

# Children, young people and families' experiences of chronic asthma management and care

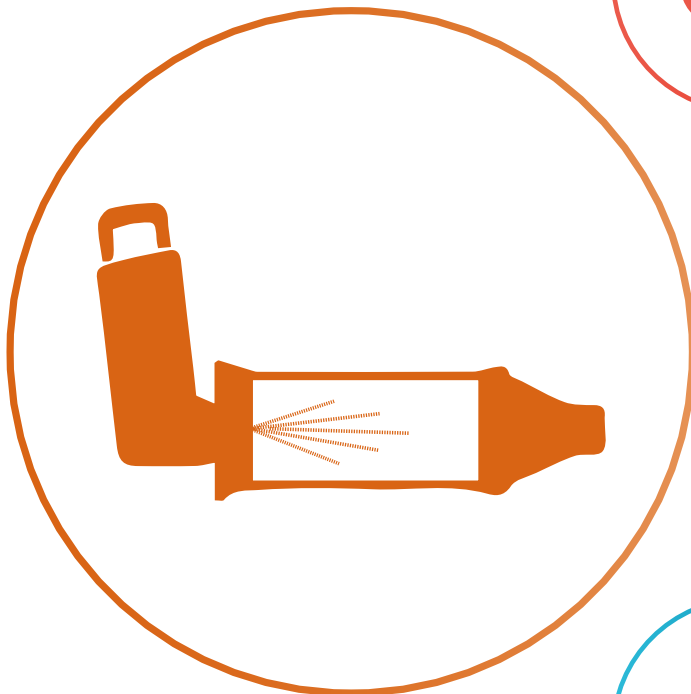
Themes from engagement work



Jeremy Sachs & Emma Rigby  
March 2021

# Contents

Executive summary	3
Introduction & context	4
Methodology	6
Who took part?	7
Themes from the engagement work	8
Recommendations	13
About the organisations undertaking this work	15



# Executive summary

How do young people feel about the way in which their asthma is managed? What kind of information works best for them and what kinds of services and support do they need to ensure good care and asthma control?

Improving asthma care for children and young people is a priority of the NHS England Children and Young People's Transformation Programme. This project was designed to ensure that young people's and parent's voices are at the heart of the programme and was undertaken alongside a scoping review of published evidence about children and young people's experiences of asthma. Given that asthma has a disproportionate effect on young people living in deprived areas and ethnic minority groups our aim was to better understand the experiences of groups of young people from communities which have been marginalised and those living in more deprived areas.

One to one interviews and focus groups with parents and young people were held and identified some key areas for future focus that would support young people to better manage their asthma, and enable them to take greater agency over their health management.

These included:

- **Access to trusted information in formats** that work for young people and using non-clinical language
- **Youth friendly services and care in non-clinical settings** that young people can access easily with the opportunity to build relationships with key staff
- **Anti-prejudice training for healthcare staff** as the general prejudice that some groups face impacts their asthma care
- **Myth busting in communities** to help support the sharing of accurate information and avoid delayed diagnosis
- **Broader education in the community** so that teachers, youth workers, sports coaches and wider society better understand the impact of asthma and stigma is reduced.

This project took place in the context of the Covid-19 pandemic which led to significant challenges to engagement. Despite these constraints rich qualitative data was gathered from young people and parents whose voices are often not heard. The messages from the different groups of young people and parents highlighted many common themes as well as some issues which were distinct for particular communities.

# Introduction & context

This work was a priority project of the [Health and Wellbeing Alliance](#), a group of organisations that have been brought together to bring the voluntary sector's voice and expertise into national policy making. The project was designed to directly inform the work of the Children and Young People's Transformation Programme in NHS England and NHS Improvement (NHSE&I).

The [Young People's Health Partnership](#) led the project working closely with our partners the [Race Equality Foundation](#), [Friends, Families and Travellers](#) and [RCPCH &Us](#). The project included a scoping review and an engagement programme with young people with asthma and their families. The aim of this engagement was to better understand young people's experience of managing chronic asthma and how asthma care and management could be improved particularly for groups experiencing exclusion and living in areas of deprivation.

