Improving lives **together**
Norfolk and Waveney Integrated Care System

NHS Norfolk and Waveney Community Voices

Children and Young People's Asthma (Core20Connectors)

Community Voices
Using your feedback to improve care

Purpose of the report:

To provide readers the

- Background of the children and young people's asthma project
- Insights from the conversations collected by trusted communicators- experiences of children, young people and their families of accessing support for and management of asthma- recorded on the Insight bank
- Findings from the project and process evaluation
- Recommendations/Key reflections

Background

The Norfolk and Waveney Integrated Care Board received a grant from NHS England as part of the national Core20Connector programme (Wave 4). In 2023-24, we led a Children and Young People's Asthma project through the Community Voices programme, which emphasises the role of trusted communicators in addressing health inequalities specifically for children and young people.

We co-designed the approach for this project with a group of young people via Norfolk County Council's Children and Young People's services and with the input from the Children and Young People's Team at the ICB, our participating voluntary sector organisations, Norfolk Community Foundation, the Holiday Activity and Food Programme providers and Active Norfolk.
The young participants provided input on three key areas:

- the essential skills and qualities needed in trusted communicators
- the best locations for engaging with children and young people
- and how the conversations should be conducted

The feedback gathered was used to shape the training and onboarding of organisations for the project.
Ten organisations were commissioned via the Community Voices programme

- through Norfolk Community Foundation- Community Sports Foundation, Action Community Enterprises CIC, Shrublands, Great Yarmouth and Gorleston Young Carers
- through Active Norfolk- Premier Education, East Norfolk Sixth Form, Hoopstars, Pav Funball Academy, ESKA (Eastern Shotokan Karate Association)

The organisations were to engage children and young people and their families in conversations about their awareness, knowledge and experience of asthma.
We followed a data based approach to focus on children and young people living in neighbourhoods in Norwich and Great Yarmouth of higher need and the clinical area of asthma.

Conversations between trusted communicators and children, young people and their families were recorded on the Community Voices Insight Bank.

229 conversations recorded

39 group + 190 individual

Age groups of C&YP spoken to:

61% → 0-15 yrs

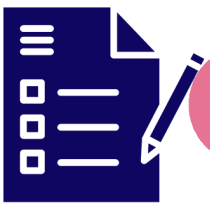
16% → 16-24 yrs

23% → 25+ yrs

Actions taken by trusted communicators as a result of the conversation

21.3% signposted to information about housing issues such as damp and mould

30.6% signposted to information about asthma management and how to get a plan in place



21.3% accessing asthma training

40% other included signposting to GP surgery

Conversation Analysis

This report provides analysis and a summary of conversations captured as part of the Community Voices Children and Young People Asthma Project during 2024. Conversations between trusted communicators and participants were recorded on the Community Voices Insight Bank.

Analysis of the conversations was undertaken by the Norfolk Office of Data and Analytics (NODA) in the Insight and Analytics Team at Norfolk County Council. The below sections describes key findings and the analysis of the conversations [1]

Key findings

- People described the main causes of asthma as environmental factors (smoking in the house, pets, pollution) and poor housing (mould, damp, poor ventilation).
- People identified the main symptoms of asthma as breathlessness, especially, during physical activities and wheezing, coughing, or chestiness. People's ability to correctly identify symptoms, or recognise the seriousness of some symptoms, was mixed.
- People described their main management strategies as seeking medical support (advice from healthcare professionals and use of inhalers) and reviews or care plans.
- People were generally confident in their ability to manage their or their child's asthma.
- Where barriers to seeking support were identified (many people said they could not identify any barriers or there are none) the main issues were lack of support in schools, lack of information, attitudinal issues, and lack of medical support.
- A need for more information and training about asthma (in a range of children's preferred communication methods) was identified as the main way to overcome barriers in accessing support. The important role of schools in supporting children and young people was also recognised.
- There were many examples of Trusted Communicators offering advice or signposting to sources of help including asthma management, housing and training.

