



Children and young people's asthma support

Norfolk and Waveney

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healthwatch
Suffolk

Trusted Insights

Contents

Navigate this report.

Content	Page number
1. About this report	4
Our approach and method	5
Co-production and project development	6
2. Who took part?	8
3. Key findings	12
3.1 - Getting a diagnosis	13
3.2 - Asthma medication	16
3.3 - Asthma plans	17
3.4 - Improvements to asthma support	20
3.5 - Asthma attacks and triggers	22
3.6 - Hospital care	28
3.7 - Primary care follow-up	29
3.8 - Information about asthma care	30
4. Key learning	34

Acknowledgements

Healthwatch Suffolk 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 to our survey and engagement events.

This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Suffolk 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 and Healthwatch Suffolk CIC. Find out how we worked together to capture people's experiences of local asthma support for children and families.



1.1 – About Healthwatch Suffolk

Healthwatch Suffolk CIC is a social enterprise delivering trusted insight and evidence to influence standards of health, care and wellbeing support.

We passionately believe that listening and responding to people's lived experiences is vital to create health and social care services that work for everyone.

Our approach is founded on locally defined principles of co-production, and ten years of development on research and engagement practice. The Healthwatch Suffolk team is adept at working in partnership to bring people's experiences, including those of the health and social care workforce, into the decision-making of health and care leaders, commissioning bodies and other authorities.

With an extensive reach into local communities, and staff with the right mix of skills, the Healthwatch Suffolk team can support evidence-based service design and commissioning.

Through a combination of surveys, interviews, and other methods, we are able to bring people's experiences together in an impactful way and share them with those who can make change happen.

We always have impact in mind, ensuring our projects are planned and delivered together with local people and system leaders, wherever possible. That includes the development of any recommendations for improvement or change.

The delivery of our projects and services is underpinned by a commitment to transparency and inclusivity in everything we do. We want everybody to feel equally valued, listened to, seen and heard, and we are prepared to respond when people tell us we can do better.

If you have a question about Healthwatch Suffolk, it is also possible to make enquiries of our team by email to research@healthwatchsuffolk.co.uk, or by calling freephone 0800 448 8234.

- 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

1.2 – Our approach and methodology

Healthwatch Suffolk was commissioned by the Norfolk and Waveney Integrated Care Board (ICB) to explore people's experiences of support for children and young people with asthma (aged 5-18) in Waveney.

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 to plan asthma care and support for children and young people in the future.

Co-production and project development

This project was developed further to a joint project coordinated by Healthwatch Suffolk and Healthwatch Essex about experiences of children and young people's asthma care and support in Suffolk and north east Essex (SNEE), commissioned by the SNEE ICB.

The publication of this report (featuring responses from 25 parents, carers and young people) adds to 149 responses gathered by the two local Healthwatch across several research methods (a survey, interviews and through engagement in local acute hospitals). The findings of both projects feature themes and key learning that is applicable across all parts of Suffolk, and further afield.


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

Post co-production, Healthwatch Essex led on the development of an anonymous online survey (in partnership with Healthwatch Suffolk) that has subsequently been adapted for use across Waveney. The survey could be completed by parents, carers, guardians, children and young people, and featured routing to manage ethical and GDPR considerations that applied differently to each group.

Sharing the survey

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

- Social media activity, including promoted posts on Facebook and Instagram.
- The Healthwatch Suffolk website, and newsletters.
- Communication activity by the Norfolk and Waveney ICB communication team.
- Leaflets were distributed widely to contacts in communities (e.g., Libraries and local networks), 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. The survey was featured prominently on local GP practice websites.



Learn more about this project, and find information about sources of help for children, young people and families on <https://healthwatchesuffolk.co.uk/cypasthma/>

2. Who took part?

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

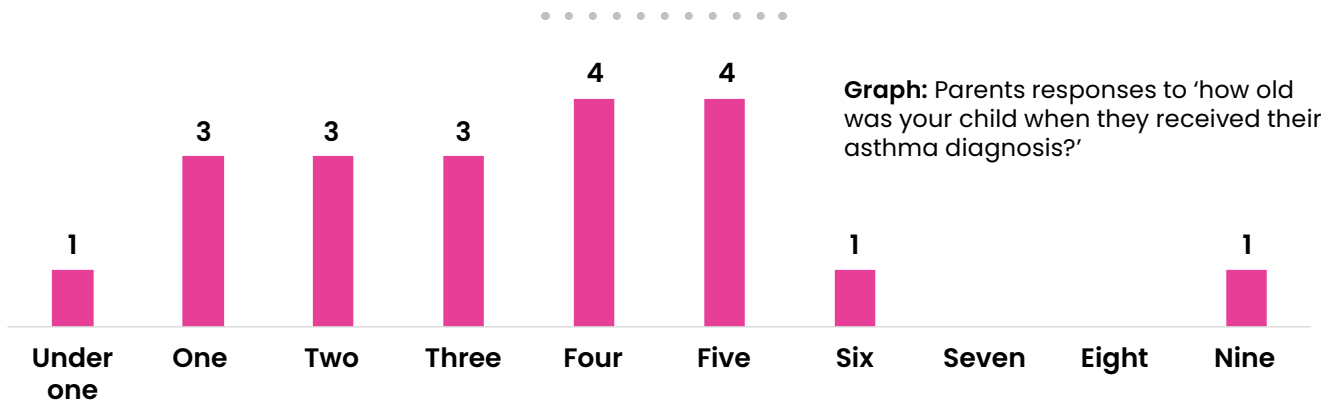


2.1 – Survey participants in Waveney

Twenty-two parents, carers and guardians, and three children and young people (aged 16 or above) responded to the anonymous survey. The survey ran from 8th September to 10th November 2023.

Age of diagnosis

Parents, carers and guardians were asked how old their child was when they received their asthma diagnosis. Most responses indicated children were six years old or under when they were diagnosed. Their responses are shown in the chart below.

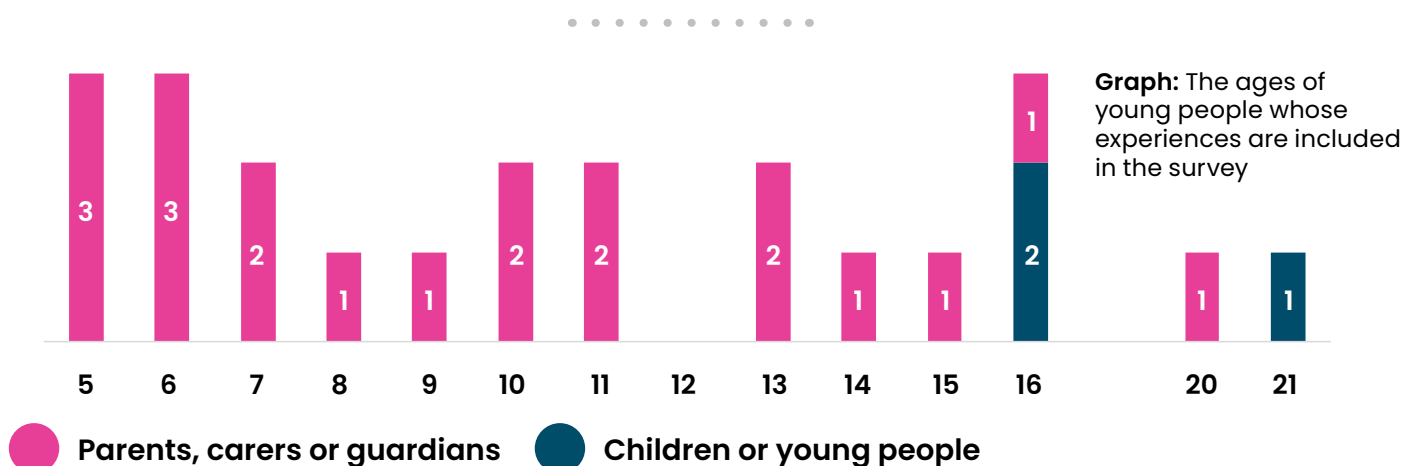


One parent, carer or guardian said their child was 'not officially diagnosed'.

Two children or young people responded to the question about when they had been diagnosed with asthma. One was nine when they were diagnosed, and one was 19 when they were diagnosed.

