



**Leicester, Leicestershire  
and Rutland**

# **Asthma Hub Evaluation**

**1 December 2021 to 31 March 2022**

**September 2022**

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**Version 1**

NHS Leicester, Leicestershire and Rutland is the  
operating name of Leicester, Leicestershire and  
Rutland Integrated Care Board

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**Leicester, Leicestershire  
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Health and Wellbeing Partnership



## Overview

### Background & Context:

An Asthma Hub Pilot, commissioned by Leicester, Leicestershire and Rutland's Clinical Commissioning Group and provided by the Respiratory Team at UHL, saw patients being referred to the hub within 48 hours of attending ED after an asthma attack. The pilot took place in Leicester between 1<sup>st</sup> December 2021 and 31<sup>st</sup> March 2022. The hub provided a new way of providing follow up care for children and young people who presented at A+E after an asthma attack. The hub offered rapid access, a one stop service: Testing - Spirometry with bronchodilator reversibility and Fractional Exhaled Nitric Oxide (FeNO) testing and Patient management (in line with national guidance on 48-hour review) - patient education, inhaler technique and completion of asthma action plan. This resulted in fast-track consultant asthma reviews, referral back to GP with detailed follow up advice including asthma action plan and to see children within 48 hours-latest within a working week after.

It was identified that a piece of engagement work was needed to be carried out to collect the views, voices, and ideas from the children, young people and their families who attended the Asthma Hub, to evaluate the service.

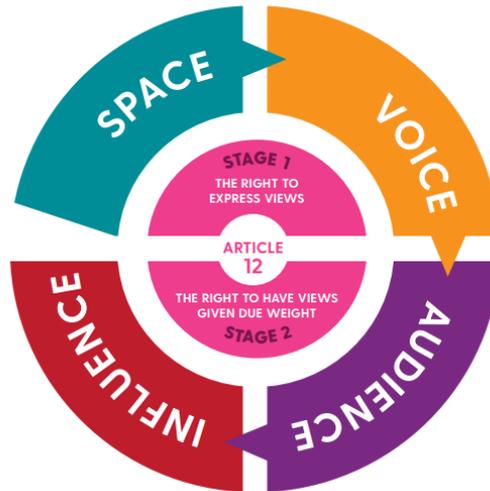
### Engagement Process

**From June to September 2022** the engagement process with patients started. We offered a range of activities and methods to support the feedback process. We offered an online survey, one to one video interviews, and a creative participatory evaluation workshop day.

To engage as many Children, Young People and Families (CYPF) who attended the Asthma Hub, the ICB's Engagement Team worked closely with UHL to contact patients via their parents. The team also worked with a local charity to identify a young person friendly venue for the creative evaluation day.

294 children and young people attended the Asthma Hub. 244 families said they would be interested in taking part in a future evaluation.

The LLR ICB, is committed to the active participation of children, young people and families wherever possible. However, we recognise that children, young people and families may want to engage at different levels with services that affect them. Some may wish to be informed, some may wish to be consulted while others may wish to be actively involved in both decision making and service delivery. There are a number of models that help us identify different types and levels of participation and understand which approach is most beneficial to what is trying to be achieved through participation activity. The **Lundy (2007) Model of Child Participation** provides a way of conceptualising a child's right to participation, as laid down in Article 12 of the UN Convention on the Rights of the Child, using four elements: *Space. Voice. Audience and Influence*. These four elements will help us develop our delivery method.



**Lundy (2007) Model of Child Participation**

**Space:** We provided a safe and inclusive spaces to engage Children and Young People (CYP) – both physical and online space. Using young people friendly venues in central city location. We also gave options for CYPF to engage virtually as well engage via a survey

**Voice:** We use creative participatory engagement activities which were designed to encourage CYP to express their views and voice to be heard in a way that makes sense for them. We used model making as a tool to encourage young children to express themselves.

**Audience:** The voices of the CYP will be listened to by the Respiratory and Asthma team, including clinical leads and then fed into CYP Design Group. The CYPF's were told during their engagement who important their voice was and where it would be fed into.

**Influence:** The views of the CYP will help form future funding bids and business cases to extent the Asthma Hub so other CYP can access support. The CYP also were given the opportunity to ask one question for an asthma doctor to answer. The CYP will receive a video answer from a doctor

**Feedback:** All CYPF will be informed of their influence in the future of LLR's Asthma Hubs.

## **What we managed to achieve:**

Throughout the consultation we managed to engage with a total of 22 families through the survey, and 3 families took part in a face-to-face creative evaluation workshop.

The following report provides details of the activities delivered, the people involved and the outcomes of the evaluation.

## Creative participatory evaluation workshop

**Saturday 3 September. Location: Leicestershire Cares**

**Attendance:**

**CYP:** 2 Female, 5 and 7 years old. Asian/British Asian and Black/Black British. 1 Male, 6 years old, Asian/British Asian

**Parents:** 3 Mothers



**ICB Staff:** Jacob Brown, CYPF Engagement Officer. James Hickman, CYP Services Transformation Manager

**Aim:**

Encourage children and young people to express their views and opinions of their experience of the Asthma Hub Pilot.

Eliciting a rich narrative of their experiences.

**Method:**

CYP were asked to create a range of models that represent a moment / feeling / idea / experience, at certain stages of their engagement with the Asthma Hub. The moments focused on were:

- 1) How did you feel before attending the Asthma Hub?
- 2) How did you feel during your time at the Asthma Hub?
- 3) What did you learn or come away with from the Asthma Hub?
- 4) Since attending the Asthma Hub, how do you feel now about your condition?

These models were presented on a journey map.

The facilitator encouraged the CYP to explain / decode / their model to the rest of the group.

During the building time, facilitators engaged with CYPF's and spoke to them about their experiences, views of the Asthma Hub and ideas for improvement.

## What we found out through the face-to-face participatory workshop

The young people felt happier, more confident and safer after their visit to the Asthma Hub



### Navreeta:

“This is me, feeling ok, but a bit nervous before finding out about my asthma. I’m not very colourful.” (Left picture)

“But now I know I have asthma, and I know how to take care of it. I have more confidence. I don’t let it stop me having fun. Here I am bright colourful!” (Right picture)



**Mwindem**, produced a big smiling yellow face for how she feels now, along with a colourful butterfly. (Right picture)

The children's experience of attending the Asthma Hub was good, however questions still remain about how well young children understand the condition, and to what level it may impact their lives

**Shivam:**



"This represents me during my visit to the Asthma Hub. It's face shows that he is a bit nervous, wondering if I do have asthma. I didn't know what asthma meant, and I still don't, but at least the hub has helped me feel fine."

## If I could ask the doctor one thing?

Mwindem: "If I could ask the doctor anything it would be: Am I feeling better? I don't know if I am well? How long will I have to take my inhaler?"

Navreeta: "If I could ask the doctor anything it would be: Do I have bad asthma or am I ok?"

Shivam: "If I could ask the doctor anything it would be: Am I ok? Am I fine?"

*Video answer from: Dr. Manisha Ramphul, Paediatric Respiratory Consultant. LRI – <https://youtu.be/E0-O20JNRVs>*



## The Asthma Hub gave the children the skills to manage their asthma

Mwindem's Mother: "It was great that Mwindem could get better access faster than seeing the GP, and that it had specialist there that knew about asthma. She has learnt to manage her asthma herself. She knows when she is feeling bad and getting worse, and she knows what to do. This is empowering for her."

Navreeta's Mother: "She learnt the proper techniques of using her pump at the Asthma Hub. It has given her control over things."

## Can the design of the Asthma Hub be more Child and Young Person friendly?

Mwindem's Mother: "The Asthma Hub was a bit clinical. It could be more child and young person friendly."

## Delays which increase's distress

Shivam's Mother: "It's been six months since visiting the Asthma Hub and we are still waiting for a review appointment. Does he need his brown pump two times, or one times a day?"

Navreeta's Mother: "I was really worried about Navreeta health. I eventually got a GP appointment two days later. The GP told me to take Navreeta to A+E. Why did it take two days just to tell me to go to A+E?"



Mwindem's Mother: "We needed to find out what was happening to her, because every time she had an attack she would end up in an ambulance going to A+E and that is scary for a child especially if it is happening over and over again."

## **Feedback from participations about the participatory workshop**

### **Satisfaction with the event:**

The participants stated that they were very satisfied with the event. The date (Saturday), location (a central location with free parking) and communication about the event was scored at 5/5.