[1] Some conversations on the Insight Bank noted the topics discussed ("we talked about symptoms") but there was no further information about the content or outcome of the conversation for coding. This may be linked to lack of understanding about how the information is used, or the result of focusing on a higher number of conversations rather than fewer, richer conversations (quantity v quality) and could be a useful learning point for future training.

Causes and triggers of asthma

Across all of the conversations, the main causes of asthma identified during conversations were:

- **environmental factors** (parents smoking in the house, pets, pollution, dusty atmosphere);
- **housing** (mould, damp, poor ventilation); and
- **weather** (cold, wet), though knowledge depended in part on age and lived experience.

"When asked what could trigger asthma – One girl said pollution. 1 boy said pollen. Lots of children said aeroplanes. When prompted further they suggested the following triggers – running, humid weather, winter, summer, dust, allergies, rape seed field that is right up against the school, when farmers are harvesting there is dust in the air."

People identified **poor housing conditions** such as dampness or mould as a cause of asthma or an aggravating factor.

"We discussed living and environmental conditions that may have an impact on personal health - children were very open to mention parents smoking, mould and damp at home in bedrooms, bathrooms and kitchens. Neighbours that smoke marijuana, pets in the home, dust around the home - if they have carpets or hard flooring, shared bedrooms."

There was some confusion about **how asthma is diagnosed**: whether having an inhaler means a child has asthma, whether the condition requires a formal diagnosis, and whether diagnosis is only possible when the child reaches a certain age. This gap in understanding may link to the need for more information and training about asthma identified in question six.

Signs and symptoms of asthma

Two main symptoms were identified.

People recognised **breathlessness during physical activities as a possible sign of asthma** and noted that exertion can make asthma worse.

“His asthma makes physical activity, including getting to college, a challenge for him. The young person also mentioned that he knows he is overweight, he said he knows he should exercise more and that his asthma prevents this.”

The other symptoms of asthma mentioned most frequently were **coughing, wheezing, breathlessness, or chestiness**.

"I become out of breath and have a tight chest at times and so I know I need to use my inhalers.”

A question (on the insight bank) was specifically about signs and symptoms and asked: **‘Please provide us with a summary of your conversation relating to asthma signs, symptoms and management’**.

The **main sign or symptom** of asthma recognised by people was breathlessness, chestiness, coughing or wheezing.

“A history of many visits to A&E and numerous as an inpatient with breathing difficulties/coughing/wheezing.”

More people said they have **some or good awareness** of asthma symptoms than those who said they have no or limited understanding.

“None of the children in the group had asthma but several knew people who had asthma. I angled the conversation towards identifying the symptoms of asthma, did they know how asthma was treated and who helps people control their asthma. All the children knew lots of the answers to my questions.”

Managing asthma

Across all the conversations, there was a general sense of the child or young person's **asthma being under control**, although examples of how it is controlled were not always provided. Themes around managing asthma include (in order of frequency with most comments first):

Managing asthma through medical means (using inhalers, attending routine appointments or seeing GP or asthma nurse when necessary) was mentioned more than any other means of control.

"The GP was very swift with the diagnoses and administering his pumps." / "They feel confident from the support the doctors have given where they show how to use the inhalers and also give reasons as to why they help which gave the child more reasons to remember why they need to take the inhalers."

Managing asthma through planned reviews and care plans (though frequency varies).

"Both parents and subject are very confident in dealing with condition asthma plan in place and reviews are on time." / "His "yearly" asthma review is currently at least 18 months."

Other ways of managing asthma such as i**ndividual behaviour** (remembering to carry an inhaler, not smoking, seeking help when necessary) or through **support from nursery, school or college** were recorded less often. A few children and young people described their frustration with managing asthma.

"This YP said that when they had asthma they always kept both asthma inhalers with them at all times."