Our partnership enabled us to reach young people and their families from groups whose voices may be missing from mainstream conversations about health and inequalities. Our focus was to hear from Black and Minority Ethnic young people and families, including Gypsy and Traveller young people and families and young people from a range of different geographical locations with the focus on the most deprived areas.

The scoping review examined evidence from the UK of children's, young people's and families' experience of managing and receiving care for chronic asthma. Where possible, the review identified the specific experience of marginalised groups. The review identifies useful themes for the future and should be read alongside this engagement report. It also highlights significant gaps in our knowledge. In particular, a lack of recent participatory research focussed on eliciting the views and experiences of older adolescents and young adults as independent users of healthcare services. There is also a dearth of evidence on the specific views and experiences of young people from different marginalised groups. This includes a lack of evidence relating to a diverse range of minority ethnic children, young people and families including for example African, Caribbean and Gypsy, Roma, Traveller communities. Whilst our engagement work was not designed to respond to these findings as it ran alongside the drafting of the scoping review the findings highlight the importance of better understanding the experiences of the young people and their families in relation to asthma.

## Why is this important?

Around 1.1 million children (one in eleven) currently receive asthma treatment in the UK, making it the most common long term medical condition among this age group. It is also the most common reason for urgent admissions to hospital in children and young people in England. Furthermore, emergency admissions for asthma are strongly associated with deprivation.

These findings are drawn from the [Scoping Review](#).



### Friends, Families and Travellers gave us examples of additional barriers that some communities face:

Romany Gypsy and Irish Traveller communities are ethnic groups and are therefore protected from discrimination under the Equality Act. Gypsies and Travellers' experience stark educational inequalities which contribute to barriers to services relating to a lack of accessible information. We know from [previous research](#), that this relates to verbal, as well as written, information. Around 40% of people who use FFT services have low or no literacy. In addition to this, Gypsies and Travellers experience disproportionately high levels of [digital exclusion](#), as a result of factors such as low or no literacy, and lack of access to wifi on sites, or data and devices.

Some evidence also shows that Gypsy and Traveller sites are disproportionately located by motorways and sewage works, which contributes to high levels of air pollution.

# Methodology

The aim of the project was to better understand the challenges and barriers children and young people face when managing chronic asthma, with a particular focus on understanding different types of vulnerabilities and reducing health inequalities.

## Questions from engagement methodology

- For children and young people who have chronic asthma **what gets in the way of them getting good care?**
- **Where** do you think children and young people would like to get more support from to manage their asthma?
- **Who** are the people who can best support care – what is their role (teacher, GP, youth worker) AND what skills do they have that help you?
- **What** do you think is the most effective way to communicate with children and young people like you to support better asthma care?
- **What methods** of communication are the best for you? Staff, teachers, social media, AND which social media?
- **What one thing** did young people say they would like to change for the next generation of children and young people who have asthma?
- **Anything else** that emerged but which did not fit the framework.

The organisations involved in the work collaborated to create an appropriate methodology which was then agreed with NHSE&I policy leads. Focus groups and interviews were structured around agreed questions (listed in the box above), which were used by facilitators consistently throughout the data collection process. However, to access young people, who may not usually engage with projects or focus groups, the methodology allowed for flexibility in its delivery.

Each conversation was run by a facilitator with expertise in directly working with children, young people and families from their communities / areas of focus. This enabled young people and parents to feel as comfortable as possible answering the questions. The facilitators had the freedom to respond to the needs of those involved by amending or asking additional questions or designing and running activities around the questions, to make the session as engaging and safe as possible for those involved.

All groups and discussions took place remotely via video call or by telephone due to the fact that the work took place during the Covid-19 pandemic and third national lockdown and all conversations were recorded with consent of participants.

# Who took part

Overall we engaged with 22 parents and 14 young people. Significant efforts were made to recruit young people and parents to take part in the project. Engagement work which seeks to engage with young people with a specific experience of a health condition is always challenging to recruit to in large numbers.

