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National Bundle of Care for Children and Young People with Asthma: Phase one

Version 1, September 2021

Contents

Executive Summary

1. 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[1]. The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe[2]. Outcomes are worse for children and young people living in the most deprived areas.[3]

2. 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. This will be achieved by taking a whole system approach to asthma management that includes addressing environmental triggers, a comprehensive education programme, promoting personalised care, effective preventative medicine and improved accuracy of diagnosis.

3. NHS England and Improvement have been working with key stakeholders, including young people and their families, to develop a National Bundle of Care for Children and Young People with Asthma 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

4. The target audience for this document is Regional Leads, Integrated Care System Leads, Commissioners, Healthcare Providers and Healthcare

[1] https://www.asthma.org.uk/about/media/facts-and-statistics/,
[2] https://www.england.nhs.uk/2019/09/nhs-warning-to-parents-as-asthma-season-hits
[3] Royal College of Paediatrics and Child Health (2020) *State of Child Health*. London: RCPCH. [Available at: stateofchildhealth.rcpch.ac.uk]

Professionals. It concerns the management and delivery of developmentally appropriate asthma care for all children and young people.

Summary of actions for Systems with associated enablers from NHS England and NHS Improvement

Component of Patient Pathway	National Actions/Enablers	System Action
Organisation of Care	The CYP Transformation Programme has disseminated funding to local systems to make improvements in asthma care.	Integrated Care Systems should have a named lead with asthma expertise who is responsible and accountable for the dissemination and implementation of asthma standards and good asthma practice which includes CYP.
Environmental Impacts	NHSE/I have signposted ICS leads to existing tools that will enable staff to do this. The Asthma Competencies, Training, and Education Needs national working group have developed capabilities that include enabling conversations with patients around mitigating the risks of air pollution, indoor air quality and smoking.	All healthcare professionals working with CYP with expected or diagnosed asthma should understand the dangers of air pollution, indoor air quality and parental smoking and ensure they discuss these risks and potential mitigation strategies with them. Integrated care systems should ensure staff are equipped with the tools that will enable them to do this.
Early and Accurate Diagnosis	NHSE/I have been working with NICE, and other arms lengths bodies. Existing guidance is available, and we are working with organisations on their forthcoming updates.	The diagnosis of asthma in CYP should be based on clinical features of a comprehensive history and when a diagnosis of asthma is made in CYP, this should be recorded in the notes and coded accordingly. Diagnostic hubs should be used to support diagnoses.

Effective Preventative Medicine	An example of a PAAP and asthma review template can be found in the resource pack associated with this document.	All CYP with asthma should have a Personalised Asthma Action Plan. Prescription of inhaler medication should include the appropriate device and education. Inhaler technique should be reviewed and graded, and regular asthma reviews should be conducted.
Managing Exacerbations	Providers of care should follow current guidance on minimum standards, the Managing Exacerbations working group will develop National Standards prior to final publication of the Bundle.	All providers of emergency and urgent care should adhere to minimum standards of assessment, treatment, referral, discharge planning and follow-up.
Severe Asthma	The Severe Asthma national working group has developed standards for CYP severe asthma services, these can be found in the resource pack, section 4.	Each ICS should ensure that CYP with severe or difficult to treat asthma should have access to a severe or difficult to treat asthma service.
Data and Digital	The national data and digital working group have proposed a minimum asthma dataset that will feed into a National CYP asthma dashboard. See appendix 2 for more detail on the dashboard and dataset.	ICS leads for CYP asthma should use the reports from the CYP Asthma dashboard to benchmark their services against national averages and use this information to make targeted improvements in asthma services.
Competencies, Training and Education Needs	A 5-level tiered framework for anyone involved in the care of CYP with asthma has been developed. See the resource pack, section 6 for full framework. We are working with professional bodies and royal colleges to align the capabilities with other established frameworks and to determine their future ownership as well as the required accreditation for training partners.	All people involved in the management of CYP with asthma should be trained to the appropriate level depending on their role. Tier 2 training for example is currently supported by Health Education England through their e-learning for health platform. ICS' will be held to account to ensure their CYP asthma workforce have met the required levels of training.

Background

1. 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. This will be achieved by taking a whole system approach to asthma management that includes addressing environmental triggers, a comprehensive education programme, promoting personalised care, effective preventative medicine and improved accuracy of diagnosis.

2. The Children and Young People's (CYP) Transformation Programme has prioritised improvements in asthma care as it oversees implementation of the NHS Long-Term Plan. The CYP Transformation Team have supported the appointed of CYP Regional Leads and allocated programme funding for asthma clinical leadership and asthma service improvements. Through the work of the CYP Asthma Programme, asthma care now has a bigger platform, regional leadership, system led governance and accountability and direct funding to improve outcomes for CYP in England.

3. In response to feedback from our NHS colleagues and other stakeholders this is phase one of our plan to support NHS teams to deliver high quality asthma care. Integrated Care System CYP Transformation Teams were clear that early steer on the direction of travel for improving asthma care from the national team was imperative. This first phase of the National Bundle of Care for CYP with Asthma, has been developed with clinical and patient experts to provide a framework for Local Systems to lead work on a range of improvements to support Children and Young People with asthma.

4. A final and complete version of the National Bundle of Care will be published in Spring 2022, until then it will be considered an iterative document that will be built upon as the work develops.

Case for change

5. 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[4]. The UK has one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe[5]. Outcomes are worse for children and young people living in the most deprived areas.[6]

6. In 2015, The Royal College of Physicians, reviewed deaths from asthma between 1 February 2012 and 31 January 2013 in the UK and published a report (NRAD, 2014)[4]. It identified avoidable factors in relation to both the care people received and the recognition of risk and avoidable factors relating to patients, their families and environments[7]. Despite pockets of good practice emerging since this report, widespread improvements in CYP asthma care are yet to be realised. The bundle has been drafted to ensure the NHS continues to build on the improvement recommendations outlined in this report thereby ensuring high quality of care for CYP with asthma.

7. Asthma is a long-term condition but can be perceived as a mild disease and research shows that it is often not taken seriously enough. A study showed that 1 in 6 people in the UK do not know or are unsure if the condition can be fatal.[8]

[4] https://www.asthma.org.uk/about/media/facts-and-statistics/,
[5] https://www.england.nhs.uk/2019/09/nhs-warning-to-parents-as-asthma-season-hits
[6] Royal College of Paediatrics and Child Health (2020) *State of Child Health*. London: RCPCH. [Available at: stateofchildhealth.rcpch.ac.uk]
[7] Royal College of Physicians. Why Asthma Still Kills 2014. National Review of Asthma Deaths
[8] Charity Awareness Monitor, January 2017

Perspective from young people living with asthma

8. This programme of work has been supported by youth representatives living with asthma, they currently sit on the Asthma Oversight Group and contribute to the National Working Groups. They share their experience of the management of their asthma

"One experience I found helpful in terms of my asthma management was a consultation I had with an asthma nurse when my asthma wasn't controlled. This is because she explained my condition to me in a holistic way, by educating me why I was experiencing symptoms and not just focusing on treatment. By doing this, it reassured me as I now understand my condition more.

