



British  
Thoracic  
Society



# **Designing and commissioning services for children and young people with asthma: A good practice guide**

# Contents

## Foreword

### Part one - introduction

1.	Executive summary	4
2.	Who is this document for?	8
3.	The vision for children and young people with asthma	10
4.	Why do we need to improve outcomes for children and young people with asthma?	12
5.	Understanding the differences between asthma in children and adults	14
6.	The policy context	16
7.	Role of commissioners in improving outcomes for children and young people with asthma	22
8.	How to use this guide	24

### Part two - guidance on good practice

9.	A child-centred service and shared decision-making with children/young people and their parents	26
10.	Preventing asthma	28
11.	Accurate and timely diagnosis	30
12.	Information for children/young people and their parents	32
13.	Supporting self management	34
14.	Structured review by asthma-trained clinicians	38
15.	Optimising medication	42
16.	Allergy and asthma	46
17.	Asthma at school and in childcare settings	48
18.	Asthma in adolescents and transition to adult services	52
19.	Risk assessment and at risk registers	54
20.	Severe/difficult-to-control asthma	56
21.	Managing acute and life-threatening episodes	58
22.	Avoiding hospital admissions and emergency department attendances	62
23.	Following up acute episodes	66
Annex A	Asthma service checklist	68
Annex B	CQUINS and care bundles	70
Annex C	Asthma quality standard	74
Annex D	Examples of self-management plans	76
Annex E	Partner organisations	78
Annex F	Children's asthma group	80
	References	82

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August 2013.

## Cartoons

The cartoons included in this document were created by Graham Ogilvie who attended patient events run by Department of Health in 2009 at which people with asthma talked about their experiences. Graham captured some of the key themes in cartoons, and these have been included to highlight important issues from a patient and carer perspective.

## Foreword by Professor Martyn Partridge

There are no grounds for complacency with regards to asthma. The United Kingdom has the highest prevalence of asthma in the world. For many people, asthma is a lifelong condition, since it often develops in childhood. Levels of morbidity in children and young people remain high, with large numbers continuing to report having symptoms during daily activity and disturbed sleep at night, and a significant number having asthma attacks. Many are not achieving the goal of asthma management, which is to lead lives free of symptoms, despite the availability of well-constructed guidelines and good medicines. Some parameters have shown a recent plateauing suggesting that improvements are not being maintained and information regarding inequalities in healthcare suggest that significant differences in outcomes exist between geographical areas. If we are to control this on-going burden of asthma we need to look in detail at the services available for children and young people with asthma to ensure optimal configuration of care and services suitable for all. This document is designed to provide information for all who are involved in commissioning and delivering care for children and young people with asthma, so that they can work alongside clinicians, young people, children and their parents to improve outcomes.

### **Professor Martyn Partridge**

*Professor of Respiratory Medicine,  
Imperial College London*



# 1 Executive summary

Asthma is a long-term condition – one that cannot be cured, but for most children and young people, it can be effectively managed. People with asthma live with their condition and should be the primary decision makers in managing their own health and healthcare as soon as they are old enough to do so. Clinicians should be supporting children and young people and their families to make the right choices to manage their own asthma, by giving them information about their condition and providing clinical expertise. Asthma varies from day to day and from person to person, so its daily management is not a straightforward process. Children and young people need help getting to recognise when their asthma is worsening and when they need access to the expertise of the NHS. When they do have contact with a healthcare professional, the aim must be to make the interaction as productive as possible and this means within a partnership of care based upon a process of shared decision making. Inputs of care must also be integrated across the traditional boundaries of hospital and community based services. Everyone involved in designing, commissioning or providing services for children and young people with asthma should ensure that services are designed with these principles in mind.

## **A child-centred service and shared decision making with children/young people and their parents**

A collaborative approach to asthma care, where clinicians and children/young people and their parents share decision making, has been shown to deliver improved outcomes in asthma management, by increasing their confidence to deal with their condition, and improving their self-management skills. Commissioners should actively involve families in the development of services.

## **Preventing asthma**

The causes of asthma are not yet well understood, so preventing asthma from developing is not possible. Efforts should go into encouraging breastfeeding, supporting pregnant women to quit smoking, and reducing the impact of environmental smoke.

## **Accurate and timely diagnosis**

Commissioners should ensure clinicians are adequately skilled to make an accurate diagnosis of asthma, and have access to the required diagnostic facilities and expertise.

## **Information for children/young people and their parents**

Age appropriate information tailored for individual children and young people with asthma, and their families is important to support them at all life stages, so they can be active participants in their care and lead lives free from symptoms.

## **Supporting self management**

Commissioners should ensure that children and young people are supported to manage their own asthma, wherever possible, using appropriate media, since there is Grade A evidence that effective self-management can improve outcomes of care.

## **Structured review by asthma trained clinicians**

Commissioners should ensure that high-quality structured reviews are being undertaken with children and young people by staff with asthma training, that QOF exception rates are low, and that age-appropriate tools for monitoring control are used.

## **Optimising medication**

For children and young people to derive optimum benefit from their medicines and use their inhalers effectively, commissioners, clinicians and pharmacists need to work together to actively audit all aspects of medicines usage to ensure it is aligned with clinical guidelines, while minimising wasteful use of medicines.

## **Allergy and asthma**

The co-existence of allergies with asthma is common, associated with higher risk, but is much neglected.

Commissioners could usefully review allergy services available for children and young people with asthma and allergies, and ensure there is adequate provision.

## **Asthma at school and in childcare settings**

Commissioners should work with local authorities, public health, primary care and the school health service to create the most supportive and enabling environment possible for children and young people with asthma. They should help improve asthma outcomes through school-based initiatives such as asthma-friendly schools programmes.

## **Asthma in adolescents and transition to adult services**

As adolescents move towards adulthood and independence, theirs can be a particularly challenging and high-risk group in which to maintain good asthma control. It is important that services and communication with them are organised in a manner that engages them, meets their needs and encourages them to take more responsibility for their asthma.

## **Risk assessment and at risk registers**

Young people should be assessed for their risk of an attack, and potential hospitalisation, and care tailored to their needs accordingly so they remain well controlled and free from symptoms.

## **Severe/difficult-to-control asthma**

This group accounts for a large proportion of expenditure on asthma. Commissioners should ensure that appropriate services are available to support this small group to maintain good asthma control, with referral to a comprehensive multidisciplinary specialised service as appropriate.

### **Managing acute and life-threatening episodes**

Managing acute attacks well requires well-trained staff in emergency departments and other healthcare settings who have access to paediatric respiratory specialist clinicians for expertise and advice in managing acute asthma in children and young people.

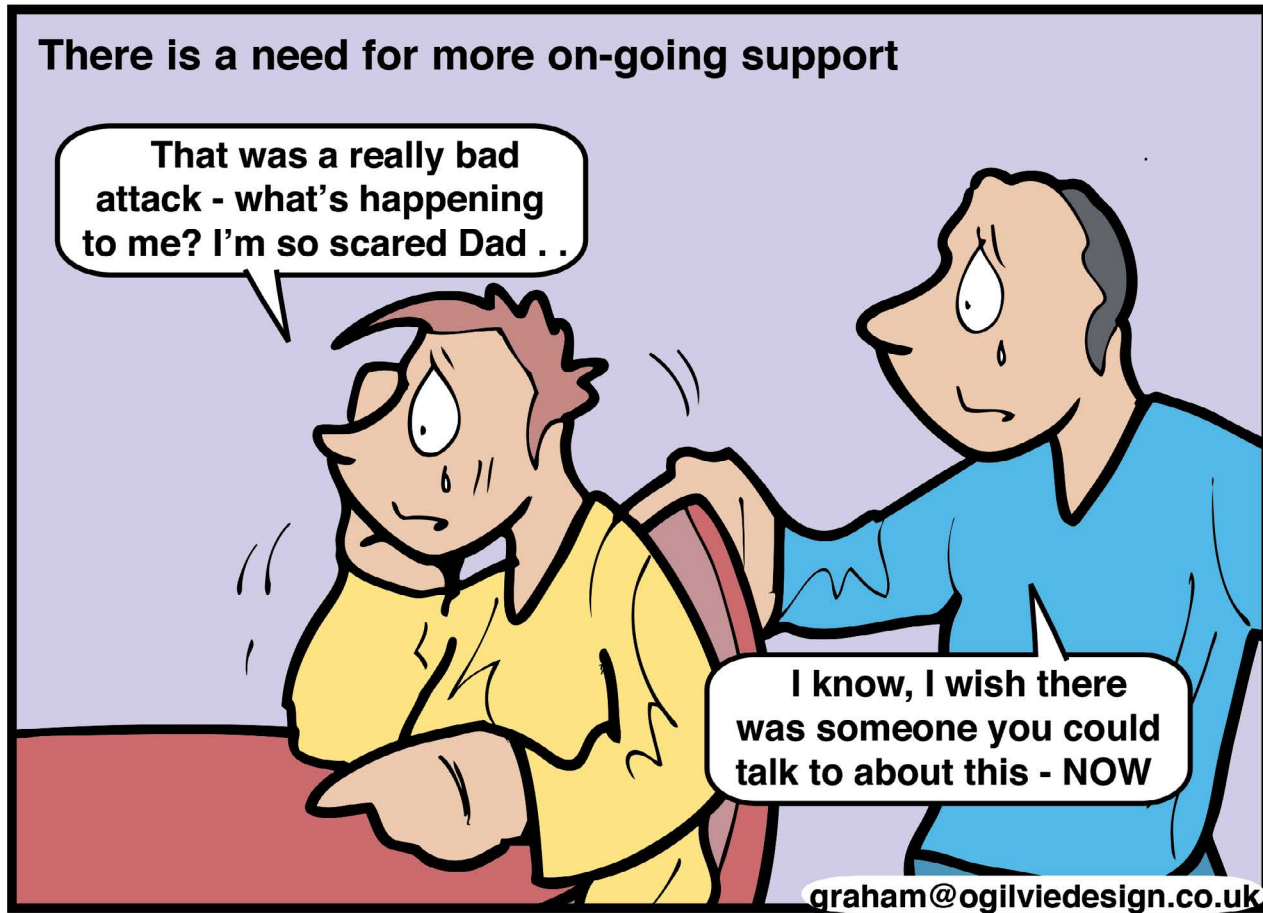
### **Avoiding hospital admissions and emergency department attendances**

Asthma is one of the most common reasons for acute admissions in children so deserves a high priority if admission rates are to be reduced, and the condition is to be well controlled. Commissioners should expect to see primary and secondary care and emergency services working collaboratively to find ways of reducing admissions through high quality continual management and early intervention to address deterioration in control.

### **Following up acute episodes**

Comprehensive and rapid follow up of children and young people after hospital attendance is critical to avert future episodes and should be specifically commissioned.

Finally, children are not 'young adults' but have their own clinical and socio-psychological needs that must be met.





## 2 Who is this document for?

This document focuses on the design of services for children and young people with asthma. Delivering excellent child-centred services requires co-operation and partnership between clinicians, children's professionals in health and education, strategic leaders in local services and children, young people and families.

The document is aimed at:

- **Strategic leaders and commissioners:** Locally, those who lead on services for children and those leading on healthcare services whether in clinical commissioning groups or area teams, working closely together and engaging with clinicians in tertiary (specialist services), secondary and primary care, public health, health and wellbeing boards and the children and young people with asthma, and their parents and carers
- **Primary care:** All healthcare professionals working in general practices, community pharmacists and also non-clinical staff (eg receptionists) who are often the first person a family will encounter in an emergency. Primary care is the cornerstone of child-centred asthma care
- **Urgent care and hospital care:** Everyone in emergency and urgent care settings (emergency departments, ambulances, out of hours, walk-in centres) who are involved in designing and delivering services – whether for emergency, in-patient or out-patient care, including administrative staff who are receiving emergencies
- **Community health providers:** community health colleagues should be involved in the design and delivery of services eg school nurses, community matrons, health visitors, community paediatricians
- **Other healthcare providers:** staff in walk-in centres, GP-led health centres, out-of-hours services providing support to children and young people with asthma and their families

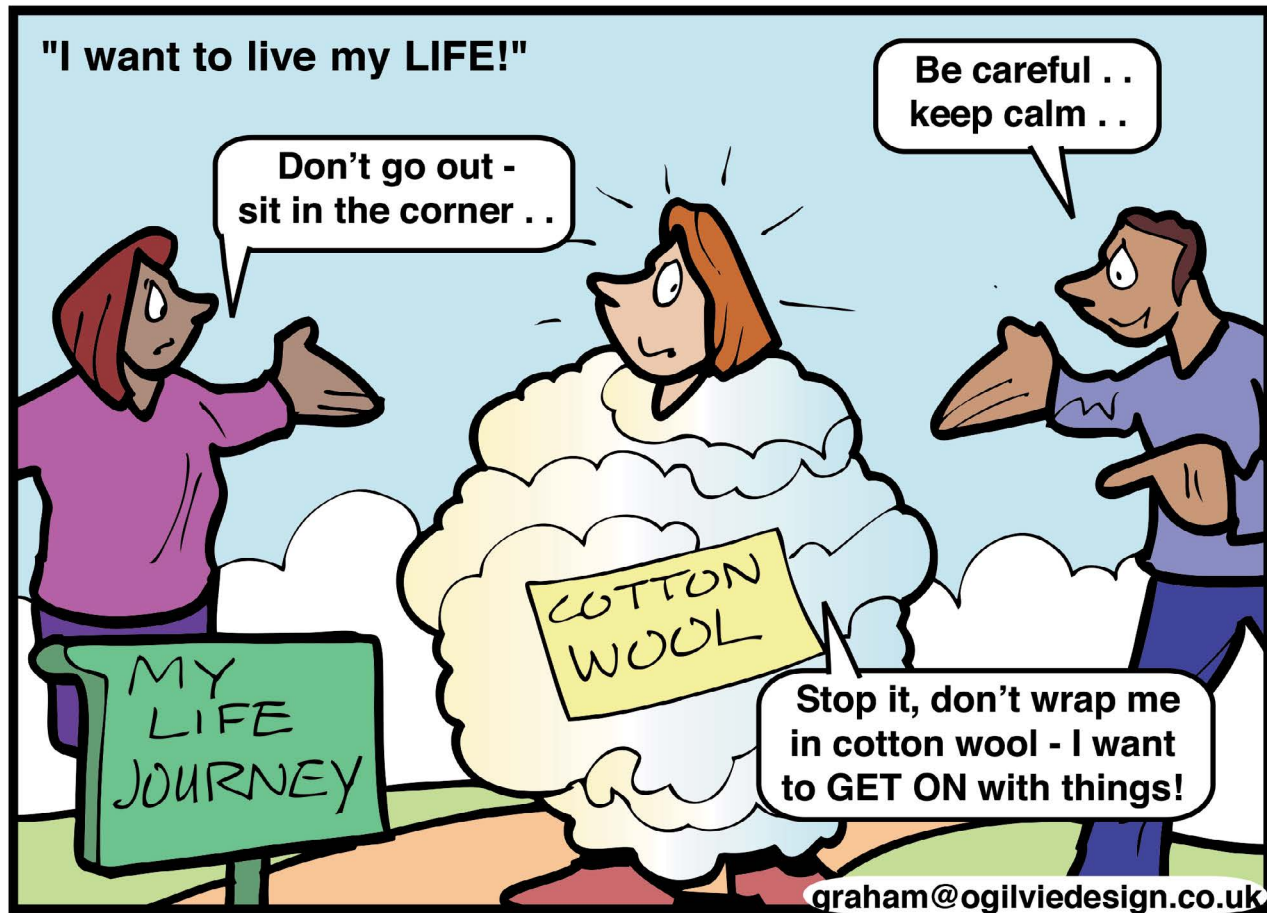


- **Schools, colleges and early years settings:** Head teachers, teachers, teaching assistants, nursery staff, school secretaries and other support staff who may all have to support children with deteriorating asthma, self management or an acute attack
- **Other adults in children's lives:** Adults supervising children and young people outside of school – and before reaching school age: sports coaches, nursery attendants, child-minders, youth workers, clubs and associations etc. Social workers, where appropriate.

# 3 The vision for children and young people with asthma

- All children and young people with asthma are able to lead lives free from asthma symptoms
- Children, young people and families feel that care is personalised to their needs, organised around them, and they are active participants in their care
- Asthma is diagnosed early, accurately and comprehensively, using age-appropriate tools and strategies
- Children and young people are supported by their families, early years settings and schools, as well as health services to self manage their asthma, to receive regular structured review and to have rapid access to appropriate services when control deteriorates
- In the event of an acute attack, that control is regained as quickly as possible, and the child/ young person is supported to avoid future loss of control
- Deaths from asthma in children and young people are prevented
- Variations in the quality of care across the country are explored, addressed and minimised.

This document sets out how commissioners and clinicians can work together towards achieving this vision for young people from birth to age 19.



# 4 Why do we need to improve outcomes for children and young people with asthma?

**The UK has the highest prevalence of asthma in the world<sup>1</sup> and asthma is the most common long-term condition in children and young people.**

- Asthma accounts for nearly one third of all long term childhood illnesses<sup>2</sup>
- Around a million children in the UK have asthma – an average of two children with asthma in every classroom across the country
- The National Institute for Health and Care Excellence (NICE) estimates that between 17% and 23% of children in the UK have asthma. More conservative figures come from the Health Survey for England, which found that 11% boys and 8% girls have asthma.

**Mortality rates for asthma are higher in the UK than in many other European countries.**

- There were 12 deaths from asthma among children aged 14 or under in England in 2010.
- Yet it is widely believed that there are preventable factors in 90% of deaths.

**There were 24,744 emergency admissions for asthma among children in England in 2009/10.<sup>4</sup>**

- The Respiratory Atlas of Variation highlighted the 19-fold variation between PCTs in the number of emergency admissions for asthma in children, which is not fully explained by socioeconomic variation

- There is also up to five-fold variation between general practices within CCGs

- Transitional age young people, aged 16 to 19, are much more likely to be admitted to hospital with an asthma exacerbation than other age groups and stay in hospital longer when they are.

**The goal of freedom from asthma symptoms is not being met in many children and young people.**

- 47% boys and 48% girls with asthma had experienced an asthma attack in the previous 12 months
- 30% had experienced daytime symptoms in the previous week
- 20% had had their sleep disturbed by asthma symptoms<sup>6</sup>
- 1 in 8 children under 15 with asthma symptoms experience attacks so severe they can't speak.

**There are also significant indirect costs, beyond healthcare, to the wider economy.**

- A child with poorly controlled asthma is three times more likely to take time off school, than a child whose condition is well controlled. This poorer attendance is likely to have a detrimental effect on their emotional wellbeing, as well as their educational attainment
- Their carer is four times more likely to take time off work, with a further effect on their own productivity.

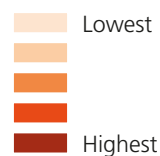
# Why do we need to improve outcomes for children and young people with asthma?

