

children's asthma

NHS

**Leeds West
Clinical Commissioning Group**

Engagement dates: October 2014 – March 2015

Patient feedback report

Final July 2015



Summary

Asthma is a serious condition, and if not treated properly can lead to asthma attacks, which can be life threatening. But with the right medicines, taken properly and as prescribed, children should be able to lead a full life without symptoms.

This NHS Leeds West CCG engagement asks children, their families and their schools to share their experiences of asthma. Feedback from the engagement will help us plan our asthma activities over the next two years, which will support local children with asthma. This report outlines the findings of the engagement.

We used a survey, focus groups and a video to gather the thoughts and experiences of children with asthma. We asked people to tell us what it was like to have asthma or to have a child or friend with asthma. We also asked what we could do to support them with their asthma. The survey was shared across the city with a variety of community and school networks. The focus groups and videos took place in three schools in west Leeds:

- Hollybush,
- West Park
- Morley Newlands

370 people shared their thoughts about asthma. They told us that it was scary to have asthma or have a friend with asthma. People told us that children, parents and teachers had mixed understanding and knowledge about asthma. They also said that inhalers were not always kept in the same place in schools and that teachers and children were not always aware where their inhaler was. During the focus groups and filming we asked children to show us their inhaler technique. We noticed some very good and some poor techniques. People also told us that their asthma care plan was not regularly reviewed.

You can watch the children's asthma video here:
<https://www.youtube.com/watch?v=gD6UIPOibQM>

This report makes a series of recommendations to the project team who will use the findings of the engagement to prioritise their asthma work over the next two years. We will seek to recruit patient leaders to the project who will champion the voice of the people involved in the engagement.

We will produce a poster for schools to share the findings from this engagement with children.

A regular briefing will be produced once the project has begun to show to what extent the engagement recommendations have been implemented.

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

The report will be shared with those involved in the engagement and the report will also be available on the NHS Leeds West CCG website.

1. Background information

a. Clinical Commissioning Groups in Leeds

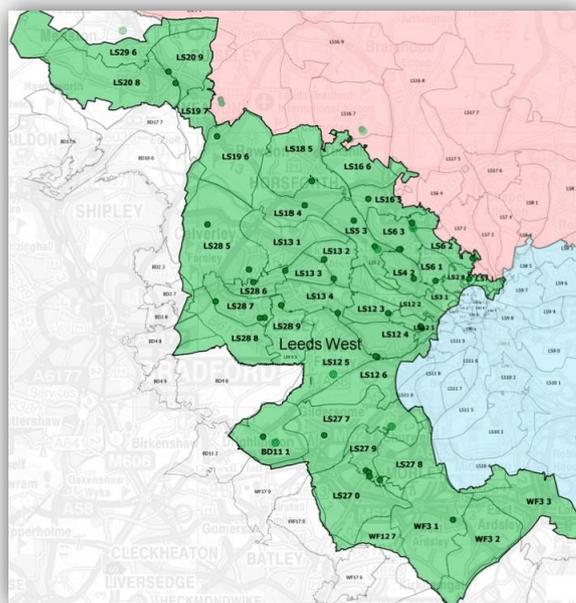
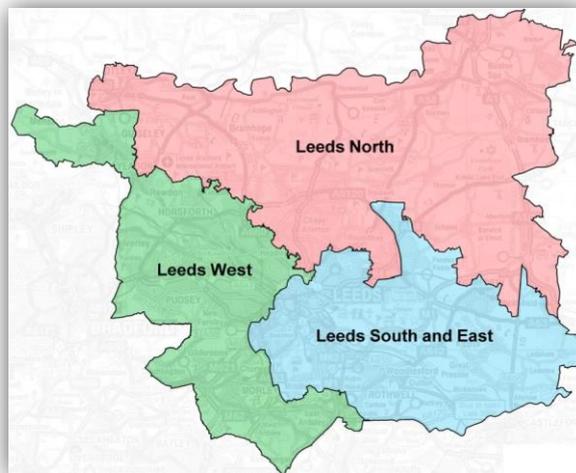
There are three clinical commissioning groups (CCGs) in Leeds; NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These organisations are responsible for planning and buying (commissioning) local healthcare services.

The CCG is very different from previous NHS organisations. For the first time, healthcare services will be commissioned by organisations that are led by locally based doctors and nurses, supported by experienced managers.

This means we can have a real, detailed understanding of the health and social care issues there are in our neighbourhoods, and a genuine opportunity to shape health services at a much more local level as well as across the city of Leeds.

The CCGs are made up of 114 GP practices, covering a population of around 800,000 people. Our population extends from some of the most affluent neighbourhoods of Leeds to some of the most deprived. When working on citywide projects, we work together to ensure that we meet the needs of people across the city.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.



b. This project - Children's Asthma

Asthma is a serious condition, and if not treated properly can lead to asthma attacks, which can be life threatening. But with the right medicines, taken properly and as prescribed, children should be able to lead a full life without symptoms.

We want to help children, their families and their schools to manage their asthma better. This will mean that children feel better and families and schools are better prepared.

This NHS Leeds West CCG engagement asks children, their families and their schools to share their experiences of asthma. Feed from the engagement will help us plan our asthma activities over the next two years.

2. How did we identify and engage with patients?

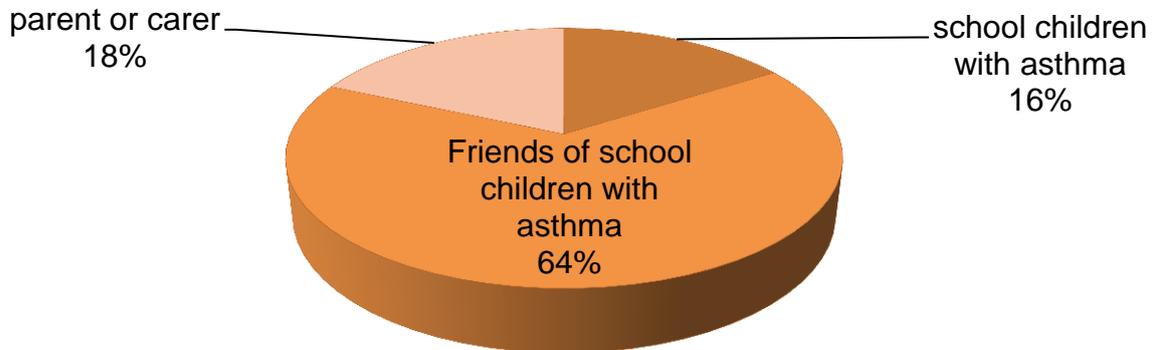
An engagement plan (available on request) was developed by patients, clinicians and commissioners to ensure that the right people are consulted in the right ways. The plan was taken to the NHS Leeds West CCG Patient Assurance Group (PAG). This group is made up of patients and assures the CCG's Governing Body that adequate patient involvement has taken place during consultations and engagement. Patients from the PAGs at the other CCGs were also invited to this meeting. The PAG agreed that the patient groups and engagement methods outlined in the plan were appropriate.

