



Child Health and  
Wellbeing Network  
North East and North Cumbria

# ASTHMA:

## *Roll out, implement and embed the National Asthma Bundle across Education, Social Care, Healthcare and Community Systems*

**NENC CHWN**

*Findings and Recommendations Paper*

June 2022

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## Executive Summary

The overarching long-term aim of the Asthma Leadership Group is to roll out, locally develop and embed the National Bundle of Care across the whole Education, Health, Social Care and Universal and Community Service systems to:

- Reduce avoidable harm from Asthma (control and reduce the risk of asthma attacks)
- Improve quality of life
- Whole system approach (environment, education, personalised care, preventative medicine and improved accuracy of diagnosis)

The key stages of the work are as follows:

- A. Collectively map and understand the wider pathways and interdependencies of services and settings that will need to be engaged across the system and how best to engage them at the earliest possible opportunity
- B. Co-develop programme of work and work across the system to be able to achieve delivery of the framework
- C. collaboratively develop (influencing commissioning decisions) and implement effective services by means of a range of interventions that are flexible and respond to the identified needs in the localities
- D. Develop systems of accountability
- E. Develop effective and meaningful data flows between organisations and agencies to enable improved risk stratification and management of this
- F. Develop and implement systems to record and monitor the impact of the interventions
- G. Delivering an effective engagement and programme of communication to inform parents, carers and CYP and the local populations about the work that is ongoing throughout the project

This report provides details and reports on the first four of the project milestones

1. Establish core steering group and key roles and responsibilities, identify resources.
2. Mapping Exercise to understand various regional pathways, position and map gaps (training needs analysis) across the system against the framework of deliverables
3. Local engagement with CYP and Families to understand local need and aspirations
4. Co-develop a credible plan and delivery model to address the gaps identified in line with the framework
5. Utilise Healthier Together/Beat Asthma as a vehicle to support the delivery and implementation of the model
6. Implement actions, monitor implementation, review and evaluate progress

We have been able to identify positive findings and some areas for improvement across the system for example the positive awareness and use of PAAP in primary care, but have identified an urgent need to find a solution to facilitate 48 hour reviews in practice

This scoping exercise has enabled us to draw seven key recommendations relating to pathways, referrals, process and procedural development and training between primary, secondary and tertiary care. The recommendations also relate to the wider system for example priorities for

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pharmacy and education settings and highlight the scope and potential for wider system working. Another key facet to the recommendations is the need to find a way to enable the effective and meaningful engagement of children and young people and their families in the development of initiatives and the further roll out of the bundle.

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## Acknowledgements

We have been able to benefit from learning from other system wide colleagues and professionals. Part of this work has been to collaborate with others to understand and baseline the current position.

We thank all those colleagues who have participated in the information gathering and survey respondents, who are far too numerous to list here and also to those Children Young People and family members who have shared their views and experiences as part of the focus groups.

In addition we would like to also thank the following individuals for their expertise and assistance throughout all aspects of our project and for their contribution to the drafting and finalisation of this findings and recommendations paper.

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# Background

Asthma is the most common long-term medical condition in children in the UK, with around 1 in 11 children and young people living with asthma. The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe. Outcomes are worse for children and young people living in the most deprived areas. NHS England and NHS Improvement's ambition is to reduce avoidable harm to children and young people from asthma and improve their quality of life. There is wide geographical variation in emergency asthma admission rates for children across the UK. Most emergency admissions are preventable, with high-quality management (including the use of asthma plans) and early intervention to address deterioration in control. The children and young people asthma audit, a component of the National Asthma and COPD Audit Programme (NACAP), is a continuous clinical audit with an episodic organisational audit component. It launched in June 2019 and captures the processes of care, clinical outcomes of treatment for children and young people admitted to hospital with asthma attacks. The most recent data found that 66.8% of children and young people admitted to hospital with asthma attacks presented with severe or life-threatening features of acute asthma, and 19.5% were so severely ill they required intravenous therapy.