## Emergency admission rate for children with asthma per population aged 0–17 years by PCT

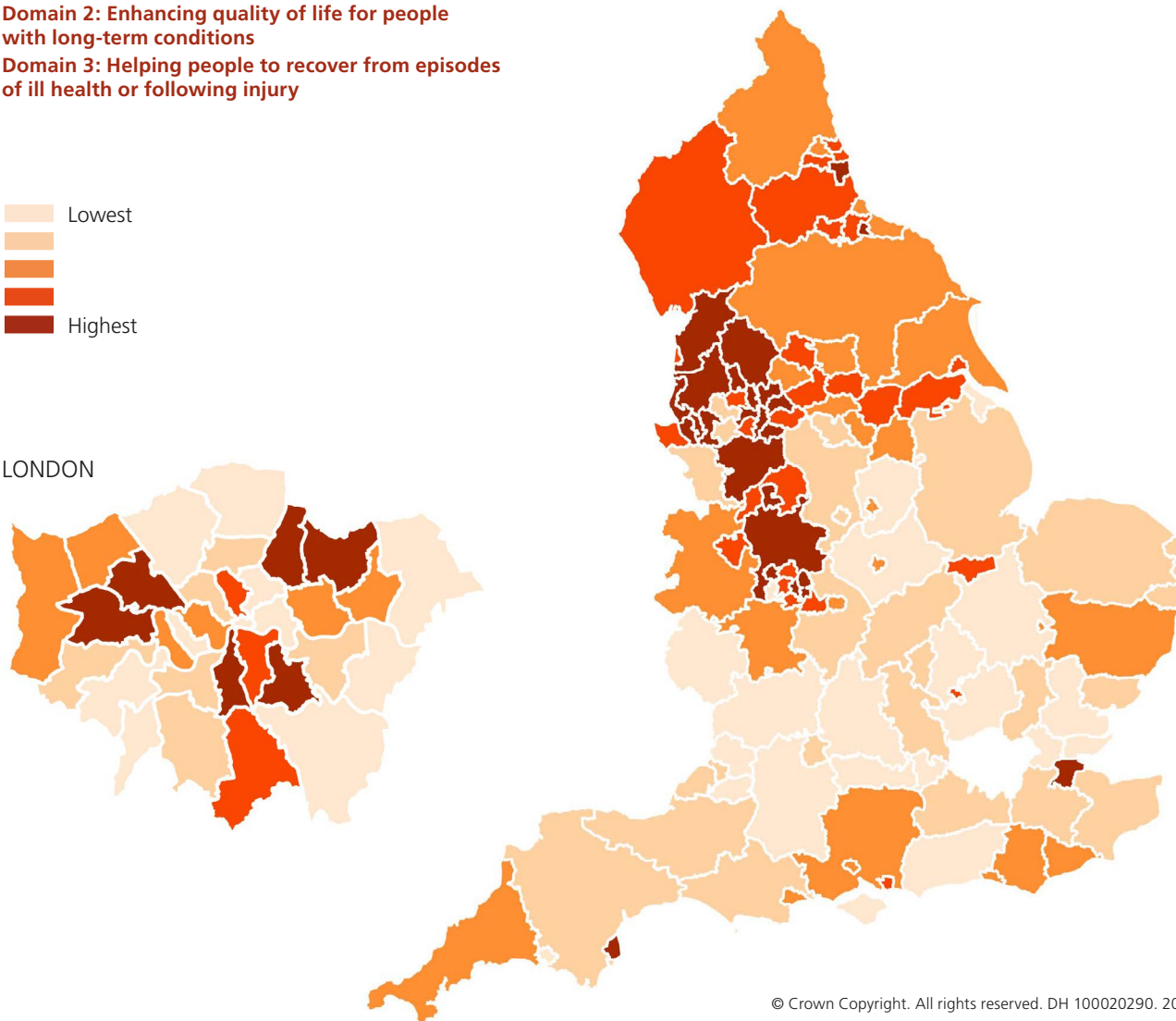
Directly standardised rate 2010/11

Domain 2: Enhancing quality of life for people with long-term conditions

Domain 3: Helping people to recover from episodes of ill health or following injury



LONDON



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# 5 Understanding the differences between asthma in children and adults

While asthma is essentially the same condition in children and adults, there are significant differences in the way that asthma is diagnosed and treated. Children are not little adults: children of different ages have different needs and abilities and they respond to treatments in a different way from adults. It is vital that commissioners recognise the special physical, emotional and educational needs of children with asthma and how they differ from those of adults.

The main differences can be summarised as:

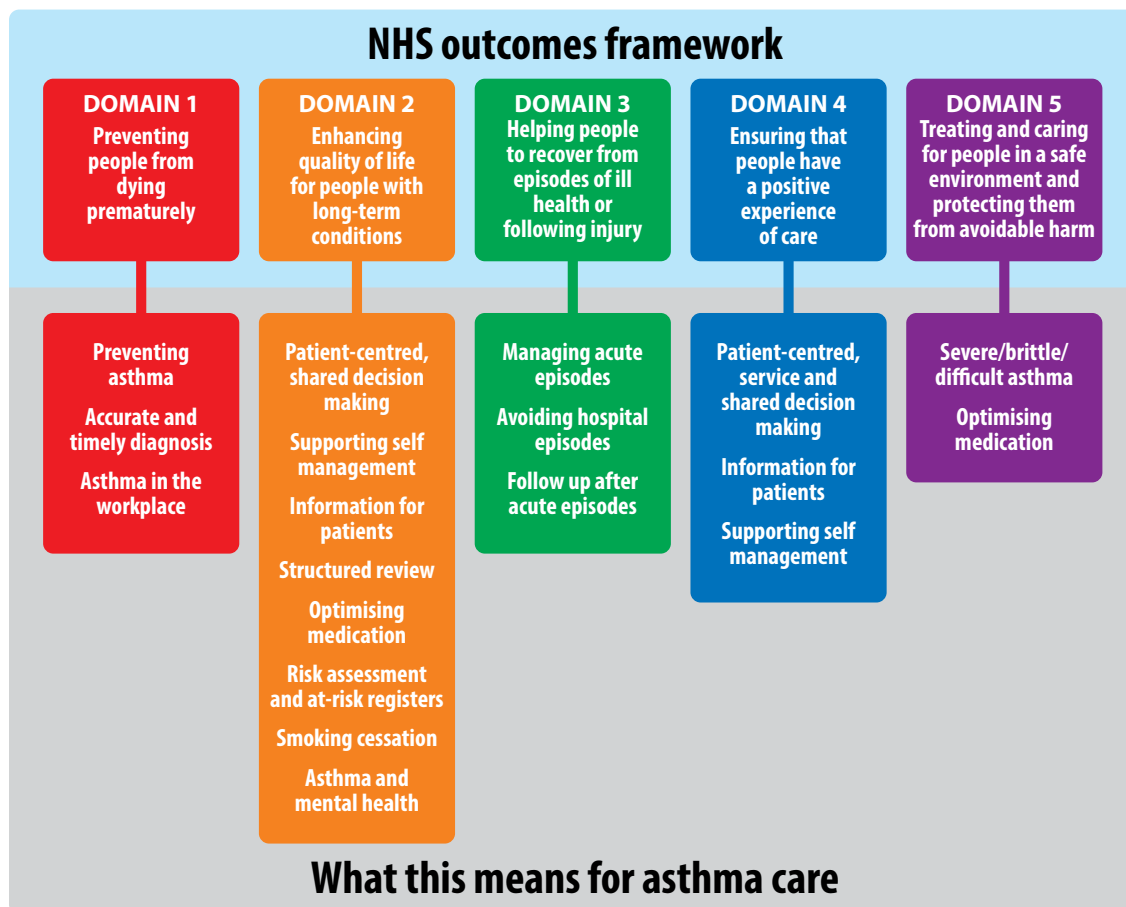
- **Gender differences in prevalence:** Up to puberty, there are more males than females with asthma. At puberty, this reverses
- **Partnership:** Clinicians need to work in partnership with parents if young children are to be free from symptoms. Education and partnership working must focus on both parent and child, and as the child moves toward independence in adolescence, the parent needs to be supported to pass control to the young person
- **Developmental stage:** Attention needs to be given to the developmental stage of children and young people and all aspects of care tailored accordingly
- **Safeguarding issues:** robust systems for safeguarding children need to be in place. Concordance in children may be poor and impact control of symptoms due to insufficient parental supervision or understanding
- **Diagnosis:** There are significant problems in diagnosing asthma in children under the age of five, partly due to their difficulty in performing the diagnostic tests, and partly because viral wheezing illness can be confused with asthma. Many children have episodes of wheezing, cough and difficulty breathing, which are associated with viral upper respiratory tract infections, but these symptoms are not persistent, and such episodes often stop by school age
- **Allergic component:** It is more common for asthma to be associated with allergies in children than in adults. And children may have more than one allergic condition – such as eczema or food allergy – alongside their asthma

# Understanding the differences between asthma in children and adults

- **Treatment:** While generally the same range of medications is used in adults and children, the preferred delivery devices may be different, doses may vary and the stepwise treatment pathway varies
- **Emergency care:** The British asthma guideline outlines different approaches to emergency care in children under two, 2-5 and over five years of age
- **Adolescence:** Symptoms may reduce or disappear altogether in adolescence, yet these people should be apprised of the risk of asthma returning again in later life, sometimes after years of apparent improvement
- **Deaths:** Deaths from asthma are relatively uncommon in children and young people. Less than 35% of the deaths from asthma are in the under-75 age group, (352 deaths in 2010 for England and Wales) and, of these, only 18 were under 20 years of age (1.78%).



# 6 The policy context



## The mandate from government to NHS England

This sets out the objectives for the NHS and highlights the areas of health and care where the government expects to see improvements.

- Preventing people from dying prematurely
- Enhancing quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury
- Ensuring that people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm.

What this means for children and young people is that the NHS will work with other agencies to promote health and wellbeing in a joined-up approach, to give them the best start in life.

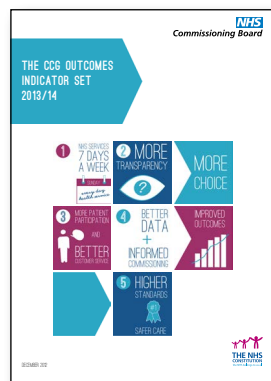
## The outcomes frameworks

Since 2010, the DH has published three outcomes frameworks, one for each part of the health and care system. The outcomes framework for public health, adult social care and the NHS include the outcomes for health and care that matter most to all of us, including children, young people and their parents. As one of the primary mechanisms by which the health and care system is held to account, they will act as a focus for action and improvement.

## NHS Outcomes Framework<sup>7</sup>

The NHS Outcomes Framework 2013–14 includes measurable outcomes to demonstrate improvement in critical areas: for example in infant and perinatal mortality, and through better support to children and young people with asthma, diabetes and epilepsy. A number of improvements recommended by the forum have now been included in the NHS Outcomes Framework 2013–14:

- A new indicator to measure potential years of life lost for children and young people
- A new indicator to measure cancer survival for children
- All data will be presented in five-year age bands up to 25 to enable effective transition to be monitored.



## Public Health Outcomes Framework<sup>8</sup>

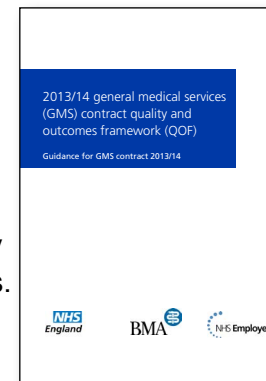
The Public Health Outcomes Framework details the broad range of opportunities to improve and protect health across the life course and to reduce inequalities in health that still persist. The framework is focused on two high-level outcomes to be achieved across the public health system and beyond. They are:

- Increased healthy life expectancy
- Reduced differences in life expectancy and healthy life expectancy between communities.



## The CCG Outcomes Indicator Set<sup>9</sup>

The aim of the CCG Outcomes Indicator Set is to support clinical commissioning groups (CCGs) and health and wellbeing partners in improving health outcomes by providing comparative information on the quality of health services commissioned by CCGs and the associated health outcomes. It will cover a balanced range of indicators, reflecting each of the five domains of the NHS Outcomes Framework, including clinical effectiveness, patient experience and patient safety.



## Quality standard for asthma

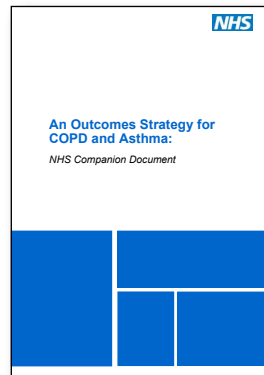
NICE has developed a quality standard for asthma to cover people of all ages. Eleven statements encapsulate the most important points from the British asthma guideline, and these focus on some of the areas of current weakness in asthma management. Commissioners can use the quality standard in their contracts, to drive improvements in quality and providers can use the quality standard as a benchmark against which to provide best practice care. A guide specifically for commissioners accompanies the quality standard and provides some guideline costs for implementation. See Annex C

## Quality and Outcomes Framework (QOF) for asthma

There are currently four asthma indicators in QOF that relate to children to varying degrees.<sup>10</sup> All children receiving medication for asthma should be on an asthma register, all on register should have an assessment of their asthma control using a recognised tool, those over 8 years old should have had their diagnosis confirmed, and 14-19 year olds should have their smoking status recorded.

### **An outcomes strategy for COPD and asthma: NHS companion document<sup>11</sup>**

This strategy includes a chapter on improving asthma outcomes and identifies key areas to focus on under the five NHS England domain headings. This echoes many of the key areas highlighted in this Good Practice Guide for Children and Young People.



### **Children and Young People's Health Outcomes Forum<sup>12</sup>**

In January 2012, the then secretary of state for health established the Children and Young People's Health Outcomes Forum to:

- Identify the health outcomes that matter most for children and young people
- Consider how well these are supported by the NHS and Public Health Outcomes Frameworks, and make recommendations; and
- Set out the contribution that each part of the new health system needs to make in order that these health outcomes are achieved.



### **The Forum's report highlighted two key messages:**

- Too many health outcomes for children and young people are poor and for many this is related to failures of care
- There is substantial and unexplained variation in many aspects of children's healthcare. The UK is worse than many other countries in Europe for many outcomes that could be improved through better healthcare and preventative interventions.

They recommended four new outcome indicators for inclusion within the NHS outcomes framework – all of which would benefit children and young people with asthma:

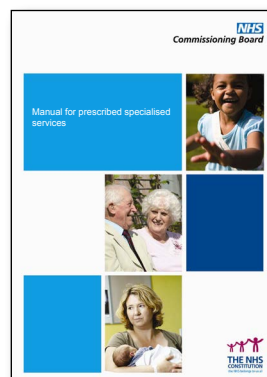
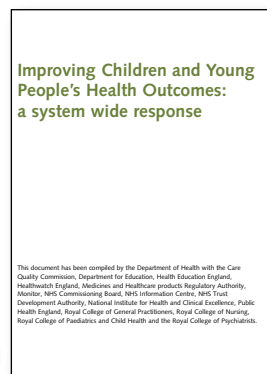
- Time from first NHS presentation to diagnosis or start of treatment
- Integrated care – developing a new composite measure
- Effective transition from children's to adult services
- Age-appropriate services – with particular reference to teenagers.

## Improving children and young people's health outcomes – a system-wide response

The Government published its response to the Forum: Better Health Outcomes For Children And Young People: Our Pledge<sup>13</sup> and Improving Children And Young People's Health Outcomes: A system wide response in February 2013.<sup>14</sup> The importance of supporting children with long term conditions was highlighted in the third ambition for the pledge – 'Good mental and physical health and early interventions, including for children and young people with long-term conditions, will be of equal importance to caring for those who become acutely unwell.'

## Specialised services for difficult to control/ severe paediatric asthma

While most children and young people with asthma will be managed in primary care with some input from secondary care, there is a small proportion with asthma that is very difficult to control. This group will be covered by specialised services as outlined in specification 128 in the manual for prescribed specialised services<sup>15</sup> and will be managed by specialised services in tertiary care.



## Facing the Future – Royal College for Paediatrics and Child Health (RCPCH)

This is a suite of publications under the banner Facing the Future, which sets out standards of care in paediatrics (2010), what is required to deliver these standards, and most recently, an audit of the extent to which these standards are being met. (April 2013)<sup>16</sup> Its focus is on the capacity and staffing required to meet the desired standards, and may therefore be useful for commissioners of paediatric services.

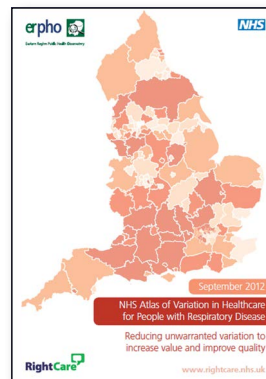


## You're welcome – quality criteria for young people friendly health services

The Department of Health published this 10-point guide to making health services more accessible and sympathetic to young people in 2011. It covers the importance of involving young people in the design of health services, of supporting them as they move from paediatric to adult services, and of supporting those with long-term health issues.

### Respiratory Atlas of Variation<sup>17</sup>

Published in September 2012, the Respiratory Atlas highlights considerable variation in respiratory services across England. Map 14 shows that there is a 19-fold variation between PCTs in the emergency admission rates for children with asthma. It proposes that this may be due to suboptimal symptom management in the community, suboptimal management in emergency departments, and variation in admission criteria between centres or clinicians. Fig 14.2 also indicates that deprivation may be linked to admissions rates for children with asthma. Case study eight shows how one area used pharmacists to undertake Medicines Use Reviews (MURs) to address issues of control. Guidance is given to commissioners for how to address a high admission rate.



### National review of asthma deaths<sup>18</sup>

In the first project of its kind, this review is designed to learn more about why so many people still die from asthma in the UK. From February 2012 to March 2013, every death from asthma across the UK was systematically investigated. Results are expected in early 2014, which may contribute to our understanding of how to avoid and manage acute attacks. The number of deaths from asthma in England each year has been at a plateau of around 1,000 for several years, with up to 30 deaths in the under 25 age group.



# 7 Role of commissioners in improving outcomes for children and young people with asthma

Commissioners need to be working towards the goal of asthma management just as clinicians and patients are. By working towards freedom from symptoms for patients, they should be able to reduce emergency department attendances and asthma admissions, manage the cost of medication, and achieve improved patient experience and quality of life for the patient.

‘The NHS and social care have been designed around the system, rather than the individual. To children, young people and their families, that system feels fragmented and often means they have to tell their story repeatedly, striving unsuccessfully to be heard and get the properly joined-up care they need. Designing and planning health and healthcare round the needs of the individual child or young person, taking account of their changing needs over time, will improve their experience of the service and their health outcomes – not just at a point in time, but for the longer term – and improve their lives enormously.’

*From report of Children and Young People’s Health Outcomes Forum*

## What do commissioners need to know to design a good asthma service for children and young people?

- What asthma care looks like locally. Their local figures and geographical context for prevalence, consultations, attendances in emergency departments, admissions and readmissions, deaths, cost of care, cost of prescribing, smoking prevalence rates and how these vary from national and/or similar areas. These data should be available from:

- The local public health observatory
- The Respiratory Atlas of Variation, and Children and Young People’s Atlas of Variation<sup>19</sup>
- INHALE (Interactive health atlas for lung conditions in England) is a repository of valuable information on respiratory disease which can be interrogated at PCT level<sup>20</sup>
- The disease management information toolkit for asthma in children was developed by ChiMat and is a useful tool for commissioners to assess the impact of asthma locally.<sup>21</sup>

- What the main challenges/weaknesses/issues are in managing asthma locally – such as access to care during flare ups, care provided in emergency departments and on wards, speed and content of follow up after exacerbation, competence/ training of health professionals conducting reviews, education/ self management support, education/ healthcare interface
- What the clinical guidelines say about best practice – the quality standard sums up the key areas for attention in 11 statements
- How these translate into service needs for people with asthma



# Role of commissioners in improving outcomes for children and young people with asthma

- The experience and expectations of people with asthma and their carers: people with asthma should be invited to become involved in the design and evaluation of asthma services
- Levers for change – the national and local levers that are available to them to drive improvements in quality and outcomes of services
- It is important that commissioners work closely with local authorities, particularly since local authorities have a new role. From April 2013, local authorities are statutorily responsible for delivering and commissioning public health services for children and young people aged 5-19. This will include providing prevention and early intervention services, delivering the Healthy Child Programme and addressing key public health issues such as sexual health, emotional health and wellbeing issues, obesity, drug, alcohol and tobacco misuse.<sup>22</sup>

The checklist in annex A outlines what a good service should look like. It should support leaders to determine how they are doing and where to focus improvement efforts.

## **Example of good practice**

**Yorkshire and Humber Children and Young People's (CYP) Asthma Impact Project July 2012-March 2013 – phase 2 – Commissioning for Better Outcomes**

To influence effective local practice it was important to assist the commissioners to understand their local picture and what level of intervention was needed. This included providing the context; background, the aims, goals and purpose, the available research as well as evidence (national and local) relevant to improving asthma outcomes. ChiMat was commissioned to provide an analysis of a range of data relating to hospital emergency admissions for asthma in the under 18s. This information was found to be invaluable to PCTs. It included emergency admissions by age, gender, ethnicity and potential costs savings.

Each PCT was supported to identify their priorities and their relative impact versus the ease of implementation and the potential gains in terms of health outcomes, CYP experience and cost savings.

For further information contact: Pauline.  
[Dumble@caresolutionsyorkshire.com](mailto:Dumble@caresolutionsyorkshire.com)

# 8

## How to use this guide

This publication is not about managing individual patients. Instead it aims to identify the elements of good service that people with asthma need, so that:

- Commissioners know what a good service looks like and commission it
- Providers can see what a good service should include and deliver it.