In addition we sought to engage with groups that have been marginalised within the context of a global pandemic and (for part of the project) during the third national lockdown. We also faced the challenge of engaging young people with asthma during the winter months when asthma is likely to be worse and therefore in itself could be a barrier to engaging. Despite these significant barriers we had rich feedback from parents and young people. Finally we recorded and transcribed a session with project workers from all partner organisations which set out common themes and issues from their perspectives which we have referred to in drafting this report.

## **Friends, Families and Travellers (FFT)**

Interviews were held with six women and one man aged 10 years, 20 years, three aged 24 years, 45 years and 50 years. The participants were from a different ethnicities, including three Romany, one Irish Traveller, one from a White British from a New Traveller/Showman background and one dual heritage, Mixed White/Black African.

## **RCPCH &Us**

Interviews were held with seven young men and three young women aged 11-16 years and based geographically in Nottingham, Birmingham, Sheffield, Essex, Oxfordshire and Liverpool. The participants were from White British & Asian Bangladeshi ethnicities.

## **Race Equality Foundation**

Interviews were held with 13 parents of children with asthma and three young people living with asthma in one to one interviews. A focus group of four parents was also held. The young people were two 19 year old young women and one 10 year old boy. The parents were all women. Participants came from a wide range of ethnic groups including Caribbean, African, Mixed White/Black Caribbean, Egyptian, Bangladeshi, Turkish, Pakistani, Kashmiri, Columbian, Somalian and Albanian.



# Themes from the engagement work

The young people and parents who took part in the project shared a range of thoughts and challenges relating to their (or their child's) experiences of asthma. Here we have summarised some of the main themes that emerged. The headings used reflect the questions that were asked of each young person and parent / carer.

## How does asthma affect young people?

Young people from different backgrounds feel that asthma is a complex condition to live with. It not only affects their health but also their social and emotional lives. Asthma can put limitations on young people's lives, from managing and adhering to medication and wearing appropriate clothes in winter to symptoms being frightening and painful and inhibiting them from taking part in activities.

Constantly having to do assessments of what activities they can and cannot take part in is a challenge for young people with asthma. This can be made worse when there is a lack of understanding or stigma around the condition. Youth leaders highlighted how many of the young people felt stigmatised for having asthma and therefore did not want to use their inhalers at school.

A smaller number of young people also told us that they do not let asthma define them. It is a condition they have always lived with and it is a way of life that does not bother them.

*“ It can feel like a heart attack. ”*

Young person

*“ I was particularly surprised by how many people mentioned the stigma thing and kids being scared to pull out inhalers. ”*

Youth leader

## What do young people do to keep healthy?

All young people, regardless of background, told us that they try and look after their general health in order to support their asthma. For example, they reported drinking plenty of water and eating a balanced diet.

*“ I find that sugar and dairy foods can make asthma worse, so we just try to eat clean. ”*

Parent

*“ Seeds from Saudi Arabia mixed with warm milk, it's been a life saver. ”*

Young person

Some young people told us they had to take extra care of themselves when unwell, so as not to exacerbate their asthma. Some young people, particularly the young people from the [RCPCH &Us](#) mentioned doing specific activities to stay healthy. These involved targeted things like breathing exercises and swimming.

Alongside general wellbeing and adhering to care plans, some young people told us about herbal remedies that have helped them. Non-conventional beliefs about asthma and use of herbal or alternative medicines were raised a number of times with both young people and



parents. They told us alternative remedies often are more reliable because they can't get clear information from NHS sources.

Parents told us that they needed to be very mindful of the environment their child was in and how to make it more asthma friendly.

However, this can be difficult for a parent if they are not aware of what triggers there could be in the home environment that make asthma or breathing difficult.