NHS England and Improvement worked with key stakeholders, including young people and their families, to develop a National Bundle of Care for Children and Young People with Asthma (NBAC) to support local systems with the management of asthma care. The programme sets out the blueprint of evidence-based interventions to help children, young people, families and carers, to control and reduce the risk of asthma attacks and to prevent avoidable harm. The bundle covers each of the following components based on the patient pathway:

- Environmental impacts
- Accurate and early diagnosis
- Effective preventative medicine
- Managing exacerbations
- Severe asthma

Two additional working groups were formed to support the development of the bundle as golden threads through the programme:

- Asthma Competencies, Training and Education Needs
- Data and Digital

Anaphylaxis Campaign reports that 17% of fatal food-anaphylaxis reactions in school-age children happen while they are at school and 20% of anaphylactic reactions in schools are in children with no prior history of food allergy.



The European Academy of Allergy and Clinical Immunology report that allergy is the most common chronic disease in Europe. Up to 20% of patients with allergies live with a severe debilitating form of their condition, and struggle daily with the fear of a possible asthma attack, anaphylactic shock, or even death from an allergic reaction.

BeatAnaphylaxis paediatric anaphylaxis audit data from 2019 showed that there were 76 cases of confirmed anaphylaxis admitted to hospitals in the North East region in that year, one of which resulted in death of a young person. This work has highlighted that pre-hospital management of anaphylaxis was often sub-optimal.

## Health Inequalities

The Facts of Life for children and young people growing up in the North East and North Cumbria (NENC): Published September 2021 had the following relevant findings.

The NENC region as a whole has a higher proportion (29.4%) living in the 20% most deprived areas of England than the national average (20.2%), and all of our local authorities with the exception of Eden have a higher Index of Multiple Deprivation (IMD) 2019 deprivation score than the national average of 21.7. At a locality level using the most recent available data:

- In Middlesbrough in 2014 57.2% of people lived in the 20% most deprived areas in England, almost three times the national average.
- The percentage in child poverty using the Income deprivation affecting children index (IDACI) varies across the region. The highest rates are in Tees Valley, particularly Middlesbrough (32.7%) which is almost twice that of England (17.1%). Middlesbrough also has the highest crime deprivation score (0.6) and the highest level of income deprivation (25.1%).
- For most indicators relating to deprivation North Cumbria has lower or similar values to the national average, with the exception of Copeland having 24.9% living in the 20% most deprived areas in England.

In regards to asthma, at a locality level, the data indicates that on average:

- For admissions for asthma for children aged 0 to 9 years in NENC there is a notable geographical divide with all CCGs in the North of Tyne and Gateshead ICP having significantly higher rates than the England average but all other CCGs, except Sunderland, having rates similar to that of the England average.
- The majority of NENC CCGs have significantly higher rates of admissions for asthma for young people aged 10 to 18 than the England average (119.0 per 100,000). This is most notable in South Tyneside (238.6 per 100,000). North Cumbria (117.8 per 100,000) is the only CCG with a lower rate than the England average, but not significantly so.
- For young people aged 19 to 24 years rates of admission are lower in all CCGs than in 10 to 18 year olds, suggesting better management of their condition. In Newcastle Gateshead (63.9 per 100,000) the rate is significantly lower than the England average (103.1 per 100,000).

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# Aims and Objectives

Before we can plan how to implement the NBAC it was important to gain more information on the management of asthma CYP in NENC, to highlight areas of good practice and identify areas that require improvement.

## Methodology

To aid with implementation of NBAC an ICS lead for asthma in CYP and 2 advisors were appointed in October 2021. Following this 3 asthma nurse educators were appointed in December 2021.

As well as the data from the Facts of Life report, the national asthma audit and data from a prior project (Beat Asthma +) it was felt important to gain more detailed information from primary care, secondary care and schools as to the current level of services.

Individual questionnaires (appendix 1) for each setting were developed and circulated widely via existing network contacts, personal contacts, and word of mouth.

Distribution Lists were collated for Primary Care, Secondary Care and Education settings by bringing together existing network lists together with additional and newly discovered contacts. In addition, the Asthma Leadership Group developed a range of resources (PowerPoint presentations and informative letters) to support with the distribution and promotion of these surveys.

### Primary Care Questionnaire

The Primary Care questionnaire was developed as an MS Form by Dr Neelmanee Ramphul with the support and input of Dr Vaishali Nanda, Primary Care Advisor to the CHWN, they were written to enable data capture from colleagues who have either a clinical role, a lead role, or both.