Group	Who	How
School children	School children with asthma Friends of school children with asthma	<ul style="list-style-type: none"> • Paper copies of survey shared via schools • Small focus groups held in school • Interviews to camera held in school
Families of children with asthma	Parents, and guardians of children with asthma	<ul style="list-style-type: none"> • Surveys sent to parents via school registers • Small focus groups in school • Interviews to camera in school
Teachers	Teachers in school	<ul style="list-style-type: none"> • Surveys shared with schools
Group	Who	How
People with protected characteristics as defined by Equality Act 2010	Black and minority ethnic (BME) communities	<ul style="list-style-type: none"> • Contacted members of our VCF sector network and informed them of the engagement. • Promoted via social media
	Carers	
	Children and young people	
	Older people	
	People with disabilities	
	Users of mental health services	
	Lesbian, gay, bisexual and transgendered people	
	Gypsies and travellers Homeless people	
Partners	Leeds City Council (including public health and adult social care)	Details of the engagement shared through social media.
	Leeds North and Leeds South and East CCGs	<ul style="list-style-type: none"> • Contacted other CCGs with details of the engagement • Engagement added to the CCG websites
	Healthwatch Leeds	We shared the engagement with the Patient Assurance Group (on which we have rep from Healthwatch) and on Twitter.
Political	Leeds City Council	Contacted LCC with details of the engagement
Providers	<ul style="list-style-type: none"> • LTHT, LCH and LYPFT • GP practices • PRG's 	<ul style="list-style-type: none"> • Contact all key partners with information for them to disseminate using in-house channels such as newsletters and social media
Media	Local media	Sent out a press release about the engagement and included the media in Twitter and Facebook activity.

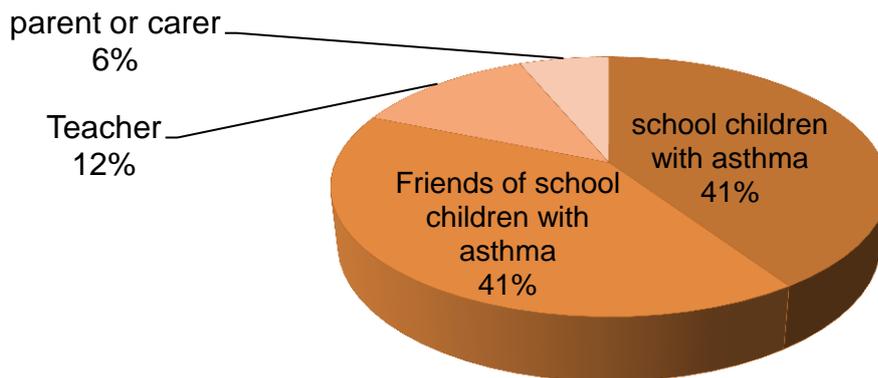
3. Who replied?

In total **370** people contributed to the engagement. Feedback was received from the following groups;

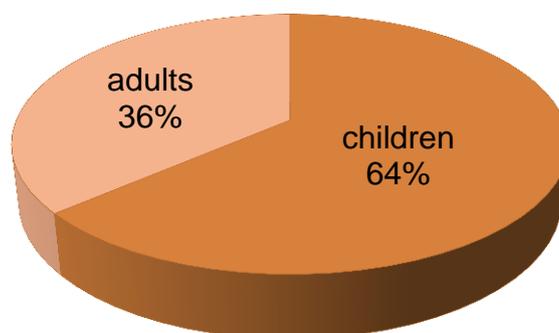
294 people were involved in the survey



32 people were involved in the filming



44 people were involved in the focus groups



Detail about the people involved can be found in appendix A.

4. What did people tell us?

Focus Groups

38 people were involved in small focus groups at three primary schools in west Leeds; Hollybush, West Park and Morley Newlands. Local GPs invited children, parents and teachers to share their thoughts about children's asthma. Hollybush Primary School also held a focus group with six parents of children with asthma. The findings of these focus groups are available on request.

- Children described how asthma made them feel. They told us they cough, get a sore throat and sometimes find it difficult to breathe.

'It feels bad when you breathe'

'I feel excited in my chest and it makes me vomit'

- Some children told us that they had their inhaler at school. Others told us that they kept their inhaler at home. Many of the parents told us that their child did not carry an inhaler with them.

'My inhaler is in my class'

'They have my blue inhalers in a cupboard at school. It's low down so I can reach it easily'

'I keep my inhaler at home'

- Many of the parents had a good understanding of which inhaler to use and when. Some parents and many of the children were confused about what the different inhalers did.

'The brown one stops an asthma attack. The blue one stops you coughing'

'She takes the purple one morning and night'

'I don't take the brown one anymore'

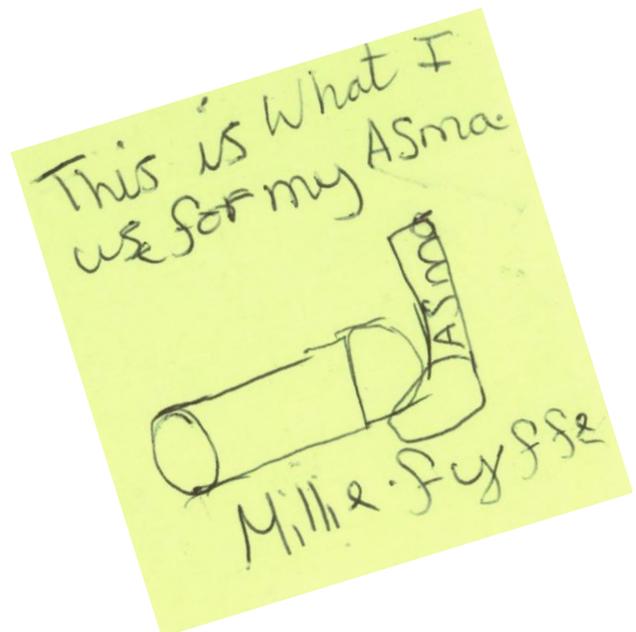
- Very few children talked about having an asthma plan. Many of those who told us they did have a plan had received it after an admission to hospital. In Morley Newlands Primary School only one of the eight children reported having an asthma plan. They received this plan from the hospital but no longer used it.

'I got an asthma plan from the hospital'

- Parents told us that their GP did not give advice about how they could support their child with their asthma.
- Parents told us that they did not think their child had regular reviews for their asthma.
- Parents said that they didn't have enough information about asthma. They were particularly interested in whether it was a lifetime condition and whether their child could use someone else's inhaler during an attack.
- There was some confusion amongst parents about when they should take their child to hospital.
- Children and parents thought that the teacher played an important role in managing asthma at school.