However, I would have found this information extremely useful if it was explained to me earlier on in my asthma care. As I would have felt empowered and would have experienced less anxiety regarding my asthma management." Haania

"If I could change one thing about my asthma care it would be to have a face to face appointment – I've only had one telephone appointment about my asthma in the last 12 months" Aishah

9. NHS England and NHS Improvement commissioned the Association of Young People's Health to publish a scoping review of all CYP asthma engagement to date. They worked with the Race Equality Foundation, Friends of Families and Travellers and RCPCH & US to conduct engagement sessions with CYP around the management of their chronic asthma. This project was designed to ensure that young people's and parent's voices were at the heart of the programme. Given that asthma has a disproportionate effect on young people living in deprived areas and ethnic minority groups, the aim was to better understand the experiences from communities which have been marginalised and those living in more deprived areas. The review identified key areas for future focus that would support young people to better manage their asthma and enable them to take greater control over their health management. These include:
    - **Access to trusted information** in formats that work for young people and use non-clinical language
    - **Youth friendly services and care in non-clinical settings** that young people can access easily with the opportunity to build relationships with key staff
    - **Anti-prejudice training for healthcare staff** as the general prejudice that some groups face impacts their asthma care

- **Myth busting in communities** to help support the sharing of accurate information and avoid delayed diagnosis
- **Broader education in the community** so that teachers, youth workers, sports coaches and wider society better understand the impact of asthma and stigma is reduced.

Evidence and Standards

10. In 2017, NICE published a set of guidelines for the Diagnosis and Monitoring of Asthma and also for the Management of Stable Asthma in Adults and Children (see Annex A for summary of guidelines)[9]. NHS England and NHS Improvement have based the National Bundle of Care for CYP with Asthma, around these guidelines, as well as those of the Global Initiative for Asthma (GINA) strategy and the British Thoracic Society (BTS) and the Scottish Intercollegiate Guidelines Network (SIGN). BTS SIGN and NICE are working together to produce UK-wide guidance on asthma diagnosis and monitoring, and chronic asthma management that will update and replace the 2017 NICE guideline. NHS England and Improvement will input into the development of this guideline, based on learning from experts involved in producing the asthma bundle and ensure future versions of the bundle are updated to reflect new national guidance.

11. The National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP) published a Clinical Audit of CYP Asthma in 2021. The report outlines three key national quality improvement priorities for providers of CYP asthma secondary care:
    - **National QI priority C1:** Record smoking status and exposure to second-hand smoke for ***95%*** of children and young people. The audit showed it was only recorded in 57.7% of cases.
    - **National QI priority C2:** Administer systemic steroids within 1 hour of arrival at hospital to ***95%*** of children and young people aged 6 years old or over, who have not received systemic steroids as part of pre-hospital care. The audit showed it was only recorded in 38% of cases.
    - **National QI priority C3:** Provide ***95%*** of children and young people with the following as part of their discharge bundle:
        i. Review or issue of a personalised asthma action plan (PAAP). The audit showed it was only recorded in 45.5% of cases.
        ii. Check of their inhaler technique. The audit showed it was only recorded in 61.9% of cases.
        iii. A follow-up appointment in a paediatric asthma clinic requested within 4 weeks. The audit showed it was only recorded in 28.8% of cases.

    They were chosen based on their strong evidence base and effectiveness for improving care and outcomes for CYP with asthma. The recommendations of this report have been recognised by the expert clinicians, patients and carers involved in the development of this National Bundle of Care.

[9] https://www.nice.org.uk/guidance/ng80

12. The findings of a report by the Healthcare Safety Investigation Branch also published in 2021[10], produced a number of recommendations for system-wide change, following the investigation of a near fatal asthma attack of a five-year-old boy. The recommendations have been collaboratively produced with the CYP Asthma programme and have been accounted for within this Bundle.

[10] Management of chronic asthma in children aged 16 years and under - Healthcare Safety Investigation Branch (hsib.org.uk)

Health Inequalities

13. There are significantly higher rates of asthma incidence in black and minority ethnic (BAME) groups in England and Wales, with high rates reported among second and third generation descendants of South Asian and African Caribbean migrants and Irish children living in England[1]. Poor air quality is an issue which particularly affects Gypsy and Traveller communities due the location of sites next to motorways and in areas with poor air quality[11]. Asthma outcomes are worse for children and young people living in the most deprived areas.[12] Young people with asthma are more likely to have special educational needs for mental health reasons, perform worse in exams and leave school earlier than those without an asthma diagnosis.[13] A recent global asthma report found that the impact of asthma, measured in disability adjusted life years, was highest in 5-19 year olds and people over 60[14]. Commonly the burden of disease is highest in older people and not young people as well, but this is not the case for asthma.

14. The National Bundle of Care has imbedded the recommendations of the work of the AYPH (section 8) who have worked with the Race Equality Foundation and Friends and Families of Travellers to understand the barriers to accessing asthma care for these marginalised groups. In addition, the CYP Asthma Dashboard will be able to identify asthma care by race, geography, age and social deprivation to ensure that those CYP with asthma that are facing the starkest health inequalities are prioritised.

[11] Greenfields M and Brindley M, The Travellers Movement (2016) *Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health (publishing.service.gov.uk)*
[12] Royal College of Paediatrics and Child Health (2020) *State of Child Health*. London: RCPCH. [Available at: stateofchildhealth.rcpch.ac.uk]
[13] M Fleming, Eur Respir J 2019; 54.
[14] http://globalasthmareport.org/Global%20Asthma%20Report%202018.pdf