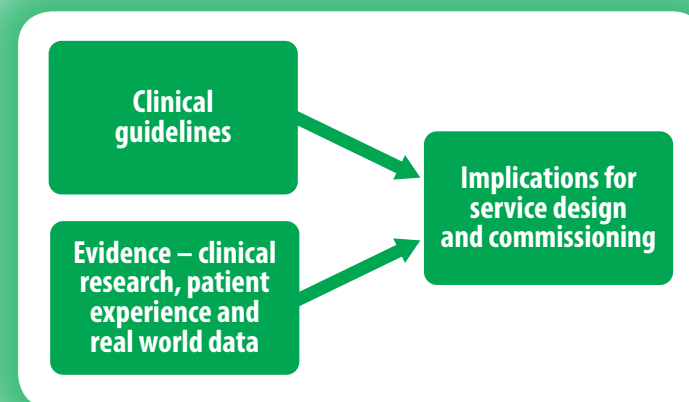
This good practice guide is not prescriptive about where care happens, (unless there is clear evidence in the guidelines), so the content will be of value to people commissioning services from secondary care, those considering the services that primary care and pharmacy provide, and public health and local authorities in the context of their role in providing prevention and early intervention services.

This publication has been organised around key headings, which set out:

- What the clinical guidelines say about best practice relevant to service design and delivery. The SIGN/BTS asthma guideline 2012 is the source of this material unless otherwise specified<sup>23</sup>
- What the evidence tells us – either from literature or from other studies, audits and surveys on current patterns of care in the NHS and other healthcare systems
- What this means for those designing, commissioning and providing services
- Relevant examples of good practice.

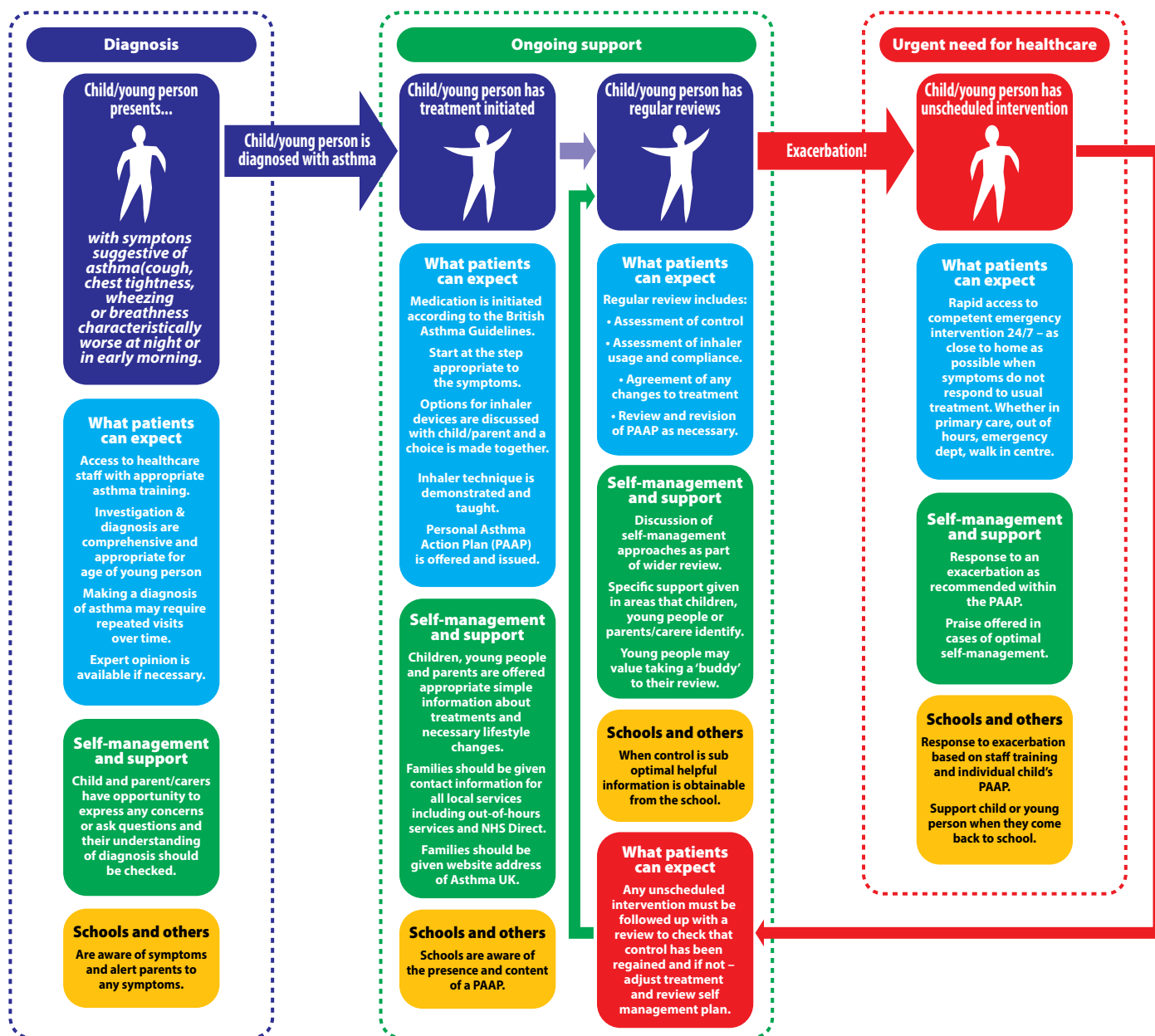
At the end there is a checklist of good practice points that commissioners and providers can use to benchmark their own locality or service against. (Annex A)

This document has been organised around areas of weakness in asthma care, which if addressed, could make a significant impact in improving outcomes for people who live with this condition. These are the areas that commissioners and anyone involved in service design should focus on. They are closely aligned with the 11 statements of the NICE asthma quality standard (annex C), and these statements are highlighted in the relevant chapters. There is excellent evidence for these areas and clear guidance in the SIGN/BTS guidelines, yet they are not being translated into practice. It is these areas that this good practice guide will focus on.



## The care pathway

The sections follow broadly in the order of the asthma pathway shown here.



# 9 A child-centred service and shared decision-making with children/young people and their parents

One of the key messages within the Report of the Children and young people's health outcomes forum was:

*'Children, young people and their families really struggle to get their voices heard and to be involved in decisions about their own health. This makes it difficult for them to take responsibility for their treatment and care.'*

Children and young people reported that they want:

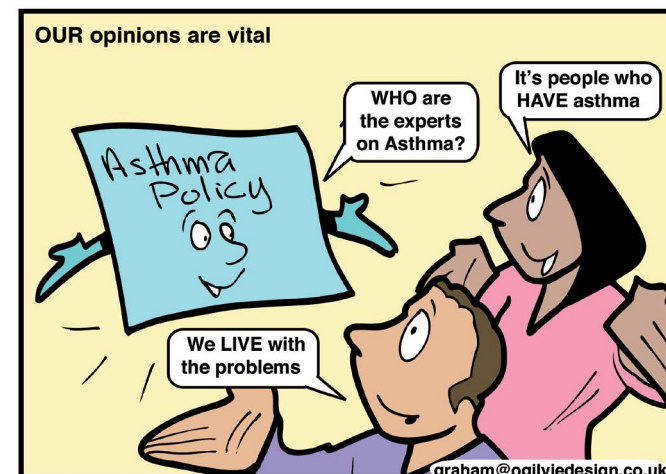
- To have a say and to be listened to in decisions about their health, and to take a lead where able
- Health staff to show respect and recognition of their right to be involved in decisions about their health and care
- To give their own views about their health needs and the care they receive.

This theme is reiterated throughout the document, stressing the need for high quality services that are co-ordinated around individual and family need, and emphasising the importance of a collaborative approach and shared decision-making.

The government supports the development of programmes to allow children and their families to self manage and be fully informed about health related issues by ensuring that they are provided with the information they need to lead a healthy life. In February 2013, the encouraged a wide range of healthcare organisations to sign up to a commitment to improve outcomes for children and young people – its first ambition was: 'Children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority.'<sup>24</sup>

Involving parents and children, and young people actively in the diagnosis and management of asthma is essential. Most of the time, they will be managing on their own, so it is key that they/ their parents understand the condition, how it affects them as an individual, and how to control symptoms effectively so that they can live symptom-free lives. Shared decision making in healthcare requires a mutual partnership between the clinician, and the parents and young children, or the young person. Sharing decision-making in asthma is associated with improved outcomes by increasing their confidence to deal with their condition, and improving their self-management skills. Specific skills and tools to use with school age children include visual aids; turn taking, clarifying communication and role modelling. The goal is to change a two-way discussion between clinician and parent into a genuine three-way discussion.<sup>25</sup>

The British asthma guideline is clear that reviewing patients using a patient centred style of consultation can lead to improved outcomes.



## What this means for commissioners and service developers

Children and young people with asthma should not just be considered as service users but also as co-creators throughout the commissioning cycle, particularly in planning and reviewing services. In practice, this means:

- Asking children/parents and young people about the quality of local asthma services
- Inviting children/parents and young people to plan, develop and monitor asthma services in their area
- Consulting with and inviting children/parents and young people to become members of respiratory working groups to improve local asthma services
- Involving children/parents and young people in creating care pathways, so their perspectives are central to the process
- All involved in designing services for people with asthma ensuring that children/parents and young people are treated as equal and expert partners with their healthcare professional at each stage of their treatment and care.

The RCPCH document *Not Just a Phase: A Guide to the Participation of Children and Young People in Health Services* gives practical advice on how to encourage participation of children and young people at different levels of service design and care provision.

- Service leaders should develop a culture of participation within their organisation.

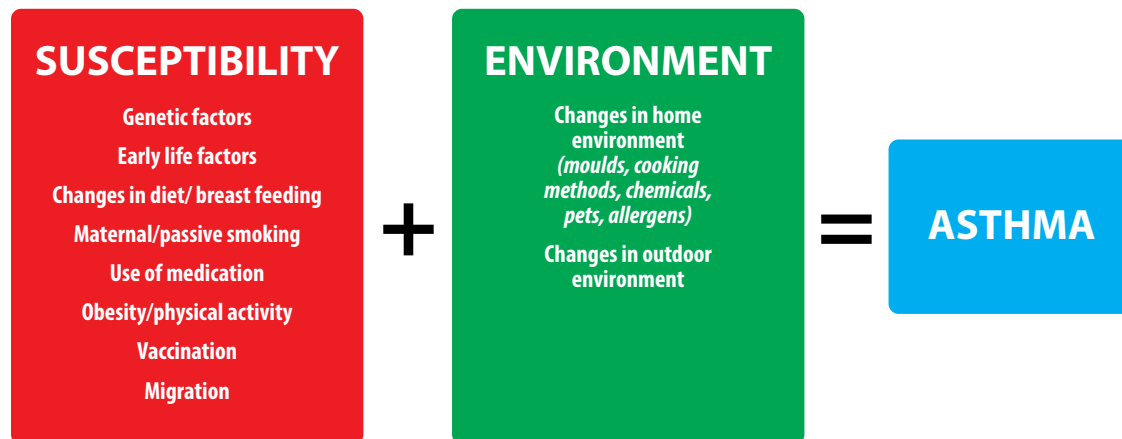
- The participation of children and young people should be evaluated systematically and the outcomes shared with key stakeholders. The contribution that children and young people make should be valued and any successes celebrated.<sup>26</sup>

Commissioners should require providers to produce evidence of joint decision-making, and should expect to find this in patients' notes. In this context shared decision making involves:

- Eliciting the child's/parent's or young person's goals for treatment
- Determining the child's/parent's or young person's relative priorities regarding symptom control and regimen convenience
- Discussion of side effects
- Cost of medications where relevant
- Sharing with the child/parent or young person information about available treatments (both devices and dosing)
- The child/parent or young person and clinician then coming to a mutual decision regarding the optimal treatment regimen.

Significantly enhanced concordance is seen with such interventions and a reduced need for unscheduled health care.

# 10 Preventing asthma



## Recommendations in clinical guidelines

- The guideline states there is little evidence for any strategies for preventing asthma from developing in children, although breast feeding may have a potential protective effect regarding early asthma
- There is an increased risk of infant wheezing associated with maternal smoking during pregnancy, which adversely affects infant lung function. Early life exposure to environmental tobacco smoke is associated with later persistent asthma.

## What the evidence tells us

- Unfortunately, apart from the avoidance of occupational sensitizers in adults, asthma cannot yet be prevented from developing and cannot be cured. Asthma arises as a result of an interaction between a susceptible host and a factor or factors in the environment
- Maternal smoking during pregnancy appears to increase the risk of wheeze and asthma among children who are not exposed to maternal smoking after birth<sup>27</sup>
- The major risk factors for childhood asthma are a family history of asthma and allergies, early and persistent allergic sensitisation to environmental allergens – including tobacco smoke, and viral lower respiratory illnesses in early life<sup>28</sup>
- Children with a predisposition to develop asthma may be at greater risk of developing asthma during childhood if their mother was overweight before their pregnancy.<sup>29</sup>

## What does this mean for commissioners and service developers?

- There is no value in developing or commissioning services designed to prevent asthma occurring (primary prevention)
- However, all of the following represent good practice and should be encouraged:
  - Breastfeeding where possible
  - Avoidance of smoking in the pregnant mother due to adverse effects on foetal lung development
  - Avoidance of exposure of young children to tobacco smoke, particularly in cars and the home. Evidence is emerging of the impact of the English ban on smoking in public places on emergency admissions in children, and a paper from 2013 suggests that admissions in children have reduced.<sup>30</sup>

Although good practice, these cannot at present be claimed to definitely reduce the risk of a child developing asthma. More research is needed.



## Accurate and timely diagnosis

### Recommendations in clinical guidelines

- There are important differences between diagnosing asthma in children and adults; age impacts on differential diagnosis, natural history of wheezing illnesses, ability to perform certain investigations and their diagnostic value
- There is no single test to diagnose asthma. More rather than less testing may be required, and in difficult cases, extra, more sophisticated testing is worthwhile
- There is a well documented method for diagnosis of asthma – based on the probability of the presenting symptoms being asthma
- The initial assessment of children suspected of having asthma should focus on the presence of key features in the history and clinical examination – including age at presentation, sex, severity and frequency of previous wheezing episodes, coexistence of atopic disease, family history of atopy, abnormal lung function. Scoring systems such as the Asthma Predictive Index (API) may be of benefit in quantifying these. Alternative diagnoses should be carefully considered
- The basis for diagnosis should be recorded in patient notes, as should the probability of an asthma diagnosis – high, intermediate or low
- Repeated assessment and measurement may be necessary before confirmatory evidence is achieved
- Primary care staff trained in asthma management deliver improved diagnosis.

### What the evidence tells us

- A prompt diagnosis is crucial to reducing the impact of asthma on children and their families and yet making a definite diagnosis of asthma can sometimes be difficult
- There is evidence of over-diagnosis, delayed diagnosis and mistaken diagnosis of children with more serious disorders (eg cystic fibrosis)
- The major risk factors for childhood asthma are a family history of asthma and allergies, early and persistent allergic sensitization to environmental allergens and wheezing caused by viral lower respiratory illnesses in early life<sup>31</sup>
- Under fives: The diagnosis of asthma in children who cannot do lung function tests (ie under five or six years of age) can be challenging and may result in misdiagnosis. The challenge is that there can be many causes of these symptoms (particularly viral wheeze) in childhood
- Children under three with recurrent respiratory symptoms are more likely than older children to have a diagnosis other than asthma as a cause of their symptoms
- Some parents find the diagnosis of asthma difficult to accept and some may find it difficult to understand. This is particularly important to address when children are young, as the responsibility for self-management relies on the parents managing symptoms. Parents need to have support and information as much as their children; this needs to be tailored to their context, concerns and circumstances.

## What this means for commissioners and service developers

The asthma quality standard highlights the importance of accurate and high quality diagnosis.

**Statement 1. People with newly diagnosed asthma are diagnosed in accordance with BTS/SIGN guidance.**

- Children over five should have access to a comprehensive diagnostic service with all appropriate tests as set out in the guideline
- Healthcare professionals in primary care should be trained in asthma diagnosis and management, and be competent in undertaking and interpreting quality assured spirometry, in any setting where diagnosis takes place
- Healthcare professionals need to be aware and have an understanding of differential diagnoses in children
- Comprehensive allergy testing services should be available to establish whether a child has concomitant allergies, since children with asthma have a higher risk of associated allergic conditions such as eczema and allergic rhinitis (see chapter on allergy)
- Auditing general practice records will help to establish whether the probability of asthma (high, intermediate, low) has been determined and the basis for diagnosis has been recorded in the notes.

## Examples of good practice

### Video observation

Asthma symptoms are intermittent, and a child who was badly short of breath and coughing at three in the morning may be normal when seen at midday in a GP surgery. However, technology is helping to overcome this. It is increasingly common for parents to be able to film children when they are having trouble breathing; this can provide very useful information to clinicians. Children and their families are excellent sources of innovative approaches to diagnosis.

*I was extremely scared when Sion was diagnosed with moderate asthma at the age of one. However, I was given a full explanation of what asthma is, how to recognise asthma symptoms, how to avoid asthma triggers and how to use an inhaler.*

**Mother of 10 year old**

*Thomas was diagnosed with asthma in 2003 when he was three years old, after repeated hospital admissions with severe coughs and breathing problems. Having a son with severe asthma is incredibly frightening and stressful, which is made worse when health care professionals lack vital knowledge about the condition.*

**Sandra, mother of 8 year old**

# 12 Information for children/young people and their parents

## Recommendations in clinical guidelines

- Every consultation is an opportunity to review, reinforce and extend knowledge and skills of younger children and their parents, or of older children
- Information for patients and families about how to recognise and respond to loss of control or increasing symptoms is essential
- Simple verbal and written instructions and information on drug treatment should be provided to patients and parents
- Parents should be advised about the relationship between cigarette smoke exposure and wheezy illnesses
- Information for adolescents – written and oral – should be personalised, rather than general and use non-medical language that adolescents can understand.

*Information can fundamentally improve our health, our wellbeing, our care services and the outcomes of our care. Improved information quality and information sharing is critical to modernising care through raising the quality of that care, improving outcomes and reducing inequalities, as well as improving productivity and efficiency.*

**The power of information:** *Putting all of us in control of the health and care information we need*  
(The Information Strategy May 2012 )

## What the evidence tells us

- Giving information is an important component of any partnership approach to a long term condition, as set out in Equity and Excellence: Liberating the NHS, and patients should be given information according to their needs and preferences
- The need to give information to parents and children will exist during investigations, at diagnosis and throughout the life of an individual with asthma. However the type of information they need may vary at these different stages, and certainly it will vary as the child gets older
- Information needs to be age appropriate, and ideally would have the target age group involved in design of any materials used to give information
- Giving information in isolation should usually be accompanied by structured self management support, and shared decision making about treatment
- Asthma UK reports that members of their children's and young people's forum want:
  - Good, child friendly information about what is available and how they can access it
  - To be able to receive information directly from health staff, as well as from parents who are important providers and translators of information.

## What does this mean for commissioners and service developers?

- Provision of information should be built into every step of an asthma care pathway, so there is discussion and agreement about appropriate and consistent information for parents and children
- Commissioners should expect providers to demonstrate that they are providing parents and children with information tailored to their asthma as an individual, which encourages them to be active partners in their care
- Clinicians should be providing information to patients in a format appropriate and understandable to them, taking account of issues such as language and levels of health literacy.<sup>32</sup> Commissioners can expect to see evidence of this in clinical practice. This sharing of information could include signposting patients to a range of sources including:
  - Reputable organisations such as Asthma UK and the British Lung Foundation
  - NHS sources such as NHS Choices
  - Relevant helplines
  - Self-management courses
  - Local self-support groups
  - Other community support resources, including local physical activity groups
  - Voluntary sector organisations
  - Other sources of information about asthma.

## Examples of good practice

Using new media and technology to provide information to parents and children can bring a fresh approach to giving information. One example is an online support group for parents of children with asthma. Parents received information and reassurance from other parents in peer support sessions. Parents appreciated the accessibility and anonymity of the online support group. This innovative online peer support intervention, informed by parents' preferences, could be adapted for different cultural groups or for specific types of asthma.<sup>33</sup>

Asthma UK has developed programmes such as Big Up Your Chest (See chapter 18 – asthma in adolescents) and My Asthma as educational initiatives for children and young people, using innovative ways of communication such as Facebook to engage young people in the media they are familiar with.