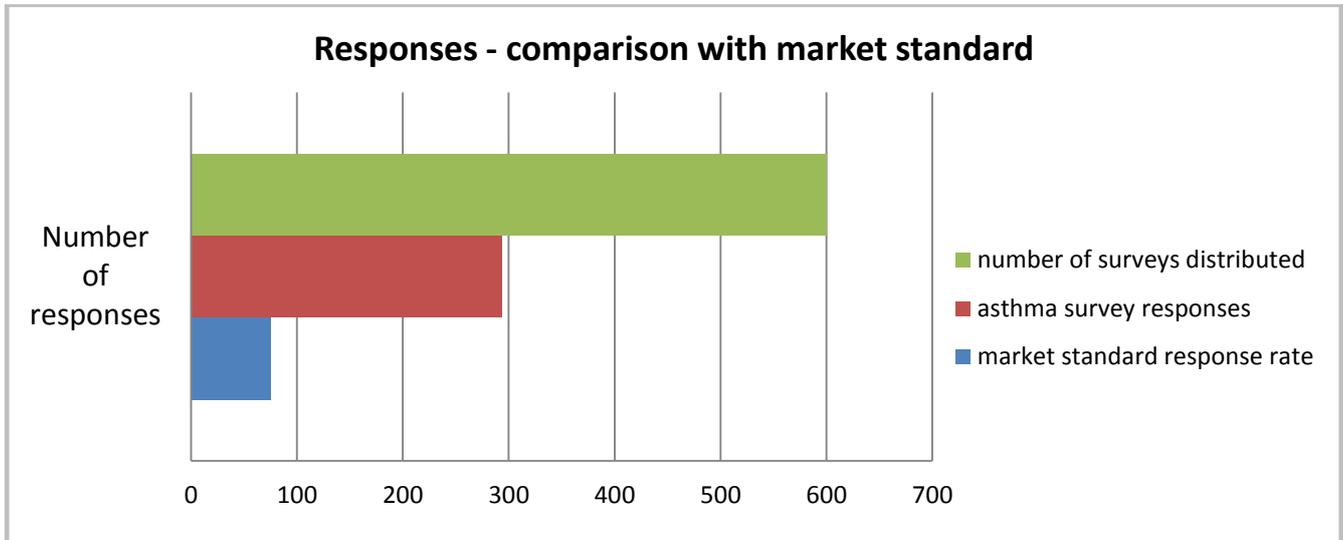
'You tell the teacher and they get you your inhaler'

'I went to my teacher'



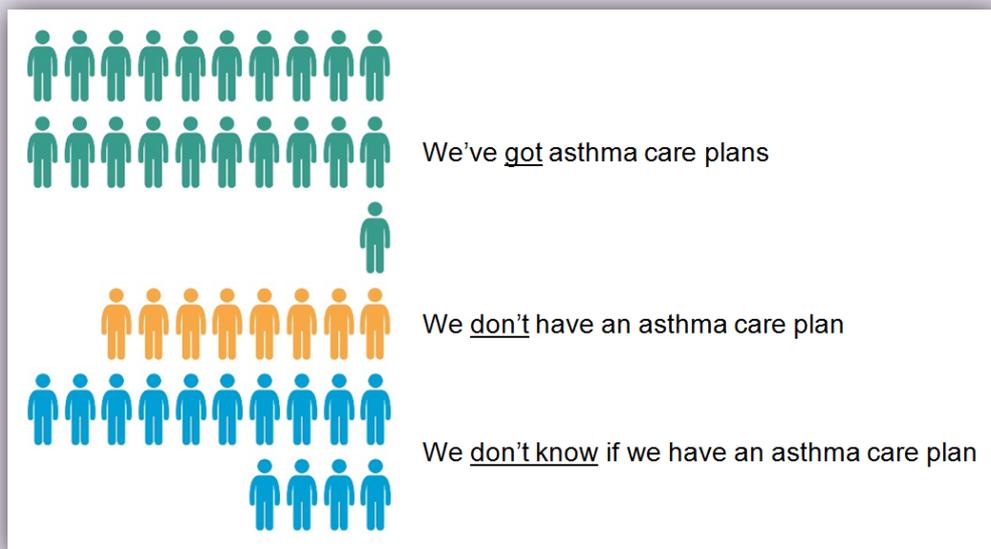
Survey

294 people shared their thoughts on children’s asthma using our survey. The survey and the findings of the survey are available on request.



Responses from children at primary (45) and secondary school (2) with asthma - (47 responses)

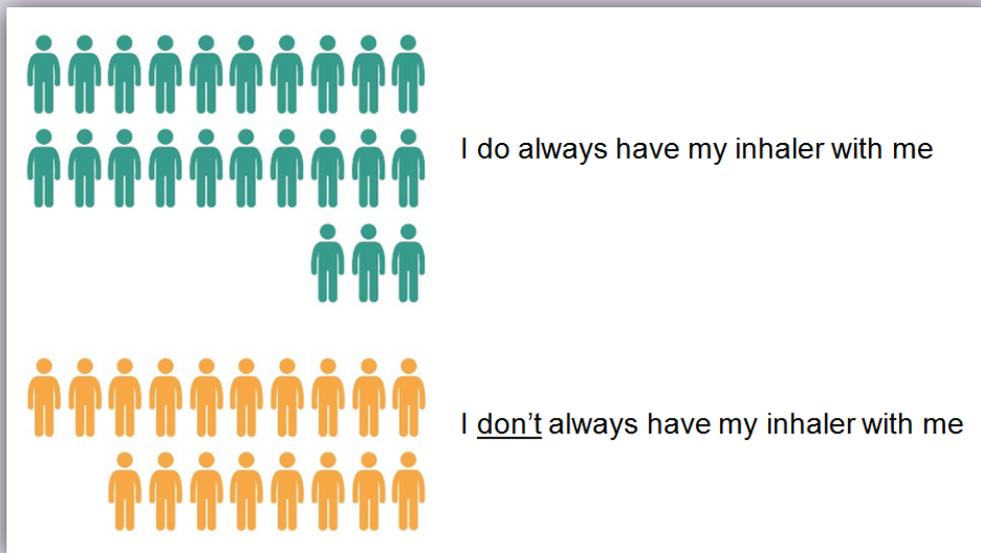
- Children with asthma told us that they sometimes find it hard to breathe, they have a cough and feel wheezy. They also told us that having asthma was scary.
- Children told us that there were lots of things that made their asthma worse. These included; having a cold, strenuous exercise, passive smoking and cold windy weather.
- Of the children with asthma who responded, half (49%) said that they had a care plan.