Current age of children and young people with asthma

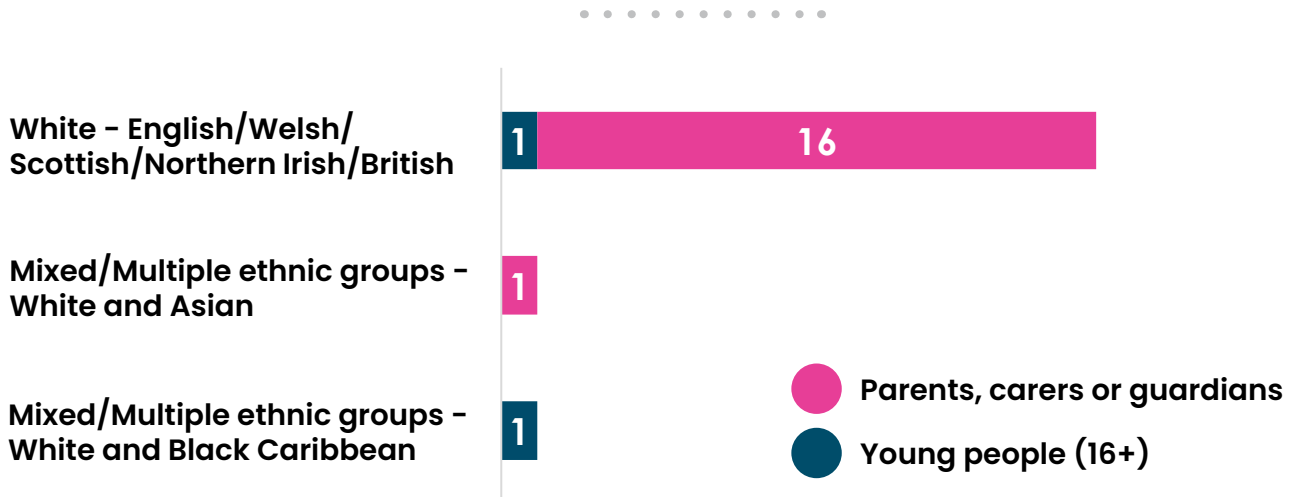
In total, 20 parents and three children or young people answered the question 'How old are you/is your child now?'. Their combined responses are shown in the chart below.



The ethnicity of children and young people with asthma

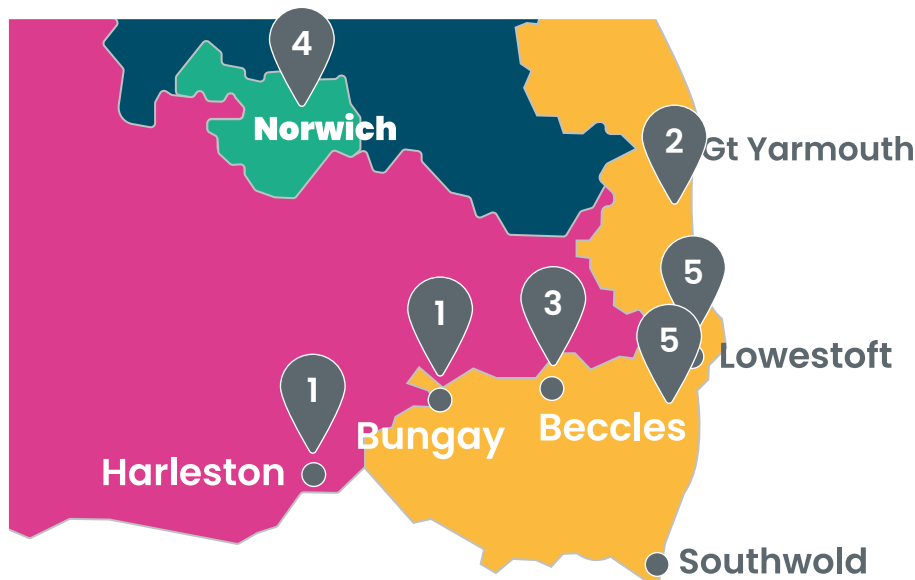
Seventeen parents, carers and guardians, and two children or young people answered the question ‘Which of the following best describes your or your child’s ethnicity?’

Their combined responses are shown in the chart below.



Graph: The ethnicity of young people whose experiences are included in the survey.

The location of respondents



Responses were gathered from across both Norfolk and Waveney. See the table below and map left for more detail.

Location	No.
Lowestoft	5
Pakefield	5
Beccles	3
Norwich	3
Bungay	1
Drayton	1
Redenhall with Harleston	1
Gorleston-on-sea	2

Graphic: The location of respondents.

Although the project was focused in waveney, wide promotion meant that people responded from both Norfolk and Suffolk postcodes.

“The process wasn’t easy as at the time a lot of the doctors and specialists etc didn’t believe it could be asthma. They just thought I needed to become more active. It took a good year or two and I finally got the diagnosis. Since then, the care has been outstanding they are really proactive with appointments and anything that may need adjusting to my care.”



3. Key findings

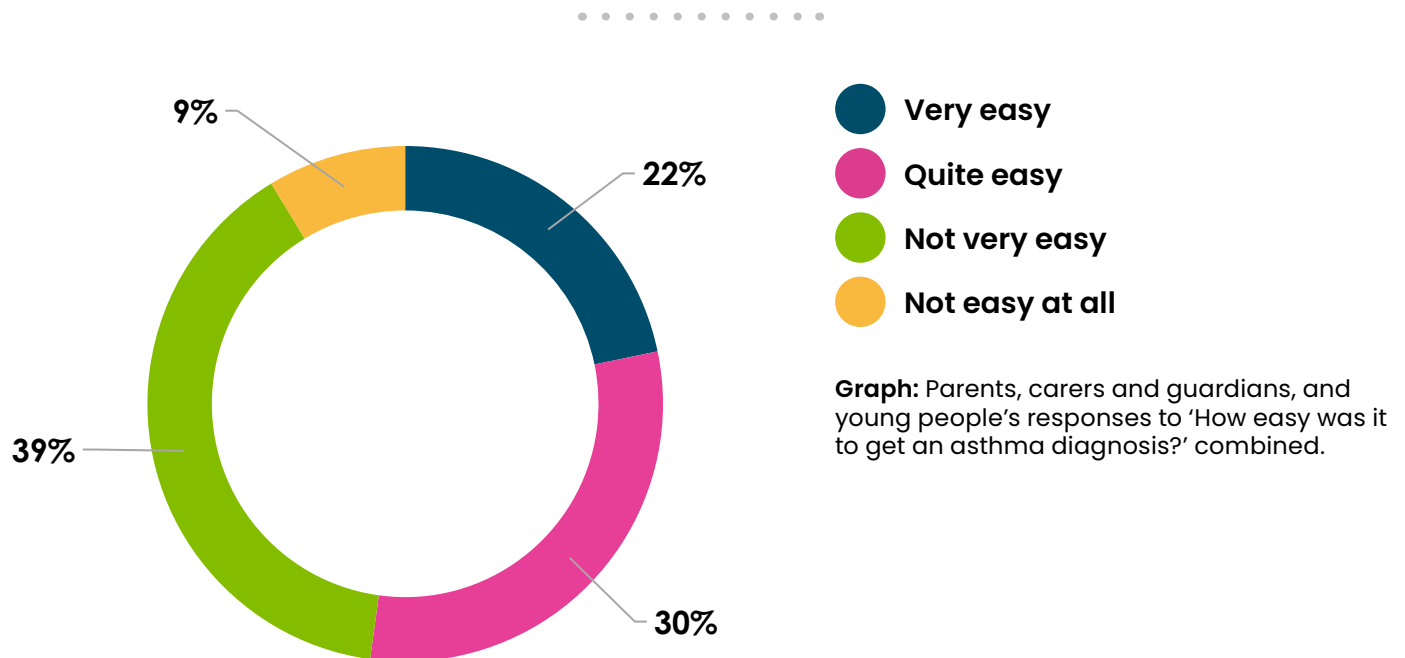
This section will share each of the questions asked and the responses that were received.



3.1 – Ease of getting a diagnosis

Twenty-one parents, carers and guardians, and two children and young people, answered the question 'How easy was it to get an asthma diagnosis?'

Their combined responses are shown in the chart below.



