagnosis

Some parents, carers, guardians and young people felt that it had taken a long time to receive a diagnosis of asthma despite having symptoms. Where people gave a positive experience of diagnosis, their experience tended to reflect being promptly diagnosed after a short number of visits to either primary or secondary care. Some felt they were not listened to or believed about asthma symptoms.

It is clear from the experiences shared that people have varied, and inconsistent, experiences of getting an asthma diagnosis. And whilst some had found the process 'easy' because symptoms had been clear, two in five (39%) said it had been 'difficult' to get a diagnosis. In some cases, diagnosis appeared to be dependent on specific professionals who had taken the time to fully assess patterns of repeated visits to services or diagnosis had been in response to an urgent admission to hospital.

People's understanding of how clinicians assess the likelihood of asthma to make a diagnosis could be improved, and it was clear from responses that people sometimes interpreted treatment for potential asthma symptoms as being the same as a formal diagnosis.

It is difficult to address some of the challenges associated with providing a quick and accurate diagnosis due to the variability in symptoms, families expectations and difficulty providing a diagnosis at a young age. Ensuring that parents, young people and professionals are clearly informed about the signs and symptoms of asthma would help to improve communication and understanding between all of these groups. Better communication overall across services and clinicians will help families to understand more about the process, and advocate for themselves around getting a diagnosis.

Asthma Plans

An asthma action plan supports patients to take the right actions at the right time and lowers the risk of a potentially fatal asthma attack. This is supported by a recent NHS campaign ('Ask About Asthma Week') which highlighted how a written asthma action plan drawn up between a healthcare professional and patient means people are four times less likely to have to go to hospital for their asthma. Yet, findings indicate that almost two out of every five (39%) children and parents were unsure, or did not have an asthma plan in place.

The need for better asthma planning is noted in the national Bundle of Care, which states:

> *"All CYP with asthma should have a Personalised Asthma Action Plan that is developed collaboratively with them and their significant others… ICS' should ensure these tools are made available to healthcare professionals working with CYP with asthma." (P.26 National*

Bundle of Care for Children and Young People with Asthma: Phase one).

Systems and services should therefore continue to promote the use of this important tool, and make it a central focus of the support offered to every child, young person, and family. The conversation about having an asthma plan should start at the point of diagnosis, with patients and families fully informed about why having a plan in place is important.

A child's asthma plan should be referenced whenever practical, and at every contact with professionals providing asthma care and support. It should be portable and shared (with the permission of the child, young person and their parent, carer or guardian) with professionals responsible for their care at school, in hospitals, and in primary care. If possible, changes in a child or young person's condition should be noted at key moments and their plan updated.

By being given a personalised asthma plan that is regularly reviewed, CYP and their families will have a structured approach to managing their asthma. This will increase their confidence in using their medication, help them understand what their potential triggers are and what they should do if they were to have an asthma attack.

There are three key aspects to consider:

1. **Having a plan –** Professionals need to make sure every patient and family has an asthma plan in place, as early as possible and from the point of receiving a diagnosis.
2. **Making sure plans are accessible and understood –** Asthma plans need to be fully accessible, provided in a format appropriate to the communication needs of the child, and their parent, carer, or guardian, and professionals need to make sure people understand the information in them (including any details about prescribed medication, and how to ask for a review).
3. **The plan should be monitored -** Asthma plans should be regularly reviewed, and children and young people's asthma should be monitored regularly to align with their changing care needs.

Compliance with the NHS Accessible Information Standard

All NHS and social care should be fully accessible to those who have specific communication needs and preferences. Although we did not explore accessible information needs as a part of this project, Healthwatch Suffolk and Healthwatch Essex have extensive evidence about the impact of poor compliance with accessible information standards on people's care and support.