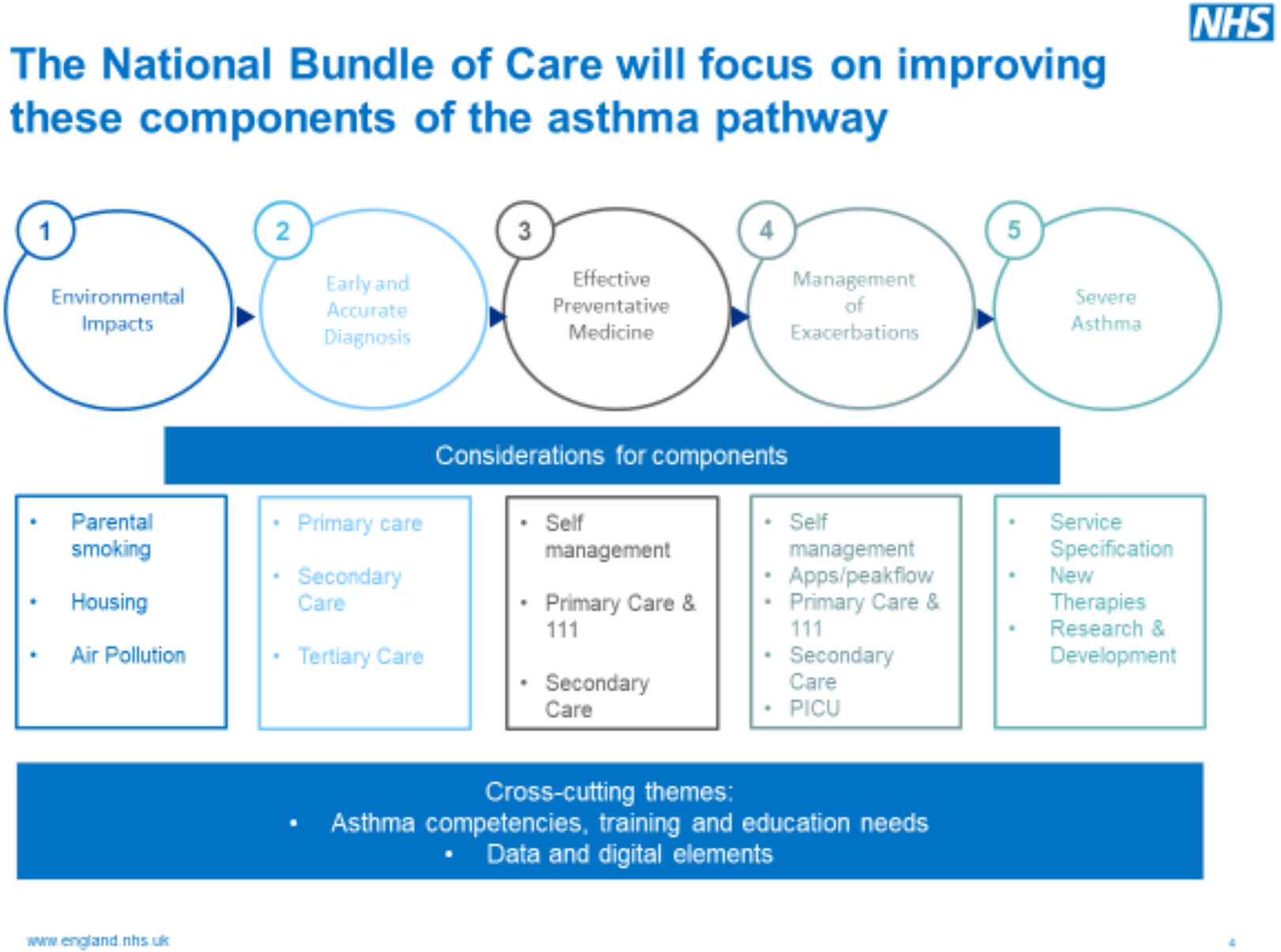
The National Bundle of Care for CYP with Asthma

15. NHS England and Improvement have been working with key stakeholders, including young people and their families, to develop an asthma bundle to support local systems with the management of asthma care in children and young people. 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


NHS
The National Bundle of Care will focus on improving these components of the asthma pathway
1
Environmental Impacts
2
Early and Accurate Diagnosis
3
Effective Preventative Medicine
4
Management of Exacerbations
5
Severe Asthma
Considerations for components
Parental smoking
Housing
Air Pollution
Primary care
Secondary Care
Tertiary Care
Self management
Primary Care & 111
Secondary Care
Self management
Apps/peakflow
Primary Care & 111
Secondary Care
PICU
Service Specification
New Therapies
Research & Development
Cross-cutting themes:
Asthma competencies, training and education needs
Data and digital elements
www.england.nhs.uk
4

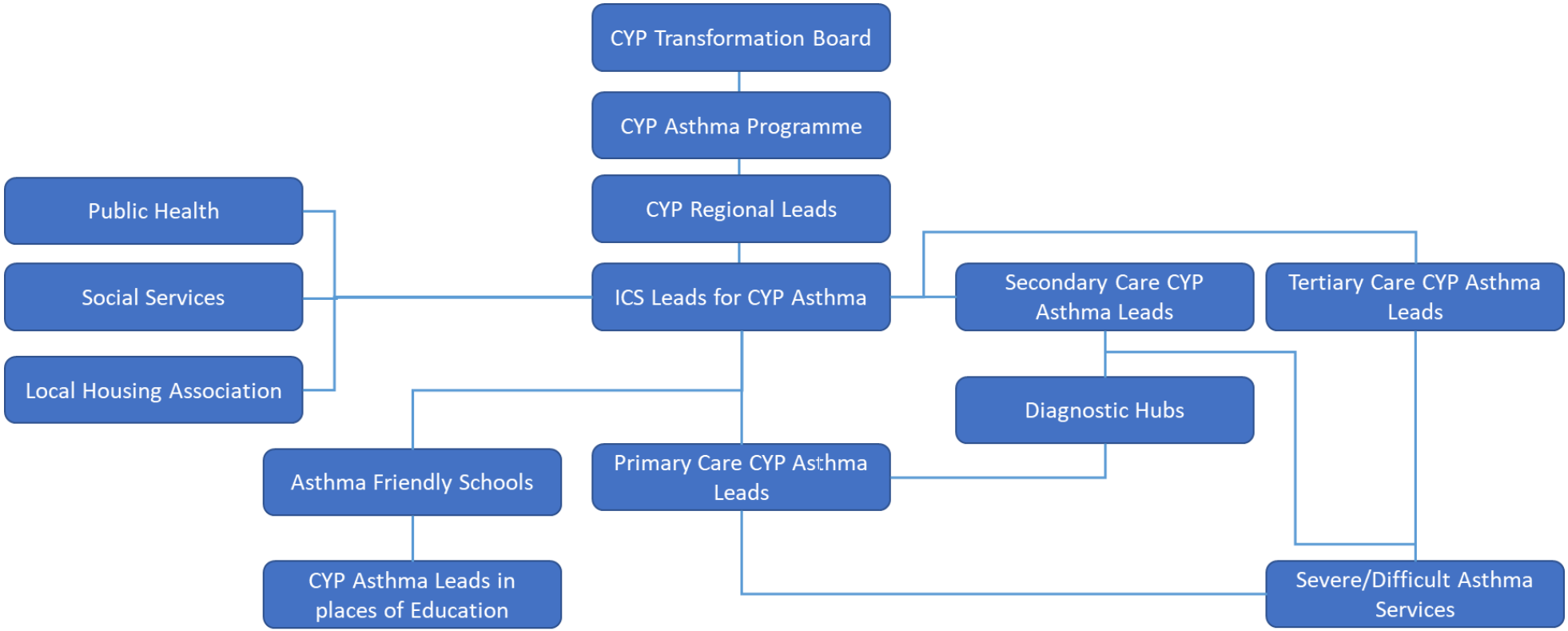
16. Each of the components formed National working groups, chaired by prominent experts in that field, with membership spanning all regions of England, healthcare professionals, young people, carers and other key stakeholders including the voluntary sector, local government, social care and education. The programme was overseen by an Asthma Oversight Group, with representation from across health systems, National Bodies, Royal Colleges and the third sector.

Organisation of Care (OC)

17. Lack of leadership, accountability of pathways adversely impacts CYP with suspected or diagnosed asthma[4]. The implementation of Integrated Care Systems provides the NHS with a real opportunity to improve the outcomes for CYP with suspected or diagnosed asthma by integrating care across different organisations and settings, joining up hospital and community-based services, physical and mental health services and health and social care. In addition to the specific standards around each element of the patient journey, the National Bundle of Care for CYP with Asthma sets out the following standards for organisations:

    - **OC 1**- All organisations/services; including Primary Care Networks (PCN), secondary and tertiary services as well as places of education, must have a named lead with asthma expertise who is responsible and accountable for the dissemination and implementation of asthma standards and good asthma practice which includes CYP.
    - **OC 2**- Each Integrated Care System (ICS) should have a paediatric asthma network with an identified lead in paediatric asthma who interfaces with place-based systems and PCNs, secondary care, pharmacy, schools, community and severe asthma services. This network should integrate and transition with adult services.
    - **OC 3** - Each ICS should develop and maintain a pathway of referral and ensure responsibilities between primary, secondary and tertiary care. This should include safeguarding at all levels of care.