The venue scored 5/5 for being suitable for young people (a youth club with plenty of space, well ventilated, inclusive and bright and colourful)

The activities score 5/5 for being age appropriate (modelling, crafts and building), the facilitation scored 5/5 for being interactive and engaging.

### **Voice**

All the young people reported feeling that their views were listened to, and were confident that their views will make positive change in the future. Two out of the three young people said that they were very likely to attend another NHS service evaluation for CYP if they were invited.

### **What did you like most about the event?**

"I like the colouring the most"

"The activities were fun"

"The facilitators made the session enjoyable and listening to all of our views and concerns"

### **What did you like least about the event?**

"I was the first person to the event and had to wait around for it to start"

"Nothing"

## **What insight did we gain from the survey?**

40 people started the survey and 22 completed.

1 CYP filled it out themselves, and 3 survey's were filled out by a CYP and parent/carer together. The rest (27) were filled out by a parent/carer.

20 were from Leicester City, 3 from Leicestershire County West, 5 from Leicestershire County East, and 1 from Rutland

The age profiles of the patients who took part in the survey were, twelve 5-9 years old. Nine 10-14 year olds and two 15 and above.



16 Male, 7 Female

\* Extra engagement work could be considered to gather more of a representation from different groups. Analysis of Asthma Hub patients demographics could provide a proportionality reference for targeted engagement. We should also be mindful of protected characteristics

**1. Quality of care at Asthma Hub was of a high standard**

**2. Children and young people felt that their asthma had improved since attending the Asthma Hub and they were happier and enjoying life more. Only 2 patients reported returning to E+D**

“I found the asthma hub to be a great safety net for my daughter, she'd attended A&E regarding her breathing and was sent home, she hadn't made much improvement by the time we saw the asthma hub who had her admitted again, their attention to detail is second to none and ensured my daughter got the care she needed”.

**3. Children and young people came away from the Asthma Hub with the skills and knowledge to manage their condition.**

**4. Children and young people felt empowered and were more confident to speak to their peers, teachers, and adults in their life, about their condition and what support they might need.**

**5. The information the children and young people received from the Asthma Hub was age appropriate and easy to understand. People would like more pictures, diagrams, some would like video's and more explanations. One recommendation is a dose card that the child could carry.**

“Just an idea but for children you could develop a more user-friendly flow result chart as the one provided in the equipment is very technical. It would also be useful for children to have some form or card they can carry with them which states what dose they are on and what they can have in the event of an attack”

**6. Majority of patients felt follow up care was appropriate and would rather attend an Asthma Hub than a GP.**

“The consultant was very knowledgeable and excellent at demonstrating how my daughter should use her inhaler.”

“Our GP refused to see our 12 yr old child twice, didn't mention him having asthma and it took an attack and a trip to the hospital to diagnose. The asthma hub after the hospital visit was amazing.”

“By having Lesley, our asthma nurse at the asthma hub, she was fully aware of XXXX's severe condition and currently treats her. If I attend A&E I have to repeat her history over and over again, by being at the asthma hub the team are able to assist XXXX's condition promptly.”



“More personalised service and access to patient’s full medical history. Also, specialised asthma doctors seen so less likely to misdiagnose / mistreat as often occurs when presenting at A&E.”

### **Disappointments with the Asthma Hub**

**7. Feedback provided shown that children felt they were not spoken too directly, instead verbal questions/information was directed to the adult accompanying the child**

**8. Gaps in follow up support due to the absence of the Asthma Hub**

“The initial visit was great but no contact after the initial visit and told to discuss with gp going forward. Would have preferred to see the consultant at the hub.”

“After visit with asthma hub once no one contact us later.”

“Constantly trying to phone the asthma hub for advice i was totally ignore and when someone did finally get back to me days later i had so much attitude from them i would not go back to them absolutely disgusted at the way my child was treated. should be close down.”

“I would like to be seen more regularly for my child’s asthma.”

**9. Improved joined up working across services**

“Better liaison/streamlined service with allergy clinic as I'm sure a lot of children have both allergies and asthma, and it would help with fast-tracking care and reducing issues.”

## **Summary**

1.1 Through utilising the Lundy Model of Child Participation (2007) using a Children, Young Peoples and Families centred engagement approach, the Integrated Care Board was able to create a safe space for CYP to provide an honest and transparent response to their experience with the asthma hub service.

1.2 Children and Young People have widely reported that their voice was listened too regarding feeding into the service evaluation, as well as feeling they had an influence in shaping the future decision made around improving asthma care within LLR.

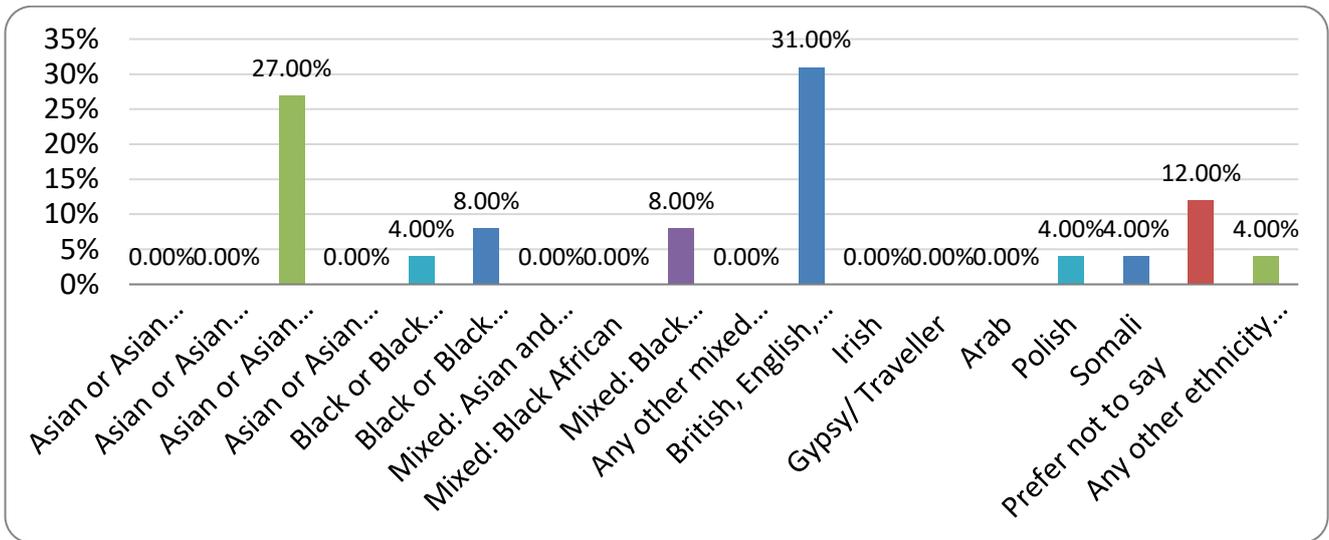
1.3 Children, Young People and their Families broadly reported to ‘feeling better’ after attending the asthma hub, in addition to feeling ‘more confident’ in managing their condition and feeling ‘more knowledgeable/empowered’ to communicate their health needs to adults within their own environments.

1.4 Feedback has also highlighted negative responses to the absence of follow-up care provided after visiting the hub. The nature of the 6-month pilot meant that there was not a service available once the asthma hub had closed to provide Children and Young People with the recommended/required follow up. This supports and emphasises the

system need to commission asthma hubs recurrently to avoid incomplete patient journeys, ultimately leading to worse patient experience following an asthma diagnosis.