*The readability of materials is highly relevant to health literacy, as adolescents cannot use information to guide their choices about health behaviour if they fail to understand information provided to them.*

*Manganello Health education research 2008*

# 13

## Supporting self management

(See also chapter on information for children/young people and their parents)

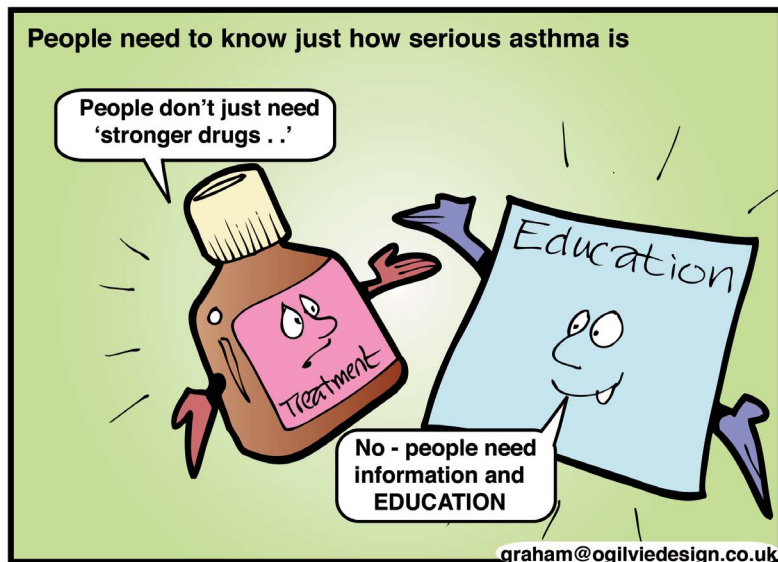
### Recommendations in clinical guidelines

- Self-management plans have been recommended in asthma guidelines since 1990 and are supported by grade A evidence. They can decrease hospitalisation for and deaths from asthma
- Personalised action plans should be introduced as part of a structured educational discussion
- Children and young people with asthma should be offered self-management advice on that is age-appropriate, that focuses on individual needs and is reinforced by a written personalised action plan
- Clinicians need to educate and empower adolescents to manage as much of their asthma care as they are capable of doing while supporting parents to gradually hand over responsibility for management to their child
- Innovative approaches to self-management advice in teenagers (web-based, in groups, peer-delivered within schools) appear to have more success than more traditional programmes
- A hospital admission represents a window of opportunity to review and reinforce self-management skills. Before hospital discharge, patients should receive written personalised action plans, given by clinicians with expertise in asthma management.

### What the evidence tells us

- Educational programmes for the self management of asthma in children and adolescents improve lung function and feelings of self control, reduce absenteeism from school, number of days with restricted activity, number of visits to an emergency department, and possibly number of disturbed nights. Educational programmes should be considered a part of the routine care of young people with asthma<sup>34</sup>
- Learning self-management strategies related to asthma prevention or attack management can help improve children's lung function and feelings of self-control, as well as reduce school absences and days of restricted activity and decrease emergency department attendances<sup>35</sup>
- Educational interventions for children who have attended the emergency department for asthma lowers the risk of the need for future emergency department visits and hospital admissions. A Cochrane review looked at studies which compared usual care for asthma to more intensive educational programmes and the results showed a statistically significant reduction in the treatment groups needing subsequent emergency department visits or hospital admissions<sup>36</sup>
- In general, self-management advice works well for persons with moderate to severe asthma as well as for those with mild to moderate asthma<sup>37</sup>
- Several studies have confirmed that asthma specialist nurse support of school-age children at or shortly after hospital attendance improves symptom control, self-management and re-attendance rates<sup>38</sup>

- Schools can be a setting for children and young people to learn skills in self management – potentially mediated by a trained community health worker, not a health professional, and in groups or individual. This approach can improve knowledge of asthma, self-efficacy, and self-management behaviours<sup>39,40</sup>
- Self management is a cost effective intervention for all children and young people<sup>41</sup>
- Yet many children and young people with asthma do not have a written self-management plan.



## What does this mean for commissioners and service developers?

**Self-management plans feature in the asthma quality standard from NICE and are an important lever for driving improved care.**

### **Statement 3. People with asthma receive a written personalised action plan.**

- Commissioners should stipulate in contracts that every child and their family, or young person should receive tailored information about their asthma, and have a personalised asthma action plan, so they can respond appropriately to symptoms and particularly to any worsening of control.
- Evidence of written asthma action plans should be available in patients' notes, and commissioners should actively audit this
- Commissioners should know the percentage of children and young people in their locality that have written asthma action plans
- Asthma trained practice nurses are key to supporting children, young people and their families in understanding their asthma, and knowing how to maintain control.
- Commissioners should ensure that no child or young person with asthma leaves hospital without a written self-management plan, developed and agreed jointly by the clinician and child/parent or young person, and a discussion about how to avoid future exacerbations. This should be communicated to the patient's practice and pharmacist, so they can reinforce the content of the plan, and give consistent advice. This includes patients who have been in-patients, and those who have attended an emergency department
- Developing a CQUIN or discharge bundle would help to ensure that more children and young people are given self-management plans.



## Examples of good practice

**The North West region** has developed a CQUIN for paediatric asthma, which shows the key points defining good practice in dealing with an asthma attack in a child. Included in these points is the development of a written asthma plan on discharge. <http://tinyurl.com/a8pdxep>

(see also a poster describing CQUIN in annex B)

**The State of California** requires health maintenance organisations (HMOs) to expand their existing self-management support for children with asthma to education in clinic settings (including group education) for symptomatic children, and in clinic and community settings (to include school or home based education) for children with uncontrolled asthma. Their assessment of the cost found that the expansion of coverage in education for children would not be very costly, particularly for children with uncontrolled asthma given the potential improvements in asthma outcomes.<sup>42</sup>

See examples of self-management plans in annex D.

**Asthma UK** has a range of resources to support patients in understanding their condition and in managing their own asthma. This includes a checklist of the information they need and the actions they should be able to take if their asthma worsens. The Be in Control pack is available from their website, and comprises a personal asthma action plan, a medicine card, a peak flow diary and a copy of Making the Most of Your Asthma Review. It is suitable for children aged over 12. <http://tinyurl.com/ac7m9le>

Professionals and parents of younger children should be encouraged to use Asthma UK's award-winning My Asthma self-management resources, which engage children in monitoring their own symptoms to stay on top of their asthma. <http://tinyurl.com/bz8utcj>

### **Asthma UK and NHS Yorkshire and Humber**

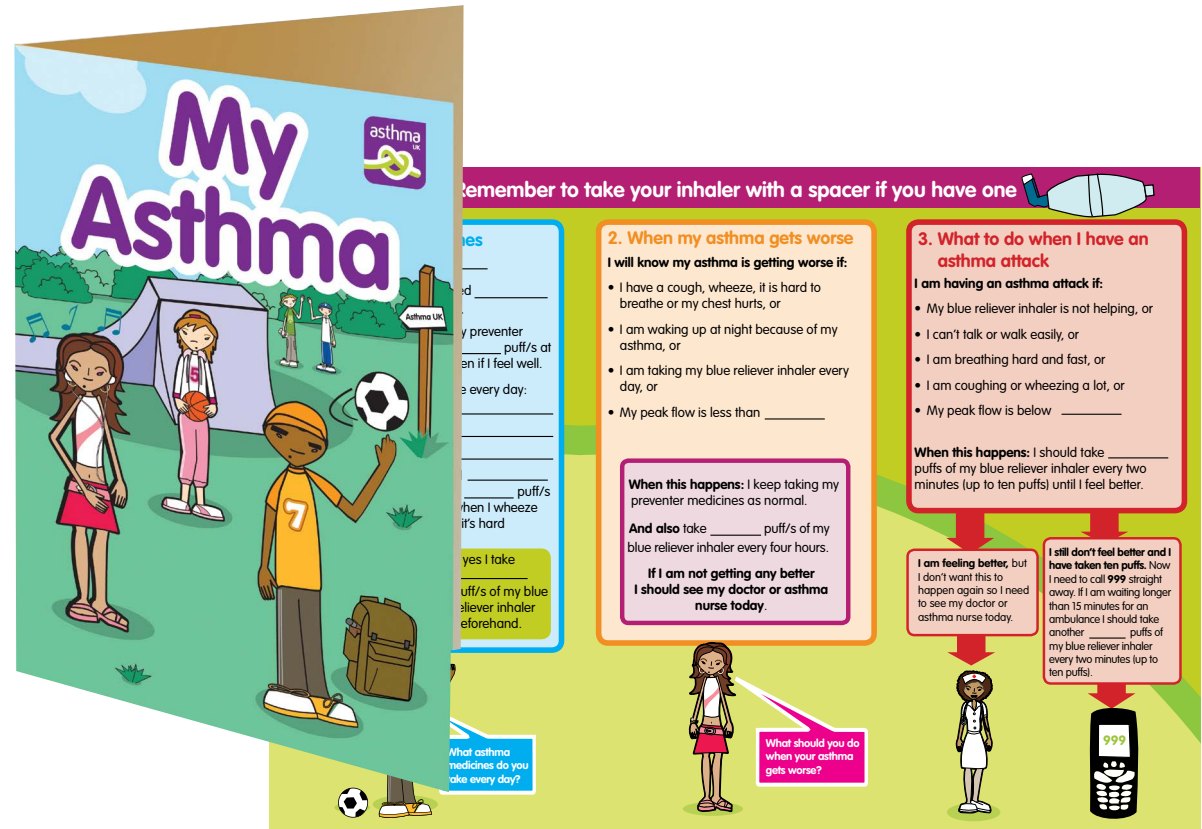
A project to improve care in primary care involved five GP surgeries in Hull, Wakefield and Leeds and was undertaken jointly with Asthma UK over a 12-month period. They identified the number of children at risk at the start and undertook a structured review/consultation in line with an agreed specification. They undertook 288 reviews and 19 follow-up reviews. A key outcome was that the use of self-management plans increased from 22% to 86%



## Components of a successful self management programme

Successful programmes may comprise –

- Structured education, reinforced with personalised action plans
- Specific advice about recognising loss of asthma control, assessed by peak flow or symptoms or both
- 2 or 3 action points summarising what to do if asthma control deteriorates.



*What would have really helped us, as a family is having a detailed asthma plan, to help us understand when to use different medicines and when to seek medical help. I'm convinced that being better equipped would have prevented some of Thomas's hospital admissions.*

**Sandra, mother of 8 year old**

# 14

## Structured review by asthma trained clinicians

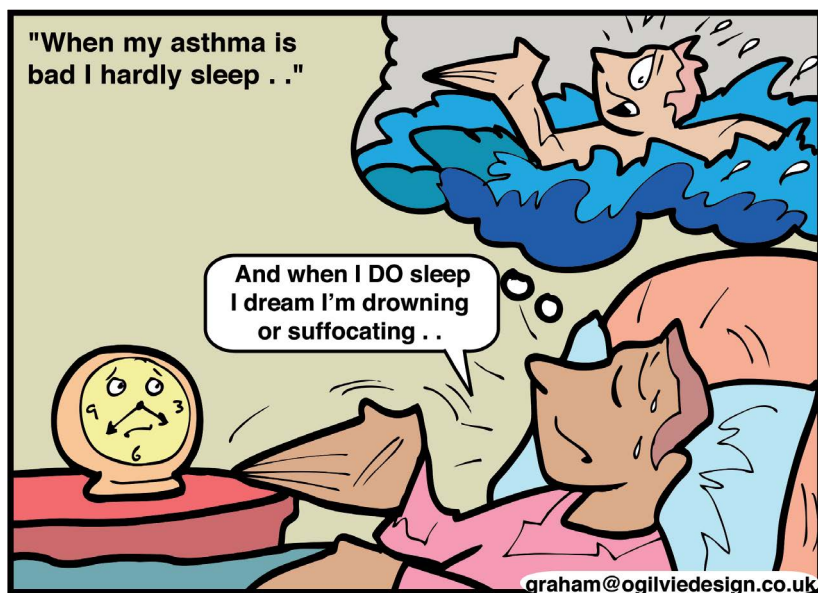
### Recommendations in clinical guidelines

- Proactive regular reviews have been shown to improve clinical outcomes such as reducing exacerbation rates, improving symptom control, and to reduce attendance at emergency departments and time off school. People most at risk of fatal or near-fatal asthma are those who do not participate in regular review
- Regular reviews are most effective when they include discussion and use of a written action plan
- Adolescents make less use of structured reviews than others, and have more frequent use of emergency asthma services. They are particularly vulnerable to the adverse effects of asthma
- Staff trained in asthma care achieve better outcomes for patients
- It is recommended that an audit be undertaken of the percentage of clinicians who have undertaken a suitable educational update on asthma in the previous two years
- Sub optimal control of asthma leading to exacerbation is more expensive to manage than well-controlled asthma.

### What the evidence tells us

- Holding structured asthma reviews in schools may improve attendance in adolescents. A study achieved 91% attendance by holding asthma reviews in a school setting compared to 51% for practice-based review<sup>43</sup>
- Communication using new media may also help to engage teenagers
- Regular review should include specific morbidity questions, ideally using one of the recognised assessment tools to establish symptom levels, examination of frequency of use of short-acting bronchodilators (quantity may indicate poor control) and recent history of acute attacks. Adherence to treatment, inhaler technique, smoking status, trigger factors and concomitant rhinitis should all be checked<sup>44</sup>
- Use of scoring systems such as the asthma control test (ACT) and Children's ACT are recommended adjuncts to assessment and management of individual patients. When used routinely, they also offer an opportunity to identify high-risk patients within communities and monitor the success of a healthcare community in attaining asthma control. For example, measuring and increasing the number of children who have an ACT score of more than 20, signifying that their asthma is well controlled, could be done in general practice
- Parents may under-report their children's symptoms. It is therefore good practice to ask the child him/herself about asthma symptoms during a consultation. The children's asthma control test can be used from the age of four, with good reliability and validity

- Every effort should be made to develop a shared decision making approach in reviews. Parents may dominate the discussion with clinicians, yet involving school age children in the discussions and decisions is good practice<sup>45</sup>
- Some of the tools developed for monitoring control have been specifically tested and validated in children and young people. Although the Quality and Outcomes Framework (QOF) recommends the Royal College of Physicians three questions for asthma control, other tools such as the children's asthma control test (4-11 years), asthma control questionnaire (ACQ) (over 5) and asthma control test (ACT) (ages over three) have been well validated in children and may be used as alternatives.



## What does this mean for commissioners and service developers?

**The Asthma Quality Standard specifically recommends an annual structured review for every patient with asthma, and an assessment of control for those who present with symptoms. Commissioners should be building these into the contracts with providers to reinforce best practice**

**Statement 5. People with asthma receive a structured review at least annually.**

**Statement 6. People with asthma who present with respiratory symptoms receive an assessment of their asthma control.**

- Commissioners should ensure that there are staff in primary care adequately trained to deliver high quality asthma care to children and young people, and commission education and training accordingly. Practice nurses play an important role in asthma care, and it is important that they have experience and competence in dealing with children and young people with asthma
- Audit the number of primary care clinicians who have received specific education in asthma in the previous two years
- Commissioners should check that reviews take place in a planned rather than opportunistic way should monitor the quality of the regular reviews being conducted, and whether the detail of what a review should comprise, as outlined in the QOF guidance notes, asthma guidelines, and quality standard, is being followed by practices. The guidance for commissioners that accompanies the asthma quality standard indicates that 20 minutes should be allowed for a structured review

- Practices with high numbers of asthma patients 'excepted' from the QOF indicator for regular review should be investigated, and encouraged to find ways of reviewing them. This may require the commissioning of good communication systems between practices and pharmacists
- Where there are high QOF exception rates for asthma reviews, pharmacists can play an important role in encouraging people to attend their general practice for regular review. Community pharmacists are potentially an untapped resource in asthma care. Pharmacists can identify higher risk patients, signpost them to GPs, check inhaler technique, support with smoking cessation, education, and self-management support. The new, targeted MUR service introduced in October 2011, which aims to encourage MURs in respiratory conditions, presents an ideal opportunity for pharmacists to discuss medication issues and improve concordance, and should be actively encouraged and commissioned by commissioners. Commissioners should ensure that pharmacists have adequate asthma training in asthma care to contribute fully to supporting patients with asthma.

## **Examples of good practice**

### **Regional guideline package on asthma in children**

Yorkshire and Humber worked with Asthma UK to develop a summarised guideline for use across the region highlighting the key areas to improve for children and young people with asthma so that best practice information was available in a single, accessible reference source. <http://tinyurl.com/a5ls8g7>

Contact Asthma UK for a copy of their summary report.

### **Development of clinical recording template for primary care**

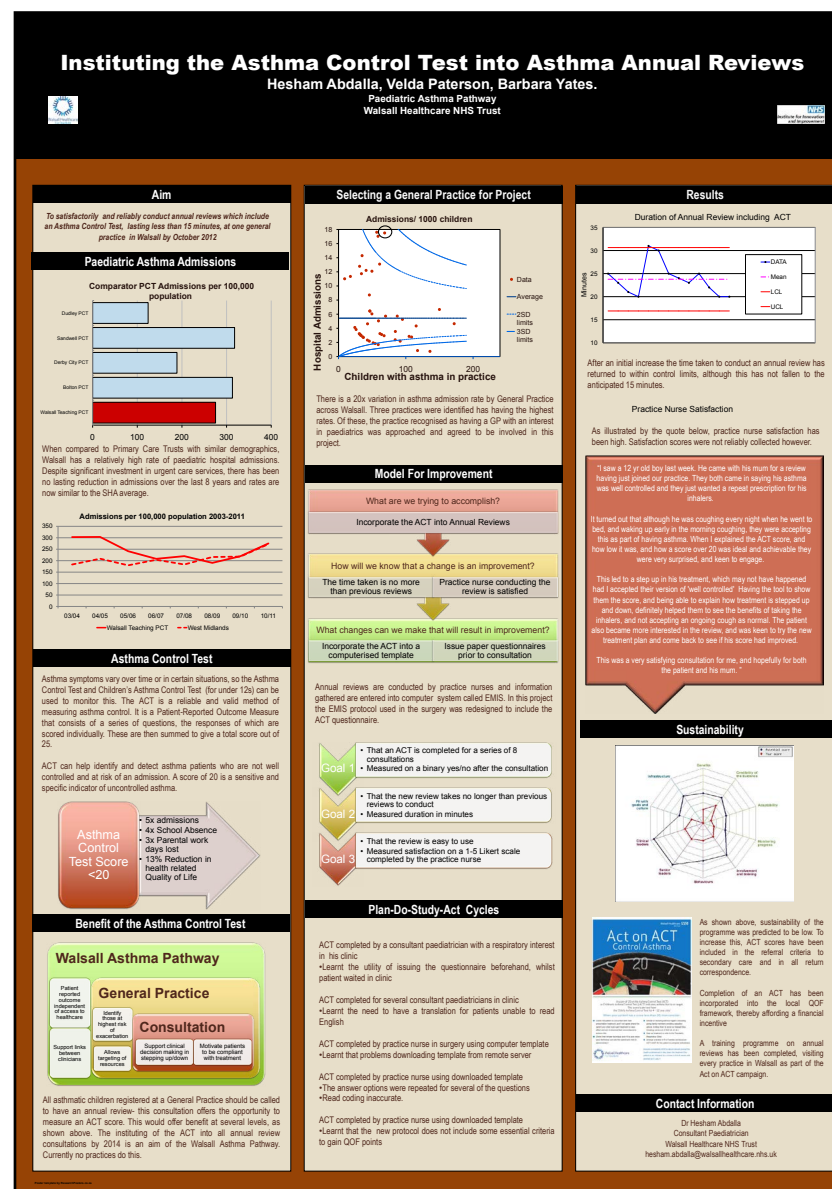
The Yorkshire and Humber asthma template, incorporating all QOF requirements, was developed to provide clinical advice and prompt healthcare professionals to ensure a gold standard asthma review was performed. Following a successful trial in eight general practices in 2011, this recording template was amended in 2012 and is now being introduced across the region, for use in consultations with children and young people. See annex C for some screen shots of the template.