*“ Remedies like black seed oil, honey, warm milk, I do things like that. ”*

Parent

*“ With the carpet, even though I'm hoovering, cleaning it took me a while to realise that carpets were a trigger, so when we recently moved houses we got a laminate. Temperature definitely makes a difference, the minute it's cold, I may not feel as cold, but his chest gets heavy, wheezy to the point where I always try and layer him but he's a teen now so with teenagers you can't tell them what to do because they start making choices and think they know better. ”*

Parent

### **What advice have young people been given about keeping well?**

#### **Does it work and could it work better?**

Asthma care for young people is often a family effort and all young people involved in the project said they often turn to family first for health advice, that family support was essential and had the power to be very supportive. However, it can become problematic when the information family members have is incorrect or based on myths. Some young people from **Friends, Families and Travellers** mentioned “old wife's tales” told to them by families, that asthma skips a generation. These beliefs have caused delays in getting medical support or meant that children sometimes go without a diagnosis. Due to the barriers these young people face some will not have access to mainstream health messages and therefore only receive information on how to manage asthma from family members and peers.

A lack of age appropriate materials and the over use of clinical language made young people from all three groups feel isolated and without the knowledge they needed to manage well.

A lack of accessible information was particularly challenging for the young people and parents from **Friends, Families and Travellers** and the **Race Equality Foundation**. Barriers included written and verbal advice which did not feel clear to them, leaving them feeling in the dark about asthma care, how to use inhalers, how to get a diagnosis, and follow up care. Families and young people for whom English is not their first language highlighted that they had no way of accessing asthma information in their first language. One parent had recently completed an online asthma health check for their young person's asthma and had stated that they had left a number of the questions blank as they had felt this was confusing and the wording was complicated.

All young people taking part acknowledged that better access to information means they are able to manage their condition better. This is true in relation to using inhalers, avoiding environmental triggers such as avoiding dusty rooms, managing pollen season and dressing well in cold weather. Young people felt that the advice they have received that worked best was delivered in three different ways:

- **youth friendly videos demonstrating inhalers and giving advice**
- **time with doctors or asthma nurses**  
that was not rushed, was directed at them (not a parent) and in plain language
- **healthcare in non-clinical settings**  
(home visits and schools)

### Who do you go to if you need support?

It is clear from the feedback received that young people reach out to different people for support. They mentioned multiple people within their communities who serve this role. Close family members were mentioned frequently by all the young people, as were teachers, football coaches, support workers and friends. Healthcare professionals, such as doctors, nurses and pharmacists were also mentioned, however, some young people felt that support from these professionals was limited by a reliance on written information and feeling unwelcome or discriminated against in clinical settings.

Young people told us that within their broader communities they will look for people who have good listening skills, are friendly and able to keep conversations light and provide age appropriate information.

Parents expressed frustrations when trying to access support from doctors and that they would turn to the internet for advice. Many parents and carers felt left in the dark about how to care for asthma and lacked accessible information about it. Some parents highlighted bad experiences in primary care, where they felt healthcare professionals rush them or don't take time to make sure appropriate information about asthma is understood by the young person or parent / carer.

Some young people told us that where good relations have been built between them and healthcare professionals, those professionals become a trusted source of support.

*“ I do use the internet a lot for information on anything I'm intrigued about. Who else are you supposed to use? Can't get hold of your doctor. ”*

Parent

*“ She's amazing (asthma nurse). She's really really good. She knows me on a personal level, but I've always reviewed with her. ”*

Young person

### Where do you think children and young people would like to get more support from to manage their asthma?

All young people told us that better support from clinical professionals would be welcome. Access to healthcare professionals on a drop-in basis and one-stop-shops in GP practices that could include asthma nurses or respiratory clinics were mentioned specifically by young people and parents from FFT. Nomadic Gypsies and Travellers may face significant barriers (such as refused registration) in primary care services, and difficulty establishing continuity of care. One-stop-shops provide opportunities to proactively engage with the health needs of groups who face more transient engagement with services.

The **RCPCH &Us** young people reflected similar ideas suggesting that Community Hubs and specialists in pharmacies would be useful. Young people from the **Race Equality Foundation** highlighted the continuity in staff at asthma reviews held every few months, which was felt to be very supportive and the staff felt like friends, which aided good asthma treatment.