- Of the children who responded, just over half of children (58%) said they knew the difference between their inhalers

*“The blue one is stronger”
The brown one stops your asthma getting worse, the blue one helps your asthma feel better”*

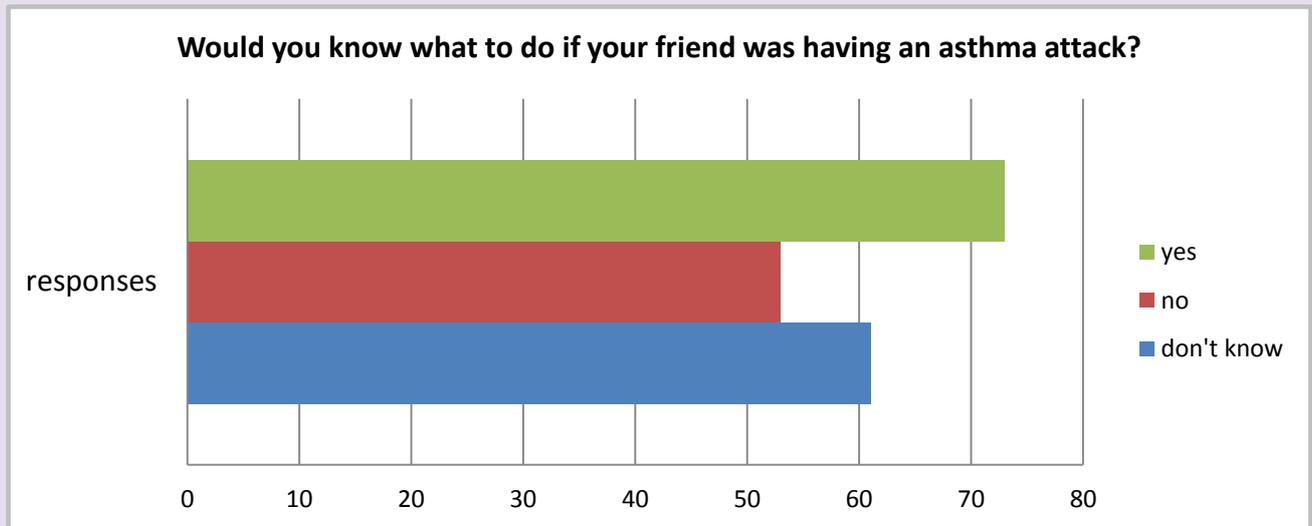
- Just over half (56%) of children with asthma told us they carry their inhaler with them.



- Children told us they did not carry their inhaler because;
 - 'I always forget'*
 - 'because I will lose it'*
 - 'My mum and dad don't think I need it'*
- Children with asthma told us that taking their inhaler (69%) and their parents (71%) were important in controlling their asthma. They also thought that asthma nurses (50%) and their teachers (45%) played important roles. Almost a quarter of children (23%) said that talking to other children helped them look after their asthma.

Responses from children who have friends with asthma (193 responses)

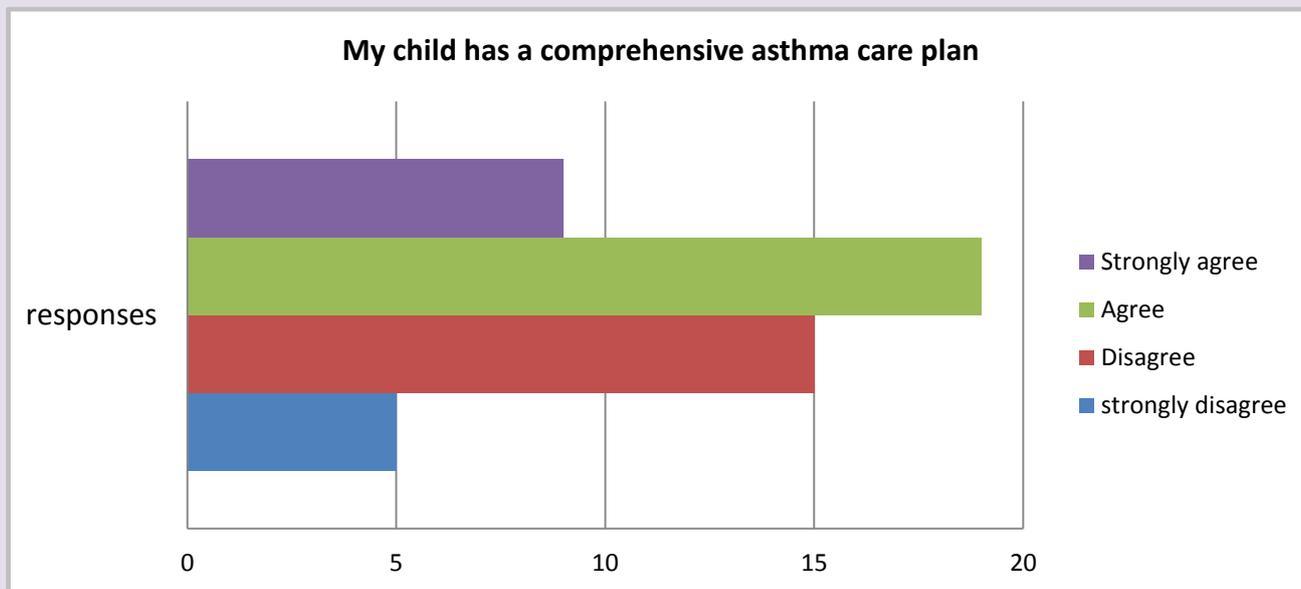
- Less than half of children would know what to do if their friend had an asthma attack.



- Most children would take their friend away from anything causing the attack and over half of children (53%) would call 999. Less than half of children (48%) would ask their friend if they had an inhaler
- Almost all children (81%) did not know the difference between their friends inhalers
'The blue on has more things inside it'
'The blue on stop it and the brown on is for special occasions'
- Children told us what might help them support their friend with asthma:
 - More information about asthma (through videos, posters or classroom teaching)
 - Knowing how to respond if their friend was having an asthma attack.
 - Knowing where the inhalers are kept
 - First aid training
 - A lot of children were not sure what we could do to help their friend with asthma.
- Children with friends who have asthma said that children should be encouraged to bring their inhalers to school and that there should be better asthma education for students and teachers.