## Walsall – supporting a GP practice in incorporating ACT into routine consultations in asthma

The paediatric department in Walsall undertook an exercise to encourage a general practice to use the asthma control test (ACT) in all consultations for asthma. ACT is similar to the RCP three questions, which is advocated in QOF, and which establishes to what extent asthma symptoms are impacting the life of the individual. Their poster, ACT on ACT, outlines the initiative, and presents a good example of encouraging uptake of good practice into clinical practice.

## The British Asthma Guideline defines controlled asthma as:

- No daytime symptoms
- No night-time waking due to asthma
- No need for 'rescue' medication
- No exacerbations (i.e. acute episodes)
- No limitations on activity, including exercise
- Normal lung function.





# 15

## Optimising medication

### Recommendations in clinical guidelines

- A step-wise approach to asthma medication is now well established, according to the degree of control of asthma, stepping up to the next step if the child or young person still has symptoms, and stepping down when control is achieved. The guideline indicates that the strength of the evidence varies by age, so clinicians need to follow recommendations in the separate charts for children under five, 5-12 and over 12
- Before initiating a new therapy, clinicians should recheck concordance, inhaler technique and eliminate trigger factors
- The delivery device of choice in the under fives is a pressurised metered dose inhaler (pMDI) with a spacer device
- Adolescents' preference for devices should be taken into account in selecting treatment for them
- Concordance with asthma treatment is particularly poor in adolescents – sometimes unintentionally, sometimes deliberately. And poor concordance may be linked to other risky behaviours such as use of tobacco, alcohol and drug use and also to depression
- Patients are more likely to under-use than over-use medication. Patient self-reporting and clinician assessment both overestimate regular use of prophylactic medication
- Frequent use of short acting bronchodilators and oral steroids is an indicator of poor control. Heavy or increasing use of short acting bronchodilators is associated with asthma death. Over-reliance on short acting bronchodilators is a particular issue in adolescents
- Inhaled steroids are the most effective preventer drugs for achieving overall treatment goals in both children and adults. They should be prescribed to any patient using their short acting bronchodilator treatment three times a week or more
- The dose of inhaled steroids used by children is lower than in adults to avoid systemic side effects. Growth of children on inhaled steroids should be monitored and recorded annually
- Inhaled steroids should be considered in any child over five who has had a course of steroid tablets in the previous two years
- Long-acting bronchodilators should not be prescribed without inhaled steroids for safety reasons following guidance from the MHRA in 2007. Combination products of inhaled steroids and long acting bronchodilators are therefore preferred for over fives with asthma (rather than using two separate inhalers) since they have safety benefits, and aid concordance
- Simple verbal and written instructions and information on drug treatment may help to improve concordance, and may be incorporated into a self-management plan.

## What the evidence tells us

- Pharmacological treatment is the mainstay of asthma management. Yet many clinicians are not following the stepwise asthma guidelines
- Regular use of low dose inhaled steroids is associated with a reduced risk of death from asthma<sup>46</sup>
- Poor concordance with treatment is a significant issue in asthma management, and concerns about the safety of treatment are often at the root of this. Children and their parents, and older children need help understanding that the benefits of medicines far outweigh the risks
- Poor concordance may be linked to suboptimal doctor parent/child communication, lack of opportunity to discuss side effects, fear of side effects such as weight gain, omission of shared decision making, and not feeling in control
- School age children may prefer to use a dry powder inhaler that can be carried in a pocket with no need to use a spacer device
- Poor inhaler technique is common and can lead to patients not getting the benefit they should from their medication. Inhalers should only be prescribed after a patient has received training in the use of that specific device, and inhaler technique should be checked and demonstrated as part of regular review
- Though it is critical that concordance with current treatment, inhaler technique and elimination of trigger factors are checked before any changes are made to treatment, this is generally not done systematically in practice.

## What does this mean for commissioners and service developers?

### Asthma Quality Standard

**Statement 4. People with asthma are given specific training and assessment in inhaler technique before starting any new inhaler treatment.**

**Commissioners should ensure that they audit whether inhaler technique is being checked routinely. NHS resource is often wasted on patients not being able to use their inhalers properly and not getting the benefit of prescribed medication.**

**The asthma quality standard from NICE reinforces this.**

- Practices can be asked to audit their asthma register to determine the number of prescriptions for short acting bronchodilators, since this is an indicator of poor control. Use of a short acting bronchodilator three times a week or more is an indication that treatment should be stepped up
- Prescribing records can be examined to ensure that no long acting bronchodilators are being prescribed without inhaled corticosteroids, following a review in 2007 by and safety advice from the Medicines and Healthcare products Regulatory Agency (MHRA)
- Prescribing records can be audited to check whether inhaled steroids have been tried on their own and whether control can be achieved, before stepping up to combination treatment, in line with guideline recommendations. Considerable savings may be possible by using inhaled steroids appropriately first
- All children under five using a metered dose inhaler should be using a spacer or facemask to deliver the medication. Prescribing records should be checked to ensure this is happening.



- Patient notes could be audited to see whether there has been any documented discussion of stepping down treatment
- The New Medicines Service (NMS) and MURs are both tools in the pharmacy contract (October 2011) that can help people get the best from their medicines, and improve adherence to medication. They are targeted to respiratory patients, and both pharmacists and general practices should see that these services are offered to their young patients with asthma
- Primary care arrangements for the supply of repeat asthma medications should be optimised, and every person encouraged to obtain repeat supplies when they start using their last full inhaler(s) so that exacerbations do not develop simply because of medication supply running out.

*We've had excellent support from an asthma nurse specialist and as a result Sion's asthma is under good control. Over the last few years he has also become an expert at managing his asthma and knows when he needs his inhalers and how to use them himself.*

**Mother of 10 year old**

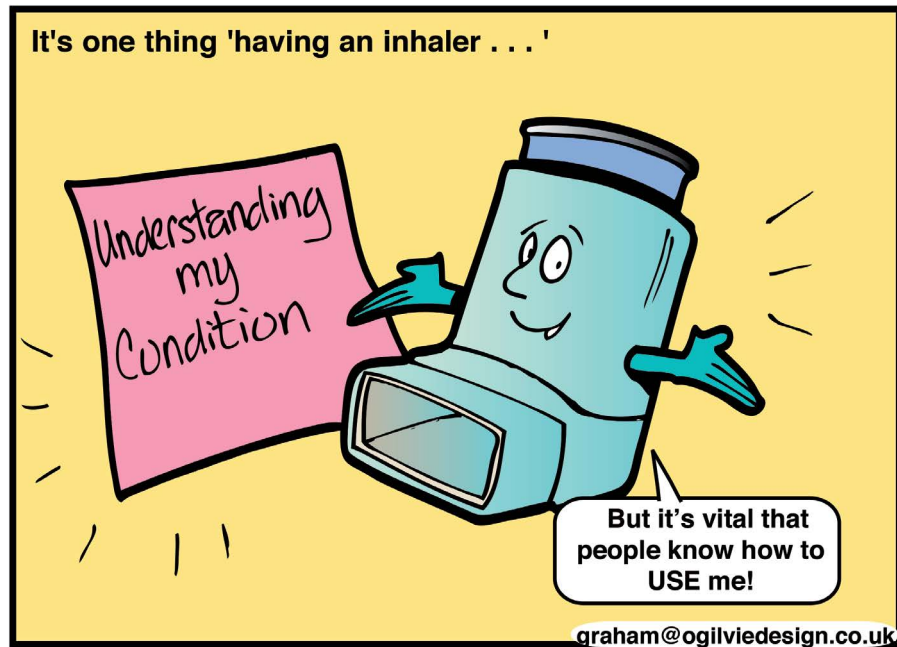
## **Examples of good practice**

### **Videos on teaching inhaler technique**

North West region - Ten PCTs in the North West were granted innovation funds to replicate and extend work done on inhaler technique training for community pharmacists, so they could support their patients in using a range of inhalers correctly. The result was a set of short videos demonstrating the correct use of nine different commonly used inhalers, using real doctors/nurses/pharmacists and real patients. These are publicly available on the internet for patients, have been made mandatory training for junior staff in at least one foundation trust, and training events have been held for GPs and practice nurses. This excellent resource provides consistent messages on inhaler technique and is freely available. <https://wessexhiecpartnership.org.uk/wires/video-series/inhaler-technique/>

### **Asthma UK and NHS Yorkshire and Humber – increasing inhaler technique checks**

A project to improve care in primary care involved five GP surgeries in Hull, Wakefield and Leeds and was undertaken jointly with Asthma UK over a 12-month period. They identified the number of children at risk at the start and undertook a structured review/consultation in line with an agreed specification. They completed 288 reviews and 19 follow-up reviews. A key outcome was that checks on inhaler technique increased from 49% to 91%.

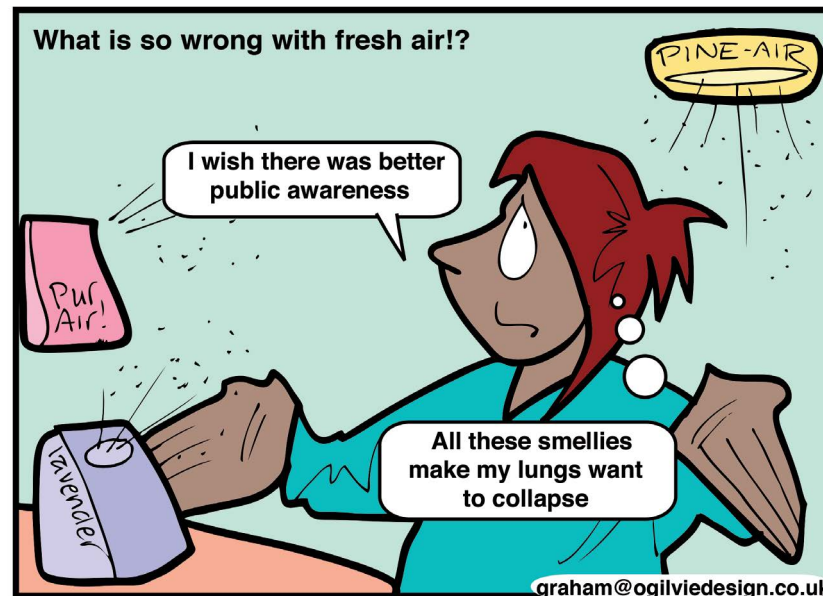


Screenshots taken from NW region inhaler technique videos – with thanks.

# 16 Allergy and asthma

## Recommendations in clinical guidelines

- A history of other atopic conditions such as eczema or allergic rhinitis increases the probability of asthma, as does a family history of allergic conditions. Having an early allergic reaction to allergens such as house dust mite, cat dander, egg white or wheat predicts later childhood asthma
- Failure to address a parent/child's or young person's concern about environmental triggers may compromise concordance with recommended therapy
- The evidence for removal of or avoidance of individual allergens to avoid symptoms is conflicting or weak, though avoidance of known allergens makes good sense for an individual.



## What the evidence tells us

- GPs often have poor understanding of allergy and their awareness of services is often patchy. This highlights the importance of improving knowledge among GPs to ensure that children and parents have access to appropriate services<sup>47</sup>
- When a child has food allergy as well as asthma, an allergic reaction is likely to be more serious, and may be life threatening<sup>48</sup>
- The East of England confidential enquiry into asthma deaths found that over five years, 13 of out of the 20 children that died from asthma were atopic (had allergies)<sup>49</sup>
- Several studies have shown that teenagers with allergies and asthma can feel 'different' and socially isolated. They report difficulties in transition to self-care, balancing restrictions with safety. Online chat sessions, virtual communities and supportive networks led by older teens and role models can help to reduce social isolation and restore more confidence and sense of normality.<sup>50,51,52,53</sup>

## What does this mean for commissioners and service developers?

The NHS has much neglected allergy services, in spite of growing prevalence of allergies and several high level reports from the Royal College of Physicians, House of Lords, and House of Commons between 2003 and 2010 highlighting that provision of appropriate services for people with allergies is insufficient.

Commissioners should ensure that people with allergies have access to multi-disciplinary allergy centres to address their complex needs and provide a one-stop shop, which include paediatricians, allergists, dermatologists, gastroenterologists, dieticians, and specialist allergy nurses.

Commissioners should ensure that primary care staff are trained to identify allergies and to refer to specialist services appropriately.

Commissioners should work with local authorities to develop appropriate links between healthcare and education, so that schools are able to support children with allergies.

## Examples of good practice

### Walsall – one-stop-shop paediatric asthma clinic and allergy clinic

These clinics are run simultaneously to provide a one-stop shop to meet all needs. A respiratory consultant, allergy consultant, asthma nurse, allergy nurse and dietician are all available at the same session, as well as access to diagnostic services such as skin prick testing, spirometry and FENO monitoring. This affords patients and their families a comprehensive assessment and the opportunity to have all their concerns addressed, without the need for repeat appointments. The clinic runs seamlessly and is highly acclaimed by patients, while reducing costs.

### Itchy Sneezy Wheezy in North West London

This is an initiative designed to improve the patient pathway for all children with allergic conditions by earlier recognition, accurate diagnosis and effective management. Both healthcare professionals and children and their families are involved, with educational material available for both, including the use of videos to help inform and instruct about allergic conditions. The appointment of allergy champions in care settings, locally adapted management guidelines and community support groups for parents and children in schools and early years settings are some of the measures designed to achieve their aims. <http://tinyurl.com/b7m4o4n>



## Recommendations in clinical guidelines

- The guidelines have little to say on the boundary between healthcare, and schools and childcare settings – except to review the literature on schools as a setting for healthcare delivery and asthma education
- Adolescents are poor attenders of clinical reviews and uptake of asthma reviews was improved from 51% attendance to 91% by holding reviews at a school based nurse-led clinic
- Asthma education in the school setting via peer led groups or web-based learning have been demonstrated to improve outcomes such as days missed from school, days with restricted activity and reduced hospitalisations
- Integration of school-based clinics with primary care services is essential.

## What is recommended in other guidelines/policy?

- A document published jointly by Department for Education and the Department of health in 2005 – Managing Medicines in Schools and Early-Years Settings – advises:  
'It is for local authorities, schools and governing bodies, settings and management groups to work out their own policies (on the management and administration of pupils' medicines) in the light of statutory responsibilities and their own assessment of local needs and resources.'

- It gives guidance on the roles and responsibilities of employers, parents and carers, governing bodies and management groups, head teachers and heads of settings, teachers and other staff, and of local health services. It considers staffing issues including employment of staff, insurance and training. Other issues covered include drawing up a health care plan for a pupil, confidentiality, record keeping, the storage, access and disposal of medicines, home to school transport, and on-site and off-site activities. The document also contains a set of forms, which can be photocopied by users to ensure proper processes are in place around storage and administration of medicines, for example
- Medical Conditions at School: A Policy Resource Pack followed from the Medical Conditions at School Group in 2007 to complement the department guidance. This group is an alliance of third sector medical charities, including Asthma UK who worked alongside the Long Term Medical Conditions Alliance to develop this pack. This document aims to set out best practice in supporting children who may need support in the school environment, across health and education
- Countries such as Australia and New Zealand have well-established national programmes, which ensure that schools can deliver appropriate first aid and emergency response to students with asthma.<sup>54</sup>

## What the evidence tells us

- Other countries and many parts of England have developed local initiatives in an attempt to ensure that schools within an area are equipped to support students with asthma. This has included training the staff in understanding asthma and how to recognise an emergency, developing an asthma policy for the school and how to support children with self-management, and policies on children's access to medication
- The proportion of schools with asthma policies varies from 25% to 33%, though a higher percentage have procedures for the use of medicines<sup>55,56</sup>
- An asthma policy may specify how children have access to inhalers and where they are kept. Department of Health/ Department for Education policy advises that children should have immediate access to their inhalers when they need them, and should carry their own inhaler wherever possible. Some schools are keeping inhalers locked away, with potential difficulties for a child to access them in an emergency<sup>57</sup>
- A survey of schools in one region found that there was a designated member of staff responsible for children with asthma in 54.2% schools (out of 203) and in 37.9% schools had an asthma policy in place. Schools were less likely to have received asthma training if there was no designated person responsible for pupils with asthma<sup>58</sup>
- Schools are interested in having more support for training of staff and more support to help children with asthma<sup>59</sup>
- Primary schools are proposed as a setting for reducing asthma morbidity and to promote the health and psychosocial wellbeing of students with asthma. This follows a project involving 33 schools, which found that nurse-led intervention in schools resulted in reduced need for medication and higher self esteem in the children with asthma<sup>60</sup>
- School-based education for children with asthma can improve knowledge of asthma, self-efficacy and self-management behaviours, and may reduce days lost from school.<sup>61,62</sup>

### **What this means for commissioners and service developers**

- There is an important opportunity for commissioners and service developers to work with local authorities to ensure that children with asthma are supported in the school environment and childcare settings. Cross-boundary working between clinicians, service managers, school nurses, and education will be essential to ensure success, and the involvement of parents and young people with asthma should be a core component
- Providing school nurses with asthma training is vital if they are to support teaching staff in understanding asthma and creating a supportive environment in schools. Specialist respiratory paediatric nurses in hospitals can play an important role in driving best practice and raising standards of care and in bridging healthcare and education
- The Department of Health and Local Government Association have published a briefing on school health services for the lead member for children's services in local authorities, which sets out how school health services can be used to deliver better outcomes for 5-19 year olds<sup>63</sup>
- Commissioners and service developers should work with local authority colleagues to establish the current status in schools regarding asthma registers, school asthma policies, staff training about asthma, individual healthcare plans for children with asthma, procedures for emergencies, children's access to medicines and recording days lost from school due to asthma. This is key if children with asthma are to be safe in the school environment and able to achieve their potential by participating fully in school life
- Commissioners should work with local authorities to set up a system to record school absence due to asthma if there is no system in place.

### **Examples of good practice**

#### **North West – training 500 school nurses in asthma care**

The North West has had, over the last few years, several children die from asthma, including Sam Linton, who died aged 11 following an asthma attack at school. The enquiry into his death highlighted that there was a relative lack of knowledge about asthma among teachers. The NW respiratory team set out to train all school nurses about asthma so they were equipped and committed to passing on that knowledge to teachers and other school staff. They created a programme on a 'train the trainer' basis, focused on keeping a register of children with asthma, recognition of asthma symptoms, and appreciation of what action needs to be taken when asthma worsens. By April 2013, 94% of school nurses had received the Wize up to Wheezing training.

#### **USA national asthma education and prevention programme**

In USA the Healthy People 2010 initiative has identified asthma as a priority area and has set eight national goals including reducing deaths, hospitalisations, activity limitations and school or work days lost. This operates alongside a national asthma education and prevention programme. They believe schools can make an active contribution in reaching those goals by establishing policies and programmes that create a safe and supportive environment for students with asthma. A checklist – How asthma friendly is your school? – helps schools to benchmark themselves in terms of the support they are providing to children and young people.<sup>64,65</sup>



## **Medical Needs in Schools and Early Years Service (MNISEYS) Birmingham**

Birmingham has approximately 800 schools and early years settings. The MNISEYS provides continual training, advice and support on the most common chronic medical conditions of childhood to all staff working in schools and early years settings. The service works in partnership with lead clinicians in both primary and secondary care, in developing local asthma guidance to support the delivery of training to teaching staff. Guidance includes an asthma attack flow chart and a framework for developing an asthma policy, and schools and early years settings are encouraged to develop medication, asthma and emergency aid policies, and management and care plans. The service works collaboratively with other key local agencies including the ambulance service, the lead community pharmacist and a local children's asthma charity.

## **Two in every classroom – Scotland**

Asthma UK Scotland has developed a free online resource for teachers called Two in Every Classroom. The resource helps schools use asthma as the context for learning across the curriculum in a range of subjects from numeracy and English to sciences and religious and moral education, helping to raise the profile of asthma among children and teachers. For every subject it provides the basic information teachers may need to deliver a lesson, ideas for lesson plans, the curriculum areas these plans cover and possible learning intentions for pupils. The resource is available at <http://tinyurl.com/mufax9a>

## **Alert to Asthma in Scotland**

Asthma UK Scotland was funded to deliver Alert to Asthma awareness sessions covering 25% of schools in Scotland and a programme of peer support to school students. The evaluation indicated greatly increased awareness and confidence in managing an asthma attack among school staff and an increase in the likelihood of improved self-management among school students.