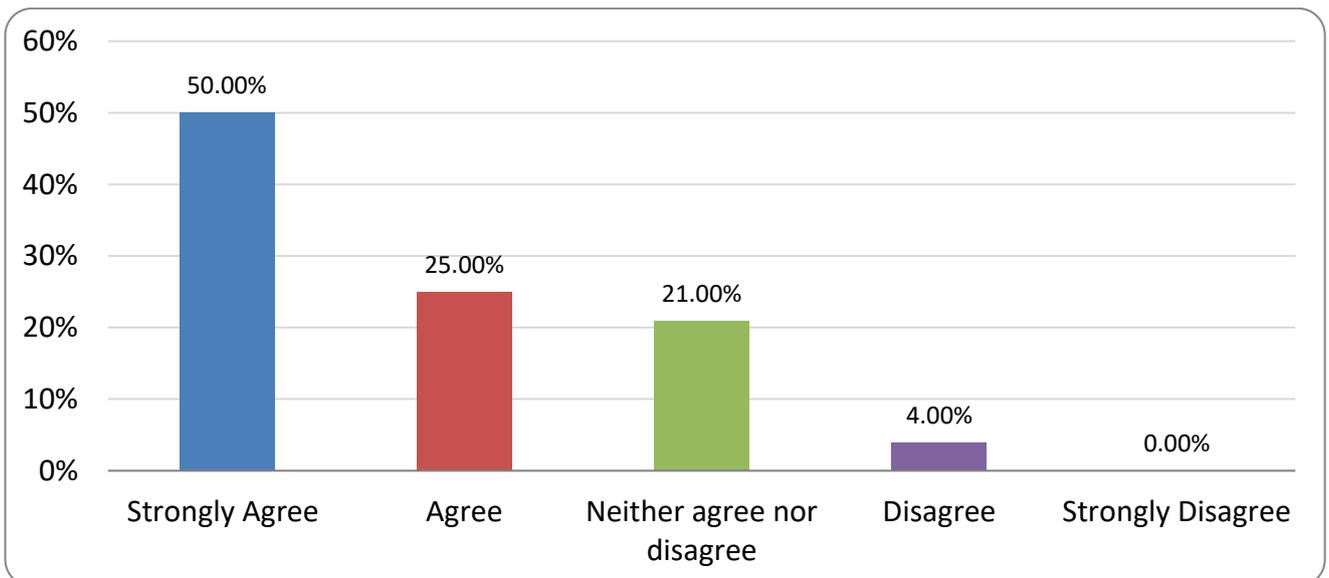
## Survey results in detail

### What is your ethnicity?



### Your experience

To what extent do you agree with the statement below. My experience (patient) within the Asthma Hub has been of high-quality care?

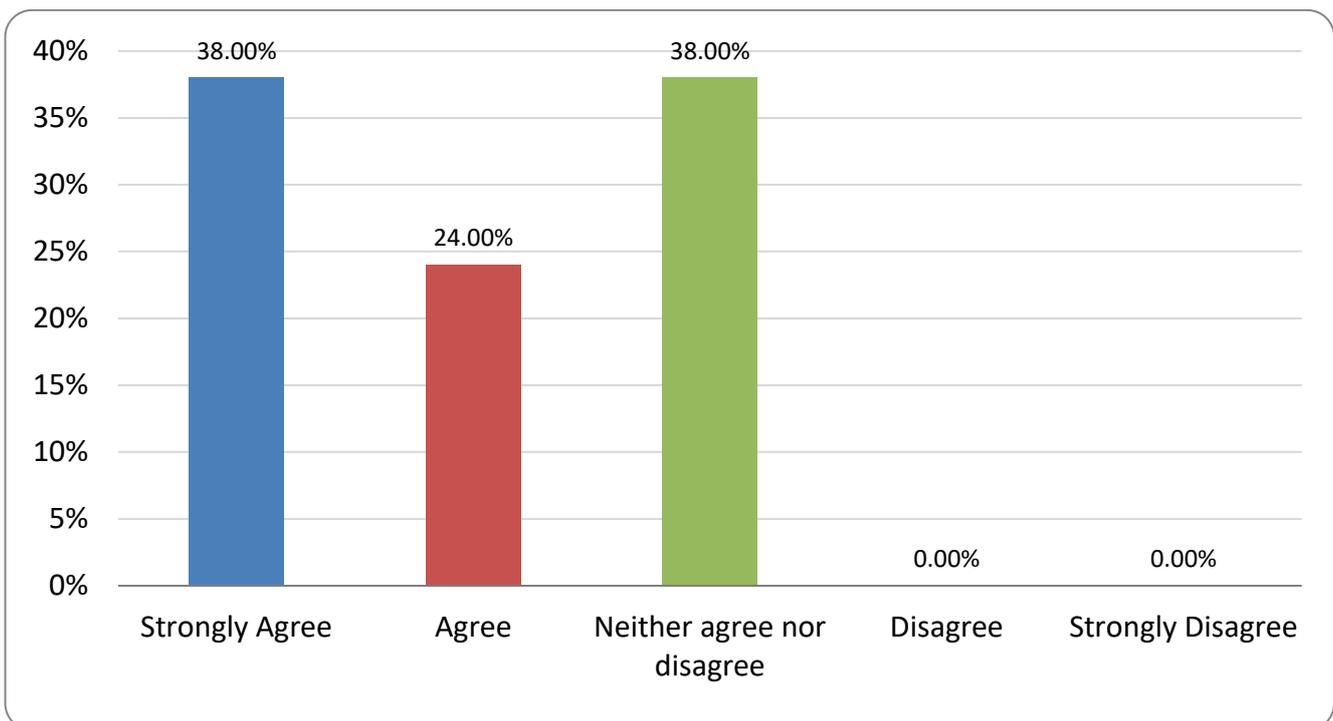


If you disagree with the above question, please tell us why...

1. I agree with the they treat [sic] us with respect

2. Kept going between patients
3. the doctor was not very pleasant to the child, she was unable to encourage her to do research
4. Still waiting for follow up that was going to be in 3 weeks that was nearly 5mths ago
5. Although we were seen within the 48 hour window, there was an incredibly long wait to be seen on the day. There has been absolutely no follow up care since this appointment and no communication with the GP.

Since attending the Asthma Hub my asthma has improved and I am happier and enjoying life more?

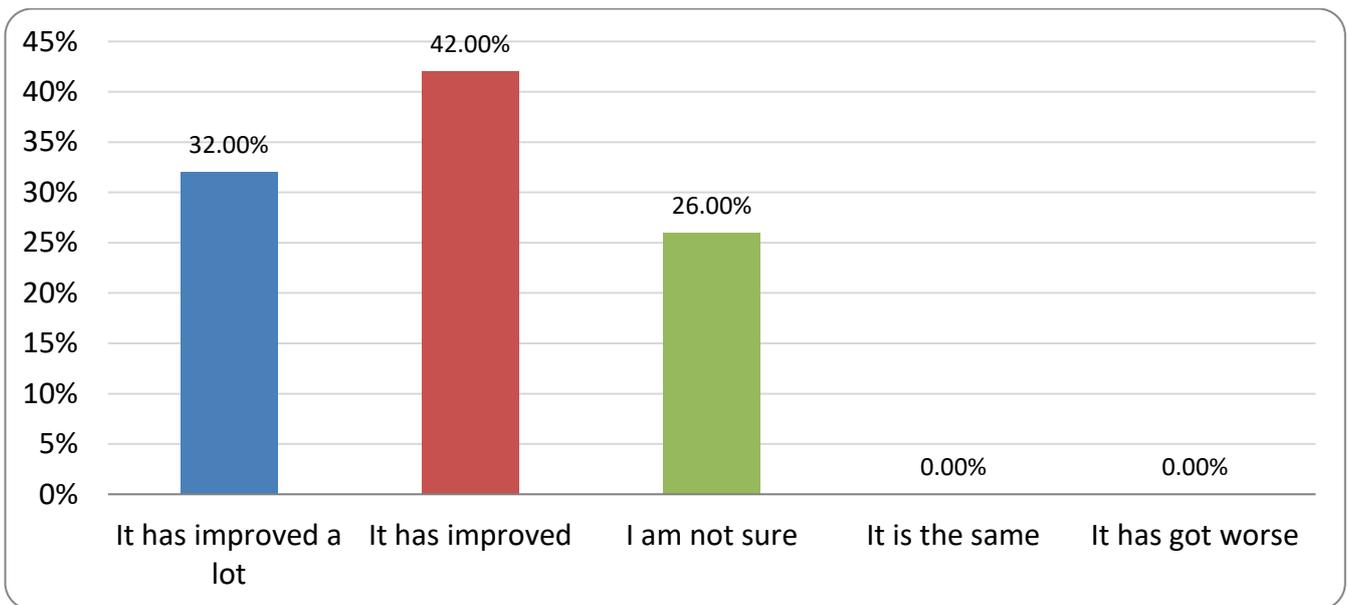


**If you have any other comments, positive or negative, about your experience at the Asthma Hub, please write them here:**