Youth leaders highlighted young people transitioning to adult services as something that required focus. The conversations highlighted a need for professionals to start preparing young people for adult services in KS3 (aged 13 to 14). Examples were given of young people being held back in paediatric care because adult services weren't going to provide appropriate care for the young person.

Young people also spoke about the importance of broader education about asthma in their communities. This included at work, school and among friends. Not only would they like trusted adults in their lives to have reliable asthma information, they also felt that better knowledge would lead to less stigma about living with asthma.

It was also acknowledged that better knowledge not only means more trusted sources of information and less stigma, but that knowledge could save someone's life during an asthma attack.

*“ I'm not using it as an excuse to get out of doing PE. ”*

Young person

*“ Well we're currently staying with my mum, because the mold and damp in my flat is so bad. That makes both of our breathing so, so much worse. Everything's so damp, I had to keep my daughters clothes in plastic boxes. ”*

Parent



**Tell us one thing that you would like to change for the next generation of children and young people who have asthma?**

All the young people agreed that better health literacy delivered in accessible formats, be that videos, more access to jargon free youth friendly medical staff or leaflets and infographics would be a welcome development. Better environmental conditions were also welcome. This ranged from asthma education in communities to improved housing with no damp or mould and improved air quality. Health services advocating on young people's behalf were also welcomed by a young person whose GP had written to the local authority regarding the poor air quality / damp in their current home. Medical evidence that health professionals provide on the impact of environmental factors can play an important role in improving asthma symptoms and control.

There are particular environmental issues which affect Gypsy, Roma and Traveller young people and families which were highlighted in the Scoping Review and referred to again by a young person in the engagement work. It is clear that air pollution and its relationship to asthma is of key concern for many Gypsy, Roma and Traveller families.

The young people wanted to see non-medical professionals have better asthma knowledge as well. Teachers and youth workers understanding more about asthma management would mean young people had trusted people to go to for advice, and this advice could be shared among all young people in different communities. This would not only help young people with asthma access trusted information but could also help to decrease stigma. Many parents told us their child did not adhere to their treatment due to not wanting to look bad or be judged at school. Young people may use their inhaler occasionally but not their spacer due to the fear of stigma it may bring.

Some parents told us that they would like to see more young people with asthma be able to take agency over their own asthma, so that the young people themselves have the tools they need to spot the signs of an asthma attack and know how to manage it. This may be particularly pertinent for older young people as they transition to managing their asthma independently. Parents and carers told us that they felt the lack of information for young people and this was a crucial area for change.

*“ Some sites are really bad. When I was living on a site in London when I was younger, that’s what made my asthma so bad as a kid. There were always cars driving past you, and petrol, non-stop. That definitely makes it worse. ”*

Young person

*“ She’s just ashamed that she’s getting out of breath, you know and all her other friends aren’t getting out of breath, you know. And I don’t know sometimes if she equates it to a weight thing, like ‘I’m overweight, is that why I need to use a pump’ so I think she might have been like that sometimes. ”*

Parent

*“ Teaching her more how to manage it when she’s by herself and for her to look for the signs more. ”*

Parent

# Five recommendations from young people

## 1. ACCESS TO TRUSTED INFORMATION

Information on asthma needs to be provided in a variety of formats to meet the different needs of different young people in a developmentally appropriate way. Online resources like videos and infographics work really well for some young people. Other young people, due to educational and digital exclusion, may not find this as accessible. Co-producing information with young people and the organisations they trust to ensure it is clear and meaningful would be welcomed.

Drop in sessions at GPs and pharmacies where young people and families can speak to healthcare professionals all under one roof would be beneficial to both young people and parents.

*“ I find that most of the time what they tell you isn't clear and information is worded in a complicated way so you don't always know what you're supposed to do, or how to use inhalers and stuff. ”*

Parent

## 2. YOUTH FRIENDLY SERVICES AND CARE IN NON CLINICAL SETTINGS

Access to youth friendly services is also important. Communication in GP practices, hospitals and pharmacies with accessible language that is jargon-free and age appropriate is important. Young people value friendly, non-judgemental, informed and knowledgeable styles of communication.