There were few examples of asthma being **poorly managed or not at all managed** though lack of plans or reviews and partial management were mentioned. A **lack of understanding about how to manage asthma** in a practical sense and in an emergency (such as how and when to intervene, the difference between healthy post-exercise breathlessness and an asthma attack, how to prepare an inhaler/spacer, how often to administer inhaler during an asthma attack, at what point to contact emergency services) was noted.

"When asked what to do in an emergency nobody knew what to do. It was suggested to them that they rang 999."

Confidence in managing asthma

Across all the conversations, children, young people and their parents or carers were generally **confident in their ability to manage their or their child's asthma**.

Question 32 was specifically about confidence in managing asthma and asked 'In your conversation did you find that the person feels confident in managing their asthma. If your conversation was with a parent, how confident did they think their child is managing the asthma?'

Comments which recorded that **children and young people (or their parents) are confident in managing their or their child's asthma** tended to link confidence with knowledge; for example, understanding the need for an inhaler and how to use it or understanding the care plan.

""I am confident dealing with treatment"" says parent. "He (son) is very confident. He knows how to use his asthma pump when required."
"Mum is very confident in managing, as is her son. Mum thinks the support she gets from the G.P's, Hospitals and Pod System "is great". Reviews an regular and on time. they do have Asthma plans."

Few comments were recorded which explicitly stated the child, young person or parent **lacked confidence**. However, reference was made, as in the previous question, to lack of knowledge about how to manage asthma.

"This person does not have asthma and limited knowledge may find him difficult to manage or even help other people when need it."

Barriers to accessing support

A question was specifically about barriers and asked '**What did you find were the barriers that the person (child or parent) faced in accessing support?** You can pick more than one barrier [confidence, complacency, convenience, communication and context][2]. Please tell us more about what the barriers meant to the person'. There were few other comments about barriers in other questions.

The barriers selected most frequently in response to the closed question were **confidence and communication**, followed by complacency. Few people identified convenience and context as barriers.

In the open-text part of the question, there were 44 comments about there being **no barriers or an inability to identify any barriers**:

"This person could not see any barriers to getting support or help to manage his condition."

Comments (in order of frequency, highest first) included:

- issues with support from schools - "the young person mentioned how they are penalised for poor attendance, but not supported well enough to help manage the condition".
- lack of information about support - "unsure of symptoms due to lack of information/awareness via communication".
- behavioural or attitudinal - "they didn't seem to think asthma was very serious or common. They were very complacent about it."
- access to medical care - "confidence in GP Surgery communication (lack of) between health agencies."
- other barriers including mental health, parental inability to support access to care, and language barriers.

[2] The five barriers are: Confidence (trusted sources, open and honest conversations, allaying fears and concerns); Complacency (underestimate of personal risk and possible impact of disease); Convenience (barriers and access); Communication (sources of information); Context (socio-demographic factors, Community Voices).

Overcoming barriers to accessing support

A question asked '**What do you think could be done to overcome the barriers? Was the person able to identify anything that would have made their experience different to the one they had?'**

A need for **more information and training about asthma** was identified as the main way to overcome barriers to accessing support. Suggestions for how to make information accessible included using children and young people's preferred communication methods, extending the current community-based project approach, and including managing asthma in emergency medical training.

"Partnering with community organisations and youth centres such as this one to host asthma awareness events that prioritise inclusive communication strategies."

Schools were identified as having an important role to play in helping children and young people and their parents and carers to overcome barriers.

"Encouraging schools to designate asthma-friendly zones equipped with inhalers and trained staff."
"Training teachers and school staff to recognize signs of low confidence or communication difficulties in young people with asthma and provide appropriate support."

Supporting **behavioural change** and improving wider **attitudinal** responses to asthma was also recorded: suggestions included practical tips and examples of inclusive approaches.

"I suggested asking mum to help remind him (by setting an alarm on her phone each morning) which he said was a good idea."
"Only give them the best training or important part of the matches. Some people might not be able to complete the whole football or sports session. Give them the ownership to decide which part they get involved with."