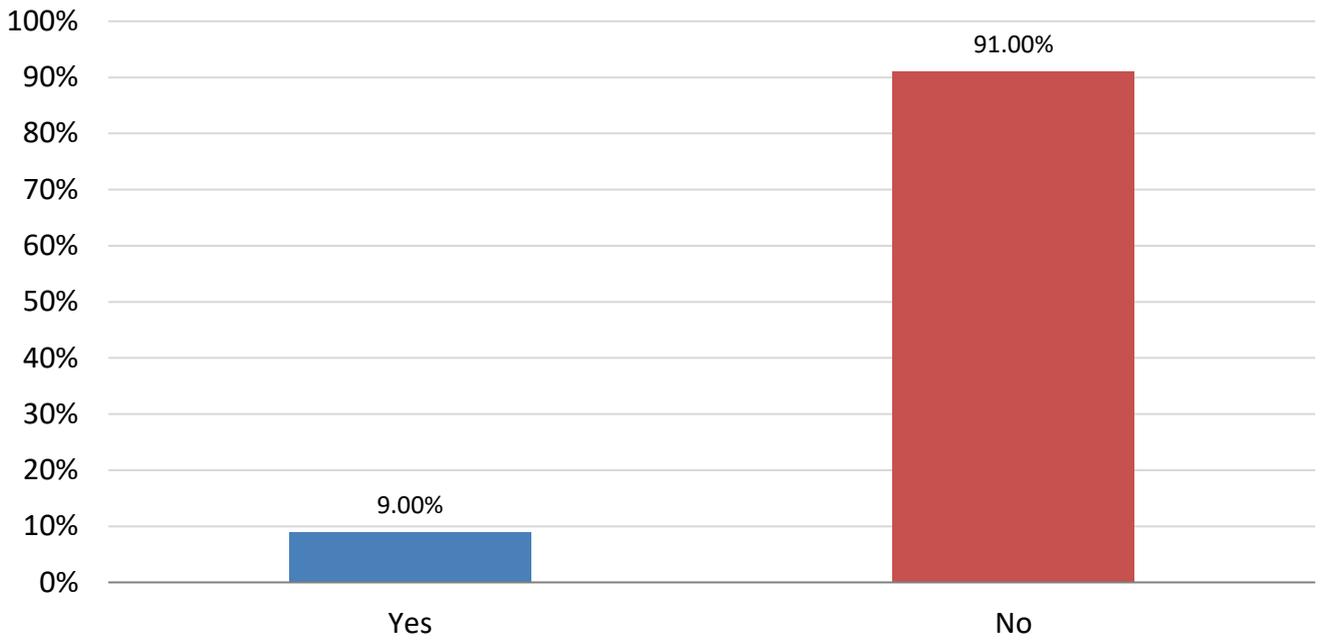
1. fewer asthma attacks after treatment is started
2. After visiting the asthma hub there was no help after my visit
3. Not as bad but no medication given so wasn't asthma hub that helped
4. I found the asthma hub to be a great safety net for my daughter, she'd attended A&E regarding her breathing and was sent home, she hadn't made much improvement by the time we saw the asthma hub who had her admitted again, their attention to detail is second to none and ensured my daughter got the care she needed

## Your health

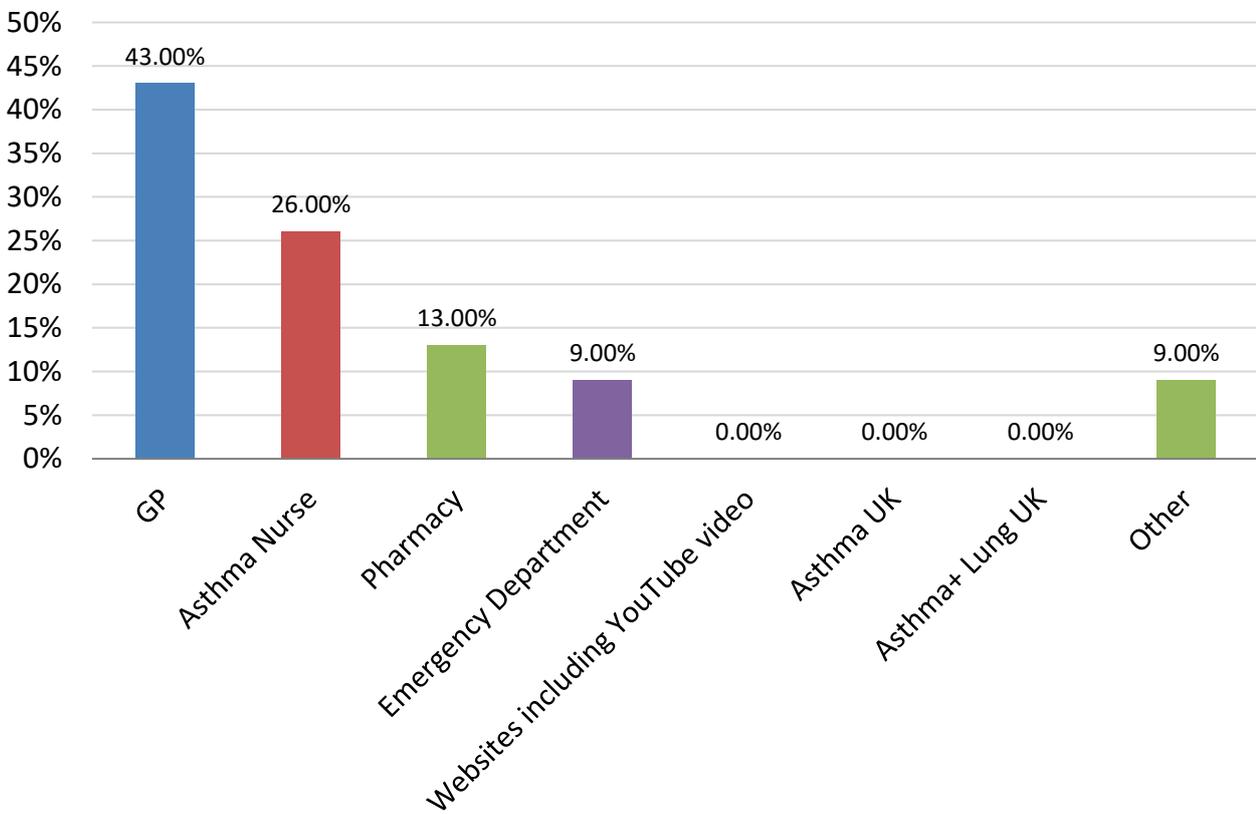
How has your asthma condition been since attending the Asthma Hub?



Have you returned to the Emergency Department because of your asthma condition since attending the Asthma Hub?



Since attending the Asthma Hub, have you engaged with any other services about your asthma? Tick all that apply