We were unable to access a clear list for GP practices so refined a 20/21 list that was included within the National Asthma Dashboard which identified over 570 practices provided by 516 Primary Care Providers. This list was refreshed by confirming and consolidating the contact email addresses with those provided within secondary care contacts lists and also with what information was publicly available online on the GP Practice Websites. Other vehicles for distribution included the CCG Primary Care Commissioning Leads in each of the ICP areas, the GP Federations in place across the NENC ICS footprint and also HEENE were asked to support the work by undertaking onward distribution. In addition personal and professional contacts were made in the meantime. This was also promoted through various network forums and other primary care and respiratory forums that were already in existence



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This questionnaire was distributed on 20th December 2021, and was due to close on 31st January 2022, this was followed up on 14th January 2022 and the closure date was extended on the 28th January to close on 13th February 2022. There were 104 responses for a possible (approx.) 570 which is a return rate of c18%. Average completion time was 10.5 minutes.

## Secondary Care Questionnaire

The Secondary Care questionnaire was developed as an MS Form by Dr Ahmed Hegab and was written to enable detailed information about the services offered and the variation and diversity across the Trusts.

We were able to assemble a clear list of delegates to receive and participate in this survey via the Paediatric Asthma network for the North east and North Cumbria (PAN-NEC) and through our Respiratory Network Colleagues. Our aim was for a minimum of one response from each unit. This was also promoted through various network forums and other secondary care forums that were already in existence.

This questionnaire was distributed on 11th January 2022, and was due to close on 31st January 2022, this was followed up on 17th January 2022 and the closure date was extended on the 28th January to close on 6th February 2022, and then again on the 4th February a further extension was applied to close on the 13th February 2022. We received at least one response from each of the NHS provider trusts across the NENC ICS footprint which represents 100% feedback rate in relation to geographic representation. The average completion time was 28 minutes.

## Education Questionnaire

The Education Settings questionnaire was developed as an MS Form, led by Dr Samantha Moss and Dr Andrew Bright with the support and input from Mrs Kate Swaddle, Education Advisor to the CHWN. This questionnaire was developed to capture intelligence from across settings early years to secondary and higher education (sixth form settings) covering an age range of 3 –18 years in relation to both allergy/anaphylaxis and asthma and allowed the data capture to be sensitive enough to be able to extract the relevant responses to each condition/element.

We had access to a range of contacts however in order to comply with necessary guidance in relation to GDPR and information sharing we reviewed these lists against information that was publicly available. We also distributed these questionnaires via colleagues and professionals who were identified as members of the Child Health and Wellbeing Network. It is estimated that there are approximately 1400 education settings in the NENC ICS footprint that had potentially received a request to complete this survey. Other vehicles that were used to promote this are listed below. All colleagues received an explanatory letter asking them to be aware of and share the survey form completion:

- Schools North East (UK Regional Network)
- LA Education, SEN and Inclusion Leads
- CCG Designated Clinical Officers

- CCG CYP Commissioning Leads
- Directors for Education and for Children's Services
- Directors for Public Health
- LA Public Health Commissioning Leads
- 0-19 Universal Service - Service Leads
- Various Network/Education Leads Meetings and Heads Forums

This questionnaire was distributed on 12th January 2022, and was due to close on 13th February 2022, this was followed up on 27th January 2022, the 8th February 2022. There were 198 responses for a possible (approx.) 1400 which is a return rate of c14%. Average completion time was 14.8 minutes.

## Focus Groups

In order to consider the views of families of CYP with asthma 124 contacts were made with a variety of parent/carer and family orientated groups. Due to the restrictions of the pandemic, it was evident that a significant number of support groups had remained in contact on line only and had not re-established meetings in person. There was a small number of groups that replied and agreed to accommodate the request to meet up or contact members of their group.

Out of these groups 15 families/carers and 4 young people agreed to take part. The focus sessions were conducted individually or within a group either face to face or using a virtual platform. The families were able to speak freely, but the facilitator did help direct the conversation. Every opportunity was taken at each point of communication to share with the members of each group the work of the NENC ICS in the implementation of NBAC to deliver high quality asthma care.

## Risks and Issues

A key role of the Asthma Leadership Group has been to manage, mitigate, respond to and resolve risks and issues that have been presented throughout the duration of the project and as such logs and actions have been captured and recorded as part of the risks and issues log which have been reviewed throughout the programme.

Issues that were unable to be managed as risks for example limitations to data and ability to quantify impact/measurable change, COVID pandemic and system wide focus on recovery impacted prioritisation of work as well as more practical issues. This included a delay to the availability of the Beat Asthma training resources Levels 1-3, and ensuring that processes in place to collect information across the system were compliant with confidentiality and GDPR provisions. Another major challenge to the work that we encountered was the availability of clear contacts and distributions lists for GP and for Education settings, a range of methods were engaged to manage and mitigate this.