In some cases, problems with contacting services and receiving accessible care has had serious consequences for people's condition, treatment and wellbeing. Please see:

- Experiences of people who are d/Deaf or hard of hearing in Suffolk, and top tips for services to provide better care and support (Healthwatch Suffolk): https://healthwatchsuffolk.co.uk/your-care-your-way/aissurveyresults/
- Experiences of people who need accessible information and support (Healthwatch Suffolk): https://healthwatchsuffolk.co.uk/news/your-care-your-way-experiences/
- Information about the national picture from Healthwatch England: https://

healthwatchsuffolk.co.uk/news/is-the-nhs-meeting-peoples-needs-for-accessible-information-the-national-picture/

Accessible information and care is not optional, it's the law.

Services are required to provide alternative formats of information to meet the needs of children and families, such as braille, large print, and easy read. They must also support people to communicate, for example by arranging a British Sign Language (BSL) interpreter, deafblind manual interpreter or an advocate. Therefore, signposting to a single format of asthma planning will not adequately meet the needs of every child, young person, or family.

Children and young people with disabilities, or accessible information needs, must receive asthma plans and care that is appropriate to their communication and support preferences. Healthwatch Suffolk has content available online to support people's understanding of their rights to accessible information, care and support under the NHS Accessible Information Standard. Please see https://healthwatchsuffolk.co.uk/your-care-your-way/knowthefiverights/.

The following poster can be shared or displayed in local services: https://healthwatchsuffolk.co.uk/aisresources/

Medication management and reviews

The 'national bundle of care for children and young people with asthma' highlights the importance of effective medication management in preventing the exacerbation of the patient's condition and in avoiding unnecessary hospital admissions.

> *'Poor adherence to preventer treatments from any cause, intentional or non-intentional, is associated with worse outcomes. An essential element of any prescription for inhaled therapies includes a consideration of the drug, the device and the training. Without education and training inhaled treatments cannot be reliably delivered to children. Effective delivery of medication to the lungs of younger children and infants requires the use of spacer device. Neither inhaler types or spacer devices are interchangeable without additional training and education and inhaler technique should be checked regularly.'*

It also establishes a clear expectation that 'all CYP with asthma should undergo a structured review at least annually. However, the feedback from the surveys was clear that parents and young people do not feel that their asthma or medication use is reviewed often enough.

- 30% of respondents said that they/their child had not been shown how to use their inhaler.
- 48% of children, parents and guardians, felt children and young people's asthma was not monitored regularly enough.
- When asked what could be improved about asthma care, over a quarter of respondents mentioned wanting more regular asthma reviews.
- Some respondents also indicated that it would be helpful for people to have access to more medication or equipment. For example, that children and young people should have access to more than one inhaler and spacer for use at home or in schools.

Systems and services must ensure that children, young people and families receive clear and accessible information about their medication, and the use of inhalers. Ideally, this should include demonstration of how to use inhalers with a spacer, with reference and signposting to ongoing sources of help and information families can refer to if they have a concern. As with the content of asthma plans, any such resources must account for the specific needs and communication preferences of the child, young person or their parents, carers and guardians. People should also be informed about how they can request a review of their medication if symptoms of asthma do not change or improve.

Asthma Attacks

Parents and young people often lacked the information they needed to be able to feel confident when managing an asthma attack.

Professionals, including GP's and asthma specialists play an important role in explaining to CYP, and their parent or guardian, what to do in the event of an asthma attack. Professionals can check that patients have understood the information they are given about asthma attacks, and build their confidence by including information about asthma attacks as part of regular reviews.

Clear educational materials, as well as an accessible asthma plan, could help young people, parents and schools to understand what is 'normal' for a young person with asthma and when they should seek additional support. Information could also be provided to help people understand potential triggers, and how to mitigate for these, for example, pets, housing or parental smoking.

Information about managing an asthma attack could be presented as a checklist or symptom progression (e.g. breathing changes, peak flow levels). These should be available in multiple formats, for example simple hard copy resources or online video content. It should be tailored to suit individual communication needs.

Health services could also be more proactive in sharing existing resources, for example those provided by Asthma and Lung UK and locally developed information (e.g., the 'Jot the Robot' resources created by Suffolk County Council). Healthwatch Suffolk has a page with links to multiple sources of information around asthma care and support for children and young people. Please visit https://healthwatchsuffolk.co.uk/signposting/cypasthma/.