More (or alternative) support or **training from health care professionals or access to medical aids** (such as different inhalers) were also noted.

"A conversation with the GP Surgery."
"Utilising technology to provide virtual consultations and support for young people who may feel more comfortable discussing their symptoms remotely."

Signposting people to support

A question asked '**As a result of the conversation, did you support the person with any of the following?**

- asthma **management** and how to get a **plan** in place (23 conversations)
- **housing issues** such as damp and mould (16 conversations)
- accessing **training** about asthma (16 conversations)
- **other sources of advice and support** such as Asthma UK, engagement with a GP or asthma nurse, and youth workers to support wellbeing (22 conversations).

Throughout all the conversations there were 51 recorded incidences of **trusted communicators offering advice or support** (in addition to those noted above). The support offered ranged from practical help "we gave a print out of how to use their spacer effectively which now stays in the pouch" to **signposting to further sources of support with housing and health care issues.**

"There were in a council property which is damp and has issues which they have reported and are still waiting for help with this from the council we have passed on details of who to contact and if they have do not have a happy conclusion how to contact the ombudsman."

"We discuss his management as he had not had an attack for a while and are supporting him to contact the doctor for an assessment/check up to see if he still requires inhalers and to support him access them if needed."

In addition to offering practical support, Trusted Communicators opened up conversations to allay concerns about asthma and provided a space for honest, non-judgmental discussions about asthma: such discussions may b**enefit children and young people's mental health and wellbeing**.

"We discussed how understanding your asthma better can empower you to explain it to your friends and teachers, helping them support you when needed."

"Our conversation acknowledged the emotional aspect of managing asthma and how important it is to share your feelings and concerns with those close to you for added support."

Case Study

Great Yarmouth and Gorleston Young Carers

Background:
Great Yarmouth and Gorleston Young Carers (GYGYC) provide peer support groups to young carers (5-15) and young adult carers (16-21), as well as a programme of positive activities that the young people help to develop, plan, and evaluate. GYGYC received funding from the Norfolk Community Foundation and the Norfolk and Waveney Integrated Care Board (ICB) who were working in partnership to enable VCSE organisations to participate in the Community Voices programme, focussed on children and young people's experiences of asthma care.

Approach:
GYGYC surveyed parents to find out which children were asthmatic, and then targeted those children individually to talk about asthma. They also ran awareness sessions for all young carers they work with; "So, we had that list of those that we were working with that had asthma, but we'd also given all the other young people information about how they can support their mate, if they had an asthma attack."

GYGYC are experienced at having conversations with the young people in their groups and built on these existing relationships to explore young peoples' knowledge and experiences of asthma. They varied their approach "depending on the age of the group" and how many children and young people in the group had asthma. This included variations such as "whether we did that with showing the film or whether we just did a conversation with flipchart. But depending on the group and who they were and which way we thought would be the best way, to then highlight those that we needed to ask in more in depth."

Learning:

GYGYC supported young people and their families with a number of follow-up actions after conversations about asthma. These included, helping families to get support from the council about damp in their houses, and supporting young people to access medical support.

GYGYC had one conversation with an older group of young people, when one young person flagged to the trusted communicator that he did not have any medical support for his asthma; “he sat next to me, and then said ‘I do not have any inhaler’, I asked if he had had an assessment lately and he said never and he did not know how to get one and his mum was unable to support him with his.”

GYGYC then followed up with the young person individually: “The Youth Worker supported him to call the medical centre to request a prescription for his inhalers.” However, the young person was unable to get a prescription for his inhalers “because he needed to see the doctor/ asthma nurse for a check-up.”

The Youth Worker continued to support the young person “to have the conversation with his mother to arrange, had an appointment, which he attended with mum and was given a prescription for his inhalers.” This outcome demonstrates that asthma conversations not only raised awareness but led to actionable support that enabled a young person to access essential healthcare.