Responses from parents and carers (54 responses)

- Parents told us that their knowledge of asthma was very good. Only two parents told us that they did not know the difference between the inhalers.
- A number of parents (25%) told us that they initially mistook their child's asthma for other conditions.
- Almost all parents told us that they make sure their child always carries their inhaler. Those that did not told us that this was because their asthma was 'mild'. One parent raised concerns about other children at school 'wasting' the inhaler. Another parent told us that their child was 'not allowed' to carry an inhaler at school.
- The majority of parents (80%) are confident that their child uses their inhaler correctly
- Just over half of parents thought that their child had a comprehensive asthma care plan



- Almost three quarters of parents (74%) told us that their children did not carry a care plan with them.
- Over two thirds of parents (70%) were confident that the teachers at their child's school could manage an asthma attack
- Over two thirds of parents did not think their child's friends would know what to do if they had an asthma attack
- Half of parents told us that their school gave them enough support with their child's asthma.
- Just over half of parents (53%) did not think their GP involved them in the care of their child. Many of the patients (20%) did not know what we meant by 'being involved in your care'.
- 87% of parents think that it would be good for their children to carry around a small asthma care plan.
- Parents felt that more education for teachers and parents would help children manager their asthma better. People also told us that they thought that their children would benefit from an increase in knowledge in the general population. Parents said that regular asthma reviews and care plans would also improve care for children with asthma.

Filming

We filmed 32 children, parents and teachers from three different primary schools talking about their experiences of asthma. The material has been used to create a video which will be used to develop the children's asthma work at NHS Leeds West CCG. You can watch the video on our Youtube channel here: <https://www.youtube.com/watch?v=gD6UIPOibQM>

During the filming we asked children to role play a patient – doctor consultation about asthma. Children and their friends took it in turn to interview each other about their experiences of asthma. Children also interviewed parents and teachers from the school about what it was like caring for someone with asthma.

Some of the themes that emerged during the filming are outlined here:

- Children told us that it was 'frightening' and 'scary' to have asthma or have a friend with asthma.
- Children with asthma described how they felt 'wheezy' and out of breath, especially when they exercised.
- Most of the children had never been to hospital with their asthma. Four of the children we spoke to told us that they had been to hospital.
- Most of the people (75%) we spoke to told us that they or their friend did not have an asthma care plan. Many of the children did not know what an asthma care plan was.
- Almost all the children told us that they would speak to a teacher if someone was having an asthma attack. Only one friend of a child with asthma told us that their first response would be to find their friend's inhaler.
- Some of the children told us that they did not know the difference between the different inhalers
- Most of the children (61%) told us that they had their inhalers with them. Some of those who did not have their inhalers with them told us that they were in school. It is worth noting that the children were aware that we were coming to speak to them and perhaps this had prompted them to bring in their inhaler.
- Children who have friends with asthma found it difficult to tell us how we could help them to support their friend.

Teachers had different views on how well their school managed asthma. They all agreed that there was more that schools and the health service could do to support children with asthma in school. Teachers gave the following feedback during the filming:

- Inhalers are kept in different places in the school. Some are kept in the office, some are kept in classrooms and some are with the child.
- I thought my asthma knowledge was good but I've learnt a lot during this campaign.
- If asthma is managed properly it shouldn't be a problem.
- Asthma is in our first aid training but we have not had formal asthma training.
- I hope that children use their inhalers properly, but I can't be sure.
- It would be useful to have access to an asthma nurse during school hours.
- I'm not aware that the school has an asthma policy.

Parents had mixed views about how well the school managed their child's asthma:

- Sometimes the teachers don't administer my child's inhaler as I'd like them to.
- I don't think the teachers know enough about asthma
- My understanding of asthma is very good because my child is under a consultant at the hospital. I don't think I would know as much if it was managed by my GP.

Children, parents and teachers asked us a number of questions about asthma during the filming. These questions and answers can be seen in appendix B.

5. What are the key themes from the feedback?

A number of themes can be identified through the engagement process:

Access to inhalers in school <ul style="list-style-type: none">• Inhalers are not all kept in the same place in school. They can be found in the following places:<ul style="list-style-type: none">○ With the child○ In the main office○ In the child's classroom• Teachers and children are not always clear where this inhalers are• Some inhalers are kept in inaccessible cupboards which may be locked
Diagnosis of asthma <ul style="list-style-type: none">• Some teachers are not confident that they are aware of every child in the school with an asthma diagnosis
Asthma policy <ul style="list-style-type: none">• Some schools do not have an asthma policy• There is no clear guidance on whether children can 'share' inhalers
Asthma knowledge and understanding <ul style="list-style-type: none">• Most parents of children with asthma say they have a good understanding of asthma• There is no asthma training for teachers• Many of the children did not have a good understanding of asthma• Some of the adults and many of the children did not know the difference between the different inhalers• Parents said they did not get enough information from their GP about managing their child's asthma• Parents and children thought that the teachers role in managing asthma was very important
Asthma technique <ul style="list-style-type: none">• Asthma technique varied significantly between pupils• Many of the pupils were not administering their inhalers correctly• The teachers were not clear what good inhaler technique looked like.
Asthma care plans <ul style="list-style-type: none">• Many people we spoke to did not have an asthma care plan and/or did not know what these looked like.• Those that did have an asthma care plan did not carry it with them.• Some schools had asthma plans for some children.
Asthma reviews <ul style="list-style-type: none">• Parents and children told us that their asthma was not regularly reviewed by a clinician
Attending hospital <ul style="list-style-type: none">• Some of the children had attended hospital because of their asthma• Over half of the children would call 999 if their friend had an asthma attack. Under half would look for their inhaler• Parents were often unclear whether attending A&E was necessary

6. Recommendations

During the engagement we asked children to tell us what we could do to help them manage their asthma. Children made the following recommendations:

- We want more information about asthma. We would like to get this information in different ways such as; videos, posters and classroom teaching
- We want to know how to help our friend if they are having an asthma attack
- We want to know where inhalers are kept in case we need to get it quickly

Following the engagement the children's asthma project team are also asked to consider ways to:

- Support schools to identify all children with an asthma diagnosis
- Support schools to develop a school asthma policy which includes training requirements, use of shared inhalers and storage of inhalers
- Develop training for teachers which includes; asthma awareness, asthma policy awareness, use of shared inhalers, storage of inhalers, inhaler technique, responding to an asthma attack, when to call 999.
- Encourage GPs, children and their parents to develop an asthma plan
- Encourage children to carry a copy of the asthma care plan with them
- Encourage schools to have a copy of every child's up-to-date asthma care plan.
- Encourage GPs, children and parents to carry out regular asthma reviews
- Support parents and teachers to decide when calling 999 is necessary
- Provide children with the opportunity to learn about asthma (using the recommendations from children)

In addition to these, the NHS Leeds West Clinical Commissioning Group Engagement team make the following recommendations:

- Provide people involved in the engagement with regular project updates (the engagement team will support this work)
- Recruit patient representatives to the project steering group to ensure that the engagement recommendations are considered by the group. In this case you might like to consider holding asthma steering group meetings in school to support attendance from young people.