Young people also value being able to see doctors or specialist asthma nurses in non-medical settings. Home visits and school nurses make young people feel they are able to engage with asthma treatment and advice in their own time in environments where they feel more comfortable. Confidentiality too can be inconsistent when a young person can see a GP alone but needs an adult with them to pick up medication from the Pharmacy. Healthcare services linking with [VCSE Health and Wellbeing Alliance](#) organisations with trusted community networks can support the provision of assertive outreach and care in non-clinical settings.

*“ I think there needs to be a specific asthma clinic, for asthma and other respiratory issues. Just one place you can get to easily that you can drop-in to and get support for a whole range of stuff. GPs don't always have the time or the right information, so if there was just one place you could go where they'd focus on respiratory stuff it would really help...a place you could drop-in to. ”*

Parent

### 3. ANTI-PREJUDICE AWARENESS

Young people told us that they have encountered prejudice when trying to access healthcare support for their asthma. Attitudes from GP reception staff and doctors can present more barriers to young people getting support for managing their asthma. For some socially excluded groups refused registration in primary care can lead to delayed diagnosis of asthma.

Better awareness of these barriers, anti-prejudice policies and training to tackle discrimination for staff needs to be in place to ensure young people are getting the treatment they are entitled to.

*“ If you’re a Traveller you wouldn’t get no support because they didn’t like you. That was both school and the doctors. ”*

Young person

### 4. MYTH BUSTING

Myth busting about asthma in community appropriate ways is needed. Young people want to turn to their families for support and work to provide families with information about asthma that is accessible to them is needed. This has the potential to support earlier diagnosis and support better care management. Knowing what information is true and what is not can also help young people take agency over their own healthcare, manage their asthma and get on with their lives. Peer led approaches such as the Royal Society for Public Health Youth Champion model can support the cascading of key health messages which are tailored, and accessible to those with low or no literacy.

*“ Children may go undiagnosed due to the belief that asthma skips a generation. ”*

Parent

### 5. BROADER EDUCATION AND STIGMA REDUCTION

Young people and parents told us about the stigma and misconceptions about asthma that they have experienced. A broader education programme for young people and all professionals that come into contact with young people as well as society at large could help to increase awareness of how asthma impacts young people and reduce stigma.

*“ It would also just be really handy if they did more awareness raising campaigns in school, where medical staff go in to the schools and teach about asthma and support young people with it. Asthma support and information shouldn’t just about the person – everybody will have a family member or close friend with asthma, so we need to teach this in school so everyone has a better understanding. ”*

Young person

# About the organisations undertaking this work



Young People's  
Health Partnership

ayph | Association for  
Young People's Health

The **Young People's Health Partnership**, led by the **Association for Young People's Health**, is a consortium of six national youth and young people's health charities working to represent the interests of young people and young adults aged 10 – 25. We focus specifically on young people facing health inequalities.



Friends Families and Travellers

**Friends, Families and Travellers** works on behalf of all groups of Gypsies, Roma and Travellers regardless of ethnicity, nationality, culture or background. We have strong roots in Gypsy, Roma and Traveller communities of all ages.



The **Race Equality Foundation** seeks to explore discrimination and disadvantage, and use that knowledge to help overcome barriers and promote race equality in health, housing and social care.



The **Royal College of Paediatrics and Child Health/ RCPCH &Us** is the voice of children, young people, parents and carers for the college, created to actively seek and share their views to influence and shape policy and practice.



**VCSE Health and Wellbeing Alliance** is a partnership between voluntary sectors and the health and care system to provide a voice and improve the health and wellbeing for all communities. This work has been funded via the Health and Wellbeing Alliance.

[info@youngpeopleshealth.org.uk](mailto:info@youngpeopleshealth.org.uk)  
[www.youngpeopleshealth.org.uk/yphp](http://www.youngpeopleshealth.org.uk/yphp)



@YPHealth