In future GYGYC plans to run the awareness sessions on asthma for the new groups of young people – “It is just being aware of it, isn't it? Cause it is quite silent, but deadly, isn't it?” – to ensure their young people are informed.

Process evaluation

Norfolk Community Foundation (NCF) carried out interviews with the 10 organisations to evaluate their experiences of participation in the Community Voices Children and Young People Asthma Project. All the organisations (with one exception) had not worked on a Community Voices (CV) project so undertook the Community Voices and subject specific skills training for the first time for this project.

Thematic analysis of the interviews was undertaken by the Norfolk Office of Data and Analytics (NODA) in the Insight and Analytics team at Norfolk County Council and the below summarises the key findings of the interviews undertaken-

- People found the **application process** simple and most described it as easy or straightforward.
- People were positive about both elements of the **training** (subject specific training – causes, signs, and management of asthma - and skills training for the Community Voices data element).
- The importance of establishing rapport in **setting up a conversation** was noted. Most conversations were set up as group exercises and were incorporated into natural breaks in activities (such as lunchtimes).
- Conversations, resources, and methods were **adapted** according to children and young people's ages, their experience and understanding of asthma, but built on existing practice expertise and knowledge.
- Approaches to **selecting** children and young people (and their families) ranged from targeted to untargeted whole population methods. Selecting participants highlighted issues around being able to identify which children have asthma.
- People found **conducting** the conversations a positive experience.
- Every organisation said they felt **supported** during and after training.
- The **learning** identified by organisations involved increased knowledge about asthma, and better understanding of the children and young people they support including how to engage them in meaningful conversations. Positive impacts on organisational practice were also mentioned.
- **Recording and submitting** conversations to the Insight Bank was straightforward for most people.
- **Every organisation said they would like to be involved in future projects.**

Application process and Training

People found the application process simple and most described it as easy or straightforward.

Factors which helped to make the application process run smoothly were:

- the pre-application meeting
- previous experience in bid writing or having completed previous bids
- the application form being easy and simple to navigate
- existing trusted relationships with NCF, Active Norfolk and the holiday/activity providers

No improvements were suggested.

"No, that [the application process] was that was really easy. And so obviously we, we, were invited, like, as we've been a partner with Active Norfolk for quite a while and I said we might want to get on board with it... And so in terms of improving anything, I wouldn't, it was just quite easy and straightforward as it was."

People were positive about both elements of the training (subject specific training – causes, signs, and management of asthma - and skills training for the Community Voices Insight Bank element).

Although for the organisations involved, talking to children and young people is 'business as usual', the difference between day-to-day conversations and having targeted conversations about a medical condition was acknowledged. People welcomed the opportunity to learn about asthma (the extent of awareness and expertise varied) and recognised how being better-informed could help them support other children and young people.

Positive aspects of the training included:

- good training: praise for trainer and 'step-by-step' explanation of CV processes
- access to resources (film, 'visuals') to use during conversations
- opportunity to share ideas with other organisations in the room
- variety of learning resources
- ability to follow up with questions after training

Challenges included:

- dual approach (learning about asthma and CV process simultaneously) was intensive making retention potentially difficult: follow-up support mitigated.
- timing – space between signing up to the project and availability of training compressed the period for learning before conversations started: flexibility around timescale and undertaking subject-specific training only for subsequent projects will mitigate.

Impacts included:

- being better informed about the signs and management of asthma
- gaining knowledge about available support and where to signpost people
- increase in confidence to carry out conversations
- upskilling ("what I learned from it is how to conduct a better conversation")

"So it was it was a bit both as a bit on the Community voices and then the subject specific. Again, it was really good. It kind of clarified a lot of things and I think from a kind of a training point of view from a kind of personal point of view, the subject specific was really good as well and certainly kind of pointing to, like signposting and stuff like that."

Setting up conversations and adapting methods and processes

The importance of establishing rapport before having a conversation was noted. Most conversations were set up as group exercises and took place during breaks in activities so conversations appeared as a natural extension of the activity.