7. What will we do with the information?

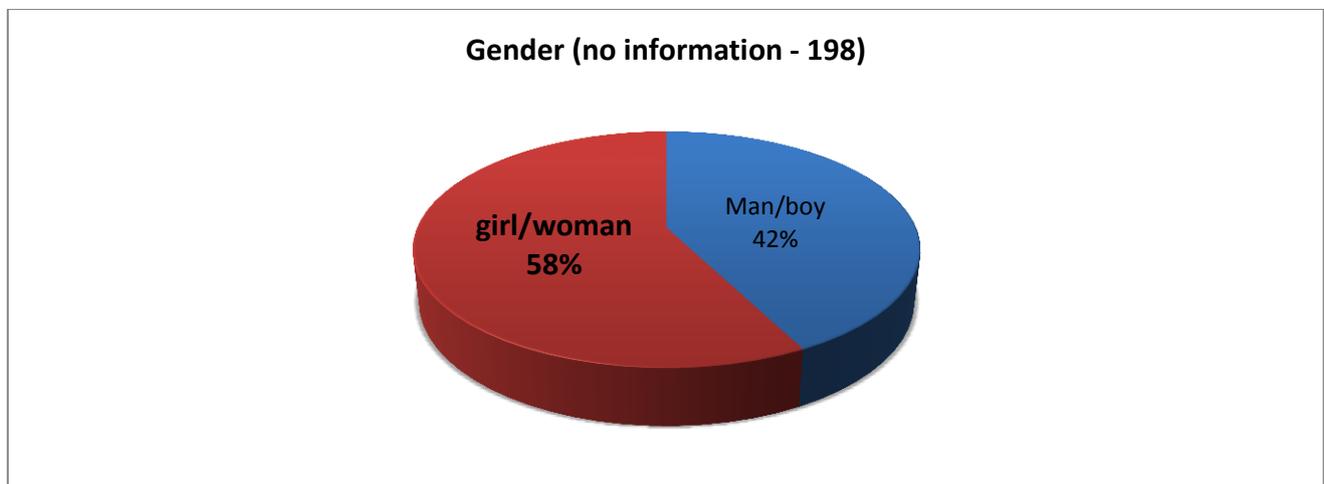
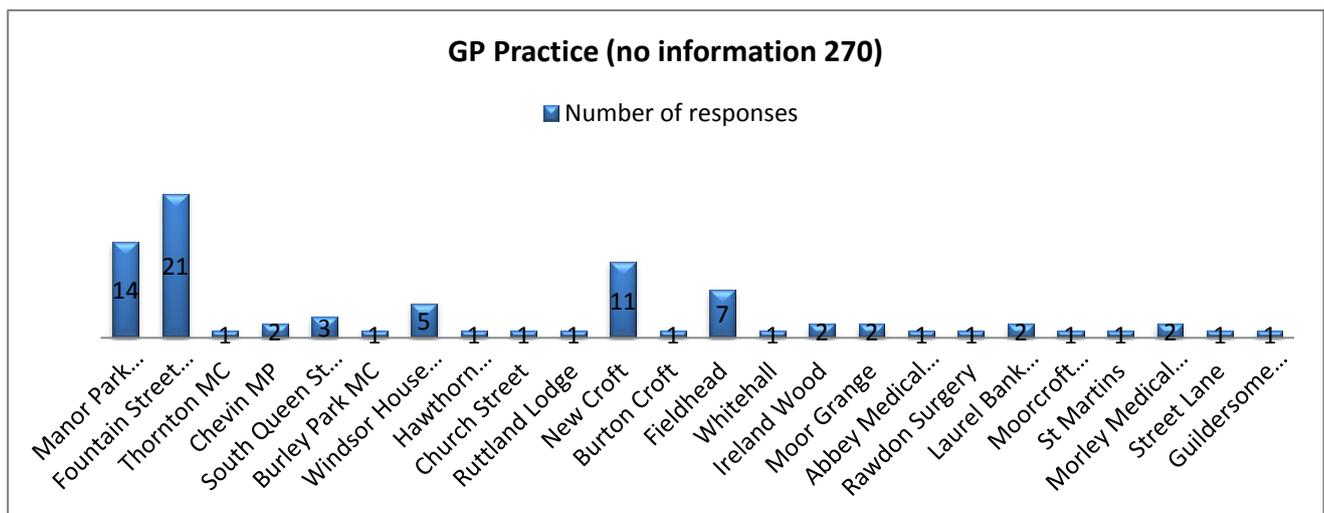
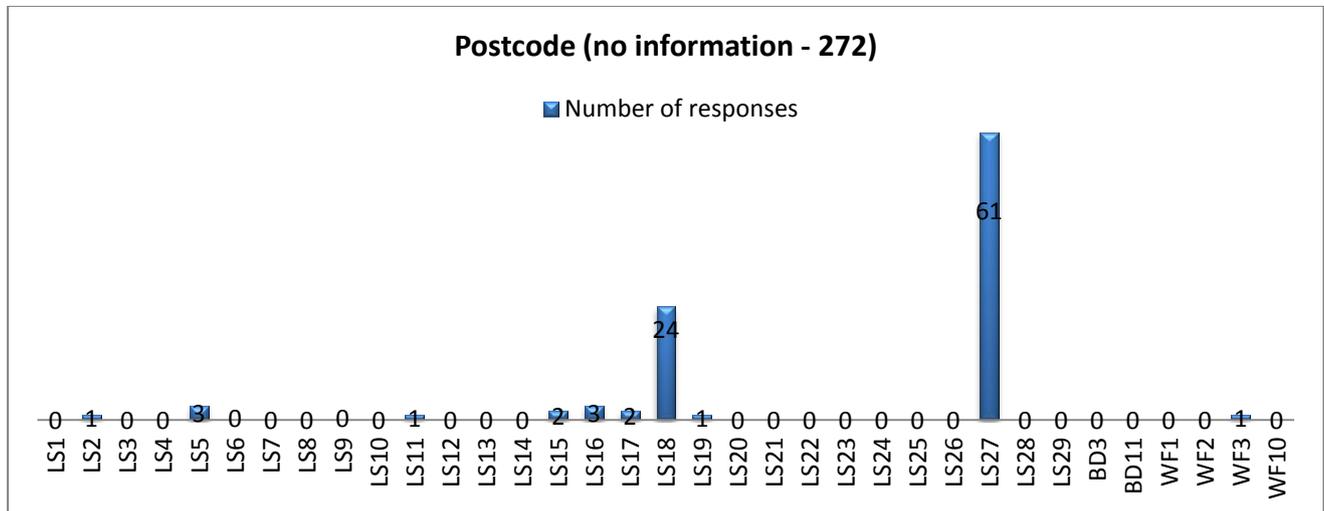
The report will be shared with all the people involved in the project. The report will also be featured in our next newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services. The report will also be available on the NHS Leeds West CCG website and will be shared with the other CCGs in Leeds.