Of the twenty-three parents who responded:

- Two said it was 'Not at all easy' to get a diagnosis,
 - Nine said it was 'Not very easy',
 - Seven said it was 'Quite easy' and;
 - Five said it was 'Very easy'.
-

Qualitative insights – getting an asthma diagnosis

Nineteen parents and two young people also left a comment about their experience of getting an asthma diagnosis. Their comments are summarised below according to how easy they said it was to get an asthma diagnosis.

Four parents who said getting an asthma diagnosis was 'Very easy' indicated that they had received testing and a diagnosis promptly after noticing symptoms.

"After sports my daughter felt breathless. As a parent with mild asthma, I was able to recognise the symptoms. The nurse practitioner at our GP tested and diagnosed asthma." (Parent/ guardian)

"Diagnosed after being admitted to hospital. Breathing deteriorated over course of a day. GP accessible and confirmed diagnosis promptly after discharge." (Parent/ guardian)

"Child had first asthma attack at 3 years old, took to doctors and they sent him to hospital!" (Parent/ guardian)

Six parents who said that they had found it 'Quite easy' to get a diagnosis of asthma for their child left a comment.

Most of these comments implied that it had taken multiple occurrences of symptoms, appointments, or hospital admissions to get an asthma diagnosis. Two noted that their child or young person's symptoms could be worse in the winter. Two mentioned that their child had been diagnosed after symptoms responded to inhaler use.

"My son had various episodes when he was little where he was struggling to breathe. He was hospitalised, the first time when he was a baby and a further 2 times when he was a toddler... When he was five, he was diagnosed with asthma." (Parent/ guardian)

"After repeated visits to the GP with suspected chest infections and regular night-time waking through persistent coughing the GP suggested trying a ventolin inhaler to relieve symptoms. After this had worked for a period, the doctor diagnosed asthma." (Parent/ guardian)

"It was clear from an early age my son had asthma, after continuously being admitted to hospital in the colder months he was referred to the asthma clinic quite quickly." (Parent/ guardian)

Eight parents, and two children or young people, who said that they found it 'Not very easy' to get a diagnosis of asthma left a comment about their experience.

One child/young person said they had multiple blood tests and experiences of breathing difficulties before receiving a diagnosis. Another felt they had not been believed by doctors and specialists.

"I had many blood tests, and after many throat infections and difficulties breathing and appointments I was diagnosed with it in the end." (Child or young person)

"The process wasn't easy as at the time a lot of the doctors and specialists etc didn't believe it could be asthma. They just thought I needed to become more active. It took a good year or two and I finally got the diagnosis. Since then, the care has been outstanding they are really proactive with appointments and anything that may need adjusting to my care." (Child or young person)

Three parents reflected on having multiple appointments with the hospital and GPs before being diagnosed with asthma. Two felt that their GP had not provided easy access to a

diagnosis, but they had received a diagnosis from an asthma or allergy nurse. Two parents said their child had been diagnosed after an emergency admission to hospital, one of which reflected on an experience of waiting for an ambulance for an asthma attack during COVID.

"We were backwards and forwards to GP and hospital and just kept being pushed from pillar to post." (Parent/ guardian)

"Multiple hospital admissions with my eldest. It was the doctors that diagnosed as he just coughs constantly without his inhalers. And my youngest got hospitalised with an asthma wheeze and the asthma clinic seen him." (Parent/ guardian)

"Daughter had croup on numerous occasions. I explained to doctors that asthma runs in the family... was sent on my way a few times until a nurse practitioner recognised my daughter having asthma... when I explained what has happened in previous appointments the nurse tried my daughter on the inhalers and they worked well." (Parent/ guardian)

"Asthma attack occurred (not aware it was an attack as never seen one) rang 111, waited five hours for ambulance as it was COVID time... she was lethargic and heavy breathing, rang 999 as she was struggling with breath, ambulance came, put mask on her, went to hospital where it was a toss up between whooping cough or asthma. Three hours later it was asthma which was eight hours after initial attack." (Parent/ guardian)

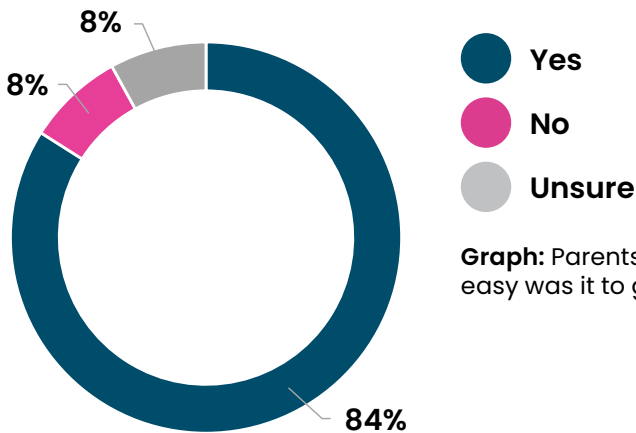
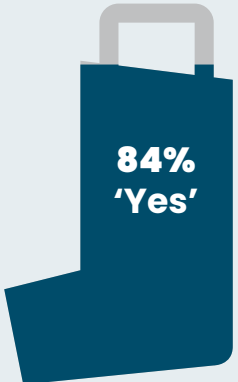
3.2 – Asthma medication

Having medication explained

Twenty-two parents, carers and guardians, and three children and young people, answered the question 'Has a professional explained to you and your child what asthma medicines they have, what they do and how/when to use them?'

Their combined responses are shown in the chart below.

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



Graph: Parents, carers and guardians, and young people's responses to 'How easy was it to get an asthma diagnosis?' combined.

The three young people were evenly split in their responses, with one indicating 'Yes', a professional had explained their medicines, and another indicating 'No'. A third young person was 'Unsure'.

The majority of parents, carers and guardians (20) said a professional had explained their child's asthma medicines to them. Two said 'No', and one was 'Unsure'.

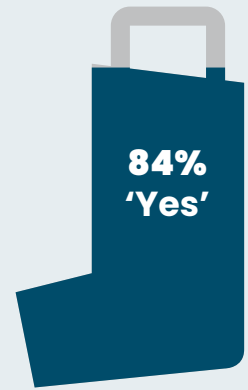


Parents, carers and guardians were asked about whether a professional had shown their child how to use a spacer. Twenty-two people responded.

Nineteen said 'Yes', one said 'No', and two were 'Unsure'.

Parents, carers, guardians and young people were asked about whether a professional had shown them or their child how to use an inhaler.

- Of the twenty-two parents who responded, the majority (18) said they and their child had been shown how to use an inhaler. However, four parents had not been shown.
- All three young people who answered the question had been shown how to use their inhaler.



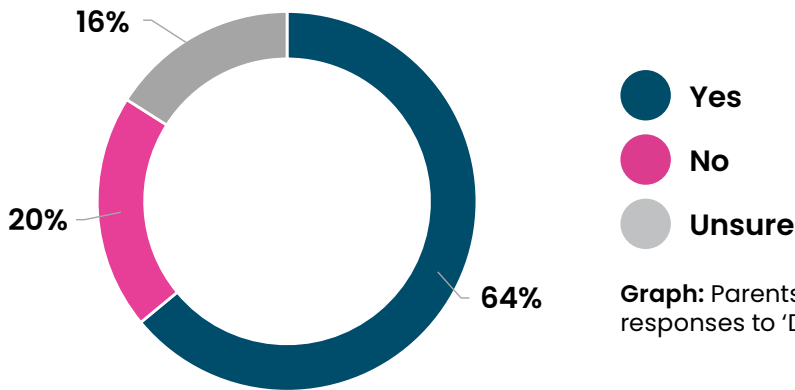
3.3 – Asthma plans

Having an asthma plan in place

Twenty-two parents and three children and young people, answered the question, 'Do you or does your child have an asthma plan?'

Their combined responses are shown in the chart below.

.....



Graph: Parents, carers and guardians, and young people's responses to 'Do you or does your child have an asthma plan?'

While most people said they did have an asthma plan (64%), a third of people (36%) either said they didn't have a plan or were unsure whether they had a plan.