**Other:**

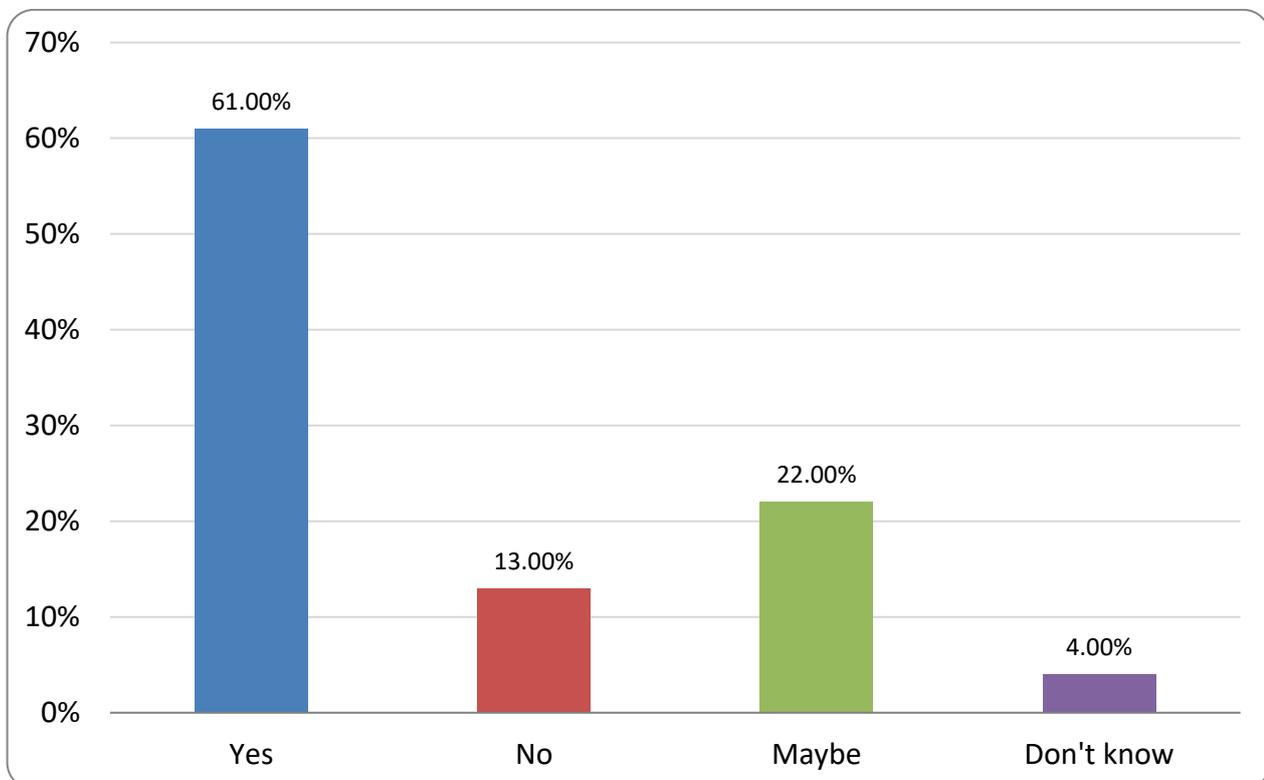
Respiratory paediatrics clinic

Gp send nurse

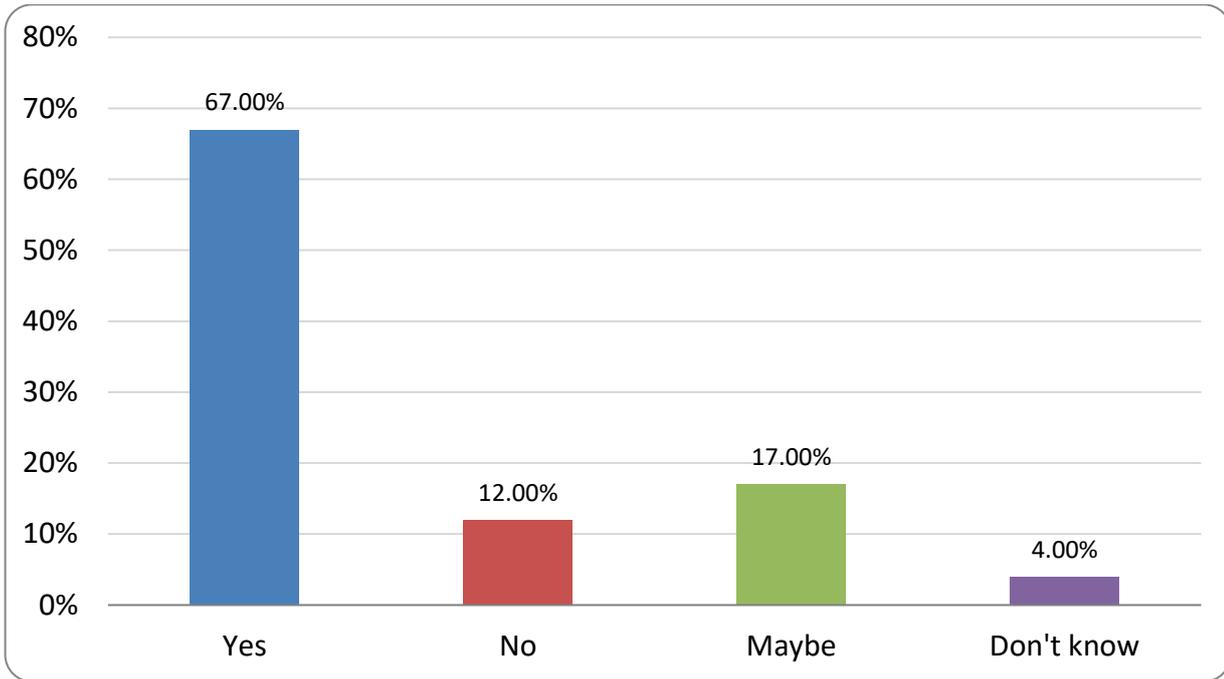
The consultant stated that once the symptoms had gone the dose of inhaler needed to be decreased and she needed to stop using the brown one so.i had to contact the gp.for that. The GP has also called me to arrange an asthma review appointment

**Learning and education**

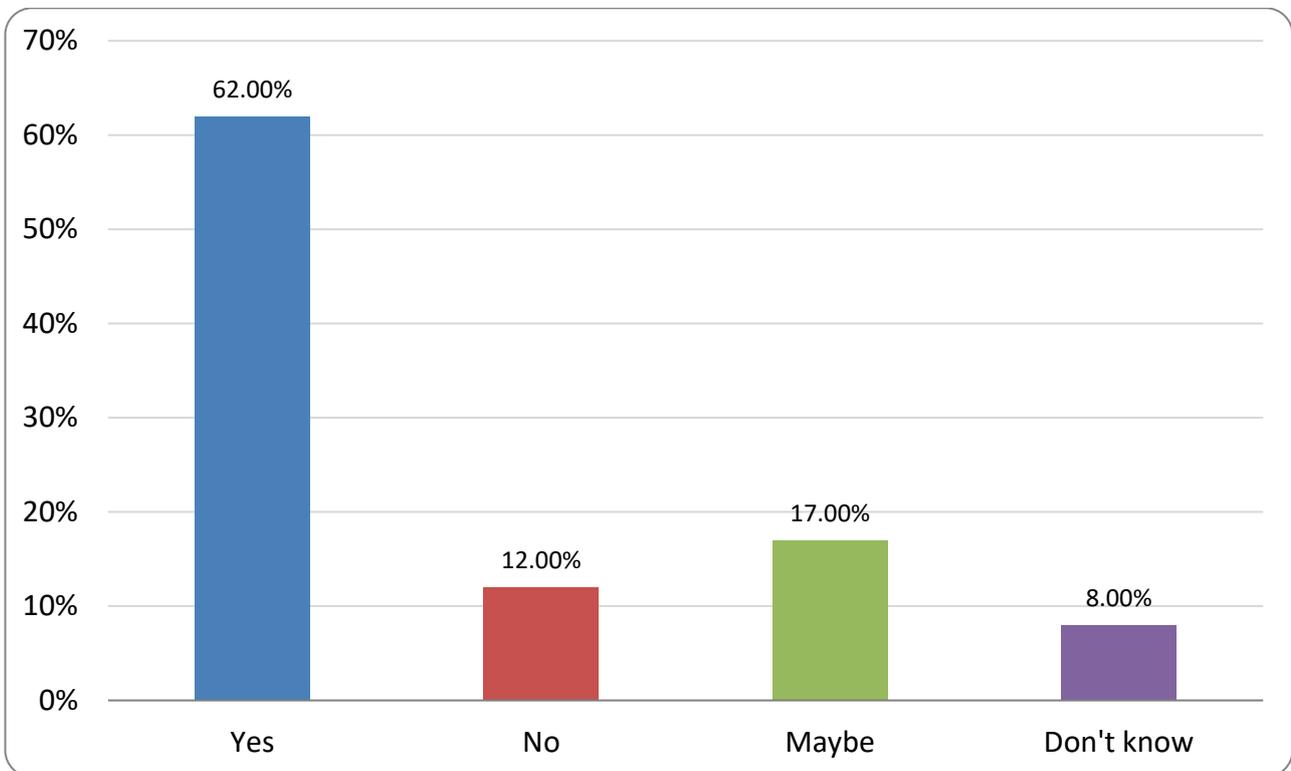
Do you feel more informed about your asthma condition as a result of attending the Asthma Hub?