Risks that have been identified, assessed, mitigated (to the best possible extent) and monitored are numerous ranging from the limitations of the funding into future years to be able to deliver

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suggested recommendations on the back of the findings of this paper as well as making sure there is efficient use of funds for the monies that had been made available in year 21/22.

Risks to project delivery due to resource (staff capacity and skillset) were identified due to the technical nature of some of these project tasks, resources and support were identified and resources to secure delivery of the key requirements to ensure that this was available.

Another key risk that impacted the project was the need to place additional demands on an already pressurised system for example primary care, plans were put in place to be able to obtain a representative view and to be able to use the knowledge and experience of the Primary Care Advisor to the Network.

# Findings and Interpretation

## Primary Care

### Questionnaire

From the information available there are approximately 570 GP practices, but 516 GP providers across the NENC. There are 7 GP federations and 66 PCNs. 104 responses were obtained from all areas across the North East and North Cumbria, with the highest return rate from county Durham (15% of total number of responses) and the lowest return rates from Hartlepool and North Tyneside (3% each). The average completion time was 10.5 minutes.

The majority of respondents were clinicians who identified themselves as Practice/Asthma nurses (59%) followed by GPs (18%). Of the respondents, 13% had a lead role within the CCG or the Primary Care Network. Pharmacists accounted for 3% of the respondents.

18% of respondents had access to paediatric asthma training with only 7% of the total number of respondents being able to access it yearly or more frequently. Training accessed was variable and consisted of webinars, online courses from Asthma UK, e learning for Health (e LFH), local education events delivered by community, secondary and tertiary care teams and one respondent had completed a diploma in asthma.

The majority of respondents (85%) were aware that national guidance recommends a review at 48 hours post discharge after hospital attendance with an acute asthma attack but only 63% of respondents were able to offer a 48 hour review, primarily due to a lack of capacity. It was also reported that communication relating to the admission is not always available within 48 hours especially if the patient was discharged on a Friday evening.

94% of respondents offered an annual review automatically if there was a diagnosis of asthma or suspected asthma and the remaining 6% offered an appointment if the family requested one. Non-attendance was reported as an issue in some cases. It is understood that if GPs have called for an annual review twice and the patient fails to attend they are then removed from the numbers in terms of QoF.

93% reported giving out Personalised Asthma Action Plans (PAAP) regularly and 66% performed a peak flow measurement routinely in CYP who were able to perform the test.

Although 69% reported being able to trigger an asthma review based on the number of Short Acting Beta2 Agonist prescriptions collected, only 17% reported triggering a review if the number of SABA prescriptions exceeded the recommended maximum of 3 per year.

98% of respondents were able to direct patients and their families to additional resources with Asthma UK being the most commonly cited resource followed by Beat Asthma.

Out of the guidelines available currently, BTS/SIGN and NICE guidance were the ones respondents referred to mainly.

Only 76% reported recording a smoking history in the household routinely.

The majority (59%) did not have access to diagnostic services like spirometry or exhaled nitric oxide (FeNO) in primary care.

Most respondents (66%) were not aware that a National Asthma Bundle had been published.

39% had a designated lead for Children and Young People and 67% had a lead for respiratory conditions in general.

Out of the 18 respondents who identified themselves as having a lead role, 67% were aware that they can refer directly into a severe asthma service if needed in tertiary care. 61% had a guideline or policy for when to refer to secondary care. 50% audit how many annual reviews are being conducted and how many SABA prescriptions are being collected per patient per year. 39% audit the number of patients who have a PAAP. 28% audit the number of courses of oral steroids prescribed per patient per year and the number of unscheduled hospital attendances per patient per year. Only 11% audit the number of 48 hours review conducted. 39% have a link pharmacist who can monitor the number of SABA prescriptions collected

### Beat Asthma+

The Beat Asthma+ pathway was created from two separate pieces of work which were developed in the NENC to improve outcomes for asthma patients. The pathway relates to the identification and treatment of children at higher risk of adverse asthma outcomes through the use of a novel digital triage tool, PEDAAT (Paediatric Emergency Department Asthma Assessment Tool) and the delivery of increased asthma surveillance and an education programme to children, young people and their families in primary care. The aim of the project was to understand the impact of this Beat Asthma+ pathway on the outcomes of children and young people with asthma in primary care, based on data collected from GP practice clinical systems over time.