18. Figure 1: CYP Asthma Governance and Accountability



ICS Leads will be invited to quarterly meetings with the National Programme as we build a Network of Practice around CYP Asthma.

Environmental Impacts (EI)

Rationale

Air Pollution has been linked to serious health conditions such as cancer, asthma and cardiovascular disease. The findings of a number of studies underline an urgent need to reduce children's exposure to air pollution in order to reduce a child or young person's likelihood of developing or aggravating asthma and other allergic disease. In a landmark case, coroner's findings concluded that air pollution from road traffic made a significant contribution to the death of a 9-year-old girl with asthma.

Indoor Air Quality - children are spending more and more of their lives indoors, and the health impact of the air within our homes and schools needs to be taken seriously as a significant source of ill health. Social deprivation and poor housing quality in particular are strongly associated with asthma morbidity. A study from Sweden found that moisture-related problems in buildings are a risk factor for asthma and allergic symptoms among preschool children.

Parental Smoking – the link between parental smoking and an increased risk of asthma in CYP is well documented. In a European study, children with high early-life exposure to tobacco smoke were more likely than unexposed children to have early transient and persistent asthma. Discouraging maternal smoking is understood to be particularly crucial in improving asthma outcomes for CYP.

Sources for rationale[15,16,17,18,19,20,21,22,23]

[15] RCPCH. The inside story: Health effects of indoor air quality on children and young people (Available at The inside story: Health effects of indoor air quality on children and young people | RCPCH

[16] Whitehouse, A. & Grigg, J. Air pollution and children s health: where next? 1–4 (2021) doi:10.1136/bmjpo-2020-000706.

[17] Khreis H et al. Outdoor air pollution and the burden of childhood asthma across Europe. (Available at https://pubmed.ncbi.nlm.nih.gov/31391220/)

[18] To et al. Early life exposure to air pollution and incidence of childhood asthma, allergic rhinitis and eczema (Available at https://erj.ersjournals.com/content/55/2/1900913)

[19] BMJ news. Air pollution from road traffic contributed to girl's death from asthma, coroner concludes (Available at https://doi.org/10.1136/bmj.m4902)

[20] Hughes et al. Paediatric asthma health disparities: race, hardship, housing and asthma in a national survey (Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5337434/)

[21] Bornehag et al 'Dampness' at home and its association with airway, nose, and skin symptoms among 10,851 preschool children in Sweden. (Available at https://pubmed.ncbi.nlm.nih.gov/15926944/)

[22] Thacher et al. Maternal smoking during pregnancy and early childhood and development of asthma and rhino-conjunctivitis (Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6071724/)

[23] Kanoh et al Longitudinal study of parental smoking habits and development of asthma in early childhood (Available at https://www.sciencedirect.com/science/article/abs/pii/S0091743511004294)

National Standards of Care

Air pollution

EI 1 - All healthcare professionals working with CYP with expected or diagnosed asthma should understand the sources and dangers of air pollution with this cohort and ensure they discuss these risks and potential mitigation strategies with them. Integrated care systems should ensure staff are equipped with the tools that will enable them to do this

EI 2 - CYP, parents and carers should always receive information on how they can manage asthma with regards to air pollution. Information should be accessible in such a way that is appropriate to that CYP, this may include live updates through digital apps. Advice around air pollution and activity is shared on the Department for Environment, Food and Rural Affairs

EI 3 - ICS' should ensure they are linked with schools where education around asthma should also be provided. ICS' should consider influencing education bodies to make all schools Asthma Friendly

Indoor Air Quality

EI 4 - All healthcare professionals working with CYP with expected or diagnosed asthma should understand the risks associated with poor indoor air quality with this cohort and ensure they discuss these risks with them as part of their personalised asthma action plan. Integrated care systems should ensure staff are equipped with the tools that will enable them to do this

EI 5 - Severe and Difficult to Treat Asthma Services should agree criteria for recommending rehousing CYP when the environment is thought to be critical. ICS CYP asthma leads should share these criteria with local authority housing departments.

Parental Smoking

EI 6 - All healthcare professionals working with CYP with expected or diagnosed asthma should understand the risks associated with parental smoking with this cohort and ensure they discuss these risks with them.

EI 7 - Parents and carers should be offered support to quit smoking and ICS' should ensure staff are equipped with the tools that will enable them to do this. All clinicians managing CYP with asthma should be able to refer parents into smoking cessation service.

Next steps

19. The Environmental Impact National working group will look to support these recommendations through the development of a partner hosted resource for health care professionals. This site should include;

    - Information of sources and types of air pollutants that children with asthma are exposed to in the UK.
    - Summaries of the key evidence for the adverse effects of air pollution in children with asthma.
    - Information on air pollution mitigation strategies for both short and long-term exposure and child and parent appropriate information.
    - Exemplar letter to parents who smoke providing information about local smoking cessation services.
    - Information for parents and schools about actions they can take on air pollution.
    - Contact details of health care professionals who are clean air champions and resourcing of CAA's across the UK.
    - A CPD-accredited webinar on air pollution and asthma.

20. NHS England and Improvement would advocate research into:

    - effectiveness of exposure reduction strategies – including the wearing of masks
    - the most practicable advice for children on high air pollution days
    - research into air quality outside schools and subsequent actions required
    - integration of air pollution (background and spatial) data into asthma apps
    - integration of air pollution mitigation strategies into clinical practice

Early and Accurate Diagnosis

Rationale

It is important that asthma is diagnosed early and accurately. Unrecognised and untreated asthma leads to dangerous attacks and significantly impairs quality of life for children and families. Long term airway inflammation can also lead to airway remodelling and reduced lung growth.

Asthma can be effectively managed with inhaled corticosteroids (ICS). This treatment has a beneficial influence on airway inflammation, respiratory symptoms, asthma exacerbations, quality of life, and lung function. ICS are not very effective in children with transient wheezing which may cause unnecessary treatment with preventable costs and side-effects. Therefore, an early diagnosis will prevent under-treatment of true asthmatics and over-treatment of transient wheezers and will improve asthma control. It is widely accepted that asthma can be diagnosed in pre-school children.

Under-diagnosis of moderate and severe asthma was recognised as a key factor in the National Review of Asthma Deaths, 30% of all those that died had a diagnosis of mild asthma. Diagnostic hubs and a means of stratifying those at risk of asthma has been recognised as key to improving outcomes in CYP.

In a survey conducted as part of the information gathering for this document, health care professionals collectively agreed that diagnosis of asthma in CYP can be difficult and therefore continued review of their response to treatment and their diagnosis is necessary. The participants of the survey identified a number of themes, the three most common responses were:

1. Asthma is a difficult diagnosis to make and can take time to form a diagnosis.
2. There are difficulties associated with selecting an appropriate testing method, interpretation of results, and lack of one defining investigation to diagnose asthma.
3. Knowledge of asthma as a disease process, in particular identifying clinical features and recognising it is a chronic disease.

See Appendix One for more detail on the survey.