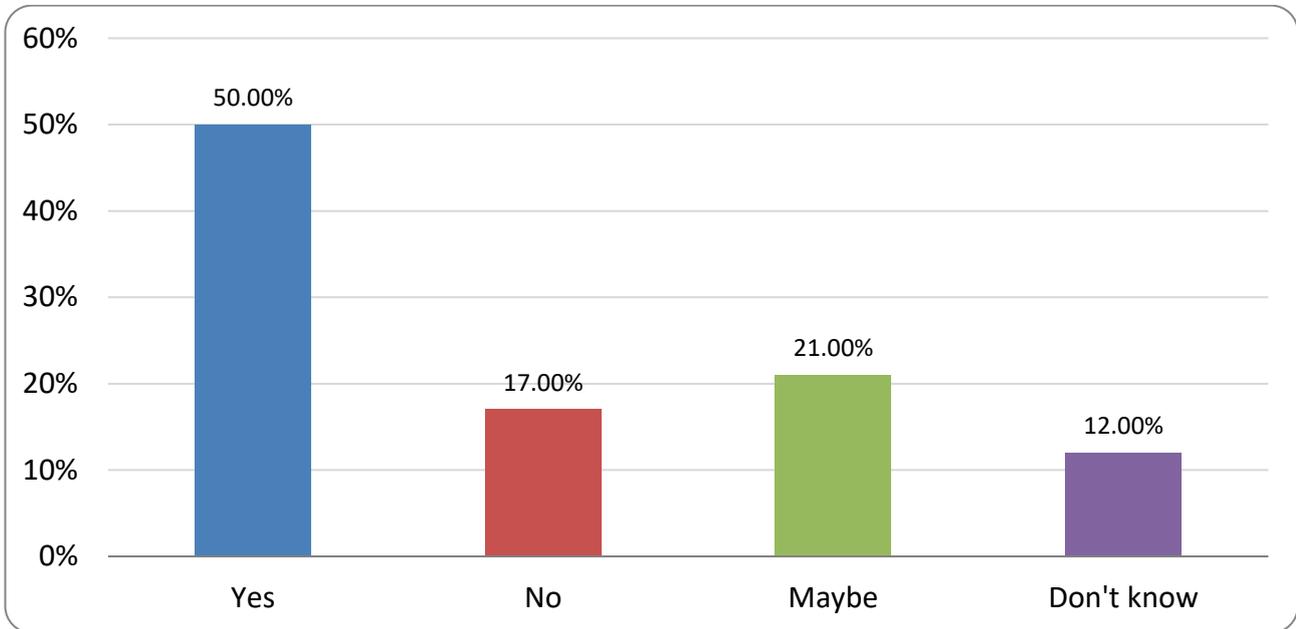
Are you managing your condition better following your attendance to the Asthma Hub?



After attending the Asthma Hub, do you feel more confident in talking to your friends about your condition?

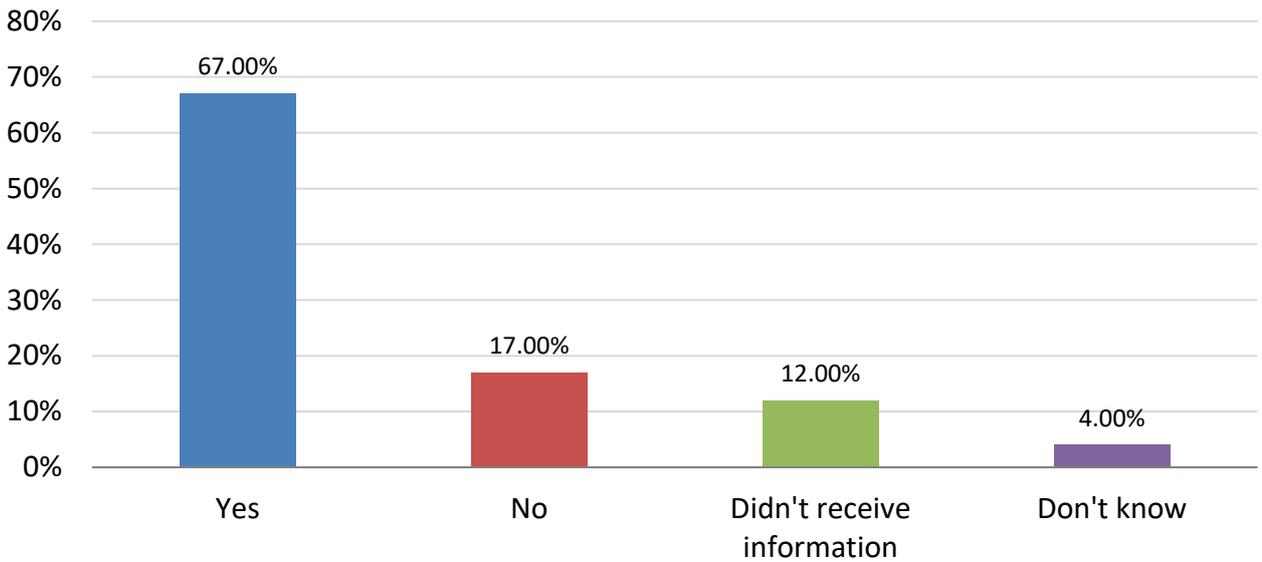


After attending the Asthma Hub, do you feel empowered to speak to adults in your life and explain your condition to them, and what support you might need? For example, teachers, sport coaches, youth workers

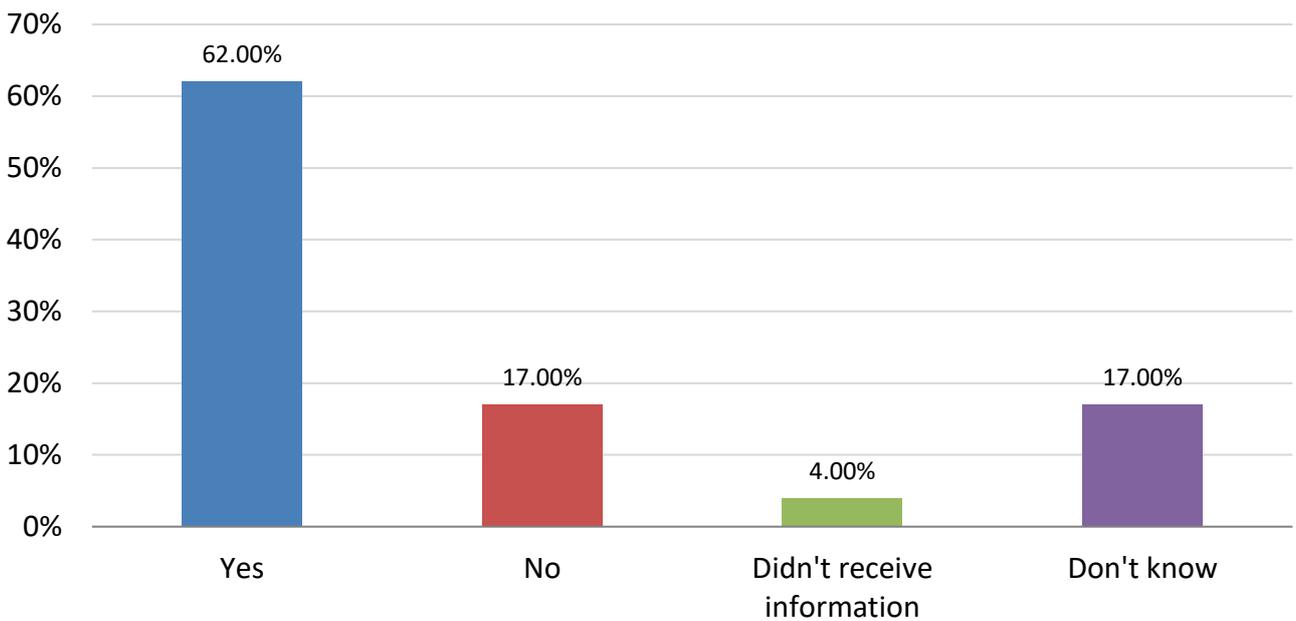


**We would like to ask you about the information you received from the Asthma Hub**

Was the information you received from the asthma hub suited to your needs?