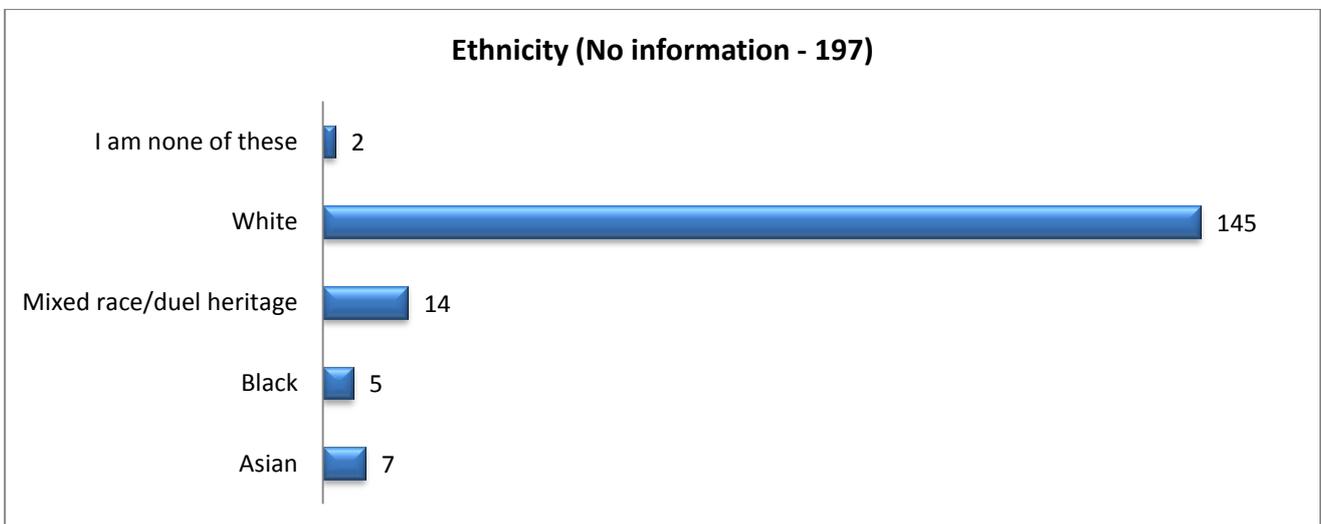
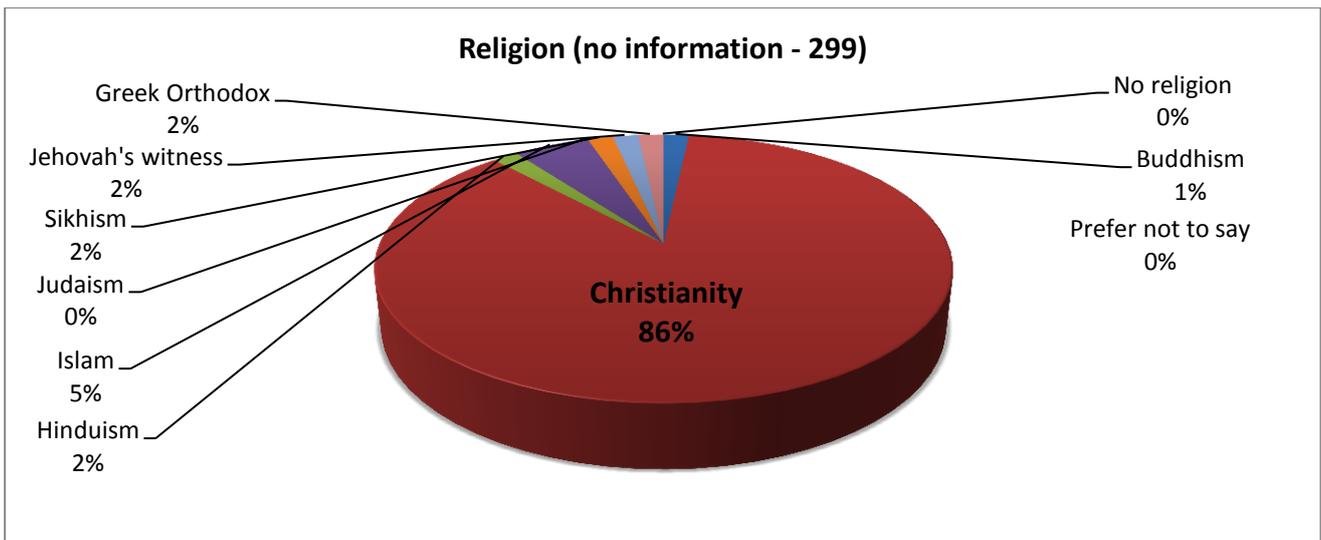
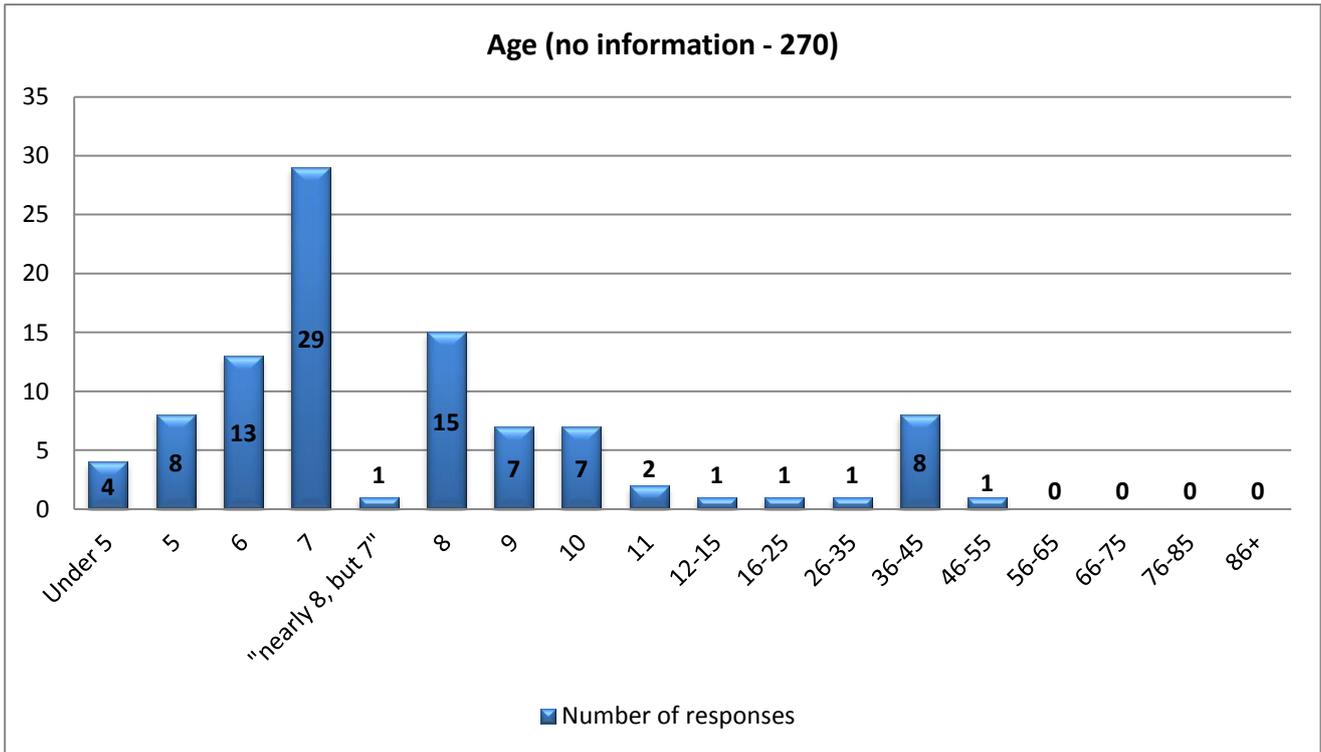
The project team will use the report to prioritise their asthma work over the next two years. We will recruit patient representatives to support the development of the project and ensure that the recommendations made in the report are considered by the project group. Briefings will be produced at regular intervals through the project to show to what extent the recommendations have been implemented. This briefing will be shared with the people and organisations involved in the project.