When discussing setting up conversations responses were often related to recruiting participants (please see '5. Selecting Participants') but the following points about setting up conversations were raised:

- **warm up** - establishing rapport and building trust before setting up the conversation was beneficial
- **timing** - conversations set up during natural breaks in activities (such as lunchtime or breaks) allowed the topic of asthma to be linked to discussion about physical activity and health
- **group v individual** - group conversations made the activity an enjoyable social experience and allowed children and young people to learn from their peers: it could be challenging to single out individuals for one-to-one discussions.
- **preparation** - one organisation found that grouping the conversation questions into broader themes helped the conversation flow (but made inputting more complicated).

Ways of advertising the project included word of mouth, newsletter, posters, questionnaire, and QR codes.

Setting up conversations within a school setting (on-site, within the school day as opposed to an extra-curricular activity off-site) presented different challenges.

Conversations, resources and methods were adapted according to children and young people's ages, their experience and understanding of asthma, and built on organisations' existing practice expertise and knowledge.

Adaptations included:

- choosing the most appropriate communication style (play, quiz, presentation, cartoons) for the audience
- tailoring questions in different ways using age-appropriate language
- adapting conversation depending on the degree of lived experience in the group
- switching between different sized groups (or one-to-ones) as appropriate
- offering parents and children a shared activity to do together
- being aware of how the setting influences engagement (school-based setting compared to community-based setting for example).

"So it was just about adapting our own kind of communication styles dependent on the young person in question, really because we do like holiday clubs over Easter and whatnot. So we have super young people up to, you know, 18-19 year olds, so obviously adapt new communication style."

Selecting participants

Approaches to selecting children and young people (and their families) ranged from targeted to untargeted whole population methods.[3] Selecting participants highlighted issues around being able to identify which children have asthma.

- **General** - no selection process “Yeah we just spoke to kind of all of the children there again, you know, I thought that would be kind of a good, a good cross-section and get lots of opinions”.
- **Whole population** - One organisation targeted schools through existing contacts but had no control over which children were invited to participate.
- **Dual -** two-stage selection process with a smaller cohort derived from a wider group
- **Targeted by condition** - children and young people already identified as having asthma “We sent the questionnaire out to all our families, asking the question who, whether anyone got asthma to narrow the field down.”
- **Targeted by need** - “So we know that those schools that we targeted are in those real kind of high need areas.”

There was no evidence that one method was intrinsically better than another. It is likely that the organisations involved, who are closest to potential participants, are best placed to decide the best recruitment method for their cohort.
The selection process highlighted issues about being able to identify which children have asthma, which have asthma-like symptoms, and which may have asthma but are currently undiagnosed and unsupported (under-reported prevalence of asthma).
Organisations’ estimates of the prevalence of asthma in their groups (as distinct from the number of emergency inhalers held) ranged from “quite high” and (precisely) six out of a class of 16, to “we’ve got none this time!” and around 30-40% though this varied from group to group.
Challenges in identifying this particular target group may be a consideration for future projects. The link between wider determinants of health (deprivation and differences in pollution levels of rural and urban locations) and their potential impact on the prevalence of asthma was also referenced.

“And I knew off the top of my head such and such had asthma. I knew that and I'll be able to go to them. But then I quickly realised when I would then go and have these or attempt to have these conversations, they would say, “oh, I'm not actually, I don't actually have an inhaler or I just have breathing difficulties. You know, I get short of breath quite quickly.” And so things that you could probably still correlate to asthma but where they didn't definitely have it. I was like, “oh, I was always under the impression that you did have asthma.”

[3] How organisations sought informed consent from participants was not part of the interview brief so is not covered here.

Encouraging participation and conducting conversations

Group sessions and the trust evidenced in existing friendship groups were identified as factors which encouraged other children and young people to participate in conversations (please see section: Setting up conversations). Only one organisation offered an incentive (a free prize draw).