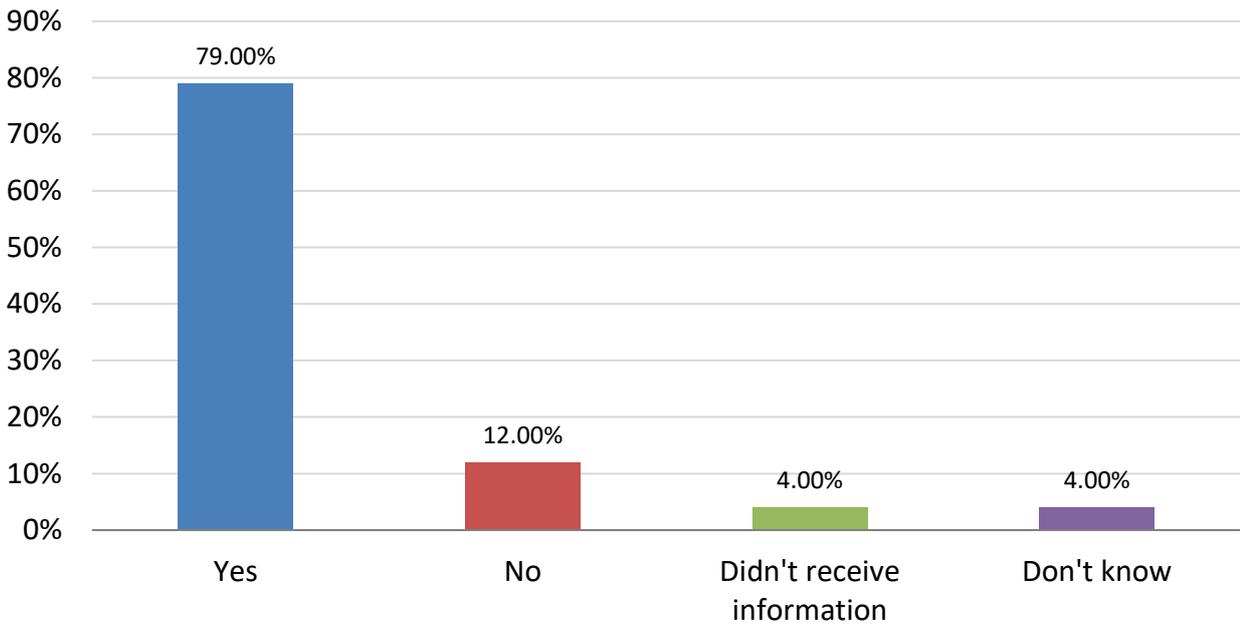


Was the information you received age appropriate?

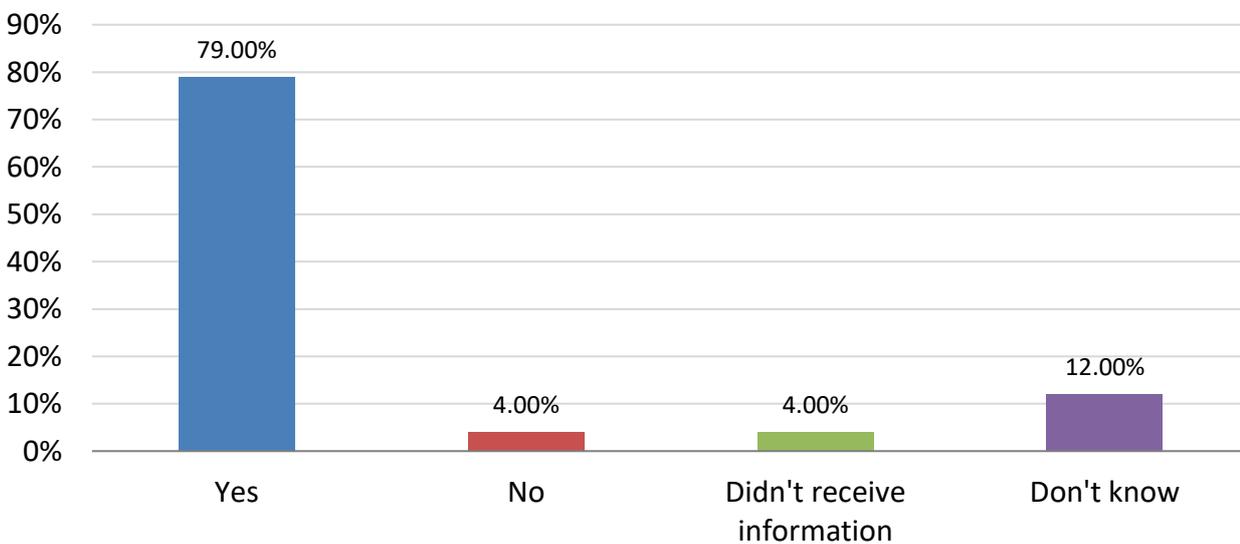


1. Spoke to me not my child

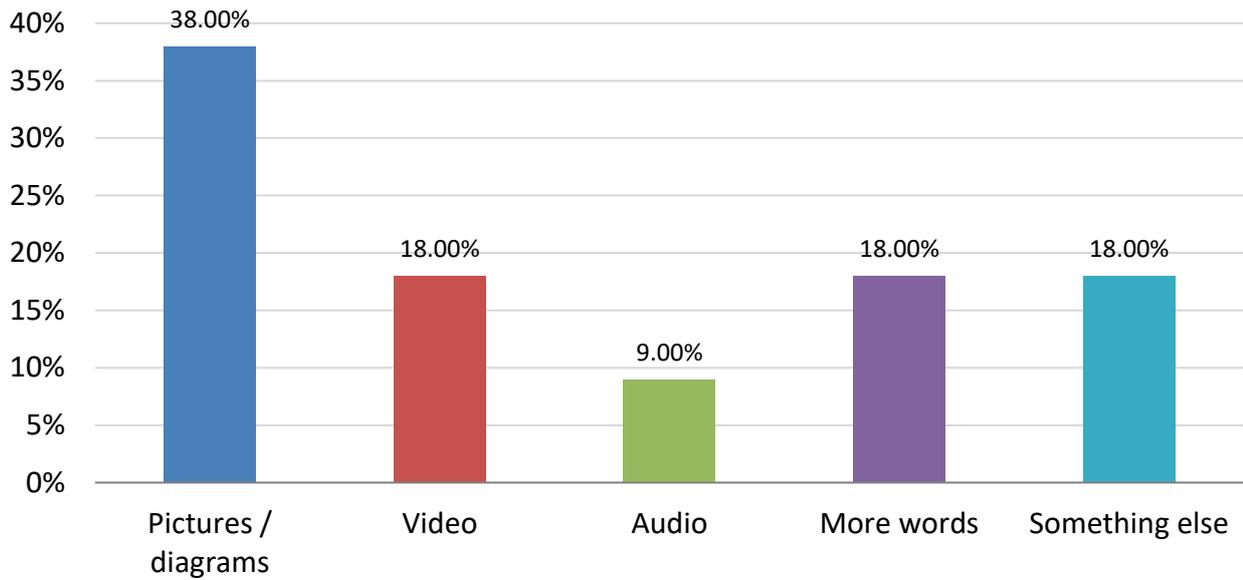
Was the information you received in a language which is spoken at home?



Was the information you received, easy to understand  
(i.e. communicated in simple words/terms)



Would you prefer the information provided to you to include more pictures, diagrams, video, audio, or something else? Tick which ones you would like more of:

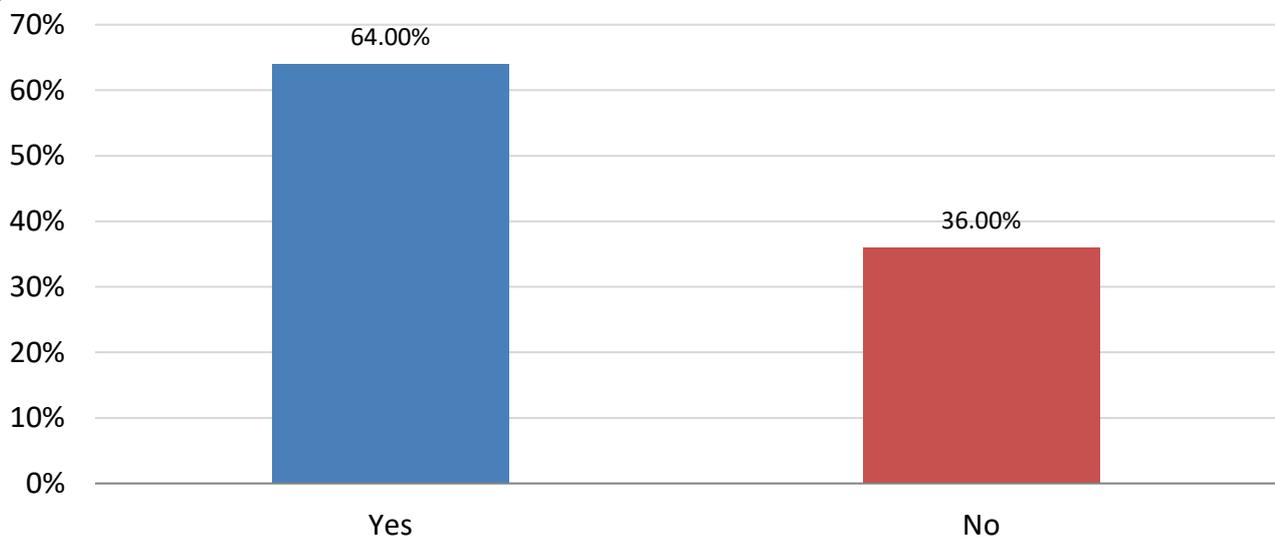


**If you answered something else in the above questions, could you please add your ideas here:**

1. Just an idea but for children you could develop a more user friendly flow result chart as the one provided in the equipment is very technical. It would also be useful for children to have some form or card they can carry with them which states what dose they are on and what they can have in the event of an attack