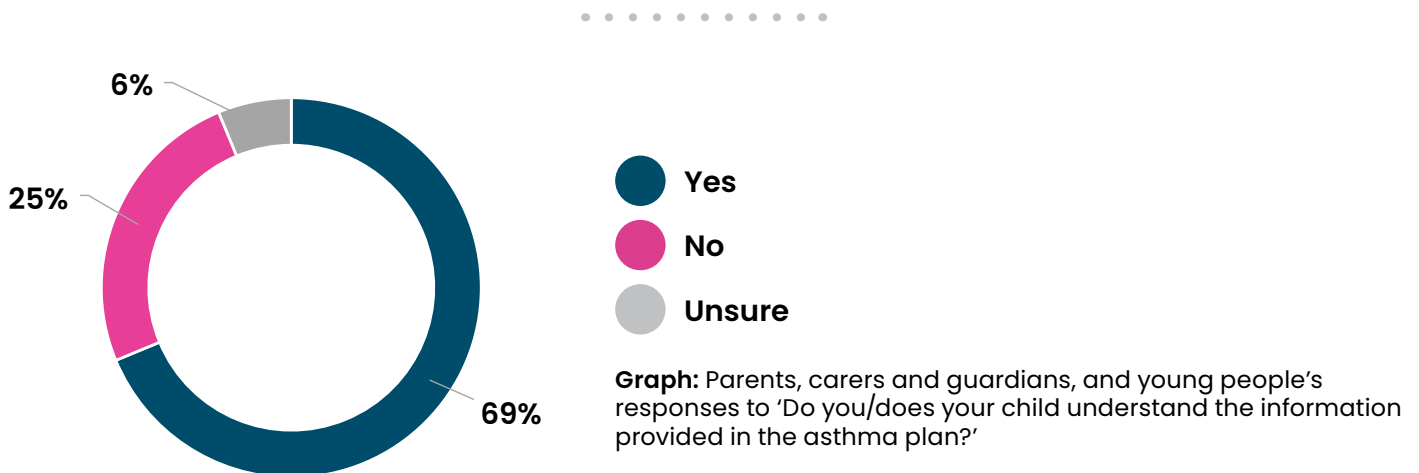
- Of the twenty-two parents who answered, 15 said their child had an asthma plan. Two were "unsure", and 5 said "no".
- Two of the three young people said that they were "unsure" whether they had an asthma plan. Both were aged 16. One, aged 21, said "yes" they had a plan.

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Understanding asthma plans

Of those who said they had an asthma plan, fifteen parents and one child or young person answered the follow up question, 'Do you/does your child understand the information provided in the asthma plan?'

Their combined responses are shown in the chart below.



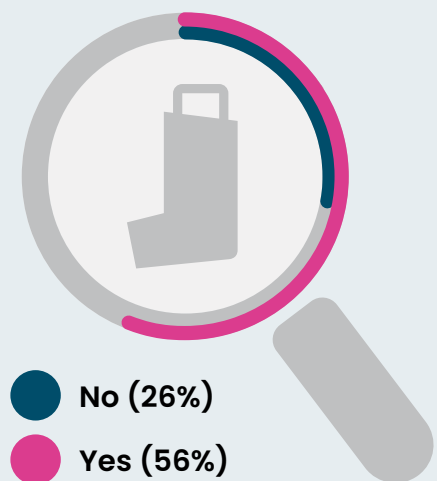
A quarter of respondents (25%) did not understand the information in their asthma plan, and a further 6% were 'Unsure' about the information in their plan.

- Of 15 parents, carers and guardians who responded, 10 said they and their child understood the information in the asthma plan. One was 'Unsure' and four indicated they did not understand the information in the asthma plan.
- The one young person who responded said that they understood the information in their asthma plan.


Is CYP asthma monitored regularly enough?

Just over a half of respondents (56%) felt their or their child's asthma was adequately monitored.

- Of the 22 parents who responded, 13 felt their child's asthma was monitored regularly enough. Two were 'Unsure', and seven said 'No'.
- Of the three children or young people who responded, one felt their asthma was monitored regularly enough, and two were unsure.



“As a young child being diagnosed, I think that some sort of story book should have been provided to show how asthma really affects the lungs... [or] a child friendly and a teen friendly leaflet/app. Knowledge at schools, a school nurse visit to talk monthly around medical issues... would be a great to encourage safe medications and Q&A. Children could feel empowered to take responsibility and teach their care givers.”



3.4 – Improvements to asthma support

Fifteen parents answered the free-text question 'Is there anything which could be changed or improved to help you support your child with their asthma care?'

Themes in their responses are outlined below.

Six parents said nothing needed to be improved about the asthma care for their child or young person.

Some of these comments were very simple for example, "no". One said that it was managed well by their current GP practice, but their previous surgery did not have an asthma nurse. Another said they received their annual review, and that their child's asthma was well controlled. Finally, one said they understood their asthma plan.

"Now it is well managed by her asthma nurse at our GP practice, our previous practice didn't even have an asthma nurse" (Parent/ guardian)

"My child has an annual review with the asthma nurse which I feel is sufficient, as his asthma is well controlled now." (Parent/ guardian)

"No. Everything is fine and as an adult, I understand the plan." (Parent/ guardian)

Five parents said that they would like to have more regular follow ups or reviews of their child's asthma.

One said that they felt a year was a long time between reviews, and another said that they would like yearly reviews, implying that they were not currently receiving them. One said that they would like regular telephone calls to discuss their child's symptoms. Finally, one said that they would like an official diagnosis of asthma and to receive regular reviews and medication.

"Offer yearly check-ups perhaps?" (Parent/ guardian)

"Going a year between reviews is a long time for a child." (Parent/ guardian)

"Being officially diagnosed and receiving regular reviews and medication." (Parent/ guardian)

"Check that medication is ordered regularly and telephone calls to discuss symptoms and whether or not the asthma is stable, got better or worsened. Then from that decide if the child needs to be seen in person." (Parent/ guardian)

Two highlighted the importance of training or information for schools to support their young person with asthma.

One also said in their comment that they would like to see more information targeted at young people generally.

"Train staff in schools. It could be the difference between life and death." (Parent/ guardian)

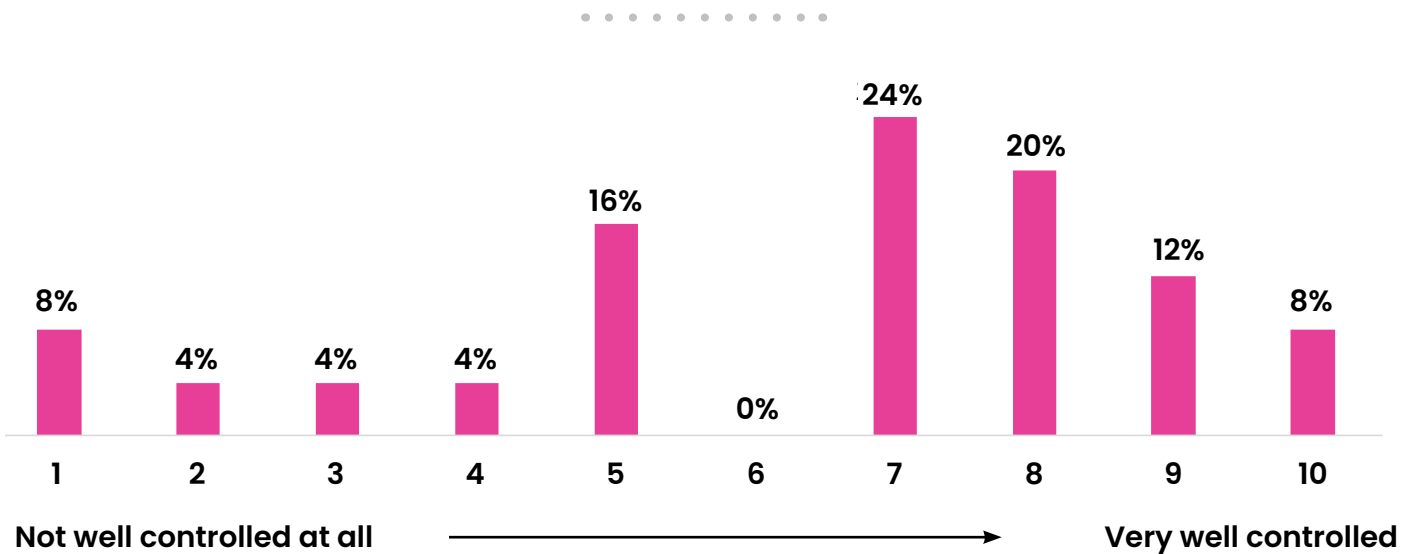
"Yes. As a young child being diagnosed, I think that some sort of story book should have been provided to show how asthma really affects the lungs... [or] a child friendly and a teen friendly leaflet/app. Knowledge at schools, a school nurse visit to talk monthly around medical issues... would be a great to encourage safe medications and Q&A. Children could feel empowered to take responsibility and teach their care givers." (Parent/ guardian)

3.5 – Asthma attacks and triggers

How well controlled is CYP asthma?