Approaches to engaging parents and carers included:

- building on existing good relationships and prior experience of working with parents
- informing parents and offering them the chance to 'opt-out'
- catching parents at drop-off/collection to get their perspective

"They might be a bit more reserved, but if a few people start talking then the others join in, yeah, and if they're already sitting with their friends - like normally at lunchtime, they go into their groups that they might know."

People's reflections on conducting the conversations were predominantly positive. When people described highlights from their conversations these tended to focus on:

- offering advice or signposting: signposting to support about medical checks, or health care and especially to housing
- learning: understanding more about the wider context of children and young people lives (their knowledge, concerns and experiences), and gaining better understanding about asthma and how children manage their symptoms
- new skills: acquiring new research or communication skills
- keeping children safe: helping parents understand the symptoms and potential effects of asthma; identifying a safeguarding concern
- enabling: seeing children's confidence build as their views and experiences were sought and relationships with interviewers built, facilitating peer to peer learning, offering a safe place to share for children to share their views.

People experienced few challenges conducting conversations though getting sufficiently detailed responses from children was mentioned. Thoughtful reflections on the risks of falsely inferring meaning when summarising conversations and social desirability bias in children and young people's comments were made.[4]

[4] Social desirability bias is the over-reporting of desirable behaviours and under-reporting of undesirable behaviours by research participants.

Feeling supported and Learning from taking part in Community Voices

Every organisation said they felt supported during and after training because:

- training was comprehensive and the resources (video) were helpful
- useful post-training resources were provided (email of slides, signposting to additional resources, updates)
- contact details for support were clear and it was possible to make contact in a variety of ways
- support was not time limited
- queries were resolved through advice, practical solutions, and flexibility around timescales
- queries were dealt with promptly (in all but one case when advice about low numbers of participants was sought)

One person (who felt supported overall) wanted more clarity about next steps and timelines.

“Yeah, but overall we enjoyed it and your guys help was amazing. Like I said and all the additional training information was really useful, so on the whole, yeah, super positive.”

The learning identified by organisations involved increased knowledge about asthma, and better understanding of the children and young people they support including how to engage them in meaningful conversations. Positive impacts in organisational practice were also mentioned.

People’s learning about asthma covered:

- variation in symptoms and how children present
- perceived v actual prevalence
- management (care plans/reviews)
- how to support asthmatic children
- types of support available and how to signpost families to relevant support

So I think I think for me is it's the awareness of asthma, and again, you know I've never had asthma. I don't – I'm not around anyone that has asthma, so for me it was again, I had that very superficial of I know they have a brown inhaler, I know there's a blue inhaler. But what I didn't know that there had to be like a care plan in place with the school.”

People's learning about the children they support and how to engage them covered:

- better understanding about the children and young people supported ('more inclusive')
- awareness of children with asthma who were previously unidentified as having asthma
- increased awareness of the importance of having one-to-one conversations with children and young people (not just their parents) to understand their knowledge/knowledge gaps and needs
- children's extent of understanding about the risks posed by asthma
- the impact of different engagement and research methods.

"*It's definitely added another lens to some of the students we support. And like I said, things that I wouldn't have usually kind of engaged in conversation about I now am doing so with our young people with asthma. So it's just, I think it's just improved awareness overall and our approach being more inclusive of that.*"

Changes to organisational culture and practice included:

- updating the staff handbook with advice on having conversations to better understand what children and young people are experiencing (knowledge sharing)
- 'normalising' inhaler use and stressing the requirement for children and young people to bring inhalers to sessions (safety)
- adding asthma awareness sessions in future activities (promoting learning)
- building on acquisition of skills developed during the project to start planning wider engagement activities (development)
- willingness to have further subject specific health and wellbeing conversations
- being better able to support parents with advice and signposting.