Nine GP practices in the NENC (four of which work as a partnership) agreed to participate in this work, along with a further 5 'matched' control practices. Each practice was required to identify children who were registered patients in their practice who were at risk of adverse asthma outcomes including asthma exacerbations, hospital admission and death, based on four key parameters. These parameters were: i) patients with 6 or more prescriptions in 1 year for a short acting beta2 agonist (SABA), and ii) those prescribed 1 or more courses of prednisolone for use as emergency rescue medication, iii) patients with 1 or more asthma-related emergency admissions, and iv) patients with 2 or more asthma-related A&E attendances in the last 12 months.

The project was discontinued in November 2021 due to issues with patient recruitment and retention (in particular patients not attending appointments), competing demand on primary care resources due to the pandemic and introduction of NBAC. Data is available for the years March 19- Feb220 and March 2020-Feb 2021

Over the course of the project 47-87% of patients were prescribed >6 SABA a year, 47-70 % of patients received <6 preventer inhalers a year. 32-37% of patients had more than one course of oral corticosteroids in a 12 month period and 21-29% were documented as having 2 or more exacerbations of their asthma.

## Secondary Care

### Questionnaire

We have sent our questionnaire to all secondary care trusts across NENC. We received 12 responses from all nine secondary care trusts across the region. Three trusts had multiple responses from different team members. The average completion time was 28 minutes. It was noted that responses from different team members from same trust sometimes varied, so some results are based on the number of responders rather than the number of trusts.

Six out of nine trusts have a Paediatric Asthma Lead who is responsible for dissemination of asthma standards and good practice. 41% (5/12) of the responders have less than one full time equivalent asthma nurse. 50% of the responders (6/12) have between one and two full time equivalent asthma nurses. One trust reported no paediatric asthma nurse.

41% of the responders (5/12) were aware that their CCG/local area has a paediatric asthma/CYP lead. 25% (4/12) indicated that their local area has no local CCG asthma or CYP leads. 33% of the responders (3/12) are not aware of CCG or local area asthma or CYP leads. 75% of the responders (9/12) have links with CCG/PCN in relation to asthma/respiratory, with 16% of the responders (2/12) having no links and one responder is not sure of any links. Only 58% of the responders (7/12) attend CCN/PCN meetings regularly and discuss paediatric asthma. 3 trusts did not attend any regular meetings with CCG/local authority. 2 trusts were not sure if they attend any meetings with CCG/PCN.

Six of nine trusts have access to resources about air pollution, housing and smoking and its effect on asthma patients, but only 58% (7/12) of responders discussed risk of air pollution on paediatric asthma, with patients and their families.

Three of nine trusts use Beat asthma as the main source to discuss effects of air pollution on paediatric asthma, one trust uses asthma UK as the main source of information. One trust uses kids' health website, one trust uses BMJ publications. one trust uses smoking cessation websites with no clear specifications.

One trust has a diagnostic hub within primary care, one trust is not sure if there have any diagnostic hubs, and 7 out of nine trusts have no diagnostic hubs. Only two out of nine trusts regularly audit their ability to diagnose and code asthma, two responders are not sure if they regularly audit asthma diagnosis and coding, and six out of nine trusts do not audit their ability to diagnose and code asthma.

All trusts have access to spirometry, eight of nine trusts have access to paediatric spirometry and only one trust uses adult spirometry service. Six of nine trusts include FeNO in their assessment. Only 58% of responders (7/12) are aware of ICS referral pathway between primary, secondary, and tertiary care. 16% of responders (2/12) are not aware of referral pathways. 3 trusts (3/12) are not sure if there is a referral pathway.

Only half of responders (6/12) regularly provide children with a PAAP. Of these, only two trusts were able to monitor children with PAAP. Only four trusts have a structured asthma annual review for all their patients. Four trusts include spirometry results, three trusts include peak flow, five



trusts include FeNO, six trusts include inhaler technique check, four trusts include PAAP, three trusts include Asthma Control Test (ACT), one trust includes Asthma Quality of Life Questionnaire (AQLQ) and four trusts include concordance check in their structured annual review.

Only one third of responders (4/12) believe their patients have a review 48 hours post discharge.