Hospital care and follow up

The crucial recommendation from this research for hospital care for children and young people with asthma is to improve the access to a follow up review with a GP.

The National bundle of care for children and young people with asthma says all children and young people discharged from hospitals should undergo a review within 48 hours by an appropriately trained clinician in primary care. Yet, only 49% parents and guardians (24 of 49) and 25% (one of four) young people aged 16+ who had been admitted to hospital had a follow up review with their GP. Of these, only two parents of 23 said they had received the review within 48 hours.

These findings demonstrate how lack of primary care follow-up remains a concern in the care and support of children and young people with asthma. This is a critical opportunity to take the time to review the asthma plan of children and young people who have experienced a sudden exacerbation of their condition in order to avoid future admission to hospital. Communication should extend from hospital, to primary care, and to schools in order that all concerned with supporting the children and young people affected can contribute to meeting any changes applied to asthma plans.

Although this research does not explore this link between primary and secondary care, the bundle of care lists possible reasons for this as:

> *"A lack of standardised discharge pro-forma… as well as poor primary and secondary care interface, including IT systems." (P.26 National Bundle of Care for Children and Young People with Asthma: Phase one).*

However, people's overall experiences of receiving asthma care and treatment in hospital were generally positive. It was clear in the responses that many had found the experiences of receiving hospital treatment for their child difficult emotionally, however, most reflected that they had received the treatment that they needed.

Positive experiences of hospital care often related primarily to receiving prompt and effective treatment. For some parents, hospital admission had provided their route to diagnosis. Some negative experiences were linked to accurate diagnosis and treatment. Improving hospital staff's understanding and awareness of asthma could contribute to improving patient outcomes and ensuring that patient's feel their concerns about asthma are heard.

Access to appointments

Health services should be flexible and responsive to children and family's needs when offering appointment times for asthma treatment and care. Just over a third of young people and parents said that they had been unable to access an appointment because the times they were offered were in school or college times. A quarter said that they had been offered appointments during times that parents were at work.

While urgent treatment or testing may sometimes take priority over attending school, every reasonable effort should be made to schedule routine care, such as clinics, or appointments with an asthma specialist at times that are easily accessible for parents and young people.

Its notable that over two thirds of people felt that they had not received an appointment for their asthma. Another one in five said there was no asthma specialist at their GP surgery. This is perhaps not surprising given that we understand provision of asthma specialists or clinics specifically for children and young people in SNEE is limited. Local commissioners could consider developing these roles in order to address some of the challenges associated with appointment times, provision of asthma plans, and regular monitoring and review for young people with asthma.

Promoting general awareness of asthma

Although most of the recommendations of this report focus on the children and families with a diagnosis of asthma, it was clear throughout the findings that there is a general lack of awareness of asthma symptoms and management in the SNEE community.

Communicating information generally about the signs, symptoms and effective management of asthma could help to address a number of challenges children and families highlighted.

Firstly, and perhaps most crucially, schools and school staff must receive adequate information or training on how to support children with asthma and recognise the symptoms of exacerbations and triggers. Provision of an asthma plan is an essential part of informing schools, however, schools could also benefit from other resources giving them the information they need to better support children and young people with their asthma generally.

Secondly, providing information to the SNEE community more widely (for example through information campaigns or other methods), would help to ensure that:

1. Parents whose children do not currently have asthma understand the symptoms and seek help where required, in line with the findings around diagnosis.
2. People in the community have an awareness of asthma, and how to support young people if they experience an asthma attack.

This general information could be targeted to locations in the community that have contact with young people, such as youth groups, scouts, cadets and sports clubs.

A big thank you to everyone that has supported this work, or taken the time to share experiences with Healthwatch Suffolk or Healthwatch Essex. More information about the project can be found on **https://healthwatchsuffolk.co.uk/cypasthma/**.

healthwatch Essex healthwatch Suffolk

We will be making this report publicly available by publishing it on the Healthwatch Suffolk and Healthwatch Essex websites.

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