Poor communication through healthcare systems can lead to a delayed or incorrect diagnosis. Lack of leadership, accountability and standardisation of pathways adversely impacts CYP with suspected or diagnosed asthma.

Inconsistency of diagnostic guidelines is causing confusion, particularly in primary care. There is a need for one single set of guidance for the UK, which is regularly updated, comprehensive and evidence based covering both diagnosis and management.

Sources for rationale[24,25,6,26,4]

[24] Early diagnosis of asthma in young children by using non-invasive biomarkers of airway inflammation and early lung function measurements: study protocol of a case-control study | BMC Public Health | Full Text (biomedcentral.com)

National Standards of Care

Diagnostic Hubs

EAD 1 - ICSs should develop diagnostic hubs , that incorporate:

- Healthcare professionals trained in making a clinical diagnosis of asthma in CYP
- Spirometry and FeNO appliances that are suitable for use in CYP
- People trained to conduct these physiological tests in CYP. There should be clear criteria to support appropriate referral to secondary care from these hubs.

Diagnostic Pathways and Guidance

EAD 2 - The diagnosis of asthma in CYP should be based on clinical features of a comprehensive history (incorporating symptoms, attacks, personal and family history), and efforts should be made in children 6 years and older to ascertain an objective marker of airway inflammation and/or variable airway obstruction. These should be conducted according to the most recent national guidelines and protocols.

EAD 3 - When a diagnosis of asthma is made in CYP, this should be recorded in the notes and coded. When asthma is 'suspected', this should be clearly stated but should only be a temporary classification while further information is sought (e.g. 'watch and wait', referral to secondary care, further testing, or trial of treatment). Children <6 years should either be coded as having 'asthma' or 'episodic wheeze' and further testing should be performed when able. A relevant decision aid is shown in the resource pack.

EAD 4 - ICSs should develop health education strategies for their local population to:

- Improve awareness about what asthma is
- Its potential severity
- Symptoms that should warrant review by a healthcare professional
- This should include efforts to address cultural and societal stigma around asthma. Linking with schools - in particular PE teachers - is recommended to reach as many CYP in the population as possible, and empower them to identify if they may need to see a healthcare professional.

Tools from Asthma UK could be helpful.

[25] Asthma diagnosis in infants and preschool children: a systematic review of clinical guidelines. *April 2019* https://doi.org/10.1016/j.aller.2018.05.002

[26] Levy M 2021. Risks of poor asthma outcome in 14,405 children and young people in London. (Available from: https://doi.org/10.1038/s41533-020-00215-7)

Next Steps

21. The Early and Accurate Diagnosis National working group will look to develop the following actions prior to finalising the National Bundle of Care for publication.

    - The development of Implementation Guidance for Diagnostic Hubs

Effective Preventative Medicine

Rationale

Asthma is a serious, chronic illness that can result in attendance or admission to hospital and sometimes death. Research shows that it is often not taken seriously enough.

Childhood asthma should be managed effectively across primary and secondary care to prevent exacerbations. Asthma deaths are largely attributable to avoidable factors. These include over-reliance upon reliever inhalers and under-prescription or use of preventer medications. The use of either short or long-acting relievers in isolation has been identified as a particular risk. Poor adherence to preventer treatments from any cause, intentional or non-intentional, is associated with worse outcomes.

An essential element of any prescription for inhaled therapies includes a consideration of the drug, the device and the training. Without education and training inhaled treatments cannot be reliably delivered to children. Effective delivery of medication to the lungs of younger children and infants requires the use of spacer device. Neither inhaler types or spacer devices are interchangeable without additional training and education and inhaler technique should be checked regularly.

Personalised Asthma Action Plans (PAAP) and education are also recognised to improve asthma care. The National Review of Asthma Deaths (NRAD) identified that despite recommendations PAAP and annual asthma reviews were not in place for many individuals who subsequently died from asthma.

Sources for rationale [5,4]

National Standards of Care

Prescription of medication

EPM 1 - The prescription of inhalers should be more comprehensive to include age appropriate medicine, device and education. The Effective Preventative working group is working with the British National Formulary for Children (BNFC), Medicines and Healthcare products Regulatory Agency (MHRA) and NICE to develop a package of care that is plainly described on the BNFC, including their app.

EPM 2 - Regular use of short-acting bronchodilators is associated with increased risks. All asthma patients who have been prescribed more than 3 short-acting reliever inhalers in the previous 12 months should be invited for urgent review of their asthma control. Inhaler technique should be reviewed at least annually to ensure the CYP is receiving their medicine effectively.

EPM 3 - Adherence to prescribed medicine should be monitored routinely. This should include a regular review of prescription collection of preventer medication and assessment of inhaler technique to address intentional or non-intentional non-adherence.

EPM 4 - Where there is a continued requirement for frequent use of bronchodilators a combination inhaler (bronchodilator and inhaled steroid) should be considered.

Personalised Asthma Action Plans and annual reviews

EPM 5 - All CYP with asthma should have a Personalised Asthma Action Plan that is developed collaboratively with them and their significant others, an example of a PAAP can be found in the resource pack. ICS' should ensure these tools are made available to healthcare professionals working with CYP with asthma.

EPM 6 - All CYP with asthma should undergo a structured review at least annually. Adherence should be discussed as part of this review and inhaler technique should be assessed and where necessary extra training provided. Healthcare professionals should also signpost CYP to useful inhaler technique resources. An example of a template for an annual review can be found here. ICS' should ensure these tools are made available to healthcare professionals working with CYP with asthma. The review should include an assessment of risk and severity and recent asthma control. Where loss of control is identified, immediate action is required. This should include escalation of responsibility, treatment changes, conversations about adherence and arrangements for follow-up.

National Standards of Care (continued)

Patient education

EPM 7 - Patient self-management should be encouraged to reflect their known triggers including stress and air pollution, e.g. increasing medication before the start of the hay-fever season, when there is High or Very High air pollution, avoiding non-steroidal anti-inflammatory drugs or by the early use of oral corticosteroids with viral- or allergic-induced exacerbations.

EPM 8 – All patient encounters should be viewed as an opportunity to improve the understanding of children and their families. Regular assessment of inhaler technique and re-training where necessary are essential to ensure effective delivery of inhaled medications.

EPM 9 - Parents and children, and those who care for or teach them, should be educated about managing asthma. This should include emphasis on 'how', 'why' and 'when' they should use their asthma medications, recognising when asthma is not controlled and knowing when and how to seek emergency advice.

Next Steps

22. The Effective Preventative Medicines National working group will look to develop the following actions prior to finalising the National Bundle of Care for publication:

- Review the National prescribing data for children who receive inhaled therapies to determine the patterns of current prescribing for children
- Determine what additional information can be added to the BNF and BNFc that clarifies the importance of ensuring appropriate prescribing
- Discuss with the MHRA what additional information can be added to patient information upon prescribed inhaler devices.

Management of exacerbations

Rationale

Asthma has a huge impact on CYP and the NHS. Every 10 seconds someone is having a potentially life-threatening asthma attack in the UK and in 2016/17 there were 77,124 admissions to hospital for asthma in the UK.