Half of responders (6/12) have a forum to discuss high risk cases, the other 50% (6/12) do not have any forums to discuss high risk cases.

Only four trusts reported to have a transition policy. Of these, one trust has a joint clinic with adult team as part of the transition process. Three other trusts use a structured transition program such as Ready Steady Go.

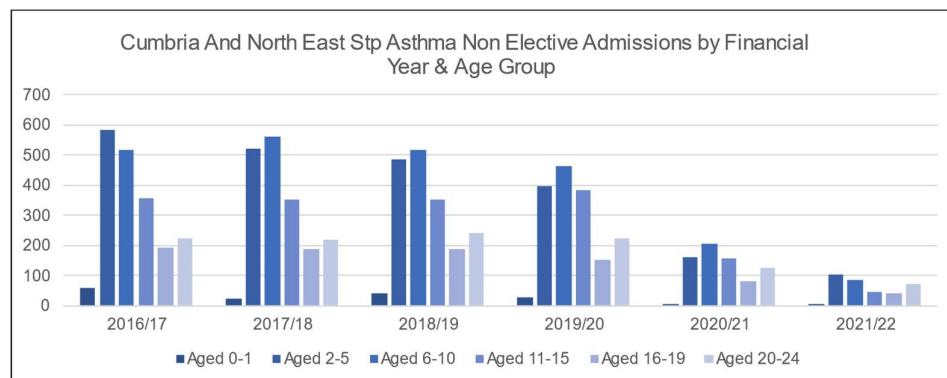
All trusts have been collecting paediatric asthma data. Four trusts have asthma patients' data base, two trusts have severe asthma data base. Eight of nine trusts do regular asthma audits, and five trusts collect different asthma data bases.

### National Asthma Audit (NACAP)

NACAP collected data prospectively from children admitted acutely with asthma from 1st June 2019 until 30th November 2019. In NENC 1 trust (Sunderland and South Tyneside) did not contribute any data. The findings from the trusts that did contribute were as follows 45 % of patients had steroids administered within 1 hour of arrival (range 29-70). Patient tobacco dependency was addressed in 71% (0-100). Parent carer tobacco dependency was addressed in 21% (0-78). 83% of children had their inhaler technique checked (24-100). 31% of patients had an updated PAAP (15-100). The results varied between trust, with no 1 trust performing particularly well, or particularly poorly in all areas.

### Children & Young People Transformation Programme Asthma Dashboard

As part of the national work an asthma dashboard is available. This is developed from coding data from hospital trusts. The data currently is actual numbers and per 100 000 population. This therefore made it difficult to compare data across geographical areas. However, as can be seen in the graph below asthma admissions across NENC are relatively high with a decrease during the pandemic.



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## Education

It was estimated that there were c1400 in North East and North Cumbria. Schools were not contacted directly unless we had contact details from the methods described above. In total there were 198 responses, 10 of which related to EYFS which were excluded from the asthma lines of enquiry (this represents a response rate in the region of 13%). Of these 142 (75%) were primary education settings of some sort (including first schools and run through schools etc). We had responses from all areas of the region, with the majority, 40 (21%) from Northumberland, and the fewest (4) from Darlington.

Of the responses 70/188 (37%) had no asthma policy, 76 (64%) of those who did have a policy shared it with parents and staff. Of the settings 52% (97/188) had access to annual training in asthma, but 63% (175) feel they would benefit from further training. 93% (175/188) of respondents had reasonable confidence in dealing with an acute asthma attack (rating  $\geq 3$  on a scale of 1-5, with 1 being the lowest confidence and 5 the highest).

67% (126/188) of respondents would like to explore the possibility of becoming an asthma friendly school.

Unlike the asthma-specific questions, the allergy/anaphylaxis elements of the survey included responses from all educational settings including those from Early Years.

Of all the responses, 39% (77/198) stated there was no allergy/anaphylaxis policy in place in their educational setting. 55% (66/121) of those working in settings that did have a policy, stated this was shared with parents and staff.

58% (115/198) respondents stated they worked in a setting where they had access to annual training in allergy/anaphylaxis. However, 70% (139/198) felt they would benefit from further training in allergy and anaphylaxis.

Overall, respondents' confidence in initially dealing with anaphylaxis was suboptimal, with the mean rating being 3.7/5.0 (ratings: 1 = not at all confident, 2 = somewhat confident, 3 = neutral, 4 = confident, 5 = very confident).