The patient feedback will also be used to inform a wider strategy for improving communication, access and the quality of services.

Appendix A - Detail about the people who were involved

We want our events to be attended by a representative section of our population. When we ask people to get involved we also ask people to give us some information about themselves so that we have a better understanding of which groups are not represented. Using this information we will work hard at future events to invite people from under-represented communities. Patients are able to opt out of giving personal information.





Appendix B – Questions from the events

Q. What happens if you take too many or too few puffs on your inhaler?

A. If you take too many puffs of your blue inhaler it may make you feel a little jittery or cause you to shake a little but it is unlikely to be anything to worry about. Remember to tell your mum, dad or teacher.

- If you take too few puffs on your blue inhaler it may not make you feel better. You may still feel short of breath or wheezy.
- If you take too many puffs of the brown inhaler it is very unlikely that you will notice any difference. It is very unlikely to cause you any problems. Remember to tell your mum, dad or teacher.
- If you take too few puffs on your brown inhaler (preventer) then you are more likely to cough, feel wheezy and short of breath. Coughs and colds and other triggers are more likely to trigger asthma symptoms.

Q. How many different types of inhaler are there and what do they do?

A. There are lots of different inhalers but there are two main groups.

- Those that make you feel better when you have asthma symptoms called relievers (blue inhalers). Remember it is important to have your blue inhaler near to use if you get wheezy.
- Those that stop or make it less likely that you will get asthma symptoms called preventers (brown, orange, purple and sometimes red). Remember to take these inhalers every day or as recommended by your doctor or nurse.

Q. What does asthma make you wheezy?

A. Asthma makes you feel wheezy because when your asthma is not well controlled the small tubes, in your lungs that you breathe through, become narrow and this makes it harder to breathe in and out and causes wheeze.

- Your blue inhaler makes the small tubes less narrow and makes the wheeze better.
- Your brown inhaler makes it less likely that your tubes will become too narrow.

Q. Are there any common medications that you can't use with an inhaler, such as cough medicines and pain killers?

A. No you can use all common medicines with inhalers, including cough medicines and common painkillers. If in doubt you can ask your doctor, nurse or pharmacist.

There is one group of painkillers called non-steroidal anti-inflammatory drugs that you need to be careful with if you have asthma. Ask your doctor or pharmacist.

Q. What is the difference between the blue and the brown inhaler?

A. The brown inhaler stops or makes it less likely you will get asthma symptoms (preventer).

The blue inhaler makes you feel better by making your airways less narrow so that it is easier to breathe (reliever).

Q. What happens if you get wheezy at school but you don't have your inhaler?

A. If you get wheezy at school but don't have your inhaler with you then:

- a. Tell a teacher or get a friend to tell a teacher, sit down and keep calm.
- b. The teacher may have your inhaler to help you or they may have a school inhaler and spacer that they can give you. (Remember to tell your mum and dad to leave an inhaler and an asthma action plan at school for you to use if needed and to fill in the forms so the teacher knows what to do if your asthma causes you problems).
- c. Your teacher can call your mum or dad or sometimes call for someone one else to come and help you like a doctor or an ambulance.

Q. Is the brown inhaler for older children and the blue inhaler for younger children?

A. Brown and blue inhalers are used by children of all ages. Some children with very mild asthma only have a blue inhaler. Most people with asthma have a preventer that they use at home every day and everyone has a blue inhaler to use just in case they become wheezy or get short of breath.

Q. How does your age affect your asthma?

A. Lots of children with asthma get better as they get older. There are lots of reasons for this.

Q. How does asthma get into your blood?

A. This is a really good question. Asthma is in your lungs and in your blood. Nobody really knows why some people get asthma and others don't. You are more likely to get asthma if your mum or dad has asthma, eczema or hay fever and if you have allergies.

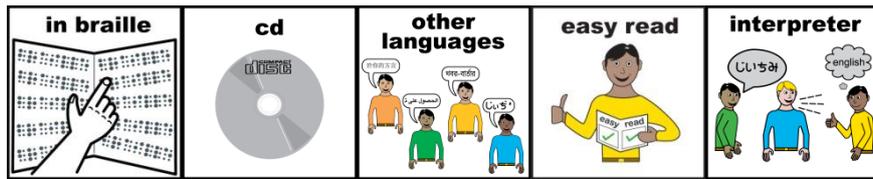
Alternative formats

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اگر آپ کو ان معلومات کو سمجھنے کے لیے یہ کسی اور زبان یا صورت میں درکار ہوں تو برائے مہربانی سے اس نمبر پر فون کر کے رابطہ کریں: 0113 8435470 یا اس پتہ پر ای میل لکھیں: commsleedswestccg@nhs.net



Further information

If you would like any more information about this project or NHS Leeds West Clinical Commissioning Group, or have any questions or comments, please write to:

Chris Bridle

Engagement Lead

NHS Leeds West Clinical Commissioning Group

Suites 2-4

Wira House

West Park Ring Road

Leeds, LS16 6EB

Main switchboard: 0113 84 35470

Email: commsleedswestccg@nhs.net

www.leedswestccg.nhs.uk

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