Twenty-two parents and three children or young people answered the question 'How well controlled is your or your child's asthma?'

Respondents were asked to provide a rating on a scale of one to ten, from one 'Not well controlled at all', to ten 'Very well controlled'. Their combined responses are shown in the chart below.



Graph: Parents, carers and guardians, and young people's responses to 'How well controlled is your or your child's asthma?'

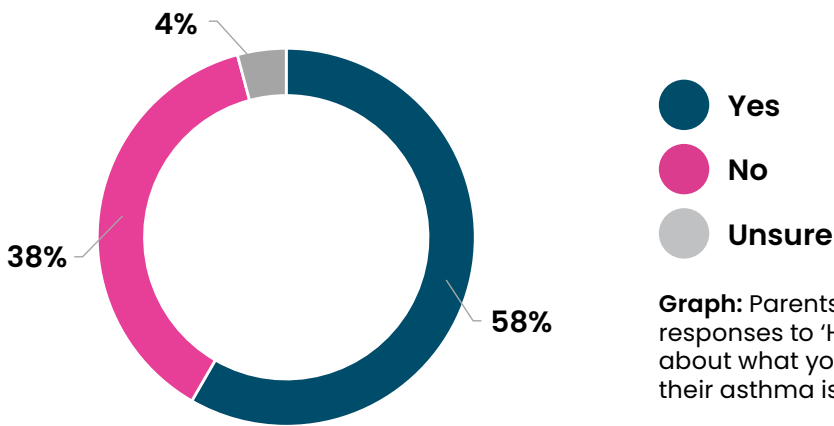
The 22 parents and guardians who answered the question gave an average score of 6.8. The average of the three young people's score was 3.3.

- 64% of respondents felt their child's asthma was reasonably well controlled (providing a rating of between 7 and 10).
- However, around a third of respondents (36%) felt their asthma was 'not very well controlled' or only 'somewhat well controlled'. This included all three children and young people who responded to the survey.

Explaining asthma triggers

Twenty-one parents and three children or young people answered the question 'Has a GP or another professional spoken to you/your child about what your or your child's triggers are and what to do if their asthma is triggered?'

Their combined responses are shown in the chart overleaf.



Graph: Parents, carers and guardians, and young people's responses to 'Have professionals spoken to you or your child about what your or your child's triggers are and what to do if their asthma is triggered?'

Only 58% of respondents said that someone had spoken to them about triggers or what to do in the event of their asthma being triggered.

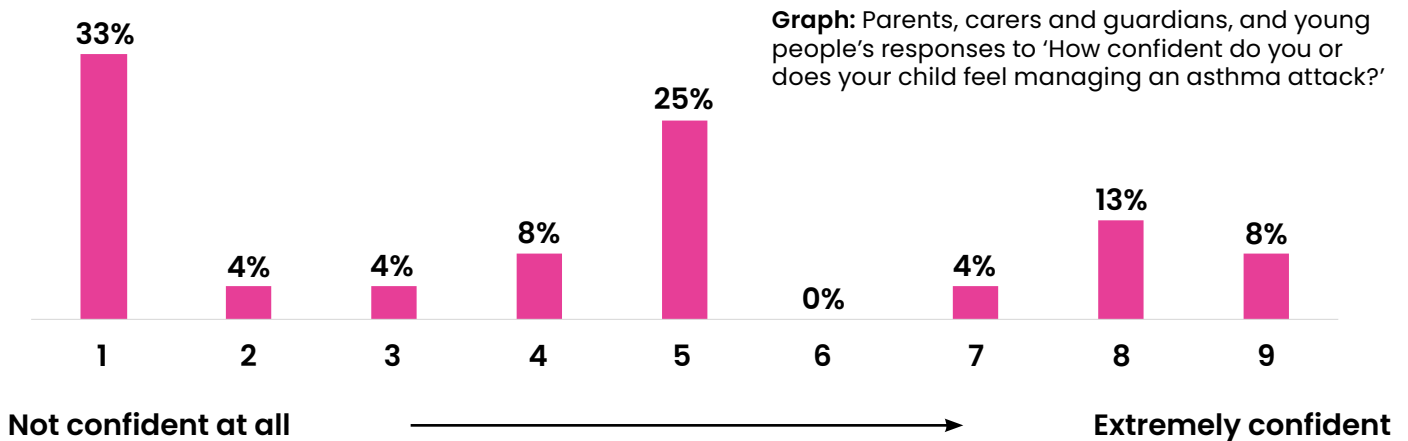
- Of the 21 parents who responded, 13 said a professional had spoken to them about their triggers, and eight said "no", they had not received this.
- The three children and young people who responded were evenly split in their answers. One said "yes", a professional had spoken to them about their triggers, one said "no", and one said they were "unsure".



Confidence managing an asthma attack

Twenty-one parents and three children or young people answered the question 'How confident do you/does your child feel managing an asthma attack?'

Respondents were asked to respond on a scale of one to ten, from one 'Not confident at all', to ten 'Extremely confident'. Their combined responses are shown in the chart below.



Graph: Parents, carers and guardians, and young people's responses to 'How confident do you or does your child feel managing an asthma attack?'





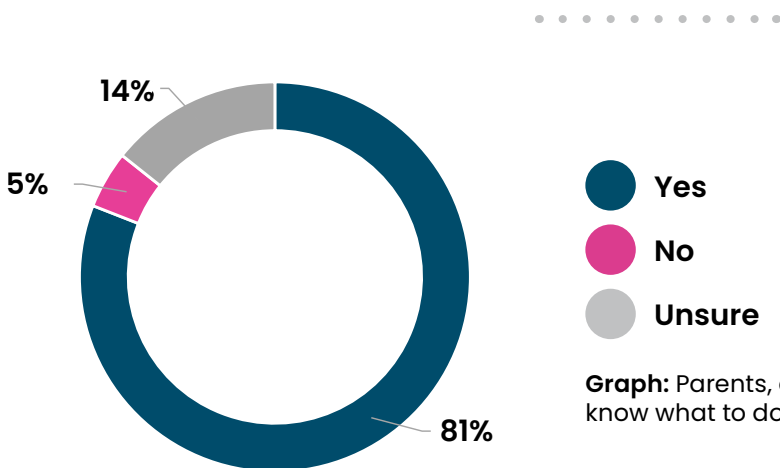
Confidence managing asthma attacks continued...

Only a quarter of respondents rated their confidence levels a five or above (somewhat confident to extremely confident) and none of the children or young people rated their confidence levels above a 5.

Knowing what to do

Twenty-one parents answered the question 'Would you know what to do if your child was having an asthma attack?'

Their responses are shown in the chart below.



Graph: Parents, carers and guardians responses to 'Would you know what to do if your child was having an asthma attack?'

Nearly 1 in 5 parents said they would not know or were unsure what to do in the event of their child having an asthma attack.

Of the 21 parents who responded, 17 said 'Yes', they would know what to do. Three were 'Unsure', and one said 'No'.

In the follow up question about what could help parents to feel more confident managing an asthma attack, the parent who said 'No' stated:

"Never been explained what an asthma attack actually looks like or what to do." (Parent/guardian)

Although 81% of parents said they would know what to do in the event of their child having an asthma attack, only 64% of people had an asthma plan.

Qualitative insight – Increasing confidence in managing asthma attacks

Sixteen parents and two young people answered the question 'What could increase your or your child's confidence in knowing how to manage an asthma attack?'

Themes in their responses are described below.

Of 18 comments, 14 said that they would like more information of some kind about how to manage asthma attacks.

This included both children and young people who responded. The types of information they wanted included:

- Seven parents mentioned more information or resources for themselves, their community, and schools on how to recognise and manage an asthma attack.

One said they would like general training. Others mentioned included printed materials or bracelets, online videos or emails, apps and letters. One parent said that they had no information about asthma attacks or what to do (see question above). Their comments included:

"To have a card that can be carried in a wallet or a medical bracelet which has step by step instructions in what to do if an asthma attack occurs. Offer training courses to child and parents and to schools with an annual refresher. Or a video recorded and emailed to child/parent annually as a refresher." (Parent/ guardian)

"More training in general about asthma, some people don't even recognise an asthma attack." (Parent/ guardian)

Two parents and one young person said that they wanted regular reviews of their asthma to help them feel more confident managing an asthma attack.