Asthma should be managed effectively in primary care to prevent exacerbations resulting in attendance and admissions to hospital. There are risk factors for asthma that should be identified in primary care. With appropriate management of these factors, attendance at the emergency department and hospital admissions could be avoided. Asthma that is well-controlled, typically requires one SABA prescribed per year.

Should a child or young person present at the emergency department or require admission, there are a number of existing guidelines that healthcare professionals should follow. In the 2014 NRAD, it was shown that 46% of healthcare professionals involved in the care of patients that died from asthma, did not correctly follow clinical guidelines. Issues around the coding of CYP being admitted to hospital has also been identified. Many CYP are admitted to hospital and treated with asthma medication but have no asthma diagnosis and therefore not coded as such. An asthma attack is the most significant predictor of a further attack and therefore should be a trigger to review why the attack occurred, ameliorate those factors and prevent a further attack.

Evidence shows that many CYP discharged from hospital following an exacerbation of asthma fail to have a follow-up in primary care within the recommended 48 hours. A lack of standardised discharge pro-forma may be one reason for this, as well as poor primary and secondary care interface, including IT systems. The NACAP report also highlighted that many CYP aren't having their inhaler technique checked, systemic corticosteroids aren't administered quickly enough on presentation at the ED and CYP weren't asked about exposure to second-hand smoke.

Sources for rationale: [1,27,4,17,28]

[27] Carroll et al 2019. If it's 'only' asthma, why are children still dying? (Available from: doi:10.1136/archdischild-2019-318215)
[28] National Asthma and Chronic Obstructive Pulmonary Disorder Clinical Audit – Children and Young People Clinical Audit 2019/20

National Standards of Care

Acute presentation

ME 1 - All providers of emergency and urgent care should adhere to minimum standards of assessment, treatment and referral including:

- An objective assessment of the severity of the attack and of the severity of the CYP's underlying asthma
- Systemic steroids should be administered within one hour of presentation at the emergency department or urgent care centre
- All CYP should undergo a review of their current asthma management prior to discharge, this should include:
  - A review or issue of their PAAP
  - A review of their inhaler technique which is recorded in their patient records as poor or good
- All CYP should be assessed for their risk of a severe asthma attack

Discharge

ME 2 - All providers of emergency and urgent care should adhere to minimum standards of discharge planning:

- Electronic communication should be provided to the patient's primary care provider within 24 hours of discharge
- CYP must be referred to a paediatric specialist asthma service if they have required more than two courses of systemic corticosteroids, oral or injected, in the previous 12 months or require management using British Thoracic Society (BTS) stepwise treatment 4 or 5 to achieve control and/or have had a life threatening asthma attack requiring HDU care. Life threatening asthma requiring ICU care and other patients who meet the criteria for severe asthma should be referred to Multi-Disciplinary Severe Asthma Service (SA1)
- All CYP that have had a life threatening asthma attack (admitted to ITU or HDU) should be referred to severe asthma services
- A referral to an asthma clinic should be made within 4 weeks
- Discharge plans should be shared with educational settings
- All CYP discharged from hospitals should undergo a review within 48 hours by an appropriately trained clinician in primary care

National Standards of Care (continued)

Risk Stratification

ME 3 - ICS asthma leads should have an overview of the landscape of CYP asthma in their patch and support providers to be able to identify at risk individuals, communities and geographical risks. At risk individuals are identified as those that have had two attacks in a 12 month period.

- At risk patients should be assigned a key worker
- All CYP presenting frequently to primary care or emergency departments or requiring frequent admission to hospital are identified and discussed within a formal multidisciplinary forum within a primary care network / cluster. The core membership of such a group should include a GP, health visitor or school nurse (for children 5-19) and paediatrician. Where appropriate, a local authority children's services representative and/or mental health professional should attend. The input of multi-agency colleagues working with the family at the time should also be sought.
- A home visit should be conducted, see the resource pack for a home visit proforma.

Next Steps

23. The Managing Exacerbations National working group will take the following actions prior to finalising the National Bundle of Care for publication:

- The development of minimum standards for assessment, treatment and referral of any CYP with asthma presenting in urgent and emergency care
- A standardised discharge letter template and guidelines for referral into tertiary services
- Develop a proposal for further research into capturing the barriers that clinicians describe in relation to adherence to CYP asthma guidelines.
- Development of tool to identify risk level for individuals and communities.

Severe Asthma

Rationale

Severe asthma is asthma that remains uncontrolled despite optimised treatment with high dose ICS (step 4/5 of treatment), or that requires high dose ICS to prevent it from becoming uncontrolled – where control is defined as presence of symptoms and/or attacks in the previous year. Asthma is not classified as severe if it markedly improves when inhaler technique and adherence are addressed. Children with severe preschool wheeze or severe asthma are usually atopic and have impaired quality of life that is associated with poor control and airflow limitation. Patients with severe asthma often feel isolated and alone as their experience of asthma is different from other people's, poor mental health is more common in people with severe asthma.

Careful evaluation and characterisation is essential to correctly diagnose severe asthma and to implement appropriate management strategies. The main objectives of management are to control symptoms, optimise activity and minimise the risk of asthma attacks and medication side-effects.

Referral to and provision of specialist asthma services despite clinical indication remains patchy across England. The NRAD found that the majority of people who died from asthma (112, 57%) were not recorded as being under specialist supervision during the 12 months prior to death. Only 83 (43%) were managed in secondary or tertiary care during this period.

Currently severe asthma services for children are not formally commissioned and only mentioned as part of the service specification for Paediatric Medicine: Respiratory (EO3/S/g). The service specification sets out the requirements for a tertiary respiratory centre (including team members and interventions and investigations available) but gives little other detail of the specific requirements of a specialist difficult asthma service.

The current service specification offers little guidance on which children should be referred and what the referrer and the child and their family can expect from a specialist difficult asthma service. As such the asthma service provided by a tertiary respiratory centre can vary between providers.

Sources for rationale[29,3031,32,33,4]

[29] SIGN 158 British guideline on the management of asthma. Revised edition published July 2019
[30] GINA-Severe-asthma-Pocket-Guide-v2.0-wms-1.pdf (ginasthma.org)
[31] The burden of severe asthma in childhood and adolescence: results from the paediatric U-BIOPRED cohorts by Fleming, L. et al. Available at: https://erj.ersjournals.com/content/46/5/1322
[32] Severe asthma facts available from: What is severe asthma? | Asthma UK
[33] Evaluation and management in children. A Mehtap Haktanir et al 2019. Available from: https://doi.org/10.1183/2312508X.10024418

National Standards of Care

Severe Asthma Services – A Framework for Delivery

SA 1 - The Severe Asthma National working group has developed standards of care for CYP severe asthma services (see resource pack). Each ICS should ensure that CYP with severe asthma should have access to a severe asthma service. The standards include detail on:

- Referral criteria and referral pathway
- The service model for a severe asthma service
- The type of assessments that should be carried out
- Pharmacological interventions
- Non-pharmacological interventions
- Transition of young people into adult services
- Expected outcomes of a severe asthma service

CYP difficult to treat and severe asthma registry

SA 2 - The Severe Asthma National working group support the implementation of a severe asthma registry for CYP.