## **Other resources:**

Managing medicines in schools and early years settings DfE/DH 2005 <http://tinyurl.com/mnz6yag>

Medical conditions at school 2007  
<http://tinyurl.com/n96jyjj>

Briefing for Leads for children's services on using School health service to support health of children in schools  
<http://tinyurl.com/k9hze2g>

Managing asthma in a school environment – US website and resources <http://tinyurl.com/k6jtt9g>

# 18 Asthma in adolescents and transition to adult services

## Recommendations in clinical guidelines

- Adolescence is a transitional time of growth and development during which two key principles should operate in healthcare:
- Seeing them on their own without a parent or other adult for at least part of the consultation
- Discussing confidentiality and its limitations.
- Asthma in adolescence is associated with an increased likelihood of major depression, panic attacks and anxiety disorder, which in turn is associated with increased asthma symptom burden
- Non-adherence to medication regimes has been linked to other health risk behaviours including tobacco, alcohol and drug use and also to depression
- Transition from paediatric to adult services should be seen as a process not an event. It should be a planned, co-ordinated process, involving the young person and parent, multi-disciplinary and multi-agency involving both the adult chest team and paediatrics. Support for parents is important as they gradually pass responsibility for their asthma to the young person
- Adolescents should be respected and motivated to take responsibility for themselves, and education and support tailored to their individual needs
- There is a whole section of the guideline devoted to the management of asthma in adolescents.

## What the evidence tells us

- The barriers to adolescents managing illness include: socio-demographic characteristics, medication adherence, psychosocial barriers, and parental involvement<sup>66</sup>
- Poorly planned transition can be associated with increased risk of non-adherence to treatment and lack of follow up with potentially adverse consequences in morbidity and mortality, as well as social and educational outcomes<sup>67</sup>
- Adolescents have been a neglected group in healthcare because paediatricians have traditionally focused their attention on infants and the under 3s.<sup>68</sup> However, the National Service Framework for Children and Young People (DH, 2004) was clear that paediatric services should retain responsibility for people up to the age of 18
- Poor communication and an absence of a designated professional to support the transition are barriers to an effective process<sup>69</sup>
- Smoking of tobacco and other substances are a particular concern in young people with asthma. Young people with asthma need specific advice on the increased impact of smoking upon their particular condition, since cigarette smoking actually reduces the effectiveness of inhaled steroids (preventer medication)
- Young people with asthma are likely to be exposed to passive smoke and are more likely to take up smoking than their peers<sup>70</sup>
- There are particular risks associated with smoking cannabis for people with a lung condition. The British Lung Foundation produced a special report on the subject and outlined all the recent evidence of harm<sup>71</sup>

- The combination of non-compliance with treatment regimes and the addition of smoking can be a potentially dangerous mix for young people with asthma and despite rigorous health education campaigns a growing number of young people with asthma continue to smoke.

## What does this mean for commissioners and service developers?

- Commissioners should require acute providers – both paediatric departments and adult respiratory departments – to demonstrate they have a structured programme of transition in place which will be used for adolescents with asthma when they are ready – in which supporting self-management is a core part of the process. This should start early in the teens, but progress gradually in line with the readiness of the adolescent to become more independent
- Commissioners should ensure that the young person is an active participant in the transition process, and the timing and content are tailored to the needs of the individual
- Commissioners should ensure that parents' needs and concerns are taken into account in the transition process, as they relinquish control to the young person
- Commissioners may wish to trial and champion the use of novel approaches in communicating with teenagers. For example:
  - Text messaging teenagers to encourage compliance with medication
  - Use of lay (non clinical) educators and peer educators

- Buddy systems, whereby older children take a friend to consultations to better understand their asthma
- Use of group education – possibly online
- Innovative approaches to structured reviews including holding reviews at schools with school nurses/practice nurses/community children's nurses and telephone review with specialist respiratory nurses
- There are also a number of free apps that encourage self management through simple reward systems.
- Commissioners should ensure there are appropriate and accessible services to encourage young people with asthma who smoke to quit.

## Examples of good practice

### The adolescent health programme for teens

The Royal College of Paediatrics and Child health has an online module specifically on adolescents and health for healthcare professionals – the Adolescent Health Programme <http://tinyurl.com/mujf424>

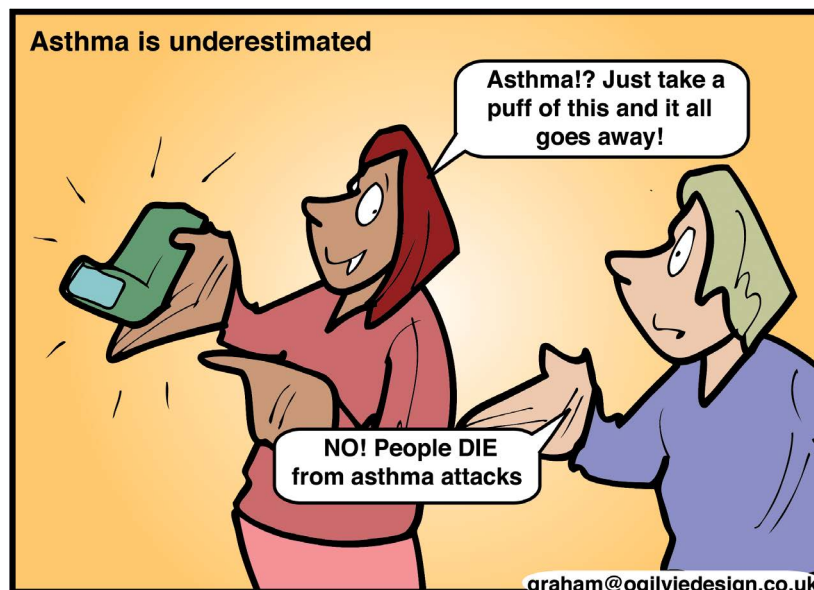
### Big Up Your Chest

This is Asthma UK's online community of 16-25 year olds, which seeks to provide asthma advice, a place for young people to communicate with others with asthma. Some 56% of people surveyed said their asthma had improved since joining the Facebook group. It allows for directly targeted information to be shared with a captive audience and this greatly improves the message reach, with over 3,000 people being reached weekly with asthma management tips and advice.

# 19 Risk assessment and at-risk registers

## Recommendations in clinical guidelines

- Patients with poor lung function and a history of exacerbations in the previous year may be at greater risk of future exacerbations, so may need more frequent monitoring than an annual review
- Specifically identifying patients with high-risk asthma (eg those with frequent admissions) in an effort to target more detailed input is logical, but supported by limited evidence
- Non-adherence to medication in adolescents has been linked to other health risk behaviours including tobacco, alcohol and drug use and also to depression
- Lower socioeconomic status and being from an ethnic minority is associated with adverse asthma outcomes.

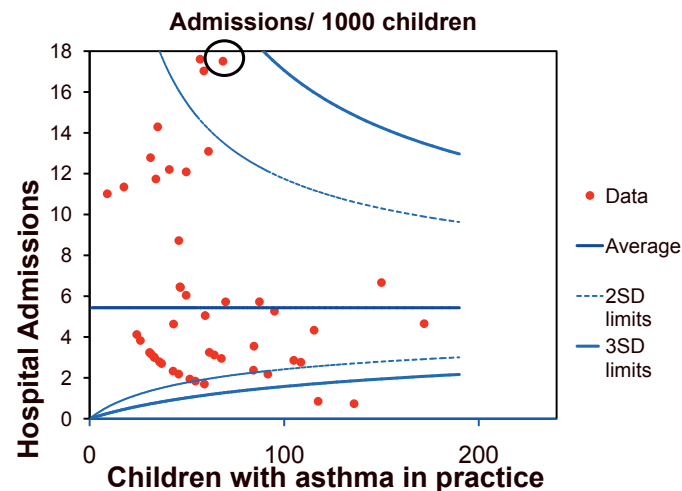


## What the evidence tells us

- A Cochrane review found that educational input for children who have attended an emergency department lowers the risk of the need for future emergency department visits and hospital admissions<sup>72</sup>
- Self management and educational programmes are even more cost effective if targeted at high risk groups and patients with severe asthma<sup>73</sup>
- Adolescents with asthma may be more likely to experience psychological distress than those without asthma<sup>74</sup>
- The NHS has developed a range of tools to help to profile people with long-term conditions according to their risk status. These enable a greater focus on those most at risk, so that resources and interventions can be targeted to them accordingly.<sup>75</sup>

## What does this mean for commissioners and service developers?

- Patients at risk of future exacerbations should be put onto a high-risk register and offered more frequent reviews and encouraged to attend. This includes those with poor lung function, a history of exacerbations or course of oral steroids in the previous six months, using a bronchodilator more than five times a day, concomitant allergic rhinitis, food allergy or psychosocial problems
- Commissioners can expect practices to have identified their high-risk asthma patients. Those who have had an attack in the previous 12 months are likely to cost 3.5 times as much as someone who has not had an asthma attack.<sup>76</sup>



## Examples of good practice

### Triple A test: Avoid asthma attacks

Asthma UK has developed the Triple A asthma test – an online test that people with asthma can take to check whether they are at risk of an asthma attack. By answering just eight questions about their medication, other conditions, and recent asthma control, their risk of an asthma attack is assessed and they are advised whether there is any action they should take. Asthma UK is collecting the data from this test and will be publishing the results and undertaking further work to develop a validated risk-assessment tool tailored for commissioners, clinicians and people with asthma. <http://tinyurl.com/n5h7mly>

### Walsall risk management in primary care

A retrospective review identified the general practices that had the highest number of hospital admissions with asthma exacerbations the preceding year. The paediatrician, asthma specialist nurse, lead GP and practice nurse conducted a review of the primary and secondary care notes of those patients to identify the reasons for the admissions and what could be done to protect these children from further admissions. As well as improving the management of these individual patients, an unanticipated benefit of this exercise was mutual learning by the clinicians involved of how to improve communication and a deeper understanding of their respective roles. There was also identification of system failures that local commissioners and managers could address.

# 20

## Severe/difficult-to-control asthma

### Recommendations in clinical guidelines

The guideline does not cover severe asthma specifically in children and young people but general points about severe asthma are as follows:

- The guideline defines difficult asthma as persistent symptoms and/or frequent exacerbations despite treatment at step four or five of the treatment pathway
- Patients need a dedicated multidisciplinary difficult asthma service, by a team experienced in the assessment and management of difficult asthma
- Patients with severe asthma or who have had near-fatal asthma should be under specialist supervision indefinitely
- Poor adherence, psychosocial factors and concomitant conditions are associated with difficult asthma, so a comprehensive approach to assessment, diagnosis and management is key. Children with severe asthma may also have behavioural difficulties
- Patients with difficult asthma should be systematically evaluated – to confirm diagnosis, to identify the mechanism of persisting symptoms and assessment of adherence.

### What the evidence tells us

- It has been estimated that these patients may comprise 5-10% of the asthma population (all ages) and be responsible for 50-80% of asthma expenditure<sup>77,78</sup>
- There are considerable issues around protecting and supporting children and young people with severe asthma. Schools often do not recognise the special needs of this group because asthma can be on a continuum from mild to severe. They do not have policies in place that would ensure the children with more severe asthma are able to manage their asthma effectively and can take an active part in school life<sup>79</sup>
- School nursing services are not uniformly available and too many areas lack the leadership that school nurses can provide in putting appropriate policies in place for children at the more severe end of the spectrum and providing training for staff in schools<sup>80</sup>
- Children requiring treatment in paediatric intensive care often have additional complications on intubation; so early effective management of acute episodes in these children is key to avoid risks associated with intubation<sup>81</sup>
- Research with patients has identified considerable demand for peer support for severe asthma and that peer support can improve quality of life outcomes and concordance.<sup>82,83</sup>



## What does this mean for commissioners and service developers?

**The NICE Quality Standard for asthma includes the following statement about providing for people with difficult asthma.**

**Statement 11. People with difficult asthma are offered an assessment by a multidisciplinary difficult asthma service.**

- Children and young people with severe asthma will comprise a small part of the overall asthma population, but they will be large consumers of NHS resource, so warrant attention by commissioners to ensure that holistic, effective services are available
- Commissioners should ensure that services are available in their area for those with difficult asthma, as this has traditionally been a very poorly served subgroup of the asthma population. Special clinics for this group are available in all parts of the country and commissioners should ensure that all appropriate children have access. NHS England has drafted a service specification for a specialised service for children and young people with complex respiratory problems, which includes difficult/severe asthma<sup>84</sup>
- Such services need to have specialist diagnostic and monitoring methods available in order that treatment is finely tailored to the individual needs of children and young people. They should also offer treatment and support from psychologists, dieticians, and physiotherapists as well as specialist doctors and nurses in paediatric respiratory disease and allergy

- Commissioners should ensure that ambulances and emergency departments have staff trained to assess and treat young people attending with severe asthma. It is also important that these services have good links with paediatric and respiratory departments within their trust for expert advice in resolving acute asthma exacerbations
- Commissioners should ensure that newer treatments are available for people with severe asthma, who form a very small percentage of all people with asthma. NICE has issued guidance on omalizumab (from age six) and bronchial thermoplasty, which would both be indicated for initiation by specialist severe asthma clinics for appropriate patients. New biologics are also becoming available and would be trialled by these centres
- There is an important opportunity for commissioners and service developers to work with local authorities to ensure that children with severe and difficult-to-control asthma are supported in the school environment and childcare settings. Cross boundary working between clinicians, service managers, school nurses, and education will be essential to ensure success, and the involvement of parents and young people with asthma should be a core component
- Young people with severe asthma may benefit from provision of peer support services.



## Recommendations in clinical guidelines

- Guidance on management of acute asthma in children and young people is divided by age into guidance for children over two and under two
- Adolescents and young adults make more frequent use of emergency services than other groups
- Emergency units dealing with children with acute attacks should have staff available at all times who are trained in and familiar with the specific needs of children
- Structured care protocols to manage acute events have been shown to reduce hospital stay
- Sub optimal control of asthma leading to exacerbation is more expensive to manage than well controlled asthma
- Assess accurately the severity of the symptoms
- Inhaled short-acting beta agonists are the first line of treatment for acute asthma and they are best delivered by a metered dose inhaler and a spacer, not nebuliser unless the asthma is severe and life threatening
- Oral or IV steroids should be given early in the treatment of acute asthma
- The guideline provides clear guidance for the assessment and treatment of acute asthma in children in general practice, the accident and emergency department and in hospital (see annexes 5- 8 of the British asthma guideline). Guidelines also mention that if clinical staff fail to assess severity of an acute exacerbation by objective measurement and underuse of corticosteroids it can lead to poor outcomes including avoidable deaths.

## What the evidence tells us

- Asthma is a leading cause of admission to hospital in children. More than two out of five hospital admissions for asthma in 2004 were for children aged 15 years or under, and on average, every 18 minutes a child with asthma is admitted into hospital needing emergency hospital care to help them breathe.<sup>85</sup>
- Most admissions for asthma are emergency admissions and up to 70% may have been preventable<sup>86</sup>
- There is enormous variation in the rate of admissions for asthma in young people. Across the country there is a 19-fold variation between PCTs as illustrated in the Respiratory Atlas of Variation<sup>87</sup>
- Most children admitted for asthma are five or under and average length of stay across all ages is a day or less<sup>88</sup>
- Most children are receiving care in line with the British asthma guideline, though only 82% receive corticosteroids, as recommended<sup>89</sup>
- Discharge planning was highlighted as an area of significant weakness, with fewer than 50% of young people having inhaler technique checked and having a written discharge plan before discharge<sup>90</sup>
- Roughly half of all children admitted for asthma report never having received a personalised asthma plan even though there is grade A evidence that they improve outcomes.<sup>91</sup> The British asthma guideline is clear that a hospital admission represents an opportunity to review self-management skills

- Hospital-based education delivered by trained paediatric respiratory nurses can deliver improvements in environmental control in the home and in symptoms and lung function in children with moderate to severe asthma<sup>92</sup>
- An earlier audit highlighted that children admitted under the care of a respiratory specialist were more likely to have been given written asthma information and a written asthma plan and had their inhaler device technique checked, than if under the care of a general paediatrician<sup>93</sup>
- Use of care pathways in emergency care for asthma has been shown to improve outcomes such as reducing length of stay and optimise asthma care<sup>94,95</sup>
- Too many children are still being x-rayed on admission, though there is little support in the guidelines for this.<sup>96</sup>

*I hate my asthma. It's the worst thing in the world. I don't like going into hospital as I'm scared that like people on the TV I will die there.*

**Lloyd, 12 years old**

## What does this mean for commissioners and service developers?

- Reducing unplanned hospital admissions for children and young people under 19 for asthma is a national quality indicator in the CCG outcomes indicator set for 2013/14

**Several statements in the NICE Quality Standard for asthma are relevant to the management of children and young people being treated for acute episodes**

**Statement 6. People with asthma who present with respiratory symptoms receive an assessment of their asthma control.**

**Statement 7. People with asthma who present with an exacerbation of their symptoms receive an objective measurement of severity at the time of presentation.**

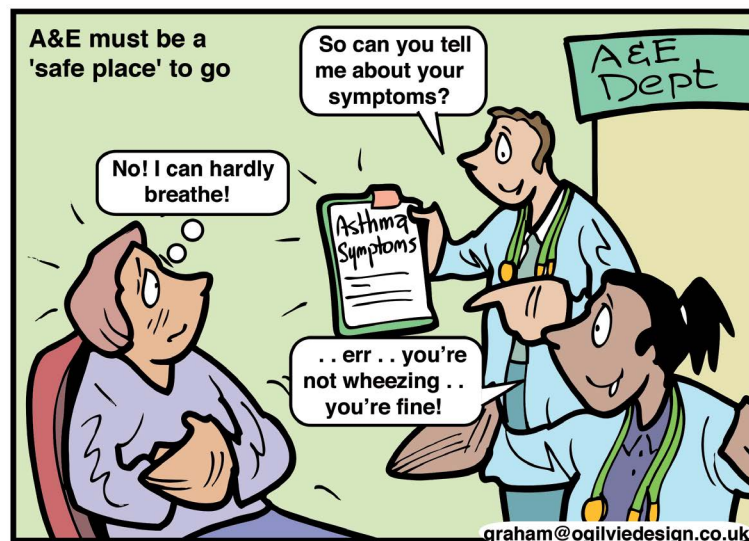
**Statement 8. People aged five years or older presenting to a healthcare professional with a severe or life-threatening acute exacerbation of asthma receive oral or intravenous steroids within one hour of presentation.**

**Statement 9. People admitted to hospital with an acute exacerbation of asthma have a structured review by a member of a specialist respiratory team before discharge.**

- The Respiratory Atlas of Variation recommends that commissioners investigate and understand the cause of rising emergency admissions and variation with other areas
- Acute attendances and admissions may have their roots in prior care in the community and in patient self-management, so a system-wide approach will be needed to address poor control

- Nurses play an important role in managing children with asthma in the acute sector. Specialist respiratory paediatric nurses often manage the relationship with families and individual young people, play a crucial role in patient and family education, and may be a key influencer of any work with school nurses to improve asthma care in schools
- Ambulance staff may be the first healthcare professionals that people will encounter in an emergency. They need to have the right skills and training to provide support before patients can reach more specialist treatment.
- Commissioners should ensure that all NHS staff involved with young people experiencing an exacerbation have appropriate training in arranging rapid assessment, including receptionists, in all healthcare settings, which patients may attend in an emergency

- Staff in out-of-hours and walk-in centres need to be as well trained as in all other settings and in particular need to have close communication with primary care to ensure prompt and appropriate follow-up after the episode. It is particularly important that out-of-hours services are aware of people at greatest risk of having an attack, are knowledgeable and competent in dealing with them
- Where nebulisers are appropriate to deliver medication in an exacerbation, these should be oxygen-driven rather than air-driven, and commissioners should check which are being used locally
- Commissioners should consider setting up a CQUIN for acute asthma care to encourage adherence to best practice guidelines.



## Examples of good practice

### Development of a secondary care service specification – Yorkshire and Humber

Developing a specification for children's asthma across the whole region was an important step in the process of improving secondary care asthma services. The service specification was completed in February 2012 after the active involvement of key clinicians and commissioners. It was promoted and trialled in 2012/13 with full implementation planned for 2013/14. It will form part of an integrated care pathway with primary care.