"Every few appointments maybe getting a recheck on how to cope, but also, education within the community." (Child or young person)

"Yearly face to face visits with a nurse or other trained professional." (Parent/ Guardian)

One parent and one young person said that they would like more information about triggers.

"Discussion on triggers and how to pre-emptively manage this" (Parent/ guardian)

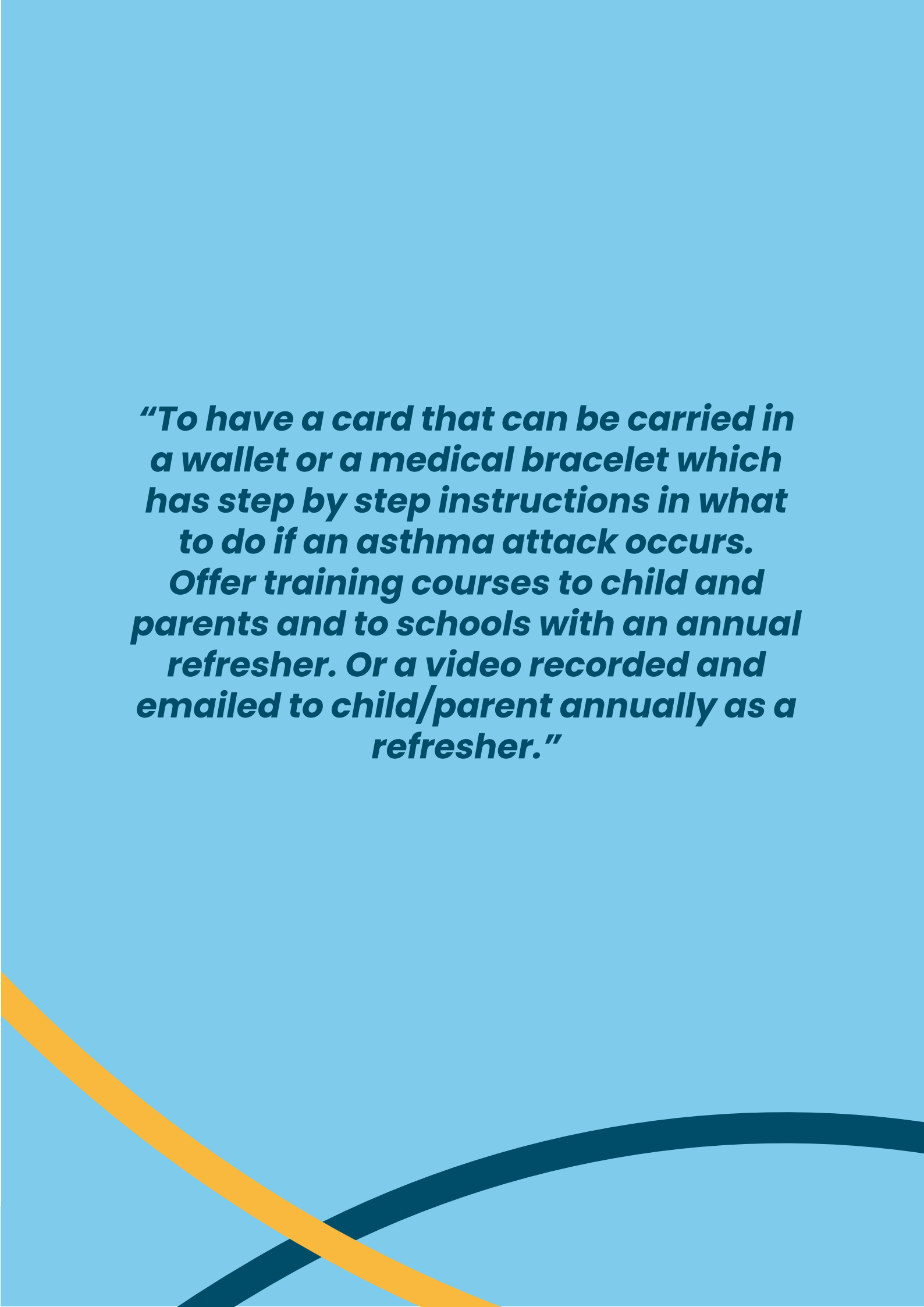
"Damp, wet weather, dust, certain cleaning products, smoke and cats." (Child or young person)

Other comments and feedback

Other comments about what could help parents and young people to feel more confident managing an asthma attack included:

- One parent said they would like more responsive access to primary care.
- One said *"Nothing, just call 999."*
- One said they already felt confident managing asthma attacks.
"Nothing. Happy to use the inhalers and monitor blood oxygen levels at home."

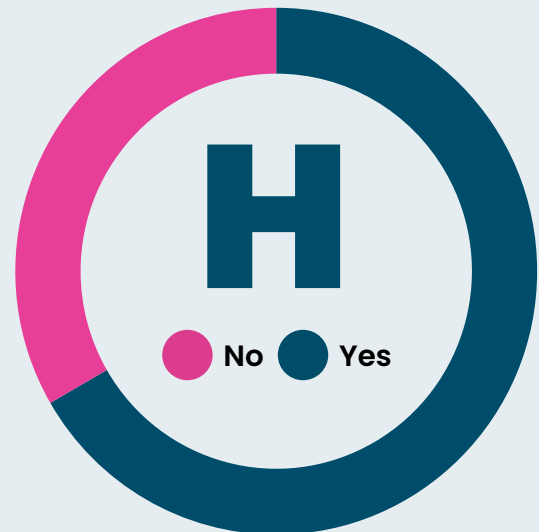
“To have a card that can be carried in a wallet or a medical bracelet which has step by step instructions in what to do if an asthma attack occurs. Offer training courses to child and parents and to schools with an annual refresher. Or a video recorded and emailed to child/parent annually as a refresher.”



3.6 – In the hospital

Twenty-one parents and three children or young people answered the question **'Have you/has your child ever been admitted to hospital due to asthma?'**

- Of the twenty-one parents who responded, twelve said their child had previously been admitted to hospital due to asthma.
- Of the three young people who responded, two said 'Yes', they had been admitted to hospital due to their asthma.



Qualitative insight – Experiences in hospital

Nine parents and one child or young person answered the follow up free-text question 'If you or your child has previously been admitted, what was their experience of receiving asthma care in hospital?'

Most (five parents and one young person) were positive about their experience of asthma care in hospital.

The positive responses to this question were very general. Examples of these comments included: "Really good", "Good", "Very good". One parent gave more detail, saying:

"Asthma care in hospital was amazing. Very thorough" (Parent/ guardian)

One parent left a negative comment, stating that the experience was "traumatic" for them and their son. However, they did not elaborate on the care they had received at hospital.

"It was very traumatic and distressing for both me and my son." (Parent/ guardian)

Three parents left mixed comments.

One said that their experience at Norwich hospital was poor, but that they had received good care in West Suffolk. Another reflected on confusion about their diagnosis in hospital. Finally, one gave a neutral experience of receiving care, but said that they had received no further medication or review.