Only 64% (127/198) of respondents were aware of the national 'Spare Pens in Schools' initiative, with just over half (55%) of those aware actually working in education settings that were participating in this programme and keeping spare adrenaline auto-injectors on site.

78% (155/198) of respondents were interested in exploring the possibility of becoming an accredited allergy and anaphylaxis-friendly education setting.

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## Focus Groups

The discussions from the focus groups revolved around several themes, these included diagnosis, education & Advice, asthma reviews, medication, anxiety and communication. There were positive and negative comments in all areas. Families didn't like telephone consultations and appreciated hospital services. Families did express frustration at the lack of formal diagnosis. Families found PAAP helpful as was education from all sources including pharmacies. However, many families felt they had little or no education re the where diagnosis and management and at times advice was felt to be contradictory. In addition, smoking and pollution had not been discussed with some of the families. Whilst some patients were getting regular reviews, either in hospital or in primary care some families had no follow-up and others described difficulties getting appointments with primary care. Whilst some families felt confident in the management of asthma others were worried. Some families particularly felt worried about how their child's asthma would be managed at school. There were good experiences of communication between primary and secondary care in some cases, but not in others.

## Limitations of data

Completion of the questionnaires and attendance at focus group was voluntary. These obviously only represent a small proportion of relevant parties and may have bias towards those more invested in the care of CYP with asthma. The methods used to contact relevant parties were not comprehensive and we could have inadvertently missed select groups.

Self-reporting such as questionnaires may in itself contain bias and with people giving positive responses when they know something should be done may not actually translate to it being done.

NACAP did not have any resources for the local hospitals and as such data sets may be incomplete.

The data collected for the Beat Asthma+ project (and the Facts of Life Data) and Children & Young People Transformation Programme Asthma Dashboard were from mass interrogation of computerised data, such as coding systems and so may have a small proportion of error in built

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# Conclusions

## Positive Findings

1. There is good awareness and use of PAAPs in primary care.
2. Patients and families are being directed to accessible web-based resources such as Asthma UK and Beat Asthma.
3. There is awareness that a 48 hrs review post discharge from hospital needs to happen.
4. An annual review is being offered in the majority of cases.
5. The majority of schools have some measures in place for CYP with asthma and are willing to improve those measures.
6. Most secondary care settings have access to spirometry and FeNO
7. All trusts across the region collect asthma related data and do regular asthma audits.
8. Well established secondary care network.

## Areas for improvement

1. Training specific to paediatric asthma should be more widely available and accessible.
2. There is an urgent need to address the overuse of SABA inhalers to improve disease control and reduce the risk of dying from asthma attacks. This will also contribute towards sustainability in healthcare as metered dose inhalers (MDIs) are the most commonly used device in the paediatric population and it is widely acknowledged that they contribute significantly to the carbon footprint of the NHS.
3. Concordance checks need to be a routine part of asthma care with staff being armed with appropriate techniques to address this.
4. Better access to diagnostic services like spirometry and FeNO measurement is needed in primary care.
5. There is an urgent need to find a solution to facilitate 48 hrs reviews in practice.
6. Every opportunity should be utilised to enquire about and deter smoking and environmental impacts in young people and their families.
7. Every contact with a child with asthma should be used as an opportunity to improve their care.
8. All secondary care trusts should have paediatric asthma lead and local forum to discuss cases.
9. All healthcare professionals should understand dangers of air pollution, have access to up-to-date resources on effects of air pollution on asthma and discuss these risks with patients.

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10. A referral pathway between primary, secondary, and tertiary care needs to be developed promoted.
  11. All children with asthma should have PAAP and structured annual review where concordance and inhaler technique are discussed and recorded.
  12. The annual review should also include an assessment of risk and severity and recent asthma control and a change in management accordingly.
  13. All secondary care settings should have a transition policy in place.
  14. All health professionals dealing with children with asthma should be aware that SABA overuse is a sign of poor control and should be aware of NHS sustainability program.