- Providers of severe asthma services in an ICS should ensure that patients are listed on the registry if they have been initiated on biologics or deemed to be appropriate candidates for a biologic but ineligible for treatment due to licensing or NICE criteria
- The registry should be linked with the National CYP asthma dashboard and substantively funded

Severe asthma networks

SA 3 - The Severe Asthma National working group have developed terms of reference for CYP severe asthma networks. The full terms can be found in the resource pack. The purpose of the networks are to advance the standard of clinical care for children and young people with severe or difficult to control asthma by:

- Advising NHS Commissioning Groups and other NHS organisations on relevant matters which are referred to the group
- Developing, standardising, publishing, consensus guidelines and other authoritative evidence-based information
- Developing, standardising and updating educational resources
- Coordinating relevant educational activities for network members and locality sub networks.
- Supporting NHS England in the implementation of relevant policy
- Developing, maintaining, interrogating and reporting on disease registers and databases and related research.
- Collating relevant information and reporting the above disease registries and databases annually
- Fostering collaborative clinical research.

Next Steps

24. The Severe Asthma National working group will look to develop the following prior to finalising the National Bundle of Care for publication:

- Map the service pathway from secondary care into tertiary services
- Review the data currently gathered by the difficult to treat and severe asthma registry and streamline it to make it more user friendly and to ensure the data is able to be linked into the CYP Asthma Dashboard
- Develop a regional plan for severe asthma services to ensure a joined-up approach to the delivery of severe asthma services in each region
- Develop terms of reference for paediatric severe asthma networks
- Develop the role of a CYP severe asthma network lead.

Data and digital

Rationale

Studies have confirmed that poor communication between secondary and primary care due to differences in IT systems contributes adversely to the care of CYP with asthma. . Routinely collected data could be used to create dynamic 'at risk registers' aimed at identifying modifiable risk factors (updated on a weekly basis to ensure all risk factors are included – like attacks) – so that individuals in need of optimisation can be easily identified and seen by appropriately trained clinicians.

There is huge potential for NHS data to be shared and used more efficiently and to ensure information is more widely available. There is a strong argument that data interpretation could be transferred into clinical practice, such as identifying variations in care, prescribing and to monitor any changes that are implemented. This includes better use of remote consultations and asthma apps, making it easy for people with asthma to attend appointments and self-manage effectively.

Accuracy of coding of asthma is also contributing to poor outcomes for CYP. Some CYP are coded as having asthma without a formal diagnosis and others are treated with asthma inhalers without being coded with asthma diagnosis. There is huge variation in the coding of CYP on discharge from hospital and the discharge letter is often relied upon which is often not detailed enough. It is important to find ways of improving the accuracy of coding throughout the pathway of care for CYP with asthma.

Sources for rationale[34,35,36]

[34] BREATHE's Evidence

[35] Trung N. Tran et al. Oral corticosteroid prescription patterns for asthma in France, Germany, Italy and the UK. European Respiratory Journal 2020 55: (Available from: https://erj.ersjournals.com/content/55/6/1902363)

[36] APPG Report Improving Asthma Outcomes In The UK 2020

National Standards of Care

CYP Asthma Dashboard – phase 1

DD 1 - The National working group have proposed a minimum asthma dataset that will feed into a National CYP asthma dashboard. See Appendix Two for more detail on the dashboard and dataset. The dashboard will highlight areas of good practice, enable benchmarking between peers and provide a comparison of national activity. The first phase of the dashboard utilises secondary care data across a number of healthcare settings including 111, urgent and emergency care and secondary care to monitor:

- Total calls to 111
- Total attendances to different types of emergency care
- Total acute admissions

ICS leads for CYP asthma should benchmark their services against national averages to:

- Highlight areas of good practice and facilitate shared learning
- Identify providers where asthma improvements are required and allocate resource appropriately
- Identify geographies and groups where CYP with asthma are most at risk of health inequalities

Risk Stratification – phase 2

DD 2 - The dashboard will facilitate a local and national comparison of metrics to support identification of the number of CYP with asthma who are at high risk of poor outcomes.

ICS leads for CYP asthma should support diagnostic hubs and asthma services to review these CYP and provide the appropriate intervention.

Next Steps

25. In the next three months, the Data and Digital National working group will:

- Create a set of baseline metrics at primary and secondary care level to support commissioners and clinicians in identifying the level of risk in their area, across primary and secondary care.
- Place an emphasis on metrics where the focus for change supports improvement in patient outcomes i.e. reducing the number of exacerbations, which will reduce emergency care attendances and acute

admissions to hospital, enabling the system to further support asthma patients to manage their condition in the community.

Future aspirations

26. Within the next six months the National working group for data and digital will:

- Agree a minimum dataset for CYP asthma which may include:
  - Air pollution data mapped geographically against asthma attacks through hospital admissions, presentations to the ED and 111as well as GP prescriptions for Oral Corticosteroids
  - Numbers of patients with repeat attendances in primary and secondary care
- Create an interactive dashboard to support the commissioning and planning of patient care that enables clinicians to improve patient outcomes.

Asthma Competencies, Training and Education Needs

Rationale

Healthcare professionals inadequately trained to provide high quality care in CYP asthma, has been recognised as a factor by each of the National working groups in this programme. Addressing this inadequacy is integral to the improvement of asthma care across the country.

The expert panels in the NRAD identified factors that could have avoided death in relation to the health professional's implementation of asthma guidelines in 89 (46%) of the 195 deaths, including lack of specific asthma expertise in 34 (17%) and lack of knowledge of the UK asthma guidelines in 48 (25%). Both the NRAD and NACAP identified that CYP were not appropriately educated in how to manage their asthma and by educating staff on the use of PAAP and reviewing inhaler techniques, exacerbations of asthma could be reduced and deaths from asthma prevented.

NRAD recommends that people with asthma should have a structured review by a healthcare professional with specialist training in asthma. In addition, a safety recommendation following the HSIB report has led to a commitment by NHSEI to support clinical experts to work with professional bodies to develop training competencies for healthcare professionals with responsibility for caring for children with suspected or confirmed asthma.

There are CYP asthma courses available but there is a lack of standardisation, accreditation and quality assurance leaving healthcare professionals unsure which courses meet the needs of their role in the care of CYP with asthma.

National Standards of Care

Core Capabilities Framework

A 5-level tiered framework for anyone involved in the care of CYP with asthma has been developed. See the resource pack for the full framework. These have been approved by professional bodies, Royal Colleges and relevant Arm's Length Bodies.

Future Accountability and Governance

The tiered framework should sit with a host organisation and be easily accessible to all, including those working outside of healthcare. ICS' should ensure that all people within their systems working with CYP with asthma are able to access the capabilities and complete the associated training.

ICS' will be held to account to ensure their CYP asthma workforce have met the required levels of training.

Training

Existing education materials and training courses will be cross-checked with the tiered capabilities and assigned accordingly as part of a formal accreditation process.

Appendix One - Diagnosis Survey Results

Early and Accurate Asthma diagnosis Steering Group Initial Survey results: 32 responses for the survey distributed to the CYP Asthma Working Groups. The survey contained two questions: "what are the top 3 things that CYP/carers/ parents should know about diagnosing asthma" and "what are the top 3 things that healthcare professionals should know about diagnosing asthma". The responses were analysed using a mixed methods approach of qualitative and quantitative analysis; a thematic analysis using an inductive approach was utilised to identify themes within the responses; the frequency that themes occurred within the responses was then identified to rank the most prominent of these which should be addressed in the new National Care Bundle.