"Both times, after being unwell with colds, we took him to our local A and E and were transferred by ambulance to the nearest children's unit at an alternative hospital. He received medication by nebuliser and was kept in overnight for observation. He took short courses of steroids and was given a (very small) spacer and we were shown how to use it with him. But no further regular medication or reviews." (Parent/ guardian)

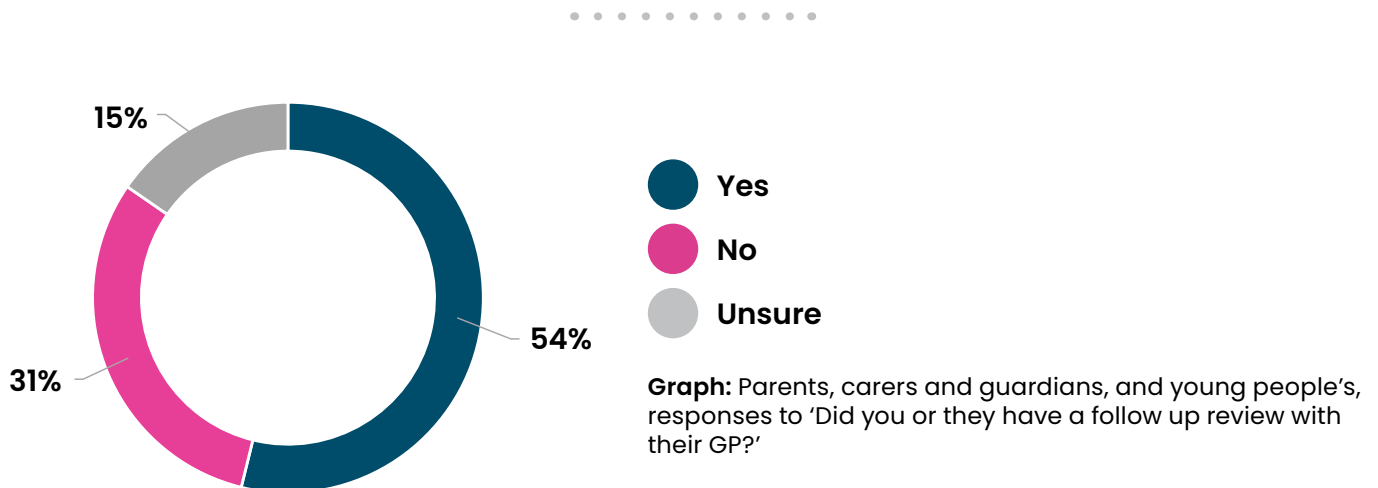
"Our experience at Norwich hospital was absolutely horrendous, she needed to see the respiratory team and they wouldn't see her. We ended up at the West Suffolk Hospital under Choose and Book and they were absolutely amazing, referred her for physio and regular check-ups." (Parent/ guardian)

"Some confusion if it was whooping cough or asthma, back and forth thing, again I had no prior experience with asthma so did not know myself." (Parent/ guardian)

3.7 – Primary care follow-up (post hospital)

Twelve parents and one child or young person who had previously been admitted to hospital answered the question 'Did you/they have a follow up review with their GP?'

Their combined responses are shown in the chart below.



Over a third of people said they had not, or were unsure if they had, received a follow up appointment after a hospital in-patient stay.

- Of the twelve parents, carers or guardians who responded, seven said their child had received a follow up. Two were 'Unsure' and three said 'No'.
- The one young person who responded had not received a follow up review.

Time it took to have a review in primary care

Seven parents of young people who had received a post discharge review answered the free-text question ‘How long after you/ your child was admitted to hospital, did they have their asthma review?’

- Two parents said their child had a review with their GP within 48 hours.
- One said “straight away”.
- One said a “few days” and another said two weeks.
- Two said that they could not remember.
- The longest experience said that they had waited two years, and that another of their children had not yet received a review following their hospital admission.

*“My eldest 2 years. My youngest was admitted at the beginning of the year and was told he would be seen in 3 months, and we have not been seen by the hospital.”
(Parent/ guardian)*

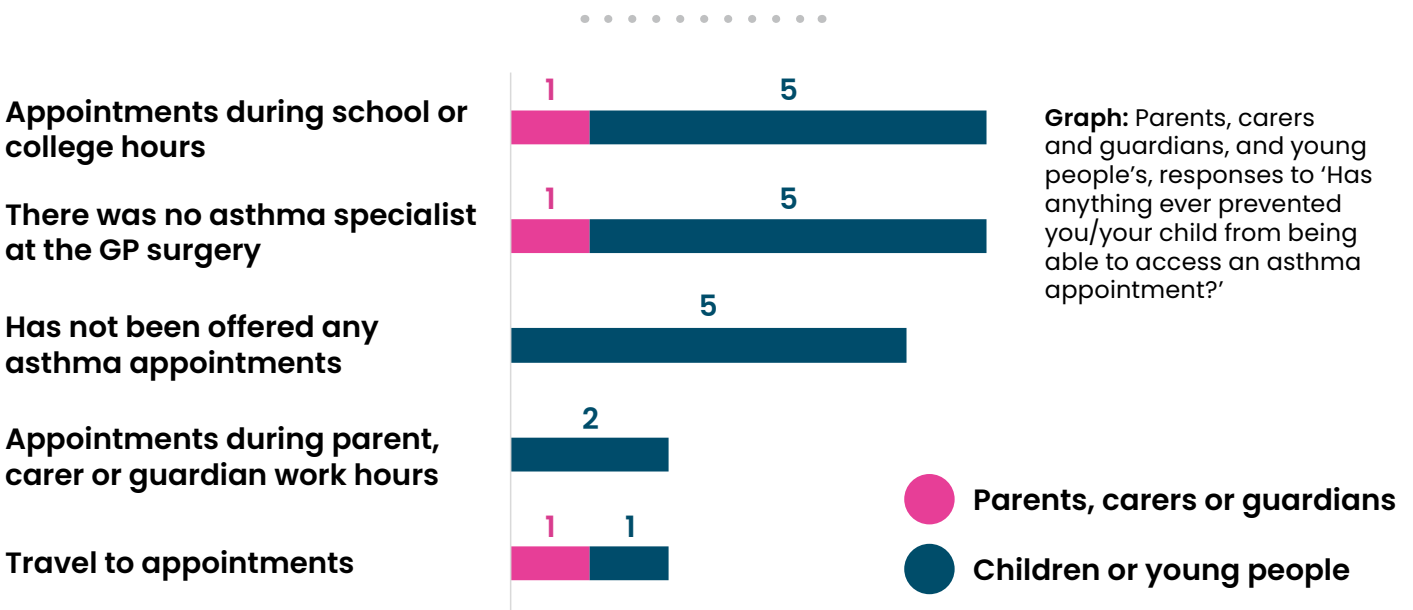
One young person also answered this question, however, they had received a review from the hospital, rather than their GP.

“I had a hospital review as I’m under their care, and it was 2 weeks and then another 2 weeks after.” (Child or young person)

3.8 – Information about asthma care

Eleven parents, and three children or young people, answered the question ‘Has anything ever prevented you/your child from being able to access an asthma appointment?’

Respondents could choose multiple options. Their combined responses are shown in the chart below.



Almost half of parents (5 people) said their child had not been offered any asthma appointments. Lack of access to asthma specialists and issues with the times of appointments (i.e. during school hours) were also issues for parents.

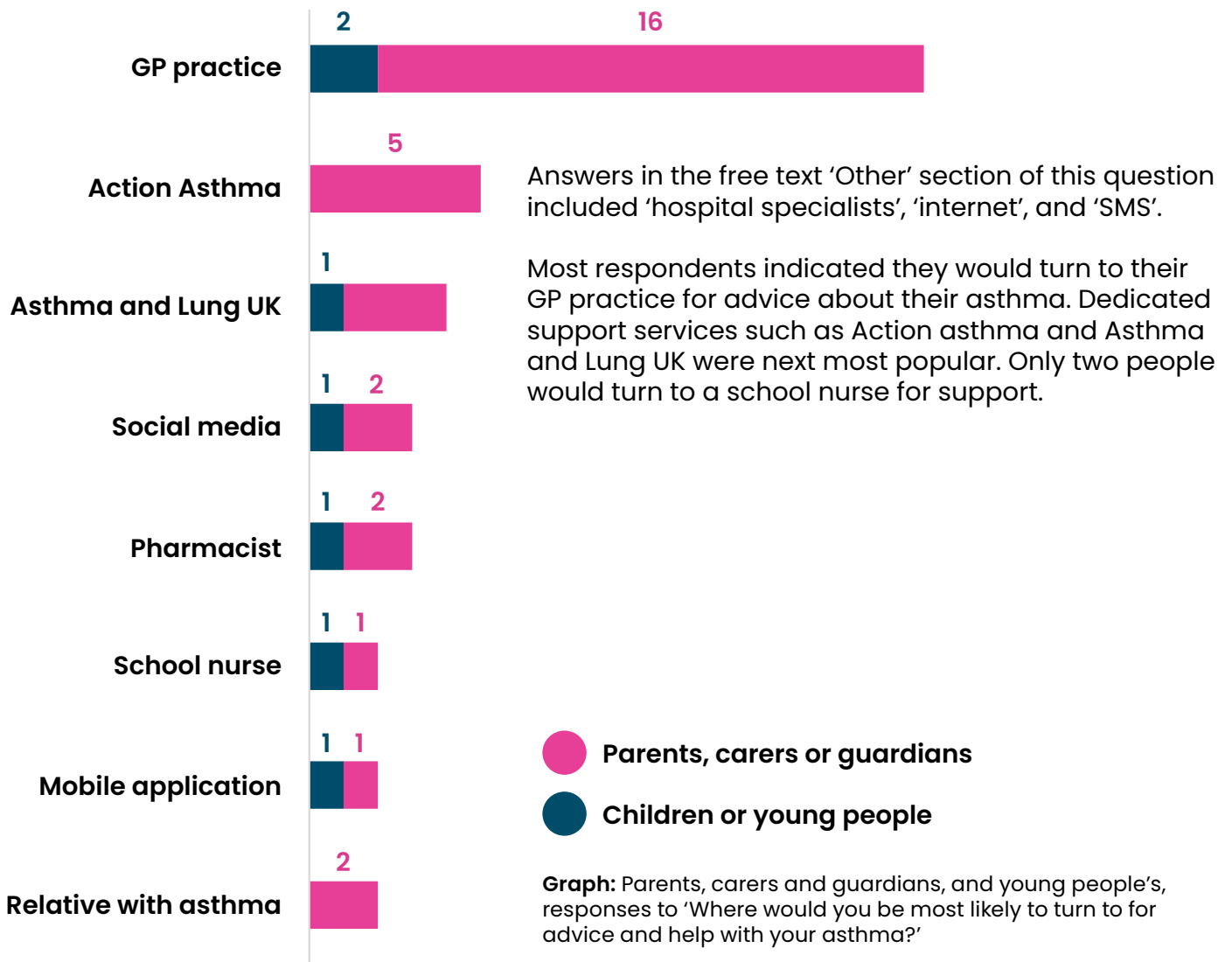
Travel was identified by one young person as being an issue.