### **Service improvements/follow-up**

**Do you feel you are still supported with your asthma following your attendance to the asthma hub?**





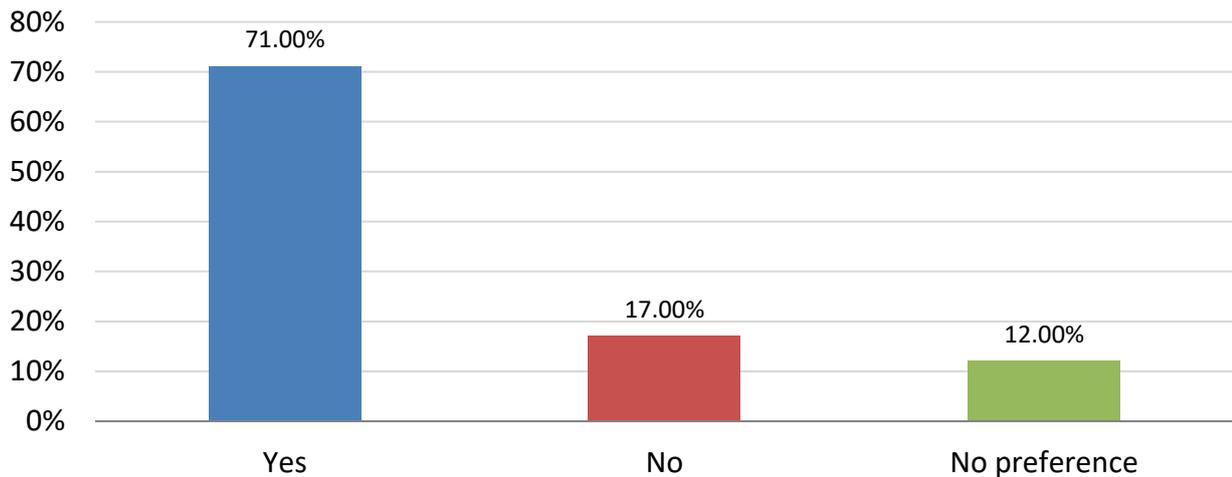
**If you answered no to the above questions, please explain why.**

1. The initial visit was great but no contact after the initial visit and told to discuss with gp going forward. Would have preferred to see the consultant at the hub
2. Struggled to get initial repeat prescription from GP. Was initially refused extra prescription to ensure medication didn't run out while on holiday. No follow up or information from GP surgery about what happens next.
3. After visit with asthma hub once no one contact us later
4. Didn't see anyone after the hub, felt a bit left to get on with it
5. As above waiting months for an appt that was meant to be in 3 weeks is ridiculous
6. constantly trying to phone the asthma hub for advice i was totally ignore and when someone did finally get back to me days later i had so much attitude from them I would not go back to them absolutely disgusted at the way my child was treated. should be close down.
7. There has been no follow up, my gp wasn't aware.
8. Don't normally see them again unless readmitted to hospital. Once discharged from there care Gp is supposed to take over but they don't normally offer any additional help or support

**What improvements would you like to see to this service for yourself and other children/young people? ( i.e. if you could change one thing in the service what would it be?)**

1. Easier access to consultant regarding concerns or questions
2. I would like no one else to be in the position we were in where it took a severe asthma attack and A&E visit to even diagnose the issue after the GP has refused a face-to-face visit twice and had not even considered asthma as a possibility.
3. Speak to the child as well
4. More friendlier atmosphere, more information. contact information regarding continuation of treatment or information on what to do next
5. Speed of appointment
6. A follow up appointment to see someone to talk to about how you are coping or if you need more help
7. To be seen
8. better support the staff not to be so rude and for them to pick up the phone
9. I would like to be seen more regularly for my child's asthma.
10. Better liaison/streamlined service with allergy clinic as I'm sure a lot of children have both allergies and asthma and it would help with fast-tracking care and reducing issues.

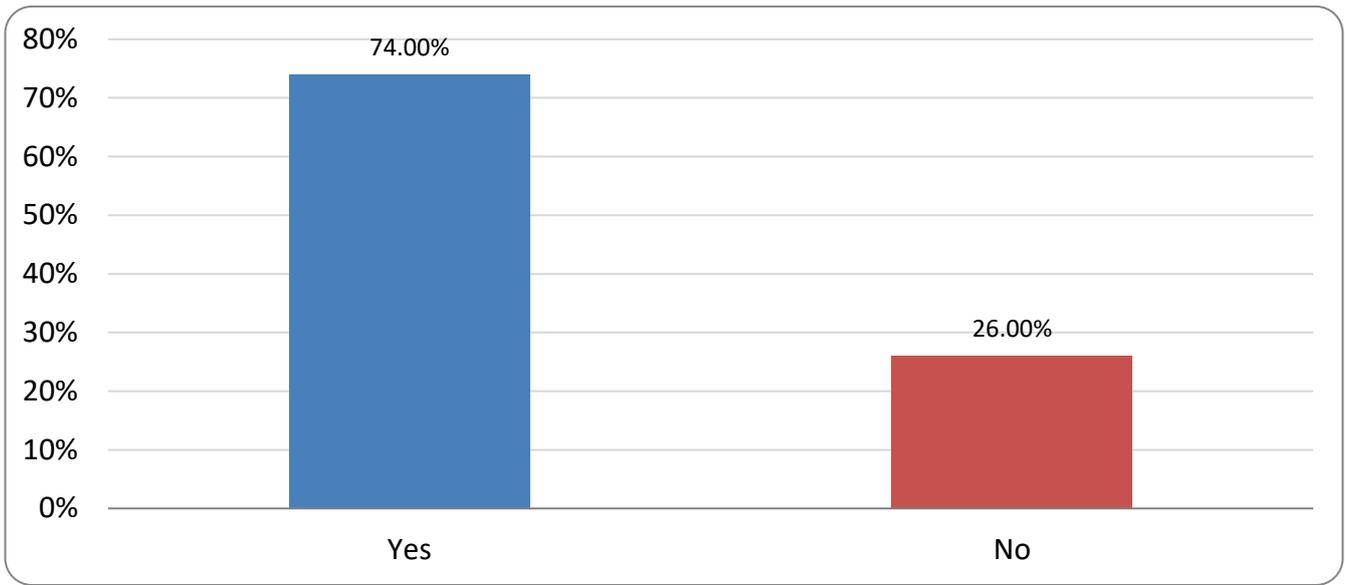
Would you prefer to attend an Asthma Hub instead of your GP/A&E for asthma support?



**Can you explain the reason to your answer to the above question:**

1. Feel more supported
2. The consultant was very knowledgeable and excellent at demonstrating how my daughter should use her inhaler
3. They are more trained
4. Because our GP refused to see a 12 yr old child twice, didn't mention him having asthma and it took an attack and taking him to hospital to diagnose. The asthma hub after the hospital visit was amazing.
5. Gp might not be specialised in it.
6. more qualified people. knowledge typically for asthma
7. More attention
8. Specialist in condition
9. GPS don't always understand
10. Gp would see my son sooner
11. By having Lesley, our asthma nurse at the asthma hub she is fully aware of Erin's severe condition and currently treats her, if I attend A&E I have to repeat her history over and over again, by being at the asthma hub the team are able to assist Erin's condition promptly
12. More personalised service and access to patients full medical history. Also, specialised asthma doctors seen so less likely to misdiagnose / mistreat as often occurs when presenting at A&E.

Did you feel the Asthma Hub was appropriately placed geographically (i.e., is the location of the asthma hub appropriate?)







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