*My asthma is very hard to control and can get me quite worked up. When it's bad I can't breathe properly and I feel really frightened.*

**Millie, 12 years old**

*Chloe's asthma is so severe that she has to be admitted to hospital every couple of months, but I feel that clinic and hospital staff don't take her condition seriously enough. I've also been told different things by different doctors about Chloe's medication which can be very confusing.*

**Mother of 9 year old**

*What's so frightening about my son's asthma is how suddenly it comes on and how quickly he deteriorates. We know we have to get him to hospital as soon as his chest starts to tighten. We just try to make sure that when he does have an asthma attack, we can get him the assistance he needs to stay alive.*

**Sue, mother of 12 year old**

# 22 Avoiding hospital admissions and emergency department attendances

## Recommendations in clinical guidelines

- Most attacks of asthma severe enough to require hospital admission develop relatively slowly over a period of six hours or more. There is therefore time for effective action to reduce the number of attacks requiring hospitalisation
- Asthma action plans can decrease hospitalisation for and deaths from asthma
- Before discharge, trained staff should educate about asthma. This should include inhaler technique, a symptom and peak flow based action plan, which allows the child/parent or young person to adjust their medication within recommendations. These measures have been shown to reduce morbidity after exacerbation and reduce relapse rates
- Steroids reduce mortality, relapses, subsequent hospital admissions and requirement for Beta-2 agonist therapy. The earlier they are given in an acute attack the better the outcome
- A register of patients at risk may help primary care health professionals to identify patients who are more likely to die from their asthma, and therefore such a register may also help to identify those most likely to require emergency hospital care.

## What the evidence tells us

- Educational intervention for children who have attended the emergency department for asthma lowers the risk of the need for future emergency department visits and hospital admissions. A Cochrane review looked at studies which compared usual care for asthma to more intensive educational programmes and the results showed a statistically significant reduction in the treatment groups needing subsequent emergency department visits or hospital admissions<sup>97</sup>
- One study found that clinicians, children and their parents had different perceptions about the preventability of attacks leading to hospitalisation. Researchers concluded that lack of understanding by parents and children of asthma and medications, the need for follow-up care and importance of avoiding known triggers, resulted in admissions<sup>98</sup>
- Emergency departments use a range of strategies to manage asthma in children. Pre-printed order sheets and access to paediatricians are associated with important reductions in return-visit rates within 72 hours<sup>99</sup>
- Discharge planning has been highlighted consistently in the BTS paediatric asthma audit as an area of significant weakness, with fewer than 50% of young people having inhaler technique checked and having a written discharge plan before discharge<sup>100</sup>
- Children who do not have a primary care doctor have poor outcomes following an admission and are more likely to have a repeat admission<sup>101</sup>
- Follow-up after an acute admission, which is important to prevent future readmissions, is a significant area of weakness in asthma management. (See next chapter)

## What does this mean for commissioners and service developers?

- Since it is usually possible to identify deterioration in symptoms before this happens and
- Acute attendances and admissions may have their roots in prior care in the community and in patient self-management, so a system-wide approach will be needed to improve control and reduce hospital attendances and admissions. Better integration across all sectors of healthcare, could mean that resources can be used more efficiently
- Since it is usually possible to identify deterioration in symptoms before this happens and so prevent emergency department attendances and admissions, commissioners are encouraged to focus on initiatives that will help to prevent admissions
- Commissioners should work with general practices to identify the children and young people who have attended once or more in previous 12 months as at-risk patients (see chapter x). This creates the opportunity to:
  - Review these patients' management in detail
  - Support them and their parents in their understanding of how deterioration happened
  - Put written asthma management plans in place
  - Give patients/parents a number to call in event that symptoms deteriorate for urgent advice
  - Ensure practices give priority appointments to these patients when they seek a consultation

- Alert ambulances to these patients to explore whether a member of the community team can attend
- Recall such patients for review in primary care more frequently than annually, and see them in their home if necessary.

Commissioners should consider building into contracts with paediatric departments that they train staff in emergency departments to incorporate into their protocol the elements of asthma care shown to reduce repeat attendances, such as checking inhaler technique, patient education and development of self management plans

- Commissioners should expect to see links between paediatric acute units and smoking cessation services, so that parents who smoke and have children with asthma are referred to a smoking cessation service to be supported to quit
- Commissioners should require emergency departments to audit the extent to which they are delivering care in line with the British asthma guideline, and to compare their care with the British Thoracic Society acute paediatric asthma audit
- Commissioners should consider introducing a CQUIN for acute asthma care to encourage adherence to best practice guidelines
- Commissioners should consider commissioning an integrated care pathway to ensure good communication and co-ordination across the health economy.



## Improving outcomes in asthma by Commissioning Quality and Innovation

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## Introduction to Care Quality and Innovation (CQUIN)

The Childhood Asthma CQUIN payment framework enables commissioners to reward excellence, by linking a proportion of healthcare providers' income to the achievement of local quality improvement goals. Since the first year of the CQUIN framework (2009/10), many CQUIN schemes have been developed and agreed.

## Background

Pennine Acute Hospitals' catchment population has had higher than national average of asthma attendances to primary care and the emergency department.

The main objective of the CQUIN was to reduce admission rates and improve patient experience.

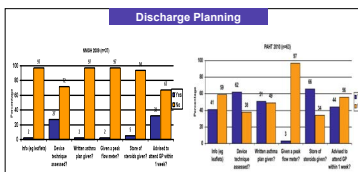
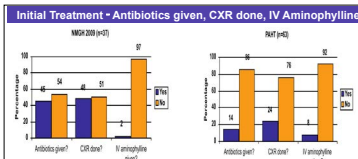
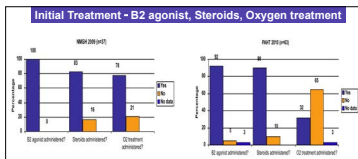
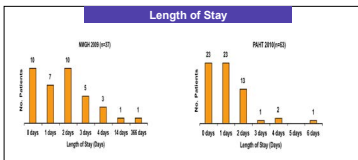
### Clinical Setting

Initial audit results in November 2009 identified suboptimal performance in number of CXR's, antibiotic use, asthma education, discharge planning and the early use of oral steroids.

Following the CQUIN, a team was formed to address the issues raised and a robust strategy was developed and the outcomes were evaluated by a repeat BTS audit in November 2010 across the trust.

## Interventions

- Development of robust trust guidelines adapted from BTS 2008/09 Asthma guidelines
- Four nurses enrolled for Diploma in asthma management, and to lead the change
- Robust education programme for all frontline medical staff looking after children in A&E and Paediatrics
- Seamless Integrated Care Pathway from point of first contact to discharge
- Strong focus on discharge planning to prevent readmissions
- Drive towards good clinical practice mainly in relation to reduction of CXRs, antibiotic usage and better prescription practice



CQUIN Outcomes to be achieved	Results
All patients have their Heart Rate and Respiratory Rate recorded on admission/initial assessment	100%
75% of patients receive oral steroids within an hour of diagnosis	95%
All patients have had their inhaler technique is checked by a trained health care professional.	62%
All patients have a written asthma plan on discharge	51%
All junior doctors receive training in childhood asthma	78%
All patients will have their oxygen saturation measured on admission/initial assessment	100%
If a spacer was given, was it prescribed?	50%
Oxygen prescription in drug cardex	23%
Documentation of review of preventive treatment	90%

## Summary Statement

Focused education to patients, parents and clinical personnel improves outcomes

Integrated Care Pathway standardises care and improves patient experience

Actions taken to improve on areas of suboptimal performance are new drug cardex to include Oxygen prescriptions and delivery devices

CQUIN schemes reward excellence and improve outcomes

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The Pennine Acute Hospitals   
NHS Trust

## Examples of good practice

## CQUIN for children's asthma

The North West region has developed a CQUIN for paediatric asthma, which shows the key points defining good practice in dealing with an asthma attack in a child. Included in these points is the development of a written asthma plan on discharge. See its poster <http://tinyurl.com/a8pdxep> (Also in annex B)

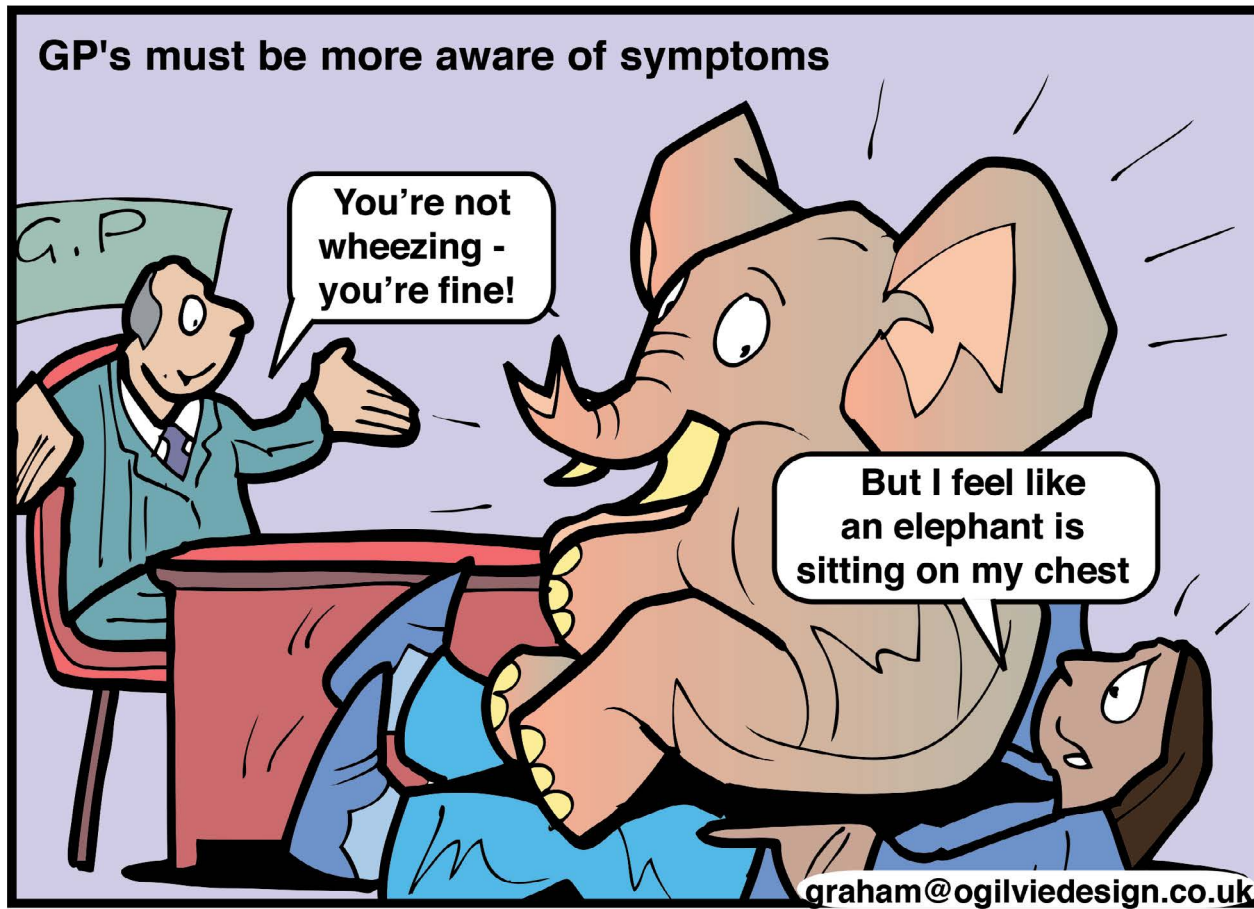
**NHS Ealing**

Asthma UK worked with NHS Ealing to reduce children's asthma admissions and improve the quality of support children with asthma and their families received. A children's asthma specialist nurse worked closely with schools, healthcare professionals and families and communities to provide education, support and training. After a year, more than 2,000 school and early years staff had been provided with asthma training, nearly a quarter of schools had a asthma friendly school asthma policy, 40 parent sessions had been held at school, training sessions had been conducted in 15 surgeries and over 250 children had been referred to the nurse. Children's asthma admissions went down 10% and NHS Ealing estimated it had saved around £51,000 as a result.

## Smoking cessation pathway for parents in Walsall

When children attend the paediatric assessment unit for an asthma attack, parents are asked if they smoke. Those that do are informed that second-hand smoke can provoke asthma attacks and are offered a referral to a smoking cessation team. Eighty percent of parents have been receptive to this advice. Paediatric assessment unit staff have been trained to give this brief advice and arrange referral. This service is now being developed so that a smoking cessation clinic will be run from the paediatric ward three days a week, so that receptive parents can act on this as soon as their child has been discharged.





# 23

## Following up acute episodes

### What is recommended in clinical guidelines

- Follow up in primary care within 48 hours should be arranged as part of the discharge process. This is now a priority for implementation since its inclusion in the NICE quality standard for asthma. Ideally this should be arranged before discharge, since this improves follow-up rates – and checked with the patient/parent and the general practice to see that it takes place
- Follow-up in a paediatric asthma clinic within one to two months should be arranged
- Review within 30 days after hospital attendance with acute asthma is associated with reduced risk of further acute episodes
- A careful history should elicit the reasons for the exacerbation and explore possible actions the patient could take to prevent future emergency attendances. Inhaler technique should be checked and corrected and the importance of adherence to prescribed medication discussed. Medication should be optimised and the patient provided with an asthma action plan aimed at recognising their asthma is worsening, preventing relapse, optimising treatment and preventing delay in seeking assistance in the future.

### What the evidence tells us

- Follow-up is poorly implemented, with many primary care clinicians not knowing that a child has had an episode treated as an emergency. And even if follow-up is planned, this is not chased - and followed through with the young person/parent<sup>102</sup>
- Scheduling an appointment after an emergency department visit for a follow up in primary care – and checking to see that the child was going to attend increased the likelihood that urban children with asthma would follow up<sup>103</sup>
- Provision of a written action plan significantly increased patient adherence to inhaled and oral corticosteroids and asthma control and physicians' recommendation for maintenance steroids and medical follow-up.<sup>104</sup>

## What does this mean for commissioners and service developers?

The NICE quality standard for asthma highlights the importance of following up people who have required treatment for an asthma exacerbation.

**Statement 10. People who received treatment in hospital or through out-of-hours services for an acute exacerbation of asthma are followed up by their own general practice within two working days of treatment.**

- Commissioners should lead the establishment of system-wide communication systems to ensure that information about acute events and arrangement of follow-up is co-ordinated across the local health economy with clear accountabilities and procedures in place, including checks that follow up has taken place. Secondary care needs to be aware of and have confidence in the services available in the community
- Commissioners should require secondary care providers to demonstrate that they are following the guidelines for education before discharge and for following up these patients after an exacerbation, as they represent a high-risk group of patients. Follow-up after acute events should be specifically commissioned
- Practice systems should enable patients who have had an exacerbation to access an asthma- trained nurse or GP for a follow-up after a discharge as specified in the asthma quality standard statement 10
- Commissioners should consider setting up a CQUIN for acute asthma care to encourage adherence to best practice guidelines, to include follow-up.

## Examples of good practice

### Asthma bundle to guide hospital care

Mid Yorkshire Hospitals NHS Trust targeted readmissions by introducing a three-sticker bundle to guide emergency care. The first sticker is for emergency department (ED) staff (supported by a CQUIN requiring 75% adherence); the second includes actions for discharge home from ED and the third sticker is a checklist for actions on discharge from ED to be admitted as an in-patient. See annex C.

# A

## Annex A – Asthma service checklist

**The following checklist can be used to help commissioners identify whether the patients in their area have the services they need, whether best practice guidelines are being followed, and whether different sectors of the NHS are working effectively together to deliver seamless care.**

An integrated care pathway for asthma that encompasses all healthcare settings, so that the child/young person's journey is supported by good communication between professionals who are aware of the role of other parties and all are working to best practice in the British asthma guidelines	<input type="checkbox"/>
Good understanding of the burden of asthma in children and young people locally to provide a sound basis for a local asthma strategy to improve outcomes – prevalence rates, outcomes in primary and secondary care, deaths,	<input type="checkbox"/>
All children and young people with suspected asthma have access to a professional appropriately trained in performing diagnostic level spirometry or other appropriate tests, and the basis upon which the diagnosis of asthma was made is recorded in the clinical records	<input type="checkbox"/>
A lead health professional for asthma in each practice who co-ordinates services in accordance with the British Asthma Guideline and local care pathways	<input type="checkbox"/>
At least one practice nurse in every practice is trained in managing asthma (ie holds a recognised certificate of competence e.g. an asthma diploma) and has experience in supporting children with long term conditions	<input type="checkbox"/>
Routine use of personalised asthma action plans for all children and young people with asthma – developed by professionals in collaboration with patients and their families, who are competent in the skills required to support young patients in self management	<input type="checkbox"/>
Regular reviews of all children and young people with asthma, at least annually and definitely after any need for urgent healthcare in any part of the healthcare system	<input type="checkbox"/>
Primary care practices can demonstrate that they are providing asthma care in line with the Asthma Quality Standard from NICE.	<input type="checkbox"/>
Audits of medication in primary care are undertaken to ensure that medication is being optimised and in line with the British asthma guideline	<input type="checkbox"/>
A system for stratifying children and young people with asthma according to risk, so that appropriate interventions are available to those at higher risk of acute attacks, and high cost care	<input type="checkbox"/>
High quality Information sources (e.g. Asthma UK, and BLF materials/websites) are made available to all children and young people with asthma (and their families) at diagnosis and regular review to encourage understanding of asthma and support self care	<input type="checkbox"/>
Systematic approach to help parents of children and young people with asthma to quit smoking, both in routine consultations and as part of treatment of an acute episode	<input type="checkbox"/>
Young people with asthma are warned of the detrimental effect that smoking can have on their lungs, and of the potential for reduced efficacy of inhaled steroid treatment, and that support is actively offered to quit	<input type="checkbox"/>

A named lead for respiratory emergencies in children and young people in emergency departments is responsible for ensuring that appropriate emergency care is given	<input type="checkbox"/>
Children and young people admitted to hospital for asthma have a structured review with a member of the paediatric respiratory team before discharge.	<input type="checkbox"/>
Robust systems of communication and follow-up are in place for those with asthma who have received care in out-of-hours services, ambulances, hospitals, walk-in centres or other urgent health care settings, and follow up in primary care is in line with the NICE Asthma Quality Standard	<input type="checkbox"/>
Schools are providing an environment where children and young people with asthma feel supported, because an asthma school policy is in place, the school holds a register of pupils with asthma, and staff are receiving training on asthma so that they can ensure immediate access to appropriate medication and support a pupil in the event that their condition deteriorates	<input type="checkbox"/>
Hospital services operate a systematic approach to the transition of young people with asthma to adult services, as a joint initiative between paediatric and adult asthma services	<input type="checkbox"/>
Specialist services for people with severe / difficult –to-control asthma are available and accessible to patients who need a comprehensive multidisciplinary approach to asthma care	<input type="checkbox"/>
Monitoring and audit arrangements are in place to ensure all levels of care are available and delivered according to the British Asthma Guideline	<input type="checkbox"/>

# B Annex B – CQUINS and care bundles

## Examples of CQUINS for asthma

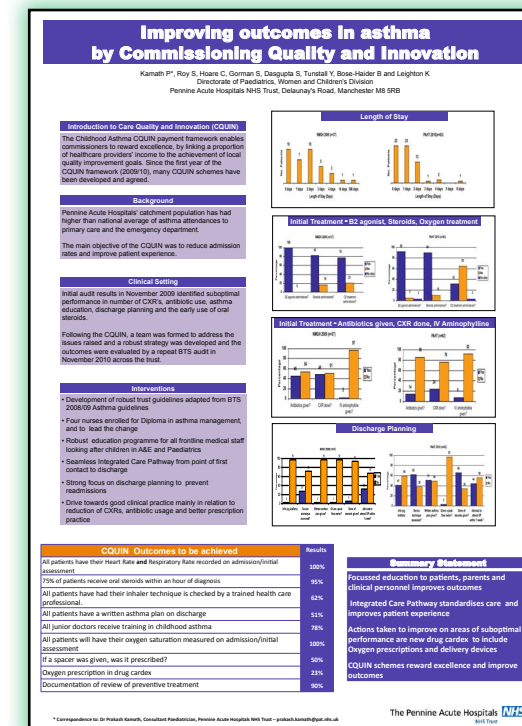
NHS North Yorkshire and York CQUIN for management of asthma in emergency departments