Recording conversations and Future involvement

Recording and submitting conversations to the Insight Bank was straightforward for most people; the offer of recording a test conversation was a useful exercise. There were a few queries, all of which were, or could be, easily resolved. A few issues were raised about recording:

- lack of certainty about how much of the conversation to record and the value of very short exchanges
- lack of certainty about whether to link separate parent and child conversations.

There were also some reflections on inputting:

- potential for repetition or confusion because of the box (input) order
- uploading multiple similar responses was 'tedious' – easier in blocks than individually
- inputting was time consuming and three months was a tight turnaround
- understanding how responses should be inputted was helpful prior to having the conversations.

Every organisation said they would like to be involved in future projects.

People noted the benefits of participating in Community Voices:
"Yes, If I feel it's contributing to community and contributing to, you know, to people's health in general and specifically to children then yes, I have no problem."

There were examples of how learning from the Asthma project are being incorporated into other workstreams to raise awareness:
"And we did say the end of it that the awareness part is something that we'd like to drop in again so that the next ones that we have also. It is just being aware of it, isn't it? Cause it is quite silent, but deadly, isn't it?"

People were keen to be involved in future projects with the proviso that they had sufficient staff resources and time:
"Yes. One hundred percent, I think, yeah. It was really successful. I think you know if we were able to train our staff on how to do it and have the time to process that then 100% we yeah we would definitely do that."

Supplementary reporting

During the conversations, points were made which did not fit neatly into the interview structure but which are worth noting.

1. Community Voices was praised for seeking people's views but the importance of feeding back results to participants was observed:
"Yeah, I think it's really important, because the whole title is Community Voices is to be able to tell the community that their voices were heard, and what's happened to it. Um and if we want to continue to use the community by asking them questions, we have to show that we listen. If not, at some point, they're gonna say "No I've done this before, there's no point."

2. The Community Voices project promoted connectivity between organisations and created potential to improve outcomes for families:
"I think the only other thing that was we found quite helpful was and being in touch or knowing where to signpost families to and it's something that, that's another thing that we would keep doing. Um now that it's kind of like, we know other agencies are out there, but it never really clicked to actually, OK, let's use this opportunity to sign post families to them. So that's been helpful."

Many of the organisations providing sports activities noted their activity led very naturally to talking about the symptoms of asthma and then onto a wider discussion of asthma (playing sports / physical exertion / breathlessness / asthma symptoms).

However, craft activities also provide a valuable reflective space for similar discussion and there may be differences in the audiences for different activities which is worth exploring in future projects. A hospital in a neighbouring region has approached an organisation involved in this CV project about a similar asthma project – could this be an opportunity for shared learning?

Finally, there was no noticeable difference in the evidence from interviews between VCSE and the holiday/activity providers' experiences of participating in the CV Asthma project. The fact that all the organisations (bar one) were new to CV may have been a unifying factor.

Recommendations and key reflections

1. **Address Wider Determinants of Health**: The impact of factors like poor housing on health outcomes. The role of the trusted communicators in directing families to housing support based on their discussions.
2. **Improve Asthma Diagnosis Awareness**: Clarifying the difference between perceived and actual asthma prevalence to address issues around diagnosis.
3. **Enhance Confidence and Knowledge**: Focus on improving both confidence and knowledge among children and young people and their families to encourage seeking support, addressing ongoing challenges in this area.
4. **Strengthen Signposting and Resource Mapping**: The key role trusted communicators play in signposting, with the added benefit of helping organisations better understand local resources available for support.
5. **Diverse Provider Engagement**: Ensure a diverse range of service providers to reach children and young people and families from different community groups effectively.
6. **Balance Conversation Quality and Quantity**: Specifically for Community Voices as a programme emphasise richer, more informative conversations over a high volume of surface-level discussions. Training will help address this balance.
7. **No Distinction Between Provider Types**: There is no significant difference in outcomes between VCSE and holiday/activity providers, suggesting equal effectiveness across provider types.

Contact: nwicb.communityvoices@nhs.net