Sources of information and advice

Nineteen parents and three children or young people answered the question 'Where would you be most likely to turn to for advice and help with your asthma?'

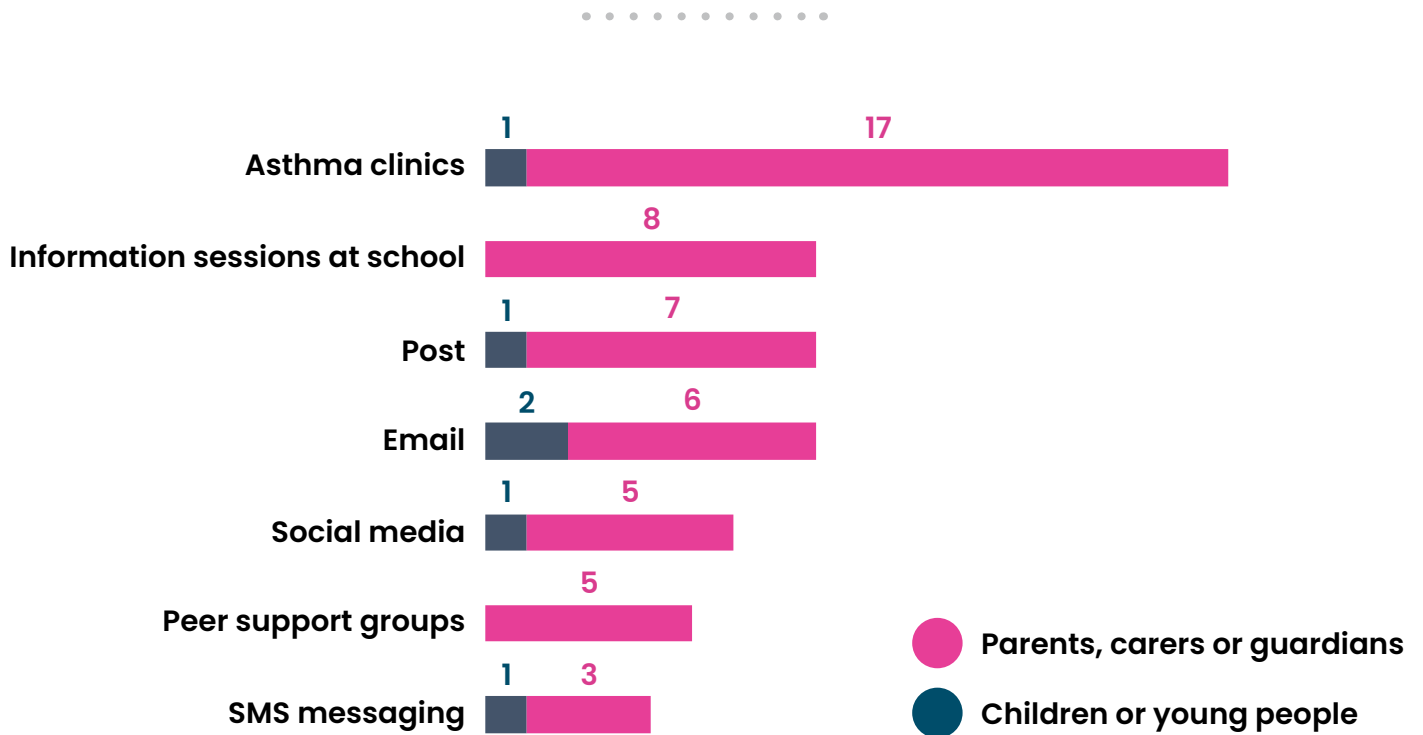
Respondents could choose multiple options. Their combined responses are shown in the chart below.



Receiving general information

Twenty-two parents and three children or young people answered the question 'How would you like to receive general information about asthma care?'

Respondents could choose multiple options. Their combined responses are shown in the chart below.




Graph: Parents, carers and guardians, and young people's, responses to 'How would you like to receive general information about asthma care?'

Asthma clinics were the most popular choice amongst parents, followed by information sessions at school. Amongst children and young people, email was the most preferred method of receiving information.

None of the children and young people chose 'information sessions at school' or 'peer support groups'.

.....

“Our experience at Norwich hospital was absolutely horrendous, she needed to see the respiratory team and they wouldn’t see her. We ended up at the West Suffolk Hospital under Choose and Book and they were absolutely amazing, referred her for physio and regular check-ups.”



4. Key learning

Areas of key learning regarding asthma care and support for children, young people and families in Waveney.



4.1 – key learning for systems and services

After engaging with children, young people and their families in Norfolk and Waveney, as well as Suffolk and north east Essex, it is evident that having access to clear and transparent information about asthma care is vital.

As residents in both ICS' received the same survey, the recommendations and key learning from both are presented together here to add value to the findings for Norfolk and Waveney. Comparisons between the two areas should be treated with caution due to the relatively low response rate in Norfolk and Waveney (25 responses).

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, nearly half (48%) of respondents in Norfolk and Waveney said it had been 'not very' or 'not at all' easy to get a diagnosis. Two in five (39%) in SNEE said it was 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 over a third (36%) of children and parents in Norfolk and Waveney, and almost two out of every five (39%) in SNEE 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.

- Within SNEE, 30% of respondents said that they/their child had not been shown how to use their inhaler. This figure for Norfolk and Waveney was 16%, although the small sample size makes it hard to generalise this finding.
- 44% of children, parents and guardians in Norfolk and Waveney, and 48% of respondents in SNEE felt children and young people's asthma was not monitored regularly enough.
- It was common for parents to say they wanted more regular asthma reviews when they were asked what could be improved about asthma care, both in SNEE and Norfolk and Waveney.

- 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 54% parents, guardians and young people who had been admitted to hospital in Norfolk and Waveney had a follow up review with

their GP. Of these, three parents of seven who answered how long it took them to receive a review said they had received the review within 48 hours. Within SNEE, only two of twenty-three said that they received their review within 48 hours.

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).

The 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.

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. Two in five respondents in Norfolk and Waveney, and just over a third of young people and parents in SNEE said that they had been unable to access an appointment because the times they were offered were in school or college times. A quarter in SNEE 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. It is notable that over two thirds of people in SNEE and a third of people in Norfolk and Waveney felt that they had not received an appointment for their asthma. Another one in five in SNEE and two in five in Waveney 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 the East of England 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 Norfolk and Waveney 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 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. More information about the project can be found on <https://healthwatchsuffolk.co.uk/cypasthma/>.

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

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