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# Recommendations

There is a region and system wide need for improvements in the quality and equity of asthma care to:

- Reduce avoidable harm from Asthma (control and reduce the risk of asthma attacks)
  - Improve quality of life
  - Whole system approach (environment, education, personalised care, preventative medicine and improved accuracy of diagnosis)
1. Primary, Secondary and tertiary care should continue to work together to deliver a hybrid model of training as respondents reported they would like a combination of e learning packages and face to face training. An e learning package of training aimed at different tiers of professionals in education, health and community organisations including the voluntary sector is already in progress and expected to be rolled out in the near future and should be extensively promoted across all services.
  2. There is scope to work with stakeholders in primary care especially GP practices and pharmacists to build a more robust mechanism that can trigger an asthma review should a patient or family/carer collect more than three SABA inhalers per year as prescriptions are generally issued electronically and therefore an inbuilt alert can be generated.
  3. All stakeholders should work together to develop and support more diagnostic hubs to enable spirometry and FeNO measurement to become more accessible in primary care.
  4. The 48 hours review process may need to be shared both by primary and secondary care as capacity is likely to remain a pressing issue in primary care especially post pandemic. Discharge letters although sent electronically in some areas do not always appear to be available in primary care promptly. There is therefore scope to get electronic records to “talk to each other” more effectively as more digital transformation sweeps the NHS.
  5. A more holistic approach needs to be taken towards asthma exacerbations in both primary and secondary care – why did this exacerbation happen and how can we prevent further exacerbations.
  6. Smoking cessation and reducing environmental factors remains a priority and a significant public health issue. We need to ensure that all young people and families who attend for an asthma review are asked about their smoking practices and then signposted to smoking cessation services. There is also scope for pharmacists to support with more signposting when prescriptions are collected for example.
  7. An asthma friendly school initiative needs to be rolled out in NENC and this should involve input from CYP themselves



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## Recommendations Specific to Anaphylaxis

1. Development of allergy/anaphylaxis policy frameworks for all settings, which should be co-designed with relevant stakeholders and build upon the existing National Department for Education and Department of Health guidance.
2. Run focus groups with a range of staff from a sample of education settings across the region to provide better insight into their specific learning needs and to identify logistical barriers to the successful implementation of allergy/anaphylaxis educational interventions in these environments.
3. Co-design of a targeted education programme for staff working in education settings. Gaining a clear understanding of the existing gaps in knowledge and confidence of in how to manage CYP with allergies/anaphylaxis from recommendation 2. will be essential.
4. Pilot introduction of an allergy/anaphylaxis learning programme for education staff and trial of 'BeatAnaphylaxis Friendly Education Setting' accreditation processes within a range of different education settings.
5. Organisation of virtual engagement activities with education settings across the region in parallel to above pilot. These would aim to raise awareness and promote national initiatives such as 'Spare Pens in Schools'. Increasing regional implementation may greatly reduce health resource burden of individual prescriptions of adrenaline auto-injectors for these environments.

Roll out of 'BeatAnaphylaxis Friendly Education Setting' accreditation across NENC and this should involve input from CYP in these environments

## Barriers

1. Beat Asthma+ struggled with patient engagement, deprived families are less likely to engage with health resources and so we need to find solutions to this.
2. Stakeholder engagement – the number of stakeholders across the NENC is huge. Stakeholders who are already interested in the care of CYP with asthma are relatively easy to engage, we need to develop pathways/incentives to engage those who currently do not prioritise this.
3. There are currently very few new resources allocated to the delivery of NBAC. We will need to ensure that any resources are used to the maximal effect and try and persuade stakeholders the advantage of committing existing resources to asthma care for CYP.
4. There are currently very few people formally trained to deliver Pulmonary Function Testing in CYP – we are trying to organise a regional trainer who can help facilitate this

5. The delay in training packages will inevitably result in a small delay in delivery of NBAC. This can be mitigated by ensuring relevant parties are engaged and ready to access the courses as soon as they are available
6. The on-going pressures of the pandemic and the backlog of care caused by the pandemic will continue to impact on the priorities of stakeholders (both in education and health).
7. Different management/organisational structures across the region for different stakeholders is challenging. It makes it harder to access stakeholders and also means that interventions that have worked in one area may need changes before implementation in another area.

## Next Steps

### Priorities and Plan for the next 12 months

The Child Health and Wellbeing Network Asthma Leadership Group team plan to develop the following actions over the next 12 months to support colleagues in developing the recommendations highlighted in this report.

1. Develop local asthma friendly school programme and pilot in a school in each Local Education Authority
2. Improve secondary care acute exacerbation outcomes
3. Identify target areas in primary care and begin pilots to improve
4. On-going education re NACB and training resources available through existing networks