Local contract ref.	
Goal number	
Goal name	Respiratory
Indicator number	
Indicator name	Asthma in emergency department (ED) 7
Indicator weighting	
(% of CQUIN scheme available)	
Description of indicator	Improving management of patients presenting with asthma in ED
Numerator	<p>a. Number of patients (under 18) attending ED with asthma discharged home/not admitted with completed care bundle</p> <p>b. Number of patients (over 18) attending ED with asthma discharged home/not admitted with completed care bundle</p> <p>The care bundle reflects College of Emergency Medicines standards and BTS/Sign guidelines and includes all of the following measures:</p> <ol style="list-style-type: none"> <li>1. Vital signs measurement and recording – peak flow, O<sub>2</sub> saturation, pulse and respiratory rate measured and recorded on arrival in ED</li> <li>2. Beta 2 agonist administration in ED within 20 minutes of arrival</li> <li>3. Steroid administration in ED within 30 minutes of arrival</li> <li>4. Repeat vital sign measurement and recording – peak flow, O<sub>2</sub> saturation, pulse and respiratory rate measured and recorded in ED before discharge</li> <li>5. Inhaler technique checked and explanation of action</li> <li>6. Discharge prescription of oral steroids – oral prednisolone 30-50mg for five days for adults, oral prednisolone 20mg for three days for under fives, oral prednisolone 30-40mg for three days for children over five</li> <li>7. Appropriate follow-up arrangements within primary care</li> </ol> <p>* Written symptom based and peak flow based self-management plan given, which allows patients to adjust therapy within recommendations</p> <p>* Information about what to do if they have another asthma attack/how to recognise deterioration, for example given a copy of After your Asthma Attack or After your Child's Asthma Attack leaflet from Asthma UK</p> <p>* Advised to see GP/practice nurse within two working days of ED attendance</p> <p>* Practice informed of ED attendance by fax within 24 hours</p>



<b>Denominator</b>	a. Number of patients (under 18) attending ED with asthma who are discharged home/not admitted b. Number of patients (over 18) attending ED with asthma who are discharged home/not admitted
<b>Rationale for inclusion</b>	One in four people who have attended ED because of an asthma attack receive no information about follow-up treatment and only 35% of those with asthma know what they need to do after an attack (Asthma UK). One in six people who have received emergency treatment for an asthma attack need treatment again within two weeks. Those attending ED often do not receive the same level of information and follow-up as those admitted to a ward, even though this is a crucial time to deliver that education to patients and their carers. By providing the correct assessment, education and support re-attendance rates will be reduced, admissions prevented and patient outcomes improved.
<b>Data source</b>	Identify and audit 50 consecutive attendances diagnosed as asthma during the previous quarter – at least 20 to be aged 18 or over.  Only measures v. and vii. are applicable for patients presenting with mild symptoms.  Patients presenting with acute severe or life threatening symptoms and those admitted to hospital are excluded from the audit.
<b>Frequency of data collection</b>	Twice yearly
<b>Organisation responsible for data collection</b>	Provider
<b>Frequency of reporting to commissioner</b>	Twice yearly report (quarter two and quarter four)
<b>Baseline period/date</b>	2012/13 Q2
<b>Baseline value</b>	to be added
<b>Final indicator period/date (on which payment is based)</b>	Quarter two Quarter four
<b>Final indicator value (payment threshold)</b>	75% of all measures
<b>Rules for calculation of payment due at final indicator period/date (including evidence to be supplied to commissioner)</b>	Completed audit report required for quarter two and quarter four to be submitted to the commissioner by the end of the month following the quarter end.
<b>Final indicator reporting date</b>	Quarter two – 31 October 2012; Quarter four – 30 April 2013.
<b>Are there rules for any agreed in-year milestones that result in payment?</b>	No
<b>Are there any rules for partial achievement of the indicator at the final indicator period/date?</b>	No

## Asthma CQUIN from North West region



This Asthma care bundle from Mid Yorkshire Hospitals has been adapted for use with children.

## Mid Yorkshire Hospitals ADULT ASTHMA CARE BUNDLE

This care bundle is designed to assist in the implementation of key steps and targets in the management of patients in the Emergency Department (ED) with acute exacerbations of asthma, it should be continued if they are admitted to hospital.

1. Please attach and complete **STICKER 1.** into the ED notes for **ALL** patients attending with an exacerbation of asthma.
2. Please attach and complete **STICKER 2.** into the ED notes if the patient is being **discharged** home from the ED department.
3. If a patient is **admitted** from ED with an exacerbation of asthma **STICKER 3.** should be put into the medical notes and completed (by the medical team).

\* BTS guidelines (2011) on the management of acute asthma are attached to the back of this form.

### 1. ADULT ASTHMA CARE BUNDLE – ED INITIATION PHASE

Element	Order	Action	Timing from admission	Time completed & signed
ASSESS	1	Peak Flow Rate	On Arrival	
		Saturations		
		Respiratory Rate		
		Pulse Rate		
		Determine severity of asthma exacerbation (moderate/severe/life threatening)*		
TREAT	2	Administer Oxygen - Aim saturations 94-98%	On Arrival	
	3	Administer Bronchodilators (via spacer or nebuliser with oxygen) according to severity*	Within 20 minutes	
	4	Administer Steroids - Prednisolone 40-50mg oral - Hydrocortisone 100mg iv	Within 30 minutes	
	5	Peak Flow Rate	Within 60 minutes	
RE-ASSESS Measure response to therapy and decide to admit or discharge*		Saturations		
		Respiratory Rate		
		Pulse Rate		

### 2. ADULT ASTHMA CARE BUNDLE – PATIENTS BEING DISCHARGED FROM ED

Element	Order	Action	Timing from admission	Time completed & signed
EDUCATE	6a	Check inhaler technique	On discharge	
	7a	Provide Asthma Self Management Plan		
	8a	Provide "After your asthma attack" leaflet		
	9a	Provide smoking cessation advice where appropriate		
MEDICATE	10a	Supply with steroids - Prednisolone 40-50mg (5 days)	On discharge	
	11a	Ensure has inhaled corticosteroid (preventer inhaler) & $\beta_2$ agonist (reliever inhaler)		
FOLLOW-UP	12a	Advise to see GP / Practice Nurse within 2 working days	On discharge	
	13a	Practice informed of A&E attendance	Within 24hrs	

### 3. ADULT ASTHMA CARE BUNDLE – PATIENTS ADMITTED TO HOSPITAL

Element	Order	Action	Timing from admission	Time completed & signed
EDUCATE	6b	Check inhaler technique	Pre-discharge	
	7b	Provide smoking cessation advice where appropriate		
	8b	Referral to Respiratory Nurse for in-patient Asthma Review		
MEDICATE	9b	Prednisolone (40-50mg) continued for at least 5 days	On discharge	
	10b	Ensure has inhaled corticosteroid (preventer inhaler) & $\beta_2$ agonist (reliever inhaler)		
FOLLOW-UP	11b	Advised to see GP / Practice Nurse within 2 working days	On discharge	
	12b	Follow-up in 4 weeks by respiratory nurse or respiratory physician		

Embedded IT templates from Yorks and Humber region to enable systematic data collection

The image displays three screenshots of embedded IT templates for asthma monitoring and review, designed for systematic data collection.

**Top Left: Yath Asthma Monitoring - Triggers**

This window shows a list of asthma triggers under the heading "Asthma Triggers". The triggers include:

- Asthma trigger - airborne dust (XaOb)
- Asthma trigger - animals (XaLi)
- Asthma trigger - cold air (XaLJ)
- Asthma trigger - damp (XaLJ)
- Asthma trigger - dust mites (Y01e)
- Asthma trigger - emotion (XaLJ)
- Asthma trigger - exercise (XaOe)
- Asthma trigger - humidity (XaOe)
- Asthma trigger - perfume (XaOe)
- Asthma trigger - perfumes (YAS9)
- Asthma trigger - pollen (XaOb)
- Asthma trigger - respiratory infection (XaLi)
- Asthma trigger - seasonal (XaLi)
- Asthma trigger - wind (XaLi)

**Top Right: Yath Asthma Monitoring - Asthma Review**

This window shows the "Asthma Review" section. It includes fields for "Asthma review", "Smoking Status and Advice", "Investigations", "Peak Flow values for under 15 years", "Peak Flow values for 15 years and over", "Best ever peak flow rate", "Inhaler technique observed", "Inhaler technique shown", "Inhaler Technique", "Spacer device in use", "Only for patients on ICS treatment:", "Record Vaccination", "Seasonal influenza vaccination declined", and "Pneumococcal vaccination declined".

**Bottom: Asthma Control Test (CHILDREN)**

This window shows the "Asthma Control Test (CHILDREN)" form. It includes instructions for the test and a table for recording answers.

**Instructions:**

- Step 1:** Let your child respond to the first 4 questions (1 to 4). If your child needs help reading or understanding the question, you may help, but let your child select the response. Complete the remaining 3 questions (5 to 7) on your own and without letting your child's response influence your answers. There are no right or wrong answers.
- Step 2:** Click an answer button for each question. You will see a number score populate the column to the right.
- Step 3:** When all 7 questions have been answered, press the "SEE YOUR SCORE" button to view your child's score.
- Step 4:** Take a printout of the test results to the doctor to talk about your child's total score.

**Questions and Answers:**

Question	Answer	Score
1. How is your asthma today?	N/A	
2. How much of a problem is your asthma when you run, exercise or play sports?	N/A	
3. Do you cough because of your asthma?	N/A	
4. Do you wake up during the night because of your asthma?	N/A	
5. During the last 4 weeks, how many days did your child have any daytime asthma symptoms?	N/A	
6. During the last 4 weeks, how many days did your child wheeze during the day because of asthma?	N/A	
7. During the last 4 weeks, how many days did your child wake up during the night because of asthma?	N/A	

**What does the score mean?**

**19 or less**

If your child's score is 19 or less, it may be a sign that your child's asthma is not controlled as well as it could be. Bring this test to the doctor to talk about the results.

**Footer:** © PCC 2013

# C Annex C – Asthma quality standard

Find guidance
NICE Pathways
Quality standards
Into practice
QOF

Quality Standards
Issued: February 2013

**QS25**
Quality standard for asthma

View the summary and implementation tools
Previous
Next

Select chapters to print, save or share

List of quality statements

**Statement 1.** People with newly diagnosed asthma are diagnosed in accordance with BTS/SIGN guidance.

**Statement 2.** Adults with new onset asthma are assessed for occupational causes.

**Statement 3.** People with asthma receive a written personalised action plan.

**Statement 4.** People with asthma are given specific training and assessment in inhaler technique before starting any new inhaler treatment.

**Statement 5.** People with asthma receive a structured review at least annually.

**Statement 6.** People with asthma who present with respiratory symptoms receive an assessment of their asthma control.

**Statement 7.** People with asthma who present with an exacerbation of their symptoms receive an objective measurement of severity at the time of presentation.

**Statement 8.** People aged 5 years or older presenting to a healthcare professional with a severe or life-threatening acute exacerbation of asthma receive oral or intravenous steroids within 1 hour of presentation.

**Statement 9.** People admitted to hospital with an acute exacerbation of asthma have a structured review by a member of a specialist respiratory team before discharge.

**Statement 10.** People who received treatment in hospital or through out-of-hours services for an acute exacerbation of asthma are followed up by their own GP practice within 2 working days of treatment.

**Statement 11.** People with difficult asthma are offered an assessment by a multidisciplinary difficult asthma service.

In addition, quality standards that should also be considered when commissioning and providing a high-quality asthma service are listed in related [NICE quality standards](#).

Introduction and overview
List of quality statements
Quality statement 1: Diagnosis
Quality statement 2: Diagnosing occupational asthma
Quality statement 3: Written personalised action plans
Quality statement 4: Inhaler technique
Quality statement 5: Review
Quality statement 6: Assessing asthma control
Quality statement 7: Assessing severity
Quality statement 8: Treatment for acute asthma
Quality statement 9: Specialist review
Quality statement 10: Follow-up in primary care
Quality statement 11: Difficult asthma
Using the quality standard
Development sources
Related NICE quality standards
About this quality standard

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Help

Previous
Next

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Index

A publication for commissioners is also included with this quality standard: <http://tinyurl.com/kz5x885>

## Implementation Programme

### NICE support for commissioners and others using the quality standard for asthma

February 2013

#### Introduction

Implementing the recommendations from NICE guidance and other [NICE accredited](#) guidance is the best way to support improvements in the quality of care offered to patients in line with the statements and measures that comprise the [NICE quality standards](#). To support implementation, this document:

- considers the cost of implementing the changes needed to achieve the quality standard at a local level
- identifies where potential cost savings can be made
- highlights the areas of care in the quality standard with potential implications for commissioners
- signposts commissioners and service providers to a package of support tools that can assist with the implementation of NICE guidance and service redesign.

#### Using NICE Quality Standards

[NICE quality standards](#) define high-quality care for patients across a care pathway or clinical area. They are based on NICE guidance, and other [NICE accredited](#) guidelines, and are presented as a set of specific, concise statements that represent high-quality care, with associated measures. The NICE quality standard for asthma was developed by a Topic Expert Group (TEG) using the best available evidence, and was produced collaboratively with the NHS, along with their partners and service users.



# Annex D – Examples of self-management plans



Remember to take your inhaler with a spacer if you have one



## 1. My asthma medicines

- My best peak flow is \_\_\_\_\_
- My preventer inhaler is called \_\_\_\_\_ and its colour is \_\_\_\_\_
- I take \_\_\_\_\_ puff/s of my preventer inhaler in the morning and \_\_\_\_\_ puff/s at night. I do this every day even if I feel well.

Other asthma medicines I take every day:

\_\_\_\_\_

\_\_\_\_\_

- My reliever inhaler is called \_\_\_\_\_ and its colour is blue. I take \_\_\_\_\_ puff/s of my blue reliever inhaler when I wheeze or cough, my chest hurts or it's hard to breathe.

Does playing, running or doing PE normally make it hard to breathe?



If yes I take \_\_\_\_\_ puff/s of my blue reliever inhaler beforehand.



What asthma medicines do you take every day?

## 2. When my asthma gets worse

I will know my asthma is getting worse if:

- I have a cough, wheeze, it is hard to breathe or my chest hurts, or
- I am waking up at night because of my asthma, or
- I am taking my blue reliever inhaler every day, or
- My peak flow is less than \_\_\_\_\_

**When this happens:** I keep taking my preventer medicines as normal.

**And also take** \_\_\_\_\_ puff/s of my blue reliever inhaler every four hours.

**If I am not getting any better I should see my doctor or asthma nurse today.**



What should you do when your asthma gets worse?

## 3. What to do when I have an asthma attack

I am having an asthma attack if:

- My blue reliever inhaler is not helping, or
- I can't talk or walk easily, or
- I am breathing hard and fast, or
- I am coughing or wheezing a lot, or
- My peak flow is below \_\_\_\_\_

**When this happens:** I should take \_\_\_\_\_ puffs of my blue reliever inhaler every two minutes (up to ten puffs) until I feel better.

I am feeling better, but I don't want this to happen again so I need to see my doctor or asthma nurse today.

I still don't feel better and I have taken ten puffs. Now I need to call **999** straight away. If I am waiting longer than 15 minutes for an ambulance I should take another \_\_\_\_\_ puffs of my blue reliever inhaler every two minutes (up to ten puffs).







# E

## Annex E – Partner organisations

### Partner organisations

The children's asthma group was formed in 2009 to support the work of the respiratory and children's teams at the Department of Health for England in developing its asthma work. Chaired by Professor Martyn Partridge, this group included doctors, nurses, young people with asthma and a parent of a child with asthma. They were charged with shaping and contributing to the asthma work programme. Three organisations had representatives on this steering group and we would like to thank both the group members and these organisations for their commitment and support.

### Asthma UK

Asthma UK is the charity dedicated to improving the health and well-being of the 5.4 million people in the UK whose lives are affected by asthma. It aims to substantially reduce the number of asthma attacks that result every day in preventable hospital admissions and deaths. It also aims to encourage the development of new treatments that will give more people control over their asthma. Asthma UK pursues its goals by funding world-class medical research, providing practical and life-saving services and giving people with asthma a strong voice in public policy and local care delivery. Its resources for patients and health professionals have won prestigious medical awards and are independently accredited. These include a free advice line service (0800 121 6244), a comprehensive website, self management plans, an active Facebook site and a range of targeted materials for both adults and children with asthma and their healthcare professionals.

[www.asthma.org.uk](http://www.asthma.org.uk)

### British Thoracic Society

The BTS is a professional body and registered charity. Its members include doctors, nurses, respiratory physiotherapists, scientists and other professionals with an interest in respiratory disease. The society had 2,797 members at 1 July 2012. BTS' main charitable objective is to improve the care of people with respiratory and associated disorders, which is achieved in various ways:

- By promoting optimum standards of care and developing tools for quality improvement: treatment best practice guidelines; clinical audit tools; the development of the BTS lung disease registry and the forthcoming work on care bundles
- By promoting and advancing knowledge about the causes, prevention and treatment of respiratory diseases
- By promoting and disseminating research (through the winter meeting as well as the journal Thorax).

**[www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk)**

### The Primary Care Respiratory Society UK

The Primary Care Respiratory Society UK (PCRS-UK) is a membership-led charity supporting primary care health professionals. Its mission is to give every member of the primary care practice team the confidence to deliver quality respiratory care, improve the quality of life for patients with respiratory disease, and help practices hit their Quality and Outcomes Framework (QOF). Through practice and individual membership schemes, PCRS-UK offers a wealth of practical resources for primary care health professionals, whether they are relatively new to respiratory medicine or a respiratory expert.

- The PCRS-UK respiratory leaders programme also provides primary care health professionals with training workshops, policy updates and IMPRESS resources, to enable them to take the lead, motivate and inspire best practice within their locality
- The PCRS-UK quality award sets out the principles that best define high quality respiratory care in primary care and provides a developmental framework that can be used at practice, local and national level to promote, support and reward quality respiratory care in the primary care setting.

**[www.pcrs-uk.org](http://www.pcrs-uk.org)**

## Annex F – Asthma steering group

Professor Martyn Partridge – chair

	Representing	Role
Dr Jon Couriel	Consultant respiratory paediatrician	
Noel Durkin		DH Children and young people strategy team
Dr Dougal Hargreaves	Clinical adviser to national clinical director	DH Children and young people strategy team
May Holloway	Lay member	
Dr Duncan Keeley	GP	Primary care respiratory society UK
Vicky Keenan	Lay member	
Vivienne Marsh	Paediatric asthma nurse specialist	Asthma UK
Liz Morgan	Professional adviser – children and young people's services	DH Children and young people strategy team
Dr Maria O'Callaghan	Consultant respiratory paediatrician	
Prof John Price	Consultant respiratory paediatrician	
Kim Price	Parent	Asthma UK
Alexandrea Reay	Food and health in schools team	Department for Education
Bronwen Thompson	Asthma lead	DH Respiratory Team
Edwina Wooler	Specialist paediatric respiratory nurse – hospital	Asthma UK
Dr Ted Wozniak	Medical adviser	DH Children and young people strategy team



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- <sup>6</sup> <http://tinyurl.com/ay03l9r>
- <sup>7</sup> <http://tinyurl.com/am5po45>
- <sup>8</sup> <http://tinyurl.com/aw93tpj>
- <sup>9</sup> <http://tinyurl.com/a7n5vkv>
- <sup>10</sup> <http://tinyurl.com/aygczkz>
- <sup>11</sup> <http://tinyurl.com/aq25vab>
- <sup>12</sup> <http://tinyurl.com/as8mzer>
- <sup>13</sup> Department of Health, Better Health Outcomes for Children and Young People: Our pledge 2013 <http://tinyurl.com/a57bant>
- <sup>14</sup> <http://tinyurl.com/a6bc5a9>
- <sup>15</sup> <http://tinyurl.com/awz3dlu>
- <sup>16</sup> <http://tinyurl.com/bzwj5td>
- <sup>17</sup> <http://tinyurl.com/ayaemu8>
- <sup>18</sup> <http://tinyurl.com/a5lmze5>
- <sup>19</sup> <http://tinyurl.com/86staje>
- <sup>20</sup> <http://www.inhale.nhs.uk/>
- <sup>21</sup> <http://tinyurl.com/aqcln2y>
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