3 THINGS THAT CYP/CARERS/PARENTS SHOULD KNOW ABOUT DIAGNOSING ASTHMA:

- 8 key themes identified

  - EDUCATION
  - INVESTIGATIONS FOR DIAGNOSIS- including testing, the timing/difficulties with testing different age groups, sensitivity/specificity of existing tests
  - TREATMENT- including correct use of treatment, timing of treatments, technique, autonomy of treatment, concerns and questions related to treatments
  - LONGTERM MANAGEMENT- including surveillance, adherence, treatment response, and risks of poor control
  - WHAT IS ASTHMA? - including the nature of disease, clinical history, clinical features, different types of asthma, and triggering factors
  - ONGOING SUPPORT and services available
  - WHAT A DIAGNOSIS OF ASTHMA MEANS FOR CYP/CARERS including the importance of diagnosis and the impact of results/diagnosis on CYP
  - COMMUNICATION

EDUCATION	**15**
INVESTIGATIONS FOR DIAGNOSIS	**32**
- Testing	13
- Timing/difficulty of testing	15
- Sensitivity/specificity of tests	4
TREATMENT	**35**
- Correct use	8
- timing	3
- technique	3
- concerns/questions	2
- autonomy	4
LONGTERM MANAGEMENT	**21**
- surveillance	6
- adherence	2
- treatment response	4
- risk of poor control	1
WHAT IS ASTHMA	**23**
- Nature of disease	9
- History	4
- Clinical features	5
- Types of asthma	1
- triggers	4
ONGOING SUPPORT	**2**
WHAT A DIAGNOSIS OF ASTHMA MEANS FOR CYP/CARERS	**7**
- Impact of results	2
- Importance of diagnosis	5
COMMUNICATION	**1**

3 THINGS HEALTHCARE PROFESSIONALS SHOULD KNOW ABOUT DIAGNOSISNG ASTHMA IN CYP

- 9 key themes identified:

  - EDUCATION- includes guidelines, pathways, improving clinical knowledge
  - ASTHMA KNOWLEDGE- includes triggers, different types of asthma, clinical features, pathophysiology, nature of disease and longevity
  - DIAGNOSING ASTHMA- includes confounding/contributing factors, good history taking, how to diagnose, difficulty in diagnosis/time, differential diagnoses, accuracy of diagnosis, objective assessment, importance of diagnosis, CYP vs adult presentation
  - TREATING ASTHMA- includes correct use of/ different inhalers
  - MONITORING ASTHMA IN CYP- including how to follow up, continued review, understanding clinical deterioration, escalating treatment, trial treatment/response to treatment
  - WORKING WITH CYP/CARERS- including education/ communication, support
  - CODING- including documentation
  - INVESTIGATIONS- including tests, interpretation, limitations
  - WORKING WITH MDT- including specialist referral

EDUCATION	**6**
- Guideline/ pathway	5
- Improve clinical knowledge	1
ASTHMA KNOWLEDGE	**13**
- Triggers	1
- Different types of asthma	2
- Clinical features	6
- Pathophysiology	1
- Nature of disease/ longevity	3
DIAGNOSING ASTHMA	**41**
- Contributing/ confounding factors	1
- Good history	5

- How to diagnose	4
- Difficulty in diagnosis/ time	11
- Differentials	5
- Accuracy	3
- Objectivity	7
- Importance of diagnosis	3
- Adult vs CYP presentation	2
TREATING ASTHMA	**6**
- Correct use of/ different inhalers	6
MONITORING ASTHMA IN CYP	**8**
- How to follow up	1
- Continued review	3
- Understanding clinical deterioration	1
- Escalating treatment	1
- Trial of treatment/response to treatment	2
WORKING WITH CYP/CARERS	**12**
- Education/ communication	6
- Support	6
CODING	**3**
- Documentation	1
INVESTIGATIONS	**18**
- Tests	12
- Interpretation	3
- Limitations	3
WORKING WITH MDT	**6**
- Specialist referral	5

- 3 of 32 responses referred to previous answer-> difficult to correlate which answer was from same person

TOP 3 AREAS IDENTIFIED BY SURVEY RELEVANT TO EARLY ASTHMA DIAGNOSIS:

These top 3 are taken from the responses of both questions in the survey, suggesting what CYP/parents' carers and healthcare professionals should know about diagnosing asthma in CYP.

1. Asthma is a difficult diagnosis to make and can take time to form a diagnosis.
2. What investigations/tests are used to make an objective assessment of asthma.
3. Knowledge of asthma as a disease process, in particular identifying clinical features and recognising it is a chronic disease.

Other key areas identified which are outside the jurisdiction of the EAD group (but may be of interest to other steering groups):

- Treatment, including the different inhalers/medications available, correct use of treatment and inhaler technique
- Long-term management of asthma, including lifelong treatment and continual review of diagnosis/clinical features
- Education for CYP/parents/carers regarding asthma and it's management
- Communication with and support for CYP/parents/carers

Appendix Two CYP Asthma Dashboard

Dataset Proposal

The proposed asthma dataset will utilise available data from a range of healthcare settings - primary care (TPP and EMIS), 111, EC (ECDS) and secondary care (SUS) to provide an overview of the asthma patient population including risk factors.

Phase 1 dataset - this will include linked data available across multiple healthcare settings, 111, EC (all settings) and secondary care (non-elective admissions).

Primary Diagnosis Asthma (monthly refresh update of data):

- Total calls to 111
  - Exacerbations
  - Prescription only (inhaler)
    - Number of distinct patients for each group
    - Number of calls (group) / count of patients per group
- Total attendances to different types of EC
  - number of distinct patients for each EC type 1-5
    - number of attendances (group) / count of patients in per group
- Total acute admissions
  - number of distinct patients non elective admissions
    - number of admissions (group) / count of patients in per group

In addition to the monthly refreshed data investigations are underway to assess the feasibility of accessing data only currently available from a small number of local systems (CCG and CSU) and the Royal College of General Practitioners where there is already linked data (including primary care) available to support the improvement of patient outcomes locally. This data will be used to create a visualisation of the proposed full CYP asthma dashboard metrics to provide a draft overview of the proposed final CYP Asthma dashboard.

Phase 2 dataset - will incorporate the currently unavailable datasets, open prescribing data and primary care data. This will enable the link of phase 1 datasets and support identification of patients who are under prescribed (inhalers), over prescribing (use) of inhalers and/or oral Corticosteroids which indicate poor control of asthma and increased risk of exacerbation. We will also use the index of multiple deprivation rank in conjunction with patients ethnic group to identify healthcare inequalities in CYP with asthma.

A minimum dataset will utilise the various systems and data metrics together, starting with existing nationally available data, identifying existing data that requires dataflows to be set up to support national data flow and reporting. Data that would be beneficial and is not currently recorded consistently in data systems, (this data is often recorded directly into patient notes) will also be identified.

Dataset Proposal (continued)

There is also a recommendation to include a suite of robust data quality reports to identify inconsistent recording within local systems (including availability of appropriate data recording within local systems) and national variation. Included in this dataset will be the identification of patients who have:

- Inhalers prescribed but do not have an asthma diagnosis,
- An asthma diagnosis without inhalers prescribed.